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# Data and Research

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## Overview

Information is at the heart of understanding disease and discovering disease mechanisms and treatments. Neil leads the clinical data team whose work supports studies by applying statistical methods to understand the links between the disease and the individual's DNA sequence (BioInformatics).

This is important for rare and undiagnosed conditions because 80% of rare diseases are determined by changes in DNA.

Neil's session will help you understand where data is central to research, how we go about data collection and analysis and what types of data are particularly valuable.

The session will focus on:

- What can Research do for me?
- What can I do for Research?

## Who will find this session relevant?

Any Rare Disease patient, who wants to understand the world of data, from how data is managed and the ethical constraints of sharing data to processing and utilising data. Then we will cover how data can provide the clues to understand rare disease.

## Covering the following

- Why is data collection important to rare disease patients?
- How NIHR BioResource for Translational Research manages data access
- How will the new GDPR legislation affect rare disease patient data?
- How is data collected and stored and what is the significance of Biobanks?
- Who looks at your data during the research process?
- How data could be shared and with whom?
- New technologies, including the growing use of Apps to collect and store patient data

## Activities

### To include:

- Discussion on data issues for Rare Disease patients

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Session Four is repeated at the following times:

11:30 to 12:30 (1 hour)

13:30 to 14:30 (1 hour)

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## Neil Walker



**IT Director for  
NIHR BioResource for  
Translational Research**

Neil is the IT Director for NIHR BioResource for Translational Research. He has worked for the University of Cambridge in Clinical Informatics and the Medical Research Council, working on various big data initiatives, including epidemiology and genetics trials.