

Health Modernisation Bill Second Reading: Briefing for MPs

This briefing has been prepared by the APPG on Spinal Cord Injury to support Members participating in the Second Reading debate on the Health Modernisation Bill. It focuses on two areas of particular importance to spinal cord injury (SCI) patients and their families:

- Proposed changes to specialised commissioning
- The proposed single patient record and opportunities linked to Diagnosis Connect

Members may wish to draw directly from the speaking points contained in this briefing during their Second Reading contributions.

Specialised Commissioning and Spinal Cord Injury

Spinal cord injury is a low-incidence but extremely high-complexity condition. Patients often require lifelong specialist rehabilitation, coordinated community care, specialist equipment, respiratory support, continence support, mental health support, housing adaptations, vocational rehabilitation and ongoing clinical oversight.

The APPG's inquiry last year identified serious systemic failings across the spinal cord injury pathway, including:

- Patients being discharged with no coordinated support
- Severe postcode inequality in access to services
- Delayed or inconsistent rehabilitation
- Poor transition between hospital and community care
- Patients effectively becoming responsible for coordinating their own care
- A lack of long-term follow-up and accountability

Importantly, these concerns are not new. NHS England's own peer review work in 2016 identified many of the same weaknesses almost a decade ago.

Key Concern

The APPG is concerned that moving responsibility for specialised spinal cord injury services into Integrated Care Boards (ICBs) risks worsening fragmentation rather than solving it particularly at a time when ICBs are themselves under intense financial pressure and are being asked to make substantial reductions (50%) in management and operational costs.

Spinal cord injury services require:

- National coordination
- Specialist clinical expertise
- Consistent rehabilitation pathways
- Workforce planning Long-term follow-up
- National standards and accountability
- Strong data collection and oversight

Without robust national safeguards, there is a serious risk that delegation to local systems could deepen regional inequality and reduce consistency of care.

Questions MPs May Wish to Raise

- Where is the national clinical risk assessment for transferring specialised spinal cord injury commissioning into ICB structures?
- Where is the Equality Impact Assessment examining the effect on disabled people and regional inequality?
- How will Government ensure national consistency of care if commissioning responsibility becomes fragmented locally?
- What safeguards will prevent highly specialised services from being deprioritised under financial pressure?
- How will Government ensure specialist workforce expertise is protected and developed nationally?
- What accountability mechanisms will exist if outcomes worsen or regional inequities increase?

Single Patient Record and Diagnosis Connect

The APPG welcomes the ambition within the Bill to develop a single patient record across healthcare systems. If implemented effectively, this could significantly improve continuity of care for patients with complex conditions such as spinal cord injury.

However, the APPG believes digital integration must be matched by service integration.

Many spinal cord injury patients report that, once discharged from specialist centres, they are left to navigate highly complex systems alone including benefits, housing, equipment provision, social care, community healthcare and employment support.

This is particularly problematic because most healthcare professionals outside the eight specialist SCI centres in England have limited experience or training in spinal cord injury.

Diagnosis Connect

Diagnosis Connect is a Government led initiative intended to connect newly diagnosed patients directly into specialist charity and community support pathways.

The APPG strongly supports this principle and identified coordinated referral pathways into specialist third-sector support as one of its immediate recommendations in the APPG inquiry report.

For spinal cord injury patients, early connection into specialist support can provide:

- Peer support and lived experience guidance
- Benefits and financial advice
- Housing and accessibility support

- Advocacy and care coordination
- Mental health and family support
- Employment and rehabilitation guidance

When somebody experiences a spinal cord injury, their life changes instantly. At that moment, patients and families are often not able to self-advocate through fragmented systems.

The APPG believes spinal cord injury is precisely the kind of condition where Diagnosis Connect could have the greatest impact because awareness and expertise outside specialist settings remain limited.

The development of a single patient record presents a major opportunity to integrate Diagnosis Connect pathways directly into the healthcare system from the outset. It is important that the Government uses this opportunity to include this in the Bill, in order to ensure that all patients with long term conditions are able to access directly the invaluable help provided by charities, specific to the conditions.

Questions MPs May Wish to Raise

- Why has Diagnosis Connect currently been restricted to only certain conditions?
- Will Government consider including spinal cord injury within future Diagnosis Connect pathways?
- How will the single patient record connect patients into practical support and advocacy not simply store information?
- Could diagnosis-triggered referral pathways into specialist charities and support organisations be built into the new system architecture?
- How will Government ensure newly injured patients do not fall through gaps between primary care, secondary care and community support systems?

Suggested Speaking Points for MPs

- Moving an already fragmented specialised service into financially pressured ICB structures is not a solution to fragmentation.
- The APPG inquiry found evidence of severe postcode inequality in spinal cord injury services and patients falling through gaps in care.
- NHS England's own peer review work identified many of these same systemic weaknesses nearly a decade ago.
- Spinal cord injury services require stronger national coordination and accountability not weaker oversight.
- The single patient record could be transformative if combined with coordinated support pathways.
- Diagnosis Connect recognises that specialist charities are part of the support infrastructure patients rely upon after life-changing injury.

- Newly injured spinal cord injury patients should not be expected to navigate housing, benefits, equipment and care systems alone.
- The APPG has already recommended structured referral pathways into specialist support organisations as an immediate practical reform.

Conclusion

The APPG supports genuine reform that improves outcomes, consistency and dignity for people living with spinal cord injury. However, reform must strengthen coordination, national accountability and specialist support; not inadvertently deepen fragmentation and postcode inequality.

The Health Modernisation Bill presents an important opportunity to build a more connected and humane system. The APPG urges Government to ensure that spinal cord injury patients and specialist services are fully considered as the Bill progresses.

About the All-Party Parliamentary Group on Spinal Cord Injury

The All-Party Parliamentary Group on Spinal Cord Injury are a cross-party group of Parliamentarians who are committed to tackling issues that affect people with spinal cord injuries. Officers of the APPG on SCI: Andy McDonald MP (Chair), Gill Furniss MP (Vice Chair), John Glen MP (Vice Chair), Helen Morgan MP (Vice Chair). The Secretariat is provided by the Spinal Injuries Association (SIA)

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About SIA

The Spinal Injuries Association (SIA) is the leading national charity dedicated to supporting over 105,000 individuals affected by spinal cord injury (SCI) across the UK. Our mission is to be the expert guiding voice for life after spinal cord injury, ensuring that everyone touched by SCI can lead a fulfilled life. We offer a comprehensive range of services, including a free advice line, specialist nurse support, accredited training for healthcare professionals, and a network of community groups. Through advocacy, education, and direct support, we strive to break down barriers and promote inclusion for the SCI community.

For more information contact Spinal Injuries Association's Public Affairs Team, campaigning@spinal.co.uk

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