hertility

The Inequality Report



The Inequality Report

Executive Summary of the Report
This resource is a collective analysis
bringing together current published
literature and Hertility's own data to
create a consolidated overview of the
trends, current practices and gaps in
the research, service provision and care
for Black women in the UK regarding their
reproductive health across the
life course.

Through analysis of data taken from women who have accessed Hertility's platform between September 2020 and April 2023, we have found that:

- Approximately 4/5 (79.9%) Black women report experiencing at least one symptom, the most common being fatigue
- Menstrual cycle irregularities are common in Black women: over 1/5 (22.4%) of women reported having irregular periods and over 1/10 (11.6%) reported having heavy periods
- Sexually transmitted infections are more commonly reported by Black women compared to White women, and Black women were 8x more likely to report a previous Trichomoniasis (Trichomas Vaginalis) infection than White women (4.2% vs 0.5%)

- Black women were more likely to have a pre-existing reproductive health condition, and were more than 6x more likely to report a diagnosis of fibroids or uterine polyps compared to White women (14.3% vs. 2.3%)
- 1/5 (20.2%) of Black women reported they were smoking occasionally or regularly, and 37.7% were consuming alcohol on a weekly basis whilst actively trying to conceive
- Black women who were trying to conceive approached Hertility at an older age (1.5-3.6 years older) and were more likely to be trying to conceive for 5+ years compared to White women (14.4% vs. 8.9%)
- Of those who had experience at least one pregnancy, 51.5% of Black women had a termination (abortion) compared to 37.7% of White women
- 1.3% of Black women had experienced a stillbirth

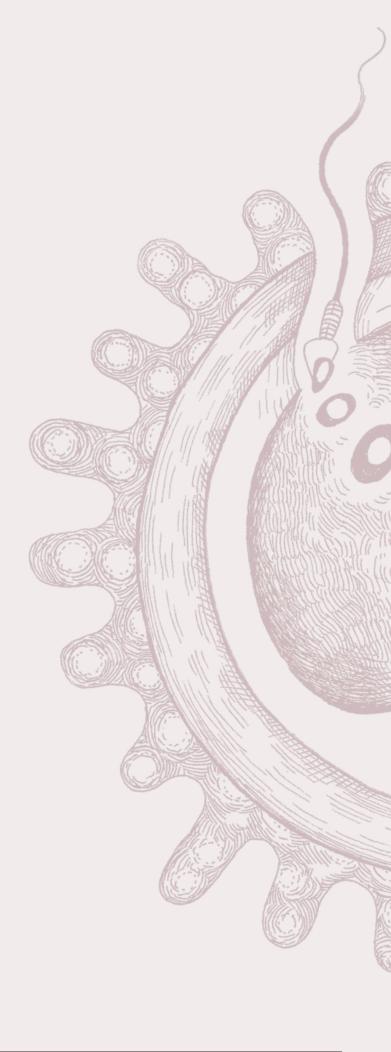


Whilst the women who have accessed Hertility may not be representative of the overall Black female population in the UK, this data shows the urgent need for improvement in reproductive health screening, symptom management, sexual health education, preconception counselling and fertility awareness by professionals delivering healthcare across the UK in order to improve the health outcomes and wellbeing of Black women. Importantly, it also highlights the need for more research into conditions and outcomes that are more prevalent in Black women in order to improve clinical care pathways in the future.

Broadly, we have defined the need for improvement in:

- Research
- Education
- Action

Hertility is committed to addressing the challenges above by filling in the knowledge gap, the care gap and the data gap. Our ultimate aim is to improve the reproductive health and wellbeing of Black women in the UK.



Outcomes from this report

We have seen from this research that at each stage of their reproductive life, Black women are uniquely affected by multiple disadvantages stemming from systemic racism and the intersectionality of race and gender. They have been and continue to be excluded from research, their experiences disregarded, and their voices not heard when it comes to their health wishes. At the end of each section, we have identified key areas for research, advocacy and education which, if acted on, we believe will improve the outcomes and experiences of Black women and lead to equity in reproductive health.

Broadly these are;

Research

More needs to be done to identify the biological and social factors which put Black women at an increased risk of developing reproductive health conditions such as fibroids, having adverse outcomes of pregnancy and of maternal morbidity and mortality.

Education

Providing inclusive and representative education resources is lacking. Education and outreach initiatives engaging key members of communities can help Black women feel empowered in healthcare settings, armed with insights translated from existing and future scientific findings. A key consideration with this is dissemination and uncovering the ways in which we can ensure equitable and timely access to health information.

Action

Action at a governmental level and support at a grassroots level needs to be provided to both women and healthcare practitioners to ensure there is the provision of compassionate care. In addition, creation of an environment where co-creation and partnership with primary care providers is encouraged and allowed to flourish is essential.



Meet the contributors



Cheyenne Morgan

Cheyenne creates fun and interactive content on her social media handles which incorporates the importance of self-care, manifesting healthier lifestyles, managing stress, talking about periods and normalising this topic within society, mental health and finally, creating community events which is a safe and intimate environment for women to come together share their experiences and stories around reproductive health, as well as learning from each other.



Victoria Abrahams

Originally working in human rights law, Victoria (Tora) Abrahams led a judicial review against the prison service for forcing a strip-search of her client who refused because she was menstruating. Through this successful claim, Tora recognised the repeated misogyny within public services, which were designed by men and for men, therefore failing women. After leaving the law, she moved to the women's sector and found her passion in advocating for stronger conversations and attention to female reproductive rights. Whilst managing a charity focusing on period poverty, Tora spearheaded the first ever UK project that looks into the reproductive and menstrual health journeys and needs of Black and Black-mixed women*.

Note: The Black Women's Reproductive Health project supports African and Caribbean women with access to information, advocacy, peer support and has created the first ever UK report that details the menstrual-reproductive needs and experiences of Black and Black-mixed women.

* The BWRH project represents women and people with female reproductive systems



Sophia Ufy Ukor

Sophia Ufy Ukor is the founder of Violet Simon, a media-tech company that uses authentic storytelling to amplify the voices and experiences of women from all walks of life to improve equitable representation and equality, inspire, entertain and generate class to action on women's issues. She has been vocal about her mental illness diagnosis (BPD), her challenges during pregnancy due to Hyperemesis and aims to draw awareness and support to women who deal with issues.

Sophia is passionate about feminism, storytelling, equitable representation, entrepreneurship, mental health and women's health. She is also a volunteer delegate for the UN Women UK.





Dr Danielle Perro

Dr. Danielle Perro is a women's health Researcher and science communicator specialising in women's reproductive health across the life course. Dr Danielle joined the Black Women's Reproductive Health project in 2020 in a volunteer capacity as Research Lead. For too long, Black women's reproductive health has been poorly understood, with little evidence available within the UK capturing the lived experience of Black women's reproductive health, and experiences of accessing care for it. As Research Lead on the project, I've ensured that the questions we've asked, how our data is analysed and presented are done so in the most meaningful way to impact the beneficiaries of the project.



Noni Martins

Noni Martins is a former IVF patient who is passionate about using her experience to offer a diverse lens and nuance to the dialogue on infertility & IVF. Noni tried to conceive for almost 6 years, 3 of which she spent undergoing 6 unsuccessful IVF cycles. After not finding the safe space to have the conversations and the dialogue she was looking for, Noni decided to create her own and that's how Unfertility came to be. Through her website unfertility.com Noni is using her experience to raise awareness about unconventional fertility journeys. As well as contributing to the wider conversation on infertility & IVF.



EXECUTIVE SUMMARY

"Healthcare was built for the white, middle-aged, healthy man. We're not trying to retrofit everyone else into that system. Instead, we're building an entirely new version of healthcare from the ground up. One designed with every single person in mind.

One backed by relevant data, and that's evidence-based. One that is constantly reaching more and more people to provide a personalised medical experience. It's not going to happen overnight, but we're committed to our long-term vision and won't stop until there is nobody left behind"

Dr Helen O'Neill, Dr Natalie Getreu and Deirdre O'Neill Founders of Hertility

Our commitments & next steps

This report is our first step on a journey in which we hope to address the inequalities experienced by Black women in the UK through tangible improvements in education, research and clinical guidelines.

The Knowledge Gap

We will disseminate a series of free educational seminars delivered by experts in reproductive health to various community centres and relevant organisations. We will also be creating a series of free, short videos on menstrual health education, which community leaders will be able to access and download to ensure the dissemination of good quality, actionable information that women can use.

The Care Gap

We believe a key component in improving women's healthcare outcomes is providing proactive, high-quality care that gives women insights into their reproductive health and fertility. We will be working with sponsors and key organisations to provide access to Hertility services to communities in need in the hope of breaking down some of the barriers to private healthcare that these communities face.

The Data Gap

We recognise that data is an incredibly powerful catalyst for change. Our data has shown that more Black women approach our services later in their fertility journey and at an older age than White women. Our next step is to continue this work to find out why and what can be done to address the inequities in access to fertility treatment and care experienced by Black women in the UK.



Foreword



Dr Helen O'Neill

MSc, PhD

CEO and founder, Hertility Health

When we started Hertility, we began with a mission to make reproductive healthcare accessible and to empower women with information about their bodies. This is by no means a small mission to embark on, and as we grew, we knew we always wanted to do more to address not only the gender care gap but also the systemic barriers that prevent people from marginalised communities from getting care.

This is where our Black Women's Health Initiative was born.

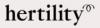
Black women are consistently left out of the equation when it comes to their reproductive health. Their experiences and voices continue to go unrecorded, and we see the effects of this every day. There are conditions like uterine fibroids where, despite it being established for years that there is a clear disparity between the prevalence, outcomes and understanding, there is a lack of research on a UK-based population.

It is unacceptable that we still do not fully understand why Black mothers and birthing people are up to 4 times more likely to die during pregnancy and up to 6 weeks after birth than White women. That Black mothers are at 40% increased risk of having a miscarriage.

And that consistently, Black women report experiencing a lower quality of care when it comes to their reproductive health and fertility.

In a time when years of austerity have meant that our healthcare system has become so stretched and women's health services are impacted (1), we are only going to see inequalities that Black women face when it comes to their health and the standard of care they receive grow. We have made it our mission to prioritise research that is designed to improve outcomes and that take into account Black women's experiences and amplify their voices.

The entire Hertility team are committed to changing the reproductive health experiences and outcomes for Black women in the UK through tangible improvements in education, research and clinical guidelines.



Starting this initiative, our Research Scientists, Dr Tharni Vasavan and Ruby Ross Relton, have worked tirelessly alongside our communications lead, Charlotte Ponnelle and data analyst Sofia Rodriguez, to create this resource and establish what is needed next from us as a company, scientific community and society. This report forms part of our long-term strategy, which involves providing information developed by experts in the form of educational seminars and reports, engagement with key community leaders and providing our services to those who need it most.

We have worked alongside experts in reproductive science, obstetrics and gynaecology, sexual health, nutrition, genetics and assisted reproductive technology, actively leading or championing race inequality research in the UK.

But we believe being an expert in your healthcare does not require a clinical degree. Experts in healthcare are not just practitioners. When we say "experts in healthcare", we are also talking about the patients. This is why we wanted to include the experiences of real women. Women who have given us the privilege of telling us their stories so we can learn from their journeys.

We thank each and every one of the contributors to this guide. Without their help, this report would not have been possible.



Sophia Ufv Ukor



Cheyenne Morgan



Victoria Abrahams



Dr Danielle Perro



Noni Martins



Laura

And to Dr Christine Ekechi (MBBS, BSCCP, MSc, MCROG, BMedSci) and Dr Stephanie Kuku (MBCHB MRCOG MD) for acting as advisors to this work. We would also like to thank our in-house graphic designer, Laura Martins for her patience and tireless work on this project.

We would also like to thank you, the reader. Your investment into this by downloading this piece of work, reading it, sharing it and supporting it means that this research has reached one more person and will hopefully be part of a new wave of change.

Dr Helen O'Neill



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SECTION 01

Introduction

Why we created this report

Unlike for the majority of White women, accessing unbiased, culturally sensitive, inclusive information about their reproductive health is not easy for many Black women in the UK. When searching for information about reproductive health conditions, many patients are faced with pictures of women who look nothing like them. What's worse is that this is very rarely even spoken about.

As part of this report, we're proud to build on work from organisations like FivexMore and the Black Women's Reproductive Health Project, to spotlight these important issues experienced by Black women across their life course, to challenge the way things are currently done and to champion a better way for all Black women in the UK and worldwide.

We created this report to emphasise the crucial need for more diversity in reproductive health, to shed light on the experiences and stories of Black women in the UK and to finally empower Black women with up-to-date, evidence-based information that was designed with them in mind.

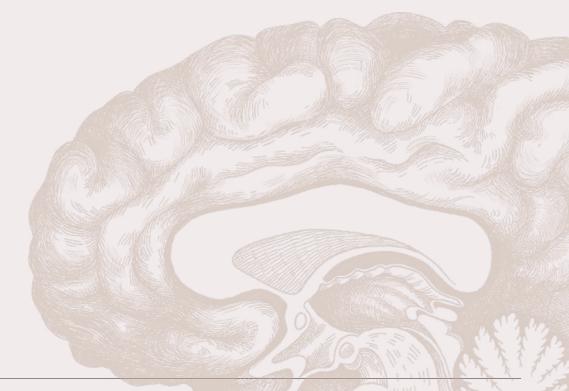
At the end of each section, we have included some crucial next steps/ recommendations based on our findings from our research. We are sharing these with you, the reader, for inspiration, direction and ultimately, to bring about action.



Who this report is for

As a company, Hertility is here to support women from menstruation through menopause. In a similar vein, this report follows a life-course approach to help Black women access any information they might need about their reproductive health, across every life stage. But importantly, this report can (and should) be read by everyone. Black women are constantly told to educate themselves and fight for the care they deserve. But this report is for anyone who wants to gain insight into what it's like for Black women when it comes to their reproductive health as well as for those at the forefront of the healthcare system, striving for better ways to better support the unmet needs of their Black female patients. We're all in this together.

Currently, Black women are being let down by the healthcare system, and we're here to change that. This means not only addressing gender bias but also looking at the intersectionality that affects Black women and tackling racial biases, which are, a part of our past and present. But whilst opening up the conversation and making education the norm is key, in order to impact meaningful change, we need to do more. That's why Hertility is working to build the largest dataset in women's health, complete with information on all women of all races and walks of life. So we can fill in the knowledge gaps and create an alternative clinical experience that works for the many, not just the few. We hope you'll join us in our mission, we'd love to have you.



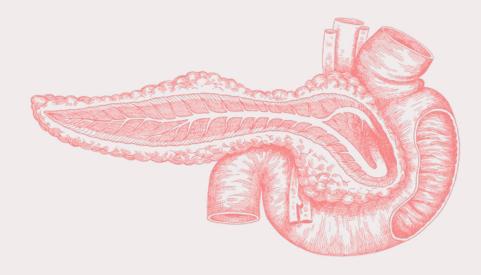
Methodology

This report consists of a review of previous literature, statistics from Hertility's own data, quotes from women who have lived experiences around certain topics, and signposts towards selected internal and external resources.

The literature review conducted for this report aimed to gather evidence on Black women's health experiences across their life course. The review focused on obtaining peer-reviewed scientific literature, relevant public inquiries and reports, as well as historical evidence and experiences from resources such as podcasts and books. The review summarised the evidence collected to date around Black women's health across the life course. While not every piece of published material around the various topics in this report has been mentioned or cited, the review provides a comprehensive overview of the existing evidence around Black women's health. In order to understand the experiences

of Black women who have approached Hertility or used our services, we also conducted exploratory analyses of our own data that had been collected via Hertility's online health assessment. This assessment is accessible to anyone who is assigned female at birth and above 18 years of age. Users are required to fill out the assessment before purchasing a Hertility testing kit, however, not all users proceed with purchasing after completing their assessment. The online health assessment collects information on the user's medical history, symptoms, menstrual cycles and reproductive goals. The number of questions presented to the user differs depending on their archetype and their previous answers.

Every person who approaches Hertility and begins their journey with us is asked whether they consent to their anonymised data being used in research and only the people who consented were included in this report.



We used data collected from 183,886 unique users who were 18-70 years old and completed the online health assessment between September 2020 and April 2023. Of these users, 8,082 (4.4%) were Black and 152,356 (82.9%) were White. Following stratification of data into Black and/or White ethnicity groups, we calculated percentages and/or averages (means) on the following:

- Symptoms most frequently experienced
- Frequency of menstrual cycle irregularities
- Frequency and types of sexually transmitted infections
- Prevalence of pre-existing reproductive health conditions
- Lifestyle behaviours of women who were trying to conceive or planning for babies in the future
- Typical age of women who had been trying to conceive and the duration they had been actively trying to conceive
- Frequency and types of pregnancy loss experienced

The findings from the above analyses have been presented in the relevant sections of this report.



Inclusivity disclaimer

Throughout this report, we use the word "woman" or "girl" when referring to the inequalities experienced by those assigned female at birth who may or may not still identify with this gender. When we refer to women, we are quoting scientific literature and research publications that have previously conducted this research on those assigned female at birth.

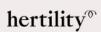
Whilst we aim to be as inclusive as possible, we understand this may mean gender-diverse people who were assigned female at birth and are Black may not identify with this report. We also recognise that this report does not cover inequalities that are prevalent and unique to this community.

We hope in the future to be able to produce reports with scientific research which is applicable to all and strive to improve our inclusivity and address inequalities for everybody, no matter their gender, sex or ethnicity. We have begun to address this internally by continuing our research to be inclusive of gender diverse people so we can begin to address the dearth of evidence and lack of amplification of these voices in research.

Trigger Warning

In this report we will touch on subjects such as baby loss, sexual violence, prejudice, discrimination and inequalities. We recognise these subjects may be triggering or upsetting, and whilst our intention is to educate and empower, we know that this guide may bring up feelings of trauma. Where possible, we have signposted to support groups and included links to further information from reputable sources.

We encourage you, the reader, to take any steps necessary to ensure your emotional safety and would be happy to arrange a session with our counsellor should you need it. Please get in touch with ruby@hertilityhealth.com if you would like to discuss any of the topics and language in this guide and work with us to strive to be as inclusive as we can.



SECTION 02

Healthcare as we know it

What is reproductive health?

Reproductive health is defined by the World Health Organisation (WHO) as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so".

Looking back at Black women's reproductive health

Throughout history, Black women's wishes and needs when it comes to their fertility and reproductive health have been disregarded and violated. They have been unwillingly included as research subjects for decades, from the non-consensual reproductive surgeries performed By Dr Sims on enslaved Black women without anaesthesia to the well-known story of Henrietta Lacks.

The colonial roots of modern medicine has had a huge impact on the ways in which non-White people experience healthcare. These effects span far more than just reproductive health and this racism and systemic oppression has led to the inequalities we see today across all aspects of healthcare, such as:

Black people are more likely to have their symptoms dismissed

and experience harmful racial profiling and stereotyping in a healthcare setting than White people, which leads to a lower standard of care and worse health outcomes (2–4).

Black people are under-represented in clinical trials

and other forms of medical research conducted in the UK, even in trials investigating conditions that disproportionately affect those groups, e.g. cardiovascular disease (5).

Even when Black people are included in the research, different ethnicities are often grouped together

not taking into account the variations in their genetic background and environment. This lack of research means an understanding of the ethnicity-specific risk, symptom presentation and disease is not often known or implemented in clinical practice, furthering symptom dismissal.

Black people are, therefore, often more likely to experience worse health outcomes in comparison to White patients both in the UK and globally, across many areas of healthcare (3).

If you are looking for more information on how colonialism has affected our healthcare system and the effects this continues to have on the healthcare outcomes and experiences of racialised communities, the book <u>Divided: Racism</u>, <u>Medicine and Why We Need to Decolonise Healthcare</u> by Dr Annabel Sowemimo is an essential read.

"We all swear on the Hippocratic oath to do no harm, but if the system works such that the resources and the human capacity are lacking, there is a dearth of compassion.

As a result, unfortunately, I think that, as with everything in life, some people are going to suffer more than others, and the human reflexes are that when you have no capacity, you are less likely to treat people the same"

Dr Stephanie Kuku

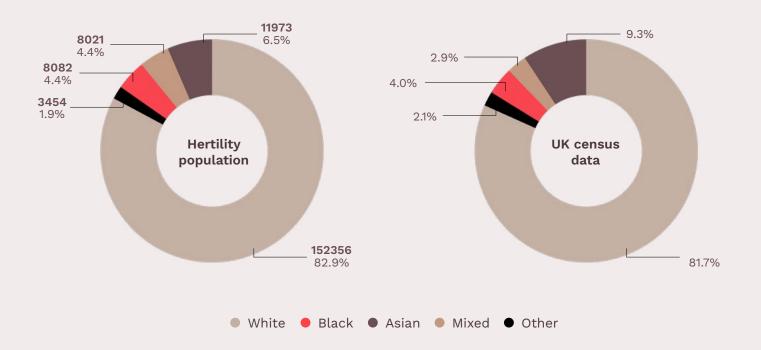
Advisor, Consultant and Health Technology Executive (MBCHB MRCOG MD)

We're here to help change this

We know that patient and personcentric, data-led research is the way to impact real, lasting change. Currently, the ethnic diversity of our dataset reflects the UK population (Figure 1); whilst this is something we're proud of, we're not going to stop there. We're working towards increasing our data from minority ethnic communities to reflect the diversity that we believe is imperative to improve the outcomes and experiences of Black women in the UK healthcare system and globally. In the meantime, we are continuing our research on our current data to identify trends we can use to

improve the health of Black women. Where appropriate, we have included findings from women who have gone through the Hertility journey. We collected and analysed self-reported broad ethnicity data from 183,886 women who completed the Hertility online health assessment between September 2020 and April 2023.

The diversity of the Hertility user base was comparable to the England and Wales population, according to the Census 2021 (6).



A graphical representation of the ethnic diversity of our own Hertility population (left) in comparison to UK census data (right)

(fig.1)

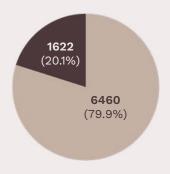
We currently allow people accessing Hertility to select from over 90 different coded ethnicities (specifically 15 Black ethnicities). We also allow for people to write their specific ethnicity if it is not on the list or they come from a mixed background.

There is huge power in providing insights into health and collecting information on the experiences of specific ethnic minority groups that have been underserved for too long. We hope this data can improve the screening and management of reproductive health conditions, particularly for individuals

Our Data Collection We allow for the self selection of:

Over

different ethnicities



Experiencing symptomsNo symptoms

A breakdown of Symptomatic vs. Asymptomatic Black women who approached Hertility

from varied ethnicities who may experience them differently.

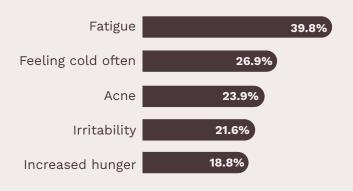
Not only this, but we also looked into the prevalence of symptoms reported by Black women completing our online health assessment (Figures 2 & 3).

We found that Black women were most likely to report symptoms of fatigue, feeling cold often and acne (Figure 3).

We are investigating what this may mean in order to create actionable changes in the symptom assessment and symptom management of Black women.

With

different black ethnicities



The breakdown of most common symptoms reported by Black women who approached Hertility

(fig.3)

SECTION 03

Menstrual Health & Periods

What is menstrual health?

Menstrual health refers to "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in relation to the menstrual cycle" (7).

Achieving good menstrual health requires proper education of the menstrual cycle, adequate care supplies for periods, timely diagnosis of period-related issues, access to resources and support, and the absence of discrimination (7). Black women and girls are less likely to receive this criteria, which means they are less likely to have good menstrual health.

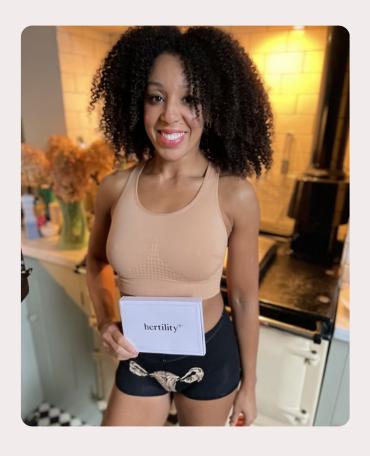
The menstrual cycle and taboos surrounding it exist in many cultures. From an early age, young girls are told not to discuss periods in "mixed company", and that periods are unclean and a "woman's issue". However, with big stores like Asda and Tesco only changing the aisle names from "sanitary products" (implying that a natural process, getting your period, is, in fact, dirty) to "period products", there appears to be a shift from period-shame to period positivity. But why is this important in the Black community?



The problem

Throughout history, the Black community have continuously been told that they are "wrong" and their bodies are less than. From their natural hair being "unprofessional", to young girls being sexualised or being "too aggressive" these narratives have created a very complicated relationship between Black women and their bodies. However, it is of vital importance that Black women and the wider community are seen to be celebrating not only menstrual health but also supporting their overall reproductive wellbeing. This means opening up the conversation around menstruation to help Black women identify symptoms relating to reproductive health conditions such as fibroids or infertility. A lack of knowledge surrounding what is "normal" will prevent women from seeking help for their symptoms earlier, increasing the time spent suffering in silence and without adequate treatment.

Some Black girls and women may have a different experience of menstruation than White women. This is, in part, due to the societal stigma that is attached to periods in general compounded by cultural expectations to keep discussions about periods private. Symptoms related to periods are therefore vastly underreported and subsequently untreated.



Even where periods are openly discussed, recognising periodrelated symptoms that are signs of conditions that disproportionately affect Black women (such as fibroids or endometriosis, highlighted in section (6) may be difficult if you have grown up seeing your mother, sisters, and aunties experience those symptoms and therefore consider them to be normal. The normalisation of menstrual symptoms is one of the biggest barriers to seeking care (8).



For Black girls and women, negative experiences with menstruation may be further compounded by harmful, incorrect societal preconceptions regarding Black women's experiences of pain, making it difficult to seek help or trust healthcare providers. This dismissal, compounded with a lack of specific, qualitative research on Black girls and women's experiences when it comes to their periods throughout their reproductive life means that we do not have a clear picture of the experiences of Black women when it comes to their menstruation. What research is available is either focused on a US-based population, and therefore has limitations in terms of its applicability to the UK population, or presented and bundled under the BAME umbrella.

Important work conducted by the Black Women's Reproductive Health (BWRH) project sought to provide insight into the experiences of Black British women alone through a thorough literature search and qualitative surveys of peer support groups. They found that of women who rated their health below a 6 on a 10-point scale, 60% of those suffering from period pain and/or chronic pain. Barriers to care reported by these women included a lack of both representation and information (9). Even when women overcame these barriers and approached primary care providers, 75% did not have a positive outcome from this experience (9).

"One of our most significant findings regarded the complexities around Black women's experience of period pain."

"The Black Women's Reproductive Health project as part of T.A.P The African Pot Project, was borne in 2020 with the aim of understanding how systemic racism impacts Black and Black-mixed British women's experience and access to support for their menstrual and reproductive health. Since then, we have collected both qualitative and quantitative data from over 160 women across the UK, as the first project to investigate Black women's reproductive health in a strictly UK-context. Read our report here.

One of our most significant findings regarded the complexities around Black women's experience of period pain. Whilst experiencing pain was very common amongst our beneficiaries, there was a high degree of uncertainty about what degree of pain was 'normal' or required further investigation. The understanding of pain was compounded by a limited understanding of menstrual and reproductive health conditions, which was primarily attributable to the lack of comprehensive menstrual education, and pervasive outdated beliefs about Black women's pain. Systemic barriers to reporting that pain to a healthcare provider and having that listened to and acted upon played a large role in this uncertainty as well.

Working as a group of volunteers, creating time for this project both during the pandemic and around our other commitments, was not always straight forward. Given this, we welcome the further input, investment, and contribution from organisations like Hertility. Their report provides a comprehensive overview of the experiences of our co-beneficiary group detailing Black women's menstrualreproductive and even sexual health experiences across the female reproductive lifespan. The detail concerning specific conditions known to exist prevalently in women of African heritage, combined with potential reasons for this, from diet to the impacts of systemic racism and bias, is simply brilliant and absolutely welcomed.

Not only does this detail assist in shedding light on Black women's needs and experiences which is crucial, as they say, for everyone committed to eliminating racism from female reproductive health, but it also creates important and useful information that all activists in this space can use to support in improving the outcomes and dayto-day quality of life of so many Black women.

Victoria Abrahams and Dr Danielle Perro, Black Women's Reproductive Health Project Black women's reproductive health across the life course urgently needs to be considered and prioritised, especially as the Women's health strategy implementation begins across England.

We have called for such action (see our recent publication), not only from researchers and educators, but importantly, from policy and change makers in this space who are able to inform systemic change that is so long overdue."

Victoria Abrahams and Dr Danielle Perro. Black Women's Reproductive Health Project

Our Hertility data shows

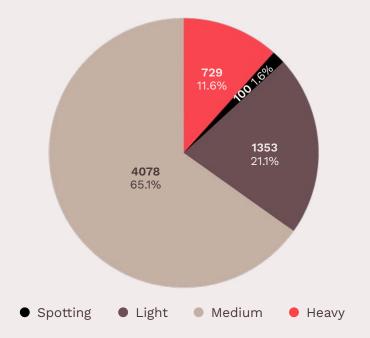
We looked at the menstrual cycle data from Black women who took Hertility's online health assessment to find out how many experienced menstrual cycle irregularities, namely irregular or heavy periods (Figure 4). We found that 22.4% (1,473 of 6,567 Black women) reported experiencing irregular periods and 11.6% (729 of 6,260 of Black women) reported experiencing heavy periods.

What needs to be done

Research looking specifically at Black women's experiences of menstruation & menstrual health care

The development of inclusive education resources for young Black girls in schools to help delineate symptoms indicative of a reproductive health condition from those which occur as part of a normal menstrual cycle.

Education & training for primary care providers on providing inclusive care to combat the negative impact of past experiences.



Period flow reported by Black women who approached Hertility

(fig.4)



"Many black women face mental health challenges as they live in silence with gynae problems and think that a lot of their symptoms are normal.

"Within my scope of practice, I have definitely seen a rise in the number of Black women who have a lack of understanding and insight into female reproductive health. The vast majority of these women have expressed issues with accessing care, either being too afraid to speak up about their symptoms, feeling too embarrassed to talk about parts of their genitals, or it might be due to previous bad experiences with health professionals and not feeling like they have a voice.



I believe it is crucial for every Black woman to be aware of gynaecological conditions and signs and symptoms. Good health promotion is key to paving the way for women to have the opportunity to learn about what is normal and when to seek help from a health professional.

Many Black women face mental health challenges as they live in silence with gynae problems and think that a lot of their symptoms are normal, as they have been suffering from it for a very long time and have become immune to the pain they feel. I always stress that it is very important to stay in tune with your body and to be aware of anything that may seem out of the ordinary, such as irregular or absent periods, sexual dysfunction, difficulty getting pregnant and so on."



Cheyenne Morgan, **Registered Adult Nurse**

Resources



Menstrual Cycle Basics Hertility Health.



Happy Period

#HappyPeriod is the first Black-led organisation with a focus on menstrual health education, advocacy, and access.



Free Periods

Free Periods is a not-for-profit campaign group started by Amika George. They work so no young person has to miss school because they menstruate.



"Break the Barriers: Girls Experiences of Menstruation in the UK" Plan International UK.



The White Dress Project

An organisation designed to spread awareness on a global scale about the widespread occurrence of uterine fibroids. They promote education, foster research, provide a supportive community, and advocate for better health.



Black Women's Reproductive Health Project

The Black Women's Reproductive Health project, working under The African Pot (T.A.P), advocates for racial equality and racial justice in female reproductive healthcare, focusing on the needs and wellbeing of Black women.



Recognizing Lucy, Betsey and Anarcha

A Live Conversation with Veronica Maria Pimentel, MD, FACOG, and Deirdre Cooper Owens, PhD | ACOG.



SECTION 04

Sexual Health

What is Sexual Health?

Sexual health has the power to impact your physical, emotional and mental well-being. Poor sexual health is linked to sexually transmitted infections (STIs), sexual violence, and unplanned pregnancies. However, good sexual health also means having open and honest conversations with your partner(s), experiencing pleasure and being able to recognise the red flags that signal a potential health condition.

The problem

Continued exploitation of Black women, who exist at an intersectionality of systemic racism and gender-based violence, has led to Black women experiencing disparate sexual health outcomes. This inevitably places them at a disadvantage when it comes to their relationships with their own bodies and partners as well as their physical and mental health. We've broken down some of the key issues that disproportionately affect the sexual health of Black women.

Contraception

Contraception is used to describe any method or intervention used to prevent pregnancy. There are several different types of contraception, hormonal and non-hormonal, permanent, longor short-term and even emergency contraception. Each type of contraceptive method varies in terms of how they work, how successful they are and how long they can be used.

"We must acknowledge the justice of ensuring equal access to birth control for poor and minority women without denying injustice of imposing birth control as a means of reducing their fertility"

Dorothy Roberts Killing the Black Body; Race, Reproduction and the meaning of Liberty



Whilst contraception is largely regarded as a scientific success, it is one whose history with Black women is rooted in racism, slavery, eugenics and trauma. When contraceptives became available, many women celebrated its ability to provide women with reproductive choice. However, in America and Britain, the birth control movement and contraceptives such as the pill were quickly used as a way to push the agenda of eugenicists to prevent Black people from conceiving. During this time, Black women were encouraged to use contraception, often offered the pill for free or at a lower cost by government-sponsored family planning programmes, reinforcing genocidal fears in the Black community at the time. Black women were also offered longacting methods of contraception such as Intrauterine Devices (IUDs) or the Depovera implant - they were seen to be a "more suitable option" than White women as they had the least amount of user failure (10).

An excerpt from "The Heart of the Race: Black women's lives in Britain" by Beverley Bryan, Stella Dadzie and Suzanne Scafe, speaks to the experiences of Black women in Britain during this time.

"Black women had to point out that they had 'always been given abortions more readily than white women and are indeed often encouraged to have terminations we didn't ask for. It's for this reason, too, that when the women's movement demanded 'free, safe, and available contraception for all women', we had to remind them that for Black women this often means being used as guinea-pigs in mass birth control programmes, or as objects of 'research' when new forms of birth control need to be tested."

The Heart of the Race: Black women's lives in Britain by Beverley Bryan, Stella Dadzie and Suzanne Scafe



Several different types of hormonal contraception were tested in women in countries such as Mexico, Puerto Rico and India before arriving in America (10-12). Once approved, they were then administered to large numbers of African-American and Hispanic women, so these groups were disproportionately affected by the side effects that hormonal contraception usually causes (See here for stories of women such as Minnie Lee Relf and Mary Alice Relf).

Unfortunately, access to contraceptives for Black women is becoming increasingly difficult as evidenced by fewer Black women seeing their GP for contraceptives and Sexual and Reproductive Health services struggling to meet the increased demand (13,14). Additionally, Black people's voices and experiences are often not represented when it comes to clinic staffing, or in research. Additionally, lack of resources for contraceptive care could impact uptake of contraceptives. This is why initiatives such as Black Voices on Contraception Choices are needed and the work of organisations such as Decolonising contraception celebrated.

Gender-based violence

Sexual violence and exploitation against Black women has been prolific and to this day in the UK, Black, Black British and Mixed ethnicity adults are more likely to experience sexual assault than those of any other ethnicity.

Data from Refuge showed that "despite Black survivors being more likely to report abuse to the police, they were 14% less likely to be referred to domestic violence support services than white women" (15).

Effectively, by police failing to direct women to these services, they are failing Black women. Organisations such as Sistah Space are imperative to ensuring Black women experiencing sexual violence are protected and supported, and that police offers are culturally competent and trained to support women of diverse backgrounds.

Visit their website to seek support or donate here https://www.sistahspace.org/

Extra Listening:

- Stream What Does Eugenics Mean To Us? Episode 6
- Transcript: What Does Eugenics Mean To Us? Episode 6 | Sarah Parker Remond Centre - UCL - University College London



Sexually Transmitted Infections

Looking at the frequency of STI diagnoses in the UK, a disproportionately higher number of diagnoses are made in Black people (16). There are also differences between Black African and Black Caribbean populations within the UK. A 2022 study found that Black Caribbean people had a three-fold higher incidence of STIs than people of White British ethnicity, even though the risk factors for contracting an STI were the same between both groups (17). This reinforces the fact that this is a multifaceted issue, which involves "a complex interplay between broader structural determinants of health and their influence on individual-level and sexual network factors" and therefore necessitates more research.

Sexual health organisation PreventX released some research which showed that women from Black, Black British, Caribbean, or African backgrounds are more likely to have Trichomoniasis than White British women (18).

Trichomoniasis is the name given to the STI, which comes about after infection with the parasite Trichomonas vaginalis (TV). It is passed through unprotected sexual contact and sharing of sex toys, but unlike gonorrhoea and chlamydia, it is not thought to be passed through oral or anal sex.

Higher rates of TV infection among Black women is an important issue for the following reasons:

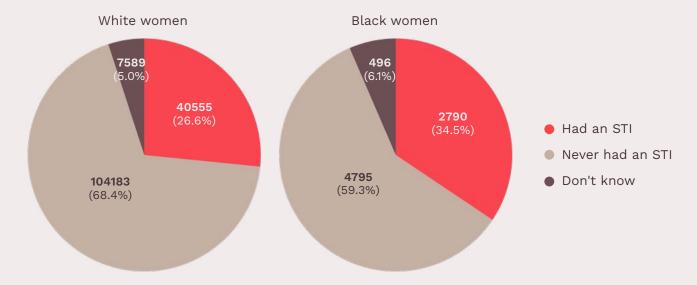
- Half of people with infections do not get any symptoms which means Black women are even less likely to visit their GP to get treatment.
- Untreated TV leads to an increased risk of becoming infected with HIV, which Black women are already disproportionately affected by (19).
- Untreated TV whilst pregnant results in a higher risk of preterm birth, which is more common in Black women and is the leading cause of death in young children.



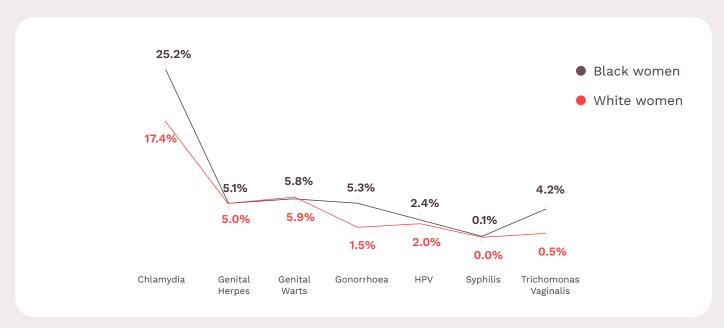
Our Hertility data shows

We investigated the number of women who reported being previously diagnosed with a common STI in their online health assessment. Our Hertility data showed

that 34.5% (2,790 in 8,081 women) of Black women have previously had one or more STIs, compared to 26.6% (40,555 in 152,327) of White women (Figure 5).



A breakdown of Sexually Transmitted Infections diagnoses in Black and white women who approached Hertility (fig.5)



The breakdown of the type of Sexually Transmitted Infection reported by both Black and White women approaching Hertility

(fig.6)

Resources



Sexual Health London

A discreet sexual health service for Londoners to access STI testing service and to request free regular and emergency contraception (effective up to 5 days after unprotected sex).



SH.UK

SH offers a range of free sexual health services such as STI testing, treatment and contraception across the UK.



Sexwise

Give honest advice about contraception, pregnancy, STIs, and pleasure.



Brook

Brook is a charity supporting people's sexual health and well-being. We offer a range of services to support our mission of helping people to live healthier lives.



BHA for Equality

A collective developed to ensure that Black communities had access to accurate and culturally appropriate information on HIV. BHA further advocated for the delivery of health and care services for Black and ethnic minority communities at local, regional and national levels. BHA runs funded projects for racially marginalised communities and those who are otherwise disadvantaged across the North of England.



My Body Back

Cervical screening, contraceptive care, STI testing and maternity care for people who've experienced sexual violence.



London Black Womens Project

LBWP works with Black, Asian and minority ethnic women who have experienced domestic violence and abuse.



Sistah Space

A charity supporting African & Caribbean heritage women affected by domestic and sexual abuse.

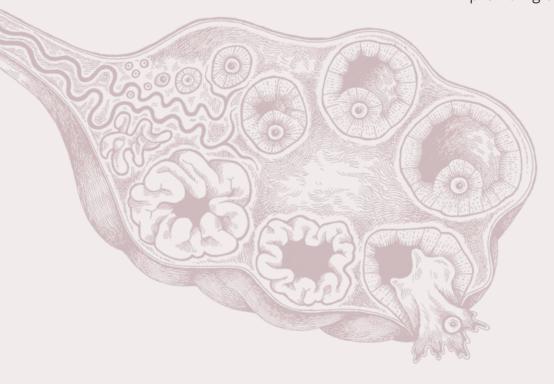
Disclaimer

Sexual health and wellness is about much more than the topics we have discussed above. We haven't touched on the plethora of other factors that help you to have a happy, healthy sex life, and for this, we suggest you visit Sexwise.



What needs to be done?

- More research and understanding needs to be gathered on Black women's experiences of accessing and using contraception to address any systemic barriers which may be leading to adverse sexual health outcomes.
- Proper characterisation of how these conditions may present differently in Black women, and adequate training of primary healthcare professionals to consider ethnicity when assessing symptoms.
- Specific clinical guidance for counselling Black patients on their risk of infections with TV.
- Increasing nationwide campaigns which destigmatise STIs and encourage testing.
- The creation and distribution of inclusive and represent of inclusive and representative resources on sexual health conditions.
- Governmental support for organisations such as Sistah Space, the London Black Women's project and others throughout the UK who are providing lifesaving support.



SECTION 05

Women's Health Screening

What is screening?

Screening refers to the method that health services use to check whether groups of people (who are apparently healthy) have a condition that they have a higher risk of developing. The most common women's health conditions that are routinely screened for by the NHS are cervical cancer (usually from 25 years old) and breast cancer (usually from 50 years old).

Screening programmes are an important part of our healthcare system. They form the bedrock of preventative medicine and enable people to access potentially lifesaving care earlier.

Screening for cervical cancers saves up to

2,000 lives

per year (20)

Screening for breast cancer saves up to

1,300 lives

per year (21)

The problem

Data has shown that Black women, alongside Asian and minority ethnic women, are less likely to attend screening programmes in the UK (22,23). Reasons why Black women in the UK are less likely to attend screening are multifaceted but have been attributed to things such as past negative experiences with healthcare professionals, certain cancers being seen as "White" diseases, a lack of awareness of symptoms to look out for, accessibility and problems with language and literacy (24–26).

Cancer survival rates are closely linked to the stage at which the cancer is diagnosed, lower attendance rates of Black women to national screening programmes may be contributing to the disparities in outcomes we are seeing between Black and White women in the UK when it comes to breast cancer (27,28).

Recent research published in January 2023, showed that Caribbean and African women were more likely to be diagnosed with late stage breast, ovarian and uterine cancer compared to White British women. Caribbean and African women had over double the odds of late-stage uterine cancer than White British women (29).

Resources



'Being open will help bring awareness': Meet the fashion vlogger who went public on her diagnosis.



Cancer Research UK

A charity designed to fund scientists, doctors and nurses to help beat cancer sooner. They also provide cancer information to the public.



Breast Cancer Project -Race Equality Foundation

A project designed to improve access to breast cancer screening programmes for groups that are struggling to access them at the moment.



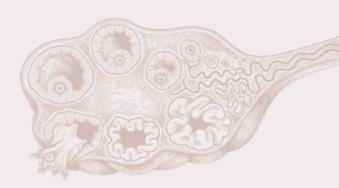
Eve Appeal

The UK's Gynaecological Cancer Research Charity raising awareness & funding research into five gynaecancers: Womb, Ovarian, Cervical, Vulval and Vaginal.



Black Women Rising

A registered UK charity offering vital help, information and practical advice for people of colour who have been diagnosed with cancer.



What needs to be done

A concerted effort from healthcare practitioners, governmental bodies and charitable organisations to encourage Black women to attend national screening programmes through the development of resources that are accessible and representative this could be through using a range of different mediums such as social media or television campaigns as well as community outreach at local GP surgeries.

Education on fertility decline and the factors that effect fertility treatment should be widespread.

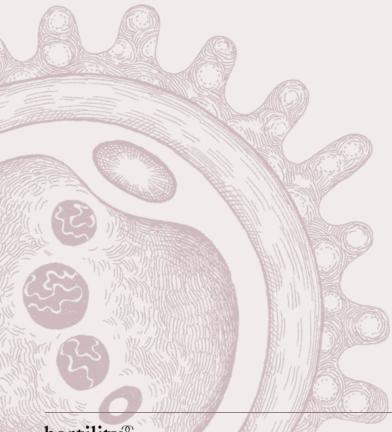
Up-to-date good quality evidence of the specific prevalence and risk factors of cancer within different Black communities.

SECTION 06

Reproductive Health Conditions

What is a reproductive health condition?

Put simply, a reproductive health condition refers to any diagnosis or disorder which impacts one or more parts of your reproductive system i.e. vagina, cervix, uterus, ovaries or Fallopian tubes and endocrine system (the hormones that are essential for menstruation, reproduction and overall health.) Conditions that affect reproductive health are commonly discussed in the context of fertility and pregnancy. However, it is important to note that poor reproductive health can affect general health and wellbeing too, with clear evidence showing it impacts mental health, metabolism and heart health to name a few.



The problem Certain reproductive health conditions are more prevalent in different ethnicities.

This means that Black women are more likely to develop certain reproductive health conditions than others, a common example being fibroids. A lack of research into how various reproductive health conditions affect Black women means that there are also no specific clinical guidelines on how to recognise or diagnose these conditions in Black women, or whether Black women need different treatment or management. A lack of knowledge around Black women's reproductive health may be resulting in higher rates of the associated conditions we have mentioned above, such as poor mental health and infertility. We have described three of the most common reproductive health conditions and evidence of how they specifically affect Black women.

Fibroids

Fibroids, also known as uterine myomas or leiomyomas, are non-cancerous growths which develop either inside or outside the uterus. These are formed of fibrous and muscle tissue that are affected by the hormones oestrogen and progesterone (30).

Over a woman's life, there is a 2 in 3 chance of developing fibroids however, the risk of developing fibroids increases with age, if you hit puberty earlier, if you have a higher BMI, a family history of fibroids or are of Black ethnicity, particularly Afro-Caribbean ancestry (31,32).

Research has shown that Black women have different experiences with fibroids than White women (33,34). Data from these studies show Black women:

- Are on average 4.9 years younger
- Have a 41% longer duration of symptoms
- · Have a 49% larger fibroid volume
- Are more likely to have rapidly growing fibroids
- Are more likely to be anaemic
- Are 2 to 3 times more likely to undergo hysterectomy for fibroids
- Are more likely to have symptomatic, recurrent fibroids (i.e. fibroids which grow back after surgical removal)

Vitamin D deficiency in Black women has been found to be linked to the presence of fibroids, in addition to history of abuse (35,36). Research published in the last year has also shown that chemical relaxers which are frequently used for afro-textured hair have been linked to a higher risk of developing fibroids and uterine cancer (37–39).

However, despite Black women being at a significantly increased risk of developing uterine fibroids throughout their lifetime in comparison to White women, they are often underrepresented in research conducted to underpin things such as the genetic aetiology and treatment outcome of the disease (34,40–42). Not only this, but there is a lack of research on Black British women's experiences in the UK in comparison to the United States (43), forcing us to extrapolate and apply data from a completely different population of people.



Endometriosis

Endometriosis is caused by the presence of endometrial-like cells, similar to the inner lining of your uterus, found elsewhere within your body. These cells respond to the same hormones during the menstrual cycle, resulting in deep pain which is often debilitating. Endometriosis affects approximately 1 in 10 women and can take up to 8 years to diagnose (44,45)

Research published in the BJOG has shown that Black women are 50% less likely to be diagnosed with endometriosis than white women (46). However many are sceptical of this simply being equated to 'less black women are affected by endometriosis'.

Systemic racial biases and stereotypes relating to certain ethnic groups' experiences of pain has led to these groups receiving a lower quality of pain care (47,48). Coupled together with the poorly conducted research focused on one particular ethnicity in this area amongst other barriers to care, it could be argued that many women either do not approach the healthcare system or that healthcare providers are less likely to diagnose this condition in Black women. In fact, the same paper which showed the Black women were 50% less likely to be diagnosed with endometriosis also found that "there is scarce literature exploring the influence of race/ethnicity on symptomatology, as well as treatment access, preference, and response", furthermore, the "Majority of studies included in the meta-analysis do not explore potential variability in presenting symptoms, diagnostic delays, or therapeutic responses based on race." (46)

Interestingly, this perception is recorded in many foundational medical textbooks of gynaecology including but not limited to Williams Gynecology, Blueprints Obstetrics & Gynecology, and Speroff's Clinical Gynecologic Endocrinology and Infertility (49).

More research is needed to understand the differences in presentation of different reproductive health conditions in different ethnicities and how this may affect prevalence and time to diagnosis.

Black women are

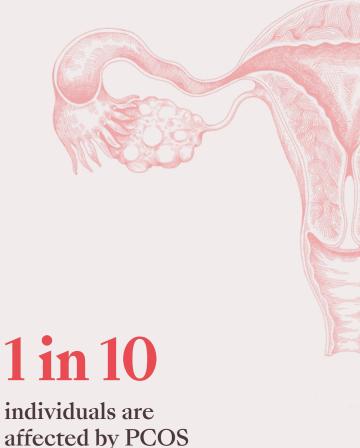
50% less

likely to be diagnosed with endometriosis than White women (46)

Polycystic Ovary Syndrome (PCOS)

PCOS is one of the most common endocrine disorders, affecting close to 1 in 10 individuals, with reproductive and metabolic consequences. PCOS is characterised by imbalances in certain hormones, namely androgens (i.e. testosterone) and often insulin. High levels of androgens lead to symptoms like excessive body hair growth, hair loss from the scalp, oily skin and acne. Insulin is involved in blood sugar regulation and imbalances in insulin levels leads to many of the metabolic consequences of PCOS.

PCOS affects people of all ethnic backgrounds, however, research has shown that those from ethnic minority communities, especially those who are Black or South Asian, are at a higher risk of developing PCOS (50). There is evidence that PCOS presents differently depending on your ethnicity, and Black women with PCOS are more likely to experience symptoms of insulin resistance and hirsutism (51) although evidence is conflicting (52).



Living with PCOS also means you have a higher risk of developing long-term health conditions such as hypertension, heart disease and type 2 diabetes (53). Black women already have a higher risk of developing these conditions due to genetic and environmental factors, which likely contributes to why Black women with PCOS have a higher incidence of developing long-term health conditions than White women.

"In 2017, I created an online platform called Let's Talk Gynae, which was birthed from my personal experiences as a young Black woman, being diagnosed with Endometriosis, Polycystic Ovary Syndrome (PCOS), retroverted uterus and large ovarian cysts.

I found it very difficult in the beginning living with these reproductive health conditions as it affected my entire life. At the age of 17, I didn't have a clue about what gynaecological problems were, whether it was normal to have extreme pain during my period or if this amount of blood and bloating I experienced was normal. I always had so many questions, but I was afraid to speak up as I had very little knowledge of the topic.

I was admitted to hospital on so many occasions due to the debilitating pain I would experience which targeted my back, pelvic region and legs.

I couldn't carry out daily activities or go out with my friends as I was curled up in bed with a hot water bottle on most days. I was so afraid I wouldn't be able to bear children.

There were so many times I would be told by different doctors to go on contraception; "you may have to have more surgeries in the future", "you may have problems with fertility", "here are a few leaflets to read", or "have a baby and the problems will subside" or "cure" my menstrual dysfunction. I was left feeling alone and very frustrated as my concerns were very much ignored most times.

One thing I have learnt on this journey is that pain doesn't always correlate with the severity of the disease a person has. When I was diagnosed with endometriosis, the pain I experienced was unimaginable and prevented me from living a normal life. When I had two surgeries to remove the endometriosis scar tissue and large ovarian cysts, at my follow-up appointments, I was told: "the endometriosis found was on the borderline between stage 1 and 2, which means your pain couldn't be so bad". Everyone's body is different, and we will experience pain differently, too.

I think it's important that women living with gynaecological health conditions need their voices to be heard. This means taking into consideration the worries and concerns and just actively taking the time to listen and observe how reproductive health is affecting Black and ethnic women within society. It's time to make changes in the educational systems and put patients first, at the centre of their care."



Cheyenne Morgan, **Registered Adult Nurse**

Resources



Our Journey & Mission - Cysters A community led charity designed to combat some of the misconceptions around reproductive health.



@letstalkgynae

An online community, which aims to empower, elevate and educate women about the importance of female reproductive health and the challenges that some individuals are facing with reproductive health disorders.



The White Dress Project

An organisation designed to spread awareness on a global scale about the widespread occurrence of uterine fibroids. They promote education, foster research, provide a supportive community, and advocate for better health.



My Journey with Endometriosis by Temi Labinjo



Black, Broke & Anxious Podcast

The Black, Broke and Anxious podcast has been created by June-Ann to raise awareness about Polycystic Ovarian Syndrome and its effects.



British Fibroid Trust

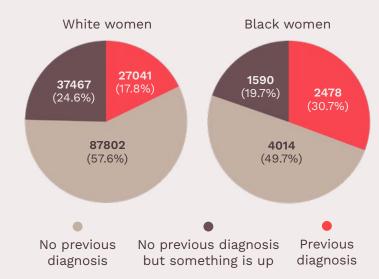
British Fibroid Trust is a UK-based voluntary not-forprofit patient support Group which is run by volunteers.



Our Hertility data shows

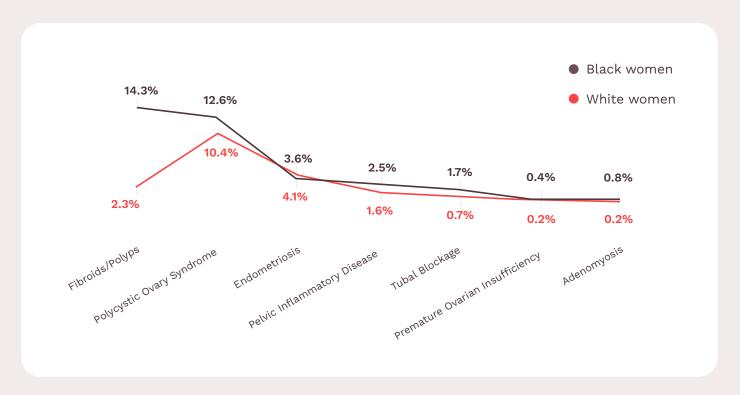
We investigated the number of women who reported a diagnosis of a common reproductive health condition during their online health assessment. Our Hertility data showed that 30.7% (2,478 in 8,082 women) of Black women approached Hertility with one or more pre-existing reproductive health conditions, compared to 17.8% (27,041 in 152,310) of White women (Figure 7).

We found that Black women were most likely to have been diagnosed with fibroids or polyps, followed by PCOS and endometriosis (Figure 8).



A breakdown of previous diagnosis status of health outcomes in Black and White women who approached Hertility.

(fig.7)



The breakdown of pre-existing reproductive health conditions reported by both Black and White women who approached Hertilty.

(fig.8)

What needs to be done?

Research is needed to understand the risk factors that make Black women more prone to developing reproductive health conditions such as fibroids, endometriosis and PCOS.

02 Proper characterisation of how these conditions may present differently in Black women, and adequate training of primary healthcare professionals to consider ethnicity when assessing symptoms.

Specific research is needed to understand the experiences of Black women seeking diagnoses and care for reproductive health conditions and time to diagnosis.



SECTION 07

Preconception Health

What is preconception health?

Preconception health is a term that is often used to describe the state of your health before trying to have a child. Good preconception health is important, and can impact the lifelong health of both the mother and her baby.

Having good preconception health includes the obvious things like ensuring your diet is balanced, stopping smoking and drinking, cutting down on caffeine and exercising, but it also includes the less obvious things like STI & cervical screening, getting your vaccinations and checking up on your oral health.



The problem

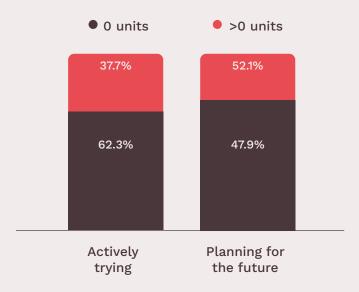
It is known that Black women approaching healthcare providers are more likely to have a negative experience than White women in the UK, which may mean they may be less likely to approach their GP during the preconception period and are also less likely to receive adequate preconception care. It is likely that many healthcare providers have not been adequately trained to deliver culturally-inclusive dietary advice which may also result in suboptimal preconception advice for Black women. In addition, pre-existing conditions that Black women are more likely to have (such as insulin resistance) require specialist preconception advice, adding another difficulty to Black women getting proper preconception care.

Looking after Black mothers-to-be's mental health is paramount, there are many scary statistics surrounding pregnancy complications, maternal deaths and neonatal morbidity which are well known in the Black community. Ensuring that primary care providers, particularly antenatal care providers, are there to reassure Black women and advise them accordingly is important.

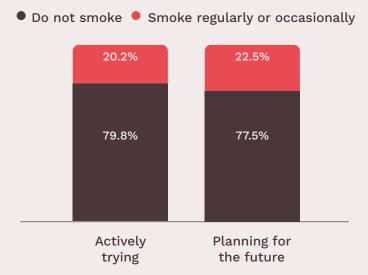
Our Hertility data shows

We know how important preconception health is to ensure both the mum and baby experience the best outcomes. We looked into our own data at how ethnicity may play a role in different preconception habits.

Of the 2,255 Black women who were actively trying to conceive, 456 (20.2%) stated they smoked regularly or occasionally (Figure 9). A similar percentage of Black women (22.5%) who were planning for babies in the future were also smoking regularly and occasionally (800 of 3,563 Black women).



A breakdown of the frequency of alcohol consumption by stage of reproductive journey. (fig.10)



A breakdown of the numbers of smoking status by stage of reproductive journey. (fig.9)

We also found that a high percentage of Black women who are actively trying to conceive or planning for babies in the future were consuming alcohol every week. Of 2.000 Black women who were actively trying to conceive, 754 (37.7%) were consuming one or more units of alcohol per week (Figure 10).

For pregnant women and those trying to conceive, the NHS say the safest approach is to avoid alcohol to keep risks to the foetus to a minimum, more so because there is a chance that you may not know you are pregnant until a few weeks into the pregnancy.

Preconception health tips

01

If necessary, start making changes as soon as possible - at least 3 months before trying to conceive is the magic number

02

Get your pre-pregnancy check-up and make sure your vaccinations are up to date with your doctor

03

Check-in on your hormonal health

04

Get on top of your routine screening

05

Be physically active

06

Put a spotlight on your nutrition (more tips below!)

07

Start taking prenatal vitamins - this means supplementing with Vitamin D & Folic Acid

08

Limit your alcohol consumption and caffeine intake and stop smoking/using recreational drugs

09

Check-in on how you are feeling & your environment

10

Get your partner to do the same!

Expert commentary



Emily Moreton BSc MSc ANutr RN Fertility Nurse and Clinical Nutritional Practitioner

Whilst there are no specific guidelines for a recommended fertility diet, research has pointed toward the Mediterranean -style diet as being optimum for fertility due to the richness of antioxidants (which have been shown to protect sperm and eggs from DNA damage and oxidative stress).

Although traditional cultural foods and diets consumed by Black African and Caribbean individuals in the UK may vary greatly from the Mediterraneanstyle diet, the African and Caribbean healthy eating guide helps to display a more visual representation of how to get a better balance of healthier and more sustainable cultural food and you can see that most of these foods feature in it. The guide shows you how much of what you eat overall should come from each food group. Fortunately, traditional African and Caribbean diets feature an abundance of fruits and vegetables and fresh ingredients such as fresh fish. However, health surveys have shown that out of all ethnic groups, Black African and Caribbean people have the lowest percentage of people getting their 5-a-day, and this has been dropping over the years.

Tips from Emily

- Choose a rainbow of colours of fruit and veg to be able to increase vour micronutrient and antioxidant content. Choose different colours like cho cho, mango, ackee, papaya, jackfruit, eggplant, guava, sweet potatoes and green vegetables like green beans, callaloo, okra and spinach.
- Try having fruit or veg sticks as snacks
- If you feel like you are not consuming enough variety of fruit and veg, opt for a preconception supplement.
- Opt for healthier cooking methods. For example, steam your vegetables instead of boiling them to retain flavour, colour and nutrients.



Vitamin D



Emily Moreton BSc MSc ANutr RN Fertility Nurse and Clinical Nutritional Practitioner

Everybody should be supplementing 10 micrograms (µg) or 400 IU a day of vitamin D from the preconception period, right the way through pregnancy to breastfeeding, especially people of African and Afro-Caribbean descent living in countries at lower latitudes i.e. the UK. This is because vitamin D deficiency and suboptimal intake of the vitamin are more prevalent (54). Adults who don't get enough vitamin D can develop osteomalacia.

This makes the bones softer as the minerals needed to keep them strong cannot get into the bone. People with osteomalacia experience bone pain and muscle weakness. Those in the atrisk groups, including people of African and Afro-Caribbean descent living in the UK should consider taking a daily supplement containing ten micrograms (µg) or 400 IU of Vitamin D all year round.

What needs to be done

Preconception care is a vital part of ensuring someone has a safe pregnancy and healthy baby. Training & resources should be provided to GPs, midwives, obstetricians and fertility specialists to provide culturally sensitive and inclusive preconception tips and dietary recommendations.

Research into the the specific areas of preconception health advice which are currently lacking for Black mothers in the UK, the barriers to uptake and their experiences when receiving preconception care.



SECTION 08

Fertility Treatment

What is fertility treatment?

While there are lots of stories of couples conceiving without any problems, it's important to get to grips with the facts. It's estimated that 1 in 7 heterosexual couples experience infertility. One-third are due to female factors (e.g. issues with ovulation, blocked Fallopian tubes), one-third are due to male factors (e.g. low sperm count, poor sperm quality) and the final third is either a combination of both or could have an unknown cause called unexplained infertility. Treatment for these issues can come in the form of medication (such as Clomid), assisted reproductive treatment (such as IUI, IVF and ICSI) and/or surgery (such as fibroid removal).

The problem

Disparities which affect different ethnicities' success with fertility treatment need to be widely studied, from the existing published research, it is very evident that the inequalities present in the fertility sector and reproductive health space are multifactorial.

So, what do we know about the inequalities in fertility treatment experienced by Black women/patients? Well, in March 2021, the Human Fertilisation and Embryology Authority (HFEA) published a report which crossexamined the UK's fertility sector, focusing on how access to and the outcomes of fertility treatment varied

by ethnicity (55). Using the aggregated ethnicity categories that census data is recorded in the report found that;

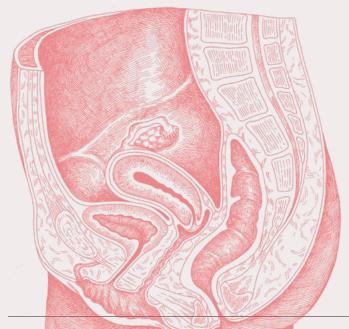
- IVF birth rates were lowest for Black patients (an average of 23% for black patients aged 30-35 compared to 30% for Mixed or White patients).
- There was limited choice of a matched donor for ethnic minority patients. In fact just 3% of the egg & sperm donors in the UK are Black.
- Only 3% of IVF cycles and 2% of donor insemination cycles are black patients.
- NHS funding was highest among Asian patients, followed by White, Black, Other and Mixed patients.
- Black patients started fertility treatment on average 2 years later than the overall average.

of the egg & sperm donors in the UK are Black (55)



An update to this report, published in 2022, unfortunately, revealed that there had not been much change in the uptake and delivery of care in the fertility sector (56).

- White respondents were more likely than Black, Asian, Mixed or Other ethnicity respondents to speak to their GP earlier (77% vs. 72%).
- When looking at wait times, Black, Asian, Mixed and Other ethnicity patients were more likely to wait more than 18 months before starting treatment.
- Waits for donor gametes appear to be longer for Black, Asian, Mixed and Other ethnicity patients than White patients.
- Black, Asian, Mixed and Other ethnicity patients were more likely to have had a multiple embryo transfer than White patients.



So, what does this mean?

The data highlights the various disparities, including lower success rates, lack of access and lack of choice available to Black patients in the UK seeking fertility treatment. Research looking into why these inequalities are occurring is well overdue.

With fertility treatment, success depends on multiple factors, it is of course, a multifaceted issue. The barriers which are preventing black patients from accessing fertility treatment earlier on in their fertility journey, where not only success rates are going to be higher but also the risk of adverse outcomes of pregnancy lower. These barriers could be social, cultural or economic.

Antiquated harmful beliefs around Black women's fertility in our society that Black women may become pregnant easily may prevent people from seeking care earlier. The stigmatisation of fertility treatment within different communities may also prevent earlier uptake. Economically, changes to NHS funding in areas where there are higher proportions of Black residents in the UK, meaning restricted access to NHS-funded care may also impact uptake.

When speaking to Noni Martins, founder of the online community Unfertility on what she believes next steps should be, she said...



It is known that the age at which someone seeks fertility care is an important factor for treatment success. Further analysis of 2018 HFEA data showed that Black women were at an increased risk of cycle cancellation, failed fertilisation, failed implantation and pregnancy loss compared to White women (57).

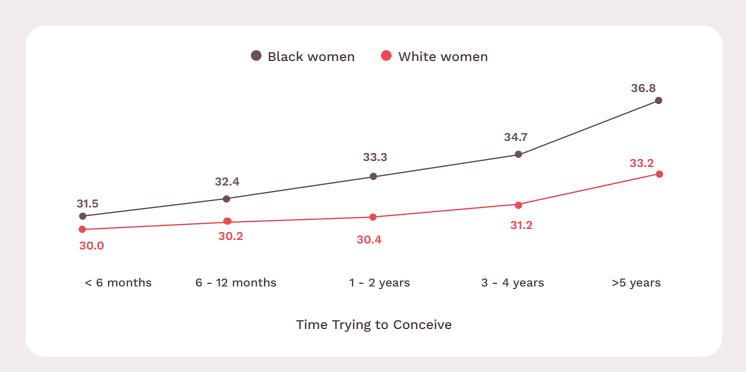
The authors of this paper then adjusted this increased risk to age and found that had Black women "initiated treatment at the same age as women who were White, around a quarter of the differences for most outcomes may have been eliminated.

Our Hertility data shows

In order to understand the fertility journeys of Black women, we investigated the age of Black and White women who were trying to conceive as well as the duration they had been actively trying at the time of completing their online health assessment. To date, our research has shown that Black women approached Hertility later in their fertility journey and at an older age than White women. On average, Black women were between 1.5 and 3.6 years older than White women who had been trying to conceive for the same amount of time (Figure 11).

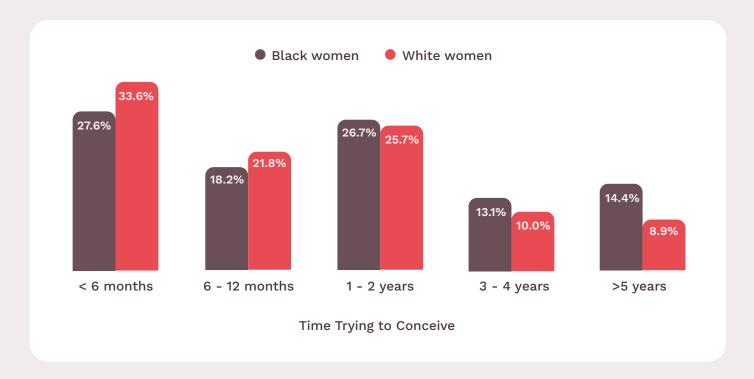
We also found that the percentage of Black women that approached Hertility later in their fertility journey was also higher in comparison to White women, with 14.4% of Black women vs 8.9% of White women approaching Hertility after trying to conceive for 5 years or more (Figure 12).

It is well established that maternal age is one of the factors that affects the success of fertility treatment. Later access to fertility investigations and care may be one of the contributing factors to the lower success rates we are seeing for Black patients accessing fertility treatment in the UK.



The average age of Black and White women actively trying to conceive at specific time intervals from less than 6 months up to 5 years or more.

(fig.11)



The percentage of Black and White women actively trying to conceive who approached Hertility at specific time intervals from less than 6 months up to 5 years or more.

(fig.12)

A lack of access to an ethnicity-matched donor can present a significant barrier to fertility treatment for Black patients. Patients using donor conception often seek donors who are matched in ethnicity as this may be seen as a chance for the child to have some 'familial resemblance' (58). Motivations for finding a matched donor may include sociocultural factors such as acceptance of the child by different community members. A lack of available donors at regulated clinics can increase the risk of patients seeking unsafe donor arrangements.

More Black patients undergo multiple embryo transfers and are more likely to experience multiple births, linked to Black patients taking up fertility treatment later on in life and prompting clinicians to try to maximise outcomes. Considering the fact that Black mothers are at higher risk of certain pregnancyrelated conditions and are at an increased risk of experiencing adverse pregnancy outcomes and of maternal mortality (see section 9), this is worrying.



"Infertility within the Black community is a complex topic that embodies cultural and religious ideologies. In general, Black women seek fertility treatment later in life leading to significantly reduced success with assisted reproduction.

It is important to address the financial burden that fertility treatment imposes on all women; however, healthcare professionals could improve the experience for Black women by being mindful of the socio-economic challenges that many of them face, and therefore, scrutinising the need for 'addons' with no sound evidence. Greater efforts could be made to attract Black gamete donors so those in need of it have a chance at building families with some familial resemblance. Overall, avoiding a one-size-fits-all style of treatment and understanding the challenges Black women face when seeking healthcare could improve IVF outcomes."

Dr Naki Adjirackor

Former Embryologist and Regulations Manager at Hertility

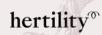
Add-ons

IVF add-ons are defined as anything that is added to a standard IVF cycle. These are technologies which are classed as experimental and often do not have good quality evidence to show their success. IVF add-ons are an extremely controversial topic in the fertility sector. These techniques come at an additional cost to patients, often adding to an already eye-watering bill.

The regulator of fertility treatment in the UK, the HFEA, has a traffic light system for the available add-ons. This system is reviewed yearly by the Scientific and Clinical Advances Advisory Committee (SCAAC), which looks at the published evidence for each technique and assigns it a traffic light based on this.

- Red No good evidence for this technique, it should not be offered e.g. Asswisted Hatching
- Yellow There is conflicting evidence and therefore, add-on should not be routinely recommended e.g. **Endometrial Scratching**
- Green technique has high quality evidence that it will increase IVF success

Research from the HFEA has shown that Black and other ethnic minority patients are more likely to have used add-ons listed as 'red' by the HFEA traffic light system than wWhite patients (56). This is particularly worrying as not only do these techniques not have enough goodquality evidence behind them to prove their success but they end up leading to people spending lots of money on treatment that may not necessarily be needed.



"[The fact that we are seeing increased uptake of red add-ons in Black patients] is really interesting to know but I can certainly speak to the desperation of doing "everything" you can to hopefully have a successful transfer.

"[The fact that we are seeing increased uptake of red add-ons in Black patients] is really interesting to know but I can certainly speak to the desperation of doing "everything" you can to hopefully have a successful transfer. Because from our point of view, as the patient, you always want to do something different to the last failed round.

I personally would be interested to know the tailored success rates for my ethnicity. At the time as a 32-year-old patient, the success rate I had been holding onto for hope was that 29% success rate but now, I am wondering whether that even applies to me at all. And I think it's important to stress: I know that it won't improve outcomes for me, so some might say well what's the point, but in IVF, well for me anyway, knowing is all you have. There is no

guarantee of anything so knowing how the odds are stacked for/against me, manages my expectations. All of us go into IVF hoping it will work the first time but when it doesn't, I found knowing the success rate helped me process that. And also, if for example the success is in fact lower than 29% for me, that difference might determine how long I do this for, how long I keep trying via IVF or how soon I turn to other avenues towards parenthood. So I think it's crucial information, personally."





Resources



Unfertility

An online platform created by Noni Martins to offer a diverse lens and nuance to the dialogue on infertility & IVF.



Vanessa Haye

Vanessa Haye is a writer and reproductive health advocate who openly speaks to her own personal experiences throughout her pathway to parenthood and comments on healthcare inequalities.

Extra Reading

- Why are there lower IVF success rates for black women?
- HFEA Report | Thoughts from Noni Martins, founder of UNFERTILITY
- BAME Fertility: A conversation looking behind ethnic minority treatment

What needs to be done

Research needs to be done to understand why there is such a disparity in terms of access to fertility care in the UK to plan out and action next steps.

Education on fertility decline and the factors that effect fertility treatment should be widespread.



SECTION 09

Pregnancy & Maternal Health

What is maternal health?

Doctors and scientists use the term "maternal health" to describe the health of a woman during the entire pregnancy, childbirth and postpartum period. The postpartum (or postnatal) period usually refers to the first 6 weeks after birth, and we will touch upon this separately in the next section.

The problem **Black Motherhood**

At a time in a woman's life when you are creating a new life, it is normal to feel anxious about becoming a parent. However, Black women and mothers-tobe have an additional layer of fear. One related to the fact that Black mothers are almost four times more likely to die in childbirth or in the six weeks after than White women (59,60). They are also more likely to have a pregnancy-related complication or experience a miscarriage or stillbirth (61). Knowing the statistics and hearing the birth stories of women in your immediate sphere who have previously experienced complications quickly shapes something which should be a positive experience into something quite different.

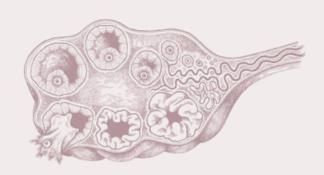
In a <u>piece</u> written by Caroline Bazambanza, she refers to the difficult relationship between Black women and the healthcare system they face today.

With a system that has historically excluded, experimented with, and exploited their reproductive health and freedom to serve societal goals, mistrust, unfortunately, is a given (62).

She quotes a woman called Ella,

"You don't realise how much vou need a stable and reliable healthcare system until you're in the vulnerable state of pregnancy."

"It's impossible to place trust in a system that is committed to letting you down. You don't realise how much you need a stable and reliable healthcare system until you're in the vulnerable state of pregnancy. Until then you're questioning whether it's the system that killed your babies or your own incompetent body. When I was pregnant, I found myself having to lean on a system I wasn't sure could support me and my baggage, my fears, my history and my questions."





Women from minority ethnic groups have not only been shown to access antenatal care later on in pregnancy but had fewer ultrasounds, less checks and fewer screenings (63). When women did access care, they were less likely to report that they received good quality care, e.g. spoken to in a way they could understand, be involved in decisions, and had a positive experience compared to White women (63). This distrust of a healthcare system that has failed them on multiple occasions has real impacts on the uptake of potentially lifesaving screening and care.

Abortion

Abortion, also known as termination, is a medical procedure which is used to end a pregnancy and can either be done using medication or a surgical procedure. An abortion is a safe practice that has a low risk of major complications at any stage of pregnancy.

According to government health data, "7% of women having abortions reported their ethnicity as Black" (64). This is in contrast to the 3.5% of Black people who are estimated to be living in the UK (6,65). In the UK, one in three women will have an abortion in their lifetime.

Despite this, abortion is very much still stigmatised within certain communities, with religion and culture playing a role in the decision-making process and support beyond the procedure.

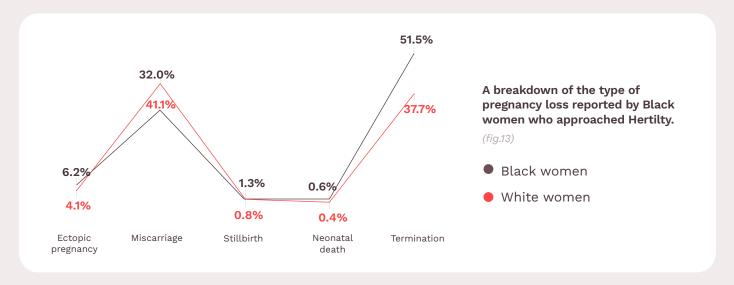
Our Hertility data shows

We investigated the number of women who experienced pregnancy loss, as well as the type of pregnancy loss reported in their online health assessment.

According to our own Hertility data, If we consider all women that had a termination, 7.6% of women self-identified as Black, which corroborates the government health data presented.

When looking at the proportions of both Black and White women approaching Hertility who reported having a previous pregnancy (3,203 and 45,579 women, respectively) we see that 51.5% of Black women had one or more terminations compared to 37.7% of White women (Figure 13).

If you are considering having an abortion or have gone through one previously, the majority of resources of support are filled with White faces, but a report by <u>Decolonising Contraception</u> spotlights the experiences of Black African, Caribbean and Asian people in the UK (read the report <u>here</u>).



Resources



British Pregnancy Advisory Service (BPAS)

An independent healthcare charity which advocates and cares for women and couples who decide to end a pregnancy.



SANDS on terminations for medical reasons Educational resource.



MSI Reproductive Choices
Provider of NHS-funded abortion

and vasectomy care as well as other self-funded options.



Tommy's Charity on terminations for medical reasons
Educational resource.

Miscarriage

A miscarriage is the loss of a pregnancy before 24 weeks (66). About half of early miscarriages are due to chromosomal abnormalities, but often the reason for miscarriage is unknown. Miscarriage affects around 1 in 8 confirmed pregnancies (66). However, this figure rises to 1 in 6, including people who didn't yet know they were pregnant (61).

Preterm birth

Preterm birth is when a baby is born before 37 weeks of pregnancy and very preterm birth is when a baby is born before 32 weeks. Despite advances in neonatal care units, babies born prematurely are still at risk of problems with the development of the respiratory system, feeding, vision and hearing abnormalities. This is because the development of several organ system(s) can take up until the final weeks of pregnancy to be complete. Complications that have arisen from preterm birth are the leading cause of death in children under 5 years old (67).

Babies born from Black mothers were the only ethnic group to see an increase in preterm birth rates between 2019 and 2020 (68)

1.3% of the 3,203 Black women who reported having a previous pregnancy had one or more stillbirths

Stillbirth

Stillbirth is when a baby dies in utero after 24 weeks of pregnancy or during labour. The cause of stillbirth can be due to maternal health conditions, problems with the placenta or a congenital disability. In England, 1 in 200 births are stillbirths (69). Mortality rates remain exceptionally high for babies of Black and Black British ethnicity; stillbirth rates are almost twice those for babies of White ethnicity (68,70,71).

When looking at the intersectionality of ethnicity, deprivation and pregnancy outcomes, a higher portion of Black and Black British mothers giving birth were living in areas of higher social deprivation, an independent risk factor for stillbirth (70,72).



Black women are at a 43% increased risk of having a miscarriage in comparison to White women (61)

Our data shows that **32.0%** of the 3,203 Black women who reported a previous pregnancy also reported having had one or more miscarriages.

Neonatal death

A neonatal death refers to the death of a baby up to 28 days after their birth. The average neonatal death rate in the UK between 2014 and 2017 was 0.16%. For Black mothers, this rate was 0.25% in 2015 and increased to 0.29% in 2017 (73). Again, social deprivation was reported as a risk factor for increased death rates.

Our data shows that 0.6% of the 3.203 Black women who reported having a previous pregnancy had one or more neonatal deaths.

Maternal outcomes

An analysis of 1414 admissions showed Black mothers were almost twice as likely as White mothers to be admitted to intensive care during pregnancy and postpartum. A risk that was only moderately reduced after adjusting for demographic, health, lifestyle, pregnancy and birth factors (74).

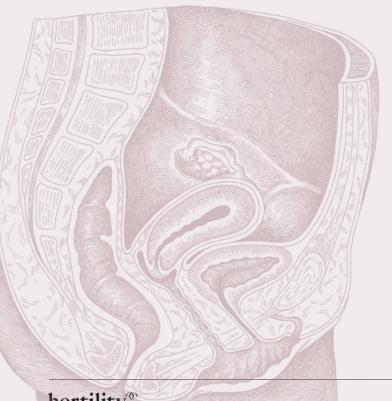
The increased prevalence of admissions in Black women needs to be further investigated. Screening for the conditions linked to ICU admission should be conducted in a timely manner to prevent hospitalisation and other adverse outcomes.

The ninth annual MBRRACE-UK report yet again highlights that more needs to be done to address the systemic disparities which lead to women of different ethnicities and socioeconomic backgrounds being more likely to die during pregnancy and after birth.

Despite a slight decrease from the previous report, there remains a significant disparity between the maternal mortality rates of Black women (3.7x) and Asian women (1.8x) compared to those seen in White women (60). Although lower than the report in 2021 (59), this reduction is not significant.

1.7x

Black mothers are almost twice as likely to be admitted to intensive care during pregnancy and postpartum period as White mothers (74)





3.7x

Black women are almost four times as likely than White women to die during pregnancy or 6 weeks after childbirth (60)

The reasons behind the ethnic disparities seen in maternity and pregnancy outcomes are multifactorial and complex. Even when adjusting for the increased prevalence of certain pregnancy-related conditions, which increase risk, lower socioeconomic background and lifestyle factors, the risks to black mothers and their children persist. Work to address these inequalities is ongoing but still has far to go.

The charitable organisation, FivexMore, has focused on tackling this disparity and changing the experiences of black women. In doing so, they have highlighted the voices of black mothers and recently reported outcomes on a survey designed to assess the maternity experience of black women in the UK.

The survey found that 43% of women felt discriminated against during their maternity care because of race, ethnicity, age and class. Furthermore, only 12% were informed about how to make a complaint despite ~30% reporting that they received a poor or very poor standard of care during pregnancy, labour and postnatally (2).

42%

of Black women felt their standard of care received during childbirth was poor or very poor (2)

36%

of Black women felt dissatisfied with how healthcare professionals addressed their concerns during labour (2)

42%

of Black women felt that "their safety had been put at risk by professionals during labour or the recovery period" (2)

The report highlighted three key areas leading Black mothers to receive negligent care from healthcare practitioners. These centred around the attitudes, knowledge and assumptions of healthcare professionals (2). The systemic barriers preventing Black women from accessing unbiased, quality care must be addressed. When Black women do present with symptoms, they are often dismissed. This means Black women are put in situations where their lives and babies are at risk.

In the media, we have heard from the likes of Serena Williams and Candice Brathwaite, who have come forward with their birth stories to raise awareness of the need for healthcare professionals to listen to black women, to be further educated and address the racial bias which is prevalent in our healthcare system today.



At the time of publication, a report written by the House of Commons was released exploring Black Maternal Health in the United Kingdom (75). From 2000 onwards, ethnicity data on maternal deaths in the UK has shown that mothers from ethnic minority communities, particularly Black mothers, experience worse outcomes and whilst there are signs of improvement; in 2000 Black African women were almost 7 times more likely to die in than white women, the increased risk Black women face still remains. The report covers the work done to date and highlights the lack of data on the experiences of Black women and the recommendations to tackle disparities for the future.

Sophia Ufy Ukor shared her birth experience with us.

"All my life, I had been scared of getting pregnant. I wanted to have kids, but I always said I would either opt for surrogacy or adopt because of the stories I heard of women, both family and strangers, dying in childbirth and how painful childbirth is. I didn't want any of that, but years later, I decided I was ready, and my husband and I started trying.

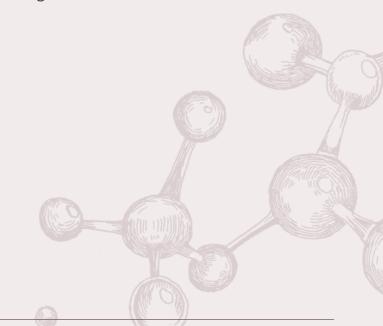
During my first pregnancy, I had severe hyperemesis. Before that, I had no idea what hyperemesis was or that it even existed. I thought I just had 'normal pregnancy sickness'.

As much as I come from a family of scientists and doctors, I found that no one around me really understood what Hyperemesis was.

I was in the hospital throughout my first pregnancy - I would spend a few days to a couple of weeks in the hospital, get discharged and soon after leaving become so sick and end up right back at the hospital. This was the continuous cycle throughout the whole of my first pregnancy.

I got so weak at some point I had to rely on a wheelchair, the midwives and my husband to get me from my bed to the toilet. I just didn't think I was going to be alive to see my child.

Two weeks ago, I stumbled across a video I made for my son, telling him how much I loved him. I did that video because, at the back of my mind, I believed I would not get to meet him.



Despite this, I had a good experience because when I was looking for a doctor, I looked for a woman of colour, and the first thing I said to her was, 'I don't want to die'. I knew when I met my doctor that I could trust her, and she said "You won't die", I believed her. She didn't just talk the talk, she walked the walk and made sure that everyone paid attention, listened to me and gave me the help I needed.

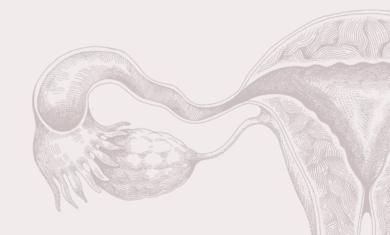
When I was in the hospital and told the staff that I couldn't eat the food they were serving me due to it triggering my sickness, my doctor advocated for me and told them that anything I wanted to eat, they should prepare. But even with that support, there were times some medical practitioners and other people told me that it was all in my mind and it was just morning sickness, that I should be strong. At that point in time, I was so vulnerable. I did not have the energy to correct people.

After my pregnancy, I still felt sick. Everyone kept telling me it would go, and I would forget about it. But I was still nauseous after pregnancy and struggled with digestion and other issues postpartum. I had many scans to rule out diseases, cancer, and autoimmune diseases. It ended up being because of how severe my hyperemesis was and the trauma my body and I had gone through. My doctor understood that and listened to me, but so many people told me it was in my mind.

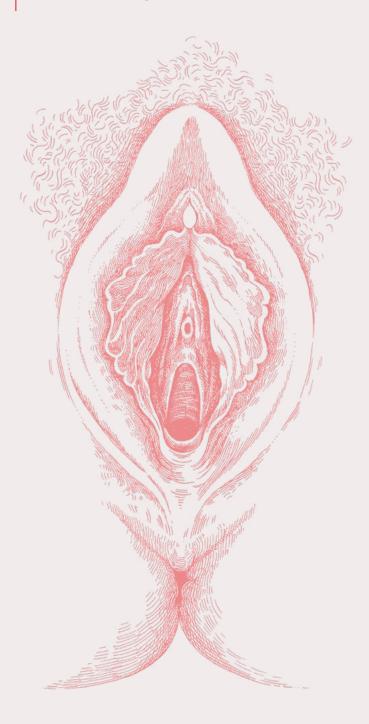
When I had my miscarriage in 2022 and with my current third pregnancy now - 2023, my experience has been better. There is a change in the language, the culture and the way they listen to you. I felt seen. I believe my previous experiences have made me more aware. I have more information. More importantly, I am more confident and will not let anybody silence me regarding my health.

I get asked, "What are the things that you think women should have around them to ensure they have the best outcomes" a lot, and my response to this is always the same. Knowledge is light. I think women should go in with iron-clad information about what is going on with them. The truth is, at the end of the day, it's your life. Yes, you are putting it in the hands of the doctor, but it is very important to do your research and to have information to be able to go there to say the things you need.

Make your case, argue and don't let anyone invalidate or belittle what you feel.



Another essential thing is the support network. I am now in my third pregnancy, expecting my second baby and a village surrounds me.



If I am going to an appointment and I am not too satisfied with it, I can call my husband or sister, and they help me process and manage this. I am lucky to have an amazing support system that helps with work, childcare and dayto-day life which makes things easier. Especially on the days that I am so sick I can't leave bed.

Another thing is being able to talk about what you are going through. When you have health issues, it is important to be very vocal about the issues because if you have a good support system, they would be able to help you through it and help relieve the burden for you. Your support system could be your family, partner, siblings, friends, doctor or even colleagues. A loyal and caring support system is priceless. It is what is making me thrive right now, even though I am sick most days."



Sophia Ufy Ukor Founder and CEO of Violet Simon

Resources



Birthrights

The leading charity on human rights in pregnancy and childbirth in the UK focused on championing respectful care during pregnancy and childbirth. They provide advice and information on your legal rights, train healthcare professionals and campaign to drive change within maternity policy and systems.



The Motherhood Group

A social enterprise founded by Sandra Igwe, a Black maternal health advocate, TEDx speaker, dedicated to improving the maternity experiences of Black mothers through events, training workshops, peer-to-peer support and campaigns.



Black Mums Upfront

A London-based collective of Black mothers who are shifting the narrative of Black Motherhood and making it more inclusive through sharing, discussing and supporting Black mothers.



FivexMore

An organisation started by Tinuke and Clo dedicated to supporting and empowering Black mothers to make informed choices and advocate for themselves throughout pregnancy and childbirth. You can read their most recent report here.



Tommy's

has a midwife video call service for Black mums which can be accessed here.

What needs to be done

Research into understanding the underlying factors/conditions which contribute to the increased risk of adverse pregnancy and neonatal outcomes for Black women and birthing people.

Training to HCPs on providing culturally sensitive and considered care.

Working with organisations like FivexMore and Black Mums Upfront to provide the correct support to support Black mothers and parents throughout their pregnancy journey and postpartum.



SECTION 10 Postpartum health

What is postpartum health?

Postpartum health usually refers to the six week period after birth. Ensuring all women have good quality postnatal care is essential to ensure both mum and baby are healthy. Most maternal and infant deaths occur in the six weeks following childbirth and postnatal care is vital in preventing many of these.

The problem

NICE guidelines state that women from some minority ethnic backgrounds and those who live in deprived areas may need closer monitoring due to the disproportionate risk of adverse outcomes in these groups (76). An important part of postnatal care involves assessing the psychological health and well-being of the woman. This is because there is a significant risk of suicide in mothers. Maternal suicide remains the leading cause of direct deaths occurring within a year after the end of pregnancy and MBBRACE Assessors felt that improvements in care might have made a difference in outcome for 67% of the mothers who died by suicide during the years of 2017-2019 (70). Literature has demonstrated that women from minority ethnic groups are more likely to experience common mental health disorders such as postnatal depression and anxiety (77-79).

But healthcare practitioners are failing Black women...

Research conducted by Fivexmore looking at Black women's experiences of perinatal mental health care showed that 40% of respondents said HCPs did not ask about previous or current mental health and well-being. Of those asked about their mental health and well-being, 66% said they were not signposted to any additional support (2). Shockingly, 61% of women who experienced miscarriage or pregnancy loss reported that they were not offered any additional support to deal with the pregnancy outcome.

A report produced by the NHS Race and Health Observatory exploring Ethnic Inequalities in Healthcare showed that not only did Black women have significantly lower access to community mental health services, echoing an earlier study (80), but they are more likely to receive no treatment in the antenatal period and the first year postpartum compared to White women (3). Even at consultation, women from minority ethnic communities are affected as healthcare practitioners have been found to be less likely to ask case-finding questions in women with limited English or from non-White backgrounds and feel that cultural and language barriers affect case-finding ability (81,82).

Elaine Amoah, from the University of East London School of Psychology, looked further into the way in which stigma impacts perinatal low mood and depression (83). The majority of women from marginalised communities (62%) were found to have possible depression (83). Additionally, for those who identified as Black, internalised stigma (mistrust in the healthcare system/practitioners from past negative experiences) and treatment stigma (not seeking care due to the stigma which will come from having diagnosis/treatment) were significantly associated with perinatal depressive symptoms (83). This is similar to findings from a systematic review on studies conducted in the UK on women from marginalised groups which found that several factors impact their experiences

of perinatal mental ill health and health services such as lack of awareness. cultural expectations and stigma in addition to lack of continuity of care and fragmented services with healthcare practitioners who did not provide culturally competent and compassionate care during the perinatal period (84).

Whilst it is known that women of all ethnic backgrounds are often prevented from seeking mental health support during the perinatal period due to feelings of stigmatisation, what must be considered is the intersectional nature in which Black women (and women from other ethnic minority communities) are affected when it comes to their healthcare and how this may affect help-seeking behaviours.

61%

of women who experienced miscarriage or pregnancy loss reported that they were not offered any additional support to deal with the pregnancy outcome (2)



Support for mums



The Motherhood Group

A social enterprise founded by Sandra Igwe, a Black maternal health advocate, TEDx speaker, dedicated to improving the maternity experiences of Black mothers through events, training workshops, peer-to-peer support and campaigns.



The Black Working Mothers Network
A platform to connect women of
black heritage to speak about all
things to do with motherhood
and work.



Black Minds Matter

a fully registered charity operating in the UK; connecting Black individuals and families with free mental health services.

What needs to be done

Further research into why Black mothers and birthing people are more at risk of developing postnatal depression.

1 Improvements in service provision and groups working with service providers and Black mothers to understand what support they may need.



Black Mums Upfront

A London-based collective of Black mothers who are shifting the narrative of Black Motherhood and making it more inclusive through sharing, discussing and supporting Black mothers.



FivexMore

An organisation started by Tinuke and Clo dedicated to supporting and empowering Black mothers to make informed choices and advocate for themselves throughout pregnancy and childbirth. You can read their most recent report here.



SECTION 11 Menopause

2023

The Inequality Report

What is menopause?

Menopause is defined retrospectively, officially diagnosed when it has been a full year after the last menstrual period. Prior to this, perimenopause occurs, which is a time when periods become irregular or stop completely and menopausal symptoms are experienced. At this time in an individual's life, the menopausal transition encompasses so much change to both physical and psychological health. The average age at which menopause occurs in the UK is 51 but on average occurs between the ages of 45 and 55.

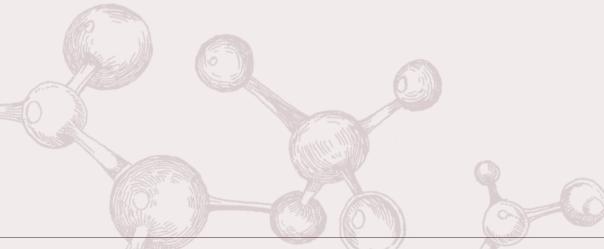
Many of the symptoms of menopause can be attributed to fluctuating and overall declining levels of oestrogen. These symptoms can impact the quality of life. For example, vasomotor symptoms or, as they're more commonly known, hot flushes and night sweats, affect up to 80% of women going through menopause to varying degrees of severity. On average these last for around 4-7 years but in some women can be up to 12 years.

The problem

We have seen the inequalities which Black women face throughout their fertile years but does this change once a woman approaches menopause?

We only have to look at longitudinal research done on women to see the key differences in experiences of menopause between women of different ethnicities. The Study of Women's Health Across the Nation (SWAN) study was a 25-year longitudinal study of a multi-ethnic cohort in America designed to explore the midlife health of women (85). Researchers looked at this rich data set and drew several conclusions about Black women's experience of the menopausal transition.

Black women experienced menopause on average 8.5 months earlier than White women. However, when adjusting for the effects of multiple social and lifestyle factors such as alcohol consumption, education attainment, employment, contraceptive use, weight, physical activity etc, this difference was no longer significant.



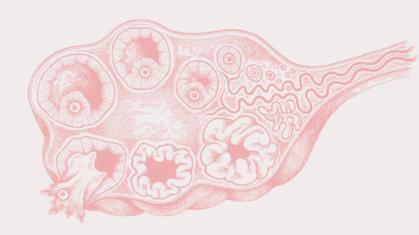
The differences seen between the age of menopause in women of different ethnicities and backgrounds are thought to be influenced by genetics but also by differences in environmental, lifestyle, reproductive or social factors. For example, when looking at the SWAN study's results, upon further analysis, when taking into account the effects of multiple social and lifestyle factors such as alcohol consumption, education attainment, employment, contraceptive use, weight, physical activity etc., the difference seen was no longer statistically significant (the difference fell to around 3 months).

So, it is more than probable that the underlying reason behind differences in menopause onset between people of different ethnicities is complex and multifactorial and definitely an area which requires more research, a part of what we are trying to achieve at Hertility.

When looking at symptom experience of menopausal women, Black women are 50% more likely to experience vasomotor symptoms (i.e. hot flushes, night sweats) than White women (86). Black women are 60% more likely to report their symptoms as frequent (occurring more than 6 days of the week) and bothersome.

Not only are Black women more likely to experience more bothersome vasomotor symptoms at a higher frequency than White women, but work has also shown that Black women experienced vasomotor symptoms on average 10 years compared to 6.5 years for White women (87).

Complications such as osteoporosis and cardiovascular disease, which arise as a result of the oestrogen withdrawal that occurs as part of the menopausal transition, can seriously affect quality of life and increase mortality. Research indicates that Black women in the midlife period and beyond who are affected by these conditions may experience worse outcomes. For example, research on a US-based cohort showed postmenopausal Black women who experienced osteoporotic fractures had significantly higher rates of mortality and placement in long-term nursing facilities than White women (88). It is also known that premature menopause is an independent risk factor for cardiovascular disease, which one study has shown Black women had almost three times the likelihood of developing than White women (89).



Identifying the racial and ethnic inequalities experienced in perimenopause, menopause and postmenopausal life ageing is essential to improving the midlife health of everyone. As we are living longer, women could be spending over a 1/3 of their life in the period between peri to post menopause.

For all women, menopause represents a time point in life where there is a huge amount of social, physical and environmental change at both an individual and wider level. Ensuring there are support networks in place for women is paramount. This needs to be done by amplifying the voices of Black women and people of colour's voices around menopause. Many of the stories/ experiences of menopause which are told are those of White women. This is definitely a multifactorial issue and could be partly due to cultural taboos and a lack of a safe space available for Black and Brown women to share their experiences.

Support networks and resources



Black Women in Menopause A platform created to explore the experiences of menopause in an inclusive way.



Menopause Whilst Black a podcast created by Karen Arthur designed to spotlight the menopausal experience of Black UK based women.

Extra Reading

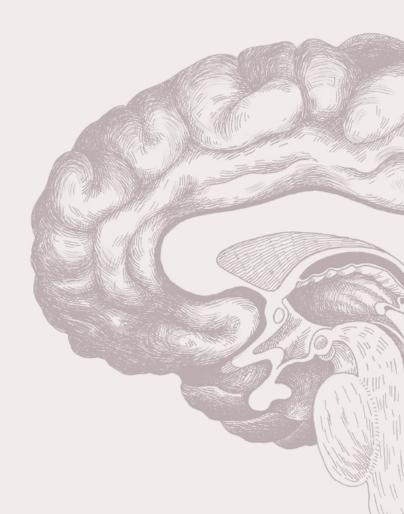


5 Black & Asian British womenshare their menopause experiences

What needs to be done

Research into the experiences of Black women going through menopause in the UK.

Scientific research into the modifiable factors that contribute to the quality of midlife health in Black women going through the menopause and beyond.



SECTION 12

Close

This report represents the first step from Hertility and highlights our commitment to bringing the data to light and being proactive and creating positive, sustained change within areas that disproportionately impact marginalised groups and minority communities.

Our first action in this is the production of this report. In their most recent publication, the Black Women's Reproductive Health Project put it aptly, what is needed is "comprehensive menstrual health and reproductive health education" (90). Education that not only addresses the intersectionality that affects Black women for all people to be aware of but provides Black women specifically with the tools to be able to feel confident in healthcare situations where internalised stigma and systemic barriers have historically existed.

Another tool we are using to create change is our research. It is no longer good enough (and never has been) that ~80% of our genome-wide association data is from people of European descent (91) or that Black people are consistently underrepresented in clinical trials.

For too long Black women have been the victims of medical decisions that are made, reliant on datasets which are not relevant to them, at the hands of a healthcare system already at its knees and unequipped to be able to make necessary systemic changes to be able to combat the unmet need for care for Black women.

We are a team of educators and for too long we feel information has been gatekept from women, rife with complex terminology and not reflective of the lived experiences of the women it is designed to reach. We created this report to provide accessible information (where it was available) on Black women's experiences when it comes to their reproductive health. Moving forward we will be looking to provide inclusive education resources to support healthcare practitioners to provide compassionate care and help women advocate for themselves in healthcare settings.

We are a small company on a big mission, and we hope you will come on this journey with us.

Meet the Hertility team behind The Inequality Report

Hertility's Black Women's Health Initiative Team



Dr Helen O'Neill CEO and Founder, (BSc, MSc, PhD)

When we started Hertility, we began with a mission to make reproductive healthcare accessible, to leave nobody behind and to empower women with information about their bodies. This is by no means a small mission to embark on.

Our goal with Hertility is not to retrofit women, especially those who are affected by the various levels of intersectionality, into a healthcare system that was not built for them. This means focusing on closing the gaps in the data (of which there are many), and not just those related to biological characteristics or binary data. But fuelling research, which explores experiences, thoughts and perceptions and sees women's voices amplified and heard. We want to reimagine and reinvent reproductive healthcare for each and every woman. We are building the future of healthcare, one that takes into account the person, their life, their background and their experiences.



We started our Black Women's Health Initiative after looking into the disparities evident in the data and wanted to use our own data to make change. We are cognisant of the information that already exists and see the demand for change, but we want to be the change that is needed. The passion of the team internally to drive this initiative has made me extremely proud. Seeing each team member flourish during this process has been so important. We hope to continue this work and to collaborate with organisations, institutions and people that are already on this journey to create change. Collective action is our most powerful tool, and when we stand together, there is no limit to what we can achieve.

Meet the Hertility team behind The Inequality Report

Hertility's Black Women's Health Initiative Team



Ruby Ross Relton Senior Scientific Research Associate (BSc, MSc)

I am a Senior Scientific Research Associate at Hertility with a background in Biomedical Science, Reproductive Science and Women's Health, I am an active researcher who is passionate and committed to addressing inequalities in reproductive health care and outcomes for people from marginalised communities. I am one of Hertility's Diversity and Inclusion Officers and the project lead for Black Women's Health Initiative.

Coming from a Mixed White-Afro-Caribbean background, I have always aspired to be part of the vital work to reduce the health disparities faced by people from marginalised communities. As a young researcher, I am proud to be able to contribute to the work being done to reduce these inequalities, to raise awareness about the unique health challenges that Black women face and to develop innovative solutions to help improve Black Women's health outcomes.



Dr Tharni Vasavan **Head of Scientific Product** Research (BSc, MSc, PhD)

As a result of working in several different settings relating to women's health, such as labour wards, antenatal units and IVF clinics, I have been exposed to the prevalent and very serious issue of racial inequality within this sector. In particular, my PhD research on preterm birth and stillbirth led me to the important work that the MBRRACE group has been doing, which further spurred my interest in improving the health, safety and well-being of Black women and other communities facing poor health outcomes.

I look forward to gathering a highquality dataset on Hertility's various specific minority ethnic groups, so we can play our part to bridge the knowledge gaps around conditions which disproportionately affect the reproductive health of Black women.

Meet the Hertility team behind The Inequality Report

Hertility's Black Women's Health Initiative Team



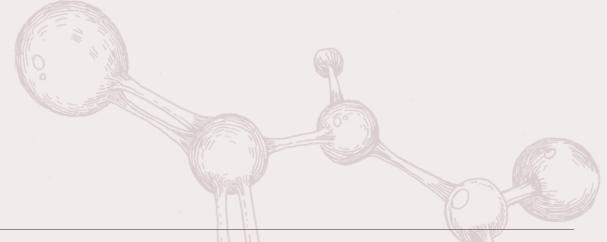
Charlotte Ponnelle
Brand & Communication Lead
(BSc)

Having been part of the team to craft our brand mission 'to reinvent healthcare for every woman', reading our own statistics showing the inequality in access to fertility care for Black women made me realise how much still needed to be done. Being in the marketing team, even for a purpose-driven brand, you don't often get the opportunity to work on projects that will really change people's lives so being a member of the Black Women's Health Initiative means that I can make sure that our brand mission is not just a line on our website but something that we are taking steps to work towards every day.



Sofia Rodrigues Vaz Data Analyst (BSc, MSc)

As a data analyst, it is my job to find answers in data and use numbers as a tool to describe reality and tell stories that need to be shared and heard. The data shows that some women face greater challenges than others when trying to access the healthcare they need and deserve, including fertility care. There are racial inequalities in healthcare, and that is simply unacceptable. I look forward to diving deeper into the data, understanding the root causes of such inequalities, and continuing to work with a passionate team on developing life-changing fertility care solutions for minority ethnic groups.







Emily Moreton Fertility Nurse and Clinical Nutritional Practitioner (BSc, MSc, RNutr, RN)

Emily is a Registered Nurse and a Registered Associate Nutritionist registered with the Royal College of Nursing and the Association for Nutritionists. She holds a Bachelor's degree in adult nursing and a Masters degree in clinical nutrition and public health and is a trained nutrition counsellor. Emily is a non-diet practitioner specialising in women's health, focusing on health-promoting behaviours, empowering clients to improve their health and well-being by leaving the diet mentality behind and improving their relationship with food, movement and their body, whether it be to optimise fertility chances, manage PCOS symptoms or guide you through menopause.



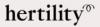
Dr Naki Adjirackor **Quality Assurance and Regulatory** Manager (BSc (Hons), MSc, PhD)

Dr Naki Adjirackor obtained a Bachelor of Science degree in Biological Sciences at the University of Liverpool, a Master of Science degree in Clinical Embryology at the University of Oxford and a PhD in Biological Sciences at Christ Church University. Over the last decade, she has gained clinical embryology and andrology experience from both NHS and private sectors, and presented at the ESHRE and ASRM conferences. Her research interests include quality control in IVF and scaling-up systems and processes for large scale screening of culture media. She has knowledge of medical device regulations and experience setting up quality management systems for ISO13485.

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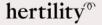
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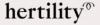
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