

In partnership with

healthwatch
North East and North Cumbria



North East and
North Cumbria



Women's
health...



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Introduction

Women, making up 51% of the national population, live longer than men but spend more time in ill health and living with disabilities. There is not enough focus on women specific conditions or how conditions, that affect both men and women, impact on women differently.

In 2022, the UK Government published their first strategy focusing on women's health inequalities. The 10-year **'Women's Health Strategy for England'** set out commitments to improve the health and wellbeing of women and girls and deliver better health outcomes. The strategy aims to reduce gender-based health inequalities.

In our region, the North East and North Cumbria Integrated Care Board (NENC ICB) are committed to driving forward the Women's Health Strategy at pace and are turning their ambition for women's health into action – using the strength, collaboration, and energy to create an implementation programme to make the changes that will benefit local people and future generations. The NENC ICB believe that **"If we can make things better for girls and women, everyone benefits."** The NENC ICB's implementation programme builds on work already underway including recent investments in women's hubs and launching a regional health profile.

The implementation programme has seven key priorities:

- Menstrual Health & Gynaecological Conditions
- Fertility, Pregnancy, Pregnancy Loss & Postnatal Support
- Menopause
- Mental Health
- Cancers
- Health Impacts of Violence Against Women and Girls
- Healthy Ageing & Long-Term Conditions

It is crucial that the voices and experiences of women and girls are heard within plans and developments, with improvements that are co-produced.

During the ICB's second annual Women's Health Conference in July 2024, the 'Women's Health 'The Big Conversation' was launched in partnership with the North East and North Cumbria Healthwatch network.

'The Big Conversation' included an online survey which was shared across the North East and North Cumbria, and focus groups targeting specific groups of women who we identified as 'seldom heard' e.g. who have additional health inequalities or barriers to accessing health care. The information gathered has been analysed with key themes and recommendations included in this report.

This report will be shared with the NENC ICB and used to further inform the key priorities including future 'Big Conversations', what improvements are needed, and what other topics are of most importance to women. We would like to thank the North East and North Cumbria ICB for giving the Healthwatch network the opportunity to undertake this engagement.

The BIG Conversation survey findings

Headline findings

- 61% of women said they feel confident to speak with a healthcare professional about their women's health issues. However, many went on to say they aren't confident they will be heard or get the help they need.
- Women said they aren't listened to, they are dismissed and not taken seriously when seeking support from healthcare professionals.
- GPs have a critical role as the 'gatekeepers to support' for most women. We heard that many women are concerned that their GP does not listen to them, act on what they are told or doesn't have up to date knowledge about many women's health issues. Improving experiences in primary care will significantly improve confidence in women's health care.
- Women want the choice to have a female healthcare professional; this is a strong message from our general engagement but particularly important in our targeted work with underrepresented groups.
- The GP (75%) and NHS website (75%) were selected as the most common place to find information on women's health. Our session with underrepresented groups highlighted the need for targeted accessible communications and the importance of peers in their communities and community support organisations.
- It is important to women that their health records are easily accessible by healthcare professionals and kept up to date.
- Women would like more research into women's health concerns.
- Additional insight was provided which was specific to the cohort e.g. it was felt by the focus group of women with learning disabilities that there was a lack of knowledge around the impact of neurodivergence on women's health. Confidentiality was a concern for the focus group which included women who had experienced sexual assault.

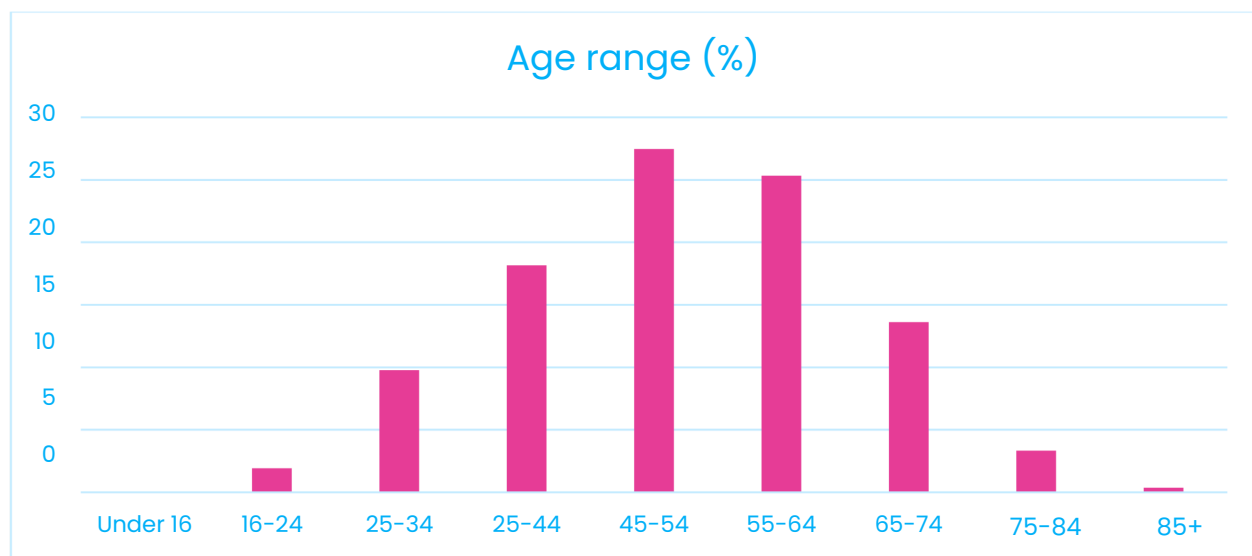
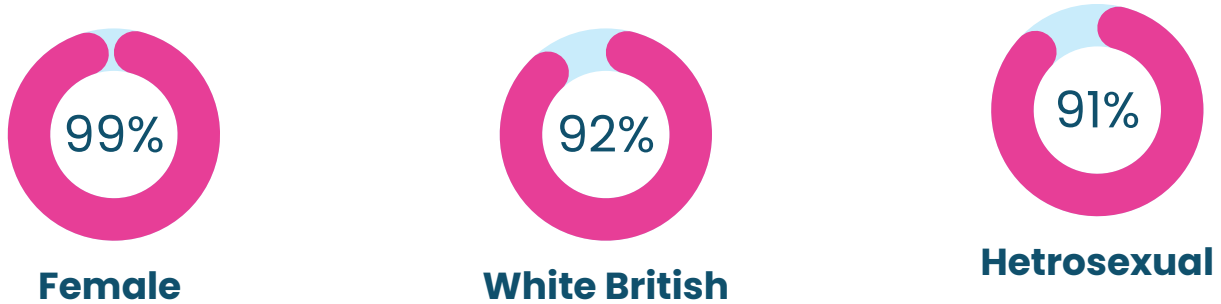
Overall, women told us their top 5 priorities in relation to women's health are:

- Mental health and wellbeing: Including depression, anxiety and eating disorders.
- Healthy ageing and long-term conditions: Including falls, heart disease, stroke, diabetes, dementia, bone, joint and muscle health, and bladder/urinary.
- Menopause, perimenopause and hormone replacement therapy (HRT).
- Screening services: Including cancer screenings for cervical, breast and bowel.
- Menstrual and gynaecological health.



Who we heard from

We had **4,497** responses to this survey. The breakdown of these results are:



A survey was distributed across the North East and North Cumbria between 11th July and 8th September 2024.

We received 4,553 responses; 56 were out of area, therefore analysis was carried out on 4,497 (see appendix for breakdown by region).

Only 2 people who are under 16 years old completed our survey, therefore their data has been removed from numerical data analysis to not skew the data.

6 focus groups were held across the region targeting specific groups of women who were identified as seldom heard:

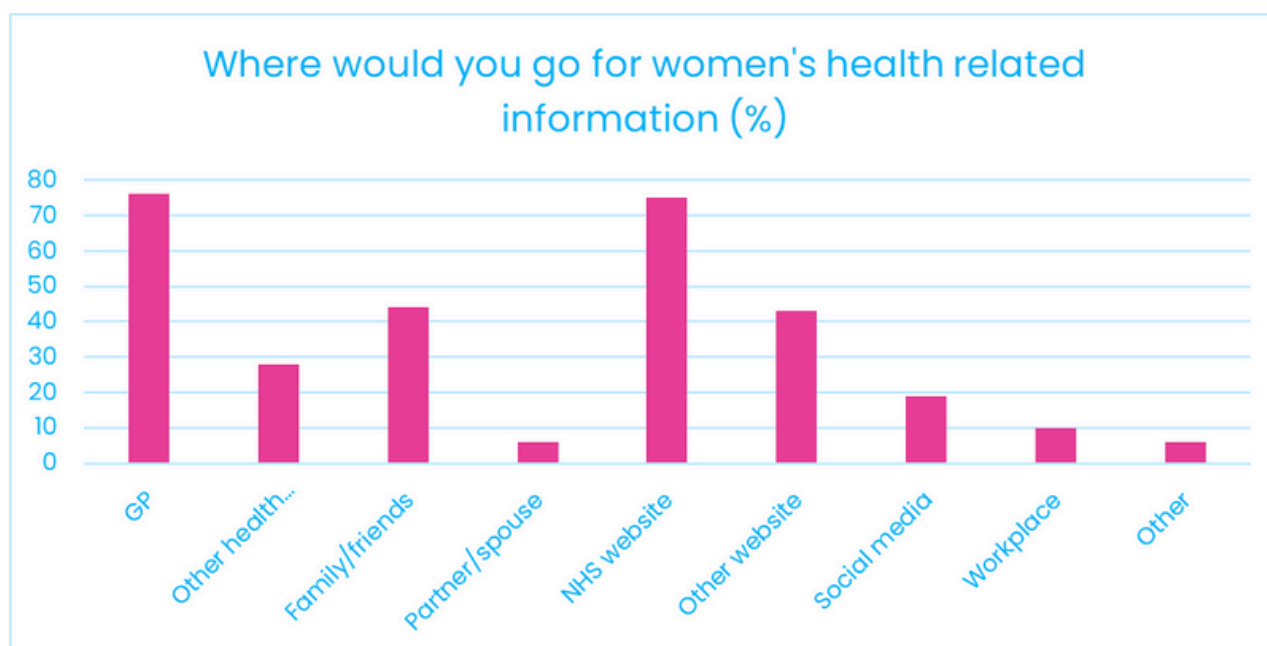
- Women who have experienced sexual abuse (Darlington)
- Women with learning disabilities (Cumberland)
- Women who are refugees and asylum seekers (Stockton)
- Women who are unpaid carers (Northumberland)
- Women from ethnic minorities (South Tyneside)
- Women with lived experience of maternal mental health issues (Westmorland and Furness).

Detailed survey findings

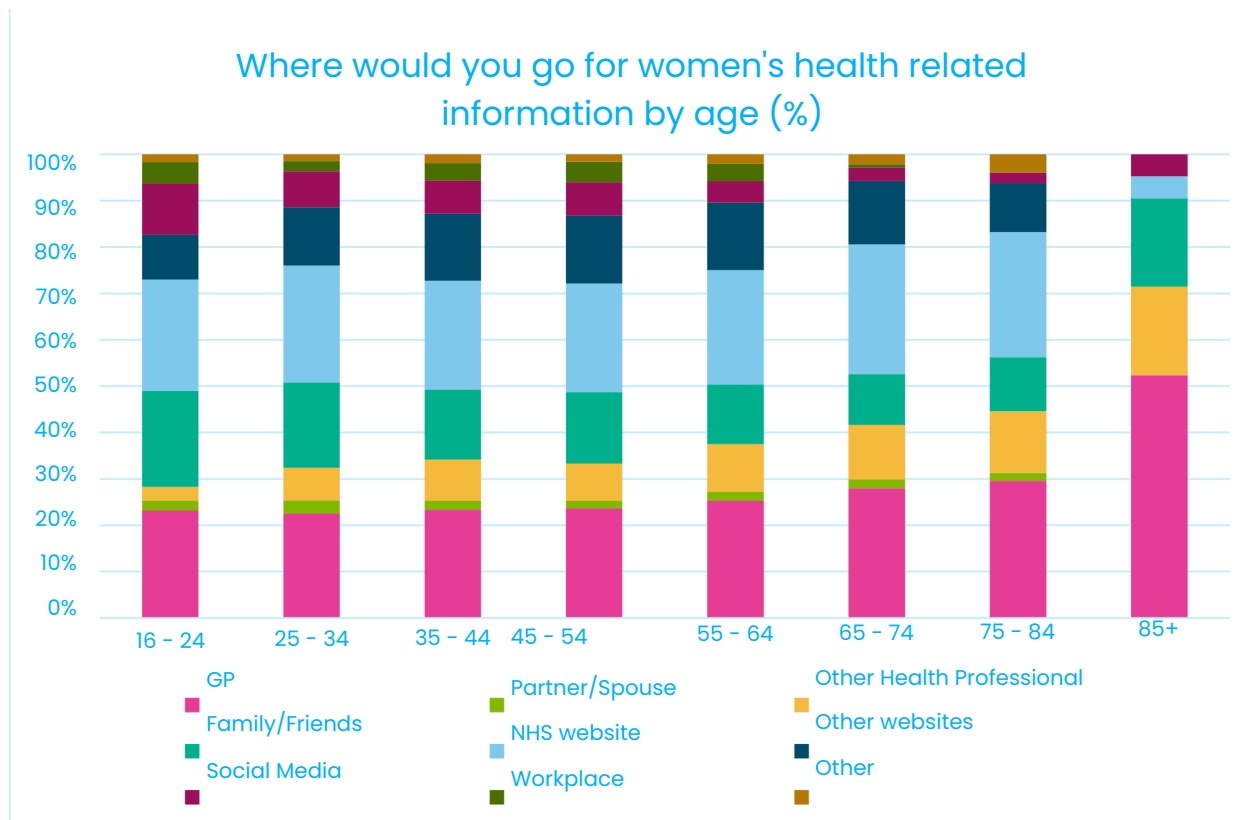
Where would you go for women's health related information?

We asked women where they would go for women's health related information, and we found GPs and the NHS Website were the most frequently used. Also mentioned was the internet, where people may research the issue before approaching a health professional. Specialist websites run by charities e.g. Diabetes UK or specialist clinics such as sexual health clinics or menopause clinics were also favoured to find specific health information.

We heard about people using the library and books for further information or research articles published around specific health conditions. Podcasts, apps, forums and specialists or celebrity experts by experience online along with help and advice from peers and other women were also mentioned.



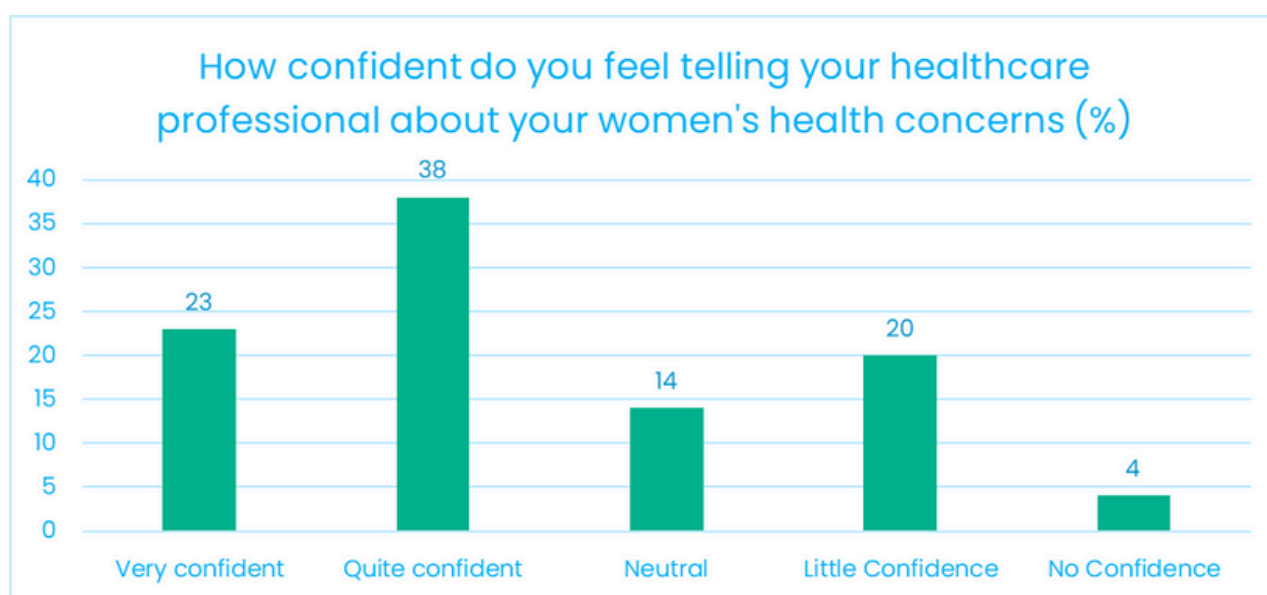
When we look at where people access information across the age ranges there are similarities; except for those over 85 years old where 50% would seek the GP for information compared to between 20-30% of other age ranges, younger generations are more likely to look to social media for information.



How confident do you feel telling healthcare professionals about your women's health concerns?

Out of **4,497** people we heard from, 197 (4%) had no confidence discussing their women's health concerns with a healthcare professional. 2,715 (61%) women said they were either very or quite confident. However, women went on to say that speaking to someone who listened to them and had the specialist knowledge about their issues was crucial – many women said their experiences did not meet this standard. Speaking to the right professional at the right time was crucial.

The consensus in the feedback suggests it is unusual for women to get the right help the first time and not the norm. Women told us they are concerned there is a lack of up-to-date knowledge in specific women's health conditions by professionals (particularly GPs), which, along with negative experiences in the past, put some people off bringing health worries or symptoms up again.



You told us...

"We have a GP with a special interest in menopause and other aspects of women's health, very lucky." **North Tyneside**

"I have often been dismissed – both with endometriosis and more recently with menopause. Being told that it's "just life". However, when you find the right person to help and they are compassionate and educated it makes a huge difference." **South Tyneside**

"It all depends on the practitioner and if they have actually taken any recent updates on women's health matters." **Northumberland**

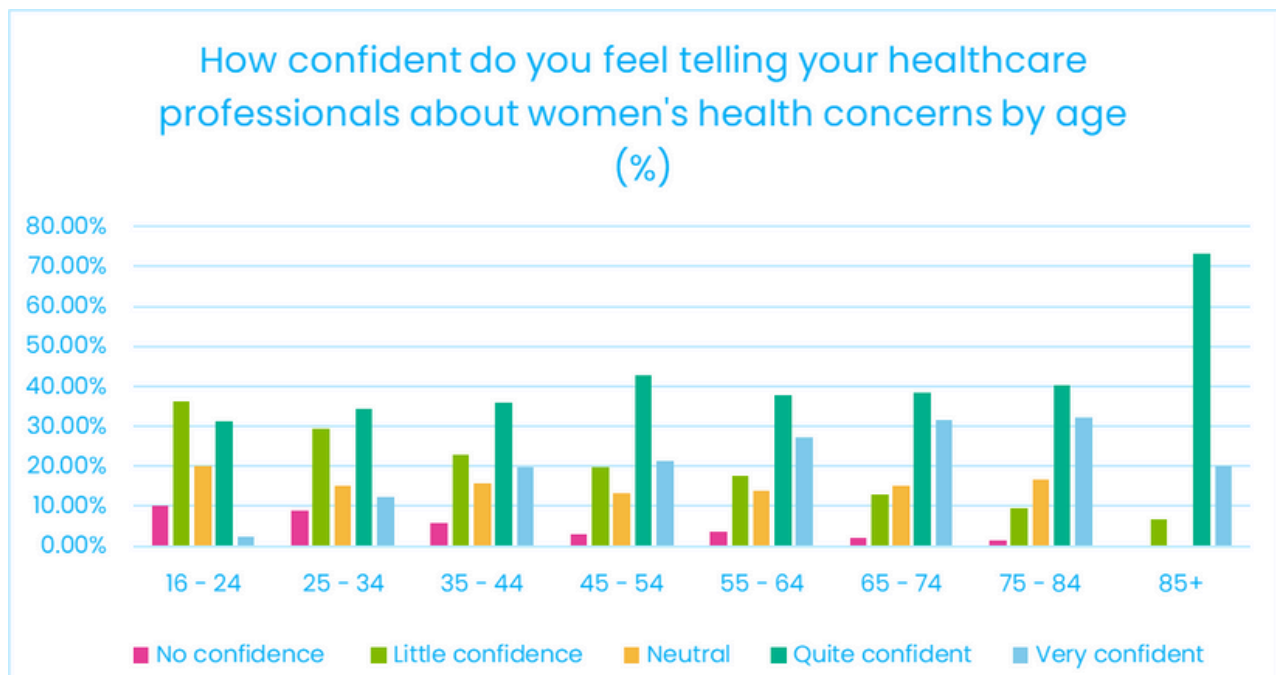
"I am confident in telling health professionals about health concerns – I am less confident that I will be listened to." **County Durham**

"I'm confident to tell them, I'm just frustrated by the lack of knowledge & understanding surrounding PCOS & sufferers are just left to deal with it on their own, as NHS & GPs don't appear to be trained in this area."

Northumberland

"I'm comfortable talking about issues with a health professional but feel like I'm not listened to and rushed out of the appointment with misinformation or the cheapest prescription available." **Newcastle**

When we look at how confident people felt by their age group, our survey responses suggest that as people age they gain more confidence in addressing their women's health issues.



61%

feel confident telling healthcare professionals about their women's health concerns.

Personal stories

If I am completely honest **I have pretty much stopped engaging with healthcare professionals** most of the time.

I feel very anxious about speaking with health professionals after many, many years of being dismissed or spoken down to, to the point where it is quite traumatic to attend a hospital or GP surgery. At this point in my life, every time I ask for healthcare advice or support the response has been to 'lose weight and it will improve' whatever the issue I raise (even when I had severe pain in my collar-bone!), apart from one time where I was getting ongoing pelvic and kidney pain and was told to 'take some paracetamol and drink more water' by a nurse (I received no further testing). I also experienced difficulties losing weight in comparison to what I eat and have a disability/condition that worsens with exercise - I have asked for support with this multiple times but it is swept to one side and I often feel 'blamed' for not being at a healthier weight by my consultant and GPs despite some medical staff admitting they don't really know what I can do within my particular circumstance.

I was diagnosed with an incurable (non- life threatening) condition a few years ago and despite all the diagnostic tests confirming this - my consultant still recorded this as 'suspected', he said he believed it was just because of my weight (??) and also took me off the medication to treat this condition.

A female consultant covering his patients saw me one day, immediately changed the wording on my notes to highlight the diagnosis was confirmed, ran further tests to discover my condition was worsening without treatment and put me back on the medication - this is just one story of many.

There are some very good health professionals out there but the damage from those who aren't as supportive has a significant impact on trust and confidence. **I come from a very deprived area which I believe is very much linked to how I am often treated or 'believed'.**

Newcastle

What is important to you when using women's healthcare services?

'To be listened to' The most common request from the people who completed our survey was to be listened to when discussing their health concerns with a healthcare professional. It was important that people felt they were being heard and understood but also provided with options and not made to feel belittled or embarrassed.

Women don't want to have to fight to be heard or have to make several appointments before someone listens to their needs. They want the time to discuss their symptoms and concerns fully without judgement. We heard how valuable empathy and compassion are when speaking about women's health to professionals as this leads to trust and open conversations.

Women wanted to be treated as an individual without assumptions being made about them.

You told us...

"Listened to.... it took 2 years to get my endometriosis diagnosed and then a further 6 months to get treated... initially I was made to feel like I was making it up or it was normal." **Hartlepool**

"To be listened to and not rushed through and ignored, or laughed at." **Darlington**

"Getting the information I need to make an informed decision, not using medical jargon and pushing me toward the use of medication if a simple life-style /dietary change can help. Feeling really listened to and supported, not just feeling like a number or a statistic."

Cumberland

"Being made to feel comfortable and welcomed; having time to get around to talking about the problem - difficult to just launch into something like pain during sex with a literal stranger within the first 2 minutes of meeting them. Being confident that I am not overheard by others is also important - a curtain or flimsy walls are not going to help me feel comfortable and open up." **Newcastle**

"That I am listened to and that medical professionals are trained in women's health. Too many say nothing is wrong and come back if symptoms persist- well I'm not going to come back because after 5 attempts it's clear no one will listen. You need to stop just using someone's age as a trigger for a test or disease and listen to their actual symptoms and how it's affecting their daily life. If you don't know what the answer is-tell me that and tell me you will seek help from another medical person." **Cumberland**

"I want to feel heard and understood and if there is something I am concerned about or confused by, I would like to be talked through different scenarios and not sent away thinking it's all in my head. I want to be given options or pointed in the direction of someone that CAN help. During my pregnancy I felt very let down by the Drs surgery. It was my first child and I was unaware of any of the process (I still am) I have now accepted that I have to suss everything out on my own, from health care checks for my child to her education level. I have had no support from any health visiting service or midwives throughout. It is important to me to have that voice there to guide you through pregnancy and the first years as they are the most crucial and I feel like we have been left to fend for ourselves, especially now I am a single mother. The health visitor identified that I was struggling with my mental health but never followed up with me after she discovered I was struggling." **Stockton**



‘To be taken seriously and not have concerns or symptoms minimised’

Many individuals spoke about the importance of being taken seriously by healthcare professionals and not being dismissed. Women felt like their weight or age or even the fact they are women was often used to excuse their symptoms or diminish the intensity.

We have heard about experiences of being dismissed for several years leading to detrimental consequences due to symptoms being overlooked or assumptions being made about individuals. Women told us they want to have open and honest conversations with healthcare professionals who understand they are the experts of their own bodies and therefore know when their symptoms change. They don't want to be in pain and would like an individual's pain thresholds to be respected during procedures, but also symptoms they are experiencing. Being looked at holistically was emphasised by many individuals as important.

Overall, people wanted to be believed when they spoke with healthcare professionals and not to be dismissed.

You told us...

I often feel dismissed by doctors as a “silly woman.” **Cumberland**

“That I am getting up to date, accurate and relevant information. That I am looked at holistically. That not every question starts with “when was your last period?” I want to be treated with kindness and understanding by experts who are interested in getting it right, not box ticking. Also I don't want assumptions to be made about me because of my age, weight, marital status, mental health profile or health profile.” **Sunderland**

“As a medical professional I am aware of the stigma and bias around women's health conditions with colleagues joking about various conditions and the women presenting with them. Often inferences are made about the mental health/mindset of the woman and physical aspect relatively disregarded (perhaps threads of female hysteria persist).” **Newcastle**

To be taken seriously and not dismissed. It took for me to become clinically anaemic before anyone believed I was experiencing heavy blood loss. Then after this I've been dismissed again because I am reluctant to take hormones as treatment. Please can someone fund some research into better treatments for women like me!" **County Durham**

"It is also really important that my pain or discomfort is not dismissed. I find having a speculum examination painful but have felt dismissed during my smear before and an inconvenience that I needed a smaller speculum. I appreciate a smaller speculum may make the smear-taker's job a little more tricky but if you want me to come back for my repeat smear, or be able to tolerate it all, it is important to do, and to not make me feel "wrong" for needing it." **Newcastle**

"[It's important] I have someone who listens to me, I know my body better than any medical professional. If I say it isn't right, I mean something is wrong with how I know my body works. If I have a problem it is not because I am female, nor is it my hormones, time of month or age. Everything a man is not asked at a health appointment." **South Tyneside**

"I went to my GP for years with gynae/abdominal pains and was brushed off – it's just part of being a woman, it's because you're overweight etc. I ended up in A&E with a perforated bowel and an abscess that was wrapped around both of my ovaries. I ended up with an emergency Hartmann's procedure and spent 3 days in ICU." **County Durham**

"I have suffered with my menstrual cycle since I was 17 (I am now 35) and have been told numerous times by doctors that nothing can be done unless I either fill my body full of chemicals and hormones or until after I have children (which I do not want). I need someone to listen and to understand my situation. I need someone who doesn't care if I'm married or what my partner thinks. These patriarchal ways should not determine what care I get. I need better treatment options that are catered to my symptoms and needs, instead of a tick list of options to try." **Newcastle**

'Stop quoting out of date information!'

Speaking with healthcare professionals with the correct knowledge of women's health and women's health concerns and symptoms was seen as an important priority for those people who completed our survey.

Women wanted to feel confident that the professional they were speaking to had up-to-date, evidence-based expertise in the issue and if they didn't, that women would be referred to the correct service. It was important for professionals to acknowledge gaps in their own expertise and recognise more research is required into women's health. Having the option of female healthcare professionals is seen as a key component to meeting women's needs when discussing their health.

Many women felt speaking with a female professional would reduce embarrassment and provide empathy, and female professionals would be more likely to understand the issue. Some people would prefer female only services and venues, others would like the choice. Although predominantly women wanted to be seen by other females, those who wanted the choice, felt whatever the gender, they wanted the professional to be trained and have up-to-date knowledge of women's health and women's health issues and concerns; their knowledge base was key to a successful interaction.

We heard of experiences where women felt medication was prescribed without thorough investigation or alternative options considered, especially anti-depressants with menopause symptoms or the coil/pill with menstruation.

You told us...

"The opportunity to be seen by another woman, or a man who has undergone training in women's issues specifically in order for them to respond with insight." **Newcastle**

"I also expect doctors to be properly trained on women's health, including menopause. It's taking the medical community far too long to realise women's bodies are different to men's. They behave differently, they react differently to drugs etc." **Redcar and Cleveland**

"Doctors and nurses need to be held to account to improve their own knowledge in the current science and support and medication available to women and girls. Provide pain relief and anaesthetic for procedures like colposcopy etc.

Provide HRT and know about various delivery methods and dosages including testosterone for women. To not prescribe anti-depressants to every woman and girl experiencing health issues related to their reproductive systems and most importantly LISTEN to patients who know their own bodies better than anyone else. Health professionals need to be well educated and open minded when dealing with women's health."

Cumberland

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That the staff have the competence, skills and non-judgemental attitude to listen to your concerns and help you navigate the healthcare system."

Newcastle

"Don't offer the pill or coil as a catch all solution to all problems related to periods, they are not suitable or desirable for all women." **South Tyneside**

"That the healthcare professionals are up to date with current guidelines and information, I am quite well read on the benefits of HRT and quite often know more than my GP. On a few occasions I have been given information contrary to the BMS & NICE guidelines which when I have challenged my GP, they have investigated further and found my information to be correct, this does not give me much confidence in my GP and so I feel I have to research everything myself so that I know what I require before approaching my GP."

Northumberland

‘Timeliness and convenience’

It is important that people can be seen promptly with short waiting times for referrals and specialists.

Location is crucial, especially across North East and North Cumbria where rurality can be an issue. Women highlighted the breast screening programme as being particularly challenging. The women in our survey felt convenient appointment times and locations are crucial, not necessarily 9 am – 5 pm, which for working women or those with caring responsibilities can be difficult to attend. Appointments should also be available on evenings and weekends to accommodate this. It was important to the people we heard from that they had confidentiality and privacy regarding their health.

Women also said it was important that conversations about health are in private rooms, where other patients or staff can’t overhear. Women didn’t want to discuss or have intimate examinations where the only privacy was a curtain around the area.

You told us...

“Being able to get an appointment. For example, I have been sent breast screening appointments that are in the middle of the day during the working week. I was told that if I couldn’t attend I couldn’t have an alternative appointment. Never managed to get a screening yet.” **Northumberland**

“Accessible! Why is it so easy to participate in the breast screening programme, yet you have to jump through hoops, only to fail to get an appointment for a pap smear at a GP surgery? I don’t need ‘reminder’ letters, I need an appointment.” **Cumberland**

'Access to clear, consistent and impactful information'

Women want clear pathways to know where to go for information and to be provided with choices on treatments and managing symptoms along with choosing a provider.

Preventing future health issues was important to the people we heard from. They felt information, screening and knowledgeable professionals from menstruation to menopause and beyond were vital in navigating women's health.

We heard that although preventative care and reminders to be screened were forthcoming, people were not always able to get an appointment.

You told us...

"Ease of access – close to home, preferably within my own practice. A health professional I already trust. Embedded in my general health not a separate service, unless I've been referred to them. Enough time in the initial appointment to fully explain and confidence that I'm being truly listened to and understood (not necessarily a language issue, more empathy). All appointments in a timely fashion, preferably within a month)." **County Durham**

"That a holistic approach is taken to my concerns and not just treat one aspect. I would be very keen for every woman, even everyone, to be able to have a full MOT with useful feedback and guidance and not it just being a tick box exercise. A service that looks at the lifetime and the impacts that any concerns now may have in the future." **Stockton**

"Being able to access care locally. Last breast screening I had to travel for several hours on a train and multiple buses." **Northumberland**

"Would like a one stop shop. Doesn't have to be at the GP surgery, would prefer Cottage/local hospital/Health Centre. Book an appointment, have blood, weight taken, screening programmes, menopause, contraception advice/clinic all in one place. So that the people working there have an interest in women's health and therefore offer better patient care. Also by having all the services together have a better basic knowledge of women's health." **Cumberland**

"Speed, efficiency, understanding, professionalism, respect, knowledge, confidentiality. Easy to understand information – both written and verbal. I am supported by professional, caring people. I can find information easily. I am treated with respect and understanding. I am treated as an individual (one size does not fit all) I am seen and supported quickly. I am kept informed at every stage. I feel heard and listened to." **Sunderland**

Personal stories

"That if I need healthcare services for women's health problems, they have the understanding to act and get to the bottom of the issue. For two years I've been complaining of heavy periods and wasn't taken seriously until I went to the doctors in a suit! I don't need to express how wrong this is! Initially I was being tested for perimenopause but the doctors ruled that out with no follow up. And the doctor literally shrugged at me when I said what am I meant to do then. To be wearing 5 size 6 nighttime pads a day and leaking regularly is not any way to live.

My heavy bleeding continued until I was wearing nappies and having clots the size of tennis balls. By this time it was a concern that I had endometrial cancer. Luckily I didn't and I just had a giant polyp. I'm still bleeding daily so I know there is something still wrong but I've been made to feel a pain that much that I'm reluctant to go see my GP or the sexual health nurse who also just fobbed me off as being hormonal. Like I could help being hormonal? I'd even been suicidal at the beginning.

It's been a difficult couple of years."

Westmorland and Furness

What matters in terms of health and wellbeing

We asked people what matters to them in terms of health and wellbeing; we found the following things made a difference:

- Accessing the right service at the right time.
- Seeing female healthcare professionals.
- Not necessarily needing to see a GP but would like a local service, a knowledgeable person or to know where to source the correct information.
- To be able to choose a female professional without being penalised with a long wait time.
- Able to discuss more than one issue at appointments.
- being seen as an individual and looked at holistically.
- The healthcare professional to understand the impact of any health concerns they had, but also to understand how everyday stresses such as work, caring responsibilities, children and work/life balance all can impact on an individual's health.
- Access to evening or weekend services so time off work wasn't needed.

Many women spoke about the importance of being 'healthy'.

This included a variety of factors such as eating well, exercising, sleeping, reducing stress, spending time with friends and family, and access to the outdoors and green spaces. Some mentioned being healthy to look after their children and/or family, or healthy to grow old whilst maintaining independence.

Some felt the important factors changed as they progressed with life, looking after their health for fertility when they were younger, managing hormones during menopause and keeping fit for good bone health and cognition in the later years.

You told us...

"Maintaining health as I enter middle age. Before this it was maintaining health for fertility and pregnancy." **Newcastle**

"Before menopause it was having easy access to family planning clinics as opposed to going to GP. Before 70 regular screening for breast and cervical cancers. After menopause access to HRT and bowel screening. As I age sufficient support for healthy ageing through appropriate medication and other services e.g. physiotherapy." **North Tyneside**

Being believed and not made to feel we're exaggerating, being dramatic, overly anxious or that our concerns are in our minds. Easy access to testing for things like Strep B in pregnancy, Perimenopause, Menopause etc Full range of information around all areas of women's health that can be accessed without seeing a GP. E.g. information on female cancers, diet/nutrition for different stages of life, perimenopause/menopause, PMS, pregnancy/loss etc. Reduced waiting time for counselling and other mental health services." **Westmorland and Furness**

It is important for women to access regular screening and preventative care. Women told us their family history isn't always taken into consideration and early screening or tests would help to reassure women. Certain age brackets were mentioned, women wanting to be screened after the age of 65 years.



Personal stories: What matters in terms of health and wellbeing

"More healthcare for periods and more investigations when these are heavy, irregular and unbalanced.

Support around hormonal cycles and if there is anything we can do to help this. Increased awareness of neurodiversity.

More awareness around mental health and referrals to counselling/ therapy. More education around language and body image appropriate things to say. Previous family experiences of eating difficulties and the doctor discussed exercising which was unhelpful for someone with bulimia.

Ensuring a non-judgemental approach in sexual health services and encouraging relationships with people to access these services more freely."

Sunderland

You told us...

"Fertility (I'm concerned about what I don't know) - I am not yet trying to have a child but would like to in the future. With no offer to have fertility tests/conversations unless actively trying to have a child means it is difficult to plan." **County Durham**

"Routine checks for bowel cancer, cervical cancer and mammography have been excellent in the last 10 years or so. Those tests provide touch points with health care services and give me confidence that I'm not missing diagnosis of significant health issues." **Cumberland**

"Continued screening for over 65's, I feel should be offered and those of that age shouldn't feel the NHS/GPs are doing their patients a favour" **Gateshead**

We heard women want to have strong mental health and know the impact physical health has on mental health and vice versa.

We heard experiences of women who felt they were struggling with hormonal changes being dismissed as mental health issues and conversely those with mental health issues being dismissed as hormonal.

You told us...

"Mental health is another aspect that is personally very important. I think there are still not enough services and getting appointments for therapy takes way too long. I think these services need to improve drastically as it directly impacts all other aspects of life also. My mental wellbeing has a great impact on my energy levels as well as other (more accepted) illnesses and conditions." **Gateshead**

"Reassurance, mental health issues taken seriously and not just deemed as hormonal." **Sunderland**

"Access to psychology services needs to be made more accessible, we as a society need to change the stigma of psychological support. Access to dentistry, gyms need to be free or a small fee. Again, accessible for everyone. It's well documented that if you walk and or talk to someone it is good for you." **Sunderland**

"Being happy, feeling physically fit and capable, low/no stress or pain or anxiety, being active enough to run around with my children, no brain fog so I can undertake my job" **North Tyneside**

You told us...

"My weight, and then everything else falls out of that. If I am in control of my eating habits and I am exercising then my mental health follows. I struggle with my mental health on occasion, linked to the menopause mainly and my low thyroid and when I am gaining weight I feel so very low. Controlling how much I drink, which I am conscious of. Checking my breasts regularly and moles etc. I would like to be able to access my GP more to check out my moles but it is difficult to get an appointment and I feel like I don't want to bother them. Access to green space is also important" **County Durham**

There was a focus on healthy eating, diet and exercise as important contributions to people's health and wellbeing.

"I'd like to see more promotion of healthy eating - I'd like healthy food to be more accessible and some real education on processed and ultra-processed foods. It is so easy for women to become overwhelmed with everyday life and not prioritise themselves. Work places are getting better at valuing health and wellbeing but I think there could still be more, the main responsibility for 'family' life still falls heavily on women and there is still a long way to go to improve this." **County Durham**

"Everything! But if I am thinking specifically currently then nutrition, exercise, sleep and menopause issues" **Redcar and Cleveland**

Personal stories: What matters in terms of health and wellbeing

"As a woman, my health and wellbeing priorities include:

1. Physical health: Access to quality medical care, healthy food, and exercise opportunities
2. Mental wellbeing: Support for stress management, anxiety, and mood balance
3. Self-care: Time for relaxation, hobbies, and personal growth
4. Nutrition and fitness: Wholesome eating and regular physical activity
5. Sleep and rest: Adequate restful sleep and power naps
6. Social connections: Nurturing relationships with loved ones and community
7. Emotional resilience: Coping skills and adaptability in the face of challenges
8. Personal growth: Opportunities for learning, creativity, and self-improvement
9. Body positivity: Self-acceptance and self-love, regardless of shape or size
10. Mindfulness and presence: Staying grounded in the present moment

These aspects of health and wellbeing are interconnected and essential for my overall quality of life."

"Healthy relationships with family and friends. Being safe out of the home, and inside it. Feeling healthy and able to be proactive about my health. Weight management, healthy interaction with food. Good non-judgemental support around unhealthy alcohol and drug use, gambling support when feeling vulnerable. Effective and timely clinical interactions when I'm unwell or worried about that.

Acknowledgement of the stresses of life that we face in 2024. Support to be working and contributing to public life. Support to be active and in natural space. Social engagement and support for wellbeing, happiness and fulfilment. Prevention of ill health"

Newcastle



Personal stories

"To be able to function and have a good quality of life, to have the support to keep myself healthy. **As a perimenopausal woman I am well aware of the treatments that should now be available to women to manage symptoms. They tell me at work all the time but I have no access to them.**

By December last year after 18 months trying, I had managed HRT and testosterone to achieve the balance I need to support my work life and marriage, with the support of my, then, named GP. However when that GP left the rural practice I was part of, the other two (female) GPs unilaterally declared they were no longer willing to prescribe me the testosterone I had been taking and would be reducing the level of oestrogen I was on (and had been taking for 18 months, prescribed by the practice, until then) as they didn't believe it was licensed for this use.

They advised me my only option was to go private or be referred to a secondary care specialist (I am still on the waiting list to see this specialist over 6 months later).

My wellbeing crashed. I began struggling again with fatigue, brain fog, depression, anxiety and suicidal thoughts and insomnia and other distressing symptoms. My ability to function at work (I am a psychotherapist in NHS Talking Therapies) and in my studies (trying to do a health based PhD) were significantly affected. Despite my referring them to up to date NE pharmacy commissioning guidance that my previous GP had followed, they refused to follow it. I even complained to the practice manager which did no good.

I have now been advised by my GP that I need to have my coil replaced as it will be no longer protect me but as this is for HRT reasons and not contraceptive reasons, they will also no longer do it at the practice and the local sexual health clinic will no longer do it.

I again, have to wait until I can see the specialist. Over the last 6 months my wellbeing has continued to plummet and there is absolutely nothing I can do to stop it without access to the medication that was helping me previously. I feel trapped, powerless and unheard. I cannot move practices as I am outside the catchment area of any other practice. I cannot afford to go private and could only do this once to secure the testosterone supply as I was not prepared to let my reduced sex drive impact on my marriage the way it had been.

I have friends in Cumbria who have lost marriages due to this, one becoming temporarily homeless in the process, one avoiding this only by borrowing money from her elderly parents to fund a deposit for a flat. This needs to change. I don't fully understand why the GP will not follow the guidance – the only rationale that they could give me is that one of them once had a patient who had a severe adverse reaction to testosterone – this patient was MALE!

I am not the only woman in Cumbria who is being treated this way. I know lots of other women whose GPs are not trained to offer best practice care in this area and some that are – it is still a postcode lottery and the nuances of the rural landscape mean that we can't just go down the road and register with a different GP."

Westmorland and Furness



What are your 5 top health priorities?

1

Mental Health and Wellbeing – Including depression and anxiety.

2

Healthy ageing and long term conditions – including falls, heart disease, stroke, diabetes, dementia, bone, joint and muscle health, and bladder/urinary.

3

Menopause, perimenopause and hormone replacement therapy (HRT).

4

Screening services – including cervical, breast, bowel – and cancers.

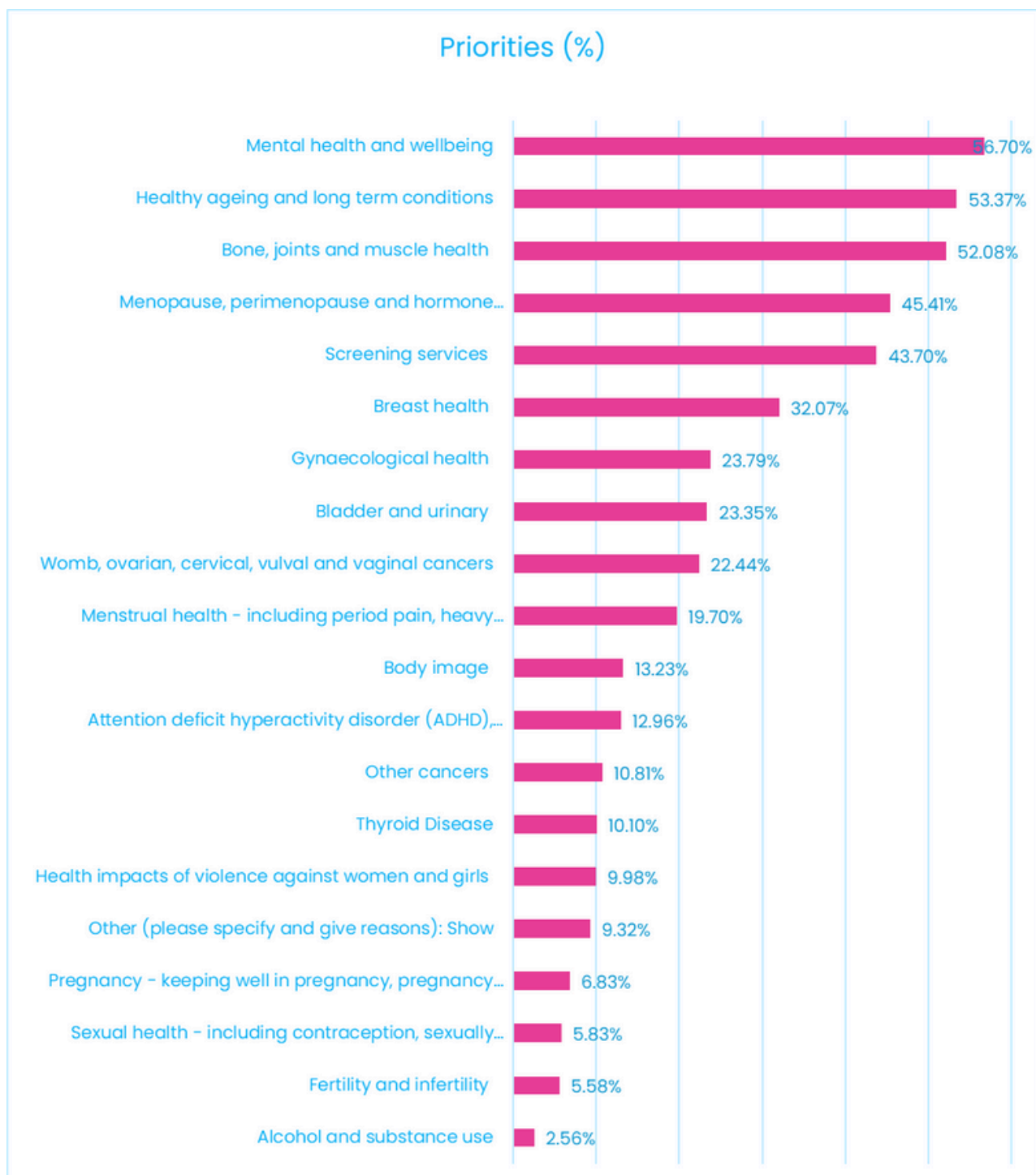
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Menstrual and gynaecological health.

We asked women to rate their top 5 health priorities from a list of 20 choices.

Mental health and wellbeing, health ageing and bones, joints and muscle health all received over 50% of the votes. Some women commented to tell us they felt all the priorities were important to them, or their priorities changed at different stages of their lives therefore it was difficult to only pick five.

Other health topics we heard were missing from the list were diet and nutrition and maintaining a healthy lifestyle through exercise, eye health and autoimmune disease.



Focus Groups

We held 6 focus groups across the North East and North Cumbria to understand in more depth the issues and priorities of communities we often don't hear from.

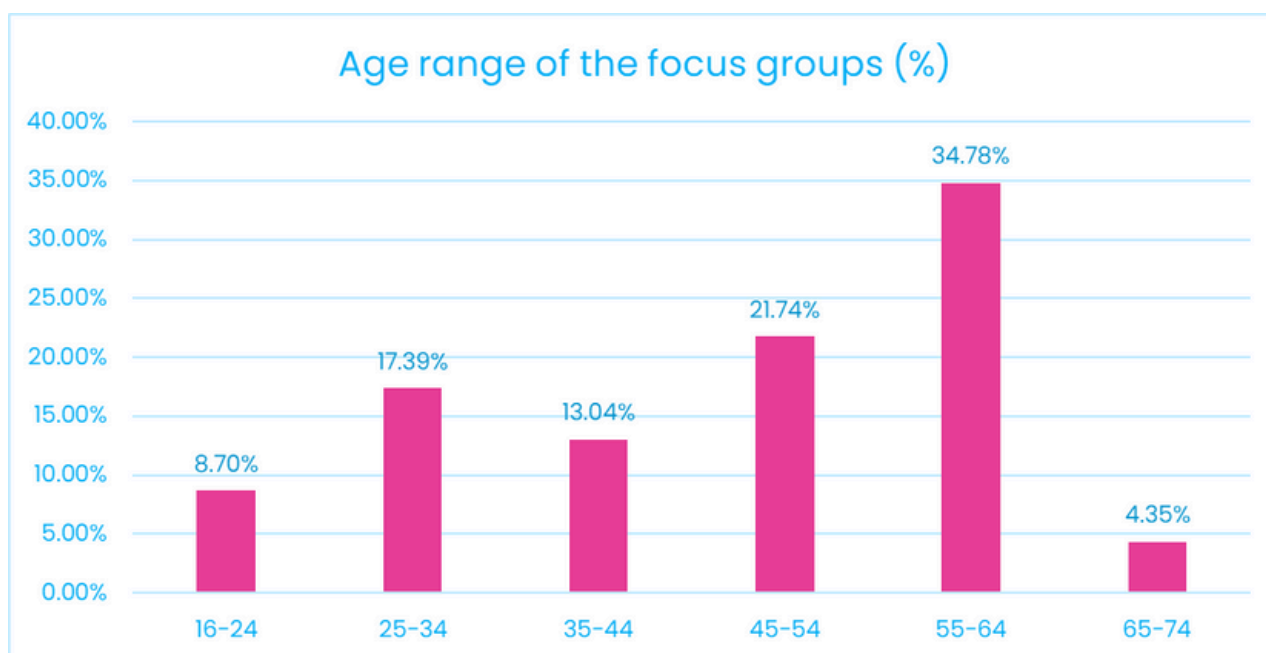
We spoke with 35 individuals from the following groups:

- Women who have experienced sexual abuse in Darlington*
- Women with learning disabilities in Cumberland
- Women who are refugees and asylum seekers in Stockton
- Women who are unpaid carers in Northumberland
- Women from ethnic minorities in South Tyneside
- Women with lived experience of maternal mental health issues in Westmorland and Furness

***Please note we were unable to speak directly to women who have experienced sexual abuse in Darlington. Therefore the information was gathered from staff feedback on their experiences of helping women in this category.**

We spoke with a range of age groups 16–74 years old, the ethnic minorities group were Bangladeshi, refugees and asylum seekers were from a range of places including Africa, Pakistan, Iraq, Ukraine, Vietnam and Syria; all other groups were white/British women.





We asked all our focus groups what ‘general health’ meant to them.

Across the groups ‘being healthy’ included strong mental and physical health. Sleep was mentioned as being important (asylum seekers, refugees and women who have experienced sexual abuse groups). Half the groups mentioned good health in terms of their relationship with services specific to their needs.

The women who had experienced sexual abuse felt access to sexual health services anonymously was important, whereas unpaid carers felt a relationship with their GP was important in maintaining good health, where the GP was aware of their priorities in caring for someone else.

Those with experience of maternal mental health wanted receptive support when it was needed.

“I hardly ever prioritise my health ... it’s always getting everyone else sorted first.” **Unpaid carer, Northumberland**

Where would you go to find general information about keeping healthy:

The table below details where women would go for general information by the focus group.

Focus group	GP	NHS professional	Internet	Community (church, groups etc)	Other
Refugees and asylum seekers	✓			✓	
Ethnic minorities group	✓		✓ (NHS website, Google, Tik-Tok)	✓ (local community group friends, peers within NHS)	
Learning disabilities group	✓		✓	✓	✓ (Church, current projects)
Experiences of maternal Mental health	✓	✓	✓ (Google, podcasts)		✓ (Doula)
Experience of sexual abuse		✓ (Clinic???)	✓ (Google, NHS website)		
Unpaid carers			✓ (NHS website, Google)		✓ (Leaflets)

The consensus across all groups was that they would look for information about keeping healthy online, either for general information, a starting point to then seek professional advice, or to enhance their knowledge after speaking with a healthcare professional.

Where would you go to find information about specific women's health issues:

It was important to our focus groups that they spoke with someone they trusted about a specific issue; quite often this would be friends/family with some medical knowledge or experience of this issue themselves.

Those with learning disabilities mentioned doctors and specialists were the experts with accurate advice and information. However, an unpaid carer paid a subscription to an IBS charity to speak with a nurse led helpline, but felt pessimistic if she brought this information to the GP that they would take the advice on board.

The table below shows where women would go to find information about a specific health issue:

Focus group	GP	Online	Specialist services/ charities	Peer support	Other
Refugees & Asylum seekers				✓ Peers	
Ethnic minorities group	✓	✓ (NHS website, Google, Tik-Tok)			✓ (Colleagues and friends who work in the NHS and peers)
Learning disabilities group	✓	✓	✓		✓ (Friends and family)
Experiences of maternal Mental health			✓ (Midwives and breastfeeding groups)	✓ Peers	
Experienced sexual abuse	✓	✓ (Google)	✓ (Social Worker)		
Unpaid Carers			✓	✓ Peers	✓ (Pharmacy)

We wanted to know about the barriers the focus groups faced when accessing healthcare services; the table below outlines what we heard.

Focus group	Barriers
Refugees and asylum seekers	• Language • Embarrassment • Confidentiality • Knowing where to go for help.
Ethnic minorities group	A male Doctor
Learning disabilities group	• Requiring accessibility arrangements • Stigma • Assumptions being made • Limited research of the impact of neurodivergence • on women's health • Access to prompt GP.
Experiences of maternal mental health	• Location, travelling costs • Being dismissed • Painful experiences i.e. coil fitted • Worry about serious health issues like cancer.
Experienced sexual abuse	• Lack of confidentiality • Busy waiting rooms • The healthcare professional has similarities to the perpetrator • Instruments used • Lack of information • Religion • Fear of being seen by someone they know.
Unpaid carers	• Triage GP system • Overuse system – ring for carer and self • Dismissed, not taken seriously • Seeing multiple professionals about the same issue • Unable to see female • Distance to travel • Cost to travel

We asked each of the focus groups about specific experiences of services; the tables below detail what they told us.

Visiting a GP	
Refugees & Asylum seekers	Housing and social care providers help with making and attending appointments, and no issues are experienced.
Ethnic Minorities group	Difficult to get an appointment and a long wait for an interpreter. No time is provided for a telephone appointment which makes it difficult to ensure an interpreter is on hand.
Learning Difficulties group	50% had a positive experience – supportive and easy to get an appointment; 50% had a negative experience – struggled to communicate the issue, and lacked support.
Experiences of maternal mental health	Find it easier to make future appointments but would prefer more face-to-face appointments. Telephone appointments need a solution for those people who miss the call, especially as not always given an accurate time frame of when to expect the call.
Experienced sexual abuse	Difficult to get an appointment. A fear of telling the receptionist and repeating history to the GP was made more difficult by the lack of continuity of GP care.
Unpaid Carers	Would like to feel listened to and sometimes feel like being a carer affects relationship with GP as more frequent contact and feel like a 'burden', or real health issues being put down to caring role.

Visiting a hospital (outpatients or inpatients)	
Refugees and asylum seekers	Transport is an issue, especially for appointments out of the area. Concern once they are no longer residents of the housing and social care provider about how they will get to appointments.
Ethnic minorities group	Male staff are a barrier – one lady refused a breast screening on this basis.
Learning difficulties group	Found it easy to get appointments, sometimes support is needed.

Visiting a hospital (outpatients or inpatients) Continued

Experiences of maternal mental health	One person waited 6 months for an appointment and when she arrived, the appointment had been cancelled but she had not received notification.
Experienced sexual abuse	Concerns over confined spaces with male medical professionals, especially if they are the same ethnicity as the perpetrator. Communication struggles and busy waiting areas cause barriers.
Unpaid Carers	Continuity of care is important

Visiting a pharmacy

Refugees & Asylum seekers	Only issue is a language barrier and understanding the instructions around how to take the medication.
Ethnic Minorities group	Long wait to collect prescriptions, useful when text to confirm repeat prescriptions are ready for collection.
Learning Difficulties group	50% had visited the pharmacy and had a positive experience, useful and private.
Experiences of maternal mental health	No mention.
Experienced sexual abuse	The consulting rooms are too small, opening times aren't suitable. Struggle with communication with the pharmacist.
Unpaid Carers	Highlighted as a useful source of help for specific health issues.

Visiting sexual health services

Refugees & Asylum seekers	Don't know where to find sexual health services.
Ethnic Minorities group	No one has used this service.
Learning Difficulties group	With support, one person was able to access the service.
Experiences of maternal mental health	One person found getting an appointment easy, but the procedure to have a coil replaced was extremely painful.
Experienced sexual abuse	Struggle to find local services. Concerns that their friends and/or family will find out about the sexual abuse/trauma. Embarrassment is a barrier.
Unpaid carers	Prefer an appointment with women. Distance to travel and cost of travel. Time away from caring responsibilities.

Visiting mental health services

Refugees & Asylum seekers	Would like to access support, but don't know where to go. Many feel they have a lot of anxiety and struggle with sleep.
Ethnic Minorities group	A lot of stigma around mental health especially with the older generations. There is a tendency to turn to religion. The language barrier is a problem and often an interpreter is not available, the form to request an interpreter is too difficult. Medication is too often handed out before looking at the wider issue.
Learning Difficulties group	Difficulties with communication and being taken seriously, not enough knowledge and training of neurodivergence.
Experiences of maternal mental health	Since being discharged, one person found it very easy to reconnect with the service.
Experienced sexual abuse	Would like to access mental health services, but difficulty getting through by telephone and when they do, the services available aren't suitable for someone who has experienced sexual abuse/trauma.

Future direction

The focus groups were asked to select their top 3 priorities from 7 preselected areas:

- Menstrual health and gynaecological health conditions
- Fertility, pregnancy, pregnancy loss and post-natal support Menopause
- Mental health and wellbeing
- Cancers
- The health impacts of violence against women and girls
- Healthy ageing and long-term conditions

All groups felt the 7 priorities were important, with some specifically highlighting their top three priorities:

1 Menstrual health and gynaecology

2 Mental health and wellbeing

3 Menopause

Sleep and dental care were mentioned as missing priorities, along with diabetes from the Ethnic Minority group where this community are at high risk.

Improvements

The women from the asylum seekers and refugees focus group felt awareness of services could be improved, particularly for those who aren't familiar with how to access services. The location of services was important, specifically where there is a reliance on public transport. The views of the ethnic minorities focus group were around language and ensuring it can be understood along with an interpreter where necessary.

Women also wanted to be able to request a female health professional.

Awareness of learning disabilities and women's health was raised as an area to be improved by the learning disabilities focus group, along with improving how internal examinations are conducted to be sensitive to pain and anxiety around the examination. They would also like to see an improvement to waiting lists and waiting times to access services.



The maternal mental health focus group agreed with the learning disability group that more awareness and education were needed about women's health in general. It was also felt better knowledge of services and resources from health professionals could be improved. They felt one resource which all services and families could access would be beneficial.

"If you were listened to at that initial stage you might save an awful lot of money for the NHS in the long run" **Unpaid carer, Northumberland**

We asked the focus groups if they could tell us how services could best meet their needs when sharing health information, for support and advice, health programmes and initiatives and healthcare professionals themselves. The table below outlines what they told us:

Focus group	Sharing health information	Support and advice	Healthcare professionals	Health programmes and initiatives
Asylum seekers and refugees	Available in other languages and accuracy of interpretation.	Utilise community settings.	Females and more access to female interpreters.	Female only swimming/ exercise classes.
Ethnic minorities group	Workshops for specific conditions, i.e. diabetes. Health checks in local settings.	More education; diabetes, cervical screening.	Increase understanding of women's issues, listen, female.	
Experienced sexual abuse	Texts, radio and TV advertisements, anything which isn't directly aimed at the demographic.	More specialist services such as rape and sexual assault charities.	Minimise fear, person-centred, increase awareness of services.	
Learning disabilities group	Use social media, advertising, and workshops around all health. Less jargon.	Easy read, peer support and health professionals who specialise in an area, i.e. menopause.	Consistent staff to build rapport. Understanding and knowledge about reducing assumptions and contradictions.	Holistic approach, women's health campaigns and festivals, peer support groups/ workshops. Mentors who can understand the individual's needs.

Conclusion

The Big Conversation... Women's Health heard from over **4,500 women** from across the North East and North Cumbria about their health priorities and their experiences of interacting with healthcare professionals and obtaining the help they needed. The large response to the survey highlights the need for women across the region to be heard.

The North East and North Cumbria ICB are keen for the voices and experiences of local women to further shape their current Women's Health workstreams which include:

- Menstrual health & gynaecological conditions
- Fertility, pregnancy, pregnancy loss and postnatal support
- Menopause
- Mental Health
- Cancers
- Health impacts of violence against women and girls
- Healthy Ageing & Long-Term Conditions

Therefore, the Big Conversation asked women what their top health priorities are. The **overall top 5 priorities** and those selected by the survey respondents were:

1. Mental health and well-being: Including depression, anxiety and eating disorders. (ICB work stream)
2. Healthy ageing and long-term conditions: Including falls, heart disease, stroke, diabetes, dementia, bone, joint and muscle health, and bladder/urinary. (ICB work stream)
3. Menopause, perimenopause and hormone replacement therapy - HRT (ICB work streams)
4. Screening services: Including cancer screenings for cervical, breast and bowel. (Could map across to ICB work stream).
5. Menstrual and gynaecological health. (ICB work stream)

Due to the high number of survey respondents, the priorities selected by the focus group attendees did not impact the overall priorities identified. It is noted that all of the priorities identified, with the exception of screening services, map to ICB workstreams. Screening services could be integrated in considerations across other work streams.

What mattered to women?

It mattered to women that they were healthy overall and could live fit and pain-free lives, with access to information and guidance on healthy eating and exercise. They emphasised their needs change across their lifespan and wanted it to be acknowledged by healthcare professionals. They wanted proactive advice around their life changes.

Women want prevention and screening services to be at the forefront of care, along with information so informed choices can be made to ensure they stay healthy.

What women want from women's health services:

Women want to be listened to and be taken seriously. Although they were generally confident to discuss their health concerns with a healthcare professional, they were not confident they would be taken seriously and get the help they needed. The overwhelming finding of the report was that women were too often dismissed, not heard or misunderstood when seeking help. This was apparent across the wider community through the survey and under-represented populations within our focus groups, regardless of age, ethnicity, religion or background. It also spanned across service providers within primary and secondary care.

The healthcare professionals talking to women have the most up to date knowledge on women's health issues. Women want healthcare professionals to understand they are individuals and would like a holistic approach to their care.

It is important that assumptions aren't made, and healthcare professionals see the value in women knowing their own bodies and symptoms. Women feel there is too much emphasis on women's age, weight, mental health or menstruation and they are often used as an excuse or reason for the symptoms. Women feel there is a lack of recent and relevant research into generic health conditions, particularly the specific impact medication, treatment and interventions have on women. It is crucial that research is updated and is wholly focussed on women. The latest research should be circulated to ensure healthcare professionals are provided with current and accurate information.

Women have the choice to see a female health professional. Women want to speak with a healthcare professional who recognises the issues they are facing. Many feel a female professional can offer the empathy, compassion and understanding they need. Women would like to have the choice to request a female healthcare professional, without this causing a delay to their appointment.

Appointments are available at different times, including outside standard working hours and in convenient locations. We heard women struggled to get the care and support required, often needing several appointments before they were taken seriously. Unfortunately, some women stopped trying to get the help they needed or lost confidence before anyone could assist them. Being seen promptly, with short waiting times is important, along with local services being available in the community to be accessed by all. Information about women's health issues is kept up to date, available online, in paper and in a range of different formats to meet individual communications needs – BSL, easy read, community languages etc.

Ensuring all services and information are accessible and where needed in a language suitable for women is essential. Specifically, from the focus groups there was a concern of stigma around seeking help and worry they would be dismissed. The focus groups also mentioned further issues with access, particularly language barriers and additional support to attend services. The focus groups would like to raise awareness of the women's health issues they face, but also of services available to help and assist them. They believe information should be provided in a format that can be easily understood by all.

Women have access to their health records and a clear understanding of the pathways of care they are accessing and what the next step for them is. We heard women want a holistic approach to their healthcare with services communicating effectively with each other. Women want to know how and when to access services, but to have the knowledge across the lifespan. They want clear guidance on where to seek advice when needed.

Excellent service through primary care as standard. The results from both the survey and focus groups concluded that women look to the GP and online for information about women's health issues, and for specific women's health concerns they seek out the GP and specialist services and charities. There is a strong emphasis on primary care to meet the needs of women first time.

The findings of the report highlight specific areas of improvement for women across the region, and whilst they mention specific conditions, the issues raised are pertinent to all women's health conditions. The following recommendations have been identified to reflect this.

Recommendations

The findings of our report are based on the feedback we received from the online survey and focus groups and developed in line with NENC ICB's Women's Health 7 key workstreams and the top 5 priorities from the survey.

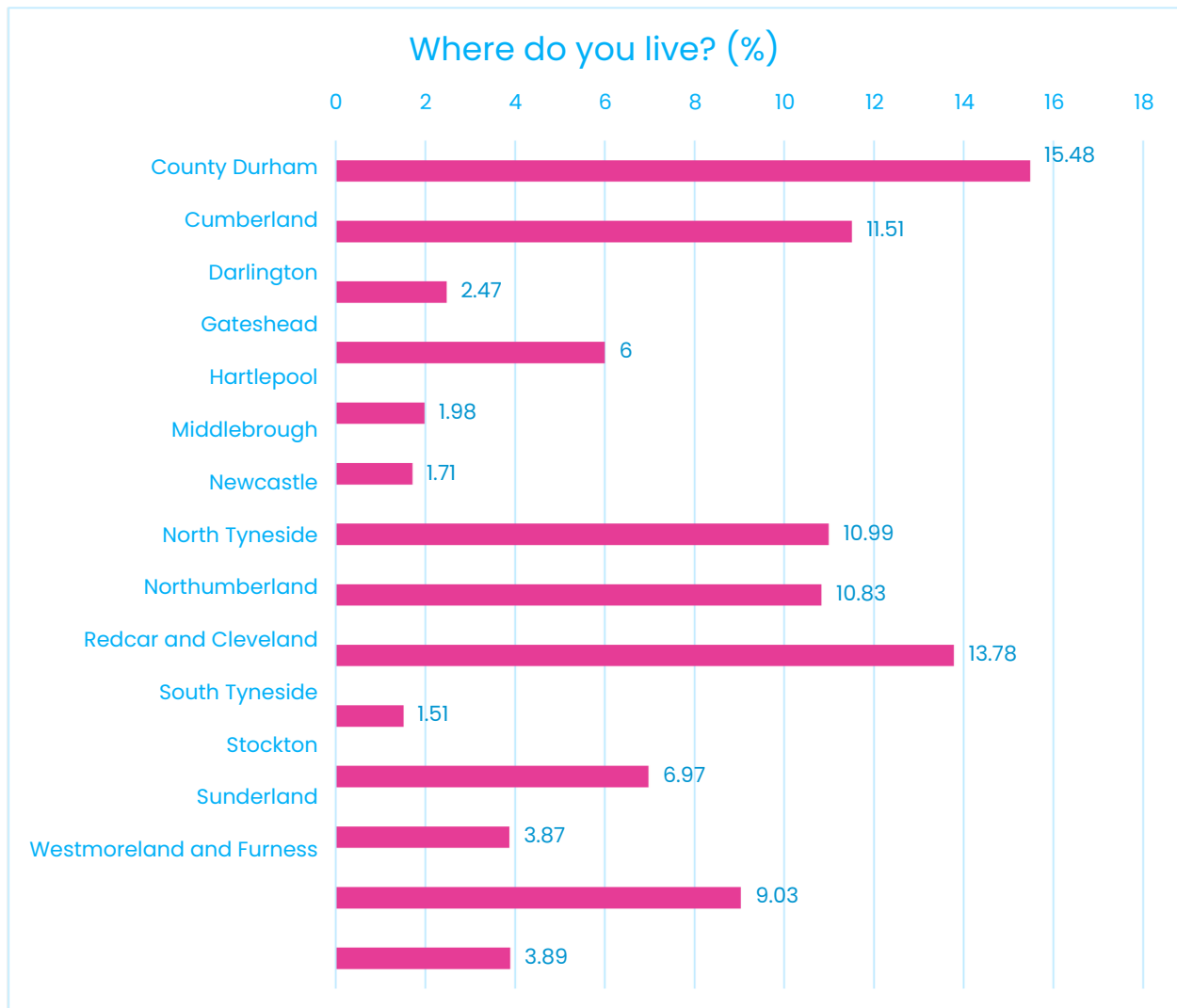
- 1.** Ensure the NHS constitution is at the forefront of all patient care, irrelevant of gender. Specifically putting the patient at the heart of everything the NHS does and it's values of respect, dignity and compassion.
- 2.** Co-produce a 'Women's Promise' which details the level of care and support women can expect in the North East and North Cumbria, specifying that healthcare professionals will be conscious of the need to show women that they are being listened to and their concerns taken seriously.
- 3.** Create a directory of women's specific health services across the North East and North Cumbria, including Women's Hubs, and promote locally to raise awareness and encourage use.
- 4.** Ensure women are aware of their rights, including to request:
 - To see a female healthcare professional if preferred
 - A second opinion
 - To have a chaperone
 - To escalate their concerns
- 5.** Develop a Women's Health Training matrix which includes the desired levels of training for all healthcare roles. Training must be continuous to ensure knowledge and understanding among all health professionals reflects the latest research.
- 6.** Ensure the Women's Health Training matrix is included in contracts and future contract monitoring, particularly in primary care (GP practices).
- 7.** Introduce women's health 'MOTs' across the lifespan to provide regular health-checks, screening and a space for women to raise concerns.
- 8.** Increase the capacity to offer women's healthcare services particularly in remote and rural areas to ensure more equitable and local access.
- 9.** Offer flexible appointment times at evenings and weekends to maximise accessibility recognising the additional access requirements women may need e.g. due to caring responsibilities.
- 10.** Ensure published (physical and digital) information on women's health is easily accessible, and available in a range of formats including easy read, British Sign Language, and relevant non-English languages.

11. Prioritise medical research on women's health to close the national 'health gap' and create a more equitable healthcare system for all.

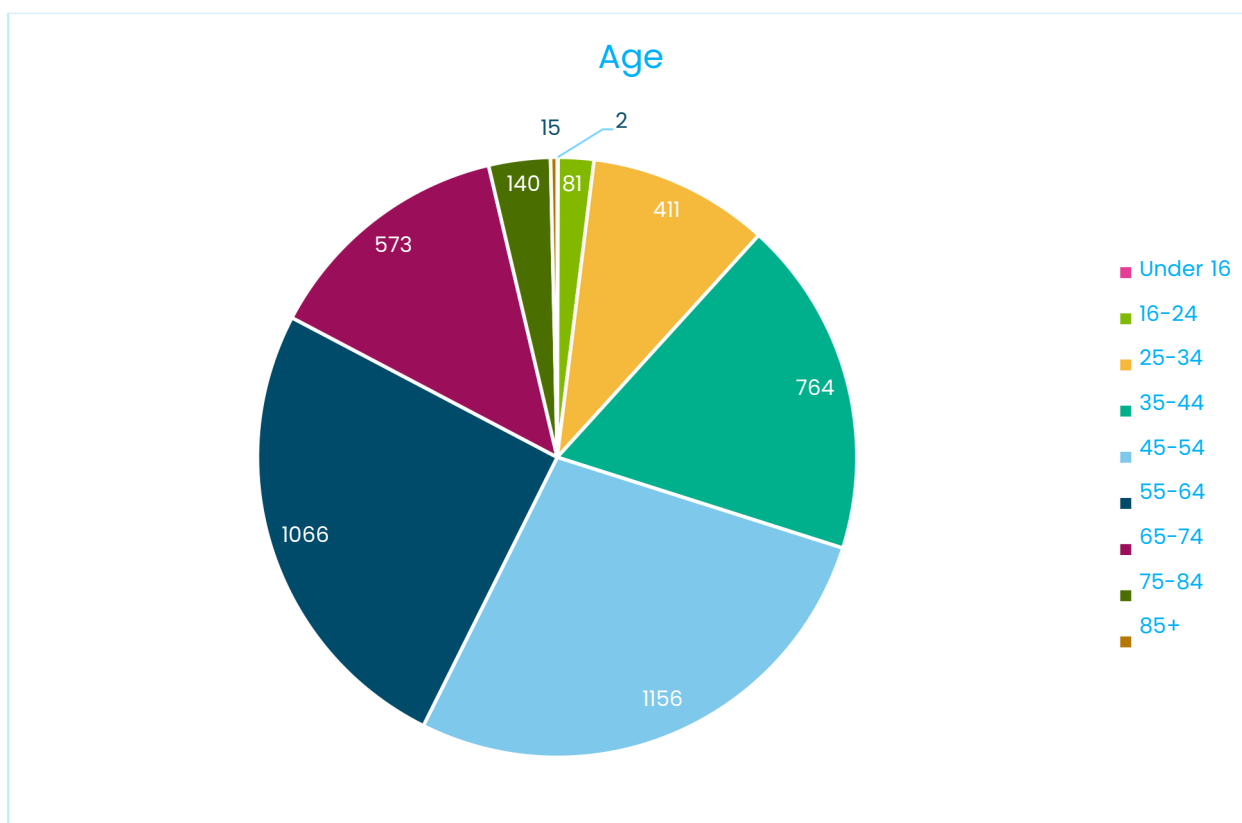
12. Conduct further research and engagement on women's health, including the priority areas identified by The BIG Conversation – particularly those areas not currently selected as an ICB work stream (Healthy ageing and long-term conditions and Bones, joints and muscle health).

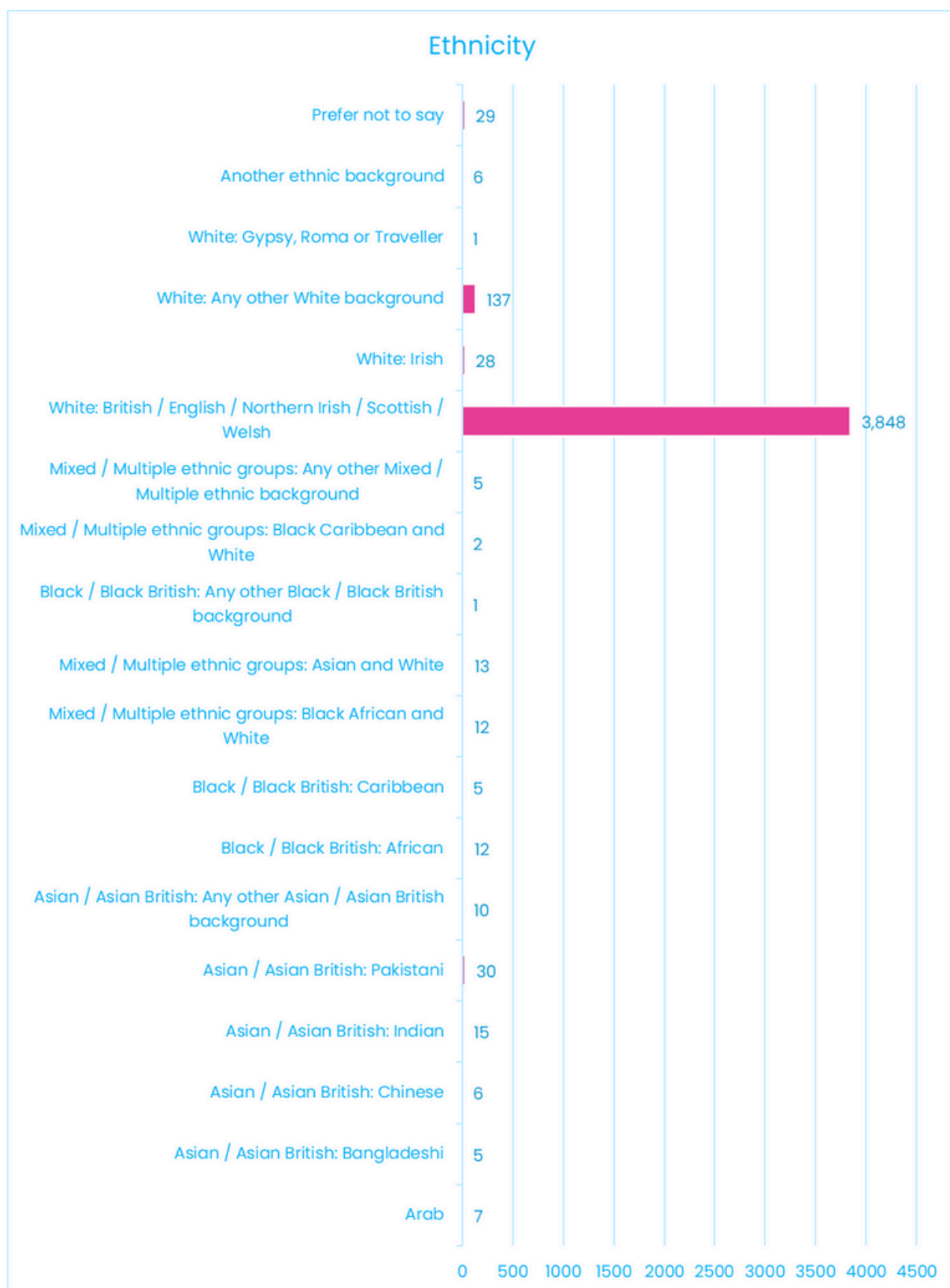
Appendix

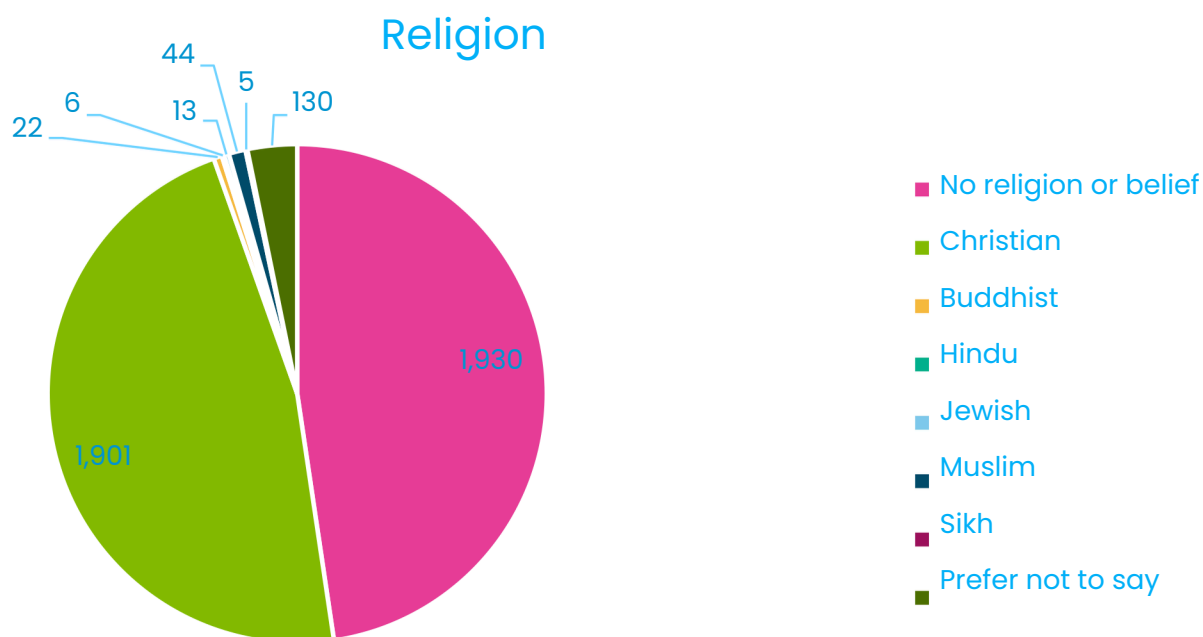
Demographics survey responses



What is your gender?		Is the gender you identify with the same as your sex registered at birth?	
Female	99%	Yes	98.74%
Male	0.26%	No	0.43%
Non binary	0.36%	Prefer not to say	0.83%
Prefer not to say	0.38%		



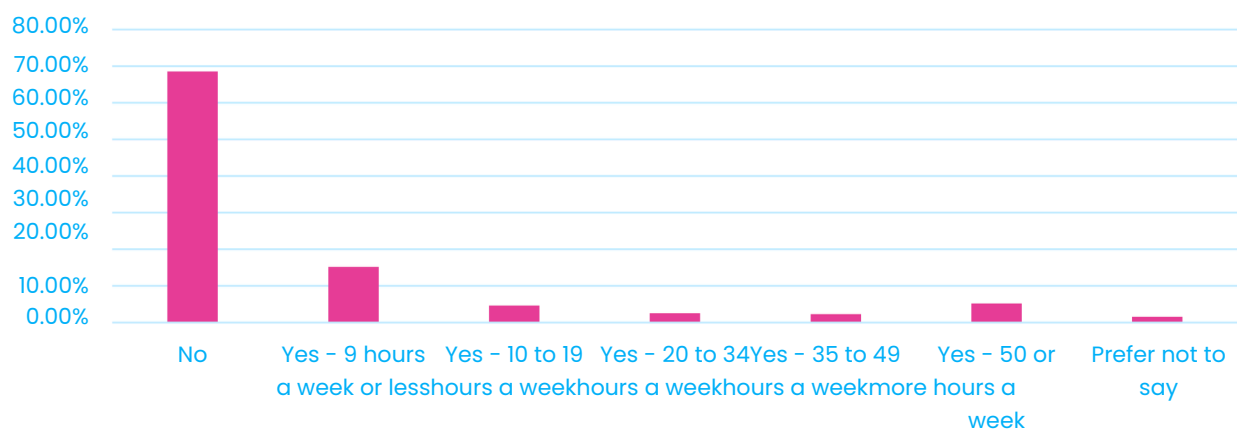




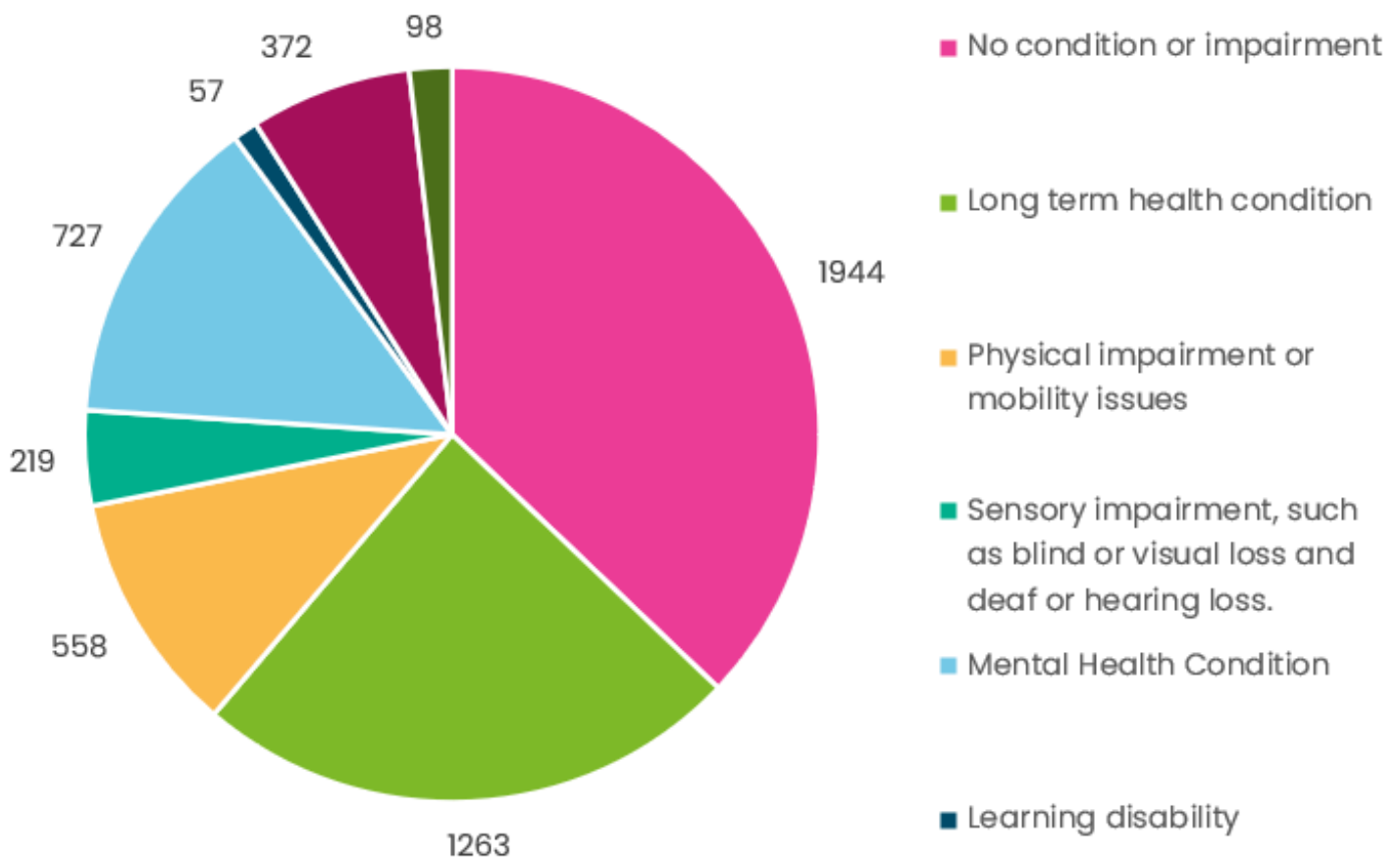
What is your sexual orientation?

Straight or heterosexual	91.16%
Gay or lesbian	2.06%
Bi or bisexual	3.63%
Prefer not to say	3.15%

Are you a carer?



Conditions or impairment



Are you pregnant or have you been in the past 6 months?

Yes	1.81%
No	95.76%
Prefer not to say	0.34%
Not applicable	2.10%

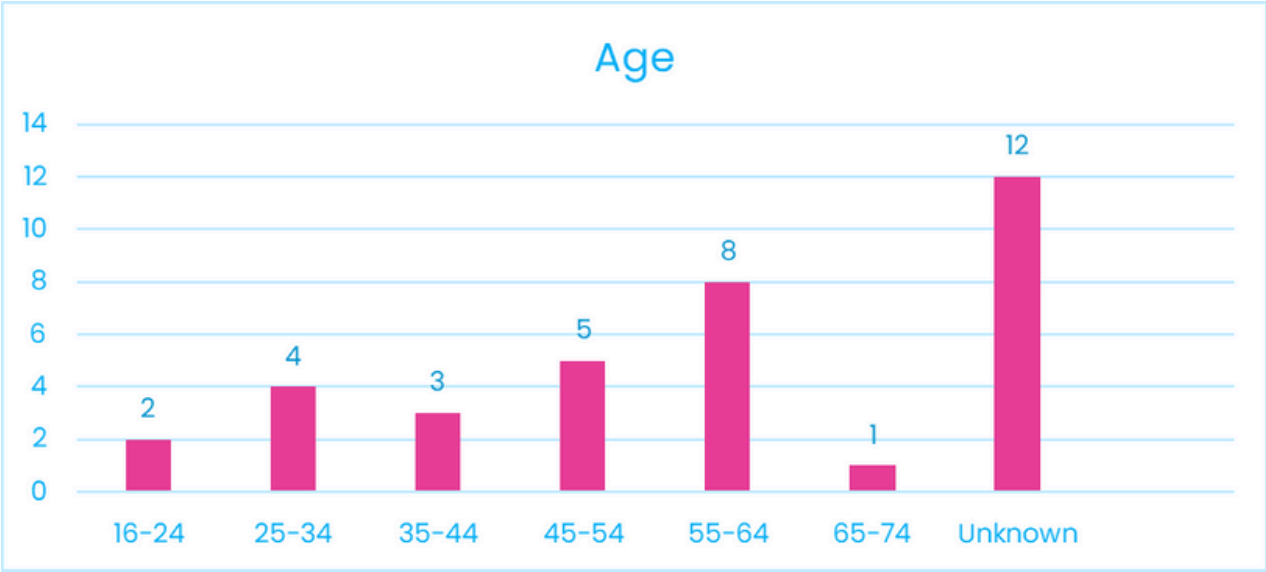
Are you a parent or a legal guardian for any children aged under 16 living in your home?

Yes	26.10%
No	73.90%

Do you serve, or have you previously served in the UK armed forces?

Yes, I serve in the regular armed forces	0.92%
Yes, I serve in reserve armed forces	0.48%
No	98.24%
Prefer not to say	0.36%

Demographics: Focus groups





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