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Women's Health Wales:

A Quality Statement for the
Health of Women, Girls, and those
Assigned Female at Birth

2022



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Rationale, Key Themes, Structure



Rationale

→ Wales Needs to Plan for the Health of Women, Girls, and those Assigned Female at Birth

Women, girls, and those assigned female at birth (AFAB)* make up 51% of the population in Wales¹. Despite this, medicine and healthcare services have not necessarily met their needs, resulting in significant disparities in care between men and women, which have only been exacerbated by the pandemic.

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 men² so inequalities are costing women their health, their wellbeing, their quality of life, and their lives. As such, we are calling on the Welsh Government to make a firm commitment to this Women's Health Wales Quality Statement by ensuring the timely implementation of its recommendations.

Whilst 'A Healthier Wales' makes clear its aim of ensuring person-centred care across the country, it fails to account for substantive pre-existing inequalities which prevent person-centred care being a reality for many groups in Wales, not least women

The Welsh Government has pledged to being a 'feminist government'³ and undertaken a Gender Equality Review which saw health as a top priority for women across Wales⁴. However, somewhat incongruously, its existing long-term plan for health and social care, 'A Healthier Wales'⁵ does not explicitly mention women's health.

Whilst 'A Healthier Wales' makes clear its aim of ensuring person-centred care across the country, it fails to account for substantive pre-existing inequalities which prevent person-centred care being a reality for many groups in Wales, not least women. Indeed, in Wales and beyond, there has been a historical lack of investment and research into health conditions which disproportionately affect women and AFAB, resulting in a lack of suitably specialised service provision for many of those conditions⁶.

* 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.

¹ UK Government <https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/male-and-female-populations/latest>

² ONS (2021) <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/healthstatelifeexpectanciesbynationaldeprivationdecileswales/2017to2019>

³ Welsh Government (2020) Advancing Gender Equality plan, <https://gov.wales/sites/default/files/publications/2020-03/advancing-gender-equality-plan.pdf>

⁴ Chwarae Teg (2019) Gender Equality: A Roadmap, <https://chwaraeteg.com/wp-content/uploads/2019/09/Gender-Equality-a-roadmap-for-Wales.pdf>

⁵ Welsh Government (2019) A Healthier Wales Action Plan, <https://gov.wales/sites/default/files/publications/2019-10/a-healthier-wales-action-plan.pdf>

⁶ UK Clinical Research Collaboration, (2015) UK Health Research Analysis, <https://www.ukcrc.org/wp-content/uploads/2015/08/UKCRCHealthResearchAnalysis2014-WEB.pdf>

When it comes to women's health, Wales is not an exception but merely part of a wider cultural landscape which has historically tended to marginalise their needs. 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 1990s⁷ – even now, clinical data doesn't always break down the efficacy / side-effects of treatments by sex. An additional complexity is the tendency for research data to conflate sex and gender, using them as interchangeable terms even though they are distinct concepts. It is of vital importance that this distinction is acknowledged and accurately recorded if we are to see real progress in women's health research and clinical outcomes^{7a}.

Further, diagnostic criteria and treatment for conditions that affect both sexes are often based on the male experience, largely because 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 or dismissed⁸. Medical journals and papers still regularly describe females' presentation as 'atypical' which is both unhelpful in terms of making a diagnosis but also underlines the 'othering' of women, despite women making up over half of the population⁹.

When it comes to pain, including both treatment of post-operative pain and in emergency settings, evidence suggests that women wait longer than men for pain relief¹⁰, and are more likely to be given sedatives instead¹¹. At the same time, data reveals a longer time from the onset of symptoms to diagnosis in female patients in 6 out of 11 types of cancer¹², with women having to visit their GP more often than men to get a diagnosis¹³. Further, many women report having their symptoms dismissed as either 'normal' or erroneously attributed to psychological causes¹⁴, resulting in significant diagnostic delay, worsening prognoses, and considerable impact on wellbeing¹⁵.

As both England¹⁶ and Scotland¹⁷ move towards implementing their own women's health strategies, it is vital that Wales follows suit in recognising and seeking to ameliorate these issues. Not only because tackling inequality is a core part of Welsh Government's work programme, but also because without proactively addressing underlying problems, the recommendations listed in 'A Healthier Wales' will be difficult to achieve for many women.

⁷ Jackson, G. (2019) The Female Problem, the Guardian, <https://www.theguardian.com/lifeandstyle/2019/nov/13/the-female-problem-male-bias-in-medical-trials>

^{7a} <https://www.bmj.com/content/372/bmj.n735?msclkid=2b4dca31b1d011ecb-fd-8cd3e55ef10fa>

⁸ Cleghorn, Elinor 'Unwell Women: Misdiagnosis and Myth in a Man-Made World', Dutton, June 2021

⁹ Improving Diagnosis in Healthcare (2015) <https://www.ncbi.nlm.nih.gov/books/NBK338593/>

¹⁰ Robertson, J. (2014) Waiting Time at the Emergency Department from a Gender Equality Perspective https://gupea.ub.gu.se/bitstream/2077/39196/1/gupea_2077_39196_1.pdf

¹¹ Calderone, K. (1990) The influence of gender on the frequency of pain and sedative medication administered to post-operative patients, <https://link.springer.com/article/10.1007/BF00289259>

¹² Din et al, (2015) Age and Gender Variations in Cancer Diagnostic Intervals in 15 Cancers <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0127717>

¹³ Lyratzopoulos et al Gender inequalities in the promptness of diagnosis of bladder and renal cancer after symptomatic presentation, BMJ Open, Vol.3:6 <https://bmjopen.bmj.com/content/3/6/e002861>

¹⁴ Floyd, B. (1997) Problems of accurate medical diagnosis of depression in female patients <https://europepmc.org/article/med/9004374>

¹⁵ Kiesel, L. (2017) Women and Pain, <https://www.health.harvard.edu/blog/women-and-pain-disparities-in-experience-and-treatment-2017100912562>

¹⁶ UK parliament, Women's Health Strategy March 2021 <https://hansard.parliament.uk/Commons/2021-03-08/debates/C097866A-F77A-4745-B599-4240BD-2D72EB/Women%E2%80%99SHealthStrategy>

¹⁷ Scottish Government (2021) Women's Health Plan <https://www.gov.scot/publications/womens-health-plan/>

→ The Women's Health Wales Coalition - Who are we?

It is against this backdrop that the Women's Health Wales Coalition has come together to create a Quality Statement for the Health of Women, Girls, and those Assigned Female at Birth. The work of this coalition of organisations and individuals has been greeted positively by Welsh Government and seeks to support Welsh Government commitments to diversity and equality action plans co-produced with disabled, LGBTQ+, black, Asian, and minority ethnic people.

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 rightly prioritised in Wales as it is now being in other UK nations. To do so will address underlying and multi-generational health inequalities and disparities affecting women, negative and dismissive attitudes which have resulted in horrifying reports like the 2020 Cumberlege review, 'First Do No Harm'¹⁸, and see practical steps taken to improve medical research, efficacy of treatment, and service provision across the country.

→ How to Use this Document

The Women's Health Wales Quality Statement attempts to provide both a holistic and life-course approach to women's health, encompassing a range of both physical and mental health issues. A life course approach necessitates a strategy which moves beyond the traditional conceptualisation of women's health as including only so-called 'bikini medicine' and maternity care and looks at women's health 'in the round'.

If Wales is to provide equitable care and treatment for women, this health plan must look at all disease areas where women are disproportionately impacted or can expect worse health outcomes attributable to their sex or gender

Where maternity care is concerned, we would ask that this QS be viewed in conjunction with the work of the Maternity and Neonatal Network, part of the NHS Wales Health Collaborative¹⁹.

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.

¹⁸ Cumberlege (2020) First Do No Harm, https://www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf

¹⁹ NHS Wales <https://collaborative.nhs.wales/networks/wales-maternity-and-neonatal-network/>

The purpose of this Quality Statement is to drive improvements in the health of women across a wide range of conditions and diseases. As well as those organisations contributing content to this document, we anticipate collaborative and complementary working alongside other groups and strategies which aren't explicitly referenced in this document. A Wales-wide mapping exercise would be prudent in the first instance to establish where women's health and related experiences might be considered integral.

The Women's Health Wales Quality Statement should therefore be used as providing recommendations to support the achievement of best practice in women's health and care.

→ **Public Awareness**

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

It is most important that partners work together to overcome any sense that women's health is either 'niche' or exclusively a female 'issue'. There can be little doubt that improving women's health has positive benefits for society as a whole and so men too will play a vital role as supportive, collaborative partners on this journey. Indeed, going forward, we would urge the Welsh Government pay particular attention to sex and gender considerations when developing all future healthcare delivery plans: whilst as this document evidences, women disproportionately experience sex and gender-related health inequities, care that is specifically tailored to individual needs would undoubtedly benefit all recipients.

Wider engagement with stakeholders, including patients and public, must be a key part of any consultation process on the Women's Health Wales Quality Statement as a whole, including its content, aims, and implementation. Patients and patient advocates have been involved throughout the process thus far, from the document's inception to its publication so, to ensure wider feasibility, acceptance, and effectiveness of the Quality Statement, we recommend that this co-productive and consultative approach continue.

For many of the specialist charities involved in the writing of content for this document, diagnostic delay for the health conditions they represent results in significant problems and costs for both patient and health and social care services. This can often be attributed to lack of awareness amongst patients, their wider social circle, and healthcare professionals, as well as the 'normalisation' of symptoms.

Educational resources and their dissemination in a wide range of settings – not least schools, colleges, and workplaces – are key to improving outcomes for patients. Good practice in this regard is already underway in Wales, with Welsh Government's Women's Health Implementation Group providing funding and expertise for the co-production of resources on both menstrual health and endometriosis for use in educational settings across Wales. This approach has required effective cross-departmental working, with the Equality Team's Period Dignity Group, Public Health Wales, and the Education Directorate all having buy-in to the project.

²⁰ WEN Wales <https://wenwales.org.uk/wp-content/uploads/6033-WEN-Unpaid-Care-FINAL.pdf>

²¹ The Health Review (2020) Health Equity in England, <https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on>

Almost half of the UK's workforce are women, and, in Wales, women make up 78% of health and social care personnel

Improved support in the workplace is also vital to ensuring women are able to remain in employment whilst balancing other responsibilities²⁰. Almost half of the UK's workforce are women, and, in Wales, women make up 78% of health and social care personnel. It is therefore vital that employers are equipped to better understand and appreciate the impact of various health issues on their employees and create an environment which supports them to manage their health needs.

→ Intersectionality

The Women's Health Wales Coalition is also very much aware of underlying health inequalities and their intersectional impacts on women's health and wellbeing here in Wales. There has been much discussion both within the coalition and wider networks about the role economic and social conditions play in causing, perpetuating, and compounding poorer health outcomes. The Marmot Report 2020²¹ showed that the health gap has grown between wealthy and deprived areas, with marked regional differences in life expectancy.

The Covid-19 pandemic has shone a light on many of these health inequalities, with disabled people, black, Asian and minority ethnic people, and those living in poor economic conditions, more likely to die as a result of Covid-19²². For the purposes of this Quality Statement and Appendices, the focus is predominantly on clinical issues. However, the Women's Health Wales Coalition would urge Welsh Government to see this document as a starting point for further discussions on intersectional health inequalities, with women's experiences being a key part of that. For further discussion on this, we would urge reference to the Welsh NHS Confederation's work on Health Inequalities which asks Welsh Government to commit to a cross-governmental strategy to eliminating health inequalities²³.

Joined-up working with the panoply of strategic groups responsible for delivering action plans in Wales will be vital if we are to make sure that the multifarious factors implicated in women's health are properly considered. These may include, amongst others, Gender Equality, Period Dignity, the Disability Rights Taskforce, Race Equality Action Plan, LGBTQ+ Action Plan, Together for Mental Health, Violence Against Women, Domestic Abuse, and Sexual Violence (VAWDASV). To ensure the avoidance of silo-ed working, duplication or omission, a robust governance structure will be required.

→ Governance

We suggest that consideration be given to changing the remit of the Women's Health Implementation Group (WHIG) and the Women's Health Implementation Programme (WHIP).

Going forward, the WHIG's programme of work should primarily become 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. The WHIG's role would be to provide ongoing support and liaison for its representatives, enabling regular and consistent recording, monitoring, and evaluation of all women's health-related activity in these high-level, strategic spaces.

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. In the first instance, its programme of work should focus on establishing a network of personnel with sufficient knowledge of the Women's Health Wales Quality Statement, and the relevant appendices therein, as well as wider health inequalities, to ensure that these issues are embedded in both clinical action plans and wider policy development and implementation. It may be that personnel are derived from existing membership of networks and groups but that additional training and support is provided by the WHIG.

²² Public Health England (2020) Disparities in the risk and outcomes of COVID-19, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf

²³ The Welsh NHS Confederation (2021) <https://www.nhsconfed.org/sites/default/files/2021-05/Making%20the%20difference%20-%20April%202021.pdf>

Personnel would be required to report back to the WHIG on progress so that it is possible to monitor how far women's health needs are being accommodated across Wales and in each clinical and policy area. The Period Dignity Roundtable, hosted by the Communities Division and Jane Hutt MS, Minister for Social Justice, is a good example of how a women's health representative, facilitated by the WHIG, provides health-focused expertise and input to both strategy and resources under development.

→ 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.

Patients, advocates, and clinicians have repeatedly raised concerns about the inequity of access to planned care and elective surgical services across Wales. As reported by the Royal College of Physicians, 'There is a real postcode lottery of care, and this comes at an enormous human and financial cost'²⁴.

The Appendices to this Quality Statement highlight that there are patients, especially those with more 'complex' conditions, who are not able to access care in line with NICE or other national clinical guidance. 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. As such, there is a need for system transformation across health board boundaries, clinical specialties, and public health to enable improvement in services and patient outcomes, to reduce inequalities, and build strong governance and accountability to ensure that the NHS in Wales gets the best value from its combined resources.

It may be that this mechanism is incorporated into the Terms of Reference for any new Women's Health Implementation Group, or it may be at a higher strategic and executive level, but it should support and demonstrate the co-productive activity required for patient-centred strategic change, as well as play a fundamental role in guiding service design, ensuring implementation, and conducting evaluation across Wales. This is a forward-thinking and preventative approach, unlike complaints processes and inquiries which are, by definition, retroactive.

We would like this oversight body to have the power to instruct better data-gathering including coding of specific conditions where it currently does not always happen, and use of evidence to inform service development, audit services and patient experience across Wales. It should have sufficient authority to ensure appropriate investment in training and service delivery and oversee the implementation of joined-up pathways for all patients in Wales, irrespective of geography. This would eliminate the existing disparities in care which underpin inequalities of outcome for Wales's population.

²⁴ Royal College of Physicians
<https://www.rcplondon.ac.uk/news/rcp-joins-more-20-organisations-call-independent-nhs-wales-executive>

Key Themes



A number of commonalities are emerging from the Appendices to which the Women's Health Wales Coalition would like to draw attention:

i) 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. Presently, the system of 7 relatively autonomous health boards, each working independently, prevents out-of-area referrals for many of the health conditions represented by members of the Women's Health Wales Coalition, even though specialist services are not available locally.

As discussed already, partly, the lack of provision can be attributed to a lack of research / data around women's health needs and a historical neglect or dismissal of associated symptoms or conditions. This has led to a wholesale lack of investment and failure to develop consistent, equitable care pathways.

Most appreciate that the population size in Wales prevents specialist / tertiary services being available in every health board. However, the block funding system in Wales means that patients from outside of the health board(s) in which services are located are often prohibited from accessing them because funds don't follow the patient. This also applies to services located outside of Wales, in England, and is despite a historic commitment that borders should not prevent access. As things stand, a postcode lottery is embedded in Wales's national health service. It is vital that these systemic issues are resolved: as with 'A Healthier Wales', trying to improve women's health within the existing framework will only get us so far and will not solve the most insidious problems faced by patients in Wales.

To a degree, there is a mechanism already in place to improve access to services in Wales - the Welsh Health Specialised Services Committee (WHSSC) is a joint committee made up of, and funded by, the seven local health boards in Wales. It is hosted by Cwm Taf Morgannwg University Health Board and has an overall annual budget of £680 million. The WHSSC has a section of commissioned services on 'Women's and Children's Health' but, at present, it is entirely pregnancy and paediatric related²⁵ which does women's health a disservice and would not coalesce with a Women's Health Wales Quality Statement which seeks to see women's health considered holistically and throughout the life course.

²⁵ NHS Wales <https://whssc.nhs.wales/commissioning/commissioned-services/>

There is consensus on the part of the Women's Health Wales Coalition that the WHSSC needs to play a much more prominent role in ensuring equity of access to tertiary services wherever patients are located in Wales

ii) Improved Data Collection

This has emerged as a priority across all Appendices. Caroline Criado Perez's seminal text, 'Invisible Women: Exposing Data Bias in a World Designed by Men'²⁶ evidences how 'the gender data gap...is at the root of perpetual, systemic discrimination against women, and that (it) has created a pervasive but invisible bias with a profound effect on women's lives'. Whilst this gender data gap is 'not generally malicious, or even deliberate' it is nevertheless incumbent upon the Welsh Government and our public bodies to make a real commitment to addressing it, not least because it can have serious consequences for women's health and lives. Where healthcare is concerned, there is a clear need for data to be both collected and disaggregated according to sex and gender, and for the useful results to steer strategic direction, design, and delivery.

Thorough and consistent data collection is vital to monitor and evaluate progress and implementation of the Quality Statement and subsequent action plans, the oversight of which should lie with a new Women's Health Implementation Group (see Governance section). As it stands, the seven health boards collect data differently so the need for a standardised approach is essential. Similarly, data collection within health boards and the various specialisms therein must be uniform so we can better track patient experiences and outcomes.

One mechanism used across Wales to create datasets on particular disease areas is the Quality Assurance and Improvement Framework²⁷ used in general practice. Currently, the QAIF contains 19 active disease registers and indicators, ranging from asthma to diabetes to epilepsy to stroke, all of which carry a significant economic and public health burden. Despite the numbers affected and costs involved, there is not a single gynaecological or menstrual health condition listed, so it is unclear how far or how consistently prevalence and outcomes are being recorded for these patient populations.

There is a lack of visible Wales-specific data on numbers and locations of personnel already in primary care providing support for those health conditions which aren't linked to the QAIF which, in this instance, would include menstrual / reproductive health issues. Without that data, there is no way to establish patient need or what services are being provided, and limited ways to link in and communicate with personnel on priorities and innovations. We would strongly recommend that a survey of provision in Wales is carried out to establish existing numbers and locations of personnel so that work can be undertaken to address gaps. Improving the health of women is everyone's responsibility, therefore increasing the awareness and knowledge of women's health and the gender specific pathology of certain diseases for all health care professionals is required. Best practice would see a GP and nurse with specialist interest in women's health in each practice or shared between GP clusters.

²⁶ Priado-Perez, C. (2019). Invisible women: Data bias in a world designed for men, <https://carolinecriadoperez.com/book/invisible-women/>

²⁷ NHS Wales, Quality Assurance and Improvement Framework, <http://www.wales.nhs.uk/sites3/Documents/480/Guidance%20for%20GMS%20Contract%20Wales%20-%20Quality%20and%20Improvement%20Framework%202019-20.pdf?orgid=480&pid=96339>

Technology should be harnessed effectively to aid with data collection and communication. During the pandemic, we have seen an increasing role for technology in providing hybrid models of care, something which should continue to be explored in a co-productive way. All innovations in technology should be co-designed to ensure they tackle the challenges experienced by both patients and practitioners, including accessing digital in rural areas, ongoing monitoring of patient health via wearables and remote consultations, alongside improved mechanisms for gathering, recording, and utilising data to improve patients' experiences and outcomes.

iii) Support for Sustainable Co-production

Without exception, the organisations and individuals who have contributed evidence-papers to this Quality Statement would like their involvement to continue in the development and implementation of dedicated action plans for the specific health conditions in which they have expertise.

It is clear, both from the recommendations made throughout the Appendices, from professional clinical bodies' policies, and from Welsh Government's own strategic direction, that co-production is essential if we are to design services that properly meet service-users' needs. The Social Services and Wellbeing Act in Wales enshrines 'Voice and Control' and 'Co-production' of services designed with users, to best meet their needs²⁸ – the same must apply in health, which underpins so many people's wellbeing. A genuinely dialogical process, where patients and advocates are involved at every stage, from conception, to delivery and evaluation, is the best way to ensure efficient and effective care, in line with prudent, value-based principles.

We would urge the Welsh Government to ensure that they make engagement with the wider public a key part of the process to design and implement any action plans on women's health

One way to do this would be to utilise NICE Guidance on Shared Decision-Making²⁹ which not only provides tools to help healthcare professionals develop the skills and knowledge to have constructive conversations with the people for whom they are caring but also makes recommendations on how to embed shared decision making in organisational culture and practices.

National investment in mechanisms to ensure the continuation and sustainability of this approach in health service design, delivery, and evaluation is essential and should underpin all activity with regards to future implementation of recommendations. The Welsh Government currently supports this activity in social care through its 'Sustainable Social Services' grant funding³⁰, so something similar should be developed and codesigned, for third sector partners in health.

²⁸ Care Council for Wales
https://socialcare.wales/cms_assets/hub-downloads/Principles-Resource-Guide_March-17.pdf

²⁹ NICE Guidance [NG197]
<https://www.nice.org.uk/guidance/ng197>

³⁰ Welsh Government, Sustainable Social Services Third Sector Grant for 2020 -2023,
<https://gov.wales/sustainable-social-services-third-sector-grant-2020-2023-funded-projects>

iv) Training for Health and Care Professionals

As already described, lack of inclusivity in clinical research, alongside inadequate funding for female-specific health research may well underpin the failure to prioritise women's health in medical textbooks³¹ and training, and subsequently women's reporting of poor experiences in clinical settings.

There are challenges in establishing how long is spent on 'women's health' in medical training or in nursing, midwifery, and allied health professional training curricula, not least due to variation in syllabuses across Wales and the UK. However, anecdotally, we know that time spent on maternity and gynaecology in Wales's medical schools is limited, with suggestions that it may be as little as 6 weeks or fewer over the course of three years.

Given that women make up 51% of the population and the gaps in knowledge and service provision that have emerged from the evidence contributed to this Quality Statement by members of the Women's Health Wales Coalition,

³¹ Science Daily, Medical Textbooks use White, Heterosexual Men as a 'Universal Model', Oct 2008 <https://www.sciencedaily.com/releases/2008/10/081015132108.htm>

³² NHS Wales, Quality Assurance and Improvement Framework, <http://www.wales.nhs.uk/sites3/Documents/480/Guidance%20for%20GMS%20Contract%20Wales%20-%20Quality%20and%20Improvement%20Framework%202019-20.pdf?orgid=480&pid=96339>

...we are calling for women's health across the life course to be prioritised and reflected 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, with data collected on how much of the health sciences curricula is subsequently allocated specifically to women's health and how far existing curricula are adapted to make explicit reference to the different needs of women, girls, and those assigned female at birth.

In General Practice in Wales, the Quality Assurance and Improvement Framework (QAIF) is designed to incentivise cluster working, where practices share resources, personnel, and expertise, and embed quality assurance and quality improvement into a 'reformed contractual framework that benefits patients and general practice'³².

The QAIF rewards and financially incentivises GP contractors for the provision of quality care. The fact that gynaecological and menstrual health conditions are not included in the QAIF is a glaring omission from measures designed to improve patients' experiences of general practice. The QAIF also has the potential to be used as a mechanism to incentivise and develop projects which focus on any condition(s) where women are disproportionately affected, but it appears that this too has not yet been considered in terms of quality assurance and improvement in primary care.

The failure to make explicit reference to health issues which disproportionately impact women in the QAIF may go some way to explain why additional training in women's health is not prioritised, resulting in fewer courses being commissioned and consequent diagnostic delays and poor patient experiences reported to the Women's Health Wales Coalition. 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, alongside inclusion of diseases and projects related to women's health in the QAIF.

Any new training course should be informed by up-to-date evidence and research which focuses on symptoms, treatment and care specific to women

Further, to address both clinical and wider health inequalities, courses of this nature should be designed and delivered co-productively, with patient voices central to decision-making on content.

Structure of this Document

The Women's Health Wales Quality Statement is structured around the Welsh Government's own Assurance Markers: Equitable; Safe; Effective; Efficient; Patient (or Person)-Centred, and Timely.

Sitting within each of these markers are several recommendations to improve the health of women, girls, and those assigned female at birth in Wales, derived from health issue-specific evidence papers drawn up by coalition members and comprising the Appendices to this Quality Statement.

Each Appendix provides a description of the health condition or issue with which it is concerned, a summary of its position in the Wales context, and offers solutions to improve care. As such, each Appendix can be seen as the basis for individual implementation or action plans.

Women's Health Wales: A Quality Statement for the Health of Women, Girls, and those Assigned Female at Birth



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 include characteristics exhibited by autistic and neurodivergent females, and support systems are (re)designed to fully encompass their needs.
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 after 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.

Appendices



→ Fertility

Introduction

Fertility issues affect around 1 in 6 couples³³, and more than half of cases directly affect women³⁴.

From their work, Fertility Network UK know that women who are trying unsuccessfully to conceive are not always taken seriously. They hear regularly from women who feel their fertility problems are marginalised or ignored. Infertility is sometimes regarded as a “lifestyle” issue, and not all healthcare professionals are aware of the devastating impact fertility problems can have on an individual’s life.

The challenges of infertility and treatment are not always acknowledged or understood. A survey for Fertility Network UK and Middlesex University in 2016 found that respondents felt sad, frustrated, worried, fearful, and helpless nearly all of the time and 42% experienced suicidal feelings as a result of fertility problems and/or treatment³⁵. Fertility treatment is a very demanding process, both physically and psychologically, and research has shown that women going through treatment experience high levels of distress³⁶.

The Problem

Support from healthcare professionals: Patients often report that they don’t feel adequately supported when they first seek medical help for fertility issues, and a Human Fertilisation & Embryology Authority (HFEA) survey found that only 54% of respondents were satisfied with the advice about fertility given by their GP³⁷.

Women do not always receive the practical information and guidance they need, and some see GPs as a barrier to accessing treatment. The survey reported that many patients had been told to carry on trying to conceive naturally, or to ‘give it more time’ when they visited their GP. The survey found that those who were not satisfied with the advice from their GP were significantly more likely to go on to use private clinics, which suggests women’s experiences with GPs can play a key role in how they access treatment.

Meeting NICE guidance on fertility problems: NICE guidance on fertility problems published in 2013³⁸ recommend three full cycles of IVF for those who are eligible under the age of 40, and a single cycle for a particular group of those aged 40-42. This guidance is still not followed in Wales, even though it is based on what is both cost-effective and clinically effective.

It is reported that only 39% of IVF cycles in Wales are funded by the NHS. In comparison, 60% of IVF cycles are funded by the NHS in Scotland³⁹. The lack of NHS funded treatment results in many couples using private treatment and creating huge inequality between those who can afford to do so and those who can’t, with financial constraints adding an additional emotional burden. More than 60% of those who’d had treatment in the private sector reported that they had ended up paying more than they’d expected⁴⁰.

³³ Sizer, A. (2022) Infertility and Perinatal Mental Health, <https://maternalmentalhealthalliance.org/news/infertility-and-perinatal-mental-health/>

³⁴ NICE (2014), [https://www.nice.org.uk/guidance/qs73/documents/fertility-problems-briefing-paper2-p.3-\(section-2.3\)](https://www.nice.org.uk/guidance/qs73/documents/fertility-problems-briefing-paper2-p.3-(section-2.3))

³⁵ Fertility Network UK and Middlesex University (2016) Survey on the Impact of Fertility Problems, <https://fertilitynetworkuk.org/wp-content/uploads/2016/10/SURVEY-RESULTS-Impact-of-Fertility-Problems.pdf>

³⁶ Greil, A. et al (2009), *The experience of infertility: A review of recent literature*, *Sociology of Health and Illness*, *Sociology of Health and Illness*, 32: 1, 140-162

³⁷ HFEA (2018) HFEA Patient Survey, <https://www.hfea.gov.uk/about-us/news-and-press-releases/2018-news-and-press-releases/our-national-patient-survey-results/>

³⁸ NICE (2013) Fertility problems: assessment and treatment (clinical guideline) <https://www.nice.org.uk/guidance/cg156/resources/fertility-problems-assessment-%20and-treatment-pdf-35109634660549>

³⁹ HFEA (2020) Fertility Trends, <https://www.hfea.gov.uk/about-us/publications/research-and-data/fertility-treatment-2018-trends-and-figures/>

⁴⁰ HFEA (2018) HFEA Patient Survey, <https://www.hfea.gov.uk/about-us/news-and-press-releases/2018-news-and-press-releases/our-national-patient-survey-results/>

Evidence-based information about fertility and pre-conception

health: Evidence-based information that supports fertility and good pre-conception health is essential to ensuring as many women as possible have healthy pregnancies and families.

Lack of good, evidence-based information about fertility has an impact on a couple's ability to conceive, with Fertility Network UK often hearing women say they wish they'd known earlier about key factors that can impact future fertility. Student studies show young people are not clear about what makes a difference to their fertility⁴¹.

There is often an assumption that fertility treatment is a 'cure-all' for fertility problems, and a lack of awareness of the age-related decline in IVF success rates. Obesity brings additional risks in pregnancy and can impact a woman's ability to conceive. Fertility is a good driver for healthy eating and weight management as there is a BMI limit of 30 for women to access NHS treatment in Wales.

Good advice and information on pre-conception health for all women, whether or not they are facing challenges with fertility, is also important. In the UK there are currently high levels of obesity, smoking, poor nutrition and drug and alcohol misuse amongst pregnant women, all of which can have a negative impact on pregnancy outcomes⁴². Given that 45% of pregnancies in the UK are unplanned⁴³, it is important that any approach to deliver information and support around pre-conception health must include engaging with women before they present either as pregnant or as looking to conceive.

⁴¹ Harper, J et al (2017) The need to improve fertility awareness, Reproductive Biomedicine & Society Online, <https://www.sciencedirect.com/science/article/pii/S2405661817300096>

⁴² RCOG (2019) Better for Women, <https://www.rcog.org.uk/globalassets/documents/news/campaigns-and-opinions/better-for-women/better-for-women-full-report.pdf>

⁴³ RCOG (2019) Better for Women, <https://www.rcog.org.uk/globalassets/documents/news/campaigns-and-opinions/better-for-women/better-for-women-full-report.pdf>

⁴⁴ RCOG (2019) Better for Women, <https://www.rcog.org.uk/globalassets/documents/news/campaigns-and-opinions/better-for-women/better-for-women-full-report.pdf>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
GPs should be equipped to provide clear, evidence-based information and facts about fertility, discuss potential contributing factors and treatment options, and give realistic expectations of treatment outcomes. They should provide pathway information and explain access criteria at the first appointment.			✓	✓	✓	
Three full cycles of IVF should be funded by the Welsh Government for those who are eligible under the age of 40.	✓		✓	✓		
Use HPV vaccination and chlamydia screening as opportunities to speak to young women about fertility and pre-conception health, as per the RCOG recommendation ⁴⁴ .				✓		✓
Within primary care, women should be offered advice on diet, physical activity, contraception, healthy sexual relationships, folic acid intake, avoiding smoking, excess alcohol and obesity.			✓	✓	✓	✓
Fertility and pre-conception health should be part of wider Relationships and Sexuality Education (RSE) in schools to ensure the population know the key facts around fertility from a young age.			✓			✓

→ Maternal Medicine

Introduction

Maternal medicine describes the specialist care of pregnant women who either have pre-existing medical diseases or who develop medical disorders during their pregnancy.

The Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) report is a confidential enquiry into all maternal deaths in the UK. This project has repeatedly demonstrated that medical problems now represent the leading cause of death in pregnancy and that the death rate is slowly climbing.

There is a noted increase in the number of women identified with pregnancy risk factors such as chronic hypertension, diabetes mellitus and very advanced maternal age⁴⁵. Maternal outcomes could have been improved in around 50% of those patients, demonstrating a need for continued development of services and the training of specialist health professionals⁴⁶.

There is also a lack of specialist care during pregnancy for common medical disorders such as diabetes and cardiac disease. MBRRACE-UK recommends that maternity networks work with member organisations and professional groups to support these women, however there are currently no maternity networks in Wales, resulting in patchy or unequal access to services depending on their location.

The Problem

To discuss all aspects of maternal medicine would be beyond the scope of a single chapter. The focus here therefore is on access to placental growth factor (PLGF) testing to diagnose suspected pre-eclampsia and improving hyperemesis gravidarum services.

Pre-eclampsia is suspected in around 10% of pregnancies and is confirmed in 6% of pregnancies, usually in the second half of pregnancy or soon after birth. It is responsible for 100 deaths every day globally. Research has demonstrated that the use of PLGF testing is associated with improvement in diagnosis times (4.1 to 1.9 days) and significantly improved outcomes, such as a reduction in the number of cases of eclampsia, stroke, and maternal death (5% to 4%) for women⁴⁷. With proven patient benefit, NHS England has secured funding to roll out a routine diagnostic approach, but there are currently no plans to follow suit in Wales.

Hyperemesis gravidarum (HG) is currently the leading cause of admission to hospital in the first trimester of pregnancy. Physical consequences for the mother include electrolyte and nutrient disturbances, which may result in Wernicke's encephalopathy and fatal arrhythmia. HG is also associated with a 25.5% risk of suicidal ideation and 4.9% risk of termination of wanted pregnancy⁴⁸.

⁴⁵ Bornstein, E., Eliner, Y., Chervenak, F. A. & Grünebaum, A. Concerning trends in maternal risk factors in the United States: 1989-2018. *EclinicalMedicine* 29-30, 100657, doi:10.1016/j.eclinm.2020.100657 (2020).

⁴⁶ al., K. M. e. Saving Lives, Improving Mothers' Care, https://www.npeu.ox.ac.uk/assets/downloads/mbrance-uk/reports/maternal-report-2020/MBRRACE-UK_Maternal_Report_Dec_2020_v10_ONLINE_VERSION_1404.pdf

⁴⁷ Duhig, K. E. et al. Placental growth factor testing to assess women with suspected pre-eclampsia: a multicentre, pragmatic, stepped-wedge cluster-randomised controlled trial. *Lancet* 393, 1807-1818, doi:10.1016/S0140-6736(18)33212-4 (2019).

⁴⁸ Nana, M. et al Hyperemesis gravidarum is associated with increased rates of termination of pregnancy and suicidal ideation: results from a survey completed by >5000 participants, Published: March 10, 2021 [https://www.ajog.org/article/S0002-9378\(21\)00157-5/fulltext](https://www.ajog.org/article/S0002-9378(21)00157-5/fulltext)

In a qualitative analysis of the lived experiences of >5000 women in the UK, an urgent need for better access to appropriate therapeutic management and education amongst healthcare professionals was reported⁴⁹. A study of 251 general practitioners (GPs) across Wales reported that only 10% felt very confident managing the condition⁵⁰, confirming a demand for improved education. Only 7% of GPs had access to rehydration day units, proven to be beneficial in preventing hospital admission⁵¹.

Support from charities such as Pregnancy Sickness Support⁵² are highly valued by women with HG. However, a recent application for National Lottery funding to support the work of the charity here was declined as there is no office in Wales.

⁴⁹ Nana, M. et al. Termination of wanted pregnancy and suicidal ideation in hyperemesis gravidarum: A mixed methods study, First Published October 19, 2021
<https://journals.sagepub.com/doi/full/10.1177/1753495X211040926>

⁵⁰ Nana, M., Morgan, H., Ahmed, H. & Williamson, C. Hyperemesis gravidarum in the primary care setting: Cross-sectional study of general practitioners. BJGP Open, doi:10.3399/BJGPO.2021.0119 (2021)

⁵¹ Nana, M., Morgan, H., Ahmed, H. & Williamson, C. Hyperemesis gravidarum in the primary care setting: Cross-sectional study of general practitioners. BJGP Open, doi:10.3399/BJGPO.2021.0119 (2021)

⁵² Pregnancy Sickness Support <https://www.pregnancysicknesssupport.org.uk>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Ensure that medical students and post-graduate trainee doctors in Wales receive training on pre-conception care and the specialist care of women with acute and chronic medical problems.		✓	✓		✓	✓
Develop maternal medicine networks across Wales with a view to reducing variation in care across the country.	✓					
Expand pre-conception counselling services so that all women can access these in preparation for pregnancy.	✓		✓			
Support educational initiatives for those in primary and secondary care regarding the management of the common medical disorders that complicate pregnancy.		✓	✓			
Work with specialists to identify strategies in which care could be improved (e.g. rolling out the use of PLGF, establishing rehydration day units for patients with HG).	✓	✓	✓			
Work with charities to ensure they are able to support patients suffering with medical disorders in pregnancy across Wales.			✓		✓	

→ Pregnancy Loss / Miscarriage

Introduction

Miscarriage, defined as the loss of a pregnancy before 24 weeks, is the most common complication of pregnancy. Early miscarriages occur before 12 weeks and make up the majority (98%) of miscarriages.

The national rate of miscarriage is not currently recorded in Wales, and so it is difficult to know the exact number of women experiencing miscarriage every year. Multiple regional studies have been carried out to calculate this, and the estimated rate ranges from 15% up to 30%⁵³.

Recurrent pregnancy loss is currently defined as three or more consecutive miscarriages in the UK. There are many misconceptions surrounding miscarriage, ranging from the belief that it is a rare occurrence to the perception that miscarriage grief isn't real. The grief and psychological impact of miscarriage is often not comprehended, either by society and by healthcare professionals. The loss can often be minimised by the view that a pregnancy before 12 weeks 'isn't a real baby' or that 'it just wasn't meant to be'. Miscarriage in general is an area that has been overlooked in health and medical research.

Up to 50% of miscarriages are caused by chromosomal abnormalities in the embryo, in which case miscarriage cannot be prevented. However, even when this is the case, the experience of a miscarriage still takes a huge emotional toll on the mother and her partner. This also means that around half of miscarriages are not caused by chromosomal abnormalities and are preventable, but people are not given a reason for their loss which highlights the lack of knowledge around the causes for early pregnancy loss.

The Problem

In April 2021, researchers at the Tommy's National Centre for Miscarriage Research submitted a series of review articles on miscarriage to The Lancet journal⁵⁴. Key findings from the research indicate a wide range of challenges affecting services and care across the UK, the details of which are outlined below.

The research found that short-term national economic costs of miscarriage associated with immediate costs to hospital and community health and social services are estimated to be £471 million annually to the UK (figures for Wales are not available). This figure will undoubtedly rise if GP-associated costs, costs of caring for couples with psychological conditions brought on by a miscarriage, impact on longer-term employment and occupational status, income, and receipt of social welfare benefits are also included.

Female age is one of the most prominent risk factors for miscarriage, along with the number of previous losses. Miscarriage rate is the lowest in women aged 20 – 29 years at 12%, increasing steeply to 65% in women aged 45 years and over. In addition to this, black women are at a 40% increased relative risk of miscarriage over white women.

⁵³ Miscarriage Matters series in The Lancet (April 2021) <https://www.thelancet.com/series/miscarriage>

⁵⁴ Miscarriage Matters series in The Lancet (April 2021) <https://www.thelancet.com/series/miscarriage>

Smoking is an important modifiable risk factor for miscarriage. Women who smoke in the first trimester are 1.2 times more likely to have a miscarriage than non-smokers, and the risk of miscarriage increases with the amount smoked (1% increase in relative risk per cigarette smoked per day).

A woman's BMI is associated with the risk of miscarriage. The BMI associated with the least risk of miscarriage is 18.5 – 24.9 kg/m², considered to be the healthy weight range, whilst women with a BMI under 18.5 are 1.6 times more likely to miscarry and those with a BMI over 30 were 1.9 times more likely to miscarry.

Miscarriage, particularly recurrent miscarriage, is a sentinel risk marker for obstetric complications in a future pregnancy. The risk of preterm birth increases stepwise with each previous miscarriage, demonstrating a biological gradient. Women after one miscarriage are 1.2 times more likely to have a preterm birth, after two 1.4 times more likely and after three 1.8 times more likely. Miscarriage is associated with an increased risk of placental dysfunction disorders in later pregnancies. Our review found that after three miscarriages, women are 1.7 times more likely to experience placental abruption in a later pregnancy, and 1.6 times more likely to have a stillbirth.

Recurrent miscarriage is also associated with a significantly increased risk of cardiovascular disease and venous thromboembolism. After experiencing three miscarriages, women are 1.4 times more likely to suffer from cardiovascular diseases, and 6.1 times more likely to suffer from venous thromboembolism.

⁵⁵ Farren et al, (2020) 'Posttraumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multicenter, prospective, cohort study'

Anxiety, depression, post-traumatic stress and suicide are strongly associated with miscarriage

A recent study from the Tommy's centre found that nine months after a pregnancy loss, 18% of women met the criteria for post-traumatic stress, 17% for moderate to severe anxiety, and 6% for moderate to severe depression. This demonstrates that distress remains at clinically important levels for some months after an early pregnancy loss. One miscarriage also increased the likelihood of suicide, with women who had experienced miscarriage being 3.8 times more likely to complete suicide⁵⁵.

In Wales at present, care for women experiencing miscarriage, recurrent miscarriage, and late miscarriage is inconsistent and does not reflect latest evidence of best practice. Women who experience a miscarriage will receive their care in an Early Pregnancy Unit (EPU). Many EPUs in Wales are not open 7 days a week for those experiencing early pregnancy complications. As a result, many women have to present to Emergency Departments to access care or are left to miscarry at home with little or no help and support.

All guidelines relating to care for recurrent miscarriage agree that women who suffer from recurrent, first-trimester pregnancy loss should be offered referral to a specialist recurrent pregnancy loss clinic. Unfortunately, there are no specialist recurrent pregnancy loss clinics in Wales and it can be extremely challenging to secure a referral into England. In the limited instances where women are enabled to access specialist services, the requirement for referrals to come from a consultant adds an unnecessary level of bureaucracy and delay.

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Ensure that emergency miscarriage services are available 24/7 to all.	✓	✓				
After a first miscarriage, all women should receive both best management and pre-conception support to intervene on modifiable risk factors and underlying health conditions. This should include women and partners being formally assessed post-miscarriage and having access to follow-up mental health support to help reduce mental illness post-miscarriage.	✓	✓	✓		✓	✓
Appropriate care must be given to everyone after 1, 2 and 3 miscarriages in line with a 'graded model' of care which balances the need for evidence-based management and supportive, person-centred care, whilst targeting health care resources appropriately and efficiently: i) After one miscarriage - women offered nurse or midwife-led advice and support, signposted to information about miscarriage, physical and mental health needs assessed with appropriate signposting and referral to optimize health for future pregnancy. Personalised care pathways for those at highest risk including some black women, women over 40 and those with underlying health conditions	✓	✓	✓		✓	

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
ii) After two miscarriages - women to be offered an appointment at a nurse or midwifery-led miscarriage clinic with tests for full blood count and thyroid function offered in addition to addressing lifestyle issues. Referral for specialist care to be arranged if tests are abnormal or if a chronic medical or mental health problem is identified. Women to have access to support and early pregnancy reassurance scans in subsequent pregnancies						
iii) After three miscarriages or more - Women to be offered an appointment at a specialist consultant-led recurrent miscarriage clinic, with additional tests and a full range of treatments offered. Pregnancy tissue from the third and any subsequent miscarriages to be sent for genetic testing. Blood tests for antiphospholipid antibodies and a pelvic ultrasound scan (ideally 3-dimensional transvaginal) to be arranged, and if necessary, parental karyotyping offered depending on the clinical history and the results of the genetic analysis of pregnancy tissue from previous losses.	✓	✓	✓		✓	
Centres of excellence for those experiencing recurrent (three or more) miscarriages must be available regionally with at least one centre in North and South Wales. Where distance is a barrier to care, health boards should commission services in specialist centres in England and / or subsidise transport for those in need.	✓	✓	✓			
Ensure that those who have experienced recurrent miscarriage are advised and monitored for the development of related subsequent longer-term health conditions, ensuring timely intervention.		✓				✓
Acknowledge that miscarriage matters to parents and record every miscarriage in Wales. Data on the number of miscarriages from Early Pregnancy Units, GPs and Accident and Emergency services must be combined and published along with stillbirth and preterm birth rates to better understand the scope of the problem, establish a baseline and set appropriate targets for reduction.				✓		
Issue guidance to employers around leave to recover from pregnancy loss and subsequent support in the workplace.					✓	

→ Perinatal Mental Health

Introduction

Perinatal mental health problems are mental health problems experienced during pregnancy and/or up to a year after giving birth, although they can become chronic and long-term in nature if not adequately addressed in that period.

Types of perinatal mental health problems, including perinatal depression, perinatal anxiety, perinatal OCD, postpartum psychosis, and postpartum PTSD, often occur as a result of birth trauma.

The Problem

Perinatal mental health problems are common, with around 1 in 5 women affected. There is some evidence that the pandemic has increased the risk of perinatal mental health problems through increased levels of isolation and anxiety⁵⁶.

Having a pre-existing or previous mental health problem can be a risk factor for perinatal mental health problems. In 2020, over a quarter (27%) of women in Wales reported that they had a mental health condition at their initial maternity assessment⁵⁷.

However, many women experience a mental health problem for the first time in the perinatal period. 50% of women who develop the rare condition of postpartum psychosis have no history of previous mental illness⁵⁸.

Although rare, suicide is one of the leading causes of death in pregnant and postnatal women in the UK⁵⁹. Acts of self-harm are less common in the perinatal period so, if they do occur, they should be taken very seriously. Specific red flag presentations include thoughts or acts of a violent nature, rapidly changing mental state, expressions of incompetence as a mother, or alienation from the infant.

Experiencing a perinatal mental health problem can also impact on women's ability to bond with their infant in the early days, which can have longer-term impacts. It is vital to ensure services around women in the perinatal period can identify and treat issues early. This includes midwives and health visitors.

⁵⁶ National Centre for Population Health and Wellbeing Research (September 2020) Born in Wales

⁵⁷ Welsh Government (2021) Maternity and birth statistics: 2020

⁵⁸ Children, Young People and Education Committee (2017) Perinatal Mental Health in Wales

⁵⁹ MBRRACE-UK, National Perinatal Epidemiology Unit (2015) Saving Lives, Improving Mothers' Care

⁶⁰ Centre for Mental Health and London School of Economics (2014) The Cost of Perinatal Mental Health Problems

The estimated long-term cost of perinatal mental illness to society as a whole, for each year of births in the UK, is £8.1 billion⁶⁰.

An inquiry into perinatal mental health carried out by the Children, Young People and Education committee in 2017 found that:

- Awareness of perinatal mental health remains poor among the public and health professionals. Frontline staff - including midwives and GPs - feel ill equipped to identify and treat maternal mental illness⁶¹
- Perinatal mental health remains a very stigmatised issue, with many women fearing they will be judged by services and their support networks, labelled as bad mothers, or that they may be separated from their child(ren).

The Committee's inquiry and subsequent report has led to many improvements in perinatal mental health support, but there are still many outstanding areas where services are patchy, ranging from early intervention to the severe end of need.

In 2021, Wales's only mother and baby unit opened within Swansea Bay University Health Board, which offers mothers who need the service to receive inpatient mental health treatment without having to be separated from their babies. There is however still no such provision accessible to women in North Wales. Without a locally available unit, women are forced to choose between travelling to a mother and baby unit far from their families and support networks or staying closer to home, but being separated from their infant. There is an additional issue around being able to access these specialist services through the medium of Welsh.

Gaps also remain in community perinatal mental health services. Just two of the seven health boards currently meet the Royal College of Psychiatrists' standards for community perinatal mental health services.

⁶¹ Children, Young People and Education Committee (2017) Perinatal Mental Health in Wales

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Ensure that all healthcare professionals with whom pregnant women will have contact are equipped to detect perinatal mental health issues, including midwives and health visitors. Resources need to be in place to allow full, safe, and effective delivery of the Healthy Child Wales programme. This is fundamental in early intervention and prevention of escalating issues in association with poor perinatal mental health.	✓	✓	✓	✓	✓	✓
Commit to delivering on the outstanding recommendations from the CYPE committee's 2017 report, including a mother and baby unit accessible to women in North Wales, and ensuring all health boards meet the standards for community perinatal mental health services.	✓	✓	✓		✓	
Explore and respond to how the pandemic has impacted on perinatal mental health and women's access to the support they need, including the impact remote support is having on identifying issues early on.			✓		✓	
Ensure the upcoming mental health workforce plan identifies and addresses gaps in the delivery of perinatal mental health support.		✓	✓			
Be fully cognisant of presentations of peri-natal mental health problems and be alert to any acts of self-harm. Either or both should trigger detailed risk assessment and referral to specialist perinatal mental health services.		✓	✓			✓
Avoid over-simplistic categorisation into 'high' or 'low' risk when assessing all patients at risk of suicide. Also, avoid describing an act of self-harm as 'impulsive' as, rather than implying reduced risk, impulsivity may, in fact, be a pointer to increased risk.		✓	✓			

→ Abortion

Introduction

Abortion is the most common gynaecological procedure in the UK. Over 200,000 women in England, Scotland and Wales have an abortion each year, it means around one in three British women will have had an abortion by the time they reach the age of 45⁶².

⁶² RCOG: Abortion Care: Our Responsibility: <https://www.rcog.org.uk/globalassets/documents/members/membership-news/og-magazine/spring-2017/abortion-care-services.pdf>

⁶³ BPAS: National Review of Abortion Services: <https://www.bpas.org/media/3121/national-review-of-abortion-services.pdf>

Despite abortion being a routine part of many women's reproductive health journey, abortion care can be marginalised, stigmatised, and separate from other forms of comparable healthcare

The Problem

Current abortion services in Wales are provided by the 7 Local Health Boards (LHBs), across 14 different sites. Each LHB has developed its own methods for access, provision, and classification of the service. There is variation across the LHBs with regards to how women access termination of pregnancy (TOP) services and both lengthy travel time and costs for patients present an important consideration for LHBs, especially for women at later gestations⁶³.

The need to travel extensively for abortion care can create issues around confidentiality and access for many women. This is likely to be felt more acutely among certain groups: younger women; disabled women; women who would struggle to explain their need for care due to religious or cultural reasons; women in violent domestic situations; and women from economically disadvantaged backgrounds. There may also be issues for Welsh women living in more remote or rural areas within close-knit communities who may be less able to travel to appointments discreetly due to the time needed to be away from home and the likelihood of meeting people they know on public transport or in the hospital. In smaller communities, accessing sensitive medical care confidentially can also be difficult – particularly where referral into abortion services or signatures for HSA1 forms may be needed. This can delay or prevent access to care locally.

During the pandemic, telemedical services for women in early pregnancy were rolled out across Wales, with all LHBs providing some degree of telemedical services and either collection or delivery of abortion medication. This addressed many of the issues regarding travel time, cost, and accessibility for clients. We are pleased that telemedical abortion services have been made permanent in Wales. The continuation of this approach will allow providers to support as many women as possible across Wales.

Despite this, however, later abortion services remain difficult to access across much of Wales. There are currently no services within Wales that provide abortion beyond 19 weeks, and no general hospitals in Wales willing to accept cases with complex medical conditions and needs, meaning women are required to travel to England⁶⁴.

A full assessment of abortion services in Wales, as well as issues to address, can be found in the Welsh Senedd's Cross-Party Group on Women's Health review from 2019⁶⁵.

⁶⁴ NHS Wales (2018) A Review of Sexual Health in Wales, <http://www.wales.nhs.uk/sitesplus/documents/888/A%20Review%20of%20Sexual%20Health%20in%20Wales%20-%20Final%20Report.pdf>

⁶⁵ BPAS (2019) Women's Health Cross-Party Group Report: National Review of Abortion Services, <https://www.bpas.org/media/3121/national-review-of-abortion-services.pdf>

⁶⁶ NICE Guideline [NG140] Abortion Care (2019) <https://www.nice.org.uk/guidance/ng140>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
1. Ensure patients have access to the most appropriate service through the provision of telemedical early abortion care with home administration of mifepristone and misoprostol as clinically appropriate and in line with the law	✓		✓	✓		✓
2. Ensure that services are geographically accessible for women in remote areas through community placement and use of telemedicine.						
Abortion services should be designed and provided in line with the NICE Abortion Care guideline [NG140] ⁶⁶ .		✓	✓			
Women should be given a choice between medical and surgical abortion to take place up to and including 23+6 weeks' gestation; those women who decide to go ahead with an abortion have the option to have the procedure within 1 week of assessment.		✓			✓	✓
Doctors working in the NHS in Wales should be trained to provide abortion services up to 24 weeks' gestation, and placement should be available between Local Health Boards, Independent Sector Providers, and English sites for those clinicians who wish to train to provide second or third trimester surgical procedures.		✓	✓			✓

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Local Health Boards and NHS Wales/ GIG Cymru to work together to support a funded all-Wales strategy to ensure women with complex needs and/or later in pregnancy can access care within Wales as far as possible. This should include appropriate funding without barriers for women who may still be required to travel to NHS sites in England.	✓			✓	✓	
Establish a system within services to gather the two signatures legally required for HSA1 forms so that no women have to visit other healthcare locations or delay treatment to obtain them. This could be in the form of a national digital system funded by NHS Wales/GIG Cymru.	✓			✓		✓
Information about local services should be accurate, up to date, and easy to find for people seeking abortion treatment.	✓				✓	
Services should make up-front expenses funding available for women who need to travel or stay away from home to access the abortion care they need.	✓				✓	
Services should have a self-referral pathway in place with target waiting times in line with national best practice guidelines.			✓			✓
Women having an abortion who want contraception should be able to receive their chosen method before discharge.		✓		✓	✓	✓
All women having an abortion should be given advice on how to access onward care and support.	✓	✓		✓	✓	

→ Sexual and Reproductive Health

Introduction

The United Nations Population Fund defines good sexual and reproductive health as a state of complete physical, mental and social wellbeing in all matters relating to the reproductive system. Good sexual and reproductive health implies that people are able to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so⁶⁷.

Young people's rights to sexual and reproductive health information and their right to make decisions in line with their evolving capacity derive from the United Nations Convention on the Rights of the Child to which the UK is a signatory⁶⁸, rights which have been further detailed in the Programme of Action emanating from the UN's International Conference on Population and Development (ICPD) in Cairo, 1994⁶⁹.

The Faculty of Sexual and Reproductive Healthcare (FSRH), the largest UK professional membership organisation working in the field of sexual and reproductive health (SRH), published '*Better care, a better future*' in consultation with the FSRH Wales Committee in 2019. It acknowledges the progress made in Wales following the publication of the '*Review of Sexual Health in Wales*' in 2018, but highlights the challenges faced across clinical settings, many of which it attributes to a lack of funding⁷⁰.

The Problem

According to the '*Better care, a better future*' report, whilst services in Wales are fairly well integrated in the provision of different clinical services such as contraception, STI testing and cervical screening in one clinical setting, there is no overall set structure to SRH service design, leading to unclear service pathways for patients⁷¹.

The challenges and disparity in funding levels between health boards has wide ranging impacts – from a lack of specialist SRH staff across Wales, long waiting times for services or poorly housed services to being unable to offer outreach to reach all communities, and the full choice of contraception not being available to all⁷².

The forthcoming statutory Relationships and Sexuality Education (RSE) guidance and code as part of the new Curriculum for Wales offers a key moment for change that could have significant impact on young people. The RSE code makes clear the need for education that provides support, respect, understanding, and equitable treatment for all, regardless of sex, gender, sexuality, faith or belief⁷³.

Improved understanding and access to information on a range of SRH issues would enable people to better understand their choices and create a potential opportunity to promote and link people to local services, destigmatise and normalise conversations around sex, and better equip young people to seek timely help to support good sexual and reproductive health. This is particularly important in respect of HIV infection, where stigma remains an issue and women are routinely not offered HIV testing when they should be⁷⁴.

⁶⁷ United Nations Population Fund <https://www.unfpa.org/sexual-reproductive-health>

⁶⁸ The United Nations Convention on the Rights of the Child <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

⁶⁹ https://www.unfpa.org/sites/default/files/pub-pdf/programme_of_action_Web%20ENGLISH.pdf

⁷⁰ FSRH (2019) Better care, a better future: Implementing our Vision for Sexual and Reproductive Healthcare in Wales <https://www.fsrh.org/documents/plan-implementation-fsrh-vision-wales/>

⁷¹ FSRH (2019) Better care, a better future: Implementing our Vision for Sexual and Reproductive Healthcare in Wales <https://www.fsrh.org/documents/plan-implementation-fsrh-vision-wales/p.5>

⁷² FSRH (2019) Better care, a better future: Implementing our Vision for Sexual and Reproductive Healthcare in Wales <https://www.fsrh.org/documents/plan-implementation-fsrh-vision-wales/p.9>

⁷³ Humanists UK (December 2021) <https://humanists.uk/2021/12/15/success-in-wales-as-the-senedd-approves-rse-code-requiring-rights-based-teaching-pr/>

⁷⁴ <https://www.bhiva.org/HIV-testing-guidelines-2020>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Universal access to information and education about sexual and reproductive health to be made available to increase knowledge and understanding of SRH issues across all age ranges.	✓		✓			
Ensure that high-standard services are universally available and based on individuals' and communities' needs including: • Open access to community sexual health clinics for people of all ages • Easy access to information, with a choice of times and types of clinic services for the communities served • Targeted outreach for those difficult to reach or who face challenges in accessing services e.g. homeless people, sex workers, substance users, some Black, Asian, and Minority Ethnic people and communities • Make information accessible in a variety of media such as website, leaflets and local press • Improved use of pharmacy for access to information and contraception services.	✓	✓	✓		✓	
Develop mechanisms and systems to monitor patients who have been unable to access the services.				✓	✓	
Develop a hybrid provision model including online ordering of tests and medication; and telemedicine and face to face consultations, based on the needs of the population.	✓	✓	✓	✓	✓	
Arrangements for appropriate and timely provision of emergency contraception as well as contraceptive supplies should be available to all, at any time. In rural areas where specialist clinics may not be accessible locally throughout the week, development of appropriate alternative services should be addressed.	✓	✓			✓	

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
GP provision of comprehensive sexual and reproductive health services including all contraceptive methods.	✓	✓			✓	✓
In line with prevention and early intervention strategies, ensure condoms and safer sex messaging for primary prevention of sexually transmitted infections (STIs) are readily accessible across all health and community settings, hubs, or clinics where health and wellbeing interventions take place.	✓	✓	✓	✓		
Ensure opportunistic provision of contraception and STI testing in services such as maternity, abortion, and screening services.		✓		✓		✓
HIV related stigma remains an issue and women are routinely not offered HIV testing when they should be. Easily accessible, equitable, and non-discriminatory access to HIV testing in all settings should be available.	✓		✓	✓	✓	
Adequate time should be given for all consultations and take into account the nature of the visit. For example, first visits, initial counselling and provision of all contraceptive methods, STI treatment and partner notification, counselling for sterilisation/vasectomy and referral, pregnancy information, decision support and referral for abortion, will require more time.		✓	✓		✓	
Provide specialist sexual and reproductive health clinics for young people, which should accommodate their specific needs as recommended in The National Service Framework (NSF) for Children, Young People and Maternity Services ⁷⁵	✓		✓		✓	
Use the Relationships and Sexuality Education (RSE) guidance and code to help promote and link young people to local services so they are able to understand their choices and seek timely help to support good sexual and reproductive health.			✓		✓	✓

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Patients undergoing intimate examinations should be offered the presence of a chaperone, irrespective of the gender of the clinician. There should be prominent notices displayed in the waiting and clinical rooms informing patients of their right to request a chaperone if desired.		✓			✓	
Patients should have the assurance of confidentiality of their consultations regardless of age, gender, sexual orientation, religion or ethnicity unless the clinician has concerns about wellbeing and/or safety of the patient or others, in line with FSRH Confidentiality Standards, combined with regular safeguarding training for staff.	✓	✓			✓	
SRH specialist services and other providers of SRH-related services should collaborate to provide patient-centred care. Where it isn't possible to offer this multi-disciplinary approach in one setting, clinical networks and communications should be established so that patients can access what they need as straightforwardly as possible through a variety of means.	✓	✓	✓			
An annual user and public involvement plan should be developed and supported by an annual friends and family test, and feedback should be responded to appropriately.			✓		✓	

→ Autism and Neurodivergence

Introduction

Autism is a neurodevelopmental condition characterised by social communication differences and a need for routine and consistency which is often observed as repetitive, stereotyped behaviours.

Attention Deficit Hyperactivity Disorder (ADHD) is another neurodevelopmental condition characterised by attention differences - typically difficulty maintaining attention, difficulty in switching attention (hyperfocus), or both - and difficulties with executive function.

Women, girls, and those assigned female at birth⁷⁶ face both inequitable access to diagnostic services⁷⁷

...and - as both diagnosed and undiagnosed neurodivergent women - unequal access to healthcare more widely, including to healthcare screening such as cervical cancer screening tests⁷⁸.

The Problem

Around 1.1% of the population is autistic - that means 17,000 women in Wales could be autistic. ADHD prevalence figures vary, though NHS England states 3-5% of children and 2% of adults equating to a possible 31,800 women. However, due to inequitable diagnosis, official figures for women are lower⁷⁹.

Women can struggle to get referred to diagnostic services for neurodivergence⁸⁰, with anecdotal reports of many being forced to pursue private diagnosis. Women are also at high risk of 'camouflaging' or 'masking' their neurodivergence, which has not only been blamed for inequitable diagnosis, but puts them at higher risk of adverse outcomes⁸¹.

The impact this has on neurodivergent women is multifaceted. The inequality autistic people face in accessing healthcare could be disproportionately affecting women due to their increased risk of having co-occurring physical and mental health conditions⁸². For example, autistic women are overrepresented in anorexia nervosa figures, yet a lack of understanding means that outcomes and recovery rates for autistic women are far worse than for others with anorexia⁸³. Some studies also suggest that autistic women have elevated mortality rates compared to autistic men, including higher risk of dying by suicide⁸⁴. This is compounded for autistic women who also have a learning disability, who are at even higher risk of dying young. This figure will only grow as 75% of women with a learning disability are "ceased from recall", meaning they have chosen to remove their names permanently from recall lists inviting them for future cervical screenings⁸⁵.

⁷⁶ Note that while this document refers to women/girls, these issues also disproportionately affect non-binary people and transgender men and women.

⁷⁷ Bargiela, S., Steward, R., & Mandy, W. (2016). The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *Journal of autism and developmental disorders*, 46(10), 3281-3294. <https://doi.org/10.1007/s10803-016-2872-8>

⁷⁸ Doherty, M., Neilson, S. D., O'Sullivan, J. D., Carravallah, L., Johnson, M., Cullen, W., & Gallagher, L. (2020). Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study. *MedRxiv*, 2020.04.01.20050336. <https://doi.org/10.1101/2020.04.01.20050336>

⁷⁹ Quinn, P. O., & Madhoo, M. (2014). A review of attention-deficit/hyperactivity disorder in women and girls: uncovering this hidden diagnosis. The primary care companion for CNS disorders, 16(3), PCC.13r01596. <https://doi.org/10.4088/PCC.13r01596>

⁸⁰ Quinn, P. O., & Madhoo, M. (2014). A review of attention-deficit/hyperactivity disorder in women and girls: uncovering this hidden diagnosis. The primary care companion for CNS disorders, 16(3), PCC.13r01596. <https://doi.org/10.4088/PCC.13r01596>

⁸¹ Beck, J. S., Lundwall, R. A., Gabrielsen, T., Cox, J. C., & South, M. (2020). Looking good but feeling bad: "Camouflaging" behaviors and mental health in women with autistic traits. *Autism*, 24(4), 809-821. <https://doi.org/10.1177/1362361320912147>

⁸² Kassee, Caroline & Babinski, Stephanie & Tint, Ami & Lunskey, Yona & Brown, Hilary & Ameis, Stephanie & Szatmari, Peter & Lai, Meng-Chuan & Einstein, Gillian. (2020). Physical health of autistic girls and women: a scoping review. *Molecular Autism*. 11. 84. 10.1186/s13229-020-00380-z

⁸³ Brede, J., Babb, C., Jones, C. et al. "For Me, the Anorexia is Just a Symptom, and the Cause is the Autism": Investigating Restrictive Eating Disorders in Autistic Women. *J Autism Dev Disord* 50, 4280-4296 (2020). <https://doi.org/10.1007/s10803-020-04479-3>

⁸⁴ Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 208(3), 232-238. doi:10.1192/bjp.bp.114.160192

⁸⁵ Women's Health Care for People with Autism and Learning Disabilities infographic: <https://livingautism.com/womens-health-care-people-autism-learning-disabilities/>

Autism UK report that their focus groups and peer support groups have highlighted that autistic women are facing high levels of isolation and loneliness

...particularly in more rural areas of Wales. Stigma plays a large role in this and contributes to autistic women being more at risk of not engaging with support services, particularly as a parent, due to the risk of being at greater scrutiny by social services and the risk of having their children taken into care⁸⁶.

More generally, autistic women report poorer quality of life than autistic men⁸⁷ across multiple areas, to the extent that some studies include "being female" as a predictor of lower quality of life in autistic populations⁸⁸. This is indicative that the issues pertaining to being neurodivergent including stigma, diagnostic inequity, and inequality in access to healthcare disproportionately affect women.

It is estimated that 1.1% of the population is autistic, with a higher diagnostic rate among males than females, often reported as a male-to-female prevalence of 4-5:1, yet evidence suggests that this is due to late/misdiagnosis⁸⁹ rather than neurodivergence being truly more prevalent in male populations. Historically, neurodevelopmental conditions have been gendered as "male". This has contributed to a lack of understanding, recognition, and support for neurodivergent women. It is only in the last decade or so that the needs of women have been recognised as being different, and research is lacking when it comes to neurodivergent experiences of women's health issues, or the difficulties they have accessing diagnosis and/or healthcare.

Neurodivergent women are greatly disserved by inequitable diagnostic services. Both autism and ADHD are severely misunderstood conditions in women and - undiagnosed and unmanaged - many struggle without support for decades, with many only receiving diagnosis after or during mental health crisis⁹⁰. Furthermore, Autism UK focus groups have revealed that women with ADHD are faced with barriers in accessing medication on shared-care schemes, with the practice being a 'postcode lottery', even within the same health board. The inability to access healthcare without discrimination can result in severe adverse outcomes, whilst "associated long-term personal, social, health and economic costs are high"⁹¹.

⁸⁶ Pohl, A.L., Crockford, S.K., Blakemore, M. et al. A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism* 11, 3 (2020). <https://doi.org/10.1186/s13229-019-0304-2>

⁸⁷ Graham Holmes, L., Zampella, C. J., Clements, C., McCleery, J. P., Maddox, B. B., Parish-Morris, J., Udhmani, M. D., Schultz, R. T., & Miller, J. S. (2020). A Lifespan Approach to Patient-Reported Outcomes and Quality of Life for People on the Autism Spectrum. *Autism research : official journal of the International Society for Autism Research*, 13(6), 970–987. <https://doi.org/10.1002/aur.2275>

⁸⁸ Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism research : official journal of the International Society for Autism Research*, 11(8), 1138–1147. <https://doi.org/10.1002/aur.1965>

⁸⁹ Alis Rowe talks to the BBC about late diagnosis in autistic women: https://www.bbc.co.uk/news/world-47784849?fbclid=IwAR2fJnuGCBa3iEJT_e2ivq7TIH-WGb-c5y5IM9i8T_eksDQm5bCKExGrfH8

⁹⁰ The Guardian reports on misdiagnosis of autistic women, and the intersection of mental health: <https://www.theguardian.com/society/2018/sep/14/thousands-of-autistic-girls-and-women-going-undiagnosed-due-to-gender-bias>

⁹¹ Young, S., Asherson, P., Lloyd, T., Absoud, M., Arif, M., Colley, W. A., Cortese, S., Cubbin, S., Doyle, N., Morua, S. D., Ferreira-Lay, P., Gudjonsson, G., Ivens, V., Jarvis, C., Lewis, A., Mason, P., Newlove-Delgado, T., Pitts, M., Read, H., ... Skirrow, C. (2021). Failure of Healthcare Provision for Attention-Deficit/Hyperactivity Disorder in the United Kingdom: A Consensus Statement. *Frontiers in Psychiatry*, 0. <https://doi.org/10.3389/fpsy.2021.649399>

The Solution

⁹² Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*. <https://www.tandfonline.com/doi/abs/10.1080/09687599.2012.710008>

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Improved access to diagnosis by: 1. Ensuring gender is not used as a reason for non-referral 2. Providing equitable assessment that looks at a person-centred full neurodevelopmental and sensory profile 3. Increasing funding for timely and efficient diagnostic services to reduce waiting times, saving money in the long-term as appropriate diagnosis and support mitigates the risk of poor mental health.	✓			✓		✓
Provide holistic care through acknowledging the high prevalence of co-occurring physical conditions and treating the individual as a whole person, without resorting to diagnostic overshadowing.					✓	
Co-produce and develop ways to improve effective communication and accessibility across healthcare providers. These include: • reasonable adjustments to the methods available to make appointments • safe sensory evaluations of waiting and treatment areas • person-centred in-person communication considering the double empathy problem ⁹² .		✓	✓		✓	
GPs and consultants should explore alternatives to traditional communication modes, such as email or text, to reduce barriers for autistic people.			✓	✓		✓
Recognise the importance of lived experience, peer support, and the removal of barriers to accessing post diagnostic support.	✓	✓	✓		✓	✓
Commit to facilitating shared-care agreements in a timely manner for prescribed medications.			✓			✓
Adjust available therapies (e.g. CBT) so it's effective and safe for neurodivergent patients.		✓		✓		

→ Minor Gynaecological Procedures and Pain Management

Introduction

Minor gynaecological procedures include IUD insertions and removal, hysteroscopy, colposcopy, and LLETZ. Outpatient hysteroscopy is a very common UK-wide procedure with tens of thousands performed each year⁹³. The majority of them take place in outpatient settings such as GP surgeries, sexual and reproductive health clinics, or hospital day treatment units. These are invasive procedures in line with colonoscopy or gastroscopy but, where sedation and analgesia are routinely offered for those procedures, they are not offered as standard for minor gynaecological procedures.

The Problem

Evidence suggests that women's experiences of pain are often not taken seriously in healthcare settings, with women less likely to receive pain relief or be treated as promptly as men⁹⁴. Women from black, Asian, and minority ethnic communities are likely to have an even worse experience⁹⁵, and there is little research to provide data to capture the experiences of patients with disabilities.

Traditionally, women's reporting of pain (pelvic pain in particular) has been normalised and dismissed, resulting in patients being expected to stoically endure extreme pain situations, sometimes in clinical outpatient settings, during procedures performed by healthcare professionals⁹⁶.

It is cheaper in the immediate-term for health service providers to offer many minor gynaecological procedures in outpatient settings where access to IV sedation/analgesia is not available⁹⁷. According to patient group Campaign Against Painful Hysteroscopy, this could be due to targets imposed by NHS management necessitating a fast turnaround of patients, leading to outpatients or primary care being the go-to setting for many minor gynae procedures. Their 2016 report '*Patients' Stories: Essay on Hysteroscopy Pain*' suggests that The Department of Health's '*Quality, Innovation, Productivity and Prevention*' best practice tariff rewards Trusts who undertake at least 70% of hysteroscopies in outpatient settings⁹⁸.

A lack of accurate, unbiased information provided to patients before procedures means that they are unable to make a fully informed choice about where and how to access the correct treatment for their needs. Anecdotal evidence collated by Campaign Against Painful Hysteroscopy reports that a number of patients are not fully aware of their treatment, what it entails and treatment options⁹⁹. They report that pre-procedure assessments, which would enable the clinician to establish the patient's specific individual needs (such as a history of vaginal birth, trauma, or gynaecological condition) and most appropriate setting for the procedure, are often not undertaken. Intravenous (IV) sedatives / analgesia are not available in most primary care or outpatient settings, obviating patient choice. Additionally, GP surgeries are not adequately equipped or trained to provide gas and air.

⁹³ Ramshaw, N., & Narayansingh, G. (2019). The implications of hysteroscopy in the updated guidelines on heavy menstrual bleeding from the UK National Institute for Health and Care Excellence (NICE). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6501119/>

⁹⁴ Gender disparity in analgesic treatment of emergency department patients with acute abdominal pain - <https://pubmed.ncbi.nlm.nih.gov/18439195/> Esther H. Chen, Frances S. Shofer, Anthony J. Dean, Judd E. Hollander, William G. Baxt, Jennifer L. Robey, Keara L. Sease, Angela M. Mills

⁹⁵ Deo, N. et al (2021) Virtual reality for acute pain in outpatient hysteroscopy: a randomised control trial <https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.16377>

⁹⁶ Discussion in the House of Commons (24 September 2020) NHS Hysteroscopy Treatment, <https://hansard.parliament.uk/commons/2020-09-24/debates/2BF4B8B8-224E-4F60-B789-5FD53908B89F/NHSHysteroscopyTreatment>

⁹⁷ Saridogan, E. et al (2010) Cost-Analysis Comparison of Outpatient See-and-Treat Hysteroscopy Service with Other Hysteroscopy Service Models [https://www.jmig.org/article/S1553-4650\(10\)00121-4/fulltext](https://www.jmig.org/article/S1553-4650(10)00121-4/fulltext)

⁹⁸ Cavalli, K. Et al (2016) Patients' Stories: Essay on Hysteroscopy Pain <https://www.hysteroscopyaction.org.uk/wp-content/uploads/2020/01/sept-2016.pdf>

⁹⁹ <https://www.pslhub.org/learn/patient-safety-in-health-and-care/womens-health/campaign-against-painful-hysteroscopy-presentation-to-the-bsge-march-2021-r4167/> (March 2021)

When asked about their experience of colposcopy and treatment, pain was frequently mentioned by respondents to a survey undertaken by Jo's Trust¹⁰⁰. Experience of pain management varied and, through interviews with colposcopists, the study revealed differences in practice and opportunities available. For example, some units offer 'gas and air' widely while others do not. Use of local anaesthetic also varies for procedures such as punch biopsies, with some clinicians offering it in this situation and others not. These findings suggest that there is both a need for larger studies on pain management in these situations, and greater guidance to assess those pain management solutions offered and reduce variation.

It is most important not to discourage women from selecting IUDs as an effective form of contraception or scare women away from undergoing important minor gynaecological procedures to diagnose serious diseases quickly. In response to recent media reports highlighting cases of individuals who had experienced distressing intrauterine contraception (IUC) fitting, the Faculty of Sexual and Reproductive Healthcare (FSRH) issued a statement on pain associated with intrauterine contraception highlighting the need for informed decision-making¹⁰¹. This requires transparency around potential pain, empowering women to make an informed choice of service provider and location for their needs, rather than expecting them to endure severe pain in the name of efficiency.

The cultural expectation that women endure pain means that many patients in severe pain do not report it in the moment for fear that their experiences will not be taken seriously or that it will inconvenience their clinician¹⁰². However, when patients do report pain, many of them say they are not listened to¹⁰³. Similarly, if and when they ask to stop a procedure, they have reported that they are often rebutted, with patients told that the procedure will have to be repeated, or that a delay caused by waiting for pain relief will result in delayed diagnosis.

As well as a lack of access to pain management, there is a lack of appropriate equipment to enable patient safety or comfort. Where Xylocaine spray is used as cervical analgesia for IUD fitting, the nozzle on the bottle is not correctly manufactured for precision aim at the cervix to avoid vaginal irritation. Some clinicians have reported that they have been using a thin drinking straw in place of the incumbent nozzle to achieve a precise result. Not only are there reports of some products not being fit for purpose, they are also marketed towards time / money-saving rather than patient comfort and pain reduction, despite the long-term implications of this for both patient and services. Some patients are too traumatised to re-engage with health service providers, resulting in poorer prognoses and higher costs in the long term¹⁰⁴.

According to a survey undertaken by the patient group Campaign Against Painful Hysteroscopy¹⁰⁵, it is suspected that the Royal College of Obstetrics and Gynaecology guidance is not routinely used, leading to vast differences in experience and outcome for patients.

¹⁰⁰ <https://www.jostrust.org.uk/about-us/our-research-and-policy-work/our-research/cell-changes-experiences> (January 2022)

¹⁰¹ <https://www.fsrh.org/standards-and-guidance/documents/fsrh-statement-pain-associated-with-insertion-of-intrauterine/>

¹⁰² Lucy Cohen, Patient Safety Learning, IUD pain survey and reporting <https://www.pslhub.org/learn/patient-safety-in-health-and-care/womens-health/the-pain-of-my-iud-fitting-was-horrific%E2%80%A6and-i%E2%80%99m-not-alone-r4765/>

¹⁰³ Baroness Cumberlege (2020) First do no harm - The report of the Independent Medicines and Medical Devices Safety Review https://www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf

¹⁰⁴ Bennett, A. et al (2018) [https://www.jogc.com/article/S1701-2163\(18\)30811-9/pdf](https://www.jogc.com/article/S1701-2163(18)30811-9/pdf)

¹⁰⁵ <https://www.pslhub.org/learn/patient-safety-in-health-and-care/womens-health/campaign-against-painful-hysteroscopy-presentation-to-the-bsge-march-2021-r4167/> (March 2021)

Finally, the advice to use a ‘vocal local’ (where patients are assumed to have the capacity to talk or be distracted by talking, verbalise pain and / or the need to stop) is ableist and discriminatory. Patients with additional needs such as autistic or neurodivergent women, women who have communication difficulties or don’t speak English as a first language, not be able to articulate their needs. First language Welsh-speakers may encounter additional difficulties in accessing the care they need as not all healthcare professionals speak Welsh, although the offer of speaking with someone who does should be made wherever possible.

¹⁰⁶ Connor, M., Clark, J. (2020) Diagnostic and Operative Hysteroscopy <https://www.cambridge.org/gb/academic/subjects/medicine/obstetrics-and-gynecology-reproductive-medicine/diagnostic-and-operative-hysteroscopy?format=HB>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Ensure patients have full access to information on all potential outcomes of procedures, including pain, to allow them to make fully informed choices for their treatment, using evidence-based decision trees for them to self-select the most appropriate setting and pain management without outpatient treatment being the default treatment offered.		✓	✓		✓	
Look to models of good practice for offering colonoscopy-style sedation clinics such as those offered by anaesthetist Nicholas Ireland (Newcastle) and gynaecologist Mary Connor (Sheffield) ¹⁰⁶ .		✓	✓			
Engage with medical device manufacturers to ensure products are fit for patients.		✓	✓			
Involve service-users in evaluations to co-produce the necessary service-changes.			✓		✓	
Independent audits co-produced by service users.			✓		✓	
Increase training and capacity - including bed space - to make general anaesthetic / regional anaesthetic / IV sedation with anaesthesia / analgesia more readily available.			✓	✓	✓	
Develop strong reporting procedures to enable healthcare professionals to challenge poor practice and ensure patients feel heard during complaints procedures.		✓	✓			

→ Cervical Screening and Cell Changes

Introduction

Around 160 women are diagnosed with cervical cancer every year in Wales¹⁰⁷. A further 8,000 are diagnosed with cervical cell changes (abnormalities). Cervical cancer is the second most common cancer among women under the age of 35 but affects women of all ages.

It is a largely preventable disease through the combination of the HPV vaccination offered in schools and cervical screening. World Health Organization (WHO) research shows that one day it could be made a thing of the past¹⁰⁸ but to get there we must work to tackle the wide range of inequalities and barriers that exist.

Cervical screening has been in decline. Just 76% were up to date with screening before the pandemic, and that is likely now to be far less, with some ages and groups lower still, for example 73% among 25 - 29 year olds¹⁰⁹.

There are thought to be a wide range of reasons for this including physical, psychological, accessibility and cultural barriers. There are further issues following screening. Treatment for cell changes is highly successful and HPV extremely common, yet gaps in understanding HPV leaves many feeling anxious or stigmatised following their results and can even lead to relationship breakdown.

The Problem

Barriers to cervical screening:

These include finding the time to attend, bad past experiences, inconvenient appointment times, language or literacy factors, worries it would be painful, embarrassment, a physical disability, and personal anxieties.

This leads to widespread inequalities:

- 40% of lesbian and bisexual women have been told that they don't need to attend¹¹⁰
- 63% have been unable to attend because of their disability¹¹¹
- 72% who have experienced sexual violence have delayed or not attended, because of their experience¹¹²
- 56.1% of women from Black, Asian and minority ethnic communities report delaying¹¹³
- Deprivation has been linked to lower screening attendance¹¹⁴ and cervical carcinoma in situ incidence rate in England in females are 18% higher in the most deprived quintile compared with the least¹¹⁵.

¹⁰⁷ Cancer Research UK, <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence>

¹⁰⁸ WHO, Cervical Cancer Elimination Initiative <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence>

¹⁰⁹ Cervical Screening Wales (2019) <http://www.cervicalscreeningwales.wales.nhs.uk/sitesplus/documents/1032/Cervical%20Screening%20Wales%20Annual%20Statistical%20Report%202018-19.V1.0.pdf>

¹¹⁰ Lesbian, Gay & Bisexual Women in the North West: A Multi-Method Study of Cervical Screening Attitudes, Experiences and Uptake: <https://s3-eu-west-1.amazonaws.com/lgbt-website-media/Files/38ffed72-7d94-471f-87ad-8acec8a92819/Cervical%2520Screening.pdf>

¹¹¹ Jo's Cervical Cancer Trust <https://www.jostrust.org.uk/our-research-and-policy-work/our-research/barriers-cervical-screening-physical-disabilities>

¹¹² Jo's Cervical Cancer Trust <https://www.jostrust.org.uk/node/1075195> Saridogan, E. et al (2010) Cost-Analysis Comparison of Outpatient See-and-Treat Hysteroscopy Service with Other Hysteroscopy Service Models [https://www.jmig.org/article/S1553-4650\(10\)00121-4/fulltext](https://www.jmig.org/article/S1553-4650(10)00121-4/fulltext)

¹¹³ Jo's Cervical Cancer Trust <https://www.jostrust.org.uk/about-us/our-research-and-policy-work/our-research/barriers-cervical-screening-amongst-south-east>

¹¹⁴ Public Health England <https://www.gov.uk/government/publications/health-matters-making-cervical-screening-more-accessible/health-matters-making-cervical-screening-more-accessible-2>

¹¹⁵ Cancer Research UK <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer#heading-One>

Awareness of HPV:

Cervical screening in Wales has used HPV primary screening since 2018. As a result, more women and people with a cervix are learning they have the virus. Research by the National Federation of Women's Institutes (NFWI) has highlighted a level of misunderstanding and stigma surrounding HPV¹¹⁶. The number of service users who have contacted Jo's Cervical Cancer Trust has doubled over the last few years, in line with HPV primary screening being introduced. High numbers report feeling anxious (over 7 in 10) and ashamed (more than 4 in 10). Misperception around the nature of HPV can lead to concerns around promiscuity, infidelity and even relationship breakdown¹¹⁷.

Gaps in support and information for those with cell changes:

Anxiety among this group of women can be very pronounced, and the need for information and support is high¹¹⁸. There is a very real sense that many women do not feel prepared for what is happening to them, and side effects or experiences can be far more severe than literature sometimes suggests. There has been very little research into the experience of those diagnosed and treated for cell changes.

Limited research on HPV:

Gaps in the research around HPV can mean explaining it to patients can be difficult. This includes conversations around dormancy, persistence, and reinfection.

¹¹⁶ The Women's Institute https://www.thewi.org.uk/_data/assets/pdf_file/0019/534340/WI-cervical-screening-research-Briefing-3.pdf

¹¹⁷ Jo's Cervical Cancer Trust <https://www.jostrust.org.uk/about-us/news-and-blog/press-releases/cervical-screening-results-shame>

¹¹⁸ Jo's Cervical Cancer Trust https://www.jostrust.org.uk/sites/default/files/cervical_cancer_prevention_doesnt_end_at_screening_-_patient_experiences_of_cervical_cell_changes_0.pdf

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Deliver regular cervical screening awareness campaigns.	✓		✓		✓	✓
Clear communications and information must be developed to restore faith and trust in the programme following the introduction of 5-year screening intervals in 2022. Learnings must be made from mistakes to ensure future changes are co-produced and communicated effectively.	✓				✓	✓
Provide guidance to schools on issues including cervical cancer, the HPV vaccine and cervical screening, as part of the Health and Well-being Area of Learning and Experience in the new curriculum.	✓	✓			✓	✓
Provide best practice examples for GPs and Health Boards to increase uptake of cervical screening.				✓		

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Public Health Wales, Local Health Boards and GPs to consider strategies for improving uptake of cervical screening by making it more accessible to patients, including those unable to leave the house and those who have to travel a long way to their practice.	✓			✓	✓	
Undertake targeted interventions to engage with women who are in the lowest attending demographics such as women between 25 and 30, women over 50, ethnic minorities and women with learning disabilities.	✓		✓	✓	✓	
Wales to introduce HPV self-sampling as soon as it is recommended for use in the UK, and to support the evidence base by undertaking a pilot in Wales.	✓	✓	✓	✓	✓	
Adopt a life course approach to help make cervical screening more accessible and to support women at different stages of life for example, younger women, working women, and those who are post-menopause.	✓		✓		✓	✓
Health professionals must be equipped with the skills and resources to discuss HPV with patients, starting at first cervical screening and extending throughout the treatment pathway, and proactively work to establish patient understanding.			✓		✓	✓
A more patient-centred approach to cervical screening and follow up procedures in colposcopy in order to increase uptake and improve patient experience, saving as many lives as possible from cervical cancer.	✓	✓	✓		✓	
Greater recognition in colposcopy and general practice to ensure women are provided with, and signposted to, sources of support following a cell changes diagnosis.		✓			✓	✓
Every woman told they have HPV presented with the information they need to ensure they fully understand what a diagnosis means. Consistency in how information is presented is essential to reduce the level of confusion and misinformation that exists.	✓	✓		✓		
Deliver regular training on the barriers to women's uptake of cervical screening to clinical and non-clinical staff to ensure that women's concerns and needs are addressed.	✓		✓	✓	✓	

→ Trauma and Post-Traumatic Stress Disorder (PTSD)

Introduction

Trauma can be described as going through stressful, frightening or distressing events, which can have a long-term impact on someone's mental health and wellbeing.

Trauma can sometimes directly cause mental health problems or make someone more vulnerable to developing them

It is among the potential causes of all mental health problems. Some conditions are also known to develop as a direct result of trauma, including post-traumatic stress disorder (PTSD) and complex post-traumatic stress disorder (complex PTSD).

Complex PTSD can occur when someone has been exposed to persistent abuse, neglect, violence or abandonment over a period of time, particularly as a child. People may have experienced multiple traumas, including the harmful effects of oppression and racism.

The Problem

Data on the prevalence of different mental health problems in Wales is lacking. We know that In England, young women aged 16-24 have higher levels of PTSD than any other group¹¹⁹. Data from England also shows women are more likely than men to experience common mental health problems¹²⁰.

On average, women in Wales exhibited worse levels of mental health after the onset of the pandemic, with the gap in reported wellbeing between men and women increasing from 9.9% to 14.1%¹²¹

Many women and girls who have experienced forms of Violence Against Women (VAW) are deeply traumatised and go on to face multiple, complex issues. The links between violence and abuse and poor mental health are unambiguous. Research by Agenda¹²² shows that over half (54%) of women with extensive experience of physical and sexual violence meet the diagnostic criteria for at least one Common Mental Disorder, and are also more likely to have multiple conditions, with about one in seven (15%) having three or more mental disorders. Over a third (36%) of women in the extensive physical and sexual violence group have made a suicide attempt, and a fifth (22%) have self-harmed. One in ten (9%) have spent time on a mental health ward¹²³.

¹¹⁹ The Women's Mental Health Taskforce Final report (2018), https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/765821/The_Womens_Mental_Health_Taskforce_-_final_report1.pdf

¹²⁰ Adult Psychiatric Morbidity Survey (2014) Survey of Mental Health and Wellbeing, England <https://digital.nhs.uk/data-and-information/publications/statistical/adult-psychiatric-morbidity-survey/adult-psychiatric-morbidity-survey-of-mental-health-and-wellbeing-england-2014>

¹²¹ Cardiff University (2021) Covid-19 in Wales: the mental health and wellbeing impact, https://www.cardiff.ac.uk/_data/assets/pdf_file/0010/2533762/COVID-19-Mental-health-FINAL-08-07-2021.pdf

¹²² Agenda (2016) Hidden Hurt <https://weareagenda.org/wp-content/uploads/2015/11/Hidden-Hurt-full-report1.pdf>

¹²³ Agenda (2016) Hidden Hurt <https://weareagenda.org/wp-content/uploads/2015/11/Hidden-Hurt-full-report1.pdf>

Experiencing trauma has implications for physical as well as mental health. Complex trauma in childhood and adulthood increases the risk of developing physical health problems, including long-term or chronic illnesses. For example, women who have experienced extensive violence and abuse are also more likely to have a range of different physical health conditions, including stomach, bowel and bladder problems; asthma, allergies, migraine and skin problems; and back, joint and muscle problems¹²⁴.

Gender inequality is both a cause and a consequence of women and girls' unequal mental health outcomes. Women and girls face inequality and discrimination both in their daily interactions and through systems and institutions, which have often been designed around a male service-user by default, and can sometimes be male dominated (e.g. drug and alcohol services). Experiences of sexism and misogyny are often compounded by a woman or girl's intersecting experiences of discrimination on the grounds of their ability, age, class, ethnicity, gender identity, race, religion and sexual orientation - including racism, homophobia and transphobia. Health services, and public services more generally, are not delivered in a vacuum and can perpetuate this inequality and discrimination.

Being systematically subordinated and disempowered has long-term psychological effects. There is wide research evidencing the links between experiencing discrimination and poor mental health: including depression¹²⁵, anxiety and psychological stress¹²⁶, and Post-traumatic stress disorder (PTSD)¹²⁷.

To effectively meet women's health needs, both mental and physical, it is essential that a trauma-informed approach be delivered across services to ensure women and girls get the support they need. Without effective support that responds to the complexity of women and girls' lives, problems can spiral - with devastating impacts on women, girls and their communities, and public services ultimately paying the price. Trauma-informed practices understand and respond to the high prevalence of trauma and its effects, as well as understanding that experiences of trauma can lead women to develop coping strategies and behaviours that may appear to be harmful or dangerous.

¹²⁴ Agenda (2016) Hidden Hurt <https://weareagenda.org/wp-content/uploads/2015/11/Hidden-Hurt-full-report1.pdf>

¹²⁵ Vigod, S. N (2020) The impact of gender discrimination on a Woman's Mental Health [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(20\)30055-9/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(20)30055-9/fulltext)

¹²⁶ Paradies Y, Priest N, Ben J, Truong M, Gupta A, Pieterse A, Kelaheer M, Gee G. (2015) Racism as a Determinant of Health: A Systematic Review and Meta-Analysis , <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4580597/>

¹²⁷ Wilson, E. C. et al (2017) The impact of discrimination on the mental health of trans*female youth and the protective effect of parental support, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5025345/>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Take a trauma-informed and gendered approach to staff education and training across health services, including violence and abuse, and wider inequalities.	✓		✓		✓	
Address the mental health impact of violence against women and girls through a cross-department approach. This should be incorporated into a future mental health strategy for Wales following on from Together for Mental Health.	✓		✓		✓	
Develop ways of recording information in a clear and safe way so that sharing experiences of violence, abuse and related issues are consistently implemented across health services to avoid the re-traumatisation of women having to repeatedly re-tell their stories.	✓	✓		✓	✓	
Reduce the use of physical restraint in inpatient mental health services, which can be particularly distressing for those who have experienced trauma, and introduce a Wales-wide ban on the use of face-down restraint.		✓			✓	
Commission and deliver women-only peer support as a core component of all wider interventions to support women and girls' mental health.	✓		✓		✓	

→ Menstrual Health and Wellbeing

Introduction

Menstrual health conditions can include a whole range of conditions, including but not limited to heavy menstrual bleeding, endometriosis, fibroids, adenomyosis, poly-cystic ovarian syndrome (PCOS), and pre-menstrual dysphoric disorder (PMDD). Symptoms range dependent on the condition, and can include excessive blood loss, chronic pain, mood disorders, infertility, and a diminished quality of life.

Statistics for common conditions show, for example, that 1 in 10 can have endometriosis or PCOS¹²⁸, and 1 in 3 women can get fibroids¹²⁹. Symptoms may vary considerably in severity from having mild or no symptoms to being chronic and debilitating. They may include heavy bleeding and anaemia, chronic pelvic pain, bowel and bladder issues, fatigue, mood disorders, and infertility.

The Problem

Poor menstrual health is exacerbated by taboos, erroneous beliefs, outdated attitudes and prejudices surrounding menstruation among the public and some healthcare professionals. This lack of awareness may lead to those with menstrual health conditions to suffer in silence and fail to seek medical help, or not realise they have a medical problem. Those who do seek help can find their symptoms dismissed by healthcare professionals. Improving awareness and understanding of menstrual health conditions amongst healthcare professionals and the public is essential to improving the diagnosis and management of those conditions and outcomes for those affected.

The impact of poor menstrual health can be wide-ranging. The need to have frequent access to toilets and period products can cause stress, and women can feel unable to participate in family or social events, sports or other physical activities. It can also lead to instances of missing education or work, which can be associated with failure to achieve full academic and career potential¹³⁰ and generates considerable cost to the economy¹³¹. Poor menstrual health can also impact on sexual health and wellbeing and can cause breakdowns in relationships.

Mental health problems, including depression and anxiety, can be linked to poor symptom management, a lack of support and difficulties getting pregnant

There are anecdotal reports of women being dismissed by healthcare professionals and of pain being minimised e.g. "it's just a bad period". This leads to some people experiencing long delays in getting a diagnosis, resulting in delays in accessing the right treatment. There is also evidence to suggest an inequitable access to support for some populations, which has been made worse by the pandemic¹³². One of the causes of these issues could be the lack of sufficient investment in the provision of associated healthcare services across Wales to cope with the demand.

¹²⁸ Royal College of Obstetricians and Gynaecologists (2017) 10 things you should know about endometriosis, <https://www.rcog.org.uk/en/blog/10-things-you-should-know-about-endometriosis/>

¹²⁹ NHS UK Conditions Overview for Fibroids, last reviewed: 17 September 2018 <https://www.nhs.uk/conditions/fibroids/>

¹³⁰ Boivin, J et al (2018), "Endometriosis in Wales: A comparative study on symptom awareness and help-seeking from the patient perspective for women living in Wales and other regions of the UK", Working Paper, University of Cardiff

¹³¹ For example, endometriosis is estimated to cost the UK economy £8.2bn in treatment, healthcare costs and loss of work (Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. Hum Reprod 2012;27(5):1292-9)

¹³² Plan UK (2020) 3 in 10 girls struggle to afford or access sanitary wear during lockdown, <https://plan-uk.org/period-poverty-in-lockdown>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Improve understanding and awareness of menstrual wellbeing by appropriate education, public awareness campaigns, and training for healthcare professionals, including: 1. Menstrual wellbeing taught to all children in primary and secondary school, with age-appropriate resources available 2. Training for healthcare professionals, teaching staff, social care workers, foster parents and employers 3. Awareness campaigns to improve public understanding of menstrual wellbeing and menstrual health conditions.	✓	✓	✓			✓
Ensure equitable access to education, menstrual products, diagnoses, and clinical services, which may entail additional/differentiated approaches to ensure services meet the needs of those with protected characteristics, in rural areas, or living in poverty: 1. Inclusive resources in a variety of formats and languages 2. Pan-Wales access to healthcare professionals with awareness and, where necessary, enhanced training in menstrual health/wellbeing conditions 3. Transparent and accessible pathways for treatment for all patients experiencing menstrual health conditions. 4. Support for those with menstrual conditions as with any other chronic condition, in education, the workplace and in accessing services.	✓		✓		✓	
Work with Public Health Wales and other relevant organisations to develop awareness campaigns on menstrual wellbeing and menstrual conditions.			✓			
Invest in data collection/research on the prevalence and impact of menstrual health conditions in Wales.				✓		

¹³³ NICE guidance NG73 on Endometriosis: diagnosis and management (6 September 2017) & Quality Standards QS172 on Endometriosis, (6 August 2018)

¹³⁴ RCGP menstrual wellbeing toolkit and e-learning module for GPs was developed with Endometriosis UK <https://www.rcgp.org.uk/clinical-and-research/our-programmes/clinical-priorities/menstrual-wellbeing.aspx>

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Fully implementing relevant NICE and other guidance¹³³ to ensure healthcare professionals in Wales: 1. Understand and recognise symptoms of menstrual health conditions, and know how and where to refer on (to include investment in associated specialist services and pathways) 2. Undertake appropriate training – including working with Royal Colleges, Health Boards and other bodies to ensure appropriate training is available, for example the RCGP menstrual wellbeing toolkit and e-learning module¹³⁴.	✓		✓	✓		✓
Ensure at least one HCP per GP practice has received enhanced training on menstrual wellbeing and associated health conditions.	✓	✓		✓		
Support a stakeholder driven initiative to develop a Quality Assurance Mark or equivalent for menstrual wellbeing policies and practices.			✓			

→ Endometriosis

Introduction

Endometriosis occurs where cells similar to those lining the womb are found elsewhere in the body. These cells can cause inflammation, pain and the formation of scar tissue. It is a chronic and sometimes debilitating condition.

Endometriosis affects 10% of women and those assigned female at birth¹³⁵ and can result in a wide range of symptoms, which may vary considerably in severity from mild or no symptoms to being chronic and debilitating. Common symptoms include chronic pelvic pain, painful periods, pain during or after sex, painful urination and bowel movements, fatigue or tiredness, and difficulties getting pregnant.

The impact of endometriosis can be wide ranging, from mental health problems such as depression and anxiety, to difficulty in obtaining reasonable adjustments at work or access to welfare benefits¹³⁶

Missing work, which can be associated with lack of career development and job insecurity, generates a huge cost to the economy. For example, endometriosis costs around £8.2bn a year to the UK economy in healthcare costs and work and employment impact¹³⁷. It is a challenge not only in workplace settings, but also in schools, causing some young women to miss or drop out of education, stopping them from achieving their full academic potential¹³⁸. The need to have frequent access to toilets can cause additional stress and result in women being unable to participate in family or social events and in sports and other physical activities. It can also have a knock-on effect on relationships.

Endometriosis can also result in poorer long-term health outcomes, including shorter disability-free life expectancy¹³⁹.

The Problem

Public awareness about the condition is generally poor, resulting in some with endometriosis not realising they have a medical condition and not seeking help. However, there are also anecdotal claims of a lack of awareness and understanding from some health professionals resulting in symptoms being missed or dismissed as “just a bad period” and not receiving an appropriate referral. Myths such as “teenagers can’t get endometriosis” or “pregnancy is a cure” still persist.

This could be because there is a lack of research into endometriosis, meaning the cause is not known and there is no cure. The effectiveness of treatments to manage endometriosis are also under-researched, which could mean that some patients are not receiving effective care.

¹³⁵ Royal College of Obstetricians and Gynaecologists (2017) 10 things you should know about endometriosis, <https://www.rcog.org.uk/en/blog/10-things-you-should-know-about-endometriosis/>

¹³⁶ Endometriosis UK (2017) <https://www.endometriosis-uk.org/news/endometriosis-it-disability-37511>

¹³⁷ Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. Hum Reprod 2012;27(5):1292-9:

¹³⁸ Boivin, J et al (2018), “Endometriosis in Wales: A comparative study on symptom awareness and help-seeking from the patient perspective for women living in Wales and other regions of the UK”, Working Paper, University of Cardiff

¹³⁹ Disability free life expectancy (DFLE) in Wales is 59.6 years for men and 59.1 years for women, lower than UK average (Health State Life Expectancies 2017-19”, ONS, 21 January 2021, <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bull/>

The 2018 Welsh Government review on endometriosis concluded that variations in endometriosis care in Wales “leads to non-prudent use of resources and waste and harm for individuals and service providers.”¹⁴⁰

Diagnosis in Wales takes on average 9 years, a year longer than in England, and can involve the distress of repeated medical appointments that fail to identify a cause for symptoms¹⁴¹

On average, patients will have 26 visits to the doctor before receiving a diagnosis in Wales¹⁴². Diagnostic delay results in delays in accessing treatment. Endometriosis is a chronic, complex condition for many who have it, requiring specialist, multi-disciplinary, long-term management, which is severely lacking across Wales, with problems identified at all levels of care.

In primary care, patients can expect multiple GP visits. GPs may not be aware of referral pathways, which can prevent out-of-area specialist referrals. Further, there is a lack of provision of pain management, including pelvic physiotherapy and psychological support.

- Prior to diagnosis 81% of those with endometriosis in Wales visited their GP five or more times (UK average 78%), and 56% ten or more times (UK average 60%)¹⁴³
- 94% of those with endometriosis in Wales would have liked psychological support but were not offered it (UK average 90%)¹⁴⁴.

In secondary care, there are long waiting times for gynaecology appointments and surgery and a lack of access to gynaecologists with expertise in endometriosis. NICE guidance outlines that access to specialist gynaecologists with expertise in diagnosing and managing endometriosis should be available¹⁴⁵, including those sufficiently skilled and trained to undertake diagnostic laparoscopy.

NICE guidance also states that patients needing tertiary care should be referred to a BSGE-accredited endometriosis specialist centre¹⁴⁶, for example in cases of suspected or confirmed deep endometriosis, but that is not always the case.

- 44% of patients got gynaecology appointment within 6 months of referral (UK average 69%), while 41% were waiting 7-12 months (UK average 19%)¹⁴⁷
- 52% waited 0-6 months for surgery (UK average 70%), 48% waited more than 6 months (UK average 30%) and 15% waited more than 1 year (UK average 7%)¹⁴⁸.

¹⁴⁰ Welsh Government Report from Endometriosis Task and Finish Group (16 April 2018) Endometriosis care in Wales: Provision, care pathway, workforce planning and quality and outcome measures, <https://gov.wales/sites/default/files/publications/2019-03/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf>

¹⁴¹ Inquiry Report of APPG on Endometriosis (October 2020) Endometriosis in the UK – Time for Change, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

¹⁴² Boivin, J et al (2018), Endometriosis in Wales: A comparative study on symptom awareness and help-seeking from the patient perspective for women living in Wales and other regions of the UK, Working Paper, University of Cardiff https://www.cardiff.ac.uk/_data/assets/pdf_file/0009/1319571/Boivin_Working_paper_Series_Endometriosis_in_Wales_16APR_2018.pdf

¹⁴³ Inquiry Report of APPG on Endometriosis (October 2020) Endometriosis in the UK – Time for Change, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

¹⁴⁴ Inquiry Report of APPG on Endometriosis (October 2020) Endometriosis in the UK – Time for Change, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

¹⁴⁵ NICE guidance NG73 on Endometriosis: diagnosis and management (6 September 2017) <https://www.nice.org.uk/guidance/NG73> & NICE Quality Standards QS172 on Endometriosis (6 August 2018) <https://www.nice.org.uk/guidance/QS172>

¹⁴⁶ British Society of Gynaecological Endoscopy (BSGE) Accredited endometriosis specialist centres <https://www.bsge.org.uk/centre/>

¹⁴⁷ Inquiry Report of APPG on Endometriosis (October 2020) Endometriosis in the UK – Time for Change, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

¹⁴⁸ Inquiry Report of APPG on Endometriosis (October 2020) Endometriosis in the UK – Time for Change, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

There have been anecdotal reports of patients being told they do not have endometriosis following laparoscopies undertaken in general gynaecology, but later laparoscopies undertaken by endometriosis specialists found extensive endometriosis. There are also anecdotal incidents where patients have been referred to fertility services without their endometriosis being properly investigated leading to failed IVF, which is upsetting for the patient and costly for the NHS. There have also been reports of patients who do not want children feeling like their care is given a lower priority than those who want children¹⁴⁹.

In Tertiary care there is lack of BSGE-centre provision for the patient population in Wales.

There is a BSGE centre at University Hospital of Wales Cardiff and a second, provisional centre at the Singleton Hospital Swansea. Patients outside Cardiff needing specialist care have anecdotally reported that referrals have been refused due to funding arrangements not enabling out of area referrals¹⁵⁰.

Those in North Wales should be referred to Arrowe Park hospital in Birkenhead, but it would appear that there is insufficient use of cross-border referral arrangements to refer those needing specialist care in North Wales. No pathways exist for tertiary care referral in Mid Wales - patients may be referred to gynaecology at County Hospital Hereford¹⁵¹, but County Hospital cannot refer Welsh patients for tertiary care at a BSGE centre. It is suspected that inadequate funding arrangements are preventing out of area referrals for tertiary care, resulting in a postcode lottery.

There should be a joined-up approach and regular communication, including for patients to have appropriate and timely access to fertility services, as the NICE guidance states¹⁵²

...as well as access to other surgical and non-invasive specialisms including menopause expertise, pain management, and psychological support. There is especially a need when “out of area” services are utilised and there is no holistic post-surgery care.

¹⁴⁹ Inquiry Report of APPG on Endometriosis (October 2020) Endometriosis in the UK – Time for Change, <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

¹⁵⁰ FTWW Event (2021) Improving Endometriosis Care in Wales <https://www.ftww.org.uk/endometriosis-care-in-wales-event-follow-up-report/>

¹⁵¹ County Hospital Hereford, part of Wye Valley NHS Trust, is not a BSGE accredited endometriosis specialist centre.

¹⁵² NICE Clinical Guideline CG 156 on Fertility problems: assessment and treatment (6 September 2017) <https://www.nice.org.uk/guidance/cg156>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Appropriate resourcing for endometriosis care in Wales – recognise the scale of the care need, existing inequities, and commit appropriate resources to raise awareness, diagnose, treat and manage the condition: 1. Bring tertiary endometriosis care under the remit of the Welsh Health Specialist Services Committee (WHSSC)¹⁵³ to overcome existing funding challenges and end the postcode lottery 2. Ensure appropriate resources for newly appointed Health Board Endometriosis Specialist Nurses to enable them to lead on improving awareness in primary and secondary care and support pelvic wellbeing services as well as providing advice, support and pharmaceutical management of symptoms 3. Ensure Welsh Government funded research programmes include endometriosis, with a particular focus on identifying the cause of the condition, as well as developing better treatments.	✓	✓	✓	✓	✓	
Improve knowledge and skills of healthcare professionals involved in endometriosis care: 1. Commit to reducing average time to diagnosis for endometriosis from 9 years to under 4 years by 2025 and under one year by 2030, requiring improved public and practitioner awareness and training for healthcare professionals, clear pathways for diagnosis, and investment in diagnostic capacity in gynaecology departments 2. Improve awareness and understanding of endometriosis to ensure signs and symptoms are recognised and patients treated or referred on appropriately 3. Invest in advanced surgical skills training for minimal access surgery to avoid open surgery, improve diagnostic procedures and initial surgical treatment, priorities which echo the direction of those outlined in the Welsh Government's Covid-19 Recovery Plan¹⁵⁴ 4. Identify endometriosis leads in all Health Boards, and ensure MCNs are in place.	✓	✓	✓	✓	✓	✓

¹⁵⁵ Welsh Government Report from Endometriosis Task and Finish Group (16 April 2018) Endometriosis care in Wales: Provision, care pathway, workforce planning and quality and outcome measures, <https://gov.wales/sites/default/files/publications/2019-03/endometriosis-care-in-wales-provision-care-pathway-workforce-planning-and-quality-and-outcome-measures.pdf>

¹⁵⁶ NICE guidance NG73 on Endometriosis: diagnosis and management (6 September 2017) <https://www.nice.org.uk/guidance/NG73> & NICE Quality Standards QS172 on Endometriosis (6 August 2018) <https://www.nice.org.uk/guidance/QS172>

¹⁵⁷ Royal College of Obstetricians and Gynaecologists, Restoration and Recovery: Priorities for obstetrics and gynaecology, published 20 April 2021 <https://rcog.org.uk/media/heppbups/2021-04-20-restoration-and-recovery-priorities-for-obstetrics-and-gyn.pdf>

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Care pathways for endometriosis should be in line with current NICE guidance and address gaps identified, including but not limited to: - Full implementation of recommendations of 2018 Welsh Government review on endometriosis care¹⁵⁵ in line with NICE guideline NG 73 and NICE quality standard QS 172¹⁵⁶ - Undertake or commission an audit to identify any gaps and challenges to implementation - Address gaps in existing NICE guidance including extra-pelvic endometriosis, post-surgery including hysterectomy care, menopause care, pain management and psychological support - Ensure that the same treatment, attention and care is available for those who do not want children as for those who do.	✓	✓	✓	✓	✓	
Pre-pandemic, 48% of endometriosis patients in Wales could expect to wait more than 6 months for a hospital appointment (versus the UK average of 30%), a situation worsened by pandemic-related delays. Therefore: - Publicly commit to tackling the Covid-19-related backlog for endometriosis patients as an urgent priority - Base resumption of appointments on clinical need, for example using the RCOG Covid-19 prioritisation framework¹⁵⁷, which would prioritise those with severe endometriosis who had surgery cancelled or postponed.			✓	✓	✓	✓

→ Adenomyosis

Introduction

Adenomyosis is a disease where cells similar to those in the lining of the womb (the endometrium) grow within the muscle layer of the wall of the womb. They respond to the hormonal menstrual cycle including bleeding and causing pain, with the most common symptoms being heavy, painful or irregular periods, pre-menstrual pelvic pain and feelings of heaviness/discomfort in the pelvis. About a third of those with adenomyosis experience few or no symptoms, whilst for others the impact can be chronic and debilitating.

It affects 1 in 10 women¹⁵⁸ and those assigned female at birth (AFAB), and many women with adenomyosis will have endometriosis and vice versa. As with endometriosis, the cause is not known and there is no cure. The symptoms between the two diseases overlap.

Less common symptoms of adenomyosis include pain during sex and pain relating to bowel movements.

Adenomyosis is not thought to impact on chance of pregnancy, but is linked to an increased risk of miscarriage and premature birth¹⁵⁹

There has been limited research into adenomyosis, however impacts can include:

- Reduced health-related quality of life
- Impairment at work and daily activities including a negative impact on work productivity
- A negative effect on psychological health including a higher risk for anxiety and depression
- Symptoms usually improve or go away after the menopause¹⁶⁰.

There are different options available for managing adenomyosis¹⁶¹ which may involve doing nothing if symptoms are mild or if menopause is approaching, or using anti-inflammatory medication such as ibuprofen. There are non-hormonal treatments available such as tranexamic acid or mefenamic acid to reduce pain and bleeding with periods, as well as hormonal treatments such as oral contraceptive pills, progestin intrauterine devices (IUDs) or contraceptive injections, and injectable medications to induce temporary menopause (the latter of which is not suitable for long-term use).

The only definitive treatment for the condition suitable for women not wishing to preserve fertility, is Hysterectomy (removal of the womb).

¹⁵⁸ North Bristol NHS Trust "What is adenomyosis?" <https://www.nbt.nhs.uk/our-services/a-z-services/gynaecology/adenomyosis>

¹⁵⁹ North Bristol NHS Trust "What is adenomyosis?" <https://www.nbt.nhs.uk/our-services/a-z-services/gynaecology/adenomyosis>

¹⁶⁰ Alcalde et al (2021), Impact of Adenomyosis on Women's Psychological Health and Work Productivity: A Comparative Cross-Sectional Study, Journal of Women's Health (e-pub ahead of print), <https://www.liebertpub.com/doi/10.1089/jwh.2020.8789>

¹⁶¹ North Bristol NHS Trust "What is adenomyosis?" <https://www.nbt.nhs.uk/our-services/a-z-services/gynaecology/adenomyosis>

Some women undergoing a hysterectomy experience loss of ovarian function and may subsequently need menopause care including Hormone Replacement Therapy (HRT)^{162,163}

Uterine artery embolisation is also an option, and is a procedure whereby tiny particles are injected into blood vessels via a catheter in the groin to block off blood supply to adenomyosis and cause it to shrink, thus reducing symptoms.

The Problem

A lack of public awareness of the condition can result in those with adenomyosis not realising they have a medical condition and therefore not seeking the help they need

There may also be a lack of awareness and understanding from some health professionals which can result in an individual presenting with symptoms of adenomyosis being dismissed and not investigated further, or not referred on to secondary care. The overlapping symptoms of endometriosis and adenomyosis could also be a contributing factor leading to the latter not being diagnosed.

There is currently no national guidance (such as NICE or other) or established care pathways for the diagnosis and treatment of adenomyosis in Wales, which can contribute to patchy or unequal access to care.

There is also a lack of research into adenomyosis and the effectiveness of treatments to manage the condition. Where hysterectomy is advised, there also needs to be clear discussions on post-surgery consequences, including those related to ovarian function.

¹⁶² Khadilkar S (2020) "[Does saving uterus save ovaries?](#)" The Journal of Obstetrics and Gynecology of India volume 70, pages 99–102

¹⁶³ Moorman et al (2011), "[Effect of Hysterectomy With Ovarian Preservation on Ovarian Function](#)", Obstetrics & Gynecology, December 2011, vol 118, issue 6, p 1271-1279

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Commit appropriate resources to diagnose, treat and manage adenomyosis, as well as appropriate resourcing to recognise and measure the scale of adenomyosis care needs in Wales.	✓	✓	✓	✓	✓	✓
Ensure Welsh Government funded research programmes include dedicated research funding for adenomyosis with a particular focus on developing better treatments.		✓	✓			
Invest in training for healthcare professionals to speed up diagnosis and timely, equitable access to adenomyosis care in Wales.	✓	✓	✓			✓
Develop care pathways for adenomyosis: • Work with expert clinicians and Royal Colleges to develop appropriate care pathways for those with adenomyosis in Wales • Care pathways should allow for post-surgery care including menopause care for those having a hysterectomy who may need it • Encourage the National Institute of Health and Care Excellence (NICE) to develop guidance on the diagnosis and management of adenomyosis which could then be adopted by the Welsh Government and implemented in Wales.	✓	✓	✓	✓	✓	

→ Premenstrual Dysphoric Disorder (PMDD)

Introduction

Premenstrual Dysphoric Disorder (PMDD) is a chronic neuroendocrine condition and emerging women's health and mental health issue.

Thought to be an abnormal reaction in the brain to normal monthly hormone fluctuations, PMDD causes debilitating emotional, mental, and sometimes physical symptoms in the luteal phase of the menstrual cycle for 5.5% of women and those assigned female at birth (AFAB) who are of reproductive age¹⁶⁴

Symptoms include depression, anxiety, mood swings, irritability, and often suicidal ideations, as well as physical symptoms such as breast tenderness and bloating¹⁶⁵. These symptoms often impair daily functioning at work, school, and in relationships and diminish an individual's quality of life leading to a high incidence of suicide. PMDD can start or be triggered at any point throughout the reproductive lifetime - from menarche up to perimenopause.

PMDD was added to the *Diagnostic and Statistical Manual of Mental Disorders*¹⁶⁶ in 2013 as a mood disorder. In 2019, PMDD was also included in the newest edition of the World Health Organization's International Classification of Diseases¹⁶⁷ cross-listed as a disease of the genitourinary system and a depressive disorder.

The Problem

Stats Wales states that there are 971,731 women between the ages of 16 and 64¹⁶⁸. With an incidence rate of 5.5%, it is thought that around 53,445 of women in Wales are living with PMDD.

There are anecdotal reports of many patients in Wales struggling to receive a diagnosis, support, and appropriate treatment due to limited awareness in the medical community at the primary and secondary levels - and also inadequate specialist centres for onward referrals if needed. This leads to poor health outcomes for women, many of which could be avoided with early diagnosis and appropriate treatment.

Dr Nick Panay, a member of the IAPMD Clinical Advisory Board and President of the Royal Society of Medicine has acknowledged that there is very little in the training curriculum for GPs for PMS and PMDD, resulting in them coming out of training without the skills to deal with this condition, admitting this to be an obstacle for diagnosis¹⁶⁹.

¹⁶⁴ International Association for Premenstrual Disorders, What is PMDD? <https://iapmd.org/about-pmdd>

¹⁶⁵ American Psychiatric Association (2013) Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: DSM-5

¹⁶⁶ American Psychiatric Association (2013) Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: DSM-5

¹⁶⁷ World Health Organization (2019) International Classification of Diseases, 11th edition: ICD-11

¹⁶⁸ StatsWales, Population and Migration, <https://statswales.gov.wales/Catalogue/Population-and-Migration/Population/Estimates>

¹⁶⁹ IAPMD (June 2021) Written submission to the UK Women's Health Strategy <https://iapmd.org/position-statements-1/2021/6/24/iapmd-written-submission-to-the-uk-womens-health-strategy>

Patients in the United Kingdom wait an average of 12 years for an accurate diagnosis and see 11 healthcare providers in the process¹⁷⁰

A recent study by Elizabeth Osborn highlights the critical importance of the accurate and timely detection of PMDD, with the aim of preventing women from experiencing severe and prolonged psychological distress¹⁷¹.

Recent IAPMD research of 591 patients shows the wide-ranging impacts of PMDD¹⁷²:

- 86% of individuals with PMDD reported experiencing thoughts of suicide and 30% reported making a suicide attempt during a PMDD episode. This is 50% higher than the suicide risk for major depression
- 56.7% reported having lost an intimate partner relationship due to PMDD
- 98% and 97% feel PMDD puts a significant strain on their intimate partner relationship and family relationships, respectively
- 42.7% reported problems with parenting due to PMDD, with 10.5% feeling completely unable to parent during PMDD
- 16.8% reported having lost a job due to PMDD.

¹⁷⁰ Divine et al (2019) Brief Summary: Lifetime Prevalence of Self-Injurious Thoughts and Behaviors in a Sample of 591 Patients Reporting a Prospective Clinical Diagnosis of Premenstrual Dysphoric Disorder via IAPMD <https://iapmd.org/position-statements-1/2021/6/24/iapmd-written-submission-to-the-uk-womens-health-strategy>

¹⁷¹ Osborn, E., Wittkowski, A., Brooks, J. et al. Women's experiences of receiving a diagnosis of premenstrual dysphoric disorder: a qualitative investigation. BMC Women's Health 20, 242 (2020) <https://doi.org/10.1186/s12905-020-01100-8>

¹⁷² IAPMD (June 2021) Written submission to the UK Women's Health Strategy <https://iapmd.org/position-statements-1/2021/6/24/iapmd-written-submission-to-the-uk-womens-health-strategy>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Introduce mandatory training in Premenstrual Disorders (PMDD and PME) for professionals who work with any female/AFAB individuals, including GPs, psychologists, psychiatrists, social workers, nurses, and family planning teams, etc.	✓	✓	✓			
Implement a cross-disciplinary collaborative care model in management of PMDD, including joint-working with relevant agencies offering wider support, such as easier access to the various social security benefits for those who are living with cyclical, reproductive health care issues like PMDD and Endometriosis as they often struggle to maintain employment, even with reasonable accommodations.	✓		✓		✓	
Include Menstrual tracking as part of the mental health screening process for PMDD and PME to reduce missed opportunities for diagnosing PMDD, especially in mental health settings.		✓	✓	✓	✓	✓
Ensure PMDD is included in the development of a secondary school education syllabus, defining what kind of mood shift is 'normal' and what to do when the mood shifts are outside of this range, saving years of suffering alone and In line with the prudent healthcare principles of prevention and early intervention.	✓	✓	✓	✓		✓
Develop and implement an integrated screening process within the NHS to make screening for PMDD a common practice in primary and secondary care settings including gynaecology, psychiatry, psychology, family planning, and sexual and reproductive health clinics, as well as for those reporting to A&E in crisis.		✓	✓		✓	
Ensure patient-centered, holistic, and sufficiently knowledgeable care locally for those living with premenstrual disorders and the development of clear, joined-up referral pathways for various specialisms involved in caring for patients affected.	✓	✓	✓	✓	✓	

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
For those with complex needs, ensure adequate funding and support for the development of regional specialist tertiary PMS and menopause clinics across Wales, with equitable access for all eligible patients assured.	✓	✓	✓		✓	
Ensure that systems are in place for patients requiring crisis intervention, including increased awareness in emergency care settings and associated services.		✓	✓		✓	
Include hormone sensitivity in any development of menopause education, training, and service provision - many patients have an extremely challenging time during perimenopause due to the increased hormone fluctuations.		✓	✓		✓	
Ensure that the particular needs of those undergoing surgical menopause are included in the development of menopause training for healthcare professionals so that those patients affected have sufficiently specialised follow-up and aftercare to reduce likelihood of longer-term mental and physical health problems and costs to the public purse.	✓	✓	✓		✓	✓

→ Polycystic Ovary Syndrome (PCOS)

Introduction

Polycystic ovary syndrome (PCOS) is an endocrine disorder caused by an underlying hormone imbalance. It affects 1 in 10 women and those assigned female at birth (AFAB)¹⁷³ from puberty to menopause. It can cause irregular periods and ovulation, fertility problems, unwanted facial or body hair, oily skin/acne, thinning hair/hair loss, weight problems, depression and mood changes.

PCOS is also associated with an increased risk of developing health problems in later life, such as type 2 diabetes and high cholesterol levels¹⁷⁴

The Problem

Despite so many being affected and the long-term consequences of delayed diagnosis and treatment, there has historically been insufficient research into this very common condition. The result is that people with PCOS are still waiting for the cause of their condition to be discovered, for speedy diagnosis, and for better treatments to be developed. A March 2021 search of PubMed, a global database of published medical research revealed that there were only 18,631 results for PCOS, approximately one tenth of the number of results for prostate cancer, which affects the equivalent number of men¹⁷⁵.

A lack of research has led to very limited treatment options for those living with PCOS with the focus on managing symptoms rather than the underlying condition. This has significant impact on longer-term health and fertility

Like most conditions perceived to be gynaecological in nature, when it is in fact an endocrine condition, the lack of investment in research into PCOS is reflected in a failure to prioritise it in medical training or make available sufficiently specialised or joined-up NHS services to manage its multifarious effects. There are anecdotal reports of patients experiencing long delays to diagnosis with symptoms normalised, dismissed, or misattributed to 'over-eating' or generalised anxiety. The lack of clear diagnostic pathways could be a contributor to significant mismanagement of the condition, including poor or absent treatment.

The Royal College of Obstetricians and Gynaecologists explores the long-term health consequences of PCOS in its Green Top Guideline¹⁷⁶ and makes specific references to links with diabetes, sleep apnoea, cardiovascular disease, psychological disorders, and increased risk of endometrial hyperplasia and later carcinoma, all of which would be better served by ensuring prompt diagnosis and early intervention.

¹⁷³ NHS Polycystic Ovary Syndrome, <https://www.nhs.uk/conditions/polycystic-ovary-syndrome-pcos/>

¹⁷⁴ NHS Polycystic Ovary Syndrome, <https://www.nhs.uk/conditions/polycystic-ovary-syndrome-pcos/>

¹⁷⁵ Searches for research papers can be undertaken by anyone: <https://pubmed.ncbi.nlm.nih.gov>

¹⁷⁶ Royal College of Obstetricians and Gynaecologists (2014) Long-term Consequences of Polycystic Ovary Syndrome, https://www.rcog.org.uk/globalassets/documents/guidelines/gtg_33.pdf

Prompt diagnosis and early intervention are both dependent upon healthcare professionals having sufficient knowledge of the condition and how it presents, and their ability to make timely referrals for testing and treatment.

Currently, PCOS is often incorrectly approached as a gynaecological issue rather than an endocrine matter, however recognition of the condition as an endocrine disorder would likely lead to improved treatment. Care is often limited to 'management' rather than solutions, with many patients advised merely to 'mask' symptoms by taking the Combined Oral Contraceptive Pill. This does not suit every patient and can cause side-effects which are not well-tolerated. This approach doesn't necessarily prevent disease progression and the development of PCOS-related long-term health issues either.

Lack of investment in understanding and treating PCOS has also resulted in variation in service delivery in Wales. There is inconsistency regarding referrals from primary care into secondary services across health boards. There are anecdotal reports of many patients being referred to gynaecology rather than endocrinology when a multi-disciplinary approach would enable more appropriate testing and treatment. Similarly, those affected by PCOS tend to see fertility prioritised over and above long-term health conditions caused by the condition, an approach which fails to consider the need for holistic wellbeing as well as Wales' prudent healthcare principles.

¹⁷⁷ Coventry and Warwickshire NHS Trust
<https://www.uhcnw.nhs.uk/wisdom/clinical-expertise/endocrinology/>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Increased access to funding for research into PCOS.	✓	✓				
Health Education and Improvement Wales to work with patients and specialist charities to develop and deliver training for healthcare professionals that would enhance their knowledge of PCOS and expedite testing and diagnosis.				✓		✓
Look to models of good practice, such as the PCOS clinic hosted by the Coventry and Warwickshire NHS Trust ¹⁷⁷ where care is centralised and managed by linking into relevant specialisms, ensuring a patient-centred multi-disciplinary approach.		✓	✓		✓	
Develop guidance that ensures a holistic and standardised approach to patients' health and wellbeing, with prevention and early intervention key to improved outcomes. This should include access to fertility treatment alongside, not 'instead of' other specialisms.	✓		✓		✓	✓

→ Menopause

Introduction

Women and those assigned female at birth account for over half the population of Wales and at some point in their lives, the majority of them will experience menopause. It isn't uncommon for women to have to leave employment as a consequence of symptoms in the transition to and beyond menopause and/or to require many interventions from healthcare professionals in an effort to deal with them. Given the economic and societal burden upon women aged 45 and over, universal access to better menopause support and treatment is essential.

The problem

Between 60-70% of women aged between 50 and 64 years, the age at which menopause typically falls, are in employment, comprising almost half of Wales's workforce¹⁷⁸. The transition time to menopause (peri-menopause) can take place over the preceding ten years and is the time at which most will experience hormone fluctuations and associated symptoms¹⁷⁹. In addition to working, women going through menopause may be caring for dependants¹⁸⁰. The TUC reports that 80% of working women experienced noticeable changes during the build-up to menopause and that, of these, 45% found their symptoms difficult to deal with¹⁸¹.

Menopause is erroneously considered 'just an older women's problem' however 1 in 100 under-40s¹⁸² will experience premature ovarian insufficiency (early menopause), whilst medical menopause and surgical menopause will affect significantly more^{183,184}.

Despite the high numbers of people affected, awareness of menopause both on the part of healthcare professionals and the wider public is lacking¹⁸⁵

Currently, it does not feature in school-based menstrual education, nor is it covered in any great depth in medical training. The result is that women do not realise that their symptoms can be attributed to menopause, causing delays in them seeking help, and healthcare professionals not guiding discussions adequately to diagnose menopause. In many practices, there isn't a GP or nurse with sufficiently specialised knowledge of menopause and Hormone Replacement Therapy (HRT) to provide input to patients¹⁸⁶, in fact there are only 7 registered NHS menopause specialists in Wales¹⁸⁷.

The lack of oestrogen during this time has considerable repercussions for wider health, including increased rates of cardiovascular disease, dementia, and osteoporosis¹⁸⁸. These diseases incur a significant cost burden for Wales¹⁸⁹. Those women with a more complex medical history, who may require access to a more specialised menopause clinic, are often unable to access one, resulting in a continued failure to provide optimum treatment with significant impact on wellbeing and health¹⁹⁰.

¹⁷⁸ Stats Wales, <https://statswales.gov.wales/Catalogue/Business-Economy-and-Labour-Market/People-and-Work/Employment/Persons-Employed/employmentrate-by-welshlocalarea-year-gender>

¹⁷⁹ TUC, Supporting Working Women Through the Menopause https://www.tuc.org.uk/sites/default/files/TUC-menopause_0_0.pdf

¹⁸⁰ WEN Wales, The Position in Wales Today on Unpaid Care <https://wenwales.org.uk/wp-content/uploads/6033-WEN-Unpaid-Care-FINAL.pdf>

¹⁸¹ TUC, Supporting Working Women Through the Menopause https://www.tuc.org.uk/sites/default/files/TUC-menopause_0_0.pdf

¹⁸² FTWW (2019) Making the Case for Better Menopause Services in Wales <https://www.ftww.org.uk/2021/wp-content/uploads/2019/07/FTWW-Making-the-Case-for-Better-Menopause-Services-in-Wales-Report.pdf>

¹⁸³ Circle Health Group <https://www.circlehealthgroup.co.uk/health-matters/health-and-wellbeing/hysterectomy-your-questions-answered>

¹⁸⁴ NICE Guidance, Item 1.10.5 <https://www.nice.org.uk/guidance/ng73/chapter/Recommendations#pharmacological-pain-management>

¹⁸⁵ NICE, Menopause Implementation: Improving knowledge among healthcare professionals: <https://www.nice.org.uk/guidance/ng23/chapter/Menopause-implementation-getting-started>

¹⁸⁶ NICE, Menopause Implementation: Communicating the long-term benefits and risks of hormone replacement therapy, <https://www.nice.org.uk/guidance/ng23/chapter/Menopause-implementation-getting-started>

¹⁸⁷ British Menopause Society <https://thebms.org.uk/find-a-menopause-specialist/>

¹⁸⁸ FTWW (2019) Making the Case for Better Menopause Services in Wales: Long-term Health Implications of Menopause <https://www.ftww.org.uk/2021/wp-content/uploads/2019/07/FTWW-Making-the-Case-for-Better-Menopause-Services-in-Wales-Report.pdf>

¹⁸⁹ FTWW (2019) Making the Case for Better Menopause Services in Wales: Long-term Health Implications of Menopause <https://www.ftww.org.uk/2021/wp-content/uploads/2019/07/FTWW-Making-the-Case-for-Better-Menopause-Services-in-Wales-Report.pdf>

¹⁹⁰ Welsh Government, A Healthier Wales, <https://gov.wales/sites/default/files/publications/2021-09/a-healthier-wales-our-plan-for-health-and-social-care.pdf>

In addition, many of those presenting with menopause-related mental health issues, such as anxiety and depression, are erroneously prescribed anti-depressants¹⁹¹

The lack of menopause education in schools, in medical training, and throughout the life-course results in a lack of awareness on the part of both women themselves and healthcare professionals, educators, and employers. There are numerous missed opportunities to raise awareness of peri-menopause, menopause, and HRT at key moments in women's lives and in key locations, including the GP practice, sexual and reproductive health clinics, screening appointments, and hospitals.

Menopause has not been prioritised for investment in improved care and support, either by health service providers or employers. Indeed, women's health, including menopause, is not incentivised in primary care settings resulting in patchy or insufficient knowledge on the part of GPs, a lack of specialist women's health nurses, and widespread failure to prescribe HRT appropriately¹⁹².

Despite the subsequent debunking of key findings of the Women's Health Initiative report, findings which had led to fear of prescribing HRT, there still remains a lack of knowledge around its benefits¹⁹³, and women are not able to access HRT without a prescription. Age-related decline in sexual function may significantly reduce quality of life, making recognition of sexual dysfunction by physicians important for getting menopausal women effective care. However, HRT, which can improve both low sexual desire and physiological symptoms which make it more difficult to engage in sexual activity, is not available over the counter in the same way as treatment for erectile dysfunction¹⁹⁴. This is despite menopause commonly causing loss of libido, vaginal dryness and atrophy which make penetrative sex painful.

The failure to include women's health in Welsh Government's strategy, 'A Healthier Wales'¹⁹⁵ has led to variation in care and inequality of access across Wales. Not all health boards offer a specialist (tertiary) menopause service / clinic for their more complex patients (i.e. those with a medical history which requires more bespoke prescribing, or where conventional therapies are not providing symptom relief).

Wales's NHS system often prevents out of area referrals, including self-referrals, resulting in a postcode lottery for patients where specialist clinics do not exist locally. Anecdotally, where clinics do exist, patients have reported that they have not been able to access their services following surgical menopause because GPs don't know of the clinics' existence.

¹⁹¹ Balance, Menopause symptoms are killing women's careers, <https://www.balance-menopause.com/news/menopause-symptoms-are-killing-womens-careers-major-survey-reveals/>

¹⁹² NHS England, BMA <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0456-update-on-quality-outcomes-framework-changes-for-21-22.pdf>

¹⁹³ NICE, Menopause Implementation: Communicating the long-term benefits and risks of hormone replacement therapy, <https://www.nice.org.uk/guidance/ng23/chapter/Menopause-implementation-getting-started>

¹⁹⁴ Thornton et al (2018) Menopause and Sexuality, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5994393/>

¹⁹⁵ Welsh Government, A Healthier Wales, <https://gov.wales/sites/default/files/publications/2021-09/a-healthier-wales-our-plan-for-health-and-social-care.pdf>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Invest in co-produced research and data collection on the impact of menopause on Wales's population, to include access to services and wider social, employment and financial considerations.			✓	✓	✓	
Raise public awareness and provide accessible information to all by: - Co-producing resources on menopause to be available in key locations online, in-person and via mainstream media - Utilising opportunities to discuss peri-menopause, menopause, and HRT at appropriate intervals in women's lives, including the GP practice, sexual and reproductive health clinics, screening appointments, and hospitals.	✓		✓	✓		✓
Incentivise and make menopause a priority for Wales-based nurse / GP curriculum and continuing professional development.	✓	✓	✓			
Ensure that every GP practice in Wales can offer access both to a specialist women's health nurse and a GP formally recognised as having a 'special interest and training in Women's Health, including menopause'. This should have the same sort of funding and training allocated to it as do other health conditions listed in the Quality Assurance & Improvement Framework for Primary Care in Wales.	✓		✓		✓	
Ensure specialised training of healthcare professionals at every level incorporates understanding of both chemical and surgical menopause and appropriate prescribing of HRT.		✓			✓	
Women undergoing operations resulting in surgical menopause should routinely be given adequate information in advance, enabling them to make informed decisions.		✓			✓	✓
Develop and routinely apply Patient Reported Outcome Measures to assess health boards' menopause-related provision.	✓		✓		✓	

→ Heart Conditions

Introduction

Systemic inequalities which existed before, have only been exacerbated by the pandemic and women continue to face unconscious biases and disadvantages at every stage of their heart disease journey. The British Heart Foundation (BHF) estimates that there are 100,000 women living in Wales with heart disease.

Coronary heart disease alone kills twice as many women as breast cancer¹⁹⁶

And yet, heart disease is often perceived as something which only affects men. This assumption is incorrect and is costing women their lives.

The Problem

Women are not seen as being at risk of heart attacks: Each year 1,700 women are admitted to hospital in Wales due to a heart attack¹⁹⁷. Despite this, the people of Wales are not well aware that heart attacks happen to women too. This may lead to symptoms being dismissed or not taken seriously. A 2021 BHF Cymru survey found that over a third of women in Wales do not feel confident in recognising the symptoms of a heart attack, and only 7% feel very confident¹⁹⁸.

High blood pressure is the biggest modifiable risk factor contributing to premature deaths from heart and circulatory diseases in Wales¹⁹⁹ and has been more strongly associated with heart attacks in women than in men²⁰⁰. The BHF estimates that there are thousands of women living in Wales with undiagnosed high blood pressure. High blood pressure during pregnancy is associated with an increased risk of several heart conditions later in life, including coronary heart disease, heart attack, heart failure, and cardiomyopathy²⁰¹.

Around 1 in 10 women develop high blood pressure during pregnancy in the UK²⁰². Despite these statistics, our survey showed that women are not seen as being at risk of heart disease by the Welsh public - with 65% of people unable to identify heart disease as one of the leading causes of death of Women in Wales²⁰³.

After a heart attack, an incorrect initial diagnosis increases the risk of death after 30 days by 70%. Research suggests that women are 50% more likely than men to receive the wrong initial diagnosis for a heart attack²⁰⁴

The Babylon app is described as a virtual GP app service, which uses artificial intelligence to identify and digitally diagnose health problems in England. Doctors have expressed concern that due to the algorithm

¹⁹⁶ BHF (2021) estimate based on Welsh Health Survey responses and latest ONS population estimates.

¹⁹⁷ Digital Health and Care Wales (2020). via correspondence.

¹⁹⁸ YouGov Plc. Total sample size was 1007 adults. Fieldwork was undertaken between 10th - 14th June 2021. The survey was carried out online and results have been weighted for the Welsh adult population.

¹⁹⁹ Institute for Health Metrics and Evaluation (IHME). (2019). Global Burden of Disease Study 2019 (GBD 2019) Results. <https://bit.ly/3DlBzJZ>

²⁰⁰ Millett, E. R. C., et al. (2018). Sex differences in risk factors for myocardial infarction: cohort study of UK Biobank participants. BMJ (Clinical research ed.). <https://bit.ly/2UpBXki>

²⁰¹ Lo, C. C. W, et al. (2020). Future Cardiovascular Disease Risk for Women with Gestational Hypertension: A Systematic Review and Meta-Analysis. Journal of the American Heart Association. <https://bit.ly/3j7JZaV>

²⁰² National Institute for Health and Care Excellence (NICE). (2019). Hypertension in pregnancy: diagnosis and management. NICE guideline. <https://bit.ly/3y4DY3j>

²⁰³ YouGov Plc. Total sample size was 1007 adults. Fieldwork was undertaken between 10th - 14th June 2021. The survey was carried out online and results have been weighted for the Welsh adult population.

²⁰⁴ Wilkinson, C., Bebb, O., Dondo, T. B., et al. (2018). Sex differences in quality indicator attainment for myocardial infarction; a nationwide cohort study. Heart. <https://bit.ly/2VxfqV4>

used, a 60-year-old female smoker who consults the app about sudden chest pain and nausea is informed that she is probably experiencing a panic attack, not a heart attack, despite stating her risk factors and age²⁰⁵.

Women are less likely to receive optimal treatment: BHF-funded researchers at the University of Leeds conducted a study which found that women are less likely to receive optimal treatment after a heart attack²⁰⁶. The study revealed that there are stark differences in the use of evidence-based medicine that disadvantage women with heart disease, causing worse health outcomes and poorer care.

BHF-funded research estimated that if systemic inequalities were addressed to achieve equity in treatment, at least 8,243 female deaths over a ten-year period (2003-2013) could have been prevented in England and Wales²⁰⁷

There is no evidence to suggest that this has improved.

Women are less likely to access cardiac rehabilitation: Female participation in cardiac rehabilitation is low. Across the UK, the proportion of women recruited to cardiac rehabilitation programmes from those eligible is lower than expected. In Wales, the average number of female cardiac rehabilitation patients has remained stagnant in recent years, despite the National Cardiac Rehabilitation Audit reporting repeated calls for cardiac rehab programmes to recruit more women²⁰⁸.

Cardiac rehabilitation providers reported that their female patients were more likely to struggle to attend on-site cardiac rehab services due to a range of socioeconomic factors, such as being more likely to be the primary carer for children or elderly relatives, or being unable to travel to services which are not close to home^{209,210}.

The Covid-19 pandemic has disrupted cardiac rehabilitation services in Wales, often prohibiting the provision of in-person cardiac rehabilitation services. Cardiac rehabilitation providers adapted by embracing digital platforms. Cardiac rehabilitation providers reported an increased uptake across men and women in cardiac rehabilitation throughout the pandemic, suggesting that a digital offering increases patient participation.

²⁰⁵ The Times. (2019). It's hysteria, not a heart attack, GP app Babylon tells women. <https://bit.ly/3hdB1HW>

²⁰⁶ Wilkinson, C., Bebb, O., Dondo, T. B., et al. (2018). Sex differences in quality indicator attainment for myocardial infarction; a nationwide cohort study. Heart. <https://bit.ly/2VXfgV4>

²⁰⁷ Wilkinson, C., Bebb, O., Dondo, T. B., et al. (2018). Sex differences in quality indicator attainment for myocardial infarction; a nationwide cohort study. Heart. <https://bit.ly/2VXfgV4>

²⁰⁸ BHF. (2019). National Audit of Cardiac Rehab (NACR) Quality and Outcomes report 2019. <https://bit.ly/2X91OhQ>

²⁰⁹ UK Government Department for Transport (2021), Vehicle Licencing Statistics. <https://bit.ly/3gtdW3P>

²¹⁰ Criado-Perez, C. (2019). Invisible women: Data bias in a world designed for men.

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Welsh Government should commit to implementing a women's health quality statement which addresses inequalities experienced by women with heart disease. The quality statement should seek to improve outcomes for women with heart disease through: 1. Improved public awareness 2. Timely diagnosis 3. Equitable treatment 4. Equitable access to cardiac rehabilitation.	✓	✓	✓	✓	✓	✓
Commit to a public awareness raising campaign which underlines that cardiovascular disease is a leading cause of death in women.		✓	✓			
The NHS in Wales should provide continuing professional development to support clinicians in primary and secondary care to understand the risks and symptoms of heart disease to improve diagnosis and treatment for women with cardiovascular disease.		✓	✓		✓	✓
Welsh Government should work with the Wales Cardiac Network, the Heart Conditions Implementation Group and Health Education and Improvement Wales to: - understand and address the challenges leading to women receiving sub-optimal treatment and address this through All-Wales Cardiac Pathways and continuing professional development for clinicians - identify and address barriers to women pursuing a career in cardiology to allow recruitment from the widest possible talent pool and enable optimal cardiovascular clinical research and care.	✓	✓	✓		✓	

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Welsh Government should work with the Wales Cardiac Network to build on the innovation in rehabilitation from the pandemic and develop All-Wales Cardiac Pathways. Pathways should ensure that patients continue to be offered flexible, menu-based approaches to cardiac rehabilitation depending on personal and clinical circumstances. This will support female participation where there are personal circumstances borne out of societal biases which act as barriers to women attending cardiac rehabilitation.	✓		✓	✓	✓	

→ Autoimmune Conditions

Introduction

Rare Auto-Immune Rheumatic Diseases (RAIRDs), including Lupus²¹¹ and Sjogren's Syndrome affect approximately 9,500 people in Wales²¹². At least 80% of those affected are female²¹³

Long diagnostic delays are common which, for complex, multi-system, progressive conditions like these can have significant, sometimes catastrophic, implications for wider health and general wellbeing. It is essential that what is described by researchers as the 'diagnostic odyssey' for patients is reduced, utilising improved diagnostic technologies to detect, test, and treat patients earlier. This would improve the outlook for patients, and reduce inefficiencies and costs to the public purse²¹⁴.

The Problem

There are well documented diagnostic delays for lupus patients, where the average is 6.4 years²¹⁵. The same can be said for Sjogren's Syndrome and other rare auto-immune diseases. It would seem that the multiplicity of symptoms associated with autoimmune conditions are often not viewed holistically resulting in numerous visits to general practice and multiple inappropriate referrals. Historical prejudice and unconscious bias around women's reporting of symptoms can see patients dismissed or disbelieved, extending time to diagnosis, as can the erroneous reliance on blood tests for diagnosing lupus and RAIRDs in general²¹⁶.

Current practice in Wales sees patient care provided by non-specialists in general Rheumatology departments²¹⁷, conversely to national guidance which recommends access to multi-disciplinary centres of excellence for the development of bespoke treatment plans and more complex care²¹⁸. As Wales operates an NHS system of 7 autonomous health boards, there are also anecdotal reports of variation and inequality between regions.

Wales presently has no Centres of Excellence, no LUPUS UK-funded specialist nurses, and no confirmed referral pathways in place to access those in existence elsewhere. LUPUS UK is also unaware of any lupus research currently taking place in Wales²¹⁹.

Without careful monitoring and treatment, both lupus and Sjogren's Syndrome can have severe, even fatal, complications

Lupus patients are more likely to die from heart disease or infection, with life-expectancy averaging 53.7 years, whilst Sjogren's Syndrome is linked to an increased risk of some forms of cancer (Non-Hodgkin lymphoma), heart disease and infection²²⁰.

²¹¹ Rare Autoimmune Rheumatic Disease Alliance <https://rairda.org/>

²¹² The RECORDER project identified a cohort of 168,680 people with a RAIRD in NHS England records. Based on 2020 population figures, the population of Wales is approximately 5% that of England. This would mean there are roughly 9,500 people in Wales living with a RAIRD – although this is a very rough figure not taking demographics into account.

²¹³ FTWW, Response to WG Musculoskeletal Consultation 2021- <https://www.ftww.org.uk/making-the-case-for-better-lupus-and-rare-auto-immune-disease-provision-for-patients-in-wales/>

²¹⁴ Find A Cure <https://www.findacure.org.uk/2021/01/15/what-the-new-uk-rare-disease-framework-means-for-you/>

²¹⁵ RAIRDA's 2018 report "Reduce, Improve, Empower" reported 46% waited more than three years from first symptoms to getting a correct diagnosis. Fewer than 1 in 10 were diagnosed in less than three months. Lupus patients reported the longest delay in diagnosis, with 58% that it took over three years.

²¹⁶ FTWW Report, Making the Case for Better Lupus and Rare Auto-Immune Disease Provision for Patients in Wales - which includes lupus patient testimony - <https://www.ftww.org.uk/making-the-case-for-better-lupus-and-rare-auto-immune-disease-provision-for-patients-in-wales/>

²¹⁷ Rheumatology in Wales: State of Play' 2016 https://www.rheumatology.org.uk/Portals/0/Documents/Policy/Reports/Rheumatology_Wales_State_of_Play.pdf?ver=2020-07-24-155937-130

²¹⁸ BSR Nice Guidelines for the Management of Adults with SLE 2017 <https://academic.oup.com/rheumatology/article/57/1/e1/4318863>

²¹⁹ Department of Public Health & Primary Care – Cambridge University – Melanie Sloan – links to all lupus research papers <https://www.phpc.cam.ac.uk/pcu/tag/melanie-sloan/>

²²⁰ The Lupus Encyclopaedia 6th September 2020 - Bottom Line on Diabetes vs Lupus and Stroke & Heart Attacks

Reportedly, ongoing expert monitoring of patients, including regular and recommended tests, are not routinely carried-out across Wales. This is largely because so many patients are either only under the care of the GP or, at best, a general rheumatologist, both of whom (by definition) lack specialist knowledge and understanding of the condition.

²²¹ Lupus and Stroke and Heart Attacks: A bigger problem than we thought! Lupus patients had a 27% higher chance of having heart attacks and strokes than the diabetics. <https://www.lupusencyclopedia.com/lupus-vs-diabetes-which-causes-more-heart-attacks-and-strokes/?fbclid=IwAR1AyiDNn5HAIEFBN3d2SZmMJi6FKGhitkyOdbfJwOOP6SEpUEYvjR3FMlQ>

²²² Welsh Government's Covid19 Clinical Recovery Plan, 'Looking Forward' March 2021 <https://gov.wales/health-and-care-services-pandemic-recovery-plan-published>

Women's cardiovascular risks are often under-estimated and inadequately treated, which is compounded if the patient has lupus

A 7- to 10-fold increased risk of developing cardiovascular disease has been reported across the Systemic Lupus Erythematosus (SLE), the most common type of lupus) patient population²²¹, and a 50-fold higher risk has been reported in women with SLE aged between 35 and 44 years. Despite this, gender bias in the healthcare received by these patients persists.

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Set up an Implementation Group which includes patient advocates and specialist charities for lupus and other RAIRDs to ensure compliance with latest guidance on the diagnosis and management of these conditions across Wales, pays particular attention to women's experiences and needs, and co-designs and evaluates new models of service delivery.		✓	✓		✓	
GP practices / hubs to share more specialised resources and personnel, including a GP with a special interest in rheumatological disease.	✓		✓	✓		
In line with the Welsh Government's 2021 health and care services pandemic recovery plan, 'Health and Social Care in Wales COVID 19: Looking Forward' ²²² , work with specialist patient organisations, including LUPUS UK and RAIRDA, on facilitating access to specialist nurses for patients in every health board. Specialist nurses should have authority to link up with centres of excellence either in Wales or elsewhere whilst none in Wales exist. Use of digital technology may assist with monitoring / treatment close to home.	✓		✓	✓		

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Ensure that all Rheumatology Departments in Wales and NHS Wales / health board websites hold more information on RAIRDs, including signposting to dedicated support groups.	✓		✓	✓		
Work with GP Trainers and GP Surgeries to improve management and care for patients with RAIRDs between consultant appointments. GPs should also be empowered to refer patients directly to Centres of Excellence, irrespective of location, where there is clear evidence of patient need and preference, in line with NICE principles of Shared Decision-Making.		✓	✓	✓	✓	
Consider facilitating a funding scheme that would give general rheumatologists in Wales the opportunity to apply for training and development of expertise and work towards developing tertiary services in Wales.	✓	✓	✓			
Welsh Government to write to all health boards to insist that they follow the NICE-approved BSR Guidelines for the Management of Adults with SLE, including the recommendation that patients have access to both a local rheumatologist and a Centre of Excellence from the start of the diagnostic process.	✓	✓	✓		✓	✓
Ensure that all lupus patients have both an Emergency Treatment Plan and a Formal Care Plan.		✓	✓		✓	
Ensure that Quality Statements for those major health conditions relevant to RAIRD patients refer to them where appropriate and that this information is communicated to all associated healthcare professionals.		✓	✓	✓	✓	
Consult with patients and established lupus / RAIRD specialists on how the principles of prevention and early intervention can and should apply for these disease areas.			✓	✓	✓	✓

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Work with patients / patient advocates to map out what constitutes a multi-disciplinary team approach to the management of lupus and other RAIRDs and invest in provision accordingly, including specialised physiotherapy and co-design of self-management programmes. Ensure consistent, streamlined, universally accessible communication mechanisms are in place and centre around the individual			✓	✓	✓	
Consider the development and implementation of a 'red flag' system which highlights when interventions need to be initiated and / or expedited, for example in pregnancy.				✓	✓	✓
Consider making funding for specialist services for lupus and other RAIRDs the responsibility of the Welsh Health Specialised Services Committee to ensure equitable access for all patients in Wales and avoid postcode lotteries.	✓		✓			
Establish a clear, transparent and comprehensive pathway for all RAIRD patients living in Wales, reducing variation and inequality of access and outcomes.	✓		✓	✓		
Consider a public inquiry into the effectiveness of the IPFR mechanism and, in the meantime, ensure it is fairly applied to patients across Wales requiring tertiary specialist care. Set up a Task & Finish Group made up of patients, clinicians, and NHS executives to review any Inquiry's results and oversee development of best practice.	✓		✓			
Agree on a plan and timescale to establish Wales's own Centres of Excellence for lupus and other RAIRDs, initially in North and South Wales. Whilst numbers in Wales may not warrant centres offering full-time provision, this should not be a barrier to their development.	✓		✓		✓	

→ Eating Disorders

Introduction

Eating disorders are serious mental illnesses. According to Beat's latest estimation²²³, nearly 58,800 people in Wales have an eating disorder. Eating disorders affect people of any age, gender, ethnicity or background. Around 75% of those affected are female and some research has found that female relatives of anorexia sufferers were 11.4 times more likely to suffer from anorexia compared to relatives of unaffected participants²²⁴.

²²³ Beat is the UK's eating disorder charity, but please note these figures are based on analysis of international data, due to lack of proper epidemiological study in the UK.

²²⁴ Beat <https://www.beateatingdisorders.org.uk/media-centre/eating-disorder-statistics/>

²²⁵ Beat <https://www.beateatingdisorders.org.uk/media-centre/eating-disorder-statistics/>

²²⁶ Welsh Government, Eating Disorders Service Review 2018 <https://gov.wales/eating-disorders-service-review-2018>

Eating disorders have major impacts on individuals, families, the NHS, social care, and wider society

The Problem

Eating disorders have high mortality rates, with anorexia having the highest mortality rate of any mental illness²²⁵. The mortality rates of bulimia nervosa, binge eating disorder and other eating disorders are also high. Without early intervention, many become unable to participate in education or employment. Although improvements have been made in eating disorder care, there is much more work to do before Wales has a healthcare system and society that enables everyone affected by eating disorders to get the help they need.

In 2018, a review commissioned by Welsh Government into Welsh Eating Disorder Services²²⁶ was undertaken with close engagement and input from patients and carers across the country. It found that

...the current system in Wales is based on reacting to patients who are already severely ill, rather than intervening early

It also found that there is a postcode lottery in the level and quality of treatment.

Research undertaken by Beat has found that demand for eating disorder treatment in Wales has increased significantly since the 2018 review and that referrals of children and young people to Child and Adolescent Mental Health Services (CAMHS) appear to have increased significantly in 2020/21. Since the onset of the COVID-19 pandemic, inpatient eating disorder admissions in Wales have increased significantly, particularly for children and young people, indicating that people are not receiving effective treatment fast enough.

During 2020/21, Beat has seen a 250% increase in the number of people supported in Wales compared to 2019. The coronavirus pandemic has exacerbated the detrimental impact that these serious mental illnesses have on people's daily lives. It is important that this is recognised by the Welsh Government to ensure that necessary resources are provided to support this vulnerable population now and beyond.

While some high-quality research is underway and effective therapies have been developed, we still don't have a full understanding of what causes eating disorders or how best to treat them

This is not surprising when considering the way that research funding is allocated in the UK; funding is based around competition. Due to eating disorders having a small research field, it is in a weaker position to compete against larger fields²²⁷. The Welsh Government is a significant funder of health research and a partner in various UK-wide forums that agree research priorities. It has committed to ensuring that mental health conditions are treated with the same level of importance as physical health conditions. This principle must be applied in its approach to research funding.

Research suggests that most non-specialist doctors lack confidence in and knowledge of how to help patients with eating disorders, and this leads both to delays in treatment, and inappropriate management²²⁸. On average, just 3 hours is spent on teaching about eating disorders in Welsh medical schools²²⁹.

Early intervention provides the best chance for recovery²³⁰

Delays prolong the suffering, and significantly increases the costs to the NHS as hospital admission becomes more likely. Despite this, a 2017 Beat survey of respondents who lived in Wales at the time of first being referred for eating disorder treatment found a mean average of three years and one month between onset and the start of treatment. This was due to delays in identification, referral, and waiting times.

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Commit sufficient funding to enable the expansion of services and initiatives that support early identification of eating disorders, help-seeking and easy access to specialist treatment in Wales.		✓				✓
Ensure that families and other carers affected by eating disorders are fully informed, engaged and supported including being offered assessment of their own mental health needs, and access to peer-to-peer support.			✓		✓	

²²⁷ Beat <https://www.beateatingdisorders.org.uk/about-beat/policy-work/all-party-parliamentary-group-appg-on-eating-disorders/>

²²⁸ Ayston,A, Ibrahim, A (June 2018) https://www.researchgate.net/publication/325574377_Does_the_UK_medical_education_provide_doctors_with_sufficient_skills_and_knowledge_to_manage_patients_with_eating_disorders_safely

²²⁹ Royal College of Psychiatrists https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/position-statements/ps03_19.pdf?sfvrsn=b1283556_2

²³⁰ Ayston,A, Ibrahim, A (June 2018) https://www.researchgate.net/publication/325574377_Does_the_UK_medical_education_provide_doctors_with_sufficient_skills_and_knowledge_to_manage_patients_with_eating_disorders_safely

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Invest in the workforce and support staff wellbeing: - Ensure that all current and future medical professionals are provided with comprehensive education in eating disorders to support early identification and effective treatment - Ensure investment and opportunities for progression within the field of eating disorder research to encourage health professionals into the field of eating disorders.	✓	✓	✓			
Increase funding for research into eating disorders to improve our understanding of how best to treat and ideally prevent eating disorders. Eating disorders research receives less than 1% of mental health research funding in the UK.		✓	✓			
Ensure public health campaigns to address obesity in Wales are informed by experts from the field of eating disorders, including experts by experience. There is a risk that campaigns to address obesity can promote messages that are harmful to people with eating disorders and those at risk of developing one.					✓	
Co-produce and publish an implementation framework with timelines for achieving all recommendations.			✓		✓	✓

→ Self-Harm

Introduction

Self-harm is a strong risk factor for suicide²³¹, yet little is known about the quality of support available to people who have self-harmed in Wales. Self-harm is also complex, and whilst it is a strong risk factor for suicide, self-harm is often not suicidal²³², which impacts on the support people need. As a result, the focus in this appendix is on self-harm without suicidal intent, as is reflected in Samaritans 2021 self-harm report²³³.

Self-harm is a sign of serious emotional distress, and it is vital that timely, effective support is available following self-harm

Self-harm is a complex behaviour that is not always easy to define as suicidal or not, and a person's reasons and intentions when self-harming can change over time²³⁴. Regardless of intent, self-harm is a serious public health issue and is one of the top five reasons for being admitted to hospital as an inpatient in the UK²³⁵. For many, non-suicidal self-harm is a way of coping with difficult or distressing feelings and circumstances²³⁶, and this is distinct from suicide attempts²³⁷.

Self-harm is often hidden and the specific and distinct needs of people who have self-harmed without suicidal intent are poorly understood and, according to Samaritans Cymru, are too often not taken seriously²³⁸.

The Problem

The true scale of self-harm is estimated to be 1 in every 130 people²³⁹. The most reliable data for self-harm available in Wales is derived from hospital admission data, with approximately 5,500 admissions for self-harm, regardless of suicidal intent, in Wales each year²⁴⁰.

Self-harm can affect people of all ages and genders, but we know it is more common in females across all age groups²⁴¹

The Royal College of Psychiatrists reports a 68% increase in self-harm incidence among girls aged 13-16 between 2011 and 2014, which indicates an urgent need to develop and implement effective interventions for girls in their early to mid-teens²⁴².

²³¹ McManus et al., 'Mental Health and Wellbeing in England: Adult Psychiatric Morbidity Survey 2014.', no. Generic (2016), https://files.digital.nhs.uk/pdf/q/3/mental_health_and_wellbeing_in_england_full_report.pdf

²³² S. McManus et al., 'Mental Health and Wellbeing in England: Adult Psychiatric Morbidity Survey 2014.', no. Generic (2016), https://files.digital.nhs.uk/pdf/q/3/mental_health_and_wellbeing_in_england_full_report.pdf

²³³ Samaritans Cymru (2021) The right support at the right time? <https://media.samaritans.org/documents/SamaritansCymru-self-harm-report-English-version.pdf>

²³⁴ Samaritans Cymru (2021) The right support at the right time? <https://media.samaritans.org/documents/SamaritansCymru-self-harm-report-English-version.pdf>

²³⁵ Welsh Government. (2015). Talk to me 2: Suicide and self-harm prevention strategy for Wales 2015-2020 Cardiff: Available at: <https://gov.wales/sites/default/files/publications/2019-08/talk-to-me-2-suicide-and-self-harm-prevention-strategy-for-wales-2015-2020.pdf>

²³⁶ R. Wadman et al., 'An Interpretative Phenomenological Analysis of Young People's Self-Harm in the Context of Interpersonal Stressors and Supports: Parents, Peers, and Clinical Services', Social Science & Medicine 212 (1 September 2018): 120–28, <https://doi.org/10.1016/j.socscimed.2018.07.021>

²³⁷ L. Stănicke et al., 'How Do Young People Understand Their Own Self-Harm? A Meta-Synthesis of Adolescents', Subjective Experience of Self-Harm. Adolescent Research Review 3 (2018): 173–191

²³⁸ Samaritans Cymru (2021) The right support at the right time? [SamaritansCymru-self-harm-report-English-version.pdf](https://media.samaritans.org/documents/SamaritansCymru-self-harm-report-English-version.pdf)

²³⁹ Welsh Government. (2015). Talk to me 2: Suicide and self-harm prevention strategy for Wales 2015-2020 Cardiff: Available at: [talk-to-me-2-suicide-and-self-harm-prevention-strategy-for-wales-2015-2020.pdf](https://gov.wales/sites/default/files/publications/2019-08/talk-to-me-2-suicide-and-self-harm-prevention-strategy-for-wales-2015-2020.pdf) (gov.wales)

²⁴⁰ Welsh Government. (2015). Talk to me 2: Suicide and self-harm prevention strategy for Wales 2015-2020 Cardiff: Available at: <https://gov.wales/sites/default/files/publications/2019-08/talk-to-me-2-suicide-and-self-harm-preventionstrategy-for-wales-2015-2020.pdf>

²⁴¹ S. McManus et al., 'Mental Health and Wellbeing in England: Adult Psychiatric Morbidity Survey 2014.', no. Generic (2016), https://files.digital.nhs.uk/pdf/q/3/mental_health_and_wellbeing_in_england_full_report.pdf

²⁴² Royal College of Psychiatrists (2017) Incidence, clinical management, and mortality risk following self-harm among children and adolescents: cohort study in primary care, [https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/suicide-prevention/monthly-clinic/\(2\)-incidence-clinical-management-and-mortality-risk-following-self-harm-among-children-and-adolescents-\(2017\).pdf?sfvrsn=91135723_2](https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/suicide-prevention/monthly-clinic/(2)-incidence-clinical-management-and-mortality-risk-following-self-harm-among-children-and-adolescents-(2017).pdf?sfvrsn=91135723_2)

The Royal College of Psychiatrists goes on to report an increased risk of self-harm in people living with physical illnesses, particularly so in women. Using the General Practice Research Database, Webb et al²⁴³ found significantly higher risk of self-harm in patients with asthma, back pain, Chronic Obstructive Pulmonary Disease (COPD), coronary heart disease, diabetes, epilepsy, hypertension, osteoarthritis and stroke. Depression explained 57% of the elevated risk among all patients diagnosed with one or more long-term health conditions. However, even after adjustment for depression, the risk of self-harm remained elevated in women with asthma, back pain, diabetes, epilepsy or hypertension.

According to a survey undertaken by Samaritans Cymru, only a third (34%) of people in Wales sought support for their most recent self-harm, compared to over half (52%) of respondents from across the UK and Ireland. However, they go on to report that self-harm is discussed in twice as many calls from women than men (12% vs 6%) and that callers using its phone service who discuss self-harm were 2.5 times more likely to express suicidal thoughts than other callers²⁴⁴.

Whilst distinct from self-harm, the Royal College of Psychiatrists' report²⁴⁵ highlights the link between suicide risk and physical illness. Women with cancer or coronary heart disease have an elevated risk of suicide independent of clinical depression. Their findings demonstrated that the risk of suicide is greater in younger, physically ill women and in older women with multimorbidity.

The steps taken by the Welsh Government to make self-harm a priority in its suicide and self-harm prevention strategy is welcomed. Yet we still know little about the full range of support offered to people who have self-harmed, both in clinical and community settings, or enough about what good quality support looks like.

Almost half (45%) of the adults we surveyed in Wales said they did not know where to find support or information about self-harm²⁴⁶

²⁴³ Webb et al (2012) General Practice Research Database

²⁴⁴ Samaritans Cymru (2021) The right support at the right time? [SamaritansCymru-self-harm-report-English-version.pdf](https://www.samaritans.org.uk/media/1000000/samaritans-cymru-self-harm-report-english-version.pdf)

²⁴⁵ Royal College of Psychiatrists (2020) https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr229-self-harm-and-suicide.pdf?sfvrsn=b6fdf395_10

²⁴⁶ Data from YouGov online survey: This research was conducted by YouGov in October 2020 among a sample of 979 adults in Wales age 18+ via an online survey

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Thresholds for therapies and other sources of help to be set at a level which means they are available as an early intervention. People need to be able to access therapies such as DBT early on and not have to wait until their self-harming becomes serious enough to meet current thresholds.			✓			✓
Research into the mechanisms responsible for the recent apparent increase in the incidence of self-harm among early to mid-teenage girls, and coordinated initiatives to tackle health inequalities in the provision of services to distressed children and adolescents.			✓		✓	✓
Healthcare professionals working across all medical specialties should be vigilant for signs of undetected psychological symptoms when providing care and treatment to people with any Long-Term Health Condition and be particularly alert to the risk of suicide in younger physically ill women, especially those with multiple physical health conditions, and anyone presenting with significant self-harm.	✓		✓		✓	
Recognise the importance of a compassionate response to self-harm. Responding with compassion to someone experiencing distress can help ensure better outcomes and future help-seeking.		✓			✓	
Develop a proactive, positive intervention approach to follow up with people who have been discharged from A&E following self-harm.			✓	✓		✓
Establish a known, central repository for information and good practice on self-harm, bringing together the many examples of effective projects and good practice which exist.			✓	✓		
Increase awareness of self-harm in multiple settings, particularly with regards to early intervention and inquiry, monitoring, and targeting of support for children and adolescents who may not openly engage with healthcare services for their self-harming behaviour.	✓	✓	✓		✓	✓

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Support GPs through more training, so they are properly equipped to: - Deal with people who have self-harmed in a person centred and trauma-informed way which better understands self-harm and its drivers - Be better informed about the types of care, both clinical and non-clinical, that can be effective in supporting people with lived experience of self-harm so that they can make the most appropriate referral to further support - Spot the warning signs of distress so they can help prevent people from reaching crisis point.		✓	✓		✓	
All support services for people who self-harm, whether NHS provided or community based, should provide trauma-informed support, which acknowledges and supports the person to better manage issues driving self-harm.					✓	
Investment in evidenced-based interventions to develop appropriate support for people who self-harm from different communities.	✓				✓	

→ Hypermobility Spectrum Disorders (HSD) and Ehlers-Danlos Syndromes (EDS)

Introduction

The Ehlers-Danlos syndromes (EDS) are a group of thirteen individual genetic conditions, all affecting the body's connective tissue, which can cause stretchiness in the joints. These are complex syndromes affecting many systems of the body at once, resulting in long-term pain, chronic fatigue, dizziness, and digestive disorders. Problems and their severity differ from person to person, even within the same family.

The most prevalent type of EDS is hypermobile Ehlers-Danlos syndrome (hEDS). Hypermobility spectrum disorder (HSD) has four subtypes, which are distinguished according to which joints are involved, whether the hypermobility is generalized throughout the whole body, and whether other musculoskeletal problems are present. Research shows that the median time to diagnosis is around 10 years²⁴⁷ but this is higher for women in Wales.

The Problem

In 2016/2017 194.2 per 100,000 of the population in Wales had a diagnosis of EDS or HSD according to their medical records.

70% of diagnosed EDS/HSD patients are women, however only 41% of women with EDS/HSD are diagnosed during childhood compared to 72% of men²⁴⁸

A study was conducted by Demmler et al involving 6,021 individuals in Wales, 70% of whom were women²⁴⁹. This research has shown that there is a 'significant difference of 8.3 years in the mean age of diagnosis between men and women'²⁵⁰.

These statistics highlight the disparity in diagnosis time between men and women, with diagnostic delay potentially having a detrimental impact on women's health. This is something that has previously being reported by patients as being responsible for damaging consequences²⁵¹. The outcome of this for women means delay in preventative therapies; an area that is extremely important in managing EDS.

In addition to this, comorbid conditions are often not investigated due to this late diagnosis, despite early diagnosis being crucial to implement preventative therapies, and the implications of this will impact the patient's life heavily²⁵². Those with EDS or HSD who were assigned female at birth and who go through pregnancy and childbirth have a higher risk of an early birth, and there is an increased risk of maternal morbidity and mortality²⁵³.

²⁴⁷ Hakim, A. J Rheumatology, Volume 51, Issue suppl_3, 1 May 2012. Iii2 (I11) (Abstract)

²⁴⁸ Demmler et al (2019) Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK, <https://bmjopen.bmj.com/content/bmjopen/9/11/e031365.full.pdf>

²⁴⁹ Demmler et al (2019) Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK, <https://bmjopen.bmj.com/content/bmjopen/9/11/e031365.full.pdf>

²⁵⁰ Demmler et al (2019) Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK, <https://bmjopen.bmj.com/content/bmjopen/9/11/e031365.full.pdf>

²⁵¹ EurordisCare, The Voice of 12,000 Patients, https://www.eurordis.org/IMG/pdf/voice_12000_patients/EURORDISCARE_FULLBOOKr.pdf

²⁵² Demmler et al (2019) Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK, <https://bmjopen.bmj.com/content/bmjopen/9/11/e031365.full.pdf>

²⁵³ Spiegel et al (2019) Pregnancy outcomes in women with Ehlers-Danlos Syndrome, <https://www.tandfonline.com/doi/abs/10.1080/14767058.2020.1767574>

If a woman has received her diagnosis before going through pregnancy and childbirth, they can be under consultant care and monitored more closely to prevent issues from arising. Dismissing these additional needs may lead to trauma and needless morbidity²⁵⁴. Although anxiety is not officially part of the classification of hypermobile EDS, it should be considered when classifying and diagnosing due to its higher prevalence²⁵⁵.

Demmler et al's study discussed the lack of referrals being made and therefore lack of appropriate management. There is a 'widespread belief among clinicians that EDS is rare' and misdiagnosis can result in 70% of patients experiencing inappropriate treatment²⁵⁶. Ehlers-Danlos Support UK is not currently aware of any EDS-knowledgeable consultants in Wales to suggest to patients looking to request a referral. Although public awareness of EDS is limited, this is the case for many invisible health conditions and, so, current priorities need to address providing management for patients living with EDS and similarly invisible illnesses, and increasing awareness amongst healthcare professions.

There is not enough research on EDS in the general population, but what research has been conducted, especially Demmler et al.'s study which focuses on Wales, we clearly see the prevalence of the condition in women²⁵⁷.

²⁵⁴ Pezaro et al (2020) Understanding hypermobile Ehlers-Danlos syndrome and Hypermobility Spectrum Disorders in the context of childbearing, <https://www.sciencedirect.com/science/article/abs/pii/S0266613820301212>

²⁵⁵ Malfait et al (2017), The 2017 International classification of the Ehlers-Danlos syndromes, <https://onlinelibrary.wiley.com/doi/full/10.1002/ajmg.c.31552>

²⁵⁶ Demmler et al (2019) Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK, <https://bmjopen.bmj.com/content/bmjopen/9/11/e031365.full.pdf>

²⁵⁷ Demmler et al (2019) Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK, <https://bmjopen.bmj.com/content/bmjopen/9/11/e031365.full.pdf>

²⁵⁸ Ehlers-Danlos Support UK <https://ehlers-danlos.org/toolkit>

²⁵⁹ British Journal of Midwifery <https://www.britishjournalofmidwifery.com/content/clinical-practice/a-clinical-update-on-hypermobile-ehlers-danlos-syndrome-during-pregnancy-birth-and-beyond>

²⁶⁰ hEDS Together <https://hedstogether.com/projects/eds-maternity-co-created-tools/?fbclid=IwAR3W-0xud-22ZYj1T5-uXvihndLyN4DDaJm6mJN3RQeQHpdD4gGicDT4M>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Universal use of recommended resources: - Ehlers-Danlos Support UK currently has an EDS toolkit that is ideal for primary care physicians in spotting and managing EDS²⁵⁸, including a section within the toolkit specifically based on women's health - The September issue of the British Journal of Midwifery features a clinical update on hypermobile EDS (hEDS)²⁵⁹ and provides an excellent resource - The hEDStogether toolkit²⁶⁰ focusing on childbearing in women with hEDS which provides a quick access toolkit for practitioners providing care for assigned female at birth women going through pregnancy and birth.	✓	✓	✓		✓	

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Funding to ensure women with EDS in Wales benefit from the same time to diagnosis as men, as well as management and treatment of comorbid conditions.	✓		✓	✓		✓
Invest in enhanced training for healthcare professionals in Wales as well as resources and multi-disciplinary management, benefiting both provider and patient. For example, physiotherapy, hydrotherapy, and orthotics are just some of the areas where investment would have a positive impact on patients with EDS to support them in effective management of their EDS.			✓		✓	
Invest in chronic health conditions such as EDS to help meet Wales's Gender Equality Roadmap ²⁶¹ .	✓		✓		✓	
Develop a gender-focused approach to healthcare which includes investment in research, guidance, practice and service delivery, ensuring a proactive approach in line with the 'principles of Prudent Healthcare' which include prevention and early intervention.	✓	✓	✓	✓	✓	✓

→ Myalgic Encephalomyelitis (ME)

Introduction

Myalgic Encephalomyelitis, sometimes erroneously known as Chronic Fatigue Syndrome, (CFS) is a long-term, fluctuating, neurological condition characterised by post-exertional malaise (PEM) - a deterioration of symptoms due to an abnormal response to all types of activity. ME encompasses a wide-ranging collection of symptoms, including sleep disturbance, muscle fatigue, and cognitive impairment. There are over 250,000 people in the UK with ME (or CFS), and it can affect people of all ages²⁶². Research has uncovered multiple dysfunctions in the body but, as yet, no specific diagnostic laboratory test is available.

It is believed that 25% of people with ME are severely affected to the point where they are housebound or bedbound²⁶³. As a result, these patients will have limited access to care.

Historically, there have been conflicting approaches to managing the symptoms of ME, some of which are highly controversial - particularly Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT). Some rehabilitation practitioners in Wales are registered with the British Association for CFS/ME (BACME), which until recently promoted GET and CBT as treatments for ME/CFS. The updated NICE Guideline for ME was published on 29 October 2021 and removed GET and CBT as treatment recommendations²⁶⁴.

The Problem

ME affects more women than men, in an approximate ratio of 4:1²⁶⁵

People with ME score lower overall on health-related quality of life tests than most other chronic conditions²⁶⁶. 'Invisible' illness makes it more difficult to convince the public, healthcare professionals and service providers of need and, subsequently, it is more challenging to access the care and support needed to improve quality of life.

A significant proportion of people with ME report that their ability to work or remain in full-time education is lost, impacting income and future opportunities²⁶⁷. Benefits are notoriously difficult to obtain, with the assessors often failing to consider fluctuating levels of activity²⁶⁸ or marking down patients who are not receiving high levels of pain medication - despite guidance issued by the UK government²⁶⁹.

There are a number of reasons for the lack of support on offer to people with ME, such as healthcare professionals dismissing or misattributing symptoms to a psychological (and often gendered) cause²⁷⁰, or other attitudinal challenges which see the public and healthcare professionals underestimating symptoms which are invisible and not easily measured in primary care²⁷¹.

There has also been a lack of investment in training/service provision which has resulted in inadequate or non-existent care pathways, no

²⁶² NICE: <https://www.nice.org.uk/guidance/ng206/chapter/Context>

²⁶³ NICE: <https://www.nice.org.uk/guidance/ng206/chapter/Context>

²⁶⁴ Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management NICE guideline [NG206] <https://www.nice.org.uk/guidance/ng206>

²⁶⁵ ME Research UK <https://www.meresearch.org.uk/sex-differences-in-mecfs/>

²⁶⁶ The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) (Hvidberg et al, 2015) <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0132421>

²⁶⁷ NICE: 2.1.3 Findings - <https://www.nice.org.uk/guidance/ng206/evidence/appendix-2-involving-adults-with-severe-mecfs-symptoms-pdf-333546588759>

²⁶⁸ ME Association: <https://meassociation.org.uk/2019/06/meeting-with-minister-raised-important-concerns-about-welfare-benefits-for-people-with-me-26-june-2019/>

²⁶⁹ PIP assessment guide part 1: the assessment process- 1.6 The consultation <https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/PIP-assessment-guide-part-1-the-assessment-process#the-consultation>

²⁷⁰ NICE: 2.1.4 Discussion - <https://www.nice.org.uk/guidance/ng206/evidence/appendix-2-involving-adults-with-severe-mecfs-symptoms-pdf-333546588759>

²⁷¹ PIP assessment guide part 1: the assessment process- 1.6 The consultation <https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/PIP-assessment-guide-part-1-the-assessment-process#the-consultation>

consistent diagnostic criteria used in general practice and no specialist care provision.

Research is under-funded so, whilst much is being uncovered about ME, there is much research that is poorly designed and not co-produced, resulting in a lack of consensus on best practice.

There is also a lack of ME-specific pathway which incorporates the panoply of symptoms and services needed to manage them. Access to services is difficult because existing pathways for other chronic illnesses/symptomatology aren't open to ME patients and/or are insufficiently joined-up to provide an effective multidisciplinary team approach to management. Patients across Wales report widely variable experiences in accessing care packages which incorporate health and social services. Most have not benefited from a joined-up approach due to both lack of communication and a widespread failure to appreciate the specific characteristics of ME.

In Wales, the 2014 'framework' for fibromyalgia and ME²⁷² has been, at best, only partly implemented and at worst, largely ignored. Health boards have autonomy to decide on which elements are implemented and how far, resulting in variation and inequality. There is lack of NHS oversight and accountability to address this implementation gap.

The Health Minister's office made clear to Members of the Senedd and health boards that the £5m fund aimed at improving care for Long Covid patients should also include other post-viral illnesses (including ME)²⁷³, but this has not been prioritised by health boards.

²⁷² Myalgic encephalopathy chronic fatigue syndrome and fibromyalgia task and finish group report and recommendations <https://gov.wales/sites/default/files/publications/2019-03/myalgic-encephalopathy-chronic-fatigue-syndrome-me-cfs-and-fibromyalgia-fm-task-and-finish-group-report-and-recommendations.pdf>

²⁷³ Welsh Government replies re ME/ CFS and long COVID – WAMES: <https://wames.org.uk/cms-english/health-minister-delegates-reply-re-me-cfs/>

²⁷⁴ ME Association <https://meassociation.org.uk/2019/04/forward-me-and-oxford-brookes-university-announce-results-of-patient-survey-on-cbt-and-get-in-me-cfs-03-april-2019/>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Ensure healthcare professionals are following the updated NICE guidance, removing GET and CBT as treatments in rehabilitation clinics which include people with ME. Many patients with ME are also referred to the National Exercise Referral Scheme (NERS), but the lack of expertise or monitoring constitutes unsafe practice and has historically proven harmful to those with confirmed ME ²⁷⁴ .		✓				
Develop cross-team understanding of the nature and impact of people's illness and ensure they are aware of the specific characteristics of ME so to provide appropriate patient-centred care. This includes a better understanding of ME's main characteristic, which is post-exertional malaise.		✓			✓	

²⁷⁵ Diagnostic Delay and benefit from having an Early Diagnosis <https://meassociation.org.uk/about-what-is-mecfs/diagnosis/#Part%204>

²⁷⁶ Shared decision making NICE guideline [NG197] <https://www.nice.org.uk/guidance/ng197>

²⁷⁷ NICE guideline [NG206] - Managing ME/CFS 1.11.3: <https://www.nice.org.uk/guidance/ng206/chapter/Recommendations#managing-mecfs>

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Work with patient advocates, specialist groups, and clinicians to develop straightforward medical pathways for ME patients across Wales which should include: - Sufficiently trained GPs to identify specific characteristics of ME and diagnose - Occupational therapy for day-to-day management - Trained community nurses who can provide care and monitoring for those who are housebound due to severity of condition or relapse - Access to additional specialist expertise wherever it is located.	✓	✓	✓	✓	✓	✓
Increase training for GPs to diagnose and manage the condition. A 2016 patient survey found that over 60% had waited a year or more for a diagnosis²⁷⁵.			✓			✓
Patients must be empowered to make informed decisions about approaches to symptom management and able to work in partnerships with their healthcare professionals to co-design treatment plans/pathways which suit their individual needs and experiences as part of a commitment to shared decision making²⁷⁶.		✓			✓	
Urge service providers to provide support for healthcare professionals to implement the NICE guideline's recommendation of developing individualised energy management plans, which take account of the need for both rest & maintaining physical condition²⁷⁷.			✓		✓	
Ensure co-produced training is delivered both to medical students and existing healthcare professionals.		✓		✓		

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Oversee an all-Wales commitment to ensuring GPs accurately diagnose and record incidence of ME using SNOMED system which enables health boards and service providers across Wales to understand prevalence and commission/ design services accordingly. Data collection should also include patients who have received private diagnosis or one from 'out of area'.	✓			✓		
Clearer messaging and guidance about the Equality Act 2010 and associated rights and support, including provision of independent advocacy as referenced in the Social Services and Wellbeing Act Wales 2014, part 9 ²⁷⁸ and reasonable adjustments in the workplace.					✓	

→ Long COVID

Introduction

Long COVID is a new condition which disproportionately affects women and, despite National Institute for Health and Care Excellence (NICE) guidelines describing the services required for this condition, the services provided in Wales are inadequate, inequitable in comparison to England, and highly variable across Wales.

Long COVID is a commonly used term to describe the long term effects following an acute COVID-19 infection. It is clinically defined as “ongoing symptomatic COVID-19” between 4-12 weeks and “post-COVID-19 syndrome” beyond 12 weeks²⁷⁹. Long COVID is a complex, multisystem condition caused by infection with COVID-19, irrespective of the severity of the initial acute infection²⁸⁰. Long COVID can be continuous or relapsing and remitting in nature²⁸¹.

There is increasing evidence of significant long term medical complications including cardiac, respiratory and renal disease, new-onset diabetes and excess deaths²⁸²

A report issued by the Office of National Statistics (ONS) in September 2021 estimated that 970,000 British people were affected by long COVID²⁸³ and in March 2021, the ONS reported that 56,000 people in Wales were living with the condition²⁸⁴. Both reports also highlighted that the condition is more prevalent in those aged 35 to 69, and in women. The latter has been confirmed in studies stating that long COVID is twice as common in women than men²⁸⁵.

A multicentre study has reported that women under 50 years old are five times less likely to report a full recovery following acute COVID-19 infection compared to men of the same age²⁸⁶

In addition, women were significantly more likely to report fatigue and breathlessness, and more likely to report worsening difficulties relating to memory, mobility, communication, vision, hearing and self-care compared to men of the same age²⁸⁷.

Long COVID negatively impacts an individual’s ability to perform daily activities and to work normally. The ONS have stated that 66% of long COVID patients report that their symptoms adversely affect their day-to-day activities and 19% report that their ability to undertake day-to-day activities is “limited a lot”²⁸⁸. Studies have also shown that 18% percent of long COVID patients have been unable to return to work and 19% have had to make adjustments to the way of working²⁸⁹. Given the increased prevalence of the condition in working age women, and the impact on daily living and ability to work, women are at increased risk of financial hardship.

²⁷⁹ COVID-19 Rapid Guideline, managing the long-term effects of COVID-19, NICE Guideline published 18 December 2020 <https://www.nice.org.uk/guidance/ng188>

²⁸⁰ Nurek M, Rayner C, Freyer A, Taylor S, Järte L, MacDermott N and Delaney B., Recommendations for the recognition, diagnosis, and management of long covid: A Delphi study. *British Journal of General Practice* 2 August 2021; <https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265>

²⁸¹ Long COVID: An overview. Raveendran AV, Jayadevan R, Sashidharand S. *Diabetes Metab Syndr*. 2021 May-June; 15(3): 869–875. doi: 10.1016/j.dsx.2021.04.007 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8056514/>

²⁸² Nurek M, Rayner C, Freyer A, Taylor S, Järte L, MacDermott N and Delaney B., Recommendations for the recognition, diagnosis, and management of long covid: A Delphi study. *British Journal of General Practice* 2 August 2021; <https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265>

²⁸³ Office of National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 2 September 2021. [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/20210902)

²⁸⁴ Office of National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 1 April 2021. [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/20210401)

²⁸⁵ Covid-19: Middle aged women face greater risk of debilitating long term symptoms. *BMJ* 2021;372:n829. doi: <https://doi.org/10.1136/bmj.n829> <https://www.bmj.com/content/372/bmj.n829>

²⁸⁶ University of Glasgow, Women under 50 had worse long-term outcomes after hospitalisation with COVID-19. First published: 24 March 2021. https://www.gla.ac.uk/research/coronavirus/headline_782580_en.html

²⁸⁷ University of Glasgow, Women under 50 had worse long-term outcomes after hospitalisation with COVID-19. First published: 24 March 2021. https://www.gla.ac.uk/research/coronavirus/headline_782580_en.html

²⁸⁸ Office of National Statistics. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 2 September 2021. Office of National Statistics. [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/20210902)

²⁸⁹ Covid-19. Middle aged women face greater risk of debilitating long term symptoms. *BMJ* 2021; 372. doi: <https://doi.org/10.1136/bmj.n829> <https://www.bmj.com/content/372/bmj.n829>

The Problem

NICE guidance published in December 2020 recommended the provision of “access to multidisciplinary services (these could be ‘one-stop’ clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. They should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms”²⁹⁰. Similarly, a Delphi study published in June 2021 stated that “Medically-led multi-disciplinary clinics are required as serious cardiovascular, neurocognitive, respiratory and immune sequelae can present with non-specific symptoms”²⁹¹.

Despite the NICE guideline, there are currently no recognised Long COVID clinics in Wales that meet this description

England, however, has invested over £100million into long COVID services, setting up 89 clinics²⁹² including 15 paediatric hubs²⁹³, creating a stark inequality between the two nations.

Research regarding the pathogenesis of long COVID is ongoing, therefore a curative treatment has not yet been identified. Despite this, medical assessment of long COVID patients is required as a number of serious complications have been identified. These include conditions such as pericarditis, myocarditis, autonomic dysfunction, postural orthostatic tachycardia syndrome, blood clotting disorders (such as central venous thrombosis and pulmonary embolism), thyroid dysfunction and new-onset diabetes²⁹⁴. Given the increasing evidence of serious long term medical complications, patients should not be assumed to have a self-limiting post-viral fatigue syndrome and provision of solely rehabilitation services should not be considered adequate for this patient group.

So far, health boards across Wales have been tasked with developing long COVID services. In some regions of Wales, long COVID services have been made available. However these are therapies-led, concentrating on rehabilitation and self-management of the condition only. Some health boards in Wales are still in the development stages of creating long COVID services, resulting in an unfair postcode lottery. All women living with long COVID in Wales are equally deserving of medically-led, multi-disciplinary services as their English counterparts and Wales must therefore invest in the provision of effective, safe and equitable medically-led services across all regions of Wales.

Inequitable healthcare for long COVID sufferers has exacerbated by lack of knowledge and understanding on the part of some healthcare professionals. For example, there have been reports on the *Long COVID Wales* Facebook group of patients having symptoms dismissed as anxiety, being told nothing is wrong when standard tests return as ‘normal’, or encountering a lack of recognition of long COVID in the absence of a positive COVID test despite this not being a requirement for the diagnosis.

²⁹⁰ COVID-19 rapid guideline: managing the long-term effects of COVID-19. NICE guideline [NG188]. Published: 18 December 2020. <https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742>

²⁹¹ Nurek M, Rayner C, Freyer A, Taylor S, Järte L, MacDermott N and Delaney B., Recommendations for the recognition, diagnosis, and management of long covid: A Delphi study. British Journal of General Practice 2 August 2021 <https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265>

²⁹² Long COVID: the NHS plan for 2021/22. Document first published: 15 June 2021

²⁹³ NHS sets up specialist young people’s services in £100 million long COVID care expansion. NHS England. 15 June 2021. NHS England » NHS sets up specialist young people’s services in £100 million long COVID care expansion

²⁹⁴ Nurek M, Rayner C, Freyer A, Taylor S, Järte L, MacDermott N and Delaney B., Recommendations for the recognition, diagnosis, and management of long covid: A Delphi study. British Journal of General Practice 2 August 2021 <https://bjgp.org/content/early/2021/07/27/BJGP.2021.0265>

Long COVID patients have also reported that GPs have been unaware of which long COVID services are available and unwilling or resistant to refer to secondary care. Given the delay in Wales in developing medically-led long COVID clinics, we have lost over a year of potential time to learn about long COVID patients and contribute such knowledge to the wider stage.

With the difficulty some patients are finding in receiving referrals to secondary care, secondary care consultants are not gaining sufficient exposure to this new disease to develop expertise here in Wales.

A proportion of long COVID patients have been referred to secondary care services. However, due to long waiting lists, in some cases greater than a year, many long COVID patients have sought private healthcare. Given that long COVID is a multisystem disorder, some patients report paying thousands of pounds for consultations and investigations by various specialists. This is not financially viable for many patients and widens the divide between those women who are able to access healthcare and those who aren't. Many patients with long COVID, particularly those from the first and second waves, are key workers, often working for our health and social services. These patients had to leave the safety of their homes to work for the benefit of others. It seems unjust therefore that these patients cannot access the healthcare that they deserve, even worse that they are having to pay to receive it.

When discussing the number of key workers affected by long COVID, we must consider the consequent impact on our public services, such as education, health, and social care, given the high proportion of female workers in these sectors. A report published in 2019 by Health Education and Improvement Wales stated that women account for 77% of the NHS Wales workforce²⁹⁵. The Women Adding Value to the Economy (WAVE) programme at Cardiff University found that 75% of women working in professional roles in Wales work in the education, health and social care sector²⁹⁶. Given the high proportion of women and the high levels of self-reported long COVID in these sectors - as reported by the ONS - the workforce in these sectors will inevitably be impacted by long COVID. The prioritisation of developing medically-led long COVID clinics will therefore be of economic value.

Key workers, particularly in the first and second waves, were at increased risk of COVID-19 as they had to leave their homes to work. The Industrial Injuries Advisory Council (IIAC) has reviewed the ONS reports and found that there is evidence of doubling risk of COVID-19 in some occupations²⁹⁷. They report that they are reviewing ongoing emerging data and, although they have not yet recommended COVID-19 as an occupation illness, they describe themselves as being on the pathway to doing so²⁹⁸. Should this recommendation be made by IIAC and accepted by the UK government, eligible persons could receive the Industrial Injuries Disability Benefit, worth up to £180 a week. In addition, such a recommendation by IIAC may assist persons seeking financial compensation from their employers²⁹⁹.

²⁹⁵ NHS Wales Workforce Trends (as at 31st March 2019). Health Education and Improvement Wales <https://heiw.nhs.wales/files/key-documents/workforce/nhs-wales-workforce-trends-as-at-31-march-2019-docx/>

²⁹⁶ WAVE, Working patterns in Wales: gender, occupations and pay. March 2014. Women Adding Value to the Economy. <https://www.cardiff.ac.uk/research/explore/research-units/women-adding-value-to-the-economy-wave>

²⁹⁷ UK Government, COVID-19 and occupation: IIAC position paper 48. Industrial Injuries Advisory Council. 25 March 2021. COVID-19 and occupation: IIAC position paper 48 - GOV.UK (www.gov.uk)

²⁹⁸ UK Government, COVID-19 and occupation: IIAC position paper 48. Industrial Injuries Advisory Council. 25 March 2021. COVID-19 and occupation: IIAC position paper 48 - GOV.UK (www.gov.uk)

²⁹⁹ TUC, Covid as an industrial disease: What it would mean for workers in Wales. Williams C. 30 Jul 2021. Covid as an industrial disease: What it would mean for workers in Wales | TUC

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Training on long COVID should be provided to healthcare professionals in Wales to improve knowledge of this complex condition and its associated complications.		✓	✓			
NHS Wales leaders of such clinics should communicate with successful long COVID clinics in NHS England and further afield to learn from the knowledge and experience developed in such clinics over the last year. This will expedite the development of equitable, effective, efficient, timely, safe, and patient centred services.		✓	✓	✓		
Investment to establish medically-led long COVID clinics in Wales. Such clinics should provide: • A medically- led service by doctors with long COVID expertise • Holistic care pathways • Physical assessment • Cognitive assessment to assess any potential memory, attention or concentration problems • Direct access to diagnostic testing, with investigation of specific complications • Management of symptoms clusters • Tailored rehabilitation.	✓	✓	✓		✓	
The existence and benefits of clinics as described above should be widely known and understood by all healthcare professionals in Wales. Clinics should be accessible in a timely manner to all patients who need or express a preference for treatment in them, regardless of location, to enable more efficient healthcare and provide economic savings when contrasted with the short- and longer-term impacts of long COVID on high prevalence occupations such as those in the education, health and social care sectors.	✓					✓
The Welsh Government should support calls for COVID to be made a recognised occupational illness. This would support patients affected by long COVID and would allow for equitable treatment when compared to workers suffering with alternative occupation-related injuries.	✓					

→ Fibromyalgia

Introduction

Fibromyalgia, also known as fibromyalgia syndrome (FMS) is a long-term condition that causes widespread chronic pain. The two main symptoms are chronic pain and debilitating fatigue. Most recent diagnostic criteria are severe pain in 3 to 6 different areas of the body or milder pain in 7 or more different areas with symptoms staying at a similar level for at least 3 months and / or no other reason for symptoms identified. However, many patients report outdated criteria of 18 tender points still being used as a means to diagnose the condition, suggesting a need to clearly communicate latest guidance. Like People with ME, fibromyalgia patients can also experience cognitive dysfunction ('brain fog' or 'fibro fog'), mobility issues, headaches, Irritable Bowel Syndrome (IBS), and difficulty sleeping.

Fibromyalgia has no cure. Medications, such as painkillers, muscle relaxants, antidepressants, anticonvulsants, and sleep medication can help some patients

Exercise is also considered to be good for those suffering with fibromyalgia as it helps improve blood flow to muscles, relieves stress and improves quality of sleep³⁰⁰. Patients can be referred to physiotherapy and occupational therapy, while some patients benefit from Cognitive Behavioural Therapy (CBT), counselling, or support groups.

Many fibromyalgia patients benefit from medical support from a rheumatologist, particularly as increasing evidence suggests an autoimmune component to the condition³⁰¹. In Wales however, referrals are unavailable as standard, with rheumatologists largely unable to support patients in addition to the care that can be delivered by GPs.

The Problem

The majority of fibromyalgia patients are women (around 80-90%), but men and children can have the condition too³⁰²

There is a lack of research into fibromyalgia, which means that the cause is not yet known and there is no cure.

People living with fibromyalgia will likely find that their ability to work or remain in full-time education is impacted, which also impacts their income and future opportunities. Benefits are notoriously difficult to obtain, with anecdotal evidence of benefit assessors regularly dismissing patients who have variable levels of activity, or who are not receiving high levels of pain medication – despite the guidance that is issued by the UK government³⁰³. Due to lack of information, lack of public awareness, and ableism (internal and within society), many people with fibromyalgia don't realise that as it's a 'chronic illness',

³⁰⁰ Fibro Support Wales – Treatment options <https://fswales.org/treatment-options>

³⁰¹ University of Liverpool, Fibromyalgia likely the result of autoimmune problems, study shows – July 2021) <https://news.liverpool.ac.uk/2021/07/02/fibromyalgia-likely-the-result-of-autoimmune-problems-study-shows/>

³⁰² Fibromyalgia Quick Facts – Fibro Support Wales <https://fswales.org/quick-facts>

³⁰³ PIP assessment guide part 1: the assessment process- 1.6 The consultation <https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/PIP-assessment-guide-part-1-the-assessment-process#the-consultation>

they qualify as disabled under the Equality Act 2010³⁰⁴ - meaning they are unaware of social care and welfare benefits they may be entitled to access.

A lack of specialist multi-disciplinary care available sees patients with fibromyalgia in Wales at a disadvantage. Patients are unable to be referred to specialist teams in England. With anecdotal reports of rheumatologists across Wales refusing to see fibromyalgia patients on the NHS, patients are left to either try and cope with their condition or pay for private appointments. The NHS UK website advises some patients will be referred to a rheumatologist, neurologist, and/or psychologist³⁰⁵. However, this does not appear to be the case in Wales, with services differing between health boards creating a postcode lottery for patients. In addition to this, the lack of appropriate communication between healthcare providers and patients can cause delays in accessing treatment and support.

Many healthcare professionals are poorly trained about fibromyalgia, meaning that appropriate referrals aren't made, or suitable medical pathways aren't followed. Treatment pathways are often in silos, with insufficient communication between providers, including primary care and related specialisms such as pain management, especially if 'out of area' services are utilised. It also appears that information is hard to find - none of the links when searching for fibromyalgia on NHS Wales work³⁰⁶.

Many patients - particularly female patients - experience what might be described as systemic bias, with significant numbers reporting their physical symptoms as being attributed to gender stereotypes or psychological factors, meaning diagnosis and access to appropriate healthcare is delayed.

³⁰⁴ Definition of Disability under the Equality Act 2010: <https://www.gov.uk/definition-of-disability-under-equality-act-2010>

³⁰⁵ Fibromyalgia treatment - NHS UK <https://www.nhs.uk/conditions/fibromyalgia/treatment/>

³⁰⁶ Fibromyalgia search on NHS Wales <http://www.search.wales.nhs.uk/search/?q=fibromyalgia>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
Clear communication of latest guidance regarding diagnostic criteria to be issued to all relevant healthcare professionals in Wales.		✓	✓	✓		
Improved funding for research and the development of expertise and associated services should be made available.	✓		✓			
Ensure that relevant clinicians undertake sufficiently specialised training to appropriately identify and support the numbers affected by the condition: fibromyalgia creates physiological symptoms that must be better understood and managed and in a timely fashion.	✓	✓	✓		✓	✓
Liaise with charities such as Fibro Support Wales, Fibromyalgia Action UK (FMA UK) and Fair Treatment for the Women of Wales, to ensure that equitable best practice is followed, that patient voices are heard, and co-production is at the heart of any clinical plans or reforms, to include training and co-design of services.			✓	✓	✓	
Care should be person-centred, with referrals to MDTs, such as independent advocacy services, social support, and other healthcare specialties where appropriate.			✓	✓	✓	

→ Skin Conditions

Introduction

Dermatology deals with diseases of the skin, hair, and nails. There are more than 4,000 dermatological conditions and around half of people at any time consider they have a problem³⁰⁷. Skin, nail and hair disease are among the most common reasons for seeking NHS help with around one in four people in England and Wales (13.2m) seeing their GP about a dermatological condition every year³⁰⁸. Dermatological conditions can have a significant impact on a patient's quality of life.

The Problem

There is a fundamental problem with the lack of access to a dermatologist which affects patients from all ethnic backgrounds. There is a severe workforce shortage. Data collected in 2019 for the GIRFT report shows that there is a national shortage of consultant dermatologists with just 659 consultant dermatologists working in the NHS in England³⁰⁹. In addition to this, there are 159 whole time consultant vacancies. Although this data is for England, the situation is similar in Wales.

A series of Freedom of Information requests submitted by the Dermatology Council of England to all Welsh health boards and reported to the All-Party Parliamentary Group (APPG) on Skin in 2019 revealed there were approximately 38 substantive Consultant Dermatologists and 8 locums, which equates to 36.8 WTE doctors in total in Wales. This represents 1 WTE per 81,300 of the population – which is 18,800 above the RCP and BAD's recommended target. 11.1 WTE Dermatologists would need to be trained and employed to meet this target – representing a 30% increase³¹⁰. This lack of access to a dermatologist leads to delayed diagnosis and treatment.

There is ethnic variation in the prevalence of some skin diseases and also variation in the presentation of skin diseases³¹¹. However, there is lack of data in the UK about the prevalence of skin diseases in people with skin of colour³¹² compared to the USA, where there is data about the prevalence of some skin diseases in different ethnic groups³¹³ and studies on racial /ethnic bias³¹⁴.

There is also a reported lack of training and confidence amongst dermatologists in diagnosing skin of colour, as shown in surveys of dermatology trainees in the UK³¹⁵

There has also been a lack of representation of skin of colour images in dermatology textbooks and education resources, which is now being addressed in dermatology training materials, to include skin of colour images and a new section on dermatology in skin of colour similarly embedded in e-learning modules.

³⁰⁷ <https://www.pslhub.org/learn/patient-safety-in-health-and-care/conditions/other-conditions-and-diseases/dermatology-girft-programme-national-specialty-report-september-2021-r5314/>

³⁰⁸ <https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/11/Dermatology-overview.pdf>

³⁰⁹ <https://www.pslhub.org/learn/patient-safety-in-health-and-care/conditions/other-conditions-and-diseases/dermatology-girft-programme-national-specialty-report-september-2021-r5314/>

³¹⁰ http://www.appgs.co.uk/wp-content/uploads/2019/05/APPGSDCE_Audit_of_Dermatology_Coverage2019.pdf

³¹¹ Salam A, Dadzie OE. Dermatology training in the U.K.: does it reflect the changing demographics of our population. *British Journal of Dermatology*. 2013; 169(6): 1360-1362

³¹² F J Child 1, L C Fuller, E M Higgins, A W Du Vivier. A study of the spectrum of skin disease occurring in a black population in south-east London. *Br J Dermatol*. 1999 Sep;141(3):512-7

³¹³ Tatyana E.Shaw, Gabriel P.Currie, Caroline W.Koudelka, et al. Eczema Prevalence in the United States: Data from the 2003 National Survey of Children's Health. *J Investigative Dermatology* 2011; 131 (1), 67-73

³¹⁴ Hall W, Chapman M, Lee K, et al. Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: a systematic review. *Am J Public Health* 2015;105:e60-76. (not used here)

³¹⁵ Ma Y, Millette D, Nalluri R, Yoo J. UK-based dermatologist online survey on the current practice and training in the management of melasma and postinflammatory hyperpigmentation. *Clinical and Experimental Dermatology*. 2020; 45(4): 483-484

³¹⁶ BAD Skin Descriptors: <https://www.bad.org.uk/shared/get-file.ashx?itemtype=document&id=7094>

There is also a recognition that the terminology used to describe skin conditions is outdated and not inclusive of all skin tones³¹⁶, which the British Association of Dermatologists is addressing by commissioning a new international lexicon taskforce to review skin descriptors used to describe dermatology conditions .

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
The newly formed Skin Diversity Sub-committee is working with the British Association of Dermatologists (BAD) to embed skin of colour throughout all the BAD workstreams, including education, communication, and patient-facing work.	✓	✓	✓			
Health boards in Wales should invest in ensuring that all relevant professionals attend training and utilise up-to-date resources and literature such as: - Attending the annual Skin of Colour Training Day - Utilise the new BAD skin descriptors - Use the undergraduate dermatology handbook to refer to images of skin of colour - BAD patient Information leaflets, which are in the process of being updated, to be more inclusive of skin of colour. The BAD communications team has also prepared video content specifically relevant to skin of colour.	✓	✓	✓		✓	
Health boards in Wales should ensure that all dermatology services and personnel are sufficiently trained, resourced, and person-centred to offer a consistently inclusive environment.	✓	✓	✓		✓	

→ Palliative and End of Life Care (PEOLC)

Introduction

Women³¹⁷ can face disproportionate challenges when it comes to end of life care and support - whether this is receiving care themselves or providing care to others. This Appendix will focus primarily on the inequalities faced by some women when it comes to receiving care at the end of life.

Although research looking specifically at the Welsh context does not exist, international evidence shows that there are sex and gender differences in reported symptom burden and pain management, preferences and experience of interventions at end of life, and women being less likely to state a preference for and ultimately achieve a home-based death, if that is their choice.

The Problem

Women typically have a longer life expectancy than men and are therefore more likely to live with a greater number of 'years with a disability'³¹⁸

In Wales, life expectancy at birth for males in 2017 to 2019, is 78.5 years old, whereas for women it is 82.3 years³¹⁹. Between 2017 and 2019 in Wales, women lived an average of 22.1 years with a disability, in comparison to men who lived with an average of 17.1 years with a disability³²⁰.

Research estimates that by 2040, annual deaths in England and Wales will rise by 25.4%³²¹. In addition, an ageing population combined with a rise in comorbidities, means that demand for palliative care is set to increase by 42% in England and Wales over the next two decades³²². The biggest proportion of those in need will be people aged over 85, and the leading cause of death is projected to be dementia. Estimates show that by 2040, dementia deaths will be more than three times higher than the current mortality rate³²³.

Due to women having longer life expectancy and the fact that Alzheimer's/dementia is the leading cause of death for women³²⁴, the above projections point towards an increasing number of the female population in need of palliative and end of life care in the imminent future. However, many still face disproportionate challenges in accessing the care and support services they need.

Pain Management and Symptom Burden at end of life: One of the key pillars of PEOLC is a focus on quality of life and pain management.

Being pain free enables people to experience a good quality of life for as long as possible

³¹⁷ The following appendix strives to be an inclusive document that respects the full spectrum of gender identities. We are aware that there will be a myriad of inequalities in PEOLC that will impact on non-binary individuals and trans men (as they may have female anatomy), but exploration of this will require more extensive and specialist consultation and research. For the purposes of this appendix, references to 'women' are gender specific, relating to cis and transgender women.

³¹⁸ ONS defines 'years with disability' as the number of years that a person lives with restricted activity as a result of a long-lasting physical or mental health condition.

³¹⁹ ONS, 2020. National life tables – life expectancy in the UK: 2017 to 2019: <https://www.ons.gov.uk/releases/nationallifetablesuk2017to2019>

³²⁰ ONS, 2020. National life tables – life expectancy in the UK: 2017 to 2019: <https://www.ons.gov.uk/releases/nationallifetablesuk2017to2019>

³²¹ Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017

³²² Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017

³²³ Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017

³²⁴ ONS, 2019. Deaths registered in England and Wales: 2019, <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2019#leading-causes-of-death>

Despite this, research shows that sex and gender can lead to differences in how men and women report symptoms, the pain they experience, and the treatment they receive as they approach the end of their lives.

Evidence shows that women often report more severe daily feelings of pain, nausea, and fatigue^{325,326,327}, than men but may also have to report greater symptom distress than men for their pain to be acknowledged³²⁸

This is partly a result of gender bias and women's pain sometimes being underestimated, resulting in healthcare professionals being less likely to document symptoms³²⁹. Women are also more likely to have pain attributed to psychological rather than physical needs and to then be prescribed sedatives³³⁰. The gender bias at play when it comes to how women and men are expected to cope with symptoms can directly affect some women's access to pain management medications, meaning some women may be suffering from severe unmet palliative care needs.

Physiological differences when talking about pain at end of life have also been found and documented. In fact, research around sex differences in analgesia (medication to relieve pain) is not novel³³¹. Studies have demonstrated that there are disparities in how the male and female body receives and responds to the main pain relief drug prescribed at end of life - opiates - with findings showing that women may be less likely to benefit from such medication³³². Consequently, women's quality of life may be disproportionately affected at end of life due to many clinical decisions stemming from laboratory research which is generally biased towards male biology³³³.

End of Life Care Interventions: PEOLC can be initiated at any point during a patient's journey and can include a range of holistic treatments focusing on psychological, social, and spiritual aspects of care³³⁴. When it comes to choices around end of life care interventions, the understanding and views of women appear to be affected by social norms and gender bias. While some research shows that terminally ill women can be more open, accepting of palliative support, and engaged with their end of life journey^{335,336}, other studies show that some women can be less likely than men to state a preference for end of life care treatments, including chemotherapy, cardiopulmonary resuscitation and artificial feeding^{337,338}. Evidence for the reasons behind this is not yet substantive and should be fully explored. Findings to date highlight potential inequalities in the way women are approaching, and thus accessing, treatments which could improve their quality of life.

One example of this is how females may not be benefitting from early palliative care (EPC) in the same way as males³³⁹. EPC is believed to be best practice and is attributed to better quality of life and lower rates

³²⁵ Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. *BMC Palliative Care*

³²⁶ Fillingim, R. et al., 2008. Sex, Gender and Pain; a review of recent clinical and experimental findings. *Science Direct*

³²⁷ Husain, A. et al., 2007. Women experience higher levels of fatigue at the end of life: a longitudinal home palliative care study. *PubMed*

³²⁸ Gott, M., Morgan, T., Williams, L., 2020. *Gender and Palliative Care: A Call to Arms*. SAGE Publications

³²⁹ Falk, A., et al. 2015. Differences in symptom distress based on gender and palliative care designation among hospitalised patients. *Journal of Nursing Scholarship*

³³⁰ Schafer G., et al., 2016. Health care providers' judgments in chronic pain: the influence of gender and trustworthiness. *Pain*, 157(8)

³³¹ Sorge, R. and Totsch, S.K., 2018. Sex differences in pain. *Current Opinion in Physiology*, 6

³³² Sorge, R. and Totsch, S.K., 2018. Sex differences in pain. *Current Opinion in Physiology*, 6

³³³ Becker, J., Prendergast, B. and Liang, J., 2016. Female rats are not more variable than male rats: a meta-analysis of neuroscience studies. *Biology of Sex Differences*, BMC

³³⁴ NHS, 2020. What end of life care involves, <https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/>

³³⁵ Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. *BMC Palliative Care*

³³⁶ Fahad Saeed, M.D. et al., 2018. Preference for Palliative Care in Cancer Patients: Are Men and Women Alike? *Journal of Pain and Symptom Management*, 56(1)

³³⁷ Fahad Saeed, M.D. et al., 2018. Preference for Palliative Care in Cancer Patients: Are Men and Women Alike? *Journal of Pain and Symptom Management*, 56(1)

³³⁸ Bookwala J, Coppola K, Fagerlin A, et al., 2001. Gender differences in older adults' preferences for life-sustaining medical treatments and end-of-life values. *Death Studies*. 25

³³⁹ Nipp, R. et al., 2016. Age and gender moderate the impact of early palliative care in metastatic non-small cell lung cancer. *Oncologist*

of depression^{340,341}, but findings have shown that females in some instances report lower quality of life and mood than male counterparts receiving similar treatment³⁴².

Many clinical decisions continue to rely on research findings and assumed best practice which neglects potential differences in sex and gender. To ensure women are not at risk of suffering from poorer quality of life than men, a sex and gender specific approach must be considered throughout a person's PEOLC journey.

Place of death: We know that over half of all people would prefer to die at home³⁴³, but for many women this is often not possible.

Social norms have dictated a society where it is women who are the natural caregivers and many even feel it is their duty when it comes to providing care³⁴⁴. Nonetheless, many women express fears around feeling like a burden if they themselves need care from family and loved ones³⁴⁵

In fact, more women receive care and support from healthcare professionals and specialists than they do from unpaid carers³⁴⁶.

The fact that women have longer life expectancy and are more likely to outlive their partner (in a heteronormative relationship), reinforces this trend. Additionally, those who have been carers (of which the majority are women), are less likely to want to die at home³⁴⁷. This is assumed to be due to a greater understanding of the reality of caring for someone at home. We therefore see more women dying in other settings such as hospitals, care homes, hospices and specialist palliative care settings³⁴⁸.

A wider challenge in supporting women to die at home if this is their preference, is insufficient resources and capacity in health and social care community provision. Recent research projects a substantive increase in demand for care in the community by 2040 in England and Wales, with deaths at home increasing by 88.6%, while deaths in care homes are projected to increase by as much as 108%³⁴⁹. The insufficient capacity in community provision could be impacting on women's ability to die at home if this is their preference. Everyone in Wales should be able to die where they wish, if safe and feasible, and more research is needed to understand whether gender norms are currently inhibiting this.

³⁴⁰ Fliedner, M., et al., 2019. An early palliative care intervention can be confronting but reassuring: A qualitative study on the experiences of patients with advanced cancer. *Palliative Medicine*, 33(7)

³⁴¹ Nipp, R. et al., 2016. Age and gender moderate the impact of early palliative care in metastatic non-small cell lung cancer. *Oncologist*

³⁴² Nipp, R. et al., 2016. Age and gender moderate the impact of early palliative care in metastatic non-small cell lung cancer. *Oncologist*

³⁴³ Hoare, S. et al., 2015. Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. *PLOS ONE*, 10(11)

³⁴⁴ Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. *BMC Palliative Care*

³⁴⁵ Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. *BMC Palliative Care*

³⁴⁶ Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. *BMC Palliative Care*

³⁴⁷ Gott, M., Morgan, T., Williams, L., 2020. *Gender and Palliative Care: A Call to Arms*. SAGE Publications

³⁴⁸ Gott, M., Morgan, T., Williams, L., 2020. *Gender and Palliative Care: A Call to Arms*. SAGE Publications

³⁴⁹ Bone, A., Gomes, B., Etkind, S. et al., 2018. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliative Medicine*, 32(2)

PEOLC is a severely under-researched aspect of health and social care, and looking at preferences, access, and experience of such services through a sex and gender lens is rarely carried out. The limited research is partly responsible for a lack of awareness of the disparities in end of life care for different sexes and genders, which ultimately has tangible impacts on some women's quality of life at end of life.

Most research today continues to use the word 'women' with a misunderstanding that sex and gender are interchangeable. There is a need to fully understand how sex and gender – as distinct (but closely related) concepts – intersect with health and social care preferences and experiences³⁵⁰. The notion of sex and gender-specific care should not be viewed in isolation from the key concepts of prudent, person-centred, and value-based healthcare advocated by the Welsh Government. The importance of care being tailored to the individual, including to their sex and gender, must be central to any progressive system of health and care.

We know that there is a significant shortage of district nurses and social care staff in Wales, and anecdotal evidence shows that many GP clusters are having to 'borrow' district nurses from neighbouring areas to support people dying at home³⁵¹.

Lastly, it is not only healthcare professionals that can work to support more women to live well in their communities for longer. Initiatives like Compassionate Cymru are important to build communal networks to allow people to feel supported in their local communities. This may be in the form of volunteers collecting prescriptions for older women who are living alone, or end of life care companions who could support women who may be suffering from loneliness and thus poorer quality of life in their final years, months or days of life.

³⁵⁰ Gott, M., Morgan, T., Williams, L., 2020. Gender and Palliative Care: A Call to Arms. SAGE Publications

³⁵¹ Marie Curie, 2021. How do we support people to live and die well in Wales by 2040? <https://www.mariecurie.org.uk/globalassets/media/documents/policy/event-briefing-23-july-2021.pdf>

The Solution

Recommendations	Equitable	Safe	Effective	Efficient	Person Centred	Timely
The Welsh Government and PEOLC research community should work together to identify funding opportunities for research that considers PEOLC through both a sex and gender lens, to better understand challenges faced as a result of physiological factors and / or gender norms and ensure more person-centred care.					✓	
Ensure research findings which could impact on the wellbeing of women at the end of life are translated into future health policy and clinical guidance and disseminated amongst relevant stakeholders and practitioners in the health and social care sector, including PEOLC decision-makers in both local and national capacities.	✓		✓		✓	
Provide more education and training on the sex and gender disparities in PEOLC to healthcare professionals.					✓	
The End of Life Care Programme must have a focus on shifting PEOLC to the community to enable everyone in Wales to die in the community if this is their preference. The workforce must be fully equipped to provide sex and gender specific care.	✓					
Recognise local initiatives like those encouraged and coordinated by Compassionate Cymru as a significant part of the End of Life Care infrastructure in Wales and ensure continued resourcing, as well as recognition by the new End of Life Programme to support everyone in their communities for longer.	✓					