

What does the Health Bill mean for rare diseases?

The Health Bill creates an uncertain future for services supporting patients with rare and complex conditions; this briefing sets out the key questions requiring urgent clarification from the Government and how you can help.

What are specialised services?

150+

Over 150 specialised services¹



Support people with a range of rare and complex conditions¹



Covering everything from chemotherapy to hand transplants¹

What's changing?

Specialised services have historically been commissioned at a national level by NHS England (NHSE).² Since 2023, NHSE has gradually delegated more responsibility to Integrated Care Boards (ICBs).² After the abolition of NHSE, it is expected that:³

- Only the most highly specialised services will be commissioned by the Department of Health and Social Care (DHSC)
- DHSC will maintain a framework of standards, service specifications and clinical commissioning policies
- When services are delegated, full *accountability* – on top of existing *responsibility* – will transfer from NHSE to ICBs
- Seven Offices for Pan-ICB Commissioning (OPICs) will be established from April 2027 to support ICBs to discharge their commissioning responsibilities

The Health Bill seeks to introduce the legislative provisions needed to enact these changes, but the SHCA believes that greater scrutiny is needed.

What needs clarification?

Significant questions remain regarding the future of specialised services. For example:

- **Commissioning responsibilities:** Which services will be commissioned by DHSC and which by ICBs?
- **Status of national standards:** Will national standards, such as service specifications and clinical commissioning policies, have statutory status?
- **Accountability:** What actions will be taken if ICBs fail to meet national standards? How will DHSC be held accountable for highly specialised commissioning?
- **Transparency:** How will transparency be improved, given the current lack of publicly available data on compliance with national standards?
- **Clinical leadership:** What will happen to the leadership currently provided by National Clinical Directors (NCDs), National Speciality Advisers (NSAs) and Clinical Reference Groups (CRGs)?
- **Wider responsibilities:** Who will take on NHSE's wider functions, including specialised commissioning clinical audits, databases and registries?

What amendments is the SHCA proposing?

Impact assessment: A detailed impact assessment on the delegation of specialised services and public consultation on changes to specialised commissioning regulations

Clear accountability: Measures to strengthen accountability, for example a requirement for the Secretary of State to lay an annual report on specialised services performance before Parliament

Retention of clinical leadership: Mandated clinical involvement in specialised commissioning and the appointment of a national rare diseases clinical lead

Meaningful patient involvement: Patient involvement and co-production across all specialised commissioning, whether services are commissioned by the Secretary of State or ICBs

Implementation of national screening recommendations: A legal duty on the Secretary of State to implement National Screening Committee recommendations

Mental health investment: Making the Mental Health Investment Standard (MHIS) a statutory requirement on ICBs, as recommended by the Health and Social Care Committee

What can you do?

- Meet with the SHCA to discuss the implications of the Health Bill
- Ask parliamentary questions, particularly on areas which require clarification
- Raise the above issues during future debates on the Health Bill and table the SHCA's [drafted amendments](#)

¹ NHS England. [Specialised services](#). No date. NHS England. [Roadmap for integrating specialised services within Integrated Care Systems](#). 2022. ³ NHS England. [Direct commissioning update](#). 2026.