
PUBLIC POLICY PROJECTS

A Women's Health Agenda: Redressing the Balance

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Foreword



FOREWORD BY DAME CLARE GERADA

It is my personal feeling that women have no more rights regarding their bodies and healthcare than when I was born 62 years ago. As a GP of over 40 years, I have treated thousands of women. However, throughout the process of crafting this report, I have been shocked to learn that many of the medical interventions and procedures held up by institutions and policymakers are not in place for the good of women's health but serve to prevent women from being in control of their own bodies.

Health systems are infantilising women, deeming them incapable of looking after their own health, without the state interfering at every stage. Whether that is by demanding attendance at a clinic to obtain contraception or through insisting that women are assessed for psychiatric illness if they request an abortion. Women are constantly told throughout pregnancy what they can

and can't do, so it is no wonder that so many pregnant women have been hesitant to take up the Covid-19 vaccine. It is now a devastating reality that a huge number of patients suffering with the virus in ICU are expectant mothers. The total policing of women's bodies by the systems and structures that are set up to look after them has resulted in a situation where women don't trust themselves or their instincts, about their own health.

We have gathered both women and men from all over the world together to discuss why it is that women remain isolated from the services and medical interventions they need. These problems cannot be fixed overnight but gathering to discuss the solutions is a step in the right direction. Women account for over 70 per cent of the global health workforce and make up 50 per cent of the global population.¹ If enough of us keep talking, the world must start listening.

Foreword



FOREWORD BY DAME LESLEY REGAN

Across the span of my career as a gynaecologist I have had the privilege and opportunity to provide advice and care for women across their life course. It is vital to understand that women's health extends far beyond reproduction; the wellbeing of the woman sitting in front of me has been largely determined by the ability to make informed decisions about her own health. Empowering women with the tools and information needed to make personal choices is key to enabling her to achieve better long-term health outcomes for herself.

This report considers the global needs of women in the 21st century, which has brought us the largest generation of adolescent girls in history, treatments that can circumvent infertility, increasing complexities during pregnancy in older women, the first ever generation of women whose improved life expectancy will dictate that they spend longer as a menopausal woman than they had reproductive years. Across the world, women's respective health

systems are failing to cater to their needs and many of their most important issues remain shrouded in taboo. We must seize every opportunity to advocate for women so that they can become ambassadors for each other, understanding where their respective healthcare systems may be falling short and what they should do to access the advice and practical help they need.

The many individuals we invited to contribute to the evidence gathering and debate underpinning this report, confirmed how the very same issues are being experienced by women across the globe. It is clear that cross systems leadership and accountability are required to deliver improved health services for women.

Women's health outcomes impact not only the individual woman and her family, but the healthy functioning of society as a whole. We must ensure that women's health holds a place at the top of the healthcare and wider political agenda. Every one of us has a part to play in achieving this goal.

Recommendations

CONTRACEPTION

Sexual and reproductive health services must be prioritised to counter patchy healthcare service provision – and access must be made available, in and out of hours.

NICE should re-examine guidelines that recommend routine appointments for oral contraception users – with a view to limiting unnecessary medical checks that may only serve to limit contraception access.

Progestogen-only pill (POP) should be made available on general sales (off the shelf) and not require consultation with a pharmacist unless the woman wishes.

Those who plan and purchase healthcare must ensure provision of full range of contraception services to all women that is person centric and at all reproductive ages, with a particular focus

on targeting women of low socioeconomic status (SES) and minority ethnic women. This should include ensuring emergency hormonal contraception is free in 100 per cent of healthcare service provision.

While Long Acting Reversible Contraception (LARC) should be encouraged, the greatest impact for reducing unplanned pregnancies must focus on influencing women who use no contraception to begin using any form of reliable contraception.

Post birth contraception must become an integrated part of maternity services and funded appropriately. Women should be routinely offered a choice of contraception post delivery and given information about the importance of birth spacing to improve their health and that of their baby/family.

ABORTION

To further increase access to telemedicine abortion, health providers should enable a greater number of staff to undertake telemedicine abortion and prescribe the medications – this should include enabling training nurses and pharmacists to undertake the clinical consultation.

Post-abortion care can be self-managed by the woman and this should be advocated for within local sexual and reproductive health services.

Access to telemedicine should be enhanced and obstacles to access removed wherever possible. This should include removing the need for women to have a routine scan within a clinical setting in order to qualify for a telemedicine abortion.

Abortion should become further integrated with contraception services and wider sexual and reproductive health service provision. Health providers should ensure that contraception is offered at the time of abortion if desired by the woman.

ASSISTED CONCEPTION

Access to fertility treatment should be determined based on need, not by geographical location. Disparities in funding levels between different Clinical Commissioning Groups (CCGs) and soon to be integrated care systems must be addressed so that women are able to access the recommended three cycles of IVF treatment from anywhere in the country.

Those going through fertility treatment must be provided with far clearer information and assisted conception 'add-ons' must be regulated with patients clearly informed when

treatment options are not fully evidence based. The reproductive genomics sector must be subject to greater structure and regulation – women should receive independent advice about their options from genomic experts before they are referred to commercial providers.

A large proportion of the genomics of women's fertility lies outside of existing NHS England and PHE governance structures. This should be addressed as a priority by ensuring it is brought into the remit of existing structures.

MENSTRUATION AND MENOPAUSE

The UK government must promote menstrual equity by ensuring that girls and women of reproductive age have access to adequate menstrual hygiene, including basic facilities and products.

Menstrual period products should become free in England thereby following the framework set by Scotland's successful campaign to end 'period poverty'.

The UK government tampon tax relief fund should be replaced with another women's health relief fund, ensuring that organisations previously reliant on this funding are supported.

Governments must place greater priority upon menstrual health within educational settings, encouraging dialogue with boys and girls of all ages to break down historical taboos. Building on this enhanced knowledge and understanding of menstrual health,

educators, clinicians and policy makers should phase outdated terminology with regards to menstrual health.

Each interaction women and girls have with healthcare systems should be used as an opportunity by clinicians to understand how menstrual health is impacting their lives. Health providers must receive greater support to engage in dialogue around women's health and be supported by a comprehensive data infrastructure that records comments and scales best practice.

Policymakers must continue to support the health sector in supporting campaigns that end misinformation around Hormone Replacement Therapy (HRT). Women should be presented with the risks and offered HRT consistently in order to make the decision themselves. There needs to be a specific focus on targeting women of low SES.

Recommendations

BREAST CANCER

Governments should prioritise producing preventative strategies targeted at lifestyle change, as well as focusing on producing screening guidelines that can be adapted to suit local resources.

In the UK, the NHS recovery programme needs to assess extensive waiting lists and overhaul

the breast screening programme and shift the focus within breast cancer strategies away from screening towards prevention.

Breast density should be routinely measured within breast screening clinics as part of the NHS recovery programme's overhaul of screening programmes.

CERVICAL CANCER

When governments with limited resources are looking at strategies to eliminate cervical cancer, prioritising HPV vaccination of girls should be advocated for as recommended by the World Health Organization.

The UK's Women's Health Strategy must focus on targeting ethnic minority groups to improve cervical screening uptake. A holistic approach is needed to address the widening cervical cancer inequality gap.

In the UK, cervical screening services should be integrated with regular sexual and gynaecological health services for ease of access.

Efforts to introduce self-sampling need to be scaled up in low-to-middle-income countries. Following the YouScreen study in London, HPV self-sampling should be implemented across the UK targeting groups with lower screening uptake.

A GENDERED LENS: RESEARCH, DATA & POLICY

Women of childbearing age and pregnant women should be given the choice to participate in clinical trials themselves, rather than being excluded from the outset. Male, especially white male, participation in clinical trials should be capped to ensure participation from underrepresented groups, notably women and pregnant women.

To increase sex and gender integration in the health and biomedical research funding and regulation in the UK must advocate for mandatory inclusion of sex and gender analysis plans on application forms, resources to train and educate applicants, funders and evaluators, and reward proposals that engage deeply with sex and gender analysis.

Introduction

This report highlights the importance of embracing a culture of change in the design and delivery of women's health to achieve national systems and local services fit to meet the expectations and needs of the 21st century woman. It describes the many failings of health services across the world whose default position is to treat women as second-class citizens and place unnecessary barriers to the delivery of high-quality accessible care. Over the course of writing this report, discussions have been held with men, women, and girls from across the world. These conversations have shown that women are rarely trusted to be masters of their own bodies, but instead are frequently subjected to paternalistic and overly medicalised interventions.

The recommendations of this report are founded on common sense and rooted in the belief that women should be in control of their own bodies. They are the direct outcome of the concerns, suggestions and ideas generated by people we have brought together from across the world, who are determined to make their environments healthier and fairer for all.

The United Nations Sustainable Development Goals (SDGs) 2016-2030 represent a set of targets for countries across the world, designed to end poverty, protect the planet, and ensure prosperity for all. Two of the 17 SDG goals explicitly recognise the importance of girls and women, and their health, to achieving this ambitious aim.

SDG 3: to "ensure healthy lives and promote wellbeing for all at all ages", includes a commitment to "reduce the global maternal mortality ratio to less than 70 per 100,000 live births", and to "ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes."

SDG 5: - to "Achieve gender equality and empower all girls and women", again underlines the importance of sexual and reproductive health, while also including commitments to "eliminate all forms of violence against women and girls in the public and private spheres, including trafficking and sexual and other types of exploitation" and "eliminate all harmful practices, such as child, early and forced marriage and female genital mutilation." Unlike its predecessor Millennium Development Goal 3, SDG-5 calls on governments to achieve, rather than just promote, gender equality and the empowerment of all girls.²

This report builds upon the Royal College of Obstetricians and Gynaecologists (RCOG) 2019 publication *Better for Women*, which made 23 clear recommendations to policymakers on how to improve the health of women and girls.³ However, the primary aim was to encourage the creation of national strategies for women's health based on a life course approach. The emphasis was on placing women at the centre of preventative health services which are designed to address their many predictable areas of need.

The UK government's women's health strategy, due to be published in Spring 2022, offers the unique opportunity to see the evidence-based recommendations from *Better for Women* and this report, *A Women's Health Agenda* be brought to fruition.

The chapter topics of this report were selected because of the important contributions they make to women's daily lives and because historically these issues have been shrouded in taboo and stigma, frequently leading to polarised opinions and viewpoints. They also provide opportunities to redress the balance by adopting practical solutions which redirect valuable resources to areas of greatest need and reduce barriers to achieving measurable improvements in:

- Contraception
- Abortion
- Assisted conception
- Menstruation and Menopause
- Breast Cancer
- Cervical Cancer
- A Gendered Lens: Data, Research and Policy

The subjects covered within this report are by no means exhaustive nor are they

representative of every woman across the world. However, this document makes a significant contribution to the growing body of evidence which demonstrates that women's health has been disproportionately disadvantaged globally. It also draws attention to the fact that equitable health systems are more cost-effective and efficient, because healthy women are the cornerstone of healthy societies.⁴

Chapter One

CONTRACEPTION

Introduction

Contraception is the most cost-effective medical intervention in healthcare and is unique in the breadth of its positive outcomes.⁵

Increasing contraceptive use in developing countries has reduced the number of maternal deaths by nearly 40 per cent over the last three decades, simply by reducing the number of unplanned pregnancies.⁶ Yet globally, approximately 45 per cent of all pregnancies remain unplanned, and around one third of births are unplanned even in countries which have good healthcare systems.⁷

There is substantial evidence that unplanned pregnancies result in poorer health outcomes for women and their babies due to late presentations for care and an increase in obstetric complications during pregnancy, delivery and

the postnatal period, as well as an increase in postnatal depression. Unplanned pregnancy also has negative sequelae for the baby, both in utero and later in life – low birth weight, prematurity, mental health problems and lower intelligence and cognitive testing are well recognised as being associated with unplanned pregnancy.⁸

A short interval of less than six months between pregnancies is an independent risk factor for future preterm delivery and neonatal death. Poor outcomes are more likely to occur

“There is substantial evidence that unplanned pregnancies result in poorer health outcomes for women and their babies”



in women living in disadvantaged areas with lower educational achievement and poor dietary intake.⁹ As such, they are less likely to follow infant feeding advice and the cycle of poor health is transmitted to the next generation. Similarly, it is well recognised that intervals of 18 – 24 months between births affords both mother and baby significantly improved outcomes. This highlights the importance of not missing the opportunity to provide a range of contraceptive options to women immediately after delivery, compatible with breast feeding, to avoid short intervals between pregnancies.

As noted earlier, SDG-3 stresses the importance of universal access to contraception in addressing inequalities and achieving health equity worldwide.¹⁰ However, numerous barriers preventing women from accessing and benefiting from reliable contraception remain, many of which result from outdated health systems and the continuing paternalistic views of many health care professionals.

The UK's policies on contraception have been, until recent years, progressive. In 1967, contraception was made available regardless of marital status and by 1974, 1000 NHS family planning clinics were established to make contraception free and more accessible to all.

Emergency hormonal contraception (EHC) has been available since 1984 and was refined by introducing progestogen-only EHC as a pharmacy medicine.¹¹ Between 1999 and 2010 the national strategy to improve sexual health and reduce teenage pregnancy rates achieved an impressive 51 per cent fall in under 18-year-old pregnancies.¹²

Since 2005, long-acting reversible contraception (LARC) methods (intrauterine devices, implants, and injections) have been recommended by the National Institute of Health and Care Excellence (NICE). More clinically effective than pills or barrier methods, LARCs are also highly cost effective - even if the duration of use is for one year or less.

Demographic trends: Increasing demand and declining provision

Shifting global demographics and changes in social expectations are increasing demand for contraceptive services. A falling birth rate, smaller families and increase in childlessness has resulted in longer intervals during which pregnancy needs preventing. In the UK, one in five women now remain childless and the interval between first sexual relationship and first pregnancy has also lengthened, with an average of 13 years in which contraception is needed before a woman's first birth.¹³

Following the Health and Social Care Act (HSCA) of 2012, sexual and reproductive health (SRH) services in England have been subject to serious disruption due to financial cuts in public health budgets and fragmented commissioning. The transfer of family planning services to local authorities created patchy service provision and by 2020, 54 per cent of all clinics had closed and the Family Planning Association went bankrupt.¹⁴

Commissioning and governance of SRH services was split between three separate organisations, which created a postcode lottery for users, siloed working and a lack of accountability and ownership. The impact of this disruption was evidenced by a fall in the use of emergency contraception and a sharp increase in abortion rates, predominantly in older women who had completed their families and were unable to access LARCs. From 2016 to 2020, the number of abortions rose from 190,000 to over 210,000 per year in England and Wales.¹⁵ This situation was further exacerbated by the onset of the Covid-19 pandemic in 2020 which led to a fall in contraceptive service access generally and LARC usage plummet, resulting in a sharp increase in complex maternities and abortion requests after very short birth intervals. It is worrying that, as we emerge from the pandemic, the UK has cut its pledge to the UN family planning programme by 85 per cent.¹⁶

Global patterns of contraceptive use still favour user dependent methods such as male and female condoms, diaphragms and caps, spermicides and digital tools supporting natural family planning, all of which are significantly less effective than hormonal methods. Oral contraceptive pills (OCP) are the most used form of contraception and are simple to take – as a daily pill – but are still user dependant. OCPs and barrier methods still dominate over the use of LARC which are the most reliable and cost-effective method. The percentage of women of reproductive age using LARCs is estimated to be 14 per cent, mainly due to a shortage of health care professionals trained to fit implants and uterine devices.¹⁷

The combined COCP, containing both oestrogen and progestogen has been available for over 60 years and has been extensively researched. However, in the UK it is still only available on prescription from a medical practitioner, which serves as a barrier to both starting and continuing use. The progestogen only pill (POP) has fewer contraindications and associated health risks and third generation preparations that inhibit ovulation are as effective as COCPs. The POP was reclassified as an over the counter (OTC) medication in July 2021, which is a welcome development and could potentially pave the way to relaxing regulations for other contraceptive options.

Simple solutions to cut the red tape

The need for contraception does not require a diagnosis to be made since these women are not ill and do not have a disease requiring regular monitoring. They simply need a reliable method to control their fertility and avoid or postpone becoming pregnant. There are simple solutions to removing many of the barriers women face when trying to access contraceptive services.

Family planning strategies have tended to focus on younger women (under 20-year-olds), since these pregnancies are more likely

to be unplanned. However, the reality is that 77 per cent of pregnancies in women over 40 are unplanned, a group who are likely juggling work, childcare, and other family commitments.¹⁸

Recommendation: Sexual and reproductive health services must be prioritised to counter patchy healthcare service provision – and access must be made available, in and out of hours.

Despite a 60-year safety record, women are still likely to be given a three-month prescription for any form of OCPs and are told to make an appointment for a medical check-up to renew their prescriptions. Indeed, 50 per cent of all contraception appointments are for repeat prescriptions imposing unnecessary pressure on services. It is important to recognise that even for women with significant medical problems, such as raised blood pressure or poorly controlled diabetes, it is far safer to avoid an unplanned pregnancy than have a minor complication from taking their COCP.

Recommendation: NICE should re-examine guidelines that recommend routine appointments for oral contraception users – with a view to limiting unnecessary medical checks that may only serve to limit contraception access.

There are unnecessary obstacles within prescription practices throughout health systems that may limit access to contraception. For example, in the UK, current guidelines from NICE recommend that POP users have their blood pressure taken every year – a routine for which there is little clinical benefit as the risk of hypertension is negligible.¹⁹ Yet this requirement for regular checks, many of which may be unnecessary, could further limit contraception access for women and girls who are unable access timely appointments. If clinicians could be further educated and

empowered to remove such appointments, it may lead to increased contraception uptake among women and girls.

Despite being made available over the counter in pharmacies from July 2021, women still have to consult with a pharmacist to obtain the POP. If provided over the counter, the POP is not free of charge, unlike if the same medication was obtained via an NHS prescription. This raises inequalities of access and places disadvantaged women with limited income or difficulties accessing the health system at unnecessary risk of an unplanned pregnancy.

Recommendation: POPs should be made available on general sales (off the shelf) and not require consultation with a pharmacist unless the woman wishes.

There is a reported six-fold difference in teenage conception and birth rates between the poorest areas in England and the most affluent areas.²⁰ Among ethnic minority women, contraceptive use is also consistently lower.²¹ The UK government's Women's Health Strategy must focus on targeting these groups to ensure equity of access for contraception.

Emergency hormonal contraception (EHC) has been available over the counter in UK for 20 years with no evidence that it is misused or overused. Scotland and Wales have made EHC available without prescription from all pharmacies free of charge. Whereas, in England, it is often not free, making it unaffordable for many girls and women.²² A mandatory consultation with the pharmacist is required for EHC. This acts as a barrier to access. The most effective form of EC is the insertion of an intra uterine device (IUD) within five days of unprotected sex, but time delays facing women trying to access a clinic appointment for this procedure frequently makes this option impractical.²³

“There is a reported six-fold difference in teenage conception and birth rates between the poorest areas in England and the most affluent areas”

Recommendation: Those who plan and purchase healthcare must ensure provision of full range of contraception services to all women that is person centric and at all reproductive ages, with a particular focus on targeting women of low SES and minority ethnic women. This should include ensuring emergency hormonal contraception is free in 100 per cent of healthcare service provision.

LARCs are the most reliable and cost-effective methods of contraception and do not require renewal for three to five years. There are many missed opportunities for GPs, midwives, specialist nurses and gynaecologists to provide women with LARCs due to funding to provide training and fees for the provision of injectables, implants and IUD insertions not being prioritised.

LARC methods of contraception should be encouraged, but not to the exclusion of women being able to use any reliable form of contraception. Research has shown that a woman's decision as to what form of contraception she uses has less impact than her decision to use contraception in the first instance.²⁴ This means that efforts need to be focused on encouraging behaviour change of sexually active women who do not use birth control to use any reliable contraceptive method, if they do not want to become pregnant.

Recommendation: While LARC should be encouraged, the greatest impact for reducing unplanned pregnancies must focus on influencing women who use no contraception to begin using any form of reliable contraception.

The immediate post-delivery (postpartum) period is another opportunity to provide women with reliable contraception. Ideally, discussing family planning options should begin during the antenatal journey and be offered again soon after birth, so that all women can be provided with a long-acting method which is compatible with breast feeding, before they leave the health facility. Since the midwife plays the key role in continuity of care in maternity services, she is best placed to provide post-delivery contraception. However, the *State of the World's Midwifery 2021 report* points out the shortage of midwives globally and estimates a shortfall of 900,000 midwives across the world. While midwives make up less than 10 per cent of the Sexual, Reproductive, Maternal, Newborn and Adolescent Health (SRMNAH) workforce, they could provide 90 per cent of essential SRMNAH interventions across the life course.²⁵

Enabling a greater contribution by midwives in providing family planning services (especially LARC), has been a major factor in increasing the contraceptive prevalence rate in some middle and low-income countries. A study conducted in Nigeria has demonstrated that the contraceptive uptake rate has doubled in less than five years because of midwifery led contraceptive services.²⁶

Enabling midwives to provide contraceptive care, by designing e-learning tools and practical sessions to master LARC insertion requires protected time for training, upskilling and continued professional development. Rather than contraceptive services being viewed as an additional task for midwives to undertake, it should be considered an extension of their current role and an opportunity for career development which provides them with further autonomy in delivering maternity care. Better



links between midwifery and specialist sexual and reproductive health services need to be encouraged.

Recommendation: Post birth contraception must become an integrated part of maternity services and funded appropriately. Women should be routinely offered a choice of contraception post delivery and given information about the importance of birth spacing to improve their health and that of their baby/family.

CASE STUDY

UNFPA: The Family Health House Model

As sited from the Mid-Term Review, the Family Health House Model is a piloted model funded through the United Nations Population Fund (UNFPA) and aims to improve the access to reproductive and child health services in underserved districts.²⁷ Through the implementation of mobile support teams, containing trained healthcare staff, the aim is to reduce morbidity and mortality, as well as improving quality of life. This coincides with UNFPA global strategy to enhance women's rights and empowerment, especially within these deeply deprived locations.

An outline of services

- Each Family Health House, known as the Ashiana-e-Sehi, covers a population of 1,500-3,000 and holds a trained midwife and effective referral system to Basic Package of Health Services (BPHS) facilities
- Health posts connect the members of the community to the Family Health Houses through provision of more basic health services

- Family Health Action Groups contain a handful of female volunteers that promote good healthcare within their communities, as well as encouraging others to use the Family Health House
- As well as female volunteers, each community develops a Health Shura. This is an assemble of leaders and spokespeople that delivery public health procedures and enforce guidelines

From the outlined project, 95 per cent of community midwives that completed their community midwifery education remain within their communities. Although there is more work to be done to reduce the political impacts on women's health and liberties, the Family Health House Model reflects how crucial communities are within improving national healthcare systems. Not only does it encourage further education for women through the midwifery training, but it also provides services to rural areas that would have been unable to reach them previously.

MARIE STOPES KENYA: IMPROVING ACCESS TO CONTRACEPTION FOR UNDERSERVED WOMEN IN KENYA

Marie Stopes Kenya (MSK) is a leading specialized Sexual and Reproductive Health (SRH) and Family Planning (FP) organization in Kenya and aims at expanding healthcare equity focusing on increasing access to and uptake of SRH/ FP services among the underserved populations including youth, people with disability, rural populations, and the urban poor.

The problem

According to a MSK client exist survey in 2020, 63 per cent of high impact clients don't have access to modern contraceptive and post abortion care (PAC) services at government public facilities.²⁸ The high impact clients at MSK include:

- Women living on less than \$1.25 per day
- FP Adopters
- Clients under 20 years of age
- Those who would not otherwise have access to FP

The solution

MSK has crafted a model called Public Sector Strengthening (PSS) with the aim of providing affordable and quality assured FP and PAC services to high impact clients by strengthening the health system.

PSS can be implemented across each of the four high impact clients outlined.

- Women on less than \$1.25 per day: To ensure lower income earners can access SRH services, PSS services should be free, unless government regulations require otherwise. By giving couples the choice over their fertility, they can better care for their children to help break out of the cycle of poverty
- Adopters: By targeting clients not currently using modern contraception, this can help to reach the MSI goal: to ensure one in four women have their demand for contraception met by 2030.²⁹ Providing first time users with a quality client experience at PSS sites will encourage them to continue to use FP, and potentially become advocates within their community

- Adolescents: For those under 20 years of age, there is a considerable unmet need for SRH services, particularly in the rural areas. As such, PSS has a key role to play in reducing this unmet need
- Those without access to FP: PSS adds access points for those in need of family planning, by training staff who would otherwise not have been able to offer these services

Reported via internal data sourcing, MSK has helped to increase the use of Long-Acting Reversible Contraception (LARC) from 27 per cent in 2020 to 33 per cent in 2021 among women served in public health facilities.³⁰ This shift to long-acting methods is likely to reduced discontinuation rates and may better meet women's needs in the public health facilities in Kenya.

POST-DELIVERY CONTRACEPTION: IMPERIAL LOCAL MATERNITY SYSTEM PILOT

Following the first UK Covid-19 lockdown in March 2020, it quickly became evident that women were unable to access contraception from their GP or community clinics after leaving the maternity facility. Women can become pregnant again within 21 days of delivery and 50 per cent of couples resume sex within six weeks of delivery.³¹ Women who are breastfeeding or have absent periods are poorly protected from conceiving again and short interpregnancy intervals (<12 months) are associated with serious obstetric complications. Since sexual and reproductive health commissioning is not integrated with maternity services, 29,000 women per year in North West London have no access to reliable contraception >

after delivery.³² The escalating costs of this oversight has been estimated at £1.6 million a year for North West London alone, despite the knowledge that the overall return on investment (ROI) for post-birth contraception is £16 for every £1 spent.³³

Since 2020, a collaborative team of midwives, obstetricians, sexual and reproductive health colleagues and commissioners have built a post-delivery contraception service by developing theoretical and practical courses for all midwives and doctors to be trained in contraception counselling and LARC fitting. All pregnant women are provided with antenatal counselling and a range of breast-feeding friendly contraception, including the progesterone-only pill, sub-dermal implants and if delivering by caesarean section, copper or levonorgestrel intra-uterine devices.

This North West London service serves as an exemplar for other regions in England to adopt and benefit from this learning curve by using similar models of care. This post birth contraception model should be rolled out nationally to assist in the levelling up required in the aftermath of the Covid-19 pandemic. Contraception plays an essential role in the health and wellbeing of women everywhere. This innovative pilot programme has demonstrated that providing new mothers with a choice of contraception including LARCs, immediately post-delivery, is highly cost-effective, protects NHS resources and is popular with women.

RECOMMENDATIONS

- Sexual and reproductive health services must be prioritised to counter patchy healthcare service provision – and access must be made available, in and out of hours.
- NICE should re-examine guidelines that recommend routine appointments for oral contraception users – with a view to limiting unnecessary medical checks that may only serve to limit contraception access.
- POPs should be made available on general sales (off the shelf) and not require consultation with a pharmacist unless the woman wishes.
- Those who plan and purchase healthcare must ensure provision of full range of contraception services to all women that is person centric and at all reproductive ages, with a particular focus on targeting women of low SES and minority ethnic women. This should include ensuring emergency hormonal contraception is free in 100 per cent of healthcare service provision.
- While LARC should be encouraged, the greatest impact for reducing unplanned pregnancies must focus on influencing women who use no contraception to begin using any form of reliable contraception.
- Post birth contraception must become an integrated part of maternity services and funded appropriately. Women should be routinely offered a choice of contraception post delivery and given information about the importance of birth spacing to improve their health and that of their baby/family.

Chapter Two

ABORTION

Introduction

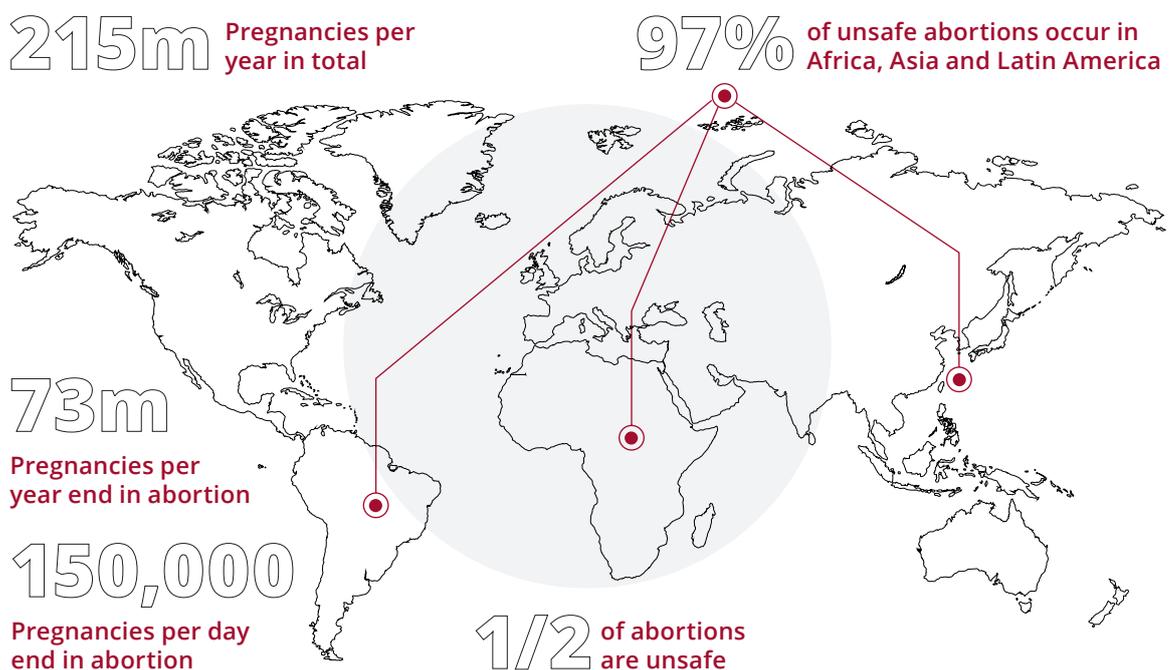
Abortion is one of the most common procedures that women of reproductive age undergo. Globally the total number of pregnancies is in the order of 215 million per year, of which 73 million end in abortion. This equates to over one in four pregnancies or 150,000 cases of abortion per day.³⁴ Nearly half of these abortions are unsafe, with complications usually developing when they are performed by untrained individuals, in unsuitable locations or via medications bought illegally.³⁵ Of these unsafe abortions, 97 per cent occur in areas of Africa, Asia, and Latin America, where restrictive abortion laws lead to unsafe abortions and maternal deaths. Unsafe abortions are sought by an estimated three million adolescent girls every year, who have no access to contraception.³⁶

Abortion accounts for 14 per cent of the global total of 303,000 maternal deaths which occur every year, which is eight women in the world dying from abortion every hour.³⁷ The figure of

14 per cent is the same as the mortality in the UK from unsafe 'backstreet' abortions prior to the introduction of the 1967 Abortion Act.³⁸ Nevertheless, it took several years following the act for mortality from abortion in the UK to reach zero for the first time. To this day, abortion remains the only procedure in UK medicine requiring two medical doctors' signatures on the consent form - which is still a criminal offence if not adhered to.

More than any other women's health issue, societal attitudes towards abortion are polarised. However, laws impact heavily on whether abortions result in serious health effects. Legal restrictions have little effect on the number of girls and women seeking an abortion, but they have a major effect on the outcome of that abortion in the health of the girl or woman.

Where abortions are carried out in countries with few or no legal restrictions, around 99.9 per cent are completed without any serious complications.³⁹ This contrasts with only 25



per cent in countries where it is illegal or where the woman must pass through barriers to obtain the procedure. Restricting access to abortion does not reduce the number of abortions, indeed the opposite is true, since the provision of abortion and contraceptive services are invariably linked. Banning abortion does not make the problem disappear it simply moves underground and becomes unsafe, leading to maternal deaths and life altering morbidities.

Countries with more progressive attitudes towards women generally have more liberal abortion laws. Nevertheless, recent world events have revealed little room for complacency and that attitudes and access to safe abortion can change rapidly. During the Covid-19 pandemic, for instance, elective abortions were banned in six European countries and suspended in one.⁴⁰ Meanwhile, in the USA where women have a constitutional right to have an abortion, numerous individual states have used Covid-19 as an excuse to ban all forms of abortion, by classifying abortion as non-essential healthcare.⁴¹

“Banning abortion does not make the problem disappear it simply moves underground and becomes unsafe leading to maternal deaths and life altering morbidities”

The Guttmacher Institute, a leading research and policy institution which is committed to advancing sexual and reproductive rights, made a prediction in April 2020 of the potential impact that Covid-19 would have on women’s SRH services in 132 low-to-middle-income countries (LMICs). They suggested that a 10 per cent disruption in essential SRH care (both the use of short and long-acting contraception and a shift in abortions from safe to unsafe) would result in a massive increase in the number of unintended pregnancies (15.5 million) unsafe abortions



(3.3 million) and maternal deaths (10,000). Recent data from Guttmacher suggest that this prediction may have been an underestimate and that the year 2021 will be remembered as “the most devastating anti-abortion year in history.”⁴²

The World Health Organisation (WHO) asserts that there is a clear and unambiguous right to normalise abortion as a public health right.⁴³ Human rights frameworks are the most effective vehicles in which to push for less restrictive abortion laws. All abortion procedures should be subject to regulatory and professional standards, in line with other medical procedures, rather than to criminal sanctions.

The introduction of telemedicine abortion

Women in England and Wales can have an early medical abortion (EMA) before the end of the 9th week of pregnancy, within a legally approved setting. In Scotland the gestational limit is less than 13 weeks. EMA involves taking two drugs, mifepristone, followed 24-48 hours later by misoprostol. Women used to be required to attend the clinical setting on two separate occasions to take their medications in the presence of the supervising health professional. This requirement was despite good evidence that there was no need for these drugs to involve face to face meetings. In 2018, it was agreed in England that women could be allowed to take the second drug misoprostol in their homes in the same way that she would be managed for an incomplete miscarriage.

Protecting NHS resources and reducing Covid-19 transmission was the catalyst for the necessary legal orders to be agreed (on a temporary basis), for both EMA drugs to be provided at home following a structured remote (telephone or video) consultation. Telemedicine early medical abortion (TM-EMA) can now be provided at home following the remote consultation with the medicines

administered to the patient from a pharmacist who dispenses the prescription provided by the qualified abortion care provider.

Telemedicine abortion is proven to be safe, effective and is preferred by women. Studies from across the world demonstrate that being able to take the abortion drugs at home is far more convenient for women. In Norway, 95 per cent of women opted to have an abortion at home, citing, ‘greater privacy’, ‘more control’ and ‘better emotional support’.⁴⁴ The method has been recommended for years by WHO, NICE and RCOG, Faculty of Sexual and Reproductive Health (FSRH) – all of whom have published clinical guidelines to aid health professionals provide safe, compassionate, high-quality care.

In the UK, the swift introduction of TM-EMA during the first wave of the pandemic in spring 2020 was extremely successful. The average waiting time for treatment was halved, resulting in the gestation at the time of the procedure falling by more than a week, thereby reducing the rate of complications which increase incrementally with each passing week of pregnancy.⁴⁴ Together these factors have meant that the need for late gestational abortions has fallen and removed additional strain on surgical services during the pandemic. Only a very small number of women require a scan or clinical examination due to uncertainty about the date of their last menstrual period or other potential complicating factors. There has been no increase in undiagnosed ectopic pregnancies and the overall rate of abortion success has increased.⁴⁶

There is no clinical reason for a woman to need to attend a clinic for a routine follow up after an abortion. Instead, advice should be provided so that she understands when, how and why she might need to seek medical attention. The outcome of an early medical abortion can be self-assessed at home, with low sensitivity pregnancy tests being suitable for use.

“There is no clinical reason for a woman to need to attend a clinic for a routine follow up after an abortion”

The implications of telemedicine abortion for women are significant. Patient satisfaction rates with the service are high, exceeding 83 per cent.⁴⁷ Women can receive this healthcare in the comfort of their own home, providing them with privacy and obviating the need to make long journeys, take time off work and arrange childcare. For women in vulnerable situations, safeguarding has improved since women no longer have to risk being seen entering a clinic and can communicate with the trained provider confidentially. Furthermore, the illicit sourcing of abortion drugs from the internet has melted away and cost savings for the health service associated with the TM model of care.^{48 49}

Currently in the UK, only a fully trained abortion provider (usually a doctor) can administer telemedicine abortion. Global data demonstrates that TM-EMA can be safely delivered by appropriately trained health care providers such as nurses, midwives or pharmacists and it is hoped this would be the next logical step to long term improvements in abortion care.

Despite the unprecedented success of telemedicine abortion during the pandemic, in February 2022, the UK government made the decision to scrap the scheme by the end of September 2022. While being kept under review, this decision was criticised by several senior organisations including the Royal College of Obstetricians and Gynaecologists, the British Medical Association and the Royal College of Midwives.

Recommendation: To further increase access to telemedicine abortion, health providers should enable a greater number of staff to undertake telemedicine abortion and prescribe the medications – this should include enabling training nurses and pharmacists to undertake the clinical consultation.

Recommendation: Post-abortion care can be self-managed by the woman and this should be advocated for within local sexual and reproductive health services.

Recommendation: Access to telemedicine should be enhanced and obstacles to access removed wherever possible. This should include removing the need for women to have a routine scan within a clinical setting in order to qualify for a telemedicine abortion.

MSI REPRODUCTIVE CHOICES

The Telemedicine Abortion Service: giving women choice during the Covid-19 pandemic

MSI Reproductive Choices (MSI) is one of the world’s largest providers of sexual and reproductive health services. They are advocates for gender equality and reproductive choice, working work in 37 countries as a key partner to ministries of health, private providers, and civil society organisations. By the end of 2021, over 34 million women globally were using a form of contraception supplied by MSI, as estimated by the MSI Impact 2.5 model.⁵⁰

Before the pandemic, 60 per cent of pregnancies in South Africa were unintended, and 52-58 per cent of abortions were unsafe. Covid-19 also led to the implementation of domestic travel restrictions, with public transport only

available between 6am-9am and 4pm-7pm. Citizens would require a permit to leave the house and were forced to attend the clinics alone, limiting their support network and safe travel. The Early Medical Abortion at Home (telemedicine) service was permitted in South Africa and the UK during the pandemic to address all the following challenges of accessing abortion.⁵¹

The Problems

- **The over-medicalisation of abortion, and ineffective use of resources.**
There is no clinical reason why everyone seeking an abortion must have a scan. This is a poor use of pressurised resources, an unnecessary intrusion, and within the UK context, an addition to already lengthy NHS waiting times.
- **The access barriers, especially for the most marginalised.**
There are people who need or want an abortion but cannot safely or easily get to a clinic in person, such as disabled women, women in abusive relationships, and young girls living with abusive families. Consequently, safe, legal abortion services become inaccessible to those who need them most urgently, resulting in people ordering unregulated medicines online.
- **The lack of privacy and dignity.**
Visiting an abortion clinic can be a stressful experience, with anti-abortion groups circulating outside some clinics. This is not only intimidating and guilt-provoking but can also be retraumatising for women that have experienced sexual violence or domestic abuse.

THE BENEFITS OF TELEMEDICINE

Telemedicine offers a solution to each one of these problems and is one of the many pandemic-resilient services that should remain available henceforth. It removes the barriers for those unable to travel to a clinic and allows clients to start on the MSI pathway once deemed clinically appropriate by a fully trained health advisor. This would allow them to end their pregnancy safely at home, in a more private and dignified setting. Ultimately, telemedicine gives women control. The limited procedures that prevented women having autonomy and respect have been appropriately modernised, and these should be kept available for future generations.

Integrating sexual and reproductive health services

Both contraception and abortion services are essential components of women's health care and need to be offered as an integrated package by all sexual and reproductive health services.

Contraception after abortion

The Faculty of Sexual and Reproductive Health recommend that abortion services should discuss the full range of contraceptive options and ensure the woman is able to commence the method of her choice at the time of abortion or soon after.⁵² Studies show that women value the opportunity to discuss contraception during a pre-abortion assessment and that not including this advice is missing the opportunity to avoid an unplanned pregnancy.⁵³

More than 50 per cent of women will resume sexual activity within two weeks of their abortion, and one in eight women will

have given birth within a year of having an abortion.⁵⁴ Several randomised trials have demonstrated that providing contraception at this time significantly lowers the risk of another unintended pregnancy or short birth interval, thereby reducing future pregnancy complications.⁵⁵ If the desired form of contraception cannot be administered immediately, ‘bridging’ methods should be discussed and preferably provided in the home termination pack or arrangements made for the woman to have a consultation. Bridging contraception refers to contraceptive methods that can be started immediately and used until the desired form of contraception can be made available to the user. Condoms, pills and injectables are all useful bridging methods. The latest injectable subcutaneous preparations can be self-administered monthly, using prefilled syringes, and have proven to be an extremely popular option for women.

Recommendation: Abortion should become further integrated with contraception services and wider sexual and reproductive health service provision. Health providers should ensure that contraception is offered at the time of abortion if desired by the woman.

MSI REPRODUCTIVE CHOICES

Supporting self-management of medication abortion from pharmacies

In low and middle-income countries, pharmacies are often the first port-of-call for people seeking an abortion, as pharmacies are seen as easy to access, discreet and a more affordable option. Evidence shows that self-management of medical abortion is acceptable,⁵⁶ safe and effective via a pharmacy as in facility settings.⁵⁷ However, what is needed is a quality product, accurate information on

“Studies show that women value the opportunity to discuss contraception during a pre-abortion assessment”

how to self-administer the drugs and access to in-facility care, in the unlikely chance that someone faces a complication or requires follow-up care.

Evidence shows that pharmacy users do not always have access to a continuum of care.⁵⁸ For example, products are sometimes low quality, or users are given products outside of their original packaging, meaning they lack the instructions needed to administer the drugs correctly. Even when instructions are provided, if they are written in technical language, they can be difficult for low-literacy audiences to understand.

For these reasons, MSI and partners are advocating for a continuum of care to be available for all clients. To do so, it is essential to ensure quality products are accessible, in line with national laws, and that accurate information is available to clients on how to self-administer the drugs, via pictorial instructions in all product packaging and accessible digital resources.

Ensuring efforts to build awareness on medical abortion are culturally relevant

In 2018, MSI conducted a study in Zambia to evaluate whether more promotional material on medical abortion would increase contact with the MSI centre.⁵⁹ However, the study did not see an increase in contact centre use associated with the intervention. Instead, research demonstrated that although the

promotional materials were acceptable to pharmacy staff, for service users, the notion of calling a stranger on a hotline to speak about the sensitive issue was considered culturally unusual. As a result, MSI and partners developed and tested different means of communicating information directly to medical abortion users, such as user-friendly product labelling, signposting users to contact centres, and by working with national health legislature to ensure pharmacy staff and medical abortion users have access to high quality information.

The key takeaway is the importance of building up an appropriate, multi-format information infrastructure for medical abortion users to safely manage medical abortion from pharmacies.

BRITISH PREGNANCY ADVISORY SERVICE (BPAS) PILLS BY POST

The Covid-19 pandemic resulted in women unable to leave their house to access care and, with a third of BPAS clinics closed by 23rd March 2020, many urgent treatments were delayed. Immediate action was needed to restore women's autonomy, so in March 2020 BPAS led the campaign to provide evidence-based requests for telemedical abortion provisions to be implemented. Within nine days of the law being changed, Pills by Post (PBP) was launched which allowed midwives and nurses to hold virtual consultations and post medication to a woman's home address when suitable. These packages contained both mifepristone, to break down the uterine lining, and misoprostol, to expel the pregnancy tissues. >



This world-leading service led to significant reductions in abortion waiting times, gestational age and complication rates. Not only did this service obtain a 97 per cent client satisfaction rate, with 52,147 women using the service during its first year, it also set the standard of care for meeting women's needs in a time of crisis.

A cost-benefit analysis

A 2021 study estimates the change to telemedicine abortion will save the NHS over £3 million a year, through the reduced need for surgery beds, anaesthetics, and staff contact hours.⁶⁰ Moreover, no clinic visits or ultrasound scans are required with this service. BPAS have also collaborated with other organisations to provide additional women's health information and support via the Pills by Post service. Examples of this include a partnership with CoppaFeel! to deliver breast-checking guides within the Pills by Post packages, and Covid-19 vaccine factsheets addressing the false fertility rumours. There are key benefits to delivering these messages directly into women's home at a time when they are thinking about their own health.

RECOMMENDATIONS

- To further increase access to telemedicine abortion, health providers should enable a greater number of staff undertake telemedicine abortion and prescribe the medications – this should include enabling training nurses and pharmacists to undertake the clinical consultation.
- Post-abortion care can be self-managed by the woman and this should be advocated for within local sexual and reproductive health services.
- Access to telemedicine should be enhanced and obstacles to access removed wherever possible. This should include removing the need for women to have a routine scan within a clinical setting in order to qualify for a telemedicine abortion.
- Abortion should become further integrated with contraception services and wider sexual and reproductive health service provision. Health providers should ensure that contraception is offered at the time of abortion if desired by the woman.

Chapter Three

ASSISTED CONCEPTION

Introduction

The investigation and treatment of subfertility is often viewed as secondary to other reproductive health services. In 2020 the WHO stated that it “recognizes that the provision of high-quality services for family-planning, including fertility care, is one of the core elements of reproductive health.”⁶¹ Worldwide, more than 48 million people are affected by infertility, defined by the failure to achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse.⁶² Ultimately, an in-depth evaluation of the role of assisted conception as a medical issue in society is needed.

Some women are delaying childbearing until they have completed their education and established their career, a choice which was not an option for previous generations of women. The benefits to women to be financially secure and in stable relationship

before they embark on motherhood must be weighed against the impact of age on reduction in fertility.

The consequences of infertility are significant and are recognised in levels of severity. They include fear, guilt and self-blame; marital stress, helplessness and depression, marital violence and social isolation, economic deprivation and loss of social status, violence induced suicide, starvation and disease. In some cultures, women are not accepted by society unless they have at least one living child.⁶³

“The benefits to women to be financially secure and in stable relationship before they embark on motherhood must be weighed against the impact of age on reduction in fertility”

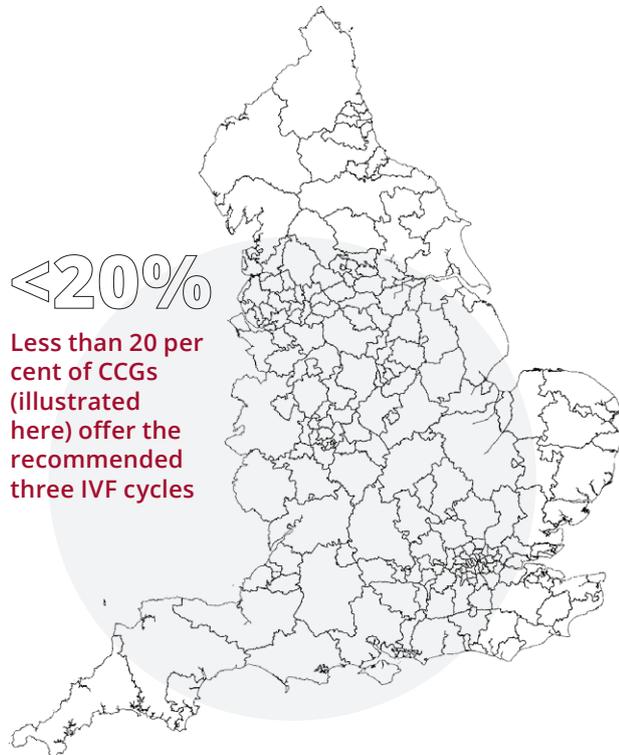


Regulating a commercialised field of medicine

In 1978, Louise Brown, the first live child following In vitro fertilization (IVF) was born. Despite this global landmark of scientific innovation and achievement, the UK can no longer be considered as the best place for those with subfertility problems to seek help. Fertility treatment is offered on the NHS but is devolved to clinical commissioning groups (CCGs) whose service provision depends on geographical location. As a result, whether a woman can undergo fertility treatment and have access to IVF services depends upon the area in which they live – a trend often referred to as a ‘postcode lottery’.

In the UK, NICE recommends three full cycles of IVF should be provided by the NHS. NICE guidelines have proven three cycles to be the most cost efficient and effective number.⁶⁴ Currently, less than 20 per cent of CCGs are offering the recommended three cycles, with some areas offering no fertility treatment at all.⁶⁵ CCGs often redefine the guidelines, and provision can depend on localised CCG policies, such as not having any children already (irrespective whether those children live with the women or couple, or if, for example, the male partner has a child from another relationship), being a healthy weight, not smoking and falling into a certain age range (for example, some CCGs only fund treatment for women under 35).⁶⁶

Recommendation: Access to fertility treatment should be determined based on need, not by geographical location. Disparities in funding levels between different CCGs and soon to be integrated care systems must be addressed so that women are able to access the recommended three cycles of IVF treatment from anywhere in the country.



The lack of fertility provision, a problem affecting many countries across the world, has helped to fuel a booming private industry for fertility treatment. In 2018, the UK assisted conception market was valued at nearly £400 million with one cycle of IVF costing upwards of £5000.⁶⁷

The WHO recognises infertility as a reproductive disease and recommends that infertility treatment be viewed as an integral part of healthcare. Private fertility patients are often offered ‘add ons’ – optional treatments that claim to be effective in improving chances of live birth. The Human Fertilisation & Embryology Authority (the UK regulator for IVF, artificial insemination, and the storage of human eggs, sperm and embryos) has created a list of traffic light ratings list for add-ons. Each colour denotes whether a treatment has been subject to trials and evidence that improve chances of live birth. Not one of the treatments listed has scored higher than amber.⁶⁸ Add-ons can be extremely costly, and these charges are levied on top of standard infertility treatment costs.

Individuals that are desperate to have a child are extremely vulnerable and many find that they are prepared to do or pay anything to realise their dream of becoming parents. When given a shopping list of costly add-ons, many find themselves going to extraordinary lengths to raise the necessary funds, only to find that their hopes are never realised. The emotional burden of infertility is significant and the responsibility for this disorder usually sits on the shoulders of women.

Recommendation: Those going through fertility treatment must be provided with far clearer information and assisted conception ‘add-ons’ must be regulated with patients clearly informed when treatment options are not fully evidence based.

MAKING LOW-COST IVF A REALITY

The British Pregnancy Advisory Service (BPAS) is an independent healthcare charity that delivers pregnancy counselling, abortion care, miscarriage management, contraception and testing for sexually transmitted infections. Taking care of 100,000 women each year in over 60 reproductive healthcare clinics nationwide, BPAS works to empower people to gain control over their own reproductive decisions.⁶⁹

Parallels: fertility services today and abortion care in 1967

Despite abortion being illegalised in 1967, access remained difficult, and women were frequently forced to privately fund their abortions for lack of NHS provision. BPAS has provided women with a not-for-profit, high-quality alternative in the absence of NHS-funded services (while simultaneously campaigning for the right of all women to

“The emotional burden of infertility is significant and the responsibility for this disorder usually sits on the shoulders of women”

access funded care) since their founding. Undisclosed add-on costs are a frequent issue for self-funded IVF patients, as a survey in 2020 uncovered only 37 per cent of respondents had no hidden fees.⁷⁰ To combat this, treatment prices at BPAS are completely transparent (£3,500 for one IVF cycle) and the service does not offer non-evidence based add-ons that do not benefit treatment.

The opportunity area to address

More women are trying to conceive outside of the natural fertility bracket, due to societal changes such as career progression, job stability and house prices. There is also an increasing want for single people and LGBT+ groups hoping to conceive through fertility treatment. The current fertility care provision does not only leave behind these groups but forces self-funded care onto those most in need. Current guidelines in some areas have a patient cut-off point as low as 35 years, while others have been denied care due to their partner having a child from a previous relationship. This lack of consistency to NHS-funded care forces those that can afford to pay turning to private routes, and those that cannot afford this are left without options. Privately funded care is frequently reported to lack full disclosure, with offered add-on treatments providing additional costs but with little evidence for success. >

BPAS aims to fight against the IVF postcode lottery, challenge unfair practises in the private sector, and contest discriminatory policies that disadvantage patients due to their sexual orientation. While the ultimate goal is for fertility treatment to become free for all, BPAS presents a novel opportunity to the assisted conception sector, and this equal-opportunities framework should be replicated elsewhere.

HFEA: HUMAN FERTILISATION & EMBRYOLOGY AUTHORITY

High quality care for everyone needing fertility treatment

The HFEA (Human Fertilisation & Embryology Authority) are the UK's independent regulator of fertility treatment and research using human embryos. Predominantly focused on the licensing and monitoring of fertility clinics, the HFEA aim to ensure that everyone entering a fertility clinic, and those born as a result of treatment, receives high quality care.⁷¹

Fertility treatment options vary on a case-by-case basis, and the HFEA provides impartial information giving people the autonomy to make their own, informed decision. Examples of areas included are LGBT+ couples/individuals, women over 38, single women, people with genetic diseases and donors.⁷² In an increasingly commercial fertility market, the HFEA also provides impartial advice on treatment add-ons, to help patients navigate the complex choices they now face.⁷³

The HFEA also provides guidance when considering fertility treatment options

abroad. The guidance highlights the ethical and legal issues of fertility tourism in countries where treatment is unregulated. The HFEA maintains a register of all licenced treatment undertaken in the UK, so donor-conceived individuals can find out identifiable information about their donor when they are 18. In contrast, donation in many countries is anonymous, denying children the right to access information about their genetic origins. It also means moving away from support systems, which can have a psychological effect on individuals and there may be greater risks of multiple pregnancies which increases the overall pregnancy risk.

A scalable initiative

After Costa Rica became the last country to lift their ban on IVF treatment in 2017, there is now a push to make fertility treatments more widely accessible and to remove the restrictions placed on single women and LGBT+ couples around the world.⁷⁴ Providing equal treatment options not only across the UK, but globally and in a way that can be understood by all, is a priority on the women's health agenda. The HFEA offers a model that could be replicated around the world.

New genomics and reproductive health: battling inequity of access

The ability to detect genetic change has transformed care for people with genetic diseases or who might benefit from personalised medicine. Equitable and fair access to the benefits of genomic tests is a key deliverable of the NHS Long Term Plan, which highlighted the need for more precision medicine for cancer, as well as the power of diagnostic DNA sequencing for rare diseases. The NHS has led the world

in access to Whole Genome Screening, which is capable of examining single letters of the genetic code. Recently made available for urgent prenatal tests on foetuses and sick newborns, it has already benefited large numbers of families in the UK.

For women with foetal abnormalities or babies suspected to have rare diseases, access to testing, choice, expert advice and support are all available. The situation is very different for women on fertility journeys who are desperately trying to conceive. Reproductive genomics remains a subgroup of the 'Rare Disease' framework and has no infrastructure, strategy or robust regulation of its own.

The NHS provides pre-implantation genetic testing (PGT) for couples who are at risk of transmitting serious genetic conditions. The development of PGT-M (monogenic or single gene faults) and PGT-SR (larger gene changes) has been a huge success in fertility care. Pre-

implantation testing allows for the selection of embryos free from disease, an option which is now available for those who choose it. benefit.

Eligible parents benefit from access to specialised and expert counselling about PGT-M and SR, but provision is dependent on postcode and only if the local healthcare team are aware of the service. Couples who have a child with a rare disease may be unaware that NHS-funded PGT exists and some parents endure further losses, childhood disability or undergo repeated prenatal testing in order to terminate an affected foetus. Waiting lists are lengthy, with the only NHS-commissioned service based in London. Review of NHS PGT provision has been delayed by the pandemic but is urgently needed to ensure eligible couples have access to reproductive choice.

Commercial providers also provide PGT services and many eligible couples endure financial hardship to prioritise their treatment.



Fertility patients have unlimited access to embryo genetic testing if they can afford it and private IVF clinics may promote PGT-Screening (PGT-S: also referred to as PGT-Aneuploidy – PGT-A) of embryos for previously unsuspected problems, such as Down syndrome. Research suggests that overall clinical pregnancy rates are not improved by PGT-S and there is concern that healthy embryos may be discarded in the process. Testing for a known disease, as in PGT-M/SR, is very different from blind screening of the entire genetic code (PGT-S). Embryonic genetic variation may not translate into human disease and many developmental pathways are still poorly understood. The Human Fertilisation and Embryology Authority (HFEA) issued updated guidance about expensive optional add-on fertility treatments in 20203 – their traffic light summary placed PGT-S in the red category, ‘no evidence of benefit’, and do not recommend it.

Despite this guidance, self-pay PGT-S/A is growing rapidly in the UK with virtually all of the private clinics offering this option, despite the potential for harm raised by many experts. Some embryos are genetic mosaics – mixtures of healthy and abnormal cells and cells of uncertain significance. Many such embryos will be present in healthy couples and will produce healthy children. Mosaic embryos are categorised as safe to use according to criteria used by the industry, but there is limited literature and no national agreement as to best practice. Couples may be asked to choose between embryos and despite apparently healthy resulting pregnancies, worries may persist. These are important issues which need regulation and expert consensus – but in the absence of either, an industry has been created and vulnerable fertility patients are treated as consumers, forced to navigate their own way through a series of heavily marketed interventions. No data is available on PGT-S uptake within the private sector, a gap which should be urgently addressed.

“The current system has facilitated inequity and has unintentionally resulted in fertility patients being treated as consumers and not patients”

These are issues with global reach. Genetic disease is one of the largest contributors to pregnancy loss, childhood disability and death, while fertility concerns affect millions of women across the world. The current system has facilitated inequity and has unintentionally resulted in fertility patients being treated as consumers and not patients. The UK can, and should, lead the way with robust regulation of reproductive genomic services and the implementation of best practice guidance.

Recommendation: The reproductive genomics sector must be subject to greater structure and regulation – women should receive independent advice about their options from genomic experts before they are referred to commercial providers.

Recommendation: A large proportion of the genomics of women’s fertility lies outside of existing NHSE and PHE governance structures. This should be addressed as a priority by ensuring it is brought into the remit of existing structures.

VERITY: EDUCATING, SUPPORTING, AND EMPOWERING WOMEN WITH POLYCYSTIC OVARIAN SYNDROME

Verity is the only national charity for women with polycystic ovarian syndrome (PCOS) and is run completely by volunteers, with no statutory funding. They provide information verified by medical professionals in line with international guidelines, local support groups for peer support and an online forum of peer support.

PCOS is a common condition, with symptoms affecting the ovaries. It affects about one in 10 women in the UK, causing irregular periods, excess androgen, and follicle growth. This can also present with reduced fertility in 70-80 per cent of those affected, which can be distressing for couples trying to conceive.⁷⁵ Medication is available for women with PCOS trying to conceive, which usually proves to be successful, but IVF can also be available if criteria are met.

The Problems: IVF and the postcode lottery

The restrictive IVF policies in place make assisted conception a postcode lottery of care, with Clinical Commissioning Groups' (CCGs) policies deciding their own funding for the treatment. This has resulted in less than one in five CCGs offering the full number of NICE-recommended cycles, according to an investigation by Fertility Fairness.⁷⁶ Moreover, couples struggling with infertility in the Vale of York are denied IVF treatment altogether, reflecting the ongoing inequality in healthcare across the UK.

The Verity solution: advocacy, access, and control for women

Improving the understanding of conditions such as PCOS within the medical profession can help to minimise delays in diagnosis and, therefore, improve quality of care. Enforcing a national guidance on fertility treatment would eliminate the location bias and, in turn, improve the access to treatment, such as IVF for all.

Verity challenges the negative stereotypes surrounding female health and fertility. There remain misconceptions surrounding IVF and fertility services within many cultures, as well as a stigma for being childless. Through their work with women suffering from PCOS,

Verity holds open conversations regarding fertility treatments and awareness events to challenge the status quo.

This approach to tackling location-based health inequalities can set a precedent for all fields of medical care facing inequity. The mass privatisation of IVF is a step backwards in national inequity progression, and widespread guidelines would aid access to treatments uniformly across the UK. Verity continues to improve the lives of women with PCOS in the UK, but a global initiative is required to see an improvement in overall statistics.

RECOMMENDATIONS

- Access to fertility treatment should be determined based on need, not by geographical location. Disparities in funding levels between different CCGs and soon-to-be integrated care systems must be addressed so that women are able to access the recommended three cycles of IVF treatment from anywhere in the country.
- Those going through fertility treatment must be provided with far clearer information and assisted conception 'add-ons' must be regulated, with patients clearly informed when treatment options are not fully evidence based.
- The reproductive genomics sector must be subject to greater structure and regulation – women should receive independent advice about their options from genomic experts before they are referred to commercial providers.
- A large proportion of the genomics of women's fertility lies outside of existing NHSE and PHE governance structures. This should be addressed as a priority by ensuring it is brought into the remit of existing structures.

Chapter Four

THE INEVITABILITY OF WOMANHOOD: MENSTRUATION AND MENOPAUSE

Introduction

Most women will have a menstrual period each month for approximately 30 to 40 years of their lives, following which they usually enter the menopause between the ages of 45 and 55 years. Despite the predictable timing and the reproductive importance in a woman's life course, menstruation and menopause remain taboo subjects in households, communities and workplaces globally. In some societies the inevitability of womanhood is a source of shame, discrimination, ridicule and exclusion for girls and women.

Education and open discussion about 'what is normal' and 'what girls and women should be prepared to deal with' needs to become commonplace within schools, homes and workplaces for both menstruation and the menopause. Girls and women need to be given the information and confidence needed to seek advice about common problems such as

heavy menstrual bleeding, menstrual and non-menstrual pelvic pain, irregular bleeding, and the symptoms of menopause.

In recent years, increased societal awareness of gender imbalances has started to address the widespread problem of predictable women's health issues being ignored or trivialised. It is crucial that policymakers respond to the public appetite and growing momentum to recognise menstruation and menopause as inevitable milestones in women's lives. They should not need to become disorders or illnesses that damage a woman's mental and physical wellbeing and quality of life before they attract attention or qualify women for help from health services.

Recommendation 21 of the RCOG's 2019 report *Better for Women* argues that "Women's health issues should be embedded in school and workplace policy and processes."⁷⁷ Access to clear information and education about



menstruation and menopause are key to ensuring this recommendation is fulfilled in all schools and working environments. This will ensure that girls and women can participate fully within society and reach their potential. This ambitious but achievable target will be dependent upon harnessing both political will and the engagement of a broad range of agencies.

Menstrual Health

An article published two decades ago described menstruation as an anomaly in modern medicine, with respect to how little interest it generated from the medical and scientific establishment. The authors wrote “there can be no other disease or condition that affects so many people on such a regular basis with consequences, at both the individual and societal level, which is not prioritised in some way by health professionals or policy makers.”⁷⁸

The stark reality is that governments have failed to prioritise menstruation, either as an individual health or wider societal issue, even though at this moment in time 800 million women and girls across the world are having a menstrual period.⁷⁹ Heavy menstrual bleeding (HMB) and menstrual pain are two of the most common reasons for referral to gynaecology clinics, and may be an indicator of underlying conditions that require further medical or surgical treatment. Given that half of the world’s population menstruates, it is absolutely vital that menstrual health pathways are optimised to the fullest extent.

Within the UK, nearly two million girls miss school because of their periods.⁸⁰ Women make up 51 per cent of the population and play a vital role in the UK’s workforce and productivity. However, 40 per cent of women feel unable to perform all their regular domestic or workplace activities at menstrual period time.⁸¹ In the UK, heavy and painful periods account for nearly six million sick days a year, costing the British

economy over £530 million.⁸² It is not difficult to make the business case for investing in adequate menstrual health services, improving access to period products and increasing employers’ awareness and practical support for their female workforce. This is a considerably cheaper option when compared to the cost of ignoring soluble problems.

There is a growing movement to provide all adolescent girls and women with access to safe hygienic menstrual management to ensure their menstrual health. However, menstrual health services have been particularly hard hit by the Covid-19 pandemic and resultant delays to care.

Menstrual equity - access to menstrual hygiene products

Lack of access to menstrual period products is a global problem. It is estimated that 500 million adolescent girls and women of reproductive age (one in four) do not have the resources

500m(est)

It is estimated that 500 million adolescent girls and women of reproductive age do not have the resources to manage their periods



they need to manage their periods.⁸³ Evidence from low-, middle- and high-income countries indicates that schoolgirls, displaced girls and women, and women in the workplace, face significant menstrual related challenges including stigma, insufficient education, limited access to menstrual materials, toilets with water, mechanisms for disposal of used materials, or privacy. Sadly, these disparities have been further exacerbated by disruption faced by health providers from the Covid-19 pandemic.⁸⁴

In 2018, the Scottish government embarked on a three-year campaign to “end period poverty” – addressing the problem of girls missing school every month because they cannot afford to buy menstrual products. By November 2020, Scotland had become the first country in the world to make free menstrual products available in every school, college, university and public building.⁸⁵ The Scottish parliament voted unanimously to support the Free Provision Bill, which makes it a legal duty for local authorities to ensure period products are available to “anyone who needs them.”⁸⁶ They have also recently launched PickupMyPeriod, an app used to locate free sanitary towels.⁸⁷

Between 2015 and 2021, the UK government distributed over £90 million of funding to charitable organisations supporting women and girls, with these groups including women’s refugee organisations and domestic abuse charities. Funding was diverted from the five per cent VAT levied on period products by EU law. This so-called “tampon tax” was abolished in early 2021, which marked the first tax cut since Brexit and the central fund was then closed.⁸⁸ Although the tax cut will benefit some users, as with most VAT reductions it is wealthier individuals who stand to gain the most.⁸⁹ Further, the government has yet to illustrate what will replace the charitable funding previously generated from the “tampon tax” (which raised £15 million from 2015 to 2021⁹⁰). Girls and women who were previously reliant

on this government support for women’s health charities may suffer the consequences if alternative funding is not found.

Recommendation: The UK government must promote menstrual equity by ensuring that girls and women of reproductive age have access to adequate menstrual hygiene – basic facilities and products.

Recommendation: Menstrual period products should become free in England, thereby following the framework set by Scotland’s successful campaign to “end period poverty”.

Recommendation: The UK government “tampon tax” relief fund should be replaced with another women’s health relief fund, ensuring that organisations previously reliant on this funding remain supported.

Education, access to accurate information and use of appropriate language

Breaking down taboos about menstruation includes educating school children (boys and girls), their parents and communities about this normal physiological process. The school curriculum needs to include clear descriptions of the male and female reproductive organs and body parts, and encourage parents to do the same and avoid ambiguity and using confused terminology. Girls need help to understand what they are likely to experience during their monthly period and to be offered some parameters against which they can assess whether their own periods are “normal” or “abnormal”.

Providing girls with advice in terms of the type and length of the bleeding and the degree of pain or discomfort they should expect or are likely to experience, will help them decide when they may need to seek help. It is never too early to discuss with girls the importance of healthy lifestyles (obesity, exercise, smoking, alcohol, recreational

drugs, respectful sexual relationships) and their potential impacts in determining future health. A variety of high-quality information for both women and healthcare professionals about menstrual health and the management of menstrual disorders (HMB, fibroids and endometriosis) are readily available. Good examples include the RCOG's Green-top Guidelines, the NICE guidelines on Heavy Menstrual Bleeding and the RCGP's Menstrual Wellbeing Toolkit.

Menstrual health issues are often referred to within clinical settings as "benign" medical problems, a term that is often inadequate in reflecting the chronic and often debilitating nature of menstrual issues - as well as their potential impact on society. While menstrual problems may not always be malignant or life threatening, they are frequently life altering and disabling. Waiting lists for girls and women with non-malignant gynaecological problems have always tended to be lengthy but the Covid-19 pandemic has worsened this situation. Although there have been no recent medical treatment innovations for menstrual problems, there are a range of treatment options that girls and young women should be able to access care to combat heavy bleeding and pain. If they are not responsive to these initial measures, it is reasonable to request a referral for specialist advice since the problems are likely to recur every month and will interfere progressively with the woman's ability to undertake her daily life.

The term "period poverty" has been used over the last decade to describe the situation of girls and women who are unable to access menstrual products because of financial hardships. However, more recent public opinion has suggested that the term is outdated and should be replaced. Some young women consider that referring to their financial difficulties accessing period products as a form of "poverty", and the association of this word with "food poverty", is unhelpful.

"While menstrual problems may not always be malignant or life threatening, they are frequently life altering and disabling"

They argue that it risks further isolating those girls and women who feel ashamed and stigmatised by not being able to afford period products.

Recommendation: Governments must place greater priority upon menstrual health within educational settings, encouraging dialogue with boys and girls of all ages to break down historical taboos. Building on this enhanced knowledge and understanding of menstrual health, educators, clinicians and policy makers should move away from outdated terminology with regards to menstrual health.

Recommendation: Each interaction women and girls have with healthcare systems should be used as an opportunity by clinicians to understand how menstrual health is impacting their lives. Health providers must receive greater support to engage in dialogue around women's health and be supported by a comprehensive data infrastructure that records comments and scales best practice.

Menopause

As global life expectancy increases, there will be over one billion post-menopausal women in the world (12 per cent of the total population) by 2025.⁹¹ When women enter the menopause, they stop having menstrual periods and are no longer able to become pregnant naturally. This transition usually occurs between 45 and 55 years of age, although about one per cent of women experience an earlier (premature) menopause, at or before 40 years, which is known as Premature Ovarian Failure (POI).

For the first time in history, many women will now be living for an equal or longer period of time in the menopausal state, as they spent in the reproductive stage of their life course. This is one reason why policy makers must ensure that women have the best possible information and advice about how to manage the menopause and optimise their general health in later life. However, the menopause remains a taboo subject which often prevents women from discussing the problems they are experiencing with their family, friends or work colleagues.

In the UK, the average age of menopause for women is 51 years, but despite the inevitability of reaching this milestone, many women have no idea what to expect during the menopause and feel both distressed by, and unprepared, for the experience. Common symptoms of the

menopause affect about half of all women at the menopause and include hot flushes and night sweats, joint and muscle pains, low mood, poor sleep patterns, problems with memory, reduced sex drive and vaginal dryness.⁹² These symptoms are particularly challenging for the 25 per cent of menopausal women who experience severe menopausal symptoms, which are potentially avoidable and may lead to the earlier onset of future health problems such as cardiovascular disease, osteoporosis and dementia.

Despite there being a range of treatments and lifestyle advice to combat these symptoms, which arise from low levels of the hormone oestrogen, many women struggle to disclose how menopausal symptoms are affecting the quality of their lives, both physically and mentally. This is due to embarrassment or lack of support, both at home and in the workplace.



Hormone replacement therapy – busting the myths

Integral to helping women manage their own health, stay at work and prevent future health problems is access to appropriate medication and support. About one million women in the UK currently use hormone replacement therapy (HRT), the most commonly prescribed treatment for the symptoms of ovarian failure, and one which offers many benefits, from improving quality of life to protection from bone loss and fragility fractures.⁹³

However, a generation of women lost the opportunity of improved quality of life due to a series of reports in the early 2000s about the safety of HRT. In 2002, the Women's Health Initiative (WHI) reported an increased risk of breast cancer and cardiovascular disease in menopausal women using HRT, which heightened hesitancy around the treatment amongst women and doctors. As a result, HRT prescriptions fell by 50 per cent in many countries, including the UK and US.⁹⁴ A by-product of this trend was soaring demand for unregulated products, the market for which is now worth over \$30 billion a year.⁹⁵

Worldwide, the major causes of death for women after menopause are cardiovascular (coronary heart disease (CHD)) and the complications of osteoporosis and dementia. However, the 1998 Heart and Estrogen/progestin Replacement Study (HERS) found many confounding issues which cast serious doubt on the published conclusions. The mean age of women participating in the study was 63 years (ten years above the average age of women taking HRT). Many of the women recruited had additional risk factors for CHD and more than 20 per cent of participants were above 70 years of age.⁹⁶ Reanalysis of the HERS study data in those women aged 60 years or less, shows that HRT does not cause harm, and indeed offers beneficial effects, including reduced cardiovascular mortality and morbidity.⁹⁷

The results of the WHI study confirmed an increased risk of breast cancer, although there was no increase in breast cancer mortality. As the graph below shows, the risk factors for breast cancer including obesity, alcoholism and smoking put the risk of breast cancer and HRT into perspective. In 2013, it was reported that 92,000 women may have died prematurely because they had not received hormone therapy in the United States.⁹⁸

A comparison of lifestyle risk factors versus Hormone Replacement Therapy (HRT) treatment

Difference in breast cancer incidence per 1,000 women aged 50-59. Approximate number of women developing breast cancer over the next five years.

23 cases of breast cancer diagnosed in the UK general population



An additional four cases in women on combined hormone replacement therapy (HRT)



Four fewer cases in women on oestrogen only Hormone Replacement Therapy (HRT)



An additional four cases in women on combined hormonal contraceptives (the pill)



An additional five cases in women who drink 2 or more units of alcohol per day



Three additional cases in women who are smokers



An additional 24 cases in women who are overweight or obese (BMI equal or greater than 30)



Seven fewer cases in women who take at least 2.5 hours moderate exercise per week



(Original Source: Women's Health Concern)

Misinformation has created confusion among women and clinicians alike: one third of women are not made aware of HRT when they first present with menopause symptoms to health professionals. Of concern is the fact that women of lower socioeconomic status are less likely to receive HRT. Studies have demonstrated that

the overall prescribing rate for HRT was 29 per cent lower in primary care settings from the most deprived quintiles.⁹⁹

Menopausal women need to be presented with the evidence with which they can weigh up the risks and benefits of taking HRT and make individual decisions about their menopause management. An editorial published in the *British Medical Journal* in October 2019, by the RCOG's President, Vice President and Chair of the Womens Network makes the following point:

"We all have a role in empowering women to make the best choices for their health by providing high quality, unbiased evidence and supporting them to make decisions...After decades of misinformation and scaremongering headlines focusing on side effects of hormone treatment, we must all work together to avoid another damaging setback in women's health. We need to treat individual women, not statistics."¹⁰⁰

Recommendation: Policymakers must continue to support the health sector in supporting campaigns that end misinformation around HRT. Women should be presented with the risk and offered HRT consistently in order to make the decision themselves. There needs to be a specific focus on targeting women of low SES.

THE MENOPAUSE CHARITY: AN EFFECTIVE CASCADE

How awareness of menopausal symptoms can increase uptake of cancer screening

The Menopause Charity provides evidence-based information and advice on the menopause, with individual case studies and expert knowledge to allow women to understand more about this inevitable

stage in their lives. The key focus is to normalise vaginal health awareness through education platforms and increase communication between services to support these common issues.¹⁰¹

Addressing the solutions as a case study: A smear test review

A 55-year-old woman attended a smear test with a nurse. She had been putting it off due to fear of discomfort and the procedure could not go ahead as the speculum was intolerable (a medical device used to separate the vaginal walls). After arranging a consultation and receiving a leaflet on genital syndrome of menopause, it transpired she had recurrent dysuria, vaginal dryness,¹⁰³ and discomfort. After starting vaginal oestrogen, she went on to successfully have her smear 6 weeks later.

This is a prime example of how signposting and referral can combat menopausal struggles, as well as improving the uptake of smear tests (cervical screening to help prevent cancer).¹⁰²

A scalable initiative

Women over the age of 55 account for lower levels of smear test uptake due to painful examination, typically due to vaginal dryness. The smear test case study portrays how important access to information and communication between services are. Addressing the primary issues, such as lack of education on the menopause, will trigger a domino effect of benefits, such as increasing smear uptake in older women. If this mentality was applied at scale to matters of women's health, there is potential to not only improve individual lives but to achieve larger global goals such as eliminating cervical cancer.

RECOMMENDATIONS

- The UK government must promote menstrual equity by ensuring that girls and women of reproductive age have access to adequate menstrual hygiene, including basic facilities and products.
- Menstrual period products should become free in England thereby following the framework set by Scotland's successful campaign to "end period poverty".
- The UK government tampon tax relief fund should be replaced with another women's health relief fund, ensuring that organisations previously reliant on this funding remain supported.
- Governments must place greater priority upon menstrual health within educational settings, encouraging dialogue with boys and girls of all ages, to break down historical taboos. Building on this enhanced knowledge and understanding of menstrual health, educators, clinicians and policy makers should phase out dated terminology with regards to menstrual health.
- Each interaction women and girls have with healthcare systems should be used as an opportunity by clinicians to understand how menstrual health is impacting their lives. Health providers must receive greater support to engage in dialogue around women's health and be supported by a comprehensive data infrastructure that records comments and scales best practice.
- Policymakers must continue to support the health sector in supporting campaigns that end misinformation around HRT. Women should be presented with the risk and offered HRT consistently in order to make the decision themselves. There needs to be a specific focus on targeting women of low SES.

Chapter Five

BREAST CANCER

Introduction

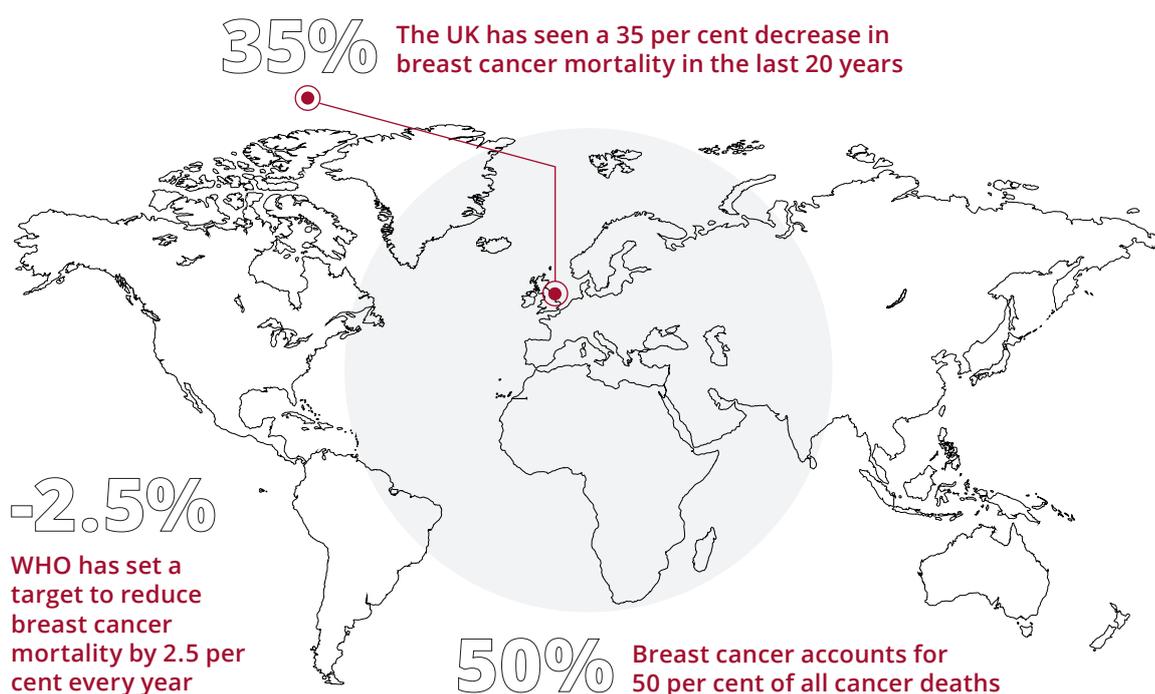
Worldwide, there are major disparities in the rates of breast cancer survival and mortality. Mortality increases with age and improved survival in high-income countries is due to a combination of early diagnosis and effective treatments, resulting in 90 per cent or more women being alive five years after diagnosis.¹⁰⁴ The comparable figure in India is 66 per cent and in South Africa 40 per cent, the differences reflecting later diagnosis and inadequate treatment options.¹⁰⁵

Breast cancer today accounts for 50 per cent of all cancer deaths and continues to rise globally, accounting for 50 per cent of all cancer deaths. This trend is dependent on changing lifestyle factors such as escalating obesity, alcohol intake, smoking habits and reduced personal physical activity, as well as an ageing population. Health systems unable to fund the infrastructure required for

early detection, diagnosis and treatment with surgery, drugs and radiotherapy will face major challenges.

The WHO has set a target to reduce breast cancer mortality by 2.5 per cent every year, but achieving this will require a major shift in how health providers and patients manage the disease.¹⁰⁶ Increasingly, global health providers will need to focus on preventative health measures, and address the social and economic determinants of health that lead to cancer. Crucial to achieving this will be harnessing local solutions that are required to match local needs with available resources.

In the UK, there has been a 35 per cent decrease in mortality from breast cancer in the last 20 years.¹⁰⁷ This decrease is the result of improved breast cancer awareness, screening, and rapid diagnosis, coupled with good access to surgery, drugs, and radiotherapy.¹⁰⁸ Further reductions in breast cancer incidences in the UK require a



shift in focus towards prevention and a better understanding of modifiable risks, with the focus on maintenance of breast health and wellness. Shifting the focus is needed in order to avoid spending more money for minimal gains to women's health, which is neither desirable nor sustainable.

The importance of innovation and local solutions for managing breast cancer

Identifying innovative methods for breast cancer prevention will be key to improving outcomes and slowing the predicted increase in breast disease for women in emerging economies, where expensive diagnostic and treatment options are simply not affordable. There are already examples of innovation emerging in LMICs across the world. Earlier detection programmes focusing on removing the stigma and fear of breast cancer, educating girls and young women to become breast aware (with or without targeted screening programmes) are showing signs of impact. Best practice guidelines for the use of surgery, drugs and radiation can be adapted to reflect local resources and channelled towards those women who are likely to receive most benefit. Preventative lifestyle measures can also be promoted in countries with limited health resources.

It should not be assumed that high-income countries with improved outcomes are best placed to lead future innovation within breast cancer. These countries have much to learn from creative solutions for preventing breast cancer being introduced in emerging economies. There is a wealth of epidemiological data regarding women who are at greater risk and these should be appropriately targeted for assessment; older women, some ethnic and cultural groups, those with strong family history, poor lifestyle choices or who are living in deprived areas. Prevention can be improved with healthier living choices and genetic testing where appropriate. Earlier detection rates would benefit from a redesign of referral

pathways and standardising breast assessment reporting, leading to risk adapted breast screening for women. Even in the UK, equity of access to surgery, drugs and radiotherapy has not been achieved and the development of biologically focussed personalised treatments are likely to widen the health inequality gap.¹⁰⁹

Recommendation: Governments should prioritise producing preventative strategies targeted at lifestyle change, as well as focusing on producing screening guidelines that can be adapted to suit local resources.

Time for a rethink: breast health, prevention of disease and screening

While breast screening is valuable, women also need to be encouraged to become involved in managing their own breast health. The WHO global breast cancer initiative has set a target to avert 2.5 million deaths from breast cancer between 2020 and 2040. This translates into a 25 per cent reduction in deaths by 2030, reaching 40 per cent by 2040 among women below 70 years of age.¹¹⁰ Their strategy has 3 pillars: health promotion for early detection, timely diagnosis, and comprehensive breast cancer management.

The Covid-19 impact

The pandemic has created unprecedented disruption to elective care across the world, and figures suggest that there is a growing backlog in undetected breast cancers.¹¹¹ Delays in diagnosis have led to a higher proportion of women being found to have more advanced breast disease with predictable and negative effects on survival and mortality.¹¹² The delays have also increased anxiety and stress for these women and their families, with measurable deterioration to mental health and wellbeing being recorded. The economic impact of more severe disease at presentation leading to more extensive treatments and inevitably poorer outcomes is already evident at a personal and national level in many countries.

The pandemic has led to a reduction in breast screening. In the UK, a report published in 2021 documented that the numbers of women screened over the same 10-month period in 2019-2020 and 2020-2021 fell by almost 50 per cent.¹¹³ Lessons need to be learnt from the negative consequences that women are experiencing following the shortfall in breast screening caused by the Covid-19 pandemic. There is an urgent need to use the potential opportunity to overhaul existing breast screening programmes and identify the most cost-effective and acceptable ways for women to be offered screening for breast cancer and receive the highest standards of care possible for proven disease.¹¹⁴

The NHS recovery programme states that cancer referrals will continue to be prioritised as they have done so throughout the pandemic.¹¹⁵ However, tackling the Covid-19 backlog in screening offers a chance to reconsider who needs to be prioritised for breast screening. In the UK, the number of breast cancer referrals rose steadily between 2015 and 2019, but the number of breast cancers diagnosed did not change.¹¹⁶ It is believed that ad-hoc community screening in women less than 50 years of age who are not yet eligible for the national breast screening programme, has contributed to this statistic. Fear of breast cancer of those with very low risk further emphasises the need to adopt targeted screening approaches based on clear evidence of benefit and equitable access. The NHS screening programme offers UK women routine breast screening every three years from the ages of 50 to 71 years. It is estimated that early diagnosis through screening saves 1,300 lives per year, which means that one life is saved for every 200 women screened.¹¹⁷ However, breast cancer is most prevalent in older women - about one in three breast cancers occur in women aged over 71 years. In the UK, women can continue to be screened for breast cancer at their local NHS screening unit if they choose to do so.¹¹⁸

“Tackling the Covid-19 backlog in screening offers a chance to reconsider who needs to be prioritised for breast screening”

The downside to breast screening is that some 4000 women per year in the UK will be found to have a cancer that will never become life threatening and may be offered treatment they do not need.¹¹⁹ Over-diagnosis becomes more common as women get older. The counter argument is that breast screening with mammograms saves lives and that a three-year recall service is too long an interval, since cancers developing in years two and three after screening will become unnecessarily advanced before diagnosis and treatment can be started.¹²⁰ However, more regular testing may increase cancer risk due to radiation exposure, although many breast cancer specialists report that most women they care for are more concerned about peace of mind rather than the potential risks of frequent screening. A screening programme for women aged 40 to 74 years undergoing annual mammograms has reported that a potential 968 breast cancer deaths per 100,000 women screened can be prevented, although this could potentially lead to 16 deaths from additional radiation exposure.¹²¹

Recommendation: In the UK, the NHS recovery programme needs to assess extensive waiting lists and overhaul the breast screening programme and shift the focus within breast cancer strategies away from screening towards prevention.

Screening for breast density

Breast density is a significant and independent risk factor for breast cancer. For every one per cent increase in density, there is a two per cent

increase in risk of cancer. Breast density is higher in women living in urban environments who are still in the workplace.¹²² However, in many countries including the UK, breast density is not routinely measured or reported and there is currently no official legislation or guidance for clinicians to follow. By contrast, it is mandatory for breast density to be reported in 46 of 50 states in the US.¹²³ Currently, the UK Breast Screening – Risk Adaptive Imaging for Density (BRAID) trial is investigating the use of supplemental imaging techniques to better identify breast cancer in women with dense breast tissue.¹²⁴ Evidence suggests that targeted adjunct screening in addition to traditional mammography offers the potential of picking up 1.5 more cancers per 1000 women.¹²⁵ Nine European countries have already adopted ultrasound scans for women found to have dense breast tissues and the Netherlands has launched a trial to examine the benefits of additional MRI screening for this group of women.¹²⁶

Within the UK, the NHS recovery programme offers the opportunity for focus to be shifted away from mass screening programmes to more targeted screening that includes measuring breast density. The new community diagnostic centres that have been set up to offer medical checks to patients referred by the GP should consider offering this more advanced and targeted screening.

Recommendation: Breast density should be routinely measured within breast screening clinics as part of the NHS recovery programme's overhaul of screening programmes.

Clearly there is a balance to be struck, since breast screening is effective in finding breast cancer and saves lives, but mass screening programmes are inefficient and need to be optimised. Further imaging techniques can enhance the accuracy of diagnosis of breast disease compared with mammography alone,



including breast ultrasound, tomosynthesis and MRI. It is hoped that by moving the narrative away from looking for breast disease alone and shifting the focus to breast health and wellness, women can be empowered to be part of the solution and ensure that health resources in cancer pathways are used optimally.

PIONEER STUDY: A PILOT STUDY OF LIFESTYLE INTERVENTION TO REDUCE BREAST CANCER RISK¹²⁷

The Pilot of Lifestyle Intervention to Reduce Breast Cancer Risk (PIONEER study) is aimed at understanding how best to support women to undertake lifestyle changes to reduce their breast cancer risk.¹²⁸ Ensuring appropriately targeted awareness and education about lifestyle choices that increase modifiable risks in different cultural contexts will be key to drastically reducing breast cancer incidence.

According to Cancer Research UK, of the 5000 breast cancer cases diagnosed each month, about 23 per cent are preventable. The PIONEER study completed recruitment in October 2021 and offered women the opportunity to learn their estimated risk of developing breast cancer. It then moved on to a bespoke online target-setting process to help the participants set goals to change their lifestyle in the way most relevant to their risk of developing breast cancer.

As this is a randomised controlled trial, not all participants received the same level of instruction or virtual interactions. All participants received a booklet explaining breast cancer risk factors and the study team is available to discuss concerns with any of the participants. In addition to the bespoke online goal-setting process, a third of participants have access to tailored

online information about breast cancer risk reduction and a third can use the website and have been invited to facilitated peer support sessions.

The first outcome measure is whether women are more likely to have achieved their goals after 12 months if they were provided with basic written information, access to the website, or the group sessions. However, crucial secondary outcome measures will provide more information on which breast cancer risks women were able to modify, and whether knowing that they carry a genetic component of risk made it more or less likely that the participants had achieved their goals.

TARGETED PREVENTION OF BREAST CANCER WITHIN LATIN AMERICA AND THE CARIBBEAN (LAC)

The European Code Against Cancer outlines 12 ways in which every individual can reduce their risk of developing cancer, and includes lifestyle changes, as well as encouragement for vaccination and screening uptake.¹²⁹ The Pan American Health Organisation (PAHO) identified the need to adapt the European guidance for risk prevention, in order to be used within the context of the LAC region. Highlighted within this study are two prevalent risk factors for breast cancer and how these can be reduced through mHealth platforms (platforms that use mobile phones to support the practice of medicine).

Key message: tobacco prevention

This has been reported as a major public health problem, with a staggering 32

per cent of all adults in the LAC region identifying as smokers.¹³⁰ Smoking for more than 10 years has been shown to increase the risk of developing breast cancer by 21 per cent, which highlights the urgency for tobacco prevention strategies throughout the region.¹³¹

Key message: obesity prevention

By 2030, it is predicted that 90 per cent of women in Cuba and Panama will be classed as obese. As major risk factors for breast cancer, the promotion of physical activity and reduced alcohol consumption are among the key areas that PAHO hopes to address in their prevention strategy. Despite the implementation of WHO tobacco and alcohol policies, a personalised approach is needed to see an improvement in the incidence of LAC breast cancer cases.

PAHO aims to disseminate these LAC-specific messages via digital means, through their mHealth platform. Following an automated text message, the recipient can view Q+A services, as well as country-specific breast cancer statistics. Technological advancements within the mHealth market include wearable devices linking to mHealth apps and allowing users to track their cardiovascular, respiratory, and metabolic health.¹³² Poor health within these markers has been identified among risk factors for breast cancer development, and mHealth provides the means for LAC citizens to visualise their own health impacts in real-time.

RECOMMENDATIONS

- Governments should prioritise producing preventative strategies targeted at lifestyle change, as well as focusing on producing screening guidelines that can be adapted to suit local resources.
- In the UK, the NHS recovery programme needs to assess extensive waiting lists and overhaul the breast screening programme and shift the focus within breast cancer strategies away from screening towards prevention.
- Breast density should be routinely measured within breast screening clinics as part of the NHS recovery programme's overhaul of screening programmes.

Chapter Six

CERVICAL CANCER

Introduction

Globally, cervical cancer is now the fourth most common cancer in women, with over 600,000 new cases and more than 340,000 deaths occurring in 2020.¹³³ This means that deaths from cervical cancer currently exceed the global toll of deaths from maternal mortality and that every two minutes a woman will die of cervical cancer. The human papillomavirus (HPV) is responsible for 95 per cent of cases of cervical cancer, with the burden mostly borne by countries where women's health is considered a low priority and services are poorly funded.¹³⁴

Approximately 85 per cent of all new cases and deaths worldwide are among young, undereducated girls and women who live in low- and middle- income (LMIC) countries, predominantly those in sub-Saharan Africa.¹³⁵ This geographical disparity is further aggravated by the fact that women living with

the Human Immunodeficiency Virus (HIV) are six times more likely to develop cervical cancer and do so at a much younger age. There are few diseases that reflect global inequality and inequity as much as cancer of the cervix. Many of the young women who die are also mothers of young children whose survival is then compromised by the premature deaths of their mothers.

Cervical cancer is a preventable disease and can be cured if diagnosed and treated early. High-income countries have developed programmes to ensure girls receive vaccinations against HPV infection and women undergo cervical screening regularly. This allows precancerous lesions to be identified at an early stage when they can be easily treated by local ablative techniques. In LMICs, limited access to preventative measures results in delayed identification of cases of cervical cancer, by which time the disease is further advanced.



The death rate in these countries is higher because once diagnosed, access to treatment for invasive cancerous lesions are often limited. For example, radiotherapy is the mainstay of treatment for invasive cervical disease, but less than 50 per cent of countries in Africa have any form of radiotherapy service available, with the rest sharing one machine between about five million people.¹³⁶

It has been calculated that cervical cancer cases will increase dramatically if global efforts to eliminate the disease using a combined strategy for prevention, screening and treatment are not scaled up as a matter of urgency. Experts have estimated that by 2040, there could be a 50 per cent increase in deaths equating to 450,000 preventable deaths annually.¹³⁷

Timeline for HPV and Cervical cancer

HPV is the most common viral infection of the reproductive tract and is mainly transmitted via sexual contact. Most infections occur shortly after the onset of sexual activity, with most men and women being affected at some stage of their lives and some being repeatedly infected. However, in 90 per cent of HPV infections, the body's immune system clears the infection at some point, with no long-term sequelae.¹³⁸ Although most precancerous lesions resolve spontaneously, there is a small risk that the HPV infection becomes chronic, and the precancerous lesion progresses to becoming invasive.

There are many different strains of HPV, but the subtypes 16 and 18 are responsible for at least 70 per cent of all cervical cancers and 50 per cent of high grade precancerous lesions. In women with normal immune systems, it usually takes 15 -20 years for cervical cancer to develop, but the interval may be as short as five or ten years in women with untreated HIV infection, due to their weakened immune state.

“It has been calculated that cervical cancer cases will increase dramatically if global efforts to eliminate the disease using a combined strategy for prevention, screening and treatment are not scaled up as a matter of urgency”

HPV vaccination

HPV vaccines are safe and effective in preventing HPV infections, high grade precancerous cervical lesions and invasive cancers, and are most effective when administered prior to first HPV exposure. Hence, the WHO recommends vaccinating girls aged nine to 14 years, before the majority have become sexually active.¹³⁹ It is important to recognise that HPV vaccination does not replace cervical cancer screening population screening-based programmes are still needed to identify and treat cervical precancerous lesions and established cancers to reduce the incidence of cervical cancer and deaths.

HPV vaccination has, however, been highly successful in preventing cancer of the cervix, and the global implementation of HPV vaccination programmes needs to be prioritised. The potential for effective treatment of such a preventable cancer underpins why the WHO Director General announced a global call for action in 2018, to eliminate cervical cancer as a public health problem.¹⁴⁰

In the UK, the first school-based programme was introduced in 2008 with the vaccine offered to girls aged 12-13 years. The vaccination programme was extended to include boys in 2019. Since 2021 a nonvalent vaccine active against nine strains of HPV has been available in HIC's with an established HPV screening

programme. Proof of the efficacy of the UK vaccination programme was published in November 2021 demonstrating a 97 per cent fall in precancerous cervical changes in women offered HPV vaccine at 12-13 years of age (who are now in their 20s), 75 per cent for 14-16-year-olds and 39 per cent for 16-18-year-olds when compared to an unvaccinated population.¹⁴¹

The WHO elimination of cervical cancer initiative

The WHO's global strategy to accelerate the elimination of cervical cancer was adopted by the World Health Assembly (WHA) in 2020. It calls for renewed political will to make elimination a reality and to unite all stakeholders behind a common goal. To eliminate cervical cancer each country must reach and maintain an incidence rate of less than four cases of cervical cancer per 100,000 women.¹⁴²

Achieving this goal will be dependent on countries meeting the "90-70-90 targets" set out in the WHO strategic plan, which is based on three integrated pillars: prevention with vaccination, screening, and treatment by 2030. The targets are:

- 90 per cent of all girls fully vaccinated against the HPV virus by the age of 15 years
- 70 per cent of women screened with a high-performance test by 35 years of age and again by 45 years
- 90 per cent of women identified with cervical disease receive treatment – 90 per cent of women with pre-cancer treated and 90 per cent of women with invasive cancer managed.

If the 90 per cent vaccination target is reached, an estimated 45 million deaths from cervical cancer in LMICs will be prevented over the next decade.¹⁴³ However, only 58

“To eliminate cervical cancer each country must reach and maintain an incidence rate of less than four cases of cervical cancer per 100,000 women”

per cent of countries across the world are currently offering vaccination to girls between ages nine to 15 years, which means that overall, less than 20 per cent of girls in LMICs can access the HPV vaccine, compared with 90 per cent in high income countries.¹⁴⁴

Clearly, optimising the availability and uptake of HPV vaccines is a crucial first step in reaching the WHO's targets. However, systems that work well in one country or cultural setting are rarely directly translatable to another. One in three girls in Africa are married in childhood, and one in ten young women are married before their 15th birthday.¹⁴⁵ Additionally, there are at least 52 million girls not attending school.¹⁴⁶ This means that reaching girls most at risk presents a significant challenge even if the infrastructure needed to vaccinate them is available. Research into offering HPV vaccination with other childhood vaccination should be accelerated as one of the potential solutions to overcome this problem.

Vaccinating boys as well as girls is another potential way of achieving cervical cancer prevention in women and other HPV related cancers in men and women. However, the financial and supply implications of doubling the vaccination programme needs to be considered in a global context. In the UK, vaccination of schoolboys aged 11 and 12 years old has begun to a positive reception, and uptake has been high. However, if

approximately 80 per cent of women get at least one type of HPV in their lifetime, vaccinating boys as well as girls in countries with limited resources is an ineffective use of vaccines when targeting cervical cancer specifically.¹⁴⁷ The long-term goal for HPV vaccination programmes should include boys but this is not presently a realistic or affordable strategy for many countries. In the context of current constraints, the most efficient and effective impact is via female HPV vaccination alone.

Recommendation: When governments with limited resources are looking at strategies to eliminate cervical cancer, prioritising HPV vaccination of girls should be advocated for as recommended by the World Health Organization.

The second pillar of the WHO 2030 target is for 70 per cent of girls worldwide to receive cervical screening on at least two occasions by the age of 45 years. Introducing two cervical screenings across a woman's life time, in addition to achieving the high HPV vaccination target, would enable LMICs to reach the goal of eliminating cervical cancer at least 10-15 years earlier than current projections.¹⁴⁸

The UK is often perceived as having one of the best cervical screening programmes in the world and it is estimated to save around 4,500 lives annually.¹⁴⁹ The programme offers screening to women aged 25-49 years every three years and every five years from the ages of 50-64. However, a screening programme is only successful if it is well utilised, and it is concerning that over the past ten years there has been a decline in the number of women in the UK taking up cervical screening, the number reaching a 20-year all-time low of 71 per cent in 2018. Further decline is anticipated as a result of the Covid pandemic.¹⁵⁰

There are many reasons for this decline in uptake but fragmentation of women's health services and a lack of cross-system leadership and clear accountability has resulted in confusion, delays and risks to patient safety. Women are less likely to take up an offer of screening if they are from the most deprived quintile. Women from black and Asian minority backgrounds are significantly less likely to attend cervical screening appointments than white women.¹⁵¹ Again, the UK government's Women's Health Strategy must focus resources on targeting minority ethnic groups to improve cervical screening uptake.

ADDRESSING INEQUALITIES IN HPV VACCINATION UPTAKE

For more than a century, MSD has been inventing for life, bringing forward medicines and vaccines for many of the world's most challenging diseases. Today, MSD continues to be at the forefront of research to deliver innovative health solutions and advance the prevention and treatment of diseases that threaten people and animals around the world.

The widening cervical cancer inequality gap

In the decade since its introduction, the UK's HPV schools vaccination programme has made significant progress, reducing HPV prevalence in 16-18-year-old women from 15 per cent to below two per cent.¹⁵² Combined with cervical screening and cervical cancer treatment, there is a real opportunity to eliminate cervical cancer as a public health threat. This could change the lives of thousands of women in the UK,¹⁵³ and save the NHS over £20m every year,¹⁵⁴ whilst taking an important first step in efforts to eliminate other HPV-related cancers in both women and men. >

But, amidst a backdrop of significant disruption to the school-based HPV vaccination and cervical screening programmes due to the COVID-19 pandemic, HPV vaccination coverage is well below the WHO's recommended 90 per cent benchmark. Even before the pandemic, national coverage rates have seen a small but steady decline since 2015/16, with significant regional variation.¹⁵⁵ High levels of deprivation have been linked directly to both low vaccine uptake,¹⁵⁶ and incidence of cervical cancer: with 65 per cent of cases in women from the lowest socioeconomic group.¹⁵⁷ As we strive to recover and improve vaccination and screening rates, we must act to ensure no woman is left behind in the face of a widening cervical cancer inequality gap.

How has MSD addressed this?

The recovery of the HPV vaccination programme is a critical step in driving the opportunity to eliminate HPV-related cancers in the UK and ensuring that it does not lose the success to date in reducing cervical cancer cases.

Tailored messaging

One of the biggest opportunities to ensure high uptake of the vaccination programme is to ensure parents are aware of the need to consent for their child to receive HPV vaccination in school. In order to develop an awareness campaign that would improve parental awareness of the HPV vaccination programme, MSD undertook market research to understand the key messages that would most resonate and proceeded to update the existing HPV public awareness site to include tailored messaging including things such as focusing on cancer messaging to improve parental awareness of HPV.

Focusing on low uptake areas to address inequalities

Several different advertising mechanisms, including outdoor advertising, social media content and radio ads, were used as part of the campaign and were scaled up in areas of low uptake. The granular level of data that was available on HPV vaccine uptake allowed the campaign to be specific to each locality. For example, having bus advertising target key bus routes in London or Manchester with lower uptake.

A scalable and successful campaign

Considering the impact the Covid-19 pandemic has had on the HPV vaccination programme, it has been critical to understand the areas of lowest uptake to reduce further vaccine inequalities. The ability for MSD's campaign to tailor its interventions in specific areas using local data provides an opportunity for other services to do the same to ensure that increased investment is made in places that need it most. This campaign highlights the need for accurate and timely data and evidence to inform decision-making and campaign development, which is something that should be a key priority in any health system and can be leveraged across all health areas to support recovery and address health inequalities.

In 2021, 83,000 people visited the HPV public awareness site, with the vast majority (72,000) visiting the FAQ section, demonstrating the desire for more information around HPV. Most importantly, the majority accessing the site were in the low uptake areas of London, Glasgow, Birmingham, Manchester, where MSD differentially increased investment.

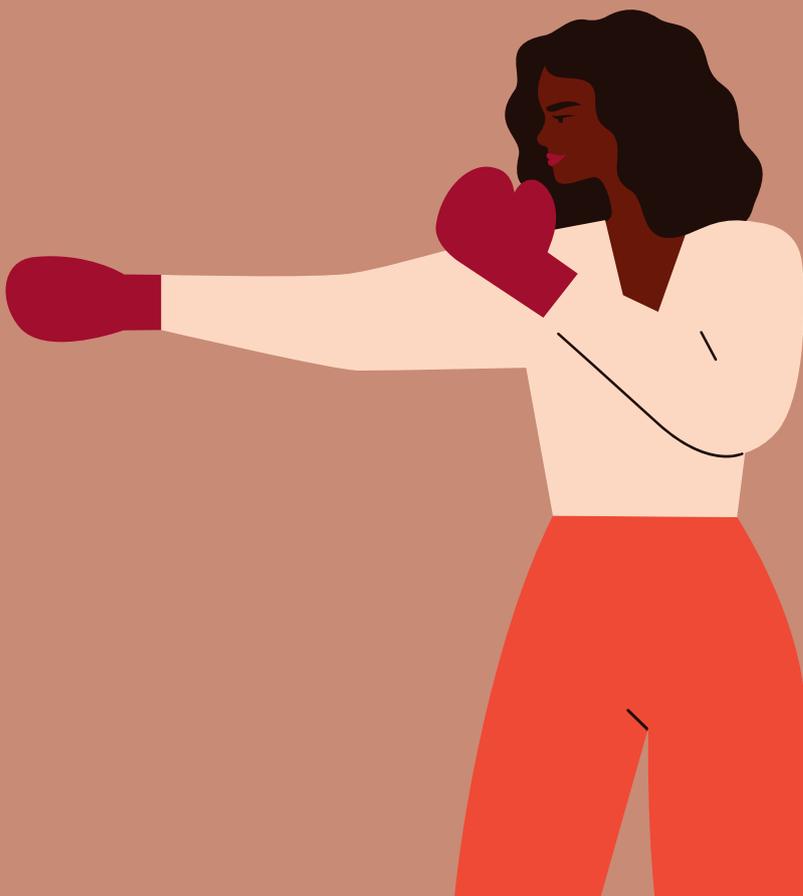
Furthermore, a poll on the site that asks users "after visiting this site are you more

likely to consent for your child to receive HPV vaccination?" found that 92 per cent of those who clicked on the poll clicked YES. This demonstrates that providing the educational material tailored to feedback from previous market research may be increasing belief and confidence in vaccination and driving parents to consent for their child to receive the HPV vaccination.

At a time where the HPV vaccination programme has had significant declines in its coverage rate due to the pandemic, the priority must be on restoring and

strengthening the programme to pre-pandemic levels to protect future generations from HPV-preventable cancers. The UK should continue to be driven by the data in its decision-making to ensure all the strides that have been made to date in reducing HPV-related diseases and cancers are not reversed, especially for the most vulnerable.

MSD have provided sponsorship funding for this programme of work, and have had editorial control of this case study only. Public Policy Projects have retained full editorial control over the rest of the report.



Recommendation: The UK's Women's Health Strategy must focus on targeting ethnic minority groups to improve cervical screening uptake. A holistic approach is needed to address the widening cervical cancer inequality gap.

Fear, embarrassment, pain and poor access to appointments are all contributing to the problem of low cervical screening uptake. Moreover, women are frequently told that they must undergo a further intimate examination in a different clinic to have cervical screening due to commissioning rules. This is not just inconvenient; it acts as a positive disincentive for many women. Integrating cervical screening within a single appointment for other gynaecological or sexual health services would be more acceptable to women and far more cost-effective. Establishing women's health hubs in the community, in which women can access all their wellbeing and screening needs, must be the way forward.

Recommendation: In the UK, cervical screening services should be integrated with regular sexual and gynaecological health services for ease of access.

Recommendation: Efforts to introduce self-sampling need to be scaled up in low-to-middle-income-countries. Following the YouScreen study in London, HPV self-sampling should be implemented across the UK targeting groups with lower screening uptake.

RWANDA: NATIONAL CERVICAL CANCER PROGRAM

Rwanda has implemented a successful HPV vaccination scheme alongside piloting a screen-and-treat program, and is now on track to becoming the first country to eliminate cervical cancer. With an emerging economy, Rwanda has shown resilience

through its successes, and is overtaking the work seen within the UK and US, despite more limited funds.



Vaccinations

In 2020, over 2500 HPV vaccines were administered to Rwandan girls between the ages of 11 and 15. This achievement follows the initial introduction of the vaccine into schools in Rwanda in 2011, which provided two-doses free of charge. This pilot was launched by Rwanda's First Lady Jeannette Kagame, who is also known for her work as co-founder for the Organisation of African First Ladies against HIV/AIDS.¹⁵⁸ Uneasiness around initial uptake was remedied by teachers speaking to students during a three-month 'sensitisation' period. This involved education surrounding what the vaccine is, how it is administered and how it fights the disease.

Screening and treatment

The screen-and-treat pilot program runs across seven hospitals and 89 health centres, offering screening services to women between 30 and 49 years old. The

programme not only offers screening, but also ensures a follow up for women testing positive for precancerous lesions. This initiative has seen 16,563 women attending screening, followed by 559 receiving treatment with thermal ablation at the same facility in which the screening was carried out.¹⁵⁹ This is crucial as it ensures both accurate continuity of treatment and reduces the travel costs that women would face if expected to move to another district or facility for their treatment.

Setting a precedent

As seen with implementing polio, MMR and now HPV vaccinations, Rwanda has shown a determination to improve the health of all citizens.¹⁶⁰ This has been led by a key female figurehead within the country, who passionately advocates for improving women's health and acts as inspiration to girls and younger women within the community. The screen-and-treat pilot program presents other nations with an example of the innovation needed to eliminate this disease and remove the effects it has on women's social and economic status.

RECOMMENDATIONS

- When governments with limited resources are looking at strategies to eliminate cervical cancer, prioritising HPV vaccination of girls should be advocated for as recommended by the World Health Organization.
- The UK's Women's Health Strategy must focus on targeting ethnic minority groups to improve cervical screening uptake. A holistic approach is needed to address the widening cervical cancer inequality gap.
- In the UK, cervical screening services should be integrated with regular sexual and gynaecological health services for ease of access.
- Efforts to introduce self-sampling need to be scaled up in low-to-middle-income-countries. Following the YouScreen study in London, HPV self-sampling should be implemented across the UK targeting groups with lower screening uptake.

Chapter Seven

A GENDERED LENS: RESEARCH, DATA & POLICY

Introduction

Underpinning women's health concerns is the need for good data, research and policy, to ensure women's health outcomes are the best that they can be. Increased awareness of the structures that are biased against women have come to the fore, particularly since the Covid-19 pandemic has exposed how a lack of attention to gender disaggregation within medical research has caused adverse outcomes for women.

Good women's health starts before the doctor's surgery. It is only when clinical trials recruit a balance of female representation that equality within healthcare is possible. Concurrent to this is the need to ensure female representation within both the medical research and medical professions, to push this agenda forward. At every step in the chain, taking a gendered lens is necessary to ensure women are provided with the best healthcare.

Pregnancy: Protecting through research not protecting from research

Prior to 2010, over 90 per cent of the American Food and Drug Administration approved drugs had no data on efficacy and safety within pregnancy and still, over 80 per cent of women who take a drug during pregnancy will do so with minimal safety data.¹⁶¹ Indeed, until the 1990s, women of childbearing age were kept out of clinical trials entirely due to historical concerns about the harm of drugs to unborn children, rooted in the case of thalidomide, which was offered to women during the 1950s to prevent morning sickness but caused children to be born with deformities.¹⁶² The focus on the unborn child has implicitly led to the health of women becoming deprioritised.

Exclusion from clinical trials perpetuates the view that women are reproductive vessels, and results in risks for post-licensing, where there is less monitoring and safety reporting than



in clinical trials. Even if not included in clinical trials, women are still more likely to receive new drugs through non-evidenced based pathways. Evidence gaps present difficulties for health workers offering advice to pregnant and breastfeeding women on drug treatment.

Never has this been more apparent than during the pandemic. Despite pregnant women being recognised as more vulnerable to Covid-19 than non-pregnant women, pregnant women were excluded from early phase vaccination trials. There remains very limited clinical trial data on the immune response caused by the vaccines for these women. This has driven uncertainty and confusion for pregnant women whether they should be receiving a vaccination at all. As of January 2022, almost all pregnant women admitted to intensive care with Covid-19 within the UK have been unvaccinated.¹⁶³

FEMTECH: THE FUTURE OF WOMEN'S HEALTH

Femtech (female technology) is a market for products and software focused specifically on women's health issues such as contraception, menstruation pains, fertility, and sexual wellness.¹⁶⁴ There is an extensive range of companies across the globe that offer solutions ranging from period-tracking to contraception-prescribing apps, as well as data storage of wearable breast pumps. These modernised health services have the ability to revolutionise outdated resources previously used within women's health.

As the market expands there is an opportunity to close not only the gender gap, but also the gap in technology accessibility. Within the UK, the NHS is working alongside Femtech companies such as Peppy Health to benefit their workforce. Examples of their work include supporting NHS staff going through menopause, in which a pilot

study discovered that 55 per cent of staff had taken time off work due to menopause symptoms. Through offering a safe space and personalised expert practitioner support, the trial left 81 per cent of staff feeling more committed to the NHS, thereby contributing to increased workplace productivity.¹⁶⁵

The sector is expected to grow, and with half of the population as a market size, there is ample opportunity for progression. As a means of closing the gender gap by addressing inequalities within women's health, Femtech promotes the acceleration of women's health awareness and support, as well as offering an arena for female entrepreneurs to expand.¹⁶⁶

PRESUMPTIVE EXCLUSION TO FAIR INCLUSION - WOMEN IN CLINICAL TRIALS THROUGH THE LENS OF HIV

Human Immunodeficiency Virus (HIV) severely weakens the immune system, but an early diagnosis allows time for effective drug interventions with antiretroviral drugs (ARVs) that allows those diagnosed to live longer and healthier lives.¹⁶⁷ Despite more than half of global HIV cases being women, they have represented only 15 per cent of trial participants in phase III HIV trials in the last five years.

Groups commonly excluded from registration studies include pregnant women, members of the trans community, lactating women, and children. This is counterproductive to ensuring effective clinical trials, as these under-represented groups require more research and more data, not less.

This under-representation is not confined to HIV but can be seen across all clinical trials; >

greater than 90 per cent of FDA approved drugs had no data on safety in pregnancy prior to 2012.¹⁶⁸

Standardising a diversity norm in clinical trials

The development of the long-acting HIV therapy allowed people to be free of the burden of daily oral treatment and to instead receive only six injections per year. However, early-stage trials saw an underrepresentation of female participants. An Implementation trial (phase IV) on long-acting therapy is to be carried out across six UK HIV centres; however, these trials will involve changes to recruitment strategy.

Professor Chloe Orkin, of Queen Mary University of London Barts Health NHS Trust, has insisted on capping male and white participation for these trials at 50 per cent maximum. These restrictions insist on a proactive approach to offering women and ethnic minority candidates the chance to take part in research. This study will also allow women who become pregnant while on the trial to remain on the trial if they choose.

Steps to a solution

There should be a focus on empowerment of women to make choices about their care, and a shift of concentration from the unborn child onto both the maternal and foetal health equally. Implementation of a representative cohort across clinical trials will not only ensure pharmacokinetic disparities are detected, but it will also allow for a more even gender distribution across data sets. Women and pregnant women are not a niche group, they are 50 per cent of the population and the drive from a presumptive exclusion to a fair inclusion will ensure they are equally represented across drug studies and in healthcare guidelines.

Recommendation: Women of childbearing age and pregnant women should be given the choice to participate in clinical trials themselves, rather than being excluded from the outset. Male and white male participation in clinical trials should be capped to ensure participation from underrepresented groups, notably woman and pregnant women.

The need for sex and gender disaggregation within clinical trial data

Women are under-represented in clinical trials relative to the burden of disease. Fewer than 22 per cent of women take part in Phase I trials.¹⁶⁹ Current guidelines suggest that, at a minimum, women should be represented in trials in proportion to the prevalence of specific health conditions among them. This target falls short in serious disease areas, such as cardiovascular conditions. The British Heart Foundation has coined the phrase ‘the heart attack gap’ to demonstrate how, between 2002 and 2013, over 8000 women needlessly lost lives for this reason.¹⁷⁰ Of the 40 medicines registered by the FDA in 2019 for conditions affecting both sexes, 16 saw female participation during trials at 50 per cent or less.

The issue is that even if women do make up 50 per cent of the research, the data generated is rarely sex disaggregated. Again, during the Covid-19 pandemic, of nearly 2500 Covid related studies published by September 2020, fewer than five per cent of investigators had pre-planned for sex-disaggregated data analysis in their studies. Not one of the 11 clinical trials published in scientific journals in June 2020 reported sex-disaggregated results.¹⁷¹

To counter this problem, various government based international research funding agencies have implemented policies that require the integration of sex and gender analyses into the design of research studies. Funder policies have been introduced within the US, Canada and most recently by the European Commission.

Analysis of all 39,390 applications submitted to the Canadian Institutes of Health Research (CIHR) from 2011 to 2019 shows reporting on sex rose from 22 to 83 per cent and reporting on gender rose from 12 to 33 per cent. Such policies work, and it should be a requirement that all research studies disaggregate data based on sex and gender. Applications with female principal investigators were more likely to integrate sex and gender.¹⁷² When 17 of the largest UK medical research charities and the four UK medical regulators were asked whether they had sex and gender policies for the research it funded, zero per cent said yes. The UK needs to do much more.

GENDER AND COVID-19

Accelerating progress towards fully inclusive data analysis

The Gender and COVID-19 Working Group is a global group of experts and advocates with the aim to address the gendered impacts of COVID-19, inclusive of cis and trans women and men, and gender minorities. With their work spreading internationally to more than 700 members, they are continuing ongoing communications regarding the gendered effects of the pandemic and the need for integrating a gender lens into data.

The problems with the data

There is a pattern of historic neglect when it comes to gender-based analysis of health that is reflected in gender-neutral approaches to interventions. Resources produced by the Gender and COVID-19 Project illustrate an evidence-based analysis of some of these disparities. During the pandemic, non-pharmacological responses – such as school closures and lockdowns – disproportionately affected women and

gender minorities. For example, these groups were more affected by job losses and gender-based violence. Moreover, gendered effects have been seen before in the Ebola and Zika epidemics, highlighting the need for gender-specific research and increased data inclusion.¹⁷³

The Gender and COVID-19 Research Project A gender matrix documents how different genders experience an event and has been used in this instance to record the differences in health and social factors globally throughout the pandemic. Individual cases collated from Australia, Brazil, China, Kenya, Nigeria, and the UK were entered into this matrix in order to assess the levels of risk, and the social, economic and security impacts these posed.¹⁷⁴ Not only can this tool help conduct a detailed gender analysis, but it also provides qualitative and quantitative data sets. Initiatives such as this have great potential to be implemented globally throughout health research to close the gaps in data inequalities, particularly involving gender and race.

HOW THE HEALTHCARE INDUSTRY CAN HELP TACKLE THE GENDER HEALTH GAP

Laura Steele, President & General Manager, UK, Ireland, and Northern Europe at Eli Lilly and Company

Women have been consistently under-represented within the healthcare industry for hundreds of years. From facing inequalities in accessing healthcare services to being written out of clinical trial data through male-dominated participation; >

women's health is a public health issue. As awareness of the extent of this issue grows, it is key that we use our position in the healthcare industry to act, address the historical mistreatment of women in healthcare and ensure that the next generation does not face the same gender health gap.

There is a widely acknowledged disparity in medical research regarding treatment outcomes and side effects for women. The widespread use of the male body as 'the norm' in clinical trials has led to gender bias in research for many years. For example, we know that cardiovascular disease is the leading cause of death among women, but only 34 per cent of participants in trials supporting 36 different cardiovascular approvals were women.^{175 176}

So why are we still seeing these gender disparities within medical research? There are a number of barriers to women entering into clinical trials, which can include apprehension due to historic unethical research, or interference in family and work obligations.¹⁷⁷ The Covid-19 pandemic catalysed Lilly's commitment to increasing diversity in our clinical trials. We are working to remove barriers and make our trials more accessible, for example by decentralising clinical trials and increasing use of virtual technology for follow-up appointments or offering childcare for mothers with no childcare support. We are also aiming to recruit more clinical trial investigators and external advisors who are representative of the populations our medicines aim to serve.

Research is not the only way we can reduce the barriers facing women within healthcare. Women make up 75 per cent of the health workforce yet occupy less than 25 per cent of

the most influential leadership positions.¹⁷⁸ Research shows that the pandemic has exacerbated gender inequalities in the workplace with surveys revealing that women were one-and-a-half times more likely than men to lose work or be burdened with childcare during nursery and school closures.^{179 180} It is vital that women are supported to equally contribute to the workforce, and that companies in the healthcare industry are diverse and inclusive to be able to understand and meet the needs of all communities.

Building a diverse, equitable workplace at Lilly is a top priority. In 2015, we launched our own award-winning Women's Journey research to understand the daily challenges and barriers preventing women from all levels within the workforce reaching top leadership positions. The research involved around 400 women and included both quantitative and qualitative findings. It ultimately led to five recommendations that have been implemented to drive change and pave the way for a more inclusive culture.

We are now seeing results from our commitment to elevating women in the workplace. As of the end of 2020, women represented 46 per cent of our global management team, up from 38 per cent at the beginning of 2017. But there is still more to do. Having the right support systems in place helps to foster an open environment and that's where employee-led initiatives, with leadership support, can make a real difference. For example, Lilly's Gender Inclusion Network (GIN) has been designed to raise awareness of bias and stereotypes that impact all genders. Our Women's Initiative for Leading at Lilly (WILL) is a community of women and men that works towards accelerating our progress in gender equity, and encourages unapologetic ambition from women.

We continue to learn and encourage hard conversations to improve diversity and inclusion within Lilly. We are committed to closing the gender health gap and helping to create a diverse healthcare industry with women at the forefront of leadership and innovation. Together, we can ensure that women of any age, race or social standing feel fully supported to lead healthy, fulfilling lives.

Eli Lilly and Company have provided sponsorship funding for this programme of work, and have had editorial control of this case study only. Public Policy Projects have retained full editorial control over the rest of the report.

Recommendation: To increase sex and gender integration in the health and biomedical research funding and regulation in the UK must advocate for mandatory inclusion of sex and gender analysis plans on application forms, resources to train and educate applicants, funders and evaluators, and reward proposals that engage deeply with sex and gender analysis.

RECOMMENDATIONS

- Women of childbearing age and pregnant women should be given the choice to participate in clinical trials themselves, rather than being excluded from the outset. Male and white male participation in clinical trials should be capped to ensure participation from underrepresented groups, notably woman and pregnant women.
- To increase sex and gender integration in the health and biomedical research funding and regulation in the UK must advocate for mandatory inclusion of sex and gender analysis plans on application forms, resources to train and educate applicants, funders and evaluators, and reward proposals that engage deeply with sex and gender analysis.

Conclusion

This report has made the case that it is possible to create a women's health system that is fit for the 21st century. It has given ample evidence, backed up by clear examples of best practise, that when women's health is managed with a common-sense approach, real change is possible.

This report has been written during a pandemic which has led to the premature death of millions of people world-wide. Running in parallel has been another pandemic, a silent one. The United Nations Women has named this the 'shadow pandemic' and it is one which has also affected millions, but this time, only women. It has not been caused by a coronavirus but rather by the intimate partners of girls and women. Research carried out by the United Nations points to an estimated 243 million women across the world who have experienced physical or sexual violence during Covid-19.¹⁸¹

Although not included as a separate chapter, violence perpetrated against women has emerged as a persistent thread throughout this report, linking each topic. Women as victims, was a subject talked about in every group held during the evidence gathering. This is not just through the abuse that women are subjected to by their partners, but also indirectly, through systems, practices and policies which place women at increased risk through unintended pregnancies, cancer, or infections. These risks are multifactorial and as discussed in this report range from denying women information and access to core services which cause harm and render them more vulnerable, through to infantilising them by insisting they undergo unnecessary tests before they are allowed to receive healthcare interventions. It is not surprising that the net result is that many women become reluctant to seek simple treatments and learn to avoid exposing themselves to barriers and bureaucracy.

Both the chairs of this report are women in their 60s. Both have grown up with access to free contraception, legal termination of pregnancy, infertility treatment, maternity care, breast, and cervical screening programmes. However, progress appears to be plateauing and women today, may soon have fewer rights than their mothers. Abortion services across the world are becoming more restrictive. The contraceptive pill, one of the most researched and safest medicines in healthcare, still requires a prescription and unnecessary clinical assessments. Women are being priced out of infertility treatment and seduced to pay for unproven add-on treatments. The lack of support for menopausal women has resulted in many talented women leaving the workplace prematurely, instead of contributing their experience and skills at the most productive time of their working lives.

If women are to have more control and power over their own bodies, women's health must be made everyone's business. This must start with those who plan health services to make care more accessible and progress through to those who provide it by removing unnecessary hurdles to receiving care.

It is time for every government globally to commit to improving women's health. In the UK, too many women's health interventions are currently based on postcode lotteries creating vast inequity of access. Globally, many of these health interventions remain completely out of reach. However, this report has demonstrated that it should not be presumed that western cultures can simply transfer their own approaches to developing countries, whose infrastructure and societies are vastly different.

It is the sincere hope of all of the people who gave their insights to this report that policymakers and politicians chose to work together to achieve its vision.

Recommendations Summary

CONTRACEPTION

Sexual and reproductive health services must be prioritised to counter patchy healthcare service provision – and access must be made available, in and out of hours.

NICE should re-examine guidelines that recommend routine appointments for oral contraception users – with a view to limiting unnecessary medical checks that may only serve to limit contraception access.

POPs should be made available on general sales (off the shelf) and not require consultation with a pharmacist unless the woman wishes.

Those who plan and purchase healthcare must ensure provision of full range of contraception services to all women that is person centric and at all reproductive ages, with a particular focus

on targeting women of low socioeconomic status (SES) and minority ethnic women. This should include ensuring emergency hormonal contraception is free in 100 per cent of healthcare service provision.

While LARC should be encouraged, the greatest impact for reducing unplanned pregnancies must focus on influencing women who use no contraception to begin using any form of reliable contraception.

Post birth contraception must become an integrated part of maternity services and funded appropriately and women should be routinely offered a choice of contraception post delivery and given information about the importance of birth spacing to improve their health and that of their baby/family.

ABORTION

To further increase access to telemedicine abortion, health providers should enable a greater number of staff undertake telemedicine abortion and prescribe the medications – this should include enabling training nurses and pharmacists to undertake the clinical consultation.

Post-abortion care can be self-managed by the woman and this should be advocated for within local sexual and reproductive health services.

Access to telemedicine should be enhanced and obstacles to access removed wherever possible. This should include removing the need for women to have a routine scan within a clinical setting in order to qualify for a telemedicine abortion.

Abortion should become further integrated with contraception services and wider sexual and reproductive health service provision - health providers should ensure that contraception is offered at the time of abortion if desired by the woman.

Recommendations Summary

ASSISTED CONCEPTION

Access to fertility treatment should be determined based on need, not by geographical location. Disparities in funding levels between different CCGs and soon to be integrated care systems must be addressed so that women are able to access the recommended three cycles of IVF treatment from anywhere in the country.

Those going through fertility treatment must be provided with far clearer information and assisted conception 'add-ons' must be regulated with patients clearly informed when treatment options are not fully evidence based.

The reproductive genomics sector must be subject to greater structure and regulation – women should receive independent advice about their options from genomic experts before they are referred to commercial providers.

A large proportion of the genomics of women's fertility lies outside of existing NHSE and PHE governance structures. This should be addressed as a priority by ensuring it is brought into the remit of existing structures.

MENSTRUATION AND MENOPAUSE

The UK government must promote menstrual equity by ensuring that girls and women of reproductive age have access to adequate menstrual hygiene – basic facilities and products.

Menstrual period products should become free in England thereby following the framework set by Scotland's successful campaign to end 'period poverty'.

The UK government must tampon tax relief fund should be replaced with another women's health relief fund, ensuring that organisations previously reliant on this funding are supported.

Governments must place greater priority upon menstrual health within educational settings, encouraging dialogue with boys and girls of all ages to break down historical taboos. Building on this enhanced knowledge

and understanding of menstrual health, educators, clinicians and policy makers should phase outdated terminology with regards to menstrual health.

Each interaction women and girls have with healthcare systems should be used as an opportunity by clinicians to understand how menstrual health is impacting their lives – health providers must receive greater support to engage in dialogue around women's health and be supported by a comprehensive data infrastructure that records comments and scales best practice.

Policymakers must continue to support the health sector in supporting campaigns that end misinformation around HRT. Women should be presented with the risk and offered HRT consistently in order to make the decision themselves. There needs to be a specific focus on targeting women of low SES.

BREAST CANCER

Governments should prioritise producing preventative strategies targeted at lifestyle change, as well as focusing on producing screening guidelines that can be adapted to suit local resources.

In the UK, the NHS recovery programme needs to assess extensive waiting lists and overhaul

the breast screening programme and shift the focus within breast cancer strategies away from screening towards prevention.

Breast density should be routinely measured within breast screening clinics as part of the NHS recovery programme's overhaul of screening programmes.

CERVICAL CANCER

When governments with limited resources are looking at strategies to eliminate cervical cancer, prioritising HPV vaccination of girls should be advocated for as recommended by the World Health Organization.

The UK's Women's Health Strategy must focus on targeting ethnic minority groups to improve cervical screening uptake. A holistic approach is needed to address the widening cervical cancer inequality gap.

In the UK, cervical screening services should be integrated with regular sexual and gynaecological health services for ease of access.

Efforts to introduce self-sampling need to be scaled up in low-to-middle-income-countries. Following the YouScreen study in London, HPV self-sampling should be implemented across the UK targeting groups with lower screening uptake.

A GENDERED LENS: RESEARCH, DATA & POLICY

Women of childbearing age and pregnant women should be given the choice to participate in clinical trials themselves, rather than being excluded from the outset. Male and white male participation in clinical trials should be capped to ensure participation from underrepresented groups, notably woman and pregnant women.

To increase sex and gender integration in the health and biomedical research funding and regulation in the UK must advocate for mandatory inclusion of sex and gender analysis plans on application forms, resources to train and educate applicants, funders and evaluators, and reward proposals that engage deeply with sex and gender analysis.

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This report uses the term woman and women. However, we recognise that people who do not identify as women may need to access women's health services and to whom the recommendations of this report may be applicable. Healthcare must be inclusive to both women but also those whose gender is different from the sex they were assigned at birth.

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