



Infant Mortality and Pakistani communities: Social, genetic or what?

Dr Ghazala Mir
Dr Katie Spicer

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



ESRC Grant Ref: RES-061-25-0509





- Social exclusion and inequalities in infant mortality
- UK rates of infant mortality for mothers born in Pakistan, the Caribbean and teenage mothers are 100%, 63% and 60% higher than the national rate respectively
- Risk reduction strategies suggested include optimising maternal and mental health and addressing environmental stressors (DH 2007), improved services and increased social support for women at risk



Four phases:

- Explore the current evidence, policy guidance and local context (Leeds and Bradford).
- Recruit and interview women from a range of backgrounds in two matched groups (30 at each site) who have
 - (i) experienced an infant death
 - (ii) a child over one year old
- Analyse data using quantitative and qualitative methods.
- Project development group aimed at finding solutions to the problems identified using participatory research methods



- Review of infant mortality policy with reference to ethnicity
- Review of evidence for impact of pre and post natal social support on birth outcomes
- Data from key informant interviews
- Questions for group discussion

National Infant Mortality Policy and Ethnicity



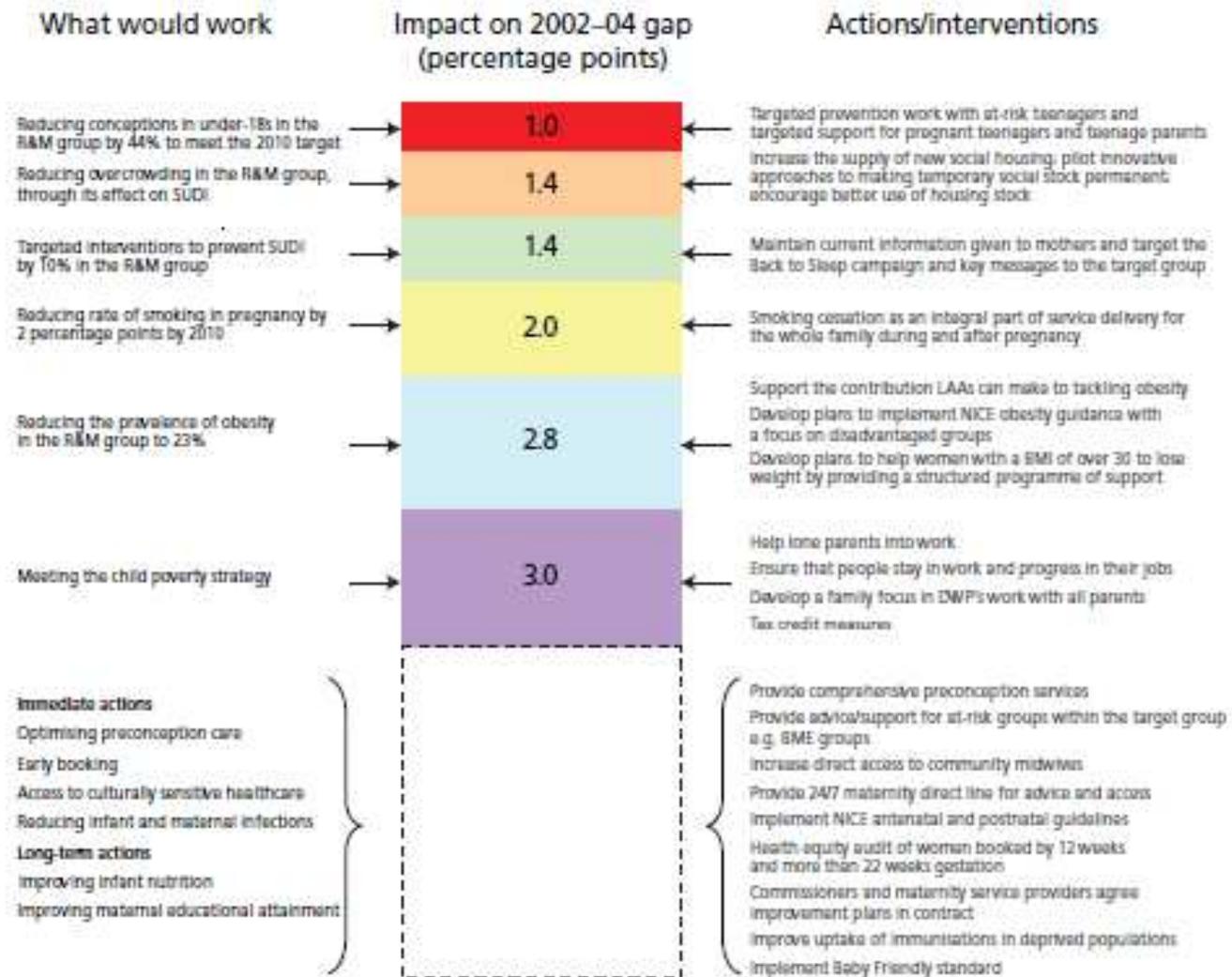
UNIVERSITY OF LEEDS

- Infant Mortality as a component of NHS plan (2000)
- 2002 National Health Inequalities PSA target and infant mortality action plan a key part of public health strategy
- Main focus of target is socio-economic inequality
- However, recognition within 2007 Dept of Health review of target that certain groups such as women born in Pakistan have significantly higher risk

Scarf Diagram



UNIVERSITY OF LEEDS



Scarf diagram: key focus of national and local policy



UNIVERSITY OF LEEDS

- National policy centred around actions modelled in the Scarf diagram, a modelling of 7 interventions targeting R&M group
- Significant impact on shaping of local policy
- Interventions may have an impact on some of the risk factors for teenage mothers in particular
- Arguably don't directly address issues facing women of other high risk groups
- Risk of perpetuating inequality in infant mortality for those at highest risk



- Recognition within DoH review of significance of interplay between poverty and ethnicity
- Yet not reflected in key targets as outlined in scarf diagram
- Genetics service in Blackburn given as good practice example, among other case studies
- Risk of obscuring significance of complex interaction of socioeconomic status and other factors around access to care in causal pathways for IM



Evidence for complexity within explanations of variations in infant mortality:

- 4% of consanguineous couples have a child with a congenital abnormality compared to 2% otherwise (Modell and Darr 2002)
- Rates of terminations for an anomaly vary among different ethnic and socioeconomic groups
- Socio-economic status as a key risk factor for infant mortality, closely intertwined with ethnicity
- Support available to women also linked to higher rates of infant death



- Evidence for significance of quality and type of support accessible to women and families pre- and post-natally
- Health outcomes for mothers and infants influenced by
 - presence of a birth companion (Sosa et al 1990)
 - quality and type of social support from partner, family and friends (Austerberry et al 2007)
 - connectedness in social network- facilitating access to material and informational resources, but network may reflect poverty and disadvantage/lack of resources (Gayen and Raeside 2007)
 - Perceived **quality** of support from all sources more impactful on health outcomes, not frequency of support (Oakley et al, 1994)



- NPEU survey of women's experience of maternity care (2010) found:
 - later booking for women from minority ethnic groups (which may result in inequalities in prenatal testing (Smith et al, 2011))
 - less awareness of choices around maternity care
 - less trust and confidence in staff
- Health Care Commission review of maternity services (2008): women from minority ethnic groups more likely to be left alone during labour and report feeling worried by this, an example of discrimination within healthcare contexts
- Recognition from health care professionals of training needs such as in **effective communication**, and **skill gaps** beyond dealing with particular issues such as sickle cell anaemia (Chevannes 2002)



- Complex area with lots of uncertainty (Kurinczuk 2010)
 - Congenital anomalies contribute about one third of the extra infant deaths in routine and manual groups
 - 4 x higher risk of infant death from CA in Pakistani babies
 - underlying cause most often not known
 - not always possible to offer genetic screening
- Inequalities between socioeconomic and ethnic groups for 9 fatal anomalies disappear when terminations taken into account (Smith et al 2011)
 - Lower rates of termination amongst Pakistani women not taken into account in infant mortality figures
 - But rare conditions may not be covered by the anomalies investigated



- **Deprivation (lbw), prematurity, communication barriers, genetic risk/terminations, quality of healthcare, health literacy, confidence and capacity to seek support**
- Good practice **adaptations** to meet needs but **not routine or embedded** within mainstream services:
 - Haamla, Choto Moni, Mothers in Exile, Maternity Outreach Volunteers
 - Bradford Doulas, Genetics training/campaign
- **Ethnicity not a trigger** to explore related risk factors despite higher rates of infant mortality



Staff shortages/pressures/dynamics within teams

Staff in mainstream services not representative of minority ethnic communities - impact on relationships

- Ability to respond, lack of empathy - 'task-based' rather than caring relationships
- Interactions influenced by perceptions of group identity /stereotypes and what people 'think they know'/ 'instincts':

“it’s very like when you read accounts of Britain in Victorian times, that, you know, the woman was the last person to eat in the family. She makes sure the children eat, her husband eats, that they’re all sorted, and then, if she’s got time, she thinks of herself”



- Consanguinity perceived as a ‘sensitive area’, ‘inherently dangerous’ and major explanatory factor
- Reduced credibility of those who suggest a more complex perspective - ‘in denial’; ‘minimiser’; ‘not an expert’. Different positions seen as a ‘cultural divide’
- Genetic awareness a part-solution: clearer pathways needed for better access to genetic counselling for individuals/affected families - ‘primary prevention’.
- Termination after diagnosis of CA a moral decision with consequences for well being of woman and child – need for broader service responses to these decisions



- Research role in Family Nurse Partnership programme - exclusion of young BME women with language needs and risk factors not explored if with family (migration, isolation, deprivation, access)
- Parallel intervention suggested for BME women – ie targeted programme of comprehensive support
- Lack of local research a reason for lack of local action (cf teenage pregnancy pathway).
- Feedback mechanisms for service development underrepresent BME women



- **Supportive:** eg Muslim chaplains/religious authorities supporting breastfeeding advice; mosques disseminating health promotion materials.
- **Supporting women/conflicting with professionals:** Some religious authorities perceived to be 'in denial' about genetic explanations for infant mortality. Muslim staff seen as 'dissuading' post mortems considered 'very important indeed' by doctors re potential for informing about future pregnancies. Religious teachings on terminations
- **Stereotypes/prejudicial views** of Islam may be promoted amongst professional actors – influenced by ethnic and social class as well as religious differences. Professional relationship with individual women may be influenced by their perception of women's social identity before interaction has even taken place



- Importance of a broader approach, responsive to specifics of local context
- Design and delivery of a genetics service must be tailored to local situations, needs and perspectives
- Vital to address challenges in delivering health care and support to women and families from minority ethnic groups
- These challenges are likely to play out in the delivery of a genetics service and could threaten its success



What should a strategy for reducing infant mortality in the Pakistani community look like?

How might this address:

- deprivation: low birth weight, prematurity
- access to support
- genetic risk factors/termination decisions
- quality of healthcare
- specialist support services?



- This work was supported by the Economic and Social Research Council [grant number RES-061-25-0509]
- Ghazala Mir and Katie Spicer can be contacted at:
 - Leeds Institute of Health Sciences, University of Leeds, 101 Clarendon Road, Leeds LS2 9LJ
 - Ghazala: 0113 3434832, medgm@leeds.ac.uk
 - Katie: 0113 3430835, k.spicer@leeds.ac.uk