Community Engagement, Behaviour Change and Infant Mortality/Disability

Existing Research

- Findings from Ajaz et al (2015) study in Luton states that "their findings corroborate existing research which highlight that the presentation of genetic risk that singles out a particular community, in this case the Pakistani/ Kashmiris, also simply alienates them and results in the community refuting findings from studies that associate consanguineous marriages with negative health outcomes (Ali et al. 2012; Atkin et al. 1998)."

- There is a real issue with stigmatising communities through emphasizing consanguinity in infant mortality without clarity on all the risk factors and an explanation of disabilities across communities.

Behaviour Change

- Very difficult to change behaviour, if individuals and communities don't see themselves as susceptible to this happening to them.
- If communities don't see infant mortality and disability as an issue for them then this is not a threat to them and unlikely to take up any behavior change.

Unrealistic Optimism

- Even when people understand risk they don't apply the risk to themselves. "My grandmother smoked all her life"
- We call this unrealistic optimism
- To counter this we must communicate risk is real and serious.
- Through changing attitudes of some people this will lead to motivation for others to also comply over time.

So what is needed to get communities engaged

- A clear focus on Infant Mortality across the city and its relevance across communities

- Clear identification of factors

- Solutions in collaboration with the communities that come from within those communities.

- Work across communities and across the variables that are predictors of infant mortality.

Possible solutions

- Put the figures and facts out in the limelight to create an environment for discussion and change that doesn't target specific communities
- Engage with community leaders/councillors
- Engage the communities on ways to present information and finding their own solutions.

Co-producing knowledge and solutions

- Community knowledge through community researchers
- Community education through communities
- Use real life scenarios of change.