

The Rt Hon Andy Burnham MP
Prime Minister
10 Downing Street
London
SW1A 2AA

Tuesday 13th October 2026

Protecting Specialised NHS Services: National Standards, Accountability and Equitable Access to Care

Dear Prime Minister,

Coordinated by the Spinal Injuries Association (SIA), we are writing to you as a coalition of patients, charities, healthcare professionals, and organisations from across the specialised services community, who have come together to raise our shared concerns about the impact of the Health Bill on the people and communities we represent. As the Government aims to modernise the NHS and reduce bureaucracy, we are deeply concerned that the essential NHS services supporting our communities could be weakened without clear national safeguards, oversight, and accountability within the Health Bill.

The Health Bill (the Bill) includes extensive reforms across a number of consequential areas that amount to far more than an organisational restructuring, with the intention of creating a framework for the future of the NHS. Specialised services support people with a range of rare and complex conditions, including: spinal cord injury, muscular dystrophy, neurological conditions, and children requiring palliative care. These are services that are not available in every hospital, Integrated Care Board (ICB), or NHS region because of the complexity and relative low volume of patients who require each service.

We are broadly supportive of the Government's ambition to modernise the NHS and improve outcomes for patients. However, we are concerned that reforms to specialised commissioning could unintentionally weaken protections for patients with rare, complex, and life-changing conditions unless accompanied by appropriate safeguards, accountability, and transparency. The question is not only where a service is commissioned, but how patients are protected whichever commissioning arrangement applies.

Specialised services are national assets that exist because expertise, workforce, clinical networks, patient populations, and infrastructure cannot be replicated in every community. National commissioning has been effective in reducing geographical variation and 'postcode lotteries', national service specifications have improved consistency, and national leadership has provided a clear line of oversight and accountability.

We therefore believe it is imperative that services should remain nationally commissioned where their clinical complexity, patient population, workforce, infrastructure, or need for national coordination makes this necessary. Where specialised services are commissioned by ICBs, patients should have equally strong protections: nationally mandated standards and service specifications, effective

national oversight of their implementation, transparent assessment of the impact of commissioning changes, and clear accountability for performance.

It is our belief that patients should not face different standards of care simply because they live in a different part of the country. Nor should organisational change create fragmentation, weaken specialist clinical expertise, or make it harder to identify who is accountable when services fall below the standards patients should be able to expect. Experience to date has demonstrated significant limitations in securing clear and effective accountability from ICBs, particularly where responsibility is dispersed across local and regional structures. These concerns were echoed by MPs from across the political spectrum during the Commons stages of the Health Bill. As ICBs take on greater responsibility for specialised services, it is therefore essential that clear national oversight and routes of accountability are built into the new system from the outset.

We are therefore asking the Government to use the Health Bill to establish a durable national framework for specialised services, including: national retention where services require national commissioning; assessment and consultation before significant changes to specialised commissioning arrangements; enforceable national standards and service specifications for services commissioned by ICBs; national oversight and assurance of those standards; and transparent reporting to Parliament on the performance of specialised services and geographical variation in access and outcomes.

These protections would not prevent appropriate local integration or innovation. They would strengthen those by providing the national framework within which it can happen safely, while ensuring that where a patient resides does not determine the standard of specialised care they receive.

We request a meeting with you, and other relevant ministers, as soon as possible to discuss how the recommendations can be reflected in the Health Bill and its implementation. We want to work constructively with Government to ensure that NHS modernisation strengthens specialised care and protects the expertise, standards and accountability on which patients with rare and complex conditions depend.

We look forward to your reply.

Yours sincerely,

Shockat Adam MP
Bob Blackman MP
Carla Denyer MP
The Rt Hon John Glen MP
Dr Caroline Johnson MP
The Rt Hon John McDonnell MP
Jim Shannon MP
The Rt Hon Sir Desmond Swayne MP

Professor the Lord Alton of Liverpool
Dr Ellie Chowns MP
Gill Furniss MP
Baroness Grey-Thompson
Andy McDonald MP
Helen Morgan MP
Greg Smith MP



Specialised Healthcare Alliance

FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS

