MAPPING AND ANALYSIS OF THE MULTIPLE SCLEROSIS WORKFORCE IN WALES

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Shelley Elgin
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We are delighted to support this report, which highlights the complexity of MS service provision across Wales' seven health boards, due to the geography and infrastructure of the nation, in the context of cross-border (Wales and England) and cross-health board service provision.

MS Society Cymru was pleased to bring the voices of the MS community to the report, to highlight the lived experience of individuals navigating this complex health service landscape.

This report collects and collates data from all seven health boards in a way that is not simply available, offering a real opportunity to highlight different approaches and challenges in each of the health boards.

We are glad that there are tangible, tailored recommendations offered for each health board – the report highlights the need for leadership that understands the unique context of each service and the wider picture across each distinct area of Wales.

We see the benefit of a whole team approach, breaking down siloes between staff within MS teams, and the benefits of engagement in pilots and clinical trials. We also see how shared business cases between health boards have benefited more MS patients across two health board areas.

The report also shows how business cases do not necessarily add to successfully adopted improvements, where they have not been successfully made.

No one living with MS should be forced to make treatment choices based on avoiding a six-hour road trip to Birmingham for infusions, or wheelchair inaccessible appointment spaces.

We have huge concerns about the lack of MS-specific psychological support. While MS Society Cymru offer some services to help plug this gap, this is funding dependent, and not always available. We know that specialised psychological interventions designed specifically for MS patients result in better outcomes both in terms of CBT (cognitive behavioural therapy) for psychological well-being and MS-related symptoms like fatigue.

We know that seven senior consultants are due to retire over the next five years, and many senior MS specialist nurses are also likely to retire in the next few years – succession planning is paramount to enable the MS community right across Wales to live well with MS.

Although this report does highlight some work of the third sector, we would like to see the neurology/MS teams in each health board work closer with MS Society Cymru and other third sector partners to ensure that patients receive a holistic approach to their care, treatments and wellbeing throughout their newly diagnosis journey and living well with MS, both at clinics and in their communities.

This report comprehensively outlines provision gaps and practical suggestions for how to learn from good practice across Wales' health boards – we must preserve the specialist MS services for the almost 7,000 people in Wales living with MS through ambitious leadership in delivering these improvements for today and the years to come.

Shelley Elgin
Director for Wales, MS Society Cymru

Foreword

Professor Neil Robertson
Professor of Clinical Neurology, Cardiff University

Care of people with MS has been revolutionised over the last three decades, not only with the continued emergence of disease modifying treatments for the inflammatory phase of disease but also, more recently, treatments and research focussed on the progressive phase of disease, neuroprotection, remyelination, and an increasing array of symptomatic treatments. The overall effect has been to reduce relapse rates, slow the accumulation of disability and improve quality of life for patients. However, these advances come at a financial and resource cost which is increasing as a larger proportion of patients are receiving active treatment and a more holistic and comprehensive approach to patient management is adopted. Immunotherapy strategies in particular, are complex and associated with a wide range of adverse effects that require safety monitoring and careful patient counselling. As a result, people with MS are now mainly cared for within the wider structure of regional specialist MS units who are able to offer a wide range of medical expertise. The structure of these units remains variable and highly dependent on local leadership and funding to provide essential services but significant gaps exist and marked gradients of care between regions are evident. The challenges in Wales are also compounded by geography, socioeconomic factors and provision of services from healthcare providers outside Wales.

In this paper we have attempted to document regional numbers of people with MS as well as existing resources across Wales, aiming to identify gaps in services as a blueprint for providing a more equitable service for patients and their carers. I hope this work will provide some interesting insights both for existing specialist units and those planning resource allocation and expansion of existing services. In addition, we hope it will act as an opportunity to develop a more interactive network, sharing best practice and improving communication.

Professor Neil Robertson
Professor of Clinical Neurology, Cardiff University

Executive Summary

Multiple sclerosis (MS) affects over 6,900 people in Wales, with prevalence having risen by 13% since 2019.[1] The evolution of the treatment landscape, with around 20 disease-modifying therapies now available,[2] has had a significant impact on patient outcomes. This evolution however,[3] also requires healthcare systems to adapt to optimise care delivery. In this context, this report provides the first systematic analysis of MS workforce and service provision across Wales, benchmarked against national recommendations, to inform strategic planning and business case development at both regional and national levels.

This comprehensive mapping exercise was commissioned following a 2024 roundtable that identified gaps in understanding MS service resources and workforce across Wales' seven health boards.

Key Findings

This analysis drew on primary evidence collected from MS teams across all seven Welsh health boards, supplemented by data from English providers serving Welsh patients. Through standardised questionnaires and structured interviews with MS specialists (primarily MS nurses), current workforce capacity and service provision were mapped. The findings were benchmarked against national guidelines including the National Neurosciences Advisory Group recommendations, MS Trust caseload standards, and the National Institute for Health and Care Excellence (NICE) guidance for MS management.

Workforce capacity

- Wales has **1.3 whole-time equivalent (WTE) consultant neurologists** per 100,000 population, which is 50% lower than the 2.6 per 100,000 population in the UK as a whole
- MS nurse caseloads average **410 MS patients per WTE nurse** – 30% above the recommended sustainable level of 315 per WTE nurse by the MS Trust[4]
- There is a **succession planning gap:** seven consultant neurologists and eight MS nurses are approaching retirement in the next five years with a limited replacement pipeline

Geographic inequities in care

- Patients can face up to **6-hour round trips** for specialist care, with treatment decisions often influenced by travel constraints rather than clinical need
- **North Wales has the highest caseloads per WTE:** Betsi Cadwaladr patients have lowest consultant access (0.8 WTE per 1,000 MS patients) and highest nurse caseloads (501 patients per WTE) compared to the rest of the health boards in Wales
- **Powys presents unique challenges,** with fragmented care across multiple English and Welsh providers

Service gaps across multidisciplinary teams

- **There is a clinical need for neuropsychologists:** Only Cardiff & Vale and Cwm Taf have MS-specific neuropsychologists, despite depression rates being 2-3 times higher in MS patients[5]
- **No Advanced MS Champions** are deployed across Wales, despite pilot data showing potential savings of £465,376 annually[6] per site
- **Home visit capacity is low across Wales** with only 3 health boards providing domiciliary services, creating barriers for mobility-impaired patients

Variable performance against clinical standards

- While most health boards report meeting NICE guideline timescales, there are inconsistencies in how the recommended pathway is implemented
- **There are disparities in DMT access,** with high-efficacy first-line treatment[7] uptake ranging from 16% (Betsi Cadwaladr) to 70% (Cardiff & Vale). According to the Association of British Neurologists, high-efficacy therapies are considered as those with >50% reduction (or otherwise significant reduction) in relapse rate compared to placebo/comparator

Strategic Recommendations

Based on the key findings, the report sets out a number of recommendations at a health board and national level, aimed at ensuring equitable patient access to standardised MS care across Wales.

1 Establish a new MS specialist centre for mid-Wales

Due to the geography and fragmented MS service for patients in Powys, there is a lack of local accountability for patients who receive care from other health boards. This can have an effect on patient safety monitoring, appointment travel time, and inconsistent commissioning policies, all of which can influence treatment choices and affect patient outcomes. Implementing an independent MS specialist centre for Powys with local responsibility could reduce necessity for patients to seek care from other health boards, allow more efficient inward investment and improve local MS services for local patients.

2 Continue development of independently resourced MS specialist centre in North Wales

Whilst South Wales has three specialist centres, North Wales remains under resourced and is reliant on the Walton Centre, in Liverpool, resulting in patients frequently travelling across national boundaries to access services. This partnership should continue but with a dedicated funding stream for MS services in North Wales, separate from general neurology budgets. Additionally, more sufficient funding and resources should be provided to BCUHB to develop a more locally resourced MS centre in Glan Clwyd hospital. This could reduce the care gradient currently evident across Wales while complementing the Walton Centre's ongoing role. Such investment would likely attract and retain specialist staff and strengthen patient engagement with research opportunities. The current resident specialist team is performing well with the limited resources currently available, however, the development of an additional MS specialist centre in North Wales would enable them to optimise care and provide greater flexbility and sustainability to address the region's challenges.

3 Develop minimum service requirements for healthcare professionals (HCPs) per 1000 patients

Whilst there is guidance from the MS Trust on the recommended patient caseload for MS nurses (315 per WTE nurse), there are no comparable figures for other roles. The service evaluation contributors suggest expanding guidance to encompass consultants and administrative staff. Initial estimates based on data provided from investigators suggest a maximum caseload of 400 per specialist MS consultant, 0.5 WTE secretary per consultant and 2 care coordinators per 1500 patients. Additional work is required to provide caseload estimates for other HCPs including physiotherapists, occupational therapists, and neuropsychologists. Recruitment to all these allied HCP roles remains crucial to enable delivery of a holistic and high-quality MS service.

4 Standardise policy and processes for annual reviews

Availability of several aspects of specialist MS services demonstrate considerable variability across health boards which include patient initiated follow up (PIFU), domiciliary visits, specialised clinics and remote consultations. Whilst these aspects of clinical care are not specifically mentioned in NICE clinical guidelines, they offer benefits for patients in remote locations or with difficulty accessing services and should be provided via a standardised protocol. There was a strong consensus on the value and importance of domiciliary appointments for selected patient groups and support that they should be enabled across all health boards.

5 Implement and encourage an MS specific electronic patient record (EPR) across Wales

Continued development of a national specialist EPR, such as PatientCare and MSBase, should be encouraged. Compatibility of individual systems and how they align with national systems such as the Welsh Clinical Portal (WCP) remains a challenge. PatientCare currently enables all patient data to be available in a standardised format across NHS Wales with approximately two-thirds of all MS patients already registered, offering a realistic goal of engaging all remaining sites. Whilst there are concerns regarding HCP time to input data and a period of frontloading data before it becomes useful, the benefits outweigh these issues and would allow standardised comparison of services. Data input of electronic clinical records should be a component of job descriptions.

6 Prioritise succession planning through engagement and training

A focus on students, resident doctors and other HCPs will be required in order to encourage and identify MS specialists of the future. This can be achieved through engagement with curricula development, expansion of research and clinical trial activity, fellowship programmes and a wider exposure to regional MS specialist teams. All relevant HCP disciplines (i.e. neurologists, physiotherapists, neuroscience nurses etc.) should have dedicated exposure to neuroinflammatory/MS specialist services during their training. These steps could strengthen Wales' reputation for high quality care, attract HCPs and generate a sustainable model for staff appointment and retention.

This mapping exercise reveals variability in MS service provision across Wales, with workforce capacity constraints and geographic barriers creating inequitable care delivery. While some health boards demonstrate excellence in specific areas, the overall system requires coordinated investment and strategic planning to meet the needs of Wales' growing MS population.

The recommendations provide a framework for both immediate improvements and long-term sustainability. Success will require collaboration between health boards, Welsh Government, and patient advocacy groups, supported by sustained investment in workforce development and service infrastructure.

Without coordinated action, the identified workforce crisis and service gaps will worsen, potentially compromising care quality and patient outcomes across Wales' MS community.

Introduction

MS is a chronic, immune-mediated neurological disorder that affects the central nervous system, leading to a wide range of physical, cognitive, and psychological symptoms. In the UK, the prevalence of MS has risen significantly, with over 150,000 individuals currently living with the condition – a nearly 13% increase since 2019.[8] Each year, more than 7,100 people are newly diagnosed, most commonly in their 30s and 40s, with women being two and a half times more likely than men to be affected.[9] The disease imposes a substantial burden on patients, often resulting in progressive disability, reduced quality of life, and increased mental health challenges.[10]

The treatment landscape for MS is rapidly evolving, with around 20 DMTs now available for both relapsing and progressive forms of the disease.[11] Together with other recent advances in MS management, health care provision must adapt to these changes in order to optimise care, which is compounded by a rising number of people living with MS in the UK.[12] In this context a roundtable discussion with healthcare providers who work in MS was organised by Merck in April 2024 to examine the challenges and opportunities for MS service delivery in Wales. Attendees identified four key areas requiring consideration and potentially policy intervention:

- A lack of understanding of Wales' MS service resources and workforce
- The need for clarification of MS service delivery and coverage across and between each health board
- Regional resource disparity for MS services
- Succession planning for the MS workforce, in particular consultants and MS specialist nurses

Objectives

In order to address these challenges, regional MS service leads and representatives from each of the seven Welsh health boards agreed to map the workforce across MS specialist services in Wales and to explore the potential for future developments. One of the aims of this work was to develop an accurate picture of current MS service provision in Wales, and to enable current services to be compared to national recommendations and standards. This report sets out the findings from this mapping exercise, including:

- **An overview of the MS workforce and MS specialist care provision across Wales**
- **Health board specific MS workforce and specialist care provision with key insights and gap analysis**
- **A set of key themes and future recommendations for improving and developing MS care and services in Wales**

This report has been developed for Welsh MS services as a tool to benchmark current provision to support business case development; ensure regional and national policy makers support clinical services; and enable best practice for MS care in Wales.

Methodology

The development of this report used a combination of primary evidence collection (in the form of questionnaires and interviews) and desk research. The methods, results, findings, limitations, and recommendations are detailed below.

Primary evidence collection

Primary evidence was collected through a mixed-methods approach combining structured questionnaires and telephone interviews. MS teams were asked to complete a standardised set of questions (Appendix 1). Following collation of initial responses, structured telephone interviews were conducted with each regional MS team to validate submitted data and gather additional qualitative insights to provide contextual understanding. After review of these responses and interviews, supplementary questions were distributed via Microsoft Forms to regional investigators, followed by a final verification telephone interview to confirm accuracy and completeness.

Evidence was gathered from MS clinical teams providing care across the seven Welsh health boards. As MS care is frequently delivered across healthcare borders — and in some cases is partly or wholly provided by services in England — relevant English clinical services were also contacted. Two to three specialist staff members were interviewed from each of the following services:

- For **Aneurin Bevan University Health Board (ABUHB),** the ABUHB MS team
- For **Betsi Cadwaladr University Health Board (BCUHB),** the Walton Centre Foundation Trust MS team
- For **Cardiff & Vale University Health Board (CVUHB)**, the CVUHB MS team
- For **Swansea Bay University Health Board (SBUHB),** the SBUHB MS team
- For **Hywel Dda University Health Board (HDUHB),** the SBUHB MS team
- For **Cwm Taf Morgannwg University Health Board (CTMUHB),** the CVUHB and SBUHB MS teams
- For **Powys Teaching Health Board (PTHB),** the Royal Wolverhampton Trust MS team; the Wye Valley Trust MS team; and the MS teams at ABUHB, the Walton Centre, CVUHB and SBUHB. Although some Powys patients are seen at Stoke, data from this site were not available.

The standardised questionnaire and interviews covered the following areas:

- Current MS workforce
- Succession planning
- Workforce and service gaps
- Specialist MS services
- MS clinic and service locations
- Recommendations to address identified challenges

Secondary research and patient survey

In order to effectively analyse the data on workforce and service provision, it was agreed that this report would evaluate each health board's MS workforce and service against national recommendations and guidelines. The primary metrics used were:

- **To assess workforce roles: The National Neurosciences Advisory Group** 'Optimal clinical care pathway for adults with MS' recommends the following:[13]
  - MDTs for people with advanced MS should have: local, community based, neuro-rehabilitation team with a designated lead for MS, occupational therapists (OTs), psychologists, physiotherapists, MS nurse, speech and language therapist (SLT), dietician, designated team administrator, and a link to rehabilitation medicine specialist
  - MDTs allowing clinical guidance for DMT provision should have: a minimum of two specialist neurologists, MS nurses, pharmacist, radiologist, administrator/co-ordinator and preferably a non-medical prescriber (pharmacist or MS nurse) to support the neurologist
- **To assess caseload: The MS Trust's MS Nurse Mapping 2021,** which recommends the following for sustainable caseloads:[14]
  - 315 MS patients per MS WTE specialist nurse
  - Administrative support of 0.6 WTE per MS nurse
- **To assess service provision: The NICE guidance for management of MS in adults,**[15] with a focus on the following three guidelines:
  - Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis
  - Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms
  - Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year

Additionally, to help analyse the impact of services on the MS patient population, Merck worked with the MS Society Cymru to share a survey of questions with their patient network.

The survey was collated using Microsoft Forms and the survey questions were developed by Merck in collaboration with MS Society Cymru. It was an anonymous short survey with 6 questions (Appendix 2) including multiple choice and freeform answers. The questions focused on patients' experience of accessing healthcare services in Wales, what works well and what are some of the challenges or barriers they face.

The survey was shared with MS Society Cymru's network of groups, volunteers and supporters across Wales via e-mail, social media and word of mouth. It was open for 4 weeks between 10th March and 6th April. We received 20 responses to the survey with responses from across Wales. The anonymous responses were collated into a spreadsheet and shared with Merck. The responses demonstrated the range of experiences patients receive depending on where they are in Wales and what stage of the diagnostic journey they are at.

Limitations

This report was based on thorough and detailed interviews with investigators from each health board. However, the service evaluation does come with limitations:

- All data was self-reported by investigators. As a result, the data is open to human error, and some more qualitative data (for example on the three biggest workforce gaps) could be the subjective opinion of the investigators involved in the project at each site
- Investigators at each site highlighted the limitations of their service's patient data with some sites acknowledging they were not fully up to date
- There are some data gaps across the report:
  - We were not able to estimate the proportion of patients prescribed high-efficacy[7] DMT (as defined by the Association of British Neurologists) first line or the the proportion of patients who had ever received a DMT across some health boards, and as such accurate comparison across the health boards could not be drawn
  - Data from Powys is also incomplete and derived from data obtained from Royal Wolverhampton, Wye Valley, Walton Centre and the other six Welsh health boards. Despite our best endeavours, we were also not able to gather data from Stoke which supports a significant portion of patients from Powys
  - Numbers of clinics were estimated but may have been affected by external factors including annual, study and sickness leave

Results

Wales overview

The population in Wales of approximately 3.17 million[16] is served by a healthcare system that faces distinctive geographical and socioeconomic challenges. The Welsh Index of Multiple Depravation (WIMD) shows the most deprived fifth of localities are in post-industrial communities of South Wales and certain coastal areas.[17] These patterns of deprivation significantly affect health outcomes with Public Health Wales reporting an 8.6-year gap in healthy life expectancy between the most and least deprived regions.[18]

The healthcare landscape across Wales varies considerably, as highlighted throughout this report. Urban centres like Cardiff, Newport and Swansea benefit from concentrated services and specialist facilities. In contrast, post-industrial valley communities face high rates of chronic illness coupled with limited access to services.[19] Furthermore, in rural areas in mid and north Wales patients contend with extended travel times to healthcare centres and workforce challenges in recruiting specialist staff. As a result, and to address the rural-urban divide, healthcare delivery in Wales is commissioned and provided by seven local health boards that are responsible for integrated hospital, community, and primary care services.

MS care in Wales

There are an estimated 6,904 people with MS in Wales,[20] which is above the reported 6,643 total patient caseload reported by the regional investigators that were engaged as part of this project (Table 1).

Table 1: Estimated prevalence of MS by health board and patient case load reported by the investigators

Health Board	Estimated prevalence (no. patients)[11]	Caseload reported by investigators (includes all subtypes of MS)
Aneurin Bevan University Health Board	1,320	1169
Betsi Cadwaladr University Health Board	1,534	1153
Cardiff and Vale University Health Board	1,149	1,104
Cwm Taf Morgannwg University Health Board	990	1,177
Hywel Dda University Health Board	749	891
Powys Teaching Health Board	298	386
Swansea Bay University Health Board	864	763
TOTAL	**6,904**	**6,643**

The provision of MS care varies across each health board, with some offering comprehensive local services, whilst others depend on cross-border arrangements between health boards and in some cases with England, and support from multiple providers.

The largest MS service providers in Wales are CVUHB, SBUHB and ABUHB. Patients in other health boards access MS care through a mix of these providers, as well as from local non-specialised services and specialist MS services based in England, such as the Walton Centre in Liverpool. Patients in Hywel Dda, Cwm Taf, and Betsi Cadwaladr rely on access to MS services in centres outside their health board. Patients from Powys access MS care through multiple providers across different Welsh health boards and the English National Health Service (NHS), creating a more fragmented care pathway for their patients.

Wales MS workforce overview

Investigators based their reporting of the MS workforce on whole time equivalent (WTE) staff. According to investigators' reports, there are 11.1 WTE consultant neurologists with a specialist interest in MS and related disorders (although not all of this time is spent delivering specialist MS services) and 16.2 WTE MS nurses for the 6,643 MS patients in Wales.

Table 2: The total Wales whole-time equivalent (WTE) workforce based on the combined health board WTEs reported by the investigators

Combined Wales WTE	WTE
Consultant MS neurologists	11.1
MS nurse specialists	16.2
Neuro-pharmacists	4.3
MS occupational therapists	1.6
Neuropsychologists	1.0
Neuro-physiotherapists	6.7
Non-clinical administrative staff	15.4
Advanced MS Champions	0.0

International comparison

For MS nurses this equates to an average patient caseload of 406 per 1.0 WTE MS nurse in Wales. This compares favourably to the UK as a whole (472 patients per WTE MS nurse).[12] However, it is important to note that the patient caseload remains above the MS Trust's recommended sustainable caseload of 315 patients per MS nurse.[21]

Whilst nurse patient caseload ratios remain on average lower in Wales compared to the rest of the UK, access remains difficult due to the rural geography of Wales and high levels of deprivation.[17]

A 2024 survey of Wales neurological (non-MS specific) services, found there are 1.3 WTE consultant neurologists per 100,000 population in Wales.[22] This is 50% lower than the 2.6 per 100,000 population in the UK from 2022 data.[23] Similarly, when compared to the European average of 9 neurologists per 100,000 population, Wales was lower.[20]

When compared with other World Health Organisation (WHO) European countries, Wales has one of the lowest ratios of neurology consultants per population globally. The only countries with a lower ratio than the UK, were Ireland (1.3) and Uzbekistan (2.3). All other comparator countries had a higher ratio: Germany (13.4), Netherlands (7.8), Spain (7.8), France (4.5) and a WHO European average of 9 per 100,000 population.[20]

Health board comparison

A detailed breakdown and analysis of the workforce in each health board is given in the following sections. Below is a topline analysis of the MS workforce accessed by the patients in each health board across all of Wales.

Table 3: The current whole-time equivalent (WTE) workforce per 1,000 MS patients across each health board*

● indicates WTE is above Wales average, ● indicates that it is on par (+-0.1) with the average, ● indicates it is below Wales average

Workforce per 1,000 MS patients	Aneurin Bevan	Betsi Cadwaladr	Cardiff & Vale	Cwm Taf	Hywel Dda	Powys	Swansea Bay	Wales Average**
Consultant MS neurologists	2.2 ●	0.8 ●	2.1 ●	2.0 ●	1.5 ●	1.1 ●	1.6 ●	1.7
MS nurse specialists	3.3 ●	2.0 ●	2.4 ●	2.4 ●	2.5 ●	2.4 ●	2.6 ●	2.5
Neuro-pharmacists	1.6 ●	0.2 ●	0.5 ●	0.5 ●	0.5 ●	0.6 ●	0.5 ●	0.7
MS occupational therapists	0.0 ●	0.4 ●	0.5 ●	0.4 ●	0.0 ●	0.3 ●	0.0 ●	0.3
Neuropsychologists	0.0 ●	0.0 ●	0.5 ●	0.4 ●	0.0 ●	0.0 ●	0.0 ●	0.2
Neuro-physiotherapists	0.0 ●	2.0 ●	0.9 ●	0.9 ●	1.0 ●	1.6 ●	1.1 ●	1.0
Non-clinical administrative staff	2.8 ●	1.5 ●	2.8 ●	2.6 ●	1.8 ●	3.1 ●	1.2 ●	2.3
Advanced MS Champions***	0.0 ●	0.0 ●	0.0 ●	0.0 ●	0.0 ●	0.0 ●	0.0 ●	0.0

**The numbers combine WTE from all providers for MS patients in that health board.*
***The Wales average is worked out from the total WTE reported for patients in each health board and on the reported caseload of 6,643.*
****For further information on Advanced MS Champions, please refer to: Advanced MS Champion programme.[24]*

The data provided by MS teams highlights that workforce in terms of WTE is not standardised across all health boards.

Compared with other health boards Aneurin Bevan, Cwm Taf and Cardiff & Vale are above, or on par with, the Wales average of WTE for consultant MS neurologists and MS nurse specialists. Betsi Cadwaladr and Powys have the most limited coverage (based on total combined number of consultant MS neurologists and MS nurse specialists). For Betsi Cadwaladr, this is evident in the higher MS nurse caseload (501 patients per WTE nurse).

In addition, specialist neurology registrars working in Wales had traditionally rotated through specialist MS services to gain experience in this subspeciality, but exposure to this training opportunity has become more limited with other neurological conditions taking priority and, as a result has implications for both service provision and succession.

As reported by one of the investigators, many specialist MS consultants currently working in Wales, were appointed around 30 years ago as a result of a national focus on MS and availability of new treatments. However, many of these consultants are now approaching retirement, with no clear pathway and capacity for succession.

Table 4: The MS nurse case load in each health board, and the whole-time equivalent (WTE) administrative support per WTE nurse

● indicates that the nurse caseload is below the MS Trust recommendation, ● indicates that it is above the MS Trust recommendation. For administrative support green indicates it is above the recommended WTE.

	MS nurse caseload (315 cases per nurse is recommended by the MS Trust)	Administrative support per WTE nurse (0.6 is recommended by the MS Trust)
Aneurin Bevan	307 ●	0.9 ●
Betsi Cadwaladr	501 ●	0.7 ●
Cardiff & Vale	418 ●	1.2 ●
Cwm Taf	484 ●	0.9 ●
Hywel Dda	405 ●	0.7 ●
Powys	417 ●	1.3 ●
Swansea Bay	381 ●	0.8 ●
Wales average	**410** ●	1

Although MS specialist nurses and consultant MS neurologists are two key components of MS service provision, high quality services also require engagement with a wide range of disciplines. The data also indicates workforce gaps across Wales in some of these areas:

1 **Neuropsychologists**

Only patients in Cardiff & Vale and Cwm Taf (on account of Cardiff & Vale providing full MS services to 900 patients in Cwm Taf) have access to an MS specialist neuropsychologist. However, even for patients in these health boards, investigators reported long waiting lists – at times over 12 months – for both specialist and general neuropsychology support. As a result, almost all MS patients in Wales have difficulty accessing MS-specific psychological support.

The context for this is important to understand since depression rates are 2-3 times higher in MS patients than the general population,[25] with anxiety affecting approximately 40% of MS patients.[26] It is generally agreed that specialised psychological interventions designed specifically for MS patients have better outcomes than general approaches, with tailored cognitive behavioural therapy demonstrating improvements in both psychological well-being and MS-related symptoms including fatigue.[27]

This evidence has informed clinical guidelines, with the NICE guidelines[20] explicitly recommending psychological assessments and interventions as essential components of MS management.[28] Similarly, the Royal College of Physicians emphasise that multidisciplinary care, including neuropsychological support, represents the standard of care for MS patients.[29] The absence of neuropsychologists in Wales creates a service gap that contradicts both evidence-based practice and established clinical guidelines for MS care.[20]

2 Advanced MS Champions[30]

No health boards in Wales have Advanced MS Champions as part of their MS service, despite the success of the 2022 MS Trust pilot of Advanced MS Champions which took place across six trusts in England and Wales (including Swansea) and found that, on average, each site saved:[31]

- 52 hospital admissions annually
- £465,376 annually
- 403 emergency bed days annually
- 91 MS Specialist Nurse appointments annually
- 115 GP appointments annually

It is important the value of these posts is understood by health care providers, and consideration should be given to Advanced MS Champions in future business cases.

3 MS specific pharmacists

With the exception of Aneurin Bevan and Cardiff and Vale, all health boards in Wales lack dedicated MS pharmacists.

There are now over two dozen MS drugs within nine diverse drug classes.[32] The impact of these DMTs on services varies considerably across posology, administration routes, monitoring protocols and risk management strategies that require specific expertise. As access to DMTs in Wales grows, all investigators highlight a continued and increasing need for dedicated MS pharmacist support; an important service gap which may have implications for drug safety.

Overview of symptom management and specialist clinic provision

Specialist services

Table 5: Available specialist services by health board

🟢 *indicates the service is available,* 🟠 *indicates that it is partially available,* 🔴 *indicates that it is not available*

Clinic	Aneurin Bevan	Betsi Cadwaladr	Cardiff & Vale	Cwm Taf	Hywel Dda	Powys	Swansea Bay
Fampridine	🟢	🟢	🟢	🟢	🟢	🟠*	🟢
Nabiximols	🟢	🟢	🟢	🟢	🟢	🔴	🟢
Sexual dysfunction	🟢	🔴	🟢	🟢	🟢	🟠**	🟢
Bowel and bladder dysfunction	🟢	🟢	🟢	🟢	🟢	🟢	🔴
Spasticity	🟢	🟢	🟢	🟢	🟢	🟠*	🔴
Neuro-rehabiliation	🟢	🟠	🟢	🟢	🟢	🔴	🔴
Home visits	🔴	🟢	🟠	🟠	🟢	🟠**	🟢

*Available in North Powys, but not South Powys.

**Available in South Powys, but not North Powys.

Table 6: The percentage of patients in each health board that have ever received disease modifying therapies (DMTs) and those that are on a high-efficacy[7] DMT first line*

	Patients ever received a DMT	Patients on a high efficacy DMT first line	Patient numbers
Aneurin Bevan	87%	80%	1,169
Betsi Cadwaladr	34%	16%	1,153
Cardiff & Vale	73%	70%	1,104
Cwm Taf	N/A	86%	1,177
Hywel Dda	N/A	83%	891
Powys	76%	22%	386
Swansea Bay	N/A	86%	763

**Note, Betsi Cadwaladr figures do not include natalizumab or alemtuzumab.*

Whilst most specalised services in Table 5 are available across Wales, there are gaps in provision for Betsi Cadwaladr and Powys patients. Table 6 demonstrates the variability in access to DMTs across health boards.

Despite having just below average workforce numbers (see Table 3), patients in Powys have limited access to the specialised services that patients in other health boards benefit from, including elatively limited access to high-efficacy DMTs as defined by the Association of British Neurologists (natalizumab, alemtuzumab, ocrelizumab, cladribine and ofatumumab).[7]

Home visits

Another gap across most of Wales is provision of home visits. Many MS patients (such as elderly patients or those with advanced disease*) experience mobility limitations, and clinical visits can become a barrier to care.[33] This is a particular issue in Wales as a result of large rural expanses with limited transport options. For some patients with prolonged travel times to specialist clinics this significantly influences DMT choices, as reported by investigators.

Home visits could mitigate some of these challenges whilst also enabling healthcare professionals to assess patients in their everyday environment, identifying practical barriers to self-management and medication adherence that might go undetected in clinical settings.[34] Research suggests that MS patients receiving regular home visits report greater satisfaction with their care and improved quality of life outcomes compared to those attempting to manage with clinic visits alone.[35]

Despite an identified need, access to home visits is limited in Wales with only three health boards reporting a functioning service. Only South Powys suggested that home visits played a central role in service provision.

This section has outlined the trends seen across Wales, below sections include an evaluation of the workforce, access to services, gaps within the service, and key challenges reported by the investigators for each health board.

**A stage in the progression of MS marked by the accumulation of severe and persistent symptoms.*

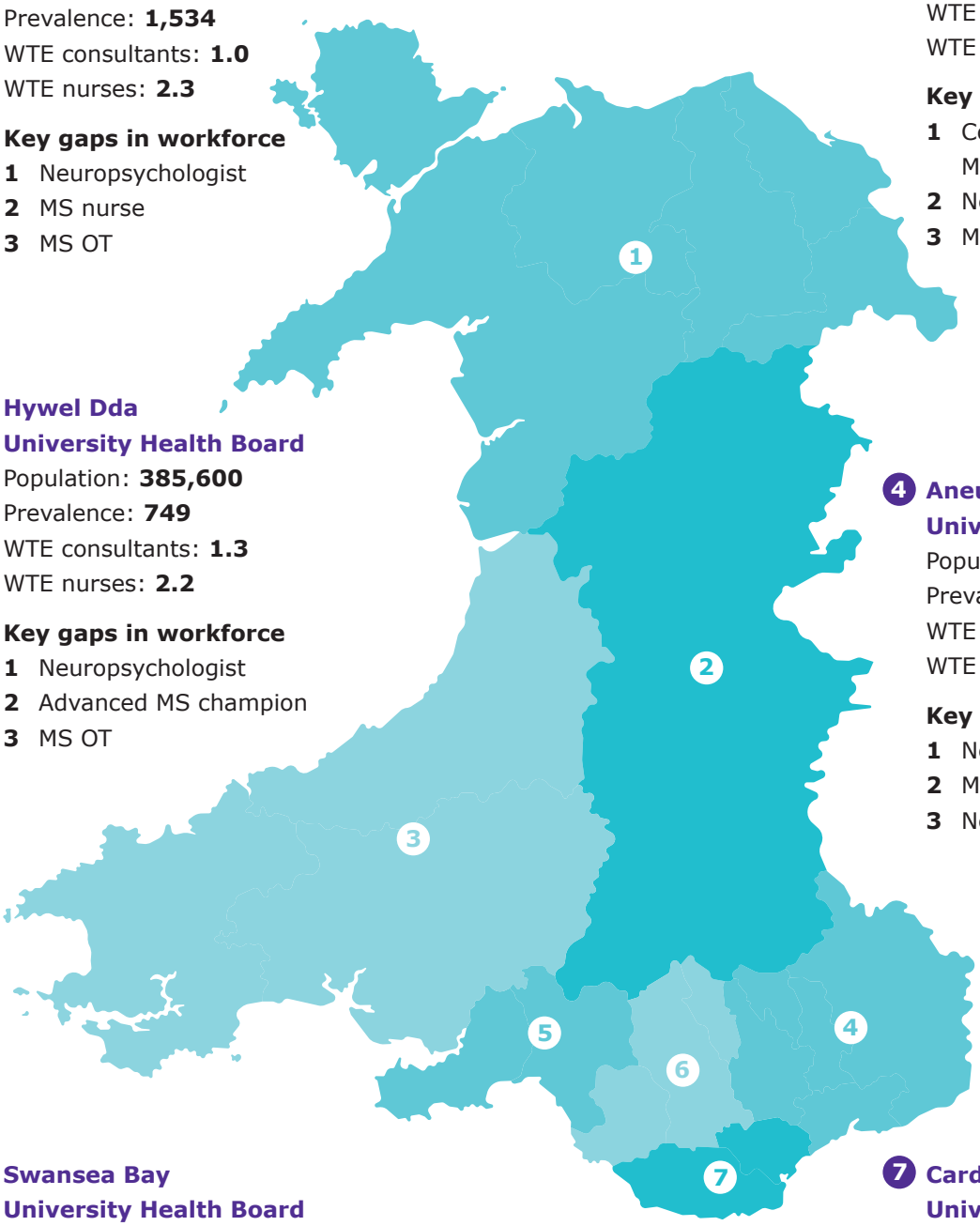
Local health board MS services topline findings

1 Betsi Cadaladr University Health Board
Population: **700,000**
Prevalence: **1,534**
WTE consultants: **1.0**
WTE nurses: **2.3**

Key gaps in workforce
1 Neuropsychologist
2 MS nurse
3 MS OT

2 Powys Teaching Health Board
Population: **133,000**
Prevalence: **298**
WTE consultants: **0.4**
WTE nurses: **0.9**

Key gaps in workforce
1 Consultant MS neurologist
2 Neuropsychologist
3 MS nurse



3 Hywel Dda University Health Board
Population: **385,600**
Prevalence: **749**
WTE consultants: **1.3**
WTE nurses: **2.2**

Key gaps in workforce
1 Neuropsychologist
2 Advanced MS champion
3 MS OT

4 Aneurin Bevan University Health Board
Population: **600,000**
Prevalence: **1,320**
WTE consultants: **2.6**
WTE nurses: **3.8**

Key gaps in workforce
1 Neuro-rehabilitation
2 MS pharmacist
3 Neuropsychologist

5 Swansea Bay University Health Board
Population: **390,000**
Prevalence: **864**
WTE consultants: **1.2**
WTE nurses: **2.0**

Key gaps in workforce
1 Neuropsychologist
2 Advanced MS champion
3 MS OT

6 Cwm Taf Morgannwg University Health Board
Population: **450,000**
Prevalence: **990**
WTE consultants: **2.29**
WTE nurses: **2.9**

Key gaps in workforce
1 Neuropsychologist

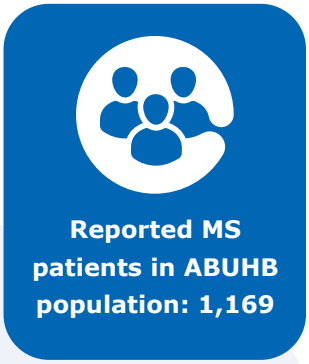
7 Cardiff and Vale University Health Board
Population: **472,400**
Prevalence: **1,149**
WTE consultants: **2.31**
WTE nurses: **2.64**

Key gaps in workforce
1 MS nurse
2 Neuropsychologist
3 MS pharmacist

Aneurin Bevan University Health Board

Health board context

ABUHB covers a population of approximately 600,000 across Blaenau Gwent, Caerphilly, Monmouthshire, Newport and Torfaen.[36] Despite covering a much smaller geographical area than the other health boards in West Wales, Aneurin Bevan still provides care for a mix of rural, urban and valley communities. With only 5% of the health board's area falling into the most deprived 10% of Wales, it covers a less deprived population than other health boards.[37]



The health board predominantly provides MS services for patients in Aneurin Bevan itself but also for 71 patients residing in Powys who travel to Aneurin Bevan for care. This section sets out the workforce and services that are accessed by the 1,169 Aneurin Bevan patients with a confirmed MS diagnosis. Provision for patients from Powys is covered in the Powys section.

Current workforce

Following two years of negotiation with Aneurin Bevan's executive board, the MS service recently received funding for additional team headcount. The successful business case secured £5 million in funding for infrastructure and drug costs over two years for the addition of:

- 2 MS coordinators
- 1 MS specialist nurse
- 1 consultant MS neurologist

The WTE workforce set out below includes these additional positions:

Table 7: The current whole-time equivalent (WTE) workforce for Aneurin Bevan University Health Board patients and the equivalent per 1,000 MS patients

● indicates WTE is above Wales average, ● indicates that it is on par (+-0.1) with the average, ● indicates it is below Wales average

Workforce	WTE	WTE per 1,000 MS patients	Wales average
Consultant MS neurologists	2.6	2.2 ●	1.7
MS nurse specialists	3.8	3.3 ●	2.5
Neuro-pharmacists	1.9*	1.6 ●	0.7
MS occupational therapists	0.0**	0.0 ●	0.3
Neuropsychologists	0.0	0.0 ●	0.2
Neuro-physiotherapists	0.0	0.0 ●	1.0
Non-clinical administrative staff	3.3	2.8 ●	2.3
Advanced MS Champions	0.0	0.0 ●	0.0

*There are two neuro-pharmacists that work across the health board, including for the MS service.

**The MS service has access to the neurology occupational therapy (OT) team.

Top 3 priority workforce gaps

1 **Neuro-rehabilitation**
Neurorehabilitation is only available in Aneurin Bevan for stroke patients and patients with any other neurological condition requiring neurorehabilitation must be referred to Cardiff, which can take weeks or months. For outpatient support in Aneurin Bevan, patients will be seen by a general physiotherapist or occupational therapist.

2 **Dedicated MS pharmacist**
Although Aneurin Bevan has two neurology pharmacists, the service could benefit from a dedicated MS pharmacist who could offer additional support with prescriptions and blood monitoring, the management of which currently falls on consultants and nurses, adding to their workload.

3 **Neuropsychology**
With no neuropsychologist in Aneurin Bevan, the MS service must refer patients to Cardiff where there is only one neuropsychologist who supports patients across Cardiff & Vale, Cwm Taf, and Aneurin Bevan. Long waiting lists mean it can take over a year for patients to be seen. As such, the team only refers patients in critical need and attempts to address this gap through primary care and the voluntary sector, for example via MS Society Cymru. Despite these efforts, neuropsychology was highlighted as a gap by patients in the MS Society Cymru survey.

Current services and treatment provision

Map 1: MS service locations that can be accessed by ABUHB patients

1 **Nevill Hall Hospital**
Consultant clinics
MS nurse clinics
Infusion clinic

2 **County Hospital**
MS nurse clinics

3 **Ysbyty Ystrad Fawr**
MS nurse clinics
Consultant clinics

4 **Royal Gwent Hospital**
Main MS hospital
Majority of consultant clinics and MS nurse clinics

5 **University Hospital**
Neuro-rehabilitation

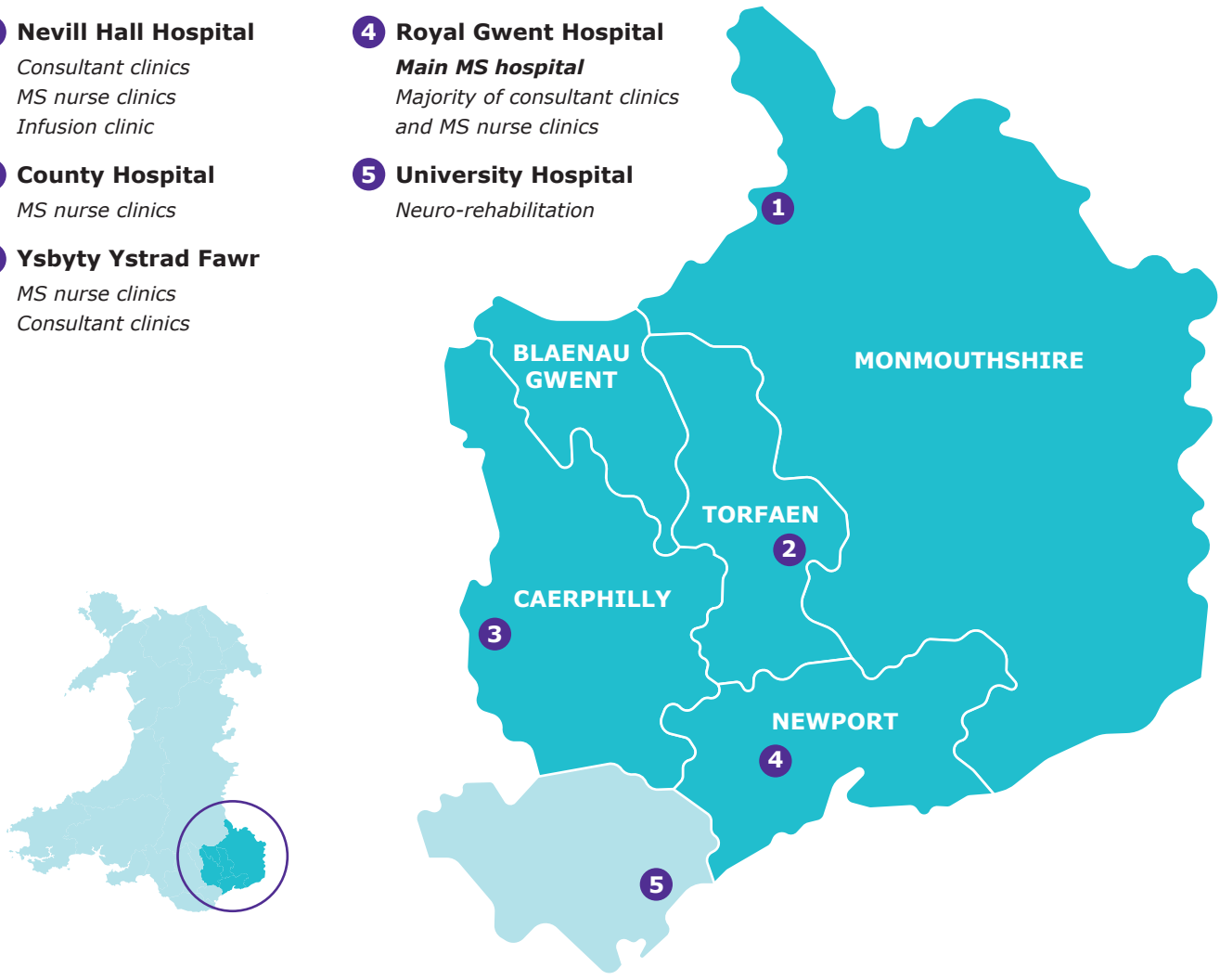


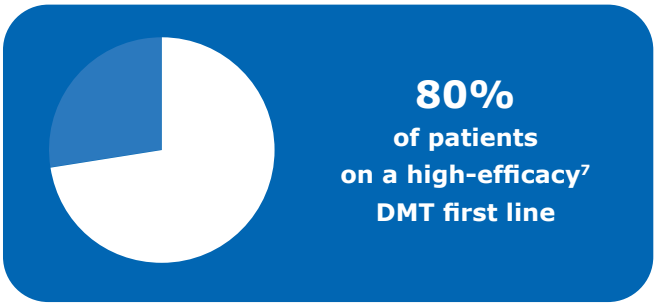
Table 8: The number of consultant and MS nurse clinics and templates

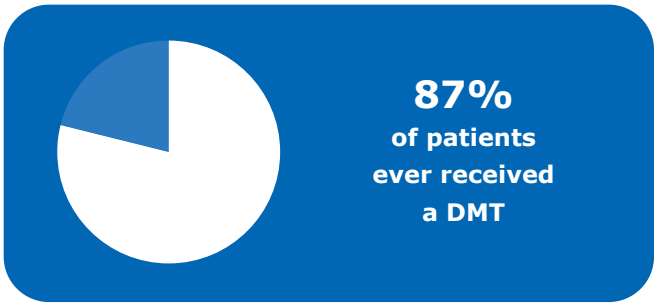
	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	Face-to-face: 4	Face-to-face: 2 new, 5 follow-up	Face-to-face: 208	Face-to-face: 1,456 (516 new, 1,040 follow-up)
	Virtual: 1	Virtual: 2 new, 5 follow-up	Virtual: 52	Virtual: 364 (104 new, 260 follow-up)
	Total per week: 5		**Total: 260**	**Total: 1,820**
MS nurse clinics	Face-to-face: 7	Face-to-face: 1 new, 5 follow-up	Face-to-face: 84	Face-to-face: 504 (84 new, 420 follow-up)
	Virtual: 7	Virtual: 6 follow-up	Virtual: 84	Virtual: 504 (all follow-up)
	Total per month: 14		**Total: 168**	**Total: 1,008**

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*

Table 9: The investigator reported performance of Aneurin Bevan University Health Board against the National Institute for Health and Care Excellence (NICE) guidelines

NICE guideline[38]	Performance	Further details
Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis	100%	N/A
Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks as early as possible and within 14 days of onset of symptoms	100%	N/A
Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year	48%	This 48% includes a mixture of virtual and face-to-face clinics





Overview and analysis

Based on interviews with the MS team at ABUHB, this section sets out further details of MS service provision across the health board, with a particular focus on resource challenges and gaps which, if addressed, could support the team to optimise their service:

Dataset challenges

As a result of previous under-resourcing and limited administrative support, the ABUHB MS service acknowledges that their patient register/database is incomplete and requires updating. The team has robust data for patients on DMTs or with early-stage (where symptoms are mild or intermittent) disease – with their active total patient caseload of 1,238 patients across Aneurin Bevan and Powys falling into this cohort. However, they suspect that their actual patient caseload is closer to 1,500 with patients not on treatment or with progressive MS missing from the database.

The analysis in this section is based on the data provided and must be caveated by its incompleteness.

Workforce gaps

Despite the successful business case (covered below in further detail) which has increased team headcount and addressed some workforce gaps, there remains a number of core MS MDT paraclinical roles that do not exist in the service or that ABUHB patients have challenges in accessing, including neuro-physiotherapy, neuropsychology, an MS specific OT, and an Advanced MS Champion.[39] Whilst access to these services (apart from ACC access) is covered through ABUHB's general teams (e.g. general physiotherapy and neurology OT team) or through referral to Cardiff, the investigators reported long waiting lists, meaning ABUHB's MS patients have reduced access to these elements of care. In response to the MS Society Cymru's patient survey, (n=20) two thirds of responders using Aneurin Bevan's MS services highlighted that they would like increased access to neuro-physiotherapy and occupational therapy services. The team acknowledges that they have used the business case to address gaps in the core MS team and that they then hope to turn attention to the wider MDT.

Additional capacity pressures on MS nurses

Whilst the additional MS nurse headcount from the business case provides much-needed additions to the team making ABUHB the only health board with an MS caseload below the recommended 315 patients per nurse, there remains additional pressure on the service's MS nurses with ongoing issues that impact nursing capacity including:

- **Lack of infusion nurses**
  Only one infusion nurse is currently in post. Funding for a second nurse was agreed however, before this vacancy could be filled, the original infusion nurse resigned. With no infusion nurses currently in place (despite funding for two), the MS nurse team is used for infusions which has a knock-on impact on their clinics and workload.
- **Non-MS clinical demand**
  Whilst the service does not report non-MS clinical demand to be huge, there are patients with neuromyelitis optica (NMO), myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD), sarcoidosis and other neuroinflammatory diseases that take up the time of MS nurses. With no other specialist nurses for these patients, the MS nurses manage telephone advice and pass requests on to neurologists.
- **MS nurse team approaching retirement**
  Although the service predicts only one partial retirement in the MS nurse team in the next 5 years, it is worth noting that all nurses are band 7s, and therefore in the next 10 years, the team expects two further retirements of these senior level nurses. There are also concerns around the lack of newly qualified nurses coming through making recruitment and succession planning very difficult. The service notes that it is taking steps to improve succession planning.

Travel challenges for patients despite a smaller geographical area

ABUHB covers a smaller geographical area than other health boards and the service has taken steps to ensure equitable service access with nurse led clinics held across the health board and plans to have them in more hospitals going forward. Access to consultant clinics is more limited but the new consultant will be based in North Gwent which will provide access across a wider geography. However, although these challenges appear less than in the other health boards it's important to note that patient feedback to MS Society Cymru's patient survey (n=20) still flagged travel as an issue with two patients highlighting distance as a challenge and one patient who lives in Blaenau Gwent responding that:

"Without a car, some [or] all of the appointments would be extremely difficult"

MS Society Cymru patient survey responder from Blaenau Gwent

Lessons from the Aneurin Bevan University Health Board

Positive impact of the successful business case

Although the team noted that it may take a while to see the full impact of the successful business case and to reverse ten years of underfunding, they are optimistic about its potential to enable ABUHB to address service challenges and are already seeing some immediate impact, including that:

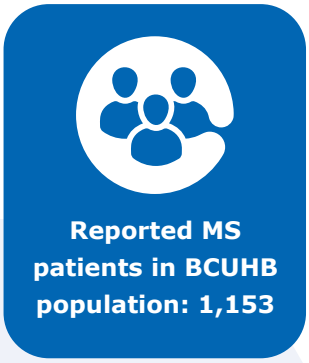
- The additional MS nurse enables a more manageable patient caseload of 307 patients per WTE, which is within the MS Trust's recommendation of 315 patients per MS nurse WTE[40]
- The nurses' capacity is further supported by the two new non-clinical administrative staff, with 0.9 WTE per WTE MS nurse, which is also within the MS Trust's recommended sustainable caseload. The team hopes this additional administrative support will allow the service to address the gaps in their database. The addition of one WTE nurse is also expected to enable the provision of a domiciliary service to the approximately 100 MS patients in ABUHB who are house bound. Whilst these patients currently access the service through telephone clinics, as noted already in this report, there are limitations to assessing disease progression virtually and provision of home visits has the potential to improve care for these patients

The impact of the ABUHB MS service's successful business case is an important case study for supporting other MS services to present similar business cases. ABUHB developed their business case using the existing structure of CVUHB's business case, which highlighted their inability to adhere to NICE guidelines – namely the failure to review all patients annually and to provide the full range of DMTs – given workforce shortages and underfunding. The success of both business cases, using this structure and evidence, could be considered by other health boards that need additional resources. The MS service teams have highlighted the importance and value of sharing business cases and related learnings across health boards.

Betsi Cadwaladr University Health Board

Health board context

BCUHB is responsible for the delivery of healthcare services across six counties in North Wales including Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham.[41] Covering a population of over 700,000, BCUHB has the largest population of any Welsh health board. Encompassing predominantly rural areas, the health board has the lowest level of deprivation across all Welsh health boards, with only 1% of the area in the most deprived 10% of areas in Wales.[42]



The health board has issues relating to finance, management and waiting lists and has been in special measures since February 2023 with quarterly updates assessing progress across key areas. The latest publication of these results noted 'some good progress' but flagged the need to deliver real improvements for patients and staff, that quality and safety processes need to improve, and that waiting times need to be reduced.[43]

Whilst these challenges are likely to impact the care received locally by MS patients and delivered by the health board itself, the MS services accessed by patients in BCUHB, including all consultant and nurse clinics, are managed by the Walton Centre Foundation Trust (WCFT) located across the border in England. The WCFT is the only specialist hospital trust in the UK dedicated to neurology services and is rated as outstanding.[44]

Overview of provision for BCUHB patients

As noted above, BCUHB commissions its MS service from the WCFT with the team there providing care for 1,250 Welsh patients with a confirmed MS diagnosis including 97 patients from Powys. All patients are triaged though the WCFT and are offered the first available appointment, whether that is in a satellite clinic in North Wales or at the WCFT, regardless of patient location and travel times.

Table 10: Where patients covered by the Betsi Cadwaladr University Health Board access care and clinics*

	North Wales	Walton Centre Foundation Trust
MS consultant care and clinics	794	456
MS nurse care and clinics	1,055	195

**Including patients from Powys (n=1,250).*

As such, this section sets out the combined workforce and services that the 1,153 BCUHB patients have access to on both sides of the Welsh border. Provision for the 97 Powys patients is set out in the Powys section and not included in the calculations below.

Current workforce

Table 11: The current whole-time equivalent (WTE) workforce available for the 1,153 Betsi Cadwaladr University Health Board MS patients seen in clinics across North Wales and at the Walton Centre Foundation Trust

● indicates WTE is above Wales average, ● indicates that it is on par (+-0.1) with the average, ● indicates it is below Wales average

Workforce	WTE	WTE per 1,000 patients	Wales average
MS consultant MS neurologists	1.2	0.9 ●	1.7
MS nurse specialists	2.3	2.0 ●	2.5
Neuro-pharmacists	0.3*	0.2 ●	0.7
MS occupational therapists	0.5	0.4 ●	0.3
Neuropsychologists	0	0.0 ●	0.2
Neuro-physiotherapists	2.7	2.0 ●	1.0
Non-clinical administrative staff	1.7	1.5 ●	2.3
Advanced MS Champions	0.0	0.0 ●	0.0

*There is also funding for one WTE pharmacy technician for all neurology across the Walton Centre and North Wales, not included in calculation above as not in post.

Top 3 priority workforce gaps

1 **Neuropsychologist**
There are no neuropsychologists available in North Wales and although there is a neuropsychology service that these patients can access at the WCFT, it is a cognitive assessment service only with no ongoing treatment. Following an assessment, patients are referred to local primary care services or the voluntary sector, none of which are able to provide the specialist care needed by MS patients. The WCFT MS team noted that there is currently an unfunded pilot service in BCUHB, delivered pro-bono, which aimed to develop a business case and clinical model for an MS neuropsychology service, but the success of the business case looks unlikely, and they are uncertain about how long it will continue.

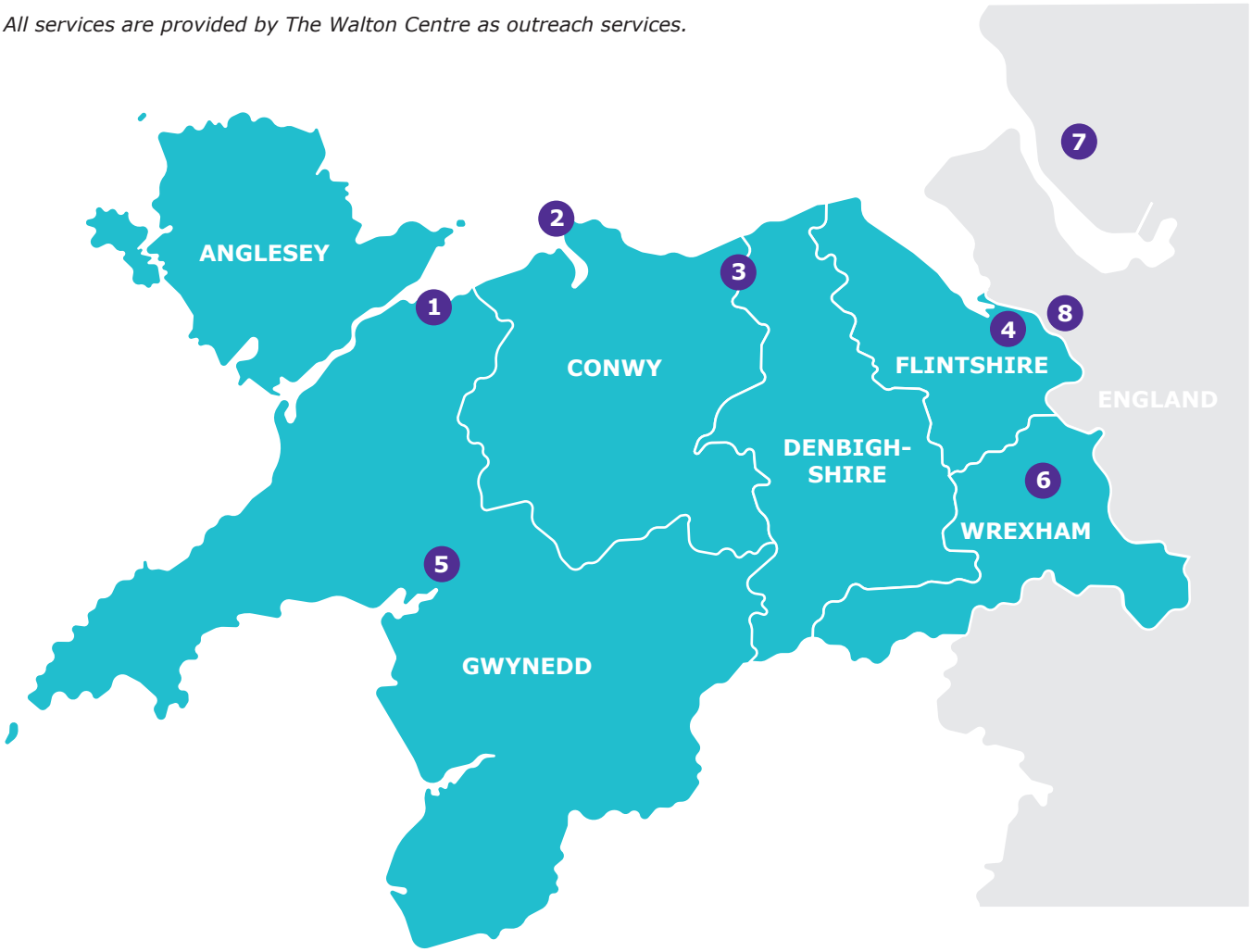
2 **MS nurse specialist**
The patient to MS nurse ratio, with 501 BCUHB patients per MS nurse exceeds the MS Trust's recommended caseload of 315 patients per MS nurse more than any other health board. With additional strains on MS nurse capacity (detailed below) waiting lists for clinics are reported by the investigators as significant and impacting patient access to care and treatment.

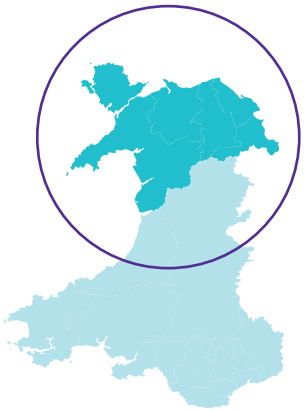
3 **MS occupational therapist**
With no dedicated MS OT in BCUHB, the WCFT MS team refers patients to social service OTs for environment/ home assessments and equipment and although BCUHB patients have access to 0.5 MS OT WTEs based at the WCFT, this does not provide adequate provision.

Current services and treatment provision

Map 2: MS service locations that can be accessed by BCUHB patients

All services are provided by The Walton Centre as outreach services.





1. **Bangor Hospital**
   MS nurse clinic
2. **Llandudno Hospital**
   Infusion service
3. **Glan Clwyd Hospital**
   MS nurse clinic
   Consultant MS neurologist clinic
4. **Deeside Community Hospital**
   MS nurse clinic
   MS consultant clinic
5. **Ysbyty Alltwen**
   MS nurse clinic
6. **Wrexham Hospital**
   MS nurse clinic
7. **The Walton Centre**
   MS MDT clinic
8. **Chester Hospital**
   MS nurse clinic
   MS consultant clinic

16%
of patients on a high-efficacy[7] DMT first line

34%
of patients ever received a DMT

Table 12: MS consultant and nurse-led clinics commissioned by Betsi Cadwaladr University Health Board in North Wales

	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	Face-to-face: 1	Face-to-face: 2 new, 8 follow-up	Face-to-face: 52	Face-to-face: 520 (104 new, 416 follow-up)
	Virtual: 0	Virtual: N/A	Virtual: 0	Virtual: 0
	Total per week: 1**		**Total: 52**	**Total: 520**
MS nurse clinics	Face-to-face: 7	Face-to-face: all follow-up (43 per week in total)	Face-to-face: 364	Face-to-face: 2,236 (all follow-up)
	Virtual: 14	Virtual: all follow-up (32 per week in total)	Virtual: 208	Virtual: 1,664 (all follow-up)
	Total per month: 11		**Total: 842**	**Total: 3,900**

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*
***There are plans to increase to 1.5 consultant clinics per week.*

Table 13: Performance of Betsi Cadwaladr University Health Board services against National Institute of Health and Care Excellence (NICE) guidelines

NICE guideline[45]	Performance	Further details
Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis	100%	Median time for a follow-up appointment post-diagnosis is 2-3 weeks
Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms	100% of patients on DMT	Patients who are not on a DMT have access to the relapse clinic via an MS advice line
Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year	100%	N/A

Overview and analysis

Based on interviews with the WCFT MS team that provides the majority of MS care for BCUHB patients, this section sets out further details of MS service provision across the health board with a particular focus on resource challenges and gaps which, if addressed, could support the team to optimise their service.

Limited and declining consultant neurologist capacity

With just 0.88 WTE consultant MS neurologists per 1,000 patients, MS patients in BCUHB have access to the lowest number of neurology consultants across all Welsh health boards.

The WCFT MS team reported long consultant waiting lists and noted that the 30-minute allocation for new consultant appointments and 15-minute allocation for follow-up consultant appointments is not compatible with completing a comprehensive review as recommended by NICE. This current model obliges consultant neurologists to work unpaid overtime which is not sustainable and makes the delivery of optimal patient care difficult.

The team also described an ongoing pilot introduced by the service and business managers which commenced in January 2025 and has instructed all consultant neurologists to convert all follow-up appointments to new appointments in one clinic per month. There are concerns that if there is not enough demand for new MS referrals, these appointments may be converted to general neurology appointments at the end of the pilot rather than back to MS follow-ups which would further impact MS patient access to consultants.

Stretched MS nurse capacity

MS nurse capacity is similarly stretched, with even greater waiting lists than for consultant clinics. The team noted that these constraints have become worse due to the increasing need for consultant MS neurologists to offer PIFU to better manage waiting lists. This has resulted in nurse teams taking on additional responsibilities to ensure adequate clinical assessments to monitor disease trajectory and DMT outcomes.

As highlighted above, not only is the MS nurse patient caseload significantly above the recommended limit, the nurses also reported a high administrative burden distracting from their clinical responsibilities. Even though the health board has above the recommended ratio of administrative staff (there are 0.7 non-clinical administrative staff per WTE nurse in BCUBH), in reality this is not sufficient for the case load of the nurses.

Limited patient access to DMTs

Patient access to DMTs in BCUHB is improving – the team highlighted the recent addition of siponimod for example – due to a successful business case and new recruitment but it remains an area of challenge. Natalizumab is currently the only infusion DMT available in North Wales and whilst ocrelizumab infusion is available at the WCFT, this requires considerable travel. Subcutaneous ocrelizumab, natalizumab, and ponesimod with homecare are also not available due to a lack of pharmacy resource.

Inequity in MDT provision

There is inequity in MDT provision between the WCFT and North Wales, with patients seen at the WCFT gaining access to weekly MDT clinics including neurologists, MS nurses, physiotherapists, and OTs. There is no such MDT clinic in North Wales, though these patients are discussed by the WCFT MDT.

Long travel time to access many services

As a result of the large areas covered by BCUHB, MS service staff report that long travel times for healthcare are unavoidable. For the MS service delivered in North Wales, the long travel times have been minimised, where possible, by hosting nurse clinics in five locations across the region. However, this requires two nurses covering five hospitals and home visits which, as a result of travel, puts a reported strain on the two nurses. Despite this, some patients still travel a long way, for example, patients who live in the southwest must travel to Glan Clwyd (which can involve a 3-hour round trip) for appointments, nabiximols and fampridine clinics, and neurological assessments at consultant clinics.

With all new patients triaged by the WCFT, they will be offered the first appointment which could be in North Wales or at the WCFT; geography and travel time are not taken into consideration. As a result, some BCUHB patients travel distances of up to 3 hours to access consultant and MS nurse care. One patient described this:

"Travelling by car can be stressful and impact fatigue levels [however] public transport would entail one bus and three trains"

MS Society Cymru patient survey responder from Holywell Flintshire

A fragmented IT and data landscape

The team noted limited IT integration between BCUHB and the WCFT, with medical records and results only accessible in each individual system, leading to delays in decision making and increases in administrative time. With many patients in Wales travelling between health boards and across national borders for care, integration between IT systems could reduce clinician caseload and improve patient experience.

Lessons from Betsi Cadwaladr University Health Board

As a team that covers a large geographical area and manages services on both sides of the Welsh border, the WCFT MS team is acutely aware of the issues facing their North Wales MS patients. To address these challenges, the WCFT MS team highlighted their use of the voluntary sector to address these gaps for patients and the need for leadership with knowledge of the local landscape and dedicated time for management responsibilities within BCUHB:

Embedding the voluntary sector in routine care

Although patients in BCUHB face service gaps particularly across mental health and occupational therapy provision, the WCFT MS team has managed to partially fill some of these gaps by using the voluntary sector. As there are no neuropsychologists in North Wales and local mental health services feel they do not have the expertise to support MS patients, the WCFT MS team refers patients to the voluntary sector. Patients have been referred to MS Society Cymru who provide a virtual 'Acceptance and Commitment Therapy' course and telephone counselling which is funded via the charity MIND. Although patients usually require more in-depth neuropsychological support, referrals to MS Society Cymru are an avenue for embedding the voluntary sector into day-to-day care.

The need for dedicated local leadership and governance

Leadership in MS care for BCUHB to date is based at the WCFT, with limited involvement from Welsh clinics and hospitals, which may limit the applicability of service design for the specific needs in North Wales. Insufficient representation of specific local needs in discussions on funding, staffing and service redevelopment can cause a disconnect between management and service delivery. Strengthening clinical leadership based in BCUHB could ensure familiarity with local policies, patients and geographies, and support advocation for appropriate service improvement for optimum care.

Cardiff and Vale University Health Board

Health board context

CVUHB encompasses a population of 472,400 across Cardiff and the Vale of Glamorgan.[46] The area covers urban and suburban communities, with around one in five geographical regions in CVUHB being in the most deprived 20% of areas in Wales, highlighting socio-economic challenges in some parts of the region.[47]

Reported MS patients in CVUHB population: 1,104

This health board hosts the largest teaching hospital in Wales (the University Hospital of Wales) and has close links with Cardiff University. CVUHB's MS specialist service has strong academic representation with a professor of clinical neurology and reader in clinical neurology providing support to clinical services from their research teams. The combined annual workforce from clinical and research teams is around 40.

As well as providing care for MS patients in CVUHB, the health board also provides specialised services to a wider population across South and mid-Wales. This includes provision of MS services for patients in CTMUHB. The Cardiff and Vale MS team estimates a current MS patient caseload of 2,000 with 55% of these patients – amounting to 1,100 – residing in Cardiff and Vale and 45% – amounting to 900 – residing in Cwm Taf. In addition to this, roughly 4 patients from Swansea Bay, 2 from Powys, and 2 from Aneurin Bevan travel to CVUHB for their MS care, often for convenience or due to long-standing patient-clinician relationships.

CVUHB has a weekly MDT meeting for neuroinflammatory diseases in which new cases are discussed, treatment decisions made, abnormal bloods reviewed, clinics and waiting lists considered, and new developments or issues discussed. Case discussion is facilitated by the PatientCare system. This is a key meeting for the MS team and allows forward planning decisions and covers mainly Cardiff and Vale and Cwm Taf services.

This section sets out the MS workforce and services that are accessed by the 1,100 reported MS patients in CVUHB itself.

Current workforce

Table 14: The current whole-time equivalent (WTE) workforce provided by Cardiff and Vale University Health Board to Cardiff and Vale patients, and the equivalent per 1,000 patients

● indicates WTE is above Wales average, ● indicates that it is on par (+-0.1) with the average, ● indicates it is below Wales average

Workforce	WTE	WTE per 1,000 patients	Wales average
Consultant MS neurologists	2.3	2.1 ●	2.3
MS nurse specialists	2.6	2.4 ●	2.6
Neuro-pharmacists	0.6	0.5 ●	0.6
MS occupational therapists	0.6	0.5 ●	0.6
Neuropsychologists	0.6	0.5 ●	0.6
Neuro-physiotherapists	1.0	0.9 ●	1.0
Non-clinical administrative staff	3.1	2.8 ●	3.1
Advanced MS Champions	0.0	0.0 ●	0.0

Top 3 priority workforce gaps

1 **MS nurse specialist**
Cardiff and Vale operates at 417 patients per MS nurse which is over the MS Trust-recommended ratio of 315 MS patients per MS nurse. An additional WTE MS nurse specialist would result in a ratio of one nurse for 302 patients.

2 **Neuropsychologist**
Reflecting a broader challenge across Wales, the health board has just one neuropsychologist who supports patients across Cardiff and Vale and Cwm Taf, as well as receiving referrals for patients from Aneurin Bevan. Only two patients can be seen per clinic and it is reported that waiting lists are long which means the team only refers for patients most in need, leaving many patients who would still benefit without access.

3 **MS pharmacist**
While there is one band 8 neuro-inflammatory pharmacist serving Cardiff and Vale and Cwm Taf, with the increased use of DMTs, a specific MS pharmacist would be highly valued.

Current services and treatment provision

Map 3: MS service locations that can be accessed by CVUHB patients

1 University Hospital Wales
Infusion centre
Nurse and consultant led clinics

2 University Hospital Llandough
Nurse and consultant led clinics
Neuro-rehabilitation

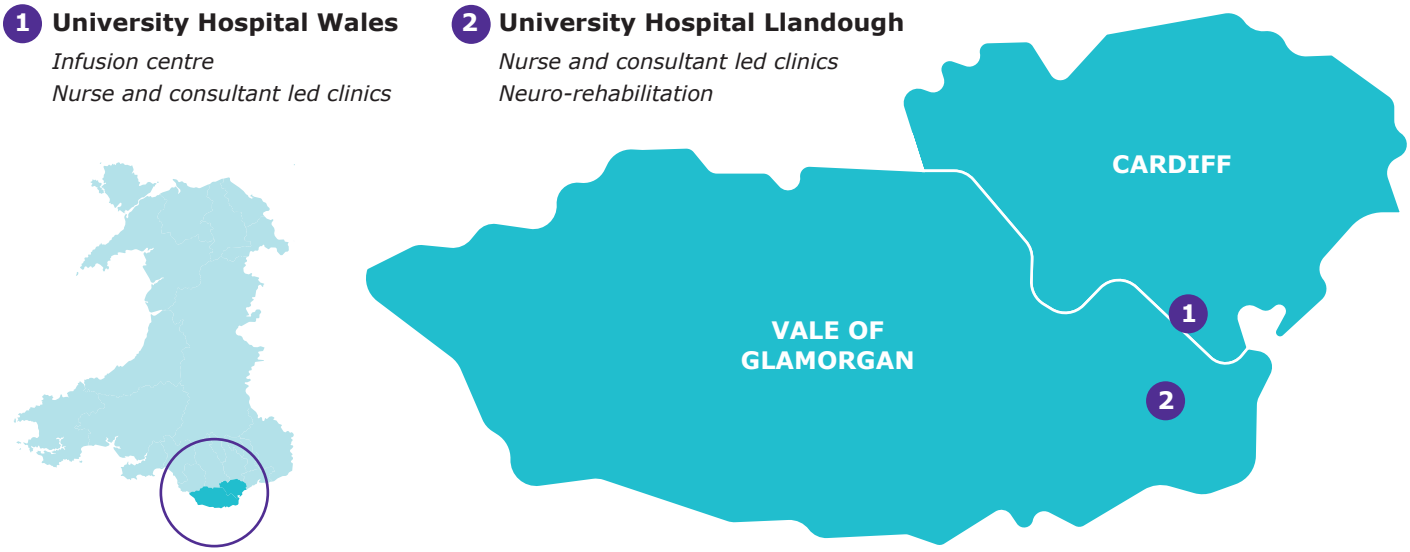


Table 15: MS consultant and nurse-led clinics provided by Cardiff and Vale University Health Board

	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	Face-to-face: 6	Face-to-face: 2 new, 6 follow-up	Face-to-face: 312	Face-to-face: 2,496 (1,872 new, 624 follow-up)
	Virtual: 0	Virtual: N/A	Virtual: 0	Virtual: 0
	Total per week: 6		**Total: 312**	**Total: 2,496**
MS nurse clinics	Face-to-face: 13	Face-to-face: 6 follow-up	Face-to-face: 156	Face-to-face: 936 (all follow-up)
	Virtual: 8	Virtual: 6 follow-up	Virtual: 96	Virtual: 576 (all follow-up)
	Total per month: 21		**Total: 252**	**Total: 1,512**

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*

70%
of patients on a high-efficacy[7] DMT first line

73%
of patients ever received a DMT

Table 16: Performance of Cardiff and Vale University Health Board against National Institute of Health and Care Excellence (NICE) guidelines

NICE guideline[48]	Performance	Further details
Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis	100%	Median time for a follow-up appointment post-diagnosis is 2-3 weeks
Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms	100% of patients on DMT	These appointments are facilitated through the provision of a weekly relapse clinic but require the patient to self-refer. Cases are triaged by phone
Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year	100%	N/A

Overview and analysis

Based on interviews with the CVUHB MS team, this section sets out further details of MS service provision across the health board with a particular focus on resource challenges and gaps which, if addressed, could support the team to optimise their service:

Non-MS clinical demand on the workforce

The practice of redeploying MS nurses to alleviate capacity pressures across the neurology service – which began during the COVID-19 pandemic – was reported uniquely as a challenge in CVUHB. Currently 75% of the service's MS nurses cover shifts on the neurological day unit, largely to alleviate infusion capacity pressures, which reduces MS nursing hours. Redeployment of MS nurses is also used to address winter pressures which further impacts MS clinic waiting lists and augments demand on clinical teams.

Workforce to patient caseload ratios

Identified as their top workforce challenge, the service's MS nurses are operating with 100 additional patients per WTE over what is recommended as a sustainable patient caseload by the MS Trust. This caseload is second only to BCUHB, leaving the CVUHB MS nurse team with a larger caseload by 22% compared to the mean of other health boards across Wales.

The health board has taken steps to mitigate the impact of this on patient care while protecting staff welfare, such as introducing virtual clinics. However, these steps are not optimal – for example more clinics are conducted virtually than NICE guidelines recommend, and the service can only deploy home visits in exceptional circumstances. This gap is a particular challenge for patients with progressive disease. One patient, when asked about challenges they experience in accessing services across Cardiff and Vale, reported that:

"As a wheelchair user it is not possible always to access appointments. Using phone or digital equipment is hard due to MS. [There is] no provision for face-to-face meetings at home"

MS Society Cymru patient survey responder from Cardiff

On the other hand, as is the case in SBUHB, the service operates with a higher proportion of non-clinical administrative staff with double the recommended WTE per MS nurse. This relieves some of the administrative burden nurses can experience. However, the team still faces administrative challenges, for example, it was reported that clinical staff have to navigate three different online portals to support the management of patient care and that in each 15-minute appointment roughly 50% of time is spent on the computer, which would be better spent communicating with the patient.

Other than an Advanced MS Champion, and unlike some of the other Welsh health boards, CVUHB is able to staff its advanced MS MDT with all the recommended roles.[49] However, despite this success, low staffing numbers relative to active patient case load makes optimum service delivery challenging.

In particular, with just 0.5 neuropsychologists and 0.5 occupational therapists per 1000 patients, access to these services is limited. Regarding neuropsychology, the health board tries to fill this gap by referring to GPs for mental health support and tapping into ad-hoc counselling provided by the MS Society Cymru when funding is available. For occupational therapy, the service aims to better support patients by running its own fatigue management course and directing patients towards patient organisations for further support. The health board runs the Living Well with MS programme in collaboration with the MS Society Cymru. The team also cited inadequate provision of neurorehabilitation with just one monthly neuro-rehabilitation clinic failing to meet demand.

Succession planning

The health board expects 2 MS consultants (one third of MS consultants), 4 MS nurses (>80% of the current workforce) and 1 non-clinical administrative staff member (<20% of the current workforce) to retire in the next five years. This represents a significant change from the current workforce and a particular challenge given the difficulty reported in replacing existing roles made vacant due to retirement.

Following retirement, there is no guarantee that funding for a role will continue and a business case to NHS Wales must be made for each vacancy. In one case, this process led to an 18-month vacancy for an MS nurse before the role was filled and there is a trend from the health boards finance team to try and save money and recruit at a lower band which impacts service delivery. Given this experience, the service is concerned about the impact these prospective retirements will have on their ability to deliver care for patients.
In particular, two of the current consultants are academic neurologists employed by Cardiff University and even if these posts were to be replaced there is no guarantee of an individual with continued interest in MS.

Team management

Currently, there is no time allocated within the NHS job plan of consultants and nurses for management of the MS service team. The team feels that this time is needed for pathway improvement, horizon scanning and planning future workforce and training needs. A grade 8 nurse who undertook some of these important higher-level tasks and managed the nursing team recently retired and reappointment was not supported by the directorate. Current senior nursing management has not been able to deliver these tasks. Overall management of such a large team (about 40 people) is also challenging for which there is no current job plan time allowance and results in consultants using overtime for managerial duties. The team believes the creation of a Director of the Unit post with allocated sessions for team management would address these challenges and support a sustainable and optimal workforce.

Wider NHS workforce challenges impacting MS patient care

Radiology capacity challenges are widely reported, and the situation in Wales is no different to other nations.[50] In busy, acute centres such as University Hospital Wales, more urgent cases push chronic conditions down the priority list and according to staff in CVUHB, it can take 12-14 weeks to receive the radiology report for an MS patient following an MRI scan, delaying clinical decision-making and potentially leading to symptom progression.

Lessons from Cardiff and Vale University Health Board

Though there are challenges for the CVUHB MS team and service, it is a leading provider of MS care in the country, with lessons that can be leveraged by individual health boards and at a national level.

The valuable role of academic links in service delivery, workforce quality and recruitment

The development of a successful research programme and close links with Cardiff University benefits the MS service, allowing the service to supplement clinical services with research staff. Beyond this however, the academic links allow an emphasis on teaching – from undergraduate to senior research fellow level – which improves the quality and quantity of applicants across all posts. Whilst this may not be possible for health boards that do not have leading local neuroscience focussed universities, an increased focus on research can help attract talented workforce and improve overall services.

Innovating to manage large caseloads

With CVUHB covering patients from multiple health boards, and patients referred to certain aspects of the service (e.g. neuropsychology) from across the country, the team at CVUHB have developed numerous strategies to help manage burgeoning caseloads, including the role of virtual clinics, and maximising the role of specialist nurses by engaging them in routine follow-up and care planning of MS patients on DMTs. Additionally, despite not aligning with NICE guidance, the service champions the appropriate application of PIFU to manage routing workload and annual reviews.

The importance of effective clinical leadership

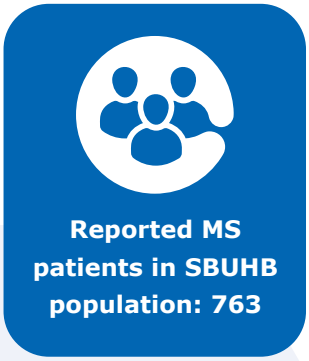
All MS teams involved in the development of this report have noted the importance of effective local clinical leadership and dedicated management time. CVUHB has demonstrated the necessity of such management for these large specialist units.

Swansea Bay University Health Board

Health board context

SBUHB encompasses a population of around 390,000 across Neath Port Talbot and Swansea.[51] Covering both rural and urban communities, over one quarter of the population falls into the most deprived fifth on the deprivation index, making it more deprived than other areas in Wales.[52]

The health board provides MS services for patients across Swansea Bay, Hywel Dda, Cwm Taf, Cardiff and Vale, and Powys. The health board is recognised for its swift adoption of new treatments, execution of clinical trials – with the existence of a commercial clinical trial unit and clinical trial team consisting of four nurses – and ability to negotiate a challenging and wide geographical area. This section sets out the workforce and services that are accessed by the 763 patients with a confirmed MS diagnosis in Swansea Bay University Health Board.



Current workforce

Table 17: The current whole-time equivalent (WTE) workforce provided to Swansea Bay University Health Board, and the equivalent per 1,000 patients

● indicates WTE is above Wales average, ● indicates that it is on par (+-0.1) with the average, ● indicates it is below Wales average

Workforce	WTE	WTE per 1,000 patients	Wales average
Consultant MS neurologists	1.2	1.6 ●	1.7
MS nurse specialists	2.0	2.6 ●	2.5
Neuro-pharmacists	0.4*	0.5 ●	0.7
MS occupational therapists	0.0	0.0 ●	0.3
Neuropsychologists	0.0	0.0 ●	0.2
Neuro-physiotherapists	0.8**	1.1 ●	1.0
Non-clinical administrative staff	1.5	2.0 ●	2.3
Advanced MS Champions	0.0	0.0 ●	0.0

*The majority of this neuro-pharmacist's workload is MS.

**This team is comprised of one MS specific physiotherapist and neurophysiotherapist on an annual rotational training contract.

Top 3 priority workforce gaps

1 **Neuropsychologist**
Whilst neuropsychology support exists within the neuro-rehabilitation service, their input in the MS team has decreased year on year. The MS service competes for funding for neuropsychology support, with the majority of funding granted to stroke services, leaving a gap for MS patients.

2 **Advanced MS Champion**
Swansea was included in the pilot scheme to assess the impact of an Advanced MS Champion at six sites across England and Wales. Despite the pilot scheme demonstrating financial savings – as well as reductions in admissions and appointments – the Swansea Bay MS service was not able to secure permanent funding for the post.

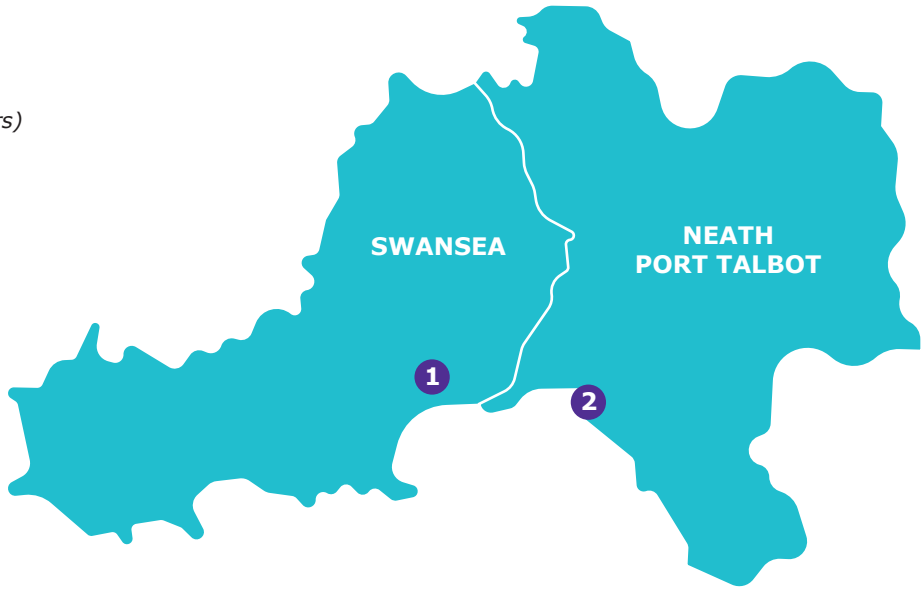
3 **MS occupational therapist**
With no MS-specific occupational therapist for Swansea Bay, the team refers to local general OTs, taps into social care – which the investigators reported to also have high waiting lists – and relies on the MS Society Cymru for support in this service. Despite the evident need, the team at Swansea Bay has received no indication that funding to fill this post will be provided by the health board.

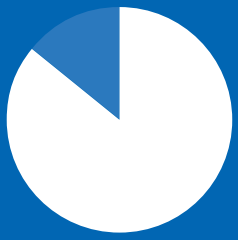
Current services and treatment provision

Map 4: MS service locations that can be accessed by SBUHB patients

1 **Morriston Hospital**
Consultant clinics,
MS nurse clinics,
Infusion centre (2 beds and 7 chairs)

2 **Neath Port Talbot Hospital**
MS nurse clinics,
Neuro rehabilitation centre





86%
of patients on a high-efficacy[7] DMT first line

Table 18: MS consultant and nurse-led clinics provided by Swansea Bay University Health Board (SBUHB) for patients in SBUHB

	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	Face-to-face: 6	Face-to-face: 2 new, 5 follow-up	Face-to-face: 312	Face-to-face: 2,184 (624 new, 1,560 follow-up)
	Virtual: 0	Virtual: N/A	Virtual: 0	Virtual: 0
	Total per week: 6		**Total: 312**	**Total: 2,184**
MS nurse clinics	Face-to-face: 13	Face-to-face: 6 follow-up	Face-to-face: 156	Face-to-face: 650 (130 new, 520 follow-up)
	Virtual: 8	Virtual: 6 follow-up	Virtual: 96	Virtual: 130 (26 new, 104 follow-up)
	Total per month: 21		**Total: 252**	**Total: 780**

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*

Table 19: Reported performance of Swansea Bay University Health Board against National Institute for Health and Care Excellence (NICE) guidelines

NICE guideline[53]	Performance	Further details
Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis	c. 50% following referral	An audit is currently underway, but the health board estimates that the median time for an MS consultant clinic after diagnosis is 8 weeks and for a nurse clinic is 6 weeks
Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms	Over 95%	Weekly relapse clinic available that runs every week of the year
Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year	79.5% in the last 6 months	Annual reviews mainly led by the nursing team

Overview and analysis

Based on interviews with the SBUHB MS team, this section sets out further details of MS service provision across the health board with a particular focus on resource challenges and gaps which, if addressed, would support the team to optimise their service:

Non-MS clinical demand on the workforce

The workforce for SBUHB MS patients is under-resourced with each WTE MS consultant typically conducting two to three MS clinics and one general neurology clinic a week to provide care for patients with other neurological conditions. Non-MS clinical demand for the specialist neuroinflammatory service across the health board includes clinically isolated syndrome (CIS); MOGAD; NMO and neurosarcoidosis. Around 284 patients with these neurological conditions use these services.

Workforce to patient caseload ratios

Swansea Bay's MS nurses have unsustainable caseloads with an average patient caseload for a WTE nurse of 379, 20% above the MS Trust recommended caseload. The impact of this is evident, with the health board reporting difficulties in achieving speedy diagnosis and ensuring a timely first nurse appointment following diagnosis (in line with NICE guidance), with only 50% of patients being seen within the recommended 6-week period following referral.

The service does have a higher proportion of non-clinical administrative staff with 0.75 per WTE MS nurse (0.6 is recommended for a sustainable workload by the MS Trust),[54] however given the stretched capacity across the team elsewhere, this shortfall remains an area of challenge and one that the team would like to address.

Workforce gaps

Looking at gaps in the service for SBUHB patients, there are multiple roles that are recommended as part of advanced MS MDTs that are not in place,[55] including robust access to a neuropsychologist, an Advanced MS Champion and an MS specific OT. Almost all patients from SBUHB that responded to the MS Society Cymru patient survey (n=20) also highlighted that they would see value in increased neuro-physiotherapy, despite there being one at SBUHB.

Succession planning

The health board expects one MS consultant, one MS nurse and one non-clinical administrative staff member to retire in the next five years, which will impact the WTE workforce and service delivery for Swansea Bay patients. There are particular concerns around the future succession for MS nurses with all nurses currently at band 7 and 8, meaning the service will likely lose senior and experienced nurses over the next five-to-ten years and will need to fill these gaps.

Perhaps more so than other health boards, Swansea Bay appears to actively manage succession planning and aims to start this a year in advance of any predicted retirement but relies heavily on short term funding from pharmaceutical companies to ensure personnel remain in post whilst new staff are trained. The individuals interviewed for this paper reported that this approach has made it easier to demonstrate to health board management the necessity of a specific role and provides key support in developing a business case for continued funding for a specialist post.

Lessons from Swansea Bay University Health Board

Although SBUHB faces challenges in providing specialist MS services across five separate health boards and a lack of core funding, it remains a dynamic service that promotes innovative ways to support service delivery in this challenging environment. As a result, there are key lessons that can be learned from Swansea Bay Health Board, including:

Securing external funding to support succession planning and workforce recruitment

The SBUHB MS team commented that they face challenges in securing central funding and resources from NHS Wales. As a result, the service has had to find innovative funding models to ensure a sustainable workload. As noted above, the service relies on short term funding from pharmaceutical companies to keep a soon-to-retire nurse in post while they train a new MS nurse. This style of funding is also used to fund new posts in the short term, to help persuade the health board that a permanent hire is needed. Caution with this short-term funding approach is advisable to ensure that posts are not created that cannot be sustained if further funding isn't available.

An innovative and inclusive approach to service design

A major strength of the MS service provided by SBUHB is the whole-team approach. Team members – from consultants through to administrative staff – work to support each other beyond the silos of their professional role.

The 'whole-team' approach is taken forward to service design. Bi-annually, the team has protected time for an away day to undertake a services and pathways audit and consider how to improve the service. Given the considerable demand on the team, this has proved an invaluable approach to catalyse change.

It was noted by the team that to push for such change and ensure the team works together to continue to be innovative, a dedicated service lead who has the time and passion to drive service change is vital.

Use of virtual clinics for remote patients

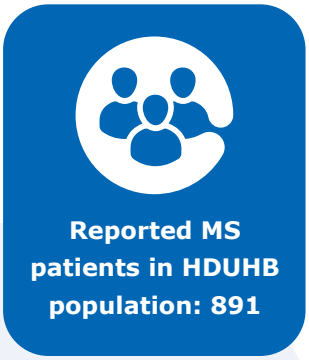
Due to the vast geography covered by SBUHB, the service has adopted virtual clinics to ensure equitable access regardless of where patients live. In Swansea Bay, they offer 0.5 virtual clinics per week as well as virtual group educational clinics to discuss drug options with between 4 and 40 attendees. The focus on equitable access for remote patients by the means of virtual clinics is seen even more so in health boards with more remote patients such as Hywel Dda, but is still an important aspect of Swansea Bay.

Hywel Dda University Health Board

Health board context

HDUHB encompasses a population of 385,600 across Carmarthenshire, Ceredigion and Pembrokeshire.[56] Covering a quarter of Wales, HDUHB is the second most sparsely populated health board in Wales.[57] Encompassing both rural and urban communities, nearly half the population lives in the most deprived areas in Wales (the lower 50%) according to the deprivation index with several areas experiencing significant levels of socio-economic disadvantage.[58]

MS services for patients in HDUHB are commissioned from SBUHB. This section sets out the MS workforce and services that are accessed by the 891 patients with a confirmed MS diagnosis in Hywel Dda. These 891 patients make up 43% of all patients receiving care from the SBUHB MS service.



Current workforce

Table 20: The current whole-time equivalent (WTE) workforce provided to Hywel Dda University Health Board, and the equivalent per 1,000 patients

● indicates WTE is above Wales average, ● indicates that it is on par (+-0.1) with the average, ● indicates it is below Wales average

Workforce	WTE	WTE per 1,000 patients	Wales average
Consultant MS neurologists	1.3	1.5 ●	1.7
MS nurse specialists	2.2	2.5 ●	2.5
Neuro-pharmacists	0.4*	0.5 ●	0.7
MS occupational therapists	0.0	0.0 ●	0.3
Neuropsychologists	0.0	0.0 ●	0.2
Neuro-physiotherapists	0.9**	1.0 ●	1.0
Non-clinical administrative staff	1.6	1.8 ●	2.3
Advanced MS Champions	0.0	0.0 ●	0.0

*The majority of this neuro-pharmacist's workload is MS.

**This team is comprised of one MS specific physiotherapist and neurophysiotherapist on an annual rotational training contract.

83%
of patients on a high-efficacy[7] DMT first line

Top 3 priority workforce gaps

Given the service is commissioned by Swansea Bay University Health Board, the workforce gaps set out in this section are the same as those examined in the Swansea Bay section. For further information on them, please view page 37.
The top three priority workforce gaps are:

1. **Neuropsychologist**
2. **Advanced MS Champion**
3. **MS occupational therapist**

Current services and treatment provision

Map 5: MS service locations that can be accessed by HDUHB patients

1. **Bronglais Hospital**
   Consultant clinics
   MS nurse
2. **Aberaeron Integrated Care Centre**
   MS nurse clinics
3. **Cardigan Health Centre**
   MS nurse clinics
4. **Crymych Health Centre**
   MS nurse clinics
5. **Withybush Hospital**
   MS nurse clinics
6. **Glangwili Hospital**
   MS nurse clinics
7. **Amman Valley Hospital**
   MS nurse clinics
8. **Morriston Hospital**
   Consultant clinics
   Infusion clinics
9. **Neath Port Talbot Hospital**
   Neuro-rehabilitation
10. **Prince Philip Hospital**
    MS nurse clinics
11. **Tenby Hospital**
    MS nurse clinics
12. **Pembroke Dock Hospital**
    MS nurse clinics

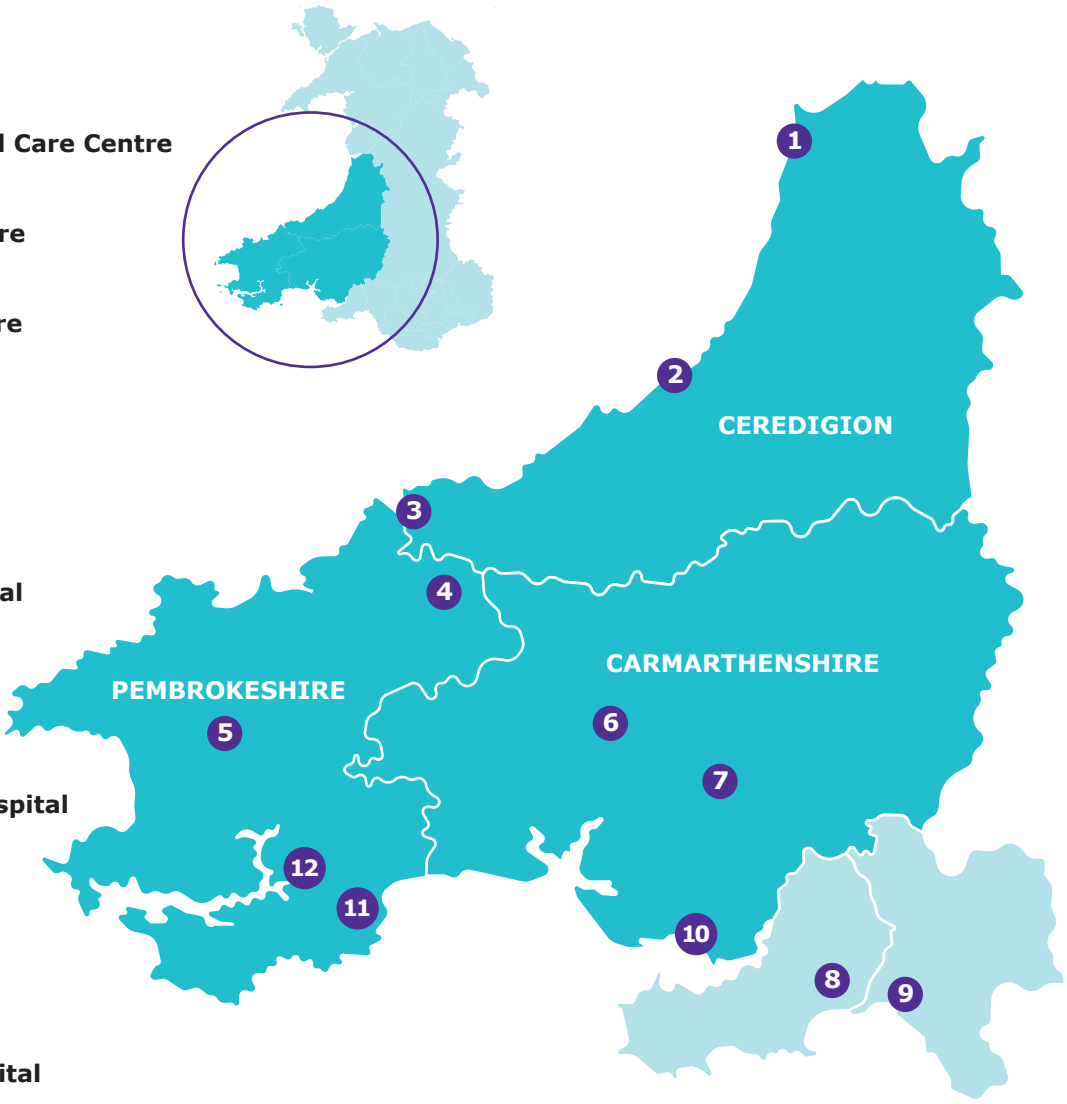


Table 21: MS consultant and nurse-led clinics provided by Swansea Bay University Health Board

	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	Face-to-face: 1 Virtual: 0 **Total per 6 months: 1**	Face-to-face: 8 follow-up Virtual: N/A	Face-to-face: 2 Virtual: 0 **Total: 2**	Face-to-face: 16 (all follow-up) Virtual: 0 **Total: 16**
MS nurse clinics	Face-to-face: 2.2 Virtual: 2 **Total per week: 4.2**	Face-to-face: 1 new, 3-4 follow-up Virtual: 1 new, 3-4 follow-up	Face-to-face: 114.4 Virtual: 104 **Total: 218.4**	Face-to-face: 514.8 (114.4 new, 400.4 follow-up) Virtual: 468 (104 new, 364 follow-up) **Total: 982.8****

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*
***Calculated based on 3.5 follow up appointments.*

Table 22: Reported performance of Swansea Bay University Health Board MS service for Hywel Dda University Health Board patients against National Institute for Health and Care Excellence (NICE) guidelines

NICE guideline[59]	Performance	Further details
Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis	c. 50% following referral	An audit is currently underway, but the health board estimates that the median time for an MS consultant clinic after diagnosis is 8 weeks and for a nurse clinic is 6 weeks
Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms	Over 95%	Weekly relapse clinic available that runs every week of the year
Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year	79.5% in the last 6 months	Annual reviews mainly led by the nursing team

Overview and analysis

Based on interviews with the SBUHB MS team, this section sets out further details of MS service provision for patients in HDUHB, with a particular focus on the challenges experienced in delivering MS services across such a wide geographical area, and the impact of this on service delivery and patient care.

The key points covered in the overview and analysis section for Swansea Bay are also relevant for this patient cohort and can be found on page 39.

Geographical considerations

As mentioned, HDUHB covers a quarter of Wales and is the second most sparsely populated health board in the country. Commissioning an MS service across this geography is challenging. Whilst the SBUHB team is committed to equitable service provision for Swansea Bay and Hywel Dda patients and has made efforts to localise care – as outlined below – they are realistic that equitable access remains an issue. Indeed, in response to the MS Society Cymru's survey, one service user commented:

"I have little or no access to services as live too far away"

MS Society Cymru patient survey responder, South-West Wales

Limited access to consultant clinics

With only two face-to-face consultant clinics delivered annually in Aberystwyth – which are reserved for patients being treated and attending follow-up appointments – patients in HDUHB have less access to consultants than patients in SBUHB. The team estimates that between 9-12 patients can be seen in each of these consultant clinics. Any new patients must travel to consultant clinics in Morriston Hospital which can involve a 4-hour round trip which is inconvenient and can be difficult for patients who experience mobility challenges.

Limited access to consultants is evident in a response provided to the MS Society Cymru's survey, with one MS patient from Carmarthenshire noting the limited consultant access but highlighting that, despite this challenge, support is always there when needed, particularly from MS nurses:

"[Whilst I] hardly see the neurologist apart from once a year, I know I can always get in touch when needed [and] I see the nurses when I have treatment"

MS Society Cymru patient survey responder, Carmarthenshire

A stretched MS nurse workforce

The patient caseload per WTE nurse in HDUHB is 405, 29% higher than the recommended 315. Whilst MS nurses are not noted by the Swansea Bay MS team as a top 3 workforce gap, they do report that care for such a wide patient cohort means the nurse team manages unsustainable caseloads.

Reduced uptake of infusions

For HDUHB patients, the only infusion centre is located in Swansea at Morriston Hospital. The SBUHB MS team noted that patients' treatment decisions are often based on travel-related considerations rather than efficacy or suitability. Some patients will choose treatments which can be delivered to their home, rather than hospital-based infusion treatments.

Lessons from Hywel Dda University Health Board

The SBUHB MS team is acutely aware of the access challenges and inequitable service provision highlighted above, and if resource constraints were lifted, the team would like to set up two further MS hubs. The team reported some measures to alleviate these challenges such as hybrid and localised care. Learnings which may be of value to other health boards include:

Use of virtual clinics for remote patients

As noted in the SBUHB section, the MS service adopted virtual clinics to ensure equitable service access regardless of patient location. The team offers two MS virtual nurse clinics a week, alongside group education clinics to discuss drug options with between 4 and 40 attendees. This provision is critical for HDUHB patients, reducing travel time for accessing care.

Setting up local clinics

The SBUHB MS team travel up to four hour round trips to provide face-to-face clinics. This provision includes two face-to-face consultant clinics each year at Bronglais Hospital and 2.2 face-to-face nurse clinics a week which are delivered across ten sites. Provision of these local clinics ensures a hybrid model of care, helps mitigate concerns over the efficacy of 'telemedicine' in MS by accurately assessing relapse and disability worsening, and contributes towards greater equity in care for SBUHB and HDUHB patients.[60] Indeed, the SBUHB team highlighted the importance of a hybrid model, noting that the impact of not seeing patients in person became clear during the pandemic.

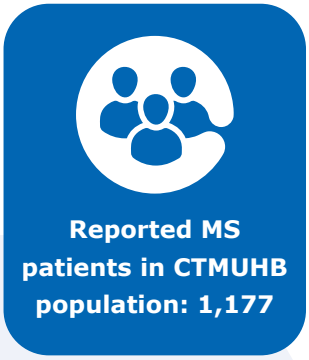
Cwm Taf Morgannwg University Health Board

Health board context

CTMUHB serves 450,000 people living across Bridgend, Merthyr Tydfil and Rhondda Cynon Taf.[61] Around 40% of the Cwm Taf region falls within the 20% most deprived areas in Wales.[62]

There are approximately 1177 people with a confirmed MS diagnosis accessing services across CTMUHB. The health board does not operate its own MS service; instead, services are provided by either CVUHB or SBUHB.

This section sets out the workforce and services that are provided by each of these health boards, and analyses service delivery for patients living with MS in CTMUHB.



Overview of provision from CVUHB

CVUHB provides MS care for around 900 MS patients in CTMUHB. These patients largely access consultant care at clinics in CVUHB at either University Hospital Wales or University Hospital Llandough, and access nurse clinics in CTMUHB at either Royal Glamorgan Hospital, Prince Charles Hospital, or Ysbyty Cwm Cynon. Roughly 5-6 patients are seen in each nurse clinic.

CVUHB has recently set up a monthly consultant clinic in CTMUHB at Prince Charles Hospital which has lessened the travel burden for patients and helps provide more equitable service access. In addition to this, there are general neurology clinics at Royal Glamorgan Hospital, Prince Charles Hospital, and Maesteg Community Hospital where some MS patients are seen.

Current workforce

Table 23: The current whole-time equivalent (WTE) workforce provided by Cardiff & Vale University Health Board (CVUHB) and Swansea Bay University Health Board (SWUHB) to Cwm Taf Morgannwg University Health Board patients, and the WTE per 1,000*

● indicates WTE is above Wales average, ● indicates that it is on par (+-0.1) with the average, ● indicates it is below Wales average

Workforce	**CVUHB** WTE	WTE per 1,000 patients	**SBUHB** WTE	WTE per 1,000 patients	Wales average
Consultant MS neurologists	1.9	2.1 ●	0.4	1.4 ●	1.7
MS nurse specialists	2.2	2.4 ●	0.7	2.5 ●	2.5
Neuro-pharmacists	0.5	0.5 ●	0.1	0.4 ●	0.7
MS occupational therapists	0.5	0.5 ●	0.0	0.0 ●	0.3
Neuropsychologists	0.5	0.5 ●	0.0	0.0 ●	0.2
Neuro-physiotherapists	0.8	0.9 ●	0.3	1.1 ●	1.0
Non-clinical administrative staff	2.5	2.8 ●	0.5	1.8 ●	2.3
Advanced MS Champions	0.0	0.0 ●	0.0	0.0 ●	0.0

**The CVUHB WTE was calculated using the ratio of CVUHB vs CTMUHB patients.*
For SBUHB the data noted is the specific WTE workforce provided by the SBUHB for CTMUHB patients.

Top priority workforce gap

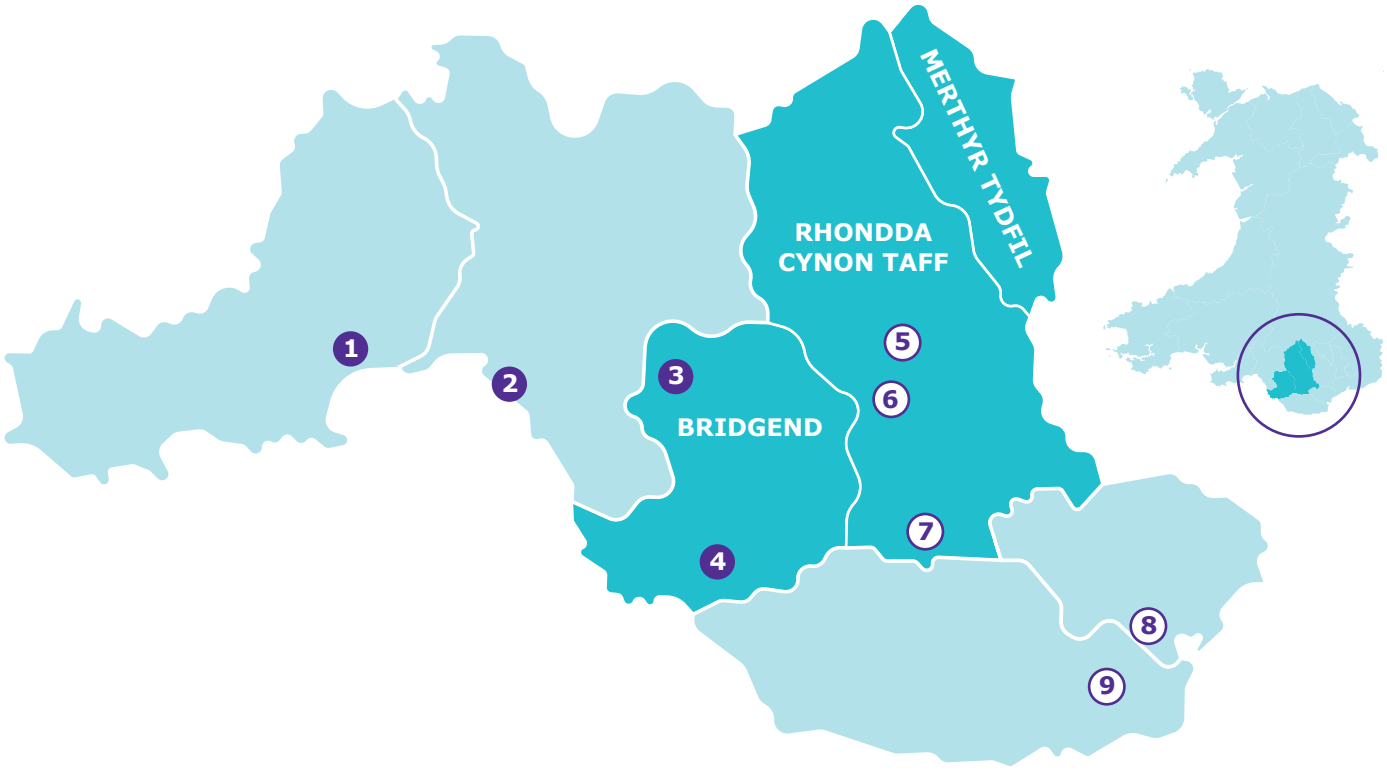
Neuropsychologist

Across both CVUHB and SBUHB's MS services, a lack of neuropsychology support was a common theme. As previously noted, CVUHB has one neuropsychologist who serves three health boards (CVUHB, CTMUHB and ABUHB), and the SBUHB is without access to a neuropsychology specialist other than limited support through their neuro-rehabilitation service meaning patients in CMTUBH have limited access to neuropsychology support.

Current services and treatment provision

Map 5: MS service locations that can be accessed by CTMUHB patients

● *indicates SBUHB provided,* ○ *indicates CVUHB provided*



1 Morriston Hospital
Consultant and nurse led clinics
Infusion centre

2 Neath Port Talbot Hospital
Nurse-led clinics
Rehabilitation centre

3 Maesteg Community Hospital
Nurse-led clinics

4 Prince of Wales Hospital
Nurse-led clinics

5 Prince Charles Hospital
Nurse-led clinics
Consultant clinic

6 Ysbyty Cwm Cynon
Nurse-led clinics

7 Royal Glamorgan Hospital
Nurse-led clinics

8 University Hospital Wales
Consultant and nurse led clinics
Infusion centre

9 University Hospital Llandough
Consultant and nurse led clinics

Table 24: Nurse and consultant clinics provided in Cwm Taf Morgannwg University Health Board by Cardiff & Vale University Health Board

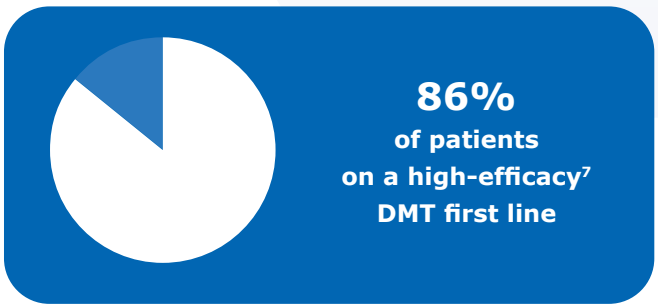
	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	Face-to-face: 1 Virtual: 0 **Total per month: 1**	Face-to-face: 2 new, 4 follow-up Virtual: N/A	Face-to-face: 12 Virtual: 0 **Total: 12**	Face-to-face: 72 (24 new, 48 follow-up) Virtual: 0 **Total: 72**
MS nurse clinics	Face-to-face: 8 Virtual: 5 **Total per month: 13**	Face-to-face: 6 follow-up Virtual: 6 follow-up	Face-to-face: 96 Virtual: 60 **Total: 156**	Face-to-face: 576 (all follow-up) Virtual: 360 (all follow-up) **Total: 936**

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*

Table 25: MS nurse clinics provided in Cwm Taf Morgannwg University Health Board by Swansea Bay University Health Board

	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	Face-to-face: 1.25 Virtual: 1 **Total per week: 2.25**	Face-to-face: 1 new, 4 follow-up Virtual: 1 new, 4 follow-up	Face-to-face: 65 Virtual: 52 **Total: 117**	Face-to-face: 325 (65 new, 260 follow-up) Virtual: 260 (52 new, 208 follow-up) **Total: 585**

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*



Overview and analysis

The key points covered in the overview and analysis of both the CVUHB and SBUHB MS services are also relevant for patients in CTMUHB. This section therefore considers the specific reflections on the delivery of care to patients in CTMUHB.

Inequitable access to services

There are differences in the services provided by CVUHB and SBUHB, meaning patients within CTMUHB experience variations in care. For example, there is no dedicated neuropsychologist or MS occupational therapist in the SBUHB MS service, but CTMUHB patients whose care is led by CVUHB do have some access to these specialists. These patients would need to travel to CVUHB to access neuropsychology support but can have both home and virtual visits from the MS occupational therapist. Access to speech and language therapists was also raised as a challenge for these patients.

In addition to this, some patients accessing care through CVUHB are now able to attend the new consultant clinic in north Cwm Taf, whilst patients accessing care through SBUHB need to travel to Morriston Hospital for face-to-face consultant clinics.

As well as inequalities in provision between services provided by these health boards, the CVUHB team explained that the CTMUHB patients they serve have access to more limited services than their CVUHB patients. They noted that although these patients have local access to bladder and bowel services these are not neuro-specific, and they would need to travel to Cardiff for neuro-specific services. Access to fampridine clinics is also only available at University Hospital Wales. The team also noted that testing facilities required ahead of commencing a DMT are limited across CTMUHB and so travel to University Hospital Wales would be required in this instance.

90-minute journey times to clinics

Although CVUHB, CTMUHB and SBUHB represent smaller geographical areas than the other health boards in Wales, travel can still be problematic and challenging for MS patients, with varying levels of mobility.

- Travelling from Cwm Taf to Cardiff via private vehicle can be time consuming as it requires travel via the main road (A470) which is very busy and there is a shortage of parking in and around the hospital. It can also be difficult to get to University Hospital Wales via public transport, which many MS patients rely on, taking many patients from Cwm Taf 90 minutes or more to travel c. 20 miles. Some infusions start at 9am, which can be another challenge if using public transport. Ambulance services are limited, and drop-off times don’t always align with appointments. For progressive MS patients, a disability chair or stretcher may be required for a long journey, and access to this equipment is limited
- As noted above, although patients receiving care from SBUHB have good access to locally run nurse-clinics, they are required to travel further to Morriston Hospital in Swansea to access face-to-face consultant clinics

Lessons from Cwm Taf Morgannwg University Health Board

Despite the lack of local MS service provision within CTMUHB, both CVUHB and SBUHB have sought to overcome challenges and deliver robust services across the area. This has been achieved through:

Provision of local clinics

As set out above, both health boards provide access to local MS nurse clinics in Cwm Taf, and CVUHB recently created the first consultant clinic. Although CTMUHB patients are still more likely to travel long distances for their MS care, this provision has eased this burden.

Use of virtual clinics for remote patients

Both CVUHB and SBUHB have utilised virtual clinics to both meet the demand on their services and workforce, and to support patients to receive support across challenging geographies.

- Cwm Taf patients have access to SBUHB's weekly virtual MS nurse clinic, as well as group educational clinics to discuss drug options with between 4 and 40 attendees
- CVUHB offers 5 virtual nurse-led clinics per month to limit the need for patient travel. Going forward, CVUHB would like to make greater use of PIFU so patients can self-refer when they need support, rather than requiring them to travel for annual follow-up when it may not be needed

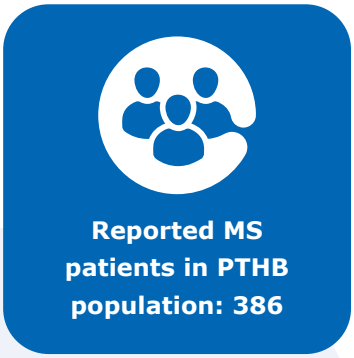
  One of the patients explained the benefit of the telephone clinics, explaining: *"nurses always call you back"*

Powys Teaching Health Board

Health board context

PTHB serves a population of approximately 133,000 across Powys, a largely rural county in Wales.[63] Within PTHB, there are pockets of deprivation with around 10% of the population living in areas that fall within the most deprived 30% in Wales, according to the deprivation index.[64]

The rural nature of Powys has an impact on how healthcare is delivered to its population. Most services are provided locally through community hospitals, with no district general hospitals in the health board at all. As a result, the majority of secondary care services – including MS services – are commissioned from adjacent health boards, including from providers in England which patients must travel to.



There are approximately 386 patients with a confirmed MS diagnosis living in Powys that are actively engaged with an MS service provider. 202 of those patients receive MS care from adjacent Welsh health board providers, whose workforce and services have been described in the corresponding sections within this report. Therefore, this section will focus on the workforce and services provided by the Royal Wolverhampton Trust (RWT) (accessed by patients in North Powys), and by the Wye Valley Trust (WVT) in Herefordshire (accessed by patients in South Powys).

Current Powys workforce

Table 26: The current whole-time equivalent (WTE) workforce at each provider for Powys Teaching Health Board patients*

● *indicates WTE is above Wales average,* ● *indicates that it is on par (+-0.1) with the average,* ● *indicates it is below Wales average*

Workforce	Wales Average	Royal Wolverhampton Trust (North Powys)		Wye Valley Trust (South Powys)		Betsi Cadwaladr		Aneurin Bevan		Swansea Bay		Cardiff and Vale		**Total**	
Patient number		104	Per 1,000	80	Per 1,000	97	Per 1,000	71	Per 1,000	32	Per 1,000	2	Per 1,000	**386**	**Per 1,000**
Consultant MS neurologists	1.7	0.0	0.0 ●	0.2	2.0 ●	0.1	0.8 ●	0.2	2.3 ●	0.0	0.0 ●	0.0	2.0 ●	**0.4**	**1.0** ●
MS nurse specialists	2.5	0.3	2.8 ●	0.2	2.3 ●	0.1	1.2 ●	0.2	3.2 ●	0.1	3.13 ●	0.0	2.5 ●	**0.9**	**2.4** ●
Neuro-pharmacists	0.7	0.1	0.8 ●	0.0	0.0 ●	0.0	0.2 ●	0.1	1.7 ●	0.0	0.0 ●	0.0	0.5 ●	**0.2**	**0.6** ●
MS occupational therapists	0.3	0.0	0.0 ●	0.1	0.8 ●	0.0	0.4 ●	0.0	0.0 ●	0.0	0.0 ●	0.0	0.5 ●	**0.1**	**0.3** ●
Neuropsychologists	0.2	0.0	0.0 ●	0.0	0.0 ●	0.0	0.0 ●	0.0	0.0 ●	0.0	0.0 ●	0.0	0.5 ●	**0.0**	**0.0** ●
Neuro-physiotherapists	1.0	0.0	0.0 ●	0.0	0.0 ●	0.2	2.3 ●	0.0	0.0 ●	0.0	0.0 ●	0.0	1.0 ●	**0.2**	**0.6** ●
Non-clinical administrative staff	2.3	0.6	5.7 ●	0.0	0.5 ●	0.1	1.4 ●	0.2	2.8 ●	0.1	3.13 ●	0.0	3.0 ●	**1.2**	**3.2** ●
Advanced MS Champions	0.0	0.0	0.0 ●	0.0	0.0 ●	0.0	0.0 ●	0.0	0.0 ●	0.0	0.0 ●	0.0	0.0 ●	**0.0**	**0.0** ●

**This table does not include the clinicians based in Stoke that Powys patients have access to, as this data was not available.*

Overview of services and treatment provision for North Powys from Royal Wolverhampton Trust

Top 3 priority workforce gaps for North Powys

1 **Consultant neurologist**
North Powys patients' neurology consultant access is primarily in Shrewsbury, however at present there is no consultant in post there due to a retirement with the position still unfilled, meaning the only access to consultant clinics is the satellite clinic in Telford once a week.

2 **Neuropsychologist**
There is no provision of neuropsychology support, with patients referred to local non-MS or neurology specific support.

3 **MS nurse specialist**
There is no dedicated MS nurse specialist for North Powys. An MS nurse who can offer home visits for remote patients would be very valuable to the service.

RWT provides care for 104 patients with a confirmed MS diagnosis in North Powys, along with 960 English patients across Wolverhampton and the Shropshire area. There is one MS nurse who covers all MS patients in Shrewsbury (350 patients) and Powys.

The MS service holds two local MS nurse clinics for Welsh patients every six weeks, in Welshpool, with patients required to travel to the Shropshire and Telford Integrated Care Board for consultant clinics. Patients also have access to one weekly nurse led clinic in Shrewsbury. The majority of input from paraclinical roles, including OT, neuropsychology and physiotherapy, rely on local and non-MS-specific provision.

Table 27: MS consultant and nurse-led clinics provided by the Royal Wolverhampton Trust and satellite providers, for MS patients in North Wales

	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	1 per week in Telford	6 (mix of new and follow-up)	52	312
MS nurse clinics	2 local clinics every six weeks in Welshpool	10 total across both clinics (mix of new and follow-up)	17	87
	1 clinic a week in Shrewsbury	5 (all follow-up)	52	260

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*

Due to limitations in engagement with providers for Powys patients, the clinic data does not include a breakdown of face-to-face and virtual, or a granular breakdown of new and follow up appointments.

Table 28: Royal Wolverhampton Trust self-reported performance against National Insitute of Health and Care Excellence (NICE) guidelines for Powys patients

NICE guideline[65]	Performance	Further details
Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis	100%	Median time for a follow-up appointment post-diagnosis is 4-6 weeks
Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms	100%	But not all of these are face-to-face
Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year	100%	N/A

Overview of services and treatment provision for South Powys from Wye Valley Trust

Top 3 priority workforce gaps for South Powys

1 **MS nurse**
All MS nurses in the service are currently based in England and unable to provide sufficient support to Powys patients. To ensure optimum care delivery, the service requires a WTE nurse who is dedicated to Powys patients and is based locally.

2 **MS occupational therapist**
Given the way the WVT initiates newly diagnosed patients – with a home visit from an MS nurse and an OT – the need for additional MS OT WTE is vital.

3 **MS physiotherapist**
Patients are referred to general physio and neuro-physio locally in Powys, but there is no MS-specific support available to patients in South Powys.

The WVT covers 80 Powys patients with a confirmed MS diagnosis, in addition to 700 patients from Hereford.

All newly diagnosed patients are seen by a general consultant at the WVT County Hospital. The consultant neurologist and general consultant will establish the diagnosis but will not provide follow-up. All DMTs are managed in collaboration with the Queen Elizabeth Hospital MS services with the infusions being delivered in Birmingham. Following diagnosis, the WVT will provide a home visit from an MS nurse and OT focused on education and wellbeing (diet, exercise and brain health). South Powys MS patients then have access to a MS nurse led follow-up clinic that runs once a month more locally in Llandrindod.

Table 29: MS consultant and nurse-led clinics provided by the Wye Valley Trust, for MS patients in South Wales

	No. of clinics	Individual clinic template appointments	Annual no. of clinics*	Patient capacity/ year
Consultant clinics	8 general neurology consultant clinics per week	10 (all new)	416	4160
MS nurse clinics	1 local clinic per month in Llandrindod	10 follow-up	12	120

**The number of annual clinics is based on 52 working weeks however, the actual annual number will be marginally less due to annual leave and study leave.*

Due to limitations in engagement with providers for Powys patients, the clinic data does not include a breakdown of face-to-face and virtual, or a granular breakdown of new and follow up appointments.

Table 30: Reported performance of Powys Teaching Health Board against NICE guidelines

NICE guideline[66]	Performance	Further details
Offer the person with MS a face-to-face follow-up appointment with a healthcare professional with expertise in MS to take place within 6 weeks of diagnosis	90%	Median time to appointment is 4 weeks after receiving referral
Assess and offer treatment for relapses of MS that affect the person's ability to perform their usual tasks, as early as possible and within 14 days of onset of symptoms	100%	Telephone triage of relapse is provided within 24 hours of reporting relapse, with a 6 week follow-up in clinic to review recovery
Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year	100%	This is done through a mixture of face-to-face, virtual and telephone

Current services and treatment provision

Map 7: MS service locations that can be accessed by PTHB patients

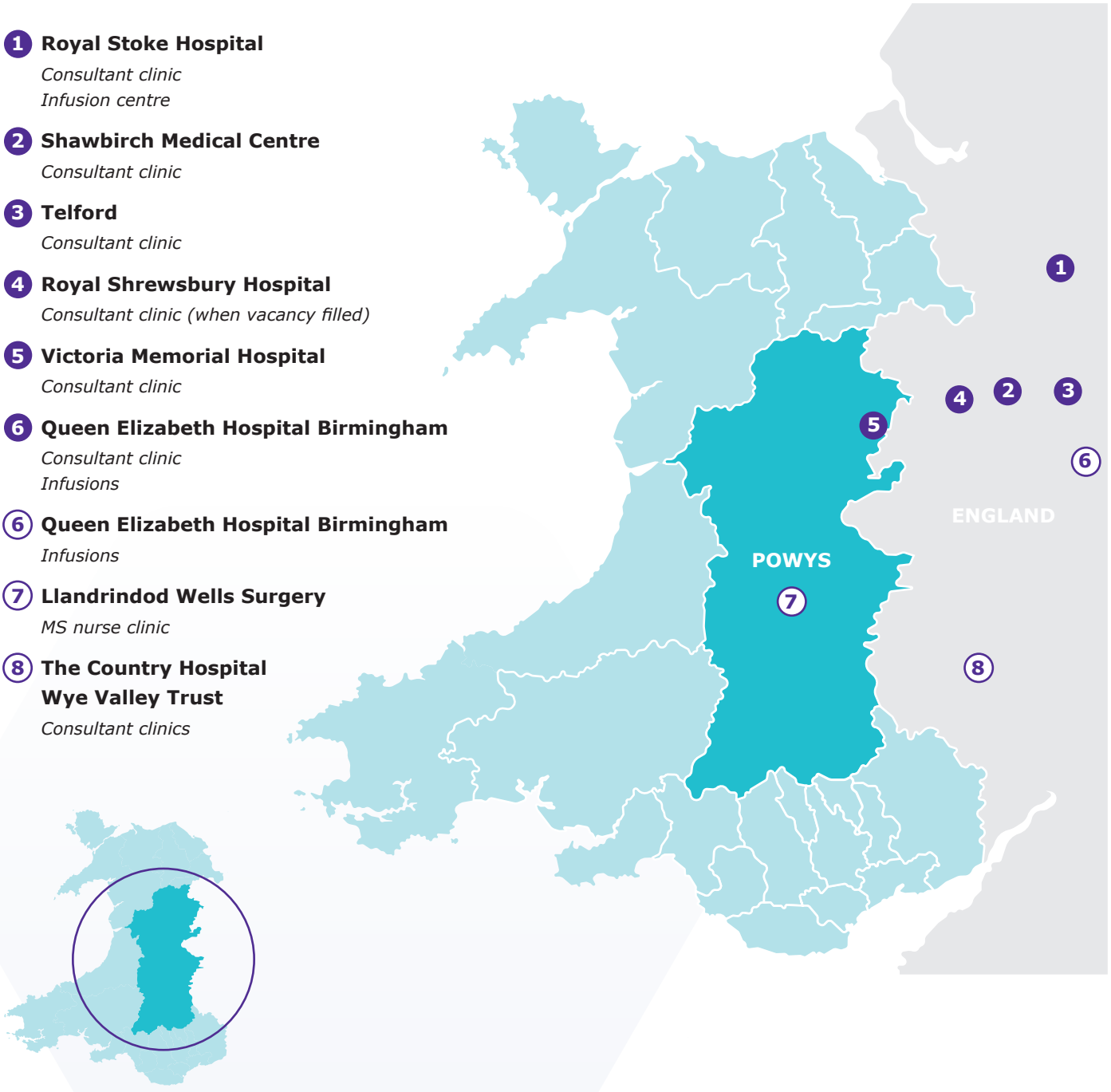
● *indicates RWT provided,* ○ *indicates WVT provided*

1. **Royal Stoke Hospital**
   Consultant clinic
   Infusion centre
2. **Shawbirch Medical Centre**
   Consultant clinic
3. **Telford**
   Consultant clinic
4. **Royal Shrewsbury Hospital**
   Consultant clinic (when vacancy filled)
5. **Victoria Memorial Hospital**
   Consultant clinic
6. **Queen Elizabeth Hospital Birmingham**
   Consultant clinic
   Infusions

(6) **Queen Elizabeth Hospital Birmingham**
Infusions

(7) **Llandrindod Wells Surgery**
MS nurse clinic

(8) **The Country Hospital Wye Valley Trust**
Consultant clinics



22%
of patients on a high-efficacy[7] DMT first line

76%
of patients ever received a DMT

Overview and analysis

Based on interviews with the SBUHB MS team, this section sets out further details of MS service provision across the health board with a particular focus on resource challenges and gaps which, if addressed, would support the team to optimise their service.

Following our interviews with MS clinicians in each provider, we outline in this section specific reflections on the delivery of care to patients in PTHB.

Disparity in provision

The provision of care for MS patients in PTHB varies depending on the health board or service they engage with, underlining the disparity in MS care across Wales.

In RWT and WVT, patient access to neurologist consultant clinics is limited. South Powys patients are diagnosed by a consultant at the WVT County Hospital, with any and all follow-up handled by MS nurse clinics. Similar issues are seen in the RWT service, where patients can only see a consultant in the satellite clinic in Telford which currently occurs once a week.

Powys patients also have limited access to neuro rehabilitation services. Neither Trust provide a local neurorehabilitation service, and as a result patients are referred to specific and separate disciplines across several providers that are often not easily accessible for patients who need them. Whilst patients can access some relevant related local services, this is not comparable to the MS-specific care that patients in other areas of Wales have access to.

Travel impacting treatment choice

Given the geography of Powys and the location of the services providing MS care, patient journey times are impacting patient access to care. For the WVT and RWT services, long travel times have the most impact on patients attending DMT infusions. Powys patients usually are required to travel to Birmingham's Queen Elizabeth Hospital to access high-efficacy[7] DMT infusions. The travel time for this can be over a 6 hour round trip. As a result, some patients are deciding on treatment and care plans to avoid travel to Birmingham, opting for oral medications or self-administered injections. The resultant impact on treatment selection is evident with only 20% of Powys patients covered by RWT MS service and 15% from the WVT MS service currently receiving a high-efficacy[7] DMT. The team did note that most newly diagnosed patients do choose a high-efficacy[7] DMT despite the travel challenges. They suggested the low proportion of patients on a high-efficacy[7] DMT may be due to the introduction of high efficacy DMTs relatively recently, in 2022, for Powys patients, so patients diagnosed prior to this may have chosen a different treatment and decided not to switch.

Need for local services

In Powys it was reported that the impact of journey times was more pronounced for the more elderly or more disabled patients, for whom limitations in ability to travel already exist. Whilst this is an issue for access to all MS services, both trusts highlighted the importance of having a Powys based MS nurse to increase access to MS care for patients. Despite the team noting that the MS nurse caseload in South Powys is manageable with the one monthly MS nurse clinic in Llandrindod, the patient caseload per 1.0 WTE nurse is at 444, above the MS Trust recommended 315.[67] Furthermore, the service also provides home visits for new patients; despite the time required to provide these visits, the local specialist considered them a valuable tool in managing patients more effectively in the long-term and establishing partnerships. The situation is more challenging in North Powys where patients only have access to two MS nurse clinics every six weeks in Welshpool, with no additional local access or home visit provision. One patient described the travel inconvenience to them:

"I have to travel 1 – 2 hours and take the whole day off work"

MS Society Cymru patient survey responder, South-West Wales

To support Powys patients, it was also noted that there is a need for an MS coordinator, a dedicated phlebotomy service and a dedicated pharmacist to support DMT patients. South Powys currently relies on the pharmaceutical industry's support and GPs to fill these service gaps, with primary care team members expressing discontent at delivering secondary care phlebetomy.

Rural location impacting recruitment

There is currently a neurology consultant vacancy in Shrewsbury, leaving North Powys patients with no dedicated MS consultant service. With only one monthly nurse clinic in Llandrindod and only two clinics every six weeks in Welshpool, it was also noted by both services that more local MS nurse provision is needed for patients across Powys. The issue in both cases however is not necessarily funding for these positions, but instead difficulty recruiting for such rural locations. Whilst there is a pool of locums who could fill the Shrewsbury consultant vacancy, they are often from abroad and therefore do not have a UK driving licence, making travel to and from the hospital difficult due to poor public transport.

Lessons from Powys

Both Trusts report strong performance against NICE guidelines, but it has been reported by investigators that more local clinical services are needed for the rural population as patients are having to travel to England to attend MS nurse and consultant MS neurologist clinics.

Conclusion: Key themes and recommendations

Key themes

Based on the challenges and learnings identified in each health board, this section outlines the key themes that have emerged in MS care provision in Wales and recommendations for delivering optimum care.

Geographic barriers to access

The geography in Wales creates challenges for MS patients accessing the care they need. Extended travel distances (sometimes requiring a six hour round trip) and poor public transport services make attending clinics and other MS services challenging and are exacerbated by impaired mobility (including from walking and gait difficulties, spasticity and fatigue)[68] for many MS patients. Across multiple health boards, it was reported that patients make treatment decisions based on travel times, rather than solely on clinical considerations. Whilst virtual appointments are increasingly utilised across health boards to address these geographical challenges, inherent limitations exist in remote monitoring, assessment, and support of MS patients that must be considered when implementing virtual solutions. Similarly, the remote geography has an impact on the workforce with some nurses travelling up to two hours to cover different local clinics in remote areas. Clinicians may also not view working in remote hospitals as attractive compared to urban settings due to the lack of infrastructure, research and specialist facilities.

Local leadership

The investigators highlighted the need for supporting dynamic local leadership with a comprehensive understanding of regional constraints and existing infrastructure. Strengthening local leadership and governance processes could help address geographical challenges and ensure the quality of MS services in Wales are maintained in the face of a rapidly evolving MS treatment landscape and other advances in MS management. In addition, it was suggested that having a representative local leadership team and a forum to meet would enable more collaborative and regular service evaluation and redesign to address specific challenges for each region.

Workforce capacity constraints

The UK faces a shortage of neurology consultants when compared to European counterparts. The situation in Wales is exacerbated by the impending retirement of seven senior consultants over the next 5 years, without adequate succession planning. MS nurse capacity is similarly strained, with caseloads exceeding recommended levels and further threatened by eight imminent nurse retirements. Critically, all health boards also highlighted, the insufficient neuropsychology services for MS patients. This results in health boards relying on general psychology (where available), local mental health services and third-sector organisations. Evidence of the value of MS-specific neuropsychology care is robust,[69] yet this remains a significant gap in the delivery of optimum MS care in Wales. Maintaining advocacy and pressure to maintain and improve MS services in the face of these constraints and gaps is essential.

Comprehensive service assessment

While NICE guidelines serve as important metrics for MS service evaluation, these standards alone provide an incomplete assessment of service effectiveness and patient outcomes. Despite generally satisfactory performance against NICE guidelines reported by each of the health boards, challenges persist including:

- Limited patient access to comprehensive multidisciplinary teams
- Substantial variation in DMT availability and use

There was a lack of consensus on the value and prioritisation of the NICE guideline for an in-person annual review. Some teams argued PIFU approaches are preferable as they allow for more responsive care tailored to patients' progression and needs while optimising limited workforce capacity. There was variable use of remote consultations and reviews which were not offered consistently across regions.

Recommendations

In order to address the challenges set out in this report and to ensure that MS teams are adequately supported to deliver optimum and appropriate care to patients across all of Wales, contributions are needed from local and national decision makers, as well as industry and the third sector. As such, the recommendations below are aimed at a system wide approach.

1 Establish a new MS specialist centre for mid-Wales

Due to the challenging geography and fragmented MS service for patients in Powys, there is a lack of local accountability for patients commonly receiving care from other health boards. This can have an effect on patient safety monitoring, appointment travel time, and inconsistent commissioning policies, all of which can influence treatment choices and affect patient outcomes. Implementing an independent MS specialist centre for Powys with local responsibility would reduce necessity for patients to seek care from other health boards, allow more efficient inward investment and improve local MS services for local patients.

2 Continue development of an independently resourced MS specialist centre in North Wales

Whilst South Wales has three specialist centres, North Wales remains under resourced and is reliant on the Walton Centre, in Liverpool, resulting in patients frequently travelling across national boundaries to access services. This partnership should continue but with a dedicated funding stream for MS services in North Wales, separate from general neurology budgets. Additionally, more sufficient funding and resources should be provided to BCUHB to develop a more locally resourced MS centre in Glan Clwyd hospital. This could reduce the care gradient currently evident across Wales while complementing the Walton Centre's ongoing role. Such investment would likely attract and retain specialist staff, and strengthen patient engagement with research opportunities. The current resident specialist team is performing well with the limited resources currently available, however, they would be able to deliver at a higher level with greater flexibility and sustainability to address the region's challenges.

3 Develop minimum service requirements for HCPs per 1000 patients

Whilst there is guidance from the MS Trust on the recommended patient caseload for MS nurses (315 per WTE nurse), there are no comparable figures for other roles. The service evaluation contributors suggest expanding guidance to encompass consultants and administrative staff. Initial estimates based on data provided from investigators suggest a maximum caseload of 400 per specialist MS consultant, 0.5 WTE secretary per consultant and 2 care coordinators per 1500 patients. Additional work is required to provide caseload estimations for other HCPs including physiotherapists, occupational therapists, and neuropsychologists. Recruitment to all these allied HCP roles remains crucial to enable delivery of a holistic and high-quality MS service.

4 Standardise policy and processes for annual reviews

Availability of several aspects of specialist MS services demonstrate considerable variability across health boards which include PIFU, domiciliary visits, specialised clinics and remote consultations. Whilst these aspects of clinical care are not specifically mentioned in NICE clinical guidelines, they offer benefits for patients in remote locations or with difficulty accessing services and should be provided via a standardised protocol. There was a strong consensus on the value and importance of domiciliary appointments to selected patient groups which should be enabled in all health boards.

5 Implement and encourage an MS specific EPR across Wales

Continued development of a national specialist EPR, such as PatientCare and MSBase, should be encouraged. Compatibility of individual systems and how they align with national systems such as the WCP remains a challenge. PatientCare currently enables all patient data to be available in a standardised format across NHS Wales with approximately two-thirds of all MS patients already registered, offering a realistic goal of engaging all remaining sites. Whilst there are concerns regarding HCP time to input data and a period of frontloading data before it becomes useful, the benefits outweigh these issues and would allow standardised comparison of services. Data input of electronic clinical records should be a component of job descriptions.

6 Prioritise succession planning through engagement and training

A focus on students, resident doctors and other HCPs will be required in order to encourage and identify MS specialists of the future. This can be achieved through engagement with curricula development, expansion of research and clinical trial activity, fellowship programmes and a wider exposure to regional MS specialist teams. All relevant HCP disciplines (i.e. neurologists, physiotherapists, neuroscience nurses etc.) should have dedicated exposure to neuroinflammatory/MS specialist services during their training. These steps could strengthen Wales' reputation for high quality care, attract HCPs and generate a sustainable model for staff appointment and retention.

Next steps

Advocacy

This paper and its accompanying infographic / summary page will be used as an advocacy tool by Welsh health boards and MS organisations such as the MS Society Cymru, patient representatives and the Wales Neurological Alliance, to target the following roles for the above recommendations to improve MS services across Wales:

- Chief Executive Officer for each health board
- Chief Pharmacist for each health board
- Chief Nurse Director
- Chief Medical Officer
- Clinical Lead for Neurological Conditions
- Cabinet Secretary of Health & Social Care
- Members of the Senedd
- National Strategic Clinical Network for Neurological Conditions
- Welsh members of Parliament

This paper is also available in Welsh.

Success metrics

All investigators agreed progress should be tracked against metrics on a regular basis. The team suggested repeating this audit exercise with a limited scope in 2026 including the following metrics for each health board:

1. All previously collected WTE data for the same roles
2. Number of new diagnoses
3. Average referral to treatment duration
4. If the above answer is over 30 days, what is the reason for this?

Improvements

The investigators agreed on two improvement points for future iterations of this project:

1. Wider representation of allied health professionals such as neuro-pharmacists, occupational therapists, physiotherapists
2. More involvement from the MS Society Cymru with a patient survey with questions of their choice and adequate time to reach a large sample of patients with adequate representation from each health board

Appendix 1

Health board questionnaire

Current workforce across your service

1. Total number of WTE MS clinical and non-clinical HCPs in service
2. Total number of WTE consultant neurologists
3. Total number of WTE MS nurse specialists
4. Total number of WTE MS pharmacists
5. Total number of WTE occupational therapists
6. Total number of WTE neuropsychologists
7. Total number of WTE physiotherapists
8. Total number of WTE non-clinical administrative staff (e.g. data managers/unit managers)
9. Total number of WTE Advanced MS Champions

Future workforce predictions

1. How many consultant neurologists are expected to completely or partially retire in the next 5 years?
2. How many MS pharmacists are expected to completely or partially retire in the next 5 years?
3. How many MS nurse specialists are expected to completely or partially retire in the next 5 years?
4. How many occupational therapists are expected to completely or partially retire in the next 5 years?
5. How many neuropsychologists are expected to completely or partially retire in the next 5 years?
6. How many physiotherapists are expected to completely or partially retire in the next 5 years?
7. How many non-clinical administrative staff are expected to completely or partially retire in the next 5 years?
8. Is there a risk of redeployment within your service?
9. Is there an active succession plan within your service?
10. What are your biggest resource challenges?
11. Where are the gaps in your team?

Caseloads

1. What is your total active patient caseload?

Service coverage and provision

1. Which health boards do you cover?
2. Do you offer any specialist services? (e.g. sexual dysfunction clinic / bowel and bladder clinic)

3. Do you feel there is a non-MS clinical demand on your time or the time of your colleagues? (e.g. CIS/MOGAD)
4. Are there any gaps in your service?
5. Do you have a local neuro-rehabilitation service?

Service allocation

1. How many MS clinics are there in your health board?
2. How many templates (e.g. new versus follow up patients) are in your clinic?

Recommendations/suggestions for service improvement

1. Any final comments on what is missing from your service and where it is missing from?
2. Do you have any recommendations on how to address these service challenges?

Appendix 2

MS Society Cymru patient perspective

1. Do you feel you have sufficient access to your consultant neurologist and MS nurse?
2. Which services would you value having increased access to as part of your MS care?
3. Do you have any challenges with your current care or in accessing the services you need and how does this impact your quality of life?
4. What works well in your MS service?
5. Are the distances you have to travel to access MS services manageable?
6. If not manageable, please provide further details of why.

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