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


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). 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.’