

Questions submitted by members of the public to the BSW ICB Board meeting – 18 March 2026

Myalgic encephalomyelitis (ME) services in BSW

People living with Myalgic Encephalomyelitis (ME) have experienced decades of neglect and abuse, due to history since the late 1980s of the illness being wrongly framed through psychological and rehabilitation narratives rather than biomedical care. Around 1.35 million people in the UK live with ME or ME-like symptoms; including families and carers, several million are affected. Many patients are young, more female, and many remain severely ill for years or decades or never recover, unable to participate in life through education, employment, or social life.

The economic burden is substantial. Tessa Munt MP cited costs were £3.3 billion/year in In 2014–15, which do not account for post-COVID prevalence or economic shifts. Recent estimates suggest costs may now exceed £20 billion. The first National Delivery Plan (July 2025^{***}) needs to be mandated with funds to address research, patient safety concerns (harm caused by lack of PEM risk assessment by NHS staff, the need for parity to change the NHS to a biomedical model, leaving vested interests of psycho/social/rehab 'NHS CFS experts' (such as Oxford and Liverpool's Infectious Disease and CFS rehab/psycho services) behind. The injustice caused to patients in the UK today is beyond any other illness; this requires urgent biomedical specialist services be commissioned.

To assist in the forward progression of the DHSC Delivery Plan, clarity and transparency, I would be grateful if the BSW-ICB Board could respond to each of the four points in turn:

1. Patient engagement

How will BSW-ICB engage meaningfully with the Patient Voice of people living with ME and Long COVID, and their carers, to inform commissioning? How will the ICB ensure engagement is **not limited to current providers or stakeholders**, but includes independent patient organisations, biomedical clinicians and researchers, and lived experience, reflecting **NICE Guideline NG206: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome**? How will the ICB prevent current service providers from shaping commissioning where conflicts of interest exist? Engagement should reflect the **multidisciplinary biomedical approach to this illness**, with rehabilitation / fatigue-focused perspectives removed.

ME/CFS services provided in BSW by the Royal United Hospitals, Bath (RUH) are delivered in line with NICE Guideline 206 (NG206).

NICE undertakes patient engagement nationally during the development of all NICE guidance, including NG206 on ME/CFS. This includes a formal, structured and mandatory process for involving patients, carers and the public in the development of all NICE guidance. They are involved throughout the entire process. NICE specifically involves lay members on every guideline committee; these may include:

- Individuals with lived experience
- Carers
- Members of patient organisations

Locally, BSW ICB remains committed to involving people with lived experience in our service planning and commissioning. We ensure our engagement work reaches a broad range of voices by actively connecting with patient and carer organisations, independent support groups, community-based organisations and wider system partners. We also promote engagement opportunities across BSW through our website, social media, newsletters and face-to-face meetings. This approach helps ensure that input into commissioning is inclusive, diverse and not limited to current providers.

2. Specialist biomedical services

What plans exist to commission and develop consultant-led biomedical specialist services for ME within the region, led by internal medicine Consultants and aligned with national guidance? Has the BSW - ICB explored collaboration with experienced Patient group - validated clinicians offering to support building NHS services, such as The Long COVID Clinic founder, Dr. Binita Kane, Respiratory Consultant*?

Collaboration was carried out by NICE in the production of those management principles.

As stated previously ME/CFS services provided by RUH are delivered in line the NICE guideline.

3. Workforce education

When and how will the BSW - ICB require ALL staff to take the NHS ME/CFS e-learning modules (Levels 1–3)? How many staff are employed directly or indirectly by the BSW-ICB? How many have taken the 3 modules of these very short remote courses please? These modules are essential for understanding **Post-Exertional Malaise** to ensure patient safety clinically in all settings and in commissioning and SEND EHCPs. Will the ICB monitor and publicly report uptake, including sharing progress with the **All-Party Parliamentary Group on Myalgic Encephalomyelitis**?

Staff learning programmes are designed to ensure they are appropriate to the level and role of individual members of staff. Most staff at the ICB are not responsible for, or have involvement in, the commissioning of services for people with ME/CFS. Where they did, training would be provided as needed.

We do not currently publicly report training data or submit information to the APPG.

We would be happy to provide the further detailed information requested under the Freedom of Information Act, within 20 working days of the date the questions were submitted.

4. Accountability and service development

What measurable steps will BSW-ICB take over 12–24 months to improve access to remote assessment, specialist care, and biomedical symptom management? Will the ICB commission **at least two consultant-led hubs alongside current internal medicine departments** to provide biomedical expertise, prescribe to manage symptoms, and oversee and direct existing auxiliary “fatigue” services and any in-hospital situations? How will services be upgraded to align with **NG206**, including assessment, treatment, and equitable (Equality Act 2010) access to NHS services and diagnostics for housebound and often bedbound Severe ME patients of which it is a known estimate that 25%** of the ME patient population are or become?

The services we commission are in line with the NICE guideline. There is no requirement for consultant-led biomedical specialist services within NG206. Specialist teams have a range of healthcare professionals, commonly including medically trained clinicians from a variety of specialisms.

5. Senior responsible officer

Finally, please specify the senior officer responsible, the timeframe for reporting progress to patients and stakeholders, and how this progress will be reviewed publicly.

Please note: as the statutory local commissioner, the BSW-ICB is responsible for commissioning in line with NICE guidance and cannot delegate accountability to NHS England,; the response should describe actions the BSW - ICB will take locally.

A clear response will help patients, carers, and stakeholders understand how the BSW - ICB intends to implement guidance and address inequalities experienced by people with ME and Long COVID.

The senior responsible officer is David Freeman, Chief Officer for Commissioning and Place.

GP services in Wichelstowe

Question

868 individuals have currently signed a petition for the ICB to commission GP services for Wichelstowe and facilitate the building of the new surgery.

This is affecting increasing numbers of residents in Wichelstowe trying to access local GP services and residents across south and west Swindon, particularly in Wroughton, whose surgeries are currently filling the gap.

There are GP practices that have indicated interest in taking on the Wichelstowe surgery, so will the ICB commit to moving forward as a priority and publish a timetable so Wichelstowe residents have clarity on when a GP surgery will be provided for them?

We want to reassure you that we remain committed to developing a health solution for the Wichelstowe community. Land has been secured and planning permission granted through Swindon Borough Council, and we continue to work closely with the Council to ensure that the site remains safeguarded for future healthcare use.

The approach to health services for Wichelstowe forms part of a wider programme to develop neighbourhood health plans across Swindon. This work will introduce integrated neighbourhood teams, bringing together primary care, community health services, local authority colleagues, and voluntary and community sector organisations. These teams will support residents through a range of planned, preventative and targeted interventions, from promoting healthy living to providing more intensive same-day support for people with complex health needs. Care will be delivered through a combination of community hubs, GP practices and services provided in people's homes.

This model is being developed in line with national guidance on neighbourhood health and within the resources available and will be implemented progressively over the coming years. The timing and nature of any new health facility at Wichelstowe will be informed by the wider strategic planning and prioritisation process, which considers population needs, service models, funding availability, and system-wide priorities across the BSW health and care system. At this stage, a confirmed delivery date for a health centre at Wichelstowe has not yet been agreed.

In the meantime, can I reassure you that residents of Wichelstowe access health services through existing primary care, community health, and secondary care facilities across Swindon. Most residents are registered with GP practices located elsewhere in the town, including central and west Swindon, depending on individual registration and availability. Community health services, such as district nursing, health visiting and some clinics, are provided at established sites across Swindon and, where appropriate, in people's homes. Outpatient, diagnostic, and specialist services are accessed through existing NHS facilities, including Swindon Health Centre and Great Western Hospital.

This position does not represent a change in our intent but reflects the need to ensure that any future investment is aligned with the broader strategic planning work currently underway across the BSW system. We recognise the importance of this issue to residents and will continue to work with partners and stakeholders, including Swindon Borough Council, as the programme progresses.