Leeds Institute of
Health Sciences

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Reaching the "Hard to Reach"

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Outline

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- Overview of recruitment: approach and challenges
- Participatory phase: motivations, challenges, feedback from women
- Questions for groups: issues arising in participatory research and how they might be overcome
- Feedback

Recruiting bereaved women

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- A wide range of sources were approached, including primary and secondary care professionals and community and voluntary sector groups at both sites as well as research partner organisations
- We aimed to recruit 15 bereaved women from the highest risk groups of Pakistani and Caribbean women and teenage mothers of any background at each site, in equal numbers if possible; decision to recruit African women who were referred
- Flexibility was necessary to achieve the sample size, and many more Pakistani women were recruited at Site B
- Personal contacts were helpful in recruitment:
  - Key informants
  - Professionals who knew researchers already

Recruiting bereaved women

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Source	Number of women recruited
Community based recruiter at Site B, contact made through Key Informant at former PCT	12
Health Visitors at both sites	2
Consultant Neonatologist (who was also a Key Informant for the study)	2
Project worker at support service for BME women, Site A	2
Bereavement support midwife at Site B	1
Consultant Obstetrician (who one of the researchers had worked with)	1
Project worker from support service for teenage mothers, Site B	1
GP (known to one of researchers)	1
Children's Centre Worker, Site A (known to one of researchers)	1
TOTAL	23

Challenges in recruitment

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- Women as bereaved potentially "vulnerable"
- Ethical principle of not causing harm, but also possible benefits for women of taking part
- Professionals as a gatekeeper to involvement:
  - Some expressed concern about approaching women who they hadn't been in touch with for a while
  - ?Paternalistic or overprotective, where involvement could potentially benefit women, and many have described it as therapeutic
  - Some were overstretched, including community midwife in a deprived area of Site A, who was aware of potential participants but didn't have the capacity to approach them
  - Where professionals knew the researchers, this may have given them more confidence to refer women
  - Possibility of defensiveness about service delivery and potential criticism from service users?

Participatory Research

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Most **ethical** method of working with groups not currently represented in decision-making

Avoids reproducing unequal social relations. Ensures women involved in the study feel the research is **relevant** to their priorities, not involved simply as objects of study

- HOPE groups established to **support women to contribute** to decision-making about addressing infant mortality
- **Priorities and suggested solutions** negotiated with key professionals
- **Co-production of knowledge** between diverse stakeholders

(Rifkin et al 2000; Hill 2004; ESRC 2010)

Ethical guidelines for participatory research 1

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- **Mutual respect**: everyone being prepared to listen to voices of others, accepting there are diverse perspectives
- **Equality and inclusion**: encouraging and enabling people from a range of backgrounds to lead, design and take part in research, including seeking actively to include people whose voices are often ignored and challenging discriminatory and oppressive behaviours
- **Democratic participation**: acknowledging and discussing differences in status and power of research participants, working to share power more equally
- **Active learning** from each other

  - From Centre for Social Justice and Community Action, Durham University: www.publicengagement.ac.uk

Ethical guidelines for participatory research 2

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- **Making a difference:** promoting research for positive change, including engaging in debates about what constitutes positive change, such as human needs or spiritual development, valuing learning and other benefits for individuals and groups from research process, as well as outputs of research
- **Collective action:** working together to achieve change, including where goals and interests differ
- **Personal integrity:** trust and honesty among participants, being open to challenge and change and prepared to work with conflict

  - From Centre for Social Justice and Community Action, Durham University: www.publicengagement.ac.uk

Enabling women to take part

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- The researcher who had interviewed each woman got in touch by phone and letter
- Trust which had been established through initial involvement and investment in the study at the interview was a key factor in on-going participation for many women
- We considered factors which might enable women to take part in the next phase:
  - Transport and childcare support
  - Preferred venues, times and dates
  - Involvement fees
  - Possible ethnic make up of groups
  - Preference for group or one to one feedback of findings

Enabling women to take part

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- **Factors which may have hindered participation for some women:**
  - Time and money constraints
  - Impact on personal bereavement process: some felt they couldn't cope with being involved at the present time
  - Possible anxiety about meeting a new group of people
  - Other factors?

Participatory phase: women's motivations

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- To improve support for women in the future
- To have a voice, for one Pakistani participant to challenge the stereotype that practising Muslim women are not confident to speak up
- For mutual support and friendship with other women, many having felt previously isolated and not having had access to bereavement support
- Curiosity as to the research findings
- Opportunity to have a say in the direction of the work
- The sense of momentum and the feeling that the groups were making a difference was a key motivation

Group Reflections

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- There was mixed feedback on extent to which initial aims had been achieved; women at Site B were more satisfied in general than women at Site A
  – Some frustration at Site A that there had not been enough opportunities to check the group was on course to fulfil the aims, and disappointment that they had not all been achieved
  – However recognition that impactful and successful work had been done at both sites
- All women felt their sense of power had increased through involvement in the project
  – Increased influence in different contexts, training opportunities taken up, networking and access to new services, media involvement

Challenges

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- Different stakeholder perspectives, different backgrounds and priorities of participants
- Frustration that change can be slow, and at lack of involvement in the project from some professionals
- Need to balance this with belief that things can change, and encouragement that many professionals have engaged
- Negative experiences for women in some contexts, for example when attending MSLC meetings at one site
- Need for realistic goals and regular review of targets, to see ideas and aspirations come to pass
- Role of researchers in this project in facilitating bridging between women and professionals, flexibility and persistence needed

Conclusions 1

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- Participatory methods are an empowering way of helping women at higher risk of infant death have a voice in how health and social care services are run. This study has shown that groups like HOPE are feasible and can have a considerable impact on service development.
- Groups should be established on a long term basis with links to influential policymakers and practitioners who can make change happen as this is a key motivating factor for women.
- There is a need to check how people feel about group activity at regular intervals, with the option for one to one feedback if preferred
- Bereavement support should be available from the time groups are established

Conclusions 2

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- Training for women involved in the group may need to include the following:
  - **Negotiation and collaboration skills**: Understanding how good relationships can enable change to happen by increasing teamwork within the group and working with partners who can help achieve change
  - **Understanding the time it may take to achieve change**: Examples of how long previous initiatives have taken to get off the ground may be helpful, along with discussion of what helped or prevented things moving speedily. Women may need greater understanding of the restrictions that large organisations work under, such as legal and ethical constraints.
  - **Participatory methods and facilitator boundaries:** Some understanding of good practice in participatory projects and what group facilitators can or should do and what they cannot or should not do.

Conclusions: reaching the "hard to reach"?

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- "There are four main areas of importance…that relate to how best to engage 'hard to reach groups': **attitude of staff; service flexibility; working in partnership with other organisations and empowering users' involvement.** In order to fully engage with the 'hard to reach' and provide an equitable health service for all, the NHS must embrace some of the philosophies that appear to underpin the VCS".

- From "Reaching the hard to reach" - lessons learned from the VCS (voluntary and community Sector) Flanagan and Hancock BMC Health Services Research 2010, 10:92 http://www.biomedcentral.com/1472-6963/10/92

Questions?

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Questions/discussion points for groups

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- **Share any experiences you have of working in a participatory way**
  - **What worked in the approach you took, in terms of recruitment of participants, the progress of the work, engaging stakeholders?**
  - **What was less successful or challenging, and why?**
  - **How did you overcome these challenges?**
- **Imagine a gathering of different stakeholders with an interest in infant mortality, and the differing understandings of factors contributing to the death of infants among them. What conflicting perspectives might be present? How would you approach this issue in a group of bereaved women and health care professionals? How could the group take steps toward positive change in this context?**