Your NHS menopause experience: Bristol, North Somerset and South Gloucestershire

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healthwatch Bristol

Contents

Intro

At Healthwatch Bristol, we listen to patient experiences and base our work on the experiences that are shared with us. These experiences also inform commissioners and providers of local health and social care services, highlighting both good practice and areas for service improvement.

This project was driven by feedback shared by Bristol, North Somerset and South Gloucestershire (BNSSG) residents regarding perimenopause, menopause and post menopause support and treatment in 2021/22. This project was also informed by the Department of Health and Social Care (DHSC) Women's Health Strategy for England 2022 (1). This report summarises the feedback we have heard from local people about their menopausal experiences and makes evidence-based recommendations from the key themes that emerged.

About Healthwatch

Healthwatch Bristol's statutory duty and remit, which is laid out in the Health and Social Care Act 2012, is to provide a voice for people who use health and adult social care services. We give people an opportunity to have a say about their local health and social care services, especially those whose voices are marginalised, and we report these views in order to influence service providers and improve outcomes. This means taking public views to the people who make decisions. Healthwatch is committed to promoting equality, and diversity and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects. We have a representative on the Health and Wellbeing Boards, Health Overview and Scrutiny Committees, and at the Integrated Care Partnership. We feed issues back to the government via Healthwatch England and the Care Quality Commission (CQC).

Aim

This project aimed to collect responses to a survey from people in the Bristol, North Somerset and South Gloucestershire area. We wanted to hear from at least 200 individuals, including from the multicultural communities that make up the three areas' demographic profile.

Our objectives involved creating a survey that could be accessible to many individuals, including translating the survey into four different languages. We intended to reach individuals who are marginalised or harder to hear from. We did this by partnering with organisations who work in these communities.

We also planned to bring printed surveys to local community events and reach out to local community leaders to help disseminate the information. By spreading awareness about the survey through our social media channels, community engagement opportunities, and through key contacts in the council, community, and local healthcare providers, we aimed to have a cross section of responses for the survey.

Executive summary

The initial feedback collected by Healthwatch Bristol which led to the creation of this project suggested misdiagnosis of menopausal symptoms, and lack of education for those who are transitioning through the stages of perimenopause, menopause and post-menopause.

Healthwatch collected feedback from 379 residents across Bristol, North Somerset and South Gloucestershire between October 2022 and March 2023, to provide evidence-based recommendations around quality, access and experience for local people. Our research explored how people are diagnosed, treated and supported during their menopause – and identify where there are gaps in services.

A steering group made up of members of the public and professionals co-produced the survey questions based on lived experience. We reached marginalised communities with the support of organisations that work with these communities. We translated the survey into four additional languages and printed hard copies of the survey to reach those who are digitally excluded.

This evidence has helped us formulate the below recommendations

- Create a specialist walk-in hub or community clinic for women during menopause, providing follow-ups and reviews, which can be accessed without referral.
- Ensure awareness information is sent to all women in preparation for pre-menopause, so women know which services are available for support, including accessible options.
- Appoint designated leads in each Primary Care Network who provide specialist advice and signposting on the menopause.
- Launch an awareness campaign that takes menopause and its symptoms seriously.
- Health settings should signpost to trusted information including those online about the menopause, with information that resonates with our diverse local communities.
- Mandate menopause and cultural competence training to health professionals who offer menopause support, to enable women to make informed choices and avoid myths.
- Create co-delivery services of support in the BNSSG area for the menopause, encouraging peer support.

Headline statistics

- We collected a total of 379 survey responses.
- 60% of respondents answered that they would prefer a 'hub' or 'clinic' specifically for menopause or women's health. 26% answered 'maybe', and 11% answered 'no'.
- 33% of respondents believed their symptoms were mistaken as a different health problem, rather than being due to the menopause. 21% were unsure of this.
- Half (50%) of the respondents felt their healthcare provider knew their symptoms were perimenopausal, compared to 50% who did not. 54% of perimenopausal individuals felt they had been supported by their healthcare provider, 46% felt they had not.
- 70% of post-menopausal respondents felt they were not given enough information by a healthcare professional at this stage.
- 27% of respondents felt their healthcare worker's advice was 'somewhat helpful', compared to 12% that found it 'extremely helpful', and 18% who found it 'not helpful at all'.
- 65% of respondents would rather have seen a female doctor for support with the menopause, compared to 34% who did not mind.
- When asked whether the healthcare worker explained clearly what was causing their symptoms, 23% of respondents said this was not explained clearly at all, 30% said this was somewhat clear, and 8% said their symptoms were clearly explained.
- In terms of understanding the different treatment options for symptoms, 15% of respondents claimed they did not understand them at all, whereas 34% felt they understood these clearly.
- 42% of respondents felt taking Hormone Replacement Therapy (HRT) was 'extremely' helpful, whereas 25% of people stated this was 'somewhat' helpful, and 3% of people said HRT was not helpful at all.
- The most common feeling respondents had when accessing healthcare support for the menopause was nervousness (28%). 20% felt awkward, and 17% felt confused.

Findings

- There are low expectations when seeking medical support for the menopause, as many respondents feel healthcare professionals are unfamiliar with symptoms and don't recognise the condition.
- Respondents' symptoms have been mistaken by healthcare professionals, primarily confusing these with mental health difficulties.
- Many respondents felt their menopause symptoms were not handled with compassion by healthcare professionals, and that they are not listened to.
- Respondents wanted better access to NHS information regarding the menopause in a digital format and more information available inside care services.
- Respondents said a healthcare hub or clinic with professionals who specialise in topics such as the menopause would help individuals feel more comfortable accessing the right support.
- Perimenopausal individuals felt they struggled to be diagnosed, despite having voiced concerns to a service that perimenopause may be the cause of their symptoms.
- Many post-menopausal individuals felt they were not given enough information on this stage.
- Confusion about links to a risk of cancer inhibits some from using Hormone Replacement Therapy (HRT). Healthcare professionals refused some individuals HRT because of their history of cancer.
- Respondents said healthcare professionals did not provide advice around alternative treatment options to HRT.
- 38% of respondents stated the organisation they work for has a menopause policy, compared to 38% who said there is no policy in place. 23% were unsure of whether their work had any provision for this.
- Respondents said follow-up care is lacking, including checking whether prescriptions are still suitable.
- Some individuals felt forced to choose private healthcare services for diagnosis, treatment and ongoing support for the menopause.
- Cultural differences impact how some communities perceive and talk about the menopause and service providers should be aware of this.
- Individuals with long-term conditions can struggle to separate the symptoms of the menopause from their condition. The menopause can worsen the effects of some individuals' long-term condition symptoms.
- Examples of good practice have been included from respondents who felt their symptoms were cared for well.

Background

The menopause is defined by the NHS England Menopause Network (2) as beginning when an individual has not had a period for 12 consecutive months. Typically, it happens between the ages of 45 and 55, but for some this can be as early as 40 (3). Premature menopause can happen at any age if women or girls don't produce ovarian hormones.

There are transitioning stages of the menopause. Perimenopause is the time leading up to the menopause – from the start of menopausal symptoms until after a woman has experienced her last period. Post menopause refers to being 12 months and one day without a period, however symptoms may continue and may require ongoing support. On average symptoms last around 4 years from when a woman's periods end, however, around 1 in every 10 women experience them for up to 12 years. There are over 30 symptoms that fall under the umbrella of menopause (4). These symptoms can occur during both the perimenopause and the menopause.

There are currently 13 million perimenopausal or post-menopausal women in the UK, however 41% of the UK's 33 medical schools do not have a mandatory menopause education program for their students. Almost 60% of doctors leave university with no education on menopause despite half of the population experiencing these at some time in their lives (5).

The lack of education around menopause was a theme that came from initial feedback and prompted this research, which is explained in our Theory of Change (appendix 6). This research therefore explored what information local services provide and if they are knowledgeable on the topic of menopause.

The National Institute for Health and Care Excellence (NICE) which sets out guidelines for the diagnosis and management of menopause recommends an individualised approach and says explanations should be given regarding stages, benefits, risks of treatment, and lifestyle modifications that are supportive (6). It recommends women are encouraged to talk about their symptoms, are made aware of hormonal and non-hormonal interventions, that psychological and sexual impacts should be discussed, and regular treatment and symptom reviews undertaken. Healthwatch Bristol's survey questions were designed to investigate whether NICE guidelines are followed and where gaps exist locally.

Research has found that the menopause can happen earlier in black and minority ethnic communities, and there are racial differences in the menopausal experience (7). We were keen to understand if there was inequity in healthcare support for the menopause and whether these were geographical or demographic. Our survey asked whether individuals felt that their race, ethnicity, or any other protected characteristic influenced their access to menopausal support from health care services.

Nationally, the Liverpool Women's NHS Trust is one of few in the UK dedicated to a broad range of care for women's health. The Trust has a dedicated

menopause clinic within their gynae service (8). In our local area of Bristol, North Somerset and South Gloucestershire (BNSSG), University Hospitals Bristol and Weston (UBHW) NHS Foundation Trust at St Michaels' Hospital runs a menopause clinic as part of their gynaecological service (9) This is accessible via GP or consultant referral, not self-referral.

Some BNSSG GP practices have created support groups for patients going through the menopause. However, currently the only universal service in the Bristol area is UHBW's menopause clinic.

Our research on the menopause aligns with local and national government initiatives, due not least to emerging figures regarding working days lost and increase in mental health issues and quality of life are impacted by the menopause (10). In October 2022, the All-Party Parliamentary Group on Menopause (APPG) said that more needs to be done urgently to help women, including boosting support in the workplace, introducing fresh training on symptoms for health workers, and improving access to treatment. Their recommendations included inviting millions of women across the UK for an NHS health check aged 45 to discuss the menopause. They also suggested that HRT prescriptions should be free of charge (11).

This research also ties in closely with the 10-year ambitions of the women's national health strategy for the menopause (12) which highlights the importance of awareness of the menopause from a young age, normalising the menopause, and ensuring primary care professionals offer evidence-based treatment options. This project will feed into the Women's Chapter (13) of the Bristol City Council's Joint Strategic Needs Assessment (JSNA) (14), which brings together expertise from local community leaders to understand and agree the needs of local people. The JSNA provides evidence for making decisions about local health and care services and enables commissioners to plan and fund services that meet the needs of their whole local community. The insights that come from this project will also be taken into consideration by the Bristol Women's Commission, who identify key issues for women and produce the Women's Strategy for Bristol.

Methodology

We began the project by forming a steering group, inviting individuals to an informal session to discuss their experiences of the menopause. We reached out to partner organisations using our social media channels, various online platforms and using networks in BNSSG.

We divided the numbers of attendees into two groups. In both groups, a member of staff and a Healthwatch volunteer were present. The staff member's role was to facilitate conversations with the group members based on a set of semi-structured questions. The volunteers' role was taking notes and facilitating conversations.

The steering group were given the option to be contacted for future contributions to an initial survey draft. We adapted the survey based on their comments. The draft was sent to key contacts representing diverse and marginalised communities to ensure these communities had the opportunity to co-design the survey with us, which is an aim highlighted in our Equality Impact Assessment (appendix 7).

After meeting with a Healthwatch volunteer who is trained in creating easy read materials, we were able to identify and ensure key terms were well defined. This was particularly important for the translation of the surveys into four commonly spoken languages in Bristol, to reach Somali, Urdu, Polish and Hindi speaking communities.

We disseminated the survey through partners and community organisations. We also had help from Bristol City Council and local healthcare services.

We created posters to display our contact information, a project summary and a QR code taking respondents straight to the survey using a smartphone or device. The posters were placed in community centres, leisure centres, hospitals clinics, and in GP reception areas. Flyers were created for face-to-face engagement events. We targeted newsletters within the voluntary sector and integrated health partners.

We printed the survey in five languages including English and arranged free postal returns. Some staff and volunteers were involved in helping respondents by filling in the survey over the phone for them.

In March 2023 we hosted a high-profile workshop at Bristol's International Women's Day event in City Hall with local charity Bristol Women's Voice what attracted widespread attention.

International Women's Day event: 'Your NHS Menopause Experience' workshop

With the assistance of a volunteer, we used interactive graphics to discuss desirable healthcare services for the menopause. The results of the workshop were recorded and included within this research.

Survey

The survey ran from December 2022 through to March 2023. The total number of responses was 379, with 250 fully completed surveys and 129 partially completed surveys. The online survey was created using Smart Survey and had a total of 54 questions (included as appendices 1-5).

This survey utilised a 'branching' tool of Smart Survey. Respondents were taken on a certain path of questions depending on their answers to a previous question. For instance, if an individual answered that they were of a particular protected characteristic, such as from a minority ethnic background, they would also be taken to a set of certain questions. These questions asked the respondent whether they felt their characteristics influenced the way the menopause is perceived by the respondent, or whether this affected the care they received. We decided to ask these sets of questions to understand the cultural and socioeconomic impacts of healthcare for the menopause.

Findings

We decided to place the demographic questions at the end of the survey. Each respondent was asked the same demographic information questions. We do not have demographic data of all respondents, which we believe is due to survey fatigue.

Demographics

Table 1: Area of BNSSG that respondents are living

Where respondents are from		Number of respondents
Bristol		151
North Somerset		60
South Gloucestershire		31

Table 2: Age differences of survey respondents

Age Range	Number of respondents
25-49 years	73
50-64 years	150
65-79 years	21
No response	5
Prefer not to say	1

Table 3: Ethnicities of respondents

Ethnicity	Number of respondents
Asian/Asian British: Any other Asian/Asian British background	1
Asian/Asian British: Chinese	2
Asian/Asian British: Indian	2
Asian/Asian British: Pakistani	1
Black/Black British: African	3
Black/Black British: Caribbean	1
Mixed/multiple ethnic groups: Any other Mixed/Multiple ethnic group background	1
Mixed/multiple ethnic groups: Asian and White	1
Mixed/multiple ethnic groups: Black African and White	1
No response	10
Other	3
White: any other White background	19
White: British/English/Northern Irish/ Scottish/Welsh	199
White: Irish	6

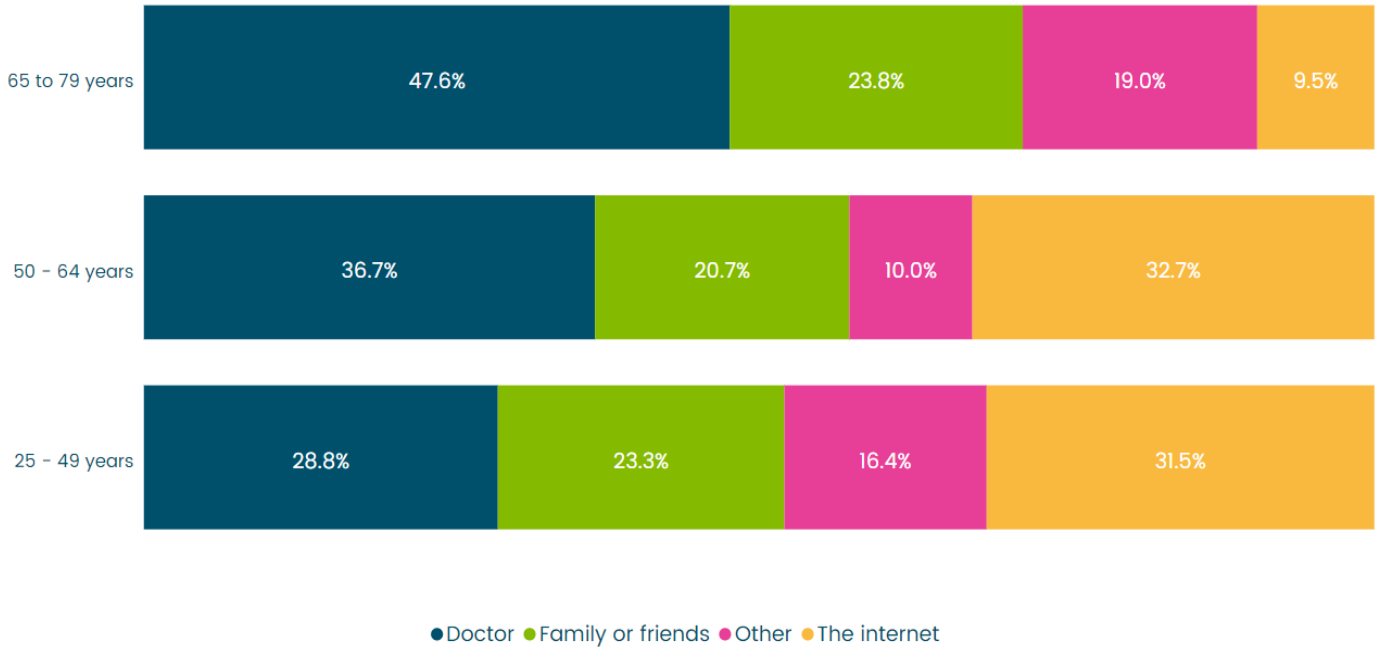
Table 4: Financial circumstances of respondents

Financial status	Number of respondents
Just getting by (I have just enough money for living expenses and little else)	54
No response	8
Prefer not to say	11
Quite comfortable (I have enough money for living expenses, and a LITTLE spare to save or spend on extras)	144
Really struggling (I don't have enough money for living expenses and sometimes run out of money)	6
Very comfortable (I have more than enough money for living expenses, and a LOT spare to save or spend on extras)	27

Table 5: Percentage of respondents who identify as having a long-term condition or as a disabled person

Disabled person or having a long-term condition	Percentage
Yes	29%
No	70%
Prefer not to say	1%

Chart 1: ‘what was the first place you went to for advice, information or treatment of the menopause?’ by age group.

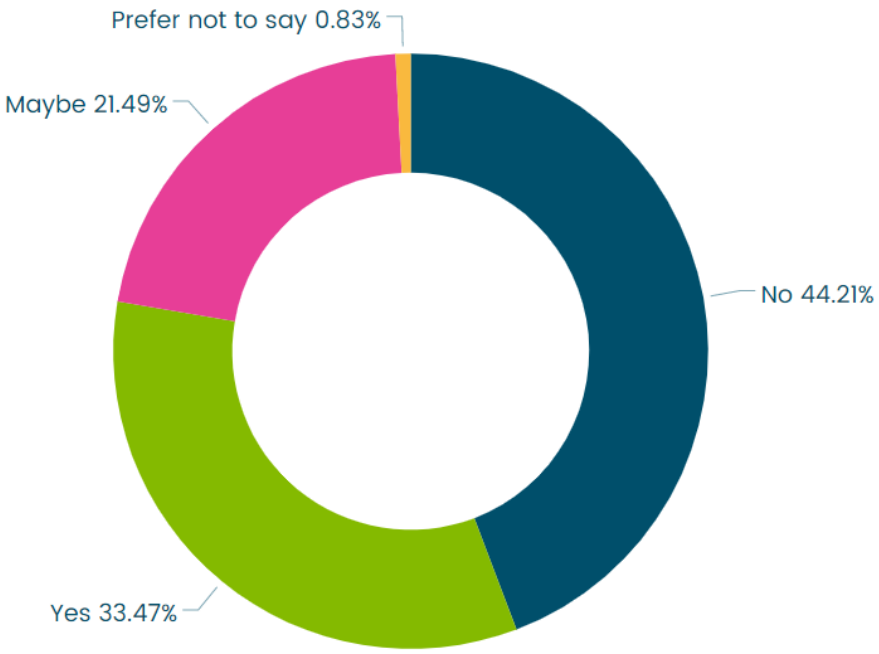


Within Chart 1, there is a difference between ages of respondents regarding their first point of contact for advice, information, and treatment of the menopause. We can see that the younger the age, the fewer respondents sought advice for the menopause with a doctor. In the youngest group, the internet was the most used place to access information. This suggests younger individuals rely more on online platforms for healthcare advice and information than directly through healthcare services.

Key Themes

Symptoms and their diagnosis

Chart 2: Responses to the question 'Were your symptoms mistaken as a different health problem, rather than menopausal?'



As shown in Chart 2, 33% of individuals felt that their symptoms were mistaken, with 21% saying 'maybe'.

Open text answers to our survey supported this finding with some respondents stating their symptoms were misdiagnosed by health professionals as issues with mental health.

- Multiple respondents were prescribed 'anti-depressants' first, before later treating symptoms as menopausal. A respondent who lived with debilitating symptoms for 7 years wrote, 'I went back to my GP practice after 7 years of being into post-menopause, still struggling with symptoms that had been put down to mental health. I had been given anti-depressants and anti-anxiety medication which did not work.'
- One respondent told us that the 'GP said I was too young (to be in menopause) and I should try antidepressants. I refused as anxiety and low mood were a consequence, not cause, of my hormone changes.'
- Another said, 'I was signed off work with low mood.'
- 'With hindsight many early symptoms were put down to depression that were actually hormone related.'
- 'I was told I was depressed and given antidepressants.'
- 'I had blood tests for thyroid problems and was offered anti-depressants which I refused. I knew it was not depression.'

- ‘Each symptom was initially viewed as a separate matter rather than holistically as one or linked.’
- Some found that they were not supported when they asked for help.
- ‘My periods went very sporadic, and the GP gave me one blood test but said it was all okay. It wasn’t until a year or two after they had been stopped completely that I went back and got help.’
- One respondent wrote, ‘it’s not so much that they were misdiagnosed, more that links haven’t been made and support offered.’
- 'It was a struggle to get GP to accept symptoms as peri-menopausal and not just menstrual.’
- Other conditions sometimes got confused with menopausal symptoms.
- ‘GPs seem to struggle to differentiate between what is or could be caused by the menopause.’

Training and awareness of health professionals

People we spoke to felt a lack of training affected the care that they received from healthcare professionals.

- One of our respondents wrote, ‘I had worsening PMS, insomnia, gum problems, heavy periods, breast pain… I’m really shocked how poorly women are treated and how inadequately GPs are trained’.
- Another wrote about her poor care, ‘my GP was a young man, and I wonder if he had any training on the menopause at all.’
- ‘I was peri-menopausal from 42 years of age. GP was dismissive, diagnosed anxiety and depression but the tablets made it way worse, it took until I was
- ‘49 years old before I was taken seriously, GPs seemed to have very little knowledge.’
- ‘We need all practitioners to have basic training and a specialist prescribing nurse in each GP practice.’
- ‘GPs need support and training in the practice that can then support other professionals.’
- ‘I would like to see all doctors trained to understand perimenopause, and the correct knowledge, support and guidance to be there from all GPs.’
- One respondent felt that ‘the lack of knowledge within the GP sector means a failure to recognise how debilitating the menopause symptoms can be.’
- ‘More training and support for healthcare professionals is vital as many do not know enough to treat the menopause well.’
- A respondent suggested that ‘more healthcare professionals getting menopause training’ would beneficial.

Chart 3: Respondents answering the question ‘did you find your doctor or healthcare worker’s advice helpful?’

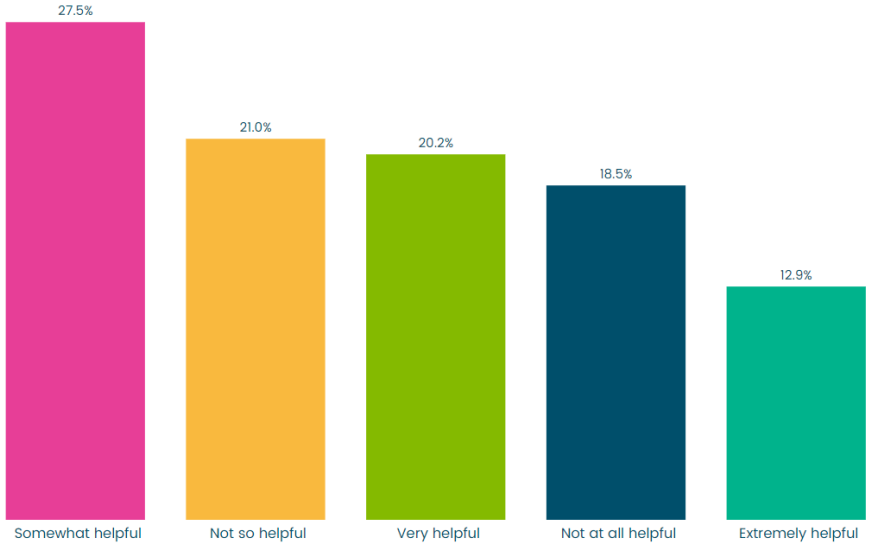


Chart 3 shows 27% found that healthcare professionals' advice was ‘somewhat helpful’. 21% ‘not so helpful’. 12% of respondents said that advice was ‘extremely helpful’. Only 20% of individuals found their health care professionals advice very helpful.

Attitudes of healthcare professionals

This project began with feedback from people who felt they were not listened to when accessing healthcare services for the menopause. This was further highlighted in our survey:

- One respondent wrote, ‘I felt as though I wasn’t being listened to’.
- Another said that the healthcare professionals gave ‘No information’ and that it is a ‘constant battle to be listened to.’

Some respondents felt that their healthcare professional did not have compassion or sensitivity:

- ‘As an overweight woman who has gone through the menopause at a younger age, I feel I wasn't taken seriously at all, no help was offered and all I was told that it was down to being overweight.’
- ‘My symptoms just weren't received very sympathetically. I had to request treatment. This is 9 years ago.’
- ‘There's always a reluctance to engage in any conversation about menopausal issues.’

- ‘I was told by my female GP; every woman has gone through it and just to get on with life.’
- ‘My initial GP was either totally disinterested or he lacked any knowledge of this area. Now, I have a knowledgeable female GP who has put me on HRT to tackle some symptoms.’
- My GP was totally unsympathetic.’
- ‘The GP dismissed my symptoms as trivial…they had a “get a grip” attitude.’
- ‘My symptoms were ignored by the GP who was reluctant to give me any time or help.’
- One felt dismissed and said, ‘they should not be treating you like you’re hysterical’.

Being informed about the menopause

Respondents to our survey said they were not signposted to helpful information by healthcare professionals.

- One respondent wrote ‘almost all the information I’ve found out is through my own research into my symptoms.’
- ‘I had to convince my doctor it was perimenopause through careful research and drawing the dots with my own symptoms.’

Many people used the survey to point out the need for specialist information and support for women.

- ‘A lot of my friends have struggled to get good information and support from their GP about the menopause.’
- ‘A respondent felt there should be ‘more information about less talked about symptoms like memory loss or brain fog.’
- Another needed ‘more advice relating to getting through the menopause.’
- ‘Improve the communication and education for women that this is a natural, normal process.’
- ‘Self-help groups that provide good information to the questions people need answering, or something like this online.’
- ‘I think knowing where to go for advice and support is so important. There could be community groups online or face-to-face where people can go for support’.
- One respondent recommended that ‘having awareness sessions online’ could help.

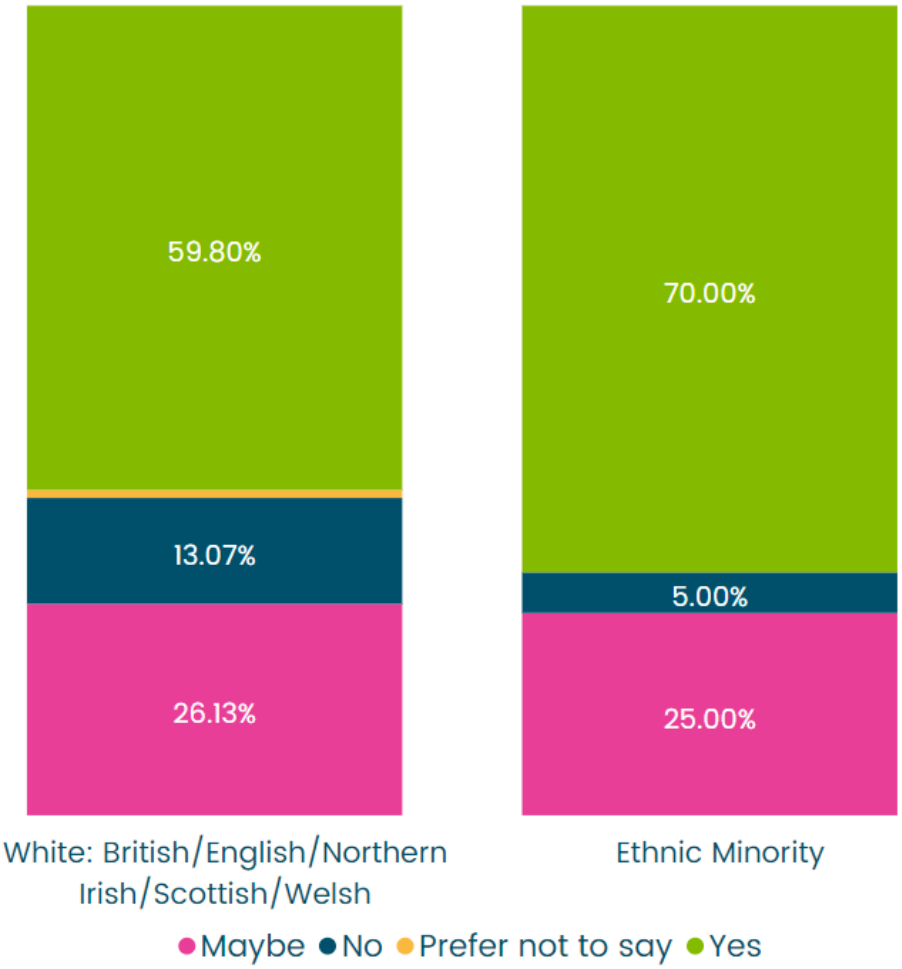
- ‘The menopause needs to be discussed with every female at a health check. I wish I had the information before I started developing symptoms.’
- ‘Simple leaflets and written down information (including doses and advice).’
- ‘I think more information needs to be in the public domain so that women don’t suffer in silence or avoid seeing a GP.’

Community based specialist services

Almost two thirds of our respondents said they wanted designated ‘hubs’ or community clinics. This is reflected in written responses:

- ‘Not only is it impossible to get a GP appointment, but I would also prefer to talk to someone with specific expertise in women’s health and the menopause.’
- ‘It would help having specialist services so that women can receive up-to-date information and care.’
- ‘Bringing gynaecological, menopause, cervical and breast screening with contraceptive services, and diagnostics all together would make a massive difference.’
- ‘If attending a (community)hub decreases pressure on GPs, then I am okay with that.’
- ‘I have a complicated gynaecological history so it would be great to go to a clinic or hub.’
- ‘This type of specialist care would be very helpful especially to ensure treatment is in line with current thinking and techniques.’
- ‘The menopause can be very complex. A hub with specialists will have a better idea of complex cases.’
- ‘It would give me confidence to know I was speaking to menopause trained professionals. I think GP appointment times are too short for women to properly understand what’s going on and make informed decisions on treatment options.’

Chart 4: Responses to the question: 'would you prefer a clinic or hub that is specifically for menopause or women's health?'. Answers split based on ethnicity of respondents.



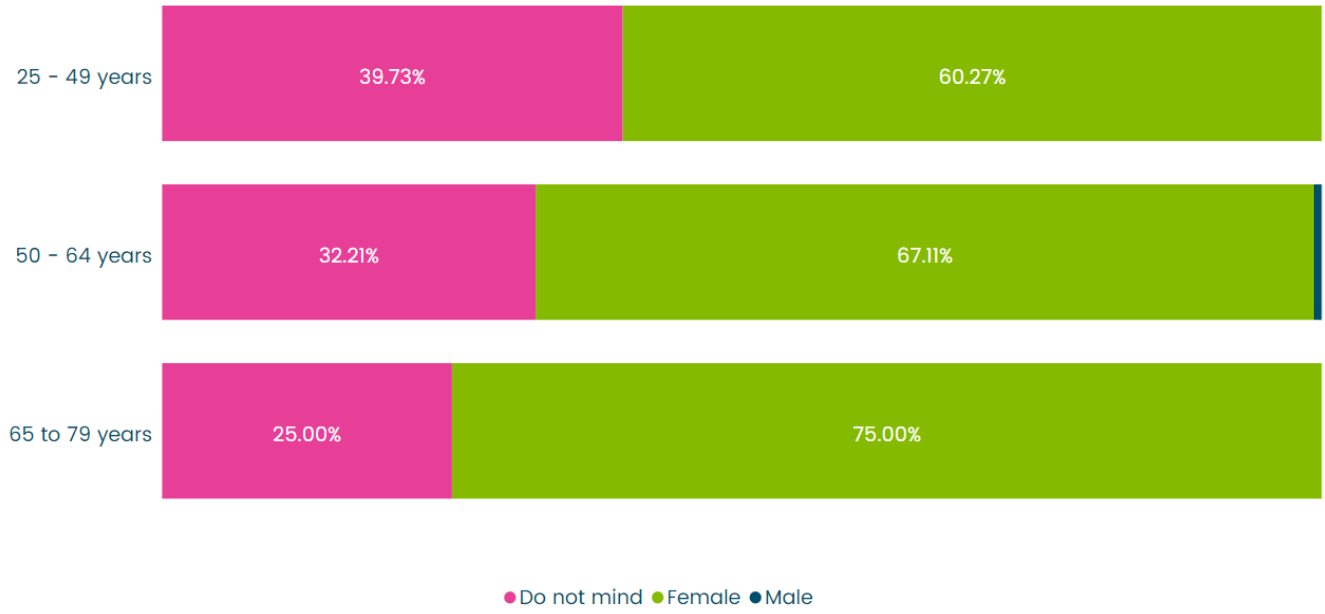
70% of respondents with ethnicities who do not identify as 'White:' said they would prefer a designated women's hub/clinic compared to 59% of 'White' communities. Those who do not identify as 'White' are more comfortable with visiting a community space for women's healthcare needs. This preference may be reducing the likelihood of these communities seeking help from a GPs or healthcare professional and may lead to health inequalities.

- 'If there was a dedicated clinic, I would have come forward for help sooner.'

75% respondents aged 65-79 years of age said they would have rather seen a female health professional than a male. This is compared to the youngest age range, 25-49 years of age, where 60% of respondents would have rather seen a female professional.

Charts 4 and 5 show the response by age and ethnicity. These differences are important to consider when creating new services for people going through the menopause.

Chart 5: respondents answers to the survey question, "if you could choose, would you have rather seen a male or female doctor or healthcare worker?"



Recognising differences in experiences for those in the perimenopausal stage

Chart 6: respondents answers to the question: if you are perimenopausal, did your doctor or healthcare worker know your symptoms were due to perimenopause?"

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Chart 7: respondents answer the question: "if you are perimenopausal, do you feel you have been supported by your doctor or a healthcare worker through the peri-menopausal stage?"

Chart 6 shows whether doctors or healthcare workers recognised menopausal symptoms. 54% said they felt that had been supported by healthcare professionals 46% of respondents felt they were not.

In open text responses individuals said they struggle to have their symptoms taken seriously.

- One respondent wrote, 'I have spoken to many GPs about my symptoms, and was told other things like, I'm too young, depressed.'
- 'At first, I was dismissed by my doctor as they said I was too young (aged 44), I eventually (was) listened to and put on medication'. 5 years later.
- 'I was told repeatedly by my GP that I was depressed and suffering from anxiety because I was too young.'
- 'Perimenopause wasn't their first or even second thought in reference to my symptoms despite me voicing that I thought they were.'
- 'My doctor has told me I'm too young. They don't accept that I know my body and that I can feel that things are changing.'

Recognising and supporting postmenopausal stages

Of the 74 respondents who answered this question, 44 said that they did not feel they were given enough information.

- One respondent who is post-menopausal, said they are 'still taking HRT to control mood ' but didn't know why.
- Others felt they were given 'no advice' or 'no information.'
- Some felt they had to pay for private consultations with an expert' or had to 'resort to the internet.'
- One individual said they had been 'experiencing hot flushes and mood swings for over 20 years.'
- 'No follow up. No diet or lifestyle advice, only prescription and no review.'
- 'Through suffering from different symptoms, it has prompted me to keep going back to my GP, and because of that I've learnt more.'
- 'You're just left to get on with it.'
- 'I didn't know symptoms would go on so long or that new ones would start.'

Alternatives to HRT treatments for the menopause

112 respondents disclosed that they are taking HRT as their primary treatment option for the menopause, however a proportion stated reasons for not using it:

- ''My doctor explained vaginal atrophy could be reduced by HRT but I was too scared to use HRT because of hearing it was linked to breast cancer.'
- One respondent said myths about HRTs link to cancer had put her off. 'I feel I have missed out of the benefits of using HRT such as reducing risk of osteoporosis and heart disease'.

Some individuals told us their request for HRT was refused:

- 'Because my mother and sister had breast cancer, I was told I couldn't take HRT. No alternative was discussed.'
- One health professionals 'said I wouldn't be able to have HRT due to my mother's stroke.' and has had no support after that.'
- One respondent who has had breast cancer said 'they didn't have a clue about the fact that I could still receive HRT, so was refused it. I have gone through years of suffering because of this.'
- 'After being told it was probably menstrual and being encouraged to have a coil fitted, the GP eventually relented and agreed to give me HRT - it felt like I had to fight to get it.'

Some respondents felt they would like to hear about alternative options, however, there appears to be a lack of knowledge:

- 'I would like to discuss the options rather than read them on a website', one respondent wrote.
- 'I have just left my job because of my cognitive decline, which made my job stressful and impossible. I now need to find something else & keep coping with what feels like dementia because HRT hasn't helped it, and I don't believe there is any other support or help available.'
- 'I had to suggest could I be perimenopausal. Then I was just given standard hormones despite wanting to discuss a different route after speaking with a specialist.'
- 'Was offered HRT but the doctor could not really offer my advice on how this would interact with other medications I am taking for a long-term health condition.'
- 'I was put on a low dose of HRT, but never again as it led to being partially to blame for a pulmonary embolism not long after. There is not enough information given about the potential risks of HRT.'
- 'Healthcare professionals should be more up to date with prescription options.'

Going private for menopause care and treatment

A reoccurring theme was respondents' decision to seek private healthcare services.

- One respondent wrote, 'I tried for 4 months to get an appointment with my GP and ended up having to see a private GP at significant cost'.
- 'I was told by the doctor that she had no experience of the menopause. So I was forced to seek private advice.'
- 'Awful experience throughout primary and secondary care medics. Had to go private. Ageist and sexist health policy – it's a disgrace.'
- 'I went to my GP when I first started getting symptoms. I was given anti-depressants. Eventually, after 3 years of struggling with multiple symptoms I went to a private menopause clinic.'
- 'I am now going back to the doctor to ask how to identify a private 'gynaecologist who can help me.'
- 'A real absence of any expertise within the NHS. I created my own hybrid care package by consulting a private menopause practitioner.'

Chart 8: ‘how much did you understand the different options for treating your symptoms of the menopause?’ Divided by economic circumstances.

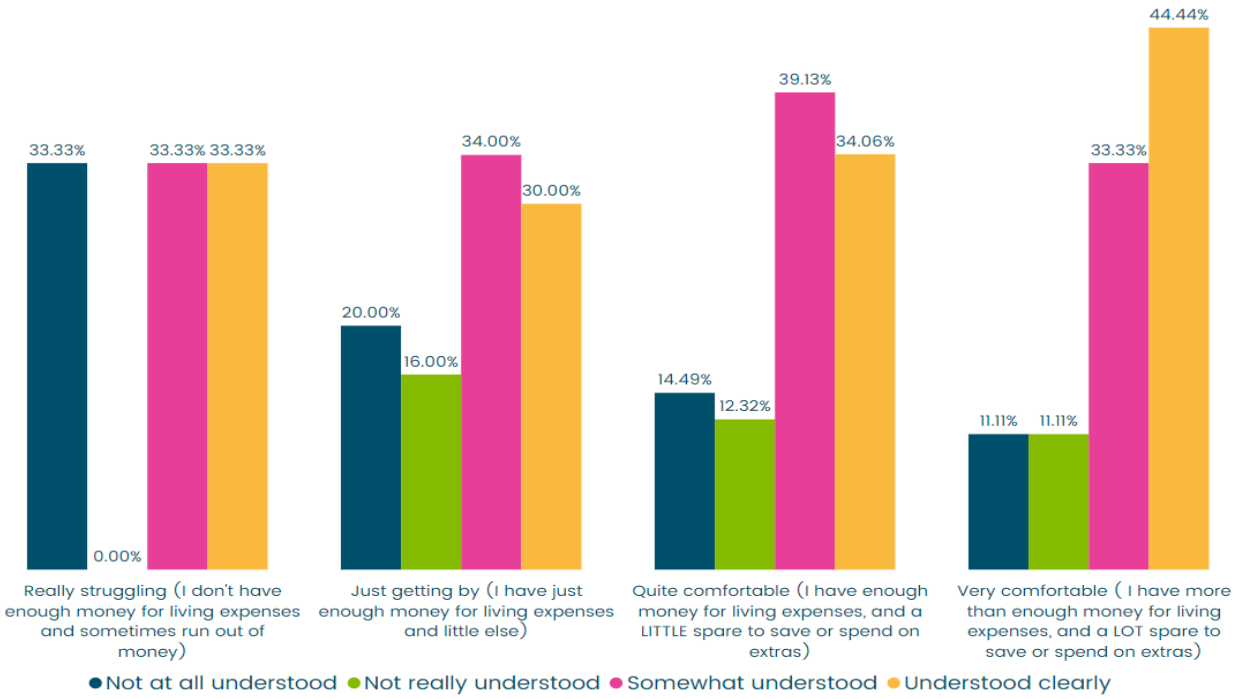

Chart 8 shows that those financially ‘really struggling’ didn’t know their treatment options. Those ‘very comfortable’ financially and able to afford private services, had a better-quality experience of menopause care and more available treatment options.

Understanding the importance of cultural differences

Chart 9: 'did the doctor or healthcare worker explain what was causing your symptoms?' Divided by ethnicity of respondents.

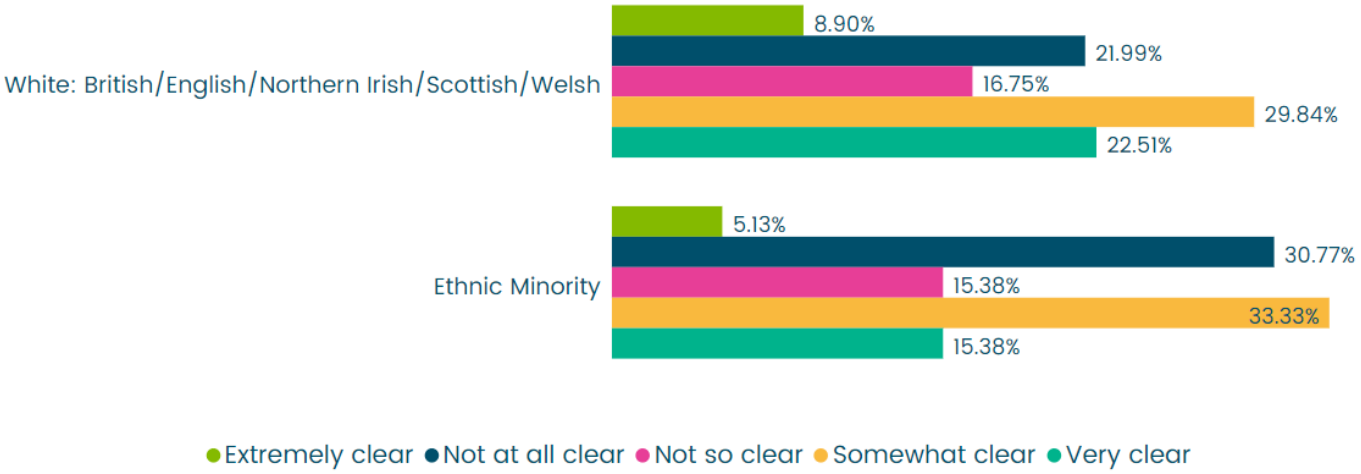

Chart 9 shows that 30% of individuals who do not identify as 'White' found a healthcare professional's explanation of what was causing their symptoms 'not at all clear'. 33% found the explanation from their healthcare worker 'somewhat clear'. There may be language barriers to understanding healthcare professionals due to English being a second language, however confusion may have been caused by limitations to professionals' cultural awareness. Some responses reflected these issues:

- 'The menopause is very personal and not something we share in my culture.'
- I saw a male GP, so I was nervous and embarrassed.'
- 'More information is needed, such as drop-in sessions and workshops.'
- 'It is still a bit of a taboo subject. This barrier really needs to be broken.'
- 'There is little information (about menopause) seen anywhere in my community.'
- 'In my culture (I am Somalian), we struggle to talk about these types of changes. A lot of us think the menopause means the end to our lives, so we do not want to accept help.'
- One respondent wrote, 'no one talks about it, even the British.'

Training around diversity and the menopause would be a significant step forward and would help to break down the barriers to accessing healthcare for these communities and the heath inequality this fosters.

The impact of disabilities and long-term conditions

63 individuals had a disability or condition and remarked on the way it affected the response to their symptoms of menopause. Many said the symptoms became mixed up , both by themselves and clinicians. For instance:

- One respondent wrote it is 'difficult to know if it's (my) condition or menopause'
- Another individual wrote this has 'somewhat confused my symptoms.'
- Others mentioned the issue of 'Chemotherapy accelerating menopause' and 'similar symptoms made gaining support more challenging'
- For one person there was a concern about using HRT because of 'Misunderstanding of hormones versus my type of cancer ' and a 'perception of increased cancer risk.'
- Respondents felt that their access to HRT had been affected by their disability, 'it has affected the response , I was told HRT was not suitable.'
- A diabetic individual said they 'tried the oestrogen gel first, which dropped (my) blood sugars.... I feel diabetic patients should be warned this is possible.'

  There were reports of conditions or disabilities exacerbated by the menopause. One respondent wrote, 'I already have migraine disorder, this got worse during perimenopause.'
- Another individual says, 'I have suffered anxiety for a very long time, but symptoms have been exacerbated by menopause.'

Examples of good practice

There are numerous examples of good practice that respondents wanted to tell us about, that they say should be built upon.

- One respondent said, 'the GP sent me links to an excellent series of videos to watch in my own time which were really informative'.
- One said, 'GP took (my) symptoms seriously and suggested lifestyle changes to help manage the menopause' leaving the respondent feeling 'listened to' and 'validated'.
- Another respondent wrote 'my GP was a very good listener and very willing to be led by my thoughts too on my menopause, and possible treatments'.
- 'I asked a general question when seeing the nurse about an issue and she listed other symptoms that I had and didn't realise were related. She alerted me to perimenopause before I had considered it. Excellent.'
- 'I was prescribed HRT for a couple of months, and I did not feel quite happy, so my doctor suggested herbal remedies which reduced symptoms within a year.'

Peer Partnership Model

One of our steering group members suggested that 'Support groups, greater awareness and sources of information are needed.' We asked them to explain.

A local voluntary service known as Peer Partnership have rolled out peer support services for people living with HIV and have now extend their model to Type 2 Diabetes and long COVID. They told us that the basis of these peer support sessions is to provide mentees with the support needed to feel less lonely and isolated and feel better able to self-manage their condition during and following the support sessions. The Peer Partnership have created a proposal for their model to be used for menopause, to support mental wellbeing. Their work includes peer and health care professional-led workshops, semi-structured peer support groups and mentoring. This service would be an asset to a women's hub or walk-in clinic.

How we could have improved our survey?

Our survey assumed respondents had sought healthcare support from local services. We soon became aware that many people choose not to seek any type of support. However, to pursue the purpose of this project which is to identify themes from public experiences of care, we continued to focus on those voices who tell us about using or trying to use public healthcare services.

We wanted to hear from a diverse range of cultures within our community, and our translation of the survey into four different languages helped us do that. However fully overcoming cultural sensitivity around the menopause and intersectional difficulties arising when attempting to discuss it, was a barrier to accessing some communities. Knowledge about the ways different cultures speak about and understand the menopause is missing and should be addressed by further research so that our services can reach all sections of our communities and help to reduce health inequalities.

Recommendations

- Create a specialist walk-in hub or community clinic for women during menopause, providing follow-ups and reviews, and which can be accessed without referral.
- Ensure awareness information is sent to all women in preparation for pre-menopause, so women know which services are available for support, including accessible options.
- Appoint designated leads in each Primary Care Network who provide specialist advice and signposting on the menopause.
- Launch an awareness campaign that takes menopause and its symptoms seriously.
- Health settings should signpost to trusted information including those online about the menopause, with information that resonates with our diverse local communities.
- Mandate menopause and cultural competence training to health professionals who offer menopause support, to enable women to consider all options and avoid myths.
- Create co-delivery services of support in the BNSSG area for the menopause, encouraging peer support.

What's next?

Next steps

- Healthwatch Bristol's 'Your NHS Menopause Experience' will inform the Women's Chapter of the Bristol City Council's JSNA (Joint Strategic Needs Assessment).
- Healthwatch Bristol's 'Your NHS Menopause Experience' will inform the Women's Chapter of the Bristol City Council's JSNA (Joint Strategic Needs Assessment).
- Healthwatch Bristol will advise local service providers and healthcare professionals of the results and recommendations of this project.
- Healthwatch Bristol will update local Sexual Health Boards.
- Healthwatch Bristol will continue to collect feedback on menopause services and signpost people to available support.
- We will track responses to this research to influence plans for women's health and care services in the BNSSG area.

A special thank you

We at Healthwatch Bristol would like to thank those who took part within this survey. We would also like to thank all external organisations who helped us to disseminate our survey, and put us in touch with key contacts who have helped us reach wider communities of individuals, such as:

Caffi Health

Sirona Health & Care

Sirona Health Links Service

Opoka (Polish Women's Group)

Our volunteers have a steering role in our projects, and we would like to thank Ann Mary, Suzanne, and Jemma from Healthwatch Bristol, North Somerset and South Gloucestershire for their continued support.

Provider responses

Shane Devlin, Chief Executive Officer, Bristol, North Somerset and South Gloucestershire Integrated Care Board

Thank you for sharing this really helpful review with us and the ideas and recommendations this has generated. In BNSSG we are committed to working with colleagues such as Public Health, General Practice and Secondary Care to improve services to women, in line with the Women's Health Strategy, which is one of our priorities within our Joint Forward Plan. Dr Joanne Medhurst our Chief Medical Officer is the champion for this strategy and a programme of work to review and implement recommended improvements under the leadership of the Health and Care professional Executive will take place in the future. We will incorporate this valuable feedback into our developing plans.

Currently Primary Care prescribing data shows that we are, like other parts of the country, investing considerably more on HRT treatment. Last year 22/23 we spent £2.8 m on HRT therapy which is an additional £1.03 million than in 21/22. Further work is needed to review who is accessing treatment and the value that this is bringing to our population.

We look forward to working with you in the future to ensure we have the optimum services and access for women.

Penny Gane, Chair, Bristol Women's Commission

Huge congratulations to Healthwatch on their excellent research into women's experiences of healthcare in relation to the menopause. This research provides solid evidence of the need for more responsive service provision and highlights the importance of better training for GPs and all health professionals. We will continue to work together to set up women's health hubs in the city and to influence decision makers both locally and nationally.

Jo Burgin, GP Academic Clinical Fellow at the University of Bristol

This report highlights women's experiences accessing menopause care in BNSSG and the work required to meet the needs of women whose lives are affected by menopausal symptoms. There is a clear need for further research to listen to the voices of traditionally underserved communities and identify barriers to accessing good menopause advice and care. I welcome the call for more investment in women's health and hope this will reinforce the importance of menopause care outlined in the Women's Health Strategy for England.

Kyra Bond, Chief Executive Officer, Womankind

We welcome the findings in this report that acknowledges the menopause can have a profound and debilitating effect on many women's lives. We agree with all the recommendations and the need to prioritise timely access to holistic treatment, personalised information and compassionate care for women across our region.

Carol Slater, Head of Service - Public Health, Communities and Public Health Division, Bristol City Council

Menopause has traditionally had low visibility in health and care settings as well as more widely in public arenas, despite it affecting more than 50% of the UK population. It's therefore timely that Healthwatch have taken a lead by publishing this important report.

The report sets out some stark findings about how a lack of awareness, a reluctance to discuss menopause openly and inconsistent access all affect the experience of women in Bristol. Areas of good practice are highlighted but sadly the report underlines how far we still have to go to improve healthcare advice and support for all – which is why it's so important that Healthwatch are giving menopause the high profile it deserves.

Anisa Patel, Engagement and Wellbeing Manager, North Bristol NHS Trust

The report is an excellent start in researching and understanding the experience of individuals accessing menopause support in the BNSSG area. It highlights some useful findings and the recommendations, in particular the introduction of a walk-in clinic, will be positive steps forward in delivering an improved menopause experience.

The report's findings give us a broad picture of numerous difficulties experienced by women accessing support from health professionals on the menopause and highlights the stark need for change in delivering improved services and medication. The report highlights the need for greater support in accessing menopause support particularly for ethnic minority communities and those groups who experience a significant degree of health inequality due their socio-economic group. More outreach support is required to engage and support these communities both in research and delivery of services.

The key question this report and its stakeholders need to answer is: how can we succeed in delivering the best for our society when we know that at least 50% of our society will be affected by this health issue in their lifetime, which is currently under supported and under resourced?

Monira Ahmed Chowdhury, Head of Equality, Diversity & Inclusion at North Bristol NHS Trust, Senior Responsible Officer for EDI at Bristol, North Somerset and South Gloucestershire ICB and Co-Chair of the Bristol Women's Commission Health Task Group

I note the Healthwatch report on menopause and its findings. I will endeavour to ensure that the report and its outcomes are linked appropriately to various initiatives relating to women's health, especially as employees within health and care.

Appendices

Appendices 1, 2, 3, 4 and 5 – surveys and their translations

Appendix 6 – Theory of Change

Appendix 7 – Equality Impact Assessment

Appendix 8 – reference list

To view or download the appendices for this report, please visit www.healthwatchbristol.co.uk/your-nhs-menopause-experience-may-2023

If you require this information in an alternative format, please email helen@healthwatchbnssg.co.uk.

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