

Stakeholder consultation workshop notes

Friday 21st September 2012

Key issues emerging from each discussion group

Group 1

The infant and infant mental health:

- Participants agreed that the postnatal time period needs to be established (6 months? 1 year? 3 years?)
- Participants reported that there has been a growth of evidence post 2007 on the impact of the mother's mental health on the infant
- Treating illness quickly was considered by the group as important because of adverse effects on the infant (rapid intervention, timing, detection).

Attachment disorders:

- Participants agreed that there is little access to specific therapies that address attachment disorders.
- The group commented that issues with diagnostic assessment in this area exist.
- The group noted that attachment issues often arise in IVF.
- Participants stated that there has been a growth of evidence in the quality of mother-infant interaction in terms of better assessment and understanding, however much less evidence exists on interventions for mother-infant interactions, especially mentally ill mothers.
- The group discussed the efficacy of family nurse-parent partnership programmes.

Personality disorders:

- Participants reported that individuals with personality disorders (PDs) occupy a large proportion of time in perinatal services (approximately 75%) and despite this, poor outcomes are observed. The question of whether specialist PD services are needed was posed.
- The group stated that individuals with PDs are often given an incorrect diagnosis - mislabelled as having postnatal depression/depression or PTSD, which has subsequent effects on care provided, e.g. re-traumatising individuals by being given poor care.
- Participants commented that interventions are needed in the antenatal period not just the postnatal period.
- Participants noted that a high degree of conflict is observed in individuals with PDs and social services.

Substance misuse:

- Participants commented that issues exist in overuse of painkillers e.g. paracetamol and co-codamol.
- The group deliberated the following: how will women with substance misuse issues be managed in services?
 - How are these individuals assessed? Often questions are posed regarding mother's substance use/alcohol consumption, but are mothers honest in their responses?
 - What psychiatry team will see these individuals?
 - The group stated that an expert in substance misuse is needed in the GDG.
 - Participants commented that in some areas/trusts the vulnerable adults and baby model has worked well, with midwives delivering the interventions.

Nutrition and mental health e.g. essential fatty acids, b vitamins

- Participants discussed nutrition and mental health, however the point was made that this area has been covered in NICE guidelines in antenatal care

PTSD/traumatic birth:

- Area of whether stillborn infants should be held or not after birth was discussed.
 - The group noted that current research evidence is largely in line with the previous guideline's recommendations.
 - Some members of the group commented that based on anecdotal experience, women who do not hold their stillborn baby grieve for longer periods of time.
- The group deliberated the following: Can we identify women who have PTSD accurately? Are assessments needed?
 - Issues appear to exist in professional's ability to assess and report what has happened at delivery accurately e.g. accounts of not traumatic birth being recorded when in fact the birth was terribly traumatic for the mothers.
 - Intrapartum risk factors should be noted – women moving from low risk to high risk.
 - Some participants reported that some professionals, e.g. health visitors, have provided incorrect diagnosis of postnatal depression instead of PTSD, resulting in GPs making incorrect referrals – this occurs in both high and low risk women.

Issues with case identification of postnatal depression:

- The previous guideline recommended that WHOOLEY questions are used and if a 'yes' response is given then an assessment tool such as the EPDS should be administered, although previous practice in some areas/trusts involved administration of EPDS without the need for a prior response to the WHOOLEY questions.
- The group stated that there are issues with this, including:
 - In some areas health visitors are no longer routinely visiting mothers to administer EPDS, hence longer time is spent with mothers not being seen by health visitors – EPDS involves face to face interaction and there are benefits of this.
 - Bad practice exists in some areas:
 - WHOOLEY questions being asked over the phone.
 - If a mother provides one 'yes' response then a referral to social services is made.
 - Lack of clear understanding in services for where to refer someone if they do answer 'yes' to one of the WHOOLEY questions.
- Participants reported that there are issues with communication between midwives and GPs, where often GPs are completely bypassed – impacts on the detection of postnatal depression. One participant stated that good practice exists in Devon and Cornwall, where communication is good and detection of postnatal depression is better.

Perinatal networks:

- The group noted that the National commissioning board is currently undergoing a review of networks.
- The group commented that perinatal networks were expanded in areas that already had services in place (this was largely due to the presence of a champion, particularly in the south west), whereas in areas where networks did not exist, they were not adopted.
- The group noted that there is other research going on for recommendations regarding perinatal networks (CCG).
- National Quality Standard for perinatal mental health.

Pharmacological interventions:

- The group agreed that there has been a change in the evidence base since the previous guideline.
 - More evidence exists on the teratogenic risk of various antidepressants.
 - Reviews in progress by the Newcastle group (Hamish McAlister Williams) and BAP.
- The group commented that based on anecdotal experience, St John's Wort appears to be useful for some women.

Suggestions for GDG members:

- Practice nurse
- Someone from social care e.g. family support worker
- Mental health nurse, clinical nurse specialist
- Mother-infant specialist

Group 2

Main outcomes

- Participants agreed that all clinical issues within the scope are important and relevant.
- Participants agreed that the outcome of 'leaving the study early for any reason' needs to be clearer.
- It was suggested that breast feeding should be added to the main outcomes.
- Participants emphasised the importance of the wider context of women's lives, the group agreed that ethnicity and culture are important.
- Participants discussed 'mother and baby interaction' and suggested that this could be changed to 'parent and baby interaction' as this would encompass fathers and same sex partnerships.
- Participants agreed that the management of risk to self and others (including baby) is important.
- Participants discussed surrogacy and it was suggested that this is a group that needs to be considered as more data on this is needed.
- Participants discussed traumatic births and PTSD - consideration of care planning and procedures is needed.
- Participants discussed the importance of a definition of 'traumatic birth'. The group discussed how women who have had a previous traumatic birth may not seek help until their next pregnancy.
- Participants discussed symptoms resulting from trauma due to miscarriage, and agreed that consideration of the needs of this group of women is important.

Measurement of outcomes

- The group discussed the measurement of outcomes and the weighting of research evidence.

Clinical need for the guideline

- Participants agreed that sections H and I are repetitive and need to be amended.
- CMACE has now changed its name and that this needs to be amended in the Scope.

- Participants emphasised that drugs such as methadone have not been included in section K.

Communication

- Participants agreed that communication needs to be improved amongst clinical staff. Issues around identification and documentation are important.
- Participants agreed that women need to be further involved in decisions about their care.
- Participants agreed that identification by health visitors was important. The group reported that issues around health visiting have become more target focused.

Population

- Participants discussed that individualised contexts are important.
- Participants discussed possible difficulties around access in relation to contacting black and ethnic minority groups.
- Participants discussed the importance of recognising the wider needs of women.

Clinical groups of importance

- Participants highlighted clinical groups, aside from mental disorders, that the new guideline might need to consider:
 - Surrogate mothers
 - Rural populations
 - Travellers
 - Immigrants
 - Teenagers
 - Women with a learning disability
 - Older mothers
 - Women affected by tokophobia

Mother-infant interaction

- Participants discussed the possible impact of the baby having a disability and how this may affect mother-baby interaction.
- Participants agreed that the relationship with the baby was fundamental.

GDG composition

The following additions to the list of current suggestions were put forward:

- A professional with a homeopathic background
- CPN

- A professional from a bereavement background
- Academic researcher
- A professional from a Children's Centre

Group 3

Making decisions about medication in pregnancy

- Participants discussed the importance of balancing risk and benefits of stopping or continuing with medications during pregnancy (and the impact on breast feeding); and the importance of communication between different professional groups (e.g. GPs and midwives) as well as women about this decision
- Participants considered the woman's choice important in making these decisions

Training

- Participants felt it was important to extend training about mental health during pregnancy and the postnatal period to GPs, health visitors and generic mental health staff
- Participants agreed that psychological health needs more emphasis in midwife training

Communication

- Participants highlighted the need to improve communication between women and services as well as within services

- Communication between services:

Psychiatric services ↔ Maternity services



- Problems also exist in electronic patient records – participants highlighted how important it was to include pregnancy in mental health records, and include mental health disorders in maternity records
- A common 'language', used by all professional groups would improve communication between women and services; and aid in care planning
- It was felt that currently, the way information was framed and different professional groups communicated with service users, contributed to barriers to care.
- Communication should always include consideration of improving and protecting the well-being of the woman

Improving implementation of the current guideline

- Participants considered the issues around communication to be linked to the issues they have experienced in their current practise regarding implementation of the current guideline. For example, participants considered implementation to be improved if a 'common language' was used across multiple professional groups
- Implementation issues included discussion of:
 - Fast tracking
 - Service delivery
 - Continuity of care
 - Differences in the delivery of treatments since the last guideline
- Participants reported that in current practise, 'the minimal' is now considered acceptable following the publication of the previous guideline
- Changes being implemented are not women or family focussed
- Participants felt that recommendations in the current guideline regarding 'debriefing', particularly with regards holding still borns, needed clarification. Participants reported that in current practise, the current recommendation leads professionals to think that it is dangerous to have any kind of conversation about still birth with mothers. It was agreed that any new recommendations needed to be worded differently, acknowledging the individual experience and the complexity of grief.

Interventions for mother-infant interactions

- Participants considered it important to look at improving the quality of the interaction between mother and infant
- Participants reported that services are not set up for this

Assessment and outcome measures/tools

- Participants discussed the difficulties inherent in different professional groups using different assessment and outcome tools. For example, GPs will use the PHQ9, midwives generally use the WHOOLEY questions and mental health professionals might use the BDI and the HADS
- Participants reported that, in their clinical experience, women liked to be asked about their mental health

Mental disorders of mild severity and associated feelings of stigma

- Participants felt the updated guideline should include information about managing women with mental disorders of mild severity. It was agreed that often mild cases can get 'lost' in amongst moderate cases which has long term health and economic consequences

- Participants felt it was important to empower women to help themselves by increasing awareness about what services and support are available (including peer support)
- Participants agreed that empowering women in this way can help reduce internalized stigma and fears around having baby taken away
- Participants reported that in current practise, health visitors are only allowed to see severe cases of mental disorder
- Participants reported that, in their clinical experience, the following had helped reduce feelings of stigma:
 - Telephone helplines
 - Home visits
 - Reframing
- It was considered important to look at the 'pyramid of need' detailed in guidance about diabetes – participants felt this would be a helpful guide in thinking about different disorders as well as stages of pregnancy

Clinical groups of importance

- Participants highlighted clinical groups, aside from mental disorders, that the new guideline might need to consider:
 - Infertile women
 - Women who have had an abortion
 - Teenagers
 - Assisted pregnancy
 - Still birth and trauma
 - Depression and PTSD in fathers
- When considered how women cope with still birth and trauma, participants pointed to the fact that bereavement counselling is usually provided by generic services such as Cruse, which do not usually provide family or couple therapy

Equalities

The following groups were considered important:

- Fathers
- Mild and moderate severity groups
- Substance disorder
- Hard to reach communities
- Low socioeconomic groups

Other guidance

- Participants considered it important to link the updated guideline to public health guidance that is already available

GDG composition

The following additions to the list of current suggestions were put forward:

- Perinatal nurse
- A community mental health professional (considered more relevant than having an inpatient professional)
- Specialist midwife
- Social services professional
- Pharmacists and psychopharmacologist was considered unnecessary.

3 key points from each discussion group:

Following the small group discussions, each group provided a summary to the wider group regarding what they felt to be 3 key issues emerging through their discussion. The following 3 key points were identified from each group:

Group 1

- Care pathways
 - Access
 - Differences between groups (e.g. PTSD/trauma, parenting (mother-infant), psychoactive substances)
- Medication
 - Communicating harms and benefits
 - Principles
- Interface with social care

Group 2

- Use of the Edinburgh Postnatal Depression Scale
 - How the data is used
- Vulnerable groups
 - Problem with labelling, e.g. not all teenagers or BME service users are vulnerable. Care needs to be individualized
- Care pathways
 - Preconceptions

Group 3

- Training
 - For all professionals involved in the care of women with mental disorders during pregnancy and postnatally
 - Normalizing
 - For service users – increasing awareness of what support is available, helping women help themselves (particularly for milder severity groups)
- Organization of, and communication between, services
 - Continuity of care
 - Using a 'common language'
- Assessment and outcome measures/tools
 - Inconsistency in the use of assessment and outcome measures used by different professionals