TAKING SOUNDINGS ON MATERNITY CHOICE

A consultation with women in South East London

Strengthening Public Influence on Health

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1. Introduction

Information is key to choice but choice is cancelled for those to whom information is inaccessible or inappropriate. This project explored how disadvantaged women who are pregnant or anticipating pregnancy, find the information to enable them to choose their care and where they have it - and indeed, whether their care preferences are available anyway.

1.2 Background

Health Link, an independent not for profit public involvement organisation, was commissioned to consult women in South East London about how these needs might be met, in preparation for Maternity Choice in 2008, and provide a brief for a Maternity Choice Guide. Women consulted were predominantly those disadvantaged in accessing services and information about those services, for a variety of reasons. The recent White Paper '*Our Health, Our Care, Our Say*'[1] reinforces the importance of accessible information to facilitate choice in maternity care and improve the take up of appropriate services. Information is currently provided after a woman is booked, so comparison between units and decisions on care before booking, are difficult. The consultation is not a systematic audit of services. Its purpose was to 'take soundings' on choice and information from women selected for their experience as disadvantaged users of maternity services. Therefore, it is not possible to draw any firm conclusions about the quality of maternity care in South East London.

1.3 Findings

There is considerable information available from the sector maternity units. A great deal of work and thought has gone into this in the units who responded. There is much to build on in producing information in a systematic and user focused way. We interviewed a range of women including travellers, refugees and asylum seekers, ethnic minority women, those who had a non-English first language, were living on low incomes or suffering disability or mental health problems. Women were mostly currently pregnant, recently delivered or in a few cases had had a baby within recent years.

Some women interviewed were not aware of any form of choice. Much of the information on offer was hard to access for these women because of format or language problems, or simply not knowing where to find it. They needed more information to understand how to have a healthy pregnancy and were totally unaware of some services, such as antenatal classes. Some were worried about the effect of pregnancy on existing medical conditions, such as arthritis. Women receiving mental health medication had been unable to find out what effect this might have on their baby and whether they could safely stop the medication. Women with disabilities reported discriminatory behaviour, such as staff persistently speaking in front of a deaf couple and refusing to write down what they were saying. Mental health service users reported being made to feel they should not be having a baby at all, because of their mental illness. Women whose first language was not English were sometimes completely in the dark about what was happening to them, such as the woman who spent her pregnancy frightened that the scan has shown her baby with a missing arm. This

was not the case but she had misunderstood what she was told. Race equality was a recurring theme with some women worried that they would not be 'allowed' to keep their headscarves on. Surestart midwives were universally praised for their care, support and advocacy to women. Several women suggested 'nanas' from their own culture to support them in a culturally appropriate way. Women wanted specific care options such as screening for genetic conditions (such as sickle cell), home birth, water birth, minimal interventions, direct access to a midwife and good postnatal support, especially after a caesarean. These care choices need to be addressed through effective woman-centred commissioning.

We were told of the need for timely, clear information in a range of accessible formats, about health and pregnancy, what services were available and where. Women wanted to be able to get this information in places they usually visit, such as benefit offices as well in the GP surgeries. Women also wanted the opportunity to discuss their options and concerns with a midwife and support when problems arose. The pressures on midwives' time to get all the necessary information across means that extra time is essential to enable midwives to offer women-centred care. Some women would need support accessing information electronically.

From the 'shopping list' of information and preferences derived from this consultation, a provider survey was developed to find out what women wanted to know from the providers in the sector. This survey is being administered by the Strategic Health Authority. Information gathered through the provider survey, combined with the information previously gathered and presented in the London pilot information tool (www.londonpilot.nhs.uk[2]) will enable providers to be compared on topics relevant to service users. It is expected that the provider survey will highlight gaps in the service and facilitate peer review and the sharing of good practice between units. The Report also includes a draft 'information prescription' for pregnant women which GPs or midwives might give women once they start to plan a pregnancy or their pregnancy is confirmed, as recommended in *Better Information, Better Choices, Better Health* (Department of Health 2004).[3] Libraries are a possible information and support point because of the synergy between public library targets to promote health and narrow health inequalities, and the provision of inclusive information for Choice.

1.4 Conclusions

In order to make choice real, women must know what options are on offer, be able to compare services and providers. One of the main barriers to choice is 'not knowing what you don't know.' National policies are clear on information and choice, but implementation is not easy, especially for disadvantaged women who already face health inequalities. However, women do know what they want and the outcomes they value. This intelligence is vital for effective commissioning as well as for the implementation of inclusive choice. Health inequalities are aggravated, or in some cases, caused by lack of access to services or by services that do not work well for some women. Choice offers an opportunity to redress some of those inequalities. What information is offered, where and in what formats is pivotal to exploiting these opportunities and making the rhetoric of choice a reality for all women and a driver for quality of services.

2. Introduction

Health Link, an independent, not for profit, patient involvement organisation, was commissioned by the South East London Strategic Health Authority to consult disadvantaged women and the voluntary sector groups who support them, on their information needs for choice in maternity care and place of birth.

The Health Link project forms part of the Strategic Health Authorities' wider Midwifery Choice Project. Midwifery Choice Project Manager, Pauline Cross, has looked at the needs of some disadvantaged groups, as well as mainstream users alongside workforce requirements, improving standards in line with the National Service Framework (NSF), National Institute of Clinical Evidence (NICE) guidelines and promoting minimum standards across the Trusts within South East London. This Report builds on and incorporates the work of Pauline Cross in consulting disadvantaged groups. It also builds on the earlier work by Health Link on the information and support needs of disadvantaged groups for choice of provider. [4]

2.1 Policy Background

2.1.1 National Service Framework for Children, Young Persons and Maternity Care[5]

The prioritisation of disadvantaged groups in the project reflects the health inequalities suffered by women in these groups. As noted in the Children's NSF: '*life expectancy is lower and infant mortality greater in disadvantaged areas and among disadvantaged groups*'.[6]

2.1.2 Choice

The *Building on the Best* policy document introduced choice in the NHS[7]. Choice of provider in maternity services, to include place of birth and continuity of care, is to be in place by 2008. Research evidence on choice of provider in acute care demonstrates how important information is to making choice of provider a reality. The Picker evaluation of the London Patients Choice Project[8] noted*: If all patients throughout the country are to have an equal opportunity to make choices about where and when they are referred, they must be made aware of their rights in this regard, support and information must be readily available, and monitoring systems must be implemented to avoid the risk of discrimination against less advantaged groups.'*

2.1.3 Information and Choice

In maternity care, there is a history of work on using information as a tool to engage women in their care and improve services. From Changing Childbirth in the early 1990s to the NSF in 2004, it has been recognised that information promotes choice in its broadest sense. Woman-centred care can only be established when women are able to access information about the services offered and make an informed choice. '*Surveys of women and their partners have also identified being treated as an individual and being provided with more information as important.*' [9]The way in which information is given is as important as the content: Standard 11 (Maternity Care) of the NSF requires not only that women are given appropriate information, but also '*enough time between receiving information and making choices to reflect upon the information,*

consider the options and seek additional information and advice where they wish to' .

2.1.4 Information Prescription

Women with a variety of disadvantages, whether arising from physical, social, language or literacy difficulties, face additional problems in accessing information. Given the importance of *all* service users knowing how to get information in a way that suits their needs, the Department of Health strategy on Choice information [10] proposes an 'information prescription' for patients, given to them when they are diagnosed with a condition requiring treatment, by GPs or, in the case of direct maternity booking, by midwives. In anticipation of this national reform, we have attempted to encapsulate the needs of women expressed in this consultation, in this format, as set out in Section 7.

2.1.5 Your Health, Your Care, Your Say

The recent White Paper *Your Health Your Care Your Say*[11] sets out a vision for choice in maternity services powered by accessible information: '*A truly individualised maternity service will give women as much control as possible during their pregnancy, birth and post-birth. It will mean midwives ensuring that women have all the information they need about this life event. This will include information about the choices available and in formats and styles appropriate to people with different needs'*.

2.1.6 Commissioning

The NSF requires Trusts to '*Improve the access and effectiveness of maternity services for women from disadvantaged and minority groups and communities by systematically taking account of the reasons why women from these groups find it difficult to access and maintain contact with maternity services, and by actively designing services to overcome barriers to care*.'

More recently, *Creating a Patient-led NHS*[12] emphasises the need for '*a far greater range of choices and of information and help to make choices*' and progress in the NHS at '*understanding patients and their needs, us[ing] new and different methodologies to do so and have better and more regular sources of information about preferences and satisfaction*'. Better commissioning depends on better intelligence about the needs of women, particularly those who suffer health inequalities. It is notable that when considering information to choose a provider, users show little or no knowledge about the information that is currently available, such as any of the Healthcare Commission performance indicators. They invariably base their information needs on their own personal needs. This makes the resulting information specification truly woman-centred, grounded exclusively in women's needs, aspirations and experiences– valuable intelligence upon which to base commissioning.

3. Methodology

The aim the project was to:

- consult women in South East London who were living with some form of disadvantage, on the information they would need and where they would need to access it, to enable informed choices about their maternity care
- produce a specification for an accessible Birth Guide based on needs identified, building on existing literature.

3.1 Baseline Assessment of existing information and accessibility

To obtain an overall picture of the current situation the following were contacted:

- PCT Commissioners on information about services in the sector
- Heads of Midwifery in Trusts within the sector regarding information sent out to women booking at their units. Queen Elizabeth Hospital was in the process of carrying out a patient satisfaction survey for maternity
- Maternity Service Liaison Committees: responses were received from Bromley, Greenwich and Southwark, expressing interest in the project.

The following specialist voluntary groups were also contacted about the information and publications they had produced to support pregnant women and new parents:

- Change,
- Disabled Parents Network
- Disability Pregnancy & Parenthood International
- Parents' Power,
- Greenwich Association for Disabled People

3.2 Identifying and making contact with groups

Groups and individuals consulted were those at risk of disadvantage in accessing services. The Midwifery Choice Project Manager had already consulted significant numbers of disadvantaged women and Health Link built on this work. In all the following 14 types of risk were identified:

Target Groups	
Black And Minority Ethnic origin	Physical Disability
Faith Group	Postnatal depression
Homelessness	Refugee and Asylum Seeking
Learning Disability	Sensory Impairment
Lesbian	Social Problems
Long Term Medical Condition	Travelling
Mental Health Service Use	Teenage Parenthood

A systematic search began for groups, both in the voluntary and public sector likely to be supporting them. Over 60 groups or individuals were contacted, including Sure Start, sector Patient and Public Involvement leads, community mental health teams, local authority outreach teams, health professionals in the community and hospitals, hostel managers, local and national organisations.

As expected, locating these women and the voluntary groups supporting them proved difficult. Numerous contacts were needed before an appropriate group or individual could be identified. In several cases, groups had lost their funding and could no longer support the women. In a few cases, support workers were interviewed as a proxy for the women they worked with, where women's personal circumstances made interviews inappropriate.

3.2.1 Organisations consulted are listed in detail at Appendix One

66 individuals participated in meetings with the Midwifery Choice Project, including:

- lesbian women
- refugees and asylum seekers,
- travellers,
- women from a faith group
- women supported by Surestart
- women with disabilities
- members of a local NCT group

Health Link obtained questionnaire responses from a further 39 women, targeting where possible those who had given birth within the last five years or those planning to become pregnant, including women who were:

- asylum seekers
- from a black or minority ethnic community
- speakers of a non-English first language
- physically disabled
- learning disabled
- sensory impaired
- homeless
- teenagers receiving support
- suffering from
  - mental distress
  - postnatal depression
  - a long term medical condition

3.3 The Questionnaire

This Health Link questionnaire (copy at Appendix 2) was structured to identify

- information needs,
- accessibility and usefulness of current information on services
- preferences in content, format and accessibility

Of the 39 questionnaire responses, 27 were conducted face to face in groups or individually 12 returned by post, 52 questionnaires having been sent by post (a 24% return rate). Telephone interviews were offered, but not taken up. However, the interviewer did telephone women who returned questionnaires where possible to thank them and clarify any inconsistencies in their replies. Across the study, 60 organisations were contacted and 105 individuals participated.

3.4 Gathering the information women said they needed

Topics specified as important to women in the consultation were compared to the dataset already developed by Health Link in partnership with the Department of Health, North West, South West, North Central and South East London Strategic Health Authorities, and NHS Connecting for Health (www.londonpilot.nhs.uk) for piloting in London Choice. The existing maternity datasets at the Department of Health and those published by Dr. Foster[13] were also scoped. Any additional information not covered by these various datasets, was incorporated as questions in a survey of Trusts (attached at Appendix 3.) The survey was piloted and sent out by the Strategic Health Authority to Trusts in the sector.

3.5 The Next Step: putting the information into an accessible format

The Strategic Health Authority plans to incorporate the information specified together with the results of the Trust survey, into an accessible 'Birth Guide' so that women will be able to make meaningful comparisons between providers and choose the maternity care most suited to their personal needs.

4. Services

4.1 The Area

South East London Strategic Health Authority comprises Bexley, Bromley, Greenwich, Lambeth, Lewisham and Southwark Primary Care Trusts (PCTs)

4.2 Maternity Units

Maternity units within this area are

- Guys & St Thomas', SE1 5912 births
- Kings College Hospital, SE5 4591 births
- The Princess Royal University Hospital, Orpington 3147 births
- Queen Elizabeth Hospital, SE18 3427 births
- Queen Mary's Sidcup 3120 births
- University Hospital Lewisham, SE13 3363 births

4.2.1 Capacity constraints

All but one unit have activity increases year on year. The Midwifery Choice Project has noted local capacity problems:

- Pressure on beds particularly disadvantages women who are unsure of the system and who do not book early.
- Travel is also a problem for women in the south of the area who have to travel a greater distance because of services moving. For example, Bromley maternity unit is housed away from the centre of Bromley at the Princess Royal in Farnborough. Women living in south Lewisham and Lambeth now have longer journeys for care for the same reason
- Time, effort and costs involved in travel all add to the pressure on pregnant women and is particularly acute for those women who may not have any support, suffer from depression or who have physical access problems.

4.3 Health Inequalities in the South East London Sector

The sector has a population of 1.5m across the six London Boroughs of Bexley, Bromley, Greenwich, Lambeth, Lewisham and Southwark.

- There is serious deprivation and diverse communities in some areas, associated with health inequalities.
- Life expectancy for females differs by over three years in different boroughs.
- There is a high incidence of sexual ill health and Lambeth, Southwark and Lewisham have the highest teenage pregnancy rates in London.
- In addition to the rising birth rate, further population expansion is expected from Thames Gateway scheme.

All these factors indicate the challenges of providing health care to such a diverse population. The Table overleaf compares the latest figures from the Office of National Statistics on deprivation and infant mortality.

MULTIPLE DEPRIVATION INDEX 2004 (1=MOST DEPRIVED)			
Borough	**Deprivation Rank**	**Borough**	**Deprivation Rank**
Bexley	212/354	Lambeth	23/354
Bromley	238/354	Lewisham	57/354
Greenwich	41/354	Southwark	17/354

INFANT MORTALITY AND LOW BIRTH WEIGHT RATES 2004				
Comparison Area	**Mortality**			**% Low Birth Weight Babies (<1500g)**
	Perinatal	**Neonatal**	**Infant**	
London	8.9	3.6	5.2	1.3
SE London	9.7	3.9	5.8	1.4
Ranked by London STHA (1=worst)	1/5	Joint 2/5	Joint 2/5	2/5

LIFE EXPECTANCY AT BIRTH FOR FEMALES (LONDON 80.8)			
Borough	**Life Expectancy**	**Borough**	**Life Expectancy**
Bexley	81.2	Lambeth	79.8
Bromley	82.2	Lewisham	79
Greenwich	80.1	Southwark	80.1

TOTAL FERTILITY RATE[14] (UK 1.64)			
Borough	**Total Fertility Rate**	**Borough**	**Total Fertility Rate**
Bexley	1.68	Lambeth	1.69
Bromley	1.60	Lewisham	1.67
Greenwich	1.77	Southwark	1.75

5. Findings on Choice in Maternity services,

NHS plans for 'Choice' in the maternity care were explained and women's own experiences of choice discussed. It was felt that choices should be genuine and information equally so. Women considered that 'the truth' about lack of help on the postnatal ward, for example, should be disclosed in advance. Barriers to care choices were described, arising from personal circumstances, staff attitudes and stigma or misinformation. One woman was uncertain whether she was given any choices in her pregnancy. She was very depressed at the time and found it all too confusing due to her poor English. Refugee and asylum-seeking women had little chance of getting adequate care, let alone exercising choice, when they were dispersed and record sharing and communication between old and new providers were frequently poor.

Findings are reported in 5 sections:

- Preconception
- Pregnancy and Birth
- Information to Choose a Provider
- The Postnatal Period
- Accessibility of Information

"Don't offer us something you can't provide."

Quotations marks indicate direct quotes from participants and women's preferences are listed in the boxes.

5.1 Preconception

This section discusses what women wanted to know before conceiving and where they wanted to get the information.

"All the information in the world would not help a woman who has no financial help".

5.1.1 What Women wanted to know about Pregnancy

All the women interviewed wanted information on how to keep themselves and their baby healthy. Difficulties were common: some women reported problems in finding even the most basic information about healthy eating, and how the baby grows in the womb. If women did receive written information it did not always register as useful or informative. It was reported that one young mother had tried unsuccessfully to get contraception advice, but later became pregnant again. Some women described difficulties in accessing information on the effect of pregnancy on their pre-existing conditions, including cerebral palsy and arthritis.

PREFERENCES: PRECONCEPTION INFORMATION

- ✓ Healthy eating
- ✓ Folic acid
- ✓ Nutrition for mother & baby
- ✓ Contraception advice
- ✓ Genetic Screening
- ✓ Vitamins and minerals
- ✓ Healthy eating for vegetarians
- ✓ Advice on giving up smoking
- ✓ Rh negative status
- ✓ Pregnancy & existing conditions

5.1.2 Where Women wanted to get Information

Experiences varied on accessing information. Respondents also had very different ideas of resources or people, from whom to obtain information. NHS Direct was familiar to some but experiences of it varied, with some women saying they were made to feel stupid sometimes when dealing with the advisor.

PREFERENCES: WHERE TO GET PRECONCEPTION INFORMATION

- ✓ A Health visitor
- ✓ A Midwife
- ✓ The doctor
- ✓ The internet
- ✓ "Someone who does blood tests"
- ✓ The library
- ✓ "Benefit places"
- ✓ A Bookshop
- ✓ A support group for disabled e.g. Deaf Parenting Newsletter

5.2 Pregnancy and Birth

This section summarises responses on

- Care choices and barriers to those choices
- Information needed to make care choices

5.2.1 Care Choices

Strong views were expressed about choices in care, particularly on interventions such as caesareans, which some women felt were forced on them unnecessarily. Women expressed concern about '*modern*' procedures such as epidurals and caesareans, thinking they were used to '*disempower women*'.

"If it wasn't for [the Surestart Midwife], I'd have missed loads of appointments because my little girl plays up in the surgery. I get so frustrated and have to wait 11/2 hours. It just puts my blood pressure up."

a) Choice of First Point of Contact

Most the women interviewed had gone to their GP first, in one case merely as a route to the midwife. A majority would prefer to go to the midwife as a first point of contact, because they had more time and more skill .As they were more likely to be female, they would meet cultural preferences for female-only care. A few women did go to the midwives clinic and had their pregnancy test there. In most cases the choice to go directly to the midwife clinic first was not given, so women did not ask. Women felt that they would have preferred a midwife as the first point of contact had they known this was possible. Others preferred GPs because that was where their records would be or because they had good relationships with their GP. A few women used the sexual health centre was their first point of call, where they got a pregnancy test done and received folic acid. Some respondents had done their own pregnancy test before going to see the doctor, although they found this expensive.

b) Barriers to Choice of First Point of Contact

Women who move around a lot, however, are obliged to go to A&E to get into maternity services, because of general difficulties in registering with a GP. When they discovered they were pregnant, refugees and asylum seekers found it difficult at first to find a GP who would take them on because of their status.

"My GP is lovely. He gave me my diagnosis (MS). He cuddles me and asks how I am... He knows my history."

"If there was a way of getting to a midwife quicker I would take it. I was scared of going to the GP and by the time I got there I was more than 3 months gone and they complained I was late."

Many women moved frequently during their pregnancy, making long journeys back to their original GP for antenatal care, as those in the new locations were reluctant to take them, although sometimes this was worthwhile to stay with a good GP.

"You have to wait 2 weeks at my doctors to get an appointment. Then he just sends you to the midwife."

Late first contact with maternity services was a barrier to many choices and caused stress and anxiety. One respondent was very worried at not having seen the midwife or had any information or scans of her pregnancy although she was already 14 weeks pregnant. Booking varied between 6 and 22 weeks.

c) Choice of Home Birth

Choice of home birth was important but some respondents found information was given too late for it to be an option. In other cases, the choice was simply refused by some hospitals: a woman who wanted to change to home birth was told that she would have to change to another hospital and would need new midwives. She stayed at the same hospital and was satisfied with their low risk unit. One suggestion was that South East London should have a birthing centre like to the one in Edgware. Water birth was another important choice to many respondents. Women were concerned that this should be a genuine choice however: unless midwives would let them have it at the time, there was little point in offering it as choice.

d) Other Care Choices

Continuity of care was raised repeatedly. Only one respondent was offered the assistance of the midwife that she had come to know for the birth, but she was off duty when the respondent went into labour. Most women would have liked to know the midwife delivering them but felt that this was probably impossible: It is "definitely" important to get to know the health professionals. Midwives attached to the local

"We don't talk freely to men. There's loads we don't talk to them about, even our husbands."

midwife clinic were perceived to be the most accessible. 'Nanas' of same culture as the woman, to act as birthing attendants and provide support postnatally, were suggested.

e) Barriers to Care Choices

Although some midwives and students were found to be excellent, their availability was variable. In some cases, Team midwives were only available antenatally. Staff attitudes acted as a barrier to choice on occasion. For example, a birth plan included an epidural but when the woman asked for it during labour, staff told her she did not need it. The woman reported receiving no explanation for this and felt let down. A request for a female doctor was met with a response from staff that this was '*not important*'. One woman had an emergency caesarean for the first baby and was told that any subsequent births would have to be caesareans. However, she had since seen on a TV programme where women in similar circumstances had delivered vaginally, so felt she had lost out.

"I asked for a lady doctor and it was, like, tough, that's not the most important thing. But it was important to me!"

Staff systems could be inhibiting to women. Midwife shift changes during labour, were also disturbing to women. Those who, for whatever reason, moved around frequently while they were pregnant, found the repeated history-taking from different health professionals impersonal and unhelpful. Poor liaison between professionals treating women for an existing condition was highlighted but one woman was impressed with this liaison and communication.

PREFERENCES: CARE CHOICES FOR PREGNANCY & BIRTH

- ✓Early Booking
- ✓Home birth
- ✓Midwives Clinics
- ✓Continuity of care
- ✓Midwife or GP as first contact
- ✓Continuous support in labour
- ✓Care from a known midwife team
- ✓Guarantees that caesareans would only be done in an emergency
- ✓Good staff handover
- ✓Water birth
- ✓Nanas from different cultures
- ✓One to one support
- ✓Female doctors at all times
- ✓Home visits from midwives
- ✓Support from community groups

f) Barriers relating to race, religion and culture

"It is not that people are racist but they think because you do not speak English you are stupid."

Lack of respect for religious needs was marked in some women's experience. One woman was asked to remove her bible from the bed and another to stop praying. Other problems related to lack of knowledge on the part of staff about different cultures and religions, such as Rastafarianism. Women explained that in both Muslim and Traveller cultures, women do

not wish to talk in front of men about childbirth. These women explained that they would not listen properly or feel able to ask questions, if men were present.

One of the most significant barriers to choice for women whose first language was not English was getting any information at all in their own language. Most who responded had not been offered this. Lack of interpreters was a further barrier. For example, attending scans without interpreters could cause misunderstandings and anxiety, upsetting rather than empowering women. Refugees and asylum seekers experienced 'confusion' among primary care staff on who was eligible for care.

"One woman who did not speak English thought she was told the baby had an arm missing. She went through the whole pregnancy worried sick. The baby was fine when it was born - nothing missing."

g) Barriers relating to disability

"Information is not a problem, but getting to and from appointments to get it, is very difficult."

Disability, including mental health problems, was also a barrier to choice, because of lack of awareness about disability on the part of staff. One hearing impaired woman reported how midwives talked to each other in front of her and failed to write down what they were saying even though she had asked them to do so. Difficulties in physical access for disabled women were a very significant barrier to getting services at all, let alone exercising choice about those services. Mental health service users felt that health professionals did not want them to have children at all.

"Staff don't want us to have children for fear of bringing another generation of mental health users into the world."

PREFERENCES: INCLUSIVE CHOICE

- ✓Information in translation
- ✓Interpreters in local languages
- ✓Cultural awareness
- ✓Women-only information sessions
- ✓Disability awareness
- ✓Disabled access
- ✓Choice about whether male partners and relatives are involved

5.2.2 Information to make care choices

While information was clearly seen as a means of enabling women to feel in control of their pregnancy and birth, its limitations were also pointed out by women whose lives were difficult. Being a refugee or asylum seeker, living on a low income or struggling with a disability, could not be overcome by information alone. However, relevant,

"I got some information from the telly. That's how I knew your waters went and that was a sign of labour - except mine didn't go and now I know they don't always go till the end."

accessible information could help make these problems less of a barrier to making choices. Some midwives seemed just too rushed to provide information even if it was available. Views on information for partners were diverse: some women felt that their partner would have benefited greatly from practical information and advice whilst others considered their male partner's involvement inappropriate anyway. Others were alone with no support at all.

Information given to women by GPs ranged from none to some - mostly about screening tests. Lack of information was also an issue for staff: ignorance about what care refugees and asylum seekers are entitled to acts as a barrier to getting services - let alone making choices once you had done so.

PREFERENCES: CARE CHOICE INFORMATION

- ✓ Pros & cons of interventions
- ✓ How babies grow in the womb
- ✓ Postnatal depression
- ✓ Aftercare of mother and baby
- ✓ Which way babies comes out
- ✓ 'How to be a Dad'

5.3 Information to Choose a Provider

The opportunity to choose a hospital was generally welcomed by the women, although they were constrained by travel and distance. They were also wary about the reliability of information offered to help choice. Information needed to be 'proper', honest and comparable. Some women chose a particular hospital because it offered water-birth but had not been able to compare this with availability elsewhere, as the information was not available. One respondent felt she had no choice as she had had to go to a specialist hospital due to her condition. She was happy with it. Women's requirements for information to choose provider were dictated by the care choices they would want and their personal circumstances, as well as their knowledge of the NHS. They particularly wanted to know how to go about finding a 'good' hospital.

"Are the midwives nice?"
"Will they be kind?"

"If women listened to their bodies they would not need all these interventions.'

Some women found pregnancy to be a stressful time and wanted support. The lack of continuity of care had heightened their concerns. One respondent asked for more support "*so I could enjoy my baby.*" Issues women worried particularly about included infections, cleanliness, and staff and shift changes, which can be very hard on women especially in labour. In some cases there was mistrust about interventions generally and worry about caesareans: would you be 'allowed' to hold your baby straight after a caesarean.

Women's personal circumstances influenced their preferences and therefore their choice information requirements. Women with cultural needs were keen to compare how they might be treated by different providers: for example, would they be 'allowed' to keep their headscarves? Those suffering from a mental

health problem wanted to choose a provider where staff would be knowledgeable about the effect of medication on the baby and what would happen if they stopped or changed it.

PREFERENCES: INFORMATION TO CHOOSE A PROVIDER

ACCESS, ENVIRONMENT AND FOOD

- ✓How to get there
- ✓Visits allowed before choosing
- ✓Comprehensive Information
- ✓Food choice, quality, quantity
- ✓Vegetarian food choice, quality
- ✓Pleasant environment
- ✓Cleanliness
- ✓Written in Plain English
- ✓Extra food if breastfeeding
- ✓Security for baby

CARE AND STANDARDS

- ✓Infection Rates
- ✓Emergency-only caesareans
- ✓Pain relief options (e.g.TENS)
- ✓One to one support in labour
- ✓Supportive staff
- ✓Enough night staff
- ✓Support after caesarean
- ✓Home visits from midwives
- ✓Liaison existing conditions
- ✓Intervention rates
- ✓Continuity of care
- ✓Death rates (mothers & babies)
- ✓Women not left alone in labour
- ✓Enough staff (all wards)
- ✓Good handover on shift change
- ✓Team midwifery throughout
- ✓Female doctors at all times
- ✓Advice mental health drugs

INCLUSIVITY

- ✓Cultural Awareness
- ✓Information in translation
- ✓Interpreters
- ✓Disability Awareness
- ✓What languages
- ✓What languages

5.4 The Postnatal period

Some women had particular problems with postnatal care in hospital and the general view was that it was poor and 'unhelpful'. This could be particularly distressing, at a time when women felt vulnerable. One woman who delivered at 34 weeks did not see her baby for 3 days as she was in bed and the baby was in special care unit. She was told to express milk. She found this very distressing and later discovered that her milk had not been given to the baby. Communication was poor generally. Her family was told that she had been discharged when she was in bed in the ward.

PREFERENCES: POSTNATAL CARE

- ✓ Help to feed and bath the baby
- ✓ Nanas or midwife assistants
- ✓ Extra help after a caesarean
- ✓ Home support for single mothers
- ✓ Good communication (wards & special care units)

The most basic support for new mothers was lacking, such as help in learning how to feed and bath the baby. This was particularly problematic for those who had had caesareans. In one case, the Sure Start midwife came into the hospital to bath the baby. Single women, who often discharged themselves early because of lack of childcare for other children, were particularly disadvantaged by postnatal support, which was poor, or absent.

5.4.1 Breastfeeding

"Breast feeding needs to be made fashionable"

Women were generally positive about breastfeeding, although some felt pressured into doing it. Breastfeeding was seen as good for bonding, for the baby and for helping the woman to regain her figure. It was also free and 'no hassle'. Although all respondents breastfed, they reported insufficient support initially, inconsistent advice, with advice before the birth a rarity. Experiences of information varied. One respondent liked the video about breast-feeding sent from Pampers, which was useful when problems arose. Another complained of having no Information about when and how to stop.

PREFERENCES: BREASTFEEDING INFORMATION

- ✓ Pros and cons
- ✓ How best to express milk
- ✓ Techniques
- ✓ Alternatives
- ✓ Common breast infections to expect, & how to cope.
- ✓ Risks of medication (e.g. antibiotics) transmitted to the baby

PREFERENCES: BREASTFEEDING SUPPORT

- ✓ A 24 hr support phone line
- ✓ Consistent advice
- ✓ Home visits from counsellor
- ✓ Information
- ✓ Breastfeeding support in the community

5.5 Access to Choice Information

Some women relied heavily on Sure Start midwives for guidance, who were universally praised. Some women did read the pregnancy books given out by midwives but found the language complicated. Others used:

- Television,
- Newspapers
- NHS Direct
- Word of mouth
- Family and Friends
- Breastfeeding Counsellor
- Websites (RCM, NCT, Babycentre[15] BBC)
- Specialist magazines (e.g. *MS Society)*
- Specialist workers (refugee or travellers' health worker, MS Specialist Nurse)

"We have our own midwife (Surestart). She's brilliant. you can ask her anything. She explains things really well. You can talk to her on her mobile and get your mind put at rest - much better than seeing strangers."

PREFERENCES: ACCCESS TO INFORMATION

- ✓Doctors
- ✓Health Centre or Clinic
- ✓Health visitors
- ✓Midwife or midwife clinic
- ✓Family Planning Centre
- ✓Antenatal Class
- ✓Local hospital maternity services
- ✓Sure Start midwives
- ✓Library
- ✓Chemist
- ✓Job Centre
- ✓Inside pregnancy test box
- ✓Familiar settings women already visit (e.g. Peckham Settlement)

5.5.1 Media for information provision

Some women had received Department of Health *The Pregnancy Book*[16] (all first time mothers are supposed to receive a copy). One woman found Boots' pregnancy literature helpful. Written information was thought good but possibly unsuitable for those who do not read well, for whom picture script would be needed. Verbal information is also difficult to understand. CDs were also a possibility, in some cases only for use when male partners were not present. Some women had little knowledge of childbirth and were embarrassed to ask.

PREFERENCES: MEDIA

- ✓Internet based
- ✓Tapes & DVDs
- ✓Television
- ✓Written information to back up spoken
- ✓Pictures explaining access (e.g. pregnant woman & phone with no.)
- ✓Pictures explaining birth (e.g. which way the baby comes out)
- ✓One-to-one support from a health professional, as standard
- ✓Information sessions for women to attend early on in pregnancy

5.5.2 Use of the internet

Views differed on how accessible this would be. Although some women had internet access at home, not all seemed conversant with using it to find information. Most would need help to access the internet for information. Respondents felt the internet should be available in the places that the users are most familiar with, where they would feel at ease using it to find information. The library was the preferred choice of some women as they thought it might improve their language skills. However, others felt that if access was only in libraries, then many women would not know about it. Librarians might not give enough help to use the internet to access information.

"I sat with a dictionary and had to look, look, look. It took a long time."

5.5.3 Special Access needs arising from religion or culture – Race Equality

The need for translation and for cultural appropriateness were emphasised as issues for both those providing information and support, and the information itself. This is a race equality issue. Choice was effectively cancelled for women who do not have English as their first language, unless these requirements are met, aggravating the existing health inequalities suffered by these women.

"If something is worth English-speaking women knowing about, then it should be worth making available in Vietnamese."

PREFERENCES: RACE EQUALITY

✓Information in local languages ✓Women-only advice sessions
✓Staff trained in cultural awareness ✓Interpreters

5.5.4 Disability and access to information – Disability Discrimination

Women raised issues of exclusion arising from a range of physical disabilities, as well as mental health disability and literacy problems. A woman with a visual impairment was only asked once during her pregnancy and birth if she needed assistance. She could not read anything given to her and had to ask friends to read it back to her when she got the chance. A deaf woman had problems accessing written English: she found it too complex in vocabulary and grammar, "too heavy", as she was used to BSL. Her partner had translated the written English into British Sign Language. Excluding behaviour by some staff was also described: midwives had persisted in talking when it was clear that deaf parents could not understand, as mentioned earlier. Disabled women generally reported poor information about disability and pregnancy, as well as patronising attitudes from staff. Those with mental health problems felt particularly stigmatised.

"It was extremely rude of the midwives to talk between themselves knowing that I couldn't understand them."

PREFERENCES: DISABILITY DISCRIMINATION

✓DVDs With subtitles ✓DVDs in British Sign Language
✓Tapes and audio CDs ✓Staff trained in disability issues
✓Literature produced by disability support groups

5.5.5 Parentcraft or antenatal classes

The most obvious point of access to information for women and their partners is the antenatal or parentcraft class. However, some women were unaware of the existence of antenatal or parentcraft classes whilst some who did know had been unable to access them. In some cases, information about classes was not given unless it was specifically requested. In one group, only one respondent had been to sessions. Certain women interviewed had no interest in antenatal classes at all and relied on a book instead.

One woman reported no difficulty with accessing classes as she had booked early. However, offering classes too late was often a problem. Antenatal classes were offered too late for a woman who went into labour at 34 weeks for both her pregnancies. Women complained that classes were overcrowded. In one case, a woman with learning disabilities found changing class venues difficult to remember, although the system had been introduced to improve access generally. Quality of classes was variable, with positive comments about a breastfeeding class but other classes described as lacking in structure and failing to address issues crucial issues such as caesareans. Teaching was described as of variable quality. One man had a very positive experience of attending a parenting course, although his partner did not want to attend classes. Some women felt that male partners might go if there were male only sessions. The idea of men being involved in any way was alien to some women.

One lesbian woman took a male friend with her to pretend to be heterosexual and avoid judgemental attitudes.

Some women had poor experiences of classes because of staff attitudes. One who attended a session, was made to feel uncomfortable by a health visitor who disputed why she had come to that particular session. She never went back. Lesbian women commented on gender bias in information. At least one unit in the sector still advertises visiting times as "father's only". Lesbian women experienced problems with some staff attitudes to same sex relationships

PREFERENCES: ANTENATAL CLASSES

✓Universal access to classes ✓Good & timely booking information
✓Classes of consistent quality ✓ Reasonable classes sizes
✓Choice of mixed/female classes ✓Accessible venue
✓Staff trained in Gender awareness and Inclusivity

6. Information currently provided or available in South East London

A telephone audit was conducted of the information available within the sector from providers as well as that available nationally, particularly in relation to pregnancy, parenting and disability. The results are set out below.

PROVIDER	INFORMATION AND MEDIUM	COMMENTS
Information available in the sector		
Queen Elizabeth Hospital NHS Trust	Pregnancy Information book	
The Princess Royal University Hospital (Bromley Hospitals NHS Trust)	Pregnancy Information pack	
Kings College Hospital NHS Trust	Pregnancy Information pack	
Queen Mary's Sidcup NHS Trust	Pregnancy Information Pack	Released in stages. Some sections targeted to specific need e.g. domestic violence
Guy's and St. Thomas NHS Foundation Trust	Pregnancy Information Pack	
Lewisham Hospital NHS Trust	Pregnancy Information Pack	
Lambeth, Southwark & Lewisham Health Authority	Your Guide to Maternity services	Discontinued 1996
NHS information available nationally		
Royal College of GPs www.emmasdiary.co.uk	*Emma's Diary Pregnancy Guide*	Contains comprehensive Information including photos of foetal development and information about care choices
NHS	*The Pregnancy Book*	Centrally funded for first time mothers
NHS	*Birth to Five*	Centrally funded
NHS	*You're Pregnant*.' magazine, limited distributed via midwife or on internet.	Information and local comparisons but funding finished in December 2005
MIDIRS Informed Choice www.midirs.org	MIDIRS information leaflets covering 21 titles ranging from place of birth to sickle cell and thalassaemia	Evidence based information on choice in maternity care funded by the NHS. Versions for professionals and

		women on each topic.
Resources for Disabled People		
Change publications www.changepeople.co.uk	*'Pregnancy'* *'You and Your Baby 0-1'*	Easy words and pictures
Royal National Institute for the Deaf www.rnid.org.uk	*'Pregnancy & Birth – a guide for deaf women'*	Aimed at those whose preferred language is British Sign Language
Disability Pregnancy Parenthood International www.dppi.org.uk	Guides in large print, tape and Braille: ▪ *Bathing your child* ▪ *Choosing cots and beds* ▪ *Nappy changing and dressing* ▪ *Carrying a baby or child on a wheelchair*	Other guides cover parenting with arthritis, visual impairment and MS, as well as guidance for midwives. *"Having a baby"*, for visually impaired parents available late March 2006
British Institute of Learning Disabilities www.bild.org.uk	*'Your Good Health - Pregnancy and Childbirth'*	
Research Institute for Consumer Affairs (RICA) www.ricability.org.uk	*Bottles, Warmers and Sterilisers*	Reports on usability of childcare products by disabled people
Resources for People of black or minority ethnic backgrounds or whose first language is not English		
Other than information provided by individual Trusts in languages other than English, an internet-based literature search revealed no resources in other languages relating to pregnancy and childbirth and no culturally specific material to support women in maternity choices.		

7. Information Prescription

The Department of Health is in the process of developing an 'information prescription' for patients, as explained above in Section 2.1.4. Below is a suggested format and content for such a prescription in the case of maternity care, based on the findings of this project.

NAME

ADDRESSES

MOBILITY NEEDS (IF ANY)
COMMUNICATION NEEDS (IF ANY)

EXISTING CONDITIONS (IF ANY) FOR INFORMATION

Please Tick Which Apply:

PREGNANCY AND YOU	☐	**PREGNANCY & THE BABY**	☐
DIET AND NUTRITION	☐	**SCREENING**	☐
ANTENATAL CLASSES	☐	**ANTENATAL CARE**	☐
CARE CHOICES	☐	**BIRTH CHOICES**	☐
BABY CARE	☐	**POSTNATAL SUPPORT**	☐
DISABILITY & PREGNANCY	☐	**BREASTFEEDING**	☐
BENEFITS ADVICE	☐	**LOCAL CHILDCARE**	☐
CULTURALLY SPECIFIC SUPPORT			☐

WHERE TO GO FOR INFORMATION

URL. for approved websites
Details of books and written literature, tapes etc.

Local library (including opening hours). How to join if required

Voluntary sector groups, contact details, opening hours

Any other support e.g. practice based arrangements

8. Brief for Maternity Choice Information Guide

Suggested content (to be checked for Plain English and tested out with users).

Objective of this template: to provide information identified by women in South East London in our consultation '*Taking Soundings on Maternity in South East London'* and which meets the Consumers Association criteria for patient information:

- Accessible
- Appropriate
- Current
- Impartial
- Transparent
- Accurate
- Consistent
- Evidence-based
- Timely
- Understandable

Choosing where to have your baby

Choices available, including home birth, any birth centres and hospitals.

Help with your choice

There is a lot of information available to help you compare and choose different options for where to have your care in pregnancy and labour. Not all of it will be relevant to you. In this Guide, we have collected the information we think might be useful to you. It is grouped under various headings to help you sift out what is relevant to you and what is not.

Developing the Guide

South East London Strategic Health Authority commissioned an independent patient organisation, Health Link, to talk to women across the 6 Boroughs of South East London, including women struggling with difficult circumstances, such as a low income, mental ill health or pregnancy as teenagers.

How to use this Guide

The Guide is divided into sections

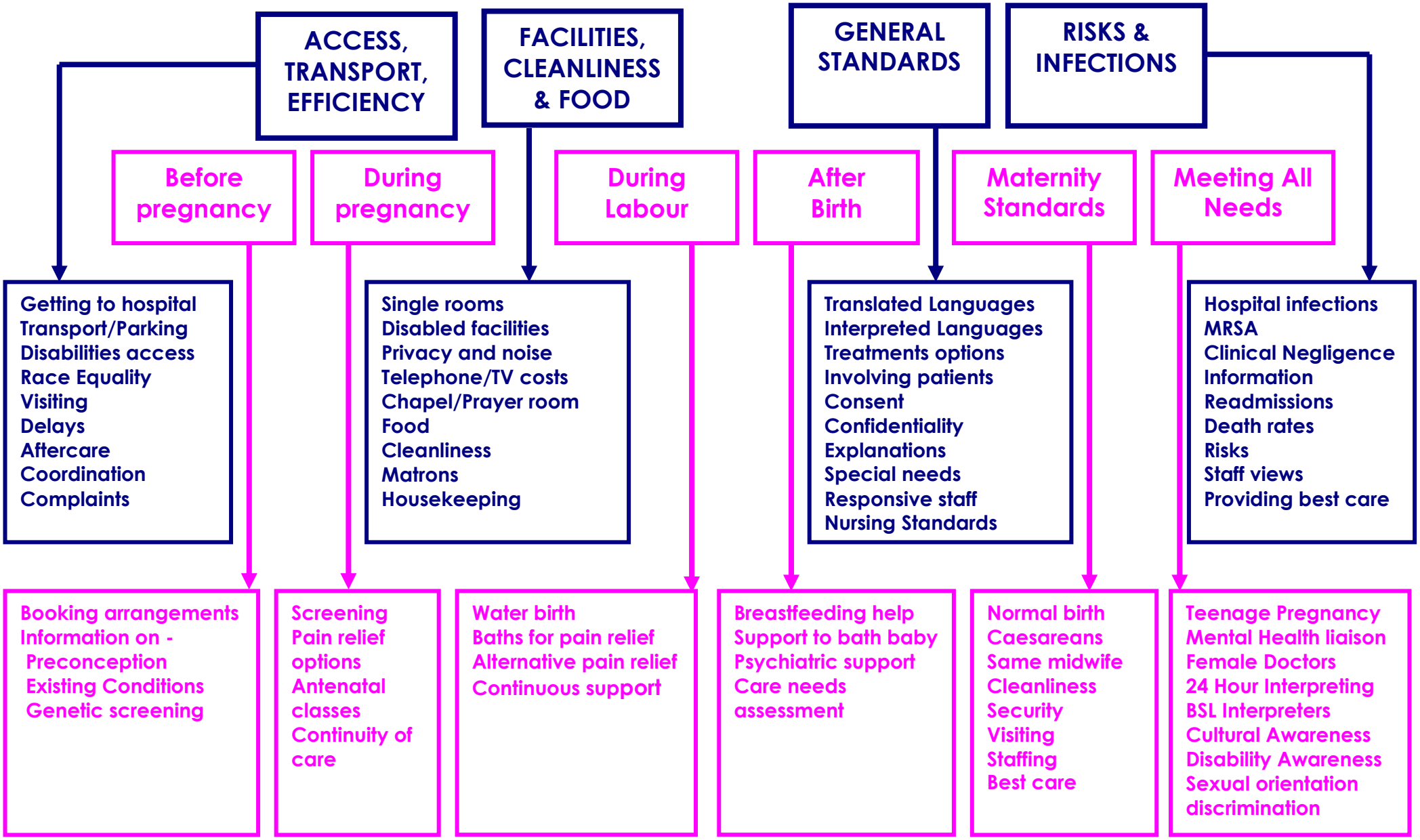
- List of hospitals and birth centres for women in South East London;
- List of topics on which you can compare hospitals you are interested in
- Comparison showing how well these hospitals do on your selected topics
- Places and contacts where you can go to get more information.

List of hospitals

List all the possible choices of provider including how to arrange a home birth.

List of topics

Compare the hospitals on the following topics:


ACCESS, TRANSPORT, EFFICIENCY
FACILITIES, CLEANLINESS & FOOD
GENERAL STANDARDS
RISKS & INFECTIONS
Before pregnancy
During pregnancy
During Labour
After Birth
Maternity Standards
Meeting All Needs
Getting to hospital
Transport/Parking
Disabilities access
Race Equality
Visiting
Delays
Aftercare
Coordination
Complaints
Single rooms
Disabled facilities
Privacy and noise
Telephone/TV costs
Chapel/Prayer room
Food
Cleanliness
Matrons
Housekeeping
Translated Languages
Interpreted Languages
Treatments options
Involving patients
Consent
Confidentiality
Explanations
Special needs
Responsive staff
Nursing Standards
Hospital infections
MRSA
Clinical Negligence
Information
Readmissions
Death rates
Risks
Staff views
Providing best care
Booking arrangements
Information on -
Preconception
Existing Conditions
Genetic screening
Screening
Pain relief options
Antenatal classes
Continuity of care
Water birth
Baths for pain relief
Alternative pain relief
Continuous support
Breastfeeding help
Support to bath baby
Psychiatric support
Care needs assessment
Normal birth
Caesareans
Same midwife
Cleanliness
Security
Visiting
Staffing
Best care
Teenage Pregnancy
Mental Health liaison
Female Doctors
24 Hour Interpreting
BSL Interpreters
Cultural Awareness
Disability Awareness
Sexual orientation discrimination

9. Conclusions and Recommendations

9.1 Conclusions

Policy direction on choice and information is clear. The recent White Paper, *Your Health, Your Care, Your Say*[17] emphasises this. The Children's NSF sets standards and indicators for quality in maternity services, especially for disadvantaged women which, seen alongside *Standards for Better Health*[18], provide a strategic framework for maternity care. Equitable choice can help promote equality in access to services, which in turn can redress health inequalities caused by poor access or inappropriate services. Our consultation was designed to draw on the views of disadvantaged women so that choice in maternity care, due for implementation in 2008 could take account of their needs, exploiting to the full the opportunity that choice offers for tackling health inequalities. Our findings reveal women's clear and detailed aspirations for their care – this is vital intelligence for commissioning services as well as for offering choice of services.

Despite the good work on information currently provided pre and post booking, pregnancy and birth, some women struggled to find the most basic information about how to have a healthy pregnancy and the birth they wanted. This was particularly striking in the case of women with a pre-existing condition. Women with any sort of special need, from language to disability, face additional problems accessing information either because it is not in the right format or the right language or they just did not know where to find it. It appears that legal requirements on race equality and disability discrimination are not always being met.

The purpose of this consultation was to not to audit services, but to define choice requirements, particularly on accessible information. Therefore, it is not possible to draw any firm conclusions about the quality of maternity services in South East London. A clear picture emerges of women's care and information preferences as well as the information they would want to choose a maternity provider. Combined with the pilot information tool developed by Health Link in partnership with NHS Connecting for Health, the Department of Health and four Strategic Health Authorities in London[19], it is now possible to develop comparative information in accessible formats, for piloting and further testing with service users.

9.1.1 Care Choices

Women were clear about the care choices they would want, from choice of first point of contact to the option of birthing and postnatal support from a 'nana' from the same culture as themselves. The reality for some women experiencing maternity care was a lack of understanding and respect for the effect of disability on a woman's experience or the needs created by different cultures and religious practices. Understanding this diversity means remembering that a deaf woman can't hear her baby cry, a woman who doesn't read English won't know what she needs to bring in labour if the list is in

English, how shameful it may feel to be examined by a male doctor and how important it is to a person of faith to observe their religious practices when facing a life changing event such as childbirth.

9.1.2 Current information

The current information system is not designed for choice of provider. Maternity provider units provide information about their services but not until the woman is booked under their care. By then, she has already chosen a provider and is committed to whatever services they offer. Based on our discussions with the Trusts who responded to our audit of information (described in Section 6), the information is likely to be in English only. All women in their first pregnancy should receive '*The Pregnancy Book*' (available electronically on the Department of Health website www.dh.gov.uk publications page) produced by the Central Office of Information, which is being updated currently for release in April 2006. Tape and electronic versions of this are offered but it is not available in any minority languages or BSL, and there are no plans to offer this. Culturally specific material is difficult to find. This is questionable in terms of race equality. Some women in the survey had not received it at all and others reported only getting a copy when they asked.

9.1.3 Format, media and access points

It is proposed to redesign the information system to make it fit for purpose once maternity choice is offered. This gives an opportunity to address access and content issues. Nearly all the women interviewed wanted to talk to a health professional, usually a midwife, to discuss options of care, general health of themselves and the baby, tests and results. They also wanted written material, picture books, tapes, DVDs and web-based material to which they could refer. Many women wanted help to find the right information on the web, so a venue they felt comfortable in where such support was provided, is important.

Antenatal classes are an obvious source of information once a pregnant woman has booked with a provider. While some women found classes easy to book, providing they booked early, others had no idea that these classes even existed. Women who move about for whatever reason are not in the same place long enough to make a booking or try to book too late. Women who did access the classes were critical of overlarge class sizes and gaps in the content. Discussions about provision of information indicate that women would prefer to get it in places they already access easily. These might include as benefit offices, chemist shops and in some cases public libraries, rather than having to go to new locations.

9.1.4 Public Libraries as Access points

The 'digital divide' between those with access to the internet and the skills to use it and those without, can be a barrier to choice if information is only web-based. Public libraries would be a suitable access point because of the free People's Network (less than 5% of libraries make any charge for the use of the Network). The internet is the 'publishing house' for information and computers can be the 'printing press.' Just as one does not have to know how to work a

printing press to read a book, so it is not necessary to know how to use a computer to read what is printed from it. Librarians are trained to support the public in accessing web-based information on the People's Network. This role can close the 'digital divide' when librarians find information for women on the web. The Public Library Service has targets to promote healthy communities and narrow health inequalities[20]. Providing this is well publicised (in the 'Information Prescription' for example see above in section 7), and librarians are briefed in advance, women should be able to access the online guide in the local familiar settings of public libraries at no cost to them or the NHS. The viability of this model is being explored by Health Link in discussion with the Museums, Libraries and Archives Council. For those women who do not find the public library accessible or require specialist one to one support, specialist voluntary sector organisations should be commissioned to support women in the use of the Guide.

9.1.5 Commissioning

Care choices are dependent on the effective commissioning of a range of services and options and on accessible information about those options, so women can make informed choices. For example, most women interviewed would have preferred a midwife as their first point of contact. As they did not know whether this was an option, they went to a GP first. Women who wanted to breastfeed needed the right information and support to do so, without feeling pressured into this choice. In the case of women with a pre-existing condition such as multiple sclerosis, choices are equally important but much more complex. At the most basic level, women in this situation even find it difficult to find out the implications for their condition of a pregnancy. Inclusive, woman-centred advice and support and multi-disciplinary working between specialties such as obstetrics and gynaecology and neurology, are a matter for commissioning standards.

Health Link has heard from women that they want

- services to promote their health before they conceive,
- information on all aspects of their care,
- information on who can support them
- information to enable them to choose where they have their baby.

A summary of their preferences is set out at the end of the Recommendations. Providers and commissioners will wish to address these issues by making services and choices about services fully accessible to all women. Information is crucial to choice. In our discussions with women, it became clear that choice is hampered by 'not knowing what you don't know.' Information needs are met by not only providing what women want to know but also providing better information about what the NHS knows. This might be about the stages of pregnancy, long term conditions or which service options are on offer. It is this use of information to link women's needs and expectations with what the NHS offers and what commissioners commission, that can really drive forward woman-centred maternity care in a patient-centred NHS.

9.2 Recommendations

9.2.1 Preconception

Commissioning - Primary Care Trusts (PCTs) should commission

Pre-conception services according to local need. These should include:

- Genetic Screening
- Care pathways between specialist and maternity services for pregnant women with pre-existing medical conditions to provide appropriate care and treatment from competent professionals
- Direct access to a midwife as an option for first point of contact and ongoing care, publicised in venues that women frequent (see below) whether pregnant or not, and described in the GP Practice Leaflet.
- Pregnancy testing offered in midwives clinics, as is done is some areas, to encourage early booking and improve access for women on low incomes.

9.2.2 Choice

Implementation – implementation plans for choice should be designed from the point of view of disadvantaged women. If choice works for them, it is likely to work for all users. This would mean:

- Information on choice of provider that is accessible and easy to understand
- Access to information where women already go
- Patient and public involvement in choice menus
- Services commissioned to include the care choices that women have specified
- Monitoring of choice uptake to test how accessible choices are
- Robust feedback system on quality of care after a chosen provider is used
- Incorporation of that feedback into subsequent commissioning

By this means, women's views will influence commissioning and service design in an incremental way. Through this 'choice loop' the choices some women make and the feedback they provide after exercising those choices, can drive up service quality and benefit all women.

9.2.3 Pregnancy and Birth

Commissioning: PCTs should commission to the standards of the Children's NSF and the additional preferences expressed by women, as summarised in the Preferences Box below. With regard to antenatal classes, this would include:

- A choice of men-only sessions, if piloting and evaluation demonstrates improved engagement of men in supporting their partners.
- Class capacity to match demand and permit early booking
- Class content tested for appropriateness and completeness with women
- Teaching quality tested with women
- Monitoring take up by all pregnant women by recording and reviewing notes.

9.2.4 Information to choose a provider

Provision of information: timing, content and accessibility need to be carefully planned to exploit the full potential of choice of provider to give women more control, and providers better intelligence about their service quality. This would include:

- A Birth Guide to enable women to compare services on topics of relevance to them (see Preferences Box below). For providers such a Guide can highlight gaps in the service and promote good practice, by enabling peer review on issues of relevance to women.
- Making the Guide available before or in the early stages of pregnancy to enable women to make informed, timely choices
- Publishing the Guide as a web-based tool so that it can be
    - updated cost effectively and easily
    - printed out for women at low cost,
    - meet the necessary accessibility requirements with minimal cost
- Liaison with public libraries to make use of the People's Network as a free access point for the Guide
- Scoping of the assistive technology already available in local public libraries, such as speech enablement and software designed to assist dyslexic people, to see how this can be used to make the Guide more accessible.
- Scope the measures taken by local public libraries to work with people who suffer health inequalities, to see how choice information can be channelled through these communication methods

9.2.5 Postnatal Care

Commissioning: PCTs should commission

1. Sensitive, accessible breastfeeding support. Providers could procure this through explicit inclusion in staff job descriptions and appraisals.
2. Specific levels of confidence in breastfeeding, achieved through standard protocols on breastfeeding advice.
3. Support on postnatal wards for women trying to breastfeed, procured through the voluntary sector to ensure sensitivity and appropriateness
4. A 24hr helpline or text phone for women after discharge from midwifery care. Readily available advice while establishing breast-feeding in particular, is crucial and a dedicated 24-hour service would build on what is already offered by midwifes.

9.2.6 Access to Information

a) Format and Media – information should cover topics specified in this report (listed in the Preferences Box below), and be commissioned in accessible formats, namely:

- written format which meets Plain English standards
- minority languages

- on DVD and audio tape
- Braille
- British Sign Language
- Easy Read and picture format
- an electronic format to Crystal Mark internet and Ability.net standards

Information in accessible formats may also be commissioned from a specialist voluntary organisation who can deliver as and when required to set response times. It is not always cost effective to fund the production of literature in different formats just in case they are required. Existing information from the specialist voluntary sector can also be used where available, such as '*Planning a baby*' and '*Your child 0-1*' in easy words and pictures, from Change[21]

b) Access points for information – in addition to libraries, (see above) information should be offered in familiar settings such as:

- Local radio
- Pharmacies
- Children's Centres
- Supermarkets
- GP surgeries
- Sexual Health clinics
- Digital TV stations
- Adverts on local buses
- Libraries (literature/web-based)
- Internet cafes
- Benefit offices
- Commercial consumer websites

c) Special Needs - PCTs should commission

1. Mobility and Communication Assessments by GPs and Trust staff to assess vulnerable women's mobility and/or communication needs, ensuring all staff are aware of their needs and preferred form of communication.[22]
2. Interpreting services in the main local languages, which are pre-booked for all appointments and for antenatal classes with 24 hour on-call arrangements for birth and the postnatal period.
3. Culturally appropriate support or nanas, exploring the role for women from particular ethnic groups of informal peer support and advocacy during pregnancy and postnatally. There are precedents for social franchising of culturally specific home care workers.
4. Training to defined quality standards ensuring that all staff are trained in
   - cultural awareness
   - disability awareness
   - sexual orientation training.

PREFERENCES BOX

PRECONCEPTION INFORMATION

- ✓ Healthy eating
- ✓ Folic acid
- ✓ Nutrition (mother & baby)
- ✓ Contraception advice
- ✓ Screening
- ✓ Vitamins and minerals
- ✓ Healthy eating for vegetarians
- ✓ Advice on giving up smoking
- ✓ RH negative status
- ✓ Pregnancy & existing conditions

WHERE TO GET PRECONCEPTION INFORMATION

- ✓ A Health visitor
- ✓ A Midwife
- ✓ The doctor
- ✓ The internet
- ✓ A support group for disabled e.g. Deaf Parenting Newsletter
- ✓ *"Someone who does the blood test"*
- ✓The library
- ✓ *"Benefit places"*
- ✓A Bookshop

CARE CHOICE INFORMATION

- ✓Intervention: pros and cons
- ✓Postnatal depression
- ✓Which way baby comes out
- ✓Aftercare of mother and baby
- ✓How the baby grows in the womb
- ✓Information on 'how to be a Dad'

BREASTFEEDING INFORMATION

- ✓ Pros and cons
- ✓ Alternatives techniques
- ✓ Risks of medication (e.g. antibiotics) transmitted to the baby
- ✓How best to express milk
- ✓Common breast infections (how to cope)

ACCCESS POINTS FOR INFORMATION

- ✓Doctors
- ✓Health visitors
- ✓Family Planning Centre
- ✓Local maternity services
- ✓Library
- ✓Job Centre
- ✓Health Centre or Clinic
- ✓Midwife or midwife clinic
- ✓Antenatal Class
- ✓Sure Start midwives
- ✓Chemist
- ✓Inside pregnancy test box
- ✓Familiar settings where women already go (e.g. Peckham Settlement

MEDIA

- ✓Internet based
- ✓Television
- ✓Tapes & DVDs
- ✓Written information to back up spoken
- ✓Pictures explaining access (e.g. pregnant woman & phone with the no.)
- ✓Pictures explaining birth (e.g. which way the baby comes out)
- ✓One-to-one support from a health professional, as standard
- ✓Information sessions for women to attend early on in pregnancy

RACE EQUALITY

- ✓Information in local languages
- ✓Women only information
- ✓Interpreters in local languages
- ✓Staff trained in cultural awareness

DISABILITY DISCRIMINATION

- ✓DVDs With subtitles
- ✓Tapes and audio CDs
- ✓DVDs in British Sign Language
- ✓Staff trained in disability issues
- ✓Literature produced by disability support groups

PREFERENCES BOX

CARE CHOICES FOR PREGNANCY & BIRTH

✓Early Booking
✓Home birth
✓Midwives Clinics
✓Continuity of care
✓Midwife/GP as first contact
✓Continuous support in labour
✓Known midwife team
✓Good staff handover
✓Water birth
✓Nanas from different cultures
✓One to one support
✓Female doctors at all times
✓Home visits from midwives
✓Support from community groups
✓Guarantees that caesareans would only be done in an emergency

INCLUSIVE CHOICE

✓Information in translation
✓Cultural awareness
✓Disability awareness
✓Interpreters in local languages
✓Women-only information sessions
✓Disabled access
✓Choice about whether male partners and relatives are involved

POSTNATAL CARE

✓ Help to feed/bath baby
✓ Help after a caesarean
✓ Good communication (wards & special care units)
✓Nanas or midwife assistants
✓Home support for single mothers

BREASTFEEDING SUPPORT

✓ A 24 hr support phone line
✓ Home visits from counsellor
✓ Breastfeeding support in the community
✓Consistent advice
✓Information about stopping

ANTENATAL CLASSES

✓Universal access to classes
✓Classes of consistent quality
✓Accessible venue
✓Good & timely booking information
✓ Reasonable classes sizes
✓Choice mixed/female classes
✓Staff trained in Gender awareness and Inclusivity

PREFERENCES BOX

INFORMATION TO CHOOSE A PROVIDER
ACCESS, ENVIRONMENT AND FOOD

- ✓How to get there
- ✓Visits allowed before choosing
- ✓Comprehensive Information
- ✓Food choice, quality & quantity
- ✓Vegetarian food choice & quality
- ✓Pleasant environment
- ✓Cleanliness
- ✓Written in Plain English
- ✓Extra food if breastfeeding
- ✓Security for baby

CARE AND STANDARDS

- ✓Infection Rates
- ✓Emergency-only caesareans
- ✓Pain relief options (e.g.TENS)
- ✓One to one support in labour
- ✓Supportive staff
- ✓Enough night staff
- ✓Support after caesarean
- ✓Home visits from midwives
- ✓Liaison existing conditions
- ✓Intervention rates
- ✓Continuity of care
- ✓Death rates (mothers & babies)
- ✓Women not left alone in labour
- ✓Enough staff (all wards)
- ✓Good handover on shift change
- ✓Team midwifery throughout
- ✓Female doctors at all times
- ✓Advice mental health drugs

INCLUSIVITY

- ✓Cultural Awareness
- ✓Information in translation
- ✓Disability Awareness
- ✓What languages

Organisations consulted by the Midwifery Choice Project

1. **Bromley NCT mother and baby group:** 10 women and an NCT teacher

2. **Contacts through a midwife**: 4 lesbian women in Lewisham and Lambeth

3. **Contacts through the Multiple Sclerosis Specialist Nurse**: 4 women with MS and registered disabled partially sighted, from Lewisham and Southwark.

4. **Refugee and Asylum seeker Group and a Muslim Women's Group:** 18 women and 1 man in Rotherhithe. Ethnic origins: Black African(Ugandan, Nigerian, Somali, Sudanese), Romanian, Anglo-Indian, Anglo-Indian, Iranian, Chinese, Mongolian White South African, Black British and White African

5. **Southwark Travellers Action Group:** 10 residents of two sites in Peckham, supported by the Maternity Alliance. Ethnic origin: Irish.

6. **Surestart Groups**: 18 women and 1 man in Bellingham and Deptford

Organisations consulted by Health Link

1. **Cardinal Hume Centre: s**ervices to homeless or displaced young people, including accommodation, counselling, training in practical skills. 2 group meetings and 5 one to one meetings, (12 participants in all). Age ranges 17-44. Ethnic origins: White and Black British, Irish, Spanish, Iraqi.

2. **Isis Family Centre, Catford:** psychological therapy and counselling for mental distress. The group consisted of 9 women who regularly attended and 3 who 'came in and out during the meetings but still contributed.
   Age range 25 yrs plus. Ethnic origins: Black African, Black Caribbean.

3. **Parents' Power:** support disabled parents in Bexley. 2 questionnaires returned: 1 respondent with cerebral palsy, 1 with arthritis in knees and hips.
   Age range 28-30. Ethnic origin: White British.

4. **The Peckham Settlement:** services based on needs, currently for asylum seekers**.** 3 interviewed, all had had one child here (1 29 weeks pregnant).
   Age range 20-30. Ethnic origins: Black African (Congo, Cambodia, Sudan)

5. **Postnatal Depression Group:** run by Penge Community Mental Health Team. 4 Questionnaires returned. Age range 30 – 36. Ethnic origin White British.

6. **Sleeping Genius Young Parent Project:** supports disadvantaged young people (homelessness, poor health, isolation) on parenting, sexual health and 'getting on with their lives'. 5 questionnaires returned. Age range 17–25. Ethnic origins Black Caribbean, Black African, Turkish and White British.

7. **Midwife Contact:** 1 questionnaire from a deaf woman who had had a baby, though a midwife contact. Age 35 yrs. Ethnic origin: White Other.

TEXT OF QUESTIONNAIRE USED BY HEALTH LINK

MATERNITY CHOICE PROJECT

Health Link

On behalf of
The South East London Strategic Health Authority

Survey Response

Thank you taking the time to complete this Survey Response Form. There are 14 questions plus an evaluation form.

The purpose of this survey is to ask women what information they need to make an informed choice about their maternity care. It is also important to learn how women wish to access the information.

Your views are vital to inform midwives, doctors, nurses and other health professionals of your needs. Your responses will be fed back to the South East London Strategic Health Authority who is commissioning this work and Health Link will keep you informed of the outcome.

Please return this form by Friday 30 September 2005

- By post to Health Link at 62 Beechwood Road, London E8 3DY
- By email to info@health-link.org.uk

1. Before you become pregnant what advice, would you like to ensure that you are in the best possible health and that your baby has the best start? This could be
   - General information about vitamins or giving up smoking or
   - if you felt you may need some screening advice on say an inherited condition

2. Where would you look to find this information?

3. If you are or have been pregnant was the information you needed available? If not what was missing?

4. Where would you look to find information about the maternity services in your area?

5. The NHS wants you to have choice about the care you receive when you are pregnant and where you have your baby. What information do you need about local services to enable you to make a choice?

6. How would you like to get this information e.g.

- Talking to a midwife, doctor, nurse, etc
- Reading a booklet
- Tape/DVD
- Internet link

7. Do you want information on who will be looking after you during your pregnancy and birth?

8. If you have a disability, would you need to access information in a different way? If so what would be best for you?

9. Does you partner need any additional information to be able to support you?

10. Do you have special needs regarding you religion or culture that you would like the people looking after you to be aware of? Could you say what they are?

11. Are parentcraft or ante-natal classes easy to find and book?

12. What information and advice would you need on breastfeeding to enable you to choose how to feed your baby?

13. If you had to move house during your pregnancy to a different area what information would you need about the maternity services in your new area to continue your care?

14. Would you need any other information about local maternity services to enable you to choose what would be best for you? If so please list below.

MATERNITY CHOICE IN SOUTH EAST LONDON

Background: Choice of provider in maternity services is to be brought forward by the Department of Health to 2008. Research evidence on choice in acute care demonstrates how important information is to making choice a reality (Picker Institute: *Evaluation of London Patient Choice Scheme* July 2005). Health Link, an independent, patient involvement organisation, has been commissioned by the South East London Strategic Health Authority to consult on information needs with disadvantaged women and voluntary sector groups who support them. These included: young deprived people, disabled people, travellers, refugees, mental health service users, families with social care needs, women with a learning disability, faith groups, and women from BME groups.

Findings: the information that women from disadvantaged groups asked for was extensive. We have scoped existing sources of information such as:

- Department of Health datasets.
- Data gathered through our earlier survey on patient choice information
- Data published by Dr. Foster and Birth Choice UK

Remaining information needs relate to the personal circumstances of women.

This Survey: we have developed a survey of providers to ask for the remaining information and have piloted it with Lewisham hospital. The final survey is being sent to all maternity units serving the South East London sector.

What will happen to the data provided through this survey? We will produce a template for a south East London Maternity Choice Guide for women, which the Strategic Health Authority plans to commission in time for maternity choice.

Why should you help us with this survey? There is considerable data available on maternity services, but not on issues important to disadvantaged women. As the NHS enters the data rich culture of choice and as increasingly commissioning is based on what service users want, Trusts will be at a disadvantage if they do not know how they perform on what really matters to the users of their services.

- *DH Guidance (Choose & Book" – Patient's Choice of Hospital and Booked Appointments*) requires 'equality of access to choice'
- The Children's NSF requires Trusts to '*Improve the access and effectiveness of maternity services for women from disadvantaged and minority groups and communities by systematically taking account of the reasons why women from these groups find it difficult to access and maintain contact with maternity services, and by actively designing services to overcome these barriers to care.'*

This survey will enable Trusts to stock take their services for these purposes.

Timescale: Please send the completed survey to ...**by .**
Queries: please all any queries to Elizabeth Manero at Health Link on 020 254 1582 or email us on info@health-link.org.uk**.** *5th December 2005*

Health Link

Compact working together better together

SOUTH EAST LONDON MATERNITY INFORMATION FOR CHOICE PROJECT

TRUST SURVEY TO GATHER INFORMATION IDENTIFIED BY WOMEN

COMMISSIONED BY SOUTH EAST LONDON STRATEGIC HEALTH AUTHORITY

PLEASE RESPOND ON A DIFFERENT FORM FOR EACH HOSPITAL SITE

NAME OF HOSPITAL SITE:	**NHS SITE CODE:**

CONTACT DETAILS OF THE PERSON COMPLETING THIS FORM

NAME:	**JOB TITLE:**	**TEL:**	**EMAIL:**

TOPIC SPECIFIED BY WOMEN	**YES**	**NO**	**DETAILS**
1. INFORMATION			
1. How can women access information about your maternity services before they are pregnant?			
2. Do you provide information on			
a) preconception advice			
b) specific pre-existing conditions (please state which ones in the Details section)			
c) screening for possible genetic conditions (please state which ones in the Details section)			
3. Do you ask women at booking how they would like to receive information (e.g. large print for sight impaired women)?			
4. Which of the following methods of providing information on pregnancy and childbirth to booked women, is available at the Trust (please provide further detail if only available on certain topics, in the Details section):			
a) one to one discussion with a professional?			
b) written information?			
c) MIDIRS Leaflets			

TOPIC SPECIFIED BY WOMEN	YES	NO	DETAILS
d) web-based information?			
e) pictures or symbols?			
f) tape/CD?			
g) DVD/video?			
h) any other alternative formats for disabled people? (Please specify which in the Details section)			
i) Languages other than English? (Please specify which languages in the Details section)			
2. THE BEGINNING OF THE PREGNANCY			
5. If free pregnancy testing is offered by the Trust, please tell us			
a) Which hospital department(s) offers this service?			
b) How is the service publicised?			
6. Do you accept self-referrals to midwives clinics?			
7. How is this facility publicised?			
8. How long is the waiting time (in weeks) between receipt of the first request by the Trust and the first appointment with a midwife			
3. THE ANTENATAL PERIOD			
9. Does the midwife discuss screening and its implications, with women at their first midwife appointment?			
10. If the Trust ever has to refuse access to antenatal classes on the grounds of lack of capacity in the classes, please estimate whether this happens:			
a) very often			
b) occasionally			
c) rarely			
11. If the Trust operates any eligibility criteria for access to antenatal classes (e.g. first time mothers only), please list the criteria			
12. Please estimate the maximum number of women in the antenatal classes			
13. Does the Trust offer male-only antenatal classes?			

TOPIC SPECIFIED BY WOMEN	YES	NO	DETAILS
14. How are the classes publicised			
15. Is a record made in the woman's notes in advance of labour, of their preferences for pain relief during labour?			
16. In what circumstances can you guarantee that a woman will be assisted in labour by the midwife who cares for her antenatally, if she has requested this?			
4. THE LABOUR			
17. Can you guarantee that every woman will have a designated midwife to provide care for them when in established labour, for 100% of the time?			
18. Please specify any complementary methods of pain relief/ relaxation which women are explicitly not permitted to use?			
19. Please estimate whether women in established labour at the unit are left alone (select one alternative only)			
a) very often			
b) occasionally			
c) rarely			
20. Does the unit have baths for use by women in labour (or only showers?)			
21. If so, what is the ratio of baths to labour rooms?			
22. What proportion of midwives per shift are trained in waterbirth?			
5. THE POSTNATAL PERIOD			
23. Does the Trust have Baby Friendly status?			
24. If not, is the Trust working towards Baby Friendly status?			
25. Does the Trust have a breastfeeding helpline?			
26. If so, what are its operating hours?			
27. Do women receive one to one guidance on the post-natal ward on the following activities:			
a) Feeding the baby			
b) Bathing the baby			

TOPIC SPECIFIED BY WOMEN	YES	NO	DETAILS
28. If the Trust monitors the percentage of women who receive guidance under a) and b), please provide most recent data and period covered. (If not monitored, please say ' not monitored').			
6. OVERALL SERVICE AND STANDARDS OF CARE			
29. Do women have a named midwife throughout their pregnancy?			
30. If you monitor the percentage of women who have a change of midwife during their pregnancy, birth and postnatal recovery, please provide most recent data and period covered. (If not monitored, please say ' not monitored').			
31. How many complaints about the unit's cleanliness have you received in the last year (2004/2005)?			
32. What are the security arrangements for the baby while on the unit?			
33. What are the visiting hours?			
34. Do you have a family room or community room for women who wish to have more than the permitted number of visitors?			
35. How many hours of consultant cover can you guarantee on the labour ward?			
36. Are you able to guarantee 1.5 midwives per woman in labour?			
37. Is obstetric cover provided to the labour ward on a 24 hour basis?			
38. If not, what are the arrangements?			
39. Is midwife cover provided on a 24 hour basis?			
40. If not, what are the arrangements?			
41. Please indicate whether or not the Trust complies with the following NICE Guidelines:			
a) Antenatal Care			
b) Pregnancy - Routine Anti-D prophylaxis for Rhesus negative women			
c) Induction of Labour			
d) Electronic Fetal Monitoring			
e) Caesarean Section			
42. Does the unit record information about the ethnic group of the mother?			
43. Does the unit record the 'maternity tail' data for all deliveries?			

TOPIC SPECIFIED BY WOMEN	YES	NO	DETAILS
44. What are your unit's rates for 2004/2005 of normal deliveries' (no surgical intervention, us of instruments, induction, epidural or general anaesthetic)?			
45. Please describe the process of choosing a lead professional in			
a) complex medical cases			
b) complex social care cases			
46. If the Trust has audited its services against Standard 11 of the Children's NSF, when was this carried out?			
47. Which of the following requirements of Standard 11 have been complied with so far?			
a) 'Easy access to information and support'			
b) 'Care pathways and managed care networks'			
c) 'Improved pre-conception care'			
d) 'Access to a midwife as their first point of contact'			
e) 'Local perinatal psychiatric services'			
f) 'Choice of most appropriate place of birth'			
g) 'Home birth'			
h) 'Delivery in midwife-led units'			
i) 'Post-birth care based on structured assessment'			
k) 'Breastfeeding support for mothers'			
48. Do you have an early pregnancy assessment unit?			
49. How is this unit publicised?			
7. MEETING THE NEEDS OF WOMEN			
50. If the Trust is notified that a woman has a disability, are all health professionals informed prior to her first appointment?			
51. Does the Trust have:			
a) a teenage pregnancy co-ordinator			
b) a mental health co-ordinator			

TOPIC SPECIFIED BY WOMEN	YES	NO	DETAILS
52. Are you able to guarantee the availability of a female doctor to all women who require it?			
53. Do you provide interpreters to			
a) antenatal clinics			
b) antenatal classes			
c) labour ward			
d) postnatal ward			
54., In the case of c) & d above, is this service provided on a 24hr basis?			
55. If No, what arrangements are in place for out of hours cover?			
56. If Yes, in what languages?			
57. Is British Sign Language included?			
58. Are all midwives trained in			
a) cultural awareness			
b) disability awareness			
c) sexual orientation discrimination			
59. Are all medical staff trained in			
a) cultural awareness			
b) disability awareness			
c) sexual orientation discrimination			

[1] [1] *Our Health, Our Care, Our Say.* Department of Health 2006
[2] A Partnership Project between Health Link, the Department of Health, NHS Connecting for Health and four of London's five Strategic Health Authorities
[33] *Better Information, Better Choices, Better Health* Department of Health 2004
[4] *Taking Soundings: a patient and public involvement exercise in Patients' Choice* Health Link 2004 www.health-link.org.uk
[5] *National Service Framework for Children, Young Persons & Maternity Care* Department of Health September 2004.
[6] Ibid.
[7] *Building on the Best 2004*
[8] *Choosing Health* Department of Health 2004
[9] *Our Health Our Care Our Say.* Department of Health 2006
[10] *Better Information* Better *Choices, Better Health* DH 2004
[11] Department of Health January 2006
[12] *Creating a Patient-led NHS* Department of Health 2005
[13] http://www.drfoster.co.uk/
[14] Average number of children that would be born to a woman, if she experienced the current fertility rates. Office of National Statistics 2006
[15] http://www.babycentre.co.uk/
[16] Department of Health 2004
[17] Department of Health January 2006
[18] *National Standards, Local Action: Health and Social Care Standards and Planning Framework 2005/06–2007/08* Department of Health July 2004
[19] www.londonpilotnhs.uk
[20] *Framework for the Future* Department for Culture, Media and Sport 2003
[21] http://www.changepeople.co.uk/
[22] Mobility and Communication Assessment Form used by Queen Medical Centre, Nottingham University Hospitals Trust