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Citation:

Thomas, C and Warwick-Booth, L (2019) The State of Women's Health in Leeds: Women's Voices Final Report. Project Report. Leeds Beckett University.

Link to Leeds Beckett Repository record:

<https://eprints.leedsbeckett.ac.uk/id/eprint/5693/>

Document Version:

Monograph (Published Version)

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# **The State of Women's Health in Leeds: Women's Voices Final Report**

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**February 2019**

## Key messages

- The social determinants of health are reflected strongly within women's voices when discussing their health needs. For example, women's caring responsibilities, experiences of domestic violence and the wider environment associated with food availability were all articulated within our focus group discussions.
- Women report high expectations associated with their gender in relation to them successfully carrying out the responsibilities seen by society as predominantly belonging to women, which serve to influence their health and wellbeing.
- Lesbian, Gay, Bisexual and Trans women cannot be identified as one single group, nor should they be categorised along with Gay and Trans men. Service provision needs to reflect this and pay attention to gender fluidity and non-binary individuals.
- The intersectionality of women's experiences requires recognition. For example, the experiences of being both black and female can have combined consequences.
- Women want their skills and experience to be recognised and considered in the development of their health care. Therefore, a strengths-based approach to working with women is ideal.
- Women reported a range of issues in relation to gender-specific health needs. Women's bodies are still considered a taboo in relation to their reproductive system (menstrual cycles, menopause, hormonal changes and the associated impact of those). Women feel that their bodies are stigmatised in relation to reproductive health, and that there is a lack of education in this area for all.
- Women reported not being treated holistically when accessing health care. Better communication and being treated as human (with respect) were important areas for improvement from the women's point of view.
- There are still many barriers for women to improve and maintain their health and wellbeing. Systems are difficult to access and navigate and there are particular challenges for marginalised groups of women including LGBT+, those with disabilities, BME groups, sex workers and older women.

## **Take-away actions**

### **Communication**

- Correspondence needs to be available in different languages and formats. Furthermore, if someone has information about communication needs on their file this should be considered when sending them correspondence.
- More targeted campaigns and awareness raising are needed.
- Ensure language, policies and paperwork are inclusive and sensitive.
- Improve communication between service providers.
- Broaden traditional language, concepts and labels to ensure that they are more inclusive of the diversity of women e.g. their age, sexuality.

### **Access**

- Reduce waiting list times
- Reduce the cost of public transport
- Provide more advocacy support

### **Services**

- Recognise the diversity of women (and communities) and ensure that provision reflects this.
- Use a person-centred approach across services that considers the needs of women holistically.
- Listen to women – use their expertise (experiences and skills) to inform the service that they receive.
- Recognise diversity within the LGBT+ community and offer characteristic specific support rather than assuming that all have the same needs.
- Include LGBT+ perspective in sex education.
- Reduce the emphasis on co-morbidities in order to access some services e.g. Gender Identity Clinic
- Ensure services are culturally and gendered informed.
- Consider the needs of marginalised groups to inform and improve services.

### **Screening**

- Increasing/reducing the maximum/minimum age limit for screening tests.

### **Training required within services**

- Mandatory training around LGBT+ (needs, language/terminology) is needed. This was suggested as being particularly important for reception staff as they are key to making women feel safe.
- Advocacy training for women (particularly carers) is needed.
- Mandatory training for healthcare staff on working with marginalised communities is important.
- Training for medical students around different gendered needs is important.

## **Issues**

### **Physical activity**

- Make physical activity more inclusive.
- Make green spaces more accessible (dogs on leads, better lighting).

### **Menopause**

- Increase public service provision and raise awareness of support that is available. Furthermore, develop a specific menopause service which includes peer support.
- A Public Health campaign is needed to raise awareness and reduce stigma.
- Use a holistic approach which considers the mental, physical and emotional health impacts of the menopause within service provision.

### **Food/Diet**

- Reduce the number of licenses given to take-aways and suppliers of cheap, processed food.
- General campaigns and awareness raising about the effects of poor diet and nutrition is needed

### **Cancer**

- Improve education about the signs and symptoms of cancers – replicate the NHS campaign on Bowel Cancer in more areas.

## **Research areas for longer term consideration**

- Carry out research into why there is a higher prevalence of cancer within BME communities
- Conduct research into the menopause so that more local data is available and appropriate medication/support can be developed.
- Further work need to consider the needs of the LGBT+ female community.

## Key Findings

### 1. Needs and priorities

#### 1.1 The need to be listened to

The women who participated in our focus group discussions reported that they felt assumptions about what women wanted (and those of specific communities e.g. BME) were commonly experienced. Therefore, there was a need to ask women themselves:

*“Not enough people from BME communities give their views and this is why things don’t change”*

*“Listening to women and what they have to say first and foremost”*

Photo 1 – BME Focus Group Discussion – 11<sup>th</sup> July 2018



#### 1.2 Health screening

Screening was discussed as an area that needed further promotion, for example there needs to be an increase in the uptake of health screening (specifically discussed in BME group, with reference to BME communities). Women who participated also suggested that raising awareness of health screening from a young age was important, for example during PHSE lessons in school). Women also queried current age-related approaches to existing provision, for example asking why there are specific age ranges for screening e.g. 50-70

years for breast screening? Thus, clearer understandings about the criteria for screening were said to be needed. One woman's own experience at an early age informed her view about the need for earlier cervical screening:

*"...cancer checks. Breast cancer cervical cancer... screening. And... cervical cancer screening at an early age. I had some polyps at eighteen... I had children at eighteen, and my daughter was refused a screening, at eighteen... me knowing I had- I had abnormal cells, at that age... then, it- I do feel quite sorry for the girls now that are- they say "oh no you've got no chance of it... I mean women are often sexually active from teenage years."*

### **1.3 Broadening perspectives of services (LGBT inclusive)**

The need to include LGBT+ perspective was particularly discussed in the focus group with lesbian and bisexual women. Frustration at the label 'LGBT' often being considered as one demographic was noted, because the needs of lesbians, gay men, bisexuals and transgender individuals differ considerably. LGBT+ support was perceived to be too generic and noted as historically being focused upon men.

Furthermore, mental health services were seen to lack an LGBT focus, or reported as being focused on gay men's priorities and needs— this was reported as a barrier to women within the LGBT+ community to access services

More generally, sex education needs to reflect the changing landscape of sexuality and be more diverse in its approach by including the LGBT+ perspective. It was suggested that if it is not included it can lead to more mental health issues for young people who are questioning their sexuality as they may be unable to identify with the education being provided.

### **1.4 Improved access to opportunities for physical activity**

Physical activity (and sometimes lack of access to it) was discussed in most groups. Participants agreed that Leeds is lucky to have a lot of green spaces, that can be used for free for physical activity: *"we are fortunate to have so much green space"*. Most participants agreed that the free gym equipment in parks was useful. However, barriers to accessing opportunities for physical activity were also discussed. For example,

- 2 Expensive public transport was identified as a barrier to women accessing green spaces:
- 3 Dogs (fear of) were identified as a reason why some women don't use green spaces (particularly BME women):
- 4 Lack of access to groups (free or low cost) when not wanting to exercise alone:

Participants acknowledged that physical activity can improve their health and wellbeing but noted the difficulties that they experienced in fitting it into their daily activities:

*"I struggle to find time to exercise"*

*“It’s whether I have physical energy for it”*

### **1.5 Improved access to healthier food options**

Food and access to healthy options was discussed by several women. The availability of and cheap cost of unhealthy food was described as problematic. The lack of understanding amongst some communities in relation to healthy eating, was noted as an issue alongside the increasing price of healthy food options. A combination of these factors was seen as leading to poor diets and subsequent health problems such as diabetes.

*“Health is what we eat”*

*“I’ll just say where I live in Harehills, looking at the local food suppliers, the cafes and stuff the quality of food I think is really poor? There’s a lot of- fried food and greasy food.”*

*“...cheap foods, there’s a lot of cheap food which is really unhealthy food and it’s about educating people really. I suppose also it’s with regards the suppliers. You know, two pieces of chicken and chips for 99p...That’s what, the way we want people to go don’t we to eat healthy but, it’s the price. So, that’s what I find it’s what people can afford.”*

*“I believe we’re really affected by visuals and environment. And those are the products that are really in our faces in my neighbourhood, and which are made very accessible to the kids who live round here, many of who have weight and teeth decay issues.”*

There was also recognition of the health implications of alcohol consumption:

*“...just anecdotally within my community I hear women all the time talking about weight loss and watching what they’re eating but then most of them are probably drinking socially quite heavily I would say... and the calories that come with it. But... that’s the cycle... of busy lives you know. I’m not saying that men are any different, but obviously we’re here talking about women.”*

There was also discussion of the disproportionate impact of the burden of food provision on women as they are often providing food for their family and dependents.

### **1.6 – Transport**

Some participants reported more general concerns in terms of the broader environment in which they live, discussing concerns with air pollution alongside the cost of public transport:

*“Another issue I think affects health is transport issues so you’ve got your pollution which in Harehills again I think is quite heavy.”*



*“And then there’s just the cost of the buses, it really makes me angry... you know in London they had a scheme where under sixteens could travel free.”*

*“I lived in London for six years and, you know this is years ago now but when I came back to Leeds, that really really stood out. Like the cost of transport, to go relatively short distances.”*

The cost of public transport was seen as a barrier for some groups of people, prohibiting them from accessing green spaces:

*“...and one of the things that lifts my spirits and makes me feel healthier is going to the park or being by water, or getting out into the countryside that has a massive impact on me and I think when that’s- then that’s made really tricky for a lot of people isn’t it [in reference to the cost of public transport].”*

Photo 2 – Disabled Women Focus Group Discussion – 22<sup>nd</sup> May 2018



### **1.6 Improved accessibility of services/reduced barriers**

Women reported that they faced multiple barriers when accessing services, across all of the focus groups conducted. Many reasons why specific services are inaccessible to any given woman were outlined. The following barriers were discussed in conversations: financial, language, childcare, timing, location, confidence, cultural and physical.

One woman felt that the telephone system used by health providers was itself a significant barrier:

*“A lot of people I see find our telephone system- you know press one for this press two for- very, very confusing it’s almost as if, people are kind of weeded out of*

*services at that point cos they can't follow, or cope with those sorts of instructions, and waiting for calls back and that kind of..."*

Both transwomen who participated in the focus groups felt that they had experienced additional barriers in navigating systems and getting medication, had experienced negative interactions and accessing services/support was a constant battle that:

*"We can't win"*

Any one or more of these barriers was noted as possibly leading to social isolation which was recognised by several women as having a big impact upon health and wellbeing.

Lesbian and Bisexual women discussed that there were not always sure if they could access services:

*"Heterosexuals assume they can use a service, we don't have the luxury of that...services might think they are LGBT friendly but unless they actively reach out we don't know"*

In addition, there were feelings from participants that LGBT+ generic services are often dominated by men and this was seen as a further barrier to LGBT+ women in relation to access.

These barriers must be considered when designing and delivering services for women – an example of this was given by a participant about York Street Health Practice. She is a professional working with sex-working women and noted that her clients only engage with their GP because they can do so at York Street Practice which is flexible, specialised and tailored to their needs. She noted that these women would not access a 'normal' GP as it isn't tailored to their specific needs

*"We need tailored accessibility to improve the health inequalities faced by marginalised groups."*

Some groups discussed how they weren't aware of services (particularly BME women) and how promotion and outreach of these services needs to be improved in order to engage women to access them. Community Champions were identified as being key to engaging marginalised communities:

*"Services can't assume that their outreach and promotion methods will work the same in all communities, they need to work out how is best to engage people."*

*"And that's what we're coming up against, people don't know how- where to signpost and things like that because they just don't know the services...and that's what we need really we need, we need more of that we need more of what- what services are here almost like a menu of services of what's going on in Leeds."*

*"So, can I just ask then how do people find that like because obviously you guys are just talking about this like... what about someone that- I'm imagining if someone just*

*came to Leeds... how would people find out about all this, cos where- how would you find out?"*

Raising awareness of existing provision was highlighted as important by one woman:

*"But there are little one-off clinics and things that people don't know about, there's a falls service whereby people can learn various... exercises and techniques and take necessary precautions to... but and again it's not well understood or evident within the resources. There are quite a lot of things on Leeds Community Healthcare website around mental health. Which are excellent facilities, but nobody actually knows they exist. Unless they've been told by a GP."*

*"But I think that could be one of your recommendations that... in general most of the services could do with making their resources better understood. And accessing those resources could be made more evidenced so that there's not just about accommodating the worried well. It's about accommodating a norm."*

Professionals were able to discuss the availability of services, and were aware of the work of statutory agencies, and the third sector in the city but not all of the participants shared their level of knowledge. There was also discussion about health check provision, awareness of this, and associated service uptake:

*"It's just going back to the point... do a lot of our women know about the free health checks? So if they're not registered with the GPs, because of you know the barriers that they encounter, they're not even gonna know about- so there's something about going back to right to the basics about, you know- we know not everybody's on the internet and so it is how do we publicise the services that are available... and then encourage those people to be able to access them? I think we have to go back even further."*

Language barriers were also recognised as an issue by several participants within the focus group discussions, for those who did not have English as a first language, and more generally in relation to navigating systems:

*"...because there's a massive language barrier, and I think in Leeds we've got a really big population, new migrants coming in, of all different nationalities, but actually we have not almost got the ESOL to help, teach these people."*

*"Connecting to what you're saying about language and systems, I think the barrier there is enormous and just small details like when my school gives out information, for the whole six seven years my daughter's been there you know I ask can you make your information more accessible for families, because it comes out with lots of jargon-y words, you have to work quite hard to read the letters so kids end up missing trips or they miss the family sharing sessions, cos their families can't read the information... just navigating your way through systems and through the complicated."*

*"You meet a blockage before you even start [with reference to language]."*

The design of services based around language was also noted as a specific challenge, as well as the approach used by professionals, with the need for a human touch demonstrated in the following example:

*"I referred a friend who had come from Tanzania, she'd been prostituted by her mum since she was twelve...we referred her to a place for counselling and, she got there and they were quite kind of cold towards her and they said "you can't have anything until you've filled out this form", and she couldn't write enough English to fill it out, and that was the end of that she went away and just said to me, it made me feel much worse, I couldn't access that service, it wasn't friendly and I think that coming back to that human touch."*

The length of waiting lists were discussed in all focus groups, with participants agreeing that this has a big impact on women's health and wellbeing as they are not able to access the support they need, when they need it. There was a particular focus upon waiting lists for mental health services; how women are often accessing at time of crisis and if they can't be seen within a few weeks this has a significant impact on their health and wellbeing. Waiting times for seeing GPs, and other services was also highlighted as an issue for many women.

*"I think, getting people seen as efficiently as possible because... I mean for example, I've had a- a tooth abscess for the last... well- since August. And I'm still waiting for it to get taken out! So that affects quite a lot of my life, like eating and sleeping and things! And that has done for... nearly a year now. So, getting people seen, as fast as possible is a very high priority, in my view."*

Building design was discussed as a specific barrier for disabled women in their focus group:

*"Yes I would also like to see any new building... having a group of people disabled people going round it as a matter of course... and especially in disabled toilets where the pull if you have a problem is... too far away for you, so you know if you do have a fall you're not going to be able to get to it... and where they put all the other facilities and the toilet paper holders are always behind you... they want to be accessible to people but they don't seem to understand that they need to get the people in, who are going to use the facilities to actually provide some information."*

## **1.8 Gender Specific Issues**

Broader barriers related to gender were also noted by one participant who suggested that services needed to focus upon advocacy as well as the wide range of **health-related challenges experienced specifically by women:**

*"...I think a lot of this stuff is really mainstream health stuff ... you can send people in the community for tests but if they're not going to be compliant with- give up drinking give up smoking do more exercise there's not really much point in the tests. It's about how we commission advocacy, so that people don't necessarily have a health check...but do know that in their local area there are women meeting to go up*

*to [location] and transport's provided. Cos that service is there if you don't know about it, and those women are talking about depression and domestic violence and all of the, crap that women have to deal with, you know in a woman only environment, and I think it's about... you know sometimes getting away from this, health focus. And I think it's about us being clever, but actually it is about how we work around women's health in the community but I realise it's only one perspective."*

Domestic violence was recognised as an issue:

*"we've got a huge problem...this country this city, with women who don't have recourse to public funds. You know and all the immigration stuff and what that costs or whatever I mean, I've been meeting with women from Afghanistan and other countries who are basically... locked in their home, financial abuse... actually don't speak the language believe everything that their partner's telling them, which is "if you go to the authorities you'll be deported you'll have to go back to Afghanistan... but I think we've gotta find a way of reaching those women."*

*"But I think even outside of GP surgeries I'd like to see the third sector really doing routine screening for domestic violence, and other forms of it I mean they will do triggered enquiry if a woman says... I had ten bells knocked out of me last week and probably do... but I just think, and we've got the drug and alcohol agencies because you know you've got your toxic sort of trinity there, drugs alcohol domestic violence but... I just think to get a wider range of women the third sector and other agencies need to start asking the question you know, do you experience domestic violence? So- so really, it's just that- it's a simple thing but I think, the impact can be, you know- anyway, you know what I mean."*

One group of women acknowledged that there was support from the third sector in relation to domestic violence, but also suggested that such provision is underfunded:

*"No. It's not but the extra help is... is very underfunded. If you had to move if you had to disappear. It's very very underfunded. And... stretched."*

One participant stressed that self-care can be difficult for women because of the many caring responsibilities that they have, related to their gender:

*"I think something else that we've probably not talked about is the- like, self-care... and I feel like at the moment self-care is something that, I know as a mum of two young kids, and I have my partner, but it's something that I put to the side because I always put their needs first... you know you're not putting yourself first and you don't always have a chance to even, sit down and have a look for services that are available or- cos you're just so exhausted to start with, or you just feel like, "oh it's not important cos I've got something else to do" or, my child's sick so that's more important than how I'm feeling."*

Gendered expectations were also mentioned in terms of stereotypes and prejudice:

*"It's almost like, if women say something's not right they're complaining but if, a man says it they're making a point. And I think that is reinforced, throughout... media and everything. Like oh you're just whingeing just a woman whingeing. Whereas if a man made the same point he'd be like... oh you've got a good point there."*

### **Menstruation**

One professional discussed period poverty as an issue, and other women highlighted health issues associated with menstruation and an associated lack of support and recognition in relation to this:

*"It's like period poverty."*

*"You know about women not being able to afford, enough sanitary products to get you through the month, through the week, and having to use them longer, for longer periods so we're getting more infections."*

One professional was involved in working towards addressing period poverty and noted that within Leeds, action was being taken in relation to this issue:

*"Yeah they're missing school... yeah it's- I mean, Leeds is great because, hopefully there's nobody suffering period poverty cos Freedom for Girls is delivering thousands every week [referring to sanitary products]. To, you know food banks and refugee agencies and refugees and conversation clubs and, you know all around. And hopefully they'll be bringing choice of Moon Cups soon as well. I've just been given twenty-five thousand pounds worth of Moon Cups."*

Menstruation was discussed more generally in relation to health and wellbeing, with some women reporting negative experiences with health professionals in relation to this issue:

*"I have really... like I can't remember the medical name, it's hard to pronounce. Extremely painful, periods and really heavy periods that had me off work... I'd gone to the Doctor's because, I thought I can't keep- being off work and it really hurts I mean it was horrible. I'd been sent for scans, and everything and the woman in the hospital that'd done the ultrasound said that oh she couldn't find anything there- I said "well what do I do next?" She went "oh you'll just have to put up with it.""*

*"I mean there is research to say that Doctors don't know a lot about periods about what the- even women Doctors, you know about what's happening to you, what the different ailments are that come with it."*

*"...with periods, you know you've got a- you know if you've got heavy periods, why have you got heavy periods and the Doctors... mostly just say "because you've got heavy periods" and you know there's nothing, but actually you know it might be a hormone imbalance, it might be... you know so there's a lot of information around... you know the whole thing, from you know, from being you know like eleven or twelve or thirteen when you start to when you finish, you know we have this secret society almost."*

There was discussion of the need for more open conversation about menstruation with younger women so that they could be better prepared:

*"I think we should definitely do more awareness of periods just- just looking back to like, being in high school and like you first get your period- you feel like you've done something wrong? You know like "oh, I shouldn't be starting before other girls..."*

*"The amount of girls who are, you know weren't prepared- forty-six percent of girls weren't prepared, when they got their first period?"*

*"It came as a shock to a lot of young people because they think they're dying. I'm bleeding to death."*

Participants noted that there needed to be more conversation in general, not just for younger women:

*"We just don't talk about it do we? We don't talk about periods, we don't talk about how contraception affects periods, you know some women take particular contraceptions to try and control their periods and, they're a bit confused about what they can and can't take..."*

*"Yeah and we should be having that conversation we should talk about it-we should talk about, you know the fact that it doesn't have to be like oh you've got a mental health issue it should be a normal subject that- during that time of the month you may feel this way..."*

One participant felt that her daughter's school was approaching the issue in a positive and beneficial way:

*"In my daughter's school, their- she's in year five, and they- they seem to be handling it really well, she came home, chatting- I mean we talk really openly anyway she came home chatting quite a lot and, saying that you know she could start any time from now on an that it's good to have a little kit in class and they seem to be handling it really well I was quite impressed."*

However, others reported that education related to women's bodies was not always good, and that there was significant variation across schools:

*"...so hit and miss, isn't it? I mean that's brilliant my daughter's had the opposite experience of... the sex education started with "so we all know what a period is..." That's how it started. That's how it started, and my daughter did know, cos... she'd known but we talked about it before... and I- but she was aghast and I was too because I mean that's- that's a basic failing isn't it, and I think... I can understand their dividing and the girls and boys up..."*

Menstruation was discussed as being taboo in general, but some participants also highlighted the importance of cultural differences in relation to women's bodies:

*"And in some cultures, that's how it is cos- you can't cook. And if you have- and after you've had a baby as well, you can't go in the kitchen and stuff like that so, there's a*

*lot of barriers to break down. Cos it's... it's a taboo subject. Especially when you've had a baby and they know you're bleeding after. You can't go near the kitchen and... No cooking no cleaning so... it's a taboo subject in a lot of cultures you know, when a woman- cos a woman is seen as unclean, you know when they're having a baby."*

The need for men to be educated especially if they were line managers of women was also discussed, alongside the need for workplace flexibility for menstruating women:

*"[name] was also talking about periods cos I know she's had a lot of problems, in the past. Just trying to persuade managers that... her period pains are to the point where she cannot work, for maybe one or two days a month. And... managers being flexible and saying well we know about this, and... you have to work another day but you can- can take today off."*

*"Well I've said to [name] this morning, like women have periods, and if you've got to be off for period pains, it goes down as sick but a man will never have that. Will they? So... I don't think that's fair."*

*"And then it becomes a pattern. So, you go, you know and then you're in trouble well it's a pattern."*

*"Straight away it's unequal, unequal playing ground isn't it?"*

The need for a less gendered approach to sex education was debated within one focus group:

*"...why are we not doing, you know...well teaching the girls and the boys together, so it stops that stigma and taboo from a very early age?"*

*"it's good that for young boys to listen and know, because then later on when they're older then they'll understand why, perhaps their partner, or their... whatever it is, is behaving that way and they can support better..."*

## **FGM**

Female Genital Mutilation was discussed by some participants as a culturally hidden issue within the city:

*"Like FGM isn't it. That is changing... regarding FGM trying to educate people that it's dangerous... we can change things but it takes forever half of us won't be here."*

*"I don't know they're kind of not really spoken about because they're sort of hidden, so things like FGM, like I know is a big issue in the city cos... I've like worked with the police on you know like campaigns and things but there's just no data about it."*

*"Leeds is just so diverse isn't it and we know we've got, like you know, a big sort of migrant population, so we know that there are all those different cultural sort of norms and some things that, are... just, yeah. Cultural for them but... criminal here. Yeah but it's all- it's just all hidden, that's the... problem I guess."*



## **Childbirth**

One participant mentioned that she felt that there needed to be a more open discussion around the physical impacts associated with childbirth:

*“I had three kids you know I- my anatomy is not what it was before I had them, and I- it’s only when you- only maybe takes one or two women, to start speaking openly about, what’s going on down there, you know for other people to go “oh actually you know for ten years I’ve had this but I didn’t wanna mention it...”*

## **Menopause**

All groups discussed the need for better menopause support, most women hadn’t received or weren’t aware of any (there is a menopause clinic in Leeds – only 1 participant was aware of this but had used the service in Bradford rather than Leeds).

*“I mean we’re lucky in Leeds we actually have a menopause clinic did anybody know that?”*

General agreement from participants was focused upon the menopause being a taboo subject, often not discussed even amongst peers:

*“Women don’t talk about it because it makes them feel old.”*

*“So people who are coming in with menopausal symptoms or, whatever- you know, we get very misdiagnosed...thinking we’ve got depression or we’ve got this or it’s the time of your life but actually- it’s a real thing that happens to you and it’s nasty and it’s horrible and... people would rather have their periods back than go through the menopause and I’ve spoken to a lot of women about this.”*

Participants discussed the need for improved education and awareness of menopause and its symptoms so that women have a better understanding of what to expect:

*“Women don’t always know what the symptoms are so they aren’t aware of what to expect.”*

*“If it happened to men then it would be better funded.”*

*“I think there is a lot of lost information around menopause. There probably isn’t available even anecdotally...”*

One woman described how her experience of the menopause had affected her ability to work, and that this was not recognised as being related to the menopause by her or others around her:

*“And at work when I was going through the menopause I did end up going off with what was labelled as stress, for a very long time I never went back to that job. And*

*just before I left they were bringing in new system after new system of computers and all kinds of things I was finding really hard to absorb the information from, and my boss said to me that I should be working like my twenty year old colleague who didn't have kids I was a single mum, my daughter was really young at that time about two, and I just was really struggling and I just remember just getting more and more frightened and more and more withdrawn in myself, and I did get a really bad set of symptoms cos I just kept thinking, oh everyone's telling me I should be able to cope and I'm not coping you know there's something wrong with me. I didn't know what was happening to myself at the time, so I'm not just blaming them, I'm really not but it ended up being a kind of lose-lose for everybody really?"*

Other participants felt that the symptoms to the menopause were understood in a very limited way, focusing upon hot flushes for example, with a lack of awareness about the wider impact in terms of mental health:

*"Well, even other stuff for example memory loss or inability to learn new tasks. That is really associated with-with a drop in oestrogen. Because the impact of all of it, is just huge. You know and I mean the memory loss in particular women think they're going mad. And that can be part of that depression of all that sort of stuff anyway and depression can be linked to that."*

Not all participants reported negative experiences of the menopause:

*"It's not always bad I think we need to remember, cos actually for me it was a relief not having periods then because I used to have so much pain."*

Participants discussed how a simple blood test that can be used to check hormone levels but that many women are not aware. Diet in relation to the menopause was also discussed – Japanese women were reported as suffering less due to high soya content in their diets.

The role of peer support in menopause was discussed and agreed that it would be beneficial to most and help reduce the stigma associated with the menopause. One woman had set up her own Facebook group to facilitate discussions.

Photo 3 – Lesbian and Bisexual Women Focus Group – 16<sup>th</sup> July 2018



### 1.9 Needs of young women

One focus group discussion included debate about the role of school nurses in relation to the prevention of head lice, with this issue being a significant problem:

*“I can remember being at school and teacher’d go “right, nit nurse is here... and we’d queue up. To see her...if they did [find head lice] ... you went home straight away they didn’t have you back at school until you were clear, then you had to go back to the nurse first to check you. It really kept it down.”*

*“That- that is a massive, massive problem [referring to head lice].”*

*“It just goes round and round. All the time they’re in class, they’re at risk of getting nits.”*

Women talked about higher rates of anxiety within younger populations for example, students:

*“In terms of, the young people that are coming up, you know starting their first-year degrees and the anxiety levels, that they just- over the last ten years, feels very different.”*

*“I was thinking like mental health, I think is a huge one... particularly... I mean obviously it can be across all different age groups but from my experience of like being here [referring to Leeds] like a University- a lot of the sort of different mental health, issues... but obviously it’s all across, different age groups.”*

## 2. Services

### 2.1 General Service Provision

Some participants felt that not enough effort was made to engage some communities:

*“Professionals don’t really go into the community, it is about more than education, it is about reach.”*

The medical model approach involves putting people into boxes for treatment – the labelling of women, which was reported as a negative area of communication. Women agreed that terms used in services (e.g. NHS) to describe them could be softer and more considerate.

Some women had experienced judgement from professionals when accessing services. One bisexual woman described her experience of accessing sexual health services for contraception and that she had to explain:

*“I may have a girlfriend but because I am bi I may also want to sleep with a man and therefore need contraception. I am judged for being poly and I might just want the implant to help with my periods.”*

Shared Care Agreements were discussed as being helpful for women engaging with multiple services, but there was a perceived lack of awareness of these:

*“Shared care agreements need to be utilised more.”*

Female carers who are in employment reported their experiences of health care professionals not being particularly flexible in ensuring that appointments are suitable for carers and dependents:

*“What the carer needs and what is suitable for them is often overlooked.”*

*“Professionals get together to discuss my son’s needs but it’s overlooked to check my availability...my son doesn’t attend these appointments but if he did and that was factored in it would make it even more difficult.”*

One woman also discussed the lack of services available to support ME patients:

*“6 sessions that you get aren’t very helpful.”*

### 2.2 GP appointments

Challenges in getting appointment with a GP were frequently discussed. Women reported that practices are often oversubscribed and there can be a wait of 2-3 weeks for an appointment, and that being able to have enough flexibility to attend a same-day appointment can be difficult. 10-minute appointment time was not seen as sufficient to go into detail. There were varying experiences in relation to accessing appointments, as well as discussion of the rigidity of GP slots, when available:

*“I don’t know my doctors are... pretty good. You know when I’ve rung up I’ve not really had to wait, I’ve always got me appointment, so... I think mine are pretty good.”*

*“...and a lot of appointments are on one particular day, and if you’re working... it’s impossible to get there. If you’re not working it’s fine!”*

A small number reported that this had resulted in them disengaging with their GP service as they felt like they would never be able to book an appointment. Home visits were discussed (particularly in discussion with female carers) and how this option is not often given anymore, whereas in the past it was much more common for professionals to carry out home visits. Some women commented how this is a barrier for them to access healthcare as they did not have the means to attend a GP surgery.

Women noted the evident pressure on GPs but also felt that there was a lack of a human approach:

*“They just faced the computer screen and didn’t look at me when speaking to me.”*

*“When I go to my doctors if I see a different one when I... you know, you know it’s your turn cos your name comes up so you go in and you go they’re... so let me finish reading your notes and it’s all... on computer. So he knows, like sort of my history, and what I come for last time, and then he’ll ask me you know what my problem is this time but... he- he knows because, they all write it down don’t they and they’ve got to really because the next time you go the- he goes “oh let me just finish reading your notes.”*

Some participants felt that younger GPs hold stereotypes about older women, that their lifestyles are limited due to their age and also lack an understanding of the issues older women face:

*“it’s easier to speak to an older practitioner.”*

Participants of older women FGD agreed that the phrase *“it’s your age”* is used too often when they present with health issues and that this is not helpful.

### **2.3 Hospitals**

Negative experiences of accessing hospitals and the lack of support from staff for the specific needs of transwomen were reported:

*“They didn’t know what to do with me.”*

*“They put a large label next to my name with ‘transgender’ which was on the clipboard that was not just shown to staff but also to the public – my friend came to visit who did not know I was transgender and she found out about it that way.”*

*“They wouldn’t help my friend with the removal of her facial hair.”*

Transwomen participants agreed that they did not want to be in isolation wards when in hospital, they would prefer to be with other patients.

More generally women discussed their experiences of giving birth. Two were labelled as a geriatric mother (aged 33 and 36), with this label making them feel uncomfortable and unhappy. However, they did not say so to professionals.

In discussing more general experiences of childbirth, participants again emphasised the need for a personalised approach in relation to service delivery:

*"[referring to a friend]...recently has given birth, and she had- she suffers from bad anxiety which... with pregnancy made it like ten times worse. And... she wanted to see where she'd be giving birth cos she didn't wanna be like on a ward, and they wouldn't show her... they- it was really sort of cold the way they were dealing with her and she said, I'd rather have the birth at home and they were like "oh no no you can't have that" and, and she had to really push with... I don't know who, if it would've been her midwife? To get it at home and she eventually got it at home and... but it was that struggle getting there and the way it was just kind of really clinical and not seeing her as a person."*

*"I understand they must see lots of... women coming and giving birth all the time but you have to treat people like they're human not like they're- on a conveyor belt of... birthing."*

## **2.4 Mental health services**

Mental health services were identified as being particularly hard to access due to high-levels of need resulting in long waiting lists. Crisis services were reported as:

*"Unable to help, unable to cope."*

Participants were aware of cases when these services took 2 days to call back someone who was in crisis – this was seen as unacceptable and as negatively impacting upon health and wellbeing.

Social prescribing in relation to mental health was discussed, one participant referred to it as *"a sticking plaster"* in that no matter how many activities and groups women can attend, if they are unable to get support for their complex mental health issues then they can't improve their health and wellbeing.

Female carers mental health was discussed at length as well as the lack of support available for them. One woman who is the carer for her daughter who has mental health difficulties explained:

*"Husband is great but doesn't do emotion...I have to deal with my daughter's mental health issues, she often self-harms."*

Mental health support was reported as being provided by other services e.g. Carers Leeds but was recognised as not being a replacement for dedicated mental health support

*“Carers Leeds massively helped but I only come once a month...I can’t afford to fund personal counselling...I need more support.”*

One woman explained her experience finding a suitable counsellor, she had to persist – she had bad experiences with the first 2 counsellors, they didn’t understand her needs and she did not find them to be sympathetic. The 3<sup>rd</sup> counsellor (a young male) was a more positive experience:

*“I said “I’m a lady and I need help” he said “I’m going to give it to you” I could have put my arms around him and say thank god for you.”*

Service and funding cuts were identified by some participants as having a big impact on women’s mental health and ability to access services to maintain and improve it:

*“Services can’t cope with the demand.”*

Over-medication was seen as common, there is a lack of referrals from GPs to specialist services and therefore:

*“Women are falling through the gaps.”*

Challenges in discussing mental health needs in a short 10-minute appointment with GP were noted with women arguing the case for longer appointments, especially if English is not the first language.

The need for more mental health support and services for female carers who often have to put their own needs after those of their dependents was also discussed:

*“Your own health comes last.”*

*“I can’t fund personal counselling, it is too expensive, and I need to have more support.”*

Age-related challenges were also discussed, for example in relation to young women suffering due to social media messages and pressures:

*“...increase in social media and you have to look like this and you have to buy this, and... you know so there’s all that pressure on teenagers nowadays, that we don’t think about- it’s evolved so quickly that we haven’t caught up almost, our services haven’t caught up with, you know... I mean my daughter’s just finished well she finished high school last year and she said Mum, you know we need- you know those little crisis cards that- yeah, she said “we need those in school’s cos there’s so many kids that are just... not, right.” You know they’re not normal- you know they’re just really suffering.”*

## **2.5 Gender Identity Clinic**

Gender Identity Clinic (GIC) was discussed at length in focus group with transwomen, one woman described it as:

*“A blot on the landscape for GPs.”*

Both women who discussed their experiences of this clinic felt that they were often referred to it even for minor ailments that had nothing to do with their gender identity. The ways of working of GIC were discussed as these were not always perceived as supportive of transwomen and their transition journey. Women have to be given a specific label to be put on the pathway to transition (primary transsexual or gender dysphoria diagnosis). Many transwomen find these labels upsetting and don't like them. Support from GIC is not always helpful, it was seen as a hindrance – long waiting lists (up to 5 years) and the need for many patients to deal with co-morbidities e.g. getting support for mental health or addiction before being put on pathway. The women felt that these co-morbidities are often worsened by the wait for transition support:

*“It is a constant battle [with the GIC].”*

The limited provision of surgery for gender transition was discussed, as well as the many barriers to surgery. At the time of the focus group, there were only 4 practising surgeons in the UK. Surgeons were reported as being financially driven- only receiving money for a certain number of operations per year.

Health records were also discussed. Gender identity can be changed in health records so that transwomen are marked as female but universal systems mean that they are invited to inappropriate interventions e.g. smear tests but excluded from needed interventions e.g. prostate screening. The lack of 'trans' label can cause these types of complications

*“The NHS is still so binary.”*

One woman had been involved with meetings in the NHS to discuss how systems can be changed to be more inclusive. She felt that although it is a very slow response that it is a step in the right direction.

## **2.6 Gender Specific Issues**

There was a reported lack of choice for menopausal women, especially in relation to experiences with GPs, around how to support menopause. Women reported that most GPs just offer HRT, but that accessing this can be challenging as there are concerns from GPs around blame culture e.g. getting sued as a result of HRT prescription.

*“I found that when I was going through the menopause that's probably when I had the least relationship with my Doctor's...I didn't feel like they connected very well with me about that. I didn't wanna take drugs or HRT I didn't want any of that. And that's **all** they could offer. And then other symptoms that I felt were happening because of the menopause they just didn't recognise they were- they weren't, interested in...”*

*“No no, it's HRT or nothing.”*

*“I think they should tell us that there is different things and not just think say well here, stick that on. You know tell us that there's different... menopause treatments,*



*that you can have. Instead of just giving you the patch straight away cos I don't want that patch."*

*"And in some respects, HRT can be a lifesaver, but the other thing I was gonna say about that was I mean there's so many different forms of HRT on the market, and you will get what your GP prescribes unless you've done your research."*

Another participant commented more generally about health services in relation to women's bodies:

*"It's about, and I feel this across any, services, medical services I've had through the NHS I've, particularly when it's to do with female issues I'm being dictated to from people who, are yeah coming out with quite a narrow criteria in terms of what they're looking to treat or are able to treat or interested in treating and anything that falls that side of that, is either like classed as anxiety, yeah some neurosis or to do with maybe..."*

One woman noted that there were some changes underway for example in relation to the approach being taken towards menopause within Leeds City Council:

*"we've got a menopause group through like Women's Voice... so we like made a manifesto of all the issues of the women we'd consulted kind of across the council and... awareness of the menopause was a huge one. And it was kind of, people... big you know making themselves aware about what was to come or what's happening is it normal, what you can do, but also about managers like supporting their staff, you know to go... okay yeah this is a potential symptom of the menopause I can support them by doing this..."*

## **2.7 - Funding and associated challenges**

*Photo 4 – Focus Group for Any Woman – 15<sup>th</sup> May 2018*



Participants noted the challenges faced by service providers given funding cuts, which had meant reduced provision in some areas:

*“...think that’s what’s missing really, for me, as a public health worker, is that we don’t have enough community development workers any more...that was my first job, was a community development worker and actually we need people in the community to- you know to give people a holding hand to say actually, I’m here I can help you, you know if I can’t I know somebody who can, we just don’t have that any more...”*

Challenges to funding were noted in relation to third sector provision, as well as the perceived expectation that volunteers were the answer:

*“...you can’t rely on volunteers for everything, because I know we struggle to get volunteers so, I don’t know what other organisations are like and if we’re... I mean, half the time you spend, filling out funding applications and trying to get that it’s- it’s... form filling again!”*

*“I think it’s just how life’s going and it’s all based on money. Everything is based on money. No there’s nothing now I don’t think that- you just were saying there, about it’s... you know, it’s a volunteer that brings things... but things like that are important so why should it be it’s down to a volunteer who can’t come on a Monday morning because, they don’t work Monday mornings it’s not- it’s sad. You know it’s sad really, that it’s based- everything is based on... the pound.”*

One woman articulated her view that gender-specific issues for women were underfunded as well:

*“Where you’re talking about domestic violence when you’re talking about sex it feels... where you’re talking about rape where you’re talking about things like that, again thinking you know the gender specific areas are very very important, you kind of support- and the peer support, that we’ve just talked about. And, when I’ve been to meetings with groups like that we talked about underfunding, again... they’ve talked about cuts again, they’ve talked about the fact that they feel, that they’re the last priority not the first I mean, they are down the pecking order as it were, for people responding to them. For instance, they’ll often have trauma or trauma related... after such incidents or ongoing with such incidents, and they feel that others are given a priority for treatment for mental health for, you know stress and other disorders and protracted stress disorder... over them. And, I’m sure if you were to go to those groups and you know talk to them...there seems to be an indirect disparity, gender wise in funding and in prioritising, need... you know they feel that their needs are lower on the list.”*

Funding challenges were acknowledged in relation to service reconfiguration specifically using the example of sexual health services:

*“yeah it was definitely funding... and I did lots on sort of sexual health awareness and that kind of thing and we were working with Leeds Sexual Health... and they- I mean they told us that their- they had had funding cuts and so they'd had to, sort of combine different areas of services into, into a sort of one stop... kind of thing.”*

One woman reflected upon her experiences of accessing the one stop shop for sexual health

*“I guess there's positives cos it's... all in one central place but... the number of staff and that kind of thing so it doesn't mean there's... anymore and so there's fewer appointments available so it's harder to get appointments like... I just wanted my implant removed and I had to wait two months. So I knew I was gonna have it and it wasn't gonna be working! So that's kind of not ideal.”*

In one focus group, a woman discussed contraceptive advice from GPs being driven by cost reduction:

*“... so there are, increasingly like more and more options but like they ... you know they try and really encourage you to go get like the coil, cos it's the cheapest cos it lasts for five years and it's... less [referring to expense].”*

Furthermore, threshold criteria for entry into some services were discussed as being too high, resulting from limitations in the available funding:

*“One of my best friends has, she has anorexia and bulimia, and she's been told... and this is the case where all- most mental health problems it seems to be at the moment cos of the funding cuts... but she's not, she's not ill enough like she needs to be hospitalised before she can get the care that she needs and at risk of dying. So, she's now purposefully trying to get more ill so she can get that health, get that support.”*

## **2.8 Consistency and communication**

Several participants commented on the inconsistency of services and support that they had received. Most reported both positive and negative experiences when accessing the same service e.g. their GP. Women also commented that the support they received really depended on the attitude and knowledge of the individual professional. A lot of the participants said something similar to:

*“The service you get depends on the member of staff you're dealing with.”*

Training was discussed as the primary way of increasing consistency across services and staff. Furthermore, participants felt that a consistently open-minded approach from professionals who were *“willing to explore and understand their issues and needs”* would significantly improve the health and wellbeing of women. One woman did note the challenges involved in training provision for professionals providing care:

*“I think ongoing training, as well because there are new needs that are arriving continuously especially with tech developing as it is, so I think that's important but I think also making sure that it's paid training as in they're still paid at the time cos I*

*know a nurse that lives next door to me, for instance that was on shift, you know she's on twelve, thirteen hour shifts... and then expected to go to unpaid... you know three hours training at the end of your shift! Which is not a good idea, you know you just can't do it can you? So, I think having that allocated time paid time for the training's very important."*

One woman discussed the need for communication between different departments, as this had been a barrier to her receiving treatment on two occasions for the same health issue:

*"I've been taking antibiotics but then, when I went for the pre-op, said well "how many sets of antibiotics have you been given?" and it's like, five, "oh you shouldn't have been given that many", but I've been waiting eight months and it keep- it- when it flares up, [referring to a tooth abscess] how do you get rid of it? Well you take antibiotics. What else can you do you're not gonna pull it out? So, it's a case of one hand's saying opposite to the other hand as well. The dentist is saying if it flares up, don't be afraid to come back in and we'll see if we can get you some antibiotics."*

*"Yeah, and I mean the other thing was, I had a discussion with the day clinic at the dental hospital, and said "oh yeah, we need to look at sleep apnoea for you", cos I answered one of the questions...And then that was the end of the conversation, so I was waiting for a referral letter to a sleep clinic, so then it got to a couple of months later and I thought well there's been nothing come through, so I phoned em back and they said "oh no we were waiting for you to phone your doctor. I were like well, if you'd told me that I had to phone the doctor, and sort this out, then I would've done it."*

She also commented upon the need to repeat your history and symptoms with different professionals, noting her personal frustration with this:

*"This is the sort of issue that gets on my nerves that you see several different people, like a new junior doctor "oh this is a new junior doctor you're seeing them again"... no but I saw a different one last-last week, or last month, and it's passing through the hands of lots and lots of different people and it's an ongoing thing. Cos you've gotta explain every time."*

*"They're not able to coordinate that's one of the big problems and they don't seem to be able to network and communicate. They're quite often on different systems, different computing systems and different computing providers, and they also haven't got the time. You nearly always find that they haven't got time to look at the history they haven't got time to look at records."*

A common theme during most discussions was the frustration at the lack of communication amongst service providers and staff. Explaining a situation multiple times (particularly if vulnerable) can be challenging and impact upon the health and wellbeing of patients. Lack of communication was reported as causing delays and impacting upon the health and wellbeing of patients even further. Most women felt that they were not included in the

channels of communication between services and so were sometimes left unaware of their situation and how to proceed.

Some participants felt that data was not shared effectively (recognising new GDPR rules and limitations in how data can be shared). Some women felt that if it was shared then it was unusually inappropriate (this was particularly felt by transwomen participants who said that the important data wasn't shared but the fact that their status was, even though this should not and did not affect the support they would receive).

## 2.9 Recognising that “One size does NOT fit all”

*Photo 5 – Focus Group with Trans Women 11<sup>th</sup> July 2018*



Most participants felt that women are often put into one single category of ‘woman’ and their intersectionality is not recognised or considered. All agreed that in order to receive the best support that these differences need to be taken into consideration. Health services and professionals need to recognise the diversity of women and their needs:

*“Services need to recognise that everyone is different.”*

Even women of the same characteristic e.g. older women are different and have varying needs. This was specifically discussed in the focus group with older women; participants agreed that the diversity of ‘older’ needs to be recognised in order to provide effective support. The changing landscape of the population, people living for longer means that the term ‘older’ has changed and many older people are now much more active in order to prevent illness and maintain their health and wellbeing – services for older people were not seen to reflect this.

Furthermore, processes and paperwork (e.g. questionnaires) used by mainstream services are standardised and don't recognise the diversity of women, their lifestyles and needs instead using one standard questionnaire for all. One participant (a professional) provided an example of a group of women she worked with. A health professional came to deliver a health session and used a standard NHS questionnaire to calculate how healthy the women's lifestyle was. The questions around food asked if they ate chocolate and crisps etc. From the women's answers they should have been the picture of health but because the questionnaire didn't consider cultural differences (although the women don't eat chocolate and crisps they eat a lot jalebis (deep fried sugar-coated flour). She felt that this demonstrates the need for health professionals (as well as paperwork and procedures) to be more open and sensitive to diverse needs rather than framed by the culture that the decision-makers live in.

Language and concepts used within the health system are traditionally set up for heterosexual sexuality and relationships and therefore not appropriate for those who do not fall into that category (LGBT+).

Services were also described as not being disability friendly and therefore access was more challenging because of the standard approach being used:

*"Things like going for screening, not all GP surgeries will have a hoist if someone is unable to get on to the bench when they go for a cervical smear. And it's things like that- Hospitals don't generally have the facilities either. I find so... you've got problems before you even start. Before you manage to get through the front door, with things...but there shouldn't be that, there shouldn't be the barriers there."*

*"I've known some people who use wheelchairs who've had to struggle on to the bed, with help, and been very uncomfortable and very very... and had an awful experience. But they wanted to go through with it and that was the only way they could. Because there was no facilities to help them, within their GP surgery. And I don't know whether you can get referred to hospital where they have facilities, but at that point they hadn't."*

*"Yeah the other thing that occurs to me is that when I'm having my eyes tested, I'm very aware that some of the facilities aren't accessible to me so I can only really have the simple eye test, or the optician looking into my eyes to see if there's any glaucoma or anything like... there are certain levels of other screening that they could do, were I not a wheelchair user. So that in terms of eye health et cetera that's not particularly well managed either."*

There was repeated discussion of this within the focus group for disabled women, one of whom noted the barriers she faced when using the self-check in system at her GP surgery and another woman commenting more generally:

*“Yeah so you know that blocks people from using them, if they’ve got problems with sight, and sometimes the height of them, so people in a wheelchair as well so they’re not best easiest to... you know to access them some of them, and the privacy as well isn’t there either.”*

*“[with reference to services needing to be] inclusive, a little bit- flexible attitude, very open-minded way of... for the different needs you know... just be focused on the different areas of needs.”*

Another woman commented upon potential issues for people with visual impairments in relation to the uptake of some forms of screening:

*“That bowel screening as well that- presents a number of problems for people who can’t see.”*

## **2.10 Holistic support**

All participants discussed holistic support and alternative therapies. Most agreed that medication was seen as best way to support health and wellbeing but that this wasn’t always their personal experience.

Holistic health providers e.g. physiotherapy, homeopathy, acupuncture etc. were discussed in most groups with the benefits of these services noted from the perspective of the women. However, the waiting lists (NHS) and cost (private) were identified as barriers to women receiving some of this support and potentially preventing issues with their health and wellbeing.

Participants also discussed how their needs are often compartmentalised and not seen as part of a bigger picture, so a patient isn’t treated holistically but rather one issue is treated then the next is considered:

*“Services seem to see issues as completely separate.”*

*“Women need to be treated as a whole not just as their conditions.”*

*“Health is treated as car parts, professionals and services don’t see the connections.”*

## **3. Experiences**

### **3.1 Physical Activity**

Women discussed how younger girls often stop exercising at a certain age (when they hit puberty) because of body image concerns, and that approaches to activity therefore needs to be more inclusive.

*“It is easier to run around when you are flat chested”*

Some participants (in the BME discussion) felt that provision for physical activity is targeted to and dominated by a white middle-class demographic e.g. charity runs cater for white middle class elite runners. One participant described how she didn't feel welcome and many of her friends reported the same. She had experienced prejudice from an local authority worker who commented that

*"Black people don't run"*

Debate was held about the dis(advantages) of separating provision which could cause further division, with no clear consensus reached.

The challenge in promoting activities to women (especially and BME and marginalised who would most benefit) were also noted.

A female carers experience of physical activity, was that she had a lack of time available to do it:

*"I go to Roundhay park or Golden Acre Park for walks...we're fortunate to have green space...but I have to fit exercising in around my caring responsibilities"*

### **3.2 Cancer**

There was a long discussion within the BME group specifically about cancer and its impact on their community. Participants felt that there seemed to be a higher number of BME people getting diagnosed and dying from cancer:

*"It seems that someone I know dies from cancer every week"*

*"My biggest concern is cancer in the community"*

*"Is it because we are a close community that we know all the people that are ill [with cancer]?"*

Lack of education about the signs and symptoms of cancer within the BME community was also reported as a concern:

*"Do we know what to look for?"*

### **3.3 Sexuality and gender**

Sexuality was recognised as an issue in some communities, with people not being able to 'come out'. This was perceived as having a negative impact upon their health and wellbeing (particularly mental health):

*"Being gay in some communities is still a no no"*

One participant discussed her experience of attending hospital as a carer, she felt she was unwelcome and was often challenged when in the ward area and felt that this was because she is a transwoman. She also discussed the difficulties with challenging such treatment amongst the transgender community, especially if someone is lacking confidence:



*“Not all transfolk are able [to challenge]”*

The same woman also noted that transwomen are seen (in society) as:

*“Scary and unknown”*

*“We laugh it off, what else can we do?”*

She then went onto to explain an experience she had when in a female public toilet when helping her partner who she cares for. She was reported as a man going into the female toilets and security was called. She had to hold her ground, fortunately she had the confidence to do this. She suggested that many trans individuals do not have such confidence and therefore avoid these situations as well as public spaces more generally, which can have a big impact on their health and wellbeing (particularly mental health).

Another participant asked whether there is too much information about sexuality/gender labels as this could be confusing for young people, as her grand-daughter was asking:

*“How will I know I am a gay?”*

Women in the LGBT+ discussion commented that

*“Heterosexual professionals don’t understand lesbians or the sensitivities of our sexuality, they don’t understand our experiences, they make assumptions and don’t realise that what they say during a consultation has an impact”*

One bisexual woman had received her sex education 5 years ago, and reported that:

*“The LGBT perspective was ignored, and there was no discussion of the dental dam”*

She also highlighted how this can feed into risk taking behaviours which impact health and wellbeing.

### **3.4 Culture and traditions**

Differences in understanding of gender roles and ‘a woman’s place’ were discussed within some focus groups, and the potential implications of this for health-related outcomes.

*“We put a lot on our plates. We try to be everything to everybody. All the time.”*

*“You’re responsible for the house, you’re responsible for the bills you’re responsible for... the husband!”*

BME communities were also discussed as traditionally use a holistic approach to health (use of food and herbs to maintain health and wellbeing) but there is an increasing reliance on medical treatment.

The role of food in culture and its link to prevalence of conditions such as diabetes was reported as an issue within the BME focus group.

There was also a discussion of the lack of understanding of how a women's voice is heard within different communities. One participant discussed how within Asian communities an older women's voice is that of support and advice but noted how assumptions are made from other cultures (Western) that these women don't have a voice. These assumptions affect the support that such groups receive in relation to their health and wellbeing.

The impact of sexuality on children was discussed by lesbian mothers, who reported that many institutions still have traditional understandings of a family i.e. all children must have a mother and father – when this is not the case for some. One woman told us of her child's experience when completing a family tree at school which was based around the concept of everyone having a mother and father:

*“Every child has a father”* was the comment from the teacher

*“But my child had no concept of a father, it is these sort of throwaway comments that matter”*

Discussion with LGBT+ around the concept of 'next of kin' and how this narrowly considered only spouses as appropriate, one woman explained her experience of giving an ex-partner (female) as her next of kin and how she:

*“Got grilled...you always have to be the trainer”*

### **3.4 Fears and Myths**

Women discussed commonly held myths about cancer, especially within the BME community e.g. it is seen as a curse, therefore people do not access services as they don't want to be stigmatised:

*“Some people believe that if we don't talk about it, it won't happen”*

There was further recognition of stigma and its associated impact on women accessing services within their communities as some reported concerns in terms of being identified/labelled e.g. women accessing mental health services when they are members of the BME community:

*“People might think you are a loony”*

One woman recounted her daughter's experience

*“My daughter couldn't tell her friends about her mental health due to stigma”*

Stigma attached to the menopause was recognised and discussed, with the menopause being reported as a taboo subject in. This led to challenges in accessing services especially for women who experience it at a younger age, one participant had gone through the menopause at 41.

Within the LGBT+ discussion, participants noted commonly held myths within their community in that many lesbians assume that they don't need a smear test but in fact they do, they are still at risk of cervical cancer. In addition, this group of women discussed self-

checking and being careful with the language they use to talk about their partners due to their fear of:

*“Outing yourself at every encounter”*

*“Self-editing is constant”*

*“Fear is the biggest barrier to accessing services”*

*“Do I have to be an activist today or can I just go to the service for myself?”*

*“I get sick of being on a soapbox”*

The women discussed the need to feel safe within conversations with healthcare professionals and how their fear would be eased if characteristic-specific services were provided. Lesbian and Bisexual women reported feeling threatened by disclosures, and held concerns about where their personal information is held and how this could affect their safety in the future:

*“What if politics change in the future?”*

*“Laws can be undone!”*

### **3.5 Peer Support/Volunteering**

*Photo 6 – Focus Groups for Female Carers – 26<sup>th</sup> July 2018*



Many participants agreed that peer support is a valuable and that it can improve health and wellbeing. Many also discussed having positive experiences of using it. This was recognised by carers, who described the importance of specialised services such as Carers Leeds and the peer support offer:

*“Coming to Carers Leeds groups helped me”*

*“I need to come to the group to maintain my own wellbeing”*

*“Carers Leeds is extremely valuable...wonderful...you don’t have to say anything...you can just come in and weep and tissues are available”*

*“It is a shame that more people don’t come”*

Women discussed how structured peer support (e.g. delivered by an organisation such as Carers Leeds) can be challenging to attend as it is often during working hours

Social isolation was recognised as an experience shared by many women (particularly carers) and peer support was identified by some participants as key to reducing this:

*“You end up in your own bubble”*

*“Your world can become very small”*

*“You get stuck in a rut”*

One woman discussed her own role in volunteering with a lunch group and how important it was for attendees:

*“It is about getting out, not the lunch. I could feed them sausages every time”*

The importance of volunteers was discussed in some groups with some suggesting that it is getting more challenging to recruit volunteers – people are working for longer in paid employment and some are providing childcare so limits their availability even after retirement.

One woman who worked with older people talked about the benefit of befriending schemes on health and wellbeing and in particular one which links students with older people:

*“These work really well...but ultimately the availability of these sort of services boil down to funding”*

Peer support was also available within the LGBT+ community, and so was discussed in the LGBT+ focus group. Women noted that the LGBT category is separated within peer support e.g. TransLeeds, BiLeeds, Sage Project. Those women who had been engaging with the Sage Project identified the need for a woman only space, which has just started, they noted that:

*“We had to fight for it”*

Trans women also stressed the importance of peer support in maintaining the health and wellbeing of their community but noted that some provision is not specific enough:

*“They [referring to peer support groups] are mixed and not specific to transwomen or men, we have different needs. Support is also needed for families”*

Peer support was recognised as being vital to supporting women through the menopause.

### **3.6 Menopause**

All participants who had experience of the menopause agreed that there was a significant lack of support available, many were told:

*“It will pass”*

Some reported that they had accepted that *“you would have to put up with it”*

Specific challenges for transwomen were reported in the universal application of rules e.g. one woman had been taken off hormone medication as GP felt it would interfere with menopause (she will not experience menopause but still needs the hormone medication). One woman commented how

*“The effect of the menopause is never gone due to the lack of oestrogen it affects the tear ducts, vaginal walls get thinner, you will dry out”*

Women reported that the wide range of symptoms associated with the menopause aren't recognised. One participant explained how her friend had suffered terribly with memory loss and she had to take time off work. She could not function properly and her mental health was affected.

### **3.7 Decision-making/Woman's Agency**

One participant expressed her frustration at not being involved in the decision around her medication, which had been stopped without her being consulted. Women reported that their agency is often removed from decisions, and they perceived that professionals believe they know best and don't consider the knowledge and experience of women themselves. This was echoed by transwomen in relation to their experience of the Gender Identity Clinic. Both reported decisions being made by professionals without input from the patient, leaving them with a sense of disempowerment:

*“You wonder, are they doing it deliberately?”*

An older women commented how she felt:

*“Passed over and invisible”*

This was in relation to her opinions not being sought (contrasting to her more positive experiences when she was younger). She felt that this impacted upon her wellbeing by reducing her confidence in her experience and skills.

Women also discussed how assumptions have often been made about them (whether it is around their sexuality, disability, responsibilities etc.) and this affects the care they receive.

Many of the women discussed their frustration when their skills, knowledge and experience are not considered, decisions are made without them or for them, without asking them what would work best for them. Some women also discussed how they felt that they aren't believed and that healthcare professionals question their motives. The need for a person-centred approach was discussed by many. An example of this was provided by one woman who cared for her partner (who has ME). She didn't want to medicate but this was what health professionals offered without an alternative:

*"GP provides medication...we knew about Phoenix so requested it but wouldn't have got this if we didn't know about it"*

*"Acupuncture helps but the GP didn't know to offer it"*

Photo 7 – work completed by young women in the FGD – August 2018



## 4 - Appendices

### 4.1 How we did the research

#### The aims of our research

The Women's Voices project aimed to collect the voices of diverse women across Leeds in order to contribute to the State of Women's Health in Leeds report. The Focus Groups Discussions (FGDs) focussed on women's health and wellbeing – their needs, experiences of accessing services and support, and what needs to be improved.

#### Approach to data collection

The focus group schedule was developed to be very open in style (see appendix 4.2), to allow the women who participated to articulate their own experiences and voices.

#### Ethics

The evaluation was given ethical approval through Leeds Beckett University ethics procedures. The following practices were adhered to ensure ethical rigour:

- Informed consent – written or verbal consent was obtained from all participants in the focus groups;
- Confidentiality and anonymity – no personal identifying information has been used in the reporting the data;
- Secure information management – security was maintained through password protected university systems.

All photographs included within this report have the permission of those shown within them. Some groups did not wish for their photograph to be taken for example, older women and this was respected.

### Qualitative Focus Group Discussions

We delivered a series of FGDs for women based on certain characteristics; these were aligned with the characteristic-specific Equality Hubs managed by Leeds City Council, we were also led by Public Health who identified groups whose voices they wanted to include in the report. We made effort to ensure that the timings and locations of the FGDs were suitable for our target groups and we also offered reimbursement for travel expenses as well as providing light refreshments. We conducted a total of 9 FGDs.

**Table 4.1 - Summary of the Focus Group Discussions**

Group of women	Date	Number who participated
Any woman	8 <sup>th</sup> May 2018 at Leeds Beckett University	12
Women's Voices - Leeds City Council Women's Staff Network	8 <sup>th</sup> May 2018 at Civic Hall	3
Disabled women	22 <sup>nd</sup> May 2018 Old Fire Station in Gipton (this venue was chosen specifically as it is very accessible)	8
Trans Women	11 <sup>th</sup> July 2018 at Mesmac (venue chosen as accessible for target group)	3
BME Women	11 <sup>th</sup> July 2018 at Women's Aid (in the evening as discussed with BME Hub Reps)	4
Older Women (age not specified)	12 <sup>th</sup> July 2018 at John Lewis Community Hub	4
Lesbian and Bisexual Women	16 <sup>th</sup> July 2018 at Mesmac	5
Female Carers	26 <sup>th</sup> July 2018 at Carers	6

	Leeds (chosen as it is a familiar place for carers, Carers Leeds also supported promotion – online and in their newsletter)	
Young Women (Girls Hub) – 13-17 years	23 <sup>rd</sup> August 2018 at Getaway Girls (Public Health asked specifically for us to hold a discussion with young women so that their voices were included in the report).	6

**Total n= 51**

### **Analysis**

All focus groups were recorded, and the initial 3 were also fully transcribed. The verbatim transcripts from the first focus groups (n=3) were analysed using Framework Analysis. The remaining FGD data was analysed using the framework as applied to notes and quotes taken by both researchers, as well as drawing upon the voice files.

Two researchers (LWB and CT) analysed the data using Framework Analysis. Framework Analysis develops a hierarchical thematic framework to classify and organise data according to key themes, concepts and emergent categories. The framework is the analytic tool that identifies key themes as a matrix where patterns and connections emerge across the data (Ritchie et al., 2003). The matrix was derived from the focus group schedule, and the final analysis and reporting were agreed by both of the research team.

### **Challenges**

Engaging women to attend the focus groups was more challenging than anticipated. We were expecting more support from the LCC Equality Hubs in promoting the opportunity to their members but the support was inconsistent, some were supportive, others were not. Developing partnerships with organisations working with the target groups e.g. Touchstone for BME women may have increased engagement. We had the support of Carers Leeds for the female carers focus group and this support was reflected in the number of women who attended.

Although having a transcript of the discussion was useful for analysis and pulling out key quotes from attendees, the transcription accrued the highest cost within the project. These funds could have potentially been used elsewhere e.g. paying for vouchers to incentivise women to attend the focus group, we think this would have increased attendance and reduced the number of no-shows.



The original timescale outlined for the project (3 months) was not enough to organise and coordinate the focus groups, collate and analyse data. Fortunately, the funder (Leeds Acts, Seedcorn Fund) agreed to an extension which meant we had sufficient time to deliver the project effectively and to maximum benefit.

#### 4.2 Focus Group Schedule

Introduction:

Housekeeping – toilets, refreshments, fire alarm

Welcome and introduction to Louise and Camille; explaining what will take place and ensuring that all of the staff have had the necessary information and agreed to take part (consent).

The women have the opportunity to introduce themselves and say something about themselves.

#### Themes to be explored

**Needs** – what are the health needs of women in Leeds? What are the priorities?

**Services/Support** – what services/support are accessed for these?

**Experience** – what has been the experiences of accessing support for these needs?

**Challenges** – what are the challenges in accessing support?

**Improvements** – how can services be improved for women?

Areas for further exploration (segmented according to group)

Equalities Hub	Topics
Older People's	Social Isolation Menopause
Carer's	Social Isolation Menopause
Disability	Social Isolation Menopause
LGBT	Sexuality Menopause
Women's	Menopause Power imbalance
BME	Characteristics Female Genital Mutilation (FGM)
Faith	Social Isolation Menopause

Focus group wind-down: Thanks for coming. Any questions or further comments?

