

Co-ordinated care for people affected by rare diseases: the CONCORD mixed-methods study

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Plain English summary

The CONCORD study

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Plain English summary

More than 3.5 million people in the UK are affected by a rare condition. These conditions can be severe and disabling and affect more than one part of the body, meaning that patients often require treatment from different experts. Many people have to visit a variety of health services to receive care, some of which, such as the local hospital or general practitioner, may be close to home, and others, such as hospitals where they can see different specialists, may be further away. This can cause problems because co-ordination between these health-care providers is often not very good and there may be gaps in care due to patients not seeing the right professionals. In addition, when patients do see the right professionals the information to facilitate the right care may not be available. The aim of this study was to find out how well the care of people with rare conditions is co-ordinated in the UK and how people affected by rare conditions would like their care to be co-ordinated. We undertook a review to develop a definition of co-ordinated care and identify what co-ordinated care might involve. We undertook a survey of patients, parents/carers and health-care professionals to find out about current experiences of care co-ordination. The survey found that for the majority of people affected by rare diseases care was not well co-ordinated, with limited access to care co-ordinators, specialist centres and care plans. We interviewed people affected by rare conditions and found that poorly co-ordinated care can have negative impacts on their mental and physical health, as well as on their finances. We found that patients and families would like their care to be better co-ordinated and, hypothetically, are willing to pay for this. We developed a way of classifying how care of rare diseases can be co-ordinated, which could help to improve the experiences of people affected by rare conditions.

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