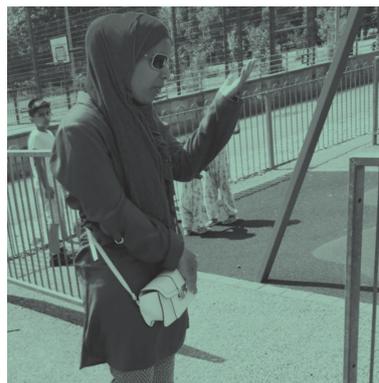


BETTER BIRTHS

Views from women and their families in North Central London

A participatory action research project



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INTRODUCTION

Better Births

In 2016 the NHS published a set of recommendations to improve maternity services across England based on a systematic review of the evidence, and consultations with NHS staff, professional bodies and user groups. The review found that, whilst strides have been made to improve the quality and outcomes of maternity care over the last decade, work still needs to be done to ensure consistency in the care women and their families receive. At its heart the review highlighted the need to make maternity services more personal and family friendly by centring care on the needs and choices of women and their families.

Better Births in North Central London

Bringing together commissioners from Barnet, Enfield, Haringey, Camden and Islington, and encompassing maternity services delivered by North Middlesex, Royal Free, UCLH and Whittington Health Trusts, North Central London was identified as one of seven pilot areas to trial women-centred approaches to maternity care.

Over the last two years North Central London (NCL) Better Births has focused on:

- providing personalised care by accommodating the specific needs of individuals, and offering choice throughout pregnancy, birth and postnatally;
- establishing community hubs with care delivered by a small group of midwives in the antenatal and postnatal period;
- developing a single point of access to maternity services by standardising the process for booking antenatal care, and developing a website to provide a centralised source of information for women and their families; and
- encouraging greater collaboration between different services and professionals.

Engaging women and their families through participatory action research

A key part of this work has been the engagement of women and families in order to place their needs, experiences and expectations at the centre of a new and more responsive system. NCL Better Births have been keen to engage with a greater diversity of women, including those whose views are not well represented by existing service user groups.

In order to improve representation, a diverse group of fifteen women who have recently used maternity services, were recruited as Patient and Public Voice Partners. The group were trained in

participatory appraisal, a community action research method, and have over a five month period engaged with parents in order to gather their experiences of, and priorities in re-shaping, maternity services in North Central London.

This document reports on the work of this group, their findings and recommendations.

Structure of this report

This report is structured around three main sections.

The first outlines the research method including the rationale for using participatory appraisal, the training and fieldwork process, and a breakdown of who was engaged in the project.

The second sets out the findings from the research, as well as case studies highlighting particularly poignant stories, organised around three key themes 1) single point of access 2) choice and personalisation 3) continuity of care.

The report concludes with a set of solutions and recommendations as defined by peer researchers and participants through the research and process of analysis.



THE RESEARCH PROCESS

This section sets out the research method used for this study, participatory appraisal, including the rationale for using it, an outline of the training and fieldwork, and a summary of the people engaged in the project.

Participatory Appraisal (PA) is an action research method that comprises research, learning and collective action. It is based around a set of interactive and highly accessible 'tools' that rely largely on visual methods that can overcome barriers such as formal literacy or numeracy. These 'tools' are used by PA researchers to facilitate conversations with members of a community around a particular problem or issue. As such PA concentrates on collecting highly qualitative information relating to participant experiences and perceptions, to acknowledge and analyse issues, and plan for change.

The difference between PA and other research or consultation methods can be summarised as a series of 'big shifts,' that seek to bridge the divide between those who fund, plan and deliver services and the people who use them. Members of a community or service users are recognised as "experts in their own lives", with local knowledge and experiences crucial to the development of successful and sustainable programmes.

A key strength of PA lies in the recruitment of people who are already embedded within a community as PA researchers. This enables access to a more diverse range of people, gathered through existing networks of family, friends, neighbours and colleagues.

At the same time the desired outcomes of a PA project can only be achieved if key stakeholders (including funders and professionals with the resource and power to make things happen) actively support the process. They are needed in order to translate recommendations into real change, to explain where budgetary or other constraints make particular recommendations difficult to implement, and to feedback to participants and the wider community when change occurs.



THE BIG SHIFTS

Teaching	Facilitation
'Uppers'	'Lowers'
Extracting	Empowering
Closed	Open
Verbal	Visual
Measuring	Comparing
Individual	Group

The training and fieldwork

In the summer of 2018 all fifteen Patient and Public Voice Partners (hereafter referred to as 'community researchers') were trained to use the PA tools, to reflect upon ethics, behaviour and attitudes, and to practice their facilitation and listening skills. The three PA team roles, including facilitator, note taker and anti-saboteur were introduced.

The community researchers were split into teams and were trained to use open-ended questions and semi-structured interviewing techniques in order to explore users' experiences and opinions of maternity services around the following themes:

- 1. Single point of access:** including how women access maternity care, where they and their partners find out about the services on offer, the facilities they use during pregnancy, labour and postnatally, as well as the type and sources of information they receive.
- 2. Continuity of care:** including the importance of access to the same midwife, and consistency of care received across antenatal and postnatal care services.
- 3. Choice and personalisation:** including the importance of being supported to make active choices, being treated with respect and as an individual, and the extra care provided to vulnerable groups.



BEHAVIOURS AND ATTITUDES

**SHOW
RESPECT**

**ESTABLISH
RAPORT**

**BE SELF
CRITICAL AND
SELF AWARE**

**WATCH, LISTEN
AND LEARN**

**ABANDON YOUR
PRECONCEPTIONS
AND KEEP YOUR
OWN VIEWS TO
YOURSELF**

**EMBRACE
ERROR**

BE FLEXIBLE

**SUPPORT
AND SHARE**

BE HONEST

**HAND OVER THE
STICK (THAT IS, THE
POWER,
SYMBOLISED BY
THE PEN)**

**THEY CAN
DO IT**

**TAKE YOUR
TIME**

PA ROLES

Facilitator - to lead participants through the PA tool, asking the questions that lead to in-depth discussions.

Observer - to take an overall view of what is happening, take notes on discussions, behaviours, levels of engagement, as well as the date, time and location of the session.

Anti-Saboteur - looks for anything that is going on that might impede participation and takes steps to overcome them.

Fieldwork and training process

7. Celebration and validation day to present and validate findings.



6. Day five of training to feedback on research process and analyse findings.



5. Phase 2 of fieldwork focusing on single point of access, continuity of care and choice and personalisation.



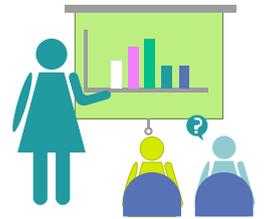
4. Day four of training to feedback, trouble shoot, and reflect upon findings.



1. Recruitment of 15 women from community venues across North Central London.



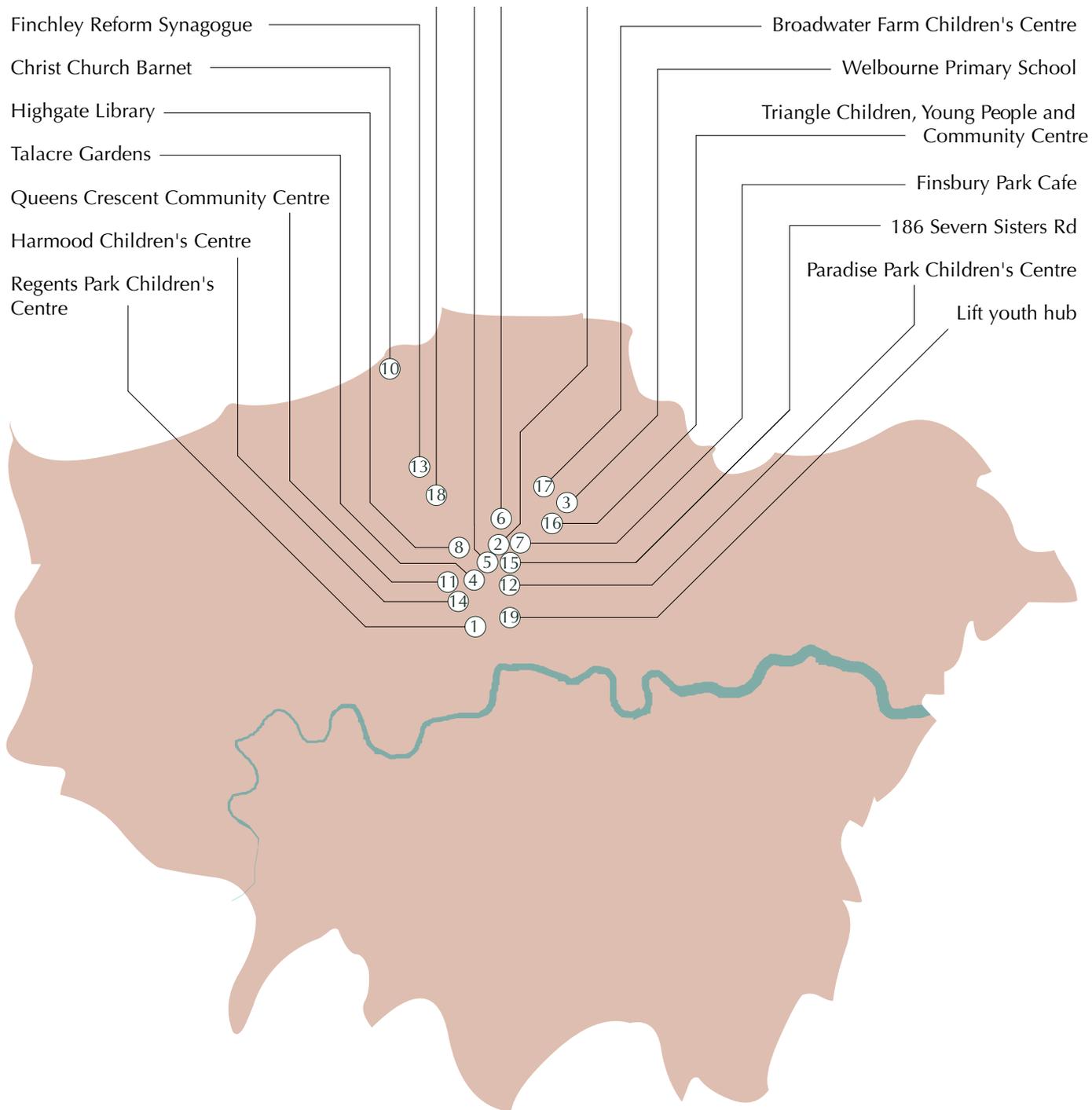
2. Three days training in PA covering the tools, behaviour and attitudes, and PA roles.



3. Phase 1 of fieldwork seeking experiences of maternity care amongst researchers' existing network of family, friends and neighbours.



Research locations



Who the study involved

During the course of the fieldwork, the researchers were successful in reaching a diverse range of women and families across North Central London. A total of 179 participants were engaged in the project during 30 participatory research sessions in community venues, including children's centres, libraries, religious buildings and parks.

As may be expected the majority of those who were engaged in the project were women [169]. Some men [10] also took part, with researchers making a particular effort to engage fathers in the process to ensure that their voices would be heard.

The multi-lingual skills of the researchers were invaluable in accessing and including stakeholders with language barriers, while the diversity of peer researchers was also reflected in demographics of the people involved. These include 78 White, 45 Black / African / Black British, 15 Asian / Asian British, 6 mixed heritage participants, and 21 from Other Ethnic Groups.

Within these broad ethnic categories include American, Bangladeshi, Belgian, Bosnian, British, Cameroonian, Chinese, French, German, Indian, Israeli, Japanese, Kurdish, Polish, Russian, Somali, Spanish, Sudanese, Turkish, Ugandan, Vietnamese and Yemeni participants.

“ What really made me happy is that we had such a mixed group. Four different ethnic groups and they really supported each other and exchanged ideas.

Najuma, community researcher

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“ I think the mothers were honest and open, they bonded together easily in an environment that they feel comfortable in.

Katherine, community researcher

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“ The session went really well, the parents were really enthusiastic - they wanted to join in,

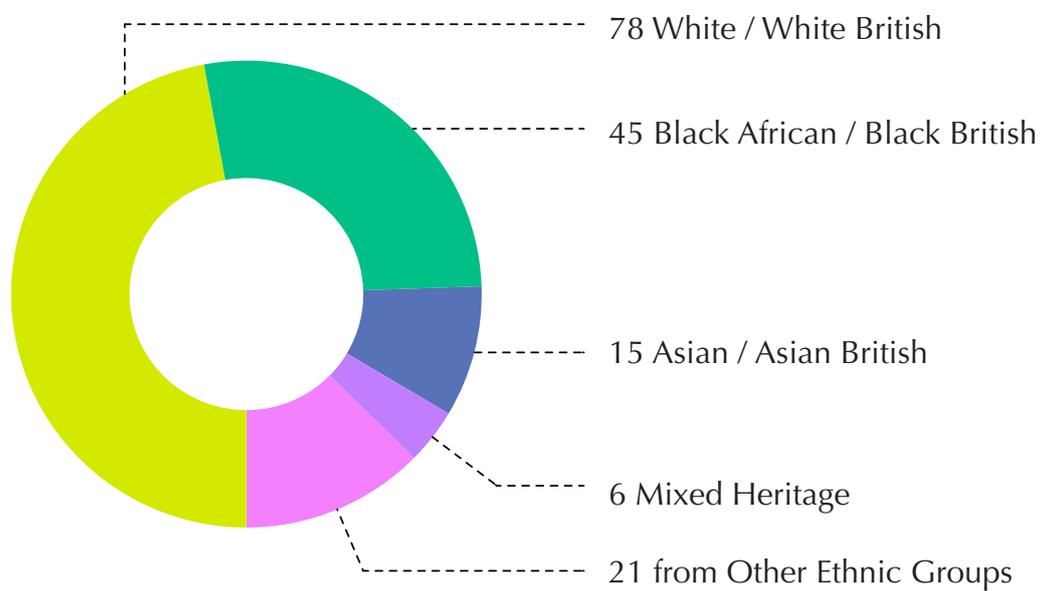
Abuk, community researcher

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Participant statistics

179 participants

30 participatory research sessions



FINDINGS

“ There are a lot of services available but a lot of minority ethnic groups don't know about them, or don't know how to access them. They don't know the language or their entitlement to the service,

Najuma, community researcher

”

“ I didn't find the midwives or GPs responsive - it's difficult to reach them. To call someone you spend 40 minutes on the line. When you do it works quite well. It's getting through the door to them that is difficult.’

Hanna, white European, 25-34

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SINGLE POINT OF ACCESS

This section reports on the positive and negative views of women and their families around the theme single point of access. These include how women access maternity care, the facilities they use during pregnancy, labour and postnatally, as well as the type and sources of information they receive.

Administration



Positives

- clarity in process of 'booking in'
- referrals via GP
- readily available appointments
- text reminders for appointments
- appointments running on time



Negatives

- confusion about the services available and how to access them, particularly amongst BME groups
- difficulty contacting midwife/GP over the phone
- problems with transfer of care on referral
- long waiting times to get appointments
- long waiting times when attending appointments
- delays in hospitals for procedures
- delays in admission / discharge from hospital



“ All the information that parents need is there but for some reason it's not connected up ... which means you are stranded. Maybe you just need one key person ... it would definitely make it a lot easier for mums and dads.'

Nina, white European, 34-44

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Facilities



Positives

- antenatal care in a community setting, or at home
- relaxed and positive atmosphere in birthing centre
- clean facilities
- availability of private room, with space to accommodate a birthing partner
- access to specialist equipment such as a birthing pool and express pump



Negatives

- small rooms with no space for birth partner
 - lack of privacy on noisy wards
 - poor internal comfort conditions including lighting and temperature
 - dirty or messy facilities
-

Information



Positives

- clear verbal and written explanations of how things work at every step including:
- the process of booking into maternity services and referrals
- what to expect during antenatal appointments
- the stages of labour and birth
- the options available to women during birth, including the pluses and minuses of inductions, pain-relief, assisted births and c-sections
- information about caring for a baby
- support with breastfeeding



Negatives

- lack of information about antenatal care, giving birth, and support offered postnatally
- too many sources of information, and uncertainty about which sources to trust
- reliance on written rather than verbal communication
- assumption that women have the information they need, or know where to look for advice
- wrong or conflictual advice
- lack of, or insufficient, feedback mechanisms

CASE STUDY 1

Building up a relationship with one midwife

In Camden we talked to three women who had taken part in the Continuity of Care pilot at UCLH. This meant that they received antenatal and postnatal care from the same midwife, who they met in a local children's centre or in their own home. The group of women came from different backgrounds, one was Japanese, another Somalian and another was White British. They also had different medical histories and birth preferences. One women wanted a home birth, another wanted to give birth in a medical setting in case something went wrong, another received extra care due to her baby's low growth rate. All these differences were understood and accommodated through their maternity care.

All three felt well informed and supported through their pregnancy and beyond. They valued and appreciated seeing the same midwife throughout. They felt that they got better care because their midwife really knew them and their history, and they felt comfortable in speaking out about any worries or concerns. Not having to repeat their medical history, and being able to pick up on any questions and concerns from one appointment to the next, was a clear benefit. They also appreciated having the midwife's phone number and email address so they could ask her advice at any time. Although not present at the birth, the midwife visited one of the women, who had experienced a difficult labour, in hospital, and all three in their homes postnatally until they were discharged.

“ She liked the good access [to her midwife], and being able to contact her direct via email. Soon after she gave birth the midwife visited her in hospital which was really sweet. She was so pleased to see a familiar face. She had a hugely positive experience overall.

Anita and Anna, community researchers

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CASE STUDY 2

Supporting Dads and birth partners

In Finsbury Park we talked to a group of Dads about their experiences of maternity services. The group felt that changes could be made to hospitals to make them more welcoming to women and their birth partners. These include a dedicated area of parking reserved for women in labour so that partners don't need to separate from them to park; improvements to the process of being admitted including welcoming staff at triage; and a more homely reception area that is less clinical and institutionalised.

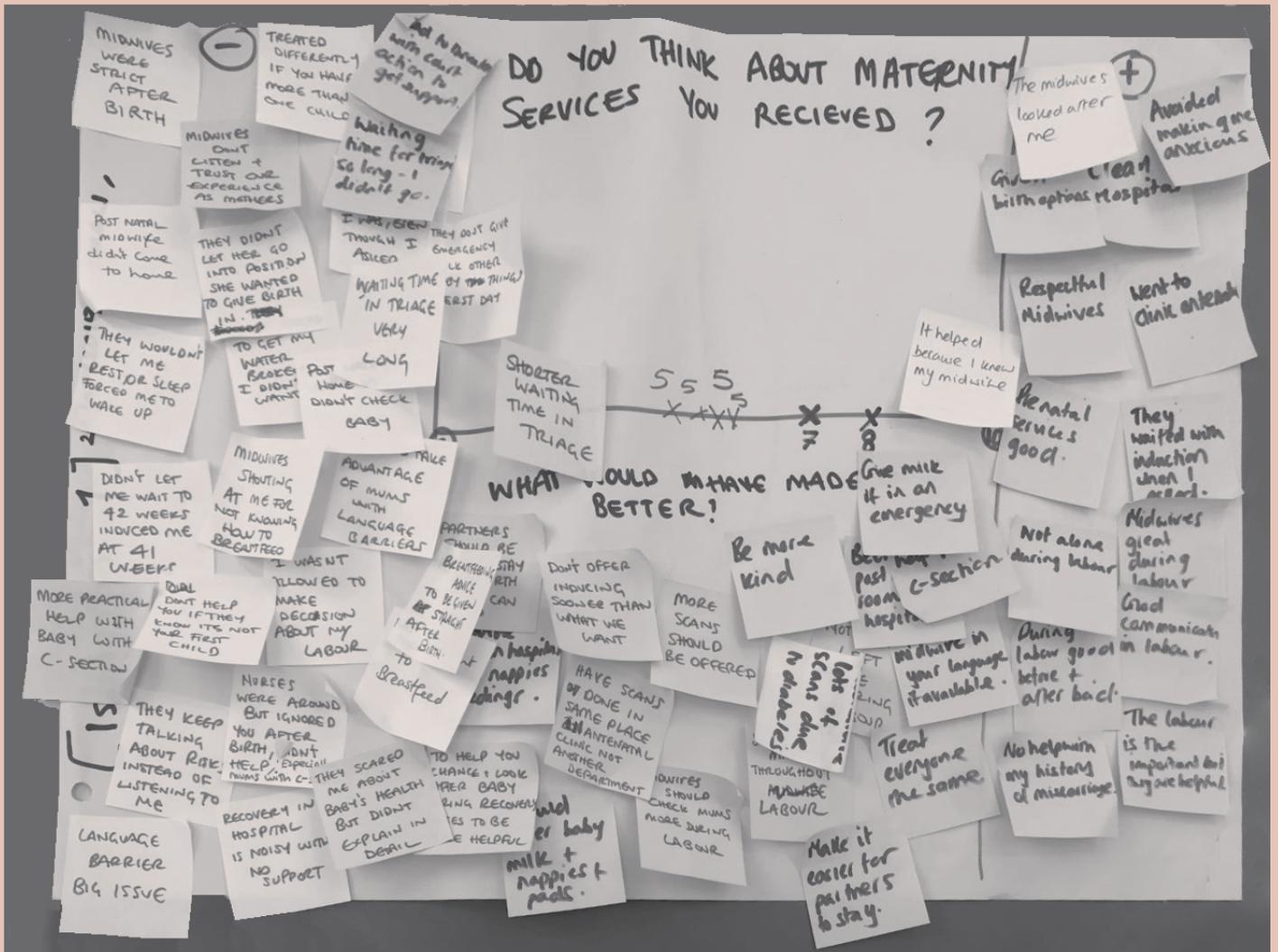
The men also felt that more effort should be made to acknowledge the role of birth partners. One father of four had supported his partner through three home births and one delivery in hospital. Whilst at home he was part of the team with a clear role, in hospital he felt sidelined. Small changes could be made to make birth partners feel more welcome and supported in the hospital environment. These include access to a comfortable chair or pillow, availability of food and refreshments, and space to stay with their partner and baby after birth. Allowing partners to take on a more active role by accommodating their basic needs was also seen as an effective way to reduce the burden on overstretched staff. This echoed the call by women that their partners should be able to stay after birth to offer support, and share the burden of caring for a newborn baby in hospital.

It was also suggested that the birth partner role could be officially recorded as part of the first 'booking in' appointment with a midwife.

“ A big theme emerged around making Dads feel more welcome. If you had a nominated birth partner they could be supported. They could be the person that the hospital gives responsibility to - it would help them to be part of the process.”

Anna and Laura, community researchers

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“ Having a positive experience with a midwife stays in your mind for the rest of your life and affects the way you are in subsequent pregnancies ... a good relationship with a midwife can help you through any birth. ”

Caroline, white British, 24-35

CONTINUITY OF CARE

This section reports on the positive and negative views of women and their families around the theme continuity of care. These include the importance of access to the same midwife, and consistency of care received across antenatal and postnatal services.

Continuity of carer



Positives

- access to the same midwife for antenatal and postnatal care, and during labour
- direct access to midwife via phone, text or 'Whats App'
- opportunity to build up a relationship with a midwife
- feeling at ease, comfortable and more open to talk about concerns
- receiving care that is customised by a midwife able to adapt to an individuals' needs



Negatives

- lack of access to the same midwife in pregnancy, in labour or postnatally
- not being able to get to know a midwife and build up a relationship
- frustrating and upsetting to repeat medical history with different clinicians
- less support given to those with low risk pregnancy, or second pregnancy

““

Many mums shared that they really wanted help to change and pick up their newborn baby during recovery, but no support was offered.

Katrin and Najmua, community researchers

””

““

You get all this amazing attention through pregnancy that abruptly ends. It's a month or two later when you need the support, the euphoria has worn off ... you are at home with your baby ... you might still be struggling.

Aygul, community researcher

””

““

The hardest decision I had to make was whether or not to have a c-section. I felt that I just had to do what I was told. I never felt I had the option of a natural birth - she is breech, you need a section, that was that.

Amanda, black British, 34-44

””

““

I had an emergency c-section in my second pregnancy. The doctor was amazing and took the time to ask how they could make the experience more natural for me as this [was] not what I wanted.

Natalie, white British, 34-44

””

Postnatal support



Positives

- help to wash/change baby
- advice and assistance with breastfeeding
- choice to stay in hospital a little longer
- access to community and peer support



Negatives

- left alone after birth
- pressured to walk, shower, change clothes too soon
- pressure to leave hospital when not ready
- no help to look after the baby when in hospital
- no support with breastfeeding
- lack of post-natal checks leading to physical/mental health problems

CHOICE AND PERSONALISATION

This section reports on the positive and negative views of women and their families around the theme choice and personalisation. These include the importance of being supported to make active choices, being treated with respect and as an individual, and the extra care given to vulnerable groups.

Choice



Positives

- given the choice about where to give birth
- birth plan was respected
- clear information on the options available if birth did not go to plan



Negatives

- not empowered to make choices
- birth plan not respected
- pressure to agree to medical interventions
- pressure to have no medical interventions
- pressure to breastfeed
- pressure to formula feed

““

A women who had a difficult birth wanted to say thank you - doctors, nurses, registrars, you don't realise the impact you have had on my life ... I'm truly grateful and I'll never forget them.

””

Aygul and Laura, community researchers

““

My midwives were brilliant, but most of the time they were too busy ... and running late ... and weren't able to answer all my calls and questions - they are massively over-loaded.

””

Anya, white European, 25-34

““

All we want is to be heard ... active listening on behalf of a professional made me feel more like a human being ... not having that connection makes you feel unsafe ... and birth becomes something to fear.

””

Rachel, white British, 25-34

““

They can be very judgmental to us because we are Somali. They assume we have lots of babies, and if you don't they act surprised. They treat you differently if you don't know English and they make decisions for you.'

””

Halima, black African, 25-34

Staff



Positives

- professional, friendly and caring staff
- good listeners and communicators
- experienced and reassuring
- patient and understanding
- attentive but respectful, giving space when needed and extra support when required
- staff that picked up on a problem
- kept informed, reduced anxieties, provided choice even in difficult situations



Negatives

- overstretched staff
- poor bedside manner - unprofessional, un-caring, unkind
- lack of social and communication skills
- not believed or listened too regarding pain / progress in labour
- lack of respect / rudeness
- felt told off and judged

Extra care for vulnerable groups



Positives

- extra support and one to one care for those with mental health needs
- access to interpreters
- access to female genital mutilation specialists



Negatives

- discrimination based on ethnicity
- assumptions and stereotypes about women's ability to bear pain of labour, or number of children they would have
- lack of interpreters during labour, felt vulnerable, invisible and unable to communicate/complain

CASE STUDY 3

Accessing community support

In Haringey we spoke to a group of Jewish Orthodox mums during a stay and play session. We learnt about the support they receive from their community during pregnancy, birth and while caring for a new born. These include a free trained doula who offers support during birth and provides aftercare. If a woman doesn't speak English the doula also acts as a translator.

After they have had their babies they also have access to a mother and baby home where they can go for up to two weeks after they have given birth. Women have to pay for the service, but it is subsidised for those on low incomes. Each woman and baby has an individual room with a cot and a bed, healthy meals are provided, support is available during the night, and there is a nursing room so they can chat to other mums, share birth stories, and access breastfeeding advice.

The peer and community support offered to these women enables them to focus on their new baby and to recover immediately after birth, whilst also connecting with other mums who are, or have gone through, similar experiences. This service was seen to fill a gap in postnatal care that many women highlighted as a downside of their experience of maternity services provided by the NHS.



It goes to show how much of a difference peer support can make ... maybe we should be thinking about what kind of community we hope to build to support maternity care.

Khloe, community researcher



CASE STUDY 4

First time mother with mental health issues

At Broadwater Children's Centre in Tottenham, a first time mother in her twenties told us about the exceptional care she received from her midwife and GP. She suffers from depression and was extremely anxious throughout her pregnancy. She opened up to her midwives about her concerns and was given more frequent antenatal appointments and an additional scan, which she really appreciated. Furthermore, she was given lots of information about local breastfeeding support, Children's Centres and baby groups before the birth so felt well informed.

The birth went well but she felt anxious and fearful afterwards. While staying on the ward she was nervous about who and when she could ask for help. During the night she desperately needed the toilet but didn't know if she was allowed to go, and was too scared to leave her baby. Like many other women she felt more support should be provided to women immediately after birth when they feel most vulnerable.

Overall she was very happy with the care she received but felt it was because she'd been able to ask for help. She expressed concern for other women with mental health issues who might not be empowered enough to ask, or who aren't aware additional support is available.

“ Having a specialist team who knew how to deal with her mental health needs was really important. Once she got the help it was amazing, but she had to ask for it - it wasn't presented to her. There could be lots of other mums out there struggling, without getting the support they need.

Laura, community researcher

”

RECOMMENDATIONS



“

Online access is great but it can't replace face to face conversation ... a person can see you are not good and can ask you questions and give you information. You might not be asking for help, but they might see you need it.

Julia, white European, 25-34

”

This final section sets out the recommendations suggested by researchers and participants. These include improvements to facilities and admin; better and more timely information; access to one midwife; more postnatal support; friendly and respectful staff; extra care for vulnerable groups; and the continued engagement of women directly in the evaluation and design of maternity services.

Facilities and administration

- use community venues for antenatal and postnatal care
- make changes to facilities to make them more comfortable and welcoming including a welcome area with a homely feel, more beds and facilities so partners can stay overnight
- reduction in use of paper and hand-held notes in favour of electronic system
- rolling out of texting services for all appointments
- investment in staff to show they are valued
- recruitment of more staff
- improved communication between services including better referral processes and hand-over of care

Improved information

- clear information about maternity services on offer, women's rights and choices
- information about labour and birth, including the positives and negatives of different locations, pain relief options and methods of delivery
- realistic view of birth and recovery to manage expectations and reduce fear
- information delivered by community midwives, during antenatal appointments and through antenatal courses
- website is only a supplement to face-to-face support, and should be tailored to particular languages and communities

Continuity of carer

- access to the same midwife or a small group of midwives, who are contactable directly antenatally and postnatally
- access to one midwife through labour and delivery

“

‘People said they want to know more about life postnatally, not just the birth ... how to cope afterwards, how your body changes and what to do.’

Amal, Vita and Alisa, community researchers

”

“

For me what would have helped in the aftercare would have been to go through what happened during my birth and why certain decisions were made ... then it would have been easier to move on.’

Carole, white European, 35-44

”

“

‘Personalised care means that I am given all the different options, and that I can make my own informed decisions as to how, where and when I wish to give birth to my child. It means that those decisions are respected and supported.’

Anna, white British, 35-44

”

Postnatal care

- more support after birth provided by staff and/or volunteers including; a longer stay in hospital; support and acknowledgement of birth partners; more help and advice to care for baby in hospital; provision of milk and other supplies for those who need it; breastfeeding advice and support from lactation consultants or specialist midwives immediately after birth
- postnatal care to continue beyond first few weeks, including a debrief session to talk through labour and delivery at six week check
- signposting to support that can be accessed in the community, including children's groups and breastfeeding support

Respect

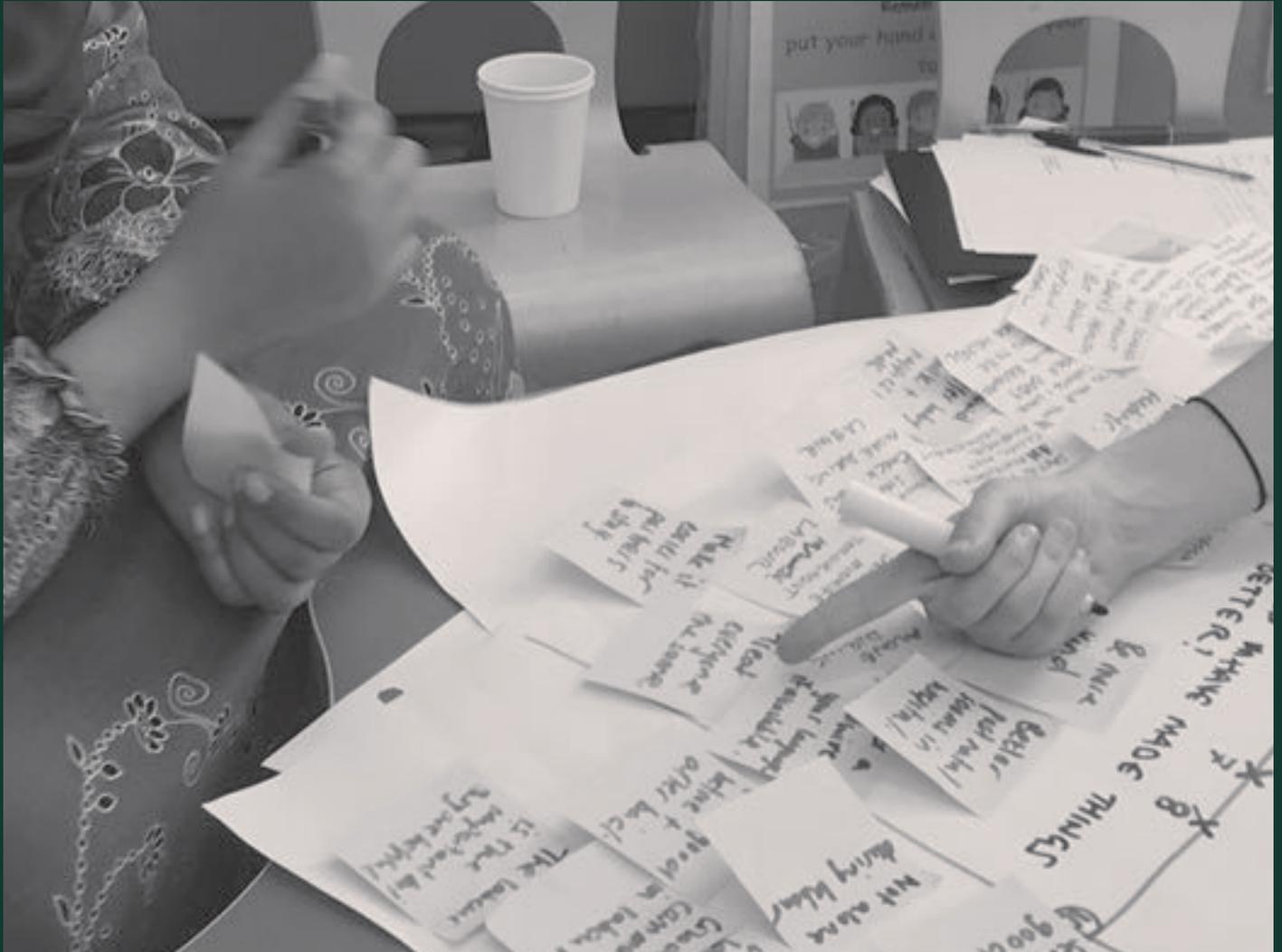
- all staff should be friendly, have good communication and listening skills
- women and their families should be treated like fellow human being, with respect and compassion
- birth partners should be acknowledged, respected and supported
- every woman should be treated as an individual so that care can be tailored
- women should be welcomed into hospital
- all staff should introduce themselves and their role
- short biographies of midwives and their specialities could be provided
- training should be provided for staff to develop social and communication skills, with a focus on empathy
- staff should be invested in and thanked for their work

Help for BME and vulnerable groups

- additional support should be provided for BME and vulnerable groups these include:
- access to interpreters
- diversity training for professionals
- access to peer groups to offer support
- website and written information provided in different languages

Review and learning

- feedback should be gathered from patients at every stage
- women and their families should be engaged directly in the evaluation and design of maternity services
- the skills and knowledge developed by the community researchers should be built upon and extended



3Ps ● people
● promoting
● participation
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