

Do you have a rare rheumatic disease?

Would you like to share your experiences and shape new research?

Vasculitis
Still's Sjögren's
Scleroderma
Relapsing-polychondritis
Behçet's ANCA
Kawasaki's
Lupus
Takayasu's
Myositis

data of **Rare Diseases** People
Methods UK Improve
Big Bioinformatics
NHS Rheumatic Services
Linked Registries
Quality Disease
Strategy
Best Health
Trials
Treatments
Data Problem
Recruitment Registration
Life Commissioning
Healthcare
Needed

If you would like to hear about and influence a planned research project, by email, telephone or attending a focus group in Nottingham please contact:

Dr Fiona Pearce
Fiona.Pearce@nottingham.ac.uk



Help create a national register for people with rare rheumatic diseases

A key commitment of the UK's Strategy for Rare Diseases is to create national registries. Better data will help us to find out how many people have each rare disease, how they are diagnosed, and how and where they are treated. This will give better information to people living with rare diseases, their doctors, and the commissioners of health services. It will mean that more people with rare diseases can be involved in research, and this will result in the development of new and better treatments. The aim of this research is to improve health for people with rare diseases.

I am working with the National Congenital Anomaly and Rare Disease Registration Service, which is part of Public Health England. They are starting to collect data on rare diseases. The work I am doing means that they can prioritise rare rheumatic diseases (such as Lupus, Vasculitis, Myositis, Sjögren's syndrome, Scleroderma and Behçet's disease). We need to do research on the best ways to find and register people with rare diseases. Can you help us find a way to do this effectively and efficiently?

If you would like to give your views, and help shape or champion research on the best ways to do this please contact:

fiona.pearce@nottingham.ac.uk, Dr Fiona Pearce, Clinical Lecturer, University of Nottingham

More information on the data collected by the NCARDRS, how it is used and your right to opt out of the register if you wish is available at www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncardrs.