



Genetic Alliance UK

Supporting. Campaigning. Uniting.

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Sir David Nicholson KCB CBE
Chief Executive of the NHS in England
Richmond House
79 Whitehall
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28th July 2011

Dear Sir David,

Genetic Alliance UK is the national charity for all those affected by genetic conditions representing over 140 patient organisation members. Many of our members support patients affected by serious life-limiting conditions which can be difficult to diagnose and require highly specialised healthcare. The voices of these patients are often the most difficult to capture due to the debilitating nature of many of these conditions and their small fragmented patient populations. Genetic Alliance UK is the founder of Rare Disease UK¹.

We were pleased to have the opportunity to see your initial thinking on the structure and working of the NHS Commissioning Board, and grateful that you chose to make your thoughts publicly accessible.

We believe the NHS Commissioning Board is of enormous strategic advantage to our membership. Two of the greatest challenges that patients and families with genetic conditions face are access to specialised cutting edge services for their complex and/or rare conditions, and access to integrated services for those aspects of their care and support that could and should be delivered locally. We believe the NHS Commissioning Board can bring excellence and consistency to the commissioning of specialised services, and through its leadership role disseminate knowledge of genetic disease through the NHS.

This is a time of great change not only for the NHS, but also for genetic disease and genetic treatments. For example:

- The cost of sequencing a full genome is coming down every year, and is likely to become clinically relevant and economically affordable in the next five years.
- The Government has committed to the delivery of a UK strategy for rare disease (more than 80% of which are genetic conditions).
- Research and pharmaceutical developments are bringing more and more new treatments for previously unmet health needs.

To realise the potential that these developments bring it will be essential that there is a designated national director at the highest level of the NHS Commissioning Board with responsibility for specialised services. We also believe the NHS Commissioning Board should include a non-executive member to champion this aspect of the organisation's work, and that clinical senates should explicitly include representatives with rare disease knowledge. Together these measures would ensure that knowledge and awareness of rare disease is propagated through the NHS.

Outcomes Framework

The Outcomes Framework is one of the NHS Commissioning Board's responsibilities that would benefit from oversight by board members with responsibility for, and expertise in, rare disease. Any system aimed at providing high level oversight should aim to achieve this without creating incentives that take away focus from the clinical needs of the patient. It is the NHS Commissioning Board's duty to achieve this, and ensure that improvements seen using the tool of overarching indicators relate directly to improvements felt on the ground by patients.

In principle, Domain 2, "Enhancing quality of life for people with long-term conditions" could bring real benefits and improvements to with patients with long-term genetic conditions. The overarching indicator and improvement areas all cover areas which are important to our members. However, at the lowest level of detail, we find that very few of the initial topics to be developed into Quality Standards by NICE have any direct meaning or relevance for those affected by genetic conditions. Of the 25 initial topics proposed in The NHS Outcomes Framework 2011/12, none are directed solely at the care or treatment of those with genetic conditions, and just eight² will describe some of the characteristics of a high quality service for patients with genetic conditions as a part of a greater whole. There is a real risk that patients with rare and complex genetic conditions will fall through the gaps in a system measured with these means.

Individuals with overall responsibility for specialised commissioning and rare diseases within the NHS Commissioning Board can feed into the development of initiatives such as the development of the Outcomes Framework, and ensure that future strategy is designed in such a way as to be inclusive to rare disease without necessarily being directed solely at our constituents' needs.

Specialised commissioning

The arrival of the NHS Commissioning Board is a welcome development for the patients we represent. The establishment of an organisation with a position within the NHS to have oversight of the commissioning of all services, and the power to directly commission appropriate services, provides an opportunity to cut through many of the issues of access and integration that patients with rare, complex genetic conditions face.

At the beginning of this year Rare Disease UK published a set of recommendations³ to inform the development of an effective strategy for rare diseases in the UK. The reorganisation of the commissioning structure in the new NHS takes us closer to realising many of the targets for commissioning set out in this report. We hope that this opportunity is capitalised upon and seen as an integral part of the delivery of a strategy for rare disease.

We understand that the means by which the NHS Commissioning Board will undertake its responsibility to directly commission specialised services are currently under development. The lack of information of the specifics of how this will be achieved in the document is therefore understandable. However, we would find it reassuring to have some of the specifics that will form the basis of the future of specialised commissioning clarified:

National structure: This NHS reorganisation offers an important opportunity to end the inequity in provision of specialised services across the country. A single set of services that will be commissioned nationally by the NHS Commissioning Board, comprising the services currently recommended by the Advisory Group for National Specialised Services (AGNSS), and the services currently listed in the Specialised Services National Definition Set (SSNDS), is the ideal model to ensure that the same set of services are commissioned to a uniform standard across the country.

We therefore assume that the Specialised Commissioning Team presence in each Commissioning Sector (as shown in figure 6 on page 25 of the document) is for regional organisation of delivery and integration of

specialised services, rather than an indication of a move towards regional strategising of specialised services. We request clarification on this point.

“It is vital that the commissioning and planning of specialised services for patients with rare diseases are carried out at the appropriate planning population level to avoid unnecessary and inequitable variations and to ensure that the service is developed. The specialised commissioning bodies of the UK should work to ensure that commissioning or planning at the appropriate level is achieved. It is hoped that the new structure in England will work to ensure that this is the case, but it is important that this occurs within all devolved nations”

[Recommendation from ‘Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy’ by Rare Disease UK⁴](#)

Budget: You are aware of the variations in the pattern and level of services currently commissioned by the regional Specialised Commissioning Groups (SCGs). These have been due to the choices of each Specialised Commissioning Group (SCG) to commission a set of services that reflect financial pressures from their constituent Primary Care Trusts as much as they incorporate robust and transparent population based needs assessments.

We understand that your strategy will be to commission all of these services nationally, from one single budget, and on single, national contracts. This model would, we expect, allow economies of scale that will ensure comprehensive commissioning of all services in the Specialised Services National Definition Set at an appropriate level to meet patient needs quickly and equitably. We request clarification on the implementation of this strategy, and the budget allocation for the commissioning of all services currently in the SSNS, and all of those currently recommended for national commissioning by AGNSS.

“Budgets for funding specialised services should be protected and allocated specifically to the specialised commissioning or planning body. This would ensure that in times of financial pressure, specialised services would not be unfairly targeted due to the [perception that funding for specialised services are] diverting resources away from local services and [the] rhetoric of localism. The budget assigned for specialised services should be flexible and allow expansion when evidence suggests that services would be better commissioned/planned by the specialised commissioning or planning body.”

[Recommendation from ‘Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy’ by Rare Disease UK⁵](#)

Staffing: Within the current workforce delivering specialised services in England there is a great deal of accumulated experience and expertise. As staff numbers are cut from approximately 8000 to approximately 3500, it will be essential to ensure that sufficient expertise is preserved to ensure the continuation of the complex commissioning roles that they currently perform.

Leadership and innovation in commissioning

We are delighted to see the strong commitment in the document for the Board to be a champion for patients and their interests, and to put patients, clinicians and carers at the heart of decision-making. We look forward to working with you to ensure that this is translated into reality for patients and families relying on nationally commissioned services.

Genetic Alliance UK is at the centre of a number of initiatives which can help to deliver patient led commissioning in the new NHS. For example:

Facilitating Networks: This is a project which brings together patients and clinicians to form information and care networks. These have delivered improved coordination of care for children, adults and families with rare genetic disorders, and improved information on the services available. The initiative has developed a protocol for establishing clinical networks that can be applied to other disorders and groups of conditions.

Route Maps for Rare Conditions: This is an initiative aimed at developing a practical and cost-effective framework for improving information, access and coordination of health and social care services for individuals and families with a wide range of rare genetic conditions. The pilot scheme will support eight user-led support groups to develop a series of condition specific Route Maps. A toolkit and a written methodology will be created alongside the Route Maps so that in the future other groups can develop a Route Map for their own condition.

These initiatives are examples of the value that patient organisations can bring to the design and coordination of services for our constituents.

We look forward to your reply to the specific questions raised above and to working with you in future to shape the arrangements for providing world class health care for patients and families with genetic disorders.

We would be pleased to meet you to discuss these issues and to explain ways in which we can work together to secure appropriate commissioning of integrated services for patients and families with all complex genetic diseases in the NHS as it evolves.

Yours sincerely

A handwritten signature in blue ink that reads "Alastair Kent".

Alastair Kent OBE
Director

Copied by email to: Clare Brassington (DH)
Kate Caston (NHS)
Rt Hon John Healey MP
Earl Howe
Liz Kendall MP
Rt Hon Andrew Lansley MP
Teresa Moss (NHS)
John Sherriff (DH)

Notes

1. Rare Disease UK (RDUK) is the national alliance for people with rare diseases and all who support them. It is an initiative of Genetic Alliance UK and other key stakeholders brought together to campaign for a strategy for rare diseases following the European Commission's Communication on Rare Diseases: Europe's Challenges (November 2008). RDUK has over 900 members including over 170 patient organisations, clinicians, health professionals, professional bodies, researchers, industry members and individuals.

2.
 - Chronic heart failure
 - Chronic kidney disease
 - Chronic obstructive pulmonary disease
 - Dementia
 - Epilepsy (adults)
 - Epilepsy (children)
 - Long-term condition/people with co-morbidities/complex needs
 - Pain relief (to include young people)Page 15, NHS Outcomes Framework 2011/12, 20 December 2010

3. Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy raredisease.org.uk/documents/RD-UK-Strategy-Report.pdf

4. Recommendation 1a, Commissioning and Planning, Page 43
Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy raredisease.org.uk/documents/RD-UK-Strategy-Report.pdf

5. Recommendation 3a, Commissioning and Planning, Page 45
Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy raredisease.org.uk/documents/RD-UK-Strategy-Report.pdf