Response to NHS Chief Executive’s Open Call for Evidence and Ideas

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The Specialised Healthcare Alliance is a coalition of 68 patient-related groups supported by 10 corporate members which campaigns on behalf of people with rare and complex conditions in need of specialised care.

General

We welcome the commitment to innovation exemplified by the NHS Chief Executive’s review. The NHS has embarked on a plethora of initiatives seeking to promote speedier uptake of innovation over the last decade, with limited results. The Alliance considers that the current reforms hold out the prospect of more effective action.

In particular, the NHS Commissioning Board (NHSCB) will combine a leadership role with direct commissioning responsibilities of its own. This will enable the Board to practise what it preaches and thereby lend real weight to its policies supporting innovation in the wider NHS.

Specialised commissioning

The NHSCB’s budget for specialised commissioning is expected to total some £10 billion or roughly 10 per cent of overall NHS expenditure. As importantly, these services do not sit in isolation but link up with care at a more local level, often incubating clinical advances which subsequently have wider application. The NHSCB therefore has a powerful opportunity to demonstrate the potential of a proactive stance on commissioning and de-commissioning services, products and technologies.

The Alliance recommends:

- Establishing an innovation fund to facilitate the introduction of new services, products and technologies;
- Drawing on the decision-making framework for the Advisory Group on National Specialised Services to inform funding of developments in specialised services more generally.

Research and outcomes

An innovation fund could additionally help with pre-trial and post-trial treatment costs that are outside national tariff in order to safeguard future research, as originally recommended in the Carter Report. The interface between research and treatment in areas of previously unmet need is crucial for people with rare and complex conditions, with registries playing a particularly important role. The licensing system provides a major incentive for commercial research.

The Alliance recommends:

- Ensuring that registries are in place to help identify patient populations, facilitate enrolment in relevant studies and capture clinical outcomes;
• Weighing carefully the impact on people with rare diseases of any dilution of the current preference for products to be licensed, as presently proposed by the GMC.

National tariff

Application of the tariff system to specialised services is presently modest and generally expressed through a crude system of percentage uplifts. The danger here is that providers treating the most challenging case-mix requiring more innovative techniques will be undercompensated. Extension of an inflexible tariff to additional services carries with it the risk that sometimes volatile costs will be poorly captured or room for innovation squeezed out.

The Alliance recommends:
• Introducing more transparent governance around the tariff with strong clinical input and patient-related involvement;
• Retaining flexibility for in-year developments and future innovation, in part through the proposed innovation fund.

Patients and innovation

The call for evidence rightly recognises the importance of harnessing patient understanding and experience around innovation. This applies to services and technologies alike. Even when they have a seat at the table, however, patients can feel excluded from discussion by the overuse of jargon and allusion by other participants to issues off the agenda.

The Alliance recommends:
• Induction training for patients alongside a determined effort to cut out obfuscatory jargon;
• Establishing a national institute for patient leadership to give people the support they need to make an effective, fulfilling contribution in the field of innovation and elsewhere.