Written evidence submitted by Action for ME

11 June 2026

About Action for ME

Action for ME is the leading UK charity supporting people of all ages living with Myalgic Encephalomyelitis (ME), providing healthcare services, information and support, and funding research into the condition. The charity provides holistic healthcare, information and support services to people with ME of all ages and their families, and supports research into ME.

ME is a complex, chronic and disabling condition affecting multiple systems in the body. It is characterised by debilitating fatigue, pain, cognitive dysfunction and hypersensitivity to light, sound and movement. The hallmark symptom is post-exertional malaise, where even minimal activity can cause a significant worsening of symptoms.

An estimated 1.35 million people in the UK are living with ME or ME-like symptoms, although the true scale is likely higher due to underdiagnosis and limited research.

Throughout this submission, there are references to Action for ME’s Big Survey, which gathered data from over 5,000 adults, children and young people living with ME and Long Covid in the UK. All responses were submitted between October 2025 and January 2026.

Executive summary

The Bill seeks to improve accountability, patient safety and service consistency. For people with ME, current arrangements have failed to deliver these objectives despite existing NICE guidance (NG206). The amendments proposed below would strengthen the Bill's ability to achieve its own aims while benefiting other complex, long-term conditions.

1. Research, innovation and post-infectious disease

- The Bill should be amended, or supported by statutory guidance, to ensure that the Secretary of State’s innovation and research duties are used to accelerate research into under-researched conditions such as ME.
- **Clause 6** should be strengthened so that innovation includes the translation of biomedical research into diagnostics, treatments, clinical trials and new models of care, not only new technologies or service efficiencies.
- Despite its prevalence, severity and economic impact, ME continues to receive disproportionately low levels of research investment compared with comparable long-term conditions. Better cost-of-illness data is needed to demonstrate the wider impact of ME on the NHS, social care, welfare system, families and the economy.

Recommended amendment:

- **Clause 6, page 3, line 10,** after “services” insert *“including through biomedical research and its translation into clinical practice.”*

- **Clause 6, page 3, line 15**, after “research” insert “*including research into under-researched conditions”.*

- **Clause 6, page 3, line 20, insert 5th subsection: T**he Secretary of State must publish an annual statement setting out how the duty under this section has been exercised in relation to under-researched conditions.

2. Strengthening NICE compliance for ME

- The Bill should be amended to strengthen **Clause 58**, which deals specifically with compliance with NICE recommendations.
- This is particularly important for ME because NICE guideline NG206 has been in place since 2021, but implementation remains poor and inconsistent across the NHS.
- 82% of Action for ME's Big Survey respondents living with severe and very severe ME reported receiving no follow-up care, monitoring, or review, from either their GP or specialist team.
- **Clause 58** currently provides that regulations *may* include provision about the time period within which a NICE recommendation must be complied with. This should be strengthened so that regulations ***must*** include a compliance period where NICE recommendations relate to conditions with significant variation in access to diagnosis, treatment, specialist services or care.
- This would help ensure that NICE NG206 is not treated as optional guidance, but as a standard that NHS bodies and ICBs are expected to implement within a clear timeframe.

Recommended amendment:

- **Clause 58, page 43, line 38**, leave out "may" and insert "must".
- Clause 58, page 43, after line 40 insert
    1. (8B) Regulations under subsection (8A) must include provision about the implementation of NICE guideline NG206 on myalgic encephalomyelitis.
    2. (8D) The Secretary of State must publish an annual statement on compliance with NICE guideline NG206, including the extent to which integrated care boards and relevant NHS bodies have implemented recommendations relating to ME specialist services and severe or very severe ME"

3. Reducing variation and strengthening accountability for ME services

- The Health Bill should be amended to ensure clear national accountability for the commissioning, quality and accessibility of ME services, rather than transferring existing gaps in accountability from NHS England to the Secretary of State and Integrated Care Boards (ICBs).
- **Clause 11 and clause 20** should be amended so the Secretary of State must set, publish and monitor national minimum standards for ME services. These standards should include access to ME specialist teams, children and young people's pathways, severe and very severe ME provision, and home-based care.
- ME care remains highly inconsistent across the country, and 83.2% of Action for ME's Big Survey respondents told us that they experienced barriers to accessing NHS ME services.
- NICE NG206 already requires referral to an ME specialist team and recommends that people with severe or very severe ME are offered home visits for assessment and care planning, but access to appropriate services remains uneven.
- In 2023 Action for ME released an FOI report into the implementation of the 2021 NICE Guideline (MG206) on ME, which found that only 28% of NHS Trusts and ICBs had implemented the guideline. Furthermore, it revealed that fewer than one in four NHS Trusts are able to track their ME patients. This points to a wider problem in the diagnosis of ME whereby the excessive range of codes available to GPs often leads to the disease being recorded inaccurately. This brings into

question the official figures and we suspect that many people are falling through the cracks.

Recommended amendment:

- **Clause 11, page 6, line 30, insert:** The Secretary of State must exercise powers under this section to secure equitable access to appropriate services for people with ME and other long-term conditions.

- **Clause 20, page 15, line 25**, insert: “(2A) In conducting a performance assessment under this section, the Secretary of State must assess how effectively the integrated care board has discharged its functions in relation to the commissioning, accessibility, quality and outcomes for people with ME.

4. Single Patient Record, data and patient voice

- The Bill should be amended to ensure that the Single Patient Record improves safety and continuity of care for people with ME by recording reasonable adjustments and key care needs, not just standard clinical information.
- **Clauses 47, 50 and 58** should be amended, or supported by statutory guidance, to ensure ME can be consistently identified, monitored and analysed across NHS data and that severity and access to specialist care can be monitored, and that NICE NG206 implementation is tracked.
- **Clauses 15 and 65** should be amended to require accessible patient involvement, including through voluntary and community organisations representing people with ME. This is particularly important because many people with severe or very severe ME cannot participate in standard engagement exercises.

Recommended amendment:

- **Clause 47, page 34, line 30** insert: (4A) Regulations under this section must make provision to ensure that the single patient record is capable of recording information necessary to support safe and continuous care for people with complex, fluctuating or energy-limiting conditions, including ME.

- **Clause 47, page 34, line 37, after subsection (6) insert:** (6A) Consultation under subsection (6) must include consultation with patients, carers, relevant clinical bodies, and voluntary and community organisations representing people with complex, fluctuating or energy-limiting conditions, including ME.

Expanded justification for amendments

1. Research, innovation and post-infectious disease

The Health Bill should be strengthened to ensure that the Secretary of State’s innovation and research duties are used to accelerate progress for under-researched illnesses such as ME.

ME remains significantly under-researched relative to its prevalence, severity and economic impact. Private investment has historically been limited because of scientific uncertainty, a lack of established biomarkers and an underdeveloped clinical research pipeline. This has contributed to a cycle in which limited research investment slows progress on diagnostics, treatments and clinical trials, while the lack of established clinical tools makes it harder to attract further investment.

There is now an opportunity to break this cycle. ME is increasingly being understood within the broader field of post-infectious conditions. Major UK research studies, including DecodeME, LOCOME and SequenceME & Long Covid, are helping to build momentum and improve scientific understanding. The Government should use the Bill to position the UK as a leader in post-infectious disease research, with ME as a central part of that agenda.

Clause 6 places a duty on the Secretary of State to promote innovation in the provision of health services. This should be amended, or supported by statutory guidance, to make clear that innovation includes the translation of emerging biomedical science into diagnostics, treatments, clinical trials and improved models of care. For ME, innovation should not be limited to digital tools, new technologies or system efficiencies. It should also include targeted action to address long-standing research neglect and to move promising science into clinical practice.

Clause 6 should therefore be amended, or supported by statutory guidance, to ensure that innovation and research duties include:

- targeted support for under-researched and high-burden conditions such as ME;
- the translation of biomedical research into diagnostics, treatments and clinical trials;
- development of the UK's post-infectious disease research capacity;
- improved research infrastructure and clinical trial readiness for ME;
- better cost-of-illness evidence on the economic and social impact of ME;
- mechanisms to ensure emerging evidence informs service design and NICE implementation.

This would not create a special exemption for ME. It would ensure that the Bill's innovation agenda reaches conditions where scientific need, patient need and economic impact are significant, but where historic underinvestment has held back progress.

2. Strengthening NICE compliance for ME

Clause 58 is highly significant for people with ME because it directly concerns compliance with NICE recommendations. NICE guideline NG206 has existed since 2021 and sets out clear expectations for ME care, including referral to ME specialist teams and appropriate support for people with severe or very severe ME. However, implementation has been poor and inconsistent.

The problem is not simply the absence of guidance, but rather that existing guidance has not been implemented consistently, and there is no clear national mechanism requiring NHS bodies or ICBs to comply with NG206 within a defined timeframe. This has contributed to a postcode lottery in ME care, with some patients unable to access specialist support, appropriate care planning or home-based provision.

Clause 58 provides an opportunity to address this gap. As currently drafted, it states that provision about NICE compliance ***may*** include a time period within which a recommendation is to be complied with. This should be strengthened from *may* to ***must***. Without this change, the Bill would leave it optional whether NICE recommendations are accompanied by a clear compliance timetable.

For ME, a compliance timetable is essential. NG206 includes recommendations that are directly relevant to patient safety, including specialist assessment, care planning, support for children and young people, and provision for people with severe or very severe ME. These recommendations should not remain dependent on local discretion or uneven implementation.

Strengthening Clause 58 would not create a special exemption for ME but would ensure that where NICE has issued guidance for conditions with significant variation in care, there is a clearer route to implementation, monitoring and accountability. ME is a strong example of why this is needed, as the guidance exists, but without a clear compliance mechanism, many patients continue to fall through the cracks.

The amendment would therefore support the wider purpose of the Bill by improving accountability, reducing variation and ensuring that national clinical guidance is translated into real improvements in care.

3. Reducing variation and strengthening accountability for ME services

Given the known variation in ME care, the Health Bill should be amended to create explicit national accountability for ME services. Without this, the abolition of NHS England risks moving existing gaps in accountability from one part of the system to another.

The Bill creates powerful new levers for the Secretary of State. **Clause 11** gives the Secretary of State a general power to direct ICBs about whether, when or how a function is exercised, conditions that must be met, and matters that must be taken into account. **Clause 20** also strengthens the framework for assessing ICB performance. These powers should be used to require consistent, measurable ME provision across the country.

We are therefore calling for **clauses 11 and 20** to be amended so that the Secretary of State must set, publish and monitor national minimum standards for ME services. These standards should include:

- access to ME specialist teams;
- children and young people's ME pathways;
- severe and very severe ME provision;
- home-based assessment and care planning;
- monitoring of NICE NG206 implementation.

NICE NG206 already sets out clear expectations for specialist assessment, paediatric expertise and home-based support for people with severe ME. The challenge is not the absence of guidance but inconsistent implementation.

In reality, access to specialist services remains inconsistent. Some areas have no meaningful specialist pathway, some services are not accessible for people who are severely affected, and some patients continue to report care that is not consistent with NICE NG206.

The Government's final ME/CFS Delivery Plan recognises the seriousness of these gaps. It states that care has varied widely, that there are inequalities in service provision, and that patient safety concerns and avoidable deaths must become “never events”. The Health Bill should therefore make ME service accountability explicit rather than leaving it to non-statutory follow-up.

4. Single Patient Record, data and patient voice

The Health Bill should be strengthened to ensure that the Single Patient Record, national data systems and patient voice arrangements work for people with ME.

First, the Bill should require the Single Patient Record to record reasonable adjustments and key care needs for people with ME. **Clause 47** gives the Secretary of State power to make regulations establishing a Single Patient Record. For ME, this could be a major safety improvement if it allows crucial information to follow the patient across primary care, hospitals, social care and emergency care.

However, this will only improve safety if the record captures the practical adjustments patients need. For example, people with severe or very severe ME may need low-stimulus environments, home-based care, shortened appointments, written communication, support to avoid post-exertional symptom exacerbation, and clear information about touch, light, sound or movement intolerance. If the Single Patient Record records only standard clinical facts, it may fail to address the risks that make care unsafe for this patient group.

Clauses 47, 50 and 58 should therefore be amended, or supported by statutory guidance, to ensure that the Single Patient Record and related data provisions support reasonable adjustments, continuity of care and national monitoring of ME services. This should include visibility of ME in NHS datasets, monitoring of severity, and tracking of NICE NG206 implementation. At present, ME is too often invisible in NHS data, making it harder to understand prevalence, service access, patient outcomes and unmet need.

Second, **clauses 15 and 65** should be amended to require accessible patient involvement. Clause 15 creates a public involvement duty for commissioning by the Secretary of State. Clause 65 removes the obligation on local authorities to make arrangements with Local Healthwatch organisations and instead provides for corresponding activities to be performed or arranged by local authorities and ICBs.

These provisions are important for ME because many patients cannot participate in standard engagement exercises. People with severe or very severe ME may be unable to attend in-person meetings, tolerate long calls, use screens, or respond within short deadlines because of the fluctuating and disabling nature of the condition.

The Bill should therefore require accessible involvement rather than merely general involvement. This should include flexible formats, longer response times, written routes for engagement, remote and low-energy options, and involvement through voluntary and community organisations representing people with ME.

The Government should also ensure that changes to Healthwatch arrangements do not weaken independent patient voice. People with ME have historically faced barriers to recognition, diagnosis and appropriate care. Effective and independent mechanisms for raising concerns and sharing patient experience are therefore essential to improving services and accountability.

Conclusion

Action for ME urges the Committee to amend the Bill to ensure that ME is not left behind as NHS accountability is rebuilt. The abolition of NHS England and the transfer of functions to the Secretary of State and ICBs creates an important opportunity to address long-standing gaps in ME care, data and research.

The Bill should be strengthened to secure national minimum standards for ME services, annual ICB performance reporting, accessible patient involvement, better data collection, and a clearer commitment to accelerating ME research through the Government’s innovation and life sciences agenda.

Importantly, these changes would not create a special exemption for ME, but rather would ensure that a serious, historically overlooked and often chronic illness is properly recognised within the new accountability framework, and that people with ME can access safer, more consistent and evidence-based care wherever they live.