Women’s voices on health
addressing barriers to accessing primary care
Maternity Action

Maternity Action is the UK’s leading charity committed to ending inequality and improving the health and well-being of pregnant women, partners and young children – from conception through to the child’s early years. Maternity Action provides online information and telephone advice on maternity rights at work and in the benefits system. Maternity Action undertakes research and campaigns to improve the lives of all pregnant women, new mothers and their families.

www.maternityaction.org.uk

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Women’s Health and Equality Consortium

WHEC is a partnership of women’s charity organisations who share common goals of health and equality for girls and women. WHEC aims ensure that health policy reflects the real needs of girls and women. It therefore pools the expertise of member organisations to better influence decision-makers and government. WHEC works to improve the sustainability of the women’s and girls’ health and social care sector, and to strengthen women’s and girls’ capacity to engage with the health and social care systems.

www.whec.org.uk

This report was written by Annah Psarros

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Acronyms

A&E – Accident and Emergency
ARC – Application Registration Card
BME – Black and Minority Ethnic
CQC – Care Quality Commission
FGM – Female Genital Mutilation
GP – General Practitioner
HC1 – The application form for the HC2 Certificate
HC2 – A certificate that entitles the bearer to full help with health costs on basis of low income
HIV – Human Immunodeficiency Virus
HPV – Human Papilloma Virus
IRIS – Identification and Referral to Improve Safety project
LGBT – Lesbian, Gay, Bisexual, and Transgender
NHS – National Health Service
NICE – the National Institute for Clinical Excellence
OECD – the Organisation for Economic Co-operation and Development
ONS – Office for National Statistics
PTSD – Post Traumatic Stress Disorder
UN – United Nations
VAWG – Violence Against Women and Girls
WHEC – Women’s Health and Equality Consortium
WHO – World Health Organisation
Executive Summary

The study

This project examines the accessibility of primary care for women in the UK. Women are a protected group under equalities legislation, and also constitute about 50% of other protected groups, meaning that they often face a multitude of risk factors.

Women earn almost 20% less than men on average. They also tend to have more unpaid responsibilities such as caring for children and relatives, and are at higher risk of violence from partners and family members. Women are also 40% more likely than men to experience depression. All of these factors interlink, and may be exacerbated by belonging to a group with comparatively poor health outcomes. Some groups will also experience additional problems relating to their situation, such as women seeking asylum.

Methods

For the first part of the project, personal accounts of accessing GP services were collected, using an online survey promoted to all UK women regardless of social or ethnic group. The second part of the research involved holding a series of focus groups for women with comparatively poor health outcomes.

Results from the survey

- 40% found it ‘hard’, or ‘relatively hard’ to get an appointment. For many, the choice was between having to miss work without prior notice for a same-day appointment, and waiting several weeks to be seen. There were similar issues around childcare.
- Many found it stressful to have to convince receptionists of their need for an appointment.
- 73% of mothers reported bringing their children into appointments, which is likely to affect communication, especially about sensitive issues.
- Only 6% of carers had discussed their caring responsibilities with their GP.
- 62% preferred to see a woman GP about sexual and reproductive health, and some preferred to see a female GP for any kind of physical examination at all. Some also preferred discussing their mental health with a woman. But 20% said they cannot ask for a female GP at their surgery, and 14% did not know if this was possible.
- Stigma, and not being taken seriously, were two of the main reasons why women had not sought help for a mental health problem. A belief they would only be offered medication was another concern.
- Prescription charges were a factor for 41% of respondents, when deciding whether or not to see their GP.
69% of the women who had experienced domestic violence did not seek help from their GP. There seemed to be little trust in the GP’s ability to help. Out of those who had sought help, two thirds had a positive experience.

**Results from the focus groups**

**Black and Minority Ethnic women**

- Several of the BME women we spoke to had bad experiences of not being listened to by doctors. This was linked with language, and not knowing the correct medical terminology.
- The majority felt more comfortable seeing a female doctor, often requesting this specifically, though this was not always possible. Sexual health and reproductive health were seen as particularly difficult to talk about.
- Two women who had undergone FGM spoke of highly traumatic experiences of childbirth, with doctors not knowing what to do. The group said that problems persist, with embarrassment preventing women affected by FGM from accessing healthcare.
- Some of the younger women had experiences of violence or abuse, but because they lacked confidence in GPs in general, they did not consider them a potential source of support.

**Refugees and women seeking asylum**

- Having had their passport retained by the Home Office made it difficult for these women to register, as GP practices demanded proof of ID but did not always accept their Application Registration Card (ARC).
- The women received mixed messages in relation to what healthcare they were entitled to. They put this down to health professionals’ lack of knowledge, but also prejudice and discrimination. Many felt that they were treated differently from non-migrants.
- Several women had found it necessary to call in a third party to negotiate on their behalf, both in relation to registration and to getting an appointment. They felt they were being ‘blocked’ by reception staff.
- Several participants spoke of being denied appointments and referred to A&E or walk-in centres instead.
- Health-related costs were a big barrier to the women, most of whom were destitute.
- Mental health problems were associated with a lot of stigma in this group.

**Women living with HIV**

- Many participants preferred their HIV-clinic to mainstream health services. They felt that GPs were lacking in knowledge and experience relating to HIV, and that clinic staff were more compassionate.
- Confidentiality was one of the main issues for this group and sometimes led to stress and conflict when receptionists asked ‘intrusive’ questions when other patients could overhear. There were also issues around taking children into consultations if they were not aware of their mother’s HIV status.
- 5 out of 8 women in the focus group had experienced domestic violence but had found it very hard to seek help, because of perceived stigmas of single motherhood and economic dependency on the partner.
- All the women in this group had experienced mental health problems. Most of them had sought help, but from their HIV-specialist rather than GP.

**LGBT women**
- Several women had previous experiences of poor treatment from health professionals, sometimes having other health problems attributed to their sexual orientation. For many, the expectation of doctors reacting negatively had become a deterrent to using health services.
- The focus group and many lesbian and bisexual women who took the general survey felt that there was very limited knowledge of their sexual health needs. Mainstream health services were seen as very hetero-normative, for example insisting very strongly on offering contraception. This left the women with the options of lying about their relationship, or coming out. Several women in the focus group and the survey said that they avoid smear tests and sexual health checks for this reason.
- Mental health was another area associated with barriers, as seeking help for depression or anxiety would invite questioning about the home situation. Not being able to talk about this had impacted on one woman’s mental health treatment.
- One woman and her partner sought help from their GP to have a child but the doctor did not know their entitlement, or the referral procedure. Later, they experienced overt discrimination during the birth when the woman who was not carrying the baby was refused access to the maternity ward, on the basis of not being a ‘husband or partner’.

**Women with learning disabilities**
- This group of women found registration forms to be inaccessible, jargon-heavy and requiring information they did not have. Two participants had asked reception staff for help to fill in the form but were both told this was not possible.
- The women found automated booking systems difficult to navigate and some had additional problems with dexterity, making it difficult for them to use the phone. Clarity of speech was another potential problem with phone booking.
- Participants identified several communication barriers relating to GPs’ use of jargon, and not having access to information in accessible formats, for example about how to manage a chronic illness, or about contraception. Not being able to make themselves understood by doctors was another problem. There are potentially serious consequences if women with learning disabilities cannot make themselves heard, as they are at high risk of sexual abuse and domestic violence, sometimes from carers. Women’s support organisations may not be well equipped to support women with complex circumstances.
- Cervical screening is a potential neglected area of health for this group. Many of the women found the issue of sexual and reproductive health difficult and embarrassing to talk about. One had asked several times to see a female doctor for this, but her request had never been adhered to.
- The women spoke of the ‘postcode lottery’ of mental health services, and the fact that their low-level disability meant they did not qualify for social worker support. Many disabled women only have access to mainstream services, which may be poorly equipped to support them.
Recommendations

The appointment system

- More flexibility is needed in terms of how appointments are offered and how clinics are scheduled by GPs.
- Audit appointment systems with the help of patient representatives.
- Open up the booking system in order to meet equal access requirements. Online booking is offered by some practices already and we welcome changes to the GP contract which will provide all patients with this option in 2014/15. Some respondents preferred going to see the receptionist in person. Some GP practices also offer a second chance to book an appointment in the afternoon.
- Offer people with learning disabilities annual health checks, which should include smear tests and breast checks for women in the relevant age groups. (Currently, the provision of such checks varies according to area and GP practice.) The Health Action Plan is another tool that can be used to monitor health.
- Consider reviewing the kinds of questions patients are asked by receptionists when they call to make an appointment.
- Awareness training for administrative staff about the entitlements of refugees and asylum seekers, about the Equality Act, and about patient confidentiality.
- In addition to offering a wider range of appointments, consider extended opening times and operating weekend clinics.
- The responsibility of informal care work should be balanced with the offer of support, to which carers are legally entitled. Healthcare professionals should raise awareness of these entitlements in their contact with people who are, or may be, carers.

Registration

- Simplify registration procedures to minimise complexity and time demands, including making all application forms available for download and registering new patients at a variety of times.
• Consider combining registration with any compulsory health checks. This would also be an opportunity to offer support with forms, for example for speakers of other languages or women with learning disabilities.

• Documentation requirements should not be a barrier to registration when passport, photo ID or utility bills are not obtainable. Insisting on these documents restricts access to healthcare for groups like asylum seekers, homeless women and members of the Irish Traveller community.

• In order to adhere to commitments and obligations relating to equal access and the reduction of health inequalities, NHS England and Health and Wellbeing boards can work with third sector organisations to provide awareness training for clinical and administrative staff about the rights of migrants, asylum seekers and refugees, and NHS obligations towards them, and to act as patient advocates.

• Health and wellbeing boards should consider working with local third sector organisations to meet equalities standards, including becoming ‘LGBT-friendly, meeting the needs of patients with HIV, patients with disabilities, speakers of other languages and others who may struggle to register.

• We welcome changes to the GP 2014/15 contract which will allow GPs to register patients from outside their practice boundary area, effective from October 2014, as some patients' needs are not necessarily met by their local practice.

**Effective use of the appointment**

• The availability of female doctors should be recognised as a potential access issue for women as a group of patients. Not meeting this requirement can be a barrier to accessing care for sexual and reproductive health, and mental health.

• Women should be made aware that they have a choice to see a female health professional, and requests should be met wherever possible, without additional questioning.

• All GP practices should have at least one female doctor in order to meet this need.

• Allocation of time should not be done in a way that inhibits communication about sensitive issues, or compromises trust between the patient and doctor.

• GPs may need training on how to provide patients with a supportive environment for disclosure about sensitive issues such as mental health and domestic violence.

• Confidential interpretation services should be commissioned and provided free of charge to those who require it, in order to meet equalities commitments about equal access as provided for by the Equality Act 2010, the Human Rights Act 1998 and the
NHS constitution. Face-to-face interpretation is preferable, but phone services may help to address the issue of small communities where confidentiality could be compromised. Female interpreters should be made available to women wherever possible.

- Awareness needs to be raised among patients about entitlement to interpreter services, for example using strategically placed posters in GP practices.
- Midwives and other healthcare professionals should have awareness of the protected period for pregnant asylum seeking women, allowing them to advocate on their behalf if necessary.
- The Royal College of General Practitioners recommends ensuring that patients with learning disabilities have their individual communication needs outlined in their patient notes. They also recommend longer appointment slots for patients with Learning Disabilities.
- NHS England is currently working towards implementing an Information Standard for accessible information for patients with disabilities, which means that health and social care organisations will be required to provide information to patients in a format that they can understand. GP practices will need to ensure they comply with this new standard when it is implemented.
- NHS England should consider following the Scottish example: in order to meet the requirement to accessible information, as per the NHS Scotland’s rights-charter, NHS Scotland now supplies accessible easy-read maternity books from CHANGE, to all expectant mothers with learning disabilities.
- NHS England should consider commissioning training for healthcare providers on how to work more accessibly, how to adapt practices and communication to become more inclusive. In recognition of equalities duties and in line with the ‘No decision about me, without me’ agenda, commissioners and providers should consider seeking advice on implementation from women with learning disabilities themselves.

Costs

- GP practices, pharmacies and other NHS organisations should support public awareness of low income schemes by providing forms and advice.
- Free prescriptions for vulnerable migrants should be retained and the HC1 form (the application form for the HC2 certificate) routinely be provided by GPs, pharmacists and other healthcare providers.

Prejudice and discrimination
• Healthcare professionals need training in order to become more confident and comfortable dealing with LGBT women patients, becoming more aware of their needs, and knowing how to eliminate discriminatory practices.

• A recent CQC inspection reveals that 1 GP service in 8 has no set complaints procedure. Official complaints can be a valuable tool for quality assurance. Complaints should be dealt with according to a set process which is open, accessible and supportive. Awareness can be created using information leaflets and posters.

• In respect of the above, however, it also needs to be recognised that bad experiences may lead to avoidance rather than active engagement. For this reason, alternative methods for evaluation and feedback should also be explored by NHS organisations in order to reach seldom heard groups.

• You cannot improve what you do not measure. Public health data should be gender-disaggregated and contain information about protected characteristics. Questions about sexual orientation need to be asked in sensitive ways and the reasons for collecting this data explained.

• Further to the above, GP practices should be required to audit their success in meeting the needs of aforementioned groups via questionnaires/patient’s group feedback, and make improvements where necessary.

• Underlying reasons as to why BME and refugee and asylum seeking women tend to report worse health experiences needs to be explored further. Such treatment appears to be discriminatory, and against the Equality Act 2010 and the NHS Constitution. For example, it is unacceptable to refer patients to A&E for non-emergencies, and investigation may be needed into the extent of this problem and how to address it.

• Reception staff should be offered training on patient confidentiality, helping them to deal with concerned patients.

Mental health problems

• The course of action outlined by the Department of Health in order to achieve ‘true parity of esteem’ between mental and physical health should be carried out; investigating the scale of the problem, and implementing maximum waiting times for treatment of mental health problems.

• GPs need training on how to provide a safe and non-judgemental space for disclosure about mental distress. Having one GP per practice specially trained in
mental health, and putting this information out to patients, is an option.

- The risk of mental health problems like PTSD in the asylum seeker group should be recognised by health professionals, including how cultural issues may affect perceptions of mental health.

**Gender-based violence**

- Work on FGM should reach outside of the maternity setting and be subject to set referral pathways, which should include advocacy support. In the case of younger girls, it should be incorporated into existing child safeguarding frameworks.

- A recent CQC inspection showed that 12% of surgeries do not know the correct procedures for safeguarding children and vulnerable adults, such as women with learning disabilities. This needs to be addressed.

- Health professionals should recognise that intimate partner violence also happens in same-sex relationships and adapt standard forms and procedures accordingly.

- Patients should be made aware that their GP services can be a first step towards getting help with gender-based violence. Information from women’s organisations, such as posters and leaflets, should be placed in waiting areas. Equally, information should be available in community settings such as libraries, pharmacies and community organisations.

- We concur with the NICE recommendation that strategic partnerships, such as Health and Wellbeing boards identify all local services that deal with domestic abuse and map them against the Home Office/AVA ‘Coordinated Community Response Model’. Services should also be mapped in order to identify other local specialist organisations such as Rape Crisis Centres, BME VAWG specialists and community based organisations that work on LGBT women, disability and other protected groups or groups with comparatively poor health outcomes.

- GP surgeries should draw on existing models of promising practice, such as the IRIS project, and the GP champions Youth Inclusion Project, which have improved collaboration between the voluntary sector and primary care through prompts for clinical enquiry, care pathways, practice – based clinical leads, and VAWG experts based in GP surgeries.

- Consistent and standardised training or guidelines are needed for health professionals about how to identify the signs of gender-based violence, the impact of gender-based violence and responding appropriately. GPs should work in partnership with specialist voluntary sector organisations to develop appropriate referral pathways that also ensure confidentiality and safety in situations where women may disclose gender-based violence. This should also include knowledge
about issues relating to asylum-seeking women and their entitlements in gender-based violence situations where their asylum claim is linked to the perpetrator of violence. Knowledge should be updated along with changes in legislation and policy, so that GPs can provide the vital support that women in this situation need.

- We concur with the 2013 intercollegiate recommendation that ‘all new patient registrations in primary and secondary care, including A&E of young girls/women, should include detailed enquiry about country of origin. If the family is from FGM practising community, document any presence of FGM to establish a baseline for monitoring and sharing information with the relevant agencies.’

- We concur with the Alberti Review recommendations, including the one that ‘NHS staff should be made aware of the issues relating to violence and abuse against women and children, and of their role in addressing those issues, including how to broach the issue sensitively and confidently with patients’.

General recommendation

- This report has flagged up several areas in which NHS providers can potentially fail to meet the needs of their patients. In order to meet equalities duties and public health duties to the local community, NHS organisations should identify where service delivery falls short of their equalities commitments, for example using the NHS Equality Delivery System EDS2.
Part 1 - Context

1.1 Aim of the project

This project, commissioned by the Women's Health and Equality Consortium, examines the accessibility of NHS primary care services, from the point of view of UK women.

The aim of this project is to explore potential barriers to healthcare, both for women in general, and for women who experience comparatively poor health outcomes, in order to contribute to an understanding of how these may be addressed.

1.2 Rationale for this project - Why women?

Women are a protected group under UK Equality Legislation. Women also constitute roughly half of all other protected groups, such as people with disabilities, Black and Minority Ethnic (BME) people and lesbian/gay/bisexual and transgender people, and may therefore face multiple disadvantages.

There is evidence that women experience significant inequalities in health outcomes compared to men. Whilst the biological differences between men and women undoubtedly play a role (including, but not limited to, factors relating to childbearing) the focus of this report will be on the wider concept of gender, defined by the World Health Organisation (WHO) as ‘the socially constructed differences between women and men, including expectations of roles and responsibilities, as well as differences in patterns of employment and unpaid work’.

The impact of social circumstances on health is well documented, and the need to address inequalities is recognised in UK health policy. The Department of Health mandate to the NHS states its responsibilities to the public as follows:

“The Government's ambition for excellent care is not just for those services or groups of patients mentioned in this document, but for everyone regardless of income, location, age, gender, ethnicity or any other characteristic. Yet across these groups there are still too many longstanding and unjustifiable inequalities in access to

1 The Equality Act, 2010. For a summary, see for example http://www.adviceguide.org.uk/england/discrimination_e/discrimination_about_discrimination_e/equality_act_2010_discrimination_and_your_rights.htm
3 ibid., Annex A
4 Health inequality is defined by NICE as “Differences in health experiences and outcomes between different population groups, depending on socio-economic status, geographical area, age, gender and ethnicity”
services, in the quality of care, and in health outcomes for patients. The NHS is a universal service for the people of England, and NHS England is under specific legal duties in relation to tackling health inequalities and advancing equality. The Government will hold NHS England to account for how well it discharges these duties.\textsuperscript{6}

The Health and Social Care Act 2012 also places a duty on the Health Secretary to ‘have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service.’\textsuperscript{7}

The relationship between socio-economic status and health is not merely a matter of the very poor being more susceptible to illness, which could have been explained by lifestyle factors alone. Research by Marmot and others has found that health status declines with each decline in socio-economic status, making a strong case for focussing on ‘the broader structure of social economic condition’ rather than on poverty alone.\textsuperscript{8} More recent research has corroborated these views.\textsuperscript{9} There is evidence that the current recession, with the associated cuts to public spending, welfare and healthcare budgets\textsuperscript{10} has disproportionately affected single parents and women\textsuperscript{11} and, according to authoritative sources, ‘will likely widen health inequalities considerably’.\textsuperscript{12}

One of the intended functions of this document and its recommendations is to support NHS commissioners, providers, and others responsible for meeting their Public Sector Equality Duty (Equality Act 2010), under which equal consideration must be given to the needs, experiences, outcomes and aspirations of people with protected characteristics under equalities law.\textsuperscript{13}

\begin{footnotesize}
\begin{enumerate}
\item The Health and Social Care Act, 2012
\item The Royal College of GPs reports that, although over 90% of patient contacts with the NHS take place in general practice, its share of the NHS budget is only 9%. Investment in real terms fell from £8,865m in 2009/10, to £8,459m in 2012/13. \url{http://www.rcgp.org.uk/news/2013/october/patients-bear-brunt-as-gps-reveal-shocking-400m-black-hole.aspx}
\item According to Jessica Allen, deputy director of the UCL Institute of Health Equity and former Project Director of the Marmot Review: ‘Health inequalities continue to widen across England, made worse by the economic climate since 2008 and by welfare reforms. Our analysis demonstrates that the combination of recession and austerity will likely widen health inequalities considerably.’ \url{http://www.theguardian.com/healthcare-network/2013/feb/01/marmot-review-progress-made}, Feb 2013)
\item For a list of bodies this duty applies to, see for example \url{https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/84984/Schedule-19.pdf}
\end{enumerate}
\end{footnotesize}
1.3 Defining access

According to international human rights standards, every human being is ‘entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity’, and this includes equal access to healthcare. Access can be quite a blurry concept in places like the UK, where health care is free at the point of use for the vast majority of users. For this reason, our definition of access here refers not only to physical access, or actual use, but also to the availability of suitable services at a personal cost which is acceptable to the user. It also requires an appropriate level of information, for example about entitlement, provision and location of facilities.

Accessibility, i.e. potential access, is less observable than actual use, but equally important. In order to include this aspect, we will be asking questions about women’s experiences of making and getting appointments, but also about the factors that influence their decisions about whether or not to seek help.

The concept of access should also include the notion of effective use of services. This takes into account aspects of quality such as the ability to communicate need and receive information effectively. Information needs to be accessible to the user and this may entail translating to other languages, or using picture support for patients who do not read. Receiving poor quality care, whether this is to do with communication or something else (for example being stigmatised on the grounds of sexuality, or treated with prejudice because of ethnicity) is both an access problem in itself and can become a deterrent to seeking help in the future. One aspect of effective communication is time. Angus found that ‘many authors reported women’s complaints about limited opportunities for fruitful communication during appointments with physicians. A commonly identified problem was insufficient time allotted for appointments, which truncated discussion of health issues; some women found primary care providers were unable to discuss details of specialty care and treatment’.

Barriers to healthcare therefore include both supply-side features like policies and processes and even physical issues like location, as well as social and economic issues like the inability to afford prescription charges or taking time off work. It also includes factors that impact on the doctor-patient relationship, such as prejudice and stigmatisation, which have a detrimental impact on trust and communication.

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15 Based on the definition used in M. Goddard and P. Smith, 2001, ‘Equity of access to health care services – Theory and evidence from the UK’, Social Science & Medicine, Volume 53, Issue 9, 1149–1162
16 This is in accordance with article 12 b of the International Covenant on Economic, Social and Cultural Rights, http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En, which states that Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party. This includes non-discrimination, physical accessibility, economic accessibility (affordability), and information accessibility, including confidentiality.
17 M. Goddard and P. Smith, 2001, op.cit.
1.4 Factors underpinning women’s health inequalities

The factors that underpin women’s health disadvantage include (but are not limited to): 19

- Factors relating to women’s economic disadvantage
- Factors relating to women’s caring roles
- Factors relating to gender-based violence

1.4.1 Economic disadvantage

UK women earn an average of 19.7% less than their male counterparts 20. Women are also more likely to be poor in terms of lacking two or more necessities, earning below 60 per cent median income, experiencing subjective poverty and receiving Income Support. 21

The Marmot Review in 2010 found a lower level of attendance of cancer screening services in lower socio-economic groups, ultimately affecting treatment options and prognosis. 22 Patients in lower social strata (variously defined by occupation, level of deprivation and overcrowding in the local area, as well as individual economic circumstances) have also been found historically less likely to take part in preventative programmes such as cervical screening and childhood immunisation. 23

Disentangling the various factors affecting health-seeking behaviour is not a straightforward matter. However, it is possible that some low-income individuals avoid (or do not prioritise) non-urgent treatment following a calculation of upfront cost versus potential long-term benefits. Although healthcare is free to most people in the UK 24, and associated expenditure (transport, phone calls and prescription charges, for example) comparatively low, cost is relative to income and should not be disregarded as a factor. 25 It is also true that people who experience poverty may have ‘chaotic lifestyles’, due to the demands of living on a low income and negotiating with various service providers and authorities, such as benefit agencies. 26 Caring responsibilities are often an additional factor for women on top of other commitments.

The majority of working people take time off to see a doctor – In a recent survey by the Patients’ Association, more than 3 in 4 respondents reported having to do this, and for more than half (58%), this amounted to a full day or more. 27 Having to request (potentially unpaid) time off can be a problem for anyone, but perhaps especially for lower income individuals in

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19 These categories are taken from WHEC, 2013, Better Health for Women op.cit.
22 M. Marmot, 2010, op. cit.
24 Excluding certain categories of migrant, and UK nationals living abroad
precarious employment situations. A Canadian study of low-income migrant women found a link between this type of work, and delays in seeking healthcare. The same was true of self-employed women without access to paid sick-leave.28

Goddard and Smith (2001) found that, although economically disadvantaged people were more likely to consult their GP about certain problems they were less likely to be referred to specialist treatment.29 It is possible that poorer patients are unable to make as effective use of services as their wealthier peers. The same meta-study found that middle-class individuals generally spend more time with their doctor, asking more questions and getting more information.30 Other studies have found a positive relationship between gender, age and class, and the quality of communication between patient and healthcare provider. 31

1.4.2 Women’s caring roles

There are around 6 million carers (for a child or adult, who may be sick or disabled) in the UK. 60% are women32. Women’s socially constructed gender role is more likely to include expectations of the roles and responsibilities associated with unpaid work such as housework and caring,33 and within families, caring responsibilities are more likely to fall on the partner who has less earning potential outside of the home.34

Although the caring role can be personally rewarding, it is also associated with a range of issues relating to health, such as poverty, isolation and discrimination, as well as physical problems like high blood pressure (associated with stress) and musculoskeletal conditions (associated with heavy lifting).35 According to research from the OECD, carers are about 20% more likely than non-carers to have mental health problems and female carers are more likely than men to be at risk of poverty as a result of their role.36

The government recognises in relation to its Carers Strategy that ‘carers often neglect their own health and need advice to maintain their wellbeing’, and that carers often lack both time and social support.37 The informal nature of their work can mean that they are effectively ‘on call’ at all times, unable to take time off in order to access healthcare. This is well illustrated by the following quote:

28 J.E Angus et al, 2012, op. cit. (Canadian healthcare is free at the point of use, much like the UK NHS)


30 ibid.


33 S. Payne, 2009, op. cit.


37 HM Government, 2010, Recognised, valued and supported, op.cit
“I am supposed to be having my cataracts done but I just can’t because who will care for Mum?”

The unpredictability of the demands associated with care work can also make it difficult to arrange a suitable GP appointment ahead of time.

Many carers are eligible for special assistance, such as Carer’s Allowance, respite services and yearly health checks and vaccinations. They also have a legal right to a needs assessment by social services, and GPs are often the entry point to all of the above. However, many do not identify with the label of ‘carer’, and therefore do not seek or receive any support. This may be especially likely to affect women whose gender-role involves caring as a societal expectation.

“I’m not recognised as a carer. In China you wouldn’t say I’m a carer, you automatically care ‘because you should’ … It’s the Chinese family way, our culture.”

For similar reasons as those described in relation to caring, mothers may neglect their own health, potentially having to juggle health appointments for themselves and their children with work and childcare or school hours. Single parents, over 90% of whom are women, are more likely to be low earners and be affected by welfare cuts, and research suggests that single mothers have ‘poorer functional health than women living as part of nuclear families’, possibly because they often have full or main responsibility for childcare whilst not being supported financially by a full-time earner.

1.4.3 Gender-based violence

According to the National Institute for Health and Care Excellence (NICE), at least 1.2 million women and 784,000 men between 16 to 59 years of age in England and Wales experienced domestic abuse in 2010/2011. This is 7.4% of women and 4.8% of men. At least 29.9% of women and 17.0% of men in England and Wales have experienced it at some point in their lives, though the real figures are likely to be higher due to under-reporting of this kind of crime. Although some sufferers are male, severe and repeated episodes and sexual violence are much more likely to be perpetrated by men towards women. According to UK figures, around half of all female homicide victims are killed by a partner or ex-partner. This is also true of about 5% of men. Prevalence of domestic violence is greater among young women (under 24 years), and those who have a long-term illness of disability (including HIV), placing them at multiple disadvantage.

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38 ibid.
40 For example, short breaks can be prescribed to carers at risk of burnout.
42 ibid.
44 ibid.
46 NICE, 2014, op.cit.
47 ibid.
48 ibid.
The Government recognises gender-based violence as violence directed against a woman because of her gender, or because it affects women disproportionately. In addition to domestic violence, the definition encompasses different forms of violence against women and girls including FGM and so-called ‘honour based’ violence, in recognition of the fact that different forms of violence are manifestations of expressions of patriarchy and gender inequality. The risk is higher during pregnancy, at which time the violent partner often begins or escalates the abuse. It is common for women in this situation to experience feelings of shame, and to be strictly controlled by their partner, and these are some likely reasons why disclosure in the healthcare setting is rare. Another potential barrier to getting help is caused by economic dependence. Women are more likely than men to be reliant on a partner’s income, for reasons relating to lower earnings potential and the caring role. For a woman who lacks the means to support a family, disclosure of the abuse could mean homelessness. Gender-based violence is also associated with depression and anxiety.

1.5 Mental health as a neglected issue

This report considers both mental and physical aspects of health to be of equal importance in terms of care and treatment. This, however, is not necessarily the experience of sufferers. Recent research from The Centre for Economic Performance’s Mental Health Policy Group found that three quarters of an estimated 6,000,000 people with anxiety and depression go untreated, and that 65% of surveyed GPs stated that they were ‘rarely’ able to provide patients with specialist psychological therapies (such as cognitive behavioural therapy) within two months. There is no maximum waiting time for mental health treatment in the NHS Constitution, as the 18-week limit does not apply here.

In acknowledgement of these problems, the Department of Health has set out the following goals in order to attain ‘parity of esteem’ between mental and physical health:

‘Too often, access to services for people with mental health problems is more restricted and waiting times are longer than for other services, with no robust system of measurement in place even to quantify the scale of the problem. The Department of Health and NHS England are committed to ending this and believe that implementing new access and/or waiting time standards is vital in order to have true parity of esteem. We expect NHS England to work with the Department of Health and other stakeholders to develop a range of costed options in order to implement these

53 ibid.
54 ibid.
standards starting from April 2015, with a phased approach depending on affordability.\textsuperscript{57}

Women are about 40\% more likely than men to experience depression and 60\% more likely to suffer from an anxiety disorder, \textsuperscript{58} but despite this many never seek professional help. A 2010 survey by the women’s organisation Platform 51 found that 29\% of the young women respondents who had experienced mental health problems had refrained from seeking professional help. Reasons given included fear of being judged as over-emotional, expectations of not being taken seriously and not wanting to waste doctors’ time.\textsuperscript{59}

Whilst these concerns may reflect the way mental health problems affect health-seeking behaviour, for example causing sufferers to become introverted, they may also provide some insight into these young women’s experiences of the doctor-patient relationship, and their views of doctors as potentially judgemental and lacking in time and patience. According to the WHO, ‘Communication between health workers and women patients is extremely authoritarian in many countries, making a woman’s disclosure of psychological and emotional distress difficult, and often stigmatized.’ \textsuperscript{60} It may be a mistake to assume that such problems do not exist in the contemporary UK context.

1.5.1 Mental health and the factors underpinning women’s health disadvantages

Mental health problems sometimes overlap with the marginalising social factors described earlier. Recent research made links between indebtedness and poor mental health\textsuperscript{61}, and figures from the Royal College of Psychiatrists suggests that as many as half of all adults who have personal debt may be suffering from some form of mental health problem\textsuperscript{62}.

As has been discussed previously, unrelenting caring responsibilities are associated with both poverty and mental health problems in some circumstances. Gender-based violence is another known cause of depression and anxiety in women. Women are at higher risk of being abused by a partner, and for reasons relating to caring and earnings; they are also more likely than men to be reliant on their partner’s income. For women who experience gender based violence, financial and material dependence can be a barrier to seeking help.

1.6 Factor increasing women’s vulnerability

Many additional factors can increase women’s vulnerability and exacerbate health inequalities. This study considers five groups of women who experience comparatively poor

\textsuperscript{57}Department of Health, 2013, NHS Mandate, \textit{op. cit.}
\textsuperscript{58} D. Freeman & J. Freeman, \textit{The Stressed Sex – Uncovering the Truth About Men, Women and Mental Health}, OUP, Oxford, 2013
\textsuperscript{60} WHO, Gender and women’s mental health, http://www.who.int/mental_health/prevention/genderwomen/en/
\textsuperscript{62} Royal College of Psychiatrists, ‘Debt and Mental Health’ http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/debtandmentalhealth.aspx
health outcomes: BME women, refugees and women seeking asylum, women living with HIV, LGBT women, and women with learning disabilities.

1.6.1 BME women

The Race Equality Foundation reports that, although it is known that BME individuals face an increased risk of experiencing socio-economic deprivation which affects their health, this does not sufficiently explain disparities in health outcomes, and that the ‘direct and indirect experiences of racism in everyday life’ needs to be included as a factor. The healthcare system can exacerbate existing problems in various ways, for example through inaccessible services, unmet needs, poor communication, and negative service experiences. Such experiences are commonly reported by BME patients, and not confined only to recent migrants or those with limited command of the English language. One example relates to the Irish Traveller community, who report open prejudice and discrimination when attempting to access GP surgeries, often accessing healthcare only through A&E as a result.

Figures from the Department of Health indicate that patients from BME groups were more likely to report negative experiences of care, especially in the primary care setting, and especially relating to issues around ‘access and waiting’, and wanting ‘better information and more choice’. A series of focus groups by WHEC, Women Care and RED on the health experiences of women from a range of BME backgrounds found that an ‘overwhelming majority’ of women reported difficulties in getting an appointment with their GP when they needed one, and almost all women from Bangladeshi backgrounds said that this was true for them.

One problem for BME women relates to communication: A majority of the women in the aforementioned focus groups had encountered language and communication barriers, even when using interpreting services. Many had experienced difficulties accessing these services. Some had also been given wrong information, for example about test results, from interpreters. The common practice of using a family member (for example a child or husband) as a translator is problematic because it compromises confidentiality and places restrictions on the kind of issues that can be raised, in all likelihood excluding disclosure of gender-based violence or sexual health issues. Some linguistic communities are also relatively small and close-knit, which can compromise confidentiality if the interpreter knows the patient or her family personally.

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64 ibid.
68 ibid.
Language proficiency has been shown to be lower for women than men in migrant communities, and this is especially true for older generations, which means that older migrant women run a particularly high risk of experiencing language barriers when using healthcare. The Office for National Statistics (ONS), in the 2011 Census, found a strong link between English language proficiency and health. 88% of the population who had a mother tongue other than English, but who were ‘proficient’ in English reported ‘Good’ general health, whereas the same was only true for 65% of the population deemed as ‘Non-proficient’ in English.

Specialist services can mitigate some of the barriers that BME women face, providing a safe and appropriate space for BME women to disclose and access support for gender-based violence, access language support and to advocate for women. According to a report from the Department of Health’s Mental Health Policy Division, ‘there is clear evidence that an approach of working in partnership with BME communities and voluntary sector organisations leads to earlier and more effective interventions, and enables activity to support good mental health to be more effectively targeted at the most vulnerable groups’. Imkaan also reports that 87% of black and minority ethnic women would prefer to be supported a BME-specific women’s service if they were to seek help for issues around gender-based violence. However, nine out of ten local authorities do not provide specialist services to BME women, and those which currently exist are threatened by funding cuts.

One potential consequence of the lack of targeted support is that female genital mutilation (FGM) goes unnoticed and untreated. FGM, which is recognised as torture by the UN, is an act of violence against a girl or woman’s right to bodily integrity which can lead to death or disability and often causes complications and related health problems - both physical and mental. According to estimates from 2001, 66,000 women resident in England and Wales in 2001 had undergone FGM and over 23,000 under the age of 15, from African communities, were considered being at risk of, or potentially having undergone FGM. Research has shown that women and girls are unlikely to disclose FGM and related health problems outside of maternity services, and there is very limited understanding of the issue in the mainstream. Additionally, health services do not have consistent mechanisms for encouraging disclosure or referral, for example through routine enquiry. A lack of

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**References**


73 ibid.


75 ibid.

76 ibid.

77 ibid.


79 ibid.
understanding and knowledge on how to respond appropriately amongst health and social care professionals are also barriers to women who experience other forms of gender based violence, including forced marriage. At the same time, it is important for health professionals to recognise that women from BME backgrounds also experience more common forms of gender-based violence, such as domestic violence.

1.6.2 Refugees and women seeking asylum

Refugees and women seeking asylum may experience many of the same problems as other BME women, but they also face a number of unique barriers relating to their legal status, and to the complexities surrounding their entitlement to care.

No patient applying to register with a GP can be turned down on the basis of race, gender, social class, age, religion, sexual orientation, appearance, disability or medical condition.

Currently, GPs have discretion to register refused asylum seekers and undocumented migrants. GPs are not required to check the immigration status of patients joining their practice, and patients have no obligation to provide evidence to this effect. However, the situation is subject to change, as charging will soon be extended to the primary setting and to all non-EEA migrants applying for more than six months leave to enter the UK. Restricting access to free healthcare, even if some individuals and conditions are exempt, is also likely to become a deterrent for anyone who struggles to provide evidence of their entitlement, for example members of the Irish Traveler community, something which the government also acknowledges.

Hospital care, including maternity care, is subject to a different set of rules: women who have an ongoing asylum claim or an appeal pending are not chargeable anywhere in the UK. In England, refused asylum seekers are subject to charging, unless they are in receipt of Home Office support, but in the rest of the UK they are not. There are recent news reports of destitute women avoiding antenatal care and giving birth with no professional involvement due to the fear of owing thousands of pounds they have no way of paying back. However, there are no plans to exempt pregnant women from charges. There are also plans to extend charging to emergency treatment for some migrants. Although care will not be denied to those who cannot pay, the prospect of incurring a debt will be a deterrent.

According to the British Medical Association ‘there exists a degree of uncertainty amongst some health professionals regarding the entitlements in place for asylum seekers and

80 Imkaan, 2011, The road to sustainability, op.cit.
83 The Immigration Bill, 2013-14, Chapter 2, Clauses 33 and 34.
refused asylum seekers and their responsibilities with respect to treating and referring these groups\textsuperscript{86}, and this is reflected in the fact that women in this group often have trouble registering with a GP.\textsuperscript{87} Refugees and people seeking asylum may also lack information about the UK system and their rights within it\textsuperscript{88}, and these issues are also likely to be exacerbated when new charges are introduced.

Another important barrier for this group relates to documentation. Evidence to the Joint Committee on Human Rights from 2007 from the support organisation Project: London revealed that asylum seekers are unable to access healthcare due to demands for very specific forms of official documentation, such as passports, utility bills, bank statements or rental agreement as proof of address. Due to unstable living arrangements, no access to bank accounts, and their passports being retained by the Home Office, asylum seekers are very unlikely to possess any of this.\textsuperscript{89}

Project: London also reported that because there is no legal requirement to provide identification or proof of residency when registering with a GP, there is some scope for them and other organisations to influence the process through negotiation and advocacy.\textsuperscript{90} Nevertheless, the many individuals who do not have access to such support still have to negotiate barriers relating to language and communication, lack of information, and lack of documentation.

Asylum seekers and refugees have often experienced trauma, such as torture or rape, in their country of origin and are at increased risk of mental health problems\textsuperscript{91}. Rape and sexual violence against civilian women in conflict zones is identified as the most common cause of Post-Traumatic Stress Disorder (PTSD).\textsuperscript{92} Survivors may also suffer stigmatisation after the event\textsuperscript{93} – According to the US National Centre for PTSD, some women feel such a strong responsibility to protect their family from this stigma that they remain silent about the trauma.\textsuperscript{94} This makes it extraordinarily difficult for these women to seek help, especially as PTSD is also associated with avoidance behaviour.\textsuperscript{95} Women also run a higher risk of being subjected to coercion, entrapment and sexual exploitation once in the asylum system\textsuperscript{96}, and barriers to a good doctor-patient relationship, such as a lack of trust, or communication problems are also barriers to getting out of such a situation.

\textsuperscript{86} BMA, 2012. Access to healthcare for asylum seekers and refused asylum seekers, op.cit.
\textsuperscript{88} BMA, 2012, Access to healthcare for asylum seekers and refused asylum seekers, op.cit.
\textsuperscript{90} ibid.
\textsuperscript{92} US Department of Veterans Affairs, National Centre for PTSD, ‘Rape of Civilian Women in a War Zone’, available at http://www.ptsd.va.gov/professional/trauma/war/rape_of_civilian_women_in_a_war_zone.asp
\textsuperscript{93} ibid. See also T. Sideris, 2003, ‘War, gender and culture: Mozambican women refugees’, Social Science & Medicine, Vol. 56, Issue 4, 713–724
\textsuperscript{94} US Department of Veterans Affairs, op. cit.
\textsuperscript{95} US Department of Veterans Affairs, National Centre for PTSD, Symptoms of PTSD, Available at http://www.ptsd.va.gov/public/PTSD-overview/basics/symptoms_of_ptsd.asp
Pregnant asylum seekers and refugees have some of the worst pregnancy outcomes in the UK and are often ‘late bookers’ with maternity services. Although NICE recognises them as a group experiencing ‘complex social factors’, warranting special care provisions, pregnant women, like other asylum seekers, are subject to routine dispersal, which entails being moved suddenly to a different area, often away from partners and any existing social support networks. Apart from expensive duplication of effort, such as re-taking blood tests to ensure they are correct, it also causes problems relating to signing up with a new GP and maternity service with each move, and potential loss of information about sensitive issues. Issues like mental health and domestic violence are not stored in handheld notes and women may not be prepared to disclose such information several times, to a person with whom no prior relationship exists. A ‘protected period’ of four weeks either side of delivery exist in the government’s official guidelines, although the same guidelines contradict themselves by also recognising the importance of six weeks postnatal care, and mentioning the fact that women seeking asylum may give birth earlier than estimated by UK standards.

Asylum seekers and refugees are some of the most socially excluded people in the UK. Home Office support is subject to a destitution requirement and paid at a rate below that of state benefits such as Income Support. As has been discussed earlier, poverty and economic disadvantage are associated with worse health and less participation in public health programmes. Cost is also a barrier to treatment if money for prescriptions is not available.

1.6.3 Women living with HIV

Thanks to modern drug regimes, people living with HIV can have normal lives and women can give birth to healthy children with the help of antiretroviral therapy. Despite medical advancements, however, HIV is still surrounded by stigma and ignorance, and people living with the condition often report a lack of trust in GPs, and a low uptake of mainstream primary care services. Women’s physiology makes them more susceptible to HIV infection. Women from conflict areas are also at increased risk if they have been subjected to systematic sexual violence, as are women who are involved in prostitution, or engaging in transactional relationships in which they may have little control over the use of protection.

100 ibid.
101 R.Feldman, 2013, op.cit, p: 64
A survey of people in East London living with HIV, showed that nearly one third of all respondents had experienced discrimination because of their health condition, and almost half of these instances involved a GP, dentist or other health care professional.\textsuperscript{105} This is against the law under the discrimination under the Equality Act 2010 which incorporates the Disability Discrimination Act (2005) and includes people with HIV.

GP practices usually require new patients to fill in a form stating their existing health problems, sometimes asking specifically about HIV. As mentioned previously, all people in the UK have the right to register with a GP regardless of race, gender, social class, age, religion, pregnancy or maternity, sexual orientation, appearance, disability or medical condition. Nevertheless, there are reports of patients being excluded from GP practices after disclosing their condition.\textsuperscript{106}

Perhaps justifiably then, some people choose not to disclose, which can compromise the quality of care – knowing about existing diagnoses and medications is important for doctors in order to treat patients safely and effectively. Even when patients do disclose, Positively UK reports that GPs do not have much knowledge on HIV drugs and possible interactions\textsuperscript{107}, and there is anecdotal evidence that women who attend mainstream services often have their unrelated health complaints attributed to HIV/AIDS, or medications\textsuperscript{108} and the needs they have in other areas of their lives may be overlooked.

For these reasons, HIV clinics often end up providing primary care to patients who are reluctant to attend mainstream primary care services. However these clinics may not be fully equipped to provide general healthcare.

Another barrier for this group relates to confidentiality. In 2012-2013 85% of respondents to the GP Patient Survey said that other patients can overhear what they say to their GP’s receptionist. Whilst 57 % did not feel that this was a problem, 25 % were not happy about it.\textsuperscript{109} Patients with stigmatised conditions such as HIV are likely to feel more strongly than others about this, as many have not disclosed the condition even to their families. A study carried out in East London showed this to be especially true of African heterosexual women and men, who reported high levels of HIV-related stigma, and were less likely to have told friends, family and partners.\textsuperscript{110}

Stigmatisation is a barrier in itself, especially if it deters people from seeking help. It is also associated with high levels of stress and anxiety, which can contribute to poor mental health. Research indicates that people living with HIV have a higher prevalence of mental health problems than the general population.\textsuperscript{111} As we have seen, women are already more likely than men to develop anxiety and depression, and women with HIV are therefore at an exceptionally high risk.

\textsuperscript{106} A. Namiba & A. Anderson, 2010, \textit{op. cit.}
\textsuperscript{107} \textit{ibid.}
\textsuperscript{110} J. Elford, 2009, \textit{op. cit.}
\textsuperscript{111} A. Namiba & A. Anderson, 2010, \textit{op. cit.}
Gay men (and men who have sex with men) are the largest group of HIV positive people in the UK and African women are the second largest. Both of these groups may experience multiple disadvantages associated with sexual orientation, gender, race and socio-economic status as well as ‘HIV-phobia’ when accessing mainstream services. A 2008 UK study of HIV positive BME people linked race and HIV status with poverty, indicating that 40% of Black African heterosexual men and women with HIV were experiencing severe economic hardship, and that this group ‘consistently reported more difficulties in relation to employment, income and housing’. The nature of this relationship is not entirely clear, but the research suggests that HIV affects economic activity and causes individuals to become lost from the labour force, placing this group at higher risk of poverty. There are also additional overlaps with other potential disadvantages relating to ethnicity, language and migration status, which have been discussed in previous sections of this report.

Recent international research suggests an increased risk of gender-based violence for women living with HIV both as a ‘cause’ and ‘consequence’ of having the condition. As we have seen, gender-based violence often begins or worsens during pregnancy, which is a crucial time for a mother with HIV to receive antiretroviral treatment, advice and support for the benefit of herself and the unborn baby. Violence can cause women to retreat from health services due to stigma, fear and economic dependence.

### 1.6.4 LGBT women

The NHS constitution states:

> ‘You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.’

Research from the national charity Stonewall does however indicate that lesbian, gay and bisexual people experience discrimination from health services. Lesbian women are twice as likely as gay men to expect poor treatment from local services, and figures from a 2007-08 report indicated that half of lesbian and bisexual women did indeed have negative experiences with healthcare in that period. Recent research of 253 women found that whilst 64% of gay men had positive experiences of coming out to their GP, the figure was 20% lower for lesbian and bisexual women. Stonewall also reports that seven out of ten

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112 ibid.
113 J. Elford, 2009, op. cit.
119 L. River, Director of Age of Diversity and an Ambassador for Opening Doors London, Presenting research at the National LGB&T Partnership Lesbian and Bisexual Women’s Event – London 2012
lesbian and bisexual women got inappropriate comments from healthcare workers when they told them about their sexual orientation.\textsuperscript{120}

The risk of encountering homophobic or prejudiced attitudes, which according to these figures appears to be considerable, can affect health-seeking behaviour and lead to avoidance of sexual health services and other healthcare. A report from 2008 found that sexually active respondents who had not disclosed their LGBT identity to their GP were less likely to have ever had a sexual health check, especially women, who often believed that they did not need it.\textsuperscript{121} 29\% of gay men in this survey had accessed sexual health services in the last six months, whereas this was only true of 8\% of lesbian women.\textsuperscript{122} 64.1\% of transgender respondents to a different survey had never visited a sexual health clinic, which is especially problematic as an international study of transgender women showed them to be 49 times more likely to have HIV, compared to a reference group.\textsuperscript{123}

Research, health promotion and targeted services for LGBT women’s health are sparse compared with what exists for gay men.\textsuperscript{124} Many LGBT women also view mainstream services as heterosexist, homophobic and discriminatory. There appears to be a lack of knowledge and information about sexual health needs, on both sides. For example some lesbian and bisexual women do not think they need cervical screening, sometimes having been told this by health professionals.\textsuperscript{125} This goes against official NHS advice which states that Human papilloma virus (HPV) can be transmitted during sex between women, and that screening should be offered.\textsuperscript{126} With regards to maternity and fertility for female same-sex couples, health professionals may have very little previous experience. NICE has only recently outlined the entitlements of same-sex partners in official guidelines.\textsuperscript{127}

Lesbian women run a higher risk of developing eating disorders, and self-harming. An American study links this to the pressures of concealing sexual identity, the threat of hate crime, discrimination and stigmatisation. Lesbian and bisexual women also have higher rates of smoking, alcohol use and recreational drug use than the general population.\textsuperscript{128} Bisexual women have been found to be at especially high risk of mental health problems and

\begin{flushright}
\textsuperscript{120} R. Hunt & J Fish, 2008, \textit{op. cit.}
\textsuperscript{121} K. Browne & J. Lim, 2008, \textit{Count Me In Too – LGBT Lives in Brighton and Hove}, Additional findings report, available at \url{www.countmeintoo.co.uk}
\textsuperscript{122} ibid.
\textsuperscript{123} S. Keeble, 2013, \textit{Transgender Sexual Health in Birmingham: Needs assessment}, Birmingham LGBT
\textsuperscript{124} ibid.
\textsuperscript{126} L. River, 2011, \textit{Appropriate Treatment – Older lesbian, gay and bisexual people’s experience of general practice}, Age of Diversity and Polari, available at \url{http://www.ageofdiversity.org.uk/sites/default/files/AppropriateTreatment.pdf}
\textsuperscript{128} Since 2013, NICE Clinical Guideline 156, ‘Fertility Assessment and treatment for people with fertility problems’, paragraph 1.9.1 recommends physicians to consider intrauterine insemination for people in same-sex relationships.
\end{flushright}
suicidal ideation, both according to international and UK figures. As we have seen, many women feel vulnerable when asking for help with mental health, and this could be an even bigger problem if there is also an expectation of discrimination or homophobic treatment.

Lastly, there are few targeted services available for lesbian, bisexual or transgender women experiencing intimate partner abuse. Research from the United States indicates that transgender women are especially vulnerable to sexual exploitation and abuse.

1.6.5 Women with learning disabilities

"Promoting equality and equity are at the heart of NHS England’s values – ensuring that the organisation exercises fairness in all that it does and that no community or group is left behind in the improvements that will be made to health outcomes across the country.” (NHS England)

The Royal College of GPs points out that several formal enquiries in the UK have found that people with learning disabilities have comparatively worse health outcomes than the general population, yet they are less likely to access healthcare. Research indicates that the quality of service for women with learning disabilities is highly dependent on the personal attitudes of health professionals. For example, prejudiced attitudes about disabled women’s lives (i.e. the belief that they do not have intimate relationships) can lead some health professionals to overlook the need for cervical screening, family planning and sexual health.

All women between 20 and 64 years of age should be called for cervical screening by the NHS, but research shows that women with learning disabilities are less likely to take part in cervical screening programmes. One study found that women in this group were 45% less likely to do so in 2008-2009.

According to CHANGE, mainstream sexual health services are not well resourced to support young people with learning disabilities, and generally lack of accessible-format information.
material, for example using easy-read formats supported by pictures.\textsuperscript{139} Sex education can also help to define boundaries in personal relationships, something which could be especially important for women with learning disabilities, who face a much higher risk of violence and sexual abuse than other women.\textsuperscript{140}

Women with learning disabilities have historically been deprived of their mothering role and their right to a family life. A case study by CHANGE suggests that this still persists to some extent and that women may not be getting the information needed to make informed choices about abortion.\textsuperscript{141} The Royal College of Midwives reports that ‘disabled women have identified insensitivity and poor understanding of the nature of their disability in relation to pregnancy as key factors in their maternity care’.\textsuperscript{142}

As has been discussed previously, mental illness is more common in women, and tends to be under-diagnosed. People with learning disabilities have a higher incidence of mental health problems compared to the general population, and early symptoms are often misattributed by doctors as relating to the disability.\textsuperscript{143} This means that women in this group are both at higher risk, and may experience more barriers to treatment.

Apart from the aforementioned problems with inaccessible written information, patients with learning disabilities may also experience verbal communication barriers. They may have trouble describing their symptoms, and health professionals may be using clinical jargon which is difficult to understand.

Many people with learning disabilities also have physical disabilities and may not be able to drive or use public transport. This affects how flexible they can be when booking an appointment, as they may have to ensure the availability of a support worker or transport service. Building access is also a potential barrier for wheelchair users, as Care Quality Commission (CQC) inspections found in 2013 – 24% of GP premises were deemed unsafe or unsuitable for reasons which included the absence of disabled access.\textsuperscript{144}

\textsuperscript{140} WHEC, 2013, \textit{Better Health for Women}, op. cit.
\textsuperscript{143} M. Hoghton, 2010, \textsc{op.cit.}
Part 2 - The study

This study focuses on women’s use of GP services. GPs are the gatekeepers to health services in the UK – hospital care and specialist services are accessed through referral, and about 90% of all contact a patient has with the NHS is in the primary care setting\(^\text{145}\). GPs and other primary healthcare professionals support patients and families through life changing events such as pregnancy and long-term illness, and can be the first point of contact for someone experiencing emotional distress, or violence in the home. GPs can also refer to social services and signpost specialist third sector support, as well as sometimes being required to support applications for welfare benefits.\(^\text{146}\) This places them in a very powerful and important position in their patients’ lives.

2.1 Methods

The study was in two parts. The first part took the form of an anonymous online survey, which was promoted to UK women using social media and on web forums and blogs. The only criterion for participation was that respondents identify as female (including transgender women). Questions centred on processes like registration and appointments systems, as well as on themes identified in the literature review, such as communication and caring responsibilities.\(^\text{147}\) The main objective was to gather anecdotal evidence about the general barriers to healthcare that women in the UK face, regardless of social or ethnic group.

For the second part of the study, a series of focus groups were held, for five groups of women with comparatively poor health outcomes: BME women, refugee and asylum seeking women, women with HIV, LGBT women, and women with learning disabilities. The groups were hosted and facilitated in Leeds, Manchester and London by Maternity Action, The Foundation for Women's Health Research and Development (FORWARD), Imkaan, Women Asylum Seekers Together (WAST) Manchester, Positively UK, The East London Out Project (ELOP) and CHANGE. Organisations recruited the focus groups participants from within their service user networks. The groups were given open-ended discussion items around the same themes as the survey questions\(^\text{148}\). Some groups were also asked about any additional relevant issues drawn from the literature – for example, the women with HIV were asked about using their HIV clinic. Focus groups were recorded with the participants’ consent, and recordings were deleted after the research was finalised. All responses were anonymised.

\(^\text{145}\) The Patients Association, 2012, Primary Care Patients and GPs - Partners in Care? Available at http://patients-association.com/Portals/0/Public/Files/Research\%20Publications/Patients\%20and\%20GP's\%20-%20Partners\%20in\%20Care.pdf


\(^\text{147}\) See Appendix A – Survey questions

\(^\text{148}\) See Appendix B – Focus group questions/discussion items
### 2.2 Findings from the survey

#### 2.2.1 About the respondents

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*Total respondents: 261

**Question:** What is your age?

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<th>Survey respondents</th>
<th>UK 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>215</td>
<td>82%</td>
</tr>
<tr>
<td>BME</td>
<td>23</td>
<td>9%</td>
</tr>
<tr>
<td>White Other</td>
<td>23</td>
<td>9%</td>
</tr>
</tbody>
</table>

*Total respondents: 261

**Question:** What is your ethnicity?

<table>
<thead>
<tr>
<th>Highest educational attainment</th>
<th>Survey respondents</th>
<th>UK 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Degree level or above</td>
<td>203</td>
<td>78%</td>
</tr>
<tr>
<td>A-Level or below</td>
<td>56</td>
<td>22%</td>
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</table>

*Total respondents: 259

**Question:** What is the highest level of education that you have completed?

<table>
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<tr>
<th>Household Income</th>
<th>Survey respondents</th>
<th>UK 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than £15,000</td>
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<td>9%</td>
</tr>
<tr>
<td>£15,000 - £19,999</td>
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<td>8%</td>
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<td>£20,000 - £29,999</td>
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<td>22</td>
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<td>£70,000 - £99,999</td>
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<td>11%</td>
</tr>
<tr>
<td>£100,000 and above</td>
<td>19</td>
<td>8%</td>
</tr>
</tbody>
</table>

*Total respondents: 233

**Question:** What is your approximate annual household income?

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149 ONS, 2011, UK Census
150 ibid.
151 ibid.
The survey cohort was younger than the general population, with women over 61, (the most numerous group in the UK) the least represented. It is possible that the online format and promotion had the effect of reaching fewer women in this particular age bracket. With regards to ethnicity, BME women were under-represented. Educational attainment was vastly higher than UK estimates, and reported household incomes were also higher. Issues faced by socio-economic groups who were under-represented in the cohort may therefore appear less prominent here than they are in the general population.

2.2.2 Barriers to registration

Process of registration
Registration was not one of the more important barriers identified by our cohort. However, some respondents described some very time-consuming and complex processes:

“It was a real pain. I had to physically go there to pick up the papers and later on drop them off, only during office hours. This meant I had to take time off from work. When I later on got ill, they told me they only register people when they have an appointment. So I had to fill in everything again.”

“You may only register at the health centre at certain hours in the morning, week days, or for one hour on a Friday afternoon. I had to provide photo ID and a recent utility bill. I went to register at the wrong time and faced a huge telling off by the receptionist who then decided she’d try and register me anyway but kept looking over her shoulder worried someone might see and tell her off. I had to fill in four forms which I downloaded from their website and then had to print off. It was not an easy process.”

It was also clear from our responses that some GP practices require a health check, or urine samples and blood pressure readings before allowing new patients to make a doctor’s appointment, necessitating multiple appointments for each family member.

Choice when registering
Choice has been a buzzword in discussions about mixed market commissioning which allows third sector and private organisations to compete for contracts, as set out in the Health and Social Care Act 2012. The Department of Health states: ‘Patients tell us they want more choice and control over their health and care; it’s something they increasingly expect from a modernised NHS.’ As some respondents pointed out however, patient choice regarding GP practices is limited, because it is tied to location. Many smaller areas are only served by one practice or health centre, giving residents no choice at all. Lack of alternatives can be particularly problematic when there is some form of conflict. According to the Patient’s Association, patients who have made formal complaints are disproportionately represented among those who have been subject to removal from GP lists. The General Practitioners Committee, while it states that ‘normally the sole criterion for removal should be an irretrievable breakdown of all or part of the patient-practice

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relationship, usually that between patient and doctor\textsuperscript{155} it nevertheless ‘neither supports nor condones the removal of patients solely because they have made a complaint’. The rationale for this is that sometimes a complaint is sufficient to cause the relationship to break down, and GPs may also consider some complaints to be unfounded.

Sometimes, the expectation is that the patient moves to a different GP of their own accord. One of our respondents recalled:

“I filed a complaint once and was asked if I wanted to go to another GP. I said no, I did not. I had done nothing wrong but the doctors had. Therefore since trust had been lost by them it was up to them to forge new and better trusting relationships with me.”\textsuperscript{156}

Whilst it may in some cases be in the best interests of both parties that the patient gets a new doctor, patients in smaller areas may have no choice but to stay with a GP they are not happy with, and may refrain from raising concerns.

\subsection*{2.2.3 Getting an appointment}

Approximately 40\% of our respondents found it ‘very easy’ or ‘relatively easy’ to get an appointment. About an equal proportion found it ‘very hard’ or ‘relatively hard’, and the last 20\% found the situation ‘acceptable’.

A large number of responses focused on the need for more flexible opening times, and many respondents described very restrictive appointment systems:

“The surgery offers two types of appointments: Normal appointments - You have to wait typically 4 or 5 weeks for an appointment but can usually get one at a convenient time. [The second type is] Emergency same-day appointments - This is the only other option if you need to see a doctor sooner than in 4 or 5 weeks time but you have to just phone up at 8 am and can be allocated any time slot that day which can be really difficult to arrange with work - especially as I’d been giving work absolutely no notice of having to take time off”\textsuperscript{157}

“Because my GP practice rarely gives appointments the prospect of going to one of their ‘drop-in sessions’ and waiting an indefinite amount of time is not a good one. It is very hard to tell my work that I will need a morning off to see the doctors but being unable to be more specific about appointment times with them because I am unable to get one.”\textsuperscript{158}

The 48-hour maximum waiting time to see a GP was scrapped in 2010, and although the 18-week maximum wait to start specialist treatment after GP referral, (2 weeks where cancer is suspected) is still operational, it becomes compromised when patients are waiting several weeks for that initial referral. Further, the fact that primary care services fail to


\textsuperscript{156} In response to the question: ‘Is there anything else you want to add, on the subject of communicating with doctors?’

\textsuperscript{157} In response to the question: Are there any other costs (money, time or anything else) that influence whether or not you make an appointment when you need one?

\textsuperscript{158} In response to the question: ‘What would make it easier for you to get an appointment with your GP?’
accommodate working people is clear. Lastly, conceptualising same-day appointments as ‘emergency’ or ‘urgent’ may be a barrier to the timely treatment of relatively minor and commonly occurring ailments which could then become more serious, difficult and costly to treat. As one woman remarked:

“...I only go if I feel in pain. I left a cystitis problem and tried to manage it myself and now have a [more serious] urinary tract infection.”

Reception staff
Many respondents viewed reception staff as gatekeepers whom they had to ‘get past’. Patients are often required to state the reason for the appointment to the receptionist, something which respondents both in the general survey and the focus groups thought was inappropriate, and which may become a deterrent. One woman conceptualised the problem as an emotional ‘cost’ associated with seeing a GP:

“Just the sheer difficulty of making an appointment and dealing with the reception staff.”

Reception staff also came up in response to the question: What, if anything, would make it easier for you to get an appointment with your GP?

“The receptionists being less stroppy and making you jump through hoops to see a doctor – I should not have to explain in detail why I feel I need to see a doctor to admin staff...”

“When you get through, you are told there are no appointments available unless you argue your case therefore you are required to tell the receptionist why you want too see the GP otherwise you are unable to see the GP.”

Perceptions of reception staff may be a reflection of inefficient systems and processes which are frustrating for both patients and staff. Indeed, many respondents described them in terms such as ‘long-suffering’, ‘overworked’ and ‘overwhelmed’.

Incompatibility with work
Many women said that they live and work in different areas, with some distance in between. Many also said that their GP requires them to call around 8.30, when they are meant to be travelling to work or taking children to school, but that even if they take time out of their morning schedule to call, all appointments may be gone by the time they get through.

58% of working women in the survey responded that they ‘usually have to take time off in order to see a GP. Just over half (51%) of those who were in paid work stated that this is a factor that influences their decision about whether to make a health appointment when they need one, and another 34% of them stated ‘maybe’, or ‘sometimes’ the prospect of having to take time off will be a factor.

“I work on a freelance basis on half or full day fee. A doctor’s appointment often means cancelling or not accepting work and losing money. If I am unable to get an

159 In response to the question: ‘Are there any other costs (money, time or anything else) that influence whether or not you make an appointment when you need one?’
appointment that fits my timetable I can’t afford to lose the money so I cancel and hope the situation improves/ a suitable appointment time becomes available”

“60 mile round-trip if the appointment is in the middle of the day, would need about 3 hours out of work - as a teacher this is not feasible”

“I get allowed an hour free from work to take doctor’s appointments - but I don’t drive and there’s no way I can get to the doctors on the bus, have a 10 minute appointment (which is probably running late anyway) and then get back to work again on the bus in that time! Just doesn’t seem worth it unless I believe I’m seriously ill.”

“...If I go to the GP, I have to go for a blood test afterwards, then see the GP again and that’s 3 separate times off work. I work an hour’s journey from my GP surgery so for a 10 minute visit I’ve got to take half the day off. I can’t do that 3 times in two weeks, for example.”

Inflexible appointment systems and opening times are access barriers for working people, many of whom are unable to take time off without prior notice. The problem of accessing healthcare for working people has recently been recognised by the Government, and longer opening hours put forth as a potential solution to these issues.160

2.2.4 Caring for children

The majority of mothers (73%) stated that they usually have to take their child with them when they have a health appointment. The nature of the appointment system makes it difficult to arrange childcare. Having children present is likely to become a barrier to discussing certain issues, for example relating to mental health, sexual health or violence in the home.

Problems with getting appointments for children were mainly regarding surgery hours interfering with school, work and caring responsibilities for other children, such as school drop-off times.

Responses to the question ‘What would make it easier for you to get an appointment?’ Included:

“[...] the wait for non urgent appointments is 2-3 weeks. [Otherwise] patients are required to turn up in person at the GP surgery at 8am to book an urgent appointment which will be at any time during the day requiring 2 trips - this is completely inhumane as a mother coping with ill children”

“Not having to telephone them at 8.30am which is when I am taking five young children to school. Totally discriminating against what is usually mums.”

2.2.5 Barriers faced by carers

22% of the women in our survey said that they regularly support or care for a person with a long-term illness or disability, in a personal rather than professional capacity (either practical or emotional support). 32% of them found it either ‘relatively difficult’ (23%) or ‘very difficult’ (9%) to get an appointment for the person they care for, whereas 25% found it either ‘very easy’ (12%) or ‘relatively easy’ (12%). 18% thought the situation was ‘acceptable’ and 12% did not know, or were not responsible for this part of the care. As one person commented, carers need to juggle their own availability with the needs and preference of the person:

“[It is] easy to get an appointment, but difficult to get one I can accompany her to.”

One woman’s father had suffered a recent stroke and had mobility problems, and she described the time and effort required to help him to and from appointments. Many GP practices are reluctant to offer home visits to disabled patients, partly because it takes longer than a practice visit and uses up more GP time. This can be a physical barrier for people with disabilities, and adds to the workload of unpaid carers.

In our survey, only a small minority (6%) of the women who regularly supported someone with a long-term illness or disability (regardless of whether they identified with the label of ‘carer’ or not), said that their GP had discussed their caring responsibilities with them. Only 33.9% of the women with responsibilities for someone with a long-term illness or disability considered themselves to be carers. Not identifying as a carer (perhaps thinking that the relationship should not be formalised, that is it ‘only natural’, or viewing only personal care as ‘caring’) can be a barrier to getting the extra support recommended by The Department of Health.

Many long-term conditions are degenerative. Regular monitoring helps ensure the right level of support, helping carers to cope with an increasing workload. For many people with disabilities and their carers, the GP may be the only source of information about social care services and entitlements. Barriers to GP access can therefore have knock-on effects on social support, and by extension, quality of life.

2.2.6 Doctor/patient relationship

Communication
The Patients Association reports that 26% of calls to the its dedicated advice line relate to issues around communication in Primary Care, and that only six out of ten patients feel they are treated with compassion by their doctor.161

Most of the women (82%) in our cohort said that they ‘are generally are able to explain their symptoms and concerns when they see a GP’. 67% ‘usually feel that GPs understands what the problem is’. 62% stated that GPs usually explain medications, treatments and referrals to them, and 71% were able to ask questions during the consultation. It is possible that the high level of education in our cohort may have affected this result.

For the respondents who did not feel able to ask questions, the main issue was the time restriction. One woman wrote that her GP sets a timer to ten minutes, which causes her to become stressed and forget what she wanted to ask. The 'one problem per appointment' rule was also mentioned by many. Both of these aspects of communication can be barriers to talking about more complex issues, like domestic violence or stress. As one woman commented:

“5 minutes isn’t enough to speak about something emotional.”

Seeing a female doctor
Most women will need to see health professionals about their sexual and reproductive health across their lifetimes, not least in connection with contraception, fertility, pregnancy and menopause.

Some research indicates that seeing a female doctor is ‘essential for women’s ability to feel in control’ during internal examinations and that ‘women’s willingness to access such services is mediated by psychosocial factors such as embarrassment’. Not being able to request a female GP could therefore become a barrier to accessing sexual and reproductive healthcare for some women. The NHS constitution states that patients have the right to express a preference for a female doctor, and the practice should try to meet this demand.

In our survey, the majority (88%) responded either that ‘it matters to them’ which doctor they see (44%), or it ‘matters sometimes / in certain situations’ (also 44%). For many this translated to a preference for a female health professional. 62 % stated that they find it easier to discuss reproductive health, contraception and sexual health with a woman health professional and for some this extended to any physical examination:

“I generally want to see a female GP for anything where I will have to undress. Definitely for gynaecological issues.”

“Smears or internal examination. Men have no idea of how it feels for a woman.”

Others gave different reasons, seemingly relating to gender- and power dynamics:

“Prefer to see a female doctor as generally I find that male doctors are less sympathetic to female patients.”

“If I see my GP I find that he does not want to talk to the women about things and does not take it seriously. If my other half is there, then he directs all the talking to him and not me. Really bad.”

“There are some male doctors who patronise me.”

One woman wrote, in response to a different question: “There are some GPs that are respectful and some that just love power and treat women like naughty children.”

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164 In response to the question: ‘Is there anything else you want to add, on the subject of communicating with doctors?’
One of our respondents described a different aspect of the issue. She had been seen three times for the same gynaecological problem, but was only examined the third time, when she was seen by a woman. The last doctor was astonished to find that her two male colleagues had prescribed treatment without making any kind of examination.

Our responses indicate that not being able to request a female GP can be a deterrent for some women. Regardless of whether reservations reside with the patient or the doctor, the outcome could be a lower standard of care, if a necessary examination is not made. However, whilst 66% of our respondents stated they can choose a particular GP when they book the appointment, 20% said they cannot do this, and 14% did not know whether or not their practice allows it.

2.2.7 Barriers faced by lesbian and bisexual women

Many lesbian and bisexual women expressed frustration with what they felt was an ever-present presumption of heterosexuality in health services, often leading to ‘awkward’ situations, for example with regards to contraception advice

“[It is] awkward. They normally ask what contraception I use, without asking if I need any. I then have to answer that I have sex with a woman...”

“[It is] awkward as I’m with a female partner. "Do you have sex?" "Yes" "What contraception do you use?" "None" "Are you trying to get pregnant?" "No" "I think you should look into contraception methods" etc, etc, etc, etc”

“I feel uncomfortable about anything regarding sexual health, smear tests etc because I am gay but don’t want to ‘out’ myself and don’t really want to have to lie or be evasive either”

In order to get health advice that actually suits their needs, lesbian, bisexual and transgender women will have to challenge such assumptions. Understandably, many said that they find this difficult to do and wanted to avoid it. One woman remarked that not having contraception meant she does not get sexual health advice either, and another said that lesbian and bisexual women’s needs ‘are just not on the radar’ of mainstream health services.

The ‘blanket promotion’ of contraception may be well-intended. However, attitudes found in wider society also exist in the healthcare setting, and barriers caused by homo/bi and transphobia should not be underestimated. One respondent described it as a ‘cost to emotional wellbeing’, and said that sometimes she would rather not see a doctor than risk being met with prejudiced or homophobic attitudes. Another said that she feels the need to conceal her sexual orientation to health providers, as she ‘wonders how she would be treated if they knew.’

165 In response to the question: ‘How do you feel about discussing things like reproductive health, contraception and sexual health with doctors and nurses?’
166 As above
### 2.2.8 Mental health

71% of our survey respondents stated that they had experienced anxiety, depression, panic attacks or another non-physical health problem at some point during their lives. 77% of these women had sought help from their GP. Their experiences were mixed, but a number of discernible themes emerged. Also here did many women feel more comfortable with a female GP:

> “I usually like to see a female GP. If I just have a general medical problem like a chest infection then I don’t mind which doctor I see. But if I have a more personal problem I prefer to see a female GP.”

For many of those who had experienced some form of emotional distress, but had not sought help for this from their GP, the main barrier had been the expectation that they would only be offered medication:

> “I didn’t want to be prescribed antidepressants and had found them unhelpful in the past.”

> “Unlikely to get help - and don’t want pills”

> “Expected he [GP] would just say its natural in a woman of your age - whatever age I was!”

The expectation of not being taken seriously can be a barrier to good communication, and a deterrent to seeking help. This issue was identified in several parts of the survey:

> “Telling me that ‘anxiety isn’t a medical condition’ is not appropriate. It’s hard enough to talk about mental health but when GPs don’t take you seriously it’s even harder.”

> “Whether you think you will be listened to or whether they just tell you to go away - this happened before but I finally received treatment by registering at a new practice”

For many, the main barrier to seeking help was a concern about being ‘labelled’, and ‘stigmatised’ by a mental health diagnosis. One respondent feared that her capacity as a mother might be called into question and that social services would be contacted if she spoke to her GP about her emotional health.

Emotional problems can affect health-seeking behaviours, and be a barrier in themselves. Many depression sufferers, for example, retreat from social interaction. One respondent described being caught in a situation whereby her social anxiety prevents her from going to the doctors to get help.

As has been discussed previously, there are problems in the NHS relating to timely treatments for mental health, and sometimes months or years can pass between referral and

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167 In response to question: “Is there anything else you want to add on the subject of communicating with doctors?”

168 As above
the start of treatment. One respondent who had sought help for severe emotional distress stated:

“A year on from my suicide attempt I was still on the NHS waiting list for talking therapy”

The availability of free or subsidised counselling offered by third sector organisations is subject to geographical variation, and is being affected by current funding cuts. Paying for private treatment is only an option for those who can afford it, but even small costs like prescription charges can be problematic for many, as will be discussed next.

2.2.9 Costs associated with accessing a GP

41% of our survey respondents, when deciding whether or not to make a necessary health appointment, stated that they take prescription charges into account as a factor, or sometimes do. (18% answering ‘yes’ and 24% answering ‘maybe/sometimes’)

Although it is sometimes possible for individuals on low incomes to get prescription expenses reimbursed, one woman reported that this can take up to three months. Another respondent stated that she only takes prescribed medication on those occasions when she can afford to pay for it, and another wrote that she always tries to time her prescription renewals to coincide with the first two weeks of the month, after which she is ‘skint’. Cost is thus a potential barrier to treatment even though the appointment itself is free. It is also a potential deterrent to seeking help in the first place - one woman wrote that the reason she did not tell her GP about her emotional distress was that she expected to be prescribed ‘more medication’, which she would not be able to afford.

The cost of travelling to the appointment is a lesser barrier, but still relevant to 16% (8% responded ‘yes’, it is a factor in making this decision, and 7% said it was ‘maybe/sometimes’ a factor.

2.2.10 Gender-based violence

Research suggests that approximately 1 woman in 4 in the UK will experience domestic violence at some point during their lifetime. Women are encouraged by the NHS to talk to their doctor, health visitor or midwife about this.

21% of the women who responded to the survey had experienced violence or abuse from a partner or family member, but 69% of these women had not spoken to their GP about it. The most common issues mentioned included shame, stigma, not being taken seriously and fear that doctors would not be sympathetic:

“I did not talk to anyone about it. I was ashamed and brushed it under the carpet.”

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169 In response to the question: ‘Please tell us your GP’s reaction to this and what they did to help.’
171 ibid.
“[Was afraid of] being judged, not finding the right words, getting too upset…”

“…Didn’t want anyone to know”

“Worried about stigma.”

Many also viewed domestic violence as a personal problem, and not something that the health service would be able to help with:

“It’s personal. How would they help? What decent options are there for GPs to refer to?”

“I did not think they would do anything other than tell me to leave [my partner]”

Some of the barriers to seeking help for gender-based violence, such as stigma, and the belief that doctors will not be sympathetic, take the problem seriously, or be able to help overlap with those experienced by sufferers of mental health problems.

Out of the small number of women who did seek help from their GP, approximately two thirds of respondents had a positive experience, and one third a negative one. It is worth noting that many of the incidents happened many years ago and the women may have had a completely different response today.

2.3 Findings from the focus groups with Black and Minority Ethnic women

2.3.1 About the groups

Two focus groups for BME women were held in London by the WHEC partner organisations Imkaan and FORWARD. Imkaan is a UK black feminist organisation dedicated to addressing violence against women and girls. FORWARD is an African Diaspora women’s organisation dedicated to advancing and safeguarding the sexual and reproductive health and rights of African girls and women.

One of the groups focussed specifically on younger women. One participant in this group did not return a demographic form. Out of the remaining four, two were under 18. One identified as Black African and the rest as Asian British, or Asian Pakistani. The group had A-levels and GCSE qualifications. No-one answered the question about household income. Two described their sexual orientation as ‘heterosexual’ and two as ‘other’.

In the second group, three women were in the age range 31-35, and the other two were between 36-40 and 46-50. All identified as Black African. Levels of education ranged from no formal qualifications, to Bachelor degree level. Incomes were below 15,000 for all participants. Four participants had children, two of whom were single mothers. None of the women answered the question about sexual orientation.
2.3.2 Registration

Several of the women found registration a difficult and lengthy process, starting off with being placed on hold for long periods of time when calling up to register or make an appointment.

Others talked about the volume of information required, and the long forms they were expected to complete. Participants felt the registration process would be easier if receptionists were more attentive and listened to patients needs. For example, one of the younger women said that it would really help if practice staff could just take a couple of minutes to explain how to fill in the form. Another had registered over the phone, and found the process ‘easy’.

As one of the participants in the younger women’s group pointed out, finding and providing all the required details (for example about previous doctors) can be especially challenging for someone coming from overseas.

There were concerns in the groups relating to confidentiality. It was felt by some that the kind information that goes on the application form should only be seen by the patient’s doctor. Many did not think it appropriate to hand this to receptionists, who were perceived as potentially judgemental.

Another issue raised in the group in relating to registration was the documentation required for identification purposes. As has been discussed in relation to asylum seekers, GP practices often require passports as proof of ID. As one woman pointed out, it may be necessary to renew an existing passport or apply for one before being able to register, which can take a long time and costs money. All of the women in the two groups had however been able to provide the necessary documentation to register.

2.3.3 Access

A variety of issues were raised relating to getting an appointment with a GP. In the younger group, being placed on hold for long periods of time was an issue. Not all households have a landline – many people use only mobile phones, perhaps especially younger people and those who frequently move. One woman said: ‘If you’ve got specific minutes or credit, it just goes’.

Some participants felt it was very hard to get appointments within a reasonable time frame. One woman recalled a situation in which her sister had been asked to wait three days to see a GP for an urgent matter, resulting in the need for emergency treatment. It was felt that if women did not have someone who could help them get access by explaining the details of the problem and its urgency to the receptionist, then it could be very difficult to get access. The need to ‘argue the case’ is likely to be especially problematic for women whose first language is not English. It could also be problematic for sufferers of depression and anxiety, as these conditions can affect the ability to reach out and get help, let alone having to convince someone about the need for an appointment.

Incompatibility with other commitments was identified as problem. One of the younger participants found it difficult to schedule appointments around college. The group also said that being held on the phone for long periods can cause them to be late for other things.
2.3.4 Staff attitudes

When the groups were asked about the attitudes of staff in their practice, there was a general consensus of reception staff as ‘unhelpful’ and ‘preoccupied’, and this was a deterrent for some. Some of the women also reiterated their concerns about reception staff maintaining confidentiality:

‘Receptionists will often ask for personal details like your address and date of birth and again, everyone in the room can hear what you say.’

‘I don’t like speaking to the receptionist. There are confidentiality issues because everyone in the waiting room can hear. I prefer to ring.’

One young participant said that she finds her doctor to be ‘rude and racist. She said that he assumes that she always wants tablets, and that this has prevented her from visiting the GP in over a year:

“My Doctor is really rude. He thinks all Asian people just come there to take his medicines… I’ve stopped going GP, it’s been over a year….I don’t even want their tablets… I’m here to tell you my problems, I don’t want tablets, I hate tablets.”

Another young participant had a very negative experience with a GP, who failed to diagnose that she had tuberculosis for over 6 months. Within that time she also went to a private doctor who also failed to diagnose her, resulting in her having to take a year off university to recover.

Another young woman had seen a doctor in Saudi Arabia for a scan, and had a diagnosis, but her GP in the UK did not take the results seriously, and six months later, this woman still had not received any treatment.

2.3.5 Doctor-Patient communication

The language barrier was one factor that impeded communication for the women in our focus groups. One participant expressed concern that she is not taken seriously by doctors because she does not know the right words to use when describing her symptoms. “Just because I can’t say it in a medical term doesn’t mean it’s not real.”

Several also highlighted the effect that time, or the lack of it, can have on the quality of communication, and the doctor-patient relationship:

“I usually find that Doctors can understand me. They do need to be patient and take time to listen, there’s meant to be a relationship between the two of you.”

“They don’t have time to really invest and really look into what your problem is. They usually just say ‘oh try this medicine and see if it helps’.”

“They’re rushing to see other patients”
Many of the younger women described communication barriers relating to not being listened to, and not being given information or advice about for example medication.

All of the younger women and many in the other BME group preferred to speak to a woman rather than a man, as they felt women would understand them better. They all said they would feel more comfortable seeing a female health professional, particularly with regards to issues relating to their reproductive health. Several said that they ask to see a female doctor when making an appointment, though some said it was not always possible to get one.

2.3.6 Costs

The younger women mentioned prescription charges as a barrier, noting that costs quickly add up when multiple items are required:

“They say it doesn’t go above £7.65\(^\text{172}\)...but that’s a lie. It’s £7.65 for each medication not for everything together. That’s what I was under the impression of, so when the doctor’s giving me loads of tablets, inhalers and everything...they didn’t say it’s going to cost you more than £7.65”

One participant mentioned that she could potentially claim free medication but she is deterred by the lengthy form that she would have to fill in. Another participant said that she prefers to buy medication because she believes that she gets a better service and more information from the pharmacy when she pays, than when she gets her medication for free which may relate to stigma and prejudice around benefits and healthcare.

In the second BME group, prescription charges were less of a problem. One woman stated: ‘Paying is fine because you should be willing to prioritise spending your money on health’. One participant said that taking time off work was not a problem, as she did not work afternoons but another woman stated that doctors sometimes run as much as 3 hours behind the time at her clinic. Such delays can interfere with work and other commitments.

2.3.7 Caring

One woman identified as a carer, and had responsibility for attending health appointments with her mother. She found it difficult to combine this with her work commitments.

2.3.8 Sexual and reproductive health

Many women struggle to talk about their sexual or reproductive health. As one woman stated:

‘I find it very uncomfortable to discuss sexual and reproductive health issues because in my culture such issues are taboo and not spoken about.’

The younger women had concerns regarding confidentiality, trust and understanding. It was felt that in order for them to comfortable talking about sexual and reproductive health, the

\(^{172}\) Prescription charges in England rose by 20p to £7.85 in April 2013.
doctor must be trusted to maintain confidentiality, listen to the patient and communicate effectively including body language that makes the patient feel like the doctor is listening and understands the problem. Putting the patient at ease was felt to be an important aspect of communication. Again, the time issue was brought up as a barrier to communication. Some participants felt that a 10 minute appointment was too short for patient and doctor to build a positive, trusting relationship.

The most serious barrier to proper sexual and reproductive health for this group of women related to the incidence of female genital mutilation (FGM) and the lack of understanding of these issues in mainstream healthcare services, something that several of the women could relate to.

One woman had experienced life-threatening complications caused by FGM when giving birth to her first child:

“The doctor didn’t understand what had happened to me. They just cut me open and forced the baby out. I almost bled to death.”

Whilst she acknowledged that there is more knowledge and resources for women in this situation today, she also said that although women can now refer themselves for de-infibulation during pregnancy, this rarely happens, as ‘they are often too embarrassed to do so’.

Another participant talked about a friend who had been told she needed to have a cervical smear, but was too shy and embarrassed to explain that this would not be possible, as she had undergone type 3 FGM. This woman said that what women need most is awareness from doctors about FGM. She also suggested having a counsellor or advocate who would be able to explain the issues to the doctor on behalf of other women who felt unable to do so themselves.

2.3.9 Mental Health

There was a general consensus in both groups that doctors are not best placed to help with mental health problems, that it tends of be medicated rather than talked about, and that there is a taboo or stigma surrounding it.

I haven’t heard mental health being discussed at GPs. People aren’t comfortable in discussing it. They just take anti-depressants instead.

One suggestion from the group was to have one person in each practice specifically trained in mental health.

Most of the younger women felt that GPs are not yet dealing appropriately with mental health issues. Comments to this effect included: “they’re working on it” and “they’re not there yet”. They felt that counsellors are better able to respond to mental health problems than doctors.

The group also felt that doctors lacked empathy and need to work on their approach with patients; open up, listen actively and respond to what patients say in a way that makes patients feel understood.

173 Infibulation: narrowing of the vaginal opening through the creation of a covering seal. The seal is formed by cutting and repositioning the inner, or outer, labia, with or without removal of the clitoris. WHO factsheet, available at http://www.who.int/mediacentre/factsheets/fs241/en/
“They’re not appreciating that they are actually being trusted here.”

2.3.10 Violence and abuse

In the younger group, participants said they would not speak to a GP if they were experiencing violence/abuse, as they lacked confidence in GPs ability to respond to it. Several of the younger women had bad experiences with their GP in relation to physical illnesses, which meant that they were less inclined to trust them with other issues as well:

“If they’re not helping you out with your own illnesses, how would they help you with this?”

Another participant stated:

“My whole life was surrounded by [violence] but I never even thought of going to my GP about that.”

2.4 Findings from the focus group with refugees and women seeking asylum

2.4.1 About the group

The focus group was held in Manchester by Maternity Action and WAST Manchester, in conjunction with one of their drop-in sessions. WAST is a women’s campaign and support organisation that provides a safe and mutually supportive space for asylum seeking women to get involved in fighting for their rights and raising awareness of issues relevant to their situation.

The group consisted of 13 women in various age groups between 26-30 and 51-55. All of the women were residing in Manchester and surrounding areas at the time. The group was to an extent self-selecting, and most of the women who came forth to take part had a good command of English. The level of qualifications ranged from no formal qualifications to Bachelor’s Degrees. Everyone in the group identified as Black African except one woman who identified as Indian. A majority identified as heterosexual and a minority as lesbian. The vast majority were destitute and had no income. Four of the women had children and two were single mothers.

2.4.2 Registration

Most of the women in the group said that registration had been ‘very difficult’.

As has been discussed previously, asylum seekers often have trouble providing identification and this was something that the women had experienced.

“When I went to the GP (to register) they started asking me so many, many things – they wanted my ID, they wanted this and that – I didn’t have anything. The Home
Office had taken my passport, they had taken everything and I had nothing with me [...] They said: If you don’t have any ID, there is no way we can register you.”

Eventually, a family member was able to negotiate on her behalf and she was allowed to register. She said that without this help, registering would have been ‘very, very difficult’.

When identification documents such as passports are retained by the Home Office, most asylum seekers are issued with another photo ID, the Application Registration Card (ARC), after the initial screening interview. One woman said: “When you go through the asylum process, they tell you that the card they give you works as a passport [...]” However, she had quickly found that this was not the case. “So, when you take this card [ARC]... and move from one place to another [when you are dispersed], you are like someone who has just arrived and you do not have any identification at all.”

Some of the women thought that the reason for this related to GP staff and their unfamiliarity with the card. Others thought it was more likely to be due to prejudice: “They just take it for granted that anyone who is in the asylum process is a liar”.

Sometimes it was difficult to identify whether the main barrier may have related to lack of knowledge on behalf of professionals, or discrimination on the basis of BME status or legal status. One respondent recalled very mixed experiences. The first time she had attempted to register with a GP, she has been asked whether she was an asylum seeker and subsequently been refused. After asylum had been granted, she moved to another area, where she registered with a GP whom she held in very high regard. This GP referred her to a dental practice, where again she was met with conflicting information:

“The first dentist I met was very nice to me and checking my teeth. They said they have to fill something [...] but then another dentist came, and she said ‘no, I don’t have to help you’. Since that time I have problems with my teeth, but I don’t know where to go.”

Another woman had successfully managed to register her daughter with a dentist, but when was asked for £10 to register herself. Producing her HC2 certificate did not help, and at the time of the research, she had still not managed to get registered with a dentist.

2.4.3 Access

The group had more to say on access and getting appointments than on any other subject. When barriers to registration are overcome, challenges remain in terms of getting to see a doctor. Negotiating access, sometimes through an advocate, was a recurrent theme in the group.

One of our participants said that whenever she phones for an appointment, the receptionist seems to know who she is, and acts as a “very big barrier” to access:

“I can’t remember how many times social services had to get involved before I was able to see my GP. Each time I’m calling... because they already know my circumstances [...] I think it’s because of my immigration status. When I ring, they must have known my voice, or they know my name. At the other end, they say: ‘Is
As soon as they answer the phone... they are thinking of things to tell me: ‘Is it OK if you go to A&E?’, or whatever.”

It was only when a social worker was contacted that practice staff eventually ‘backed down’, and she was able to see her GP. Another participant agreed: “My GP is alright, but the problem I have is with the receptionist.” Many in the group concurred with this sentiment. “Yes. You get ‘blocked’.

As in the general survey, the group found it very difficult to get an appointment at a suitable time. In some cases, they found that urgent appointments were available only at very short notice, and therefore difficult to get to in time. Non-urgent appointments could sometimes be a month or more away.

“I book appointment. And they put me on, next month or 20 days later. If I say: ‘This is an emergency – I need!’ They say: ‘No, no, no, the doctors are busy’, or ‘the doctor is going to holiday’, or something like this. I can’t get appointment from my doctor, it’s no good.”

“In my area, there are no emergency appointments. You can die, I tell you! ‘No! You can wait next week’, for everything! There is no emergency.”

One woman had been unwell recently and was asked by the receptionist whether she could come in February. The focus group was held in December.

Several women stated that they had taken to using A&E or walk-in centres, sometimes on the advice of GP practice staff. Although they realised it was not appropriate, it sometimes seemed like the only choice:

“One of my children was sick last week. They had to send him back from school. I called my GP. They said, ‘Oh no, he has to come in 3 days. Go to A&E.’ and we go to A&E, and they will be looking down at you like: ‘Are you out of your mind? This is not an emergency. Go to your surgery!’ And surgery will not answer you, so you get stuck; you don’t know what to do.”

According to recent research by Monitor, the NHS regulating body, around three-fifths of individuals using walk-in centres are female and in lower socio-economic groups. The vast majority were registered with a GP, but 24% of these said that they go straight to the walk-in centre instead of trying to get an appointment as they did expect not to be offered a suitable time. 50 of England’s 230 walk-in centres have closed since 2010.

2.4.4 Staff Attitudes

Several participants had experienced treatment they characterised as discriminatory. The woman who had been denied treatment by a dentist was reluctant to call it racism, but at the same time believed that she had been discriminated against and given the wrong

174 Not the woman’s real name
information because of her colour. The incident had deterred her from returning, despite the fact that the other staff had been helpful and willing to treat her.

Many of the women did not feel that they received the same treated as non-migrants from doctors and receptionists. The group agreed that GPs and practice staff could benefit from “more training in how to deal with people.”

Other comments included:

‘They just discriminate, that’s the truth because they hear your accent... The treatment is different.’

‘It’s because of immigration. It’s wrong – We are all human.’

2.4.5 Doctor-patient communication

Some of the women did not feel they were listened to by the GP, which they partly attributed to lack of time:

“At times you get access to them, but they don’t have time to listen to you. They don’t have time... You can’t expect someone to look after your health when they can’t listen to your problems.”

One woman said that GPs do not pay enough attention to the personal circumstances of their patients, and do not know enough about the complex issues that affect asylum seekers. She said GPs treat all people the same, whether they have depression or a cough, ”just talking and writing”. She said GPs needed training to deal with asylum seekers.

Another woman emphasised the importance of treating all patients as individuals. She had often found that GPs did not listen to her, instead attributing all of her health problems to her legal status and her ethnic origin:

‘The moment you say asylum, they treat you in a different way. They say: ‘Because of where you come from, that’s why you get this illness. You come from Africa, that's why you have this illness’, but not really listening properly to what you problem is.’

Many, but not all, group participants said they found it easier to speak to a female doctor. One woman said: ‘Me, I prefer any of the female or male, what I want is for someone to pay an ear to what I am saying. As long as you listen to what I am saying, I am contented and I will be happy.’ There was quite a lot of agreement with this. One woman said her (female) GP is very abrupt, which prevents her from talking freely with her. She said: ‘I feel scared; I hold some things back that I wanted to tell her because of her attitude...’

Some, but not all participants, preferred seeing a woman for intimate examinations. A few felt that since all doctors are equally qualified, their gender does not matter and were happy being examined by a male GP if there was a female chaperone in the room.

One participant had recently been dispersed to a new area, and in her new practice had been seen by different doctors every time. She said: “I don’t feel comfortable with that, because I feel they won’t know me.” The lack of an established relationship is not
necessarily a problem for everyone, but could affect the patient’s ability to disclose issues like mental health or violence.

### 2.4.6 Costs

Prescription charges were identified as a barrier by this group. Although many have entitlement to free prescriptions, they may not know their entitlement or how to go about getting the necessary certificate. One woman came out of detention needing medication but was turned away from the pharmacy on account of not being able to pay. She eventually managed to get help from social services, and now has the certificate that shows she is entitled to free medication.

The majority of our focus group participants were destitute asylum seekers, and it became clear that even very minor costs can be a real problem in their situation.

> ‘At my doctors, if you tell them a kind of minor sickness, they'll tell you to go and buy paracetamol over the counter. And if you say; ‘I don't have money’, [they say] ‘It’s just 20 p! You can just go and buy that. If you say: ‘Can't you prescribe it?’ They say ‘no, that’s so cheap, you can buy it.’

> “Our money is limited; we don’t have that money to buy that medicine.”

> “Even one pound, it will be difficult. Even that one pound, I don’t have it.”

Another participant said that she had no money and no HC2 certificate, and the only way that she could get the medication she needed was to pretend she had left her certificate at home. Although she did not do take this decision lightly, she felt it was her only option if she wanted to prioritise her health. Some of the others agreed.

One woman told the group about close friend, an asylum seeker whose husband had the right to remain, who was being ‘bombarded with letters’ demanding thousands of pounds for maternity care, which she could not afford.

### 2.4.7 Mental Health

Mental health problems came across as a stigmatised issue for some of these women. One participant said that she had been referred to mental health services for depression after leaving Yarl’s Wood detention centre and upon receiving the letter, she called her doctor and told him: “No, no, no, I’m not mad, I’m not mental. Don’t take me to the [psychiatric ward]. I’m depressed, but I’m not mad." This anecdote was met with some laughter from the rest of the group.

This woman did not view depression as a mental health problem, and did not wish to be associated with psychiatric services, possibly because of stigma. Another woman used the term ‘mental’ to describe people with mental health problems. Referring to people wrongly diagnosed with mental health problems, she said: ‘some people are not mental and they have to fight these people and say: ‘I’m not mental.’
The asylum process places applicants under intense scrutiny. People seeking asylum may be concerned that a mental health label could weaken their claim. As in the general survey responses, there was also concern regarding children being taken away from mothers:

’Some people with children, they might have mental health problems, but they don’t want to say, because if they [admit this] they might take your baby away. Some people are fearful to come forward.’

One participant said that the waiting list was so long for counselling services that timely treatment was only available to those who were suicidal.

One participant said she had been referred to counselling by her GP, but the ‘referral’ consisted of a list of counsellors she could contact, who all charged in the region of £50 / session. This woman eventually found a free counselling service, though not through her GP.

2.4.8 Gender-based violence and abuse

Responses were mixed on whether GPs could help with problems relating to gender-based violence and abuse. The initial response was that such issues are not part of a GPs duty, or GPs may not think it is. About half the group disagreed: ‘General practitioners, they do cover almost everything, so I’m sure they can refer you to someone who can help you. They have to. It’s their duty, to refer you to someone else.’ Lack of time was also brought up as a potential barrier: ‘They can only help if they have enough time, because they only give you ten minutes. So what can you say in ten minutes?’

2.5 Findings from the focus group with women living with HIV

2.5.1 About the group

The group was hosted in London by the WHEC partner organisation Positively UK, the leading provider of peer support to people living with HIV in the UK. Apart from supporting individuals to achieve physical emotional and social wellbeing, the organisation also champions the rights of those diagnosed with HIV.

The focus group consisted of 8 women in various age groups between 36-40 and 51-55, all residing in London. The year of diagnosis ranged from 1991 – 2008. All of the women were registered with a GP, and all of them had disclosed their diagnosis to their current GP. Six of the women were Black African, one was Black Caribbean and one was White European. A few were asylum seekers. Formal qualifications ranged between GCSE’s to Masters Degrees. Five participants were on incomes of less than £15 000, and the incomes of the remaining three were in brackets encompassing between £15 000 – 39 000. Six of the women were single mothers and all identified as heterosexual, except one woman who identified as bisexual.
2.5.2 Registration

Participants who had registered recently commented that the registration pack was ‘enormous’ and took a long time to complete. They felt that receptionists could be friendlier and more helpful.

Most of the women had chosen a GP close to where they lived. Two had been referred by their HIV consultant and only had to show the referral letter when registering. One woman was referred to an ‘HIV-friendly’ GP through her specialist due to negative experiences with previous GPs, and the group felt that it would be helpful to have access to a list of GPs in every area that have knowledge and understanding of HIV, and also which practices had female doctors.

2.5.3 Access

Participants stated that it is hard to get an urgent appointment, as this means phoning at 8 am to book, and all the appointments are often gone in the first 5 minutes. This was also the time when the mothers in the group were taking their children to school. When asked what might make it easier for them to get access, some suggestions were a second time-slot to make urgent appointments later in the day.

2.5.4 Choosing a female GP

The women said that it is possible to choose a specific GP where they are registered, but only when the appointment is booked well in advance. However, many participants said that they preferred walk-in clinics and didn’t mind seeing an unfamiliar doctor, as long as they got treated. A few even preferred locum doctors, saying that they tended to be good listeners.

2.5.5 Experiences of specialist and mainstream healthcare

The women were asked to share their experiences of their HIV clinic, and their GP practice. All participants agreed that their clinic meets the needs of women, and some said that theirs has special women-focused days. Most participants preferred the clinic to mainstream services, as they felt that it was more compassionate and that staff in the HIV-clinic were more likely to look at them holistically. As has been discussed earlier, this group is at risk of being ‘reduced to their condition’ by GPs, in that all of their health problems are attributed to the disease or its treatment. This is a potential deterrent to accessing mainstream services in which doctors may have very little knowledge and experience of HIV. One woman recalled:

“When I went to a new GP, the GP was so shocked I was HIV positive. He was really patronising saying I looked really well. I was so brave. I was his inspiration, blah, blah, blah. He seemed like he had never seen anybody with HIV and didn’t know anything about it. I left immediately and looked for another GP.”
“I have to go to my GP for the diabetes, but I prefer the HIV clinic.”

One woman had sought help several times for severe back pain, but was told by her GP that this was normal for a woman over 40. When she told her HIV-specialist about the problem, it was investigated and treated. Not all HIV clinics will be able to meet all the patient’s needs however, which is why it is important to be able to see a GP as well. A few of the women preferred their GP to the HIV clinic. One reason given was the opportunity to discuss their children’s health with the GP, which they cannot do at the specialist clinic.

### 2.5.6 Confidentiality

Many women with HIV are secretive about their health. Stigma and prejudice prevents some from disclosing their condition even to close friends and family, and one woman had been ostracised by her housemates after they found out by mistake. The group was very concerned about patient confidentiality, and one woman described the stress of being questioned by reception staff in front of other patients:

> “Receptionists can be aggressive and ask intrusive questions while you are in the queue with other people listening. You are already tired and sick so you lose it and have an argument.”

Many surgeries have screens in waiting areas, on which the patients name is displayed when they are called in, and even this small display of their name made several women in the group uncomfortable. One participant said that in her practice, she is contacted by text message instead, which the others thought was ‘brilliant’.

One woman’s GP had made a very serious mistake relating to confidentiality:

> “Once I went to see the doctor with my daughter, she didn’t know about my status and the doctor started talking about HIV in front of her and so disclosed my status. It was really bad. I felt awful.”

In the general survey, we found that mothers often have to take their children into the consultation, which can limit the issues that can be discussed. Women with HIV are likely to find this especially problematic.

### 2.5.7 Costs

Only 3 of the 8 women were in full-time employment. When asked if the prospect of taking time off work influenced their decision about making an appointment with their GP, one woman said that because she already has to take time off to see her HIV-specialist, it seems like too much to also take time off for additional doctor’s appointments.

Costs relating to medication, and travelling to the appointment were also relevant to some of the women. “Travel cost stopped me. I had no credit in my oyster card.”

GPs are often called upon to provide supporting information, such as copies of medical records or support letters for various purposes, including sickness benefits. One woman said
that her GP charges between £30 and £70 for such services.

2.5.8 Gender-based violence

5 of the 8 women had experienced violence in the family, reflecting the increased risk in this group of women. This was mainly gender based violence from a partner, except one case involving the woman’s sister. However, all had found it very hard to seek help. For one woman, separation was unthinkable: “In my culture, marriage is perseverance.”

Many of the reasons given overlapped with those found in other parts of our research, including being financially dependent on a partner, stigma, and fear of being judged as a bad mother (especially as a single mother), and fear of having children taken away:

“I would have to support the whole family before talking to a GP”

“How am I going to raise those children by myself?”

“Especially when there are children involved, you have to keep it all together or they [social services] will take them away.”

One participant stated that her husband’s alcoholism had caused her to become so stressed that she started neglecting her own health and stopped taking her medication.

2.5.9 Mental Health

The incidence of mental health problems in the population of women with HIV is high, and this was reflected in our focus group. All of our participants stated that they had experienced anxiety, depression, panic attacks or a similar problem.

“I was suicidal and I was referred to a talking therapy group. It helped – I wanted to end my life.”

Most of the women had sought help, mainly from their HIV specialist rather than GP. Group therapy and Cognitive Behavioural Therapy had been helpful. One woman had become dependent on sleeping pills prescribed by her GP.

2.5.10 Sexual and reproductive health

The group felt that sexual health was best dealt with in a GUM clinic, or walk-in clinics, and that GPs were more for simple things like colds, and for children.

The women agreed that they preferred a female doctor, especially for internal examinations or insertion of a contraceptive device. Male doctors were only considered to be OK if they were “old and unattractive” which may indicate a wish to eliminate from the situation any aspect associated with sexuality.
Five of the women preferred to have their cervical smear test done at the HIV clinic, as they considered it more accessible. The remaining three used their GP surgery.

2.5.11 Maternity Services

Most of the mothers in the group had been allocated specialist midwives, which was seen as preferable to the regular midwife who takes over after 28 days. The women felt that mainstream midwives had limited understanding of the psychosocial aspect of facing an 18-month wait to get the all-clear.

“All you can think about is the 1% possibility your baby may be positive. They ask you if you have given the baby a bath, but not how you are coping”

“The GP keeps asking at every visit: ‘Is the baby clear?’”

2.6 Findings of the focus group with LGBT women

2.6.1 About the group

This group was held in London and hosted by the organisation ELOP. ELOP is a lesbian and gay community-led mental health charity which aims to promote wellbeing, equality and empowerment of LGBT communities. ELOP provides information, advice, advocacy, counselling and support services, and also organises social activities and events.

It was attended by 6 women in various age brackets between 19-25 and 66-70. One of the participants had a physical disability, and had also had significant use of mental health services. Another woman in this group was off work with significant health issues. One participant had made use of drug and alcohol services. One woman identified as bisexual, and the other 5 as lesbians. Some of the women were ‘out’ to their GP and some were not. Four participants identified as White English/Welsh/Scottish/Northern Irish/British, and the remaining two as Black Caribbean. Levels of formal education ranged from ‘no formal qualifications’ to Bachelor’s Degree and household incomes from less than £15 000 to between £30 000 and £39 000. One of the women had children and was a single mother.

2.6.2 Registration

None of the women had registered with a new GP recently, and they had not experienced any difficulties with registration.

One woman chose her GP practice on the basis of its reputation as lesbian-friendly. It had originally been a co-operative practice, established 20 or so years ago and had a lot of lesbian women on its books. She was aware that many women outside the catchment area had unsuccessfully tried to register there for this reason. As was also the case for many of the women with HIV, there was demand for GP practices seen as ‘friendly’ to LGBT needs.
2.6.3 Access

The group found it difficult to get through on the phone during the short time allocated for making same-day appointments. All the women had experiences of having to wait several weeks for a non-urgent appointment. Participants wanted more flexibility of appointment times, which would enable them to see a doctor before or after work. They also wanted the option to book online.

The women disliked talking to reception staff about their health in order to get an appointment. One woman said: “I feel it is not their business to know that is wrong with me – I always say it’s private.”

The group felt that receptionists could be quite demeaning in their manner and one woman said: “It feels like you have to get passed the receptionist – they do gate keep.” Another participant said that there is one receptionist at her surgery who is very helpful, but the others are not.

2.6.4 Staff attitudes

Several of the women had experiences of prejudiced and ‘low-level homophobic’ treatment from health professionals:

“I have had staff be really rude to me – and I have felt this to be because of my sexual orientation. Because I have other difficulties as well they don’t really accept that I know who I am. They also see my problems as being caused by my sexual orientation and they are not.”

“I have had nurses make snide remarks about my sexuality.”

“I have had a nurse who was clearly uncomfortable with the fact that I am a lesbian.”

2.6.5 Communication

The general survey results suggested that the possibility of encountering prejudice or homophobia is a potential deterrent to women in this group. Low expectations and negative attitudes may also affect the communication between patient and doctor. One woman said that she never talks about her sexual orientation in appointments, as she does not think that it would “go down well”. Another said that she was not sure whether health professionals really needed to know. The discussion then turned to what could happen if GPs and nurses are unaware of someone’s sexual orientation. One participant felt that doctors need to know about this aspect of her life, in order to be able to treat her mental health properly:

“What about when you are struggling with life and they don’t know who is important in your life? It is really important regarding my mental health that they know.”

Others felt it was important on the basis of sexual health advice, in terms of taking away presumptions about sex with men and the need for contraception. Two of the women who
were out to their GP, and two who were not, discussed the fact that GPs and nurses always assume heterosexuality and that this can be embarrassing.

One participant said that she uses a specialist service for smear tests, so that she does not have to disclose her sexual orientation to her GP. This woman also felt that by using a gay service she gets a better response. However, specialist services may not always be available to everyone who needs them, as this tends to vary by region.

### 2.6.6 Mental health

Three of the women had sought support with their mental health. One had suffered from depression relating to issues in her personal life, including her relationship with her ex partner, but because she did not want to tell the GP about her sexual identity, she could not disclose why she was depressed. She said:

> "I could not face being told that I should stay with my husband or the impact being gay would have on our children. I was worried I would be judged."

Her GP prescribed antidepressants, which she did not find helpful. Eventually, she was helped by a counselling service that she found elsewhere.

Another participant said:

> "My GP was really helpful – I am out to her and this helped – it meant that she could ask me about my partner and how much support I was getting."

These two accounts illustrate the issue raised in the previous section about communication.

### 2.6.7 Cost

One woman said that she cannot take time off to see a doctor because will be replaced by someone else and lose a whole day of work. At the time of the focus group she needed weekly physiotherapy and was unable to work. Another said her employer was fine about her taking time off, although she tried to avoid doing so.

### 2.6.8 Sexual health

In earlier sections of this report, we saw that some lesbian and bisexual women miss out on smear tests and sexual health checks due to lack of knowledge and information, both on their own behalf, and on behalf of health professionals.

Several of the women also said that they feel uncomfortable having smear tests in mainstream services because of the assumptions about heterosexuality. This had caused one participant to avoid cervical screening completely:

> "I have not had a smear test for over 10 years as I can’t bear the questions that they ask and the assumptions that they make. I know I should be screened, but this way I..."
can just avoid all the awkwardness of having to say again that I don’t have sex with men.”

Combined, the lack of information and fear of prejudice and homophobia could raise the risk of cervical cancer for this group.

All the women said they always prefer to see female GPs, although one was registered with a practice that does not have a female doctor.

### 2.6.9 Maternity

One woman in the group had experiences of using fertility and maternity services. When she and her partner asked for a referral to services, the GP refused, saying that this was not done for same-sex couples. It was only after the second time, when they came back with information about their rights, and the referral process, that the GP agreed. “If we had been a straight couple they would have known what to do.” Challenging the views of professionals requires some confidence, and places the burden of proof on the women themselves. The situation may improve as health professionals become more familiar with these issues, and the new NICE guidelines are a positive development.

This couple encountered the same presumptions about heterosexuality as described earlier in relation to sexual health, leading to some awkward conversations:

“*When I used maternity services – they could not put their head around two mums – I was always referred to as ‘Mrs’ and asked about my husband. After having the baby, I was asked how I would manage contraception. My partner was there as well. We just said I don’t think we need to worry about it, but honestly – what a question to ask us!*”

The partner who was not carrying the baby also experienced overtly discriminatory treatment during the birth when she was refused access to the maternity ward:

“*They kept saying to her: husbands and partners only – and she said ‘I am a partner’ – but they would not recognise her as a partner. It took her over 20 minutes of arguing to be allowed in.*”

No questions about intimate partner violence were asked in this group.
2.7 Findings from the focus group for women with learning disabilities

2.7.1 About the group

The group was held in Leeds by Maternity Action, in partnership with the organisation CHANGE. CHANGE is a leading national human rights organisation led by disabled people, which campaigns on disability empowerment, as well as delivering easy-read resources on various topics and training other organisations on how to work more inclusively.

Two participants had to cancel on the day. The group consisted of four women in the age brackets 36-40, 41-45 and 46-50, one of whom was a wheelchair user. Three of the women identified as White English/Welsh/Scottish/Northern Irish/British, and one as Asian British. Three participants stated that they had no formal qualifications and one did not answer this question. The two women who answered the question about household income gave the answer as less than 15 000. One of the women had children, who were not living with her. Three women identified as heterosexual. One participant did not understand the question.

2.7.2 Registration

Registration forms were identified as a barrier. Some of the women were unable to read and write, and forms were seen as inaccessible, containing too many big words and jargon, and asking for information that the women did not have. One participant, who is a wheelchair user, said that she does not know her height and weight. Two of the women had asked the receptionist for help with the form, but were told this was not possible:

“I went to the GP to register and because I struggle with the forms, because they’re not accessible for me to fill in, and I said to reception ‘Can you help me, I’ve got a learning disability’, she said: ‘Oh, I can’t help you.’”

One of the women said this situation had made her feel “really embarrassed and awkward.” The group wanted to be able to register by post. They also wanted more help with the forms.

2.7.3 Access

The women were asked whether they found it easy or difficult to book an appointment. There was consensus that automated booking systems are “really hard to use”, and do not allow enough time to choose between options. Some of the women had physical disabilities or struggled with dexterity which added to the difficulties of pressing the right button at the right time on their phone.

Some of the participants had some problems with the clarity of their verbal communication, which may cause problems when having a phone conversation. One participant (who did not have any such problems) said that she always goes into the surgery in person to book appointments because it is easier. Many GP practices only do bookings early in the morning, over the phone.
The group was asked whether they could usually get an appointment when they needed one. One woman said that she usually had to wait a week. She makes her appointments herself, but because she needs a support worker with her, she must also take their availability into account when she books, which limits her flexibility.

One woman, who had a chronic illness, said that she misses her 6-monthly checks because she does not get sent reminders of when to come back for her next check. She felt that there should be a system to remind her to make an appointment. Many people with learning disabilities have chronic health problems, and many struggle with forward-planning and time-management, which could cause them to miss health appointments. One of the participants said that she finds it hard to keep appointments and often found that she has to do something else instead on the day, which gets her in trouble with the receptionist the next time she calls. Another woman said: 'My surgery is quite good because you get a text message on your mobile to remind you that you have an appointment coming up.'

### 2.7.4 Communication

Several communication barriers were identified by the group. The same woman who had flagged up the issue of jargon-heavy application forms earlier also felt that the same problem applied to the consultation. She said that when doctors explain things about her health, she cannot always understand the words they use.

One participant gave the example of her chronic illness and said that when she was first diagnosed, she was only given some general lifestyle advice, and no information about what to do if she had an emergency. She had to seek this information out herself. She was given some leaflets about the disease, and although she was able to read them, she could not understand everything that was written.

With regards to making themselves understood, two out of four women had some problems. One woman said that when she goes into the room to speak to the GP: ‘I get shy, and ‘go’ in myself’. However, this woman does have a support worker who helps her to communicate with the GP. She said if she really needed to ask something, she would be able to do so, and she feels that her doctor is ‘Alright’.

Another woman had remarked earlier that it would be easier for her “if the people at the GP surgery could understand what the appointment was for”. Her response indicates that she struggles to make herself understood by the staff at the GP surgery, meaning that her needs may go unmet. This woman lives with family, but they do not support her with health appointments.

### 2.7.5 Sexual and reproductive health

**Choosing a female health professional**

All of the women present preferred to be seen by a woman health professional for women’s health issues. Some of the women were able to choose a female doctor at their GP practice,

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177 In response to the question: What would make it easier for you to make an appointment?
others were not. One participant said that she was officially assigned to a female GP, but did not usually get to see her. Last time she had a gynaecological health problem, she had requested a female doctor, but this had not been granted. She said that it had been “really uncomfortable” to be examined by a man, and “embarrassing to talk to a man about that”.

Two of the women had undergone cervical screening and two had not. One woman was sent an appointment from her GP. When she arrived, the nurse asked her why she had come, and said she did not need the test, though she did not explain why. Prejudice about women’s personal lives and relationships are a likely reason why many are excluded from screening. One of the women had never been told that she needed a smear test. Another participant said that she was overdue for a test, as she had been reminded in her recent learning disability review. Not everyone with a learning disability has such a review and it may vary according to area. The last woman in the group recalled her experience of having the test:

‘I felt embarrassed about it. The nurse explained it. She has to explain it first, before she does it. That they have my permission to do it. It was quite scary for me.’

Many of the women felt “embarrassed”, “scared”, and like they had to mentally prepare themselves for the test. One woman in the group thought that the test was something to do with sex; two said it was concerning cancer and one did not know.

Maternity
One woman in the group shared her experiences of maternity services from about 10-15 years ago. She had not attended any antenatal classes, partly because she thought she would be the only person there with a learning disability, and partly because she would have needed additional support from the instructor. She was asked whether she had been supported to make decisions about her pregnancy.

‘I feel that the first time around, I was. But the second time around, I felt the decision about what type of birth I wanted, was taken away from me. Because of diabetes, they said I had to have a caesarean. And I know that’s not true, so I felt that the choice was removed from me altogether.’

Although she found the community midwives helpful, the written information they gave her was the same as what everyone else got, and none of it was adapted for someone with a learning disability. There were no other, more recent examples of maternity care in the group. This woman felt that the hospital midwives had little understanding of her disability and little patience with her needs:

“They kept complaining about me to social services. I kept telling them that I have a learning disability, and you have to be more patient with me.”

Contraception
Some in the group had seen a health professional about contraception. One had found it embarrassing to see a male GP for advice about going on the contraceptive pill.

One participant said that she had sought out and been given information about different types of contraception by nurses and doctors in the past. She was the only woman in the group who had been to a sexual health clinic, where they had been “really helpful”. The only
issue she had was that the written information had not been accessible or easy-read and did not contain supporting pictures, which she says is always the case in GP surgeries and clinics. Because she can read this was not so much a barrier for her personally, but she thought it would have been for others.

On the subject of where to turn for advice on sex and relationships, one participant said she would ask her GP. All of the women were in contact with CHANGE, and said that they would be able to get accessible information from them.

2.7.6 Cost

There were no issues identified regarding taking time off work for GP appointments. Most of the women were volunteers, one was employed. All were part-time and said they would either arrange appointments around this, or take time off.

Everyone in the group said that they get free prescriptions and did not have to pay or claim money back. Transport costs were not a problem, as all the women had a GP close to their home.

2.7.7 Physical barriers

One woman in the group who was a wheelchair user said:

‘It’s hard if you’ve got mobility problems. It’s hard if you’re in a wheelchair, and the doctor’s surgery is up the stairs.’

She said that in her previous GP surgery, there were two steps up the entrance, but because she has a support worker, they could go inside and ask the staff to bring out the ramp for her. This calls into question the accessibility for wheelchair users without such support.

This woman also said: ‘I went to the hospital once, and the nurse says to me: come and walk over here to use the scales. I said I can’t walk. I cannot stand.’

2.7.8 Gender-based violence

Women with learning disabilities are disproportionately vulnerable to abuse, including gender-based violence. As we have seen in other parts of this report, there are many barriers to reporting this. The communication problem that many women in this group encounter is likely to add to this. There may also be prejudice about people with learning disabilities that mean their experiences are not believed or taken seriously, as some of the women had found.

One woman in the group had experiences of gender-based violence from a partner and the other three described experiences of abuse from family members or friends, for example regarding money.
The woman whose ex-partner had been violent had not sought help from her GP. Despite the fact that she had black eyes and other injuries, it did not occur to her that she could do this. “I felt that they weren’t part of... domestic violence. You can only go to your GP if you’re ill.’

When she ended up in hospital with a fracture, her ex-partner was with her the whole time, pressuring her into saying that the injury was self-inflicted: “I had to lie to the hospital and say I fell down the steps in the flat, when I never did. He told me to say that.”

At one point, she called a women’s help organisation, but because one of her children had disabilities she could not take the advice to leave the home, as that would have meant taking the child out of the special support school. Social services did not take the problem seriously, but eventually she was given support by a specialist counselling service for people with learning disabilities (Respect for All), which offered both couples counselling and individual counselling.

Another participant in the group said that there was a lot of arguing, bullying and even violence in her home. She said that her GP had not taken her concerns seriously, but CHANGE had since referred her to social services. This woman had sometimes told professionals that she wants to “run away”, but she acknowledged that she cannot actually leave, as she would not be able to support herself.

2.7.9 Mental health

All participants had experienced anxiety, depression or panic attacks. When asked about whether they had sought help from their GP, one woman said: “No. I don’t feel comfortable talking about these problems. Not to a man doctor.”

Another woman said that she did not understand what depression and anxiety had to do with health. It was explained to her that mental health can also be treated by a GP.

One participant had felt extremely stressed after the birth of her first baby. She had read about post-natal depression in a magazine and realised that this was probably the cause. However, she did not feel that she could speak to the health visitor or the GP because she did not trust them due to previous negative experiences. When asked what she thought they would have done, she said:

‘Probably remove him. And that’s what I was frightened of. So I thought: I’m not talking to her. So I talked to the social worker from the children’s team… But the social worker never responded, she just wrote it down on a piece of paper. So I never had a diagnosis.’

The effects of cuts to public services came up in relation to counselling services, but the same issues are likely to apply to other areas of support.

‘When they’re pointing you in the direction of other services, there is like a postcode lottery, especially for counselling services. In Manchester there are specialist services for people with learning disabilities. Where we live, you can’t access that because the GP won’t pay for it. And because of our level of disability we don’t
qualify for a social worker. [So apart from not living in the right area] we can't access specialist services because we don't have a social worker, so we have to use our GP counselling service."

Another participant agreed:

‘Where we live they’ve done a lot of cuts, so that people with mild disabilities and physical disabilities don’t get services now, because they’ve cut their money.’

This, and some of the other examples of access barriers given by the group, suggests that there may be a gap in provision for this ‘highly functioning’ group, whereby they are expected to access mainstream services on the same terms as other patients, without any additional support.
Part 3- Discussion and Recommendations

3.1 Securing an appointment

3.1.1 The appointment system

Many GP practices operate appointment systems which pose a barrier to timely treatment. Conditions which are not ‘emergencies’ nor particularly ‘urgent’, can worsen if left untreated for several weeks when the next ‘routine’ appointment is available.

Booking times are often restricted to the early hours of the morning, which clashes with other commitments such as the school run or daily commute. Younger women worried about the cost of being placed on hold when calling from a mobile phone. Women with learning disabilities found automated booking systems inaccessible and difficult to navigate.

Recommendations:

- More flexibility is needed in terms of how appointments are offered and how clinics are scheduled by GPs.

- Audit appointment systems with the help of patient representatives.

- Open up the booking system in order to meet equal access requirements. Online booking is offered by some practices already and we welcome changes to the GP contract which will provide all patients with this option in 2014/15. Some respondents preferred going to see the receptionist in person. Some GP practices also offer a second chance to book an appointment in the afternoon.

- Offer people with learning disabilities annual health checks, which should include smear tests and breast checks for women in the relevant age groups. (Currently, the provision of such checks varies according to area and GP practice.) The Health Action Plan is another tool that can be used to monitor health.

3.1.2 Gate-keeping receptionists

Across all groups, the need to negotiate access with gate-keeping receptionists was an issue, and especially so for asylum seeking and refugee women. This group reported serious difficulties getting access to their GPs, sometimes getting pushed into A&E. Women

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across all groups disliked having to disclose personal details about their health to non-clinical staff. For some, this related to concerns about confidentiality. Recent research by Hammond et al (2013) found that reception staff also dislike having to ask about the nature of the appointment (which is done on instruction from GPs), as it had a negative effect on their relationship with patients.

Receptionists generally have no clinical training but exercise considerable discretion when allocating access to healthcare. By necessity they must do this on the basis of limited information. Receptionists own judgement about the patient and their social group is likely to come into play, as well as the patients’ ability to negotiate, according to a group of researchers from Manchester University. 179 This study also found that reception staff saw it as one of their central roles to protect the system from those trying to take advantage of it, and that whether or not someone was seen as deserving of advocacy was partly based on the receptionist’s personal ‘perceptions of certain groups of patients.’

Recommendations:

- Consider reviewing the kinds of questions patients are asked by receptionists when they call to make an appointment.

- Awareness training for administrative staff about the entitlements of refugees and asylum seekers, about the Equality Act, and about patient confidentiality.

### 3.1.3 Work and caring responsibilities

Appointment times are often incompatible with hours of work and with women’s caring commitments, both due to ‘9-5’ opening times, and the fact that urgent appointments tend to be given at short notice, sometimes less than 30 minutes. The Patients Association estimates that time off work to access health appointments could add up to as much as 5 million working days lost each year. 180 We concur with the observation that a health system that requires taking time off is unaffordable and flawed, especially in the current economic climate.

Many women told us that they cannot afford to take time off work, and mothers pointed out that some schools are reluctant to give children time off for health appointments. Most mothers of small children reported bringing them into their consultation. This is associated with problems relating to communication and confidentiality, and will be discussed in more detail below. Childcare did not come up in discussions about associated costs, indicating it is not seen as an option. Only 6% of survey respondents who were caring for a person with an illness or disability had discussed their caring responsibilities with their GP, suggesting that uptake of carers support is low.

Recommendations:

- In addition to offering a wider range of appointments, consider extended opening times and operating weekend clinics.


180 The Patients Association, 2013, *op. cit.*
• The responsibility of informal care work should be balanced with the offer of support, to which carers are legally entitled. Healthcare professionals should raise awareness of these entitlements in their contact with people who are, or may be, carers.

3.2 Registration

Several respondents to our general survey found the registration process lengthy and time-consuming, interfering with work and other commitments. Some practices only offer registration at certain times, and new patients may be required to leave urine samples and/or have a general health check before they can be fully registered, necessitating several visits.

There was concern in the BME group about the volume and type of information required by GPs and how to meet these requirements if coming from overseas. Indeed, the majority of women in our refugee and asylum focus group found registration 'very difficult'. Reasons for this included not being able to meet the ID requirements, not being able to self-advocate, having no help to assert their rights and lack of knowledge on behalf of GPs practice staff. Prejudice and discrimination also came up and this is discussed in a separate section below.

Women with learning disabilities reported problems with inaccessible forms containing medical jargon, and unsupportive attitudes from GP practice staff when asking for help.

Focus group participants living with HIV wanted a register of suitable practices with knowledge and understanding of their health, to enable them to make an informed choice. Similar sentiments were expressed by women in the LGBT focus group in relation to 'lesbian-friendly' practices. There are at least two issues with this: Firstly, seeking out services endorsed by a third party may indicate expectations of poor treatment by mainstream health services, which goes against NHS and DoH policies and needs to be addressed. Secondly, for patients in smaller areas only served by one or a few practices, choice is limited or nonexistent.

Recommendations:

• Simplify registration procedures to minimise complexity and time demands, including making all application forms available for download and registering new patients at a variety of times.

• Consider combining registration with any compulsory health checks. This would also be an opportunity to offer support with forms, for example for speakers of other languages or women with learning disabilities.

• Documentation requirements should not be a barrier to registration when passport, photo ID or utility bills are not obtainable. Insisting on these documents restricts access to healthcare for groups like asylum seekers, homeless women and members of the Irish Traveller community.
In order to adhere to commitments and obligations relating to equal access and the reduction of health inequalities, NHS England and Health and Wellbeing boards can work with third sector organisations to provide awareness training for clinical and administrative staff about the rights of migrants, asylum seekers and refugees, and NHS obligations towards them, and to act as patient advocates.

Health and wellbeing boards should consider working with local third sector organisations on meeting equalities standards, including becoming 'LGBT-friendly, meeting the needs of patients with HIV, patients with disabilities, speakers of other languages and others who may struggle to register.

We welcome changes to the GP 2014/15 contract which will allow GPs to register patients from outside their practice boundary area, effective from October 2014\textsuperscript{181}, as some patients’ needs are not necessarily met by their local practice.

3.3 Effective use of the appointment

3.3.1 Not being able to see a female GP

The majority in our general survey (88%) responded that they have preferences regarding which GP they see, at least in certain situations. 62% found it easier to discuss reproductive and sexual health with a female health professional and many were averse to the prospect of being examined intimately by a man. Similar sentiments were expressed in many of the focus groups, for example among our younger BME women, who preferred female doctors at all times. Our survey also found anecdotal evidence that some male GPs may be reluctant to examine women, which could compromise the quality of care.

Apart from sexual and reproductive health, many respondents preferred seeing a woman health professional for their mental health, or anything seen as particularly sensitive or private. Some also felt that male GPs do not take women’s concerns seriously. Whilst 66% said they are able to choose a particular GP when they book, 34% said that they could not do this, or they did not know whether this was an option. One woman with a learning disability recalled having requested a female GP for gynaecological issues several times, but to her embarrassment, this had never been accommodated.

Recommendations:

- The availability of female doctors should be recognised as a potential access issue for women as a group of patients. Not meeting this requirement can be a barrier to accessing care for sexual and reproductive health, and mental health.

\textsuperscript{181}NHS Employers, 2013, ’GMS contract changes’, op.cit
• Women should be made aware that they have a choice to see a female health professional, and requests should be met wherever possible, without additional questioning.

• All GP practices should have at least one female doctor in order to meet this need.

3.3.2 Time constraints

29% of respondents to our general survey stated that they cannot always ask the questions they want during the consultation. The main barrier identified was the time restriction and the effect it has on communication. Appointment length varied widely, from 5 minutes or less, to 20 minutes or longer. One woman wrote that her GP sets a timer to ten minutes, which causes her to become so stressed that she forgets what she wanted to ask.

Many women with mental health problems identified concerns about being seen as a ‘time-waster’ as a barrier to seeking help. One woman said ‘5 minutes is not enough to speak about something emotional.’ Mental health is also associated with additional communication problems. This is discussed below in a separate section.

Recommendation:

• Allocation of time should not be done in a way that inhibits communication about sensitive issues, or compromises trust between the patient and doctor.

• GPs may need training on how to provide patients with a supportive environment for disclosure about sensitive issues such as mental health and domestic violence.

3.3.3 Language barriers

As we have seen, migrants are more likely to have to negotiate with GP services in order to get access, but for those who do not have any help with this, any language barrier can make it difficult to get registered, fill in forms, and to successfully convince reception staff of the need for an urgent appointment.

There were many speakers of other languages across the focus groups, although none had personal experience of using interpreters, one woman in the refugee and asylum seeking group knew of a friend whose wife had become very ill, but was told she could not be treated at her GP practice because it did not have access to an interpreter. Using family members may be necessary in emergencies, but compromises patient confidentiality and can prevent disclosure about violence, as well as a range of other issues including sexual and mental health. Similarly, in small communities, the interpreter or translator may know the patient or her family.

\[182\] In response to the question: ‘How long is the average consultation, in your experience?’
Recommendations:

- Confidential interpretation services should be commissioned and provided free of charge to those who require it, in order to meet equalities commitments about equal access as provided for by the Equality Act 2010, the Human Rights Act 1998 and the NHS constitution. Face-to-face interpretation is preferable, but phone services may help to address the issue of small communities where confidentiality could be compromised. Female interpreters should be made available to women wherever possible.

- Awareness needs to be raised among patients about entitlement to interpreter services, for example using strategically placed posters in GP practices.

- Midwives and other healthcare professionals should have awareness of the protected period for pregnant asylum seeking women, allowing them to advocate on their behalf if necessary.

3.3.4 Communication for women with learning disabilities

The focus group for women with learning disabilities identified several communication barriers, starting with the registration form. Several participants had trouble with both explaining the nature of their problem, and with understanding clinical jargon used by GPs in consultations. The lack of accessible information with picture support, for example regarding common health conditions, maternity and sexual health, was another barrier to good quality healthcare identified by this group.

Recommendations:

- The Royal College of General Practitioners recommends ensuring that patients with learning disabilities have their individual communication needs outlined in their patient notes. They also recommend longer appointment slots for patients with Learning Disabilities.

- NHS England is currently working towards implementing an Information Standard for accessible information for patients with disabilities, which means that health and social care organisations will be required to provide information to patients in a format that they can understand. GP practices will need to ensure they comply with this new standard when it is implemented.

- NHS England should consider following the Scottish example: In order to meet the requirement to accessible information, as per the NHS Scotland’s rights-charter, NHS Scotland now supplies accessible easy-read maternity books from CHANGE, to all expectant mothers with learning disabilities.

- NHS England should consider commissioning training for healthcare providers on how to work more accessibly, how to adapt practices and communication to become more inclusive. In recognition of equalities duties and in line with the

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‘No decision about me, without me’ agenda, commissioners and providers should consider seeking advice on implementation from women with learning disabilities themselves.

3.4 Costs

The costs associated with healthcare are an important factor in women’s healthcare decisions. The issue of lost earnings is also a cost factor, which has been discussed under the heading ‘Incompatibility with work, and with caring responsibilities’.

3.4.1 Prescription charges

The rationale for free healthcare is that “the critical importance of unrestricted access to early prompt diagnosis and intervention is in the best interests of both public and patient health.” This principle is compromised if patients cannot afford to pay for the medication prescribed.

Prescriptions are still an important cost factor in England, though not in the rest of the UK. 41% of the women in our survey said that they take prescription charges into account when deciding to make a doctor’s appointment, or that they ‘maybe/sometimes’ do. This is perhaps particularly noteworthy given that our cohort tended to be representative of middle class women on relatively good incomes. As one of the younger participants in the BME focus group pointed out, prescription charges (which rose by 20p to £7.85 in April 2013) can quickly add up to a substantial sum if more than one item is required and although provisions are in place for low-income individuals, questions were raised about how this is implemented in practice, with one woman reportedly waiting three months to be reimbursed.

It is evident that costs are a big problem for destitute asylum seekers. There is also a great deal of confusion about entitlements to free prescriptions, on both sides. Women in our group talked about having to make the difficult choice between allowing their health to deteriorate, and breaking the rules, something they did not take lightly. One of our focus group participants found out from social services that she was eligible for the HC2 only after becoming very ill, and being refused help in the pharmacy.

One young BME woman who did have awareness of the pre-payment scheme found the administrative process to be a deterrent. There was also a perception of stigma associated with low-income schemes, in terms of not getting the same level of service.

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186 Department of Health, 2013, ‘Sustaining services, ensuring fairness – Government response to the consultation on migrant access and financial contribution to NHS provision in England’
Recommendations:

- GPs practices, pharmacies and other NHS organisations should support public awareness of low income schemes by providing forms and advice.

- Free prescriptions for vulnerable migrants should be retained and the HC1 form (the application form for the HC2 certificate) routinely be provided by GPs, pharmacists and other healthcare providers.

3.5 Prejudice and discrimination

Several lesbian and bisexual women in our research had encountered prejudice and ‘low-level’ homophobia in healthcare, such as ‘snide remarks’, health professionals showing clear discomfort with the issue, and having their mental health problems attributed to their sexual orientation. Many of these women also found that nurses and GPs work according to a heteronormative model of care which connects sexual health with contraception and is ignorant of their needs, including their rights to fertility treatment. The fear of being met with homophobic or prejudiced attitudes, described by one survey respondent in terms of “cost to emotional health”, can prevent these women from seeking certain types of healthcare, such as cervical screening, potentially placing them at higher risk of cancer. As we saw in the focus group, it can also limit the ability to disclose emotional distress to doctors, as this tends to be followed by questions about the patient’s personal life and family situation.

Many black and minority ethnic women, both in the BME focus group and the group for refugee and asylum seeking women had encountered prejudiced and potentially racist attitudes when using healthcare. Participants said that asylum seekers are regarded with suspicion, and get worse treatment than other patients, because of their colour, accent and legal status. This group also found that their health problems were simplistically attributed to their circumstances, being told things like: ‘You have this condition because you are African’. This group also had more experiences of being refused services by receptionists than any other in our study, and of being inappropriately referred to A&E. Whilst this can be ascribed in part to a lack of knowledge and information about the legal rights of this group, media imagery of so-called ‘health tourism’ and similar narratives about migration could also play a part in influencing the personal judgement of reception staff, who exercise considerable discretion in their role. If this situation continues, many of the women we spoke to, and others like them, could be shut out of healthcare altogether when the proposed new charges for emergency care for this group are implemented.

Research suggests that women with learning disabilities miss out on sexual and reproductive health screening due to health professionals prejudiced beliefs about their lack of intimate relationships. One woman with learning disabilities, who was also a wheelchair user, reported being sent an appointment for cervical screening, turning up, and being sent home by the nurse without any explanation. Such attitudes are likely to extend to sexual and reproductive care, i.e. giving women choice and control over their fertility by offering contraception.

Participants in our focus group for women with HIV had found that GPs generally had little knowledge about their condition. Many preferred using their specialist clinics for all their health needs, as the staff there would view them ‘as a whole person’. One woman had changed GP practice after only one visit, after seeing a doctor who was openly ‘shocked’ and astonished that she had HIV, and seemed to know nothing about it. Women in this group were especially concerned about confidentiality, especially in relation to receptionists asking questions in front of other patients. This is connected to issues around stigmatisation of people with HIV.

Recommendations:

- Healthcare professionals need training in order to become more confident and comfortable dealing with LGBT patients, becoming more aware of their needs, and knowing how to eliminate discriminatory practices.

- A recent CQC inspection reveals that 1 GP service in 8 has no set complaints procedure.\(^{189}\) Official complaints can be a valuable tool for quality assurance. Complaints should be dealt with according to a set process which is open, accessible and supportive. Awareness can be created using information leaflets and posters.

- In respect of the above, however, it also needs to be recognised that bad experiences may lead to avoidance rather than active engagement. For this reason, alternative methods for evaluation and feedback should also be explored by NHS organisations in order to reach seldom heard groups.

- You cannot improve what you do not measure. Public health data should be gender-disaggregated and contain information about protected characteristics. Questions about sexual orientation need to be asked in sensitive ways and the reasons for collecting this data explained.

- In respect of the above, however, it also needs to be recognised that bad experiences may lead to avoidance rather than active engagement. For this reason, alternative methods for evaluation and feedback should also be explored by NHS organisations in order to reach seldom heard groups.

- Further to the above, GP practices should be required to audit their success in meeting the needs of aforementioned groups via questionnaires/ patient’s group feedback, and make improvements where necessary.

- Underlying reasons why BME and refugee and asylum seeking women tend to report worse health experiences needs to be explored further. Such treatment appears to be discriminatory, and against the Equality Act 2010 and the NHS Constitution. For example, it is unacceptable to refer patients to A&E for non-emergencies, and investigation may be needed into the extent of this problem and how to address it.

- Reception staff should be offered training on patient confidentiality, helping them to deal with concerned patients.

\(^{189}\) D. Campbell, 2013, *op. cit.*
3.6 Mental health problems

There was a high incidence of mental health problems across all of our research groups, many of whom are at increased risk and face multiple disadvantages. Mental health is stigmatised and difficult to talk about, especially in a short and impersonal consultation. Many of our respondents preferred talking to a female GP or nurse. GPs were not generally seen as actively listening or empathetic. Many of our respondents were concerned about being labelled negatively following a mental health diagnosis, especially the women in the group for refugee and asylum seeking women. Some feared having their children taken away, others doubted whether they would be taken seriously and many expected to be offered only medication, which they did not want. There was anecdotal evidence of long waiting times for other alternatives, such as group therapy or counselling.

Recommendations:

- The course of action put forth by the Department of Health\textsuperscript{190} in order to achieve ‘true parity of esteem’ between mental and physical health should be carried out; investigating the scale of the problem, and implementing maximum waiting times for treatment of mental health problems.

- GPs need training on how to provide a safe and non-judgemental space for disclosure about mental distress. Having one GP per practice specially trained in mental health, and putting this information out to patients, is an option.

- The risk of mental health problems like PTSD in the asylum seeker group should be recognised by health professionals, including how cultural issues may affect perceptions of mental health.

3.7 Gender-based violence

Across our research, we found that women were unsure of whether GPs could help with intimate-partner violence. Especially the younger women in the BME focus group lacked confidence in the ability of GPs to address violence and abuse. One young BME woman said her life had been ‘surrounded by violence’ but had never considered her GP as a potential source of support.

Some BME women may be at risk of harmful practices such as female genital mutilation (FGM), forced marriage and so-called ‘honour-based’ violence. Taboo, embarrassment, and mainstream services’ lack of knowledge and understanding of these problems within violence against women and girls (VAWG) framework, are all barriers to seeking and getting help, both relating to FGM, and for sexual and reproductive health more generally. FGM is often discovered at the level of maternity services, sometimes not until the woman is about to give birth. Younger women and those without children are less likely to get help.

\textsuperscript{190} Department of Health, 2013, NHS Mandate, \textit{op.cit.}
Many women across several groups were financially dependent on a partner and did not see leaving as an option. This problem is exacerbated for asylum seeking women whose claim is intertwined with an abusive partner. There may not be awareness of the special rules covering these circumstances. GPs have an important role to play here in terms of providing supporting evidence.

Some of the groups in this study are statistically more likely to be subjected to gender-based violence, as well as facing additional barriers to healthcare. This is a hazardous combination. There is a strong correlation between HIV and the risk of intimate partner violence, both before and after diagnosis. Women with learning disabilities are also statistically vulnerable to abuse, including rape. Communication problems, plus the tendency to create taboos around intimate relationships involving people with learning disabilities are additional barriers for this group. Many women fleeing conflict and war have experienced sexual violence, and can be suffering severe mental distress as a result, and associated stigmas prevalent in some societies can make this already difficult issue even less likely to be addressed by healthcare professionals. One study participant illustrated how the heterosexual bias in health services can cause violence in same-sex relationships to be overlooked. Midwives had disregarded the usual domestic violence checks and protocols because they did not think the same problems could occur between two women. Additionally, transgender women are at increased risk of intimate partner violence and sexual abuse.

Recommendations:

- Work on FGM should reach outside of the maternity setting and be subject to set referral pathways, which should include advocacy support. In the case of younger girls, it should be incorporated into existing child safeguarding frameworks.
- A recent CQC inspection showed that 12% of surgeries do not know the correct procedures for safeguarding children and vulnerable adults, such as women with learning disabilities. This needs to be addressed.
- Health professionals should recognise that intimate partner violence also happens in same-sex relationships and adapt standard forms and procedures accordingly.
- Patients should be made aware that their GP services can be a first step towards getting help with gender-based violence. Information from women’s organisations, such as posters and leaflets, should be placed in waiting areas. Equally, information should be available in community settings such as libraries, pharmacies and community organisations.

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194 D. Campbell, 2013, op. cit.
• We concur with the NICE recommendation that strategic partnerships, such as Health and Wellbeing boards identify all local services that deal with domestic abuse and map them against the Home Office/AVA ‘Coordinated Community Response Model’. Services should also be mapped in order to identify other local specialist organisations such as Rape Crisis Centres, BME VAWG specialists and community based organisations that work with LGBT women, disability and other protected groups or groups with comparatively poor health outcomes.

• GP surgeries should draw on existing models of promising practice, such as the IRIS project, and the GP champions Youth Inclusion Project, which have improved collaboration between the voluntary sector and primary care through prompts for clinical enquiry, care pathways, practice – based clinical leads, and VAWG experts based in GP surgeries.

• Consistent and standardised training or guidelines are needed for health professionals about how to identify the signs of gender-based violence, the impact of gender-based violence and responding appropriately. GPs should work in partnership with specialist voluntary sector organisations to develop appropriate referral pathways that also ensure confidentiality and safety in situations where women may disclose gender-based violence. This should also include knowledge about issues relating to asylum-seeking women and their entitlements in gender-based violence situations where their asylum claim is linked to the perpetrator of violence. Knowledge should be updated along with changes in legislation and policy, so that GPs can provide the vital support that women in this situation need.

• We concur with the 2013 intercollegiate recommendation that ‘all new patient registrations in primary and secondary care, including A&E of young girls/women, should include detailed enquiry about country of origin. If the family is from FGM practising community, document any presence of FGM to establish a baseline for monitoring and sharing information with the relevant agencies.’

• We concur with the Alberti Review recommendations, including the one that ‘NHS staff should be made aware of the issues relating to violence and abuse


196 Nia, IRIS project, see for example http://www.niaendingviolence.org.uk/advocacy/iris.php

197 Association for Young People’s Health, GP Champions project http://www.youngpeopleshealth.org.uk/5/page/71/gp-champions-project/

198 Royal College of Midwives and partners, 2013, Tackling FGM in the UK, op.cit.
against women and children, and of their role in addressing those issues, including how to broach the issue sensitively and confidently with patients’. 199

3.8 General recommendation

Recommendation:

- This report has flagged up several areas in which NHS providers can potentially fail to meet the needs of their patients. In order to meet equalities duties and public health duties to the local community, NHS organisations should identify where service delivery falls short of their equalities commitments, for example using the NHS Equality Delivery System EDS2.


200 For example NHS constitution principles: ‘You have the right to expect your local NHS to assess the health requirements of the local community and to commission and put in place services to meet those needs where considered necessary.’ And ‘The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.’
Appendices

4.1 Survey questions
Welcome, and thank you!

This survey is part of a research project undertaken by Maternity Action and a number of other partner organisations in the Women’s Health and Equality Consortium (WHEC). The results will be presented in a report to the Department of Health and the NHS early next year. The objective is to help policymakers improve access to health services, by highlighting the issues raised by women in the UK.

You will remain completely anonymous, and we will not ask your name, address or contact details. All the information you provide will be treated with complete confidentiality. If we quote you in the report, we will change key details.

The survey takes approximately 5-10 minutes to complete, and is divided into a number of topics. If you have any problems or questions, please email: annahpsarros@maternityaction.org.uk.

This survey focuses on the experiences of all people in the UK who identify as women.

*1. This survey focuses on women in the UK (including transgender / intersexed women). Please confirm whether you are a woman.

   ○ Yes
   ○ No

Thank you for showing an interest

Thank you for showing an interest in our work. This survey examines the experiences of women in the UK. If you are interested in contributing with your views on other aspects of health, you can contact other strategic partners of the Department of Health, listed here:


Registration

*2. Are you registered with a GP?

   ○ Yes
   ○ No
   ○ Other (please specify)

If you are not registered with a GP

This survey is about GP services. If you are not registered with a GP, you can still answer the questions that apply to you, if you have used GP services previously.

3. If you are not registered with a GP, can you tell us the main reasons for this?

   [Input field for main reasons]
4. Please tell us roughly how long you have been registered with your current GP.
   - 1-3 years
   - 4-10 years
   - More than 10 years
   - Other (please specify)

5. On what basis did you choose which GP practice to register with?
   (If you do not remember, please leave blank)

6. Please tell us with up to three words what you thought of the registration process
   (ex: easy, quick, long-winded, complicated).
   (If you do not remember, please leave blank)

7. Is there anything that would have made registration easier for you?

Appointments

8. When was the last time you saw a GP?
   - In the last year
   - More than one year ago
   - More than five years ago
   - Other (please specify)
9. How easy or difficult is it for you to get an appointment with a GP when you need one?

- [ ] Very easy
- [ ] Relatively easy
- [ ] Acceptable
- [ ] Relatively difficult
- [ ] Very difficult
- [ ] Other (please specify)

10. What, if anything, would make it easier for you to get an appointment with your GP?

[ ]

### Out-of-hours services

11. Have you used an NHS out-of-hours service in the last few years?

(For example: NHS direct, NHS111, an out-of-hours GP service, walk-in centre or similar services that are open when regular GP services are closed. Emergency services are not included here.)

- [ ] Yes
- [ ] No
- [ ] Do not know

**If you have used out-of-hours services**

12. Which out-of-hours service was it?

[ ]

13. How would you rate your experience with the NHS out-of-hours service you used?

- [ ] Excellent
- [ ] Very good
- [ ] Good
- [ ] Acceptable
- [ ] Poor
- [ ] Very poor
- [ ] Extremely poor
- [ ] Other (please specify)

[ ]
14. Does your GP practice give you the option of choosing which doctor you want to see?
- Yes
- No
- I do not know

15. Does it matter to you which doctor you see?
- Yes
- No
- Sometimes

16. If it matters to you, or matters 'sometimes' which GP you see - in what situations might it matter?

17. How would you describe the attitudes of the staff at your GP practice? (Leave blank if you do not know)

Doctors

Nurses and healthcare assistants

Reception staff and administrative staff

18. How do you rate the communication skills of the doctors at your practice?
- Excellent
- Very good
- Good
- Acceptable
- Poor
- Very poor
- Extremely poor
- Other (please specify)
19. When you see a GP, do you usually feel able to explain your symptoms and concerns?
   - Yes
   - No
   - Other (please specify)

20. When you see a GP, do you usually feel that they understand what the problem is?
   - Yes
   - No
   - Other (please specify)

21. Do you usually feel that GPs competently explain about your health, medications, treatments and referrals?
   - Yes
   - No
   - Other (please specify)

22. Do you usually feel able to ask the questions you want to ask in the consultation?
   - Yes
   - No
   - Other (please specify)

23. How long does a GP consultation generally last, in your experience?

24. Is there anything else you want to add, on the subject of communicating with doctors?

Costs

25. Do you currently do any paid work?
   - Yes
   - No

If you do paid work
26. Do you usually have to take time off work in order to go to see the GP?
   - Yes
   - No

Taking time off to see a GP

27. Does the prospect of having to take time off work influence your decision about whether to make a health appointment when you need one?
   - Yes
   - No
   - Maybe / Sometimes

For all respondents, whether you do paid work or not

28. Does the prospect of having to pay for medication influence your decision about whether to make a health appointment when you need one?
   - Yes
   - No
   - Maybe / Sometimes

29. Does the cost of travelling to the GP practice influence your decision?
   - Yes
   - No
   - Maybe / Sometimes

30. Are there any other costs (money, time or anything else) that influence whether or not you make an appointment when you need one?

Children

31. Are there any children under 16 in your household?
   - Yes
   - No

If there are children under 16 in your household
32. In general, how easy or difficult do you find getting a GP appointment for the child?

- Very easy
- Relatively easy
- Acceptable
- Relatively difficult
- Very difficult
- Do not know
- Other (please specify)

33. Is there anything that would make it easier for you to get an appointment for the child?

34. Do you usually need to do any of the following when you have a doctor's appointment for yourself? (Tick any that apply)

- Take the child with you to the appointment
- Ask someone to look after the child while you go to the GP
- Try to fit the appointment around the times the child needs you
- Other (please specify)

Carers

35. In your personal life, (i.e. not in a professional capacity), do you regularly support or care for a person with a long-term illness or disability? This could be anything from personal care to help with shopping or just keeping someone company.

- Yes
- No

If you have caring responsibilities

36. Do you consider yourself to be a carer?

- Yes
- No
37. In general, how easy or difficult is it to get a health appointment for the person you care for?

- Very easy
- Relatively easy
- Acceptable
- Relatively difficult
- Very difficult
- Do not know
- Other (please specify)

38. Is there anything that would make it easier for you to make an appointment for the person you care for?

39. Do you usually need to do any of the following when you have a doctor's appointment for yourself? (Tick any that apply)

- Take the person you care for with you to the appointment
- Ask someone to help the person while you go to the GP
- Try to fit the appointment around the times the person needs you

Other (please specify)

40. Has your GP ever discussed your caring responsibilities with you?

- Yes
- No

41. Please tell us about any help or advice your GP has offered you because you are a carer. Examples might be a yearly flu jab, a referral to a local support group, a referral to have a carers assessment with social services, a respite service or anything similar.

42. Has violence or abuse from a partner or family member ever been an issue for you?

- Yes
- No
- Prefer not to answer
### If you have experienced violence or abuse from partner or family

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>43. Did you talk to your GP about the violence or abuse?</td>
<td>Yes, No</td>
</tr>
</tbody>
</table>

### If you have spoken to your GP

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>44. Please tell us about how your doctor responded to your concerns.</td>
<td></td>
</tr>
</tbody>
</table>

### If you have not spoken to your GP

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>45. What do you think are the main reasons you did not talk to your GP about the violence or abuse?</td>
<td></td>
</tr>
</tbody>
</table>

### Non-physical health needs

Anxiety, depression and other non-physical health problems are common in women and a recent report states that these issues are neglected by the NHS. We want to know what patients think about how these kinds of health problems are treated by GPs.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>46. Have you ever experienced anxiety, depression, panic attacks or any other similar problem?</td>
<td>Yes, No, Prefer not to answer</td>
</tr>
</tbody>
</table>

### If you have had a non-physical health problem

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>47. If you have experienced such a health problem, did you go to your GP for help?</td>
<td>Yes, No</td>
</tr>
</tbody>
</table>

### If you did seek help from your GP

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>48. Please tell us your GPs reaction to this and what they did to help.</td>
<td></td>
</tr>
</tbody>
</table>
If you did not seek help from your GP

49. What do you think were the main reasons you didn’t ask for help from your GP?

Reproductive health, contraception and sexual health

50. Do you currently see a health professional for contraception? (For example, if you use the pill, a coil or some other method that you need to see a nurse or doctor about)

- Yes
- No
- Prefer not to answer

If you see a health professional for contraception

51. Do you see your regular GP or a separate clinic (such as a local family planning clinic or sexual health clinic) for this?

- GP
- Clinic
- Other (please specify)

Discussing reproductive health, contraception and sexual health

52. How do you feel about discussing things like reproductive health, contraception and sexual health with doctors and nurses?

53. When discussing these kinds of issues with a GP or other health professional, does it matter to you what gender the health professional is?

- Yes, I find it easier to discuss these issues with a woman
- Yes, I find it easier to discuss these issues with a man
- No, it does not matter

Maternity
54. Have you ever accessed maternity-related health services?
   - Yes
   - No

Maternity services

55. Did your GP refer you to a midwife?
   - Yes
   - No, I contacted a midwife myself
   - Other (please specify)

56. How easy or difficult did you find it to access a midwife?
   - Very easy
   - Relatively easy
   - OK
   - Relatively difficult
   - Very difficult
   - Other (please specify)

57. What, if anything, would make it easier for you to access a midwife?

Demographic information

58. What is your age?

59. Which ethnic group do you identify with?
   - Other (please specify)
60. Where in the UK are you?
- Northern Ireland
- Scotland
- England
- Wales
- Other (please specify)

61. In which county in the UK do you live?

62. What is the highest level of education that you have completed?
- Other (please specify)

63. What is your approximate annual household income?

64. How would you describe your household?
- Single, no children
- Single with children
- Couple, no children
- Couple with children
- Other (please specify)

65. How would you describe your sexual orientation?
- Heterosexual
- Bisexual
- Lesbian
- Prefer not to answer
- Other (please specify)

66. Do you have any long-term health conditions or disabilities?
67. Is there anything else that you would like to add, relating to any of the issues brought up in the survey?
4.2 Questions / items of discussion for focus groups

4.2.1 BME women’s focus group

To the facilitator:

- **The discussion items are in bold.** If you want to reword them in a way that you think is more appropriate to the group, please do. Underneath are some suggested follow-up questions.

- There may not be enough time to cover all the topics. That depends on what the group wants to talk about, and that is fine. It may be more useful to have an in-depth discussion about an issue that the group finds particularly important, than to scratch the surface of all of them.

- If you think the discussion is going off-topic, please remind the group that the focus should be their own experiences of accessing and using primary care services. (i.e. GPs and community clinics, but not specialist or hospital care.)

- Sensitive issues like mental health and violence are at the end. Include these if you feel that the group is open to discussing them.

- Lastly, if someone has an ongoing problem with domestic violence or mental health and have not sought help, we will offer to put them in touch with an appropriate support organisation after the session.

Registration

- **Please tell us about your experiences of registering with a GP practice.**

  Potential follow-up questions, if needed:

  - Is it easy or difficult to register with a GP?
  - What, if anything, would have made it easier for you?
  - Were you asked for ID/Proof of address? Did you have this?
  - How did you choose which GP to register with?
  - Do you know what your rights and entitlements are with regards to registering and seeing a GP?

Access

- **Please tell us about your experiences of making an appointment with your GP.**

  Potential follow-up questions, if needed:

  - How easy or difficult is it for you to get a doctor’s appointment?
  - Is there anything that would make it easier for you to get an appointment?

Staff attitudes

- **How would you describe the attitudes of staff at your GP practice?** – This includes receptionists, nurses and doctors.

  Potential follow-up questions, if needed:

  - How does it make you feel to talk to: receptionists/nurses/doctors?
• Please tell us about any memorable experiences, either positive or negative, that you have had with receptionists/nurses/doctors?
• Do you have a preference about which doctor you see? (+Reasons)

Doctor-patient communication/
• Please tell us about your experiences of communicating with doctors in consultations.

Potential follow-up questions, if needed:
• Please tell us about your experiences with interpretation or translation (Good/bad experiences.)
• Do you usually feel that you can tell the doctor what the problem is?
• That they understand?
• Do they explain things well?
• Do you feel able to ask questions?

Costs
• Do you usually have to take time off work to see a doctor?
• Is taking time off work a factor when you decide whether to go to the doctor?

Potential follow-up questions, if needed:
• Does the prospect of having to pay for medication influence your decision?
• Does the cost of travelling to the GP practice influence your decision?
• Are there any other personal costs (time, money, childcare or anything else) associated with seeing a doctor that influence your decision about whether or not to make an appointment when you need one?

Caring
• Do you have children? / Do you care for a person with an illness or disability?
• When you need to see a doctor, do you need to combine that with your caring responsibilities?
• How do you do this?

Sexual and reproductive health
• How do you feel about discussing intimate health issues with a GP or nurse? (Such as contraception / reproduction / reproductive health)

Potential follow-up questions, if needed:
• Can you tell us about your experiences of such discussions? (Positive? Negative? Neutral?)
• Does it matter to you if the doctor or nurse is male or female?

Mental health
• Do you think GPs are able to help with mental health problems?
• If you have experienced any such health problems, and you feel comfortable talking about this: Was your GP able to help you?
Potential follow-up questions, if needed:

- If they did seek help from GP: Please tell us about the GP’s response.
- If they did not seek help from their GP: What do you think are the main reasons?
- How could it have been made easier for you to talk to your GP about this?

Violence or abuse

- Do you think that a GP would be able to help you if you had problems with violence or abuse from your partner or someone in the family? (Reasons why/not?)

Potential follow-up questions, if needed:

- If anyone has experienced this, and you feel comfortable talking about it: Did you seek help from your GP?
- (YES) What was their response?
- (NO) What do you think are the main reasons you did not? Is there anything that would have made it easier for you?

4.2.2 Refugees and asylum seeking women

To the facilitator:

- The discussion items are in bold. If you want to reword them in a way that you think is more appropriate to the group, please do. Underneath are some suggested follow-up questions.
- There may not be enough time to cover all the topics. That depends on what the group wants to talk about, and that is fine. It may be more useful to have an in-depth discussion about an issue that the group finds particularly important, than to scratch the surface of all of them.
- If you think the discussion is going off-topic, please remind the group that the focus should be their own experiences of accessing and using primary care services. (I.e. GPs and community clinics, but not specialist or hospital care.)
- Sensitive issues like mental health and violence are at the end. Include these if you feel that the group is open to discussing them.
- Lastly, if someone has an ongoing problem with domestic violence or mental health and have not sought help, we will offer to put them in touch with an appropriate support organisation after the session.

Registration

- Please tell us about your experiences of registering with a GP practice.

Potential follow-up questions, if needed:

- Is it easy or difficult to register with a GP?
- What, if anything, would have made it easier for you?
- Were you asked for ID/Proof of address? Did you have this?
• How did you choose which GP to register with?
• Do you know what your rights and entitlements are when it comes to healthcare?

Access
• Please tell us about your experiences of making an appointment with your GP.

Potential follow-up questions, if needed:
• How easy or difficult is it for you to get a doctor’s appointment?
• Is there anything that would make it easier for you to get an appointment?

Staff attitudes
• How would you describe the attitudes of staff at your GP practice? – This includes receptionists, nurses and doctors.

Potential follow-up questions, if needed:
• How does it make you feel to talk to: receptionists/nurses/doctors?
• Do they understand you?
• Please tell us about any memorable experiences, either positive or negative, that you have had with receptionists/nurses/doctors?
• Do you have a preference about which doctor you see? (+Reasons)

Doctor-patient communication/
• Please tell us about your experiences of communicating with doctors in consultations.

Potential follow-up questions, if needed:
• Please tell us about any experiences with interpretation or translation (Good/bad experiences.)
• Do you usually feel that you can tell the doctor what the problem is?
• That they understand?
• Do they explain things well?
• Do you feel able to ask questions?

Costs
• Do you usually have to take time off work to see a doctor?
• Is taking time off work a factor when you decide whether to go to the doctor?

Potential follow-up questions, if needed:
• Does the prospect of having to pay for medication influence your decision?
• Does the cost of travelling to the GP practice influence your decision?

• Are there any other personal costs (time, money, childcare or anything else) associated with seeing a doctor that influence your decision about whether or not to make an appointment when you need one?

Caring
• Do you have children?
• Do you care for a person with an illness or disability?
• When you need to see a doctor, do you need to combine that with your caring responsibilities?
  • How do you do this? (I.e. Do you have someone who can help you? Do you take your children with you?)

Maternity services
• Please tell us about your experiences with accessing maternity services.

Sexual and reproductive health
• How do you feel about discussing intimate health issues with a GP or nurse? (Such as contraception / reproduction / reproductive health)

Potential follow-up questions, if needed:
• Can you tell us about your experiences of such discussions? (Positive? Negative? Neutral?)
• Does it matter to you if the doctor or nurse is male or female?

Mental health
• Let’s talk about emotional health – have you ever experienced anxiety or depression, or post-traumatic stress disorder, or anything similar?
• Did you seek help from your GP?

Potential follow-up questions, if needed:
• If they did seek help from GP: Please tell us about the GP’s response.
• If they did not seek help from their GP: What do you think are the main reasons?
• How could it have been made easier for you to talk to your GP about this?

Violence or abuse
• Do you think that a GP would be able to help you if you had problems with violence or abuse from your partner or someone in the family? (Reasons why/not?)

Potential follow-up questions, if needed:
• If anyone has experienced this, and you feel comfortable talking about it: Did you seek help from your GP?
• (YES) What was their response?
• (NO) What do you think are the main reasons you did not? Is there anything that would have made it easier for you?

4.2.3 Women living with HIV

To the facilitator:
• **The discussion items are in bold.** If you want to reword them in a way that you think is more appropriate to the group, please do. Underneath are some suggested follow-up questions.

• There may not be enough time to cover all the topics. That depends on what the group wants to talk about, and that is fine. It may be more useful to have an in-depth discussion about an issue that the group finds particularly important, than to scratch the surface of all of them.

• If you think the discussion is going off-topic, please remind the group that the focus should be **their own experiences of accessing and using primary care services.** (I.e. GPs and community clinics, but not specialist or hospital care.)

• Sensitive issues like mental health and violence are at the end. Include these if you feel that the group is open to discussing them.

• Lastly, if someone has an ongoing problem with domestic violence or mental health and have not sought help, we will offer to put them in touch with an appropriate support organisation after the session.

**Registration**

• Please tell us about your experiences of registering with a GP practice.

  *Potential follow-up questions, if needed:*

  • How did you choose which GP to register with?
  • Is it easy or difficult to register with a GP?
  • What, if anything, would make it easier for you to register with a GP practice?
  • Did you have to disclose all your health conditions on a form when you registered?

**Access**

• Please tell us about your experiences of making an appointment with your GP.

  *Potential follow-up questions, if needed:*

  • How easy or difficult is it for you to get a doctor’s appointment?
  • Is there anything that would make it easier for you to get an appointment?
  • Is your GP competent and confident in treating your non-HIV related needs?
  • Is there any communication between your GP and HIV clinic?

**Staff attitudes**

• How would you describe the attitudes of staff at your GP practice? – This includes receptionists, nurses and doctors.

  *Potential follow-up questions, if needed:*

  • Please tell us about any memorable experiences, either positive or negative, that you have had with receptionists/nurses/doctors?
  • How does it make you feel to talk to: receptionists/nurses/doctors?
  • Do you have a preference about which doctor you see?
  • Are there any particular reasons why you may want to see a particular doctor? Or any specific situations?
• Do you have the option of choosing a particular doctor when you book?

Doctor-patient communication/
• Please tell us about your experiences of communicating with doctors in consultations.

Potential follow-up questions, if needed:
• Do you have any memorable experiences of consultations? (Positive or negative)
• Is there anything you find it difficult to talk to your GP about? Is there anything would make it easier?
• Do you usually feel that you can tell the doctor what the problem is?
• That they understand?
• Do they explain things well?
• Do you feel able to ask questions?

Costs
• Do you usually have to take time off work to see a doctor?
• Is taking time off work a factor when you decide whether to go to the doctor?

Potential follow-up questions, if needed:
• Does the prospect of having to pay for medication influence your decision?
• Does the cost of travelling to the GP practice influence your decision?
• Are there any other personal costs (time, money, childcare or anything else) associated with seeing a doctor that influence your decision about whether or not to make an appointment when you need one?

Mental health
• Do you think GPs are able to help with mental health problems?

Potential follow-up questions, if needed:
• If you have had a mental health problem, and you feel OK discussing it, please tell us how you dealt with this. Did you seek help from your GP?
• (YES) How did your GP respond?
• (NO) What do you think is the main reason you did not go to your GP with this problem?
• How could it have been made easier for you to talk to your GP about mental health?

Sexual and reproductive health screening
• Have you ever been offered cervical screening, breast screening or sexual health screening?

Potential follow-up questions, if needed:
• Do you get offered this regularly?
• Do you usually attend?
• If no, why not?
Sexual and reproductive health

- How do you feel about discussing sexual health, fertility and similar issues with a GP or nurse? (If concerned – What are your main concerns?)
- Can you tell us about your experiences of such discussions? (Positive? Negative? Neutral?)
- Does it matter to you if the doctor or nurse is male or female?

Maternity services

- Have you ever used maternity services?
- Please tell us about your experiences with accessing and using maternity services.

Violence or abuse

- Do you think that GPs could help you if you had problems with violence or abuse?

Potential follow-up questions, if needed:

- If anyone has experienced this, and you feel comfortable talking about this: Did you seek help from your GP?
- What was their response?

1.2.4 LGBT women

To the facilitator:

- The discussion items are in bold. If you want to reword them in a way that you think is more appropriate to the group, please do. Underneath are some suggested follow-up questions.
- There may not be enough time to cover all the topics. That depends on what the group wants to talk about, and that is fine. It may be more useful to have an in-depth discussion about an issue that the group finds particularly important, than to scratch the surface of all of them.
- If you think the discussion is going off-topic, please remind the group that the focus should be their own experiences of accessing and using primary care services. (I.e. GPs and community clinics, but not specialist or hospital care.)
- Sensitive issues like mental health and violence are at the end. Include these if you feel that the group is open to discussing them.
- Lastly, if someone has an ongoing problem with domestic violence or mental health and have not sought help, we will offer to put them in touch with an appropriate support organisation after the session.

Registration

- Please tell us about your experiences of registering with a GP practice.

Potential follow-up questions, if needed:

- How did you choose which GP to register with?
- Is it easy or difficult to register with a GP?
• What, if anything, would make it easier for you to register with a GP practice?

Access
• Please tell us about your experiences of making an appointment with your GP.

Potential follow-up questions, if needed:
• How easy or difficult is it for you to get a doctor’s appointment?
• Is there anything that would make it easier for you to get an appointment?

Staff attitudes
• How would you describe the attitudes of staff at your GP practice? – This includes receptionists, nurses and doctors.

Potential follow-up questions, if needed:
• How does it make you feel to talk to: receptionists/nurses/doctors?
• Please tell us about any memorable experiences, either positive or negative, that you have had with receptionists/nurses/doctors?
• Do you have a preference about which doctor you see?
• Do you have the option of choosing a particular doctor?
• Are there any particular reasons for wanting to see a particular doctor? Or any specific situations?

Doctor-patient communication/
• Please tell us about your experiences of communicating with doctors in consultations.

Potential follow-up questions, if needed:
• Do you have any memorable experiences of consultations? (Positive or negative)
• Is there anything you find it difficult to talk to your GP about? Is there anything would make it easier?
• Do you usually feel that you can tell the doctor what the problem is?
• That they understand?
• Do they explain things well?
• Do you feel able to ask questions?

Costs
• Do you usually have to take time off work to see a doctor?
• Is taking time off work a factor when you decide whether to go to the doctor?

Potential follow-up questions, if needed:
• Does the prospect of having to pay for medication influence your decision?
• Does the cost of travelling to the GP practice influence your decision?
• Are there any other personal costs (time, money, childcare or anything else) associated with seeing a doctor that influence your decision about whether or not to make an appointment when you need one?
Mental health

- Do you think GPs are able to help with mental health problems?
- If you have experienced any such health problems, was your GP able to help you?

*Potential follow-up questions, if needed:*

- If you want, please tell us how you dealt with this, ie. Did you seek help from your GP?
- [If they have not sought help at all, offer to help them get in touch with an appropriate organisation after the session]
- How could it have been made easier for you to talk to your GP about this?

Sexual and reproductive health screening

- Have you ever been offered cervical screening, breast screening or sexual health screening?

*Potential follow-up questions, if needed:*

- Do you get offered this regularly?
- Do you usually attend?
- If no, why not?

- Do you get sexual health and reproductive health information that suits your needs?
- Where would you prefer to go for this kind of information and health screening? (GP/clinic?)

Sexual and reproductive health

- How do you feel about discussing sexual health, fertility and similar issues with a GP or nurse? *(If concerned – What are your main concerns?)
- Can you tell us about your experiences of such discussions? *(Positive? Negative? Neutral?)
- Does it matter to you if the doctor or nurse is male or female?

Maternity services

- Have you ever used maternity services?
- Please tell us about your experiences with accessing maternity services.

*Potential follow-up questions, if needed:*

- Have you ever discussed fertility, or fertility treatment, like IVF with your GP? Please tell us about this.

Caring

- Do you have children? *[Will know from previous question]*
- Do you care for a person with an illness or disability?
- When you need to see a doctor, do you need to combine that with your caring responsibilities?
• How do you do this?

Violence or abuse
• Do you think that GPs could help you if you had problems with violence or abuse?

Potential follow-up questions, if needed:
• If anyone has experienced this, and you feel comfortable talking about this: Did you seek help from your GP?
• What was their response?

1.2.5 Women with learning disabilities

To the facilitator:
• The discussion items are in bold. If you want to reword them in a way that you think is more appropriate to the group, please do. Underneath are some suggested follow-up questions.
• There may not be enough time to cover all the topics. That depends on what the group wants to talk about, and that is fine. It may be more useful to have an in-depth discussion about an issue that the group finds particularly important, than to scratch the surface of all of them.
• If you think the discussion is going off-topic, please remind the group that the focus should be their own experiences of accessing and using primary care services. (I.e. GPs and community clinics, but not specialist or hospital care.)
• Sensitive issues like mental health and violence are at the end. Include these if you feel that the group is open to discussing them.
• Lastly, if someone has an ongoing problem with domestic violence or mental health and have not sought help, we will offer to put them in touch with an appropriate support organisation after the session.

Registration
• If you remember, what was it like to register with a GP?
• Was it easy or difficult?

Potential follow-up questions, if needed:
• What did you have to do?
• Did you have help?
• How did you choose which GP to register with?
• Is there anything that would have made it easier for you to register?

Access
• Please tell us about your experiences of making an appointment with your GP.

Potential follow-up questions, if needed:
How easy or difficult is it for you to get a doctor's appointment?
Do you need help to make an appointment?
How about getting there – Do you need help with that?
Is there anything that would make it easier for you to make an appointment?
Is there anything that would make it easier for you to get there?

Staff attitudes
- The doctors who work at the GP practice, what are they like?
- How do they speak to you?
- How do you feel when you talk to them?

- How about the...
- Receptionists?
- Nurses?

Doctor-patient communication/
- Please tell me about what happens when you go into the room and speak to the doctor.

Potential follow-up questions, if needed:

- Do you have any specific negative or positive memories of talking your GP? Please tell us about this.
- Do you usually feel that you can tell the GP what the problem is?
- Do you think that they understand?
- Do they explain things properly about your health?
- Do you feel like you can ask questions?
- Are there any things that are difficult to talk to a doctor about?
- If yes, what do you think could be done about this to make it easier for you?
- Do you mind which doctor you see?
- Can you choose who you want to see when you make an appointment?
- Is there any particular thing that you might prefer to see a specific doctor about?

Choice and control
- Who do you think makes most of the decisions about your health?

Costs
- Do you work, volunteer or study during the day?
- If yes:
  - Do you have to take time off if you need to see a doctor? (Does that affect your decision about seeing a doctor or not? In what way?)
  - Do you pay for your prescriptions? (Does that affect your decision about seeing a doctor or not? In what way?)
  - Do you pay for transport to get to the GP? (Does that affect your decision about seeing a doctor or not? In what way?)
  - Is there anything else that affects your decision? (Childcare, caring responsibilities, etc)
Questions relating to women’s health

- Do you know where to get information about relationships, contraception and women’s health?

Possible follow-ups:

- Have you ever spoken to a nurse or doctor about contraception?
- Have you ever been offered cervical screening? Do you know what this is for?
- Breast cancer screening?
- Sexual health screening?

- Do you have children? Tell us about your experiences with maternity services.

Caring

- Do you have children? [will know from previous]
- Do you care for a person with an illness or disability?
- When you need to see a doctor, do you need to combine that with your caring responsibilities?
- How do you do this?

Questions relating to gender-based violence

- Nobody has to answer this question if they don’t want to, but:
  - If you have ever had problems with a partner or family member being violent or abusive to you; did you get help with this from a doctor?

  - (if yes)
  - Did you get help? What did the doctor do to help you?

  - (if no)
  - Do you think that doctors are able to help with this kind of thing?

- [If someone has an on-going issue they have not sought help for, we will offer to put her in touch with an appropriate contact]

Questions relating to mental health

- Again, nobody has to answer this question if they don’t want to, but:
  - If you have ever experienced anxiety, depression, panic attacks or any other similar problem, did you talk to your GP?

Possible follow-ups:

- (If yes)
  - What did your GP say? What did he or she do to help?
- (If no)
  - What do you think were the main reasons you did not ask for help from your GP?
  - Do you think doctors can help with this kind of thing?
• [If someone has an on-going issue they have not sought help for, we will offer to put her in touch with an appropriate contact]
1.3 Demographics form

Demographics

This form is anonymous. Please tick the relevant box. Thank you very much for giving your time to this project!

1. What is your age?

<table>
<thead>
<tr>
<th>Age Range</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 18</td>
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</tr>
<tr>
<td>19-25</td>
<td></td>
</tr>
<tr>
<td>26-30</td>
<td></td>
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<td>31-35</td>
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<td>81-85</td>
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<tr>
<td>86-90</td>
<td></td>
</tr>
<tr>
<td>91+</td>
<td></td>
</tr>
<tr>
<td>Would rather not say</td>
<td></td>
</tr>
</tbody>
</table>

2. Which ethnic group do you identify with?

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White English/Welsh/Scottish/Northern Irish/British</td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td></td>
</tr>
<tr>
<td>Gypsy or Irish traveller</td>
<td></td>
</tr>
<tr>
<td>White European</td>
<td></td>
</tr>
<tr>
<td>White Other</td>
<td></td>
</tr>
<tr>
<td>Mixed White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>Mixed White and Black African</td>
<td></td>
</tr>
<tr>
<td>Mixed White and Asian</td>
<td></td>
</tr>
<tr>
<td>Any other mixed or multiple ethnic background</td>
<td></td>
</tr>
<tr>
<td>Asian British</td>
<td></td>
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<tr>
<td>Asian (Indian)</td>
<td></td>
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<tr>
<td>Asian (Pakistani)</td>
<td></td>
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<tr>
<td>Asian (Chinese)</td>
<td></td>
</tr>
<tr>
<td>Black British</td>
<td></td>
</tr>
<tr>
<td>Black African</td>
<td></td>
</tr>
<tr>
<td>Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>Any other Black background</td>
<td></td>
</tr>
</tbody>
</table>
3. What UK city or town do you live in?

4. What is the highest level of formal education that you have attained?
   - No formal qualifications
   - GCSE or equivalent
   - A-Level or equivalent
   - GNVQ/NVQ or other vocational qualification
   - Professional qualification (for example chartered accountant or surveyor)
   - Diploma or Higher Education
   - Bachelor’s Degree
   - Master’s Degree
   - Doctorate
   - Other (please specify)
   - Would rather not say

5. What is your approximate annual household income?
   - Less than £15 000
   - 15 000 – 19 999
   - 20 – 29 999
   - 30 000 – 39 999
   - 40 000 – 49 999
   - 50 000 – 59 999
   - 60 000 – 69 999
   - 70 000 – 79 999
   - 80 000 – 89 999
   - 90 000 – 99 999
   - 100 000 – 149 999
   - 150 000 or above
   - Would rather not say

6. How would you describe your household? (The people who live with you)
   - Single, no children
   - Single with children
   - Couple, no children
   - Couple with children
   - Other (please specify)
   - Would rather not say
7. How would you describe your sexual orientation?

<table>
<thead>
<tr>
<th>Orientation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual</td>
<td></td>
</tr>
<tr>
<td>Bisexual</td>
<td></td>
</tr>
<tr>
<td>Lesbian/gay</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td></td>
</tr>
</tbody>
</table>

If you have any comments or feedback about the focus group, or the project, you can write them below, or email: annahpsarros@maternityaction.org.uk
1.4 Confidentiality statement

Confidentiality information

This focus group is part of a research project undertaken by the Women’s Health and Equality Consortium (WHEC). The results will be presented in a report to the Department of Health and the NHS early next year. The objective is to help policymakers improve access to health services, by highlighting the issues raised by women in the UK.

- This session will be audio recorded. The recordings will be destroyed after the report has been completed.
- All the information you provide will be treated with complete confidentiality. You will remain anonymous – if we quote you in the report, we will change key details if necessary, so that you cannot be identified. We will not use any names in the report.

If you have any questions, or if you want to be informed when the research is published, please email: annahpsarros@maternityaction.org.uk.