



## Public Involvement Opportunity with “Assembling the Data Jigsaw”

### Type of Opportunity

Patient-Public Involvement Contributor (known as Public Contributor<sup>1</sup>) with the research programme called “Assembling the Data Jigsaw”

### Time Commitment

There will be approximately 10 meetings during the time of the research which will run until February 2024. Meetings are likely to be between 1 to 1½ hours in length. Meetings will take place on zoom or telephone, however face-to-face meetings might be possible in the future. We can provide support for using Zoom and accessing it via a computer, tablet or phone.

### About “Assembling the Data Jigsaw”

Assembling the Data Jigsaw is a research programme in Greater Manchester that will bring together existing and new health care data to answer questions about arthritis that are important to patients. It will use records held by Salford GPs and Salford Royal NHS Foundation Trust.

### About the Public Involvement Opportunities

If you are interested in how patient records can be used for research, we'd love to hear from you.

We are looking for people who live with arthritis or a musculoskeletal condition (e.g. ankylosing spondylitis, fibromyalgia, osteoarthritis, psoriatic arthritis, rheumatoid arthritis) and live in Salford, or are a patient with the rheumatology department at Salford Royal NHS Foundation Trust.

We are especially keen for people from diverse backgrounds and with different levels of experience to join us. No experience of research or previous activity in public involvement or data is necessary. However, what is essential is that you have the enthusiasm and the confidence to comment, advise and make recommendations (as a group) reflecting the general views and concerns of patients and the public.

### What will Public Contributors do in Assembling the Data Jigsaw?

We are looking for five Public Contributors to form an advisory group and take part in meetings and discussions with some of the research team. You will help us make sure the patient and public perspective is included in our work and decision making. You will help to shape our approach to the research so that we can make sure people have trust and confidence in what we do. You will contribute especially to a theme of work focusing on building and sustaining public trust in using health data for research to improve treatments and management of musculoskeletal disease. To do this you will help us to design work that will engage diverse groups with experience of musculoskeletal conditions to help us understand their views and perspectives about data sharing for research. This will also enable us to develop materials and methods to address what information people need regarding health data sharing and the use of health care records for research. This work will be crucial to shaping our communication with members of the public and key professionals.

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<sup>1</sup> A Public Contributor is someone who undertakes patient and public involvement (PPI) in research. PPI is where research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. ‘Public’ means people living with frailty, their friends and family members as well as members of the general public with interests in the care and services for people living with frailty.



## Will training and support be available to Public Contributors?

Yes, we will provide training and support for Public Contributors. We will introduce Public Contributors to the work of the research team, discuss any training needs and answer queries. We will ensure that regular contact is maintained with Public Contributors.

## Payment and expenses for Public Contributors

Payment will be provided for Public Contributors at a rate of £20 per hour, plus any reasonable travel or other costs (to be agreed in advance).

## How do I apply?

Please email Joyce Fox, Patient and Public Involvement Lead, [Jigsaw@manchester.ac.uk](mailto:Jigsaw@manchester.ac.uk) with a short paragraph saying why you'd like to be a Public Contributor with Assembling the Data Jigsaw.

The closing date is **5pm on Friday 22<sup>nd</sup> October 2021**.

We will contact people within two weeks of the closing date with the outcome of applications, and to informally discuss the role with shortlisted people. ***Please say in your email if you would prefer a zoom or phone call. If you prefer a phone call, please include a phone number.***

## Further details about Assembling the Data Jigsaw

In *Assembling the Data Jigsaw*, we will link different sources of patient data and we will develop new ways to collect information, particularly to enable patients to add information alongside their health records. The combined information will help answer important questions about MSK disease.

The project will be run in Salford, Greater Manchester where hospital and GP records are already joined up.

We will use the safest and most secure ways to assemble the data and provide access for researchers. We are committed to ensure all research activities follow, and indeed help establish, the highest standards in dealing with medical information and patient data.

## How this will benefit patients

We will demonstrate the value of this new data by using it to answer important questions such as:

- How common is it for people to be diagnosed with this particular type of arthritis?
- Are there ways of speeding up the time it takes to be diagnosed with rheumatoid arthritis and ankylosing spondylitis?
- What are the benefits and possible harms of certain painkillers?

If collected in the right way and accessed safely, data will improve the management of health conditions for future generations. Public trust will be crucial enabling progress for research based on the use of health data. Join us to develop inclusive and open ways to work with patients and public for this important work.

## Who is funding Assembling the Data Jigsaw?

The research is funded by a £1.5m investment from The Nuffield Foundation

<https://www.nuffieldfoundation.org/project/powering-robust-population-research-in-msk-disease>