HOW ARE PATIENTS WITH RARE DISEASES AND THEIR CARERS IMPACTED BY THE WAY THEIR CARE IS COORDINATED IN THE UK? 
An exploratory qualitative interview study

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Background
UK policy frameworks highlight the importance of care coordination for rare conditions. Yet, there is a lack of evidence exploring if and how patients and carers are impacted by the way in which their care is coordinated. We aimed to explore how care coordination (or lack of) impacts on patients and carers.

Method
We conducted semi-structured interviews with 15 UK-based patients and carers/parents with lived experience of a range of rare and undiagnosed conditions. Transcript data were grouped into themes and sub-themes.

Findings
• Participants reported that their care was uncoordinated in four keyways (see ‘experiences of uncoordinated care’ in figure 1).
• Patients and carers were negatively impacted in terms of their finances, psychosocial and physical wellbeing, and access to care (see figure 1).
• Many of the impacts were attributed to the time and burden felt by the individual(s) who attended appointments and took on the key role of coordinating care.

Negative impacts could be reduced by:
1. Having the support of a professional to coordinate care
2. Changing the approach of clinics and appointments (e.g., where they take place, which professionals/services are available and how they are scheduled)
3. Improving communication between professionals, services and patients (e.g., by using technology)

Figure 1: Patient and carer experiences of uncoordinated care and their impact

Experiences of uncoordinated care

- Appointments are uncoordinated
- Patients and carers coordinate their own care
- Communication between stakeholders is ineffective
- Cars is not coordinated to meet the needs of different patients and scenarios

Impact on patients and carers

- Access to care
  - Delays and barriers to specialists, medication and non-medical support
- Physical health
  - Fatigue, indirect consequences of barriers to accessing care
- Financial
  - Travel, parking, accommodation, food, loss of earnings, childcare, carer fees, private health care, printing and postage
- Psychosocial
  - Strained relationships, disruption to education, isolation, loss of identity/self-esteem, emotional impact, lack of confidence in care

Conclusions
Our findings suggest that uncoordinated care has a negative impact on patients, and their families, in many different ways. Models of care coordination which lessen the time and burden placed on families may be particularly beneficial in reducing these impacts. Findings should influence future service developments (and the evaluation of such developments). In the first instance, findings will inform the CONCORD Care of Rare Diseases (CONCORD) Study.

*Genetic Alliance UK is an alliance of over 180 patient organisations and the national charity working to improve the lives of patients and families affected by genetic conditions

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