



NEWS LETTER



Welcome to our Patient & Public Involvement Group Summer 2024 Newsletter!

In this edition we have lots of exciting news to share as it has been a busy year so far! We begin with the BRUCES study; a new grant co-led by Dr Rosemary Hollick, and which includes Michelle Stevenson (a member of our Core PPI group) as part of the multi-disciplinary team. Next up, we have an update about some of the tasks our patient partners from the Core and Pool groups have been involved with this year, followed by a spotlight on some of our studies where patient partner involvement has greatly helped this research. We end with some personnel updates, with the announcement that Laura Moir will sadly be leaving the Epidemiology Group, and we hear from Dr Rebecca Parr who has recently joined the coordinating team.

Funding news

BRUCES study awarded £1 million to address inequalities in rural and island healthcare

A new study co-led by our very own Dr Rosemary Hollick (Consultant Rheumatologist) has been awarded £1 million from the Scottish Government's Chief Scientist Office to fund a 5-year project that will examine healthcare inequalities in rural and island areas. The study team combines lived experience with expertise from clinical medicine, health service research, health economics and human geography. The team includes Michelle Stevenson, a member of our Patient Involvement and Engagement group, who lives in remote rural Scotland and has lived experience of chronic long-term health conditions.

The project will look at important rural health inequalities, how they are caused, and effective ways to address them. Ultimately, it will support the delivery of existing policy and inform the design of future rural and island policy, promoting social justice and enhancing the wellbeing of all Scotland's residents, regardless of where they live. Research will focus initially on three common health issues: cancer, musculoskeletal conditions and frailty, which will give insight into acute and longer-term conditions across different age groups and health conditions treated locally and in specialist centres.

Rosemary said: "Musculoskeletal conditions affect around one third of

the adult Scottish population. They are associated with pain, stiffness and fatigue and are amongst the most common reasons why people take time off work or even leave their jobs. These conditions are also the most common cause of disability in older adults, and this is particularly a problem in rural communities with increasingly older populations and where social isolation and lack of carers presents additional challenges."

Michelle explained why she wanted to be involved: "Addressing rural inequalities in health is very important to me, my family and my community... (there are

real, complex challenges faced by people living in rural communities looking to access health and social care... I have a chronic inflammatory arthritis for which I receive strong medication to suppress my immune system. As a result, I developed an infection in my hip which was very serious and resulted in an emergency admission to hospital over an hour from my home in the Highlands. I needed to continue strong intravenous antibiotics at home but because there were no local district nurses I had to travel 120-mile round trip 3 days a week to receive this. I'm now receiving intensive rehabilitation at the rheumatology unit in Dingwall which means being an inpatient for 3 weeks, away from my family and friends. This has brought home to me the real, complex challenges faced by people living in rural communities looking to access health and social care."

Over the term of the project, the team will use interviews and data analysis to determine how people living in rural and island Scotland experience health services and identify when they are disadvantaged. Local, national and international policies that support care delivery in rural areas will also be examined to create guidance to support local and national service planning.



What have our Core and Pool groups been involved with this year so far?

Core Group

Our [Core PPI group](#) consists of nine patients with a variety of experiences of living with different musculoskeletal conditions. The group help us by providing in-depth feedback into our research proposals, study designs, documentation and summaries, and any other area of our work which benefits from the input of people with experience of living with these conditions.

This year, the group has been busy providing us with lots of feedback, including email comments on two research applications (one looking at looking at PPI input in lab-based studies, and one looking at knee and hip surgery), an online meeting in April to discuss some of our ongoing studies in more depth,

and a PPI training session on experiences of using PPI to improve patient care. The training session was kindly delivered by Professor Louise Locock, an experienced researcher from the University's Health Services Research Unit. You can find out more information about Louise and her amazing research [here](#).

We will continue to work closely with our Core group members over the rest of 2024 to ensure that the patient voice remains at the heart of everything we do.

Pool group

Our Pool group consists of over 100 patient partners who also have experience living with a variety of different musculoskeletal conditions, but who we contact on a more ad-hoc basis to ask for feedback on a specific issue or to update on new research opportunities.

Since January we have so far asked the Pool group to complete a survey for the [iPRPaRe](#) study (exploring how patient and public involvement in rheumatic and musculoskeletal disease research is perceived by researchers and partners

themselves), provide feedback about two fellowship applications (both looking at people with MSK conditions who are working and /or with care responsibilities), and issued updates on a number of research engagement opportunities. We also shared a request from the University of Aberdeen's Ethics Advisory Group inviting Lay Members to join their committee, and invited those who were working to take part in user testing of two online work support programmes for people with musculoskeletal conditions.

If you are receiving this email then you are already signed up to our Pool list, so keep an eye out for further opportunities over the rest of the year.



VOICES - Vasculitis Outcomes In relation to Care Experiences

New findings from the VOICES study provides evidence on how best to organise services to improve care for people with rare autoimmune rheumatic diseases

People with rare rheumatic diseases such as systemic vasculitis report an uphill struggle to navigate healthcare systems that are not designed to manage complex, rare conditions. Care is organised in different ways across the UK and currently there are no standards to guide what services should be in place.

The VOICES study set out to provide evidence of how best to deliver effective services that will improve health outcomes and experiences of care for people living with vasculitis.

We have just published the main findings from the VOICES study in *The Lancet Rheumatology*:

Hollick et al, '[Identifying Key Health System Components Associated with Improved Outcomes to Inform the Re-Configuration of Services for Adults with Rare Autoimmune Rheumatic Diseases: A Mixed Methods Study](#)' (2024).

This is the first study to identify the key parts of health care services that can improve experiences of care and health outcomes for people living with rare autoimmune conditions.

The ability to see new patients with suspected vasculitis quickly within one week, the presence of a nurse-led

advice line for patients (i.e. a dedicated telephone line for patients to access advice about their condition), seeing patients in a cohorted clinic (alongside people with similar conditions or needs) and having access to nurse-led clinics were associated with fewer serious infections and emergency admissions to hospital.

When a patient's healthcare included regular meetings of the different healthcare professionals involved in their care (multi-disciplinary team meetings), this was also associated with fewer serious infections and emergency hospital admissions to hospital.

You can listen to and download a podcast '[In conversation with...Dr Rosemary Hollick](#)', the study's Chief Investigator to hear more about the study.

The paper is also accompanied by a Plain Language Summary, and infographic detailing the key findings.

Findings from the VOICES study are already being used to inform changes to the way services for people with vasculitis are organised. The recommendations are being used to develop clinical service standards and guidelines, and strategies to overcome the difficulties to making this happen in practice.

'Stop ticking boxes: it just doesn't work'

As with all our research at the Epidemiology Group, public contributors were key members of the VOICES study team.

The *Lancet Rheumatology* have published a companion piece in which VOICES public contributors, Lynn Laidlaw and Mo McBain, discuss their frustrations in trying to navigate disjointed and ineffective care pathways not designed to support people with complex rare autoimmune conditions, and the importance of patient and public involvement in research, decision making and service provision.

You can read the article in full on [The Lancet Rheumatology's website here](#) (note: a free-sign up is required to access this content).

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



Spotlight on Studies

Making it Work™ - Scotland

Living with a musculoskeletal condition, such as back pain, arthritis, or fibromyalgia, can have a major impact on a person's quality of life, especially when it comes to navigating work and employment. Making it Work™ is an online e-learning programme which was developed in Canada to support people working with inflammatory arthritis to remain in work for as long as they wish to do so. The programme targets some of the common challenges encountered at work by people with musculoskeletal conditions, such as dealing with fatigue, coping with stress, and communicating effectively in the workplace. It also provides advice and strategies on how to set goals to tackle problems at work, reframe negative thoughts, and request modifications that can make work more manageable.

Over the past two years, the Making it Work™ - Scotland study team have been busy adapting this programme to make it suitable for a UK audience, and to expand it to cover a range of inflammatory and non-inflammatory conditions. The team began by mapping the original programme's content, which was then reviewed by people working with musculoskeletal conditions in a series of online focus groups in late 2022. Necessary changes to the programme were agreed through these sessions,

with additional input from employers and healthcare professionals, to ensure the content was suitable from multiple key perspectives.

Since then, the team have been working with the University's e-learning and graphics teams to redevelop the look, feel and content of the programme. They have also engaged with voice actors who will add a layer of narration to the new content. Throughout this process, the team have worked closely with a small group of patient partners with lived experience of working with musculoskeletal conditions to get feedback on key issues.

We are delighted to let you know that the revised programme is now almost ready.

The next step is to user-test this revised version to make any final adjustments before it is made publicly available, with this process set to begin in late July / early August 2024.

If you are currently working with an MSK condition and you would like to be considered to take part in this user-testing process, please complete the following Expression of Interest form:

<https://forms.microsoft.com/e/YvJuztdUof>

You can find out more about Making it Work™ - Scotland [here](#).



QUICK (QUantifying the Impact of Chronic pain on work)



Chronic pain can have a big effect on people's work. Until now, the impact of chronic pain on work has usually been measured by looking at the number of sick days people take or how productive someone is at work. We know from speaking to people with chronic pain, however, that the impacts of their pain on work are much broader. These can range from financial impacts, to how people

engage with their colleagues, and even how dealing with pain at work can have an effect on a person's social and family life.

The QUICK study (QUantifying the Impact of Chronic pain on work) seeks to better understand the broad range of impacts chronic pain can have on people's working life, and to design a new questionnaire tool which researchers, employers, clinicians and policy makers can use to capture these broader effects. The study team has been very busy over the past three years working to develop their new questionnaire tool, and we are delighted to announce that the questionnaire has now been drafted, through a rigorous process of refinement, and is currently undergoing final analysis.

The 14-question tool has been shaped by feedback from over 100 patients and other stakeholders, including healthcare professionals, employers and academics.

It covers topic areas including whether people have disclosed details about their pain to their employer and colleagues, whether they feel they have adequate job modifications in place, how their pain affects their commute to work, and how their pain affects their perceived work performance (including working harder on 'good' days to make up for 'bad' ones). The study team have been assisted in this process by a small PPI team who have helped provide additional feedback at key points in the questionnaire's development process.

The team are currently busy collating data from over 900 survey responses which will help them assess how well it measures the aspects it is trying to capture, and how people's responses match up with other questionnaire tools.

The finished tool will be available for publication in late 2024.

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

PPI staff team updates

Our PPI staff team are responsible for coordinating our group work and acting as a bridge between patients and researchers. Drawing on a variety of research interests and specialities, the team are on hand to make sure the voices of our Core PPI Group, PPI Pool and study-specific patient partners are represented within the research agenda of the Epidemiology Group.

Laura Moir leaving the Epi group

We begin with the sad news that Laura Moir will be leaving the Epidemiology Group as of late August 2024.

Laura has been a leading part of building PPI initiatives across the group, and



in ensuring that all our studies are designed and delivered with the patients we seek to serve at their very core. She is a pivotal part of the wider Epi Group team in terms of running studies, supporting other study coordinators, and helping organise social activities, and is a cheerful presence around the office who will be sorely missed by everyone, both as part of the PPI group and the wider Epidemiology Group team.

We would like to extend a huge thank you to Laura for all her hard work and the enormous contribution she has made to the smooth running of the PPI group since 2021.

Laura will be greatly missed. In order to attempt to fill the void left by her leaving, we are happy to announce that Stuart Anderson will take over as our new PPI Coordinator Lead and would also like to issue a very warm welcome to Dr Rebecca Parr, who is also joining the PPI coordinating team.

Welcome to Rebecca

Rebecca joined the Epidemiology Group as an Assistant Study Coordinator in January 2022.

Rebecca spends most of her time working on the UK Antimicrobial Registry, capturing data on the use of last-line antibiotics used to treat infections like MRSA and C. difficile. She also had the opportunity to interview participants of the FRESKO study about their experience of early onset knee



osteoarthritis. More recently, Rebecca looked into how effectively participants are recruited to local rheumatology studies. Currently, she is working as a Study Coordinator on a Europe-wide initiative looking at the perception of the work of patient partners in rheumatology research.

Before joining the Epi Group, Rebecca worked as a lab-based scientist within antibody drug discovery. Most recently, whilst working as a Principal Scientist for a Biotech company, Rebecca undertook a part-time PhD, looking for a way to detect toxic levels of local anaesthetics in the blood.

In her spare time, Rebecca loves being outdoors with her family, hiking, biking and gardening. Rebecca also loves to eat cuisines from around the world.



External events

The Alan Turing Institute will be holding an online event on 13th August to explore Effective Involvement in Data-Centric Research.

About the event

Bringing the public voice into frontline research is an NIHR priority. Researchers regularly acknowledge that PPIE input improves both work and outcomes. In the AI space, with issues of contested data, trust and transparency, establishing a meaningful dialogue between different constituencies takes on special importance. The Alan Turing Institute invite you to join an illuminating discussion of case studies from the front lines: what works, what doesn't – and what you can do about it.

For more information see: abdn.ac.uk/research/explore/turing/events/20888/

To register see: <https://www.turing.ac.uk/events/good-bad-and-public>

Thank you for your involvement

As always, we would like to thank you for being part of the Epidemiology Patient and Public Involvement Group. Your contribution is invaluable to the research we undertake and letting people know about our work. Thanks again for your continued engagement!

The PPI Coordinating Team

