BE BOLD
BE BIRMINGHAM

SOLDOM HEARD

Conversations about pregnancy

July 2022

Birmingham City Council

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SELDOM HEARD

Conversations about pregnancy

INTRODUCTION

Infant mortality is a key public health indicator of the health of the general population as well as standards of clinical care. Nationally the rate of infant mortality has been declining since 2001/03 but in Birmingham infant mortality rates have been statistically high for many years, nearly twice the national average.

As recommended in 'Better Births' to improve outcomes for maternity services there is a need to understand our 'seldom heard' community's perspective around pregnancy. Having relevant information and being supported to make healthier choices is known to make a positive difference in the pregnancy journey for most women. Therefore, as part of shaping the approach to creating a positive discussion regarding both desire and preparation for pregnancy, Birmingham City Council Public Health Team commissioned qualitative research targeting 'seldom heard' communities across Birmingham. These conversations took place January 2021 through to June 2021. The findings from these conversations will help influence the development of the Reducing Perinatal and Infant Mortality action plan and its overall aim to reduce infant deaths in Birmingham.

Key findings

- Women repeatedly stated they were not listened to and their concerns not taken seriously or valued.
- Participants from the Black, Asian and minority ethnicities and deaf and hard of hearing groups commented on how they felt invisible when health professionals would speak directly to family, friends or interpreters who accompanied them.
- Asylum seekers and refugee women felt unheard and wanted a voice in their care. They shared that things were 'done to them' rather than asking what it is they need not what their husband, family or nurse feels they need.
- Deaf and hard of hearing women told of the impact on their confidence, independence and mental health when they do not have access to an interpreter.
- Participants felt there were gaps in information and help when things didn't go as planned for example miscarriage or loss of a baby.
- Participants from Black, Asian and minority ethnic groups discussed how they didn't know what to expect in their first pregnancy, what signs to look for and how they wanted to be better informed about risks.
- Deaf and hard of hearing women felt it important to know interpreters will be available prior to appointments and that additional time will be allocated to allow time for a three-way conversation.

- Women identified how accessing emergency contraception through pharmacies can lack privacy.
- All focus groups expressed concerns around not being treated with dignity and respect from healthcare service providers. It was felt that personal interactions needed to be more of a positive experience.
- Delivering services, support and information using technology can create an additional barrier for women and families who don't have access to the internet and/or don't have the right equipment.
- Women from Black, Asian and minority ethnic focus groups identified their feelings of distress and low moods after experiencing stillbirths/miscarriages, was not getting picked up by their doctors or their communities.
- During conversations, women placed a strong emphasis on the importance of culture and how it impacts on the woman's pregnancy and parental journey.
- Women from the South Asian group strongly felt access to health services and treatment is not on par with pregnant women who are more proficient with English.
- Bangladeshi women discussed how they were unsure of what not to eat and had very little knowledge of any recommended vitamins etc to take during pregnancy.
- A number of participants across groups were not aware of how weight can impact on becoming pregnant.
- Participants shared the influence of others on their pregnancy journey and how this conflicting information often left them finding it difficult to know which advice to follow.
- Women spoken to were generally comfortable being asked 'one key question' by health professionals. A small number suggested they would be happy to be asked by other support agencies.
- There was a general feeling mother and baby support had been cut so there was less support on offer.

Key Recommendations

- Ask women what they need and give them options and choices.
- Health professionals to give women time to talk about their concerns and frustrations without reprimand from family or communities.
- Ensure accessible, timely and appropriate information in order for women to make decisions and choices about their care. This should be available in a range of translated formats including leaflets, digital platforms, videos and workshops to talk through the information.
- Services should be personal and focussed around their women's needs, culture and beliefs.
- Sexual health services should be delivered in different settings, including education and the workplace, making them more accessible.

- Interpreter support should be available not only for planned appointments but for emergency appointments as well.
- Ensure new parents are knowledgeable about the 'system', their rights and how they can meet their own needs with the resources available.
- More support for those who experience multiple pregnancies.
- Translators, in all languages, need to develop a repour with the pregnant women they are working with to build trust.
- Translators should understand the culture and traditions of the person they are translating for.
- Where the option exists, an opportunity to talk to a female doctor should be offered.
- Medical professionals should ask more probing questions and always check on the woman's mental health.
- Improvements to the cultural compassion of health professionals need to be made through appropriate training.
- There needs to be clear information on access to maternity services for new families to Birmingham and for women with literacy and language barriers.
- Opportunities for parent education in appropriate languages should be provided.
- Help and support for new fathers should be provided and should include education on being both a new father and a supportive partner.
- There should be opportunities for social network building and encouragement for movement and participation in green spaces, both during pregnancy and for establishing familiarity for life with a new baby.
- Information on pregnancy and parenthood for parents and their extended family, including why recommendations are made, needs to come from a reliable source.
- More information is needed on sexual health, contraception and pregnancy at universities, ensuring it meets the needs of international students.
- There needs to be personalised, empathic care with enough time for a curious conversation.

Targeted communities ('the seldom heard')

Public Health commissioned four providers to recruit at least 10 people from each 'seldom heard' community identified below (focusing on women but not to the exclusion of men), capturing their views and experiences in response to a set of questions/themes provided by Public Health (Appendix A).

a. Refugee and asylum seekers;
b. People with sensory impairments;
c. People of working age with mental health conditions;
d. People of working age with long term health conditions e.g. diabetes, COPD;
e. First/Second Year University students;
f. Teenagers (14-18yrs);
g. Care Leavers;
h. Young women (18-25yrs);
i. Black and minority ethnic communities, specifically the following separate focus groups:
  - Polish and eastern European
  - Chinese/Vietnamese/Korean
  - Black African (including Somali, Eritrean, Ugandan)
  - South Asian (including Indian, Pakistani and Bangladeshi)

Methodology

Public Health identified targeted (seldom heard) groups and developed questions/themes to aid discussion. Questions were simplified to enable British Sign Language (BSL) interpreters to translate effectively. During sessions with Asylum Seekers and Refugees, the provider introduced additional questions to gain greater insight.

We commissioned relevant providers able to undertake appropriate qualitative research with our identified groups. Research recruitment methods included: online survey's, Twitter, LinkedIn, WhatsApp, local networks, voluntary organisations, newsletters.
There were 112 participants: 105 females and seven males (see Appendix B for demographics). A number of engagement methods were used including virtual focus groups, face to face focus groups, WhatsApp, mobile phones, Zoom, Mentimeter, JotForm and individual interviews. Public Health collated and summarised key findings and themes from individual reports into this final report.

TOPICS DISCUSSED

The importance of relationships, sex and health education (RSHE) was discussed in several focus groups. Participants thought information about exploring the difficulties of getting pregnant, being pregnant including physical and emotional aspects, what a good pregnancy looks like and being a good parent should be included as part of RSHE in schools.

In addition to understanding more about pregnancy and parenthood, it was clear that participants felt education on understanding and improving self-worth and self-respect were key. Positive role models were identified as helpful. Relationships were discussed and there was support for ensuring an understanding of domestic abuse, the signs and where help can be sought.

When asked who they could speak to about relationships and sexual health the young people spoken to reported that they didn't feel like they could talk to parents/carers. They did say however, they would feel more comfortable sharing and discussing these topics amongst peers as conversations with friends were typically more open.

The young people highlighted that at University, whilst there was a lot of information about mental health, they thought more was needed around sexual health, contraception, pregnancy and appropriate support services. It was suggested that international students may benefit from this the most, helping to improve their knowledge of sexual health risks and services available in the UK.

AS A MALE, WHO LEFT SCHOOL AT YEAR 8, I DEFINITELY FEEL THERE SHOULD BE MORE INFORMATION AROUND PREGNANCY FROM A MALE PERSPECTIVE AND RESPONSIBILITIES NOT JUST IN SCHOOL BUT FROM OTHER SOURCES.

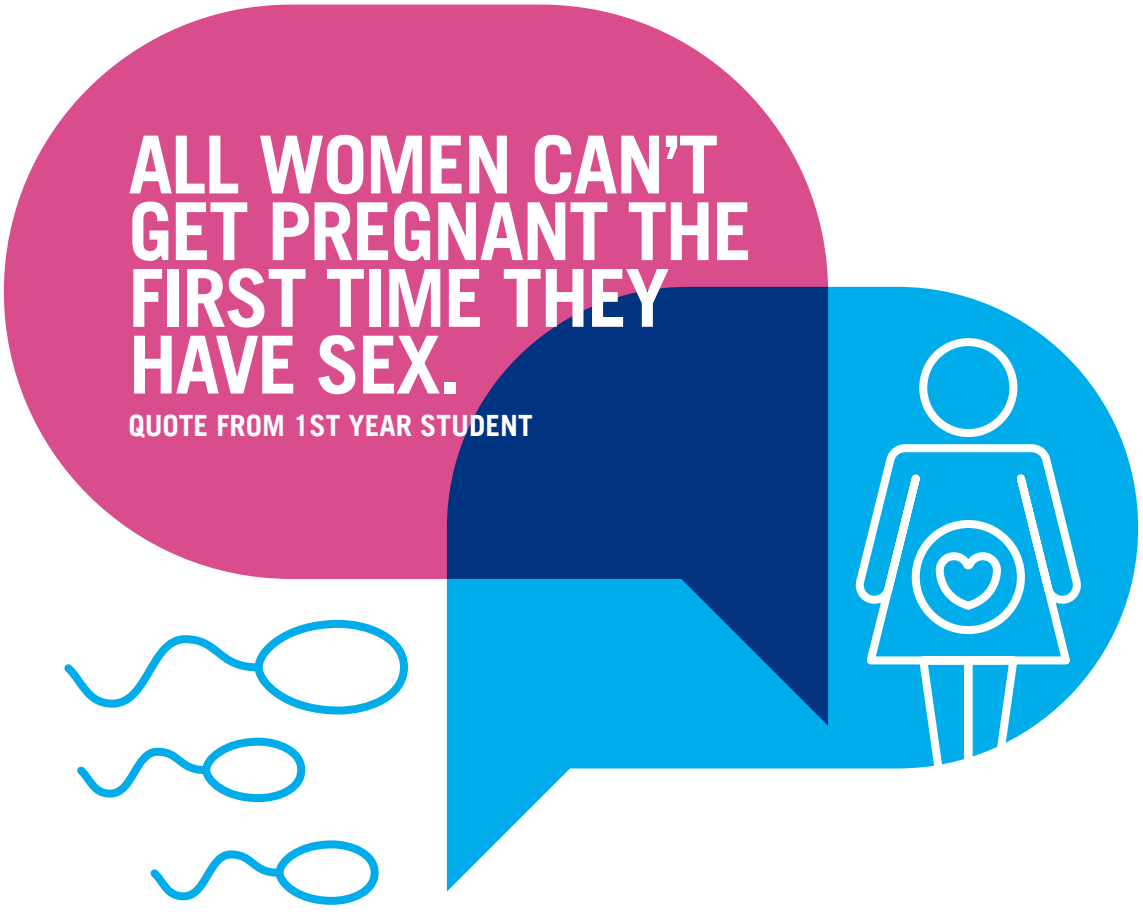
QUOTE FROM EXPECTANT FATHER

Whilst the young people spoken to were confident in identifying places, they could access sexual health information including Internet, children centres and local provider Umbrella, they suggested sexual health services could be made more accessible by delivering them in different settings, including education and the workplace. They also felt there should be a choice in the gender of the sexual health professional.

Across the young people's groups there was agreement that women do not know enough about anatomy. It was felt that there is stigma and judgement when talking about their reproductive organs and any issues or concerns they might be having. They were aware this might prevent some people, in certain cultures, discussing any issues or accessing services during their pregnancy if they had a problem.

The young people shared their thoughts on the impact of porn on relationships and sex and how they felt it distorted young people's views and makes it seem as if there are no consequences. They felt more education around this topic would be beneficial.

Some of the young people participating thought that the roles between same sex couples were more equal than roles held between heterosexual couples. They went on to discuss how they view society as 'still very traditional', with dad at work and mum at home.



CONTRACEPTION

In all the groups spoken to, women were aware that contraception was widely available with the oral contraceptive pill identified as the most commonly used. Some groups discussed preferences for accessing contraception with pharmacies, GPs and sexual health clinics coming out on top.

Young people spoken to said they preferred to access contraception from sexual health clinics rather than GPs, due to waiting times, confidentiality and they felt staff were more approachable. In addition, they said they would not go to the GP if they thought they were pregnant because they have no relationship with them.

It was suggested that further training may be required to help healthcare professionals have conversations about contraception in a respectful/approachable manner. Women shared that they often felt judged for wanting more children. One woman shared, "My GP kept insisting on the Coil for family planning. My GP was intrusive, looking down on me, because I already had two kids with a two-year gap."

EVERY GP PRACTICE SHOULD HAVE SOMEONE AVAILABLE TO TALK TO AND HELP SUPPORT WITH EMERGENCY CONTRACEPTION/ MORNING AFTER PILL.

QUOTE FROM WOMAN FROM BLACK ASIAN AND MINORITY ETHNICITIES FOCUS GROUP

An expectant dad shared how he thought most contraception didn't work and he viewed contraception as a 'woman's job'. Other dads also felt that contraception was not always 100% reliable.

There was some discussion about a male contraceptive pill and the participants believed this method was already available and people didn't know about it.

For the single Black, Asian and minority ethnic women, they felt their limited knowledge around contraception choices was acceptable at this stage in their lives and fitted with their spiritual and faith beliefs. However, if they did need to know, they would consider researching their options/choices and/or approaching health professionals.

When discussing emergency contraception participants said, it was readily available through multiple routes however, not everyone could identify what those where. For the women who could identify access points some shared that they felt access to emergency contraception through pharmacies, lacked privacy and other women felt that a direct point of contact in their GP practice would be helpful to provide support and advice around emergency contraception.

Whilst a comment was made that, "even 11/12 year olds can now access contraception", a number of barriers to use were identified by the focus groups including embarrassment, fear of being judged by health professional and others, language, stigma, religious, spiritual and personal beliefs and lack of knowledge.

PREPARING FOR PREGNANCY

Discussions were focused around the health and wellbeing of the mother when exploring preparations for pregnancy. There were some thoughts shared about how eating a healthy diet, keeping active, not smoking and taking vitamins/supplements were all positive preparations.

The women from the asylum seekers and refugees group however were unaware of how weight can impact on becoming pregnant and agreed that more education was needed to bring this to people's attention. Consideration of pre-conception clinics delivered within communities to educate on "what to expect" was put forward.

Expectant fathers spoken to mentioned the internet as a key place for them to find information on contraception and pregnancy.

STAYING WELL AND HEALTHY DURING PREGNANCY

Across the different focus groups, it was discussed how there can often be conflict between what families/communities/culture says should be done whilst preparing for and during pregnancy and what official NHS guidance says.

Nearly all deaf and hard of hearing participants looked to their family and friends, alongside health professionals for advice around planning for pregnancy and being pregnant. Participants said that whilst their families and friends shared their own experiences and advised them to eat healthily, avoid smoking, alcohol and drugs and take vitamins. they preferred to speak with deaf friends who could tell them more about what it is like for a deaf woman to be pregnant.

Across all of the focus groups with women from Black, Asian and minority ethnicities, there was a strong emphasis placed on the importance of their culture and the influence and impacts it has upon the women before, during and after their pregnancy. They discussed how their culture can cause constraints on mature pregnant women and confusion for the younger mothers.

Some of the Bangladeshi women spoken to, discussed their knowledge of what to eat during pregnancy but were unsure of what not to eat and had very little knowledge of any recommended vitamins to take during pregnancy.

The majority of women in the South Asian focus group however, had a good understanding of what a healthy pregnancy was, identifying daily exercise, healthy diet, taking vitamins (most specified folic acid) and not smoking although a few had smoked during their pregnancy. There was little understanding of why exercise was important. Participants identified some conflict with elders who thought exercise could harm the baby and they should conserve their energy and rest. In addition to the culture/NHS information conflict, it was identified that there was a lack of trust in health information. To address this, it was felt that information needs to be translated for all members of the family from elders to younger.

Based on their experience, some women thought a clear understanding of the possible consequences of not following NHS pregnancy guidelines would be helpful. One woman in her 20s of African Caribbean background commented how she followed all the guidelines in her first pregnancy and had a healthy pregnancy; however, she became more "relaxed and lazier" in her second, as a result became overweight and had a problematic pregnancy. Deaf and hard of hearing participants highlighted that they wished they'd understood more about why they should take the vitamins and iron supplements recommended and how/if they might interact with other prescribed medication. One participant shared that with her first pregnancy she did not take the supplements until she was feeling weak. It was only at this point did the midwife explain why she needed them. She proactively took supplements with her second child and felt much stronger.

Overall, it was identified that participant knowledge on staying well and healthy during pregnancy had limitations and was full of conflicting information, advice and myths, which was a concern. Pregnancy myths shared from across the groups showed how they can influence thoughts on staying well and healthy e.g. 'If you eat loads of pineapple, you will have a soft cervix', 'Baby weight depends on how big the mother is so if you are small, you will have a small baby.'

For the women aware of the importance of exercise during pregnancy they felt it was necessary for them to have access to green spaces which they knew would support their mental wellbeing as well as their physical wellbeing.

It was agreed that more information was required on what a healthy pregnancy actually means, both physically and mentally. Women identified additional information they would find of use:

- What to expect during pregnancy and birth.
- Foods they could and could not eat when pregnant.
- What appointments they needed.
- Having a healthy lifestyle.
- What causes diabetes in pregnancy and what to do to avoid it.
- Points of contact.
- Information on baby classes.
- And one person said genetic support.
- Financial stability.
- Positive environment.
- Regular check-ups.
- Detailed advice on diet and exercise.

When it came to preparation to be a parent, participants in the deaf and hard of hearing focus group thought it was very important to know if their baby would be born deaf. They did not mind if the baby would be deaf but they would want to be prepared and get the right support in place, if needed.

To help them manage as deaf mothers, participants highlighted they would have liked more information during the antenatal period, on what practical equipment and support is available to deaf mother's following baby's birth and where they could access these resources.

When discussing what options were used to know when baby cries, one deaf woman of East European background was told to "tie a bit of string to the baby so you'd get a tug on the string when they cried". She reported that she now knows she can connect a device to her watch that will vibrate when baby cries. Another woman reported that she gets her husband to wake her as they did not use the 'modern device.'

Participants felt they would have benefitted from discussions about BSL signing with their baby.

MENTAL HEALTH AND WELLBEING

The South Asian women suggested that more education was needed for male partners to help them understand the pregnancy journey and postnatal period for women alongside the difficulties they faced. They wanted men to understand the pressure and stress they experienced during this time coupled by expectations that they cannot continue to complete daily household/childcare chores without support. Despite requests for help, some of the women spoken to felt they were not seen as important and were not listened to. They felt there was an imbalance in the roles and responsibilities within the household.

These women expressed how they would like their partners to understand that they would value some support, both practical and emotional, especially following a miscarriage or loss of a child. Women went on to share how expectations and pressures from their partners to continue life as 'normal' was causing poor mental health during their pregnancy. The ongoing pressures for some women to produce a male child was also acknowledged.

The women spoke about how they felt they had needed more emotional support during their pregnancy, knowing that their wellbeing and happiness would lead to healthier and happier relationships for all and especially for the growth of their baby in the womb.

CHILDCARE IS SO EXPENSIVE SO WOMEN LOOK AFTER CHILDREN RATHER THAN MEN, AS THEY GO TO WORK CAN CAUSE ANXIETY AND TENSION.

QUOTE FROM 1ST YEAR STUDENT

The South Asian group also discussed the stigma that exists within some communities around family history, cousin/blood relations and miscarriages. They shared that this feeds a reluctance to speak about these subjects openly.

The asylum seeking and refugee women also identified how poor mental health during their pregnancy has an impact on them and their friends/relatives. One participant shared how a pregnant relative with other children, was made homeless whilst pregnant and found it put additional stress on their mental and physical health.

Participants talked about feeling isolated whilst pregnant with the expectation they should just get on with things. In most situations, the women knew no different, so did as they were told, not reaching out for help or support.

All of the groups spoken to touched upon infant mortality in their discussions. It was felt there should be more counselling support services to address the diversity of mothers/partners guilt, grief, and loss from infant death.

In the focus group for Black, Asian and minority ethnic women, there were discussions around feelings of distress and low moods after experiencing loss through stillbirths and miscarriages. They felt this was not getting picked up by their doctors or their communities. One woman said, "The faith is strong to accept, but the suffering of women is still evident but ignored." Across all the focus groups it was discussed how medical professionals should ask more probing questions and always check on the woman's mental health.

A participant from the same focus group shared that when a woman loses a baby through miscarriage, the men didn't understand or support them emotionally, there is a 'blame' culture and guilt would often be placed on the woman. When these negative experiences mounted up, the women tended to withdraw and living in fear was considered the norm. They felt that the support from the family and the community is not there and so if they are suffering, they keep it to themselves and try and manage as best they can. The women did not feel in control of their destinies and that their culture and the belief systems within their society and religions, drove the 'blueprint' that they were destined to follow.

Deaf and hard of hearing women also talked about feelings of isolation through not being able to communicate with others. One participant described how alone she felt "I don't know anyone, no-one can do BSL sign with me". Deaf people in hearing families can be very isolated, especially if their families do not learn how to sign, and their access to general family advice and conversation can be limited.

WOMEN WHO ARE DEPRESSED HAVE TO HIDE IT, AS WORRIED KIDS WILL BE TAKEN OFF THEM.

QUOTE FROM PREGNANT WOMAN

Mental Health was a strong concern in the young people groups. One expectant mother shared, "I was told by GPs I have to come off my mental health medication but I have since found that I could take alternative medications. I was not offered alternative therapy/support". When asked what concerns they might have when/if raising a baby, mental health was in the foreground for one young woman:

"…there is a big stigma, which has only recently begun to be talked about, about once you give birth that you're supposed to be 'the happiest woman alive' – in reality, this may not be the case. Having a child can be exhausting, and there are diverse issues that women can experience afterwards.

Finally, I think the loneliness element scares me to be honest. I am excited to be a parent one day, (I think anyway!) but spending so much time alone in the daytime on maternity leave with the baby, could be quite a lonely experience. I think it's important for support to be put in place for mothers, no matter their family circumstance, to ensure they still feel 'emerged in society'."

The care leavers who participated felt that their experiences of being in care had impacted on their views on pregnancy, as they don't want their children to grow up without parents.

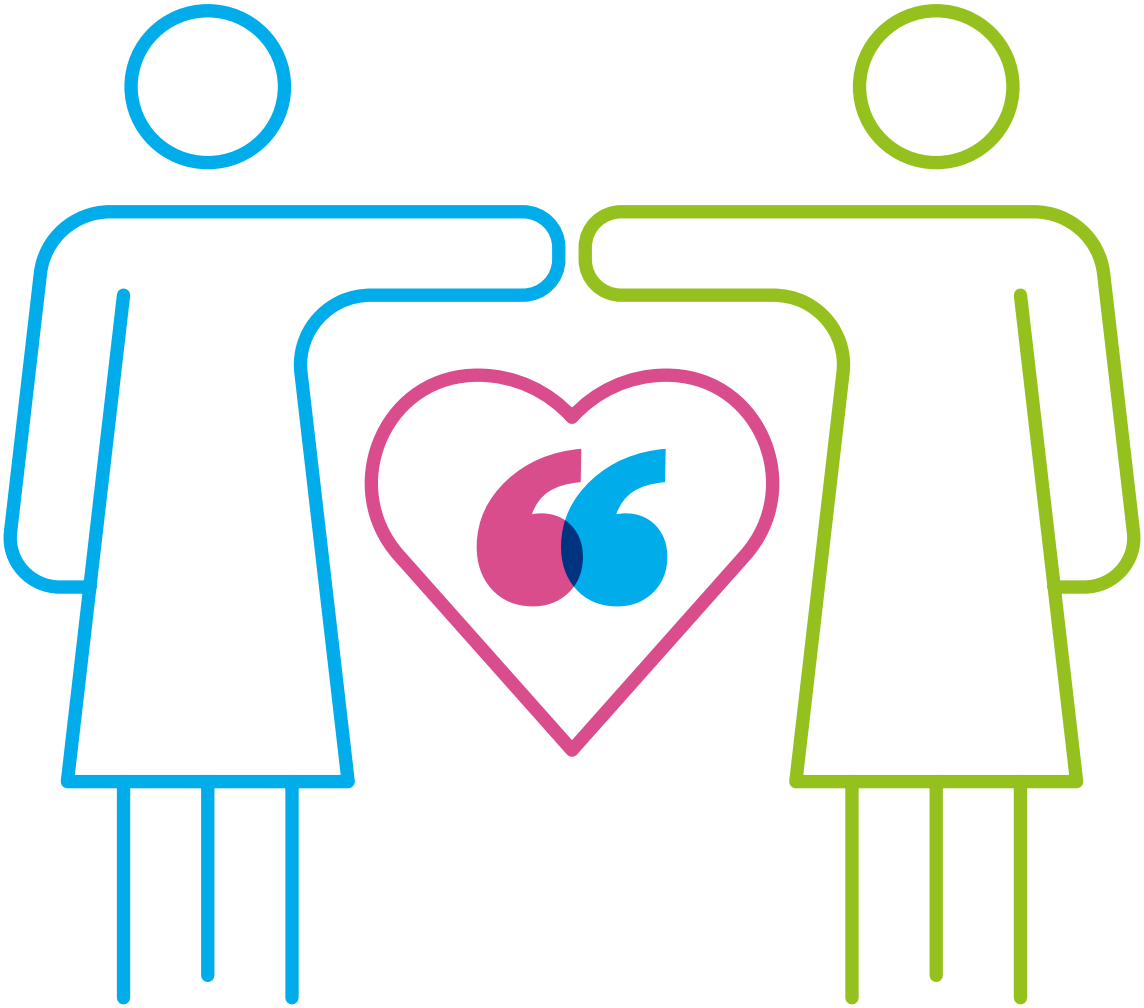
SOMETIMES... IF THERE IS NO ACCESS TO AN INTERPRETER... MY LEVEL OF CONFIDENCE DIPS.

QUOTE FROM DEAF AND HARD OF HEARING FOCUS GROUP

HAVING A VOICE

Across the South Asian and Refugee and Asylum Seeker groups, women commented about the need for an advocacy/maternity forum in order for their voices to be heard, especially where there is fear of a 'backlash' for speaking up. It was clear from some of the comments, that the women spoken to were unaware of the Maternity Voices Partnership and the support they could offer.

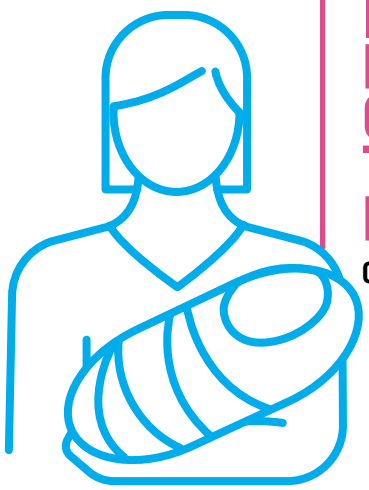
It was discussed how women's voices need to be heard and opportunities created so they have the confidence to speak up about their needs. Some of the women spoken to on this topic wanted to cry. They did not understand their basic rights and how to exercise them. They felt that the doctors they interacted with did not have the time to listen and were concerned they would not understand their experiences. In some instances, the women felt their pregnancy journey had been traumatic and that their need for help and support for this was neglected.



Women shared that they thought a peer-to-peer intervention would be useful so those who had gone through similar experiences could walk and talk others through the process, creating a 'buddy system'. They felt this approach would enable them to get advice and guidance from people who would believe them, were impartial and who understood the health system, including the language used. It was suggested by these groups that in having their voices heard, their culture would be understood and services would be appropriate to meet their needs. The participants were clear that they needed to share their experiences so that the 'younger ones' didn't have similar negative experiences.

WHO WILL HELP ME? ARE THERE DEAF MIDWIVES?

QUOTE FROM DEAF AND HARD OF HEARING FOCUS GROUP



WITH REGARDS TO BREAST FEEDING, I COULD REALLY HAVE USED AN INTERPRETER. IT WAS AWFUL REALLY AND IT WOULD HAVE BEEN GREAT TO HAVE SOME HELP WITH THAT. IT'S HARDER WHEN YOU'RE USING GESTURES AND WRITING, AND MY WRITTEN ENGLISH ISN'T GREAT ...IT WOULD HAVE BEEN SO MUCH EASIER IF I COULD HAVE JUST TALKED TO SOMEONE ABOUT THE DIFFICULTIES I WAS HAVING.

QUOTE FROM DEAF AND HARD OF HEARING FOCUS GROUP

I DON'T MIND, HOWEVER I WOULD LIKE FURTHER ADVICE (OR) ASSISTANCE HOW TO HELP COMMUNICATE WITH MY CHILD. I WANT MY CHILD TO HAVE A BETTER LIFESTYLE THAN ME.

QUOTE FROM DEAF AND HARD OF HEARING FOCUS GROUP

FOR MY FIRST BABY, WHICH I HAD IN LONDON, I GOT INTERPRETERS TO SUPPORT ME AND I WAS ABLE TO UNDERSTAND EVERYTHING AND TO CHECK EVERYTHING AND I WAS VERY HAPPY... WITH MY SECOND BABY NOW I'VE MOVED TO BIRMINGHAM, I'VE NO ACCESS TO INTERPRETERS AND THAT ISN'T MAKING ME HAPPY.

QUOTE FROM DEAF AND HARD OF HEARING FOCUS GROUP

AWARENESS OF SERVICES

It was felt that access to support and information was an equality issue across several groups, they talked about their rights and access to information. South Asian women identified that whilst they do not generally talk about pregnancy, young women from their communities, tend to have better knowledge and understanding of where to get information and advice linked to pregnancy and support services.

It was highlighted that education was needed and awareness raised of all the pre and post pregnancy support services being offered. Some women were unclear if any information around pregnancy was available as they did not have access to the internet, with some only recently coming from Pakistan and Bangladesh before becoming pregnant. Others said they thought access to information was limited and wanted more information in their own language so they can have better understanding.

Participants from the asylum seekers and refugees group shared how they did not know how to access services, so they don't and worried this could have a negative impact on their health and wellbeing. It was identified that Covid had further contributed to the negative impact on their access to the right information and health services at the right time for their pregnancy. Identifying that their treatment was not on par with pregnant women from other cultures or who are more proficient with English, had led to them feeling isolated, ignored and undermined.

Participants also wanted more information to help them understand where to access maternity services. It was agreed that more consideration needed to be given to how new families into the city and women with literacy and language barriers could access this information and the services available.

People were able to recall some negative experiences where the support information and resources offered were out of date.

COMMUNICATION

NO MANUAL FOR BEING A NEW MOM AND SO MUCH PRESSURE TO BE A CERTAIN TYPE OF MOTHER AND REASSURANCE, MORE WORRY ABOUT A CHILD.

QUOTE FROM WOMAN IN BLACK, ASIAN AND MINORITY ETHNICITIES FOCUS GROUP

Effective communication was identified as an issue when discussing barriers to accessing advice and information about pregnancy. Access to an interpreter was identified as the crucial factor for a number of women.

The deaf and hard of hearing women spoken to highlighted how Birmingham is a multicultural city where there are lots of people with differing international sign languages rather than BSL, not to mention, regional differences and shorthand signing. It was suggested the use of deaf relay interpreters would help. They are experienced deaf people, who work alongside BSL interpreters to assist understanding.

The deaf and hard of hearing women, identified that it was important to know interpreters would be available prior to maternity appointments and that additional time would be allocated to allow for a three-way conversation. Whilst interpreter support was often available for planned appointments this was not necessarily so for emergency appointments. When a woman is in labour, the women felt that the woman and midwife need to be able to communicate effectively in terms of mother and baby's safety. One woman described her experience of having an emergency Caesarean section. She woke up with abdominal pain, wondering where her baby was. She felt very scared and isolated as she did not have access to interpreting support at that time.

The deaf and hard of hearing group went on to discuss how communicating using pen and paper is not a solution when interpreters are not available. They identified that many deaf people have poor literacy skills and often English is not their first language. This causes additional difficulties when trying to understand medical terminology. Confidence grew for the women we spoke to but only with additional pregnancies, knowing what to expect and when to request an interpreter.

For the women where understanding English was a barrier, they felt their voices were not being heard or worse, ignored. During medical appointments the health professional would often speak directly to the interpreter, who may be their partner or mother-in-law. They stated that the 'doctors made them feel invisible' and they felt that 'things were being done to them', but not with their consent or with understanding of their needs. As a result, women said their feelings and emotions of what they were going through were never shared. They want to be communicated with directly.

There is a need for translators in all languages to develop a rapport with the pregnant woman building trust to make them feel comfortable. Women would prefer someone who understands their culture and traditions if possible.

What was clearly expressed by the deaf/hard of hearing women, was the impact on their confidence, independence and mental health when they do not have access to an interpreter during, what they felt was, one of the most emotional and potentially uncertain times in a woman's life. It can be frightening and isolating for women in situations where they do not understand what is happening, in the way it would be for people who communicate with a different spoken language.

I DON'T WANT TO RELY ON MY FAMILY, I WANT INTERPRETER TO DISCUSS THIS. I DON'T WANT TO SHARE (UNKNOWN) THING WITH FAMILY AS INFORMATION ALWAYS GET LOST IN TRANSLATION.

QUOTE FROM DEAF AND HARD OF HEARING FOCUS GROUP

Digital exclusion was highlighted as an issue for some of the ethnically diverse women who were spoken to. They felt that delivering services, support and information using technology can create an additional barrier for them as they either don't have access to the internet and/or don't have the right equipment e.g. smart phones, computers, laptops, tablets etc. This left them not knowing how to access the resources they needed and with language barriers as well, they identified isolation and feeling that they were being deprived of services which could help them to have better pregnancies and care.

There was an understanding amongst some of the women that if you are pregnant, information automatically comes to your home address telling you what you do or don't need to do.

FEELING 'INVISIBLE' WHEN ATTENDING A DOCTOR'S CONSULTATION.

QUOTE FROM WOMAN IN ASYLUM SEEKER & REFUGEE FOCUS GROUP

FEEDBACK TO PROFESSIONALS

There was discussion across all the focus groups on being repeatedly asked for the same basic information. The women spoken to said they would like to provide information once and this be shared across the relevant service areas.

Sensitivity, confidentiality, trust, the need to be understood and not feeling rushed was key for the women from the ethnically diverse groups spoken to. They felt this considerate approach would then enable them to discuss their concerns and needs, especially how they feel mentally and emotionally. In addition, they highlighted that they felt religion and culture could be given more consideration by health professionals when developing their pregnancy plans.

I HAVE A NEGATIVE BLOOD AND I WAS ASKED TO TAKE A VACCINE IN CASE THE BABY'S BLOOD WAS POSITIVE AS I COULD BE MADE INFERTILE, HOWEVER IF MY HUSBAND HAS POSITIVE BLOOD, I DO NOT NEED TO TAKE A VACCINE. I WOULD HAVE FELT BETTER IF THEY HAD ALLOWED MY HUSBAND TO HAVE A BLOOD TEST. IN THE END HE GAVE BLOOD TO KNOW HIS BLOOD GROUP AND I HAD A VACCINE.

QUOTE FROM WOMAN IN BLACK, ASIAN AND MINORITY ETHNICITIES FOCUS GROUP

EVERY WOMAN TO BE TREATED SPECIAL NOT LIKE A MACHINE. CULTURALLY MORE SUPPORT AND FAMILY – A VILLAGE NO MATTER BACKGROUND.

QUOTE FROM WOMAN IN BLACK, ASIAN AND MINORITY ETHNICITIES FOCUS GROUP

The South Asian women went on to share they felt their pregnancy care plans were inconsistent and inadequate because they did not fully take into consideration their particular needs. This was put down to poor communication by the health professionals they had contact with. This lack of consistency caused them a lot of anxiety. It was agreed that continuity of carer could have improved their pregnancy and birth experience. One woman said "I did not know I had a plan and rights and choices. I had no guidance and was not involved in my birth plan. I had no idea on pain relief."

Participants of the focus groups wanted to ensure that clinicians understand every pregnancy is different, even for women having more than one pregnancy. Taking a 'one size fits all' approach, they felt could lead to inappropriate services and lack of care and attention to detail.

Young people discussed how they felt adults would often talk down them, telling them what to do, when discussing pregnancy options. They also felt there was a lack of appropriate support for them during their pregnancy and after baby was born. They said they were often told how not to do things but never told how best to do things. They talked about experiencing pressure from health professionals to have certain procedures, an example was given where a woman, was told by the midwife during her pregnancy, to have stronger drugs when she wanted just gas and air.

The care leavers, who were also parents, from their experience felt that Children's Social Care staff were very judgemental. They felt they did not provide the support needed, particularly where a parent maybe struggling and needed some emotional support or help with parenting skills.

In the young people's group, it was felt that there is still stigma around single parents which was preventing some women from accessing services. It was suggested that healthcare workers needed to be more alert to the situation and signs of domestic abuse.

I KNOW THIS MASK THING IS ONLY TEMPORARY, BUT I WISH THE NURSE AND DOCTOR WOULD UNDERSTAND THE DIFFICULTY DEAF AND HARD OF HEARING FACE TO UNDERSTAND (WHEN THEY ARE WEARING MASKS).

THEY ARE IN PROFESSIONAL LINE AND THEIR ROLE IS TO UNDERSTAND DIFFERENT DISABILITY. WITH DEAF AND HARD OF HEARING SITUATION THEY TURN BLIND (EYE), OFFER NO SOLUTIONS OR FIND A WAY. THE FRUSTRATION IS REAL. THERE SHOULD BE AWARENESS.

QUOTE FROM DEAF AND HARD OF HEARING FOCUS GROUP

CULTURAL COMPASSION

It was strongly felt, by the women from the Black, Asian and minority ethnicities focus group, that Doctors/health professionals must have a better understanding of the woman's culture and beliefs. This would in turn improve the impact on her access and understanding of medical information/advice/guidance, especially around culturally acceptable options for contraception and family planning.

There were many cases of stillborn and miscarriages reported within the same focus group. They felt little exploration was carried out as to why these things were happening. The Muslim women said that in their culture it was accepted that it is the 'Will of Allah' and the real causes of the situation were not discussed. The lack of conversation around this matter was just accepted, rather than exploring what should be done differently next time for better health and a healthy pregnancy. There was also a degree of resistance in talking about the pregnancy, especially around the possibility of infant mortality. It was felt that you were 'tempting fate' if you talk about negative outcomes.

These women also expressed that they would like more help from health professionals

to tackle some of the old cultural practices that are having a negative impact on them during and following their pregnancies. It was felt however, that professionals didn't try to understand the cultural differences to be able to help/support the women.

The Somalian women's group pointed out the misconception that they are very tough and can take anything. They explained that they too are suffering from poor mental and physical health and it was felt that very little care is offered to them in the community. When it came to the delivery and pain management whilst giving birth, they experienced the same misconception with Doctors thinking they are strong and can take the pain.

This group also spoke about how Somalian women are circumcised. They shared how they were too shy to talk about what they have been through and how this continued to impact on them. The lack of communication and language barriers meant they were unable to communicate with doctors about their specific needs.

STOP ACCEPTING THAT 'THIS IS HOW IT IS IN THEIR CULTURE' AND HELP WOMEN SUPPORT THE CHANGE NEEDED TO MAKE A BETTER LIFE FOR WOMEN.

QUOTE FROM WOMAN IN ASYLUM SEEKER & REFUGEE FOCUS GROUP

The South Asian women talked about how there were often 'rifts' within their families where it is felt that the young mothers are not listening to the wise elders of the family. The women spoken to were keen to advise that, health professionals need to be mindful that it is accepted whatever the elder says will go and if it does not then there is disharmony between the family. There are many 'unwritten rules in the Indian culture' which can have a negative impact on the women in society, and especially when pregnant. There are high expectations placed upon the women, so even though they may be ill there is an expectation that they will still visit or socialise when they really do not want to or cannot.

They also discussed how genetic predispositions are considered and dealt with pre-marriage to ensure that there is no relationship connections of cousins or distance cousins as in this community, they are seen to be your brothers and sisters, and therefore marriage cannot take place. If there are similar names, the background of the mother's family is investigated to check and confirm that there are no

I SEE A LOT OF WOMEN EXPERIENCING MISCARRIAGES BECAUSE OF STRESS AND DEPRESSION IN OUR ASIAN COMMUNITY.

QUOTE FROM WOMAN IN BLACK, ASIAN AND MINORITY ETHNICITIES FOCUS GROUP

cross-linkage or overlap, if this is the case then serious consideration is given as to whether a marriage can take place or not.

Some of the young people talked about how their older relatives have more views on pregnancy and how they too also held similar views, such as pregnancy should only take place when two people are married. They talked about how they felt there is still stigma surrounding young people getting pregnant but agreed that having children young is difficult and some people are not emotionally mature enough to handle the responsibility.

The young women shared that they felt judged by some health professionals for accessing contraception or being pregnant and not being married.
Some comments on how pregnancy is viewed in the cultures of the participants was shared during the focus groups:

- **Asian Culture** – Pregnancy should be in marriage and should have structure, needs to be planned and conversations had around wanting kids.
- **Arabic Culture** – If a pregnancy goes wrong, the man does not have anything to do with it. The woman will speak to another woman, mother, or friend.
- **Nigerian Culture** – It is a community thing, raising a baby, whereas in the UK, there is less family/ community so it can be a lonelier experience. There is a need for more mother and toddler groups so Nigerian women do not feel as isolated.
- **Buddhism Religion** – Parents must be married first, it is a disgrace if not married first, dishonour to religion and family, stigma from communities. Religion does not support abortion.
- **Chinese Culture** – Young people will be forced to get married first and raise the child together. Participants felt that this can affect the mental health of baby.
- **Malaysian Culture** – Does not support use of the contraceptive pill as it can have side effects on the body but does support the use of condoms.

ONE KEY QUESTION

WOULD YOU BE HAPPY TO BECOME PREGNANT WITHIN THE NEXT YEAR?

In the main, women were comfortable being asked the 'one key question' by health professionals. A smaller number of women spoken to said they would be happy to be asked by other support workers e.g. housing officers, benefits office, social worker or support worker. One person said the question was irrelevant as she believes the decision to become pregnant is left to Allah. It was highlighted that asking the question would need to depend on the situation. Sensitivity is key taking into consideration those women who may have difficulty conceiving or those that may have lost a child.

Whilst most were comfortable with being asked the question, there were some concerns about how it would be phrased. Participants were able to suggest alternatives, including broadening it out so it was more inclusive and relative to men as well. Suggestions included:

- "Do you have any ideas / plans of when you might want to get pregnant"?
- "When are you planning on getting pregnant?"
- "How would you feel if you got pregnant in the next year?"
- "How would you feel if you had a child in the next year?"

HEALTH LITERACY

I GET MY INFORMATION FROM GOOGLE.

QUOTE FROM EXPECTANT FATHER

It was agreed that information needs to come from a reliable source, with clear explanations as to why recommendations are being made and why they are important for mother and baby. It was suggested throughout the focus groups however, that health professionals pay consideration to the terminology they use. For those with English as a second language or where there are communication barriers, it can be difficult to translate some medical terms and this can have a negative impact on the woman's understanding of what was happening with their pregnancy and any action that may need to be taken.

Some of the deaf and hard of hearing women spoken to, identified that written information or leaflets provided on all topics discussed in appointments would be useful to take away. However, they also identified how literacy is an issue for them, and how receiving letters can be difficult as they needed support to understand them, especially medical letters.

A variety of information in accessible formats was suggested including where to go for pregnancy activities, deaf clubs, accessible pregnancy information sessions and mum and baby activities post-pregnancy. It was highlighted that the use of video can be key when communicating with the deaf community: "Videos is where I'm getting most of my information… I have to ask family members to relay what is said on a letter, it is very difficult English not being my first language, I find that a real barrier and if I am showing it to my father, he is not proficient in sign language so it is not even clear when relayed from a family member."

It was suggested that it would be useful if healthcare professionals could provide workshops/spaces where women could talk through information contained in booklets etc offering face to face information as well. This approach could also help with the issue raised by the refugee and asylum-seeking women who shared that the majority of them had not been to school, so did not understand the importance of the pregnancy information shared with them.

SPECIFIC FEEDBACK FROM FOCUS GROUPS

The feedback below, pulled and collated from the individual reports, was used to shape the key recommendations at the front of the report (p5).

Identified across all groups:

- Ensure appropriate information on vitamins and supplements is offered early on in the pregnancy journey.
- Ensure awareness and education on which vitamins can be obtained from food sources.
- Ensure basic English is used for communicating and avoid using 'medical terminologies or jargon' where possible.
- Consideration of health literacy is essential when sharing information.
- Ensure antenatal classes are inviting/accessible to men.
- MVP to engage with seldom heard groups, like those taking part in the focus groups.
- Ensure the use of 'advocates' for women to air their views, concerns and issues.
- Specialist groups to offer 'peer to peer' community mentoring or 'buddy' system for soon to be mums.
- Develop information specifically for dads on pregnancy and how best to support pregnant partners through their pregnancy journey.
- Women are given a 'voice', options, and choices, regarding the service offered to them.
- Help parents to understand the impact of unhealthy relationships on mother and baby.
- Deliver 'Active and Empathic Listening' training for all clinical staff.
- Special support programmes for mothers who have lost their babies to create resilience and where appropriate, prevention strategies for the future.
- Clear explanation of processes during birth to expectant mothers and fathers. This will help to relieve stress anxiety.
- An identified contact in GP practices to provide support and advice for emergency contraception.
- Training for healthcare professionals including GPs, on how to have conversations about contraception in a respectful, culturally appropriate and approachable manner.
- Communicate changes to pregnancy plans clearly and with reasons.

- Provide new mothers with more information, especially on community support services and wellbeing.
- Raise awareness of the role and function of health visitors.
- Improve communication amongst health care professionals during transitions from one team to another/one area of the system to another.
- Ensure midwife continuity.
- Promote and ensure access to green space for women who are expecting, to support mother's mental wellbeing and physical exercise.
- Ensure more support for those who experience multiple pregnancies.
- Make it easier to book. Not just online, more localised options needed.
- Offer counselling and support services for mothers/partners to address guilt, grief, and loss from infant death.
- Offer more support for young women/mothers.
- Ensure support groups for fathers.

Identified across Black, Asian and other minority ethnicities focus groups including refugees and asylum-seeking women:

- Ensure interpreters are briefed so appropriate translation can take place.
- Structure awareness raising sessions focusing on sensitivity and cultural influences that cover the whole journey of pregnancy for men, women, and families.
- Targeted advice and guidance delivered within the community settings.
- Consider developing interpreters with specialism in health.
- Non-digital communication strategies be deployed to engage with women within their communities.
- Ensure women know where to access digital devices and have access to the help and support to use them.
- Effective Antenatal/parenting programmes be delivered within the community.
- Clinicians to review their communication styles.
- Create short videos around the contraception offer.
- Develop a sexual health out-reach service ensuring more awareness/promotion of emergency contraception.
- Where possible, choice is given re gender of doctor.
- Holistic programmes for pre-pregnancy health are promoted in all communities
- Health professionals make effective use of community links to capture the real 'voices and concerns'.
- Health materials/information are translated into various languages either into pictorial or basic video clips.
- Increase awareness about domestic abuse during pregnancy.
- More religious and cultural awareness to be considered.
- Consider a single point of access (SPA) for pregnancy related information, advice, and guidance. Not just digital offer.

- Greater level of awareness from clinicians of the culture and tradition of Refugees and Asylum seekers so they are not to be seen through a tarnished lens.
- Ensure health professionals are aware of referral routes into help and support for women who have experienced FGM.
- Improve accessibility of GUM clinics for Muslim women to access.

Identified by deaf and hard of hearing women:

- BSL interpreters should be available at all stages of pregnancy/parenting journey from pre-conception through to breastfeeding support and beyond.
- Deaf women should be clearly informed of all their options at each stage including how to access complaints processes. Understanding should be confirmed.
- Information should be available in accessible forms, such as short, signed videos.
- Upskill staff in primary care, midwifery and health visiting teams to include at least one person who can communicate with Level 2 BSL signing ability rather than relaying though a relative.
- Recognise the need for deaf relay interpreters, as well as BSL interpreters, in Birmingham as a multicultural city and put funding and systems in place to make them accessible.
- Staff should offer deaf and hard of hearing patients longer appointment times, rather than rushing the conversation through an interpreter.
- Co-design information on contraception, pre-conception health and pregnancy planning in accessible forms for deaf and hard of hearing women, such as short, signed videos in BSL.
- Translation into sign language is not as straightforward as direct translation into other spoken languages. Therefore, it is so important to brief interpreters in advance.

Identified across young people's focus groups:

- Increase in information and awareness of sexual health, in particular contraception, pregnancy, birth process, parenting skills and emotional aspects of pregnancy and being a parent. Ensure this includes a SEND offer.
- More information around sexual health for international students
- Develop Sexual Health champions, using peer on peer education approach.
- Develop parent advocates, to talk about their experiences and raise awareness.
- Increase signposting to services.
- Increase local sexual health promotions related to target audiences.
- Increase information for 'friends' so that they understand where a young parent might be struggling and what they could do to support.
- Increase access and awareness of local parenting groups
- Reduce stigma around asking for support from services, addressing fear of being labelled 'a bad parent' or concern of social care involvement.
- Ensure pregnancy information packs are relevant, in date and complete.

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Birmingham Forward Steps
Birmingham Youth Council
BSL interpreters
BVSC
Deaf Cultural Centre
Enigma Consulting
Gateway Family Services
Golden Ethics Company Limited
Malaysian University Society
Merida Associates
Mosely Exchange
Orbita CX Limited trading as Insight Now
Paddy Stanley Associates
Parent Forums/networks
Sexual Health Youth Council
Unity Streets

APPENDICES

Appendix A: Focus group questions/themes.
Appendix B: Participant demographics.

Appendix A: Focus group questions/themes

Research questions for discussion:

1. Birth Control Beliefs & Choices

a. Emergency contraception/'morning after pill'.
b. Access to emergency contraception.

2. Attitude to the 'One Key Question' – Would you be happy to become pregnant within the next year?

a. The possible responses (yes, no and maybe).

3. Pregnancy Beliefs & Choices

a. Beliefs about what facilitates a healthy pregnancy.

4. Access to pregnancy related advice

a. Exploration of where they access pregnancy related information.
b. Exploration of who provides information and how reliable it is.
c. What influences the way pregnancy related information is provided?
d. How secure do participants feel about their access to advice? This might reflect challenges with cost of accessing services, accessibility or lack of facilities where they can find acceptable trustworthy information.

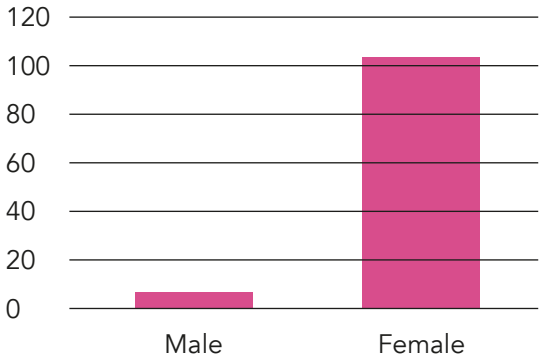
5. Understanding and Practice about Pre-pregnancy behaviours and choices

a. Folate and prenatal vitamins.
b. Health conditions – like asthma, diabetes.
c. Medications.
d. Vaccinations.
e. Smoking.
f. Alcohol.
g. Healthy weight.
h. Physical activity.
i. Genetic pre-dispositions (consanguinity).

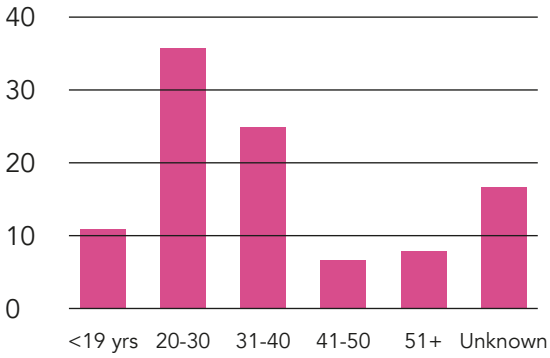
Appendix B: Participant Demographics

The research focussed on participants from Seldom Heard groups across Birmingham. We aimed for a diverse sample to gain a broader range of experiences, including people of different age groups, ethnic backgrounds etc. Demographic breakdown from 112 participants below:

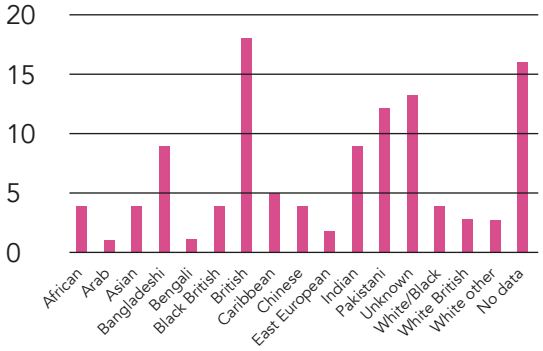
Gender



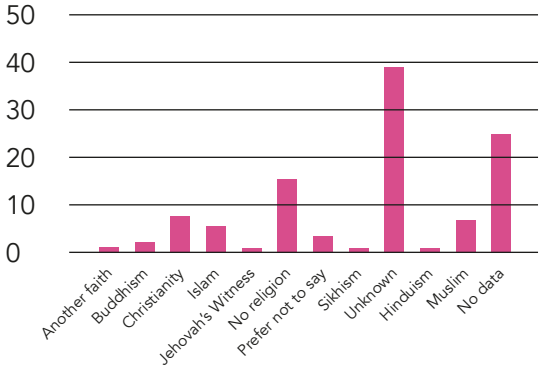
Age



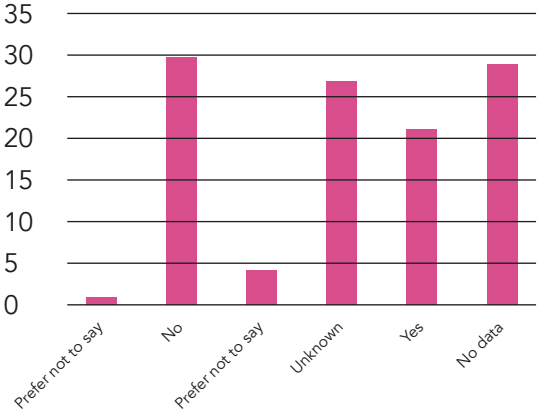
Ethnic Groups



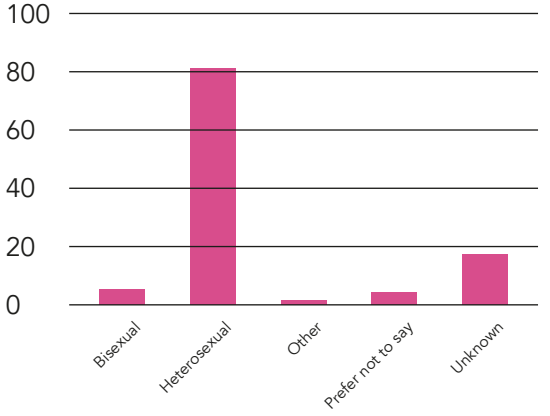
Religion



Disability



Sexuality



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