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Reproductive health and wellbeing – addressing unmet needs

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Key Messages:

- Reproductive health is vital for wellbeing, to prevent morbidity and maintain economic productivity. It encompasses pregnancy-related health, some aspects of sexual health and health unrelated to pregnancy.
- Age-appropriate education for reproductive health should start as soon as understanding develops and be continued into adulthood.
- Universal care in reproductive health is important in meeting women's contraceptive, preconception, screening and menopause care needs.
- Provision of socially or medically complex reproductive health care, such as fertility treatment, later abortion and menopause care, should be distributed in a way that prioritises those with the greatest need to help reduce inequalities in access and outcomes.
- Current indicators of reproductive health are not adequate for measuring reproductive wellbeing at population level. New measures are being developed but further work is needed to evaluate and implement them.

Introduction

Reproductive health affects both men and women but women bear the brunt of reproductive ill health, not only as a result of their biological status but also because of a wider social, economic and political disadvantage. There are public health, human rights and economic reasons for investment in reproductive health. In the UK, women make up 51% of the population and 47% of the working population.[1] Whilst the Maternity Review[2] has focused efforts on improving healthcare for women and their babies during the crucial period of pregnancy and childbirth, the greater proportion of women's lives exists outside these events. Reproductive wellbeing for the non-pregnant woman is vital both for the woman herself and for the protection of future generations through the whole life course.[3] The non-pregnancy related aspects of reproductive health are often overlooked compared with the short and intense healthcare needs of a pregnancy.

The World Health Organization (WHO) define reproductive health and healthcare as:

> *"A state of physical, mental, and social well-being in all matters relating to the reproductive system. It addresses the reproductive processes, functions and system at all stages of life. Reproductive health, therefore, implies that people are able to have a responsible, satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so.*
>
> *Reproductive healthcare is defined as the constellation of methods, techniques and services that contribute to reproductive health and well-being by preventing and solving reproductive health problems. It also includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counselling and care related to reproduction and sexually transmitted diseases."*

Reproductive health is framed here as a positive state associated with well-being although the reproductive health of a population is typically measured by pregnancy-related "morbidity" outcomes such as rates of abortion or repeat abortion and teenage pregnancy. This problem-based approach leaves less room for a positive and rights based approach to care that could be directed towards reduction in gender inequalities, violence, discrimination and stigma - the often-hidden issues that determine reproductive wellbeing.

In stark contrast with the global context, poor reproductive health in the UK is not a significant contributor to national mortality figures and is therefore often seen through the important but narrow lens of contraception and as a component of sexual health. Commissioning structures separate contraception care from other related aspects of reproductive care such as abortion, maternity, cancer screening and menopause care which further compound this single-issue approach. Thus, contraceptive needs in the immediate postnatal period or menopause advice with perimenopausal contraception are likely to be separated from usual arrangements for contraceptive provision.

> *"...I would have been a bit happier...for my midwife to discuss it (contraception) during my pregnancy...because...at no point in my life was I more scared of getting pregnant than when I just had a baby. I just couldn't think of anything more traumatic..." (Focus group participant)*

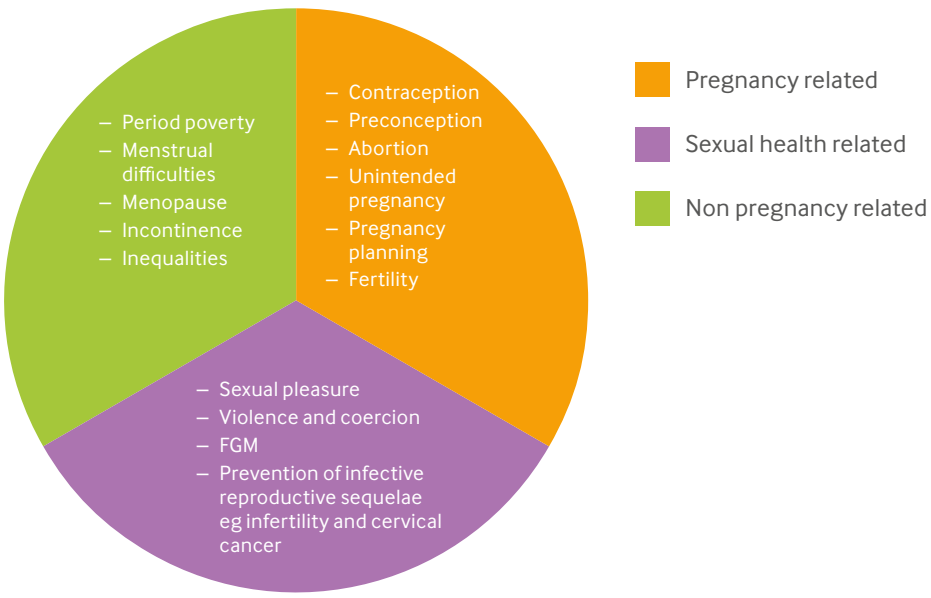
Other aspects of reproductive care such as heavy menstrual bleeding, infertility and menopause are often overlooked. This pattern in the delivery of care is at odds with the reality and needs of women's lives.

> *"...I look back and I think how much of my life I've lost to my periods... It's only when you step back and think other women don't go through this every month..." (Focus group participant)*

> *"...it's been an atrocious, ferocious and frightful experience (menopause)..." (Focus group participant)*

Comprehensive reproductive health is linked with perceptions of individual well-being and the rights agenda. It also impacts on population health across three distinct but related categories of health – pregnancy related, sex related and non-pregnancy non-sex related.

Figure 1. Three-pronged approach to reproductive health



Each of these categories is intrinsically linked with important population outcomes and the different areas of the Public Health Outcomes Framework (Figure 2).

Figure 2: Links of poor reproductive health with outcomes measured at national and local level contained within the Public Health Outcomes Framework (PHOF)[4]

Sex related	Pregnancy related	Non-pregnancy non-sex related
Domestic abuse Violent crime (including sexual violence) Cervical screening coverage Chlamydia detection rates in 15-24-year-olds Population vaccination coverage (HPV)	Percentage of live births with low birth weight Infant mortality Breastfeeding initiation and continuation Under 18 conceptions Child excess weight Excess weight in adults Drug and alcohol misuse Smoking status at time of delivery	Sickness absence (e.g. for menstrual pain and bleeding, endometriosis) Hip fractures in people 65 or over (linked to post-menopausal health) Health related quality of life for older people (menopausal symptoms, incontinence) Self-reported well being

A new model to define the scope and meaning of 'reproductive wellbeing' for women, linked to outcomes that matter to women, is needed to provide a framework for promotion, prevention and delivery of care across all domains throughout the life-course.

Defining the scope of reproductive health

Debate continues about definitions of reproductive health – what it is and is not, and how it interfaces with other aspects of health. WHO definitions may be important at policy levels, but they need to be operationalised in order to relate more closely to people's lived experiences. A modified Delphi exercise (consensus process) was therefore conducted alongside a mixed methods study (Women's Voices) to clarify the scope of reproductive health and the implications for population healthcare, exposing hidden needs and gaps in the delivery of care. Capturing the essence of reproductive health in this way ensured that a shared meaning between women themselves and those who make policy or deliver care was reached.

Consensus process

Conducting a consensus process was a way of obtaining commitment from relevant stakeholders and organisations to work together for a common goal and providing a platform on which to base future organisational action. Application of a modified Delphi process enabled this shared understanding to be formed across the wide range of stakeholders within different disciplines, at different levels of the system and geographically spread to be reached. Involvement of porposefully selected stakeholders representing all key groups, including commissioners, providers from all related disciplines, voluntary sector representatives, users and policy makers was essential to achieving the aims.

Women's Voices

Mixed methods were used to collect data from women about their views. Focus groups across the country with women from teenage to post-menopausal years were conducted. In addition, a national survey of more than 7500 women through social media was run which provided useful insights on many of the experiences that were significantly affecting women's lives.

Pillars of reproductive health

A distillation of themes emerging from both the consensus process and views of women resulted in "six pillars of reproductive health" (figure 3). These pillars offer a longer-term vision and a new framework for assessing unmet need, mapping provision and identifying appropriate outcome measures and/or information gaps.

Figure 3: Six pillars of reproductive health, from *A consensus statement: reproductive health is a public health issue*. (Public Health England, 2018)

- **Positive approach:** The opportunity for reproductive health and access to reproductive healthcare, to be **free from stigma and embarrassment.**
- **Knowledge and resilience:** The ability to **make informed choices** and exercise **freedom of expression** in all aspects of reproductive health.
- **Free from violence and coercion:** The ability to form enjoyable relationships whilst not fearing or experiencing any form of power imbalance or intimidation.
- **Proportionate universalism:** The ability to optimize reproductive health, and social and psychological well-being through support and care that is proportionate to need.
- **User-centred:** The ability to participate effectively and at every level in decisions that affect reproductive lives.
- **Wider determinants:** The opportunity to experience good reproductive health free from the wider factors (such as education and social deprivation) that directly and indirectly impact on reproductive well-being and the ability to access reproductive healthcare when needed.

Each of the pillars is illustrated with examples of hidden needs that surfaced through both "Women's Voices" and the emergent themes from the consensus forming process.

Positive approach and freedom from stigma

Women experience stigma and "reproductive shame" throughout their lives, both through their reproductive experiences and their interactions with healthcare. Societal constructions about womanhood as motherhood induce stigma surrounding both voluntary[5] and involuntary childlessness[6] and fear of social judgment when having an abortion.[7] Negative stereotypes associated with teenage motherhood affect how well young people engage with services and the responses of potential support networks.[8]

"...I never had the urge for a child and it's hard to say that." (Focus group participant)

Reproductive symptoms are also a source of embarrassment and shame. Menstrual taboo means that although one third of women take at least four days off work due to period related symptoms per year, almost half would not feel able to report the reason. Around the menopause women also report hot flushes and cognitive difficulties at a time that they are likely to be at the peak of their work life.

> *"I never did say to work, that I was off because of period pain because I worked for years in a very male dominated banking environment…I felt there was an issue of stigma with saying I was off…I would have to invent reasons month after month and soldier on and dose myself up…" (Focus group participant)*

Stigma constructs and shapes all perceptions and must be acknowledged as a central determinant of the degree to which a vision for reproductive well-being can be achieved.

Knowledge and resilience for informed choice

Learning about relationships, puberty, fertility and the reproductive life course, how to remain healthy and how to access care when needed provides a solid bedrock for making future decisions about health, although many women report large knowledge gaps.

> *"…she (my mother) gave me a pad and I didn't know what to do with it. I thought…that the sticky side went up." (Focus group participant)*

An individual who has had good quality school Relationships and Sex Education (RSE) is more likely to make behavioural choices that minimize risk.[9] Following an amendment to the Children and Social Work Bill (2017) statutory RSE will be implemented in 2019, which is a real opportunity for incorporating the comprehensive reproductive health education that is needed.[10]

Multiple knowledge sources are needed including online, intergenerational and lifelong learning. Consistent and comprehensive messaging in reproductive health should become an integral part of wider public health messaging. Society, employers and healthcare professionals also need education and encouragement to positively support women with reproductive needs.

> *"My GP just said, 'well you should have had your children earlier…you're going to find it very difficult now. You're just about to hit 30. The optimal time is about 22.'" (Focus group participant)*

Developments in the workplace are needed to ensure that women can function effectively, free from discrimination and able to access non-judgmental help when needed e.g. to facilitate breastfeeding or take time for antenatal or gynaecology appointments.

Enjoyable relationships free from violence

Having positive and pleasurable sex and relationships free from violence and coercion is not only considered as a human right but is also an important factor in maintaining wellbeing[11] and reducing sexual morbidity.[12,13] In stark contrast, adults with the most severe history of physical and sexual violence are the most likely to describe their health as poor or fair.[14] 14% of women in the UK have experienced sexual violence in comparison with 11% across the EU.[15]

Despite these important influences on public health, less than half of women who have experienced sexual violence report it.[16] Support for these women is patchy and there are no routine outcome measures that relate to either pleasure or violence in assessing reproductive health.

Universal care delivered proportionately to need

Services should be available in adequate number, physically and economically accessible and of good quality to maintain basic sexual and reproductive rights.

Basic reproductive healthcare – contraception, preconception advice, screening for reproductive disease and care around the menopause – is needed by virtually all women and often their male partners for a large proportion of their adult lives. The majority of women require contraception for around 30 years, interspersed (for about 4 out of 5 women) with shorter periods of wanting to become pregnant. All women intending to conceive have a need for preconception care – at least for folic supplementation - that mostly goes unrecognized.[17] At this time they should also receive screening for the early detection and prevention of reproductive tract morbidity such as cervical dysplasia and sexually transmitted infection. As women age, many will still require sexual health care, but their needs for contraceptive and preconception care are gradually overtaken with symptoms of the menopause with its associated impacts on wellbeing and need for care.

> *"...the whole of the symptoms of the menopause, depression, anxiety, hot flushes, sleepless nights, you feel yourself worthless...it's a horrible state. And you come back to your GP and she's telling you 'no, it's normal. Just get on with your life.'" (Focus group participant)*

Contraceptive, preconception, menopause and screening care are universal and overlapping requirements throughout life that require a population-based and integrated approach to delivery that recognizes, informs and normalizes but that is responsive to need. Historical patterns of delivery and current commissioning structures and service models have not intuitively generated this kind of system wide approach. Both universal (and light touch) coverage of care is needed but with provision of care proportionate to the scale and intensity of need, defined as proportionate universalism.[18]

Pathways into care

Successful universal provision maximizes access, information and choice for women, through innovative and potentially cost-saving pathways in a wider range of medical and non-medical settings. Nevertheless, this is offset by consequent identification of greater numbers needing equitable and timely access to more complex care such as complex contraception, colposcopy, fertility services, specialised menopause care, gynaecology or abortion.

> *"You spend years not trying to get pregnant, and then when you're trying to get pregnant, you think it's just going to happen." (Focus group participant)*

For example, whilst in the last decade there has been a strong drive to enable women to have full range of choice over contraception including the most cost-effective user-independent methods such as the implant or intrauterine device (IUD), this is not always matched by expansion of the specialized skills required to meet the resulting increased numbers requiring more complex care. Similarly, fertility services for preconception care or specialist menopause care for women debilitated by symptoms in spite of supported self-management can be hard to access. Access to these specialized services is guided by historical models of service provision and funding inconsistencies rather than need, with a potential for widening inequalities and limiting access.

Information gaps

Returning to the definition of reproductive health, meaningful measures of reproductive wellbeing can only truly be user defined. Nationally, reproductive wellbeing is measured according to rates of teenage pregnancy, rates of unplanned pregnancy as evidenced by abortion, access to contraception services and uptake of longer acting methods. Access to information about choice, uptake and satisfaction with contraception method is limited, particularly from General Practice where 70-80% of women attend, and none of the measures capture reproductive well-being *per se*.

The London Measure of Unplanned Pregnancy is a validated measure for use in pregnant populations which gives a more robust measure of reproductive choices. Implemented at population-level, it would enable the incidence of unplanned pregnancy to be estimated (using a score from 0-12) thereby providing a public health monitoring / surveillance system, just as antenatal HIV testing provides valuable estimates of HIV incidence in the population. New measures of pregnancy intention for non-pregnant women are in development, offering the promise of identifying and responding to a need for effective contraception to prevent unintended pregnancy or pre-conception care to improve maternal and infant health. Since much of reproductive health is about well-being, which is harder to measure than absence of disease such as cervical cancer, there is a great need for better quality of life measures specific to different aspects of reproductive health.

Moving forwards

The government is tasked with delivering cross-departmental plans for the attainment of the UN's sustainable development goal 5, gender equality. This is an opportunity for improving the health of women throughout the lifecourse. A framework that is meaningful to professionals and women and that advances the WHO definition for a UK context is a significant step to inform this process. This can form the basis of action acknowledging that reproductive health means more than contraception and the prevention of abortion (Figure 4) and calls for a widened set of accountability measures that truly reflect whether needs are being met. User-centred outcomes are essential for a comprehensive assessment of achievements in advancing women's reproductive health and rights.

Figure 4: Proposed actions for policy makers to advance reproductive health

- Reframe reproductive health in the context of choice and autonomy to promote wellbeing across the life-course rather than merely the absence of disease.
- Initiate campaigns that seek to reduce the stigma around reproductive health conditions and the barriers to seeking help.
- Raise awareness of prevalence of non-volitional sex and work to de-stigmatise and support reporting.
- Inform and encourage wider society, including employers, to recognise and support women with debilitating reproductive health symptoms enabling them to function effectively and free from discrimination.
- Ensure that an understanding of the reproductive life-cycle and awareness of fertility as well as teaching about healthy relationships is incorporated into the RSE curriculum and beyond through lifelong learning.
- Promote a system wide approach with leadership and accountability mechanisms that foster cross sectoral collaboration integrating maternity, primary care, gynaecology and sexual health.
- Support commissioning of reproductive healthcare in settings where risk of poor reproductive outcomes are enhanced e.g. substance misuse, mental health, weight management services.
- Implement self-reported and validated measures, such as the London Measure of Unplanned Pregnancy, into routine datasets.
- Develop new, user-reported measures that capture quality of reproductive wellbeing and can be incorporated into routine datasets.

Figure 5: Proposed actions for healthcare professionals to advance reproductive health

Develop a universal standard of care for healthcare services that supports the maintenance of sexual and reproductive health and rights that addresses stigma associated with provision and use of reproductive healthcare.

- Support users in lifelong learning about reproductive health including how to remain healthy, the importance of positive relationships and how to access care when needed.
- Provide a safe space in healthcare settings and train providers so that they can develop confidence in identifying and managing disclosures of violence and in providing holistic care to vulnerable women such as asylum seekers or sex workers.
- Take a lifecourse approach to reproductive health, integrating different aspects of care such as contraception and preconception and enabling individuals to optimize health before pregnancy.
- Develop a strategy to reach those who do not access services that they are likely to need such as contraception, preconception care, cervical cytology and menopause care. Capitalise on the "gateway" contact opportunities such as pregnancy, emergency contraception consultations, abortion and menopause.
- Link specialized and routine care through integrated care pathways that mirror the user journey and provide equitable access to specialized care when needed
- Target prevention at the marginalized who are at greater risk of poor outcomes and/or for whom the consequences of poor sexual and reproductive health are magnified, ensuring a renewed focus on proportionate universalism.
- Acknowledge and address as routine practice the influences of wider lifestyle factors on reproductive health outcomes such as smoking, substance misuse and obesity, social factors and environmental factors.

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