WRITTEN EVIDENCE TO THE WOMEN AND EQUALITIES COMMITTEE ON WOMEN'S REPRODUCTIVE HEALTH (SEPTEMBER 2023)

A short inquiry to look at women's reproductive health and the challenges that women face when they are being diagnosed and treated for these conditions. The inquiry will consider any disparities that exist in the diagnosis and treatment, and the impact of women's experiences on their health and lives.

Introduction for inquiry

Muslim Women's Network UK (MWNUK) is a national charity (reg. no. 1155092) that works primarily to improve social justice and equality for Muslim women and girls. We are informed by lived experiences by our national membership, research projects and national culturally sensitive helpline and counselling service. This work informs our resources, training, campaigning and our advocacy work.

We help and support women from diverse demographics in terms of age, socio-economic backgrounds, education levels, religiosity and ethnicities (Arab, Afghan, Bangladeshi, Black African / Caribbean, Indian, Pakistani, Other South Asian and White etc). Further information can be found on our websites: www.mwnuk.co.uk and www.mwnhelpline.co.uk and www.mwnhub.com. We also help small number of service users from non-minority backgrounds and men.

Why are we responding to the inquiry?

The women's health strategy does not sufficiently address the health needs of women from racialised minority communities that is why are responding to this specific inquiry. In order to improve services and raise standards of care, it is essential that women's voices and experiences (particularly Muslim/ racialised minority women) inform the development and delivery of health care services. Their experiences should be considered throughout the decision-making structures and processes. Before addressing the questions set out in this inquiry it is imperative to stress that existing data and studies that have been already published including our **INVISIBLE - MATERNITY EXPERIENCES OF MUSLIM WOMEN (July 2022)** demonstrate that there is significant barriers and disparities for BAME women in reproductive health. The women's reproductive health Inquiry should have considered questions around interventions and strategies that need to be in place to tackle head on barriers and disparities in reproductive health. As stated in the Women's health strategy for England that women's experiences of health services varied by characteristics such as age,

ethnicity and disability. Some of the barriers and challenges faced by Muslim women also will be faced by other minority groups especially those with intersectional identities.

The term 'racialised minority (communities)' has been used because unlike 'BAME,' it does not privilege or erase any particular social group according to real or imagined physical characteristics such as skin colour, within a system where 'whiteness' is considered the norm. Conversely, it does acknowledge that all groups are subjected to processes of racialisation, that they are not part of a single minority but may be located at the intersection of several different minoritised groups. However, the term 'BAME' (Black, Asian, and Minority Ethnic) or 'minority ethnic groups' has also been used because its use is more widespread in the UK.

Our membership that consists of Muslim Women from diverse and intersectional backgrounds have responded overwhelmingly with their lived experiences which will be embedded in our responses **(psydeoums have been used)** to demonstrate the need for radical action needed to ensure that in the treatment and diagnosis of gynaecological conditions that obstacles are replaced with inclusive service provision that caters to all women.

We will be drawing from our women's health strategy written evidence throughout this inquiry response. Please see the following link to access our women's health strategy written evidence: https://mwnuk.co.uk/resourcesDetail.php?id=243

Evidence:

What constitutes healthy periods and reproductive health:

Women and girls' experience periods in a different way throughout their lives depending on age and multitude of other factors. A good way of thinking about this is that your period shouldn't stop you doing the things you would normally. The length[1]of the menstrual cycle varies from woman to woman, but the average is to have periods every 28 days.

We have come across an example through our outreach work regarding an Islamic school that was tracking period cycles of their female pupils by keeping a period register. Muslim Women and girls are exempt from praying when they are on their periods. The information in the register was therefore used against girls who were opting out of prayers as they were on their periods. If for example they were opting out of prayers prior to their next period due date. Unfortunately, we do not think this is an isolated incident as highlighted by a case featured in the media (Lady Aisha Academy in Barking [2].) Such sexist attitudes and practices strip girls of their dignity and is also likely to be breaching the Equality 2010 Act. Such policing of girl's bodies will contribute to poor self-esteem and low confidence of young Muslim girls who may not be believed that they are having irregular periods. Which is a

[1] https://www.nhs.uk/conditions/periods/fertility-in-the-menstrual-cycle/
[2] https://www.standard.co.uk/news/london/private-school-faces-scrutiny-after-tracking-pupils-periods-a4295571.html

personal matter and should be of no business of the teaching staff or governing body. Ofsted inspections should ensure that they check and challenge faith-based schools are keeping period register and ensure that they are barred.

Regular cycles that are longer or shorter than this, from 23 to 35 days, are normal. The menstrual cycle is the time from the first day of a woman's period to the day before her next period. Girls can start their periods anywhere from age 8 upwards, but the average is around 12 years. The average age for the menopause (when periods stop) in this country is 51. Between the ages of 12 and 52, a woman will have around 480 periods, or fewer if she has any pregnancies.

With that said for some women defining a healthy menstrual cycle depends very much on their cycle length and pain experienced to determine a “healthy” period. The healthy in healthy periods and reproductive health is relative as health looks differently across all individuals. Symptoms associated with menstrual and reproductive health (E.g. fatigue, brain fog, PMS, PMDD, fertility struggles, reproductive illnesses and diseases such as STDs and cervical cancer) should be considered proportionately depending on someone’s age, disability, ethnicity, etc in order to determine their individual healthy period and healthy reproductive health definitions. Conditions such as polycystic ovary syndrome (PCOS), endometriosis, uterine fibroids, adenomyosis and pelvic inflammatory disease can affect reproductive health. Healthy periods are less likely to be associated with these disorders. Furthermore, reproductive health also includes emotional well-being during menstruation. While mood swings and mild emotional changes are common, severe mood disturbances or depression may require attention.

One of our members who is a Muslim Educator stressed that amongst her 13 to 18 cohort periods aren’t talked about with taking onboard faith and cultural sensitivities within schools and that often teenagers might be suffering in silence or menstruation is simply seen as a dirty thing to be hidden and not talked about and so if there were ‘problems’ that a girl or woman was experiencing around their menstrual cycle, they would be less likely to feel OK about seeking help or talking to someone about it. This increases the likelihood of Muslim women and girls being diagnosed much later with any gynaecological issues.

2.) What are women’s experiences of being diagnosed with, undergoing procedures and being treated for gynaecological or urogynaecological conditions:

Women's experiences of vary greatly depending on the specific condition, individual circumstances, and healthcare provider. The process of being diagnosed with condition can be overwhelming and may involve various medical tests, such as pelvic exams, ultrasounds, blood tests, or biopsies. Women may experience anxiety, fear, or confusion during this stage, especially if the condition is chronic or potentially serious. Receiving a diagnosis for a can have emotional implications. Mental health services should be made available during the diagnosis and treatment processes. Women may be offered non-surgical interventions, such as medication, physical therapy, or lifestyle changes. In some cases, surgical procedures may be recommended. Understanding the available treatment options, their benefits, risks, and potential outcomes is crucial for making informed decisions.

Effective communication with healthcare providers is essential for women to feel heard, understood, and involved in their treatment. Women may have different preferences regarding their treatment plan, and it is important for healthcare providers to listen to their concerns, answer questions, and provide clear explanations. However, we are concerned that there are communication barriers that impact women who are visually impaired, neurodiverse, require BSL and have poor mental health.

During[3] health conversations some Muslim women and girls have encountered tones and phrases that have made them feel judged and unwelcome. They feel that such phases and tone have been used due to their race and/or faith (which could have been indicated by their clothing, such as wearing hijab). If Muslim women detect negativity through such micro-aggressions then they are generally less likely to ask questions or raise concerns about their symptoms or ask important questions about their healthcare. It is therefore crucial that the language used and mannerisms are inclusive and respectful. Phrases that imply bias or may be stigmatising, even inadvertently, must be avoided as otherwise those already marginalised in the healthcare system are at risk of being excluded further.

3.) What disparities exist in the treatment and diagnosis of gynaecological or urogynecological conditions:

Factors such as socioeconomic status, postcode lotteries, lack educational resources in accessible formats for local communities and availability of healthcare facilities can create barriers to timely and appropriate care. Women from marginalized communities, low-income backgrounds, or rural areas may face challenges in accessing specialised gynecological care. Due to the current cost of living crisis travelling to appointments is a barrier to accessing treatments and further those with care responsibilities would not able to attend appointments. Muslims[4]are one of the two groups who have the highest percentage of unpaid carers and additionally Muslims have a higher percentage of lone parent households with dependent children 10.4% (77,000) compared to the general population (7.2%). Deep inequalities are perhaps the most evident in gynaecological health. For example, there is a lower uptake of cancer screening (cervical screening is a case[5] in point) among BAME women and cancer incidence and mortality rates are higher among more deprived communities[6] (including many cancers in women). For example, Black women in England are almost twice as likely to be diagnosed with advanced breast cancer[7] as white women. Do these statistics show that they are not being reached by healthcare services with information about symptoms or screening services or do women find it hard to access services for some other reason? It is important to investigate the factors contributing to lower uptake of screening and the delay in diagnosis.

[3] https://www.mwnuk.co.uk/resourcesDetail.php?id=243
[4] (Source 2011 Census, England and Wales).
[5] Please see following article in The Sun: https://www.thesun.co.uk/news/9943249/cervical-cancer-hotspots-mapped-smear-tests/
[6] Please see following link: https://www.bma.org.uk/media/2112/bma-womens-health-cancer-in-women-aug-2018.pdf
[7] Please see following BBC article: https://www.bbc.co.uk/news/health-37991460

A 2017 investigation coordinated by the All-Party Parliamentary Group on Women's Health[8] concluded that there were serious shortcomings in the provision of women's physical, mental and gynaecological healthcare. It found that negative attitudes, lack of information and choice, cost considerations and short-term thinking were the key issue areas. The Royal College of Obstetricians & Gynaecologists (RCOG) published its 'Better for Women' report[9] in December 2019 which also found that, too often, women and girls are struggling to get the right information and that health services were missing opportunities to ask the right questions, prevent illness and ensure the best outcomes.

It is evident from women reporting their experiences (thorough various research) that the health care system is not meeting their needs, particularly where Muslim/BAME women are concerned. Their specific health requirements continue to be overlooked across all life stages - from adolescence and young adulthood, to the middle and reproductive years and to menopause and later years. Women of a lower socio-economic status and BAME women lag even further behind in accessing care, receiving quality of care and improved outcomes.

Muslim women may receive suboptimal care due to factors such as lack of cultural competence among healthcare providers, language barriers, or implicit biases. This can lead to delayed or inaccurate diagnoses, inadequate treatment options, and poorer health outcomes.

Stigma surrounding gynecological and urogynecological conditions can affect diagnosis and treatment. Cultural beliefs, taboos, and misconceptions may prevent women from seeking timely medical care or discussing their symptoms openly. This can lead to delays in diagnosis, inadequate treatment, and poorer health outcomes. Disparities exist in the inclusion and representation of diverse populations in research studies and clinical trials related to gynecological and urogynecological conditions. This can limit the generalizability of findings and hinder the development of tailored treatments for specific populations. These disparities exist very much at the initial enquiry stages for Muslim women who are experiencing a gynecological condition as demonstrated in **case study 1** below:

Fatoum spoke to her GP about obtaining further information about a specific gynaecological condition, her GP not only dismissed her concerns but said she was wasting GP time and maybe she would prefer to see Nurse in the future. The GP continued to inform Fatoum that her symptoms do not seem that "bad" and that she should be able manage for now. Fatoum said she felt dismissed and felt she was spoken to like this because she was a Muslim Woman and English wasn't her first language so she was perceived as "uneducated". Fatoum returned to see the same GP with her English Partner and she was treated much more holistically and was able to have a constructive discussion with her in the presence of her English partner.

Fatoum's case study demonstrates the dangers of viewing BAME/Muslim women as uneducated and dismissing concerns about their gynaecological health, such attitudes will

[8] 16 APPG on Women's Health (2017): http://www.appgwomenshealth.org/inquiry2017
[9] RCOG (2019): https://www.rcog.org.uk/better-for-women

further deepen disparities and leave many women not seeking a diagnosis and missing out on crucial treatment due to racist and Islamophobia.

Addressing these disparities requires a multi-faceted approach, including improving access to healthcare, promoting cultural competence among healthcare providers, addressing implicit biases, increasing diversity in research and clinical trials, and raising awareness about gynecological and urogynecological conditions to reduce stigma and encourage early diagnosis and treatment.

4.) **What barriers exist in the treatment and diagnosis of gynaecological or urogynaecological conditions:**

Some Muslim women may not be willing to try contraceptive methods as part of the management of gynaecological conditions such as pre-menstrual syndrome or endometriosis. This is mainly due to religious or cultural reasons. They therefore for should be provided with alternative options however other maybe Muslim women may be willing to consider contraceptive methods but are not provided with these options due to stereotypes. The main reason for lack of uptake is inadequate or lack of education on the importance of cervical screening due to cultural taboos regarding discussions about sex and gynaecological problems within their families and amongst communities. Inadequate education also comes from language barriers. Information resources in multiple languages on cervical screening and reassurance that the procedure is carried out by a female practitioner is really important to improve uptake of the procedure. Having healthcare professionals or training health champions who are women from those communities to educate the women in their languages is also vitally important.

Another example of informational needs of BAME women not being met is access to information about contraception, particularly in respect of long-acting contraception. Not having this information may be resulting in unintended pregnancies and abortions, which in turn can have a negative impact on mental health. How women receive this information should also be widened further. For example, Muslim women may not feel comfortable speaking to their GP about such a personal issue, especially if the GP is a man and/or from the same ethnic/faith background; women have indicated they find it awkward and embarrassing. New approaches should include addressing inequalities in sexual health and reproductive health by working with the BAME women's voluntary/charity sector as they can access women, are trusted by them and can also advise on the best approaches for different segments of the BAME women's population. It is also important to remember the faith elements which may be involved in so far as Muslim women are involved. They may have been told from an early age that contraception is wrong and it is important that correct information and advice is provided to them that challenges spiritual myths.

Another common theme is Muslim women and women racialised minority ethnic backgrounds not being believed about the level of pain and suffering they are experiencing or the impact of the pain on their quality of life; resulting in them not being offered treatment to alleviate symptoms or given pain relief

Doctors do not always recognise when symptoms may be having a major impact on women's quality of life, thus leading to under-treatment. For example, Polycystic Ovarian Syndrome (PCOS) is one of the most common endocrine disorders in women and is more prevalent amongst young South Asian adolescents and women. However, it can often be overlooked even though it can result in obesity, excess body hair, and acne, which in turn can cause physical scarring and emotional distress. As mentioned earlier, language matters. During health conversations some women and girls have encountered tones and phrases that make them feel judged and unwelcome e.g., when diagnosing polycystic ovary syndrome (PCOS) in adolescents, weight gain is not always spoken about sensitively despite the high incidence of eating disorders in this population. Later in life the PCOS can also result in diabetes, heart disease and infertility. Given that PCOS is potentially linked to higher incidence of perinatal morbidity from gestational diabetes, pregnancy-induced hypertension, and preeclampsia and that South Asian women (and their babies) have a higher mortality rates, such conditions should be given greater attention much earlier in a woman's life.

Overwhelmingly PCOS was common issue brought by many of our members who expressed great concern on barriers in getting a diagnosis and often the blanket treatment given was "lose weight" however factors such as excessive facial hair growth were not viewed as serious or valid concerns around body confidence. For example, one of members Sekinah (**case 2)** was diagnosed with PCOS at age 14, she was told that this is weight related and if she lost the weight then the other symptoms would be reduced however for years Sekinah developed excessive hair growth even with steady weight loss and it severely impacted her mental health to the point she stopped socialising, turned down jobs and became isolated. Eventually her family paid for laser hair removal as they were gravely worried about her wellbeing and body confidence. Whilst Sekinah did share these concerns with both her GP and Gynaecologist it was not seen as important and it was blanket solutions about weight loss. More research needs to be done around treatment for PCOS and this should be led by those patients with lived experiences who would be able to highlight what specialist support should put in place.

Addressing these barriers requires efforts to increase awareness and education about gynaecological and urogynecological conditions, reduce stigma, improve access to healthcare services, enhance cultural competence among healthcare providers, and promote research and innovation in the field. Additionally, policy changes and healthcare system reforms are necessary to ensure equitable access to diagnosis and treatment for all women.

The Women's Health Strategy for England strategy sets out a six-point long-term plan for transformational change one which includes: *Addressing*[10] *disparities in outcomes amongst women – ensuring that a woman's age, ethnicity, sexuality, disability, or where she is from does not impact upon her ability to access services, or the treatment they receive.* Whilst the women's health strategy s long term plan aims to improve women's health over the next ten years nevertheless to tackle the barriers faced by BAME Women with gynaecological and urogynecological conditions we recommend that an impendent specialist working group

[10] https://www.gov.uk/government/publications/womens-health-strategy-for-england

should be setup to develop a robust and detailed health strategy for specialist group such as those with protected characteristics.

On behalf of Muslim Women's Network UK,

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