



## November 2021

Welcome to our second Epidemiology Patient and Public Involvement Group newsletter and thank you for continuing to take the time to be involved with our group. If you would rather not receive any further communications please reply to this email with "STOP" and we will remove your details from our database.

In this newsletter we will tell you a bit more about our team, what research is happening now within the Epidemiology Group and some opportunities to get involved, and then some interesting events that are happening at the University of Aberdeen which are open to everyone.

We will also share a really interesting article from Steve Chinn, one of our patient partners on the [VOICES](#) Study, on his thoughts on why PPI is so important to him.

Thank you for taking the time to read this email, and if you would like to contact us please email [epippi@abdn.ac.uk](mailto:epippi@abdn.ac.uk) with any comments or feedback you may have.

## Getting to know our team



**Dr Elaine Wainwright** is the academic lead of the Epidemiology Patient and Public Involvement Group.

Elaine joined the Epidemiology group in September 2021 as Lecturer in Musculoskeletal Health. She holds degrees from the Universities of York, Oxford and the Open University, in Health Services Research, English and Psychology respectively, and a PhD from the University of Bath. Elaine is working on a range of projects within the Epidemiology Group; she has a particular focus on the impact of living with pain on working lives and the role of safe and appropriate work as a health outcome. In her spare time, she likes baking and eating cakes.



**Dr Karen Forrest Keenan** joined the Epidemiology Group as a Study Coordinator in November 2015.

During this time she has co-ordinated two MRI studies; one exploring fatigue in Lupus disease and one looking at whether NSAIDs mask inflammation on MRI in Axial Spondyloarthritis ([DyNAMISM](#)), before embarking in her current role as Study Coordinator of the British Society for Rheumatology Psoriatic Arthritis Register ([BSR-PsA](#)). Prior to joining the group Karen worked as a Research Fellow in the Health Services Research Unit and Medical Genetics Group. Karen also has experience of working in the voluntary sector where she managed a National Youth Service for young people at risk of Huntington's disease.

In her spare time, Karen enjoys hill walking and watching movies with her family.



**Stuart Anderson** joined the Epidemiology group as a Project Assistant in February 2018, working on the [MAmMOTH](#) project. Since then he has worked on a number of studies providing administrative support, including [PACFiND](#), [CONTAIN](#) and FRESKO, and he is now working as a Project Coordinator on several studies involving musculoskeletal conditions and their impact on [work](#).

He holds degrees in Law from the University of Glasgow and University of Strathclyde, and in his spare time he enjoys cooking and music.



**Laura Moir** joined the Epidemiology group in May 2018 and works as a Study Coordinator across various studies within the Epidemiology group including [PACFiND](#), FRESKO, [RHEUMAPS](#), [VOICES](#) and [DyNAMISM](#).

In her spare time Laura likes walking her dog, and because her dog likes walks in the mud in his spare time, she also likes washing her dog, a lot!

## Focus on our research studies



British Society for  
Rheumatology

Psoriatic Arthritis Register

### The British Society for Rheumatology Psoriatic Arthritis Register (BSR-PsA)

The [BSR-PsA](#) is a long-term study, which has been set up to investigate the impact of psoriatic arthritis (PsA) on the quality of life of affected individuals over a number of years and to monitor the safety of treatments available for PsA. We also want to find out more about how treatments affect the lives of PsA patients in areas like work, driving, general quality of life and why some people respond well to certain drugs and others do not. There are a number of treatments available but how effective these drugs are at treating the disease can vary, with individuals responding differently to the same drug. The underlying biological reason for this variation in response to the same drug is poorly understood.

Patients are recruited to the study through their local hospital rheumatology clinic and may be eligible to participate if they are a patient at one of our recruiting centres. There are several criteria for participation which local site staff are able to assess and would discuss with any potential participant. If you would like any further information about the BSR-PsA registry study, please contact your local rheumatology team to find out if they are a study site. Alternatively, please contact the Co-ordinating centre in Aberdeen via email at: [bsr-psa@abdn.ac.uk](mailto:bsr-psa@abdn.ac.uk) or phone on [01224 437562](tel:01224437562).

You can find out more about the study [here](#).

## Patient and partner stories

Steven Chinn is a patient partner on our [VOICES](#) Study. Below he describes why patient and public involvement is important to him.

You can find out more about the VOICES Study [here](#).

### Steven Chinn

*"I was diagnosed with ANCA Vasculitis with MPO Antibodies, also known as Microscopic Polyangiitis, in December 2018. I try to give something back by acting as a patient advisor on research projects. This involves working with the research team to build a patient perspective into the way research needs are identified, and the research itself is designed and carried-out. In the end, I always want to help ensure that a study gets at the real issues and produces relevant information."*

*"Sometimes, there are questions of wording too. A patient advisor keeps a watching eye out for this. I think it is very important, as a patient advisor, to represent all patients, and not just one's own views. So, I talk to fellow patients a lot. I've learnt a few things from this."*

*"One is that what's important to patients often isn't what's treated as important in medicine. Another is that there's a reason we're called patients – it's that we have to be infinitely patient. Another is that what counts as quality of life in medical research can still leave patients with sizeable day to day challenges."*

*"Research is crucially important in a number of ways. It produces the information that helps to achieve two goals:*

1. **Better understanding of our needs** as patients and carers, so services can better meet them.
2. **Develop and trial new treatments, behaviours and devices** (including both brand new meds, and new ways to use existing meds) - so that genuine progress will be made in how medicine can treat vasculitis and all the knock-on problems that come with it."

*"I think the most important thing to know about research is this:*

*Research is how medicine and healthcare move forward. We, the patients, are the partners of the scientists, medical professionals and other researchers who make it happen. Our role is crucial. Without us, there is no research. Without research, there is no progress.*

*The patient advisor is there to help this all happen, and that's very rewarding."*



# Get involved with our research

We currently have several different opportunities to get involved with our research:



## Move & Snooze

*Study participants required*

The Move & Snooze study is looking for participants who would like to be involved in a research study to help develop a new programme aimed at improving activity levels and sleep.

To take part you should have a osteoarthritis diagnosis and be based anywhere in the UK.

For more information email [epidemiology@abdn.ac.uk](mailto:epidemiology@abdn.ac.uk).



## Understanding the impact of Non-Inflammatory musculoskeletal conditions on work and work transitions: a QUALitativE investigation (UNIQUE)

*Study participants required*

Musculoskeletal conditions affect around 1 in 3 of Scotland's population and can have a substantial impact on people's ability to work. The Making it Work™ programme in Canada has been successful in supporting people with inflammatory arthritis to stay in employment for as long as they wish to do so. The [UNIQUE](#) study aims to contribute to future work which will help to extend the scope and reach of this programme. Through a series of telephone interviews with people with non-inflammatory musculoskeletal conditions, we hope to identify key issues that are important to people working with non-inflammatory conditions.

***We are currently recruiting participants for this study.***

If you have been diagnosed with a **non-inflammatory musculoskeletal condition** (for example, osteoarthritis or fibromyalgia), would you be willing to help us?

You can get further information about the study [here](#), and you can contact us by email at [unique@abdn.ac.uk](mailto:unique@abdn.ac.uk) to register your interest in participating. We'll then get in touch with a brief

questionnaire which will help us to identify participants for interview.

*You will be compensated for your time.*



### **QUICK Study**

*Patient and public input required*

Chronic pain has many causes and is often musculoskeletal in nature. It affects the kind of work people do and how they engage in it - from impacting how much work one can do on a day-to-day basis, to long-term career choices. However, there is currently no standard questionnaire that can fully explore and measure the many different impacts of chronic pain on people's ability to work.

The [QUICK](#) study are looking for people who are either **currently employed** and are **experiencing chronic pain** or who have had **recent experience of being in work while living with chronic pain**. We are currently looking for 2 patient collaborators to work closely with us and help us in developing all aspects of this study, and an additional pool of around 4 patient partners to provide additional input as required.

If you would like to express your interest in joining the [QUICK](#) study as a patient collaborator or patient partner please click [here](#) and complete the form.

## **University of Aberdeen events**

### **2021 Festival of Social Science**



**THE 2021 FESTIVAL OF SOCIAL SCIENCE**  
1st - 30th November



**Economic and Social Research C**

The University of Aberdeen's Festival of Social Science is running from the 1st -30th November.

Social science remains central to confronting and meeting the most important challenges of our time, stretching from the local to the international. This year, COP26 is being held in Glasgow and is a once in a generation opportunity to tackle climate change. The Festival of Social Science will showcase the latest insight and analysis on the COP26 negotiations and much more

All events are free, to find out more visit: [www.abdn.ac.uk/engage/foss](http://www.abdn.ac.uk/engage/foss)



### **Physiological Society: new animation**

Aberdeen University's Professor Derek Scott, Chair in Physiology and Pharmacology Education, has been involved in developing a new animation with The Physiological Society.

The three-minute animation tells the story of how our cells come together to build tissues, organs and systems, and what can happen when these systems are disrupted.

You can watch the video [here](#).

## **PPI training resources**

As part of the preparation for undertaking our first Epidemiology Group PPI meeting we wanted to identify some training materials for our patient partners, and ourselves, as these activities are fairly new to the Epi PPI team and some of our members. During our first meeting we undertook some introductory training about PPI for the group but also collated a list of key resources which members can refer to in their own time. We thought these resources may be of interest to share with the wider PPI pool in this Newsletter.

Of course, if you know of any other training resources which may be of help, please do [contact us](#) and let us know!

**INVOLVE: Starting Out: Essential information for members of the public getting started in involvement:**

<https://www.invo.org.uk/wp-content/uploads/2018/01/Induction-public-v3.pdf>

**National Institute for Health Research: Training and Resources for Public Involvement in Research:**

<https://www.learningforinvolvement.org.uk/>

## Glossaries

Health research is full of acronyms! Here are the links to a couple of glossaries we found particularly helpful:

<https://www.invo.org.uk/resource-centre/jargon-buster/>

<https://toolbox.eupati.eu/glossary/>

**Thank  
You**

Thank you for taking the time to read this newsletter!

Have you got a story for us? Maybe you have examples of good PPI involvement that you would like to share with the group, or you would like to tell us about your PPI journey and how you got involved? We would welcome all feedback or suggestions for articles to include in future newsletters.

Please email any feedback to [epippi@abdn.ac.uk](mailto:epippi@abdn.ac.uk)

Kind regards,

The PPI Team

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