

McCourt, C., Cheyne, H. & Semple, K. (2012). Mothers Involved in Research Agenda Setting: Report of the MIRAS project. Stirling, UK: NMAHP Research UNit, University of Stirling.



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Original citation: McCourt, C., Cheyne, H. & Semple, K. (2012). Mothers Involved in Research Agenda Setting: Report of the MIRAS project. Stirling, UK: NMAHP Research UNit, University of Stirling.

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Mothers Involved in Research Agenda Setting:

Report of the MIRAS project

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October 2012
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Introduction

The provision of high quality maternity care is central to Scotland's health policy. Around 58,000 babies are born in Scotland every year and mothers and their families rightly expect to receive care which is based on the best possible evidence for what works and which is focussed on their needs and the needs of their babies. Significant research effort on the part of academics and clinicians has made birth safer for mothers and babies worldwide. However, decisions about what research is undertaken are rarely made in consultation with women. Research strategies and funding priorities are usually set by senior academics, policy makers and even private industry (Scadding and Chalmers, 2009) and this may result in substantial mismatch between research undertaken and the issues that are important to those who use the health service (Petit-Zeman et al 2010). While the notion of patient involvement in clinical decision making and provision of patient focused health services is well established the meaningful involvement of those who use health care in research is as yet scant. The question "*would researchers be helped to do more relevant research if the public became more involved in planning and promoting research?*" (Chalmers, 1995) challenges the prevailing culture of academic paternalism, although effectively involving healthcare users in research planning is also challenging. Organisations such as the James Lind Alliance and INVOLVE support and advocate for partnership between academics and the public. However, it is not as yet clear how best to meaningfully involve service users in research.

In undertaking this project we aimed to work in partnership with groups of mothers across Scotland to develop a set of questions for research which reflected issues that mattered to them and at the same time to gain greater understanding of ways of eliciting researchable questions from women's experiences of maternity care. The project was undertaken with 12 groups of mothers in four geographically diverse areas of Scotland. We found that women were very willing to describe their birth stories and in discussing these, to identify important topic areas and questions about the care they received or would like to receive. While not all the groups were familiar with the ideas and language of research, following brief literature review and subsequent discussion with the research team the majority of groups were able to prioritise topic areas using a modified nominal group technique.

A wide range of topics and questions were identified although there are remarkable areas of consensus. In particular, these focussed on content and quality of routine care with questions about information, communication, decision making and support across all areas, giving strong indication of what issues are important to women. Rapid literature reviews identified that some research has been conducted in most of the topic areas but in many cases further primary research, research syntheses and in particular translational research is required to ensure that research efforts result in improvement in the health care experience and wellbeing of women.

Aim

The aim of the MIRAS project was to work with maternity service users to develop a set of priority themes and questions for research in maternity services that reflect their priorities.

Method

The project used a participatory approach in a diverse sample of localities across four Health Board areas in Scotland. Within each area a working group, comprising local service user and service provider representatives assisted the project team to identify pre-existing, diverse, community-based groups of maternity service users. A total of 12 community groups participated with between 8 and 20 mothers in each.

Each group met twice with facilitatory work by the project team as follows:

1. group discussion to identify areas of interest and potentially important topic areas for research, facilitated by project team members
2. the project team conducted rapid literature reviews and scoping work to develop a discussion document on the state of existing evidence on the topics raised. This was fed back to each group verbally as well as circulated in writing to support the decision-making of the group members
3. a follow-up group discussion was held to discuss the potential topic areas further, and to agree a set of research questions and priorities

Findings of the local groups were discussed at area and national group levels to compare and merge the local findings to form a national picture. This included discussion of the ranked priorities, and a more qualitative exercise to re-read, explore and discuss the emerging findings and gain a sense of what was important to participants.

Key topics were raised across different individuals and groups and key themes readily began to emerge. We first used visual presentation and tabulation to identify a set of key topics that were raised repeatedly by different groups. The women's votes for research questions were then counted grouped under each topic. Some topics were broader than others, as will be illustrated in the findings below, but these were discussed on several occasions to agree that the topic and questions grouped under that topic were sufficiently coherent to form a research topic. A 'top ten' list of priority topics was thus identified. These represent both the number of votes by individual participants and the number of groups in which a topic was prioritised. The top ten topics are presented below, together with a brief summary to give a flavour of the questions asked under each topic. Overall over two hundred individual questions were raised, some were common questions while others were raised by only one woman, however as agreed by the groups all of the questions have been included. A full list of questions is provided in appendix 7.

Background

The Scottish Government report *Better Health, Better Care: Action Plan* recommended working towards a health service that is 'mutual', where Scottish people and health service staff are partners in care. To achieve this, it set out proposals that should 'shift ownership and accountability to the people of Scotland and offer them the opportunity to take more control of their health' (Scottish Government 2007: foreword). The Action Plan noted the importance, for patients of 'communication, participation, being listened to and having the opportunity to play a stronger part within the NHS' (Scottish Government 2007: foreword).

Over the last decade there has been a consistent health policy focus on developing high quality maternity care which is woman focussed and evidence based (Scottish Executive 2001; 2002; Scottish Government 2011) The Keeping Childbirth Natural and Dynamic (KCND) programme, for example, aims to provide evidence based care, reduce unnecessary intervention, ensure informed choice for women and introduce multi-professional antenatal, intrapartum and postnatal care pathways. This and other development programmes should be informed by the perspectives of service users.

Women's views should also help to inform outcomes that are measured in research. Patient involvement and public partnership can take place at a number of stages and levels, and this should include partnership and involvement in setting the agenda for research that can inform the future delivery of health services. Kuruvilla and Mayes (2005) in discussing the challenges of implementing research findings in practice argued that science must be understood as working within a social context, and having social implications. Therefore, providing opportunities for diverse groups to share their views and experience will help to ensure that a range of perspectives and resources can be integrated to address complex health concerns (McCourt et al. 2006).

Principles of involving consumers in research have now been established, including equity and effectiveness considerations (Hanley et al. 2000, DoH 2001, McCourt et al. 2006) but work on the process of doing so remains less well developed (Oliver et al 2004). Only limited work has so far been conducted on the impact of involvement in how research is commissioned, but it has been argued the effective involvement and partnership should commence with involvement in setting questions and priorities, rather than attempting to commence involvement only at later stages such as advising on particular projects, or commenting on research findings (Buxton et al. 2000, Hanley et al. 2000, Oliver & Gray, 2006). The James Lind Alliance has identified that frequent mismatches occur between the issues described as important to clinicians and consumers and has championed the development of methods to illicit joint clinician patient priorities (Petit-Zeman, 2010).

Project aims

The aim of this project was to develop, in collaboration with maternity service users, and with support from maternity service providers and researchers, a set of topics for future research in maternity care that reflect users' priorities. We are defining maternity service users broadly to include women who have used maternity services, their partners and close family members.

Better Health, Better Care (Scottish Government 2007) also highlights the importance of service development which is inclusive in tackling the health effects of social inequality. In keeping with this principle, the MIRAS project aimed to include methods and approaches to ensure a diversity of women's voices are heard, such as groups conducted in specific areas of social deprivation and groups which are in themselves diverse, involving a range of women in the locality who have experience of maternity services.

In order to establish a set of topics our intention was that the process would be inclusive, informed by review of existing evidence, and would facilitate development of a set of researchable questions, capable of practical application.

- Inclusive – involving a range of service user and perspectives, using an accessible approach
- Informed – with all potential topics investigated to identify the current state of evidence and need for research (or research review, dissemination and implementation)
- Ordered – in terms of importance of the topic from the different perspectives and in terms of the potential for eventual impact on service development
- Focused – on the concerns of maternity care service users in Scotland, but also likely to have wider, international interest and relevance

A secondary but important aim was to develop and describe an effective process for involving ordinary people in setting agendas for health research and development that can be developed further in future work.

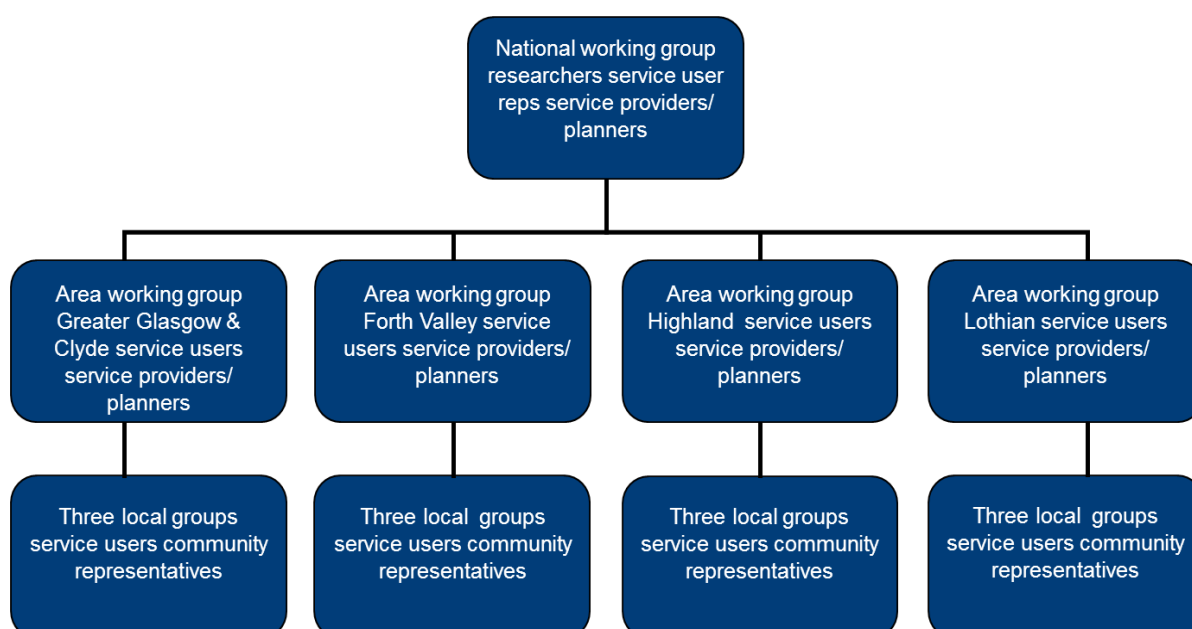
Project Plan/Process

A participatory approach was used, in a diverse sample of localities across Scotland, in order to develop a set of priority themes for research in maternity services that are fully informed by the experiences and perspectives of service users. A series of working groups were developed, where members work together to investigate an issue and develop appropriate responses. This approach was modelled on work previously conducted for NHS London to develop methods for involving health service users and practitioners in agreeing priorities for maternity research (McCourt & Beake 2000; McCourt et al. 2006). Similar approaches are

now also being developed and implemented by the James Lind Alliance (www.lindalliance.org). We organised a series of groups on three levels as follows:

1. National Working Group: of researchers and policy analysts to advise on the project work, and then to advise on and support the synthesis of findings for an overall priorities report. (see appendix 1 for membership)
2. Area Working Groups: a mix of professionals and user representatives from selected Health Board areas to help us to plan the local work and then to synthesise the local group findings into an area-level report (appendix 2)
3. Local Groups: existing groups of service users/community members to generate and discuss priority topics for research

Project chart



The National Working Group

The National Working Group was planned to include a balance of user, professional and research representatives (see appendix 1). This group met twice. Their role was to advise on general directions at the start of the project and at the projects conclusion, to analyse discussion documents and priority topics identified at the local and area levels, with the aim of identifying and highlighting the key themes emerging, and achieving an agreed priority list through the analysis and discussion process. This approach has features in common with the Grounded Theory approach to research, as well as with the concept of collaborative enquiry groups. Although we used structured techniques to assist in sorting and organising the themes, and to give an overview of their importance, this was not a statistical exercise, and

we were seeking to make valid generalisations from a wide range of service users, using a participatory approach, rather than to obtain a nationally representative sample, or to make statistical inferences.

Area Working Groups

The Area Working Groups (appendix 2) comprised midwives, local consumer representatives and NHS PFPI (Public Focus Patient Involvement) facilitators. Each area group aimed to meet twice, first to facilitate identification of and contact with diverse local groups and secondly to discuss the findings of the local groups. Members of the National Working Group who were based in Lothian also participated as the Lothian area group.

The Local Groups

The local group meetings were not organised specifically for this project. Instead, our aim was to visit existing groups in local venues such as primary schools, village halls or playgroups. This approach was in order to ensure that the participation was diverse, rather than confined to 'spokespeople' or people in social groups who are more familiar and confident with putting forward their views about services or ideas for research. Group meetings were organised through the individual group's contact person who circulated project information sheets to group members in advance of the first meeting and ensured that the group were willing to participate. The information sheets given to participants and provisional meeting agenda are included in Appendices 3 and 4.

We planned to meet with each local group on two occasions, with facilitative work conducted by the project team as follows:

1. group discussion to identify areas of interest and potentially important topic areas for research, facilitated by project team members
2. the project team conducted rapid literature reviews and scoping work to develop a discussion document on the state of existing evidence on the topics raised. This was fed back to each group verbally as well as circulated in writing to support the decision-making of the group members
3. a follow-up group discussion was held to discuss the potential topic areas further, and to agree a set of priorities

The overall format of the project was the same for all groups although the specific format was negotiated with each group. In two groups, discussion was more difficult to facilitate because of the room layout or the structure of the group, so that the developing of ideas was more individually based. Additionally, three groups did not conduct a follow-up ranking exercise, because it was not practical or, in the case of the SANDS group, this was not what the group wished to do.

Each group member was asked to speak from their own perspective and experiences but also to discuss the project as widely as they could with friends, family and community members, and to bring their findings to bear on the group's work. While some service users, particularly those actively involved in user groups may already have considerable awareness of research, and developed ideas about what the priorities should be, many are less familiar with research or policy, and developing priorities will be a process for them which involves starting with personal experiences (their own and those of their social network), sharing these with others, and shaping these into issues that can be addressed through research.

The role of the researchers facilitating each group was to support them through this process. We felt an open approach would be important, but to help to stimulate and structure the discussion we compiled a series of visual 'triggers' such as photographs, pregnancy calendars etc. This was found not to be useful in the first group, so we did not pursue this plan further. Groups usually preferred to generate ideas by sharing birth stories and by discussing shared experiences. It was also important to facilitate the group to generate researchable topics and questions. The aim of the discussion was to explore the topics and reach a reasonable level of consensus, but voting was also used to help arrive at a priority list, using methods commonly used in Nominal Group Technique (see Appendix 5). We hoped this would also reveal the level of consensus within the group and allow the views of less vocal participants to be counted. The findings and level of consensus could then be compared with all the other local groups and drawn together for the National discussion paper.

Ethics

This project did not require NHS research ethics approval. Ethical approval was granted by the University of Stirling, School of Nursing, Midwifery and Health Ethics Committee.

Wider consultation

To maximise the range of perspectives involved, a summary of the final list of topics and questions was circulated for comment to a range of service-user focused groups UK-wide including the National Childbirth Trust (NCT) the Association for Improvement in Maternity Services (AIMS), AMINA—the Muslim Women's Resource Centre and the Scottish Women's Convention.

This report, therefore, is the outcome of a detailed process of generation of themes, discussion, searching and review, involving a diverse range of people who have used maternity services, supported by maternity professionals and researchers.

Sample

We used snowball techniques to contact potential participant groups and invite their involvement. The Health Board areas were selected to cover a range of geographical, social and organisational settings within Scotland. Glasgow and Clyde represents a mainly urbanised area, including a major city and areas of high social deprivation as well as those of relative affluence, with good transport links and a diversity of maternity services. Lothian represents a mixed urban/rural area, with socially diverse localities. Forth Valley includes unique environmental (chemical plants, de-industrialised villages, motorways, pylons, and agriculture) and demographic characteristics. The Highland area represents a geographically extensive rural and remote area with a highly dispersed population, more limited transport links, small-scale health services and long travel times to regional hospitals and significant, often hidden rural poverty.

Within each selected Health Board area, three local groups were identified to provide a diversity of settings, using the local knowledge of the relevant area working group members. This sampling approach was not intended to exclude voices and views from other areas of Scotland, but represented a pragmatic approach to inclusion of a range of localities and groups within limited resources. Views from other areas were also sought through a wider consultation process with user-focused groups to inform the final decision-making. Most of the participants were mothers with babies or toddlers, but three grandmothers and one father also participated. The local groups and numbers of participants were as follows:

Table 1: Local groups

Health Board	Local group	Participants	Urban/ rural*	SIMD *
Greater Glasgow & Clyde	Group 1 Synagogue Toddlers	14	1	8
	Group 2 SANDS**	4	1	2
	Group 3 Local Toddlers	8	3	10
Highland	Group 4 Toy Library	6	4	1
	Group 5 Postnatal group	3	6	5
	Group 6 Local Toddlers	6	6	6
Forth Valley	Group 7 Local Toddlers	9	2	1
	Group 8 Mothers Adult Learning Group	5	2	1
	Group 9 Church Mother & Toddlers	7	2	3
Lothian	Group 10 Local Toddlers	14	1	10
	Group 11 Sure Start	3	2	6
	Group 12 Sure Start Young Mothers	3	2	6

* From the Public Health Observatory: Scottish Index of Multiple Deprivation 1= most deprived; 10 = least deprived; Rural/ Urban 1= large urban area; 6= remote rural area. **Stillbirth & Neonatal Death Support Group

Analysis Process

Following the plan outlined above we took the following steps in order to make sense of the data and to merge the findings from local to national level in a way that reflected, as well as possible, the priorities of the participants. The process was challenging because there were a range of possible options for categorising the questions and the topic areas. In the analysis, we have organised the material primarily under topic headings, as this reflected most closely the way participants discussed the issues. Although some participants had very clear and formulated research questions to put forward from the outset, most commonly participants were moving from topics of interest or concern to formulating research questions through the process.

Step one was the local level analysis, where we agreed a set of research questions for each group, organised into broad topic areas. This organisation could be challenging as many questions potentially crossed several topic areas. A brief literature review was undertaken for each of the questions. In the follow-up meetings the groups ranked their topic priorities by voting as described in appendix 5. Numbers and ranking from votes is therefore on a topic basis.

Step two was to compare and discuss the local group findings on a health board level with the Area Working Group. We did not attempt to merge findings at this stage but more to explore and understand the emerging patterns.

Step three was to discuss the findings with the National Working Group, to compare and merge the local findings to form a national picture. This included discussion of the ranked priorities, and a more qualitative exercise to re-read, explore and discuss the emerging findings and gain a sense of what was important to participants. Through this exercise, a small set of core linking priorities emerged, building on the priority list. To reanalyse the rankings nationally, we first used visual presentation and tabulation to identify a set of key topics that were raised repeatedly by different groups (see tables 2-5). Then, once a set of key recurring topics had been identified, we recounted the women's votes for research questions grouped under each topic. Some topics were broader than others, as will be illustrated in the findings below, but these were discussed on several occasions to agree that the topic and questions grouped under that topic were sufficiently coherent to form a research topic.

While ranking was a useful part of the exercise, we aimed to include some discussion of all topics raised, as all were important to the women involved. All the questions identified are listed in appendix 7. Additionally, the local area level of analysis illustrates that some topics were very important to specific groups for regional or more personal reasons. These specific interest areas are discussed in the findings section. A small number of questions raised in the initial meetings were agreed to be direct questions about organisation of local services or care, which did not form researchable questions, and these were excluded from the analysis.

Project Findings

Reflecting the participatory nature of the work and the analysis, and the number of levels involved in our process, we present the findings here in a sequence of steps which reflect the stages of the project and the analysis process. In the first section we present and discuss the key topics raised by each local group, the questions which were grouped under these topics, and the results of the topic ranking exercise. Section two then provides an overall synthesis, qualitatively in terms of key themes and more quantitatively in terms of an overall ranked set of priority topics.

Although the groups were very diverse and put forward a number of topics and questions, key topics were raised across different individuals and groups and key themes readily began to emerge. Although group members often felt all or most of their topics were important, they found the voting exercise very helpful for attempting to summarise and get a view of priorities within all the important issues. There were some distinct areas of priority which emerged for particular groups, or varied between the more urban and remote rural settings and we discuss these below. Nonetheless, even these 'local' or specific themes were very coherent with the overall emergent themes.

Section 1 – Local and area-based topics and priorities

Highland Health Board Area

The priority topics for each of the three Highland area groups are shown in brief in table 2, ranked in order of votes for those groups which conducted a voting exercise.

Table 2: Highland Health Board Area – local groups’ priority topics

*Topics were not ranked

Islay & Jura	Murkle	Oban*
Induction of labour	Position in labour/normal birth	Assessment of risk for place of birth
Impact of transfer to central units	Communication & attitudes of caregivers	Facilities & skills for rural care
Remote monitoring/risk assessment?	Induction of labour	Information and choices
Inter-professional communication	Communication of risk	Knowing the midwife
Use & interpretation of guidelines (preterm babies)	Support in labour & postnatal wellbeing – is there a link?	Fathers & labour – needs & experiences
Postnatal care – lack of care, conflicting advice	Caesarean Section and VBAC	Midwives attitudes
Safety of rural services	Attitudes post Caesarean Section	Perineal Suturing
Information, communication & decision-making	Preparation for labour – confidence & normal birth	Midwife unit provision inc. 24 hour cover
Antenatal classes – what is more effective	Expectations & experience of birth	Induction of labour
Early labour	Costs of intervention	Skills for normal birth

Key topics in the Highland area, emerging from thematic analysis and by number of groups prioritising the topic, were as follows:

- Information giving, how risk is assessed and communicated, and impact of these on choice and decision-making
- Induction of labour and other interventions (particularly questions around choices and how guidelines are used)
- Rural and remote service issues: these included questions around skills for rural care, facilities, risk perception and management of rural practitioners (are they more risk averse) and the impact of centralisation of services on professionals, families and communities.
- What could help to reduce interventions and what benefits might there be to this (such as cost saving and wellbeing of women)
- Continuity of care – how to increase continuity. What is the impact of transfer to central units

Greater Glasgow and Clyde Health Board Area

The priority topics for each of the three Glasgow area groups are shown in brief in table 3, ranked in order of votes for those groups which conducted a voting exercise.

Table 3: Greater Glasgow and Clyde Health Board Area – local groups’ priority topics

*topics were not ranked

Kilmalcolm	Giffnock	SANDS*
Induction of labour	Antenatal care – number & purpose of visits?	Risk factors for stillbirth?
Breastfeeding – what helps, choice?	Communication about risk factors	Placental size – is this an issue?
Risk communication	Postnatal care – quality, effect, neglect	Listening to parents
Sharing birth stories –impact?	Antenatal screening – consistency, information?	Antenatal care – appropriate number of visits?
Caesarean Section – effects? care? recovery?	Information, choice and decision-making	Early labour care – how to improve?
Antenatal care & information	Attitudes and behaviour of midwives	Insensitive professionals
Partners preparation for birth	Home birth choice?	Care after stillbirth
Communication between professionals	Women’s postnatal health , including post CS health	Links with medication in pregnancy?
Choice of type of birth	Birth partners support roles	Risk communication
Choice of place of birth	Breastfeeding	

Key topics in the Glasgow area, emerging from thematic analysis and by number of groups prioritising the topic, were as follows:

- Role and purpose of antenatal care, including how risk screening is handled and communicated & what is appropriate care/number of visits
- Communication – between professionals and with women. What is the impact on choices, and on quality & safety of care?

- Postnatal care – why is it so neglected, what are the needs and what helps? (including post CS care)
- Why are some professionals so insensitive?
- Induction of labour – how much choice, effects?

Forth Valley Health Board Area

The priority topics for each of the three Glasgow area groups are shown in brief in table 4, ranked in order of votes for those groups which conducted a voting exercise.

Table 4: Forth Valley Health Board Area – local groups' priority topics

*Topics not ranked

Langlees	Stirling	Dawsons*
Information and communication	Debriefing after birth	Breastfeeding
Antenatal classes	Antenatal care	Continuity of care
Baby checks & help	Breastfeeding	Early labour
Continuity of care	Postnatal support	CS and postnatal health
Medicalisation of birth	Continuity of care	ECV – does it work?
Positions in labour	Early labour	Tongue tie
Induction of labour	Induction of labour	Medication and breastfeeding
Postnatal care in hospital		
Choice of birth place		
Eating/drink in labour		

Key topics in the Forth Valley area, emerging from thematic analysis and by number of groups prioritising the topic, were as follows:

- How could effective feeding support be provided and why it is so poor?
- What is the impact of seeing one or a small group of midwives and how could more continuity be provided?
- Induction of labour: how do professionals interpret the guidelines? What is the impact of induction and related interventions?
- Antenatal preparation – what is the best way to provide it?
- Postnatal care – what is best approach – early vs. late discharge, timing and number of baby checks, post CS care, is debriefing helpful?

Lothian Health Board Area

The priority topics for each of the three Glasgow area groups are shown in brief in table 5, ranked in order of votes for those groups which conducted a voting exercise.

Table 5: Lothian Health Board Area – local groups’ priority topics

Trinity	Penicuik Stepping Forward	Penicuik Stepping forward – young mums
Continuity of care	Care from health visitors	Young mothers’ experiences
Postnatal and feeding support	Young mothers’ experiences	Recovery from CS
Support in labour	Continuity of care	Continuity of care
Midwives’ attitudes	Early postnatal discharge	Is there discrimination
Communication between professionals	Postnatal care in hospital	Organisation of postnatal care
Early pregnancy care	Information	Midwives listening to you
Information, communication & decision-making	Postnatal care in the community	Symphysis pubis dysfunction
Listening to women		Privacy & dignity in labour ward
Early labour care		Communication
Needs of fathers		Pain relief in labour

Key topics in the Lothian area, emerging from thematic analysis and by number of groups prioritising the topic, were as follows:

- Communication, information & decision-making: what are the barriers and how to improve, listening to women, conflicting advice, quality of information
- Continuity of care: what is the impact and how to improve it
- Postnatal care: how to improve care, could more practical classes be provided, timing of discharge
- Needs of young mothers: what are midwives’ attitudes, experiences of young mothers
- Communication between professionals: how to improve

Section 2 – synthesis

Table 6 summarises the key topic areas that were identified in the discussion ranking process and illustrates how the topics were raised across the groups.

Table 6: Key topic areas by group

	Jura and Islay	Murkle	Oban	Langlees	Stirling	Dawson's centre	Giffnock	Kilmalcolm	SANDS	Trinity Toddlers	Penicuik Young mums	Penicuik Stepping Forward
Communication & Information Giving/ Informed Choice	x	x	x	x			x	x		x	x	x
Postnatal care	x			x	x		x	x		x	x	x
Continuity of care			x	x	x	x				x	x	x
Breastfeeding		x		x	x	x	x	x		x		
Midwives/ professional attitudes	x	x	x				x	x	x	x		
Induction of labour	x	x	x	x	x			x				
Risk	x	x	x				x	x	x			
Antenatal care	x			x	x		x	x				
Early labour	x			x	x				x	x		
Caesarean section		x				x		x				x

Following the counting exercise described above, we identified a 'top ten' list of priority topics. These represent both the number of votes by individual participants and the number of groups in which a topic was prioritised. These priority topics are presented in table 7 below, together with a brief summary to give a flavour of the questions asked under each topic. We then describe the questions in more detail under each 'top ten' topic header.

Table 7: 'Top ten' priority topics with a brief indication of question type

Priority Topic	Nature of questions
1. Postnatal care	Why is postnatal care so poor and how can the quality of care be improved? (communication, support, physical health and emotional aspects)
2. Antenatal care	What is the right number and purpose of antenatal visits? How can more positive preparation for birth be provided in antenatal education?
3. Communication & information giving	How can communication be improved? What is the impact on informed choice? What is the importance of women being listened to?
4. Risk	How is risk interpreted, monitored and communicated? What impact is this having on care?
5. Continuity of care	How can it be improved? What are the effects?
6. Induction of labour	How are guidelines interpreted and what choice do women have? How clear is the evidence basis for timing? How can care for induction of labour be improved?
7. Professional attitudes & manner	Why are some midwives insensitive or nasty? How can listening to women be improved?
8. Feeding support	How can more effective support be provided?
9. Caesarean section	What are the health and maternal effects? What post-caesarean support is needed?
10. Early labour care	What is the impact of 'gatekeeping' of labour admission? How can women's experience or support for early labour be improved?

Priority Topics and Questions

1. Postnatal care

The topic of postnatal care was raised as a priority by eight of the groups, and received a total of 52 votes in the ranking exercises. This included 7 votes for a question relating to care by Health Visitors. Although this was a priority topic for a large number of groups, this was less so for the Highland area groups. Similar questions were asked, however often under the topic of caesarean, around post-CS health and support needs.

The questions under the postnatal care topic fell into three broad areas of questions about postnatal care in hospital and at home and the role of support in postnatal care. There were also some questions about health and wellbeing, and about health visiting, as follows:

Postnatal care

- Should there be different postnatal care pathways depending on the type of birth?
- Why is postnatal care perceived more negatively than other stages of care in successive surveys of women's views on maternity care?
- What is the impact of a bad birth experience on postnatal physical and psychological health?
- Are women in rural/remote areas receiving less or insufficient postnatal care?
- How could the level and quality of postnatal care and support be improved in hospital and community?

Postnatal care in hospital

- What are the benefits/effects of early postnatal discharge?
- How could discharge procedures be improved?

Postnatal care in community

- Would the provision of practical classes in the postnatal period be effective?
- What are the barriers to communication between women and maternity care providers in postnatal care?

Support in postnatal care

- Why is so little attention given to women's emotional and psychological support needs in postnatal care?
- Is there evidence for benefit of provision of support in the postnatal period?
- Who should provide postnatal support (including Maternity Care Assistants)?

Wellbeing

- What are women's' experiences of pain in the early postnatal period?
- How can problems such as postnatal depression or breast-feeding difficulties be effectively picked up?

Care from health visitors

- What impact do health visitors have?
- What is the best way of providing health visitor support?

2. Antenatal care

The topic of antenatal care was raised as a priority by five of the groups, and received a total of 44 votes in the ranking exercises, including 12 votes for questions around antenatal classes and preparation.

The questions under this topic fell into several coherent areas – relating to content and efficacy and preparation for birth and parenthood - as follows:

Content and efficacy of antenatal care

- What is the 'right' number of antenatal visits and does this correspond with what women want?
- What is the purpose of antenatal care?
- What advice and support do women need in early pregnancy and how can this be provided?
- Can early pregnancy services make a difference to women's wellbeing?

Preparation for birth and parenthood

- What is the best way of providing antenatal classes/preparation classes?
- Could mothers be involved in groups to give information and to put parents more in touch with each other?
- Are antenatal classes meeting women's and their partners' information needs?
- How can practical aspects of childcare/parenting advice be given? And when would it be best to do this?
- What positive methods of preparing for and coping with labour are available and what is their effectiveness?
- Does increasing women's confidence improve experience or outcomes of birth?
- Does increasing information give more confidence to women?

3. Communication & information giving

This topic was raised as a priority by nine groups, with 42 votes for questions under this topic in the ranking exercises, including three on questions about informed choice of place of birth.

The key questions under this topic fell into several coherent areas – how do and should professionals communicate with and inform women, what is the impact on choice and decision-making, and what is the impact of women not being listened to - as follows:

Communication and information

- What are the barriers to communication between women and maternity care providers?
- What styles of communication do staff use?
- How can professionals' communication and information giving be improved?
- What is the most effective way of giving information to women?
- How is information communicated to women during pregnancy and during labour?

Choices and decisions

- Are women provided with enough information antenatally to choices and informed or shared decisions?
- Is there shared decision making?
- How do maternity professionals communicate with women about options, risks or benefits?
- Do women feel that they have choice?
- Are midwives truly able to provide informed choice – is this affected by the level of midwives own knowledge and level of fear?

Listening to women

- What is the effect of women feeling not listened to in labour?
- Are there safety implications of women not being listened to in labour?
- Do women feel that they are listened to in general?
- How can midwives better take into account the mothers feelings?
- Does midwives' listening to women increase their confidence and reduce anxiety?
- How can the problem of conflicting advice be addressed?

It is important to note that questions about mothers being listened to were raised both by those concerned about lack of informed choice and over-medicalisation of care, and those who were concerned about problems or worries they raised being overlooked and the potential risk or safety implications, so these questions touched on both quality and safety of care.

4. Risk

This topic was raised as a priority by six groups, with 37 votes for questions under this topic in the ranking exercises. Questions included specific questions related to appropriate monitoring and risk assessment for women in rural areas. Rural and remote issues did not emerge as a

priority topic in its own right as it was only of interest to the three Highland area groups. A number of the risk-related questions also overlapped with questions about information and communication with parents, as discussed above, as many women felt the area of communication around care options and interventions and risks and benefits of these was an area needing attention. Risk assessment was a topic of particular interest to the SANDs group. The questions about risk fell into several broad areas – is care becoming more risk-focused, what is the impact on parents and risk factors for stillbirth - as follows:

Increasing focus on risk status in pregnancy

- Are maternity professionals becoming more anxious or risk focused?
- How is low or high risk defined? And has this shifted over time?
- Do professionals have adequate awareness of evidence on risks and benefits of interventions? What might enhance their use of evidence?
- How is risk assessed in rural areas?

Impact of risk assessment

- What is the impact on women of being labelled high risk?
- What is the impact for women categorised as high risk when the 'risk' may not be so relevant to labour and birth itself?
- How do women understand and interpret risk in relation to their pregnancy and birth?
- Does the presentation of risk, with emphasis on risks and dangers create a negative feedback cycle?
- How do professionals communicate with women about being high or low risk?
- How much information do women want or need about their risk assessments?

Risk factors for still birth

- How are the risk factors for stillbirth identified during the pregnancy?
- What are the factors that trigger increased vigilance?
- Is there a link between stillbirth and painkillers/medication during pregnancy?
- Placental size - How much of an issue is placental size?
- Are professionals dismissive of women's concerns?

5. Continuity of care

This topic was raised as a priority by seven groups, with 34 votes for questions under this topic in the ranking exercises. Women in rural & remote areas did not raise direct questions about continuity of care, as locally their experience was good, but they conversely raised questions about the impact of centralisation of care and the lack of continuity when having to attend city hospitals.

The questions raised and voted on in the ranking exercises were around the effects of continuity and how the level could be improved, as follows:

Effects of continuity

- What is the impact of having a known midwife or small group of midwives for care?
- What is the importance of continuity for informed choice?

Improving continuity

- Can maternity services be organised to provide more continuity of care(r)?
- Could the more routine visits with obstetricians be reduced?
- Could the NHS work more closely with independent midwives and provide insurance cover for them?

6. Induction of labour

This topic was raised as a priority by six groups, with 31 votes for questions under this topic in the ranking exercises. A number of the questions overlapped with those around communication and informed choice, and how risk is dealt with.

The questions raised and voted on in the ranking exercises were around either clinical and support questions relating to induction or informed choice around induction of labour. Similar questions were raised about other labour interventions, but did not receive the same level of ranking. The questions raised were as follows:

Clinical questions about induction

- How effective, accurate or sensitive are the different approaches to dating pregnancy?
- What is the risk or benefit of continuing with pregnancy and monitoring vs. induction of labour post-term?
- How are protocols and evidence around induction of labour used in practice?
- What are maternity professionals' knowledge of evidence on induction for post-term pregnancy, and how do they interpret and act on it?
- Do policies and practices on induction vary nationally, and if so, why?
- Is there a higher rate of labour induction for women from remote areas who have to transfer to urban areas for birth?
 - Are professionals more likely to recommend induction in these circumstances (rural areas)?
 - Do women themselves want induction because of the stresses involved?
- What is the best method for induction of labour?
- What is the clinical evidence and how consistent is the practice of induction of labour after membrane rupture?
- Should amniotomy be performed if the woman has already gone into spontaneous labour?

- What is the impact of induction of labour and associated interventions (like CTG and oxytocin drip) on mobility in labour?
- Are you more likely to end up having a caesarean section if you have been induced?

Communication and choice relating to induction of labour

- Do women have a choice about induction of labour? And if so, is this communicated to women?
- How are the risks or benefits of induction of labour presented to women?
- How are women informed about induction of labour and what is involved, including effects on pain and how they feel?

Women's experience of induction

- What is the woman's experience of Induction of Labour?
- How women are supported when being induced and are midwives sufficiently aware or sensitive about how difficult (pain/anxiety etc) it is?

7. Professional attitudes & manner

This topic was raised as a priority by seven groups, with 17 votes for questions under this topic in the ranking exercises. The questions focused particularly on the variations in care between midwives, with some found to be insensitive or uncaring in their manner and the impact of this on women. The questions raised were as follows:

- What affects midwives being supportive and caring in labour, and how can this be improved?
- Why are some professionals insensitive, nasty or bad tempered?
- What is the impact of midwives own attitudes and fears?
- What is the impact on labour experience of professionals' attitudes and support?

The young mothers' group also raised specific questions about midwives attitudes, and whether there is discrimination

- What are midwives' attitudes to young mums?
- Do young mums experience discrimination?

8. Feeding support

This topic was raised as a priority by seven groups, with 14 votes for questions under this topic in the ranking exercises. The questions focused particularly on the quality of support for breastfeeding, but also some concerns about the pressures put upon women. The questions raised were as follows:

Support for breastfeeding

- How can breast feeding advice be made more consistent and support more effective to meet women's actual needs?
- Why is the support for breastfeeding so poor (lack of support or pressure to breastfeed) and how can it be improved?
- What is the role or value of breast feeding consultants?
- What strategies could help to improve midwives' attitudes and approaches to supporting breastfeeding?
- Is better breast feeding training for midwives needed?

Infant feeding

- Can community-based centres providing feeding advice and support help improve mothers' experience?
- How can more effective support for infant feeding be provided?
- Why is there a gap between policies and practices about feeding?
- What is the effect of current policy/guidance for midwives supporting women? What is the most effective approach to tongue-tie?
- What is the evidence of cup feeding as an alternative to bottle feeding?
- Is there a link between breastfeeding mothers taking antibiotics and babies having lactose intolerance?

9. Caesarean Section

This topic was raised as a priority by four groups, with 14 votes for questions under this topic in the ranking exercises. The questions focused mainly on post-caesarean support and health impacts, as follows:

- What is the health impact of caesarean section, short and long term?
- What are women's symptoms and patterns of recovery following CS?
- Is bonding with the child different after different birth experiences, CS vs. natural etc?
- Perception of CS as failure – does it lead to negative feelings for women?

Care and support after Caesarean section

- How much and what type of care do women require after CS?
- How can better support /postnatal care be provided for women after CS?
- How many CS can you have?
- Does breast feeding support differ for mothers who have undergone CS?

One group also raised questions about vaginal birth after caesarean, these have not been listed although they were not ranked as a priority topic by the group.

- Rates of vaginal birth after caesarean section (VBAC) varies nationally – what is this associated with?
- What are professionals' level of awareness of evidence on VBAC and how do they interpret or act on the evidence?
- Rates of caesarean section (CS) also vary nationally – what is this associated with?

10. Early labour care

This topic was raised as a priority by five groups, with 2 votes for questions under this topic in the ranking exercises. The questions focused mainly on appropriate support and concerns about gatekeeping, as follows:

- Why is there so much emphasis on gate keeping of early labour admission when women find this difficult? How can better information and care be provided for women in early labour?
- How effective is telephone triage for assessing a woman's labour progress?
- What is the experience for women? Do they need more support and reassurance?
- What are the implications of being sent home in early labour?
 - For safety?
 - For women's confidence and experience?
- How can the management of early labour be improved?

Thematic Analysis: Core Linking Priorities

In the thematic analysis several core linking priorities were identified. These were questions that were not necessarily posed directly by individuals but which began to emerge through the discussion in the groups and as we looked across different questions and found similarities and links between them.

These questions were:

- How do professionals understand evidence and interpret and put across guidelines?
- How is risk or choice being framed and presented to women? (including induction of labour, place of birth, eating and drinking in labour, positions in labour, VBAC)
- Why are some areas of evidence on effective care not getting into practice?
- Organisation of care:
 - Urban – why so little continuity/how can it be improved?
 - Rural – impact of transfer to central units – disruptions and discontinuities, skills and facilities
- Why is postnatal care so neglected and what is its value?
- What is the role of antenatal care and what works?

A range of questions directly or indirectly related to the issue of communication and information. Questions were raised about how professionals interpret and put across evidence and impact of this on choices, decision making, and interventions. Questions about risk were concerned with how professionals interpret and communicate this and impact on women and choices as well as safety. Questions were also raised about how risk-focused care is becoming and way guidelines are used, but also what is effective in terms of monitoring and what is important for safety.

Key variations between groups

Rural areas had a lot of questions about skills and facilities for rural and remote care, impact of centralisation, risk assessment and how more care and facilities could be provided locally. They raised lots of interesting questions and ideas about how rural and remote provision might be improved, including questions about rural training opportunities, possibilities for more remote monitoring and discussed in depth the impact of transfer to cities on families but also raised questions about the impact on professionals' decision making and outlook.

Reflecting geographical factors, urban areas conversely had more questions about continuity of care and support in pregnancy and labour and the difficulty of getting access to care in early labour. Rural women experienced high levels of continuity locally but very marked disjuncture when they migrated to urban centres for antenatal monitoring for labour, so the

nature of the continuity questions were rather different, but all focused on questions of how to enable more continuity of care.

The SANDS group raised specific questions about risk assessment and monitoring and the impact of women not being listened to when they raise concerns. They were concerned to see increased knowledge through research on how to screen effectively for stillbirth risks, and of how to support women effectively after losing a baby. However, other groups shared similar broad questions and the theme of being 'listened to' or able to speak up and be heard emerged as a safety and quality issue across the groups.

Young mothers had specific questions about how to provide for them, whether separate or special provision is better or whether they were treated differently because of their age. Nonetheless, other groups raised similar general questions about quality of care, information and relationships to those raised in the young mothers' groups.

One mother participating in a Lothian-based group also reported from her personal experience of supporting more socially excluded women in a project in the Lothian area. The questions which she felt the women would want to raise, if they felt confident enough to participate in a group discussion were around the need for good quality support in general, which is particularly important for women who are more vulnerable. This included help with practical issues, inter-professional and inter-agency communication, domestic violence, mental health and other forms of screening, and appropriate approaches to health promotion that support rather than pressurise people. She argued that continuity of care versus fragmented services needed particular attention for vulnerable women and a complete rethink of antenatal care needed. Again, although a number of research issues were raised that were particular to traumatised and vulnerable or disadvantaged women the broad research themes were very coherent with those of the different groups.

The wider consultation

A summary of this report including all questions raised was distributed for comment to a range of women-focused organisations who were asked to comment on whether the topics and questions 'rang true' and whether there were additional issues which they felt should be included. Ultimately three organisations responded (The Scottish Women's Convention, the National Childbirth Trust and AIMS). These organisations felt that the topics were consistent with their sense of what issues are important to women. The Women's Health Convention stressed that provision of maternity care is of prime concern within rural communities and emphasised the deficits of care provision in these areas. The National Childbirth Trust highlighted that the views of particular groups of women who may be reluctant to attend local community groups would be underrepresented in this project and suggested that efforts should be made to specifically include these women. AIMS raised the issue of how women

can feel supported when making decisions that go outside national or local guidelines or usual practices, suggested that where women feel unsupported they may be less likely to follow advice. They also echoed questions raised in this project about early labour care, in particular triage, and benefits or risks of antenatal care shared between midwives and general practitioners where midwifery services are overstretched.

Strengths and limitations

This project aimed to include diverse groups of maternity service users; this was balanced by the desire also to be as representative as possible of maternity service users in Scotland, and to complete the project within the constraints of time and resources available. The project was successful in achieving geographical diversity, including groups from some of the most remote areas in Scotland as well as inner city areas, likewise groups from both the most and least areas of socio-economic deprivation were included, as well as younger mothers and some wider family members. However, the project lacked diversity in other areas; in particular, minority ethnic groups were not represented, despite attempts to contact relevant organisations. In order to compensate for this a summary report was circulated for comment to a range of organisations that represent diverse women's voices. Ultimately only three groups responded, however, their comments endorsed the representative nature of the topics and questions raised by the groups. Further work is required to elicit the research priorities of women from different ethnic groups and from groups of women who have experiences specific health problems related to pregnancy, for example preeclampsia or post-natal depression, and also to integrate the research priorities of clinicians to produce a joint research agenda for maternity care as advocated by groups such as the James Lind Alliance.

Conclusions

We recognise that not all maternity service users' research priorities are represented here. However, the project was successful in engaging with a wider range of 'ordinary' maternity service users, the majority of whom were initially unfamiliar with the ideas of research evidence and developing research question. We used a systematic, inclusive and evidence informed approach to eliciting research priorities and ultimately produced a list of questions many of which would be capable of direct application to research while others will be useful in underpinning systematic reviews or translation research projects.

Health professionals often assume that they understand fully their patients' points of view and concerns, and that additional efforts to identify these are unnecessary. However this is not always the case (Tallon et al., 2000; Petit-Zeman et al., 2010). This project demonstrates that women are well able to articulate researchable questions when asked and provided with well-structured support.

Our overarching aim in understanding this project was to elicit research questions of importance to women and to disseminate these as widely as possible. We hope that midwifery, and maternity services researchers will use the questions presented here to inform development of and to support the case for their future research and that service user groups who represent the voices of women on research funding bodies will draw on these topics and questions to advocate for a greater emphasis to be placed on women's priorities.

- What were our main findings – key topics and questions?
- What we have learned through undertaking the project
- What do we do now with the findings?

Appendix 1: National Working Group Membership

Dr Pat Hodinott, General Practitioner and Senior Clinical Research Fellow, University of Aberdeen

Dr Andrew Symon, Senior Lecturer in Midwifery, University of Dundee

Dr Imelda Hametz, Senior Research Officer Scottish Government health Department

Lesley Marr, Reproductive Health Programme Coordinator, NHS Health Improvement Scotland,

Cynthia Clarkson, National Childbirth Trust, nominated representative

Carol Sinclair Director of the Better Together Programme, Scottish Government

Appendix 2: Area Working Group Membership

(note – not all members were able to attend the meetings, but all were sent information and discussion documents and asked to comment)

Glasgow & Clyde:

Sally Butt, NCT rep

Samina Ansari Muslim women's resource centre (AMINA)

Pauline Cameron, PFPI facilitator NHS GG&C

Margeret McCartney, GP & user (apologies)

Sheona Brown, Consultant Midwife

Debbie Gilmour, Netmums & Birthchoices

Haley Groden, User (SANDS)

Vicki Brace, Obstetrician

Highlands and Islands:

Sarah McLeod, Consultant Midwife

Maree Todd, User Group Rep (apologies)

Sarah-Jane Edwards, NCT user rep

Caroline Champion, PPF facilitator, Argyll & Bute

Lucy Caird, Obstetrician (apologies)

Fiona Matthews, Murkle Toddlers Group & Breastfeeding support group

Stirling and Forth Valley:

Ann Patterson, Consultant midwife

Teresa Cannavina, GP and user

Appendix 3: Information sheet for potential participants – Local Working Groups

What are service users' priorities for research in maternity care?

Introduction and aim

This consultation project is being conducted by the Nursing, Midwifery and Allied Health Professions (NMAHP) Research Unit based at the University of Stirling. You have been asked to participate in a working group to contribute to this exercise. The aim is to identify and develop a set of priority topics for research relevant to maternity care in Scotland, since users' priorities may be different from the priorities of researchers or people who work in the services.

Reasons for doing this work

The Scottish Government report Better health, Better Care recommends working towards a health service where Scottish people and health service staff are partners in care. We hope this consultation project will contribute to this, by involving more people, and especially those who use the maternity services, in talking about what evidence is important and what is needed to help to improve the services in future. The NMAHP research unit, NHSScotland and other organisations can use the findings to inform their decisions about what research should be supported.

Who is involved

We are developing a set of Working Groups involving different people with an interest in maternity care in Scotland. The local groups will include a range of women who have used maternity services, and their partners, and local community members. Although you can't be expected to represent an entire group of people, we hope that you will talk about the project to other people – such as family, neighbours and friends – about their views, and bring these to the group.

A National Working Group, which includes service user and policy and professional representatives, will oversee the project. There is also a Working Group for each of the three Health Boards involved, including mothers, midwives and GPs, who have worked with us to develop the local groups in which you have been invited to participate.

What is involved

Each group will meet twice, in a local community venue.

In the first meeting we will share and discuss views and experiences of maternity care and draw up an initial list of possible topics for research which group members think are important or needed.

After this meeting, members of the research team at NMAHP will undertake some background work to help you to decide on priorities, looking at what research has already been done on each topic, what the gaps in the evidence are and what types of research could be used to answer the questions. A document or CD based on this work will be sent to you to think about and discuss with family and friends before the second meeting.

In the second meeting the research team will report back on the information gathering and the research topics will be discussed again. We will try to agree on a priority list and may use votes to help with this. The research team members will write a report from the meeting, to be sent to the area Working Group. If everyone in the group is happy with a tape recording being made, we will tape record the meeting, to help us to write the report. If so, you will be asked to give permission for the recording, and the tape will be kept in a secure place at the university office and confidentiality will be protected. The Working Groups will discuss and put the priorities together, and these will then be consulted on and discussed nationally.

We will be able to cover all participants' expenses for attending and can provide food/drink to keep our energies up. If you have children to care for, you will be able to bring them with you and we will ensure that some play facilities are provided.

To prepare for the first meeting, please think and discuss with your family, friends and local people what you think the important issues are for research in maternity care. We will do our best to arrange a time to suit most participants but if you can't attend on any date, please contact us with your thoughts and ideas.

Appendix 4: Provisional meeting agenda/process – Local Working Group

Meeting 1:

1. Introductions, welcome agreeing aims and methods (and if appropriate whether the group wishes to make an audio record of discussions, and permissions if relevant.)
2. Ideas session: establishing and drawing up on charts an initial set of themes or topics (use triggers and prompts as appropriate)
3. Discuss the ideas generated and how they could be framed as researchable questions
4. Agree priorities for the Project Team's searching and scoping work before meeting 2.
5. Any plans for meeting 2. Thanks and goodbyes. (expenses forms)

Before meeting 2: Brief discussion (print/audio) circulated to group participants on what we have found and its implications for research priorities.

Meeting 2:

1. Review of initial themes/topic ideas in the light of information gathered by the Project Team
2. Discussion to agree a priority list. Nominal Group Technique or alternative exercise agreed by the group to support decision making.
3. Discuss contents of report to be sent to Area Working Group
4. Agree member(s) to attend Area Working Group follow-up meeting and how the process and outcomes will be reported back to the local group. Thanks and goodbyes. (expenses)

Appendix 5: Nominal group technique

During discussion of the themes, a participant writes up all topics agreed by the group to be important on flip chart paper.

The thematic areas are translated into more focused questions. During this phase, the group may decide not to chart issues that do not translate well into research questions. Appropriate methodologies for researching each can be discussed.

Two main types of topic can identified and divided into separate lists for voting purposes: those considered to require the commissioning of structured reviews rather than, or prior to, any further primary research.

Those considered suitable for primary research

The charts are then pinned up for review. Each participant can be given a number of stickers, with different colours to cover different dimension of priority:

- importance of topic
- feasibility of research and potential for impact on practice

Participants are free to choose how to use their 'votes': they could use all their votes for one topic of exceptional priority or divide them as they chose between a range of topics.

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