



Summer 2022

Welcome to our Epidemiology Patient and Public Involvement Group newsletter and thank you for continuing to take the time to be involved with our group.

We hope you are all enjoying the lovely summer weather so far, or at least managing to keep cool if you are not. As our group is based in Aberdeen, in the northeast of Scotland, we are more accustomed to talking about the cold weather, we are rather enjoying a whole new experience of being able to complain about the heat!

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

PPI within the Epidemiology Group

Identifying determinants of self-advocacy of female patients at the primary care setting in the UK

HERU
HEALTH ECONOMICS RESEARCH UNIT
Promoting Excellence in Health Economics

(Self-advocacy is the ability to speak-up for yourself and the things that are important to you. Self-advocacy means you are able to ask for what you need and want and tell people about your thoughts and feelings)

Thank you to everyone who responded to the survey regarding identifying self-advocacy of female patients in primary care, the study team have informed us they have had 350 responses to date!!

This study is looking to understand how a patients personal and social characteristics affect their ability to self-advocate when attending a GP appointment. During a GP appointment, patients are 'on their own' and must navigate medical advice and treatment plans with their own knowledge and understanding. The self-advocacy of patients, therefore, is of utmost importance so patients can communicate effectively with the care providers and take greater responsibility for the care they receive.

The study aims to understand these characteristics further, evaluate the causes of self-advocacy, and identify possible barriers based on a sample of female patients in the UK who attended GP practices within the past 12 months. If you would like to complete the survey, please click on the following link: [Link to Survey](#)

PPI Awards



Vasculitis Outcomes In relation to Care Experiences Study



Well done to the VOICES Team!!

As part of our [VOICES](#) Study, Dr Rosemary Hollick and our patient partner Lynn Laidlaw presented a talk at the Health Services Research UK 2022 conference, the talk titled *"Voicing experience to improve care for people with rare autoimmune conditions"* won an award for **Innovation in Inclusion** and is a great example of researchers and PPI partners working together to achieve a common goal.

The full recorded presentation can be watched here:

<https://www.youtube.com/watch?v=qpcJntk1YAc>

Focus on our research studies

FRESKO Study Stage III Officially Underway



Exciting news from our FRESKO (Feasibility of Recruiting an Early Scottish Knee Osteoarthritis cohort) study, where we have recruited our first participant to Stage III of the project

Stage III involves comparing standard MRI imaging with Fast Field Cycling (FFC) MRI, a brand new technique developed here in Aberdeen by Professor David Lurie and his team. The benefit of this imaging technique is that it can detect OA tissue abnormalities at an earlier stage, when they are more likely to be reversible.

To find out more about FFC click here: [Fast Field-Cycling MRI](#), to find out more about the FRESKO study click here: [FRESKO Study](#)



British Society for Rheumatology

Psoriatic Arthritis Register

The British Society for Rheumatology Register in Psoriatic Arthritis (BSR-PsA) tracks the progress of a cohort of patients with psoriatic arthritis who are commencing biologic (including biosimilar) or targeted synthetic Disease Modifying Anti-Rheumatic Drugs, plus a comparison cohort of patients not on these drugs. This register is a collaboration between the University of Aberdeen and the British Society for Rheumatology.

Our Chief Investigator Professor Gareth Jones recently joined the National Rheumatoid Arthritis Society (NRAS, <https://nras.org.uk/>) to give a live presentation on the BSR-PsA register, if you would like to view this, please click here: <https://www.youtube.com/watch?v=MsxevBLm4W0>

Patient and Partner Stories

Epidemiology Patient and Public Involvement Group



The Epidemiology Group currently has a PPI group at the heart of its commitment to PPI, this group currently consist of 10 people with a variety of experiences of living with different musculoskeletal conditions. We meet regularly to discuss a variety of study issues brought to them by the research team, and to feed back their lives experience to help guide our work.

An example of what we achieve together:

A study to develop a measure of social engagement; why this is important: The group provided feedback on what social engagement meant to them, and their own experiences of how living with a MSK condition has affected their social engagement. This feedback was then used to help shape the initial grant proposal. The initial grant proposal was accepted, and the team are now working with us again in the second stage of application by looking at the tools that are currently available to measure social engagement.



You can find out more about our PPI group members here: [Meet the Group](#)

Get involved with our research

We currently have the following patient and public involvement opportunity:



If you have experience of working or if you wish to be in paid work and have a chronic pain condition we would like to hear from you!

The QUICK Study is looking at how people are affected at work by their chronic pain. In particular, we are currently looking for people who have experience working multiple part-time jobs, under a zero-hours contract or in gig-economy work to take part in a focus group to tell us about your experiences.

If this sounds like you, or someone you know, you can register your interest here:

<https://redcap.link/quick-patients>

**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

Kind regards,

The PPI Team

You are receiving this email because you have agreed to be part of the Patient and Public Involvement Pool at University of Aberdeen Epidemiology 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. If you have any questions or comments, you can contact us at epippi@abdn.ac.uk