MEETING OF FOUR GROUPS WITH MABON AP GWYNFOR, CABINET MINISTER FOR HEALTH AND CARE

TUESDAY 28 JULY

In attendance:

Mabon ap Gwynfor (CMHC)	Cabinet Minister for Health and Care
<redacted s40(2)>	Assistant Senior Private Secretary
<redacted s40(2)>	Severe ME Difrifol Cymru
<redacted s40(2)>	Severe ME Difrifol Cymru
<redacted s40(2)>	Long Covid Support
<redacted s40(2)>	Long Covid Support
<redacted s40(2)>	WAMES
<redacted s40(2)>	WAMES
<redacted s40(2)>	Action for ME
<redacted s40(2)>	Action for ME
<redacted s40(2)>	Head of Post Infection Associated Illness
<redacted s40(2)>	Post Infection Chronic Illness

1. Welcome and Introductions

CMHC welcomed all to the meeting and [redacted] lead on introductions of those present.

2. Setting the Context

[redacted] commenced by thanking CMHC for agreeing to meet with the groups and for the way CMHC had spoken up for people with ME in the past. [redacted] referenced CMHC's contribution to the Senedd debate on severe ME last December and that his direct personal encounter with ME would make a difference to his understanding of the condition.

[redacted] outlined how all at the meeting had brought this personal lived experience to the meeting either as sufferers or as family members of those with ME or Long Covid. These illnesses have changed their lives.

[redacted] referenced that in last December's debate CMHC had said, *"People suffering from ME have been waiting far too long".* He furthered that adding up just the people in the meeting, they have been waiting over 100 years – 'a century of waiting'. Collectively, the groups looked within the NHS in Wales for:

- Recognition of ME as a serious multi-system disabling illness.
- Access to trained clinicians with appropriate expertise.
- Clear, safe and consistent care pathways.
- Increased investment in biomedical research to improve understanding and treatment options.

Drawing on his own personal experience [redacted] explained that affected individuals and families have not simply waited for change but have actively sought knowledge,

support and solutions by engaging with charities, research, clinicians and peer networks. The value of lived experience and patient expertise, including contributions from health professionals affected by these conditions, was highlighted.

[redacted] stressed the importance of genuine co-production between government, NHS services and patient communities and referenced the Plaid Cymru manifesto statement that the starting point for individual Care and Treatment Plans should be a conversation about ‘What matters to you?’ but suggested that this principle should also inform national policy development for ME and Long Covid.

Finally, [redacted] in handing over to [redacted] reflected on the emergence of Long Covid in 2020, noting that many of its symptoms were immediately recognisable to people living with ME. This reinforced the need to learn from existing patient experience and expertise when developing services and policy responses for both conditions.

[redacted] on behalf of the Long Covid community highlighted that, six years after the start of the Covid-19 pandemic, many people remain profoundly disabled by Long Covid, affecting their ability to work, maintain social relationships and undertake everyday activities. It was noted that there are still no definitive diagnostic tests, approved treatments or assurances of recovery.

Concerns were raised about ongoing stigma and misinformation surrounding Long Covid, including misconceptions that it is not a real condition, that symptoms are linked to laziness, or that they are solely attributable to vaccine injury. Participants noted that some healthcare professionals continue to question the legitimacy of Long Covid, creating barriers to diagnosis, support and access to financial assistance.

[redacted] emphasised that, while many regard the pandemic as over, Covid-19 continues to circulate and remains a public health concern. It was stressed that anyone can develop Long Covid, ME or other longer-term health complications following infection, regardless of age, gender, vaccination status or the severity of previous infections.

[redacted] expressed concern about the lack of recent data collection on Long Covid prevalence, while highlighting wider trends including increasing levels of chronic illness, record levels of long-term sickness absence from work, ongoing school absenteeism, and declining healthy life expectancy. Participants suggested these trends warrant further investigation given their timing since the onset of the pandemic in early 2020.

[redacted] drew parallels between Long Covid and ME and reflecting that the longstanding experiences of people with ME demonstrate the consequences of post-viral illnesses being underestimated and under-researched. Participants suggested that lessons from both conditions should inform future policy and service development.

[redacted] on behalf of the four groups presented four key requests to Welsh Government:

1. **Establish an Expert Working Group** to provide strategic leadership and advice on ME and Long Covid.
2. **Appoint an All-Wales Clinical Lead** to drive service improvement and clinical consistency across Wales.
3. **Develop a ME and Long Covid Research Strategy** to strengthen understanding, evidence and treatment development.
4. **Ensure post-viral illnesses are considered within prevention strategies and future pandemic preparedness planning.**

3. Four Key Asks

i) Key Ask 1 - A National Expert Group

[redacted] on behalf of the ME and Long Covid communities requested the establishment of a **National Expert Working Group**, bringing together healthcare professionals, people with lived experience, third sector organisations and service leaders to **co-produce an All-Wales Strategy and Delivery Plan** for ME and Long Covid.

[redacted] noted that previous initiatives, including the **2014 Task and Finish Group recommendations**, the **2021 NICE ME/CFS guideline (NG206)** and the development of **Adferiad services**, had created expectations of improved care. While some patients had benefited, significant variation in access to diagnosis, treatment and support remains across Wales, resulting in a postcode lottery of services.

Particular concern was raised regarding the experiences of:

- People with severe and very severe ME.
- Children and young people.
- Family members and unpaid carers.

[redacted] highlighted the need for stronger national coordination to reduce inequity and ensure consistent implementation of NICE guidance.

Key areas identified for inclusion within a national strategy and delivery plan were:

- **Accurate and timely diagnosis**, supported by improved clinician training and awareness across all health boards.
- Development and implementation of **clear clinical pathways** for ME and Long Covid, including appropriate recognition and management of **Post-Exertional Malaise (PEM)**, the defining symptom of ME and commonly experienced in Long Covid.
- Establishment of **consistent specialist services** across Wales, aligned with the NICE service model and supported by national standards.

- Improved **education and training** for healthcare professionals, including mandatory training for staff working with people with ME and Long Covid, particularly within Adferiad services.
- Introduction of **standardised data collection and diagnosis recording** across all health boards to better understand prevalence, unmet need and service requirements.
- Enhanced support and planning for people with **severe and very severe ME**, who are often underrepresented in existing datasets and service planning.
- Consideration of **prevention, early intervention and future planning**, including the impact of Covid reinfections and other viral illnesses on the development and progression of ME and Long Covid.

[redacted] stressed on behalf of the groups that meaningful **co-production** with patients, carers and third sector organisations is essential to designing effective services and avoiding costly mistakes. Government oversight and leadership would be necessary to ensure timely implementation and accountability.

In summary, attendees argued that Wales requires a **National Expert Working Group** to provide coordinated leadership, ensure compliance with NICE guidance, reduce variation in services, and deliver equitable, evidence-based care for people with ME and Long Covid across all ages and levels of severity.

ii) Key Ask 2 - Appoint an All-Wales Clinical Lead

[redacted] on behalf of participants highlighted that the absence of national clinical leadership has contributed to significant variation in the diagnosis, treatment and support available for people with ME and Long Covid across Wales. They noted that access to specialist advice and services remains inconsistent, particularly for those with the most severe forms of illness.

[redacted] highlighted the four group's second key request was the appointment of an **All-Wales Clinical Lead/Medical Consultant for ME and Long Covid** to provide strategic and clinical leadership across Wales. The proposed role would:

- Coordinate services across health boards.
- Reduce regional variation in care.
- Support the management of complex and severe cases.
- Lead workforce education and training.
- Guide the development of treatment approaches and clinical pathways.
- Ensure Wales remains aligned with emerging UK and international research evidence.

[redacted] emphasised that ME and Long Covid are complex, multi-system conditions requiring a multidisciplinary approach. However, he stressed that medical oversight at both local and national levels is essential and that any All-Wales leadership model should include a consultant-level clinician with specialist expertise.

The discussion highlighted the severity and disabling nature of ME, referencing NHS England's educational materials which describe severe ME as comparable in impact to late-stage multiple sclerosis, advanced cancer and end-stage renal failure. It therefore led to the question: Why do people with ME often lack access to a dedicated specialist medical service or clinical specialty equivalent to those available for other serious long-term conditions.

Concerns were raised that some of the most severely affected patients currently receive the least support. Reference was made to Prevention of Future Deaths reports relating to individuals with severe ME, which identified a lack of specialist clinical expertise as a contributing factor. [redacted] on behalf of participants stressed the importance of learning from these cases and ensuring access to safe, equitable and specialist care for all levels of illness severity.

[redacted] also highlighted the longstanding stigma and misunderstanding associated with ME, noting that many people with Long Covid are experiencing similar challenges. He argued that addressing these issues requires leadership from a respected senior clinician with the authority and credibility to:

- Promote evidence-based practice.
- Challenge outdated perceptions.
- Influence clinical culture and service development.
- Support implementation of NICE guidance.
- Provide accountability and oversight across health boards.

In summary, RM stated that appointing an **All-Wales Clinical Lead for ME and Long Covid** is critical to improving consistency of care, strengthening clinical leadership, supporting service development, and ensuring that patients across Wales receive safe, equitable and evidence-based care.

iii) Key Ask 3 - Develop ME and Long Covid Research Strategy

[redacted] on behalf of participants called for the Welsh Government to develop a ME/CFS and Long Covid Research Strategy by 2027, aimed at accelerating research, improving understanding of disease mechanisms, and supporting the development of effective diagnostics, treatments and preventative approaches.

[redacted] highlighted that although major research programmes such as DecodeME, LOCOME and Sequence ME & Long Covid are generating significant new insights into the biology and genetics of these conditions, there is a need for Wales to be prepared to translate these discoveries into tangible benefits for patients.

[redacted] noted that a national research strategy would:

- Bring together researchers, clinicians, people with lived experience, universities, the NHS and industry partners.
- Establish clear national research priorities.

- Strengthen collaboration across Wales and internationally.
- Attract investment and support growth within Wales' life sciences sector.
- Accelerate the translation of research findings into clinical practice.

[redacted] emphasised that the proposal aligns with Welsh Government priorities around health innovation, digital transformation, life sciences, reducing health inequalities and creating a sustainable health and care system.

The economic impact of ME/CFS and Long Covid was also discussed. [redacted] noted that both conditions contribute significantly to reduced participation in education, employment and community life, while creating substantial pressures on healthcare and support services. Improved diagnostics, treatments and disease management were viewed as having the potential to deliver both health and economic benefits.

The group highlighted increasing evidence of overlap between ME/CFS and Long Covid, including research suggesting that many people with Long Covid meet the diagnostic criteria for ME/CFS. They argued that research efforts should be coordinated across related post-infectious illnesses to maximise impact and improve outcomes.

[redacted] stressed that people with ME/CFS have historically experienced underinvestment in research, delayed diagnosis and limited access to services. While Long Covid has increased awareness and research activity, there remains an opportunity to address longstanding health inequalities affecting these patient groups.

[redacted] stated that Wales is well placed to take a leadership role in this emerging field by bringing together expertise from across the research, healthcare and patient communities. They argued that a Welsh Government-led research strategy would help build critical research capacity, foster collaboration, and ensure patients in Wales benefit from scientific advances as quickly as possible.

ME/CFS and Long Covid (LC) remain poorly understood, despite their high prevalence and significant impact on individuals and society. Emerging evidence suggests considerable overlap between the conditions, with around 50% of people with Long Covid experiencing symptoms that mirror ME/CFS.

The burden on society and the economy is substantial. Across the UK, an estimated 1.35 million people are living with ME and ME-like symptoms, with annual economic costs exceeding £23.5 billion. In Wales, the estimated impact is more than £1 billion per year, excluding the additional burden from overlapping conditions.

Developing a coordinated response presents an important opportunity to address longstanding health inequalities. People with ME/CFS have historically faced delayed diagnosis, limited service provision, and insufficient research investment.

The response to Long Covid has demonstrated what can be achieved when government, health systems, researchers, and people with lived experience work together around a shared objective.

Although Wales represents less than 5% of the UK population, it has a strong track record of innovation and leadership. There is an opportunity for Wales to become a leading nation in this area by committing to a Welsh Government-led ME/CFS and Long Covid Research Strategy by 2027.

Current challenges include a small research community, limited funding, and insufficient collaboration across the ME/CFS and Long Covid research landscape. While initiatives such as the MRC-funded PRIME programme are helping to strengthen activity, research capacity in Wales remains limited.

The key challenge is to improve understanding of disease mechanisms and develop evidence-based diagnostic tests and treatments for ME/CFS, Long Covid, and related post-infectious conditions. Progress on research, diagnosis, and treatment development should be pursued in parallel.

Wales is well placed to bring together expertise across health, academia, and lived-experience communities to accelerate research, improve outcomes, and position itself at the forefront of this emerging healthcare priority.

iv) Key Ask 4 – Consider Post-Viral Illness in Future Pandemic Planning and Prevention Strategies

[redacted] on behalf of representatives from the Long Covid and ME communities called for greater recognition of the long-term health consequences of infectious diseases within future pandemic preparedness and prevention planning. He emphasised that, while the Covid-19 pandemic resulted in significant loss of life, it also left many people living with long-term disability, including Long Covid and ME.

[redacted] highlighted that lessons learned from the pandemic should include consideration of the health, social and economic impacts of post-viral illnesses. He requested that any Wales-specific review or inquiry into the pandemic examine the experiences of people living with Long Covid and ME and use these insights to inform future planning.

[redacted] noted the significant impact of Long Covid on healthcare workers, with many unable to return to previous levels of work or leaving the profession altogether. Concerns were raised about the loss of experienced NHS staff due to Long Covid and the need for stronger protections for healthcare workers who remain at increased risk of exposure to infectious diseases.

[redacted] on behalf of attendees called for an **urgent review of Infection Prevention and Control (IPC) guidance in healthcare settings**, arguing that existing measures do

not fully reflect current understanding of airborne transmission. Suggested areas for review included:

- Greater use of FFP3 masks where appropriate.
- Improved ventilation and air filtration.
- Wider use of CO_2 monitoring.
- Stronger measures to reduce transmission within healthcare environments.

The discussion also focused on concerns about the cumulative health impacts of repeated Covid-19 infections and the need to protect vulnerable groups from further deterioration. [redacted] stressed the importance of ensuring that prevention strategies consider the risks posed by ongoing and future viral outbreaks.

Several additional recommendations were made:

- **Reinstatement of wastewater surveillance programmes** in Wales to support early detection of infectious disease threats, including Covid-19, influenza, RSV and norovirus.
- Greater use of surveillance data to support NHS planning and preparedness during winter pressure periods.
- Development of a **public health information campaign** to provide evidence-based information on Covid-19 and reduce misinformation and stigma associated with Long Covid.
- Increased awareness and education for healthcare professionals, particularly in primary care, to support earlier recognition, diagnosis and management of Long Covid and other post-viral conditions.
- Improved access to vaccination for people living with chronic illnesses such as Long Covid and ME, who may be concerned about the impact of reinfection on their health.

[redacted] emphasised that he was not advocating for a return to lockdown measures, but for practical, proportionate and cost-effective interventions that would help individuals make informed decisions and reduce the burden of long-term illness. In closing, [redacted] thanked the Cabinet Minister for meeting with them and expressed a willingness to work collaboratively with Welsh Government to improve outcomes for people living with Long Covid and ME. They welcomed the opportunity to have their concerns heard and viewed this engagement as an important first step towards meaningful change.

4. Alignment with Welsh Government Policies

[redacted] highlighted that the four key requests align closely with commitments set out in Plaid Cymru's manifesto and offer an opportunity to deliver tangible improvements for people living with ME and Long Covid across Wales.

Ending the postcode lottery in healthcare - [redacted] noted that the proposed All-Wales Strategy and Delivery Plan and the appointment of an All-Wales Clinical Lead would

help establish consistent pathways and standards of care across health boards. These measures would reduce variation in services and support equitable access to diagnosis, treatment and care, regardless of where patients live.

Strengthening clinical leadership and workforce development – [redacted] emphasised that inconsistent knowledge and understanding of ME and Long Covid remain significant barriers to effective care. The proposed Clinical Lead role would support workforce development by promoting best practice, improving professional education and training, and providing clinical leadership across Wales. This was presented as supporting broader ambitions to strengthen NHS capability and improve service quality.

Prioritising prevention and early intervention – [redacted] highlighted that earlier diagnosis, coordinated care pathways and increased research activity could help prevent deterioration, reduce long-term disability and enable more people to remain active in work, education and their communities. The proposed Research Strategy was described as supporting a shift towards prevention, earlier intervention and the development of improved diagnostics and treatments.

Learning lessons from the Covid-19 pandemic – [redacted] noted that Plaid Cymru's commitment to reviewing Wales' Covid response and strengthening future preparedness aligns with the request that post-viral illnesses and the long-term consequences of infection be explicitly considered in future pandemic planning and public health strategies.

[redacted] concluded that the four key asks provide a practical framework for delivering manifesto ambitions around reducing health inequalities, strengthening leadership, improving prevention, and ensuring people with ME and Long Covid receive consistent, high-quality care across Wales. [redacted] emphasised that these proposals offer an opportunity for Wales to demonstrate leadership in addressing the challenges of post-viral illness.

5. Final Thoughts

[redacted], on behalf or participants, thanked the Cabinet Secretary for his time and engagement throughout the meeting.

Reference was made to the Senedd debate on Severe and Very Severe ME in December, during which the Cabinet Secretary acknowledged the lack of a clear national strategy and highlighted the need for a robust plan, clear direction and meaningful co-production. Attendees noted that these principles align closely with the requests presented during the meeting.

The group recognised the broad cross-party support expressed during the debate but observed that limited visible progress had been made since then, largely due to the impact of the recent election period.

Participants requested that, if the Welsh Government is supportive of the proposals presented, progress is accelerated so that by the end of the year:

- A National Expert Working Group for ME and Long Covid is established.
- All-Wales Clinical Lead(s) for ME and Long Covid are appointed.
- A clear timeline for developing a National Strategy and Delivery Plan is agreed.

[redacted] emphasised that people living with ME and Long Covid in Wales have been waiting too long for coordinated action and improved services. They highlighted the significant expertise available within patient communities, charities, carers, healthcare professionals and the NHS, and expressed confidence that Wales has an opportunity to become a leader in developing effective, compassionate and evidence-based models of care.

The discussion concluded with a focus on the practical impact of change, stressing that the ultimate goal is to ensure that people living with ME and Long Covid, their families and carers receive the support, care and recognition they need and deserve.

The presentation concluded by inviting the Cabinet Secretary to share his reflections on the issues raised and to ask any questions of the group.

6. CMHC Response

CMHC thanked participants for their powerful contributions, highlighting the value of both evidence and lived experience (amounting to over 100 years across participants).

CMHC asked participants about their experiences of Adferiad Services. [redacted] expressed concern about the significant variation in service provision across Wales.

WAMES has repeatedly offered to support health boards with service development, but there has been limited appetite to engage in genuine co-production. Existing services often cover a broad range of conditions without sufficient understanding of the distinct needs of each condition. [redacted] highlighted that greater understanding of ME/CFS, particularly Post-Exertional Malaise (PEM), is required before effective support can be provided. [redacted] proposed the development of standardised training resources for all health boards to ensure consistent messaging and understanding of ME/CFS and PEM across Wales. It was agreed that significant improvements could be achieved through education and awareness.

CMHC asked where there was good practice.

[redacted] informed that both [redacted] and [redacted] heath boards had recently presented their service models, and the audience had been pleasantly surprised as to what they had to offer.

Concerns and areas for improvement identified related to a continued reliance on psychological approaches and historic assumptions linked to graded exercise therapy

The audience had been surprised that [redacted] did not have the information they needed to make a service work whereas [redacted] was a good example.

[redacted] informed that she, [redacted] and [redacted] had spent some time at [redacted]. They had a clearly different and progressive attitude with strong links with their local university and research programmes, active involvement in innovation and service development. It was noted that the health board was due to present research work at a conference in Amsterdam in August.

Concerns were expressed that although the Adferiad service guidance included a requirement for co-production, there was an assumption that health boards would know how to do this. Very few had up-to-date knowledge and therefore carers were forced to do their own research and often knew more than the professionals.

[redacted] UHB had engaged in some discussions but had undertaken no real co-production. Services were largely designed according to professional assumptions rather than patient priorities and they had an old view of ME. They had asked those who had been involved in their services to join focus groups and had indicated that they were working towards co-production.

Participants emphasised that service design should begin by asking patients, "What is important to you?". Strong consensus emerged that co-production is the single most important factor in developing effective services. Participants stressed that people living with ME/CFS and Long Covid possess significant expertise through lived experience. It was argued that co-production is especially important for this patient group because many have become knowledgeable advocates and researchers due to gaps in professional understanding. A recurring theme was that carers and patients often know more about the condition than health professionals because they have been forced to seek information independently.

[redacted] highlighted that the [redacted] model is regarded by some as one of the better examples of how services are delivered and there is a potential there to share good practice with other health boards. He understands [redacted] was the last of the Long Covid services to be established because time was taken to undertake meaningful co-production before implementation. Co-production was identified as a key factor required to ensure future investment delivers meaningful outcomes.

He noted that existing services revolve largely around rehabilitation services. While he feels there is a place for those services, rehabilitation-focused approaches alone are insufficient to address the full needs of people with ME/CFS and Long Covid. There is a concern that some patients might still be offered graded-exercise therapy which can cause further harm.

There was a distinction made between the NICE guidelines for ME/CFS and Long Covid. [redacted] pointed out that, while services may use the UK NICE guidelines as a basis for implementing their services, the Long Covid NICE guidelines were last updated in November 2021 and, given the vast amount of research on Covid-19 and Long Covid since then, an update to those guidelines is well overdue.

Lived Experience was shared by [redacted], describing her involvement in [redacted] health board's Chronic Conditions Co-production Group. Although service leads attended meetings, [redacted] reported that service users were not meaningfully asked for their views when services were established.

<redacted>

CMHC asked about collaboration between the four UK nations in relation to knowledge sharing and resource development. [redacted] advised that current collaboration is limited. Existing examples include some joint funding arrangements with Scotland for fellowship programmes and partnerships. Concerns were raised that UK Government delivery plans remain largely England-focused, although devolved administrations have had observer status and some opportunity to contribute. Participants felt there is significant scope for greater strategic collaboration across the UK with shared learning and pooled resources and a coordinated approach to research and service improvement.

It was noted that the UK is well positioned to become a leader in research on ME/CFS and Long Covid. Germany and the Netherlands were cited as examples of countries making substantial investments in research and service development.

CMHC thanked participants for their openness, honesty and constructive contributions. He acknowledged the four key requests identified by participants during the discussion.

Reflecting on [redacted] experience, he recognised the profound frustration experienced by patients and carers and the widespread lack of understanding of these conditions, both publicly and clinically. That care is often perceived as being done "to" patients rather than "with" them and that those living with the conditions are often best placed to inform service design and improvement.

CMHC concluded that, for him, two key themes had emerged - Participants' frustration with the current system and the lack of understanding and support available.

He noted the strong commitment from patients, carers and stakeholders to be part of the solution and work collaboratively to improve services.

7. Next Steps

CMHC confirmed that he would speak with Welsh Government officials to explore how the Adferiad service can be amended and adapted to better meet the needs of people living with ME/CFS and Long Covid.

CMHC reiterated his personal interest in the area and committed to keeping stakeholders informed regarding future policy developments and considerations.

While unable to make any firm commitments at this stage, CMHC expressed a desire to continue discussions and maintain close engagement with stakeholders going forward.

CMHC stated that stakeholders should expect a formal update by **November**.

Whilst concerns were expressed that November felt like a long time to wait for further information which CMHC acknowledged, he explained that he did not want to overcommit or create unrealistic expectations or make promises that could not be delivered. CMHC indicated that if opportunities arise to progress matters sooner, updates would be provided at the earliest opportunity.