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

NICE guideline
Draft for consultation, February 2010

If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.
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Introduction

The NICE guideline ‘Antenatal care: routine care for the healthy pregnant woman’ (NICE clinical guideline 62) outlines the care that women should expect to be offered during pregnancy. However, women with complex social factors may have additional needs\(^1\), \(^2\). This guideline sets out what healthcare professionals as individuals, and antenatal services as a whole, can do to address these needs and improve outcomes in this group of women.

The guideline applies to all women with complex social factors and contains a number of recommendations on standards of care for this population as a whole. However, four groups of women were identified as exemplars:

- women who misuse substances
- women who are recent migrants, asylum seekers or refugees, or who have difficulties reading or speaking English
- women aged under 20 years (teenagers)
- women who experience domestic abuse.

Because there are differences in the barriers to care and particular needs of these four groups, specific recommendations have been made for each group.

The guideline describes how access to care can be improved, how contact with antenatal carers can be maintained, the additional support and consultations that are required and the additional information that should be offered to pregnant women.

Specific issues that are addressed in the guideline include:

- the most appropriate healthcare setting for maternity care provision
- practice models for overcoming barriers and facilitating access, including access to interpreting services and all necessary care

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• ways of communicating information to women so that they can make appropriate choices
• optimisation of resources.

In addition to the recommendations in this guideline, the principles of woman-centred care and informed decision making outlined in ‘Antenatal care’ (NICE clinical guideline 62), specifically recommendations on the provision of antenatal information and individualised care, are of particular relevance to women with complex social factors.

**Woman-centred care**

This guideline offers best practice advice on the care of pregnant women with complex social factors.

Women, their partners and their families should always be treated with kindness, respect and dignity. The views, beliefs and values of the woman, her partner and her family in relation to her care and that of her baby should be sought and respected at all times.

Treatment and care should take into account women's needs and preferences. Pregnant women with complex social factors should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If women do not have the capacity to make decisions, healthcare professionals should follow the Department of Health’s advice on consent (available from www.dh.gov.uk/consent) and the code of practice that accompanies the Mental Capacity Act (summary available from www.publicguardian.gov.uk). In Wales, healthcare professionals should follow advice on consent from the Welsh Assembly Government (available from www.wales.nhs.uk/consent).

If the woman is under 16, healthcare professionals should follow the guidelines in ‘Seeking consent: working with children’ (available from www.dh.gov.uk).

Good communication between healthcare professionals and women is essential. It should be supported by evidence-based written information tailored to the woman’s needs. Treatment and care, and the information women are given about it, should be
culturally appropriate. It should also be accessible to women with additional needs such as physical, sensory or learning disabilities, and to women who do not speak or read English.

If the woman agrees, families and carers should have the opportunity to be involved in decisions about treatment and care.

Families and carers should also be given the information and support they need.
Key priorities for implementation

Organisation of services

- Commissioners should ensure ongoing audit of antenatal services, with audit to include the following items.
  - The percentages of women in each of four groups (women who misuse substances; women who are recent migrants, refugees or asylum seekers, or who have difficulties reading or speaking English; women aged under 20 years; and women who experience domestic abuse) who:
    - attend for booking by 10, 12+6 and 20 weeks
    - attend for the recommended number of antenatal appointments in line with ‘Antenatal care’ (NICE clinical guideline 62)
    - experience or have babies who experience mortality or significant morbidity
- The satisfaction of women in each of the four groups with the services provided. [1.1.1]

Information and support for women

- For women who do not have a booking appointment:
  - discuss the need for antenatal care and offer referral for a booking appointment if the woman wishes to continue the pregnancy, or
  - offer referral for sexual health advice if the woman is considering termination of pregnancy. [1.1.3]
- Consider initiating a multi-agency needs assessment, including safeguarding issues (for example, using the Common Assessment Framework). [1.1.4]
- Respect the woman’s right to confidentiality and sensitively discuss her fears, but be clear about when and why information about her pregnancy may need to be shared with other agencies. [1.1.5]
- Provide each woman with at least one opportunity for a one-to-one consultation. [1.1.6]
Women who misuse substances (alcohol and/or drugs)

Service organisation

- Healthcare commissioners and individuals responsible for the organisation of local maternity services should work with local agencies, including third-sector agencies that provide substance misuse services, to coordinate antenatal care by, for example:
  - integrating care plans
  - including information about opiate replacement therapy in care plans
  - co-locating services
  - offering women information about other services. [1.2.2]

Training for healthcare staff

- Healthcare staff, including non-clinical staff such as receptionists, should be provided with training on the social and psychological needs of women who misuse substances and how to communicate with these women sensitively. [1.2.3]

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

Information and support for the woman

- Offer 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 and DVDs
  - settings, including pharmacies, community centres, GP surgeries, family planning clinics, children’s centres and hostels
  - languages. [1.3.9]
Women aged under 20 years (teenagers)

Service organisation

• Commissioners should consider commissioning a specialist antenatal service for teenagers 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. [1.4.3]

Women who experience domestic abuse

Service organisation

• Commissioners and providers 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
    ◊ Department of Health guidance³
    ◊ sources of support for women, including addresses and telephone numbers, such as social services, the police, victim 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 phone 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. [1.5.3]
Guidance

The following guidance is based on the best available evidence. The full guideline (add hyperlink) gives details of the methods and the evidence used to develop the guidance.

In this guideline the term ‘commissioners’ refers to primary care trusts, GP partnerships and joint directors of public health.

1.1   General principles

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

Organisation of services

1.1.1   Commissioners should ensure ongoing audit of antenatal services, with audit to include the following items.

- The percentage of women in each of four groups (women who misuse substances; women who are recent migrants, refugees or asylum seekers, or who have difficulties reading or speaking English; women aged under 20 years; and women who experience domestic abuse) who:
  - attend for booking by 10, 12\(^6\) and 20 weeks
  - attend for the recommended number of antenatal appointments in line with ‘Antenatal care’ (NICE clinical guideline 62)
  - experience or have babies who experience mortality or significant morbidity.
- The satisfaction of women in each of the four groups with the services provided.

Training for healthcare professionals

1.1.2   Healthcare professionals should be provided with training on the Common Assessment Framework and national guidelines on information sharing\(^4\).

Information and support for women

1.1.3 For women who do not have a booking appointment:

- discuss the need for antenatal care and offer referral for a booking appointment if the woman wishes to continue the pregnancy, or
- offer referral for sexual health advice if the woman is considering termination of pregnancy.

1.1.4 Consider initiating a multi-agency needs assessment, including safeguarding issues (for example, using the Common Assessment Framework).

1.1.5 Respect the woman’s right to confidentiality and sensitively discuss her fears, but be clear about when and why information about her pregnancy may need to be shared with other agencies.

1.1.6 Provide each woman with at least one opportunity for a one-to-one consultation.

1.1.7 Provide each woman a contact telephone number for use outside of normal working hours, for example the telephone number of the hospital triage or labour ward.

1.1.8 Offer the woman a booking appointment in the first trimester, ideally before 10 weeks.

1.2 Women who misuse substances (alcohol and/or drugs)

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

1.2.1 Healthcare professionals should work with social care professionals to overcome barriers to care for these women. Particular attention should be paid to:

- integrating care from different services
• ensuring that the attitudes of staff do not prevent women from using services
• offering women information to help overcome fears about the involvement of children’s services and potential removal of their child
• addressing women’s feelings of guilt about their misuse of substances and the potential effects on their baby.

Service organisation
1.2.2 Healthcare commissioners and individuals responsible for the organisation of local maternity services should work with local agencies, including third-sector agencies that provide substance misuse services, to coordinate antenatal care by, for example:
• integrating care plans
• including information about opiate replacement therapy in care plans
• co-locating services
• offering women information about other services.

Training for healthcare staff
1.2.3 Healthcare staff, including non-clinical staff such as receptionists, should be provided with training on the social and psychological needs of women who misuse substances and how to communicate with these women sensitively.

Information and support for the woman
1.2.4 At the first contact offer the woman referral to an appropriate substance misuse programme.
1.2.5 Use a range of strategies, for example text messages, to remind women of upcoming appointments.
1.2.6 Offer the woman a named antenatal carer who has specialised knowledge of, and experience in, the treatment of substance misuse, and include a direct contact number for the antenatal carer.
1.2.7 The named antenatal carer should tell the woman about relevant additional services and encourage her to use them according to her individual needs.

1.2.8 Consider offering information about available help with transport to appointments if needed to support the woman’s attendance.

1.2.9 Consider ways of ensuring that, for each woman:
- progress is tracked through the relevant agencies
- clinic notes from different agencies are combined into a single document
- there is a coordinated care plan.

1.3 Women who are recent migrants, asylum seekers or refugees, or who have difficulties reading or speaking English

Women who are recent migrants, asylum seekers or refugees, or who have difficulties 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.

1.3.1 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

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

1.3.3 Commissioners should monitor emergent local needs and adjust services accordingly.
1.3.4 Healthcare professionals should enable women to take a copy of their handheld notes when moving from one area or hospital to another. Ensure that the handheld notes contain a full record of care received and the results of all antenatal tests.

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

Training for healthcare professionals

1.3.6 Healthcare professionals should be provided with training about the specific health needs of women who are recent migrants, asylum seekers or refugees, such as needs arising from female genital mutilation or HIV.

1.3.7 Healthcare professionals should be provided with training about the specific social, religious and psychological needs of women who are recent migrants, asylum seekers or refugees.

Information and support for the woman

1.3.8 Offer women Department of Health information on access and entitlement to healthcare.

1.3.9 Offer 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 and DVDs
- settings, including pharmacies, community centres, GP surgeries, family planning clinics, children’s centres and hostels
- languages.

1.3.10 At the first contact tell the woman to inform her healthcare provider if her address changes, and ensure she has a contact telephone number for this purpose.

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1.3.11 At the first contact discuss with the woman the importance of keeping her handheld maternity record with her at all times.

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

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

1.3.13 Offer the woman an interpreter (who may be a link worker or advocate) who can communicate with her in her preferred language.

1.3.14 When giving spoken information ask the woman to repeat the information to ensure she has understood it correctly.

1.4 **Women aged under 20 years (teenagers)**

Teen-aged women 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.

1.4.1 Healthcare professionals should encourage teenagers to use antenatal care services by:

- offering age-appropriate services
- being aware that the teenager may be dealing with other, age-specific problems
- offering practical help with transportation to and from appointments
- offering antenatal care for teenagers in the community.
Service organisation

1.4.2 Primary care trusts and commissioners should work in partnership with local education authorities and third-sector agencies to improve teenagers’ access to and continuing contact with antenatal care services.

1.4.3 Commissioners should consider commissioning a specialist antenatal service for teenagers 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.

Training for healthcare professionals

1.4.4 Healthcare professionals should be provided with training to ensure they are knowledgeable about the need to offer teenagers consultations without parental or partner input, safeguarding responsibilities and Department of Health guidance on consent for examination or treatment.
Information and support for the woman

1.4.5 Offer age-appropriate information to teenagers, including information about care services, antenatal peer group education or drop-in sessions, housing and other benefits. This information should be provided in a variety of formats, including leaflets.

1.4.6 Offer the teenager a named antenatal carer who should take responsibility for and provide the majority of her antenatal care. A direct-line telephone number for the antenatal carer should be provided.

1.4.7 Offer the teenager opportunities for one-to-one consultations without parental or partner input.

1.5 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.

1.5.1 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 domestic abuse
- providing a more flexible series of appointments when appropriate
- offering women information to help overcome fears about the involvement of children’s services
- telling the woman that disclosure of domestic abuse will not be communicated to the perpetrator of the abuse.
Service organisation

1.5.2 Commissioners and providers 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.

1.5.3 Commissioners and providers 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
  - Department of Health guidance\(^6\)
  - sources of support for women, including addresses and telephone numbers, such as social services, the police, victim 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 phone 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.

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1.5.4 Commissioners and providers should provide for flexibility in the length and frequency of antenatal appointments, over and above those outlined in the ‘Antenatal care’ guideline to allow more time for the woman to discuss domestic abuse she is experiencing.

1.5.5 Offer the woman a named antenatal carer, who should take responsibility for and provide the majority of antenatal care.

**Training for healthcare professionals**

1.5.6 Commissioners and healthcare professionals should consider providing training with social care professionals to enable healthcare professionals to inform and reassure women who are apprehensive about the involvement of social services.

1.5.7 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 provided with training on the care of women 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 the woman**

1.5.8 Tell the woman that the information she discloses will be kept in a confidential record and will not be communicated to the perpetrator of the abuse or included in her handheld record.

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

1.5.10 Consider offering the woman referral to a domestic abuse support worker.
2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover. The scope of this guideline is available from www.guidance.nice.org.uk/CG/Wave14/29

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How this guideline was developed

NICE commissioned the National Collaborating Centre for Women’s and Children’s Health to develop this guideline. The Centre established a guideline development group (see appendix A), which reviewed the evidence and developed the recommendations. An independent guideline review panel oversaw the development of the guideline (see appendix B).

There is more information about how NICE clinical guidelines are developed on the NICE website (www.nice.org.uk/HowWeWork). A booklet, ‘How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS’ (fourth edition, published 2009), is available from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1739).

3 Implementation

NICE has developed tools to help organisations implement this guidance (see www.nice.org.uk/guidance/CGXX).

4 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future. The Guideline Development Group’s full set of research recommendations is detailed in the full guideline (see section 3).

4.1 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.

4.2 Effect of early booking on obstetric and neonatal outcomes

Does early booking (by 10 weeks, or 12+6 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’\(^7\) 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, and
to have their pregnancies accurately dated using ultrasound scan.

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\(^8\). It seems likely that facilitating early booking for these
women is even more important than for the general population. There is, however,

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\(^7\)Department of Health (2007) Maternity matters: choice, access and continuity of care in a safe
service. London: Department of Health. Available from

\(^8\)Confidential Enquiry into Maternal and Child Health (2007) Saving mothers’ lives: reviewing maternal
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.

4.3 **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. At the moment 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.

4.4 **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 (teenagers, women who misuse substances, recent migrants, asylum seekers or refugees, women who have difficulty reading or speaking English, and women experiencing domestic abuse)? How do these models compare, both with each other and with standard care, in terms of outcomes?

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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.

4.5  **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.

5 Other versions of this guideline

5.1 Full guideline
The full guideline, ‘Pregnant women with complex social factors: a model for service provision’ contains details of the methods and evidence used to develop the guideline. It is published by the National Collaborating Centre for Women’s and Children’s Health and is available from [NCC website details to be added] and our website (www.nice.org.uk/guidance/CGXX/Guidance). [Note: these details will apply to the published full guideline.]

5.2 Quick reference guide
A quick reference guide for healthcare professionals is available from www.nice.org.uk/guidance/CGXX/QuickRefGuide

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N1XXX). [Note: these details will apply when the guideline is published.]

5.3 ‘Understanding NICE guidance’
A summary for women and carers (‘Understanding NICE guidance’) is available from www.nice.org.uk/guidance/CGXX/PublicInfo

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N1XXX). [Note: these details will apply when the guideline is published.]
We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about the care of pregnant women with complex social factors.

6 Related NICE guidance

Published


7 Updating the guideline

NICE clinical guidelines are updated so that recommendations take into account important new information. New evidence is checked 3 years after publication, and healthcare professionals and patients are asked for their views; we use this information to decide whether all or part of a guideline needs updating. If important
new evidence is published at other times, we may decide to do a more rapid update of some recommendations.
Appendix A The Guideline Development Group and NICE project team

Guideline Development Group

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\textsuperscript{11} Until October 2009
\textsuperscript{12} Until 19 November 2008
\textsuperscript{13} From June 2009
Appendix B The Guideline Review Panel

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring adherence to NICE guideline development processes. In particular, the panel ensures that stakeholder comments have been adequately considered and responded to. The panel includes members from the following perspectives: primary care, secondary care, lay, public health and industry.

[NICE to add]