

What ways of coordinating care for rare conditions currently exist and are possible?

Exploring models of care coordination and stakeholder preferences

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Our aim

This research aims to develop a **'taxonomy'** outlining different ways to coordinate care for rare, ultra-rare and undiagnosed conditions.

Why is this research important?

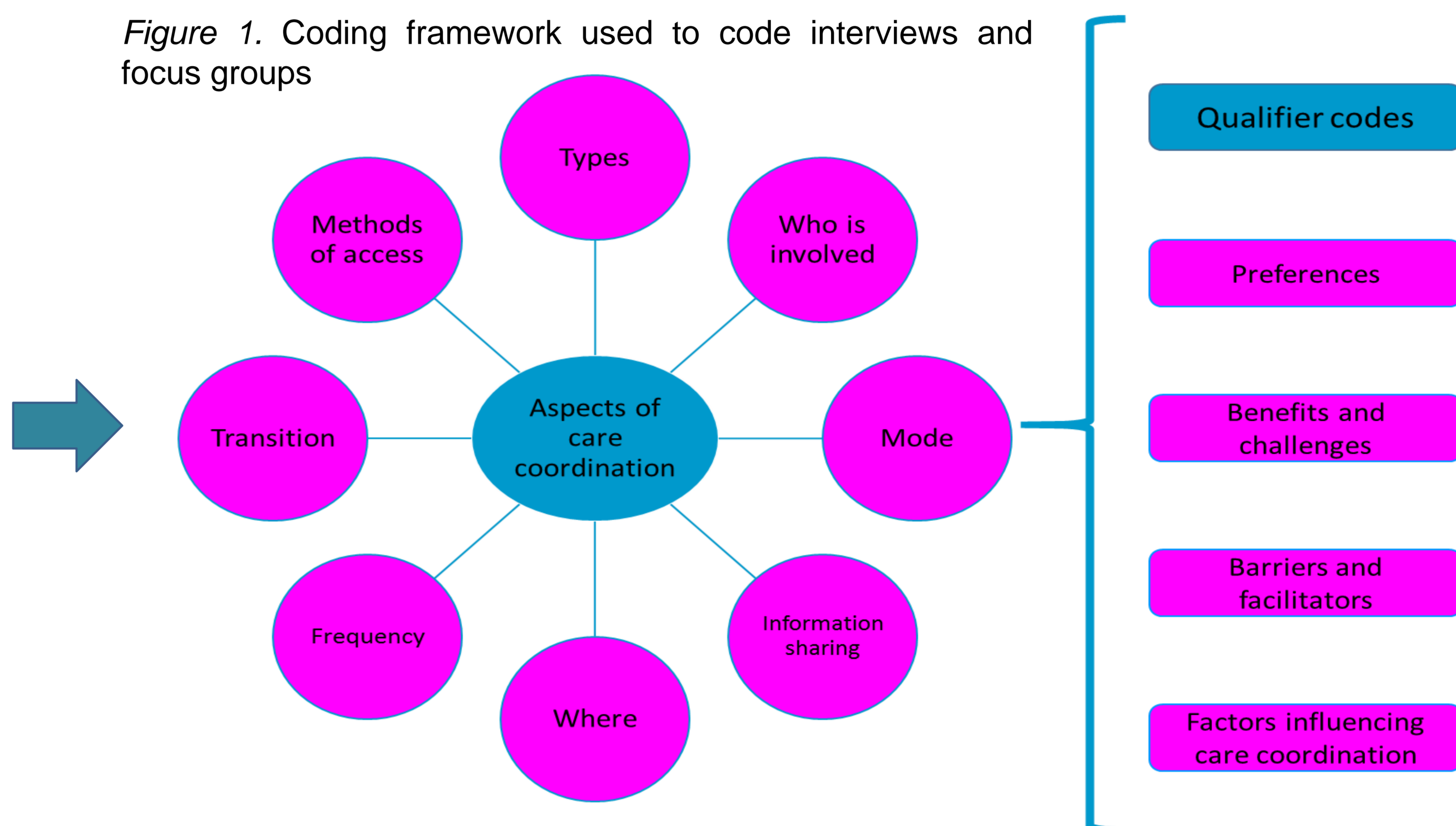
- Difficulties associated with accessing treatment for rare conditions might be reduced by improving **care coordination**
- This need for coordinated care was emphasised in the UK Strategy for Rare Diseases
- To improve coordination, we need to understand what different ways of coordinating care exist and what types of coordination stakeholders prefer

A **taxonomy** is a table used to organise complex phenomena (Bradley et al, 2007)

Progress so far

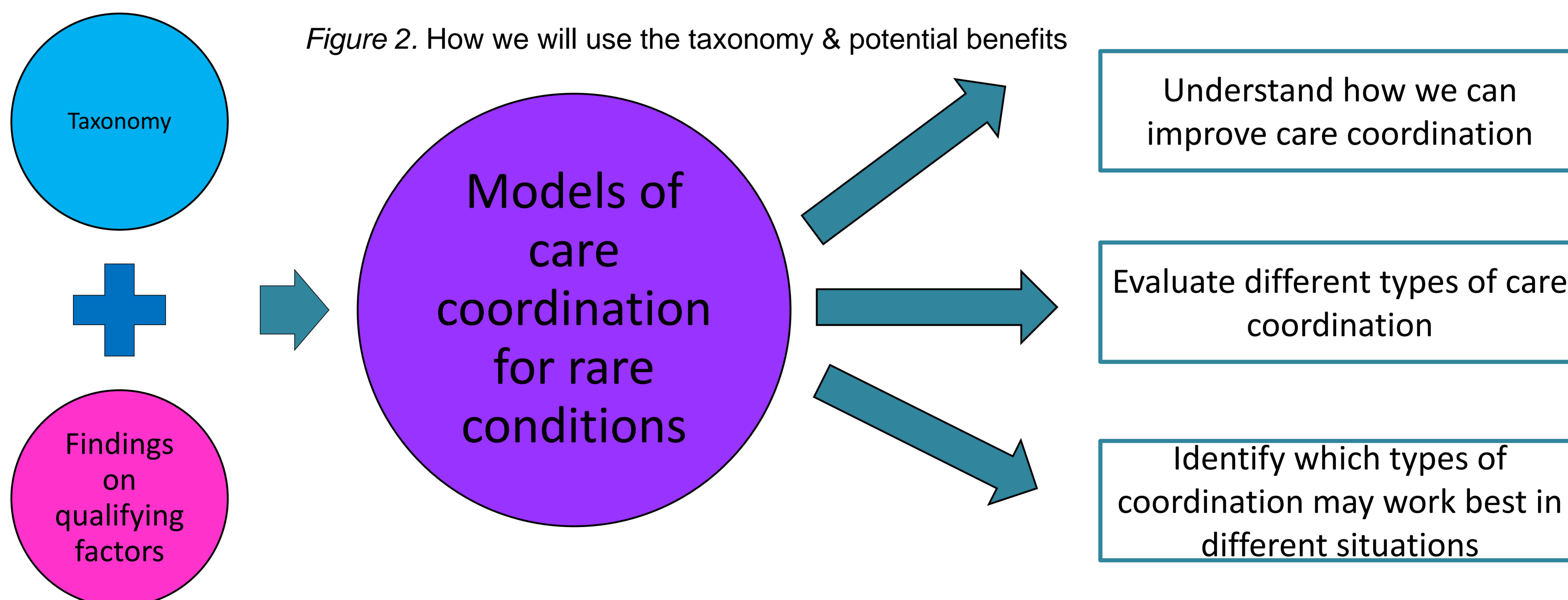
- Thirty interviews (healthcare professionals/charity representatives/commissioners) conducted
- Four focus groups (patients living with rare or undiagnosed conditions or parents/carers) were conducted
- All interviews/focus groups coded using a coding framework (see Figure 1)
 - Aspects of care coordination
 - Qualifier codes
- Findings are being grouped into themes and sub-themes & used to develop a taxonomy outlining different ways of coordinating care
- Analysis is currently underway and not yet finished

Figure 1. Coding framework used to code interviews and focus groups



What will the taxonomy look like?

- The taxonomy will outline different ways in which care can be coordinated for rare conditions
- It will consist of domains, characteristics and examples
- Models of care coordination will then be developed (see Figure 2)
- Understanding different ways to coordinate care will help us in a number of ways (see benefits in Figure 2)



Conclusions

- The development of a taxonomy of care coordination may help key stakeholders to make decisions about how care for rare diseases is organised
- If different ways to coordinate care are evaluated and eventually used within health systems, findings could potentially improve care coordination and reduce burden for people living with rare conditions

Find out more

More information on the CONCORD study can be found [here](#)

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#CONCORDStudy



Key references: Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res*, 42(4), 1758-1772.

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