

What does Coordinated Care mean for Rare Conditions?

What did we want to find out?

In this research, we wanted to find out three things:

1. What does coordinated care mean?

2. What does coordinated care look like?

3. Is care for rare conditions coordinated?

To answer these questions, we searched for, read and analysed **154 published review papers**, about coordination of care for chronic (long-term) conditions. Most of these papers focused on common chronic conditions e.g. diabetes.

To find out if the findings apply to rare conditions as well as common chronic conditions, we also held **three discussion groups** with people living with rare conditions, their family members, and healthcare professionals.

Why is this research important?

Getting treatment for chronic or rare conditions can be difficult for patients and families. This may be because they need to attend many health appointments, with different specialists, on different days in different places. This can have a huge impact on everyone involved – especially patients and carers. If we can find out how to coordinate care better for people with rare conditions, we might be able to reduce this impact. Before we can improve coordination, we need to understand what ‘coordination’ means and what ‘coordination’ looks like.

What did we find?

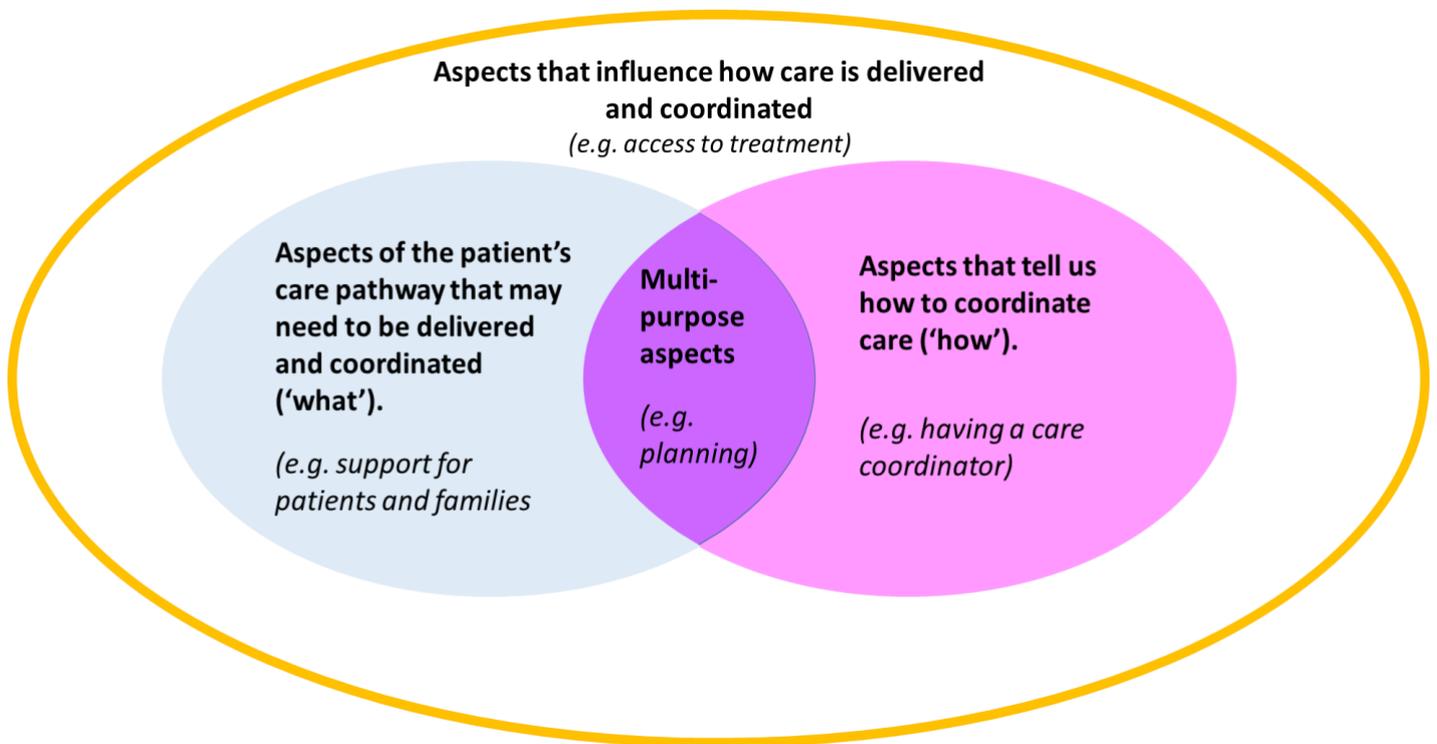
1. What does coordinated care mean?

We think that coordination means: working together across multiple aspects of care to help everyone involved in a patient’s care to avoid repetition and achieve shared goals. We say that care must be coordinated throughout a person’s whole life, across all parts of the health and care system. We say that coordination needs to be based around the family, consider the whole person, be based on research and that people must have equal access to coordination regardless of their diagnosis or place of living.

2. What does coordinated care look like?

We found many different aspects of coordinated care. This suggests that there are many different ways to coordinate care for people living with rare conditions. We grouped these aspects into four categories:

The four categories of coordination



3. Is care for rare conditions coordinated?

We found that findings from common chronic conditions are relevant for people with rare conditions. We found that care is not currently coordinated for people with rare conditions. There may be additional challenges which limit care coordination for rare and undiagnosed conditions e.g. Difficulties diagnosing rare conditions and the small numbers of people diagnosed with each condition. Some extra aspects may also be appropriate for rare conditions e.g. genetic screening.

Summary

Our findings suggest that coordinated care is complicated as we can coordinate care in many different ways. Our findings can help us to create and eventually test different ways of coordinating care for people living with rare and common chronic conditions.

About the study

Researchers (based at University College London, Genetic Alliance UK, the University of Cambridge and the University of Nottingham) have recently published a paper in the *International Journal of Integrated Care*. The title of the research is: 'Defining Coordinated Care for People with Rare Conditions: A scoping review' (Walton et al, 2020). This document provides a summary of this research.

What is CONCORD?

CONCORD is a project trying to find out if and how care services for people with rare diseases are coordinated in the UK. It is also trying to find out how patients and their families affected by rare diseases and healthcare professionals who treat rare diseases would like them to be coordinated.

The Coordinated Care of Rare Diseases (CONCORD) project is funded by the National Institute for Health Research Health Services and Delivery Research programme (HS&DR Project: 16/116/82). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

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The full paper can be downloaded from: <https://www.ijic.org/articles/10.5334/ijic.5464/>

Find out more about CONCORD: <https://geneticalliance.org.uk/our-work/healthcare-and-delivery/coordinated-care-of-rare-diseases-concord/>

Thank you to members of the CONCORD Public and Patient Involvement Group for providing feedback on this summary.