Hi Gail, thank you for forwarding the evidence gathering seminar, it was incredibly insightful; however, I was not surprised on the detailed projections presented by the speakers on infant mortality as the factors and causes of death correlate with other pre-determinants of poor health affecting BAME groups living in areas of high deprivation.

To begin with, it might be useful to provide you a very brief outline of our work in supporting BAME Women in their health and wellbeing within Sparkbrook.

Women Wellbeing Hub

We run a women wellbeing programme for BAME women and children from low income households, experiencing greatest barriers to health services due to poverty, isolation, language /cultural barriers and low levels of education. This programme tackles important root causes of health inequalities experienced by BAME women and their young children: poor quality nutrition, lack of knowledge and support on following a healthier and more active lifestyle. The service provides holistic care to help improve physical, mental, social and emotional wellbeing

Supplementary to this, in partnership with Birmingham University we have carried out a pilot project to which investigates on how to improve health outcomes for those with Type 2 Diabetes from communities with the greatest health inequalities in Birmingham through, improved healthy lifestyle support. This lead to producing 3 reports on the effectiveness of streamlining services through social prescribing via local GP's and community centres providing wellbeing support. The study involved interviews with 6 GP surgeries and clinical trials with two GPs, and 20 patients diagnosed with Type 2 diabetes and the results were effective, where patients experienced an improvement in at least one clinical measure and one patient with a congenital kidney problem showed marked improvement in kidney function.
The GP commented:
'As a practising GP working with many BAME patients it has been an ongoing challenge to get many patients to take up existing support provision. Not only has this programme largely solved that problem but it has also delivered clinical results over a 5 month period that way exceeded my initial expectations'

Further-more there is greater impact using a community based model of engagement where by services are centred around patient care, using a culturally sensitive approach. This is done in co-production with service users, local GP's and Public Health and other health practitioners. Our experience of this work is built on our existing evidence base of women's lived experience of socio – economic disadvantage and their experience of accessing health support. Presently, we are looking to expand possible interventions, combining our wellbeing and diabetes programme with a focus on pre-conception advice and support, in order to improve the infant mortality rate in Birmingham.

I felt it was important to highlight some of the work we are currently doing, as the learning outcomes and project methodology can be shared across your wider network around reducing rates of infant mortality through improved access to

healthcare but also taking into consideration of culture, beliefs and behaviours that may concomitantly contribute to infant mortality such as close relative marriages amongst Pakistani communities.

This moves on to the questions that you have requested, and my answers are based on my experiences of working with women of Pakistani heritage, of which a high percentage are married to a person of close relative. However, it appears there is limited evidence available in this subject area and can be of an sensitive nature; as the custom has been traditionally practiced over generations along family lines.

I do feel there is a need at a community level to raise genetic literacy and encourage uptake of services to create awareness on the risk of marrying close relatives. It would be useful (as we have done with the Diabete's project) to Work with University of Birmingham to undertake a piece of research into infant mortality and consanguinity with a culturally sensitive approach and train local people as community researchers. We will be happy to lead on this and carry-out some local data analysis as we are currently working in this field, and have links with women that fit into this category and will provide a more accurate perception.

Q.1 With the people you come into contact with in the community are they generally aware of the risks of infant mortality?

From our wellbeing project, infant mortality has not been highlighted nor identified as a discussion point / concern from the community. They have shown health concerns in obesity, depression, diabetes, and hypertension with a willingness to improve their health outcomes through participation of wellbeing activities for weight loss through diet and exercise. Majority of our service users do live with a chronic illness or experience poor mental health. However, there is a need for more information / educational programmes to build awareness around infant mortality.

Then, more specifically, what are their perceptions of risks associated with marrying close relatives?

A proportion of our users are Pakistani and 35+ and married to a relative; there are no clear perceptions of associated risks of marrying a close relative, and if there is, it is often over-ridden on the perception that this choice of marriage is 'safer' than going 'outside of the family', further reinforced by parental / family expectations, caste system and widely practiced within their community circle. It is common whose either spouse have migrated from Pakistan and married a UK resident and one or both of the parents to be in favour of their child marrying a close cousin either in the UK or abroad, for the same reasons and recommend a suitor on that basis. Another complication are family pressures to marry within family ties as a 'senior member' of the family have 'promised' an engagement of marriage and can cause family drifts and shame if they are not fulfilled.

For example, we do have a high number of Domestic Violence cases of victims married to first cousin's, some are on spouse visa's. It is very difficult for them to move away from an abusive situation as they have deep connections with Pakistan,

and many are inter-related (in laws are related to both families). To ensure their safety they have isolate not only from their spouse but the whole family.

Non- traditional families / parents are aware of the risks associated with first cousin marriages and were not always in favour marrying first cousins (along with other cultural complications) but may consider distant relatives. These families used wider social networks to identify suitors that were not related but having similar backgrounds.

However many would see the probability / risks as quite low as many of parents / grandparents and generations before have been married to a first cousin / relative, and 'go outside the family' based on the choice of their child's preference.

Overall close related marriages could not be seen as a single factor, but is deeply associated within complex cultural and religious connotations. This practice goes back a hundreds of years and will require a culturally sensitive and grass-root approach to inform affected communities on the risk. The message will have to be consistent, accessible via a grass-root community friendly approach, using community languages to share scientific facts on infant mortality.

We're trying to gain an insight into how those risks are perceived amongst communities across the city

This would require collation of wider research as the views of people will vary across different geographical areas across Birmingham depending on ages, cultural diversities, education and socio-economic backgrounds etc.

What health messages would help these people make a balanced decision and who is best to convey those messages to the communities you work with?

As mentioned messages will have to be delivered through a community educational framework, that is accessible and delivered in co-production with service users, local GP's and Public Health, midwifery services and other GP/ health practitioners. Further more address and reduce existing barriers that increase health inequalities that widen the gap of infant mortality across specific communities.

For example, health inequalities experienced by BAME women and their young children in certain areas of Birmingham are due to poor quality nutrition, lack of knowledge and support on following a healthier and more active lifestyle.

Through our work we have put in place the following recommendations:

- **Delivering a lifestyle support programme that is twice as effective at engaging and retaining BAME women on programme as standard GP provision/referral provision**

Service users felt engagement between healthcare professionals / GPs was not an equal process of engagement, and apart from medication, many did not rely on their GP provision could provide alternative intervention (health and nutritional lifestyle changes) that could potentially improve their condition. Language was also a huge barrier.

Service users felt dis-empowered and other than medication from their GP, they had no information, knowledge or access to wellbeing services surrounding obesity and pregnant care for mothers; also DR's negative stereotypes often disempowered patients to make positive changes to improve their health. They felt they needed a Wellbeing programme for good health to provide the best possible start for their child.

On this feedback, we worked with service users via feedback forms, consultations, focus groups, wellbeing activity classes to develop a service giving them a stronger voice, choice and greater control through an educational and culturally appropriate wellbeing service attached to their GP. Service users felt that referrals from the GP gave credibility and trust to engage with the wellbeing service. They were not aware of any existing Wellbeing Provision in their area, where they could get advice, knowledge on existing services available in the area. Through the programme service user wanted to be trained as Health Coaches to lead with professionals to provide a high quality health care, that can be tracked to ensure service user experiences are captured. They wanted:

- High quality nutrition for mothers
- Importance of a healthy lifestyle for mental wellbeing
- Advice and practical, support on providing high quality nutrition to young children in support of their physical, emotional and intellectual development
- Disease prevention through managing weight and obesity

Health Coached proposed a longer-term sustained engagement where the well-being Programme will be lead by local citizens and act as a conduit to advocate their needs and voice.

Furthermore there is a need to;

- Delivers better clinical results around weight reduction, blood sugar and cholesterol control than standard GP provision. These are risk factors for pre-eclampsia and help reduce the risk of Type 2 Diabetes and obesity in mothers and their children; particularly in areas of high deprivation such as Sparkbrook, Ladywood and Bordsley Green areas of Birmingham.
- Providing an integrated approach to improving nutrition and wellbeing that is empowering and effective in encouraging participants to change their mind-set actively explore their wider circle of life and achieve better mental health.
- Provide mothers with a comprehensive and tailored education on the importance of wholefoods for hormone health, gut health and immunity breastfeeding and mental wellbeing and the practical skills and support to make the relevant lifestyle changes. Information has to be accessible; available in community languages and obtainable within their lifestyles. Self-care is not a priority for many of the women that use our services and do programmes to help change mind sets.
- Working in close co-operation with GPs, Local Maternity Units to provide the maximum synergy between clinical and health coaching expertise, all within a local context.

- The parent's voice is core to delivery and integrated via community collective approach, whilst utilising existing & local community wrap around intervention i.e, Women Wellbeing Hub and other wellbeing initiatives.
- The Women Wellbeing is our platform to improve poor health outcomes of local women as this fits seamlessly into our over-arching aims of wellbeing, so that existing women can fully benefit from the scheme, either as participants or volunteers. We also have a strong steering group of women that have been involved in project design, and rolling out any health programme with in informal community structures. We have evidenced the effectiveness of our work, please see results of an evaluation:

Women's Wellbeing Hub outcomes
Of 50 interviewed

- 80% committed on the programme having lost weight
- 95% reported improved mental wellbeing
- 90% retention of programme and experienced wider benefits via nutrition / diet and family support

First group of 9 patients run through the GP surgery in North Edgbaston

- 7 lowered their HbA1c by an average of 4.2
- 8 lowered their cholesterol by 0.51
- 5 patients lost an average of 3.2 kg
- 6 self-reported increase in weekly fitness
- All reported an improved diet with more whole foods
- 1 reported significant improvement in asthma

Participant quote 'This holistic programme has helped me piece things together. Without you I would not get the results that I have achieved. Absolutely understand now the importance of diet to manage Diabetes . . '

Second group of 8 patients with same GP Practice - on-line programme

- The average weight loss has been 75kg
- All reported improvements in diet and exercise
- Clinical measures still being taken by the GP

Further recommendations:

- A local volunteering programme, with parents involved in the project. They should be instrumental in leading as Health Coaches to provide peer support and sharing resources in community languages with in their own existing family and community networks. They should be provided training on supporting healthy outcomes for families and community engagement as their strength in reaching out to isolated families. Training is an incentive that attracts women to get involved, particularly around parenting and families. It provides them confidence in their abilities, in area that they feel passionate about.

- Referrals from GPs, working in partnership with maternity units, particularly when supporting women that are at high risk of chronic diseases such as Obesity, Diabetes and hypertension.
- Wellbeing Activities with wider partners including community resources such as local schools, nursery provision, and wider wellbeing partners such as Cycling UK, Muath Trust, Aging Better, Forward Carers, Farm Road Health Clinic and many more
- Use services with a high footfall of affected communities for example our advice and Guidance project has over 600 women that access the service every year