Trafford Women's Health Voices Qualitative Analysis

Introduction

This qualitative analysis is based on the lived and reported experiences of women[1] who either attended the Trafford Women's Voices event on 6th December 2022 or who contributed their story in the lead up to this event. The intention is to give an overall insight into the overarching themes of the stories contributed by these women. The data has been analysed using thematic analysis and direct quotes from the original data have been used to illustrate salient points.

Data set

The Trafford Women's Voices event had 75 attendees. This was made up of council employees, local charity and non-governmental organisation representatives as well as local women who shared their viewpoints. In total 19 stories of the lived experiences of women and their interactions with local services were collated as well as 13 statements written up by women on the day onto a 'priority for change' vision board. This analysis also included a spoken word video from one participant.

The raw data was entered onto a form provided in a paper format and electronically, which included a tick-box system for age group (young person and adolescent age group (<24), middle years age group (25-50 years) and later years (51+)) and perceived topic area. There was a free text option for name, 'your story', 'main thing you want to see changed' and 'positives you want to see more of'. Many of the participants used the last two boxes interchangeably and they have been collated together within the data interpretation. 13 out of 19 participants consented for their story to be published anonymously, 2 out of 19 did not consent and the remaining 4 did not complete this box. The data of the participants who did not give consent has still been analysed but their raw quotes have not been used within this document and all participants' data remains anonymous.

Data themes

Analysis of the dataset showed five overarching health themes which the stories could be divided into:

- Menstrual health and gynaecology services
- Menopause and healthy ageing
- Cancer
- Mental health and wellbeing
- Health effects of violence against women and girls

Within these themes there are multiple subthemes, many of which cross-cut and share a commonality between the sub-themes. This analysis includes an analysis of each thematic area and then a sub-analysis of the areas of commonality. The above areas also tie in with some of the subject areas of the Women's Health Strategy for England 2022. The major data gaps we experienced were the lived experiences of women experiencing pregnancy loss, fertility issues and interactions with maternity services as well as women with learning disabilities and neuro-divergence. We will endeavour to recruit more women with these lived experiences at future events, using targeted strategies.

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[1] The noun 'women' is used to describe service users frequently throughout this analysis, as it was during the event and by service users in their own stories, however, some of the datasets identify issues which apply to those who identify as transgender or non-binary.

Prescient quotes have been included within the analysis to emphasise key thematic points taken from the raw data.

Menstrual health and gynaecology services

This topic area included five lived experiences. These came from one service user in the young person and adolescent age group (<24), two females who identified within the middle years age group (25-50 years) and two of whom identified as later years (51+). The quotes from the users in the later year's group referenced past experiences. There were also six written quotes from the priority for change vision board which pertained to this thematic area as well as content from the spoken word video.

Themes that were present within this topic area included:

- Lack of communication regarding test results/having to chase the results of a test
- Long wait in the emergency department/not seen by a healthcare professional after a long wait
- Difficult to access appointment system
- Felt stigmatised by the clinic
- Not heard by/not received help from healthcare professional (HCP)
- Multiple clinicians or multiple consultations
- Given medication to treat a symptom without a diagnosis

Areas that were highlighted by service users as areas for positive change and development.

- Consultant follow-up ensured
- Timely delivery of test results and timely follow-up after referral
- Waiting times updates or updates from nursing staff
- Frequent communication
- More healthcare professionals
- Women-centred care
- Development of Women's Health Hubs
- Improved access to services
- Empathetic professionals/understanding that patients know their own bodies

The above areas can be broadly divided into three sub-thematic groups:

- Communication, inclusivity and empathy within healthcare
- Service access and continuity of care
- Women-centred care

Communication, inclusivity and empathy within healthcare

This predominantly centred on women's individual interactions with healthcare professionals within the outpatient or emergency setting. This often appeared to present itself as a perceived barrier to a successful healthcare outcome.

One participant described a lack of awareness of diversity within the patient population, highlighting that she was often misidentified and highlighting the heteronormative/racial assumptions she experienced within the healthcare population:

"Every GP and nurse presumed I was heterosexual … and white British, as I am very light skinned. I constantly had to prepare to out myself and correct staff regards to my ethnicity. This was exhausting and really delayed my confidence! … My internal homophobia intensified, and the racism and micro-aggressions left me feeling disempowered, angry and lost."

It is of particular note that she highlights that this experience in healthcare made her feel disempowered and therefore potentially less likely to display health seeking behaviours in future settings. This is echoed by a quote from the vision board: *"Services to use inclusive language. Don't make assumptions about identity or how people wish to be addressed."*

"To have an accessible front door approach to "females", inclusive of transgender and non-binary individuals and communities. By women for women and inclusive with language, culture, ethnicity, etc etc etc."

Another participant described a feeling of disempowerment due to poor communication within her healthcare experience and a sense of passivity:

"I wasn't aware of peri-menopause … I was referred back to a male GP (who said) he didn't know about menopause… I wasn't made aware of options. My GP wanted me to have an ultrasound scan, specialist said no it can't just be arranged (I) felt things were happening to me, without my understanding."

One participant highlighted that she felt the healthcare professionals did not treat her holistically and did not actually look at her medical history, leading to a very unnecessary, uncomfortable experience:

"I had a smear test and it was so uncomfortable (…) They could not find my cervix and I was in pain and I spoke to my daughter and she said 'Mum they removed your cervix 20 years ago.' (…) They should have known this and they have done it better, more considerate and they should have known more about me. They can make it better."

In keeping with this are a number of further quotes regarding a lack of understanding of the situation as well as disempowerment plus items on the agenda for change:

"Ask if patients are aware of what happens before during and after procedures, enabling professionals to offer correct pain relief"

"Awkward for me to question and challenge a medical professional"

"Feeling I'm causing a fuss – I'm a bit crazy."

"I had started to research things for myself to get clarity" shared experience with professionals, *"common ground… we are people with human experiences and being listened to is important to me."*

"Doing my own research to get answers and be captain of my own ship."

All of the above quotes highlight a need for better communication throughout the patient journey and that participants felt a disconnect with the healthcare service, the patient pathway was happening to them, not something that they were an active participant in. Worryingly, the first quote highlights concerns regarding effective analgesia and consent within the process. The two final quotes highlights participants' stories including a feeling of loss of faith in the system and a need to be their own advocates in the absence of an advocate within the healthcare system.

Service access and continuity of care

A key issue within the access to gynaecology services was the long wait times for both elective and emergency care in the sector.

"Long waits to be seen at St Marys, when eventually seen appointment was with a Doctor but was told I would be seeing the nurse."

"I waited 8 weeks for (biopsy) results and when I rang up, I was told I had been discharged from the services."

"I have given up on asking for preventative care, what's the point? I will only have to live through my earlier experiences again, and the hurdles to get help are enormous! (…) We just can't access GPs anymore, it's totally inaccessible."

These lived experiences across all participants highlight difficulties in both the timeliness and the accessibility of the healthcare professionals involved in both secondary and primary care. The distress that this lack of access has caused to the individuals has clearly been demonstrated as above. There may also be an aspect of managing expectations, for example where the participant has detailed that she had expected to be seen by a doctor and instead saw a nurse. With the evolution of the multidisciplinary team, it may be entirely appropriate for a patient to see a specialist nurse, but again this is a communication issue.

Participants also highlight the lack of continuity of care in their experience of the women's health sphere:

"Having to explain to three different professionals, the same situation. Feeling irrelevant."

For one participant in the youngest age group, having to leave what she perceived to be the safety, continuity and anonymity of her GP to access contraceptive services at a sexual health clinic was distressing and she highlighted this issue as below:

"Need to stop running lots of different clinics at the same time as it doesn't provide anonymity or calm/safe space. I felt like I had done something wrong rather than doing something positive for my health. (…) When I needed to access contraception again I went to my GP as it felt safe, personal, provided anonymity."

Interestingly this same service user did also raise the concept of Women's Health Hubs as a safer space and continuity concept, which leads onto the next theme in the analysis:

"Consider setting up Well women's clinic – these seem more supportive and focus on positives"

Women-centred care

This thematic area had two main subthemes: the concept of inclusivity of women and the development of women's healthcare hubs.

The concept of inclusivity had overlaps with the participant themes from the first thematic domain regarding empathy and communication.

"Services to begin to use inclusive language and not make assumptions about identity or how people wish to be addressed. We need to hear our younger generations and those brave enough to transition into another gender. WOMEN ARE A PRIORITY."

"To have an accessible front door approach to "females", inclusive of transgender and non-binary individuals and communities. By women for women and inclusive with language, culture, ethnicity, etc etc etc."

These service users highlight the importance of a sense of inclusivity for non cis-gender individuals to be potentially included within the sphere of consideration of women's health services and hubs as part of the provision of women's centred care.

The concept of Women's health hubs was raised by multiple participants in different conceptual settings:

"The term "family planning clinic" means nothing to me as I'm not planning to have children – consider how contraception services should be promoted better (…) Consider setting up (a) Well women's clinic"

"More accessible venues and places like libraries to learn about women's health through displays, promotions, women to talk to."

"I would like to see a Women's Hub/ Wellbeing Centre in Trafford, that could support residents to access Women Focused medical and social frontline intervention services, under one roof."

These participants all suggest the formation of Women's Health Hubs would help improve some of the barriers and areas highlighted previously. The precise details varied between participants but this varied between a medicalised 'Well women's' clinic and a more holistic offering of information provision and social frontline services alongside medical care.

Finally, a few participants highlighted that they would value autonomy over the gender of medical professional treating them:

"Be offered the option to choose a female GP, to understand my right to ask or challenge a professional."

"A choice of doctors based on gender, make this a visible option on a poster, so this encourages women to ask. Many of us have been totally intimidated, with feelings of powerlessness by GPs and the health sector, use more visible prompts, and videos on the screens to promote inclusion and choice. More women will then ask for their needs to be met."

One participant focussed on the positive aspect from previous engagement with women centred services that she now felt she understood the smear programme better:

"I understand the importance of smear tests (…) I feel empowered to attend on my own from the information and the groups."

<u>Menopause and healthy ageing</u>

This topic area included two lived experiences which were submitted on the form, both of which were submitted by participants in the later years (51+) age group. Due to the cross-topic nature of women's health, women's experiences of premature menopause have also been included in this topic area. There are also three quotes included from the vision board pertaining to this topic area. Within this theme, as well as content explicitly relating to the menopause, there are also aspects which relate more to healthy female ageing.

The themes found within this topic area include:

- Not listened to by health professional
- Wrong diagnosis
- Given medication to treat symptom without diagnosis
- Lack of appointments for services
- Difficulty to access appointment system

Thematic areas suggested for positive change and improvement:

- To be heard by clinicians
- Improved access to services
- Development of Women's Health Hubs
- Women-centred care
- Request for female health care professional

There are strong echoes of the overarching themes between the menstrual health and gynaecology and menopause domains, the broad thematic areas for this topic area would be:

- Accessibility and barriers to healthcare
- Communication between patient and clinician
- Support and information around the menopause

Accessibility and barriers to healthcare

This thematic area was particularly pertinent to menopause as multiple participants found difficulty accessing both clinical consultations and subsequently hormone replacement therapy during their time of clinical need. This meant that instead of the clinicians being able to ease and treat their symptoms, it lead to a time of increased anxiety.

One participant spoke in depth around her difficulty accessing both of these resources:

"I decided I would try HRT. (…) my only option to converse with my GP was via their website with an option for a telephone conversation, which I did then receive. (…) It was a positive intervention where I was listened to, and where he agreed my suggestion of having my blood taken, so my prescription was the appropriate hormonally balanced replacement. (…) Since this time over 6 months ago, I have been unable to access my GP to get a prescription!"

This service user obviously had an initial positive experience of a consultation regarding menopause and hormone replacement therapy but has subsequently struggled to access the medication she needs. There is a well-publicised ongoing issue regarding general practice access during the pandemic recovery, with increased and unmitigated demand on a background of a resource poor environment. Women and service users approaching the menopause and requesting HRT will be particularly impacted by this as often multiple consultations, reviews and medication changes are needed to optimise the HRT regimen.

Communication between patient and clinician

As well as accessibility, the main thematic area pulled out from this topic area was regarding the actual consultation that many of the service users experienced. There was a concern that many women felt they were being sent away with medication or treated for other things without a full appreciation of the underlying issues:

"Women not being listened to in respect of symptoms of menopause, pacified with anti-depressants for anxiety and mental health – no discussion regarding menopause symptoms, just pick up on anxiety and palpitation, fell that they are dismissed."

"More women's services around menopause. Not being 'fobbed' off with tablets."

"I was referred back to a male GP (who said) he didn't know about menopause… I wasn't made aware of options."

These lived experiences highlight a sense of frustration amongst service users that their symptoms are either not acknowledged or that they are given what they perceive to be a 'sticking plaster' for their symptoms. This potentially highlights a lack of knowledge or clinical confidence in the menopause amongst healthcare professionals.

Support and information around the menopause

The final overarching thematic area is that of information and support and service users highlighted that they felt this was something they struggled to access:

"Better health support and info – we are older ones – what (should) you expect"

"Having better menopause support groups, interventions and holistic advice relating to later in life unavoidabilities."

These participants both highlight the need for further resources allocated to education for women regarding menopause. Combined with the previous thematic area, this highlights that menopause education for service users and clinicians is clearly an area of need.

Cancer

Three out of the five topic areas centre around physical health, the third of which is cancer. The cancers which service users discussed were all gynaecological or breast cancers, but clearly there are a large number of lived experiences of women with all types of cancer who interact with Trafford services. There were three written experiences that contributed to this analysis; two of which were from the middle years age group and one form the later years age group. The cancers included endometrial and breast cancer. There were two middle years participants and one from the later years age group. There was also a quote from the vision board which contributed.

The main thematic areas highlighted from this topic were the following:

- Multiple clinical consultations
- Delayed diagnosis
- Wrong diagnosis
- Given medication to treat symptom only
- Not listened to by health professional
- Not given pain relief

It should be of note that the most common thematic area was multiple clinical consultations, which was a theme across all three lived experiences.

Areas that were highlighted by service users as areas for positive change and development:

- Continuity of care
- To be heard by clinicians/listening to patients

- Macmillan Team support
- Improved explanations
- Understand patients know their own bodies

These can be broadly subdivided into the following sub-thematic areas:

- Continuity concerns and the need for a multi-disciplinary team (MDT) approach
- Effective communication in cancer diagnosis and treatment

Continuity concerns and the need for an MDT approach

The participants who described their cancer journey often spoke of the lack of continuity between consultations and clinicians, a theme previous raised within the topic area of menstrual health. This resulted in significant frustration for the service users.

"(feeling of) being passed between hospitals, between Macmillan teams, all offering different levels of support."

"I also had to tell three different doctors my situation on three different occasions as my wishes were not recorded on my records."

"I have seen 18 consultants/registrars in 5 different hospitals. Retold my gynae history too many times."

It is sobering to observe the impact this lack of continuity has had on the participants. As well as having to see different clinicians, which may come down to the nature of the healthcare system and a resource issue, the participants also highlight the lack of communication between the healthcare teams to ensure some continuity is maintained between individual HCPs. Every participant highlighted continuity of care and provision of Macmillan teams as something that was a priority for change.

Effective communication in cancer diagnosis and treatment

All of the participants highlighted that the lack of explanation and communication during their cancer diagnosis made what was already a distressing process, more confusing and anxiety inducing:

"After attending a cancer exclusion clinic, I was not made aware of what was to follow (…) on one occasion they said that I had to come in for an appointment and when I actually got there it was a procedure to remove a polyp (…) I had already expressed I was anxious and this ended up being a wasted journey as they then had to book me into surgery for the procedure."

"I knew something was wrong and I was not being listened to (…) finally diagnosed (…) with endometrial cancer (…) I was never properly heard."

These lived experiences highlight that these women felt that they had not been listened to and secondarily they had not had interventions such as procedures explained in an effective manner to them. This meant rather than helping and soothing their experience, the HCPs actually increased their anxiety, which is an area for improvement.

There was a positive reflection on this theme regarding MacMillan nurses:

"Macmillan were supportive with a clear description of services offered (…) have a wonderful team who I feel confident with at (hospital) who listen and get back to you."

Finally one of the quotes from the vision board highlighted a general need for information for all women around cancer:

"More (information) around cancer for women (needed)"

Mental health and wellbeing

The fourth topic area concerned the lived experiences of mental health concerns and services of participants. Whilst the previous areas explored the mental health impact of physical pathology, the themes focussed on mental health as the primary issue. There were four participants who gave their stories within this domain. This included two women from the middle years group, one from the adolescent age group and one where this was not stated. There were very diverse lived experiences, ranging from the participant having a mental health condition themselves, the mental health impact of a family bereavement and the health impact of being a carer. One participant from this domain did not give permission for her raw quotes to be used.

Themes within this domain included:

- Lack of appointments for services
- Not heard or not helped by health professional
- Challenges of being a carer for member of family
- Having to chase results of test causing distress

The two most popular themes which were mentioned by multiple participants was the lack of appointments for services and not feeling heard or helped by health professional.

The areas which were suggested for change and positive improvements:

- Improved access to services
- Listening to patients
- Healthcare follow-up ensured
- Support for bereaved families
- Women-centred care

These have been used to create the following broad thematic areas:

- Accessibility and barriers to mental healthcare and services
- Empathy, communication and autonomy

Accessibility and barriers to mental healthcare and services

Multiple service users described a frustration with their inability to be able to access the services they felt they needed at a time when they were already struggling:

"(She) was turned away due to the (mental health) hub being busy and (…) she was upset. She was told to come back another time, each time she went she was told the same thing (…) she gave up in the end and decided not to get help."

Clearly this demonstrates a worrying implication that there were such significant barriers for this participant in seeking mental health services, she did not access them at all, which is likely to have implications in terms of worse outcomes for mental health.

Another participant details that she has a rare mental health condition associated with her menstrual cycle for which she has been referred to a specialist centre but despite an already very

long wait, she has not heard anything regarding her referral which is impacting her mental health further.

Empathy, communication and autonomy

The second thematic area within the mental health and wellbeing group concerns participants feeling acknowledged and heard within the healthcare setting. There were some positive aspects to this domain:

"I think there should be more trained counsellors in place to help with (bereavement), it can be very difficult (…) this has helped me to come to terms with my mum passing because talking to different people and different healthcare (professionals) who helped me to understand it more."

This patient underlines the importance of targeted, empathetic services to help with adverse life events such as bereavement.

<u>Health effects of violence against women and girls</u>

This topic area featured in the lived experiences of two service users from the event, one of whom was from the middle years group and the second of whom was from the later years group. Only one participant gave consent for her direct quotes to be used. A third service user gave a video account of her lived experience and we have also included prescient quotes from this.

The following themes were derived within this topic area:

- Stalked
- Domestic abuse
- Lack of continuity of care
- Substance abuse resulting from experiences of DA

The following improvements in services were suggested by the participants:

- Support for those experiencing domestic abuse
- Awareness of abuse by Authorities
- To be heard by clinicians and empathetic professionals
- Support services for partners of those with mental health issues availability
- Continuity of care
- Improved access to services

There is less raw data that can be used for the analysis of this topic area than others but the overarching themes would be the following:

- Empathetic and consistent care
- Support, awareness and access

Empathetic and consistent care

Participants discussed wanting to feel like they were being listened to and that they were experiencing empathetic and consistent care at such a vulnerable time in their lives:

"Don't want to feel like I'm crying wolf or that I'm being rushed, or crazy and just signposted to somewhere else. Want consistency and continuity. Would like to have had a liaison person who know what's going on and services that are available. Because when I was low and frightened, I couldn't pick up the phone and start to speak to a different person & have to explain things again."

This lived experience details how a perceived lack of continuity of care can even deter service users from accessing important interventions. The concept of a liaison or key worker role is introduced here as a positive intervention.

This service user describes her hopes for a better service:

"we need more caring and helpful attitude. "It's hit and miss if you are listened to""

Support, awareness and access

This theme consisted of service users hoping that they could be cared for by professionals with a good understanding of their trauma and needs, on a timely basis:

"Services that know about trauma and how women feel"

This again introduces the concept of the importance of women-centred care as well as awareness of trauma. Another service user goes on to detail that she wants to see an increase in awareness on the prevalence of abuse and increased support for those who experience abuse.

One participant discussed the difficulties she encountered on her journey with substance misuse, which was a direct result of her experience of domestic abuse, and how she felt supported by her key worker and a targeted women's group:

"(She) introduced me to a women's group (…) full of women, nice and inviting (…) I felt safe, I didn't feel judged (…) I was still drinking"

She goes on to tell a positive story regarding how the group impacted her experience and helped her to overcome her issues with substance misuse:

"I have been in two abusive relationships and I was drinking to help with it (…) things had to change, I was killing myself. (…) After I was attacked, (my support worker) got me onto a detox (…) I had to be sober for the court case. (…) Now I'm sober, I love the groups, I am doing so many activities. (…) This is a relief."

This final quote of the analysis shows the positive impact that good quality, empathetic and well targeted interventions can have on women's lived experiences, even in their most vulnerable moments.

Overarching themes and conclusion

Over the five topic areas, with differing amounts of qualitative data, the following overarching themes for improvement of women's services emerge:

- Empathetic care
- Improved access
- Women-centred care or women's health hubs

The above themes created from the collation of qualitative data can form a base from which we can improve women's services within the Trafford area in accordance with the Women's Health Strategy for England 2022.

We will continue our endeavours to collate women's voices, especially in the areas not included within this document such as fertility and learning disability, and use this grassroots approach to improve the way Trafford serves the women who live within our area.

We will also ensure all women who have contributed to this piece will receive a copy of the work they have so kindly given their voices to.