



Rare Disease UK response to Liberating the NHS: Commissioning for Patients

About Rare Disease UK

Rare Disease UK (RDUK) is the national alliance for people with rare diseases and all who support them. We have over 550 registered members including: over 130 patient organisations, clinicians, researchers, academics, industry and individuals with an interest in rare diseases.

It is estimated that 1 in 17 people will be affected by a rare disease at some stage in their lives. This amounts to 3.5 million people across the UK. Collectively, rare diseases are not rare.

RDUK was established by Genetic Alliance UK, the national charity of over 130 patient organisations supporting all those affected by genetic conditions, in conjunction with other key stakeholders in November 2008 following the European Commission's *Communication on Rare Diseases: Europe's Challenges*.

Subsequently RDUK successfully campaigned for the adoption of the Council of the European Union's *Recommendation on an action in the field of rare diseases*. The Recommendation was adopted unanimously by each Member State of the EU (including the UK) in June 2009. The Recommendation calls on Member States to adopt plans or strategies for rare diseases by 2013.

RDUK is campaigning for a strategy for integrated service delivery for rare diseases. This would coordinate:

- research
- prevention and diagnosis
- treatment and care
- information
- commissioning and planning

into one cohesive strategy for all patients affected by rare disease in the UK. As well as securing better outcomes for patients, a strategy would enable the most effective use of NHS resources.

Robust commissioning structures enabling the effective service delivery for patients with rare diseases should form a key element of a strategy for rare diseases. RDUK believes that a strategy is necessary to ensure that the vision set out in the White Paper also applies to patients and families with rare diseases, who are frequently forced to accept an inequitable service as they have the misfortune of their condition being rare. As a result, we welcome the opportunity to comment on the proposals in the consultation document.

Overview

Rare Disease UK wishes to stress that localism is not always best in order to understand the health needs of the patients we represent. The strength of GPs lies in their understanding of a broad range of conditions that they see on a regular basis. There are over 6000 rare diseases and GPs may only come across some of these conditions once (if at all) in the duration of their careers. Many patients with rare

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diseases have complex needs and GPs do not have the knowledge necessary to understand what services are necessary to meet these needs the majority of the time.

GPs' lack of knowledge of rare conditions has been a great source of distress to many patients and families with these conditions. This is true both before and after diagnosis. Some examples of what we have heard from our members include:

- When a mother went to visit her son's GP about his care she was told: "Well at this stage you know a lot more than I do about [the son's condition] so I really don't think I can help you much".
- One woman who had been prescribed anti-depressants and had been referred to a psychiatrist by her GP told us "I was telling my GP and psychiatrist that my illness was real, but it seemed no one believed me". The woman had a rare neurodegenerative disease, but not once in the eight years that it took her to get a diagnosis was she referred on to a neurologist by her GP(s).
- Another member told us "It is very isolating and frightening to be diagnosed with a rare disease that you, your family and friends have never heard of, and even more distressing when your GP, dentist and even doctors at A&E need it explained to them".
- After receiving a diagnosis (a process taking six distressing years) and subsequently receiving good treatment, one member said "I paid a final visit to my GP, at which point he told me that he had not seriously considered the possibility of my problems being caused by [the rare condition] because he was taught that it is so rare that no GP should expect to encounter such a patient during a whole career. Is this truly a justified excuse for not performing a few simple tests?...Throughout the time preceding my diagnosis I felt that I was not being taken seriously by my GP".

These are just some of the experiences we have heard from our members illustrating some of the common issues which arise time and time again. Many GPs themselves feel poorly equipped to meet the needs of people with rare diseases, particularly those with more complex needs. This is not any slight on GPs, but it demonstrates that there is not sufficient understanding locally for informed commissioning decisions for services for patients with rare diseases to be made properly.

The most "common" single rare disease will affect around 25,900 people¹ in England (the vast majority of rare diseases affect far fewer people). If this maximum figure is distributed evenly across the current 151 PCTs then each PCT would have 171 patients with this specific condition. If GP consortia cover smaller population bases than PCTs do currently, then they will cover even fewer patients with that condition. It seems doubtful whether the expertise will be available to commission all the services necessary for the most "common" rare diseases, let alone the majority of rare diseases which affect far fewer people. There is a real danger that these conditions could be overlooked.

In reality, the distribution of rare disease patients will not be even due, to greater prevalence in certain populations e.g. some conditions are more common in population sub-groups. Examples include thalassemia in Mediterranean populations, and the increased prevalence of recessive single gene genetic conditions in people of Pakistani origin. Effective commissioning structures should be able to take account of such local needs.

Patients with rare diseases are extremely vulnerable when service providers do not have the expertise and do not take the responsibility to provide relevant services. As a result, RDUK strongly supports the

¹ Based on the Office of National Statistics Population Estimates June 2010 - <http://www.statistics.gov.uk/pdfdir/pop0610.pdf>

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proposal that the NHS Commissioning Board be responsible for commissioning national and regional specialised services.

Patients with rare diseases are likely to need access to health services at different levels, from local health services and social care which a patient is likely to use most frequently, to specialised services commissioned on a national basis, and from both a chronic and acute position of need. An effective commissioning structure for rare diseases needs to ensure good communication and coordination between those commissioning services at the local level and those commissioning specialised services.

Comments on the consultation paper and answers to questions:

Scope of GP commissioning

RDUK strongly endorses proposals for the NHS Commissioning Board to take responsibility for commissioning specialised services. We believe that the Board should have responsibility for commissioning those services currently commissioned at a national level and those services listed in the Specialised Services National Definitions Set (SSNDS) currently commissioned by regional specialised commissioning groups (SCGs).

The establishment of the NHS Commissioning Board provides the opportunity to address some of the issues inherent in the commissioning of specialised services currently, most notably the weaknesses of the SCGs in delivering equitable service provision across England. Currently no SCG commissions all of the services in the SSNDS and no two SCGs commissions the same set of services as each other. This leads to a “postcode lottery” where some people with certain rare diseases are able to access services in one part of the country while others living elsewhere cannot. This issue was recognised in the House of Commons Health Select Committee’s Fourth Report of Session 2009-10, entitled ‘Commissioning’; and the problems identified were accepted by the Government in its response published in July 2010. Having one national body responsible for commissioning specialist services can ensure that services are available to those who need them and the correct amount of services are provided according to population need.

While we regard the location of all specialised commissioning responsibilities in the NHS Commissioning Board as sensible, we recognise in practice this may need a devolved regional structure that allows proper understanding of regional variations and to help ensure integration between services commissioned by GP consortia and specialised services. However, any regional system must be under tighter central control by the NHS Commissioning Board to avoid the present situation which has led to wild inconsistencies in service provision.

The budget for specialised services must be allocated directly to the NHS Commissioning Board specifically for specialised services. This is in contrast to the current funding method for national and regional commissioning i.e. the top-slicing of funds for national commissioning and the pooling of funding by PCTs for regional commissioning. This has led to a perception among many PCTs that specialised services are a drain on their budgets, rather than a risk sharing structure that allows them to better discharge their responsibility of care to patients such as those with rare diseases.

The budget for specialised services must take into account that, as the SCGs do not currently commission all the services in the SSNDS, their expenditure may not adequately reflect the budget that the NHS Commissioning Board will need to provide an equitable service across England.

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The budget for the NHS Commissioning Board must also be flexible to allow for new services to be commissioned when evidence shows a need for services to be commissioned at this level in order to provide good quality, equitable services.

Systemic data collection is essential to compare service provision between GP consortia and to support effective commissioning. The International Classification of Diseases (ICD) 11, which makes a greater granularity in rare disease classification possible, will be complete by 2015 and advance preparation should be made in order to ensure its swift implementation.

In what practical ways can the NHS Commissioning Board most effectively engage GP consortia in influencing the commissioning of national and regional specialised services and the commissioning of maternity services?

RDUK believes that GP consortia should not use their influence to try and claw back specialised services to increase their budgets; this is a danger, as demonstrated by the reluctance by PCTs to pool their budgets for specialised services. The rhetoric of localism can be powerful, but is inappropriate for specialised services for patients with rare diseases. The benefits of commissioning specialised services nationally, both in terms of ensuring good quality care for patients such as those with rare diseases and the effective use of NHS resources, need to be communicated by the National Commissioning Board to the wider GP commissioning community.

It is crucial that engagement is facilitated between the NHS Commissioning Board and GP consortia to ensure that services commissioned at all levels are integrated and that there are no gaps in service provision. We welcome the recognition of this in the consultation document.

How can the NHS Commissioning Board and GP consortia best work together to ensure effective commissioning of low volume services?

The proposals do not indicate what population bases GP consortia will cover, although we understand that they are likely to be smaller than PCTs currently. This means that a large number of services could fall in the area between being too low-incidence to be commissioned by individual GP consortia and too high volume to require a planning population greater than one million as the SSNDS currently provides for. The commissioning of those services that fall between these thresholds should be carefully monitored to ensure they are available equitably to people across England. A key component of the duty of the NHS Commissioning Board to hold consortia to account should be to ensure that patients have access to services commissioned at the level above a consortium-unit volume of population.

It may be desirable to retain some level of regional oversight of commissioning to ensure the linkage between services provided by the NHS Commissioning Board, GP consortia and groups of GP consortia. Many patients with rare diseases are likely to access services from each of these levels so the integration of these levels of commissioning is crucial.

The role of the NHS Commissioning Board

RDUK believes there should be a designated expert accountable for commissioning for rare diseases on the NHS Commissioning Board. This member should work closely with the National Clinical Director for Rare Diseases (as proposed in the Chief Medical Officer's report of 2009) who RDUK would like to oversee the implementation of a strategy for rare diseases.

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Additional comments

- There will never be a specialised service for each of the 6000 plus rare diseases. However, commissioning structures should be flexible to allow patients to access services, not specifically designated for their condition, but that they would benefit from nonetheless as many of the effects or services needed may be similar. One of our members summarised the current farcical situation which is experienced by many:
“Being a rare condition there are no support or therapy services I can access locally...there is an excellent MS therapy centre nearby but only for MS patients, ditto with other conditions' therapy centres even though the symptoms and treatment would be ideal to my own condition. Being able to access these, and to have a determined care plan would be an immense improvement for me”
- Specialised services for rare conditions have developed in an ad-hoc fashion. Services often gain national designation as a result of proactive moves by a strong patient organisation and interested clinicians. We have heard from our members that the application process is also becoming increasingly burdensome. This is clearly inequitable as in particular, most patient organisations for rare diseases (if they exist at all) are small and do not have the resources to undertake this work.
- Care must be taken to ensure that those with expertise in commissioning specialised services are retained during the transition period and that an arbitrary approach to cutting “bureaucracy” is not taken, resulting in the loss of necessary expertise.

Rare Disease UK – October 2010

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