

Black Women's Reproductive Health

Project Report

July 2022



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Acknowledgements

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Acronyms

BAME	Black and Minority Ethnic
BWRH	Black Women’s Reproductive Health (project)
BWMH	Black Women’s Menstrual Health (project)
GP	General Practitioner
NICE	National Institute for Health and Care Excellence
PCOS	Polycystic ovary syndrome
TAP	The African Project
UK	United Kingdom
USA	United States of America
WOC	Women of Colour

Glossary

Beneficiaries	Refers to those within the project's chosen cohort who completed the project's survey reflecting that those who contributed to the data collection and research stage are also primarily benefitting from the project's mission and aims.
Black British	This project has adopted the definition as defined by Wikipedia: <i>Black British people are a multi-ethnic group of British citizens of either African or African-Caribbean (sometimes called "Afro-Caribbean") descent.</i>
BWMH.	The Black Women's Menstrual Health Project. The project's original name when it rested under initial charity, Freedom4Girls UK.
BWRH	The Black Women's Reproductive Health Project.
Endometriosis	A chronic inflammatory disease caused by the implantation of tissue similar to the lining of the womb elsewhere, most typically found within the pelvis. This disease impacts an estimated 10% of women of reproductive age (more research is needed to better understand the experience of endometriosis in transgender and non-binary people), and is associated with chronic pain, infertility, reduced quality of life, amongst many others.
Grey Literature	Sources of relevant literature which are not peer reviewed journal articles. Grey literature used in this piece of work includes articles and blog posts written by Black women and reports from the UK Government, the National Health Service, and non-for-profit organisations such as humanitarian charities.
Healthcare Providers	Refers to organisations whose primary remit is to provide healthcare assistance, support, care and treatment for physical health conditions. Worthy of note, not all Healthcare Providers who were invited into the project and/or engaged with the project specialised or practiced solely in female reproductive health.
Misogynoir	Refers to the anti-black and sexist prejudice experienced by Black women alone.
Misogyny	Dislike of, contempt for, or ingrained prejudice against women.
Participants	reflects those beneficiaries who engaged in the Focus Groups and/or Peer Support Groups.
Pelvic Pain	Pelvic pain is felt in the lower part of your tummy. The type of pain varies, and it may be sudden and severe (acute pelvic pain) or last 6 months or longer (chronic pelvic pain).
People with female reproductive systems	Refers to people who have female reproductive systems and whom can relate to the experiences and issues raised within this project, but whom may not identify as women and/or female. This includes transgender men, non-binary people and gender fluid individuals. Due to the wide range of health conditions, symptoms and issues that are drawn from this project, the reference to 'female reproductive system' was determined the most concise and clear way to articulate the range of beneficiaries that this project aims to support.
Period Pain	Are pains that occur due to your menstrual cycle. The NHS defines period pains as It's usually felt as painful muscle cramps in the tummy, which can spread to the back and thighs.

	The pain sometimes comes in intense spasms, while at other times it may be dull but more constant. It may also vary with each period. Some periods may cause little or no discomfort, while others may be more painful. Sometimes you may get pelvic pain even when you do not have your period.
Poly-cystic ovary syndrome	<p>Polycystic ovary syndrome (PCOS) is a common condition that affects how a woman's ovaries work. The 3 main features of PCOS are:</p> <ul style="list-style-type: none"> • Irregular periods, which means your ovaries do not regularly release eggs, (ovulation) are: irregular periods – which means your ovaries do not regularly release eggs (ovulation) • excess androgen • high levels of "male" hormones in your body, which may cause physical signs such as excess facial or body hair • polycystic ovaries – your ovaries become enlarged and contain many fluid-filled sacs (follicles) that surround the eggs (but despite the name, you do not actually have cysts if you have PCOS)
Project and Research Team	<ul style="list-style-type: none"> - Project Coordinator - reflects members of the team who contributed and coordinated the primary stages of the project's development and delivery, including initial concept, survey design, survey promotion, focus and peer support group design and promotion and so on. - Research Lead – refers to members of the team who took chief responsibility in researching external sources, literature and data that was considered towards this project; and further references team members who had responsibility for data collection towards the 'research' part of this project. - Report Writer – refers to team members who had responsibility in contributing to the drafting and development of this report. - Peer Support Group Facilitator - are those team members who were responsible for development and delivery of the peer support groups, (pre, during and post sessions). - Events Organiser – reflects members of the team who lead the August 2022 Report Launch and Showcase Event. - Volunteer - refers to members of the team who contributed to an array of activities that supported the project's mission, aims and overall delivery.
Support Organisations	Voluntary, community and/or third sector organisations whose mission and aims is to support and represent our chosen cohort.
Uterine Fibroids	Are non-cancerous growths that develop in or around the womb, (uterus). The growths are made up of muscle and fibrous tissue, and vary in size.
Women	Refers to people whom have female reproductive systems and identify as women.



Executive summary

Systemic and institutional racism is present and prevalent in most, if not all, sectors. We live in a world that is not yet free from its history of colonialism, oppressive imperialism and where a select few benefit from mass inequality.

It was the summer of 2020. The world was stuck indoors, glued to our phones as we witnessed the murder of George Floyd. For people who have worked in and campaigned for a better, fairer, and more just criminal justice system, as myself, there is widespread acknowledgement that police brutality towards the Black community is an everyday reality; George was not the first, nor will he be the last, Black person to lose his life as a result of engrained racial biases and accepted institutional racism. Yet, the 13-minute video of his death was enough to spark peoples' attention back, or in many cases for the first time, towards the Black Lives Matter movement.

At the time, the Black Women's Reproductive Health project team, (previously Black Women's Menstrual Health project), under period poverty charity, Freedom4Girls UK, sat back and took time to assess the rise in this activism; what did it mean generally for addressing systemic racism and conscious and unconscious biases against Black people? What did it mean for our work representing Black women and people who menstruate across Leeds, West Yorkshire and regions of East Africa?

The data we came across concerning Black women's reproductive health justice was, unfortunately, not surprising. Thanks to the courageous, innovative and tireless work of campaigners and organisations like [Five x More](#), research showed us that Black women going through poor maternal health, pregnancy or labour complications, were five times more likely to experience serious or fatal consequences than women from other racial backgrounds.

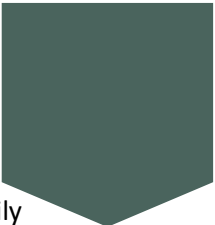
The decision our team then made was pretty simple: pregnancy cannot happen without periods, and periods were our bag.

You're reading this because you care about the state of Black women's reproductive health. This is the Black Women's Reproductive Health Project, (BWRH). We are a team of volunteers working to highlight the experiences of Black women and people with female reproductive systems' menstrual and reproductive health needs.

Since October 2020 over 165 Black British women have spoken to us about their periods, their general reproductive health needs and how seeking healthcare support has made this better, the same or worse. We've analysed their words and considered how misogyny and racism have impacted their experiences; now we're ready to share this with you.

Within this report you'll see that our work and research have gone further in the field of menstrual and female reproductive health for Black British and Black-mixed British women than any other UK research piece has before. Some of our greatest findings evidence that:

Black women's experience, awareness and understanding of their period pain is challenging, internally in respect of whether said pain is 'normal;' externally in respect of how it impacts their day to day lives including overall wellbeing and access to work; and in relation to how reporting that pain to healthcare providers is or isn't actioned upon appropriately or at all.



Black women's understanding of menstrual and reproductive health conditions is limited, primarily owing to the lack of adequate menstrual health education and more broadly, as a result of widespread stigmas associated with periods and women's gynaecological health.

And in conjunction with both of these points, that access to care and support for said conditions is lacking, inadequate and framed by unconscious and conscious biases in a racist healthcare system.

This report is the start of the journey of this project. Whilst our project aims are much wider than purely data collection and analysis, this report acts as necessary evidence and justification of why schemes like the Black Women's Reproductive Health project and generally, why approaches that centre the experiences of women based on their individual backgrounds, including specificity concerning racial heritage, economic status and so on, should be looked at through individual lenses.

We are the first menstrual-reproductive report to solely focus on women of African and African-Caribbean heritage, and we did that because 'BAME' is no longer an appropriate term or cause of action if society is seriously committed to eradicating racism. My life experience, including my experiences of seeking female reproductive healthcare support as a woman of mixed-African heritage, will not be the same as my friends of South Asian heritage nor of my friends who are Black women. Our project seeks to represent each cohort's experiences and therefore their needs, separately to achieve equality; whilst we are proud to be women of colour, women of colour are not one homogenous group.

Further, this project is committed to using its findings to provide tangible improvements for the beneficiaries we serve. As well as continued campaigning for racial equity in this space, we will be continuing to provide support and education. This will be via a detailed and accessible information/education resource that seeks to empower, develop confidence and act as an advocacy tool for Black women seeking gynaecological healthcare support. We will also continue to develop the peer support groups both online and in the community, to reach and support more Black women in their reproductive health journey, wherever it finds them. By working together, we can strive to achieve improved reporting on Black women's experience of reproductive health across the lifespan, with the hope of one day improving the racialised disparities that both pervade healthcare and contribute to the dismissal, mistreatment and devastating outcomes for Black women accessing care.

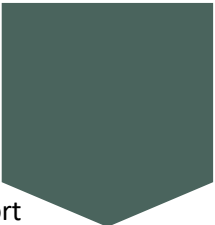
Finally, thank you.

Thank you to [Freedom4Girls](#) for supporting in the development of this project in the 2020 early pandemic days, when we were seeing a SEVEN TIMES increase in requests for access to free period products because of how much people who menstruate were struggling.

Thank you to [The African Pot Project](#) of my hometown, Manchester, who work hard, create meaningful solutions in the fight against racism day in and day out, concentrating on their four pillars of service; education, community, business and health.

Thank you mostly to my amazing team! This is a longer Executive Summary than you typically find in research pieces, but as you will see in the report and as this project continues to develop, we are radical, we are different, and we are proud of that.

Thank you to Christine, Danielle, Holly and Isabelle for your ongoing commitment and dedication to this work. You have given up your evenings, weekends, lunch times, in person and online, all



voluntarily (!) to ensure we made something meaningful. This project and the outcomes of this report reflect your work as allies and as amazing women who want to see change in the world.

Thank you to Jasmine for being my right-hand-woman in the preparation and management of the launch event on top of all the work you've done towards the report; we and I would not have made it through this last month without you!

Thank you to Simran for conducting the most extensive literature review we think there has ever been concerning the gynaecological experiences of Black British women!

Thank you to our volunteer Laura for her ongoing support, to Sheona and Tina from Freedom4Girls and to Otis, Alexandra and the rest of the team at T.A.P for the ongoing moral support.

And finally thank *you*, for choosing to invest some of your time into our work. The state of affairs for Black women in this space has been shocking and disgusting for long enough. It is unacceptable. Please do join us in our project's next steps to achieve change in the space: we've only just begun.

Peace and period love,


Tora

The BWRH project works with and represents women and people with female reproductive systems who are of African and/ or African - Caribbean heritage. While our project has largely included female participants, as our work progresses, we hope to further capture the lived experienced of transgender men, non-binary, gender non-conforming and gender fluid folks.

We do refer to Black women throughout this report and in other areas of this project, and we do so necessarily, as the rights, needs and well-being of Black women is a human rights and a political issue. As a team we concluded it was necessary to maintain this representation and to be clear about our project's aims and political stance.

Table of Contents

<i>Acknowledgements</i>	<i>i</i>
<i>Acronyms</i>	<i>ii</i>
<i>Glossary</i>	<i>ii</i>
<i>Executive summary</i>	<i>iv</i>
1. Introduction	1
Literature Review: What we know already	2
2. Scope and methodology	8
Sample selection	8
Research design and procedure	9
Data analysis	10
Literature review	10
3. Results	13
Survey findings	13
Demographic profile of respondents	13
General health	15
Missed work	17
Access to care and support	19
Access to education	21
4. Discussion	24
Pain, pain awareness & general health	24
Missed work	26
Lack of good quality menstrual-reproductive education	27
5. Conclusion and Recommendations	32
Recommendations:	35
6. Project: next steps	38
We need more data	38
How will we achieve this?	39
A Final Thank You	41
<i>References</i>	<i>43</i>
<i>Annex 1: Community groups contacted</i>	<i>47</i>



<i>Annex 2: BWRH Surveys</i> -----	48
<i>Annex 3: Focus group and peer support group agendas</i> -----	53
<i>Annex 4: The importance of lived experience</i> -----	57
<i>Annex 5: Flowchart of literature review methods</i> -----	59



1. Introduction

There is an urgent need to thoroughly explore the menstrual health experiences amongst Black African and Black African-Caribbean communities. This area of much needed investigation is under-researched – there is a requirement for the documentation of menstrual experience itself and the experiences of seeking healthcare to manage their disruptions to or pathologies associated with their cycle.

Literature has documented the experiences of menstruation; however, the current body of menstrual health literature is deeply problematic. Whilst studies within gynaecological health literature often involve women across various ethnic divides, there is a consistently low percentage of Black women involved in these studies. Currently, menstrual health literature represents only the experiences of White women and therefore, does not consider the unique issues and challenges faced by Black women e.g. the impact of misogynoir on health outcomes.


There is no single piece of published research to date which thoroughly documents both the experiences of Black British women who menstruate and their experiences of accessing healthcare to manage their cycle. In order to work toward combating existing health inequalities within the field of gynaecological healthcare, it is integral that the voices of Black women are heard. It is only then when we have a thorough understanding of the menstrual experiences of Black Women, that we can shape healthcare services to provide good quality, culturally sensitive care.

Further, and from the outset, we reference the project's decision to move from Black Women's Menstrual Health project to the Black Women's Reproductive Health Project.

It is integral to note that the importance of menstrual health cannot be understated within the wider context of reproductive health. Within women's health literature, there is a large focus on maternal health outcomes and little focus on menstrual health issues. Considering that the stark racial disparities in maternal mortality illustrates a culture of systemic racism (within healthcare) toward Black women, we of course recognise and acknowledge the importance of maternal health research. We are thankful to the work of organisations such as Five x More in spearheading research and awareness raising in the maternal health space for Black British women.

However, we also argue the body of women's health literature needs to be supplemented with research investigating menstrual health experiences and disorders, which are part of the puzzle of reproductive healthcare. Menstrual health is an extension of gynaecological health and therefore, should be acknowledged and treated as such.

Chronic conditions such as the growth of fibroids, endometriosis and Polycystic ovary syndrome, influence both the ability to get pregnant and the healthcare care needs of women when they do become pregnant. As poor menstrual health related conditions can clearly have a knock-on effect on women's reproduction, it is vital to capture the barriers that Black women face in having their menstrual health related needs attended to effectively. Furthermore, the existence of pre-reproductive-menstrual conditions that are under diagnosed, under researched and underfunded, has created a culture where women are forced to take a 'grin and bear it' approach to the subject of gynaecological pain and distress. If research can thoroughly explore the nature and ways in which existing, menstrual-reproductive health conditions result in poor health outcomes for Black women, this moves us closer to tackling such outcomes.



Menstrual taboo, misogyny, dismissal of pain and lack of gynaecological related research, are all components which need to be acknowledged and studied in order to inform policy and therefore improve the reproductive health outcomes of Black women.

This report is part of a pilot project and acts as a baseline, discovery data to a previously untapped area within the gynaecological and female reproductive health sector. Whilst we are excited about the evidence we have created, the BWRH team acknowledges there is still much work to do in improving the healthcare outcomes for Black British women and people with female reproductive health conditions; this report is our commitment towards the first stages of that.

Thank you for investing time into reviewing the data we have collected, analysed and presented as part of our efforts into reducing systemic racism, conscious and unconscious biases that exist in female menstrual-reproductive health.

Literature Review: What we know already


Gendered and ethnic disparities within pain management

The pain caused by menstrual cramps – commonly known as dysmenorrhea, is one of the threads connecting the menstrual experiences of people around the globe. The burden of dysmenorrhea is larger than any other gynaecological related complaint seen in the developed world (Patel et al., 2006). Dysmenorrhea is also one of the main contributors of school and work absenteeism (Santos et al., 2017) and over 1 million British students between 14 – 21, missed school, citing dysmenorrhea as the main factor (Plan international, 2018).

The gendered perception of pain refers to the fact that historically, women's pain and discomfort has been dismissed by healthcare professionals and the systems around them. This is not least illustrated by the ways in which endometriosis is viewed within society. Endometriosis - referred to as the "missed disease" (Hudson, 2022) is a debilitating condition where endometrial-like tissue grows outside of the uterus, resulting in pelvic pain, fatigue, fertility issues and many other health issues such as fibromyalgia (Bellelis et al., 2010). We know that for many, endometriosis is characterised by severe and excruciating pain, impacts 10% of women of reproductive age globally (World Health Organization, 2021) and yet, takes on average 7.5 years to diagnose in the UK (Nice, 2017). As such, it is fair to assume a lack of attention and awareness to such conditions, and further important to acknowledge that menstrual misinformation and misconceptions contribute to the poor treatment outcomes of women with pain disorders (Guidone, 2020).

Healthcare workers can often perceive menstrual pain as being imaginary (Bloski and Pierson, 2008). According to Grundström et al. (2017, cited in Guidone 2020), results from a study involving 9 women with endometriosis, found women believing that their healthcare professionals generally perceived them as having low pain thresholds and exaggerating symptoms.

The National Institute for Health and Care Excellence England, (NICE, 2017) updated their guidance on endometriosis to specifically urge doctors to better listen to the symptoms of women, thus acknowledging that there is a culture of pain being dismissed (Boseley, 2017). Furthermore, the fact that many healthcare professionals regard endometriosis as "painful periods" (Guidone, 2020), undermines the seriousness of endometriosis, menstrual pain and the impact of these conditions on women's general reproductive health and general wellbeing. Dysmenorrhoea appears to be regarded as a condition which women are expected to deal with. It can be seen how the culture of



gynaecological issues not being treated seriously within the healthcare professionals community (by way of dismissing women's pain), can fuel a sense of women's reluctance to talk to their GP about their menstrual pain/distress.

Whilst research has highlighted women's pain as something that is easily dismissed, there is very little discussion regarding perceptions of pain (on part of healthcare professionals) within the context of menstrual health. This combined with the fact that the narratives surrounding period pain are largely representative of Caucasian women, means that we do not have a picture of how the perception of Black women's pain, impacts on the menstrual healthcare experiences of such women.

Research has illustrated that conscious and unconscious racial biases have led to healthcare professionals on a systemic level, believing that Black people experience less pain (Dore et al., 2014), with some healthcare professionals expressing that Black women have thicker skin (Summers, 2022) and therefore, a higher pain threshold. Black British women are 4 times more likely to experience maternal mortality (MBRRACE, 2021) and in a study where 50 thousand women were given questionnaires to explore their experience of maternity services, it was found that that ethnic minority women were less likely to have been given pain relief during labour and more likely to receive less frequent care from midwives (Hunderson, Gao and Redshaw, 2013).

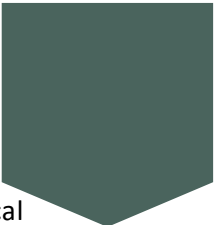
It can be seen how the racially motivated misconceptions surrounding pain and the poor quality of care given to Black women, will consequently impact on the experiences of Black women seeking healthcare for their menstruation and menstrual-reproductive health conditions. The healthcare encounter within a menstrual health context is a subject that remains unexplored and considering that structural racism ingrained within Western healthcare systems has shown to impact on the treatment of Black women, this current project aims to explore how the attitudes of healthcare professionals have shaped the menstrual healthcare experiences of Black women.

Black women and uterine fibroids

Black women are up to three times more likely to experience uterine fibroids - non-cancerous tumours causing irregular, severe menstrual bleeding and a multitude of health issues such as pelvic pain, pelvic pressure and infertility (Navarro et al., 2021). Debilitatingly heavy menstrual bleeding is a major concern of women who experience fibroids (Uimari et al., 2022). Furthermore, fibroids tend to be of greater number, size and severity in Black women, therefore resulting in Black women experiencing more severe symptoms compared with women of other races (Myles, 2013).

The definitive reasons as to why Black women experience more frequent and complex presentation of fibroids, is unknown. Research has found that the increased risk of vitamin D deficiency of those with darker skin (Baird et al., 2013), experience of childhood physical and sexual abuse (Wise, Palmer and Rosenberg, 2013) and use of hair relaxer chemicals typically used by Black women, may all be linked to the presentation of fibroids within Black women. Despite the fact that Black women are disproportionately impacted by fibroids, more likely to experience debilitating menstrual bleeding and more likely to undergo a hysterectomy due to fibroids (Wechter et al., 2011), these women remain neglected within fibroid research. Seminal genetic studies which have utilised genetic sequencing methods to study fibroids, have largely involved participants from Finland and Japan - countries where are few Black women (Eltoukhi et al., 2011)

Where research on fibroids within Black women does exist, these papers (like much of the literature within the menstrual health field), tends to reference African American women only. Considering that 1) fibroids can cause Black women to experience much more severe, debilitating periods 2) systemic



racism and dismissal of women's pain (on part of health professionals), impacts on the gynaecological health outcomes of Black women and 3) there is a paucity of research exploring Black women's experiences of menstruation and help seeking behaviour, our current study moves towards understanding the unique challenges which shape the menstrual healthcare outcomes for Black British women alone.

Menstrual taboo

Menstruation is a difficult experience for women globally. Centuries of menstrual taboo has created a sense of “menstrual etiquette” where women are burdened with the task of concealing every aspect of their menstrual experience from others (Moffat and Pickering, 2010). Menstrual taboo can be seen from two perspectives – the negative attitudes surrounding period blood and negative, gendered attitudes towards women menstruating.


Perceptions of menstrual fluid vary greatly, ranging from notions of dirt and disgust (Bramwell, 2001), to the belief that menstrual blood is poisonous, toxic and magical (Golub, 1992). Flynn (2006) spoke of a ‘menstruation-as-pollution agenda’, noting that many anthropological studies which have explored attitudes towards menstruation, have conformed to this agenda.

Menstruating women themselves have been seen as weak, blemished and unfeminine by men (Roberts et al., 2002; Johnston-Robledo and Chrisler 2013). In a study by Forbes et al. (2003), involving European American college students, it was found that menstruating women were rated as annoying, angry, less sexy and nurturing. It is easy to see how women internalise negative attitudes toward themselves and subsequently feel pressured to adopt “menstrual etiquette” in their lives. The embarrassment and shame of the clinical encounter, is one of the main barriers to women seeking menstrual healthcare (Sánchez, 2020).

The secrecy surrounding menstruation has stifled conversations which would otherwise enable women to discuss difficulties and crucially, seek the help they need to relieve distress. This lack of open menstrual discussion means that people who menstruate can often lack understanding of the differences between a healthy (non-debilitating) period and a problematic period, thus normalising debilitating symptoms. Similarly, according to Denny (2009, cited in Drabble et al., 2020), those experiencing dysmenorrhea in their adolescence, may not have insight into the experiences of others which in turn, contributes to the perception of debilitating endometriosis pain being normal.

Open menstrual conversations are vital in relation to women having a sound understanding of their own cycle. The belief that menstrual symptoms are normal is one of the biggest barriers preventing women from seeking menstrual healthcare in the first place (Chen et al. 2017). Debilitating menstrual experiences being perceived as normal is problematic in that it can be symptomatic of a ‘grin and bear’ approach where discomfort is considered part and parcel of a women's prerogative. This was indeed seen by Chen et al. (2017) where in a survey documenting the reasons underpinning the lack of help seeking behaviour for over 500 American people who menstruate, many reported that menstrual discomfort was a part of the status quo of having a period. This normalisation of dysmenorrhea and associated health issues has contributed to the culture of women avoiding help-seeking behaviour (Critchley et al., 2020).

The marketing of menstrual products also plays a part in women internalising negative cultural messages surrounding period blood. Where large corporate menstrual product brands e.g. Always, market period products as discreet and leak free, this contributes to a culture in which women's insecurities and worries are weaponised to sell products (Karzai, 2010).




It is important to note that there are positive, cultural shifts which attempt to move Western society away from dirt and disgust discourse. Bodyform became the first brand in Britain to use red liquid to realistically mimic menstrual blood in television adverts as opposed to the commonly used blue liquid (Petter, 2017). Similarly, Boots – the leading health and beauty retailer in the UK renamed their “menstrual hygiene” aisles to “period products”, again responding to an increased awareness of menstrual taboo (Javed, 2022).

Despite marketing campaigns responding to the growing awareness of period shaming, menstrual taboo remains deeply ingrained in society. In a project which held focus groups for 84 young people across England and North Ireland, it was found that girls expressed a deep fear of leaking in front of other people and used words such as ‘embarrassed’, ‘ashamed’ and ‘terrifying’ when describing their menstrual experiences (Plan International, 2018). In another piece of research by Plan International (2017) where 1000 girls between 12 – 21 years old responded to a survey, 48% expressed embarrassment over their periods, 82% admitted to hiding sanitary products and only 22% felt comfortable enough to disclose their period with teachers. Furthermore, in 2017, private healthcare provider Bupa ran a survey with 2000 British women to explore how menstruation affected their daily lives, finding that 58% respondents under 25 years old told employers they had the flu or a stomach bug as justification for having the time off when they were in fact, experiencing period related discomfort. A long history of menstrual taboo has clearly resulted in women still feeling the need to follow “menstrual etiquette” dealing with discomfort discretely and privately.

As mentioned previously, there is no single study to date which solely explores the experiences of Black British women who menstruate. Whilst menstrual taboo is universally experienced, the current body of menstrual literature does not represent the unique challenges or stigmas faced by Black women due to the overwhelming focus on White, US based participants. In an interview for Well+Good – a digital health and wellbeing publication, US based menstrual activist Cece Jones Davis stated that African American women have historically, been perceived as dirty and pressured into looking respectable, clean and tidy (compared with their White counterparts), which in turn may underpin debilitating psychological relationships with their period (Bunch, 2021). Similarly, Dr Charis Chambers - a US based Obstetrician Gynaecologist and public speaker, stated for Well+Good that the reason why Black women may be particularly reluctant to seek menstrual healthcare is due to the dark history of sterilizations being enforced on them, thus creating a strong culture of mistrust between Black women and healthcare establishments (Bunch, 2021). Published research does not capture the contexts in which menstrual experience for Black women is rooted. By the current research making use of focus group methodology with Black British women, this enabled for more light to be shed on the Black menstrual experience.

Menstrual health knowledge and education

Whilst menstrual taboo can underpin the reasons for women not being able to acknowledge their periods as debilitating, the lack of menstrual health literacy must also be discussed. In a poll of 1000 women between ages 12 – 21, one in five were found to have experienced bullying over their period, with 67% of teasing taking place at school and the highest proportion of negative comments being related to (perceived) negative mood and leaking (Plan international, 2019). Similarly, a YouGov poll found that 42% of respondents mentioned boys joking about periods, with 40% of this teasing taking place in lessons. The internalisation of negative cultural messages surrounding menstrual taboo, coupled with direct bullying behaviour, highlights the need for young boys and girls to be provided with a menstrual education which destigmatises periods and explains the reality of menstruating.



September 2020 marked the first year in which mandatory menstrual health education was rolled out in English secondary schools. Whilst menstrual education has been delivered previously, UK schools had discretion in relation to choosing the age at which students accessed education and the content which was taught to them (Plan international, 2018). The results from focus groups with 84 young people across England and North Ireland indicated that many young people believed their menstrual health education to have been inadequate, with 14% of British young people explaining that they did not know anything about menstruation until their very first cycle (Plan International, 2018).

Teachers are central to creating an environment in which young people can learn about menstrual health experiences (Brown et al., 2022). However, much of the menstrual health education has focused on basics of the biological processes and failed to address the social and emotional impacts of menstruation. Furthermore, in a survey of over 700 primary and secondary school teachers conducted by (Brown et al, 2022), only 52% of secondary teachers stated that menstrual cycle education was provided and over 100 reported a maximum of up to 2 lessons being dedicated to menstrual education in a year. High quality, standardised menstrual education is yet to be seen across British schools.

Whilst schools can be powerful institutions within which young boys and girls can learn about menstruation, it is also important to consider how community initiatives can foster menstrual literacy. A report commissioned by Barnados (2018) highlighted that many young people would perceive PHSE education as being much less awkward if they were provided by services outside the school setting. Freedom4Girls aimed to explore where Black British women and people who menstruate looked for support in relation to menstrual/reproductive health needs and also, what form of support they believe to be most beneficial e.g. menstrual health workshops, peer support groups and so on. By gaining insight into what ideal menstrual health support looks like for women, this will enable training and healthcare tools to be developed.

Aims of the current Black Women's Reproductive Health Project

There is a lack of published journal articles, research and rich qualitative exploration of the lived experiences of menstruation. This omission was one of a multitude of motivations underpinning the creation of this project. Through conducting surveys, focus groups, peer support groups and engaging with a vast range of stakeholders this project has sought to:

- Highlight the experiences of Black women, Black girls and people with female reproductive systems who require healthcare assistance regarding their menstrual and reproductive health needs;
- Understand how systemic racism and unconscious bias has impacted our core beneficiary group's experience of their menstrual health needs being met and addressed by healthcare professionals;
- Bridge the gap in reducing structural racism and unconscious bias held by healthcare professionals about Black women, via;
 - Creating learning and training tools for healthcare professionals; and
 - Designing an education resource for Black women, Black girls and people with female reproductive systems that assists in empowering, informing and advocacy tools for our chosen cohort.

"Discussion on the issues that affect women - from period pain to fibroids to endometriosis - should be commonly discussed and well-documented within the health-sector. It is not fair to tell women to fix issues that are adversely affecting their health - not by their own doing. We as a society should be more aware of what women suffer with, and these conversations should not be driven underground."

(BWMH Survey 2022, direct quote)

"Community-based approaches such as training workshops may benefit practitioners in developing an understanding of the culture they are embedded in. They would be more able to apply a person-centric rather than purely medical approach which alienates and often offends the women they are meant to help."

(BWMH Survey 2022, direct quote)

"I would welcome information relevant to ethnic minority communities in order to reduce barriers of communication and to promote a wider scope of inclusion for these women."

(BWMH Survey 2022, direct quote)

2. Scope and methodology

Over the course of 24 months, the BWRH project and research team designed and ran surveys, focus group discussions, peer support groups, and a literature review. These approaches to research aimed to collect the real experiences of Black women when seeking healthcare support for their menstrual needs, while also providing a safe and supportive environment. This section of the report sets out the research and sample design, data analysis, and methods through which the study was conducted.

Sample selection

Participatory research forms the basis of the approach adopted by the team due to the importance of conducting the research with and for, not on, members of our chosen cohort. This ensures that results both come from, and go directly back to, the people who need them most and who can make best use of them.

Multi-stage sampling (a combination of different sampling methods), was employed throughout. Initially stratified random/cluster sampling was used to select those participants who had the greatest influence on our beneficiaries.

- Beneficiaries
- Healthcare Professionals
- Support Organisations

Surveys were constructed for these three different survey populations and were carried out either online (promoted via social media and email), or in person (via paper survey), either through collaborating with Support Organisations or during project ran street canvassing events.

Google Docs was used for the initial survey launch but it was soon switched to SurveyMonkey for ease of access across different devices.

Limited response was received from Healthcare Professionals and Support Organisations due to wider societal challenges during the time of research; (2020-2021 and the peak of the COVID-19 pandemic). Further, it is also now recognised that the relatively limited network of the project and research team also fed into this poor response rate. Focus was instead placed solely on collecting data from our beneficiaries, a decision taken roughly six months into the publishing and promotion of all surveys. Purposive sampling was then used to ensure responses came from the study's chosen beneficiaries with a description of such as introduction to the surveys.

Any survey respondents who indicated they would like to be involved in the ongoing research were invited to participate in the focus or peer support groups. Recruitment for the peer support groups was further undertaken between August 2021 - September 2021 through social media. Emails to Black and Women of Colour community groups (Annex 1 below) were also used to encourage participation.

Research design and procedure

All social media adverts, surveys and focus and peer support group agendas were crafted, edited and facilitated by a core member of the project and research team and peer reviewed within their team.

The main focus was collecting evidence from Black women, girls and people who menstruate/with female reproductive systems in the UK to determine:

- This groups' experience of being supported and assisted by healthcare professionals.
- This groups' experience of having their menstrual health needs supported by health care professionals.
- What this group would want to achieve from the project.

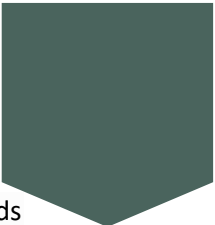
A clear explanation of the aims and objectives of the project were prominent in both the social media promotions and the surveys.

Latterly, the questions requesting gender and ethnicity were changed from open-ended questions to a selection of tick boxes to support in our cleansing and consideration of the data as responses were in obvious groupings at this stage. Given all beneficiary responses were cleansed to confirm eligibility, these changes have no bearing on the results.

Focus groups were conducted via Zoom and lasted between 1.5-2 hours with up to 7 participants in May and June 2021. The focus groups were designed to dive deeper into the survey responses collected and to further engage and support beneficiaries. They began with short, fun and engaging ice breaker sessions to better understand the stigmas faced around periods and ethnicity. To follow was an exploration of what a good and bad experience would look like with beneficiaries offered provocative words, statements or images from the news for comment and reaction. A series of healthcare professional images (downloaded from the internet) depicting male and female health professionals, both of Black and Caucasian origin, were then presented, again for comment and reaction. These activities were designed to explore the ways discrimination manifests itself, the impact it has and how beneficiaries needs can be best catered for. Sessions ended with a discussion on what could best be achieved from this research, and the project generally, as well as the sharing of tips for overcoming barriers and discussion around the broader awareness, or lack thereof, of menstrual and female reproductive health conditions.

Peer support groups were conducted in December 2021 and January 2022. They consisted of four online sessions which again were hosted over Zoom. The peer support groups sought to provide a safe, inclusive and participant-led space in order to facilitate discussion on a range of menstrual and reproductive health topics. The topics discussed each week were guided by the peer support group facilitators through the review of survey data and the analysis of the focus group data. After the completion of the peer support groups, participants were given the opportunity to leave written or verbal feedback and were also provided with a Peer Support Resource Pack. This pack, detailed the key discussion points explored during the sessions and additional resources including descriptions of various menstrual health conditions, sourced from websites such as NHS.co.uk and Women's Health, and links to organisations and social media accounts which advocate for Black women's health equality.

Qualitative methods were used as a means for exploring and understanding individuals and how they associate with their menstrual and/or reproductive health, their experiences of seeking support and



to ensure beneficiaries could express their experiences in their own words. Quantitative methods included the use of statistics gathered during the research, analysis and presentation of the results. This enabled assurance of representation and cross-referencing with statistical records as collected from public websites or during the literature review.

All surveys and focus group and peer support group agendas can be found in Annex 3 (below).

Research findings will be presented during an organised event in August 2022.

Data analysis

All survey responses, whether collected online or in person, were uploaded onto SurveyMonkey then downloaded in bulk onto a spreadsheet. Analysis was completed in March 2021 and April 2022.

Before analysis began the data was cleansed to remove those participants who did not fall within the chosen cohort for this study (e.g. male, white, non-UK). Where the option of an open-ended question was given, some responses were grouped into categories to allow for a high-level overview and ease of reporting (e.g. occupation). All original data has been maintained and all comments are in the beneficiaries' own words.

Individual responses were examined with filters applied to allow for trend identification, comparison, observations and further exploration of the responses. It is worth noting that, during the course of collecting responses, the survey format changed slightly and therefore some questions have a significantly lower response rate than others (eg. born with a female reproductive health system).

Focus group discussions were scribed as part of facilitation with participant's responses and experiences complimenting and bolstering the survey results. For the peer support groups, consent was provided by participants to use focus group discussions to further the project's overall research and data collection. During the focus groups, participant's responses and experiences discussed were scribed by a project team member. These notes have been analysed and have been incorporated into the results section of this report (see below). Similarly, for the peer support groups, consent was gained from participants for the written recording of their discussions for research purposes, and so, meeting minutes were taken by a peer support group facilitator. Qualitative analysis of these minutes was undertaken by a peer support group facilitator and have been incorporated into the results section of this report (see below).

The peer support groups varied in size and attendance throughout the month of their delivery fluctuating between

Literature review

The literature review was conducted between November 2021 and April 2022. The review principally used academic and grey literature sourced through Google Scholar. Literature sources include reports commissioned by the UK Government, the National Health Service, and non-for-profit organisations such as humanitarian charities. The literature review was guided by the following questions:

- What does the current body of menstrual health literature tell us about the experiences of Black British women who menstruate?
- What does the current body of menstrual health literature tell us about Black British women's experiences of seeking menstrual/ gynaecological healthcare support at large?

Literature search topics were organised into three overarching areas. These included women's experiences of menstruation; Black British women's experiences of menstruation; and the impact of structural racism on healthcare outcomes amongst Black women.

A list of keywords was compiled in relation to these three overarching subject areas, such as 'menstruation', 'period', 'taboo', 'Caribbean', 'diaspora', and 'help seeking'. From the literature sourced, common and recurring themes and gaps were identified by a research lead. The gaps identified from the literature review reiterate the importance of the current project in working towards the filling of said gaps. (See further detail in Annex 5: Flowchart of literature review methods).

In reviewing existing literature under these search terms, the following gaps were identified:

- Black women's experiences of a multitude of aspects relating to menstruation (e.g., pain, perceptions of menstruation self and taboo), were severely lacking due to the majority of menstrual health related research not involving an appropriate number of Black women.
- There is no single study which documents the menstrual health experience of Black British women.
- Where small amount of research does exist in relation to Black women's experiences of health encounters and health outcomes, this tends to be very United States centric.
- There is no single report or piece of research which focuses on Black British women's experiences of 'female repro health' and /or 'repro-menstrual health.' Where reports and research on this topic does exist, a monolith perspective of experiences are provided under the BAME label and therefore, do not represent Black British women alone.

Themes elicited from online blog posts and articles

Due to the extensive gaps in academic and grey literature, the literature review widened its search by incorporating blog posts and articles. Here, the literature review found that there are, in fact, numerous online blog posts and articles which have documented the menstrual experiences of Black women. These posts and articles form two categories – those which interview Black women and those which are reflective accounts written by Black women themselves. The project team agreed that such online accounts provide an avenue for capturing experiences that are otherwise missing from published literature. Therefore, blog posts and articles were identified and analysed via Google search engine. Once all relevant posts and articles were summarised by the research lead responsible for the literature review, themes and patterns across all the online accounts were set out. A final list of themes was used to inform the discussion section of this report.

*"We need to do more to educate others about our needs
we need people with lived experiences and experts who
know our cultural issues "
(BWMH Survey 2022, direct quote)*

*"I live in England and every time I have talked to the
doctors about my pain levels or heavy, I am always just
told it's normal for my age?"
(BWMH Survey 2022, direct quote)*

*"As a mature women of colour there is way too much
information to get my head around from why women of
colour might be susceptible to certain medical issues such
as Fibroids and what the impact can be on our day to day
health. when also experiencing the mental struggle of
being perimenopausal at times the physical and mental
pain is all too heavy to even consider exploring."
(BWMH Survey 2022, direct quote)*



3. Results

Survey findings

As of June 2022, 168 responses were collected. Following data cleansing, 160 were used for analysis. The remaining 8 responses were either submitted by those not resident in the UK or those who do not fall under our chosen cohort (e.g., White), and were thus void for further analysis.

All those who completed the survey agreed to their data being used and stored for 6 years. Those who completed surveys by hand provided verbal consent at the time of submission. The majority of respondents (43%) heard about the survey through other people, rather than via social media. This is somewhat to be expected as no social promotion took place from June 2021 onwards. Prior to this, most participants found the survey through Instagram.

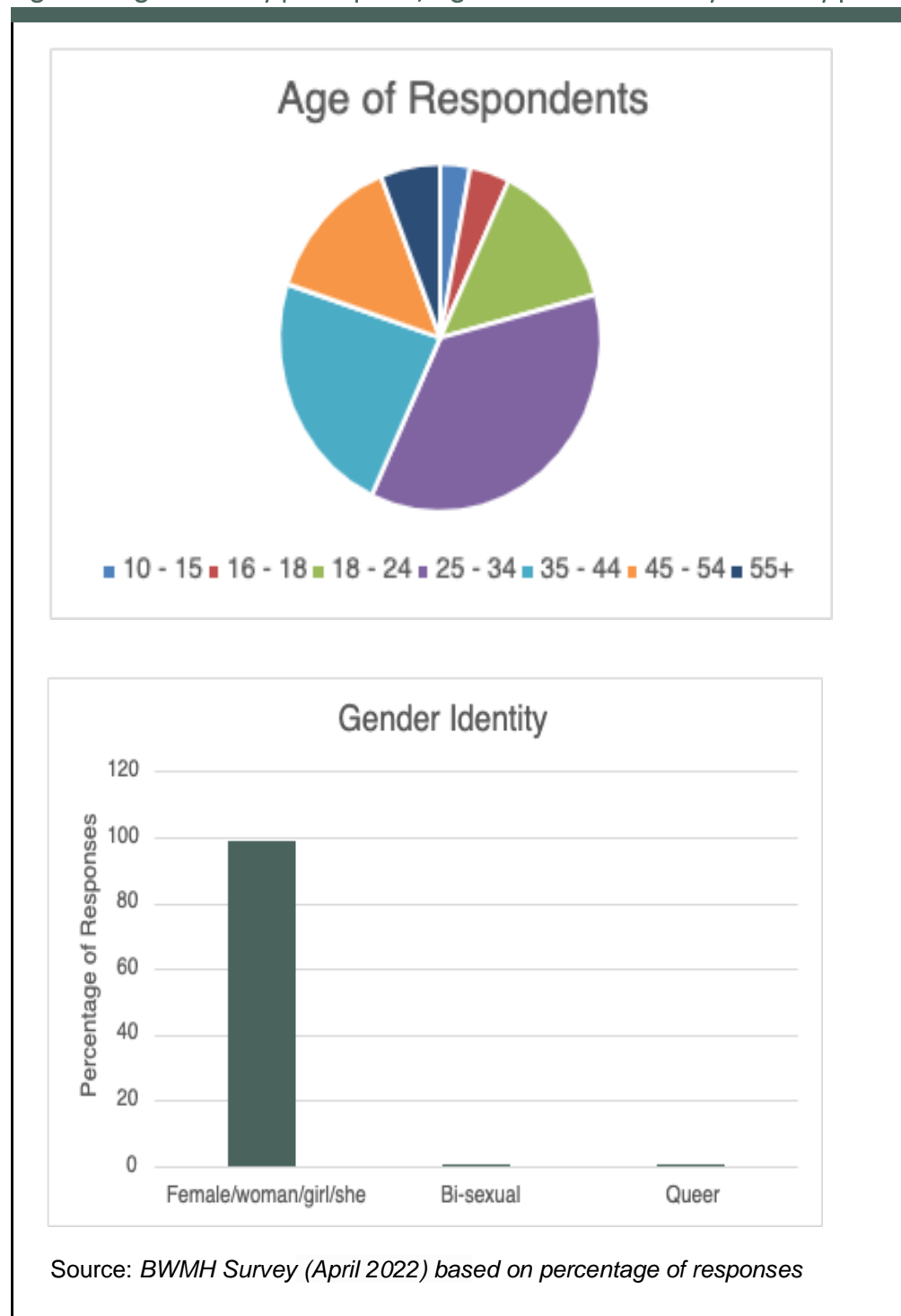
7 participants took part in the May focus group discussion, there were a further 2 focus group participants who requested their participation take place as 'one to one' interviews, rather than in group format. A further 8 participants contributed to the peer support groups, (but not all 8 participants attended each peer support group session).

Demographic profile of respondents

Age and Gender

The age and gender represented through the data collection included 80% of beneficiary responses who were aged over 25 years and 99% of those who responded identified as female, woman, girl, she, F or cis.

Figure 1: Age of survey participants; Figure 2: Gender identity of survey participants

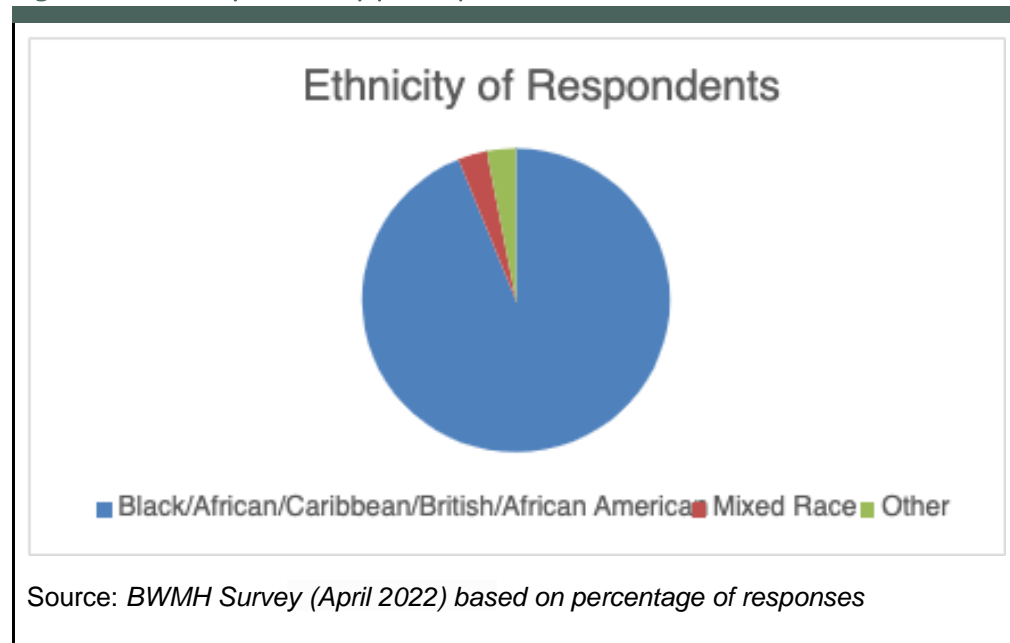


Ethnicity

In response to ethnicity, 94% of participants identified as either Black, African, Caribbean, British, African American or combined racial ethnicities which still fell within the cohort of beneficiaries. The 'Other' grouping was used when ethnicity was not explicit - simply stated Scottish, British or British Asian.

23% chose not to answer this question. Reasons for this are unknown, however, from analysis of responses and clear sign-posting during the research campaign, it can be concluded the research project was successful in engaging the target cohort.

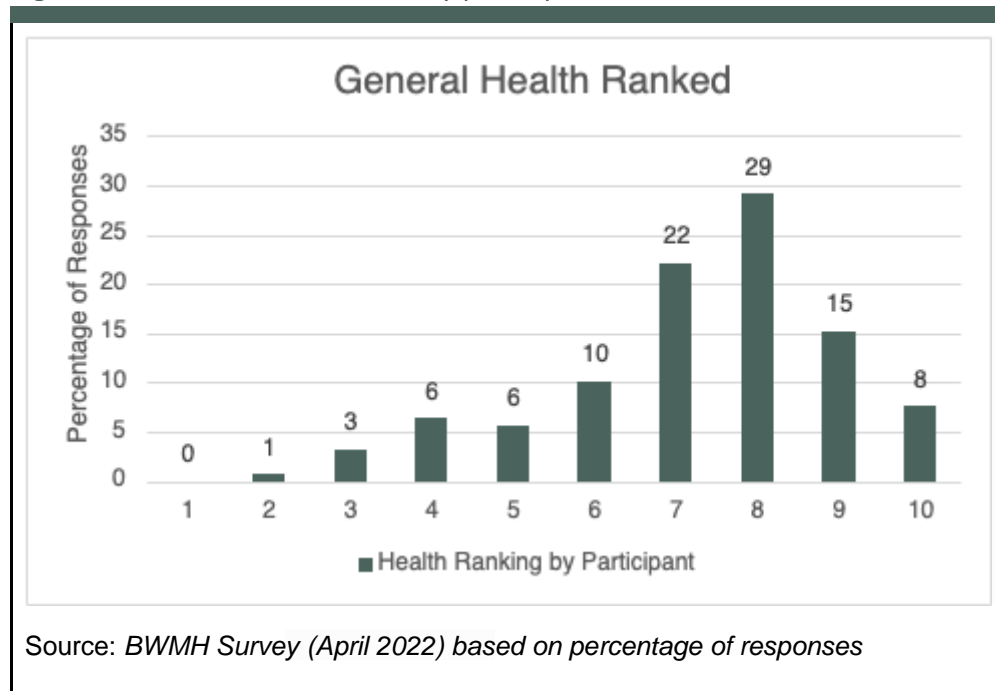
Figure 3: Ethnicity of survey participants



General health

To gain a better understanding of the health needs of Black women, people who menstruate and those with female reproductive systems in the UK, beneficiaries were asked about their general health. With the criteria being 1 poor health, 10 excellent health, all but 2 respondents answered this question, with 84% of those that did rating their general health 6 or above.

Figure 4: General health ranked by participants from 1-10

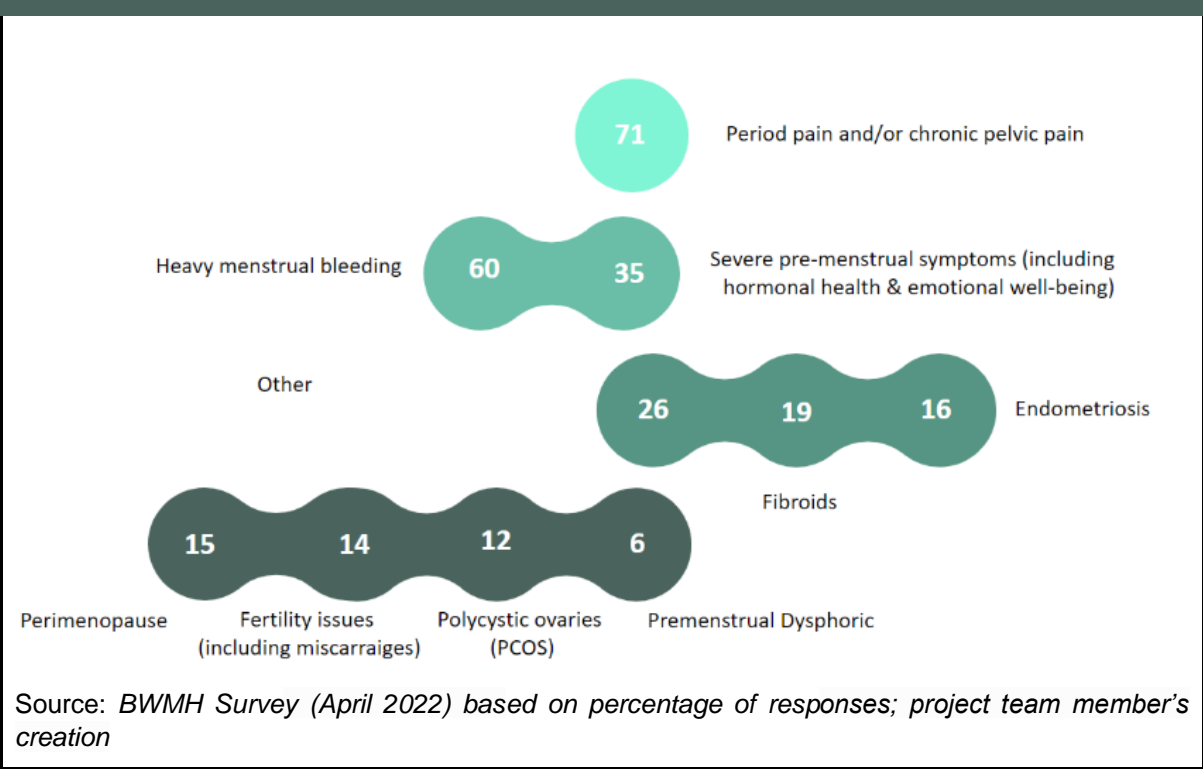


60% of respondents who rated their health less than 6, reported suffering from period pain and/or chronic pain with 38% missing work due to chronic pain. Of this same group, 56% reported lack of representation and 68% reported lack of information as a barrier when trying to access and receive menstrual and/or reproductive health care.

However, menstrual health-related pain was not restricted to those who ranked their health to be lower than six on the scale. For respondents who rated their health a '9' or '10', 50% noted heavy menstrual bleeding with 53% noting period pain and/or chronic pelvic pain.

Respondents were asked to report on their reproductive-related symptoms and diagnosis (90% of response). Leading symptoms/diagnosis included 'period pain and/or chronic pelvic pain (71%) and heavy menstrual bleeding (60%).'.

Figure 5: Reported menstrual health issues suffered by survey participants set out by percentage of survey respondents.



74% indicated that they suffered from 2+ symptoms/diagnosis. Of the 25% suffering from 4+ symptoms, 91% missed work due to chronic pain with 37% missing work 6+ times a year.

Further, the vast majority of respondents suffering from 4+ indicated period pain and/or chronic pelvic pain (94%), heavy menstrual bleeding (83%) and severe pre-menstrual symptoms (77%). 77% also sought support from their GP.

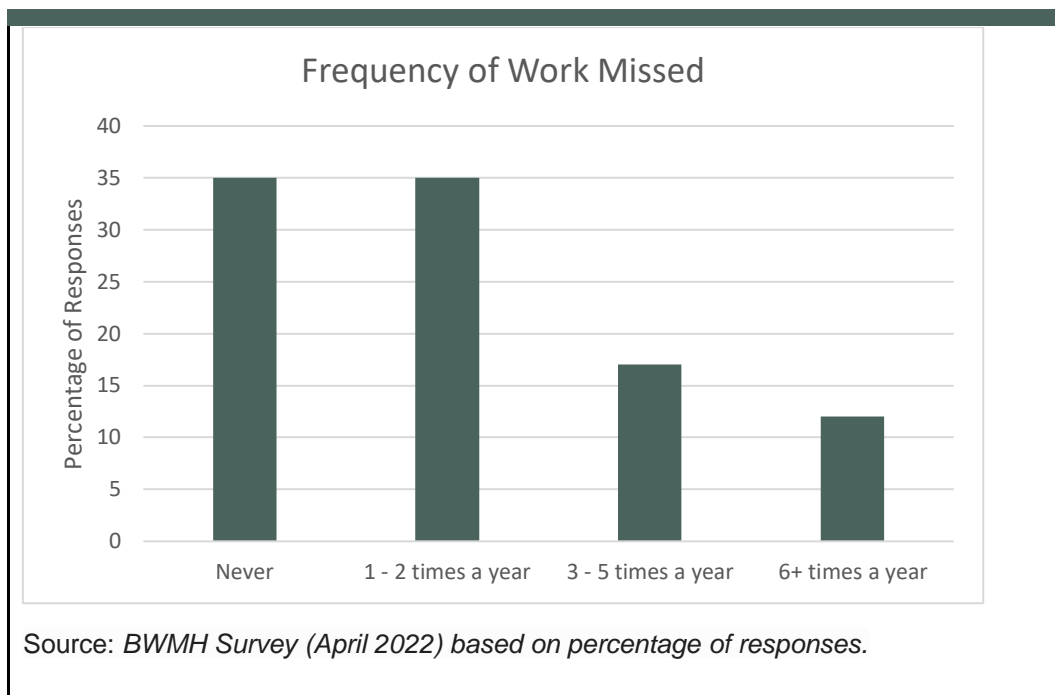
Under the option of 'Other', 10% stated they had not suffered from the symptoms/diagnosis listed. Other symptoms noted were Toxic Shock Syndrome, miscarriage, ovarian cysts, hyperthyroidism, adenomyosis or pelvic problems.

Missed Work

Of the 158 responses to this question, 65% had annually missed work due to the symptoms/diagnosis listed and all had consulted their GP for support. Of the 35% that had never missed work, 37% of those also indicated symptoms suffered in the follow-up question.

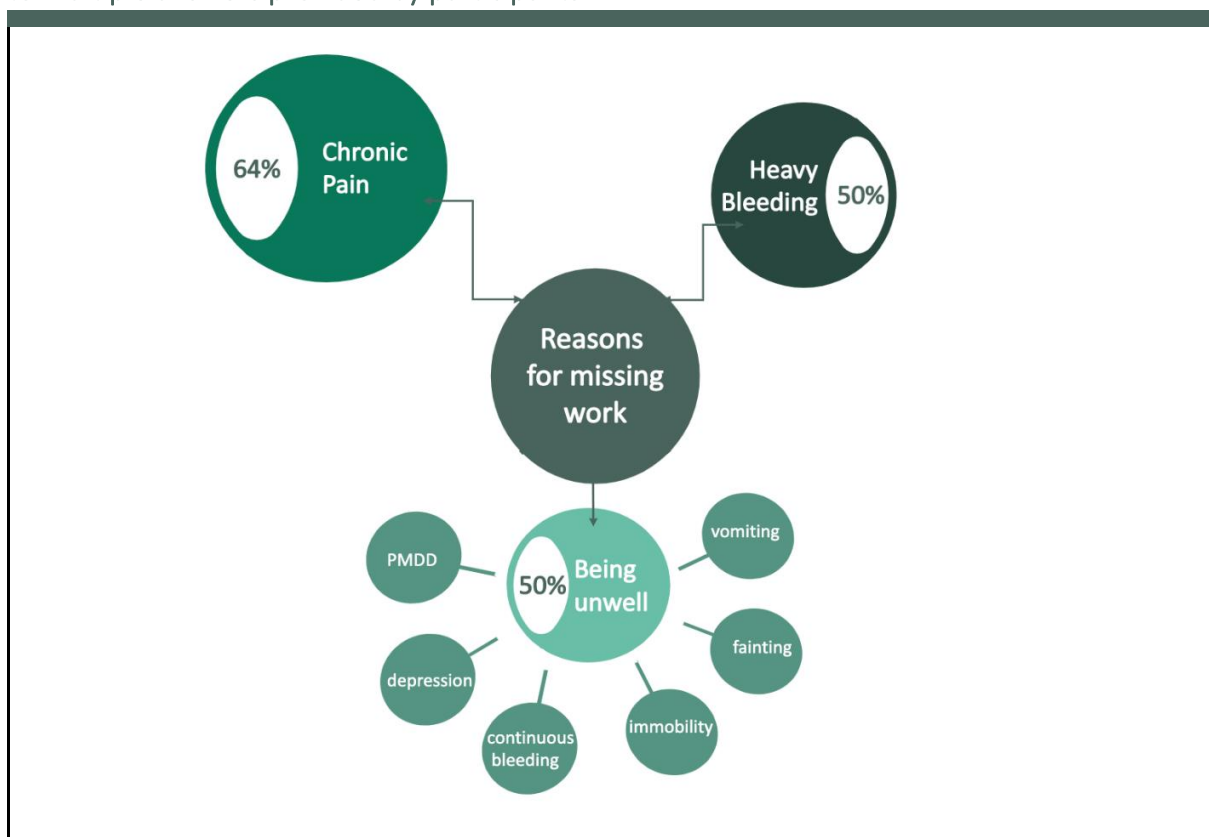
Of the 12% that missed work 6+ times a year all but one noted chronic pain as being a reason. Notably, almost half (47%) of those who missed work 6+ times rated their general health as 7+ with 2 respondents rating 10 on the general health scale.

Figure 6: Frequency of missed work reported by participants, represented as percentage of respondents



Of the 65% of respondents who reported missing work, all but 3 respondents gave reasons why with 35% indicating they had never looked for support. Chronic pain was the lead cause for absence with 64% of responses followed by heavy bleeding with 50% of responses. For those who reported 2+ symptoms/diagnosis, 94% reported chronic pain.

Figure 7: Visual representation of reasons for missing work, not equating to 100 per cent due to multiple answers provided by participants.



Source: *BWMH Survey (April 2022) based on percentage of responses; project team member's creation*

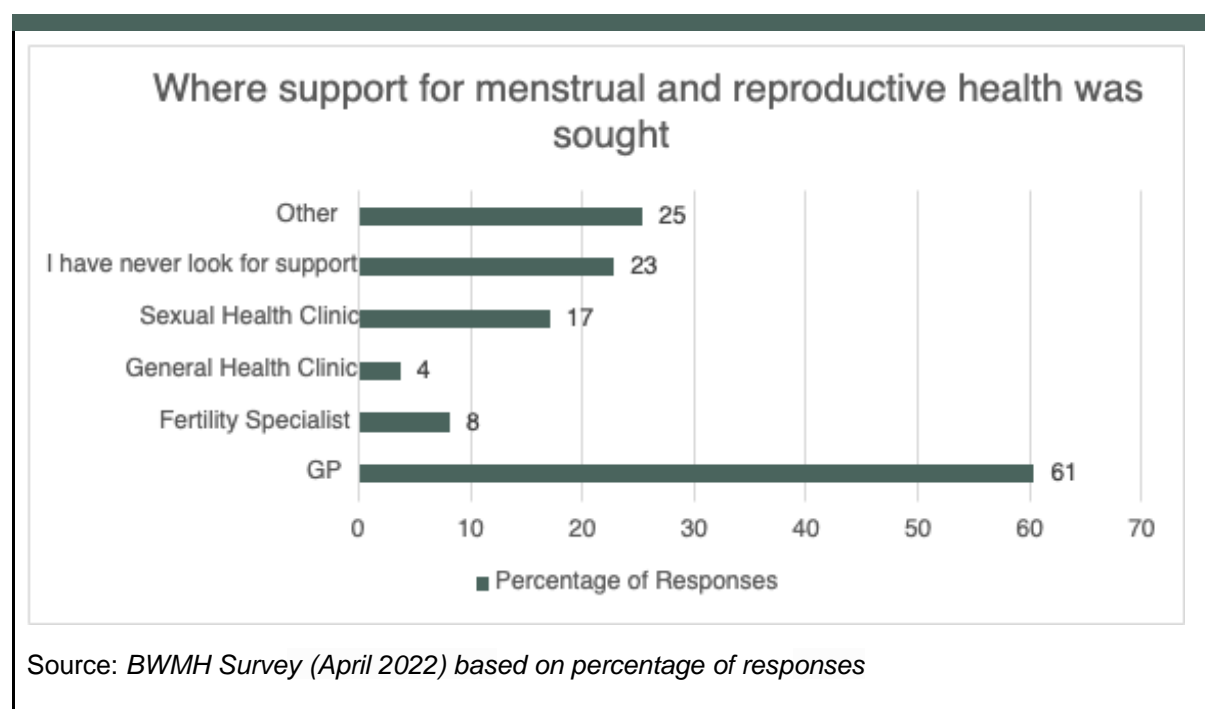
50% of those who selected 'Other' symptoms noted no/not applicable. Of the remaining 50%, symptoms reported included being unwell, vomiting, fainting, immobility, continuous bleeding (causing rashes), strong cramping, PMDD and depression. 50% of those who missed work experienced 2 or more symptoms.

Access to care and support

Seeking support

61% of those who indicated where they looked for support for their menstrual/reproductive health needs said they looked to their General Practitioner (GP). Of this 61%, 37% were missed work 6+ times a year. 23% of those who responded had never looked for support.

Figure 8: Where participants reported seeking support for their menstrual and reproductive health needs



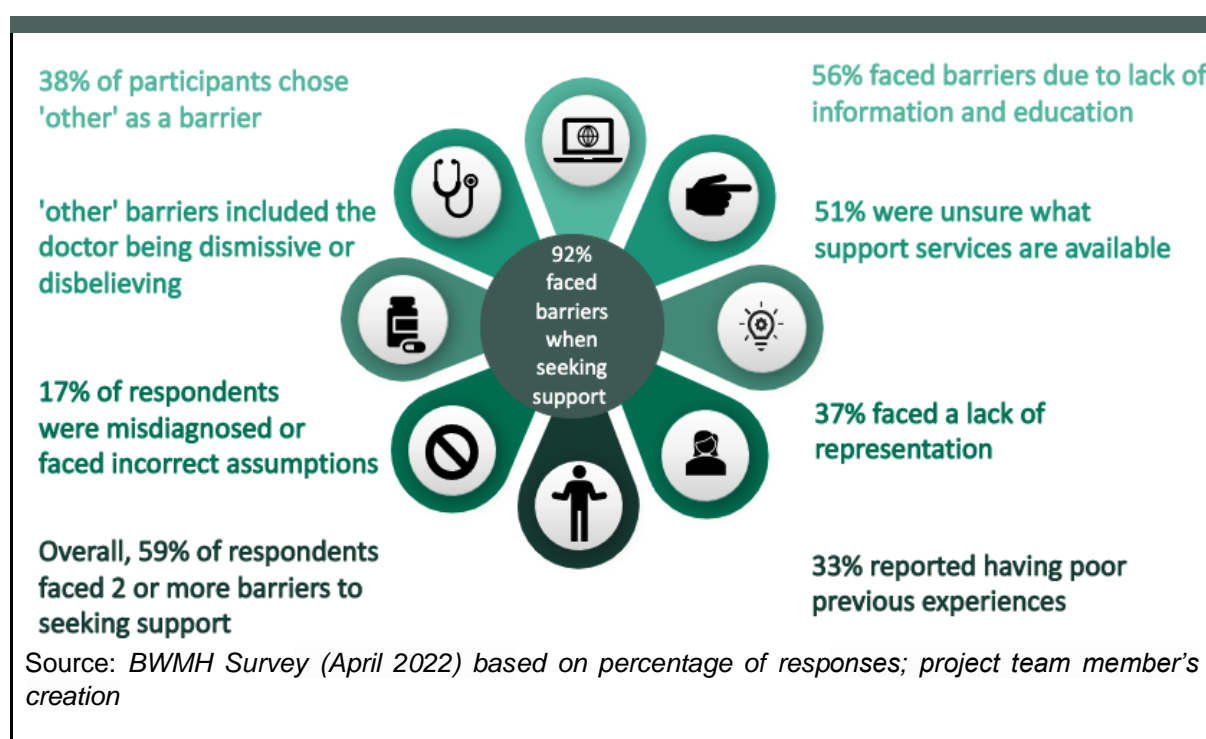
Of the 'Others' mentioned there were an array of answers with online/own research being the most common (45%) followed by family/friends (25%).

75% of focus group participants indicated they had been to their GP once for menstrual health related queries and did not get a positive outcome. The group were in agreement that a negative experience with a health-care professional can be a barrier to seeking support thereafter.

Likewise, during the peer support groups, participants expressed frustration and a need to use a degree of verbal force when visiting their GP. Examples included one individual having to argue with a GP to successfully be given a referral for further investigation for their menstrual health needs. The same participant explained that she had the confidence to be persistent as a result of having undertaken a wealth of personal research on women's menstrual health. Since these encounters, the participant has subsequently been diagnosed with endometriosis.

92% of respondents advised on the barriers they face when accessing or receiving menstrual/reproductive healthcare.

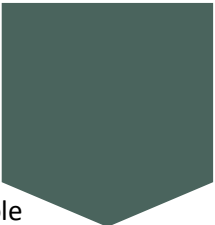
Figure 9: visual representation of the barriers to support reported by respondents, not equating to 100 per cent due to multiple answers provided by respondents



Importantly, these indicative results suggest a clear need for the BWRH project with 56% of responders facing barriers due to a lack of information and education, 51% are unsure of the support services available, 37% face a lack of representation and 33% have had poor previous experiences. 38% of those who chose 'Other' explained how their doctor was dismissive or disbelieving with 17% being misdiagnosed or facing incorrect assumptions. 59% of respondents faced 2+ barriers.

These findings were echoed in the focus group sessions where participants were shown different photos of different medical staff. In response to a picture of a male health professional one participant commented they would "have to defend yourself, your experiences". Most agreed that they would not be taken seriously, that the appointment would be a waste of time and the Dr dismissive, disbelieving or minimising of their experience.

Participant's responses didn't differ greatly from the above when shown a female health professional agreeing that there were similar challenges with support and understanding. Negative experiences



were shared where participants struggled in appointments, felt let down and lost trust in the whole system. One participant commented;

“Is it just doctors in general, have we all had such negative experiences that we have lost trust? the whole sector is so underfunded and under researched, it makes us so angry that maybe our experiences are reflected in these - no one listens, we’re not helped enough - no matter who by”

However, relief was expressed by some at the sight of a female health professional commenting there would be less effort involved in expressing themselves.

The main barriers faced by participants of the focus groups were lack of support and aftercare, lack of information, no holistic view of the patient and that menstrual pain was downplayed or mis-diagnosed. Many felt they were ‘forced’ contraception with one participant commenting “Is the pill the female specific paracetamol?”.

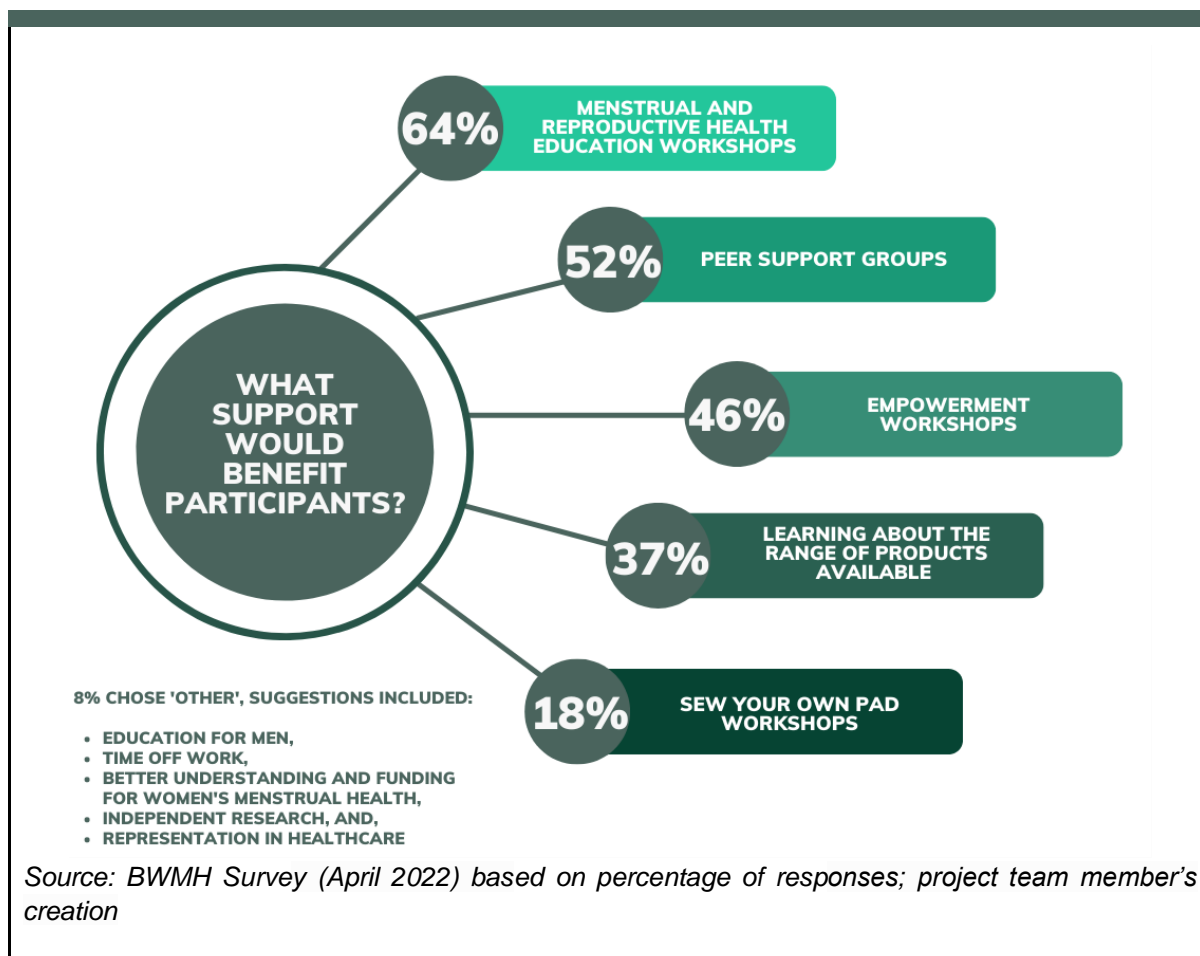
Similarly, discussions on how women’s health is largely centred around maternal health was raised in the peer support groups with participants highlighting the needs to be a shift away from this focus. Participants also discussed how there is no ‘one size fits all’ approach in women’s menstrual healthcare, and yet, care and support for menstrual healthcare is limited in its approach. Interestingly, barriers expressed in the peer support groups also included societal stigmas and taboos around menstrual health. For example, participants of the peer support groups discussed how there is a great need to normalise conversations around women’s menstrual health as “we don’t even know when we are suffering in silence if we don’t talk about it” (Peer Support Groups 2021, paraphrasing).

Access to education

Beneficial support

90% of respondents advised on other support that would benefit them regarding their menstrual/reproductive health needs. Respondents proposed Workshops, with 64% agreeing that Menstrual/Reproductive Health Education Workshops would benefit, and a further 46% noting Empowerment Workshops. Also popular were Peer Support Groups as indicated by 52% of respondents.

Figure 10: Beneficial support proposed by participants based on percentage of responses



Within responses for 'Other', 50% felt there needed a better understanding of women's menstrual health in wider society followed by training of Health Care professionals (25%). Also of note is the repeat of Workshops by respondents (17%).

Focus group participants agreed there was a need for better understanding of menstrual and reproductive health both in wider society and within the health care system. They felt better representation within healthcare was needed with pictures and examples of how a side effect may look different for those with melanated skin. Participants also spoke of better self-awareness, community advocacy and empowerment projects so that they could learn and understanding their bodies better. One particular idea that was popular was the availability of checklists to help when attending an appointment or possible scripts that could be used.

On the other hand, the peer support group participants raised the need for bringing younger teenagers of all genders into conversations around menstrual health in order to tackle persistent taboos. The peer support groups further highlighted the current lack of representation of Black practitioners, with one participant noting that they had only ever seen one Black gynaecological practitioner in hospital.

*“I don't know where to go for menstrual health help and my gp was useless although I've been suffering monthly for years with very bad pms”
(BWMH Survey 2022, direct quote)*

*“It would be helpful to have some information about the types of menstrual issues that particularly affect women of colour.”
(BWMH Survey 2022, direct quote)*

*"I struggled to get help from my GP for my painful periods. I think because he (white male) did not take my description of the pain seriously. So I had to go back home with no solution and wait until I could book with a woman."
(BWMH Survey 2022, direct quote)*

4. Discussion

Our discussion of the results has centred around three main areas:


- Pain:
 - Understanding pain and the connection of chronic pelvic pain and/or period pain to general health, and by consequence, how said pain is perceived by healthcare professionals.
 - Missed Work: How pain has impacted our chosen cohort's capacity to maintain 'normal' life.
- Poor Menstrual Health Education.
- Failures in Access to Adequate Care and Support for menstrual-reproductive health conditions.

Pain, Pain Awareness & General Health

Interestingly, the general health of our beneficiaries was moderate-good: more than 80% rated their general health greater than six out of ten. However, the beneficiaries included in this project were not without pain and diagnoses of gynaecological conditions. More than 70% experienced period pain or chronic pelvic pain. Chronic pelvic pain in women from the United Kingdom, is as common as asthma and back pain (Zondervan et al., 1999), and is estimated to impact as many as one in fifteen women.

Our results shockingly showed that a much higher proportion were impacted by pain than would be expected. This suggests that chronic pelvic pain is highly prevalent in Black British women. Why our beneficiaries experience significantly higher levels of pain remains to be further explored. As such, we raise a call to action for researchers in the reproductive health sphere to collect and analyse important variables known to influence pain (i.e. socioeconomic status, mental health, support, genetics), in women from this beneficiary group. This call aligns with the Government's Women's Health Strategy 10-year ambition of including more women from ethnic minority groups in research (Department of Health and Social Care, 2022). Only with this broader understanding as to causal factors into pain and a woman's interpretation and assessment of her pain, will we begin to further understand why such disparities may exist in the UK.

We would be remiss if we did not acknowledge the burden that pain has on the quality of life of women experiencing it. Aside from the physical health condition impacting the individual, there is a massive impact on mental health, relationships, and ability to go about one's day-day life. For Black women who are repeatedly ignored, having their pain dismissed, and constantly advocating for their experience to be taken seriously, the significant toll that this took on their wellbeing was evidenced by the lived experiences of our Beneficiaries. It is not just the physical pain or chronic condition they are living with, it is the fact that they experience great anxiety about going to a doctor's appointment for fear that they won't be listened to again; it's the time spent after an appointment in frustration that, despite your best efforts to communicate your pain and your needs, you were once again dismissed; it is a vicious cycle that is a by-product of the pain or disease.



There is also more to be said on the disconnect between perceived general health and chronic pelvic pain or period pain that was observed in our cohort. For too long period pain has been normalised in society, and by consequence, discussions around periods and period pain, have been highly stigmatised. This has created a culture of silence surrounding menstruation and its oftentimes associated pain. Whether messaging about period pain being normal was perpetuated by peers, family members or healthcare professionals, it is possible that this is what drives the divide between an awareness of the connection between period pain and general health. They are often discussed and treated as two distinct things, and therefore were likely reported as such in our study.

The BRWH team submits that it is important to further explore this phenomenon in order to determine if there are additional causes which have driven the disconnect between menstrual health and physical health. We note that if we were discussing pain outside of a menstrual or female reproductive health context, such as for chronic headaches, if a person were to report suffering monthly chronic headaches and confirmed their general, physical health was still above average, (6/10), there would arguably be a disconnect in respect of how they have determined and defined general health as such ongoing pain would or at least, should not impact general good health. Whilst acknowledging that the beneficiary survey fell short in terms of failing to define 'general health' when asking our beneficiaries to rate theirs, it can still be accepted that suffering from period pain and/or chronic pelvic pain, would suggest general health was not good.

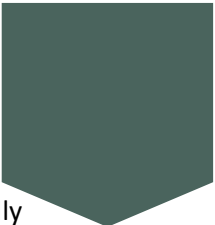
Heavy menstrual bleeding was also very common amongst beneficiaries, (83%). In a study conducted in the United States amongst African American women, they found that heavy menstrual bleeding was more common in African American women than the nationwide average (Marsh et al., 2015). It has been suggested that uterine fibroids, which are an estimated 2-3 times more common in Black women, may in part be responsible for the excess heavy menstrual bleeding in Black women previously reported (Eltoukhi et al., 2015). Since uterine fibroids were common amongst beneficiaries, it is possible that they are the main reason so many have experienced heavy menstrual bleeding.

However, there is again a disconnect between the percentage of beneficiaries who experience heavy menstrual bleeding and percentage with self-reported or diagnosed uterine fibroids. It is completely possible and likely that for many, their fibroids have gone undiagnosed. The lived experiences of Black women time and time again show that racial biases in medicine are detrimental to receiving a proper diagnosis and treatment of pain and other conditions. This has been further supported by the academic literature (Hoffman et al., 2016), which shows that Black women's pain is not taken seriously, especially when compared to the pain experienced by White women.

Further considerations

As referenced within the limitations section of our methodology, we did not define what 'general health', 'period pain' or 'chronic pelvic pain' meant in our Beneficiary surveys. This was a conscious decision made by the research team for two reasons. Firstly, we recognised that pain is an inherently subjective experience, and as such leaving it undefined meant that we would be able to capture a more robust array of responses. As our project is steered by and comprised of the lived experiences of our Beneficiaries, we are confident that their completion of the pain scale and their own awareness and interpretation of pain, is an important piece of this research.

The project and research team also recognised that the way that 'pain' is communicated in a practical sense is very rarely defined in healthcare literature, rather it is accepted that a person living with pain



is able to communicate this experience to a healthcare professional. Further, having spoken informally to healthcare professionals, there is a mixed approach with regards to measuring pain and the assessment tools in doing this. Some confirmed using a pain scale as in our survey, i.e. rating pain from 0-10; others took a different approach and accepted descriptive communications of a patient's pain. While we were aware that chronic pain is defined by pain persisting for 3+ months, we decided to leave this question more open ended to better understand the pain experience.

That being said, what is clear from our own research and consideration of the literature is that pain is a subjective phenomenon.

The possibility for bias in our results must also be acknowledged. It is possible that there was an element of selection bias in our study, such that women who wanted to participate in the project were more likely to be impacted by chronic pelvic pain or other chronic conditions than Black women who didn't participate. Nonetheless, this work highlights how burdensome pain and other chronic conditions, such as uterine fibroids and endometriosis are amongst Black women in the UK. It further points to evidence of systemic racism in medicine, from points of likely failed diagnoses and failures to act on reporting of period and/or chronic pain, and lack of proper education about menstrual health and related conditions.

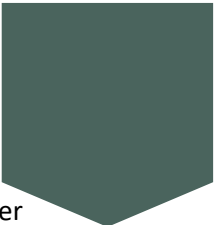
Missed Work

As above, 65% survey beneficiaries reported missing work at least once a year, and pain, amongst many other factors (such as heavy bleeding), was the primary factor which caused said absenteeism.

Previous work conducted in the USA has shown that women who experience heavy menstrual bleeding were more likely to miss work, and this was associated with personal economic losses to those women (Côté et al., 2002). Furthermore, conditions like endometriosis, which are often associated with chronic pelvic pain, are also associated with decreased productivity at work. This once again results in a financial burden on the individual (Zondervan et al., 2011). In addition to a financial burden of missing work, it is likely that if symptoms are causing women to miss work, that it is also challenging to fulfil additional work, such as childcare responsibilities (Sims et al., 2021).

To further perpetuate the disconnect between menstrual and physical health described in the previous section, studies have shown that when women called in sick due to period pains, only around 20% told their employer or school the true cause of absenteeism (Schoep et al., 2019); and as we have seen in our Introduction, the 2017 report from Plan International found that reasons given as to absenteeism were more common conditions such as flu. This suggests that there is a lack of understanding, including potentially empathy, amongst employers on menstrual-reproductive health and the impact that it can have on the day to day lives of their employees.

Endometriosis UK has developed an [Endometriosis Friendly Employer Scheme](#) to tackle this. Employers can join the scheme to receive comprehensive information about endometriosis and menstrual health related conditions, as well as practical training on how to support staff living with the condition. Signing up to the scheme however, is dependent on a number of variables, not least including the employer's awareness and willingness to participate. The employer must have sufficient funds to obtain relevant training, (which is a huge concern for workplaces found in more economically disadvantaged regions, regions which are perpetually known to be resident to Black people); and, as emphasised above, the awareness of endometriosis sufferers that the pain they are experiencing is



justifiably worth advocating for to support general health and wellbeing. All of these, as well as other issues act as likely barriers, particularly for Black British women, in being provided the relevant and effective support from their employers to manage chronic pain experienced from menstrual-reproductive related conditions.

Further considerations

Missed work in Black women is associated with economic losses and a negative impact on psychological health. While not yet a reality in the UK, this project advocates for the importance in menstrual-reproductive health literacy across all sectors, from healthcare to education, (further details below), as well as a flexible work approach, flexible menstrual-reproductive health practices and generally, the importance in removing the stigmas surrounding all parts of menstruation and menstrual-reproductive health conditions.


Experiencing pain or heavy menstrual bleeding are out of the control of those experiencing it. For Black women who are not taken seriously even when symptoms do present or encounter racism along their journey to receiving appropriate treatment, there are even more barriers to adequate symptom management. If our recommendations concerning broader menstrual-reproductive health education is implemented in the UK, we would argue that this could help alleviate some of the financial burden of missed work on account of chronic pain or heavy menstrual bleeding. We submit that many sectors have taken such a stance on menopause and the impact this has on a person's health and wellbeing; the same awareness, resource and conversation should be applied to menstrual-reproductive health conditions.

Lack of good quality menstrual-reproductive education

Consistent with prevailing academic literature and activism, our research demonstrates that there is a lack of good quality, accessible menstrual and reproductive health education in the UK. This was highlighted by 56% of our beneficiaries surveyed as being the most common barrier when accessing support (see Figure 9). Without this fundamental education to recognise where new symptoms and/or bodily changes, such as heavy bleeding, may be indicative of underlying menstrual and reproductive health conditions, people with female reproductive systems may “be suffering without even knowing it,” (paraphrasing, peer support groups, 2021).

Being unfamiliar with certain conditions, with the language and specific terminology used in healthcare settings concerning a range of menstrual-reproductive health conditions can lead to a dissonance in communication with medical professionals. This in turn can impact on the speed and accuracy of diagnosis as well, and crucially, on the provision of appropriate treatment plans; something that as we know, has been explored in significant detail by other researchers in the Black female reproductive health space, e.g. Five x More's report on maternal and baby deaths of Black and Black mixed British women; being unaware of symptoms associated with conditions creates an inability to articulate or even recognise a need to address symptoms that may be potentially detrimental, both short and long term.

Of course, we want to be clear and state that education alone cannot solve deeply rooted structural issues in healthcare that we know lead to systemic inequality, particularly in female reproductive health; however, as our participants rightly point out, being equipped with essential knowledge and



tools will empower people to fully understand their bodies and be confident in self-advocating for necessary medical care and support.

In our survey, we asked respondents what support would be beneficial regarding their menstrual and reproductive health needs and the most popular answer was education workshops (see Figure 10). The topic of education was further discussed in our focus groups and peer support groups to identify several important considerations for improving and disseminating comprehensive menstrual and reproductive health education. Firstly, it was widely recognised that education needs to be culturally specific to Black people and better account for ethnic minorities experiences. Not only will this be beneficial for Black women, girls, and people with female reproductive systems to feel accurately represented when learning about their own bodies, but this will also address detrimental gaps in existing medical knowledge.

Interconnected with this, a second point participants raised was that education should not be limited to individuals with reproductive systems but wider society - particularly drawing attention to what educational training healthcare professionals receive around different menstrual and reproductive health conditions. Furthermore, there is a need to ensure that people of *all* genders, including men, boys and those who do not have female reproductive systems, are educated about menstrual and reproductive health. Speaking openly and unashamedly about the realities that women and people with female reproductive systems face will directly address and dismantle taboos and stereotypes rife within our patriarchal society. Our research shows that menstrual-reproductive health education needs to extend beyond formal education received in schools (if at all) and supported across the life course, from menarche to menopause, as well as raising awareness of different health conditions, such as fibroids and endometriosis.

However, as one beneficiary highlighted, there is a crucial balance to be struck here between the provision of detailed education resources and not overwhelming people with vast amounts of knowledge. Practical education on the science of menstrual-reproductive health conditions is just half of the battle and, this project argues, all education should be focused on removing the stigmas and taboos about a general need for societal recognition of menstrual-reproductive health issues.

While not explicitly outlined by our beneficiaries, there is a distinction to be drawn between different types of menstrual and reproductive health education. ‘Formal’ or ‘institutional’ forms of education covering biological processes and the physiological signs and symptoms of menstrual and reproductive health could be grouped as education workshops, medical training, and learning in schools/colleges. Meanwhile, more ‘informal’ or ‘community’ education where lived experiences, personal tips, and accounting for mental and emotional well-being of menstrual and reproductive health conditions can be fostered through every day, intimate conversations, support groups, and empowerment projects that facilitate collective learning. This way, removing stigmas and shame, and steering away from ‘menstrual etiquette’ can be achieved.

We would also submit the widely held misconceptions by healthcare professionals concerning Black women’s capacity to endure pain and/or the misbelief about Black women’s representation of their own pain, (referenced above in ‘pain’ discussion section), could be effectively addressed by creating a proactive menstrual-reproductive education environment that was both formalised and an ongoing, more casual conversation.



Failures in Access to Support and Care


92% of women surveyed, expressed that they faced barriers to accessing menstrual and reproductive health support, with over half experiencing at least 2 barriers. The failure in access to support is a multi-faceted issue, relating to the experiences women face within a healthcare encounter (e.g. during a GP appointment), and wider structural issues such as lack of information, held even by healthcare professionals, and underfunded services.

Our survey highlighted the power of primary care as a first port of call for women wanting to seek gynaecological support with 61% turning to their GP. This is, however, a concerning statistic considering that 33% of focus group participants indicating that they did not experience a positive outcome during their GP appointment. The reluctance of GPs to refer women to gynaecological specialists is a wide-ranging problem. Dr Edward Morris, President of The Royal College of Obstetricians and Gynaecologists, stated that GP's often regarding symptoms as benign and "not serious enough," which has directly contributed to the heavy backlog of women waiting to be seen by specialists (Devlin, 2022). One respondent in our survey, who is now diagnosed with endometriosis, explained the exhausting process of having to consistently persuade their GP to be referred for further investigation. This echoes research conducted by Hoffmann and Tarzian (2002) who stated that, despite women reporting more frequent and intense pain, there was a culture of women having to present extensive evidence for their discomfort which, in turn, contributes to lack of treatment.

It is integral to reiterate that whilst research has widely established that women's gynaecological pain and distress is often dismissed (Boseley, 2017), the misogynoir faced by Black women, creates additional, systemic challenges. Our report and the research conducted is the first to document the experiences of Black British women alone. We believe that discussing Black's women's health disparities through a BAME racial lens, is not useful in highlighting the unique challenges faced by Black Women for whom poor health outcomes are rooted in specific historical and cultural contexts.

The largest barrier that beneficiaries identified through the survey was the barrier to accessing support caused by the lack of gynaecological related information and knowledge of services. Following GP visits, internet usage was the second most common form of help seeking behaviour with 45% expressing that they independently researched support and guidance. Furthermore, one focus group participant, explained that the knowledge gained from their independent research, gave her the confidence to persistently persuade her GP to make a referral to a specialist. Our survey results coupled with accessibility of the internet, illustrates the potential for online support being a discrete, powerful and empowering avenue for Black women seeking help and resources.

The Transforming Elective Care Services Gynaecology handbook (NHS, 2019), highlighted that self-management education, patient decision aids, videos and the provision of information specific to certain diagnoses are ways in which individuals can become better educated about gynaecological healthcare. Our survey results indicate that the suggestions put forward in the handbook have not had a far-ranging impact. We can see from beneficiaries who completed the survey that menstrual-reproductive health education workshops and peer support groups would be the most beneficial forms of educational support. However, we would also submit that this work left to small, often volunteer-led, under-funded organisations and community groups cannot hold the burden for this access to care and support; not only due to it being resource intensive, but, and as a result of the



combined internal research and external data considered within this report, a much wider societal approach is required in order to see the much needed systemic change. We submit that large-scale research needs to explore what and how information, care and support can better reach Black communities.

Whilst there is a severe need for more information and support, what is equally as important is the people/organisations who provide this in the first place. Lack of representation was the second most common barrier face regarding seeking support. Interestingly, when photos of male and female medical staff were used to prompt focus group discussion, narratives of not being taken seriously and having symptoms trivialised, emerged regardless of whether the staff member was male or female. This is interesting, considering that female patients tend to prefer same gender primary care physicians (Fink et al., 2020). What was clear in focus group participants' response though, was discussion that confirmed having 'less confidence' in the approach and care provided by White doctors. One focus group participant commented that if she was to see a Black female GP she would 'feel like I've got to remove one less layer of myself, like she would relate to that part of me easier,' (focus group participant, May 2021).

Our results signal the importance of Black healthcare professionals and educators occupying roles within gynaecological healthcare as a means to provide empathetic and culturally sensitive support.


Furthermore, in a project which explored Black voices on contraception choice/access to sexual health services, participants voiced the need for visibility and representation in the form of Black healthcare staff across all roles and levels. (Briscoe-Palmer, 2022). Systemic racism and its impact on healthcare has created a need for care and support services which acknowledge the challenges experienced by Black women. Considering that such services do not exist within the NHS, it is integral for charities such as Five x More, Cysters and us at the African Pot Project to continue facilitating a space for marginalised women.

In the focus group, it was expressed that women's health tends be centred within the context of maternal health as opposed to menstrual-reproductive health specifically. The literature search conducted by Freedom4Girls indeed found that in the small body of UK centric research which did touch on health disparities amongst Black women, these papers were largely related to maternal health outcomes and referenced Black women under the BAME term.

The lack of research into racial disparities within a gynaecological health context hinders the development of health related policy and best practice guidelines that would otherwise serve to provide good quality gynaecological care to Black women, girls and people who have experienced menstruation. It is therefore important to acknowledge that culturally sensitive gynaecological support does not exist in part due to the gap between Black women centred gynaecological research and policy.

We acknowledge that the Women's Health Strategy for England (Department of Health and Social Care, 2022) outlined commitment to conducting (menstrual and gynaecological focused) research into healthcare professionals' perspectives of listening to women in primary care. We welcome this as a move towards closing the gynaecological research and policy/support gap.

However, we also note that the strategy once again, has not recognised the differences in the menstrual-reproductive health experiences between, what they have called, 'women from ethnic minority groups.' This report, amongst others, has highlighted menstrual-reproductive related conditions as uterine fibroids, as being prevalent in African and African-Caribbean women. This report, amongst others, has highlighted that Black women face serious barriers compared to other ethnicities,



when it comes to having their conditions addressed, including having their reports of pain actioned. Within our conclusions and recommendations we provide the views of this project team in relation to where the government's strategy falls short, what the approach should be to work in reducing inequality and institutional racism within female reproductive healthcare, and finally, what this project aims to do in addressing those areas that have not been thus far implemented into public health or gynaecological health policy.

5. Conclusion and Recommendations

This research piece is the first of many actions this project is committed to taking in addressing the disparities in across female reproductive health.

Our baseline, pilot research clearly highlights the disparities in access to healthcare support, inadequate yet necessary menstrual-reproductive education and the discrimination that Black women experience when it comes to pain awareness and addressing pain. As emphasised in the report introduction and throughout, this project is not solely a research piece. Whilst the research is integral to both shedding light on the experiences and needs of Black women, it in turn acts as an important justification to wider community and stakeholders with regards inviting proactive approaches to tangible, systemic change.

Our conclusions touch upon what our research has taught in regards to what should now take place in the wider world of menstrual and reproductive health, focusing on the below areas:

1. Previous and existing research as reflected within the literature does not provide an awareness and insight into the menstrual and reproductive health needs and experiences of Black women, and certainly not Black British women.


From our literature review, it became clear that Black women have not been given a platform for their voices to be heard. There is no single, peer reviewed piece of research which documents the lived experiences of Black women seeking gynaecological healthcare. This acts a disservice to the millions of Black women for whom a climate of systemic misogyny has created stark racial disparities within reproductive health outcomes, (as compared with White women).

Existing academic research has not employed focus group or interview methodology to capture Black women's beliefs as to who and what contributes to the barriers to accessing good quality, gynaecological healthcare. If we do not provide spaces in which Black women can articulate their struggles and past healthcare experiences, how can society work toward shaping culturally sensitive services and improve accessibility to care and support?

The Black Women's Reproductive Health project acknowledges that Black women are the experts of their own experience. Lived experiences of accessing and experiencing gynaecological healthcare, especially against the backdrop of systemic racism, should provide a foundation for policy change and the implementation of best practice guidelines.

2. There remains a disconnect with our understanding of Black women's experiences of menstrual and reproductive health throughout the lifespan, outside of pregnancy, and post-partum

Disparities in Black women's reproductive health are well acknowledged, as evidenced by the injustices and discrimination faced by Black women, resulting in disproportionately harmful maternal health experiences. We would argue that this project has evidenced that the scope of reproductive health research in Black women should expand to include a consideration of menstrual health related conditions and outcomes.



US centred research on maternal health outcomes have thus far dominated the field of reproductive/gynaecological health at large, and quite rightly owing to the concerns pertaining to the disproportionate number of serious and fatal instances involving pregnant Black women. We submit that all of the work done pertaining to maternal health in Black women is critical to improve maternal outcomes and the safety of Black women. This campaign and research has created more conversations between policy makers, activists, researchers, academics and so on, and has notably gained momentum around the ever important issue in the UK. The results of this project suggest, however, that now is the time to continue this momentum. To do so, we must supplement our knowledge of the maternal health experience through further investigation of menstrual and reproductive health conditions, and general reproductive health across the life course.

We put forward the argument that one of the main, missing pieces of the gynaecological research puzzle, is the acknowledgment and study of menstrual health related disorders amongst Black women. Conditions such as the growth of fibroids, endometriosis and Polycystic ovary syndrome, impact on the healthcare care needs of Black women and yet, there is little acknowledgement of the way in which Black women and healthcare professionals attend to and alleviate the consequences of such disorders. Furthermore, there is a pervasive issue in medical research such that when research is conducted on women to better understand these conditions, participants are largely White European, and are not sufficiently diverse to understand the nuances of such conditions in Black women. This is particularly alarming considering the systemic, racist climate in which Black women live.

Menstrual healthcare and the study of how it is accessed and delivered is a vital extension of maternity healthcare outcomes. From our work we heard that Black women were dismissed and their concerns were not taken seriously, resulting in a detriment to their health when presenting to their GP or gynaecologist. The experiences before pregnancy, in which a Black woman accesses care for anything related to reproductive health shapes her perspectives on healthcare, and it is reasonable to believe that this may influence her confidence in speaking up when things are not right or her concerns are not taken seriously. Our concern is that, due to medical racism, further compounded by the proper lack of menstrual-related education and empowerment to discuss their bodies, that Black women are being set up for failure when (if the time comes), they access maternity care. While there are many reasons contributing to disparities in maternal mortality, we worry that without proper education and a foundational understanding of Black women's menstrual and reproductive health experiences, we are doing a disservice to our understanding of maternal health as well.

3. There is a concerning lack of education, awareness and appropriate care and support into broader menstrual and reproductive health issues. This was evidenced by the following in our research:

- The knowledge or lack of knowledge of menstrual and reproductive health conditions perceived by the beneficiaries;
- The knowledge or lack of knowledge of menstrual-reproductive health conditions held by healthcare professionals;
- How the project beneficiaries perceive their own pain;
- How the project beneficiaries action / treat their own pain, including how this is or isn't supported by healthcare professionals;
- How the project beneficiaries determine their general health and wellbeing, and how their menstrual-reproductive health conditions do or don't link to that;
- How the stigmas associated with menstrual and female reproductive health conditions impact the project's beneficiaries quality of life and access to socio-economic status at a significantly high proportion given the data we discovered on missed work;

- Fears and failures of having menstrual-reproductive health conditions addressed by healthcare providers;
- The need for an intersectional approach across organisations that are practising in this field, with a large call for assistance via peer support education.

As we've shown, more than 70% of our beneficiaries reported experiencing period pain and/or chronic pelvic pain, and that whilst we know that generally one in fifteen women report period pains (Zondervan et al., 1999), our results showed that shockingly, a much higher proportion of Black women suffered from such pain.

Within the Discussion we referenced the need for further investigation into the causes of this as our research has only taken us so far, citing the potential reasons as:

- Women of African and African-Caribbean heritage being more 'prone' to developing recognised painful menstrual-reproductive health conditions such as uterine fibroids and endometriosis.
- Our beneficiary cohort experience racism, conscious and unconscious discrimination when it comes to the reporting of pain.

As such, we raise a call to action for female reproductive health researchers and healthcare providers to consider and analyse important variables known to influence pain (i.e. socioeconomic status, mental health, support, genetics), in Black British women. This call aligns with the Government's Women's Health Strategy 10-year ambition of including more women from ethnic minority groups in research (Department of Health and Social Care, 2022). Only with this broader understanding as to causal factors into pain and a woman's interpretation and assessment of her pain, will we begin to further understand why such disparities may exist in the UK.

There is also more to be said on the disconnect between perceived general health and chronic pelvic pain or period pain that was observed in our cohort. For too long period pain has been normalised in society, and by consequence, discussions around periods and period pain, have been highly stigmatised. This ties in with our discussion point concerning education and the lack of good, well-researched, informative menstrual and reproductive health education.

We have seen that there is a connection between the lack of detailed and meaningful menstrual-reproductive health education as being a reason for Black British women and people with female reproductive systems struggling to have these needs met, due to an inability in understanding the breadth of symptoms and conditions that women experience, the potential treatment options or even need for treatment.

There are many points we could raise in relation to the reasons menstrual-reproductive health stigma exists and how patriarchal structures weaponize said stigma as cause for maintaining sex-based and gender inequality; (but we appreciate this is an entire project in and of itself!) What we will say is that, as a team committed to the erasure of misogyny and misogynoir in female reproductive health, good quality education that seeks to empower, confidence build and remove stigmas associated with normal bodily functions is fundamental in moving towards improvements in healthcare outcomes for Black British women.

Recommendations:

This project and research report now represents a call to action for the female reproductive health sector. We have evidenced some of the fundamental reasons as to the disparities and impacts systemic racism is having on Black British women's access to good female menstrual-reproductive healthcare.

So what do we recommend should now happen in this broad space?

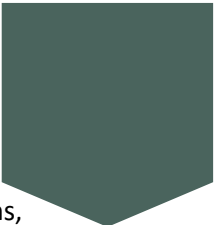
Education and Access to Support

It is exceptionally profound that for every beneficiary who answered the survey question and engaged in the peer support or focus groups, when asked if they faced barriers - **everyone answered yes** - to either one or more of the listed barriers. Lack of information and education represented the single largest barrier to women getting support for their gynaecological health needs. Where institutions are uniquely positioned to provide a wealth of information to Black women who menstruate e.g. universities, refuges GP surgeries and schools, we advocate that they push for resources which details menstrual-reproductive health conditions, tips in managing symptoms and crucially, the next steps women can take in dealing with concerns/debilitating symptoms. These resources should be disrupted widely and be available in many different forms e.g. leaflets, posters, information packs and online documents. It is integral that institutions provide educational material which acknowledge Black women's unique challenges in accessing healthcare in order to ensure such resources are relatable. Furthermore, as our project highlighted online research as a powerful medium for learning, we call on services with powerful online platforms/websites to provide comprehensive gynaecological health information pathways or, at the very least, a directory of services which acts as signposts for further support.

The wide distribution of resources which highlight the reality of menstruation as an often difficult, yet ultimately, shared human experience further paves the way for menstrual health stigma to be reduced. Moreover, by creating and widely distributing resources which comprehensively talk about menstrual health, this acts as a major step toward moving society away from a sense of "menstrual etiquette" where women feel that their periods are something to be dealt with alone. Friends and family also have a role to play in supporting women with their menstrual cycle and it would be beneficial for sources to be tailored to them also.

The current project acknowledges that safe, cultural sensitive spaces, particularly those run by Black women for Black women, are powerful spaces in which Black women can learn about navigating gynaecological health issues. Most beneficiaries stated that reproductive education workshops, empowerment workshops and peer support groups, would be the most beneficial forms of educational support. This therefore highlights the importance of organisations such as Freedom4Girls, Cysters and the African Pot Project, continually receiving the funding they need in order to provide peer/emotional support groups for Black women.

The current project acknowledges that there is limited capacity for charities to facilitate such spaces. We therefore call on more research to be done in relation to exploring the ways in which Black women would like to experience menstrual health related information and support. We advocate for the collection of lived experience through participatory, focus group and interview research as a means to enable Black women's voices to directly shape and improve the way in which information, support and services are delivered. Our seminal but small- scale, preliminary project, was limited in the



numbers of Black women who could be involved in this study. We urge academic institutions, healthcare providers, stakeholders and other funders committed to tackling inequality, to fund this data collection which will in turn help Black women with gynaecological health needs.

Better Understanding of Pain

Our results echoed published literature which has established Black women's pain and discomfort as something that is easily dismissed. This is hugely concerning considering that pain represents one of the biggest burdens associated with gynaecological health issues and over 70% of our beneficiaries expressed experiencing chronic pelvic pain.

In order for society to work towards alleviating the discrimination experienced by Black women and Black women's suffering, two main action points come to play – the lack of research into Black women's pain and the racial biases of healthcare professionals which underpin the dismissal of debilitating symptoms. In regards to the first point, we call for research to identify the factors which are known to influence pain e.g. overall physical health, mental health and socio- economic status. The more we can understand the nature and variables which influence pain in women, the more avenues can be provided through which Black people can be supported with their pain.

In regards to the wide-scale dismissal of Black women's pain, we raise a call to action for systemic racism and conscious and unconscious biases, to be made more aware of within British healthcare communities. We would welcome the creation of proactive, menstrual-reproductive education in the form of campaigns, written resources and mandatory training which communicates to doctors, the historical context underpinning racial biases. Furthermore, we call for powerful institutions such as the NHS, to make healthcare professionals aware of the concerns voiced by Black women and how Black women would like to be supported within the healthcare encounter. This further reinforces the importance of large-scale research projects documented lived experienced of Black women as a means to provide the foundation for sensitive and empathetic support within the classroom.

The project and research team recognised that there is little discourse surrounding the ways in which women articulate pain. As a particularly abstract concept, it is understandable how women may struggle to find the language to describe their intensity of pain. The difficulties in explaining pain, coupled with the fact that Black women experience racist attitudes toward their pain and discomfort, further increases the likelihood of their gynaecological symptoms not being taken seriously. We would welcome more work, research and campaigning into ways in which pain can be better articulated. We would like the healthcare field to explore the effectiveness of more objective methods of pain recognition e.g. through assessment tools as a means to highlight Black women's suffering and also, make professionals more aware of discrepancies between their Black patients' pain readings and the advice/ actions they have followed through.

Further considerations

It is possible that there was an element of selection bias in our study, such that women who wanted to participate in the project were more likely to be impacted by chronic pelvic pain or other chronic conditions than Black women who didn't participate. Nonetheless, this work highlights how burdensome pain and other chronic conditions, such as uterine fibroids and endometriosis are amongst Black women in the UK. It further points to evidence of systemic racism in medicine, from points of likely failed diagnoses and failures to act on reporting of period and/or chronic pain, and lack of proper education about menstrual health and related conditions.

Available support

In the UK, there are some resources and support available if you are suffering from chronic pain, or other chronic conditions such as endometriosis or uterine fibroids. [Cysters](#) is an inclusive community for anyone suffering from reproductive or menstrual health issues, and provides support to share experience, effectively becoming an advocate for your own health in a healthcare setting. [Endometriosis Survivors](#) and [Endo.of.an.Era](#) are each UK based voluntary organisations spreading awareness and empowerment for endometriosis sufferers in the UK. Although not in the UK, [EndoBlack](#) is a USA organisation which supports African American women and women of colour affected by endometriosis. They have a newsletter that can be subscribed to, and online events. While not specific support for Black women, Endometriosis UK does offer [local support groups](#) for those suffering from endometriosis across the UK.



6. Project: next steps

From the outset of this section, we note that the next steps as listed below do not differ significantly from the project aims as listed within our original concept note of July 2020.

As a team, we have always recognised the importance of collecting data and creating a research piece to then justify the practical steps that are, and always have been, clearly needed in order to remove racism from female reproductive health and improve the healthcare outcomes of Black British women and people with female reproductive systems.

These tangible steps include both the need to empower, booster confidence and foster knowledge of various menstrual-reproductive health conditions in our beneficiaries, and also to place responsibility back onto healthcare providers and decision makers such that they listen, accept and acknowledge the feedback Black British women and people under this cohort, are stressing is their lived experience.

We identify the ways in which we aim to achieve these points below, and comment on other areas of learning that we have obtained from this research piece.

We need more data


We have identified the challenges the research stage of this project experienced due primarily to the global COVID-19 pandemic and the shift in priorities of both individuals and organisations in completing voluntary surveys.

We are proud of the efforts and results we achieved. However, the BWRH team also acknowledge that, to further justify the recommendations herein and the project's overall aims in respect of systemic change and removing racism from female reproductive health spaces, a larger pool of beneficiaries should be interviewed. In collating more data from a larger number of the cohort, the impacts this project can have will be far more wide reaching, including:

- Opening avenues for stronger awareness raising amongst both our core beneficiaries and stakeholders into learning about the project findings and aims.
- Presenting as more persuasive to the stakeholders and decision makers who have influence in the sector in which we are attempting to shape.

Further, and as reflected in the methodology section, (specifically limitations), we recognise the benefits in slight revisions to the original beneficiary survey questions, including, (but not limited to), ensuring an awareness / definition of 'general health,' is provided such that analysing this feedback and the links of this with 'period / pelvic pain' are better determined.

In addition to expanding our data collection for a wider reach, we also acknowledge that more resource should be applied to responses and engagement of our cohort of beneficiaries who fall under category of 'people with female reproductive systems.' As the project develops into the next stages, we aim to apply more specific strategies to engage people with female reproductive systems who don't identify as women or as female, trans-men, non-binary people and gender fluid individuals;



anyone who has a female reproductive system and has experiences of the conditions this project aims to address, is welcomed and included in this work.

We submit this is an important addition / upgrade to be made as not only from our research, but the wider literature also indicates that awareness of and expression of pain experienced by Black British women is impactful on the success or detriment of how their issues are actioned by healthcare providers.

How will we achieve this?

1. Collective Activism

Multi-agency and partnership working has been a driving force towards systemic change against inequality across a range of sectors, and typically, voluntary organisations are at the forefront of this.

The Black Women's Reproductive Health Project are a small, voluntary group under a slightly larger, but still very much, grass-roots non-for-profit organisation. We cannot achieve the changes we wish to see to better improve the health and quality of life for Black British women alone.

This is a call to action for our fellow activist sisters, friends and community to help us in promoting our survey for Black British women and people with female reproductive systems to complete. The more responses we receive, the more we can consider the experiences, needs and wellbeing of our beneficiaries, not only to shape the project outcomes but also, in how we will advocate for the much-needed changes to systemic racism in female reproductive healthcare.


Here, we also highlight the exceptional, resource intensive and the emotional labour that is placed on our fellow activist community. As referenced in earlier stages of the report, we acknowledge and thank individual Black women and the people who are activists within this space, documenting their own menstrual-reproductive health experiences and providing resources, narratives, and emotional support to our beneficiary group and beyond.

As we know, this project and the research so far has created an additional space to the work these people have already done and to the support they have already provided to so many in need. The BWRH project is about lived experiences and we thank those activists for sharing theirs, in the majority of cases, without receiving acknowledgement or funding from the sector in doing so. We want our work to support and compliment theirs moving forward also.

2. Funding

Our project thus far has received funding in the form of travel and resource expenses by the Trustees from charity Freedom4Girls UK and through a small pot of money via NSUN, (who supported our initial peer support groups of 2021).

In order to continue to provide support to the Black female reproductive health space, to develop the work more substantially and with quicker timescales, the BWRH project is sourcing unrestricted and restricted funding.



As the project moves forward, we will be seeking both grant funding and donor/ sponsorship from companies and individuals who are also committed to the project aims; we argue that all people everywhere have vested interest in the work of this project, as reducing sex-based inequalities and removing racism impacts each and every one of us, as in doing so we create stronger socio-economic and mental health outcomes for a better society.

If you would like to discuss opportunities in relation to financially supporting us, please do get in touch.

3. Developing Empowering Educational Programmes and Resources for Beneficiaries:

Removing stigma, providing positive and meaningful menstrual and reproductive health education is fundamental to removing misogyny and misogynoir within female reproductive health.

It was an overwhelming requested project outcome from our beneficiaries, that this type of education is needed to improve their own and other Black women's access to good quality reproductive healthcare and in feeling confident and empowered in understanding their bodies.

We see the development and delivery of this work occurring two-fold:

- Continuing and evolving the peer support group sessions that combined both information and education on certain menstrual-reproductive health conditions, (more information under point 3).
- Creating an accessible and inclusive resource that details known menstrual-reproductive health conditions, tips in managing symptoms, confidence building activities that support in both improving comfort in menstrual-reproductive health experiences, e.g. difficult periods, and advice on self-advocacy before a healthcare professional, will all be provided in this resource. Given the intentions for the resource to be accessible, we will ensure that it is not only available electronically but for our beneficiaries who do not have internet access, cannot navigate social media, and through the right research, we will aim for the resource to be in the first languages of as many beneficiaries as possible.

4. Delivering Peer Support Groups:

Should we be successful in gaining funding, the BWRH team will be offering community based and online peer support groups that provide both

- Safe spaces without taboos, stigmas and racial biases that exist in menstrual and female reproductive healthcare; and
- Informational sessions that empower and educate our beneficiaries.

We have a successful and effective model of these peer support group sessions and resources that we aim to utilise in the community and online for any beneficiary or support organisation who believes they will benefit from this work.

Sharing stories and creating a community is an integral part to the project aiming to address systemic racism and poorer female reproductive health outcomes for Black British women.

5. Disseminate Research Findings to Healthcare Providers:

The aim of this stage is to ensure relevant healthcare providers are aware of our project's findings and aims through the distribution of this report. We must remove the shame, stigmas, lack of awareness and racist ignorance that surrounds Black British women's menstrual – reproductive pain to see better outcomes for our beneficiaries in and out of the doctor's office or hospital.

As above, whilst this project has relied on our research to justify our overall aims in removing racism from female reproductive healthcare, we know more is needed to see a genuine addressing of the changes in dismantling racism. We will be utilising our research and this report to call for healthcare providers to take practical steps and solutions into creating these tangible changes.

One of the ways in which we envision this occurring is through positioning ourselves as anti-racist consultants and trainers for the female reproductive healthcare sector.

We have already and will work with additional Equality, Diversity and Inclusion specialists to create packages of consultancy training and support to healthcare providers, organisations (statutory and private), who work in female reproductive health.

Whilst this area of our project is the most under-developed, we are fortunate to have team members and other peers who have assisted in the creation of this project and are versed in anti-racism practices such that the BWRH project can draw on this expertise in creating such training for healthcare providers and professionals.

6. Campaign for Racial Equity in Menstrual-Reproductive Health Space


This will be an ongoing aim and deliverable within this project. The BWRH team are now in a fortunate position to use this report to tell the stories of and articulate the experiences and needs of our beneficiaries. As a beneficiary-led project, this is driven by those people who gave their time to supporting in these outcomes, and with this data we can lobby government, healthcare providers and stakeholders into action.

More specific examples of what this looks like will be:

- Calls for existing training and decision-making processes to be evaluated
- Incorporating an awareness of the history around menstrual-reproductive health
- Moving beyond tokenistic / reductive representation of Black women and people
- Working closely with the parliamentary work that is within the same space as this project; e.g. the APPG on Black British women and maternal health.

A Final Thank You

Thank you to you, for investing time into reading this report and learning more about the Black Women's Reproductive Health Project.



Thank you to all of our beneficiaries, supporters, partners who have contributed to the development of this research piece; with more specific thanks provided in the Acknowledgement section.

We encourage you to follow our progress on social media via @blackwomensreprohealth and @tapeventsmcr on Instagram.

Please also sign up to our mailing list by emailing brwh.tap@gmail.com and look onto T.A.P's website for more updates www.tapproject.co.uk

*The BWRH team is committed to providing effective support and welcoming environments for all potential beneficiaries who may not identify as women or female, and we are open to conversations about bettering our language in order to create an integrated project for ALL beneficiaries.

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Annex 1: Community groups contacted

Table 1 Community groups contacted for involvement in study

BAME Health and Wellbeing Service
Black Lives Matter – Leeds
Black, Broke and Anxious Podcast
Bloody Good Period
Cysters
Dial House @ Touchstone (Led by Leeds Survivor-Led Crisis Service and Touchstone)
Doing Good Leeds - BME HUB Managed by Voluntary Action Leeds (VAL)
Gendered Intelligence
Getaway Girls
Girl Gang Leeds
Heritage Corner
Leeds Beckett Student Union - BAME Students
Leeds Black Elders Association (LBEA)
Leeds Feminist Network (LSFN)
Leeds Girls Can
Leeds University Union
Leeds West Indian Centre Women's Group
Leeds Women and Girls Hub
Leeds Women's Aid
London Black Women's Project
On your reds
Periodical Diary
ReSisters United
Sharing Voices
The Black, African and Asian Therapy Network (BAATN)



Annex 2: BWRH Surveys

Service User / Beneficiary Questionnaire

Welcome

Freedom4Girls is exploring how systemic racism and unconscious biases impact experiences of menstrual and/or female reproductive health needs.

This survey is to gain an understanding of the experiences of women, people with a female reproductive health system and/or people who menstruate who are of African and/or Caribbean heritage, when seeking healthcare assistance regarding their menstrual and/or reproductive health related needs.

The survey is estimated to take between 5 – 10 minutes to complete.

The information you provide will help Freedom4Girls advocate and campaign for menstrual equality.

. All information provided will be stored securely and confidentially.

This survey can be completed anonymously (there is no obligation to provide your contact details). However, if you would like to take part in the next stage of this project, which will involve more detailed interviews, please complete the box at the end of the survey with your contact details.

If you have any questions or concerns about completing the survey please contact Freedom4Girls at info@freedom4girls.co.uk or by filling in the 'contact us' form on our web-site [Freedom4Girls](https://freedom4girls.co.uk).



How did you hear about this survey?	<ul style="list-style-type: none">• Email• Facebook• Instagram• Twitter• Other Social Media (please state)• Other (please state)
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What is your occupation/job title?	
What age group are you in? (please select one)	<ul style="list-style-type: none">• 10-15• 16-18• 18-24• 25-34• 35-44• 45-54• 55 and over
What is your gender identity?	
What is your racial ethnicity?	

<p>How would you describe your general health? (please circle on the scale)</p>	<p>1 – 2 – 3 – 4 – 5 – 6 – 7 – 8 – 9 - 10</p> <p>Very Poor Excellent</p>
<p>Have you ever suffered from or been diagnosed with any of the following? (please select all that apply)</p>	<ul style="list-style-type: none"> • Period pain and/or chronic pelvic pain • Heavy menstrual bleeding • Severe pre-menstrual symptoms (including hormonal health & emotional well-being) • Polycystic Ovaries (PCOS) • Endometriosis • Fertility issues (including miscarriages) • Perimenopause and/or menopause • Fibroids • Premenstrual Dysphoric Disorder (PMDD) • Other (please state)
<p>How often have you missed school and/or work because you were menstruating?</p>	<ul style="list-style-type: none"> • Never • 1-2 times a year • 3-5 times a year • 6+ times a year <p>If absent, please select a reason(s) from the below;</p> <ul style="list-style-type: none"> • Lack of products • Stigma surrounding menstruation • Premenstrual Symptoms (PMS) – including hormonal health and emotional well-being • Chronic pain • Heavy bleeding

	<ul style="list-style-type: none"> Other (please state)
Where do you look for support in relation to your menstrual and/or reproductive health needs? (please select all that apply)	<ul style="list-style-type: none"> General Practitioner (GP) Fertility specialist General Health Clinic Sexual Health Clinic Other (please state) I have never looked for support
What, if any, barriers do you face when trying to access and receive menstrual and/or reproductive health care? (please select all that apply)	<ul style="list-style-type: none"> Discrimination Language barriers Cultural barriers Poor previous experience Lack of information and education Lack of representation Unsure of support services available Other (please state)
What other support regarding your menstrual and/or reproductive health do you think would benefit you? (please select all that apply)	<ul style="list-style-type: none"> Menstrual/Reproductive Health Education Workshops Peer support groups Empowerment Workshops 'Sew your Own Pad' Workshops Learning about the range of Period Products available Other (please state)
What is your preferred method of engagement with this, or similar, projects?	<ul style="list-style-type: none"> Facebook Instagram Twitter Other Social Media (please state)

(please select all that apply)	<ul style="list-style-type: none"> • Email • Face-to-face • Community Groups • Other (please state)
We welcome any other comments.	

Contact Details - if you would like to participate further.	
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THANK YOU.

Our sincere thanks for your time, honesty and participation in our survey.

*With the exception of one new open-ended question on location, the survey set out above is the original version used for data collection by the Project Team.

In July and August 2021, the team reflected and amended three questions, on location, racial identity and gender identity. After July 2021, respondents were asked 'where are you primarily based?' and provided with three available responses, these being UK, USA or other.

It was also agreed that the surveys would offer multiple choice answers to the gender identity and racial ethnicity and heritage question. As such, from August 2021, gender identity also included a section asking the respondent to 'please confirm you were born with a female reproductive system'. For racial identity, categories were added, these included Black African; Black Caribbean; Black African and Caribbean; Mixed-race African; Mixed-race Caribbean or Other.

Annex 3: Focus group and peer support group agendas

Table 2: Focus Group Discussion Agenda

Intro 15 mins	<ul style="list-style-type: none"> o Welcome/Thank You/House rules/introduce team etc o Background to F4G, why we're doing the project o Some findings/statistics o Explain Focus Group structure, objectives 	Welcome: F4G
Ice Breaker - Stigma Around Periods 15 mins	<ul style="list-style-type: none"> o Get folk talking o Gauge group dynamic etc o Better understand stigmas faced <p>Could also be 'Stigma's about Black Women'?</p>	<ul style="list-style-type: none"> o Quiz - true or false o 2 lies, 1 truth, which is which? o What is the funniest/worst/most ridiculous myth/stigma you've heard? o How many words can you think of to describe your period? o How would you describe periods to someone who had never heard of them?
Q1 - What Types of Discrimination (stigmas) are faced?	<p>To understand;</p> <ul style="list-style-type: none"> o What is it that Health Professionals' are not understanding? o In what ways does discrimination manifest itself for the participants? o What impact does it have? Would they report? 	<ul style="list-style-type: none"> o Write 3/5 words to describe discrimination/what a 'bad' experience looks like o We provide 'words/statements/images', perhaps provocative, and ask for comment/reaction o Describe, perhaps non-period related, misunderstanding/mishap to draw out/ascertain any commonalities in language/cultural barriers faced o show one group a black Dr and another a white Dr and ask to provide words - eg. what does this image make you think of?
re-group	o Group feedback	o presented by participants
Q2 - What Does Good Look Like?	<p>To understand;</p> <ul style="list-style-type: none"> o What is it they are looking for? o How can their needs be best catered to? o What are those needs? What is 'good'? 	<ul style="list-style-type: none"> o Draw a picture of what 'good' look likes o Write the top 3 things you would expect when seeking support o Can you share a 'good' experience? o Think of a good experience and name the top 3 ways it made you feel (this could be non-period related) o Rank 7 topics by order of importance (ie. same

	support? O How do participants want to feel before/after appt?	gender, same ethnicity, specialist in female health, opening hours, feel respected/heard, sense of belonging etc)
re-group	o Group feedback	o presented by participants
Guest Speaker	could this be pre-arranged questions? Or on a pre-arranged topic? le. Ask participants in advance what they want to learn about here	
Sign Off	<ul style="list-style-type: none"> o Thank You o Tips on overcoming barriers o Signpost support o Invite feedback (survey monkey?!) o Encouraging words 	Tips from Dr speaking at (Danielle's) PCOS discussion; o ask for double appt so have time to discuss concerns o ask that any refusal to refer/provide treatment/prescriptions etc is noted on file

Table 3: Peer support group discussion agenda

Peer support group 1: All about periods	<p>Topics to Discuss</p> <p>What is a period and why do we have them</p> <p>Acknowledgement of our age and experiences with periods</p> <p>Do you think society perpetuates certain aesthetics/moods about periods? What are they?</p> <p>Potential activity: looking at period product ads - are they glamorizing or focusing on 'hiding' periods? Do they seem to be targeting certain audiences?</p> <p>Discussion on different products</p> <p>Bleached tampons; diva cups; unbleached tampons; pads; essential oil pads</p> <p>The environmental impact?</p> <p>How these products may or may not be 'good' and/or 'bad'</p> <p>Further discussion points:</p> <p>Do you remember your first period?</p> <p>How did getting a period make you feel? Society might glamourize or 'horrify' the idea of periods - did you associate with main-stream cultural responses to periods?</p> <p>What is something that you wished you knew before having a period?</p>
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<p>Peer support group 2: Conditions I didn't know existed</p>	<p>Topics to Discuss</p> <p>What conditions do we know about?</p> <p>PCOS Amenorrhea Dysmenorrhea Menorrhagia; PMDD Perimenopause: Fibroids: Endometriosis:</p> <p>Ask if they've ever heard of these If yes, then did they seek treatment for it? Were they taken seriously while asking for medical help? At what point do we go to the doctors?</p> <p>Activity - Go onto a padlet and add experiences of conditions, tips for treatment and management, or questions</p> <p>Are there any conditions you know of that we haven't discussed?</p> <p>Further questions and discussion points: When (if) did you all hear about these different conditions? From a young age? When you moved away from home? Did you ever resort to having to Google symptoms and do research yourself? Was it because: you were not taken seriously when you asked for help; you didn't think it was serious enough to ask a professional for help; or did you feel shame/discomfort in asking for help? Or maybe a combo of all three? In having one of these conditions, what would you like to see changed in how people perceive it? Did you feel like you knew what these conditions were before this presentation? Was that because you have had personal experience with them or did someone tell you about them?</p>
<p>Peer support group 3: What support is there?</p>	<p>Topics to Discuss</p> <p>Where can we find information on our periods? Add examples such as: Helping Women Period The Menstrual Health Hub Brook Add links and names of information sources to the chat box!</p>

	<p>What are the barriers we face to accurate information?</p> <p>Can we share any good practices on dealing with PMS/menstrual related issues?</p> <p>Activity : Go to Blooklet and play myths vs facts</p> <p>Further questions and discussion points:</p> <p>Who do you turn to for advice and support about your menstrual health?</p> <p>Have you ever sought help and felt unsupported?</p> <p>Has anyone ever been misled about the truth of their menstrual health reality?</p> <p>How can we tackle these myths ourselves?</p>
<p>Peer support group 4: What should be done and what can we do?</p>	<p>Topics to Discuss - add question about what they want to talk about</p> <p>How can we break the stigma around periods?</p> <p>What would you like to see done to improve the experience of menstrual health for all those that menstruate in the UK?</p> <p>Potential activity: Design an app for all things period/all we need to know. Facilitators create a visual board with bubbles on and fill these with sections of the app proposed by participants i.e period tracker, periods in the news, pads vs cups debate, local spots that provide free provisions, details on menstrual related conditions and when to see a doctor tips on dealing with symptoms etc</p> <p>Potential activity Letter to Our Younger Selves - ask each individual to write a letter to themselves about what they wish they knew about periods, support, etc.</p> <p>Questions we can ask:</p> <p>Do we think the stigma and menstrual health is getting better?</p> <p>What can we do to promote the sharing of menstrual health experiences?</p> <p>How can support look differently in the workplace, in public/in general, and in between friends and family ?</p>



Annex 4: The importance of lived experience

From our literature review, it became clear that Black women have not been given a platform for their voices to be heard. There is no single, peer reviewed piece of research which documents the lived experiences of Black women seeking gynaecological healthcare. This acts a disservice to the millions of Black women for whom a climate of systemic misogyny has created stark racial disparities within reproductive health outcomes, (as compared with White women).

Existing academic research has not employed focus group or interview methodology to capture Black women's beliefs as to who and what contributes to the barriers to accessing good quality, gynaecological healthcare. If we do not provide spaces in which Black women can articulate their struggles and past healthcare experiences, how can society, work toward shaping culturally sensitive services and improve accessibility to care and support?

The Black Women's Reproductive Health project acknowledges that Black women are the experts of their own experience. Lived experiences of accessing and experiencing gynaecological healthcare, especially against the backdrop of systemic racism, should provide a foundation for policy change and the implementation of best practice guidelines.

Themes echoed across blog posts and magazine articles

The literature review widened its search by incorporating blog posts and articles. Numerous online blog posts and articles have captured the first hand experiences of Black women navigating their menstrual cycle. We maintain that such online accounts, capture lived experiences that are otherwise missing from published literature. The following themes were illustrated:

- Mothers are hugely influential in shaping their daughters' attitudes toward menstruation. Many Black women explained that they observed their mothers experiencing severe menstrual pain and discomfort as a child. However, because mothers did not communicate that pain and rather dealt with their symptoms (presumably) privately, daughters internalised this "grin and bear" approach and believed that (as modelled by their mothers), debilitating pain is a normal expectation to be dealt with
- Black women live with debilitating and worsening pain until the extreme limits of the body are tested. It was referenced that experiences of pain and discomfort need to reach an unbearable level before Black women speak to a doctor.
- Black people visit doctors and communicate their debilitating pain only to be dismissed as having regular pain or being a phase that will pass.
- Multiple trips to doctors and a narrative of "begging for support" was seen across online accounts.
- Black women expressed that there is no culture of prevention in relation to gynaecological health; being dismissed by doctors multiple times, has led to diseases such as endometriosis worsening.
- Black women stated that they were often prescribed medication as first line treatment; however these were either ineffective or become ineffective.

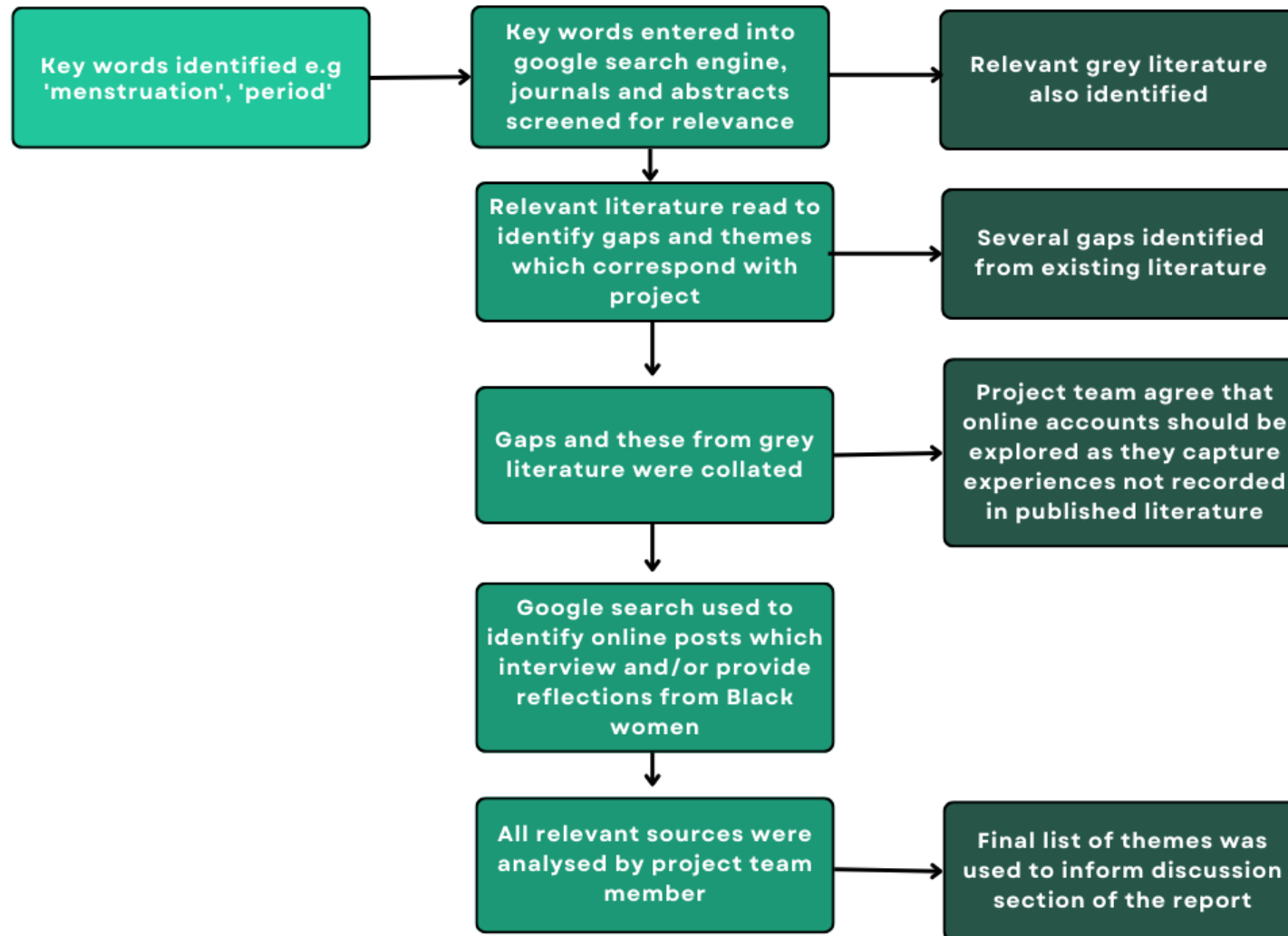
- Black women acknowledged historical oppression as contributing to the relationship with their period. For example, white nationalism and slavery led to Black women internalising that their bodies are already “wrong” and “dirty.” Historical oppression has contributed to Black women feeling a hyper sense of shame in relation to their periods and period blood.
- When Black children started their period, there was an absence of positive messages around this event. The onset of a period tended to be accompanied by practical information such as the location of pads and provision of pain relief medication as opposed to, or at least supplemented with, important emotional guidance.
- The lack of knowledge around menstrual health related disorders such as fibroids and endometriosis mean that when Black women did get a diagnosis, they felt extremely shocked and upset.

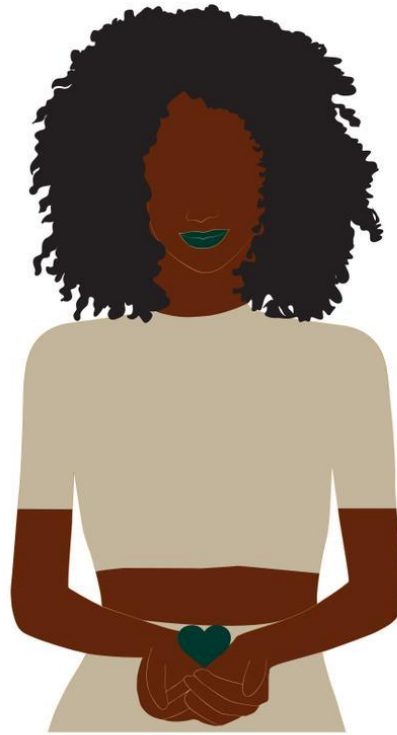
These findings highlight that Black women not only experience poor health outcome as a result of dismissive healthcare professionals and lack of information but also, unique historical contexts and menstrual taboo play a part in Black women feeling a sense of menstrual shame.

Online spaces appear to be an avenue through which Black women take ownership and advocate for an improvement of the experiences that otherwise render them powerless. Whilst blog posts and interview extracts do not fall under the label of traditional sources e.g. journal articles, we argue that online sources which capture lived experience accounts warrant the same level of attention as that given to peer reviewed literature.

The numerous online accounts and repeated themes, highlight the need for systemic change and the importance of charities such as Freedom4Girls, Cysters and the African Pot Project in providing spaces for solidarity and emotional/ peer support.

Annex 5: Flowchart of literature review methods





Black Women's Reproductive Health



freedom4girls