

## Maternity Public Workshop

**Wednesday 25 January 2023 9 – 11am on Microsoft Teams (online)**

On Wednesday 25 January 2023, the [Leeds Health and Care Partnership](#) held a public workshop to discuss maternity care in Leeds. The aim of the workshop was to ‘develop our approach to public involvement on the population board’. The presentation and a recording of the session is available on our website here: [Maternity - Leeds Health and Care Partnership \(healthandcareleeds.org\)](#)

The objectives of the session were to:

- Introduce population health and the board
- Review and agree the findings of the insight report
- Begin planning involvement on the gaps in our knowledge
- Review and agree the draft outcomes for the board
- Agree how we represent people at the board and provide public assurance

The outcomes of the session were

- Understand the role of the board
- Discuss the findings of the draft insight report
- Influence the draft insight report
- Discuss gaps in our knowledge
- Suggest other gaps
- Discuss the draft outcomes for maternity
- Explore ways we can provide assurance that people's voices are heard at the board
- influence our approach to public representation and assurance on the board

The agenda for the session was:

- Population Health - What are population health boards and what is their role?
- Experience of maternity care - What do we know about the experiences of people using maternity care and their family? (Our insight)
- Population outcomes - How do we want things to be different for people using maternity care and their families? (Our outcomes)
- Public representation and assurance – What does public representation look like on the board?
- Next steps - What happens next?

The session was attended by 34 people made up of representatives of the voluntary sector, staff and members of the public with an interest in maternity care. Two people who couldn't attend shared their views through one-to-one conversation (please see [Appendix A](#)).

Organisations represented included:

- The Integrated Care Board (ICB) in Leeds
- Maternity Voices Partnership (MVP)
- Leeds and York Partnership Foundation Trust
- Maternal Medicine Network NHS

- Irwin Mitchell Solicitors
- British Pregnancy Advisory Service
- DAMASQ
- Health for All

## Workshop feedback

The chair of the board, Dr Julie Duodu, introduced the population health approach and the role of the Maternity Board in Leeds.

Helen Butters at the Integrated Care Board in Leeds (ICB is responsible for planning and buying NHS services) outlined the approach-starting with what we already know about the needs and preferences of people in Leeds. She shared the findings of the insight report and asked for feedback on the themes and gaps.

- There was general agreement with the themes that have been identified in the insight report
- People felt continuity of care has more than one aspect – good to understand this more – what does this mean?
- Could we be better at picking up potential mental health problems antenatally?
- How did covid impact the maternity experience?
- Are the resources and access for preparation for parenthood accessible?
- There was agreement that feedback from Gypsy and Traveller communities is a gap in our insight
- Need to understand the needs of autistic mums better
- Women from Eastern European countries receive maternity care quite differently (more medicalised) Should we be explaining our processes better to reduce anxiety?
- Is there a gap around obesity?
- Better clarity around pathway and the language used, can be a complex system to navigate
- Staff having an understanding of culture
- Include family/dads/partners better
- Agreement that LGBTQ plus is a gap as well as the deaf community: people also raised gaps in hearing from surrogate parents, or parents who have fertility issues and people who are involved in care proceedings.
- Due to lack of funding many groups have now disbanded, peer support as well as Haamla service matter to people
- BSL should be used more
- We identified that having continuity of carer for diverse communities was key as well as an appropriate interpreter. We discussed body language being important to all people with language barriers to feel comfortable with professionals to enable them to share information.
- Adoptive parents- what care is available for them?
- Better communication and support for people who have experienced miscarriage: “happiness when you leave hospital and your hands are full, profound sadness when you leave with empty hands” lasting impact on subsequent pregnancies and raising “rainbow children”

- Often people who have migrated to the UK be they economic migrants or those seeking asylum, or who are refugees, have very little or no social or community support. Provision or consideration of their childcare for older children and transportation needs would be tremendously helpful. I.e., childcare onsite when attending midwifery or obstetric appointments and financial assistance if needed to attend these appointments.

Nikki Stanton at the ICB in Leeds outlined the maternity outcomes that have been developed with partners. These outcomes explain what we want to achieve to improve the lives of people using maternity services. Nikki asked for feedback on the outcomes.

- There was general agreement with the maternity outcomes developed by partners in Leeds.
- People questioned whether the public would understand the term “personalised care”
- Staff being culturally aware was important
- There was general agreement of the ambition of the outcomes
- Consider changing wording “personalised care” emphasis on optimising physical and mental health for everyone
- How does what we do on the board translate to frontline staff?
- Felt the outcome ‘people receive personalised care maternity care safely’ was too wordy. Felt these were two separate statements; Discussed whether safety be an outcome as all care should be safe. Where is quality?
- General agreement personalised care should be an outcome but that not everyone will understand what this means, and personalised care will be different depending on the person.

Helen Butters outlined the importance of public representation and assurance. She explained that our approach would ensure that all our partners and the public were confident that the board has put people at the heart of its decision-making. The group discussed our approach to representation and assurance.

The group discussed a number of ways we could have representation at the board and provide public assurance.

- **Visit community groups**  
The group discussed the idea of some board members visiting community groups
- **An involvement sub-group for the board**  
The group discussed having a wide group of public representatives who meet regularly without professionals as they felt this would be a more honest conversation. Possibly chaired by the rep from the board. They could have the outcomes measures as an agenda item
- **Public representation on the board**  
The importance of getting a wide diverse voice around the table is important. It was questioned whether the Maternity Voices Partnership (currently the patient rep on the board) currently represents that wider voice to the table.
- **Following a maternity journey**

Follow a family's maternity story from start to finish. This would give us some rich insight into the whole pathway from the family's perspective, i.e., not us coming up with survey questions.

## Next steps

The group discussed the next steps for developing an approach to public involvement in the board.

- The feedback will be used to update the insight report
- Participants will be invited to join a small working group to
  - Develop an approach to representation and assurance
  - Explore the gaps in our insight and prioritise involvement

## Stay in touch

Stay involved in our work to improve health and care services in Leeds by joining our citywide public network here: <https://www.healthandcareleeds.org/have-your-say/shape-the-future/join-our-network/>

For more information about this work please email [hbutters@nhs.net](mailto:hbutters@nhs.net)

## Appendix A

Conversation with parents who are expecting a down syndrome baby boy

18 January 2023

Both parents work in the NHS and have a wealth of experience of working and caring for children with special needs.

The Maternity care has been amazing throughout their journey but the communication around their baby's condition has caused distress. They were first told that they had a 95% risk of their baby being down syndrome.

Termination was discussed and they decided that they would keep their baby. Following the decision, after every clinic appointment, they were asked if they wanted to terminate and every clinic letter they received offer of termination was written on the bottom of the letter. This made them question their decision and feel staff knew more information than they were telling them. They feel that parents who do not have the experience and knowledge they have may terminate.

Language around down syndrome was negative. Using the word risk of baby being down syndrome is a negative term. They feel the word risk should be replaced by the word chance. "I'm really sorry to tell you....." was also used. They feel down syndrome and other illnesses, for example Edward's syndrome are lumped together. The syndromes are very different and have very different levels of outcomes. Again, parents who do not have the knowledge could be misled.

They feel that once you have made your decision to keep the pregnancy you should not be continually asked about it but told you can discuss it with them anytime.

The National Down Syndrome Association has some great training resources for professionals, and they feel this is needed with the staff they encountered.