## National Institute for Health and Clinical Excellence Pregnancy and Complex Social Factors

## **Guideline Consultation Comments Table**

Туре	Stakeholder	Order No	Docu ment	Section No	Page No	<b>Comments</b> Please insert each new comment in a new row.	<b>Developer's Response</b> Please respond to each comment
SH	Association for family therapy and systemic practice	1	Full	General	Gene ral	Members of AFT work across a range of services within the NHS, Local Authorities and Third Sector, with different levels of family therapy training. Some are employed as UKCP Registered Family Therapists, whilst others use family therapy within their roles, eg as social workers, community psychiatric nurses, clinical psychologists, psychiatrists. Working with complex problems in specialist services for refugees, asylum seekers, vulnerable children and young people, substance misuse, or domestic violence will include some pregnant women. It will build on family strengths and support, while addressing difficulties, conflict or trauma to create changes in relationships and lifestyles.	Thank you very much for your comment.
SH	Association for family therapy and systemic practice	2	Full	General	Gene ral	There is a strong evidence base for the effectiveness of systemic family and couple therapy in improving relationship difficulties and various diagnoses, including	Thank you very much for your comment. We have not specifically reviewed evidence relating to family therapy and so did not make any recommendations about it. However,

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						substance misuse. Details of family therapy practice and evidence can be found in <i>Evidence base for Family Therapy</i> and <i>Current practice, future</i> <i>possibilities</i> <u>www.aft.org.uk</u> .	where we have made recommendations about referral to third sector agencies, we anticipate that family therapy could be considered
SH	Association for family therapy and systemic practice	3	Full	3.3	25	Access to family / couple therapy is possible when there are links between the services catering for women with complex social factors (eg asylum seekers, substance misuse, looked after children) and services for maternity services.	Thank you for your comment. The guideline recommends co-ordination of care between services, including health and social care services, for example by sharing documentation and jointly planning care. Family therapy and systemic practice may form part of these additional services which would benefit from close working with maternity services.
SH	Association for family therapy and systemic practice	4	Full Draft	3.3 1.1.2.	25	Suggest more attention is given to aspects of the emotional wellbeing, since some of the complex social factors covered will be associated with feelings and distress that may lead to attachment and bonding difficulties after birth. Trauma and abuse will be why some women seek asylum, start misusing substances; become looked after, or following domestic violence, and these factors lead to the loss or disruption of family contacts. Having staff that 'Think Family' and can support and foster attachment relationships by providing continuity in contacts	Thank you very much for your comment. We recognise that emotional wellbeing is particularly important in these groups of women and that providing women with the opportunity for supportive relationships by, for example, ensuring continuity of carer is vital. The group did not feel able to make a specific recommendation about provision of support from the antenatal period through to the postnatal period as this was outside of the scope of this guideline.

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						and treatment from ante natal to post natal care will also help the women to feel supported during stressful times, and when the women need to make changes, as with substance misuse. Access to training for the staff involved can by found through http://www.aft.org.uk/docs/Trainin g_000.pdf	
SH	Association for Improvements in the Maternity Services (AIMS)	1	Full	1.1		LATE BOOKING AND REFERRAL FOR MULTI- AGENCY ASSESSMENT This is of great concern to us since we are getting frequent feedback from clients in many areas on how this is being used already. It is being used routinely, not selectively. Because there is a statistical correlation between late booking and higher risk of bad outcomes, staff are wrongly implying (or perhaps even believing) causality - and blame. In some areas women who book late are automatically referred to social services. Where is the evidence that such referrals are beneficial and have no adverse effects? We see many (including damaging levels of stress for the fetus), and increase of suicidal behaviour, as outlined in	Thank you for your comment. The recommendation about offering a booking appointment to women who don't yet have one was meant not only for late bookers but for all women e.g. who have just found out they are pregnant and will want a booking appointment as soon as possible. The need to consider a multi-agency needs assessment is written as something the health care professional needs to "consider", it may or not be appropriate and it is for that professional to decide this. If one is needed it is better to set this in motion as soon as possible so support services etc. can be put in place. The recommendation does not mention late booking, nor does it state that women who book late need a multi-agency needs assessment. We are sorry that you feel the recommendation can be misinterpreted in this way.

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						Confidential Enquiries into Maternal Deaths.(1,2) "the finding that so many deaths from psychiatric causes took place shortly after a child protection case conference of a child being removed into care is striking"(2) We also see abortions of wanted (and grieved for) children in subsequent pregnancies. Much of this is to do with quality, style, content purpose and culture of current social work. (For quality of social work training see report of House of Commons Select Committe on Children, Schools and Families on Training of Social Workers, and our written evidence to that committee, attached ; we also gave oral evidence) (3) (4) It is high time there was a randomised trial since these are as scarce as hen's teeth in social work, thus most of what is done is not evidence-based. We note that on pp. 33-5 you mention US and Australian studies where fear of child custody prevented women from using services - which echo our experience here. A number of our clients describe late booking or failure to attend all antenatal appointments	We agree that there is a paucity of good quality evidence in social care. Whilst this guideline is developed for the NHS in England and Wales and does address the interface between health and social care services we do not have the remit to directly address social care professionals and social care research. This work is undertaken by the Social Care Institute of Excellence, who were represented on this guideline's development group. We absolutely agree that women may book late or not attend appointments for a variety of reasons. Many of these have been highlighted in the evidence reviews looking at barriers to care. Recommendations have been made in order to bring about changes to services that make them more acceptable and accessible to women, taking in to account women's needs and circumstances. We also agree that poor behaviour from staff is not acceptable. We have reviewed and included evidence in the guideline that states that poor attitudes are a problem and act as a barrier to women accessing care and have made recommendations to address

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						for a variety of good reasons (eg having moved, finding difficulty in getting into the system, high cost of travel, sick children who could not be left, transport difficulties, problems taking a number of small children to the clinic, or justifiable dissatisfaction with services or attitudes of staff). Problems in attendance seem to increase with non-car ownership and in multips with small children. Even when they have telephoned inability to attend, women are sometimes still recorded as late bookers or non-attenders and treated with the same punitive attitudes and made to feel they deliberately put their babies at risk. For non-EU overseas women and asylum seekers there are cost, and access issues. " <i>Did you have problem finding or getting care</i> " is a question that should be asked, and the answers should be added to the data which is collected. Research by Forrester et al describes confrontational style used by social workers with parents and that it is a systemic issue(5) - and this is the picture we are increasingly getting from	staff behaviour and training needs in this respect.

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						in a new row. numerous clients in different areas. We can confirm this by personal observation of meetings by AIMS committee members. The evidence for adverse effects of severe stress in pregnancy on the foetus is now incontrovertible and there is extensive research (e.g.6). Diego et al (7) specifically include "hassles" as one factor reducing fetal growth. Many women in the groups covered in this report will already have other sources of stress. However, fear of losing their children (whether justified or not) is the greatest stress of all, and professionals seem to have no concept of the potential toxicity of their own behaviour. We had expected to see more premature deliveries in such women, but in fact what we are seeing is more post-term pregnancies, as if baby and mother feel the baby is safer in than out - though of course the sample is too small to draw conclusions. <i>We suggest that approaches to</i>	
						the many difficulties some of these women may encounter in their lives should be aimed at reducing stress from external	

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						causes, intervening in ways which do not add to that stress, and certainly not intervening in ways for which there is no proven benefit. It is essential therefore to include feeddback from women as to what they find stressful. Unfortunately when they report professional behaviour and policies as a source of stress, these unpalatable messages are not heard. (1) Gwyneth Lewis.(2004) Why	
						Mothers Die 2000-2002. Chapter 11A. RCOG Press, London. (2) Gwyneth Lewis (2007) Saving Mothers' Lives 2003-5. Reviewing maternal deaths to make motherhood safer. Chapter 12. CEMACH, London (3) House of Commons Children, Schools and Families Committee. (2009) Training of Children and Families Social Workers. Seventh Report of Session 2008- 9 Vol I. (4) Jean Robinson(2009) Memorandum submitted by the Association for Improvements in the Maternity Services Ev 172-Ev 177. House of Commons Children, Schools and Families Committee . Training of	

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						Children and Families Social Workers. Seventh Report of Session 2008-9 Vol II. (5) D. Forrester et al (2008) How do child and family social workers talk to parents about child welfare issues? Child Abuse Review 17(1): 23-25 (6) B.R. Van den Bergh et al (2005) Antenatal maternal anxiety and stress and the neurobehavioural development of the fetus and child: possible mechanisms. A review. Neursci.Biobehav.Rev. (2): 237- 58. (7) M. A. Diego et al.(2006) Maternal Psychological Distress, Prenatal Cortisol, and Fetal Weight. Psychosomatic Medicine 68: 747-753	
SH	Association for Improvements in the Maternity Services (AIMS)	2	Full	1.3.1	10	ENCOURAGING ANTENATAL ATTENDANCES FOR MISUSERS OF SUBSTANCES. Encouragement for this group is similar to that for other groups: to be treated respectfully, not to be further disempowered, and to have the continuous care of a named midwife (and the	Thank you very much for your comment. We agree that there is a need to treat all women, including substance misusing women, with respect and to have continuity of carer. We have recommended both in relation to this group. However, these recommendations are based on low quality evidence from the

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						possibility of changing that midwife without hassle if required) The kind of care given by the Albany group of midwives would have been ideal - with the addition of a trained drugs worker. Dr Gwyneth Lewis wrote in the Confidential Enquiries into Maternal Deaths that if maternity services did not suit the needs of high risk groups, <i>then it was up to</i> <i>the service providers to change,</i> <i>to provide the kind of service they</i> <i>wanted.</i> So far we have seen no sign of this; it has been the stick rather than the carrot, and such reports are increasing in our mailbag. Our clients who are past, or current users of drugs, invariably have other former or current problems. Above all, they want a non-judgmental approach, and often practical help, as well as recognition of the steps they are taking or have taken themselves to improve their health and prospects for their baby. They get labelled, monitored, subjected to testing and surveillance, but where is the real support, care and practical help for people who have had less than their fair share of those things in the past?	United States and it is hoped that by conducting good quality research in the UK further measures that will encourage contact to be maintained can be identified.

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SH	Association for Improvements in the Maternity Services (AIMS)	3	Full	1.3.2	10	PROVIDING INFORMATION TO PARTNERS AND FAMILY MEMBERS TO IMPROVE EARLY ACCESS This is vague, and fraught with problems. What information, and what about consent? We often ask clients whom they have to talk to and rely on, and have sometimes met them with partners/family members. One needs to proceed with caution. Domestic violence may not be revealed - and certainly not at first. With the threat of social service intervention, it is now more often hidden from official eyes by women. Emotional domination and control without physical violence may be less obvious, but is nonetheless a problem - and is rated worse by women than the violence where they co-exist. Violent and dominating partners are often superb manipulators and convincing to outsiders - as a number of clients tell us. Women may want to share part of their history or problem with a relative or partner, but are selective about what, and with whom - and have a right to be -	Thank you very much for your comment. This recommendation for research was meant to find out whether providing such information had the required impact on women accessing care and booking early. The information would be that provided through posters, leaflets etc and would thus only be read by women if they chose to do so. It does not in any way imply that the woman, her partner or family provide information to anyone themselves – it is meant only to apply to information they might choose to access.

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						about this and wish to remain in control of disclosures. Alas social work practitioners seem to lack ethical and practical training and can unwittingly breach those boundaries. We have even seen this deliberately used in order to enlist a relative in "control" to try to diminish the woman's right to make choices for her own medical care. And since we are in long term contact with a number of parents, we know only too well how divulging personal information can cause later repercussions between partners and among the family in future. It can cause splits which lead to long term lack of support and contact long after the social workers have left.	
SH	Association for Improvements in the Maternity Services (AIMS)	4	Full	2.1.	12	BOOKING BY 10 WEEKS TO FACILITATE SCREENING Please note that late booking can be a <b>choice</b> (and women have the right to choose) and it can be a choice made e.g. by multips with extensive previous experience of the services they would receive. Some women choose late booking largely in order to avoid hassle and pressure to have unwanted tests	Thank you for your comment. We agree that choice and respect for the woman's views are paramount. These issues are also detailed on this same page of the guideline in paragraphs immediately preceding the one you refer to here, where it is made clear that services need to be flexible in order to meet the needs of women, that women should be at the centre of care with an emphasis on choice, and that women, their

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						(including ultrasound). Women at risk of carrying a baby with genetic problems (e.g. Tay Sachs) may choose to avoid early booking until it is too late for screening and termination to be an option. In our experience women in the groups covered here are more likely to have their autonomy ignored and their choices not accepted - yet another black mark to be sent to social services. The answer is for every professional to scrupulously treat them as having the same rights as everyone else, and it is essential this NICE guideline should repeat the statement that they have an absolute right to refuse. Consent under duress is not valid - but surprisingly few social workers understand this. You may train the receptionists to "make nicey- nicey", but the first episode of disrespect for autonomy blows it away - and affects the woman's attitude in any subsequent pregnancies. Many of our current complaints centre on one issue: women (especially those deemed higher risk for whatever reason) feel they are increasingly being	partners and families should be treated with kindness, respect and dignity. These principles are reported here from the NICE Antenatal Care guideline as they are considered key components of good care. The woman's right to decline treatment/care is also highlighted in the Antenatal Care guideline. There are legal issues pertaining to the rights of young women aged under 18 years to decline care that mean it is not possible for us to make overarching statements to this effect in the current guideline.

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						treated as containers for the fetus, and a potential risk to it, not as autonomous being with rights of their own, with the staff implying they care about unborn child more than the woman does. This is most deeply resented. Antenatal care should start by caring for and about the mother; this also benefits the child.	
SH	Association for Improvements in the Maternity Services (AIMS)	5	Full	3.2	23	COMMUNICATION HAMPERED BY STAFF ATTITUDES Communication is far too often interpreted as giving out (selected) information and making sure the woman understands it and "complies". There is too little listening, above all listening <i>with a</i> <i>willingness to be changed by what</i> <i>you hear.</i> This is more likely to take place with continuous care by one midwife, as in the Albany practice or independent midwifery care. Communication between agencies should include informing social services (when they really need to be involved), of ethical standards on consent to which health care professionals are expected to adhere by their professional bodies, and that there is no proven evidence of	Thank you for your comment. We agree that communication can be hampered by staff attitude meaning staff are not willing to listen and take on board what the woman is saying. This is represented by the categories listed as bullet points below under "staff - poor attitudes/ judgemental" and may be contributed to by a lack of understanding of the woman's circumstances. The GDG felt very strongly that poor staff attitude towards women with complex social factors needs to be addressed and have recommended training in each of the four population chapters to try to improve staff understanding of the issues faced by women. Codes of professional conduct for health care professionals are in place to provide guidance as to how staff are expected to behave towards clients, including the need to respect

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						benefit for some interventions. Multi-agency involvement means participation by social workers who have no understanding of why women might refuse ultrasound, for example, that many of those offered carry no evidence of benefit, and that in any case women have an absolute right to refuse. Yet we have clients being taken to the Family court solely because they "endangered" their unborn children by exercising their legal and moral right to refuse intervention or tests. Their reasons for doing so are invariably carefully thought out, and show them as caring parents rather than the reverse. However, in the present culture "compliance" is all.	a woman's dignity at all times.
SH	Association for Improvements in the Maternity Services (AIMS)	6	Full	3.3	25	CONSIDER MULTI AGENCY ASSESSMENT USING COMMON ASSESSMENT FRAMEWORK The C.A.F. is increasingly criticised by professionals (e.g. 1) and judges. In our experience from clients' documents we have seen, it encourages viewing the mother and family solely as a series of risk factors, "tramlines" parents on a one-way track whatever new	Thank you very much for your comment. We agree that it is very distressing to hear when systems that have been put in place to aid inter-agency communication and thus more effective and appropriate care have been wrongly used, thereby leading to the opposite. The GDG felt, based on their own experience, that some form of multi-agency needs assessment (such as the Common Assessment Framework) is

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						information they supply, is unbalanced, and results in an understandable sense of hopelessness and wherever possible non-co-operation and concealment of problems for which real help is needed. Again, where is the evidence that this is beneficial - other than to professionals who have the defence that appropriate boxes have been ticked? RESPECT CONFIDENTIALITY BUT BE CLEAR ABOUT WHEN AND WHY INFORMATION MAY NEED TO BE SHARED. It is this very policy, and the doublespeak in this sentence, which is preventing women from using services, or from revealing problems once in the system. They don't have to read Animal Farm to know this is the equivalent of "Four legs good, two legs better". We feel really sad when women share with us accounts of rape or mistreatment which preceded their drugs or alcohol addiction, but which they no longer feel able to discuss with a service which long since ceased to offer confidentiality. (1)S. White et al.2009. The	an appropriate approach to recommend in order to enable different agencies to communicate effectively and work together in planning a woman's care. The CAF can be used as a needs assessment thus enabling carers to carry out comprehensive assessment and thus plan appropriate care. The fact that the CAF is not always used correctly does not indicate an inherent problem with the tool itself but rather may suggest that more training on its use is required, and that staff may need more time to implement it properly. The need for training on multiagency needs assessment has been included in the guideline.

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						descriptive tyrrany of the Common Assessment Framework: technologies of categorization and professional practice in child welfare.	
SH	Association for Improvements in the Maternity Services (AIMS)	7	Full	4.8	47	RECOMMENDATION "OFFERING WOMEN INFORMATION TO HELP OVERCOME FEARS ABOUT THE INVOLVEMENT OF CHILDREN'S SERVICES AND POTENTIAL REMOVAL OF THEIR CHILD" There is a wide variation in local standards and attitudes, but in fact the more women learn - from their own, friends' and consumer groups' information about parents' experiences of social services, the more fears they have. We have seen this many times over at first hand, and their fears of unfair, unsupportive and punitive treatment are all too frequently justified. So what information are you proposing to offer? Only radical change would make a difference, since at present "the atmosphere is accusatory and for this reason, traditional investigations evoke anger, fear and other negative emotions" (2) There is, in fact, evidence from top grade US randomised large	Thank you for your suggestions re evidence pertaining to social work attitudes and approach to care. The evidence base for this guideline and the target audience is health care rather than social care. Whilst we recognise that the guideline also addresses the interface between the two services and encourages close co-ordination and joint working, NICE's remit is to provide guidance to the NHS and as such our recommendations are directed towards health care professionals and health services rather than social services. We have included a research recommendation to investigate methods for encouraging women who misuse substances to maintain contact with antenatal services, and it is hoped that this will go some way to identifying more effective approaches that healthcare professionals can adopt.

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						scale trials with long term follow up that a different, supportive rather than witch-finding, approach to social work brings far better results at no greater cost on which there are numerous publications. (eg. 1, 2) We have continuously campaigned for this to be tried in this country but without effect so far.	
						<ul> <li>(1) L. A. Loman and G. Siegel</li> <li>(Dec. 2006) Extended follow-up study of Minnesota's Family</li> <li>Assessment Response. Final report. Conducted for the</li> <li>Minnesota Department of Human Services. A report of the Institute of Applied Research, St. Louis</li> <li>Missouri.</li> <li>(2) L. A. Loman and G. Siegel</li> <li>(2005) Alternative Response in</li> <li>Minnesota. Findings of the</li> <li>Program Evaluation. Protecting</li> <li>Children - Differential Response in Child Welfare. Vol 20 numbers</li> <li>2 &amp; 3 pp 72-84</li> </ul>	
SH	Association for Improvements in the Maternity Services (AIMS)	8	NICE	General	4	DECISION MAKING "Pregnant women with complex social factors should have the opportunity to make informed decisions about their care and	Thank you very much for your comment. The care outlined in this guideline represents care over and above that outlined in the Antenatal Care Guideline, where a woman's

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						treatment in partnership with healthcare professionals". This does not make clear, unlike other guidelines, that women have the right to make their own decisions about investigation and care - including young teenagers who are Gillick competent. Women especially in these groups find that when they make choices, professionals disapprove of (including social workers who are surprisingly ignorant of NICE guidelines or other professions' codes of ethics) they are threatened with child protection action even when the child is in the womb, has no legal existence and the state has no power over it, to ensure compliance. We see many such cases - including especially when women opt for home birth. We cannot emphasise too strongly <i>that</i> <i>nothing is more likely to deter</i> <i>women from using care, in their</i> <i>current and subsequent</i> <i>pregnancies, than lack of respect</i> <i>for their autonomy.</i> We urge NICE to make their legal and ethical rights clear.	rights to information and to accept or decline screening and treatment are clearly stated. These rights apply to the women in the current guideline, remembering the issue of Gillick competency as you rightly point out. We agree that women's rights to autonomy should be upheld.
SH	Association for Improvements in the Maternity	9	NICE	General	4	"IF THE WOMAN AGREES, FAMILIES AND CARERS SHOULD HAVE THE	Thank you very much for your comment. Although the introduction to the NICE guideline is standard

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	Services (AIMS)					OPPORTUNITY TO BE INVOLVED IN DECISIONS ABOUT TREATMENT AND CARE". No. If she agrees, they could be involved in <i>discussions</i> but the <b>decision</b> is always the woman's. We know only too well, that decisions which are not really the woman's, can result in long term problems, including severe depression, post-traumatic stress disorder, resentment, and future distrust of professionals not only in later pregnancies, but other forms of health care.	text, the developers will be working with NICE to ensure that the text is appropriate for this guideline
SH	Association for Improvements in the Maternity Services (AIMS)	10	NICE	1.4	15	TEENAGERS "Women aged under 20" can include mature woman who are married, in long term partnerships with good accommodation, and schoolgirls below the legal age for consent to sexual intercourse. To put them all into one group where they will be labelled as at "risk" on arrival is potentially disempowering and damaging. In fact Scottish health statistics which can be analysed by age and social class show that teenage mothers in higher income groups are very low risk indeed. The problem is largely because in many societies early pregnancies occur more frequently in those	Thank you very much for your comment. We acknowledge that there are many women aged under 20 who are mature and who will in no way be disadvantaged by being pregnant. This has now been included in the introduction to the guideline. The use of this population as an exemplar group is based upon the CEMACH report (2003-5) "Saving Mothers' Lives" which identified this group as being at higher risk of poor pregnancy outcomes. As you rightly point out these poor outcomes are likely to be related to social disadvantage and poverty and not simply due to young age For younger women/girls within this

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						with lower income and educational levels - and these in themselves are associated with risk. As one of the Growing Up in Scotland Reports showed (1) , those with lower income and education are more likely to distrust, and to avoid using, formal health services, feeling that they cannot trust them, and our contacts suggest this is based on real past experiences. We therefore suggest that approaches which are truly respectful of their autonomy, and are empowering rather than disempowering, are the most likely to bring not only short term, but longer term, trust. Sure Start research has also shown that centres which empowered parents were the most effective in improving parenting (2) We think that the lessons from a study of successful empowering approaches used both in individuals and groups would be most helpful for the "complex social problem" groups in this guideline (3) We think it is quite wrong to see " teenagers" as a group. having "complex social factors" since so often birth (properly	group e.g. aged below 16, other issues are also likely to have an impact, such as those relating to maturity, education and the possible unexpectedness/unpreparedness of the young woman for pregnancy and the birth of a baby. Identifying these needs and how they can bet be met is also within the remit of midwives and other health professional providing antenatal care. We recognise that for this population and that of recent migrants, asylum seekers, refugees and women with little or no English, women within these groups may well not be facing complex social factors and not be vulnerable. However, it is important for midwives and other health professionals to consider that a woman in one of these groups may be facing such problems and suffering stress or anxiety as a result. Individual needs assessment at this point will alert the antenatal carer to what these needs might be and allow a plan of care to be made accordingly. As you rightly point out having a baby can be a

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						supported) proves to be maturing and an incentive to improve their lives. In fact there is a considerable body of research showing this to be so, and it might be helpful to quote it in the guideline. (4) For younger teenagers especially, we approve the OFFER of antenatal care and classes geared specially to their needs - but they should have a choice. Incidentally the Department of Health referral asked NICE to look only at pregnant teenagers who had been brought up in care. How and why did this vanish from the agenda and get replaced by ALL teenagers? (1) Growing Up in Scotland Study. Use of informal support by families with young children (2008) http://www.Scotland.gov.uk/Public ations/2008/03/12110018/0 (2) Research Report NESS/207/fr/024 (2007) Understanding variations in effectiveness amongst Sure Start Local Programmes HMSO (3) Fiona Williams & Harriet Churchill(2006) Empowering	positive experience for a young women (teenager) when this is properly supported – it is ensuring that this proper support is provided that is the focus of this guideline. Following stakeholder consultation on the scope of the guideline it was decided to expand the population from young women who had been brought up in care to teenagers generally as the latter group is poorly represented in health care research, thus severely restricting the evidence base for the guideline.

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						parents in Sure Start Local Programmes. HMSO (4) Simon Duncan, Rosalind Edwards, Claire Alexander (eds)(2010) Teenage Parenthood: What's the problem? Tufnell Press.	
SH	Association for Improvements in the Maternity Services (AIMS)	11	NICE	1.3	13- 15	MIGRANTS, ASYLUM SEEKERS AND REFUGEES may arrive in late pregnancy. When service is under pressure busy midwives often, understandably, resent this extra workload and see them as demanding and freeloaders, as midwifery contacts tell us. One of our English speaking Asian clients arrived at a London hospital in labour and was not just unkindly but punitively treated. In fact she had fled Pakistan because she feared murder by in-laws for inadequate dowry: a sister-in-law had already been killed for that reason, and no police action had followed. Staff should be told that such women may be traumatised, and are certainly stressed .INTERPRETERS Family members should NEVER be used as interpreters. The latest Confidential Enquiry into Maternal Deaths reports that 5 of the 19	Thank you very much for your comment. We are very sorry to hear that care received by migrant women can fall so far short of what is expected. The guideline recommends that healthcare professionals be provided with training on the psychological needs of migrant women, this would include recognition of the stress that these women may be experiencing. We have now added to the recommendation on use of interpreters that these should not be partners or family members. The systematic reviews undertaken to inform the guideline focussed on specific questions targeting access and barriers to antenatal care, maintaining contact, plus additional consultations, support and information needed in order to improve pregnancy outcomes. Wider questions about needs and problems faced by migrant women would

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						women who were murdered could not speak English and the husband had been the interpreter.(1) Anyone brought in to interpret should sign a strict confidentiality agreement (with penalties attached) , and the woman must also be assured of this. There is often well-founded fear of confidential details circulating in immigrant communities. Guidelines to staff should include much more information about needs and problems of these women, and we suggest a study of the Dublin study of Kennedy and Lawless, who outline many problems in ante- natal, intrapartum and post- partum care. (1) Gwyneth Lewis (2007) Saving Mothers' Lives. Reviewing maternal deaths to make motherhood safer - 2003-2005. CEMACH, London. Chapter 13. (2) Patricia Kernnedy & Jo Murphy-Lawless. (2000) The maternity care needs of refugees and asylum-seeking women: a research study conducted for the Women's Health Unit, Northern Area Health Board. University College,	require different review questions which lie outside the scope of the guideline.

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SH	British Dietetic Association	1	NICE	General	Gene ral	Dublin. We feel this version presents the guidance in a clear manner.	Thank you very much for your supportive comment
SH	British Dietetic Association	2	NICE	Introducti on	Pg 4 Wom an centr ed care	Add into 2 <sup>nd</sup> para 'non- judgemental'.	Thank you very much for your comment. Although the introduction to the NICE guideline is standard text, the developers will be working with NICE to ensure that the text is appropriate for this guideline
SH	British Dietetic Association	3	NICE	Key Priorities	7	In section re migrants add in 'provision of interpreters'.	Thank you very much for your comment. The guideline development group are asked to choose 10 key recommendations through consensus voting. Following stakeholder consultation the group were given theopportunity to revise this list of priorities but felt they were happy with their original list.
SH	British Dietetic Association	4	NICE	1.1.2	10	Add in training for non clinical staff such as receptionists.	Thank you for your comment. Whilst we have made a recommendation that non-clinical staff should receive training on sensitive communication, we did not feel that it was necessary for them to receive specific training on documents such as CAF
SH	British Dietetic Association	5	NICE	1.1.5	11	Add in 'non-judgemental manner'.	Thank you very much for your comment. We have included the wording that you suggested.
SH	British Dietetic Association	6	NICE	1.3.1	13	Add in non clinical staff such as receptionists.	Thank you very much for your comment. The development group felt that the bullet points in this recommendation apply specifically to healthcare professionals and would not be appropriate for non-clinical

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SH	British Dietetic Association	7	NICE	1.3.3	13	Commissioners should ensure funding is available and used for interpreting provision.	staff Thank you for your comment. Since provision of interpreters is a recommendation within this guideline it would be hoped that commissioners would ensure this service is provided.
SH	British Dietetic Association	8	NICE	1.3.13	15	This section needs to state more strongly that an interpreter should be used rather than offered. Should also state that it is recommended not to use family members or partners and that children should not be used.	Thank you very much for your comment. We have amended the recommendation to say "provide" rather than "offer", and have specified that partners and family members should not be used as interpreters
SH	British Dietetic Association	9	NICE	1.4.5	17	Add in after other benefits 'such as Healthy Start'.	Thank you very much for your comment. The development group felt that as the different services available (such as Healthy Start) may change over the lifetime of the guideline, it was best not specify them by name.
SH	British Maternal and Fetal Medicine Society	1	Appen dix E	Q2	37	In the "Findings" column, there is a missing colon which alters the meaning. Should read 'Group 3: 7.1%'	Thank you very much for your comment, this error has now been corrected
SH	British Maternal and Fetal Medicine Society	2	Full	general	gene ral	Overall, lack of evidence to guide practice, but very helpful summaries of what research (including qualitative studies) have been done. Conclusions and recommendations are appropriate and helpful throughout.	Thank you very much for your supportive comments.
SH	Care Quality Commission	1	NICE	1.1.1	10	The suggested items for inclusion is really data collection rather than	Thank you very much for your comment. We have now split this

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						audit– it's not clear how this information will be managed locally and whether numbers will be sufficient to be statistically viable. There should also be something about data collection/audit by providers who will need to identify whether local policies/practice are effective -for example if providers have instigated specialist midwives who focus on women with complex needs – local audit could help to determine the effectiveness of these posts	recommendation. The first recommendation is now for data collection regarding the numbers of women in all vulnerable groups accessing services. The subsequent recommendation is then an audit of services. We agree that data collection should enable providers to determine effectiveness of services. It is anticipated that local service providers will be able to use the audit data identified in the recommendation to evaluate their services; this will include the effectiveness of any changes to services.
SH	Care Quality Commission	2	NICE	1.1.6	11	For women with complex social factors – they may require a 1:1 consultation with a variety of different healthcare professionals, depending on individual circumstances – therefore the wording of the current statement maybe misinterpreted, confusing or prohibitive for service users – section 4.5 page 24 states 'the provision of tailored antenatal care may influence improved outcomes' – this could be cross referenced with section1.1.6 to provide greater clarity.	Thank you very much for your comment. We agree that this recommendation was unclear and have now explained the reason for conducting the one-to-one appointment.

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SH	Care Quality Commission	3	Gener al	General	Gene ral	Little mention of the involvement of partners/families/significant others particularly in antenatal care. Where it is stated that care will be provided without parental/partner input – reference could be made to wider family or advocate involvement in order to support the women.	Thank you very much for your comment. Although we did specifically search for evidence relating to the involvement of partners and families, none was found. Without this evidence the group did not feel able to make any specific recommendations about their involvement. We have now included a research recommendation to discover whether involving partners and families improves access to and contact with antenatal services
SH	Care Quality Commission	4	NICE	1.3.13	15	Use of interpreters – providers should be reminded to discourage using family members as interpreters for safeguarding reasons but also to ensure the accuracy of translating accurate 'medical' information for the women.	Thank you very much for your comment. We have now added a sentence to this recommendation to clarify that partners and family members should not be used as interpreters
SH	Care Quality Commission	5	NICE	1.4.1	15	There is no reference to the involvement of teenage partners in antenatal care –the needs of teenage fathers/partners should also be taken into consideration when planning delivery of antenatal care services.	Thank you very much for your comment. Although we specifically searched for evidence relating to the involvement of partners and families in antenatal care, we were unable to find any which met the inclusion criteria for the evidence reviews. As a result, the development group did not feel able to make specific recommendations for this group. We have now included a research recommendation to address this issue

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SH	Care Quality Commission	6	NICE	4.3	22	The last paragraph makes reference to the need for 'routinely collected pregnancy data' – the first phase of the maternity minimum dataset is planned for release in April 2011 – this should begin to address data requirements.	Thank you very much for your comment. We agree that the standardisation of data collection using the maternity minimum dataset will begin to address these issues.
SH	Centre for Maternal and child enquiries	1	Full	General	Gene ral	There were concerns at the recent Implementation Planning Meeting that the recommendations within this guideline are not based on direct evidence and that it is not known whether the suggested interventions are associated with improved pregnancy-related outcomes. It was felt there was a strong need to obtain evidence from the UK to determine whether the recommended services and care are associated with important outcomes. National-level audits that also obtain information on pregnancy- related outcomes could provide the necessary evidence. Organisations experienced in obtaining national-level maternity data and conducting national-level audits could be utilised to carry out this work.	Thank you for your comment. We agree there is a paucity of UK evidence to support the guideline recommendations, although GDG consensus was firmly held that the recommendations made based on US evidence and GDG experience of UK practice would bring about the anticipated positive outcomes. We agree that there is an urgent need to conduct ongoing audit of any service change based on this guideline, particularly in relation to improved maternal and neonatal outcomes, hence the overarching recommendation asking that this be carried out.
SH	Department of Health	1	Full	6	6	("Organisation of services",	Thank you very much for your

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						first bullet, third sub-section): Could you please confirm whether this should be as stated, that is, antenatal appointments in line with NICE antenatal care guidance, or that plus the minimum number of appointments planned at the 12 week assessment.	comment. This should be as stated i.e. antenatal appointments in line with the NICE guidance. It was felt that this would be a more useful audit standard as it will then be a consistent measure across England and Wales.
SH	Department of Health	2	Full	6	6	("Organisation of services", first bullet, fourth sub-section): Could you please define the term 'significant'.	Thank you very much for your comment. By 'significant', we mean morbidity that has a lasting impact on either the woman or the child. We have added this to a footnote for clarity.
SH	Department of Health	3	Full	6	6	("Information and support for women", first bullet): Could you please verify whether 'booking appointment' actually means 'at first access'.	Thank you for your comment, we have amended this recommendation to say "at first contact with any healthcare professional"
SH	Department of Health	4	Full	6	6	("Information and support for women", first bullet, second sub-section): Could you please consider amending the word 'advice' to 'services'.	Thank very much for your comment, we have changed the wording as you suggest
SH	Department of Health	5	Full	7	7	("Service organisation", first bullet): Could you please consider adding to the sub- section on integrating care plans; sharing information with the women's permission.	Thank you very much for your comment. The emphasis of this recommendation was on ways to effectively coordinate care and the development group did not feel it was necessary to refer to sharing information with the woman's

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							permission here. It has been addressed as one of the overarching recommendations.
SH	Department of Health	6	Full	7	7	("Information and support for women", first bullet): Could you please consider adding 'reception centres' to the second sub-section.	Thank you for your comment. We have added reception centres to this recommendation
SH	Department of Health	7	Full	7	10	("Organisation of services", first bullet, first sub-section): Could you please verify whether, instead of 12+6 it should be 'a completed health and social care assessment of needs, risks and choices'.	Thank you very much for your comment. We do mean 12 +6. The group felt that booking by this time was a standard measure of early booking and thus was a useful audit standard
SH	Department of Health	8	Full	7	10	("Organisation of services", first bullet, second sub- section): We consider that it is alright, but could be according to plan of care in hand-held records (please see earlier point).	Thank you very much for your comment. This should be as stated i.e. antenatal appointments in line with the NICE guidance. It was felt that this would be a more useful audit standard as it will then be a consistent measure across England and Wales.
SH	Department of Health	9	Full	7	10	("Organisation of services", second bullet): Could you please clarify how the satisfaction of women will be measured	Thank you for your comment. It was agreed that the development of national audit tools falls outside the scope of this guideline. Satisfaction can be measured using locally developed tools or by nationally developed tools e.g. from the Audit Commission.
SH	Department of Health	10	Full	1.1.3	11	For women who do not have a	Thank you very much for your comment. We have amended the

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						booking appointment 'at any contact with health or social care professional'.	recommendation to refer to any contact with a healthcare professional. We are not able to address social care professionals directly in the guideline as it is written for NHS staff
SH	Department of Health	11	Full	1.1.3	11	(Second bullet): Could you please consider amending the word 'advice' to 'services'.	Thank you very much for your suggestion. We agree that "sexual health advice" was unclear and have amended the recommendation to say "offer referral to sexual health services"
SH	Department of Health	12	Full	1.1.7	11	Could you please consider adding 'midwife' to the list of contacts shown.	Thank you for your comment. In this overarching section the GDG felt it appropriate to recommend the use of a 24 hour telephone number manned by a healthcare professional. This would usually be a midwife in the examples given but it was felt not appropriate to be prescriptive that this should always be the case. Recommendations including contact with a midwife are made for particular groups where the evidence showed that provision of continuity of carer and a named midwife was particularly useful e.g. for teenagers and substance misusers.
SH	Department of Health	13	Full	1.2.2	12	(First bullet): In our view, there is a need to explain how we will get integrated care plans,	Thank you very much for your comment. The group felt that the decision about how best to integrate

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						that is, encouraging all agencies to link in the woman's hand-held notes.	care plans should be taken at a local level and be based on the services available. We recognise that this might include encouraging agencies to link in the woman's hand-held notes.
SH	Department of Health	14	Full	1.3.1	13	(First bullet): We consider that "Medact" is a good example.	Thank you very much for your comment. The group did not want to name specific organisations in the recommendations as potentially these might change within the lifetime of the guideline. However, we may be able to include reference to Medact in the understanding NICE guidance document which accompanies the guideline
SH	Department of Health	15	NICE	1.3.7	14	Whilst this is obvious, could you please clarify whether there is a training package to support this. Could you please also clarify whether 'specific social' includes Home Office rules and processes etc.	Thank you very much for your comment. The GDG did not have a specific training package in mind when developing this recommendation, rather they felt that the content of the training would be determined at a local level. This training could include information about the Home Office rules and processes.
SH	Department of Health	16	NICE	1.3.9	14	(Second bullet): Could you please consider the inclusion of faith groups and centres.	Thank you very much for your comment. We have now included the settings you suggest in the recommendation
SH	Department of Health	17	Full	1.3.11	15	Could you please consider replacing the word 'discuss' with the term 'help her	Thank you for your comment. It was felt that the term "help her understand" could be considered patronising and that the word discuss

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SH	Department of Health	18	Full	General	15	understand'. Regarding communication with women who have difficulty reading or speaking English, could you please consider the inclusion of an additional bullet to say specifically, 'not to use family members to interpret'.	was more appropriate Thank you very much for your comment. We have now included a sentence to the recommendation to indicate that partners and family members should not be used
SH	Department of Health	19	Full	1.3.14	15	Could you please consider amending the text 'to repeat the information to ensure she has understood it correctly' to read 'her understanding of what she has been told.'	Thank you very much for your comment. We have amended this recommendation as you suggested
SH	Department of Health	20	NICE	1.4.1	15	Could you please consider the addition of a bullet, relating to the involvement of partners and fathers.	Thank you very much for your comment. Sadly, there was no evidence identified which related specifically to partners and fathers for any of the populations. The group developed a research recommendation to investigate the effect of involving partners and families in antenatal care
SH	Department of Health	21	NICE	1.4.4	16	With regard to 'partner input', this does not appear to acknowledge that the partner might also be a teenager. Could you please clarify this.	Thank you very much for your comment. This recommendation has been amended to remove reference to providing consultations without partner input, as it is now an overarching recommendation for all four populations. It was not felt necessary to refer specifically to the fact that the partner might also be in

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							the same social situation as the woman,
SH	Department of Health	22	NICE	1.4.6	17	Could you please consider replacing the word 'carer' with 'midwife'.	Thank you very much for your comment. We have changed the wording as you suggest
SH	Department of Health	23	Full	2.7	17	Regarding the section on women who experience domestic abuse, we feel that this section appears to be condescending, as if it has been written by professionals, and it is what they think women subject to domestic violence want and need. Could you please confirm whether users and/or victims have been consulted.	Thank you very much for your comment. The recommendations in this section, (and the paragraph at the beginning which highlights the difficulties women experiencing domestic abuse may have with accessing antenatal care), were derived from the evidence reviewed. The development group considered all of the barriers to care which had been identified in the evidence and identified those in this section as being particularly key. Many of the studies reported here contain views and experiences of women who experience domestic abuse. Although the group did not contain a lay member specifically from a victim support organisation, it did contain two lay members who provided a great deal of input into this section. We acknowledge, however, that the section has also received input from professionals (including midwives, obstetricians and social workers) who, along with these lay members, have used the evidence reviewed to make recommendations that they believe reflect what women who

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							experience domestic abuse want and need from antenatal services.
SH	Department of Health	24	NICE	1.5.5	19	Could you please consider replacing the word 'carer' with 'midwife'.	Thank you very much for your comment. We have changed the wording as you suggest
SH	Department of Health	25	Full	2.7	21	Regarding the final sentence, we agree that this is important if the guideline is to be implemented.	Thank you very much for your supportive comment
SH	Department of Health	26	Full	4.2 2 <sup>nd</sup> paragrap h	21	Regarding the final sentence, this appears to omit the rationale that a plan of care is developed, setting out the number of visits, and with whom and what additions need to be made	Thank you very much for your comment. We have amended this paragraph to include the rationale that you highlighted.
SH	Hertfordshire Partnership NHS Foundation Trust	1	NICE	1.1.1	10	In the recent confidential enquiry in to maternal deaths (Saving Mothers Live 2003- 2005) majority of pregnant women with complex social factors did not get care from integrated drug addiction services or were poorly managed with significant interagency communication failures. Similarly we highlighted ineffective interagency liaison in addiction services in a recent audit in	Thank you very much for your comment. We agree that it would be valuable to have information about the effectiveness of interagency communication. We have highlighted this to the implementation team at NICE who will consider using this within the implementation support tools for the guideline

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						Hertfordshire. NICE should recommend organisations to include audits on quality of interagency liaison in managing women with pregnancy and complex social factors.	
SH	Hertfordshire Partnership NHS Foundation Trust	2	NICE	1.2.3	12	Training should encourage professional to develop special interest in women with complex social factors including women who misuse substances. Training should be specifically targeted to deliver skills in assessment of drug and alcohol misuse/dependence and screening of co-morbid perinatal mental health conditions.	Thank you very much for your comment. The group felt that the assessment of drug and alcohol dependence should be conducted by the specialist drug service (following initial screening). It was not necessary to recommend training on screening for perinatal mental health conditions as this information is already contained within the NICE Antenatal and postnatal mental health guideline CG45
SH	Hertfordshire Partnership NHS Foundation Trust	3	NICE	1.2.2	12	It is vital to have a named key worker from each agency involved (e.g. named worker from drug misuse services) to ensure effective liaison between agencies.	Thank you very much for your comment. The recommendations include suggestions about jointly developed care plans, co-located services etc. as examples, as these were specifically identified from the evidence. This would not preclude the use of named key workers within agencies.
SH	Hertfordshire Partnership NHS Foundation Trust	4	NICE	1.2.4	12	At first contact all women should be effectively screened for co-morbid psychiatric	Thank you very much for your comment. Screening for psychiatric disorders is not within the scope of

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						disorders; screening programmes should be implemented in each service where women with complex social factors could present.	this service guidance. Antenatal and postnatal screening for co-morbid psychiatric disorders is recommended for all women (including women with complex social problems) in the NICE Antenatal and Postnatal Mental Health guideline (CG45, 2007).
SH	Maternity Action	1	Full	5.3	57	These comments relate to the section: 'Immigration status' There is UK evidence of immigration status as a barrier to accessing maternity care, as women who are not considered to be 'ordinarily resident' are subject to charging for NHS maternity care. Women who are subject to charging are amongst the most vulnerable women in the UK, including trafficked women and refused (failed) asylum seekers. Relevant reports and papers include: Project London, 2007, <i>Project London: Report and recommendations,</i> London: Medecins du Monde http://www.doctorsoftheworld.org.uk/lib/docs/104524-	Thank you very much for your comments; we agree that women subject to charging are a particularly vulnerable group of women. We have now made a recommendation that healthcare professionals should receive training about the entitlements of recent migrants, asylum seekers and refugees to care to ensure that they are able to understand these entitlements and that they are able to communicate them effectively to these women. The GDG considered your suggestion of referral to an overseas visitor manager but agreed that they did not want to be that specific in the recommendation, as they had not considered evidence relating to overseas visitor managers

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						report2007light.pdf Joint Committee on Human Rights, 2007, <i>The treatment of</i> <i>asylum seekers: tenth report of</i> <i>session 2006-7, volume 1,</i> London: The Stationery Office Medact, 2007, 'Submission to the Joint Parliamentary Committee on Human Rights inquiry into treatment of asylum seekers', London: Medact http://www.medact.org/reachin g_out_home.php	
						Kelley, N. & Stevenson, J., 2006, <i>First do no harm:</i> <i>denying health care to people</i> <i>whose asylum claims have</i> <i>failed</i> , London: Refugee Council <u>http://www.refugeecouncil.org.</u> <u>uk/Resources/Refugee%20Co</u> <u>uncil/downloads/researchrepor</u> <u>ts/Healthaccessreport_jun06.p</u> <u>df</u> People's Health Movement –	

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						<ul> <li>UK, 2009, 'Shadow</li> <li>Submission on the Right to the</li> <li>Highest Attainable Standard of</li> <li>Health in the UK for the</li> <li>International Committee on</li> <li>Economic, Social and Cultural</li> <li>Rights</li> <li>http://www2.ohchr.org/english/</li> <li>bodies/cescr/cescrs42.htm</li> <li>Maternity Action continues to</li> <li>receive phonecalls from</li> <li>individual women who are</li> <li>unable to access maternity</li> <li>care, and their advisors.</li> <li>Some examples are: <ul> <li>A woman who was</li> <li>subject to charging was</li> <li>deterred from seeking</li> <li>care by requests for</li> <li>payment which she and</li> <li>her husband could not</li> <li>afford to pay. She</li> <li>received no antenatal</li> <li>care. (Nov 2009)</li> </ul> </li> <li>A woman was unable</li> <li>to obtain GP</li> <li>registration because of</li> </ul>	

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			mem				
						they cannot afford; and who are refused GP registration because of their immigration status.	

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						Department of Health regulations and guidance states that all maternity care is immediately necessary so should not be refused or delayed because of inability to pay in advance. As outlined in the reports and papers noted above, there is widespread failure to follow this policy. To address this barrier to access, maternity services should review their care pathways to incorporate charging policies. Specifically, they should include referral to Overseas Visitor Managers (or similar) where appropriate. They should state that there is no delay in allocating an appointment with a midwife while charging issues are being resolved. Women should receive clear and accurate information about their entitlement to maternity care. There should be active follow-up for women who do not attend appointments.	
						Trusts may wish to refer all	

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						women subject to charging to a community midwife or specialist midwife. Information on entitlement to care provided by the Department of Health is complex and difficult to understand. It is not suitable for anyone with limited English language skills. The Department of Health guidance covers all aspects of healthcare and it is difficult to find the text relating to maternity. This is an important issue as the rights in relation to maternity care differ to most other forms of care. Women need clear information about their entitlement to maternity care, including their entitlement if they are unable to pay the charges.	
SH	Maternity Action	2	NICE	1.3.8	14	As discussed above, immigration status is a barrier to access and women from abroad. The guidelines should recommend strategies to address the barriers to access	Thank you very much for your comments, We have now made a recommendation that healthcare professionals should receive training about the entitlements of

Туре	Stakeholder	Order No	Docu ment	Section No	Page No	<b>Comments</b> Please insert each new comment in a new row.	<b>Developer's Response</b> Please respond to each comment
						posed by immigration status and charging policies. Women from abroad require clear and accurate information about charging policies and their entitlement to NHS care. The guidance recommends that women be offered Department of Health information on entitlement to care (1.3.8). Department of Health information is unsuitable for anyone with limited English language skills and individuals with good English skills may find it difficult to interpret. Written information specifically relating to maternity care should be produced and this should articulate women's entitlement to care even if they are unable to pay the charges. Ideally, this information should be made available in different languages. Maternity Action has produced an information sheet, 'Entitlement to NHS maternity care for women from abroad', which is available at: http://www.maternityaction.org.	recent migrants, asylum seekers and refugees to care to ensure that they are able to understand these entitlements and that they are able to communicate them effectively to these women. The GDG considered your suggestion of referral to an overseas visitor but agreed that they did not want to be that specific in the recommendation, as they had not considered evidence relating to overseas visitor managers. We will recommend to NICE that details of link for the Maternity Action information sheet are included in the "Understanding NICE guidance" which accompanies the guideline

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						uk/sitebuildercontent/sitebuilde rfiles/entitlementtonhscarenov 09.pdf In addition to the provision of information, we recommend that the guidance state that maternity services review their care pathways to incorporate charging policies. Specifically, they should include referral to Overseas Visitor Managers (or similar) where appropriate and state that there is no delay in allocating an appointment with a midwife while charging issues are being resolved. There should be follow-up for women who do not attend appointments. Trusts may wish to refer all women subject to charging to a community	
SH	Maternity Services Action Group- Scottish Government	1	Full	General	Gene ral	midwife or specialist midwife. The draft guidance is a very helpful distillation of the available literature as it pertains to the high risk groups detailed within the guidance.	Thank you very much for your supportive comment.
SH	Maternity Services Action Group-	2	Full	General	Gene ral	The guidance makes clear recommendations for service	Thank you very much for your supportive comment.

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	Scottish Government					planning and organisation- being explicit about assumptions in the absence of evidence.	
SH	Maternity Services Action Group- Scottish Government	3	Full	General	Gene ral	We suggest that active outreach to engage with vulnerable women and women from minority cultures including those who are asylum seekers and refugees needs more emphasis. Active outreach is the means to early intervention, especially for individuals and groups who are reluctant to make contact with statutory services. The guideline talks about the need to use all types of media to communicate with women from these groups and that is welcome. But many of these women are hard to reach, often not by choice but force of circumstances, and it is necessary for community staff to be proactive and seek them out. This will involve developing good networks, often on a local patch basis, with workers in other agencies who may come into contact with these women in other contexts.	Thank you very much for your comment. The evidence reviewed for this topic relating to active outreach was equivocal and so the group did not feel that they could make a recommendation about it.
SH	Maternity Services Action Group- Scottish Government	4	Full	General	Gene ral	Whilst recommendations re service planning or organisation are often explicit- there is a lack of detail when the issue of workforce development or training is dealt with. Assumptions and/or	Thank you very much for your comment. We disagree and feel that the guideline contains a series of recommendations relating to training staff about the specific needs of each group of women. Where findings

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						evidence re the effectiveness of inequalities sensitive, person centred care could and should have been dealt with more thoroughly.	from the review enabled us to make detailed recommendations, this was done. However, the evidence was not always strong enough to allow this.
SH	Maternity Services Action Group- Scottish Government	5	Full	General	Gene ral	The need for service planners to raise awareness about the needs of vulnerable pregnant women with wider NHS services and with partner organisations, both statutory and voluntary, who may be in contact with them, should be included in the guideline. Local authority services and other statutory bodies. All public service staff need to be aware of how they can help women overcome any fear or reluctance they may have to access maternity services when appropriate	Thank you for your comment. We agree that it is vitally important that service planners work with providers to raise awareness of the needs of vulnerable women and how women can be encouraged to access and use maternity services. It is very much hope that the implementation of this guideline will achieve just that and NICE will provide an implementation tool kit to support this work.
SH	Maternity Services Action Group- Scottish Government	6	Full	General		It would be helpful if the guidance made stronger links to issues of parenting and the need for antenatal services to be assessing for parenting and attachment risks and indeed programmes for parenting support.	Thank you very much for your comment. Postnatal interventions are outside the scope of this guideline and assessment for parenting support was not considered as a clinical question.
SH	Maternity Services Action Group- Scottish	7	Guida nce Summ	1 -1.3.2	1 -11	The Guidance summary is very helpful and useful – likely to be so for service planners and	Thank you very much for your supportive comment

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	Government		ary			managers	
SH	Maternity Services Action Group- Scottish Government	8	Econo mic Model	8	117 Last para grap h	The economic model is clearly defined and the assumptions clearly stated. The phrasing of the sentence in the last paragraph of this sections should be revised. Although practice may be changing regarding observation in neonatal facilities, there will still be a requirement for level 3 care for those infants with severe consequences. If the proportion of infants requiring neonatal intensive care is not predicted to change as a result of specialist care then the sentence is not required. If the proportion is likely to change then an assumption should be made and built in to the model	Thank you very much for your comment. It is difficult to use a model like this where there was so little data available. We don't know how many babies require intensive care for neonatal abstinence syndrome, and we don't know if improved access to antenatal care would have any effect on this number. But as neonatal intensive care is expensive it was felt that there needed to be an explanation of why this cost has not been included.
SH	National Childbirth Trust	1	Full	General	Gene ral	NCT welcomes the opportunity to provide comments on this important guidance.	Thank you
SH	National Childbirth Trust	2	NICE	Intro	3	Suggest change to 'This guidance is of relevance to' rather than 'applies to'. Due to the sensitivity of grouping and labelling women with a wide variety of complex social factors together it would perhaps be better to refer to there being a particular focus on four particular, and diverse, groups	Thank you very much for your comment. Although the introduction to the NICE guideline is standard text, the developers will be working with NICE to ensure that the text is appropriate for this guideline

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SH	National Childbirth	3	NICE	Intro	3	'exemplars'. Full stop missing at end of	Thank you this has been added.
SH	Trust National Childbirth Trust	4	NICE	Intro	4	sentence in last paragraph. The use of the word 'appropriate' at the top of the page could be construed as a choice that is appropriate as judged by the woman's healthcare provider. Instead of 'appropriate' recommend change to 'informed decisions' which would be more clear.	Thank you very much for your comment. Although the introduction to the NICE guideline is standard text, the developers will be working with NICE to ensure that the text is appropriate for this guideline
SH	National Childbirth Trust	5	NICE	Intro	4	2 <sup>nd</sup> paragraph after heading: 'woman centred care' is particularly good, highlighting early on the myriad, individual influences on each woman and how they need to be taken into account. We welcome this acknowledgement.	Thank you very much for your supportive comment
SH	National Childbirth Trust	6	NICE	Intro	5	Would be good to also include that information needs to be accessible to parents with low levels of literacy.	Thank you very much for your comment. Although the introduction to the NICE guideline is standard text, the developers will be working with NICE to ensure that the text is appropriate for this guideline
SH	National Childbirth Trust	7	NICE	Intro	5	Last 2 paragraphs seem a little disjointed. They could be one paragraph.	Thank you very much for your comment. Although the introduction to the NICE guideline is standard text, the developers will be working with NICE to ensure that the text is appropriate for this guideline
SH	National Childbirth	8	NICE	1.1.0	6	First point on the list at the top of	Thank you very much for your

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	Trust			and 1.1.1	and 10	the page has 'the' missing. Should read 'The percentage of women in each of THE four groups'	comment, we have amended the wording accordingly
SH	National Childbirth Trust	9	NICE	1.1.1	6	How will women 'who have difficulties reading or speaking English' be measured?	Thank you very much for your comment. It was felt that this information is commonly collected by asking women, either directly or through an interpreter
SH	National Childbirth Trust	10	NICE	1.1.1	6	Do clearer recommendations need to be made about when and how to collect information about migrant / refugee / asylum status?	Thank you very much for your comment. It was felt that this is information which is collected as standard at booking and so it was not necessary to add more detail to the recommendation.
SH	National Childbirth Trust	11	NICE	1.1.1	6	Percentages of women who experience abuse should be changed to 'women who <b>disclose</b> experience of domestic abuse' – in acknowledgement that some women will not have opportunities to disclose, or will not disclose. Or would women who have not disclosed abuse but are suspected to be experiencing abuse also be included in this group?	Thank you very much for your comment. The recommendation has now been amended to refer to all groups of women with complex social factors and does not make specific reference to any of the four exemplar groups (including women experiencing domestic abuse). We recognise that for the purposes of the audit, this would only include women who had disclosed experience of domestic abuse.
SH	National Childbirth Trust	12	NICE	1.1.1	6	'The satisfaction of women in each of the four groups'. Should further guidance on how to evaluate satisfaction be give? Would standard measures to be used by all service providers need to be used in order to allow for	Thank you very much for your comment. We recognise that the evaluation of satisfaction can be difficult. Use could be made of national audits conducted by the National Audit Commission. It is hoped that the NICE implementation

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						comparisons to be made? We welcome collection of this data but it is complex so requires further guidance. Lower response rates would be expected from women with complex social factors so the data collection methodology would need to be designed with this in mind to maximise responses from these women and to facilitate their participation – considering language, literacy, disability etc.	advice that accompanies the published guideline, will include suggestions and examples for how this evaluation could be conducted.
SH	National Childbirth Trust	13	NICE	1.1.1	6	'Consider initiating' Could this be made stronger? The lack of multi-agency working and information sharing is a common finding in critical incident enquiries etc. If 'consider' has been chosen because the guidance is for all health professionals and this would be more of a role for some than others, this is a problem with the format which effects the whole document. If recommendations, or the strength, of recommendations depends on the exact audience then specific recommendations should be made for specific health professionals / audiences.	Thank you very much for your comment. The strength of the recommendation is determined by the strength of the underlying evidence. As there was not much good quality evidence identified relating to multi-agency working, the group felt that they should only recommend that multi-agency working be "considered"
SH	National Childbirth Trust	14	NICE	1.1.1	6	Would it also be possible to audit the number of women who are followed up my a midwife / health care provider if they fail to attend	Thank you very much for your comment. We have now included an additional audit item to investigate the number of appointments missed

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						for an appointment? Follow up is recommended by CEMACH (CEMACE) in the Saving Mothers' Lives reports as a way of promoting regular access to antenatal care for vulnerable women.	which require follow-up.
SH	National Childbirth Trust	15	NICE	1.1.1	6	'significant morbidity' – how is this defined and should a definition be included here?	Thank you very much for your comment. By 'significant', we mean morbidity that has a lasting impact on either the woman or the child. We have added this to a footnote for clarity.
SH	National Childbirth Trust	16	NICE	1.1.6	6	Could this be stronger? The DH and CEMACH (now CEMACE) recommend that all women are seen at least once during their pregnancy on a one- to-one basis. Just 'offering' it may make it difficult for a woman who is experiencing abuse to accept as in that situation, opting-out would raise more suspicion than opting-in in the eyes of an abuser, for example. It would be helpful to make the reason for this explicit, ie. to facilitate routine enquiry for domestic abuse (and possibly) to share other personal information or concerns.	Thank you very much for your comment. We agree that it would be helpful to make the reason for the one-to-one appointment clear and so have reworded the recommendation to make this more explicit. We have also strengthened the recommendation to say "provide" rather than "offer"
SH	National Childbirth	17	NICE	1.2.2	7	or concerns. Reference should be made in this	Thank you very much for your

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	Trust					paragraph to working and sharing information as necessary with social services (given CEMACH Saving Mothers Lives' findings and recommendation about this group).	comment, we have now made specific reference to social services in the recommendation
SH	National Childbirth Trust	18	NICE	1.2.2	7	'co-locating services' – does this refer to services to address holistic needs – including housing etc as well as health services? If yes, should be made explicit.	Thank you very much for your comment. This recommendation could apply to any kind of services and the GDG felt that it was better to leave the wording open to reflect this
SH	National Childbirth Trust	19	NICE	1.2.3	7	Strongly agree re training for ancillary staff too (ie receptionists) as anxieties are so high that every contact counts, including how they are greeted as they enter. There is a definite need to ensure that the initial, and subsequent, contact of the woman with antenatal services is sensitive and welcoming and not frightening or judgmental.	Thank you very much for your supportive comment.
SH	National Childbirth Trust	20	NICE	1.3.9	7	Would be good to also recommend audio formats.	Thank you very much for your comment. We have included audio formats into this recommendation as you suggest
SH	National Childbirth Trust	21	NICE	1.3.9	7	When referring to languages, good to highlight the importance of verbal information (provided by professional interpreters) and written information, also highlighting that not everyone is literate in their first language. We	Thank you very much for your comment. The recommendation highlights the importance of providing information in a wide variety of formats. The group discussed the possibility of recommending

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						would welcome here a strong recommendation about providing access to professional interpreters.	professional interpreters but felt that it was not appropriate – they agreed that it would be reasonable for other healthcare professionals in the hospital to perform the role of an interpreter where applicable. We have now clarified that interpreters should not be partners or family members
SH	National Childbirth Trust	22	NICE	1.4.3	8	See comment about 'consider', formatting and different recommendations for different professionals, as per page 6 above. There is a lot of evidence that teenage parents feel judged and uncomfortable accessing mainstream services so we would support a stronger recommendation in support of specialist maternity services for teenagers. We have been unable to look at the evidence on provision of antenatal services in schools but would imagine this requires careful consideration. For the reasons that: - some pregnant teenagers may have negative perceptions and experiences of schools	Thank you very much for your comment. The strength of the recommendation is determined by the strength of the underlying evidence. As there was not much good quality evidence for this recommendation, the group felt that it was more appropriate that this should be considered. Although we recognise that there is evidence that teenage parents feel judged, the group did not feel that it was of high enough quality to make a stronger recommendation. The group considered making a recommendation about school- based provision but agreed that there were a number of reasons why it was not appropriate to the UK setting.

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						<ul> <li>(which could perhaps impact on their perceptions of / willingness to engage with antenatal services in schools).</li> <li>Some pregnant teenagers will already have disengaged with schooling.</li> <li>Pregnancy can be a source of bullying in schools.</li> </ul>	
SH	National Childbirth Trust	23	NICE	1.4.3	8	We would strongly support the provision of antenatal education specifically for young parents. We would also recommend additional postnatal services specifically for young parents, for example drop- in postnatal groups and breastfeeding peer support schemes.	Thank you very much for your supportive comment. We acknowledge that specific postnatal services may also be very valuable for this group of women, however postnatal service provision is outside the scope of this guideline.
SH	National Childbirth Trust	24	NICE	1.5.3	8	Suggest changing 'victim support groups' to 'domestic abuse support groups' and suggesting providing information about specialist support groups for particular groups of women, for example LGBT or BME women experiencing abuse etc. Also good to highlight provision about local and national support groups. This page could be linked to	Thank you very much. We have changed "victim support groups" to "support groups" in the recommendation. The guideline development group felt this was sufficient within the recommendation and that health professionals would be able to use their own knowledge of local services (or know where to find out about local services) in order to give the woman individualised advice.

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						where you can search for support groups (including specialist service providers) by geographical area: http://www.womensaid.org.uk/lan ding_page.asp?section=0001000 10024&sectionTitle=Find+a+local +service It would be good to highlight the need for referrals to meet the holistic support needs of women experiencing abuse, including counselling, housing, financial and legal support etc, emphasising needs additional to health considerations.	Thank you too for the helpful link, again it was not felt appropriate to include this in the recommendation as keeping such links current in guidance is very difficult. We agree that women who experience doestic abuse should be offered a range of support interventions to meet her needs holistically. The recomemndations reflect this by referring to provision of information about other agencies that can offer support, the development of protocols that include support and infromation women may require, safety information. The provision of a named midwife who will provide continuity of carer and longer and/or additional antenatal appointments also recognises the additional emotional needs women experiencing domestic abuse may have.
SH	National Childbirth Trust	25	NICE	1.5.3	8	It should be highlighted that providing information in small, discreet formats is good practice – for example credit card sized with national women's aid support	Thank you very much for your comment. We have added this recommendation as you suggest

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						number on it etc, so women can keep the information discreetly and it is less likely to be found by an abusive partner.	
SH	National Childbirth Trust	26	NICE	1.5.3	8	The importance of staff training in awareness and sensitive, effective and safe response to domestic abuse should be highlighted.	Thank you for your comment. There is a recommendation on training for healthcare professionals that covers the issues you raise.
SH	National Childbirth Trust	27	NICE	1.5.3	9	'Contact details of other people who should be told' Reference should be made here to the need to develop and disseminate clear policy and guidance on information sharing procedures, also covering confidentiality, child protection etc. Info sharing is usually recommended on a strictly need- to-know basis which isn't reflected in this paragraph. The Department of health domestic abuse handbook for health professionals recommends that all PCTs should have documentation, confidentiality and information sharing procedures in place.	Thank you very much for your comment. A recommendation exists that outlines key components of a protocol outlining care for women who experience domestic abuse and states that this should include the DH guidance on documentation, confidentiality and information- sharing.
SH	National Childbirth Trust	28	NICE	1.1.4	11	See points above for page 6.	Thank you, we have addressed these points in the responses above
SH	National Childbirth Trust	29	NICE	1.1.6	11	See points above for page 6.	Thank you, we have now amended this recommendation for greater

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SH	National Childbirth Trust	30	NICE	1.1.7	11	Agree that an out-of-hours phone number is extremely helpful but strongly disagree that this should be the labour ward or similar. Women will then be immediately in the hands of those who do not have the specialist training that the whole document describes they so desperately need. The out of hours number should be a mobile phone of specialist midwives take turns in having over night.	clarity Thank you very much for your comment. The group discussed this but did not feel that it was reasonable to expect specialist midwives to be on call in this way, especially given that many work as a lone specialist. The experience of the development group was that the system described in the recommendation provides safe care without placing undue strain on specialist services.This rationale has been added to the GDG interpretation of evidence in the full guideline.
SH	National Childbirth Trust	31	NICE	1.2.1	11	'addressing women's feelings of guilt about their misuse of substances and the potential effects on their baby'. This recommendation needs clarification and explanation. Is the aim to address feelings of guilt (and if yes when disclosed or assuming it applies to all women?) or to address the potential affect of substances on the baby? If both it needs two separate points. Further recommendations about how this should be done would be useful.	Thank you very much for your comment. The aim of the recommendation is to address women's feelings of guilt where these are disclosed. This could be done, for example, by encouraging her to discuss these feelings in a non- judgemental atmosphere. The development group felt that this was a standard that should be expected of all specialist midwives and so did not feel that it was necessary to make a specific recommendation about it.
SH	National Childbirth Trust	32	NICE	1.2.5	12	We agree that use of text message reminders of appointments would be useful for	Thank you for your comment. We agree that text messages could be useful for following up missed

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						all of the vulnerable groups and would strongly recommend follow up of missed appointments in similar ways.	appointments as well and have included this in the recommendation. We felt that it would not be appropriate to make this an overarching recommendation for all vulnerable groups as the evidence regarding texting related specifically to this group of women. In addition, the development group felt that it might not be a safe strategy for women experiencing domestic abuse
SH	National Childbirth Trust	33	NICE	1.2.6	12	Having a named carer is very valuable but it rarely works out in practice due to illness, holiday etc. It can quickly lead to disillusionment and lack of trust. Having an additional named carer as a backup, who the woman has also had opportunities to get to know is much more realistic as they can cover each other and it is much more likely that at least one of them will be available when the woman needs them. If a woman is only comfortable with one carer she may delay seeking help until the one person she will speak to is available and this could be detrimental to her and her baby.	Thank you very much for your comment. The guideline development group felt that it was not necessary to specify the need for a backup carer. In instances where the named carer would not be available (i.e. annual leave), it was anticipated that they would be able to make clear who should be contacted in their absence and ensure women are provided with accurate information about the level of continuity of carer they can expect
SH	National Childbirth Trust	34	NICE	1.2.7	13	Would much prefer 'named antenatal team' for reasons described above.	Thank you very much for your comment. The development group did not feel that care should be provided by a named team but rather

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							by a named carer who could then clearly explain when care would need to be provided by another healthcare professional.
SH	National Childbirth Trust	35	NICE	1.2.9	13	Agree strongly that all notes should be in one place with a multidisciplinary team working closely together. I think this is essential for caring for women with complex needs and a major strength of the document	Thank you very much for your supportive comment
SH	National Childbirth Trust	36	NICE	1.3.9	14	As per comments on 1.3.9 on page 7	Thank you for your comment, please see the response above
SH	National Childbirth Trust	37	NICE	1.3.10	14	Would a woman with language difficulties be happy to phone through this information? Maybe a form as well so she could get someone close to her to help her fill it in and information about accessing interpreting services?	Thank you for your comment. The GDG felt it was not necessary to also provide a form as women who were not comfortable in phoning through information would be able to ask someone to do this on their behalf in much the same way as they may need to ask for help completing a form.
SH	National Childbirth Trust	38	NICE	1.3.13	15	The need for use of professional interpreters, who have been properly briefed beforehand should be emphasised here. Would also be good to emphasise not using family members for interpreting. Training should also be recommended for health professionals in effective ways of communicating using interpreters.	Thank you for your comment. The GDG considered your comment and have now amended the recommendation to state that interpreters should not be partners of family members. They did not feel it appropriate to recommend use of professional or trained interpreters however. Thank you for information concerning free on-line

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						There is a free online training for health professionals on <i>Breaking</i> <i>Down the Barriers</i> when working with BME women, particularly refugee and asylum seekers that covers cross-cultural communication and use of interpreters: <u>http://www.training.medact.org/training/package/6/</u>	communication training for health professionals. The technical team will work with the NICE implementation team to see if this information can be used in implementation support.
SH	National Childbirth Trust	39	NICE	1.4	15+	Acknowledgement of the different needs of teenage mothers and fathers, and reference and recommendations relating to young fathers in general, is missing from the guideline. Young fathers are likely to feel even more marginalised by maternity services than young mothers. Specific steps should be taken to engage with them. Early involvement of fathers is known to increase fathers involvement overall, with positive impacts for the whole family. Consideration needs to be paid of course to the relationship (if any) between the mother and father and their individual wishes about involvement.	Thank you very much for your comment. Although we specifically searched for evidence relating to the involvement of partners and families in antenatal care, we were unable to find any which met the inclusion criteria for the evidence reviews. As a result, the development group did not feel able to make specific recommendations for this group. We have now included a research recommendation to address this issue

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						Recommendations for engaging with young fathers could be taken from the DH publication on <i>Getting Maternity Services Right</i> <i>For Pregnant Teenagers and</i> <i>Young Fathers</i> (2009) – recently republished with input on fathers from the Fatherhood Institute.	
SH	National Childbirth Trust	40	NICE	1.4.1	15	We strongly agree with this acknowledgment and recommend a further addition: 'Teenage women may feel uncomfortable using antenatal services in which the majority service users are in older age groups. They may also be reluctant to recognise their pregnancy or inhibited by embarrassment and fear of judgement or parental reaction.	Thank you very much for your supportive comment. The wording we have used in this section is derived from the evidence review which highlighted those three issues as being key reasons for why teenagers may feel uncomfortable using antenatal services. As fear of judgement was not specifically identified in the evidence, the development group felt that it was not appropriate to include it.
SH	National Childbirth Trust	41	NICE	1.4.1	15	'age-specific problems' – good to clarify. Do you mean for example school or other social problems sometimes faced by teenage parents – poverty, family problems, housing etc?	Thank you very much for your comment. We have now amended this recommendation to say "social problems" rather than age-specific problems. These could include the examples that you have suggested.
SH	National Childbirth Trust	42	NICE	1.4.6	17	See comment for 1.2.6 page 12 above.	Thank you very much for your comment. The guideline development group felt that it was not necessary to specify the need for a backup carer. In instances where the named carer would not be available (i.e. annual leave), it was anticipated

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							that they would be able to make clear who should be contacted in their absence.
SH	National Childbirth Trust	43	NICE	1.5	17	Agree with the need to explain these fears or reasons why women may not disclose abuse.	Thank you very much for your supportive comment. We were not sure which comment
						Please see comments above on 1.5.3 on page 8 and 9.	you were referring to but hope that we have addressed it above.
						Additionally, domestic abuse does not seem to be defined in the document, which may lead some professionals to consider only physical abuse. We would recommend including a wide ranging definition of abuse, including not only the various forms of physical and non- physical abuse, as well as clarification that abuse can be perpetrated by family members as well as partners or ex-partners. The Home Office uses the following definition of domestic abuse:	The definition for domestic abuse has been included in the full version of the guideline and is derived from the Home Office definition as you suggest. We have also made specific reference to forced marriage, female genital muitilation and "honour-based" violence. We will suggest to NICE that this definition is also included in the NICE version.
						'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	

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						members, regardless of gender or sexuality'.         Home Office. Crime reduction:         domestic violence mini-site.         Available from:         http://www.crimereduction.h         omeoffice.gov.uk/dv/dv01.ht         m         It would also be helpful to refer to         various forms of honour based         violence that are perpetrated by         members of the family or the         community. The Home Office         consider these to be forms of         honour based violence:	
SH	National Childbirth Trust	44	NICE	1.5.4	19	<ul> <li>female genital mutilation (FGM) (see sections 5 and 8.6)</li> <li>forced marriage</li> <li>other types of honour based violence, such as murder or attempted murder associated with behaviour perceived to bring shame upon the family or community.</li> <li>Strongly agree. Women attending NCT antenatal frequently report feeling a bit abandoned by the lack of antenatal appointments they are offered. This would</li> </ul>	Thank you very much for your supportive comment

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					situation.	
National Childbirth Trust	45	NICE	1.5.5	19	See comment for 1.2.6 page 12 above.	Thank you very much for your comment. The guideline development group felt that it was not necessary to specify the need for a backup carer. In instances where the named carer would not be available (i.e. annual leave), it was anticipated that they would be able to make clear who should be contacted in their absence.
National Childbirth Trust	46	NICE	1.5.6 & 7	19	We strongly support recommendations about health professionals receiving training on domestic abuse. This should be included as a key priority for implementation. Should be stronger than 'consider'. See points above for page 6 about the use of 'consider'.	Thank you for your comment. The development group chose the key priorities for implementation through a formal voting procedure and confirmed that they wished to keep the key recommendations as they stand. The word "consider" was used to reflect the underlying strength of the evidence for joint training with social care professionals. As there was not a lot of strong evidence for this particular practice, it was felt that it was appropriate to use the word "could". Recommendation 1.5.7 does use the term "should" in relation to the training that healthcare professionals should receive
National Childbirth	47	NICE	1.5. 7	19	Suggest changing 'features	Thank you very much for your
	National Childbirth Trust National Childbirth Trust	NoNational Childbirth Trust45National Childbirth Trust46	NomentNational Childbirth Trust45NICENational Childbirth Trust46NICE	NomentNoNational Childbirth Trust45NICE1.5.5National Childbirth Trust46NICE1.5.6 & 7	NomentNoNoNational Childbirth Trust45NICE1.5.519National Childbirth Trust46NICE1.5.6 & 719	NomentNoNoPlease insert each new comment in a new row. woman is in a vulnerable situation.National Childbirth Trust45NICE1.5.519See comment for 1.2.6 page 12 above.National Childbirth Trust46NICE1.5.6 & 719We strongly support recommendations about health professionals receiving training on domestic abuse. This should be stronger than 'consider'. See points above for page 6 about the use of 'consider'.

Туре	Stakeholder	Order No	Docu ment	Section No	Page No	<b>Comments</b> Please insert each new comment in a new row.	Developer's Response Please respond to each comment
	Trust					suggesting domestic abuse' to: 'awareness of signs indicators of domestic abuse'. The list about what training should include should also refer to confidentiality and safeguarding issues, including information sharing procedures. See comment for 1.5.3 on page 9. 'Women known to be experiencing abuse' should be changed to 'Women known <b>or</b> <b>suspected</b> to be experiencing abuse', throughout the entire document.	comment. The group felt that the term features was more appropriate as it is a broader term which includes behaviour. The list of what training should involve includes reference to local protocols and we have recommended that these include details about information sharing. The group agreed that safeguarding training is mandatory and that it was not necessary to make a specific recommendation about it. We have added the phrase "or suspected" as you suggest
SH	National Childbirth Trust	48	NICE	4	20	We agree with these research recommendations.	Thank you very much for your supportive comment
SH	National Childbirth Trust	49	Gener al			We fully support the focus on multidisciplinary approach and integrated care. I feel this is very important and helpful.	Thank you very much for your supportive comment
SH	National Treatment Agency for substance misuse	1	NICE	General	Gene ral	The guideline purports to consider women experiencing complex social factors but, curiously, then divides these women into "exemplars" of particular social factors, without considering those who might experience a combination of these and other	Thank you for your comment. The division of the heterogenous group of women with complex social factors into 4 exemplar groups was done so as to enable the systematic reviewing that underpins the guideline to be undertaken in a thorough and

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						factors, especially – for example – under 20 year-old substance misusers, and substance misusers also suffering domestic abuse.	effective way. We agree that it is important to recognise that many women will have a number of social factors to deal with. The introduction to the guideline and chapter 3 have both been amended in the light of stakeholder comments to make this more clear.
SH	National Treatment Agency for substance misuse	2	NICE	1.2 (and its key priorities)	11	The section on women who misuse substances is rather light on content, doesn't recommend the clear protocol that is in the domestic abuse guidance or cross-refer to existing national guidance such as the 2007 Clinical Guidelines*.	Thank you very much for your comment. The only evidence for protocols identified in this guideline related specifically to the domestic abuse population. As a result, the group did not feel able to make a more specific recommendation about a protocol for substance misusers. The recommendations for this population include a range of practical strategies, based on the evidence reviewed aimed at improving access to and maintained contact with antenatal care for this group of women, namely: provision of a named antenatal carer who is responsible for co-ordinating care, referral to a substance misuse treatment programme, development of a co-ordinated care plan that is integrated across different agencies as well as provision of information and advice pertinent to the woman's needs, reminders of appointments

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							and follow-up of missed appointments and help with transport to and from appointments. We have now added guidelines on substance misuse to the related guidance section of the guideline.
SH	National Treatment Agency for substance misuse	3	NICE	1.2 (and its key priorities)	11	We believe there should be an explicit reference to the benefits of engaging and retaining pregnant women who misuse substances in drug or alcohol treatment.	Thank you for your comment. We have made a recommendation stating the need for referral to a substance misuse treatment programme and have now added the importance of this to the GDG interpretation of evidence.
SH	National Treatment Agency for substance misuse	4	NICE	1.2 (and its key priorities)	11	There is no mention of the importance of links between substance misuse, maternity and – crucially – safeguarding services.	Thank you. We recognise the importance of making links between different services and have recommended that substance misuse services should work together with maternity services and other agencies to ensure care is co- ordinated . Other examples of how links can be built and maintained are also provided such as use of a co- ordinated care plan, co-location of services and simply informing women of all services available and following up her appointments across sectors.
SH	National Treatment Agency for substance misuse	5	NICE	1.2 (and its key priorities)	11	There is little by way of guidance to ensure that this group of women receives a sexual health screen, BBV testing and the appropriate pre- and post-test	Thank you for your comment. While this guideline does address service provision including additional support and information for substance misusing women, clinical care is

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						advice.	outside the scope. We recognise that this is a very important area and would recommend that you suggest this as a topic for consideration for a future NICE guideline where it could be covered comprehensively. Some areas of sexual health screening would be the same as currently recommended for all pregnant women and can be found in the NICE Antenatal Care guideline.
SH	National Treatment Agency for substance misuse	6	NICE	1.2.2	12	Substance misuse services are provided by a range of statutory and third sector agencies, often depending only on which agency has been successful in winning a local contract. We do not understand why only "third-sector agencies that provide substance misuse services" are specified here.	Thank you very much for your comment. We have stipulated both local agencies and third sector agencies in the recommendation as we recognise that these services will be provided by a number of different agencies depending on local arrangements.
SH	National Treatment Agency for substance misuse	7	NICE	1.2.2	12	Perhaps it is only because anything post-pregnancy is outside the scope of the guidance but we thought it was as important to coordinate post-natal as ante- natal care – the former is not mentioned.	Thank you very much for your comment. We agree that coordinating postnatal care is extremely important. However, as you acknowledge, postnatal care was outside the scope of the guideline and so the group was not able to make recommendations about it.
SH	National Treatment Agency for substance misuse	8	NICE	1.2.2	12	A wide range of drug and alcohol treatment is available and may be appropriate to a pregnant woman (for example, psychosocial interventions are the frontline	Thank you very much for your comment. The development group felt that it was important to highlight the details of the opiate replacement therapy in care plans to allow

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						treatment for women addicted to cocaine). We do not understand why only "opiate replacement therapy" is selected to be included in care plans or how including information about a treatment option in a care plan helps to coordinate antenatal care anyway.	effective coordination between maternity care and paediatric services (for example in determining whether tertiary care will be required). It is not intended that this should be the only information included in care plans but instead has been chosen as a useful example
SH	National Treatment Agency for substance misuse	9	NICE	1.2.2	12	"Co-locating services" is only one solution to the desirability of having multiple services available to pregnant women at one site. Although it is only listed as an example, we think it might be more helpful to make this recommendation broader.	Thank you very much for your comment. The suggestions listed in this recommendation were those highlighted from the evidence reviewed.
SH	National Treatment Agency for substance misuse	10	NICE	1.2.2	12	We suggest that 'Healthcare commissioners' responsible for organisation of local maternity services should liaise with local commissioners of drug and alcohol treatment services to co- ordinate antenatal and post- pregnancy care for drug and alcohol dependent pregnant women.	Thank you very much for your comment. The group did not want to specify that the healthcare commissioners should work specifically with drug and alcohol treatment services as the wanted to include other agencies as well e.g. mental health services
SH	National Treatment Agency for substance misuse	11	NICE	1.2.4	12	We believe this offer of referral to substance misuse treatment is key and should be included in the key priorities for implementation.	Thank you for your comment. The key priorities for implementation were chosen by the guideline development group using a formal consensus voting process. The group considered your suggestion carefully following stakeholder consultation but

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							confirmed that they felt they did not wish to add it to the current list of key priorities.
SH	National Treatment Agency for substance misuse	12	NICE	1.2.6	12	It is not clear who this "antenatal carer who has specialised knowledge of, and experience in, the treatment substance misuse" is and where they might come from. Unless it is clear that such highly competent staff already exist, should there not be a recommendation that they be created by appropriate recruitment and/or training?	Thank you for your comment. The experience of the guideline development group is that staff with a special interest in, and empathy for, substance misusing women, can be appointed to a specialist post and acquire specialist knowledge through experience, working alongside more experienced specialist staff and attendance at occasional training days. A recommendation for training relating specifically to the social and psychological needs of substance misusing women is included as this was felt to be key to providing appropriate additional care over and above that recommended in the NICE antenatal care guideline and alongside care provided by specialist substance misus services
SH	National Treatment Agency for substance misuse	13	NICE	1.3.4	14	We were not clear why only women who are recent migrants, etc should be enabled to take a copy of their handheld notes when moving. Should this not apply to all?	Thank you for your comment. The GDG have considered your suggestion and have now made this an overarching recommendation applicable to all women with complex social needs.
SH	National Treatment Agency for substance misuse	14	NICE	1.4.1	15	We were not clear why only women under 20 years should be offered practical help with transportation to and from appointments. Should this not	Thank you very much for your comment. Problems with transportation was an issue that was specifically identified from the evidence for this group of women.

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						apply to all?	The development group did not feel that it was appropriate to make this an overarching recommendation.
SH	Nottinghamshire Healthcare NHS Trust	1	Full	General	gene ral	These comments are confined to Section 4 on Women who misuse substances, page 28 to 48 and the relevant part of the Summary page 7 and page 11. We are disappointed that the guidelines do not contain specific recommendations for the treatment and management of substance misuse in pregnancy. Whilst these might not be to the highest level of NICE evidence i.e. RCTs, there are in existence a number of national guidelines for the management of pregnant substance misusers, particularly in relation to the management of methadone substitution, the avoidance of multiple prescribing and the importance of the involvement of specialised professionals who have knowledge and experience in the management of substance misuse in pregnancy. Whilst there is frequent reference to the need for integration, care planning and multi-agency involvement, there is no specific mention of the need for	Thank you very much for your comment. We recognise that the treatment and management of women who misuse substances is an important aspect of care. However, this aspect of care is outside the scope of this guideline. It would be well worth suggesting this as a topic for a future guideline where it could be dealt with comprehensively. We share your concern of the need to provide excellent care postnatally to substance misusing women. We recognise that the points you raise are very important but postnatal care is outside the scope of this guideline which concentrates on antenatal care and interventions to improve maternal and neonatal birth outcomes. Postnatal care for vulnerable women, including substance misusing women, could be put forward to the topic selection group for consideration as a future NICE guideline. The guideline development group included a very experienced specialist midwife who has established, and now manages, a

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						specialised drug liaison midwives, he involvement of specialised drug treatment services and the role of an obstetrician with a special interest in this area. The absence of these areas of enquiry and consequent recommendations would seem to reflect the disappointing make up of the guidance committee. No psychiatrist with special expertise in the management of pregnancy substance misusers was included in the committee. <u>Confidential Enquiry into maternal deaths 2000/02 and 2003/05.</u> The publication of 2006/08 is awaited. Whilst the maternal deaths enquiries are referenced in this section, apart from a numerical account of the numbers of substances misusers who died from the complications of their disorder no mention is made of the other findings of the Enquiry in relation to substance misuse nor of its recommendations. A prominent finding was the apparent relationship between the involvement with social services child protection and the subsequent avoidance of	specialist service for substance misusing women and women who are experiencing domestic abuse, a specialist psychiatric nurse who is the clinical substance misuse lead in offender health, a social worker who is the manager of a perinatal mental health service and a health visitor who is a strategic lead in parental mental health.

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						maternity care and between the timing of the maternal death and the decision to remove the child into care. A second and very important finding was that postnatal care of the substance misusing mother by both maternity and drug addiction services seemed to disappear once the child was removed. This is particularly relevant as most of the deaths from substance misuse, either from an accidental overdose of their recreational drug or from medical complications of substance misuse occurred after delivery. We would therefore have welcomed a recommendation that greater effort is required to maintain contact following delivery, women who are substance misusers and that particular vigilance is required if there is current child protection involvement and/or if the child has been removed. There is no mention of the involvement of mental health substance misuse services. Midwives even if they are	
						specialists in substance misuse cannot be expected to manage	

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						such as these without specialised input.	
SH	Nottinghamshire Healthcare NHS Trust	2	Full	4.8	47	"Offering information to women about the involvement of social services and the potential removal of their child" is both inadequate and naïve. Referral to social services in the case of substance misusing mothers appears to be automatic. In cases reported to the Maternal Deaths Enquiry over the last 9 years, the overwhelming majority of substance misusing women who died had been involved with child protection case conferences. In the majority of cases previous children had been removed into care and the decision had been made to remove the current infant as well. Information and reassurance set against this background is unrealistic as the reality for these women is that involvement with social services does result in the removal of their child. We would have appreciated a recommendation that there needs to be an urgent consultation at high level between social services and health about the management of women with substance misuse in particular	<ul> <li>Thank you very much for your comment. The wording of this recommendation has now been amended so as not to infer a woman's fears can be overcome, but rather that they should be acknowledged and discussed. The GDG agree that it is not appropriate to provide unrealistic information but to ensure issues are addressed openly and honestly. This has now been added to the GDG interpretation of evidence. The recommendations for substance misusing women address the following issues: <ol> <li>The need to integrate care from different services, and jointly developing care plans across health and social care agencies.</li> <li>The named antenatal carer may be a midwife or an obstetrician, however, as stated in the recommendation, this named carer should have a specialist knowledge of and interest in care of substance misusing pregnant women.</li> </ol> </li> </ul>

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						<ul> <li>and mental health problems in general. Whilst their priority must be the safety and wellbeing of the child, there is also a need to make more prominent the duty of care to the mother.</li> <li>To summarise: <ol> <li>There need to be specific recommendations about the involvement of social services</li> <li>The expertise and type of professional and service involved in the care</li> <li>Some emphasis on postmental care</li> <li>A role of specialised mental health services</li> <li>With regard to the high levels of both physical and psychiatric co-morbidity in this group, recommendations about the involvement of consultant obstetrician with a special interest and input from specialised drug addiction services.</li> </ol> </li> </ul>	The GDG have considered the comments you made and felt it was not appropriate to specify that care should be provided by a consultant obstetrician as this need not be the case. There is a need to involve specialist substance misuse services however, and referral to substance misuse treatment is recommended. The recommendation relating to inter-agency working and care co- ordination includes all types of services including mental health services and social care – the latter has now been made explicit in the recommendation. Postnatal care is outside the scope of the guideline . The role of mental health services is covered in depth by the Antenatal and Postnatal Mental Health guideline (CG45, 2007)
SH	Nursing and Midwifery Council	1	Full	General	Gene ral	As the regulator for nurses and midwives, we welcome the fact the guideline reflects The Code: Standards of conduct, performance and ethics for nurses and midwives (2008). We would stress that we regulate individual nurses and midwives and	Thank you very much for your supportive comments

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						therefore cannot comment specifically on service models, but can comment on the detail in the guidance that impacts on individual practitioners. Focusing on four specific groups of women with specific issues is a helpful way of structuring the guidance.	
SH	Nursing and Midwifery Council	2	Full	General		Treatment and care should take into account women's needs and preferences – the Standards of Proficiency for Specialist Community Public Health Nursing (NMC, 2004) place the assessment of need within the search for health needs domain. Specialist public health practitioners should have the skills and competence to undertake health needs assessment in partnership with clients /users of services.	Thank you very much for your comment. We agree that specialist public health care practitioners would be expected to have the skills necessary for comprehensive needs assessment. Comprehensive health and social care needs assessment and determination of women's preferences also falls within the sphere of practice of midwives, who carry this out at booking.
SH	Nursing and Midwifery Council	3	Full	General	5, 8, 38, 47, 90,1 12,	Whilst we appreciate that a multi agency approach will be taken in the provision of care of women with complex social needs, the use of the term <i>named antenatal</i> <i>carer</i> could indicate that a health care professional other that a medical practitioner or a midwife	Thank you very much for your comment. We have used this term as the care could be provided by a midwife, GP or an obstetrician.

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						could be providing antenatal care. This would be contrary to the requirements of Article 45 of the Nursing and Midwifery Order (SI 2002 No 253) as it would be an offence for anyone other than a registered midwife or medical practitioner to attend a woman in childbirth This is further clarified in the Rule 2 of the Midwives rules and standards, which states that <i>Childbirth includes the antenatal,</i> <i>intranatal and postnatal periods.</i> Rule 6.1 also requires that a <i>practising midwife is responsible</i> for providing midwifery care, in accordance with such standards as the Council may specify from time to time, to a woman and baby during the antenatal, <i>intranatal and postnatal periods.</i>	
SH	Nursing and Midwifery Council	4	Full	5.7	70	We agree that ensuring a system is in place to track the residential address of women who move address frequently and/or at short notice will enhance the safety of mothers and babies by ensuring they remain within the healthcare system. Furthermore, the guidance makes reference throughout the text to the importance of joint working	Thank you very much for your supportive comment. We agree that it is important for nurses and midwives to work together to acheive integrated care planning

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						when developing protocols. Nurses and midwives need to develop appropriate networks and work across organisational boundaries in order to achieve integrated care planning.	
SH	Nursing and Midwifery Council	5	Full	1.3.1, 3.4	9, 26	We applaud the recommendation for the creation of a national database collated routinely collected pregnancy data. Ideally this would include enabling every midwife and or obstetrician to record their personal outcomes of care to women and families. This will enable effective mapping and benchmarking of care systems and individual practice against national averages. It would also identify best practice and enhance the care, and ultimately the safety, for mothers and babies. It is also helpful that the guidelines include the collection of data concerning user satisfaction regarding services received.	Thank you very much for your support. We agree that audit data evaluating the effectiveness of specific service changes would be a very valuable aid in deciding what changes bring about the desired outcomes of improved access and maintained contact, and which ones are not effective. Whilst the mapping of personal outcomes for staff members might be useful, this was not something the GDG considered and which lies outside the scope of this guideline.
SH	Nursing and Midwifery Council	6	Full	General		The guidance makes reference to safeguarding issues and is a key area where all nurses and midwives should ensure they keep themselves skilled in order to minimise and identify risks for children and young people. The	Thank you very much for your comment. We agree that the Common Assessment Framework is an important tool in identifying safeguarding needs. The group did not include a specific recommendation about training in

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						Common Assessment Framework is an assessment tool that practitioners should be trained to use, in order to ensure that needs are identified and targeted.	using the CAF as there is already a statutory requirement for healthcare professionals to receive this training
SH	Nursing and Midwifery Council	7	Full	General	Gene ral	Training needs for each group of women are identified in the guidance. We would concur with the decision to highlight training needs in this way. Training is essential to ensure that high quality care is delivered and in order to safeguard the health and wellbeing of the public. Training requirements are important to prioritise but equally values and attitudes of staff will influence the extent that patients and clients access services. The NMC Code includes principles around attitude and ethics which are equally as important as knowledge and skills.	Thank you very much for your supportive comment. We agree that values and attitudes of staff are important and have made recommendations that healthcare professionals should receive training about this. As the guideline is aimed at a range of healthcare professionals, we have not specifically referred to the NMC code but would hope that all healthcare professionals should comply with their respective codes of practice.
SH	Obstetric Anaesthetists Association	1	Full	5.7	69	The OAA has produced information on obstetric anaesthesia, which has been translated into 32 different languages. This is available on our website www.oaaformothers.info. We suggest that this would be a	Thank you very much for your helpful suggestion. We will investigate the possibility of including reference to this resource in the "understanding NICE guidance" document which is produced specifically for women, their partners and families

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						useful link to be included in the guideline.	
SH	Perinatal Institute	1	Full	General		We commend the development of a national guideline for pregnant women with complex social factors and we welcome the opportunity to comment on the draft consultation document.	Thank you
SH	Perinatal Institute	2	Full	General		We recognise that much of the current evidence is based on qualitative studies many of which are outside the UK.The transferability of these studies to reflect UK demographics, health and social care systems may prove challenging. However, we acknowledge that the evidence base surrounding social care and impact is universally limited.	Thank you very much for your comment. We agree and share your frustration that it is very difficult to draw conclusions based on predominantly US evidence. The GDG were tasked with interpreting the evidence in light of their own experience and expertise, thinking about NHS service provision. This interpretation is detailed in the full guideline and shows how the recommendations are derived.
SH	Perinatal Institute	3	Full	2.1	12 -13	Evidence from Maternity Matters has been utilised to identify women with complex social risk and the subgroup of 4 exemplar populations. However we would suggest that page 13, (paragraph 4) should be strengthened to encourage practitioners to consider the wider spectrum of need eg. Women with poor mental health; physical and learning disabilities, families known to child protection services, prisoners and remand	Thank you very much for your comment. We have amended this paragraph to refer more explicitly to other potential complex social factors which might need to be considered.

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						prisoners; travellers; lowest educational achievers; families where one or both parents are unemployed. (Ref NICE CG062).	
SH	Perinatal Institute	4	Full	General		Community midwifery caseloads should reflect demographics and levels of maternal population social/medical risk. Commissioners and providers need to work collaboratively with Public Health colleagues to ensure maternal needs are addressed by appropriate resource allocation. Midwives who are caring for women with complex social needs will require a smaller caseload to provide effective care.	Thank you for your comment. The economic model was developed to demonstrate how increasing service provision would affect the health outcomes of vulnerable mothers and their babies. Differing levels of local provision will require different levels of effectiveness in order for a service to be cost-effective and this depends on the local demographics. The main research recommendation is to encourage data collection and audit of services which should provide better evidence for future analysis to support better resource allocation.
SH	Perinatal Institute	5	Full	General		Continuity of carer is important for women with complex needs as it promotes improved care compliance and enhanced maternal satisfaction. (Ref Maternity Matters 2007, NICE Ante Natal Care Clinical guideline March 2008. NSF for Children, Young People and Maternity Services).	Thank you for your comment. We found evidence for 2 of the included populations (women aged under 20 and substance misusing women) showing positive outcomes associated with continuity of carer, thus recommendations have been made for provision of a named antenatal carer for women in these vulnerable groups.
SH	Perinatal Institute	6	Full	General		There is a need for identified care pathways in the management of women with complex social risk and the inclusion of existing examples would be beneficial.	Thank you very much for your comment. The final guideline will include algorithms which will set out in further detail both how services should be set up for women with

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							complex social factors, and how healthcare professionals should manage their care. None of the service descriptions in the guideline exactly match the algorithms but do provide examples of how some elements of care are currently provided.
SH	Perinatal Institute	7	Full	1.2	6	We recommend the use of hand held notes which should incorporate full health and social risk assessment - for example the West Midlands Perinatal Institute's Pregnancy notes.	Thank you very much for your comment. We agree that a standardised form of health and social needs assessment may well be of benefit. The National Collaborating Centre for Women's and Children health has developed such a needs assessment which is currently with the DH awaiting validation. The aim of this assessment tool is to help midwives to identify women who face complex social factors and refer them for appropriate additional support.
SH	Perinatal Institute	8	Full	1.1	2	You recommend training for HCP's in Common assessment framework (CAF) and this is a mandatory requirement. However, lack of protocols and care pathways to address maternal social need may limit midwives' ability to fully embrace the CAF process.	Thank you very much for your comment. We very much hope that the recommendations contained in this guideline will be used as the basis for local protocols and care pathways for care provision for women with complex social needs. We have provided details to support the development of protocols for care of women who experience domestic abuse and we have developed

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							algorithms to summarise the recommendations to help in this respect.
SH	Perinatal Institute	9	Full	4	28- 47	We welcome the suggestion of a Drug Liaison Midwife (DLM) and co-location of services, however evidence from DfES (NESS, 2005) indicates that co-location alone will not improve outcomes but multi-agency training and whole team meetings will.	Thank you very much for your comment. We recognise that whole team meetings may well also improve outcomes. The development group chose to refer specifically to co-locating services as it was identified through the evidence reviewed. The list of bullets are provided as examples and do not preclude commissioners adopting other strategies.
SH	Perinatal Institute	10	Full	7 3.3	91- 111 25	We agree with your suggestion that training of health and non health care professionals will improve outcomes and satisfaction of women with the service provided.	Thank you very much for your supportive comment
SH	Perinatal Institute	11	Full	7	91- 11	Staff should to be trained on the use of routine enquiry into domestic violence which should be underpinned by locally agreed protocols.	Thank you very much for your comment. We agree with your comment, but screening for domestic abuse is outside the scope of this guideline. This topic has been covered in the NICE Antenatal Care guideline (CG 62)
SH	Perinatal Institute	12	Full	6	86	Use of inappropriate terminology e.g. mental retardation – learning disability is the accepted term.	Thank you very much for your comment. This was the terminology which was used in the original paper. However, we agree that it was inappropriate and have changed it to say learning disability as you suggest
SH	Perinatal Institute	13	Full	3.3	26	While the national maternity	Thank you very much for your

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						database is planned, the West Midlands Perinatal Institute already collects a denominator dataset of 90 items on all births from the 19 units in the West Midlands, including demographics and social and medical risk factors.	comment. We recognise the work that the Perinatal Institute does in collecting these valuable data. It is hoped that the research recommendation will provide greater clarity about the data which need to be collected at a national level.
SH	Perinatal Institute	14	Full	3.2	24	We welcome the suggestion of a 24 hour contact number for pregnant and postnatal women. We suggest examples of good practice for example Hackney/Newham Midwifery call centre.	Thank you. We have included the Hackney maternity helpline in the guideline.
SH	Perinatal Institute	15	Full	3.4	26- 27	We agree with the suggestion of developing a clear and detailed map of existing services in the UK. The services would need to be benchmarked and assessed for effectiveness. There are existing resources that need to be linked i.e. CHAMP; CHiMAT; IM NST; Consultant Midwives Network. (hosted by RCM).	Thank you very much for your comment. We agree that there are a number of existing resources that would need to be linked and would anticipate that whichever organisation conducts this research would refer to the resources that you suggest.
SH	Perinatal Institute	16	Full	Appendix D	153- 167	As above: we would suggest expanding this section with wider links and examples that have been evaluated for impact, outputs, outcomes and value for money.	Thank you, we agree that examples that have been evaluated would be useful, Recommendations have been made for auditing services. We were unable to collect data on outcomes from the services described and so cannot look at value for money. We hope with better data collection in the future that this will be possible.

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SH	Perinatal Institute	17	Full	General		The identification of vulnerable women in local communities needs to be fully supported by additional service provision. Midwives identifying vulnerable women need to be assured of capacity within referring services. Therefore commissioners should assess maternity service provision and referral services within care pathways for efficacy, quality and capacity.	Thank you very much for your comment. We recognise the importance of ensuring that services are effective and meet required standards. We feel that the criteria set out in the recommendation for audit of services will ensure that these standards are assessed. The economic model was developed to demonstrate how increasing service provision would affect the health outcomes of vulnerable mothers and their babies. The main research recommendation is to encourage data collection and audit of services which should provide better evidence for future analysis to support better resource allocation.
SH	RCPCH	1	Full	General	Gene ral	The RCPCH is pleased to see the four high risk groups. We note that there are significant implications on neonatal outcome for women who misuse substances. The other three groups also have major impact on family social issues.	Thank you very much for your comment.
SH	RCPCH	2	Full	General	Gene ral	The RCPCH agrees with the key priorities for implementation.	Thank you very much for your supportive comment
SH	RCPCH	4	Full	General	Gene ral	We think that the short term focus on birth weight and prematurity is very worrying and misses a lot of potential gain that would have	Thank you very much for your comment. We agree that this work including parenting skills and other postnatal interventions/support is

SHRCPCH5FullGeneralGeneralGeneralGeneralGeneralGeneralCeneral <t< th=""><th>esponse ach comment</th></t<>	esponse ach comment
ral about reducing women's fears of comment. We recognis may not be possible to	s needed. This k lies outside nt guideline cus specifically improving birth great if you sing postnatal ntions that start mproving long- topic selection ration as a
<ul> <li>will not help. Rather, realistic working together for the wellbeing of the mother and child – forming a positive alliance with a focus on minimising harm to both – is a better way of looking at it.</li> <li>There is a need for clarity and well publicised procedures, including child protection and good complaints procedures. These guidelines as they stand seem to see social services involvement as something to be feared, and the child as having no</li> </ul>	Inise that it to s fears and so talk about s fears by n tailored to h we do not he view that children's ng to be ars of the ed as being a are, and the agreed that it
SH     RCPCH     6     NICE     Woman-     4     While the view of a mother     Thank you very much for	for your

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				centred care		regarding care of her baby must be sought, we believe we cannot undertake to comply with her view if the wellbeing of her baby is at risk. If respect simply means listen to and understand this is potentially misleading and should be clarified.	comment. Although the introduction to the NICE guideline is standard text, the developers will be working with NICE to ensure that the text is appropriate for this guideline
SH	RCPCH	7	NICE	Key priorities for implemen tation – organisati on	6	Commissioners and those who provide services need to know absolute numbers per year so that services can be planned. For example, if the numbers of women in four groups are small, services may need to be provided in collaboration with other providers.	Thank you very much for your comment. We agree that it is more useful for commissioners to know the absolute numbers and so have amended the recommendation to say 'numbers', rather than 'percentages'.
SH	RCPCH	8	NICE	Key priorities for implemen tation – training	7	We think that safeguarding must be included in all training recommendations.	Thank you for your comment. The group felt that as safeguarding training is mandatory, it would not be necessary to make a general recommendation about it for all populations. However, the group felt that it was appropriate to make a specific recommendation about it for teenagers to highlight that healthcare professionals should be particularly aware of their safeguarding responsibilities to both the young woman and her unborn child
SH	RCPCH	9	NICE	Key priorities for implemen	7	For women who do not speak English, we think that advocates/interpreters should be provided.	Thank you very much for your comment. The guideline development group are asked to choose 10 key recommendations

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				tation			through consensus voting. Following stakeholder consultation the group were given theopportunity to revise this list of priorities but felt they were happy with their original list.
SH	RCPCH	10	NICE	Key priorities for implemen tation	8	For women who experience domestic violence, we think that safeguarding of existing child and baby should be included.	Thank you for your comment. We recommend that local protocols are developed that include the DH guidance "Responding to domestic abuse: a handbook for health professionals". The advice within this handbook is to follow local safeguarding procedures where a child is suspected of being at risk due to domesrtic abuse.
SH	RCPCH	11	NICE	1.2	11	We think that a huge reason and benefit of antenatal care here is barely mentioned and not given the emphasis it needs. We note there is very good evidence that alcohol use is a major teratogen. There is no mention of prenatal work which could be helpful. There is also virtually no mention of interventions aimed at reducing alcohol use.	Thank you for your comment. While this guideline addresses service provision including additional support and information for substance misusing women, clinical care is outside the scope. We agree that guidance on the specific management and care of women who misuse substances, including alcohol, is needed and would recommend that you put this topic forward for consideration as a full NICE guideline where these issues can be comprehensively dealt with.
SH	RCPCH	12	NICE	1.2	11	We note there is no mention of potentially worse withdrawal with methadone.	Thank you for your comment. While this guideline addresses service provision including additional support and information for substance

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						There is no mention of the "Drug Courts" for which there is evidence in US and currently trials in London and Manchester.	misusing women, clinical care is outside the scope. We agree that guidance on the specific management and care of women who misuse substances, including alcohol, is needed and would recommend that you put this topic forward for consideration as a full NICE guideline where these issues can be comprehensively dealt with. Drug courts lie within the criminal justice system rather than the NHS and so are outside the scope of this guideline
SH	RCPCH	13	NICE	1.2.1	12	Removal of child is an unnecessarily emotive phrase, and should be replaced by arrangements for safeguarding of the child.	Thank you very much for your comment. The development group felt that it was appropriate to use the phrase "removal of …child" as it is this which the woman is likely to fear.
SH	RCPCH	14	NICE	1.2.1	12	We think that education on the effect of substance use on the child should be added where appropriate.	Thank you very much for your comment, we have now included a recommendation about this
SH	RCPCH	15	NICE	1.2.6	12	We recommend that the guideline specify that the named antenatal carer should be responsible for co-ordinating care.	Thank you very much for your comment. The group felt that it would not always be the named antenatal carer who was responsible for coordinating care for substance misusing women. The GDG felt that whilst this could also be role of the named antenatal carer this was not exclusively the case. In some service

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							models care is co-ordinated through an administration support person who is responsible for making appointments, ensuring women know about and are reminded of upcoming appointments and following up non- attendance
SH	RCPCH	16	NICE	1.2.9	12	We recommend that the guideline specify that results of HIV, Hepatitis B and C status must be clearly documented in both the handheld record and the hospital records.	Thank you very much for your comment. The group felt that it was a standard element of antenatal care that the results of all tests should be clearly documented. How sensitive information is recorded in a woman's handheld notes would need to be agreed between the woman and her antenatal carer. As a result, they did not feel it was necessary to make a specific recommendation about this
SH	RCPCH	17	NICE	1.2.9	13	We recommend that handheld records are photocopied at each visit or that details of that visit are included within the hospital record; women can forget to bring their handheld records in at the time of delivery.	Thank you for your comment. We agree that it is important for a record of care provided and test results to be kept at the hospital where care is provided. This could be kept electronically or on paper records. Whilst women can forget to bring handheld records in at the time of giving birth the GDG felt this was rarely the case.
SH	RCPCH	18	NICE	1.3.2 -4	13- 14	These sections are only included for this group of women. We think it may be relevant to the other groups.	Thank you for your comment. The GDG have considered your suggestion and have now made these overarching recommendations applicable to all women with complex social needs.

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SH	RCPCH	19	NICE	1.3.8	14	We think that this vulnerable group of women should also be offered a named professional to take responsibility for and provide the majority of antenatal care as well as co-ordinate care (as per the teenagers 1.4.6) with a direct telephone line provided.	Thank you very much for your comment. The development group felt that there was not sufficient evidence for this population about this issue to make a recommendation for providing care over and above that stated in the NICE Antenatal care guideline CG62.
SH	RCPCH	20	NICE	1.4	15- 17	We think there is too little focus / mention of the safeguarding needs of the young women themselves, particularly, looked after children, disabled children, those on a safeguarding plan. Specific mention should be made in the guideline about (the need for professionals to be aware of) the possibility of the pregnancy being due to rape or other sexual abuse – including incest – and the need to know what to do about any such suspicion. The vague comment about safeguarding in paragraph 1.4.4 needs to have added detail.	Thank you very much fror your comment. We have amended this recommendation highlight that healthcare professionals' safeguarding responsibilities are to both the young woman and her unborn baby. It was not neccessary to specify what to do if either rape or sexual abuse is suspected as this is covered in the NICE clinical guideline on When to suspect child maltreatment CG89.
SH	RCPCH	21	NICE	1.4	15	All of these at least need a mention of more than just Gillick competence or the child's own needs can get left out when they become pregnant.	Thank you very much for your comment. The group felt that these recommendations were aimed at addressing the young woman's needs. The wording for the recommendation regarding training has now been amended

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							to highlight that healthcare professionals have a safeguarding responsiblity to the young woman as well as her unborn baby
SH	RCPCH	22	NICE	1.4.4	16	We think that safeguarding issues for teenagers, e.g. circumstances of conception, as well for the baby, should be listed separately	Thank you for your comment. We have now amended this recommendation to highlight that healthcare professionals should consider the safeguarding needs of the young women aged under 20 as well as their baby
SH	RCPCH	23	NICE	1.5.1	17	We would like clarification on whether the disclosure of domestic abuse not being communicated to the perpetrator can be guaranteed, e.g. if there are care orders or criminal proceedings or if other children are involved.	Thank you very much for your comment. After discussion, the development agreed that it would not be possible to guarantee that the disclosure of domestic abuse wouldn't be communicated to the perpetrator. As a result, this bullet point from the recommendation has now been removed
SH	Royal College of Midwives	1	NICE	General		The Royal College of Midwives (RCM) welcomes the opportunity to comment on the draft of this guideline. The comments in this response are based on feedback from midwives who reviewed and responded to the RCM on the document.	Thank you
SH	Royal College of Midwives	2	NICE	General		The RCM considers it would have been useful to have identified all complex issues/social factors and addressed them in the guideline.	Thank you very much for your comment. We agree that all women with complex social issues are important. However, it is not possible

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						Maternal mental health is one of the biggest areas affecting maternity care followed by: drug, alcohol, domestic abuse, teenage pregnancy, disability, social problems, current/previous involvement with social work, partner's substance misuse, patient/partners involvement with criminal justice system and finally poor engagement with services where reasons have not been identified.	to address all potential complex social issues within the bounds of one guideline as these are so many, so varied and far-reaching. In order to address this problem we chose to focus on 4 specific groups so that the underlying systematic reviews of the evidence could be carried out comprehensively and with rigour within the time scale of one full guideline's development (approx. 18 months). We believe by doing this we have been able to make recommendations for these groups that are evidence-based (albeit poor quality evidence in some areas) and these have been extrapolated to all socially vulnerable women where possible, which will include all the groups you mention. Maternal mental health during pregnancy is covered by the NICE guideline Antenatal and Postnatal Mental Health.
SH	Royal College of Midwives	3	NICE	General		Women who are living in poverty or in poor financial circumstances are also not mentioned. This is a major social need that has an impact on emotional well being in pregnancy that should be highlighted - eg:	Thank you for your comment. We agree that this is an important consideration that affects many women. Many of those in the exemplar groups will face issues relating to poverty. This has now been mentioned explicitly in the

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						http://www.fsa.gov.uk/financial_ca pability/pdfs/final_demand.pdf	introduction to the full guideline, along with examples of other groups of women who face complex social factors
SH	Royal College of Midwives	4	NICE	1.4		Using the term teenagers under the age of 20 is a difficult generalisation. The needs of women with a teenage pregnancy is different for those who are 14- 15 than for those who are 18-19. We think it is important to include some discussion of the differences in care for these women.	Thank you very much for your comment. We have now replaced the word "teenager" with the phrase "young woman under 20 years". We agree that this is disparate group with varying needs and have made this more explicit in the introduction to this section in the full guideline
SH	Royal College of Midwives	5	NICE	1.3.4		Some women may take offence to this request to repeat information. Asking for her interpretation may be more acceptable.	Thank you very much for your comment. We have reworded the recommendation to make it more acceptable
SH	Royal College of Midwives	6	Full	3.3		It would be useful for audit to be able to identify all factors within the health authority, as discussed in point 2, rather than just the four groups.	Thank you very much for your comment. We agree that the audit should cover more than just the four exemplar populations and have amended the recommendation accordingly.
SH	Royal College of Midwives	7	NICE	4.5 Last paragraph		'at present it is not clear how this should be done'. Encouraging each health authority to identify best practice could be a way of achieving this	Thank you for your comment. We agree that it is important for health authorities to highlight best practice when it is identified. Currently, given the lack of UK data, it is not always possible to identify what constitutes best practice and which interventions are successful in encouraging women to maintain contact with

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							services. It is hoped that this research recommendation will go some way to addressing this
SH	Royal College of Midwives	8	NICE	General		There is no mention of partners in this guideline. Within a health promotion role it is important to include them	Thank you very much for your comment. Although we specifically searched for evidence relating to the involvement of partners and families in antenatal care, we were unable to find any which met the inclusion criteria for the evidence reviews. As a result, the development group did not feel able to make specific recommendations for this group. We have now included a research recommendation to address this issue
SH	Royal College of Midwives	9	Full	1.3.1		<ul> <li>Members have expressed concerns regarding the use of a database for routinely collected pregnancy data and asked <ul> <li>who would be responsible for collecting the data?</li> <li>who would be responsible for the security of this personal and possibly sensitive information?</li> <li>who would have access to this information and would this database of personal information have any effect on pregnancy outcome?</li> <li>or will this database just be a collection of</li> </ul> </li> </ul>	Thank you very much for your comment. It is generally held that early booking and attendance at antenatal appointments is an important way of improving pregnancy outcomes. The recommendations within this guideline suggest ways of improving uptake of antenatal care by women who have socially complex lives. In order to ascertain whether implementation of the recommendations does indeed lead to the hoped for improved contact it is essential these data relating to gestation at booking and number of appointments attended is collected. This data collection can be carried

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						anonymous statistics relating to pregnancy? A clearly defined purpose and use of the database is essential	out by a person responsible for audit or service organisation and delivery, or service improvement. The data does not need to include personal details of individual women, however it would be expected that all trusts have procedures in place to ensure confidentiality of sensitive information since this is commonly held in all maternity units. It is not intended that the database be used to map personal care details of women and so would not be expected to impact on individual pregnancy outcomes. It would be expected that collection and analysis of such data, both on a local and national level, could provide information relating to improvements in access to care (reflected in gestation at booking) and maintained contact with care as a way of monitoring the impact of the guideline's implementation. If it did transpire that despite improved access and contact there was no improvement in maternal and infant morbidity and/or mortality at a population level that would be an important finding that would merit further investigation.
SH	Royal College of Obstetrics and Gynaecologists	1	Full	1.3.2	10	"General research recommendations" is then followed by a series of questions not	Thank you very much for your comment. The style for research recommendations in the guideline is to present them as questions which

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SH	Royal College of Obstetrics and	2	Full	1.3.2	11	recommendations "Is it acceptable to use male translators in a maternity setting?"	need further research Thank you for your comment. We have removed this research
	Gynaecologists					This question addressed later in the text may not pass scrutiny of Gender Discrimination Legislation	recommendation
SH	Royal College of Obstetrics and Gynaecologists	3	Full	1.3.2	11	"What do recent migrants, asylum seekers, and refugees see as specific barriers to accessing and maintaining contact with antenatal care" There is no question mark here	Thank you for your comment, we have added a question mark
SH	Royal College of Obstetrics and Gynaecologists	4	Full	2.3	14	MD is not an acronym for "medical doctor" by any common parlance. In healthcare it may represent Medical Director, or Medicinae Doctorem the MD degree. Managing Director is used in the wider world. Do not use this unrecognised term.	Thank you very much for your comment. The abbreviations list has been amended to indicate that MD stands for Medicinae Doctorem and that this has been used in the text to refer to physicians
SH	Royal College of Obstetrics and Gynaecologists	5	Full	3.3	25	"Offer the woman a booking appointment in the first trimester, ideally before 10 weeks" This is addressed as not being evidence based- is it worthy of being a recommendation?	Thank you for your comment. This recommendation is derived from one from the NICE Antenatal Care guideline (2008). Whilst we acknowledge that there is little evidence of its benefit on outcomes from income-rich countries, the development group agreed from their clinical experience that it was likely to be of particular benefit to women with complex social problems.
SH	Royal College of	6	Full	4.2	31	"Findings from one UK	Thank you very much for your

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	Obstetrics and Gynaecologists					retrospective cohort study show that the introduction of a drug liaison midwife who provided antenatal care, and home visits when hospital appointments were missed and co-ordinated care between health and social care providers and revised clinical management of newborns (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 babies developed neonatal abstinence syndrome or on any other clinical grounds) were associated with more women booking in the first trimester of pregnancy." This paragraph is all one sentence with only one comma for punctuation- this would not pass any "plain English" scrutiny and is extremely difficult to understand.	comment. We agree that the sentence was unclear and have now amended it
SH	Royal College of Obstetrics and Gynaecologists	7	Full	4.4	37	"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>55</sup> [EL=2-]." There are a number of references that have such small numbers in	Thank you very much for your comment. We agree that it is difficult to interpret findings from such small studies. This is reflected in their evidence level. The cut off for sample size for the guideline was set as n=5. It was set low so that potentially useful descriptive data from small

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						the study. Much apology is made for paucity of data and also very heavy reliance on non UK and especially US data. Also evident page 43 3 <sup>rd</sup> paragraph where n=7	studies could be included.
SH	Royal College of Obstetrics and Gynaecologists	8	Full	5	49	Title- this makes no distinction between migrants from the EU and those from the under developed world. Resources require more direction than this all encompassing title. As an example, a person recently migrated from Poland who has had a high standard of healthcare previously, cannot speak English, but will be able to speak English in several months, cannot be identified as the same and needing the same intensity of care, as a migrant form an underdeveloped country who may still not be able to speak English in months or years to come. There must be greater sophistication in stratifying risk.	Thank you very much for your comment. We agree that women in this group will have very different needs. We have highlighted this in the introduction to this section and made it clear that women should be treated as individuals. The stratification of risk will be addressed during the comprehensive needs assessment undertaken at booking as recommended in the NICE Antenatal Care guideline (update) CG62.
SH	Royal College of Obstetrics and Gynaecologists	9	Full	5.4	62	"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	Thank you. The intention of this was to put in place practical and informal systems such as letting a woman know her nearest hospital, giving her a phone number to keep in touch if she needs help, and phoning the new hospital to get the woman into the system. We agree that this requires

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						evidence is lacking in this area". It appears counterintuitive to make such a recommendation which has massive health service financial implications without a pilot UK research.	research and have added a question on the resource implications of setting up a tracking system.
SH	Royal College of Obstetrics and Gynaecologists	10	Full	5.6	66	Why a change of Font?	Thank you for your comment. This was a styling error which occurred when converting the document from a word format to a pdf format. This will be corrected in the final document
SH	Royal College of Obstetrics and Gynaecologists	11	Full	6	71	Title" Women aged under 20 years (teenagers)" Using teenagers in brackets is not helpful, as a description of women aged under 20 is not necessary, and also "teenagers" appears to exclude and probably ignores pregnant females under thirteen. Whether these are called women or children highlights at what point a pregnant female becomes a "woman". This is a whole area that perhaps this guideline does not wish to cover but inadvertently may stray into. The issue of very young pregnant females requiring paediatric nurses/ care on a paediatric ward and paediatric liaison staff, is not addressed.	Thank you very much for your comment, we have removed reference to "teenagers" and used the phrase "women aged under 20 years" instead. The group felt that it was not necessary to refer to paediatric services as antenatal care would be delivered within maternity services regardless of the young woman's age.
SH	Royal College of Obstetrics and Gynaecologists	12	Full	7	91	Title "Women who experience domestic abuse" in introduction to this section- definitions are given	Thank you very much for your comment. We recognise that abuse can take a large number of forms.

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						linking violence of whatever type to a domestic situation, including honour based violence or FGM. By concentration on "domestic" other examples of abuse, related to knowledge or control of a woman by a person in authority are ignored. Examples would include abuse by those in religious roles, those in medical professional roles and those who may have control in an employment setting. These abuses though not domestic, may have ongoing control issues which may have adverse effects on the pregnancy. Many of the good policy recommendations in this section would apply to a wider group of "abused" pregnant women.	The scope was drawn up to specifically look at women experiencing <i>domestic</i> abuse and as a result all of the evidence that was reviewed focussed on this group of women. Therefore, the development group did not feel it was appropriate to make recommendations about women experiencing other forms of abuse.
SH	Royal College of Obstetrics and Gynaecologists	13	Full	8	114- 7	The Health economics chapter concentrates on the additional costs to the NHS of setting up the various strategies to address the four women's groups needs. The burden of costs relates to increased midwifery costs but does not address the additional burden to medical staffing budgets or personnel involved. With every problem that is identified a change in the management plan will need to be	Thank you for your comment. If women with medical problems are identified early and require treatment from an obstetrician there will be additional costs involved. There would also be benefits from morbidity and mortality avoided. In an economic evaluation these would be compared to the costs to the health service if these medical problems are not identified until later in the pregnancy and also the losses through morbidity and mortality from

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						made by an obstetrician. If there are to be the supposed benefits to perinatal morbidity and mortality from initiatives outlined by this guidance, then some planning needs to go into that section of this paper related to outputs, and these will by their very nature involve considerable medical costs. The stratification of costs of specialist antenatal care into discrete bands would suggest that initial costs based on Table 2 p 117 where investment has gone into specialist midwives, will not be giving the full picture. This may have very considerable financial impact in areas where there are high proportions of women in these groups.	delayed care. We hope to be able to improve the model in the future when more data becomes available.
SH	Royal College of Obstetrics and Gynaecologists	14	Full	General	Gene ral	This is an extremely full and researched proposed guideline that should be welcomed. It has selected four groups of women who have complex social interactions during their pregnancies which may lead to a poorer outcome than desired. It should be recognised that there will be many women, especially in the groups related to age and migrancy status, who will not have a risk of poorer outcome and thus	Thank you very much for your supportive comment. We agree that it is important not to make assumptions about these women, based on the particular group that they fall into. We have developed the introductions in the guideline to make this more explicit

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						neither assumptions nor conclusions regarding these groups should be made. The paucity of data, the reliance on US or non UK data and the economic basis of this advice are all areas where caution should be adopted but the RCOG welcomes focussed attention on these groups of women who can be further helped by health and social services.	
SH	Royal College of Obstetrics and Gynaecologists	15	NICE	1.3.1	13	Are women from countries outside the UK aware of the maternity care services in the UK? For example, women from Sub- Saharan where the concept of maternity care will be completely new to them. It needs careful explanation – What antenatal/postnatal care is, the investigations/scans that will take place and why these investigations/scans are performed. This aspect of care needs to be clearly addressed to ensure that asylum seekers/refugees are aware of the services they are able to access. Moreover, there needs to be effective communication in relation to payment for health services, as these women are	Thank you very much for your comment. Recommendations for this target population cover many of the issues you raise. For example it is recommended that: Women should be told about antenatal services and how to use them; The NICE Antenatal care guideline (CG62, 2008) contains a number of recommendations relating to information giving, explanation of screening and antenatal testing, informed consent and the need to respect a woman's wishes regarding her care. These recommendations apply to all women, including women who are recent migrants. It is recommended within the current guideline that women be provided

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						often reluctant to seek medical care as they think they will have to pay. This is particularly important in the case of those women with HIV – where medical care can be crucial in the safety of the mother and baby. Health professionals, when attending to asylum seekers/refugees should be acutely aware that smiling, touch, eye contact and other non- verbal communication will be an important part of the consultation. The importance of this should <u>not</u> be underestimated, as non-verbal communication can say much more than words. The non-verbal communication helps to foster a positive relationship between the patient and the health professional. There should be some sort of central telephone system providing advice for women in different languages so as women in labour – or requiring assistance – are able to access help they can understand. For example, a woman goes to hospital as she thinks she is in labour, it turns out to be a false alarm and she is advised to go home and ring later. How can she ring to ask for advice when she is	with information regarding entitlement to care and that healthcare staff are trained to ensure they know what these entitlements are so they can explain them to women. Recommendations regarding sensitive communication were not felt to be appropriate as these apply to all communications between clients and health care staff, in any setting. The use of interpretation services (face to face or telephone) is recommended. Situations where a woman is unable to communicate and has no-one to help her communicate would have to be resolved on a local basis, the GDG felt it was not appropriate to recommend a national service providing interpreters for numerous languages.

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						unable to communicate with the midwife over the phone? Health professionals need to take into account that a procedure seen as relatively safe in this country may be viewed in a very different way to that of the woman from a developing country. This issue is not easily addressed, as even when communicating through an interpreter, there may not be a direct translation of the word, so the precise meaning may be misunderstood. Central to communication is the issue of informed consent. If there has been difficulty trying to secure an interpreter to discuss the woman's condition – and necessary treatment – it is essential to ensure that the woman does not feel coerced into accepting interventions.	
SH	Royal College of Obstetrics and Gynaecologists	16	NICE	1.3.4	14	It is ESSENTIAL that women are able to take a copy of their hand- held notes when moving from one area to another so as health professionals involved in her care are able to offer continuity of care – and, more importantly, that she	Thank you very much for your comment. We agree that women should be able to take their hand- held notes with them when moving areas. The development group were aware of areas where this was not possible and so agreed that they

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						receives the appropriate care for her individual needs.	should make a recommendation about it. The group have now agreed that this will be an overarching recommendation for all populations
SH	Royal College of Obstetrics and Gynaecologists	17	NICE	1.3.7	14	<ul> <li>ASYLUM SEEKERS AND FEMALE CIRCUMCISION</li> <li>Challenges faced when dealing with women who have undergone female genital mutilation (FGM): <ul> <li>Sensitive nature of the topic – women may be unwilling to come forward for help, and may be fearful of the reaction of healthcare workers</li> <li>Language difficulties</li> <li>Fragmented antenatal care due to asylum seekers being moved around the country</li> <li>There is difficulty in accessing dedicated clinics offering services for those women who have undergone female genital mutilation. These clinics should be open with flexible access, in collaboration with other agencies</li> <li>Cultural differences – when discussing health care per se and the differing perceptions of</li> </ul> </li> </ul>	Thank you very much for your comment. We appreciate your passion for women who have undergone FGM. Within this guideline which covers a range of issues relating to care of women who are recent migrants, refugees and asylum seekers it has been necessary to address a wide range of issues. The provision of dedicated clinics for women with FGM has to be decided on a local level determined by local need. In addition, education of partners and family members regarding FGM and specific care surrounding the issue of FGM is beyond the scope of this guideline. The need to train staff so they are equipped to address issues relating to women's cultural and religious needs, including FGM, is recommended. We have clarified in the GDG interpretation that the need for obtaining partner or family consent when conducting a physical examination is an example of a cultural issue about which healthcare professionals should be aware.

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						the need for health care When in discussions with women: Interpreters should appreciate the problems these women face; but crucially the interpreter <b>should</b> <b>not</b> be relatives or children. To ensure confidentiality, the woman and interpreter should not know each other socially. This allows the woman to feel free to discuss any issues or concerns without feeling pressurised – and to make decisions she feels comfortable with. It is seen that marriage is the only secure future for women in these societies, and elders in the family may overrule the woman's wishes and FGM will be performed. The sexual ramifications, together with the fear of the attitude of her husband towards her need to be considered; therefore husbands should be supplied with appropriate medical facts and advice leading to mutual understanding. When seeking information/performing examinations, the woman may feel that permission needs to be granted by an appropriate male relative in order for a male	We agree that interpreters should be provided and that these should not be partners or family members. The recommendation has been amended to reflect this. Page 16: Whilst we acknowledge the importance of encouraging pregnant young women under 20 to stay in education NICE guidance is developed for the NHS and does not extend to education services. An overarching recommendation has been made to ensure women are provided with the opportunity for at least one one-to-one consultation without partner or family input. This recommendation includes young women under 20.

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						healthcare worker to examine her, if not this may be interpreted as abuse by the woman and her family Accessing clinics provides the opportunity to open up a dialogue for other services which may be required by the woman in the future e.g. sexual health, contraception and cervical screening. In summary: • Need to work in a joined-up way – gynaecologists, psychologists and midwives to ensure women receive the care and support they need • Treat these women with kindness and sympathy, while being mindful of cultural issues within the scope of treatment • Ensure health professionals know of the dedicated clinics – and how to contact them if need be From Page 16 The young mother is very dependent on many people and available services – health care, social care, accommodation,	

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						education and benefits. In encouraging her to engage with antenatal services, she can be assured of receiving the most appropriate help and support. It is important to encourage, and put into place the appropriate strategies, for the young mother to continue her education during her pregnancy – and following the birth of her child. Teenagers should be offered consultations without parental or partner input, as the girl's parents will often take control of the situation, leading to the teenager feeling disempowered. If she is offered time alone with the health professional, this will make her feel more in control and it provides the opportunity to openly discuss any concerns she may have.	
SH	Royal College of Pathologists	1	Full	General		There appears to be no cross- referencing between this guideline and other NICE guidance on Drug Abuse. The place of testing for drugs in minimising a chaotic life- style, which is an issue that interests social services, is not recognised and should be. There is a further aspect though typically post-natal, of demonstrating the mum is drug-free so that either	Thank you very much for your comment. We have now included reference to the relevant NICE guidelines on substance misuse in the "additional guidelines" section. The development group did not feel it was appropriate to refer to testing for drug use as this would not be conducted within antenatal care but rather within specialist

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						children are not put into care or if they are, they are returned to them [this may also apply to partners]. I would also note that I do not think there is a definitive guide on drug addiction services, which is about more than opiate detoxification.	substance misuse services. It was outside the scope of this guideline to consider post-natal substance misuse. In addition, it was outside the scope of the guideline to look at what care should be provided within specific addiction services
SH	Royal College of Psychiatrists	1	Full	General		This document is a welcome addition to the NICE guidelines, addressing the service needs for women with complex social problems. The four 'exemplar' groups pose particular challenges to service providers. It is unfortunate that the evidence base is so poor for the questions	Thank you very much for your comments. We share your frustration that the evidence base is poor and agree that there is a need for further research to be carried out, ideally based on the research recommendations included in the guideline.
						set and so the recommendations are broadly derived from expert opinion. Nevertheless, the recommendations for future research have particular importance in this light. It is of concern that the representation from addictions mental health was very limited.	Although we didn't have specific representation from addictions mental health, one GDG member is a clinical substance misuse lead in offender health and another is a midwife running a specialist service for women misusing substances.
SH	Royal College of Psychiatrists	2	Full	General		The evidence, particularly that coming from the Confidential Enquiries into Maternal Deaths, highlights the need for effective communication between agencies and multiagency working. While this is mentioned in the	Thank you very much for your comment. We agree that effective cross-agency communication and multi-agency working is extremely important. The general recommendations highlight the need for healthcare professionals to

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						recommendations, it doe not achieve the prominence of being included in the general recommendations applicable to all groups. This applies particularly to the need for good communication and information sharing with primary care/general practice.	receive training on national guidelines on information sharing, and that healthcare professionals should consider initiating a multi- agency needs assessment.
SH	Royal College of Psychiatrists	3	Full	General		The Section was concerned that there was very little mention of the mental health needs of these groups of women. While the guideline does not address specific treatment needs, each of these groups has a higher risk of comorbid mental illness. Service provision recommendations should include the need for effective joint working and referral procedures into mental health services where need is identified. This should include locally agreed protocols with specialist addiction, adolescent and perinatal mental health (or general adult mental health where such specialist services do not exist).	Thank you very much for your comment. We recognise that often women in these groups will have specific mental health needs. The evidence reviewed for this guideline did not provide sufficient detail about women's mental health needs for the development group to make specific recommendations about this issue. Where the recommendations make reference to referral to other local agencies, we intend this to include mental health services (as well as other agencies such as social services)
SH	Royal College of Psychiatrists	4	Full	General		Many of the recommendations about engagement and service provision apply equally to non- health organisations, such as social services. It would be helpful if NICE had a dissemination policy that could include other relevant	Thank you very much for your comment. We agree that the guideline will be of relevance for a number of other agencies. Although the guideline is aimed at the healthcare professionals and providers within the NHS, it was

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						agencies.	produced in collaboration with the Social Care Institute for Excellence. NICE produces a number of implementation tools which accompany the guideline and we anticipate that these will look at ways of engaging with other relevant agencies.
SH	Royal College of Psychiatrists	5	Full	1.2		Efforts to ensure engagement for drug misusers also require an openess about the need for ongoing monitoring of use, including regular drug testing. Evidence is present for adverse outcomes for mothers and babies of undetected continued use in pregnancy. Less experienced workers may be reluctant to utilise such measures, misperceiving them as barriers to engagement.	Thank you very much for your comment. We agree that openness and good communication are vital for maintaining contact with this group of women and so have recommended continuity of carer provided by a specialist substance misuse midwife to promote this. It was felt that it is the responsibility of substance misuse services to carry out ongoing monitoring whilst it is the midwife's role to ensure that the woman stays in her substance misuse programme. As a result, the group did not feel it necessary to make a specific recommendation about ongoing monitoring within antenatal care.
SH	Royal College of Psychiatrists	6	Full	1.2	7; line 33-4	This may be unrealistic where child safeguarding procedures need to be invoked. A similar point relates to page 5 line 1-2. Effective engagement with services is essential but the prioritisation of child safeguarding must be explicitly recognised and discussed in an open fashion with	Thank you very much for your comment. We agree that there may be occasions where the woman's disclosure may need to be communicated perpetrator of the abuse. We have now removed this bullet from the recommendation.

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SH	SCAN	1	Full	4.1	28	Numerical data regarding characteristics of maternal deaths would be more useful if presented as percentage figures rather than just raw numbers especially when there is no reference to the total numbers assessed.	Thank you very much for your comment. We have now provided more information about the number of women assessed
SH	SCAN	2	Full	4.2	30	Lack of clarity in the Australian retrospective study on whether women were using illicitly at all in the three groups. For example the 'previous' treatment group were defined as those whose last treatment programme ended at least a year prior to the birth. It is assumed that all are therefore abstinent after treatment but data re any potential additional illicit use would be important in deciphering the later neonatal outcomes, especially as risk of relapse would be high. It is noted that limitations of the lack of information on methadone dosage and treatment policy are stated in the draft.	Thank you for your comment. Unfortunately the degree to which women are misusing ssubstances is not reported in the paper. The incidence of neonatal abstinence syndrome is reported however was was found to be 20.5% in the late entry group, 23.4% in the early entry group and 4.0% in the previous treatment group, suggesting that the level of substance misuse was lower in the latter group. This detail is reported in the evidence table.
SH	SCAN	3	Full	4.3	33	Typo 3 <sup>rd</sup> paragraph, line10, excess 'were'	Thank you for your comment, this sentence has been reworded and the additional "were" removed.
SH	SCAN	4	Full	4.5	39- 45	Poor quality of evidence was found for this particular question (3). The small numbers is some studies and the difficulty in	Thank you very much for your comment. We agree and share your frustration that it is very difficult to draw conclusions based on the poor

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						generalising US data to UK situation are already mentioned but make any conclusions very difficult to draw.	quality of underlying evidence. The GDG were tasked with interpreting the evidence in light of their own experience and expertise. This interpretation is detailed in the full guideline and shows how the recommendations are derived.
SH	SCAN	5	Full	4.6	46	Although no good quality evidence for question 4; the provision of additional information to pregnant women, was evident, agree with GDG recommendations in the interpretation of evidence paragraph.	Thank you very much for your comment and support for the GDG interpretation of evidence and recommendations.
SH	SCAN	6	Full	4.7	48	Welcome further consultation described on methods to aid pregnant users contact with antenatal services given evidence that late antenatal booking and poor attendance are associated with poor outcomes.	Thank you very much for your support for this research recommendation.
SH	SCIE	1	Full	General		Substance misuse: research outcomes may not be available or clear-cut but good interim 'messages from practice' could be drawn from current service models, as in Appendix, including where they use existing principles and frameworks eg integrated care pathway This would show the work as mainstream albeit	Thank you for your comment. The service survey was undertaken on the understanding that services would be used to provide examples of how care could be delivered within an NHS setting. Without evaluative data to show the effectiveness of these services in relation to improving access, maintained contact or pregnancy outcomes it was felt inappropriate to use them as "evidence" upon which to base

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						dealing with particular patient groups. The nature of the evidence- the draft states that it is difficult to comment on research about 'pregnancy outcomes'. It might be helpful to state what these would be for substance misusing women and their babies eg some contact with ante-natal services, which is better than none; engagement that gives information, shared understanding and realistic reassurance about immediate and future involvement with a range of services (child protection, family support, substance misuse treatment and support) and that helps to broker and sustain these.	recommendations. The outcomes focussed on for the reviews are stated in the introductory section for each review and do include gestation at booking and number of antenatal visits made, as well as pregnancy outcomes. We agree that these outcomes are useful as proxies for improved pregnancy outcomes and the GDG used this evidence as the basis for recommendations. How the decisions reached were arrived at is recorded in the GDG interpretations of evidence.
SH	SCIE	2	Full	General		Recommendations for services outwith antenatal services Section 7 recommends a local protocol is written on domestic abuse. This would usefully apply to all groups covered in the Guideline and should include identification and	Thank you very much for your comment. The group discussed the possibility of developing a protocol for each population considered in the guideline. The only evidence identified relating to protocols was for the domestic abuse population and so the group did not feel that they could make recommendations about

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						<ul> <li>implications for relevant commissioners across the services considered under a protocol:</li> <li>Substance misuse- incorporating Safeguarding requirements and local Working Together arrangements.</li> <li>Women who are recent migrants etc- integration with existing protocols and arrangements for these groups. These may be situated more widely across the local authority, but include social care services. The current SCR in Westminster indicates the difficulties HIV+ women have in disclosing their status and in using community interpreters. The Homerton Hospital, Hackney, service has considerable experience of this.</li> <li>Women aged under 20 - incorporating Safeguarding requirements and local</li> </ul>	<ul> <li>protocols for the other populations.</li> <li>The group agreed that as training on safeguarding is mandatory, it was not necessary to include it in the recommendations. We have included reference to the working together arrangements in a footnote.</li> <li>Thank you for highlighting the upcoming NICE/SCIE guideline, we have now included reference to this in the list of other related guidance</li> <li>In response to stakeholder comments, we have now removed the recommendation that disclosure of domestic abuse will not be communicated to the perpetrator as it was recognised that this would not always be possible.</li> <li>We have recommended that healthcare professionals receive training in how to respond to domestic abuse which we anticipate would include what healthcare professionals should do with that information.</li> </ul>

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						in a new row. Working Together arrangements for vulnerable young people. Integration with Children & Young people's Plans, including Looked After Children & Young People ( NICE/SCIE Guideline due October 2010) Women who experience domestic abuse – incorporating Safeguarding requirements and local Working Together arrangements and family support arrangements. Work on the NICE/SCIE guideline on domestic violence begins in September 2010. I would hope that this considers the implications of screening, identification and information sharing. In the meantime, it would be helpful to expand on Recc 7.8 'telling the woman that disclosure of domestic abuse will not be communicated to the perpetrator of the abuse' so	
						that ante-natal staff have confidence in sharing	

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						information, including within the context of safeguarding, in knowing what happens to that information and the protective support provided to the woman.	