



RARE DISEASE | UK

The National Alliance for people with rare diseases & all who support them

## Response to Future Forum 2: integration of services

### 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 1000 registered members including over 170 patient organisations, clinicians, researchers, academics, industry and individuals with an interest in rare diseases. RDUK was established by Genetic Alliance UK, the national charity of over 140 patient organisations supporting all those affected by genetic conditions.

**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.**

The Council of the European Union's Recommendation on an action in the field of rare diseases 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. A key priority of an effective rare disease plan should be to ensure better coordination of care and integration of services.

RDUK has developed comprehensive recommendations to inform a rare disease plan in the UK. These recommendations were developed over the period of a year and a half in consultation with over 1000 organisations and individuals. These recommendations can be found in our report, 'Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy' (February 2011, available at: [www.raredisease.org.uk/documents/RD-UK-Strategy-Report.pdf](http://www.raredisease.org.uk/documents/RD-UK-Strategy-Report.pdf)). All of our recommendations below are based on key components of what RDUK would like to see in an effective plan for rare diseases.

One of RDUK's main aims is to ensure that a plan for rare diseases supports improved integration of services for patients with rare diseases. It is vital that the Health and Social Care Bill creates the structures and an environment that can allow seamlessly integrated services to become a reality. As a result, we welcome the opportunity to participate in the Future Forum listening exercise.

Where relevant, we have answered both the questions aimed at patients and those aimed at professionals.

### Do health and care services join up well enough?

In RDUK's experience, poor integration of services is a major issue for patients with rare diseases and their families. Most rare diseases affect multiple systems of the body and as a result, many health professionals from different specialities and disciplines need to be involved in the care of a patient. Moreover, many patients with a rare disease will access services commissioned at different levels of the system including locally commissioned services, those services in the Specialised Services National Definitions Set (SSNDS), which are currently meant to be commissioned regionally and, for certain very rare diseases, services that are commissioned nationally by the National Specialised Commissioning Team.

---

#### Rare Disease UK

Unit 4D, Leroy House, 436 Essex Road,  
London, N1 3QP

[www.raredisease.org.uk](http://www.raredisease.org.uk)

T: +44 (0)20 7704 3141 | F: +44 (0)20 7359 1447

E: [info@raredisease.org.uk](mailto:info@raredisease.org.uk)

An initiative of



**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

A charity registered in England and Wales (no. 1114195)  
in Scotland (no. SC039299).

A company Limited by Guarantee (Number 05772999)



RDUK has found that treatment and care for patients with rare diseases is often fragmented and poorly coordinated, and there is frequently a lack of communication between all professionals involved in the care of the patient. Some of the resulting impacts on patients identified by RDUK include:

- Individual professionals are concerned only with a specific aspect of the patient's condition while no one professional is concerned with the condition as a whole. This is particularly problematic for adults when there is no multidisciplinary paediatrician role;
- patients (or their carers) having to repeatedly explain their condition and medical history to all professionals involved in their care;
- feelings of being lost in the healthcare system;
- patient notes being lost;
- patients and families not knowing where to go for queries about their condition and their care/treatment;
- lack of continuity of professionals involved in the care of a patient<sup>1</sup>.

RDUK has also found that many patients with rare diseases have to attend multiple clinics for different aspects of their condition, often at a long distance from where they live as the more specialist elements of care may not be available locally. RDUK's research identified:

- a quarter (25%) of patients have to attend either 3 or 4 different clinics to obtain treatment and care, with over one in ten (12%) having to attend more than five different clinics.
- Two-thirds (66%) of patients have to travel over an hour from home to reach their furthest clinic, with 32% having to travel for over two hours and 15% travelling over three hours<sup>2</sup>.

The need to attend multiple different clinics and the need to travel to access services can cause enormous disruption to patients' and families' lives. In RDUK's experience, patients and families affected by rare diseases accept the need to travel to access good-quality services, however, with improved coordination and integration of services, the burden on patients and families can be minimised.

## What could be done to give people a seamless service?/ Who needs to do what next to enable integration to be progressed in a pragmatic and achievable way?

It is essential that the planning and integration of services is driven at the level where there is the best understanding of the needs of patients affected by a particular condition. Under a plan for rare diseases, RDUK would like to see the implementation of a system of centres of excellence for rare diseases or clusters of rare diseases. These centres would have the expertise necessary to describe the optimum care pathways for these diseases and, as a result, would be well placed to ensure the integration of all the services needed by a patient. This process should be informed by a personalised care plan for all patients with a rare disease.

<sup>1</sup> 'Experiences of Rare Diseases: An Insight from Patients and Families' (December 2010, available at: <http://www.rare-disease.org.uk/documents/RDUK-Family-Report.pdf>).

<sup>2</sup> As above

---

### Rare Disease UK

Unit 4D, Leroy House, 436 Essex Road,  
London, N1 3QP

[www.raredisease.org.uk](http://www.raredisease.org.uk)

T: +44 (0)20 7704 3141 | F: +44 (0)20 7359 1447

E: [info@raredisease.org.uk](mailto:info@raredisease.org.uk)

An initiative of



**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

A charity registered in England and Wales (no. 1114195)  
in Scotland (no. SC039299).

A company Limited by Guarantee (Number 05772999)



RDUK believes that each person with a chronic rare disease should have a designated care coordinator. Care coordinators offer a multitude of benefits including providing a pivotal role in liaising between a patient and the services they use to ensure all the right services are brought together at the right time. Other benefits include empowering patients to more effectively self-manage their condition and providing an important source of information and support. The care coordinator should be a trained professional whose ultimate role is to ensure that a patient has a care plan in place and this is being effectively acted upon. The role is often carried out by specialist nurses, but depending on the condition, could be conducted by other professionals including social workers or occupational health workers.

Effective integration of care necessitates partnership working between specialised and local commissioners and providers, in collaboration with patients and patient organisations.

### What are the obstacles to joined up services and how would you like them to be overcome?/ What, if any, barriers to integration should be removed, and how can we incentivise better integration of services at all levels?

Currently integration of services is hindered due to poor communication between all the professionals involved in the care of a patient. This may be because there are barriers in place that prevent communication between professionals such as strict confidentiality and access regulations, or it may be that professionals do not know who they should be talking to. The result is that patients frequently meet professionals who have not previously been informed of their condition or situation leading patients to repeat their case-history. This is not the best use of a patient's or a health professionals' time resulting in an inefficient use of NHS resources, as well as reduced patient satisfaction.

We recognise that patients may want part of their care to remain private, therefore we recommend that a system of consent be established that enables a patient to agree to sharing their notes between departments, and allows this access once consent is given. A system such as this, whereby all patients' information can be accessed from any NHS computer, once patient consent has been given, would facilitate communication between all professionals, and would ensure that they were aware of all information that might influence their decision on treatment or therapy options. Furthermore, patients should be able to access this information to enable them to gain a full overview of the care they are receiving, as well as all their test results and other medical information.

Patients should be given the option of being provided with copies of their own medical records. Patient-held records would be kept up-to-date by patients and the professionals they see, and patients could take these records with them to each appointment to ensure that all the health professionals they see have access to their most recent medical notes. As well as ensuring that professionals have all the information they need, this would also give some control back to the patient and make sure that they know all the details of their own condition.

Silo budgeting is a major obstacle to the provision of integrated care for patients with rare diseases. As noted previously, patients with rare diseases often access services commissioned at a range of different levels and services spanning health and social care. This can lead to disputes between commissioners on different levels over who should pay for the various aspects of care. Moving forward, this could arise

---

#### Rare Disease UK

Unit 4D, Leroy House, 436 Essex Road,  
London, N1 3QP

[www.raredisease.org.uk](http://www.raredisease.org.uk)

T: +44 (0)20 7704 3141 | F: +44 (0)20 7359 1447

E: [info@raredisease.org.uk](mailto:info@raredisease.org.uk)

An initiative of



**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

A charity registered in England and Wales (no. 1114195)  
in Scotland (no. SC039299).

A company Limited by Guarantee (Number 05772999)



particularly in the case of those services which are not utilised frequently enough to be commissioned by a single Clinical Commissioning Group (CCG), but are not commissioned by the NHS Commissioning Board.

Truly integrated care ultimately relies on a willingness by health professionals to work across institutional boundaries, to consider the wider care received by the patient, open communication between professionals and to the principles of shared decision-making. Effective integrated care should coordinate all aspects of the multidisciplinary care as opposed to creating narrow pathways of care that will be inappropriate for patients with rare multi-system diseases.

## What works well already? What doesn't work?

There are a number of examples of good-quality multidisciplinary services for rare diseases. Those services commissioned nationally by the National Specialised Commissioning Team should be viewed as models for other services, although more still needs to be done to ensure that the some of these services are effectively integrated with locally commissioned services.

## What does good look like?

Effective integration should place the patient at the centre of their care. Ultimately, the main objective of improved integration of care should be to provide a better experience and better outcomes for a patient. RDUK also believes that improved integration of services would lead to more efficient use of NHS resources, but this should not be the primary driver per se.

Horizontal integration across those services provided at one tier of the system and vertical integration, not just across the tiers of care, but across services commissioned at different levels is an important aspect of integration. The majority of services needed by a patient affected by a rare disease on a day-to-day basis will be non-specialised services commissioned at a local level. Currently, there is often a lack of integration between services commissioned at different levels resulting in poor collaboration and coordination of care. A patient may receive a good quality service commissioned nationally, for example, but can then struggle to access the necessary services and support locally and their health can suffer as a consequence. In the new NHS, there will be a need to ensure the integration of services commissioned by CCGs and the NHS Commissioning Board.

Where should services be better integrated around patients, service users and carers – both within the NHS, and between the NHS and local government services? We are particularly thinking of social care – for example, better management of long term conditions, better care of older people, more effective handover of a person's care from one part of the system to another, etc.

As has been described, there is a need for improved integration of services for patients with rare diseases. Many rare diseases are long-term and incurable, and affect multiple systems of the body. This

---

### Rare Disease UK

Unit 4D, Leroy House, 436 Essex Road,  
London, N1 3QP

[www.raredisease.org.uk](http://www.raredisease.org.uk)

T: +44 (0)20 7704 3141 | F: +44 (0)20 7359 1447

E: [info@raredisease.org.uk](mailto:info@raredisease.org.uk)

An initiative of



**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

A charity registered in England and Wales (no. 1114195)  
in Scotland (no. SC039299).

A company Limited by Guarantee (Number 05772999)



RARE DISEASE | UK

The National Alliance for people with rare diseases & all who support them

necessitates effective integration of services, both health and social care, to ensure the best outcomes for patients.

Transition from paediatric to adult, and adult to elderly services are particular areas where poor integration of services is endemic. Patients often report feeling like they have “fallen off a cliff” following transition as support structures that were previously in place are removed, services no longer are available, and benefits which patients and carers previously relied on have to be fought to be retained. There is an urgent need to ensure better advance planning to militate against these problems during transition periods.

## How can integrated services achieve better health, better care and better value for money?

Seamlessly integrated services should be seen as a key means by which to ensure the most efficient use of NHS resources. Fragmented care often results in added expenditure for the NHS due to the inefficient use of services and poor use of professionals’ and patients’ time. Poorly coordinated care makes forward planning more difficult and can result in missed opportunities for interventions, sometimes necessitating more costly interventions further down the line or avoidable emergency hospital admissions.

Rare Disease UK – November 2011

---

### Rare Disease UK

Unit 4D, Leroy House, 436 Essex Road,  
London, N1 3QP

[www.raredisease.org.uk](http://www.raredisease.org.uk)

T: +44 (0)20 7704 3141 | F: +44 (0)20 7359 1447

E: [info@raredisease.org.uk](mailto:info@raredisease.org.uk)

An initiative of



**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

A charity registered in England and Wales (no. 1114195)  
in Scotland (no. SC039299).

A company Limited by Guarantee (Number 05772999)