



## The Reaching Out Project

A report on the development of  
the Maternity, Access and Advocacy  
Pack



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## **Executive summary**

The Maternity Access and Advocacy Pack (MAAP) consist of four storyboards and an accompanying booklet. The storyboards give information through pictures about standard care for pregnant women and their families through pregnancy, birth and becoming a parent, up to the first week of the baby's life. The booklet builds on the information and contains further information, for example about access and sources of help.

The MAAP was developed in response to discussions within the community about what information people needed to help them access and use maternity services effectively. The outcome was that people wanted something to look at and someone to talk to. The research identified that people wanted a resource that was pre-clinical, before they met the midwife or doctor. It is aimed at promoting and enhancing advocacy from self-advocacy to health advocates.

It was developed with a high level of user involvement by men and women of all ages reflecting cultural capital through a range of ethnic diversity, social need and geographical location. A large proportion of the engagement and development was conducted in the capital but 'one off' workshops, meetings and focus groups were held nationally in Durham, Manchester, Liverpool, Dover and Leicester.

Listening to the conversations that the storyboards provoked provided rich and diverse data into experiences and perceptions of maternity services. Community knowledge and understanding, grounded in everyday life collaborated other research (DH, 2005) but was also illuminating and user rather than research led. These finding will be outlined in this report.

In sum this report has three interlocking themes; why and how the MAAP was developed; lessons in community engagement around maternity services and insights into why for some individuals and groups in society access and ongoing engagement are problematic.

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Anna Gaudion is a project officer within the Reaching Out Project at Medact. She has an academic background in anthropology, museum ethnography/ anthropology of art and refugee studies. Anna has an eclectic career history. She previously worked as a curator in the ethnographic department of the British Museum and as a lecturer in the anthropological aspects of women's health. She directed and produced the film entitled 'Florence the experience of becoming a mother in exile'. She is an experienced midwife in both hospital and community settings.

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## **Contents**

Executive Summary  
Acknowledgements  
Contents

## **The Maternity Access and Advocacy Pack**

Introduction

### Rationale

- Background
- The need for accessible information
- Delivery of Information and Community Players
- The Role of Advocacy
- Preliminary Consultations
- Using Pictures; Anthropology of Art

### Methodology

- Engaging with hard to reach groups
- The consultations
- Ethics
- Exploring Pictures
- Active Involvement and ownership
- Keeping Professionals in the loop
- Time constraints

### Issues Identified

- Access, Entitlement to care, Encountering Prejudice and Stigmatising Labels
- Interpreters
- Choice
- Mental Wellbeing
- Feeding Back to the system
- Clinical Issues

### Design and Development

Limitations of MAAP  
Feedback from the Community

Conclusion

Appendix

## **THE MATERNITY ACCESS AND ADVOCACY PACK**

This is a discursive information resource about maternity services consisting of four storyboards depicting pathways through pregnancy, birth and becoming a parent and an accompanying booklet.

It is a resource requested and developed with a diverse range of people. Specifically participants have asked for a resource situated in the community, which can be accessed pre-clinically. They are for women and their families, advocates and non-midwifery staff who may encounter pregnant women and new parents. They are not intended to replace advice from a midwife but to extend the taxonomies and systems around childbirth and early parenthood.

The storyboards open out in a concertina fashion and are printed on both sides. They are covered with plastic so that they have a level of robustness when used repeatedly especially in groups where young children are present or food and drink is being consumed. The accompanying booklet has text and photographs of people who have been involved in the development.

Three symbols weave their message along the bottom of the storyboards, reiterating the central issues; ask for an interpreter; ask about your choices and talk about how you are feeling. These symbols are designed to encourage women and their families to be active partners in care by highlighting the importance of asking questions and talking within a holistic framework of need. They are explained further in the accompanying booklet. The booklet describes how the resource was developed and provides an outline for suggested use. The text enlarges on points made in the storyboards, clarifies issues that have arisen from listening to people within the community and signposts further information. The material reflects the information requested by the people involved in the consultation and development.

## INTRODUCTION

This report documents the development of the Maternity Access and Advocacy Pack (MAAP) from its inception at a focus group with Vietnamese women in south London to the end product. The journey to creating it has been one where policy and practice has linked to a identified need within the community for a resource that informs about maternity service in the UK and encourages families to be equal partners in planning care.

The MAAP was developed with over 380 people from a wide range of different ethnic backgrounds and needs. From the embryonic beginning to the final stages, the tool has facilitated stories, debates and numerous insights into community perceptions of maternity services. Ongoing engagement and the relaxed unobtrusive unstructured nature of the sessions meant that a few pointers as to why, for some groups of people, gaining access are difficult. Some of these issues will be outlined in this account.

The MAAP consists of storyboards depicting pregnancy, birth and becoming a parent and an accompanying booklet. It is a picture-based tool aimed to increase the 'choice' agenda for people who experience marked inequalities in access and ongoing engagement with maternity services. The community asked for something to look at with someone they trusted, pre-clinical. They wanted a discursive rather than an instructive tool that would inform non-directionally about maternity services. In sum, they wanted a tool to encourage discussion and facilitate empowerment.

*"When you are new to this country, even when language is not a problem...I could speak English when I arrived there is no information about what to do when you find yourself pregnant...it is easier to find out about getting a new kitchen, but the issue that is likely to involve many women, most women there is nothing...what is needed is advertisements telling you what to do and where to go then of course people would"* (Refugee from the Democratic Republic of Congo).

## RATIONALE

### Background

Although excellent statutory and voluntary initiatives exist, aimed at delivering appropriate support for all pregnant women and new parents, research indicates that many women are missing out because of their lack of awareness of such services, because of their lack of language skills makes them wary of using existing support or because of a lack of permanent housing they are not integrated into their local communities and health services (Cemach, 2004; DH, 2004; DH, 2005; DH, 2007).

The Confidential enquiry into Maternal Deaths 2002, 'Why Mothers Die' indicated that women from some minority ethnic groups in the UK have twice the risk of maternal death than a white woman. In addition women from ethnic minority groups made initial contact with maternity services later than their white counterparts. A large number of these women spoke little English and in many cases family members acted as interpreters. The subsequent report (CEMACH, 2004) indicated that these remain current issues.

Poverty and the encompassing factors of deprivation affect both maternal and child morbidity and mortality,

*"The most disadvantaged women are 20 times more likely to die than those from higher socio-economic backgrounds, and women from ethnic groups other than white are three times more likely to die. Mortality rates among refugees and asylum seekers are particularly high. These problems are related to accessing health care and need to be addressed"* (CEMACH, 2004,pvii).

Further it asserted that,

*"...Disproportionate numbers of women who died were from vulnerable and more excluded groups of our society. The findings also show that these women were less likely to access or continue to remain in contact with maternity services"* (CEMACH, 2004.55).

Key findings in the Prenatal Mortality Surveillance Report 2004 were that,

*"A high proportion of stillbirths and neonatal deaths were born to women in socially deprived areas",*

and,

*"...both the stillbirth rate and neonatal mortality rate were higher in women of Black, Asian or Other ethnicity"* (CEMACH, 2006.6).

The Review of Health Inequalities Infant Mortality PSA Targets highlights actions to reduced the widening gap in health between socioeconomic groups in order to meet the manifesto target, to,

*“Reduce inequalities in health outcomes by 10% as measured by infant mortality and life expectancy at birth” (DH, 2007.3).*

Among the actions cited that could prevent infant mortality were to optimise pre-conceptual and prenatal maternal and mental health (DH, 2007).

The key issues here are that there is a disparity in uptake of services between different socio-economic groups with under-privileged people in the country having disproportionately poor outcomes for themselves and for their babies. Priorities to actively meet these individuals and communities and encourage them to take up the services offered is a central thread in recommendations aimed at reversing these trends.

### **The need for accessible, quality information about maternity services**

In October 2004 the Department of Health published the National Service Framework for Children, Young People and Maternity Services. Standard 11 concerns maternity services. It stressed that maternity services should provide information to women about their choices for childbirth including hospital practices.

*“Delivering effective ante-natal care is dependent upon effective and sensitive provision of non-directive information and support” (DH, 2004.18).*

In the Access to Maternity Services Research Report (DH, 2005) it highlights the need for;

*“Targeted information materials should be used to raise understanding of maternity services and encourage women from ‘hard to reach’ groups to access them. This should refer women to information written for the general public, that has been made more accessible by using a range of formats, structuring the information carefully, using more visual prompts and making resources available in community languages. Inclusive information will reassure women from these groups that maternity services can cater effectively for their needs” (DH, 2005.12).*

To address practical barriers to access the research recommended,

*“Attempt to raise awareness of the existence of maternity services by developing accessible information materials that cater for different languages and literacy skills” (DH, 2005.35).*

Further it stipulated

*“a need for providing targeted and community-wide education of the role and importance of the service”*(DH, 2005.34).

### **Delivery of information and Community Players**

Choosing Health (DH, 2004) recognised community members as key players in passing on information to enable people to making healthy choices for themselves and their families. It asserted that,

*“Individuals belong to a range of overlapping communities, their local neighbourhood or estate, a faith or age group, communities related to common interests or social networks such as sports clubs or work networks. Some will be informal groups, while others will be more formally recognised within the public sector and may already be involved in specific programmes or initiatives to promote health. Many of these can provide support for individuals who are trying to make more healthy choices through opportunities that they cannot provide for themselves”* (DH, 2004.78).

and

*“Voluntary sector and community organisations are often much better than the statutory sector at engaging with groups of people who face most difficulties or who do not access traditional sources of advice on health”* (DH, 2004.79).

and

*“Communities are vital in improving health and can play a significant role in promoting individual self esteem and mental wellbeing and reducing exclusion. Help and encouragement from friends and family, neighbours and work colleagues can make a significant difference in ensuring that individuals feel supported in making positive choices about their lifestyles”*(DH, 2004.79).

### **The Role of Advocacy**

*“Advocacy is in its simplest means supporting and empowering disadvantaged individuals so that their views and concerns are heard in order to secure enhanced rights and entitlements”* (Herr, 2004.6)

Models of advocacy are broad from self-advocacy, group, peer, formal or professional and bilingual to name but a few. There is substantial evidence that it can be an effective mechanism in promoting access and use of services and in doing so promote the health of those in need. It includes;

- Supporting and protecting individuals
- Representing service users to service providers

- Empowering individuals and groups to define their own needs make their voice heard and to gain access to the knowledge, support and services they require.
- Self-advocacy in which individuals can argue their own case and access services themselves (Herr, 2004).

A five-year study in Hackney, London showed that providing women from a minority ethnic group with the support of an advocate during their pregnancy had a significant effect on maternal and infant health. The researchers speculated that this may be because the women felt more confident to voice concerns, ask questions and provide information when they had support of an advocate. (Tew et al, 2006).

“As members of communities they serve, advocates are familiar with their ethnic, cultural, social environmental and historical experiences. They may therefore be more effective in...disseminating health information than health care providers, who often do not share the same experiences or understandings of health as those they serve” (Heer, 2004.14).

### **Preliminary Consultations**

The development of the storyboards was the result of an initial piece of research aimed at ascertaining what people wanted to know about maternity services in order to access and use them effectively.

The original scope of the project was to design a leaflet, however on listening to people this was not a useful resource. There was a unanimous response that what people wanted was something to look at and someone to talk to who they trusted.

It became apparent that for those outside the system maternity services within the NHS are ‘a foreign land’ and what was needed was a guide as to what to expect and what to do and what some of the words mean, in sum a map for a foreign land. They requested a pre-clinical non-directive resource that would impart information primarily about the culture of the NHS, the policies and practices to expect and what constitutes standard care in the UK.

Ongoing engagement strengthened this outlook but further developed the vision to one that was inclusive. Participants wanted something to look at that was non-stigmatising, that is, that it was not specifically aimed at particular groups, for example asylum seekers and refugees or people with problematic addiction but instead something delightful which imparted information about becoming a parent.

They wanted to share this with people they trusted, a friend, an advocate, a sister or an older person in a community centre. They especially asked for something, which was not delivered but

available and flexible, and something they could refer to and return to (Gaudion, 2006). They wanted the resource to be available in the community, for example, in churches, mosques and community centres.

### **Using Pictures: Anthropology and art**

Art embodies relationships, expresses narratives and captures its audience yet it is often neglected in the west as a rich means of conveying information; marginalised to the printed and spoken word. Yet we live in a world of advertisements and imagery in our newspapers, televisions and homes. Producing a visual, pictorial, information resource that cuts across spoken language and literacy gives the possibility of reaching a large audience. It is a means of conveying layered information. Art, Hoffman (1995) argues may act as a dynamic, complex, independent reservoir of many types of knowledge. This recognises that art has the potential to generate discussion and narratives and to act as a conveyor of information.

The MAAP was developed around the anthropological theory of Art and Agency (Gell, 1998). In this theory art objects embody complex intentions and mediate social agency. Gell's inspirational work takes art to be active as doing something. It relies on the artwork to attract and retain the attention of the viewer. The theory is not about looking at art only as alternative text but as part of a social process. The theory recognises that people interact, both with and through art with one another (Gell, 1998). The MAAP works in this way. It does not constitute a defined package but a springboard dependent on the users dynamics over time. Information is conveyed in the pictures, which further stimulates onlookers to exchange ideas and information. In sum it is active.

## PROJECT METHODOLOGY:

### **Engaging with “hard to reach’ communities**

The MAAP was developed mainly in the capital through a broad spectrum of groups with different ethnic, social and clinical needs. A diverse variety of people were engaged both professionals and members of the public including recent and current users of maternity services. In particular, efforts were made to consult with 'hard to reach' groups including:

- Asylum seekers and refugees,
- Women with insecure immigration status,
- Homeless people,
- Women with mental health problems/and or problematic addiction,
- Migrant workers,
- Black and minority ethnic groups including women who do not speak English,
- Women recently discharged from prison,
- men

Over 380 People from 49 different counties were involved. Participants did not always specify their ethnicity but defined themselves in relation to their 'homeland'. The consultations included people from Afghanistan, Albania, Algeria, Argentina, Bangladesh, Bolivia, Burundi, Cameroon, Canada, Democratic Republic of Congo, China, Egypt, Ethiopia and Eritrea, India, Jamaica, Hungry, Iran, Iraq, Israel, Ireland (Travellers), Ivory Coast, Kenya, Malawi, Mongolia, Morocco, Nigeria, Pakistan, Peru, The Philippines Poland, Portugal, Rwanda, Russia, Sierra Leone, Tanzania, Uganda, Somalia, Spain, Sri Lanka, Sudan, Tanzania, Turkey, Venezuela, UK (Black British and White British) Vietnam, Wales, Yemen and Zimbabwe.

Participants in the initial consultation were pregnant women and new parents. However, as the research indicated the importance of significant influencing others this was broadened out in the development stage, to include anyone who was interested in maternity services (DH, 2005; Gaudion, 2006). Thus consultations were encompassing a wide range of people across categories of age, gender, ethnicity, parity, but included approximately 140 pregnant women or new parents. The sessions attracted a number of people who were planning a family or were having difficulties becoming pregnant. Fathers and prospective fathers demonstrated an interest. In a GP waiting room in Leicester a group of three young men looked at the storyboards together and commented that it should be available for men to look at.

It was important to reach and engage with the very groups which research has outlined under use services, for this reason recruitment was mostly through community groups rather than through health avenues. Internet searches were conducted e.g.

[www.multikulti.org.uk](http://www.multikulti.org.uk).

Lists from organisations such as the Refugee Council or Black and Minority Ethnic Forums provided a base for telephoning or writing, both by e-mail and/or post.

A flier was developed inviting people to take part (appendix No.1).

A number of groups were engaged through word of mouth or through spontaneous meetings brought about by seeing organisations whilst travelling around London on a bicycle.

Known connections were also fostered, these were from previous work as a Sure Start midwife but also in the making of the film, *Florence, the experience of becoming a mother in exile*. The trust needed in order for the film to become reality became a warrant of confidence as many of the groups had heard of the film even if they had not seen it.

Groups were contacted via initial gatekeepers and passed on to others. Many times there were three to four meetings and numerous telephone conversations before sufficient trust was engendered for the people invited to take part. Gatekeepers were suspicious of researchers parachuting in under the rubric of consultation and then just leaving, other groups felt overwhelmed with pressure to be involved in projects. In addition people were unused to be asked what they thought of something or of giving their opinion.

There was not a homogenous category of people who were the gatekeepers. The project was interested in hearing, both the voices of people who are less visible in giving their perspective of maternity services but also to ascertain whom the MAAP would be useful for. Gatekeepers were frontline staff who through their capacity as paid or voluntary workers voluntary or paid formed the interface between the target groups and services. They could thus have the position as an advocacy worker specialising in health or they may be the person who has a sewing class every Wednesday in an inner city community hall.

Funds were available for providing the groups or organisations with money to pay for food, interpreters, venue hire, transport or individuals to have a nominal token of money or tokens each, Boots and Superdrug vouchers were particularly welcome. The groups that engaged over the length of the project, namely Southwark Travellers Action Group (STAG), Waltham Forest Somali Women's Group (WFSWG), Southwark Refugee Community Forum, Maya Project, Muslimaat, The HOPE Project, Birth and Breast Feeding Support (BABS), South London and Maudsley Mental Health Services (SLAM) and Camden Womens Aid were particularly generous with their time.

The majority of groups were not related to maternity or health facilities and personal, although a few were, Sure Start Groups etc. This was in order to reduce the bias and to endeavour to listen to people who were not already in a system that gave them a voice but also to minimise the bias that the environment may engender.

At the same time it was important to try the pack out in some health situations. The gatekeepers, advocates and community workers and a few health professionals would arrange to invite people to a meeting. This was often in the evening or at the weekend, sometimes at sessions, which were already in diaries, but frequently participants were posted invitations and then later telephoned and telephoned again on the day.

### **The Consultations**

Consultations took the form of one to one interviews, unstructured focus groups, workshops and 'stalls' at health days and open presentations in forums such as Southwark Refugee Forum where the audience fed back their thoughts. Informal situations at forums and community centres and meetings sometimes resulted in focus groups at a later date. I would be recommended to groups and by word of mouth and having 'passed the test' would be invited to meet individuals and groups.

It was pre-arranged or group led as to whether I took notes during the focus groups or not, some groups felt it important that I did scribe, for others it was off putting. At the beginning of every session I explained about participation being voluntary, the photographs, that they could leave at any point and that any discussions or queries they had would be used to improve the resource. In addition the participants were informed that a report to the funders (the Department of Health) would include lessons learnt from the consultations. I reiterated that their views would be anonymous.

### **Ethics**

All the people who participated in the development of the MAAP were invited to do so. It was explained that their involvement was voluntary, that they could leave the session at any time if they wished and that their views would remain anonymous.

People were asked if they would consent to having their photograph taken to be used in the MAAP. The photograph was taken with a digital camera so that participants could check the image after it was taken.

Consent for having your photograph used in the MAAP and displays etc was not a prerequisite for having a photograph taken or participation. This was in order that people did not sign the consent form just because they wanted a photograph, as a means of payment.

People were also assured that although a consent form was necessary for the use of the photographs that their names and addresses and the group, which they were attending, would remain unlinked. This was welcomed because although many people did not mind being connected to a particular group and for notoriety sake would have liked to see their name under the photograph for many who through their circumstances preferred not to. This was particularly the case where groups were connected to organisations that associated them with clinical or social needs such as HIV or Domestic Violence.

People gave their time freely and were honest and welcoming in their reception of the MAAP and this was valued. Thank you cards were sent to the groups who participated (appendix No.2).

### **Exploring the pictures**

*"The key message that these storyboards portrays is that maternity care is more than turning up at the hospital to have your baby. They clearly articulate pathways of care and choice and offer an opportunity for discussion. They embody a means of delivering assertive outreach and exemplifies a tool that could be used in motivational interviewing" (Jill Demilew).*

Group discussions were led by the pictures and peoples needs and interests at that point of time. No two sessions were the same. Where there was ongoing engagement and ownership of the project, participants were more confident and the potential of MAAP as a resource was empirically tested. This was partly because the trusting relationship between myself and the participants was more concrete, where as in situations where focus groups were a 'one off' the men and women were sometimes more hesitant and self-consciously wanting to say the right thing. In these sessions, it was often at the end that people would start asking each other questions and debating issues such as choice.

An example of this was a consultation with a group of women from Afghanistan. The interpreter was held up in traffic and none of the women spoke English, I had an hour for the group and they were all looking at me. I took the storyboards, an early rendition of the booklet and a small photograph album of participants out of my bag and placed them on the table smiling and indicating that I wanted them to look at them. The purpose of my visit had been explained to them previously with an interpreter and many of them had seen me the previous week with a group of Tamil women. I then briefly excused myself and returning observed them talking, laughing and pointing at the storyboards, turning them over and gesticulating. My return, heralded silence. The interpreter arrived soon after this and I was able to explain that I had come to ask them to help

me make this resource better, to find out from them whether they thought it was useful and if there was anything they did not like. One person answered that she thought it was good and that the maternity care they had all received or were currently having was excellent. The interpreter having arrived late with no idea what the session was about and having missed out on the initial viewing was perceptively captivated by the pictures and started to talk with the group. Discussions around choice, who to accompany you in labour, and what you were allowed to do in hospital followed.

Many times the presentation of the MAAP for people to look at initiated a reaction not dissimilar to a group of friends finding a bargain in the January sales, people would hold pictures up, gather round, talk excitedly, look annoyed or laugh. In one session with a group of women from Morocco the advocate translated my questions into Arabic, there was silence before one woman said "Quite nice Anna". If the MAAP was to be a measure of my employers annual review of my work, comments such as these were frequent, "Not bad Anna, its good Anna, Very nice thank you" would probably have assured me continuation of employment but were not particularly helpful in finding out what the community wanted. At times like that I would laugh and reiterate that I really needed their help to make it useful for people like themselves and that I also would rather know at this stage how it could be improved. Discussions would follow then, testing the ground before usually I was forgotten and the strength of cultural capital within communities was made paramount as people guided each other about where to go to see a midwife if you thought you were pregnant, what they had found helpful, what they wished they had asked about.

Women and their families talked about their personal experiences both abroad and locally. There were few questions directed at me as for the main part the knowledge was already there. I explained that I was a midwife so that I would be able to answer any questions and, that if I did not know, I would find out. I was never asked a clinical question but I was sometimes a sounding board for discontent with services provided.

### **Exploring Text: The Booklet**

The storyboards were developed first but ever present was a cover for the booklet, awaiting text. This provoked much laughter and gradually themes emerged that would prove useful such as how to access services, the role of supervisor of midwives and how to complain.

Certainly it was more difficult to engage people in developing the book, later as early drafts with pictures and colour codes to connect the booklet to the storyboards were shown there was more interest and periods of quiet as people read.

Some groups thought that there was no need for a booklet. "*It's wicked just how it is...you don't need a book*" (Black British teenager).

"*Pictures speak louder than words...there has been much thought and imagination as to how pictures impact on people...the storyboards work on their own*" (woman from Uganda).

"*What do you want a book for?*"

People were more interested in the small photograph album of people involved, which were carried with me. An initial text based booklet with the rudiments of information, how to access services, how to feedback to services, and a glossary proved uninspiring to the participants. Informants felt the initial drafts were too wordy and too dense and requested more photographs to break the text up.

A group of women with problematic addiction were very candid about the book. They said it should have information in it about social services and that if you engage with services and look as though you are coming off the drugs and or alcohol you may be able to keep the baby. When this was later taken back to them they said they would not read a section headed 'Social Services' but that they liked what was written. Subsequently this was edited into the storyboard section of the booklet under what to expect at your booking appointment. Returning once again to the group this received approval.

Later editions of the booklet were often stuck together, rearranged scrapbook fashion with the groups. This was a very positive way of getting interest and input. There was a unanimous agreement that the booklet should be available for everyone and that it was more important as a booklet to be 'dipped' into rather than read from cover to cover.

Informants felt that it was imperative that the MAAP did not become a tool that was delivered, rather something that could impart information in an informal non-directive way. They said it was important that the booklet was user friendly and not too wordy or intimidating. In groups where an interpreter is needed the resource will by nature be less informal until the user is more familiar with it.

### **Active Involvement and Ownership**

A number of groups have given sustained input into the development of the MAAP. This included groups radiating from Southwark Refugee Community Forum, the Maya project for problematic addiction, Waltham Forest Somali Women's Group, The Southwark Travellers Action Group (STAG), Birth and breast feeding support project (Babs), South London and Maudsley Mental Health Services, Camden Aid (Domestic Violence) and Muslamaat (East London Mosque).

One of the groups who have been central to the development of the pack is Southwark Travellers Action Group (STAG). The group has been involved from the beginning. From writing up the initial consultations in the summer of 2005 and displaying the report in their office, proof reading the text on numerous occasions and giving ongoing suggestions, for example, to write husband not partner as,

" It's only those white middle class women who have partners, if you write partners we don't recognise that".

The Travellers, amongst others said that they did not want the written text to be too simplified as this was patronising and they wanted to see and hear the words that were commonly used. They requested the glossary in the booklet. Ownership developed and further engagement. In the autumn we co-wrote a piece for the Southwark Travellers News recounting a health day the storyboards had been shown in.

“There were a number of stalls with lots of interesting health information...we were helping with something called the Reaching Out Project”.

Research has found that pregnant Gypsy and Traveller woman have poorer outcomes for themselves and their babies. Good access and continuing care with maternity services can help to identify any problems early so, that care may be planned between the woman and her midwife.

The Reaching Out Project has been working with Traveller women and STAG to make three storyboards showing pregnancy, birth and becoming a parent. Issues highlighted include;

- How to access midwifery services when you travel,
- Being aware of the language that is used by health professionals,
- Gaining confidence to ask questions and be involved in planning care...” (Southwark Travellers Times (December 2005.2-3).

A participant in a health advocacy course used copies of the ‘mock-up’ versions of the storyboards in a presentation and a copy of the final stage of the MAAP was presented at the London Gypsy Forum in City Hall.

### **Keeping Health Professionals in the Loop**

During the project, the stakeholders were consulted at regular intervals together with the midwifery advisors Claire Homeyard and Jill Demilew. In addition a number of senior midwives were consulted, the London Maternity review subgroup on users views, mental health specialists including people working with people with problematic addiction and those affected by domestic violence, a public health doctor, and a consultant anaesthetist.

### **Time Constraints**

The development of the MAAP happened in “the real world” and began simultaneously with the World cup, schools breaking up for summer holidays and the annual series of day trips out of London for picnics etc by community groups. One consultation with a group of 20 volunteers at a refugee organisation was rather truncated as 18 left after 10 minutes in order to be home in time for the Brazil v Argentina match. Other sessions and meetings were cancelled because other more pressing matters arose, an advocate needing to go to an appointment with someone, a sick relative, thunderstorms etc. Many times sitting and waiting proved worthwhile and the gatekeeper

would arrive and engagement would follow. The geographical nature, time scale and diversity of people to be consulted meant that occasionally groups were not followed up, as there were clashes in the calendar.

## ISSUES IDENTIFIED

Developing the map produced a plethora of information and insights into public understanding, experience and evaluation of maternity services. The participants wanted their voice to be heard around certain recurring themes; namely, access, prejudice, choice, interpreting services, and a number of clinical issues.

### **Access**

#### **Entitlement to NHS Care**

*“I mean where people come from there is no NHS it is just pay, pay, pay...they do not know about free antenatal care but they are frightened at the same time about people asking too many questions, about immigration and if it not their first baby why do you need to go?”* (Woman from Rwanda).

*“When you should be enjoying the arrival of your baby it is terrible to be hounded about money, its like psychological warfare, if you do not have the money how can you pay?”*  
(Advocate from the Latin American Community Organisation).

*“For some undocumented migrants or people who have overstayed their visa the issue is not the money, one can borrow a little bit here and there to make the £3000, it is the status issue, the fear of being reported...one woman recently who was eight months pregnant, she was too frightened to go for antenatal care, because of her status, her passport had expired and she was frightened that she would be deported”* (Advocate from the Latin American Community Organisation).

*“Women think they will be charged for care and sent back to Africa because they are HIV positive”* (woman from Kenya).

An advocate for migrant workers detailed how one client was billed for her maternity care even though she had a valid visa. The woman did not want to bring attention to her self and has been paying the money in spite of being in a situation of extreme poverty. The advocate explained that families wanting to avoid attention on either their immigration status or financial situation avoid care because they fear that their babies will be taken away from them ...they go ‘*underground*’.

Negotiating the service was difficult for people who were less confident. Maternity services were seen as opaque and difficult to access especially if you were not integrated into the community and were transient in the neighbourhood, for example Travellers, Asylum seekers and refugees and people fleeing domestic violence. Participants from the community including advocates and

community workers felt a level of confidence in being able to help someone in their local area, what was more problematic was advising someone who had travelled across the city to attend an activity or advice session. Where women encountered racism and prejudice further attempts to access were dependent on finding someone to help them.

*"If you know how the system works you are more confident and that changes everything"*  
(Chinese advocate).

*"Sometimes people tell you things, sometimes not, it depends on the person and you do not know what to ask, you do not know what you do not know"* (Somali woman).

*"If people are frightened or doubtful what to do, people leave"*(Black African woman).

*"Different places have different policies, I did not understand what I was supposed to do so I did not go"*(Egyptian woman).

### **Encountering Prejudice**

*"In the event of injustice we do not speak or find help, there are just too many barriers"*(Chinese woman).

*"Sometimes it feels that you are a disappointment, some people do not even give you the basic care, some are very rude...you need to know what to do before you complain"*(Somali woman).

Some women described experiences they had had personally or someone they knew had had that made them reluctant to access services. During one interview with an advocate a pregnant woman arrived distressed. She had received an official looking letter from her local hospital which had had further inscribed on it in red capital letters diagonally across the page that,

*"If you do not attend this appointment you will lose your bed"*.

The woman did not speak or read English but she understood the tone of the letter. She came to the advocate for help. The advocate telephoned the hospital and needs rewarding for her tenaciousness in trying to get an appointment as she was received with rudeness and indifference. Afterwards she informed me that that was not unusual, the telephone conversation had been half an hour long and a satisfactory conclusion had only occurred after the phone had been put down on her and she had redialled and luckily been answered by a sympathetic person.

### **Stigmatising Labels**

Women who felt that they had stigmatising needs such as problematic addiction, or mental health problems asked for an information phone line that was anonymous so that they could 'test

out questions and concerns.' There was a unanimous call for posters and pocket sized cards about access to be everywhere from libraries, health centres and post offices to police stations. The posters should stress the value to the women of early engagement within a holistic spectrum of need.

*"When you are HIV positive they don't care, your file is marked and they talk about you so that everyone can hear"* (Woman from Democratic Republic of Congo).

*"They just see your label, the label they give you and then they look for problems to qualify it"* (Woman with mental health problems).

*"They made me feel in the way"* (Problematic addiction support worker).

Women who had particular needs such as problematic addiction, which made them, feel stigmatised wanted to be treated as every other woman. They felt that they often missed out on the information around pregnancy and becoming a parent because the health professionals focused on their addiction. Where care was given which reflected their individual needs they said they were more likely to attend.

*"Stuff is done behind my back, so I don't know nothing, nothing was explained to me, they never said nothing"* (Jamaican woman)

*"I did not understand what was happening, they scared the hell out of me"* (Black British Teenager).

*"I put it off, going I mean till I was 8 months gone, it was their attitude, therefore I put it off...it makes you feel afraid...they didn't want to know...I mean the organic women, you know those ladies with a partner and flowers and a bag packed they get treated differently they get asked not told"* (Woman with problematic addiction).

*"You know it would just be nice if we were recognised as human beings"* (Advocate from the Latin American Community Organisation).

Many participants focused on the picture in the storyboard, which articulates being accompanied in labour. The verb protect was used rather than support to describe what they would be doing. Listening to comments there was a real portrait of being viewed as 'other' within a system that was non negotiable,

*"Midwives are quieter, less bossy when there is an advocate or doula with the woman"* (Orthodox Jewish advocate).

Other people described trying to be an advocate and being shunned or turned away.

*“Midwives and health visitors are scary and do not really want to engage with us they just want to stay within their professional boundaries, that makes it easier for them, it means that they can just carry on doing things because that is how it is done” (Somali advocate).*

## **Interpreters**

Access and engagement is bound up with understanding the system and being equal partners in care.

A Vietnamese woman described how there was never an interpreter available for her antenatal care and she did not understand what was happening. In the end she did not go to all her appointments because she knew her baby was growing and she felt well. To her there was no point in attending.

Interpreters, or rather the lack of them, the over use of medical terminology and a presumption that language and literacy skills were the same were pointers to poor communication at times between the providers of care and the women.

People are just told, *“Sign this letter”*...and otherwise *“You just get questioned loudly”* (Woman from Egypt).

*“They say sign this letter...but you do not know what you are signing”* (man from Iran remembering the experience when his daughter was born).

*“You need a template of what to say so you can articulate your rights...you need an interpreter but that takes time and they do not want you to have time so why attend, there is no point”* (Advocate from Somalia).

*“People are not given a choice, there is no space to talk about what they want...no one seems to understand that if it is your second or third language you may need a little time to take in any information, as a woman you need to create space if you are articulate or everything is just forced on you and you have no choice”* (Somali advocate).

## **Choice**

Choice was the most talked about issue; many women felt that because they came from a particular milieu or social group that they were not allowed choices. Other groups were amazed that there were choices. Others felt that because of lack of interpreting services, lack of time or perceived racism they did not get any options about care.

*"Options and choice are difficult for us...we do not have this at home".*

*"People are not given a choice...it is all too rushed...there is no space to talk about what they want...when English is not your first language it can take longer to express yourselves...you need to be able to create space if you are articulate or things are just forced on you."*(Woman from Somalia).

*"We want to talk about our choices, about risks about what our options are"* (Black African woman).

*"You need to know what you are being offered, that you are being offered something and then you need to know what you can ask for in case it is not offered"* (Polish woman).

*"They are in a hurry, are busy and therefore they expect you to make a split second decision...this is in the clinic...but you don't have to...I felt pressurised...they freak you out saying 'your baby is not safe'"* (Woman from Bangladesh).

One group of Irish Travellers on discussing choice and the issues raised in the storyboards said,  
*"...so nothing is set in stone?"*

*"People do not ask people what they want"* (Kurdish woman).

*"If you do not know, you do not ask and then you get a rawer deal"* (Irish Traveller).

*"You get to see what is happening...would be useful if you saw it with someone in your own community, especially if you cannot read well, its too embarrassing; the word for it is rejection, if you do not know what is written you just look stupid"* (Irish Traveller).

A Moroccan woman described the care she received as being similar to,

*"a Ford Factory mechanism, no informed consent...no means of stopping the conveyor belt...not really worth me going, I got nothing out of it, they said my baby was OK but I knew that".*

Other people cited similar experiences, a rushed atmosphere and not wanting to bother the midwife or doctor.

## **Mental Wellbeing**

*"I think I have this postnatal depression, what do I do?"* (Chinese mother with a 6-week-old baby).

*“I had depression, I was afraid...I would not tell them anything, I felt I had to be confident or they would undermine me and speak down to me and talk down to me” (woman from Bangladesh).*

### **Making a complaint /Feeding back to the system**

There was a real need within the community to be able to feed back to services anonymously, to have a voice but also shadowing this a fear that if people complained it would affect other people like them, for example Muslim women.

Although there was some awareness of PALS within the community no one had heard of the MSLC or were aware of the presence or role of supervisor of midwives if they personally or someone they knew was having problems accessing care or had concerns about the care they were receiving.

“You need to warn people that everyone is not nice...there is no system for saying what you think, there is a commonality of experience, often the same for English people” (advocate from Somalia).

### **Clinical Issues**

#### **Scans**

Discourse around scans crossed all the groups, for some women it was a means of “getting into the system”, for many a source of delight but others reported that they wished that they had never had them done, confusion why they had been done and anxiety during the procedure. An Irish Traveller described the experience as “like being in a morgue because no one spoke and you ended up holding your breath thinking there was something wrong”. A woman from Somalia said that she was frightened because she did not speak English and could not ask, but that it looked as though something was very wrong from the doctors’ face. She said that the worry had remained with her until she held the baby in her arms.

Many people reported that they did not know the reasons for the scans and that they had found the experience negative.

The storyboards seem to reassure people about standard care offered in the UK thus reducing perceptions that substandard, discriminatory care is given to people from overseas.

#### **Symphysis-fundal height**

In spite of the recommendation that,

“symphysis –fundal height should be measured and plotted at each antenatal appointment” (NICE, 2003.21);

The image of a Muslim woman, with the midwife measuring fundal height was a surprise to a number of women, in particular a group of women in the East London Mosque. In another session with a group of women from Albania this picture was cross-referenced in their conversation with the image of the woman having a scan, after much conferring they turned to me. They retorted that their expectation of care was that they should be scanned every two weeks and that they had not known that foetal growth was ascertained on palpation and measuring. A group of Polish women who were either pregnant or new parents voiced that they were surprised not to be regularly weighed during their pregnancy, information about estimation of BMI was therefore included in the booklet under the section on fungal height measurement. Drawing someone standing on some scales was considered but we needed to be mindful that the pictures were not misinterpreted and that a woman was not given the impression that she would be routinely weighed.

### **Urine Tests**

Although, there was widespread understanding that readings of blood pressure would be taken regularly in the antenatal period, the picture of the woman with the urine sample created consternation within some groups in the capital. Repeatedly this picture was questioned, women even said that that picture should come out because “*they do not test urine any more*” or “*I have never had my urine tested, why is that picture there*”. This feedback came from women whose first language was not English and people who spoke the language fluently; it was the primary clinical issue that caught the participant’s attention. Reporting this back to the professional advisors provoked an imperative retort that the picture and message remain.

### **Blood Tests**

There was interest in the fact that blood tests were offered, that you did not have to have them,

*“I did not know you were asked permission about blood tests...I just thought that was for HIV”*  
(Woman from the Cameroon).

Mostly the concerns were not clinical...the storyboards depiction of diversity prompted people to say that everyone was the same, no one was singled out because of their ethnicity or social situation, however there was deep uneasiness that large amounts of blood were taken. There was an underlying lack of trust in the system as it was thought that blood was sold, or used in research without permission. With a backdrop in the media about stem cell research there was particular unease about identity transference through blood and tissue. This anxiety was

reiterated around the disposal of the placenta. There was scarce interest in how the placenta was delivered but a number of conversations revolved around what happened to the placenta after it was delivered. Again a fear that,

*"...bits of me will be used in experiments"* (young woman from the Caribbean).

### **Birth and postnatal issues**

Positively the storyboards engendered discussions about the normality of birth and being active. Stories were swapped across generations about practices in different countries and "the old days" and then the storyboards checked for what happens in the UK. There was delight at the pictures of the woman dancing in early labour, the woman birthing her baby leaning over a beanbag and another squatting. The ambience engendered by the pictures of the home like atmosphere stimulated conversation about giving birth at home.

Postnatal as a term was seen as negative by many people who engaged and they preferred the term becoming a parent, this was because they felt it implied that something was wrong. There was a level of suspicion about midwives and health visitors coming to the home, many people thought that they were being checked up on. There was anxiety about not sleeping with a new baby in the bed in hospital because people expressed a fear about hospital security, citing that 'back home' someone always watches the baby whilst you are asleep. Information about positioning a baby on his back with his feet at the bottom of a cot was not familiar to people even those with a new baby. Worryingly a number of professionals were also unaware of the current guidance.

There are several pictures depicting breast feeding which provoked discussion. Within a group of teenagers it heralded talk about body image, privacy and losing weight gained in pregnancy. One young woman talked about how easy it was.

Although there were many reports of good practice, lack of adequate advice and support with breastfeeding was held responsible on many occasions for changing to bottle-feeding.

The Skin-to-Skin picture was inclusive for people who chose for personal, social or clinical reasons not to breast-feed. A focus group at the Terrance Higgins Trust talked extensively about all the positive things you could do if you were HIV positive and had been advised not to breast feed. At a Travellers Health day the picture evoked pride and recognition that skin-to-skin was something "*their men folk had always done*".

### **Summing up the Issues**

Clearly, although there were many reports of excellent care across the broad spectrum of people engaged the issues discussed clearly point to pivotal areas where policy does not reflect practice.

In order to reduce this structural divide for the people concerned and the resulting inequalities in health certain lessons can be learnt.

In the Government Manifesto in 2001 choice within the NHS was pivotal,

*“That choice has to be real rather than just theoretical. It has to be available to the many not just the few. And it has to be the route to equity as well as excellence”* (DH, 2003.3).

This was by far the most talked about issue, provoked by the symbol “Ask about your choices”; however for these groups it was the pre-cursor of the choice agenda in the National Service Framework (DH,2004) and Maternity Matters (2007) . It became apparent that without adequate baseline information and knowledge people were unable even to make the choice to access services.

Fears about official enquiries into status, entitlement and ones private life frightened people as their perception was that once they engaged with services their lives could become perceptively worse. This was because of fear of being reported to other services such as social services, the Home Office or because they would be required to pay large amounts of money.

Once in the service, lack of interpreters, a rushed intimidating atmosphere and not being given a chance to ask questions meant that maternity services were something you passively received, a far cry from the partnership working prioritised in Maternity Matters (2007). The service was at times perceived, by some people, as bullying and totalitarian.

Although Maternity Matters underlines the premise that *“It is important to recognise that pregnancy and birth are normal life events for most women”* (DH, 2007.11) people often felt that hospital practices such as not being able to have the curtains around them in postnatal wards belied this. This was particularly true for Muslim women. A Canadian woman thought it was rather patronising to be told that she should talk to the other women in the postnatal bay. She retorted that she had enough friends thank-you.

The difficulties experience in knowing how to access services and then the ongoing problems in communication in an environment where the use of interpreters appears at times to be spasmodic or non existent undercuts the premise that,

*“Early contact with a midwife is very important since it gives more time for making informed choices in planning their care and ensures women can take advantage of all support and tests...Evidence suggests that this will improve clinical outcomes”* (Shribman, 2007.6).

## DESIGN AND DEVELOPMENT OF THE MAAP

Paintings, picture-boards, flip charts and cartoons are used widely around the world to portray health information in a visual format. A current exhibition at the British Museum in the Wellcome Trust gallery draws together ethnographic material culture concerning wellbeing. One of the exhibits is a painting by a Swahili artist, Hassan-Mocha which depicts information about living with HIV and AIDS. The people and events are recorded stylistically, everyone looks forward.

The US AID funded program 'Casp-Cedpa' Safe Motherhood program in India has a colourful flip chart, which exemplifies in words and pictures how to be prepared for birth. The tool is essentially informative, it is directive rather like the skills and drills training required by NHS Trusts to fulfil their CNST requirements. Although the MAAP stems from a genre of pictures as conveyors of information it deviates at this point from being purely directive to one that loses the imperative and invites people to be equal partners in care.

People, with time, welcomed the opportunity to be involved in the development of the MAAP,

*"It gives us a chance to include our voices, to bring our experiences and ideas forward, creativity emerges from interaction"*(woman from Sierra Leone).

Many of the modifications were made after group consultations; for example, a woman said that she thought the pack was like a map in and around maternity services. This resulted in a name change from Access and Advocacy pack for Maternity services to Maternity Access and Advocacy Pack (MAAP).

The storyboards were designed around NICE standards of care and recommendations. (NICE, 2003,2006,2007). Although the pictures for the pregnancy storyboard are within a general structure of a pathway it is not inflexible. Initially there were attempts to lay out the pictures in accordance with the schedule of ante-natal appointment recommended but this proved to be problematic. Firstly the response from the focus groups was that it was too rigid and there was fear that if you did not access care at the right time it would be too late and you would be frowned upon, whereas the intention was to try to encourage women to access early, when ever possible but failing that to convey the message that they could approach maternity services at any time. The objective was to express that care is individualised according to need. Secondly, the amount of information pictorially to do this was too much, resulting in a plethora of symbols, so that the resulting boards looked like curtains from the 1970's. The aim was to produce simple clear pictures where each frame in the storyboard told only one main message.

A number of considerations were taken in their design. Firstly, that they needed to be easily readable to people who were not familiar with NHS services, equipment and culture. For this reason, the images were simplified and slightly stereotypical. The doctor in a white coat, blood in

a syringe not a vacu-container, midwife attending a birth with glasses on, a glass hospital trolley, a woman obviously awake during a caesarean section. The midwife is drawn as the primary care giver, to emphasise 'normality' and role in the UK. She wears 'scrubs' and an identity badge so that she can be quickly identified in relation to other women in the picture.

Although depictions of a partner or other male relative or friend are evident in the MAAP, the primary focus is women. This is not only to highlight women focussed care but to be sensitive to the needs of women who are alone, some of who may have been subjected to abuse and rape. It is also to encourage women to talk to their midwife alone to facilitate disclosure of domestic violence.

The pictures themselves are inclusive and efficacious. The caregiver and receiver change ethnicity throughout. The people depicted have broad ethnic backgrounds. The Irish Travellers, Albanian women, teenagers and non-professional white working class identify with a white person with hoop earrings. The other characters are broadly black African, Asian, Latin American and Chinese. They are not specifically coded for particular ethnic groups.

The images are slightly whimsical, women are drawn to looking at the details, the teapot with spots on, the bags, the toys and smiling about these things confidence is increased to talk about more pressing matters.

The storyboards are formatted so that the front page opens in the opposite way to a book. This encourages the user to open it out to the full length, thereby facilitating learning and insight to be group led as particular images attract their attention. The images act as windows into issues and are not designed, nor intended, to be viewed one after another. By opening them out to full length and turning them over, they work impressionistically giving an idea of time scale, inclusive of different ethnicities, and reiterate, through the repetitive nature of the symbols, the importance of asking questions and talking about needs. They are covered in plastic for durability over time and so that they can be looked at whilst people are eating and drinking.

The text included in the storyboards together with the unfolding design is intended to dissuade people from misusing them as directive 'flash cards'.

It also gives an opportunity to link the storyboards with the booklet as the sections are coded with colours, orange for pregnancy, pink for birth and green for becoming a parent. Each picture has a number so that further information can be sought from the booklet. The information included in the booklet was chosen because it was information that people wanted to know about and discussed during the consultations. Issues such as the disposal of placentas, choice, how to feed back to services and confidentiality.

The photographs in the book were included because on consultation with groups I would show photographs of other people who had been involved. It was extraordinary to me how many people

recognised individuals. The reactions were very positive giving value to the project. The photos are mainly of people using the storyboards. One quickly gets an impression that the MAAP is informal. It can be looked at outside in the garden, in groups around a table where chocolate cake is being eaten or in a mother and toddler group with young children walking across them. The front cover and images within the booklet emphasise the people as central, as individual and thus adds levels of ownership for those involved.

The symbols were originally more numerous and more clinical showing urine, blood pressure, blood tests etc, but as consultations progressed there was an increasing understanding that the social, emotional, and cultural issues were of greater importance than the clinical. The repetition of symbols was intended to show that care needs to be given repeatedly overtime and not just once. However the three symbols, 'Ask for an interpreter', 'Ask about your choices' and 'talk about what you are feeling', were the issues most discussed and are reflective of policy direction within the Department of Health.

The booklet under went a number of modifications in content and layout with specific heed made to the information that the communities had asked for. Issues around access, Supervisor of Midwives, how to feed back to services and interest in working as a midwife or other health professional were core. In designing the booklet they were therefore placed at the beginning.

Empirically, the development process revealed that people look at the pictures first, both the storyboard pictures and the photographs in the booklet. This process familiarises people with the layout and content of the booklet. Viewed simultaneously, allowing spontaneity in the group participants quickly made the connections between the storyboard coloured numbering system and the additional information in the booklet.

The consultations with the Reaching Out Project were seen as a useful means to articulate feedback to the system but there was a clear need for more localised ongoing engagement with services; however people did not know how to do this and requested, then valued, the information in the booklet. One of the most voiced concerns was that of access, this resulted in access being primary at the beginning of the booklet. Much of the following information in the booklet is for referring to as necessary or to provide signposts for further information. It was felt to be less imperative and more user-led to have information 'tucked' under the storyboard pictures in the booklet, so that a range of people with different needs could read it. They asserted you could find out information without being embarrassed or self conscious, in sum they liked the fact that the MAAP was directed at women and their families first, but that there was a range of initial information around specific needs such as entitlement, problematic addiction and social services within the body of the text. The primary milieu of the whole pack was seen as childbirth as a 'normal' event.

A Kurdish woman said,

*“...makes it visible for everyone...then there is choice, otherwise there is a hierarchy of information and the more privileged have greater access and choice”.*

### **Limitations of the MAAP**

The MAAP was taken to a number of Sure Start venues but this proved to be a less valuable home for the tool, partly because the philosophy behind the resource is that it is ideally used as a pre-cursor for accessing and engaging with maternity services.

Good outreach work within these environments meant that the women were informed and asking questions. The sessions were less successful, partly perhaps because having a knowing professional there discouraged people from asking one another questions. Certainly the groups were more formal and cultural capital less evident. It may be because professionals are less experienced in discursive spaces than in ones where they impart information. One Sure Start in South London was unable to find any ‘marginalised’ women for a focus group, a difficulty with engagement that never happened with community groups.

The developing MAAP supported an opening for a range of women’s health issues. In the same way that the community did not segregate pregnancy and childbirth as an issue only for those immediately concerned they did not separate it from a linear concern with reproductive health issues from family planning and pre-conceptual advice through to the menopause. There were many requests for information about fertility and difficulties in conceiving. There was a clear need for a resource for broad public health awareness in this area.

There were a number of other issues beyond the scope of the project namely the first year of a baby’s life including immunisations, weaning and developmental checks. There is significant scope for developing similar resources around these identified needs. Although the MAAP highlights issues around mental health and radiates acceptance to promote disclosure there is clearly further work and a tool to be developed in this area. The MAAP is self-limiting because it is pre-clinical.

### **Feedback from the community**

The pictures have multiple meaning, which empirically were understood and evoked in the consultation process. The text with each picture is not intended to explain the pictures but as additional material. Although the diverse range of people consulted all used the pack as a springboard for discussion it is recognised that people have varying levels of visual literacy. A number of professional people were somewhat self-conscious about looking at the tool and focussed initially on the text before the efficacious nature of the pictures took over and without fully appreciating it they looked again and again at the images.

Both the storyboards and the booklet impart messages of inclusively. On viewing the storyboards one woman said,

*“Oh look we are all the same ...we all get the same care...it is not just because you are black that something is done”.*

This perception was repeated many times. There was also an interest generated in working as a midwife or other health professional, which led to information being included in the booklet. The booklet itself was an opportunity for the people who developed the tool to be a focus for imparting the message of inclusion and value and to demonstrate non-textually how the tool can be used. It was important in the development stage to the participants that the booklet and boards remained together. People who were not able to read the text in English found value in looking at the pictures. A number of people who did not have the confidence to speak English were able to read the text. People valued the peer support that the whole MAAP engendered.

*“Health professionals do not have time to listen and people do not know how to talk about problems they have...some things just are not talked about”(a young woman from Somalia)*

*“People ask within their community for help and guidance and then they need signposting” (a woman from Albania).*

*“It is a very pertinent piece of work because many people come to this country semi-illiterate and do not know where to go so this focus is good because we can help each other”(an older woman from Uganda).*

*“Information is power...it is a way of getting messages out into the community, of getting people talking and increasing awareness” (A woman from Vietnam).*

*“Gets you talking about things, examinations and what have you...it would have been useful before I had my baby because you just have no idea what is going to be done to you” (Irish Traveller).*

*‘Would be useful if you saw it with someone in your community...so you can talk...if you don’t read and all you get is leaflets the word for it is rejection and anyway we keep our place nice and paper just goes in the recycling” (Irish Traveller).*

*“People do not talk about these things otherwise, you know like being examined, it is just not discussed but it is so much better to be warned”(woman from Angola).*

*“The storyboards and talking to someone you trust gives you some control and ownership about how you want to do things...Information is power...it is a way of getting messages out into the community, of getting people talking and increasing awareness” (Sudanese woman).*

*“When you talk to clients it backs up what you are saying so it is not just you saying it” (advocacy worker)*

At a health day for Irish Travellers the storyboards empirically attracted attention and discussion that waxed and waned, one woman commented, *“this is the chill out table...no one gives out to you and you can just look and it gets you talking and everything is there”.*

*“Creates a space where people can come together so that they can support each other...it helps you navigate the system”.*

### **Lessons Learnt in accessing ‘marginalised’ communities**

Writing to people did not work, what worked was talking to people by telephone and in person.

The fliers, letters and invitation were sent to a large number of organisations but this was not an affective way of engaging as the only reply was a returned envelope from the post office as the organisation was not known at that address

People prefer to talk to people and this lesson was reiterated when responses to the final MAAP were slow in being returned in spite of thank-you tokens of gift vouchers or donations to the organisation. Respondents to written information may not have the skills in English or confidence to reply, which is not the same thing as reading literacy.

An advocate from Somali explained to me that pressure of work especially within the time, environmental and cost constraints of small voluntary organisations means that information and forms etc that arrive in the post are secondary to the immediate needs of a person in front of them. Interest in opinions that people have for this project worked best in person as people took time spent in the visit as recognition of value and worth. This perspective can be translated to how communities feel about feeding back to services but because of power and knowledge inequalities are un-empowered to do so.

Assertive outreach in person may herald greater insights as to how ‘hard to reach’ communities feel about services. Certainly the social capital and networks can be generated in this way. A broad range of community groups arranged by ethnicity or religion, held health days, they reported that although they had asked local maternity units to join them the offer had not been taken up. Mobility of the researcher meant that the groups met in a place that they were comfortable and relaxed, metaphorically almost an extension of their home rather than a purpose

built health environment. One of the strongest messages was that people did not want to be told what to do, rather they wanted information so that they could make informed decisions. Importantly the message that people wanted to 'test the ground' about what to expect with someone they trusted was repeated again and again.

## CONCLUSION

At a time when health and social care are moving towards joint commissioning (Childcare Act,2006; DH,2007 ) the MAAP provides a means to engage whole communities in information about maternity services. Improving the general understanding of service provision to a wide spectrum of people means that significant influencing others have access to correct information and that there is a greater awareness of services for prospective parents, those that are currently pregnant or planning a family.

The MAAP as a resource permits a flexible approach to the users requirements. It exploits the efficacious nature of the artists impressions to engender laughter and discussion. Distributing it in the community requires a fluidity and flexibility in our understanding about what people want to know but to lay out in pictorial form the standard policies as outlined by the NSF and NICE and goes towards making the service less opaque.

The initial consultations indicated that people wanted to talk to someone they trusted about maternity services before they met the midwife and that they wanted something to look at to guide those discussions. Through the ongoing development stage the core issue of the trusted individual, the peer has been reiterated and the necessity to have a resource which is discursive rather than instructive and one that assists people to help themselves and others by providing them with information has been underlined.

Difficulties around access are not only concerned with language and lack of awareness but with perceived and at times stigmatising labels. Again and again as the storyboards were shown to people they said how nice it was to have a resource that allowed them to be prospective parents, pregnant or new parents first and to find out information irrespective of their particular labelling need. It is all too easy to say that people with more chaotic lives or lives they have less control over because of their immigration status or because they have problematic addiction or are fleeing domestic violence have issues that they prioritise over their pregnancies. What the development of this pack demonstrated was that there is a clear demand for information about the service and how to access it.

Feedback from the many participants both professionals and the public suggests that for the main part those involved in the process have been successful, although one can never satisfy all the voices.

In conclusion,

*“Communities are wise, if you give us a choice and include and embrace our voices, allow us to bring forward our experiences and visions we can become doorways rather than divisions”  
(Woman from Rewanda).*

*"It would have helped me to give support ....could be my neighbour or my daughter in law...I am only sorry my reproductive years are over, informstion is power....this is a way of getting information out into the community, people find out things by looking very quickly and then they get talking" (woman from Uganda).*

## APPENDIX

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## Maternity Access and Advocacy Pack

### The Reaching Out Project:

The Reaching Out Project is based at Medact, a UK-based charity which works on key global health issues. The project aims to improve access to maternity services for Black and minority ethnic women, including refugees, asylum seekers, women with little or no English and women with insecure immigration status.

### Maternity Access and Advocacy Pack:

The Pack is an information resource for community workers to use to engage women and their families in discussion about maternity care in the UK. It will consist of 3 storyboards with minimal text in English and a resource pack to expand the information. It is hoped the resource will increase awareness about what is offered and what choices are available to all women during pregnancy, birth and becoming a parent.

The pack is currently being developed and we are interested in the views of women and their families about their knowledge and experiences and how we can make the storyboards better.

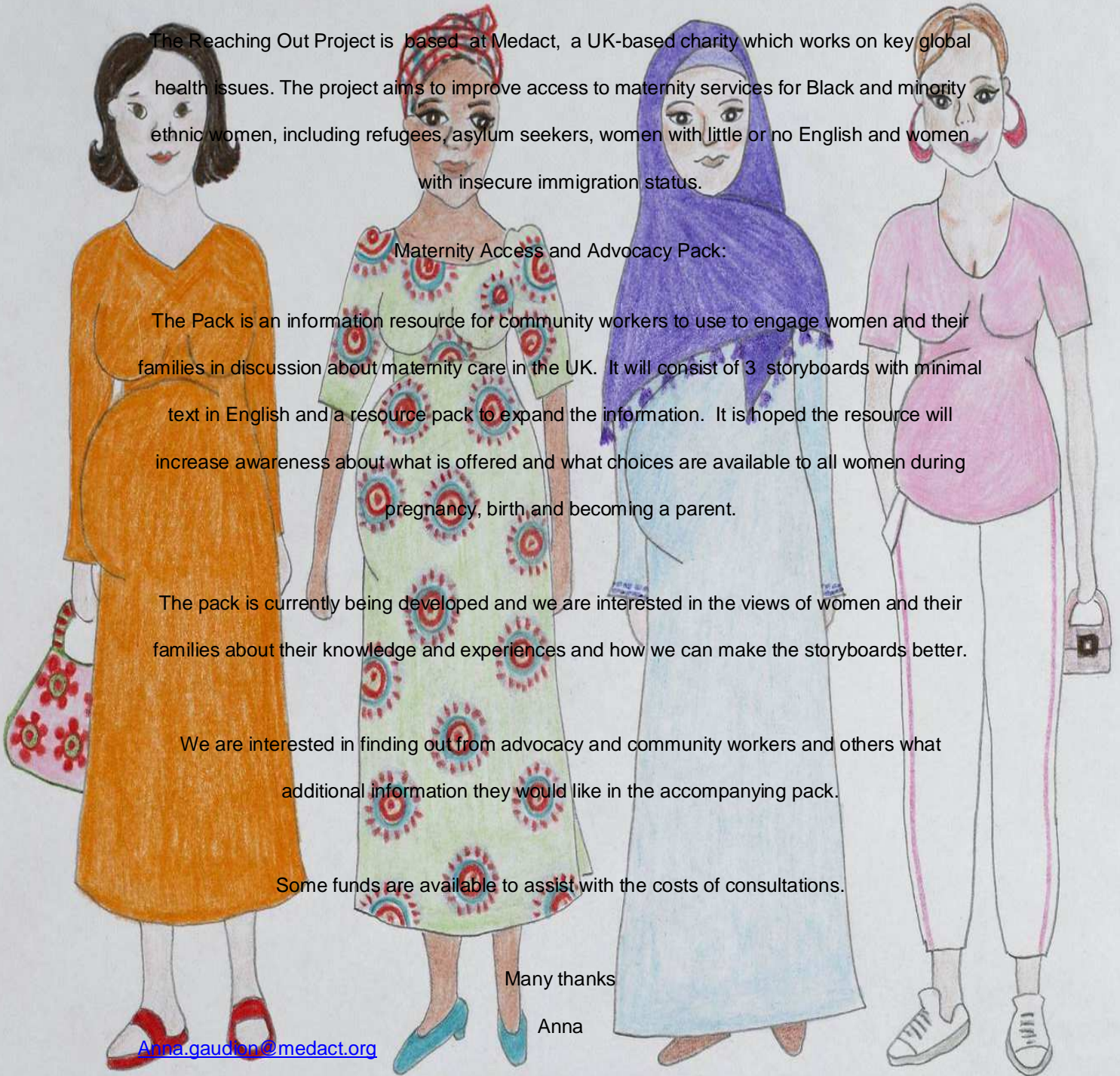
We are interested in finding out from advocacy and community workers and others what additional information they would like in the accompanying pack.

Some funds are available to assist with the costs of consultations.

Many thanks

Anna

[Anna.gaudin@medact.org](mailto:Anna.gaudin@medact.org)



## Access and Advocacy Pack for Maternity Services

The Reaching Out Project is developing an information resources to help improve access to maternity services for black and minority ethnic women, including refugees, asylum seekers, women with little or no English and women with insecure immigration status. The resource may also prove suitable for women who find it difficult to negotiate services because of other issues in their lives such as mental health problem, problematic addiction, learning difficulties or shyness. Research has highlighted that this group of women have poorer outcomes for both themselves and their babies.

The Pack consists of three storyboards that open out in a concertina fashion to emulate pathways (depicted as pictures with minimal text in English) through pregnancy, birth and becoming a parent. They are discursive rather than instructive and aim to encourage women and families to talk about access and choices within maternity care within an environment that they feel safe. The materials are designed to encourage women to share their stories whilst providing a prompt for care in the UK. The storyboards will be accompanied by a resource booklet that will enlarge on the issues raised by the women and advocates in the community consulted in the development stage.

The Pack is intended as a tool to assist advocacy and other link people within the community to engage women in discussion. Highlighted are issues around interpreting services, the concept of choice and control over care offered and the importance of talking about feelings. The resource echoes an ethos of holistic care that encompasses childbirth within a social, psychological and physical sphere.

The project is interested in the views of women and their families about their knowledge and experiences and how we can make the resource better. For people who may facilitate discussion be it advocacy worker, voluntary worker, non maternity clinicians and women themselves we are interested in what additional information should be included in the accompanying pack.

Some funds are available to assist with the costs of consultation.

For further information please contact Anna; 020 7324 4737  
Anna.gaudion@medact.org.uk

The Reaching Out Project is also engaged in campaigning work. This work is focussing on entitlement to care and direct access to midwives.

For more information, see [www.medact.org](http://www.medact.org)

# Thankyou



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Thank you for all your help



**Community Consultation for the Maternity Access and Advocacy Pack (MAAP)  
Organisations**

Albanian Womens Group  
 Ahwazi Community Association  
 Bede House  
 Bethlem Royal Hospital  
 BEMWG (Hackney)  
 Brady Centre, Family Outreach,  
 Camden Womens Aid  
 Chinese Healthy Living Centre  
 Derman  
 El Hasaniya Moroccan Women's Group  
 Eritrean and Ethiopian Centre Stockwell  
 Filipino Centre, Hammersmith  
 GAP Training for Volunteers in Southwark (Asylum seekers)  
 Hackney Women's Group  
 Hans Josovic Maternity Trust  
 Homerton Health Advocates  
 Hope Project, Hillingdon  
 Latin American Community Organisation, Kings Road.  
 Lifeline (church based charity) Barking and Hackney  
 Jacquoni Education Centre, Whitechappel  
 Jewish Maternity Programme, Stamford Hill  
 Eritrean and Ethiopian Centre Stockwell  
 Merseyside Refugee and asylum seekers pre and postnatal support group.  
 Maya Project, Peckham  
 Mash Project, Manchester  
 Migrant Helpline, Dover and Margate  
 Migrant and Refugee Forum (Westminster)  
 Muslimatt (East London Mosque)  
 Orthodox Jewish Community, Stamford Hill  
 Polish/ Russian Group  
 Refugee Arts Project  
 Refugee Action Kingston  
 Refugee Council  
 Refugee Council womens Group  
 Refugee Action Kingston,  
 Refugee Arrival Project, Hounslow  
 Refugee Forum, Stratford  
 Rotherhide Muslim Womens Group  
 Rotherhide Sure Start  
 Sleeping Genius (teenagers)  
 Social Action for Health  
 Southwark Refugee Forum  
 Peckham Asylum Seekers and Refugee Day Centre  
 Southwark Travellers Action Group  
 Stockwell Chinese Group  
 Terrance Higgins Trust  
 Three Boroughs Health Team  
 Vietnamese Group, Deptford.  
 Vietnamese Womens Group, Greenwich  
 Waltham Forest Somali Out Reach FGM Clinic  
 Westway Community Trust

**Profile of Community Consultation**

Name of Organisation	Ethnicity	Particular need	Number of people consulted	Pregnant or new parent	men	Advocate	Number of times consulted
BABS	Black African, Black British, Indian, European, Somali	Buddy support	30	20		3	9

		system for vulnerable women and families					
Refugee Council	Mixed, Iranian, Black African, Asian, Somali, Eritrean	Asylum seekers/refugees; mental health needs	10	3		3	3
Refugee Action	Tamil, Afganisatani, Arab	Asylum seekers and refugees/migrants	28	23		1	3
Refugee Arrival Project	mixed	Asylum seekers	4		1	4	3
Migrant Helpline	mixed	Asylum seekers				1	1
Southwark Travellers Action Group	Irish Travellers		10	3	3	3	8
Southwark Refugee Community Forum	Asylum seekers and refugees	Asylum seekers	20			3	
Hasaniya Moroccan Womens Group	Moroccan women	Domestic Violence	18	5		1	4
Hope Project, Hays and Hillingdon	Tamil, Afganistani, Albanian		15			3	3
Waltham Forest Somali Womens Group	Somali	fgm	20			4	7
Muslimat	Bangladeshi, Canadian, Argentinian	Muslim women	25				
Jewish Maternity Programme	Orthodox Jewish		14				
Chinese Healthy Living Centre	Chinese		10				
Camden Womens Aid	Irish Travellers, Hungarian, Iranian, Egyptian		12			3	
Maya Project	Black British, Black African, Caribbean, White British	Problematic Addiction					
South London and Maudsley	Black African	Mental health problems					
Kayalan	Filipino, Tamil	Migrant workers					
Southwark Asylum seekers and Refugee Day Centre	Black African. Cameroon						
Brady Centre	Somali, Bangladeshi	Sure Star health				3	
Hackney Womens Group (Check name)	Black African	HIV positive	14		6	3	
Homerton Health Advocates	Indian, Chinese, Vietnamese, Bengali, Somali	Health Advocates				5	
Migrant Refugee Community Forum	Somali					1	
Terrance Higgins Trust	Black African	HIV positive Group	11		6	3	
Bede House	mixed	Domestic Violence				2	
Liverpool			30				
Filipino organisation, Hammersmith	Filipino		5		1	1	

Southwark Volunteers	Democratic Republic of Congo, Rewanda, Iran		7		2		
Vietnamese Womens Group	Vietnamese		6		1		
Sleeping Genius	Black British, Venezualian, Black British, White British		10			3	
Aylesbury Somali womens group	Somali					1	
Arab Womens Voice	Egyptian					1	
Eritrean,Ethiopian Cultural Centre	Eritrean/Ethiopian		12		6		
Chinese group Stickwell			3				
Breastfeeding Peer Support, Peckham	Russian, Spanish				6		
Asylum Aid						2	
Polish and East European Group	Polish		10				
Refugee Arrival Project	mixed				6		

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Consent to be Photographed:

Thankyou for taking part in the 'Reaching Out Project' and in the development of the storyboards and the information that will accompany them.

I wish to obtain your consent to be portrayed in photographs and small film clips which will be used in publications and displays. In addition they may be shown at conferences and events when the project is presented. These images may be used by the Department of Health and may be in public places.

I would like your permission to film you/your child or use your photograph and/or photograph of your child for these purposes.

Many thanks for your contribution.

I will show you the photographs/ film clips for your approval prior to using them.

Anna Gaudion  
The Reaching Out Project

The Reaching Out Project,  
Anna Gaudion,  
Medact,  
The Grayston Centre,  
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London,  
N1 6HT.

Name of Contributor:

Address of Contributor:

Date:

Consent to be Photographed:

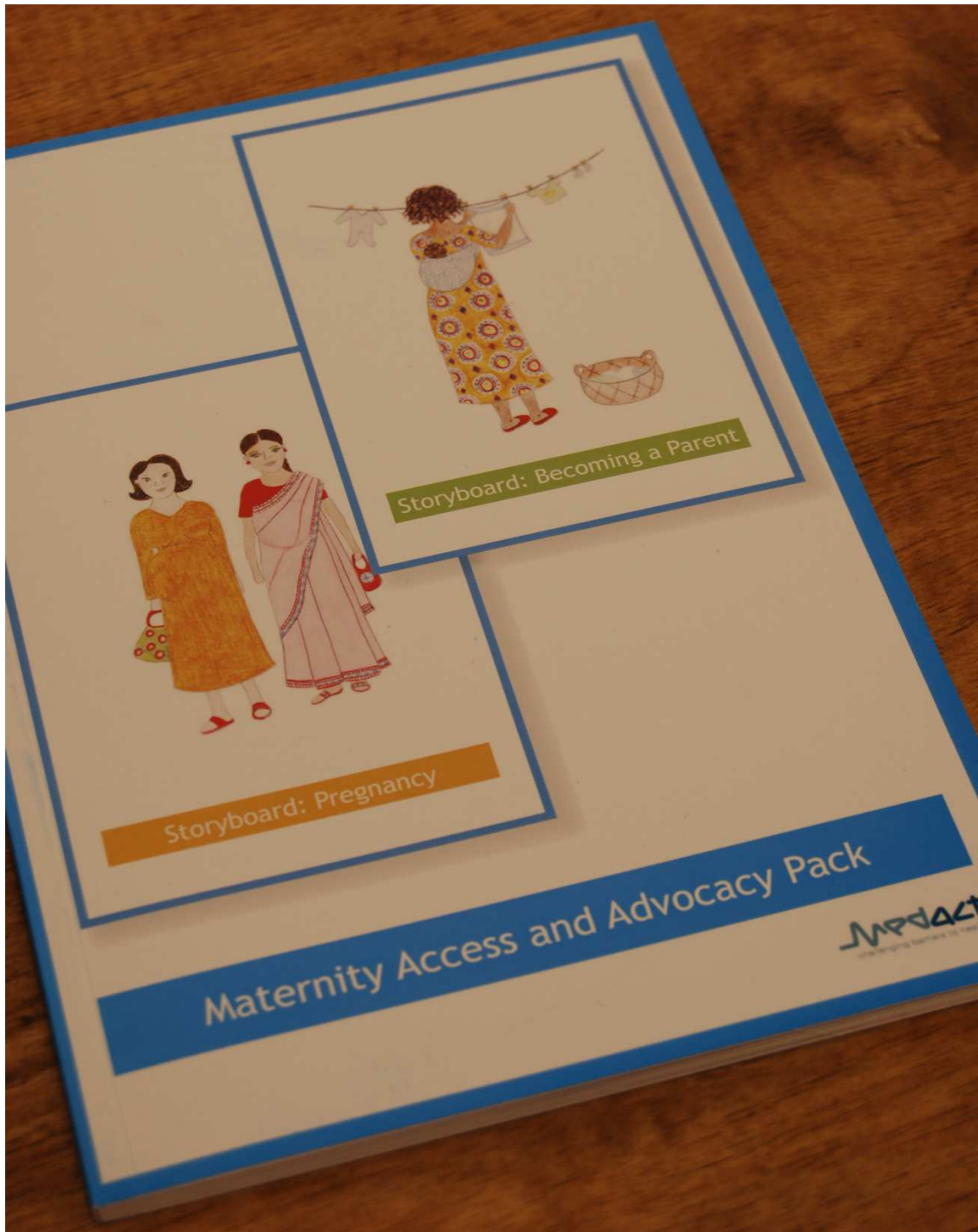
I agree to the inclusion of my self / my child in a film clip / photograph for The Reaching Out Project'.

These images may be used by the Reaching Out Project, Medact, Care Services Improvement Partnership or the Department of Health and may be in public places.

I understand that it may be used for reports, publications and displays and may be shown at conferences and venues where the project is presented. I understand that images may be distributed in any medium in any part of the world.

Signed:

Counter signed where interpreter is required.



**The Reaching Out Project:**  
A report on the piloting and further development of the Maternity Access and Advocacy Pack  
Prepared by Rosalind Bragg  
March 2008

The Reaching Out Project

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The financial support of the Department of Health is gratefully acknowledged.

The Reaching Out Project, Medact, developed the Maternity Access and Advocacy Pack (MAAP) with the aim of improving access to maternity services for marginalised women from Black and minority ethnic communities. The MAAP is a picture-based resource consisting of three storyboards and a booklet.

This report outlines the piloting and further development of the MAAP. It follows on from an earlier report which outlined the process of development of the MAAP prior to the piloting phase: A.Gaudion , 2007, *The Reaching Out Project: A report on the development of the Maternity Access and Advocacy Pack*.

## **1. Background**

Following extensive community consultation in the development of the MAAP the materials were pre-tested as part of the formative evaluation stage of the development cycle. The focus of formative evaluation is on identifying improvements to the resource before implementation commences. Formative evaluation is distinct from impact and outcome evaluations which seek to determine how effective a particular intervention has been.

The MAAP targets vulnerable groups and will predominantly be delivered by community workers or community members who do not have expert knowledge about maternity services. As with all community-based communication tools, it is particularly important that the resource is tested to ensure that it does not confuse, mislead or offend.

The pilots were held in June 2007. They were originally scheduled for January and February 2007 but delays in the development phase meant that the resource was not ready for piloting until late April 2007.

Medact commissioned Dr Rigmor Berg of BB Professional Services to advise on the methodology for the pilots and review the findings. Dr Berg is a highly experienced psycho-social and strategic researcher, who has provided needs assessment, evaluation, strategic review, social marketing and social impact research consultancy services to various government agencies as well as non-government and international organisations.

Consistent with good practice, the pilot research was undertaken by someone who was not involved in the development of the resource. Jenny McLeish, who undertook and wrote-up the pilot research, is experienced in community-based research and has worked for some years on issues of maternal health and access to health services. Her report is printed in full in the next chapter.

The project officer who worked on the development of the resource, Anna Gaudion, and the midwifery advisors, Claire Homeyard and Jill Demilew, participated in the review of the pilot findings and further development of the resource.

## **2. Report on piloting of the MAAP**

By Jenny McLeish

### **2.1 Methodology**

The piloting process was primarily designed to identify whether any of the images in the MAAP could confuse, mislead or offend. It aimed to ascertain whether the different components were acceptable and appealing to migrant women. It did not attempt to evaluate how the MAAP might be used in practice.

Piloting was carried out during June 2007 with six focus groups of migrant women who had not been involved in the development of the MAAP. These groups were a convenience sample recruited in short time frame with the assistance of community organisations and support services in north, east and south London. They included women from a variety of cultural backgrounds, women with and without experience of using the maternity services in the UK, and both women who could and could not speak or read English. Three focus groups were carried out in English and three in the mother tongue using interpreters.

Following advice from the expert advisor, each focus group lasted 1-1 ½ hours and followed a structured interview schedule (Appendix A). Participants were invited to share their opinions about what they liked, disliked, did not understand or thought could be improved. Specifically participants were asked to describe what the symbols suggested to them, what was happening in the storyboard pictures, what they expected to find in the booklet based on its cover, and whether they would want to use the booklet.

The six focus groups were:

Group A: 12 women of mixed backgrounds, predominantly North African, at the Migrant Resource Centre (Pimlico). All had experience of UK maternity services. Group conducted in English.

Group B: 10 young Chinese women, most with no experience of the UK maternity services, at the Chinese Healthy Living Centre (Soho). Group conducted in Cantonese with interpreter.

Group C: 6 Kosovan women with experience of UK maternity services, at the Drop-in Centre for Asylum Seekers and Refugees (Streatham). Group conducted in English with some informal interpreting.

Group D: 10 Somali women (traditionally dressed) including two elders, at HCVS (Hackney). All but one had experience of UK maternity services. Group conducted in Somali with two informal interpreters.

Group E: 11 Bangladeshi women, most with experience of the UK maternity services, at the Women's Health and Family Services (Tower Hamlets). Group

split into two, each conducted in Bengali with an interpreter (one formal and one informal).

Group F: 5 young Somali women (wearing Western dress), all with experience of the UK maternity services, at the Sanctuary Clinic (Finsbury Park). Group conducted in English.

## 2.2 Key Findings

Detailed findings are contained in Appendix B: The Symbols, Appendix C: Storyboard pictures and Appendix D: Booklet cover.

This discussion focuses on issues where the pilot suggests room for improvement. It must be remembered that this was in the context of participants having also made numerous positive comments about both the storyboards in general and individual pictures.

Participants engaged positively with the storyboards whether or not they read English. However, the difficulties that group B in particular faced in interpreting some pictures suggests that the current advice “For people who do not speak or read English the storyboards have been designed to work on their own once the symbols have been explained” (booklet page 10) needs qualification. The storyboards conveyed only limited information where participants did not read English *and* did not have previous experience of UK maternity services. In other groups, participants who had experience of UK maternity services or read English explained meanings to fellow participants who did not (usually, but not invariably, accurately). It was notable that where there was a discrepancy between the storyboards and a participant’s own maternity experience, in each case the participant told fellow participants that the storyboards were wrong on that point. This suggests that while the storyboards clearly facilitate information sharing within a group, there is also scope for the perpetuation of misinformation within a group.

Participants felt that it would be better if the text was in their own language (or bilingual). Participants who read English frequently had questions about specialist terminology, but nothing signposted them from the storyboards to the booklet to get more information. Participants often flicked through the booklet and put it down, whereas the storyboards commanded their full attention: this suggests that users may not always read through the booklet to find the glossary on page 58.

No participants in this piloting process responded positively to the symbols, whether or not they read English. The first two symbols in particular were not felt to link discernibly to what they were intended to represent. No participants felt that the repetition of the symbols along the bottom of the storyboards added to their significance. This raises the difficult question of how the three key messages that are intended to pervade the storyboards can most effectively be communicated and emphasised. The contents of the

booklet were not part of this pilot, so the pilot was not able to test whether issues related to the symbols would be overcome by the use of the booklet in conjunction with the storyboards, nor whether people would use it in that way (the detailed explanation of the symbols starts on page 23 of the booklet).

A potential fourth important message is the need to book for antenatal care early in pregnancy. Although this is implied by the wording of Pregnancy 1, many participants thought that the pictures (especially Pregnancy 1 to 4) showed a woman initiating maternity care only in mid to late pregnancy. This suggests that there is a risk not just of failing to communicate the importance of early booking, but possibly of communicating the message that a woman should *not* seek maternity care early in pregnancy.

Reactions to the cover of the booklet were mixed, but negative reactions dominated. While two participants liked the varied pictures, others thought there were too many pictures or were put off the booklet because there was no one represented from their own community. Most participants did not identify the subject matter of the booklet as maternity care from the cover images, and some stated that a single image of a pregnant woman or a mother and baby would be preferable.

There were a number of pictures where participants suggested specific minor clarifications. The only picture where there was serious misunderstanding was *Becoming a Parent 6*, where two participants misinterpreted the crib stand as a cross and assumed it was conveying a specific (false) message.

### **2.3 Recommendations from the pilot**

1. The booklet text should clarify that the storyboards are ideally intended to be used by people at least one of whom can read English, or at least one of whom has experience of the UK maternity services. It should not suggest they are free standing with only an explanation of the symbols. While no damage would be done in using them in this way it would not be so effective.
2. The project should re-consider the use, form and positioning of the symbols to convey key messages. If symbols are used they should be redesigned to relate more evocatively to the messages they represent. The repetition of the symbols along the bottom of the storyboards is unnecessary.
3. The project should ensure that the storyboards do not give the impression that maternity care begins in mid to late pregnancy. For example, this could be done by a redesign of Pregnancy 1 to 4, or by adding the importance of going for maternity care early (and regularly) to the key messages / symbols panel at the end of each storyboard.
4. There should be signposting from the storyboards to the more detailed explanations and glossary in the booklet (for example, this could replace the symbols along the bottom of the storyboards).

5. The project should re-consider the formatting of the booklet, to ensure that it is highly accessible to navigate from the storyboards to relevant parts of the booklet (for example, 'contents' and 'how to use' should come first; photographs should come in between sections rather than in the middle of sections.)
6. The project should re-consider the cover of the booklet. For example, a picture of a pregnant woman would make the subject matter more apparent, and reduce the risk of alienating users who do not see their community represented. Using one of the storyboard (style) drawings would make the link between storyboards and booklet more obvious.
7. The MAAP should be translated into key community languages.
8. The following essential clarification should be made to the Becoming a Parent 6 - the crib stand should be redrawn to make it clear that it is not a cross.
9. The following desirable clarifications could be made:
  - a. Pregnancy 2 - add a hospital or clinic sign
  - b. Pregnancy 4 - remove suitcase
  - c. Pregnancy 6 - distinguish blood test band from blood pressure cuff.
  - d. Pregnancy 8 - add picture of toilet
  - e. Pregnancy 11 - add background to show they are not at home, move book so you can see women are pregnant.
  - f. Birth 3 - woman needs to look pregnant
  - g. Birth 11 - operating theatre light
  - h. Birth 14 - clarify it is man's trousers not underwear showing at top
  - i. Parent 3 - Distinguish colours of baby and coat.
  - j. Parent 7 - add room thermometer.
  - k. Parent 8 - add syringe.
  - l. Parent 9 - health visitor should hold red book (child development record)

### 3. Comments on the text

The consultant, Dr Berg, provided comment on the language used in the booklet:

The language used in the booklet is quite formal and uses professional jargon which is not appropriate for community members without medical training. For example, “the best possible outcome”, “early and ongoing engagement”, “all information will be treated in confidence”, “it is not appropriate”, “it is important to request”, “to confirm that you understand”, “midwifery-led unit or consultant-led unit”, “you can specify”, “demonstrates”, “how dilated your cervix is”, “caesarean section”, “epidural”. Simpler language and explanations in the text are needed.

Dr Berg also commented on the option of translating the resource:

I do not agree that the resource should be printed in many community languages. Past experience shows that the large majority of health resources printed in many languages end up occupying many shelves in storerooms while they collect dust, because need for specific language varies and few [locations] would need all of the languages. If the storyboards are to be used in a stand alone, read it yourself way, it would be more cost-effective to have translations available in ready to print form on the relevant website (flagged in the booklet) so that health and community workers can download the languages they need for their specific client base and stick them onto the storyboards. The storyboards could be fitted with a transparent sleeve on each panel into which the text of the required community language can be inserted, but it would be best for a service to have a set of storyboards for each of the languages they actually require.

All translations would need to be tested, to ensure not only that they are accurate but also that they use an appropriate tone or level of language.

## **4. Further development**

### **4.1 Review of pilot findings**

There was a detailed review of the pilot report in a meeting of the consultant, the Project Officer who worked on development of the resource, the Project Officer who undertook the pilot research, and the Project Lead. Dr Berg participated in the three hour meeting by phone.

Another detailed review took place in two meetings with the midwifery advisors.

Following these discussions, it was decided to implement recommendations 1, 3, 6, 8, and 9(b,c,h,i) and to undertake a comprehensive edit of the text to improve accessibility. In addition, it was decided to revise the cover of the birth storyboard and the illustration and text of Pregnancy-9. The action taken is outlined below.

Options for redesign of the symbols (recommendation 2) were considered however it was not possible to develop a symbol which effectively communicated the complex issues required. Text stating the importance of someone explaining the symbols to the group was included in the booklet.

The recommendations for amending the formatting of the booklet and signposting from the storyboard to the glossary were considered (recommendations 4 & 5) and some amendments were made to the booklet during the editing process. Signposting from the storyboards to the glossary were explored however it was not possible to find a suitable format for doing this.

Funds were not available for translation of the resource so no further action could be taken on recommendation 7 at this time.

The suggested clarification of images in recommendation 9(a,d,e,g,j,k,l) were considered and some amended illustrations were commissioned. It was decided that these did not offer significant improvements and these were not adopted. These amendments were not considered essential for the resource to be effective.

At the time of writing, Medact was seeking funding for a training course to support the delivery of the resource. This was seen as a useful strategy to support effective use of the material including communication of the complex ideas represented by the symbols.

## **4.2 Action taken**

### **4.2.1 Text**

Following the recommendation from the pilot, the booklet text was amended to remove the text: 'For people who do not speak or read English the storyboards have been designed to work on their own once the symbols have been explained.' Instead, the text emphasised that ideally at least one participant in the group would have read the booklet and also recommended that the symbols be explained.

The text was edited by a professional editor to improve accessibility. The revised text was exhaustively reviewed by the midwifery advisors and Medact staff over a ten week period. The resulting text retained technical terms where appropriate, avoided policy jargon, and employed simpler sentence construction than the original. When the printer's proofs were received, the text was again reviewed by the midwifery advisors and the project officer who worked on development of the resource. This resulted in further changes to improve clarity and to incorporate recent changes to policy.

### **4.2.2 Illustrations**

When contacted about changes to the illustrations, the artist explained that she was too busy to undertake this work now or in the future. Some delay was experienced while another artist was found to complete the work.

The following changes to the images were made:

#### *Pregnancy 1-4*

Participants in three of the pilots thought that the illustration for Pregnancy-1 showed a woman who was four to six months pregnant. To avoid giving the impression that maternity care begins in mid to late pregnancy, the tummy was flattened in two illustrations (Pregnancy-1 and Pregnancy-4). The panels were re-ordered to place these two images at the beginning of the pregnancy storyboard.

Some participants had interpreted the large handbag in Pregnancy-4 as a suitcase with implications for going to hospital. The size of the handbag was reduced.



Pilot image

Final image

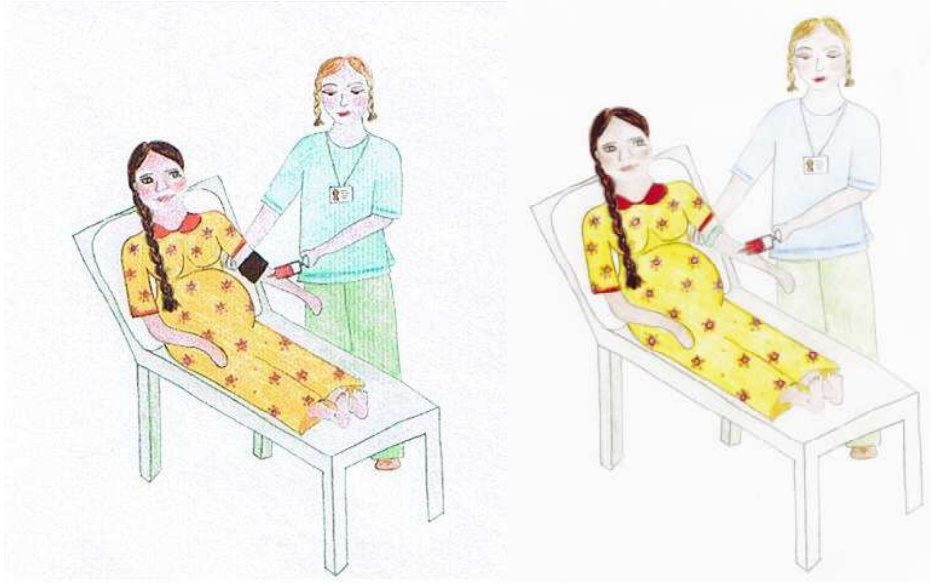


Pilot image

Final image

### *Pregnancy 6*

Participants in the pilots had been confused as to whether this image represented the taking of blood pressure or a blood test. Following the suggestion of a participant, the band on the woman's arm was made skinnier and a different colour used in order to make it look different to a blood pressure cuff.



Pilot image    Final image

### *Pregnancy 9*

During the review of the pilots, there was discussion about how to reconcile the text and illustration representing the measurement of fundal height. The illustration showed a veiled woman with the measurement being taken over her clothes. The text stated: 'The midwife will check the baby's growth by feeling and measuring the distance between your pubic bone and the top of your womb. This will need to be done on your skin.'

While the illustration represented desirable practice in providing culturally sensitive care, it did not represent standard practice. In the majority of cases, a woman who wanted the fundal height measured over her clothes would not receive this form of care unless she specifically requested it. As a result, it was decided to depict a woman having the fundal height measured on her skin and to state in the text that a woman could ask for this to be done through her clothing.



Pilot image



Final image

#### *Birth 14*

Some participants in the pilot criticised the depiction of the man in his underwear. The illustration was amended to show the man in trousers by placing a belt on the waistband.

#### *Becoming a parent-3*

Some participants in the pilot thought that the baby was hard to see against the pink coat. The colour of the coat was changed to make it easier to see the baby.



Pilot image



Final image

#### *Becoming a parent-6, Becoming a parent-9*

Two participants in different groups interpreted the crib stand in *Becoming a parent-6* as a cross. One thought it meant that the baby had died while the second thought that it meant that you should not put the baby on the floor. To

remove any confusion, the crib stand was changed. As the same crib image appeared in *Becoming a parent-9*, this illustration was also changed. Both were made consistent with the illustration in *Becoming a parent-7*.



Pilot image

Final image



Pilot image

Final image

#### 4.2.3 Format

The birth storyboard, which was originally in two parts, was collapsed into a single storyboard for ease of use. The cover image had previously been a woman holding a baby, however this had caused some confusion during the pilots. This image was replaced by an illustration from the storyboards (*Birth-9*) of a woman giving birth.

The storyboards retained a single symbols page on each storyboard, rather than two such pages.

#### 4.2.4 Booklet cover

Participant reaction to the images on the booklet cover were mixed, however negative responses predominated. Most participants did not identify the subject matter of the booklet from the cover images. To facilitate ready identification of the subject matter of the booklet, the cover images from two of the storyboards were placed on the front and back cover of the booklet. The original cover image were moved to the inside front and facing pages.

## **Appendix A: Interview schedule**

Hello, I am ...

Thanks for coming along today.

We are going to look at some stories we have developed about maternity care, that is, health care for women who are going to have a baby.

We want to check if they are helpful and easy to understand and we want to know what you think of them.

We would like to hear from you what you think is good about them. We would also like to hear about anything you don't like or find hard to follow. If you tell us where you see a problem, then we can make changes to make the stories more useful. It is important that you tell us what you really think so we can make the resource as useful as possible.

Our group will take about 60 minutes (90 minutes for groups with an interpreter), so we will finish at (time).

You don't have to answer any questions you don't like and you can leave at any time.

What you say in this group is confidential. That means we will not put your name in any report or tell anyone else what you said.

Remember we are not here to test you, but to test the stories. Anything you say will be helpful to us. If you find something hard to understand, then lots of other people will too.

Do you want to ask me anything about what we are doing before we begin?  
[Promise to answer information requests at the end of the group or to provide an information resource or referral if available and appropriate.]

Now my name is ..... and I would like to know your first names only so I will know what to call you .  
[Jot down names]

Does anyone have children? [Ask a few questions to establish some rapport]  
Did you have your babies in the UK or in another country?

[hand out the first storyboard: pregnancy]  
[refer to the symbols page]

There are three symbols here. What do you think they mean? What does this one mean? Could it mean anything else?

This one is to ask for an interpreter. This one is to ask about your choices.  
This one is to talk about how you are feeling

[refer to the rest of the storyboards]

What is happening here?

[prompt to get a verbal description of each picture: How is she feeling? Who is he? Where are they? What is he doing? Have you been in a situation like this or was your experience different?]

What do you like about this picture?

What don't you like about it?

Is there anything confusing about this picture?

Is there anything here that anyone would find offensive?

[hand out the second set of storyboards: birth 1 & 2]

What is happening here?

[prompt to get a verbal description of each picture: How is she feeling? Who is he? Where are they? What is he doing? Have you been in a situation like this or was your experience different?]

Is there anything here that anyone would find offensive?

[hand out the third storyboard: parent]

What is happening here?

[prompt to get a verbal description of each picture: How is she feeling? Who is he? Where are they? What is he doing? Have you been in a situation like this or was your experience different?]

Is there anything here that anyone would find offensive?

[refer back to the symbols page]

We discussed the symbols earlier. This one is to ask for an interpreter. This one is to ask about your choices. This one is to talk about how you are feeling.  
What do you think they mean when we use them on the storyboards?

[hand out the booklet]

Just looking at the cover, what do you think it could be about?

What is happening in these pictures?

[prompt for comments on the photos on the front/back covers]

If you saw this in a waiting room, would you pick it up?

Do you like the look of it? Do you like the colours?

What would you expect to find inside a booklet with this cover?

What would you hope to find?

Would you look inside it? Would you read it or just look at the pictures? Would you read it all or just look for bits that interest you?

How would you find the bits that interest you? Would you look for a list at the front (table of contents) or just flick through? If you flicked through, would you be looking for pictures or words?

Do you think this booklet could be useful for you?

How would it help you?

When would you want to have it?

Would you read it yourself or ask a friend or (service provider) to explain it to you?

Would you use this? How?

[prompt for further information: why they won't use it or why they will use it in a particular way]

The booklet is in English but a lot of people don't read English. Do you think it would be useful if we translated it

Would you read it if we translated it into your first language?

[put all the storyboards back on the table]

We have had a look at the storyboards and the booklet. I would like to know what you think of them. What do you think is most useful about them?

How could they be more useful?

Is there anything else women having babies would like to know about?

How could we make them better?

Thank you for giving us your time today. It is really helpful for us to hear what you have to say.

[Close]

## Appendix B: Detailed findings: The symbols

### 2.2.1 *The symbols*

Participants were asked what they thought the symbols meant. Many women from all groups guessed that the first symbol meant “multi-cultural”, other descriptions included “a map”, “something about holidays, travel”, “a womb with many babies”, “happy faces around the world”, “UNICEF”. Almost all participants found it hard to articulate a meaning for the second symbol: “faces”, “a boy and a girl”, “happiness in different cultures”, “it means OK”. A health advocate interpreting for group E suggested of the second symbol: “this means choice of Chinese or Bengali interpreter. Do you point to the Chinese face if you are Chinese?” Most participants identified the lower part of the third symbol as representing a happy face and a sad face but some were unable to identify what was meant by the top two faces. Suggested meanings were: “Four babies with different feelings”, “some people are happy and some are sad when pregnant”, “it shows how life is”.

The meanings of the symbols were explained. Some participants in group D felt that they could understand them once they had been explained. Women in groups A, B and E felt that even with explanation, the first and second symbols were “not clear”, “confusing”, “not easy to understand”, “this picture doesn’t work”, “I wouldn’t have thought it meant interpreters”. One participant in group E commented that in her community they were used to identifying an offer of interpreting services from a multi-lingual list; one participant in group A suggested that the concept of the first symbol could be conveyed by a pregnant woman with a voice balloon in different languages speaking to a receptionist. A participant in group E said that after explanation, the third symbol was good as it corresponded to what it was trying to express, and that it could be used (like picture cards for children in hospital) for women to point to how they are feeling.

After discussion of the storyboard pictures, participants were asked “What do you think the symbols mean when we use them on the storyboards”. Participants from all groups replied that they had not noticed them, or that they did not pay attention to them: “they don’t mean anything more”, “decoration”, “can’t see them in the bottom of the box”, “didn’t really notice, I was looking at the pictures”, “they don’t help”. One participant suggested: “they are there to remind you”. When asked if they had reminded her, she said “no.”

## Appendix C: Detailed findings: Storyboard pictures

### 2.2.2 Storyboard pictures

Participants were asked to look at each picture in turn and to describe what was happening. Some participants in groups A, B, C and F, read the English text before they did this, but most participants did not.

All groups were in general very positive about the storyboard pictures, and several participants expressed a wish that a similar resource had been available to them at the time they had their baby. Participants who did not read English stated that it would be better if the text were in their mother tongue, although participants in group E felt it would be better if it were in both English and Bengali. Participants who did read English frequently asked the meanings of specialist terminology.

Some participants liked the fact that the ethnicities in the pictures changed, but others (in group B) found this confusing and thought it made the 'story' hard to follow. Many participants were comfortable with the stylised drawings but others took a more literal approach and criticised discrepancies, for example, between the pain a labouring woman must be feeling and the smiling face in the picture, or the representation of a heavily pregnant woman from the first picture onwards. Several women were confused by the chronology, particularly because in some pictures they were unsure whether she had given birth or not and because the "cover" picture of the birth storyboards depicts a woman already holding her baby.

Where participants' own experience of services contradicted the pictures, they asserted the primacy of their experience and stated that the storyboards were wrong. For example, when looking at Pregnancy 2 a participant stated that there should be a picture of a doctor first because you must go to see a GP first before seeing a midwife. Looking at Becoming a Parent, a participant stated that it was misleading to show such a lot of postnatal contacts as this did not happen in reality. Looking at Becoming a Parent 4, participants in group C were stated that the hearing test occurs at the 8 week check up and thought it should not be in this group of pictures.

Overall, the women who had experience of the UK maternity services generally found it straightforward to interpret most of the pictures. However, participants in group B, where most did not have experience of the UK maternity services, found many pictures difficult to understand.

After discussing each storyboard, participants were asked whether there was anything that anyone might find offensive. Most said no on each occasion. The exceptions were: one participant thought the birth pictures were "too clear" and participants in group B thought the placenta picture (Birth 13) was frightening. Participants in group B did not like the fact that the man in Birth 14 had no shirt on and his pants were visible. One participant in group E said

that in her community, the details of birth were normally hidden from men and children.

### ***2.2.3 Discussion of individual pictures***

#### *Pregnancy - 1*

“Oops I am pregnant, what do I do?”

“She has a lot of questions or worries”

“Surprised, unexpected, wondering, unhappy because she is looking down”

“She is unsure, confused”

“She is not sure if she is pregnant or not”.

Participants in groups A, B and C thought that the woman was four to six months pregnant: “surprising she has only just realised”, “her stomach is too big, why doesn’t she know?”

#### *Pregnancy - 2*

“She has contractions”

“She has seen a doctor in late pregnancy”.

“She is upset, ill”

“They are going for a walk”

“There should be an extra picture with the GP first as this is what you are supposed to do.”

“It is about nursing when she comes home after the baby comes home.”

“The midwife is helping the pregnant woman”

“She is taking her to bed to rest.”

“The nurse is measuring her”

One participant suggested it would be clearer if there was a hospital sign.

#### *Pregnancy -3*

“A check up”

“Antenatal care”

“Baby getting checked”

“Text is essential to understand” (Group B)

#### *Pregnancy - 4*

“Doesn’t look like early pregnancy because of size of bump”

“She is seeing someone, getting information, antenatal class”

“Regular check ups”

“Need text to understand” (Group B)

“Some problems with the family”

“Having interpreter with her”

“Is this the one where you talk to the midwife and they ask a lot of questions?”

Group E discussed why there was a suitcase. Participants speculated they were discussing her staying in hospital, or it must be very near her time to deliver.

#### *Pregnancy - 5*

All participants stated that this was a “scan” or “checking baby” or “checking baby’s heart”. Several commented “best so far”, “very clear”. One thought the baby was too big.

*Pregnancy - 6*

Participants were divided between identifying this as taking blood or testing blood pressure.

“Need to have detail in Chinese” (Group B)

One participant in group E commented that to make it look different from a blood pressure band, the band should be skinnier and a different colour.

*Pregnancy - 7*

Participants in all groups identified this as testing blood pressure.

*Pregnancy - 8*

Participants with experience of maternity services identified this as a urine test. Others thought: “She’s got a girl”, “She’s giving her a drink”, “the nurse is telling her to drink medicine”. Participants suggested it could be more obvious if a toilet was visible or the word “toilet” was used.

*Pregnancy - 9*

Participants in all groups identified this as measuring the baby.

*Pregnancy - 10*

“Maybe late in pregnancy and very tired, maybe pregnancy depression, looks like she has pain, maybe scared, lonely, crying.”

“Who is the pregnant one? Why is she so old? Why is she crying? Is it her friend?”

“Showing emotional change in pregnant lady”

“She has seen a sad film”

“The baby is coming”.

“Something is wrong with the baby, the lady is comforting her.”

*Pregnancy - 11*

“Reading information about maternity, sharing, communicating, supporting”

“Three people together, all pregnant, reading something”

“Antenatal class”

“Reading their file”

“Reading the Pregnancy Book”

“Looks like they’re at home. Needs background”.

“Take off the book so you can see their stomachs or write on the book what it is.”

*Pregnancy - 12*

“Check up, more information and advice”

“Appointments should be one by one not two together.”

“It looks the same as the previous (4) unless you can read.”

“Just sitting down discussing something”

*Birth - 1*

“You need to take exercise during pregnancy - aerobics?”

“What does the circle mean?”

“She’s dancing, happy. Keeping her body fit during pregnancy for a better labour.”

“Happy? Maybe not happy?”

#### *Birth - 2*

“Her family is supporting her”

“They are standing around - who are they? Waiting for a bus? Going on an outing?”

“She’s not showing pain”

“Pregnant lady smiling so she’s not in labour”

“With her parents, taking her to hospital”

“Not her husband because he looks old.”

“Scarf says Muslim people but not usual for dad to come or man to be there.”

“Mum and dad or mother-in-law taking her to hospital.”

#### *Birth - 3*

“Not clear what stage - given birth or not? A picture with staff”

“Not a clue what that means” (group B), “don’t understand what’s going on” (group E)

“The team in hospital, lots of people, big deal, very scary.”

“Nurse and doctor - welcome, welcome”

“If not happy with one you can have the team”.

“She’s at the hospital but the baby’s gone.”

“The party after birth in Somali culture”.

Many participants were confused by the fact that the woman in this picture no longer appears pregnant but “the step between going to hospital and leaving - the most important bit - it’s not there.”

#### *Birth - 4*

“Oh - now she’s still pregnant”

“Having a baby in the water”

“Warm bath for pain”

“Having a bath to clean herself after having the baby”

#### *Birth - 5*

“Oxygen - she is in pain”

“Would be good to show a woman having an epidural”

“What is that, it looks like a dummy? It’s not obvious”

“The gas, rubbing her back”.

“Some sort of pain relief, she seems stressed out”

#### *Birth - 6*

“Feeling position of baby”

“She looks too relaxed”

“Touching her stomach so the baby can come”

#### *Birth - 7*

“Monitoring the baby’s heart”  
“Checking up the pain”  
“Has she given birth?”

#### *Birth - 8, 9, 10*

Participants in each group commented emphatically that it would better if picture 10 came first as that shows a “normal” position.

“Teaching you different positions to give birth”  
“Why does it show the options after she’s already given birth?”  
“English women like different positions; it’s good to know beforehand”

On 8:

“Some people might find it a bit in the open.”  
“Cord is a bit frightening, you won’t feel it so better not show it.”  
“It’s on the floor, not clean”.  
“Why is her tummy so big when she’s given birth?”  
“It’s the wrong way around”.  
“I would prefer baby half in, half out, shows what’s going on.”

On 9:

“Is it a home delivery?”  
“Maybe she has twins, she is giving birth again”  
“Waiting to deliver placenta”  
“Would prefer her lying down and father holding baby, not like this.”  
“Never seen this position before”

On 10:

“This is the safe way.”  
“The best position.”  
“Forceps or caesarean. They are getting ready.”  
“Caesarean”  
“Problem with the placenta”  
“I think the baby’s head is too big and have to cut.”

#### *Birth 11*

Participants in every group identified this as a caesarean, although one participant thought it was a normal delivery and suggested an operating theatre light.

#### *Birth 12*

Participants in all groups identified this as a doctor checking the baby.

#### *Birth 13*

Participants in all groups identified this as the placenta. Participants in group B said it was “too revealing, frightening”. A participant in group B, having read the text, wondered about the use of the word “delivered”: “I did not know it was delivered anywhere. Who is it delivered to?”

### *Birth 14*

“Twins,” “Skin to skin,” “Feeding the baby,” “Bonding,” “Family”. Participants in group B made negative comments about this picture: for example, they thought the babies were “too white” and they didn’t like the man’s pants being shown. One participant stated that as the midwife in Birth 12 was clearly a Muslim, “that man should put his shirt on.”

### *Becoming a Parent 1*

Participants in all groups identified this as a woman breastfeeding and the midwife advising her.

### *Becoming a Parent 2*

Participants in all groups identified this as a baby being weighed. One participant commented it would be good to show a ruler measuring length.

### *Becoming a Parent 3*

Participants who could read the text stated that this was a doctor examining the baby. Those who could not read the text suggested it was a family visit or the midwife visiting at home. Participants in group A thought the baby was hard to see against the pink coat. Participants in group B thought the baby “looks like the nurse because of the hair - is it her child?”

### *Becoming a Parent 4*

Most participants in all groups except group B identified this as a hearing test. Participants in group C stated that this occurred at the 8 week check up, that the baby shown in the picture was too small and that this picture did not belong in this group. Participants in group B suggested that the picture showed “another check up”, “playing with the baby”. One participant in group E suggested this was “changing the baby”.

### *Becoming a Parent 5*

“Coming home from hospital, nurse saying goodbye”.

“Someone visiting her at home”

“Mum comes to the clinic with two children”

“Health visitor is coming to see how things are going”

In each group there was discussion about who was visiting who. One participant suggested that if the aim was to show a home visit, it would be better to show a sofa.

### *Becoming a Parent 6*

Participants in all groups identified this as a woman who was sad, depressed, tired, unhappy (except one participant who thought she looked relaxed because she had done all her laundry neatly). Other comments included: “the baby has died, the basket is empty”, “she need help, support”, “can’t cope with the baby”, “some women don’t have someone to talk to”. Participants in group A commented that the pictures do not show the man helping her, and that it would be good to see him holding the baby while she is sleeping, or

doing the washing up - to give men the idea they should help. Two participants in different groups interpreted the crib stand as a cross. One thought it meant that the baby had died. The other thought it meant that you should not put the baby on the floor.

#### *Becoming a Parent 7*

Most participants saw this as a positive picture after the previous one, especially those who thought Becoming a Parent 6 showed that the baby had died: “baby happy”, “baby playing with his toys”, “normal growing baby”. A couple of participants recognised the “feet to foot” position in the cot. One participant suggested showing a thermometer.

#### *Becoming a Parent 8*

Most participants identified this picture as a home visit by a midwife or health visitor: or with more detail “showing mum how to give baby massage”, “shows how to do baby washing”. One participant thought interpreted the bowl on the table as a bowl of tea that the mother had made for the midwife. One participant suggested showing a needle.

#### *Becoming a Parent 9*

Participants in most groups identified this as a home visit by a midwife or health visitor, but many were unsure how it differed from the previous picture: “sitting there, having a chat”. Some participants suggested it was a friend visiting. Participants in group B described it as “Two women, another visit, don’t know what it’s about”. One participant suggested that it would be clearer if the health visitor held the red book (child development record).

#### *Becoming a Parent 10*

Many participants identified this as a visit to the GP to check the baby. Others suggested it was the midwife or nurse talking about the baby or showing her how to look after the baby. One participant commented that GPs do not wear white coats.

#### *Becoming a Parent 11*

“Nurse talking about breastfeeding”

“Having a chat with the nurse”

“Family gathering”

“Watching TV”

“Position for breastfeeding”

“Friends visiting”

“This is too many visits: in reality, they just come once a month”.

#### *Becoming a Parent 12*

There were three main interpretations of this picture: a happy family, the family with health staff, and taking a photo with staff. Other interpretations were: “A lot of people helped”, “Are they back at the hospital again?”, “relationships”. Several participants commented that the text did not match

the picture because it showed a family group or photo but the text referred to the community.

*Other comments:*

Two participants in different groups said they would like to see pictures on health promotion - folic acid, stop smoking, exercise and healthy diet. One participant said she would like a picture about immunisations, and one said she would like a picture about family planning.

## Appendix D: Detailed findings: The booklet cover

### 2.2.4 Booklet cover

Because of time constraints (and because not all participants read English), discussion of the booklet was very limited. Participants in all groups except group C were asked what they thought the booklet would be about, based on the cover; what they would expect or hope to find inside it; and whether they would pick it up if they saw it in a waiting room.

Participants suggested that based on the cover, they would expect the booklet to be “a community book, not pregnancy”, “about children, how to look after them”, “different ethnic groups”, “women and babies, children”, “a documentary”, “something about family, culture”. Several participants said they could not guess what would be inside. Groups A and B said it would be better to have a picture of a pregnant woman or a mother and baby on the cover. Participants in group A stated that this was important because it “needs to look relevant” and they felt it would make it more useful. Participants in groups B and D said that there were “too many pictures” or “too many different women”. Participants in group B said it would be better if all the pictures were Chinese (this applied to the storyboards as well). Participants in group E said that they did not like the cover because there was no Bengali woman on it. Two participants in group F responded positively to the cover, stating that they liked the variety of people and would pick it up.