

Leeds Institute of
Health Sciences



Infant Mortality and Social Networks: supporting women at higher risk of infant death

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**NHS Airedale, Bradford and Leeds; Leeds Teaching Hospitals
Trust; Bradford Teaching Hospitals Trust; Bradford District
Care Trust; Leeds Community Health Trust**



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Outline




Background

- What we already know
- Research questions and plan
- Details of women involved in the study

Research Findings

- Risk – perceptions and management
- Sources of support within networks
- Relationships within women's networks of support
 - The HOPE groups
- Participatory work – process and outcomes

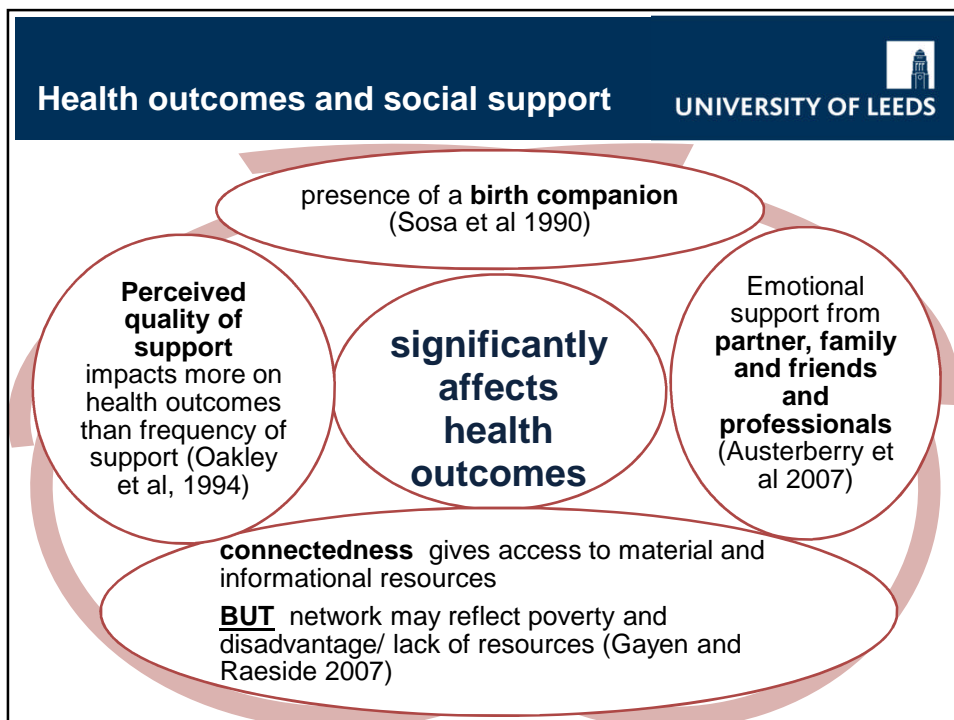
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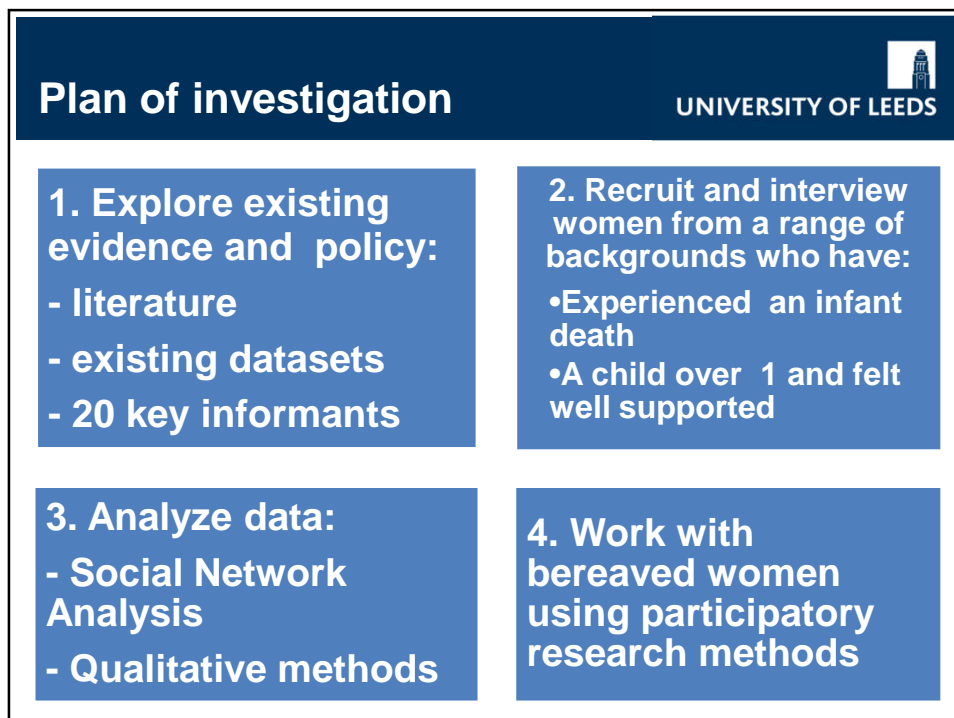
Background


- UK rate of infant mortality (death of a child born alive during first year of life): 4.2 per 1000 live births but much higher for some groups of women
- Social exclusion/disadvantage linked to inequalities in infant mortality: deprivation, access, quality of care
- Risk reduction strategies suggested include addressing environmental stressors, **improved services and increased social support for women at risk** (DH 2007)


	<u>Rate</u>	<u>Higher by</u>
Caribbean Mothers	(9.7)	131%
Pakistani Mothers	(7.6)	81%
W. African Mothers	(7.4)	76%
Teenage Mothers	(5.4)	29%

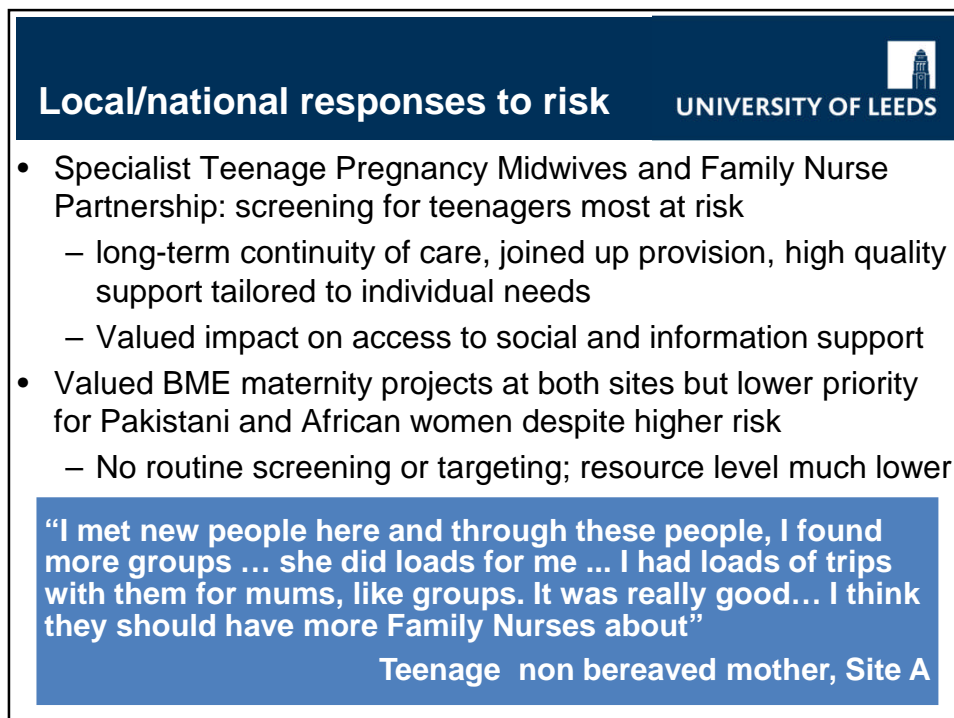
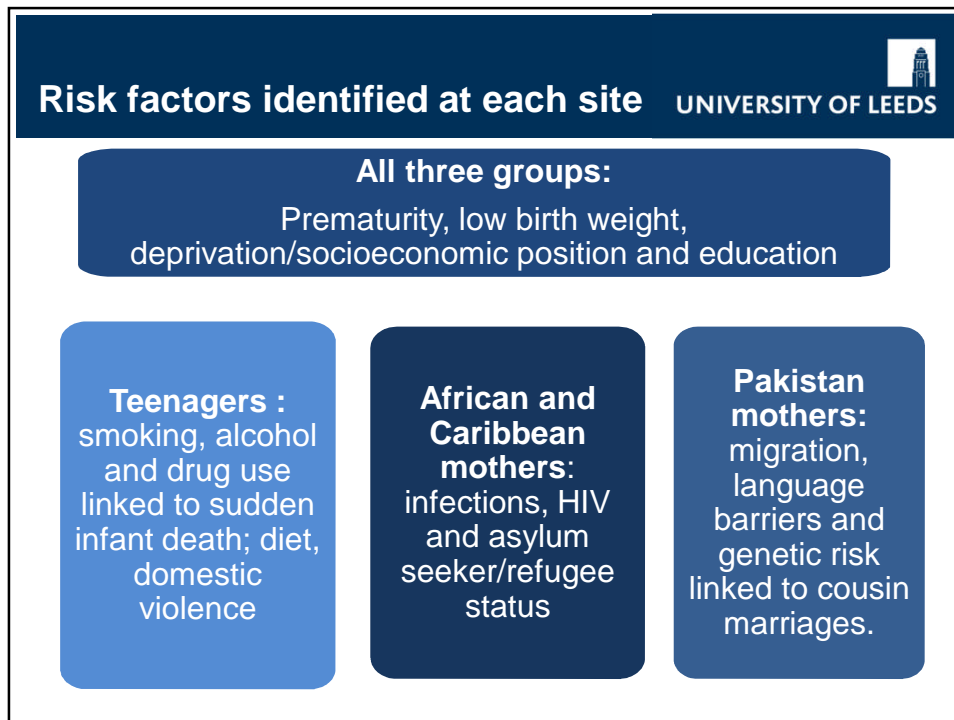
(ONS 2013)






Details of sample		 UNIVERSITY OF LEEDS	
Risk group by ethnic background, age, bereaved and non-bereaved mothers	Site A	Site B	Total
Pakistani bereaved 1 T	5	12	17
non-bereaved	1	4	5
WB bereaved teenagers	2	2	4
WB teenagers (NB)	2	1	3
White British adults (NB)	9	7	16
African bereaved (no T)	1	1	2
African/Caribbean NB	2	-	2
Total	22	27	23 + 26

Bereaved mothers		 UNIVERSITY OF LEEDS	
Cause of infant death (reported by mother at interview)	Numbers affected		
Genetic condition confirmed or suspected	10		
Prematurity (included incompetent cervix, bicornuate uterus)	6		
Perinatal death, one associated with preeclampsia	3		
Sudden death at home, cause unknown	2		
Infection in utero (CMV) and sepsis in neonatal period	2		
TOTAL	23		





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Response to risk

NICE commissioning guidance (2010):
dedicated staff; routine interpreting and coordinated care; joint training; gathering/acting on feedback

- Lack of language support even for news of a child's illness or death.
- Mainstream maternity staff not representative of populations served.
- No strategy to address lack of diversity in mainstream settings.
- BME staff could feel marginalised

“I’ve sat in meetings where I’ll listen to people’s kind of prejudices about certain groups [...] there’s a lot of blame isn’t there?”


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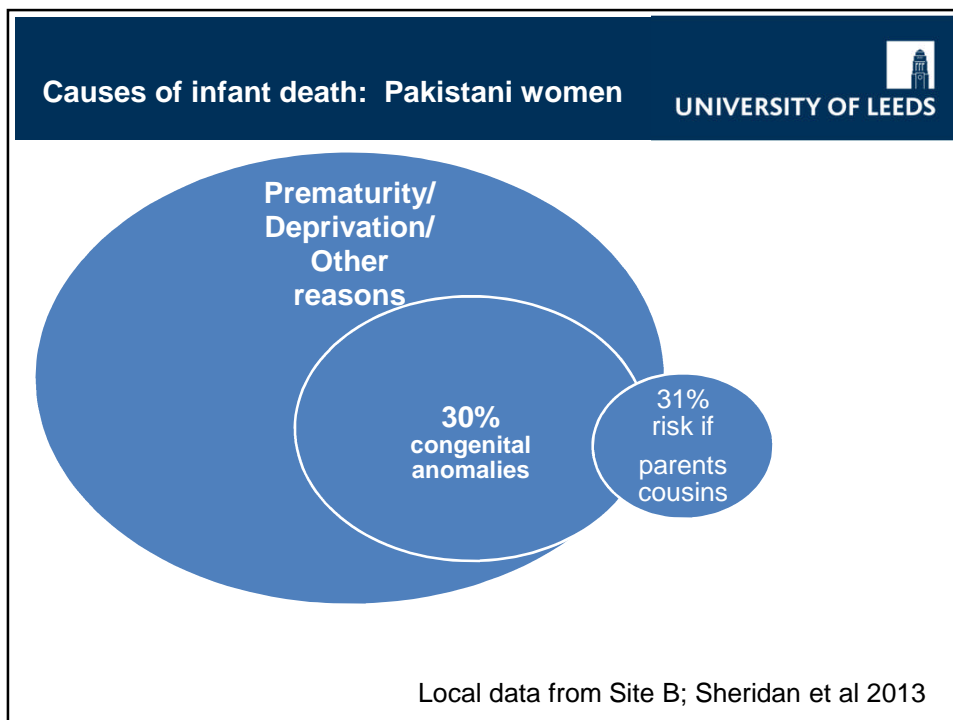
Risk factors for Pakistani women


Local reviews highlighted:

- **Overlap between ethnicity and deprivation – little difference in rates of White and Pakistani women in 2 most deprived groups at one site.**
- **6% cousin couples affected by congenital anomalies - 94% are not, suggesting need for a targeted approach**

Despite this:

- **Local research and policy very strongly focused on congenital anomalies, particularly at one of the sites.**
- **Inadequate policy attention to prematurity and deprivation in this group**
- **Awareness campaigns on genetic risk - no increased access to support for consanguineous couples/families**



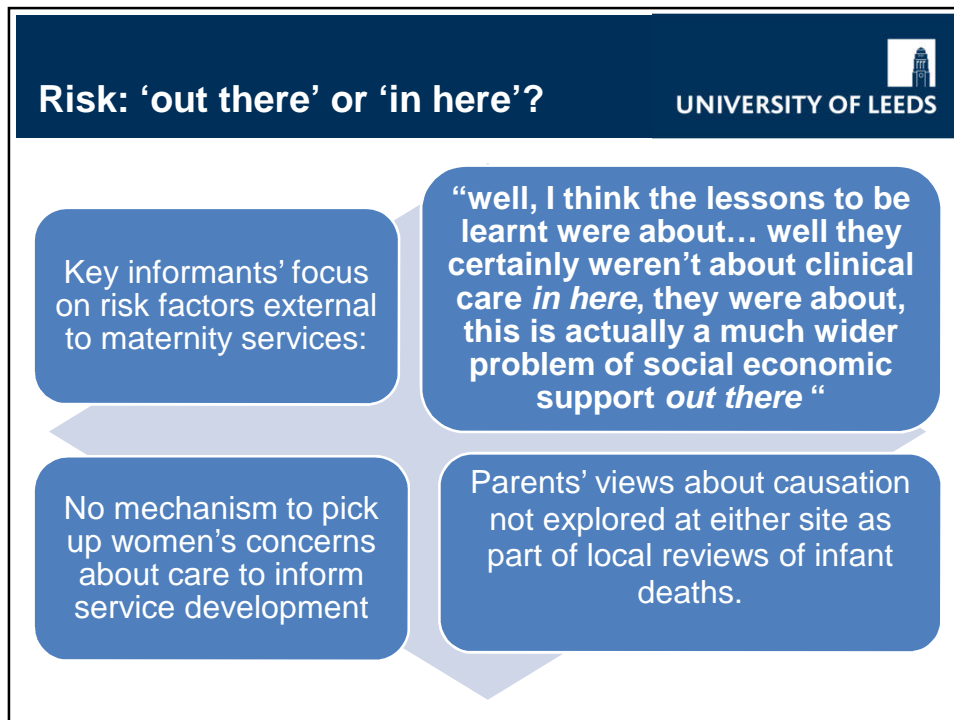
Risk: missed opportunities  UNIVERSITY OF LEEDS


“I couldn’t feel her moving so we put that down to because it’s a girl and she’s lazy. That’s what my husband said, ‘Oh it’s a girl, look she’s lazy...”

↓

“I said ‘look, I’m in a lot of pain and I think probably my waters have broken ... I didn’t feel that they took me seriously. They just advised me to manage it and to watch it”

- Poor knowledge of pregnancy complications amongst bereaved women
- Delay in reporting/responding to warning signs.
- Concerns sometimes not taken seriously
- Could occur in primary and secondary care settings
- Need for more sensitivity to warning signs to avoid crisis intervention later on



Network data  UNIVERSITY OF LEEDS

'Select cards showing whoever was involved with you during your pregnancy, labour, delivery or afterwards...who you went to for any kind of help to do with having your baby'.

- **80 potential sources** of personal or professional support
- **Support:** place card as near or far from yourself depending on how much support you received from this person/ organisation.
- **Well-being:** score each card according to how much each person/organisation contributed to your wellbeing.
- **Connections** between networks – who knew who?
- **Characteristics** of network actors –how long known, ethnicity, age, gender, accessibility.
- **Types of support:** emotional, practical, decisions, challenges/ difficulties, confidence

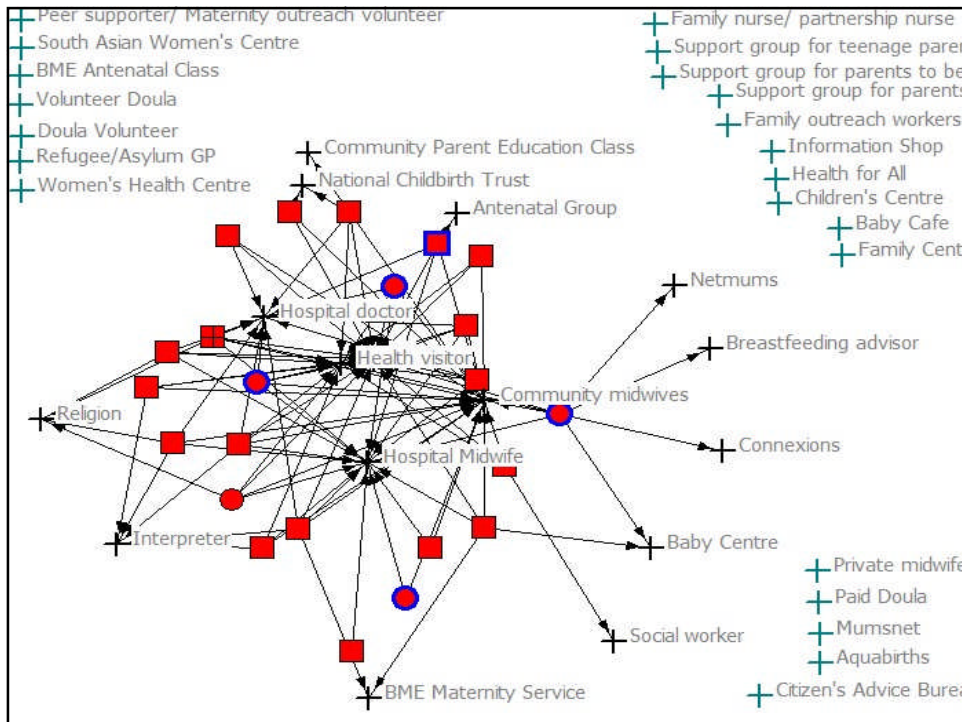
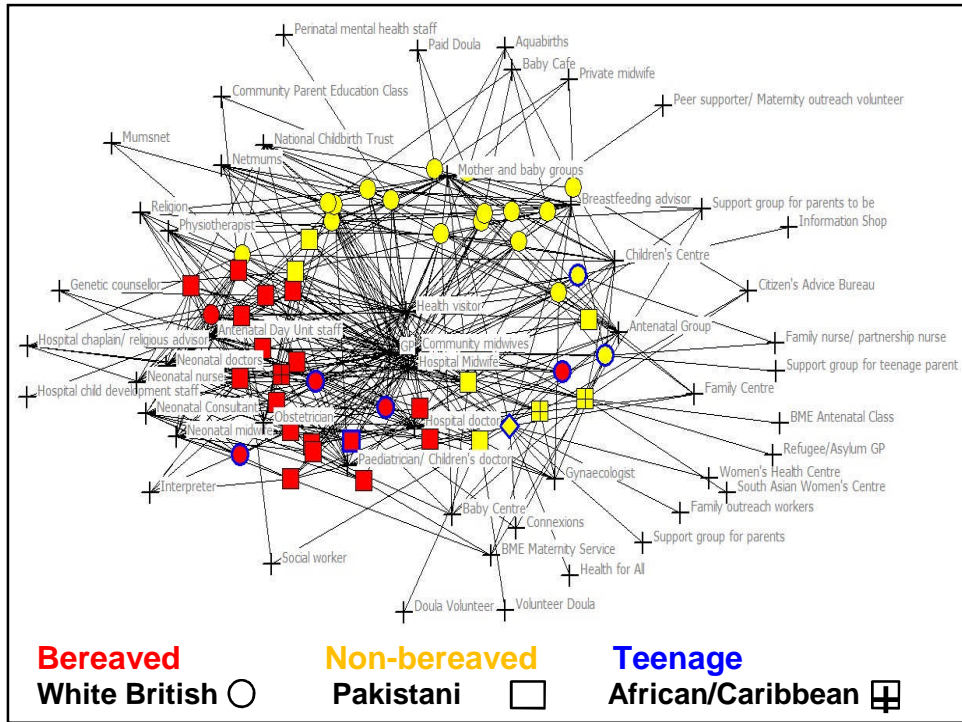
Creating the network

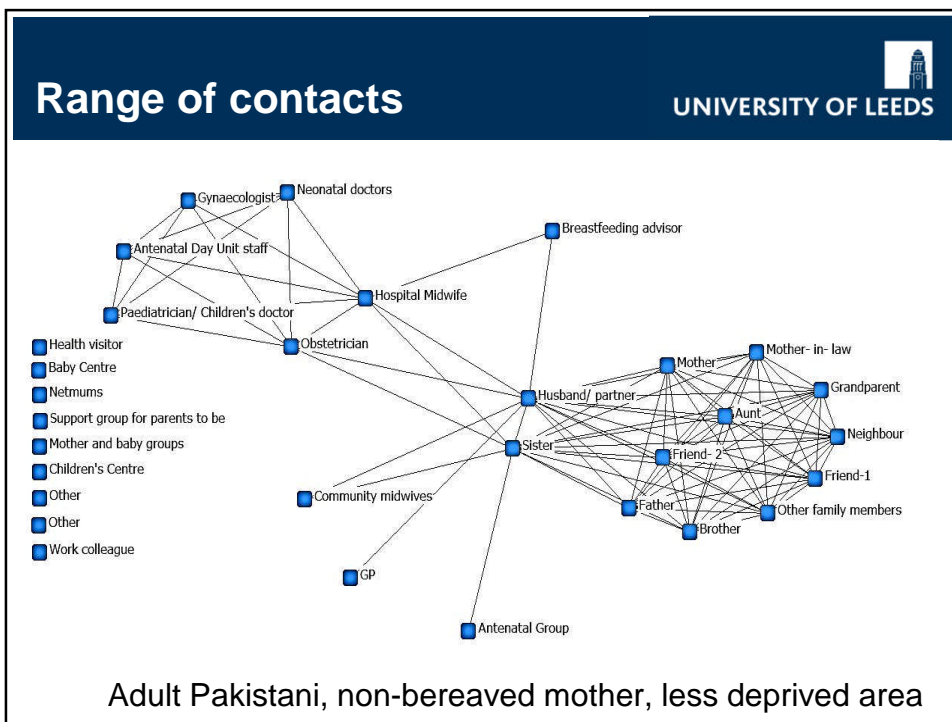
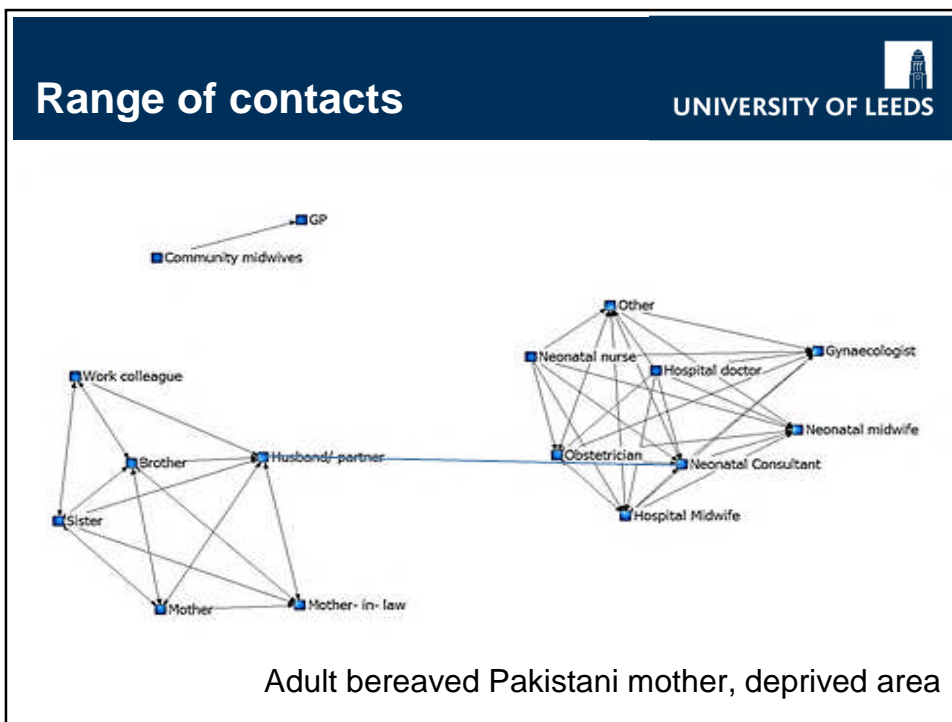


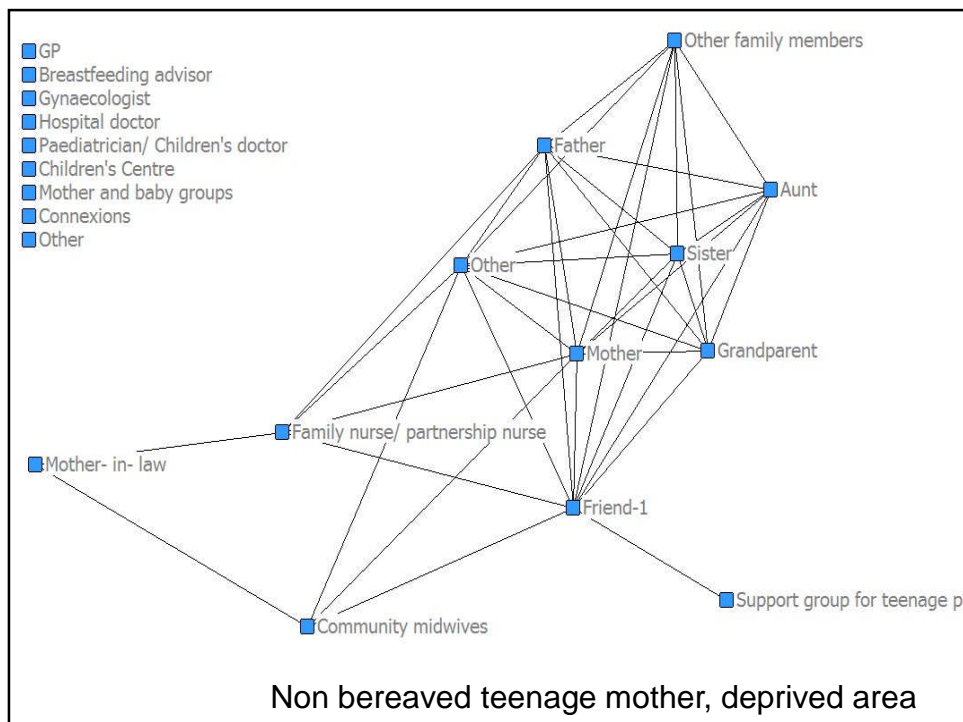
Sources of professional support

Grouped women with similar connections to professional support together

- Women's different experiences eg child illness and longer time with child could affect who was in the network eg more secondary care professionals for bereaved women
- However bereaved mothers closer to some antenatal sources (primary care, hospital midwife) - more dependent on primary and secondary care professionals to develop knowledge and support specific to maternity.
- Non-bereaved mothers closer to others (parents to be classes, NCT, online sources, private services) - more likely to have a range of additional support sources








Connections between support sources



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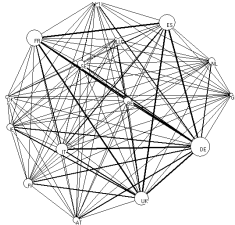

- **Bereaved women: more tightly knit networks with a narrower range of contacts – less opportunity for new information**
- **Non bereaved women: More likely to have support sources that were not in touch with each other. More ability to weigh advice from different sources and take up the support they felt was most valuable to them.**
- **Complex relationship between ethnicity, age and deprivation - BME /teenage mothers overrepresented in deprived areas.**
- **Deprived women tended to have more connections between actors than more affluent women.**
- **A strong personal support network - Pakistani women might not perceive need for alternative sources of support and professionals might also regard them as not requiring additional support.**

High network cohesion


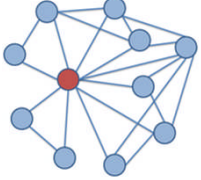


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Can create opportunity for:
trust, shared values/norms, bonding, closeness/strong ties.

Low network cohesion can create opportunity for:
Weak ties, fragmentation (structural holes), resource diversity, access to new information/knowledge.

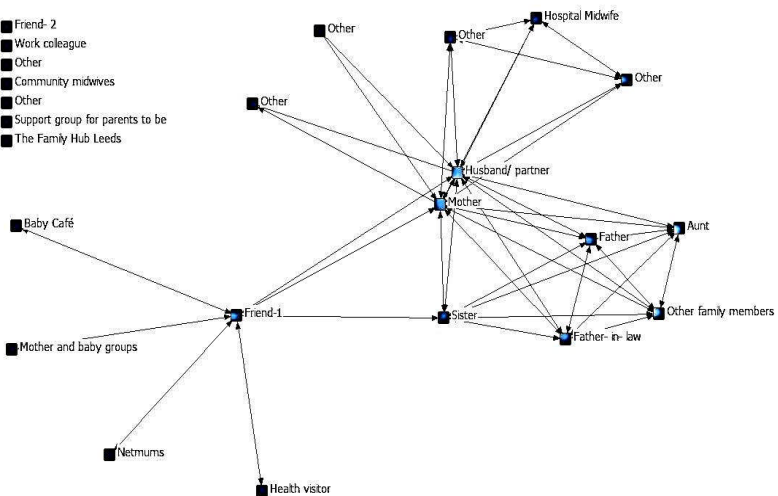
Links between connections



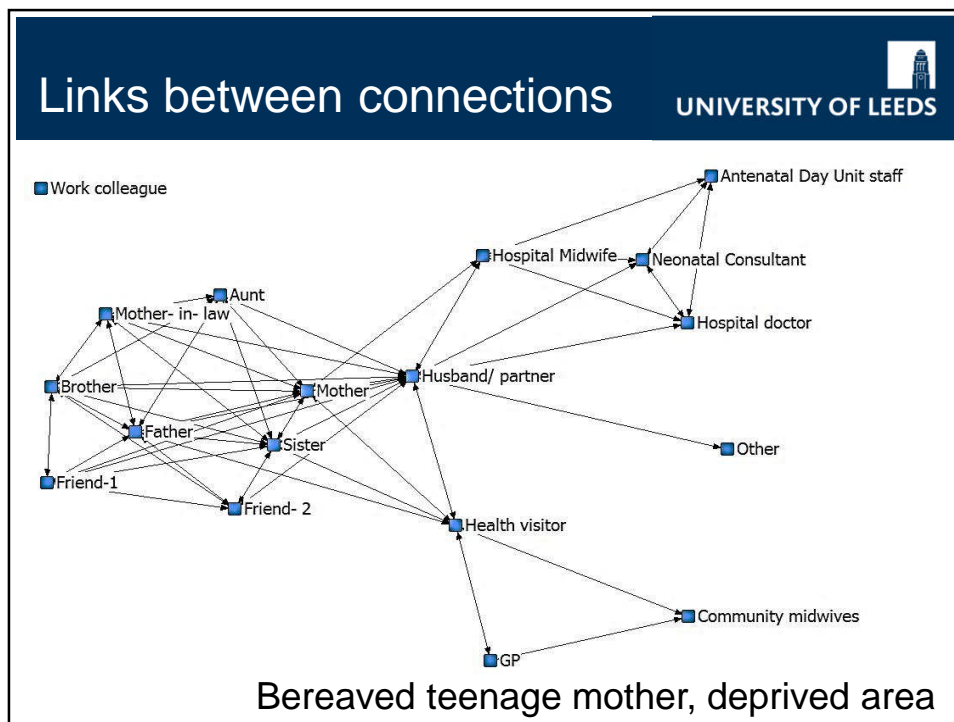
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- Friend- 2
- Work colleague
- Other
- Community midwives
- Other
- Support group for parents to be
- The Family Hub Leeds

- Baby Café
- Mother and baby groups
- Netmums
- Health visitor
- Friend-1
- Other
- Other
- Hospital Midwife
- Other
- Other
- Husband/ partner
- Mother
- Sister
- Father
- Aunt
- Other family members
- Father-in-law



Adult White British non bereaved mother, affluent area



Antenatal information and advice

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- White British women often sought out antenatal classes for friendships rather than information, which could be too generic.
- Pakistani women often felt they already had access to emotional support and tailored advice so were less likely to access antenatal groups
- Encouragement to attend could be helpful if women had misconceptions or concerns about antenatal classes. Some women found these useful and good for knowledge.
- Classes had not prepared bereaved mothers to recognise warning signs for the complications they experienced.

“just very basic information over three evenings and there was no opportunity to make friends, which is what I'd really hoped for”

Participatory Research



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)

Rezvana: being listened to



- I am very grateful to the NHS for everything they do. However through my journey of the hospitals I noted that 'being listened to' is a key factor, but not implemented.
- I have lost two sons: Hashim seven years ago and Haider Ali just over a year ago.
- My planned Caesarean section for Haider was on the date of Hashim's death anniversary. I explained this to the consultant. How could I celebrate one son's birthday on the date of my other son's death anniversary? But that didn't matter. I had to have the Caesarean.

Rezvana: being listened to



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- The doctors said my son was ready for discharge even with a chest infection. I explained I had not slept for two days, I had no support on the weekend but even then they stood by their decision.
- Listening to the concerns is not enough. They need to be acted on. It's hard enough for parents to lay out their fears without feeling like they don't matter. Why listen if you're not going to do anything about it?



Rezvana: what needs to change



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- I have become a member of the Maternity Services Liaison Committee since joining HOPE, and want to be able to influence decisions about maternity care for women in the city.
- I raised my point about listening & acting at the MSLC meeting and expressed my concerns as a parent. I hope that changes will be made as a result of this.



Rezvana: being part of HOPE

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- A chance to make my voice heard.
- Supported in many ways/encouraged by Ghazala and Katie.
- Since joining I am:
 - A MSLC member
 - A parent representative
 - Coordinator for West Yorkshire (COJ charity)
 - All a result of more confidence, support and network connections.

Naz: delays in admissions

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- Unfortunately in 2008 my third baby Uzair passed away with Congenital Myopathy.
- About 5 or 6 weeks before he was due, I rang the hospital delivery suite at 9 am and said I was having sharp pains. I could tell it was labour because I'd had a baby before.
- They said "Oh, stay at home, you're not ready, take pain killers". A few hours later I rang the hospital again and they said "take pain killers".
- We went to the hospital ourselves about 5pm. By 6.15pm they had to rush me and then they started panicking. They had to rush me to delivery through the corridors into the delivery suite when I delivered Uzair.
- This also happened to me in 2001 when I had my daughter Elesha, they wouldn't admit me when I knew I was in labour, I wanted to be in hospital.

Naz: being involved in care



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- When Uzair was born, I knew that he was not going to be with me forever. It was so difficult for me and my husband but we wanted to do everything for our son and make him comfortable.
- With the supervision from the staff in the neonatal department, I was able to write up the feed charts and medicine charts and having a good cross-infection control around my son's cot area, writing up diaries and keeping daily records.
- Memories are the best things you can have once you have had the loss. If I look back, I don't regret for one minute that I didn't do anything for him, I did everything as I would do at home, whatever I could do.



Naz: what needs to change



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- Regarding admissions - I feel that the staff should listen to mums because they know their body best. The staff should let the mums come in for an assessment and be reassured.
- I feel that parents should be encouraged to do more for the baby than sitting and watching and feeling lonely, especially when the child has a short time to live



Naz: what needs to change

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- HOPE group is working to make some changes:
 - We have met with a Consultant Midwife to discuss problems with admissions, who will report back to the group
 - We met with a Neonatal Consultant and will become members of a service user group for the Neonatal Unit
 - We worked to get diaries printed by the Neonatal Unit for parents with sick children
 - Come and see my DIARIES at the break

Naz: being part of HOPE

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- I feel like a stronger person and not afraid to speak up.
- Through HOPE we have been able to learn about and work with lots of local and national organisations like BRI, Health Visiting, befriender training with SANDS, and BLISS for parent support.
- I've had my voice heard at conferences and been able to take a lead role.
- I've enjoyed doing things that will help other parents to get support that we didn't get.
- HOPE is like a team where everyone supports each other and we make joint decisions.

Nazreen: genetics

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- After my daughter Mariam died, I was told several times that because I'm married to my cousin, this is why my daughter was ill. This was really upsetting and shocking to me.
- When I was marrying my husband we didn't have the intention of having disabled children. There were lots of reasons apart from children that we chose each other. It's not our fault – in no way would I want to lose a child.
- Please don't judge me because I'm married to my cousin. I've had three beautiful baby boys and we've had enough losing a daughter. It doesn't help to be blamed for something that I didn't even know about.



Nazreen: what needs to change

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- Children can have genetic conditions for lots of different reasons – for example having children when you are older. Sometimes nobody knows for sure what the cause is.
- It's important to find some kind of way to do tests and find out why this has happened. But don't blame us for something that we didn't even want to happen to us.
- Being part of the HOPE group has helped me understand this issue more and that I should not be blamed.
- In the HOPE group we are talking to people who work in the NHS. Some of the group are members of the Maternity Services Liaison Committee that makes decisions about how maternity services are run.

Ansa: discrimination/quality of care



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- I have had both negative and positive experiences, in terms of interaction with hospital and community professionals.
- During labour when I was losing my daughter Mariam the midwife made insensitive, derogatory and racist comments to me and my husband.
- There was no interpreter offered to us, so I had to translate what was happening for my husband when I was trying to come to terms with it myself. There was also no counselling available in our mother tongue.
- Two weeks after the loss of my son Tariq, community midwives came to my door asking to weigh my baby, it was a painful heart-wrenching experience, and very distressing for my husband also.

Ansa: knowing about risk factors



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- Antenatal classes are tailored to normal pregnancies and don't give you any information about risk factors or what to do when things don't go well.
- After I lost two babies a consultant started looking at my case in detail and the problem with my pregnancies was identified and dealt with
- I am really grateful that this happened but I feel these issues could have been picked up before I lost Mariam.

Ansa: what needs to change

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- I would like a referral to be made to a support service as soon as it is established that a woman is going to lose or has lost a child. There is a need for support to liaise between families and professionals and advocate for women, to promote good mental and physical health following a loss. This needs to be consistent across the board.
- In HOPE we are working with the MSLC to improve the bereavement support pathway, and we will have befriender training ourselves.
- Counselling should be available in other languages and I am looking into training for this myself.
- I now have my son Mustafah who is 9 months old. The care provided throughout my pregnancy was outstanding; I was treated with respect and dignity.

Ansa: what needs to change

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- The HOPE group is working with Public Health professionals to adapt the “Pregnancy, Birth and Beyond” antenatal programme. We are also aiming to set up a specific antenatal support group for women who have experienced an infant death
- The voice of HOPE members has led the Maternity Services Liaison Committee to create a subgroup to improve the bereavement support pathway, using SANDS guidelines.

Ansa: being part of HOPE



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- A journey of many revelations of my own self-awareness, strengthening of my own resolve and becoming very motivated to help other bereaving parents even more by empowering them with the right information, which I have come to learn of through HOPE
- A great opportunity to meet other bereaved mothers and have a support group, a safe and open place where I could share my experiences, feelings and thoughts on improvements needed for the maternity services currently provided in Leeds.
- The research group empowered me to be motivated to set up a support HOPE group for bereaved parents
- I have also now enrolled on a Professional Counselling course to further my career in helping others which I have done for many years in my various voluntary roles in my community
- Dr Ghazala and Dr Katie have been great support and mentors for me personally, in introducing us to community groups and providing contacts such as the MSLC and SANDS

Tahira: feeling isolated



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- I felt isolated after my emergency C-section and after my twins passed away.
- I was placed at the end of the ward right at the end of the corridor and I didn't get any support from the midwives. They didn't really come to my room much.
- I felt isolated and a bit angry, all of these mixed emotions. The only support was from my family that came to visit me.
- I think the hardest thing is leaving the hospital with no baby, and at one point I felt like I wouldn't be able to. I think women need support then.

Tahira: what needs to change

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- The thing I'd change is to give more support to those women who are going through a bereavement. If a midwife could come downstairs with you when you leave hospital - just a little support would make a big difference.
- Being involved with the HOPE group has enabled me to meet other women going through similar experiences, helping us in some way to deal with our loss.
- One thing we are doing is working with health visitors and midwives to create a support pathway for women who have lost a child.

Tahira: being part of HOPE

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- More confidence as I was a shy person.
- Support from other people from the group and support from Ghazala and Katie.
- Help to deal with the loss and bereavement.
- Knowing/feeling I can make my voice heard.

Shameem: safeguarding

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- My son Tabraiz Ali died suddenly aged 9 months in 1997. I still don't understand how this happened. I was questioned by the police and a post mortem was carried out. I was not accused of harming Tabraiz or shown any photographs at that time.
- Ten years after Tabraiz died I became pregnant again. A few weeks before I was due Social Services told me they would remove my baby. I was shown photographs from Tabraiz's post mortem ten years after they had been taken and accused of harming him.
- Because of the delay, my solicitor could not get hold of evidence such as the ambulance report. I did not understand how to defend myself and my solicitors tell me I have to prove I am not guilty but I don't understand how I can do this.

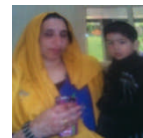


Shameem – safeguarding

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- The coroner's decision against me in 2007 suggested I was mentally ill because he didn't understand my cultural beliefs and practices.
- Social workers and others have often not behaved professionally towards me. They told me and my husband I was a 'bad woman' and that he could only keep our child if we separated. They also tried to get me sacked from my job. They insist on meeting me at very short notice without an interpreter and without advocates that I have obtained through the HOPE group.
- Because of the action against me four children have been taken from me immediately after they were born.



Shameem – what needs to change UNIVERSITY OF LEEDS

- Social workers meet me for short periods and do not know me. Evidence from my two older children or my employers, midwives and health visitors and people who know me should be taken into account.
- There should be some way in which I can challenge the evidence on which the coroner's decision was based, without 'new evidence'.
- I should not be treated worse than a criminal – even convicted criminals are given a chance to start again but I cannot. I am unable to live with my children or spend time alone with my grandchildren.

Shameem: being part of HOPE UNIVERSITY OF LEEDS

- I think HOPE is really good – it helped me feel better and get help.
- Whether things get better or not, people are trying.
- I enjoyed being part of the group.
- I feel much less stressed as I have met a lot of people who are trying to help me.
- I realise things may take time to change and how I speak to people makes a big difference.
- The group should carry on and there should be leaflets and help for more women who don't know how to get help.

Kim: delays seeing GP

- I lost Ashley on 16th December 2004 due to an infection called staphylococcus, which was white spots around the genital area. I was given something by my midwife, like white powder, to use.
- I tried to make a GP appointment on the Monday but no appointment was available until the following Monday. He passed away the Thursday of that week. He would have been 9 years of age this year. It was especially hard as it was the Christmas period.



Kim: my experience

- My first two pregnancies were straightforward and very positive. The hospital was supportive as they knew I was a young mum at the age of 17. My labours were great with no complications. Then I went on to have two more healthy pregnancies, Katelyn and Jayden which again were positive experiences.
- After my son Ashley passed away, no support or counselling were offered. I did not receive my postnatal check-up, which could have led to depression. I only received one leaflet. All I needed was someone to speak to. I wasn't happy with the overall experience.

Kim: what needs to change

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- In the future I would like to see more bereavement groups, a place where children, siblings and family members can talk about their loss. More support in hospitals, more distribution of leaflets and overall a buddy system.
- Since I came to the HOPE group I have come a long way, I have come out of my shell because of all the support from mums in the group and the professional help from the team.

Other projects

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- **Parent pathway** – Health Visiting/Midwifery
- **Routine screening** – all first pregnancies in 3 areas
- **Staff diversity**: attracting BME student nurses/midwives; raising issues in Strategic Clinical Networks (Neonatal Unit); using ABL Doula Scheme as pathway into training
- **Interpreting**: getting feedback from families and providers; training for staff (Neonatal/Health Visitors)
- **Bereavement support**: support meetings in daytime (SANDS); chaplaincy support to improve spiritual/cultural understanding; use of parent diaries
- **Capacity building** – training/involvement in dissemination

Key finding that bereaved women's priorities focus on a broader approach and specifics of the local context

Projects being developed



Apart from work already mentioned:

Training/capacity development:

- Priority development/preparation for invited speakers
- Sessions on communication/media skills
- Opportunities to be involved in dissemination (Radio 4 and SANDS conference in Ireland)

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