

Are you an adult 18+ living with a rare, ultra-rare or undiagnosed condition or a parent or carer of a young person or adult living with a rare, ultra-rare or undiagnosed condition?

Would you like to take part in a workshop to help refine a classification of care coordination for rare diseases?

Researchers working on the **COordiNated Care of Rare Diseases (CONCORD) project** at University College London are looking for participants!

What is CONCORD?

A research study which looks at how care of people with rare diseases is coordinated in the UK and how patients and healthcare professionals who treat rare diseases would like them to be coordinated.

What would taking part involve?

What? Attending a workshop with 20 attendees (patients and carers)

Where? Face-to-face in different central locations (you will be invited to the nearest workshop).

Why? The purpose of the workshop will be to offer feedback on a draft classification of coordinated care and offer recommendations to improve the classification.

How long will it take? The workshop will take between two and three hours.

Will I be reimbursed for travel? Yes

Am I eligible to take part? Not everybody will be eligible to take part, but we will ask you some basic questions about you or the person you are caring for and the condition. This way we will be able to select participants that represent a broad range of experience.

Who should I contact for more information or to take part?

If you would like to take part in this research or would like to ask further questions, please contact:

Holly Walton (University College London, Department of Applied Health Research)

Email: holly.walton@ucl.ac.uk | **Tel:** 02031083068

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