North Central London
Integrated Care System

Foreword from the North Central London Integrated Care Board Chief Nursing Officer

This report summarises engagement that was undertaken to support the development of the Start Well Interim Integrated Impact Assessment. This engagement aimed to gain an understanding of how proposals developed through the Start Well Programme may impact service users and to support with the development of mitigations to address these.

Through doing this work, we have heard powerful first-hand accounts of the experience of care, and these have also been summarised in this report. As a system, we are taking this feedback very seriously and are taking proactive steps to put in place actions to address the feedback through our Local Maternity and Neonatal System (LMNS).

Through consultation we will be working to engage further with the groups identified in this document to understand the impact of the specific proposals put forward in the Start Well pre-consultation business case. However, many of the themes that require action do not rely on any possible changes associated with the Start Well programme to put into place and require action now. These priority actions will be reflected in an updated LMNS equity and equality action plan and work is already underway on aspects of this.

We are grateful for all those that took part in the engagement for sharing their experiences and we hope to continue to work with communities in NCL to hear their feedback and to use it to improve care in the future.

C. Caldwell

Chris Caldwell

Chief Nursing Officer, North Central London Integrated Care Board

Start Well

North Central London Integrated Care System

Pre-consultation engagement report

Author: Verve Communications
Date: November 2023

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EXECUTIVE SUMMARY

Health and care organisations in North Central London have been working together on a long-term programme called Start Well, looking at maternity services, neonatal services and acute services for children and young people. Some changes to current services are being considered.

The Start Well team conducted engagement about maternity and neonatal services to identify potential impacts changes to services might have. This document reports the findings of the engagement and will be used to inform an Integrated Impact Assessment being undertaken on the wider impacts of potential service changes.

Discussions were held with groups of people who have used maternity and neonatal services to understand their experiences and views, and to understand, broadly, how future service changes might affect them. All the engagement used qualitative methods; some groups were online and some in person. For some groups who were particularly hard to reach representatives of organisations, or people who provided specialist services were interviewed. 38 discussions took place.

Most of the discussions centred around general experiences, views on transport and travel, continuity of care, information and communication and access to services. The discussions with users of Edgware Birth Centre related to why participants had chosen the Centre, their views of other options, and their experiences of using the Centre.

Headline findings from specific groups were:

Women over 35 were willing to travel further for maternity care, generally because they want to choose a birthing site they considered to offer high quality care.

Potential issues for **people with a disabilities and long term conditions** included:

- Travelling, particularly to unfamiliar places
- Communications and their needs being understood
- Information and interpretation being in the right format

Some people **from different ethnic groups** felt they were sometimes treated differently, particularly if they did not speak English.

Some people felt **religious needs and observances** were not understood

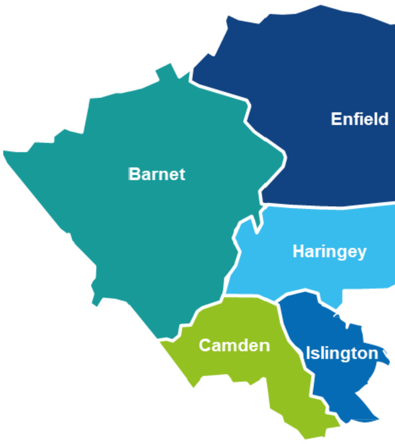
LGBTQ+ people identified lack of inclusivity from some staff and in communications

Parents of children with disabilities wanted more information about their babies' conditions

The report concludes by making recommendations for potential service improvements based on the findings of the engagement, and recommendations for the engagement to be undertaken as part of the consultation process.

1. INTRODUCTION

North Central London (NCL) comprises five boroughs: Barnet, Camden, Enfield, Haringey and Islington.



In April 2023 NCL Integrated Care System (ICS) published the North Central London Population Health and Integrated Care Strategy[1]. The following section uses information and terminology from that document to explain the population of NCL.

Just under 1.8 million people live in NCL. The population is relatively young. Some residents are not registered with GPs, including people from health inclusion groups such as people who are homeless, refugees and asylum seekers, sex workers, Irish Traveller and Gypsy, Roma and Traveller communities, transgender people and (ex) offenders.

NCL is the second most deprived ICS in London, with all five boroughs having areas of deprivation – often in close proximity to areas of affluence. More than 1 in 5 people in NCL live in the 20% most deprived areas nationally, whilst almost 1 in 3 live in the second most deprived 20% areas. There are particular concentrations of deprivation towards the east of NCL in Enfield, Haringey and Islington.

The population is ethnically diverse. More than half of NCL residents are White, around 20% are Asian and around 20% are Black. Barnet and Camden have larger Asian communities whilst Haringey and Enfield have larger Black communities.

Different communities comprise different age structures with higher proportions and numbers of children and young people in Bangladeshi (30%), Black African (28%), Black Somali (32%) and Mixed (39%) communities compared with the NCL average of 21%.

The North Central London Integrated Care System (NCL ICS) brings together local health and care organisations and local councils to work together to improve health outcomes for residents and tackle health inequalities.

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[1] https://nclhealthandcare.org.uk/wp-content/uploads/2023/05/PH-IC-Strategy-V.Final-long-version.pdf

1.1 BACKGROUND

Health and care organisations in NCL have been working together on a long-term programme looking at maternity services, neonatal services and acute services for children and young people – this is called the Start Well programme. The programme started in November 2021 and the Case for Change was published on 30 June 2022.

A full version of the Case for Change can be found here: https://nclhealthandcare.org.uk/wp-content/uploads/2022/07/NCL_Start-Well-Case-for-Change-FINAL.pdf

A summary version of the Case for Change can be found here: https://nclhealthandcare.org.uk/wp-content/uploads/2022/07/NCL_Start-Well-Summary-FINAL.pdf

Over a ten week period in the summer of 2022 patients, the public, staff and partners were asked to share their views on the opportunities in the Case For Change. The findings can be read in this report: https://nclhealthandcare.org.uk/wp-content/uploads/2022/09/Start-Well-engagement-report-September-2022.pdf

In November 2022 NCL's Integrated Care Board (ICB) approved a paper which set out proposed care models developed by clinicians and stakeholders. The models describe the care which NCL aspires to deliver in the future. The paper can be found here: https://nclhealthandcare.org.uk/wp-content/uploads/2022/12/StartWell-ICB-Board-paper-221129.pdf

The Board agreed that planning could start on how to implement the proposed care models which did not need changes to how services were currently organised. For maternity, neonatal and paediatric surgical services the Board agreed that the Start Well programme should begin an options appraisal process.

To understand people's experiences of current maternity and neonatal services, and to identify potential impacts of future service changes, the Start Well team undertook engagement with NCL residents. The findings of the engagement are presented thematically in this report. The themes will be used to inform an overarching Integrated Impact Assessment being undertaken for Start Well, which will incorporate both the findings from the engagement with quantitative analysis such as resident demographics and travel time changes.

The engagement was undertaken by the Start Well team with groups identified as potentially being impacted by future service changes. The discussions did not relate to specific service changes, as these were not fully formulated at the time of the engagement, rather they covered experiences of current services, what worked well and the sorts of issues which might arise for people if changes were made to services.

1.2 THE AIMS OF THIS ENGAGEMENT

The aim of the engagement activities reported here was to explore the experiences of people who had used maternity and neonatal services in NCL. There was a focus on particular groups who might be disproportionately or differentially impacted by service changes. The themes and recommendations for potential service improvement presented in this report will be used to inform the Integrated Impact Assessment which will consider potential impacts on future service users.

1.3 ABOUT VERVE

Verve is an independent full-service agency specialising in working with NHS organisations to assist with engagement, communications, transformation and change. We were commissioned to analyse and report on engagement undertaken by the Start Well programme team.

1.4 THIS REPORT

This report is based on pre-consultation engagement undertaken by the Start Well programme team with groups of people identified as potentially impacted by any changes required to implement the proposed care models in maternity and neonatal services. It should be noted that at the time of the engagement the site specific options for service change required to implement the proposed care models had not been finalised so the discussions were about people's use of current services, rather than how specific service changes might affect them. A separate Integrated Impact Assessment report has been commissioned by Start Well which will specifically consider proposed service changes, considering the themes from this report.

There has been a significant amount of other additional patient and public engagement throughout the programme, development of the options appraisal and proposals to be consulted on. This additional engagement is outlined in the pre-consultation business case.

The data is all qualitative and was presented to Verve in a series of anonymised thematic notes from group discussions and interviews. Most participants were people who had recent experience of maternity and neonatal care and they were asked about these services in relation to: communications and information; continuity of care; travel and transport; and site accessibility. Some interviews were undertaken with specialist providers, such as midwives providing care for vulnerable people and providers of bereavement services. The report presents the methods used in the engagement, and discusses experiences of maternity and neonatal services, and goes on to identify what good services look like. The report ends with recommendations for further engagement during the consultation process.

It should be noted that this report, and the statements made herein, are based solely on the feedback of the people who took part in the engagement and may not represent the experiences of all people from particular groups or having particular characteristics. The report makes recommendations in the final chapter for seeking further input from engagement during the consultation phase.

The themes and findings from this report will inform the IIA being undertaken for the Start Well programme.

1.5 STRATEGIC CONTEXT OF THE REPORT

The engagement that informed this report was commissioned as part of the Start Well programme Integrated Impact Assessment with the intention to identify impacts of potential changes.

Given that the site-specific options were not covered as part of the engagement, some more general feedback about service users experience of maternity and neonatal care is also reported. Actions that may be needed to address some of the areas raised outside of a change to services will need to be explored through the NCL Local Maternity and Neonatal System (LMNS) who have business as usual oversight of maternity services in NCL. Many of the themes raised later in this report link to ongoing work that has commenced by the LMNS through their equity and equality action plan. This report should be seen as a further driver for that work to continue.

1.6 ACKNOWLEDGEMENTS

We would like to thank our colleagues in the Start Well programme team who undertook the planning and the fieldwork for this engagement, which involved making many contacts and talking to groups and individuals across all five boroughs. Input and comments from the Start Well IIA Steering Group and Start Well Programme Board supported the development of the engagement; Carnall Farrar's quantitative analysis for the IIA helped to define the groups to be included in the engagement.   We would also like to thank the people who participated in the fieldwork for sharing their experiences and views.

2. METHODOLOGY

This chapter describes the methods used in the engagement, how participants were recruited and how the analysis of the qualitative data was carried out.

The engagement was designed to hear from people who had used services and who fitted into scoped in groups (discussed below). As the options appraisal was still ongoing at the time of engagement, this engagement did not discuss potential services changes, rather people gave views on current services based on their experiences and they were asked about the importance of information, continuity of care, travel and access to services, to understand where impacts might arise.

2.1 ABOUT QUALITATIVE RESEARCH

This engagement used qualitative methods to ensure that people's views and experiences could be explored in detail.

The aim of qualitative research is to define and describe the range of emergent issues and to explore linkages, rather than to measure their extent. The use of qualitative methods means that we do not collect, or report, on the numbers of people holding particular views or experiences.

2.2 PROTECTED CHARACTERISTIC GROUPS

The Equality Act 2010[2] created a duty on listed public bodies to have due regard to ensure equality of opportunity amongst those who share the protected characteristics described in the Act, and those who do not. The nine protected characteristics are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation

2.3 SCOPING IN GROUPS FOR ENGAGEMENT

A scoping exercise was undertaken to identify groups to scope in for the engagement work. The starting point was tabulating all the protected characteristics groups discussed in Chapter 8; Equalities in the Case for Change document[3] together with the health inequalities discussed in relation to each group; the quantitative work undertaken by Carnall Farrar was used to cross reference the groups potentially impacted by future service changes. The Start Well programme

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[2] https://www.legislation.gov.uk/ukpga/2010/15/contents/enacted

[3] https://nclhealthandcare.org.uk/wp-content/uploads/2022/07/NCL_Start-Well-Case-for-Change-FINAL.pdf

team developed the following categories of potential impacts on service users whatever the detail of the future service models:

- Transport and travel
    - People might have to travel further, have more complex journeys, or journeys might be more expensive
- Continuity of care
    - There might be disruption of care for some people or care may be delivered from a different location to previously
- Information and communication
    - How and what information people received about their care
- Access to services
    - Having care in less familiar locations
- Other factors
    - Raised by engagement participants and which should be considered

We also considered that these categories would be likely to yield potential mitigations in later stages of the work.

The table below shows the groups identified for scoping in and the disproportionate health impacts identified for each group in the Case for Change (see Chapter 8: Equalities).

Scoped in protected/other characteristic	Disproportionate Health Impacts identified in Case for Change
Age – under 20	Adverse maternal outcomes
Age – over 40	Poor maternal outcomes Maternal mortality
Disability, including long term conditions and learning disabilities (neurodiversity/neurodivergent)	Maternal mortality Poorer maternal outcomes
Race – Black	Admissions to neonatal units Obesity and comorbidities Maternal mortality
Race – Asian	Maternal mortality Diabetes
Race – Gypsy, Roma and Traveller Communities (see below re. inclusion health groups)	Maternal mortality Poorer maternal outcomes Stillbirth
Religion or belief – Muslim	Poorer experience of maternity services
Religion or belief – Jewish	Poorer experience of maternity services
Sexual orientation – Lesbian and bisexual women	Poorer maternal outcomes
Other vulnerabilities including homelessness (see below re. inclusion health groups)	Admissions to neonatal units Heath behaviours (e.g. smoking) Stillbirths Poorer maternal outcomes
Asylum seekers	Poorer maternal outcomes

A workshop with the Start Well IIA Steering Group considered the scoped in groups derived from the Case for Change, and suggested adding in the following groups:

Group	Rationale
Those who use services who have specific vulnerabilities such as domestic abuse	Some maternity services have teams who care for women with particular vulnerabilities
Those with experience of Female Genital Mutilation	Services are in place at some sites for those who have experienced FGM
Those accessing perinatal mental health services	Potentially poor outcomes from maternity care
White non-British groups who may not speak English as their first language	May have challenges with communication and language
People with poor level of literacy	Challenges around understanding written communication
Bereaved families	Services are in place for families who have experienced bereavement
Carers, including parents of children with disabilities or long term conditions	A group known to have additional needs or likely to be impacted by changes
People experiencing socio economic deprivation	Potential challenges accessing services
Inclusion health groups, including: people experiencing homelessness; drug and alcohol dependence; vulnerable migrants; Gypsy, Roma and Traveller communities; sex workers; people in contact with the justice system; and victims of modern slavery.	People these groups tend to have poorer health outcomes than the general population, leading to increased health inequalities.

2.4 RECRUITMENT

The Start Well team used a variety of methods to reach potential participants, including:

- Social media to reach older mothers
- Advocacy groups
- Voluntary sector groups
- Asking Trust staff to put them in touch with recent service users

2.5 METHODS

Where possible the Start Well team visited groups in person – either visiting sessions which were scheduled to take place or convening special meetings to talk about maternity and neonatal services. Some groups took place online.

The size of the fieldwork sessions varied from one participant to over twenty people in the same room. In some sessions voluntary organisations provided interpreters.

2.6 TOPICS DISCUSSED

All fieldwork sessions asked people about their experiences of using maternity and neonatal services, and sought to understand what was important to people on four topics:

- Information – e.g. making appointments, communications and any barriers such as language barriers
- Continuity of care – what is important to people
- Travel – what considerations people have, what barriers there are, how far people would be willing to travel
- Access to services – e.g. physical access to sites, what is important for people with disabilities

2.7 WHO TOOK PART IN THE ENGAGEMENT

The following table describes the groups and participants in the engagement, including the numbers who took part.

Note: For groups which were not able to be included in this engagement see Section 4.6 and Section 9 for recommendations regarding including groups in further engagement.

Engagement with service users	Number of events	Total number of attendees
Online discussion groups or interviews with women aged 35+	5	8
Online discussion groups with Jewish women convened by charities in North Central London that support Jewish families	3	17
In person discussion group with women at a community centre in Islington who support vulnerable people including asylum seekers	1	8
Online discussion group convened by a Camden and Islington based charity that supports African communities	1	7
In person discussion group with parents of children who have learning disabilities and autism convened by a Barnet-based charity	1	5
One to one interview with an advocate for parents who have learning disabilities and autism	1	1
In person discussion group with parents who have learning disabilities	1	5
Interviews or online discussion groups with women who have given birth at Edgware	3	5
In person discussion group at a Haringey based community centre who support people who originate from outside the UK	1	22
Online discussion group with parents who have experienced bereavement	1	7
Online discussion groups with parents who have had recent experience of neonatal care across NCL sites	9	18
Online discussion groups facilitated through a charity that supports LGBT+ parents	2	4
In person discussion with parents who are deaf and deafblind	1	2
Online discussion with parents who are seeking asylum facilitated through a charity that supports those seeking asylum	1	2

In person discussion group with parents of Eastern European background	1	2
Engagement with specialist staff		
Online interview with a hospital chaplain who supports women who experience bereavement	1	1
Online interview with a midwife who supports vulnerable women with a focus on women who are homeless	1	1
Online discussion group with clinicians who support women who have experienced female genital mutilation (FGM)	1	3
Online discussion groups with midwives who support women who have experienced domestic violence or have severe mental illness	2	4
Online discussion group with specialist midwives who support women who have experienced bereavement	1	2

2.8 HOW THE ANALYSIS WAS UNDERTAKEN

Group discussions and interviews were facilitated by a member of the Start Well programme team; a second member of the team took notes.

The method used to analyse the data produced by the fieldwork involved summarising research notes according to the themes of the topic guide and then identifying features within the data, for example, looking for similarities and differences between people with different characteristics, comparing and contrasting their perceptions, accounts and experiences.

Anonymised verbatim quotations are used in this report to illustrate points made, however, quotations are not used if it would be possible to identify an individual by the words used or the experience being discussed.

3. EXPERIENCES OF MATERNITY SERVICES

This chapter presents the findings in relation to maternity services. Participants talked about their experiences in general and views on the importance of communications, information, continuity of care and travel and transport. The focus was on what was important to them. The chapter ends with a table showing notable findings in relation to the groups who took part in the engagement.

3.1 COMMUNICATIONS

3.1.1 METHODS OF COMMUNICATION

Many people were happy to have some communications electronically, however there were strong views that there should always be alternatives to digital communications. Concerns were expressed about how people would access information if, for example, their phone was broken or lost.

Some communities do not engage well with digital devices, for example Orthodox Jewish women said that they did not own smart phones, nor have access to computers, so they needed paper communications. An advocate for the community said:

> ***"How you communicate with our community must be clear and concise. Putting information on public websites really fails. Paper options are really best."***

For some people letters were better because they could be used for reference , and if help was needed to understand them, they could be taken to friends, relatives or support groups.

There was a risk of digital exclusion for those who had unreliable access to Wi-Fi and/or could not afford large amounts of mobile data, so reading documents online would not be possible; SMS messages could be read, but links could not be followed.

Some people noted that making and changing appointments could be difficult, for example, if people telephoned they were often put on hold for long periods of time, and emails can take a week to be answered.

People experiencing domestic abuse sometimes change phones and numbers frequently to prevent partners seeing their messages. Some do not have smart phones or Wi-Fi so find it difficult to use online services or digital communications.

For homeless people it was reported that the best method of communication is by mobile phone. However, self-referral to maternity services can be difficult for those who are digitally excluded.

People who are deaf or have hearing loss may require additional support to ensure that health appointments are accessible. Virtual appointments can be challenging and appropriate interpreters are needed to ensure accessibility.

There were examples from women who had a miscarriage, or their baby died soon after birth who received reminders about appointments, which was very distressing for them. One mother said:

> ***"It was traumatic getting the reminders."***

3.1.2 IN PERSON COMMUNICATIONS

LGBTQ+ people reported that there were sometimes assumptions made that a male parent would be involved in maternity and neonatal care. One woman said that during a scan the radiographer had tried to guess the relationship between the pregnant woman and her female partner by asking 'Is this your sister/mother/friend'. This made the couple uncomfortable and upset the pregnant woman. When they said they were partners the radiographer was immediately apologetic and said she should not have tried to guess. Further, LGBTQ+ couples said that for the partner not giving birth the experiences at hospitals can be isolating and non-inclusive.

LGBTQ+ participants said they felt safer with people who wore rainbow lanyards or badges, with the expectation that those people would be allies and be supportive.

Older mothers said that they had heard the term 'geriatric mums' being used which they felt was derogatory.

Parents with disabilities sometimes found it difficult to have a lot of people involved in their care, including having to repeat their stories multiple times. It was apparent that their extra needs were not always documented in their medical notes, so some staff were unaware of their situation.

Some parents with learning disabilities felt that they were not understood. The views of two mothers are:

> ***"Just 'cause you have a learning disability doesn't mean you cannot love your children."***
>
> ***"Things need to change. Midwives need to understand more what it is like to have a learning disability and give us more time to learn."***

For some people telling staff that they had a learning disability was uncomfortable and they hoped that staff would 'pick up' signs – but this did not always happen.

Further, when social workers were involved, parents felt that communications between maternity teams and social services could be improved.

A learning disability advocate explained that agency staff in particular are not always well informed about how best to support parents with learning disabilities and/or neurodiversity; they had heard of cases where new parents had become distressed by the way they were treated and spoken to on maternity wards.

Some parents said that they felt they were not listened to when interacting with maternity staff. This ranged from people's cultural needs not being understood to people's views about their own health. One woman said:

> ***"I didn't feel like I was listened to. I'd go in and say, 'I don't feel well' and then be dismissed with anxiety. If it had been my first experience things could have gone wrong as I needed to say it multiple times."***

There were strongly held feelings from some women that they believed they were treated differently because they did not speak English and because of the colour of their skin. These people said they did not feel listened to, felt that their needs and preferences were not considered, and they did not always know what was happening around them. There were instances when interpreters were not available, and many would have preferred a female interpreter, but this was not always possible. One woman said:

> ***"The midwives don't listen to what mums have to say, they just don't want to know. Disrespect. First time they see you they see you as nothing. That you aren't human. They talk to you in a way that they don't want to listen to you, they just dismiss you."***

Another woman said:

> "***The nurses need to listen to mums and provide more individual care and compassion, they were very rude. My sister's husband is English, and she received a far better service than me, I was shocked. She was looked after, midwives holding her hand, calming her. I feel like because I'm not English and have had children before I was ignored."***

Eastern European people who do not speak English faced barriers accessing maternity services. They felt that because they could not communicate directly with health professionals they were not always listened to:

> ***"They don't listen to my concerns and I tend to be dismissed. When you are ignored and you don't know what's going on you feel more worried. I feel that because I don't speak English it's easy for them to ignore me, even if I have a translator."***

Participants thought that their cultural differences were not understood and were not accommodated, and this could be addressed by training staff in different cultural traditions, practices, expectations and norms.

There were examples of misunderstanding about the interpreting needs of people who were deaf. Whilst many deaf people would need a British Sign Language (BSL) interpreter, those who are deaf and blind would need might require a Deafblind Manual interpreter (a method of communicating with touch only). Participants in the engagement who needed Deafblind Manual interpretation felt that assumptions were made about their needs, and the wrong type of interpreters were booked, rather than there being difficulty in getting Deafblind Manual interpreters.

3.2 INFORMATION

Assessing the right amount of information to give people is difficult; some people wanted all the information that was available, whilst others found too much information overwhelming.

How information is delivered was considered to be important – it needs to be accessible and understandable.

LGBTQ+ parents said hospital leaflets and letters could be non-inclusive, talking about fathers only. One couple said:

> ***"This made us feel different all the time."***

Parents with disabilities said that information was not always available in formats they required such as easy read, including on how to find hospital sites and clinics.

People with disabilities might need extra time in appointments to ensure that they understand information which is being given to them.

Kosher food was not always available for Orthodox Jewish women. This could be because they were not asked if they had dietary requirements or because there was a lack of understanding about their needs.

Parents whose babies had disabilities would have liked more support and information. One parent said:

> ***"People don't speak to you. No midwife explained that having Down Syndrome could lead to your child having feeding difficulties."***

Another woman, whose first language was not English said:

> ***"No-one told me how to tell my partner. How do you tell your husband that your child has a disability? All I was given was an information sheet to take home."***

3.3 CONTINUITY OF CARE

Continuity of care from health professionals was considered to be very important by participants. Parents reported they were less anxious if they knew their midwife and/or the team who were looking after them. They also felt that seeing the same healthcare professionals meant they did not have to explain themselves each time they saw someone new.

In situations where mothers were unwell or there were complications with pregnancies continuity of care was even more important to parents – their views being that care was likely to be better and their situation better understood if they saw the same teams.

Women with mental health issues valued being seen by the same midwife throughout their pregnancies and deliveries. One woman who told that she would be on this scheme was disappointed to find out, some way into her pregnancy, that the service of having the same midwife for labour was no longer available.

Participants assumed that there would be less continuity of care in larger hospitals because of the number of staff and the high volumes of patients.

Women from Somalia said that lack of continuity of care could, for them, be a positive thing; they felt that there was a lot of discrimination against them from their experiences of maternity services, and seeing different midwives might lead to them being cared for by someone who did not discriminate against them.

3.4 TRAVEL AND TRANSPORT

Generally, people preferred maternity services which was close to home, to mitigate the need to travel for care. When people did have to travel they reported issues with travel times, the cost of travel and difficulties with finding parking spaces if they drove.

For people who felt ill during their pregnancy travel could be difficult; people cited travelling at rush hour as uncomfortable on public transport. Some people chose to walk to hospitals if they could, to overcome the problem of cost, crowding and parking.

Travel was also a consideration for people who had children; they either needed to take the children with them to appointments or have them looked after. The time needed for journeys, the difficulties of taking buggies on public transport and looking after young children were cited as issues by some people.

People who were unable to use public transport and did not have access to a car sometimes took taxis to hospital appointments, but this was costly and unaffordable for many people.

Older mothers who took part in the engagement were happier to travel than other groups of people, saying that they would prefer to travel further for their first choice of maternity care, based on previous experience or recommendations for others. One said:

> ***"Quality of service is more important to me than distance to travel."***

For parents with disabilities travel and transport could sometimes present problems. Issues such as transport not arriving, taxis or public transport not being able to accommodate wheelchairs, not having sufficient information on how to get to unknown or unfamiliar locations.

Participants from the Orthodox Jewish community said that cost and travel time could prevent people from attending appointments. These participants pointed out that their observance of Shabbat could mean that visitors would not be able to travel to visit patients if they were beyond walking distance, so care closer to home was preferred.

For people who are homeless, travel to appointments can be problematic because of their lifestyles and non-attendance is high. A specialist midwife suggested that taking services to homeless people would overcome some of the problems.

3.5 SITE ACCESSIBILITY

Parents sometimes found signage in hospitals difficult to understand, often using words and acronyms which were unfamiliar to them. One person said:

> ***"There are lots of words that you don't know what they mean – antenatal, neonatal, perinatal, NICU ward etc."***

This was especially a problem in settings parents had not visited before. Generally, once people knew their way around a hospital, they did not need to read the signs, so the language became less important.

In locations where mobile reception was poor parents said they found it difficult to communicate with partners. Some people said that their partners might be within the hospital but unable to find them because of bad reception.

3.6 NOTABLE FINDINGS ON MATERNITY SERVICES FROM SCOPED IN GROUPS WHO TOOK PART

The Start Well Programme team made efforts to engage with the full breadth of groups that were identified as potentially experiencing differential experience or outcomes. However, despite these attempts, it should be noted that not all scoped in groups took part in the engagement. We report here on the groups who did and make recommendations at the end of the report for including other groups in the consultation.

Scoped in groups	Notable findings
Age – under 20	Not included in this engagement.
Age – over 40	Women over 35 during a pregnancy were more likely to say they would be willing to travel further for maternity care – generally this was based on being able to choose a birthing site which they considered to provide high quality care or they had used before.
Disability, including long term conditions and learning disabilities	Parents with disabilities said that travelling to unfamiliar places was difficult, and often there was little information to help with this. Some parents with disabilities had problems with how staff communicated with them, and staff expectations and understanding of their needs. Information was not always available in appropriate formats. There was an instance of the wrong type of sign language interpreter being booked. Communications between maternity and social services could be improved. Staff did not always understand that people with learning disabilities might need more time for physical tasks, such as changing a baby's nappy, and also to understand information being given to them. Double appointments might be needed for some parents with disabilities.

Scoped in groups	Notable findings
	People's needs for interpreters such as BSL or Deafblind Manual were not always understood – with an assumption made that if people were deaf BSL was what was needed.
Race – Black	Somalian women reported feeling discriminated against. They thought this was because of their ethnicity and because they did not speak English. Appropriate translators were not always available.
Race – Asian	Not included in this engagement.
Race – Gypsy, Roma and Traveller Communities	Not included in this engagement.
Religion or belief – Muslim	Muslim women reported feeling discriminated against; their comments suggest that the discrimination they felt was on the grounds of race rather than religion or beliefs (see above)
Religion or belief – Jewish	Care closer to home was preferred as costs and travel time sometimes prevented people from attending appointments. Religious observance meant that patients in hospitals beyond walking distance may not get visitors during Shabbat. One advocate for the Orthodox Jewish community said that communications should be clear and easy to read. The use of technology is low within the Orthodox Jewish Community, therefore paper communications are necessary.
Sexual orientation – Lesbian and bisexual women	People reported that they had to 'come out' time and again during appointments because of assumptions about who their partner/other parent of their baby was. A lot of paperwork categorised the other parent as 'father' Participants said they felt there was a lack of inclusivity of language on information, forms and posters
Inclusion health groups including homelessness	A consultant midwife in Public Health and Education discussed homelessness. Mobile phone is the best way to contact people who are homeless. For many homeless people there are other issues to consider such as substance abuse and domestic violence. Non-attendance of appointments by homeless people is high.

Scoped in groups	Notable findings
Asylum seekers	Asylum seekers and their advocates reported difficulties in accessing services and sometimes being billed for maternity services. For some asylum seekers language can be a barrier to engaging with maternity and neonatal services.
Carers, including parents of children with disabilities or long term conditions	Parents of children with learning disabilities said that they did not get enough information about their babies' conditions or how to deal with taking a baby home to a wider family.
Those who use services who have specific vulnerabilities such as domestic violence	Specialist midwives said that they struggle to keep on top of their caseload. They see both women experiencing domestic violence and those with severe mental illnesses. Language and translation can be a problem when communicating with women experiencing domestic violence who do not speak English. People experiencing domestic violence sometimes change phones and numbers frequently to prevent partners seeing their messages. Some do not have smart phones or Wi-Fi so find it difficult to use online services or digital communications. People with severe mental illness report better experiences when there is continuity of care.
Those with experience of Female Genital Mutilation	Three people working in a specialist FGM service spoke about the experiences of their patients. A lack of joined up of services was highlighted, with people not being identified by some departments, such as A&E and some surgical departments.
Those accessing perinatal mental health services	Some people interviewed were users of mental health services, but there was no direct engagement with users of perinatal mental health services.
White non-British groups who may not speak English as their first language	Language could be a barrier to accessing maternity and neonatal services including issues such as interpreter availability.
People with poor literacy	Not specifically included in this engagement.

Through the consultation, efforts will be made to engage with people within the scoped in groups to further understand their views of proposals being put forward as part of the Start Well Programme.

4. EXPERIENCES OF NEONATAL SERVICES

Parents talked about their experiences of having babies who needed neonatal services. Some knew before their baby was born that they would be transferred to neonatal care whilst for others the need for neonatal services was unexpected, and the decision was taken after the birth.

For parents who knew they would require neonatal services being able to visit the units was important and supported an understanding of what the experience was likely to be like.

4.1 COMMUNICATIONS

There were mixed experiences of communications. Several parents praised the communications that staff had had with them whilst they were on neonatal units, and some who had experienced transfers felt they had gone well. However, others felt that with so many people involved in a baby's care confusion and miscommunication could happen, leaving them feeling stressed and anxious.

Participants praised the staff on neonatal units, saying they were supportive and made difficult situations easier to handle. One parent praised the calm and reassuring manner of staff who were imparting hard to hear information, making a difficult situation easier than it might have been.

A mother with learning disabilities said that she thought staff on a neonatal unit became frustrated with her because it took her longer than other mothers to do things such as changing her baby's nappy. She wondered whether staff understood the extra needs of people with learning disabilities.

4.2 INFORMATION

Generally, people welcomed having as much information as possible. However, one parent felt overwhelmed on the day her baby was born. She said:

> ***"On the day of birth I was told they would transfer us… you don't know if your baby will live or die and I felt It wasn't the right time. Patient transfer is traumatic, it's an uncertain time where you meet new people, new environments, new rules and guidance. Over the first few days there is a balance to not overload people with information. It's a tricky balance of how much information you need to know."***

4.3 TRAVEL AND TRANSPORT

A common theme was the difficulty of parking at hospitals. Some parents had been given parking permits but unless they arrived very early there were no spaces. For those who had to pay parking was costly.

People who used public transport found travelling after a caesarean section difficult. There were also issues for people taking their babies home if they did not have a car. One mother said:

> ***"Without a car, how do you take the baby home?... you need to get a special taxi to go home and you could be left waiting for ages. It would be good to have a list of numbers of taxis that could help with neonatal discharges."***

4.4 CONCERNS

The parents who took part in the engagement who had had to stay on a labour ward after their baby had been taken to a neonatal intensive care unit (NICU) said they found the situation distressing. They wanted to be in a different and separate environment.

Some people had worries about the staffing levels in neonatal units:

> ***"There were four to five babies in the room but only two nurses. They have to attend to everyone but can't at the same time. Three or four nurses in the room would have really helped."***

Parents said that there were problems with space in some hospitals:

> ***"The only thing is the space issue - in that neonatal unit when it was full in the bay you were in, parents were there it did become quite awkward and tight"***

4.5 IDEAS FOR IMPROVEMENT

The care babies received in neonatal units was generally praised, as was the kindness of staff to parents. The ideas for improvement were around the environment within neonatal units. Some parents experienced their babies being in neonatal units for long periods of time, and there were suggestions about some things which could be improved.

Not all units had ensuite facilities, and some parents found conditions cramped.
Parents would like facilities to be more home-like environment in neonatal units, with comfortable furniture, proper crockery and fridges, and rooms for some privacy.

5. EXPERIENCES OF EDGWARE BIRTH CENTRE

Edgware Birth Centre is a midwife-led birth centre located at Edgware Community Hospital offering services to those who have had a straightforward pregnancy with no medical or obstetric problems, and who go into labour between 37 and 42 weeks. The birth centre is staffed by midwives employed by Royal Free London and is used as a centre for antenatal care and appointments for those booked in to deliver their babies at Edgware Birth Centre or Barnet Hospital. In 2022/2023 there were 34 deliveries at the birth centre.

Given the small number of people who give birth at the site, the staff at Edgware Birth Centre were asked to support identifying some people who had given birth there in the recent past to talk to members of the Start Well team about their experiences and names of women who were happy to be interviewed were put forward by the Edgware team.

It was not possible to recruit users of the birth centre with an equalities lens; the numbers are small, the Start Well team relied on staff to find and put forward people who were willing to be interviewed and the birthing centre can only be used by people with no medical or obstetric problems, therefore people from some protected characteristics groups would not be in the cohort of service users.

All participants the team talked to who had experience of the Edgware Birth Centre praised the ambience and setting of the delivery rooms, and said that there was a more individualised approach than in hospital-based services:

> ***"It doesn't smell clinical, you feel automatically relaxed, and the staff that work there just make you feel so at ease. You have your own room and a real bed afterwards and every room has got a pool in it. It's just completely different to being in a hospital and it's just such a lovely place to give birth."***
>
> ***"I knew the birth wouldn't be rushed, I would be in charge and they would support me".***

The individualised approach and continuity of care appealed to those who used the birth centre.

> ***"I knew that from past experience, continuity of care is very important. I was looking for a place that has a home vibe where you know everyone. Other units are great, but the freestanding aspect of Edgware makes it so much more of a home from home. In a hospital you constantly feel like there is a clock ticking and you are put under more pressure to give birth. You don't get this with Edgware."***

Having antenatal appointments and giving birth in the same location was reassuring for people, who said it reduced anxiety and nervousness – parents said they trusted the staff and felt that the staff trusted them. Further, participants commented that the staff seemed to be under less pressure than in hospitals, and looked as though they enjoyed their jobs.

Generally, participants thought that the option of using Edgware Birth Centre was not promoted enough.

Parents did not report choosing the birth centre due to its proximity to their home. They did not consider travel to be a problem; some said that parking at the birth centre was easier than at hospitals.

It should be noted that the Edgware birth centre service users who participated in this work were all put forward by staff at Edgware Birth Centre, rather than being recruited from a wide pool of people, some of whom might have had different experiences.

6. BEREAVEMENT SERVICES FOLLOWING THE LOSS OF A BABY

Services for bereaved families were included in the work. A group comprising family members who had lost babies (a specialist bereavement midwife from the hospital site was also in attendance), an interview with two specialist bereavement midwives from Royal Free Hospital and Barnet Hospital and an interview with a hospital chaplain from Royal Free London were undertaken.

6.1 FAMILIES' EXPERIENCES

Families discussed the importance of having supportive staff around them when babies die. Parents talked about staff being kind and knowing how to talk to families. One person said:

> ***"Although it was harrowing for us, she said the right things and there was a lot of empathy and professionalism."***

One participant raised that they could have been given more information about the involvement of police following the death of their baby who was a few weeks old. This is standard procedure, but it was felt that this wasn't properly explained to them. They also felt that staff kept their distance from them and offered them leaflets on bereavement but no other emotional support.

The families who took part in the engagement to talk about their experiences of bereavement said there was no follow up support for them when they left the hospital; they said they were not offered counselling but were told about charities and support groups which they had to proactively contact.

Participants said that being directed to charities and private counselling services was inadequate; private sessions can be very expensive and not all could afford to go this route, and they felt there should be NHS options for following them up at home.

Within hospitals there was not always adequate space for privacy and parents were often in situations where they could hear babies crying after their own baby had died and reported being surrounded by posters with information such as about breast feeding. Participants said there should be dedicated spaces, away from maternity services, for bereaved families, preferably in settings which were not hospital like (for example, with soft furnishings and lower levels of lighting); there were also suggestions of having space where families could spend time with their babies before leaving the hospital without the pressure of others needing the delivery room.

6.2 SPECIALIST BEREAVEMENT MIDWIVES

The specialist bereavement midwives noted challenges around interpretation for families whose first language is not English. Interpretation is done via the telephone language line was thought to be very impersonal, and face to face interpreting would be better; further, some women would prefer a female interpreter, but waiting for a female interpreter can cause more distress at an already very distressing time.

Where possible bereavement teams signpost families to voluntary services according to their needs, for example, a charity which supports bereaved parents who are Muslim.
The bereavement team try to ensure that all services are informed of a baby's death so that families do not continue to receive appointments and letters, although they acknowledge that even with a robust process sometimes families do get contacted.

The midwives noted that there is a room at Royal Free London which is away from the delivery rooms and set up as a comfortable place for bereaved families to go. At Barnet Hospital there was only one bereavement room, which is used as a labour room when the unit is busy, so is not always available for women who are losing their babies.

The midwives noted that having a 'cold cot'[4] was very important.

In some Trusts specialist bereavement midwives were able to support women for up to twelve weeks after their bereavement.

It was noted that stillborn babies (24+ weeks) have to be registered which can be very traumatic for parents. During the pandemic this could be done by telephone, and the midwives suggested that this service should be available at all times to families who have lost a baby. They said that explaining the process to people who did not have English as their first language could be difficult.

6.3 CHAPLAINCY

Chaplaincy services are available across all Trusts.

A chaplain at Royal Free London explained that the chaplaincy offers a bespoke service for all parents who experience a bereavement; and a variety of spiritual and non-spiritual support can be made available. Parents are routinely given a telephone number so they can get in touch with the chaplaincy service for follow up, but onward care is expected to be provided by the bereavement midwives, rather than the chaplaincy team.

It should be noted that one participant had been offered the services of a chaplain after their baby died, but they felt offended by this because they are not at all religious, regardless of the intent to minister to people from all religions or none.

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[4] A cold cot is a refrigerated cot that allows parents to spend more time with their deceased baby than would otherwise be possible.

7. RECOMMENDATIONS FOR POTENTIAL SERVICE DEVELOPMENTS TO IMPROVE EXPERIENCES

This chapter presents recommendations for potential service developments based on findings from the pre-consultation engagement undertaken by Start Well; many of the recommendations could be considered by the local maternity and neonatal system whether there are service changes or not. The recommendations should also be considered as future service delivery is developed. The recommendations are about wider service developments rather than any specific service changes being considered by Start Well.

7.1 SENSITIVITY TO INDIVIDUALS

Throughout the engagement there were several types of sensitivity which were described as lacking: LGBTQ+ parents described being asked about their relationships; women from different cultures felt they were misunderstood or ignored or at worst felt that they were discriminated against; people with disabilities did not have their needs met; religious requirements for food were not met.

We recommend that sensitivity to individuals' needs receive much more attention. Simply asking people whether they have any cultural requirements could alleviate some of the problems, for example enabling appropriate food choices to be available, but it may require some training for staff on how to ask questions, and to expect that people might have cultural practices around maternity and birth.

Consideration should also be given to how to ask people whether they need interpreters (for languages or disabilities) and how it can be ensured that the exact needs are noted. Further, we recommend that training is given to staff on advanced communication skills to help them to both ask questions and give information in meaningful ways.

A maternity passport, containing information about the pregnant person and their needs might mitigate some of these problems.

We recommend ensuring that equality and diversity training is accessed by all staff, and that the training makes specific references to the cultural needs during pregnancy and birth.

7.2 CONTINUITY OF CARE

Continuity of care has been identified as a national priority to contribute towards reducing healthcare inequalities. It is one of the five clinical priority areas in the CORE20PLUS5 framework[5] and NCL sites are working to prioritise continuity for those most at risk of complications. Delivering this is however dependent on safe staffing levels. Since the Ockenden report[6], Trusts have been asked to review their provision of continuity of carer and prioritise minimum safe staffing[7].

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[5] https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/

[6] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1064303/Final-Ockenden-Report-print-ready.pdf

[7] https://www.england.nhs.uk/wp-content/uploads/2022/09/B2011-Midwifery-Continuity-of-Carer-letter-210922.pdf

In general people desired continuity of care and felt more comfortable seeing the same midwife and team throughout their pregnancy and birth. For some people continuity of care meant not having to explain their situations repeatedly and made their maternity experience more comfortable.

A maternity passport, mentioned above, might also go some way to improving continuity of care.

7.3 BIRTHING ENVIRONMENTS

People who used the Edgware Birth Centre described a calm homelike environment which engendered a pleasant atmosphere to give birth in. The overall feedback about Edgware Birth Centre was positive, with none of the problems described by people who had used other birthing wards.

We recommend considering how the positive aspects of the Edgware Birth Centre can be replicated in hospital settings to enhance the birthing experience of many more people.

7.4 PEOPLE WHO ARE HOMELESS

Specialists in the care of people who are homeless describe how the effects of homelessness lead to low attendance at appointments. They suggested that services should go to homeless people to mitigate some of these problems.

7.5 INFORMATION

Good information at appropriate times was highly praised, but this did not always happen. Some people did not get enough information, for example, parents of babies with disabilities, and some people were overwhelmed with too much information at the wrong time, for example, parents of babies being transferred to neonatal units. Other people got information when it was distressing, for example people who had miscarried or whose babies had died sometimes got reminders for future appointments. Further, information was not always available in appropriate formats such as easy read.

If appropriate information could be given in the right format at the right time many of these issues could be ameliorated.

8. RECOMMENDATIONS FOR CONSULTATION ENGAGEMENT

This work was undertaken with groups, representatives and advocates of groups who were considered likely to be impacted by potential service changes in maternity and neonatal care. It should be noted that the engagement did not discuss any actual potential service changes, rather it explored people's views and experiences of services.

The work shows that there are some differences in experience based on protected characteristics and other characteristics. Some groups who were scoped in were not able to be included in this engagement and we make suggestions below where we think further work could be done with some groups, to get a deeper understanding of potential impacts, and groups where there are currently gaps in the engagement.

Our recommendations, below, fit within the Core20PLUS5 (adults) approach to reducing healthcare inequalities. Core20 requires consideration of the most deprived 20% of the population, identified by the national Index of Multiple Deprivation. PLUS requires identification of populations such as ethnic minority communities, people with learning disabilities and autistic spectrum disorder , people with multiple long-term health conditions, other groups sharing protected characteristics as defined by the Equality Act 2010 and groups experiencing social exclusion. Inclusion health groups include people experiencing homelessness, drug and alcohol dependence, vulnerable migrants, Gypsy, Roma and Traveller communities, sex workers, people in contact with the justice system, victims of modern slavery and other socially excluded groups. 5 refers to five clinical areas of focus: maternity, severe mental illness, chronic respiratory disease, early cancer diagnosis and hypertension case-finding and optimal management and lipid optimal management.

We recommend that the engagement for the consultation be undertaken using materials specifically designed to explain sometimes complex potential changes as simply but as completely as possible to enable all participants to fully discuss potential on them. Such engagement will enable an understanding of where differential or disproportionate impacts are likely to come into play and what might help to offset those impacts.

8.1 YOUNGER MOTHERS – AGED UNDER 20

This group is shown to have disproportionate adverse maternal outcomes. They were scoped in for engagement but were not included as a specific group. We suggest that the consultation ensures that their views are heard.

8.2 OLDER MOTHERS – AGED 35 AND OVER AT TIME OF GIVING BIRTH

Some mothers aged 35 and over took part in the engagement, and their views differed somewhat from those of other participants, for example, they tended to find travelling further less burdensome than other groups. However, it may be that their views were influenced not just by their age but by other factors such as socio-economic situation. We suggest that for the consultation a wider and more diverse group of older mothers are included to ensure that a full range of views are heard.

8.3 RACE/ETHNICITY

People reported perceiving negative differential treatment based on their race or ethnicity. We suggest that work is undertaken through the LMNS to probe much more deeply on these issues to ensure that future provision can be planned to take account of the issues raised. Not only did some people feel that their race, ethnicity or skin colour made a difference to how they were treated, there were examples of not having appropriate interpreters and cultural differences not being understood.

We suggest that efforts be made to include Gypsy, Roma and Traveller communities and Asian communities in the consultation.

A deeper understanding would help to improve services for these groups .

8.4 DISABILITY

This work included parents with disabilities and parents of children with learning disabilities. Specialist midwives with a brief for severe mental illness discussed the needs of their patients. We suggest that the consultation includes engagement with people with a wide range of disabilities including (but not exclusively):

- Physical disabilities
- Long term conditions
- Fluctuating or recurring conditions such as rheumatoid arthritis and fibromyalgia
- Sensory disabilities including deafness, blindness and people who are deaf and blind
- Neurodiversity
- Mental health conditions and illnesses

Exploring the needs of people with a wider range of disabilities will ensure that the impacts of service changes are better understood, and mitigations can be developed. Where possible we recommend engaging directly with people with disabilities, rather than with advocates, to ensure that their voices are heard, and their needs understood.

8.5 SOCIO-ECONOMIC DEPRIVATION AND ASSOCIATED VULNERABILITIES

This worked has touched on some issues relating to socio-economic deprivation, including the cost of travelling to appointments, or to visit babies in neonatal care and issues around digital exclusion. We recommend that more work be undertaken with people who are homeless and people who are drug or alcohol dependent to ensure their voices are heard and understood, and what the impacts of service change might be for them. The consultation should make efforts to include sex workers in the engagement.

Specialist midwives took part in this work, whose work involved domestic violence, homelessness and female genital mutilation. Accepting the sensitivities around these areas, if possible, we suggest that the consultation engages directly with people experiencing these issues to get firsthand accounts of the potential impacts of service changes. A deeper understanding will be needed to begin to develop mitigations for these groups.

8.6 CARERS

The engagement talked to some parents who had children with disabilities. To get a wider understanding of the impacts for carers we would suggest including carers of adults with extra needs and parents caring for a wider range of children with extra needs.

8.7 WOMEN WHO HAVE EXPERIENCED FEMALE GENITAL MUTILATION

Advocates were included in the engagement. We suggest that, if possible, the consultation seeks first-hand accounts from women who have experienced FGM to understand at a deeper level how service changes might affect them.

8.8 USERS OF PERINATAL MENTAL HEALTH SERVICES

We suggest this is an important group to include in the consultation to understand what the specific impacts of service change would be for them.

8.9 PEOPLE WITH POOR LITERACY

People with poor literacy may struggle to understand written communications. We recommend that the consultation should seek to understand the specific needs and the potential impacts of service change for people with poor literacy. We suggest that the consultation should go beyond speaking to advocates, to gain firsthand accounts from people.

9. APPENDICES

9.1 TABLE OF CONTACTS MADE

The programme made significant efforts to contact a range of residents and organisations to be part of the engagement reported:

- In total, 93 different organisations were contacts to set up engagement opportunities
- Targeted social media posts were used to encourage older mothers and LGBTQ+ people to participate in the engagement
- Trust clinical and patient experience teams supported with identification of service users and staff who participated in the engagement

9.2 TABLE OF ENGAGEMENTS

Engagement with service users	**Number of events**	**Total number of attendees**
Online discussion groups or interviews with women aged 35+	5	8
Online discussion groups with Jewish women convened by charities in North Central London that support Jewish families	3	17
In person discussion group with women at a community centre in Islington who support vulnerable people including asylum seekers	1	8
Online discussion group convened by a Camden and Islington based charity that supports African communities	1	7
In person discussion group with parents of children who have learning disabilities and autism convened by a Barnet-based charity	1	5
One to one interview with an advocate for parents who have learning disabilities and autism	1	1
In person discussion group with parents who have learning disabilities	1	5
Interviews or online discussion groups with women who have given birth at Edgware	3	5
In person discussion group at a Haringey based community centre who support people who originate from outside the UK	1	22
Online discussion group with parents who have experienced bereavement	1	7
Online discussion groups with parents who have had recent experience of neonatal care across NCL sites	9	18
Online discussion groups facilitated through a charity that supports LGBT+ parents	2	4
In person discussion with parents who are deaf and deafblind	1	2
Online discussion with parents who are seeking asylum facilitated through a charity that supports those seeking asylum	1	2
In person discussion group with parents of Eastern European background	1	2

Engagement with specialist staff		
Online interview with a hospital chaplain who supports women who experience bereavement	1	1
Online interview with a midwife who supports vulnerable women with a focus on women who are homeless	1	1
Online discussion group with clinicians who support women who have experienced female genital mutilation (FGM)	1	3
Online discussion groups with midwives who support women who have experienced domestic violence or have severe mental illness	2	4
Online discussion group with specialist midwives who support women who have experienced bereavement	1	2

9.3 TOPIC GUIDES

Two topic guides were used by the Start Well team to guide their conversations with participants. The first is a general topic guide, used for most discussions, the second is a topic guide used for discussions about Edgware Birth Centre. At the start of all discussions, participants were informed that notes would be taken of the discussions and themes recorded but that the discussion would be anonymised and nothing attributed to individuals that took part in the discussion.

9.3.1 GENERAL TOPIC GUIDE

- **Introduce meeting**
- **Ground rules**
- **Find out about contributors to get a sense of their background**
    - Where they live
    - What their local hospital is
    - Have they used maternity services?
    - Neonatal services?

Travel and transport
What do you think the impact on pregnant people would be of needing to travel further or somewhere different for maternity care, and therefore neonatal care should it be needed?
Change in journeys due to site changes:

- Is travel time to receive maternity care important to you?
- Is there a difference between travel time for appointments and travel time once you are in labour?
- What if your journey to receive care was longer?
- What is the maximum amount of time you think it would be reasonable to travel for maternity care?
- What if it was more expensive?
    - what would make it more expensive? If people didn't have travel cards? If people were driving and it was a longer journey? If parking was more expensive?
- What if it was more complicated for example there were multiple bus changes?

For those with experience of neonatal care:

- Is travel time important when thinking about neonatal care?
- What would the impact of longer journey times be on you as a parent?

Possible other areas for exploration:

- What might the impact of this be on birthing partners?
- Is there a different impact if you have children already? If people already have children what the impacts would be that are different from those for people with no other children.
- What might the impact be if you are carer?

Mitigations:

- How might you mitigate any of the impacts you have identified with travel and transport?

Information and communication

Thinking about your own experiences, what worked well or not so well with the communication between you and the maternity service? Why was this?

By information we mean:

- Information about appointments
- The way hospital staff communicate with you
- The way medical information about you is shared with you
- The way you are able to communicate your preferences around your maternity care

Areas for exploration

- How would you like to receive medical information about your pregnancy?
- What if you were to receive information via email?
- What if appropriate appointments were virtual?
- What if your first language wasn't English, or you have other communication needs?

For those with experience of neonatal care:

- What worked well and not so well about communication with you about your baby while they were in the neonatal unit?
- Were you able to easily find out information about your baby while they were in the neonatal unit? What made that easy / difficult?
- Is there anything that the NHS could have done to make this better?

Continuity of care

How important do you think it is to see the same midwife or team throughout maternity care? Why do you think this?

Depending on answer, probe questions could include:

- Why do you think this? How did this affect your care? Why is it important?
- Probe for examples from different groups (prompt: such as those with long term conditions, disabilities, people from different ethnic backgrounds)

Accessibility of a site

Explore whether the group think there would be any issues for people needing to go to a hospital they don't know for maternity care. What might be the problems for people?

Prompts:

- What is important about the environment or accessibility of the site where you receive maternity care?
- Are there different factors that are important for your antenatal care compared to when you are giving birth?
- What would make finding their way around a hospital easy / difficult
- How could signage help
- What would help people with mobility problems
- What would help people with conditions like autism

For those with experience of neonatal care:

- What is important about the environment or accessibility of the site where your baby is admitted to a neonatal unit?

Other factors to consider

- Are there any other impacts that the NHS should consider when thinking about making changes to maternity / neonatal services?

9.3.2 TOPIC GUIDE FOR DISCUSSIONS ABOUT EDGWARE BIRTH CENTRE

- **Introduce meeting**

Edgware discussion framing points

- The NHS in North Central London is working to improve maternity care in the region through undertaking a review of current services
- This includes speaking to people about their experiences of care
- One of the areas that we want to gain a better understanding of is the Edgware Birth Centre as currently, a very small number of women are choosing to give birth there
- We are speaking to patients who have experience of giving birth there to understand:
    - What drove their decision to choose to give birth at Edgware?
    - What their experience was like and what aspects of that experience were most important to them?
    - Understanding what other choices people might make should Edgware no longer be an option to have their baby, and what impact this would have?

- **Ground rules**

- **Find out about contributors to get a sense of their background**
    - Where they live
    - What their local hospital is
    - Understand in what capacity they have used Edgware - did they give birth there? Did they have their outpatient appointments there?
    - When?

Choice of Edgware

- How they came to know about the option giving birth at Edgware?
- Gain an understanding of reasons for choice of Edgware…
    - Proximity to home?
    - Recommendation from friend / relative?
    - Desire for midwife-led birthing experience
        - Reasons they chose Edgware over an alongside midwifery-led unit
        - Is the separation from a main hospital site something that was important to them?
        - Reasons they chose Edgware over home birth

Experience of Edgware

Gain an understanding of experience of giving birth at Edgware:

- Did they see the same midwife and team antenatally?
- What was their birthing experience like?
- What aspects of their care had an impact on their experience?
    - Environment?
        - What specifically about the environment had an impact?
    - Staff?
        - What specifically about the staff had an impact?
        - Why did it have this impact?
    - How care was delivered? -
        - What specifically about the way care was delivered had an impact?
        - Why did it have this impact?
    - Anything else?
        - What about this had an impact?
        - Why?
- What was the most important aspect of their experience care that made a difference to them?
    - Why?

- Is there anything that they would change or want to improve?
    - Why?

Understanding of other options

- If they were considering alternative options, what would be their preference? - e.g., different midwifery-led unit, standalone MLU in another area, home birth?
- What would the impact of that choice be on…
    - Travel - is that important in choice of maternity care?
        - What would change for them?
    - Birthing environment
        - What aspects of the care that was delivered at Edgware should be replicated in other birth settings - e.g., in an alongside MLU?