

Women's Health Coalition Wales: Evidence for Senedd Health & Social Care Committee

A Women and Girls' Health Plan and Quality Statement for Wales

1) Rationale

- **Wales needs to plan for the health of women and girls**

Women, girls, and those assigned female at birth (AFAB)* make up 51% of the population in Wales. Despite this, medicine and healthcare services have not necessarily met their needs, resulting in significant disparities in care between men and women. *Hereafter, reference will be to 'women' but, for the purpose of this document, should be considered inclusive of girls and people assigned female at birth.

Inequalities can be seen across Wales in the provision of women's health services, but they also exist in the care of diseases which impact both men and women, with women experiencing comparatively poor outcomes. Data from the Office of National Statistics (ONS) reveals that women can expect to live fewer years 'disability free' than men.

The Welsh Government's Gender Equality Review saw health as a top priority for women across Wales. However, its existing long-term plan for health and social care, 'A Healthier Wales' does not explicitly mention women's health. This risks a continuing lack of research and investment in those issues which impact them.

Women's exclusion from health service design is encapsulated in the failure to routinely include them in clinical trials, a situation not remedied until the 1990s – even now, clinical data doesn't always break down the efficacy / side-effects of treatments by sex.

Diagnostic criteria and treatment for conditions that affect both sexes are often based on the male experience, reflecting the fact that many clinical guidelines are not sex or gender-specific but based on a 'typical' male model. This means that women's reporting of symptoms can be over-looked, dismissed, or erroneously attributed to psychological causes, resulting in significant diagnostic delay, worsening prognoses, and considerable impact on wellbeing.

As both England and Scotland implement their own women's health strategies, it is vital that Wales follows suit, not only because tackling inequality is a core part of Welsh Government's work programme, but also because without proactively addressing underlying inequalities, the recommendations listed in 'A Healthier Wales' will be difficult to achieve for many women.

- **The Women's Health Coalition: Who are we?**

Members of the Coalition range from independent patient advocates to condition-specific charities, UK-wide umbrella organisations, and Royal Colleges. We all share one ambition: to see women and girls' health prioritised so that underlying and multi-generational health inequalities, and negative and dismissive attitudes which have resulted in horrifying reports like the 2020 Cumberlege review, 'First Do No Harm', are addressed. We want to see practical steps

taken to improve medical research, efficacy of treatment, and service provision across the country.

- **What is a ‘Women and Girls’ Health Wales Quality Statement’?**

The document attempts to provide a holistic and life-course approach to women’s health. It encompasses appendices focused on various physical and mental health issues and uses the Welsh Government’s own accountability measures: equitable; safe; effective; efficient; person-centred; timely.

Though the Quality Statement is wide in its scope, it is by no means exhaustive. There are many other areas of health where women are disproportionately impacted, and we look forward to working with the Welsh Government and patients themselves to identify these.

- **Public Awareness**

Although the Quality Statement focuses on clinical services, there are some elements which will require cross-departmental working, notably to support the development of public knowledge and supportive practice around women’s health.

Wider engagement with stakeholders, including patients and public, will be vital.

- **Intersectionality**

The Covid-19 pandemic has shone a light on many health inequalities, with disabled people, black and Asian groups, and those living in poor economic conditions, more likely to die as a result of Covid-19. The document should be seen as a starting point for further discussions on intersectional health inequalities, with women’s experiences being a key part of that.

- **Governance**

We suggest that consideration be given to changing the remit of the Women’s Health Implementation Group (WHIG) and Programme (WHIP) to one of co-ordination and oversight, ensuring that there are personnel tasked with representing women’s health concerns on all the NHS Wales networks and groups responsible for devising and implementing action plans for specific disease areas. It should also be able to facilitate personnel with a ‘women’s health brief’ on relevant Welsh Government tables outside of health, including education and employment, and have sufficient authority to direct activity where women’s health is not being adequately considered.

This approach will require additional resourcing, capacity, and new terms of reference for the WHIG which would see it encompass third sector and patient representatives as equal partners in activity to ensure a co-productive approach.

- **Oversight and Accountability**

The WHIG needs to be part of a mechanism in Wales which has sufficient powers of oversight and enforcement to drive improvements in the NHS, ensuring that everyone in Wales gets the best possible treatment in line with the values of prudent, value-based and patient-centred healthcare.

2) Key themes:

- **Access to specialist services**

Addressing the postcode lottery for care is a priority area raised by many of the organisations contributing to this Quality Statement. Existing models of healthcare provision in Wales have historically not worked for women by not being person-centred or tailored to their specific needs. Those requiring care from different specialties find that they are not adequately joined-up, and that there is a lack of collaboration between health boards in developing specialist services and making them universally accessible. Sometimes this results in NICE / equivalent guidance to best practice not being followed.

One potential way of addressing this issue lies with the Welsh Health Specialised Services Committee. The WHSSC has a section of commissioned services on 'Women's and Children's Health' but, at present, it is entirely focused on pregnancy and paediatrics which does women's health a disservice.

- **Improved data collection which, where possible, should be disaggregated by sex and gender**

This has emerged as a priority across all appendices and is vital to steer strategic direction, design, and delivery.

One mechanism used across Wales to create datasets on particular disease areas is the Quality Assurance and Improvement Framework used in general practice. Currently, the QAIF contains 19 active disease registers and indicators, none of which are gynaecological or menstrual health-related so it is unclear how far or how consistently prevalence, outcomes, or personnel working in this space are being recorded for these patient populations.

- **Support for sustainable co-production**

This is essential if we are to design services that properly meet service-users' needs. The Social Services and Wellbeing Act in Wales enshrines voice, control, and coproduction of services designed with users, to best meet their needs – the same must apply in health.

- **Enhanced training for health and care professionals, both as part of medical school curricula and continuing professional development**

There are challenges in establishing how long is spent on ‘women’s health’ in medical, nursing, midwifery, and allied health professionals’ training, not least due to variation in syllabuses across Wales and the UK. However, there are suggestions that it may be as little as 6 weeks or fewer over the course of three years.

We are calling for women’s health across the life course to be prioritised in the curriculum for all healthcare professionals, with a correlating increase in time allocated to the subject. Further, we believe that there is a need for oversight of this from Welsh Government.

We are unaware of any universities in Wales delivering a post-graduate women’s health module but would recommend that investment be made in such a course.

A QUALITY STATEMENT FOR WOMEN AND GIRLS IN WALES

- **EQUITABLE**

A Wales committed to proactively addressing health inequalities experienced by women, girls, and people assigned female at birth

1. All of those who are eligible under the age of 40 can access 3 full cycles of IVF, funded by the NHS in Wales, in line with NICE Guidance.
2. Maternal medicine networks are in place for patients wherever they live in Wales.
3. All of those experiencing recurrent pregnancy loss (miscarriage) in Wales have access to a specialist clinic offering nurse-led support, testing, and treatment.
4. Dedicated Mother-and-Baby inpatient beds for those experiencing severe peri-natal mental health issues are available in every health board.
5. Co-production and implementation of targeted interventions to engage with women who are in those demographics least likely to attend cervical screening or access sexual and reproductive services.
6. Diagnostic criteria and support systems are inclusive of the ways in which autistic and neurodivergent females present.
7. All health boards conform to best practice in provision of pain management, IV sedation, and general anaesthesia to patients requiring minor gynaecological procedures.
8. Sex and gender-specific interventions commissioned to better support women and girls’ mental health.

9. An all-Wales abortion strategy is in place so that services are geographically accessible to all women.
10. Women's health is prioritised in foundation doctors' training to address mythologising, normalisation, unconscious bias, diagnostic delay, and lack of adequate support associated with menstrual health conditions like endometriosis and adenomyosis.
11. The Welsh Health Specialised Services Committee playing an integral role in ensuring equitable access to tertiary care for patients in Wales living with complex, chronic conditions like endometriosis, lupus, and rare autoimmune conditions.
12. A consistent pan-Wales pathway for patients with premenstrual disorders in Wales.
13. A universal understanding of the multifarious and long-term impacts of PCOS which reduces variation in care across primary and secondary services and between health boards.
14. Public health information about menopause and HRT is communicated to all women at age 40, alongside incentivisation of training for healthcare professionals in primary care, and pan-Wales access to specialist menopause clinics.
15. Women's risk of heart disease is widely understood by both public and healthcare professionals and optimal treatment is routinely provided equitably to men.
16. Resources ringfenced to tackle the 250% increase in incidences of eating disorders during the Covid19 pandemic.
17. Evidence-based interventions to appropriately support people who self-harm from different communities, including young women and those living with long-term physical health conditions.
18. Enhanced training for healthcare professionals to better support the disproportionate number of women and girls living with chronic health conditions like Ehlers Danlos Syndrome.
19. Widespread acknowledgement of the existence and impact of post-viral illnesses, such as Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), and Long Covid, alongside equitable access to high-quality multi-disciplinary services.
20. A Wales-wide commitment to tackling the gender bias that too often sees fibromyalgia symptoms and their impact underplayed or dismissed.
21. All dermatology services and personnel in Wales sufficiently trained and resourced to offer an inclusive environment where ethnic variation in prevalence and presentation of skin diseases in women is understood.
22. Investment in research on palliative and end of life care through a sex and gender lens and dissemination of results so that Wales's workforce is fully equipped to provide appropriate care.

- **SAFE**

A Wales where every woman has the right to expect safe care, in line with clinical guidance, best practice, and as part of an informed decision-making process

23. Educational initiatives for those in primary care enabling GPs to feel more equipped to manage common medical disorders that complicate pregnancy.
24. Effective, safe, and equitable abortion care for all women in Wales.
25. All service-users undergoing minor gynaecological procedures are provided with evidence-based and patient-reviewed information about pain management options in advance so that they can make informed choices about their care.
26. An HPV self-sampling pilot is undertaken in Wales to examine efficacy and improve take-up.
27. All lupus patients in Wales to have both emergency and formal care plans so that their needs are appropriately managed at all points in their patient journey.
28. Expanded services and initiatives that enable early identification and help-seeking for eating disorders and self-harm, alongside straightforward access to specialist and in-patient care within Wales.

- **EFFECTIVE**

A Wales invested in working with patients, healthcare professionals, and third sector to research, co-produce and implement models of service delivery that work effectively for women

29. Women and girls are provided with a full range of sexual and reproductive health services.
30. Mandatory autism awareness training which incorporates the specific needs of autistic women and girls to be provided to all healthcare professionals in Wales.
31. Abortion services designed and provided in line with the NICE Abortion Care Guideline.
32. Increased public and clinical awareness of menstrual wellbeing and pathways for the diagnosis and management of associated health conditions including endometriosis, adenomyosis, premenstrual syndromes, and polycystic ovary syndrome (PCOS).
33. Investment in research into common gynaecological and endocrinological conditions is prioritised to better understand causation and develop improved diagnostic tools and treatments.
34. Work underway to increase uptake of cervical screening and follow-up procedures to ensure the effectiveness of the cervical screening programme, saving as many lives as possible from cervical cancer.

35. Redesigned cardiac rehabilitation services to include digital provision which has been shown to increase patient participation in women and men.
36. Increased funding for research into mental health conditions like eating disorders, bringing investment in line with physical health conditions of a similar prevalence.
37. To improve understanding, knowledge, and management of hypermobility spectrum disorders like Ehlers Danlos Syndrome, to include development of a comprehensive care pathway.

- **EFFICIENT**

A Wales where services and personnel work together seamlessly, communicating effectively with each other and the patient so that care is provided at the right time, in the right place, by the right person

38. Investment in Wales-wide provision of Advanced Skills Women's Health Nurses in primary care, to provide information and support on a range of commonly experienced issues and conditions, including fertility.
39. Data collected on the number of miscarriages being reported to Early Pregnancy Units, GPs, and Emergency Departments to better understand the scope of the problem and enable appropriate target-setting for reductions and support services.
40. Development of best practice guidance on opportunistic provision of contraception and testing for sexually transmitted infections in services such as maternity, abortion, and screening appointments.
41. A joined-up approach with Welsh Government's Period Dignity Strategy to ensure equitable and timely access to educational resources, period products, and positive messaging which empowers individuals to challenge misconceptions about menstruation.
42. Improved awareness of menstrual wellbeing and the diagnosis and management of associated health conditions including endometriosis; adenomyosis; PCOS and pre-menstrual dysphoric disorder (PMDD).
43. Streamline care pathways to secondary and tertiary gynaecology services to reduce repeat and 'wasted' appointments and free up NHS resources for other conditions.
44. Include hormone sensitivity and impact of surgical menopause in enhanced menopause training to improve patient experience and access to timely and appropriate treatment and support.
45. Increased public and clinical understanding of menopause, with dedicated and multi-disciplinary centres in each health board.
46. Increased medical research into areas of medicine which disproportionately impact women as well as proportional representation in clinical trials.

- **PERSON-CENTRED**

A Wales which offers a holistic, life course approach to women's health, privileging women's voices and expertise on their own bodies and tailoring healthcare to the individual's needs and preferences

47. Collaboration with specialist charities and peer-led initiatives to sustainably support patients across Wales experiencing medical disorders in pregnancy.
48. Hybrid models of testing and care for sexual and reproductive health, including online ordering of tests and medication, telemedicine, and in-person consultations, based on individuals' needs and preferences.
49. Health education, training, communication, clinical environments and interventions are more accessible and inclusive to neurodivergent females.
50. Identifying and challenging unconscious bias in relation to women's health is a core part of healthcare professionals' training so that prevention of pain and trauma in outpatient gynaecology settings is a fundamental part of service provision.
51. Staff education and training across all health and care services takes a trauma-informed approach which incorporates understanding of gendered experiences and inequalities.
52. A suite of options is offered to individuals affected by chronic gynaecological conditions to help them better manage the impact of their condition, including pan-Wales provision of pelvic physiotherapy, mental health support, and pain management clinics.
53. Where hysterectomy is advised, information on post-operative issues, including those relating to ovarian function, is routinely provided and includes access to menopause services.
54. Multi-disciplinary care pathways for PCOS patients, tailored to individuals' needs and ensuring a holistic approach to service provision.
55. A collaborative approach to menopause management and support, to include various government departments, employers, and the third sector.
56. Information and signposting to sources of support following diagnosis of cell-changes during cervical screening.
57. Increased vigilance and capacity to provide compassionate, trauma-informed support across all healthcare settings for people who are self-harming or at increased risk of doing so.

- **TIMELY**

A Wales which uses all mechanisms at its disposal to ensure that women are able to access prompt and optimal care, thereby improving patient experiences and longer-term outcomes

58. Partnership-working established between Health and Education departments to provide evidence-based resources and training to deliver menstrual wellbeing, fertility and pre-conception health education in all schools in Wales, enabling earlier help-seeking and expedited diagnosis for a range of menstrual and reproductive health conditions.
59. Long-term monitoring of those who experience recurrent miscarriage to enable early intervention in possible development of associated health conditions later in life.
60. All relevant healthcare professionals receive ongoing training so that perinatal mental health issues can be identified early, and support provided to prevent long-term physical and mental health impacts on mother and child(ren).
61. HRT is provided in a timely manner as part of a package of measures to protect women from longer-term health conditions like osteoporosis and cardiovascular disease.
62. Public messaging, early diagnosis, prompt treatment, and ongoing monitoring of risks identified in pregnancy to reduce women's risk of developing heart disease later in life.
63. Early and expert intervention to prevent patients with lupus and Sjogren's sustaining life-limiting organ damage at great cost to both their health and the public purse.
64. Ensure that no woman goes into labour with undiagnosed EDS to avoid complications for both mother and baby, and long-term health implications.

Women's Health Wales Coalition, Contributing Organisations (in alphabetical order and who have contributed to the development of the work; we anticipate a larger list of organisations who endorse the proposal):

Action for ME

Autistic UK

Beat – the UK's Eating Disorder Charity

British Association of Dermatologists

British Heart Foundation Cymru

British Pregnancy Advisory Services

Brook

Campaign Against Painful Hysteroscopy

Compassionate Cymru

Disability Wales

Ehlers Danlos Support UK

Endometriosis UK

Ethnic Minority Women in Welsh Healthcare (EMWWH)
Fair Treatment for the Women of Wales (FTWW, supporting patient advocates on most appendices)
Fertility Network UK
Faculty of Sexual and Reproductive Health (FSRH)
Fibromyalgia Support Wales
International Association of Premenstrual Disorders
Jo's Trust
Learning Disability Wales
LUPUS UK
Marie Curie
Mind Cymru
National Federation of Women's Institutes
Plan International
RareQOL
Royal College of General Practitioners (RCGP)
Royal College of Nursing (RCN)
Royal College of Obstetricians and Gynaecologists (RCOG)
Royal College of Physicians (RCP)
Royal College of Psychiatrists (RCPsych)
Samaritans
The Autistic Women's Empowerment (AWE) Project
The Fibromyalgia Association UK (FMAUK)
The Hypermobility Syndromes Association (HMSA)
Tommy's
Verity PCOS
Welsh Association of ME and CFS Support
Women's Equality Network (WEN) Wales

Health Condition / Issue-specific Appendices (in order of appearance):

Fertility

Maternal Medicine

Pregnancy Loss / Miscarriage

Perinatal Mental Health

Abortion

Sexual and Reproductive Health

Autism and Neurodivergence

Minor Gynaecology Procedures and Pain Management

Cervical Screening and Cell Changes

Trauma and Post-Traumatic Stress Disorder (PTSD)

Menstrual Health

Endometriosis

Adenomyosis

Premenstrual Dysphoric Disorder (PMDD)

Polycystic Ovary Syndrome (PCOS)

Menopause

Heart Conditions

(Rare) Autoimmune Conditions

Eating Disorders

Self Harm

Hypermobility Syndromes and Ehlers Danlos Syndrome (EDS)

Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS)

Long Covid

Fibromyalgia

Skin conditions

End of Life Care