

# BME healthforum

A study into the experiences of Black and Minority Ethnic  
Maternity Service Users at Imperial College Healthcare  
NHS Trust  
April 2011-March 2013

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## **Recommendations**

### **1) Improve quality of information gathered during antenatal care (See Main Findings 2 and Case Studies 1,2,4,5)**

This project found that a number of women were not asked key questions during the booking appointment. Furthermore, some of these questions were written up in the women's notes as if the women had been asked the questions and had responded as saying they had nothing to report on these questions which was not accurate. It is recommended that:

- Information sent to women prior to the booking appointment should explain the kind of information that will be sought from women at booking so that women have a chance to gather any relevant information (e.g. date of last period, dates of operations etc). This will also allow them to be proactive in informing their midwives of any issues that may otherwise be missed. If there is information that the woman is not fluent in English this information should be translated to the relevant language.
- Where a midwife perceives that there is some difficulty communicating with a woman (for example, lack of fluency in English, hearing impairment) the midwife should ask the woman whether anything can be done to help her communicate e.g. an interpreter, induction loop, easy read material). The maternity notes should record how the woman prefers to be communicated.
- Midwives must ask all women questions regarding mental health, postnatal depression, domestic violence, family history of mental illness and whether a woman is content to continue with the pregnancy without pre-judging the outcome of these questions on the basis of a woman's demeanour or her answers to similar questions. Questions must be asked in a simple way using everyday language that is easy to understand. Staff should be aware that women may not regard bouts of depression and anxiety (including postnatal depression) as a mental illness.
- If for some reason (e.g. lack of time, lack of interpreter, lack of privacy) a midwife is unable to ask all the questions, the maternity notes should reflect that these questions have not been asked so that these topics can be covered at a later date e.g. at the 16 week appointment.
- All women from ethnic backgrounds originating in Yemen or in Africa (particularly Burkina Faso, Côte d'Ivoire, Djibouti, Egypt, Eritrea, Ethiopia, Gambia, Guinea, Guinea-Bissau, Liberia, Mali, Mauritania, Nigeria, Sierra Leone, Somalia, Sudan) should be asked whether they have been circumcised (FGM) even if they are not at their first pregnancy.
- A survey of 50 women should be conducted to see the extent to which the information recorded in maternity notes is accurate and complete. This should be repeated in a year's time to see if there are any improvements.

### **2) Improve the use interpreting services (See Main Findings 3 and Case Studies 2,9)**

The study highlighted that there are many instances where women who are not fluent English speakers are not offered interpreters and that even when they request this service, their request is refused. For the two women in this project who were not fluent English speakers, this led to a number of profound misunderstandings about their choices, which have cost implications as well as resulting in poorer care for the women. This inconsistent use of interpreting services has negative implications for safeguarding women and children as well clinical care.

- Implement the recommendations with regard to interpreting services made by CMACE in the report 'Saving Mothers Lives, Reviewing maternal deaths to make motherhood safer: 2006–2008', 2011. These recommendations include collecting data about the use of interpreting services which is then regularly audited.
- The use of interpreting services by maternity services must be recorded and monitored both by the service itself and by commissioners.
- GPs must include information about interpreting need when referring women to maternity services so that face to face interpreters can be booked for the booking appointment.
- Training given to midwives should explain why expanding the use of interpreters would be beneficial. Such training should use real case studies to demonstrate how misunderstandings in communicating to women can lead to poor care. Training needs to include a discussion about where the appropriate threshold for using interpreters should be exploring the fact that there may be situations where women who speak some English may nevertheless not be able to comprehend complex issues. The benefits of asking women if they understand what they have been told and if they need an interpreter should be discussed.
- Women who ask for an interpreter should never be refused on the grounds that their English is good and they don't need an interpreter.
- Family members and friends should never be used as interpreters in clinical appointments.
- Communication from the Trust to women prior to the booking appointment (by letter or text) should include information about the availability of interpreters and how to request one.
- If a woman who is not fluent in English arrives at the booking appointment where no face to face interpreter has been booked, it is recommended that the midwife uses language line but also books a face to face interpreter for the woman's 16 week appointment so any gaps from the booking appointment can be covered.
- Face to face interpreters should be booked for at least 3 out of the total number of maternity appointments (booking appointment, anomaly scan, 34 weeks), while routine appointments can be managed with language line.
- Where a woman who is not fluent in English is booked for a planned delivery such as an induction or c-section, a face to face interpreter should be booked in advance.
- The options of using mobile phones on loud speaker to use language line or fitting all clinical rooms with telephones should be explored.
- The option of establishing an in-house interpreting service for ICHT should be explored.
- An independent survey of 50 women who are not fluent English speakers should be conducted to assess how many used interpreters and in how many cases their interpreting need was recorded in their notes.
- There are many administrative barriers to using interpreters and it is important that these are reduced as much as possible so that midwives' workloads are not increased as a result of increased use of interpreting services.

### **3) Provide continuity of antenatal care for vulnerable women in a community setting (See Main Findings 4, Case Studies 6, 9)**

Two women in this project experienced some continuity of antenatal care (seeing the same midwife) and this enhanced their antenatal experience considerably. For these women, continuity of antenatal care came from either the caseloading team or from a community midwife based at a children's centre. It is recommended that all vulnerable women are given the opportunity to have their antenatal care provided by the same midwife either within the caseloading pathway or an alternative pathway. Furthermore it is recommended that:

- The criteria for vulnerability are expanded to include women with a history of FGM, women who are not fluent in English and women living in temporary accommodation unless they are evidently not vulnerable.
- Midwives working with vulnerable women have some special training around using interpreters, domestic violence, FGM, homelessness and safeguarding.
- Vulnerable women who live out of area should also be able to access continuity of antenatal care.

### **4) Provide better information to women about the different pathways (Main Findings 5, Case Studies 4, 8, 9, 10)**

This project found that some women were very confused about the number of appointments they were supposed to have and who was supposed to book these. The result was that some women had some tests done later than recommended and at least 1 woman received very little antenatal care. It is recommended that:

- During booking, women are told to book the two scans and the 16 week appointment.
- At the 16 week appointment, women are told to book the 27, 34 and 40 week appointments.
- Women who have extra set of interventions e.g. regular growth scans or cervical scans are given written information which shows how these appointments complement their existing routine appointments so that they are not confused. The Maternity Services Liaison Committee (MSLC) should be consulted on how this information should be presented.

### **5) Provide information to women regarding fasting (See Main Findings 6, Case Studies 2,5)**

In this project two women fasted while pregnant during Ramadan without having received substantial advice from midwives on how to do so. It is recommended that a leaflet for women is produced that informs women that there are different religious opinions on the suitability of fasting during pregnancy and gives advice on:

- The existing evidence on whether fasting in pregnancy is safe.
- Types and quantities of food and drink that are recommended for pregnant women when breaking the fast.
- Warning signs and symptoms that fasting may be affecting the woman's or the baby's wellbeing.

**6) Ensure greater awareness of the birth centre among BME women (See Main Findings 8, Case Studies 1&5)**

In this project two women were not told about the birth centres by their midwives and found out about the service only as a result of the project. They both gave birth at the birth centres and gave very positive feedback about their experience. Information about the birth centre should be given to all women who may be eligible at their booking appointment and at the 34 week appointment.

**7) Ensure birth plans include plans about when to arrive at the hospital in labour (Main Findings 9, Case Studies 5, 6, 8)**

Birth plans should be given greater significance by staff and should include a discussion about when a woman should arrive in the hospital once labour begins. In this project three women were told to go home after they arrived at the hospital, two of which refused while the third went home only to return soon after in an ambulance. It is recommended that:

- At the 34 week appointment there should be a discussion between women and their midwives about when they should come into hospital once labour has started. This should take into consideration where a woman lives, what support she has, how she will travel, and her experience in previous deliveries. The decision should then be documented in the notes so that it can be presented by the woman on arrival to the hospital.
- A review should be undertaken to see if a large proportion of women who are sent home return to hospital via ambulance since if that is the case, this increases healthcare costs and it would be more advisable to keep the women in or near the hospital.

**8) Ensure women are involved in their care and their wishes and concerns are heard (Main Findings 1, 7,10, Case Studies 1- 6, 8-10)**

This project found that most women felt that they were occasionally treated by staff who did not respect them. Examples include staff who had not read their notes prior to appointments, treated their concerns with indifference, gave the appearance of prioritising the wellbeing of the baby over the wellbeing of the woman and did not seek to involve women in their own care. Women sometimes felt that they were being 'told off' and judged. It is recommended that:

- Women are treated respectfully and politely at all times even when they have made mistakes or made decisions with which staff disagree.
- Women should always be given information about their care in a setting which is private and where they are able to ask questions.
- Staff should listen to women carefully and give them time to explain their situation.
- Staff should communicate clearly with women about what they should expect from their care
- Clinicians should read case notes prior to appointments with women so that they have an understanding of why a woman is attending the appointment.
- Women's concerns about how and where they want to give birth should be treated respectfully even when staff disagree with them.
- Women's health concerns about matters that are not directly affecting the pregnancy should be referred appropriately.
- Wherever possible, women should be given information about how they can care for themselves and how they contribute to their own wellbeing.

## **Introduction**

In April 2011 the BME Health Forum was awarded a grant from Imperial College Healthcare Charity to undertake a study into the experience of Black and Minority Ethnic (BME) users of Imperial College Healthcare NHS Trust's (ICHT) maternity service (St Mary's and Queen Charlotte's hospitals). The study set out to follow ten women from early on in their pregnancy until their discharge from the service and record their perceptions and experience of the care they received. The purpose of the study was to look in great depth at the factors that impact on BME women's experience of the maternity service and use these findings to influence how care is delivered to BME women. The study has used qualitative in-depth case studies within a formative approach that has allowed emerging findings to be shared during the study period to inform and improve the care delivered by the maternity service.

## **Previous Research**

Research has shown that BME women experience worse maternity outcomes compared to the White British population. For example, the Confidential Enquiry into maternal deaths which reviewed maternal deaths in 2000-2002 showed that women from ethnic groups other than White had, on average, three times higher peri-natal mortality than White women. Black African women, including asylum seekers and newly arrived refugees had a mortality rate seven times higher than White women. (Confidential Enquiry into maternal deaths, 'why mother die?' 2004, p. 26). This report also found that using family members as interpreters was poor practice (Confidential Enquiry into maternal deaths, 'Why Mother Die?' 2000-2002, 2004, pp. 47; 210).

A more recent report has shown that perinatal mortality among Black African as well as White women has significantly fallen so that Black African women now have 4 times the peri-natal mortality of White women. 'Saving Mothers Lives, Reviewing maternal deaths to make motherhood safer: 2006-2008', 2011, p.48). The report also recommends that all women who are not fluent English speakers are offered a professional interpreting service and that the use of such services is monitored and audited ('Saving Mothers Lives, Reviewing maternal deaths to make motherhood safer: 2006-2008', 2011, p.8)

The Health Care Commission report 'Towards Better Births, A review of Maternity Services' (2008) states with regard to women of Black and Asian origins 'they are less likely to be booked within 12 weeks, they felt they had less choice as to where to have their baby and they were less likely to have a scan at 20 weeks'. Furthermore, 'they had less confidence in the staff during labour and birth and were more likely to be left alone and worried by it.' (Healthcare Commission, 2008 p.78). The same report found that women from BME groups have a greater risk of poor maternal and infant outcomes such as needing to stay in hospital for longer and having their baby cared for in a neonatal unit (Healthcare Commission, 2008, pp. 90, 92).

## **Methodology**

The women in this project were recruited from several community organisations in which adverts were placed and by word of mouth. Seven women were recruited between 14-20 weeks of pregnancy while one woman was recruited before 12 weeks and two women were recruited after 36 weeks.

Women were interviewed every one-two months by the same researcher. Women were encouraged to tell their story in their own words and to keep a diary where practical. They were prompted by the researcher over certain key events such as

information sought at booking appointment etc. With the exception of the two women who were recruited late and where most interviews happened postnatally, women also showed the researcher their hand-held maternity notes to see if all relevant information was recorded appropriately. Women received a payment of £35 per interview.

This study adopted a formative approach. At appropriate points service users taking part in the study were given information or guidance aimed to positively influence their experience of care. In instances where women reported sub-optimal care, the researcher raised the relevant issues with maternity services and/or encouraged women to raise these issues themselves. For example, women who did not speak fluent English were encouraged to request an interpreter and the researcher also requested an interpreter on behalf of the women (unsuccessfully in each case). The researcher also gave two women who had concerns from previous experience of labour, information about the birth centre. Women were also encouraged to attend the MSLC and one woman was able this way to access feedback on the patient experience scores of the labour wing and the birth centre which encouraged her to use the Birth Centre. The researcher also requested that one woman access the independent domestic violence worker and that she is placed under the care of the caseloading team. Both of these requests were actioned by the maternity services.

The formative approach of this study also allowed the researcher to raise early findings with the maternity service at regular intervals. This led to a review of the case notes of certain patients where the maternity services could offer their view of what had taken place. This feedback is recorded in the Case Studies.

The researcher is an active member of the MSLC and the active championing of the early findings of the study by the MSLC has almost certainly contributed to certain improvements before the end of the project. These include improvements in the antenatal environment, greater focus on screening women for mental health problems, posters in clinic reminding midwives to enquire about FGM and collaboration between midwives and the Muslim Chaplain on the advice given to pregnant women who fast during Ramadan. The MSLC also used a scenario around women requesting advice on fasting during Ramadan as an exercise in the recruitment of midwives.

The study was overseen by an active steering group which has reviewed the study's progress and findings and provided advice and guidance to the project researcher. The group met quarterly over the duration of the study and comprised of;

- Administrator, BME Health Forum
- Consultant Midwife for Public Health/ Acting named Midwife for Safeguarding, Imperial College Healthcare NHS Trust
- Director & Maternity Project Researcher, BME Health Forum
- Grants Manager, Imperial College Healthcare Charity
- Head of Equality & Diversity, Central London Community Healthcare & Advisory Group Member, BME Health Forum
- Health & Maternity Project Coordinator, Standing Together
- Lay Chair, Maternity Service Liaison Committee, Imperial College Healthcare NHS Trust
- Senior Children's Commissioning Manager, Inner North West London Primary Care Trust
- Specialist Safeguarding Health Visitor, Central London Community Healthcare

## **Main Findings**

### **1) The information given by GPs to pregnant women does not meet the full standards set by NICE guidelines**

**Context: The NICE guidelines 'Antenatal care: routine care for healthy pregnant women', 2008** state the information pregnant women should receive prior to booking, by the first health professional they see (**See Appendix 1**).

#### **Project Findings**

The project found that the information given to pregnant women by GPs did not fully meet the guidelines by NICE. While all the women in the project were told to start taking Folic Acid, there was minimal or no information given to them about lifestyle or food hygiene. Women who were not fluent English speakers did not receive any information in their own language. None of the ten women received information about antenatal screening as recommended in the guidance.

Furthermore, in the case of a woman (Case Study 4, Rahma) who had become pregnant after contraception failure (because her contraceptive methods had been recently changed because of health concerns) she was not asked by her GP if she was glad to be pregnant or offered any choice about whether to continue with her pregnancy but was just booked into maternity services. Rahma was not at all sure at that stage that she wanted to proceed with the pregnancy and would have very much appreciated a supportive discussion about her choices.

Another woman (Case Study 5, Mallika) was asked about domestic abuse by her GP in front of her husband. While in this instance there was no issue for her to report, this is not good practice.

### **2) Some medical histories collected at the booking appointment are incomplete and/or inaccurate leading to vulnerable women not being identified by the service or accessing relevant services**

**Context: The Imperial College Healthcare Trust (ICHT) Maternity Operational Policy For The Safeguarding Of Children & Young People (2009)** states that: "Maternity staff have a duty to recognise vulnerable families who have known risk factors and identify strategies to achieve optimal maternal and fetal wellbeing, a safe place of birth and effective parenting of the baby."(p.4). This policy identifies among other risk factors: homelessness, FGM, little or no spoken English.

**NICE Guidelines Antenatal and postnatal mental health (2007)** states that women should be asked about any history of serious mental illness, treatment by a psychiatrist and specialist mental health team and family history of perinatal mental illness. The guidance also states that women should be asked two questions to assess their current mood.

## **Project Findings**

In this project 4 out of 10 women had medical histories collected at booking that were incomplete, inaccurate in some way or were lost.

From the 7 women who booked at St Mary's, 1 woman's notes were lost (Case Study 2, Sara) possibly because of a misspelt name and 3 women had medical histories which contained certain gaps and inaccuracies. In general, most of the women did not recall being asked questions around mental health besides whether they were happy to be pregnant. This was particularly noticeable for two women who had significant issues to report around mental health.

The first woman (Case Study 4, Rahma) was on her third pregnancy having suffered from post natal depression in both previous pregnancies which was significant enough that she had been taking antidepressants for the 7 years between the 1<sup>st</sup> and 2<sup>nd</sup> pregnancy. She had also accessed a number of support services after her second pregnancy which she had found very helpful. She was not depressed at the time of her booking appointment. She did not recall being asked any questions around mental health at booking besides whether she was happy to be pregnant and she had no opportunity to discuss her concerns about the possibility of suffering from post natal depression again and how this could be prevented. Her handheld maternity notes specifically wrote that there was 'NAD' (Nothing Abnormal Detected) about her mental health.

The second woman (Case Study 5, Mallika) lives with several members of her extended family including her mother and brother who suffer from Schizophrenia and she is the main carer for her mother. She had no recollection of being asked any questions around mental health besides whether she was happy to be pregnant and her notes specifically stated 'no family history of mental illness'. After the birth of her child, her husband was asked again by the midwife about family history of illness (but not specifically mental illness) and he was able to provide this information.

The third woman is from Somalia and has had type 3 FGM (Case study 9, Hafsa). Her eldest daughter has had FGM (type 1 or 2) immediately after she was born in Tanzania. Hafsa's maternity notes have no record of the fact that she had had FGM and she had no recollection of being asked any questions about it during her pregnancy. In a previous pregnancy she had been given information that FGM was illegal in the UK and had been asked if her daughter had had FGM.

From the 4 women booked Queen Charlotte's, 1 had a considerable error in her notes (Case Study 1, Emily). Emily told her midwife that she has a hearing impairment which is corrected through the use of hearing aids. She was very surprised when she saw in her notes that she had been described as 'deaf'.

### **3) Current use of interpreting service is inconsistent and does not meet the needs of women who are not fluent English speakers**

#### **Context:**

##### **ICHT Interpreters Policy, revised 28<sup>th</sup> April 2011**

This policy states that: "CPG, Ward and Department managers should ensure that services are being used effectively. This includes: Ensuring all patients requiring interpreter services receive them."

This policy also states that face to face interpreters rather than telephone interpreters should be used in certain instances which include "obstetric deliveries". Furthermore, the policy states that: "patients' choice should be taken into consideration when booking an interpreter" and that telephone interpreting is not suitable for bookings that will exceed 20 minutes".

##### **The ICHT Maternity Operational Policy For The Safeguarding Of Children & Young People (2009)**

states that: "Maternity staff have a duty to recognise vulnerable families who have known risk factors and identify strategies to achieve optimal maternal and fetal wellbeing, a safe place of birth and effective parenting of the baby."(p.4). This policy identifies among other risk factors: little or no spoken English.

##### **NICE guidelines 'Pregnancy and complex social factors', September 2010.**

##### **Communication with women who have difficulty reading or speaking English**

1.3.10 Provide the woman with an interpreter (who may be a link worker or advocate and should not be a member of the woman's family, her legal guardian or her partner) who can communicate with her in her preferred language.

1.3.11 When giving spoken information, ask the woman about her understanding of what she has been told to ensure she has understood it correctly.

##### **'Saving Mothers' Lives, Reviewing maternal deaths to make motherhood safer: 2006–2008' 2011 Recommendation 2:**

Professional interpretation services should be provided for all pregnant women who do not speak English. These women require access to independent interpretation services, as they continue to be ill-served by the use of close family members or members of their own local community as interpreters. The presence of relatives, or others with whom they interact socially, inhibits the free two-way passage of crucial but sensitive information, particularly about their past medical or reproductive health history, intimate concerns and domestic abuse.

##### **Baselines and auditable standards:**

Maternity service commissioners and maternity services:

- The availability of a local service guideline on care for women who do not speak English, including interpretation services.
- As part of a local maternity services needs assessment, a local audit of the numbers and percentages of pregnant women who require and are using professional interpretation services per visit. Baseline measurements by December 2011 and then by the end of 2013.

### **Project Findings**

In this project 2 women who were booked at St Mary's had considerable difficulties communicating in English but were not given access to interpreters. The women's difficulty with English was significant enough that the researcher for this project had to use interpreters at each appointment.

The first woman (Case Study 2, Sara) had an interpreter booked for a single appointment, when she was given the news that she had hepatitis, and no family member could attend the appointment with her. She found this service to be excellent. In the other appointments she used her sister as an interpreter but this worked less well. The researcher for this project also used this patient's sister as an interpreter initially but found that her English was not good enough and that she tended to feedback her own views rather than those of her sister.

As a result of poor communication between herself and staff members, Sara was considerably confused about the choices she had. For example, when giving birth she was under the impression that she had a choice between an epidural and a c-section (which is technically impossible as a C-section requires anaesthesia such as an epidural or spinal block). After having a c-section Sara was not aware of any instructions on how to look after her scar. Subsequently her scar was infected and she was readmitted for a week. During that week, although Sara was in a single room with a phone, no staff used an interpreter or language line. She did not understand what the doctors were telling her and she felt very stressed and unhappy. When the researcher asked the staff, if the doctor could use language line, they said they were supposed to use only face to face interpreters for medical consultations but that was difficult to do as they were never sure what time the doctor would come. Sara then arranged for her sister to visit her in the morning so she could interpret but she was not allowed in as she had brought her own baby with her and children other than siblings are not allowed in the postnatal wards. The following morning, Sara's sister came without her baby but the reception staff did not want to let her in as partners only are allowed to visit in the mornings. Sara went to the front desk to complain and her sister was allowed in order to interpret.

The second woman (Case Study 9, Hafsa) in the project whose English was quite poor did not have an interpreter for any of her appointments. In contrast, the researcher had to use an interpreter for each appointment. Hafsa's own assessment of how well she understands English was: "If they ask me 10 questions, I understand 4." When the researcher advised her to ask for an interpreter, she did and was told that she didn't need one because the staff could understand her. "But I don't understand THEM!" she told the researcher. This led to serious misunderstandings during her care. For example, after fainting she went to the hospital where she thought she was offered a blood transfusion. She turned it down because she was worried about infection and was offered an alternative medication. She was also asked to come back on a different day –Hafsa wasn't sure why but she thought it may have been because her children were with her. She went back the next day without her children and after waiting at the hospital for several hours she was given the medication and had to stay overnight at the hospital. When the researcher raised this with the Head of Midwifery, she checked the notes and explained that the woman had not been given the option of a blood transfusion but of a choice of two types of medication –one which could be administered quickly but had greater risk factors and another which had to be administered more gradually.

When Hafsa was 41 weeks she agreed with her midwife to come in to have her waters broken. She arrived late and had to see a different midwife than the one she saw usually. She found this midwife very hard to understand and once again asked for an interpreter but was told again that there was no need because the midwife understood her. Hafsa saw a nurse who she thought was Somali and asked if she could interpret but her midwife again told her there was no need.

The project also found further evidence that the issue of insufficient use of interpreters is a systemic problem. When a community midwife who has been

working in a very deprived area of London was interviewed, she said that in the last two years she has never once needed to use a formal interpreter, although she has occasionally used other staff to help out with some phrases. This came from a midwife who was clearly very committed to her role and who had received very positive feedback from patients.

Overall, there appears to be a lack of recognition that interpreters are an essential component of delivering safe care to women and supporting women to make informed decisions. Staff tend to focus on the immediate and problematic consequences of interpreters (cost and inconvenience) and while this is understandable within the context of a busy service, performance measures and targets need to reflect the impact of using interpreters on outcomes.

#### **4) Women who experience continuity of antenatal care, have a better antenatal experience.**

**Context: NICE Quality Standard for Antenatal Care, Issued September 2012**

**Quality statement:** Pregnant women are cared for by a named midwife throughout their pregnancy.

**Quality measure:**

- a) Evidence of local arrangements and audit to ensure that pregnant women are cared for by a named midwife throughout their pregnancy.
- b) Evidence of local arrangements to ensure that systems are in place to coordinate a pregnant woman's care should her named midwife not be available.

**Definitions:** A named midwife is a named registered midwife who is responsible for providing all or most of a woman's antenatal and postnatal care and coordinating care should they not be available

#### **Project Findings**

In this project, 2 women received the majority of their antenatal care from the same midwife and in both instances the women very much appreciated it.

The first woman (Case Study 9, Hafsa), spoke very little English, had fled domestic violence, and was living in temporary accommodation with 3 children. Although these facts were known to the maternity service, Hafsa was not being seen by a caseloading midwife because she was considered to live out of area (Her temporary accommodation was all over London while the address where she had lived with her husband was 'in area' within Westminster). Following an intervention by the researcher for this project, Hafsa was referred into the caseloading team and assigned a one-to-one midwife. Hafsa found having the same midwife at each appointment very reassuring, because the midwife was very supportive and caring and reduced some of the uncertainty she was experiencing. She also found that with increased contact, she was more able to understand the midwife even though her own level of English was very limited. Hafsa continued finding contact with other midwives very difficult as she was frequently unable to understand them.

The other woman (Case Study 6, Lena) received a lot of midwifery care from a Sure Start midwife based at a Children's Centre in Ladbrooke Grove whom she saw every couple of weeks. Lena was able to get advice from this midwife on different sorts of

issues including information on housing issues and benefits and she found this support very helpful –far more helpful than the support she received from the hospital.

During her pregnancy, Lena started experiencing very severe headaches. While the service she received from the hospital did not extend beyond her being checked for pre-eclampsia, the Sure-Start midwife went through a list of possible causes for her headaches one by one. They agreed that the problem could be her eyesight, so the woman visited the optician and had an eye test. The optician found that her eyesight in one eye had deteriorated rapidly which was probably causing the headaches.

## **5) Many women experience difficulties in navigating the pathway**

### **Project Findings**

Five women in this project experienced difficulties navigating the pathway. One woman (Case Study 4, Rahma) found navigating the pathway particularly difficult because as she was high risk she had many additional appointments made for her but nobody checked that she was still having the routine appointments. She therefore found herself being ‘told off’ for not having made her appointment for the anomaly scan when she was having growth scans on a weekly basis. She similarly found that she had missed out on her glucose testing. Two other women (Case Studies 8, Halima & Case study 9, Hafsa) also found the system confusing, particularly the ticket arrangements for the glucose testing at ST Mary’s and as a result ended up having to rebook appointments and have the tests later than advised. One woman (Case Study 10, Fatima) did not understand that she had to make maternity appointments herself and therefore reported that she only had two maternity appointments (as well as 2 scans) during her entire pregnancy. Another woman (Case Study 3, Shabana) found it very frustrating that while she was repeatedly told that at a subsequent appointment, she would be seen by a particular professional e.g. a consultant, that frequently turned out not to be the case.

## **6) Many Muslim women fast during pregnancy. Pregnant women who fast are not currently receiving evidence-based advice from the Maternity Service about how to do so safely.**

### **Project Findings**

In this study, 2 Muslim women fasted during Ramadan (Case study 2, Sara; Case Study 5, Mallika). They did so without any advice from midwives beyond being told to ensure that they eat and drink a lot during the night and break their fast if they need to. During this project, Ramadan fell in the summer months which meant that the period of fasting lasted for up to 16 hours per day.

## **7) Many women feel that on occasion staff do not listen to them or are rude towards them**

### **Project Findings**

Nearly all women in the project had some negative experiences with staff who were rude, or did not engage or listen to them (Case Studies 1-6, 8-9). In some instances this led to poorer care. For example, Halima (Case Study 8) felt that when she went to the labour ward in labour and told the midwife that her baby would be coming very soon, the midwife did not believe her and was only interested in how dilated she was. This resulted in Halima having to go into a room to give birth by herself and spending

almost her entire labour alone, with the midwife arriving only as the baby was coming. Lena (Case Study 6) also felt that when she went to the hospital in labour, midwives were only concerned about how dilated she was. She was advised to go home and because she refused she was asked to walk up and down the hospital. Lena found it very difficult to control her contractions and she therefore spent a lot of her early labour falling to the floor with each contraction. She found this experience humiliating.

Shabana (Case Study 3) found most staff to be very polite and helpful but she found that the midwife who looked after her after her C-section was so rude that Shabana could not ask her for pain relief even though she was in a lot of pain. Shabana was distressed with having her decision to have an elective C-section challenged at the point she was calling in to come in to the ward in labour by a midwife who had no understanding of Shabana's reasons for her decision. Shabana also found that a number of doctors did not behave appropriately towards her – firstly by saying that she did not need to see a doctor without having first read her medical history which explained why she needed a doctor and for telling her that she could not have a C-section due to funding cuts. Shabana was also upset by the fact that she was only told that her placenta was lying low after her scan had finished while she was in the corridor with no opportunity to ask questions and no advice besides being told 'if you start to bleed, go to hospital' which she found worrying.

Another service user (Case study 2, Sara) was reduced to tears by a member of staff who told her that she should learn English and treated her in a very abrupt and rude manner. She was also upset by the staff in the labour ward who while making no effort themselves to provide her with an interpreter, made it very difficult for her sister to interpret for her, by refusing her entry because she had brought her baby with her and then again because it was 'partners only' visiting time.

Another service user (Case study 4, Rahma) found that certain staff 'told her off' for not having booked certain appointments which was difficult for her as she was having appointments nearly every week and had no clear understanding about which appointments were routine and she was expected to arrange for herself and which were related to being 'high risk' and were arranged by staff. Rahma also found that she was excluded from the discussions about how to control her hypertension with no advice given to her about what she could do to improve her health.

Another service user (Case study 5, Mallika) found that her sonographer did not have any eye contact with her and addressed only Mallika's husband. Mallika thinks that this was because the sonographer assumed that Mallika did not speak English because Mallika was wearing a hijab.

### **8) Women who are eligible to give birth at the Birth Centre are not routinely told of this option.**

#### **Project Findings**

In this project 2 women (Case study 1, Emily; Case Study 5 Mallika) were not told about the birth centre although they were eligible to use it and did so after being told about this option from the researcher. Two other women (Case Study 8, Halima, Case Study 9, Hasna) who had previously given birth at the birth centre did not have this option discussed with them with the result that Halima turned up to the birth centre in labour and was then sent to the labour ward while Hasna had an induction arranged for her without being aware that this would preclude her from using the birth centre.

### **9) Lack of planning means that some labouring women are being sent home inappropriately.**

#### **Project Findings**

In this project, 3 women were asked to go home after arriving at the hospital in labour (Case study 5, Mallika; case study 6, Lena; Case study 8, Halima). Only Mallika did so, and she returned by ambulance which in this instance increased health service costs. From the other 2 women, Halima gave birth within 2 hours and was very angry that she had been asked to go home as all her babies have come very quickly. She was also alone for nearly the entire labour as the midwife had not believed she was ready to give birth because when she came to the hospital she had not dilated. Lena gave birth several hours after arriving at the hospital but she had not wanted to leave because she was very worried that if she went home she would not be able to come back because of the stairs at her home. It is likely that had she gone home she would also have returned by ambulance. All three women would have benefited from having had a discussion with midwives about when to go to hospital, enabling women to explain their reasons for needing to come to the hospital early (eg about having babies that come very quickly). This could avoid the use of ambulances, avoid the risk of women giving birth outside the hospital and relieve women of some anxiety.

### **10) Many service users' experience of labour is positive but often their overall experience is marred by poor communication, some difficult outcomes and poor aftercare**

#### **Project Findings**

Most women in this study had positive labour experiences. The most positive came from the two women who used the birth centre (Case study 1, Emily; Case study 5 Mallika) and one of the women who had an elective C-section (Case study 4, Rahma). All three women were very enthusiastic about the quality of care they received.

For the majority of the other women, most of the experience of labour was positive but was marred to a certain degree by other factors. The worse patient experience was probably that of Sara (Case Study 2) and this related to her not being able to understand what's going on (because she did not speak English and no interpreter was provided), being under a lot of pain, having a fever, and this culminating in a C-section and a post operative infection. Another poor experience was that of Halima (Case study 8) who was told to go home and when she refused, ended up spending most of her (very short) labour alone. Halima was also unhappy about the care given to her baby.

Other issues that marred the experience of patients related to poor outcomes and to a certain degree poor communication and aftercare relating to these outcomes. For example, Hasna and Fatima (Case studies 9 &10) did not expect that because their waters were broken their labour would be more painful than usual. Shabana (Case study 3) felt her experience during her C-section was excellent but naturally she was very concerned when she was told that her womb collapsed. After the operation, she was under a lot of pain and had no suitable analgesia. Lena (Case study 6) felt that after a rocky start when she was not allowed a room in the birth centre because she was not dilated enough, a lot of her care during labour was excellent but this was marred afterwards by the fact that she developed pubic symphysis and was discharged with no extra support or advice on how to manage her condition.

## **Case Studies (All women's names have been changed):**

### **1) Emily**

Ethnicity: Indian

Language: Speaks fluent English

Pregnancy: 2<sup>nd</sup>

Booked at: Queen Charlotte's

Gave birth: Summer 2011

Emily had her baby in Queen Charlotte's in June 2011. Her first child was born at a different London Trust but she had a poor experience which motivated her to try another maternity service.

Emily found her antenatal care at Queen Charlotte's to be satisfactory but impersonal:

"The care before hand in terms of appointments etc. felt very standardised. There was nothing personable about it...mainly just ticking boxes and checking my blood pressure and off I'd go."

In addition, Emily said:

"I do remember a very random conversation, where I was asked if I had any special needs and I said that I didn't but that I am hard of hearing and wear hearing aids in both my ears. The lady then asked me a question, referring to my hearing condition by a clinical term that I had never heard before...and when I told her I didn't understand what she was asking me, she just kept repeating the same thing. In the end, she said it didn't matter and that she would note down this information. Later in my pregnancy, when I had a few complications and ended up in the hospital, I noticed that everyone was shouting at me and asked if I needed someone to sign for me...I then looked at what had been written. I had been classified as being deaf!"

With regard to her labour Emily had a discussion with the researcher about her options in terms of where to give birth and decided to give birth at the birth centre.

"I didn't have a birth plan, mainly as I didn't see the point after the last time, when they didn't take note, however, after a discussion with you, I did go to the birthing centre and mentioned that I was keen on having a water birth, if I didn't have any complications. After looking over my notes, they said to call when I was having my contractions and if they had space they'd book me in.

This is exactly what I did and as they had space I went straight into the birthing room when I reached the hospital. The room was all ready for me. The midwife was in control and was very professional throughout. It was clean and as relaxing as a labour could be. I was given tea and toast as soon as I had him (as was my husband) I was impressed with the level of care I was given and had a good birth. no complications whatsoever, not even a single tear, no drugs or drama. I had my son at 3 o'clock at night and was sent home in the morning. All in all, it was efficient, slightly surreal but such a completely different experience that my impression of what labour was totally changed and even though I didn't have any drugs this time round, I found it a 100 times easier than the last time."

## **2) Sara**

Ethnicity: Arabic

Language: Very little English

Pregnancy: 1st

Booked at: St Mary's

Gave birth: Autumn 2011

Sara understands very little English and tends to use her older sister as an interpreter. When the researcher interviewed her for this project using her sister as an interpreter she found that the sister also had some difficulties understanding English herself and tended to put across her own point of view rather than Sara's. Therefore the researcher used professional interpreters whenever possible to interview Sara.

Sara had some difficulties with her booking appointment as the notes from her appointment were lost in the system (Sara thinks it was because they misspelt her name). Sara also had a very poor experience with a member of staff who took down her personal information and who she felt told her off for not being able to speak English. Sara found this humiliating as she has been attending English classes and has been trying to learn English.

After her blood tests were done Sara was found to have Hepatitis B. Sara was contacted by the hospital and as her sister was away, the hospital booked an interpreter for her. Sara found the experience of using an interpreter excellent and felt she understood everything about her condition and the schedule of immunisations for her husband and her baby. For the rest of her appointments, and for her labour, Sara used her sister as an interpreter.

Sara fasted throughout Ramadan even though she was 9 months pregnant and the fasting lasted up to 15 hours per day. She knew that technically she did not have to fast but she believed that if she did not fast she would have to make up the days later which would be very difficult. She asked the midwife for advice and the midwife told her she could fast if she wanted to but would have to eat well after breaking her fast.

Sara's labour started when she went to the toilet at 1.30am to find out that her water had broken and that she was bleeding. Her sister rang an ambulance who advised her to stay in bed and not go to the toilet until they arrived. They arrived after 30 mins and she went to the hospital where she was told that she should only call an ambulance if it is a real emergency.

The pain continued until the next day and she found it very difficult to deal with, she said: 'I felt I was going to die'. She called the midwife but she was just told to wait. Finally her sister spoke to the midwife in the afternoon who advised her to have a warm bath but that didn't help. She then received an injection that helped her sleep for a couple of hours. When she woke up the rest of her water had poured out and she was taken to the labour ward. There she was examined, told she was only 3cm dilated and told she would have to wait. They offered her an induction which she thought would be a good idea. At this point she developed a high fever and they tried to induce her for 4 hours but it was unsuccessful and she was in a lot of pain and very tired. They then told her that if she wanted to have a natural birth she would have to wait at least 8 hours and she didn't feel she could do that. They told her she could have an epidural to relieve the pain but she was too worried about the dangers to accept. Then the consultant told her that she didn't have to worry about the side effects and that if she didn't have the epidural she would have to have a c-section. She said: "I felt both were difficult choices. In the end, I decided to take the epidural."

However, she had to have 3 epidurals before they had sufficient effect. At this point she began to shiver and lost all feeling in her feet. Her temperature was found to be 40C and she was taken to theatre where she had a c-section. She found the rest of her stay in hospital very good.

Sara went home a couple of days later without being aware of any advice on how to look after wound. The midwife visited once and then Sara had to come in to the hospital to have her stitches checked. It turned out she had an infection and had to stay in hospital for a week. During that week, although Sara was in a single room with a phone no staff used an interpreter or language line. Sara did not understand what the doctors were telling her and she was very stressed and unhappy. When the researcher asked the staff if they could use language line with Sara when the doctor came they said they were supposed to use only face to face interpreters for medical consultations but that was difficult to do as they were never sure what time the doctor would come. Sara arranged for her sister to visit her in the morning so she could interpret but her sister was not allowed in as she had brought her own baby with her and children other than siblings are not allowed in the postnatal wards. The following morning Sara's sister came without her baby but the reception staff did not want to let her in as partners only are allowed to visit in the mornings. Sara went to the front desk to complain and her sister was allowed in order to interpret. Sara thought that the reception staff were very rude to her sister. Sara still feels very unclear and disappointed about her care at the hospital.

When Sara's son was checked out by the paediatrician he was found to have undescended testicles. Sara's sister interpreted for her to explain what the paediatrician said.

### 3) Shabana

Ethnicity: Mixed Asian/African

Language: Fluent English

Pregnancy: 2nd

Booked at: Originally at St Mary's, then switched to Queens Charlotte's

Gave birth: Autumn 2011

Shabana found out that she was pregnant at the emergency gynaecology department at St Mary's where she went because she was experiencing prolonged bleeding. She had been told two months previously that she would be unlikely to get pregnant soon because of fibroids.

Shabana was immediately told 'congratulations' by the staff at St Mary's even though it was clear at the time that the pregnancy was unplanned. At the time Shabana thought she must have had a miscarriage. When she told the doctor, the doctor was initially very apologetic but when the scan confirmed the pregnancy she congratulated Shabana again.

Shabana was also told by staff that she could not be referred to maternity on the system and would have to go through her GP to book in. She was already 9 weeks pregnant at the time. Because she was going away for a week the next day she rang her GP and asked to speak to the doctor but was told she couldn't. Shabana said that she was pregnant and needed to book an appointment so she could be booked into maternity and they booked her an appointment for a week later. Her GP was quite rude, about the fact that Shabana was presenting so late in her pregnancy (nearly 10 weeks). Also the GP did not give Shabana any information about antenatal screening. She tried to book Shabana at St Mary's but there were problems with faxing the forms and Shabana still had not received a booking appointment at nearly 12 weeks. The patient then found out that she could book in herself through the maternity line (the hospital had still not received the fax from the GP) but they couldn't give her an appointment over the phone and she was told she had to wait for the letter. The letter arrived on the same day as the appointment –she received it in the evening. The next day she tried to ring the W9 Woodfield clinic repeatedly but couldn't get through. She rang the maternity line again and asked to be given a booking in appointment over the phone which they did.

At the booking appointment, Shabana was told that there weren't enough midwives to do the appointment and was asked to come back another day (she was over 12 weeks pregnant). Shabana refused. In the end a woman who Shabana assumes must be a midwife told her that she would book her even though she does not normally take bookings but was doing this as a favour because her colleague couldn't take the booking. During the booking appointment when Shabana was giving the history of her first labour, she found that she had to spell 'shoulder dystocia' and explain what it was to the midwife. Instead of Shabana and the midwife having a conversation together, the patient sat next to the midwife and helped her input information on the computer.

Shabana was offered the testing for thalassaemia trait because of her mixed African ethnic background. Shabana already knew she was positive for the trait as she had been previously tested for this at St Mary's. However, because this was not on her maternity records, the midwife asked her to be re-tested and her husband was called in to be re-tested also.

Shabana does not think HIV testing was discussed or that she was asked about substance misuse, mental health or domestic violence. Her notes showed that she had been tested for HIV. She was told about the Down's screening and Shabana agreed to do the scan which she did at 13 weeks.

Shabana found the conditions at the W9 Woodfield antenatal clinic very unpleasant. She found that the receptionists were abrupt and that there were so few seats, that some women were forced to sit on the floor. When she asked for a glass of water she was told to get water from the toilets.

Shabana's following appointment at 16 weeks was with a doctor (presumably because the midwife at the booking appointment had identified Shabana as high risk due to the complications of her previous pregnancy). Shabana thought she was going to see a midwife. The doctor was concerned about Shabana's labour history (very large baby, shoulder dystocia, blood transfusion, third degree tears). The doctor told her she may have to have a C-section, would not be able to use the birth centre & needed an extra scan at 24 weeks to check on the size of the baby. The doctor made notes on the computer screen about Shabana's case. He also asked Shabana to bring all her notes from her first labour in Australia. Shabana had no hand held notes at this point and the doctor wrote the notes on the computer. The doctor booked Shabana an appointment for 24 weeks.

At 20 weeks Shabana had her anomaly scan with a midwife (the practitioner explicitly told Shabana that she was a midwife). The scan was very good and detailed. At the end of the scan, when the patient asked about the gender of the baby, the midwife reapplied jelly and told them it was a girl. Once Shabana and her husband were walking out and were in the corridor, the midwife told Shabana that her placenta is low and that she will need to have another scan at 32 weeks. She then said 'If you start to bleed go to hospital'. There was no other information just another scan booked. Shabana found this very stressful as she had no opportunity to ask any questions and had to resort to getting her information from the internet.

At 24 weeks Shabana went to her appointment thinking she was going to see the same doctor who was going to do a scan and check the size of the baby. At the appointment she saw a different doctor who told her 'I don't know why you're here'. Shabana tried to explain that the baby might be big and that she was expecting a scan to measure the size of the baby and that she had her notes from her first birth from Australia. The doctor kept repeating 'I don't know why you're here.' The doctor did the usual observations and then afterwards told the patient again 'I don't know why you're here.' When the patient tried to give the doctor the notes from Australia, the doctor said that she already had her notes. In the end, Shabana told the doctor that she was having a very bad antenatal experience, had not appreciated being told she had a low placenta in the middle of a corridor, did not want to request a c-section but did not want to have shoulder dystocia, a blood transfusion and third degree tears again. The doctor was surprised by this and then asked her for her notes from Australia. It is clear that until this point doctor had not accessed Shabana's medical history. Shabana felt that it was only when she started using medical language that the doctor started listening to her. When the doctor started discussing the issue she recommended trying for a normal delivery with a doctor present. Shabana was concerned about whether the doctor was putting her at risk just because she did not want her to a caesarean section.

Shabana then decided to transfer from St Mary's to Queen Charlotte as Queen Charlotte's was closer to her home and she was not happy with her antenatal experience. Shabana called the Maternity helpline who were extremely helpful in

helping her transfer from St Mary's to Queen Charlotte's. Shabana found the experience of booking in at Queen Charlotte's much better than at St Mary's. For example, she got her hand held notes at her first appointment as well as information about the pathway. Also, as soon as she arrived for her appointment she was greeted by a nurse who took her urine sample, blood pressure, weight and height while she waited for her booking appointment and gave her advice about how much water to drink and was generally very friendly. Queen Charlotte's also had more reception staff who were more polite than at the W9 clinic. Also the clinic had maternity information on screens which was helpful. The initial wait was only half an hour and the midwife that did the booking was very nice and helpful.

At Queen Charlotte's Shabana had to redo all the blood tests and give her history again because Queen Charlotte's had no means of accessing the St Mary's notes (but they could access Shabana's non-maternity files from St Mary's). The procedure in Queen Charlotte's is that the patient fills the forms giving her own medical history and the midwife then queries and discusses certain issues only. However, when Shabana looked at her notes she noticed that some of the issues that the midwife had recorded as 'discussed' had not been discussed. There was no discussion on birth plan, sex, physical & emotional effects of pregnancy, home/work safety, maternity benefits, breastfeeding benefits etc. The midwife had also ticked that Shabana had been given a breastfeeding booklet but she had not. Other questions e.g. about substance misuse had also not been asked but the midwife left those blank at the notes rather than tick them as 'discussed' as she had done with the others.

Due to long delays Shabana was asked to come back in a few days to see a doctor and the staff were very helpful in booking this appointment to coincide with her appointment for her scan.

Shabana then had a couple of appointments with doctors where the issue of whether she should have a caesarean section was discussed. These appointments were supposed to be with consultants but the consultants were not available. Both doctors said that Shabana would not be able to have a caesarean section because of lack of funding. The first doctor brushed off her request but the second was very sympathetic and said that if she had the power to book her a caesarean section she would but she did not have the power. She also referred her to a specialist to check how Shabana was healing from the 3<sup>rd</sup> degree tears of her previous labour.

When Shabana had the appointment with the consultant, the consultant also said that she should not have a caesarean section and since there were concerns that the baby was very large she should be induced right away (Shabana was 37 weeks at this point) before the baby grew anymore. Shabana insisted that she wanted a caesarean section because she felt any other type of birth was putting her at risk and she felt very scared and started crying. She also told the consultant that she was already experiencing some incontinence and was worried that would get much worse with a natural labour. Then the consultant agreed to give her the option of a caesarean section but also booked her for an induction in 3 days time in case she changed her mind. Shabana feels that it was the fact that she was becoming incontinent that convinced the consultant to agree to a caesarean section. Shabana also had to explain to the consultant over and over again that she only wanted a caesarean section because the baby was very large that she would not have requested a caesarean section under normal circumstances.

Before her due date Shabana developed a fever and she called the out of hours service for advice. The doctor told her to take some paracetamol and have a cool

shower and called her back to check the temperature had gone down. He also advised her that if she developed a high fever to go straight to hospital. Shabana found the out of hours service very helpful.

Shabana's waters started leaking two days before the date her c-section was scheduled. She called the hospital and asked what to do. The midwife told her that the labour ward was very busy but she could come in. When the patient explained about the c-section, the midwife asked her why she was having one and told her she should try and give birth naturally. Shabana ended the conversation and called again 3 hours later and spoke to a different midwife who also asked her why she is having a c-section but who was very understanding and asked her to come in to check if her waters have broken. She went in and was examined by a very sympathetic doctor who she had seen before and who remembered her. The doctor asked her if she definitely still wanted a c-section. She said she did. The doctor explained that there were already two women in surgery and emergency c-sections would take precedence over an elective c-section so they don't know when they would be able to operate. The patient asked what would happen if the labour progressed. The doctor said that there was a small chance that she would deliver naturally but that she would try and get her in the operating theatre that day. Shabana felt worried.

Later that day, Shabana was told by another doctor that she'll be taken in to have a c-section in an hour. The environment in the operating room was very nice as were the anaesthetists and the other doctors and Shabana thought it was very nice that all the staff were women. She told them she was scared and they were all very reassuring and chatted to her to take her mind off things. The baby was born. Half an hour later, Shabana felt ill and asked her husband to take the baby. There was a big rush and more doctors and consultants came in. They told her that her womb has collapsed and she was bleeding. They cauterised her womb. She finally left surgery half an hour later to go into recovery. Midwives were still very helpful and gave her medication. Because of the blood loss Shabana had no colostrum so she asked the midwives to bottlefeed the baby which they did. Shabana was told by the doctor that she would stay in recovery for the night.

At 2.30 am, a new doctor came in and told Shabana that she's going to be moved to the postnatal ward. The midwife who moved her was rude and dismissive when Shabana told her she was in pain and told her that nothing can be done. She was given morphine but the pain was still unbearable. Shabana stayed awake all night but didn't want to call the midwife again.

At 8am Shabana saw the doctor and told her she wished she had not had a c-section because the pain was unbearable. The doctor asked her about when the last time she had painkillers and the patient explained that she didn't want to talk to the rude midwife. The doctor told her it's important to have pain relief and gave her morphine. Within 5mins Shabana was in agony which she thought was caused by the morphine. She called the midwife and asked her to call the doctor. The doctor came two hours later, told her she is having an allergic reaction to morphine, gave her intravenous paracetamol and wrote in her notes that she should not be given morphine. She also said she is sorry about what happened in surgery.

The rest of the stay in hospital was very positive and the staff were all very nice. Shabana was visited by the anaesthetist who brought her a fan. Shabana felt very grateful to the staff for their help. Shabana breastfed the baby and was offered support if she needed it.

After Shabana went home, she received 3 visits by midwives who were all very helpful. One of the midwives called her to apologise because a different midwife was going to come because she was in training. She was advised to take the baby to hospital because the midwife thought she was still jaundiced at 14 days (Shabana didn't think so). The baby turned out not to have jaundice but when the midwife saw that Shabana was still walking in pain she examined her and sent her to a doctor who examined her and gave her antibiotics and more painkillers for an infection. The visit by the health visitor was ok but felt a bit rushed and pointless.

#### **4) Rahma**

Ethnicity: Tanzanian  
Language: Speaks fluent English  
Pregnancy: 3<sup>rd</sup>  
Booked at: St Mary's  
Gave birth: Winter 2012

##### Contraception failure

After feeling tired Rahma went to the Raymede clinic where she was advised to have a blood test. It was discovered that she was anaemic and the likely cause being excessive bleeding due to the coil that she was using. She was advised to stop using the coil and had a discussion about alternative contraception methods. While she was deciding what would be most appropriate she was advised to use a condom. However she had had many accidents in the past and repeatedly had to go back to the clinic for morning after pills. After missing a period she did a pregnancy test that came up as negative but was booked for a scan anyway to double check. She missed the scan appointment but had a very light period shortly afterwards. She went back to the Raymede clinic to double check about the light period she had had. They gave her a pregnancy test and discovered that she was pregnant. She was then told to visit her GP.

##### GP practice

The GP confirmed her pregnancy but had no discussion with her whether she was happy about the pregnancy or not. Rahma would have liked this discussion as her pregnancy was not planned and she was very anxious about her job and how her employers would react. The GP told her that her next appointment would be at St Mary's and to take folic acid.

The GP did not mention anything about screening. Previously Rahma had had this discussion at the hospital but not with the GP. However as she was now 38 years old and the risks are higher she would have liked a discussion about this earlier to have time to make a more considered decision.

##### Booking Appointment –History Taking

At the booking appointment Rahma did not remember being asked her any questions about her mental health. Her notes under mental health say N.A.D. 'nothing abnormal detected'. Rahma had in fact suffered from post-natal depression after her first child was born and was subsequently on anti-depressants for 6 years. She was advised to come off them with her second pregnancy. After the birth of her second child she suffered from post natal depression again but accessed some very helpful support services that helped her cope without anti-depressants.

##### Vitamin D

Rahma was not given any information on Vitamin D. As a result of the project it was suggested that she asks the midwife about this. She did so and was told: 'to go out and get some sun'.

##### Hypertension

Rahma suffers from high blood pressure and is on medication for this. Because of this condition she has had to have regular growth scans and regular monitoring of her blood pressure with the GP. The medication makes her feel very tired and

despite taking it she continues to have high blood pressure when it is recorded. This is very frustrating for her, especially as she is not offered any other advice on how to keep her keep her blood pressure low and she does not feel involved in her care.

#### Scan

Rahma did not know she had to book a 20 week abnormality scan. At the time she was having growth scans every 2 weeks because of her high blood pressure and these scans were being booked for her so she had no idea that the 20 week scan was different and that she had to book it herself. The sonographer who noted she had missed her 20 week scan was quite abrupt with her although eventually offered to do it at the same time as the growth scan which Rahma did. Subsequently Rahma was sent a letter telling her she had missed a scan appointment on a date that was not recorded in her notes. There was obviously some confusion with how this was handled and noted.

#### Glucose test

As Rahma was attending the hospital nearly every week she expected that she was having all the routine care as well as the high risk care. However, she noticed herself that she had not had the glucose test at the time she was meant to have had it and had to ask to have it. Rahma found it stressful that even though she was receiving so much attention from the hospital she had to constantly check she was receiving everything she was meant to.

#### Labour and birth

Rahma was booked to have an elective C-section on the 27<sup>th</sup> December. She had enquired about a natural caesarean but was told that St Mary's don't offer this procedure. She was explained thoroughly the procedure and what she should expect.

Rahma started having painful contractions on Christmas day and called the hospital. She was asked how often they come and she told them about every hour. They said that when they came every 5 mins she should come to the hospital.

The contractions continued to be more painful at boxing day and so in the evening she went to the hospital. On arrival she was told by the doctor that she should have mentioned that she had high blood pressure as she should have come in straight away when she called on Christmas Day and they would have given her the caesarean section earlier. She was told: 'We take high blood pressure very seriously'. She was got ready for the operating theatre for the next morning (which was her scheduled time anyway). The birth went very well and they gave her the baby to hold skin to skin immediately.

#### Postnatal ward

Everyone in the post natal ward was very nice. The only problem was that she didn't get breakfast (only tea) the morning after she had the baby because the hospital had run out of bread and this was really difficult as she was very hungry and needed to take food with all her various medications - she had to ask her husband to bring her something to eat finally.

The first night she asked for formula as her milk had not come yet and the baby was very hungry and crying while Rahma had been feeding her for 9 hours. When she asked for the formula it was given to her. Once she went home Rahma breastfed exclusively.

At one point a nurse came over with an injection. Rahma asked her what it was for and she said it was for an infection. Rahma said she thought there had been a mistake because she didn't have an infection but the lady in the bed next to her did. The nurse checked her notes and indeed the injection was not for Rahma. This incident concerned Rahma.

### At home

Rahma gave birth on Wednesday and was out of the hospital by Friday. The midwife visited her the 1<sup>st</sup> week at home and came back the 2<sup>nd</sup> week.

Rahma suffered terrible headaches and had to go to the hospital. She went there with her midwife who waited with her. She was told that the headaches were due to the medication she was taking for her high blood pressure. She was advised to stop taking them and go to her GP to review her medication.

While pregnant Rahma had bumped into the midwife from Maxilla Children's Centre who had helped her with postnatal depression after her second child. When she saw that Rahma was pregnant again, she arranged to visit after the baby was born and gave her lots of advice and reassurance regarding warding off feelings of depression. The midwife gave Rahma her telephone number to call when she needed to and also gave information about a drop in clinic where she can see her. She encouraged Rahma to come out of the house as often as she can and suggested groups and exercise classes she can come to during the week with her baby.

Rahma had felt a bit lonely during the first week after her daughter was born but she made sure she went out a lot and kept busy which helped her a lot.

### Healing of C- section

Rahma's caesarean section was done very well and she healed fast with a minimal scar. Rahma was very happy about this.

## 5) Mallika

Ethnicity: Bangladeshi  
Language: Fluent English  
Pregnancy: 2nd  
Booked at: St Mary's  
Gave birth: Spring 2012

When Mallika suspected she was pregnant she went to her GP who did a pregnancy test which was positive. He asked her which hospital she had had her first baby and when she said it had been St Mary's he booked her there without asking if she was happy with that choice. Mallika would have liked to have been given a choice because even though St Mary's is the hospital closest to her she had a very poor experience there with her first baby six years ago which had put her off having anymore babies. The GP gave Mallika Folic Acid, Vitamin D and Iron tablets because she had already been tested and found to have iron and vitamin D deficiency. He told her that pregnancy is not an illness which she found very helpful. Mallika attended the appointment with her husband and was nevertheless asked by the GP 'Any domestic violence issue?' The GP did not give her any advice about what to eat or antenatal screening.

Mallika's experience of arranging her booking appointment was very stressful. She was given the details to book herself online which she did but then she received a letter saying that she had cancelled the appointment. When Mallika rang to query this she had to go through several people until she spoke to the right person. Mallika was not sure of the job title of the person she spoke to but she was extremely rude and told her that she would just have to wait until she received an appointment letter to find out when her appointment was. Mallika said that she needed some notice to arrange the time off work and the woman said 'I'm not going to say another word you just have to wait for your letter'. Mallika was quite upset and when she went home she told her husband – 'no wonder I waited 6 years before having another baby'.

Then she received another letter telling her she had an appointment but this was followed by a third letter also saying she had cancelled her appointment and Mallika had to ring the hospital again. She then spoke to someone helpful who confirmed her appointment and then she went to her appointment at 10 weeks. Because of this delay Mallika had her booking appointment after the end of Ramadan so she wasn't able to ask the midwife's advice about fasting during Ramadan. Mallika searched information about Ramadan on the internet and she spoke to her GP. She concluded that she didn't have to fast during Ramadan but if she didn't, she would have to either make up the days later or pay money. She also asked her GP who said that she didn't have to fast but she could if she wanted to as long as she felt well and was healthy and drank enough fluid during the night and that if she feels unwell she should break the fast straight away. (The GP had not originally known that fasting during Ramadan meant she wouldn't be drinking water during daylight hours, and she had to explain it to him). Mallika's husband also asked the mosque for advice and was also told by the Imam that she didn't have to fast. Mallika chose to fast because as she was on annual leave from work, she was able to be up all night so she found it easy to fast during the day and eat and drink during the night. Her husband was really insistent that she should not fast and told her she was being irresponsible. After the end of Ramadan, she found it difficult to stop fasting and she started feeling morning sickness. Mallika feels that she was open minded about the issue of fasting – she thought she might have to break her fast but she felt very well so she didn't. She said she thinks her motivation was that when she was growing up in Bangladesh her mum, her grandmother, and her mother in law all fasted when

they were pregnant (but broke their fast when necessary). She was also thinking that she may not be able to fast the following year because she would be breastfeeding.

### **Booking appointment**

Mallika went to the booking appointment on her own and saw a very nice midwife who found the notes of her previous pregnancy, took her history, talked about screening and had the blood tests. Mallika was asked about whether the pregnancy was planned and how she was feeling, morning sickness etc but there was no discussion about mental wellbeing, mental illness in the family or postnatal depression. Mallika's maternity notes specifically stated 'no family history of mental or learning disability'. This is inaccurate as Mallika's mother and brother suffer from Schizophrenia and Mallika is a carer for her mum. Also, Mallika feels she may have had postnatal depression after her first baby as she was frequently crying but once she went back to work after her maternity leave finished she felt much better. Mallika was asked about STIs, drugs and alcohol and domestic violence. Mallika was happy to be asked about these things. She was also offered antenatal screening which she accepted.

Mallika also requested a blood test for thyroid function as she was already taking medication about it. The midwife didn't want to include it and told her to go back to her GP. Mallika insisted so the midwife included it which was good because she turned out to need an increase in her dose. She got a call from the hospital to see an endocrinologist specialist although when she went to the appointment she saw a midwife who told her the specialist had recommended an increase in the dose. She was then retested and she was fine.

During this appointment, the midwife totally blanked Mallika, had no eye contact with her and only talked to her husband. Mallika couldn't understand why until her husband said 'she thinks you don't speak English'. Then Mallika started talking and the midwife started talking to her and was very nice. Also during this maternity appointment her husband told the midwife that Mallika had fasted during Ramadan, thinking that the midwife would tell her she was wrong but the midwife said that's fine as long as she ate and drunk enough during the night.

On the same day Mallika had her scan. The sonographer was not very nice and was quite rude. When Mallika asked for a photograph she was asked to wait outside in an abrupt, unfriendly way.

Mallika had two more scans (the anomaly scan had to be repeated because the baby was not in the right position) and these sonographers were extremely nice. She was asked if she had a preference for the gender of the baby, and Mallika said she preferred a girl and she was told the baby was a girl.

Mallika was not given any information about the birth centre from the midwives, but the researcher for this project told her that the birth centre was an option and that the feedback from the birth centre was very positive. Mallika then attended an MSLC meeting where the stats for patient satisfaction were presented for the labour ward and the birth centre so that Mallika decided to request to use the birth centre.

Mallika had two very useful visits to the birth centre, first to meet the midwives and then for a class. She said she wished she had had this information for her first baby. She was due to visit a third time but she went into labour that day.

Mallika started having contractions and she rang the hospital and she was given the advice to have a bath which she did and the contractions started getting stronger so

she went to the hospital. The midwife there examined her and sent her home. When she was home the contractions started getting completely unmanageable and she went back to the hospital by ambulance because she didn't feel she could get there any other way.

Mallika found the culture at the birth centre very different to the labour ward in 2005, as everyone was very courteous, gentle and nice. While with her first baby she remembers calling for a midwife during labour because the baby was distressed and nobody coming, this time the midwife didn't leave her alone at all, in the 4 hours she was giving birth not even to go to the toilet. Mallika spent sometime in the birthing pool and then used the birthing ball and the baby came after a few hours at 7pm. Mallika described her midwife as having been like an angel and she was very happy with her experience.

When Mallika had to have stitches for 2<sup>nd</sup> degree tearing the midwife couldn't ask her permission because she was too high on antinox so she asked her husband's permission. The next day the midwife came to explain to Mallika that she had had to do that and Mallika said she found the way her midwife spoke to her very nice and very caring.

A midwife also asked Mallika about any family history of illness and Mallika's husband was able to explain about the family history of mental illness in Mallika's family.

Mallika had to be discharged a little bit early the next day which was a bit of a rush. Also after she went home she was told that the midwife would visit the next day but in fact nobody visited until a couple of days after. When Mallika called to ask about the visit, she was told that the midwife had recorded it as having visited her even though she had not.

## **6) Lena**

Ethnicity: British, Mixed Heritage Black/White

Language: Speaks fluent English

Pregnancy: 1st

Booked at: St Mary's

Lena received a lot of support during her pregnancy from a Sure Start midwife whom she saw every couple of weeks at a local children's centre. She was referred there through her GP. Lena was able to get advice from this midwife on all sorts of issues including information on housing issues and benefits and she found this support very helpful –far more helpful than the support she received from the hospital.

During her pregnancy, Lena started experiencing very severe headaches. When she called the maternity line she was told to go to hospital where they would be expecting her. When she arrived at the hospital nobody was expecting her and they told her she would have to wait 2 hours to be seen by the doctor. She then had to wait 5 hours during which she felt extremely ill. Her blood pressure was measured and found to be normal. When she finally saw the doctor she only had a very brief discussion with her and was told to go home as the doctor was called for an emergency.

When Lena approached her Sure Start midwife for the same problem, she went through a list of possible causes for Lena's headaches one by one. They agreed that the problem could be her eyesight, so Lena visited the optician and had an eye test. The optician found that her eyesight in one eye had deteriorated rapidly which was probably causing the headaches. Lena found that if she rest her eyes her headaches went away.

Lena had been booked to have her baby at St Mary's birth centre. She attended a parental education class and a birth centre induction session. She found the parental education class very useful, but the birth centre session less so as it was quite busy and didn't have the chance to ask questions and she felt quite scared. It was unfortunate that the birth centre sessions came before the parental education session.

When Lena's contractions started the baby was 10 days late. She phoned the hospital several times but was always told to stay at home. After 5 hours she decided to go to the hospital anyway because she was worried that if she left it any longer she wouldn't be able to go down the stairs at home. She had also heard stories of women being told to wait at home who ended up giving birth at home so she was worried. At the hospital she was advised to go back home without being examined first on the basis of how frequent the contractions were. She refused to go home and was told to walk up and down the hospital. At this stage however, she couldn't manage the contractions so she was collapsing on the floor with each contraction. When she was examined she was only 2-3 cm dilated. As she was lying on the floor, a midwife told her to get up and walk and that she wasn't allowed to be in the birth centre. She told the midwife she couldn't get up. She told her partner that she didn't want to go to the main hospital and lie on the floor in front of people walking in and out that this would be humiliating. She felt that the baby would come within 24 hours and she had been told that she would be allowed to be in the birth centre for 24 hours so she couldn't understand why she couldn't be admitted. Also she felt that some midwives were not very nice and only cared about how dilated she was.

After a couple of hours Lena got control of her breathing and with the help of her partner and godmother she started walking around the hospital. Then the pain got

really bad and she went back to the birth centre where she was examined and found to be 4cm dilated but also bleeding and the baby's heart rate was going down so she was sent to the labour ward. In the labour ward, she had needles put in her hand, her legs were put in stirrups and she couldn't move. She was lying on her back until she was 10cm dilated. She had gas and air, she was offered an epidural but she refused. She found the experience very horrible. She could hear lots of voices around her but she didn't have a person who could explain to her what was important for her to hear or how to manage her breathing and her contractions. There were lots of instructions but she was trying to ignore them and focus on the contractions, as she felt she didn't know how to push and was worried about panicking.

In the end, the doctors wanted to give Lena a c-section but all the operating rooms were full. She had an episiotome and a ventouse was tried but neither worked. Finally, a very good midwife came in and really anchored her, had lots of eye contact, and told her how to push and that the baby had to come out immediately. She pushed, and two midwives pulled her legs apart, wider than they could go and the baby came out.

When Lena was due to be discharged, she suddenly fell to the floor and couldn't walk. She was examined by a doctor and told that it was simply because the painkillers had worn off and was given more painkillers and sent home. Her partner had to ask for a wheelchair to get Lena out of the hospital, as well as pushing the pushchair with the baby. At home he had to carry her three flights of stairs because she could not walk. The pain did not get better with pain killers and she could not walk so she called the out of hours GP who said she probably has pubis symphysis because her legs were pulled apart in labour. He told her to take paracetamol and call her GP and that it would probably get better in two days. Her GP told her he had been dealing with women giving birth for 10 years and had never heard of this condition. The midwife from St Mary's was very good and also diagnosed the condition as pubic symphysis. She tried to get a doctor to come round but nobody would come.

Lena had to have 24 hours help from her family for the next two weeks as she could not walk and could not go to the toilet by herself or look after the baby and was in unbearable pain. She was not able to get help from St Mary's and she found it difficult to convince the local GP surgery staff that something was wrong as she had no diagnosis to offer and she could not get a GP to visit her. During this time, Lena's Sure Start midwife and the community midwife were very concerned about her physical state and started to pressure her GP and St Mary's with phone calls, to get pain relief and a diagnosis. Eventually an arrangement was made for a friend to pick up some pain killers from the local GP surgery. However, she was told that breastfeeding was affected for 5 hours of taking them so she only managed to take two. The out of hours doctor refused to come 5 times. Eventually he came on the 10<sup>th</sup> day and gave her a formal diagnosis. Lena was then referred to Chelsea and Westminster (with hospital transport) for physiotherapy which was helpful, gave her lots of advice, explained how to get in and out of bed, move on crutches, and gave her a support band which helped a lot. However, she only managed 1 session there as she found the stairs impossible to manage by herself and it was all too difficult to do with a new baby. After 8 months she was well enough to attend weekly physiotherapy at St Charles which was a lot closer. However, Lena continued to be in some pain for up to a year after her baby's birth.

As a result of this project, Lena decided that she would like to have a review of her notes with a midwife. Although when she had the review, the midwife was very supportive and nice, Lena was disappointed that her case notes omitted a lot of

information –for example, the notes did not state that the doctors wanted Lena to have a C-section and it was only when it was clear that there was no theatre available, that the midwives pulled her legs apart to get the baby out. There was also no mention of the fact that Lena collapsed as she was being discharged and that she was seen by a doctor who told her that the problem was simply that the painkillers had worn out and to take more, or that her partner had to take her home in a wheelchair.

**Note:** When this case study was discussed with the maternity service at Imperial it was stated that a formal diagnosis of pubic symphysis had been made by the hospital before Lena was discharged and a care plan had been written. This raised many additional questions for Lena, including why she had not been told this at her review, why Lena and her partner were not given a diagnosis before she left the hospital and were not told what to expect, how to manage the condition and what help they would need. As a result, Lena is making a formal complaint.

## **7) Akari**

Ethnicity: Japanese

Language: Intermediate English

Pregnancy: 1st

Booked at: St Mary's, switched to the Portland

Gave birth: Autumn 2012

Akari found the antenatal care in St Mary's to be very good and she was very pleased with the support she received. She felt that the booking appointment was very thorough and she was asked lots of questions about her medical history, including questions about her mental wellbeing and domestic violence.

Akari had been told in Japan that because she had a number of fibroids, she would most probably have to give birth by Caesarean Section. St Mary's confirmed that this was the safest option although they would support her if she wanted to give birth naturally.

Akari was under a lot of pressure from her family to have a C-section and to switch to a private hospital, which they felt would give her better care, particularly in an emergency. Also the costs were covered by her husband's employer. In the end Akari agreed to switch her care to the Portland where she had a C-section.

## **8) Halima**

Ethnicity: Somali

Language: Intermediate English

Pregnancy: 6<sup>th</sup> (7<sup>th</sup> baby)

Booked at: St Mary's,

Gave birth: Summer 2012

### Previous pregnancies

Halima is 37 years old and has had FGM. When she had her first baby at St Mary's, FGM had not been diagnosed so her vagina was cut open during the delivery. The baby was coming very fast and she told the midwife but the midwife did not believe her so she only cut her open at the last moment and so the baby ended up having a cut on his head.

After the delivery, the stitching was not done very well but Halima had no experience of what her vulva and vagina should look like and whether having loose bits of flesh was normal or not. She asked a friend who told her it was not normal so she went back to the hospital who referred her to a clinic and she had a procedure to sort things out.

Halima's second baby was a baby girl who was born without her external genitalia being fully formed. Halima does not regard this as abnormal or problematic in anyway but as the baby having been born circumcised (i.e. having already had FGM). Her GP told her that when her daughter is old enough to menstruate they may have to open up her vagina a bit so the menstrual flow can leave the body. Halima says that that her daughter is fine now.

Halima's third pregnancy at Queen Charlotte's was very stressful because she was told at 11 weeks that she had an overactive thyroid and she needed to take medication. At the second scan she was told that her baby's skull was not formed properly, and that her brain was 'wobbly'. She was advised to have an abortion but Halima refused. When Halima was due to have her third scan, the scanner at Queen Charlotte's was not working so she was sent over to Hammersmith Hospital for a scan where the sonographer told her that everything was fine but the consultant still insisted that there were abnormalities with the baby and gave her medication. Halima's GP on the other hand told her that her thyroid levels were normal.

When Halima went into labour she went to the hospital where she was told that she had to give birth with a consultant present as the midwife would not be able to help or examine the baby because of the abnormalities. However, while she was looking for the phone to call the consultant, Halima gave birth and the baby arrived completely normal at 1am. Halima was told that that the consultant who had examined her when she was pregnant would see the baby at 9am so she left at 8am because she didn't want the doctor who had said there was something wrong with the baby to see her again, as she was worried he might hurt the baby.

At her next pregnancy, Halima had the twins, one of whom was born with a very low birth weight. Halima had a caseloading midwife for her twins and for her subsequent pregnancy.

### Latest pregnancy

Halima went to the GP when she was 8 weeks pregnant after having tested her self the same day. She was told that Queen Charlotte's was full but she preferred St Mary's because of her previous poor experience. Halima was happy with her antenatal care although she was disappointed to no longer have a caseloading

midwife. She also found that the new ticketing system for the glucose testing was very confusing and so she had to have the test repeated in order to have it done correctly. At her 20 week scan Halima was told that she had a low placenta and this worried her. At her third scan she was told that the placenta was now fine but this was recorded in a way which was confusing and Halima's Sure Start midwife was not certain if this meant that her placenta was low or not. Halima was reassured in a subsequent appointment but she continued to have concerns up to her delivery.

When Halima's labour started she went straight to the birth centre where she had given birth before. However, the midwife there told her that as it was her 6<sup>th</sup> delivery and it was likely she would lose a lot of blood she needed to go to the labour ward and be examined by a doctor. Halima said that she was told that if she was seen by a doctor and the doctor said it was fine for her to give birth at the birth centre they would take her back, but they said 'you need the doctor with you'. The midwives did not help Halima get to the labour ward they just said 'first floor'.

When Halima went to the labour ward, her husband explained that she was supposed to be examined by the doctor. A lady appeared who did not introduce herself took her notes, asked her for a urine sample, and examined her in a bed in a sideroom. She told her she was only 1cm dilated, used a monitor to check on the baby and told her that not much was happening and she should go home. Her husband went downstairs to wait for her Halima but Halima said that she was not going to go home because the baby would come very quickly –she said that the baby would be coming in exactly 3 contractions. (Halima says that all her babies have come very quickly after very few contractions). The midwife told her to start walking around. After about an hour Halima went back into the room, removed her clothes, got into bed and started pushing. She was completely alone as her husband was still downstairs waiting for her. No doctor came to examine her, but eventually the midwife came back with a student (without asking Halima's permission). The baby came very soon after (after 3 contractions according to Halima) less than 2 hours after arriving at the hospital.

After giving birth, Halima's blood pressure was very high. Halima thinks that this was because she was very upset that no doctor had examined her. Also she felt the staff were behaving incompetently –when the baby was born they did not put her on her chest but in a heater to warm her but the student did not turn the lamp on, so the baby was left cold near a window. Also the baby had meconium all over herself. Halima did lose a lot of blood and her blood pressure kept going up and down so she had to stay at the hospital. The next day in the afternoon the doctor came by but she did not examine Halima, just told her that since her blood pressure had been fine when she came in and was not that high now she could go home whenever the midwife decided to discharge her.

Halima was upset because after being told at the birth centre that she needed to be examined by a doctor, she expected this to happen but it did not. Halima has had other babies at the birthcentre with no doctor present so she would not normally expect to see a doctor, had she not been told otherwise. Also, because during her pregnancy she had been concerned about having a low placenta when they told her at the birthcentre that she had to see a doctor, Halima thought that maybe the placenta was still low.

Halima was also upset with the paediatrician who examined her baby. The first paediatrician said that there may be something wrong with the baby's chest or heart (Halima thinks she caught a cold because they didn't warm her) and they had to stay a second night. The next day the paediatrician who examined her had a cold and he

wiped his nose with his hands (he was wearing gloves) and then put his finger with the glove in the baby's mouth. Halima was very upset by this.

**Note:** When the researcher queried this case with staff at St Mary's birth centre, she was told that their midwives would never suggest that someone could be accepted into the birth centre on a doctor's recommendation. The midwife also said that women who are eligible to use the birth centre are normally booked to do so at 30-35 weeks and therefore it is not always possible to accept women who turn up in labour.

## 9) Hafsa

Ethnicity: Somali

Language: Very little English (Hafsa's own assessment of how well she understands English is: "If they ask me 10 questions, I understand 4.")

Pregnancy: 4th

Booked at: St Mary's

Gave birth: Summer 2012

### Background

Hafsa is a Somali woman with FGM on her fourth pregnancy. She speaks very little English –the researcher tried to interview her without an interpreter and couldn't, so used Hafsa's friend to interpret all sessions.

Hafsa's maternity notes make no mention of FGM. Hafsa said that in the past she has had discussions with staff about FGM and knows it is illegal in the UK. Her eldest daughter who was born in Tanzania had a milder form of FGM done to her as soon as she was born (In Somalia, type 3 FGM is the norm).

At the first session, (Winter 2012) Hafsa she was technically homeless, as she was being housed in different hostels for a few weeks at a time which was very difficult with 3 children. Just before finding out she was pregnant, Hafsa had left her husband because of ongoing domestic violence.

The researcher looked at Hafsa's maternity notes, and noticed that while the midwife was aware that Hafsa was homeless and had fled domestic violence Hafsa was not being seen by the caseloading team. Midwives did not use interpreters for any of her appointments and her notes made no mention of FGM. The researcher raised these issues with the Head of Midwifery who ensured that Hafsa was placed in the caseloading team which Hafsa really appreciated. The reason why this had not happened earlier was because the hostels Hafsa was staying were dispersed all over London and were therefore out of the catchment area of the Imperial maternity service. Had Hafsa stayed with her husband in Westminster she would have been 'in area'.

The researcher also asked Hafsa to request an interpreter in subsequent appointments. Hafsa did so, but was told that she didn't need one because the staff could understand her. "But I don't understand THEM!" she told the researcher.

One day, during her pregnancy Hafsa fainted on the street. She reported this to the midwifery staff, and Hafsa understood from what they said that she was anaemic and they were offering her a blood transfusion. She turned it down because she was worried about infection and then they had offered her an alternative medication. They didn't give it to her that day but asked her to come on a different day –Hafsa wasn't sure why but she thought it may have been because her children were with her. She went back the next day, without her children and after waiting at the hospital for several hours she was given the medication and had to stay overnight at the hospital.

When the researcher raised this with the Head of Midwifery she explained that it was very unlikely that a pregnant woman would have been offered a blood transfusion. She checked at Hafsa's notes and confirmed that Hafsa had been given a choice of two types of medication –one which could be administered quickly but had greater risk factors and another which had to be administered more gradually. The Head of Midwifery then spoke to the staff concerned and explained to them that because Hafsa did not speak much English she had not understood her treatment or the choices she had been offered. The staff were very surprised.

When Hafsa was 41 weeks pregnant she agreed with her midwife to come in to have her waters broken. This was partly because she lived far away and was worried about getting into the hospital in labour. Hafsa arrived late and had to see a different midwife than she did normally. She found this midwife very hard to understand and once again asked for an interpreter but was told again that there was no need because the midwife understood her. Hafsa saw a nurse who she thought was Somali and asked if she could interpret but her midwife again told her there was no need. Hafsa found this very stressful.

Then the midwife told her that she would have to leave but that Hafsa's regular midwife would be arriving in half an hour. The midwife did not ask any other staff to look in on Hafsa in the meantime and Hafsa found this experience very frightening.

Hafsa's caseloading midwife arrived half an hour later, broke her waters and a healthy baby boy was born. However Hafsa found that giving birth this way was extremely painful.

Hafsa did not have an interpreter for any of her appointments.

## 10) Fatima

Ethnicity: Somali

Language: Intermediate English

Pregnancy: 3rd

Booked at: Queen Charlotte

Gave birth: Autumn 2012

### Background

Fatima has had FGM. This was identified by the midwifery service during her first pregnancy and she was given the option of being defibulated before giving birth but she chose not to be. This was a decision she later regretted as she found the experience of being cut open during birth extremely painful and had to spend two hours afterwards having stitches, which took 7 months to heal. Fatima regards FGM as a very bad practice which Islam regards as wrong.

### Latest Pregnancy

In terms of her antenatal care, Fatima appears to have attended very few antenatal appointments. She had two scans, and two other antenatal appointments (the booking appointment and the glucose testing appointment at 27 weeks). Fatima said that no other appointments were booked for her and so she didn't know whether she should be going to the hospital or not. She was aware that she could go to her GP clinic if she had any problems but she did not have any problems. At 40 weeks she looked at her appointment schedule and saw that she was supposed to have an appointment but since no appointment was booked she did not go. Finally, at 42 weeks Fatima decided to go to the hospital even though she had no appointment.

When Fatima saw a midwife at the hospital and explained that she was 42 weeks pregnant she was told that she would not be allowed to leave and was put on a monitor which showed she was having contractions, although Fatima could not feel any. In the evening she was transferred to the Labour Ward where they broke her waters and Fatima eventually gave birth. The birth was extremely painful and Fatima lost a lot of blood and had to have stitches for an hour and a half. Her blood pressure was very low she was shaking and she had a blood transfusion. She then had to stay in hospital for a week, during which she had 3 more blood transfusions. She also started suffering from extreme headaches which she was told were due to the blood loss, but she had no further investigations.

When Fatima went home, she experienced headaches, swelling and vomiting and was told to go back to the hospital where she stayed another week. She was told she suffered from low sodium and an MRI scan showed she had some brain damage due to the blood loss. She was then discharged and has been attending the hospital every two weeks to receive medication (hydrocortisone) for her headaches.

**Note:** The Head of Midwifery has repeatedly requested the maternity notes for this service user but has not been able to obtain them as they are being used by another department (not clear which). Therefore it has not been possible to confirm the issues discussed which are therefore presented from the service user's perspective only.

**(Appendix 1) Extract from 'Antenatal care: routine care for healthy pregnant women' (2008).**

1.1 Woman-centred care and informed decision-making

The principles outlined in this section apply to all aspects of the Antenatal care guideline.

1.1.1 Antenatal information

1.1.1.1 New Antenatal information should be given to pregnant women according to the following schedule.

• At the first contact with a healthcare professional:

- folic acid supplementation
- food hygiene, including how to reduce the risk of a food-acquired infection
- lifestyle advice, including smoking cessation, and the implications of recreational drug use and alcohol consumption in pregnancy
- all antenatal screening, including screening for haemoglobinopathies, the anomaly scan and screening for Down's syndrome, as well as risks and benefits of the screening tests.

1.1.1.2 New Information should be given in a form that is easy to understand and accessible to pregnant women with additional needs, such as physical, sensory or learning disabilities, and to pregnant women who do not speak or read English.

1.1.1.9 New Information about antenatal screening should be provided in a setting where discussion can take place; this may be in a group setting or on a one-to-one basis. This should be done before the booking appointment.