



RARE DISEASE | UK

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

Response to the Royal College of General Practitioner's Integration of Care Consultation Paper

About Rare Disease UK

Rare Disease UK (RDUK) is the national alliance for people with rare diseases and all who support them. We have nearly 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 improve the integration of services for patients with rare diseases.

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 stakeholders. These recommendations can be found in our report, 'Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy' (available at: <http://www.raredisease.org.uk/documents/RD-UK-Strategy-Report.pdf>). All of our recommendations below are key components of what RDUK would like to see in an effective plan for rare diseases.

Introduction

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, RDUK supports this consultation exercise by the Royal College of General Practitioners (RCGP) in looking to develop a policy that can guide decision making and service design.

Integration of services is a major issue for patients with rare diseases and their families. Many 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.

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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 impacts to the patient of poor integration that RDUK has identified include:

- each professional a patient comes into contact with being concerned only with a specific aspect of the condition, but no one concerned with the condition as a whole;
- patients or their family 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 those involved in the care of a patient.

RDUK has also identified 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.
- 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 hours¹.

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.

Fragmented care can also result 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.

What definition of integrated care do you believe should be used to inform policy?

Any definition of integrated care should place the patient at the centre. Ultimately, the main objective of improved integration of care should be to provide a better experience and better outcomes for a

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

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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 clinical commissioning groups (CCGs) and the NHS Commissioning Board.

Many references are made in the consultation paper to the need for “locally agreed” care pathways, or that integrated care should be locally determined. In the RCGP’s definition of integration, integrated care should be led by primary care. RDUK acknowledges that the involvement of local services and primary care is vital in ensuring seamlessly integrated care; however, in the case of rare diseases the knowledge to coordinate all the services necessary may not be available at a local level. The specialist centre may be better placed to ensure that all the necessary services are integrated and informed of a patients’ condition. RDUK believes that each patient affected by a chronic rare disease should have a designated care coordinator to aid the integration of care across all levels of the NHS.

What in your view are the three main benefits of integrated care? What are the risks of integrated care?

The three broad main benefits of integrated care are:

1. Improved experience of the NHS for patients and families by ensuring that care and support is patient-centred.
2. Improved health outcomes by ensuring that patients have access to all the necessary services at the right time.
3. Ensuring the most efficient use of NHS resources.

The main risk to a patient comes from poorly integrated care, whereby a patient is unable to access all the services needed at the right time. One risk not identified in the consultation document is the possibility of disputes between commissioners on different levels over who should pay for the various aspects of care. This could arise particularly in the case of those services which are not utilised frequently enough to be commissioned by a single CCG, but are not commissioned by the NHS Commissioning Board.

How can competition and choice of provider be reconciled with integrated care services?

In the field of rare diseases, in terms of choice of provider for any specific disease, there may only be one specialist in England, or expertise may be located in only a handful of centres. Therefore, traditional

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notions of choice in healthcare do not apply. This again reinforces the need to effectively integrate these specialist aspects of care with local services to ensure that local services are able to provide effective care. Integration of services for rare diseases should not be seen as a barrier to choice, rather than the means to ensure that patients can in fact access the good quality services that are needed.

Who should make decisions about what integrated care services are required in a given area? What role should providers take in developing integrated care services?

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 implemented 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. As referred to previously, designated care coordinators would aid the integration of services around a patient in practice.

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

What leadership and management skills are required to lead on the development of integrated care services?

As in our response above, the lead needs to come from the level where there is the best understanding of the disease and the services needed by patients. The NHS Commissioning Board will have an important role to play in ensuring a strong oversight of the integration of services.

What do you need from information systems to support integrated care, and how should they be funded?

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

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patient consent has been given, would facilitate communication between all professionals involved in the care of rare disease patients, 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.

How can integrated care services prevent silo working?

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.

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