White Rose Research Online

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk
Universities of Leeds, Sheffield and York

Deposited via The University of York.

White Rose Research Online URL for this paper:
https://eprints.whiterose.ac.uk/id/eprint/195722/

Monograph:
Essex, Holly Nicole, Cream, Julia, Hanratty, Barbara et al. (2021) Women's priorities for women's health: a focus group study: PREPARE report for the Policy Research Programme. Report.

Reuse
Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

UNIVERSITY OF LEEDS
University of Sheffield
UNIVERSITY of York

PRELIRE

Informing Policy with Evidence

Women's priorities for women's health: a focus group study

Holly Essex, Julia Cream, Barbara Hanratty, Laura Jefferson, Laura Lamming, Asri Maharani, Jane McDermott, Thirimon Moe Byrne, Gemma Spiers, Karen Bloor

December 2021

The Kings Fund

NIHR | Policy Research Unit Older People and Frailty

University of York

Partnership for
REsponsive
Policy
Analysis and
REsearch

The Partnership for Responsive Policy Analysis and Research (PREPARE) is a collaboration between the University of York and the King's Fund, producing fast-response analysis to inform developing policy. The research programme is funded by the NIHR Policy Research Programme (grant number NIHR200702). Views expressed are those of the women who participated in the focus groups and the authors, and not of the NIHR or the Department of Health and Social Care.

Researchers at the University of York, led by Dr Holly Essex, conducted this research and drafted the report, with contributions from our collaborators at the King's Fund. A research team from the NIHR Older People and Frailty Policy Research Unit (OPFPRU) conducted and analysed the two focus groups with women aged over 65.

We would like to thank the women involved in our focus groups for sharing their experiences, which have provided fascinating and useful insights into women's health. We are also grateful to our Involvement@York PPI group and Dr Hannah Grey for assistance with the development of the study materials. We thank Criteria Fieldwork Ltd for recruiting women to our study. Finally, thanks are due to Alex Baylis and Shilpa Ross (The King's Fund), Lauren Ging, Robyn O'Connor, Beth Holloway, Isabel Taylor, Holly Brown and Arpitha Paramesh (Department of Health and Social Care) for their helpful comments on an earlier draft of this report.

Table of Contents

Executive summary 1
1. Background, aims and objectives 4
1.1. Research aims and objectives 5
2. Methods 6
2.1. Ethics and governance 6
2.2. Patient and public involvement 6
2.3. Inclusion criteria, sampling and recruitment 6
2.4. Conduct of the focus groups (women aged 18-65) 8
2.4.1. Summary of amendments to data collection for women 65+ 8
2.5. Analysis 8
2.5.1. Analysis: women aged 18-65 8
2.5.2. Analysis: women aged 65 and over 9
2.6. Sample characteristics 9
3. Findings: Women aged 18-65 12
3.1. Words associated with women's health (age 18-65) 12
3.2. Women's health priorities (age 18-65) 14
3.2.1. Menstrual health 16
3.2.2. Reproductive health 17
3.2.3. Perinatal health 20
3.2.4. Menopause 21
3.2.5. Screening for women's cancers 23
3.2.6. Preventative care 26
3.2.7. Mental health 29
3.2.8. Other physical health conditions 32
3.2.9. Gender differences 34
3.2.10. Domestic abuse 34
3.2.11. Women's health education and raising awareness 34
3.2.12. Health care service-related priorities 35
3.3. Ranking women's health priorities (age 18-65) 35
3.4. Barriers to open discussions about women's health (age 18-65) 37
3.4.1. Societal barriers 39
3.4.2. Personal barriers 40
3.4.3. Health service-level barriers 43
3.4.4. Health professional barriers 47
3.5. Women's voices in health care 53

3.6. Facilitators to open discussions about women's health/good examples of being listened to 55
3.6.1. Societal facilitators ... 56
3.6.2. Health service-level facilitators ... 58
3.6.3. Health professional facilitators ... 61
3.7. Women's health information sources (age 18-65) ... 63
3.7.1. Health information ranking exercises ... 64
3.7.2. Health information sources: open discussion ... 66
3.8. Areas of women's health where information is sparse (age 18-65) ... 70
4. Findings: Women aged 65 and over ... 72
4.1. Sample characteristics ... 72
4.2. Thematic findings: women aged 65 and over ... 73
4.2.1. Theme 1: Women's health priorities ... 73
4.2.2. Theme 2: Being seen and heard in healthcare ... 75
4.2.3. Theme 3: Barriers in access to care ... 75
4.2.4. Theme 4: Sources of information about their health ... 76
5. Discussion ... 77
5.1. Summary of findings ... 77
5.2. Strengths and weaknesses, and opportunities for further research ... 79
5.3. Implications and recommendations for the Women's Health Strategy ... 80
5.3.1. Increased education and availability of reliable information on women's health ... 81
5.3.2. Increased access to services for support and advice about women's health ... 81
5.4. Conclusion ... 81
Appendices ... 83
Appendix A: Participant information sheet and consent form ... 83
Appendix B: Annotated topic guide ... 88

Executive summary

Gender-related inequalities in health and in access to health care are evident internationally, with wide recognition of the need for a more targeted approach to women's health. This project is part of a national Call for Evidence,[1] aiming to inform development of a Women's Health Strategy for England.

Using stratified sampling, we recruited 79 women into eleven focus groups across England in 2021 (two pilot groups, eight based on age group and area-level deprivation and one comprising women of South Asian heritage[2]). We generated discussion and debate on four main areas:

- Women's priorities for women's health
- Barriers to accessing health and care services
- Being 'heard' by health care professionals – women's voice.
- Sources of information about health conditions and treatment options.

Our focus groups revealed differences in emphasis between the groups at different stages of life, but many shared concerns.

Despite making clear at the outset of the study that we were interested in all aspects of health, discussions were dominated by issues relating to female-specific anatomy and physiology. With the exception of mental health, discussions regarding health matters that are common to men and women were relatively limited, but featured more in the older groups, where managing long-term conditions was a priority. Few women reflected on gender differences within health conditions which affect male and female bodies, and there seemed to be little awareness among women of biases which can affect negatively the diagnosis, care and treatment of women.

In our focus groups, women aged 18-24 prioritised menstrual health and contraception, women aged 25-44 prioritised reproductive disorders, fertility and perinatal health, and conversations between women aged 45-64 were dominated by menopause. Women over 65 described feeling '*invisible*' in the health care system, and their priorities related to managing their weight, fitness and general health, managing long-term conditions, financial barriers to accessing health care and prevention (e.g. eye care costs), and caring responsibilities.

Concern was expressed in many groups about the age cut-offs for both cervical and breast screening[3] – women believed that the age threshold for both should be lowered, due to media reports and other knowledge of serious cases among women too young for screening. Older women felt '*written off*' by the age 70 cut-off for breast screening. There was a lack of awareness about women's cancer screening

[1] https://www.gov.uk/government/consultations/womens-health-strategy-call-for-evidence/womens-health-strategy-call-for-evidence

[2] South Asian women were specifically recruited in a separate focus group when it became apparent that this group were particularly underrepresented in the concurrent Call For Evidence survey about women's health. Despite efforts during recruitment to include women from varied backgrounds, our initial sample was predominantly White British.

[3] In the NHS, cervical screening is offered to women from six months before they turn 25, to age 64 (with continued screening post 64 only for those with a recent history of abnormal tests). Breast screening commences for women aged 50-53 and continues to age 71.

in general and also about the rationale behind existing age cut-offs. Women felt that education around cervical and breast cancer should be significantly increased.

Aside from priorities relating to female-specific physiology, mental health was the most common topic for discussion amongst women of all age groups, and the COVID-19 pandemic was viewed as exacerbating problems with mental health and wellbeing, particularly in older women.

There were calls across all groups for increased access to health care, particularly primary care, where appointments were perceived as hard to access and rushed. Many women would value primary care sessions specific to their needs ('well-woman clinics', perhaps with different topics relating to different stages of the life course), more frequent health checks and a greater focus on preventative care.

Many of our participants felt their voices were not always heard by health professionals, they shared experiences of feeling '*brushed off*' and felt that clinicians on occasion diminished their symptoms and concerns. There was a clear perception that women's health problems were not always taken seriously, and some had experienced significant delays to diagnosis of long-term conditions (such as endometriosis). Many participants expressed a preference for seeing a '*female doctor for female things*' due to the '*private'* nature of women's health and a greater level of perceived understanding and empathy, although some were less concerned with their clinicians' gender than their communication style.

Barriers to and facilitators of open discussions about women's health focused on societal awareness (stigma and taboo, women's health not being taken seriously, older women feeling invisible or 'fobbed off'), health services and systems (access to appropriate services and a more holistic approach), health professionals (their gender, age, knowledge and communication style) and individual women themselves (primarily embarrassment, particularly in our youngest and South Asian groups, and lack of awareness and time). Information and education were thought to be lacking in many areas of women's health – participants frequently mentioned uncertainty and unease about 'what's normal', particularly in relation to menstruation and menopause. Sources of information varied between different age groups, with younger women using social media, and older women reluctant to use internet-based sources, in contrast to other ages where 'Dr Google' was frequently consulted, although less frequently trusted. Overall, health professionals and the NHS website were the most trusted sources of information about health.

Focus groups were undertaken in 2021, during the COVID-19 pandemic. Although women spoke of experiences which pre-dated the pandemic, more recent experiences may have been influenced by the impact of COVID -19 on the health system more generally, e.g. contributing to delays and disrupted treatment.[4] This should be taken into context when considering the study findings.

Further research could address some limitations of this rapidly conducted focus group study, in particular canvassing the views and experiences of women from minority ethnic groups (especially older women), individuals whose gender identity does not align with the sex they were assigned at birth, and women in poverty or otherwise digitally excluded. A longer timescale for research could enable more in-depth discussion of topics including sensitive issues which may be better explored in one-to-one interviews (e.g. sexual health, the impact of unpaid caring on health, the role of poverty and material

[4] Propper C, Stoye G, Zaranko B. The wider impacts of the coronavirus pandemic on the NHS. Fiscal Studies. 2020 Jun;41(2):345-56.

deprivation). Finally, although we stratified groups into life stages, these included quite wide age ranges (25-44 and over 65 particularly), which created quite heterogeneous groups.

Our focus groups reveal areas of potential improvement for women's health and health services. First, there is a widespread desire amongst women for more education, information and awareness about women's health, assisting women to know when to seek help and how to do this with confidence. Second, the participants reported a need for better access to services, including investment in primary care to enable longer appointment times and better availability, provision of women's health clinics to provide a single point of access to professional advice and support, enhanced mental health and postnatal care, and a greater focus on prevention.

This research revealed considerable perceptions of unmet need and limited access to appropriate health care for some women, with consequent treatment delays and associated anxiety. Overall, it reinforces the need for a national women's health strategy.

1. Background, aims and objectives

Gender-related inequalities in health and in access to health care are evident internationally, with wide recognition of the need for a more targeted approach to women's health.[5,6] In the UK, women represent 51% of the population[7] and 47% of the workforce.[8] Although they live on average longer than men (83.1 years life expectancy vs.79.4 years for men[9]), women have a lower disability-free life expectancy (61.0 years vs 62.3 years for men[10]), reflecting differences in reported health states across the life course. Women spend on average over a quarter of their lives in ill-health or disability, compared with around a fifth for men.[4] There are also clear inequalities in health between women in different socio-economic groups, ethnicities and geographic regions, and inequalities in disability-free life expectancy are wider for females than males.[11]

The UK government has recognised the need for a national and strategic approach to women's health. In 2018 the Department of Health and Social Care (DHSC) launched a Women's Health Taskforce for England, led by specialists in women's health and involving policy-makers with expertise in workforce, social care, reproductive health, violence against women and girls, screening, inequalities, mental health, cancer, and maternity. In 2019, the Royal College of Obstetricians and Gynaecologists (RCOG) published 'Better for Women', highlighting unmet needs of women, describing problems for women in accessing health care and outlining recommendations to underpin the formation of a national women's health strategy.[12] The recommendations from 'Better for Women' follow a life course approach, recognising anticipated health care needs from adolescence and young adulthood, through middle and reproductive years, to later life.

The Report of the Independent Medicines and Medical Devices Safety Review (the Cumberlege review) outlines starkly the importance of listening to women in the health care system, and the consequences when their voices are not heard.[13] The report explored three disparate interventions (hormone pregnancy tests alleged to cause serious birth defects, the anti-epileptic medicine sodium valproate, which can cause birth defects and developmental delays, and pelvic mesh, a medical device implanted surgically in thousands of women to treat organ prolapse and urinary incontinence, with reports of serious long-term adverse effects). All three interventions were provided for women without adequate evidence or follow-up, with striking reports of lack of informed consent for treatment. All three resulted in physical and emotional harm despite repeated attempts by the women affected to draw attention to

[5]WHO. 2016. 'Strategy on women's health and well-being in the WHO European Region'. World Health Organization Regional Office for Europe: Copenhagen.
[6]Australian Government Department of Health. 2018. 'National Women's Health Strategy 2020-2030'. Australian Government Department of Health: Canberra.
[7] Office for National Statistics 2020. 'Population estimates for the UK, England and Wales, Scotland and Northern Ireland: mid-2020'. Office for National Statistics: London.
[8] Office for National Statistics 2020. 'Labour Market overview, UK; June 2020'. Office for National Statistics: London.
[9] Office for National Statistics. 2020. 'National life tables - life expectancy in the UK: 2017 to 2019'. Office for National Statistics: London
[10]Office for National Statistics. 2021. 'Health state life expectancies, UK: 2017 to 2019'. Office for National Statistics: London.
[11]Allen, J., and F. Sesti. 2018. 'Health inequalities and women – addressing unmet needs'. British Medical Association: London.
[12] RCOG. 2019. 'Better for Women'. Royal College of Obstetricians and Gynaecologists: London.
[13] Cumberlege, J. 2020. 'First Do No Harm: The report of the Independent Medicines and Medical Devices Safety Review'. Open Government Licence: London.

the problems resulting from these interventions. Similar concerns were raised by the Independent Inquiry following the conviction of the surgeon Ian Paterson,[14] in response failures of the health care system to protect women from his actions, which included conducting incomplete mastectomies and unnecessary surgery, providing misleading information and lack of consent.

To produce an appropriate and evidence-based women's health strategy, it is crucial to reflect what women identify as priorities. In 2021, the Women's Health Strategy 'Call for Evidence' sought to collate a wide range of views on women's health; this included a public survey and encouraged written submissions from individuals and organisations.[15] This concurrent research project forms part of the Call for Evidence, canvassing views of women using focus group methods to explore, in more depth than might be possible in a survey, women's experiences of health and health care, and their priorities for future services.

1.1. Research aims and objectives

In this project we aim to inform the development of the national women's health strategy, alongside other calls for evidence and stakeholder consultations. Our objectives are to explore women's priorities, finding out what women believe is most important to address in the national strategy. We focus on four particular areas:

- Women's priorities for women's health
- Barriers to accessing health and care services
- Being 'heard' by health care professionals – women's voice.
- Sources of information about health conditions and treatment options.

[14] Department of Health and Social Care. 2020. 'Report of the Independent Inquiry into the Issues raised by Paterson'. Open Government Licence: London.
[15] Department of Health and Social Care. 2021. 'Women's Health Strategy: Call for Evidence'. Open Government License: London.

2. Methods

We used focus groups with women to explore knowledge around women's health issues and priorities for health, barriers to accessing health and care services and health information sources utilised by women. Focus group methods were chosen as they can provide rich qualitative data rapidly, enabling exchanges of views between participants, as well as being a useful method for conducting prioritisation exercises.

2.1. Ethics and governance

The University of York's Health Sciences Research Governance Committee conducted an ethical review of our plans for focus groups. We contacted participants outside the NHS and sought their general views, not relating to specific experiences as a patient, therefore NHS ethical review was not required.

2.2. Patient and public involvement

We incorporated patient and public perspectives through discussion with women identified through Involvement@York, a patient and public involvement (PPI) network at the University of York. We held an online meeting during the development stage of the project to outline the project plans, responding to our PPI group's thoughts and recommendations as we refined the focus group methods.

2.3. Inclusion criteria, sampling and recruitment

Our broad inclusion criteria were women,[16] living in the UK, aged over 18 and able to speak and write in English. We carried out two pilot focus groups comprising University of York colleagues, to test and refine topic guides. Pilot participants were identified and approached through email invitations sent to staff groups populated by women, such as the University of York Women's Forum. Interested parties were sent full details of the study and consent forms. As we did not change methods significantly following the pilot groups, we included them in the overall analysis.

Nine further focus groups were then recruited via a third party recruitment agency, using a stratified approach to sample purposively based on age and area-level deprivation, with attempts to reflect ethnic diversity within these groups. One focus group was recruited to measure the views of women of South Asian heritage specifically, as this ethnic group was underrepresented in responses to the women's health Call for Evidence.

A third-party recruitment agency, Criteria Fieldwork Ltd., recruited women from England using a pre-agreed screening framework (see below). Initial identification of participants was through the recruiters'

[16] Our criteria explicitly included women whose gender identity does not align with the sex they were assigned at birth, although none of the women in our groups identified themselves as such.

networks and fieldwork offices. Women interested in taking part in the study were sent further information including a consent form by email. Participant information sheets and consent forms are in Appendix A.

We aimed to recruit six to eight participants in each group (one group included only five). For the two pilot groups we aimed to recruit women aged 25-44 and 45-64. We did not impose age restrictions on the group of women of South Asian heritage. For the remaining eight groups we stratified by age (18-24, 25-44, 45-65 and 65+) to promote rapport and reflect likely differences in the way women experience health across the life course. We also stratified these eight groups by area level deprivation based on the 2019 English Index of Multiple Deprivation (IMD2019). Participants were selected from Local Authorities categorised as in the most deprived and least deprived tertiles. The recruitment strategy is summarised in Table 1.

For participants recruited for the nine main focus groups (i.e. not the pilot groups), each participant received a small honorarium to recognise the value of their time, following the usual practice of Criteria Fieldwork Ltd.

Table 1: Summary of recruitment

One pilot group of University of York staff aged 25-44: **Group UP24-44**	
One pilot group of University of York staff aged 45+: **Group UP45+**	
Four groups from *more deprived* areas (recruited from Local Authorities in the upper tertile of IMD2019)	Four groups from *less deprived* areas (recruited from Local Authorities in the lower tertile of IMD2019)
Group MD18-24: Age 18-24	**Group LD18-24: Age 18-24**
Group MD25-44: Age 25-44	**Group LD25-44: Age 25-44**
Group MD45-65: Age 45-65	**Group LD45-65: Age 45-65**
***Group MD65+: Age 65+**	***Group LD65+: Age 65+**
One group of women of South Asian heritage, recruited from the Leeds/Bradford area, aged 18-65: **Group SA18-65**	

*Focus groups conducted, analysed and reported separately by GS, JM and BH.

The focus groups among the oldest women (aged 65+) were conducted, analysed and reported by a separate team of researchers (from the NIHR Older People and Frailty Policy Research Unit) who have expertise with older populations. Some adaptations to the study methods were made to accommodate the needs of these groups. Because of the slight differences in the study methods and reporting for these older groups, as well as the different themes arising from their findings, the methods and findings for these groups are reported separately.

2.4. Conduct of the focus groups (women aged 18-65)

Focus groups took place between April and June 2021, during the COVID-19 pandemic. Each focus group lasted around 1.5 - 2 hours, including a ten-minute break. Focus groups were conducted virtually through an online video software package (Zoom), led by a facilitator using a topic guide. A second facilitator took notes and shared these with the group using screen sharing and visual tools ('Jamboard' for online sticky notes). The focus group sessions were recorded and participants were asked to keep their cameras on in order to easily establish who was speaking and facilitate a better rapport between participants.

The annotated topic guide (see Appendix B) shows how the focus groups were managed. We included an introduction, ice breaker and a three word exercise, then focused on three main areas: women's health priorities, women's voices (including barriers and facilitators to open discussions) and information sources. For all of the 18-65 focus groups, we used visual tools to share notes with the participants, and used the 'chatbox' to ask participants to rank the most important health care issues for women, and the most frequently used and most trusted sources of health information.

2.4.1. Summary of amendments to data collection for women 65+

While the age criterion for the 'older women' groups was 65+, the third party recruiter recruited one person aged 64 years, who was included in the discussions.

Initially the intention was for all focus groups to be facilitated in the same way across age groups, but some participants in the oldest age groups were unable to enter information in the chat function (for example, because they were using mobile phones) and their approach to answering questions was discursive. We therefore omitted the ranking exercises and the three word exercise at the start for the second focus group. In the second focus group, we added prompts about how experiences of health and healthcare compared to when they were younger.

2.5. Analysis

Researchers HE, JC, LL and TMB analysed the nine focus groups for women aged 18-65; GS, JM, BH and AM analysed the two groups for women 65 and over.

2.5.1. Analysis: women aged 18-65

Focus groups were video and audio recorded. As is now frequently adopted with rapid qualitative research of this kind,[17] we analysed the content directly from audio/video recordings and detailed contemporaneous notes taken by the second facilitator. We removed names and any other identifying information before data analysis, giving codes to each participant to maintain anonymity.

[17] Wherton J, Greenhalgh T. 2020. Evaluation of the attend anywhere / near me video consulting service in Scotland, 2019-20. Edindburgh, Scottish Government.

Using an inductive approach, we applied the principles of thematic analysis to the data, using the six-step approach described by Braun and Clarke (2006).[18] We transcribed sections of the focus group recordings for use as quotations, rather than transcribing discussions in full. Table 2 details the six steps undertaken for thematic analysis of the focus group data to organise and describe the data.

We took a reflexive approach to the qualitative analysis, considering how the presence, background and prior assumptions of the researchers leading the focus groups could influence the data collection and analysis. All facilitators and researchers undertaking coding and thematic analysis were women, and as such share some of the experiences discussed. The lead researcher (HE) is also a qualified midwife. These factors could have influenced how themes were developed and described. To minimise the impact of researcher bias, we used a fully annotated topic guide (appendix B), creating consistency across the focus groups, and discussed themes as a team during analysis. Direct quotations are provided to provide transparency, contextualise the findings and demonstrate further meaning.

2.5.2. Analysis: women aged 65 and over

Due to the small volume of data, we applied an adapted version of Braun & Clarke's (2006) thematic analysis to the data. Transcripts were read independently by each researcher for familiarisation. As the two older women's focus groups generated a modest dataset, each researcher independently applied broad brush coding to the transcripts, and from this an initial set of themes. These preliminary themes were then pooled and discussed as a team, and a final set of themes and sub-themes were agreed.

2.6. Sample characteristics

Table 3 shows the sample characteristics of the eleven focus groups. Each group comprised between 5 and 8 women; 79 women were included in total. The two pilot focus groups comprised women employed by the University of York. The South Asian group included women from Leeds and Bradford. All other (eight) groups were recruited from a sample stratified by age group and area level deprivation. Overall, 68% of women were White British, 14% South Asian, 8% White Other, 4% Black British, 3% Asian Other, 1% Mixed ethnicity, 1% Black Caribbean and 1% Other ethnicity.

[18] Braun V, Clarke V. 2006. Using thematic analysis in psychology, Qualitative Research in Psychology, 3:2, 77-101 https://doi.org/10.1191/1478088706qp063oa

Table 2: Phases of thematic analysis for women aged 18-65, based on Braun and Clarke (2006)

Six-step approach to thematic analysis	Description of the process
1. Familiarisation with the data	Data comprised video recordings, 'Jamboard' virtual whiteboard notes made during the focus groups and downloaded text data from the 'chat box' function. Familiarisation involved reviewing the video and text data multiple times.
2. Generating initial codes	Initial coding was undertaken primarily by HE, with a subset of focus groups independently coded by JC, LL and TMB, with a discussion before and following to discuss codes. LL and TMB had not facilitated the focus groups. Data, in the form of focus group notes and transcribed sections were sorted using Microsoft Excel, allowing for organisation based on focus group demographics.
3. Searching for themes	Initial codes were sorted and re-organised using the Excel software into themes and sub-themes, to permit cross-group comparisons.
4. Reviewing themes	During the ongoing process, themes were reviewed and refined by HE in discussion with the wider team. For example, women discussed priorities relating to antenatal screening, and postnatal care, which were re-organised into a higher-order theme 'perinatal health' comprising these two themes.
5. Defining and naming themes	A final framework of themes and sub-themes was developed for each of the main questions.
6. Producing the report	Qualitative findings were combined with the findings from the more quantitative ranking exercises, to develop the final report. Participant quotes were used as illustrative examples of themes, to allow for transparency in the research process, as well as reflecting the voices of participating women.

Table 3: Sample characteristics

Group[*]	N	Age range	Geographic area	Ethnicity[**]	Area level deprivation
UP24-44	7	30-45[***]	University of York employees	5 WB, 1 WO, 1 SA	N/A
UP45+	8	45-52	University of York employees	4 WB, 4 WO	N/A
MD18-24	5	18-23	Bristol/Manchester	4 WB, 1 BB	More deprived tertile
MD 25-44	8	29-42	North London/Birmingham	4 WB, 1 BB, 1 M, 2 SA	More deprived tertile
MD45-65	6	45-65	North London/Birmingham	4 WB, 1 WO, 1 AO	More deprived tertile
MD65+	8	64-73[****]	Bristol/Manchester	5 WB, 1 BB, 1 BC, 1 SA	More deprived tertile
LD18-24	8	18-24	Hertfordshire/York	8 WB	Less deprived tertile
LD25-44	8	26-44	East Cambridgeshire/Harrogate	8 WB	Less deprived tertile
LD45-65	8	49-57	Hertfordshire/York	8 WB	Less deprived tertile
LD65+	6	66-76	Hampshire/York	4 WB, 1 O, 1 AO	Less deprived tertile
SA18-65	7	31-58	Bradford/Leeds	7 SA	N/A

[*]Group labels as follows UP = University pilot, MD = more deprived area, LD = less deprived area, SA = South Asian.
[**]WB= White British, WO = White Other, BB = Black British, BC = Black Caribbean, M = Mixed, SA = South Asian, AO = Asian Other, O = Other.
[***]One woman who had recently turned 45 joined the UP24-44 group as the other University of York pilot was fully subscribed.
[****] The age criterion for MD65+ was 65 and over. However, the third party recruiter also included one person aged 64 years.

3. Findings: Women aged 18-65

3.1. Words associated with women's health (age 18-65)

As part of the 'ice breaker', allowing women to introduce themselves to the group and become more at ease speaking to one another, we asked each participant to write down three words that came to mind when they thought of the term 'women's health'. These words are collated across the nine focus groups, described in the text below, and visually represented in 'word cloud' form in Figure 1. The more times a word was mentioned, the larger it appears in the graphic representation.

Mental health: Mental health was the term most commonly mentioned by women across all groups, with other associated words also mentioned such as mental, stress, emotional, wellbeing and mood.

Women's cancer screening: Words associated with women's cancer screening were also common, particularly breast screening, e.g. breast cancer, breast checks, mammograms. Cervical screening was also frequently mentioned, with terms such as smear test, cervical screening, cervical smear and smear.

Female physiology: Other regularly mentioned words related to female physiology, including words such as, vagina, stomach, breasts / 'tits', hormones and gynaecology.

Menstrual health: Periods was the word mentioned most often relating to menstrual health as well as menstrual cycle.

Sexual health: Words included contraception, sex, sexual and sexual health.

Reproductive health: Fertility was frequently included, and IVF (in vitro fertilisation) was mentioned by one woman.

Perinatal health: Words related to perinatal health were common, particularly pregnancy, but words also included pre and postnatal, midwife, maternity, maternity services, childbirth and birth-centred.

Menopause: Menopause was commonly mentioned and HRT (hormone replacement therapy) was also stated.

Diet and exercise: Quite a number of women mentioned words relating to diet and exercise, such as weight, fitness, nutrition, balanced lifestyle and healthy eating.

Women's health understudied: A number of words or phrases related to women's health being understudied or undervalued, such as neglected, increasing awareness, undervalued, understudied, under discussed and importance downplayed.

Barriers and negative words: Many words that initially came to mind for women appeared to relate to barriers for women's health, such as difficult, frustrating, time consuming, misunderstanding, delay, bad, negative, inadequate, impossible communication.

Positive words: For some women, positive words came to mind, such as strong, independent and pleasing.

Support: Some words related to support, such as peer support, enough support, supporting each other and community.

Gender inequalities: Some words related to inequalities, such as unequal, discrimination and gender blind spots.

Private: The words private and sensitive were cited by some women.

Service-related: Holistic approach and words related to women's specific services were used, such as well women clinics and women's wellbeing services.

Figure 1: Words associated with women's health for women aged 18-65

3.2. Women's health priorities (age 18-65)

In our first substantive question, we asked women to brainstorm as a group "*what do you think are the most important healthcare issues for women that should be incorporated in the women's health strategy?*".

Although at the outset of each focus group facilitators explained that we were interested not only in women's-specific health issues, discussions focused on issues that only affect women, and particularly issues 'relating to the uterus' dominated conversations. The elements of women's health that were important changed depending on the age groups, reflecting the natural changes that occur for women across their life-course; moving from puberty and menstrual health, through reproductive years and then to perimenopause and menopause. Table 4 describes the themes and sub-themes arising from discussions around women's health priorities.

Box 1: Summary of women's health priority findings (age 18-65)

Women's primary concerns were:

- Menstrual health (age group 18-24 and South Asian women), and access to information about contraception (age group 18-24);
- Fertility, access to infertility treatment (including the perceived unfairness of differing regional treatment provision), support following miscarriage, access to information and education about reproductive disorders (e.g. polycystic ovaries and endometriosis), perinatal care and improved support for mothers during the postnatal period (age group 25-44);
- Access to timely information, clinical expertise and treatment for the menopause (age group 45-65 predominantly);
- Access to information and educational resources about diet and exercise (age 45-65 and South Asian women predominantly)
- Managing long-term conditions, and balancing caring responsibilities with health (age groups 25-44 and 45-65);

Across all age groups (18-65), women advocated for:

- Increased investment in NHS services and much greater support for mental health;
- Lowering age thresholds for cervical and breast screening;
- Increased access to health care, particularly primary care;
- Primary care clinics dedicated to their needs;
- More frequent health checks and a greater focus on preventative care.
- Increased education and awareness about women's health, for both genders, from school onwards.

Table 4: Women's health priorities themes and sub-themes

Priorities	Themes	Sub-themes
Women's-specific health	**Menstrual health**	Periods
	Reproductive health	Contraception
		Fertility
		Infertility
		Miscarriage
		Reproductive disorders
	Perinatal health	Antenatal screening
		Postnatal care
	Menopause	Perimenopause/early menopause
		Lack of awareness, information and education
		Support needs for women
		HRT vs. alternative treatments
	Screening for women's cancers	Breast cancer screening
		Cervical screening
Further preventative care	**Preventative care**	Healthy eating and exercise
		Supplements
		Regular health checks
Mental health	**Mental health**	Women's responsibilities
		Stigma
		Lack of services and support for mental health
		Reliance on pharmaceutical therapies
		Lack of follow-up
		Perinatal mental health
		COVID-19 and mental health
		Eating disorders
		Social media and mental health
General physical health	**Physical health (non-gender specific)**	Headaches
		Type 2 diabetes
		Immune diseases
		Chronic pain
Other	**Gender differences**	Gender differences
	Domestic abuse	Domestic abuse
	Women's health education	Women's health education
	Healthcare service-related priorities	Women's specific services/ clinics
		Underfunding NHS
		Improved access/timeliness
		Holistic approach/alternative therapies
		Lack of individualised care
		Women not taken seriously/listened to
		Healthcare stereotyping
		Female doctor preferred

3.2.1. Menstrual health

Women in the youngest age groups (18-24), and in the mixed aged South Asian group, discussed menstruation as a priority for women's health. Periods were extremely painful for some women, affecting their ability to carry out day-to-day activities and their mood. Young women voiced that they did not know what was 'normal' or 'what to expect' making it difficult to know when to seek help with regards to menstrual health. Peer support groups were suggested as an idea to increase awareness and provide support for menstrual health.

> *"it affects everyone differently and… it's thought of as such a general thing… it's not the same for everyone… there needs to be more knowledge about the different ways a period can affect you".* MD18-24, participant 1, age 23.

> *"period pains - I go through them and those days I can't even move from bed. Two days or three days sometimes. All the doctor can give me is painkillers, that's it. It's been years and years - I'm probably used to it now as well, but still, I can't move for two days when I'm bleeding so badly. I'm just in bed for two days - like not life. For those two days if I'm working, I'm home, I'll take it off sick. I just can't move. And every time I go to the doctors the only thing they can do is give me some painkillers, or give me some contraception pills to stop the bleeding".* SA18-65, participant 5, age 32.

> *"My suggestion was the women's groups, you know, at different stages, not just for menopause, I mean for period pains - there should be groups for that. I mean people don't like to talk in groups but, you know. But... if you're really interested in something you would go for it"* SA18-65, participant 7, age 48.

Menstruation was an element of women's health recognised as being a 'taboo' subject, perpetuating a lack of knowledge about what was normal, as women were less likely to discuss their experiences with their peers. Many young women felt that education needed to be increased in school, among girls and potentially boys to increase understanding and decrease the 'stigma'. Some women also discussed their experiences of a lack of general support in school settings, e.g. not being allowed to go to the bathroom in class, leaving them unable to change sanitary products, but feeling embarrassed and unable to explain this to staff.

> *"more education on like periods and women's stuff in school - I think it should it should start earlier and make it less of a taboo… if you were taught stuff in school and it wasn't treated as such a weird embarrassing thing… people don't talk about periods now, they like hide. I'm blushing, I can see I'm blushing"* MD18-24, participant 2, age 20.

> *"When they say you can't go to the toilet at school… paranoid I was going to leak… not focussing in lessons as I couldn't change my pad"* MD18-24, participant 2, age 20.

For some women in the South Asian group, these feelings of embarrassment around discussing menstrual health extended into the workplace, leaving them feeling unable to explain to colleagues that they were feeling unwell when they were menstruating. These women also expressed concerns about being viewed as weak or 'slacking' from their jobs. Participant 1 and 3 from group SA18-65 discussed their contrasting experiences within their workplaces:

"The menstruation cycle - it can be really painful, but at the same time some days it can be better. But the first initial days are just absolutely awful and I get very low in mood, very depressed, very teary and I just want to, you know, hide in a room and not come out. Even at work sometimes, it's just very hard to even get up and go to work. And you know then not being able to tell your colleagues, you know, what's happening. But at the end of the day, you have to go to work and just get on with it." SA18-65, participant 1, age 42.

"I work in a school as a teaching assistant... I've told them from day one that my periods are very heavy and I need to go. I literally have to, if I don't go I'll leak through. I've made them aware. Sometimes, even if they're female, just make them aware that this is the issue... Some places are quite understandable - my school is. You need to tell them...". SA18-65, participant 3, age 45.

Some of the young women recognised 'period poverty' as a societal problem, reflecting on the disadvantage experienced by women who could not afford sanitary products and the wider effects this could have, e.g. potentially leading to missing school.

"women don't get sanitary products [provided free by the NHS] and a lot of women are going without… it is a health issue" MD18-24, participant 4, age 18.

Women also spoke of a lack of understanding and support from health professionals, particularly male doctors, when seeking help with menstrual health. This had led for some to a delay in receiving treatments for symptoms or investigation and diagnosis of further issues.

"I had period pain, it was a male doctor. I was having a really bad week that time... and all he had to say was 'you should be used to that, how long you had the periods for?'" SA18-65, participant 5, age 32.

3.2.2. Reproductive health

3.2.2.1. Contraception

Contraception was a priority for women in the youngest age groups particularly. Young women commented on the lack of education provided about different types of contraception available, particularly in the school setting.

"wasn't really much of a conversation about it [in school]… I still don't understand every type… boys get taught how to put a condom on". LD18-24, participant 8, age 21.

The contraceptive pill was a distinct focus for discussions, as this seemed to be the default option given to most women, with some noting resistance or a sense of judgement from health professionals when wanting to explore other options. There were concerns around the side effects of the pill too, including hormone changes, mental health and long-term risks, e.g. cancer. The recent media attention around the COVID-19 vaccine had also highlighted the known risk of blood clots for women. Further research on the long-term impact of taking the pill on under-researched outcomes such as cysts and polyps was suggested.

"like the pill... it's so bad with … mental health. All of my friends go on the pill and they always switch or come off it or switch to another thing as they're like 'it made me depressed… crying all the time'… I think it's so bad... Then there was that thing... with the COVID vaccine, they like

pulled it because of the blood clots ... but then with the pill there's more health risks than with the vaccine and that was pulled, but then they don't change it with the pill." MD18-24, participant 2, age 20.

3.2.2.2. Fertility, infertility and miscarriage

Fertility-related topics were discussed predominantly by women in the focus groups aged 25-44. Women spoke of discussions with health professionals during what one woman described as the 'golden window' for fertility. Some women had experienced unwelcome discussions with health professionals who had 'preconceived ideas' about family planning, assuming they would want to have children without a discussion.

"I think they [health professionals] look at women… and they think they should have babies, even if that isn't what they want" UP24-44, participant 6, age 30-35.

Infertility and fertility treatment was an area where women felt more information was needed. It was viewed as unfair that women had unequal access to fertility treatment on the NHS depending on their location.

"infertility - all you ever hear in the news is that oh you can get certain treatments in this part of the country but you can't get the same treatment in different parts of the country. I've never really understood why that should be" LD45-65, participant 4, age 52.

Miscarriage was described as a 'taboo' subject where there was an 'appalling' lack of support, particularly as investigations are not normally initiated until a woman has experienced three pregnancy losses (as is routine in the NHS). Women also reported mixed experiences of early pregnancy services depending on their area. One woman described a positive experience of being able to self-refer to her local Early Pregnancy Unit, but others reported 'traumatic' delays of several days waiting to be scanned not knowing if they had miscarried, and feeling dismissed by A&E services.

"miscarriages and things like that. If you're anything before sort of 12-16 weeks it's a little bit like you're pushed aside... it's like... it doesn't count... but for the person who is experiencing it, it very much does" MD25-44, participant 4, age 29.

"I think a good topic would be miscarriage. I think that is still quite a taboo subject around women's health. I've suffered 3 miscarriages... It's something that I don't think get fully supported with... There are different charities out there that I am aware of... but I still don't think there's enough support out there" LD25-44, participant 4, age 35.

"I've very recently had a miscarriage… there's very little support, there's very little research. No one will even look into it until you've had three miscarriages, which having just had one - I don't want to go through this two more times before someone even starts to explore and investigate why this happened to us." UP24-44, participant 1, age 30-35.

3.2.2.3. Reproductive disorders

Polycystic ovary syndrome (PCOS), endometriosis and endometritis were areas of women's health highlighted as a priority by women predominantly in the 25-44 age groups, as well as some women in the 18-25 category. Some women in the older 45-65 age group also spoke of these conditions affecting their daughters.

Several women discussed the links between these reproductive disorders and fertility. Despite this important link, women had experienced or were aware of misdiagnoses or significant delays, with women taking many years to be diagnosed with a reproductive problem. There were similarities to other experiences of seeking help with broader menstrual health, with doctors viewed as not listening to concerns, women feeling 'brushed off' and that their symptoms were diminished by doctors. This was also an area that women felt there was a dearth of information.

> *"years of trying to get ultrasounds for my periods… after pestering them…for years… I found out I have polycystic ovaries"* MD18-24, participant 5, age 20.

> *"it took me a while to be diagnosed with endometritis. And it mainly came about because my mum is quite pushy, and it worked in my favour that I get on really well with my mum and could talk to her about it. You go in and you're like, 'it really hurts and 'it's made me sick a couple of times like it is really painful - no painkillers [help]'. Everything like that... the fact that it took me that long to get to that point was quite sad. And then to be told 'well we can give you surgery to fix it but other than that I'd tell you to just keep taking your contraception'. And I was like 'is that it?'. And she was like 'well if it's really bad take some painkillers'. And I was like 'well I've been doing that it hasn't fixed anything'. Erm and it ended up going to a female gynaecologist for them to be like 'Okay we can definitely figure out some things to do with this'. But I think in general unless you do say everything that could possibly be wrong and exaggerate a little bit... you can be dismissed quite quickly."* LD18-24, participant 8, age 21.

> *"what I meant by fertility is things like endometriosis as well as PCOS. Miscarriages play a part in that... Fertility I meant it's like all-encompassing - what is going to prevent you having a child? Because sometimes they don't, the doctors... they don't really listen... they just kind of brush it off sometimes. At least that's in my experience. It's only when things get a bit more like serious that they actually listen to you. I've had friends with PCOS and it really affects them and it's taken years for them to get a diagnosis, and by that point you don't know if they've caused severe damage to being able to have a child and I think that's one of the most fundamental differences between a man and a woman, to be honest."* LD25-44, participant 2, age 30.

> *"I think it's really important around, er, gynaecology, there is very little development and there is always this minimisation of the symptoms, as if...we were making them up. I don't know if I could share my screen to show you something [shares screen with letter from GP]. And it's about polycystic ovary syndrome and [reads from letter] 'this condition can result in irregular periods and excess hair'. I found this letter a little bit strong, because I thought there is much more than that. It's not only that 'you're gonna have hair so why don't you shave?' and that's what the doctor said or 'go wax' or something like that, which I think is minimising and demeaning all the symptoms that women may have. And I think it's at all ages...until you reach menopause. There is this minimisation of symptoms 'it's normal, it's okay'. And one thing cures it all. The pill cures everything, no? Like from contraception to polycystic ovary syndrome, to irregular periods, to*

PMS [premenstrual syndrome]. And I find obviously from that point of view, research needs to be a lot wider." UP45+, participant 4, age 45-50.

3.2.3. Perinatal health

Postnatal care was the area of perinatal health most commonly discussed by women relating to childbearing. The exception was antenatal screening for foetal abnormalities, which was a priority highlighted by one participant.

3.2.3.1. Antenatal screening for foetal abnormalities

Antenatal screening was highlighted as a priority by one participant, who contrasted care in the UK to her home country, where non-invasive prenatal testing (NIPT – a maternal blood test that can detect free foetal DNA) was adopted as a national programme far earlier than in the UK:

"More regular and better screening during pregnancies. I know that here they offer, for example, for checking if a foetus has genetic abnormalities, here … you would be offered either one thing or the other but not both, so you could end up having to rely on an amniocentesis that would be done very late during the pregnancy when actually the abortion would be basically like giving birth type of abortion which is...big trouble for a woman." UP45+, participant 8, age 50-55.

3.2.3.2. Postnatal care

In terms of perinatal health, postnatal care was an area highlighted as requiring attention by some women in the 25-44 age group. Women felt that postnatal care was inadequate in terms of the amount of contact; they particularly talked about the six to eight week check with the General Practitioner (GP), which was deemed to be too brief, mainly focussed on the baby, and lacked a woman-centred approach (taking into account the individual needs of the women).

"having recently had a baby, your body changes in a huge way… I feel like, quite rightly, the focus is sort of on the baby immediately after the birth but actually your body has gone through a really traumatic event and… the thing that I find really difficult at the moment is that I've got no sense of like what actually is normal for my body and I feel like that is very different for a man in his 30s... There's not really any kind of resource or thing or awareness of how to kind of manage that... When you do try and get help around those issues sometimes it's like 'oh yeah it's because you've just had a baby'." UP24-44, participant 5, age 30-35.

"postnatal care, after you've had a baby. Rightly it's all about the baby - I don't want to seem like 'it's all about me' but erm whilst I had my children postnatal care was just next to nothing. They do your 6-week check, and that's not really a physical check, it's more of a conversation with your GP (well mine was). And I've got all sorts of issues after having my girls and there just doesn't seem to be much postnatal care... I just think you need more of a physical examination. I don't know whether that's just by borough or GPs are different, but erm I was with two different surgeries, when I had my children, and I didn't have a physical check-up and I'd had a third degree tear with one daughter and a second degree tear with my other daughter and, you know, that just has different implications erm as you kind of heal. But yeah, I just didn't feel that it was a priority, they didn't really talk about, you know, how I was feeling. It was just a bit like I was

supposed to come to them with floods of tears if I had postnatal depression or, you know, I didn't feel like there was much of an assessment" MD25-44, participant 8, age 40.

"My daughter is 11 weeks … care needs to be a bit more woman-focused. Sometimes it seems very generic and very erm, so like my check-up was like 'do you want to get checked?' and like [participant 8] I had a massive third degree tear and it was like 'do you want me to check you?' and I was like 'yes please'. And it was like 'is everything okay at home, okay thanks, bye'." MD25-44, participant 4, age 29.

3.2.4. Menopause

When asked about priorities for women's health, menopause dominated discussions among women aged 45-65, with conversations regarding the menopause being raised at almost all points in the focus groups in those age groups. Women recognised that the menopause had the potential to have a significant impact on women's life, influencing both their physical and mental health, but that there was a considerable lack of awareness, information or support for women experiencing this inevitable process.

3.2.4.1. Perimenopause and early menopause

The menopause was also a priority for some of the women in the age 25-44 groups, with perimenopause being mentioned by some women in their early 40s and who had begun to experience symptoms, or were wondering about when they may experience the menopause.

"Myself and my friends have been talking a lot about the menopause and like perimenopause cos some of my friends have got symptoms coming up, and there doesn't seem to be much said about that." MD25-44, participant 8, age 40.

"Menopause, because not that I'm there yet but I'm 44 and it's sort of on my mind. My mum went through it when she was 50. So… I'm wary of it." LD25-44, participant 1, age 44.

One woman also discussed that she had 'fought' to be diagnosed with early menopause, taking 9 months to be diagnosed.

"I've recently fought really really hard to have lots of tests that show I'm in early menopause. It took 9 months… had several blood tests before they did the one they needed to do." UP45+, participant 2, age 45-50.

3.2.4.2. Lack of awareness, information, and education around the menopause

A lack of awareness of the 'hidden' symptoms of the menopause, what was considered normal and what to expect was expressed by many of the women, even among those who were actually experiencing the menopause. Women felt they were just 'left to get on with it' and that there was not enough general discourse about the menopause from health professionals or in the media to help with their understanding.

"you just sort of find yourself scrabbling around, not sure what symptoms to blame on the menopause or stress or COVID or whatever, and I think it would just be nice when you get to that age to have more information before you start going through symptoms" LD45-65, participant 5, age 51.

"No one teaches you, it just happens, you're unaware, you think you're going mad." MD45-65, participant 5, age 52.

Greater education and information needs were very commonly cited by women, who reflected on a complete dearth of information available at any point in their life with regards to the menopause. Interestingly when asked about areas of health where information was sparse, a lack of menopause-related information was noted by women in all age groups; some younger women felt that education about the menopause should start much earlier.

"menopause and stuff that affects older women… the media that they consume like TV or whatever, I don't see anything on it… needs to be more spoken about and more resources need to be pushed out there" LD18-24, participant 4, age 22.

3.2.4.3. Support needs for women

Women felt support was lacking for menopause, including in health services. GPs were viewed by some as unsympathetic or displaying a lack of knowledge or understanding about the menopause, leaving women feeling unsupported. Dedicated menopause services, such as women's clinics or professionals who specialised in the menopause were advocated as possible solutions. In addition, women felt more peer support was needed, such as support groups which could be held face-to-face or via online video services.

"You used to be able to go into a group and talk about your pregnancy… They do [antenatal classes]… but they don't do programmes for menopausal stages, where people could sit and have conversations… We should have group… with like-for-like ladies who can talk about their menopause" SA18-65, participant 2, age 58.

3.2.4.4. HRT vs. alternative treatments

Hormone replacement therapy (HRT) was a particular area where women expressed a lack of awareness and understanding, feeling that this could also be improved among health professionals. Where HRT was prescribed, it was viewed by some not to be sufficiently explained. It was felt there was a reliance on HRT over other alternative therapies, and there was a perceived lack of knowledge about non-pharmaceutical treatments for menopause among health professionals. Women also conveyed concerns about the side effects of HRT and felt greater follow-up was needed to see how the hormone therapies were affecting women.

"if you need to take something … they won't tell you … that that tablets can bring you on [menstruating] every month, whereas the patches, like Evorel Conti for instance, will stop you sort of from menstruating totally – but that was never explained to me ... With the menopause, people don't explain, do they? When you are taking something, it's not until you take it that you realise, you know, what's going to happen and how it will affect your body" MD45-65, participant 1, age 65.

You hear so many stories about HRTs – are they good for you, should you take them, which type do you need, do you actually need them in the first place, what sort of tests do they need to do to see if you need them – so it's all a bit confusing really." LD45-65, participant 6, age 57.

3.2.5. Screening for women's cancers

Screening for women's cancers (cervical screening and breast cancer screening) was a topic raised by seven of the nine focus groups as a priority for women's health, with a particular focus on reducing the age at which the programmes start. In general, participants felt that awareness needed to be raised, with more positive messaging about screening programmes, symptom monitoring and self-checking, to counteract the negative media attention:

"I think highlighting the risks a bit more. And almost having that open discussion to make it not so scary almost. Because all the stories that you tend to see on the internet, in the news, is all about really young people that have sadly passed away from cervical cancer because they've been too young for the smears. You never kind of have that really good story where someone comes in and says it was a breeze I went through it, it was no problem. The focus is always on negative experiences and I think we need... for women's health as a whole we need to try and put a positive spin on it almost." UP24-44, participant 2, age 30-35.

3.2.5.1. Breast cancer

Lowering the age for breast screening

For breast cancer, one of the most dominant discussion topics was that women felt that the age threshold for NHS screening programmes should be reduced,[19] and this was particularly raised among women in the 45-65 age group. There was also a lack of understanding about the rationale for the current age cut-offs. One woman who previously lived overseas compared the breast screening programme in the UK:

"Contrasting UK to [country of previous residence], I find that… a cancer that is, you know, prevalent in women is breast cancer. Cervical less so now, with the things that have been done. But in this country you don't get screened until 50. Which, you know is really late... and there is no systematic call for it. It's very badly organised, even though there are centres here. And we know that many of these cancers are genetically connected, right? And there is some talk about genetic profiling but that's very little and far too late. So, I think that's a big blind spot." UP45+, participant 3, age 45-50.

There were frustrations and concerns for women who were too young to be eligible for screening but when there was a familial link with breast cancer:

"*I'm 49. My mum had breast cancer at 48 and they still won't screen me, or reassure me, or genetically test me, or anything"* UP45+, participant 7, age 45-50.

[19] In the NHS, breast screening commences for women aged 50-53 and continues to age 71.

Young women expressed concern for their older relatives, who they felt had inadequate or no screening for their age, especially in the context of family history of breast cancer. The late onset of breast screening was also perceived as a barrier to accessing care for young women who might have concerns about their breasts.

> *"I might feel too young almost to go and speak to someone about breast cancer… even though it can happen to people our age…".* LD18-24, participant 7, age 24.

Lack of awareness about symptoms/self-checking

Many women highlighted a lack of awareness about how to check for breast lumps and signs of breast cancer. Women had little understanding of how to check themselves which was an added concern given that most women we spoke to were too young to be involved in the national screening programme.

Women in our groups tended to assume that breast self-checks are beneficial (despite their effectiveness lacking a sound evidence base[20]). Several women advocated increased education to help increase awareness of self-checking, suggesting that this could start as early as school age. Women also talked about how best to disseminate information about breast checking, e.g. posters in toilets or by GPs prompting the discussion. There was also a suggestion that information should include pictures, which should be true to real life, rather than cartoon images.

> *"Talking about breast awareness… I'll be honest with you I'm nearly 50 now and I've never ever felt my breasts. I wouldn't know where to start... The doctor needs to tell you… I'm one of them that learns by someone showing me how to do something, I'm not very good with leaflets and things like that."* SA18-65, participant 7, age 48.

> *"I found out about checking yourself… through a TV show… and the fact that we get screened so late. But I feel that it's only just now come about that you check yourself... We have the 'cop a feel' stickers in our bathroom [at university], but that's really new"* LD18-24, participant 8, age 21.

> *"breast cancer and breast changes - if you google them, you tend to get cartoon pictures to compare to and that's a really tricky thing to compare to a cartoon… Because some of the changes are visible, what those visible changes actually look like on a real life human rather than Marge Simpson"* LD25-44, participant 3, age 39.

3.2.5.2. Cervical screening

Lowering the age for cervical screening

A reduction in the age of eligibility for smear test screening dominated discussions around cervical cancer[21] and this was discussed by several women in the two youngest age groups (women aged 18-44). Women were aware of cases from personal experience, friends or family, or in the media where women

[20] Kösters JP, Gøtzsche PC. Regular self-examination or clinical examination for early detection of breast cancer. Cochrane Database of Systematic Reviews. 2003(2).

[21] In the NHS, cervical screening is offered to women from six months before they turn 25, to age 64 (with continued screening post 64 only for those with a recent history of abnormal tests).

had experienced cancer (some of whom had died), or had pre-cancerous cells identified by the time they reached age 25.

> *"by the time I come to have my first smear test at 25, I was actually diagnosed as having...level 3 pre-cancerous cells around my cervix... and I had to undergo therapy, I had to undergo treatment for it. I do agree that it [cervical screening age] should be lowered a little bit"* LD25-44, participant 4, age 35.

Some women did recognise that screening should be commenced when it is likely to identify more cases.

> *"the age is so high for breast screening and then smears it's quite high for women as well… you'd think if it was serious they would put the age down"* MD18-24, participant 1, age 23.

> *"depends on whether screening tests works for [younger] people. Because you don't want it to be done unnecessarily, so it depends if it works in that lower population"* LD25-44, participant 7, age 38.

HPV vaccination

Given that the human papillomavirus (HPV) vaccination programme in the UK commenced in 2008 for 12-13 year olds, with a catch-up programme in 2009 to capture those up to 18 years old, only women aged 30 and under in our focus groups would have been eligible for the HPV vaccination programme. This was noted among some women who had not been vaccinated. Some younger women recalled having the vaccine, but did not recall receiving much information about what the vaccine was for.

Increasing awareness/information about cervical screening

More information about smear tests and HPV vaccination was recommended by women in order to increase engagement with the screening programme.

> *"I didn't have my first smear test until I was 28…because the only information I had was from people telling me 'it's like this it's like that'. Don't get me wrong it wasn't bad at all when I had it...I don't know why I delayed it so long."* MD25-44, participant 4, age 29.

Smear test acceptability

There was an awareness that for some women, attending for cervical smear tests could be a source of embarrassment and could make them feel uneasy, which could be a barrier to engaging with screening. This was particularly noted among young women and women in the South Asian group.

> *"within our Asian community I just feel like a lot of women can hide away from that and feel very uncomfortable in going and getting these done... It's just not a nice experience, and I do feel that quite a lot of Asian women will probably feel uncomfortable in going there. But if they're told that, you know, 'you're gonna get this done and this is what it can avoid' then maybe they would be more open to go"* SA18-65, participant 1, age 42.

Physically, smear tests were viewed as invasive and uncomfortable, which also was perceived as a barrier. One woman reflected on whether this could be improved:

"Obviously it's not a particularly nice process... It would be nice to see investment into trying to make those things a little bit less invasive. You sort of feel like if it was to happen to men they might find a way of doing it in a slightly more comfortable way. It's that - looking things from a woman's perspective and how things can be improved" LD45-65, participant 2, age 50.

3.2.6. Preventative care

There was a distinct discourse around preventative medicine as a priority for women's health. Women discussed that there was not enough focus on healthy lifestyle changes or monitoring of general health, which left women more at risk of developing long-term health problems.

3.2.6.1. Healthy eating and exercise

Diet and exercise were considered a women's health priority predominantly among women aged 45-65 and in the South Asian focus group. Women discussed a lack of general education and research about a healthy diet and that this was something that more information should be shared about in schools and by health professionals. Diet was recognised as an important step in reducing the likelihood of long-term preventable conditions, e.g. diabetes, and reducing reliance on pharmaceutical interventions once health problems occurred.

"This is not just women, but for men as well. For everyone actually - children up to old people. I think they should promote preventative measures such as your diet, because diet can affect your health and that's also not just physical but mental as well. Because your diet can really affect you mentally - if you're eating all bad stuff it can, erm, put so many toxins in your body, and that can affect you mentally. So I think they should, erm, not just dish out tablets when not well, but... encourage a healthy way of life, that's physical and eating, to act as preventative measures." MD45-65, participant 4, age 54.

"Diet and exercise. How important it is throughout your life, whatever stage you're at. It's so, so crucial. And understanding how it works is most important. And then, you know, it helps you deal with issues I think. But it has to be long-life education, starting from the school and continuing, so that it becomes a way of life." MD45-65, participant 3, age 61.

Two women with concurrent long-term health conditions, however, reflected that for some women, making changes through diet and exercise was not easy. For example, participant 5 in group MD45-65 discussed her experiences of a long-term condition:

" It's hard when you're on medications and things like that ... like steroids and things. I'm on steroids...so people can't see that whatever you do, some people can't physically do things. So it works for some and not for others, even though they try" MD45-65, participant 5, age 52.

Women in the South Asian focus group discussed that their traditional diet could be unhealthy, for example containing a lot of fried food, but there was little information and education to support them to make healthier choices:

"Women are generally the ones that are cooking and looking after the family. I think there should be advice there for them, to tell them 'too much of this will harm you in this way'… [You

should be told to] change your way of life, you know, how much exercise you do. If you're sitting around a lot... And that is passed on to your kids as well, so, if you're acting in the wrong way. Just because you don't get all this advice from schools - we did home economics, back in the days, but it was just how to bake and stuff like that. But we never really got told how important it was. We've learnt all this from my parents, you know how to cook and everything. And you know our dishes [South Asian food] are healthy, they can be healthy because at the end of the day we use raw products. They can still taste the same just putting the right things in them, and how much of it we eat. So it's not what we eat is wrong, it's how much we eat and what we do afterwards. Half of these illnesses, especially diabetes and stress and headaches, we wouldn't get that if we drank enough water. We just need to be told that to eat less would help us. If we got told that by a professional, from the doctors [it would reduce] visits to them" SA18-65, participant 2, age 58.

In terms of exercise, one woman felt that a priority for women's health should be to provide women's specific exercise facilities, although it was noted by another participant that female only sessions may not be permitted.

> *"One of the main issues is like the confidence in a gym - I don't think that gets mentioned enough. For a woman to enter a gym full of men, it can be quite hard, so a lot of people not wanting to exercise and things like that could be to do with entering a gym. So, like maybe just having more facilities for women to be able to go...workout, without feeling like they're being looked at by men would be a good idea."* LD25-44, participant 8, age 26.

> *"I read an article that there was a gym… that decided to do a… women's session. They said that was discriminatory towards men…[when] they wanted to provide women with a safe place to work out".* LD25-44, participant 2, age 30.

In terms of research, the effects of the menstrual cycle on exercise performance was recognised as an under-researched area by one participant:

> *"I've noticed a lot of research on exercise is based on men…how your monthly cycle affects your performance is just not really studied very much or taking into account… sometimes if you have like muscle soreness… it's just like hormonal. I think… like women and sport and exercise - that's the area that when you read anything, there is a fine print "it was conducted on young white men", which is none of me, so I think it's important".* UP24-44, participant 1, age 30-35.

3.2.6.2. Supplements

Food supplements were a discussion point for some women in the 45-65 age group. There was an awareness that supplements could be beneficial, but that there was a lack of reliable information about them and concern that they were unregulated. One woman had been advised to explore supplements by the GP, but was left confused by the huge variety of supplements available.

> *"I do take a couple of supplements, but, erm, it would be good to know what supplements do what, what you actually need. You know, is it safe to take two or three, or is there one that you can take that has other things in? So yeah, be good to get a bit more information about that really"* LD45-65, participant 7, age 49.

"I went to my GP for another condition and I was told I to 'go to the supermarket - there's loads of supplements there, there's a real variety. You can choose one that best suits you'. But they are, to my knowledge, they're unregulated, they're not medically tested and there is no unilateral standard. So how do you know what you're buying? And is it worth buying it, or is it just a complete waste of money that's funding a private company?" LD45-65, participant 4, age 52.

3.2.6.3. Regular health checks across the life course

Regular health checks were advocated by many women, (not the youngest group of women, aged 18-24). Women felt 'in the dark' about their health due to the lack of regular health checks or an 'MOT' to monitor their general health. A more 'proactive' and 'structured' approach with routine checks at key points across the life course was supported, to detect health problems before they became more serious. Routine blood testing was felt by some to be lacking.

"regular checks throughout your life course. I think [this] maybe happens just by accident until you're maybe at certain ages, and then I think there's maybe a gap from… late 30s into your 40s where you're maybe not picked up necessarily by accident if you're having regular drop-in sessions, you know...when you're in your sort of 20s and 30s, you're getting a regular check maybe if you're going for the pill or whatever, you're getting your blood pressure checked, you know, you're just getting picked up by accident. But it probably needs to be more structured... I think at the moment there is probably a gap in... these little checks" UP24-44, participant 3, age 40-45.

"Blood testing... recently I had problems where down the side of my face, it sort of went numb and everything. I wasn't quite sure what it was at the time and then basically, I saw the doctor and I was sent off for blood tests and also I had a brain, you know, head scan and it turned out that I've got high cholesterol. I wouldn't have known that. And it was up really quite high, at about 9, and now I'm on statins." MD45-65, participant 1, age 65.

There was a belief that this kind of preventative care, such as blood testing or general health checks were not provided due to their expense. Some women who could afford it had paid for private blood tests.

"there is a private service from Nuffield that you can pay to have a 360, I think it's called a 360 service, where they're looking [at] your blood tests and everything about you general well-being to flag up whether there's any issues arising and I would like to see in the future that be introduced as part of a process, like you have a three year smear, or breast screening... I'm 59 now and I've never had anything like that from a doctor. And... I have to go to look privately to make sure that I've had just a general overhaul really. And I really think that that would be, erm, a preventative measure, as well as a positive reassurance that everything's okay and you've got nothing to worry about. Because you only go to a doctor when there's an issue, so there's no early intervention is there? There's no prevention. So that's why I would really like to see." LD45-65, participant 6, age 57.

As discussed in a later section, women's health specific services were proposed as a way of introducing a preventative care model to monitor women at critical time points. For reasons that are explored in the next section of this report (around barriers to accessing healthcare), some women felt the GP might not be best placed to be the gatekeeper for women's health.

"My feeling that is that a lot of very important things about women's health, for example, prenatal care, postnatal care, menopause and things like that, is left to the GP. And the GP treats it like when you have a problem come and talk to me. And I agree with [participant 8] that the problem is that there needs to be a prevention programme that's separate from your GP, that follows critical points. I mean, medicine's shown critical points in women's lives that is different and that is completely overlooked. As I said, it's mostly centred around birth, so there is something there, but menopause is a critical point for many women. You know, getting into going from puberty to womanhood. Many of these things. And it just seems to me that there is no national programme that will A) study it, B) follow it, so that when something happens you can get to information... Because not everybody is, you know, educated and can look for these things". UP45+, participant 3, age 45-50

3.2.7. Mental health

Mental health was raised as a priority for women's health in 7 of 9 focus groups among women aged 18-65, although it was less of a focus for discussion among the youngest groups (18-24).

3.2.7.1. Women's responsibilities

A number of women reflected on the additional pressures they experience, juggling work and family life, as they were often in caring roles, for example, caring for children or elderly relatives. These extra responsibilities left them little time for self-care and put additional strain on their emotional wellbeing. These extra pressures were not discussed by women in the youngest groups.

"I think mental health… just day to day whatever a woman is going through. Because I know like just being a woman in general and having kids and working. There's a lot, just basic stuff that we could be going through that we end up suffering in silence as well. So, I think... just to be aware of the mental health support that's out there would be a good thing" MD25-44, participant 6, age 36.

"And I think mental health is a big, big thing that a lot of people are dealing with, especially women, because of everything that they are dealing with. As I say, you're not just carrying your children, you're carrying everything else as well". MD45-65, participant 2, age 45.

3.2.7.2. Stigma

Women with mental health problems spoke of the barrier this could present when speaking openly about their concerns, or considering seeking help from health professionals. Women with children were anxious there would be safeguarding concerns, and that their children may be removed by social services. For example, participant 7 in group MD25-44 spoke about her experience of postnatal depression; even though she experienced symptoms soon after the birth, she delayed seeking help from her GP until her baby was a year old:

"I think I held back for that year because I was scared. I was only 23, I had a baby, I was scared that they were going to think 'she can't look after her own child'. MD25-44, participant 7, age 42.

For women in work settings there were worries that speaking out about their mental health may affect their employment.

> *"As a female, they may feel some special circumstances that may trigger them to be mentally unwell. For instance, from my perspective, I could say like there are so many social desires for a woman, whether you like work as a housewife, or a professional with a high professional status, whatever it is. But there are some social demands or expectations from you, that puts you [under] so much mental pressure, but that is not often expressed in the workplaces... [women] are not seeking help for the mental counselling... they just keep it within themselves. And it's not spoken much about - the kind of mental health or pressure that you are going through"* UP24-44, participant 7, age 35-40.

> *"I knew somebody who was working with children, and she was in a quite a high position. I know she was dealing with things from her childhood. Erm, but she didn't want to... see a counsellor because she thought it might affect her job looking after children, so that stopped her from getting help"* MD45-65, participant 4, age 54.

3.2.7.3. Lack of services and support for mental health

Women who had experienced mental health problems, or knew of others who had, spoke of the lack of services and support available in an area of the healthcare system that was deemed to be underfunded. Women gave examples of long waiting lists, limited numbers of counselling sessions and queuing at a drop-in centre to access mental health services. Because of the dearth of mental health service provision, women who had experienced mental health problems described a 'fight' to get help and felt that their symptoms needed to be severe before they could access services. For example, needing to be sectioned under the mental health act or being suicidal before receiving any support, when earlier prevention and intervention was needed.

> *"Counselling. Like if you go, 'cause I had a dietitian 'cause I put on a lot of weight with the menopause and everything. And I've got a lot of things wrong with me. But... I feel like counselling, they only do it for six weeks. It should be for longer. So, counselling. More offered for that and for not only just six weeks. At six weeks just getting going... And you have to wait about a year."* MD45-65, participant 5, age 52.

> *"Regardless of lockdown, I have personally suffered a lot with my mental health. The doctors diagnosed me with depression in 2012. I was 21/22. I've had to fight to get any kind of help for that.... This is why I said emotional. Basically, it's your mental health... A lot of the doctors that I've seen at my GP have been male. They kind of play it off as a thing where it's more down to your biological sense that you're going to be emotional. I self-harmed, probably starting when I was aged 26… And it's been very hard to get into any kind of group therapy sessions for CBT. I've come a long way by myself. But I would like to have not been waiting a year and a half to get any kind of, like, group therapy sessions. The first time I tried, they told me that they didn't think I was suitable… That may be down to COVID, the delay in that."* LD25-44, participant 2, age 30.

> *"So my daughter is 15. And she has got mental health issues. She got referred to a local mental health psychiatry team here. And they wouldn't actually touch her, or take on her case, as she was not to the point where she was suicidal or self-harming."* LD25-44, participant 4, age 35.

3.2.7.4. Reliance on pharmaceutical therapies

Related to the lack of mental health services, some women commented on a reliance on pharmacological treatments by GPs.

> *"The GP just constantly prescribes antidepressants."* MD25-44, participant 4, age 29.

> *"With the doctors they just kept giving me more tablets, more tablets, more tablets, and in the end, I just had to stop them completely and try and sort myself out myself. Because, I think, there was no support, err, at all with the mental health and how you should deal with certain things. They just think that a tablet, which obviously, let's be honest, it does turn you into where you're just this non-caring zombie."* MD45-65, participant 2, age 45.

3.2.7.5. Lack of follow-up

Even when women had received treatment from a specialist mental health service, there was not necessarily adequate follow-up as one participant described:

> *"I was arrested under the Mental Health Act. I was sectioned. I went to [service name removed]. I received no follow-up care from that, at all. I'd four officers restraining me, I received no help whatsoever after that. And that was prior to COVID."* LD25-44, participant 2, age 30.

3.2.7.6. Perinatal mental health

Postnatal depression was spoken about by a number of women. There was some recognition (among women who had experienced it) that postnatal depression was more common than women realised, and that peer support could be a way of helping women to open up about their experiences with other women in a similar situation. Women also spoke of the 'tick box' approach to being screened for mental health problems in pregnancy or after birth; being asked closed questions or how the use of mental health screening tools could potentially underdiagnose mental health conditions. (This is discussed further in a later section about communication style as a barrier to women discussing their health).

3.2.7.7. COVID-19 and mental health

Our focus groups took place during the COVID-19 pandemic. The pandemic and subsequent 'lockdown' was recognised as having resulted in less social contact and more people working from home. A number of women thought that this could contribute to a rise in mental health problems as a society, putting extra pressure on already stretched primary care and mental health services.

3.2.7.8. Eating disorders

Eating disorders were discussed by a few women who either had a personal experience of being assessed for an eating disorder, or knew of other women who had. In all cases the focus of the appointment had been on women meeting a threshold weight or BMI, before being considered for any support.

> *"When I was younger, I wouldn't say I had an eating disorder, I was just very careful about what I ate. And, erm, my Mum thought I did so she took me to the doctors. But all they did basically was like just check your weight and if your BMI was like healthy, they were just happy for you to go."* LD18-24, participant 6, age 23.

"My cousin had anorexia. But her Mum sort of saw it coming before it happened, really. And she went to the doctors to try and get some help before and they said, erm, that she wasn't at a low enough weight for them to be able to help her yet. And then she ended up from there going into hospital, being on tubes, she was on life support at one point, you know. Luckily she's pulled through it. But if the doctors helped at the time, instead of saying she's not at a low enough weight as yet, then it might not have got to that stage." LD25-44, participant 8, age 26.

3.2.7.9. Social media and mental health

A few of the younger women discussed social media as a source of negative impact on mental wellbeing, from spending long periods of time scrolling through social media on their devices and the pressure to have a certain unrealistic body image. One woman suggested pop-ups, like on the TV streaming service Netflix, could serve as a reminder to take a break from social media. Another young woman suggested trigger warnings could be implemented for content which could negatively affect people, signposting them to where specialist support was available.

"social media can create such mental health issues for young girls. Whether it could be when you're on Instagram, or Facebook, or something, that there can be pop-ups every half an hour that can remind you of reality. Because obviously some girls get warped into this perfect image that's on Instagram. I don't know, just something to spread awareness of where there is help if you are struggling or feeling down because of what you're seeing" LD18-24, participant 3, age 23.

3.2.8. Other physical health conditions

3.2.8.1. Headaches

Headaches were not a topic explicitly discussed as a women's health priority, but it was notable that in the South Asian group, three of the seven women chose the word headache as one of the first words that came to mind when thinking about the term women's health. Participant 1 remarked after making her three word choices; *"migraines and headaches - that's something that I suffer quite a bit"* (group SA18-65, age 42). When completing the ranking exercise participant 1 also listed 'headaches' as her second most important health priority, even though it did not appear in the list of topics discussed within that group.

3.2.8.2. Long-term health conditions

Three long-term conditions were raised as priorities for women.

Type 2 diabetes

Linked with the discussions about preventative care, type 2 diabetes was mentioned by one woman in the 45-65 age group and among several participants in the South Asian focus group as warranting extra focus. It was felt that there was inadequate awareness of the link between a healthy diet and type 2 diabetes, as well as a lack of blood testing to identify type 2 diabetes early.

"often we don't talk about this, but it's a big problem in women is diabetes and it's got nothing to do with weight, because a lot of us are genetically predisposed and under 50 many women get diabetes and they don't notice it until it's too late." UP45+, participant 4, age 45-50.

"Diabetes. People are diagnosed with diabetes type 2 and I think that there should be more awareness as well. You know like doctors and you know 'cause it's rising as well so they should have more like nutritionists and more one-to-one care. Obviously because of COVID there's a lack of information out there. So I think really they should recognise that and help women, yeah" SA18-65, participant 6, age 31.

Immune diseases

One woman in the 45-65 age group raised immune diseases as an area that there should be greater research focus because of the impact on quality of life and the higher prevalence among women. Two further women in this age group discussed having arthritic conditions and described delays in diagnosis with this.

"so I was diagnosed about 18 months ago with something called psoriatic arthritis, which is an autoimmune arthritis condition. And I must have spent the last 15 years going back and forward to the GP saying my hand's hurting my ankle's hurting. I even had a hip replacement in the middle of it, at the age of 40, cause my hip bone had crumbled, yet still no one listened to me and did the test that they would have had to pay for." LD45-65, participant 8, age 56.

Chronic pain

Two women described their ongoing problems with chronic pain. For both women their chronic pain affected many areas of their life, and a lack of support and services for chronic pain sufferers was evident from their accounts.

Participant 5 in group MD45-65 had been diagnosed with fibromyalgia and a separate back problem, and described experiencing back pain and bone pain which affected her quality of life and mental health.

"I've had back pain since I had my daughter who is now 23. And it's just continuous. 'Oh it's just this, it's nerve pains'. You get the MRI and… cause physio doesn't work, it just makes me worse, you're just left. Steroids don't work. What do you do? You live in pain all your life, you know? Listen to me, there must be something out there" MD45-65, participant 5, age 52.

Participant 4 in group LD25-44 described her experiences of chronic pain:

"Chronic pain. That word you probably wouldn't think of, particularly in young women, or middle-aged women. But as a sufferer myself, I am currently disabled, mostly bedridden due to chronic pain and I don't think there is enough support or services out there to help deal with it." LD25-44, participant 4, age 35.

3.2.9. Gender differences

At the outset of each focus group, the primary facilitator explained that the focus of the research was not only to explore women's-specific health, and that some conditions that affect both men and women can affect women differently. For most women this came as a surprise, and some felt this should be a priority:

> *"Just to go back to the difference between the conditions that can affect both male and female health such as various heart issues. I think it would be better if it was more widely known that there are certain differences between symptoms that can be overlooked"* LD25-44, participant 3, age 39.

A few women were already aware of the differences observed for men and women for certain conditions and felt more research was required in this area. Autism and ADHD were particularly raised.

> *"I know that mental health illnesses can look very different in men and women. But particularly things like neurodevelopmental difficulties, like autism and ADHD. So, we're very, like, aware of the typical signs of autism, but they're very predominant in young boys and males rather than girls."* LD18-24, participant 4, age 22.

3.2.10. Domestic abuse

Domestic abuse was raised by two women who felt there were inadequate services and support for women who experienced domestic abuse. Participant 4 in group MD25-44 worked with women who experienced domestic abuse and spoke of the limited counselling services for these women:

> *"As a job, I work with women who flee domestic abuse. But there's not really a lot of alternatives. So it's like domestic abuse. Okay, you've got depression, see you later, bye. There's no like, there's not a lot of offering of counselling. And the services that there are, like, 'if you go there and wait in a queue, if they've got time, they'll see you'. But it's a walk-in service and the first like 10 people get seen. So, some women can go consistently for three months and won't see anybody."* MD25-44, participant 4, age 29.

One participant felt that domestic abuse was an area where awareness and information needed to be increased:

> *"I think, sort of, women's abuse is sort of quite a taboo topic, that's not really talked about or sort of where helps available like women's shelters possibly and things like that."* LD25-44, participant 4, age 35.

3.2.11. Women's health education and raising awareness

A very common thread running through all focus groups, and an area highlighted as a priority, was the need to increase education and awareness about women's health. It was felt that women's health education should be increased not only among women, but also among wider society, including greater

training among health professionals. This was an area that was discussed in much greater depth during discussions about barriers and facilitators to women's health, and will therefore be described in greater detail in the next section.

3.2.12. Health care service-related priorities

When asked about priorities for women's health, women raised a number of issues which related to health service provision, rather than to specific health conditions. As we went on to ask about barriers and facilitators to having open conversations with health professionals, these issues were again raised by women, and in more depth. Therefore, the service-related priorities are listed briefly here, but described in detail in the next section.

- Women-specific services should be offered, such as women's drop-in clinics or local women's specialist practitioners.
- A more holistic/whole body approach is needed, including offering alternative therapies.
- Female doctors are often preferred for women's health-specific issues.
- A need for individualised care.
- Women not taken seriously or listened to by health professionals.
- Healthcare stereotyping.
- Underfunding of the NHS.
- Improved access to health services.

3.3. Ranking women's health priorities (age 18-65)

Following the request to 'brainstorm' their priorities for inclusion in a national strategy for women's health, and after collating and displaying their responses, each woman in the nine under-65 focus groups was asked to rank her top five priorities for inclusion. We aggregated their answers by broad topic area, and calculated overall ranks. This exercise was not included in the over-65 focus groups where more women dialled in by telephone, as video software was less familiar.

Table 5 shows the priorities which were included as part of any woman's 'top five' priorities, along with the number of groups where at least one person included it in the top five ranking, and a weight. The weight combines the number of women who listed the theme as a top five priority, and how highly this was ranked (with the highest rank given a score of 5). So, if all 65 women listed this theme as their highest rank the weight would be 65 x 5 = 325.

Mental health was listed as a priority in seven of the nine under-65 focus groups, and it was ranked highly by many. General NHS systems, including general perceptions of under-funding and problems of accessing primary care, were viewed as a priority in six groups, and in five groups there was a strong feeling that women should be able to access regular health checks (e.g. through a 'well-woman clinic'). This reflected a more general desire for preventive care. Better education, with a focus on 'what's normal' was a priority across the age groups – this was raised particularly in relation to menstruation and menopause. Menopause and perimenopause were clear priorities for women in the 45-64 age group, but also scored highly in two of the younger age groups, where knowing what to expect was viewed as important. Cancer awareness and screening (breast and cervical cancer) was a priority for many.

Table 5: Women's priorities for a women's health strategy

Rank and broad theme	No. of groups (n=9)	Weight*
1. Mental health	7	138
2. General health screening and well woman checks and clinics	5	74
3. Menopause and perimenopause, including knowledge about HRT	5	73
4. Breast cancer, awareness and screening	5	71
5. General NHS systems - over-emphasis on GP care, short GP appointments, under-funding, co-ordination of services, better use of technology, understanding family responsibilities	6	66
6. Cervical screening	4	65
7. Education and knowing what's 'normal'	6	57
8. Prevention and preventative care, positive messaging and reducing fear to consult	5	47
9. Fertility, infertility and miscarriage	3	45
10. Better knowledge of women's bodies and how they change, preference for women doctor, blind spots and stigma, gender differences	6	45
11. Periods	5	44
12. Healthy Eating, weight and exercise	5	44
13. Contraception	3	42
14. Post-natal care - focus on mother as well as child	1	26
15. Being taken seriously and not patronised	4	26
16. Alternatives to medication - including for depression	4	20
17. Domestic abuse	1	9
18. Eating disorders	1	9
19. High cholesterol	1	9
20. Genetic risks (particularly cancer)	1	8
21. Diabetes	1	6
22. Advice on dietary supplements	1	5
23. Support groups	1	5
24. Chronic pain	1	4
25. Screening in pregnancy	1	4
26. Headaches**	1	4
27. Women's health at work	1	4
28. Musculoskeletal health - bone pain and arthritis	2	2

*This weight is a combination of how many women ranked this in the top five of their priorities, and how highly it was ranked. Higher ranks were given a bigger score, rank 1=5, so the range is 1 (one woman ranking the theme fifth) to 365 (all women ranking the theme as the highest priority). **Headaches were added to the ranked list by one woman after the main discussion, so this was not included on the list for all women

3.4. Barriers to open discussions about women's health (age 18-65)

We asked women to discuss any barriers they experienced in speaking to healthcare professionals about their health, using the question: "*Thinking about women's health and the topics we've discussed, do you think there are barriers to women having open discussions with healthcare professionals about these issues? [PROMPT] What are those barriers?*"

Box 2: Summary of barriers to open discussions about women's health findings (age 18-65)

Open discussions about women's health were hindered by:

Societal barriers

- Societal attitudes that mean that women's health can be stigmatised and not taken seriously;

Personal barriers

- The challenge of approaching 'taboo' or embarrassing subjects (particularly women aged 18-24 and South Asian women) and the 'private' nature of many women's health issues (South Asian women);
- Limited time due to caring responsibilities (excluding women aged 18-24).
- A lack of adequate information and education in many areas of women's health, contributing to limited awareness about conditions,
- Uncertainty about what is considered 'normal' added further challenges to accessing help.
- Cultural barriers, such as language or religion (South Asian women).

Service-level barriers

- Difficulty accessing appointments, particularly with a GP, exacerbated during COVID-19;
- Under-resourced services that can result in rushed, time-limited appointments and delays in diagnosis and referral;

Health professional barriers

- Perceived lack of understanding and/or compassion of some health professionals, sometimes related to gender (e.g. a common a preference for female doctors), age, and communication style;
- A limited use of holistic approaches and an over-reliance on pharmaceutical therapies (age 45-65 and South Asian women).
- Perceived stereotyping and a less individualised approach;
- A perceived lack of knowledge of some areas of women's health (e.g. menopause) among health professionals (age 45-65).

The barriers raised by women are summarised in Table 6. As above, some of these issues had already been raised by women when they were asked about the priorities for women's health.

Table 6: Barriers to open conversations with health professionals about women's health

Themes	Sub-themes
Societal	Women's health not taken seriously
	Stigma
Personal	Embarrassment and 'taboo' subjects
	Pride
	Knowledge
	Mood
	Cultural
	Seriousness of the issue
	Lack of time
Health service	Underfunding/lack of resources
	Inadequate access to appointments
	'Rushed' appointments
	COVID-19 pandemic
	Lack of preventative care
	Delay in diagnosis or referral
	Lack of women's services
Health professional	Characteristics - gender
	Characteristics - age
	Knowledge
	Stereotyping; symptoms blamed on women's physiology
	Stereotyping; symptoms blamed on other conditions or attributes
	Lack of continuity of care
	Lack of holistic approach
	Communication style/not being listened to

3.4.1. Societal barriers

3.4.1.1. Women's health not taken seriously

This was an overarching theme from women's discussions that encompassed all age groups. There was a perception that for many areas of women's health, e.g. periods, contraception, or the menopause, women's concerns were not taken seriously because these issues affected all women and they should just 'get on with it' as their symptoms were 'normal'. This overall impression of women's health led to personal barriers, where women avoided accessing health services, or staff barriers, where professionals were less likely to listen to their concerns.

> *"with the contraception and… periods it gets brushed off like it's not a big thing because everyone has to do it so… it's as if you're being dramatic if there is a problem"* MD18-24, participant 1, age 23.

> *"There's a tendency for health professionals to confuse what's common with what's normal. So, you go to them with a problem, and their answer is 'oh, but that's really common' …. And that doesn't mean that its ok or that it's normal and my body should be doing this. So as an example, I started with acne for a long time, and I went over and over again, and I'd been on antibiotics for literally years, and I felt like it was destroying my gut bacteria .. and I kept going, and saying 'I'm convinced that there is something wrong with my hormones' and they kept saying like 'no, acne is really common and everyone is having acne, don't worry about it, just keep taking these antibiotics'. Now I've had a miscarriage and once again I was, like 'guys, there's something wrong here, something is wrong with my hormones, and they just said 'no, miscarriage happens to 1 in 4, it's completely, it's totally normal'. And I'm like 'no, just because it's common, doesn't mean normal. And it it's happening to this many people maybe we should find out why. And perhaps it's a coincidence, but it just so happens that all these people are women so maybe that's why it's not a priority?".* UP24-44, participant 1, age 30-35.

> *"Personally, I just got so into my own head and thought 'it's normal' and so I had really bad period pains, and just the whole thing of it being 'it's normal, everybody gets them' ... it took me a while to actually be willing to go to a doctor, to not be wasting my time and the doctor's time, for them to turn around and be like 'that's just a normal symptom, everybody gets it'. And so it took longer for me to be diagnosed, and those period pains were not normal."* LD18-24, participant 8, age 21.

> *"My daughter had the same problem … but she wouldn't discuss the terrible period pains with the doctor because to her that was something, she was female and she had to put up with - just crack on and get on with it. And eventually we managed to persuade her to see a consultant and it turns out she was suffering from endometriosis. Terrible - she thought - she had a bad back at the same time and that was ok to go to the doctor's with - that was something anyone could get, but the terrible period pain was something she was just supposed to put up with because she was a girl"* LD45-65, participant 4, age 52.

> *"And [the menopause] it's almost a bit of a joke, isn't it? Because it's like [imitates a condescending tone] 'are you menopausal?'… People that don't go through it look on it as a bit of a lightweight thing that all women go through… you know, 'get on with it'. It is like that"* MD45-65, participant 6, age 52.

3.4.1.2. Stigma

There was also a perception that some areas of women's health there were stigmatised. Stigma around mental health and menstruation were discussed earlier, under the women's health priorities section, as factors that could adversely impact on women's experience in the workplace. Participant 8 in group LD18-24 discusses her experiences of endometriosis:

> *"And I think there's a really big stigma around telling your employers as well, I've known a lot of people who've never really wanted to put it out there, because there's certain things that are so untreatable, and then it's not manageable or it could just flare up one day and you might not make it into work, and you don't want to be 'oh well, I've just got a really bad period', and them be like 'ugh, she's so dramatic, and it's just girls being hormonal again."* LD18-24, participant 8, age 21.

3.4.2. Personal barriers

3.4.2.1. Embarrassment and women's health as a taboo subject

For some women, embarrassment around women's health was a significant barrier to accessing healthcare and having open conversations about a 'taboo' subject. Embarrassment was particularly discussed among women in the youngest age groups, or older women with teenage daughters, therefore young age also presented a barrier in itself. The lack of discourse about women's health in society in general contributed to feelings of embarrassment when discussing women's health issues as these were not normal conversations, even among friends or family members.

> *"with like smear tests so many people don't go because they are embarrassed… they need a lot more reassurance and things"* MD18-24, participant 3, age 22.

> *"it is scary speaking to a doctor and it is embarrassing"* MD18-24, participant 1, age 23.

> *"I think as well, a lot of subjects for women are quite taboo. So that's probably why it's hard to talk about them. Because people don't - I mean like periods - and everyone gets slightly embarrassed because of the nature of our health issues … But even, not that we've experienced it in this group due to age, but then the menopause, and periods and I think fertility even, I think can be taboo subjects and I think that's why people would avoid appointments or avoid talking about it"* LD18-24, participant 2, age 24.

> *"I think it's the embarrassment of it - like, again with education, it's like 'am I normal'? Is this a normal thing? Is everyone else going through this? And I think, sometimes you feel a bit on your own with stuff, and then I think you resort to looking on Google and stuff, and that just gives you false information and makes you worry even more."* LD25-44, participant 8, age 26.

> *"women's health…it's a bit brushed under the carpet I reckon. Get on with it, crack on - and so we don't feel comfortable going [to the GP], because we're not used to talking about it normally."* LD45-65, participant 4, age 52.

3.4.2.2. Pride

One young woman, who had a history of mental health problems, spoke of her pride being a barrier to speaking to health professionals:

> *"Pride, perhaps … I've always been quite a closed person. When I have my own personal issues I do try to keep them to myself. … Because my pride sometimes gets in the way. And if I need help, and I know I really need help, and I don't have anyone to talk to, it makes it very difficult to open up about anything. And usually it's a few steps too late."* LD25-44, participant 2, age 30.

3.4.2.3. Mood

For one woman, her low mood when menstruating could act as a potential barrier to speaking to health professionals during that time:

> *"My husband used to notice before I did that I was either going to start my period … I'd get mood swings and things like that just before a period or whilst having a period … and it was always my husband who used to point out, 'oh, it's time of the month' – and that used to make me more miserable [laughter] … and you don't really want to speak to somebody at that time"* SA18-65, participant 5, age 32.

3.4.2.4. Women's knowledge, information and awareness of women's health

A common thread running through all focus groups was that there was a general lack of information, education, support and awareness about women's health. This is explored further in the next section about potential facilitators to encouraging conversations about women's health. As women were not well informed about their own health, this served as a barrier to approaching health professionals, or making informed decisions about their care. For example, women spoke of not knowing if their symptoms were normal, not having enough information to make decisions about potential treatments or to determine when to attend screening.

> *" I hit the menopause and the only indicator to me was that my periods stopped and I thought I'd come out of it really lightly - I'm not getting hot sweats, I'm not getting x y and z but on the other hand I had a number of other things that I never would have related to the menopause...being anxious, being upset, getting very emotional at really silly little things and bursting into tears and things like that. I had no idea"* LD45-65, participant 7, age 49.

> *"I didn't have my first smear test until I was 28…because the only information I had was from people telling me 'it's like this it's like that'. Don't get me wrong it wasn't bad at all when I had it...I don't know why I delayed it so long."* MD25-44, participant 4, age 29.

Participant 7 in group MD25-44 delayed speaking to her GP about her mental health for a year after her baby was born, despite experiencing problems from shortly after the birth of her child:

> *"I remember going to the GPs and talking to this lady who was waiting in reception. And she said, 'oh I had that' [postnatal depression]. It wasn't the GP that made me feel at ease, it was realising that so many other people have the same issue as you"* MD25-44, participant 7, age 42.

A greater level of knowledge was also perceived to be a barrier, as health professionals may then be less likely to pass on information.

> *"There's an assumption that as a woman you will go away and work out what it is that you need to do, and you don't necessarily need guiding through a process. I think especially if you come across to your GP as a relatively capable person, that they wouldn't necessarily go out of their way to kind of point you in the right direction for additional support or guidance or information."* UP45+, participant 2, age 45-50.

3.4.2.5. Seriousness of the issue

In general women spoke of worrying that their issue was not serious enough to warrant visiting a health professional, and this was something that presented as a barrier from a young age.

> *"I think the problem with a lot of people is that they don't think that issue is serious enough to go to the doctors or get it checked"* MD18-24, participant 5, age 20.

> *"You do tend to downplay your own health anyway - well we do in my family. My 13 year old daughter with chronic period pain – 'I'm not going to the doctor with that, they'll laugh at me' so what about people who are really ill?"* LD45-65, participant 8, age 56.

> *"I think that sometimes quite a lot of us can trivialise anything that we maybe feeling or a condition that we might have, and waiting til it's maybe a little bit more serious before going to see somebody"* LD45-65, participant 7, age 49.

In contrast, one woman spoke of a potentially serious issue becoming a barrier due to the anxiety this could provoke:

> *"I think, also like, it's the worry – of finding out if it's – people get scared of finding out about a major problem so a lot of times it's easier to brush it under the carpet … that's where support comes back into it I think"* MD18-24, participant 4, age 18.

3.4.2.6. Lack of time

For some women, finding time to visit a health professional, especially for those who were working, was problematic. Health services typically operated a Monday-Friday service, conflicting with standard working hours, and long waiting times for appointments required taking extended or unknown periods of time away from work. Women with children also found accessing appointments difficult.

> *"My issue is about accessibility, to get into a doctor's surgery. Especially if you have to go first thing in the morning, and then you can't get an appointment, and they say you have to ring at a certain time, and all the appointments are gone ... I do breakfast club and I do after-school club – so I can't go first thing in the morning, at 8.30, and I can't go at 6 o clock cos it's when I'm working … They need more leeway – timing-wise, I think it's a very big issue.* SA18-65, participant 4, age 43.

> *"I think that a lot of women fall through the cracks, because you spend ages sitting in waiting rooms … I think with smear screening at 25, I feel like a lot of people are trying to get their life on track, and you might have just started a new job, and you don't want to start saying, 'oh, I'll just*

book some time off work, I'll just nip to my screening' … it doesn't run effectively, you end up sitting in a waiting room for probably the best part of half a day sometimes." LD18-24, participant 8, age 21.

"You are often restricted to Monday to Friday and other services do run over weekends, and hospitals run over the weekends, but often some GPs aren't. Some are being more flexible and doing evenings and stuff, but again it's getting a time where it's more flexible so you can go and you're not having to take time out of work, or you're not having to tell your employers why you need the time off as well." LD25-44, participant 7, age 38.

3.4.2.7. Cultural barriers

Two women in the South Asian focus group raised potential cultural barriers for women accessing health services; language and religion. It should also be noted that women of South Asian background also demonstrated a very strong preference for seeing female doctors.

"Language barrier – that could be an important issue, especially in the Asian background … translation could be an important one to have as an option, or somebody to be there … you know, you don't expect doctors or people to know every language or whatever, but at least sometimes they can have that translation thing where they speak into somewhere and it translates it back – you know, have some sort of technical thing [interpreter services]" SA18-65, participant 7, age 48.

"Religion – there's different religions, and I'm not just talking about the Asian religions, I'm talking about, there's Jewish, and you've got the Mormons and things like that, and they've all got a different point of view in how far they would go, with blood transfusions and things like that, so there's got to be a need for everybody to feel comfortable. So they've got places for me, as an individual. For myself, I'm a Sikh, but I was thinking of other people who have other religious connotations … [Services] should take every group into consideration when making [changes] within the GP environment." SA18-65, participant 2, age 58.

3.4.3. Health service-level barriers

Several barriers for discussing women's health with health professionals related to a perceived lack of accessibility, which was generally believed to be related to under-investment in the publicly funded NHS health care system, although it is important to note that the focus groups were carried out in a wider context of the COVID-19 pandemic.

3.4.3.1. Underfunding and a lack of NHS resources

When discussing barriers, particularly around access to health services, many women reflected on the *"underfunding"* of the NHS. This undercurrent of limited resources was perceived to have a direct negative impact on health services and women described various negative experiences, which they attributed to insufficient financing of the health system. Some women had also resorted to paying for private healthcare, and this was noted across groups, regardless of area-level socio-economic status.

"There is such a big move towards mental health, quite rightly so, at the moment - services and facilities - they only have one pot of money and you can only spend it once. And we can talk about

this until we are blue in the face, but until those fundings are doubled, there's going to be no more investment in women's health." LD45-65, participant 4, age 52.

"When I had my son, which is 16 years ago, I had a health visitor and she was amazing, she had the time, she used to set up little community groups, and I'd just moved to the area and it was brilliant, you could talk about anything, she helped you to set up your own little groups to talk about and discuss things, and she was great. And then I've seen as time went on, the time that she could give disappeared and they've reviewed the number of health visitors. So I think that my son, my most recent child, he's seven, I don't think I saw a health visitor... or if I did it was once … it was so supportive that first time, it was brilliant. She talked about mental health, she was focused on me as much as the baby … it really helped. I know it's staffing and changes in resources and less money to focus on things, and maybe it's focusing more on deprived areas … but sometimes you can forget that all women are vulnerable when you just had a baby." UP24-44, participant 3, age 40-45.

3.4.3.2. Inadequate access to appointments

In the NHS, GPs are the gatekeepers of health services, however, many women across all groups reported difficulties in obtaining an appointment at their GP practice. There were practical barriers when trying to arrange appointments, such as long waiting times to speak to a receptionist, or needing to call as soon as the surgery opened to have a chance of getting an appointment.

"It's a mission! It is! To get an appointment." SA18-65, participant 7, age 48.

"Obviously the NHS is understaffed, so a lot of the time when you ring up the doctors you have to wait, like 40 minutes in the queue, to actually talk to them, and I think a lot of people might get put off that. So you might go to ring, and it'll be a long wait, and they'll be like 'oh, I'll just do it tomorrow' and then just put it off" MD18-24, participant 2, age 20.

"you had to phone up in the morning at 8 o'clock and pray that you got a doctor's appointment." LD25-44, participant 2, age 30.

When women did get to speak to a receptionist, sometimes this in itself was viewed as a barrier. As receptionists are often tasked with triaging appointments, they are commonly required to ask patients to disclose the nature of their appointment. Women were not always comfortable to divulge the reason for their appointment to the receptionist, especially when they may be having that conversation in front of other family members.

"When you phone for an appointment you have to explain the issue to the admin team first… I don't want to tell the receptionist my problem. Especially when it's private, it's a bit awkward. So that always puts me off for the longest time" MD25-44, participant 4, age 29.

Where digitised appointment systems were in place, these also proved to be a barrier, even for those who were computer-literate. Women described long screening questionnaires with repetitive or unnecessary questions, and complicated interfaces.

"*It was just not very accessible - and I'm someone that's on the internet all day for work and I struggled with it and even trying to get repeat prescriptions - booking it but then you don't know when it's ready - it's just all a mess"* LD45-65, participant 2, age 50.

There were also difficulties expressed with alternative primary care services (e.g. walk-in-centres and sexual health clinics), and waiting lists for secondary care services.

> *"I know sometimes when you call the sexual health clinic it's quite difficult to get an appointment and then you don't want to sit there with 101 people waiting in a queue … so I guess it's like, availability"* LD18-24, participant 3, age 23.

> *"I've had a bit of a pain in my side, and I've never known what it was about, so I've actually had to go to the walk in clinics, and they've just said, it could be IBS, it could be this, could be that – but I know it's not, cos obviously you know your symptoms, you just need to find out what it is … so I've gone to the walk-in clinic, because the doctor can't fit me in"* SA18-65, participant 4, age 43.

> *"waiting lists and how long waiting lists are at the moment. It's not just with, like, your local GP - getting in to see them. I'm sort of looking at further secondary care under the NHS and their waiting lists. If you know it's something you're likely to wait for... with the NHS being so overused as it is. I just sometimes think is it worth, sort of, waiting for that? Or do I just sort of carry on as I am?"* LD25-44, participant 4, age 35.

3.4.3.3. COVID-19 and reduced accessibility

Focus groups were conducted between April and June 2021, during the COVID-19 pandemic. The impact of COVID-19 on the healthcare system created additional problems with accessing healthcare, e.g. fewer face-to-face contacts with health professionals, suspension of some normal services and longer waiting times. One participant discussed her experience of failing to get an appointment for a urinary tract infection with her GP:

> *"In the end I had to go and see a private GP, but then I just wonder if this is what we're gearing towards now, you know where you're not able to see your GP face-to-face now. It's getting more and more difficult. And you know, those three words 'due to COVID' and I appreciate that, you know, we are in a pandemic, but I'm just wondering whether they're just paving the way, where you're going to have to pay a fee to actually have an appointment with your GP."* MD45-65, participant 6, age 52.

Another experienced a delay when she wanted to try to conceive, as she could not get a timely appointment with her GP to have her intrauterine device removed:

> *" It's the middle of a pandemic, I was trying to book an appointment, I really struggled to book the appointment because I had an intrauterine device, so it wasn't as simple as just like 'I'm going to stop taking my pills', I actually needed it removed."* UP24-44, participant 1, age 30-35.

3.4.3.4. 'Rushed' GP appointments

Where appointments were obtained with a GP, many women described the experience as 'rushed' due to the limited time slot available for appointments. Limits were also imposed as to the content of the discussion, with some participants reporting being permitted to discuss only one health issue. In general, though, participants were aware of, and sympathetic to, the pressures on GPs.

"I think that GPs in general are just not allocated enough time to deal with different issues – I think they are so inundated with all the problems in society that they have no choice but to prioritise … I put the blame with the system, there are just not enough GPs" MD45-65, participant 3, age 61.

"There was a time when I went to a doctor and said "there's a couple of things' and she said 'well you'll have to book for the second thing, I've just got a slot for one thing', so it just puts me off going, and I'm always rushing, because I'm aware they've got X amount of time, and then it's got to be on to the next" LD45-65, participant 2, age 50.

3.4.3.5. Delay in diagnosis or referral

A number of women across all groups spoke of delays in being diagnosed with particular health issues, or just generally needing to 'nag' and chase to achieve follow-up care. Specific conditions where women experienced delays were women's-health conditions (e.g. endometriosis and PCOS) and hidden conditions where symptoms were perhaps less obvious and doctors '*can't see things physically*' (e.g. mental health and chronic fatigue).

"When you do get to speak to a doctor, a lot of the time … it keeps needing a review, and sometimes when you know you've got a serious problem it can take ten appointments with your doctor before you get referred to a specialist, and so if you know there's a problem you might give up trying because you feel as if you're getting nowhere" MD18-24, participant 1, age 23.

"I was kind of doggedly pursuing health professionals for about 8 years before I got diagnosed with endometriosis, before they like bothered to take it seriously enough…to have a laparoscopy to properly diagnose as that's the only way they can be sure that you've got it. So that was a really long and horrible 8 years of awful symptoms that really negatively impacted my quality of life during that time. UP24-44, participant 6, age 30-35.

"I have chronic fatigue syndrome and I had to go to the doctors for probably the best part of three years before they actually were able to refer me on to someone, and I think they didn't take me seriously because on the surface of it I was still going to school, I was still achieving good grades, I was still dancing, but at the same time I was really unwell, and that wasn't taken seriously for a long time. I think that when doctors can't see things, physically, they don't take them as seriously, because they might put it down to health anxiety, or I'm just making things up or whatever." LD18-24, participant 4, age 22.

3.4.3.6. Lack of preventative care

Similarly to discussions of overall priorities, the lack of preventative care was discussed as a barrier to open discussions with health professionals about women's health. Some women felt they should only go to the GP if they were 'ill', and needing a health issue to be 'serious' before contacting a health professional. Participant 3 in group UP45+ discussed how the unavailability of preventative programmes could act as a barrier for women's health, giving them less control over their own health:

"You go to your dentist to keep your teeth clean… and yet there is nothing like that for the whole body here … you only go to the doctor when something is wrong and at that point many times it is too late. And it's costly for the system also, because prevention also saves money... As a woman

here, you're not given the power to do that. I don't think that's different for men either." UP45+, participant 3, age 45-50.

3.4.4. Health professional barriers

Women cited a number of barriers to having open conversations which related to the health professional they were speaking to.

3.4.4.1. Health professional characteristics - gender

Some women across all focus groups described seeing a male health professional as barrier to having open conversations about women's health, or accessing healthcare for women's health problems, particularly where these problems were 'private', such as relating to gynaecological and breast health. This was the most cited barrier of any discussed, and was described as either a personal barrier, or a barrier experienced by other women. Many women talked about feeling embarrassed or uncomfortable seeing a male practitioner, and wanted to see "a female doctor for female things" (MD45-65, participant 5, age 52.).

> *"Everyone gets slightly embarrassed because of the nature of our health issues. And especially if it was a male doctor, I think then also it would make some people feel more uncomfortable about going to talk about these issues" LD18-24, participant 2, age 24.*

> *"For female issues I want a female doctor, or a female nurse. Definitely. If it's anything to do with breast screening, cervical smears, then I'm not comfortable with a male"* MD45-65, participant 3, age 61.

For some women the preference for a female doctor related to a greater perceived level of understanding of women's health problems, given that they are a woman themselves.

> *"For me, I would say a barrier is, if I'm going to the doctors about a woman's problem, then I want to speak to a woman really because - this is nothing against male doctors - but I just feel as if a woman would have more understanding and there is often a lack of women GPs, … I think that just because they are in a female body, they understand far better .. if you're a male, you can never really understand what a woman goes through.."* LD25-44, participant 1, age 44.

> *"I don't think women themselves have any issue talking about the things they want to talk about. I think it's often the healthcare professionals. Erm, again, I don't want to stereotype men but, particularly if they are men they may not have any level of understanding of those experiences, such as childbirth, periods, menopause, all of those things. So I sometimes wonder if it's about levels of understanding of the people that we are trying to communicate with, as opposed to women not feeling that they want to communicate. It's that they don't feel empowered to."* UP45+, participant 2, age 45-50.

Previous negative experiences with male clinicians were described in some cases:

> *"I went to have an internal examination and I didn't know it was a male …. and then when I spoke to him and said sorry can I rebook, I would like to see a female, he was, like, 'oh yeah yeah, fine, I*

mean lots of women don't want to see men, It's probably because of your childhood experiences or something like that', and I couldn't believe it – I was just thinking, actually, it's because you're a male, it's as simple as that, it's private, you know?." MD25-44, participant 6, age 36.

"At my six week [postnatal] check… my male GP was just like, you know, basically just saying I could have sex from six weeks. Never mind that I still had internal stitches and I wasn't feeling the best because neither of my babies slept, and yeah, it was just bizarre, his take on it" MD25-44, participant 8, age 40.

Although there was a strong preference for many women to consult with a female doctor, due to issues with generally accessing appointments, accompanied with perceived limited availability of female GPs, women were not often able to assert their choice.

"[requesting a female clinician] might be not always positively received by the GP receptionist, or somebody that you are trying to get the appointment with .... it might not be for everybody but there might be occasions, particularly for certain groups of women, where a male clinician might be a barrier." UP24-44, participant 4, age 40-45.

For women in the South Asian group, the ability to choose to see a female clinician was a prominent theme in discussions and was raised as a women's health priority, before women were asked to discuss barriers to accessing healthcare.

"Any kind of women's issues, you should be able to see - I'm not being sexist - but you need to see a female. So there should be female, you know the top consultants and things... I know when you're having a baby there's male doctors there, but you should be able to choose, you know, who you want to see... Especially when it's to do with your [Participant 7 interjects "private parts"], from cystitis to smear tests to checking for cancer on breasts and stuff. I don't think I'd be personally comfortable with a male doctor doing that. If I had stomach pain that would be different because you're not exposing yourself in any other way. Obviously, there should be a nurse present as well - I mean there always is- always two people present if they're checking in an [intimate] area - but I prefer them to be female." SA18-65, participant 2, age 58.

Not all women preferred a female GP, some women had no preference, but there was an acknowledgement for some of these women that other attributes of the clinician were important, such as their knowledge and their level of compassion.

"I'm quite happy to talk to a man or a woman about any issues that I'm having, and I've found a cross section - I've dealt with some men who've been very sympathetic, and I've dealt with some others who've had no empathy at all, particularly with female-specific issues. But likewise I've dealt with some women who I've found not to be particularly sympathetic either, and I don't know whether that is generally how that person is, or maybe they've had a bad day … I'd feel happy to talk to either, but I've had different responses from both, for whatever reason - either lack of empathy, lack of knowledge, in a particular area that may relate to female health" LD45-65, participant 7, age 49.

3.4.4.2. Health professional characteristics - age

A few women discussed the age of the health practitioner as a barrier to open conversations about women's health, as younger clinicians may display a lack of knowledge, or experience, or were perceived to be less able to relate to the health experiences of older women, such as the menopause.

> *"We've got a young nurse and I find it really difficult to talk to her, cos she looks about twenty, and there's just no empathy there, or not enough knowledge there of what I might want to discuss with her, so age is almost as important to me really. I had a really great male doctor and I could talk about anything with him - easier than the young nurse."* LD45-65, participant 4, age 52.

> *"I've also experienced that the younger female GPs also don't seem to kind of have that level of understanding [discussing early menopause]"* UP45+, participant 2, age 45-50.

3.4.4.3. Health professionals' knowledge

Some women discussed a lack of doctors' knowledge as a barrier to open conversations. This particularly related to menopause.

> *"I would want to see doctors' knowledge increased around HRT, the options on HRT, the consequences of HRT, and I'd like to feel that my doctor clearly understood what that information was, rather than me going to them saying I've got an issue and them having to research it and thanking me because it's helped them look into it – that's not really what I want from a doctor."* LD45-65, participant 6, age 57.

> *"And then they're looking on the internet as well, in front of you, which I find a bit 'I could have done that at home syndrome'. But it is lack of knowledge as well … I think it's mainly the menopause, cos it's such a big area of expertise needed, because there's so many different symptoms, people suffer with it differently at different ages."* LD45-65, participant 1, age 56.

3.4.4.4. Stereotyping women's health

Female physiology (e.g. hormones), specific time points in the female life-course (e.g. childbirth or menopause) and female-specific drugs (e.g. contraceptive pills) were felt to be 'blamed' when women presented with problems. This left some women concerned that wider health issues may be missed owing to being mis-labelled as a female-specific issue.

> *"as a woman if you go to the doctors if you do have a symptom they'll blame it on your period or your contraception. And then that will put you off going because you think oh it's just my period doing that"* MD18-24, participant 4, age 18.

> *"And when you do try to get help around these issues [breast lumps and mood], it's like 'oh, it's because you've just had a baby' or 'you've just gone on the pill' and those things can mask. So … if you had that kind of regular check-up opportunity it probably would help to disentangle what is actually a hormonal related change and what is actually there is something wider going on."* UP24-44, participant 5, age 30-35.

The framing of women's health appointments could also present a barrier for women to openly discuss what they intended to, with clinicians having preconceived expectations about the nature of the

appointment depending on the age of the woman (e.g. childbearing age), and leading the conversation based on these expectations.

> *"when I go to the doctors, no matter what I'm going for, it always ends up leading to ' are you pregnant?'. I hate that."* MD18-24, participant 4, age 18.

> *"whenever I go to the doctors, they go 'oh, you're 30, you must be pregnant'. And then until we've discussed that I'm not pregnant, they won't really tolerate anything else. And I'm pretty sure that if you were, for example, 45 or 55 the conversation would be 'oh, it's because you're menopausal'. So I feel like the whole way that consultations are framed for women, because you're a woman in the first place, it's completely different."* UP24-44, participant 5, age 30-35.

> *"[there are] judgements and preconceived ideas about what a woman's conversation is gonna be about for a start…it leaves a woman feeling like she doesn't have a space to really say what she thinks or what she feels…it's kind of already decided where the conversation is gonna start and lead.. I think that's quite a big thing … from my experience it's a very narrow focus …"* UP24-44, participant 6, age 30-35.

3.4.4.5. Stereotyping: symptoms blamed on other conditions or attributes

As well as pre-conceived conceptions, some women had also experienced health professionals blaming any symptoms they presented with on other long-term conditions they had, or on their physical attributes (e.g. weight).

> *"Sometimes I don't seek help for things because often, because I'm overweight, things are blamed on my weight. Some doctors can be very flippant in that way, like with heavy bleeding and things, they'll say 'oh, your weight is affecting it', and … so for me, sometimes if I've got a ladies' problem, I might not go to the doctor. Maybe that means I didn't need to go to the doctor anyway, but it's often blamed on weight rather than actually looking into the problem."* LD25-44, participant 1, age 44.

> *"I've noticed a lot of the times when I go, they see I'm labelled as I've got anxiety, and then they just jump right in and say 'it's probably just that you know?'. It's difficult because at that time, that's not what I feel, I don't feel like it's anxiety"* MD25-44, participant 8, age 40.

> *"I had depression eleven years ago, and because it's on the system, any time that I everything I've gone to the GPs about anything emotional, or things like anxiety, they'll say 'oh you've got a history of depression' ... Mine was circumstantial because of something that had happened trying to have a baby, so, you just get labelled then and they make assumptions"* MD25-44, participant 7, age 42.

3.4.4.6. Lack of continuity of care

Women reflected on the changes in primary care provision, which meant they were now less likely to see a GP who knew them. This lack of continuity of care left some women feeling less understood and less comfortable discussing their health with a GP they were not familiar with.

> *"in terms of health professional continuity, that used to be really good back in the days – you know, we used to have the same doctor, same midwife or same nurse, and you knew who you*

were talking to – as soon as you walk in that room they knew you, you knew them – you just felt comfortable. But you don't get that anymore – you see a different GP, and even though they've got the notes there and everything, you're just explaining everything all over again, and I just feel that's a really big let-down for anyone and everyone." SA18-65, participant 1, age 42.

"When I was growing up… if someone said to you 'who's your doctor?', you knew who your doctor was because you always saw that person and they just had a far better understanding of you because they always saw you... Now that that doesn't happen, I don't feel – not that I've got an extensive medical record - but I don't feel that just any doctor really understands me if that makes sense? It's a less personable service I guess." LD25-44, participant 1, age 44.

There was also a concern that the lack of continuity could lead to underlying health problems being missed, due to a lack of familiarity with the woman's history, either from the medical records, or through a reliance on the woman relaying information about her own health.

"Finally when you get an appointment, you don't get your own GP, every time you see someone different. Sometimes a locum. So, nobody who knows you who over the years might put those things together, you know, that whole body approach. 'Hey you came to see me for that little thing then and now this little thing' and actually there's something else going on" UP45+, participant 2, age 45-50.

"You get a different GP every time, so you have to keep explaining the story, and then you forget most of the things, so things could get missed." MD45-65, participant 5, age 52.

3.4.4.7. Lack of a holistic approach

Women in the older 45-65 age group and in the South Asian group discussed a lack of a holistic approach as a barrier in two ways. Firstly, in terms of not viewing the body as a whole and secondly an over-reliance on modern medicine and pharmaceutical care, rather than offering alternative therapies. Both definitions of holistic care were raised by various women when asked about women's health priorities.

"this fragmentation of the body that I notice in the UK [compared to the participant's country of birth] whenever I go to the GP, is definitely not useful. For example, menopause will actually affect the whole of your body... for example with the whole of your joints, and there is no way of getting the GP discuss all of this" UP45+, participant 8, age 50-55.

One participant discussed her annual check-up for hypertension with a nurse practitioner, which had a limited focus:

"Even when you get an annual check it still isn't holistic, because if it isn't related to hypertension you need to make an appointment and speak to the doctor separately about that... It's a good point - having that time to talk about all the things that are going on because actually they may not be intrinsically linked, but they may, and actually it doesn't matter if they are or not, you're still experiencing that as a whole" UP45+, participant 2, age 45-50.

Another recognised that limited appointment times restricted the ability of practitioners taking a holistic approach:

“it always feels very rushed, and not holistic, not a listening service really - and it’s just down to the time.” LD45-65, participant 2, age 50.

Some participants also discussed alternative therapies.

"There should be holistic medicine available as a choice on national health. I know national health is just conventional and it's all the 'big pharma' and everything, but they should sort of split it so its' more natural, so they're kind of giving you that advice - how to stay healthy, how to keep your weight... just to keep you healthy. - Once a woman's healthy, they pass it along to their kids and their family." SA18-65, participant 2, age 58.

"I'd like to see more involvement and more knowledge alternative therapies and alternative remedies, rather than going straight to drug route" LD45-65, participant 4, age 52.

3.4.4.8. Communication style

Poor communication style was discussed as a barrier by women, although not by those in the youngest age groups. Poor communication included a lack of eye contact, not asking questions or asking closed questions, poor phrasing during discussions and a patronising manner.

“There’s no eye contact, it’s all while you’re speaking they’re typing it all down” LD45-65, participant 2, age 50.

"I don't know if this is related to the fact that I am a woman or not, or maybe because I am a foreigner... They tend to be patronising - not just the GP but the nurses... It's very difficult to be taken seriously and to be taken like an intelligent human being... I would like discussion with proper terminology. I am sick and tired of doctors talking to me about 'tummy' instead of mentioning stomach or intestine, or I mention stomach or intestine and they answer me with 'tummy'. 'Do you have tummy ache?'. I am not a five year old, and I have experienced this only in the UK... Speak to me like an adult" UP45+, participant 8, age 50-55.

Closed questioning or a ‘tick box’ approach was particularly highlighted when women spoke about mental health.

“It’s the way they phrase a question. So, I for example, throughout my pregnancy I was going through a really traumatic grief, a life event, and actually I was OK at the time but I was never really asked about mental health, and I know that I was meant to be being asked at every maternity appointment. And the times when I was asked, it was phrased as things like ‘well, you’re OK, right?'. So I didn't even have the opportunity. Actually I didn't want to share it, but they had no idea that any of that was going on because of the way they phrased the question. … It’s used very much as a question that’s like a tick box. So because they want it to be a tick box, they phrase it in a closed kind of way … that means they don’t have to deal with that”. UP24-44, participant 5, age 30-35.

"My GP gave me one of those [a depression screening questionnaire] to do in the waiting room. I had an ectopic pregnancy and I was depressed because I'd lost my baby and she gave me one of those in the waiting room. And it was like 'on a scale of 1 to 10, how much do you think you're going to kill yourself?' A bizarre way of assessing it. And then I had to give that to her and she

determined from what box I ticked as to whether she should send me home or put me on pills. Really bizarre." MD25-44, participant 8, age 40.

The level of compassion demonstrated by health professionals was also important to women.

"And the amount of doctors that I've seen. Some of them, I'm not being horrible, but they shouldn't be doctors. You know, like you talk to some people and they get it straight away. You talk to other people, and they just look at you like you're stupid" MD25-44, participant 7, age 42.

"it was kind of hit or miss who you would get, to the point that I used to ask who the duty doctor was, cos there was one, he just didn't give a hoot, to be honest … Being able to speak to someone that you know, who will understand, or not feeling as though you can't talk to them, is important " LD25-44, participant 2, age 30.

For one woman the level of compassion demonstrated by her gynaecologist consultant overcame the potential barrier of him being male:

"For me it's not about whether it's a male or female person that I'm seeing in the consultation, it's about how compassionate they are, or how understanding and how willing they are to give you the space to discuss things on your terms rather than their terms. So I know it can have some impact for some women, like that they prefer a female GP or a female doctor, but for me personally it's more about their approach. My consultant that I have now for my endometriosis is male, and he's brilliant." UP24-44, participant 6, age 30-35.

3.5. Women's voices in health care

In addition to asking women about barriers to having open conversations about women's health, we also asked women "*Have you ever felt that you have not been listened to or taken seriously when you have sought help with your health in the past?".* Examples of women feeling that they were not listened to or taken seriously had already been discussed by many women before this question was raised, demonstrating a strong dialogue around these issues. Women were also asked for good examples of being listened to by health professionals.

Women across all age groups gave examples of not being listened to or taken seriously by health professionals.

"Going to the doctors isn't an enjoyable experience because they don't listen. That's the problem for me. I just don't go now." MD45-65, participant 2, age 45.

"I think as well sometimes you go to the doctor's, and you just don't feel very believed. And you feel like you're just wasting their time, and they sometimes make you believe that there's actually nothing wrong with you, when you know your body best, and you know if something's wrong" LD18-24, participant 4, age 22.

Women's health concerns in particular were sometimes dismissed or diminished by health professionals. Often this was due to an assumption that their symptoms related to women's physiology, such as hormones, which could lead to delays in diagnoses of long-term problems. For example, one

participant described her experiences of digestive problems that have been attributed to her hormones and menstrual cycle:

> *"I've had problems with my digestive system all year… every time I go to the doctors they just brush it off and say oh it's because you're a woman it will just be your hormones, oh it's your periods - things like that. I know males that have the same problem as me and they get seen by a specialist in a second."* MD18-24, participant 4, age 18.

Women described a 'fight' to be heard by health professionals, with many women describing instances of needing to 'nag' professionals to get them to listen, or to follow-up on a concern, leaving them feeling 'fobbed off' and powerless.

> *"I also just really empathise [with what others said] with having to be dogged and determined... I feel like I'm a reasonably intelligent, quite persistent, on the borderline of annoying at times, if I want something. But I sometimes feel like if I struggle then that's really not good. And actually, sometimes I feel like I am a strong-willed person, but in certain situations, I find that I revert to kind of like a super shy, introverted patient, because I know the outcome is going to be like 'oh it's just hormonal' or whatever.... I feel like it's not a very helpful position to be in really."* UP24-44, participant 5, age 30-35.

> *"Demand it. I find that you have to be really firm with them. For an X-ray you have to like say 'I want it', because they can't refuse you"* MD45-65, participant 5, age 52.

Other women reported needing to 'exaggerate' their symptoms to get doctors to listen to them.

> *"I've got asthma…back when I was in school, I was struggling with it. I went to the doctors and I just felt like they didn't really listen to what I was saying. I could tell in myself that it was bad, so I needed something stronger. But they just, they didn't really try to do much to help me. Like they just said 'are you definitely taking your inhaler the right way?' and stuff like that... You feel like you've got to really exaggerate some things to actually be listened to"* LD18-24, participant 5, age 19.

It was notable and perhaps surprising that women in the South Asian group had the fewest examples of 'not being listened to or taken seriously' when asked this question; answers in this group were much more positive about being heard in health care. Only one woman had a negative example when discussing menstrual health, with problems accessing a female GP and a male doctor being dismissive of her period pains, leading her to eventually access private healthcare in Germany.

> *"I had period pain, it was a male doctor...[the] pain is really bad and getting worse... 'You not gonna give me any medication?' 'No I don't have any medication unless it's painkiller'. I go 'any... further tests - anything that can relieve [the] pains?'. He goes 'I've got nothing'...I stopped going to the doctor. I don't go. I'd rather ring my Germany doctor as my parents live there. They can arrange the appointment, I ring them and then they send me medicines. It's easier that way."* SA18-65, participant 5, age 32.

Other women in the South Asian group responded that they had been 'lucky' that they had not had those experiences and that health professionals listened to their concerns. Some of the women in this group also criticised some patients for being 'regulars' who come in with 'every niggle' and doctors

don't have the time for a lengthy conversation as they are busy. One participant in the South Asian group worked as a GP receptionist, so had a dual perspective from a patient and employee standpoint:

> *"Doctors don't have time to have that 20 min 30 min conversation, they're not mind readers, you know?... GPs are so busy and rushed off their feet."* SA18-65, participant 7, age 48.

Another felt her GP did have the time for longer appointments:

> *"Often I've been in [to the GP] I must have sat there for about 20 minutes talking to a doctor, about, you know, if I've got a pain or something, I've always sat there and they've never been like 'oh I'm in a rush', they never seem like they're in a rush. They take their time. That's my experience of being with my doctors, they always seem like they have the time - and listened to me."* SA18-65, participant 3, age 45.

3.6. Facilitators to open discussions about women's health/good examples of being listened to

After discussing barriers to open discussions with healthcare professionals, women were asked *"What might help women to have more open discussions?".* In a later part of the focus group, women were also asked *"Can you think of any good examples where you have been listened to and understood? What did the health professional do well in this situation?".* As the good examples of being listened to given by women overlapped with the areas raised as potential facilitators to open conversations, the themes arising from these two questions are summarised jointly in this section.

Box 3: Summary of facilitators to open conversations with health professionals

Women suggested that open discussions about women's health could be facilitated by:

Societal facilitators

- Increased education and awareness of aspects of women's health from school onwards, to raise awareness about what is normal;
- Greater support in school settings for young women and girls, e.g. drop-in school nurses and more understanding from teaching staff about menstruation.
- Peer support groups for women, e.g. for menstrual health and the menopause.

Service-level facilitators

- Greater training for all staff about women's health
- Improved access to health services, including ease of booking and obtaining GP appointments, longer appointment times and flexibility of services, e.g. with extended opening hours.
- Women's health services tailored to their needs, e.g. women's drop in clinics

Health professional facilitators

- Improved continuity of care, individualised care, increased follow-up and referrals to specialist services and improved communication from health professionals.

It should be noted that the following section summarises the facilitators to open conversations as discussed by women, however, there was recognition that addressing any of the barriers discussed by women would also serve as positive steps to dealing with these concerns. Table 7 provides a summary of the themes and sub-themes arising from discussions where facilitators to open conversations were discussed.

Table 7: Facilitators of open discussions with health professionals about women's health

Level	Theme	Sub-themes
Societal	Increasing education and awareness and normalising aspects of women's health	
	Peer support	
Health service	Improved access to healthcare services	Extended hours, remote consultations,
	Longer appointments	
	Preventative care	
	Women's health specific services	
Health professional	Continuity of care	
	Improved communication	
	A more patient-centred approach	
	Increased follow-up or referrals	

3.6.1. Societal facilitators

3.6.1.1. Increasing education and awareness of women's health & normalising women's health

To break down the barriers of women's health being a taboo and stigmatised subject, which caused embarrassment for some women, an increase in general education, information, awareness and discourse around women's health was strongly endorsed by women of all ages and from all backgrounds. There was a strong sentiment that conversations about women's health should be normalised.

> *"But I think generally, if we talked about women's health more openly across the media, and more openly… If we all spoke normally about it and - I mean I chat to some of my friends about stuff - but again it's not easy, they've never been easy conversations. I think if they were generally more easy conversations and we talked about it more, I don't think it would matter as much whether your doctor was male or female, or 21 or 51 really."* LD45-65, participant 4, age 52.

> *"I think just normalising the issues… making it more of an open conversation…Like you walk into a GP surgery, there's not any leaflets particularly periods problems or any women's health issues, it's more just like common cold and flu. Coming back to the taboo thing, people don't want to talk about it as much as there's that element of embarrassment there. So I think... I don't know if marketing would be useful... I mean half the population don't have periods, so not everyone is*

going to talk about it all the time, but just to have more conversations flowing in life in general about it, I think would help" LD18-24, participant 2, age 24.

"if there was something a bit proactive saying 'hey, ladies, come and look here, this might help you'. Technology could better support us in getting better informed, and better connectivity and communication with people across all these sorts of issues." LD45-65, participant 7, age 49.

Many women felt that education regarding women's health needed to start in the school setting, e.g. periods, breast checking, sex education and contraception and even the menopause. The education was also recommended to be inclusive of young girls and boys. Additionally, women thought there should be increased pastoral support in school settings, for example, with a designated professional that students could go to; this was seen as especially important given that young girls would not want to discuss these topics with their parents.

"From the young people's angle I think there needs to be a big effort into changing boys' views about it [women's health]. Which is really sad considering it's our health... Like if you ever bring it up, it's the classic 'oh she's on her period' because she's a bit upset or being a bit moody or something like that that you end up not saying 'oh I need to go to the toilet' or something in the middle of a lesson, because you're worried that the boys are going to see your pad or something... I had it in school when you weren't allowed to leave the lesson to go to the toilet. You didn't want to have to be like 'I've just started my period, I need to leave now'. You couldn't say that in front of everyone as then everyone would laugh. It's a kind of culture almost that you don't say things like that because it could offend someone... Like 'don't say period in front of a male teacher, they could be offended'. It's kind of horrible. It makes people not speak out and then you take that into later life. Like I can't speak about this right now because my dad's there, or I can't buy period products because I'm shopping with my dad... It's a really big hurdle to get over." LD18-24, participant 8, age 21.

"I think sometimes when you're younger, people can't speak to their parents about things, so maybe if there was a professional going into schools, and saying 'today we have this drop-in, so whoever wants to come and speak can speak', rather than, cos when you're young you can't always just book yourself a GP appointment and take yourself there without your parents going with you. So, if there's things that you don't want to speak to them about, then that would make it more accessible for younger people to be able to speak to someone." LD18-24, participant 4, age 22.

There was agreement that any education provided in the school setting should give careful consideration to timing; early enough to educate young women when they may be starting puberty, but late enough that the information would be relevant to them. Furthermore, although there was agreement that education should be increased among both sexes to increase awareness about women's health, it was noted that classes should be split to teach boys and girls separately.

Education and training among health professionals was also suggested as a way to encourage more open discussions about women's health.

"If certain topics are discussed more and becoming more open, then the barrier for us to talk about them in front of the GP, whatever gender, whatever age, would become less. But also, if

those GPs have encountered that in their training, that might also help." UP45+, participant 6, age 45-50.

3.6.1.2. Peer support

Peer support groups for women's health problems such as menstrual health and the menopause were suggested by some women to provide a platform for sharing experiences. Some women reflected on how useful this kind of peer support had been if they had attended antenatal classes while pregnant, or community centres, and felt this format could be replicated for other women's health issues, or at different time points. Both face-to-face and virtual methods were suggested.

> *"This sort of [virtual] platform for menopause would be good [similar to the focus group] – you've got a leader who specialises in menopause, you've got participants who've got various degrees of going through the menopause – different symptoms, different experiences, and you've got women with different experiences… The leader could explain what's happening exactly in your body, so it's an education, and it also gives an opportunity to ask questions and you know, and hear other people's experiences as well".* MD45-65, participant 3, age 61.

> *"There should be places for people to walk in and have a chat… a general chit chat, a cup of tea. You know like they used to back in the days of community centres, you know. Nowadays they are non-existent. Maybe they should have a women's health coffee morning or something."* SA18-65, participant 7, age 48.

3.6.2. Health service-level facilitators

3.6.2.1. Improved accessibility of health services

Increased availability of health services

Inadequate access to primary and secondary care services was one of the most cited barriers discussed by women across all groups as discussed in section 3.4.3.2. Therefore, improved access to healthcare was also suggested as a facilitator to encouraging open conversations with health professionals about women's health.

> *"I think what we've said. Make services more available. Make it easier to make appointments, make it [conversations about women's health] part of our daily life. Even if it was an online question thing. Just something where you can have that interaction more and you're encouraged to discuss more and share more, rather than let things build up and wait while [it becomes] a big issue. Then you're firefighting a lot of problems. So, if it was more readily available and part of our life, and part of how we communicate, it would just flow a lot easier."* LD45-65, participant 2, age 50.

Increased flexibility of services was also supported by women, e.g. utilising mobile or pop-up services or increasing the opening hours of services to better meet the needs of women who worked or were otherwise unable to attend during standard opening hours. Likewise, offering home visits to those who found attending clinics more difficult, such as new mothers or disabled people.

“Being able to access somewhere where you can get advice or be examined. You know, people that work... accessibility has to be quite flexible... Like having mobile units or something where they are available maybe on a weekend... or on an evening. And for it to be consistent, cos sometimes they set these things up and then they'll blame funding or whatever and it's no longer available" SA18-65, participant 7, age 48.

Digital healthcare and remote consultations

Focus groups took place in 2021 during the COVID-19 pandemic, a time where online and phone consultations increased, to mitigate the infection risks with face-to-face consultations. Some women noted that online services could improve accessibility of health services.

> *"What my GP has started doing since COVID is, there's an app. On the app you can put down whether you want the doctor to call you - you and on the app you put what your problem is, and then they may ask for a picture... I find that more efficient because the doctor rang me before 10am, when I used the facility, whereas if you try to make an appointment with the receptionist, then they always say ring...tomorrow or whatever. It gets frustrating."* SA18-65, participant 3, age 45.

It was noted that online or telephone consultations were not a solution in all cases, as sometimes a face-to-face appointment was needed. Furthermore, some aspects of online services, e.g. sending photographs, may not be suitable depending on the issue the woman was experiencing, and there could be privacy issues with remote consultations, depending on where the woman was or who she was with when consulting.

> *"So I had to send them a picture at work [in a school], trying to keep my camera away from the children. Couldn't get a picture and I thought 'oh God'".* SA18-65, participant 3, age 45.

> *"I know I know, especially if it's a private area then you can't but if it's a spot on your face or something then you can take a picture"* SA18-65, participant 2, age 58.

Although digital access was not a problem experienced by women we spoke to, it was recognised that for other women, digital access to health services would be a barrier, perhaps due to a lack of digital literacy (e.g. among older women), or where women did not have suitable devices or internet capabilities.

> *"not a lot of people have Wi-Fi on their phones, [or] mobile data. So, I'm sort of lucky with that, but not a lot of people are lucky to have access on their phone and access the doctors and I think that's a problem. As they're saying that's going to be the new way to get an appointment. It costs money as well - it's not cheap - it's a barrier for a lot of people".* SA18-65, participant 6, age 31.

3.6.2.2. Longer appointments

As previously described, many women felt appointments with GPs were too short, leaving them feeling ‘rushed’ and restricting their ability to communicate effectively. Longer appointments were therefore suggested as a way of promoting open discussions with health professionals about women’s health, especially as shorter appointments may be counterproductive, leaving women needing to book a further appointment to fully discuss their issues, and limiting the ability of healthcare professionals to piece symptoms together.

"People come out of the consultation without the questions they really wanted [answering], so they maybe end up going back. So maybe just a bit of an extra time will save time in a long run". UP24-44, participant 5, age 30-35.

Utilising other health professionals who have greater time availability was also suggested:

"Maybe a different healthcare professional - it doesn't have to be a GP after all - and who has dedicated time" UP45+, participant 7, age 45-50.

"The nurses at the GP are more helpful and willing to listen to you than the doctors. They just seem to have more time and give you more information to be honest with you. I'm not just slagging off GPs, cos they are there for a reason, but... I do think they are so over-pressured. I think some of them have just lost the will to be honest, cos they just want you in and out to see the next person". MD45-65, participant 2, age 45.

3.6.2.3. Preventative care

Preventative health care was discussed in section 3.1.8 as a priority topic for women, with many of our participants advocating for increased prevention and early intervention to reduce the likelihood of adverse health outcomes. When asked what might help women to have more open discussions with health professionals, one woman with a history of mental health problems added that this would also be beneficial for mental health, and other areas of women's health:

"I think it's mostly about early prevention. And that feeds into a lot of the stuff, like eating disorders… miscarriage, even prenatal and postnatal … rather than a reactive mentality, it's having a preventative mentality." LD25-44, participant 2, age 30.

3.6.2.4. Women's health specific services

When asked about priorities for women's health, along with regular health screening and check-ups, women across most groups (with the exception of the youngest groups) suggested that services or clinics specific to women's health would be welcomed. Some women recalled that such 'well woman' clinics previously existed in primary care but have since closed. Women's health clinics were advocated as an initiative that could improve patient experiences and care by having professionals with a greater understanding and specialisation in women's health, whilst being a more accessible and appealing service for women to provide 'end to end' care.

"If you had a problem you could go to the 'well women' clinic to chat about domestic abuse or postnatal depression, or if you didn't want visit your doctor because you was young. It would do... a sexual health clinic as well... it kind of done everything. But when the baby clinic closed there, they closed that as well." MD25-44, participant 7, age 42.

"We have maternity clinics when people are pregnant so why don't we have women's health clinics that are staffed by people who are experienced in the field and possibly some lived experience which is huge… People cannot relate if they have not got experience of it - you can … sympathise but you can't empathise. So to my mind we need women's health clinics, even in a separate building - so we don't have to tie up an appointment for someone who is going to the GP because they think they've got bowel cancer.. Our problems may seem small but they are still

problems and we need to be able to feel confident that we can go and see someone and explain it, have them understand it and suggest a solution" LD45-65, participant 8, age 56.

"The bit in the middle - from starting your periods to going through the menopause - I'm not sure how much advice there is on contraception and where teenagers go for advice on that … a women's' clinic would be able to cover that as well - end to end." LD45-65, participant 1, age 56.

Access to specialist professionals was also advocated, particularly for issues related to the menopause.

"If you'd got someone specialised in certain areas, for example menopause, then they'll be able to guide, much better… I suppose if they're specialists you'll feel more easy about going back to them, with whatever turns up" MD45-65, participant 3, age 61.

"Like in some countries they have menopausal consultants. I went online looking and I think there might be someone in [named hospital] doing something, but I think you must be referred up to that. There's no, you know a nurse who has that as like a half day a week or something where you can see them. So, you have to muddle and find things for yourself. There's no easy access to that kind of support." UP45+, participant 6, age 45-50.

3.6.3. Health professional facilitators

3.6.3.1. Continuity of care

Women felt the ability to have continuity in their health professional (e.g. having a named GP), fostered open conversations about women's health. Continuity of care promoted a relationship and feeling of trust with their care provider, and prevented women having to repeat themselves, which was especially important for women who did not want to discuss previous issues.

"I feel like it's a lot more helpful seeing the same doctor… with my asthma… More helpful seeing the same one… [to] get to the bottom of things a lot quicker" MD18-24, participant 2, age 20.

"I'd got postnatal [depression]. Thankfully I had the most amazing doctor, she was with me before I had [my baby] so she had gone through all of the pre-pregnancy stuff. She literally was there for 2-3 years and then she [left]. And I was absolutely distraught that she'd left, because I felt like she knew [me]. I'm a very open book... but I do feel that, since my doctor left... you never see the same doctor... and they obviously can't read years of notes and what's gone on with you. With my previous doctor, she would perch herself at the end of the desk and keep you there until you were done... I loved her for that... I would sit happily in the waiting room to wait for her" LD25-44, participant 6, age 39.

"It can be quite triggering to say 'I've miscarried' or 'I've had this experience'. Definitely I think the key is seeing the same members of staff" MD25-44, participant 8, age 40.

In response to other women talking about their desire for greater continuity of care, some women responded that they did not mind seeing different doctors, provided the care they received was good. One woman, who had previously discussed embarrassment around women's health as a barrier to communication, actually felt she would prefer to see an unknown health professional:

"I'm the other way, I would rather see a doctor that I didn't really know… depending on the issue." LD25-44, participant 8, age 26.

3.6.3.2. A more patient-centred approach

A more patient-centred and individualised approach was suggested as a method of encouraging open conversations about women's health, with a preference to be involved in alternative care choices, rather than a more paternalistic model where the health professional leads decision making.

"If we were to have more of an input in our own care as well. Rather than sort of being told… If we were able to say to our GP, to a point, 'oh I've heard...this works…can we go for that option?' rather than being dictated to by the GP" LD25-44, participant 4, age 35.

When asked for good experiences of being listened to by health professionals, another woman discussed being pleased to have been advised to have physiotherapy for a meniscus tear, rather than surgery (which she understood was a more commonly used treatment). The referring doctor discussed the evidence regarding longer-term outcomes and her profession as a dancer in their advice and she subsequently found the physiotherapy to be extremely beneficial:

"I went to the doctors... I thought he was going to put me forward for an operation because I've known other people... with meniscus [tears]... who have had operations. [The doctor] said to me I don't think that's the way forward - there's not enough evidence to show long-term that it solves the problem... He put me forward for physiotherapy. Because I was a dance teacher I got priority because that was my income..." MD45-65, participant 3, age 61.

3.6.3.3. Increased follow-up or referrals

Across a number of areas discussed as women's health priorities, including postnatal care, mental health, menopause and chronic pain, women described a lack of follow-up and aftercare. When asked about ways health professionals could promote open conversations with women, one woman suggested that greater follow-up would be important.

"Follow-up. The [other participant] just said about menopause. Well, I was given a [HRT] patch and it didn't agree with me and no one has ever seen me since... So just follow-up - 'how did you get on with that?'. I know they haven't got the time, so that's what it is". MD45-65, participant 5, age 52.

When describing good experiences of being listened to by health professionals, a number of women described experiences of being referred for further tests or to specialists in a timely manner as part of their good experiences.

"I went to doctors feeling not quite right - some of symptoms led him to believe it could be a certain condition. I think within 3 days I went into hospital and had a check... then a few days later I had an MRI. Luckily things not awry, which was great - but once thought... it could be something serious things happened really quickly." LD45-65, participant 5, age 51.

3.6.3.4. Improved communication

Poor communication styles were frequently raised as barriers to open conversations. Conversely, some women discussed good communication skills, particularly listening and demonstrating empathy and compassion, as important in nurturing conversations about women's health.

> *"It's about how [health professionals] frame the conversation... I think one of the best consultations I ever had was when someone was like 'so I can see why you are here, but you tell me why you are here and what do you need from me to help you?'. That was the best conversation because, actually, they weren't saying like 'I can see you just had a baby and blah blah blah…'. It was like 'why are you here and what can I do to support you?'... It allowed that fluid dialogue... I think a lot of it is about communication and the way things are framed and allowing women to say in their own voice why they don't think things are normal for them"* UP24-44, participant 5, age 30-35.

One participant described her experience of a male doctor approaching her when she was crying following a miscarriage in hospital, and that despite the barriers to communication with face masks and the business of the shift, he took time to sit and ask her how she was feeling and listen to her responses with kindness:

> *"he sat with me in silence and he kind of watched me cry but also said really kind things that came from a place of understanding. Rather than saying 'this is really common, 1 in 4 pregnancies end in loss, you just have to go and try again' - which is what everybody else had said to me… I felt like he saw something was wrong, and he stopped to speak to me. He acknowledged that yes this is a really crappy situation, but it doesn't always need to be like this... The fact that he sat with me for 5 minutes in his busy life of running around A&E... I felt like someone was there who cares a bit about me as a human being".* UP24-44, participant 1, age 30-35.

3.7. Women's health information sources (age 18-65)

To understand where women sought information about their health, and what their most trusted sources of information were, a ranking exercise was conducted, followed by a discussion about why women ranked sources of information in the way they did.

Box 4: Summary findings of health information sources used and trusted by women (aged 18-65)

Health information sources used and trusted by women

- Women accessed information from a range of sources, but the internet was most frequently used due to accessibility and privacy, as well as being a useful research or support tool;
- Health professionals and the NHS website were the most trusted sources of information about health, however, NHS professionals were not always easily accessible and the NHS website had some mixed feedback;
- Social media was used by some women as a form of peer support, to garner experiences of other women. Social media was endorsed by some young women as a potential platform for health organisations to share information about women's health;
- Pharmacists were seen as an accessible and under-utilised resource;
- Experiences of NHS 111 were not positive;
- Women identified ways in which official sources of information could be improved.

3.7.1. Health information ranking exercises

Women in the under-65 groups were asked to consider and prioritise sources of information about their health. Using screen shared 'sticky notes' we suggested seven possible information sources (health professionals, information leaflets, the NHS website, internet search engines, friends and family, independent health organisations and online discussion boards like *Mumsnet*). We asked each group to think of other information sources that they might use, and added those to the list displayed. Following this discussion, each woman was asked to list the information sources she used most frequently. Then, after sharing their responses, each woman was asked to repeat the exercise, but listing the information sources she considered most trustworthy (both were provided as a top five in rank order). Their answers were aggregated by broad area, and overall ranks calculated (Table 8).

Table 8 shows the information sources which were included as part of any woman's 'top five' (accessed and trusted), along with the number of groups where at least one person included it in the top five ranking, and a weight. The weight combines the number of women who listed the source as in the top five most frequently accessed or most trusted, and how highly this was ranked (with the highest rank given a score of 5). So, if all 65 women listed this information source as their most frequently accessed or their most trusted, the weight would be 65 x 5 = 325.

The women in these groups most frequently used internet search engines (sometimes referred to as "Dr Google") to find information about their health. Other frequently consulted sources included health professionals, the NHS website and friends and family. Health professionals and the NHS website were by far the most trusted sources.

Women added a number of sources to the original list. Pharmacies were added and used frequently by some (not always interpreted as being within the umbrella term 'health professionals), and were trusted sources of information. Two groups added private health care providers (again not interpreted by these groups within 'health professionals'). Younger groups added apps such as period trackers and podcasts. Several groups mentioned TV (particularly documentaries), magazines and newspapers. Our University

pilot groups added books and scientific journals, which were not mentioned by the general focus groups (but would nevertheless be part of a general internet search).

Table 8: Sources of information on women's health, frequency of access and trustworthiness

Most accessed (italics = provided categories)	*No. of groups (n=9)*	*Weight**		*Most trusted (italics = provided categories)*	*No. of groups (n=9)*	*Weight**
Internet search engine	9	213		*Health professionals*	9	278
Health professionals	9	190		*NHS website*	9	221
NHS website	9	186		*Information leaflet*	9	87
Friends/family	9	152		*Independent health organisation/charity websites*	9	71
Independent health organisation/charity websites	6	29		*Internet search engine*	8	50
Discussion board e.g. Mumsnet, social media	7	28		*Friends/family*	8	48
Pharmacies	2	23		Pharmacies	2	35
Apps, e.g. period tracker, NHS app	2	19		Scientific journals	2	35
Scientific journals	2	18		Private healthcare / private doctors	2	23
Information leaflet	5	14		*Discussion board e.g. Mumsnet, social media*	4	12
Private healthcare	2	11		Apps, e.g. period tracker, NHS app	2	10
NHS 111	1	10		Walk-in centres	1	9
TV	3	8		Books	1	6
Magazines/newspapers	1	7		NHS 111	1	5
Books	1	6		NHS (unspecified)	1	5
Podcasts	1	4		Employer website	1	3
Employer website	1	4		TV	1	3
Helplines	1	3		Podcasts	1	2
Schools	1	1		Magazines/newspapers	1	2
Walk-in centres	1	1		Schools	1	1

*This weight is a combination of how many women ranked this in the top five of their information sources, and how highly it was ranked (higher ranks were given a bigger score, rank 1=5). So, if all 65 women listed this as their most frequently accessed or most trusted source, the weight would be (65 x 5) = 325.

3.7.2. Health information sources: open discussion

After women in the under 65 groups had individually ranked the health information sources discussed within their groups according to accessibility and trustworthiness, we then asked women to discuss as a group why they ranked in that way. The following section gives a summary of these discussions.

3.7.2.1. Internet search ("Dr Google")

An internet search engine was the topmost accessed source of health information by women by a large margin, but women recognised that the results they obtained may not be trustworthy. Many women used the internet, sometimes referred to as "Dr Google", as their first place for health information due to the ease of accessibility and the instantaneous nature of being able to research a health problem 24 hours a day, in contrast to waiting to speak to a health professional.

> *"[accessibility] is the main problem… you can just go on your phone and look or wait 6 weeks to see a doctor".* MD18-24, participant 3, age 22.

> *"When you're feeling not yourself, you want a quick fix, you want to know there and then what is wrong with you. You start searching the internet first because it's hard to speak to someone directly and that's when you start worrying yourself".* LD25-44, participant 8, age 26.

Women did recognise that using internet search engines for self-diagnosis could be risky given their lack of medical background and using non-verified sources, although some women did remark that they would look at the list of results and pick out trustworthy sources, such as the NHS website.

> *"contradicting idea because I always look things up online first, but when you're googling you think you're going to die… NHS website is fine, but you always google your symptoms"* MD18-24, participant 3, age 22.

> *"We all use Dr Google, don't we? Whenever you put a question in, it just fishes out like certain words, puts them together, and then can give you something that's completely wrong and that scares the living daylights out of you. We all know it's not a reliable method, but I think everyone uses that... it's the easiest."* MD25-44, participant 8, age 40.

Some women reported using a search engine first as it is completely private, this seemed to be particularly important where a problem could be perceived as embarrassing.

> *"internet first because it's really quick and it could be like embarrassing… just in case it's something silly"* MD18-24, participant 2, age 20.

> *"internet is more private, it's just you on the phone or computer"* MD25-44, participant 2, age 37.

Internet search tools were also used by some women as a research tool, or a form of triage, allowing them to find out if their symptoms warranted making a 'precious' appointment with a health professional, or providing them with background research and knowledge before attending their appointment. It was noted that this sort of research could be done without the same time pressures present in a short GP appointment, where women could get 'brain freeze' and forget what they wanted to discuss. Some women, however, had experienced feeling judged by health professionals for researching their symptoms before attending their appointment.

"I think a lot of people do use the internet just to get an idea of what the problem is… when they go to the doctors, they know what they are talking about" MD18-24, participant 5, age 20.

"Sometimes those GP appointment or specialist appointments are so precious, so you want to be prepared as much as possible... So, you need to do all of this like, background research before you go to make your case". UP24-44, participant 1, age 30-35.

"When you go to the doctor and tell them you looked up something on Google they kind of like shake their heads at you, like 'you've spent too much time on Google'. Yes, but if you actually gave me this knowledge or provided me with a resource then I wouldn't have to do this myself" UP24-44, participant 1, age 30-35.

3.7.2.2. The NHS website

The NHS website ranked among the most accessed health information resource, and one of the most trustworthy. Women discussed the strengths and weaknesses of the NHS website for accessing information about their health.

Strengths of the NHS website

The NHS website was easily accessible, and even where an internet search engine was used initially, the NHS site was present among the top few results, encouraging women to access the site, which was recognised to be a reliable resource.

The NHS site was perceived to be informative and a useful source of health information, which presented information in a simple way without too much 'medical jargon'.

As with general internet searches, women used the NHS website as a research and triage tool, helping them to decide when to contact a health professional, and what to discuss at their appointment. The summary boxes included on the website, which outlined which symptoms warranted seeking professional help, were thought to be a valuable feature.

Weaknesses of the NHS website

Women recognised that the NHS website had limited usefulness if it was accessed pre-diagnosis, and that women accessing the site as a means to self-diagnose could lead to superfluous consultations. There was also noted to be a limit to the topics covered on the site, which meant women sometimes had no choice but to seek information from other sources.

Some women found the website too simplistic or 'rudimentary', leading them to seek more detailed information elsewhere, although it was recognised that the site was likely intentionally simple in its design, partly to encourage people to seek advice from a health professional. It was also felt that there should be more links to specialist websites.

3.7.2.3. Social media and discussion boards

Almost all of our focus groups, encompassing all age groups and social backgrounds, either ranked social media among their most accessed sources of health information, or discussed this. The exception was the South Asian group who neither ranked social media in the exercise, nor spoke about this as a source of information. Some of the younger women noted that they may not actively seek out information on social media, but it was a passive source of information if they happened upon an article or video when scrolling through social media.

> *"when you're flicking through sometimes you do see things… but I wouldn't probably go on there to find out what was wrong with me"* MD18-24, participant 3, age 22.

Positives of social media for health information

Women perceived social media to be helpful in a number of ways as a health information source. Firstly, young women felt social media could help to raise awareness around women's health using a media that was 'engaging' and frequently accessed by many women, particularly as some health professionals had profiles from which they shared information.

> *"Social media for some things… like on Instagram I've seen a couple of pages that do a lot on breast checking and they have some really useful things on what to look for and how to actually check…[and] like with PCOS endometriosis. I only really found out a couple of years ago what they even was from Facebook and Instagram of people posting about their experiences and stuff"* LD18-24, participant 5, age 19.

> *"A lot of health professionals starting their own Tik Toks and using them to spread awareness of their speciality and what they are knowledgeable on."* LD18-24, participant 4, age 22.

Closed groups on social media platforms like Facebook, and discussion boards such as Mumsnet, were particularly highlighted as unique and useful areas for seeking virtual peer support, by discovering other women's experiences of particular health issues. These types of forums gave women a more relatable health information source, which allowed them to gain comfort and feel they were 'not alone'. This was especially important when seeking information about more rare diagnoses

> *"sometimes it's not a professional I need, sometimes it's someone who's in the same boat"* MD25-44, participant 8, age 40.

> *"if I wanted to know more about experiences I would go to social media... In past experience I have actually found social media really helpful, which might surprise you. I was suggested things on there [relating to fertility] that I was never suggested, that lead to me having 2 children. Because my GP, or fertility experts, never suggested what they suggested. So sometimes you get information that you just can't get... because other people I was talking to are just completely immersed and that was their life".* UP45+, participant 7, age 45-50.

Negatives of social media for health information

Social media and discussion boards were rarely ranked among women's top five most trustworthy sources of information, therein highlighting one of the biggest challenges with this as an information resource; women would not always know if a post was from a verified health source. Some young

women spoke of seeing viral videos, particularly on Tik Tok about 'health', where it was unclear if they were founded in truth, e.g. "*fake tan causing problems with your health*" (Group MD18-24, participant 4, age 18.), and others which were deliberately sharing information which was perceived as false and potentially risky, for example, apple cider vinegar for weight loss "*which can burn holes in your throat and… stomach*" (Group MD18-24, participant 2, age 20).

As with using other internet sources, some women recognised that seeking peer support, or reading other women's experiences on social media or discussion boards, particularly pre-diagnosis, should be approached with caution, as the women sharing experiences 'are not doctors' and some share very negative experiences.

> *"You can find a range of experiences and engaging conversation with people who might be most helpful to you in that moment…Although it can also lead you down a spiral of 'oh my god all these horrible things happened to these people, maybe it might happen to me too'."* UP24-44, participant 1, age 30-35.

> *"Personally I would avoid that [social media or discussion boards]… I wouldn't be putting in symptoms and getting it from a search engine or from 'Mumsnets' because, you really don't know what you've got. Whereas if you've been diagnosed with something, then those formats could be quite useful. But I think they could be really dangerous if you're just putting in symptoms and you don't know what you've got. Anything could come up and you could create more issues for yourself, psychologically".* MD45-65, participant 3, age 61.

3.7.2.4. Pharmacists

Pharmacists were spoken about by some women across age groups as being an 'underutilised' resource for health advice, without the barriers to access associated with GP appointments.

> *"I've only just started going to pharmacists as I didn't know how much they could do… I would definitely go there before ringing anyone probably about anything…. It's easier… you don't have to try get an appointment… you walk in and they are there to help."* MD18-24, participant 1, age 23.

> *"I've only found out now that you can go to a pharmacist and get advice from them as well. Not that many people know that. Sometimes the advice is... quite helpful as well. You get a bit of relief that... you're getting advice from a health professional"* SA18-65, participant 6, age 31.

3.7.2.5. NHS 111

A few women in the 25-44 age groups spoke of using either the online or telephone NHS 111 symptom checker service. It was noted that the online symptom checker may benefit from being more 'in-depth'. When speaking to an NHS 111 telephone operative, there were concerns that these non-medically trained personnel might incorrectly triage.

> *"I think that [the NHS 111 service] needs to have a radical change… The first person you speak to are actually health advisors, they actually just go through an algorithm… Depending on your answers to that they put you in touch with what service they think is appropriate. But quite a lot of the time the services they actually put you in touch with aren't the appropriate services that you need"* LD25-44, participant 4, age 35.

3.8. Areas of women's health where information is sparse (age 18-65)

The final question of the focus groups was "Are there any areas of women's health where you feel that trusted information is sparse or not well communicated, and you would like to know more?"

Most of the areas of women's health highlighted as needing further research were the same as those raised as women's health priorities and therefore these were discussed in section 3.2. Further areas not already discussed as women's health priorities were raised in this final part of the focus group, namely; sexual health, body surgeries, consent, support for carers and transgender women (see Table 10).

Table 10: Areas of women's health where information is sparse or not well communicated

Menstrual health	Periods, period poverty and reducing stigma especially in school settings
Reproductive health	Long-term effects of contraception; reproductive disorders (e.g. PCOS and endometriosis); fertility, infertility and miscarriages.
Menopause	Menopause information, education, support and treatment
Screening for women's cancers	Self-checking breasts; breast screening and cervical screening/HPV vaccine
Preventative care	Diet and exercise. The effects of the menstrual cycle on exercise performance.
Mental health	Social media; postnatal depression
Physical health (non-gender specific)	Diseases of the immune system
Gender differences	Education and research about gender differences, including increasing representation of women in research.
Domestic abuse	Women's abuse
Women's health education	See section 3.5
Other*	Sexual health, cosmetic surgeries, consent, support for carers, transgender women

*Areas not discussed as women's health priorities, but raised as needing greater information.

The following areas were raised by women as areas lacking in information, but were not identified when women were previously asked about women's health priorities.

Sexual health was mentioned by one young woman.

> *"chlamydia can make you infertile… I saw that on Twitter… they should probably teach more about that"* MD18-24, participant 2, age 20.

Another young woman felt information was lacking about the long-term effects of cosmetic surgeries:

> *"I feel like it's common for people to get BBLs [Brazilian Butt Lifts] and tummy tucks or body surgeries in general... there needs to be more information on the aftermath…"* MD18-24, participant 5, age 20.

As discussed in section 3.1.7, women were often in caring roles, adding extra pressures to their life and affecting their wellbeing. Two women raised a need for greater information and support for women in caring roles; one woman was caring for “someone with a mental health problem” (MD25-44, participant 6, age 36.) and another wanted more information on coping mechanisms for parents dealing with children from babies to teenagers (MD45-65, participant 5, age 52.).

One woman recognised the dearth of information available for transgender women:

> *“I'm going to make a niche comment. There's a whole group of transgender women who will not be able to access the right kind of information, and that's a real gap. If we're truly thinking about women as an inclusive group, then there needs to be something specific... put in place. Because there is such a massive amount of ignorance around providing healthcare to and any other kind of care to this group who have particular needs.*" UP45+, participant 2, age 45-50.

4. Findings: Women aged 65 and over

Box 5: Summary of findings from women aged 65 and over

Women aged 65 and over were concerned with:

- Managing their diet and exercise and general health, but with limited incomes experienced financial barriers to engaging with some services such as dental and eye care, or gym memberships;
- Managing long-term conditions and wishes for greater access to check-ups;
- Being a carer (e.g. to partners or children), and the extra responsibilities and pressures of this role;
- The negative impact of Covid-19, particularly affecting mental health, including feelings of loneliness and isolation, exacerbated by a reduced affinity for utilising digital technologies;
- Being excluded from breast and cervical screening due to age, contributing to feelings of being 'invisible' in healthcare.
- Better access to healthcare, particularly GP appointments, and women's health clinics with female clinicians were advocated for;
- Access to health care professionals was particularly important, as this were their most trusted source of information about health.

4.1. Sample characteristics

Fourteen women aged 64 – 76 years participated across two focus groups (Table 11). Approximately two thirds (64%) were White British. Women who took part in focus MD65+ lived in areas with a ranked as more deprived by IMD2019. Women in focus LD65+ resided in areas ranked as less deprived. There was a mix of women from geographic locations included in both groups.

Table 11: Sample characteristics for focus groups among women 65+ years

Group[*]	N	Age range	Geographic area	Ethnicity[*]	Area level deprivation
MD65+	8	64-73[**]	Bristol/Manchester	5 WB, 1 BB, 1 BC, 1 SA	More deprived tertile
LD65+	6	66-76	Hampshire/York	4 WB, 1 O, 1 AO	Less deprived tertile

[*]WB= White British, BB = Black British, BC = Black Caribbean, SA = South Asian, AO = Asian Other, O = Other.
[**] The age criterion for MD65+ was 65 and over. However, the third party recruiter also included one person aged 64 years.

4.2. Thematic findings: women aged 65 and over

Four overarching themes were identified (Table 12). In this section, we report findings on these themes, with quotes used for illustrative purposes.

Table 12: Themes and sub-themes: women aged 65 and over

Theme	Sub-theme	Linked to age (by participant)?	Linked to being a woman (by participant)?
Women's priorities for managing their health	General health	Y	Y
	Continued screening	Y	Y
	Long-term conditions	Y	
	Sexual/gynaecological health	Y	
	Being a carer		
	Costs	Y	
	Impact of COVID lockdowns		
	Menopause	Y	Y
Being seen and heard in healthcare	Invisibility	Y	Y
	Access to care specifically for older women	Y	Y
Barriers in access to care	Primary care	Y	
	Devaluing own health when cannot access care	Y	
Sources of information	Sources		
	Preferences and trustworthiness		

4.2.1. Theme 1: Women's health priorities

4.2.1.1. Managing weight, fitness and general health

Most dominant in older women's accounts of their health priorities was a need to manage their weight, fitness, and be supported with healthy eating. These issues were important for women across both focus groups. The loss of energy with age made physical exercise more challenging, and women expressed a sense of guilt and shame about their weight:

> *"As I've got older… I don't do as much exercise as probably I should and I eat more of … the wrong things."* MD65+, participant 4, age 66.

Women described a need for greater support in these areas.

4.2.1.2. Costs

Women described the financial barriers of managing their health in older age when the only income is a pension. Health-related costs incurred by women related to eye appointments, dental health, weight loss clubs, healthy eating, and gym membership. Women's accounts indicated that looking after their health was highly commodified, which marginalised those on lower incomes.

The ways suggested to address these barriers included financial support for healthy food and vouchers for commercial weight loss organisations such as Slimming World. Concerns relating to costs were more dominant for women in focus group MD65+.

> *"younger families are given healthy start vouchers… [can] a similar initiative be rolled out for us older folk?" MD65+, p*articipant 4, age 66.

4.2.1.3. Managing long-term conditions

Older women described living with long-term conditions. Having access to regular check-ups, such as for blood pressure, was an important part of managing these conditions. Women also described a need for support to prevent and delay the need for surgery, and also to manage pain medication whilst waiting for surgery.

4.2.1.4. Being a carer

Some women were carers for their spouse or adult child. A key challenge described by carers was being able to maintain their own health whilst caring for someone else. Carers relayed the pressure to keep well: not for their own sake, but to continue providing unpaid care.

> *"I'm trying my best to look after my health because I need my strength to keep him going"* MD65+, participant 6, age 69.

4.2.1.5. Impact of COVID lockdown

The impact of lockdown was felt by older women, particularly in terms of managing weight and long-term conditions when there was less interaction with health professionals. Women felt the lockdowns had compromised their mental health and increased their isolation from friends and family. The technology used to access primary care during COVID was particularly challenging.

4.2.1.6. The need for continued screening after age 70

A number of older women advocated for continued breast and cervical screening after age 70. The loss of these previously routine aspects of their health was linked to being 'written off' in healthcare as an older woman;

> *"So I don't know why they stop [breast screening] at 70 but I feel if there's a problem, you can't phone up … but you used to be able to phone up and say, "Well, can I have a screening please?" But to me it should be automatic. It shouldn't stop at a certain age. It's like we're written off when we get to a certain age"* MD65+, participant 7, age 76.

4.2.1.7. Issues not currently a major priority

We also prompted women about the extent to which issues relating to the menopause and sexual health were present concerns. Even though issues relating to the menopause were not a current concern, women recalled frustrations that health staff offered little support at the time when such issues *were* relevant. One participant indicated a female doctor was preferable for issues relating to the menopause, and better able to support her health.

Sexual and gynaecological health was rejected as a present concern, though the group then went on to discuss it. There was a majority feeling that more information was needed about gynaecological health during the menopause. Women also described being uncomfortable discussing these aspects of their health. If necessary, women preferred to discuss gynaecological issues with a specialist health practitioner, rather than a GP.

4.2.2. Theme 2: Being seen and heard in healthcare

4.2.2.1. Invisibility

Older women reported that they sometimes felt invisible in healthcare. This invisibility was linked to both being a women and older age. For example, one participant described being overlooked in healthcare and questioned whether this was rooted in social attitudes to women's roles and voices:

> *"I don't think that we're considered enough [in healthcare]. I don't know if it's because our voices aren't particularly loud 'cause as women I don't think we're brought up to be strident. We're brought up... [to be] seen and not be heard"* MD65+, participant 4, age 66

Older age added a further barrier to being seen and heard within healthcare. The termination of breast and cervical screening at older ages was characterised as being 'written off', whilst short primary care appointments could not accommodate multiple health concerns linked with older age multi-morbidity. Consequently, primary care appointments were thought to be rushed and led to a sense of being 'fobbed off'. Women pressed the importance of pushing doctors to listen to them about their health concerns. As we go on to describe later in this report, older women suggested women's health clinics as an option to ensure their concerns are heard. These issues were raised predominantly by women in focus group MD65+ (living in areas of high deprivation).

4.2.2.2. Access to care specifically for older women

Linked to the sense of being invisible, women's only health clinics were suggested as a way to enhance the health service offer for older women. Such clinics were proposed to support women in relation to issues such as weight management and long-term conditions. The importance of female doctors for these clinics was highlighted. Priority access to primary care for older women was also proposed.

4.2.3. Theme 3: Barriers in access to care

4.2.3.1. Primary care

Whilst GPs were often a preferred and trusted source of information, women described the challenges and frustrations of accessing primary care. Triage methods were off-putting (for example, health navigators, telephone calls), whilst some reported long waiting times for appointments. Whilst some had a regular GP, others did not and reported a lack of care continuity as a result. Women also expressed frustration that short primary care appointments could not accommodate multiple health issues. Difficulties accessing a GP were reported both in relation to, and outside of, COVID lockdowns.

Some noted that difficulties accessing a GP were not specific to being an older woman, and observed similar problems for younger and male family members and friends.

4.2.3.2. Devaluing own health when access to care is limited

Older women described how, when faced with barriers to primary care, they delayed seeking help for health concerns. They did not prioritise their own health because of the 'hassle' of trying to get an appointment with their GP. As a result of these barriers, health problems were 'saved up':

> *"if you've got a little lump in your leg … you think oh it's not worth going up about that".* MD65+, participant 2, age 66.

This devaluing of their own health was linked to age: women encouraged younger people to seek healthcare, but that their own health as an older women was not worth the challenges of accessing care.

4.2.4. Theme 4: Sources of information about their health

4.2.4.1. Information sources used

Older women described consulting a range of sources about their health. These included their GP, hospital consultants, 111, pharmacies, practice nurse, google, friends and family, TV health programmes, and charity websites.

4.2.4.2. Preferences and trustworthiness

Despite the range of sources used, women typically described a GP as their trusted and preferred source of health advice. This preference was matched with a frustration at the difficulties of accessing primary care. Consultants were a preferred source of information for specialist health concerns. Some older women voiced a preference for younger GPs, whom they felt made more of an effort than older GPs:

> *"if you get someone who's recently qualified it's quite nice because they do tend to go through everything and they don't just jump to a conclusion".* LD65+, participant 6, age 72.

Women also reported mixed experiences of using 111. Some expressed reluctance to use, and distrust of, social media or internet sources.

> *'I don't think that I would look at the internet … somehow I just don't feel safe with that. I'd much rather speak to a GP'.* LD65+, participant 2, age 75.

4.2.4.3. Areas where information is sparse

When prompted to think about areas of health where there was a lack of information, only one issue was identified: greater information about the use of hearing aids. In a separate discussion, women felt more information was needed about gynaecological health during the menopause. No other areas of health were identified where women perceived a particular lack of information.

5. Discussion

5.1. Summary of findings

We have described the results of a qualitative focus group study focusing on women's health priorities, women's voice, barriers and facilitators to open conversations, and health information sources used by women.

Despite making very clear at the outset of the study that we were not only interested in female-specific health issues, discussions were dominated by issues relating to female anatomy and physiology – in particular gynaecology, breasts and hormones, with limited discussion about health matters that can apply to both men and women but where gender-related health inequalities may exist. It is, however, clear that these female-specific issues were extremely important to women, and conducting focus groups among targeted age groups demonstrated the changing priorities for women as they age. Young women prioritised contraception and menstruation, women in the middle years (25-44) discussed reproductive disorders, fertility and perinatal health, and conversations between women aged 45-65 were dominated by menopause. Women in the oldest group felt invisible in the health care system, for example feeling 'written off' as they were no longer part of women's cancer screening programmes. Their priorities related to managing long-term conditions, financial barriers to accessing health on a limited pension and caring responsibilities for their spouse or adult children.

Women across all age groups expressed a desire for the age cut-offs for cervical and breast screening to be extended to include both younger and older women. Due to a lack of health education and general awareness about how to look out for signs of breast or cervical cancer, women felt unease when they were ineligible for screening due to age.

Aside from priorities relating to women's physiology, mental health was the most common topic of debate among women of all age groups. Focus groups were conducted during the COVID-19 pandemic, and it was clear from some of the discussions that COVID-19 had imposed an additional burden on women's emotional wellbeing. It was evident, however, that mental health was an important topic aside from COVID-19, with women discussing many different experiences relating to their mental health. Some women talked about 'suffering in silence' due to demands of work and home life. This was particularly relevant as women often have more caring responsibilities than men, for example caring for children or elderly relatives; this theme was echoed by women in the oldest age group. The linking thread through all discussions about mental health was that there were inadequate services, therapies, follow-up and support for women who experienced mental health problems.

Aside from screening, other forms of preventative care, such as regular health checks and blood testing were also thought to be lacking, by women from middle years onwards. As women aged, this left them feeling uninformed about their health.

Women's discussions about their experiences of healthcare reflected a view that service inadequacies are linked to NHS *'underfunding'*. Improvements to services issues ranked as one of the top five priorities by women aged 18-65.

Many women felt their voices were not heard by health professionals, and that addressing this issue should be a priority. We designed a specific part of the focus group topic guide to ask women about being listened to by health professionals, but many women across all age groups had shared experiences of their voices not being heard before we asked this question. Women felt 'brushed off' by health professionals who they felt diminished their symptoms and concerns. There was a clear perception that women's health was not being taken seriously, perhaps particularly when care was provided by male doctors. Many women shared stories of having to 'nag' their doctor for follow-up or tests, and experiencing significant delays to diagnosis of long-term conditions. These common negative experiences led some women to avoid accessing healthcare, or to resort to alternative sources, such as private consultations where this was a financially viable option.

When asked about barriers to having open conversations about women's health, problems with accessing healthcare services were most commonly cited by women. GP appointments were difficult to obtain, and made more challenging by a lack of flexibility in terms of opening times. Many women expressed a preference for seeing a 'female doctor for female things' due to 'private' nature of women's health and a greater level of perceived understanding and empathy from female clinicians, although this also related to age in some cases (e.g. a woman experiencing menopause symptoms may wish to see an older female GP). When appointments could be obtained women often felt 'rushed' because of the limited time available, leaving them unable to speak freely.

A number of facilitators to open conversations emerged in the groups. Partly these were simply to reverse the barriers mentioned (e.g. enabling access to health professionals, particularly - for some women - to women practitioners). Other facilitators focused on communication styles and perceived compassion – women highlighted examples of good practice but felt that they faced 'pot luck' as to which health professional they saw.

Women's health, particularly that which relates to female physiology, was universally thought of as a stigmatised topic that caused embarrassment for many women - this was reported particularly in our younger and South Asian groups. The taboo nature of some aspects of women's health created a barrier to open discussion, and these extended beyond conversations with health professionals, also curtailing dialogues with family and peers.

We were interested in hearing women's thoughts about information and education sources available regarding their health, and had questions designed around this. Again, women volunteered that this was an area which warranted greater consideration before we asked specific questions on this. Women's health education, information and support was deemed to be lacking for women of all ages. Women felt that there needs to be an increased national discourse around women's health to raise awareness and reduce the stigma associated with the topic, allowing women to have more open conversations. Suggestions were made to include more teaching in school settings (e.g. about periods and options for contraception), more training among health professionals (e.g. about menopause symptoms and HRT) and greater awareness of women's health throughout the population, amongst women and men. Lack of awareness and debate was viewed as reinforcing continued misplaced embarrassment about 'taboo' subjects such as menstruation, fertility problems and menopause, reducing women's empowerment in health care and in other settings such as schools and workplaces.

We stratified focus groups by area-level deprivation as a marker for socio-economic status to engage a diverse group of women and to see if any differences by socio-economic status were apparent. Women were, however, unified in their priorities and experiences across these groups. The only slight difference

noted was that more women recruited from less deprived areas spoke of accessing private services. The reason for the lack of differences between the groups may be that women's health priorities are truly consistent across social groupings, or that we did not recruit women who were very deprived given the need for women to have access to digital resources to participate in our study.

Focus groups were undertaken in 2021, during the Covid-19 pandemic. Although women spoke of experiences which pre-dated the pandemic, more recent experiences may have been influenced by the impact of Covid-19 on the health system more generally, e.g. contributing to delays and disrupted treatment.[22] This context should be taken into consideration when interpreting the study findings.

5.2. Strengths and weaknesses, and opportunities for further research

Using focus groups rather than interviews gave the opportunity to hear a diverse range of views from women, and due to the stratified design, women were able to discuss their views with other women at a similar point in their life course, stimulating a great deal of discussion. Furthermore, we used a mixture of open questions and ranking exercises to engage women, and to enable some more quantitative exploration of strength of feeling and how women prioritise areas of women's health and information sources.

Further strengths of the study relate to its size and scope. We conducted 11 focus groups, including 79 women aged 18-76. Because of the online video format, we were to able recruit from different geographic areas across England, with a stratified approach to include women from both less and more deprived areas. Although the purpose of qualitative research is not to provide a representative sample, attempts were made to capture the voices of women from a range of backgrounds, with some diversity across most groups. We also conducted a separate focus group specifically among women of South Asian origin, as this ethnic group was underrepresented in the women's health call for evidence survey respondents.

We recognise that there are many types of women with whom we were unable to engage. Conducting the focus groups online may have proved a barrier to women without access to internet or a suitable device. Women in more deprived circumstances and older age groups are more likely to experience these digital barriers; indeed our focus group methods had to be adapted to suit the methods with which this older age group engaged. Older women were less likely to fully engage with the 'chat box' facility in the video software, and these groups had a more discursive nature as a result. The topic guide and structure of our focus groups, including the ice breaker and ranking exercises were not all as well suited to women in the oldest age group.

Further research should seek to canvas the views of women from minority ethnic backgrounds in the UK, particularly as these groups are known to experience inequitable health outcomes. Although we made attempts to include a diverse sample, predominantly white women were included. The inclusion of a particular South Asian group was a strength of the design, but South Asian women still represented a small proportion of the sample, and were sampled primarily from one geographical area, limiting the generalisability of the findings for this group. Other ethnic groups were also under-represented.

[22] Propper C, Stoye G, Zaranko B. The wider impacts of the coronavirus pandemic on the NHS. Fiscal Studies. 2020 Jun;41(2):345-56.

Furthermore, due to the rapid nature of the research, we were not able to interview women who were unable to communicate well in English.

We spoke to women from a range of age groups, but there are certain groups that were not represented. Firstly, women aged 16 and over were included in the Call for Evidence, but our focus groups included women aged 18 and over. Furthermore, the focus groups among the oldest group comprised women aged between 64 and 76. Experiences and priorities of women are likely to change with advancing age. Future research should seek to understand the views of women into their 80s and beyond.

Finally, although our eligibility criteria was intended to include individuals whose gender identity does not align with the sex they were assigned at birth, we are not aware that this applied to any participating women in our sample. We are also not aware if women included had any particular disabilities unless these were disclosed during the focus groups. More research is needed to capture the voices of these women.

This focus group study, conducted in parallel with the national Call for Evidence, provides additional insights from the focus group methods which enabled open discussions with women at different stages of life. Further research could include research with older women from minority ethnic groups, individuals whose gender identity does not align with the sex they were assigned at birth, and women in poverty or otherwise digitally excluded. A longer timescale for research could enable more in-depth discussion of topics including sensitive issues which may be better explored in one-to-one interviews (e.g. sexual health, the impact of unpaid caring on health, the role of poverty and material deprivation). Finally, although we stratified groups into life stages, these included quite wide age ranges (25-44 and over 65 particularly), which are heterogeneous groups. Experiences, priorities and preferences change over time, and further work could offer a more in-depth and nuanced understanding of women's experiences of health and care across the age spectrum.

The focus of participants on topics specific to women's anatomy and physiology (e.g. reproductive health, breast and cervical cancers) is perhaps unsurprising given the lack of awareness of other areas of health and health care where experiences and outcomes may differ. Only in a minority of women was there any prior awareness of more general gender differences. To explore women's attitudes to gender differences in health and care which result from societal rather than physiological differences, it could be useful to conduct further focus groups, perhaps providing case studies of potential differences on which to base discussions. Our open questions about priorities and other matters generated discussions on matters more traditionally viewed as 'women's health'.

5.3. Implications and recommendations for the Women's Health Strategy

The findings from our focus groups reveal areas of potential improvement for women's health services in the UK, some of which align closely with the recommendations of the Royal College of Obstetrics and Gynaecology in their report 'Better for Women'.[23]

[23] RCOG. 2019. 'Better for Women'. Royal College of Obstetricians and Gynaecologists: London.

5.3.1. Increased education and availability of reliable information on women's health

- Education about women's health could be increased from school age onwards, among women and men, to help raise awareness of women's health, reduce stigma, and assist women to know when to seek help and to do this with confidence.
- Education around women's cancer screening could be increased to improve understanding of the services offered and the rationale for age cut-offs, and to increase engagement with screening and awareness of what symptoms to observe.
- Commonly used information sources, such as the NHS website, should provide easily accessible information about all aspects of women's health, including providing links to more specialist websites, such as charities, when women wish to seek further information. For groups less able to engage with digital content, information sources such as leaflets should be widely available.
- Women often do not feel listened to. Health professional training about women's health could perhaps be improved, to aid communication, understanding and help increase detection of underlying pathology.

5.3.2. Increased access to services for support and advice about women's health

- Health support for young women should be available in school settings, e.g. providing advice on issues such as menstruation, contraception and sexual health.
- Women of all ages should be able to access professional advice about their health in a timely manner and with adequate opportunity to discuss issues pertinent to them. Extended GP appointment times could help with this, as well as more flexible opening hours and greater availability of appointments in primary care.
- Differences in access to fertility treatments such as IVF were viewed as unfair and unacceptable.
- Postnatal care could address women's own health concerns as well as those of their babies.
- Women's health specific clinics were commonly advocated, led by a specialist health professional (preferably female), to provide a single point of access for women's health. These could be open to all ages, or focus on different aspects of care and life stages.
- Enhanced access to mental health services was requested, especially in light of the COVID-19 pandemic which has negatively impacted emotional wellbeing for many.
- Peer support groups could allow women to receive support from other women at critical points in their life course, e.g. for menstrual health and the menopause. These could be informal (peer-led) or facilitated by someone with expert knowledge on women's health.
- Increased continuity of care, routine check-ups, follow-up and referrals to specialist services may help to improve women's health and the detection of underlying conditions.
- Women requested a more holistic and individualised approach, with improved preventative health and clear involvement in choices about their care.

5.4. Conclusion

Our focus groups revealed women's priorities for women's health as well as barriers and facilitators to open discussions, and information about how women access information about health and health care.

There were differences in emphasis between the groups at different stages of life, but otherwise we found discussions to be similar between groups.

This research revealed considerable levels of unmet need, limited access to appropriate health care, and a widespread desire for more health education and information highlighting a critical gap in our health system; our groups reinforced the need for a national strategy for women's health. Future policy should pay close attention to the heterogeneity of women's needs and experiences across age, ethnicities and levels of socioeconomic advantage.

Appendices

Appendix A: Participant information sheet and consent form

THE UNIVERSITY of York The King's Fund

Women's Health Priorities: A Focus Group Study

Participant Information Sheet

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why this research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

Health affects women and men differently. Although women live longer than men on average, their health is generally slightly worse at all ages. This is despite the fact that women interact with medical professionals more frequently than men and have some predictable health needs across their life. In the UK, it has been recognised that a national and planned approach is needed to look at women's health, and improve health for women.

The Department of Health and Social Care (DHSC) support UK Government ministers to lead health and social care and help people live healthier lives for longer. The DHSC is developing a women's health strategy. This study aims to inform the development of the strategy, and so we would like to hear the experiences of UK women, to make sure the strategy includes things that are important to them. In order to gather these experiences and views, we are planning to undertake a series of focus groups.

Why am I being asked to take part?

An early priority identified for the women's health strategy is women's 'voice' and finding out how the health and care system listens to and supports women. Therefore, we would like to find out your experiences of accessing health services. We also want to find out what health issues are important to women and about information sources women use to learn more about their health, to help shape how women's health services are provided in the future.

What does taking part involve?

If you decide you would like to be involved you will take part in an online focus group. The focus group will consist of six to eight women and we will ask that you keep your video and audio switched on to allow you to interact as a group. Within the groups you will be asked to discuss various issues regarding women's health, such as what health issues are important, barriers to accessing health services and what health information sources you use. A female researcher from the University of York will lead the discussion in each focus group and will guide you through the various issues we want to explore. There are no right or wrong answers in a discussion of this kind – we are merely interested in your thoughts and opinions.

You can expect the online focus group to take around an hour and half to two hours (including an introduction and a 10 minute break). The focus groups will be arranged at a convenient time for the people involved. We are happy to run the groups during the day or early evening, depending on people's preferences.

The focus groups will be video-recorded, with your permission. Our analysis will involve watching the video recordings from each group, transcribing what was said and making notes. We will then look for the common themes in what people have said.

If you decide that you would like to take part in the study you will be sent a consent form electronically to read (Version 1.0), which will be discussed prior to focus group starting and you will be asked to give verbal consent. Your verbal consent will then recorded on your consent form by the researcher at the start of the focus group.

You will be given a unique study number for the duration of the study so that your name will not be used in any publications and will not be made available outside the research team.

What will I need to take part?

You will need to be able to access an electronic device, such as a computer, tablet or phone with an internet connection and video capability (ideally). This will enable you to use Zoom, the free video platform we will use to conduct the focus groups. You will be able to access Zoom via a link provided prior to the focus groups and will not need to pay for any new software. Please also have a pen and paper to hand, to make some short notes.

Before the focus group we will offer optional one-to-one five minute meetings via Zoom, where you can speak with the researcher who will be leading your focus group in order to ask questions and practice using Zoom, if you have not used this before. We will also share guides on how to use the platform prior to the focus group. Finally, there will be the option to join the focus group 5 minutes prior to the start time to make sure everything is working.

Do I have to take part?

No, it is entirely up to you to decide whether you would like to take part. If you have any questions about taking part you can talk to a member of the research team (contact details below). If you agree to take part in the study, but then decide to withdraw, then that is fine and you do not have to give a reason. Simply tell the researcher prior to the focus group and we will remove your name from our participant list.

Due to the nature of the group discussion, during and after the focus groups, it will not be possible for you to withdraw the information you shared within the group. Participants will be reminded of this at the start of the focus group.

What are the possible benefits of taking part?

The findings of this study will be shared with the DHSC to help shape the women's health strategy for the UK.

What are the possible disadvantages or risks of taking part?

Due to the nature of this study, it is possible that focus group participants may discuss topics which are sensitive. Participation will be completely voluntary. Two researchers will moderate the focus groups, ensuring each group member has an opportunity to contribute. However, participants will not be under any pressure to answer any questions they do not want to. The questions have also been designed in a sensitive manner. If necessary, following the focus groups, we will direct participants to talk through specific concerns with their local NHS care provider or Patient Advice and Liaison Service (PALS).

Expenses and payments

We will arrange focus groups at a time convenient to you. Each participant will receive £45 to thank you for your contribution.

What will happen to data that are collected about me?

We will remove all names and other identifying information before the data are analysed and results presented. Any records that identify you will be held separately to the other information we collect and your data will be held in a secure location, in accordance with the General Data Protection Regulations (GDPR) and the Data Protection Act 2018. Only researchers that are part of the research team in York and The King's Fund (who are joint collaborators on the project)[24] will have access to the data. Data will be stored for 10 years, to enable analysis and publication and will then be destroyed. You can find out more about GDPR and data storage on the following University of York websites:

[24] The King's Fund is an independent charitable organisation working to improve health and care in England: https://www.kingsfund.org.uk/about-us.

https://www.york.ac.uk/records-management/dp/
https://www.york.ac.uk/records-management/dp/guidance/gdprcompliantresearch/
https://www.york.ac.uk/records-management/dp/your-info/generalprivacynotice/
https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/
https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/research-partcipants/

You have been contacted to ask if you would like to take part in this study via Criteria Fieldwork Ltd,[25] who are a professional research recruitment company. Criteria Fieldwork Ltd will retain the data collected in order to recruit participants to the study for a period of 2 years. Under GDPR this is a legitimate interest, to facilitate quality control and validation. After 2 years the data will be destroyed.

The analysis of the video recordings will be performed by researchers at the University of York. Video recordings may be shared securely with the King's Fund to assist with analysis but will not be shared with any other external agency.

Who has reviewed this study?

This study has been reviewed by the University of York's Department of Health Sciences' Research Governance Committee.

Who is organising and funding this research?

The research is funded by the NIHR Policy Research Programme. The research funding covers only the costs of undertaking the research; researchers will not receive payment for conducting the study.

What will happen to the results?

We will video-record each focus group. Our analysis will involve watching the video recordings from each group, transcribing what was said and making notes. We will then look for the common themes in what people have said. Once we have done this, we intend to produce a short report on the findings. Findings will be reported in aggregated form, participants will not be named or otherwise identifiable when findings are reported. If you wish to receive a copy of the report once it is produced please let our research team know.

Who can I contact for more information?

If you have any queries about the study or would like to take part please contact: Dr Holly Essex Research Fellow Department of Health Sciences Area 4 Seebohm Rowntree Building University of York Heslington York YO10 5DD Email: holly.essex@york.ac.uk	If you need to make a complaint or speak to someone independent, please contact: Prof Patrick Doherty Chair of Research Committee Department of Health Sciences Area 4 Seebohm Rowntree Building University of York Heslington York Email: patrick.doherty@york.ac.uk

Thank you for reading this information sheet and for considering whether to take part in this study.

[25] Criteria Fieldwork Ltd website: https://www.criteria.co.uk/

THE UNIVERSITY of York

The King's Fund

CONSENT FORM

.
Participant Identification Number: | | | | |

Title of study: Women's Health Priorities: A Focus Group Study

Please initial the boxes to confirm verbal consent given

1. I confirm that I have read and understand the information sheet version 1.3 dated [24/03/2021] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that if I decide at any time before the focus group that I no longer wish to participate, I can notify the researchers involved and withdraw from the study immediately without giving a reason. I also understand that, due to the nature of the group discussion, it will *not* be possible for me to withdraw the information I shared within the group once the focus group has begun. ☐

3. I agree to this consent form and other data collected as part of this research study being kept at the University of York and The King's Fund. ☐

4. I understand that relevant sections of data collected during the study may be looked at by individuals from the University of York and The King's Fund and from regulatory authorities. I give permission for these individuals to have access to these records. ☐

6. I agree to the virtual focus group being video recorded and transcribed for analysis. ☐

7. I understand that direct quotations may be used in publications but no information will be released or printed that would identify me. ☐

8. I understand and agree that the research team will securely store my identifiable details in order to contact me in future regarding this study, or other related studies (e.g. telephone/text/email). Identifiable details, including a copy of the consent form, will be available only to the research team, other than for purposes of monitoring and audit. ☐

9. I agree to take part in the above study. ☐

_____ _____

Name of participant *(please print)* Date verbal consent given

_____ _____

Name of person taking consent *(please print)* Date

Appendix B: Annotated topic guide

Women's Health focus groups:
Topic Guide

Thank you so much to you all for joining our online focus group today. My name is **** and I am a researcher at the University of York. I will be leading this focus group. My colleague **** [pause for wave] is also a researcher here at York and she will be here to assist with any technical issues, to monitor the chat facility and summarise any group discussions. **** will now turn her camera off (thanks ****), but will be here in the background to assist us. [TURN CAMERA OFF]

Today we are going to be asking you to discuss women's health, which we appreciate is an extremely broad topic incorporating both physical and mental health. The Department of Health and Social Care is supporting the UK Government to develop a women's health strategy. Our focus group study aims to inform the development of the strategy. An early priority identified for the women's health strategy is women's 'voice' and finding out how the health and care system listens to and supports women. Therefore, we would like to find out your experiences of accessing health services. We also want to find out what health issues are important to women and about information sources women use to learn more about their health, to help shape how women's health services are provided in the future. There will be a mixture of discussions and exercises.

Please remember that there are no right or wrong answers. We are merely interested in your thoughts. Also, participants may disclose confidential information in these groups. We will not share any information that could identify you or anyone you mention when sharing the study findings, and we ask that you also do not discuss information shared by any other participant outside of the focus group.

CONSENT

You will all have received and hopefully had chance to look at the consent form. I am going to quickly read the consent form to you now and then ask you all to let me know if you have any questions, and if you are still happy to take part. [SCREEN SHARE **CONSENT FORM** READ CONSENT FORM].

Does anyone have any questions?

******, can you please start the recording of this video call? CLICK TO START RECORDING Thank you.**

OK. I am going to ask each of you in turn:

Have you read and understood consent form version 1.0 and are you happy to take part? [ASK EACH PARTICIPANT]

HOUSEKEEPING

Before we get started we'll just discuss some general housekeeping rules. Firstly, can we please ask that you all keep your cameras on where possible to allow us to more easily interact as a group. With Zoom, sometimes it can be difficult to hear when two people are speaking. Please raise your hand if you would like to speak.

Please have a pen and paper to hand (or another method) for making some brief notes. We have a couple of exercises where we will ask you to write down some answers and then put them in the chat box (which can also be found at the bottom of your screen).

We expect the focus group to last between 1.5 – 2 hours and we'll have a 10 minute break near the middle. We have a lot to get through, so we may need to keep any eye on timings.

Great. If there's no other questions we'll get started.

ICE BREAKER (10 mins max)

- *OK. Firstly, can you please write down your favourite biscuit and three words that come into your mind when you hear the term 'women's health'.*

CHECK ALL COMPLETED

- *Thank you, can you please in turn tell the group your first name, your favourite biscuit and the three words you wrote.* [INVITE EACH PERSON TO SPEAK]

Second facilitator to note the words on post-it notes on **Jamboard 1** and screen share with the group at the end of the exercise.

WOMEN'S HEALTH PRIORITIES

Thank you for sharing. Some great biscuit choices there [QUICK COMMENT ON TYPES CHOSEN].

It's really interesting to hear the words that come to mind when you think about the term 'women's health'. Often when we think about women's health, we may automatically think about areas of health that only affect women, for example relating to menstruation or reproduction [LINK TO EXAMPLES GIVEN BY PARTICIPANTS]. These areas are really important as the Government has recognised that we do not know enough about conditions that only affect women. However, they also recognise that we need to learn more about how conditions that affect both sexes, impact women in different ways. For example, symptoms can often differ between men and women, and studies show some conditions, like certain heart problems, are more likely to be misdiagnosed among women than men.

So, bearing in mind the breadth of the subject of women's health, we are going to complete a couple of exercises about the important issues regarding women's health.

- *"Firstly, we'd like you to please brainstorm as a group what you think are the most important healthcare issues for women that should be incorporated in the women's health strategy (**** will be making a note of these to share with us at the end* (15 mins)

Second facilitator to note the issues discussed (on post-it notes on **Jamboard 2**) and screen share with the group at the end of the brainstorm exercise.

- **"***Thank you. Now that you have generated a list of the important healthcare issues for women, individually please write down which five of these issues are the most important **for you**. Please list them from 1-5, with 1 indicating the most important.*

CHECK EVERYONE HAS COMPLETED THEIR LIST. Thank you. Can you all now please enter your list, with numbers, in the chat box (10 mins)

[ASK EACH PERSON IN TURN TO BRIEFLY EXPLAIN WHY THEY PRIORITISED THAT WAY]

WOMEN'S VOICES

We are now going to move on to the next section of the focus group, about women's voices.

- *"Thinking about women's health and the topics we've discussed, do you think there are barriers to women having open discussions with healthcare professionals about these issues? [PROMPT] What are those barriers?* (10 mins)

- *What might help women to have more open discussions?* (5 mins)

- *"We now would like you to think about being listened to by health professionals.*
    - *Have you ever felt that you have not been listened to or taken seriously when you have sought help with your health in the past?*
    - *Can you think of any good examples where you have been listened to and understood? [PROMPT] What did the health professional do well in this situation?"* (15 mins)

Thank you so much for your input in that really interesting discussion. We are going to have a 10 minute break now, so please feel free to go and stretch your legs, make a cup of tea and come back at ** for the final section of the focus group.

10 MINUTE BREAK

Welcome back! We are now going to move on to our final section of the focus group about health information and education.

<u>Information and Education about Women's Health</u>

- *"Please take a look at this list of the different places we can access health information"*

Facilitator 2 **[SHARE JAMBOARD 3]**: Health professionals, NHS website, independent health organisation/charity websites, friends/family, internet search, information leaflets, discussion boards e.g. Mumsnet, social media).

- *Can you think of any other sources of information? (*5 mins)

[Facilitator 2 adds any new sources to the list.]

- *"Thank you. Now, thinking about how you access information about your own health; please can you choose the 5 information sources you are most likely to use and then rank these from the most likely to the least likely for you to access (where 1 = the most likely to access). Once you have ranked them please type your list with numbers in the chat box* (5 mins)

- *"Thank you. Now, from the overall list, can you choose five that you think are the most trustworthy sources, where you are likely to get accurate information, and rank them (where 1 = the most trustworthy). Again please type your list in the chat box* (5 mins).

[FACILITATOR 1 EXAMINE CHAT BOX ONCE ALL HAVE ENTERED ANSWERS]. Thank you all for entering your answers.

- *Now, thinking about the sources of information you are most likely to access, can you please discuss as a group why you access those types of information more frequently?*

Thank you. We are on to our final question now.

- *Are there any areas of women's health where you feel that trusted information is sparse or not well communicated, and you would like to know more?* (10 mins)

Thank you. That brings us to the end of our focus group today. Thank you so much to you all for taking part in the fantastic discussions. We will be in touch with you when the results of the study are available later this year. If you have any questions in the meantime, please do not hesitate to get in touch via the email address on your participant information leaflet.

Partnership for
REsponsive
Policy
Analysis and
REsearch