

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

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Senedd Health & Social Care Committee Inquiry into Supporting People with Chronic Conditions

Women's Health Wales Coalition Response

In May 2022, the Women's Health Wales Coalition published a document entitled, 'Women's Health Wales: A Quality Statement for the Health of Women, Girls, and those Assigned Female at Birth'¹, which called on the Welsh Government to co-produce an official plan to address associated health inequalities and clinical needs. This document has been successful in its aims, with the Minister for Health and Social Care last year committing to a 10-year NHS Wales Women & Girls' Health Plan, work that is currently in its development stages.

In July 2022, the Welsh Government published its own Quality Statement for the Health of Women and Girls², describing the expectations it has of health boards in terms of delivering what it describes as 'good quality health services

¹ <https://www.ftww.org.uk/2021/wp-content/uploads/2022/05/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf>

² <https://www.gov.wales/quality-statement-women-and-girls-health-html>

to support women and girls'. The new NHS Wales Executive, formed in April 2023, will be tasked with creating National Strategic Clinical Networks (including one for Women's Health) to develop and oversee implementation plans capable of delivering on these Quality Statements.

As part of its Inquiry into the support provided to people living with chronic health conditions, the Senedd's Health and Social Care Committee may wish to ask for more clarity and assurances on how the public can be sure that local health boards' planning and activity will reflect the priorities outlined at a national level, by National Strategic Clinical Networks and associated Implementation Networks, not least when it comes to service design and delivery for long-term and recurrent illnesses.

During the course of the Coalition's year-long deliberations ahead of publishing its evidence, a wide range of stakeholders were brought together, including organisations focused on specific health conditions, others who provide perspectives on equality and inclusion, individual patients, academics, and healthcare professionals. Discussions referenced a number of chronic health problems which have a disproportionate and significant impact on female physical and mental health and wellbeing. Discussions also revealed that those from marginalised and disadvantaged communities will experience additional and intersectional barriers which can exacerbate poor health outcomes and which must be properly understood and actively addressed in the development of solutions.

As both England and Scotland move towards implementing their own women's health strategies, it is vital that Wales follows suit in recognising and seeking to ameliorate these issues. Tackling inequality is a core part of Welsh Government's work programme and, without proactively addressing underlying inequities, the recommendations listed in Wales's existing long-term strategy for health and social care, 'A Healthier Wales' will be difficult to achieve for many women³. This includes ensuring that those living with chronic health conditions are appropriately and equitably supported, including, where possible, in their prevention and / or escalation.

This submission draws upon the evidence collated in the Women's Health Wales May 2022 publication and, as such, sources have not been replicated here. However, there are a number of updates particularly focused on health

³ Much of this submission will refer to women but is inclusive of girls, and people assigned female at birth, including trans men, non-binary, and intersex people.

inequalities, disadvantages, and intersectional barriers experienced by marginalised people living with chronic health conditions to which we would like to draw the Committee's attention. Where new evidence is offered, we have provided citations as far as possible.

1) NHS and social care services

- **The readiness of local NHS and social care services to treat people with chronic conditions within the community.**

Members of the Women's Health Wales Coalition have pointed out that whilst it is important for there to be adequate and appropriately trained healthcare personnel able to manage people's chronic conditions closer to home, it is equally important that patients are able to access specialist care where required, including when this is the patient's choice. Currently, there are systemic barriers in Wales preventing equitable access to specialist services which the Coalition is keen to highlight as a factor in poorer outcomes for women living with health conditions which could become / are chronic in nature.

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. 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: 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 related, with no reference to chronic health conditions predominantly impacting women. Clearly, the assumption is that all health boards are capable of providing effective management for *all* long-term health conditions, including those considered 'rare' (or less frequently diagnosed). However, the Coalition's evidence suggests that this is misplaced and, potentially, unrealistic, given the size of Wales's population and, in many instances, the comparatively small numbers needing to access a specialist service. This is not to say that every local health board does not have a role to play in supporting ongoing care and monitoring closer to home, or that health boards should not be investing in optimal care themselves or facilitating regional collaboration for more prevalent chronic conditions.

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 services in rural areas, ongoing monitoring of patient health via wearables and remote consultations, and improved mechanisms for gathering, recording, and utilising data to improve patients' experiences and outcomes.

- **Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.**

Women, girls, and those assigned female at birth (AFAB) make up 51% of the population in Wales. Despite this, medicine and healthcare services have not necessarily met their needs, resulting in significant disparities in care between men and women, 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 men so inequalities are costing women their health, their wellbeing, their quality of life, and their lives.

The Welsh Government has pledged to being a ‘feminist government’ and undertaken a Gender Equality Review which saw health as a top priority for women across Wales. However, somewhat incongruously, its existing long-term plan for health and social care, ‘A Healthier Wales’ does not explicitly mention women’s health. Whilst the document makes clear its aim of ensuring person-centred care across the country, its failure to account for substantive pre-existing inequalities make this ambition hard to realise. For example, in Wales and beyond, there has been a historical lack of investment and research into health conditions which disproportionately affect women and people assigned female at birth, resulting in a lack of suitably specialised service provision for many of those conditions.

As acknowledged in the Coalition’s Quality Statement for the Health of Women, Girls and those Assigned Female at Birth, historical prejudice and unconscious bias around women’s reporting of symptoms can see patients dismissed or disbelieved, and this can extend time to diagnosis.⁴ Such prejudice and bias is even more pronounced for women from a Black or ethnic minority background. Their intersectional⁵ identity means that they are more likely to experience inequalities both in accessing healthcare and in health outcomes, as they identify with more than one group that disproportionately face health inequities in the UK.

Several reports that outline the stark health inequities that Black and ethnic minority groups experience have been published from the 1980s to the present day.⁶ The common themes emerging from these various reports

⁴ [Women’s Health Wales: A Quality Statement for the Health of Women, Girls, and those Assigned Female at Birth.](#), (2022), p.83.

⁵ Intersectionality, a term coined by Kimberle Crenshaw in 1999, illustrates that people’s identities can overlap and essentially accumulate, further compounding their experiences of discrimination. See: UN Women., (2020). [Intersectional feminism: what it means and why it matters right now.](#)

⁶ Douglas, J., (2021). [A matter of life and death: inequalities in healthcare for Black, Asian and minority ethnic communities.](#) See: Wise, J., (2022). [Racial health inequality is stark and requires concerted action, says review.](#) The British Medical Journal. Lokugamage, A., and Meredith, A., (2020). [Women from ethnic minorities face endemic structural racism when seeking and accessing healthcare.](#) Ajayi Sotubo, O., (2021). [A perspective on health inequalities in BAME communities and how to improve access to primary care.](#) *Future Healthcare Journal*, Vol.8(1). Youssef, A., (2022). [Black people four times more likely to be sectioned over talking therapy for mental health.](#) *ITV*, 12 October. Morgan, W., (2020). [Genetics is not why more BAME people die of coronavirus: structural racism is.](#) *Guardian*, 4 June.

include that Black and ethnic minority people are not listened to, not believed, and not respected.⁷

The racism experienced by Black and ethnic minority groups in healthcare can be related to longstanding historical misconceptions. Research has shown that myths, perpetuated from the days of transatlantic slavery and ‘race science’ about Black and ethnic minority people, such their skin being ‘thicker’, or that their nerve endings are less sensitive than White people’s, derive from unchallenged biases harboured by health practitioners.⁸ Such myths continue to fuel inadequate treatment of ethnic minority people; studies have found that health practitioners believing such myths were less likely to treat pain appropriately for ethnic minority patients.⁹

When it comes to women’s health in general, Wales is not an exception but merely part of a wider cultural landscape which has historically tended to marginalise women’s needs. Women’s exclusion from health service design is encapsulated in the failure to routinely include females in clinical trials, a situation not remedied until the 1990s – even now, clinical data doesn’t always break down the efficacy / side-effects of treatments by sex. 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.

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 contributes to reports of women’s symptoms being over-looked or dismissed. 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 population.

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

⁷ Douglas, J., (2021). [A matter of life and death: inequalities in healthcare for Black, Asian and minority ethnic communities](#). Sabin, J., (2020). [How we fail Black patients in pain](#).

⁸ Douglas, J., (2021). [A matter of life and death: inequalities in healthcare for Black, Asian and minority ethnic communities](#).

⁹ Sabin, J., (2020). [How we fail Black patients in pain](#). Douglas, J., (2021). [A matter of life and death: inequalities in healthcare for Black, Asian and minority ethnic communities](#).

pain relief, and are more likely to be given sedatives instead. Black and ethnic minority women face a double penalty which hugely impacts both their experience in accessing healthcare and in their health outcomes. These research findings all contribute to understanding one particularly shocking intersectional health outcome inequity: that Black women remain 4 to 5 times more likely to suffer maternal death¹⁰ and Asian women, twice as likely compared to White British women in the UK.¹¹

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 cancer, with women having to visit their GP more often than men to get a diagnosis. Further, many women report having their symptoms dismissed as either 'normal' or erroneously attributed to psychological causes, resulting in significant diagnostic delay, worsening prognoses, and considerable impact on wellbeing.

The Women's Health Wales Coalition also wishes to point out the intersectional and socio-economic impacts on women's health and wellbeing here in Wales experienced by those living with chronic conditions, many of whom will be considered disabled within the parameters of the Equality Act 2010. Multiple datasets suggest that women are more likely to be living with chronic health conditions, particularly as they age.

The Kings Fund explains that, 'Long-term conditions are more prevalent in older people (58 per cent of people over 60 compared to 14 per cent under 40) and in more deprived groups (people in the poorest social class have a 60 per cent higher prevalence than those in the richest social class and 30 per cent more severity of disease)¹². Given that women are more likely to be in poverty than men¹³, a gendered and intersectional perspective on the prevention and management of chronic health conditions is important.

When it comes to specific barriers to health services, disabled women often report encountering problems accessing optimum healthcare, not least actually being able to get to the location where services are situated. Public

¹⁰ Defined as: death in pregnancy, in childbirth, or up to 6-weeks post-partum.

¹¹ Knight, M., Bunch, K., Tuffnell, D., Patel, R., Shakespeare, J., Kotnis, R., Kenyon, S., Kurinczuk, JJ., (Eds.) on behalf of MBRRACE-UK. (2021). [Saving Lives, Improving Mothers' Care – Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19](#). Oxford: National Perinatal Epidemiology Unit, University of Oxford 2021.

¹² <https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity>

¹³ <https://research.senedd.wales/research-articles/women-are-the-shock-absorbers-of-poverty-the-impact-of-the-cost-of-living-on-women/>

transport is rarely fully accessible or available for a variety of reasons. Information provided to patients may not be provided in accessible formats. Health service staff will not necessarily have undertaken or embraced disability equality and social model of disability training or be cognisant of the multifarious ways in which 'disability' manifests. Physical spaces in which appointments and interventions are provided may not be equipped or appropriately managed to cater for disabled people's different needs, and there are limited opportunities for disabled people to engage co-productively with health service providers in the design and delivery of services. The result can be increased impairment and trauma.

Language barriers exist for some women from ethnic minority backgrounds across numerous aspects of healthcare provision. It's important for health practitioners to ensure that Black and ethnic minority women understand the information they are given by health practitioners, whether this be during an appointment or in follow-up communication (e.g., via letters). Health practitioners should not rely on a family member to translate on their behalf, nor should they assume that the patient will have access to someone who can translate any follow-up communication. A professionally trained and culturally appropriate interpreter should be present and available to interpret at appointments and health practitioners should ensure that any communication sent to the patient is in a language that they understand. This is also relevant for information resources, such as written leaflets. Furthermore, a lack of easily accessible, culturally- and impairment- appropriate information relating to different aspects of health and care, including diet, physical activity, end of life etc., provide yet another barrier to health services and contribute to widening inequalities for ethnic minority groups and disabled people. Health care providers should ensure that their resources better reflect these preferences and needs.

Many ethnic minority individuals get their health information from their friends and family, therefore healthcare providers need to utilise non-traditional channels to disseminate information to ensure that pertinent information is accessible to ethnic minority women. Information awareness sessions should be held to disseminate information about chronic health conditions and how to manage them to ethnic minority women in a suitable

location and setting. Also, training¹⁴ should be provided for all health practitioners on how to provide culturally appropriate care.

Geographical location can present another barrier to optimum health and care. All people living in rural areas are particularly vulnerable to isolation and face limited access to information, services and support compared to those living in urban areas.¹⁵ However, this is particularly true for ethnic minorities and disabled people living in rural parts of Wales, as access to health and care services is more difficult, and the scope of those services is more likely to be limited. When it comes to localised support in rural communities, it is less likely to be culturally competent or sufficiently flexible to accommodate various impairments. The result is that ethnic minority and disabled people don't trust or feel able to access such services¹⁶. This also demonstrates the need for training to be provided to all health care practitioners on how to deliver appropriate care.

The Women's Health Wales Coalition has urged the Welsh Government to see its evidence 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 the Committee to consider the Welsh NHS Confederation's work on Health Inequalities¹⁷ which asks Welsh Government to commit to a cross-governmental strategy to eliminating health inequalities. 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 long-term health and wellbeing are properly considered. These may include, amongst others, Gender Equality,

¹⁴ It is very important for this training to be worthwhile and not tokenistic, therefore, race equality organisations, religious representational bodies, and disabled people's organisations should be consulted on the content of such training. It is also important to note that there is a very real concern that such training could become a tick box exercise, so it is important for the impact of such training to be monitored and for those receiving the training to be able to measure the positive impact the training has had, as the delivery of information alone doesn't necessarily develop understanding. It is recommended for organisations to create further opportunity for discussions about the topic and allow for questions to be asked and discussions to be had after the training. It is also important that such training isn't a one-off and that top-up sessions are held. It is also important to ensure that the appropriate resources are allocated for this, particularly time, so attendance doesn't come out of personal time; allocating time for this can help ensure such training becomes embedded.

¹⁵ Race Equality First., (2021). [Joint NGO Shadow Report on Racial Inequality in Wales](#).

¹⁶ *Ibid*

¹⁷ <https://www.rcplondon.ac.uk/projects/outputs/mind-gap-cost-living-crisis-and-rise-inequalities-wales>

Period Dignity¹⁸, the Disability Rights Taskforce, Race Equality Action Plan¹⁹, LGBTQ+ Action Plan, Together for Mental Health, Violence Against Women, Domestic Abuse, and Sexual Violence (VAWDASV).

2) Multiple conditions

- **The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.**
- **The interaction between mental health conditions and long-term physical health conditions.**

Women's Health Wales Coalition members have pointed out how chronic ill health often starts with one condition which, late-diagnosed and poorly managed, leads to the development of multi-morbidities. It was agreed by the Coalition that timely and equitable 'Access to Specialist Services' was therefore a priority area, as explored in the previous section.

Another factor in the perceived reduced ability of the NHS in Wales to respond to women affected by chronic health conditions and multi-morbidities is lack of data on their experiences and needs. This too emerged as a priority in the Coalition's published evidence. 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 any action plans pertaining to Women's Health and / or Chronic Conditions.

As it stands, the seven health boards collect data differently so the need for a standardised approach is essential, not least 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 Framework 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.

¹⁸ The Period Dignity Strategy was renamed by the Welsh Government in February 2023 to become the 'Period Proud Wales Action Plan'

¹⁹ The Race Equality Action Plan was renamed by the Welsh Government in June 2022 to become the 'Anti-racist Wales Action Plan' (abbreviated to ArWAP).

Despite the numbers affected and costs involved, there is not a single chronic 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, their correlation with other (chronic) health conditions or their impact on patients' mental health.

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 focused on / specialising in 'women's health' in primary care settings 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 within a GP cluster.

The ability of the NHS in Wales to respond effectively to patients with chronic conditions in ways that meet their needs would, in the Coalition's opinion, depend on providers' willingness to co-produce services with patients, their communities, and the third sector. It is clear, both from the Coalition's May 2022 publication, 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, and this is particularly important in the management of chronic conditions and multi-morbidities, where patients will require support for extended periods of time.

The Social Services and Wellbeing Act in Wales enshrines 'Voice and Control' and 'Co-production' of services designed with users, to best meet their needs – the same must apply in health, which underpins so many people's wellbeing. One way to do this would be to utilise NICE Guidance on Shared Decision-Making 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 and would be in line with the new NHS Wales Duty of Quality.

The ability of the NHS to respond to the needs of patients with chronic conditions also very much depends on the quality and effectiveness of training undertaken by Wales's health and care professionals. As it stands, a 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 textbooks and training, and subsequently women's reporting of poor experiences in clinical settings.

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.

People with long-term physical health conditions – the most frequent users of health care services – commonly experience mental health problems such as depression and anxiety, or dementia in the case of older people. As a result of these co-morbid problems, the prognosis for their long-term condition and the quality of life they experience can both deteriorate markedly. Research evidence consistently demonstrates that people with long-term conditions are two to three times more likely to experience mental health problems than the general population.²⁰

As explained earlier within this consultation response, it is likely that women from Black and other ethnic minority groups who have chronic and painful health conditions are not getting the appropriate care, treatment and support that they need to manage their conditions due to historical biases, misconceptions and myths. Disabled women, and those with learning disabilities or neurodivergence, can find themselves similarly affected, all of which undoubtedly adds to the mental health impacts of chronic illness experienced by these patient populations.

For the most part, health and social care services in Wales are not currently organised in a way which supports an integrated response to the dual mental

²⁰ See: Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., and Galea, A., (2012). [Long-term conditions and mental health. The cost of co-morbidities](#). The King's Fund, p.2-3.

and physical health care needs of patients. The institutional and professional separation of mental and physical health can lead to fragmented approaches, in which opportunities to improve quality and efficiency are often missed.²¹ Care for large numbers of people with long-term conditions could be improved by better integrating mental health support with primary care and chronic disease management programmes, with closer working between mental health specialists and other professionals.²²

3) Impact of additional factors

- **The impact of the pandemic on quality of care across chronic conditions.**
- **The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.**
- **The extent to which services will have the capacity to meet future demand with an ageing population.**

At a time when the NHS is struggling to meet demand and the cost of living is soaring, people struggling with symptoms of long-term physical and mental health issues (and therefore not 'acute', an emergency, or malignancy) are less likely to be able to access healthcare: the Bevan Foundation's evidence²³ found that 19% of disabled people had not been able to afford to travel to a medical appointment.

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 2020 showed that the health gap has grown between wealthy and deprived areas, with marked regional differences in life expectancy. More recently, the Welsh NHS Confederation Health and Wellbeing Alliance, in partnership with the Royal College of Physicians (RCP), published its 'Mind the Gap' report calling on the Welsh Government to produce a cross-government plan to reduce poverty and tackle inequalities. This followed research which found that 60% of people in

²¹ See: Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., and Galea, A., (2012). [Long-term conditions and mental health. The cost of co-morbidities](#). The King's Fund, p.2.

²² *Ibid*, p.1.

²³ <https://www.bevanfoundation.org/views/health-impact-cost-of-living/>

Wales felt their health was being negatively affected by the rising cost of living²⁴.

The Covid-19 pandemic 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-19. The current Cost of Living Crisis is expected to further compound inequality, whilst both causing and exacerbating long-term ill health, as underlined by the Bevan Foundation²⁵.

People with long-term conditions and co-morbid mental health problems disproportionately live in deprived areas and have access to fewer resources of all kinds²⁶ and there is much evidence to suggest that socio-economic disadvantage can underpin and exacerbate experiences of chronic ill health. The interaction between co-morbidities and deprivation makes a significant contribution to generating and maintaining inequalities.²⁷

A large proportion of people of Black and Mixed ethnicities in Wales live in more socio-economically deprived areas. Across Wales, up to 70% of the Black ethnicity population live in areas that are more, rather than less, deprived according to the Welsh Index of Multiple Deprivation.²⁸ Furthermore, some of the local communities in which Black and Mixed ethnicity people live suffer from high levels of multiple deprivation.²⁹ At the same time, the Bevan Foundation recently reported that disabled and severely unwell people in Wales were more likely to be struggling financially during this latest cost of living crisis, resulting in escalating ill health. In the Foundation's YouGov survey, nearly one third of those who described themselves as 'limited a lot' by their impairments said they didn't have enough money for the basics: over 50% had gone without heating; 39% had avoided buying food, and 19% had decided against travelling to a medical appointment³⁰.

²⁴ <https://www.rcplondon.ac.uk/projects/outputs/mind-gap-cost-living-crisis-and-rise-inequalities-wales>

²⁵ <https://www.bevanfoundation.org/views/health-impact-cost-of-living/>

²⁶ See: Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., and Galea, A., (2012). Long-term conditions and mental health. The cost of co-morbidities. The King's Fund, p.2.

²⁷ *Ibid*, p.5-6.

²⁸ Brentnall, J., (2017). [Promoting engagement and academic achievement for Black and mixed-ethnicity pupils in Wales](#), p.26.

²⁹ *Ibid*.

³⁰ <https://www.bevanfoundation.org/resources/a-snapshot-of-poverty-in-winter-2023/>

It also important to note that people from minority ethnic backgrounds are at high risk of developing severe mental illness.³¹ Several studies suggest that experiences of racism (interpersonal and institutional) contribute to increased likelihood of developing mental health illnesses, as evidence shows racism to be a stressor.³² Meanwhile, data shows that, in Wales, the cost of living crisis is having a particularly pronounced impact on the mental health of disabled people with limiting illnesses, with more than 60% of respondents using that descriptor saying that their mental health was being ‘badly affected’³³. We have not been able to source disaggregated data on the extent of ethnic or sex / gender disparities in mental health conditions in Wales; nonetheless, the intersectional discrimination that women face when reporting their experiences and pain to health professionals also contributes to their likelihood of developing mental ill health.

The pandemic has had an impact on everyone’s ability to access health care across the UK, with many people struggling to obtain a GP appointment, and having to wait even longer for scans, operations, and other appointments. The pandemic has also caused diagnostic delays, and all of this will negatively impact on people’s quality of life.

Some individuals might not be able to work because of ill-health. For those living in deprived areas who are more likely to work in low-income jobs and roles which can’t be done remotely, this will have even more of a negative impact as these individuals already struggle to make ends meet. As outlined earlier, a large proportion of people of Black and Mixed ethnicities in Wales live in more socio-economically deprived areas³⁴ whilst, according to the Bevan Foundation, more than 50% of disabled and sick people unable to work and in receipt of legacy benefits in Wales report negative effects on their health by financial position³⁵.

Struggles to obtain a GP appointment and longer waiting times for scans, operations and diagnoses mean that people are turning to private healthcare, if they can afford to do so, and in some cases, even if they can’t afford it, with some people going into debt to pay for private healthcare.³⁶ For a significant

³¹ Mind., (2020). [Briefing from Mind: Inequalities for Black, Asian and Minority Ethnic communities in NHS mental health services in England](#), p.5.

³² *Ibid.* See also: Bhui, K., Nazroo, J., Francis, J., et al. (2018). [The Impact of Racism on Mental Health](#), p.5

³³ <https://www.bevanfoundation.org/resources/a-snapshot-of-poverty-in-winter-2023/>

³⁴ Brentnall, J., (2017). [Promoting engagement and academic achievement for Black and mixed-ethnicity pupils in Wales](#), p.26.

³⁵ <https://www.bevanfoundation.org/resources/a-snapshot-of-poverty-in-winter-2023/>

³⁶ See: [Endometriosis: Credit card to pay for surgery after 23 years in pain](#), (2022).

number, the private route is becoming an increasingly attractive option, however, generally speaking, ethnic minority and disabled people do not have the finances to opt for private healthcare, as they are more likely to live in socio-economically deprived areas³⁷ and to experience poverty³⁸ than their White British and / or non-disabled counterparts in Wales. This could therefore cause health inequalities for ethnic minority groups and disabled people to become even more deeply entrenched, which will result in an ever-widening gap in good health outcomes.

4) Prevention and lifestyle

- **Action to improve prevention and early intervention (to stop people’s health and wellbeing deteriorating).**
- **Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.**

Public awareness, information, and education constitute a powerful preventative tool.

For many members of the Women’s Health Wales Coalition, 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

³⁷ Brentnall, J., (2017). [Promoting engagement and academic achievement for Black and mixed-ethnicity pupils in Wales](#), p.26.

³⁸ The Welsh Black and Minority Ethnic population continues to be more likely to experience poverty than their White British counterparts in Wales. For the period 2015-16 to 2019-20 (an average of 5 financial years) there was a 29% likelihood of people whose head of household comes from a non-white ethnic group living in relative income poverty. This compares to a 24% likelihood for those whose head of household comes from a white ethnic group. Similarly, 38% of children who lived in a family where there was someone with a disability were in relative income poverty compared with 26% of those in families where no-one was disabled. For working-age adults, 31% who lived in a family where there was someone with a disability were in relative income poverty compared with 18% of those in families where no-one was disabled, See: Welsh Government., (2021). [Relative Income Poverty: April 2019 to March 2020](#). See also: Joseph Rowntree Foundation., (2020). [Briefing: Poverty in Wales 2020](#), p.5-6.

patients. Good practice in this regard is already underway in Wales, with Welsh Government's Women's Health Implementation Group having previously provided funding and expertise for the coproduction 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.

Improved support in the workplace is also vital to ensuring women are able to remain in employment whilst balancing other responsibilities. 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.

5) The Committee adds that contributors can comment generally or specifically about a certain condition.

The following constitutes some of the chronic health condition / issue-specific evidence supplied by the Women's Health Wales Coalition members, much of which has been published in the May 2022 'Quality Statement for the Health of Women, Girls, and those Assigned Female at Birth' and is referenced as such.

Where evidence has been provided to the Coalition subsequently, this is made clear and referenced accordingly.

- **Fertility³⁹**

Whilst typically not considered a chronic condition or 'illness', protracted fertility journeys and poor experiences can have mental health consequences with long-term or 'chronic' implications for health and wellbeing. Indeed, fertility issues can have a devastating impact on people's mental (and physical) health, relationships, finances and career. It is also worth noting that infertility can be linked to other chronic health conditions described in this submission

³⁹ <https://www.ftww.org.uk/2021/wp-content/uploads/2022/05/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf> page 28

and, in some instances, the treatments people receive for them, including induced medical or surgical menopause, for example.

The findings of a 2022 Fertility Network UK & Middlesex University survey⁴⁰ highlight the emotional and financial impact, as well as a lack of information provided by GPs and limited support options, such as counselling services. There is a need for more clinical help and understanding of the emotional distress caused by infertility, fertility treatment, and eventual outcomes, whether successful or not, and focus on the impact of infertility and incidence of undiagnosed and misunderstood trauma and PTSD (Post-Traumatic Stress Disorder) as a result.

Fertility challenges and the use of assisted conception are increasing. Yet access to funded treatment and associated supports, such as counselling, is often limited, so the financial and emotional impacts of treatment are problematic for many people.

Key findings from the survey include:

- 4 out of 10 respondents experienced suicidal feelings.
- Almost half (47%) of respondents experienced feelings of depression often or all the time, while the vast majority (83%) felt sad, frustrated and worried often or all the time.
- The majority of respondents (59%) reported some detrimental impact of fertility problems and/or treatment on their relationship with their partner.
- Three-quarters of respondents (75%) felt their GP did not provide sufficient information about fertility problems and treatment and 7% were not sure. Less than one-fifth (18%) were satisfied with the information GPs provided.
- The majority of respondents (78%) would have liked to have counselling if it was free. Half of respondents (51%) did have counselling, but most of these (59%) had to fund some of it themselves.

- **Perinatal Mental Health⁴¹**

⁴⁰ <https://fertilitynetworkuk.org/the-far-reaching-trauma-of-infertility-fertility-network-uk-survey/>

⁴¹ <https://www.ftww.org.uk/2021/wp-content/uploads/2022/05/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf> page 37

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.

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 anxiety. 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 assessment. However, many women experience a mental health problem for the first time in the perinatal period. 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.

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 billion. An inquiry into perinatal mental health carried out by the Children, Young People and Education committee in 2017 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 although the Coalition is aware of work underway to develop a similar unit in Chester, North-West England, which will have 2 beds reserved for North Wales patients. Just two of the seven health boards currently meet the Royal College of Psychiatrists' standards for community perinatal mental health services.

- **Autism & Neurodivergence⁴²**

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 birth face both inequitable access to diagnostic services and - as both diagnosed and undiagnosed neurodivergent women - unequal access to healthcare more widely. 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 outcomes. 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 conditions. 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 anorexia.

Autism UK's 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 part 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 care. More generally, autistic women report poorer quality of life than autistic men across multiple areas, to the extent that some studies include "being female" as a predictor of lower quality of life in autistic 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. Research is lacking when it comes to neurodivergent experiences of women's health issues, or the difficulties they have accessing diagnosis and/or healthcare.

⁴² *Ibid*, page 47

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 crisis. 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".

Members of the Women's Health Wales Coalition have, since the publication of its own Quality Statement in May 2022, submitted further evidence on issues relating to autism and neurodivergence, including barriers to diagnosis and support experienced by people within minority cultures and people with impairments.

Within some minority cultures, there is a reluctance to get a diagnosis of neurodivergence due to cultural stigma, greatly limiting the support these individuals can receive. Additionally, there is a problem with awareness amongst some ethnic minority groups, with some having only limited understanding of autism and neurodivergence, impacting their ability to identify signifiers and resulting in delays in accessing appropriate support.

Members were also concerned about the implications of a pilot being conducted by the North Yorkshire Health and Care Partnership⁴³ if replicated in Wales. The pilot involves the introduction of acceptance criteria for referral for diagnostic assessment for autism and ADHD:

- i) Those who are at immediate risk of self-harm or harm
- ii) Those at risk of being unable to have planned life-saving hospital treatment, operations, or care placement
- iii) Those at imminent risk of family court decisions determined.

Referrals are directed through a web-based screening and assessment system called Do-It Profiler.

As it stands in Wales, assessments are hard to secure and demand is high; Coalition members would not wish to see this problem 'resolved' by further

⁴³ <https://blog.yorks.ac.uk/isi/2023/04/24/changes-to-adult-autism-and-adhd-diagnostic-assessment-a-research-perspective/>

limiting access, impacting on patient safety and wellbeing. Similarly, wholly relying on online portals for screening and assessment is problematic. Patients describe continuing difficulties in accessing GP services, with online portals and telecommunications proving challenging, even impossible, to navigate for those with various impairments and processing difficulties.

- **Post-Traumatic Stress Disorder (PTSD) and Complex PTSD⁴⁴**

Trauma 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.

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 group. 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 problems.

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).

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.

⁴⁴ <https://www.ftww.org.uk/2021/wp-content/uploads/2022/05/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf> page 56

- **Endometriosis⁴⁵**

Endometriosis affects 10% of women and those assigned female at birth and can result in a wide range of symptoms, which may become 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 benefits. 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 impacts on work and employment. 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 potential. 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 expectancy.

Public awareness about the condition is generally poor, resulting in some with endometriosis not realising they have a diagnosable 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.

The 2018 Welsh Government review of 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”. Diagnosis in Wales takes on average 9 years, a year longer than in England, and can

⁴⁵ *Ibid*, page 62

involve the distress of repeated medical appointments that fail to identify a cause for symptoms.

On average, patients will have 26 visits to the doctor before receiving a diagnosis in Wales. 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. 94% of those with endometriosis in Wales would have liked psychological support but were not offered it (UK average 90%).

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 available, 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 centre, for example in cases of suspected or confirmed deep endometriosis, but that is not always the case. It is suspected that inadequate funding arrangements are preventing out of area referrals for tertiary care, resulting in a postcode lottery.

Adenomyosis⁴⁶

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. It affects 1 in 10 women and those assigned female at birth, 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

⁴⁶ *Ibid*, page 67

between the two diseases overlap. Less common symptoms of adenomyosis include pain during sex and pain relating to bowel movements.

There has been limited research into adenomyosis, however impacts can include reduced health-related quality of life; impairment at work and daily activities; a negative effect on psychological health including a higher risk for anxiety and depression. Whilst symptom management is possible for some patients with analgesia, hormone-based therapies, or medications to reduce bleeding, the only definitive treatment for the condition suitable for women not wishing to preserve fertility, is hysterectomy (removal of the womb). Some women undergoing a hysterectomy experience loss of ovarian function and may subsequently need menopause care including Hormone Replacement Therapy (HRT).

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.

- **Premenstrual Dysphoric Disorder (PMDD)⁴⁷**

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

⁴⁷ *Ibid*, page 70

cycle for 5.5% of women and those assigned female at birth (AFAB) who are of reproductive age.

Symptoms include depression, anxiety, mood swings, irritability, and often suicidal ideations, as well as physical symptoms such as breast tenderness and bloating. These symptoms often impair daily functioning at work, school, 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 Disorder 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 Diseases cross-listed as a disease of the genitourinary system and a depressive disorder.

Stats Wales states that there are 971,731 women between the ages of 16 and 64. 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 International Association of Premenstrual Disorders (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 Premenstrual Syndrome (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 diagnosis.

Patients in the United Kingdom wait an average of 12 years for an accurate diagnosis and see 11 healthcare providers in the process. A recent study highlights the critical importance of the accurate and timely detection of PMDD, with the aim of preventing women from experiencing severe and prolonged psychological distress. Recent IAPMD research of 591 patients shows the wide-ranging impacts of PMDD as follows:

- 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.

In May 2023, the UK's first research agenda for PMDD was published⁴⁸, based on comprehensive engagement with stakeholders. Five key research priorities have been identified. These are:

- Diagnosis and management of PMDD
- Best approaches for psychological support
- Suicide and self-harm prevention
- Impact of PMDD on life
- Support for hormonal 'trigger' events

Alongside the 'top 5', other areas were identified as important. These include: (a) causes and biology of PMDD; (b) destructive behaviour; (c) surgery and post-surgery support; (d) barriers to support; (e) the 'cost' of PMDD; (f) premenstrual exacerbation of existing disorders; (g) neurodivergence; (h) support from the welfare system; and (i) PMDD education and training.

This research agenda must now help shape the future of PMDD research in the UK, and decision-makers within the NHS in Wales should use the agenda to identify and implement initiatives nationally and locally.

- **Polycystic Ovary Syndrome (PCOS)⁴⁹**

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) 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 levels.

⁴⁸ Matthews L, Riddell J. (2023). Premenstrual Dysphoric Disorder (PMDD): The UK research agenda. University of the West of Scotland. Accessed from www.uws.ac.uk/pmdd

⁴⁹ <https://www.ftww.org.uk/2021/wp-content/uploads/2022/05/Womens-Health-Wales-Quality-Statement-English-FINAL.pdf>, page 74

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 men.

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 Guideline 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. PCOS is also associated with an increased risk of developing health problems in later life, such as type 2 diabetes and high cholesterol levels. 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. 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 multidisciplinary 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's prudent healthcare principles.

Since publication of the Women's Health Wales Coalition's Quality Statement, member organisations have submitted further evidence which suggests that the name of the condition and its links to fertility can be a barrier to many trying to access support; there are particular barriers for some ethnic minorities due to cultural issues around fertility, and that the mental and emotional health impact of the condition is massively under considered. New guidelines are intended to address this.

- **Heart Conditions⁵⁰**

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

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 attack. 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

⁵⁰ *Ibid*, page 79

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 confident.

High blood pressure is the biggest modifiable risk factor contributing to premature deaths from heart and circulatory diseases in Wales and has been more strongly associated with heart attacks in women than in men. 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 cardiomyopathy.

Around 1 in 10 women develop high blood pressure during pregnancy in the UK. 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 Wales.

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 attack.

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 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 age.

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 attack. 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 Wales and 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 women.

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.

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.

- **Autoimmune Conditions⁵¹**

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

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 purse.

There are well documented diagnostic delays for lupus patients, where the average is 6.4 years. 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,

⁵¹ *Ibid*, page 83

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 general. Current practice in Wales sees patient care provided by non-specialists in general Rheumatology departments, conversely to national guidance which recommends access to multi-disciplinary centres of excellence for the development of bespoke treatment plans and more complex care. 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 Wales.

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 infection.

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. 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 population, 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.

- **Eating Disorders⁵²**

⁵² *Ibid*, page 87

Eating disorders are serious mental illnesses. According to Beat's latest estimation, 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 participants. Eating disorders have major impacts on individuals, families, the NHS, social care, and wider society.

Eating disorders have high mortality rates, with anorexia having the highest mortality rate of any mental illness. 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 Services 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 fields. 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 management. On average, just 3 hours is spent on teaching about eating disorders in Welsh medical schools.

Early intervention provides the best chance for recovery. 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.

- **Self-Harm⁵³**

Self-harm is a strong risk factor for suicide, 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 suicidal, 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 report.

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 time. 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 UK. For many, non-suicidal self-harm is a way of coping with difficult or distressing feelings and circumstances, and this is distinct from suicide attempts. Self-harm is often hidden and the specific and distinct needs of people who have self-harmed

⁵³ *Ibid*, page 90

without suicidal intent are poorly understood and, according to Samaritans Cymru, are too often not taken seriously.

The true scale of self-harm is estimated to be 1 in every 130 people. 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 year. Self-harm can affect people of all ages and genders, but we know it is more common in females across all age groups. 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-teens.

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 al 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 callers.

Whilst distinct from self-harm, the Royal College of Psychiatrists' report 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-harm.

- **Hypermobility Spectrum Disorders (HSD) and Ehlers Danlos Syndromes (EDS)⁵⁴**

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 generalised throughout the whole body, and whether other musculoskeletal problems are present. Research shows that the median time to diagnosis is around 10 years but this is higher for women in Wales.

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

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 been reported by patients as being responsible for damaging consequences. 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

⁵⁴ *Ibid*, page 94

therapies, and the implications of this will impact the patient's life heavily. 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 mortality.

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 morbidity. Although anxiety is not officially part of the classification of hypermobile EDS, it should be considered when classifying and diagnosing due to its higher prevalence.

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 treatment. 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, clearly demonstrates the prevalence of the condition in women.

- **Myalgic Encephalomyelitis (ME)⁵⁵**

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 ages. Research has uncovered multiple

⁵⁵ *Ibid*, page 97

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 bedbound. 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 recommendations.

ME affects more women than men, in an approximate ratio of 4:1.

People with ME score lower overall on health-related quality of life tests than most other chronic conditions. '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 opportunities. Benefits are notoriously difficult to obtain, with the assessors often failing to consider fluctuating levels of activity or marking down patients who are not receiving high levels of pain medication – despite guidance issued by the UK government.

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) cause, or other attitudinal challenges which see the public and healthcare professionals underestimating symptoms which are invisible and not easily measured in primary care.

There has also been a lack of investment in training/service provision which has resulted in inadequate or non-existent care pathways, no 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 coproduced, 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 ME 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) but this has not been prioritised by health boards.

- **Long Covid**⁵⁶

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 "postCOVID-19 syndrome" beyond 12 weeks. 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 nature.

⁵⁶ *Ibid*, page 101

There is increasing evidence of significant long term medical complications including cardiac, respiratory and renal disease, new onset diabetes and excess deaths. A report issued by the Office of National Statistics (ONS) in September 2021 estimated that 970,000 British people were affected by long COVID and in March 2021, the ONS reported that 56,000 people in Wales were living with the condition. 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 men.

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 age. 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 age.

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". 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 working. 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.

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". 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" 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 clinics, including 15 paediatric hubs, 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 diabetes. 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.

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, there has been a considerable loss of time to learn about long COVID patients and contribute such knowledge to the world stage. Further, 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. 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 workforce. 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 sector. 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 occupations. 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 so. 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 employers.

Since publication of the Women's Health Wales Coalition's Quality Statement, those living with Long COVID in Wales have submitted additional evidence, including reports of regularly struggling to get GP appointments. Patients experiencing fatigue and cognitive issues, including poor memory, find it particularly difficult to remember to promptly call the GP at a specific time in the morning in order to get an appointment. The requirement to do this on

multiple days in order to get through on the telephone can result in patients giving up, leading to weeks or months of trying to get a GP appointment.

Long COVID patients report there still being many GPs lacking sufficient knowledge of the condition to best support patients, such as salt and fluid intake and compression socks for Postural Orthopaedic Tachycardia Syndrome (POTS) , or anti-histamines, histamine blockers and a low-histamine diet for Mast Cell Activation Syndrome (MCAS) so the onus remains on unwell patients to research and advocate for themselves. Patients without this knowledge or capacity may find themselves without appropriate treatment.

Patients reporting their concerns to Long Covid Wales describe the ongoing difficulties in securing referrals to specialist care, with GPs tending only to refer to the local health board's Long COVID Service. Long COVID affects many more women than men and, as with other chronic conditions, women are describing how challenging it is to have their concerns taken seriously and to have thorough investigations initiated. Some have been told that their weight is the issue or that symptoms are due to the menopause.

Waiting times for a Long COVID service are long (a number of months) in lots of parts of Wales. Long Covid Wales reports that people at the top of the list find they are being offered either a group service via a digital platform or an exercise based rehab programme – completely unsuitable for those suffering from Post Exertional Malaise, as documented by the recent changes to the NICE Guidelines for ME which no longer recommend graded exercise programmes and have acknowledged them as harmful. As a consequence and, as with other patients living with chronic illness in Wales, Long COVID patients describe paying out of their own pockets to access treatments like weekly Hyperbaric Oxygen Therapy or private prescriptions for medicines such as Low Dose Naltrexone, known to be effective for those with ME/CFS and Long COVID. It is important to emphasise that these are not new treatments, they come with a proven safety record and are already widely used for other illnesses so it would make sense to fast track studies to make treatments available sooner rather than later, in line with the Prevention agenda and prudent healthcare principles.

A significant concern is lack of co-production of Long COVID services which, Coalition members report, have been created without any meaningful consultation or patient input, despite the wealth of lived expertise on which to draw. A key example of this is people's experience of COVID triggering or worsening a wide range of illnesses in those affected, a key reason why many

have been asking for Consultant-led Long COVID Clinics. These would provide a one-stop-shop for patients so that they can access medical investigations as required, participate in clinical trials, and where doctors are able to develop expertise in managing this new illness by virtue of seeing a large number of patients. Where such clinics exist in England they have been very useful.

In terms of the interaction between mental health and Long COVID, members of the Coalition who are living with the illness describe how an ongoing lack of appropriate support has inevitably had a negative impact on mental health. In addition to this, post-viral conditions are badly affected by stress. For many of those living with Long COVID, an additional stressor has been the belief that their health has been de-prioritised because their illness was not understood and was not life threatening.

Further, a significant number of Long COVID patients have found that the loss of income due to the condition, extra expenditure on private healthcare, and cost of living increases have had a hugely negative effects on psychological health and wellbeing. Many are now relying on state benefits but the difficulties in getting specialist care and a diagnosis have created barriers for people needing to apply for financial and social support in this way.

- **Fibromyalgia⁵⁷**

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

⁵⁷ *Ibid*, page 105

fibromyalgia as it helps improve blood flow to muscles, relieves stress and improves quality of sleep. 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 condition. 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 majority of fibromyalgia patients are women (around 80-90%), but men and children can have the condition too. 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 government. 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' and that they qualify as disabled under the Equality Act 2010, 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, with patients 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 psychologist. However, this does not appear to be the case in Wales, with services differing between health boards, creating a postcode lottery. 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 is often delivered in silos, with a lack of joined-up pathways and 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 work.

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, resulting in delayed diagnosis and access to appropriate healthcare.

- **Skin Conditions⁵⁸**

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 problem. 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 year. Dermatological conditions can have a significant impact on a patient's quality of life.

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 Getting it Right First Time (GIRFT) report shows that there is a national shortage of consultant dermatologists with just 659 working in the NHS in England. 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 Whole Time Equivalent (WTE) doctors in total in Wales. This represents 1 WTE per 81,300 of the population – which is 18,800 more than the RCP and BAD's recommended target. 11.1 WTE Dermatologists would need

⁵⁸ *Ibid*, page 108

to be trained and employed to meet this target – representing a 30% increase. 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 diseases. However, there is lack of data in the UK about the prevalence of skin diseases in people with skin of colour compared to the USA, where there is data about the prevalence of some skin diseases in different ethnic groups and studies on racial /ethnic bias.

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

Conclusion

The Women’s Health Wales Coalition would like to offer the Health and Social Care Committee its ongoing support in gathering evidence for its inquiry into Supporting People with Chronic Conditions by contributing to focus groups or similar.

We invite the Committee to contact the Coalition via info@ftww.org.uk and [REDACTED] should members have any questions on the content of this submission or if they would wish to arrange further discussions and / or focus groups. Thank you, diolch.