

# **Pregnant women with complex social factors: a model for service provision**

National Collaborating Centre for Women's and Children's Health

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Implementation of this guidance is the responsibility of local commissioners and/or providers

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# 1 Guidance summary

## 1.1 Key priorities for implementation

### Service organisation

In order to inform mapping of their local population to guide service provision, commissioners should ensure that the following are recorded:

- The number of women presenting for antenatal care with any complex social factor<sup>\*</sup>
- The number of women within each complex social factor grouping identified locally

Commissioners should ensure that the following are recorded separately for each complex social factor grouping

- The number of women who:
  - attend for booking by 10, 12<sup>+6</sup> and 20 weeks
  - attend for the recommended number of antenatal appointments, in line with national guidance<sup>†</sup>
  - experience, or have babies who experience, mortality or significant morbidity.<sup>‡</sup>
- The number of appointments that each woman attends
- The number of scheduled appointments that each woman does not attend.

Commissioners should ensure that women with complex social factors presenting for antenatal care are asked about their satisfaction with the services provided; and the women's responses are:

- Recorded and monitored
- Used to guide service development

### Information and support for women

For women who do not have a booking appointment, at first contact with any healthcare professional:

- discuss the need for antenatal care
- offer the woman a booking appointment in the first trimester, ideally before 10 weeks if she wishes to continue the pregnancy, or
- offer referral to sexual health services if she is considering termination of the pregnancy.

Consider initiating a multi-agency needs assessment, including safeguarding issues<sup>§</sup> so that the woman has a coordinated care plan.

Respect the woman's right to confidentiality and sensitively discuss her fears in a non-judgemental manner.

Tell the woman why and when information about her pregnancy may need to be shared with other agencies.

<sup>\*</sup> Examples of complex social factors include: poverty; substance misuse; recent arrival as a migrant; asylum seeker or refugee status; difficulty speaking or understanding English; age under 20; experiencing domestic abuse; traveller. Complex social factors may vary across different local populations

<sup>†</sup> See 'Antenatal care' (NICE clinical guideline 62) Available from [www.nice.org.uk/guidance/CG62](http://www.nice.org.uk/guidance/CG62)<sup>1</sup>

<sup>‡</sup> Significant morbidity is morbidity that has a lasting impact on either the woman or the child

<sup>§</sup> For example, using the Common Assessment Framework

In order to facilitate discussion of sensitive issues, provide each woman with a one-to-one consultation without her partner, a family member or a legal guardian present, on at least one occasion.

### **Women who misuse substances (alcohol and/or drugs)**

#### *Service organisation*

Healthcare commissioners and individuals responsible for the organisation of local antenatal services should work with local agencies, including social care and third-sector agencies that provide substance misuse services, to coordinate antenatal care by, for example:

- jointly developing care plans across agencies
- including information about opiate replacement therapy in care plans
- co-locating services
- offering women information about other services.

#### *Training for healthcare staff*

Healthcare professionals should be given training on the social and psychological needs of women who misuse substances.

Healthcare staff and non-clinical staff such as receptionists should be given training on how to communicate sensitively with women who misuse substances.

### **Women who are recent migrants, asylum seekers or refugees, or who have difficulty reading or speaking English**

#### *Information and support for women*

Individuals responsible for the organisation of local antenatal services should provide information about pregnancy and antenatal services, including how to find and use antenatal services, in a variety of:

- formats, such as posters, notices, leaflets, photographs, drawings/diagrams, online video clips, audio clips and DVDs
- settings, including pharmacies, community centres, faith groups and centres, GP surgeries, family planning clinics, children's centres, reception centres and hostels
- languages.

### **Young women aged under 20**

#### *Service organisation*

Commissioners should consider commissioning a specialist antenatal service for young women aged under 20 using a flexible model of care tailored to the needs of the local population. Components may include:

- antenatal care and education in peer groups in a variety of settings, such as GP surgeries, children's centres and schools
- antenatal education in peer groups offered at the same time as antenatal appointments and at the same location, such as a 'one-stop shop' on a Saturday.

### **Women who experience domestic abuse**

#### *Service organisation*

Commissioners and individuals responsible for the organisation of local antenatal services should ensure that a local protocol is written, which:

- is developed jointly with social care providers, the police and third-sector agencies by a healthcare professional with expertise in the care of women experiencing domestic abuse
- includes:
  - clear referral pathways that set out the information and care that should be offered to women.

- the latest government guidance\*
- sources of support for women, including addresses and telephone numbers, such as social services, the police, support groups and women's refuges
- safety information for women
- plans for follow-up care, such as additional appointments or referral to a domestic abuse support worker
- ensuring a telephone number is obtained on which the woman can be contacted
- contact details of other people who should be told that the woman is experiencing domestic abuse, including her GP.

## 1.2 Recommendations

### Chapter 3 General principles

#### *Service organisation*

The principles outlined in this section apply to all women covered in this guideline.

In order to inform mapping of their local population to guide service provision, commissioners should ensure that the following are recorded:

- The number of women presenting for antenatal care with any complex social factor<sup>†</sup>
- The number of women within each complex social factor grouping identified locally

Commissioners should ensure that the following are recorded separately for each complex social factor grouping

- The number of women who:
  - attend for booking by 10, 12<sup>+6</sup> and 20 weeks
  - attend for the recommended number of antenatal appointments, in line with national guidance<sup>‡</sup>
  - experience, or have babies who experience, mortality or significant morbidity.<sup>§</sup>
- The number of appointments that each woman attends
- The number of scheduled appointments each woman does not attend

Commissioners should ensure that women with complex social factors presenting for antenatal care are asked about their satisfaction with the services provided; and the women's responses are:

- Recorded and monitored
- Used to guide service development

Commissioners should involve women and their families in determining local needs and how these might be met.

Individuals responsible for the organisation of local maternity services should enable women to take a copy of their handheld notes when moving from one area or hospital to another.

#### *Training for healthcare staff*

Healthcare professionals should be given training on multi-agency needs assessment\*\* and national guidelines on information sharing\*

\* Department of Health (2005) Responding to domestic abuse: A handbook for healthcare professionals. London: Department of Health. Available from [www.dh.gov.uk/en/Publicationsandstatistics/index.htm](http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm)

† Examples of complex social factors include: poverty; substance misuse; recent arrival as a migrant; asylum seeker or refugee status; difficulty speaking or understanding English; age under 20; experiencing domestic abuse; traveller. Complex social factors may vary across different local populations

‡ See 'Antenatal care' (NICE clinical guideline 62) Available from [www.nice.org.uk/guidance/CG92](http://www.nice.org.uk/guidance/CG92)<sup>1</sup>

§ Significant morbidity is morbidity that has a lasting impact on either the woman or the child

\*\* For example, using the Common Assessment Framework

### *Care provision*

Consider initiating a multi-agency needs assessment, including safeguarding issues<sup>†</sup> so that the woman has a coordinated care plan.

Respect the woman's right to confidentiality and sensitively discuss her fears in a non-judgemental manner.

Tell the woman why and when information about her pregnancy may need to be shared with other agencies.

Ensure that the handheld notes contain a full record of care received and the results of all antenatal tests.

### *Information and support for women*

For women who do not have a booking appointment, at first contact with any healthcare professional:

- discuss the need for antenatal care
- offer the woman a booking appointment in the first trimester, ideally before 10 weeks if she wishes to continue the pregnancy, or
- offer referral to sexual health services if she is considering termination of the pregnancy.

At the first contact and at the booking appointment, ask the woman to tell her healthcare professional if her address changes, and ensure that she has a telephone number for this purpose.

At the booking appointment, give the woman a telephone number to enable her to contact a healthcare professional outside of normal working hours, for example the telephone number of the hospital triage, labour ward or birth centre.

In order to facilitate discussion of sensitive issues, provide each woman with a one-to-one consultation without her partner, a family member or a legal guardian present, on at least one occasion

## **Chapter 4 Women who misuse substances (alcohol and/or drugs)**

Women who misuse substances need supportive and coordinated care during pregnancy.

Work with social care professionals to overcome barriers to care for women who misuse substances. Particular attention should be paid to:

- integrating care from different services
- ensuring that the attitudes of staff do not prevent women from using services
- addressing women's fears about the involvement of children's services and the potential removal of their child, by providing information tailored to their needs
- addressing women's feelings of guilt about their misuse of substances and the potential effects on their baby.

### *Service organisation*

Healthcare commissioners and individuals responsible for the organisation of local antenatal services should work with local agencies, including social care and third-sector agencies that provide substance misuse services, to coordinate antenatal care by, for example:

- jointly developing care plans across agencies
- including information about opiate replacement therapy in care plans
- co-locating services
- offering women information about other services.

Consider ways of ensuring that, for each woman:

- progress is tracked through the relevant agencies involved in her care

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\* Department for Children, Schools and Families, and Communities and Local Government (2008) Information sharing: guidance for practitioners and managers. London: Department for Children, Schools and Families, and Communities and Local Government.

Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children<sup>2</sup>

<sup>†</sup> For example, using the Common Assessment Framework

- clinic notes from the different agencies involved in her care are combined into a single document
- there is a coordinated care plan.

Offer the woman a named antenatal carer who has specialised knowledge of, and experience in, the treatment of substance misuse, and include a direct-line telephonenumber for the antenatal carer.

#### *Training for healthcare staff*

Healthcare professionals should be given training on the social and psychological needs of women who misuse substances.

Healthcare staff and non-clinical staff such as receptionists should be given training on how to communicate sensitively with women who misuse substances.

#### *Information and support for women*

The first time a woman who misuses substances discloses that she is pregnant, offer her referral to an appropriate substance misuse programme.

Use a variety of methods, for example text messages, to remind women of upcoming and missed appointments.

The named antenatal carer should tell the woman about relevant additional services (such as drug and alcohol misuse support services) and encourage her to use them according to her individual needs.

Offer the woman information about the potential effects of substance misuse on her unborn baby, and what to expect when the baby is born, for example what medical care the baby may need, where he or she will be cared for and any potential involvement of social services.

Consider offering information about help with transportation to appointments if needed to support the woman's attendance.

### **Chapter 5 Women who are recent migrants, asylum seekers or refugees, or who have difficulty reading or speaking English**

Women who are recent migrants, asylum seekers or refugees, or who have difficulty reading or speaking English, may not make full use of antenatal care services. This may be because of unfamiliarity with the health service or because they find communication difficult.

Healthcare professionals should help support these women's uptake of antenatal care services by:

- using a variety of means to communicate with women
- telling women about antenatal care services and how to use them
- undertaking training in the specific needs of women in these groups

#### *Service organisation*

Commissioners should monitor emergent local needs and adjust services accordingly.

Healthcare professionals should ensure that they have accurate and up-to-date information about a woman's residence during her pregnancy by working with local agencies that provide housing and other services for recent migrants, asylum seekers and refugees, such as asylum centres.

When using interpreting services commissioners and individuals responsible for the organisation of local antenatal services should offer flexibility in the number and length of antenatal appointments, over and above those outlined in national guidance\* because interpretation requires additional time.

Individuals responsible for the organisation of local antenatal services should provide information about pregnancy and antenatal services, including how to find and use antenatal services, in a variety of:

- formats, such as posters, notices, leaflets, photographs, drawings/diagrams, online video clips, audio clips and DVDs
- settings, including pharmacies, community centres, faith groups and centres, GP surgeries, family planning clinics, children's centres, reception centres and hostels

\* See 'Antenatal care' (NICE clinical guideline 62)<sup>1</sup>

- languages.

### *Training for healthcare staff*

Healthcare professionals should be given training on:

- the specific health needs of women who are recent migrants, asylum seekers or refugees, such as needs arising from female genital mutilation or HIV
- the specific social, religious and psychological needs of women in these groups
- the most recent government policies on access and entitlement to care for recent migrants, asylum seekers and refugees\*

### *Information and support for women*

Offer the woman information on access and entitlement to healthcare.†

At the booking appointment discuss with the woman the importance of keeping her handheld maternity record with her at all times.

Avoid making assumptions based on a woman's culture, ethnic origin or religious beliefs.

### *Communication with women who have difficulty reading or speaking English*

Provide the woman with an interpreter (who may be a link worker or advocate and should not be a member of the woman's family, her legal guardian or her partner) who can communicate with her in her preferred language.

When giving spoken information ask the woman about her understanding of what she has been told to ensure she has understood it correctly.

## **Chapter 6 Young women aged under 20**

Young women aged under 20 may feel uncomfortable using antenatal care services in which the majority of service users are in older age groups. They may also be reluctant to recognise their pregnancy or inhibited by embarrassment and fear of parental reaction.

Healthcare professionals should encourage young women aged under 20 to use antenatal care services by:

- offering age-appropriate services
- being aware that the young woman may be dealing with other social problems
- offering practical help with transportation to and from appointments
- offering antenatal care for young women in the community
- providing opportunities for the partner/father of the baby to be involved in the young woman's antenatal care, with her agreement

### *Service organisation*

Commissioners should work in partnership with local education authorities and third-sector agencies to improve access to, and continuing contact with, antenatal care services for young women aged under 20.

Commissioners should consider commissioning a specialist antenatal service for young women aged under 20 using a flexible model of care tailored to the needs of the local population. Components may include:

- antenatal care and education in peer groups in a variety of settings, such as GP surgeries, children's centres and schools

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\* Guidance from the Department of Health available from [www.dh.gov.uk/en/Healthcare/International/asylumseekersandrefugees/index.htm](http://www.dh.gov.uk/en/Healthcare/International/asylumseekersandrefugees/index.htm) Information sheet from Maternity Action available here: <http://www.maternityaction.org.uk/sitebuildercontent/sitebuilderfiles/entitlementtonhscarenov09.pdf>

† Guidance from the Department of Health available from [www.dh.gov.uk/en/Healthcare/International/asylumseekersandrefugees/index.htm](http://www.dh.gov.uk/en/Healthcare/International/asylumseekersandrefugees/index.htm) Information sheet from Maternity Action available here: <http://www.maternityaction.org.uk/sitebuildercontent/sitebuilderfiles/entitlementtonhscarenov09.pdf>

- antenatal education in peer groups offered at the same time as antenatal appointments and at the same location, such as a 'one-stop shop' on a Saturday

Offer the young woman aged under 20 a named midwife who should take responsibility for and provide the majority of her antenatal care and include a direct-line telephone number for the named midwife.

#### *Training for healthcare staff*

Healthcare professionals should be given training to ensure they are knowledgeable about safeguarding responsibilities for both the young woman and the unborn baby and the most recent government guidance on consent for examination or treatment.\*

#### *Information and support for women*

Offer young women aged under 20 information that is suitable for their age - including information about care services, antenatal peer group education or drop-in sessions, housing and other benefits - in a variety of formats, including leaflets.

## **Chapter 7 Women who experience domestic abuse**

A woman who is experiencing domestic abuse may have particular difficulties using antenatal care services: for example, the perpetrator of the abuse may try to prevent her from attending appointments. The woman may be afraid that disclosure of the abuse to a healthcare professional will worsen her situation, or worried about the reaction of the healthcare professional.

This group of women should be supported in their use of antenatal care services by:

- training healthcare professionals in the identification and care of women who experience domestic abuse
- making available information and support tailored to women who experience or are suspected to be experiencing domestic abuse
- providing a more flexible series of appointments if needed
- addressing women's fears about the involvement of children's services by providing information tailored to their needs

#### *Service organisation*

Commissioners and individuals responsible for the organisation of local antenatal services should ensure that local voluntary and statutory organisations that provide domestic abuse services recognise the need to provide coordinated care and support for service users during pregnancy.

Commissioners and individuals responsible for the organisation of local antenatal services should ensure that a local protocol is written, which:

- is developed jointly with social care providers, the police and third-sector agencies by a healthcare professional with expertise in the care of women experiencing domestic abuse
- includes:
  - clear referral pathways that set out the information and care that should be offered to women
  - the most recent government guidance on responding to domestic abuse<sup>†</sup>
  - sources of support for women, including addresses and telephone numbers, such as social services, the police, support groups and women's refuges
  - safety information for women
  - plans for follow-up care, such as additional appointments or referral to a domestic abuse support worker
  - ensuring a telephone number is obtained on which the woman can be contacted

\* Department of Health 2009 Reference guide to consent for examination or treatment (second edition). London: Department of Health Available from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_103643](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103643)

† Department of Health (2005) Responding to domestic abuse. A handbook for healthcare professionals. London: Department of Health. Available from [www.dh.gov.uk/en/Publicationsandstatistics/index.htm](http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm)

- contact details of other people who should be told that the woman is experiencing domestic abuse, including her GP.

Commissioners and individuals responsible for the organisation of local antenatal services should provide for flexibility in the length and frequency of antenatal appointments, over and above those outlined in national guidance\* to allow more time for women to discuss the domestic abuse they are experiencing.

Offer the woman a named midwife who should take responsibility for and provide the majority of her antenatal care.

### *Training for healthcare staff*

Commissioners of healthcare services and social care services should consider commissioning joint training for health and social care professionals to facilitate greater understanding between the two agencies of each other's roles, and enable healthcare professionals to inform and reassure women who are apprehensive about the involvement of social services.

Healthcare professionals need to be alert to features suggesting domestic abuse and offer women the opportunity to disclose it in an environment in which the woman feels secure. Healthcare professionals should be given training on the care of women known or suspected to be experiencing domestic abuse that includes:

- local protocols
- local resources for both the woman and the healthcare professional
- features suggesting domestic abuse
- how to discuss domestic abuse with women experiencing it
- how to respond to disclosure of domestic abuse.

### *Information and support for women*

Tell the woman that the information she discloses will be kept in a confidential record and will not be included in her handheld record.

Offer the woman information about other agencies, including third-sector agencies, which provide support for women who experience domestic abuse.

Give the woman a credit-card sized information card that includes local and national helpline numbers.

Consider offering the woman referral to a domestic abuse support worker.

## **1.3 Research recommendations**

### **1.3.1 Key priorities for research**

#### **Training for healthcare staff**

What training should be provided in order to improve staff behaviour towards pregnant women with complex social factors?

#### *Why this is important*

The evidence reviewed suggests that women facing complex social problems are deterred from attending antenatal appointments, including booking appointments, because of the perceived negative attitude of healthcare staff, including non-clinical staff such as receptionists. It is expected that education and training for staff in order to help them understand the issues faced by women with complex social factors and how their own behaviour can affect these women will reduce negative behaviour and language. A number of training options currently exist that could be used in this context; however, which of these (if any) bring about the anticipated positive changes is not known. Given the resource implications of providing training across the NHS it is important to ascertain the most cost-effective way of providing this.

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\* See 'Antenatal care' (NICE clinical guideline 62)<sup>1</sup>

## Effect of early booking on obstetric and neonatal outcomes

Does early booking (by 10 weeks, or 12<sup>+6</sup> weeks) improve outcomes for pregnant women with complex social problems compared with later booking?

### *Why this is important*

The NICE guideline on 'Antenatal care' (NICE clinical guideline 62) recommends that the booking appointment should ideally take place before 10 weeks and 'Maternity matters'\* supports booking by 12 weeks for all women. The main rationale behind these recommendations is to allow women to participate in antenatal screening programmes for haemoglobinopathies and Down's syndrome in a timely fashion, to have their pregnancies accurately dated using ultrasound scan, and to develop a plan of care for the pregnancy which sets out the number of visits required and additional appointments that may need to be made.

Pregnant women with complex social factors are known to book later, on average, than other women and late booking is known to be associated with poor obstetric and neonatal outcomes†. It seems likely that facilitating early booking for these women is even more important than for the general population of pregnant women. There is, however, no current evidence that putting measures in place to allow this to happen improves pregnancy outcomes for women with complex social factors and their babies.

## How can different service models be assessed?

What data should be collected, and how should they be collected, and shared, in order to assess the quality of different models of services?

### *Why this is important*

There is a paucity of routinely collected data about the effectiveness of different models of care in relation to demography. Although mortality data are accurately reflected in reports published by the Confidential Enquiry into Maternal and Child Health, morbidity and pregnancy outcomes are not often linked back to pregnancies in women with complex social factors. Most research in the area of social complexity and pregnancy is qualitative, descriptive and non-comparative. In order to evaluate the financial and clinical effectiveness of specialised models of care there is a need for baseline data on these pregnancies and their outcomes in relation to specific models of care.

A national database of routinely collected pregnancy data needs to be designed. Currently it is impossible to determine which data should be collected. In the first instance the database could be developed for use in areas of high ethnic diversity and social risk. Existing models of care should be designed to collect data in similar formats to allow national and international comparisons.

## Models of service provision

What models of service provision exist in UK for the four different populations addressed in this guideline who experience socially complex pregnancies (women who misuse substances, women who are recent migrants, asylum seekers or refugees or who have difficulty reading or speaking English, young women aged under 20 and women who experience domestic abuse)? How do these models compare, both with each other and with standard care, in terms of outcomes?

### *Why this is important*

The evidence reviewed by the GDG was poor in several respects. Many of the studies were conducted in other parts of the world, and it was not clear whether they would be applicable to the UK. Many of the interventions being studied were multifaceted, and it was not clear from the research which aspect of the intervention led to a change in outcome or whether it would lead to a similar change in the UK. Also, in some instances it was not clear whether a particular intervention, for example a specialist service for teenagers, made any difference to the outcomes being studied.

Developing a clear and detailed map of existing services in the UK for pregnant women with complex social factors, and the effectiveness of these services, would enable us to set a benchmark for good practice that local providers could adapt to suit their own populations and resources. A map of providers,

\* Department of Health (2007) Maternity matters: choice, access and continuity of care in a safe service. London: Department of Health. Available from [www.dh.gov.uk/en/Publicationsandstatistics/index.htm](http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm)

† Confidential Enquiry into Maternal and Child Health (2007) Saving mothers' lives: reviewing maternal deaths to make motherhood safer – 2003–2005. London: Confidential Enquiry into Maternal and Child Health. Available from [www.cmace.org.uk/publications](http://www.cmace.org.uk/publications)

their services and outcomes may also enable commissioners and providers to learn from each other, work together to develop joint services and to share information in a way that would lead to continuous improvement in services for these groups of women.

### **Antenatal appointments for women who misuse substances**

What methods help and encourage women who misuse substances to maintain contact with antenatal services/attend antenatal appointments? What additional consultations (if any) do women who misuse substances need, over and above the care described in the NICE guideline 'Antenatal care' (NICE clinical guideline 62)?

#### *Why this is important*

Women who misuse substances are known to have poorer obstetric and neonatal outcomes than other women. Late booking and poor attendance for antenatal care are known to be associated with poor outcomes and therefore it is important that measures are put in place to encourage these women to attend antenatal care on a regular basis. Some of the evidence examined by the GDG suggested that some interventions could improve attendance for antenatal care, but this evidence was undermined by the use of self-selected comparison groups, so that the effect of the intervention was unclear.

In relation to additional consultations, the GDG was unable to identify any particular intervention that had a positive effect on outcomes, although there was low-quality evidence that additional support seemed to improve outcomes. Much of the evidence was from the US and there was a lack of high-quality UK data.

It seems likely that making it easier for these women to attend antenatal appointments and providing tailored care will improve outcomes, but at present it is not clear how this should be done.

### **1.3.2 Additional research recommendations**

#### **General research recommendations**

Does providing information to partners and family members of vulnerable pregnant women help to improve early access?

What effect does involving 3rd sector agencies in providing support and coordination of care for vulnerable women have on outcomes?

Is family support provided by statutory and 3rd sector agencies effective in improving outcomes for women and their babies?

#### **Women misusing substances (drugs and/or alcohol)**

What additional consultations (if any) do women who misuse substances need over and above the care described in the NICE Antenatal care guideline?

#### **Young women aged under 20**

Which components of a specialist service for young women aged under 20 are effective at improving outcomes?

What additional information would young women aged under 20 like to receive when attending antenatal appointments?

What is the evidence that age-specific antenatal education improves outcomes for young women aged under 20?

#### **Women experiencing domestic abuse**

How should maternity services be provided in order to maintain contact with, and improve outcomes for pregnant women experiencing abuse?

Is repeated questioning about domestic abuse throughout the antenatal period acceptable to women and does this affect attendance?

What additional information should be provided to women who experience domestic abuse, and what format should this take?

A tool should be developed and validated for assessing the severity of risk to pregnant women who experience domestic abuse

**Recent migrants to the UK, refugees, asylum seekers or women with little or no English**

Is it more effective to use interpreters, lay health advocates or link workers to help with communication with women from different linguistic backgrounds? Which of these is more acceptable to women?

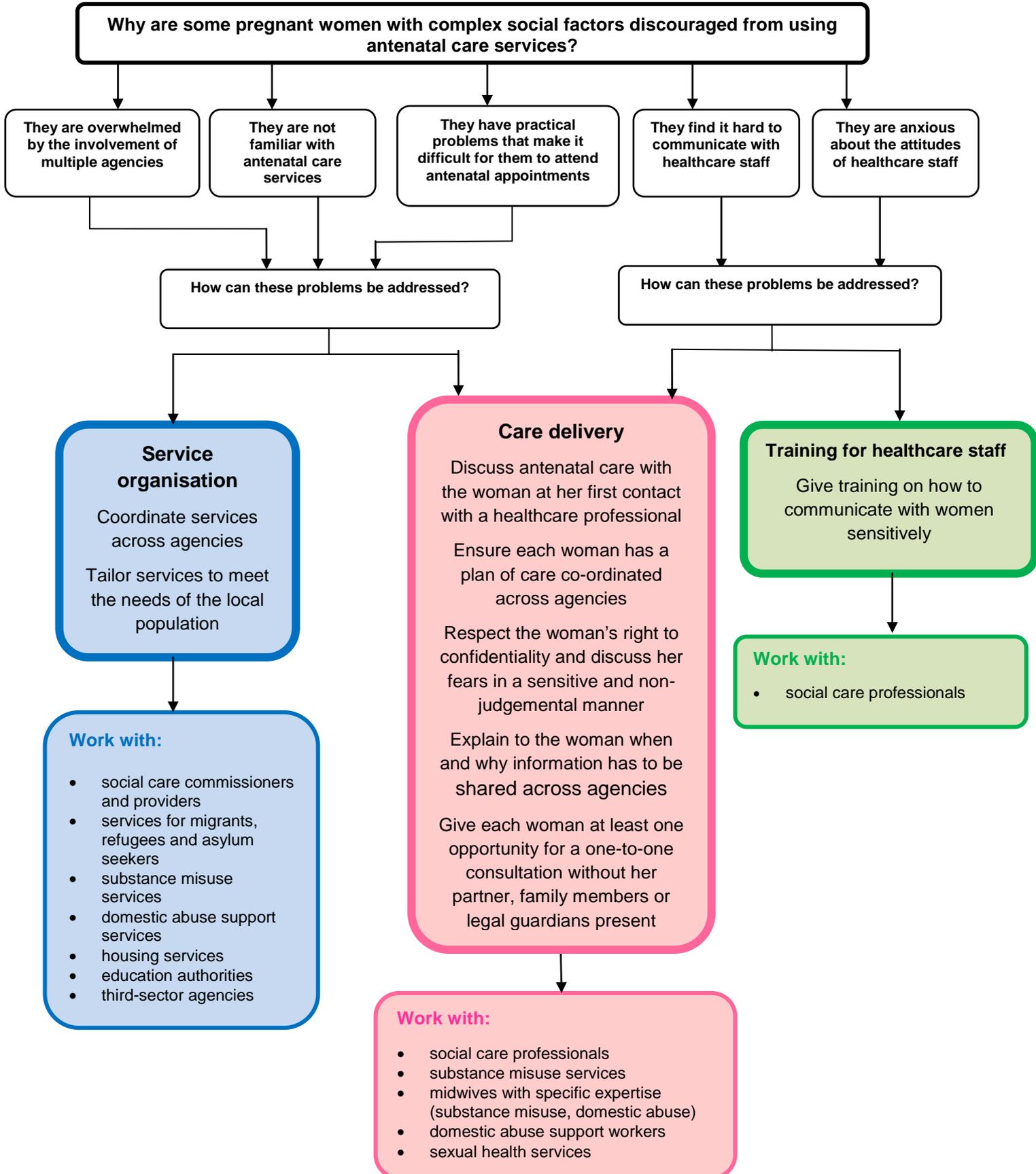
Are outcomes improved in non-English speaking women if a translator is present during antenatal consultations?

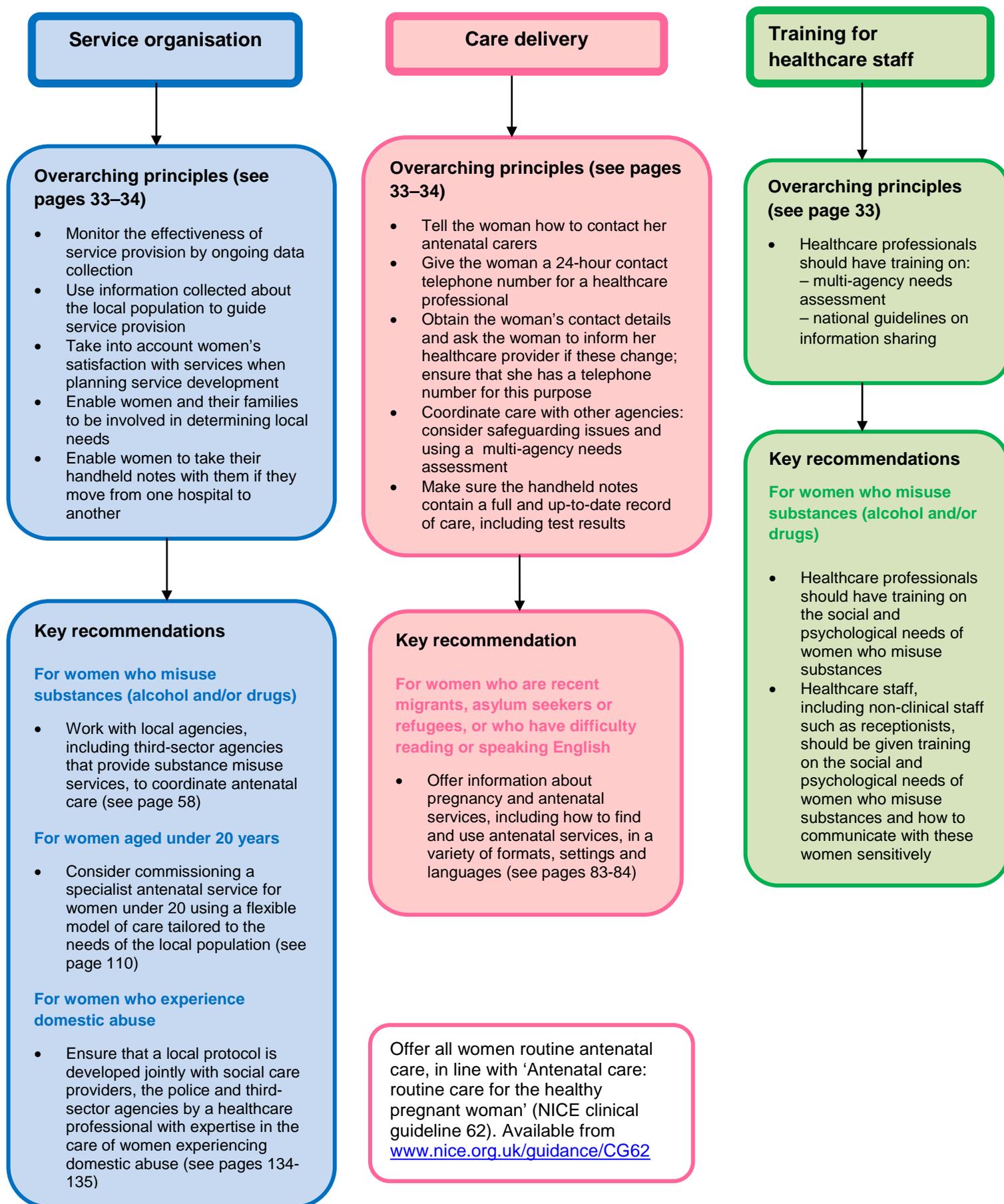
What do recent migrants, asylum seekers, and refugees see as specific barriers to accessing and maintaining contact with antenatal care?

What system can be used to effectively track the residential address of women who move address frequently and/or at short notice? What impact does the system have on the number of antenatal appointments attended?

### 1.4 Service model

## Care of pregnant women with complex social factors: a model for service provision





# 2 Introduction

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## 2.1 Pregnant women with complex social factors: a model for service provision

This Guideline was commissioned because of the acknowledgement of unaddressed problems in pregnant women with complex social factors i.e. women whose social situation may impact adversely on the pregnancy outcomes for them and their baby. A number of key reports have highlighted some of the issues faced by these women:

- *Saving Mother's Lives* (2007) drew attention to the fact that socially excluded women are at higher risk of death during or after pregnancy than other women. The vulnerable women with socially complex lives who died were far less likely to seek antenatal care early in pregnancy or to stay in regular contact with maternity services. Overall 17% of the women who died from direct or indirect causes booked for maternity care after 22 weeks of gestational age or had missed over four routine antenatal visits compared to 2% of the general population. Women who booked late or missed more than 4 routine appointments were more likely to be black African or Caribbean, women experiencing domestic abuse, substance misusers, known to social services or child protection services and unemployed than women who booked prior to 20 weeks.<sup>3</sup>
- *Maternity Matters* (2007) had a section focussing on "The Equality Impact Assessment". This reported that women in all vulnerable groups are likely to recognise their pregnancy later, to first see a health professional later, and to book later for antenatal care. Women with socially complex pregnancies, many who were known to social services and in particular the child protection services, were extremely vulnerable. Not only did they often hide their pregnancies from social services but also many also actively avoided maternity care despite being at high risk of medical or mental health problems."<sup>4</sup> *Maternity Matters* also highlighted the fact that commissioners need to understand what barriers in their current services may prevent these women from seeking care early, or maintaining contact with their maternity services, and to overcome these by providing more flexible services at times and places which meet their needs.<sup>4</sup>
- *Perinatal Mortality* (2009) demonstrated that women from non-White ethnic groups and women in the most deprived population quintile had stillbirth and neonatal death rates twice those of white women and those resident in the least deprived areas. It is also recognised that maternal stress in pregnancy has a detrimental effect on subsequent childhood development.<sup>5</sup>

The following general principles were established in the 'Changing Childbirth' report<sup>6</sup> and the NICE Guideline "Antenatal Care: routine care for the healthy pregnant woman"<sup>1</sup>:

- Women should be the focus of maternity care, with an emphasis on providing choice, easy access and continuity of care.
- Care during pregnancy should enable a woman to make informed decisions, based on her needs, having discussed matters fully with the healthcare professionals involved. It is essential that women, their partners and their families be treated with kindness, respect and dignity. This includes respect for their views, beliefs and values. Good communication between healthcare professionals and women is vital. Any information given should be evidence-based and supported by appropriate, written information. All information should also be accessible to women with additional needs e.g. those with sensory or learning disabilities, and to women who do not speak or read English.
- The NICE Guideline "Antenatal Care for the Healthy Pregnant Woman" (2007) recommends that ideally booking should occur by 10 weeks gestation in order to facilitate screening for haemoglobinopathies and other conditions.<sup>1</sup> In addition to allowing screening this will also

enable good history taking, the provision of advice as early as possible and the organisation of a booking scan at 12-14 weeks.

This guidance is especially pertinent for women with complex social problems.

If a woman has additional health problems complicating pregnancy (e.g. hypertension, diabetes) in addition to social problems the relevant NICE guideline should also be consulted to effectively direct clinical care.

In planning this guideline it was intended that four exemplar populations would be used to represent women with complex social factors that might impact on their health during pregnancy as well as pregnancy outcomes. These groups were chosen from groups highlighted in CEMACH<sup>7</sup> as having poorer pregnancy outcomes than the general population and in consultation with the guideline's stakeholders. The four exemplar populations are:

- Women who are substance misusers (including drugs and/or alcohol)
- Recent migrants, refugees, asylum seekers, and women with little or no English
- Young women aged under 20
- Women experiencing domestic abuse

It is recognised that this is not a comprehensive list and that there is a range of other complex social factors which may impact on pregnancy (such as learning disabilities, families where one or both parents are unemployed, imprisonment, poverty etc.). It is also recognised that vulnerable women often have multiple needs and may experience a number of complex social factors at the same time. Although the majority of the recommendations in the guideline have been written for the specific population groups listed above, there have been some general principles for care identified which can be applied to all vulnerable women with complex social factors (Chapter 3). It is hoped that healthcare professionals consider the full range of complex social factors which may impact on pregnancy and apply these recommendations accordingly. Whilst it can be helpful to consider general findings for a particular vulnerable population, when designing a service for that group it is important to consider each women's needs individually and to recognise that she may have needs that cross those population boundaries and require antenatal input from a range of health and social care professionals, as well as third sector agencies.

The guideline focuses on women who are recent migrants (defined here as women who have come to the country of residence within the past year), asylum seekers, refugees and women with little or no English (or language spoken in country of residence) rather than migrant women generally as these sub-groups are highlighted within CEMACH<sup>7</sup> as being particularly at risk of poor birth outcomes. These poor outcomes are thought to be related specifically to difficulty accessing services due to language barriers and a lack of knowledge and understanding of how the health and social care system works. Since improving access is a major focus of this guideline this was felt to be a more appropriate targeting of the migrant population group rather than considering all migrant women as a whole.

The Guideline describes how access to care can be improved, how contact with antenatal carers can be maintained, what additional consultations and supports are required and what additional information should be provided for pregnant women with complex social factors.

Specific issues considered include: consideration of the most appropriate healthcare setting for maternity care provision; practice models for overcoming barriers and facilitating access, including access to appropriate interpreting services and all necessary care; ways of communicating information to women so that they can make appropriate choices; and optimisation of resources.

## **2.2 Aim and scope of the guideline**

This guideline aims to:

- Identify and describe best practice for service organisation and delivery that will improve access, acceptability and use of services.
- Identify and describe services that encourage, overcome barriers to and facilitate the maintenance of contact throughout pregnancy.

- Describe additional consultations with and/or support and information for women with complex social factors, and their partners and families that should be provided during pregnancy, over and above that described in the 'Antenatal care: routine care for the healthy pregnant woman' (NICE clinical guideline 62).
- Identify when additional midwifery care or referral to other members of the maternity team (obstetricians and other specialists) would be appropriate, and what that additional care should be.

In developing this guideline, it became apparent that it would not be possible to address section 4.3e of the scope (defining a pathway of care to decide when a woman should return to midwifery care). It was recognised that this would be a decision to make on an individual basis and would not be appropriate to include in the service guidance. However, algorithms have been developed to show how services should be organised to provide care for women with complex social factors and what specific components of care should be included.

The full scope of the guideline and exclusions are detailed in Appendix A

## 2.3 Abbreviations and Glossary

### Abbreviations

AIDS	acquired immune deficiency syndrome
CAPP	Comprehensive Adolescent Parenting Program/ Children and Adolescent Pregnancy Project
CM	community midwife
CNM	certified nurse midwife
DLM	drug liaison midwife
HCP	healthcare professional
HIV	human immunodeficiency virus
IM	interface midwife
IPV	intimate partner violence
IV	intravenous
LHA	lay health advisor
MD	medicinae doctorem (used in the text to indicate a physician)
MSW	medical social worker
NICU	neonatal intensive care unit
NMU	neonatal medical unit
PCT	primary care trust
PHN	public health nurse
SGA	small for gestational age
STI	sexually transmitted infection
TB	tuberculosis

### Glossary of terms

<b>Advocate</b>	A person who provides support to the pregnant woman. This can include aiding them to access services and representing their views to healthcare professionals.
<b>Asylum seeker</b>	A person who has lodged an application for protection on the basis of the United Nations Convention Relating to the Status of Refugees (1967) or Article 3 of the European Convention on Human Rights (1953).
<b>Drop-in centre</b>	Centres which offer a range of services which can be attended without a prior appointment.
<b>Domestic abuse</b>	An incident of threatening behaviour, violence or abuse (psychological, physical, sexual, financial or emotional)

	between adults who are or have been intimate partners or family members, regardless of gender or sexuality.' (Home Office). It can also include forced-marriage, female genital mutilation and "honour violence".
<b>Domestic abuse support worker</b>	A person who provides practical and emotional support to women experiencing domestic abuse.
<b>Interpreter</b>	A person who facilitates communication between two people by providing a literal translation from one language into another.
<b>Linkworker</b>	A facilitator who acts as a contact between healthcare professionals and women. The role can include providing help to women in accessing services and support, and offering advice to healthcare professionals about cultural and religious issues.
<b>Recent migrant</b>	A person who has moved to the UK within the last 12 months.
<b>Refugee</b>	<i>"A person who owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it."</i> (Article 1 of the United Nations Convention Relating to the Status of Refugees – 1967)
<b>Safeguarding</b>	The process of protecting children from abuse or neglect, preventing impairment of their health and development, and ensuring they are growing up in circumstances consistent with the provision of safe and effective care that enables children to have optimum life chances and enter adulthood successfully.
<b>Statutory organisation</b>	A public sector body that has to exist by law. These can include district and borough councils, health authorities and the police force.
<b>Substance misuse</b>	Regular use of recreational drugs, misuse of over-the-counter medications, misuse of alcohol or misuse of volatile substances (such as solvents or inhalants) to an extent where physical dependence or harm is a risk (to women and/or their unborn baby).
<b>Third Sector</b>	Voluntary and not-for-profit organisations which attempt to provide a social or cultural benefit. Includes charities, community organisations, social enterprises and housing associations.
<b>Vulnerable woman</b>	A woman who is facing complex social problems.

### 2.4 For whom is the guidance intended?

This guidance is of relevance to those who work in or use the National Health Service (NHS) in England and Wales, in particular:

- Professional groups who are routinely involved in the care of pregnant women
- GPs, and primary care
- Professionals who may encounter pregnant women in the course of their professional duties, for example adult mental health professionals
- those responsible for commissioning and planning healthcare services, including primary care trust commissioners, Health Commission Wales commissioners, and public health and trust managers.

In addition, this guidance may be of relevance to professionals working in social services and education/childcare settings.

### 2.5 Other relevant documents

This guideline is intended to complement other existing works of relevance, including the following guidance published by NICE:

- 'Alcohol dependence and harmful alcohol use', NICE public health guidance (due to publish February 2011)
- 'Alcohol use disorders: preventing harmful drinking', NICE public health guidance (due to publish June 2010)
- 'Alcohol use disorders: clinical management', NICE public health guidance (due to publish June 2010)
- 'Antenatal and postnatal mental health', NICE clinical guideline 45<sup>8</sup>
- 'Antenatal care', NICE clinical guideline 62<sup>1</sup>
- 'Brief interventions and referral for smoking cessation', NICE public health guidance 1<sup>9</sup>
- 'Contraceptive services for socially disadvantaged young people', NICE public health guideline (due to publish October 2010)
- 'Diabetes in pregnancy' NICE clinical guideline 63<sup>10</sup>
- 'Hypertensive disorders in pregnancy' NICE clinical guideline (due to publish October 2010)
- 'Induction of labour', NICE clinical guideline 70<sup>11</sup>
- 'Interventions to reduce substance misuse among vulnerable young people', NICE public health guidance 4<sup>12</sup>
- 'Intrapartum care', NICE clinical guideline 55<sup>13</sup>
- 'Looked after children', NICE public health guidance (due to publish October 2010)
- 'Maternal and child nutrition', NICE public health guidance 11<sup>14</sup>
- 'Quitting smoking in pregnancy and following childbirth' NICE public health guidance (due to publish June 2010)
- 'When to suspect child maltreatment' NICE clinical guideline 89

Healthcare professionals should also be aware of the following documents produced by the Department of Health:

- Responding to domestic abuse: a handbook for health professionals<sup>15</sup>
- Reference guide to consent for examination or treatment, second edition<sup>16</sup>

- Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children<sup>2</sup>

## 2.6 Who has developed the guidance?

The guidance was developed by a multi-professional and lay working group (the Guideline Development Group or GDG) convened by the National Collaborating Centre for Women's and Children's Health (NCC-WCH). Membership included:

- Three obstetricians
- One commissioner
- One social worker
- One specialist in perinatal mental health
- One specialist in parental mental health
- Two midwives
- One substance misuse lead
- Three service users.

Staff from the NCC-WCH provided methodological support for the guidance development process, undertook systematic searches, retrieved and appraised the evidence and wrote successive drafts of the guidance.

## 2.7 Guideline development methodology

This guidance was commissioned by NICE and developed in accordance with the guideline development process outlined in the NICE *Guidelines Manual 2007*<sup>17</sup>, with post development phases carried out as per the NICE *Guidelines Manual 2009*<sup>18</sup>. Table 2.1 summarises the key stages of the process and which version of the guidelines manual was followed at each stage.

In accordance with NICE's Equality Scheme, ethnic and cultural considerations and factors relating to disabilities have been considered by the GDG throughout the development process and specifically addressed in individual recommendations where relevant. This includes consideration of target populations which include women with little or no English, asylum seekers, refugees and recent migrants, substance misusing women and young women aged under 20. Further information is available from: [www.nice.org.uk/aboutnice/howwework/NICEEqualityScheme.jsp](http://www.nice.org.uk/aboutnice/howwework/NICEEqualityScheme.jsp).

**Table 2.1** Stages in the NICE guideline development process and versions of 'The guidelines manual' followed at each stage

Stage	2007 version	2009 version
Scoping the guideline (determining what the guideline would and would not cover)	✓	
Preparing the work plan (agreeing timelines, milestones, guideline development group constitution, etc.)	✓	
Forming and running the guideline development group	✓	
Developing clinical questions	✓	
Identifying evidence	✓	
Reviewing and grading evidence	✓	
Incorporating health economics	✓	
Making group decisions and reaching consensus	✓	
Linking guidance to other NICE guidance	✓	

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Creating guideline recommendations	✓	
Writing the guideline	✓	
Stakeholder consultation on the draft guideline		✓
Finalising and publishing the guideline (including pre-publication check)		✓
Declaration of interests	✓	✓

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### Forming clinical questions and search strategies

Five clinical questions were developed based on the scope of the guideline. The questions focussed on access to care, barriers to care, maintaining contact with care, additional consultations, support and information needed over and above that set out in the NICE Antenatal Care guideline (2008)<sup>1</sup>. These questions were asked for each of the guideline populations which are:

- women who misuse substances
- women who are recent migrants, refugees, asylum seekers, or who speak little or no English,
- young women aged under 20
- women who experience domestic abuse

The main purpose of the guideline is to provide guidance on how services can be organised in order to improve women's access to and contact with antenatal care. In order to determine the clinical and economic effectiveness of care provision it is necessary to review evidence that shows which service interventions lead to improved pregnancy outcomes, this requires findings from comparative studies reporting "hard" outcomes e.g. birthweight, gestation at birth. Whilst acknowledging that this approach would reduce the number of potential studies for inclusion it was felt to be very important that this distinction was made in order that recommendations could be made based on evidence of effectiveness. Where this evidence was found to be lacking research recommendations have been made.

Due to the complex nature of the interventions of interest, and lack of certainty among the GDG over what terms would be appropriate to describe some of these, it was decided that searches would be carried out for a particular population rather than by guideline question, thus 4 broad searches were run covering all 5 questions for each population. This approach was similar to that adopted by Tina Lavender, Soo Downe, Kenny Finnlaysen and Denis Walsh who conducted a systematic review entitled "Access to Antenatal Care: A systematic review. Report (Unpublished report; February 2007)<sup>19</sup> and reflects the uncertainty inherent in the review questions which focus on antenatal care provision generally rather than specific interventions within antenatal care. Searching in this way increases the sensitivity of the search at the expense of specificity.

Four search strategies were developed to capture studies examining antenatal service provision for each of the guideline's target populations. For each population, searches were run in the Medline (1950 onwards), Embase (1980 onwards), Cumulative Index to Nursing and Allied Health Literature (CINAHL; 1982 onwards), and three Cochrane databases (Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, and the Database of Abstracts of Reviews of Effects) as well as PsycInfo. In addition, for three out of the four populations the ASSIA, Sociological Abstracts and Social Services Abstracts databases were searched. These databases were not searched for the population of women experiencing domestic abuse (or for the re-run searches) as the subscription to the databases was discontinued prior to this being carried out. However, the decision to stop the subscription was taken only after the contribution made by the social science databases had been investigated. It was found that the 3 social science databases contributed less than 5% of the total number of hits obtained across all 3 populations searched (young women aged under 20 1.7%; recent migrants 5.9%; substance misusers 4.9%).

Searches to identify economic studies were undertaken using the above databases and the NHS Economic Evaluation Database (NHS EED). None of the searches was limited by study type, date or language of publication (although publications in languages other than English were not reviewed). There was no attempt to search grey literature (conferences, abstracts, theses and unpublished trials), nor was hand searching of journals not indexed on the databases undertaken.

Towards the end of the guideline development process, the searches were updated and re-executed, to include evidence published and indexed in the databases by 2nd September 2009. Full details of the systematic searches, including the sources searched and the search strategies for each review question are presented in Appendix G

### **Criteria for deciding inclusion/exclusion of studies**

Studies from all countries and all dates were considered for inclusion. Studies were considered for inclusion if they involved the specific target population as defined in the PICO tables (see Appendix H for PICO tables). Studies involving exclusively small indigenous groups not common in the UK were excluded e.g. Australian Aborigines, Native Americans, Inuit. Studies originally considered for inclusion could be later excluded if the GDG felt the target population was so different from a UK population as to make generalisation of findings impossible. Where this has been the case this reason for exclusion is detailed in the excluded studies tables. The target population for women who misuse substances, including alcohol, was defined as regular use of substances and/or alcohol e.g. on a weekly basis, to an extent where physical dependence and/or harm to their health or that of their unborn baby is a risk. The level of substance misuse defined within each paper considered for inclusion was discussed with the GDG where it was unclear whether the population was one that would be defined as "substance misusers", and decisions to include or exclude made on the basis of this discussion and with the GDG's agreement. The population of recent migrants, refugees, asylum seekers and women with little or no English was identified by explicit mention of these terms, or by GDG consensus that the included population was likely to represent one or more of these groups. Recent migrants were defined as women who had come to the resident country within the past year. However, few papers used this definition and it was often necessary to decide inclusion/exclusion based on level of understanding of English (or mother tongue of the resident country), degree of acculturation or understanding of health care services where this was reported. Studies including women from black and ethnic minority groups were excluded if it appeared the sample was primarily made up of women who were not recent migrants and spoke English, or if there was no information reported that would allow a judgement to be made regarding these criteria. Where the study sample was made up of a combination of women falling across categories half or more of the sample had to comprise women who were recent migrants, non-English speaking, asylum seekers or refugees for the study to be included.

For intervention questions (Q1a, Q2, Q3 and Q4) only comparative studies were included. Types of study considered included RCTs, non-randomised controlled studies, observational cohort studies, before and after studies and case-control studies. Comparisons included cohort studies with groups that received different service interventions drawn from the same hospital, comparison between services in different hospitals/clinics and comparisons between outcomes obtained for the antenatal service under investigation and population figures for those outcomes for example for that town, city, region or US state. Comparison groups would usually be receiving standard or "usual" care, or any alternative model of care as described by the authors. Comparative studies, with sample sizes of 5 or less in any of the study groups were excluded. For questions addressing barriers to access (Q1b), qualitative and descriptive studies were also considered for inclusion. Individual or very small case reports (n=1 or 2) were excluded. Interventions aimed at improving affordability of health care in countries where women would be expected to pay for antenatal care (as in the US) were excluded on the advice of the GDG as it was felt these interventions were not applicable to a UK NHS setting. For the substance misuse population programmes aimed at helping women manage their substance misuse were excluded from the scope as these do not form part of antenatal care (i.e. this care is not delivered by midwives or obstetricians). However, programmes which combined substance misuse management with aspects of antenatal care, for example advice and information regarding healthy eating for pregnancy, preparation for parenthood, assessing progress of pregnancy etc. were included, as these focus on services that fall within the remit of antenatal maternity care.

Outcomes for clinical questions were decided by the GDG prior to reviewing being conducted and are presented in the PICO tables in Appendix H. Studies which did not report outcomes of interest were excluded.

The large number of "hits" generated using these broad search strategies were then subjected to three rounds of "weeding" (or sifting). This was carried out firstly to exclude opinion papers, letters, editorials, commentary etc. and studies which did not focus on antenatal care or the target population; secondly to remove papers that did not address the interventions or outcomes of interest. A third round of weeding

was carried out by a second reviewer to remove any remaining papers that did not meet the inclusion criteria. These rounds of weeding were necessary due to the very large databases generated by the searches and the need to check previous decision-making in order to minimise the risk of ordering large numbers of irrelevant papers. In addition, a convenience sample of weeded out papers (approx. 10%) was also checked by a second reviewer to ensure exclusion criteria had been applied correctly. Hard copies of potentially relevant papers were then obtained and each paper read in its entirety and assessed again to check it met the inclusion criteria as set out in the PICO tables, for relevant methodology and to determine which of the guideline questions it addressed. Any difficulties encountered at any stage during this process were resolved through discussion with a senior methodologist who also read all papers where a decision was sought.

The population of young women aged under 20 was the first to be reviewed. For this population, papers were assigned to the relevant guideline question(s) when they were received as hard copies, prior to assessment against inclusion criteria and quality appraisal. Papers for consideration were then re-read and data extracted. If at this stage it became apparent that the paper should be excluded from that question it was assigned as such and then recorded in the excluded studies table for that particular question. At this stage, some papers were moved from inclusion in one question to inclusion in an alternative question, or were included in more than one question depending on the outcomes reported. This tendency to include papers in more than one question reflects the high degree of similarity between the guideline questions and the iterative nature of the reviewing undertaken. Once this process had been undertaken for this population it became apparent that a more efficient system could be adopted. For the other three populations hard copies of papers to be considered were read through and if they did not address any of the guideline questions, had no comparators or did not describe any barriers to care they were excluded prior to being assigned to a particular question. These were then recorded in an excluded studies table labelled "first round exclusions". Papers that remained for inclusion were then assigned at this stage to a specific guideline question or questions prior to quality appraisal and data extraction. Many papers were considered for inclusion in more than one question due to the large degree of overlap between question content. This means that an individual paper may have been excluded from one question but included in another depending on reported outcomes. Decisions about inclusion/ exclusion of studies were further supported by input from an experienced methodologist based at NICE. All excluded studies were checked and queries raised where it was not clear whether inclusion/exclusion criteria had been applied correctly. Suggested changes were discussed and agreement reached on where changes needed to be made, and studies added to the reviews as appropriate. The total numbers of "hits" for each population, the number of hard copies assessed for inclusion and final numbers of papers included and excluded are summarised in tables presented in Appendix H. Details of excluded studies are presented in Appendix F.

Due to the anticipated high degree of heterogeneity between studies and the lack of good quality comparative evidence, meta-analysis of study results was not appropriate. Sub-group analysis was planned for English speaking vs. non-English speaking women and older vs. younger teenagers where this was not reported in the paper. However, none of the reviewed studies included data in a form that would allow such analyses to be undertaken.

### Reviewing and grading the evidence

Evidence relating to effectiveness was reviewed and graded using the hierarchical system presented in Table 2.2. This system reflects the susceptibility to bias inherent in particular study designs.

The type of clinical question dictates the highest level of evidence that may be sought. In assessing the quality of the evidence, each study receives a quality rating coded as '++', '+' or '-'. For issues of intervention effectiveness, the highest possible evidence level (EL) is a well-conducted systematic review or meta-analysis of randomised controlled trials with a very low risk of bias (RCTs; EL = 1++) or an individual RCT with low risk of bias (EL = 1+). Studies of poor quality (high risk of bias) are rated as '-'. Usually, studies rated as '-' should not be used as a basis for making a recommendation, but they can be used to inform recommendations.

**Table 2.2** Levels of evidence for intervention studies

Level	Source of evidence
1++	High-quality meta-analyses, systematic reviews of randomised controlled trials (RCTs), or RCTs with a very low risk of bias

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1+	Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias
1–	Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias
2++	High-quality systematic reviews of case–control or cohort studies; high-quality case–control or cohort studies with a very low risk of confounding, bias or chance and a high probability that the relationship is causal
2+	Well-conducted case–control or cohort studies with a low risk of confounding, bias or chance and a moderate probability that the relationship is causal
2–	Case–control or cohort studies with a high risk of confounding, bias or chance and a significant risk that the relationship is not causal
3	Non-analytical studies (for example, case reports, case series)
4	Expert opinion, formal consensus

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For each clinical question, the highest available level of evidence was sought. However, due to the nature of the interventions under investigation it was anticipated that most of the evidence would be from retrospective observational studies. Where a number of low quality comparative studies were considered, those with small sample sizes (5 or less in each group for comparative studies and one or two cases for case reports/series) were excluded along with those with 2 or more serious flaws (other than small sample size) which would contribute to significant bias.

Summary results and data from each study are presented in the text. More detailed results and data are presented in the evidence tables provided in Appendix E. Where possible, dichotomous outcomes are presented as relative risks (RRs) with 95% confidence intervals (CIs), and continuous outcomes are presented as mean differences with 95% CIs or standard deviations (SDs). It should be noted, however, that the findings reported in the included evidence rarely allows this level of analysis.

The body of evidence identified for each clinical question was synthesised narratively in clinical evidence statements.

### Formal consensus within the guideline

Formal consensus was used for three purposes within the guideline: for deciding the most important barriers to antenatal care (Question 1b), for choosing key priorities for implementation and for choosing key research recommendations.

Anonymous formal consensus voting was conducted with GDG members to identify the most important barriers to care. This was carried out during GDG meetings following presentation of the evidence relating to the barriers question. A form containing all barriers identified from the evidence was distributed to each GDG member who was then asked to place a tick by the five barriers they saw as being most important. When this had been done all forms were given to a member of the technical team and the number of votes for each barrier was totalled. The number of barriers identified as priorities was four or five, depending upon how the votes were cast. The results from the voting were fed back to the GDG at the same meeting and the barriers with the most votes were then used to form the basis of the recommendations relating to overcoming barriers to care.

Key priorities for implementation were voted for using formal consensus anonymous voting in a similar way as described above for barriers. GDG members were asked at a meeting to vote for their top 10 priority recommendations using pencil and paper voting forms. Forms were examined by a technical team member and votes summed. After the first round of voting, 8 top priorities were identified. A second round of anonymous voting was then undertaken with all remaining recommendations that had received at least one vote on the first round of voting. The two recommendations with the most votes on the second round of voting were added to the previous eight to give the top ten key priorities for implementation. Following stakeholder consultation two of these recommendations were divided into two to aid clarity. Each of the new recommendations thus made were retained as key priorities for implementation, making a total of 12 key priorities in the final draft.

Key research recommendations were chosen using anonymous voting conducted via e-mail. Again 2 rounds of voting were undertaken in a way similar to that described for key recommendations in order to identify five key research recommendations.

### Health economics

The purpose of including economic evidence in a clinical guideline is to allow recommendations to be made based on the cost-effectiveness of different forms of care as well as the clinical effectiveness. The aim is to produce guidance that uses scarce health service resources efficiently; that is, providing the best possible care within resource constraints.

The aim of the health economic input to the guideline was to inform the GDG of potential economic issues relating to providing additional specialist services and consultations to improve access and uptake of antenatal care for vulnerable women, and to ensure that recommendations represented a cost-effective use of healthcare resources.

Systematic searches for published economic evidence were undertaken for all the populations included in the guideline but no relevant economic evaluations were identified. One area was identified by the GDG as having significant resources implications and uncertainty surrounding the effectiveness. Therefore, for this guideline an economic evaluation was conducted to support the following area

- Additional specialist services for young women aged under 20 and substance misusers to encourage early booking and continued contact with antenatal care.

A simple economic model was developed in order to present the GDG with the potential consequences of providing various specialist services with differing costs. The service descriptions were based on programmes currently running across the UK. No audit data were available and no good quality analysis work had been carried out to evaluate the efficacy of providing additional services to these vulnerable groups. As there was no good quality evidence on effectiveness of specialist services the economic model was used to illustrate what level of effectiveness would be required from different services in order for those services to be considered cost-effective using the NICE willingness-to-pay threshold. The economic model in its current form does not result in an incremental cost-effectiveness ratio.

The relevance of the evidence provided by this analysis depends on the assumptions included in the model and how they apply to real-world settings. As the analyses are not based on good quality clinical evidence they can only be used to illustrate the problem as we do not know how effective specialist services will be in improving health outcomes. Where new specialist services are set-up, auditing and evaluation will provide useful inputs to update this analysis in the future.

### Evidence to recommendations

For each guideline question, recommendations for service provision and care were derived using, and linked explicitly to, the evidence that supported them. In the first instance, informal consensus methods were used by the GDG to agree service delivery and clinical effectiveness evidence statements. Evidence summaries derived from qualitative studies describing reported barriers to accessing care are presented in tabular form. Statements summarising the GDG's interpretation of the evidence and any extrapolation from the evidence used to form recommendations were also prepared to ensure transparency in the decision-making process.

In areas where no substantial good quality evidence was identified, the GDG made consensus statements and used their collective experience and expertise to identify good practice. Health economic modelling was used to support recommendations and this is also explained in the GDG interpretations of evidence. The GDG also identified areas where evidence to answer the guideline questions was lacking and used this information to formulate and prioritise recommendations for future research.

Formal consensus voting was carried out among GDG members to identify the 5 barriers they considered most important for UK NHS services to address in order to promote access to care. This was carried out independently for each population sub-group and the key barriers identified used to inform the recommendations for that population.

Towards the end of the guideline development process, formal consensus methods were used to consider all the guideline recommendations and research recommendations that had been drafted previously. The GDG identified ten 'key priorities for implementation' (key recommendations) and five high-priority research recommendations. The key priorities for implementation were those recommendations likely to have the biggest impact on provision of antenatal care and pregnancy outcomes for at-risk population subgroups in the NHS; they were selected through two rounds of formal voting using pencil and paper

during a GDG meeting. The priority research recommendations were selected using 2 rounds of formal voting carried out electronically via e-mail.

### **Service survey**

A service survey has been undertaken with the help of GDG members to identify examples of current practice within the NHS where services have been designed to deliver care to one of the 4 target populations for the guideline (young women aged under 20, substance misusers, recent migrants/refugees/asylum seekers/women with little or no English and victims of domestic abuse)..

A named person suggested by a GDG member (typically a care provider) was contacted by telephone and/or e-mail and asked if they would be willing to participate in the survey. If they agreed, the questionnaire was administered either electronically via e-mail, via telephone interview, or as a face to face interview, whatever was preferred. The questionnaire collected data under the following headings:

- 1 Access to care (source of referrals; gestation at booking).
- 2 Description of the service provided (target population, who provides care, staffing levels, degree of obstetric input, setting, home visiting, additional facilities provided (e.g. child care), length and frequency of consultations, content of consultations. Provision of antenatal education/support groups).
- 3 Additional consultations (details of appointments over and above "routine" antenatal care as set out in the NICE clinical guideline for Antenatal Care).
- 4 Attendance (maintaining contact with services - number of antenatal appointments kept, rate of DNAs (did not attend), attendance at other appointments e.g. with social services, parole officers etc., how the service encourages attendance).
- 5 Interfaces/links with other services (how the service makes these links, how communication is made with other agencies, problems with communication and how these are overcome).
- 6 Training (additional training provided to/identified as being needed by staff providing the specialist service. Also – training provided by specialist staff to other staff members).
- 7 Audit data (any audit data including process or clinical outcomes).
- 8 Any other information (including identified problems and how these have been overcome).

Each respondent was also asked if they could provide the name and contact details for another service provider involved in antenatal care designed to reach any of the guideline's target populations. Twenty-three services were suggested by GDG members and other midwives. We attempted to contact all the services and were able to speak to 16 midwives about the services they were involved in. Before the guideline went to consultation (February 2010), 1 service had been closed. Two midwives contacted were working for the Imperial College NHS Trust, and although they worked with different groups of vulnerable women the service provided was the same, therefore it was decided to include one service description to cover all the groups of women. By using this "snowballing" technique the survey was able to include 14 examples of a range of services using different models. The service descriptions are included as illustrations of what can be provided for enhanced antenatal care for vulnerable women. Some examples are used in the guideline text to illustrate recommendations where the service provided includes components contained in the recommendations.

The service descriptions have not been used to inform the evidence base for recommendations as the survey was carried out as a descriptive exercise rather than in a way that would allow generalisability of findings. In addition, none of the services have yet been evaluated in terms of their impact on key aims e.g. improving access to or contact with antenatal care, or effectiveness in improving pregnancy outcomes. Thus the service descriptions provide examples of innovative services currently provided within the NHS which show how the guideline's recommendations might be implemented. The need for evaluation of such services is a key message of the guideline.

Full details of survey findings can be found in Appendix D.

### **Stakeholder involvement in the guideline development process**

Registered stakeholder organisations were invited to comment on the draft scope of the guideline. Stakeholder comments were each taken into consideration by the guideline's technical development team

and GDG chair in reaching final decisions about its scope. Each comment was responded to individually. Stakeholder organisations have also commented on the draft guideline. The GDG has considered the comments made and amendments made to the recommendations and text of the full version in light of these comments. Again individual responses have been given for each comment received. The service descriptions reported in the guideline and used to illustrate the recommendations have all been provided by stakeholders, who have also kindly given permission for contact details to be included in the guideline so that other health care professionals and commissioners interested in finding out more about a particular service can do so.

Stakeholders will also be asked to assist in checking the factual accuracy of the guideline during the pre-publication check. A full list of the stakeholders for this guideline can be found in Appendix C.

### **2.8 Schedule for updating the guidance**

Clinical guidelines commissioned by NICE are published with a review date 3 years from date of publication. Reviewing may begin earlier than 3 years if significant evidence that affects guideline recommendations is identified sooner.

# 3 Overarching principles

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## 3.1 Introduction

This guideline aims to address the antenatal care of women with complex social problems. It is intended to provide recommendations for service provision at a service/organisational level and at an individual health care provider level. The guidance here is intended as an addition to the care set out in the NICE Antenatal Care Guideline Update (2008)<sup>1</sup> for healthy pregnant women and is focussed on providing care for women with complex social problems.

Having undertaken the systematic reviewing that underpins the guideline using the four exemplar populations (substance misusers; recent migrants, refugees, asylum seekers or women with little or no English; young women aged under 20; and women experiencing domestic abuse) the GDG looked for general common themes that could be applied to all vulnerable women with complex social problems in pregnancy. It is acknowledged that there are limitations to this approach. For example, some women would fall into more than one of the categories chosen whilst other socially disadvantaged women would not be represented specifically. It was hoped that by focussing on four disparate groups and then identifying general themes, generic guidance would be produced that would inform care provision for vulnerable women who face a range of complex social issues in pregnancy.

## 3.2 Access to Care

The main focus of this guideline has been how to improve access to antenatal care for vulnerable women. This was defined in terms of gestation at booking and uptake of additional antenatal services including antenatal education. Whilst undertaking the systematic reviews for this guideline an additional definition of access emerged. This was particularly true for recent migrant women, women with little or no English, asylum seekers and refugees, and women experiencing domestic abuse. For both these populations access to antenatal appointments per se appeared to be less of a problem, with findings from some studies showing that gestation at booking was similar to that reported for the general population.<sup>20;21</sup> However, it is apparent that these women often do not receive appropriate/optimal antenatal care. The reason for this could be described in terms of impaired access to additional supportive care due to ineffective communication with antenatal care providers.<sup>22-25</sup> For women with little or no English, or from a different cultural background, poor communication (including mistaken assumptions based on cultural stereotypes as well as language difficulties) was frequently reported as a barrier to care.<sup>26-32</sup> For women experiencing domestic abuse insensitive staff attitudes and ignorance/lack of understanding/lack of knowledge in talking with women who had disclosed or were suspected of experiencing domestic abuse led to these women feeling consultations had been unhelpful and discouraged them from attending for future appointments or discussing the issue further.<sup>33;34</sup> This lack of effective communication also meant these women were denied the help and support they needed, both from the consulting health care professional and through lack of appropriate referral to other agencies.<sup>35</sup>

It could be argued therefore that access has 2 components – physical access and cognitive/mental access. The former constitutes what is normally meant by the term “access” i.e. Uptake of services. Cognitive/mental access is an additional component which requires physical access but underlines the fact that physical access in itself is not enough. Being physically present at an antenatal consultation does not mean that a woman will benefit from it the way care providers intend. If communication during the consultation is ineffective, for whatever reason, the woman has not fully accessed care but merely attended for it. The additional care she needs may be denied her either because she has not received the information she needs, has not understood the information given or because her needs have not been fully understood and appropriate referrals have not been made.

This cognitive component of accessing care therefore relies upon effective communication between women and care providers. Through the review of barriers to service uptake a number of examples have been highlighted where communication is hampered. This occurs most obviously where there is a difference in language but can also be due to the woman feeling unable to speak openly and honestly<sup>23;34</sup> or staff being unable to provide the care she needs.<sup>30;36</sup> Examples of the latter categories are common to each of the 4 exemplar populations and are summarised below:

### *Woman herself:*

- Feeling awkward/ ill at ease<sup>27;34;37-40</sup>
- Fear of being judged<sup>23;33;34;38;41</sup>

### *Staff:*

- Judgemental/poor attitude<sup>23;24;30;34;41-43</sup>
- Lack of knowledge of support/services available<sup>26;28;30;36;43;44</sup>
- Lack of understanding of issues faced by woman<sup>27;28;31;32;36-38;41;45</sup>

Consideration of gestation at booking and maintaining contact with services is not sufficient in terms of determining good service provision. It is also important to communicate effectively with women, fully assessing her health and social needs so that the information and support she needs can be provided. Good communication lies at the heart of good antenatal care provision.

In order to enable women to fully access care, maintain contact with services and benefit from this, 3 aspects of care provision need to be considered: service organisation and delivery; training for staff and care provision at an individual level. Recommendations made within this guideline are made for each of these three areas. Many of the recommendations relate to communication. At the service level these highlight the importance of good communication between agencies whilst at the individual level they relate to communication between care providers and the women they meet as well as communication between members of staff, again including cross-agency communication. The recommendations for training recognise that in order to meet some of these recommendations staff education and support may be needed.

## **3.3 General principles of care**

Every woman is an individual with her own set of needs, wishes and concerns which need to be evaluated and acted upon. However, health and social services must provide programmes of care that best meet the needs of a wide range of women, thus it is necessary to identify general principles of care that will meet women's needs at the service/organisational level.

The recommendations outlined in this section apply to services providing care for women with complex social needs.

### **GDG interpretation of evidence**

This GDG interpretation refers to all the evidence reviewed in the following four chapters. The majority of the evidence included for each exemplar population comprised studies of very poor methodological quality, with little of it being conducted in the UK. This is explained partly by the complex nature of the interventions under investigation which makes it difficult to design studies controlling potential bias. Added to this is the almost complete absence of outcomes-based comparative data available for service innovation carried out in the UK NHS.

A new health economic model was developed for this guideline with the specific aim of assessing the cost-effectiveness of additional care versus normal antenatal care services. The analysis was based on descriptions of services that are currently provided across the UK. The framework for economic analysis in this guideline is a 'what if' analysis due to the limited clinical evidence available to populate the model. Therefore the model can only be used to illustrate the problem as we do not know how effective specialist services will be in the real world.

There is an urgent need for future service changes to be subject to rigorous evaluation in a way that allows valid comparison to be made between different service models in terms of pregnancy outcomes

and women's views of care. Without this it is not possible to determine which models of service provision are clinically and cost-effective. Furthermore, it is possible that, given the difference identified in the reviewed evidence in terms of women's needs and preferences (e.g. young women aged under 20's preference for dedicated services with age-specific content, the need to help recent migrant women, refugees and asylum seekers keep in touch with services and to communicate their whereabouts effectively between service providers) different models of service provision will be needed for different vulnerable groups. Comparative outcome data for sub-groups of potentially vulnerable women is thus needed in order to identify which service models meet these different needs and improve outcomes for these different groups. The GDG agreed this should be a key priority recommendation. Once data are available which inform mapping of the local population in terms of level of need and prevalence of particular vulnerable populations, services can be organised to better meet those needs. Based on consensus the GDG made a key priority recommendation that this information be collected in order to inform service planning. In order to do this effectively the GDG highlighted the importance of involving local community groups in both data collection and service planning in order to improve the validity of the information collected and to ensure that planned service changes respond appropriately to the needs identified, and included this as a key recommendation also.

The GDG felt that a recommendation to encourage collection of ongoing audit data for service change was a key output of this guideline. Key process outcomes for monitoring effectiveness of service change were aimed at improving access to and contact with antenatal care were identified by the GDG as being gestation at booking and the number and proportion of scheduled antenatal appointments attended. For gestation at booking the GDG agreed 3 gestations that should be used as audit targets, 10 weeks, 12<sup>+6</sup> weeks and 20 weeks of pregnancy. Ten weeks was chosen as this is the target set out in the NICE Antenatal Care Guideline Update (2008)<sup>1</sup>, The GDG acknowledged this to be a difficult target to attain, especially for women in vulnerable groups and so added a second target for early booking, a target well-recognised within maternity services, booking by the end of the first trimester of pregnancy (12<sup>+6</sup> weeks). A gestation for late booking was chosen by GDG consensus based on what the GDG recognised as a widely accepted definition and which is associated with the upper limit for carrying out serum screening for Down's syndrome and anomaly screening using ultrasound (20 weeks). If such data are collected locally in a consistent way then recommendations for future NHS service provision can be made based on much more robust, and relevant data. It was felt important to collect data to describe local populations and to identify local needs as well as audit data for all women, including women facing complex social needs. By recording which vulnerable group each woman falls into (e.g. aged under 20 years, substance misuser, non-English speaking etc) the level of need for each type of supportive service could also be measured.

Despite the poor quality of evidence it was possible to identify some recurrent themes within the findings of studies reviewed. Where these themes have been identified across all four populations and are supported by GDG expert opinion, overarching recommendations have been made.

The need for encouraging early booking has already been identified for all pregnant women (NICE Antenatal Care guideline, 2008).<sup>1</sup> The basis for this includes the importance of an early ultrasound scan in order to accurately date the pregnancy (accurate dating of pregnancy leads to reduced rates of induction of labour for post-maturity, NICE Induction of Labour guideline 2008)<sup>11</sup> and the need to conduct haemoglobinopathy screening (NICE Antenatal Care guideline).<sup>1</sup> It is likely that early assessment of pregnancy needs and screening also lead to more appropriate antenatal care which in turn would result in improved pregnancy outcomes, although there is little evidence to support this in income-rich counties. Based on their clinical experience, the GDG agreed that it is likely that this assertion would be even more applicable to vulnerable women with complex social problems. One way to achieve early booking is to encourage health and social care professionals to refer women to a midwife or antenatal clinic when a pregnancy is first disclosed. At this early stage it may also be appropriate to discuss the option of termination of pregnancy and how this might be obtained.

Evidence across all four exemplar populations highlighted the varied potential needs of women with complex social problems, including communication and housing needs of recent migrant women, asylum seekers and refugees; the need for information regarding benefit entitlements and housing advice for women across groups on low incomes; and safety advice and emotional support for women experiencing domestic abuse, as well as varied health needs across the groups. This wide range of needs across both health and social care might be provided by either statutory or third sector agencies. This underlines the

importance of effective communication between these agencies in order to ensure that women can have these needs met making best use of all available services and support.

Good communication between agencies can be promoted by assessing a woman's health and social needs using records/documentation that is common to both health and social care providers and that can be used by both agencies. In order to carry this out effectively health and social care professionals need to be aware of best practice\* and trained in the processes currently in use, for example the Common Assessment Framework. Many of the service descriptions included in the service survey include this component. Two examples from the service survey that illustrate how additional care can be provided for a range of vulnerable women are given in Box 3.1. One of the examples, the One to One midwifery teams at the Imperial College healthcare NHS Trust, is a flexible service that provides continuity of carer with planned interagency assessment and joint care planning. The other example is a much simpler intervention, the Hackney Maternity Helpline, which aims to improve access for all women.

The need for staff to communicate sensitively and the negative impact of poor staff attitudes on women accessing care were evident throughout the evidence reviewed, particularly for question 1b in each chapter. Whilst training would be felt to be beneficial, both for healthcare professionals and other staff (eg. receptionists), the form this training should take is less clear. It may well be that in-house workshop formats would be effective in enabling staff to reflect on their attitudes and change behaviour where necessary. A research recommendation has been made, therefore, to encourage work to be undertaken in this area.

There is evidence that concern over disclosure of personal circumstances e.g. substance misuse, migrant status and domestic abuse is a barrier to women accessing antenatal care. For this reason it is vital that health care professionals explain the reasons why such details are needed, with whom they will be shared, and why this sharing of information is important. The GDG agreed that in order to facilitate discussion of sensitive issues it is imperative that all women are offered at least one opportunity, and preferably more than one, for a one-to-one consultation with a health care professional with no other person present (unless an interpreter is needed, in which case this should not be a partner, friend or family member).

For all four exemplar groups some difficulty maintaining contact with services has been identified from the evidence. The reasons for this vary depending upon a woman's circumstances and may be due to, for example: frequent changes of address which may also be at short notice (e.g. recent migrant women, asylum seekers and refugees); a lifestyle that means antenatal consultations are of low priority (e.g. young women aged under 20, substance misusers); or having a partner who physically or psychologically restricts the woman's freedom (women experiencing domestic abuse). A simple way of helping women to maintain contact with antenatal services despite missing antenatal appointments is to provide at booking a telephone number which enables 24 hour contact with a healthcare professional. The provision of a contact number was described in the evidence and endorsed as common practice by the GDG. Whilst it will not always be possible for women to contact their individual healthcare professional (who may be a lone specialist in a particular area e.g. substance-misuse etc.) directly, providing a 24 hour telephone number ensures that these women will always be able to contact a healthcare professional who should be able to provide immediate support and recognise whether a woman needs to be seen urgently by a healthcare professional. A message can be left for the specialist healthcare professional to let them know what has occurred and to enable them to plan any follow up that may be necessary.

Healthcare professionals should also ask women to contact the hospital if she changes address. In addition, the GDG were aware of instances where it is not possible for women to keep her hand-held maternity records when moving from one maternity unit to another. This barrier to communication was felt to be detrimental to a woman's care and that services should be organised so that all women are able to keep their hand held notes at all times, including when they move to another area, in order to facilitate good inter-agency and cross-boundary liaison. It was also recognised that the hand-held version of the records should be kept complete and up to date, including all antenatal test results.

The needs of partners of women with complex social factors, and the role they may have to play in encouraging access and contact, are not contained in the evidence. This almost complete lack of research-based information prompted the GDG to add research recommendations to address this gap in

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\* Department for Children, Schools and Families, and Communities and Local Government (2008) Information sharing: guidance for practitioners and managers. London: Department for Children, Schools and Families, and Communities and Local Government. Available from [www.publications.everychildmatters.gov.uk/](http://www.publications.everychildmatters.gov.uk/)

knowledge. In addition, whilst the GDG felt from personal experience that involving third sector agencies in antenatal care of vulnerable women was valuable there was no comparative UK evidence to support this, particularly relating to pregnancy outcomes. Again a research recommendation has been made to encourage further work in this area.

The following recommendations were originally drafted for each of the four exemplar populations individually, derived from the evidence base and GDG interpretation for each one. Once recommendations had been drafted for all four populations common themes were identified across each of the populations. These themes were then drawn out in order to formulate “general” recommendations to guide care for all vulnerable women.

## 3.4 Recommendations

### Service organisation

In order to inform mapping of their local population to guide service provision, commissioners should ensure that the following are recorded:

- The number of women presenting for antenatal care with any complex social factor<sup>\*</sup>
- The number of women within each complex social factor grouping identified locally

Commissioners should ensure that the following are recorded separately for each complex social factor grouping

- The number of women who:
  - attend for booking by 10, 12<sup>+6</sup> and 20 weeks
  - attend for the recommended number of antenatal appointments, in line with national guidance<sup>†</sup>
  - experience, or have babies who experience, mortality or significant morbidity.<sup>‡</sup>
- The number of appointments that each woman attends
- The number of scheduled appointments that each woman does not attend

Commissioners should ensure that women with complex social factors presenting for antenatal care are asked about their satisfaction with the services provided; and the women’s responses are:

- Recorded and monitored
- Used to guide service development

Commissioners should involve women and their families in determining local needs and how these might be met.

Individuals responsible for the organisation of local maternity services should enable women to take a copy of their handheld notes when moving from one area or hospital to another.

### Training for healthcare staff

Healthcare professionals should be given training on multi-agency needs assessment<sup>§</sup> and national guidelines on information sharing<sup>\*\*</sup>

### Care provision

<sup>\*</sup> Examples of complex social factors include: poverty; substance misuse; recent arrival as a migrant; asylum seeker or refugee status; difficulty speaking or understanding English; age under 20; experiencing domestic abuse; traveller. Complex social factors may vary across different local populations

<sup>†</sup> See ‘Antenatal care’ (NICE clinical guideline 62)<sup>1</sup>

<sup>‡</sup> i.e. morbidity that has a lasting impact on either the woman or the child

<sup>§</sup> For example, using the Common Assessment Framework

<sup>\*\*</sup> Department for Children, Schools and Families, and Communities and Local Government (2008) Information sharing: guidance for practitioners and managers. London: Department for Children, Schools and Families, and Communities and Local Government. Available from [www.dcsf.gov.uk/everychildmatters/publications/](http://www.dcsf.gov.uk/everychildmatters/publications/)

Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children<sup>2</sup>

Consider initiating a multi-agency needs assessment, including safeguarding issues\* so that the woman has a coordinated care plan.

Respect the woman's right to confidentiality and sensitively discuss her fears in a non-judgemental manner.

Tell the woman why and when information about her pregnancy may need to be shared with other agencies.

Ensure that the handheld notes contain a full record of care received and the results of all antenatal tests.

### **Information and support for women**

For women who do not have a booking appointment, at first contact with any healthcare professional:

- discuss the need for antenatal care
- offer the woman a booking appointment in the first trimester, ideally before 10 weeks if she wishes to continue the pregnancy, or
- offer referral to sexual health services if the woman is considering termination of the pregnancy.

At the first contact and at the booking appointment, ask the woman to tell her healthcare professional if her address changes, and ensure that she has a telephone number for this purpose.

At the booking appointment, give the woman a telephone number to enable her to contact a healthcare professional outside of normal working hours, for example the telephone number of the hospital triage, labour ward or birth centre.

In order to facilitate discussion of sensitive issues, provide each woman with a one-to-one consultation without her partner, a family member or a legal guardian present, on at least one occasion.

## **3.5 Research recommendations**

### ***Training for healthcare staff***

What training should be provided to improve staff behaviour towards pregnant women with complex social factors?

#### **Why this is important**

The evidence reviewed suggests that women facing complex social problems are deterred from attending antenatal appointments, including booking appointments, because of the perceived negative attitude of healthcare staff, including non-clinical staff such as receptionists. It is expected that education and training for staff in order to help them understand the issues faced by women with complex social factors and how their own behaviour can affect these women will reduce negative behaviour and language. A number of training options currently exist that could be used in this context; however, which of these (if any) bring about the anticipated positive changes is not known. Given the resource implications of providing training across the NHS it is important to ascertain the most cost-effective way of providing this.

### ***Effect of early booking on obstetric and neonatal outcomes***

Does early booking (by 10 weeks, or 12<sup>+6</sup> weeks) improve outcomes for pregnant women with complex social problems compared with later booking?

#### **Why this is important**

The NICE guideline on 'Antenatal care' (NICE clinical guideline 62) recommends that the booking appointment should ideally take place before 10 weeks and 'Maternity matters'<sup>†</sup> supports booking by 12 weeks for all women. The main rationale behind these recommendations is to allow women to participate in antenatal screening programmes for haemoglobinopathies and Down's syndrome in a timely fashion, to have their pregnancies accurately dated using ultrasound scan, and to develop a plan of

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\* For example, using the Common Assessment Framework

care for the pregnancy which sets out the number of visits required and additional appointments that may need to be made.

Pregnant women with complex social factors are known to book later, on average, than other women and late booking is known to be associated with poor obstetric and neonatal outcomes\*. It seems likely that facilitating early booking for these women is even more important than for the general population of pregnant women. There is, however, no current evidence that putting measures in place to allow this to happen improves pregnancy outcomes for women with complex social factors and their babies.

### ***How can different service models be assessed?***

What data should be collected and how should they be collected, and shared, in order to assess the quality of different models of services?

#### **Why this is important**

There is a paucity of routinely collected data about the effectiveness of different models of care in relation to demography. Although mortality data are accurately reflected in reports published by the Confidential Enquiry into Maternal and Child Health†, morbidity and pregnancy outcomes are not often linked back to pregnancies in women with complex social factors. Most research in the area of social complexity and pregnancy is qualitative, descriptive and non-comparative. In order to evaluate the financial and clinical effectiveness of specialised models of care there is a need for baseline data on these pregnancies and their outcomes in relation to specific models of care.

A national database of routinely collected pregnancy data needs to be designed. Currently it is impossible to determine which data should be collected. In the first instance the database could be developed for use in areas of high ethnic diversity and social risk. Existing models of care should be designed to collect data in similar formats to allow national and international comparisons.

### ***Models of service provision***

What models of service provision exist in the UK for the four populations addressed in this guideline who experience socially complex pregnancies (women who misuse substances, women who are recent migrants, asylum seekers or refugees or who have difficulty reading or speaking English, young women aged under 20, and women who experience domestic abuse)? How do these models compare, both with each other and with standard care, in terms of outcomes?

#### **Why this is important**

The evidence reviewed by the GDG was poor in several respects. Many of the studies were conducted in other parts of the world, and it was not clear whether they would be applicable to the UK. Many of the interventions being studied were multifaceted, and it was not clear from the research which aspect of the intervention led to a change in outcome or whether it would lead to a similar change in the UK. Also, in some instances it was not clear whether a particular intervention, for example a specialist service for teenagers, made any difference to the outcomes being studied.

Developing a clear and detailed map of existing services in the UK for pregnant women with complex social factors, and the effectiveness of these services, would enable us to set a benchmark for good practice that local providers could adapt to suit their own populations and resources. A map of providers, their services and outcomes may also enable commissioners and providers to learn from each other, work together to develop joint services and share information in a way that would lead to continuous improvement in services for these groups of women.

### **Additional research recommendations**

Does providing information to partners and family members of vulnerable pregnant women help to improve early access?

What effect does involving 3rd sector agencies in providing support and coordination of care for vulnerable women have on outcomes?

\*Confidential Enquiry into Maternal and Child Health (2007) Saving mothers' lives: reviewing maternal deaths to make motherhood safer – 2003–2005. London: Confidential Enquiry into Maternal and Child Health. Available from [www.cmace.org.uk/publications](http://www.cmace.org.uk/publications)

† Confidential Enquiry into Maternal and Child Health (2009) Perinatal mortality 2007. London: Confidential Enquiry into Maternal and Child Health. Available from [www.cmace.org.uk/publications](http://www.cmace.org.uk/publications)

Is family support provided by statutory and 3rd sector agencies effective in improving outcomes for women and their babies?

Does involving partners and families improve vulnerable women's access to and contact with antenatal services?

**Box 3.1** Service descriptions for all women with complex social factors

Imperial College Healthcare NHS Trust, London, currently has 5 One to One Midwifery teams totalling 27 Midwives, all holding individual caseloads of 34-36 women per year. The One to One midwives provide full antenatal, intrapartum and postnatal care for all women referred to them. Women are allocated a named midwife to provide continuity, emotional and social support, flexible, individualised care and robust multi-agency liaison. For women, this service means having their care provided by someone that they come to know and trust - giving them the opportunity to form a strong working relationship with a professional. Where situations are complex or distressing, women do not have to keep re-telling their stories (or choosing not to). Having a known point of contact is helpful to women who might otherwise find it difficult to engage with care or ask questions and discuss issues. The Midwives also come to know their clients very well, which is invaluable in liaising and developing care plans with multi-agency colleagues, particularly in complex social cases. Potential risks to children are assessed and either early intervention or safeguarding procedures initiated appropriately. Multi-agency liaison is co-ordinated and followed up, ensuring both high quality perinatal care and that longer term plans are initiated and professionals fully briefed so that care continues effectively after discharge from midwifery. (Appendix D, number 1).

The Hackney Maternity Helpline was set up to give local women across Hackney direct access to an experienced midwife. The Helpline opened in September 2007 with the following aims:

- To pilot a maternity phone line advice service
- To provide direct access to professional clinical advice
- To facilitate earlier access to maternity care.

The Helpline is based at Homerton hospital, London, and is open seven days a week, from 10am to 6pm. It is staffed by a full-time co-ordinating midwife, in addition to six part-time Homerton clinical midwives, each working on the Helpline for one or two days per week. All Helpline staff are experienced midwives.

A telephone Helpline database system was specifically commissioned, designed and built to capture details of calls taken and advice given. Helpline midwives have access to the Homerton Hospital electronic records system, which means that they can access information about women already booked with Homerton and/or register women directly who have not yet presented for care.

Publicity business cards (printed in English, French, Turkish, Spanish, Portuguese and Vietnamese) and posters were distributed across the borough, in locations including GP surgeries and community pharmacies, who give out the small card when they sell pregnancy testing kits, or if pregnant women come to them with queries. The helpline number is clearly marked on the front of all clients' hand-held maternity records. (Appendix D, number 13)

In the following four chapters evidence is presented and recommendations made for each of the four exemplar groups of women with complex social problems. The general recommendations above apply to all four groups and will not be repeated. In the chapters relating to the exemplar groups, it will be seen that there are similarities in some of the recommendations, however the majority are particular to a specific group. This was surprising as more common themes were anticipated than actually arose from the evidence. The significance of this observation is that specific groups of women with differing needs have different requirements from their antenatal care providers over and above standard antenatal care. Whether or not a dedicated or specialist service is established to meet the antenatal needs of a particular group of women will depend upon a number of variables including the prevalence of the problem and the availability of appropriately trained and/or experienced staff to provide the service. However, the establishment of specialist services is not the main thrust of this guideline. There are additional challenges that need to be addressed when delivering services to meet the needs of women with complex social

problems: how care provided by different agencies can be better co-ordinated, how training for staff can be used to raise standards and how care provided on an individual level can better meet the specific needs of these vulnerable women.

# 4 Women who misuse substances

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## 4.1 Introduction

The 2007 Confidential Enquiry into Maternal and Child Health highlighted that some complex social factors, including substance misuse, were associated with an increased risk of maternal death and/or infant death in the perinatal period.<sup>3,5</sup>

One of the key issues leading to a poor pregnancy outcome is that women misusing substances do not access or maintain contact with maternity services and are likely to experience other social disadvantages.

*Saving Mothers' Lives* provides important information about the problems of maternity service provision in the UK for women experiencing substance misuse. Of the 295 maternal deaths identified in this triennium (2003-2005), 93 of the women who died had problems with substance misuse. Of these, 52 were drug addicts, another 32 were occasional drug users and the remaining women were alcohol dependent. Seven died in early pregnancy before they could access maternity care. Of all the deaths due to, or associated with substance misuse, it is noteworthy that the majority took place after 42 days after birth.<sup>3</sup>

The multiple and complex issues involved in working with families who have substance misuse problems have long been evident. Between 250,000 and 350,000 children are affected by parental drug misuse in the UK and up to 1.3 million children are living with parents who misuse alcohol. Parental substance misuse 'causes serious harm to children at every age from conception to adulthood'.<sup>4,6</sup>

An increasing number of maternity services within the UK have appointed specialist midwives to co-ordinate the care for substance misusing women and to promote inter-agency care planning. Funding is also often jointly commissioned with local drug and alcohol strategy teams leading to shared responsibility and improved communication. *Saving Mothers' Lives* recommended that integration be achieved for each maternity service ideally by joint care provision between addiction and maternity services for these vulnerable women. If that was not possible, there should be joint discussion of care plans between services to improve the information held by each.<sup>3</sup>

This guideline seeks to identify the service organisation and delivery which would best encourage access, contact and use of services by substance misusing women. It describes what additional consultation and support is required. This will include:

- consideration of the most appropriate healthcare setting for maternity care provision;
- best practice models for overcoming barriers and facilitating access throughout pregnancy;
- ways of communicating the necessary information to women to make appropriate choices;
- a package of appropriate levels of midwifery, other health care, as well as social care input;
- optimisation of resources.

The next section will review evidence of effectiveness of different models of care in terms of promoting access and encouraging women to maintain in contact with antenatal care services, and any additional support and information which has been shown to improve pregnancy outcomes for substance misusing women. Barriers to accessing care are also described. The target population for inclusion was women who misuse substances, including alcohol. This was defined as regular use of substances and/or alcohol e.g. on a weekly basis, to an extent where physical dependence and/or harm to their health or that of their unborn baby is a risk. The level of substance misuse defined within each paper considered for inclusion was discussed with the GDG where it was unclear whether the population was one that would be defined

as “substance misusers” and decisions to include or exclude made on the basis of this discussion and with the GDG’s agreement.

## 4.2 Access to antenatal services

### Clinical question

Q1a. What aspects of service organisation and delivery are effective at improving access to antenatal services for women misusing substances?

### Previous guidance

There is no previous NICE guidance addressing this question.

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Comparative studies investigating the effectiveness of antenatal interventions and/or service provision initiatives with improved access as either a primary or secondary outcome were included for consideration in the review. This aim did not have to be stated a priori, a study would also be considered if access outcomes were reported despite this not being described as a study objective. The main outcome of interest for this question was the stage of pregnancy when antenatal care was initiated. Thirteen papers were originally retrieved to answer this question. After weeding and quality appraisal only one UK retrospective cohort study, two US descriptive studies and one retrospective Australian study were identified for inclusion.

### Narrative summary of evidence

A UK retrospective cohort study described neonatal outcomes in methadone-exposed infants and the results of follow-up before (1991-1994) (n=78) and after (1997-2001) (n=98) the establishment of a drug-liaison midwife (DLM), a revised methadone prescribing regimen and modified neonatal care which exempted compulsory admission of all methadone exposed newborns to newborn medical unit (NMU) and advocated usual care in maternity ward with the provision of transfer to NMU if the baby developed neonatal abstinence syndrome or on any other clinical grounds [EL=2-].<sup>47</sup> The DLM provided antenatal care, including home visits when hospital appointments were missed and co-ordinated care between health and social care providers facilitated by monthly multidisciplinary meetings involving a consultant neonatologist.

In 1997-2001 the booking visit took place in the first trimester of pregnancy in 84 of 97 women (86.6%) and the dose of methadone prescribed ranged from 30 to 180mg/day. In 1991-1994 data were available for 63 women; 37 (58.7%) had booked in the first trimester of pregnancy, and the dose of methadone prescribed ranged from 8 to 160mg/day. The improvement in the number of women booking in the first trimester is statistically significant ( $\chi^2=16.09$  df=1  $p<0.0001$ ) (NCC-WCH analysis).

Due to the multi-faceted nature of the service intervention it is not possible to say for certain which components of the service changes were responsible for this observed difference in proportion of women booking in the first trimester, although it is likely that the antenatal components of the service would have contributed most to this (the introduction of a DLM and a revised methadone regimen).

A US descriptive study (1995)<sup>48</sup> [EL=3] described changes in caregiver attitude and behaviour toward substance-using pregnant women observed during the process of implementing an innovative model of enhanced antenatal care.

A model of care was developed to allow early intervention to help substance abusing women of childbearing age (CSAP project). In this model nurse midwives worked closely with each woman and with on-site counsellors to provide comprehensive and integrated care addressing medical, addiction and psychological needs. Training was given to staff on the effect of various substances of abuse on women and their developing fetus, the nature of addiction, and interviewing skills to obtain information about substance use from women attending the antenatal clinic.

Data were collected through participant observation of the staff during training sessions and meetings on a continuous basis over an 18 month period. In addition, interviews were conducted with each of the nurse midwives (n=7), 9 months into the CSAP demonstration project.

Education about the nature of addiction had a positive impact on staff attitudes and resulted in a reduction of staff anxiety that the authors concluded 'clearly affected their behaviour'. Structural changes in the antenatal clinic were also reported to have had a significant impact on the nurse midwives attitudes.

The first major structural change was the decision by the nurse midwives to keep substance abusing women in their care (formerly they were categorised as high risk and the care was handed over to physicians). These changes resulted in increased continuity of care and increased frequency of standard antenatal visits (no further details are reported).

The second major structural change in the clinic was the addition of on-site services to address addiction and other life issues. This comprised the establishment of a counsellor in the same physical space and within the same administrative system as the nurse midwives, who could see women in need of treatment. This meant that the nurse midwives received feedback from the women's acceptance of the referral and had the opportunity for collaboration with the counsellor while continuing to play a significant role in treatment. The counsellor and nurse midwives met to discuss cases on a bi-monthly basis as well as one-to-one case consultations to plan care. If a woman declined meeting a counsellor the nurse midwife would meet with the counsellor as necessary to discuss care and management issues without the woman's involvement.

Two years after the programme was initiated the proportion of drug misusing pregnant women self reporting/disclosing drug misuse had increased from 24.4% to 70.8%. The remainder were identified through urine toxicology testing.

An Australian retrospective cohort study examined the association between retention in a methadone treatment programme during pregnancy and key neonatal outcomes, by retrospective analysis of the medical records of 2993 births from women recorded as being on methadone treatment at delivery from 1992 to 2002 [EL=3].<sup>49</sup>

Maternal and neonatal outcomes were compared for 3 groups of women:

1. The 'early entry' group were those who entered continuous methadone treatment at least one year prior to birth (n=1213).
2. A late entry group who entered continuous treatment in the 6 months prior to birth (with any previous programme ending at least 1 year prior to birth) (n=306) (with attendance at a previous programme (if any) ending at least 1 year prior to birth)
3. A 'previous treatment' group comprised those women whose last treatment programme ended at least one year prior to the birth (n=711).

Late entrants to methadone treatment were most likely to access their first antenatal visit later (>20 weeks) in pregnancy (n=139, 51.9%) compared with women in the early entry group (n=368, 34.4%) or previous treatment group (n=221, 31.5%) (p<0.001) (missing data mean these figures do not tally).

A US retrospective study (2003)<sup>50</sup> [EL=2-] was undertaken to evaluate the relationship between maternal substance abuse interventions during pregnancy, as provided by a large community clinic-based programme, and subsequent neonatal outcomes.

Six thousand, seven hundred and seventy-four women members of Kaiser Permanente medical care, Northern California Region, were screened for substance abuse by a questionnaire as well as urine toxicology from July 1995 to June 1998. An obstetric clinic-based antenatal substance abuse intervention programme known as the Early Start program provided pregnant women with screening and early identification of substance abuse problems, early intervention, ongoing counselling and case management by a licensed clinical therapist - the Early Start specialist.

Four groups were compared: Group 1: 'screened assessed and treated' (SAT, n=782) consisted of women who were screened and assessed by the Early Start Programme and diagnosed as chemically dependent or substance-abusing by the Early Start specialist and had at least one follow-up Early Start appointment.

Group 2: 'screened and assessed' (SA, n=348), consisted of women assessed and diagnosed as chemically dependent or substance-abusing by an Early Start Specialist but who, for a variety of reasons, did not have any subsequent early Start follow-up appointments.

Group 3: 'screened only' (S, n=262), consisted of women who were identified as substance abusers based on screening but, for a variety of reasons, were never assessed or treated by the Early Start program. Women in group 3 had a positive universal toxicology screening test with either a positive screening questionnaire (n=108) or a negative screening questionnaire (n=154).

Group 4: 'control' (C, n=5382), was composed of women with no evidence of substance abuse during pregnancy, defined by a negative screening questionnaire and negative toxicology test.

The percentage of women who began antenatal care late, (first antenatal visit after 13 weeks of gestational age) were significantly higher in all three substance abusing groups compared to the control ( $p < 0.001$ ). However, the rates of late (>13 weeks) booking for first antenatal visit for the SAT women were significantly lower than the rates for the SA group ( $p = 0.003$ ). The SAT group received a significantly higher median amount of antenatal care than SA, S and control groups ( $p < 0.0001$ ). The SAT group also had lower rates than the SA group and S group for assisted ventilation, low birth weight and preterm delivery.

### **Evidence statement**

No good quality evidence was found that investigated components of service provision that would improve access, acceptability and take up of antenatal services by substance misusing women.

One UK retrospective study investigated the effect of introducing a new specialist service for substance misusing women including a drug liaison midwife and revised methadone prescribing regimen. The midwife provided antenatal care and home visits when hospital appointments were missed, co-ordinated care between health and social care providers, and revised clinical management of newborns. The findings show that the introduction of the drug liaison midwife and a revised methadone prescribing regimen were associated with more women booking in the first trimester of pregnancy.

Evaluation of a US service change, which included placement of substance misuse counsellors in the antenatal clinic and training for midwives in understanding the nature of substance misuse, reported that it was associated with an increase in midwives' skills and confidence in dealing with substance misusing women and an increase in the self-reporting by substance misusing pregnant women.

Findings from an Australian retrospective cohort study have shown that women who entered and remained in a methadone treatment programme for one year prior to the birth of their baby, or who completed a treatment programme one year prior to giving birth, were less likely to book their first antenatal visit after 20 weeks of pregnancy compared with women who entered the treatment programme 6 months before giving birth.

A US retrospective observational study showed that all substance misusing women attending the study hospital booked significantly later than women who were not misusing substances, although women attending a treatment and support programme were less likely to book their first antenatal appointment late, (first antenatal visit after 13 weeks of gestational age) compared with substance misusing women who did not attend the programme.

### **GDG interpretation**

It was agreed to combine the interpretation for question 1a and 1b due to the related nature of the evidence

## 4.3 Barriers to care

### Clinical question

Q1b. What aspects of service organisation and delivery act as barriers to take up of antenatal services for women misusing substances?

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. After weeding and first round exclusions, 19 papers were retrieved that answered the question and identified barriers to care, either from the woman's point of view or that of service providers. For this review both service barriers e.g. waiting times, attitude of staff, distance to antenatal clinic and personal factors e.g. woman feelings of guilt, lack of knowledge about importance of antenatal care are included. This was felt to be important as some of the personal factors may also be modifiable through service interventions e.g. information posters. It was also felt that a knowledge of these personal barriers would help service providers to provide more appropriate, personalised services. After assessment ten papers were included in the review. Two studies were comparative (2003)<sup>51</sup> (2007)<sup>52</sup>, although not RCTs, and the rest of the studies were descriptive [EL=3]. Two of the included studies were conducted in the UK<sup>38,43</sup>. Six studies were from the US, and two were Australian. Two of the studies looked at barriers as perceived by the pregnant women, four looked at barriers as perceived by staff and four investigated the views of both groups.

### Narrative summary of evidence

Please see Evidence Table for study details.

#### Studies reporting barriers identified by women

A small descriptive study with 12 women participating was carried out in Aberdeen (2006)<sup>38</sup> [EL=3]. All women had previously been intravenous (IV) heroin users. The women were reported to be sensitive to their situation and needed assurances of confidentiality regarding what was discussed during appointments. To many women it was impossible to face up to being pregnant because they felt so guilty about their drug use and the effect this would have on the baby. For several this encouraged drug use because it acted as a release. Aspects of care rated most highly were non-judgmental attitude of staff, reassurance and provision of reliable information, consistency of staff and high level of support in terms of frequency of visits and time given to each client.

A second US descriptive study (2003)<sup>51</sup> [EL=3] examined the barriers identified by 36 pregnant and parenting women in northern California. The major concern towards disclosing drug use in pregnancy was fear about the baby being taken by child protection services, arrest and prosecution. Other barriers identified to accessing care were domestic violence, poverty, homelessness and imprisonment.

#### Studies reporting barriers identified by service providers or identified from records

A UK survey of a sample of 50 nurses/midwives from a population of approximately 120 nurses/midwives in a 44 bedded regional neonatal unit was conducted in Scotland using a self report questionnaire (2003)<sup>43</sup> [EL=3]. The purpose of this study was to determine attitudes of health care providers towards mothers and infants affected by substance misuse and to examine the relationship between knowledge/education/experience and attitudes. The study found that the attitude of nurses/midwives towards women affected by substance misuse was generally negative/judgmental. The most experienced neonatal nursing staff had a more negative attitude overall than those with less neonatal experience. Formal education in neonatal nursing did not appear to have a positive effect on staff attitude to substance misusing women. On the other hand training in substance misuse was associated with a slightly more positive attitude towards substance misusing women: 71% (12/17) in the least negative attitude group had undertaken additional education in substance misuse, compared with 52% (11/ 21) of medium and 58% (7/12) of the most negative attitude group, this difference is not statistically different however ( $\chi^2=1.32$ ,  $df=2$ ,  $p=0.518$ ; NCC-WCH analysis).

A US prospective cohort study (2007)<sup>52</sup> [EL=2+] compared medical students' attitudes to substance misusing pregnant women and their comfort in addressing them. Students who had attended an antenatal clinic for substance misusing women (n=52) were compared with those who had not (n=52) using a questionnaire survey. There was a significant increase in the comfort score for students who attended the clinic compared with those who had not. However, the overall attitude towards substance misusing women was not affected, although students who had attended the clinic were more likely to feel non-judgmental towards the women than students who had not.

The perceived barriers to seeking help for alcohol use during pregnancy by US rural, small town antenatal service providers (nurses, doctors, and health educators; total n=138) were investigated (2003)<sup>53</sup> [EL=3]. This work identified a number of barriers including lack of appropriate facilities, transport, lack of support from friends and family, social stigma, and fear of partner abuse if help was sought.

A US retrospective cohort study (2003)<sup>51</sup> [EL=2-] examined the differences between women who accepted or declined referral to an antenatal addictions day treatment programme. Women were eligible if they had a current alcohol or drug use disorder or were newly abstinent, a group which has a high risk of relapse. Of those qualifying for admission, 102 accepted and 23 declined. Women who enrolled in the treatment were more likely to report higher rates of childhood sexual abuse compared to those who declined, (32% vs. 13%, p=0.07). More women who accepted treatment reported 'crack' cocaine as their primary drug (84% vs. 56%, p=0.003). Legal problems were common among women who enrolled in the programme and included being on probation, parole or having pending court dates. Women who declined treatment had lower scores for psychological distress and drug dependency compared to those who accepted referral.

#### **Studies reporting barriers identified by women and service providers**

A US evaluation of Baltimore's Comprehensive Family Support Strategy (BCFSS) was undertaken using a questionnaire survey of the paraprofessional home visitors and interviews with a selected sample of clients (2005)<sup>54</sup> [EL=3]. Paraprofessionals were used as home visitors to provide a range of services such as care coordination, parenting support, income and nutritional assistance, job training as well as services to address other malleable risks like substance abuse. One hundred and eighty nine mothers from a group, nominated by programme managers, who were believed to have the "best/strongest" relationship with the programme, were interviewed. No significant difference was observed between the communication frequency of home visitors about substance abuse based on whether they scored positive or negative for the risk of substance abuse. The majority of women reported that they had talked about substance abuse and other risk areas at least "sometimes". Only 1 out of 29 women in need of substance misuse treatment were received it following appropriate referral by a home visitor despite the fact that 76% of home visitors considered themselves adequately trained and 89% thought that they were personally effective.

An earlier US study (1999)<sup>55</sup> [EL=3] used focus groups with programme administrators, programme providers (n=25) and pregnant (n=147) and postnatal women in treatment programmes (n=88) across five states to explore views of maternity care provision for substance misusing women. Again, fear of child custody was a main theme identified. Poor communication between services (described as "linkage problems") was identified as a potential cause of delay in treatment admission where the health care provider did not have full knowledge of the services available. The providers found it difficult to conduct 'street' outreach and had found media approaches were ineffective because of high levels of denial of substance misuse behaviour and poor literacy in the target population. Thus the most effective outreach strategy was found to be word-of-mouth. A lack of range of treatments made it difficult to match appropriate treatments to women's individual needs. A major problem associated with residential programmes was the issue of childcare.

A recent small descriptive study conducted in Australia (2008)<sup>56</sup> [EL=3] was carried out to identify difficulties and barriers that opioid dependent women have in making health care complaints during their pregnancy and early motherhood, and difficulties that staff have in receiving and responding to these complaints. A total of 13 opioid-dependent women and 10 health staff at a opioid treatment service participated in the study set in an opioid treatment service in a hospital setting in New South Wales, Australia. Difficulties that prevented women from making complaints were identified as; practical difficulties in making formal written complains (illiterate), anticipation of not being or taken seriously, and fear of repercussions including infant removal. Staff were found to adopt protective responses in handling complaints; dismissing the complaint or assessing the validity of the complaints on the basis of character, rather than assessing the complaint on a situation by situation basis.

In a recent Australian qualitative study looking at factors which influence women's disclosure of substance abuse interviews were conducted with ten midwives and ten pregnant women (2007)<sup>57</sup> [EL=3]. Only five of the pregnant women were using illicit drugs, another five were included from the young women's clinic. The midwives felt it was important to portray themselves as supportive and caring rather than confrontational and intimidating. All midwives agreed that questions about substance use were better received if asked later in the interview after a rapport had been established. Some midwives found it difficult to ask about substance use and to differentiate between types of drugs. The midwives also felt it was important not to make assumptions about who might use substances. One of the major barriers identified was fear of having their baby taken away by child protection agencies, although often notification to child protection was not seen as negative because it could lead to the offer of intensive support to enable successful parenting. Continuity of care was viewed as essential and also meant they did not need to keep retelling their story.

### Evidence statement

Eight included studies are EL=3, one is EL=2+ and one is EL=2-.

**Table 4.1 Barriers reported by substance misusing women (n=10 studies)**

<b>Service barriers reported by women</b>	<b>Personal reasons which act as barriers reported by women</b>	<b>Barriers reported by providers</b>
attitude of staff (2)	feeling guilty about drug use and effect on the baby (1)	providers not comfortable asking about substance use (2)
inconsistency of staff / lack of continuity of carer (2)	fear of arrest/prosecution (2)	providers' lack of knowledge of different drugs (1)
lack of childcare (1)	domestic violence (1)	women's fear of child custody (1)
unreliable information (1)	poverty/homelessness (1)	lack of resources/facilities (1)
need integrated care from different services (1)	worried about child custody (2)	women's denial/unwillingness to quit or receive help (2)
lack of confidentiality /privacy (1)	needing a high level of support (1)	transport (1)
poor assessment of substance use meaning not referred to appropriate services (1)		women's lack of knowledge of the dangers of alcohol (1)
not able to offer level of support needed e.g. time with care, frequent visits (2)		lack of support from friends and family (1)
		social stigma (1)
		confidentiality/lack of privacy (2)
		lack of assessment by providers (2)
		poor attitude of staff (2)
		women's fear of legal action, social services intervention (1)
		fear of partner abuse if help is sought (1)
		providers' lack of knowledge of services available (1)
		reaching the population – safety and logistical issues in street outreach, denial and illiteracy for media approaches (1)

(Number of studies reporting each barrier given in parentheses)

### GDG interpretation of evidence

The evidence shows that women with a substance misuse problem value staff with non-judgmental attitudes, staff consistency, reassurance about confidentiality and child protection proceedings, information and a high level of support in terms of number of visits and time given at each appointment. There is also evidence from the review for Q1b indicating that staff are not always comfortable exploring the issue of substance misuse, and are often unaware of the support services available. The GDG agreed that these findings accurately reflected their own experience in the NHS and recommended that women

should be given information regarding the availability of additional services in order that they can access all the care they require.

The GDG noted that one of the difficulties with the evidence is that the most vulnerable women are those who are least likely to feature in research and who have no contact with any services. The group recognised the benefit of non-midwifery services receiving training in identifying opportunities to talk to vulnerable women about pregnancy i.e. opportunistic referral. The need for training all staff who meet women during the course of their maternity care is evident given the strength of evidence showing the prevalence of poor staff attitudes and the potential negative effect these have. Based on this evidence the GDG agreed to recommend that healthcare professionals should receive training to help them understand the emotional and social needs of substance misusing women. It was felt this would help to address the problem of poor staff attitudes towards this group of women. Training in sensitive communication for receptionists and other support staff who regularly come in to contact with women attending services was also felt to be required. This training could be either formal or informal depending on available resources.

The GDG noted that one (poor quality) study apparently suggested that enrolling women in an addiction treatment programme was associated with poorer outcomes. However, the women enrolled in the programme had experienced significantly higher rates of childhood sexual abuse and significantly more women used "crack" cocaine as their primary drug. As a result, the GDG felt that this group of women was comparatively more vulnerable and so it was not surprising that they had poorer outcomes. In the GDG's experience, substance misuse programmes are valuable in helping women to limit and manage their addiction during pregnancy. Given the importance of trying to reduce the woman's substance misuse during pregnancy, the GDG concluded that women should be offered referral to an appropriate substance misusing programme.

There is an assumption underlying antenatal care provision that early booking for care will lead to improved pregnancy outcomes. For women who misuse substances, part of this likely improvement will be due to the opportunity to receive addiction treatment earlier in pregnancy. The GDG therefore agreed that services should aim to book women who misuse substances during the first trimester of pregnancy. The GDG discussed how this could be achieved and agreed that one way would be to ensure that opportunistic contact with a healthcare professional in the first trimester of pregnancy should be used to offer substance misusing women an antenatal booking appointment if she wishes to continue the pregnancy or a referral to sexual health services if she is considering a termination of pregnancy. The GDG agreed that there would be value in considering joint-commissioning of services and joint provision of care in order to maximise limited resources and facilitate good communication between different service providers. They noted that poor communication between agencies had been a barrier identified in one study and that this was also reflected in their clinical experience. Commissioners should be aware of the specific needs of substance misusing pregnant women and the role that joint agency working has in providing appropriate care locally in their area. The barriers to substance misusing women accessing services need to be explored at a local level by working closely with other statutory and voluntary agencies in order to provide coordinated care and support. This was felt to be a particularly important issue for substance misusing women as they were very likely to be in contact with different agencies during their pregnancy. As a result, the need for coordinated care is particularly relevant. Examples of how this can be achieved in practice are given in Box 4.1 below and in Appendix D (see service descriptions numbers 1, 2, 3 and 6).

The need for clear referral pathways was also highlighted by the studies. The use of a DLM to case manage and co-ordinate care had a positive impact on early booking in the UK study, as did co-location of antenatal and counselling services in a US study. The GDG agreed that clear referral pathways and co-ordination of care are important for ensuring that substance misusing women are able to access the care and support that they require.

Although the evidence reviewed is of low quality, the findings seem to suggest a positive effect on access of providing substance misuse treatment and support for substance misusing women alongside or within antenatal care consultations. The introduction of a DLM appeared to contribute to the improved rate of first trimester bookings in a UK service as did provision of substance misuse treatment and support in a US service evaluation. Both of these components of service organisation appear from the evidence to be important. There is no evidence to support one particular service provision model above another with both services described suggesting some degree of benefit in terms of improving access. Five examples of

how services might be organised to meet the needs of substance misusing women are presented in Appendix D.

A large number of barriers were identified from the evidence. The GDG formally voted on which barriers they considered to be the most important and relevant. This consisted of one round of anonymous voting using pencil and paper. Following this, the results were fed back to the group and agreed. The group highlighted the following barriers as being particularly important:

- treatment and attitude of staff
- lack of integrated care from different services
- women's feelings of guilt about their misuse of substances and the potential effects on their baby
- women's concern about the potential involvement of children's services

In drafting recommendations, the group particularly considered ways in which these barriers could be overcome. When discussing women's concerns and fears relating to substance misuse and the potential involvement of social care services and custody of the newborn baby, the GDG acknowledged that it is vital that health care professionals acknowledge these fears and discuss them in an open and honest manner, and made a recommendation to this effect. Providing false reassurances is not appropriate and where there is a possibility that the baby may be taken into protective custody this should be sensitively discussed, including a clear explanation as to why this might happen.

## 4.4 Maintaining contact

### Clinical Question

Q2. What aspects of service organisation and delivery improve contact with antenatal services throughout pregnancy for women misusing substances?

### Previous Guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Papers needed to report comparative data including an outcome relating to maintaining contact with antenatal care e.g. number of visits, adequacy of care (variously defined) either as a primary or secondary outcome. Improving contact with services did not need to be a stated aim as the study, as long as the outcomes of interest were reported for an antenatal intervention the study was considered for inclusion. Within group comparisons were also included (e.g. attenders vs. non-attenders allocated to a particular programme) in order to include information relating to possible reasons not to attend. Thirty papers were considered for inclusion. After careful examination against inclusion criteria and quality assessment seven studies have been included in the review, all of a low evidence quality. The service interventions included are antenatal clinic-based treatment and support programmes (4 studies), antenatal-clinic based support group programmes (2 studies) and a residential programme (1 study).

### Narrative summary of evidence

#### Support and treatment programmes within antenatal care

A recent US retrospective cohort study was undertaken to provide a comprehensive evaluation of Early Start, an obstetric clinic-based antenatal substance abuse treatment programme (2008)<sup>58</sup> [EL=2-]. The programme had 3 components: placing a licensed substance abuse expert in the obstetric department whose appointments for assessment and treatment were linked to women's antenatal care appointments; universally screening all women for drugs and alcohol by questionnaires and by urine toxicology testing; educating all providers and women about the effects of drugs, alcohol and cigarette use in pregnancy. Study duration was from January 1999 to June 2003.

The study included 4 groups: Group 1 (n=2073) screened, assessed and treated at Early Start (at least 1 follow-up appointment); Group 2 (n=1203) screened and assessed, positive for substance misuse but did not have any subsequent Early Start appointments; Group 3 (n=156) screened only, positive for drug

misuse but not assessed or treated in Early Start; Group 4 (n=46,553) controls, no evidence of substance abuse. There was otherwise no difference in the antenatal care programme for the 4 groups.

Some statistically significant differences were noted between groups 1 and 2 regarding race, marital status, educational level and annual income. The "median" amount of antenatal care was expressed as the number of antenatal visits during pregnancy divided by the number of weeks gestation at birth and was similar across all 4 groups, with Group 3 tending to have fewer visits ("medians" (interquartile range): Group 1: 0.28 (0.23-0.33); Group 2: 0.26 (0.21-0.32); Group 3: 0.25 (0.15-0.32); Group 4: 0.26 (0.21-0.31)).

An earlier US retrospective study was undertaken to evaluate the same Early Start programme provided by a large community clinic in Northern California (2003)<sup>50</sup> [EL=2-]. The study involved a total of 6774 women. Four groups were compared as described immediately above Group 1 (SAT) n=782; Group 2 (SA) n=348; Group 3 (S) n=262 and Group 4 (C) n=5382.

The SAT group had significantly higher "median" amount of antenatal care than SA, S and control groups (p<0.0001).

A small US prospective randomised control trial (n=7 each in intervention and comparison groups) was conducted to compare treatment outcomes in pregnant opiate-addicted women in an enhanced treatment programme vs. a standard methadone maintenance programme (1995)<sup>59</sup> [EL=1-].

The enhanced treatment programme offered weekly antenatal care by a nurse midwife, a weekly relapse-prevention group, positive contingency awards for abstinence (women could earn \$15 weekly for three consecutive negative urine screens), and provision of therapeutic child care during treatment visits.

Standard treatment consisted of daily methadone medication, weekly group counselling, and three times weekly toxicology screening. Women in the enhanced programme tended to have longer gestation times (median: 40 weeks vs. 38 weeks) and larger babies (median: 3348g vs. 2951g) and significantly more antenatal visits than women in standard treatment (average 15 visits vs. 5 visits p<0.01).

There was no difference between the two groups with respect to the percentage of women's urine toxicology screens that were positive for cocaine, illicit opiates, or any other drugs.

An earlier, small US retrospective cohort study was undertaken to evaluate the same treatment programme as that reported immediately above (n=6 in each study group)(1992)<sup>60</sup> [EL=2-]. The intervention and comparison groups received the same treatment and support as outline above.

Women in the enhanced treatment programme demonstrated a lower percentage of urine screens which were positive for overall illicit substance use (59% vs. 76%) and had more antenatal care (8.8 visits vs. 2.7 visits) compared to women in the conventional programme. No statistical analysis is reported in the paper and insufficient data are presented to allow it to be carried out. However, the very small size of this study (and the one reported immediately above) severely limits the reliability of these findings.

### **Antenatal clinic based support groups**

A US study examined the clinical as well the economic efficacy of an urban, hospital-based on-site support group programme for drug misusing pregnant women (1998)<sup>61</sup> [EL=2-]. The study was a retrospective review of records of a cohort of 121 substance using pregnant women who attended the clinic during 1989-90 and comparisons were made between support group attenders (n=54) and non-attenders (n=67). Women who attended 2 or more (mean 4.9, median 4) sessions of weekly support programme were classified as attenders and those who attended one session or did not attend at all were classified as non-attenders. The support group included discussion on issues of substance use and pregnancy, establishment of social support networks and encouragement for attendance at the next meeting. Efforts were also made to minimize the barriers to attendance e.g. lunch was provided, transportation costs were covered and women were able to bring their pre-school children with them. No significant others were allowed to attend the meetings in order to protect confidentiality.

Support group meeting attendance was found to be significantly associated with more antenatal visits (8.7 vs. 6.8; p=0.002). The group allocation for this study was based on women's self selection, and although both groups had a similar socio-demographic profile, the difference between motivation levels could be an important potential confounder.

In a second US cohort study (2003)<sup>62</sup> [EL=2-], medical records of 88 substance misusing women, who had received antenatal care and had given birth in a multidisciplinary public hospital clinical setting during

1994-2001, were compared with a random sample of 97 pregnant women with an uncomplicated pregnancy over the same period. During their antenatal visits, substance using women were offered counselling, family planning advice, nutrition education and HIV education. They also participated in a support group supervised by a family therapist, which addressed their concerns involving drug use, relationships, domestic and family abuse, parenting & housing and other issues. In order to encourage attendance a private waiting area, meals, transportation and "public recognition of achievement" were offered.

Significant differences were observed in the number of antenatal appointments kept (86.6% for study group vs. 94.2% for comparison group,  $p < 0.05$ ). The study group missed more appointments than the comparison group but the difference is slightly less than one visit (1.6 vs. 0.7;  $p < 0.0005$ ). The potential confounders were age, gravidity, parity and race as the study group was found to be significantly older (28.9 vs. 25.6 years,  $p < 0.0001$ ) had had more pregnancies (4.3 vs. 2.4,  $p < 0.0001$ ) and children (2.0 vs. 0.7,  $p < 0.0001$ ) and contained a higher percentage of black women (54% vs. 8%).

### **Residential programmes for substance misusers**

A US retrospective matched cohort study investigated the effects of a residential substance abuse treatment programme during pregnancy on maternal and infant health outcomes (2003)<sup>63</sup> [EL=2-]. All women who entered the programme between 1993 and 1998 were eligible for inclusion in the study ( $n=95$ ). Those who were in the programme at the time of giving birth were included in the analysis ( $n=55$ ). Two comparison groups ( $n=55$ ) were used: Substance misusers who received no treatment programme during pregnancy (positive control group), and pregnant women who were not substance misusers (negative control group).

The study sample comprised predominantly black (45.5%) and white (41.8%) women. The socioeconomic status of the treatment group and control groups was assumed to be similar as all received medical care as economically disadvantaged patients.

The number of antenatal care visits differed significantly between women in the intervention group (mean = 6.7, SD +/- 1.3) and those in the positive control group (mean = 1.3, SD +/- 3.4;  $p < 0.01$ ), but not between women in the intervention group and those in the negative control group (mean = 5.6, SD +/- 2.7). The number of women who had no antenatal care visits was significantly higher in the positive control group (11%) compared with the intervention group (3%) ( $p < 0.01$ ).

### **Evidence statement**

There is evidence from one retrospective cohort survey and two additional very small studies (1 RCT, 1 cohort study) that providing comprehensive treatment and support programmes within antenatal care improves attendance at antenatal consultations. However, one retrospective cohort study found that involvement in an antenatal treatment and support programme was not associated with an increase in the number of antenatal visits made.

There is evidence from one retrospective cohort study that substance misusing women who attend a support group provided alongside antenatal care also attend more antenatal appointments compared with substance misusing women who do not attend the support group. In addition, evidence from a second retrospective study suggests that substance misusing women who attend a support group alongside usual antenatal care provision attend a similar number of antenatal appointments to women who are not substance misusers.

Findings from a retrospective matched cohort study of a US residential programme for substance misusing pregnant women show that women in the programme received more antenatal care than substance misusing women who were not enrolled in the residential treatment programme during pregnancy.

### **GDG interpretation of evidence**

No good quality evidence was found that investigated what aspects of service provision could improve the maintenance of contact with antenatal care in substance misusing women. The available evidence is undermined by the use of self-selected comparison groups which means it is not possible to discern whether the intervention is having an effect on service use or whether this arises from study group selection bias. Furthermore, details of interventions are not made explicit so it is not always possible to discern exactly what services are being provided, although it appears they are multifaceted, including

treatment for substance misuse and information, advice and supportive counselling. Based on this evidence and supported by their own experience and knowledge the GDG felt it appropriate to recommend both treatment programmes and the provision of information and advice, including advice about additional available services for this population of women. Enrolment in a substance misuse treatment programme was felt to be a key component of maintaining contact with antenatal services.

Due to the unpredictable nature of some women's lives the provision of a range of services in one location was seen as a useful way of improving and maintaining contact. The evidence from integrated antenatal treatment and support programmes and groups provided alongside antenatal clinics support this view. From the studies reviewed it seems that being able to access drug treatment services and antenatal services in the same location encouraged attendance at antenatal visits. The GDG agreed that this was a useful way of improving access and recommended that services should be co-located where possible.

From experience GDG members noted that a frequently used method of encouraging substance misusing women to retain contact with services was through mobile phone contact thus reminding women of both upcoming and follow-up appointments; a mobile phone conversation could also be used to establish what plans had been made for future care. The GDG expressed concern over the safety of staff involved in home visiting which meant that this might not be a service option in some areas. The GDG decided, therefore, to recommend the use of reminder systems e.g. text messaging, to help women manage their appointments, but did not feel home visiting of all women who miss appointments was appropriate.

Also from experience, the GDG agreed that there was value in substance misusing women having the majority of their care provided by a named antenatal carer with specialised knowledge of and experience in substance misuse. The GDG felt that this would likely improve the quality of the care these women would receive and would help to overcome the barrier listed above of a lack of continuity of care. It was anticipated that a named carer would also be better placed to coordinate the woman's care and maintain contact with the other statutory and voluntary organisations which might also be involved. (See for example, service descriptions in Box 4.1 and Appendix D, numbers 1, 3, 4, 5 and 6). The provision of a specialist midwife is supported by the health economics modelling for this population (see section 4.7 below) based on the assumption that one additional part-time midwife would increase the number of substance misusing women booking by 12 weeks of pregnancy by 4 per year. A service costing £150 000 would need to book an additional 20 women per year by 12 weeks of pregnancy to be cost-effective. Whilst it would commonly be a midwife who undertakes this role of co-ordinating care within and across agencies, the GDG recognised that this might not always be the case e.g. where a woman has a drug services case worker or a social worker who has known them for some time before pregnancy and who will continue to provide care after the baby is born it might well be more appropriate for this professional to take the lead in co-ordinating care. The GDG therefore decided not to stipulate in a recommendation that the named antenatal midwife should be responsible for co-ordinating care. The need for a co-ordinated care plan is recommended, based on GDG consensus, which would contain details of the lead professional responsible for co-ordinating care.

See section 4.8 (page 58) for recommendations.

## 4.5 Additional consultations and support

### Clinical Question

Q3. What additional consultations and/or support should be provided to women misusing substances, their partners and families in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline).

### Previous Guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Papers needed to report comparative data for pregnancy-related, birth or infant outcomes and involving a service intervention and/or antenatal care programme relating to antenatal consultations and support over and

above that offered as part of standard antenatal care. Thirty-eight studies were considered for inclusion. After appraisal for inclusion criteria and methodological rigour 11 have been included in the review, most of a low evidence quality. The service interventions included are multifaceted treatment and support programmes integral to antenatal care (9 studies), antenatal-clinic based support group programmes (1 study) and a residential programme (1 study). One study was conducted in the UK; all the others were from the US.

### **Narrative summary of evidence**

#### **Support and treatment programmes within antenatal care**

The UK (Manchester) retrospective cohort study described above (2006)<sup>47</sup> [EL=2-] also investigated neonatal outcomes in methadone-exposed infants before (1991-1994) (n=78) and after (1997-2001) (n=98) the establishment of a drug-liaison midwife (DLM) and modified neonatal care for the clinical management of these infants. The DLM provided antenatal care, including home visits when hospital appointments were missed and co-ordinated care between health and social care providers facilitated by monthly multidisciplinary meetings involving a consultant neonatologist.

In 1991-1994, all methadone-exposed infants were admitted to the neonatal medical unit (NMU). In 1997-2001, neonatal management was modified and in-service training in looking after these infants was offered to medical, midwifery and nursing staff by the DLM. Infants were usually admitted to a maternity ward, being transferred to the NMU as necessary on clinical grounds

In 1997-2001 the booking visit took place in the first trimester of pregnancy in 84 of 97 women (86.6%) and the dose of methadone was 30-180mg/day. In 1991-1994 data were available for 63 women, 37 (58.7%) had booked in the first trimester of pregnancy, and the dose of methadone was 8-160mg/day.

In 1997-2001, infants born to substance misusing women had less pharmacological intervention and spent less time in hospital with fewer admissions to the NMU, where they stayed for a shorter period compared with 1991-1994. In 1997-2001, the women were prescribed a higher dose of methadone, there were more preterm births and more breastfed infants, while fewer infants had jaundice or convulsions compared with 1991-1994. The reasons for the observed increase in pre-term births were not clear.

Due to the multi-faceted nature of the service intervention it is not possible to ascertain which components of the service changes were responsible for the observed differences.

A US retrospective cohort study was undertaken to provide a comprehensive evaluation of Early Start, an obstetric clinic-based antenatal substance abuse treatment programme (2008)<sup>58</sup> [EL=2-]. The programme had 3 components: placing a licensed substance abuse expert in the obstetric department, whose appointments for assessment and treatment were linked to women's antenatal care appointments; universally screening all women for drugs and alcohol by questionnaires and by urine toxicology testing; educating all providers and women about the effects of drugs, alcohol and cigarette use in pregnancy.

The study included 4 groups: Group 1 (SAT, n=2073) screened, assessed and treated at Early Start (at least 1 follow-up appointment); Group 2 (SA, n=1203) screened and assessed, positive for substance misuse but did not have any subsequent Early Start appointments; Group 3 (S, n=156) screened only, positive for drug misuse but not assessed or treated in Early Start; Group 4 (C, n=46,553) controls, no evidence of substance abuse. There was otherwise no difference in the antenatal care programme for the 4 groups.

Some statistically significant differences were noted between groups 1 and 2 regarding race, marital status, educational level and annual income.

No significant differences were observed between Groups 1 and 2 for other maternal and neonatal outcomes reported although babies born to women in Group 3 were significantly more likely to be born before 37 weeks compared to babies born to women in Group 1 (17.4% vs. 8.1%) and to be of low birthweight (<2500kg) compared to babies born to women in Group 1 (12.4% vs. 6.5%). Placental abruption and intrauterine fetal death were also significantly more common in Group 3 compared to Groups 1 and 2 (Placental abruption: Group 1: 0.9%; Group 2: 1.1%; Group 3: 6.5%. Intrauterine death: Group 1: 0.5%; Group 2 0.8%; Group 3: 7.1%).

Whilst women in the treatment group showed a marked reduction in substance misuse a similar reduction was seen for women in Group 2 who were assessed but did not receive substance misuse treatment. A reduction was also seen in some areas for Group 3 (see table 4.2).

**Table 4.2. Substance use by study group**

<b>Characteristics</b>	<b>Screened positive, assessed and treated (Group 1) (n=2073)</b>	<b>Screened positive and assessed only (Group 2) (n=1203)</b>	<b>Screened positive only (Group 3) (n=156)</b>
<i>Weekly/daily use before pregnancy (%)</i>			
Alcohol	33.1	33.9	17.3
Methamphetamine	5.7	4.6	1.3
Marijuana	34.0	28.0	12.2
Cocaine	1.5	0.8	0.6
Heroin	0.5	0.2	1.3
Smoked cigarettes	54.1	47.7	30.1
<i>Weekly/daily use since pregnant (%)</i>			
Alcohol	6.6	7.2	4.5
Methamphetamine	1.3	1.7	1.3
Marijuana	14.7	8.9	5.1
Cocaine	0.7	0.1	0.0
Heroin	0.3	0.0	1.3
Smoked cigarettes	26.6	22.1	16.7

An earlier US retrospective study was undertaken to evaluate an Early Start programme established in a large community clinic (2003)<sup>50</sup> [EL=2-]. Six thousand seven hundred and seventy four women members of Kaiser Permanente medical care, Northern California Region, were screened for substance misuse from July 1995 to June 1998. Again four groups were compared as described immediately above: Group 1: 'screened assessed and treated' (SAT, n=782); Group 2: 'screened and assessed' (SA, n=348); Group 3: 'screened only' (S, n=262) (women in group 3 had a positive universal toxicology screening test with either a positive screening questionnaire (n=108) or a negative screening questionnaire (n=154)); Group 4: 'control' (C, n=5382).

Women in the SAT group had a significantly higher "median" amount of antenatal care than SA, S and control groups ( $p < 0.0001$ ). The SAT group had lower rates than the SA group and S group for assisted ventilation, low birth weight and preterm delivery. Babies born to women in the three substance misusing groups (SAT, SA and S) had a higher likelihood of being admitted to the neonatal intensive care unit (NICU) than babies in the control group.

A US retrospective cohort study was conducted to determine the effectiveness of an integrated programme of antenatal care and substance misuse treatment in improving neonatal outcomes (2000)<sup>64</sup> [EL=2-]. Birth outcomes for 87 women enrolled in an intensive outpatient substance misuse treatment programme provided with antenatal care were compared with an equal number of women with a similar socioeconomic and demographic profile and with similar histories of substance misuse and who received an equal amount of antenatal care but did not enrol for the substance misuse treatment programme before childbirth. After regression analysis to adjust for confounders known to affect outcome, it was concluded that infants in the study group were 418g heavier ( $p < 0.001$ ) and their gestational age was 2 weeks longer ( $p < 0.001$ ) compared with babies born to women in the control group. Incidence of low birthweight was lower in the intervention group (19.5% vs. 40.2%;  $p < 0.001$ ), as was the incidence of very low birthweight (<1500g) (2.3% vs. 10.3%;  $p < 0.05$ ). Preterm birth (before 37 weeks gestation) was less frequent in the intervention group (14.9% vs. 40.2%;  $p < 0.001$ ), and there were fewer admissions to the neonatal intensive care unit (NICU) (25.3% vs. 35.6%;  $p < 0.05$ ). The study group also had lower incidence of infants with a positive toxicology screen (21.8% vs. 57.5%,  $p < 0.001$ ).

A US descriptive evaluation of a pilot drug treatment programme for pregnant and postpartum substance-using women in New York, the Parent and Child Enrichment (PACE) project, compared findings for women described as short stay (<42 days) (n=85) vs. long-stay (>42 days) (n=101) (1999)<sup>65</sup> [EL=2-]. Comparisons were also made for some outcomes with 1991-1993 cocaine-positive live birth data for the

Central Harlem Health District (n=175) and 1991-1993 Harlem Hospital Centre Special Prenatal Clinic live birth data (n=597).

The PACE project was a "one stop shop" including antenatal, postpartum, and paediatric care; group and individual counselling; nutritional assessments; on-site enrolment for food supplementation; psychosocial assessments; parenting education; high school equivalency classes; vocational preparation and counselling; and linkage to social services. Project staff included a coordinator, 2 drug treatment counsellors, a social worker, a parent educator, a part-time child care worker, and a nutritionist. Medical staff included a full-time nurse, a part-time paediatrician, and a part-time nurse midwife.

The mean total length of stay in the project was 100 days, mean pregnancy length of stay was 48 days, and mean postpartum length of stay was 56 days. The long-stay clients had a much lower percentage of positive tests than the short-stay clients: 19.5% of long-stay clients' screens tested positive compared to 55.1% who tested positive in the short-stay group. Mean birth weight was significantly higher for babies born to women in the PACE long stay group compared to those in the PACE short stay group (3045g vs. 2791g;  $p=0.006$ ). Babies born to women at the Harlem Hospital special antenatal clinic or in the Central Harlem Health District Cocaine positive comparison group were also significantly lighter than those in the long stay PACE group. Of the babies born to women in the PACE long stay group, 16.7% weighed <2500g compared with 29.2% in the PACE short stay group ( $p=0.10$ ). The incidence of low birth weight was 34.9% for the Harlem Hospital Special Prenatal Clinic ( $p=0.011$ ), and 47.4% for the Central Harlem Health District – cocaine positive group ( $p=0.0001$ ), both significantly higher than for the PACE long-stay group.

A prospective cohort study was conducted to evaluate the impact of a programme designed to provide comprehensive substance misuse prevention and treatment services to low-income pregnant and parenting women and their children in the US (1999)<sup>66</sup> [EL=2-]. The study was carried out at the Arkansas Centre for Addictions Research, Education, and Services (AR-CARES), a facility that provided a residential and outpatient substance misuse prevention as well as treatment services to low-income pregnant and parenting women and their children. The programme was based on a model (Miller's self-in relation theory) which emphasized the importance of relationships in the lives of pregnant and parenting women and the need to include relational issues in the treatment programme. The intensive phase of the programme was designed to last for at least 12 weeks and to serve 9 to 12 women at any one time. As much as possible, the programme was to be a "one-stop shopping" model implemented by a multidisciplinary team and guided by an individualized treatment plan. On-site services, in addition to education and counselling, included 24-hour on-call clinical staff, antenatal care, and Women, Infants, and Children (WIC) services. The plan for clinical services delivery included a team approach, using a masters level social worker, masters level nurse practitioner, case managers, and consultants in medicine (obstetrics, paediatrics, psychiatry), addictions, psychology, and law/ethics. The project director served as team leader. Bi-weekly group sessions were held with the woman's family of choice regarding recovery issues for pregnant and parenting women and focusing on issues ranging from communication skills to the 12-step recovery programme. It was planned that referrals would be made if needed for hospitalization, specialized services for infants/children, and for birth-related hospitalizations. The programme changed considerably over the 5 years based upon inputs from staff and clients and in response to changing community resources. Major changes were: on-campus residential support services, extending services up to 7-8 hours per day, additional educational sessions (included arts class, centre and home based nutrition classes, mother and child play groups and vocational activities), on-site infant/toddler nursery programme and transportation.

The evaluation was carried out using a quasi-experimental study design which involved comparing the birth outcomes of participating women with the women who were invited to study but refused services. It is noted that the choice of comparison group is likely to introduce bias into the results. Women were interviewed at study intake, at birth and when the child was 6, 12 and 18 months old. Birth outcome data were obtained from hospital records. Maternal interviews and child development data were collected in clinical settings.

Data containing current and past alcohol and other drug (AOD) use were obtained from 72 participating women and 23 non-participating women at study intake and birth outcome data were obtained for 27 participating women and 10 non-participating women. The reasons for the difference in size of the sample for hard outcomes are not explained in the paper. The non-participating sample included women who were offered a place in the programme but declined. These two observations regarding the study samples act to undermine the validity of the findings. The majority (75%) of the women were African

American women in their late to mid-20s who were not/never married. Few (3%) were employed when they entered the study; however most (80%) had worked at a job during the previous 5 years. The majority of women had a history of abuse (sexual, physical and emotional) and a family history of alcohol and other drug use. By the time of the birth, the numbers of participating women and non-participating women reporting the use of alcohol dropped significantly, 83.6% of participating women reported alcohol use at intake and only 4% reported any use between intake and giving birth ( $p=0.001$ ). There was also a significant reduction in the number of women reporting alcohol use in non-participating women (90.5% to 33%;  $p=0.003$ ). Although the number of both participating and non-participating women reporting continued alcohol use declined, the number of participating women reporting alcohol use declined significantly more than non-participating women ( $p=0.02$ ). At the time of giving birth, the number of participating and non-participating women reporting other drug use dropped significantly, at intake, 91.7% of pregnant participating women reported other drug use; at birth only 3.7% reported continued drug use ( $p=0.001$ ). Of the 95.7% of non-participating women reporting other drug use at intake, significantly fewer (33.3%) reported continued use at the time of birth ( $p=0.01$ ). Similar to the reports of alcohol use, participating women reported significantly less use of other substances than non-participating women at birth ( $p=0.02$ ). The rate of complications was similar for participating (12/27, 46%) and non-participating ( $n=4/10$ , 40%) women. However, significantly fewer participating women experienced premature labour ( $p=0.02$ ) and maternal infection ( $p=0.05$ ) than non-participating women. Participating women stayed in the hospital an average of 2.3 days after the birth of the target child compared to an average of 5 days for non-participating mothers ( $p=0.03$ ). These analyses included one non-participating woman with an exceptionally long hospital stay of 21 days (the reason for this long stay is not reported). When this outlier observation was excluded from the analyses, the length of stay was no longer statistically different. The number of infant hospital days after birth is not different for babies of participating and non-participating women. No statistically significant differences were found between infants of participating and non-participating women in the incidence (11% and 40%, respectively) or duration of neonatal intensive care unit (NICU) treatment (0.44 and 0.88 days, respectively). No differences were seen when the length of participation was examined. Infant birth weight was similar for each group when compared with independent t-tests. However, when length of time between programme intake and the birth of the child is taken into account, longer programme participation is associated with higher birth weight ( $F=5.08$ ,  $p=0.03$ , explaining 13% of the variance). Although the difference did not reach the 0.05 significance level, infants of participating women tended to have larger head circumferences (35 cm as compared with 33 cm;  $t=21.9$ ,  $p=0.07$ ). The gestational age of infants born to participating women was 2 weeks greater than infants of non-participating women, a statistically significant finding ( $t=2.2$ ,  $p=0.03$ ).

A small US RCT (1998)<sup>67</sup> [EL=1-] examined the relative effectiveness of 'adjunctive contingency management interventions' (primarily financial incentives) in maintaining abstinence and enhancing compliance with antenatal care in pregnant women who had the history of cocaine use in the ongoing pregnancy but had ceased use more than 30 days prior to entering the study. Twelve such women who were enrolled in a multifaceted treatment study between September 1994 and August 1996 were randomly assigned to one of two treatment groups following stratification on referral source (self vs. court/probation/parole). The stratification of such a small sample prevents this study from being considered a randomized trial. Group A ( $n=6$ ) intervention group received baseline treatment plus contingency management interventions (CMIs) were compared with Group B ( $n=6$ ) which received only baseline treatment and served as control. All participating women were screened at intake and diagnosis of cocaine dependence was made using structured clinical interviews recommended by American Psychiatric Association in Diagnostic and Statistical Manual of Mental Disorder (1987). A detailed drug history and Addiction Severity Index (ASI) was administered at the intake and the end of the study. Women in both groups received a baseline treatment (with free transportation and child care for each appointment) which included antenatal care (1 visit/week), 2 individual and 1 group sessions of behaviourally based drug counselling, monthly antenatal and nutritional education and HIV pre and post test counselling and testing every 3 months. Women in the experimental group received additional contingent reinforcement in the form of monetary incentives for each cocaine free urine sample (\$18) and a weekly bonus of \$20 if all 3 required samples were cocaine free and woman had attended all 3 required visits (weekly antenatal checkups and behavioural therapy sessions).

Drug misuse was monitored by urine screening, 3 times a week. There was a high rate of retention (82% overall) and abstinence from cocaine (99% of urine samples were negative) in both groups. Women in experimental group had a slightly higher rate of attendance at antenatal visits (100% vs. 83%,  $p=0.077$ ). None of the 6 babies born to women in the intervention group experienced any of the four adverse

perinatal outcomes (premature rupture of the membranes, preterm labour, preterm birth, low birth weight) compared to 4/6 (67%) in the comparison group ( $p=0.022$ ). The small sample size means caution needs to be exercised when interpreting this statistically significant result. Change in ASI composite score (intake to end) did not differ between the two groups.

A small US prospective randomised control trial ( $n=7$  in intervention and comparison groups) has been conducted to compare treatment outcomes in pregnant opiate-addicted women in an enhanced treatment programme vs. a standard methadone maintenance programme (1995)<sup>59</sup> [EL=1-].

The enhanced treatment programme offered weekly antenatal care by a nurse midwife, a weekly relapse-prevention group, positive contingency awards for abstinence (women could earn \$15 weekly for three consecutive negative urine screens), and provision of therapeutic child care during treatment visits.

Standard treatment consisted of daily methadone medication, weekly group counselling, and three times weekly toxicology screening. Women in the enhanced programme tended to have longer gestation times (median: 40 weeks vs. 38 weeks) and larger babies (median: 3348g vs. 2951g) and significantly more antenatal visits than women in standard treatment (average 15 visits vs. 5 visits  $p<0.01$ ).

There was no difference between the two groups with respect to the percentage of women's urine toxicology screens that were positive for cocaine, illicit opiates, or any other drugs.

An earlier, small retrospective cohort study was undertaken to evaluate the same treatment programme as that reported immediately above ( $n=6$  in each study group (1992)<sup>60</sup> [EL=2-]. The intervention and comparison groups received the same treatment and support as outline above.

Women in the enhanced treatment programme demonstrated a lower percentage of urine screens which were positive for overall illicit substance use (59% vs. 76%), had more antenatal care (8.8 visits vs. 2.7 visits), longer gestation (38.2 weeks vs. 35.7 weeks), and delivered heavier infants (median birth weight 2959 vs. 2344 grams) compared to women in the conventional programme. The very small size of these two studies severely limits the reliability of their findings.

### **Antenatal clinic-based support groups**

Another US retrospective cohort study described in detail above examined the efficacy of an urban, hospital-based onsite support group programme for drug misusing pregnant women (1998)<sup>61</sup> [EL=2-]. Women who attended 2 or more (mean 4.9, median 4) sessions of weekly support programme were classified as attenders ( $n=54$ ) and those who attended one session or did not attend at all were classified as non-attenders ( $n=67$ ). Support group meeting attendance was found to be significantly associated with more antenatal visits, increased birth weight and Apgar score at 1 minute. Only 15% of attenders had low birth weight neonates as compared to 25% in non-attender group (although this finding is not statistically significant).

### **Residential programmes for substance misusers**

A US retrospective matched cohort study investigated the effects of residential substance abuse treatment during pregnancy on maternal and infant health outcomes (2003)<sup>63</sup> [EL=2+]. All clients who entered a residential substance abuse programme for pregnant and postpartum women between 1993 to 1998 were eligible for inclusion in the study ( $n=95$ ). Those who were in treatment at the time of giving birth were included in the analysis ( $n=55$ ). Two comparison groups ( $n=55$ ) were used: substance misusers who received no treatment during pregnancy (positive control group), and pregnant women who were not substance misusers (negative control group).

The study sample comprised predominantly black (45.5%) and white (41.8%) women. The socioeconomic status of the treatment group and control groups was assumed to be similar as all received medical care as economically disadvantaged patients.

The most common primary drug used by women in the substance abuse treatment programme was cocaine (56.1%), followed by heroin (15.8%). The average length of time in treatment before giving birth was 11.7 weeks (range 1 day to 32.5 weeks). In the treatment group vs. the positive control group, mean birth weight was 3237g vs. 2800g ( $p<0.01$ ). The mean estimated gestational age was 38.9 weeks in the treatment group, compared to 38.0 in the positive control group ( $p=0.05$ ), and 39.2 weeks in the negative control group (NS).

The total number of maternal complications was significantly higher in treatment (n=12) and positive control groups (n=11) compared with the negative control group (n=1) ( $p<0.0001$  and  $p<0.0001$ , respectively). The total number of perinatal infant complications was higher in the treatment group (n=25) compared with the positive (n=10) and negative control groups (n=6) although this difference was not statistically significant.

### **Evidence statement**

A multi-faceted UK service change which included the introduction of a drug liaison midwife and change to the NICU admission policy for babies born to substance misusing women, resulted in a reduction in pharmacological intervention, shorter length of hospital stay and fewer admissions to NICU compared with a period immediately prior to the change. In addition the number of breastfed infants increased, while fewer infants had jaundice or convulsions. There were more preterm births following the change in service compared with beforehand.

Findings from two retrospective evaluations of a US comprehensive treatment and support antenatal programme (Early Start) suggest that babies born to women treated within the programme were less likely to be born before 37 weeks and less likely to weigh less than 2500g than babies born to substance misusing women who were not treated. Additionally, findings from an earlier retrospective evaluation of a similar treatment and support programme integral to antenatal care also showed a significantly higher birthweight and longer gestation for babies born to women enrolled in the programme compared with substance misusing women receiving antenatal care but not attending the programme. They also showed significant reductions in placental abruption and intrauterine deaths in women with drug misuse who were not treated compared with those who were.

An evaluation of a community-based comprehensive antenatal and postnatal care service (a "one stop shop") for substance misusing women showed that women who stayed in the project for over 42 days (long-stay) had a lower percentage of positive urine toxicology tests than the short-stay clients, and gave birth to babies of significantly higher birthweight. Compared with babies born to substance misusing women outside the project, long stay women receiving care within the comprehensive care model had significantly heavier babies, with a significantly lower proportion being under 2500g.

A quasi-experimental evaluation [EL=2-] of a second US multifaceted "one stop shop" programme providing extensive antenatal and postnatal support to substance misusing women found that women enrolled in the programme had significantly reduced alcohol and drug use at the time of birth compared with time of programme enrolment compared with women who declined the offer of programme participation, although the latter group also saw significant reductions in substance misuse. Whilst many maternal and neonatal outcomes were similar between the two groups there were significantly fewer incidences of premature labour among women participating in the programme compared with those who chose not to participate and a higher mean birthweight for babies born to women in the participating group.

Findings from a small US prospective cohort study suggested that providing financial incentives as well as comprehensive counselling and education, child care and transportation to encourage attendance for antenatal care improved birth outcomes in women provided with financial incentives compared with those who received the same antenatal care but no incentives. The very small sample size (n=6 in each group) and the composite outcome reported (premature rupture of the membranes, preterm labour, preterm birth, low birth weight) seriously undermine the validity and reliability of this statistically significant finding.

Two very small, low quality US studies examining the same incentivized enhanced antenatal treatment and support programme found that babies born to women in the enhanced programme had longer gestations and were heavier than those born to women in the standard methadone maintenance programme.

Findings from one US retrospective cohort study suggest that substance misusing women attending a support group provided alongside antenatal care consultations gave birth to babies which were heavier than babies of substance misusing women who did not attend.

A US prospective cohort study examined the effects of attendance at a residential substance misuse treatment and support programme. Babies born to women who attended the programme were significantly heavier than those born to substance misusing women in a comparison group. Women who

attended the programme had statistically significantly longer pregnancies than those in a substance misusing comparison group and of a similar length compared with women who were not substance misusers.

### **GDG interpretation**

No good quality evidence was found that investigated the effects on pregnancy outcomes of providing additional consultations and support to pregnant substance misusing women, their partners and families. The GDG were disappointed to note that none of the reviewed evidence mentioned partners and/or families and their needs during the antenatal period. As a result, of this, and the varied experience of the GDG when encountering partners and families of pregnant substance misusers,, the GDG felt they were not able to make any specific recommendations for this group

Although some studies showed positive outcomes for infants in terms of gestational age, admission to NMU, or birth weight, it was not clear whether differences were due to different demographic profiles, the motivation bias of the study groups, or to any particular aspect of the multifaceted nature of the changed practice. Although the Manchester, UK study reported a reduced number of admissions to NMU for the study group, it was not clear whether this was a positive outcome or simply indicative of a change in admissions criteria and policy. The increase in preterm births in the intervention group was unexpected. The reasons for this finding are not clear, and may be due to more accurate dating and recording of gestational age brought about by the increase in first trimester bookings.

The GDG also noted that when the drug-using profile of the women included in the US studies was reported, this was different from that of substance misusing women in the UK. The generalisability of these findings to the current UK substance misusing population was, therefore, called into question.

Given the lack of any high quality evidence that any particular intervention in terms of consultation and support, including residential programmes, has a positive impact on birth outcomes, the GDG felt unable to recommend the adoption of one particular model for providing a maternity service to substance misusing pregnant women. From the low quality evidence reviewed it seems that providing additional support (such as substance abuse treatment programmes) alongside antenatal care or as part of enhanced antenatal consultations may be beneficial in terms of neonatal outcomes such as gestation at birth and birthweight; one study even suggested an improvement in placental abruption and intrauterine deaths. A further key component of care is that of good liaison between different agencies. The experience of GDG members is that good inter-agency communication and joint care planning (including identification of the lead responsible for coordinating the woman's care) is best achieved through multi-agency assessment and the use of shared documentation, for example the Common Assessment Framework and a recommendation was made based upon this experience. This has also been highlighted in the DH guidance *Working Together to Safeguard Children*<sup>2</sup>. See Box 7.1 below and Appendix D for examples of specialised service models for providing care to this group of women.

The GDG noted that a number of studies reviewed for this population across the different questions highlighted that support with transport was offered as a means of making it easier for women to attend. From their own experience, the GDG noted that offering to personally help with transport for this group of women, although sometimes useful, may not always be appropriate or safe. The option of providing information about transport options and entitlement to reclaim travelling costs was felt to be a more appropriate way to help, and a recommendation was made to reflect this.

From experience the GDG noted that where women have appointments to attend across a number of services e.g. social care, parole services, substance misuse treatment and antenatal care, it is common for women to miss appointments and for communication between agencies to be fragmented and slow. The GDG felt it essential to include recommendations aimed at addressing these problems in practical ways that from experience they felt would achieve improved attendance and co-ordination of care. Measures known to be useful included: tracking women's appointments and attendance at appointments (e.g. through e-mail or telephone contact between agencies or text or telephone messages with the woman herself), the use of a single document to record care provided by different agencies, and a care plan drawn up between and agreed by different agencies as well as the woman herself. Based on this experience, and with the consensus of the GDG, recommendations were made to this effect.

It was also noted from within the evidence reviewed and supported by GDG members' experience that care is better co-ordinated and communication improved if the woman has a named antenatal carer who is responsible for ensuring all appointments are made as appropriate and attended by the woman.

Follow-up of missed appointments and effective communication between agencies should also be the responsibility of this named carer who should ensure the woman receives appropriate care and has access to all the services she needs. In order to be able to provide the co-ordinated care needed as well as specialist advice relating to substance misuse and its potential effects on the newborn baby the GDG also felt it important that the named antenatal carer be a specialist midwife with good knowledge of, empathy for and interest in, caring for substance misusing women.

The GDG noted the disappointing lack of outcome data and lack of high quality UK studies. The importance of evaluating service change and sharing that information was highlighted. Due to this lack of robust UK evidence to support a particular service model, and to inform the health economic modelling that underpins the recommendations for this section of the guideline, the GDG decided not to recommend one particular type of service. Since many of the assumptions made within the health economics model have little data to support them the GDG felt it more appropriate to recommend specific components of service provision which they felt would bring the most benefit and be achievable within the NHS, as supported by the evidence, their own experience, and from the service descriptions obtained through the guideline survey. Given the assumptions made in the health economics model (see section 4.7 below) the additional support recommended and provision of a specialist midwife would be cost-effective. Examples of services which illustrate how some of the recommendations can be put into practice are detailed in Box 4.1 and in Appendix D.

See section 4.8 (page 58) for recommendations.

## 4.6 Additional information

### Clinical question

Q4. What additional information should be provided to women misusing substances, their partners and families in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline).

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. In order to be considered for inclusion the study had to describe an intervention that comprised additional information only and to report outcomes relating to pregnancy, neonatal outcomes or maternal outcomes including women's views. Six papers were considered for this question. Following closer examination of the nature of the intervention (i.e. information only) 1 paper was included, although this paper is of low quality.

### Narrative summary of evidence

A prospective cohort study investigated the effects of a substance abuse education programme on women's knowledge, attitude, and drug use behaviour as well as the programme effect on newborn and infant outcomes (1993)<sup>68</sup> [EL=2-]. The study compared knowledge and medical outcomes of two groups of substance misusing women at two health centres in southern Illinois (USA).

Participants were assigned to groups based on county of residence, 113 in the intervention group, and 99 in the comparison group. The groups were significantly different in race mix with the intervention group having a larger percentage of African-American women (39.4% vs. 16.8%).

The intervention group was assigned to the ASPEN programme; a self administered series of 8 educational modules completed by participants while they waited to see a physician in the antenatal clinic. One module was completed during each antenatal care visit. Topics covered included: drug and alcohol use during pregnancy and its adverse effects on pregnancy and the baby; women's health and nutrition. The comparison group received the usual care provided in antenatal clinic.

The programme had a positive impact on substance abuse knowledge. Significantly more women in the intervention group (47.6%) than comparison group (29.5%) had quit or reduced drug use in the previous 5

months ( $p=0.0197$ ). No significant differences were seen between the two groups on infant outcomes (prematurity, infant complications, birth weight and Apgar score).

### Evidence statement

No good quality evidence was found regarding what additional information substance misusing women, their partners and families should be given.

Findings from one retrospective cohort study suggest that providing additional information about the effects of substance misuse in pregnancy may reduce substance misuse but there is no evidence that it has an effect on pregnancy outcomes.

### GDG interpretation of evidence

Whilst acknowledging there is no evidence that providing specific information relating to substance misuse, the GDG noted that there is specific information for substance misusing women that is required in addition to that recommended in the NICE Antenatal care guideline<sup>1</sup>. This includes information about the potential effect of the substances being taken on the baby's growth and development, and the likely consequences after the baby is born such as neonatal abstinence syndrome. From experience it was the consensus of the GDG that women should be provided with this specific information in order to enable them to make informed choices about their care. The GDG agreed this would be facilitated by a specialist midwife being the named antenatal carer. The absence of evidence relating to the needs of partners and families meant the GDG felt unable to make specific recommendations targeted at this group as their own experience did not allow them to do so in this case.

See section 4.8 (page 58) for recommendations.

## 4.7 Health economic considerations

A new health economic model was developed for this guideline with the specific aim of assessing the cost-effectiveness of additional care versus normal antenatal care services. The analysis was based on descriptions of services that are currently provided across the UK. It was assumed that any specialist service will be over and above routine antenatal care as described in Antenatal care: routine care for the healthy pregnant woman.<sup>1</sup> Therefore it is not assumed that a specialist service provides routine antenatal care but instead provides additional support to pregnant women and indirect support to midwives providing their care.

The clinical review of the evidence did not identify any useful studies that reported the effectiveness of a specialist antenatal care intervention in terms of health gains for either the mother or the baby. However, an underlying assumption of the guideline is that antenatal care is beneficial (see introductory chapter). Therefore it was assumed for the purpose of modelling that any woman who books early (before 12 weeks) and maintains contact will have better health outcomes for herself and her baby than late bookers and non-attenders.

Assuming that 3% of maternities are to substance misusers ( $n=20,490$ ), each service will see approximately 135 women a year (dividing the maternities between the 152 PCTs in England and Wales).

As no effectiveness data were available, the specialist service was assumed to be as clinically effective as standard antenatal care once women were in the service. It was assumed that women who book before 12 weeks and stay in antenatal care would be 80% likely to have a full-term birth.

For women who book late or do not book it was assumed that the probability of a full-term birth was 70%. The maternal mortality rate for substance misusers was 23.8 per 100,000 maternities.

It was assumed that the only benefit of the specialist service was due to increasing the number of women who book before 12 weeks and maintaining contact. Using the evidence from Miles et al., 2006<sup>47</sup> which used historical controls, in the period 1997-2001, 86.6% of women had their booking visit in the first trimester. In the period 1991-1994, before the specialist service was introduced, 58.7% of drug users had booked in the first trimester of pregnancy. Therefore it has been assumed that 59% of drug using women book before 12 weeks when only standard antenatal care is provided, this is approximately 80 women out of the 135 drug using pregnant seen by each PCT in the study.

The economic analysis considered different scenarios for specialist models of antenatal care, each with a different estimated cost. The comparison was always standard antenatal care as defined by the NICE Antenatal Care guideline 2008.<sup>1</sup> For each type of service, the model estimated the minimum additional number of women who would need to be booked and maintain contact with the service in order for it to be cost-effective at the £20,000 per QALY threshold.

If the assumptions above hold true then a specialist service costing £25,000 provided in addition to standard antenatal care would need to book four more women per year (84 vs. 80 women) by 12 weeks gestation in order for the service to be considered cost-effective (Table 8.7). This is equivalent to a part-time dedicated midwife service (see the service descriptions in appendix D for more details)

For a £150,000 service 20 more women would need to be booked early and stay in antenatal care than are booked with the standard care alone. This is equivalent to a service with a full-time midwife, a part-time addiction nurse and nursery officer, and a part-time manager and administrator.

For a £250,000 service 33 more women would need to be booked early. This is equivalent to two specialist midwives for drugs and alcohol, one specialist midwife for mental health, one specialist midwife for sexual health, a part-time consultant midwife to manage the service, and a part-time administrator.

The results of the analyses demonstrated that an additional service could be considered cost-effective if it was able to book more women in the first trimester and maintain contact than if only routine antenatal care was provided. The number of women needed to book early to make a service cost-effective varies depending on the cost of the service provided. The full results of the analyses are reported in chapter 8.

This analysis supports the recommendations for providing additional services targeted to substance misusers. Spending additional time with these women to offer information, helping to co-ordinate care plans, and to chase non-attenders; and ensuring that a named antenatal is able to provide continuity of care is likely to be cost-effective if providing these additional services increases early booking and maintains access to care. In areas with a high population of substance misusers than it may be cost-effective to provide further services with more experienced midwives. These services should be audited to allow evaluation of both the clinical and cost-effectiveness.

## 4.8 Recommendations

Work with social care professionals to overcome barriers to care for women who misuse substances. Particular attention should be paid to:

- integrating care from different services
- ensuring that the attitudes of staff do not prevent women from using services
- addressing women's fears about the involvement of children's services and the potential removal of their child, by providing information tailored to their needs
- addressing women's feelings of guilt about their misuse of substances and the potential effects on their baby.

### Service organisation

Healthcare commissioners and individuals responsible for the organisation of local antenatal services should work with local agencies, including social care and third-sector agencies, that provide substance misuse services, to coordinate antenatal care by, for example:

- jointly developing care plans across agencies
- including information about opiate replacement therapy in care plans
- co-locating services
- offering women information about other services.

Consider ways of ensuring that, for each woman:

- progress is tracked through the relevant agencies involved in her care
- clinic notes from the different agencies involved in her care are combined into a single document

- there is a coordinated care plan.

Offer the woman a named antenatal carer who has specialised knowledge of, and experience in, the treatment of substance misuse, and include a direct-line telephonenumber for the antenatal carer.

### **Training for healthcare staff**

Healthcare professionals should be given training on the social and psychological needs of women who misuse substances.

Healthcare staff and non-clinical staff such as receptionists should be given training on how to communicate sensitively with women who misuse substances.

### **Information and support for women**

The first time a woman who misuses substances discloses that she is pregnant, offer her referral to an appropriate substance misuse programme.

Use a variety of methods, for example text messages, to remind women of upcoming and missed appointments.

The named antenatal carer should tell the woman about relevant additional services (such as drug and alcohol misuse support services) and encourage her to use them according to her individual needs.

Offer the woman information about the potential effects of substance misuse on her unborn baby, and what to expect when the baby is born, for example what medical care the baby may need, where he or she will be cared for and any potential involvement of social services.

Consider offering information about help with transportation to appointments if needed to support the woman's attendance.

## **Research recommendations**

### ***Antenatal appointments for women who misuse substances***

What methods help and encourage women who misuse substances to maintain contact with antenatal services/attend antenatal appointments?

#### **Why this is important**

Women who misuse substances are known to have poorer obstetric and neonatal outcomes than other women. Late booking and poor attendance for antenatal care are known to be associated with poor outcomes and therefore it is important that measures are put in place to encourage these women to attend antenatal care on a regular basis. Some of the evidence examined by the GDG suggested that some interventions could improve attendance for antenatal care, but this evidence was undermined by the use of self-selected comparison groups, so that the effect of the intervention was unclear.

In relation to additional consultations the GDG was unable to identify any particular intervention that had a positive effect on outcomes, although there was low-quality evidence that additional support seemed to improve outcomes. Much of the evidence was from the US and there was a lack of high-quality UK data.

It seems likely that making it easier for these women to attend antenatal appointments and providing tailored care will improve outcomes, but at present it is not clear how this should be done.

What additional consultations (if any) do women who misuse substances need over and above the care described in the Antenatal care guideline?

#### **Box 4.1** Examples of services for women who misuse substances

Manchester Specialist Midwifery Service (MSMS) has operated since April 2001 and specialises in providing a service to women and their families where drug/alcohol use and mental health problems have been identified. All team members are employed by Central Manchester University Hospitals Foundation Trust (CMFT) and based in a community resource centre in Central Manchester where other voluntary and statutory agencies are located. Joint commissioning between Manchester Drug and Alcohol Strategy Team (DAST), NHS Manchester and CMFT currently supports service provision.

The two specialist midwives (drugs/alcohol) are based in a shared office with other members of the MSMS team. The cross-fertilisation of knowledge and expertise is particularly beneficial in the frequent joint case planning and safe-guarding assessments with substance misusing families. It also facilitates ongoing experiential learning for all team members. The specialist midwives provide additional expertise, in-depth assessment and input over and above the usual antenatal care provided. The role is not one of providing regular antenatal care but one of individual casework and leading on co-ordination of care and case-planning. Women are encouraged to attend for routine maternity care and are referred for consultant care when indicated.

A Common Assessment Framework checklist is completed with all clients. Risk assessment and correlating the multiple complexities involved is a key component of the specialist midwife role.

Post-delivery contraception is discussed early on, and women and their partners are referred to the outreach sexual health nurse who will then make contact. Families are also offered a referral to ECLYPSE, the young people's service for drugs and alcohol where 1:1 counselling, group work and family therapy is provided. The specialist midwives also carry out joint assessments with the family workers. (Appendix D, number 6)

The Maternity Service (Jessop Wing), Sheffield, employs a team of three midwives. Following referral their role is to encourage and engage women in appropriate maternity and drug treatment services. This ultimately leads to co-ordinating the care that women receive throughout pregnancy and the postpartum period. The specialist midwifery team support a pregnancy clinic within the drug service where the GP and social worker are present. The GP manages the prescription and medical aspects of care alongside psychosocial interventions, and the social worker provides keyworking support, focusing primarily on attachment/parenting and social aspects within an addiction framework

The midwives within the specialist service can spend a significant amount of time following up the few women who do not attend appointments, but in general most women attend. The team takes on this role on behalf of the community midwife if persistent problems arise as this is an integral part of the role; they also have direct links to all the agencies that can assist. The methods used for follow up are letters, phone calls, and texts however the midwives find that using other outreach services, such as prostitute outreach, housing etc. can be more beneficial than direct contact at times. Feedback from women has been that too many midwifery calls or unplanned home visits can make them feel like they are being hounded or coerced into having care. (Appendix D, number 3).

# 5 Women who are recent migrants, asylum seekers or refugees, and women who have difficulty reading or speaking English

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## 5.1 Introduction

*Saving Mothers' Lives* found an increase in the numbers of births to migrant women and a corresponding increase in perinatal deaths amongst migrant women arriving in the UK in poor health since the previous report.<sup>3</sup> None of the recently arrived women who died had had a routine medical examination during their pregnancy and the opportunity for remedial treatment was lost.

The guideline focuses on women who are recent migrants (defined here as women who have come to the country of residence within the past year), asylum seekers, refugees and women with little or no English (or language spoken in country of residence) as these sub-groups are highlighted within CEMACH<sup>7</sup> as being particularly at risk of poor birth outcomes. These poor outcomes are thought to be related specifically to difficulty accessing services due to language barriers and a lack of knowledge and understanding of how the health and social care system works. However, interpreting the reasons behind the increased maternal mortality for this group of women has to be done with caution, as the numbers are small and this group of women can be socially excluded in other ways apart from their migrant status.

Of all the maternal deaths reported in *Saving Mothers' Lives*, 10% of them (n=26) were in women who could not speak English. Of these women, 23% (n=6) were late bookers or missed more than 4 visits, and 12% (n=3) received no antenatal care at all. This suggests that the women accessed antenatal care at some point, but experienced barriers preventing them from receiving full care or from benefitting from the care that they had received.<sup>3</sup>

The report acknowledges that women who have recently arrived into the UK, whatever their immigration status, bring new challenges for maternity services. The key issues include poor overall health status, underlying and possible unrecognised medical conditions including congenital cardiac disease, HIV/AIDS, TB, the consequences of genital mutilation, the psychological and medical effects of fleeing war torn countries, fears about immigration status and language difficulties.<sup>3</sup>

There were no national statistics about the numbers of maternities to refugees and asylum seekers, but the last three triennial reports have shown a tripling of Direct and Indirect maternal deaths of women who were refugees and asylum seekers from four in 1997-99 to 12 in 2000-02 and 36 in 2003-05.<sup>3;69;70</sup>

An important factor influencing access and delivery of healthcare is an understanding of the healthcare system and how it works. There are a number of reasons why this can be more difficult for women in this group. Women may not understand the system of routine antenatal care if they are recently arrived in the UK. They may have difficulty understanding their healthcare professional during the appointment because of language difficulties and lack of suitable interpreters. Additionally, they may experience a negative attitude from health care professionals, discrimination and lack of understanding about their own cultural experiences. This may result in women not understanding the purpose of diagnostic testing etc. and misunderstanding appointment dates and the potential value of antenatal education.

The NICE Antenatal care guideline states that women should be able to make informed choices about their care based on the information they are given.<sup>1</sup> Pregnant women who are recent migrants to the UK, and particularly those who are refugees and/or asylum seekers, often have difficulty understanding the choices and information they are offered due to language barriers. Recent migrant women may also have different expectations of healthcare provision from that of the local population and so need information about what they are entitled to and how to access it. Effective communication is particularly important for this group of women, an issue which is also emphasised in *Saving Mothers' Lives*.<sup>3</sup> The format this information might take is important in making it accessible.

This chapter covers a large group of women and it is important to recognise that each woman's needs may be very different. A recent migrant from an affluent country with a similar healthcare system to the UK who is fluent in English, may not require the same level of additional support as a recent migrant who can speak little or no English and who does not understand the healthcare system in the UK. Whilst the recommendations in this chapter are intended to apply to all women in this group, it is important that healthcare professionals treat these women as individuals and plan any additional care accordingly.

The guideline seeks to identify the best practice for service organisation and delivery to encourage and facilitate contact to be maintained throughout pregnancy for women who are migrants to the UK, including refugees and asylum seekers, women who have little or no English, and their partners and families. The driving force behind choosing this disadvantaged population is the difficulties these women face due to not understanding the language spoken in the country of residence and/or not understanding the health and social care systems and the society/culture in which they are living. This is separate from vulnerabilities that may arise out of ethnic differences per se. Women from ethnic minority backgrounds may have been resident in the country they are receiving care in for many years, hence issues of not understanding the system would be likely to be much less, unless the woman has lived a very protected lifestyle without much integration into society. This circumstance would also often lead to the woman speaking little English (or other resident language), a group that is included in the guideline.

The population of recent migrants, refugees, asylum seekers and women with little or no English was identified by explicit mention of these terms within the paper or by GDG consensus that the included population was likely to represent one or more of these groups. Recent migrants were defined as women who had come to the resident country within the past year. However, few papers used this definition and it was often necessary to decide inclusion/exclusion based on level of understanding of English (or mother tongue of the resident country), degree of acculturation, or understanding of health care services where this was reported. Studies including women from black and ethnic minority groups were excluded if it appeared the sample was primarily made up of women who were not recent migrants and spoke English, or if there was no information reported that would allow a judgement to be made regarding these criteria. Where the study sample was made up of a combination of women falling across categories half or more of the sample had to comprise women who were recent migrants, non-English speaking, asylum seekers or refugees for the study to be included. Studies involving exclusively small indigenous groups not common in the UK were excluded e.g. Australian Aborigines, Native Americans and Inuit. Studies originally considered for inclusion could be later excluded if the GDG felt the target population was so different from a UK population as to make generalisation of findings impossible.

## 5.2 Access to antenatal services

### Clinical question

Q1a. What aspects of service organisation and delivery are effective at improving access to antenatal services for women who are recent migrants to the UK, refugees, asylum seekers, or who have little or no English?

### Previous guidance

There is no previous NICE guidance addressing this question.

### Overview of included evidence

Comparative studies from all countries and all dates were considered for inclusion in this review. Outcomes considered included gestation at booking, referral to and uptake of additional services including attendance at antenatal classes.

Nine studies were considered for this question. After further assessment against inclusion criteria and quality appraisal, six have been included in this review, all of a low evidence quality [EL= 2- or 3]. Three studies (two from the UK) examined the use of health advocates/link workers; one US study described the impact of an outreach case-finding service provided by bilingual health care workers; and one UK study considered the impact of a service change designed to improve antenatal referrals to social workers. One small qualitative study from Australia compared women's views of hospital-based care with the same women's views of a community-based clinic where services had been changed to meet the needs of recent migrant women.

### Narrative summary of evidence

#### Advocates/link workers

A UK retrospective case-control study was conducted to evaluate a programme (The Asian Mother and Baby Campaign) implemented to improve Asian women's use and understanding of health care in Leicestershire<sup>20</sup> [EL=2-]. The campaign was undertaken to help overcome the problems experienced by Asian women during pregnancy, including problems associated with communication. To achieve this aim, eight link workers were allocated to this district for a two year period. Although the role of the link worker is not described in detail it appears the role was predominantly that of an interpreter.

Four hundred and seventy-five women participated in the study. The analysis presented in the study was based on whether a woman did (n=133 "cases") or did not (n=244 "controls") have a contact with a link worker. It was reported that the link workers provided a much needed interpreter service but were less successful in imparting health education knowledge to Asian women. No effect was noted regarding difference of gestation at antenatal booking between groups although the authors report that Asian women in the study area tended to book early anyway. It should also be noted that 63% (n=286) of the total sample were Gujarati speaking and nearly 60% (n=167) of them had a good understanding of English. This high proportion of English-speakers may have undermined the potential beneficial effects of the link worker, especially given that one of the main aims of the intervention appeared to be to help improve communication.

A retrospective UK cohort study evaluated a health advocacy programme designed to improve obstetric outcomes among women of ethnic minorities in east London<sup>71</sup> [EL=2-]. Data were collected from 923 women who were designated as non English-speaking giving birth at the Mothers' Hospital, Hackney, in 1984-1986 who had been accompanied by an advocate (study group MH 1986) and compared with n=866 women who were designated as being non English-speaking women giving birth at the same hospital in 1979 (before the start of advocacy project) and two similar groups (no significant difference in terms of age and ethnicity) from a reference hospital (Whipps Cross 1979, n=999; Whipps Cross 1986, n=993). It should be noted that women recruited to the study were identified from their medical records as either Turkish or Asian by their surname. Using this method, it would have not been possible to ascertain their level of English knowledge (or indeed if they were indeed Asian or Turkish or simply married to someone who was). The Multi-Ethnic Women's Health Project (MEWHP) was started in 1980 to help meet the needs of non-English speaking women at the Mothers' Hospital. The women who worked for the project were called "health advocates" because they mediated between women and professionals to make sure that women were offered an informed choice of health care as well as providing an interpreting service. The advocates 'booked' the new women following a set protocol and presented the history to the midwife or doctor.

The authors report that women booked significantly earlier in both hospitals in 1986 compared with 1979 and attended Whipps Cross earlier than the Mothers' Hospital, Hackney at both time periods, suggesting the advocacy scheme had little impact on this aspect of care provision (Mothers' Hospital 1979 vs. 1986:

19.5 vs. 18.8 weeks; Whipps Cross 1979 vs. 1986: 17.7 vs. 16.8 weeks; no details given regarding statistical analysis or p value).

A US retrospective case control study was undertaken to analyse changes in knowledge, health status and behaviours of 470 migrant farm worker women (and their children) who were in contact with a Lay Health Advisor (LHA) in Indiana, USA<sup>72</sup> [EL=2-]. An LHA was defined as a person who naturally provides unplanned assistance to those persons familiar to her, selected from the community and trained in maternal-child health issues. Association between health status, knowledge of health practices and exposure to Lay Health Advisors were studied in 470 Latino women seen at two health centres (in North Carolina) using a knowledge test and/or exposure questionnaire.

Twenty Lay Health Advisors were assessed before they began the training programme and at 2 weeks and 6 weeks after it for their knowledge of health practices by the means of a 19 items Knowledge Test questionnaire. There was a statistically significant improvement in LHA's knowledge following their training programme ( $p < 0.05$ ). LHAs were also surveyed using the Helping Contact Questionnaire at 2 weeks and 6 weeks after their training regarding the social support they had offered pregnant women. No significant differences were observed between pregnant women with or without "LHA exposure" in regard to the trimester they initiated antenatal care and number of antenatal visits made (no figures reported).

### **Case-finding and outreach using bilingual health care workers**

A US study investigated the effectiveness of a programme designed to deliver primary health care services for migrant farm-worker women and their children by retrospective analysis of their medical records. Three hundred and fifty-nine pregnant farm-worker women who had received the primary care services at Tri-County Community Health Centres between April 1985 and September 1987 participated in the study<sup>73</sup> [EL=3].

A bilingual, multidisciplinary team of health professionals collaborated with a migrant health centre in North California to develop a model programme for delivery of primary care to migrant farm worker women and children. The programme included case finding and outreach, coordination of maternal and child health services locally as well as an interstate and innovative health education programme conducted to train migrant farm worker women as lay health advisers.

The number of migrant women initiating care in the first trimester increased from 41% in 1985 when the programme was introduced to 51% in 1987, this difference is not statistically significant (Fisher's Exact Test,  $p = 0.15$ ).

### **Service interventions to improve inter-disciplinary referral**

A UK multi-method before and after evaluation investigated working relationships between antenatal clinic nursing staff and hospital social workers and their impact on Asian women<sup>74</sup> [EL=3].

The study comprised 3 phases:

First phase: a statistical survey was carried out describing referrals received from the maternity unit and the antenatal clinic, between January 1985 and January 1986. Out of 28 referrals made from antenatal clinic to the social services department for additional social support during that period only five women appeared to be Asian in origin (as judged by the woman's name as it appeared in hospital records). This was fewer than would be expected based on the proportion of women booking at the hospital who were known to be of Asian origin.

Second phase: This comprised a survey feedback/action planning phase, including a meeting with the social work team, involving feedback and discussion of the survey result from phase one. Eighty-one nurses working in the maternity unit were given a questionnaire designed to explore the relationship between maternity unit staff and hospital social work staff. There was a low response rate to the questionnaire (37.5%), explained partly by an undermining of the research by senior midwifery staff. The staff questionnaires responses indicated difficulties with Asian naming systems and communication with Asian women. Staff attributed non-attendance at the antenatal clinic mainly to cultural restrictions rather than poor service provision. Ninety percent of respondents believed Asians in Britain to have supportive extended family networks, and therefore to have less need of social services support. Sixty percent of staff indicated that, in their view, Asian women were less likely to want such support, as they preferred to keep problems within the family. The questionnaire data also revealed the nurses' lack of understanding of work undertaken by social workers in general, and a lack of respect for their role.

Third phase: Finally action implementation and evaluation was conducted. Two social workers (one male, one female, both white) were appointed to be physically present at the antenatal clinic during booking-in sessions; where women first came into contact with the maternity services, in order to improve interagency relationships, and therefore improve general referral rates. Having 2 social workers physically present in the antenatal clinic during booking did not result in any consistent improvement in the referral rate, but some indications of modest improvements in communication were detected. The new initiative was not well implemented with social workers being provided with a small cubicle as a consulting room and no additional signage/information for women was provided regarding the service. It was also noted that social workers made attendance at the booking clinic low priority and often did not attend.

### **Women's views of a community-based service**

An Australian qualitative study examined factors that facilitate or impede antenatal care uptake among refugee communities in the western suburbs of Melbourne using observational methods and semi-structured interviews<sup>75</sup> [EL=3].

Ten African women were interviewed. They were recruited by the community clinic staff and those indicating interest were approached. The women's length of their stay in Australia varied from 3 weeks to 2 years. Parity ranged from 0 to 13. Most were in transitional housing, awaiting resettlement. Most of the participants came from Ethiopian backgrounds.

Women compared their experience of a community-based clinic with that of a hospital-based clinic. Participants indicated that staff attitudes, availability of interpreters, knowledge about the clinic at community level and convenient location of the clinic had impacted positively on their attendance at appointments. Participants spoke of feeling welcome at the community-based clinic, and also of understanding that the midwife there had an interest in their progress. In contrast, women often felt alienated when attending larger hospital clinics. This seemed to relate principally to perceptions of staff as rushed and busy, to feeling 'different' and to not speaking English.

The availability of interpreters was also considered important by women attending the community clinic. Knowing that there would be an interpreter booked specifically to be present at their appointment made it easier for them to attend. The degree of knowledge about the clinic at community level and the convenience of its location both impacted positively on attendance.

Staff at the clinic made a great effort to understand the women's needs and to 'see things from their perspective'. This approach aimed to 'make it easy for them to attend' and appeared to promote high levels of clinic attendance. The clinic staff had compiled a folder with information such as what bus to take to the clinic and the bus stop at which to alight, complete with photographs of the bus, the bus stop and the clinic. This initiative was reported to be a success and greatly facilitated the women's recognition of the venue.

### **Evidence statement**

Findings from two case control studies and one cohort study examining the impact of the role of advocates or link workers suggest these interventions have little effect on the gestation at which women book for antenatal care. Findings from two of these studies found no association between contact with a link worker and increased knowledge of issues relating to antenatal care and available health services amongst migrant women. One UK case control study found that Asian women tended to book early in pregnancy.

A US retrospective evaluation of records showed that the initiation of a service programme including outreach and case-finding involving bilingual health care workers was associated with a non-statistically significant increase in the proportion of women booking during the first trimester (from 41% to 51%) over a 3 year period.

A UK before and after study evaluating the relocation of maternity social workers into the antenatal booking clinic showed the service change did not improve referral rates of pregnant Asian women to maternity social workers. The success of the intervention was undermined by a lack of support from staff.

An Australian qualitative study found recent migrant women valued the availability of interpreters, staff who were interested in them and not rushed, and a local, convenient clinic.

## GDG interpretation

It was agreed to combine the interpretation for question 1a and 1b due to the related nature of the evidence

## 5.3 Barriers to care

### Clinical question

Q1b. What aspects of service organisation and delivery act as barriers to take up of antenatal services for women who are recent migrants to the UK, refugees, asylum seekers, or who have little or no English?

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Both comparative and non-comparative descriptive studies were considered for inclusion. After weeding, 64 papers were retrieved that answered the question in terms of what the perceived barriers to care are, either from the woman's point of view or that of service providers. After quality assessment 28 papers were included in the review. Of these papers 10 were from the UK, 11 from the US, 2 from Australia, 2 from Canada, 1 from Ireland, 1 from Greece, and 1 from Sweden. The studies were descriptive, mainly using questionnaires and also focus groups.

The groups covered were recent immigrants such as refugees and asylum seekers, and also immigrants who had been in a country for a number of years who still had experienced problems with accessing antenatal care for a variety of reasons. The studies varied in the immigrant populations covered from asylum seekers in general, to specific ethnic groups. The studies had been published between 1991 and 2008 and so some of the information in the papers may now be out of date.

### Narrative summary of evidence

Please see Evidence Table for study details.

### Language barriers

Language was mentioned in 23 of the studies for this question which were all either EL=2<sup>22;76;77</sup> or EL=3<sup>23;24;27;31;37;42;45;78-90</sup>. Women often received less information because they could not understand the language of their adopted country. In many cases interpreters were not available. In these situations staff made do by gesturing (2008)<sup>83</sup>, or using ad-hoc interpreters if available; nurses, doctors and sometimes porters (1991)<sup>89</sup>. For example:

"...the doctor spoke [in English], and I would just nod my head. I understood little, about half of what was said."<sup>83</sup> (pg 511)

One UK study (2009)<sup>87</sup> suggested that interpretations of gestures and symbolic representation could lead to serious misunderstanding. Where interpreters were available some women felt uncomfortable speaking in front of a stranger and some felt the interpreters did not understand medical terminology (2004)<sup>37</sup> (2008)<sup>27</sup>. In an Irish study<sup>27</sup> male interpreters had been provided which caused difficulties as questions about pregnancy can often be personal or intimate. A group of Somali women (n=13) in a Northern English city (2001)<sup>23</sup> had experienced some health professionals who insisted on the presence of an interpreter, refusing to see women who had not brought someone to provide interpretation. The interpretation service provided had to be booked 3 days in advance which delayed access. Friends and family members were sometimes used instead of independent interpreters which could be embarrassing for women and led to concerns about confidentiality (2001)<sup>23</sup> (2008)<sup>27</sup>. For example:

"Sometimes you bring the wrong translator, say a relative or someone, and you don't want to tell him something in case they spread it around"<sup>23</sup> (pg 242)

Questionnaires were sent to 30 multi-racial district health authorities for a UK survey (1991) of the Linkworkers service, a service launched in 1984 as part of the Asian Mother and Baby Campaign to improve communication between Asian women and health professionals<sup>89</sup>. Of the 20 questionnaires returned, 17 acknowledged that there was a client group which would require a linkworker service. No precise data on details of the languages required were available to the planners of the service and 8 authorities did not record the language spoken in women's case notes. Even where linkworker services were provided these were only available during standard working hours.

Women who did not speak English felt they were perceived as 'difficult'. A study of the 'neighbourhood project' aimed at Sylheti-speaking women in Leeds (2005)<sup>78</sup> [EL=3] reported that English speaking women believed being able to communicate in English was associated with better quality care. Even when English was spoken, difficulties could arise from the use of colloquial terms such as 'waterworks', 'tummy', and 'dizzy' (1993)<sup>42</sup>. A UK study (2009)<sup>31</sup> reported the experience of eight Somali women who had been healthcare professionals in Somalia and/or were practising in the UK. It found that complicated language and medical terminology used by staff could be a barrier to care. This was also found in another UK study consisting of interviews with 4 asylum seeking or refugee women (2009)<sup>87</sup> Videotapes to take home, tours of the hospital in different languages, audiotapes and printed materials were all suggested by Somali women in a US study (2004)<sup>37</sup> as ways of improving information for non-English speaking women, although the 2009 study<sup>31</sup> suggested that Somali women prefer verbal explanations to leaflets. In the US study<sup>37</sup> Somali women felt they were not given a choice about whether they had an interpreter and were assigned an interpreter simply because they looked Somali or because they had a Somali name. This was also found in an Australian study (2001)<sup>45</sup> with health providers making assumptions that women could not speak English based on their physical appearance (the wearing of the traditional headscarf).

An older UK study (1993)<sup>42</sup> [EL=3] reported experiences from interviews with 25 midwives working with women of Pakistani and Bangladeshi descent in 1988. Most of the women the midwives worked with were from rural areas and had limited contact with non-Asian people. The midwives reported that the level of English was generally low. The midwives characterised the women as unresponsive, rude and unintelligent. None of the midwives in the hospital was of Asian descent and the hospital did not employ interpreters. Women who tried to speak English frequently offended the midwives. The main complaint was that the women did not say 'please' or 'thank you'. In Urdu there is a polite form of the imperative and so these women were not being intentionally rude. The midwives felt working with South Asian women was unrewarding as they were unable to have a 'proper relationship' with them.

A retrospective cohort UK study was carried out to identify the level of satisfaction with the services offered, causes for inappropriate or under used facilities and the health of infants among women of different ethnic groups in east London<sup>22</sup> [EL=2-].

One hundred and one women randomly selected from birth notifications (held at Tower Hamlets District Health Authority) were interviewed 8 weeks, 8 months and 14 months after giving birth. The sample included 49 indigenous women, 28 Bengalis, 12 West Indian and the rest Sikh, Indian, Chinese, Egyptian, Vietnamese or Greek. The women were divided into 3 groups: non-English speaking, English speaking immigrants, and indigenous women.

Eighty-two percent of Bengalis, 71% of the English-speaking immigrants and 64% of the indigenous women felt that standard of care they had received in the antenatal clinic was excellent or good. Bengali mothers had a tendency to consult their GP about their pregnancy later than others (39% at 8-12 weeks of their pregnancy vs. 84% and 88% in English-speaking immigrants and indigenous women respectively).

Only 8% of Bengali mothers went to antenatal classes and none to any form of parent craft, because they did not know about their existence. Thirty-five percent of the English-speaking immigrants and 56% of indigenous women went to antenatal and parentcraft classes. Descriptive statistics (percentages) only are available for this study, no comparative analysis is reported.

A Canadian retrospective descriptive study investigated factors influencing antenatal class attendance among immigrants in Ottawa-Carleton, Canada<sup>90</sup> [EL=3]. Women who immigrated within the past 15 years either from a 'developing country' or Eastern Europe were recruited on the postnatal wards of five Ottawa

hospitals from April to October, 1990 and were interviewed a few days after birth and then 3 months later (n=283 women of the 310 recruited antenatally completed the study (91.3%). Women in the study reported to be from 75 ethnic groups, from 57 countries of birth and spoke 40 different mother tongues. The most frequently reported countries of birth were Lebanon (n=31), Somalia (n=28), Vietnam (n=24) and Poland (n=18). Plausible predictor variables which were stable throughout the pregnancy were analysed for their statistical association with the attendance at antenatal classes. Overall 46.8% of nulliparous women and 11.6% of multiparous women reported attending antenatal classes. The average number of sessions attended was 5.6 (SD=2.3). Significant predictors of antenatal class attendance were maternal age, education, knowing English, and length of residency in Canada and immigration status. Among women who reported their English or French ability as fair or poor only 2.9% attended antenatal classes as compared to 71.8% of those had excellent or very good language ability. Lowest attendance rates were recorded in refugees (14.3%) in comparison with permanent residents (48.4%) and temporary residents (66.7%).

An ethnographic study [EL=3] based on interviews and participant observation was conducted in Australia to identify the perceptions and experiences of pregnancy care, labour and birth of Thai women in Melbourne (n=30) (1998)<sup>86</sup>. All women were interviewed in the Thai language. The majority of women were married (25/30) and recently migrated to Australia. Some women reported difficulty in understanding health care providers during antenatal consultations because of language difficulties and therefore needed their husband to help with interpretation. However, despite this, the women interviewed saw antenatal care as an important aspect of pregnancy and never missed any antenatal appointments. Most women attended antenatal classes arranged by the hospital and believed that the classes were important. Undergoing a pelvic examination was reported as a major concern for most of the women. Although they felt it was reassuring, they felt uncomfortable, particularly when examined by a male doctor. Most of the women were satisfied with the antenatal care they received in Australia and considered it better than care provided in Thailand.

### **Cultural barriers**

A study of the midwives' experiences in one London hospital identified both cultural and communication problems associated with working with women from South Asia (2005) [EL=3]<sup>26</sup>. They reported limited social/cultural integration, specific dietary practices and culturally specific care in pregnancy including the women's religious beliefs and practices. Other barriers identified were limited comprehension of biomedical healthcare and communicating problems in pregnancy e.g. Down's syndrome, and explaining the diagnostic value of antenatal screening<sup>26</sup>. An Irish (2008) study identified that service providers may be unable to get accurate obstetric and medical histories due to women's lack of proficiency in English [EL=3]<sup>27</sup>. The ultrasound test was the only test that all the refugee women in a Greek study (2008) made a point of having. All other medical examinations, blood and urine test, were considered less important to them because there was no visual indication of the baby's health [EL=3]<sup>80</sup>.

More experienced midwives and those with more South Asian women in their caseloads were found to be more comfortable about communicating sensitive issues during antenatal care (2005)<sup>26</sup> [EL=3]. The midwives recommended greater representation of South Asian midwives in the profession, user participation in the planning of services, support for midwives to provide information and education, leaflets in a variety of languages, greater sensitivity and respect of modesty and religion. It was also suggested that grandparents need to be involved in the educational process during antenatal care because of their influence on the mothers. One Australian study which conducted interviews with Asian women living in Tasmania suggested that Asian women could be unassertive and reticent to speak out in the event of problems [EL=3] (2009)<sup>88</sup>

### **Discrimination**

Women encountered indifference, rudeness and racism in a study of asylum seekers in the UK [EL=3]<sup>24</sup>. Quotations reported in this qualitative study illustrate this finding, for example:

"In the end I got an infection in my scar.... I went to the midwife and said I'm feeling cold, and all my body shakes.... She looked at me like this and said "You are okay".... She said to another midwife "These Africans, they come here, they eat nice food, sleep in a nice bed, so now she doesn't want to move from here." (p. 783)

Somali women in the US perceived that nurses discriminated against them on the basis of race and were less sensitive to their needs [EL=3] (2004)<sup>37</sup>. Discrimination was seen to be due to language or being an immigrant [EL=3] (2008)<sup>83</sup>. Somali women in the UK felt they could be stereotyped as being unintelligent, lacking in knowledge about pregnancy or childbirth and unaware of family planning [EL=3] (2009)<sup>31</sup>. In a Canadian study women experienced discrimination, insensitivity, and lack of information about their cultural practice [EL=3] (2008)<sup>32</sup>. In an Irish study [EL=3] (2008)<sup>27</sup> some service providers considered that they were not racist and that they had genuine reasons for their issues in relation to ethnic minority women. Some participants referred to all ethnic minority women as African. Many classed all ethnic minority women as asylum seekers. They referred to women not conforming to the 'unwritten' rules of behaviour in the hospital and reported that the women were more "demanding"<sup>27</sup>.

Two studies suggested that recent immigrants may have complex emotional and mental health needs, may lack control over their lives and many do not have a social support network [EL=3] (2005)<sup>24</sup>, [EL=3] (2009)<sup>31</sup>. Many refugee women had no one to talk to except their husbands, but most felt uncomfortable discussing female matters with them [EL=3] (2008)<sup>80</sup>. Somali women in Sweden [EL=3] (1999)<sup>81</sup> had strong feelings of loneliness and longed for the social network of family and relatives, as illustrated by the following:

"For you it is something easy but for me it is something difficult since I am totally alone.... If I had been in Somalia I could leave the child at my mother's or my sister's place while I went shopping, but that is impossible here .... I have no friend who can help me." (p. 110)

Somali women in the UK felt that the health care professionals had negative attitudes towards women with large families [EL=3] (2001)<sup>23</sup>. UK midwives in interviews conducted in 1988<sup>42</sup> [EL=3] described South Asian women as service 'over-users' or even 'abusers' due to increased fertility. In an Irish study (2008)<sup>27</sup> [EL=3] late bookers were perceived negatively. The service providers commented that women seemed to arrive "straight from the airport" and that late bookers were not "in the system" and so used the emergency service.

### **Understanding the health care system**

Lack of understanding of the health care system was identified as a problem. A group of Somali women living in the UK (2001)<sup>23</sup> [EL=3] reported that obtaining advice from the health service was "an arduous task", understanding the different services was difficult especially for recent immigrants unfamiliar with the system. For many of the women their only point of contact with the NHS was through their GP. Non-attendance could result from a variety of factors, including misunderstanding of the date and time of the next appointment (1993)<sup>42</sup> [EL=3]. In Greece (2008)<sup>80</sup> [EL=3] the main sources of information were relatives and friends who had been in Greece for a long time, health professionals, governmental organisations, and non-governmental organisations. Suggestions to improve outreach were; conducting health campaigns, providing information at appropriate community locations, ensure cross agency referrals, identify community leaders and train them as case finders, and implementing women's support groups (1992)<sup>85</sup> [EL=3].

### **Transport and Location**

In a study of 33 asylum seekers in cities across the UK cost of transport was identified as a problem (2005)<sup>24</sup> [EL=3]. Transport was also identified as a barrier in some US studies (1996)<sup>82</sup> (1996)<sup>76</sup>. However, in a study on clinic locations in Brooklyn, New York, it was found that groups with higher rates of low birth weight infants tended to have a greater density of clinics nearby. Study authors concluded that this indicated that the clinic locations reflected the local antenatal care needs (2005)<sup>91</sup> [EL=3]. There were some exceptions noted and not all groups fitted this trend; Pakistani and Bangladeshi women had a high need for antenatal care services but poor geographic access to clinics. Women from Barbados, St. Vincent and Grenadines, and Trinidad had the highest clinic density, 1.22, 1.17, and 1.15, respectively; compared to only 0.42 and 0.21 for women from Bangladesh and Pakistan.

### **Parentcraft sessions**

## Women who are recent migrants, asylum seekers or refugees and women who have difficulties reading or speaking English

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One Canadian study showed that non-English speaking women and refugees were much less likely to attend parentcraft sessions than migrant women who could speak English<sup>90</sup>. In two studies (one Canadian and one UK), women were not told about antenatal sessions or did not understand their purpose (2005)<sup>24</sup> (2008)<sup>32</sup> [both EL=3], and when they could attend there were no interpreters<sup>24</sup>.

### Immigration status

Immigration status as a barrier to care was mentioned in four US papers (1999)<sup>92</sup> (1996)<sup>77</sup> (2004)<sup>93</sup> (1991)<sup>85</sup> [all EL=3]. Asylum seekers in the UK identified being refused GP registration as a barrier to care (2005)<sup>24</sup> and it was also noted that women with asylum seeker status could be required to move regularly due to dispersal policies and this could provide a barrier to continuity of care (2009)<sup>31</sup>, (2009)<sup>87</sup>. One UK study highlighted that being prevented from working as a result of immigration status increases social exclusion and hampers integration into the new culture. (2009)<sup>87</sup>

### Continuity of carer

One UK study identified continuity of carer as important (2000)<sup>79</sup> [EL=3]. Knowing the carers and being known by them was valued and helped women to communicate effectively with their carers:

“...my midwife and myself got on well. She was like my family there. I mean there was no difference between me and her, if I had to say to her, I can say anything and everything.”<sup>79</sup> (p. 149)

Somali women preferred to see the same midwife during the course of the pregnancy and felt that the trust that is developed with one person over nine months was difficult to achieve with a team of healthcare professionals (2009)<sup>31</sup>

Where language was a problem this was aggravated when the care was fragmented with absence of prior knowledge of the individual woman. Refugee women also reported that they would feel more comfortable with female doctors (2008)<sup>80</sup> [EL=3].

### Evidence statement

Twenty five included studies are EL=3 and three are EL=2-

**Table 5.1 Barriers reported for recent migrants, refugees, asylum seekers and women with little or no English**

Service barriers reported by women	Personal reasons which act as barriers reported by women	Barriers reported by providers
Language – lack of interpreters, use of colloquialisms (17)	Not understanding the health care system and how to access it (9)	Language (4)
Discrimination, racism towards immigrants and non-English speakers (6)	Lack of social network (4)	Lack of availability of suitable interpreters especially for emergencies, out-of-hours and unbooked appointments (1)
Lack of continuity of carer (3)	Misunderstanding dates and times of appointments (1)	Unfamiliarity of health care system, what to expect, how to use it (3)
Not told about antenatal education (2)	Not understanding the purpose of antenatal classes, diagnostic tests. (1)	Ethnic minority women do not conform to rules – use emergency services instead of clinics, can be demanding expecting health care to live up to standards of care in their home country.(1)
Refused registration with a GP (1)	Depression/ Fear/Anxiety/ other personal (5)	Lack of knowledge of cultural and religious differences (1)
Lack of transport (6)	Financial (6)	Negative attitude towards women from ethnic minorities (2)
Inconvenient time of AN clinic (8)	Lack of child care (3)	Lack of continuity of carer (1)

## Pregnant women with complex social factors

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No directing agencies (1)	Fear of Immigration services (4)	Pressures and difficulties arising from immigrations status (1)
Lack of cultural sensitivity among providers (2)	Dispersment policies for women with asylum seeker/refugee status (1)	
Negative attitude of healthcare professionals (2)	Lack of assertiveness in dealing with the healthcare system (1)	

Number of studies reporting barrier given in parentheses

### GDG interpretation of evidence

Findings from two retrospective UK studies suggest that for a proportion of Asian women, timely attendance for antenatal appointments is not an issue. However, for many women with little or no English, there is difficulty accessing knowledge and information when they attend appointments due to a lack of interpreters and information in an easily understandable form e.g. translated leaflets with photographs or illustrations, or antenatal classes in the appropriate language. An innovative example of how to provide information to women is given in Appendix D, number 12. Based on this evidence, the GDG recommended that appropriate information should be provided in a variety of formats and languages.

The evidence suggests that a large proportion of women in this population do not attend antenatal classes, but does not give robust explanations for this. Evidence from the barriers review suggests that when there are difficulties in communication women may remain unaware of the full range of services available to them, which might include antenatal education sessions. The lack of provision in a woman's native language and lack of available interpreters would also explain their reluctance to attend these sessions. There is also some evidence that at least some groups of migrant women, particularly those who do not speak English, book late for antenatal care (i.e. after the first trimester) (although the evidence regarding gestation at booking is equivocal). Findings from the evidence reviewed for question 1b were supported by the GDG's experience that the poor attendance by this group was at least partly due to this population's lack of knowledge of how to access the health service and systems in place for maternity services in the UK. It was felt to be important that women who are recent migrants, asylum seekers and refugees should be provided with the Department of Health information on access to entitlement to healthcare at first contact with a health care professional, and that the health professional should ensure she has been able to understand the information. It would also be of benefit to provide women with other supportive literature that helps to explain these entitlements e.g. the Maternity Action information sheet. Based on GDG consensus, a recommendation was made to reflect this.

It was also noted that, in the GDG's experience, despite contacting a GP early, some women have to wait a number of weeks before a booking appointment is received. Women who are less familiar with the UK health care system might be more likely to simply wait for this appointment to arrive rather than chasing it up. The GDG also raised the issue that there may be cultural issues to consider regarding pregnancy and the possible belief that medical care/intervention is only required when there is a problem and that normally in their home country women would only access care in labour. Thus "late booking" is perceived as a problem by maternity service providers but not necessarily by service users. Women also need to know where to go to access services, and this is inextricably linked with providing information in a format and language that women find easily accessible including in a variety of settings, including outside the healthcare system. This GDG decision, based on consensus, was also included in the recommendations.

The GDG agreed that there are a number of benefits to booking recent migrants early. It means that they can receive a health-check sooner which allows early identification of underlying health problems. In addition, some groups of recent migrants are particularly likely to benefit from screening for sickle cell and thalassaemia trait which should be done early in pregnancy and ideally before 10 weeks.

One qualitative study demonstrated very clearly that careful thought, preparation and an attempt to be more focussed on the service-user perspective encourages attendance. This study demonstrated that positive staff attitudes, the community-based locality of the service, and clarity of information sent to the women prior to their appointment made the service more accessible and acceptable to the women involved. The value of providing clear, illustrated information, including information about options for antenatal care and where it can be accessed, to women who may understand little English was noted by the GDG and a recommendation made to reflect this finding from the evidence.

Whilst the findings from studies investigating the effects of interpreters/link workers were equivocal, overall the GDG felt that this was likely to be a useful service, especially since language barriers were

identified frequently by both women and staff and the lack of interpreters highlighted. This would then help to overcome the difficulty reported in the evidence that women who don't speak English tend to have poorer knowledge of health care services and the benefits of antenatal care.

The included studies in the barriers review were from a number of countries, predominantly the US. They were almost all descriptive [EL=3]. The experience of the GDG confirmed much of the evidence from both the UK and non UK studies, showing that language differences, poor understanding of the health system and how to access it, providers' lack of cultural understanding and discrimination all contribute to women in this group receiving sub-optimal antenatal care. The cost of transport was identified as a problem in one UK study and one UK study cited immigration status as a barrier to care because it could result in GP registration refusal. However, most of the evidence relating to these topics came from the US and the GDG felt that these issues were likely to be more of a problem in the US than in the UK. Two studies reported the importance of continuity of carer in countering the major barriers experienced by this group of women, a view shared by the GDG.

Some studies also reported that migrant women are more likely to experience hostility and rudeness. Staff have been found to lack understanding of the specific needs of migrant women, and make unfounded assumptions about the type of support that may be needed. Lack of continuity of carer exacerbates the problems faced by women who do not speak English since it means they may have to re-tell a complex history in an unfamiliar language. Poor continuity of care (both in terms of continuity of carer and consistency of care) is also an issue for migrant women who are in temporary accommodation, or mobile due to their employment situation.

Again due to the large number of barriers identified, the GDG formally voted on which barriers they considered to be the most important and relevant. This consisted of one round of anonymous voting using pencil and paper. Following this, the results were fed back to the group and agreed. The GDG highlighted five key issues which they considered to be particularly relevant. These were:

- Language
- Lack of available interpreters
- Discrimination from healthcare professionals and other staff
- Not understanding the healthcare system and how to access care
- Healthcare professionals' lack of knowledge of cultural and religious differences

The group particularly considered these barriers along with the evidence reviewed for the question on access to care when drafting recommendations. For recommendations see section 5.7 (page 83).

Whilst the evidence has been presented under sub-headings, the health and social needs of recent migrants are complex and inter-linked. Language is an overriding issue but explains only part of the communication difficulties experienced by this group of women. As this group of women often experience multiple barriers, different ways of meeting needs should be considered, e.g. local access to healthcare at Children's Centres, women's groups etc.. This may also address the reported difficulty in understanding the healthcare system. Cultural barriers and discrimination were also reported widely in the evidence, suggesting the need for respect of each woman's individual needs and provision of tailored care. For example, in some cases, the woman may feel that it is necessary to seek permission from her partner or appropriate male relative in order for a male healthcare professional to examine her. It is important that healthcare professionals are able to respond sensitively and appropriately to needs such as these. For examples of service provision aimed at meeting the needs of this group of women see Appendix D numbers 7, 8 and 9.

*Maternity Matters*<sup>4</sup> highlights that commissioners need to understand what barriers in their current services may prevent vulnerable women from seeking care early, or maintaining contact with their maternity services, and to overcome these by providing more flexible services at times and places which meet their needs. In line with this, PCTs need to understand the migrant and non-English speaking population in their area, to assess what specific support may be necessary in order to make maternity care accessible, and to ensure that their staff are adequately trained and prepared to provide this support. In order to provide a service that reflects this need accurately it is important to involve migrant women themselves in service provision e.g. through local consultation with appropriate women's groups and recruitment of women from these groups onto maternity services liaison committees etc..

See section 5.7 (page 83) for recommendations for service provision for women who are recent migrants, refugees, asylum seekers or who speak little or no English.

### 5.4 Maintaining contact

#### Clinical Question

Q2. What aspects of service organisation and delivery improve contact with antenatal services throughout pregnancy for women who are recent migrants to the UK, refugees, asylum seekers, or who have little or no English?

#### Previous Guidance

There is no previous NICE guidance addressing this question

#### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Studies were included where there was a comparison between outcomes (including women's views) for different groups. This comparison could include groups receiving different antenatal care services or comparison between the views of different groups of women (e.g. migrant women vs. non-migrants) receiving the same antenatal care. Of the 13 studies considered six have been included in the review and seven excluded. There are three UK studies focussing on the views and experiences of South Asian (Pakistani/Indian) women, one study from Australia, focussing mainly upon women immigrants from South East Asia and two US studies investigating the effectiveness of an outreach case-finding system designed to reach Hispanic migrant farm workers.

#### Narrative summary of evidence

##### Migrant women's experiences and views of antenatal care

A 2001 prospective comparative survey assessed the quality of maternity services, as perceived by Pakistani and indigenous white women in the UK<sup>94</sup> [EL=3]. Women from different general practices in two districts within a northern UK NHS region were invited to take part in the study between July 1995 and August 1996. Participating women were interviewed in their homes before the 30th week of pregnancy and again between six and eight weeks postpartum. Donabedian-Maxwell's grid was used to highlight the dimensions of quality on which women commented in the interviews. In this grid structure, process and outcome of care were illuminated in 6 dimensions (Effectiveness, Acceptability, Efficiency, Access, Equity and Relevance). It was anticipated that dimensions of quality on which women commented would differ between the two ethnic groups and that the grid could be used to illustrate this. However, this was not the case and the dimensions of care referred to were not exclusive to either ethnic group or district. Most of the negative comments made related to women's antenatal and postnatal hospital stay, and most positive comments relating to postnatal community care. More indigenous "white" women than Pakistani women commented upon their carers' interpersonal skills, their own physiological wellbeing and the environment of care. All women commented upon the technical competency of their carer. Few non-English speaking Pakistani women commented directly about communication which is partly explained by the presence of 3 bilingual link-workers working in each district. Women focused more on the process of care rather than organizational structures or outcomes of care.

In a qualitative study to determine the attitudes and experiences of Asian women living in East London regarding pregnancy and antenatal care 32 Asian women who had at least one child less than 2 years old, were recruited from local GP surgeries and interviewed<sup>21</sup> [EL=3]. In a sub group analysis women who spoke little or no English (n=13) were compared with women who spoke "fluent English" (n=13) in terms of their experiences of pregnancy and antenatal care in the UK. There were many similarities between the groups. Three-quarters of each group of women described their pregnancies as 'smooth' and about one-third of each experienced some reasonably serious medical complication. Almost all women attended antenatal clinics regularly. The main differences were that the poor English speakers were rated as less "knowledgeable" (it is not clear how this was measured/judged) and were less likely to attend antenatal classes.

In an earlier study by the same authors conducted in a similar setting, the differences between the ideas and experiences of pregnancy and childbirth of Asian (from Indian subcontinent) and non-Asian women were examined<sup>95</sup> [EL=3]. A structured interview was conducted with 100 Asian and 43 non-Asian women to collect quantitative data about their experiences of pregnancy, antenatal care, childbirth and postnatal care. A subset of the sample of Asian women (n=32) were interviewed more extensively about their experiences in order to explore further differences found in the initial quantitative analysis. Multiple regression analyses were conducted to assess the relative impact on women's experience of a range of demographic variables. Asian and non-Asian women's experiences of pregnancy were more associated with parity rather than ethnicity. Most women felt supported by husbands/partners and families. Women living in extended families and those who had lived in the UK for a longer time were more likely to get support than those living in a nuclear family and those who had lived in the UK for a shorter time.

Findings from Asian women's interviews suggested that there was more emphasis on diet, gender of the baby and the extent to which pregnancy would bring about changes in activities compared with non-Asian women.

More Asian women (91%) attended all antenatal appointments compared to 84% non-Asian women (p=0.01). Only 22% Asian women attended parent-craft classes compared to 42% non-Asian women (fluency in English was found to be significantly associated with attendance in parent craft class; p<0.0001).

### **Interpreting needs and preferences**

An Australian study (1999) analysed the translated transcripts of a random sample (n=60) from a larger study of 318 immigrant women consisting of 104 Vietnamese, 107 Filipino and 107 Turkish women [EL=3]<sup>96</sup>. In assessing women's need for interpreting assistance it was found that 62.5% Vietnamese, 43.9% Turkish and only 1.9% Filipino women needed an interpreter. A hospital interpreter was the most preferred option, followed by the woman's partner and family/friends.

### **Case-finding and outreach using bilingual health care workers**

An American project evaluation<sup>97</sup> carried out a retrospective analysis of medical records from health centres and hospitals which provided maternity care to Hispanic farm workers between 1985 and 1989 [EL=3].

The specific objectives of the project were to increase first trimester enrolments, improve continuity of care, improve frequency of visits and improve perinatal outcomes. Specific interventions included:

- Bilingual staff
- Maternal-child focused outreach
- Maternal lay health advisers
- Multi-state tracking system

The project was successful in reaching the target population. A significant increase was seen in first trimester entry into prenatal care (from 35% in 1985 to 51% in 1989 (p=0.009)) In addition, the percentage of women receiving nine or more prenatal visits rose significantly from 24% in 1985 to 50% in 1989 (p=0.0002). The incidence of low birth weight decreased over the five year period but this declining trend was not significant. A computer-based tracking system meant pregnancy process and outcome data were available for 84% (500/599) of the participants.

In a later US study (1996)<sup>98</sup> [EL=3] focusing on the same population, a retrospective analysis of medical records was conducted to examine women's health during pregnancy and pregnancy outcomes for a purposive sample of Hispanic women (n=113) who delivered in 1991 and 1992. The study hospital had developed a comprehensive and interdisciplinary model of antenatal, postpartum and well-woman care for a predominantly Hispanic population. Several staff members spoke Spanish and some were bilingual and bicultural. Antenatal care included a comprehensive risk assessment and recommended health promotion activities. Antenatal classes were also available as part of this comprehensive-care model. A comparative analysis between the subgroups of women with 'One to Eight' and 'Nine or more' ANC visits did not reveal any significant difference in incidence of SGA babies, babies born before 37 weeks gestation or babies under 2500g birth weight. This lack of difference may be as a result of an inappropriate comparison being made (i.e. one to eight visits vs. nine or more).

### Evidence statement

Findings from three studies [EL=3] suggest that the similar aspects of quality of maternity care are important to all women (migrant or otherwise). Three studies also demonstrated that migrant women believed antenatal care to be important and did attend well for antenatal appointments. Findings from two studies report that Asian women prefer a female caregiver.

Two studies reported that non-English speaking women found language difficulties a problem. Whilst one study found that women who did not understand English well were less likely to attend antenatal classes, another study found this not to be the case. One study also found that women with poorer English also had less pregnancy-related knowledge.

There was evidence from one study that Asian women have some specific cultural concerns regarding diet, physical activity and pelvic examination during pregnancy, in addition to preference for female care givers.

Findings from one US study showed that the number of antenatal appointments attended increased following the establishment of a comprehensive antenatal care programme for Hispanic migrant farm workers involving use of bilingual staff, community outreach, maternal lay health advisors and a tracking system to help services keep in contact with pregnant women. The incidence of low birthweight babies decreased over the five year period studied. Findings from a later evaluation of a similar comprehensive antenatal care programme serving a similar migrant population found no difference between the incidence of low birthweight babies (<2500g) or pre-term births (<37 weeks) for women attending 1-8 antenatal visits compared with women attending 9 times or more.

### GDG interpretation of evidence

The GDG noted that similar aspects of quality of maternity care are important to all women. Three studies demonstrated that migrant women believed antenatal care to be important and did attend well for antenatal appointments. However these studies need to be interpreted with some caution. One of the studies looking at the experiences of Asian women recruited via GP surgeries who had a child less than 2 years old i.e. those already familiar with the NHS system. It is likely that these women were established within the community and therefore this study may not be representative of a refugee or asylum seeking population.

As a minimum, all migrant women should be able to fully access the standard antenatal care package as outlined in the NICE Antenatal Care guideline<sup>1</sup>. Whilst the evidence available is poor it is clear that the key issues in maintaining contact are language difficulties and difficulties with continuity of carer and consistency of care arising as a result of frequent changes of address. It is also seen from the evidence that women prefer an interpreter provided by the antenatal care service rather than relying upon her partner, family members or friends as interpreters. The GDG endorsed this finding and noted that in order for women to be able to discuss sensitive information confidentially it is vital that this service is provided. A recommendation was made based on this evidence.

The GDG took the consensus view that given what they perceived as the high degree of success in England and Wales of the hand-held record system, both for antenatal hand-held records and child health care records (the "Little Red Book"), it is essential that women are empowered to utilise hand-held records as a health record throughout pregnancy. Since women who are in temporary accommodation are at risk of being moved at short notice to a new home that may be many miles away it is important that these hand held records contain all relevant information including all laboratory findings. Based on GDG consensus, a recommendation was made to ensure that this is carried out. The GDG noted that in their experience, women could be relied upon to bring these records to all appointments and that they view them positively. It is also important to ask all women to let their antenatal carers know if they move address and what the new address is. In addition, the group agreed by consensus that healthcare professionals should work with agencies that provide housing services for recent migrants, refugees and asylum seekers (e.g. asylum centres and third sector agencies) in order to ensure they have up to date information about a woman's residence during her pregnancy. Other systems to help track women's place of residence may well be useful. A research recommendation has been made to encourage investigation of how these might best be organised.

Use of health advocates, link workers, appropriate interpreting support and health promotion material in different languages may be necessary in order to maintain the necessary contact with services. One of the

studies reported the improved continuity and frequency of care achieved using bilingual care workers and access to adequate interpreting facilities was felt to be essential in maintaining contact with this group. Based on this evidence, a recommendation was made that interpreters should be offered.

The GDG felt that there were particular issues with residential mobility, particularly among women who are asylum seekers or refugees, and felt that tracking systems should be considered in order to maintain health service contact. Whilst specific UK evidence is lacking in this area, one US study showed improved maintenance of contact with services when lay advocates were charged with 'tracking' women. As reported in the Equality Impact Assessment of *Maternity Matters*, discussion with consultant midwives across the country indicated that vulnerable women needed extra hours of midwife contact time, as well as care from other branches of NHS.<sup>4</sup> This must be considered when decisions are made with regards to service provision for these women, and a recommendation has been made to take this extra need for time at antenatal appointments into consideration.

See page 83 for recommendations for service provision for women who are recent migrants, refugees, asylum seekers or who speak little or no English.

## 5.5 Additional consultations and support

Q3. What additional consultations and/or support should be provided to women who are recent migrants to the UK, refugees, asylum seekers, women who have little or no English, and their partners and families, in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline).

### Previous Guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Ten studies were examined for inclusion in the review, five have been included, all evidence level 3. There is one study from the UK, one from Australia, one from Sweden and two from the US. Two of the included studies examine the efficacy of health advocates/link workers for migrant women, one looks at case-finding/outreach delivered by bilingual health care staff, one investigates women's views of different systems of antenatal care provision and one examines risk of giving birth to a small for gestational age in migrant women.

### Narrative summary of evidence

#### Advocates/link workers

A retrospective cohort study from the UK evaluated a health advocacy programme designed to improve obstetric outcomes among women of ethnic minorities in east London<sup>71</sup> [EL=2-]. Data were collected from 923 presumed non-English-speaking women giving birth at the Mothers' Hospital, Hackney, in 1984-1986 who had been accompanied by an advocate (study group MH 1986) compared with n=866 presumed non-English speaking women giving birth at the same hospital in 1979; before the start of advocacy project and two similar groups from a reference hospital (Whipps Cross (WX) 1979 n=999, Whipps Cross 1986 n=993). (For further study details see above in Question 1a under the sub-heading Advocates/link workers. "Hard outcomes" for this study are reported here relating to pregnancy and neonatal outcomes, whilst in Question 1a outcomes relating to access to care are reported.) A major flaw in this study design was the selection of women based on surname rather than a knowledge of whether or not the woman spoke/understood English.

The health advocate "booked" women and presented the history to a midwife or doctor. The uptake of ultrasound scans increased at the Mother's Hospital from 54% in 1979 to 67% in 1986. However, an even larger increase was seen at the comparison site (18% to 84%) which the authors attributed mostly to improved record keeping. The uptake of amniocentesis increased 3 fold at each study site, although uptake remained fairly low (MH 1979 5.5%, MH 1986 17% vs. WX 1979 12.7%, WX 1986 39%). It is not possible to ascertain whether these figures reflect an improvement in informed consent, although given the similarities between the two sites it seems unlikely that any difference is attributable to the health advocates. The study also found significant differences between the groups in terms of mode of onset of

labour (spontaneous vs. induced vs. elective caesarean section between the 2 hospitals over time, this difference being mainly attributable to a fall in the elective CS rate at the Mothers' Hospital (3.4% vs. 2.3%) compared with a rise over the same time period at Whipps Cross (2.9% vs. 5.9%) ( $X^2=10.3$ ,  $df=3$ ,  $p=0.02$ ). There was also a significant difference seen in the mode of birth between the two hospitals over time (spontaneous vaginal birth vs. instrumental vaginal birth vs. caesarean section) with a rise in the rate of spontaneous vaginal births at the Mothers' Hospital (75.0% vs. 84.8%) compared with Whipps Cross (75.6% vs. 72.5%) ( $X^2=22.3$ ,  $df=3$ ,  $p<0.001$ ). However, due to the complexity of these issues and the large number of possible causes which may have contributed to the observed changes, these differences cannot be directly attributed to the health advocacy scheme.

A US retrospective cohort study was undertaken to analyse changes in knowledge, health status and behaviours of 470 migrant farm worker women (and their children) who were in contact with a Lay Health Advisor (LHA) in Indiana, US<sup>72</sup> [EL=2-]. An LHA was defined as a person who naturally provides unplanned assistance to those persons familiar to her, selected from the community and trained in maternal-child health issues. Association between health status, knowledge of health practices and exposure to Lay Health Advisors were studied in 470 Latino women seen at two health centres (in North Carolina) using a knowledge test or exposure questionnaire.

Twenty Lay Health Advisors were assessed before they began a training programme and at 2 weeks and 6 weeks post-training for their knowledge of health practices. There was a statistically significant improvement in knowledge following their training programme ( $p<0.05$ ).

No significant differences were observed between pregnant women with or without "LHA exposure" in regard to birth weight. Neither was a significant association found between knowledge score and birth weight. (LHA workers were also involved in postnatal care and care provided at child health clinics and here they seemed to have a greater impact on women's knowledge and attendance at clinic.)

### **Bilingual health professionals and case-finding**

A US study investigated the effectiveness of a programme designed to deliver primary health care services for migrant farm-worker women and their children by retrospective analysis of their medical records. Three hundred and fifty-nine pregnant farm-worker women who had received the primary care services at Tri-County Community Health Centres between April 1985 and September 1987 participated in the study<sup>73</sup> [EL=3].

A bilingual, multidisciplinary team of health professionals collaborated with a migrant health centre in North California to develop a programme for delivery of primary care to migrant farm worker women and children. The programme included case finding and outreach, coordination of maternal and child health services locally as well as interstate and innovative health education programming.

The most frequently reported health problems identified from antenatal medical records were urinary tract infection (23%) and sexually transmitted diseases (7%). Forty-three percent of women in the sample had a hematocrit of less than 34 at sometime during the pregnancy.

Regarding dietary assessments; 84% had dietary recalls showing caloric intake less than 90% of their recommended daily amount (RDA) and only 53% of women had a diet containing 90% or more of the RDA for protein.

A decrease was observed in low birth weight infants from 13% ( $n=11$ ) in 1985 to 7% ( $n=6$ ) in 1986 and in 1987 ( $p=0.23$ ). Again, due to the study design employed, the reduction in the proportion of low birth weight babies cannot be attributed to the intervention under study since possible confounding factors have not been taken into consideration.

### **Migrant women's views of different types of antenatal care provision**

An Australian retrospective study was conducted to compare the views of women from non-English-speaking backgrounds who received antenatal care at the public hospital clinic with those whose care was shared between a public hospital clinic and a general practitioner<sup>99</sup> [EL=3].

All women born in Vietnam, Turkey and the Philippines who gave birth to a live healthy baby ( $>1500g$ ) were eligible for inclusion in the study ( $n=435$ ). Three hundred and eighteen women completed the study (Vietnamese ( $n=104$ ), Turkish ( $n=107$ ) and Filipino ( $n=107$ )).

Women were categorized into four groups; public clinic care (women who attended only public antenatal clinics for their pregnancy care, n=143); shared antenatal care (women who saw a local GP in combination with a hospital public clinic, n=151); obstetrician care (women who saw only a specialist obstetrician or a GP-obstetrician, n=9) and birth centre care (women who attended a team of midwives at any of the hospitals' birth centres, n=14).

Women who spoke English well were more likely to rate their care as "very good" than those who could not (47/140 (26.7%) vs. 16/163 (11.4%); OR 3.04 (95% CI 1.57 to 5.93)). Women receiving shared care were more likely to experience continuity of medical care (defined as always or mostly seeing the same doctor), although this did not reach statistical significance (67/150 (44.7%) vs. 48/143 (33.6%); OR 1.60 (95% CI 0.97 to 2.64)). Women in shared care were also more likely to see a caregiver who spoke their language (OR 17.69 (95% CI 6.15 to 69.06)). Despite this, women in the shared care group were no more likely to rate their care as "very good" (OR 1.38 (95% CI 0.72 to 2.63)). Women attending a specialist/GP-obstetrician or birth centre rated their antenatal care more positively but the numbers in these group were very small.

### **Descriptive studies examining health inequalities and support provided in antenatal services**

A Swedish survey<sup>100</sup> [EL=3] investigated the risk of small for gestational age (SGA) babies in relation to country of origin. Women were recruited among those booked for their first antenatal appointment. Data were collected from 826 women whose pregnancy resulted in a singleton live birth; 22% (n=182) of those women were foreign born (32 from western Europe, North America and Australia; 50 from Eastern Europe; 49 from middle East and North Africa; 24 from Asia and 27 from Central and South America and sub-Saharan Africa). Self administered questionnaires were completed by all women at their first antenatal visit and data on maternal pregnancy outcomes collected from the women's medical records. Social network in the study was defined using two sub-concepts of social anchorage and social participation.

Social support was defined as emotional support and instrumental support (a person's access to advice, information and available services). Foreign-born women who reported low access to social anchorage and low access to emotional support had an increased risk of giving birth to small for gestational age (SGA) babies (OR=4.4 [95% CI 0.7 to 13.2] and OR=5.2 [95% CI=1.5 to 18.9] respectively). Foreign-born women who reported low instrumental support also had an increased risk of giving birth to SGA babies (OR=2.5 [95% CI 0.9 to 6.8]). Significantly more foreign born women (16.8%) had their first antenatal visit late (>15 weeks of pregnancy) compared with Swedish born women (4.8%) (p values not reported). Fewer migrants (57.3%) than Swedish women (82.9%) attended antenatal parent classes (it is not reported whether this was a significant difference). Of all infants born, n=55 (6.7%) were classified as SGA: 37 of Swedish nativity and 18 of foreign nativity.

Immigration status was significantly related to SGA (OR=1.8; [95% CI=1.0 to 3.2]). Immigrant women who did not speak Swedish at all were at higher risk of giving birth to a baby who was SGA (OR=2.6 [95% CI 1.1 to 6.2]).

### **Evidence statement**

Findings from two retrospective studies investigating the effects of maternity health advocates are conflicting. One UK study demonstrated a reduction in length of antenatal stay, induction rate and birth by caesarean section for women identified as Asian or Turkish following the establishment of health advocates. A US study found no difference in the main birth outcome of interest – birth weight – following establishment of a lay health advisor scheme.

A US retrospective study reported a reduction in the proportion of low birth weight babies following the establishment of a case-finding outreach programme staffed by bilingual health care providers.

A descriptive Australian study showed little difference between migrant women's views of full hospital care and shared obstetric/GP care. The small number of women attending specialist obstetric or birth centre care gave positive views of this type of antenatal care.

Findings from a Swedish descriptive study suggest that low social support, including instrumental support, may increase the risk of giving birth to a baby who is small for gestational age in migrant women.

### GDG interpretation

No high quality conclusive evidence was found for the effectiveness of any particular programme of additional consultations or support for migrant women and their partners. Also, the low level of evidence that there was seemed to indicate seemingly little gain for quite intensive input of additional support. There was also a complete absence of evidence relating to the needs of partners and family members. Due to the wide variation in experiences and needs of partners and families of migrant women, and the varying views and experiences of the GDG on this matter, the GDG were unable to make a consensus-based recommendation for this group.

A variety of studies from a range of different countries have indicated that migrant women, particularly recent and non-English speaking migrants, face a variety of disadvantages during pregnancy. Some of these are associated with economic deprivation; others include lack of understanding of the health care system and difficulty in accessing care due to their legal status. The GDG has noted in the interpretation for question 2 above that measures should be taken to help ensure health care professionals are kept informed of a women's residence throughout pregnancy. Language has been identified as a key barrier to accessing services, leading to difficulty in accessing basic information and advice, or gaining appropriate support through consultations or antenatal classes. Although interpreters and link workers are helpful, their usefulness can be limited by; cultural issues e.g. use of male interpreters; use of interpreters untrained in medical terminology; lack of availability at suitable times; use of relatives and friends due to lack of availability of formal interpreter services. Although there is evidence that women are willing to attend classes, findings suggest that the content and format of standard antenatal classes may be culturally inappropriate and not geared to the specific needs of women, which limits access even if interpreters are available.

As reported in the Equality Impact Assessment of *Maternity Matters*, discussion with consultant midwives across the country indicated that vulnerable women needed extra hours of midwife contact time, as well as care from other branches of NHS.<sup>4</sup> Examples of support were: counselling services, additional time for each antenatal appointment, help in dealing with social issues, and support by trained professionals to help them make appropriate choices and understand the consequences of these choices, communication, and information. Based on GDG consensus, this need for extra time at appointments was recommended. In the GDG's experience, one effective way that professionals can ensure that they have communicated effectively is by asking the woman to repeat what has been said. This allows them to gauge what the woman has understood and address any misunderstandings. The GDG agreed to make this a recommendation based on consensus opinion.

The GDG took the view that as a minimum all migrant woman should be able to fully access the standard antenatal care package as outlined in the NICE guideline: *Antenatal Care: routine care for the healthy pregnant woman*.<sup>1</sup> The evidence suggests that the use of health advocates, link workers, appropriate interpreting support and health promotion material in different languages may well be necessary in order for this to occur, and this is reflected in the recommendations below. If women are receiving this and have no additional medical or social needs, no additional support may be necessary. However, risk assessment would need to be individual and ongoing and consider specific health, legal and social issues, such as residential mobility. When giving advice, whether in an individual or group setting, staff need to be guided by the needs and concerns of the women themselves, to ensure that the advice given is relevant to them, and that it is not founded on presumptions about their needs. The need to communicate with the woman's family also needs to be placed in a cultural context. There may also be need for staff training in order to make the staff feel more comfortable in dealing with migrant women, and to improve the experience of the women themselves. The findings from the evidence for question 3, along with the evidence from questions 1a and b underline the need for staff to have a good understanding of the needs of pregnant women. The GDG believed that training would improve staff awareness and behaviour, and improve care provided. Based on this belief, a recommendation for staff training was made. Service models for providing care to recent migrant women, those with little or no English, and asylum seekers and refugees is given in Box 5.1 below and Appendix D, service descriptions numbers 7, 8 and 9.

See page 83 for recommendations for service provision for women who are recent migrants, refugees, asylum seekers or who speak little or no English.

As services are complex and delivered across different organisational boundaries, joint commissioning arrangements and partnership working are recommended, to which reference is also made in the self-assessment tool for commissioners.<sup>101</sup>

## 5.6 Additional information

### Clinical question

Q4. What additional information should be provided to women who are recent migrants to the UK, refugees, asylum seekers, women who have little or no English, and their partners and families, in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline).

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

After quality appraisal and checking of inclusion criteria, five studies of the 12 examined are included for detailed review. All but one are US studies. Two studies (one UK) examine the effectiveness of antenatal classes for migrant women, two investigate the content of information provided during antenatal consultations and whether this meets women's needs/wishes, and one study evaluates the impact of a service reform designed to improve communication with a migrant population.

### Narrative summary of evidence

#### Antenatal classes

A US quasi-randomised control trial (1983)<sup>102</sup> evaluated the effectiveness of an antenatal education programme designed for Spanish speaking women at a health care centre, East Los Angeles, California [EL=1-]. The objective of the classes was to increase the participants' knowledge of: newborn care, labour and child birth, family planning, and dental health care. Sixty-eight Spanish speaking pregnant (20 weeks) women who were willing to take at least four antenatal sessions were randomly assigned to the experimental and control groups. Women in the experimental group were received antenatal health education classes in Spanish followed by a quiz and discussion on the answers.

Data from 40 women who completed all the phases of the study were analysed. No details are given about the 28 women who did not complete the study. The experimental and control groups were further divided into groups 1 & 2 and experimental subgroup 1 (n=10) was paired with control subgroup 1 (n=10); likewise experimental group 2 (n=10) was matched with control group 2 (n=10). All group allocation was done using the toss of a coin. Women in the control group received their questionnaire as soon as they entered the study i.e. before attending the classes whereas the women in experimental group were given a post-test after they had attended the classes on the 36th week of pregnancy. The mean knowledge score of women in the intervention group was significantly higher than for women in the comparison groups (13.20 vs. 10.30,  $p < 0.05$ ).

To evaluate the effectiveness of antenatal education within an Asian community in the UK, a prospective randomised controlled trial was undertaken involving 69 Asian women (predominantly Pakistani/Muslim) living in East London<sup>103</sup> [EL=1-]. Thirty-five women were randomly allocated to an intervention group who were supposed to be receiving a special course of 12 weekly lectures by a health visitor, midwife or nutritionist, covering topics on fertility, pregnancy, childbirth and childbearing, relayed in Urdu by an interpreter and held in a health clinic. The remaining 34 women comprised the original comparison group and were offered routine antenatal care including parent craft classes in English. Of the original intervention group only 16 women attended more than three of the classes and they were labelled by the authors as the 'educated group'. All other women, irrespective of their original allotment, were grouped together as the 'non-educated' group (n=53). The antenatal outcomes, perinatal outcomes, and infant health at approximately 1 year of age were compared for both the groups. No significant difference was observed between the two groups for any of the outcomes studied. Only three women were able to complete the course of 12 lectures and only 16 received four or more lectures. Due to this high attrition rate the 'educated group' became virtually self selected thus undermining the randomization process and making it very difficult to draw any significant conclusions from this study.

#### Service reform including provision of information through audiovisual technology

In a US qualitative study (1995)<sup>104</sup> interviews were conducted in 1987/88 with 48 Hmong women who had given birth at the university hospital of University of Minnesota and had received all antenatal care at its

outreach clinic [EL=3]. Among all the procedures pelvic examination was found to be unacceptable to the majority of women (61%) and a larger proportion of their spouses. Other concerns reported by Hmong pregnant women were limited clinic hours (25%), and the lack of continuity of physician care (63%), which they associated with an increase in pelvic examinations and medical student involvement (13%). Based on the survey results a number of changes were implemented which included recruitment of an additional staff nurse-midwife who had learned some Hmong language, a reduction in the frequency of pelvic examinations by all providers, provision of telephone interpretation services and an expansion of obstetric clinics from one to two mornings a week. In order to provide additional information, videotapes on antenatal care in the Hmong language were prepared which covered explanations of clinical procedures and their rationale, and addressed the concerns reported by women during the previous interviews. In addition, an acknowledgment of traditional practices and information regarding patients' right were also included. Eighteen women interviewed in 1993 were more positive about their antenatal care experience compared with the earlier study sample. The acceptability of all procedures increased among the 8 women who had viewed the videotape, whilst findings from the 10 women who did not see the videotape mirrored the earlier group.

Half of the women interviewed in 1993 reported a new concern, they believed early ultrasound performed in the first half of pregnancy may induce miscarriage and women reasoned that they could avoid this danger by delaying entry into antenatal care.

### **Information provided at antenatal appointments**

A prospective cohort study carried out in the US has examined the relationship between health promotion content of antenatal consultations, satisfaction with care and maternal health behaviours among low-income Mexican American and African American women (2003)<sup>105</sup> [EL=2+]. One hundred and twelve African American and 47 Mexican American English speaking, pregnant women were recruited from a low risk antenatal clinic affiliated with large Midwestern US University tertiary-care hospital. A certified nurse-midwife (CNM) and a physician (MD) delivered the antenatal care at the study clinic. At the initial antenatal visit a registered nurse or a medical assistant initiated health promotion education, informed women about the availability of the CNM and MD as primary providers and offered a choice of providers. In addition to any health promotion content provided by a CNM or MD a discharge nurse was available to conduct health promotion education following each primary provider visit. Women seen by the MD were more likely to be referred to the discharge nurse, whereas women seen by CNM were more likely to discuss health promotion content with her during the antenatal visit. The topics on which women wanted information but felt there was some shortfall were:

- Using a seatbelt in the correct position
- Dealing with stress and conflicts
- Family planning
- Caring for their baby
- Safe sex practices (not statistically significant)
- Attending childbirth classes(not statistically significant)

Similarly, there were some topics, according to the study population, which were discussed with more than required zeal. These topics included:

- Taking vitamins and minerals
- Eating specific food groups
- Drinking adequate amount of water
- Stopping/ eliminating specific substance use.

The possibility of discussing a higher number of topics was significantly associated with higher numbers of antenatal visits, being African American, residing in public housing, not drinking alcohol, not using marijuana and/or cocaine, wanting or needing to discuss higher number of topics, and having a CNM as the primary provider of antenatal care.

To examine the disparities in the reported receipt of health behaviour advice during pregnancy among US-born women of Mexican origin and Mexican immigrant women in California, a questionnaire survey

was carried out on a sub-sample of women of Mexican descent based on the data gathered in 1994 and 1995 by the California Pregnancy Risk Assessment and Monitoring System (PRAMS)<sup>106</sup> [EL=3]. PRAMS was a population-based surveillance system designed to study antenatal risk factors for the purpose of planning and assessing antenatal health programmes. One thousand, four hundred and twenty-three women of Mexican descent were surveyed using a self administered questionnaire available in English/Spanish. The main findings of the study included that US-born women were more likely to be teenage mothers (13% vs. 5%), more likely to report recent smoking (15.7% vs. 5.6%) and recent alcohol consumption (31.4% vs. 14.4%) and be more educated than the immigrant women.

Immigrant women were more likely than the US-born women to report receipt of antenatal advice on smoking, alcohol and diet (OR=1.83 (95% CI 1.22 to 2.74);  $p < 0.05$ ). The percentage of US born women who reported not receiving all three types of advice was double that of the immigrant women (29.1% vs. 14.2%). The immigrant women in the sample were 45% more likely to have participated in a Women, Infants and Children programme (WIC) during their pregnancy (80% vs. 55%) and this participation in the WIC was found to be associated with an increased likelihood of reporting antenatal health advice (OR=2.08 (95% CI 1.38 to 3.13)). Immigrant women were more likely than US born women to report receipt of antenatal advice on smoking, alcohol and diet despite evidence of the lower prevalence of related health risks among Mexican-born women.

### **Evidence statement**

Findings from one quasi-randomised RCT showed that attendance at antenatal classes provided in the woman's own language increased women's knowledge about pregnancy and birth.

Findings from another low quality RCT suggested that antenatal classes are not always well-attended by migrant women, even when they are provided with interpreters.

Findings from two studies show that health care providers do not always provide women with the information they would like and sometimes over-emphasise inappropriate areas of information and advice not relevant to the individual woman.

Findings from one small study have shown that providing information and explanations for antenatal procedures via videotapes improves their acceptability amongst women who do not understand the language of the care providers.

### **GDG interpretation of evidence**

The evidence looks at issues around language as well as cultural expectations of antenatal care. Some UK migrant populations speak a language which has no written form which adds additional difficulties to providing accessible information to diverse populations. An example of how information can be provided in an easily accessible format is provided in Appendix D, number 12.

The evidence in the UK study shows the difficulty women experienced attending an extended series of translated lectures. The GDG felt that a translated lecture was not a good way to meet the information needs of this population. The GDG also considered whether the length of the course (12 sessions) was a reason for non-completion of the course. The result was that the majority of the women did not access the information that was available to them.

Antenatal classes provided by a bilingual midwife or educator, or alternatively the use of DVDs to provide information as in the US study among Hmong women, were well-evaluated by women and resulted in an increased understanding of antenatal care. The Hmong women had different concerns about antenatal care to the general population. The study demonstrated that these concerns were identified addressed and also that they changed over time thus highlighting the importance of reviewing the content of information to ensure that it continues to meet women's needs over time. The GDG felt that the use of DVDs for information-giving could be both effective in providing information and cost-effective. On-going evaluation would ensure the efficacy of the intervention being offered.

Many of the programmes developed in the US involved lengthy information programmes which it was felt were not appropriate or necessary in the context of NHS antenatal care. However the studies explored ways to address language and cultural differences which are relevant to migrant and non-English speaking women in the UK. The GDG noted the importance of providing healthcare professionals with training to ensure a good level of understanding of women's cultural and religious beliefs and issues relating to being a recent migrant, asylum seeker or refugee, and how these might impact upon antenatal

care. Based on GDG consensus of the value of such training, a recommendation was made that it should be provided.

Many of the US studies provided a combination of bilingual workers, classes in the women's own language, childcare and transport. These studies were targeting one minority population at a time, which differs from many UK antenatal services where there may be a variety of migrant populations accessing one service. In some areas the majority of women using a service may be from a migrant non-English-speaking population. This difference, compounded by the fact that GDG experience suggested these sessions tended to be rather lengthy and poorly attended, meant the GDG felt it not appropriate to recommend this as a service addition. The provision of an interpreter who could be present (or on a telephone) at each consultation was felt to be more important.

The group noted that none of the studies reviewed for this population specifically addressed the needs of partners and families (other than some passing references to partners attending antenatal classes with women). As a result, and because of the differing experiences and opinions among the GDG members, the group did not make a specific recommendation for this group.

### 5.7 Recommendations

Healthcare professionals should help support these women's uptake of antenatal care services by:

- using a variety of means to communicate with women
- telling women about antenatal care services and how to use them
- undertaking training in the specific needs of women in these groups

#### Service organisation

Commissioners should monitor emergent local needs and adjust services accordingly.

Healthcare professionals should ensure that they have accurate and up-to-date information about a woman's residence during her pregnancy by working with local agencies that provide housing and other services for recent migrants, asylum seekers and refugees, such as asylum centres.

When using interpreting services commissioners and individuals responsible for the organisation of local antenatal services should offer flexibility in the number and length of antenatal appointments, over and above those outlined in national guidance\* because interpretation requires additional time.

Individuals responsible for the organisation of local antenatal services should provide information about pregnancy and antenatal services, including how to find and use antenatal services, in a variety of:

- formats, such as posters, notices, leaflets, photographs, drawings/diagrams, online video clips, audio clips and DVDs
- settings, including pharmacies, community centres, faith groups and centres, GP surgeries, family planning clinics, children's centres, reception centres and hostels
- languages.

#### Training for healthcare staff

Healthcare professionals should be given training on:

- the specific health needs of women who are recent migrants, asylum seekers or refugees, such as needs arising from female genital mutilation or HIV
- the specific social, religious and psychological needs of women in these groups
- the most recent government policies on access and entitlement to care for recent migrants, asylum seekers and refugees<sup>†</sup>

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\* See 'Antenatal care' (NICE clinical guideline 62) Available from [www.nice.org.uk/guidance/CG62](http://www.nice.org.uk/guidance/CG62)<sup>1</sup>

<sup>†</sup> Guidance from the Department of Health available from [www.dh.gov.uk/en/Healthcare/International/asylumseekersandrefugees/index.htm](http://www.dh.gov.uk/en/Healthcare/International/asylumseekersandrefugees/index.htm). Information sheet from Maternity Action available here: <http://www.maternityaction.org.uk/sitebuildercontent/sitebuilderfiles/entitlementtonhscarenov09.pdf>

### Information and support for women

Offer the woman information on access and entitlement to healthcare.\*

At the booking appointment discuss with the woman the importance of keeping her handheld maternity record with her at all times.

Avoid making assumptions based on a woman's culture, ethnic origin or religious beliefs.

### Communication with women who have difficulty reading or speaking English

Provide the woman with an interpreter (who may be a link worker or advocate and should not be a member of the woman's family, her legal guardian or her partner) who can communicate with her in her preferred language.

When giving spoken information ask the woman about her understanding of what she has been told to ensure she has understood it correctly.

### Research Recommendations

Is it more effective to use interpreters, lay health advocates or link workers to help with communication with women from different linguistic backgrounds? Which of these is more acceptable to women?

Are outcomes improved in non-English speaking women if a translator is present during antenatal consultations?

What do recent migrants, asylum seekers, and refugees see as specific barriers to accessing and maintaining contact with antenatal care

What system can be used to effectively track the residential address of women who move address frequently and/or at short notice? What impact does the system have on the number of antenatal appointments attended? What are the resource implications of introducing a tracking system?

**Box 5.1** Examples of services for women who are recent migrants, asylum seekers, refugees or who have little or no English

#### *St Mary's Hospital, Manchester*

St Mary's Hospital, Manchester, employs a midwife (known as the "refugee midwife") for asylum seekers and refugees with specific funding from the primary care trust. The post was set up in 2005 to meet needs arising from the extent of service use by asylum seekers and the findings of the 2002 Confidential Enquiry in to Maternal and Child Health. The refugee midwife co-ordinates with other services and spends time developing and maintaining networks. A monthly list of antenatal refugees is circulated to all clinical areas in maternity services. In addition to cultural groups the midwife works with Refugee Action, Manchester Asylum Induction Team and charities who provide support to destitute asylum seekers. The United Kingdom Border Agency (UKBA) provides a basic package of support for all asylum seekers and aims to make a decision on immigration status within 6 months. The women stay in asylum seeker accommodation during that time and may be moved (dispersed) dependant on local property providers and directions from the UKBA. This has the potential to fragment antenatal care. All women are therefore requested to contact the refugee midwife if notified of dispersal. Where it is reasonable handheld notes are updated with relevant test results and an antenatal check undertaken. All women are advised how to access maternity services in the dispersal area and when necessary the refugee midwife notifies community/child protection midwife.

When possible, appointments with the refugee midwife are made when women are scheduled to visit the hospital, e.g. after scans, specialist obstetric clinics. This is often the best use of time for clients, the midwife and translation services. (Appendix D, number 7)

\* Guidance from the Department of Health available from [www.dh.gov.uk/en/Healthcare/International/asylumseekersandrefugees/index.htm](http://www.dh.gov.uk/en/Healthcare/International/asylumseekersandrefugees/index.htm). Information sheet from Maternity Action available here: <http://www.maternityaction.org.uk/sitebuildercontent/sitebuilderfiles/entitlementtonhscarenov09.pdf>

*The Royal Berkshire Hospital, Reading*

The Royal Berkshire hospital employs a specialist midwife in social inclusion. Her role is to support women from ethnic minorities and their families to ensure they have equal access to maternity services. She provides support to other midwives who are working with women from ethnic minorities. All staff have training on equality and diversity, and in addition the specialist midwife facilitates workshops on cultural issues for midwives and maternity care assistants. (Appendix D, number 8)

# 6 Young women aged under 20

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## 6.1 Introduction

The UK has the highest rate of births to young women aged under 20 in Western Europe and 70% of teenage pregnancies are unplanned.<sup>107</sup> Although parenthood can be a positive experience for some young people, it may also bring a number of negative consequences. The effect of teenager status on pregnancy is difficult to quantify owing to confounding factors such as socioeconomic status and smoking. There is a strong association between deprivation and conception rates in young people, with conception and birth rates up to six times higher in the poorest areas than the most affluent areas.<sup>107</sup>

Whilst women aged under twenty have one of the lowest rates of maternal mortality of all age groups (9.9 per 100 000 maternities)<sup>3</sup> the most recent perinatal mortality report for England, Wales and Northern Ireland (2007) showed that babies of women aged less than 20 are at risk of higher rates of stillbirths (5.6 per 1000 total births), higher rates of perinatal deaths (8.9 per 1000 total births) and higher rates of neonatal deaths (4.4 per 1000 live births) than women aged 20-34.<sup>5</sup> The infant mortality rate of babies born at term/post term to mothers under age 20 was almost twice that of term/post term babies born to mothers aged 30-34 (2.7 deaths per 1,000 live births compared with 1.4 deaths per 1,000 live births).<sup>108</sup>

The National Service Framework for Children, Young People and Maternity Services establishes clear standards for promoting the health and well-being of children and young people and for providing high quality services which meet their needs.<sup>109</sup>

The Teenage Strategy was launched in 1999 and has included a number of government initiatives e.g. Sure Start Plus aimed at reducing the risk of long-term social exclusion resulting from teenage pregnancy, through co-ordinated support to pregnant young women and parents under 18 years.<sup>107</sup> The lessons learned from this were used to 'refresh' the strategy with the publication of Teenage Parents Next Steps (2007) which recommends that all areas provide tailored support and a targeted youth support service that includes a lead professional.<sup>110</sup> However, there will be some occasions when a young woman aged under 20 will not access antenatal services, even when a specialist antenatal service for young women aged under 20 is provided and even after they have been encouraged to attend.

Young people under 18 years require special consideration and an age-appropriate response from professionals in respect of consent and confidentiality<sup>111</sup> and, if professionals are unsure of their remit, this may prove a barrier to equitable care.

Whilst Maternity Matters recommended that commissioners need to understand what, in their current services, prevents women from seeking care early or maintaining contact with maternity services, it did not provide an assessment of how service organisation and delivery could be improved to encourage and facilitate contact to be maintained throughout pregnancy for women aged under 20.<sup>4</sup>

It should be recognised that women under 20 form a large and diverse group and that each woman's needs may be very different. A young woman aged 14 is likely to face different barriers to accessing care from a 19 year old for example. Whilst the recommendations in this chapter are intended to apply to all women in this group, it is important that healthcare professionals treat these women as individuals and plan any additional support accordingly.

The next section will review evidence of effectiveness of different models, of care, reported barriers to accessing care, and additional information that should be provided to young women aged under 20. For a study to be included in this section at least half of the study sample had to comprise women aged under 20.

## 6.2 Access to antenatal services

### Clinical Question

Q1a. What aspects of service organisation and delivery are effective at improving access to antenatal services for young women aged under 20?

### Previous Guidance

There is no previous NICE guidance addressing this question.

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. In order to be considered for inclusion the study had to report an outcome relating to access to antenatal care (e.g. gestation at antenatal booking). After weeding, thirteen papers were retrieved to answer this question. Four were excluded as there was no comparator. The nine included papers were all retrospective studies based on examination of medical records, evidence levels 2- or 3. Eight studies are from the US and one from Portugal.

### Narrative summary of evidence

#### Hospital-based services

Four included studies compared a targeted hospital-based antenatal service for young women aged under 20 with "usual care". A US cohort study included a sample of 135 pregnant young women receiving care through a comprehensive programme aimed exclusively at young women younger than 18 years<sup>112</sup> [EL=2-] (Note: Information regarding antenatal care was based on findings from postnatal interviews with women and data extracted retrospectively from medical records, whilst the postnatal component included prospective data). The "Teen Mother and Child Program" (TMCP) at the Utah School of Medicine provided medical, psychological and nutritional services to pregnant young women, including education about pregnancy, labour and birth, contraception, infant health, individual counselling about interpersonal relationships, financial management, school and work. Supplemental food coupons were also provided through the federally sponsored Women Infant and Children (WIC) programme. Adoption counselling and formal educational and vocational training were provided by outside agencies. A comparison group comprised 135 pregnant young women who received traditional medical care services through the community health provider (Salt lake City- County Health Department for WIC services). No significant differences were found in gestation at booking for women attending the Teen Mother and Child Program compared with those attending the traditional service.

A US observational study (1994) compared outcomes for young women (n=120) attending the Teens Obstetrics Perinatal Parenting Service (TOPPS): with outcomes for young women aged under 20 reported for the state of Arkansas<sup>113</sup> [EL=3]. TOPPS comprised an interdisciplinary team that provided services for pregnant young women, providing nutritional counselling and making appropriate referral as needed (i.e. WIC, AFDC, Medicaid, etc.). The percentage of young women aged under 20 with babies born weighing between 1500 and 2500g was slightly higher in the TOPPS sample compared with the state sample, 2.1% vs. 1.8%.

A large-scale US retrospective observational study conducted in the 1970s compared outcomes from a specialist antenatal clinic for young women aged under 20 with those obtained for young women aged under 20 attending the standard state hospital-based antenatal clinics<sup>114</sup> [EL=3]. The service for young women aged under 20 was provided by a multidisciplinary team and included screening, antenatal education, psychosocial evaluation and counselling including home visiting by social workers, and nutritional assessment and counselling. Young women aged under 20 from each population with a low-risk antenatal score for obstetric and medical complications were included (specialist clinic n=493; standard clinics n=2034). Young women aged under 20 in each sample were considered as being of low socio-economic status and approximately 80% of the total study sample was reported as "non-white". Half of the women in each study sample booked before 21 weeks of pregnancy. Slightly fewer women in the intervention group booked after 28 weeks of pregnancy (13.5% vs. 15.7%) but this difference is not statistically significant.

A US observational study (1994) compared outcomes for young women aged 17 years or younger (n=120) attending the Teens Obstetrics Perinatal Parenting Service (TOPPS); with outcomes for young women aged under 20 reported for the state of Arkansas<sup>113</sup> [EL=3]. TOPPS comprised an interdisciplinary team that provided services for pregnant young women, providing nutritional counselling and making appropriate referral as needed (i.e. WIC, AFDC, Medicaid, etc.). The percentage of young women initiating antenatal care in the first trimester of pregnancy was 28% in the TOPPS programme compared with 50% in Arkansas as a whole (for women aged 19 years and under).

A more recent European study conducted in Lisbon compared a specialist hospital-based clinic for young women aged under 20 with usual care provided by GPs<sup>115</sup> [EL=2-]. The programme at the specialist clinic included initiating antenatal care as soon as the young woman registered with the hospital. Care was provided by one consultant obstetrician who provided continuity of care throughout pregnancy. Findings are reported for 80 women booked to the specialist clinic compared with 60 women (of the original matched sample of 80) booked for usual care. Women booked to the specialist clinic received their first antenatal appointment significantly earlier (17.1 weeks vs. 19.5 weeks; p=0.02).

### **School-based services**

Three of the included studies compared comprehensive antenatal care for young women aged under 20 provided in school with care provided in hospital or medical centres based clinics<sup>116-118</sup>. All of these studies were undertaken in urban settings in the US. The school-based comprehensive care programmes included on-site antenatal care, family planning services, primary care to infants and children, case-management, nutrition education, parenting education and mental health services. In addition, intrapartum and postpartum care was provided by same staff and day care provided for infants in order to allow the young women to return to school.

In the earliest of these studies (data collection 1973-1976)<sup>116</sup> outcomes of a small group of young women aged under 20 enrolled in a public high school where a comprehensive programme of antenatal care was provided on site were compared to a random sample of young women aged under 20s who received their care at a non-school hospital-based clinic [EL=2-]. In the school group, 58.3% women began their care by the third month of pregnancy compared to 36.1% of the comparison group. This difference did not reach statistical significance. A second study was then undertaken with the same populations (data collection 1976-1979) following enhancement of care provided at hospital-based clinics<sup>117</sup> [EL=2-]. In the school group, 58.5% began antenatal care during the first trimester of pregnancy compared with 45.4% of the hospital based group: this difference is not significant. Bookings in the third trimester were less common in the school group, 3.0%, compared with 11.3% women in the comparison group, again a non-significant difference.

A later US study (data collection 1995-1996) compared a school-based and a hospital-based comprehensive parenting programme (CAPP)<sup>118</sup> [EL=2-]. This programme was similar to those reported in the studies above and included nutrition services, educational services related to sexually transmitted infections, mental health services and referral for educational and vocational services as well as antenatal care delivered by a multidisciplinary team. Young women in the school-based group were significantly younger than those in the hospital-based group (15.1 years vs. 16.2 years), and had a significantly lower reported incidence of sexually transmitted infections (STIs) prior to pregnancy (41% vs. 58%). Both groups had a very high proportion of African-American women (90% and 97%). On average, young women in the school-based programme initiated antenatal care significantly later than those in the hospital-based programme (mean month of pregnancy: 4.2 vs. 3.6; p=0.002).

### **Community-based services**

A US retrospective cohort study compared gestation at booking for young women aged under 20 who had attended a young adults' health centre ("The Corner") for antenatal care (n=180) with a comparison group of young women aged under 20 (n=180) matched for age and year of giving birth booked to receive care at a traditional maternity clinic in a similar neighbouring community [EL=2-].<sup>119</sup> The Corner provided a dedicated antenatal service, including peer education, for women aged under 20 in a free-standing community-based residence. No significant difference was found for gestation at booking between the two study groups, with approximately half of each group initiating care within the first trimester of pregnancy.

### **Community-based services including home visiting**

A US prospective cohort study was undertaken to evaluate a community-based support scheme involving trained lay women known as "Resource Mothers" [EL=2-].<sup>120</sup> Following intensive training the resource mothers provided advocacy and support, including home visiting, to pregnant young women aged under 20 with limited financial and social support. A study group of young women aged under 20 supported by the Resource Mothers Program (n=49) were significantly more likely to book during the first 4 months of pregnancy compared with a group of young women aged under 20 (n=46) attending a multidisciplinary programme providing professional medical care, nutritional advice and home health services (53.0% vs. 32.6% booking in the first 4 months;  $p < 0.05$ ). This finding was despite the fact that the Resource Mothers Programme contained significantly more: young women aged 17 and under; black young women, young women described as being from a "poor neighbourhood"; and those with education up to or below 11<sup>th</sup> grade.

### Evidence statement

#### **Specialist service for young women aged under 20 vs. standard care:**

Four US studies provide evidence for access/initiation of antenatal care comparing hospital-based specialist clinics with standard care. In one study where a range of services were provided through a specialised antenatal and parenting programme no difference was found in terms of gestation at booking compared with a traditional medical service. A second US study where there was a high rate of late booking (defined as during the third trimester of pregnancy) for antenatal care showed no difference between standard care and a specialised antenatal service for young women aged under 20. A third US study had a lower incidence of first trimester booking in a specialist dedicated service compared with state-wide figures. However, in a specialist obstetric-led service for young women aged under 20 where early initiation of care was an integral part of the programme, young women aged under 20 were found to start care significantly earlier than those receiving standard care delivered by GPs.

#### **School-based vs. hospital-based comprehensive se antenatal programmes:**

The evidence is contradictory regarding the effects on timing of initiation of care. Two studies from the US, evaluating the same programme show a tendency towards earlier initiation in a school-based programme and one shows later initiation in a school-based programme.

#### **Community-based services vs. standard care**

One US study comparing a dedicated community-based service for young women aged under 20 with standard care found no difference in gestation at booking between the two services.

#### **Community-based service with lay home visiting vs. multidisciplinary hospital-based care**

One US study evaluating a multi-faceted antenatal service including home visiting by trained lay advocates found a significantly higher proportion of young women booking in the first 4 months of pregnancy within this programme compared with women receiving care in a multidisciplinary service provided by professionals. This was despite the intervention group being more disadvantaged than the comparison group.

### GDG interpretation

It was agreed to combine the interpretation for question 1a and 1b due to the related nature of the evidence

## 6.3 Barriers to care

### Clinical Question

Q1b. What aspects of service organisation and delivery act as barriers to take up of antenatal services for young women aged under 20?

### Previous Guidance

There is no previous NICE guidance addressing this question

## Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. All study types were eligible for inclusion, including non-comparative descriptive studies. No comparative studies were identified which addressed the question directly. After weeding, 17 papers were retrieved that answer the question in terms of what the perceived barriers to care are, either from the young woman's point of view or that of service providers. After quality assessment ten papers were included in the review. These were qualitative studies undertaken to describe women's views of antenatal care, with a particular focus on reasons for not accessing services or late uptake of care.

## Narrative summary of evidence

Please see Evidence Table for study details.

The ten included studies were from the US (n=7) and the UK (n=3). Mainly the papers reported reasons for delaying attendance to care or not attending at all for antenatal care. On the whole the studies were descriptive, using questionnaires and/or interviews with small groups. A number of studies reported similar barriers including transportation, embarrassment and the attitude of staff. All of the studies were EL=3.

A retrospective cross-sectional US study<sup>121</sup> looked at the reasons for seeking early care. Interviews with 37 young women aged under 20 who had recently given birth or who were receiving care in antenatal programmes in Florida addressed young women's subjective reasons for initiating and delaying antenatal care. The women in the early booking group (defined as starting before the 14th week) and late group (defined as after the 27th week) were similar in age, education and parity. Reasons for respondents delaying entry into antenatal care included being afraid to disclose the pregnancy to their mother (n=5) and not knowing they were pregnant because test was negative (n=4). The late booking group had fewer perceived health problems and felt better during the early months than did the early booking group.

A US qualitative study of 31 unmarried pregnancy women aged 16 to 19 years old used questionnaires and interviews to assess their perception of social networks and experiences of seeking help. The group were 61.3% Latino, 25.8% white, 6.5% black and 6.5% Native American. The mean length of gestation was 11.2 weeks at the first antenatal care appointment.<sup>122</sup> The most common barriers to receiving care were the unavailability of a family member or friend to provide support and lack of financial resources.

Postpartum interviews were carried out with women under 17 years old at the Metropolitan Nashville General Hospital (US) to collect information about barrier perception due to money, time, knowledge of available resources and institutional factors such as when clinics were held. The adequacy of antenatal care was grouped as adequate, intermediate, or inadequate and the women's responses were compared among these groups.<sup>123</sup> Identified barriers included finding timing of antenatal clinics inconvenient and difficulties with getting transportation to and from the clinic. Young women aged under 20 who were working while pregnant perceived more time barriers than those who were not. Being in school correlated with receiving less antenatal care.

Structured interviews were conducted with 101 young women aged under 20 less than 17 years of age within 48 hours of birth at an urban university hospital in Pennsylvania (US). The young women aged under 20 were divided into those who received adequate care, intermediate and inadequate care. The attitudes of the young women aged under 20 were compared according to the antenatal care they received.<sup>124</sup> Fifteen young women aged under 20 were assigned to the adequate care groups, 49 to the intermediate, and 37 to the inadequate care group. The 3 groups did not differ in age, race, occupational score for head of household, marital status, hospital service, school grade, or last attendance in school. Young women aged under 20 in the adequate and intermediate care groups were 2 to 3 times more likely to use the Teen Obstetrics Clinic than were mothers in the inadequate care group (p=0.001). Young women aged under 20 receiving inadequate care recognized the pregnancy later. They were more likely to describe confusion about available services and medical coverage, more likely to view physicians negatively and less likely to have experienced a friend's pregnancy. Respondents in the inadequate care group also were more likely to consider antenatal care unimportant and to rely on their families for antenatal advice.

Another US qualitative study compared barriers identified by the young women seeking care and by the health care providers. All English speaking young women between 15 and 19 years old coming to five public antenatal clinics in Arkansas were interviewed to identify their motivations and barriers to

attending antenatal care. Two hundred and fifty young women were interviewed for this study.<sup>41</sup> Nearly all first-time patients and follow-up patients indicated that concern over the health of their baby was the primary motivation for obtaining antenatal care. Only one-third from both groups indicated that a personal health problem was a reason for obtaining antenatal care, whereas health care providers perceived that the most important motivation for their young clients was concern over their own health. Nearly all pregnant young women aged under 20 indicated that they came to the clinic out of concern for the health of their baby, whereas only a third of the providers perceived this as a motivating factor. Young women most frequently reported waiting time for appointment (33%), fear of procedures and not knowing where to go for care (30%), transportation (22%), and fear of providers (17%) as barriers to care. Young women aged under 20 attending for booking were also more likely to identify difficulty getting an appointment as a barrier (17%). Young women aged under 20 attending for follow-up appointments were significantly more likely to identify not wanting to be pregnant as a barrier (31%), compared with those attending for booking. Seventy-one percent of providers identified 'feeling depressed' as a barrier, while only 18% of young women mentioned this. Young women aged under 20 tended to identify system barriers as opposed to personal barriers. Providers perceived that personal barriers would be the most frequently experienced. Young women aged under 20 and health care patients and providers both agreed that 'fear of procedures' and 'not wanting to be pregnant' were important barriers

A US descriptive chart review of women who had no antenatal care found reasons for not seeking care in 43 women.<sup>125</sup> Although not targeted specifically at young women aged under 20, this study included a sub-group analysis of findings for participants aged 15-17. This group was found to have more internal barriers such as denial of pregnancy and fear of doctors.

Another US qualitative study reported barriers to care identified from focus groups with women who were either recently pregnant, currently pregnant, or who did not have children.<sup>126</sup> Young women aged under 20 comprised half of the study population. In addition, four focus groups were also conducted with groups of care providers, one each for physicians, nurse practitioners, nurses, and medical assistants. Most of the young women aged under 20 were found to begin their antenatal care during the second or third trimester. Analysis of findings from the focus group interviews with women revealed 6 general themes:

- treatment by office personnel
- rapport with health care providers
- knowledge of TennCare (state insurance program)
- transportation
- substance abuse
- recognition of pregnancy

The need to be treated with compassion and respect was also highlighted. Findings from focus groups with care providers revealed some differences in perception of the extent of the problem of antenatal care use. The physicians tended to think barriers to antenatal use were a minor problem. In contrast, the nurses, nurse practitioners and medical assistants remarked about a high degree of non-compliance by patients. Six general themes were identified from focus groups with health care providers:

- lack of education
  - Inability to see cause and effect relationship contributes to a tendency to minimize the importance of the things they are asked to do and their own responsibility for a positive outcome.
  - Women would not tell them that if they could not read or write.
- Knowledge of TennCare
- Transportation
- Child care
- Limited hours of operation – limited appointment times for working women, long wait times increases the amount of time away from work required beyond the point that these women feel they can afford. Some women are dependent on someone who works full-time for their transportation.
- Substance abuse – some respondents suspect that fear of discovery and legal consequences inhibit access of antenatal care.

- Other characteristics that were perceived as barriers included: operating with a crisis mentality and only seeking care under emergencies; having no conceptual framework for prevention; and having social problems than are more important to focus on rather than their health care.

Two studies conducted in Scotland examined the reasons for women not attending antenatal classes, rather than antenatal care per se. In one questionnaire-based survey, 26 women were recruited several years after birth, median 8.5 years postnatally. Nine women dropped out before interview, five were in the pilot study and so only 12 women were included in the main study. The study looked at a number of issues such as benefits available, and role models, not just antenatal classes.<sup>39</sup> Four women mentioned the danger of stigmatisation if a support group were organised exclusively for teenage mothers. All women felt it would be useful to gather a group of women together who shared similar circumstances because they would be able to support each other. Some of the comments made raised doubts about whether these respondents would have actually attended regular antenatal classes. All others felt inhibited to be with older mothers who were in stable relationships. Other barriers identified were: embarrassment felt from attending any kind of group, mental health problems and time pressure. Both a regular group and a drop-in session were thought to be useful. The need to advertise the group well was highlighted and the importance of a personal introduction by a health professional to persuade most young women aged under 20 to attend.

The other Scottish study involved a self-completed questionnaire and semi-structured interviews with 30 nulliparous young women less than 18 years old who had a healthy term baby and did not have the baby adopted.<sup>40</sup> Nine had attended antenatal classes, the remainder had not. Reasons for non-attendance were:

- Age discrepancy between themselves and other attendees
- Seven stated they just did not want to attend
- good support from home so felt it was unnecessary
- embarrassed by comparison of their unplanned circumstances with expectations of older attendees
- not typical of most class attendees

Young women aged under 20 felt it was important to establish the best time to hold the sessions and that they should be easily accessible. Most young women reported that they would have attended a 'young mums club' and that they would be more likely to attend education sessions if they coincided with visits to the clinic.

A third UK study conducted in North Wales attempted to seek young women's views of a dedicated antenatal service which included both antenatal and postnatal care and support, including group education<sup>127</sup> [EL=3]. Six young women aged 15-20 were asked views of the service and how they thought the service could be better publicised. Responses showed how some young women aged under 20 felt stigmatised and uncomfortable attending antenatal clinic alongside older women. When asked specifically about advertising of the clinic the young women confirmed this was very poor, saying that many of their friends had never heard of the clinic which was seen as an important barrier to attendance.

### Evidence Statement

All ten included studies are EL=3.

**Table 6.1 Barriers reported by young women aged under 20 (n=10 studies)**

<b>Service barriers reported by young women aged under 20</b>	<b>Personal reasons which act as barriers reported by women</b>	<b>Barriers reported by providers</b>
Limited hours of A/N clinic operation (2)	No pregnancy-related problems perceived (1)	Lack of education (1)
Transportation (3)	Antenatal care considered unimportant (1)	Fear of procedures (1)
Difficulty getting an appointment (2)	Not wanting to recognise the pregnancy (2)	Long waiting times (1)
Treatment by staff/attitude of staff (3)	Lack of knowledge of available services (3)	Child care (1)

Waiting time at appointment (1)	Embarrassment of unplanned pregnancy (3)	Limited hours of clinics (1)
Clinic poorly advertised/promoted (1)	Afraid to tell parents (1)	Substance misuse (1)
	Age discrepancy between themselves and other attendees (3)	Depression (1)
	Fear of procedures (1)	Having social problems that are more important to focus on than health care (1)
	Financial difficulties (2)	Transportation (1)

(Number of studies reporting each barrier given in parentheses)

### GDG interpretation of evidence

The fairly small number of included studies for question 1a (n=8), low quality of evidence and specific population groups included in these studies indicates that a cautious approach should be taken when interpreting the evidence for relevance to UK practice. Of the eight studies which were included in the review for question 1a, seven were from the US: three of these involved hospital-based clinics and two were school-based programmes. Most included a large proportion of African-Americans of low socioeconomic status which is not generalisable to the UK in 2010. The GDG considered that mainstream school-based antenatal care has limited benefit for those young women aged under 20 who are excluded from school and the stigma of attending such a service might also inhibit rather than promote access, therefore this is not recommended. The European study highlights the importance of continuity of care which was recognized by the GDG as good practice for all antenatal care and a positive factor for encouraging access to care. In order to help overcome the barriers identified. The GDG felt services should be established that would enable continuity of antenatal carer to be provided (defined as at least 50% of face to face contacts being provided by a named midwife). This named midwife should be trained to ensure she has the appropriate skills, particularly communication skills, and knowledge needed to meet the needs of this group of women. Based on this evidence and endorsed by the GDG's experience and opinion the GDG recommended that young women under 20 should be offered a named midwife who would provide the majority of her care and be responsible for co-ordinating antenatal care to ensure consistency.

The multifaceted components of the studies e.g. a variety of on-site clinical and psychological care and advice, antenatal education, home visiting and case-management make it difficult to unpick which component is the critical factor in improving access to care, or whether it is indeed a multifaceted approach that is needed in order to reach the greatest proportion of young women aged under 20. An example of a multifaceted specialised service for young women aged under 20 (in fact in this example the service is actually provided for women aged under 19) is given in Box 6.1 (details in Appendix D, number 10).

There is an assumption underlying antenatal care provision that early booking for care will lead to improved pregnancy outcomes. Possible mechanisms for this include the opportunity to undertake an early ultrasound scan (for dating the pregnancy) and early screening. This assumption underpins the health economics model which suggests that a service which books more young women aged under 20 into a service early will be cost effective (see section 6.7 below). The GDG therefore agreed that one of the stated aims of any antenatal service provided for young women aged under 20 should be to book them during the first trimester of pregnancy, and made a recommendation to this effect.

As the evidence highlighted a large number of barriers, the GDG formally voted on which barriers they considered to be the most important and relevant. The barriers were presented as a list based on the review findings from Q1b. This consisted of one round of anonymous voting using pencil and paper. Following this, the results were fed back to the group and agreed. The GDG voted for the following as the most important barriers:

- Treatment/attitude of staff
- Not wanting to recognise pregnancy/Embarrassment of unplanned pregnancy/afraid to tell parents
- Having social problems that are more important to focus on than healthcare
- Waiting times at appointment

- Transportation
- Age discrepancy

The group felt that service providers should attempt to provide services which could overcome these barriers to care.

The group felt that one potential method for overcoming young women's anxieties relating to poor treatment by staff and age discrepancy between themselves and other service users was to offer the opportunity for these women's partners to attend appointments and antenatal education sessions. Based on GDG consensus a recommendation was made to encourage this. However, in order to overcome the second of these barriers (afraid to tell parents), the GDG also recognised the importance of offering young women aged under 20 opportunities for one-to-one consultations without partner or parental input, and recommended that this should be offered. Related to this, the GDG were aware that there is some confusion about the rights of young people to give consent to medical interventions and when it is appropriate to inform parents. Based on their discussions the GDG agreed to recommend that healthcare professionals should be provided with training about these issues, and made aware of the Department of Health's "Guidance on consent for examination or treatment" (2009)<sup>16</sup>

Whilst recognising that young women's needs will vary depending upon their age, level of maturity and available support, the recommendations are made in order to support service organisation and development for this group of women in order to ensure any additional care and support necessary can be provided. It is of course the role of the antenatal carer to assess each woman's needs individually and with the woman plan care accordingly.

See section 6.8 (page 110) for recommendations.

## 6.4 Maintaining contact

### Clinical question

Q2. What aspects of service organisation and delivery improve contact with antenatal services throughout pregnancy for young women aged under 20?

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Papers needed to report comparative data including an outcome relating to maintaining contact with antenatal care e.g. number of visits, adequacy of care (variously defined). After weeding, 46 papers were identified as potentially fulfilling these criteria. Following appraisal, 25 of these papers were excluded leaving 21 for inclusion. Of the included papers, seven examined antenatal education/discussion groups as an intervention (six of these included specialised antenatal clinics for young women aged under 20 antenatal as well), three evaluated a school-based antenatal service, six reported on a home-visiting service (five of these papers investigated the same intervention; two as a pilot project and three as the programme was rolled out), one paper examined a specialised clinic for young women aged under 20 as a stand-alone intervention, and two investigated the impact of a dedicated antenatal clinic service for young women aged under 20. All studies were retrospective either evidence level 2 or 3. All studies except one were based in the US and many included study samples with high proportions of African-American or non-white young women and those of low socio-economic status.

### Narrative summary of evidence

#### Antenatal education groups

Seven US studies investigated the impact of providing specific antenatal education for young women aged under 20 on maintaining contact with antenatal care.<sup>128-133;134</sup> For one of the included studies<sup>132</sup>, improving contact with services was one of the stated aims of the project. For the remaining six studies a measure of antenatal contact was included as a reported outcome, either simply stated as number of antenatal visits or as a score to describe "adequacy of care" based on gestation at booking, expected number of visits and gestation at giving birth. The seven studies describe a programme of antenatal

education which ran within the antenatal clinic, for three of these studies it is clear that the two ran concurrently.<sup>128-130</sup> Findings from one of these studies shows that high attendance at classes equated with high attendance at antenatal check-ups<sup>128</sup> [EL=2+]. Young women aged under 20 enrolled in this programme received incentives to encourage attendance. A second study reported no difference between the intervention and comparison group, with neither group missing any antenatal visits<sup>129</sup> [EL=3]. A third retrospective cohort study [EL=2-] described a programme of 3-hour education sessions on a variety of topics. Young women in the intervention group attended significantly more sessions than the control group (6.25 vs. 5.125 (F=6.445, p<0.05)).<sup>130</sup>

For the other four studies looking at provision of specialised education for young women aged under 20 it is not clear whether these ran concurrently with the antenatal clinic visits or not. Two of these programmes also included incentives to attend the classes, and both of these report significantly higher levels of antenatal contact than seen in the comparison groups<sup>131,132</sup> [EL=3] [EL=2-]. Two of the studies where no incentives were included also report improved antenatal attendance. In one of these studies authors report a higher "average number" of antenatal visits for young women aged under 20 in the intervention group (8 vs. 6) but it is not clear whether this is statistically significant<sup>133</sup> [EL=2-]. The other, which involved a multidisciplinary dedicated clinic plus a comprehensive programme consisting of nine one hour sessions, found a significantly higher number of appointments for young women in the intervention group [EL=2-].<sup>134</sup> Overall, four of the seven studies reported significantly higher numbers of antenatal appointments attended by young women aged under 20 attending antenatal education compared with those who did not attend antenatal education, although it is not possible to establish this as cause and effect.

### **School-based antenatal services**

Five US urban-based studies investigated the effects of school-based antenatal programmes on maintaining contact with antenatal care provision. Four of the school programmes included attendance at a specialist school for pregnant young women.<sup>117;135-137</sup> The fifth evaluated the effectiveness of a nurse-run antenatal counselling programme within a public high school.<sup>138</sup>

Three of the studies reported comparative findings for maintaining contact with antenatal care. One large-scale study showed significantly more young women in the school-based group received "adequate care" compared with a matched control group not attending the school (78% vs. 67%)<sup>135</sup> [EL=3]. A further, smaller study<sup>117</sup> evaluated a scheme to improve antenatal services for young women aged under 20 at a hospital clinic. Following implementation of a more personalised service at the hospital clinic 13.2% young women aged under 20 attended 5 or fewer times compared with 7.5% at a comprehensive school-based service (p=0.0526) [EL=2-]. A third US study compared care in community-based clinics with specialised antenatal classes with school-based care and with usual antenatal care at the same community-based clinics (i.e. without the additional classes)<sup>136</sup> [EL=2-]. The mean number of antenatal visits was similar between the school-based programme and the usual care provided at community clinics (6.90 vs. 6.58), with an increased number of visits being seen for young women aged under 20s in the antenatal clinic with classes (9.80).

A fourth US study compared a comprehensive antenatal programme for young women aged under 20 provided in schools with one provided in medical centres<sup>137</sup> [EL=3]. Comparative findings for contact with services were not reported, however 35% of the total study sample were described as receiving substandard antenatal care. A composite outcome "adverse perinatal outcome" was found to be significantly associated with substandard antenatal care (20.2% vs. 6.9% of women with adverse outcomes who received adequate antenatal care;  $X^2=9.5$ , p<0.001). Adverse perinatal outcome was not significantly related to any socio-demographic variable, and nor were pregnancy complications.

One retrospective cohort study [EL=2-] evaluated the adequacy of antenatal care received by students enrolled in a school which provided a nurse-led antenatal counselling service, compared with teen mothers residing in the community.<sup>138</sup> The young women aged under 20 in the intervention group initiated care on average 23 days earlier than those in the control group (t (277) = -4.312; p<0.0001), and also made on average 1.6 more antenatal visits than the control group (t (267) = 4.914; p<0.0001).

### **Home-visiting**

Six US studies evaluated an antenatal home-visiting programme. One of these programmes provided home-visits to low-income pregnant young women aged under 20 from a certified public health nurse to discuss pregnancy-related issues (but not to provide antenatal check-ups) and provided transport to and

from antenatal appointments<sup>139</sup> [EL=3]. Findings from this study showed an increased number of antenatal visits and a decrease in the number of young women receiving no antenatal care compared with young women receiving usual care in the same area. The other five included papers reported findings from a large-scale home-visiting programme initiated in South Carolina, USA known as the Resource Moms Project<sup>120;140-143</sup>. The programme was delivered by trained lay support workers. Three of the papers describe early stages of the project<sup>120;140;141</sup> [EL=2-] and two describe the project after roll-out across 16 counties of South Carolina<sup>142;143</sup> [EL=3]. During the pilot phases of the project, the support workers received 6 weeks training and had a caseload of 30-35 young women aged under 20s. The pilot was conducted in a rural county of South Carolina with a high proportion of black young women; the comparison group was matched to the intervention group on main demographic variables. After roll-out, the training was reduced to 3 weeks and the caseload increased to 50-65 young women. The project aimed to target black, single pregnant young women aged under 20. During both phases of the project there was a significant increase in the number of young women receiving adequate antenatal care compared with young women aged under 20 in other counties not enrolled in the programme. However, a comparison between the intervention group in the main programme and a comparison group drawn from the same counties did not show a significant difference in the number of young women aged under 20 receiving adequate antenatal care.

### **Specialist antenatal service for young women aged under 20**

One European study conducted in Lisbon compared care provided at a specialist obstetric hospital-based antenatal clinic for young women aged under 20 with usual care provided by GPs<sup>115</sup> [EL=2-]. Care at the specialist clinic was provided by one consultant obstetrician who offered continuity of care throughout pregnancy. The total number of visits made by young women aged under 20 in the intervention group was significantly higher than that for the comparison group (9.0 vs. 5.2). It should be noted that this is an observational study thus young women in the intervention group were self-selected and represented a group who book for hospital-based antenatal care than more local GP-based care.

A US retrospective cohort study (1983) investigated the impact of a dedicated antenatal clinic service for pregnant young women aged under 20 (Teen clinic) on the number of antenatal visits kept, obstetric and neonatal outcomes, and breast feeding<sup>144</sup> [EL=2-]. Data were collected from 52 pregnant young women aged under 20 before the Teen clinic was established, and a matching 52 pregnant young women aged under 20 after the Teen clinic had been established. In a series of eight sessions the Teen clinic provided information for participants on nutrition, fetal movement, labour and delivery, infant care, well baby check-ups, parenting skills and contraception using a variety of teaching techniques. The team consisted of a nurse midwife conducting all antenatal checkups and a social worker/coordinator, community worker, and a second nurse midwife leading informal discussions with young women aged under 20. Significantly more young women aged under 20 allocated to the intervention group made at least the recommended number of antenatal visits compared to the control group (43/52 vs. 30/52; ( $p < 0.01$ ,  $df = 103$ )).

Another US retrospective matched cohort study compared differences in the process of care provided by a community based antenatal care programme designed especially for young women aged under 20 (known as the Corner  $n = 180$ ) relative to hospital based traditional antenatal care which was not focused on young women aged under 20 (obstetric clinic  $n = 180$ ) by review of medical records<sup>119</sup> [EL=2+].

The sample of clients attending the Corner included all young women aged under 20 who received a minimum of three antenatal visits and who gave birth at the Women's Hospital between January 1991 and June 1998. The comparison sample was constructed by selecting the first 180 medical records of women with a minimum of three antenatal visits at the Women's Hospital who had given birth there, matching age and year of delivery with clients from the Corner sample. There were no significant differences between the two groups for variables describing pregnancy, labour or birth complications.

There were no significant differences between the two groups with the variables examined (age, marriage, occupation, race, medical and obstetrics history and smoking). The mean number of antenatal visits in the Corner group was 12.9 versus 9.79 in obstetric clinic group ( $p < 0.001$ ).

### **Evidence Statement**

#### **Antenatal education groups:**

Evidence from seven retrospective studies suggests that provision of antenatal classes focussed on the needs of young women aged under 20 enhances contact with antenatal care. At least three of the

programmes included classes provided alongside a specialist antenatal clinic young women aged under 20 and three provided incentives for attending the classes. It is not clear what contribution these elements of the programme make to the improvements reported.

### **School-based services:**

There is a small amount of conflicting evidence from five retrospective studies for the effect of school-based antenatal care on continued uptake of care. Evidence from an evaluation of a school-based programme showed a significant association between substandard antenatal care and adverse perinatal outcomes; although no causal effect has been demonstrated.

### **Home-visiting:**

There is evidence from four small-scale studies and two large-scale studies that targeted home visiting by either trained health care workers or trained lay support workers and the provision of transport to and from antenatal services improves maintained contact with antenatal care.

### **Specialist antenatal service for young women aged under 20:**

Evidence from one fairly small study showed that specialist obstetric care provided by one consultant obstetrician at a hospital antenatal clinic can improve contact with care compared with usual care provided by GPs. Evidence from two other studies showed a significant improvement in the number of antenatal visits made for those attending a dedicated antenatal service designed for pregnant young women aged under 20.

## **GDG interpretation of evidence**

The GDG recognised that the evidence suggested that provision of antenatal classes designed for young women aged under 20 seemed to improve uptake of standard antenatal care. The group accepted that part of the positive effect found in the studies might be due to the intervention groups comprising young women who self-selected into them i.e. that young women who attended antenatal classes were more likely to also attend standard appointments. However, the group felt that their own experience supported the view that antenatal classes would aid uptake of antenatal care. The evidence was not clear about whether providing antenatal classes concurrently with antenatal appointments was beneficial. However, the GDG felt that as a number of barriers identified in the review for question 1b had related to the lack of time young women aged under 20 had to dedicate to antenatal care, a model of care that made it easier to access classes and standard appointments at the same time would be beneficial. Based on this evidence they recommended that age-appropriate antenatal education should be provided which might be run alongside antenatal consultations.

Given the conflicting evidence about the effectiveness of a specialist-school based antenatal service, the poor quality of the evidence and the concerns expressed in the interpretation for question 1a, the group chose not to recommend the provision of a school-based service.

Although there were positive effects observed in the studies looking at home-visiting, some of these effects were only achieved in pilot studies and not replicated when a programme was adopted on a wider scale. The GDG noted that this could be because the programme reduced the training for the support workers and increased the caseload for the roll-out of the programme as compared with the pilot studies. It was felt inappropriate to recommend home visiting as a model of care provision for this group, whilst recognising that for a small proportion of this group home visiting might be appropriate. This would be assessed on an individual basis.

The GDG noted that the findings reported from 2 studies showed improved contact with antenatal care associated with specialist antenatal services and felt this supported a recommendation for the establishment of services targeted specifically to encourage pregnant young women to attend. The GDG consensus was that this should include care provided by a trained specialist midwife. The evidence reviewed supported also the provision of age-specific information as well as provision of antenatal education groups concurrent with antenatal consultations. The health economic modelling which underpins the recommendations for this population supports this as a cost effective service intervention based on the assumption that an additional service costing £150,000 will lead to an additional 15 young women booking by 12 weeks of pregnancy. In an area where the rates of pregnancy amongst young women aged under 20 are lower, a less expensive service costing £25,000 (e.g. provision of an part-time

midwife dedicated to this group) would need to result in an additional 3 young women booking in the first trimester for the service to be cost-effective.

An example of an NHS service which contains these components of care is given in Box 6.1. No evaluative data are available for this service so it is not possible to state whether or not this specific example is cost-effective.

The group noted the positive outcomes associated with the specialist obstetric service for young women aged under 20 compared to usual care provided by GPs. Although they did not feel that the evidence was strong enough to recommend this particular model of care, they recognised the benefit of providing continuity of care to this population of women. From their own experience, they agreed that young women are less likely to attend their antenatal appointments than other groups of women. However, they agreed that enabling young women the opportunity to build up a relationship with their caregiver by providing continuity of care was an effective way of encouraging attendance. A consensus-based recommendation was made therefore that the named midwife should provide the majority of a young woman's care (majority defined as at least 50% of face to face consultations).

Overall, the GDG felt that the evidence was weak in this area. The majority of studies were from the US and so were not necessarily applicable to the UK setting. Additionally, because of poor study design, it was not easy to determine which components of the service were affecting the outcomes being considered. The group also noted that whilst studies might demonstrate a statistically significant increase in the number of antenatal appointments attended, it was not necessarily clear that this would lead to a clinically significant benefit.

See section 6.8 (page 110) for recommendations.

## 6.5 Additional consultations

### Clinical question

Q3. What additional consultations and/or support should be provided to young women aged under 20, their partners and families in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline).

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all years of publication were considered for inclusion in this review. Papers needed to report comparative data including health-related birth outcomes e.g. low birth weight, gestation at birth to be considered for inclusion. After weeding, 70 papers were identified as potentially fulfilling these criteria. Following appraisal, 25 of these papers were included in the review. Of the included papers, 12 evaluate multi-faceted services providing social support, information and facilitating contact with health and social care; ten evaluated comprehensive antenatal services including health and social care and three evaluated school-based services. Studies of all methodologies are included.

### Narrative summary of evidence

Please see Evidence Table for study details.

#### *Multi-faceted social support interventions*

Twelve papers reported the effect of multi-faceted interventions aimed primarily at providing young women aged under 20 with support and education/information, and facilitating contact with health and social services.<sup>139-143;145-150;112</sup> The evidence base comprises a systematic review plus 3 studies examining multi-faceted interventions without home visiting. A further 8 papers evaluate 5 multi-faceted services with a home-visiting component.

The first of the included papers is a systematic review undertaken to determine the effectiveness of public health, health promotion and primary care strategies to reduce or prevent the incidence of low birth weight in babies born to young women aged under 20<sup>145</sup> [EL=2++]. Eleven of the 13 included studies were conducted in the US. The interventions included were: health information, support strategies,

encouragement to attend antenatal care, standard medical care and referrals. Interventions were delivered by: nurses, public health nurses, health educators, social workers, nutritionists, health care aides, and lay or paraprofessional home visitors. Many studies included a range of interventions and care providers implemented as part of one programme. Eight studies found no significant effect on birth weight. However, five studies reported a statistically significant positive effect on birth weight associated with the intervention compared to usual/standard care. All studies reported support and health education provision as interventions. Two delivered care in the home, three were clinic based. Care was provided either one-to-one (n=3 studies) or in a class format (n=2 studies). Two studies actively encouraged young women aged under 20 to attend for antenatal check-ups and two provided transportation to appointments. One study also provided social support and referrals. These interventions tended to be specifically targeted at young women aged under 20. The authors noted that it is not possible to discern any difference between interventions that seem to have a positive impact on birth weight compared to those that do not. In addition it is not possible to decide which, if any, of the aspects of care/services have the greatest impact on outcomes or whether it is the multi-faceted nature of the interventions that is important.

### *Multi-faceted social support interventions including home visiting*

#### **Home-visiting by a professional**

Of the seven multi-faceted social support intervention studies, five included home-visiting as a component of service provision. A large (n=1139) RCT conducted in Memphis (US) compared a home-visiting programme with provision of transport to and from antenatal appointments<sup>146</sup> [EL=1+]. This trial was conducted to replicate earlier work carried out with a predominantly white, suburban population in New York State<sup>147</sup> [EL=1+] but this time with a black, urban population. As in the original study, the third and fourth trial arms included home visiting by a nurse either antenatally (trial arm 3) or antenatally and until the infant's second birthday (trial arm 4). Unlike the first trial, all women in the later study, including the "control" group in trial arm 1, received transport to and from antenatal appointments. In the earlier study transport was only provided for women in trial arms 2, 3 and 4. Whilst the earlier work had found a significant reduction in low birth weight babies and preterm babies born to participants of all ages as well as to a sub-sample of young women aged under 20, this benefit was not evident in the later study. This could be accounted for by the differences in study populations. It might also be contributed to by the fact that simply providing transport to antenatal appointments has a beneficial effect on birth outcomes, including low birth weight, thus reducing the difference seen due to the added impact of nurse home-visiting. The later study did find a significant reduction in incidence of pregnancy induced hypertension between arms 1 & 2 and 3 & 4 (20 vs.13; OR=0.6 [95% CI 0.5 to 0.9; p=0.01]) and yeast infections (0.19 vs. 0.14 [95% CI 0.00 to 0.58; p=0.05]).

A more recent UK descriptive study (2005)<sup>148</sup> [EL=3] compared traditional community-based midwifery provided to a caseload of young women aged under 20 with a midwife-advocacy service (an "interface midwife"). The interface midwife did not provide routine antenatal, intrapartum and postnatal midwifery care thus allowing her time to make contact with primary and secondary care sector, social workers, family planning services, schools and other agencies. This was in addition to usual care. No differences were seen between the two groups for pregnancy complications or birth outcomes. Significantly more women were allocated to the interface midwife (interface midwife (IM) 64/95 (70%) vs. community midwife (CM) 28/63 (44%); p=0.002). Women seeing the interface midwife were more likely to receive sexual health screening (IM 49/111 (44%) vs. CM 1/81 (1%) p=0.000). They were also more likely to receive income support (IM 104/109 (95%) vs. CM 46/69 (67%)); Sure Start (IM 34/109 (31%) vs. CM 5/69 (7%)); maternity grant IM 103/109 (95%) vs. CM 10/69 (14%) and maternity benefit IM 79/109 (72%) vs. CM 6/69 (9%). They were also more likely to breastfeed (IM 64/95 (70%) vs. CLM 28/63 (44%) p=0.002). It is inferred that there was a large number of women receiving care from the community midwife who would have been eligible for these benefits but not receiving them, but this is not made explicit. The community midwife was more likely to express concern regarding child protection issues (IM 20/106 (19%) vs. CM 36/81 (44%); p<0.001), with more babies born to women cared for by the community midwife being allocated a social worker (IM 19% vs. CLM 27%).

A recent study from the US (2008)<sup>139</sup> [EL=3] investigated the impact of a home visitation intervention, the Teen Parenting Partnership (TPP) Program, on resource utilization and birth outcomes among pregnant young women aged under 20. Participants received monthly home visits from both a public-health registered nurse (PHN) and a medical social worker (MSW). The programme lasted through the antenatal period until the child reached 1 year of age, but could continue for a period of 3-5 years after this.

Participants were provided with information about benefits and community resources, and given assistance to enrol. Young women aged under 20 were also assisted in locating and selecting an antenatal care provider, given encouragement to independently make and keep their own appointments and provided with transportation to antenatal care appointments and other healthcare appointments. They were also assessed and referred for mental health counselling, substance abuse counselling and other services as appropriate. No significant difference was seen between intervention group (10.80%) and comparison group (10.60%) in proportion of low birth-weight infants, nor mean gestational age at birth (39.0 weeks vs. 38.3 weeks).

### **Home-visiting by a trained paraprofessional**

A large-scale home-visiting programme conducted in South Carolina, US in the 1980s has also been comprehensively evaluated<sup>140-143</sup>. Known as the Resource Mothers (Moms) Program this consisted of regular home visiting by indigenous paraprofessional workers who received three or six weeks of intensive training. The programme targeted younger, black, unmarried young women and included providing transportation to and from antenatal appointments. Whilst earlier evaluations of pilot projects<sup>140,141</sup> [EL=2-] showed a significant effect on incidence of low birth weight, these findings were not replicated in a larger-scale study undertaken after the programme had been rolled-out<sup>142,143</sup> [EL=3]. The authors explain this in terms of the reduced resources available when the programme was expanded with a shorter training period and a bigger caseload for the resource mothers.

### *Multi-faceted social support interventions not including home visiting*

A US retrospective cohort study (1987) has evaluated the effectiveness of a dedicated comprehensive antenatal and parenthood intervention programme, the Teen Mother and Child Programme (TMCP)<sup>112</sup> [EL=2-]. This urban programme aimed to provide medical, psychological and nutritional services, plus education about pregnancy, birth, contraception and infant health plus information and support regarding interpersonal relationships, financial management, school and work. Supplemental food coupons were provided through the federally sponsored Woman and Children program. Birth outcomes for a sample of 135 pregnant young women receiving care through the programme were compared with a sample of young women receiving WIC aid attending a neighbouring hospital-based clinic for antenatal care. There was no significant difference in pregnancy outcomes between the two groups with the exception of a greater incidence of extended neonatal hospital stay for babies born to women in the TMCP. Repeat pregnancy rate in the 12 months following the birth were lower in the TMCP group (8/75 vs. 18/83), although this difference is not statistically significant. It should be noted that significantly more young women in the intervention group were from families of higher SES and more likely to enrolled in full-time education than those in the comparison group, thus it might have been expected that this group would have better birth outcomes.

An urban US study (1989)<sup>149</sup> [EL=3] evaluated a community-based service for young women aged under 20, the Teenage Pregnancy and Parenting Program (TAPP). The TAPP included case management, including repetitive counselling of young women aged under 20 and coordination of agencies offering service to young women. Although it is not entirely clear from the study report it would seem that the TAPP co-ordinator was an administrator rather than a health or social care professional, and the service was provided in community-based centres rather than at the young woman's home. Birth outcomes for young women enrolled in the TAPP were compared to those who gave birth prior to the programme's inception. Incidence of low birth weight was 8.1% for programme participants compared with 12.0% for young women aged under 20 not in the programme ( $p < 0.05$ ).

An RCT conducted in Detroit, US (2002)<sup>150</sup> [EL=1-] compared birth weight and repeat pregnancy rates for young women aged under 20 enrolled in a peer-centred antenatal programme with young women aged under 20 receiving individual antenatal care at the same clinic. The vast majority of participants were African-American. The unusual intervention consisted of pairing young women and teaching them to perform antenatal examinations for one another, including measuring blood pressure and fundal height, and listening to the baby's heartbeat. Education on prenatal care was also provided in a group setting. There was a tendency towards a reduction in low birth weight babies born to young women aged under 20 in the intervention group (6.6% vs. 12.5%,  $p = 0.08$ ). There were no significant differences noted in planned or unplanned pregnancy rates at one year postpartum.

### *Comprehensive dedicated antenatal care (including health care, social care, counselling and education)*

Ten studies reported on comprehensive antenatal services focussed on young women aged under 20 which included health-related antenatal care, social care, counselling, information and advice, antenatal

education and referral to other agencies/services. Two of the included studies are descriptive studies from the UK.

The most recent UK study (2007)<sup>151</sup> [EL=3] investigated of the impact of a dedicated antenatal clinic service, the Young and Pregnant Clinic (YAP), on obstetric and neonatal outcomes including low birth weight and preterm birth. Data were collected from the year 2000 (before YAP was established, n=132) and 2004 (a year after YAP had been established, n=128). The clinic provided psychosocial support and maternity care by a named midwife and a single named consultant. One-to-one and group education sessions were also conducted providing information regarding parenting skills, health in the pregnancy continuum, labour and the care of the newborn baby. There was no significant difference found between the intervention and comparison (before) group for incidence of pre-term birth (4% vs. 8%). However, the incidence of low birth weight was significantly reduced following establishment of the YAP clinic (5% vs. 14%,  $p=0.01$ ). Labour and birth outcomes were similar for the 2 study groups however there was a significantly higher uptake of postnatal contraception in the intervention group (77% vs. 36%,  $p<0.0001$ ) and a higher percentage of women breastfeeding at 4 weeks (20% vs. 2%,  $p<0.0001$ ).

The second UK study (2002)<sup>152</sup> [EL=3] evaluated outcomes achieved by a dedicated clinic for young women aged under 20 in South Shields compared with outcomes for young women aged under 20 cared for in the standard (adult) clinics at the same hospital. No significant differences were found for the incidence of most pregnancy or labour complications investigated. However, a significant difference was reported for rate of preterm births, with the incidence being lower for young women aged under 20 attending the dedicated clinic (2.5% vs. 15%, OR 0.35 [95% CI 0.028 to 0.83,  $p=0.026$ ]), although the numbers involved were very small (n=2 and 5 respectively).

An Australian multicentre prospective cohort study (2004)<sup>153</sup> [EL=2+] was designed to investigate whether hospital-based antenatal clinics for young women aged under 20 could reduce the incidence of preterm birth. In addition to usual antenatal care women also received: evaluation of anaemia with vitamin screens and dietician referral; intensive social work appraisal with psychosocial assessments for domestic abuse, housing and support levels; screening for STIs and genital tract pathogens, cervical screening abnormalities and drug use. Care was provided by a team of midwives, obstetricians, social workers and a psychiatrist. Findings showed a reduction in preterm birth (teenage clinic 12% (54/448) vs. general clinic 26% (52/203);  $p<0.0001$ ), although the adjusted birth weight was similar for the 2 study samples.

A US retrospective cohort study (1991) compared pregnancy outcomes for a sample of 180 young women receiving care from a community-based freestanding young adult health centre (the Corner) with outcomes for a matched sample (on age and year and of giving birth) of 180 young women who received care from a traditional hospital-based obstetric clinic [EL=2-].<sup>119</sup> Components of the Corner's programme comprised health services, including comprehensive pregnancy care, and peer education with an emphasis on pregnancy prevention. No significant differences were found for any of the birth outcomes reported, including low birthweight, although there was a significant reduction in the percentage of young women attending the Corner who stopped or reduced cigarette smoking compared with the comparison group. Postnatal follow up showed a clinically meaningful reduction in the proportion of young women who reported using contraception postnatally and a corresponding reduction in repeat pregnancy rates, the latter outcome being 5% vs. 27% at 6 months and 15% vs. 30% at 24 months postnatally. However, since the Corner programme continued postnatally it is not possible to determine whether it was the antenatal component or the postnatal component that contributed most to this positive effect.

A second US retrospective cohort study (1988) compared pregnancy outcomes for young women aged under 18 years (n=70) receiving care from a multidisciplinary, dedicated hospital-based antenatal service including comprehensive antenatal education, with outcomes for a comparison group (n=46) receiving usual care from a neighbouring hospital-based service<sup>134</sup> [EL=2-]. The intervention group received care from a variety of staff including a nurse, a social worker, a nutritionist and a nurse midwife, seeing an average of 3 different professionals at each visit. The intervention also included a programme of 9 one hour antenatal education groups. Young women in the comparison group received care from one physician and nurse at each visit and were referred to a nutritionist, social worker or other professional as needed. Education was provided on a one to one basis in the clinic setting. There was a significant difference in the study groups at baseline with a higher proportion of black women and a higher proportion of women in full-time education attending the dedicated service for young women aged

under 20. No significant differences were found for any of the pregnancy and birth outcomes reported, including birthweight and incidence of low birthweight.

A US retrospective cohort study (1983)<sup>144</sup> [EL=2-] investigated the impact of a dedicated antenatal clinic service for pregnant young women aged under 20 (Teen clinic) on the number of antenatal visits kept, obstetric and neonatal outcomes, and breast feeding. Data were collected from 52 pregnant young women before the Teen clinic was established, and a matching 52 pregnant young women after the Teen clinic had been established. In a series of eight sessions the Teen clinic provided information for participants on nutrition, fetal movement, labour and delivery, infant care, well baby check-ups, parenting skills and contraception using a variety of teaching techniques. The team consisted of a nurse midwife conducting all antenatal checkups and a social worker/coordinator, community worker, and a second nurse midwife leading informal discussions with young women aged under 20.

There was no significant difference found between the Teen clinic and comparison (before) group for incidence of pre-term birth (4% vs. 6%), however incidence of neonatal complications (birthweight <2500g, Apgar <5 at one and/or five minutes) was significantly reduced following establishment of the Teen clinic ( $p < 0.05$   $df = 103$ ) and there was also a higher percentage of women breastfeeding at postnatal checkup (45% vs. 28%,  $p < 0.01$ ,  $df = 103$ ) (timing of this check-up not reported).

A recent prospective observational study from Brazil, state of Sao Paulo (2008)<sup>154</sup> [EL=3] investigated the impact of an Integral Care for Pregnant Adolescent programme (ICPA) on the health of 50 young mothers and their children.

Parallel with antenatal care, participants in ICPA programme with their family were invited to a series of meetings with a team consisted of a paediatrician, social worker, psychologist, and physiotherapist. Participants were provided with information about self esteem, baby care, breast feeding, prevention of repeat pregnancy; and were encouraged to resume or carry on with study and training for a profession.

After the birth of baby, a follow up of the mother and child were carried out at the paediatric outpatient unit of the same institution on a monthly basis for the first year, every 3 months in the second year, and every 6 months from the third year onward. The low rate of pregnancy recurrence (2%) among young women aged under 20 after an average follow up of 33 months in ICPA, proved much lower than the 22.9% rate found in the state of Sao Paulo. Fifty percent of infants were given exclusively mother's milk up to sixth months of age. The prevalence of exclusive breast feeding for the first six months of age was greater in the sample studied  $p < 0.05$  compared with state of Sao Paulo and to Brazil as a whole. It is not possible to determine whether these positive changes were due mainly to antenatal input or the postnatal component of the programme however, or a combination of both.

A retrospective cohort study (1978)<sup>155</sup> [EL=2-] was conducted in the US (New York) to determine if differences existed in obstetric, paediatric and psychological outcomes of pregnant young women aged under 20 who participated in RAMP (Rochester Adolescent Maternity Project  $n = 46$ ) compared with those cared for in a traditional obstetric clinic ( $n = 64$ ) and in a neighbourhood health centre ( $n = 38$ ).

Care in RAMP was provided by a team of four physicians, an obstetrics nurse, a social worker and a psychologist. In addition to usual antenatal care, pregnant young women also received a series of group discussions early in pregnancy and antenatal classes in the last two months of their pregnancies. Women were seen every two weeks until 36 weeks gestation and then weekly thereafter. The clinic was held during early evening hours after adult clinics had closed. Postnatal visits were scheduled at 3 weeks, 6 weeks, 6 months and then every 6 months thereafter. Care at the traditional hospital clinic was provided by rotating house staff. A social worker was available on referral. No antenatal classes were offered. Women were seen once a month until 32 weeks gestation, every 2 weeks until 36 weeks and then weekly. Postnatal visits were scheduled at 6 weeks and then yearly. Care in neighbourhood health centre was provided by a team consisting of physicians, a community health nurse, and health assistants. A social worker was not available but the community health nurse worked with families with social problems. Weekly antenatal classes were offered to women of all ages and young women aged under 20 were invited to participate. Women were seen monthly until 28 weeks gestation, every 2 weeks until 36 weeks then weekly. Postnatal visits were scheduled at 6 weeks, 12 weeks, 6 months and then every 6 months thereafter.

Over 70% of women in each group had initiated antenatal care prior to their 20th week of pregnancy. Uptake of postnatal contraception after one year in the RAMP group was 59% compared with 25% of the Hospital Clinic group and 45% of the Health Centre group ( $p = 0.001$ ). No significant differences were found for incidence of low birth weight (<2500g) observed in the three groups. Over 95% of infants in all

three groups had Apgar scores of 6 or more at 5 minutes after birth. A significant difference was reported for rate of anaemia in the three groups (RAMP 2.2%, Hospital Clinic 20.3% and Health Centre 23.7%,  $p=0.004$ ).

A US observational study (1994) compared outcomes for young women ( $n=120$ ) attending the Teens Obstetrics Perinatal Parenting Service (TOPPS) with outcomes for young women aged under 20 reported for the state of Arkansas<sup>113</sup> [EL=3]. TOPPS comprised an interdisciplinary team that provided services for pregnant young women aged under 20, providing nutritional counselling and making appropriate referral as needed (i.e. WIC, AFDC, Medicaid, etc.). The percentage of young women with babies born weighing between 1500 and 2500g was slightly higher in the TOPPS sample compared with the state sample, 2.1% vs. 1.8%.

### *School-based antenatal services*

Three studies compared comprehensive antenatal care for young women aged under 20 provided in school with care provided in hospital or medical centres based clinics.<sup>116-118</sup> All of these studies were undertaken in urban settings in the US and have been described in section 6.2 above.

In the earliest of these studies (data collection 1973-1976)<sup>116</sup> outcomes of a small group of young women aged under 20 enrolled in a public high school where a comprehensive programme of antenatal care was provided on site were compared to a random sample of young women aged under 20 who received their care at a non-school hospital-based clinic [EL=2-]. There was no statistically significant difference for clinical outcomes measured, including birthweight, between the 2 groups. A second study was then undertaken with the same populations (data collection 1976-1979) following enhancement of care provided at hospital-based clinics<sup>117</sup> [EL=2-]. In the school group findings showed a higher incidence of caesarean births (23% vs. 13%,  $p<0.05$ ) and neonatal hospital stay longer than 4 days (32% vs. 17%) for young women cared for in the hospital-based group. It is not possible to tell whether this difference is attributable to differences in antenatal care received. There was no significant difference between babies born to women in each group regarding birthweight and gestation.

A later US study (data collection 1995-1996) compared a school-based and a hospital-based comprehensive adolescent parenting programme (CAPP)<sup>118</sup> [EL=2-]. This programme was similar to those reported in the studies above. Young women aged under 20 in the school-based group were significantly younger than those in the hospital-based group (15.1 years vs. 16.2 years), and had a significantly lower reported incidence of sexually transmitted infections (STIs) prior to pregnancy (41% vs. 58%). Both groups had a very high proportion of African-American women (90% and 97%). The mean birthweight of babies born to young women in the school-based group was statistically and clinically significantly higher than those in the hospital-based group (3225g vs. 3050g,  $p=0.006$ ). The incidence of low birthweight babies was lower for young women cared for in the school-based service than for those cared for in the hospital-based service (5% vs. 12%,  $p=0.06$ ). The authors also investigated the comprehensiveness of the care received in the 2 different settings, looking at screening, counselling and care provided in relation to: nutrition; condom use/sexual health advice; substance misuse (including cigarette smoking); depression/suicide; physical and sexual abuse; school problems and pregnancy complications. Young women in the school-based programme were found to be significantly more likely to have received comprehensive care as defined by a composite score based on these issues, compared to those in the hospital-based programme. Adequacy of care was defined in terms of gestation and booking and number of consultations received. Using logistic regression analysis controlling for confounding variables the authors found that comprehensiveness of care was contributing more to the differences in outcomes noted between the 2 models than was adequacy of care.

Two further US urban-based observational studies investigated the effects of school-based antenatal programmes on pregnancy outcomes.<sup>135;156</sup> Both school programmes included attendance at a specialist school for pregnant young women aged under 20.

An evaluation of a specialised school for pregnant young women aged under 20 compared outcomes for those attending the school in Kansas with a matched group in the same city but not attending the school<sup>135</sup> [EL=3]. As well as the usual school curriculum, education was given in life skills, childcare and breastfeeding. School transportation, breakfast and lunch were provided plus infant day-care for the first 6 weeks of life. Antenatal care provision was at the young woman's own choice, including an on-site nurse-midwife clinic. If another clinic/obstetrician was chosen, transport was provided. There was a significant reduction in the incidence of low birth weight for babies born to young women attending the specialist school (11.7% vs. 15.8%;  $p=0.048$ ) and cigarette smoking (4.7% vs. 9.5%;  $p=0.003$ ). No difference

was noted for other outcomes studies including gestational age, neonatal complications or repeat birth within 2 years.

A second US study evaluated the effectiveness of the Children and Adolescent Pregnancy Project (CAPP)<sup>156</sup> [EL=3]. The study included pregnant girls and young women aged 11-19 years with mild learning disabilities (n=98) and pregnant girls aged 11-15 years (n=228). Participants enrolled in a specialised school received a special education curriculum, additional antenatal care, postnatal classes and training in decision making skills. Comparison was with local and national statistics taken from Chicago, Illinois and United States figures for 1985. Incidence of low birth weight and infant mortality rate was similar for CAPP compared with local and national statistics. The incidence of repeat pregnancy rate within 18 months for girls/young women enrolled in the CAPP was approximately half that reported in official statistics.

## **Evidence statement**

### *Multi-faceted social support interventions*

Evidence of varying quality from a systematic review of 13 studies plus 8 additional studies yielded conflicting findings regarding the effectiveness of multi-faceted social support interventions on improving health-related pregnancy and birth outcomes. Whilst some studies show improved outcomes, a similar proportion do not show such benefit. Seven studies reported a significant reduction in incidence of low birth weight babies. Despite the interventions evaluated often being complex and intensive, the benefits reported are often modest. It is not clear what contribution particular elements of these complex programmes lead to the improvements reported, including the role of home visiting.

### *Comprehensive dedicated antenatal care*

Findings from a multicentre prospective cohort study and one small UK descriptive study show a reduction in pre-term birth to young women aged under 20 attending a comprehensive dedicated antenatal care programme. A second UK descriptive study and a retrospective cohort US study did not find a reduction in the incidence of pre-term birth but did report a reduction in low birth weight babies born to young women enrolled in a dedicated comprehensive care programme. A retrospective cohort study reported a significant reduction in low birthweight and Apgar score less than 5 at one or five minutes among babies born to young women aged under 20 enrolled in a comprehensive antenatal programme compared with a group cared for at the same hospital prior to establishment of the programme for young women aged under 20.

Three further retrospective cohort studies did not find any significant differences in birth outcomes for women cared for in a dedicated comprehensive antenatal service for young women aged under 20 compared with women receiving standard care.

One retrospective cohort study found young women aged under 20 attending a comprehensive dedicated service had a significantly lower incidence of anaemia compared with those receiving standard care.

One retrospective study and one prospective observational study found an increase in breastfeeding rates for young women aged under 20 attending a comprehensive dedicated antenatal programme, although both programmes also contained a postnatal follow-up component which would probably also influence this finding.

Two retrospective cohort studies and a prospective observational study also found a decrease in the rate of repeat pregnancy amongst young women aged under 20 cared for in a comprehensive dedicated programme, and a second retrospective cohort study found an increase in reported uptake of postnatal contraception by young women attending a comprehensive dedicated service. Again the part played by the postnatal component of such services is unclear although likely to be important.

An observational study of an intervention aimed at improving nutrition of pregnant young women aged under 20 and reducing low birthweight found a slightly higher percentage of low birthweight babies born to young women attending the service compared with state data for young women aged under 20.

### *School-based antenatal services:*

Findings from five evaluations of school-based antenatal care are conflicting. Two retrospective cohort studies showed no differences in terms of neonatal outcomes between a school-based and hospital-based programme, although one study found a higher rate of caesarean birth and longer neonatal stay associated with hospital-based care. Third retrospective cohort study found improved neonatal outcomes (mean birthweight and incidence of low birthweight) associated with a comprehensive school-based

service which was attributed to comprehensiveness of care given rather than adequacy of care (gestation at booking and number of visits attended), both of which were significantly higher for the school-based group. Findings from two US observational studies were also conflicting with one showing a significant reduction in low birth weight babies born to young women enrolled in the specialist school programme and the other showing no such reduction compared to US state figures.

### **GDG interpretation of evidence**

The research studies provided inconclusive evidence to answer this question, although there are a number of studies which suggest a benefit there are a similar number which show little or no benefit (although none demonstrate harm). Most of the studies shared similar characteristics, offering a mix of the following: antenatal care, benefits advice, education on health (often including nutrition) and child care issues, counselling, home visiting, a one-to-one relationship with a key worker, a case manager to co-ordinate input from a range of agencies, opportunity to form friendships, opportunity to continue with education, transport to appointments, different settings for the antenatal appointments, a positive approach, and material/financial incentives to attend. Most of the studies were conducted in the US, and caution is necessary in interpreting their applicability to UK.

Although the studies provided comprehensive, multi-disciplinary support, they differed in their setting, and the relative level of support that was provided by midwives, other health care professionals, professionals from other disciplines, administrators, and trained volunteers. The programmes also differed in their sample characteristics, e.g. white, black or Hispanic women, very young girls or older young women, or women with mild mental retardation.

It was difficult to pinpoint which particular aspects of an intervention had a positive impact as studies which adopted similar interventions did not show similar results. On two occasions, the positive effects found in small pilot studies were not replicated when the interventions were adopted on a larger scale. Whilst some of the programmes targeted at pregnant women under 20 had a positive impact on some birth outcomes, e.g. birth weight, gestational age at birth, and neonatal complications, other similar programmes did not show a significant effect. It also needs to be remembered that the pregnant women under 20 in the targeted programme may be a self-selected group, who are more motivated from the start and hence more likely to have positive birth outcomes.

Because of the poor quality of a number of the studies, it was not possible to discern from the evidence any particular aspect of the interventions which consistently led to significantly positive outcomes. However, findings from one retrospective US cohort study suggested that improved outcomes from a comprehensive school-based service were more attributable to the comprehensiveness of care provided (screening, counselling and clinical care) than to adequacy of care (gestation at booking and number of visits). The GDG again underlined the importance of providing good "basic" antenatal care as outlined in NICE Guideline "Antenatal Care: routine care for the healthy pregnant woman"<sup>1</sup>.

The GDG noted that some of the programmes may have other positive side-effects, for example in areas such as breast-feeding, cigarette smoking, unplanned repeat pregnancy, access to state benefits, sexual health screening, mental health services, social services, and other health-related services. However, these were not the primary outcomes that the group were considering. In addition, these positive effects were not found consistently across the studies, and in some cases it was not possible to determine whether these benefits were brought about through the antenatal component of an intervention or the postnatal component. Indeed it might be that both are important when provided together as part of the same service.

None of the reviewed evidence mentioned what additional consultations and support might be needed by women's partners and/or families. The GDG's experience and opinion on this matter varied and they decided not to make a recommendation. A general research recommendation has been made looking at what information is needed by partners and families of women with complex social factors.

In considering the evidence, the GDG noted that there were not any longitudinal studies to evaluate the impact of targeted maternity care programmes on long term health and well-being of mothers under 20 and their children, although two US studies (evaluation of the "RAMP" project and "the Corner" project) did investigate repeat pregnancy up to 24 months. The GDG took the view that the long term health and well-being outcomes were important considerations and probably economically beneficial, although they were difficult to quantify and fit into any existing health economics model.

Given that the programmes included in the evidence were complex, difficult to link conclusively to specific and measurable birth outcomes, and included some very costly interventions, the GDG did not recommend the adoption of any particular model for providing a maternity service to vulnerable pregnant women under 20. However, the GDG took the view that commissioners should take into account the specific needs of the under-20 pregnant women in their area and the barriers they face in accessing care, and provide a targeted maternity service incorporating aspects of the intervention programmes which have been included in the evidence. A recommendation has been made to ensure local populations are surveyed in order to ascertain their demographic make-up so that services can be appropriately targeted. In addition, due to the lack of UK evidence of effectiveness of models of service provision the GDG made an overarching recommendation that pregnancy outcome data should be collected and compared for women in vulnerable groups in relation to gestation at booking and proportion of antenatal consultations attended.

Since many of the assumptions made within the health economics model have little data to support them the GDG felt it more appropriate to recommend specific components of service provision which they felt would bring the most benefit as supported by the evidence, and which they believed from experience, and from the service descriptions obtained through the guideline survey, would be achievable within the NHS. Given the assumptions made in the health economics model the additional support recommended and provision of a specialist midwife would be cost-effective. An example of a services which illustrates how some of the recommendations can be put into practice are detailed in Box 6.1 and in Appendix D, number 10.

In order to optimise the use of existing resources and to meet, in a holistic way, the health and well-being needs of pregnant women under 20 and their babies, the GDG also took the view that commissioners should work in close partnership with other agencies, e.g. social care and education as seen in the evidence reviewed. Specifically multi-agency needs assessment should be carried out, e.g. using the Common Assessment Framework where appropriate. Recommendations were made to reflect this belief. Where there are concerns that a young woman aged under 18 may be experiencing maltreatment appropriate action should be taken as recommended in the NICE guideline "When to suspect child maltreatment" (CG89).

See section 6.8 (page 110) for recommendations.

## 6.6 Additional information

### Clinical question

Q4. What additional information should be provided to young women aged under 20, their partners and families in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline)

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. In order to be considered for inclusion the study had to have an outcome relating to uptake of antenatal care, neonatal outcomes or maternal outcomes. Thirteen papers were considered for this question. Three studies evaluating specific antenatal classes/education were included in the review following quality appraisal. The three included papers were comparative studies, but not randomised [all EL=2-]. Two studies used an historical control group, and the other used a control group from another county. All studies were conducted in the US.

### Narrative summary of evidence

A US prospective descriptive study investigated the effects of providing antenatal lessons to pregnant young women attending community antenatal clinics using trained non-professional volunteer women<sup>128</sup> [EL=3]. The extensive educational programme of 17 lessons was designed to address a multicultural

population of young women aged under 20. Course content included: preparing for labour, course of labour, care of a new baby and family planning.

Lessons included an audiovisual presentation and a manual was also provided to each participant. Lessons were provided by volunteers trained by qualified personnel from sponsor agencies and certified as instructors by the American Red Cross. After each 3-hour class, each participant received a layette item or small personal gift worth ~\$2. After completing an 8-lesson agreement, participants received a certificate, small personal gift and ticket to be exchanged at postpartum visit for a layette worth ~\$15. Labour and birth outcomes were similar for all three groups. One significant difference was reported – gestational age at birth, although all group means represent term births (>8 lessons attended  $39.63 \pm 1.15$ ; <8 lessons attended  $39.45 \pm 1.27$ ; No lessons attended  $38.86 \pm 2.68$ ; ( $p < 0.006$ ; analysis of variance)).

A prospective cohort study compared knowledge and medical outcomes of two groups of young women aged under 20 at two health centres in the Mississippi delta region of southern Illinois<sup>157</sup> [EL=2-]. Participants were assigned to groups based on county of residence to avoid 'contaminating' the groups, 113 in the study group, and 99 in the control group. The groups differed significantly in race mix, with the control group having a larger African-American population (39.4% vs. 16.8%).

All young women received usual antenatal care in health clinics. The study group also carried out a self-administered programme of 8 educational modules while they waited to see the physician. The modules covered topics such as drug and alcohol use during pregnancy, and women's health and nutrition.

The study group had a statistically significantly higher pre-test knowledge compared to the control group. Both groups' average post-test scores were higher, on average 18.58 in the study group, and 16.58 in the control group. A higher percentage of the study group had 'quite reduced' or 'reduced' drug use in the last 5 months (47.6% vs. 29.5%). The post-test medical outcomes were statistically significantly improved for the study group for diabetes ( $p=0.0402$ ), anaemia ( $p=0.0010$ ), and incidence of sexually transmitted diseases ( $p=0.0401$ ). For all other medical outcomes reported the differences were not statistically significant.

Another US retrospective cohort study was undertaken to determine if specific breast feeding education, provided by a lactation consultant in group classes for pregnant young women aged under 20, would increase breastfeeding initiation among students enrolled in a high school pregnancy programme for young women aged under 20<sup>158</sup> [EL=2-]. All study participants received their primary education from the same teacher, attended the same school, and were taught in the same classroom. The majority of the sample (63%) was Caucasian, with the remaining split between African American (26%) and Hispanic (11%).

The comparison group consisted of 48 pregnant students aged 14 to 19 who attended the dedicated pregnancy programme with limited breast feeding preparation during the 1995-1996 school years. Forty-three students who attended the same programme with the addition of 3 comprehensive breast feeding education sessions called the BEST Club during the 1996-1997 school year served as a study group. The BEST club (Breast feeding Educated and Supported Team) offered a fun way of teaching pregnant young women about breastfeeding. The programme consisted of 3 weekly 1-hour sessions on child birth preparation, CPR, infant care, and a series of parenting classes provided by a lactation consultant and a peer counsellor that integrated herself within the group to provide support and encouragement.

Students in the study group had postnatal breastfeeding support from a peer counsellor on their return to school two weeks after giving birth. The counsellor provided weekly in person support and telephone counselling on an as-needed basis. All breastfeeding mothers were followed until they chose to wean or until their babies were 6 months of age.

Rate of breast feeding initiation was significantly lower in the comparison group compared with the study group (14.6% ( $n=7$ ) vs. 65.1% ( $n=28$ )  $p < 0.001$ ). In logistic regression analyses race and age was not significantly related to breast feeding initiation. No data were collected that monitored breastfeeding duration.

### **Evidence statement**

A US retrospective descriptive study of an extensive antenatal education programme for young women aged under 20 showed no clinically significant difference in reported labour, birth and neonatal outcomes for young women attending the majority of lessons compared with those who attended fewer or no

classes. There was a statistical difference seen in gestation at birth when women who attended most classes, fewer classes and no classes were compared, although all groups gave birth to term babies.

A prospective cohort study of self-administered drug and alcohol education for young women aged under 20 found an increase in knowledge and a higher percentage of young women aged under 20 reporting a 'quite reduced or reduced' level of drug use in those who took the course. Although improved medical outcomes were reported for the study group there was a statistically significant difference in the race mix of the groups, as well as pre-test knowledge, which might indicate important underlying differences between the groups.

A retrospective cohort study of breastfeeding education found that young women aged under 20 who received a comprehensive antenatal education programme which included an enhanced breastfeeding component were significantly more likely to initiate breastfeeding than those who received the antenatal programme without the enhanced breastfeeding component.

### **GDG interpretation of evidence**

The GDG noted that although the first study showed a significant difference in gestational age at birth between the three groups, all groups gave birth at term. Whilst there was a statistical difference between the groups, it did not lead to a significant clinical difference.

With the second paper, the group noted that although a positive effect was observed with more young women under 20 showing an increase in knowledge and a reported reduction in drug use, there were statistically significant differences between the control and intervention groups in terms of their pre-test knowledge and ethnicity. As it was not clear that these variables had been controlled for, the group felt that it was not possible to discern whether the positive effect shown was due to the intervention or a confounding factor.

With the third paper, the group noted that the outcome of "initiation of breastfeeding" was not a useful one as it could simply mean breastfeeding at hospital. They felt that it would have been more valuable to know if the breastfeeding was maintained 2 weeks postpartum.

Additionally, the group noted that all three studies were conducted in the US and that therefore, their applicability to the UK setting may be limited. Disappointingly, there was no evidence to suggest what additional information should be provided to partners and families of young women under 20, the GDG felt, therefore, that it was not possible to make recommendations for this group. A research recommendation was made looking at what information is needed by partners and families of vulnerable women.

Overall, the group felt that the evidence for this section was not very useful in forming recommendations and therefore looked for examples of good practice to supplement the documented evidence.

The group noted that there are already recommendations included in the NICE Guideline Antenatal Care: routine care for the healthy pregnant woman<sup>1</sup> regarding information giving and so considered whether there were any additional recommendations they could make, specifically relevant to the population of young women aged under 20. The group agreed that from their own experience, an effective way of providing information was by offering classes in innovative settings that are more accessible than attending a clinic. More generally, they agreed that information provided to young women aged under 20 should be age-appropriate and include details of locally provided antenatal peer group education or drop-in centres, benefits that they might be entitled to, and care services provided for young women aged under 20. They agreed that this information should be provided in a variety of formats including leaflets about pregnancy specifically written for young women that could be made available in a variety of settings. An innovative example of how information can be provided in an attractive way is given in Appendix D number 12. Although this Information Wheel has been designed specifically to provide contact details of organisations in one local area and with specific vulnerable groups, it could be adapted to suit the needs of any vulnerable group in any given area including local information.

See section 6.8 (page 110) for recommendations.

## 6.7 Health Economics Considerations

A new health economic model was developed for this guideline with the specific aim of assessing the cost-effectiveness of additional care versus normal antenatal care services. The analysis was based on descriptions of services that are currently provided across the UK. It was assumed that any specialist service will be over and above routine antenatal care as described in Antenatal care: routine care for the healthy pregnant woman.<sup>1</sup> Therefore it is not assumed that a specialist service provides routine antenatal care but instead provides additional support to pregnant women and indirect support to midwives providing their care.

The clinical review of the evidence did not identify any useful studies that reported the effectiveness of a specialist antenatal care intervention in terms of health gains for either the mother or the baby. However, an underlying assumption of the guideline is that antenatal care is beneficial (see introductory chapter). Therefore it was assumed for the purpose of modelling that any woman who books early (before 12 weeks) and maintains contact will have better health outcomes for herself and her baby than late bookers and non-attenders.

Assuming that 7% of maternities are to young women aged under 20 (n=47,810). Each service will see approximately 315 young women a year based on the 152 PCTs in England and Wales.

As no effectiveness data were available the specialist service is considered to be equally as effective as standard antenatal care. It was assumed that women who book before 12 weeks and stay in antenatal care would be 80% likely to have a full-term birth. Women who book in this time are assumed to have a maternal mortality rate of 9.9 per 100,000 maternities.

For women who book late or do not book it was assumed that they would be 70% likely to have a full-term birth. The maternal mortality rate for this group was assumed to be the same as for early bookers.

It has been assumed that the only benefit of the specialist service is by increasing the number of women who book before 12 weeks. Using the evidence from a study comparing school based antenatal care to hospital based care<sup>116</sup>, in the group using the school-based service 58.5% of women had their booking visit in the first trimester, and in the group using the hospital based service 45.4% had booked in the first trimester of pregnancy. Therefore it has been assumed that 45% of women will book before 12 weeks when only standard antenatal care is provided, this is approximately 142 women out of the 315 seen by each PCT.

The economic analysis considered different scenarios for specialist models of antenatal care, each with a different estimated cost. The comparison was always standard antenatal care as defined by the NICE Antenatal Care guideline 2008<sup>1</sup> For each type of service, the model estimated the minimum additional number of women who would need to be booked and maintain contact with the service in order for it to be cost-effective at the £20,000 per QALY threshold.

If the assumptions above hold true then a specialist service costing £25,000 provided in addition to standard antenatal care would need to book 3 more women per year (145 vs. 142 women) by 12 weeks gestation in order for the service to be considered cost-effective. (Table 8.7) This is equivalent to a part-time dedicated midwife service.

For a £150,000 service 15 more women would need to be booked early and stay in antenatal care than are booked with the standard care alone. This is equivalent to a service with a full-time midwife, a part-time nurse and nursery officer, and a part-time manager and administrator.

For a £250,000 service 28 more women would need to be booked early. This is equivalent to 4 specialist midwives, a part-time consultant midwife to manage the service, and a part-time administrator.

The results of the analyses demonstrated that an additional service could be considered cost-effective if it was able to book more women in the first trimester and maintain contact than if only routine antenatal care was provided. The number of women needed to book early to make a service cost-effective varies depending on the cost of the service provided. The full results of the analyses are reported in chapter 8.

This analysis supports the recommendations for providing age-appropriate services in the community. The additional costs of providing antenatal care in a variety of settings specifically for young women, allowing longer appointments, and in ensuring a named midwife is able to provide continuity of care are likely to be cost-effective if providing these additional services increases early booking and maintains

access to care. These services should be audited to allow evaluation of both the clinical and cost-effectiveness.

## 6.8 Recommendations

Healthcare professionals should encourage young women aged under 20 to use antenatal care services by:

- offering age-appropriate services
- being aware that the young woman may be dealing with other social problems
- offering practical help with transportation to and from appointments
- offering antenatal care for young women in the community
- providing opportunities for the partner/father of the baby to be involved in the young woman's antenatal care, with her agreement

### Service organisation

Commissioners should work in partnership with local education authorities and third-sector agencies to improve access to and continuing contact with antenatal care services for young women aged under 20.

Commissioners should consider commissioning a specialist antenatal service for young women aged under 20, using a flexible model of care tailored to the needs of the local population. Components may include:

- antenatal care and education in peer groups in a variety of settings, such as GP surgeries, children's centres and schools
- antenatal education in peer groups offered at the same time as antenatal appointments and at the same location, such as a 'one-stop shop' on a Saturday

Offer the young woman aged under 20 a named midwife who should take responsibility for and provide the majority of her antenatal care and include a direct-line telephone number for the named midwife.

### Training for healthcare staff

Healthcare professionals should be given training to ensure they are knowledgeable about safeguarding responsibilities for both the young woman and her unborn baby, and the most recent government guidance on consent for examination or treatment.\*

### Information and support for women

Offer young women aged under 20 information that is suitable for their age - including information about care services, antenatal peer group education or drop-in sessions, housing and other benefits - in a variety of formats, including leaflets.

## Research Recommendations

Which components of a specialist service for young women aged under 20 are effective at improving outcomes?

What additional information would young women aged under 20 like to receive when attending antenatal appointments?

What is the evidence that age-specific antenatal education improves outcomes for young women aged under 20?

\* Department of Health 2009 Reference guide to consent for examination or treatment (second edition). London: Department of Health Available from [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_103643](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103643)

### **Box 6.1** Example of a service for young women aged under 20

Brighton and Mid-Sussex employs a midwife for young women aged under 19 (known as the "teenage pregnancy midwife") at time of giving birth. There are two clinics dedicated to young pregnant women, one in an area where there is a high rate of pregnancy in young women under 19 and one at a city centre children's centre. The latter has proved to be a good location for antenatal education groups as most women find it easy to get there. The clinic runs at the same time as the antenatal class. Antenatal classes are held weekly as drop-in sessions, and lunch and bus fare are provided.

The teenage pregnancy midwife can be contacted by phone or text for advice 7 days a week from 8am to 8pm.

Young women aged under 19 are not routinely referred to obstetricians; age is not considered a reason for referral. There are no obstetricians who specialise in working with this group.

In addition to the standard care set out in the NICE Antenatal Care guideline the teenage pregnancy midwife provides on average 3 to 4 extra visits as required by the woman or if the midwife feels they are needed. These additional visits are done at home or in a clinic.

If someone is not engaging with the service the teenage pregnancy midwife will follow them up. This may be because the young woman has moved address and doesn't know how to access the local clinic, sometimes it's because there are other issues in their life preventing them coming to clinic. Texts are used to remind women of appointments and to re-arrange missed appointments. (Appendix D, number 10)

# 7 Women who experience domestic abuse

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## 7.1 Introduction

The government defines domestic violence as: 'any incident of threatening behaviour, violence or abuse (psychological, physical, sexual, financial or emotional) between adults who are or have been intimate partners or family members, regardless of gender or sexuality'<sup>15</sup> This includes issues such as 'honour based violence', female genital mutilation and forced marriages. It also includes being denied access to healthcare by a partner or family member. The GDG felt it appropriate to use the term "domestic abuse" rather than "domestic violence" in this guideline as they felt that the former better captures the idea that abuse can take a number of forms and does not solely consist of physical violence. For all questions in this chapter the term "domestic violence" is used where this was the term used in the reviewed paper. It is not usually possible to determine whether this term is usually being used to mean all forms of domestic abuse or just physical violence, although it appears the former is more often the case.

A study from Northern Ireland reported that 60% of women residing in a refuge experienced violence during pregnancy and of these 13% lost their babies as a result of continued abuse.<sup>159</sup> This study also showed that women attending accident and emergency departments with physical injuries owing to domestic violence are more likely to be pregnant than women attending with accidental injuries.<sup>159</sup> Amongst a group of pregnant women attending primary care in East London, 15% reported violence during their pregnancy; of which just under 40% reported that violence started whilst they were pregnant, whilst 30% of those who reported violence during pregnancy also reported they had at sometime suffered a miscarriage as a result.<sup>160</sup> Between 2003 and 2005, of the 295 maternal deaths reported in *Saving Mothers' Lives*, 70 occurred in women who had features of domestic abuse (24%), and of these women, 19 were murdered.<sup>3</sup>

The impact of domestic abuse in pregnancy can be physical; including miscarriage<sup>161</sup>, low birth weight, placental separation, foetal fractures, rupture of uterus, pre-term labour, long lasting physical disability; and/or psychological including depression, anxiety, post traumatic stress disorder, flashbacks, nightmares or an exaggerated startle response.<sup>162</sup> A US study found a significant relationship between pregnancy, domestic violence and suicide. They also found that women who have experienced abuse are:

- 5 times more likely to attempt suicide
- 3 times more likely to be diagnosed as depressed or psychotic
- 15 times more likely to misuse alcohol
- 9 times more likely to misuse drugs<sup>163</sup>

Recognising that many cases of domestic abuse start during pregnancy, the department of health set up the Domestic Abuse and Pregnancy Advisory Group in 2005. Its recommendations on how health services could meet the needs of pregnant women who are experiencing abuse are documented in *Responding to domestic abuse: a handbook for health professionals* (2005).<sup>15</sup> The Advisory Group recommended that maternity units move towards universal screening of pregnant women for domestic abuse, recognising that staff training would need to be a prerequisite for this.

Routine enquiry about domestic violence in maternity settings is accepted by women, provided it is conducted in a safe confidential environment. A pilot project in Leeds found that 92% of women questioned were in favour of routine enquiry.<sup>164;165</sup>

Women may disclose domestic abuse to their midwife or other healthcare professional during antenatal care with an expectation that they will receive information and support as a result. The aim of providing information is to give women choices about how to protect themselves and their children and where to go for help. It is also important that those giving the information are trained to do so and consider the safety of the woman and her children as part of the process.

This current guideline focuses on the care of women who are experiencing domestic abuse and does not address the issue of universal screening, thus studies investigating screening for domestic abuse were excluded. Please see the NICE Antenatal Care guideline (CG62, 2008) for evidence and recommendations relating to screening for domestic abuse. The population of interest for the reviews included in this chapter is women who have disclosed domestic abuse or who are strongly suspected to be experiencing domestic abuse.

## 7.2 Access to antenatal services

### Clinical question

Q1a. What aspects of service organisation and delivery are effective at improving access to antenatal services for women experiencing domestic abuse?

### Previous guidance

No previous NICE guidelines have addressed access to and uptake of antenatal services by women who are victims of domestic abuse. The NICE Antenatal Care guideline (2008) recommends the following:

“Healthcare professionals need to be alert to the symptoms or signs of domestic violence and women should be given the opportunity to disclose domestic violence in an environment in which they feel secure.” (1.5.5.1)<sup>1</sup>

Despite attending for antenatal appointments women who are experiencing domestic abuse will not access the care and support they need unless the health care professional provides an environment in which the woman feels safe and able to discuss her situation openly. For this reason studies were included that investigated issues surrounding how to communicate effectively with women experiencing or suspected to be experiencing domestic abuse.

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Comparative studies have been included which demonstrate differences in outcomes between study groups, or before and after an intervention or change in service provision. For this population the definition of access was broadened to reflect the emerging concept of cognitive access to care i.e. access to additional consultations, information and support (as discussed in chapter 3). Since the searching had been carried out using a sensitive search strategy based on population and antenatal care provision generally, this expanded definition of access was captured by the search. Interventions considered thus included not only those aimed at improving access in terms of physical attendance for care, but also those that could impact upon women’s access to additional information and support. The primary outcome of interest remained gestation at antenatal booking. Secondary outcomes included access to antenatal education and additional support services for women experiencing domestic abuse. Of the 14 studies retrieved for potential for inclusion in this review none addressed the issue of access to antenatal care nor reported gestation at booking. Studies reporting training for staff providing care for women who are victims of domestic abuse were also considered as interventions which improve staff awareness, confidence, skills and attitudes can be seen as potentially improving access to services for these women. Of the 14 studies considered, two are included in the review, one from the US and one from Australia. Neither of these studies investigated interventions to improve access to antenatal care in terms of earlier booking but rather looked at the effectiveness of education and training interventions for staff to improve communication with women experiencing domestic abuse. The intention was that this improved communication would facilitate discussion with women experiencing or suspected to be experiencing domestic abuse and thus enable appropriate support to be provided.

### Narrative summary of evidence

### Education and training of professionals

An Australian study (2006)<sup>166</sup> [EL=2-] evaluated the effects of a 6-month educational intervention programme (1-2 hours per week) for midwives and doctors in advanced communication skills and psychosocial issues such as domestic abuse. The educational programme comprised an introductory session and 5 workshops including opportunities to identify strengths and weaknesses, role-play to practise skills, and training in active listening and picking up cues from women more effectively. Twenty-two midwives and 5 residents consented to participate in the before and after survey which covered issues such as perceived competency and comfort in dealing with psychosocial issues, self-rated communication skills, and an open-ended question about their perceptions of the participants' experience of the educational programme. Results of the survey indicated that after the educational intervention midwives and doctors were more likely to ask directly about domestic abuse compared with before attending the additional training ( $p=0.05$ ), and less likely to report that psychosocial issues made them feel overwhelmed ( $p=0.01$ ). They also reported significant gains in their knowledge of psychosocial issues and competence in dealing with them.

In a US study (2004)<sup>167</sup>, [EL=2-] the effect of an intimate partner violence (IPV) education programme on the attitude of nurses was examined using a pre-test and post-test design. All nurses of an urban health system were required to attend a 1-hour mandatory curriculum and nurses in obstetrics were encouraged to attend an extended 3-hour long session.

All sessions included presentations describing dynamics of domestic abuse, mandatory state reporting laws, proper documentation and screening techniques, and nursing interventions, as well as information about available community resources. Results showed a significant change in attitude scores of the nurses after attending the 1 hour session if they had received previous IPV education (for example education received in a previous post) (pre-test score (mean (SD)): 62.6 (2.5) vs. 72.4 (3.4) post test,  $p<0.01$ ) compared to nurses with no previous IPV education whose scores showed a non-significant increase (60.3 (9.2) to 62.2 (6.6)). Nurses with no previous IPV education appeared to get more benefit from the 3-hour session where their attitude score increased from 60.9 (5.7) to 67.3 (8.0) ( $p<0.001$ ). This longer session did not lead to a significant increase in the attitude scores of nurses who had received previous IPV training.

### Evidence statement

No studies were found that investigated interventions aimed at improving access to antenatal services in terms of encouraging early booking.

Findings from two before and after studies show that education and training for health professionals on responding to domestic abuse and how to provide care to women who are victims of domestic abuse are effective in improving staff attitudes. Findings from one of the studies also demonstrated an increase in self-reported staff confidence and perceived competence in dealing with issues relating to domestic abuse.

### GDG interpretation

It was agreed to combine the interpretation for question 1a and 1b due to the related nature of the evidence

## 7.3 Barriers to care

### Clinical question

Q1b. What aspects of service organisation and delivery act as barriers to take up of antenatal services for women experiencing domestic abuse?

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. After weeding, 32 papers were retrieved that answered the question in terms of what the perceived barriers to care are,

either from the woman's point of view or that of service providers. After quality assessment 16 papers were included in the review (5 studies focused on women and 11 studies on health care providers (HCPs).

Of these papers 5 were from the UK, 7 from the US, 2 from Sweden, 1 from Mexico and 1 from Belgium.

Seven studies were qualitative surveys, using either interviews, focus groups or a combination of both as methods of data collection. Eight studies were quantitative surveys using questionnaires. One study used a mix of qualitative and quantitative methods.

The studies had been published between 1997 and 2008 and so some of the information in the papers may now be out of date (however only two studies were published before 2000).

In the studies which focused on women, the groups covered were women victims of domestic abuse past and/or current, although some studies included women who were not victims of abuse for comparison purposes.

In the studies which focused on HCPs the groups covered were mostly midwives but some studies included other HCPs looking after pregnant women (obstetricians and gynaecologists, nurses, family physicians, internal medicine).

### **Narrative summary of evidence**

Please see Evidence Table for study details.

#### **Studies on women**

A qualitative survey conducted in the UK (2002)<sup>33</sup> [EL=3] examined women's perceptions and experiences of routine enquiry for domestic violence in a maternity service. Purposive sampling was used to select a sub-sample from a larger group of women who participated in a domestic violence in pregnancy screening study undertaken at Guy's and St Thomas' Hospitals in London.<sup>36</sup> The study population comprised ten women who had experienced domestic violence in the last 12 months (including during pregnancy), six women who had experienced domestic violence in the last 12 months, but not during pregnancy, and 16 women with no history of domestic violence. Women were assessed for domestic violence by trained midwives at the booking appointment, and follow up at 34 weeks and once during the postpartum period (within 10 days). Assessments were conducted in hospital and community antenatal clinics and women's homes. Semi-structured interviews were conducted in women's homes and general practitioners' surgeries during the postpartum period (up to 14 months) to examine: acceptability and impact of routine enquiry; need for repeat enquiry about domestic violence; perceptions of midwives' responses, who should enquire about domestic violence in pregnancy; use of referral information provided; time constraints; importance of privacy and confidential consulting; time and factors that deter women from disclosing domestic violence.

Women who had experienced domestic abuse identified different reasons to delaying care and concerns about the care provided:

- being asked only at the booking appointment (when violence started much later in pregnancy or women felt apprehensive because they did not trust the midwife) and never being given another opportunity to disclose;
- lack of continuity of care in midwifery practice thus fewer opportunities to provide ongoing support;
- midwife dealt with the domestic violence questions in a very perfunctory manner moving on to a different topic altogether without any acknowledgement of what had just been disclosed;
- midwives did not respond at all and women did not know whether the midwife had any understanding of their situation (because of the tendency for some women to blame themselves for the violence, this non-response was sometimes misinterpreted as confirmation that they were responsible for what was happening, reinforcing feelings of guilt and shame);
- insufficient time during appointments to discuss personal problems in general (most common complaint);
- women felt as if they were being treated like another case rather than a person with individual needs;

- older health professionals preferred to younger ones (not the most important factor);
- not all women experiencing domestic violence were in a position to act immediately on the referral information given to them (did not feel safe and confident enough to do so);
- women felt the questions challenged their ability to care for their children;
- questions triggered painful memories for some women who had left violent relationships and were in the process of re-building their lives;
- in the absence of routine enquiry they would not voluntarily disclose violence to any health professional (most commonly cited reasons: fear of being judged, embarrassment, shame, not knowing how to raise the subject, uncertainty about whether the health professional would be interested or equipped to deal with it, concerns about confidentiality, and fear that their children would be taken away);
- a perception that the primary role of the midwife was to deal with the physical rather than the emotional wellbeing of the pregnant woman and anxiety that their partner would find out that they had spoken to someone (women wanted positive reassurance that what they said would not be relayed to their partner and that they would have a safe, confidential environment in which to discuss the violence).

It should be noted that no data were reported on the researchers' characteristics and how this may have influenced the data collection and analysis.

A qualitative survey conducted in the US (2005)<sup>34</sup> [EL=3] explored how intimate partner abuse during pregnancy influences women's decisions about seeking care and disclosing the domestic abuse, and their preferences for health care professionals' responses. A convenience sample of 12 English-speaking women (age range 18 to 43 years (mean 29.7)) abused by an intimate male partner during the current or previous pregnancy, or postpartum comprised the study population. Five participants were recruited via prenatal clinics and seven via snowball sampling. Twenty-one in-depth, face-to-face interviews were conducted at clinics staffed by certified nurse-midwives, registered nurses and nursing or medical assistants. Women identified different reasons to delaying care and concerns about the care provided:

- a belief that no one, including health care providers, could truly alter the situation or help end the abuse;
- Healthcare Professionals' (HCP) methodical and insensitive manner of screening for abuse or treating women after an abusive episode;
- male HCPs;
- being provided with what was perceived to be inadequate information on domestic abuse and substance abuse or not being screened for abuse, even when signs or symptoms of abuse were obvious;
- thinking their concerns had been minimised or ignored (as a result a woman followed or rejected HCPs' advice depending on how that advice fit with her schema);
- lay pregnancy books failed to provide explicit information about domestic abuse, substance abuse or both;
- most of the women in the community (but not the clinics) considered their HCPs not particularly helpful, sensitive to or aware of the abuse occurring in their lives (this was consistent whether the participant's pregnancy was current, recent or longer than 10 years ago);
- participants interpreted HCPs' lack of abuse screening in the presence of injuries and cavalier treatment of abuse disclosure as a lack of concern and professionalism (this perception influenced subsequent decisions about whether to reveal the abuse to any HCPs);
- participants whose cultural or religious traditions varied from those of dominant US society felt less understood by health professionals;
- potential involvement with and punitive actions by Children's Social Services or other social and legal agencies;

- participants from the clinic frequently reported revealing the abuse at another time but the early or prenatal visit even though they had been screened at that time (this was related to being more comfortable with HCP, partner not being present, or because they needed help) and women also complained that HCPs do not have time to care for them.

Other reasons to delay care identified by the women were:

- direct consequence of the harm caused by the abuse (woman injured by partner and therefore unable to attend or directly prevented from attending by partner)
- loss of medical insurance;
- fear that her partner would find her;
- use of drugs during pregnancy
- not wanting HCPs to find out (fear of disappointing others, the potential for unknown consequences to herself, partner child or family, and lack of awareness of the potential harm to the unborn child were some of the reasons participants gave for concealing their substance abuse);
- not wanting their partners to attend appointments because they feared being embarrassed by them or worried that they might reveal something stigmatising about them such as their use of drugs;
- embarrassment (personal, not related to the partner) as the woman perceived sociocultural expectations associated with pregnancy;
- unable to identify whether they were being abused, particularly if they were only subject to emotional abuse.

It should be noted that no data were reported on the researchers' characteristics and how this may have influenced the data collection and analysis. It was unclear whether/how many women were currently living with the abusing partner and this may have influenced women's willingness to disclose some information.

A case control study (quantitative survey) conducted in Mexico (2008)<sup>168</sup> [EL=3] examined the association between violence, attitudes towards pregnancy, and initiation of antenatal care (ANC) in Mexican pregnant women. Two-hundred and thirty-five pregnant women receiving their first antenatal visit at a university hospital comprised the study population. Cases were women who reported an experience of violence whereas controls were women who did not report an experience of violence. Two instruments previously used in the US were translated and modified for this study. Benefits of prenatal care, barriers to prenatal care and attitudes towards pregnancy were measured using the "Barriers, Motivators and Facilitators of Prenatal care Utilisation" (BMFPNC 2003) questionnaire. This translated version has been previously validated by the authors. Interpersonal violence was measured using the "Woman Abuse Screen" (WAS, 2001). Negative attitudes towards pregnancy were associated with an experience of violence. When negative attitudes towards pregnancy increased, perceptions of barriers increased. Abused women did not feel well about themselves; had more family problems; reported more problems with partner; felt more stress; felt more depressed and reported more personal problems than non-abused women.

A quantitative survey conducted in the USA (1997)<sup>169</sup> [EL=3] determined whether women who had experienced physical violence by their partner were more likely to delay entry into prenatal care than were women who had not experienced physical violence, while assessing for confounders and effect modification. Authors analysed data from the Pregnancy Risk Assessment Monitoring System (PRAMS), initiated in 1988 to help conduct state-specific, population-based surveillance of selected maternal behaviours that occur before and during pregnancy. The study sample comprised 27,836 women surveyed in seven states (Alabama, Alaska, Florida, Oklahoma, Michigan, South Carolina and West Virginia). Socio-demographic variables associated with delay into prenatal care related to domestic violence were obtained from birth certificates (age, education, race, marital status) and the PRAMS questionnaire (pregnancy intendedness, poverty). Time of entry into prenatal care was obtained from birth certificates. Early entry was defined as beginning care during the first 3 months of pregnancy. Data on physical violence came from 1 question in a modified 18-item life-events inventory on the PRAMS questionnaire. The majority of women were at least 20 years of age and had received at least 12 years of education. Almost 70% were married and 75% were white. More than 40% participated in the Social Nutrition

Program for Women Infant and Children (WIC) during pregnancy and 12.1% lived in crowded housing. Fifteen per cent of women entered prenatal care in the second trimester, 2.3% in the third trimester and 0.8% received no prenatal care. Overall prevalence of physical violence among respondents was 4.7%. Women who had experienced physical violence by their partner and delayed entry into prenatal care were more likely to be older, have 12 or more years of education, not to be recipients of Social Nutrition Program for Women Infant and Children, and not living in crowded housing. The association was greatest among women 35 years of age or older and women 25 to 34 years of age. It should be noted that these results may be related to the fact that non-responders (25% of the sample) were more likely than responders to be young, less educated, black or of other race, unmarried and to have entered prenatal care late.

A recent US prospective cross sectional study (2008)<sup>170</sup> [EL=3] was designed to investigate how pregnant and parenting "battered women" participating in an innovating programme perceive their relationship and cope with the violence in their life. The project provided education and support services to pregnant and parenting "battered women", including an aftercare component offering case management, domestic violence and parenting education, and social support to mothers who have been in abusive situations. Fifty-five percent of the participants were Hispanic, 42% were between the ages of 14-19 years. Sixty-two women completed a survey and interviews were conducted with 4 women focusing on their experience and relationship with their partner/baby's father and its effect on their pregnancy. Lack of childcare was mentioned by 46% as a reason for not attending to antenatal appointments, 41% had no reliable transportation and 21% blamed lack of support and active prevention by the abusive partner for not attending the programme. Thirty-two percent of women had the support of the partner for childcare.

### **Studies on healthcare providers**

A qualitative survey conducted in the UK (2003)<sup>36</sup> [EL=3] examined midwives' perceptions and experiences of routine enquiry for domestic violence. One hundred and forty-five midwives from eight hospital teams, ten community teams, specialist midwives and midwifery managers comprised the study population at the maternity services of Guy's and St Thomas' NHS Hospital Trust. Focus groups and individual interviews were conducted to explore midwives' experiences and attitudes about the midwife's role in identifying and responding to cases of domestic violence. Identified barriers to routine enquiry were:

- lack of information or training in domestic violence;
- lack of time;
- feeling they were being pushed into yet another new role;
- that they felt they were poorly equipped and for a variety of reasons could not perform well;
- tendency to categorise problems as 'medical' (which came within the midwife's domain) or as 'social' (which was not their concern);
- belief that asking women about domestic violence should not be part of a midwife's role at all in that it was not directly related to pregnancy or the women's health;
- lack of enthusiasm and motivation related to a general lack of morale within the midwifery body associated with high staff turnover and an ever-increasing workload;
- lack of confidential time during appointments;
- in the woman's home the midwife perceives herself to be a 'guest', and is therefore constrained from asking questions of such a personal and sensitive nature;
- feeling it was not appropriate to do anything more than ascertain whether violence was an issue and provide appropriate referral information;
- difficult to maintain a professional detachment and limit the intervention when faced with a distressed woman asking for help in the clinic or community;
- feelings of helplessness about their apparent inability to offer an effective solution which, they felt they were expected to provide or if, having given advice, this advice was disregarded;
- belief that the success of screening could only be judged if women were able to leave the violent relationship;

- feeling that they had been placed in a difficult and potentially dangerous situation (working in isolation, at night, visiting the woman at home, when they were not sure who else would be present);
- lack of reliable and consistent source of support (despite receiving training);
- belief that women were at lower risk of domestic violence while they were pregnant;
- apprehension because of personal experiences of violence;
- scepticism about the need to ask all women about domestic violence or were not sure that domestic violence was prevalent enough to justify routine screening;
- attitude of the partners (very controlling, dominating);
- concerned that they might be placing the woman at increased risk of harm or retaliation from her partner;
- frustration about the perceived passivity of many women in the face of partner violence and their inability to get out or seek help;
- women pretend everything is fine and do not bring up the subject themselves even when presenting with physical signs of abuse.

Analysis would have been richer if it had included comparisons between different subgroups: community vs. hospital midwives vs. managers.

A quantitative survey (audit) conducted in the UK (2003)<sup>171</sup> [EL=3] evaluated the effectiveness of an educational programme and assessed current practice and service provision in relation to the recommendations of the Confidential Enquiries into Maternal Deaths for maternity services in relation to domestic abuse in pregnancy, with particular attention to knowledge, attitude and beliefs, education, training and support and screening in clinical practice. One hundred and twenty-six hospital and community based midwives at the North Bristol NHS Trust (NBT) comprised the study population. Standards for the audit were based on the key recommendations of the Confidential Enquiries into Maternal Deaths in the UK 1997-1999<sup>69</sup>. An audit questionnaire was sent to all clinical areas within the maternity department to assess knowledge, attitudes, beliefs, education and training on domestic abuse as well as attitudes to screening for this problem. Identified barriers to discussing domestic violence were: lack of training; lack of knowledge; hospital midwives believed screening for domestic violence should be carried out by a professional who has an ongoing relationship with the woman i.e. a community midwife; not believing it was the role of the health professional to screen at all; feeling that routine screening should not occur within professional practice; screen only if suspicious rather than as routine; belief that domestic violence is an issue of the poor and socio-economically disadvantaged; that certain ethnic groups view domestic violence as acceptable; and that women almost always return to violent relationships. It should be noted that there was only a moderate response rate (50.4%).

A quantitative survey conducted in the UK (2001)<sup>172</sup> [EL=3] compared the knowledge, attitudes, responses and levels of detection of domestic violence among a variety of health care workers in different specialities. Six hundred and eighty-five healthcare workers from primary care, community mental health and obstetrics and gynaecology (O&G) working in Oxfordshire comprised the study population. A self administered questionnaire (designed by the authors after reviewing literature and consultation with Oxfordshire Multi-agency Groups on Domestic Violence and relevant specialists) was used to collect data on knowledge, attitudes and professional responses to the issue of domestic violence. Identified barriers to screening for violence were: lack of training (O&G); not got time to ask within initial assessment interview/normal contact time (O&G); uncomfortable about asking direct questions about domestic violence (O&G); if they asked every woman if she had been abused they will offend a lot of their clients (O&G); and thinking that domestic violence usually stops during pregnancy or do not know whether domestic violence usually stops during pregnancy (O&G, primary care, community mental health). It should be noted that the overall response rate was moderate (54%). Outcomes not explicitly related to pregnant women were not extracted from the paper and not all outcomes reported for O&G referred necessarily to pregnant women.

A quantitative survey conducted in the UK (1999)<sup>173</sup> [EL=3] explored the knowledge and attitude of the midwives towards domestic violence and assessed their preparedness to deal with it in pregnant women. One hundred midwives from 2 maternity units in Scotland were randomly selected for the questionnaire

survey consisting of mainly closed questions with Likert-style responses. Two thirds of the sample (n=67) midwives completed the questionnaire. Twenty-eight (41.8%) of the respondents had knowingly cared for a victim of domestic abuse in the previous year and 78.6% (22/28) of these had asked the woman about the incident. Though the number of victims seen each year by a midwife ranged between 1 and 10 (mean: 2.82), most (63/67) midwives rated their knowledge of domestic violence during pregnancy as inadequate, with a lack of available information, education and protocol cited as main reasons for this inadequacy. Only three midwives (4.5%) indicated that their midwifery education contained at least some (minimal) information about domestic abuse and 39 had attended some form of further education on the subject (including introduction to counselling skills). Of those who had attended further education and training, 57.7% agreed that further education had assisted them in dealing with women who were victims of domestic abuse. Almost all 65/67 (97%) agreed that they would benefit from further training on identification of, approach towards and how to provide support for the victims of domestic abuse and 85.9% indicated that a protocol (containing referral procedure and telephone number of other agencies) would be beneficial. Almost 60% of midwives (40/67) stated that they were reluctant to ask women about domestic abuse, and a similar proportion (55.2%) had reservations about compulsory questioning about domestic abuse at antenatal booking. Half the sample (33/67) agreed that midwives should take the lead role in caring for pregnant victims of domestic abuse.

A quantitative survey conducted in Belgium (2008)<sup>28</sup> [EL=3] evaluated health care providers' (HCPs) attitudes toward pregnant women experiencing domestic abuse by assessing their habits and the barriers toward screening for domestic abuse. Fifty-six HCPs from the department of obstetrics (15 gynaecologists, 27 midwives, 10 social workers, 3 neonatal nurses and 1 psychiatrist) comprised the study population. Fifty-six auto questionnaires from 2 series were randomly distributed and collected anonymously. Questionnaires were designed by investigators and pre-tested on a different sample of clinicians. There were 2 questionnaires; in each the prevalence of domestic violence was evaluated. Questionnaire 1 asked HCPs to describe type of violence encountered and their practices regarding screening whereas questionnaire 2 evaluated barriers to systematic screening of domestic violence. All questions used closed-ended answers but HCPs were also invited to add comments if they wished (although it is unclear whether any of these comments were included in the analysis). Identified barriers reported by health care professionals to systematic screening of domestic violence were:

- it is time consuming (24%)
- felt insufficiently trained to deal with this situation (10%)
- felt uninformed on how to manage the problem (35%)
- insufficient knowledge about resources to which the woman can be referred (28%)
- felt uncomfortable when asking questions about domestic violence (45%)
- language and cultural barriers (79%)
- woman always accompanied by her partner (62%)

The majority (52/56) of health professionals asked questions only when they suspected that domestic violence might exist, either because of the woman's attitude (72%), when bruises were observed (100%) or when a woman complained of recurrent psychosomatic symptoms (63%). It should be noted that among 56 HCPs who participated in the study 27 answered questionnaire 1 (48%) and 29 answered questionnaire 2 (52%) but it is unclear on what basis this was decided. A questionnaire sample was not provided in the paper. Outcomes were just reported in a descriptive manner, no further analysis was performed.

A qualitative survey conducted in the USA (2006)<sup>29</sup> [EL=3] assessed the intimate partner violence-screening practices of certified nurse-midwives (CNM) during prenatal care. Eight CNMs, members of the American College of Nurse-Midwives (ACNM) who lived and practiced in the Midwest, all employed and in full-time clinical practice comprised the study population. Data were collected by means of interviews with open ended questions and a two-page written demographic survey both developed by the researcher. Interviews addressed screening patterns; midwives' understanding of universal screening; clues to detect abusive relationships; relationship with women; domestic violence health promotion activities midwives' engagement with their clients; and challenges of responding to a positive disclosure for domestic violence in health care systems and lack of outcome data on screening practices. Identified barriers to universal screening were: lack of knowledge about the outcomes for women; practical/structural circumstances ("late Friday afternoon", "rest of support staff gone home"); language

difficulties and no interpreters available; feeling “tired”; “having a bad day”; feeling scared of dealing with obvious signs of physical abuse; because woman was from another culture (Navajo); woman denied abuse, but then admitted it; and some women do not even know the meaning of “emotional abuse”. It should be noted that no data were reported on the researchers’ characteristics and how this may have influenced the data collection and analysis. Data was collected by one method only and the findings might have been strengthened through subsequent in-depth interviews.

A quantitative survey conducted in the USA (2000)<sup>174</sup> [EL=3] investigated screening practices for partner abuse among primary care physicians providing prenatal care in Alaska, to determine whether physicians’ screening practices varied between the first prenatal visit and follow-up prenatal visits, to examine how physician characteristics may influence physicians’ prenatal screening practices, and to explore the relationship between hypothesised barriers to screening for abuse and physicians’ prenatal screening practices. One hundred and fifty-seven physicians in the specialities of family practice, general practice, obstetrics-gynaecology and internal medicine licensed to practise in the state of Alaska who were engaged in clinical practice and seeing female clients older than 16 years comprised the study population. A questionnaire aimed to identify perceived barriers to screening for domestic abuse was mailed 3 times to participants with a postcard reminder after first mailing. The questionnaire was designed by the authors based on a review of the literature and semi-structured qualitative interviews with 30 HCPs (including 10 physicians) practising in Alaska. The Alaska Network of Domestic Violence and Sexual Assault and regional domestic violence shelters and advocacy programmes reviewed the survey questionnaire and made recommendations. Pilot testing was conducted with 8 physicians followed by a focus group of physicians who discussed strategies to enhance participation. Identified barriers to screening for abuse were: time constraints, belief that they do not have a responsibility to address abuse, belief that they cannot help a client and feeling uncomfortable about screening for abuse.

A qualitative survey conducted in Sweden (2005)<sup>175</sup> [EL=3] described the experiences gained by antenatal-care midwives who routinely questioned pregnant women about men’s violence against women, their thoughts and feelings about the task, persisting obstacles and possible solutions and aids in routine questioning. Twenty-one midwives aged 42 to 62 years (median 54 years), who had been midwives for 8 to 39 years (median 26 years) and had been working at antenatal clinics in the county for 0.5 to 26 years (median 12 years) comprised the study population. Focus groups were conducted to collect data on midwives’ aspirations and obstacles and how they influence procedures, the presence of the woman’s partner and his influence on practice and midwives’ perceptions of their role in abuse questioning. The question guide was designed by authors and consisted of open-ended questions on the previous themes. Identified barriers to routine questioning were: lack of time; oversight; many competing duties; language difficulties and a preconceived notion about who might or might not be a victim; no knowledge of counselling; as the women carry their records, documentation of abuse could pose a serious safety problem in antenatal care; personal experience of violence; more sensitive to assess pregnant than non-pregnant women as violence during pregnancy is taboo; pregnancy is supposed to be a hopeful time in a woman’s life; more sensitive to question women whom the midwife knew, partly because of the expectation that as they knew each other, there ought to be no secrets to disclose (similar feeling also prevented some midwives from repeating the assessment later in pregnancy); if a woman was keeping her distance some midwives avoided asking; presence of the partner; ambivalence to men’s presence (when a midwife gets to know man and did not think of him as violent, it felt as disloyalty to ask about violence when he was not present); and frustration when a woman would not accept the help she was offered or worried about the future of the women no longer in antenatal care. It should be noted that data were collected by one method only and no explanation was provided for the lack of triangulation.

A qualitative and quantitative survey conducted in Sweden (2002)<sup>30</sup> [EL=3] investigated whether and how the issue of violence was addressed in the antenatal care programme in the county of Vasterbotten, assessed the knowledge, attitudes and routines among midwives concerning violence, discovered whether they considered abuse to be a rare phenomenon or not and investigated to what extent they had personal experience of meeting abused pregnant women. Five midwives who had been working in antenatal care clinics for an average of 17 years (range 6 to 28.5 years) comprised the population who was interviewed whereas 51 midwives of all 36 antenatal clinics in the county (including previous 5 midwives) were posted a questionnaire. Interviews were conducted by one of the authors and carried out as semi-structured open ended interviews. The interview guide was constructed based on the research questions and comprised the topics to be covered along with written questions. The questionnaire was designed on the basis of the original research questions and the results of the interviews, and modified after a pilot

test with one midwife. The form comprised multiple-choice questions and invited free comments. Response rate was 82% (42/51 midwives at 31/36 clinics) after one written reminder. Identified barriers to routine enquiry were:

- authorised translators seen as expensive;
- support not easily accessible (no guidelines at the antenatal care clinics that would be helpful in meeting pregnant women exposed to violence, laws difficult to interpret);
- lack of time;
- lack of training in this area and not knowing what to do after a positive disclosure of abuse;
- lack of assessment routines and intervention plans;
- lack of support from other HCPs;
- difficult to know whether a suspicion arising from interpreting potential signs and symptoms was well founded because abuse seen as a very sensitive issue (women might not tell the truth or might not return if asked);
- easy for the midwife to get emotionally upset on behalf of the woman and abandon her professional attitude by stepping in and giving her active help;
- not possible to confirm suspected abuse (women tried to maintain the appearance that "everything is all right", others missed visits, were in secure, rejected advances and were always in a hurry, expressed fear of physical examinations, fear of taking of specimens, the coming birth and worries about the wellbeing of the baby);
- more burdensome to be pregnant, women simply did not want the midwife to interfere and it was not possible to get close to her;
- concerns on whether it would be possible to get honest responses if screening everyone;
- questions about abuse may pose a threat to the personal integrity of the woman and need to be put in a proper context;
- no reasons to be specifically suspicious of abuse within particular groups in society apart from women from "risk groups" (those with social difficulties, addicted to drugs/alcohol, immigrants);
- presence of a partner or relative during the appointment especially complicated with immigrant women when the spouse acts as interpreter because there is no way of knowing whether or not the translation is correct;
- abuse regarded as taboo (the abused woman feels ashamed, blames herself, thinks that the abuse is her fault and consequently finds it hard to talk about);
- abused woman may face obstacles if she wants to escape from her spouse.

It should be noted that authors commented that most of what the midwives said seemed to reflect their theoretical knowledge rather than their actual experience as this was limited.

A quantitative survey conducted in the USA (2005)<sup>44</sup> [EL=3] identified from a provider's perspective the existence of staff barriers and the frequency of partner violence screening at two US Army Community Hospitals. Seventy-four health care providers (55 physicians (MDs) and 19 advanced practice nurses (APNs)) comprised the study population. These 74 providers comprised 92% of all HCPs who performed antenatal care at the two hospitals. Data were collected by means of a 26-item questionnaire containing one open-ended and numerous closed ended questions. The open-ended question obtained staff comments pertinent to barriers not listed in the forced-choice responses. The questionnaire was created by staff of the Children's Hospital Medical Centre in Cincinnati, based on responses from 310 of 547 paediatric practitioners with appreciable practices on the staff of the Medical Centre. The questionnaire was not validated by its authors, but they obtained estimates of content-related validity (CVI) i.e. an estimation of how well the questionnaire assessed the issues under consideration. All questions were considered as relevant by the four raters (prenatal primary care providers with partner violence screening experience) resulting in 100% CVI. The questionnaire was mailed directly to co-investigators (appointed health care providers) at the two hospitals. Participating staff received and completed the questionnaires at work. Identified barriers to screening were: lack of confidence in legal system; inadequate referral

services; lack of support staff; lack of protocols; lack of education in screening; lack of time for screening; feeling uncomfortable about screening for violence; discomfort in educating women; and discomfort in assessing danger. Descriptive statistics only were reported without any further statistical analysis.

To identify effective strategies for influencing and improving physician screening and referral of pregnant women for domestic abuse, a qualitative study consisting of interviews and focus groups was conducted in Washington State, US (2007)<sup>176</sup> [EL=3]. Physicians involved in obstetric care were selected using systematic sampling for semi-structured interviews (n=8) and four focus groups (n=28). Overall attitude of the physicians towards screening for domestic abuse was positive. The main themes identified to increase physicians' participation in screening were their access to referral resources, time-saving tools for screening and intervention, emphasis on the avoidance of legal risk, and patient education materials. The physicians also sought information about access to referral, short and "scientific-looking" materials and on-site training for all office staff. Reported ineffective training strategies included e-mail alerts, legislative mandates, direct mailing/flyers and telephone conferences.

### Evidence statement

The barriers in this section have been divided into two tables (barriers reported by women and barriers reported by healthcare professionals) due to the large number of barriers reported in the studies

Sixteen included studies; all EL=3.

**Table 7.1 Barriers reported by women**

<b>Service barriers</b>	<b>Personal reasons which act as barriers</b>
Potential involvement with and punitive actions by Children's Social Services (fear that children will be taken away) or other social and legal agencies (2)	Anxiety that their partner would find out that they had spoken to someone. Need of a safe, confidential environment in which to discuss the violence (3)
HCPs' methodical and insensitive manner of screening for abuse or treating women after an abusive episode (2)	Embarrassment related to sociocultural expectations associated with pregnancy being in contradiction with the experience of abuse (2)
Insufficient time during appointments to discuss personal problems in general (2)	Lack of childcare (1)
Not being provided with information at all/ being provided with what was perceived to be inadequate information (e.g. in lay pregnancy books) (1)	A belief that no one can help them (including HCPs) (1)
Not being screened for abuse, even when signs or symptoms of abuse were obvious, interpreted as lack of concern and professionalism (1)	Use of drugs during pregnancy and not wanting HCPs to discover that. Fear of disappointing others, the potential for unknown consequences to herself, partner child or family and lack of awareness of the potential harm to the unborn child were some of the reasons participants gave for concealing their substance abuse (1)
Thinking their concerns had been minimised or ignored (1)	Not wanting their partners to attend appointments because they feared being embarrassed by them or worried that they might reveal something stigmatising about them such as their use of drugs (1)
Community HCPs (but not those at clinics) not particularly helpful, sensitive to or aware of the abuse (1)	Unable to attend as direct consequence of abuse e.g. physical injury or partner restricting access (1)
Participants whose cultural or religious traditions varied from those of dominant society felt less understood by health professionals (1)	Unable to identify whether they are being abused, particularly if emotional abuse only (1)
Being asked only at the booking appointment and never being given another opportunity to disclose abuse (1)	Negatives attitudes towards pregnancy associated with experience of violence(1)
Lack of continuity of care in midwifery practice, fewer opportunities to provide ongoing support (1)	Felt the questions challenged their ability to care for their children (1)
Male HCPs (1)	Questions triggered painful memories for some women who had left violent relationships and were in the process of re-building their lives (1)
Unable to access further sources of support (e.g. local refuge) (1)	A perception that the primary role of the midwife was to deal with the physical rather than the emotional wellbeing of the pregnant woman (1)

A perception that the primary role of the midwife was to deal with the physical rather than the emotional wellbeing of the pregnant woman (1)	Stress, depression (1)
A belief that no one can help them (including HCPs) (1)	Not knowing how to raise the subject (1)
Absence of routine enquiry ( health professional taking the first step and asking directly about domestic violence) (1)	Being older than 25 years, with 12 or more years of education and not poor(1)
Older health professionals preferred to younger ones (1)	Financial difficulties (lack of insurance, unemployed) (1)
Uncertainty about whether the health professional would be interested or equipped to deal with the abuse (1)	Not feeling safe and confident enough to act immediately on the referral information given to them (1)

(Number of studies reporting each barrier given in parentheses)

**Table 7.2 Barriers reported by health care professionals (n=12 studies)**

<b>Service barriers</b>	<b>Personal reasons which act as barriers reported by women</b>	<b>Staff's personal reasons which act as barriers</b>
Lack of time/time consuming process (also a reason given for not including subject in the nursing/midwifery curricula) (10)	Woman keeps distance/denies abuse/pretends everything is fine even when obvious signs of abuse/does not want HCP to interfere (6)	Screen only when suspected that violence might exist , belief in "risk groups"(women's attitude, substance abuse, bruises observed, woman complained of recurrent somatic symptoms, immigrants, social difficulties)(5)
Not trained/insufficiently trained to deal with problem (also a reason given for not including subject in the nursing/midwifery curricula)(10)	Scepticism and victim blame. Frustration about the perceived passivity of many women in the face of partner violence, and their inability to get out or seek help(4)	Uncomfortable when asking questions about domestic violence/fear of offending women if ask all of them (5)
Uninformed on how to manage the problem including what resources to which the woman can be referred (6)	Woman always accompanied by her partner/relatives (especially complicated with immigrant women when partner/relative act as translator, does not accept official translator)(3)	Belief that women were at lower risk of domestic violence while they were pregnant or unaware that incidence of domestic violence increases during pregnancy (also a reason given for not including subject in the nursing/midwifery curricula)(3)
Lack of reliable and consistent source of support (other HCPs, guidelines, protocols, programmes, plans, laws) (5)	Concerns that they might be placing the woman at increased risk of harm or retaliation from her partner, by merely asking her about partner violence(3)	Belief that asking women about domestic violence is not part of the HCP role/responsibility as not directly related to pregnancy or the women's health. Seeing the problem as "social" rather than "medical"(3)
Official/authorised translators seen as expensive or not available (2)	Concerns on women not returning or on whether it would be possible to get honest responses if screening everyone as abuse such a sensitive issue. (3)	Language and cultural barriers (apart from the obvious practical reason, also feeling scared because of this) (3)
Feeling of having been placed in a difficult and potentially dangerous situation: working in isolation, at night, visiting the woman at home, when they were not sure who else would be present(1)	Not possible to confirm suspected abuse: women expressed various fears: of physical examinations, of taking of specimens, of the coming birth and worries about the wellbeing of the baby(2)	Deny that the problem might even exist/is prevalent enough among their women to justify screening (2)
As women carry their records documentation of abuse could pose a serious safety problem in antenatal care (1)	Women do not disclose unless they had being injured and needed medical assistance (1)	Personal experience of violence, work-related or in personal life, particularly if physical or sexual (2)
Lack of enthusiasm and motivation related to a general lack of morale within the midwifery body, associated with high staff turnover and an ever-increasing workload(1)	Some women do not even know the meaning of "emotional abuse" (1)	Belief that they cannot help the woman (2)

## Pregnant women with complex social factors

Hospital midwives believe screening for domestic violence should be carried out by a professional who has an ongoing relationship with the woman i.e. a community midwife(1)	More sensitive to assess pregnant that non-pregnant women as violence during pregnancy is taboo, pregnancy is supposed to be a hopeful time in a woman's life (1)	Easy for the midwife to get emotionally upset on behalf of the woman and abandon her professional attitude by stepping in and giving her active help(2)
Questions considered somewhat taboo and left out of the pre-printed multiple choice options in the antenatal care form(1)	More burdensome to be pregnant: pressures from employer, partner, family financial difficulties, lack of support from anyone else but partner (1)	Difficult to know whether a suspicion arising from interpreting potential signs and symptoms was well founded (1)
Not asking specific questions about abuse (1)	More sensitive to question women whom the midwife knew, partly because of the expectation that as they knew each other, there ought to be no secrets to disclose(1)	Tired/having a bad day (1)
Not easy to screen at the woman's home as the midwife perceives herself to be a 'guest', and is therefore constrained from asking questions of such a personal and sensitive nature(1)	Ambivalence to men's presence: when a midwife gets to know man and did not think of him as violent, it felt as disloyalty to ask about violence when he was not present(1)	Belief that the success of screening could only be judged if women were able to leave the violent relationship (1)
Women's fear of reprisal from Child Protective Services (1)	Midwives scared of controlling, hostile partners present at the time of consultation (1)	Feeling it was not appropriate to do anything more than ascertain whether violence was an issue and provide appropriate referral information. Midwives did not want to take a more active role (like providing counselling) (1)
Woman more likely to talk to the nurse about these issues than to other office staff (1)	Women's fear of reprisal from family members (1)	
	Abuse regarded as taboo, woman feels ashamed, blames herself, thinks that the abuse is her fault(1)	
	Women disregard advice given (1)	
	Client privacy issues limit the physician's ability to check up on whether women have acted on a referral (1)	

(Number of studies reporting each barrier given in parentheses)

### GDG interpretation of evidence

The evidence for Q1a focused on how the skills, knowledge and attitudes of midwifery and other pregnancy associated health care workers impact on how women experiencing domestic abuse access services. It found that relatively small amounts of training regarding domestic abuse had a positive impact on staff confidence, skills and attitudes relating to these issues. The GDG agreed with the evidence findings that it is beneficial for healthcare professionals to be appropriately trained in asking about domestic abuse if they are to provide a supportive environment where women feel able to disclose and recommended this. Box 7.1 provides an example of a specialist nurse service for women experiencing domestic abuse.

The GDG agreed that protocols and their component parts should be standardised but also adapted to local needs. It was recognised by the GDG that in order for domestic abuse protocols to be properly adhered to and embedded into routine practice, health trusts should identify an appropriate person with a special interest in domestic abuse to take responsibility for writing the protocols. This was recommended.

Given the sensitive nature of the questions and the time needed to adequately respond to a disclosure of domestic abuse, the GDG agreed and recommended that services should allow more time for consultations with women who disclose that they are experiencing domestic abuse, and potentially additional consultations, and highlighted the importance of women being provided with opportunities to see the health professional alone.

There is good evidence for the barriers experienced by women in relation to domestic abuse replicated across many studies. A large number of potential barriers to care were identified and so the GDG formally voted on which barriers they considered to be the most important and relevant. This consisted of one round of anonymous voting using pencil and paper. Following this, the results were fed back to the group and agreed. The GDG highlighted five key issues which they considered to be particularly relevant. These were:

- The woman's fear of the potential involvement of social services and child custody
- The woman's anxiety that her partner will find out she has disclosed the abuse
- Insufficient time for healthcare professionals to deal with the issue appropriately
- Insufficient support and training for healthcare professionals in asking about domestic abuse
- Domestic abuse is seen by many as a taboo subject which should not be discussed.

The group felt that as well as being key barriers to women disclosing abuse, these issues were also areas where it would be possible to take an action to overcome them. The group agreed that providing appropriate training and support to healthcare professionals was vital in overcoming the barriers listed above. Furthermore it was felt that it would be beneficial for commissioners of health and social care services to consider commissioning joint training sessions provided for both health and social care professionals so the two groups of professionals could learn together and benefit from attending the training together by hearing one another's perspectives and experiences. The group recommended that this training be provided. In the service description obtained (see Box 7.1), and in other trusts GDG members were aware of, one of the specialist nurse's responsibilities is to provide ongoing staff training. In addition, it was felt that midwives should be allowed extra time in consultation with women experiencing or suspected to be experiencing domestic abuse in order to facilitate sensitive discussion and provide the woman with opportunities for disclosure and ongoing support. The health economics evaluation (see section 7.7 below) based on assumptions underlying early access to antenatal services has shown a service costing £25,000 per year would only need to book an additional 3 or 4 vulnerable woman before 12 weeks and maintain contact. This could equate to employing an extra midwife part-time. It is likely that a similar level of benefit in terms of health outcomes, or in other areas, could be obtained from employing an extra midwife part-time to allow midwives more time enabling women to disclose abuse and to provide the ongoing support she will need. The provision for this additional care was recommended based on GDG consensus.

See section 7.8 (page 134) for recommendations.

## 7.4 Maintaining contact

### Clinical question

Q2. What aspects of service organisation and delivery improve contact with antenatal services throughout pregnancy for women experiencing domestic abuse?

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Comparative studies were included that evaluated interventions which improved the women's degree of contact with antenatal care services, even where this was not the primary aim of the intervention. Three studies were considered for inclusion, one of which was included in this review. This US study examined the nature of consultations with health care professionals and how this impacts on women who are victims of domestic abuse.

### Narrative summary of evidence

#### Risks and benefits of consultations with health care providers

A secondary analysis of data (which had been collected for a previous study by the same authors from October 1996 to November 2000) was undertaken to investigate the reported risks and benefits following

disclosure of intimate partner violence (IPV) to health care professionals (2008)<sup>35</sup> [EL=3]. Open ended in-depth interviews (1-2 hours long) were conducted by 2 of the 4 authors (female primary care physicians) with 29 women victims of domestic abuse who were referred to the authors either by local shelter staff or who had contacted them directly in response to a flyer (n=13) sent to domestic abuse programmes in eastern Massachusetts. All women were asked to describe their encounters with clinicians, both related and unrelated to abuse, after the onset of the abuse. Interviews were audio-taped, transcribed verbatim, coded and analyzed using a grounded theory approach to identify and classify common themes.

Each client-clinician 'encounter' was categorized as being either 'related to abuse' or 'unrelated to abuse'. Encounters related to abuse were further coded according to three characteristics: outcome, speciality and attribute. The outcomes were described by three mutually exclusive types; disclosure (woman reported telling her clinician about the abuse), discovery (no explicit disclosure by the woman but perception that her clinician knew about the abuse) and non-disclosure (woman concealed/denied the abuse). Specialities were coded as emergency department, obstetrics/gynaecology, primary care and others. Attribute was described by the woman's level of satisfaction with the encounter as to whether she perceived the interaction as beneficial, harmful or unhelpful. Fifty-nine out of 185 encounters were identified as being related to abuse, representing 25 women. The majority of disclosure encounters (25/35, 71%) were reported as being beneficial, as compared with 4/7 (57%) of discoveries and 6/17 (35%) of encounters described as non-disclosure. Three-quarters of the encounters made in the obstetrics/gynaecology setting were coded as beneficial (9/12) compared with 14/14 in primary care and 2/9 in the emergency department. There were no harmful disclosures reported in any speciality, with the remainder (n=7) being recorded as unhelpful.

The most serious consequence of unhelpful disclosures included women feeling endangered (n=2), or leaving their providers (n=2, both relating to obstetrics/gynaecology encounters). The remaining 5 reported dissatisfaction but this did not lead to them leaving their providers. Women were concerned by practitioners' tendency to encourage what they perceived as being "extreme solutions" such as instructing the woman to file a police report immediately. Unhelpful disclosures were also characterised by a reported lack of emotional connection and ineffective communication with clinicians. For example, women described episodes where, following disclosure, the health professional was unable to provide any information or support to help her.

Women with no disclosure reported being upset with health care providers who they felt should have recognized the domestic abuse and described how this led to the avoidance of health care. Several women reported benefit when the clinician did not insist upon disclosure but discussed domestic abuse, conveyed their concerns and offered options for interventions without forcing women to take actions.

Benefits of disclosure included an immediate change in circumstances (11/25 women), or a positive change in a woman's self-esteem or awareness of alternatives that later led to the women seeking help for the abuse. Three types of provider behaviour were identified that typified beneficial encounters: explicit acknowledgement of the abuse (all cases); demonstration of a caring attitude after disclosure (most cases); and specific referral to other resources (some cases). In 23 of the 25 beneficial disclosures, the woman reported familiarity with the health care provider. In obstetrics/gynaecology these relationships generally formed during the antenatal or perinatal period.

It should be noted that whilst it has been assumed many of the women attending the obstetrics/gynaecology department were pregnant; this is not made explicit in the study.

### **Evidence statement**

One US qualitative study has demonstrated that encounters with health care providers can be either helpful or unhelpful for victims of domestic abuse. Components of beneficial consultations where disclosure of the abuse had been made were: explicit acknowledgement of the abuse (all cases); demonstration of a caring attitude after disclosure (most cases); and specific referral to other resources (some cases). In 23/25 beneficial disclosures the woman reported familiarity with her provider. The most common consequence of unhelpful consultations was dissatisfaction, although more serious consequences included women feeling endangered following the consultation and loss of contact with the provider.

## GDG interpretation of evidence

There is a very limited amount of available evidence on which to base recommendations with regards to maintaining contact with women who experience domestic abuse. One well conducted US study highlighted the importance of providers knowing what to do when abuse is disclosed. In particular the finding that an encounter perceived by the woman as unhelpful may lead to subsequent withdrawal from contact with services emphasised the need for all healthcare professionals to be provided with training to optimise their attitude, confidence and skills in dealing with women who are victims of domestic abuse.

The GDG agreed with the evidence that it was important that a woman who discloses domestic abuse should receive continuity of carer throughout her pregnancy i.e. one healthcare professional responsible for providing the majority (defined as at least 50% of face to face consultations) of the woman's care. It was felt that a woman was more likely to maintain contact if she could be seen by a healthcare professional who she had built a relationship with. This would also facilitate disclosure of sensitive issues including any ongoing abuse. Longer and/or additional antenatal appointments may be needed to give midwives the time needed to provide this support. Health economics considerations have shown this to be cost-effective for other vulnerable groups of women (e.g. substance misusers) in terms of assumptions made of improved outcomes relating to early access and maintained contact. It is reasonable to extrapolate these assumptions to this population also (see section 7.7 below for health economics discussion), therefore a recommendation was made that women who experience domestic abuse should be offered a named midwife who should be responsible for providing the majority of her care.

The study highlighted the need for healthcare professionals to have available a wide range of information to enable appropriate sign-posting of women who are experiencing or suspected to be experiencing domestic abuse. The GDG felt that local protocols and referral pathways should be developed, depending on the configuration of maternity services as well as the availability of other statutory and third sector resources in the area, to support women experiencing or suspected to be experiencing abuse. The need for true multi-agency working in this area was recognised along with the need for robust auditing of protocols. The GDG recommended that these components be included in locally developed protocols. The need to include government guidance on care of pregnant women experiencing domestic abuse in local protocols is recommended, this includes the need for auditing of protocol implementation and adherence.

The study also highlighted the fact that women who have not explicitly disclosed domestic abuse often feel reassured by the 'perception' that the healthcare professional is aware of the domestic abuse. The GDG therefore felt that protocols should cover women suspected of experiencing domestic abuse as well as those who have explicitly disclosed the problem. Based on their experience the GDG agreed and recommended that a woman's GP should be informed if she discloses domestic abuse when accessing antenatal services due to the importance of safeguarding the unborn child

The GDG noted the need to assess women who disclose domestic abuse for their level of risk, as highlighted from the evidence by women reporting that they felt "endangered" following some unhelpful consultations. This component of assessment was included as a recommendation for training. See section 7.8 (page 134) for recommendations.

## 7.5 Additional consultations

### Clinical question

Q3. What additional consultations and/or support should be provided to women experiencing domestic abuse in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline).

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Comparative studies only were considered for inclusion reporting outcomes relating to contact with antenatal care. Forty-two studies were examined and their quality appraised, seven have been included. One study is from the UK and the rest from the US. The six US studies examine the efficacy of professional counsellors/counselling

sessions for abused women, and the UK study examines the policies and practice in maternity services in the UK to identify and support women experiencing domestic abuse.

### **Narrative summary of evidence**

#### **Professional counsellors/counselling sessions**

A US randomised control trial was undertaken to analyse changes in behaviours of 523 abused African American women following a behavioural intervention between 2001 and 2003 collaborating with 6 antenatal clinics in Washington DC (2009)<sup>177</sup> [EL=1-]. One thousand and seventy women with baseline data, after exclusion of non African American women, were randomised to the intervention group (n=521) or the usual care group (n=523). The behavioural intervention consisted of 8 tailored counselling sessions carried out in antenatal clinic. Intervention sessions occurred immediately before or after antenatal care. Participants were presented with material during intervention sessions. A validated risk assessment instrument assessing cigarette smoking, second hand smoke exposure, depression and intimate partner violence (IPV) was used for screening baseline and follow-up telephone assessments. Follow up data collection interviews were conducted during the second and third trimesters of pregnancy (22-26 and 34-38 weeks). The total number of reported risks did not differ between the intervention and usual care groups at baseline, the second trimester, or the third trimester. Significant covariates were smoking and IPV risk at screening. The distribution of the risk did not differ significantly between two groups at either first or second following assessment. Women in the intervention group more frequently resolved some or all of their risks than did women in the usual care group (odds ratio = 1.61; 95% CI = 1.08 to 2.39; p=0.021).

A US randomised control trial study investigated the effectiveness of an individualized Nursing Case Management (NCM) to decrease stress among pregnant women at risk for or in an abusive relationship. One thousand women who were 13 to 23 weeks pregnant and receiving care at one of two antenatal clinics in the Pacific Northwest and rural Midwest were randomised to either the intervention (n=499) or control group (n=501) (2006)<sup>178</sup> [EL=1]. All participants completed the initial research assessment (T1) prior to 23 weeks and a 2nd assessment (T2) between 32 weeks and delivery. The T1 assessment included demographic information, three questions from the Abused Assessment Screen (AAS) and the prenatal (antenatal) Psychological Profile (PPP). At the completion of T1, women were randomised to one of the two groups. At T2, the AAS and PPP were repeated.

All women in the intervention and control group were also classified as high risk or low risk. All participants in the intervention group were offered an abuse video to increase participants' awareness and provided with 24/7 access to the connection nurse case manager (NCM). Additionally, within this group, participants at risk of or in an abusive relationships (n=130) received individualized nursing care management throughout the pregnancy. All women were offered a bright refrigerator magnet with the Connections logo, the 24/7 telephone number, and a letter explaining NCM service. Women experiencing abuse who were allocated to the control group did not receive any further intervention with the exception of 10 women who had a high Danger Assessment score who were referred to NCM for immediate safety planning and also to a social worker.

The total stress score of actively case managed participants (n=99) in the intervention group significantly decreased from T1 to T2 (from mean 22.91 [4.58 SD] to 19.6 [4.13]). The total stress score of the high risk control group women (n=92) also significantly decreased (from mean 24.22 [4.72 SD] to 21.73 [4.81]). The stress scores for nulliparous and multiparous women were compared at T1 and T2. For both groups, total scores and all items score except for pregnancy stress, were significantly lower at T2. Most participants in the study reported that they appreciated a non-judgmental approach with respect to their choice to stay with their partner.

A US quasi-randomised trial evaluated the differential effectiveness of three levels of intervention; Brief, Counselling, and Outreach to identify the severity of abuse and use of community resources among abused Hispanic women (2000)<sup>179</sup> [EL=1-]. Women were recruited on their first antenatal care visit. A bilingual counsellor administered a consent form and asked questions about socio-demographic status, community resource use and severity of violence. These assessments were repeated by interviews at 2, 6, 12, and 18 months post-delivery.

Women in the brief intervention group (n=94) were given a brochure and a wallet sized resource card that included phone numbers of local agencies and information about planning for personal safety. No counselling, advocacy, education, or other services were offered to women in the brief intervention group.

In the counselling intervention group, women (n=73) had unlimited access to a counselling service from a female, bilingual Spanish speaking, professional counsellor with expertise in domestic violence.

The outreach intervention consisted of the same unlimited access to the professional counsellor plus the services of a "mentor mother". The role of mentor mother, (a non-professional bilingual Spanish speaking) was to offer support, education, referral and assistance in accessing community resources through personal visits and telephone contacts with abused women (n=92).

At 2 month follow up, physical violence scores were significantly lower ( $p < 0.05$ ) in the outreach group than in the counselling only group (adjusted means = 34.7 and 39.5 respectively) but not those of brief intervention group (adjusted mean = 38.2). No significant differences among groups at 6, 12, and 18 months were reported. Threat of violence scores showed a significant decrease from entry to 2 months post-delivery regardless of intervention group. Over time use of community resources decreased in all three intervention groups. Use of community resource was correlated with severity of violence.

A US prospective cohort study was conducted to evaluate an intervention protocol, administered during pregnancy, for increasing safety-seeking behaviours of 132 abused women recruited from public antenatal clinics (1998)<sup>180</sup> [EL=2-]

The intervention protocol consisted of three education, advocacy, and community referral sessions, conducted in a private room in the antenatal clinic.

Components of safety behaviour were reviewed with each woman and women were given information and strategies for staying safe including a list of community resources.

Adoption of safety behaviours by abused women were measured before the intervention, twice during pregnancy, and at 2, 6, and 12 months after completion of the pregnancy.

All behaviours demonstrated a significant change from visit 1 (entry) to visit 2 (during pregnancy) except for removing weapons where the change was not significant until visit 4 (2 months after the delivery). Repeated measured analysis of variance showed significant change across time from visit 1 (entry) to visit 6 (12 months after the delivery) in the adoption of each safety behaviour ( $p < 0.0001$ ). Furthermore, the adoption of safety behaviour occurred across all ethnic groups.

A correlation analysis showed no difference in the proportion of applicable safety behaviours adopted by women with a parity of 1 compared to women with parity greater than 1. Age was positively related to the proportion of behaviours reported at visit 1 ( $r = 0.18$   $p = 0.019$ ) and at visit 2 ( $r = 0.21$ ;  $p = 0.008$ ).

Abused pregnant women who were offered an intervention protocol reported a significant increase in safety behaviour adoption during and after pregnancy.

A US prospective descriptive study (1999)<sup>181</sup> [EL=2-] was conducted on 216 abused pregnant Hispanic women receiving antenatal care in 3 urban public health clinics in the south western United States to determine if there are characteristics of Hispanic abused women that are associated with the women's use of the services of counselling to help end the abuse.

Women who were abused by their intimate male partner were offered unlimited access to the services of a female bilingual English/Spanish-speaking counsellor experienced in abuse whose office was located in the public health clinic.

The number of children the abused women had was significantly related to the number of visits the women made to counsellor ( $F = 5.77$ ,  $df = 2$ ,  $p = 0.004$ ). Those women who had made 4 or more visits to the counsellor had significantly more children than those who made 2 or 3 visits ( $p = 0.002$ ). No statistically significant association was found between the number of visits to the counsellor and any other characteristic, severity of violence score and use of community resource, other than police. Women who had used the police most during the previous 12 months made the fewest number of visits to the counsellor compared with 8% of the women who had 4 or more visit to counsellor ( $p < 0.05$ ).

A US prospective cohort study (1997)<sup>182</sup> [EL=2-] was undertaken on 199 physically or sexually abused women to examine the relationship between severity of abuse and use of community resources following an intervention programme in a primary care setting.

Sixty-seven abused women in the comparison group were given a wallet-sized card listing community resources for violence including law enforcement, shelter, legal aid, and crisis counselling. Abused women in the intervention group (n=132) received three counselling sessions evenly spaced throughout

pregnancy. The intervention focused on offering options to the woman and assisting her in making a safety plan. Each woman in the intervention group was administered the Relationship Inventory, Index of Spousal Abuse (ISA), and Severity of Violence against Women scales (SVAWS) by the investigators. The instruments were re-administered 6 months and 1 year after completion of their pregnancy.

There was no difference in reported resource use at 6 months between intervention and comparison groups ( $p=0.233$ ). At 12 months there was a significant difference ( $p=0.012$ ) between the groups, with the comparison group more likely to use resources.

There was no significant difference in police use at 6 months ( $p=0.761$ ) and no difference at 12 months between the intervention and comparison groups in police use ( $p=0.70$ ). At 6 months after delivery abuse ending was not related to use of resources ( $p=0.928$ ) but it was related to use of the police ( $X^2 = 8.75$ ,  $df=1$ ,  $p=0.003$ ).

At 12 months, abuse ending was not related to use of resources ( $p=0.326$ ) or use of police ( $p=0.076$ ). The results indicate that use of resources and contacting the police was correlated to severity of abuse.

### **Policy and Practice**

To explore policies and practices in maternity units that aim to identify, assess and support women experiencing domestic violence a postal questionnaire survey [EL=3] was carried out on 211 maternity units in England and Wales in 1999 (2001)<sup>183</sup>.

The questionnaire focused on provision of information, strategies for referral, liaison with other disciplines and opportunities for training. Respondents were also asked to comment on written policies and agreed common practice which did not include written documentation.

Fifty-seven percent ( $n=103$ ) of units had no written policy or agreed practice for identifying women experiencing domestic violence. Twelve percent ( $n=22$ ) of units had written policies and a further 30% ( $n=54$ ) had some form of agreed practice. Fifty-seven percent ( $n=104$ ) of units displayed material about domestic violence in places where women receive maternity care.

Having a written policy or agreed practice was statistically significantly associated with the implementation of three of the four recommendations (routinely question all women on domestic violence, offering women an appointment without partner, participating in internal or local study and training day and displaying material about domestic violence).

Trusts with written policies were significantly more likely than Trusts with no policies or practices to routinely question all women about domestic violence.

### **Evidence statement**

There were two randomised control trials [EL=1-] and one quasi randomised trial [EL=1-] investigating professional counsellors/counselling sessions for abused women. All studies were poorly conducted with no blinding or self report outcomes, and randomisation in one study was flawed. None of these studies found robust evidence in favour of professional counsellors or counselling sessions in terms of improving pregnancy outcomes. One randomised control trial found women who received counselling sessions were more likely to report a reduction in some or all of their risks of domestic abuse than women in the comparison group who did not receive counselling. Findings from a second RCT suggested that women who were provided with information relating to domestic abuse via DVD, a 24 hour contact number for a nurse case manager and a fridge magnet displaying the same number anonymously reported similar stress scores and Danger Assessment scores to women in an intervention group who received the same interventions plus unlimited access to a nurse case manager. In a quasi-randomised trial a brief intervention involving provision of information and contact numbers was found to be as effective as a counselling support intervention which included the provision of information and contact numbers plus unlimited access to a female counsellor and an outreach intervention in reducing physical violence scores and threat of violence scores at 6, 12 and 18 months postnatally in women experiencing domestic abuse.

Findings from two prospective US studies (one cohort and one descriptive, both [EL=3]), indicate that the use of resources and the police was correlated to severity of abuse and women with no counsellors or counselling sessions were more likely to use other resources, thus suggesting they were also experiencing higher levels of abuse.

A US prospective cohort study [EL=2-] demonstrated significant increase in safety behaviour adoption during and after pregnancy for abused pregnant women who were offered an intervention protocol.

Findings from a UK postal survey of maternity units [EL=3] suggest that Trusts with written policies were significantly more likely than Trusts with no policies or practices to routinely question all women about domestic violence.

### **GDG interpretation of evidence**

Due to the lack of good quality evidence, it was not possible to be clear about their benefits of any specific intervention, e.g. counselling, outreach, or use of police, since it was not clear what each one of these entailed. However, the studies did suggest that a combination or some form of education, advocacy, counselling (not necessarily conducted by professional counsellors) or community referral increases adoption of safety behaviour and reduces the risk of domestic abuse. The evidence also showed that in NHS trusts that have a written policy health care professionals are more likely to conduct a routine enquiry although staff skills and competencies in providing appropriate safety information, ongoing support or an appropriate referral to a support agency are not reported.

A consideration of evidence for other questions, (what aspects of service organisation and delivery can act as barriers, or improve access, take up and continued contact with antenatal services) provides clarity about the additional support that women find helpful and these components have been included in the recommendations.

In consideration of the evidence the GDG took the view that health care professionals need to not only conduct routine enquiry at the time of booking, but enquire regularly in a sensitive manner, which encourages the woman to disclose at a time when she is ready to do so. In order to facilitate this it is important that women have the opportunity for a one to one consultation without their partner, a friend or family member present. This is a key priority recommendation based on GDG consensus. Midwives need to be able to demonstrate a caring attitude, provide safety information, and support the woman in making the best and safest choice for herself. However the GDG also recognised that in order to do this, the healthcare professionals need to have clear written protocols, a range of screening and prompting tools, clear referral pathways, access to support staff, and training in knowledge, understanding and communication skills. Based on their own experience and knowledge of the area the GDG recommended these components of care and training. The GDG also took the view that once abuse has been disclosed, not all the follow up work needs to be done by a healthcare professional, but that the healthcare professional should be able to refer to, or work jointly with, other staff (including staff from third sector agencies such as domestic abuse support workers). The service description provided in Box 7.1 shows how a specialist nurse might be used to ensure appropriate care and support is provided for this population of women. As has been noted above, the GDG felt it was appropriate for a woman who is experiencing abuse to be offered extra antenatal appointments or longer appointments.

The GDG took the view that each NHS trust needs to develop its own protocols and referral pathways and support systems, depending on its configuration of maternity services as well as the availability of other statutory and third sector resources in the area to support women experiencing and suspected to be experiencing abuse. The issue of safeguarding was discussed. Key components of such a pathway are outlined in the recommendations and include utilisation of the DH guidance for health care professionals working with women experiencing domestic abuse<sup>15</sup> which the GDG felt was an excellent, practical document. Whilst the GDG recognised its importance they reflected that it was not necessary to include safeguarding in the recommendations as this is a statutory requirement for all health and care professionals. See section 7.8 (page 134) for recommendations.

## **7.6 Additional information**

### **Clinical question**

Q4. What additional information should be provided to women experiencing domestic abuse in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline)

### Previous guidance

There is no previous NICE guidance addressing this question

### Overview of included evidence

Studies from all countries and all dates were considered for inclusion in this review. Only comparative studies were eligible for inclusion. Two studies were identified for consideration and only one US study has been included [EL=2+]. The study evaluates the impact of an intervention protocol designed to improve safety seeking behaviours of abused women.

### Narrative summary of evidence

A US prospective cohort study was conducted to evaluate an intervention protocol, administered during pregnancy, for increasing safety-seeking behaviours of 132 abused women recruited from public antenatal clinics (1998)<sup>180</sup> [EL=2+]

The intervention protocol consisted of three education, advocacy, and community referral sessions, conducted in a private room in the antenatal clinic.

Components of safety behaviour were reviewed with each woman and women were given information and strategies for staying safe including a list of community resources.

Adoption of safety behaviours by abused women was measured before the intervention, twice during pregnancy, and at 2, 6, and 12 months after completion of the pregnancy.

All behaviours demonstrated a significant change from visit 1 (entry) to visit 2 (during pregnancy) except for removing weapons where the change was not significant until visit 4 (2 months after the delivery). Repeated measured analysis of variance showed significant change across time from visit 1 (entry) to visit 6 (12 months after the delivery) in the adoption of each safety behaviour ( $p < 0.0001$ ). Furthermore, the adoption of safety behaviour occurred across all ethnic groups.

A correlation analysis showed no difference in the proportion of applicable safety behaviours adopted by women with a parity of 1 compared to women with parity greater than 1. Age was positively related to the proportion of behaviours reported at visit 1 ( $r=0.18$   $p=0.019$ ) and at visit 2 ( $r=0.21$ ;  $p=0.008$ ).

Abused pregnant women who were offered an intervention protocol reported a significant increase in safety behaviour adoption during and after pregnancy.

### Evidence statement

Evidence from one US prospective cohort study [EL=2+] showed that women experiencing domestic abuse who received an antenatal intervention involving education, advocacy and community referral reported a significant increase in safety behaviour 12 months after giving birth compared with entry into antenatal care.

### GDG interpretation of evidence

There was little evidence available about information given to women about domestic violence. One US study showed that women adopted more safety behaviours if they were given information including a list of community resources. Much information is available from third sector organisations, and this is often displayed in public areas in hospitals such as waiting rooms and public toilets, and can be given routinely to all women.

However there is evidence that if the perpetrator of domestic violence is aware that information is being given to the woman, they may prevent her from attending for care. CEMACH data showed that a significant number of women who were murdered after experiencing domestic violence had been poor attenders for antenatal care. The GDG felt that this should not prevent information from being provided to all women, and by consensus recommended that training needed to be provided to staff to make sure that any encounter was beneficial to women and did not increase her risk. Information needs to include how to stay safe, options for alternative accommodation if this is necessary, and contact details for third sector organisations. It would be beneficial if this information could be provided in a discreet format to minimise the chances of the perpetrator discovering it. Based on the evidence reviewed and personal experience this was recommended.

See section 7.8 (page 134) for recommendations.

## 7.7 Health economic considerations

The problem surrounding accessing care for this group was related to being able to disclose abuse and appropriate referral. This population may not be easily identifiable by midwives and so any additional services related to facilitating disclosure of domestic abuse would need to be provided to all women at first in order to allow disclosure of abuse. Therefore, it did not seem appropriate to use the model developed for substance misusers and teenagers as the underlying assumption of the model was that the only benefit was derived from early booking and maintaining contact for specific groups of women. No published economic evaluations were identified for midwife led care for women experiencing domestic abuse.

Domestic abuse affects several public services such as social services and the criminal justice system. Additional time with midwives to allow disclosure of domestic abuse will have implications outside the NHS. Although this may be the case with other vulnerable groups it has been possible to show a potential impact on maternal and birth outcomes due to better antenatal attendance in these groups. The economic evaluation has shown a service costing £25,000 per year would only need to book an additional 3 or 4 vulnerable woman before 12 weeks and maintain contact. This could equate to employing an extra midwife part-time. It is likely that a similar level of benefit in terms of health outcomes, or in other areas, could be obtained from employing an extra midwife part-time to allow midwives more time enabling women to disclose abuse. As we have little good quality evidence, any additional resources applied to support vulnerable women should be audited so analysis can be carried out in the future.

## 7.8 Recommendations

This group of women should be supported in their use of antenatal care services by:

- training healthcare professionals in the identification and care of women who experience domestic abuse
- making available information and support tailored to women who experience or are suspected to be experiencing domestic abuse.
- providing a more flexible series of appointments if needed
- addressing women's fears about the involvement of children's services by providing information tailored to their needs

### Service organisation

Commissioners and individuals responsible for the organisation of local antenatal services should ensure that local voluntary and statutory organisations that provide domestic abuse support services recognise the need to provide coordinated care and support for service users during pregnancy.

Commissioners and individuals responsible for the organisation of local antenatal services should ensure that a local protocol is written, which:

- is developed jointly with social care providers, the police and third-sector agencies by a healthcare professional with expertise in the care of women experiencing domestic abuse
- includes:
  - clear referral pathways that set out the information and care that should be offered to women.
  - the latest government guidance \*
  - sources of support for women, including addresses and telephone numbers, such as social services, the police, support groups and women's refuges

\* Department of Health (2005) Responding to domestic abuse. A handbook for healthcare professionals. London: Department of Health. Available from [www.dh.gov.uk/en/Publicationsandstatistics/index.htm](http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm)

- safety information for women
- plans for follow-up care, such as additional appointments or referral to a domestic abuse support worker
- ensuring a telephone number is obtained on which the woman can be contacted
- contact details of other people who should be told that the woman is experiencing domestic abuse, including her GP.

Commissioners and individuals responsible for the organisation of local antenatal services should provide for flexibility in the length and frequency of antenatal appointments, over and above those outlined in national guidance\* to allow more time for women to discuss domestic abuse they are experiencing.

Offer the woman a named midwife who should take responsibility for and provide the majority of her antenatal care.

### **Training for healthcare staff**

Commissioners of healthcare services and social care services should consider commissioning joint training for health and social care professionals to facilitate greater understanding between the two agencies of each other's roles, and enable healthcare professionals to inform and reassure women who are apprehensive about the involvement of social services.

Healthcare professionals need to be alert to features suggesting domestic violence and offer women the opportunity to disclose it in an environment in which the woman feels secure. Healthcare professionals should be given training on the care of women known or suspected to be experiencing domestic abuse that includes:

- local protocols
- local resources for both the woman and the healthcare professional
- features suggesting domestic abuse
- how to discuss domestic abuse with women experiencing it
- how to respond to disclosure of domestic abuse.

### **Information and support for women**

Tell the woman that the information she discloses will be kept in a confidential record and will not be included in her handheld record.

Offer the woman information about other agencies, including third-sector agencies, which provide support for women who experience domestic abuse.

Give the woman a credit-card sized information card that includes local and national helpline numbers.

Consider offering the woman referral to a domestic abuse support worker.

### **Box 7.1** Example of a service for women experiencing domestic abuse

Nottingham Citihealth employs a domestic abuse nurse specialist as part of the safeguarding children team. The role is non-clinical and the nurse is available to give advice to all Trust staff regarding domestic abuse. She also provides signposting for appropriate referrals to women's aid, police, and safeguarding children. A full day of domestic violence basic awareness training is provided twice a month to all trust staff and a half day session on the Impact on Children. The nurse specialist also delivers training to partner agencies, such as Nottingham University Hospitals Trust and the Local Safeguarding Board. The basic awareness training covers aspects of domestic abuse (physical, emotional, sexual, psychological and financial), vulnerable groups and barriers to disclosure, why women stay in abusive relationships, and attitudes and opinions of Young People. The afternoon then focuses on 'Asking the Question', MARAC's, using the Risk Assessment forms, Safety Plans and specialist services in the area. The 'Impact on Children' training focuses on the holistic impact on children of different ages and evidence base, safeguarding children and links to child abuse and scenarios.

\* See 'Antenatal care' (NICE clinical guideline 62)<sup>1</sup>

# 8 Health economics

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## Cost-effectiveness question

What is the cost-effectiveness of specialist service interventions to improve access and uptake of antenatal care by vulnerable pregnant women?

## Aims

Health economic analysis in a clinical guideline can support and strengthen recommendations by making explicit comparisons between different health care alternatives in terms of their costs and their effectiveness. Where an alternative or additional service costs more but with better outcomes than the status quo or next best alternative, economic evaluation can provide guidance as to whether the additional cost represents good value to the NHS compared with all the other uses for those same resources. Cost-effectiveness analysis with the units of effectiveness expressed in quality adjusted life years (QALYs) is widely recognised as a useful approach for measuring and comparing different health interventions. The results of cost-effectiveness analyses can be used to maximise health gain from the resources available and make decisions about NHS resource use more transparent and defensible.

This guideline focuses on interventions to improve uptake of antenatal care for vulnerable women. From the clinical evidence for specialist interventions to improve uptake of antenatal care, the guideline development group (GDG) decided that specialist services may be effective for specific groups of vulnerable women, namely to substance misusers and teenagers. For both these groups of women, the problem of accessing care appeared to be due to late booking and non-attendance, where as in the other groups covered in this guideline attendance does not appear to be a problem. Additional services to increase uptake incur additional cost to the NHS. Therefore it was necessary to consider whether and in what circumstances these services would be cost-effective. This evidence did not exist in the published literature, so an economic evaluation was undertaken for this guideline.

A new health economic model was developed for this guideline with the specific aim of assessing the cost-effectiveness of additional care versus normal antenatal care services. The analysis was based on descriptions of services that are currently provided across the UK. It is assumed that any specialist service will be over and above routine antenatal care as described in the Antenatal care guideline (NICE 2008)<sup>1</sup>. Therefore it is not assumed that a specialist service provides routine antenatal care but instead provides additional support to pregnant women and indirect support to midwives providing their care. This description covers low cost interventions such as text reminders of future appointments as well as more costly services such as a specialist midwifery clinic in a children's centre.

Ideally, a robust cost-effectiveness analysis would be modelled around a single well-conducted randomised controlled trial (or meta-analysis of trial data). Otherwise, the data used in models (cost data, outcome data and probabilities) are taken from different published sources. Economic models should be underpinned by the best-quality clinical evidence available. Where this data is completely lacking, a model can still be developed using the best available evidence, such as clinical opinion or consensus, and subjecting the model assumptions to sensitivity analysis. This is done by identifying the most appropriate inputs for a 'base case', and then varying these inputs to see how they impact the cost-effectiveness results. It assesses how important a particular assumption or model parameter is in determining whether an intervention is cost-effective compared to the next best alternative.

## Methods

The framework for economic analysis in this guideline is a 'what if' analysis as there is limited clinical evidence available to populate the model. This is an approach used where important model inputs cannot be identified from the published literature. The model illustrates various scenarios in which an intervention would be cost effective, exploring different assumptions and presenting this evidence to the decision-makers (the GDG). The decision-makers then judge how likely (or not) these scenarios might be in the real

world, and decide whether or not recommendations can be made on this basis. It provides transparency in cases where robust evidence to support decision-making is missing.

In general, a cost-effectiveness model gives a result showing that an intervention is either more or less cost-effective than the next best alternative (usually routine or current care). The clinical review of the evidence did not identify any useful studies that reported the effectiveness of a specialist antenatal care intervention in terms of health gains for either the mother or the baby. However, an underlying assumption of the guideline is that antenatal care is beneficial (see introductory chapter). Therefore it is assumed for the purpose of modelling that any woman who books early (before 12 weeks) and maintains contact will have better health outcomes for herself and her baby than late bookers and non-attenders. This is the starting point for the health economic model.

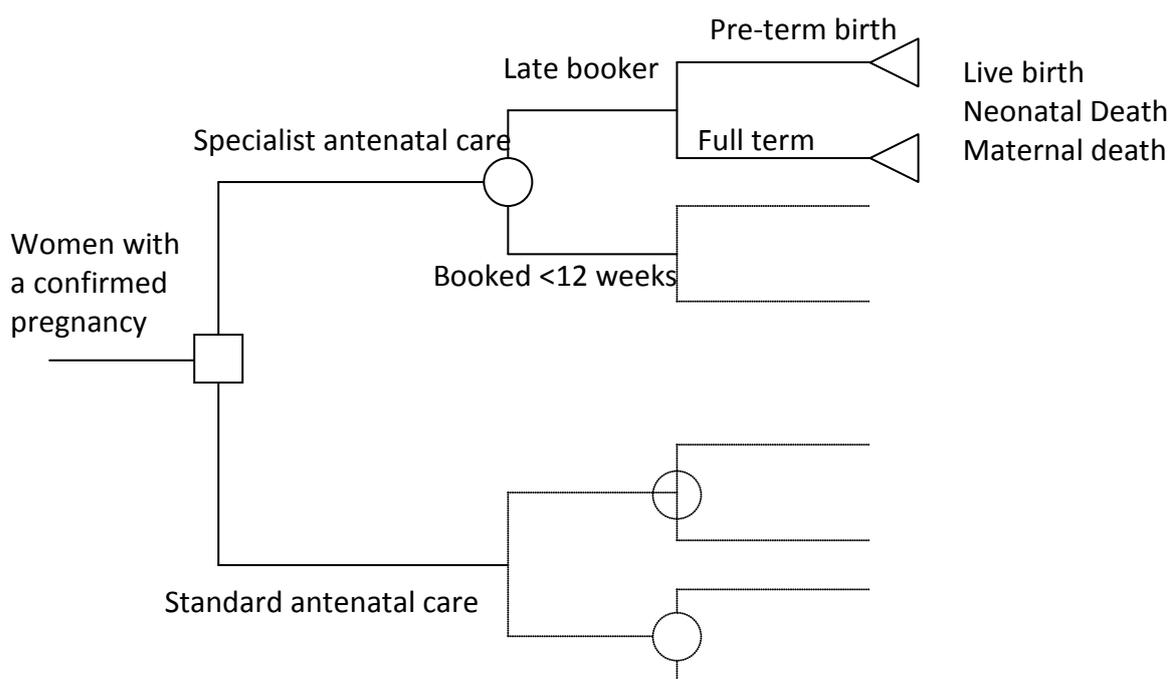
It is further assumed in the economic model that increasing uptake and maintenance of antenatal contact improves health (and therefore increases quality adjusted life years), and that this enhanced service is more costly than routine care. The economic analysis considered different scenarios for specialist models of antenatal care, each with a different estimated cost. The comparison was always standard antenatal care as defined by the NICE Antenatal care guideline (2008<sup>1</sup>). For each type of service, the model estimated the minimum additional number of women who would need to be booked and maintain contact with the service in order for it to be cost-effective at the £20,000 per QALY threshold.\*

The perspective of the model is from the NHS, and so only costs and benefits to the NHS will be included in the base case.

### The Model

A model was developed in Microsoft Excel™. The decision-maker (GDG) is able to alter the model inputs and can view the results for any specific service scenario they create where the costs of the service are known. The basic analytic approach is illustrated by the simple schematic in Figure 8.1.

**Figure 8.1** Schematic diagram showing the economic evaluation approach



\*Although there is no official threshold for cost-effectiveness, in general, interventions with an incremental cost-effectiveness ratio of less than £20,000 per QALY gained are considered to be cost effective. The threshold indicates that we are willing to pay approximately £20,000 for one additional year of life lived in full health.

## Population

The exact number of pregnancies to substance misusing women was unknown. The Hidden Harm report stated that approximately 1% of deliveries were to women with problem drug use.<sup>46</sup> Using the birth statistics for 2007<sup>184</sup> this would be approximately 6,800 maternities\* a year. As this figure was felt to be too small by the GDG the base case number of maternities to substance misusers has been assumed to be 3% of maternities, approximately 20,000 per year. This assumption is tested in the sensitivity analysis.

The National Office of Statistics reported on birth rates and mortality rates based on social and biological factors<sup>185</sup>. There were approximately 45,028 live births to women under 20 years old in 2004. This is about 7% of maternities in England and Wales.

## Evidence of effectiveness

It is assumed that health benefits are derived from early booking and maintaining contact. The specialist intervention can improve outcomes by increasing the proportion of women booking early (before 12 weeks) and receiving antenatal care. A systematic review was not undertaken for effectiveness of antenatal care for vulnerable women. The following studies were identified for substance misusers:

A study carried out in Manchester compared outcomes for substance misusing pregnant women before and after a drug liaison midwife (DLM) service was provided. Although the number of women booking in the first trimester increased, the number of preterm babies also increased when the additional service was provided. The percentage of preterm births to drug misusing mothers was 21% when standard antenatal care was provided.<sup>47</sup>

Further studies were identified reporting on the rate of premature births for drug misusing women. An Irish study looking at the effectiveness of a DLM service reported 10.5% of births to drug dependent women were premature.<sup>186</sup> The study was descriptive and this result was compared to 5.8% of all births being premature at one of the hospitals in the study. This was also compared to UK estimates for prevalence of prematurity in drug dependent women of between 20% and 33%, although these were taken from a study published in 1986. An audit carried out in Scotland on drug misuse showed that 71% of births recording drug use were full-term, normal birth weight babies<sup>187</sup>

The base case assumption is that 70% of babies born to mothers who book after 12 weeks will be full-term, this rises to 80% if mothers book before 12 weeks and maintain contact. These assumptions have also been used for teenagers. These inputs will be tested in the sensitivity analysis by varying the proportion by  $\pm 10\%$  (Table 8.1).

**Table 8.1** Inputs for effectiveness

Parameter	Base case input	Sensitivity analysis	
		Lower value	Upper value
Full-term births – late bookers/non-attenders	70%	63%	77%
Full-term births – early bookers/attenders	80%	72%	88%

It is likely that receiving timely antenatal care will have other benefits, for instance uptake of screening, identification of HIV positive women, effective treatment of gestational diabetes. Where the evidence is of poor quality it was agreed that a simple, conservative model where health benefits were confined to those relating to improving the likelihood of a full-term birth only. If it is the case that an intervention is cost-effective using these conservative assumptions for health benefit, then any additional health benefits to the mother and baby will improve the comparative cost-effectiveness of specialist intervention compared with routine antenatal care.

## Costs

The studies reporting on specialist interventions for vulnerable women did not have complete descriptions of what the intervention provided. With the help of the GDG members we contacted a number of midwives about specialist services that they were providing to each of the populations

\* A confinement resulting in the birth or one or more live-born or stillborn children

included in the guideline. The cost of staffing these services was calculated using the PSSRU unit costs<sup>188</sup> (Table 8.2). The services range from a part-time dedicated midwife, to services involving a multidisciplinary team of specialist midwives, specialist GPs, health visitors and social workers. Unfortunately no corresponding audit data were available to show the benefits of each service.

The cost of travel for a home visit was also taken from the PSSRU unit costs.<sup>188</sup> It was assumed that for a community nurse, travel will cost on average £1.40 per visit based on PSSRU estimates (see footnote to table 8.2). The GDG thought this was too low. If the cost of travel was £5 per visit, the total annual cost would increase from £1,092 to £3,900 if 15 home visits were carried out each week. Sensitivity analysis was carried out on the costs of providing the specialist service (see Figure 8.2 and Figure 8.3 in the Results section).

**Table 8.2** Annual costs of interventions based on service descriptions (see Appendix D), cost values taken from the Unit Costs of Health and Social Care 2008<sup>188</sup>

	Whole programme (ante and post natal care)	Antenatal care only	
		Cost	Time spent on AN Care*
<b>Intervention 1</b>			
Midwife 0.5WTE <sup>†</sup>		£25,393	
<b>TOTAL</b>		<b>£25,393</b>	
<b>Intervention 2</b>			
1 full-time addiction nurse (nurse specialist in PSSRU – same for items below)	£50,785	£33,857	2/3
1 full-time health visitor	£50,790		
1 full-time midwife	£50,785	£50,785	All
2 full-time nursery officers	£101,580	£25,395	¼
1 full-time manager <sup>‡</sup> (social work background)	£61,880	£30,940	½
1 part-time administrator <sup>§</sup>	£24,097	£18,073	¾
home visits ( 15 per week)**	£1,092	£1,092	
<b>TOTAL</b>	<b>£339,917</b>	<b>£160,141</b>	
<b>Intervention 3</b>			
1 consultant midwife (manager)	£61,880	£30,940	½
2 specialist midwives for drugs and alcohol	£101,570	£101,570	All
1 specialist midwife for mental health	£50,785	£50,785	All
1 specialist midwife for sexual health and HIV	£50,785	£50,785	All
1 specialist health visitor for drugs and alcohol	£50,790		
1 full-time administrator	£24,097	£18,073	1/2
<b>TOTAL STAFFING COSTS</b>	<b>£339,907</b>	<b>£252,153</b>	
home visits (25 per week)	£1,820	£1,820	
<b>TOTAL</b>	<b>£341,727</b>	<b>£253,973</b>	

Although no specific costs were found for births to vulnerable women, analysis has been carried out in the UK on the cost of preterm births.<sup>189</sup> This reported the costs of initial birth admissions by gestational age over and above the costs for a full-term birth in the following groups: <28 weeks, 28 to 31 weeks, 32 to 36 weeks (Table 8.3). For substance misusing mothers there may be an additional need for neonatal intensive care for babies suffering neonatal abstinence syndrome. Practice appears to be changing regarding this,

\* Assumptions based on the descriptions of the services

† The cost to employ a midwife is not reported in the Unit Costs of Health and Social Care 2008, the cost to employ a nurse specialist (community) was used instead (£50,785 per annum) this includes wages, salary oncosts, qualifications, overheads and capital overheads.

‡ The cost of employing a Nurse advanced (lead specialist, clinical nurse specialist, senior specialist, nurse practitioner) was used as a proxy for a manager

§ The cost of employing a home care worker was used as a proxy for an administrator

\*\* £1.40 per home visit based on community health service travel costs

and as figures on how many babies requiring intensive care was not known it was felt best to leave these costs out of the analysis.

**Table 8.3** Initial birth admission costs over full-term admission costs and the costs of first year readmission among infants who survived the initial birth admission, Petrou et al. Pediatrics 2003<sup>189</sup> uplifted to 2008 prices

	Mean initial birth admission costs over full-term admission costs	Among infants who survived the initial birth admission, the mean cost of first year readmissions
<28 weeks	£8,611	£15,293
28 to 31 weeks	£8,803	£10,325
32 to 36 weeks	£1,732	£2,546
>=37 weeks	£1,113	£440

There are likely to be additional costs related to pre-term births and maternal mortality. Cost due to readmissions in the first year will be added in a sensitivity analysis. If the intervention is found to be cost-effective with birth admission costs alone then taking into account the additional costs will reinforce this result.

### Outcomes

The guideline is looking at improving access to antenatal care. For the health economics modelling we cannot use improved access as the final outcome of the model. We need to consider the health effects of improved access to be able to determine whether the intervention is a good use of resources. The outcomes chosen for the model were based on the data available for the populations. Therefore the health outcomes used were number of pre-term births, neonatal deaths, and maternal mortality.

CEMACH reported all births by gestational age, including neonatal deaths<sup>190</sup>. These figures were used to calculate percentages of births by gestational age in the following groups; <28 weeks, 28 to 31 weeks, 32 to 36 weeks, and full-term births. These figures were for all births not specifically vulnerable women but as there were no data available for these group it is a conservative assumption that vulnerable mothers will experience the same proportions of preterm births, and corresponding neonatal deaths (Table 8.4) (Table 8.5).

**Table 8.4** CEMACH Perinatal Mortality 2006 England, Wales and Northern Ireland: Perinatal mortality = stillbirths + early neonatal deaths<sup>190</sup>

	Live births	Perinatal deaths	All maternities*
Total number of pregnancies	693,505	5,319	698,824
<28 weeks	3329	1927	5,256
28-31 weeks	6281	795	7,076
32-36 weeks	42685	1071	43,756
37+ weeks	641210	1526	642,736
Total of preterm	52,295	3,793	5,256

**Table 8.5** Proportions used in the model for preterm births

	Gestational age as % of all births	Gestational age as % of all preterm	perinatal deaths as % of all births
<28 weeks	0.01	0.09	0.37
28-31 weeks	0.01	0.13	0.11
32-36 weeks	0.06	0.78	0.02
37+ weeks	0.92		0.002

\* Maternities are the number of pregnancies that result in a live birth at any gestation or stillbirths occurring at or after 24 weeks completed gestation and are required to be notified by law.

The model includes maternal deaths. The CEMACH report showed numbers of deaths of substance misusing mothers by antenatal care attendance. But only the number of deaths was reported, not the total number of maternities or mortality rate, so we were unable to reflect increased mortality due to poor antenatal care. The mortality rate for the lowest socioeconomic group was applied to this population as a proxy, 23.8 per 100,000 maternities.\*

CEMACH did not report specifically on teenagers. The overall maternal mortality for women under 20 years is 9.9 per 100,000<sup>3</sup>. We do not know the quantity or timing of the antenatal care these women received. So it has been assumed that maternal mortality was the same regardless of when antenatal care began or how many appointments the women attended.

### QALYs

For previous maternity guidelines, health economic models have assumed that the total discounted health gain of an otherwise healthy infant is 25 QALYs over its life time<sup>†</sup>. No quality of life data were found for children who were born preterm. Prematurity can be associated with increased medical and development problems and so a decrement was applied to babies born too early. As the decrement was unknown we had to make assumptions on how the quality of life would be affected. A 0.1 decrement was applied to the quality of life of children born at 32 to 36 weeks gestation. A 0.15 decrement was applied to children born at 28 to 31 weeks gestation. And a 0.2 decrement was applied to children born at less than 28 weeks gestation. (Table 8.6)

The GDG felt that children born to substance misusing mothers were likely to have a lower health related quality of life than other children. A decrement of 0.1 was applied to represent this loss. Therefore for each full QALY that would be gained for a full-term baby born to a healthy mother it is assumed that a full-term baby born to a substance misusing mother will only gain 0.9 of a QALY. An additional decrement was applied to preterm births as described above. (Table 8.6)

The QALY loss due a maternal mortality was calculated by taking the average life expectancy of a woman in the UK, currently 82 years, and working out the number of QALYs they would expect to achieve in their lifetime, approximately 28 QALYs. The QALYs expected to be achieved by a 29 year old woman (the average age of a pregnant woman in the UK) were subtracted from this, approximately 19 QALYs.

**Table 8.6** QALY inputs for model

	Substance misusers	Teenagers
Healthy baby living to 79years	23	25
preterm birth 32 to 36 weeks	21	23
pre-term birth 28 to 31 weeks	20	21
pre-term birth <28 weeks	19	20
maternal death avoided*	9	9

\* life expectancy of a woman = 82years, average age of pregnant women = 29years.

## Substance Misuse

### Substance Misusers – base case

Assuming that 3% of maternities are to substance misusers (N=20,490), each service will see approximately 135 women a year (dividing the maternities between the 152 PCTs in England and Wales).

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\* Maternities are the number of pregnancies that result in a live birth at any gestation or stillbirths occurring at or after 24 weeks completed gestation and are required to be notified by law

† This is comprised of an estimate of an average life expectancy of 76 years, with all years lived assumed to be at full health, and discounted at a rate of 3.5% per year. This gives a figure of approximately 25 discounted QALYs per individual through their lifetime. We discount future health gains to reflect the fact that an individual would typically value health more in the present than in the future. Although it does not seem realistic to assume that all years lived will be at full health, the process of discounting health gains means that most of the QALYs gained are accrued when the individual is young, and very little health gain is accrued at an older age. (Induction of Labour July 2008)<sup>11</sup>

As no effectiveness data were available, the specialist service was assumed to be as clinically effective as standard antenatal care once women were in the service. It was assumed that women who book before 12 weeks and stay in antenatal care would be 80% likely to have a full-term birth.

For women who book late or do not book it was assumed that the probability of a full-term birth was 70%. The maternal mortality rate for substance misusers was 23.8 per 100,000 maternities.

It was assumed that the only benefit of the specialist service was due to increasing the number of women who book before 12 weeks and maintaining contact. Using the evidence from Miles et al., 2006<sup>47</sup> which used historical controls, in the period 1997-2001 86.6% of women had their booking visit in the first trimester. In the period 1991-1994, before the specialist service was introduced, 58.7% of drug users had booked in the first trimester of pregnancy. Therefore it has been assumed that 59% of drug using women book before 12 weeks when only standard antenatal care is provided, this is approximately 80 women out of the 135 drug using pregnant seen by each PCT in the study.

### Results for substance misusers

If the assumptions above hold true then a specialist service costing £25,000 provided in addition to standard antenatal care would need to book four more women per year (84 vs. 80 women) by 12 weeks gestation in order for the service to be considered cost-effective (Table 8.7). This is equivalent to a part-time dedicated midwife service (see the service descriptions in appendix D for more details)

For a £150,000 service 20 more women would need to be booked early and stay in antenatal care than are booked with the standard care alone. This is equivalent to a service with a full-time midwife, a part-time addiction nurse and nursery officer, and a part-time manager and administrator.

For a £250,000 service 33 more women would need to be booked early. This is equivalent to two specialist midwives for drugs and alcohol, one specialist midwife for mental health, one specialist midwife for sexual health, a part-time consultant midwife to manage the service, and a part-time administrator.

**Table 8.7** The threshold number of additional women booking before 12 weeks and maintain contact in order for each service to be considered cost-effective (at £20,000 per QALY).

Cost of service	% increase in women booking early	Additional number of women (over the 80 booked with standard care alone)	cost per QALY
£25,000	5%	4	<£20,000
£150,000	25%	20	<£20,000
£250,000	41%	33	<£20,000

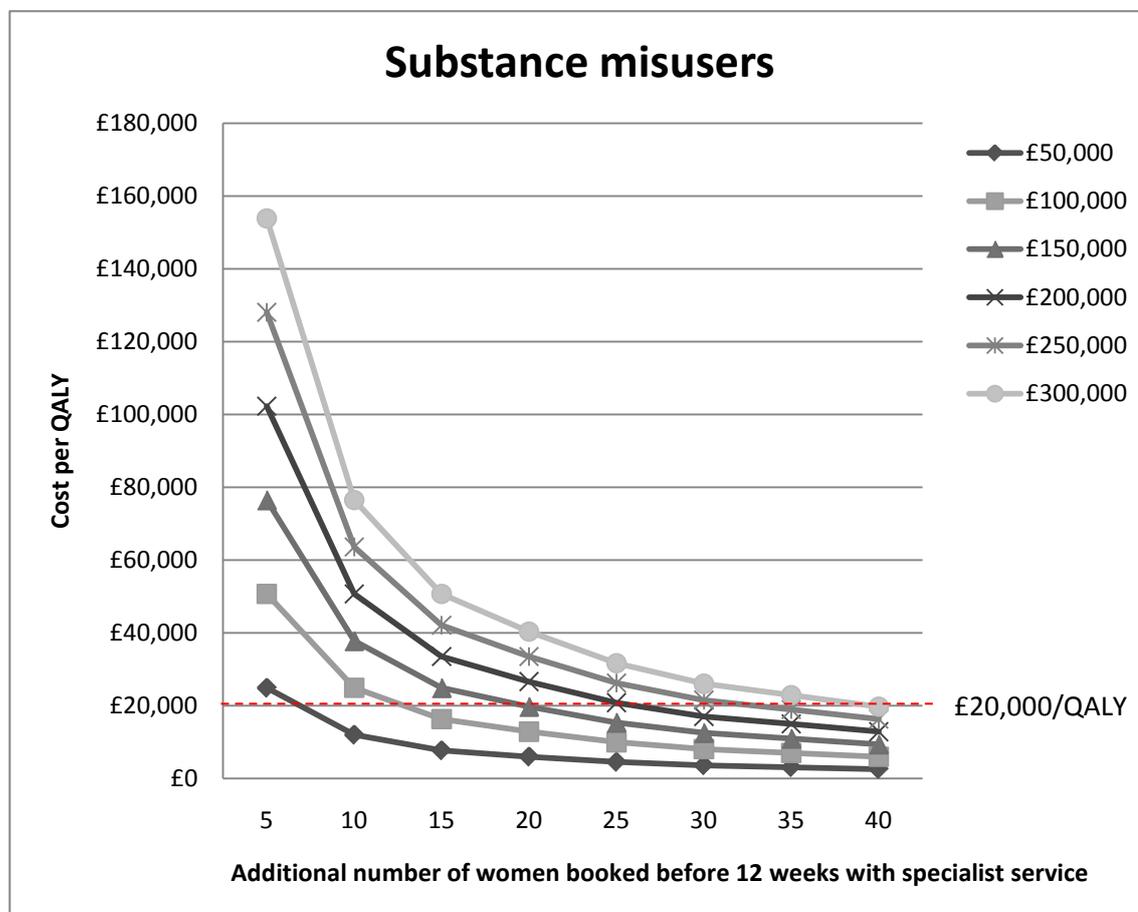
Table 8.8 demonstrates how this 'what if' analysis works. We do not know how many more women would book early with the specialist service so the model steadily increases the number until we show the service is cost-effective.

**Table 8.8** Demonstration of incremental increase in number of women booking early to find the threshold at which a £150,000 service would become cost-effective (<£20,000 per QALY)

Additional number of women booking early	Cost per QALY
5	£76,464
10	£37,778
15	£24,882
20	£19,724

Using the base case assumptions we can see how cost effective specialist services would need to be when they cost between £50,000 and £300,000. Any points below the red line, a cost per QALY of £20,000, would be where a service is considered cost effective. If a service can only book 10 more women before 12 weeks and maintain contact, then it is only worth spending £50,000 on the service. If in a year a service books 40 more women early and maintains contact during the antenatal period, then it would be cost effective to spend up to £300,000 per year on the service (see figure.8.2)

**Figure 8.2** Cost effectiveness of a specialist service for substance misusers by cost of service and additional number of women booking early and maintaining contact (over the ~80 booked early with standard antenatal care alone)



**Sensitivity Analyses for substance misusers**

As the number of maternities to substance misusers in England and Wales is unknown, we have tested how changing the number of pregnancies to substance misusers affects the number of women who would need to be booked early to antenatal care (Table 8.9).

The base case population was assumed to be approximately 20,000 maternities a year, which is 3% of all maternities. If this population is divided equally between all PCTs then each antenatal service will see approximately 135 substance misusing women a year. In this population a £25,000 service will need to increase the number of women booking early by 5%.

For the sensitivity analysis we also tested a smaller population, 13,660 maternities a year or 2% of all maternities. This would give an average population per PCT of 90 substance misusing women.

A greater number of maternities to substance misusers was also tested, 27,320 or 4% of all maternities. This would give an average population per PCT of 180 substance misusers.

If a service is set up to help a smaller population it will have to be more effective, getting a higher proportion of women to book early, in order to be found to be cost-effective. If there is a greater population that can benefit from the service then it is more likely to be found to be cost-effective.

**Table 8.9** Effect of changing the population size (number of maternities to substance misusers)**£25,000 service**

No. of maternities per year to substance misusers (% of all maternities)	% increase in women booking early to make service cost-effective	Cost per QALY
Base case 20,490 (3%)	5%	<£20,000
13,660 (2%)	8%	<£20,000
27,320 (4%)	4%	<£20,000

**£150,000 service**

No. of maternities per year to substance misusers (% of all maternities)	% increase in women booking early to make service cost-effective	Cost per QALY
Base case 20,490 (3%)	25%	<£20,000
13,660 (2%)	40%	<£20,000
27,320 (4%)	21%	<£20,000

**£250,000 service**

No. of maternities per year to substance misusers (% of all maternities)	% increase in women booking early to make service cost-effective	Cost per QALY
Base case 20,490 (3%)	41%	<£20,000
13,660 (2%)	64%	<£20,000
27,320 (4%)	32%	<£20,000

As we do not know how effective timely antenatal care is at reducing pre-term births the base case assumption was that women receiving poor antenatal care with the first appointment booked after 12 weeks would result in 70% having full-term births. Whereas women booking within the first trimester and maintaining contact, would be more likely to have a full-term birth, 80% of maternities. The sensitivity analysis shows that if the full-term birth rate is actually lower for late bookers (65%) then a service that manages to book women earlier will have to help fewer women in order to be considered cost-effective (16% increase in women booking early). If however women have full-term births regardless of when they book (75% of late bookers have full-term births) then the specialist service would need to book more women (50% increase in women booking early) in order for the service to be considered cost-effective. (Table 8.10)

**Table 8.10** Effect of changing the rate of full-term births to women who book late (£150,000 service)

Full-term births to late bookers/ non-attenders	% increase in women booking early	Cost per QALY
Base case 70%	25%	<£20,000
63%	15%	<£20,000
77%	Cost per QALY always above threshold	

As we do not know how effective antenatal care is at improving birth outcomes we have also tested the effectiveness of early booking. If timely antenatal care is less effective at improving outcomes in this population than our base case assumption of 80% full-term births then a service will have to help more women in order to be considered cost-effective (booking 50% more women booking early). And if the base case assumption underestimates the effectiveness of timely antenatal care then fewer women would need to book early before the service is considered cost-effective (16% increase in women booking early). (Table 8.11)

**Table 8.11** Effect of changing the rate of full-term births to women who book early (£150,000 service)

Full-term births to early bookers	% increase in women booking early	Cost per QALY
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## Pregnant women with complex social factors

Base case 80%	25%	<£20,000
72%	Cost per QALY always above threshold	
88%	15%	<£20,000

To make the model conservative only the initial birth costs were included. Readmissions in the first year for a pre-term baby can be considerable (see Table 8.3). These were added to see how it would affect the cost-effectiveness of the £150,000 service. Including these additional costs would make the specialist services more cost-effective but not significantly as it would need the same increase in number of women booking in the first trimester.

**Table 8.12** Effect of adding costs of readmissions in the first year to birth admission costs (£150,000 service) (see Table 3 for actual costs)

Costs of pre-term births	% increase in women booking early	Cost per QALY
Base case birth admissions only	25%	£19,724
Readmissions in first year included	25%	£18,733

No sensitivity analysis was performed varying the number of women who book early with standard care. The increase in number of women needed to book early to make a specialist service cost-effective will be the same regardless of the starting point. For example if it were considered that only 40% of women would book in the first trimester with standard antenatal care then a specialist service would still need to book an extra 20 women for a £150,000 service to be considered cost-effective.

### Teenagers

#### Teenagers – base case

Assuming that 7% of maternities are to teenagers (n=47,810). Each service will see approximately 315 teenagers a year.

As no effectiveness data were available the specialist service is considered to be equally as effective as standard antenatal care. It was assumed that women who book before 12 weeks and stay in antenatal care would be 80% likely to have a full-term birth. Women who book in this time are assumed to have a maternal mortality rate of 9.9 per 100,000 maternities.

For women who book late or do not book it was assumed that they would be 70% likely to have a full-term birth. The maternal mortality rate for this group was assumed to be the same as for early bookers.

The only benefit of the specialist service is by increasing the number of women who book before 12 weeks. Using the evidence from a study comparing school based antenatal care to hospital based care<sup>116</sup>, in the group using the school-based service 58.5% of women had their booking visit in the first trimester, and in the group using the hospital based service 45.4% had booked in the first trimester of pregnancy. Therefore it has been assumed that 45% of women will book before 12 weeks when only standard antenatal care is provided, this is approximately 142 women out of the 315 seen by each PCT.

#### Results for teenagers

If the assumptions above hold true then a specialist service costing £25,000 provided in addition to standard antenatal care would need to book 3 more women per year (145 vs. 142 women) by 12 weeks gestation in order for the service to be considered cost-effective. (Table 8.7) This is equivalent to a part-time dedicated midwife service.

For a £150,000 service 15 more women would need to be booked early and stay in antenatal care than are booked with the standard care alone. This is equivalent to a service with a full-time midwife, a part-time nurse and nursery officer, and a part-time manager and administrator.

For a £250,000 service 28 more women would need to be booked early. This is equivalent to 4 specialist midwives, a part-time consultant midwife to manage the service, and a part-time administrator.

**Table 8.13** How many more women will need to book before 12 weeks and maintain contact in order for each service to be considered cost-effective (the number of women needed to result in a cost per QALY under £20,000).

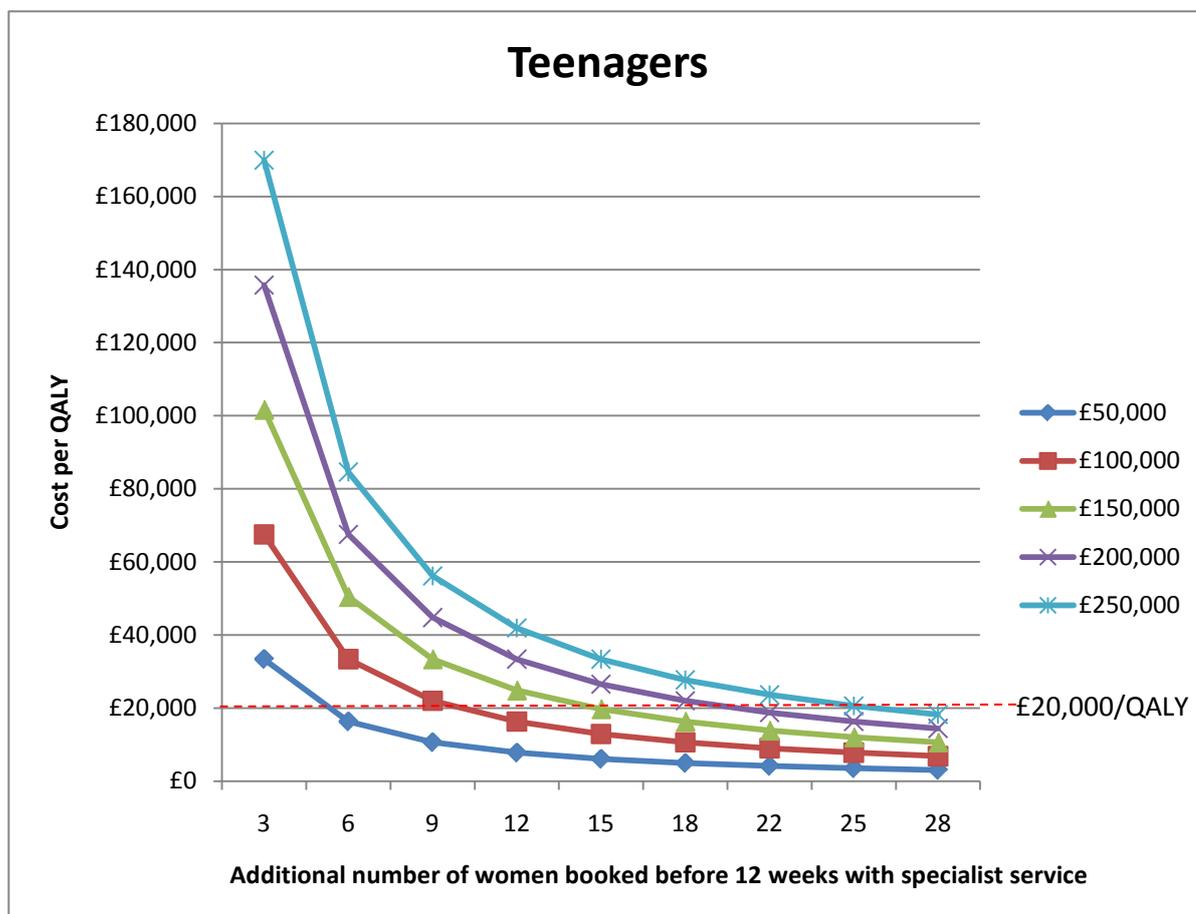
Cost of service	% increase in women booking early	Additional number of women (over the 142 booked with standard care alone)	cost per QALY
£25,000	2%	3	<£20,000
£150,000	11%	15	<£20,000
£250,000	20%	28	<£20,000

**Table 8.14** Demonstration of incremental increase in number of women booking early to find the point at which a £150,000 service would become cost-effective (<£20,000 per QALY)

Additional number of women booking early	Cost per QALY
3	£101,665
6	£50,482
9	£33,421
12	£24,890
15	£19,772

Using the base case assumptions we can see how cost effective specialist services would need to be when they cost between £50,000 and £250,000. Any points below the red line, a cost per QALY of £20,000, would be where a service is considered cost effective. If a service can only book 6 more women before 12 weeks and maintain contact, then it is only worth spending £50,000 on the service. If a service can book 28 more women early and maintain contact, then it would be worth spending up to £250,000 on the service.

**Figure 8.3** Cost effectiveness of a specialist service for teenagers by cost of service and additional number of women booking early and maintaining contact.



**Sensitivity Analyses for teenagers**

As we do not know how effective timely antenatal care is at reducing pre-term births the base case assumption was that teenagers receiving poor antenatal care with the first appointment booked after the first trimester would result in 70% having full-term births. Whereas women booking within the first trimester and maintaining contact, would be more likely to have a full-term birth, 80% of maternities in this population. The sensitivity analysis shows that if the full-term birth rate is actually lower for late bookers (65%) then a service which gets women to book earlier will have to help fewer women in order to be considered cost-effective (8% increase in women booking early). If however women have full-term births regardless of when they book (75% have full-term births) then the service will need to book more women (22% increase in women booking early) in order for the service to be considered cost-effective. (Table 8.15)

**Table 8.15** Effect of changing the rate of full-term births to women who book late (£150,000 service)

Full-term births to late bookers/ non-attenders	% increase in women booking early	Cost per QALY
Base case 70%	11%	<£20,000
63%	6%	<£20,000
77%	37%	<£20,000

As we do not know how effective antenatal care is at improving birth outcomes we have also tested the effectiveness of early booking. If timely antenatal care is less effective at improving outcomes in this population than our base case assumption of 80% full-term births then a service will have to help more women in order to be considered cost-effective (booking 22% more women booking early). And if the base case assumption underestimates the effectiveness of timely antenatal care then fewer women would need to book early before the service is considered cost-effective (8% increase in women booking early).(Table 8.16)

**Table 8.16** Effect of changing the rate of full-term births to women who book early (£150,000 service)

Full-term births to early bookers	% increase in women booking early	Cost per QALY
Base case 80%	11%	<£20,000
72%	37%	<£20,000
88%	6%	<£20,000

To make the model conservative only the initial birth costs were included. Readmissions in the first year for a pre-term baby can be considerable (see Table 8.3). These were added to see how it would affect the cost-effectiveness of the £150,000 service. Including these additional costs would make the specialist services more cost-effective but not significantly as it would need the same increase in number of women booking in the first trimester.

**Table 8.17** Effect of adding costs of readmissions in the first year to birth admission costs (£150,000 service) see Table 8.3for actual costs

Costs of pre-term births	% increase in women booking early	Cost per QALY
Base case birth admissions only	11%	£19,772
Readmissions in first year included	11%	£19,007

## Discussion

These analyses were carried out to support the GDG decision making. As they are 'what if' analyses and are not based on good quality clinical evidence they can only be used to illustrate the problem as we do not know how effective specialist services will be in the real world. With the lack of clinical evidence it was not possible to give a result as an incremental cost-effectiveness ratio which would allow decisions to be made on the opportunity costs of resources. The analyses go backwards taking the NICE threshold for what is considered cost-effective for preventative treatments and finding out what level of effectiveness a service would need to show in order to reach that threshold. Given the variations in populations of vulnerable women by location the cost-effectiveness of a particular service will very much depend on the population it serves. As the economic model in its current form does not result in an incremental cost-effectiveness ratio it cannot be used as the basis for recommendations. Rather it illustrates the problem and shows where recommendations are likely to be cost-effectiveness based on the assumptions in the model. In order to make actual recommendations based on these analyses requires data collected from specialist services.

In order to make the analyses as useful as possible we have tried to make the assumptions conservative. If the benefits from beginning antenatal care before 12 weeks and maintaining contact are better than we have assumed in the base case then it is very likely that the specialist service will be cost-effective. Of course, the opposite may also be true. For this reason it is important that where specialist services are introduced they are audited.

For a PCT that saw approximately 135 women pregnant substance misusers a year we have assumed that 59% (N=80) of women would book early and maintain contact with routine antenatal care only. In order for a £25,000 additional service to be considered cost-effective an additional 4 women would need to book early and maintain contact (84 vs. 80 women). This service could be a part-time midwife providing weekly clinics specifically for booking substance misusers.

As substance misusers can have chaotic lifestyles they may require additional appointments to help with housing, benefits, and to co-ordinate their care and a more comprehensive service would be needed. For a £250,000 service to be considered cost-effective, where there may be 4 full-time midwives who provide this additional care, the service would have to book 33 more women early and maintain their care.

For a PCT that saw approximately 315 pregnant teenagers a year we have assumed that 45% (N=142) of women would book early and maintain contact with routine antenatal care only. In order for a £25,000 service to be considered cost-effective an additional 3 women would need to book early and maintain contact. This service would be provided in addition to the routine care that is recommended in the NICE ANC guideline (2008)<sup>1</sup>. This may be a service that provided information directed to teenagers such as leaflets and posters, or having an administrator who texts teenagers to remind them of appointments.

At the other end of the scale a £250,000 service would need to book 28 more teenagers early and maintain contact for it to be considered cost-effective. This level of a service could provide additional midwives which would allow more appointments, home visits, or clinics in community settings.

The more resources required for a service the more effective the service will need to be at booking women early and maintaining contact. If the specialist service provided support for more women, there is a larger substance misusing population than has been assumed in this analysis, then the service is likely to be more cost-effective.

If women have worse birth outcomes if they book late then a service to encourage women to book earlier is likely to be more cost-effective. If in fact the timing of antenatal care has little impact on birth outcomes then the service will be less cost-effective.

The proportion of teenagers booking early into standard care was taken from a US study comparing hospital and school based care. As no UK studies were found this was the best evidence available. For the substance misusers a study in the UK using historical controls was used as again this was the best available evidence of the proportion of women booking early into antenatal care. The increase in number of women needed to book early to make a specialist service cost-effective will be the same regardless of the starting point. It has been assumed that the specialist service will not produce any additional health benefits above those gained from routine antenatal care. The only benefit is through early booking and maintaining contact. If after auditing services it was found that a specialist service did improve birth outcomes compared to routine antenatal care then the numbers of women booking into each service would become more important to the analysis.

The main driver for this analysis is the assumption that a woman who books into antenatal care early and attends their appointments will have better health outcomes than a woman who books late or only attends a few appointments. If women have healthy birth outcomes regardless of the antenatal care they receive then providing an additional service to ensure they are accessing antenatal care would be less cost-effective or even not cost-effective. And conversely, if early booking and maintaining contact has a greater effect on birth outcomes than we have assumed in the model then providing an additional service will become more cost-effective.

However, there are other benefits beyond the health of mother and birth outcomes. With vulnerable women there will be social benefits which may in turn improve health outcomes for the mother and child later in life. For instance care that improves parenting skills is a social benefit, but may in turn cause health and education benefits.

A lack of good quality UK based evidence was the main limitation for these models. The inputs used have been conservative in order to make the results useful for decision making. For instance the only costs included for pre-term births were the initial birth admission costs. When readmissions in the first year were included the services became more cost-effective.

The analyses reported here can support the GDGs recommendations to provide additional services for teenagers and substance misusers given the available evidence. Audits of existing services and new services will provide more evidence that can be used to update these analyses in the future to provide better quality economic evidence for these services.

# Appendix A

## Scope

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### NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

### SCOPE

#### 1 Guideline title

Pregnant women with complex social factors: a model for service provision.

##### *1.1 Short title*

Pregnancy and complex social factors

#### 2 Background

a) The National Institute for Health and Clinical Excellence ('NICE' or 'the Institute') has commissioned the National Collaborating Centre for Women's and Children's Health to develop a clinical guideline on the care of pregnant women with complex social factors for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health (see appendix). The guideline will provide recommendations for service provision that are based on the best available evidence of clinical and cost effectiveness.

b) NICE clinical guidelines support the implementation of National Service Frameworks (NSFs) in those aspects of care where a Framework has been published. The statements in each NSF reflect the evidence that was used at the time the Framework was prepared. The clinical guidelines and technology appraisals published by NICE after an NSF has been issued have the effect of updating the Framework.

c) NICE clinical guidelines support the role of healthcare professionals in providing care in partnership with patients, taking account of their individual needs and preferences, and ensuring that patients (and their carers and families, if appropriate) can make informed decisions about their care and treatment.

### 3 Clinical need for the guideline

a) Confidential enquiries into maternal and child deaths have consistently identified underlying social factors as having a significant influence on poor birth outcomes for mothers and babies. In the 2007 Confidential Enquiry into Maternal and Child Health (CEMACH), women living in areas of England with the highest deprivation scores were found to have a mortality rate due to direct and indirect causes during pregnancy and up to 42 days after giving birth that was five times higher than the rate for women living in areas with the lowest score. Seventeen per cent of women who died had a concealed pregnancy, no antenatal care or had registered with an antenatal service after the 22nd week of pregnancy. Forty per cent of the women of black African origin, 57% of the women of black Caribbean origin and 25% of the women of Middle Eastern origin who died were late or non-attenders for antenatal care. Complex social factors that are associated with an increased risk of maternal death include contact with the child protection services or social services, substance misuse, domestic abuse, being single, being unemployed, having a partner who is unemployed or employment unclassifiable, being a recent migrant to the UK and speaking no English. Certain ethnic groups seem particularly vulnerable: women of black African and black Caribbean origins have a higher risk of maternal mortality than women from other ethnic backgrounds. The rates of maternal death among women with a black African or black Caribbean family origin are 62.4 and 41.1 per 100,000 pregnancies, respectively, compared with 11.1 per 100,000 pregnancies for women with a white family background.

b) Babies of women living in complex social circumstances have an increased risk of dying during the perinatal period. The 2006 CEMACH perinatal mortality figures showed that babies born to women living in the most deprived areas were 1.7 times more likely to be stillborn or to die shortly after birth than babies born to women in the least deprived areas. The stillbirth rate was 3.7 for every 1000 live births in the least deprived areas and 6.4 for every 1000 live births in the most deprived areas. The neonatal mortality rate was 2.2 per 1000 live births in the least deprived areas, rising to 3.8 per 1000 live births in the most deprived areas. The rate of stillbirth in babies born to women with a black ethnicity (African, Caribbean or other) was 2.3 times higher than the rate among babies born to women of white ethnicity. The neonatal death rate was twice as high for babies born to women of black ethnicity compared with babies born to women with white ethnicity. Similarly, the stillbirth rate and neonatal death rate for babies born to women of Asian ethnicity were 2.0 and 1.8 times higher, respectively, compared with those for babies born to women of white ethnicity. Babies of women aged under 20 years were also at risk of higher rates of neonatal mortality with a stillbirth rate of 5.6 per 1000 total births and a neonatal death rate of 3.7 per 1000 total births.

c) One of the main issues appears to be that women with complex social factors do not access, or do not maintain contact with, maternity services. This may be because they find it difficult to do so or because they choose not to for a variety of reasons. For those who are in contact with a maternity service, it is unclear whether the care they receive is appropriate to their needs. The need to improve access and develop services that meet the needs of pregnant women with complex social factors is highlighted in the Department of Health publication 'Maternity matters'.

d) There are a number of complex social factors that may have an impact on maternal and infant outcome. All of these are important. The factors identified in section 4.1.1 have been chosen to illustrate the key issues that need to be considered in developing a guideline for care of pregnant women with complex social factors. There are others that could also have been chosen for this purpose but it is not possible to include all complex social factors in one guideline.

## 4 The guideline

a) The guideline development process is described in detail in two publications that are available from the NICE website (see 'Further information'). 'The guideline development process: an overview for stakeholders, the public and the NHS' describes how organisations can become involved in the development of a guideline. 'The guidelines manual' provides advice on the technical aspects of guideline development.

b) This document is the scope. It defines exactly what this guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health (see appendix A).

c) The areas that will be addressed by the guideline are described in the following sections.

### 4.1 Population

#### 4.1.1 Groups that will be covered

a) Women who do not access, or do not maintain regular contact with, antenatal maternity services. Four areas have been chosen as exemplars for this population and will be used to guide the development of service provision. These groups of women have been identified by national maternal and perinatal mortality reports as being at increased risk of poor pregnancy outcomes – pregnant women who:

- have a substance misuse problem (including abuse of alcohol)
- are migrants to the UK, including refugees or asylum seekers, particularly women who do not speak English
- are aged under 20 years
- experience domestic abuse.

b) It is recognised that there are many other identifiable groups of women who have a number of interacting adverse social factors complicating pregnancy. While systematic guideline searches will focus on the groups identified above (4.1.1a), where other overlapping factors appear in combination with those identified these groups of women will be included.

**4.1.2 Groups that will not be covered** Women who book before 20 weeks and maintain contact with maternity services.

## **4.2 Healthcare setting**

This guideline will describe what constitutes appropriate settings for maternity care provision to reach these vulnerable groups of women.

## **4.3 Service organisation and delivery**

This guideline will focus on service organisation and delivery and will not address clinical management. It will:

- a) Identify and describe best practice for service organisation and delivery that will improve access, acceptability and use of services.
- b) Identify and describe services that encourage, overcome barriers to and facilitate the maintenance of contact throughout pregnancy.
- c) Describe additional consultation with and/or support and information for women with complex social factors, and their partners and families, during pregnancy, over and above that described in the 'Antenatal care: routine care for the healthy pregnant woman' (NICE clinical guideline 62).
- d) Identify when additional midwifery care or referral to other members of the maternity team (obstetricians and other specialists) would be appropriate, and what that additional care should be.
- e) Define a pathway of care to help decide when a woman should return to midwifery care or remain under the care of the maternity team.
- f) Identify ineffective, inaccessible and/or less acceptable interventions barriers and approaches to care where possible. If robust and credible recommendations for re-positioning the intervention for optimal use, or changing the approach to care to make more efficient use of resources, can be made, they will be clearly stated. If the resources released are substantial, consideration will be given to listing such recommendations in the 'Key priorities for implementation' section of the guideline.

## **4.4 Status**

### **4.4.1 Scope**

This is the final scope.

### **4.4.2 Guideline**

The development of the guideline recommendations will begin in September 2008.

## 5 Related NICE guidance

### Published

Improving the nutrition of pregnant and breastfeeding mothers and children in low-income households. NICE public health guidance 11 (2008). Available from:

[www.nice.org.uk/PH011](http://www.nice.org.uk/PH011)

Induction of labour. NICE clinical guideline 70 (2008). Available from:

[www.nice.org.uk/CG070](http://www.nice.org.uk/CG070)

Antenatal care: routine care for the healthy pregnant woman. NICE clinical guideline 62 (2008). Available from [www.nice.org.uk/CG062](http://www.nice.org.uk/CG062)

Intrapartum care: care of healthy women and their babies during childbirth. NICE clinical guideline 55 (2007). Available from: [www.nice.org.uk/CG055](http://www.nice.org.uk/CG055)

Antenatal and postnatal mental health: clinical management and service guidance. NICE clinical guideline 45 (2007). Available from: [www.nice.org.uk/CG045](http://www.nice.org.uk/CG045)

## 6 Further information

The guideline development process is described in:

- 'The guideline development process: an overview for stakeholders, the public and the NHS'
- 'The guidelines manual'

These are available from the NICE website ([www.nice.org.uk/guidelinesmanual](http://www.nice.org.uk/guidelinesmanual)).

Information on the progress of the guideline will also be available from the website.

## Appendix A: Referral from the Department of Health

The Department of Health asked NICE:

'To prepare guidance in collaboration with the Social Care Institute for Excellence on the management of pregnant women who have complex social factors for example, children in care under Child Protection Orders, new migrants and drug users.'

# Appendix B

## Declarations of interest

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All GDG members' interests were recorded on declaration forms provided by NICE. The form covered consultancies, fee-paid work, shareholdings, fellowships and support from the healthcare industry. GDG members' interests are listed in section. No material conflicts of interest were identified.

<b>GDG member</b>	<b>Interest</b>
Helen Adams	No interests declared
Jan Cubison	No interests declared
Sarah Fishburn	No interests declared
Poonam Jain	No interests declared
Rhona Hughes	No interests declared
Helen Kelly	No interests declared
Faye Macrory	<i>Non-personal, non-pecuniary specific interest</i> Founder and manager of a specialist midwifery service for women who misuse substances.in Manchester
Dilys Noble	No interests declared
Jan Palmer	No interests declared
Eva Perales	No interests declared
Daghni Rajasingam	No interests declared
Yana Richens	No interests declared
Mary Sainsbury	No interests declared
Melissa Whitworth	<i>Personal non-specific non-pecuniary interest</i> Executive Committee Member for British Maternal and Fetal Medicine Society
Annette Williamson	No interests declared

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<b>Expert adviser</b>	<b>Interest</b>
Donna Kinnair	No interest declared

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<b>NCC-WCH staff member</b>	<b>Interest</b>
David James	No interest declared
Anwar Jilani	No interest declared
Rosalind Lai	No interest declared

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<b>NCC-WCH staff member</b>	<b>Interest</b>
Carolina Ortega	No interest declared
Roz Ullman	No interest declared
Martin Whittle	No interest declared
Danielle Worster	No interest declared

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<b>Peer reviewer</b>	<b>Interest</b>
Lynda Mulhair	No interest declared

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# Appendix C

## Stakeholder organisations

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Action on Pre-Eclampsia

Adfam

Alder Hey Children's NHS Foundation Trust

Antenatal Screening Wales

Association For Family Therapy and Systemic Practice in the UK (AFT)

Association For Family Therapy and Systemic Practice in the UK (AFT)

Association for Improvements in the Maternity Services

Association of Breastfeeding Mothers

Association of Psychoanalytic Psychotherapy in the NHS

Association of the British Pharmaceuticals Industry (ABPI)

Barnet Enfield and Haringey Mental Health Trust

Barnsley Hospital NHS Foundation Trust

Barnsley PCT

Beckman Coulter UK Ltd

Berkshire Healthcare NHS Foundation Trust

Birmingham City Council

Birmingham Womens NHS Trust

Birth Trauma Association

Birth Trauma Association

BMFMS

Bolton Council

Breastfeeding Network, The

Brighton and Sussex University Hospitals Trust

British Association for Adoption and Fostering

British Association for Counselling and Psychotherapy

British Dietetic Association

British National Formulary (BNF)

British Paediatric Mental Health Group

British Pregnancy Advisory Service

Brook London

Calderdale PCT

Cambridge University Hospitals NHS Foundation Trust (Addenbrookes)

Care Quality Commission (CQC)

Chartered Physiotherapists Promoting Continence (CPPC)  
CIS'ters  
Citizens Commission on Human Rights  
City Hospitals Sunderland NHS Foundation Trust  
City University  
Cochrane Pregnancy & Childbirth Group  
Commission for Social Care Inspection  
Connecting for Health  
Department for Children, Schools and Families  
Department for Communities and Local Government  
Department of Health  
Department of Health Advisory Committee on Antimicrobial Resistance and Healthcare Associated Infection (ARHAI)  
Department of Health, Social Services & Public Safety, Northern Ireland (DHSSPSNI)  
Depression in Pregnancy  
Derbyshire Mental Health Services NHS Trust  
Det Norske Veritas - NHSLA Schemes  
Devon PCT  
Drinksense  
DrugScope  
EGAOH  
Evidence based Midwifery Network  
Fasawareuk  
Fatherhood Institute  
Gateshead PCT  
Gloucestershire PCT  
Government Office Yorkshire and the Humber  
Greater Manchester West Mental Health NHS Foundation Trust  
Gwent Healthcare NHS Trust  
Heart of England NHS Foundation Trust  
Hertfordshire Partnership NHS Trust  
Independent Midwives UK  
Institute of biomedical Science  
Institute of Health and Society  
JBOL Ltd  
King's College London  
Kingston Hospital NHS Trust  
La Leche League GB  
Leeds PCT  
Liverpool Women's NHS Foundation Trust

## Pregnant women with complex social factors

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Liverpool Womens NHS Foundation Trust  
Luton & Dunstable Hospital NHS Foundation Trust  
Manchester Community Health  
Maternal Health and Reproduction Resarch Group  
Maternity Health Links  
Medicines and Healthcare Products Regulatory Agency (MHRA)  
Mental Health Act Commission  
Mid and West Regional Maternity Service Liasion Committe  
MIDIRS (Midwives Information & Resource Service)  
Milton Keynes PCT  
Ministry of Defence (MoD)  
Mothersvoice  
MRSA Action UK  
National Childbirth Trust  
National Forum of LSA Midwifery Officers (UK)  
National Patient Safety Agency (NPSA)  
National Treatment Agency for Substance Misuse  
NCC - Cancer  
NCC - Mental Health  
NCC - National Clinical Guidance Centre (NCGC)  
NCC - Women & Children  
NETSCC, Health Technology Assessment  
Newham Primary Care Trust  
NHS Bedfordshire  
NHS Bournemouth and Poole  
NHS Clinical Knowledge Summaries Service (SCHIN)  
NHS Direct  
NHS Forth Valley  
NHS Isle of Wight  
NHS Kirklees  
NHS Knowsley  
NHS Plus  
NHS Quality Improvement Scotland  
NHS Sefton  
NHS Sheffield  
NHS South Central vascular Network  
NICE - CPHE  
NICE - Guidelines Coordinator - for info  
NICE - Guidelines HE for info  
NICE - IMPLEMENTATION CONSULTANT Region - East

NICE - IMPLEMENTATION CONSULTANT - Region London/SE  
NICE - IMPLEMENTATION CONSULTANT Region NW & NE  
NICE - IMPLEMENTATION CONSULTANT Region West Midlands  
NICE - IMPLEMENTATION CO-ORDINATION for info  
NICE - PPIP  
NICE - Technical Appraisals (Interventional Procedures) FOR INFO  
North Cheshire Hospitals  
North East London Mental Health Trust  
North Staffordshire Combined Healthcare NHS Trust  
North Tees and Hartlepool Acute Trust  
North Tees PCT  
North West London Perinatal Network  
North Yorkshire and York PCT  
Northumberland Tyne & Wear Trust  
Northumbria Healthcare NHS Foundation Trust  
Obstetric Anaesthetists Association  
Offender Health - Department of Health  
Offender Health - Department of Health  
Oxfordshire & Buckinghamshire Mental Health Partnership NHS Trust  
Partnerships for Children, Families, Women and Maternity  
Patients Council  
Pelvic Partnership, The  
PERIGON Healthcare Ltd  
Perinatal Institute  
Programme development Group in Maternal and Child Nutrition  
Public Health North East  
Public Wales NHS Trust  
Q-Med UK Ltd  
Queen Charlottes and Chelsea Hospital  
Queen Mary's Hospital NHS Trust (Sidcup)  
Queens University of Belfast  
RCM Consultant Midwives Group  
Retreat, The  
Royal College of General Practitioners  
Royal College of Midwives  
Royal College of Midwives  
Royal College of Nursing  
Royal College of Obstetricians and Gynaecologists  
Royal College of Paediatrics and Child Health  
Royal College of Pathologists

Royal College of Physicians London  
Royal Cornwall Hospitals Trust  
Royal Society of Medicine  
Salford Royal Hospitals Foundation NHS Trust  
Sands the Stillbirth & neonatal death charity  
Sandwell & West Birmingham Hospital NHS Trust  
Sandwell PCT  
Sandwell PCT  
Scottish Intercollegiate Guidelines Network (SIGN)  
Sedgefield PCT  
Sheffield Care Mental Health Trust  
Sheffield Care Trust - Sheffield Birth Centres group  
Sheffield Health and Social Care Foundation Trust  
Sheffield PCT  
Sheffield Perinatal Mental health service  
Sheffield Teaching Hospitals NHS Foundation Trust  
Social Care Institute for Excellence (SCIE)  
Social Exclusion Task Force  
South Essex Partnership NHS Foundation Trust  
South Staffordshire & Shropshire NHS Foundation Trust  
South Tees Hospitals NHS Trust  
South West Autistic Rights Movement  
St Ann's Hospital  
Survivors UK  
Sussex Partnership NHS Foundation Trust  
Tavistock & Portman NHS Foundation Trust  
Tees Esk & Wear Valleys NHS Trust  
The British Psychological Society  
The Royal College of Psychiatrists  
Torbay PCT  
UKPHA Alcohol & Violence Special Interest Group  
United Lincolnshire Hospitals NHS Trust  
United Lincolnshire Hospitals NHS Trust  
University Hospitals Coventry & Warwickshire NHS Trust  
University of Birmingham  
University of Nottingham  
University of Southampton  
University of York  
VBAC Information and Support  
Welsh Assembly Government

Welsh Scientific Advisory Committee (WSAC)

West Hertfordshire PCT & East and North Hertfordshire PCT

West Midlands SHA

Western Cheshire Primary Care Trust

Western Health and Social Care Trust

Womens Health and Reproduction Research Group at King's College London

Worthing and Southlands Hospital

Worthing and Southlands Hospital

York NHS Foundation Trust

Yorkshire and the Humber LSA

# Appendix D

## Service descriptions

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### Introduction

This appendix includes the service descriptions collected from a survey undertaken with the help of the GDG members. The service descriptions are included as illustrations of what can be provided for enhanced antenatal care for vulnerable women. For more details of how the descriptions were collected refer to the Methodology chapter.

The descriptions are presented by specific target population with the exception of the One to One Midwifery service at Imperial College Healthcare NHS Trust which is provided for all women where risk factors or concerns are identified. In addition, a description of an innovative method for providing information (The Women's Wheel©) has been included.

### All women with complex social factors

#### 1) Imperial College Healthcare NHS Trust (ICHT), London

##### Access to Care

Where social risk factors are identified in families receiving maternity care, enhanced service provision is offered through a One to One Caseload Midwifery service. Criteria for referral to the One to One scheme include:

- Domestic Abuse
- Mental Health concerns
- Any Child Protection concerns
- Parental substance misuse
- Under 19 at booking (leading to referral to specialist 'Young Mum's Team')
- Women who have been abused as children
- Victims of rape or torture
- Women who are homeless or asylum seeking
- Women with complex or multiple social risk factors

Women can be referred for One to One care by GPs, Health Visitors, Midwives and Obstetricians, and referral can happen at any point in pregnancy - whenever concerns or risk factors are identified.

##### Description of the service

Maternity Services at ICHT are provided through two of the Trust's five hospitals in London; Queen Charlotte's and Chelsea Hospital and St Mary's Hospital. Across the two sites, ICHT totals around 9500 births per year, providing care for local communities in over 6 Primary Care Trusts and acting as tertiary referral centres. There is huge ethnic diversity across the local communities, with 30 to 47% of the local populations born outside the UK. Levels of deprivation and children classed as living in poverty are 'significantly worse' than the average for England, as are levels of substance misuse, mental health concerns and violent crime. (Information from the 2009 Health Profiles at [www.apho.org.uk](http://www.apho.org.uk))

ICHT currently has 5 One to One Midwifery teams totalling 27 Midwives, all holding individual caseloads of 34-36 women per year. The One to One midwives provide full antenatal, intrapartum and postnatal care for all women referred to them. Women are allocated a named midwife to provide continuity, emotional and social support, flexible, individualised care and robust multi-agency liaison.

The One to One Midwives work in partnerships or small teams to provide all aspects of midwifery care, including a 24 hour on-call service for their clients. Women can choose to receive their care in community settings or at home when appropriate. Where hospital care is indicated, the One to One Midwives continue support for women, acting as their advocates and ensuring their care is co-ordinated.

### **Attendance**

With a dedicated One to One midwife working autonomously and organising her own diary, care can be tailored to meet women's needs, while any missed appointments are followed up promptly and efficiently. The overall aim is that women are offered a more intensive, individualised programme of care that is as accessible as possible and provided by someone they know.

### **Interfaces/links with other services**

Potential risks to children are assessed and either early intervention or safeguarding procedures initiated appropriately. Multi-agency liaison is co-ordinated and followed up, ensuring both high quality perinatal care and that longer term plans are initiated and professionals fully briefed so that care continues effectively after discharge from midwifery.

In addition to statutory services, links are constantly being developed and strengthened with the dynamic array of third sector agencies, both by the midwives themselves and by specialist staff within the Trust.

### **Training**

The complexities and emotional demands of caseloading vulnerable women are widely acknowledged at ICHT and the One to One Midwives are fully supported by managers and ICHT's Consultant Midwife for Public Health. Specialist Midwives and a Safeguarding Lead on each site, provide non-managerial support, case management advice, training and safeguarding supervision, with particular forums dedicated to supporting the One to One Midwifery service and multi-agency working.

### **Any other information**

For women, this service means having their care provided by someone that they come to know and trust - giving them the opportunity to form a strong working relationship with a professional. Where situations are complex or distressing, women do not have to keep re-telling their stories (or choosing not to). Having a known point of contact is helpful to women who might otherwise find it difficult to engage with care or ask questions and discuss issues. The Midwives also come to know their clients very well, which is invaluable in liaising and developing care plans with multi-agency colleagues, particularly in complex social cases.

### **Audit**

Outcomes achieved through the One to One service are monitored through a programme of continuous audit.

## **Services for women who misuse substances**

### **2) The Prepare Team, Edinburgh**

#### **Access to care**

PrePare accepts referrals from all agencies as well as from individuals themselves; however 51% of referrals received to date come from community midwives. The estimated number of pregnant drug users in the Lothian area was approximately 150; about 80 of whom are chaotic users. The rest are stable methadone or alcohol users.

The women referred to PrePare must have suspected or known illicit drug /alcohol use; be over 16years of age; have a confirmed pregnancy; not be engaging with mainstream services and additionally may have had experience with child protection concerns surrounding previous children.

The aim is for PrePare to work with 40 - 50 women in a year. These are the most chaotic, illicit drug users and many clients are involved in criminality or the sex industry to fund their drug use.

#### **Description of the service provided**

## Pregnant women with complex social factors

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The PrePare team in Edinburgh is a multi-agency service for drug using pregnant women for antenatal care and up to 3-6 months after birth. It has been established since July 2006. It is staffed by two full-time addiction nurses, one full-time health visitor, one full-time midwife, one full time senior nursery officer, 1.5 nursery officers, one full-time manager (social work background), and one part-time administrator. The PrePare team has expanded as they are receiving funding from the alcohol services to increase provision as they are dealing with more cases of alcohol misuse.

The addiction nurse has a post-graduate qualification in addiction. The other staff have attended various study days on addiction, blood born viral infections, etc. The team have many years experience in working with families who have difficulties with substance misuse and other social issues including poverty, poor housing etc. The Midwife was a community midwife in areas with high incidence of drug use prior to her taking the position within the team.

PrePare is an outreach programme and appointments are held where they are needed. There is a drop-in session with the midwife and addictions nurse every Thursday 2-4pm at the Harm Reduction Service in Edinburgh. Appointments can be held at doctors surgeries where appropriate, the DLM can hire rooms in children's centres, or do home visits. Full risk assessments are undertaken when assessing safety for home visits. A high proportion of home visits undertaken by the team are done jointly, with each team member supporting the other in their intervention.

They do not have group sessions. There are parent-craft classes for pregnant women with additional needs but the most chaotic drug users don't turn up to these.

Stable drug users see the community midwives and other mainstream services. If they stop turning up to appointments then they can be referred to the PrePare team.

Ideally this population should see the obstetrician and referrals are made, but the women frequently don't turn up for appointments. In these cases the obstetrician is kept up-to-date by telephone calls and e-mail.

There is a team meeting weekly to discuss new referrals and allocations as well as case planning. A package of care is determined by the team and the orange book guidelines for Lothian's 'Working with children living in families affected by parental substance use' is followed.

### **Additional Consultations**

The antenatal appointments are more frequent and longer than standard care. They happen every two weeks and are at least an hour long. The midwife's main remit is health of the woman and baby, but can also help with benefits, child protection issues and other problems.

Either the midwife or the nursery officers will regularly take women to hospital to have scans.

The addiction nurse deals with the drug / alcohol problems, seeing clients as often as necessary. The emphasis in the treatment they receive is to establish stability within a harm reduction principle.

Whilst engaging with this client group the nursery officers are establishing a supportive relationship whilst undertaking a comprehensive assessment of their situation and understanding of parenting. This will go towards recommendations surrounding the child protection process and long term plans for the care of the child.

### **Attendance**

The team spend a lot of time trying to engage women who don't attend, texting, phoning, making home visits. Later in the pregnancy when the client is more used to them they are better at attending. They give out their mobile numbers and can be contacted every day from 8am to 6pm, and there is the Thursday afternoon drop-in session.

The clients are encouraged to make meetings, home visits etc by a team ethos of acceptance and of not judging service users. The relationship is based on openness and honesty; clients are given choices about their care and have an active role in making decisions. However, it is made clear about the impact these choices they make will have on the planning for the baby's needs.

### **Interfaces/ links with other services**

The PrePare team communicates well with other agencies. These agencies refer women to them, and PrePare refers women to other agencies as required. PrePare works closely with DTTO (Drug Treatment and Testing Order) a new programme whereby instead of going to prison drug users are given court orders requiring them to attend weekly testing, screening and counselling.

PrePare works with the prison service, and the drugs referral team which can help women access education. The cases are complicated and a high proportion of women experience domestic violence. Also more women have drug and alcohol problems which are more complicated.

### **Audit data**

Currently the PrePare Team are undergoing an evaluation by Capital City Partnership.

### **3) The Jessop Wing, Sheffield**

#### **Access to care**

Identification and referral to the Specialist Midwife initially was through maternity services, with as high as 90% of pregnant women not accessing drug treatment. Local trends have changed significantly in the past few years with the majority of women already attending for drug treatment before becoming pregnant. Referrals are received from any professional, self referral or referral via a relative/friend. There were 202 women referred into the service between April 2008 and April 2009 with 96 pregnant women carried over to the next financial year.

Referrals for women who disclose social, recreational or historical drug or alcohol use have become a more prominent aspect of our role. As the history given by women does not reach the threshold for referral to drugs agencies enhanced/specialist assessment are often only undertaken by the specialist midwifery team. This opportunistic approach has proven to be very helpful in uncovering previously hidden dependency or hazardous drug/alcohol use and appropriate referrals have been initiated with safeguarding procedures triggered that would otherwise have been missed.

#### **Description of the service provided**

The Maternity Service (Jessop Wing) employs a team of three midwives (2.60wte) all with advanced addiction training. They are all general nurse trained and all have a diploma in addiction studies which incorporates a professional qualification in addiction counselling. The role of this team is to offer a formal link with all agencies ensuring a seamless service for women attending for care. They have one full time secretary.

The aim of the service is to promote attendance for mainstream care at both maternity and drug treatment services in order to maximise birth outcomes for mothers and babies. Enhanced clinical care is provided within the hospital setting both in the clinic setting and on the ante/postnatal wards. Pregnancy outreach clinics are also held within the addiction service on a weekly basis.

The role of the specialist midwifery team is primarily to promote early identification of pregnant women who have difficulties with drugs/alcohol in pregnancy. Following referral the role is then to encourage and engage women in appropriate maternity and drug treatment services. This ultimately leads to co-ordinating the care that women eventually receive throughout pregnancy and the postpartum period.

The Specialist Midwife provides the official link between these services in order to ensure consistent evidence based care. The role has the following components:

1) Engaging women:

Engaging women in substance misuse services and improving the early identification of women with difficulties

2) Direct Client Contact:

- Provide specialist support for hard to reach women in the absence of attending named keyworker
- Provide antenatal care to the minority of women who do not attend for care with named community midwife
- Provide additional support/advice to women specific to substance misuse in pregnancy, labour and neonatal care.

- Provide harm minimisation advice regarding risky sexual behaviour.
- Offer specialist advice relating to blood borne viruses and vertical transmission rates, management in labour, care of babies etc.
- Provide advice and support daily on postnatal ward following delivery with particular reference to the management of Neonatal Abstinence Syndrome (NAS) and the promotion of positive parenting

### 3) Safeguarding Children

- Refer all women to Multi Agency Liaison and Assessment Group (MAPLAG). (Local Safeguarding procedures)
- Ensure multiagency collaboration
- Offer advice and support to colleagues
- Attend case conferences
- Member of core group in the absence of named midwife
- Write case conference and court reports

There is an agreed Integrated Care Pathway within maternity, substance misuse and social care. A member of the specialist midwifery team is allocated as the named care coordinator. This role continues into the postnatal period and ends when the woman no longer needs this level of support. The maximum length of support time is usually 6 months but more generally is around 3 months; access to the team remains available for one year

Women receive routine universal antenatal/maternity care as with any other woman e.g. each woman has a named community midwife with continuity provided within the residential Service District. The intention is to promote normality and access to local community groups. Routine midwifery clinics are held as usual at GP surgeries and children centres.

Consultant obstetric care is indicated as with any other mother, that is, poor obstetric history or with a medical complication. Women with drug use alone as a risk factor are booked within a midwifery clinic run by the specialist midwifery team. Drug/alcohol assessments; onward referral and enhanced midwifery care are provided within this clinic.

A named consultant obstetrician with special interest in addiction runs an antenatal clinic each week and the specialist midwifery team run an antenatal clinic on the following day at the hospital for all non-high obstetric risk. This allows for 2 clinics each week within the hospital and enables follow up of non attendance. It also allows for optimal time to be spent with women as required. Women move between each clinic as required without any 'red tape' or need for advance discussion.

The Specialist midwifery team have access to the named consultant daily and also have access to scanning slots as required. Women can therefore be seen outside of allocated clinic slots if required. The consultant clinic is supported by the Specialist Midwifery team who provide a substance misuse overview and addiction advice on the day. All women will see the specialist midwife and this may be for 5 minutes in order to introduce women to the doctor or to update the obstetrician. Length of time may be longer if assessment regarding drug use is required or difficult venepuncture (blood taking) will be needed.

There is a named anaesthetist who sees all women with poor venous access and other significant issues and plans are made around 32 weeks for any intervention required.

A named consultant neonatologist offers to see any women antenatally who requests additional advice and this consultant runs a neonatal clinic where all baby's are followed up for one year postnatally. The liaison health visitor feeds into this clinic and offers links for any baby who is not seen at the clinic.

Women are seen by the specialist midwifery team on a daily basis while in hospital, and staff are supported with 'on the spot' training and advice regarding mother and baby care. Home visits and visits within other units i.e. general wards; psychiatric units are undertaken as required.

Most women have one to one parenting support offered antenatally. Referral also takes place into groups provided in locality but the majority of women don't like doing this until after baby is born.

The specialist midwifery team support a pregnancy clinic within the drug service where the GP and social worker are present. The GP manages the prescription and medical aspects of care alongside some psychosocial interventions and the social worker provides keyworking support, focusing primarily on attachment/parenting and social aspects within an addiction framework. Women remain within this clinic until their baby is one year old.

Women with dual diagnosis are seen in the specialist substance misuse service which is psychiatric led.

### **Additional Consultations**

All women are offered contact with a member of the specialist midwifery team. A minimum of three visits are offered to women who are stable. These visits do not involve routine antenatal care unless requested by the client, community midwife, or if concerns are raised on the day.

Visit 1 – as early as possible

- 1) offer specialist advice ensuring that the client understands the effects of drug/alcohol use on her and her baby
- 2) introduction to neonatal abstinence syndrome
- 3) ensure women understand the implications of Safeguarding procedures (MAPLAG process) and importance of attending appointments
- 4) management of methadone if admitted to hospital.
- 5) opportunity to ask questions

Visit 2 – 28-32 weeks gestation

- 1) discuss impact of drug/alcohol use on labour
- 2) pain relief in labour
- 3) options for feeding baby
- 4) more detail on neonatal abstinence syndrome
- 5) general advice
- 6) offer opportunity to ask questions

Visit 3 – 36 weeks

- 1) preparation for labour
- 2) ensure aware of how to access care in labour
- 3) care of baby suffering neonatal withdrawal
- 4) hospital care and policy regarding illicit drug use/urine sampling etc.
- 5) offer opportunity to ask questions

The length of appointment depends on individual need. As care is connected and formally joined up between agencies repetition is not required.

Women who are finding it difficult to achieve stability are offered more frequent access to the specialist midwifery team. Some women with complex needs subsequently receive combined 'drugs keyworking' and antenatal care by the specialist midwife until they achieve stability. This is extremely rare and not encouraged.

### **Attendance**

Attendance has significantly improved and is currently not a major problem as all services are quite closely connected. Attendance is discussed as a major part of the safeguarding assessment and this is discussed with the woman and her partner at the first appointment. All non attendance and late appointments are assertively followed up. Community midwives commonly offer home visits as part of routine care if women have small children. Home assessments are completed for all pregnant women by 36 weeks incorporating 'where baby sleeps' assessment.

All women who are not accessing services are assertively outreached, and seen by the specialist midwife where and when appropriate. Advice, support, and antenatal care are therefore provided simultaneously.

## Pregnant women with complex social factors

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Information relating to partner and other drug using members of the family are covered and appropriate referrals made and supported.

A significant amount of time can be spent by the specialist midwifery team on a few chaotic women but in general most women attend. The team takes on this role on behalf of the community midwife if persistent problems arise as this is an integral part of the role; they also have direct links to all the agencies that can assist. The methods used for follow up are letters, phone calls, and texts however we find that using other outreach services such as prostitute outreach, housing etc. can be more beneficial than direct contact at times. This can be perceived by women as being more helpful. Feedback from women has been that too many midwifery calls or unplanned home visits can feel like they are being hounded or coerced into having care.

### **Interfaces/ links with other services**

The service liaises with community midwives, health visitors, GPs, family planning services, probation, police, prisons, social workers, Sheffield Working Women's Liaison Opportunity Project, voluntary drug agencies, housing, genitourinary medicine, obstetric team, ward staff and any other relevant professionals.

### **Training**

The specialist midwives provides specialist advice and support to colleagues. They provide advice and support for all professionals on issues specific to pregnancy and neonatal care, and on crisis management support for serious issues

Another component to the specialist midwife role is clinical governance and service development:

- Developing guidelines specific to maternity care in pregnancy
- Promoting non discriminatory practise to women and families
- Developing pathways and policies for blood borne viruses
- Providing in-service training for all maternity staff.

### **Audit**

The specialist midwives undertakes audits and initiates research specific to drug and alcohol use in pregnancy.

## **4) Kings College Hospital (KCH), London**

### **Access to care**

Women are mainly referred after booking where they have disclosed their drug use. Women are referred from community midwives, GPs, drug agencies, social workers, and prisons. The caseload is divided into: minimal, brief and active. In a year 70-75 women are referred. Of these approximately 35 are considered brief users, and approximately 35 are active users.

### **Description of the service provided**

KCH employs a midwife fulltime to work with pregnant substance misusing women. She did an 8 week course 4 years ago on drug awareness, and has level 3 safeguarding. Mostly she has learnt from experience or is self-taught.

KCH offers an addiction service, the Woodvine service, run by an addiction service nurse and a doctor at the hospital antenatal clinic. This is so that these women's antenatal care is normalised.

The midwife has a clinic at the hospital. She also works out of rehabilitation centres, day centres, and will do home visits. Often the women she sees have less appointments than standard care as they are difficult to engage. It can take 3 or 4 contacts before she actually meets the women. She blocks out a minimum of 45 minutes for appointments.

Substance misusing women will see the obstetrician on the same basis as other women. Being a substance misuser will not automatically mean a referral.

They run a parenting group for substance misusers, but find that women who are going through rehabilitation don't want to mix with active users. Instead of parentcraft classes the midwife will have a 2 hour appointment with each woman at 36 weeks, one-to-one.

### **Attendance**

Attendance is a big problem; half of the midwife's time is spent following up women who do not attend. She allows 2 DNAs then will actively seek the women, phoning their home, speaking to their social worker or drug worker.

#### **Interfaces/links with other services**

The midwife works with prisons and the probation service; voluntary agencies that work with sex workers, domestic violence refuges; the drug team; housing; neonatologists; and social workers. An information leaflet has been developed for clients and health care professionals with the contact details of all the relevant agencies.

The co-ordination of care has become easier now that they are more established and other professionals know her role.

### **5) The Women's Alcohol And Drug Service (Wands), Nottinghamshire**

#### **Access to care**

Women are referred from a variety of sources, which include community midwives, drug treatment services, probation services, arrest referrals, and GPs. Women can also self refer.

This is a dedicated service for women who use substances. Between 60 and 70 women are seen each year. The total number of women seen by the service in the last year was 219; this included pregnant women and women who were experiencing domestic abuse.

#### **Description of the service provided**

The service is provided in conjunction with normal antenatal care. The substance misuse midwife has a diploma in substance misuse and has received training in a number of areas related to substance use. As well as the drug and alcohol liaison midwife employed by substance misuse services there are specialist antenatal clinics in both the hospitals covered by the service. The specialist clinics are run by the midwife, obstetric consultant, a drug treatment worker and a sexual health worker, and the women can access all these services at the clinic. The appointments can cover a lot of issues such as emotional problems, mental health issues, and housing problems.

Appointments outside of the clinics are held anywhere that the women will find easy to get to and where she and her midwife will be safe. Locations can include antenatal clinics, GP surgeries, home, children's centres, probation offices, substance misuse service premises, family centres, and hostels. Women can bring their children to the appointments. Taxis can sometimes be provided to help women get to appointments particularly if they have pre-school children.

The service does not have any special group sessions for these mothers but is looking at setting this up in the future.

#### **Attendance**

The service works in a proactive way with women to help them to attend appointments and receive the care they need. The liaison midwife will follow up women who don't attend. If a woman finds it really difficult to get to clinics the liaison midwife or the community midwife can offer extra home visits. Other workers who are involved in the care of the woman are also encouraged to help her to attend.

#### **Interfaces/ links with other services**

The dedicated service co-ordinates with other services involved with the care of a particular woman. Regular multi-agency meetings are held. Examples of other services include other drug and alcohol treatment services, the criminal justice service e.g. probation, and social services.

### **6) Manchester Specialist Midwifery Service (MSMS)**

#### **Access to Care**

Women are referred to the specialist midwives (drugs/alcohol) from a variety of sources. These include:

- Drug and alcohol services
- Maternity services
- GP's (General Practitioners)
- Mental Health services

## Pregnant women with complex social factors

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- Gynaecological/ Termination of pregnancy services
- Voluntary agencies e.g. Lifeline
- Needle exchange services
- MASH (Manchester Action on Street Health) - sex workers project
- HMP Styal
- Homeless families
- GMP (Greater Manchester Police)
- Probation services
- Domestic Abuse agencies
- Referral from friends/family members
- Self-referral

Access to MSMS is not considered as problematic as the service has established referral pathways with the voluntary and statutory agencies across the city. The service is also well known to service users. It is however acknowledged that some substance misusing women may book late due to a variety of reasons. These include:

- ambivalence to pregnancy
- avoiding services
- chaotic lifestyle
- amenorrhoea associated with opiate misuse may lead to late confirmation of pregnancy
- other competing priorities to accessing health care e.g. criminal justice, probation, addiction services

### **Description of the service provided**

MSMS has operated since April 2001 and specialises in providing a service to women and their families where drug/alcohol use and mental health problems are identified. It also supports and co-ordinates the care for HIV positive women identified through the antenatal HIV screening programme. The present service originates from the drug liaison midwife post (1995-2001) which was jointly commissioned by maternity and drug treatment services and which identified a wide range of unmet needs for vulnerable women in accessing maternity care.

A consultant midwife leads MSMS and has responsibility for service development and line management. The team currently consists of five specialist midwives; HIV/sexual health – 2 midwives (1 Band 8a, 1 band 6), perinatal mental health – 1 midwife (Band 7), drugs & alcohol – 2 midwives (Band 7); and a Personal Assistant.

All team members are employed by Central Manchester University Hospitals Foundation Trust (CMFT) and based in a community resource centre in Central Manchester where other voluntary and statutory agencies are located. Joint commissioning between Manchester Drug and Alcohol Strategy Team (DAST), NHS Manchester and CMFT currently supports service provision.

The two specialist midwives (drugs/alcohol) are based in a shared office with other members of the MSMS team. The cross-fertilisation of knowledge and expertise is particularly beneficial in the frequent joint case planning and safe-guarding assessments with substance misusing families. It also facilitates ongoing experiential learning for all team members.

Experience in working with women and families where substance misuse, domestic abuse and other associated complexities is essential to undertaking the specialist midwife role as is the knowledge of both the physiology and psychology of addiction. This includes the impact of drug and alcohol use in pregnancy and on the newborn baby and how best to manage neonatal withdrawal if it occurs. Risk assessment and correlating the multiple complexities involved is a key component of the specialist midwife role.

### **Additional Consultations**

The specialist midwives provide additional expertise, in-depth assessment and input over and above the usual antenatal care provided. The role is not one of providing regular antenatal care but one of individual

casework and leading on co-ordination of care and case-planning. Women are encouraged to attend for routine maternity care and are referred for consultant care when indicated.

Following referral each woman receives a pre-arranged home visit for an initial assessment, thus childcare is not an issue. The average time is 1 hour. Follow-up visits are planned according to need and may range from between 1 to 10 with the average being 4-5 visits. Time is spent helping the woman identify and access services to meet her needs and also gives the opportunity to assess the home environment, atmosphere and family interactions. This is particularly important where there are concerns regarding child neglect and/or domestic abuse. An individual care plan is commenced following the initial assessment and updated and amended accordingly with the woman being central to the process.

A CAF (Common Assessment Framework) checklist is completed with all clients. Post-delivery contraception is discussed early on, and women and their partners are referred to the outreach sexual health nurse who will then make contact. Families are also offered a referral to ECLYPSE, the young people's service for drugs and alcohol where 1:1 counselling, group work and family therapy is provided. The specialist midwives also do joint assessments with the family workers.

Ongoing history taking/discussion with women includes the following topics:

- initiating and sustaining change
- the importance of attending for antenatal care and keeping appointments
- was it a planned pregnancy? is it wanted?
- funding a drug/alcohol habit
- prostitution/criminal activity
- family background/personal history (including sexual abuse)
- family member in prison
- previous/current domestic abuse/violence
- experience in the care system
- relationship with current partner
- identifying partner's drug/alcohol use
- relationship with the father of any other children in household
- safeguarding issues
- blood-borne viruses/sexually transmitted diseases with risk of vertical transmission e.g. HIV
- management of Methadone in pregnancy, labour and when in hospital
- potential impact on baby before and after birth, including neonatal withdrawal
- breastfeeding, nutrition, infant mental health/attachment
- referral to e.g. mental health/psychological services/parenting programmes
- involvement with Children's Services and social worker if necessary

The specialist midwives provide postnatal contact for an average of approximately 3 months and on occasions for longer depending on the specific circumstances. The contact can be a pre-arranged visit or by phone. This includes women whose babies have been taken into care. The exit plan forms part of the care plan and is regularly discussed with the woman.

### **Attendance**

Contact also takes place in the drug and alcohol treatment services (out-patient and in-patient), antenatal clinic and on the maternity wards. Texting is frequently employed to remind women of appointments and also to maintain contact should they be reluctant to access services. Clients also text the specialist midwives seeking information and reassurance, wishing to change the date of their next appointment and when they have been admitted to hospital.

### **Interface/links with other services**

MSMS service provision is firmly rooted in the sphere of public health and embraces all aspects of a vulnerable, socially excluded life-style. The service has a city-wide remit and broad ranging responsibilities that include providing input to three maternity hospitals, four drug service bases, a sexual health project for sex workers (MASH), the regional in-patient detoxification unit and a local women's prison.

### **Training**

A wide range of training is provided to voluntary and statutory health and social care agencies and the team provide regular input to Salford and Manchester University. Training is provided for many other agencies and health professionals across the city. These include drug and alcohol services, social workers, student nurses/midwives, doctors, neonatal nurses, GPs and foster carers.

## **Services for women who are recent migrants, asylum seekers, refugees or who have difficulty reading or speaking English**

### **7) St Mary's Hospital, Manchester**

#### **Access to care**

Services for asylum seekers and refugees are embedded in mainstream maternity services. Women are referred by community and hospital staff. The policy is that all women are asked at booking if they are an asylum seeker or refugee. If appropriate, the community midwife will then ask if they can refer them to the Refugee Midwife. Although the bulk of referrals are from St. Mary's, some are from neighbouring Trusts when specialist services are required or by support agencies when they are moved into the area. Many referrals are late bookers.

#### **Description of the service provided**

St Mary's Hospital employs a midwife for asylum seekers and refugees with specific funding from the primary care trust.\* The post was set up in 2005 to meet needs arising from the extent of service use by asylum seekers and the findings of the 2002 Confidential Enquiry into Maternal and Child Health. The midwife works 30 hours and sees about 150 women a year in Central Manchester. She is an experienced midwife and has worked in other specialist services, e.g. diabetes and has had training from the Refugee Council along with standard equality and diversity training.

Refugees and asylum seekers are encouraged to attend community parentcraft classes but they are not specific classes for refugees because of the diversity of cultural backgrounds among this group. Those women that have attended enjoy the classes as they are isolated and have a limited social network.

In line with NICE guidance, there is a risk assessment at booking to determine if a woman needs to see an obstetrician. Refugees and asylum seekers will see an obstetrician for the same reasons as other women.

#### **Additional consultations**

Community midwives provide general, team-based antenatal care. Standard antenatal care is supplemented by 3 to 4 appointments with the refugee midwife and a review prior to hospital discharge. When possible, appointments are made when women are scheduled to visit the hospital, e.g. after scans, specialist obstetric clinics. This is often the best use of time for clients, the midwife and translation services. Some appointments are held in GP surgeries. Women are also seen at home if required, especially if there are problems with housing and an assessment is required.

Longer appointments are needed than standard, particularly early in the care pathway. A detailed social history is necessary and often shows the reasons for other problems such as depression and non-attendance. It is important to identify concerns with asylum applications, subsistence and accommodation, and essential baby equipment. Addressing these issues in the antenatal period prevents many postnatal crises and avoids unnecessary extensions to the post-partum hospital stay.

#### **Interfaces/Links with other services**

The refugee midwife co-ordinates with other services and spends time developing and maintaining networks. A monthly list of antenatal refugees is circulated to all clinical areas in maternity services. Safeguarding issues are discussed at the monthly neonatal meeting with specialist midwives, team leaders and the named

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\* A range of job-titles was considered. Refugee Midwife was chosen because it does not pre-judge an individual woman's situation. This approach was based on the advice of Refugee Action.

midwife for Child Protection. The service also benefits from close working relationships with the antenatal clinic, triage unit, delivery suite, postnatal wards, community midwifery and specialist services for HIV, sickle cell, haematology, diabetes and social services. In addition to cultural groups the midwife works with Refugee Action, Manchester Asylum Induction Team and charities who provide support to destitute asylum seekers.

#### **Attendance**

All women are given the refugee midwife's mobile number so they can reschedule appointments or raise other concerns by phone or text. When necessary women are contacted by phone to rearrange appointments via an interpreter as this overcomes literacy and language barriers.

The United Kingdom Border Agency (UKBA) provides a basic package of support for all asylum seekers and aims to make a decision on immigration status within 6 months. The women stay in asylum seeker accommodation during that time and may be moved (dispersed) dependant on local property providers and directions from the UKBA. This has the potential to fragment antenatal care. All women are therefore requested to contact the refugee midwife if notified of dispersal. Where it is reasonable handheld notes are updated with relevant test results and an antenatal check undertaken. All women are advised how to access maternity services in the dispersal area and when necessary the refugee midwife notifies community/child protection midwife.

#### **Any other information**

The Trust employs in-house interpreters to cover the main languages; French, Arabic, and Asian languages, but the interpreters are only available until 4pm. For other languages, and out-of-hours, an agency is used for face to face and telephone translation.

### **8) The Royal Berkshire Hospital, Reading**

#### **Description of service provided**

The Royal Berkshire hospital employs a specialist midwife in social inclusion. Her role is to support women from ethnic minorities and their families to ensure they have equal access to maternity services. She provides support to other midwives who are working with women from ethnic minorities. She also works with local communities and existing ethnic minority networks to promote maternity services and educate women on the benefits of early access to services.

The social inclusion midwife has her own case load in the community and the majority of the women cared for by the social inclusion midwife are from ethnic minorities. She also has a more strategic role to develop and improve services both within the community and hospital settings.

Referral to the obstetrician is based on health need and recent migrants and non-English speaking women are no more likely to see the consultant than other women.

#### **Additional consultations**

Appointments are usually longer than standard e.g. she has twenty minutes for a follow up appointment or forty minute appointments if an interpreter has been booked. Most antenatal care is provided from GP surgeries. However, some clinics are held in Children's centres.

Vulnerable women may need extra appointments to deal with individual issues i.e., financial advice, benefits, support filling in forms.

#### **Interfaces/ links with other services**

The role involves informing women and health professionals about the different services available. These may include support groups who offer advice on different issues such as health and employment, mother and toddler groups for women from different ethnic backgrounds, refugee support groups, swimming sessions for women only, information about how to request an interpreter and also where to find information in different languages.

#### **Training**

All staff has training on equality and diversity and in addition the specialist midwife facilitates workshops on cultural issues for midwives and maternity care assistants.

#### **Any other information**

Staff have access to interpreters for either face to face or telephonic interpreting. The service used is able to provide interpreters for most languages and dialects. In addition maternity services have a Linkworker who can speak two languages in addition to English who works with Asian women.

## Pregnant women with complex social factors

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The social inclusion midwife has developed a guide for health professionals which lists all relevant services available in Reading. She can also provide information for midwives in a number of languages.

Urdu birth preparation classes have been set up in a children's centre and are being widely promoted in the community.

Working in collaboration with ESOL, they are hoping to start Antenatal Birth Preparation Classes where English language is taught to prepare women for labour and the postnatal period and to aid integration into the community.

### 9) King's College Hospital, London

#### **Access to care**

KCH does not have a dedicated service for recent migrants. Women are seen by the community midwives attached to their local GP surgery or children's centre, or by hospital based midwives. By nature of their vulnerable status these women tend to be referred to children's centre midwives who will give them additional appointments, visits and support. The area covered by King's College Hospital includes a hostel for asylum seekers in Dulwich.

#### **Additional consultations**

Recent migrants will receive the same care as other women. There are no additional consultations and their main care will be from the midwives.

For women who do not speak English and require an interpreter more appointments may be needed to make sure everything has been covered. They do schedule longer appointments when an interpreter is present.

#### **Attendance**

The main problem with working with refugees appears to be keeping track of them. The women who are placed in the hostel can be dispersed without much notice and it is difficult to find out where they have been sent. The midwives follow up these women if they stop attending appointments and will spend more time than with other women but there is a limit to what can be done. The only information available is what is on the records and often the GP will have no more information. Where the Home Office is involved it can be complicated because they are reluctant to give out information.

#### **Interfaces/links with other services**

There is a weekly meeting with social workers and other health care professionals who work with pregnant women. They do not have any formal links with third sector agencies but will sometimes contact domestic violence charities and on occasion have worked with a charity that works with torture victims.

#### **Any other information**

Finding an interpreter for an appointment was not considered a problem. Sometimes if it is an obscure language or dialect it can be difficult to find an interpreter. They have had problems with short-term cancellations or being sent the wrong interpreter. There can be problems when assumptions have been made, for instance a French interpreter is booked but the woman speaks pidgin French.

## Services for young women aged under 20

### 10) Brighton and Mid-Sussex

#### **Access to care**

The programme is well publicised. Referrals are mainly from midwives, however there are now more referrals from GPs, connexions PA's and other youth groups.

#### **Description of service provided?**

Brighton and Mid-Sussex employs a midwife for teenagers under 19 years old at delivery. The teenagers midwife was a community midwife and has a particular interest in working with teenagers. She is child protection trained and has done a number of courses on antenatal care for teenagers. She works four days a week on the teenage programme. The programme has been running for six years.

There are two clinics dedicated to young pregnant women, one in high rate area and one at a city centre children's centre as this has proved to be a good location for antenatal classes as most women find it easy to get there. The clinic runs at the same time as the antenatal class. Antenatal classes are held weekly as drop-in sessions, they provide lunch and the bus fare. Monthly labour ward visits are also arranged for teenage

mothers. The teenager pregnancy midwife can be contacted by phone or text for advice 7 days a week from 8am to 8pm.

Teenagers are not routinely referred to obstetricians; age is not considered a reason for referral. There are no obstetricians who specialise in working with teenagers.

The teenage pregnancy midwife also works with two dedicated teenage health visitors and two support workers. They work with young women under 18 years. There is also a re-integration officer who provides advice for teenage mothers up to 16 years old and a connexions PA for those 17-19. Referrals can also be made to three teenage pregnancy advisors who can spend time with the teenagers at the beginning of pregnancy to help with decision making.

### **Additional consultations**

On top of the standard care set out in the NICE guideline the teenage pregnancy midwife provides on average 3 to 4 extra visits as required by the woman or if the midwife feels they are needed. These additional visits are done at home or in a clinic.

### **Attendance**

Non-attendance can be a problem; teenagers are less likely to attend for antenatal care than older women. The teenage pregnancy service is very accessible, but the teenage pregnancy midwife does not book every young woman but altogether the community midwives and the teenage pregnancy midwife are usually successful about booking young women before 10 weeks.

If someone is not engaging with the service the teenage pregnancy midwife will follow them up. Sometimes it may be because they have moved and don't know how to access the local clinic, sometimes it's because there are other issues in their lives preventing them coming to clinic. If there is a dedicated service to teenagers it is easy to follow them up but you need to text to remind them and often have to rearrange appointments.

### **Interfaces/ links with other services**

The health visitors, midwife, reintegration officer and connexion PA meet every month but they also work and meet with other agencies including youth advisory centres, social workers, housing and domestic violence groups.

## **Services for women experiencing domestic abuse**

### **11) Nottingham Citihealth**

#### **Description of service provided**

Nottingham Citihealth employs a domestic abuse nurse specialist as part of the safeguarding children team. The role is non-clinical and the nurse is available to give advice to all Trust staff regarding domestic abuse.

Midwives are able to get support from the specialist nurse. She also provides signposting for appropriate referrals to women's aid, police, and safeguarding children.

#### **Interfaces/ links with other services**

The specialist nurse attends the MARAC where there approximately 20 high risk women identified every fortnight. She also co-ordinates with social care, women's aid, the Nottinghamshire Domestic Violence Forum, probation, women's safety officers, housing, and she spends half a day a week with the police.

#### **Training**

A full day of domestic violence basic awareness training is provided twice a month to all trust staff and a half day session on the Impact on Children. She also delivers training to partner agencies, such as Nottingham University Hospitals Trust and the Local Safeguarding Board. The basic awareness training covers aspects of domestic abuse (physical, emotional, sexual, psychological and financial), vulnerable groups and barriers to disclosure, why women stay in abusive relationships, and attitudes and opinions of Young People. The afternoon then focuses on 'Asking the Question', MARAC's, using the Risk Assessment forms, Safety Plans and specialist services in the area. The 'Impact on Children' training focuses on the holistic impact on children of different ages and evidence base, safeguarding children and links to child abuse and scenarios.

## Providing information for women with complex social factors

### 12) The Women's Wheel©

The Polyanna Project is a non-profit making organisation which develops resources with and for communities around health and social need.

The project was originally commissioned to develop an information resource for women in Hackney within a reducing infant mortality framework. A CD sized wheel with eye-catching images on the cover which rotates to reveal telephone numbers for help lines and services was developed in consultation with local women and expertise in the team. Further projects have been commissioned including three pieces of work in Barking and Dagenham, a Women's Wheel and an evaluation of its effectiveness and as a result of the positive feedback a Maternity Wheel.

The Barking and Dagenham project had specific focus on:

- The importance of new emerging communities having improved access to services
- The issue of domestic abuse/violence in line with recommendations in the last CEMACE report, *Saving Mother's Lives* (Lewis, 2007)<sup>3</sup>

The projects engaged with the local community thereby increasing awareness of services both nationally and locally. In addition it highlighted gaps in awareness and increased understanding of available services. It was felt that by designing a tool to address these gaps it could go some way towards reducing inequalities and inequity around access and engagement with services.

The Barking and Dagenham project involved ten focus groups that were held in community forums and venues. The priority was to try to meet women, across the borough, that were representative of different ethnic groups and needs. In particular the project focused on more vulnerable women such as asylum seekers, people who did not speak English, teenagers and women fleeing domestic abuse.

The numbers and relevance of the services were discussed with all individuals and groups. There appeared to be particular gaps in awareness and understanding around services for sexual health and postnatal depression and there were anxieties about confidentiality.

The Wheel contains both local and national numbers, as many women are not comfortable ringing local numbers.

The Wheel may inform someone about a service they did not know about or give 'permission' to ask for help, for example about domestic abuse services. It engages people, facilitates questions, interactions and information sharing. Women can refer to The Wheel, keep it and share it, so that the services can become increasingly well known and seen as 'for them'. It works as an instigator of conversation, highlighting and giving permission to acknowledge and seek assistance for needs which can be stigmatised such as teenage pregnancy, domestic abuse, disability and mental health problems.

The images on The Wheel are loosely representative of the community, with different ages and ethnicities included.

The selection of telephone numbers of advice lines was achieved through user consultation with cross cutting professional advice. All the numbers were checked with a series of follow-up calls to establish suitability based on:

- matching women's needs
- helpline or phone advice given
- good signposting to other services
- good quality of answer and answer phone and consistent advice.

The Maternity Wheel developed for Barking, Havering and Redbridge University Hospitals NHS Trust will be given out at booking and offered again in the postnatal period for all women. As a tool to 'initiate a conversation' The Wheel not only provides information for the women attending the clinic, but also for the midwives. Further information on the services is included in the report which will be available on both the hospital intranet and internet sites.

### **13) Hackney Maternity Helpline**

The Hackney Maternity Helpline is an innovative service which was set up to give local women across Hackney direct access to an experienced Hackney midwife. The Helpline opened in September 2007 with the following aims:

- To pilot a maternity phone line advice service
- To provide direct access to professional clinical advice
- To facilitate earlier access to maternity care.

#### **Description of the service**

The Helpline is based at Homerton hospital and is open seven days a week, from 10am to 6pm. It is staffed by a full-time co-ordinating midwife, in addition to six part-time clinical midwives, each working on the Helpline for one or two days per week. All Helpline staff are experienced (Band 7) midwives.

A telephone Helpline database system was specifically commissioned, designed and built to capture details of calls taken and advice given. All calls are logged on this system. The database has a reporting function. Helpline midwives have access to the Homerton Hospital electronic records system, which means that they can access information about women already booked with Homerton and/or register women directly who have not yet presented for care.

Publicity business cards (printed in English, French, Turkish, Spanish, Portuguese and Vietnamese) and posters were distributed across the borough, in locations including GP surgeries and community pharmacies, who give out the small card when they sell pregnancy testing kits, or if pregnant women come to them with queries. The helpline number is clearly marked on the front of all clients' hand-held maternity records.

#### **Training**

A protocol has been developed to ensure that all clinical advice provided through the Helpline service is evidence-based and consistent. The Maternity Helpline Reference Guide was written specifically to assist Helpline staff to effectively deal with Helpline calls, and is a resource incorporating protocols of Homerton Hospital and summaries of evidence-based guidelines such as NICE and other national and local guidelines. This is essential as whilst all midwives working on the Helpline have a broad knowledge of midwifery issues, their knowledge may differ depending on their experience and areas of expertise.

The Helpline staff underwent specifically tailored training events delivered by the Terence Higgins Trust and Domestic Abuse specialist organisations. The focus was on issues including confidentiality and handling difficult emotional calls.

#### **Audit**

From September 2007 to September 2008 the Hackney Maternity Helpline dealt with over 7,000 calls. The majority of calls relate to clinical queries, although a number of the calls are also focused around social issues.

Data analysis was conducted on a 'typical' week of calls to the Helpline service. During the sampled week the Maternity Helpline dealt with a total of 134 calls.

- The majority of calls (61%) were from pregnant or postnatal women, with 32% of calls from health professionals (predominantly community midwives), and 5% from pregnant or postnatal women's friends or family. 2% of calls were outgoing calls in response to previous calls made to the helpline.
- Of the 56 clinical queries received by the Helpline during the sampled week, in more than two-thirds (38) of cases, the Helpline midwives were able to offer advice to the caller which was sufficient to deal with their query.
- Just over half of calls dealt with resulted in callers being referred or signposted onto other services or professionals.

- A number of calls (27%) resulted in blood results being provided for health professionals (predominantly community midwives), suggesting that the Helpline may be an important resource for midwives and other professionals, giving them easy access to information about their clients.

Writing in May 2010, the helpline now deals with between six and nine hundred calls each month. This figure includes calls initiated by helpline midwives to as many Hackney mothers as possible the day after discharge, offering support and advice on breastfeeding if required.

### Example of a flexible model of care

#### 14) Centering Pregnancy at Kings College Hospital NHS Trust

Centering Pregnancy is a new model of care, practiced in over 200 sites in North America, which is being piloted at Kings College Hospital NHS Trust. The aims of the feasibility study are:

- To assess whether it can be successfully transferred to the UK NHS maternity system
- To assess whether women find this model of care acceptable
- To assess whether midwives and other stakeholders find it acceptable to provide antenatal care in groups

In Centering Pregnancy women receive all their antenatal care in groups of 8-12 women with a similar due date. Partners are invited to four of the sessions. Each session lasts 2 hours. There are nine sessions, reflecting NICE guidance of schedule of care with a reunion meeting one month after the birth. The group size is stable to promote trust and there are two named midwives providing continuity of carer.

Women complete self care activities including testing their urine, Blood pressure estimation and calculation of gestation. Abdominal palpation is conducted at the edge of the circle on a mat on the floor. The care provided is the same as in 'traditional' 1: 1 care and women are invited to attend for additional assessments if they have particular needs. The hospital maternity notes have been adapted for the women in the project to encourage partnership working, self efficacy and involvement.

An important element of the model is the social support, friendships and motivation facilitated by meeting women regularly in a similar situation. The social philosophy is encouraged with the provision of healthy snacks and attractive name tags. The sessions are held in the morning, afternoon and evening and the women are provided with all the dates for their whole pregnancy. The sessions are based in the community, in Children Centres and GP surgeries and one in the hospital.

Women and their partners have an opportunity to discuss issues around pregnancy, birth and early parenthood. A facilitative leadership style is used and each session has an overall plan but they are not classes. Attention is paid to core content but emphasis may vary according to the women's needs. The key is that it is designed around what the women want to discuss and share with each other rather than what the midwife feels women need to know. Women are invited to share their experiences and perspectives gleaned from the plethora of material available from the media and professional sites such as NHS Choices and NICE.

There are seven groups in the pilot, the last to amalgamate all the learning. One group was for teenage women. The women attending have all been English speaking with a diverse range of demographic characteristics. The women have a longer consultation time and the more confident women lead initially with questions and points of view but this encompasses most of the women as the sessions progress. Women benefit from a shared experience with women going through the same stage of pregnancy together. Midwives report that anecdotally women who would not 'normally' attend traditional antenatal classes benefited from the wisdom of the other women. Women attend because it is their antenatal care but benefit from a longer consultation time and the trusting relationships that develop.

There is an ongoing evaluation of care: each session the women record in the Choices and Discussion sheet what has been discussed; there is a formal evaluation questionnaire at 36 weeks and when the baby is about a month old at the reunion meeting and the midwives complete a reflection sheet after each session.

		<b>Suggested discussion topics</b>	<b>NICE guidance discussion</b>
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<b>16 weeks:</b>	Getting acquainted Choice Dealing with discomfort during pregnancy	Centering model of care Confidentiality Group guidelines Choice Common ailments in pregnancy Antenatal assessments	
<b>25 weeks:</b>	Eating well Nutrition for you and your baby Money Matters	Nutrition during pregnancy and for a lifetime Breastfeeding Money Matters and benefits	
<b>28 weeks:</b>	Relationships Relaxation	Relaxation How are you feeling? Staying healthy Thinking about support networks	RH negative information where appropriate
<b>31 weeks:</b>	Becoming a parent	Parenting Is my baby alright?	Care of newborn Vitamin K prophylaxis Newborn screening tests
<b>34 weeks:</b>	Your new baby and you	Feeding your baby Skin to skin Getting to know your baby Infant care and the early postnatal period	Discuss results of screening test Breastfeeding advice
<b>36 weeks:</b>	Birth	Getting ready for the birth Talking about the placenta	Preparation for labour and birth Birth plan Recognising active labour and coping with pain
<b>38 weeks:</b>	Plans for parenthood	Birth Prolonged pregnancy Parenthood Family planning	Information on the management of prolonged pregnancy
<b>40 weeks:</b>	Women's choice	Group led	Further discussion re prolonged pregnancy
<b>1 month later:</b>	Sharing stories and advice	Our experience Reunion with new babies Where to go for help Parenting	

# Appendix E

## Evidence tables

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See separate document

# Appendix F

## Excluded studies

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See separate document

# Appendix G

## Search strategies

### Adolescents

Ovid MEDLINE(R) 1950 to October Week 3 2008

SCIP\_adolescents\_all\_medline\_231008

#	Searches	Results
1	MIDWIFERY/	11262
2	PRECONCEPTION CARE/	782
3	PRENATAL CARE/	16147
4	PERINATAL CARE/	1601
5	(midwife or midwifery or midwives).ti,ab.	10633
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	248
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	12596
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	180
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9152
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	875
11	exp MATERNAL HEALTH SERVICES/	25303
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	5184
13	MATERNAL-CHILD NURSING/	1469
14	OBSTETRICAL NURSING/	2507
15	NURSE MIDWIVES/	5335
16	REPRODUCTIVE HEALTH SERVICES/	444
17	or/1-16	61310
18	PREGNANCY IN ADOLESCENCE/	5685
19	ADOLESCENT/ and PREGNANCY/	53057
20	MATERNAL AGE/	13748
21	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	3782
22	((adolescen\$ or teen\$ or young) adj3 (mom or mum\$ or mother\$)).ti,ab.	3277
23	or/18-22	67172
24	23 and 17	7309

25	editorial.pt.	232551
26	historical article.pt.	257648
27	interview.pt.	19500
28	in vitro.pt.	356352
29	letter.pt.	651197
30	news.pt.	115312
31	newspaper article.pt.	16336
32	or/25-31	1630392
33	24 not 32	7189
34	limit 33 to humans	7077
35	limit 34 to english language	6255

### EBM Reviews - Cochrane Central Register of Controlled Trials 4th Quarter 2008

#### SCIP adolescents\_all cctr\_231008

#	Searches	Results
1	MIDWIFERY/	132
2	PRECONCEPTION CARE/	20
3	PRENATAL CARE/	564
4	PERINATAL CARE/	46
5	(midwife or midwifery or midwives).ti,ab.	364
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	3
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	634
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	6
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	333
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	52
11	exp MATERNAL HEALTH SERVICES/	758
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	313
13	MATERNAL-CHILD NURSING/	34
14	OBSTETRICAL NURSING/	25
15	NURSE MIDWIVES/	76
16	REPRODUCTIVE HEALTH SERVICES/	4
17	or/1-16	1898
18	PREGNANCY IN ADOLESCENCE/	90
19	ADOLESCENT/ and PREGNANCY/	1536
20	MATERNAL AGE/	182

21	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	120
22	((adolescen\$ or teen\$ or young) adj3 (mom or mum\$ or mother\$)).ti,ab.	149
23	or/18-22	1855
24	23 and 17	253
25	editorial.pt.	280
26	historical article.pt.	58
27	interview.pt.	2
28	in vitro.pt.	756
29	letter.pt.	4515
30	news.pt.	192
31	newspaper article.pt.	157
32	or/25-31	5953
33	24 not 32	252

**DARE, CDSR****SCIP adolescents\_all cdsrdare\_231008**

#	Searches	Results
1	(MIDWIFE\$ or MIDWIVES).kw.	20
2	PRECONCEPTION CARE.kw.	5
3	PRENATAL CARE.kw.	42
4	PERINATAL CARE.kw.	7
5	(midwife or midwifery or midwives).ti,ab.	24
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	2
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	25
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	0
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	1
11	MATERNAL HEALTH SERVICES.kw.	7
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	26
13	MATERNAL-CHILD NURSING.kw.	5
14	OBSTETRIC\$ NURSING.kw.	2
15	NURSE MIDWI?E?.kw.	7
16	REPRODUCTIVE HEALTH SERVICE?.kw.	2
17	or/1-16	122
18	PREGNANCY IN ADOLESCENCE.kw.	9
19	(ADOLESCEN\$ and PREGNAN\$).kw.	26

20	MATERNAL AGE.kw.	9
21	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	8
22	((adolescen\$ or teen\$ or young) adj3 (mom or mum\$ or mother\$)).ti,ab.	4
23	or/18-22	40
24	23 and 17	3

**EMBASE 1980 to 2008 Week 43****SCIP\_adolescents\_all\_embase\_241008**

#	Searches	Results
1	MIDWIFE/	2191
2	exp PRENATAL CARE/	53474
3	MATERNAL TREATMENT/	417
4	exp PERINATAL CARE/	14353
5	exp OBSTETRIC CARE/	136043
6	(midwife or midwifery or midwives).ti,ab.	2997
7	PRENATAL PERIOD/	3664
8	PERINATAL PERIOD/	11809
9	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	216
10	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	9445
11	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	112
12	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	6261
13	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	650
14	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	3236
15	OBSTETRICAL NURSING/	8
16	or/1-15	156331
17	ADOLESCENT PREGNANCY/	2616
18	ADOLESCENT/ and PREGNANCY/	5271
19	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	2211
20	((adolescen\$ or teen\$ or young) adj3 (mom or mum\$ or mother\$)).ti,ab.	2061
21	or/17-20	9508
22	and/16,21	2810
23	editorial.pt.	218573
24	letter.pt.	428716
25	note.pt.	237839
26	or/23-25	885128
27	22 not 26	2704

28	limit 27 to human	2497
29	limit 28 to english language	2303

### CINAHL - Cumulative Index to Nursing & Allied Health Literature 1982 to October Week 3 2008

#### SCIP\_adolescents\_all\_cinahl\_241008

#	Searches	Results
1	exp MIDWIFERY/	9694
2	PREPREGNANCY CARE/	523
3	PRENATAL CARE/	5061
4	PERINATAL CARE/	1026
5	MATERNAL HEALTH SERVICES/	2111
6	MATERNAL-CHILD NURSING/	966
7	OBSTETRICAL NURSING/	2084
8	NURSE MIDWIVES/	1181
9	PERINATAL NURSING/	624
10	(midwife or midwifery or midwives).ti,ab.	11387
11	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	144
12	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	3231
13	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	54
14	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	1987
15	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	193
16	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	1421
17	or/1-16	28836
18	exp PREGNANCY IN ADOLESCENCE/	2460
19	ADOLESCENT/ and PREGNANCY/	6242
20	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	1585
21	((adolescen\$ or teen\$ or young) adj3 (mom or mum\$ or mother\$)).ti,ab.	1208
22	or/18-21	7636
23	and/17,22	1658
24	editorial.pt.	93616
25	exam questions.pt.	49409
26	letter.pt.	66451
27	or/24-26	209270
28	23 not 27	1617
29	limit 28 to english	1550

**SCIP\_adolescents\_all\_assia\_241008**

((KW=((antenatal care) or (prenatal care) or (perinatal care)) or KW=((ante natal care) or (pre natal care) or (peri natal care)) or KW=((preconception care) or (prepregnancy care) or (obstetric\* care)) or KW=(midwif\* or midwives or (reproductive healthcare)) or KW=((obstetric\* nurs\*) or (antenatal clinic\*) or (prenatal clinic\*)) or KW=((maternal healthcare) or (maternal care))) or ((DE=("prenatal testing" or "amniocentesis" "prenatal care" or "midwifery" or "perinatal mortality"))) and((KW=((teen\* pregnancy) or (pregnan\* teen\*) or (adolescent pregnanc\*)) or KW=((pregnan\* adolescen\*) or (adolescen\* mom\*) or (adolescen\* mother\*)) or KW=((adolescen\* mum\*) or (pregnant child\*) or (young mom\*)) or KW=((young mother\*) or (young mum\*))) or (DE=("pregnant adolescent girls" or "low income pregnant adolescent girls" or "adolescent motherhood" or "adolescent mothers" or "disadvantaged adolescent mothers" or "adolescent parenthood" or "adolescent parents"))) or (DE=("adolescence" and "pregnancy")))

**SCIP\_adolescents\_all\_sociologabs\_271008**

(KW=((antenatal care) or (prenatal care) or (perinatal care)) or KW=((ante natal care) or (pre natal care) or (peri natal care)) or KW=((preconception care) or (prepregnancy care) or (obstetric\* care)) or KW=(midwif\* or midwives or (reproductive healthcare)) or KW=((obstetric\* nurs\*) or (antenatal clinic\*) or (prenatal clinic\*)) or KW=((maternal healthcare) or (maternal care)) or (DE=("prenatal testing" or "amniocentesis" or "prenatal care" or "midwifery" or "infant mortality" or "Womens Health Care" or "health care utilization" or "Gynecology" or "nurses" or "physicians" or "practitioner patient relationship")) and((KW=((teen\* pregnancy) or (pregnan\* teen\*) or (adolescent pregnanc\*)) or KW=((pregnan\* adolescen\*) or (adolescen\* mom\*) or (adolescen\* mother\*)) or KW=((adolescen\* mum\*) or (pregnant child\*) or (young mom\*)) or KW=((young mother\*) or (young mum\*))) or (DE=("adolescent mothers" or "adolescent parents" or "adolescent pregnancy")) or (DE=("adolescents" and "pregnancy")))

**SCIP\_adolescents\_all\_socservabs\_271008**

(KW=((antenatal care) or (prenatal care) or (perinatal care)) or KW=((ante natal care) or (pre natal care) or (peri natal care)) or KW=((preconception care) or (prepregnancy care) or (obstetric\* care)) or KW=(midwif\* or midwives or (reproductive healthcare)) or KW=((obstetric\* nurs\*) or (antenatal clinic\*) or (prenatal clinic\*)) or KW=((maternal healthcare) or (maternal care)) or (DE=("prenatal testing" or "amniocentesis" or "prenatal care" or "midwifery" or "infant mortality" or "Womens Health Care")) and((KW=((teen\* pregnancy) or (pregnan\* teen\*) or (adolescent pregnanc\*)) or KW=((pregnan\* adolescen\*) or (adolescen\* mom\*) or (adolescen\* mother\*)) or KW=((adolescen\* mum\*) or (pregnant child\*) or (young mom\*)) or KW=((young mother\*) or (young mum\*))) or (DE=("adolescent mothers" or "adolescent parents" or "adolescent pregnancy")) or (DE=("adolescents" and "pregnancy")))

**PsycINFO 1967 to October Week 3 2008****SCIP\_adolescents\_all\_psycinfo\_231008**

#	Searches	Results
1	exp PRENATAL CARE/	972
2	REPRODUCTIVE HEALTH/	216
3	PRENATAL DIAGNOSIS/	374
4	PRENATAL DEVELOPMENT/	2878
5	exp OBSTETRICS/	820
6	PERINATAL PERIOD/	932

## Pregnant women with complex social factors

7	((midwife or midwifery or midwives).ti,ab.	850
8	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	27
9	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	1702
10	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	21
11	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	992
12	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	252
13	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	1475
14	exp HEALTH CARE SERVICES/	47199
15	or/1-14	55957
16	ADOLESCENT MOTHERS/	1574
17	ADOLESCENT PREGNANCY/	1685
18	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	2283
19	((adolescen\$ or teen\$) adj3 (mom or mum\$ or mother\$)).ti,ab.	2917
20	or/16-19	5391
21	and/15,20	454
22	book.pt.	234374
23	edited book.pt.	193086
24	or/22-23	234374
25	21 not 24	411
26	limit 25 to human	408
27	limit 26 to english language	392

## Adolescents – Health Economics

Ovid MEDLINE(R) 1950 to November Week 2 2008

SCIP\_adolescents\_economics\_medline\_241108

#	Searches	Results
1	ECONOMICS/	25927
2	"COSTS AND COST ANALYSIS"/	37714
3	COST ALLOCATION/	1868
4	COST-BENEFIT ANALYSIS/	45114
5	COST CONTROL/	18116
6	COST SAVINGS/	6198
7	COST OF ILLNESS/	11241
8	COST SHARING/	1452
9	HEALTH CARE COSTS/	17529

10	DIRECT SERVICE COSTS/	869
11	DRUG COSTS/	9032
12	EMPLOYER HEALTH COSTS/	998
13	HOSPITAL COSTS/	5782
14	HEALTH RESOURCES/	6549
15	"HEALTH SERVICES NEEDS AND DEMAND"/	31064
16	HEALTH PRIORITIES/	7065
17	HEALTH EXPENDITURES/	10495
18	CAPITAL EXPENDITURES/	1846
19	FINANCIAL MANAGEMENT/	14569
20	FINANCIAL MANAGEMENT, HOSPITAL/	7012
21	QUALITY-ADJUSTED LIFE YEARS/	3703
22	"DEDUCTIBLES AND COINSURANCE"/	1215
23	MEDICAL SAVINGS ACCOUNTS/	402
24	ECONOMICS, HOSPITAL/	8768
25	ECONOMICS, MEDICAL/	7354
26	ECONOMICS, NURSING/	3859
27	ECONOMICS, PHARMACEUTICAL/	2005
28	MODELS, ECONOMIC/	3350
29	MODELS, ECONOMETRIC/	2869
30	RESOURCE ALLOCATION/	6095
31	HEALTH CARE RATIONING/	9134
32	"FEES AND CHARGES"/	7497
33	BUDGETS/	7798
34	VALUE OF LIFE/	5086
35	(financ\$ or fiscal\$ or funding).ti.	13721
36	(QALY\$ or life?year\$).ti.	200
37	(econom\$ or cost\$).ti.	81598
38	pharmacoeconomic\$.ti.	1096
39	or/1-38	290019
40	MIDWIFERY/	11310
41	PRECONCEPTION CARE/	795
42	PRENATAL CARE/	16251
43	PERINATAL CARE/	1616
44	(midwife or midwifery or midwives).ti,ab.	10680
45	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	250
46	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	12687

Pregnant women with complex social factors

47	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	182
48	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9224
49	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	889
50	exp MATERNAL HEALTH SERVICES/	25461
51	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	5229
52	MATERNAL-CHILD NURSING/	1475
53	OBSTETRICAL NURSING/	2511
54	NURSE MIDWIVES/	5344
55	REPRODUCTIVE HEALTH SERVICES/	454
56	or/40-55	61675
57	PREGNANCY IN ADOLESCENCE/	5864
58	ADOLESCENT/ and PREGNANCY/	53448
59	MATERNAL AGE/	13813
60	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	3898
61	((adolescen\$ or teen\$ or young) adj3 (mom or mum\$ or mother\$)).ti,ab.	3350
62	or/57-61	67650
63	62 and 56	7397
64	editorial.pt.	234352
65	historical article.pt.	258423
66	interview.pt.	19575
67	in vitro.pt.	358336
68	letter.pt.	653898
69	news.pt.	115936
70	newspaper article.pt.	16363
71	or/64-70	1638241
72	63 not 71	7272
73	limit 72 to humans	7160
74	limit 73 to english language	6336
75	and/39,74	355
76	limit 74 to ("costs (optimized)" or "economics (optimized)")	288
77	75 or 76	475

**CLEED, CLHTA**

**SCIP\_adolescents\_economics\_htaeed\_241108**

#	Searches	Results
1	MIDWIFERY/	20

2	PRECONCEPTION CARE/	3
3	PRENATAL CARE/	117
4	PERINATAL CARE/	18
5	(midwife or midwifery or midwives).ti,ab.	14
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	2
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	31
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	0
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	18
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	0
11	exp MATERNAL HEALTH SERVICES/	189
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	14
13	MATERNAL-CHILD NURSING/	4
14	OBSTETRICAL NURSING/	2
15	NURSE MIDWIVES/	9
16	REPRODUCTIVE HEALTH SERVICES/	4
17	or/1-16	232
18	PREGNANCY IN ADOLESCENCE/	6
19	ADOLESCENT/ and PREGNANCY/	79
20	MATERNAL AGE/	31
21	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	3
22	((adolescen\$ or teen\$ or young) adj3 (mom or mum\$ or mother\$)).ti,ab.	1
23	or/18-22	110
24	23 and 17	24

**EMBASE 1980 to 2008 Week 47****SCIP\_adolescents\_economics\_embase\_241108**

#	Searches	Results
1	ECONOMICS/	5687
2	HEALTH ECONOMICS/	10340
3	ECONOMIC EVALUATION/	4377
4	COST BENEFIT ANALYSIS/	29585
5	COST CONTROL/	16951
6	COST EFFECTIVENESS ANALYSIS/	56523
7	COST MINIMIZATION ANALYSIS/	1431
8	COST OF ILLNESS/	4770

Pregnant women with complex social factors

9	COST UTILITY ANALYSIS/	2412
10	COST/	20282
11	HEALTH CARE COST/	61708
12	DRUG COST/	34639
13	HEALTH CARE FINANCING/	9327
14	HOSPITAL COST/	6458
15	SOCIOECONOMICS/	31371
16	ECONOMIC ASPECT/	70677
17	QUALITY-ADJUSTED LIFE YEARS/	3940
18	FINANCIAL MANAGEMENT/	23490
19	PHARMACOECONOMICS/	923
20	RESOURCE ALLOCATION/	7545
21	(financ\$ or fiscal\$ or funding).ti.	6311
22	(QALY\$ or life?year\$).ti.	153
23	(econom\$ or cost\$).ti.	53440
24	pharmacoeconomic\$.ti.	1316
25	or/1-24	303375
26	MIDWIFE/	2199
27	exp PRENATAL CARE/	53755
28	MATERNAL TREATMENT/	420
29	exp PERINATAL CARE/	14481
30	exp OBSTETRIC CARE/	136797
31	(midwife or midwifery or midwives).ti,ab.	3016
32	PRENATAL PERIOD/	3699
33	PERINATAL PERIOD/	11913
34	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	219
35	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	9507
36	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	113
37	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	6311
38	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	656
39	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	3268
40	OBSTETRICAL NURSING/	7
41	or/26-40	157232
42	ADOLESCENT PREGNANCY/	2628
43	ADOLESCENT/ and PREGNANCY/	5300

44	((adolescen\$ or teen\$ or youth? or minor?) adj3 pregnan\$).ti,ab.	2222
45	((adolescen\$ or teen\$ or young) adj3 (mom or mum\$ or mother\$)).ti,ab.	2071
46	or/42-45	9558
47	and/41,46	2829
48	editorial.pt.	220012
49	letter.pt.	431106
50	note.pt.	239303
51	or/48-50	890421
52	47 not 51	2721
53	limit 52 to english language	2501
54	and/25,53	275
55	limit 53 to "economics (2 or more terms min difference)"	72
56	55 or 54	301

## Drug and Alcohol Misuse

Ovid MEDLINE(R) 1950 to October Week 5 2008

SCIP\_alcohol\_drug\_misuse\_medline\_101108

#	Searches	Results
1	MIDWIFERY/	11272
2	PRECONCEPTION CARE/	783
3	PRENATAL CARE/	16180
4	PERINATAL CARE/	1609
5	(midwife or midwifery or midwives).ti,ab.	10644
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	248
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	12629
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	180
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9169
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	881
11	exp MATERNAL HEALTH SERVICES/	25350
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	5199
13	MATERNAL-CHILD NURSING/	1470
14	OBSTETRICAL NURSING/	2511
15	NURSE MIDWIVES/	5341
16	REPRODUCTIVE HEALTH SERVICES/	445
17	or/1-16	61425

Pregnant women with complex social factors

18	exp SUBSTANCE-RELATED DISORDERS/	181628
19	ALCOHOL DRINKING/	38644
20	ETHANOL/ae, po	6321
21	TEMPERANCE/	2036
22	exp ALCOHOLIC BEVERAGES/	9856
23	(liquor or beer\$ or lager or wine?).ti,ab.	14108
24	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	37405
25	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	11604
26	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	6657
27	BEHAVIOR, ADDICTIVE/	2545
28	(dependency or dependencies or addict\$).ti,ab.	51445
29	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	1368
30	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	962
31	((drug? or substance?) adj (abus\$ or use\$ or misus\$)).ti,ab.	64822
32	exp METHADONE/	8595
33	amidone.ti,ab.	4
34	dolophine.ti,ab.	3
35	methadone.ti,ab.	7635
36	methadose.ti,ab.	3
37	phenadone.ti,ab.	1
38	physeptone.ti,ab.	2
39	symoron.ti,ab.	1
40	76-99-3.rn.	8515
41	exp MORPHINANS/	60231
42	naltrexone.ti,ab.	4174
43	naloxone.ti,ab.	17970
44	METHAMPHETAMINE/	5053
45	meth??amphetamine?.ti,ab.	5312
46	(crank or crystal meth).ti,ab.	496
47	(deoxyephedrine or desoxyephedrine).ti,ab.	20
48	(metamfetamine or n-methylamphetamine).ti,ab.	50
49	(madrine or desoxyn).ti,ab.	7
50	exp COCAINE/	19019
51	cocaine.ti,ab.	22468
52	50-36-2.rn.	18217
53	LYSERGIC ACID DIETHYLAMIDE/	4334
54	(LSD or lysergic acid diethylamide).ti,ab.	3404
55	50-37-3.rn.	4334
56	lysergide.ti,ab.	58
57	tetrahydrocannabinol.ti,ab.	3796

58	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	1187
59	(marijuana or marihuana).ti,ab.	6574
60	MARIJUANA SMOKING/	1568
61	hashish.ti,ab.	423
62	cannabis.ti,ab.	4638
63	SOLVENTS/	29818
64	((glue or solvent? or chemical) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	623
65	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	1998
66	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	3974
67	(IDU or IDUs).ti,ab.	3030
68	NEEDLE SHARING/	1062
69	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxymethamphetamine).ti,ab.	1498
70	(ecstasy or mdma).ti,ab.	2952
71	codeine.ti,ab.	3009
72	(n methylmorphine or ardinex or isocodeine).ti,ab.	15
73	exp BENZODIAZEPINES/	52304
74	(valium or diazepam).ti,ab.	16024
75	(xanax or alprazolam).ti,ab.	1643
76	(librium or chlordiazepoxide).ti,ab.	2774
77	(prosom or estazolam).ti,ab.	116
78	exp BARBITURATES/	48860
79	(Mephobarbital or mebaral).ti,ab.	78
80	(Nembutal or pentobarbitalsodium).ti,ab.	881
81	NARCOTICS/	12617
82	narcotic?.ti,ab.	10410
83	HYDROCODONE/	219
84	(Vicodin or hydrocodone).ti,ab.	294
85	OPIUM/	1674
86	opium.ti,ab.	1162
87	TRAMADOL/	1399
88	tramadol.ti,ab.	1565
89	DESIGNER DRUGS/	470
90	((designer or illicit or illegal) adj2 drug?).ti,ab.	5535
91	STREET DRUGS/	5571
92	((street or dealer) adj2 drug?).ti,ab.	398
93	((psychoactive or psychedelic) adj3 drug?).ti,ab.	1823
94	PSYCHOTROPIC DRUGS/	13861
95	exp HALLUCINOGENS/	18562
96	(hallucinogen\$ adj2 drug?).ti,ab.	342

97	(detox\$ or withdrawal).ti,ab.	70836
98	(rehab\$ adj3 (drug? or alcohol\$ or substance?)).ti,ab.	958
99	SUBSTANCE ABUSE TREATMENT CENTERS/	3263
100	NEONATAL ABSTINENCE SYNDROME/	606
101	heroin.ti,ab.	8152
102	or/18-101	571877
103	and/17,102	2310
104	letter.pt.	652579
105	editorial.pt.	233379
106	104 or 105	885909
107	103 not 106	2280
108	limit 107 to humans	2206
109	limit 108 to english language	2039

**EBM Reviews - Cochrane Central Register of Controlled Trials 4th Quarter 2008**  
**SCIP alcohol\_drug\_misuse\_ctr\_061108**

#	Searches	Results
1	MIDWIFERY/	132
2	PRECONCEPTION CARE/	20
3	PRENATAL CARE/	564
4	PERINATAL CARE/	46
5	(midwife or midwifery or midwives).ti,ab.	364
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	3
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	634
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	6
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	333
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	52
11	exp MATERNAL HEALTH SERVICES/	758
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	313
13	MATERNAL-CHILD NURSING/	34
14	OBSTETRICAL NURSING/	25
15	NURSE MIDWIVES/	76
16	REPRODUCTIVE HEALTH SERVICES/	4
17	or/1-16	1898
18	exp SUBSTANCE-RELATED DISORDERS/	6065
19	ALCOHOL DRINKING/	1510

20	ETHANOL/ae, po	270
21	TEMPERANCE/	171
22	exp ALCOHOLIC BEVERAGES/	262
23	(liquor or beer\$ or lager or wine?).ti,ab.	493
24	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	1699
25	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	505
26	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	514
27	BEHAVIOR, ADDICTIVE/	159
28	(dependency or dependencies or addict\$).ti,ab.	2039
29	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	71
30	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	48
31	((drug? or substance?) adj (abus\$ or use\$ or misus\$)).ti,ab.	1856
32	exp METHADONE/	622
33	amidone.ti,ab.	0
34	dolophine.ti,ab.	0
35	methadone.ti,ab.	1121
36	methadose.ti,ab.	0
37	phenadone.ti,ab.	0
38	physeptone.ti,ab.	1
39	symoron.ti,ab.	0
40	exp MORPHINANS/	5541
41	naltrexone.ti,ab.	684
42	naloxone.ti,ab.	1258
43	METHAMPHETAMINE/	119
44	meth??amphetamine?.ti,ab.	189
45	(crank or crystal meth).ti,ab.	55
46	(deoxyephedrine or desoxyephedrine).ti,ab.	1
47	(metamfetamine or n-methylamphetamine).ti,ab.	4
48	(madrine or desoxyn).ti,ab.	0
49	exp COCAINE/	522
50	cocaine.ti,ab.	1428
51	LYSERGIC ACID DIETHYLAMIDE/	47
52	(LSD or lysergic acid diethylamide).ti,ab.	121
53	lysergide.ti,ab.	1
54	tetrahydrocannabinol.ti,ab.	300
55	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	71
56	(marijuana or marihuana).ti,ab.	585
57	MARIJUANA SMOKING/	97
58	hashish.ti,ab.	4
59	cannibis.ti,ab.	1

Pregnant women with complex social factors

60	SOLVENTS/	139
61	((glue or solvent? or chemical) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	13
62	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	23
63	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	152
64	(IDU or IDUs).ti,ab.	145
65	NEEDLE SHARING/	27
66	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxymethamphetamine).ti,ab.	48
67	(ecstasy or mdma).ti,ab.	94
68	codeine.ti,ab.	694
69	(n methylmorphine or ardinex or isocodeine).ti,ab.	2
70	exp BENZODIAZEPINES/	6590
71	(valium or diazepam).ti,ab.	2677
72	(xanax or alprazolam).ti,ab.	656
73	(librium or chlordiazepoxide).ti,ab.	266
74	(prosom or estazolam).ti,ab.	37
75	exp BARBITURATES/	1732
76	(Mephobarbital or mebaral).ti,ab.	2
77	(Nembutal or pentobarbitalsodium).ti,ab.	4
78	NARCOTICS/	499
79	narcotic?.ti,ab.	1096
80	HYDROCODONE/	57
81	(Vicodin or hydrocodone).ti,ab.	79
82	OPIUM/	86
83	opium.ti,ab.	30
84	TRAMADOL/	454
85	tramadol.ti,ab.	823
86	DESIGNER DRUGS/	3
87	((designer or illicit or illegal) adj2 drug?).ti,ab.	211
88	STREET DRUGS/	80
89	((street or dealer) adj2 drug?).ti,ab.	10
90	((psychoactive or psychedelic) adj3 drug?).ti,ab.	99
91	PSYCHOTROPIC DRUGS/	269
92	exp HALLUCINOGENS/	471
93	(hallucinogen\$ adj2 drug?).ti,ab.	15
94	or/18-93	28722
95	and/17,94	97

**DARE, CDSR**

**SCIP\_alcohol\_drug\_misuse\_cdsrdare\_071108**

#	Searches	Results
1	MIDWIFERY.kw.	15

2	PRECONCEPTION CARE.kw.	5
3	PRENATAL CARE.kw.	42
4	PERINATAL CARE.kw.	7
5	(midwife or midwifery or midwives).ti,ab.	24
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	2
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	25
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	0
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	1
11	MATERNAL HEALTH SERVICES\$.kw.	7
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	26
13	MATERNAL-CHILD NURSING.kw.	5
14	OBSTETRICAL NURSING.kw.	2
15	MIDWI?E?.kw.	7
16	REPRODUCTIVE HEALTH SERVICES\$.kw.	2
17	or/1-16	122
18	SUBSTANCE-RELATED DISORDER\$.kw.	69
19	ALCOHOL\$.kw.	125
20	ETHANOL.kw.	13
21	TEMPERANCE.kw.	9
22	ALCOHOLIC BEVERAGE?.kw.	2
23	(liquor or beer\$ or lager or wine?).ti,ab.	11
24	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	21
25	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	14
26	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	20
27	ADDICT\$.kw.	3
28	(dependency or dependencies or addict\$).ti,ab.	113
29	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	0
30	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	0
31	((drug? or substance?) adj (abus\$ or use\$ or misus\$)).ti,ab.	48
32	METHADONE.kw.	25
33	amidone.ti,ab.	0
34	dolophine.ti,ab.	0
35	methadone.ti,ab.	31
36	methadose.ti,ab.	0

Pregnant women with complex social factors

37	phenadone.ti,ab.	0
38	physeptone.ti,ab.	0
39	symoron.ti,ab.	0
40	MORPHIN\$.kw.	22
41	naltrexone.ti,ab.	14
42	naloxone.ti,ab.	10
43	METHAMPHETAMINE.kw.	1
44	meth??amphetamine?.ti,ab.	1
45	(crank or crystal meth).ti,ab.	0
46	(deoxyephedrine or desoxyephedrine).ti,ab.	0
47	(metamfetamine or n-methylamphetamine).ti,ab.	0
48	(madrine or desoxyn).ti,ab.	0
49	COCAINE.kw.	13
50	cocaine.ti,ab.	16
51	LYSERGIC ACID DIETHYLAMIDE.kw.	0
52	(LSD or lysergic acid diethylamide).ti,ab.	0
53	lysergide.ti,ab.	0
54	tetrahydrocannabinol.ti,ab.	0
55	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	0
56	(marijuana or marihuana).ti,ab.	1
57	MARIJUANA.kw.	2
58	hashish.ti,ab.	0
59	cannibis.ti,ab.	0
60	SOLVENT\$.kw.	2
61	((glue or solvent? or chemical) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	0
62	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	0
63	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	6
64	(IDU or IDUs).ti,ab.	2
65	NEEDLE SHARING.kw.	0
66	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxymethamphetamine).ti,ab.	0
67	(ecstasy or mdma).ti,ab.	0
68	codeine.ti,ab.	12
69	(n methylmorphine or ardinex or isocodeine).ti,ab.	0
70	BENZODIAZEPINE?.kw.	62
71	(valium or diazepam).ti,ab.	20
72	(xanax or alprazolam).ti,ab.	4
73	(librium or chlordiazepoxide).ti,ab.	0
74	(prosom or estazolam).ti,ab.	0
75	BARBITURATE?.kw.	3
76	(Mephobarbital or mebaral).ti,ab.	0

77	(Nembutal or pentobarbitalsodium).ti,ab.	0
78	NARCOTIC?.kw.	116
79	narcotic?.ti,ab.	12
80	HYDROCODONE.kw.	1
81	(Vicodin or hydrocodone).ti,ab.	0
82	OPIUM.kw.	1
83	opium.ti,ab.	1
84	TRAMADOL.kw.	4
85	tramadol.ti,ab.	8
86	DESIGNER DRUG?.kw.	0
87	((designer or illicit or illegal) adj2 drug?).ti,ab.	6
88	STREET DRUG?.kw.	3
89	((street or dealer) adj2 drug?).ti,ab.	0
90	((psychoactive or psychedelic) adj3 drug?).ti,ab.	2
91	PSYCHOTROPIC DRUG?.kw.	30
92	HALLUCINOGEN?.kw.	1
93	(hallucinogen\$ adj2 drug?).ti,ab.	0
94	or/18-93	603
95	and/17,94	3

**EMBASE 1980 to 2008 Week 44****SCIP\_alcohol\_drug\_misuse\_embase\_071108**

#	Searches	Results
1	MIDWIFE/	2191
2	exp PRENATAL CARE/	53531
3	MATERNAL TREATMENT/	418
4	exp PERINATAL CARE/	14385
5	exp OBSTETRIC CARE/	136210
6	(midwife or midwifery or midwives).ti,ab.	2997
7	PRENATAL PERIOD/	3670
8	PERINATAL PERIOD/	11840
9	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	217
10	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	9464
11	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	112
12	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	6268
13	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	651
14	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or	3246

	clinic?)).ti,ab.	
15	OBSTETRICAL NURSING/	8
16	or/1-15	156541
17	ADDICTION/	5091
18	ALCOHOLISM/	39980
19	WITHDRAWAL SYNDROME/	11060
20	exp DRUG DEPENDENCE/	40610
21	ALCOHOL ABSTINENCE/	1938
22	DRINKING BEHAVIOR/	10367
23	ALCOHOL ABUSE/	12093
24	exp ALCOHOLIC BEVERAGE/	6824
25	METHADONE/	13679
26	exp DRUG ABUSE/	42438
27	ILLICIT DRUG/	5432
28	RECREATIONAL DRUG/	223
29	STREET DRUG/	281
30	DESIGNER DRUG/	272
31	(liquor or beer\$ or lager or wine?).ti,ab.	13091
32	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	32755
33	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	10246
34	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	5833
35	(drug? dependency or drug? dependencies or addict\$).ti,ab.	23368
36	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	1145
37	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	802
38	((drug? or substance?) adj2 (abus\$ or use\$ or misus\$)).ti,ab.	80033
39	((drug? or substance?) adj3 overuse\$).ti,ab.	113
40	methadone.ti,ab.	6734
41	naltrexone.ti,ab.	3967
42	naloxone.ti,ab.	16892
43	meth??amphetamine?.ti,ab.	4873
44	(crank or crystal meth).ti,ab.	515
45	(metamfetamine or n-methylamphetamine).ti,ab.	48
46	cocaine.ti,ab.	21115
47	heroin.ti,ab.	7311
48	(LSD or lysergic acid diethylamide).ti,ab.	1906
49	lysergide.ti,ab.	31
50	CANNABIS/	11088
51	tetrahydrocannabinol.ti,ab.	3057
52	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	2390
53	(marijuana or marihuana).ti,ab.	4873

54	(tranquilizer? adj3 abus\$).ti,ab.	13
55	hashish.ti,ab.	285
56	cannabis.ti,ab.	4336
57	exp SOLVENT/	172433
58	((glue or solvent? or chemical) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	502
59	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	1739
60	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	3641
61	(IDU or IDUs).ti,ab.	2635
62	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxymethamphetamine).ti,ab.	1517
63	(ecstasy or mdma).ti,ab.	2990
64	(codeine adj3 (abus\$ or overuse\$)).ti,ab.	28
65	((barbituate? or benzodiazepine?) adj3 (abus\$ or overuse\$)).ti,ab.	251
66	tramadol.ti,ab.	1960
67	(valium or diazepam).ti,ab.	13744
68	(xanax or alprazolam).ti,ab.	1736
69	(librium or chlordiazepoxide).ti,ab.	1841
70	(prosom or estazolam).ti,ab.	146
71	(Mephobarbital or mebaral).ti,ab.	53
72	(Nembutal or pentobarbitalsodium).ti,ab.	429
73	narcotic?.ti,ab.	7270
74	(Vicodin or hydrocodone).ti,ab.	285
75	opium.ti,ab.	799
76	(overus\$ or abus\$ or misus\$ or addict\$).ti,ab.	84446
77	or/66-75	27093
78	and/76-77	2167
79	(opiate? adj3 abus\$).ti,ab.	484
80	((designer or illicit or illegal) adj2 drug?).ti,ab.	5195
81	((street or dealer) adj2 drug?).ti,ab.	351
82	PSYCHOTROPIC AGENT/	11588
83	exp PSYCHEDELIC AGENT/	27051
84	((psychoactive or psychedelic) adj2 drug?).ti,ab.	1568
85	PSYCHOSTIMULANT AGENT/	2825
86	(hallucinogen\$ adj2 drug?).ti,ab.	230
87	DRUG DEPENDENCE TREATMENT/	3749
88	DETOXIFICATION/	9915
89	ALCOHOL WITHDRAWAL/	3319
90	WITHDRAWAL SEIZURE/	61
91	((detox\$ or withdrawal) adj5 (drug? or alcohol\$ or substance?)).ti,ab.	8863
92	(rehab\$ adj3 (drug? or alcohol\$ or substance?)).ti,ab.	740

93	or/17-65,78-92	425072
94	and/16,93	4966
95	editorial.pt.	218883
96	letter.pt.	429218
97	note.pt.	238215
98	or/95-97	886316
99	94 not 98	4691
100	limit 99 to english language	4299
101	limit 100 to animals	937
102	100 not 101	3362
103	from 102 keep 1-10	

**CINAHL - Cumulative Index to Nursing & Allied Health Literature 1982 to November Week 1 2008**

**SCIP\_alcohol\_drug\_misuse\_cinahl\_101108**

#	Searches	Results
1	exp MIDWIFERY/	9712
2	PREPREGNANCY CARE/	524
3	PRENATAL CARE/	5089
4	PERINATAL CARE/	1027
5	MATERNAL HEALTH SERVICES/	2116
6	MATERNAL-CHILD NURSING/	967
7	OBSTETRICAL NURSING/	2089
8	NURSE MIDWIVES/	1189
9	PERINATAL NURSING/	626
10	(midwife or midwifery or midwives).ti,ab.	11423
11	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	144
12	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	3246
13	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	54
14	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	1992
15	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	194
16	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	1428
17	or/1-16	28939
18	exp "SUBSTANCE USE DISORDERS"/	40755
19	ALCOHOL DRINKING/	6234
20	SUBSTANCE DEPENDENCE/	3926

21	ALCOHOLISM/	4749
22	exp ALCOHOLIC BEVERAGES/	1066
23	(liquor or beer\$ or lager or wine?).ti,ab.	843
24	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	6365
25	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	1744
26	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	1594
27	BEHAVIOR, ADDICTIVE/	938
28	(dependency or dependencies or addict\$).ti,ab.	6887
29	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	499
30	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	148
31	((drug? or substance?) adj (abus\$ or use\$ or misus\$)).ti,ab.	14244
32	NARCOTICS/	3313
33	methadone.ti,ab.	1077
34	morphine.ti,ab.	1562
35	naltrexone.ti,ab.	255
36	naloxone.ti,ab.	303
37	exp METHAMPHETAMINE/	898
38	meth??amphetamine?.ti,ab.	429
39	(crank or crystal meth).ti,ab.	150
40	(metamfetamine or n-methylamphetamine).ti,ab.	1
41	exp COCAINE/	1835
42	cocaine.ti,ab.	2023
43	LYSERGIC ACID DIETHYLAMIDE/	56
44	(LSD or lysergic acid diethylamide).ti,ab.	93
45	tetrahydrocannabinol.ti,ab.	45
46	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	10
47	CANNABIS/	1908
48	(marijuana or marihuana).ti,ab.	1212
49	hashish.ti,ab.	19
50	cannabis.ti,ab.	798
51	SOLVENTS/	349
52	((glue or solvent? or aerosol?) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	42
53	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	112
54	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	981
55	(IDU or IDUs).ti,ab.	599
56	NEEDLE SHARING/	280
57	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxymethamphetamine).ti,ab.	57
58	(ecstasy or mdma).ti,ab.	358
59	codeine.ti,ab.	174
60	exp ANTIANXIETY AGENTS, BENZODIAZEPINE/	2295

61	(valium or diazepam).ti,ab.	261
62	(xanax or alprazolam).ti,ab.	68
63	(librium or chlordiazepoxide).ti,ab.	10
64	exp BARBITURATES/	415
65	narcotic?.ti,ab.	887
66	(Vicodin or hydrocodone).ti,ab.	82
67	exp OPIUM/	3855
68	opium.ti,ab.	91
69	HEROIN/	886
70	heroin.ti,ab.	1033
71	DESIGNER DRUGS/	42
72	((designer or illicit or illegal) adj2 drug?).ti,ab.	1348
73	STREET DRUGS/	1223
74	((street or dealer) adj2 drug?).ti,ab.	116
75	((psychoactive or psychedelic) adj3 drug?).ti,ab.	135
76	exp PSYCHOTROPIC DRUGS/	15281
77	exp HALLUCINOGENS/	528
78	(hallucinogen\$ adj2 drug?).ti,ab.	12
79	(detox\$ or withdrawal).ti,ab.	3924
80	(rehab\$ adj3 (drug? or alcohol\$ or substance?)).ti,ab.	154
81	"SUBSTANCE USE REHABILITATION PROGRAMS"/	1433
82	ALCOHOL REHABILITATION PROGRAMS/	244
83	DRUG REHABILITATION PROGRAMS/	816
84	SUBSTANCE WITHDRAWAL, CONTROLLED/	298
85	SUBSTANCE ABUSE, PERINATAL/	931
86	SUBSTANCE WITHDRAWAL SYNDROME/	929
87	ALCOHOL WITHDRAWAL DELIRIUM/	215
88	or/18-87	79284
89	and/17,88	1089
90	letter.pt.	66997
91	editorial.pt.	94143
92	brief item.pt.	184808
93	exam questions.pt.	49540
94	or/90-93	393507
95	89 not 94	1022
96	limit 95 to english	1013

**SCIP\_alcohol\_drug\_misuse\_assia\_101108**

(KW=((antenatal care) or (prenatal care) or (perinatal care)) or KW=((ante natal care) or (pre natal care) or (peri natal care)) or KW=((preconception care) or (pregnancy care) or (obstetric\* care)) or KW=(midwif\* or midwives or (reproductive healthcare)) or KW=((obstetric\* nurs\*) or

(antenatal clinic\*) or (prenatal clinic\*)) or KW=((maternal healthcare) or (maternal care)) or (DE=("prenatal testing" or "amniocentesis" or "prenatal care" or "midwifery" or "infant mortality" or "Womens Health Care")) and ((KW=(alcohol\* or drug\* or liquor or drinking or beer or lager or wine or temperance or sobriety or binge\* or methadone or crack or cocaine or heroin or meth or methamphetamine\* or crank or cannabis or hash\* or marijuana or marihuana or THC or LSD or (LYSERGIC ACID DIETHYLAMIDE) or solvent\* or glue or needle or IDU or ecstasy or mdma or methylenedioxymethamphetamine or methylenedioxyamphetamine or barbituate\* or benzodiazepine\* or opiates or opium or narcotic\* or addict\* or withdrawal or detox\* or rehab\*)) or (DE=("hallucinogens" or "ayahuasca" or "lysergic acid diethylamide" or "lysergic acid diethylamide" or "addiction" or "alcoholism" or "familial alcoholism" or "drug addiction" or "intravenous drug addiction" or "withdrawal symptoms" or "addictive" or "addictive behaviour" or "addicts" or "drug addicts" or "intravenous drug addicts" or "addition" or "alcohol related violence" or "alcohol withdrawal syndrome" or "alcoholic beverages" or "alcoholic soft drinks" or "banana beer" or "beer" or "designer drinks" or "martinis" or "spirits" or "gin" or "wine" or "alcoholic soft drinks" or "alcoholics" or "violent alcoholics" or "alcoholics anonymous" or "alcoholism" or "familial alcoholism" or "alcohols" or "ethyl alcohol" or "barbiturates" or "cannabis" or "skunk" or "cocaine" or "crack" or "detoxification" or "rapid detoxification" or "ecstasy drug" or "flatliner drug" or "heroin" or "intoxicants" or "methadone" or "methamphetamine" or "morphine" or "narcotics" or "heroin" or "opium" or "psychotropic drugs" or "methylphenidate" or "rehabilitation" or "computer assisted rehabilitation" or "environmental control systems" or "industrial rehabilitation" or "work hardening" or "neuropsychological rehabilitation" or "psychosocial rehabilitation" or "social rehabilitation" or "sobriety" or "sobriety checkpoint programmes" or "solvent abuse" or "temperance" or "tranquillizers" or "benzodiazepines" or "alprazolam" or "clobazam" or "flunitrazepam" or "triazolam" or "valium" or "buspirone" or "withdrawal")))

#### **SCIP\_alcohol\_drug\_misuse\_sociologabs\_101108**

(KW=((antenatal care) or (prenatal care) or (perinatal care)) or KW=((ante natal care) or (pre natal care) or (peri natal care)) or KW=((preconception care) or (pregnancy care) or (obstetric\* care)) or KW=(midwif\* or midwives or (reproductive healthcare)) or KW=((obstetric\* nurs\*) or (antenatal clinic\*) or (prenatal clinic\*)) or KW=((maternal healthcare) or (maternal care))) and ((KW=(alcohol\* or drug\* or liquor or drinking or beer or lager or wine or temperance or sobriety or binge\* or methadone or crack or cocaine or heroin or meth or methamphetamine\* or crank or cannabis or hash\* or marijuana or marihuana or THC or LSD or (LYSERGIC ACID DIETHYLAMIDE) or solvent\* or glue or needle or IDU or ecstasy or mdma or methylenedioxymethamphetamine or methylenedioxyamphetamine or barbituate\* or benzodiazepine\* or opiates or opium or narcotic\* or addict\* or withdrawal or detox\* or rehab\*)) or (DE=("abstinence" or "addiction" or "alcohol" or "alcohol abuse" or "alcoholism" or "cocaine" or "detoxification" or "drug abuse" or "drug addiction" or "drug injection" or "drugs" or "drunkenness" or "heroin" or "lysergic acid diethylamide" or "marijuana" or "methadone maintenance" or "narcotic drugs" or "needle exchange programs" or "psychedelic drugs" or "rehabilitation" or "relapse" or "sober/sobriety" or "substance abuse" or "tranquilizing drugs" or "treatment programs" or "withdrawal")))

#### **SCIP\_alcohol\_drug\_misuse\_socservabs\_101108**

(KW=((antenatal care) or (prenatal care) or (perinatal care)) or KW=((ante natal care) or (pre natal care) or (peri natal care)) or KW=((preconception care) or (pregnancy care) or (obstetric\* care)) or KW=(midwif\* or midwives or (reproductive healthcare)) or KW=((obstetric\* nurs\*) or (antenatal clinic\*) or (prenatal clinic\*)) or KW=((maternal healthcare) or (maternal care)) or (DE=("prenatal testing" or "amniocentesis" or "prenatal care" or "midwifery" or "infant mortality" or "Womens Health Care")) and ((DE=("withdrawal" or "abstinence" or "addiction" or "alcohol abuse" or "alcohol use" or "alcoholic beverages" or "alcoholism" or "cocaine" or "detoxification" or "drinking behavior" or "drug abuse" or "drug addiction" or "drug injection" or "drugs" or

## Pregnant women with complex social factors

"drunkenness" or "heroin" or "lysergic acid diethylamide" or "marijuana" or "methadone maintenance" or "narcotic drugs" or "needle exchange programs" or "needle sharing" or "opiates" or "psychedelic drugs" or "rehabilitation" or "relapse" or "substance abuse")) or(KW=(alcohol\* or drug\* or liquor or drinking or beer or lager or wine or temperance or sobriety or binge\* or methadone or crack or cocaine or heroin or meth or methamphetamine\* or crank or cannabis or hash\* or marijuana or marihuana or THC or LSD or (LYSERGIC ACID DIETHYLAMIDE) or solvent\* or glue or needle or IDU or ecstasy or mdma or methylenedioxymethamphetamine or methylenedioxyamphetamine or barbituate\* or benzodiazepine\* or opiates or opium or narcotic\* or addict\* or withdrawal or detox\* or rehab\*))

### PsycINFO 1967 to November Week 1 2008 SCIP\_alcohol\_drug\_misuse\_psycinfo\_071108

#	Searches	Results
1	exp PRENATAL CARE/	972
2	REPRODUCTIVE HEALTH/	218
3	PRENATAL DIAGNOSIS/	374
4	PRENATAL DEVELOPMENT/	2883
5	exp OBSTETRICS/	820
6	PERINATAL PERIOD/	933
7	(midwife or midwifery or midwives).ti,ab.	850
8	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	27
9	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	1704
10	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	21
11	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	992
12	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	252
13	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	1478
14	or/1-13	9389
15	exp DRUG ABUSE/	62877
16	exp SOLVENTS/	453
17	ADDICTION/	3232
18	SOBRIETY/	927
19	DRUG ABUSE PREVENTION/	2412
20	DRUG SEEKING/	65
21	ILLEGAL DRUG DISTRIBUTION/	274
22	DRUG ABUSE LIABILITY/	213
23	DRUG OVERDOSES/	739
24	DRUG WITHDRAWAL/	4372
25	NEEDLE SHARING/	323

26	NEEDLE EXCHANGE PROGRAMS/	200
27	DRUG ABSTINENCE/	1249
28	SOBRIETY/	927
29	exp DRINKING BEHAVIOR/	44339
30	exp ALCOHOLIC BEVERAGES/	1330
31	exp DRUG REHABILITATION/	20486
32	(liquor or beer\$ or lager or wine?).ti,ab.	2090
33	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	21481
34	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	8445
35	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	7322
36	(drug? dependency or drug? dependencies or addict\$).ti,ab.	21169
37	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	1088
38	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	1031
39	((drug? or substance?) adj (abus\$ or use\$ or misus\$)).ti,ab.	48986
40	exp NARCOTIC DRUGS/	16483
41	methadone.ti,ab.	4299
42	naltrexone.ti,ab.	2002
43	naloxone.ti,ab.	3654
44	METHAMPHETAMINE/	1443
45	meth??amphetamine?.ti,ab.	1978
46	(crank or crystal meth).ti,ab.	67
47	(metamfetamine or n-methylamphetamine).ti,ab.	18
48	exp COCAINE/	8263
49	cocaine.ti,ab.	11363
50	LYSERGIC ACID DIETHYLAMIDE/	920
51	(LSD or lysergic acid diethylamide).ti,ab.	1574
52	lysergide.ti,ab.	8
53	CANNABIS/	1384
54	tetrahydrocannabinol.ti,ab.	1193
55	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	54
56	(marijuana or marihuana).ti,ab.	5282
57	HASHISH/	93
58	MARIJUANA/	1440
59	MARIJUANA USAGE/	1537
60	hashish.ti,ab.	261
61	cannabis.ti,ab.	2801
62	((glue or solvent? or chemical) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	446
63	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	143
64	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	1743
65	(IDU or IDUs).ti,ab.	1116

66	METHYLENEDIOXYMETHAMPHETAMINE/	1068
67	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxyamphetamine).ti,ab.	724
68	(ecstasy or mdma).ti,ab.	1578
69	codeine.ti,ab.	285
70	exp BENZODIAZEPINES/	8083
71	(valium or diazepam).ti,ab.	3703
72	(xanax or alprazolam).ti,ab.	1045
73	(librium or chlordiazepoxide).ti,ab.	1466
74	(prosom or estazolam).ti,ab.	25
75	exp BARBITURATES/	1829
76	(Mephobarbital or mebaral).ti,ab.	5
77	(Nembutal or pentobarbitalsodium).ti,ab.	126
78	narcotic?.ti,ab.	2097
79	(Vicodin or hydrocodone).ti,ab.	58
80	exp OPIATES/	13230
81	opium.ti,ab.	283
82	tramadol.ti,ab.	187
83	((designer or illicit or illegal) adj2 drug?).ti,ab.	3957
84	((street or dealer) adj2 drug?).ti,ab.	234
85	((psychoactive or psychedelic) adj3 drug?).ti,ab.	1435
86	exp HALLUCINOGENIC DRUGS/	2636
87	(hallucinogen\$ adj2 drug?).ti,ab.	259
88	(detox\$ or withdrawal).ti,ab.	19258
89	(rehab\$ adj3 (drug? or alcohol\$ or substance?)).ti,ab.	991
90	or/15-89	163572
91	and/14,90	1106
92	book.pt.	235196
93	edited book.pt.	193250
94	or/92-93	235196
95	91 not 94	1018
96	limit 95 to human	720
97	limit 96 to english language	706

## Drug and Alcohol Misuse Health Economics

Ovid MEDLINE(R) 1950 to November Week 2 2008

SCIP\_alcohol\_drug\_misuse\_economics\_medline\_241108

#	Searches	Results
1	ECONOMICS/	25927
2	"COSTS AND COST ANALYSIS"/	37714

3	COST ALLOCATION/	1868
4	COST-BENEFIT ANALYSIS/	45114
5	COST CONTROL/	18116
6	COST SAVINGS/	6198
7	COST OF ILLNESS/	11241
8	COST SHARING/	1452
9	HEALTH CARE COSTS/	17529
10	DIRECT SERVICE COSTS/	869
11	DRUG COSTS/	9032
12	EMPLOYER HEALTH COSTS/	998
13	HOSPITAL COSTS/	5782
14	HEALTH RESOURCES/	6549
15	"HEALTH SERVICES NEEDS AND DEMAND"/	31064
16	HEALTH PRIORITIES/	7065
17	HEALTH EXPENDITURES/	10495
18	CAPITAL EXPENDITURES/	1846
19	FINANCIAL MANAGEMENT/	14569
20	FINANCIAL MANAGEMENT, HOSPITAL/	7012
21	QUALITY-ADJUSTED LIFE YEARS/	3703
22	"DEDUCTIBLES AND COINSURANCE"/	1215
23	MEDICAL SAVINGS ACCOUNTS/	402
24	ECONOMICS, HOSPITAL/	8768
25	ECONOMICS, MEDICAL/	7354
26	ECONOMICS, NURSING/	3859
27	ECONOMICS, PHARMACEUTICAL/	2005
28	MODELS, ECONOMIC/	3350
29	MODELS, ECONOMETRIC/	2869
30	RESOURCE ALLOCATION/	6095
31	HEALTH CARE RATIONING/	9134
32	"FEES AND CHARGES"/	7497
33	BUDGETS/	7798
34	VALUE OF LIFE/	5086
35	(financ\$ or fiscal\$ or funding).ti.	13721
36	(QALY\$ or life?year\$).ti.	200
37	(econom\$ or cost\$).ti.	81598
38	pharmacoeconomic\$.ti.	1096
39	or/1-38	290019
40	MIDWIFERY/	11310
41	PRECONCEPTION CARE/	795
42	PRENATAL CARE/	16251

Pregnant women with complex social factors

43	PERINATAL CARE/	1616
44	(midwife or midwifery or midwives).ti,ab.	10680
45	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	250
46	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	12687
47	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	182
48	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9224
49	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	889
50	exp MATERNAL HEALTH SERVICES/	25461
51	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	5229
52	MATERNAL-CHILD NURSING/	1475
53	OBSTETRICAL NURSING/	2511
54	NURSE MIDWIVES/	5344
55	REPRODUCTIVE HEALTH SERVICES/	454
56	or/40-55	61675
57	exp SUBSTANCE-RELATED DISORDERS/	182340
58	ALCOHOL DRINKING/	38860
59	ETHANOL/ae, po	6345
60	TEMPERANCE/	2043
61	exp ALCOHOLIC BEVERAGES/	9896
62	(liquor or beer\$ or lager or wine?).ti,ab.	14183
63	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	37645
64	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	11637
65	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	6695
66	BEHAVIOR, ADDICTIVE/	2557
67	(dependency or dependencies or addict\$).ti,ab.	51674
68	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	1385
69	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	964
70	((drug? or substance?) adj (abus\$ or use\$ or misus\$)).ti,ab.	65226
71	exp METHADONE/	8759
72	amidone.ti,ab.	15
73	dolophine.ti,ab.	4
74	methadone.ti,ab.	7689
75	methadose.ti,ab.	3
76	phenadone.ti,ab.	1
77	physeptone.ti,ab.	2

78	symoron.ti,ab.	1
79	76-99-3.rn.	8678
80	exp MORPHINANS/	60619
81	naltrexone.ti,ab.	4184
82	naloxone.ti,ab.	18096
83	METHAMPHETAMINE/	5073
84	meth??amphetamine?.ti,ab.	5334
85	(crank or crystal meth).ti,ab.	499
86	(deoxyephedrine or desoxyephedrine).ti,ab.	21
87	(metamfetamine or n-methylamphetamine).ti,ab.	50
88	(madrine or desoxyn).ti,ab.	7
89	exp COCAINE/	19087
90	cocaine.ti,ab.	22574
91	50-36-2.rn.	18281
92	LYSERGIC ACID DIETHYLAMIDE/	4353
93	(LSD or lysergic acid diethylamide).ti,ab.	3429
94	50-37-3.rn.	4353
95	lysergide.ti,ab.	58
96	tetrahydrocannabinol.ti,ab.	3821
97	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	1193
98	(marijuana or marihuana).ti,ab.	6661
99	MARIJUANA SMOKING/	1580
100	hashish.ti,ab.	426
101	cannabis.ti,ab.	4671
102	SOLVENTS/	29905
103	((glue or solvent? or chemical) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	627
104	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	2000
105	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	3985
106	(IDU or IDUs).ti,ab.	3039
107	NEEDLE SHARING/	1062
108	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxymethamphetamine).ti,ab.	1505
109	(ecstasy or mdma).ti,ab.	2965
110	codeine.ti,ab.	3020
111	(n methylmorphine or ardinex or isocodeine).ti,ab.	15
112	exp BENZODIAZEPINES/	52568
113	(valium or diazepam).ti,ab.	16168
114	(xanax or alprazolam).ti,ab.	1644
115	(librium or chlordiazepoxide).ti,ab.	2787
116	(prosom or estazolam).ti,ab.	117

117	exp BARBITURATES/	49077
118	(Mephobarbital or mebaral).ti,ab.	79
119	(Nembutal or pentobarbitalsodium).ti,ab.	933
120	NARCOTICS/	12659
121	narcotic?.ti,ab.	10478
122	HYDROCODONE/	220
123	(Vicodin or hydrocodone).ti,ab.	295
124	OPIUM/	1678
125	opium.ti,ab.	1164
126	TRAMADOL/	1406
127	tramadol.ti,ab.	1575
128	DESIGNER DRUGS/	470
129	((designer or illicit or illegal) adj2 drug?).ti,ab.	5584
130	STREET DRUGS/	5596
131	((street or dealer) adj2 drug?).ti,ab.	401
132	((psychoactive or psychedelic) adj3 drug?).ti,ab.	1827
133	PSYCHOTROPIC DRUGS/	13961
134	exp HALLUCINOGENS/	18643
135	(hallucinogen\$ adj2 drug?).ti,ab.	343
136	(detox\$ or withdrawal).ti,ab.	71108
137	(rehab\$ adj3 (drug? or alcohol\$ or substance?)).ti,ab.	961
138	SUBSTANCE ABUSE TREATMENT CENTERS/	3269
139	NEONATAL ABSTINENCE SYNDROME/	609
140	heroin.ti,ab.	8175
141	or/57-140	574711
142	and/56,141	2328
143	letter.pt.	653898
144	editorial.pt.	234352
145	143 or 144	888201
146	142 not 145	2298
147	limit 146 to humans	2222
148	limit 147 to english language	2055
149	and/39,148	76
150	limit 148 to ("costs (optimized)" or "economics (optimized)")	76
151	149 or 150	120

**CLEED, CLHTA**

**SCIP\_alcohol\_drug\_misuse\_economics\_htaed\_241108**

#	Searches	Results
1	MIDWIFERY/	20
2	PRECONCEPTION CARE/	3

3	PRENATAL CARE/	117
4	PERINATAL CARE/	18
5	(midwife or midwifery or midwives).ti,ab.	14
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	2
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	31
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	0
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	18
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	0
11	exp MATERNAL HEALTH SERVICES/	189
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	14
13	MATERNAL-CHILD NURSING/	4
14	OBSTETRICAL NURSING/	2
15	NURSE MIDWIVES/	9
16	REPRODUCTIVE HEALTH SERVICES/	4
17	or/1-16	232
18	exp SUBSTANCE-RELATED DISORDERS/	452
19	ALCOHOL DRINKING/	53
20	ETHANOL/ae, po	2
21	TEMPERANCE/	6
22	exp ALCOHOLIC BEVERAGES/	2
23	(liquor or beer\$ or lager or wine?).ti,ab.	3
24	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	16
25	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	13
26	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	11
27	BEHAVIOR, ADDICTIVE/	5
28	(dependency or dependencies or addict\$).ti,ab.	43
29	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	0
30	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	0
31	((drug? or substance?) adj (abus\$ or use\$ or misus\$)).ti,ab.	168
32	exp METHADONE/	43
33	amidone.ti,ab.	0
34	dolophine.ti,ab.	0
35	methadone.ti,ab.	28
36	methadose.ti,ab.	0
37	phenadone.ti,ab.	0

38	physeptone.ti,ab.	0
39	symoron.ti,ab.	0
40	76-99-3.rn.	0
41	exp MORPHINANS/	68
42	naltrexone.ti,ab.	6
43	naloxone.ti,ab.	3
44	METHAMPHETAMINE/	3
45	meth??amphetamine?.ti,ab.	3
46	(crank or crystal meth).ti,ab.	0
47	(deoxyephedrine or desoxyephedrine).ti,ab.	0
48	(metamfetamine or n-methylamphetamine).ti,ab.	0
49	(madrine or desoxyn).ti,ab.	0
50	exp COCAINE/	7
51	cocaine.ti,ab.	6
52	50-36-2.rn.	0
53	LYSERGIC ACID DIETHYLAMIDE/	0
54	(LSD or lysergic acid diethylamide).ti,ab.	0
55	50-37-3.rn.	0
56	lysergide.ti,ab.	0
57	tetrahydrocannabinol.ti,ab.	0
58	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	0
59	(marijuana or marihuana).ti,ab.	5
60	MARIJUANA SMOKING/	0
61	hashish.ti,ab.	0
62	cannabis.ti,ab.	4
63	SOLVENTS/	4
64	((glue or solvent? or chemical) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	2
65	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	1
66	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	19
67	(IDU or IDUs).ti,ab.	0
68	NEEDLE SHARING/	5
69	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxymethamphetamine).ti,ab.	0
70	(ecstasy or mdma).ti,ab.	1
71	codeine.ti,ab.	0
72	(n methylmorphine or ardinex or isocodeine).ti,ab.	0
73	exp BENZODIAZEPINES/	124
74	(valium or diazepam).ti,ab.	4
75	(xanax or alprazolam).ti,ab.	0
76	(librium or chlordiazepoxide).ti,ab.	0

77	(prosom or estazolam).ti,ab.	0
78	exp BARBITURATES/	16
79	(Mephobarbital or mebaral).ti,ab.	0
80	(Nembutal or pentobarbitalsodium).ti,ab.	0
81	NARCOTICS/	26
82	narcotic?.ti,ab.	2
83	HYDROCODONE/	1
84	(Vicodin or hydrocodone).ti,ab.	0
85	OPIUM/	1
86	opium.ti,ab.	1
87	TRAMADOL/	4
88	tramadol.ti,ab.	3
89	DESIGNER DRUGS/	0
90	((designer or illicit or illegal) adj2 drug?).ti,ab.	5
91	STREET DRUGS/	10
92	((street or dealer) adj2 drug?).ti,ab.	0
93	((psychoactive or psychedelic) adj3 drug?).ti,ab.	0
94	PSYCHOTROPIC DRUGS/	34
95	exp HALLUCINOGENS/	1
96	(hallucinogen\$ adj2 drug?).ti,ab.	0
97	(detox\$ or withdrawal).ti,ab.	20
98	(rehab\$ adj3 (drug? or alcohol\$ or substance?)).ti,ab.	3
99	SUBSTANCE ABUSE TREATMENT CENTERS/	59
100	NEONATAL ABSTINENCE SYNDROME/	2
101	heroin.ti,ab.	11
102	or/18-101	794
103	and/17,102	1

**EMBASE 1980 to 2008 Week 47****SCIP\_alcohol\_drug\_misuse\_economics\_embase\_241108**

#	Searches	Results
1	ECONOMICS/	5687
2	HEALTH ECONOMICS/	10340
3	ECONOMIC EVALUATION/	4377
4	COST BENEFIT ANALYSIS/	29585
5	COST CONTROL/	16951
6	COST EFFECTIVENESS ANALYSIS/	56523
7	COST MINIMIZATION ANALYSIS/	1431
8	COST OF ILLNESS/	4770
9	COST UTILITY ANALYSIS/	2412

Pregnant women with complex social factors

10	COST/	20282
11	HEALTH CARE COST/	61708
12	DRUG COST/	34639
13	HEALTH CARE FINANCING/	9327
14	HOSPITAL COST/	6458
15	SOCIOECONOMICS/	31371
16	ECONOMIC ASPECT/	70677
17	QUALITY-ADJUSTED LIFE YEARS/	3940
18	FINANCIAL MANAGEMENT/	23490
19	PHARMACOECONOMICS/	923
20	RESOURCE ALLOCATION/	7545
21	(financ\$ or fiscal\$ or funding).ti.	6311
22	(QALY\$ or life?year\$).ti.	153
23	(econom\$ or cost\$).ti.	53440
24	pharmacoeconomic\$.ti.	1316
25	or/1-24	303375
26	MIDWIFE/	2199
27	exp PRENATAL CARE/	53755
28	MATERNAL TREATMENT/	420
29	exp PERINATAL CARE/	14481
30	exp OBSTETRIC CARE/	136797
31	(midwife or midwifery or midwives).ti,ab.	3016
32	PRENATAL PERIOD/	3699
33	PERINATAL PERIOD/	11913
34	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	219
35	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	9507
36	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	113
37	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	6311
38	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	656
39	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	3268
40	OBSTETRICAL NURSING/	7
41	or/26-40	157232
42	ADDICTION/	5099

43	ALCOHOLISM/	40070
44	WITHDRAWAL SYNDROME/	11080
45	exp DRUG DEPENDENCE/	40736
46	ALCOHOL ABSTINENCE/	1958
47	DRINKING BEHAVIOR/	10427
48	ALCOHOL ABUSE/	12126
49	exp ALCOHOLIC BEVERAGE/	6878
50	METHADONE/	13711
51	exp DRUG ABUSE/	42541
52	ILLICIT DRUG/	5446
53	RECREATIONAL DRUG/	230
54	STREET DRUG/	285
55	DESIGNER DRUG/	272
56	(liquor or beer\$ or lager or wine?).ti,ab.	13155
57	((drink\$ or use\$ or consum\$) adj2 alcohol\$).ti,ab.	32886
58	((misus\$ or abus\$) adj2 alcohol\$).ti,ab.	10269
59	((hazardous or harmful\$ or problem\$) adj2 (alcohol or drink\$)).ti,ab.	5847
60	(drug? dependency or drug? dependencies or addict\$).ti,ab.	23442
61	((drink\$ or alcohol\$) adj2 (spree? or binge? or bender?)).ti,ab.	1154
62	(Temperance or sobriety or teetotal\$ or tee total\$).ti,ab.	803
63	((drug? or substance?) adj2 (abus\$ or use\$ or misus\$)).ti,ab.	80316
64	((drug? or substance?) adj3 overuse\$).ti,ab.	114
65	methadone.ti,ab.	6744
66	naltrexone.ti,ab.	3977
67	naloxone.ti,ab.	16901
68	meth??amphetamine?.ti,ab.	4908
69	(crank or crystal meth).ti,ab.	517
70	(metamfetamine or n-methylamphetamine).ti,ab.	50
71	cocaine.ti,ab.	21158
72	heroin.ti,ab.	7318
73	(LSD or lysergic acid diethylamide).ti,ab.	1911
74	lysergide.ti,ab.	31
75	CANNABIS/	11128
76	tetrahydrocannabinol.ti,ab.	3064
77	(9-ene-tetrahydrocannabinol or delta\$-tetrahydrocannabinol or delta\$-thc).ti,ab.	2396
78	(marijuana or marihuana).ti,ab.	4884
79	(tranquilizer? adj3 abus\$).ti,ab.	13
80	hashish.ti,ab.	285

Pregnant women with complex social factors

81	cannabis.ti,ab.	4361
82	exp SOLVENT/	173130
83	((glue or solvent? or chemical) adj3 (sniff\$ or abus\$ or huff\$)).ti,ab.	503
84	((intravenous\$ or intra venous\$ or IV) adj3 (drug? abus\$ or drug? misuse\$)).ti,ab.	1739
85	(inject\$ drug? adj3 (user? or misuse\$ or abus\$)).ti,ab.	3653
86	(IDU or IDUs).ti,ab.	2645
87	(n-methyl 3,4 methylenedioxyamphetamine or methylenedioxymethamphetamine).ti,ab.	1527
88	(ecstasy or mdma).ti,ab.	3010
89	(codeine adj3 (abus\$ or overuse\$)).ti,ab.	28
90	((barbituate? or benzodiazepine?) adj3 (abus\$ or overuse\$)).ti,ab.	251
91	tramadol.ti,ab.	1959
92	(valium or diazepam).ti,ab.	13760
93	(xanax or alprazolam).ti,ab.	1739
94	(librium or chlordiazepoxide).ti,ab.	1843
95	(prosom or estazolam).ti,ab.	147
96	(Mephobarbital or mebaral).ti,ab.	53
97	(Nembutal or pentobarbitalsodium).ti,ab.	429
98	narcotic?.ti,ab.	7273
99	(Vicodin or hydrocodone).ti,ab.	286
100	opium.ti,ab.	801
101	(overus\$ or abus\$ or misus\$ or addict\$).ti,ab.	84714
102	or/91-100	27117
103	and/101-102	2171
104	(opiate? adj3 abus\$).ti,ab.	486
105	((designer or illicit or illegal) adj2 drug?).ti,ab.	5214
106	((street or dealer) adj2 drug?).ti,ab.	355
107	PSYCHOTROPIC AGENT/	11626
108	exp PSYCHEDELIC AGENT/	27170
109	((psychoactive or psychedelic) adj2 drug?).ti,ab.	1570
110	PSYCHOSTIMULANT AGENT/	2838
111	(hallucinogen\$ adj2 drug?).ti,ab.	230
112	DRUG DEPENDENCE TREATMENT/	3762
113	DETOXIFICATION/	9942
114	ALCOHOL WITHDRAWAL/	3327
115	WITHDRAWAL SEIZURE/	62
116	((detox\$ or withdrawal) adj5 (drug? or alcohol\$ or substance?)).ti,ab.	8856
117	(rehab\$ adj3 (drug? or alcohol\$ or substance?)).ti,ab.	742

118	or/42-90,103-117	426560
119	and/41,118	4992
120	editorial.pt.	220012
121	letter.pt.	431106
122	note.pt.	239303
123	or/120-122	890421
124	119 not 123	4715
125	limit 124 to english language	4322
126	and/25,125	249
127	limit 125 to "economics (2 or more terms min difference)"	101
128	127 or 126	288

**BME****Ovid MEDLINE(R) 1950 to November Week 3 2008****SCIP\_BME\_communication\_medline\_031208**

#	Searches	Results
1	MIDWIFERY/	11319
2	PRECONCEPTION CARE/	796
3	PRENATAL CARE/	16266
4	(midwife or midwifery or midwives).ti,ab.	10694
5	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	250
6	((prenatal\$ or antenatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	10709
7	((pre natal\$ or ante natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	178
8	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9234
9	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	889
10	exp MATERNAL HEALTH SERVICES/	25488
11	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	5241
12	MATERNAL-CHILD NURSING/	1477
13	OBSTETRICAL NURSING/	2512
14	NURSE MIDWIVES/	5345
15	REPRODUCTIVE HEALTH SERVICES/	458
16	or/1-15	59665
17	"EMIGRATION AND IMMIGRATION"/	20960
18	immigration.ti,ab.	4347
19	"EMIGRANTS AND IMMIGRANTS"/	723

Pregnant women with complex social factors

20	"TRANSIENTS AND MIGRANTS"/	6716
21	REFUGEES/	5323
22	exp AFRICAN CONTINENTAL ANCESTRY GROUP/	51689
23	exp ASIAN CONTINENTAL ANCESTRY GROUP/	19277
24	OCEANIC ANCESTRY GROUP/	4578
25	exp ETHNIC GROUPS/	82069
26	(African? or Middle eastern or Persian? or Ethiopian? or Muslim? or Moslem? or Islamic or Somali\$ or Nigerian? or Pakistani or Cantonese or Hindu? or Arab\$).ti,ab.	121181
27	((India? or Black or Chinese or Asia? or China) adj5 (wom?n or people? or person? or immigrant? or patient?)).ti,ab.	29660
28	(Turkish or Moroccan? or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan\$ or Tunisian or Ugandan).ti,ab.	26068
29	(Caribbean or Haitian or Jamaican).ti,ab.	6819
30	(migrant? or immigrant? or emigrant? or refugee? or fugitive? or expat\$).ti,ab.	19793
31	(noncitizen\$ or non citizen\$).ti,ab.	72
32	(ethnic or ethnicities or minorities).ti,ab.	35469
33	(foreign adj2 national?).ti,ab.	182
34	(asylum adj3 seeker?).ti,ab.	435
35	(displaced adj3 (person? or people? or wom?n)).ti,ab.	344
36	(alien? adj3 (legal\$ or illegal\$ or enemy)).ti,ab.	54
37	(deport\$ or exile?).ti,ab.	567
38	COMMUNICATION BARRIERS/	3291
39	((linguistic\$ or language or communicat\$) adj3 (barrier? or problem? or difficult\$ or trouble?)).ti,ab.	5215
40	LANGUAGE/	18901
41	VOCABULARY/	5592
42	(english adj3 (first language or second language or third language)).ti,ab.	299
43	(foreign adj3 language?).ti,ab.	425
44	(multilingual or bilingual or multi lingual or bi lingual).ti,ab.	1760
45	((english or non english or nonenglish) adj3 (speak\$ or communicat\$ or read\$ or writ\$)).ti,ab.	4108
46	(fluent or fluency or non fluen\$ or nonfluen\$).ti,ab.	5574
47	(mother tongue? or native tongue? or native language?).ti,ab.	752
48	vocabulary.ti,ab.	3836
49	accent?.ti,ab.	651
50	or/17-49	340030
51	and/16,50	4617
52	limit 51 to humans	4465
53	limit 52 to english language	4270
54	letter.pt.	654631
55	editorial.pt.	234808

56	or/54-55	889390
57	53 not 56	4189

**EBM Reviews - Cochrane Central Register of Controlled Trials 4th Quarter 2008**  
**SCIP\_BME\_communication\_cctr\_031208**

#	Searches	Results
1	MIDWIFERY/	132
2	PRECONCEPTION CARE/	20
3	PRENATAL CARE/	564
4	(midwife or midwifery or midwives).ti,ab.	364
5	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	3
6	((prenatal\$ or antenatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	591
7	((pre natal\$ or ante natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	6
8	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	333
9	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	52
10	exp MATERNAL HEALTH SERVICES/	758
11	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	313
12	MATERNAL-CHILD NURSING/	34
13	OBSTETRICAL NURSING/	25
14	NURSE MIDWIVES/	76
15	REPRODUCTIVE HEALTH SERVICES/	4
16	or/1-15	1842
17	"EMIGRATION AND IMMIGRATION"/	47
18	immigration.ti,ab.	3
19	"EMIGRANTS AND IMMIGRANTS"/	3
20	"TRANSIENTS AND MIGRANTS"/	24
21	REFUGEES/	37
22	exp AFRICAN CONTINENTAL ANCESTRY GROUP/	1265
23	exp ASIAN CONTINENTAL ANCESTRY GROUP/	426
24	OCEANIC ANCESTRY GROUP/	37
25	exp ETHNIC GROUPS/	1468
26	(African? or Middle eastern or Persian? or Ethiopian? or Muslim? or Moslem? or Islamic or Somali\$ or Nigerian? or Pakistani or Cantonese or Hindu? or Arab\$).ti,ab.	2937
27	((India? or Black or Chinese or Asia? or China) adj5 (wom?n or people? or person? or immigrant? or patient?)).ti,ab.	2085
28	(Turkish or Morrocan? or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan\$ or Tunisian or Ugandan).ti,ab.	603

29	(Caribbean or Haitian or Jamaican).ti,ab.	128
30	(migrant? or immigrant? or emigrant? or refugee? or fugitive? or expat\$).ti,ab.	193
31	(noncitizen\$ or non citizen\$).ti,ab.	1
32	(ethnic or ethnicities or minorities).ti,ab.	759
33	(foreign adj2 national?).ti,ab.	2
34	(asylum adj3 seeker?).ti,ab.	1
35	(displaced adj3 (person? or people? or wom?n)).ti,ab.	8
36	(alien? adj3 (legal\$ or illegal\$ or enemy)).ti,ab.	1
37	(deport\$ or exile?).ti,ab.	25
38	COMMUNICATION BARRIERS/	37
39	((linguistic\$ or language or communicat\$) adj3 (barrier? or problem? or difficult\$ or trouble?)).ti,ab.	187
40	LANGUAGE/	263
41	VOCABULARY/	155
42	(english adj3 (first language or second language or third language)).ti,ab.	18
43	(foreign adj3 language?).ti,ab.	13
44	(multilingual or bilingual or multi lingual or bi lingual).ti,ab.	70
45	((english or non english or nonenglish) adj3 (speak\$ or communicat\$ or read\$ or writ\$)).ti,ab.	184
46	(fluent or fluency or non fluen\$ or nonfluen\$).ti,ab.	462
47	(mother tongue? or native tongue? or native language?).ti,ab.	30
48	vocabulary.ti,ab.	161
49	accent?.ti,ab.	28
50	or/17-49	8566
51	and/16,50	145

**DARE, CDSR**

**SCIP\_BME\_communication\_cdsrdare\_031208**

#	Searches	Results
1	MIDWIFERY.kw.	14
2	PRECONCEPTION CARE.kw.	5
3	PRENATAL CARE.kw.	43
4	(midwife or midwifery or midwives).ti,ab.	26
5	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	2
6	((prenatal\$ or antenatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	21
7	((pre natal\$ or ante natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	0
8	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9

9	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	1
10	MATERNAL HEALTH SERVICES.kw.	7
11	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	26
12	MATERNAL-CHILD NURSING.kw.	4
13	OBSTETRICAL NURSING.kw.	2
14	NURSE MIDWIVES.kw.	7
15	REPRODUCTIVE HEALTH SERVICES\$.kw.	2
16	or/1-15	116
17	IMMIGRATION.kw.	0
18	immigration.ti,ab.	0
19	IMMIGRANTS.kw.	0
20	MIGRANT\$.kw.	0
21	REFUGEE\$.kw.	0
22	AFRICA.kw.	14
23	ASIA.kw.	2
24	DEPORT\$.kw.	0
25	ETHNIC GROUP\$.kw.	11
26	(African? or Middle eastern or Persian? or Ethiopian? or Muslim? or Moslem? or Islamic or Somali\$ or Nigerian? or Pakistani or Cantonese or Hindu? or Arab\$).ti,ab.	34
27	((India? or Black or Chinese or Asia? or China) adj5 (wom?n or people? or person? or immigrant? or patient?)).ti,ab.	28
28	(Turkish or Morrocan? or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan\$ or Tunisian or Ugandan).ti,ab.	6
29	(Caribbean or Haitian or Jamaican).ti,ab.	20
30	(migrant? or immigrant? or emigrant? or refugee? or fugitive? or expat\$).ti,ab.	1
31	(noncitizen\$ or non citizen\$).ti,ab.	0
32	(ethnic or ethnicities or minorities).ti,ab.	14
33	(foreign adj2 national?).ti,ab.	0
34	(asylum adj3 seeker?).ti,ab.	0
35	(displaced adj3 (person? or people? or wom?n)).ti,ab.	1
36	(alien? adj3 (legal\$ or illegal\$ or enemy)).ti,ab.	0
37	(deport\$ or exile?).ti,ab.	0
38	COMMUNICATION BARRIER\$.kw.	4
39	((linguistic\$ or language or communicat\$) adj3 (barrier? or problem? or difficult\$ or trouble?)).ti,ab.	12
40	LANGUAGE\$.kw.	30
41	VOCABULARY.kw.	0
42	(english adj3 (first language or second language or third language)).ti,ab.	0
43	(foreign adj3 language?).ti,ab.	4

Pregnant women with complex social factors

44	(multilingual or bilingual or multi lingual or bi lingual).ti,ab.	0
45	((english or non english or nonenglish) adj3 (speak\$ or communicat\$ or read\$ or writ\$)).ti,ab.	3
46	(fluent or fluency or non fluen\$ or nonfluen\$).ti,ab.	0
47	(mother tongue? or native tongue? or native language?).ti,ab.	0
48	vocabulary.ti,ab.	1
49	accent?.ti,ab.	0
50	or/17-49	163
51	and/16,50	3

**Cinahl Ebsco**

**Thursday, December 04, 2008 12:12:22 PM**

#	Query	Limiters/Expanders	Last Run Via	Results
S57	S54 and S53	Limiters - Gender: Female Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	1482
S56	S54 and S53	Limiters - Language: English Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	1750
S55	S54 and S53	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	1775
S54	S15 or S14 or S13 or S12 or S11 or S10 or S9 or S8 or S7 or S6 or S5 or S4 or S3 or S2 or S1	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	28139
S53	S52 or S51 or S50 or S49 or S48 or S47 or S46 or S45 or S44 or S43 or S42 or S41 or S40 or S39 or S38 or S37 or S36 or S35 or S34 or S33 or S32 or S31 or S30 or S29 or S28 or S27 or S26 or S25 or S24 or S23 or S22 or S21 or S20 or S19 or S18 or S17 or S16	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	63789
S52	TI (vocabulary or literacy or illiterate or illiteracy) or AB	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search	3539

	(vocabulary or literacy or illiterate or illiteracy)		Database - CINAHL with Full Text	
S51	TI (mother tongue* or native tongue* or native language*) or AB (mother tongue* or native tongue* or native language*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	175
S50	TI (fluent or fluency or non fluen* or nonfluen* or accent*) or AB (fluent or fluency or non fluen* or nonfluen* or accent*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	1787
S49	TI (multilingual or bilingual or nonenglish or non english) or AB (multilingual or bilingual or nonenglish or non english)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	1255
S48	TI (foreign language*) or AB (foreign language*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	114
S47	TI ("english as a second language") or AB ("english as a second language")	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	138
S46	MH VOCABULARY	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	649
S45	MH LANGUAGE	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	3065
S44	TI (language* N3 barrier*) or AB (language* N3 barrier*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	412
S43	TI (language* N3 difficult*) or AB (language* N3 difficult*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with	400

			Full Text	
S42	TI (communicat* N3 difficult*) or AB (communicat* N3 difficult*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	642
S41	TI (communicat* N3 barrier*) or AB (communicat* N3 barrier*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	322
S40	MH COMMUNICATION BARRIERS	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	1800
S39	TI (deport* or exile*) or AB (deport* or exile*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	117
S38	TI (alien or aliens) or AB (alien or aliens)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	149
S37	TI (displaced N3 people*) or AB (displaced N3 people*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	34
S36	TI (displaced N3 person*) or AB (displaced N3 person*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	53
S35	TI (asylum N3 seeker*) or AB (asylum N3 seeker*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	291
S34	TI (foreign N3 national*) or AB (foreign N3 national*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	42
S33	TI (migrant* or immigrant* or emigrant* or refugee* or fugitive* or expat*) or AB (migrant* or	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	4757

	immigrant* or emigrant* or refugee* or fugitive* or expat*)			
S32	TI (Caribbean or Haitian or Jamaican) or AB (Caribbean or Haitian or Jamaican)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	936
S31	TI (Asia* N3 woman) or AB (Asia* N3 woman)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	19
S30	TI (Asia* N3 women) or AB (Asia* N3 women)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	437
S29	TI (Chinese* N3 women) or AB (Chinese* N3 women)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	423
S28	TI (Chinese* N3 woman) or AB (Chinese* N3 woman)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	22
S27	TI (India* N3 women) or AB (India* N3 women)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	303
S26	TI (India* N3 woman) or AB (India* N3 woman)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	6
S25	TI (black* N3 women) or AB (black* N3 women)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	1173
S24	TI (black* N3 woman) or AB (black* N3 woman)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	34
S23	AB (Turkish or Moroccan* or Surinamese or Greek	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search	1718

	or South African or Rwandan or Malaw\$ or Sudan* or Tunisian or Ugandan)		Database - CINAHL with Full Text	
S22	TI (Turkish or Morrocan* or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan* or Tunisian or Ugandan)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	1850
S21	TI (African* or Middle eastern or Persian* or Ethiopian* or Muslim* or Moslem* or Islamic or Somali* or Nigerian* or Pakistani or Cantonese or Hindu* or Arab*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	7276
S20	MH ETHNIC GROUPS+	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	41536
S19	MH REFUGEES	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	2006
S18	TI (immigration) or AB (immigration)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	840
S17	MH "TRANSIENTS AND MIGRANTS"	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	837
S16	MH "EMIGRATION AND IMMIGRATION"	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	2101
S15	TI (pre pregnan* N3 service*) or AB (pre pregnan* N3 service*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	1
S14	TI (pre pregnan* N3 care*) or AB (pre	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic	11

	pregnan* N3 care*)		Search Database - CINAHL with Full Text	
S13	TI (pregnan* N3 care*) or AB (pregnan* N3 care*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	16
S12	TI (pregnan* N3 service*) or AB (pregnan* N3 service*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	216
S11	TI (pregnan* N3 care) or AB (pregnan* N3 care)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	1064
S10	TI (maternal care or maternal healthcare or maternal service*) or AB (maternal care or maternal healthcare or maternal service*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	93
S9	TI (antenatal or ante natal) or AB (antenatal or ante natal)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	2380
S8	TI (prenatal or pre natal) or AB (prenatal or pre natal)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	5239
S7	TI (preconception or pre conception) or AB (preconception or pre conception)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	322
S6	TI (midwife or midwifery or midwives) or AB (midwife or midwifery or midwives)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	11660
S5	MH MATERNAL-CHILD NURSING	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	960
S4	MH MATERNAL HEALTH SERVICES	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic	2137

			Search Database - CINAHL with Full Text	
S3	MH PRENATAL CARE	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	5165
S2	MH PREPREGNANCY CARE	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	528
S1	MH MIDWIFERY+	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Basic Search Database - CINAHL with Full Text	9823

**EMBASE 1980 to 2008 Week 48****SCIP\_BME\_communication\_embase\_041208**

#	Searches	Results
1	MIDWIFE/	2201
2	exp PRENATAL CARE/	53822
3	MATERNAL CARE/	5756
4	(midwife or midwifery or midwives).ti,ab.	3019
5	PRENATAL PERIOD/	3703
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	219
7	((prenatal\$ or antenatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	8093
8	((pre natal\$ or ante natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	110
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	6317
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	656
11	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	3274
12	OBSTETRICAL NURSING/	7
13	or/1-12	73922
14	exp MIGRATION/	9385
15	immigration.ti,ab.	2517
16	IMMIGRANT/	4917
17	ILLEGAL IMMIGRANT/	36
18	REFUGEE/	2504

19	"ETHNIC OR RACIAL ASPECTS"/	17835
20	RACE/	9798
21	exp NEGRO/	19611
22	exp ASIAN/	22323
23	ETHNIC GROUP/	17933
24	HISPANIC/	5318
25	(African? or Middle eastern or Persian? or Ethiopian? or Muslim? or Moslem? or Islamic or Somali\$ or Nigerian? or Pakistani or Cantonese or Hindu? or Arab\$).ti,ab.	80272
26	((India? or Black or Chinese or Asia? or China) adj5 (wom?n or people? or person? or immigrant? or patient?)).ti,ab.	25277
27	(Turkish or Morrocan? or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan\$ or Tunisian or Ugandan).ti,ab.	20344
28	(Caribbean or Haitian or Jamaican).ti,ab.	4435
29	(migrant? or immigrant? or emigrant? or refugee? or fugitive? or expat\$).ti,ab.	12757
30	(noncitizen\$ or non citizen\$).ti,ab.	38
31	(ethnic or ethnicities or minorities).ti,ab.	27255
32	(foreign adj2 national?).ti,ab.	96
33	(asylum adj3 seeker?).ti,ab.	304
34	(displaced adj3 (person? or people? or wom?n)).ti,ab.	224
35	(alien? adj3 (legal\$ or illegal\$ or enemy)).ti,ab.	14
36	(deport\$ or exile?).ti,ab.	360
37	COMMUNICATION DISORDER/	1803
38	ENGLISH AS A SECOND LANGUAGE/	140
39	LANGUAGE/	16172
40	READING/	8709
41	((linguistic\$ or language or communicat\$) adj3 (barrier? or problem? or difficult\$ or trouble?)).ti,ab.	3892
42	LINGUISTICS/	6146
43	(literacy or literate or illiterate).ti,ab.	3054
44	(english adj3 (first language or second language or third language)).ti,ab.	196
45	(foreign adj3 language?).ti,ab.	260
46	(multilingual or bilingual or multi lingual or bi lingual).ti,ab.	1219
47	((english or non english or nonenglish) adj3 (speak\$ or communicat\$ or read\$ or writ\$)).ti,ab.	2943
48	(fluent or fluency or non fluen\$ or nonfluen\$).ti,ab.	5099
49	(mother tongue? or native tongue? or native language?).ti,ab.	548
50	vocabulary.ti,ab.	2483
51	accent?.ti,ab.	460
52	(reading adj3 (abilit\$ or level?)).ti,ab.	1226
53	or/14-52	241638
54	and/13,53	4049

55	limit 54 to english language	3874
56	letter.pt.	431555
57	editorial.pt.	220296
58	or/56-57	651851
59	55 not 58	3758

**PsycINFO 1967 to December Week 1 2008**  
**SCIP\_BME\_communication\_psycinfo\_031208**

#	Searches	Results
1	exp PRENATAL CARE/	978
2	REPRODUCTIVE HEALTH/	225
3	PRENATAL DIAGNOSIS/	377
4	PRENATAL DEVELOPMENT/	2934
5	exp OBSTETRICS/	821
6	PERINATAL PERIOD/	954
7	(midwife or midwifery or midwives).ti,ab.	856
8	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	27
9	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	1724
10	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	21
11	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	1004
12	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	256
13	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	1489
14	or/1-13	9514
15	IMMIGRATION/	7208
16	EXPATRIATES/	356
17	REFUGEES/	2233
18	FOREIGN WORKERS/	361
19	BLACKS/	30104
20	AFRICAN CULTURAL GROUPS/	238
21	exp "RACIAL AND ETHNIC GROUPS"/	62989
22	MINORITY GROUPS/	6736
23	"RACE AND ETHNIC DISCRIMINATION"/	1787
24	(African? or Middle eastern or Persian? or Ethiopian? or Muslim? or Moslem? or Islamic or Somali\$ or Nigerian? or Pakistani or Cantonese or Hindu? or Arab\$).ti,ab.	35597
25	((India? or Black or Chinese or Asia? or China) adj5 (wom?n or people? or person? or immigrant? or patient?)).ti,ab.	9107

26	(Turkish or Moroccan? or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan\$ or Tunisian or Ugandan).ti,ab.	8143
27	(Caribbean or Haitian or Jamaican).ti,ab.	1808
28	(migrant? or immigrant? or emigrant? or refugee? or fugitive? or expat\$).ti,ab.	13168
29	(noncitizen\$ or non citizen\$).ti,ab.	43
30	(ethnic or ethnicities or minorities).ti,ab.	27089
31	(foreign adj2 national?).ti,ab.	62
32	(asylum adj3 seeker?).ti,ab.	327
33	(displaced adj3 (person? or people? or wom?n)).ti,ab.	201
34	(alien? adj3 (legal\$ or illegal\$ or enemy)).ti,ab.	26
35	(deport\$ or exile?).ti,ab.	717
36	CROSS CULTURAL COMMUNICATION/	1027
37	COMMUNICATION BARRIERS/	154
38	((linguistic\$ or language or communicat\$) adj3 (barrier? or problem? or difficult\$ or trouble?)).ti,ab.	6626
39	LANGUAGE PROFICIENCY/	1966
40	ENGLISH AS SECOND LANGUAGE/	2160
41	LANGUAGE/	19041
42	VOCABULARY/	3586
43	(english adj3 (first language or second language or third language)).ti,ab.	1061
44	(foreign adj3 language?).ti,ab.	2362
45	(multilingual or bilingual or multi lingual or bi lingual).ti,ab.	5464
46	((english or non english or nonenglish) adj3 (speak\$ or communicat\$ or read\$ or writ\$)).ti,ab.	7111
47	(fluent or fluency or non fluen\$ or nonfluen\$).ti,ab.	8385
48	(mother tongue? or native tongue? or native language?).ti,ab.	1699
49	vocabulary.ti,ab.	9847
50	ORAL COMMUNICATION/	8890
51	((oral\$ or verbal\$) adj3 communicat\$).ti,ab.	2756
52	accent?.ti,ab.	812
53	or/15-52	176766
54	and/14,53	893
55	limit 54 to human	881
56	limit 55 to english language	872

## BME Communication

Ovid MEDLINE(R) 1950 to November Week 3 2008

SCIP\_BME\_communication\_economics\_medline\_091208

#	Searches	Results
1	ECONOMICS/	25938

Pregnant women with complex social factors

2	"COSTS AND COST ANALYSIS"/	37767
3	COST ALLOCATION/	1868
4	COST-BENEFIT ANALYSIS/	45206
5	COST CONTROL/	18144
6	COST SAVINGS/	6207
7	COST OF ILLNESS/	11286
8	COST SHARING/	1455
9	HEALTH CARE COSTS/	17562
10	DIRECT SERVICE COSTS/	870
11	DRUG COSTS/	9054
12	EMPLOYER HEALTH COSTS/	999
13	HOSPITAL COSTS/	5799
14	HEALTH RESOURCES/	6561
15	"HEALTH SERVICES NEEDS AND DEMAND"/	31115
16	HEALTH PRIORITIES/	7087
17	HEALTH EXPENDITURES/	10506
18	CAPITAL EXPENDITURES/	1849
19	FINANCIAL MANAGEMENT/	14576
20	FINANCIAL MANAGEMENT, HOSPITAL/	7018
21	QUALITY-ADJUSTED LIFE YEARS/	3719
22	"DEDUCTIBLES AND COINSURANCE"/	1218
23	MEDICAL SAVINGS ACCOUNTS/	402
24	ECONOMICS, HOSPITAL/	8777
25	ECONOMICS, MEDICAL/	7383
26	ECONOMICS, NURSING/	3861
27	ECONOMICS, PHARMACEUTICAL/	2012
28	MODELS, ECONOMIC/	3356
29	MODELS, ECONOMETRIC/	2879
30	RESOURCE ALLOCATION/	6106
31	HEALTH CARE RATIONING/	9159
32	"FEES AND CHARGES"/	7501
33	BUDGETS/	7819
34	VALUE OF LIFE/	5091
35	(financ\$ or fiscal\$ or funding).ti.	13746
36	(QALY\$ or life?year\$).ti.	200
37	(econom\$ or cost\$).ti.	81772
38	pharmacoeconomic\$.ti.	1099
39	or/1-38	290512

40	MIDWIFERY/	11321
41	PRECONCEPTION CARE/	796
42	PRENATAL CARE/	16268
43	(midwife or midwifery or midwives).ti,ab.	10700
44	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	250
45	((prenatal\$ or antenatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	10711
46	((pre natal\$ or ante natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	178
47	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	9236
48	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	889
49	exp MATERNAL HEALTH SERVICES/	25496
50	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	5242
51	MATERNAL-CHILD NURSING/	1477
52	OBSTETRICAL NURSING/	2512
53	NURSE MIDWIVES/	5346
54	REPRODUCTIVE HEALTH SERVICES/	459
55	or/40-54	59685
56	"EMIGRATION AND IMMIGRATION"/	20963
57	immigration.ti,ab.	4350
58	"EMIGRANTS AND IMMIGRANTS"/	724
59	"TRANSIENTS AND MIGRANTS"/	6716
60	REFUGEES/	5323
61	exp AFRICAN CONTINENTAL ANCESTRY GROUP/	51708
62	exp ASIAN CONTINENTAL ANCESTRY GROUP/	19283
63	OCEANIC ANCESTRY GROUP/	4580
64	exp ETHNIC GROUPS/	82102
65	((African? or Middle eastern or Persian? or Ethiopian? or Muslim? or Moslem? or Islamic or Somali\$ or Nigerian? or Pakistani or Cantonese or Hindu? or Arab\$) adj3 (wom?n or person? or people? or patient?)).ti,ab.	10573
66	((India? or Black or Chinese or Asia? or China) adj5 (wom?n or people? or person? or patient?)).ti,ab.	28833
67	(Turkish or Morrocan? or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan\$ or Tunisian or Ugandan).ti,ab.	26075
68	(Caribbean or Haitian or Jamaican).ti,ab.	6820
69	(migrant? or immigrant? or emigrant? or refugee? or fugitive? or expat\$).ti,ab.	19799

Pregnant women with complex social factors

70	(noncitizen\$ or non citizen\$).ti,ab.	72
71	(ethnic or ethnicities or minorities).ti,ab.	35484
72	(foreign adj2 national?).ti,ab.	183
73	(asylum adj3 seeker?).ti,ab.	435
74	(displaced adj3 (person? or people? or wom?n)).ti,ab.	344
75	(alien? adj3 (legal\$ or illegal\$ or enemy)).ti,ab.	54
76	(deport\$ or exile?).ti,ab.	567
77	COMMUNICATION BARRIERS/	3292
78	((linguistic\$ or language or communicat\$) adj3 (barrier? or problem? or difficult\$ or trouble?)).ti,ab.	5220
79	LANGUAGE/	18908
80	VOCABULARY/	5596
81	(english adj3 (first language or second language or third language)).ti,ab.	299
82	(foreign adj3 language?).ti,ab.	425
83	(multilingual or bilingual or multi lingual or bi lingual).ti,ab.	1760
84	((english or non english or nonenglish) adj3 (speak\$ or communicat\$ or read\$ or writ\$)).ti,ab.	4108
85	(fluent or fluency or non fluen\$ or nonfluen\$).ti,ab.	5576
86	(literate or illiterate or illiteracy or literacy).ti,ab.	5151
87	(mother tongue? or native tongue? or native language?).ti,ab.	752
88	vocabulary.ti,ab.	3840
89	accent?.ti,ab.	651
90	((oral\$ or verbal\$) adj3 communicat\$).ti,ab.	1618
91	(reading adj3 (problem\$ or difficult\$)).ti,ab.	1126
92	or/56-91	263375
93	and/55,92	4263
94	and/39,93	285
95	limit 94 to english language	274
96	limit 93 to "economics (optimized)"	195
97	limit 96 to english language	188
98	95 or 97	381
99	letter.pt.	654713
100	editorial.pt.	234908
101	99 or 100	889572
102	98 not 101	377

**CLEED, CLHTA**

**SCIP\_BME\_communication\_economics\_htaecd\_091208**

#	Searches	Results
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1	MIDWIFERY/	20
2	PRECONCEPTION CARE/	3
3	PRENATAL CARE/	117
4	(midwife or midwifery or midwives).ti,ab.	14
5	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	2
6	((prenatal\$ or antenatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	26
7	((pre natal\$ or ante natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	0
8	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	18
9	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	0
10	exp MATERNAL HEALTH SERVICES/	189
11	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	14
12	MATERNAL-CHILD NURSING/	4
13	OBSTETRICAL NURSING/	2
14	NURSE MIDWIVES/	9
15	REPRODUCTIVE HEALTH SERVICES/	4
16	or/1-15	222
17	"EMIGRATION AND IMMIGRATION"/	27
18	immigration.ti,ab.	0
19	"EMIGRANTS AND IMMIGRANTS"/	1
20	"TRANSIENTS AND MIGRANTS"/	4
21	REFUGEES/	8
22	exp AFRICAN CONTINENTAL ANCESTRY GROUP/	74
23	exp ASIAN CONTINENTAL ANCESTRY GROUP/	15
24	OCEANIC ANCESTRY GROUP/	10
25	exp ETHNIC GROUPS/	121
26	(African? or Middle eastern or Persian? or Ethiopian? or Muslim? or Moslem? or Islamic or Somali\$ or Nigerian? or Pakistani or Cantonese or Hindu? or Arab\$).ti,ab.	37
27	((India? or Black or Chinese or Asia? or China) adj5 (wom?n or people? or person? or immigrant? or patient?)).ti,ab.	25
28	(Turkish or Morrocan? or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan\$ or Tunisian or Ugandan).ti,ab.	31
29	(Caribbean or Haitian or Jamaican).ti,ab.	8
30	(migrant? or immigrant? or emigrant? or refugee? or fugitive? or expat\$).ti,ab.	24
31	(noncitizen\$ or non citizen\$).ti,ab.	0
32	(ethnic or ethnicities or minorities).ti,ab.	11
33	(foreign adj2 national?).ti,ab.	0

Pregnant women with complex social factors

34	(asylum adj3 seeker?).ti,ab.	2
35	(displaced adj3 (person? or people? or wom?n)).ti,ab.	0
36	(alien? adj3 (legal\$ or illegal\$ or enemy)).ti,ab.	0
37	(deport\$ or exile?).ti,ab.	0
38	COMMUNICATION BARRIERS/	4
39	((linguistic\$ or language or communicat\$) adj3 (barrier? or problem? or difficult\$ or trouble?)).ti,ab.	2
40	LANGUAGE/	3
41	VOCABULARY/	0
42	(english adj3 (first language or second language or third language)).ti,ab.	0
43	(foreign adj3 language?).ti,ab.	0
44	(multilingual or bilingual or multi lingual or bi lingual).ti,ab.	2
45	((english or non english or nonenglish) adj3 (speak\$ or communicat\$ or read\$ or writ\$)).ti,ab.	1
46	(fluent or fluency or non fluen\$ or nonfluen\$).ti,ab.	0
47	(mother tongue? or native tongue? or native language?).ti,ab.	0
48	vocabulary.ti,ab.	0
49	accent?.ti,ab.	0
50	or/17-49	280
51	and/16,50	9

EMBASE 1980 to 2008 Week 49

SCIP BME communication economics embase\_091208

#	Searches	Results
1	ECONOMICS/	5694
2	HEALTH ECONOMICS/	10364
3	ECONOMIC EVALUATION/	4392
4	COST BENEFIT ANALYSIS/	29680
5	COST CONTROL/	16991
6	COST EFFECTIVENESS ANALYSIS/	56700
7	COST MINIMIZATION ANALYSIS/	1439
8	COST OF ILLNESS/	4786
9	COST UTILITY ANALYSIS/	2425
10	COST/	20312
11	HEALTH CARE COST/	61918
12	HEALTH CARE FINANCING/	9341
13	HOSPITAL COST/	6476
14	ECONOMIC ASPECT/	70766
15	QUALITY-ADJUSTED LIFE YEARS/	3964

16	FINANCIAL MANAGEMENT/	23585
17	PHARMACOECONOMICS/	928
18	RESOURCE ALLOCATION/	7577
19	(financ\$ or fiscal\$ or funding).ti.	6336
20	(QALY\$ or life?year\$).ti.	153
21	(econom\$ or cost\$).ti.	53543
22	pharmacoeconomic\$.ti.	1318
23	(value adj1 (money or monetary)).ti,ab.	182
24	or/1-23	263776
25	MIDWIFE/	2204
26	exp PRENATAL CARE/	53964
27	MATERNAL CARE/	5764
28	(midwife or midwifery or midwives).ti,ab.	3029
29	PRENATAL PERIOD/	3713
30	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	219
31	((prenatal\$ or antenatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	8103
32	((pre natal\$ or ante natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	110
33	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	6324
34	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	656
35	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	3283
36	OBSTETRICAL NURSING/	7
37	or/25-36	74095
38	exp MIGRATION/	9406
39	immigration.ti,ab.	2523
40	IMMIGRANT/	4937
41	ILLEGAL IMMIGRANT/	37
42	REFUGEE/	2507
43	"ETHNIC OR RACIAL ASPECTS"/	17835
44	RACE/	9808
45	exp NEGRO/	19665
46	exp ASIAN/	22410
47	ETHNIC GROUP/	17950
48	HISPANIC/	5348
49	(African? or Middle eastern or Persian? or Ethiopian? or Muslim? or Moslem? or Islamic or Somali\$ or Nigerian? or Pakistani or Cantonese or Hindu? or Arab\$).ti,ab.	80467
50	((India? or Black or Chinese or Asia? or China) adj5 (wom?n or people? or person? or	25353

Pregnant women with complex social factors

	immigrant? or patient?).ti,ab.	
51	(Turkish or Morrocan? or Surinamese or Greek or South African or Rwandan or Malaw\$ or Sudan\$ or Tunisian or Ugandan).ti,ab.	20414
52	(Caribbean or Haitian or Jamaican).ti,ab.	4451
53	(migrant? or immigrant? or emigrant? or refugee? or fugitive? or expat\$).ti,ab.	12787
54	(noncitizen\$ or non citizen\$).ti,ab.	39
55	(ethnic or ethnicities or minorities).ti,ab.	27323
56	(foreign adj2 national?).ti,ab.	97
57	(asylum adj3 seeker?).ti,ab.	304
58	(displaced adj3 (person? or people? or wom?n)).ti,ab.	224
59	(alien? adj3 (legal\$ or illegal\$ or enemy)).ti,ab.	14
60	(deport\$ or exile?).ti,ab.	360
61	COMMUNICATION DISORDER/	1806
62	ENGLISH AS A SECOND LANGUAGE/	141
63	LANGUAGE/	16186
64	READING/	8722
65	((linguistic\$ or language or communicat\$) adj3 (barrier? or problem? or difficult\$ or trouble?)).ti,ab.	3901
66	LINGUISTICS/	6152
67	(literacy or literate or illiterate).ti,ab.	3064
68	(english adj3 (first language or second language or third language)).ti,ab.	196
69	(foreign adj3 language?).ti,ab.	261
70	(multilingual or bilingual or multi lingual or bi lingual).ti,ab.	1221
71	((english or non english or nonenglish) adj3 (speak\$ or communicat\$ or read\$ or writ\$)).ti,ab.	2949
72	(fluent or fluency or non fluen\$ or nonfluen\$).ti,ab.	5104
73	(mother tongue? or native tongue? or native language?).ti,ab.	549
74	vocabulary.ti,ab.	2484
75	accent?.ti,ab.	460
76	(reading adj3 (abilit\$ or level?)).ti,ab.	1228
77	or/38-76	242171
78	and/37,77	4060
79	limit 78 to english language	3885
80	letter.pt.	432301
81	editorial.pt.	220749
82	or/80-81	653050
83	79 not 82	3769
84	and/24,83	308
85	limit 83 to "economics (2 or more terms min difference)"	165
86	84 or 85	359

**Domestic Violence****Ovid MEDLINE(R) 1950 to May Week 1 2009****SCIP\_domesticviolence\_medline\_080509**

#	Searches	Results
1	MIDWIFERY/	11389
2	PRECONCEPTION CARE/	836
3	PRENATAL CARE/	16105
4	PERINATAL CARE/	1662
5	(midwife or midwifery or midwives).ti,ab.	11484
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	281
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	13760
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	198
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	11807
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	1004
11	exp MATERNAL HEALTH SERVICES/	25325
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	5950
13	MATERNAL-CHILD NURSING/	1491
14	OBSTETRICAL NURSING/	2490
15	NURSE MIDWIVES/	5353
16	REPRODUCTIVE HEALTH SERVICES/	478
17	or/1-16	65111
18	sex offenses/ or child abuse, sexual/ or rape/ or violence/ or domestic violence/ or spouse abuse/	36951
19	BATTERED WOMEN/	1616
20	((violen\$ or abuse\$) adj2 (home or house or dwelling)).ti,ab.	136
21	(domestic adj3 (abuse\$ or violen\$)).ti,ab.	2979
22	FAMILY RELATIONS/	5185
23	((partner or spouse\$) adj3 (abuse\$ or violen\$)).ti,ab.	1947
24	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).ti,ab.	36142
25	(intimate adj2 violen\$).ti,ab.	1285
26	(violen\$ adj2 relationship\$).ti,ab.	343
27	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).ti,ab.	356
28	(living adj2 violen\$).ti,ab.	25
29	(abus\$ adj2 wom?n).ti,ab.	1560
30	(surviv\$ adj2 (abuse or abusive)).ti,ab.	202

31	love hurts.ti,ab.	3
32	((family or families) adj3 (abuse\$ or violen\$)).ti,ab.	1816
33	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).ti,ab.	491731
34	(stalking or harrass\$).ti,ab.	309
35	(jealous\$ or imprisonment).ti,ab.	1322
36	restrictive behaviou?r\$.ti,ab.	6
37	(intimidat\$ or fear\$).ti,ab.	33106
38	(isolation or isolated).ti,ab.	678637
39	molest\$.ti,ab.	723
40	(control\$ adj2 behavio?r\$).ti,ab.	5424
41	or/18-40	1242563
42	and/17,41	3400
43	limit 42 to humans	2876
44	limit 43 to english language	2623

**EBM Reviews - Cochrane Central Register of Controlled Trials 2nd Quarter 2009**  
**SCIP\_domesticviolence\_ctr\_080509**

#	Searches	Results
1	MIDWIFERY/	136
2	PRECONCEPTION CARE/	23
3	PRENATAL CARE/	585
4	PERINATAL CARE/	45
5	(midwife or midwifery or midwives).ti,ab.	372
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	3
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	651
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	7
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	339
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	55
11	exp MATERNAL HEALTH SERVICES/	785
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	320
13	MATERNAL-CHILD NURSING/	35
14	OBSTETRICAL NURSING/	26
15	NURSE MIDWIVES/	76

16	REPRODUCTIVE HEALTH SERVICES/	4
17	or/1-16	1954
18	sex offenses/ or child abuse, sexual/ or rape/ or violence/ or domestic violence/ or spouse abuse/	500
19	BATTERED WOMEN/	26
20	((violen\$ or abuse\$) adj2 (home or house or dwelling)).ti,ab.	8
21	(domestic adj3 (abuse\$ or violen\$)).ti,ab.	83
22	FAMILY RELATIONS/	76
23	((partner or spouse\$) adj3 (abuse\$ or violen\$)).ti,ab.	89
24	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).ti,ab.	1680
25	(intimate adj2 violen\$).ti,ab.	52
26	(violen\$ adj2 relationship\$).ti,ab.	12
27	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).ti,ab.	9
28	(living adj2 violen\$).ti,ab.	1
29	(abus\$ adj2 wom?n).ti,ab.	89
30	(surviv\$ adj2 (abuse or abusive)).ti,ab.	13
31	love hurts.ti,ab.	0
32	((family or families) adj3 (abuse\$ or violen\$)).ti,ab.	57
33	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).ti,ab.	19328
34	(stalking or harrass\$).ti,ab.	1
35	(jealous\$ or imprisonment).ti,ab.	12
36	restrictive behaviou?r\$.ti,ab.	0
37	(intimidat\$ or fear\$).ti,ab.	1509
38	(isolation or isolated).ti,ab.	5263
39	molest\$.ti,ab.	12
40	(control\$ adj2 behavio?r\$).ti,ab.	654
41	or/18-40	28521
42	and/17,41	113
43	limit 42 to humans [Limit not valid; records were retained]	113
44	limit 43 to english language [Limit not valid; records were retained]	113

**DARE, CDSR****SCIP\_domesticviolence\_cdsrdare\_080509**

#	Searches	Results
1	MIDWIFERY.kw.	16
2	PRECONCEPTION CARE.kw.	6
3	PRENATAL CARE.kw.	47
4	PERINATAL CARE.kw.	7

Pregnant women with complex social factors

5	(midwife or midwifery or midwives).tw,tx.	247
6	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).tw,tx.	8
7	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).tw,tx.	289
8	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).tw,tx.	6
9	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).tw,tx.	127
10	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).tw,tx.	32
11	MATERNAL HEALTH SERVICES.kw.	7
12	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).tw,tx.	187
13	MATERNAL-CHILD NURSING.kw.	6
14	OBSTETRICAL NURSING.kw.	2
15	NURSE MIDWIVES.kw.	7
16	REPRODUCTIVE HEALTH SERVICES.kw.	2
17	or/1-16	652
18	(SEX OFFENSES or CHILD ABUSE, SEXUAL or RAPE or VIOLENCE or DOMESTIC VIOLENCE or SPOUSE ABUSE).kw.	57
19	BATTERED WOMEN.kw.	5
20	((violen\$ or abuse\$) adj2 (home or house or dwelling)).tw,tx.	7
21	(domestic adj3 (abuse\$ or violen\$)).tw,tx.	25
22	FAMILY RELATIONS.kw.	9
23	((partner or spouse\$) adj3 (abuse\$ or violen\$)).tw,tx.	23
24	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).tw,tx.	518
25	(intimate adj2 violen\$).tw,tx.	12
26	(violen\$ adj2 relationship\$).tw,tx.	7
27	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).tw,tx.	10
28	(living adj2 violen\$).tw,tx.	1
29	(abus\$ adj2 wom?n).tw,tx.	19
30	(surviv\$ adj2 (abuse or abusive)).tw,tx.	5
31	love hurts.tw,tx.	0
32	((family or families) adj3 (abuse\$ or violen\$)).tw,tx.	28
33	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).tw,tx.	1841
34	(stalking or harrass\$).tw,tx.	2
35	(jealous\$ or imprisonment).tw,tx.	22
36	restrictive behavio?r\$.tw,tx.	0
37	(intimidat\$ or fear\$).tw,tx.	333

38	(isolation or isolated).tw,tx.	780
39	molest\$.tw,tx.	8
40	(control\$ adj2 behavio?r\$).tw,tx.	127
41	or/18-40	3097
42	and/17,41	220
43	limit 42 to humans [Limit not valid in DARE,CDSR; records were retained]	220
44	limit 43 to english language [Limit not valid in DARE,CDSR; records were retained]	220

**SCIP\_domesticviolence\_cinahl\_110509\_6**

**Monday, May 11, 2009 4:42:29 AM**

#	Query	Limiters/Expanders	Last Run Via	Results
S75	S24 and S72	Limiters - Abstract Available; Peer Reviewed; Research Article; Language: English; Pregnancy Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	587
S74	S24 and S72	Limiters - Language: English; Pregnancy Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	1173
S73	S24 and S72	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	2151
S72	S69 or S70 or S71	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	71605
S71	S45 or S46 or S47 or S48 or S49 or S50 or S51 or S52 or S53 or S54 or S55 or S56 or S57 or S58 or S59 or S60 or S61 or S62 or S63 or S64 or	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced	52790

Pregnant women with complex social factors

	S65 or S66 or S67 or S68		Search Database - CINAHL with Full Text	
S70	S40 or S41 or S42 or S43	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	8904
S69	S25 or S26 or S27 or S28 or S29 or S30 or S31 or S32 or S33 or S34 or S35 or S36 or S37 or S38 or S39	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S68	TI (control* N2 behavior*) or AB (control* N2 behavior*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S67	TI (control* N2 behaviour*) or AB (control* N2 behaviour*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S66	TI (molest*) or AB (molest*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S65	TI (isolation or isolated) or AB (isolation or isolated)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search	Display

			Database - CINAHL with Full Text	
S64	TI (intimidat* or fear*) or AB (intimidat* or fear*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S63	TI (restrictive behavior*) or AB (restrictive behavior*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S62	TI (restrictive behaviour*) or AB (restrictive behaviour*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S61	TI (jealous* or imprisonment) or AB (jealous* or imprisonment)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S60	TI (stalking or harrass*) or AB (stalking or harrass*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S59	AB (shak* or smack* or punch* or kick* or stab* or suffocat* or intimidat* or critici*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database -	Display

			CINAHL with Full Text	
S58	Ti (shak* or smack* or punch* or kick* or stab* or suffocat* or intimidat* or critici*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S57	TI (famil* N2 violen*) or AB (famil* N2 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S56	TI (famil* N2 abus*) or AB (famil* N2 abus*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S55	TI (love hurts) or AB (love hurts)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S54	TI (surviv* N2 abus*) or AB (surviv* N2 abus*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S53	AB (abus* N2 woman) or AB (abus* N2 women)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with	Display

			Full Text	
S52	TI (abus* N2 woman) or TI (abus* N2 women)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S51	TI (living N2 violen*) or AB (living N2 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S50	TI (threaten* N3 abuse*) or AB (threaten* N3 abuse*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S49	TI (threaten* N3 violen*) or AB (threaten* N3 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S48	AB (threaten* N3 behaviour*) or AB (threaten* N3 behavior*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S47	TI (threaten* N3 behaviour*) or TI (threaten* N3 behavior*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display

S46	TI (violen* N2 relationship*) or AB (violen* N2 relationship*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S45	TI (intimate N2 violen*) or AB (intimate N2 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S44	TI (intimate N2 violen*) or AB (TI (intimate N2 violen*))	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S43	AB (sexual* N3 abuse*) or AB (sexual* N3 violen*) or AB (sexual* N3 behaviour*) or AB (sexual* N3 behavior*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S42	TI (sexual* N3 abuse*) or TI (sexual* N3 violen*) or TI (sexual* N3 behaviour*) or TI (sexual* N3 behavior*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S41	AB (physical N3 abuse*) or AB (physical N3 violen*) or AB (physical N3 behaviour*) or AB (physical N3 behavior*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S40	TI (physical N3 abuse*) or TI	Search modes -	Interface -	Display

	(physical N3 violen*) or TI (physical N3 behaviour*) or TI (physical N3 behavior*)	Boolean/Phrase	EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	
S39	AB (spouse N3 abuse*) or AB (spouse N3 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S38	TI (spouse N3 abuse*) or TI (spouse N3 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S37	AB (partner N3 abuse) or AB (partner N3 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S36	TI (partner N3 abuse) or TI (partner N3 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S35	MH FAMILY RELATIONS	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S34	AB (domestic N3 abuse) or AB (domestic N3 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost	Display

Pregnant women with complex social factors

			Search Screen - Advanced Search Database - CINAHL with Full Text	
S33	TI (domestic N3 abuse) or TI (domestic N3 violen*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S32	AB (abuse* N2 home) or AB (abuse* N2 house) or AB (abuse* N2 dwelling)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S31	TI (abuse* N2 home) or TI (abuse* N2 house) or TI (abuse* N2 dwelling)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S30	AB (violen* N2 home) or AB (violen* N2 house) or AB (violen* N2 dwelling)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S29	TI (violen* N2 home) or TI (violen* N2 house) or TI (violen* N2 dwelling)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S28	MH BATTERED WOMEN	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen	Display

			- Advanced Search Database - CINAHL with Full Text	
S27	MH INTIMATE PARTNER VIOLENCE	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S26	MH DOMESTIC VIOLENCE	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S25	(MH "SEXUAL ABUSE+")	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S24	S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S23	TI (prepregnan* N3 clinic*) or AB (prepregnan* N3 clinic*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S22	TI (pre pregnan* N3 clinic*) or AB (pre pregnan* N3 clinic*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced	Display

Pregnant women with complex social factors

			Search Database - CINAHL with Full Text	
S21	TI (pre pregnan* N3 service*) or AB (pre pregnan* N3 service*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S20	TI (pre pregnan* N3 care*) or AB (pre pregnan* N3 care*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S19	TI (prepregnan* N3 care*) or AB (prepregnan* N3 care*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S18	TI (pregnan* N3 service*) or AB (pregnan* N3 service*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S17	TI (pregnan* N3 care) or AB (pregnan* N3 care)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S16	TI (maternal care or maternal healthcare or maternal service*) or AB (maternal care or maternal healthcare or maternal service*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search	Display

			Database - CINAHL with Full Text	
S15	TI (obstetric* or family planning or reproductive) or AB (obstetric* or family planning or reproductive)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S14	TI (peri natal* or perinatal*) or AB (peri natal* or peri natal*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S13	TI (antenatal* or ante natal*) or AB (antenatal* or ante natal*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S12	TI (prenatal* or pre natal*) or AB (prenatal* or pre natal*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S11	TI (preconception* or pre conception*) or AB (preconception* or pre conception*)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S10	TI (midwife or midwifery or midwives) or AB (midwife or midwifery or midwives)	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database -	Display

			CINAHL with Full Text	
S9	MH PERINATAL NURSING	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S8	MH NURSE MIDWIVES	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S7	MH OBSTETRIC NURSING	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S6	MH MATERNAL-CHILD NURSING	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S5	MH MATERNAL HEALTH SERVICES	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S4	MH PERINATAL CARE	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with	Display

			Full Text	
S3	MH PRENATAL CARE	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S2	MH PREPREGNANCY CARE	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display
S1	MH MIDWIFERY+	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	Display

**EMBASE 1980 to 2009 Week 18**  
**SCIP\_domesticviolence\_embase\_080509**

#	Searches	Results
1	MIDWIFE/	2261
2	exp PRENATAL CARE/	55204
3	MATERNAL TREATMENT/	443
4	exp PERINATAL CARE/	15143
5	exp OBSTETRIC CARE/	141021
6	(midwife or midwifery or midwives).ti,ab.	3124
7	PRENATAL PERIOD/	3879
8	PERINATAL PERIOD/	12496
9	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	253
10	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	9764
11	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	117
12	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	6575

Pregnant women with complex social factors

13	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	683
14	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	3390
15	OBSTETRICAL NURSING/	7
16	or/1-15	162292
17	violence/ or domestic violence/ or battered woman/ or family violence/ or partner violence/	18727
18	sexual crime/ or rape/	5661
19	((violen\$ or abuse\$) adj2 (home or house or dwelling)).ti,ab.	91
20	(domestic adj3 (abuse\$ or violen\$)).ti,ab.	1819
21	family relationship\$.ti,ab.	1199
22	((partner or spouse\$) adj3 (abuse\$ or violen\$)).ti,ab.	1326
23	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).ti,ab.	30501
24	(intimate adj2 violen\$).ti,ab.	822
25	(violen\$ adj2 relationship\$).ti,ab.	251
26	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).ti,ab.	289
27	(living adj2 violen\$).ti,ab.	15
28	(abus\$ adj2 wom?n).ti,ab.	1093
29	(surviv\$ adj2 (abuse or abusive)).ti,ab.	178
30	love hurts.ti,ab.	3
31	((family or families) adj3 (abuse\$ or violen\$)).ti,ab.	1345
32	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).ti,ab.	432901
33	(stalking or harrass\$).ti,ab.	275
34	(strangle or strangling).ti,ab.	73
35	(jealous\$ or imprisonment).ti,ab.	971
36	restrictive behavio?r\$.ti,ab.	5
37	(intimidat\$ or fear\$).ti,ab.	25552
38	(isolation or isolated).ti,ab.	523306
39	molest\$.ti,ab.	466
40	(control\$ adj2 behavio?r\$).ti,ab.	4456
41	or/17-40	1007686
42	and/16,41	9337
43	editorial.pt.	228356
44	letter.pt.	445246
45	note.pt.	246689
46	or/43-45	920291
47	42 not 46	9119
48	limit 47 to human	7176

49	limit 48 to english language	6362
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**PsycINFO 1967 to May Week 1 2009**  
**SCIP\_domesticviolence\_psycinfo\_080509**

#	Searches	Results
1	exp PRENATAL CARE/	1024
2	REPRODUCTIVE HEALTH/	268
3	PRENATAL DIAGNOSIS/	388
4	PRENATAL DEVELOPMENT/	2998
5	exp OBSTETRICS/	874
6	PERINATAL PERIOD/	1007
7	(midwife or midwifery or midwives).ti,ab.	914
8	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	28
9	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	1806
10	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	22
11	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	1051
12	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	267
13	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	1566
14	exp HEALTH CARE SERVICES/	49587
15	or/1-14	58865
16	sex offenses/ or sexual abuse/ or sexual harassment/	18267
17	rape/	3538
18	domestic violence/ or battered females/ or family relations/ or intimate partner violence/ or marital conflict/ or partner abuse/ or physical abuse/	41906
19	((violen\$ or abuse\$) adj2 (home or house or dwelling)).ti,ab.	180
20	(domestic adj3 (abuse\$ or violen\$)).ti,ab.	4922
21	((partner or spouse\$) adj3 (abuse\$ or violen\$)).ti,ab.	2885
22	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).ti,ab.	52524
23	(intimate adj2 violen\$).ti,ab.	1638
24	(violen\$ adj2 relationship\$).ti,ab.	929
25	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).ti,ab.	591
26	(living adj2 violen\$).ti,ab.	49
27	(abus\$ adj2 wom?n).ti,ab.	2031
28	(surviv\$ adj2 (abuse or abusive)).ti,ab.	662
29	love hurts.ti,ab.	5

30	((family or families) adj3 (abuse\$ or violen\$)).ti,ab.	4280
31	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).ti,ab.	71044
32	(stalking or harrass\$).ti,ab.	632
33	(jealous\$ or imprisonment).ti,ab.	2713
34	restrictive behaviou?r\$.ti,ab.	5
35	(intimidat\$ or fear\$).ti,ab.	37512
36	(isolation or isolated).ti,ab.	24867
37	molest\$.ti,ab.	1267
38	(control\$ adj2 behavio?r\$).ti,ab.	7104
39	or/16-38	232022
40	and/15,39	5030
41	limit 40 to (("0110 peer-reviewed journal" or "0500 electronic collection") and english)	3742

## Domestic Violence - Health Economics

Ovid MEDLINE(R) 1950 to November Week 3 2009

SCIP\_domesticviolence\_economic\_medline\_091209

#	Searches	Results
1	costs.tw.	87883
2	cost effective\$.tw.	50854
3	economic.tw.	80777
4	or/1-3	190464
5	(metabolic adj cost).tw.	551
6	((energy or oxygen) adj cost).tw.	2178
7	4 not (5 or 6)	190202
8	MIDWIFERY/	11847
9	PRECONCEPTION CARE/	938
10	PRENATAL CARE/	17374
11	PERINATAL CARE/	1863
12	(midwife or midwifery or midwives).ti,ab.	12049
13	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	326
14	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	14990
15	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	221

16	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	12581
17	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	1096
18	exp MATERNAL HEALTH SERVICES/	27100
19	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	6461
20	MATERNAL-CHILD NURSING/	1548
21	OBSTETRICAL NURSING/	2546
22	NURSE MIDWIVES/	5447
23	REPRODUCTIVE HEALTH SERVICES/	560
24	or/8-23	69353
25	sex offenses/ or child abuse, sexual/ or rape/ or violence/ or domestic violence/ or spouse abuse/	39299
26	BATTERED WOMEN/	1781
27	((violen\$ or abuse\$) adj2 (home or house or dwelling)).ti,ab.	139
28	(domestic adj3 (abuse\$ or violen\$)).ti,ab.	3181
29	FAMILY RELATIONS/	5760
30	((partner or spouse\$) adj3 (abuse\$ or violen\$)).ti,ab.	2202
31	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).ti,ab.	39136
32	(intimate adj2 violen\$).ti,ab.	1471
33	(violen\$ adj2 relationship\$).ti,ab.	378
34	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).ti,ab.	380
35	(living adj2 violen\$).ti,ab.	26
36	(abus\$ adj2 wom?n).ti,ab.	1673
37	(surviv\$ adj2 (abuse or abusive)).ti,ab.	216
38	love hurts.ti,ab.	3
39	((family or families) adj3 (abuse\$ or violen\$)).ti,ab.	1937
40	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).ti,ab.	531772
41	(stalking or harrass\$).ti,ab.	343
42	(jealous\$ or imprisonment).ti,ab.	1406

Pregnant women with complex social factors

43	restrictive behaviour\$.ti,ab.	8
44	(intimidat\$ or fear\$).ti,ab.	36002
45	(isolation or isolated).ti,ab.	717757
46	molest\$.ti,ab.	789
47	(control\$ adj2 behaviour\$).ti,ab.	5936
48	or/25-47	1328091
49	and/24,48	3679
50	and/7,49	283
51	limit 50 to humans	190
52	limit 51 to english language	177

**EBM Reviews - NHS Economic Evaluation Database 4th Quarter 2009**

**SCIP\_domesticviolence\_economic\_nhseed\_211209**

#	Searches	Results
1	costs.tw.	18369
2	cost effective\$.tw.	9441
3	economic.tw.	26796
4	or/1-3	27261
5	(metabolic adj cost).tw.	0
6	((energy or oxygen) adj cost).tw.	0
7	4 not (5 or 6)	27261
8	MIDWIFERY/	14
9	PRECONCEPTION CARE/	1
10	PRENATAL CARE/	120
11	PERINATAL CARE/	17
12	(midwife or midwifery or midwives).ti,ab.	9
13	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	1
14	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	32
15	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	0
16	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or	18

	clinic? or nurs\$)).ti,ab.	
17	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	0
18	exp MATERNAL HEALTH SERVICES/	177
19	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	16
20	MATERNAL-CHILD NURSING/	2
21	OBSTETRICAL NURSING/	2
22	NURSE MIDWIVES/	9
23	REPRODUCTIVE HEALTH SERVICES/	6
24	or/8-23	221
25	sex offenses/ or child abuse, sexual/ or rape/ or violence/ or domestic violence/ or spouse abuse/	44
26	BATTERED WOMEN/	4
27	((violen\$ or abuse\$) adj2 (home or house or dwelling)).ti,ab.	0
28	(domestic adj3 (abuse\$ or violen\$)).ti,ab.	2
29	FAMILY RELATIONS/	5
30	((partner or spouse\$) adj3 (abuse\$ or violen\$)).ti,ab.	8
31	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).ti,ab.	8
32	(intimate adj2 violen\$).ti,ab.	7
33	(violen\$ adj2 relationship\$).ti,ab.	0
34	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).ti,ab.	0
35	(living adj2 violen\$).ti,ab.	0
36	(abus\$ adj2 wom?n).ti,ab.	1
37	(surviv\$ adj2 (abuse or abusive)).ti,ab.	0
38	love hurts.ti,ab.	0
39	((family or families) adj3 (abuse\$ or violen\$)).ti,ab.	0
40	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).ti,ab.	53
41	(stalking or harrass\$).ti,ab.	0
42	(jealous\$ or imprisonment).ti,ab.	0
43	restrictive behaviou?r\$.ti,ab.	0

Pregnant women with complex social factors

44	(intimidat\$ or fear\$).ti,ab.	0
45	(isolation or isolated).ti,ab.	18
46	molest\$.ti,ab.	0
47	(control\$ adj2 behavio?r\$).ti,ab.	0
48	or/25-47	125
49	and/24,48	0
50	and/7,49	0
51	limit 50 to humans	0
52	limit 51 to english language	0

**EBM Reviews - Health Technology Assessment 4th Quarter 2009**

**SCIP\_domesticviolence\_economic\_hta\_211209**

#	Searches	Results
1	costs.tw.	1362
2	cost effective\$.tw.	1180
3	economic.tw.	845
4	or/1-3	1980
5	(metabolic adj cost).tw.	0
6	((energy or oxygen) adj cost).tw.	0
7	4 not (5 or 6)	1980
8	MIDWIFERY/	5
9	PRECONCEPTION CARE/	1
10	PRENATAL CARE/	15
11	PERINATAL CARE/	1
12	(midwife or midwifery or midwives).ti,ab.	5
13	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	1
14	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	4
15	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	0
16	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	1

17	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	0
18	exp MATERNAL HEALTH SERVICES/	29
19	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	1
20	MATERNAL-CHILD NURSING/	1
21	OBSTETRICAL NURSING/	0
22	NURSE MIDWIVES/	0
23	REPRODUCTIVE HEALTH SERVICES/	1
24	or/8-23	36
25	sex offenses/ or child abuse, sexual/ or rape/ or violence/ or domestic violence/ or spouse abuse/	15
26	BATTERED WOMEN/	2
27	((violen\$ or abuse\$) adj2 (home or house or dwelling)).ti,ab.	0
28	(domestic adj3 (abuse\$ or violen\$)).ti,ab.	3
29	FAMILY RELATIONS/	2
30	((partner or spouse\$) adj3 (abuse\$ or violen\$)).ti,ab.	3
31	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).ti,ab.	2
32	(intimate adj2 violen\$).ti,ab.	1
33	(violen\$ adj2 relationship\$).ti,ab.	0
34	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).ti,ab.	0
35	(living adj2 violen\$).ti,ab.	0
36	(abus\$ adj2 wom?n).ti,ab.	0
37	(surviv\$ adj2 (abuse or abusive)).ti,ab.	0
38	love hurts.ti,ab.	0
39	((family or families) adj3 (abuse\$ or violen\$)).ti,ab.	0
40	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).ti,ab.	29
41	(stalking or harrass\$).ti,ab.	0
42	(jealous\$ or imprisonment).ti,ab.	0
43	restrictive behavio?r\$.ti,ab.	0
44	(intimidat\$ or fear\$).ti,ab.	0

Pregnant women with complex social factors

45	(isolation or isolated).ti,ab.	9
46	molest\$.ti,ab.	0
47	(control\$ adj2 behavior\$r\$).ti,ab.	0
48	or/25-47	57
49	and/24,48	1
50	and/7,49	0
51	limit 50 to humans	0
52	limit 51 to english language	0

**EMBASE 1980 to 2009 Week 51**

**SCIP\_domesticviolence\_economic\_embase\_211209**

#	Searches	Results
1	costs.tw.	69955
2	cost effective\$.tw.	44650
3	economic.tw.	58320
4	or/1-3	146485
5	(metabolic adj cost).tw.	410
6	((energy or oxygen) adj cost).tw.	1760
7	4 not (5 or 6)	146298
8	MIDWIFE/	2396
9	exp PRENATAL CARE/	57355
10	MATERNAL TREATMENT/	459
11	exp PERINATAL CARE/	16061
12	exp OBSTETRIC CARE/	147448
13	(midwife or midwifery or midwives).ti,ab.	3328
14	PRENATAL PERIOD/	4142
15	PERINATAL PERIOD/	13361
16	((preconception\$ or pre conception\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$)).ti,ab.	268
17	((prenatal\$ or antenatal\$ or perinatal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	10169
18	((pre natal\$ or ante natal\$ or peri natal\$) adj3 (care or healthcare or service? or clinic? or welfare or program\$ or control)).ti,ab.	125

19	((obstetric\$ or family planning or reproductive) adj3 (care or healthcare or service? or clinic? or nurs\$)).ti,ab.	6874
20	((pregnan\$ or expectant or maternal or pre?natal\$ or ante?natal\$) adj3 (contact\$ or access\$)).ti,ab.	723
21	((maternal or expectant or pregnan\$) adj3 (healthcare or service? or care or clinic?)).ti,ab.	3585
22	OBSTETRICAL NURSING/	8
23	or/8-22	169878
24	violence/ or domestic violence/ or battered woman/ or family violence/ or partner violence/	19642
25	sexual crime/ or rape/	5928
26	((violen\$ or abuse\$) adj2 (home or house or dwelling)).ti,ab.	95
27	(domestic adj3 (abuse\$ or violen\$)).ti,ab.	1921
28	family relationship\$.ti,ab.	1249
29	((partner or spouse\$) adj3 (abuse\$ or violen\$)).ti,ab.	1472
30	((physical\$ or sexual\$ or psychological or emotional) adj3 (abuse\$ or violen\$ or behavio?r\$)).ti,ab.	31987
31	(intimate adj2 violen\$).ti,ab.	946
32	(violen\$ adj2 relationship\$).ti,ab.	273
33	(threaten\$ adj3 (behavio?r\$ or violen\$ or abuse\$)).ti,ab.	298
34	(living adj2 violen\$).ti,ab.	17
35	(abus\$ adj2 wom?n).ti,ab.	1133
36	(surviv\$ adj2 (abuse or abusive)).ti,ab.	186
37	love hurts.ti,ab.	3
38	((family or families) adj3 (abuse\$ or violen\$)).ti,ab.	1413
39	(shaking or smack\$ or punch\$ or kick\$ or stab\$ or suffocat\$ or intimidat\$ or critici\$).ti,ab.	452829
40	(stalking or harrass\$).ti,ab.	289
41	(strangle or strangling).ti,ab.	76
42	(jealous\$ or imprisonment).ti,ab.	1011
43	restrictive behavio?r\$.ti,ab.	6
44	(intimidat\$ or fear\$).ti,ab.	26974
45	(isolation or isolated).ti,ab.	538606

## Pregnant women with complex social factors

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46	molest\$.ti,ab.	480
47	(control\$ adj2 behavio?r\$).ti,ab.	4707
48	or/24-47	1045986
49	and/23,48	9838
50	and/7,49	257
51	editorial.pt.	241636
52	letter.pt.	467155
53	note.pt.	257701
54	or/51-53	966492
55	50 not 54	255
56	limit 55 to human	222
57	limit 56 to english language	203

# Appendix H

## PICO tables

PICO tables were generated for each question defining the target population, interventions and comparators (where appropriate) and outcomes. These are presented below with a summary of the searching activity for each question.

**Question 1a.** What aspects of service organisation are effective at improving access to antenatal services for the following groups of women:

- Women misusing substances (drugs and/or alcohol)
- Recent migrants to the UK, refugees or asylum seekers, or women with little or no English
- Teenagers
- Women experiencing domestic abuse

Primary outcome: Gestation at booking

Secondary outcomes: Women's views of antenatal care; attendance at antenatal education sessions; incidence of low birthweight (<2500g); incidence of preterm birth (<37 weeks)

**Table H.1- Q1a PICO table**

Populations	Intervention	Comparison	Outcomes
Teenagers Adolescents Women aged under 20  Substance misusing women Drug and/or alcohol use/misuse/dependency/addiction Recreational drug users Illicit drug users  Recent migrants Immigrants Non English-speaking women Non native-speaking women Women with little or poor English Asylum seekers Refugees  Women experiencing domestic abuse Victims of domestic abuse/violence Intimate partner violence	Any antenatal intervention/service provision that might improve access/uptake of antenatal care/prenatal care/first appointment/booking appointment	Usual care/standard care  Any other system of antenatal care provision	Gestation at booking first appointment  Attendance at antenatal education sessions  Referral for/access to additional services/support (women experiencing domestic abuse only)  Women's views of antenatal care  Incidence of low birthweight (<2500g)  Incidence of preterm birth (< 37 weeks)

**Question 1b.** What aspects of service organisation and delivery act as barriers to take up of antenatal services for the following groups of women:

- Women misusing substances (drugs and/or alcohol)
- Recent migrants to the UK, refugees or asylum seekers, or women with little or no English
- Teenagers
- Women experiencing domestic abuse

Primary outcomes: women's reported barriers to accessing care

## Pregnant women with complex social factors

Secondary outcomes: health professionals' views of barriers to care; gestation at booking/first appointment; reasons for non-attendance at second or subsequent appointments; attendance at antenatal education sessions

**Table H.2- Q1b PICO table**

Populations	Intervention	Comparison	Outcomes
Teenagers Adolescents Women aged under 20  Substance misusing women Drug and/or alcohol use/misuse/dependency/addiction Recreational drug users Illicit drug users  Recent migrants Immigrants Non English-speaking women Non native-speaking women Women with little or poor English Asylum seekers Refugees  Women experiencing domestic abuse Victims of domestic abuse/violence Intimate partner violence	Any antenatal intervention/service provision that might act as a barrier to access/uptake of antenatal care/prenatal care/first appointment/booking appointment  Any other aspect of a woman's personal circumstances that might act as a barrier to uptake of care.	Non-comparative studies were considered for inclusion for this question.  Where applicable: Usual care/standard care  Any other system of antenatal care provision	Women's and/or health professionals' views on barriers to receiving or accessing appropriate antenatal care services. Barriers could include those personal to the woman herself e.g. home circumstances, lifestyle or barriers relating to how she perceives services and/or staff e.g. waiting times, as well as physical barriers e.g. distance to antenatal clinic.  Reported barriers to/reasons for non-attendance at second and subsequent appointments  Gestation at booking/first appointment  Attendance at antenatal education sessions

**Question 2.** What aspects of service organisation and delivery improve contact with antenatal services throughout pregnancy for the following groups of women:

- Women misusing substances (drugs and/or alcohol)
- Recent migrants to the UK, refugees or asylum seekers, or women with little or no English
- Teenagers
- Women experiencing domestic abuse

Primary outcomes: Number of antenatal appointments attended (or missed); attendance rates for antenatal appointments

Secondary outcomes: Women's views of antenatal care; attendance at antenatal education sessions; incidence of low birthweight (<2500g); incidence of preterm birth (< 37 weeks)

**Table H.3- Q2 PICO table**

Populations	Intervention	Comparison	Outcomes
Teenagers Adolescents Women aged under 20  Substance misusing women Drug and/or alcohol use/misuse/dependency/addiction Recreational drug users Illicit drug users	Any antenatal intervention/service provision that might improve contact with antenatal services	Usual care/standard care  Any other system of antenatal care provision	Number of antenatal appointments attended (or missed)  Attendance rates as a percentage of recommended appointments attended  Women's views of antenatal care

<p>Recent migrants Immigrants Non English-speaking women Non native-speaking women Women with little or poor English Asylum seekers Refugees</p> <p>Women experiencing domestic abuse Victims of domestic abuse/violence Intimate partner violence</p>			<p>Incidence of low birthweight (&lt;2500g)</p> <p>Incidence of preterm birth (&lt; 37 weeks)</p>
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**Question 3.** What additional consultations and/or support should be provided to women, their partners and families in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline).

- Women misusing substances (drugs and/or alcohol)
- Recent migrants to the UK, refugees or asylum seekers, or women with little or no English
- Teenagers
- Women experiencing domestic abuse

Primary outcomes: Incidence of low birthweight (<2500g); incidence of preterm birth (< 37 weeks)

Secondary outcomes: Women's views of antenatal care; partners' and families' views of care (this outcome is not included for women experiencing domestic abuse); breastfeeding; admission to NICU.

**Table H.4- Q3 PICO table**

Populations	Intervention	Comparison	Outcomes
<p>Teenagers Adolescents Women aged under 20</p> <p>Substance misusing women Drug and/or alcohol use/misuse/dependency/addiction Recreational drug users Illicit drug users</p> <p>Recent migrants Immigrants Non English-speaking women Non native-speaking women Women with little or poor English Asylum seekers Refugees</p> <p>Women experiencing domestic abuse Victims of domestic abuse/violence Intimate partner violence</p>	<p>Any antenatal intervention/service that provides additional consultations and/or support over and above standard/usual care.</p>	<p>Usual care/standard care</p> <p>Any other system of antenatal care provision</p>	<p>Maternal outcomes: Satisfaction/views of services and care</p> <p>Partners' and other family members' views (excluding women who experience domestic abuse)</p> <p>Breastfeeding initiation and longevity</p> <p>Reported uptake of contraception (teenagers)</p> <p>Time elapsed before next pregnancy (teenagers)</p> <p>Neonatal outcomes: Birthweight/incidence of low birthweight (&lt;2500g)</p> <p>Gestation at birth/incidence of preterm birth (&lt;37 weeks)</p> <p>Admission to SCBU/NICU</p>

## Pregnant women with complex social factors

**Question 4.** What additional information should be provided to women, their partners and families in order to improve pregnancy outcomes? (Additional here means over and above that described in the NICE Antenatal care guideline).

- Women misusing substances (drugs and/or alcohol)
- Recent migrants to the UK, refugees or asylum seekers, or women with little or no English
- Teenagers
- Women experiencing domestic abuse

Primary outcomes: Incidence of low birthweight (<2500g); incidence of preterm birth (< 37 weeks)

Secondary outcomes: Women's views of antenatal care; partners' and families' views of care (this outcome is not included for women experiencing domestic abuse); breastfeeding; admission to NICU.

**Table H.5- Q4 PICO table**

Populations	Intervention	Comparison	Outcomes
Teenagers Adolescents Women aged under 20  Substance misusing women Drug and/or alcohol use/misuse/dependency/addiction Recreational drug users Illicit drug users  Recent migrants Immigrants Non English-speaking women Non native-speaking women Women with little or poor English Asylum seekers Refugees  Women experiencing domestic abuse Victims of domestic abuse/violence Intimate partner violence	Any antenatal intervention/service that provides additional information over and above standard/usual care. This includes antenatal education sessions.	Usual care/standard care  Any other system of antenatal care provision	Maternal outcomes: Satisfaction/views of services and care  Partners' and other family members' views (excluding women who experience domestic abuse)  Women's knowledge on health-related issues, pregnancy and birth or infant care  Breastfeeding initiation and longevity  Reported uptake of contraception (teenagers)  Time elapsed before next pregnancy (teenagers)  Neonatal outcomes: Birthweight/incidence of low birthweight (<2500g)  Gestation at birth/incidence of preterm birth (<37 weeks)  Admission to SCBU/NICU

### Searching and reviewing activity summary

	Substance misusers	Recent migrants	Teenagers	Domestic abuse	All populations
No. hits in search	7593 (5515)	10352 (7144)	10941 (7817 after deduplication)	13658 (11604)	32080 (after deduplication)
No. of papers in rerun/update searches	2564 (2337)	844 (454)	2750 (2443 after deduplication)	1508 (678)	5912 (after deduplication)
Total no. of papers ordered	175	223	329	144	876

Total no. of papers excluded*	128	118	99	105	450
No. of papers included Question 1a	4	6	9	2	17
No. of papers included Question 1b	10	28	10	16	63
No. of papers included Question 2	7	6	21	1	33
No. of papers included Question 3	11	5	25	7	42
No. of papers included Question 4	1	5	3	1	11
Total no. papers included	33	50	68	27	167

\* Excluded papers: This figure does not equal number of papers ordered minus number of reviewed papers for 2 reasons: some papers were not obtainable/never received and some on arrival are seen to have been ordered in error e.g. foreign language papers, editorials etc.

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