

✗ Lack of information and advocacy provision for patients accessing specialised services

The draft Bill states that Local Healthwatch organisations are **for the area of each local authority**; must provide information on **local services**; and that each local authority must make provision for advocacy **in its area** (clauses 179-182). We can see no organisation which has the responsibility to provide information and advocacy to patients who access healthcare outside of their locality, such as patients accessing specialised healthcare in designated centres of excellence.

Possible question for debate: Can the Secretary of State explain where patients who receive care outside of their local area, such as those accessing specialised services, will go for advocacy and information? Local Healthwatch organisations are required to provide advocacy and information only to patients accessing local services.

✗ Tension between the remit of NHS Commissioning Board and health and wellbeing boards

In order to rationalise the delivery of specialised services in England, the NHS Commissioning Board will need to strategically position centres of excellence to focus clinical expertise in larger centres, and to ensure adequate patient populations for maintenance of patient safety and training of specialists. In carrying out this function, the NHS Commissioning Board may come into conflict with health and wellbeing boards which may wish to oppose relocation of centres of excellence as they carry out their remit to promote high quality healthcare in their local area, rather than taking a broader strategic view.

We would like the Minister's explanation as to how disputes arising due to the conflicting remits of health and wellbeing boards (local) and the NHS Commissioning Board (strategic commissioning of specialised services) will be resolved.

✓ Commissioning for patients with rare diseases: specialised commissioning

Arrangements for the future commissioning of services for small numbers of patients, permitted by the Bill in its current version, and currently under implementation, are a significant improvement on the previous regional delivery arrangement. The incoming structures will allow strategic allocation of resources across England, significant efficiency savings, and a reduction of regional inequality of access to specialised services.

[Genetic Alliance UK supports this part of the Bill: Clause 12, page 7, line 29, to page 8, line 2.](#)

✓ Integration between nationally and locally commissioned services

Requirements for the NHS Commissioning Board to promote integration between different types of health service provide a starting point for valuable cooperation between providers of specialised services and providers of local care. This relationship is essential for continuity of care for those who receive a component of their care from centres of excellence. We hope to see endorsement from the Minister during the debate that this is the Government's intention in framing the legislation.

[Genetic Alliance UK supports this part of the Bill: Clause 20, page 18, line 38, to page 19, line 33.](#)

Genetic Alliance UK (formerly Genetic Interest Group) is the national charity supporting all those affected by genetic conditions. Genetic Alliance UK aims to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them. Our membership represents more than 140 voluntary organisations working for a wide range of conditions, many of which pose complex health and social care needs.

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