







Maternity inequality report comprising of an evaluation into the process and methodology of using community connectors to gather research and share information 'Inequalities in Maternity Services - *Testing NHS Core20Plus5 connectors Model'* and a full evaluation into the finding of the research 'Presenting Maternity Care - of course it hurts, you've just had a baby'

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1. INTRODUCTION

Reducing healthcare inequalities: Core20PLUS5

Designed to reduce inequalities in healthcare, Core20PLUS5 is an approach developed by NHS England that seeks to inform action at a national and system level (NHSE, 2023). Core20PLUS refers to the target population, the most deprived 20% of the national population in addition to groups identified locally that are facing health inequalities, for example those with protected characteristics.

5 refers to five clinical areas which require accelerated improvement, these are: maternity, severe mental illness, chronic respiratory disease, early cancer diagnosis and hypertension case-finding. Smoking cessation is considered as a factor that impacts all 5 clinical areas. Figure 1 provides an overview of the approach.

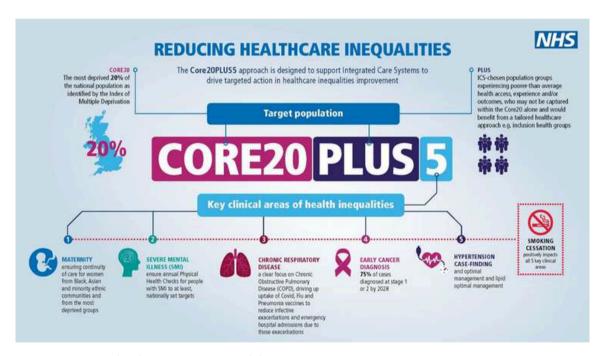


Figure 1: NHS England Core20PLUS5 model

The Core20PLUS5 approach has resulted in three programmes being delivered in England:

- Core20PLUS Accelerator Sites:
- Core20PLUS5 Community Connectors
- Core20PLUS Ambassadors

In addition, the Core20PLUS5 has now been extended to children and young people.

This evaluation focuses on the Core20PLUS5 Connector Programme, which 'funds integrated care systems (ICS) and place-based initiatives to recruit, mobilise and support influential community connectors to take practical action to improve health and reduce inequalities in their area' (NHSE, 2023).

The programme has taken learning from other community-based initiatives to develop a role similar to that of other champions/advocates/social prescribers.

Individuals who are influential in their community are recruited to the role to help engage local people with health services. Connectors are key for understanding barriers that communities face and can offer recommendations on how to overcome these to reduce health inequalities. The programmes focus on the five clinical areas outlined in the Core20PLUS5 approach above.

Involve Kent: Proposed Community Connectors Model

Involve Kent were commissioned by Kent and Medway Integrated Care Board (ICB) to deliver a 12-month project using Community Connectors to identify and reduce inequalities in maternity services in Dartford, Gravesham and Swanley. The delivery model was designed with two functions in mind, one, to disseminate information in the community and two, to engage with women to collect and feedback their experiences of maternity systems.

This delivery would be provided by a full-time Engagement Officer (EO) and a team of volunteer Community Connectors (CC). Working closely with the Kent and Medway Local Maternity and Neonatal System (LMNS), the EO would develop a bank of resources used to train CC on current antenatal care provision. The information would then be shared in the community with those experiencing the biggest inequalities, predominantly black, Asian, and minority ethnic women and those in areas of highest deprivation.

CC and the EO would also speak to women about their experiences of care, whether antenatal, in hospital or during the postnatal period and collect data to be thematically analysed and fed back to key stakeholders.



Aims

To test a Community Connector model focussed on maternity inequalities in Dartford, Gravesham and Swanley that:

- 1. Collects qualitative data of maternity experiences to be thematically analysed to share with key stakeholders to encourage system change
- 2. Shares information from NHSE about maternity care, including importance of attending scans, appointment information and other essential information relating to antenatal care to encourage and enable more women to access care

2. SERVICE DELIVERY

Delivery of the service began in March 2023 and was delivered in three stages in the first six months:

1. Recruitment, mapping and community embedding

The project began with recruitment of an Engagement Officer (EO). The vacancy was advertised extensively online and through networks, with particular focus on recruiting from the BAME community. Applications from this group were low and the EO appointed was White British. Though not from a BAME heritage, the EO had extensive experience of working with vulnerable adults and in areas of high deprivation. In addition, they were local to the area and brought a wealth of local knowledge and existing contacts. Following an induction period, the EO focussed on mapping services, activities and groups in the area (Dartford, Gravesham and Swanley) and began reaching out to key stakeholders.

They focused on services supporting pregnant women and mothers and nonspecific organisations that may be attended by these groups, in both statutory and voluntary sectors. The Local Maternity and Neonatal System (LMNS) provided connections to maternity professionals including midwives, health visitors and others. The EO was active in connecting with all children's centres across the area as these were identified as being a core location to connect with pregnant women and mothers. The EO began building trusted relationships with professionals and this provided an understanding of the landscape for those we were trying to engage with to become Community Connectors.

Connector recruitment, early learning data collection

Following the period of mapping and relationship building, the EO was based exclusively in the community and

attended groups, activities and clinics to engage with potential Community
Connectors (CC). A role description and training programme were developed as well as marketing materials promoting the vacancy. The EO began to promote the role but had very little uptake due to women having competing responsibilities including work or other caring roles.
Potential CC included those leading mother-baby groups and faith leaders, who were seen as key points of contact within the community for new or expectant mothers.

In addition, the EO began to informally collect qualitative data in the form of narratives which were recorded to be analysed and sent back to key stakeholders. Narratives were collected in person which resulted in rich data with potential to follow up on any queries or for clarification. A single opening question was used which empowered the individual to share what was most important to them and to have control over the conversation, disclosing as much or as little as they wanted. It was clear from these initial stages that collecting feedback in person in a safe environment for the individual would be an effective way to collect data. Using an open question also proved effective at opening up a conversation and empowered women to share what was most important to them.

3. Amended delivery and progression

After considering experiences from phase 2, the CC role was adjusted to be more flexible and accommodating of the needs of the target group.

This involved removing the need for a DBS check, full training/induction and other bureaucratic processes that acted as a barrier. To ensure safety by removing these elements, the role was altered to be focussed solely on the provision of information in the community. This involved creating information packs about essential maternity care including midwife appointments, the importance of scans and key contact details. All information was approved by the LMNS. The information packs were then shared with key stakeholders within the community so they could informally share with women as they saw appropriate. Each of the individuals holding and sharing information were then considered to be CC. The EO continued to collect qualitative narrative data but on a reduced scale as focus shifted to ensuring the community was provided with enough information packs in the right places, which required additional mapping and relationship building.



3. CHALLENGES

Notable challenges included:

Building a network: gaining access to and connecting with some services could be difficult if there was not a single point of contact or if the service was under resourced. We found some services were too busy to engage or did not fully understand the importance and impact of the work. Due to the nature of some services, e.g midwife clinics, appointments were often cancelled at short-notice or with no notice at all. Working with the LMNS did ease this, and this challenge reduced the longer the EO was in the community as they became a familiar, trusted face.

Recruiting volunteers: the biggest challenge was recruiting pregnant women or mothers to the Community Connector role due to their time constraints. Many simply did not have time to sign up and others were only available very briefly as they would be returning to work, sometimes early than expected due to the cost-of-living crisis. Some potential volunteers had other caring responsibilities in addition to looking after their children. Group leaders were often keen to volunteer but were also limited by time as they had several other responsibilities.

4. OPPORTUNITIES

Opportunities presented through this model included:

Partnership working: working with the LMNS and ICB provided opportunities to work across sectors and was an important example of how the voluntary sector can work closely with health and social care systems. A strong relationship was built between all partners which was facilitated by regular update meetings, frequent communication and sharing of reports/data. This provided us an opportunity to showcase the agility and strength of the voluntary sector as well as demonstrate ability to collect, process, analyse and present data. This was particularly evident when making changes to delivery as there were not

layers of bureaucracy to navigate and decisions and changes could be made quickly.

Knowledge sharing: collecting narratives allowed us to build a large dataset of maternity experiences which was analysed thematically. We understood the importance of this data and also the trust placed in the EO through sharing narratives so felt it was essential that it was shared with relevant partners and services. A report of the main categories identified in the data was shared with the Maternity and Neonatal Voices Partnership to ensure they could feed these through to decision makers within maternity care.

5. CONCLUSION

The key takeaway was that to engage with those in hard-to-reach communities. or with a specific audience, it is essential to be based within that community for an extended period of time. This allows for trust to build and for the person to become recognised in the community. We found that the longer the EO was in the role, the better the quality of data collected and the more women we could speak to. Not only this, but those who had engaged began to refer friends/family and organically spread the word within their communities.

In addition, we found that recruiting volunteers who were pregnant or mothers to young children was very difficult due to their limited availability and other responsibilities. Our experience shows that resource is needed from the lead organisation to be able to support and nurture individuals in the community to fully understand the engagement work and to adapt the volunteer role to ensure it is sustainable.

We also learned that excessive bureaucracy is off putting and creates a barrier between communities and participation.

This evaluation also highlights the importance of working with the voluntary sector to develop and deliver engagement work. Many of the women we spoke to were wary or distrustful of statutory bodies including health professionals and social services, with a fear amongst some that their children could be at risk. The EO represented a voluntary sector organisation and therefore had less misconceptions around their role and were a more approachable point of contact in the community that did not pose the same issues around trust. Delivery from a voluntary sector organisation also proved successful in that changes to the programme could be made quickly with minimal disruption.

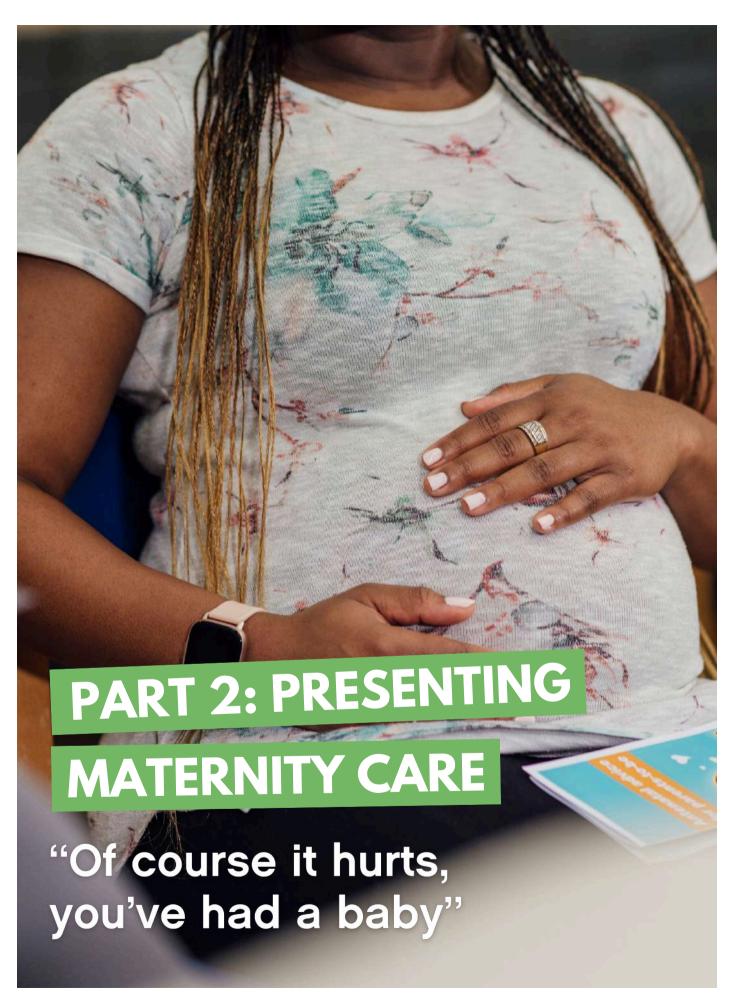


7. RECOMMENDATIONS

Our evaluation presents the following recommendations:

- An 'at your level' approach is needed - do not expect people to come to you when you are the one who needs something - meet them at their own level in their own environment.
- · Take time to build and nurture relationships, identifying key stakeholders and those in a position of trust.
- · Follow through on promises made and be realistic about change explain how the data collected will have a wider system impact and what that means to communities.
- Work with or consider commissioning the voluntary sector to conduct engagement work due to relationship with and trust from communities as well as an agile and flexible way of working.







1. BACKGROUND

Maternity care in the UK

Whilst it is generally safe to give birth in the UK, the rate of maternal mortality is increasing, with women dying from childbirth-related causes, conditions including preeclampsia, and mental health conditions (Knight et al, 2023). Extensive reviews have been conducted into maternity care, notably the Ockenden review of maternity services at Shrewsbury and Telford Hospital NHS trust, which reviewed 1,486 family cases in the period 2000-2019 (Ockenden, 2022). Ockenden's review investigated the deaths of 12 women, none of whom had received care in line with best practice.

It also investigated the 498 cases of stillbirth, concluding that 25% of these could or might have resulted in a different outcome if provided with better care. Following concerns about Nottingham University NHS Trust, Ockenden is now leading an independent review into maternity services at the hospital, with a final report later in 2025. Maternity services at the trust were rated inadequate by CQC (CQC, 2022) due to not having enough staff to keep women safe, not having staff trained in key skills, not always keeping good records and not having enough capacity, amongst other issues. The CQC Maternity Survey 2024 did show signs of improvement in some areas, however there are still many areas that need addressing.

Improvements were noted in mental health support, particularly in antenatal care, and there was an increase in number of partners able to stay in hospital and offer support. Areas of concern included confidence in staff providing care and the availability of staff.

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Inequalities in maternity outcomes

MBRRACE-UK is a collaboration responsible for national surveillance and investigations into the deaths of women and babies who die during pregnancy or shortly after pregnancy in the UK (NPEU, 2024). They produce several reports, including the annual 'Saving Lives, Improving Mothers' Care' report, which is used as a point of reference in both this report and the wider project.

The Saving Lives, Improving Mothers' Care report not only presents data to improve and inform maternity care, but it highlights several inequalities of significance. In the 2023 report, which presents findings from 2019-21, it showed that black women were four times more likely to die in pregnancy or in the six weeks following end of pregnancy, with Asian women and those in the most deprived areas being two times more likely (Knight et al, 2023). 12% of the women who died experienced severe and

multiple disadvantage, predominantly mental health diagnoses, substance misuse and domestic abuse. There is additional evidence supporting findings from MBRRACE-UK, for example Raleigh et al, who reported that not only did ethnic minority groups experience poorer maternal outcomes, but that they had poorer experiences in care (2010). Knight et al also found that there were clear disparities within maternity care for ethnic minority, and other socio-economic groups (2020), calling for policies specifically focussed on these groups.

The 2024 Maternity Survey also highlighted differences in care, with those from Indian, Pakistani and 'any other White background' reporting poorer experiences, including not feeling listened to and not receiving help during antenatal and postnatal care (CQC, 2024).



2. INTRODUCTION

Inequalities in maternity outcomes

Designed to reduce inequalities in healthcare, Core20PLUS5 is an approach developed by NHS England that seeks to inform action at a national and system level (NHSE, 2023). Core20PLUS refers to the target population, the most deprived 20% of the national population (Core20) in addition to groups identified locally that are facing health inequalities (PLUS), for example those with protected characteristics.

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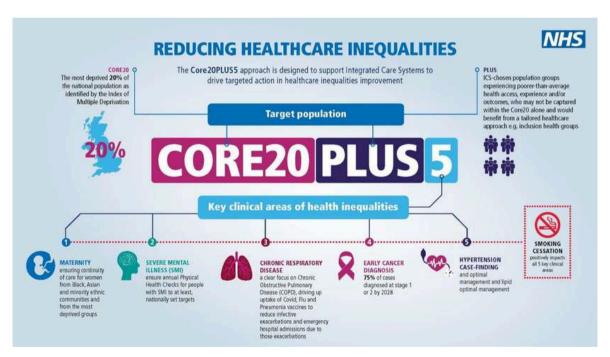


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Involve Kent: Community Connectors

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This information would then be shared in the community with those experiencing biggest inequalities, predominantly black, Asian and minority ethnic women and those in areas of highest deprivation. CC and the EO spoke to women about their experiences of care, whether antenatal, in hospital or during the postnatal period and collected data that was thematically analysed and fed back to key stakeholders. This paper summarises these findings and highlights key themes from qualitative data collected. An additional paper, "Model Evaluation NHS Core20PLUS5 Community Connectors", discusses in detail the model used. strengths and weaknesses of the model and recommendations on how to continue engagement with this cohort.

3. METHODOLOGY

Qualitative data was collected via a fulltime Engagement Officer (EO) based in the community. The EO spent the first quarter of the project building and nurturing relationships with those working in services accessed by the target group.

These included midwives, health visitors, children's centre staff, group leaders, faither leaders, training providers and more. Extensive mapping and networking provided opportunities for making new contacts and connections with the Local Maternity and Neonatal System (LMNS) were able to facilitate several conversations.



Working closely with the LMNS allowed us to gain access to healthcare professionals and the Maternity and Neonatal Voices Partnership (MNVP). Once established within the community, the EO attended groups, clinics and other activities to speak to women in person about their experiences. Data was collected by starting a conversation with the mother, gaining consent, and then asking for further information. Formal questions were not used, to ensure that conversation flowed organically and that the participant could focus on what was most important to them.

The only standard question used was an opener: "How would you rate the maternity care you received on a scale of 1 to 10?". Women were then encouraged to elaborate in their own words why they had given that score. These conversations were recorded in note form and then stored digitally. Data was anonymised and demographic data collection was minimal, including only a postcode and ethnic background to determine whether the individual was represented in the Core20PLUS5 group.

4. RESULTS

321 women provided qualitative narrative data. Data was analysed thematically, with 167 codes created, which were arranged into 22 categories within three overarching themes. Some categories presented within multiple themes. The main theme is 'care and support' and contains all categories.

An additional two themes were developed which contained some of the same categories, but with further analysis providing additional meaning. Final categories within themes can be seen in figure 2. This section presents the data collected by the Engagement Officer (EO) and Community Connectors (CC).



	Themes		
Category	Care & Support	Barriers	Judgement
Bias/stereotyping/discrimination	Х	Х	Х
Choices explored/supported	Х		
Effects of consistency/ inconsistency of care	Х	Х	Х
Consistent care and support	Х		
Effects of good communication	Х		
Effects of poor communication	Х		Х
Felt judged	Х	Х	Х
Good care	Х		
Good communication	Х		
Good organisation of care	Х		
Good support	Х		
Inconsistent care and support	Х	Х	
Issues with care	Х		
Issues with organisation of care	Х	Х	
Language barriers	Х	Х	
More information wanted	Х	Х	
More support wanted	Х	Х	
No choice/pressured choices	Х	Х	
Poor communication	Х	Х	Х
Poor resources	Х	Х	
Staff pressure	Х	Х	Х
Worry/anxiety/mental health	Х	Х	Х

Figure 2: table showing categories assigned to themes

THEME 1: CARE AND SUPPORT

Categories: bias/stereotyping/discrimination, choices explored/supported, consistent care and support, effects of consistency/inconsistency of care, effects of good communication, effects of poor communication, felt judged, good care, good communication, good organisation of care, good support, inconsistent care and support, issues with care, issues with organisation of care, language barriers, more information wanted, more support wanted, no pressure/pressured choices, poor communication, poor resources, staff pressure, worry/anxiety/mental health.

Women spoke at length about their care and support during and/or after their pregnancy, which included care from community midwives, hospitals and postnatal care, for example Health Visitors and GPs. Feedback about care was often positive, with those who had previously received care overseas stating care in England is better. Midwives particularly received good feedback:

"Midwife was brilliant she was like a therapist for me. Nothing was too much trouble and always felt well informed."

"Baby became distressed during labour so had an assisted delivery but the whole time the midwives were calm and explaining things and very professional".

Women would like to have received more care in the antenatal period, this was particularly highlighted by those who were not first-time mothers, who felt unsupported due to a reduced number of appointments in later pregnancies.

"As it's her second baby there are not as many antenatal appointments, but she would like there to be the same amount as with her first as "just because it's your second doesn't mean you don't have as many questions or worries"."

"I feel like they expect you to be an expert when you've had a baby before but who remembers what their pregnancy was like 4 years ago".

Concerns were also raised about the lack of antenatal education provided, particularly around feeding, which left women feeling vulnerable and ill-equipped when they had their babies. Women liked to see one healthcare professional throughout their care, claiming it helped them build a relationship and helped with communication.

"Saw the same midwife each time which made it easier as she got used to her accent and she felt comfortable to ask when she didn't understand a word."

"Saw different midwives each time and was a bit off putting and felt a bit uncomfortable to ask questions."

"Saw the same midwife each time and she was very good. "She was very aware that coming from Kenya I might have cultural traditions that might be an issue during pregnancy"."

There were several examples of poor care received in hospital. Many of these relate to issues that can be linked to understaffing and resourcing and included being left alone on wards following birth, having their requests ignored, having pain poorly treated or negative experiences during delivery. Postnatal care was referred to often, with concerns including limited staff, noisy environment, concerns around access to pain relief, poor food and not being able to rest. Many women spoke of relying on partners or family to take care of them, with more serious reports including issues being missed and treatment or tests not being administered. Several respondents reported feeling the need to self-discharge.

"Had a horrendous experience with her first child where she was induced and then her water broke but she was left over 24 hours on the ward waiting and the baby became very distressed and then had to have an ECS. Mother and baby both got sepsis and were in hospital for 2 weeks. Feels it wasn't anybody fault but a result of bad communication about how long she had been left because they were so busy."

"This is her first baby and felt she was left alone a lot in the postnatal ward. They did some checks, but she felt very vulnerable and worried she was doing things wrong. No one was around to show her how to do things, how to hold the baby properly or change his nappy and when she went home, she had no idea how to do the car seat and had to ask another parent if she had done it correctly."

"I felt a bit abandoned after the attentiveness of the labour room. I'm glad it wasn't my first baby or I'd of been petrified on my own".

"Had a ECS and afterwards was in pain and asked for some relief but they didn't bring any and she had to wait 2 hours before they came back again to check on her. She asked again and they said yes and then walked off again and didn't come back. "It was so busy but I was in pain and I had asked, begged the second time and still I didn't get any so I got my mum to bring some from home and took them"."

Other negative feedback related to feeling unheard or not being listened to. Women reported that they weren't listened to in relation to pain relief, their choices or how they were feeling. Some felt that they were misunderstood due to language barriers or accents and others felt staff were too busy to listen. Some shared experiences where they had been given medical procedures they did not ask for or consent to.

"She suffers from hypermobile joints and was told by her specialist that they needed to be aware in labour as some practices were not going to be advisable. As it is mainly in her hips the specialist said she could not be put in stirrups. In the delivery room they put her in them, and she told them "I can't have stirrups it's in my notes and the midwife said its ok, you're progressing nicely it won't be for long". Her baby is now 3 months old, and she is having to go to physiotherapy once a week to help repair the damage her specialist said has been done because of the stirrups. "Wish I had been more vocal about not having my feet up because now I'm in a lot of pain, but you think that they know what they are talking about so trust them"."

"Still didn't get an epidural. I heard the midwife who took me up to delivery tell the midwife there that I had changed my mind as I was progressing so well and didn't want an epidural. I never said that!! I'd been asking for ages."

"She said she noticed her baby had some jaundice when she got home but struggled to get anyone to listen to her."

"The consultants were annoying; they scare you and feel like they push you into doing things". The midwives always took the time to explain why the consultants had made then decisions, but she felt her choices had not really been listened to."

"She said another midwife later on examined her and broke her waters with her hand. She wasn't asked if she wanted this and wasn't sure if it was done by accident or on purpose."

"She feels she was pushed into having an epidural, the midwife told her most women have them at this point and her husband did ask if they could wait a bit, but they pushed ahead with it anyway. She said she didn't really want it and felt it was forced on her."

"The consultant shouted at me and said I was being selfish wanting to deliver early at 36weeks with a c-section and that I should put my babies needs first and wait until labour started naturally. She made me feel like s*** and I walked out in tears. After being told to prepare for the worst every week for months I just wanted to have my baby as quickly as possible."

In addition to not being listened to, women also felt they were not given information or support. This led to worry and stress during their care as they did not always know what was going on, or did not understand, having not been explained to.

"Had to have emergency scan and they didn't explain what was going on and were worried. Would of felt more reassured if they were communicated with."

"The only negative was the scan at the hospital. The sonographer didn't explain what was happening said she couldn't find anything, then left her waiting in the room alone while she left to get another sonographer. It made her really worry as thought the baby had gone but when the new sonographer came in, they were brilliant, very calming and told her not worry said it was all fine and showed her everything. Even though everything was ok with the baby she was upset she had been left thinking her baby had died."

This was not always the case, and positive examples of good communication were provided.

"The consultant has been outstanding. Drawing me diagrams when needed and so informative and supportive."

"Baby was stuck but the midwives explained clearly what was happening and made her feel calm."

Following discharge, many women reported feeling a need for more support. They often referred to feeling like part of a 'tick-box' exercise when being seen by midwives at home and felt there was very little support available to them after these appointments.

"The home visit midwife was kind and asked lots of questions, but it did feel like it was a standard set of things to be checked off with yes or no answers. The biggest thing is that after the midwife home visits you get no other care or support. I have no family close by and don't have any friends with young babies and it would be nice to have someone to ask where to go for support. And you don't want to keep getting your baby weighed every week."

"They were friendly and asked questions but felt they were working though a list and, in a rush, to get to the next person. They asked how she was feeding but they didn't watch her feed. "The midwife said, 'oh well this is your third baby I don't supposed you even need me here'. I had a few questions but after that didn't feel I could ask as she was pretty much putting her coat on."

Whilst feedback on midwives was mixed, feedback around GP appointments was mostly negative. Many women felt rushed and commented the appointment was only good for the baby. Several reported not actually being check by their GP, particularly in relation to wound care, with some women needing to access urgent care after having symptoms missed. Many appointments focussed on contraception.

"Rang her GP as had pain in her stiches, but they were dismissive and said it was normal. As a nurse she said she knew it wasn't healing as it should so went to urgent care, and they said she had a stitch infection and prescribed antibiotics. She said she is glad she has medical knowledge, or she would of listen to the doctor and become unwell "I was quite shocked he didn't even ask to see me, just said pain after caesarean is normal"."

"She said she was relieved it was with a female GP as felt they would understand the situation better. She said the GP was blunt and very unwelcoming and questioned why she wanted to be seen. She stated that they don't offer postnatal appointments as standard unless the women had a CS. She said she thought all women were given them and was told 'We are women. You just get on with it!'. No support was given, in answer to her questions she was told to go to the health visitor and no mental health advice given even though she mentioned she is anxious she is looking after her baby properly."

Support from groups proved invaluable to mothers who accessed it. Women didn't always know about these groups and were late to access them, if at all.

"When her baby was 4 months old, she said she found out about the baby groups at the children's centre and said they have been so helpful and that she wishes she had been told about them soon after her baby was born."

THEME 2: BARRIERS

Categories: bias/stereotyping/discrimination, effects of consistency/inconsistency of care, effects of poor communication, felt judged, inconsistent care and support, issues with organisation of care, language barriers, more information wanted, more support wanted, no choice/pressured choices, poor communication, poor resources, staff pressure, worry/anxiety/mental health.

Several barriers to accessing care and support were identified in the data. Some related to factors that slowed down processes or generally made the patients experience difficult, and included awkward appointments, inflexibility, poor communication, difficult locations, delayed/missed referrals and lack of access to transport.

"She said the only negative of her care has been that the midwife clinic is very hard for her to get to without a car. She is having to use public transport and it takes over an hour to get here and there is a children's centre with a midwife clinic only 20 minutes by bus away from her so didn't know why she wasn't referred there."

"Very stressful having to travel to different places for scans and prenatal appointments. Were told if they didn't attend, they would be charged even though train strike was on – worried so got 3 buses."

"She said the care was good antenatally, but it was annoying having to visit 3 different hospitals including Kings for scans, was difficult with a toddler."

"Wanted to change the date of the scan so her partner could come but couldn't get through on the phone or online to rebook. Kept trying but they just never answer the phone. Ended up going alone and I was nervous and really wanted baby's dad to be with me."

Some of the women we spoke to are seeking asylum and had issues relating to lack of knowledge about how to access support and care, and some struggled to follow feeding advice due to living in temporary/emergency accommodation with no cooking facilities. Several women had issues accessing appointments due to childcare. Many women missed postnatal appointments because they were not advised that they would be in a clinic rather than in the home. This caused anxiety in some. Some women experienced difficulty self-referring for antenatal care or registering their pregnancy. This resulted in delayed checks and appointments in early pregnancy. There were some instances where women needed to go between different services to coordinate this themselves due to breakdown in communication between services.

"Felt quite alone at the beginning as after self-registering she got lost in the system and didn't get a scan until 14 weeks and didn't see a midwife until 2 weeks after that."

"The communication between hospitals and the midwives was bad. The notes were not shared between the consultants and the midwives so often the majority of the time in appointments was spent updating the staff. She said it was difficult to get to her scans as they were at Kings, yet antenatal care was at QM and the Pru. "I was never quite sure where I was meant to be and there was a couple of occasions, I had to visit two different hospitals in the same day for scans, bloods and consultant appointments"."

"She said she got a UTI 3 week after the birth and went to urgent care who gave her antibiotics and told her to get a repeat of them from her GP as it was bad. Her GP refused to prescribe them because she didn't have a letter from Urgent care despite them saying it was put on her notes. So, she had to go back to urgent care the following week to get the next lot of antibiotics."

"She missed her day 5 postnatal midwife appointment as thought it was a home visit and that they hadn't shown up and then got a call from the midwife to say they were expecting her in the clinic."

A notable barrier was a need for translation services, with many women needing to rely on partners, friends, family or in some cases, strangers, to support with translation of letters and other communication. Some women used Google to translate during their appointments. Having translation available is positive for the women who need/access it.

"Is pregnant now and is seeing the midwife but her English is very limited, and she has to use google translate. There is a lady who works at the children centre who has a relative that speaks Spanish who has been attending to translate when she can, but she is not there every appointment and worried they will not have a translator when in the hospital."

"Speaks basic English but didn't fully understand the medical information and advice from the midwife in her last pregnancy so they have given her an interpreter for all her appointments this time. This has made her feel more relaxed and in control."

THEME 3: JUDGEMENT

Categories: bias/stereotyping/discrimination, effects of consistency/inconsistency of care, poor communication, felt judged, poor communication, staff pressure, worry/anxiety/mental health.

Examples of judgement were present amongst the data. This presented in several ways, but the leading concerns were age, ethnicity and weight (of baby or mother).

Some women also reported feeling judged for either their choices or for a sense of 'time wasting'.

"I felt they were almost telling me off for having a baby at 42 and made me feel guilty, telling me that I had added risks to my baby."

"I didn't feel I could ask any questions as she was judgemental to me. I think it was because I'm so young." [she was 17 years old when had her baby]

"I've been fat shamed 3 times in this pregnancy!! My mental health is already bad, and I've had treatment for eating issues before. I have a constant guilt around food now and that I'm hurting my baby."

More concerningly, some women reported feeling that they had been discriminated against or treated differently due to their ethnicity.

"She said she felt they gave the 2 white English women in the ward much better care and attention then her and the other lady (from Romania) got."

"Was offered no pain relief "there is a perception that black women don't need as much pain relief, and I didn't make a fuss or scream so they didn't offer me anything"."

"I overheard nurses talking to patients with accents and they definitely did it in a lesser nice way than to those with English accents".

"I don't think I got worse care than anyone else, but I did feel I was treated differently because I'm from Poland."

Some women provided feedback that highlighted how they were feeling was diminished, particularly regarding pain, or coping with pain.

"She said they didn't treat her with much dignity or respect, and they hurt her during the examination, and she was upset. "I heard her [the midwife] say quietly as she walked away 'it's going get a lot worse than that love' I felt so degraded"."

"She was in a lot of pain so asked the home visit midwife about her concerns and was told 'of course it hurts you've had a baby'. The pain got worse, so her partner made her go to A&E the next day and they said she had an infection where she had torn slightly during birth and was given antibiotics and pain relief and told if didn't feel better in 2 days to come straight back."

"Midwife didn't listen to her saying about her pain (said she was screaming). Told she wasn't trying. Consultant decided to do an ECS. Found out after that labour didn't progress because the bowel was blocking the cervix."

5. DISCUSSION

The data analysis found three overarching themes within the data: care and support, barriers and judgement. Each theme had examples of overlapping categories and there was a cross-cutting theme relating to infrastructure. All themes had one factor in common – communication. These findings are presented in figure 3. Our findings were consistent with those from the 2024 Maternity Services Survey, which looked at experiences of pregnant women and new mothers who used NHS maternity services in 2024 (CQC, 2024).

This survey reported concerns around communication, confidence in staff and staff availability, all of which were reflected in the data collected. There were examples found where those from global majority groups were treated differently, in addition to older and younger mothers and those who were overweight, which has also been widely reported in the survey and by MBRRACE-UK (Knight et al, 2023).



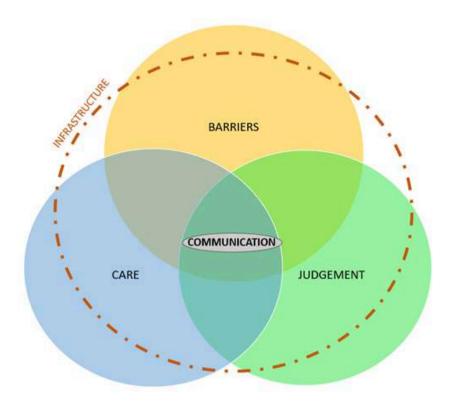


Figure 3: Summary of themes from therapeutic analysis

Care and support

Women were very keen to speak about the care and support they had received and most of our data collection was focussed on this area. Findings were mixed, with experiences of good and bad care, either during or after pregnancy, or experiences of birth itself. There was often a correlation between reporting good care and having the same professional throughout care in their pregnancy, highlighting importance of consistency, particularly in antenatal care.

Barriers

Data showed that there were several practical barriers that women were facing to accessing care and support, many of which related to infrastructure and resources. Issues were highlighted in booking and rearranging appointments, attending appointments due to inaccessible or difficult locations or not having childcare in place to attend.

Other practical barriers included not having access to translation services and therefore either missing appointments or not being able to fully understand information being provided at appointments.

Judgement

Women felt that they were judged due to their age, their weight and/or their ethnicity. Several examples were seen of women feeling they were either too old or too young to be having a baby. Others felt that they were judged for being overweight. Alarmingly, women felt they were judged based on their ethnicity and were treated differently.

This included black women being denied pain relief as they were perceived to not need it, and women from Eastern European backgrounds being discriminated against throughout their care.

Infrastructure

Several women commented on staffing and resources in relation to their care. There were many references to lack of staff, mainly in hospitals, lack of facilities and lack of antenatal education. This was seen to be an issue that ran through all three themes. Resources, or lack of, were blamed in several examples for poor care and support. Many women reported that they felt 'left to it' in postnatal wards because there were simply not enough staff available. Infrastructure also relates to the barriers identified in that better resourced services would reduce some of these factors.

For example, more translation services, easily accessible venues, more public transport. Infrastructure arguably can be linked to the judgement experienced by some women in that better training could be provided to ensure that health professionals are treating all patients equally and respectfully. Better resources may also result in better management and quicker identification of issues, particularly those relating to discrimination from healthcare professionals.

Communication

Communication was the overarching theme that tied all the experiences together. Those that reported better care often linked this to seeing the same healthcare professional and building a strong relationship with them. Those with positive stories also reported being able to make their own decisions and choices. felt they were informed, felt listened to and felt cared for.

Those with negative experiences often felt that they were left alone, had their voices unheard, were pressured into things or had decisions made for them. Better communication could easily alleviate some of these issues.

6. CONCLUSIONS & RECOMMENDATIONS

The results and discussion set out and explore the findings from a rich and detailed dataset, presenting a series of interconnected themes, linked to broader and more complex issues. Whilst it is difficult to address all the issues presented in the data, there are some key conclusions and recommendations that can be drawn:

1. Care should be caring and consistent

Women repeatedly told us that they would have preferred to see the same healthcare professional (HCP) throughout their pregnancy, and beyond if possible. They often found they had to repeat themselves or felt that their care was not joined up. They appreciated when they felt genuinely cared for and were given information and choices. This often led to positive experiences and feedback.

2. Patients are empathetic to, but suffer because of lack of resources

Many women associated their poor experiences with a lack of resource but accepted this as standard. They were sympathetic toward overstretched midwives and were quick to excuse what could be regarded as poor care due to lack of resources. Despite their concerns for the services and HCP supporting them, patients are being harmed by stretched resources and lack of infrastructure, for example not being

offered essential appointments, having symptoms missed that might, for example, lead to infections or in rare but serious cases, losing their pregnancy.

3. Women must be listened to and informed:

Those reporting poor experiences often reporting feeling unheard or that they were not listened to. Women did not always understand the treatment or care they were given, or did not make informed choices. Some women were denied pain relief despite asking for it.

4. Judgement and discrimination are harmful to women and services:

In several cases, women felt judged because of their age, weight or ethnicity. This creates an unpleasant environment in which women must access care and support. For those who experience the most extreme judgement, there is a risk that they will not access the essential care that they need. In other cases, women are denied pain relief or are treated differently, increasing the risk of poor outcomes in groups already facing disadvantage.

6. LIMITATIONS

The project was restricted to 12 months, and it took time to develop trusting and meaningful relationships in the community. Time was needed to identify women to sign up as Community Connectors (CC) and places to engage with the wider community. Many of those who were interested in becoming CC were restricted due to other commitments, predominantly caring for children or returning to paid employment. Some CC were able to commit for short periods but then had to return to their paid roles.

Data collection was informal and captured through informal conversations with women in community and other settings. Because of this, it was often recorded in note form and presented in third person, reflecting back the conversation rather than presenting experiences verbatim. Whilst this did not affect data analysis, as the subject matter remained the same, it should be recognised in this report.



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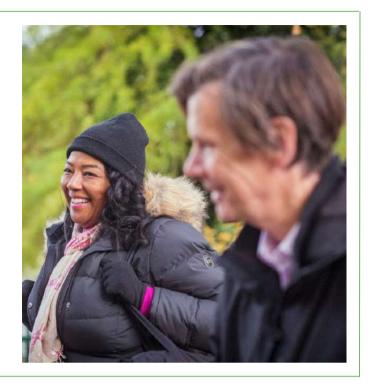
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Involve's mission is to help people live happier, healthier lives. Empowering communities to live well by tackling the root cause of ill health, including isolation, loneliness, disadvantage and frailty.

In 2023/24 Involve supported:

26,655 adults, children, young people parents, and carers.

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