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WOMEN'S
HEALTH STRATEGY
SUBMISSION

The UK healthcare system is currently failing women. The outcome of this failure is not just fixed within clinical outcomes but also has an impact on women's societal and economic roles in the UK. A culture of shame, stigma, and taboo solidified over decades ensures that women are disempowered to discuss debilitating and life-affecting conditions in all aspects of their lives. With current policy and legislation providing little to no support when women do raise their voices.

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EXPERT ROUNDTABLE



Shakti Dookeran
Innovation Lead
Imperial College Health Partners



Amy Thomson
Founder and CEO
Moody



Jenny Thomas
Programme Director
Digital Health. London



Hannah Samano
Founder and CEO
Unfabled



Dot Zacharias
Co-Founder & COO
Nourish App



Nicole Leeds
Head of Marketing Strategy
Clue



Karina Vazirova
Co-Founder
FemTech Lab



Efftichia Dower
Commercial Solicitor
Stephenson Law



Terri Harris
Head of Community
FemTech Lab

EXECUTIVE SUMMARY

The UK healthcare system is currently failing women. The outcome of this failure is not just fixed within clinical outcomes but also has an impact on women's societal and economic roles in the UK. A culture of shame, stigma, and taboo solidified over decades ensures that women are disempowered to discuss debilitating and life-affecting conditions in all aspects of their lives. With current policy and legislation providing little to no support when women do raise their voices.

The current design of the healthcare system is failing to serve women's needs and is still entrenched in a system designed by men, and for men. This lack of women-centred design means that more often than not women's views are overlooked, not captured and not reflected in the healthcare system. This has created a healthcare system that is unable to keep women safe or to listen to their needs.

Our discussion found that women have been denied basic access to education and information about their bodies from a young age. This lack of information has perpetuated myths, taboos and stigma which damage women's health outcomes and prevent women from starting conversations about their health or seeking support for health issues.

Due to the government's failure to implement policy and legislation which is reflective of women's health needs, women's health issues are continuing to have a deep impact on women's participation in the workforce.

The Government's inaction to implement legislation that increases dialogue among employers and their colleagues, as well as greater recognition of specific conditions and their impact on women's lives is having devastating impacts on women's careers throughout their life course.

An analysis of current literature illustrates a dearth in women's health data which has occurred due to a focus on the male experience of health within all aspects of clinical data collection both within the NHS and medical trials. Generating research and data-driven insights to better understand and tailor services to women's health needs must be an ongoing priority for the government going forward.

There is an increasing need for the government to improve innovation within the healthcare system by opening opportunities for health technology and digital health companies to enter the NHS. FemTech offers an increasing number of innovative solutions that can help to target women's health problems that are overlooked and under prioritised within the current health system. There is a huge opportunity for the NHS to utilise the services, products and software being developed by the FemTech industry for women-specific health issues.

This report builds upon the above statements by outlining our recommendations and summarising current data and expert discussions during our roundtable.

RECOMMENDATIONS

Ensure that women's health strategies reduce inequalities by placing women-voices at the center of the structural design process, and prioritise women's voices and feedback through a user-centered approach. These strategic changes must be prioritised, fully funded and sustained in order to create meaningful change.

Prioritise comprehensive and quality data collection and recording of female-led outcomes as part of routine NHS data collection systems, as well as undertaking a deep analysis of existing data to drive improvement in women's health, and embedding this data into the NHS operating framework so that it is readily available to medical practitioners to inform diagnosis and service pathways.

Support women-led feedback in all aspects of the healthcare system, which is supportive of women's diverse needs (e.g. care responsibilities), and offers safe, inclusive spaces in which women feel confident to share their experiences.

Accelerate opportunities for female health technology and digital health companies to be deployed in a variety of healthcare settings and support NHS staff to implement these technologies within their care pathways for female patients.

Mandate sustained women's health training as part of NHS workforce development, including information on diagnostic tools, signposting to care pathways, utilising technology as a support tool, awareness-raising around eradicating shame and taboo, and incorporating holistic approaches beyond medication to improve the experiences and outcomes of female patients.

Implement partnerships with female health technology companies to collaborate on data collection and data analysis of key women's health topics, to stimulate research and insights into common symptoms and, diagnostic and treatment innovation.

Develop and imbed women's health education and awareness campaigns, working in partnership with other government departments such as Department for Education, to improve understanding and knowledge of female health across the population; reinforce anti-stigma, shame and taboo messages around women's health; and prepare all genders, and all ages, for conversations about women's health across the life-course.

WOMEN'S VOICES

The experts in our roundtable welcome the government's focus on women's voices. As Shakti Dookeran, Innovation Lead at Imperial College Health Partners stated:

“We know that it [the NHS] has predominantly been built by men, so just thinking through the women's voice in the design and the clinical pathways in terms of uptake and access, is definitely something which has been overlooked.”

Stakeholders clearly articulated that the design of the structures within the UK healthcare system was failing to serve the women's needs due to a lack of understanding of what their core needs were.

This is in part due to the fact the healthcare system in the UK has been mostly designed by and for men. In this respect, the design has never centred on women and the issues they face.

As Hannah Samano, Founder of FemTech company Unfabled noted:

“Due to the patriarchy, these systems have never been designed with who the core user is. So unfortunately there is an abyss of ignorance stemming from the male-centred design thinking which has occurred.”

So what reality does this male-centred design create for women accessing healthcare in the UK? Well, despite living longer than men, women spend a greater proportion of their lives in ill health and disability, and there are growing geographic inequalities in women's life expectancy.

Listening to Women

Experts felt a lot more could be done to include the voices of women within the healthcare system, and that often when women's voices had been captured these did not enact real change.

The example of the Royal College of Obstetrics and Gynecology report Better for Women - which surveyed 3,021 women aged 18 to 65 across the UK in August 2019 - was provided. The report outlined the need for a Women's Health Strategy at the time, providing enormous amounts of data that supported its ambition. Yet, as our experts acknowledged no significant change was made.

This tendency to gather feedback with inaction was seen as preventative to women raising their voices on key issues both in clinical settings and in wider society. This was due to the sense of disempowerment it created amongst women who had chosen to raise their voices. Experts also highlighted the role language had to play in this disempowerment, something which is detailed in Section 2.

There was a recognition that maternal health services were often the exception to this rule, as there has been a requirement for many years to have user feedback. However, this is not a requirement within other women's health strategies.

As Jenny Thomas, Programme Director of Digital Health London, outlined:

“Because of how these meetings were organised - they were face-to-face, in a hospital, women had to travel, they had their kids - it was really quite hard to make it really useful! You didn’t hear the voices. Now, since the pandemic, a lot of those user groups have moved online now, and the head midwife of each clinic can have much more contact with women and get more insight into the different community needs.”

Jenny’s point is indicative of the whole group’s feelings. That even when women were given space to voice feedback there were often many barriers to providing that, as their specific needs as care providers, part-time workers or other gender issues were not developed into the design of the feedback sessions.

There was a clear agreement amongst experts that technology could and is currently offering more accessible and immediate feedback options for women. Due to the flexible nature of technology-based feedback approaches, as well as the anonymity offered to users, technology was seen as an excellent way to allow women’s voices to be heard.

Experts repeatedly referred to conditions such as PCOS, Endometriosis and Fibroids and the long diagnosis times for these conditions. The example of Endometriosis diagnosis being roughly 7-9 years for those experiencing symptoms was seen as indicative of women’s voices experiences, and their symptoms being overlooked.

Some experts felt that women’s voices were not being listened to in relation to specific conditions

due to a lack of awareness and knowledge around the diagnosis of these conditions. As Nicole Leeds summarised:

“My understanding from the user journey experience is that this has less to do with women not knowing their cycles, but more to do with practitioners and GPs not being taught how to diagnose.”

I think the timeline for endometriosis diagnosis in the UK is still around 7.5 years. And this is not because women don’t report symptoms, it’s because practitioners don’t know how to diagnose it or how to refer, treat them appropriately.”

However, others believed that these conditions were often overlooked due to issues with capacity, staffing and normalisation of these reproductive health conditions.

As Jenny Thomas, Programme Director at Digital Health London, highlighted through her experience of these diagnosis pathways within the NHS:

“Endometriosis pathways that required surgery from a gynaecologist and a GI-consultant were always particularly challenging because of theatre capacity.”

There was also a belief that the healthcare’s evaluation structures, which focus on streamlining processes and services, also led to women’s symptoms being disregarded or overlooked as clinical staff attempt to meet their delivery requirements.

INFORMATION & EDUCATION

There was a real consensus amongst experts that too often women's health is focused on reproductive health areas, and neglects other key areas of health for women. This is evidenced by the fact that despite women comprise 51 per cent of the population, there is less evidence and data on how conditions affect women differently, despite the fact we know being female puts people at higher risk of some of the most challenging conditions (this is expanded on further in Section 5).

The key concern that was raised was that medical professionals within the NHS just did not have the information necessary to diagnose and support women's health conditions as well as to provide service pathways.

Dot Zacharias, COO of The Nourish App, illustrated this point perfectly through the experience of The Nourish App's users:

“We've spoken to a lot of mother's with experiences of post-natal depression and mild to moderate mental health conditions, and the theme that came up time and time again was that those who had spoken to someone who had been through it before, understood their condition, were so much more likely to get picked up [diagnosed].

There were a lot of people who didn't connect with their professional. And it is that ability to connect and to understand. I'm not saying that people who haven't been through it cannot understand but because there isn't enough education around it then you can't really get your head around it.”

Experts uniformly felt that placing women's health as a priority within the UK healthcare system, and more importantly within clinical training was key. Speaking about the NHS Operating Framework, Jenny Thomas, noted that women's health was really lacking and that this was a main reason for clinicians' lack of understanding as there were few pathways to improving awareness about particular conditions.

As she stated:

“If there are some things that come out of this call for evidence which are the most important then they do need to be embedded in documents like the operating framework.”

Underrepresented Groups

Whilst this submission recognises the important need for the consultation to focus on women's health, it is also important to raise the issue that not all those impacted by poor women's health outcomes identify as female. In particular, trans men, Gender Non-Conforming and non-binary people who do not identify as women, yet still have female reproductive health organs will be impacted by this submission.

An important anecdote by Hannah Samano, Founder of Unfabled, also illustrates the importance of reflecting on the intersectional nature of womanhood, and how protected characteristics such as sexuality can often create barriers to accessing support and information:

“A cis-woman who is queer was presenting with symptoms of endometriosis for the past couple of years and so it was recommended she would get the Mirena coil to test if that would improve her symptoms.

So she went to the GP, and through family planning services, and the first question she was always asked was whether the coil was for ‘contraceptive purposes’. Well, because she’s in a same-sex relationship and it wasn’t for contraceptive purposes she was denied access to the coil for about half a year. This anecdote just proves some of the issues that queer women might face when accessing reproductive health services.”

Empowerment through Information

Experts consistently identified education as an important tool in reducing shame and stigma, increasing women’s confidence in discussing health issues and improving awareness of the services available.

Some experts recognised a need for education to take a more holistic approach to women’s health, in which women’s health across a life course is acknowledged with hormone fluctuations as a central learning point. This disconnect between physical and mental wellbeing from the hormonal cycle was highlighted as an important communication pathway.

As Hannah, Founder of Unfabled highlighted in her experience of working within women’s health:

“My experience of working in the menstrual health space is that women are really out of sync with their hormones, and it’s often not in a way that’s impacting their day-to-day life.

How can we embed very early in the education system, education processes and systems that allow women and girls, as they journey through life, that they are just in sync with their hormonal fluctuations.”

However, many acknowledged that this lack of knowledge was not from lack of want and that many women are curious about their bodies but just lack the opportunity to learn more.

Data from a survey Unfabled undertook with 39 British women showed:

- **100%** did not feel like they had a good education in menstrual health and hormones
- **97%** want to learn more about what causes premenstrual symptoms
- **97%** want practical advice and training on how to improve difficult menstrual symptoms

Some experts suggested utilising public spaces to provide educational resources around women’s health to increase access and awareness of these topics, through partnerships with publishing houses such as Penguin. As Amy Thomson, Founder of Moody proposed:

“There are a lot of women’s health books that are rooted in the academic space but have been made more colloquial, and I think getting those resources and these books available to people, and in audiobook format, provided in libraries and other places. Again, it’s connecting the dots - we have the design, we have the assets, how do we get it into the right hands so more people can access it.”

For our experts, data such as this is evidence of a need to improve health education for women and girls. It was important for many experts that this education started at a young age via the education system, and that a key priority should be to integrate this consultation with the new Sex and Relationships curriculum, to ensure that health information remained consistent across a women's lifetime.

Experts emphasised that this education should not be limited to women and girls, and the importance of engaging men and boys in conversations around women's health. The separation of girls and boys during menstrual education at school was highlighted as a point of concern. With experts agreeing there was a need for a more expansive health education curriculum for both genders, and inclusive of all genders.

THE LIFECOURSE

The pandemic has shown that technology has a vital role to play in the delivery and development of better health outcomes not just for women but the whole population. Therefore, innovations within the FemTech sphere, which are developed and tailored to the specific needs of women, can play a fundamental part in how the UK healthcare system better delivers services to women.

Jenny Thomas highlights perfectly in [her article](#) for Digital Health London, the many opportunities FemTech offers in providing more accessible, more data-driven and innovative solutions to women's health. However, as our experts noted the entry routes into the NHS for FemTech companies are minimal. Nicole Leeds, Head of Marketing Strategy for Clue, emphasised the point perfectly:

“I haven't seen a lot of entry routes into the NHS for apps that were made outside. From the perspective of tech companies trying to engage there isn't an easy route. We are trying to find ways to get the NHS and FemTech to collaborate more.

The only way I have seen at the moment is the NHS digital library... which is paid, and it's treated more like 'you should pay because it gives you access to more users' as opposed to 'we as the NHS really value the role that these companies can play in helping us improve our systems'”

Shakti Dookeran highlighted that beyond the digital library the NHS was already partnering with some FemTech companies to improve women's health through digital:

“The NHS is already working with several FemTech companies, including Peppy Health and Elvie. Healthy.io is one FemTech company that also became a global NHS partner in September 2020. Healthy.io provides urinary tract infection (UTI) detection in many parts of the UK, using urine sample kits, strips, computer vision and artificial intelligence to diagnose women in the comfort of their own home. This further benefits the NHS workforce, saving GP's time and the NHS money.

The Elvie Trainer, for a stronger pelvic floor, is helping the NHS to save £424 per patient. More so, research presented at the International Continence Society annual conference 2017 found that 80% of the women who used Elvie Trainer to treat a problem saw improvements and 98% did so in less than six weeks.”

Experts agreed that there was a need to prioritise specific women's health conditions, and open pathways for FemTech entrepreneurs and companies to engage with the NHS in providing treatments, as well as tracking, diagnostic and management tools. The increasing number of solutions coming from the industry can help to target women's health problems that are often overlooked and under prioritised.

The growing opportunity for the NHS to utilise the services, products and software being developed by the FemTech industry, for women-specific health issues is currently being overlooked. Experts felt it was necessary for the integration of FemTech products into the healthcare system should be a part of the overall Women's Health Strategy.

IN THE WORKPLACE

Workforce Participation

Women's health has a direct and difficult impact on their participation in the workforce. Experts concluded that a culture of silence around women's health issues, lack of understanding and awareness amongst colleagues and a dearth of legislation and policy to direct HR policies around women's health issues were all to blame.

The following evidence speaks to a whole host of structural problems within the workplace which impact women's participation:

- **1 in 4 women** consider leaving their workplace during the menopause transition
- A report by Work Foundation highlights that women's health conditions, such as endometriosis or infertility, having a long-term condition during pregnancy, and the experience of menopause, are still considered **taboo and are under-recognised** in the workplace.
- Women with endometriosis experience reduced work performance, losing on average almost **11 hours of work each week**.

The following anecdotes and experiences were shared by experts illustrating the far-reaching culture of ignorance and dismissal of women's health conditions across all sectors of the British workforce.

Effthichia Dower, Commercial Solicitor at Stephenson Law, shared her experiences within the legal sector:

“In the big city law firms, there was a culture of having to perform and be on my best every single day, and actually the women in charge of me pushed this too. Ultimately I left because I just thought ‘this is not going to work’. There is a belief that as a woman you have to disconnect from your body to complete this work that everyone above you is setting an example of. And you have to work extra hard, and you can't complain because everyone before you has done this.”

Amy Thomson, Founder of Moody, shared her experiences within the business and corporate sector:

“Although we have 25-30% of women in positions of CEOs, when we look at this qualitatively across the board, the conversation around menopause, the reality is that menopause has a hugely challenging impact in the workforce. The gender disparity of these conversations doesn't solve the problem, it's actually about unifying people around conversations of hormone health at all ages. Men are going through these hormonal changes too!”

Shakti Dookeran, Innovation Lead at Imperial College Health Partners, shared her experiences within the NHS:

“I have had a colleague whose symptoms of the menopause were affecting her confidence and ability to concentrate, and she was performance managed. It was awful what she had to go through, and that was within the NHS.”

Another anecdote was provided by experts who referred to Rachel Lord, Senior Managing Director, Chair and Head of Asia-Pacific at BlackRock who shared her experiences of Menopause in a [LinkedIn post](#).

Experts called for the stigma and taboos surrounding women's health to be removed within the workplace. The experts agreed that greater awareness and recognition of conditions and their effects on women, as well as parity of these conditions with other workplace health concerns, would improve things. However, the most important thing experts raised was for legislation and policy to recognise women's health conditions as often debilitating, and to use such policies to increase dialogues amongst employers and businesses.

RESEARCH & DATA

The NHS

Experts emphasised the need for more robust and focused data collection and evaluation in relation to women's health within the NHS. All experts agreed that data drives action, and therefore by better understanding the impact and opportunities of women's health issues across the life course, it would push the prioritisation of certain health conditions.

Shakti Dookeran emphasised this point:

“I think personally we [the NHS] haven't had the opportunity to look into more deeply other women's health issues across the life course. For example, we have lots of data, inquiries and policy publications on maternal health. We have the data, so maternal health is a priority for the NHS.”

It was noted that data on women's health was lacking and that the majority of experts struggled to find comprehensive data on women's health issues that were not related to maternal health.

These issues were summarised by Jenny Thomas when discussing the NHS Operating Framework. She stated:

“If there was more information in there [NHS Operating Framework] about what needed to be collected - so female-led outcomes and things broken down by gender, ethnicity - and maybe particular pathways... [There is a need to] raise awareness about particular conditions and getting the data collection but also demonstrating improvements.”

The importance of data collection was emphasised continually, with experts agreeing that without solid data very little would change in women's health. However, it was highlighted (as above) that the NHS would need to reconfigure its data collection processes and tools to be able to capture the data which is needed.

An example highlighted by Dot Zacharias illustrates this lack of concrete women's health evaluation tools within the NHS:

“I was working with someone from the NHS's digital health team to support our app to get online, and they were explaining that they have this tool which helps us analyse at a local level and you can tag maternity outcomes. Great! But there wasn't one on mental health - so there is a need to review current data sets.”

Women's Health

Experts emphasised the huge disparity in evidence and data on women's health and how conditions affect women differently. This disparity has huge implications for the health and care women receive, their options and awareness of treatments, and the support they can access afterwards. The following data provided by Shakti Dookeran illustrates the gaps which currently exist:

- Being female puts someone at **higher risk of some of the most challenging conditions**. Autoimmune diseases, for example, affect approximately 8% of the global population, but 78% of those affected are women.
- Females are **three times more likely than males to develop rheumatoid arthritis** and **four times more likely to be diagnosed with multiple sclerosis**, an autoimmune disease that attacks the central nervous system.
- Women makeup **two-thirds of people with Alzheimer's disease**, and are three times more likely to have a fatal heart attack than men.
- Women are **at least twice as likely to suffer chronic pain conditions** such as fibromyalgia, chronic fatigue syndrome and chronic Lyme disease.
- On average, women are **diagnosed with heart disease seven to ten years later** than men. This often results in other chronic diseases being prevalent by the time of the diagnosis.
- A University of Leeds study showed women with a total blockage of a coronary artery were **59 per cent more likely to be misdiagnosed than men**, and found that UK women had **more than double the rate of death** in the 30 days following a heart attack compared with men, for example.
- Female life expectancy has also been **improving more slowly than male life expectancy** since the 1980s.

This lack of data was seen to occur because of two major reasons. Firstly, male bias within clinical trials and studies has meant that the majority of healthcare takes the approach that what works for men will also work for women. However, because every cell in a person's body has a sex. This means diseases and medications used to treat them will affect women differently, a fact which has had catastrophic results for women's health.

Secondly, because clinical trials tend to focus on pharmaceutical outcomes, they tend to neglect women's health issues. Amy Thomson believes this is because women's health are areas where business models tend to have little opportunity for patenting or brand equity and are thus not financially viable. With these two issues in mind, experts believe there is a need to generate research and data-driven insights which focus specifically on women's health needs.

There was a strong consensus that even once data and research were gathered in the area of women's health, there was a need to design information in a way that was accessible for medical professionals and women alike.

As Amy Thomson, Founder of Moody highlighted:

“Looking at the intersection of experts and doctors, one of the difficult things about the research and academic space is that people are working in silos - so how do we create better information deployment? As well as how we connect and utilise networks across those spaces.”

Experts noted the power of FemTech to change the current system due to the data sets which many companies have regarding women's health and their ability to communicate these topics with a range of stakeholders.

Through anonymised data FemTech companies are able to ascertain the impact their solutions have had on patients, provide key data sets regarding under-researched health conditions and consult on best-practice solutions for evaluating women's health.

As Amy Thomson, Founder of Moody suggested:

“Moody anonymises data which we would love to use, with the permission of our users, utilise for research purposes. How can we potentially use this as a resource?”

FemTech offers an increasing number of innovative solutions that can help to target women's health problems that are overlooked and under prioritised within the current health system. There is a huge opportunity for the NHS to utilise the services, products and software being developed by the FemTech industry for women-specific health issues.

LITERATURE REVIEW

With particular thanks to Shakti Dookeran for her rapid literature review prior to our discussions.

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