



Leeds Inpatient Maternity and Neonatal Services Reconfiguration Review.

Summary of Service User Engagement
and Patient Experience review.

Pre Engagement Phase
September 2013

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Introduction

Maternity is often called the NHS's 'shop window', with services used by over 700,000 families in England every year. Having a baby is the single largest reason for admission to hospital and the experience families have during pregnancy and postnatally often colours their long-term health and wellbeing and their use of health services.

Commissioning Maternity Services; A Resource Pack to support Clinical Commissioning Groups
NHS Commissioning Board. July 2012

Each year around 10,000 women give birth in Leeds and approximately 1,800 babies require neonatal care (specialist care after birth). The birth rate has increased significantly over the past few years and although there is evidence that this is beginning to level off, the number of complex births is on the rise, not just in Leeds but across the whole country.

Leeds Teaching Hospitals NHS Trust (LTHT) currently delivers a range of maternity and neonatal services on both the St James's University Hospital site and at Leeds General Infirmary (LGI). LTHT have been looking at how they might deliver maternity and neonatal services to meet the needs of mothers and babies in the future. One change that is being considered is to move all the inpatient maternity and neonatal services to one modernised unit at LGI. (For more information on the changes being suggested please see Appendix A).

NHS Leeds South and East Clinical Commissioning Group (CCG) is responsible for making sure that the right NHS maternity services are in place to meet the needs of local people and NHS England (South Yorkshire and Bassetlaw Area Team) is responsible for making sure that the right neonatal services are in place. Together they have been working with LTHT to carry out a review on behalf of people in Leeds and surrounding area to make sure that any changes meet the needs of all women and families in the area and provide the safest and most effective care.

The review has been planned to cover three distinct phases: Pre engagement, Formal Consultation, Post-consultation. The pre engagement phase took place between June and August 2013 and provided an opportunity for LTHT, the CCG and NHS England to share emerging ideas and get local views on them to help shape the final proposals. It was also an opportunity to prepare for the full consultation by

- Collating evidence of people's experiences to be used as a baseline before any changes are made to the services.
- Gathering more detail to inform the stakeholder analysis and the communication and engagement plan for the project.
- Identifying what issues there might be for different groups within the community to inform the equality impact assessment for the project.

This report is a summary of the pre engagement phase of work. It includes details of what is in place to collect feedback about people's experiences of maternity and neonatal services in Leeds and what it tells us, a description of the methodology and results of the pre engagement survey, a summary and recommendations.

Section 1:

What information was already available about the people who use the LTHT maternity and neonatal services?

- 85% of Leeds residents having a child choose to use the LTHT maternity service.
- The proportion of people giving birth at St James's and LGI is fairly similar – there are around 450 more births at LGI each year.
- More than 41% of births at St James's Hospital are to mothers who identify themselves as non-British compared to 25% at the LGI. There is particularly high representation of African and Pakistani ethnicities compared to those giving birth at LGI.
- There are also an increasing number of people from Eastern European communities using both services.
- According to Leeds Language Link, the most requested alternative languages at St James's during 2012/2013 were Polish, Kurdish, Czech, Urdu closely followed by Tigrinya and Arabic.
- The Lesbian and Bisexual Consultation for NHS Leeds in 2009 highlighted that many lesbian and bi sexual co-mothers felt services were not fully meeting their needs and information and support tends to have a bias towards heterosexual couples. Similar results are cited in a larger national study reported in the Journal of Nursing in 2009.
- Women from south Leeds and west Leeds are overwhelmingly more likely to deliver at LGI. People from east Leeds are more likely to deliver at St James's. People from north Leeds are slightly more likely to deliver at St James's.
- Data shows that people from non-deprived areas are much more likely to deliver at LGI than St James's. People from deprived areas are fairly evenly likely to deliver at both hospitals.
- 15% of people using maternity care at LTHT do not live in Leeds and over 50% of those using neonatal services.
- The age profile of women giving birth at each hospital site is similar. This is not true for outpatient appointments where more women over 35 used St James's and more women under 35 attended LGI.
- Around 55% of births at St James's Hospital are to women under 30 and around 6% to women under 20. At LGI 49.7% of births are to women under 30 and around 5.6% are to women under 20.
- It has not been possible to gather data on the numbers of disabled women using maternity services.
- The 2007/09 Maternity Health Needs Assessment for Leeds identified the need for specific maternity care pathways for teenage mothers, people with learning disabilities and disabled women and work is ongoing to improve these.

Section 2.

Overview of Existing Patient Experience Data.

What is already in place to collect feedback about people's experiences of maternity and neonatal services in Leeds?

Service user feedback is currently collected by LTHT via:

- Comments slips given to Mothers on discharge, returned and collated by one of matrons
- Complaints process
- PALS services (LTHT and Commissioners)
- The CQC maternity survey (every 2 years)
- Maternity Services Liaison Committee (MSLC)
- Neonatal patient stories project

Other sources of information;

- Patient Opinion
- NHS Choices
- Web based forums and social media sites

There have also been a number of projects in Leeds that have identified specific aspects of patients and their family's experiences:

- Homebirth group - Availability of midwives study (2012)
- NHS Leeds LGB survey (2009)
- Maternity needs assessment (2007)
- Fathers and Fathers-to-be Insight Development Project- feedback report (2012)

What do they tell us about people's experiences?

In order to understand the experiences of those who use maternity and neonatal services - the above sources of patient experience information have been collated and reviewed. The review focussed predominantly on the period between April 2012 and March 2013 although there are some examples from outside this period. A summary of this information is below.

2.1 Comments slips and LTHT website feedback.

A total of 21 responses were received on the tear off comments slips given to women with their notes on discharge from hospital, by midwives following home deliveries and via the patient feedback form on LTHTs website. The feedback was received between June 2012 and January 2013. A breakdown of the responses is included in Table 1. Some of the feedback referred to either a particular hospital site or home birth. Those without any reference are also noted accordingly in the respective heading.

Table 1: Summary of feedback from maternity service comments forms		
Site	Positive comments	Negative experiences
LGI (6 responses)	Three very positive reviews of the midwives and staff. Positive feedback about kind and supportive staff throughout a difficult birth. Positive feedback about medical team and midwives care and support through C-section.	One concern about the number of different midwives seen at home following discharge.
St James's Hospital (5 responses)	Positive feedback from grandmother on behalf of her daughter regarding staff on the delivery suite during difficult birth. One positive response regarding medical care in the antenatal unit. One very positive review of the medical team who performed C-section. Two positive comments about midwives during birth. Positive comments about the delivery suite environment- clean, spacious and comfortable and en-suite shower. One positive comment about staff during antenatal inpatient care.	One negative comment about lack of parking close to the delivery suite.
Home Birth (5 responses)	Five positive responses regarding care by midwives during delivery.	One negative comment regarding having to take the baby out in freezing fog for head to toe health check.
No place of birth mentioned (4 responses)	Two positive responses regarding care by midwives and staff.	Two negative experiences; 1. Lack sensitivity and understanding of midwife following stillbirth and incorrect completion of death certificate. 2. Poor wound care and lack of communication between staff about medication used.

The majority of feedback received was positive and the word cloud below shows the key words from the feedback. The main theme was that people valued friendly, caring, helpful and professional midwives and staff. Where particular staff or teams are mentioned this is fed back directly to them by the matron who collates the comments. She also investigates further where more serious concerns are raised.

Over half of all the complaints received related to medical care and a quarter to nursing care. Communication was also one of the primary subjects on both sites (see Table 3). There were no complaints about the facilities or environment at either site.

Table 3: Maternity services complaints grouped by subject and site.

A. Obstetric complaints grouped by Top Five Primary Subject

LGI		St James's	
Medical Care	11	Medical Care	19
Nursing Care	9	Communication	6
Communication	4	Nursing Care	7
Attitude	1	Attitude	1
Drug Issues	1	Discrimination Issues	1

B. Obstetric complaints grouped by Top Five Primary Sub-Subjects

LGI		St James's	
Clinical treatment - medical	10	Clinical treatment - medical	19
Clinical treatment - nursing	8	Lack of info/clarity to patients	6
Lack of info/clarity to patients	3	Clinical treatment - nursing	7
Nursing staff attitude	2	Lifestyle discrimination	1
Lack of info / clarity to relatives	1	Nursing staff attitude	1

2.2.2 Neonatal service complaints

Nine complaints were received about neonatal services by the LHT customer relations' team between 1 April 2012 and 31 March 2013. Of these six were about services at St James's and 3 about LGI services.

Roughly half of the complaints made were by women. There was only one complaint received from someone who described their ethnicity as mixed white and black African, 2 where it was not stated and all other complaints came from people who were White British.

Although there were only a small number of complaints half of those received relate to medical care with staff attitudes being the second most common theme (see Table 4).

Table 4: Neonatal services complaints grouped by subject and site.

A. Neonates grouped by Top Five Primary Subjects

LGI		St James's	
Attitude	1	Medical Care	4
Communication	1	Attitude	1
Medical Care	1	Nursing care	1

B. Neonates - Complaints grouped by Top Five Primary Sub-Subjects

LGI		St James's	
Lack of info/clarity to patients	1	Clinical treatment - medical	4
Medical staff attitude	1	Nursing staff attitude	1
Clinical treatment - medical	1	Clinical treatment - nursing	1

2.3 Patient Advice and Liaison Service (PALS)

There are two PALS services that people may contact about their experiences of maternity and neonatal services in Leeds:

- LTHT PALS service
- PALS run by commissioners. For the period of time reviewed the PALS service was run by NHS Leeds which no longer exists but is now hosted by West South Yorkshire and Bassetlaw Commissioning Support Unit (WSYBCSU).

Feedback from both PALS services is included here.

2.3.1 LTHT PALS summary.

Two separate PALS reports were received from LTHT. The first was produced for the maternity service as part of their governance process. It covers June to Oct 2012 and includes only maternity services. The second was produced specifically for this piece of work, covering 1st November 2012 to 31st March 2013 and includes maternity and neonatal services on both sites.

A summary of the two reports is included below:

- **Maternity services.**

Between June 2012 and March 2013 there were 44 PALS concerns raised. 26 of these were about services at St James's and 17 about LGI.

Some examples of the type of concerns raised about LGI are;

- Lack of antenatal care
- Issues arising at child birth
- Difficulty contacting department and attitude of clinic clerk
- Complaint letter not acknowledged
- Clinic Clerk attitude
- Issues about care during and after birth

Some examples of the type of concerns raised about St James's are:

- Care around birth of baby
- Doctor's attitude
- Early Cord Clamping
- Attitude of Midwife
- Cancelled appointment without notice
- Delay in giving scan
- Medical care during labour and antenatal care
- Lack of care
- Unhappy not being able to have a Caesarean

A summary of these concerns can be seen in Table 5. The main theme across both sites is medical care and medical treatment, followed by staff attitude, communication issues and lack of information.

Table 5: Maternity services PALS concerns grouped by subject and site (Nov- March 13)

A. Maternity – PALS concerns grouped by Top Five Primary Subjects

LGI		St James's	
Communication/Information/Attitude	3	Medical Care	5
Medical Care	2	Communication/Information/Attitude	4
Attitude	1	Attitude	2
Cancellations/Waiting Lists/Waiting Times	1	Care, Nursing Care	2
		Waiting Times	1

B. Maternity - PALS concerns grouped by Top Five Primary Sub-Subjects

LGI		St James's	
Clinical treatment - medical	3	Clinical treatment - medical	8
Lack of info/clarity to patients	1	Nursing staff attitude	3
Inpatient Waiting lists	1	Communication Issues	2
Communication Issues	1	Medical Staff Attitude	1
Nursing staff attitude	1		

- **Neonatal services.**

Only three PALS concerns about neonatal services were logged between November 2012 and March 2013 and these were **all** about services at LGI. See table below for the subjects.

Table 6: Neonates PALS concerns grouped by top Five Subject and top Five Sub-subject:

Top Five Primary Subjects (LGI)		Top Five Primary Sub-Subjects (LGI)	
Care, Nursing Care	1	Lack of Adequate Staff/Facilities	1
Communication	1	Medical staff attitude	1
Medical Care	1		

2.3.2 West, South Yorkshire and Bassetlaw Commissioning Support Unit (WSYBCSU) PALS

A brief review of the feedback received by the Leeds PALS service since it has been hosted by WSYBCSU shows five entries recorded since WSYBCSU began hosting the PALS service (July – August 2013) directly relating to Midwifery and neonatal care in Leeds.

- Three related to LTHT (no specific hospital mentioned) regarding insufficient or badly managed care / advice.
- One complaint regarding planned home birth and subsequent hospital admission (LGI)
- One request for access to birth records (LTHT)

2.4 Care Quality Commission (CQC) - Maternity Services Review 2010.

The CQC Report 2010 presents the results of the second survey of maternity services provided by NHS Trusts in England. It shows how each Trust scored on a number of questions in the survey, compared with the national average results. The report enables an understanding of the Trust's performance, and identifies areas where it needs to improve. The report is not broken down by each of the specific hospitals (LGI and St James's).

The following areas were scored against other Trusts' performance as either 'worse' or 'better':

- Care during pregnancy (Antenatal Care)
- Labour and birth
- Staff during labour and birth
- Care in hospital after the birth (Postnatal care)
- Feeding the baby during the first few days

In general LTHT scored 'better' than Trusts in all other areas, although there was a trend towards the 'worse' end of spectrum for specific areas including:

- If you had a cut or tear requiring stitches, how soon after the birth were the stitches done?
- Looking back, do you feel that the length of your stay in hospital after the birth was appropriate?
- After the birth of your baby, were you given the information or explanations you needed?
- After the birth of your baby, were you treated with kindness and understanding?
- Did you feel that midwives and other carers gave you consistent advice (over feeding advice)?
- Did you feel that midwives and other carers gave you active support and encouragement (over feeding advice)?

81 % of respondents to the CQC maternity survey review 2010 identified themselves as White British.

The results of the latest CQC survey are due to published later this year. A sample of mothers, who gave birth in Leeds during February 2013, received surveys during June and July.

2.5 Patient Opinion

Ten comments were received about maternity services in Leeds on the Patient Opinion website between April 2011 and March 2013. Four of these were about LGI and six about St James's and whilst some were entirely positive or negative, some were mixed picking out positive and negative experiences. Many of the negative comments relate to staff attitude and availability of staff and the positive comments relate to the quality of the staff and their kind and compassionate care. There were **no** stories posted about neonatal care at either St James's or LGI in the past 2 years. A summary of the responses is in Table 7 below:

Site	Positive comments	Negative experiences
LGI maternity care (4 responses)	Positive feedback about the delivery suite staff. Grateful for kind and compassionate inpatient care.	2 negative experiences of lack of antenatal care. 1 negative experience about lack of postnatal care for mother on the ward. A negative comment about environment and cleanliness of facilities. 1 describing a lack of postnatal care after miscarriage.
St James's (6 stories)	3 very positive comments about excellent care and expressing thanks. 1 describing the delivery suite midwives as fantastic.	1 extremely negative experience after being transferred to St James's because LGI was shut - horrendous and would never use St James's again (inconsistency of midwives, lack of staff, disorganisation) 1 insensitive handling of miscarriage. 1 dismissive attitude of maternity assessment unit staff when in labour.

2.6 NHS Choices Website

In total, eight reviews of maternity services in Leeds were posted on the NHS Choices website between November 2011 and January 2013. These were free text reviews. Four stories were about the LGI and four stories were about St James's.

- **LGI (four stories)**
 - Two positive reviews of midwives and staff
 - One negative review of inconsistency of midwifery support
 - One negative review of wound care following C-section and little support for breast-feeding.
 - One negative review regarding contacting the Maternity Unit and poor website information (response to this included confirmation that website would be checked).
- **St James's (four stories)**
 - Three positive responses regarding midwives and staff
 - One negative response – 'would not go to St James's again'

2.7 Social media and web based discussion forums:

Discussions about maternity and neonatal services in Leeds on discussion groups and social media sites in the past couple of years have been about:

1. Choosing between LGI and St James's- (several net mums discussions on this topic)
2. Unit closures (Twitter)
3. Shortage of midwives (Twitter)
4. Sharing experiences of services and gaining support and information about options for giving birth and services available. (Facebook groups like Leeds Home Birthers And Hopefuls, Bliss discussion board, iWantGreatCare, netmums)
5. The TV series One Born Every Minute filmed at LGI.

Figure 2: Snapshots of social media/ web based discussions about maternity and neonatal services.



2.8 Review of Availability of Midwives for Homebirths in Leeds (2008-13)

A survey about the availability of midwives for homebirths was carried out between 10 – 22 January 2013. It was an online survey circulated via members of the Leeds Homebirth group. This is a brief summary of the survey's findings;

- 72% of women warned that there maybe no homebirth midwife available, and 44% of women were concerned about this in advance.
- 27% of women were told a midwife was not available for homebirth when they called in labour. Of those who were told a midwife was available, 25% felt s/he did not arrive when expected.
- Reasons given for non-availability were
 - Hospital too busy (35.71%)
 - Another homebirth taking place at the same time (50%)
 - No reason given (21.43%)
 - Other (21.43%) (e.g. Person taking call did not seem to know the procedure for calling out the homebirth team)
- 66% of women who were told there were no midwives available felt affected by this (during labour).
- 31% agreed to go to hospital, 46% insisted that a midwife come (and presumably the midwives did), 23% responded 'other'.

This study highlights concerns about the availability of midwives for homebirths and the impact this has on women. The full report also includes lots of other really interesting information about women's experiences of homebirth's, however this detail is not included here as the focus for this project is on inpatient services.

2.9 Lesbian and Bisexual Consultation (NHS Leeds) January 2009

In this 2009 consultation postnatal, antenatal and fertility services were the services most commonly used and spoken about. Given the significant and growing number of lesbians having and wanting to have children, it was clear from the findings that NHS services were not fully meeting the needs of lesbians and bisexual women. It found that information and support specifically aimed at lesbians was not available; publicity and information tended to have a more heterosexual bias. The needs of the non-pregnant partner were also not being met at a time when partner support is vital, especially around things like supporting breastfeeding and postnatal depression support. The consultation also highlighted difficulties around accessing antenatal classes which resulted in a lack of information about birth options, pain relief and choices, which in turn had a negative effect on the physical and emotional wellbeing of the mother.

2.10 Maternity Needs Assessment

The Maternity Needs assessment was carried out by NHS Leeds in response to the Dept of Health document *“Maternity Matters: Choice, access and continuity of care in a safe service (2007)”* which set a requirement for Primary Care Trusts to undertake strategic needs assessments of maternity care for their population. The report brought together information gathered from a variety of local and national sources and stakeholders, to give an overview of a wide range of issues affecting maternity services in Leeds at the time. It included:

- Local demographics – an overview of the local population along with information on trends in births and maternity outcomes for the city.
- Maternal factors – describing the population of new mothers in Leeds, and report on factors which can influence outcomes such as smoking, obesity and substance use.
- Vulnerable groups – brought together available information on mothers from potentially vulnerable groups in Leeds, where possible including national and local information on the experience of maternity services, specific maternity health needs and outcomes.

This report has been used to help identify some of the groups we needed to engage with and to inform the equality impact assessment. However it is several years old and many of the recommendations have resulted in changes to practice or service developments so it does not necessarily reflect current needs. Plans are already in place to update the needs assessment.

2.11 Father’s to be project 2012

The Fathers and Fathers-to-be insight development project was initiated as a result of recommendations from the Leeds ‘Reducing Infant Mortality Demonstration Sites’ Evaluation Report which recommended that further work should be developed to support men in the antenatal period. This project explored the specific experiences of fathers and fathers-to-be from a Pakistani background who were engaged with through the religious setting of a mosque. The insight was collected with a view to develop new resources if required or feed in to citywide antenatal education work planning. There was little evidence to suggest that Pakistani fathers needed significantly different information to that of other white British UK fathers (although different languages and formats might make information more accessible). It recommended that information for fathers needs to recognise the importance of explaining terminology related to pregnancy, child birth and fatherhood. Another finding which is of relevance to the consultation strategy is that community buildings such as mosques are used frequently by Pakistani fathers and fathers-to-be and should be seen as a useful resource for sharing information with this community.

Summary of Existing Patient Experience Information

On the whole there is a great deal of positive feedback about neonatal and maternity services via surveys, on websites and via comments cards.

Where negative feedback or complaints have been received there have been slightly more about St James's site for both maternity and neonatal services over the past 12 months. The exception to this being PALS feedback for neonatal services where there were no concerns logged about services on the St James's site. However it must be noted that this is based on relatively small numbers.

The themes from this review of patient experience are:

- Staff attitude - it is clear from all the sources of information reviewed that people who use maternity and neonatal services value caring, compassionate, professional and supportive midwives and staff very highly, and the attitude of staff has a significant role in making their experience positive or negative.
- Concerns about numbers of staff - concerns over the number of midwives in Leeds have been reported in the local news and picked up by people on social media, as have the number of times units are closed in Leeds. Some people also refer to a lack of staff having an impact on their care and resulting in long waits. There is also some evidence of the availability of midwives to support homebirths being an issue.
- Lack of information and communication is also a recurring theme. 'Being given the information or explanations you needed' was picked up as an area for improvement in the last CQC survey for maternity services and continues to appear in complaints, PALS and some of the online patient stories.
- Medical care - a significant number of complaints and PALS concerns related to medical care and medical treatment received. The reports received did not go into any detail about the nature of the complaints so further information would be needed before it was possible to see if there were any trends within these.
- There is an absence of feedback from some of the main ethnic groups who use these services. Disabled women and young mothers are also under represented in the feedback via existing mechanisms.
- Choice over site to give birth - there is evidence that women find it difficult to choose between the two hospital sites reasons cited include there is no real difference between what the two offer, they both work as one service and the number of closures means that there is a chance that people could be transferred from one site to another.
- Choice over birthing options - there is a lot of discussion on the internet about the options available for giving birth in Leeds. There is a particularly active homebirth network in the area and an increasing interest in other active birth options can be seen online.

In putting together this review it was noted that whilst there are lots of places where feedback is collected the full range of patient experience information about maternity and neonatal services does not appear to be routinely collated, analysed and reported in one place or evidence of how the voice of people who use the service has been used to inform the proposals made by LTHT. The Trust will be introducing real time feedback in the form of the Friends and Family test into maternity services later this year and this could provide an opportunity to review how the full range of feedback is analysed and routinely used by the maternity service and commissioners in the future.

Section 3:

Pre engagement survey methodology and results.

3.1 What did we do?

A survey consisting of eight questions was designed to

- Find out more information about people's experiences, particularly those who were under represented in existing patient experience feedback.
- Collect views on the proposed changes to maternity and neonatal services from those who are most likely to be affected and those from protected groups under the Equality Act (2010)

The survey was developed with a group of service user representatives nominated by the Maternity Services Liaison Committee (MSLC) which is a local forum for maternity service users, providers and commissioners of maternity services to come together to advise on developments in maternity services, and reviewed by Leeds Bliss (Bliss is a UK charity working to provide the best possible care and support for all premature and sick babies and their families).

The survey can be seen in Appendix A. It was **not** intended to be a formal research tool.

The survey was made available to be completed as

- A paper based questionnaire with freepost envelopes, which were handed out to relevant people or posted to those who had used services and lived out of Leeds.
- A web based survey (the link was circulated via email or relevant social network groups and included on the paper survey).
- Facilitated one to one interviews or group discussions.

We had face to face contact with over 350 people in Leeds and posted out 1000 to those who used services in the past 12 months but live out of area (not in the three Leeds CCGs postcodes). The responses received were then analysed by an independent market research agency (see full Enventure analysis report in Appendix B and the summary of additional responses in Appendix C) before being summarised in this report.

3.2 Who did we ask?

The aim was to collect views from a range of people who had recently used maternity and neonatal services in Leeds and who may be affected by the changes being proposed. This included those living in the geographical areas where people are most likely to use St James's maternity services and those from protected groups under the Equality Act 2010.

Therefore we approached specific groups, centres and services to gather views during June and July (a full list of places/ groups attended or contacted is in Appendix D). Surveys were also posted to people who had used maternity and neonatal services in the past 12 months and lived out of the Leeds area, along with a prepaid envelope.

The surveys were translated into Polish, Urdu and Tigrinya (with option to translate into any language or format) and responses were received in Polish and Urdu.

3.3 Who responded?

- 486 responses were received in total. 453 were analyzed initially and the outstanding surveys were reviewed separately and a summary of this is included on Appendix C.

- Of these responses 73% came from people in Leeds and 17% were returned by people from out of the three Leeds CCG areas. The results were analyzed as a whole and then split up into those 'in area' and those 'out of area'.
- Only 65 people completed the survey online and these were mainly white British females aged 24-35. All other surveys were completed on paper and either handed to one of the team or returned in a prepaid envelope.
- Over half the respondents provided names and addresses for future contact or ongoing involvement in the project.
- Most people completed some or all of the equality monitoring form. Of the 486 people who responded the number of people who completed each section is as follows;

Gender: 434	Age: 447	Ethnicity: 432	Sexual orientation: 418
Religion: 425	Disability: 431	Carer: 415	Relationship status: 406

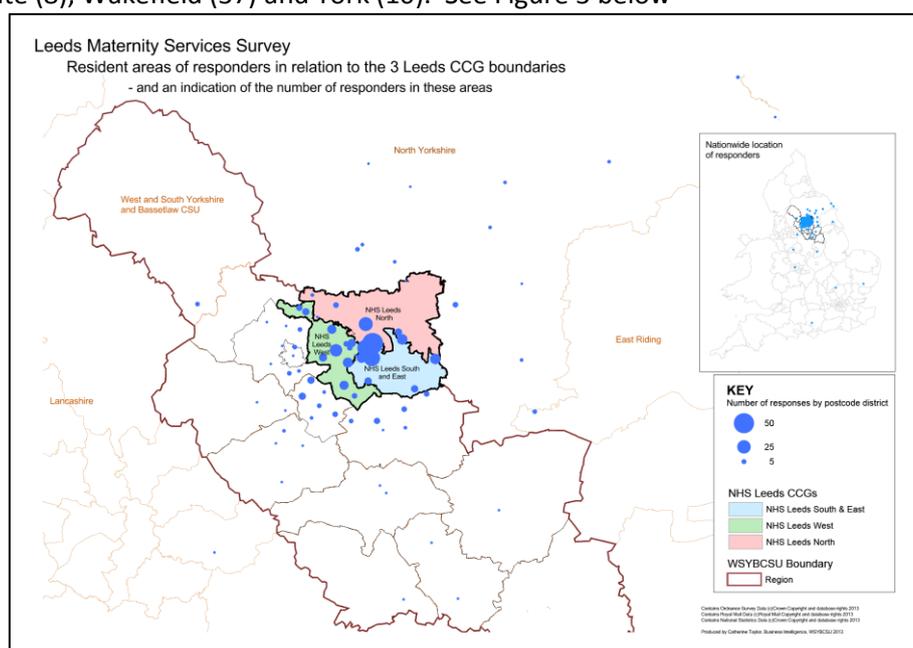
- There were 52 respondents who did not indicate their ethnicity.

Please note: In some instances throughout this report, the responses to the survey may not add up to 100%. There are several reasons why this might happen: the question may have allowed each respondent to give more than one answer; only the most common responses may be shown in the chart or table, or individual percentages are rounded to the nearest whole number so the total may come to 99% or 101%.

As a self-completion questionnaire was used, not all respondents have answered all questions. Therefore, the base size also varies for each question.

Geographical location

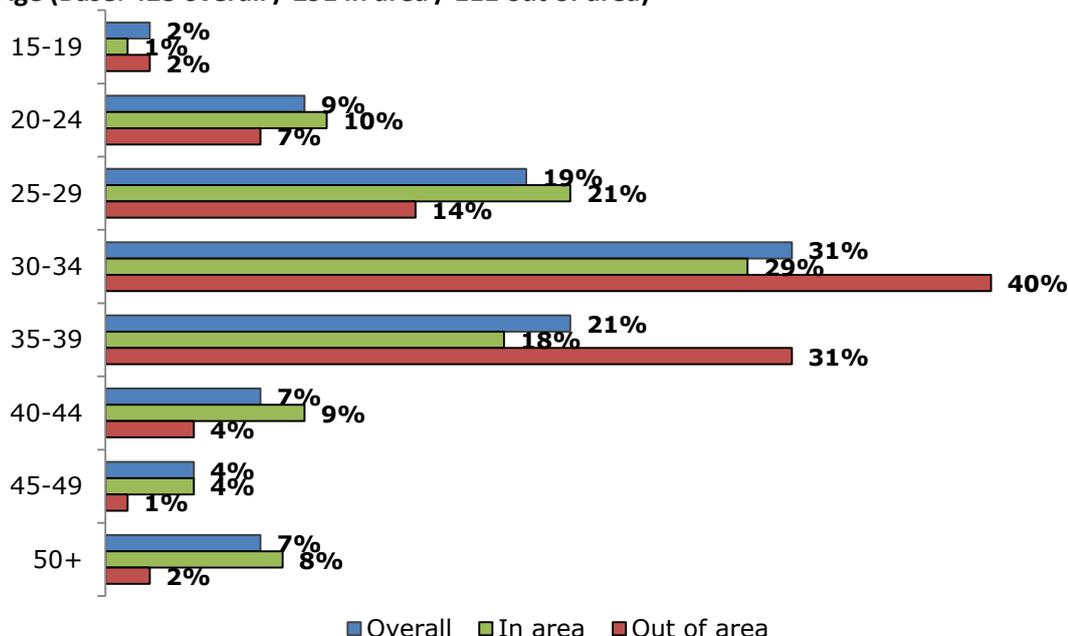
Of the respondents with a Leeds postcode (301), 118 came from postcode areas LS7, LS8 and LS9 the area around St James's. Most of the other responses were received from Bradford (32), Huddersfield (6), Harrogate (8), Wakefield (37) and York (10). See Figure 3 below



Age and Gender

The majority of respondents (91%) were female, and the largest proportion (31%) were aged between 30 - 34. Although there was some joint work with groups for young mums the number of responses from 15-19 year olds was low (only 2%) and does not correspond with the 6% of births at St James's to women under 20. More intensive work with these groups will be needed in the consultation phase to ensure better engagement with teenage mothers

Figure 4 - Age (Base: 428 overall / 291 in area / 111 out of area)

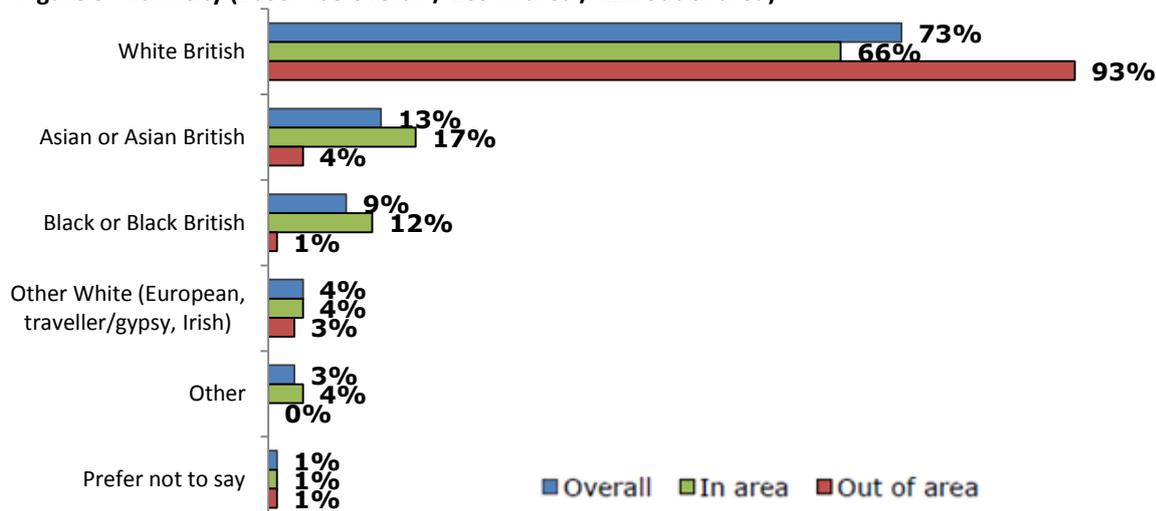


Ethnicity

26% of all responses were by people from Black, Asian and Minority Ethnic (BAME) groups. This increases to 37% when out of area responses are taken out which is similar to the population who use St James's maternity service (41% from BAME groups). This suggests that the approach taken in Leeds (joint work with community groups and face to face contact) was more successful in engaging with these groups than that taken out of area (postal surveys).

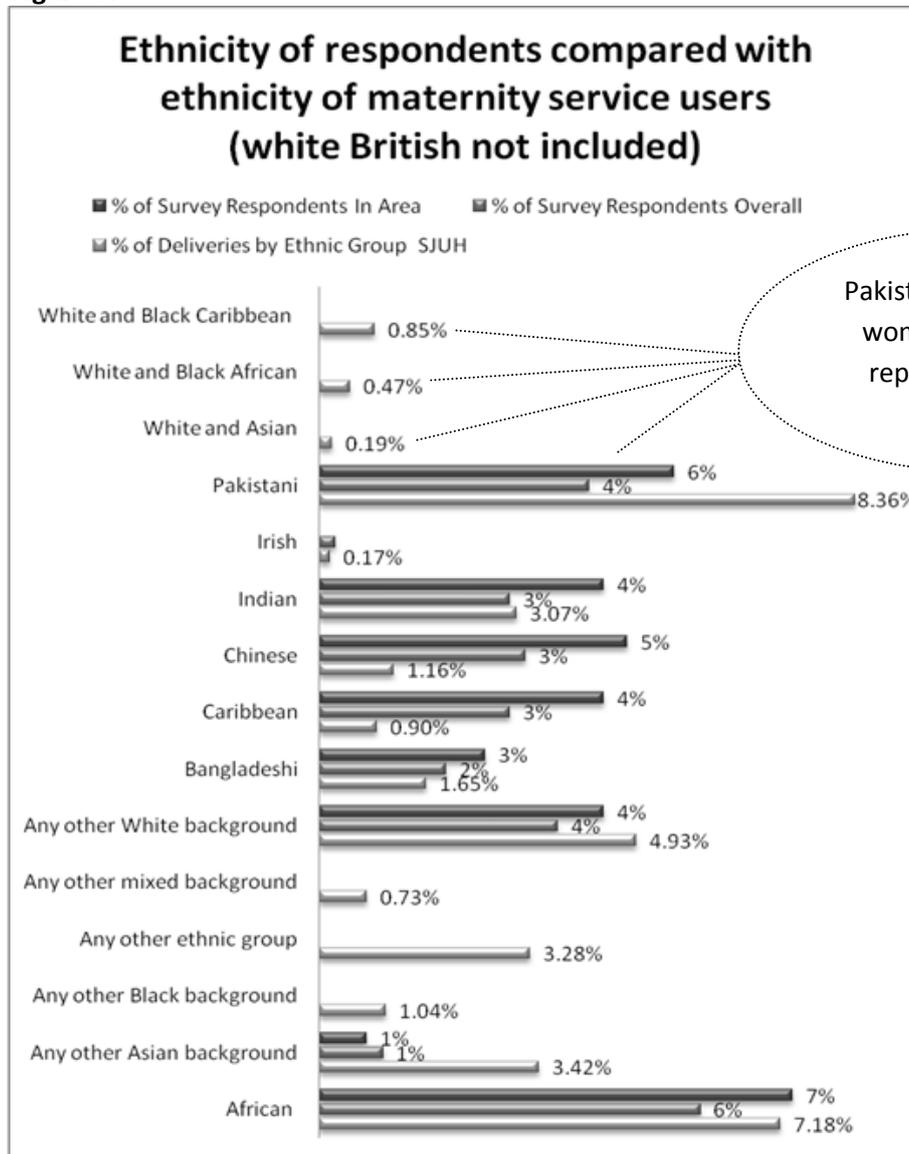
A more detailed look at the ethnicity of respondents shows the diversity of the respondents across the broad ethnicity groupings of (see Figure 5).

Figure 5- Ethnicity (Base: 408 overall / 269 in area / 111 out of area)



When this is looked at in even more detail and compared with the ethnicity of the people who have used St James’s maternity services in the past 12 months (see Figure 6) there was a comparable response rate from people who described themselves as Indian, Chinese, Caribbean, African, Bangladeshi and other white (which includes Eastern European and Gypsy Travellers). However, Pakistani women and those of mixed race were not as well represented in the survey responses. Again this indicates areas that will need specific focus during the consultation.

Figure 6:



Pakistani & mixed race women were under represented in the survey.

Sexual orientation and relationship status

In relation to sexual orientation and relationship status, the majority of respondents were heterosexual (94%) and married or in a Civil Partnership (62%). Although links were made with Lesbian, Gay and Bisexual groups as part of this piece of work this only resulted in 11 responses. Further work with these groups in order to generate a higher response rate would be desirable in the full consultation. The contact made with these groups during the short pre engagement phase was mainly via email and circulating the web based survey so it maybe that more face to face contact would be beneficial.

Disability

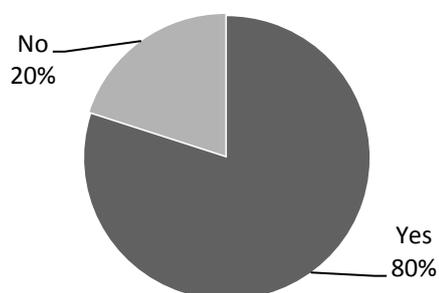
One in fourteen respondents (7%) indicated that they had some kind of disability. 44% of these respondents stated that their disability was a long-standing illness or health condition, 41% said that it was a mental health condition and 4% had a physical or mobility disability. The remaining 11% indicated that they preferred not to say. It is not possible to conclude if this is representative of the people who use LTHT maternity and neonatal services as it has not been possible to find any data about this.

Pregnancy, maternity and use of neonatal services.

Eight in ten respondents (80%) stated that they, or a member of their family, had had a baby in Leeds in the past three years.

Figure 7 – Have you or a member of your family had a baby in the past 3 years in Leeds?

Base – 436



Of those who had not had a baby in Leeds in the last three years, 33% indicated that they had had a baby in another area but still required the use of neonatal services in Leeds in the last three years.

In total, 114 respondents indicated that they had used the neonatal services in Leeds (24% of all the responses). This is seen as a good response rate given approximately 10% of babies born will require neonatal services.

Just under half of respondents (48%) indicated that their baby had been born within the last 12 months, with the remainder stating that the baby had been born between 12 months and three years ago.

The majority of respondents (84%) were the mother of the baby, with a further 6% as grandparents, 5% fathers and 5% 'other'. Of the 111 respondents who answered the question, 44% stated that they were currently pregnant and 43% had given birth within the last 26 weeks.

It is worth noting that a high proportion of respondents said the mother had required inpatient care after the birth. This is not comparable with LTHTs data about the percentage of mothers who require this care which is much lower. There are a couple of potential explanations for the high numbers. One is that the geographical areas targeted were generally more deprived areas, where there is evidence of more complex births and therefore mother's are more likely to need postnatal inpatient care. The other observation (made by those administering the questionnaire) is that some people may have ticked yes to this question when the mother had remained in hospital only for a few hours after the birth as is routine procedure because what was meant by the term 'inpatient care' was not clearly explained.

3.4 What did we find out?

3.4.1 People's experiences.

Survey questions 3 to 5 asked about people's experiences of inpatient care before birth, at birth and inpatient care for mother after the birth and question 6 asked about people's experiences of neonatal care. (For full details of responses to these questions and a list of all the responses please see Enventure analysis report in Appendix B)

Rating levels of both hospitals throughout pregnancy and birth

The survey findings show that both LGI and St James's have had a consistently high score in terms of the rating of care throughout all stages of pregnancy and birth, including before birth, at birth, after the birth and in neonatal services. Only a small proportion of respondents rated the care they received lower than 7 out of 10.

The table below provides a mean score of ratings for both the LGI and St James's. The LGI has been rated higher on average at every stage of maternity than St James's, but most notably at birth. This suggests that the experiences of respondents have been slightly better at the LGI in comparison to St James's.

Table 8: Mean scores for the rating of care received at all stages of pregnancy and birth.

Stage	LGI mean score rating	St James's mean score rating
Before birth	8.3	8.1
At birth	8.4	7.8
After the birth	7.3	7.1

Staffing levels and quality of care

A clear finding of this survey is that those who have given birth in Leeds recently, or who have a relationship to someone who has, base their experiences primarily on the quality of care provided by staff. This can be seen at all stages of pregnancy and birth.

There has been an overall positive response towards staff. The majority of respondents included references to their experiences and what would be on their wish list for maternity and neonatal services in the future. The service provided by staff was praised highly, with respondents highlighting the caring, attentive, committed, professional and understanding nature of staff. The responses relating to staff also included areas for improvement at various stages of pregnancy and birth, particularly after the birth. In these cases, respondents suggested that staff could be more attentive, communicate better, provide greater support, and also that greater staff numbers are needed to provide the best levels of care.

This strong focus on staff during the experience of hospital use before, during and after pregnancy shows that the staff providing the care are one of the most crucial elements in people deciding how they rate the hospital they visited.

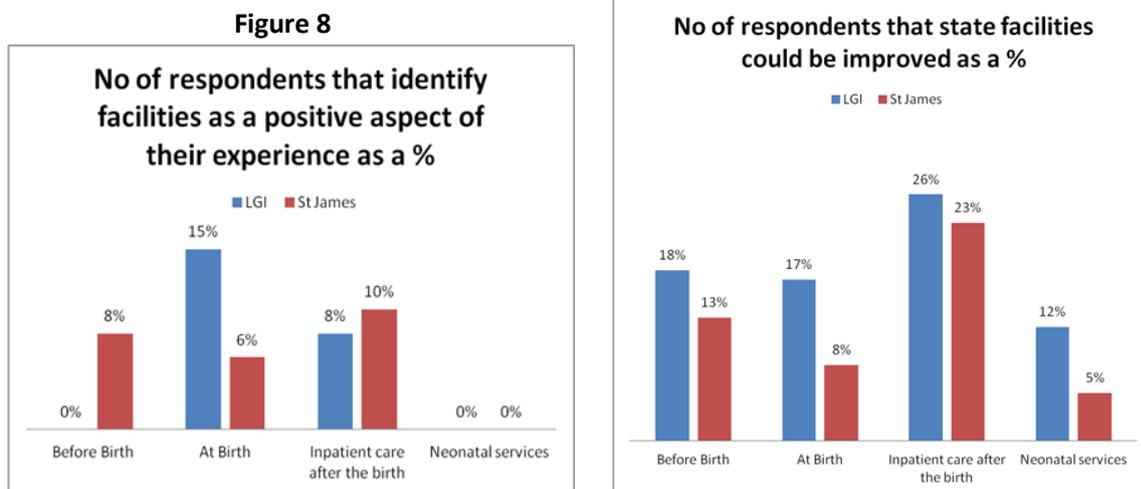
Positive comments about staff...

- Care I received from nurse and consultants was amazing (LGI and St James's)
- Understanding and support from all staff (LGI)
- A lot of care, midwives were excellent, very supportive and doctors were fab (St James's)

Facilities

Facilities on both sites feature as both a positive aspect of the experience for some respondents and as an area for improvement for others. Figure 8 shows the percentage of respondents who mentioned facilities in response to the question 'what was good about your experience?' and Figure 9 shows the percentage of respondents who referred to facilities in response to the question 'what could be improved?' Please note that the heading 'facilities' includes all responses relating to environment, cleanliness, equipment and space.

Figure 9



It can be seen that whilst some respondents were positive about the facilities (most notably when giving birth at LGI) a significant proportion of respondents suggested that the facilities at each hospital needed improvement. This was particularly noticeable in relation to inpatient care for the mother after the birth. In general a higher percentage of respondents felt that facilities needed to be improved at LGI than St James, and this was true at all stages of the pathway. It is interesting to note that 5% of respondents specifically cited having their own room when admitted to St James's before the birth as positive, whilst 4% of respondents suggested that quieter wards/ rooms as an area for improvement for those admitted before the birth at LGI. Where facilities were referred to positively it was often in relation to having had a private room. Improved facilities and more private rooms were also themes in the wish lists (see section 3.4.3).

Comments about improving facilities

- *The equipment whilst I was being "stitched" was faulty. The leg support did not work and the lamp would not be supported so this delayed the process (St James's)*
- *Quality of room on ward was poor, no functioning curtains, grotty toilet / shower (LGI)*
- *Better birthing suites more privacy (both)*
- *Better facilities for relatives (St James's)*
- *The delivery room was clinical, it would have been much nicer to have a home from home experience in a birthing centre (LGI)*
- *The bathroom in my room - no hot water and light did not work. (St James's)*
- *On main ward - very cramped (LGI)*

Positive comments about facilities

- *I was able to have a private room to myself (St James's)*
- *Clean and tidy hospital room (LGI)*
- *I had my own room (St James's)*
- *I enjoyed having a large, private room with mood lighting to give birth in and access to a bath ensuite afterwards. (LGI)*

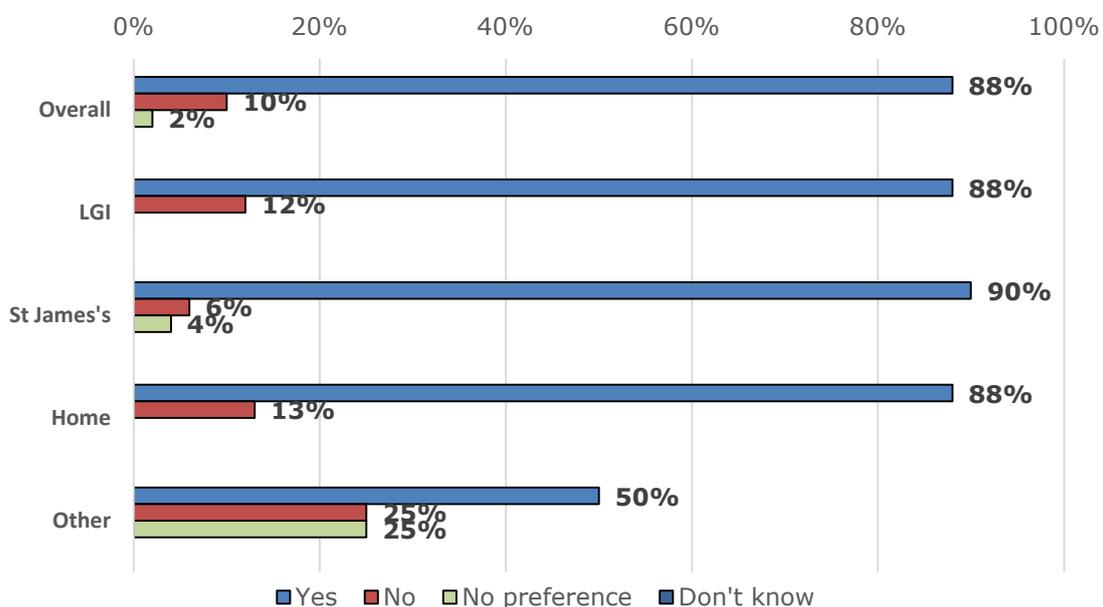
Experiences at LGI and St James's

Opinions of St James's and LGI appear to be very mixed. Many respondents have praise for one and negative reports of the other, which are based on previous personal experiences. **It is undoubtedly these experiences that will be shaping their attitude towards the proposed changes to the maternity and neonatal services.**

Planned vs. actual place of birth

Overall, 88% stated that the birth took place where the mother had planned to give birth. A slightly higher proportion of those who gave birth at St James's had planned to give birth there (90%) compared to those who gave birth at LGI (88%) and at home (88%). Those who gave birth elsewhere were far more likely to state that this was not planned (25%).

Figure 10 – Was this where the mother planned to give birth? Base: 356



Those who indicated that the mother had not given birth where planned were additionally asked why this was the case. The reasons provided have been categorised and are presented below:

- Chosen hospital was full/lack of facilities (6 respondents)
- LGI was full/no staff (8 respondents)
- Baby born earlier than planned (7 respondents)
- Medical complications (9 respondents)
- Planned homebirth not possible (5 respondents)
- St James's was too busy (2 respondents)

Experiences of using neonatal services

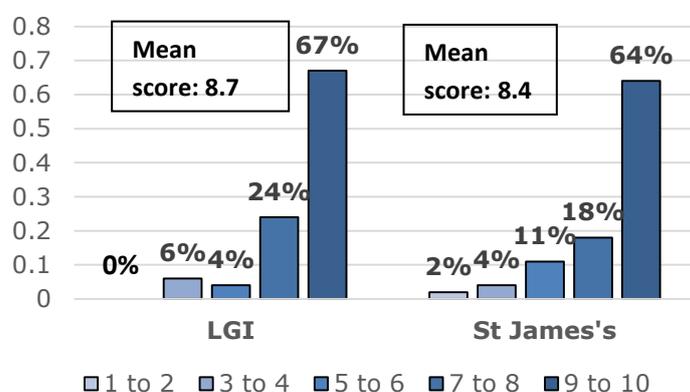
Three in ten respondents (31%) stated that the baby had required neonatal services (specialist care for baby) after birth. Neonatal services provide expert, 24-hour care for newborn babies who are ill or born prematurely, including neonatal intensive, high-dependency, specialist and transitional care.

52% of these respondents indicated that the baby had been cared for in LGI and 40% had been in St James's. One in twelve (8%) had been cared for in both hospitals.

- **Rating of care received**

These respondents were then asked to rate the care provided by the neonatal service during this stay in hospital, highlighting what was good about the experience and what could have been improved.

Figure 11 – How would you rate the care provided by the neonatal service (with 1 being poor and 10 being excellent)? Base: LGI (57), St James's (45)



Similar ratings of the neonatal service were recorded at both LGI and St James's, with large majorities providing a score of 9 or 10 at both LGI (67%) and St James's (64%). As seen at other stages of pregnancy and birth, the two hospitals have received very similar mean scores, with LGI just 0.3 points ahead of St James's at 8.7.

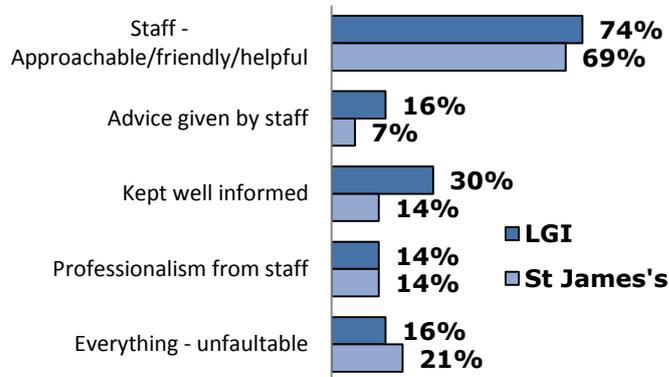
Looking at the overall satisfaction ratings for both hospitals, subgroup analysis highlights that a smaller proportion of respondents from a non-White ethnic background provided a lower satisfaction rating with the care they received from neonatal services (mean score of 7.5) when compared with those from a White ethnic background (mean score of 8.8). This would benefit from further investigation.

- **What was good about neonatal services?**

Respondents explained what was good about their experience of neonatal services at the hospital they used.

Figure 12 – What was good about the experience?

Base: Respondents who required the neonatal services at LGI (43) / St James’s (29)



Almost all responses in some way praised the neonatal staff at both LGI and St James’s in terms of their manner (approachable, friendly, and helpful), the advice they provided, keeping them informed and their professionalism.

Positive comments about neonatal service staff;

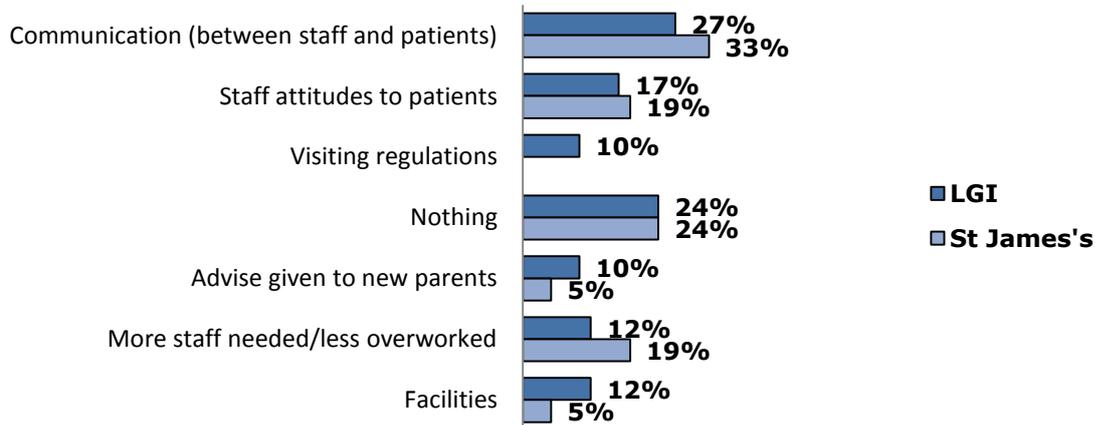
- *Constant care, understanding staff, doctors / specialist explained everything. Totally looked after the both of us. Without their care my baby would not be here. I would recommend this hospital to anyone (LGI)*
- *Staff being able to provide care for your baby/being involved. We were kept well informed. Open access and staff always happy to answer questions (LGI)*
- *Dedicated, helpful, caring, supportive, understanding staff (St James’s)*
- *The staff made a lot of effort just after the birth to make sure I got to see the baby and were good at providing me and my husband with training and education to look after the baby's N.G feeding tube (St James’s)*

Some respondents stated that everything about their experience was good and that they could not fault it (16% LGI, 21% St James’s). No significant differences were seen between demographic subgroups in response to this question. All verbatim responses to this question can be found in Appendix B

- **What could have been improved in neonatal services?**

The chart below presents the categories of responses provided when respondents who used the neonatal services for their baby thought it could have been improved at both LGI and St James’s. The full range of response categories are summarised in the chart below.

Figure 13 – What could have been improved? Base: Respondents who required the neonatal services at LGI (41) / St James’s (21)



Communication was highlighted as the main area for improvement by those who answered this question. Responses varied in this respect, with some stating that communication between staff and patients needed improvement, and others stating that communication between healthcare staff needed improvement to improve continuity of care.

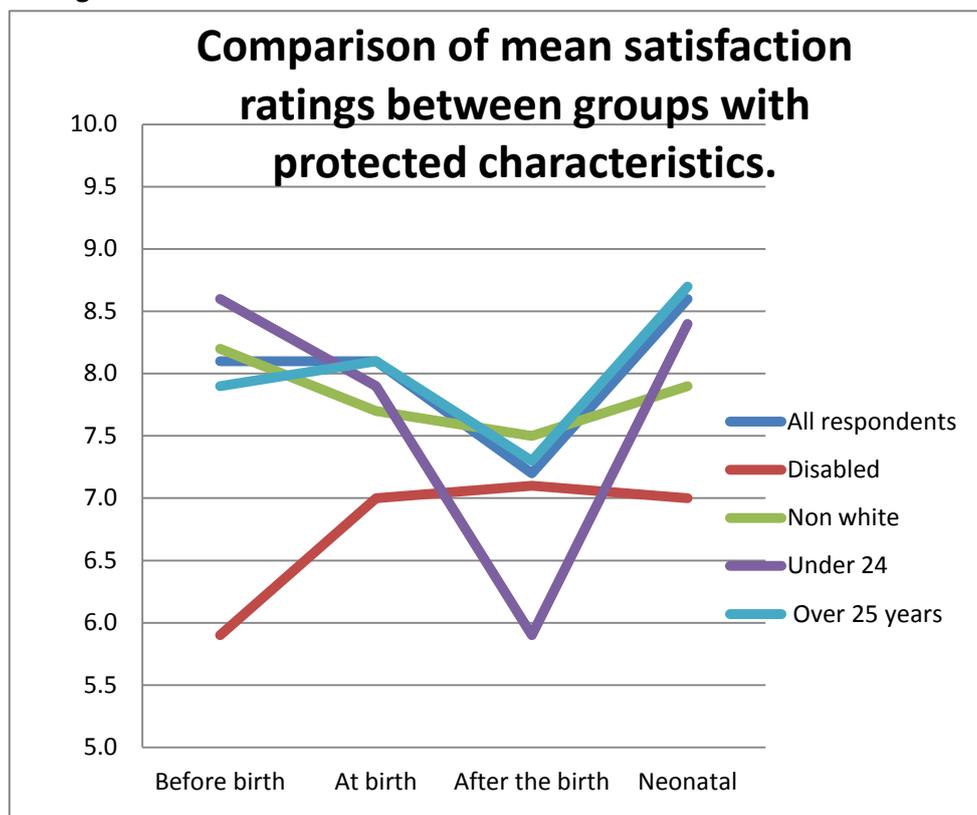
- *More communication about feeding and how to express milk to allow breast milk to be fed. The staff were extremely busy there was no communication sent to me recovering in the antenatal ward about when my child needed feeding. (St James’s)*
- *Sometimes when staff changed over, there was a difference in the advice they gave. This could be confusing at times. (LGI)*
- *More consistency of staff for each baby as you feel you have to explain the situation each day (LGI)*
- *Them telling me what was happening (St James’s)*

It is positive to note that almost a quarter of respondents suggested that nothing needed improving about neonatal services at either hospital (24% respectively).

The experiences of those with protected characteristics

The following section details some of the findings from questions 3, 4 and 5 with particular reference to information pertaining to respondents who fall within the protected characteristics groups. It is not possible to include all the figures given in the Enventure Report, which should be the primary reference document.

Figure 14



People with a disability

- **Before birth**

In figure 14 it can be seen that respondents with a disability provided a significantly lower satisfaction rating (mean score of 5.9) compared to those without a disability (mean score of 8.2) before birth. However 45% respondents with a disability felt nothing could be improved compared to 17% of those without a disability.

- **At birth**

There continues to be lower satisfaction ratings for people with a disability at birth (although not statistically significant). However there was a significant difference in the response to the question 'What was good about the experience?' where 31% of those with a disability referred to 'professional staff' compared to those without a disability – 13%. This was also true in response to 'What could have been improved?' with 25% of those with a disability suggesting that communication could be improved compared to 9% without a disability.

- **After the birth**

Once again a lower satisfaction rating is noted along with a higher percentage of those with a disability (40%) stating nothing could be improved as compared to 8% of those without a disability.

People of non white ethnicity

- **At birth**

There was a slightly lower satisfaction rate amongst respondents of non white ethnicity but again not statistically significant, but 29% of those from the Asian or Asian British ethnicity felt communication at this stage could be improved compared to those of White ethnic group at 9%.

- **After the birth.**

44% of Asian or Asian British respondents suggested that more staff were needed and more emotional support from staff was needed (56%) after the birth compared to 20% and 19% respectively.

People aged 24 and under

- **After the birth**

It is noticeable that a smaller proportion of those aged under 24 provided a lower satisfaction rating with the care received after the birth (5.9) compared to those over 25 (7.3).

The discussion above highlights areas which would benefit from further investigation and more targeted work to understand some of these experiences in more detail.

3.4.2 The potential impact of proposed changes to maternity and neonatal services.

Respondents were asked to explain what the potential impacts would be on themselves or the views of people they represent if the maternity and neonatal services were centralised on the LGI site.

Figure 15 below is a word cloud summarising the different categories of response to this question. The categories displayed in larger text were suggested by a larger proportion of respondents, and those in smaller text were suggested by a smaller proportion.

Figure 15 – If maternity and neonatal services are moved to the LGI site, what might be the impact on you or



people's views you represent? (All responses)

Travel and parking issues

The most common concerns regarding the proposed changes relate to transport, travel and parking. This concern appears to be held by all respondents regardless of age, gender, ethnicity, disability etc.

- *Easier to find parking at Jimmies*
- *I had my children in St James's and I like it because it is local and easy to find parking.*
- *I went to LGI at early stages of our pregnancy, the hospital was very nice but parking was awful. Due to this I asked for all our care be at St James's*
- *LGI hard to find parking place.*

Overall responses to proposed changes

Whilst a number of concerns were raised, including travel, parking, reduced choice, increased visitor numbers and decrease in quality of care, it is important to note that a significant proportion of respondents provided positive feedback in relation to the proposed changes to the maternity and neonatal services in Leeds. Many comments indicate that the changes are a good idea and that there are potential benefits to having the services moved to the LGI, such as having all services in one place, improved care, modernised facilities and, for some, easier access. **This is enhanced by the finding that those who have used the neonatal services in the past are less concerned about issues of parking, travel and accessibility.**

Impact of changes for different groups;

- **People with a disability**

A word cloud filtered by those with a disability shows a greater focus on travel problems, accessibility and car parking issues in comparison to all other potential impacts that the proposed changes could have.

Figure 16 - If maternity and neonatal services are moved to the LGI site, what might be the impact on you or people's views you represent? Filtered by those with a disability.



- **People of non-white ethnicity**

When generating a word cloud based on the responses to this question for those of non-White British ethnicity (Asian/Asian British, Black/Black British, White other or other), we can see that the greatest impact is travel and accessibility, and that parking issues are not as much of a concern.

Figure 17 – If maternity and neonatal services are moved to the LGI site, what might be the impact on you or people's views you represent? (Filtered by ethnicity- not White British)



- **People who have used neonatal services**

It is interesting to note that, if looking at the responses to this question based on whether the respondent had used neonatal services at either LGI or St James's, differences can be seen. The word cloud overleaf presents the responses to this question, split between those who had used neonatal services (in blue) and those who had not (in red).

As can be seen, the majority of negative impacts, particularly car parking issues and travel problems/accessibility, are suggested by a much larger proportion of those who had not used the neonatal services when compared to those who had, as the text is much larger for these specific impacts in red than in blue. This suggests that those who have used neonatal services in Leeds may not see the potential negative impacts as strongly as those who have not.

Figure 18 - If maternity and neonatal services are moved to the LGI site, what might be the impact on you or people's views you represent? Filtered by - Did the baby need specialist care after birth?



- **Out of area respondents**

When looking at the response to this question by those classed as 'in the area', a difference can be seen between the proportion of respondents focusing on travel problems / accessibility and seeing the changes as a great idea / no negative impact. However, both respondents in and out of the area focused most heavily on car parking issues.

Figure 19 - If maternity and neonatal services are moved to the LGI site, what might be the impact on you or people's views you represent? Filtered by those IN AREA



Figure 20 - If maternity and neonatal services are moved to the LGI site, what might be the impact on you or people's views you represent? Filtered by those OUT OF AREA



In Figure 19 (which shows the responses of just those within the three Leeds CCG areas) travel problems/accessibility is featured prominently, where as in Figure 20 (which shows the responses of those outside the area) the focus is switched to 'great idea/no negative impact'.

3.4.3 Wish lists for maternity and neonatal services

Respondents were finally asked to state what would be on their wish list for maternity and neonatal services in Leeds in 2016. Responses were again categorised into common themes and are presented in the word cloud below.

Figure 21 – What would be on your wish list for maternity and neonatal services in Leeds in 2016?



As can be seen, sufficient staff was the most common feature on respondents' wish lists (suggested 109 times), followed by compassionate staff (52 times), **showing once again the importance that people place on staff as part of their hospital experience.** Below are a list of verbatim responses within these two categories:

- *More midwives - they were understaffed and stretched. Could be unsafe. I was afraid I would drop my baby as I couldn't manage due to my operation*
- *To have consistently safe staffing levels, to deliver a consistently high standard of safe appropriate, supportive maternity and neonatal care to the women of Leeds*
- *Need enough staff, more people having babies at the same time-staffing levels*
- *Understanding midwives and educated about different scenarios*
- *More compassion from nurse felt quite intimidated, needed to ask permission to touch my own baby, refused and was shouted at*
- *Bright welcoming friendly service, support - continually for parents who have a child born with a disability*

Improved parking is also prominently featured on wish lists (mentioned 39 times), suggesting it is of great importance if changing the maternity and neonatal services as outlined.

Other specific issues included improved facilities, more private rooms and relaxed visiting hours, as detailed below:

- *I think moving the maternity and neonatal services so they're in one place makes a lot of sense. The best parts of each current maternity suite should be brought together. Easy parking. Ensuite rooms*
- *Postnatal wards. More postnatal staff to aid with breast feeding advice*
- *Bigger room, more privacy*
- *Private rooms rather than wards, extended visiting hours, better quality of food*

The following terms relating to options for giving birth were also suggested by a number of respondents (below are a series of verbatim responses relating to these categories):

- Water birth facilities (34 respondents)
- Midwife led unit (18 respondents)
- More options (15 respondents)
- Active birth facilities (10 respondents)
- Standalone unit (6 respondents)
- Increasing support for home births (16 respondents).

Comments about having more options for giving birth...

- *Active birth and water birth facilities for every woman who would like to use them i.e. more facilities to reduce shortage*
- *More options available on labour day (if they don't have a suite with water bath you can't have water birth)*
- *A maternity unit with active birthing rooms where you are able to stay in the same room from start to finish*
- *Development of a midwife led unit located away from the LGI site so this could sit within an entirely different environment*
- *Some kind of "middle ground" between a home birth and hospital birth e.g., a birthing centre; continuous care by a consistent midwife where possible*
- *An increase in the availability of birth pools in hospitals. A stand-alone midwife-led birth centre. A greater emphasis on case-loading midwifery care both ante and postnatally. The continuation and growth of the dedicated homebirth teams*
- *A genuine stand alone birth centre*
- *Dedicated midwife led birth centre, with a childbirth education centre on site as well*
- *Extend the home birth team so that anyone wanting a home birth is able to have one.*

Wish lists for people of non-white ethnicity:

The word cloud below presents the responses provided specifically filtered by those not of White ethnic background. It is interesting to highlight that ‘cultural needs met’ features much more prominently here, suggesting that having staff who speak the same language and cultural food available are very important to those of non-White ethnicity.

Figure 22 – What would be on your wish list for maternity and neonatal services in Leeds in 2016? Filtered by ethnicity (not White British)



Wish lists for people in Leeds and those out of area.

Again, when looking at the response to this question by those classed as ‘in the area’ (with a postcode that places them within the three Leeds CCGs), slight variations in responses can be seen, presented in **Figure 23** and **Figure 24**

Figure 23 – What would be on your wish list for maternity and neonatal services in Leeds in 2016? Filtered by those IN AREA



Those inside the area focused more heavily on keeping both hospitals when compared to those outside the area, and only respondents from in the area suggested a midwife led unit and cultural needs met.

Figure 24 – What would be on your wish list for maternity and neonatal services in Leeds in 2016? Filtered by those OUT OF AREA



A larger proportion of respondents from outside the area focused on improved parking, improved facilities and relaxed visiting hours compared to those inside the area.

Section 4:

Summary.

Experience of current services:

Overall, survey respondents rated their experiences of care before, during and after birth positively but experiences at LGI were on average rated slightly higher than St James's. Variations to this were noted where disabled people rated their experiences slightly lower before birth and those under 24 rated the care they received after the birth lower than other respondents.

Several areas for improvement were also identified, including attentiveness and attitude of staff, communication between staff and patients, more emotional support, facilities, standard of medical care and more staff. Some of these themes were also reflected in the other patient experience data reviewed. There was some variation in the views of what needs to be improved between ethnic groups, with a greater proportion of Asian or Asian British respondents suggesting that more staff were needed and more emotional support from staff was required. More disabled people suggested that their experience of giving birth would have been improved with better communication.

Respondents who had used neonatal services mostly rated their experiences positively. Some issues were raised about communication and there was also an indication that people who are not White British have a slightly less positive experience of neonatal services. Both of these issues would benefit from further investigation.

Impact of changes:

Car parking and transport to the LGI was both an issue affecting experience of current services and a major cause for concern shared by all groups of people if the changes go ahead. Concerns were also raised about one unit being too busy and not being able to cope with the demand.

There were positive comments about the changes from many people, particularly those who had used neonatal services and those who live out of area, with the main perceived benefit being better facilities and everything being in one place.

Wish lists for maternity services:

The 'wish list' for maternity and neonatal care was focused predominantly on staff and parking. The need for sufficient staffing levels was by far the most common suggestion. Experience of the quality of care provided by staff particularly in respect of compassionate care, during many stages of the pregnancy, was also frequently cited on people's wish lists.

Another theme on wish lists for Leeds residents in particular was around increasing options for giving birth in Leeds with more water birth facilities a midwife led unit featuring amongst the top responses. For non White British respondents cultural needs being met (for example language and food) appeared frequently on their wish lists.

Lessons learnt for the consultation:

People really want to talk about maternity services and it will be important to prepare for a large response to consultation. It was possible to get views from a diverse range of people by working alongside existing religious, community and voluntary sector groups - but it takes time and several

visits to groups over a few weeks to access a large number of views. The consultation will need to pay particular attention to engaging with the Pakistani community, people of mixed race, young mums, disabled women and lesbian and bisexual women. The largest number of responses were on paper, not online and those who responded on line were not as ethnically diverse. So it is important that both online and paper based approaches are adopted for future communications and engagement.

Recommendations

There are a number of recommendations that can be taken from both the review of patient experience and the results of the pre engagement survey to inform the future proposal for changes to the maternity and neonatal services and the next stage of the project. These include:

When reviewing and refining the proposals LTHT and commissioners need to consider the following feedback from service users and the public:



The project should explore options for increasing other birth options as identified in respondent's wish lists.



Any plans for the development of the new LGI site, should incorporate reference to how transport arrangements to and from the hospital will be managed. Current public transport is felt to be insufficient for those living on the other side of the city, near to the St James's site.



Ensuring adequate parking facilities are available at the LGI. Current provision is seen as insufficient and poorly designed.



Staffing levels for the proposed new service should be carefully assessed to ensure that safety and quality of care is maintained.



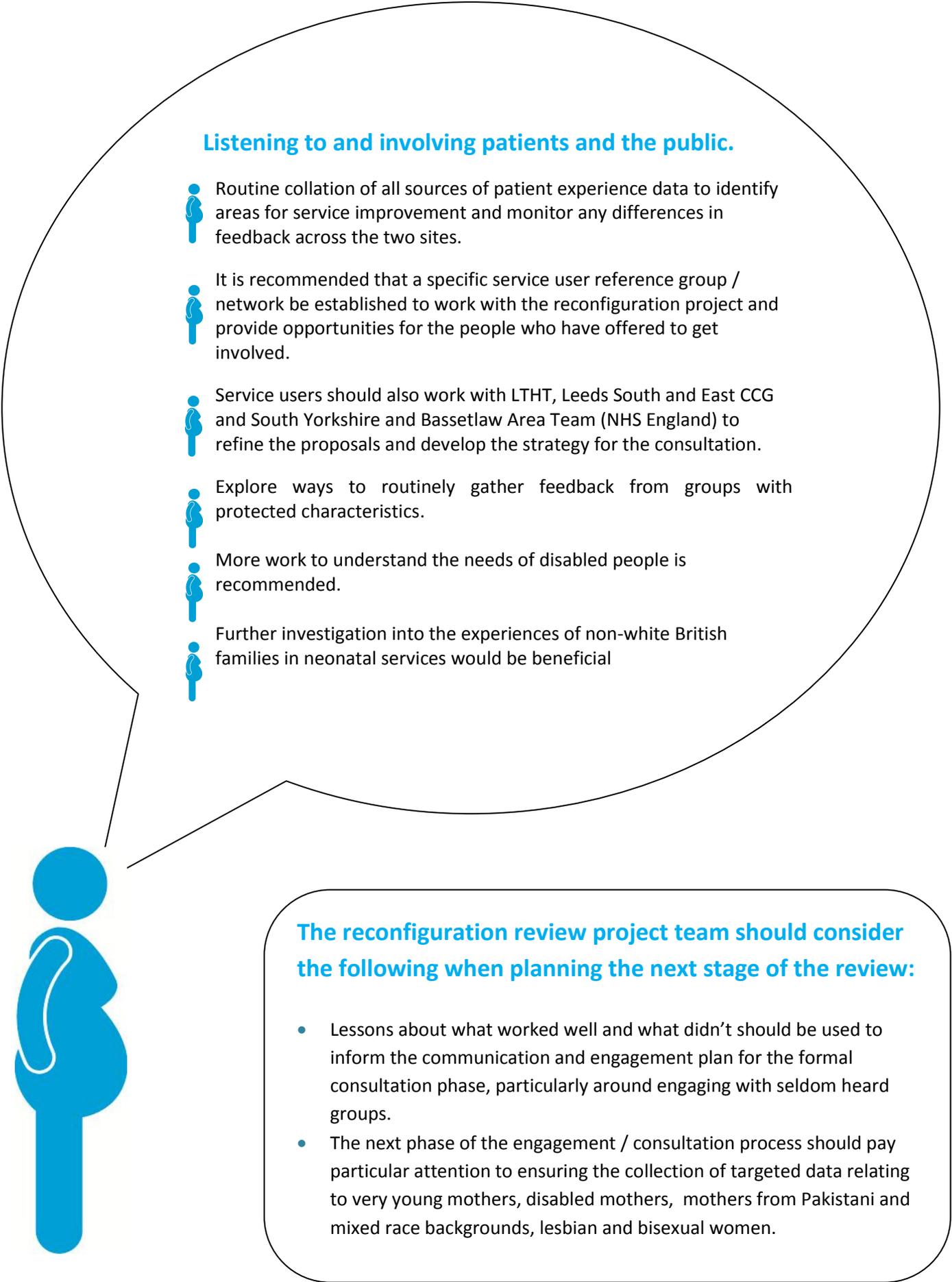
Quality of care and a focus on how it will improve service user's experiences should be a key feature of any proposal to redesign services.



One third of service users raised concerns about communication in neonatal services. This should be addressed in the service specification for any newly configured service.

It would be beneficial to provide an opportunity for midwives and staff who deliver the services that would be affected to share their views and feedback on the proposals.





Listening to and involving patients and the public.

- Routine collation of all sources of patient experience data to identify areas for service improvement and monitor any differences in feedback across the two sites.
- It is recommended that a specific service user reference group / network be established to work with the reconfiguration project and provide opportunities for the people who have offered to get involved.
- Service users should also work with LTHT, Leeds South and East CCG and South Yorkshire and Bassetlaw Area Team (NHS England) to refine the proposals and develop the strategy for the consultation.
- Explore ways to routinely gather feedback from groups with protected characteristics.
- More work to understand the needs of disabled people is recommended.
- Further investigation into the experiences of non-white British families in neonatal services would be beneficial

The reconfiguration review project team should consider the following when planning the next stage of the review:

- Lessons about what worked well and what didn't should be used to inform the communication and engagement plan for the formal consultation phase, particularly around engaging with seldom heard groups.
- The next phase of the engagement / consultation process should pay particular attention to ensuring the collection of targeted data relating to very young mothers, disabled mothers, mothers from Pakistani and mixed race backgrounds, lesbian and bisexual women.

Acknowledgements:

We would like to thank the following groups for their support with this project:

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- MSLC members who worked with us to develop the survey
- Nicky Elmsley and Helen Jackson at Leeds Bliss.
- Enventure Research - Mark Robinson and Matt Thurman
- Ginger Nut Creative

Appendices

A: Pre-engagement Survey

B: Eventure Research analysis and report.

C: Summary of late responses

D: List of groups worked with and places visited.

Appendix A: Pre-engagement Survey



Leeds South and East
Clinical Commissioning Group

We would like to know your views on maternity and neonatal care in Leeds

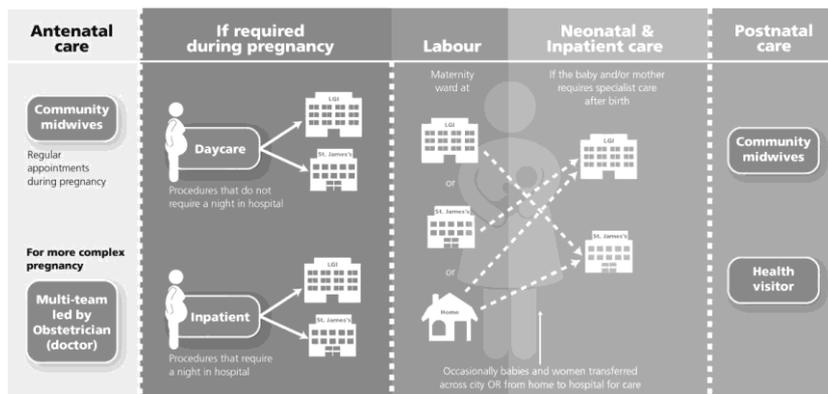
What is being proposed?

Leeds Teaching Hospitals NHS Trust is thinking about changing the way it delivers some maternity and neonatal services from 2016 onwards. It would mean that people choosing to have a baby in Leeds would give birth in a modernised unit at the Clarendon Wing, Leeds General Infirmary (LGI) or in their own home. It would also mean that all babies needing specialist care after birth would be looked after at Leeds General Infirmary too. As part of the proposal there would be no facilities to give birth or provide specialist care for babies after birth (known as neonatal care) at St James's University Hospital (St James's).

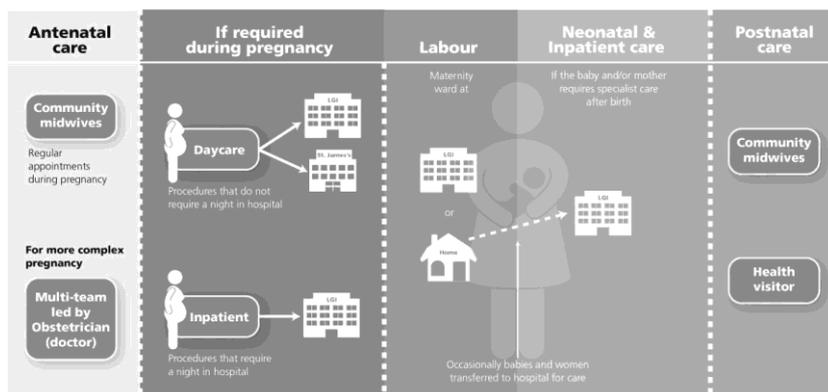
Both hospital sites would continue to offer antenatal outpatient appointments (before a baby is born) for hospital services that services that do not need an overnight stay (for example blood tests, blood pressure and baby monitoring). Along with any postnatal outpatient appointments that need to be in a hospital setting, after the baby is born.

The following diagrams show how maternity care is currently provided and the changes that are being suggested.

Current provision of maternity care in Leeds



Proposed provision of maternity care in Leeds



Why change?

This proposal has been developed by the team of Doctors and Midwives at LGI and St James's to continue to improve the safety and quality of maternity and neonatal services in Leeds. The team feel there are a number of potential **benefits** to centralising services at the LGI:

- Women and their families would experience more modern and pleasant surroundings.
- A dedicated operating theatre for planned caesarean sections would mean fewer delays for women due to emergency cases.
- National guidelines recommend that maternity & neonatal services should look at the best ways they can safely meet the demands of increasing birth rates and offer a full range of delivery options for pregnant women*. One larger, centralised unit at LGI would be a way of doing this.
- Leeds Children's Hospital services are already located at LGI. Having maternity services in the same place will provide easier access to a wider range of clinical skills and expertise.
- All high dependency, intensive and special care services for babies (also known as neonatal services) would be in one place. This would mean that mothers and babies would no longer need to be transferred across the city when they need them.

Why do we want your views?

NHS Leeds South and East Clinical Commissioning Group (CCG) is responsible for making sure that the right NHS services are in place to meet the health needs of local people. We are carrying out a review on behalf of people across the whole of Leeds to make sure that the proposals put forward by the Leeds Teaching Hospitals NHS Trust meet the needs of women and families and would provide the safest and most effective care.

We would like to know your views on current services and the proposed changes. For example how might the changes affect transport and travel arrangements, family visiting, cost to individuals and families, quality of care, access to services, the care environment or choices for women and families?

What will happen to my views?

The CCG will use your views to help understand the needs of local people and how proposed service changes could have an impact on their experience. We will take into account getting the best outcomes for patients whilst managing issues such as patient safety, quality and sustainability. Your feedback will inform this process.

Please use the questionnaire to tell us your views.

You can complete it online at www.leeds.nhs.uk/maternity OR fill it in and return it in the FREEPOST envelope provided by Wednesday 31st July 2013.

If you would be happy for us to contact you again about your views on maternity and neonatal services or you would like to be more involved please add your name address in the space provided and return with the questionnaire.

Thank you very much for your time.

* Reference: *High Quality Women's Health Care: A proposal for change. Royal College of Obstetricians & Gynaecologists 2011*

Question 1

Have you or a member of your family had a baby in the past 3 years in Leeds?

Yes No

If no, have you had a baby in another area but needed specialist care after birth in Leeds (known as neonatal services) in the past 3 years?

Yes No *(If yes you may prefer to go to question 6. If No, you may prefer to skip to question 7 & 8)*

When was the baby born? Within the last 12 months Between 12 months and 3 years

Question 2

What relationship are you to that baby?

Mother Father Grandparent Other

Before the Birth

Question 3

Was the expectant mother admitted to hospital *during* this pregnancy (before going into labour)?

Yes No *(If No, please go to question 4)*

If yes, which hospital?

LGI St James's Both Other Please specify _____

How would you rate the care received during this stay in hospital (with one being poor and 10 being excellent)?

 1 2 3 4 5 6 7 8 9 10 

What was good about the experience?

What could have been improved?

If admitted to both hospitals please tell us about any differences?

At Birth

Question 4

Where was the baby born?
 LGI St James's Home Other Please specify

Was this where the mother planned to give birth?
 Yes No Don't know No preference

If no, please can you tell us why?

How would you rate the care received during the birth of this child (with one being poor and 10 being excellent)?
 1 2 3 4 5 6 7 8 9 10

What was good about the experience?

What could have been improved?

After the Birth

Question 5

Did the mother require hospital care after the baby was born?
 Yes No (If No, please go to question 6)

If yes, which hospital were they in?
 LGI St James's Both Other Please specify

How would you rate the hospital care and treatment received by the mother after the birth of this child (with one being poor and 10 being excellent)?
 ☹️ 1 2 3 4 5 6 7 8 9 10 😊

What was good about the experience?

What could have been improved?

Question 6

Specialist Care for baby after birth

Did the baby need specialist care after birth (known as neonatal services)?

(Neonatal services provide expert, 24 hour care for newborn babies who are ill or born prematurely. Which include neonatal intensive care, high-dependency care, special care and transitional care)

Yes No (If No, please go to question 7)

At which hospital was the baby cared for?

LGI St James's Both

How would you rate the care provided by the neonatal service (with one being poor and 10 being excellent)?

 1 2 3 4 5 6 7 8 9 10 

What was good about the care?

What could have been improved?

Question 7

If maternity and neonatal services are moved to the LGI site as, outlined in the diagrams, what might be the impact on you or people's views you represent (if completing the survey on behalf of others)?

Please consider: transport and travel arrangements, family visiting, cost to individuals and families, quality of care, access to services, the care environment and choices for women and families.

Question 8

What would be on your wish list for maternity and neonatal services in Leeds in 2016?

If you would be happy for us to contact you again or if you would like to be involved in this project in the future please fill in the following details:

Name:

Email address:.....

Postal address:

Contact telephone number:

If you need help to understand this information in another language or format please contact the maternity review team by telephone: 0113 8431670 or by email: leeds.maternityreview@nhs.net

Jeśli w celu zrozumienia tych informacji potrzebujecie Pan(i) pomocy w innym języku lub innej formie, prosimy o kontakt z zespołem ds. kontroli położniczej (maternity review team) pod numerem tel.: 0113 8431670 lub poprzez e-mail na adres: leeds.maternityreview@nhs.net

اگر آپ کو ان معلومات کو سمجھنے کے لیے یہ کسی اور زبان یا صورت میں درکار ہوں تو برائے مہربانی مٹرنیٹی ریویو ٹیم سے اس نمبر پر فون کر کے رابطہ کریں: 0113 8431670 یا اس پتہ leeds.maternityreview@nhs.net پر ای میل لکھیں:



Equality Information

So that we can check we have asked as many different groups of people as possible about their views, and have not missed any groups or sections of our community out by mistake, please can you fill out this form.

This information cannot be used to identify you and will be kept confidential. You do not have to answer any of these questions, but it helps us do a better job if you do. **Thank you.**

What is the first part of your postcode? e.g. LS28, HD2, WF10 etc.	
Please enter here	Prefer not to say

What gender are you?		
Female	Male	Prefer not to say

Do you consider yourself to be transgender?		
Do you live in the gender opposite to that assigned at birth?		
Yes	No	Prefer not to say

What is your age?					
10-14	15-19	20-24	25-29	30-34	35-39
40-44	45-49	50+	Prefer not to say		

What is your sexual orientation?			
Bisexual (both sexes)	Lesbian (same sex)	Gay man (same sex)	Heterosexual/ Straight (opposite sex)
Other:	Please specify:		Prefer not to say

Do you consider yourself to belong to any religion?			
Buddhism	Christianity	Hinduism	
Islam	Judaism	Sikhism	
No religion	Prefer not to say	Other:	Please specify:

Please turn over

What is your ethnic background?						
Asian, or Asian British		Black, or Black British		Mixed		White
Bangladeshi		African		White & Asian		British
Chinese		Caribbean		White & Black African		European
Indian				White & Black Caribbean		Gypsy/Traveller
Kashmiri						Irish
Pakistani						
Prefer not to say			Other:	Please specify:		

Do you consider yourself to have a disability?

Under the Equality Act 2010 a disability is defined as 'a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities'

Yes		No		Prefer not to say	
-----	--	----	--	-------------------	--

If yes, what type of disability do you have?					
Learning disability/difficulty		Long-standing illness or health condition		Mental Health condition	
Physical or mobility		Hearing		Visual	
Prefer not to say		Other:	Please specify:		

Do you provide care for someone?

Such as family, friends, neighbours or others who are ill, disabled or who need support because they are older.

Yes		No		Prefer not to say	
-----	--	----	--	-------------------	--

What is your relationship status?					
Married/Civil Partnership		Live with partner		Single	
				Widowed	
Prefer not to say		Other:	Please specify:		

Pregnancy and Maternity					
Are you pregnant		Have you given birth within the last 26 weeks		Prefer not to say	

Appendix B: Eventure Research analysis and report.

See separate attachment or click on the link:

<http://www.leedssouthandeastccg.nhs.uk/Downloads/maternity%20services/Maternity-and-Neonatal-Care-Survey-Results.pdf>

Appendix C: Summary of late responses

	What is the first part of your postcode?	Age	Ethnicity	Hospital baby was born	Rating from that hospital	Neo natal Care Required	How did they rate it	Postive about change? Or raised concerns
1	LS8	20-24	Pakistani	St James	3			Concerns on parking and enough staff
2	DN14	20-24	Black or Black British	LGI	10	LGI	10	N/A
3	S8	20-24	British	Neither		LGI	10	Yes
4	BD5	25-29	Other	LGI	8	LGI	7	Yes
5	LS25	25-29	British	LGI	9			N/A
6	HG2	25-29	British	LGI	9			Concerns on travel. Parking and new faciiliites
7	BD10	30-34	British	LGI	10			N/A
8	HD9	30-34	British	LGI	10			Yes. Parking mentioned
9	WF15	30-34	British	LGI	9			Yes
10	HD8	30-34	British	Neither	10	LGI	9	Parking an issue
11	Wf6	30-34	British	Neither	10	LGI	10	Yes
12	WF1	30-34	Pakistani	Neither				Yes
13	BD11	35-39	British	LGI	9			Yes
14	LS7	35-	British	St James	10			Concern over number of beds

		39						
15	HD2	35-39	Black or Black British	LGI	10	LGI	8	Not affected
16	LS29	35-39	British	LGI	10	LGI	10	yes
17	HD2	35-39	Indian	St James	10	St James	1	Concern over parking
18	BD10	40-44	Black or Black British	LGI	8			
19	YO22	40-44	British	LGI	9	LGI	9	Not affected
20	LS14	N/A	White	St James				Transport and bus connections. Along with SJUH is more spacious
21	WF4		Black or Black British	LGI	9	LGI	8	Parking an issue
22			Black or Black British	LGI	8	LGI	9	Parking an issue
23			Asian					Parking and travel an issue
24			Asian					Parking and travel an issue

Appendix D: List of groups contacted and places visited.

Organisation/ group	Characteristics *reference delivery data 2012/13
Children's Centres LCC (Chapel Allerton)	Local to SJUH. 47 births at LGI & 42 SJUH
Children's Centres LCC (Chapelton)	BAME 41 births at LGI & 129 SJUH
Children's Centres (Carr Manor)	48 births at LGI & 50 SJUH
Children's Centres (City and Holbeck)	BAME City - 72 births at LGI & 48 SJUH Holbeck - 79 births at LGI & 58 SJUH
Children's Centres LCC (Gipton North)	19 births at LGI & 132 at SJUH
Children's Centres LCC (Gipton South)	15 births at LGI & 86 at SJUH
Children's Centres LCC (Harehills)	BAME 57 births at LGI & 471 births at SJUH 55 births by mums aged 10-19
Children's Centres LCC (Kentmere)	Close to SJUH
Children's Centres LCC (Meadowfield)	37 births at LGI & 144 at SJUH
Children's Centres LCC (Meanwood)	Meanwood - 57 births at LGI & 41 at SJUH Meanwood 6 estates -33 births at LGI & 77 at SJUH
Children's Centres LCC (Shakespeare)	BAME
Children's Centres LCC (Shepherds Lane)	BAME
Children's Centres LCC (New Beverley)	BAME
Children's Centres LCC (Seacroft)	Teenage parents group (30 births by mums aged 10-19). 43 births at LGI & 153 at SJUH
Archway (Teenage Parent Housing Support)	Young People
Belle Isle Family Centre (Health for all)	BAME/ Seldom heard
Black Health Initiative	BAME/ Seldom heard
Carers Leeds	Carers (Grandparents group?)
Leeds Older People's Forum	Older people (Grandparents)
Connect In The North	Learning Disability
Leeds Deaf and Blind Society	Disability/ Seldom heard
East Leeds Health For All	Disability/ Seldom heard
Feel Good Factor	Seldom heard /BAME
Getaway Girls	Young Mums
Health for All (Family Support)	Seldom heard
Health for All (Breastfeeding Support)	BAME

Health for All (Cupboard Project)	Young People
Leeds Chinese Women's Group & Mum's & babies group at Chinese Church (Kirkstall)	BAME
Leeds Gypsy & Traveller Exchange	BAME/ Seldom heard
Leeds Involving People	BAME/ Disability/ LGBT
Migrant Access Network	BAME
Shantona Womens' Centre	BAME (Bangladeshi)
Women Health Matters	All characteristics (incl women with disabilities)
Women's Health Matters (Flowers & Bloomers)	
Womens Health Matters (Gipton Young Womens Groups)	BAME/ Disability
Zest Health for Life	BAME/ Seldom heard
http://lesbiangayparents.ning.com/	LGBT
http://www.gayleeds.com/contact/	LGBT
Voluntary Action Leeds (Third Sector Leeds)	Forums
Voluntary Sector (Healthy Lives Leeds)	Contact with lots of voluntary sector groups
Voluntary Action (PSI Network)	
Voluntary Action (Young Lives Leeds)	
Youth Association	Young People
Advocacy Support	East European Communities
Hamara centre (Beeston)	BAME
Touchstone	BAME/ Mental Health
Fathers research project	Muslim Fathers
Production & Promotion group (making a film for Father's in Leeds) LCC	Fathers
Leeds Home Birth group	Mothers
Leeds North West Bliss family group	Families of premature & sick babies
Service user contacts at the university (midwifery course)	BAME
Market Place, Leeds.	Young parents
Harrogate & Knaresborough Bliss Family group	Families of premature & sick babies from outside Leeds.
Richmond, North Yorkshire Bliss Champion	Families of premature & sick babies from outside Leeds
Leeds SANDS	Bereaved parents.
Leeds Maternity Services Liaison Committee	Maternity service users
Hamala service -LTHT	BAME Asylum seekers
Corrine Liddle-Johnson Matron (Inpatient & Safeguarding)	Current service users- outpatient clinics, parent craft, waterbirth & active birth classes.
Health Visitors (employed by Leeds Community Healthcare)	New Mums
	New Mums

PPI lead for health visitors at LCH	
Children's Nursing team, Continuing care and Children with complex health needs Team (LCH)	Parents of children with complex health needs
Child development Centres (LCH)	Parents of children with developmental needs
Child Development Centre (SJUH)	Parents of children with developmental needs
LYPFT Perinatal Service	Mothers with Mental Health Problems
Leeds Addictions Unit (LYPFT) Pregnancy & Parenting service	Mothers with addictions