



NEWS LETTER



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Welcome to our Patient & Public Involvement Group Newsletter!

Dear Patient Partner

Welcome to our 2026 Newsletter. In this edition we would like to introduce our new core group members and provide you with key updates, including a spotlight on the new LIFT (Listening, Involving, And Forging Trust In Musculoskeletal Research) programme and the new Scottish Centre for Work and Health - read on to find out more about the

fantastic launch day and how some of our members are involved. Finally, we would like to say a huge thank you and farewell to our colleague Rebecca Parr who has stepped down from the PPI Coordinating Team, and welcome Claire Hunter, a PhD student, who is keen to learn more about PPI and get involved. It has been a very busy year so far!

With best wishes,
[The PPI Coordinating Team](#)

Welcome to our new Core Group members

As well as our wider pool of over 130 patient partners we also have a 'Core' Group of 12 patient partners who attend meetings three or four times a year to provide more detailed input about our research activities. Last year, after discussion amongst existing members, we agreed we should try to recruit some younger members to the team. We are very lucky to have a fantastic pool group, and as a result, we were able to recruit four amazing new people onto the Core Team: Abdul, Aleysha, Isaac and Lucy.

Lucy, one of our newest Core Group members, said:

"I initially got involved with the Epidemiology group by signing up to the PPI pool. I feel honoured to be part of a team where patient voices are not only welcomed but they are truly valued. I hope to help build more pathways of support and drive improvements in care by being an active member of the Core PPI Group because every patient deserves to feel seen, heard, and cared for."

Read Lucy's full story and find out about more of our Core group members [here](#).



We've won an award!

We are delighted to announce that the Epidemiology Group PPIE Team was awarded the Principal's Prize for Public, Patient and Community Involvement and Engagement at the University of Aberdeen Excellence Awards 2026. Our team received the award at a dinner in Elphinstone Hall, Old Aberdeen, on 23 April. Attending on behalf of the group were Dr Rosemary Hollick, Mrs Laura Moir, Dr Karen Keenan, Mr Stuart Anderson, and Dr Rebecca Parr, also representing in absentia Dr Elaine Wainwright and Mrs Claire Hunter.

In recognising the award, the judging panel noted that the team had created a sustained partnership model embedding people with lived experience across the musculoskeletal research lifecycle, and cited studies including VOICES, PACFiND, and a dedicated national

PPIE group as evidence of genuine co-production, methodological innovation, and meaningful impact on research, resources, and healthcare delivery.

Dr Rosemary Hollick said, *"This award reflects the commitment of our patient partners, who work with us to shape the questions we ask, how we answer them, and how findings are translated into practice. Building sustained relationships over time allows us to ensure our research remains grounded in what matters to people living with rheumatic and musculoskeletal conditions."*

This award is for you – our patient partners – for contributing your time, expertise, and lived experience since 2021. Thank you for your dedication in helping shape our research to ensure the patient voice is right at the heart of everything we do!



Spotlight on studies

Arthritis UK Consortium

We are delighted to share that our role in [the Arthritis UK Consortium in Epidemiology](#), a major collaborative initiative with universities across the UK including Manchester, Keele, Oxford, and Nottingham, is now underway.

The consortium is part of the charity's drive to harness 'team science' to better understand the causes and risk factors for arthritis and improve treatment options.



Here at the University of Aberdeen Epi Group, we are leading on two key areas of this collaboration:

- Inequalities and Musculoskeletal Health explores how access to care varies across different parts of the UK and for different groups of people. We are working with patients and the public to identify what inequalities matter most and develop practical solutions and recommendations that services can actually use.
- Reducing the Population Impact of Chronic Musculoskeletal Pain will help us understand how early experiences of pain in childhood can shape pain experiences later in life.

Additionally, Dr Rosemary Hollick is academic PPIE lead for the consortium.

By identifying patterns, we hope to find the best times to offer support and prevent pain from becoming long-term.

Both workstreams have been co-designed with patient partners and researchers, ensuring that the evidence we generate reflects what matters to people living with musculoskeletal conditions.

So far, our Inequalities theme has made great progress, having completed two workshops and a priority setting exercise that will inform and refine ongoing research across the consortium. Our population impact theme is set to get fully underway later this year.

We look forward to bringing you further updates as this important project progresses.

Patient-Initiated Follow-Up

Some rheumatology services are now shifting towards patient-initiated follow-up (PIFU), where people book their own appointments rather than having them scheduled automatically.

This can give patients more hands-on control and agency over their care; however, some may worry that PIFU might leave some people 'out of sight, out of mind'. The [new PIFU study](#) aims to evaluate how PIFU is working for patients across NHS Grampian with inflammatory arthritis, and to better understand what the effects of this are in practice.

PIFU will look at:

- The characteristics and health outcomes of people on PIFU who do and do not access care
- The experiences of PIFU from a patient, primary care, and rheumatology staff perspective



This study will use surveys, linked health records, and focus groups to build up a full picture of experiences of PIFU service in Grampian.

We'll also hold a summary workshop to share what we find, with findings being used to develop guidance for rheumatology services across the UK.

The study has **started sending out invitations** to people who are currently on PIFU across NHS Grampian to participate via an initial online survey – if this applies to you, please keep an eye out in your post or email inbox!

Social Prescribing Interventions to Reduce Barriers to Social Engagement in Rheumatic and Musculoskeletal Disorders

For many people living with rheumatic and musculoskeletal conditions, participation in hobbies, socialising and getting involved with their local community can be hard. Withdrawing from these activities can affect both people's physical and mental wellbeing.

The [SPARK](#) project explores whether "social prescribing" - where healthcare professionals refer people to community programmes designed to enhance wellbeing and connection - can improve social engagement for people living with these conditions.



In SPARK, we want to:

1. Describe the components of social prescribing interventions in the UK to better understand how these may help support social engagement for people with MSK conditions.
2. Map what's currently available across NHS Grampian that could support people with rheumatic conditions.
3. Understand the acceptability of referral to social prescribing interventions to help address the barriers to social engagement which people may have.

We hope that understanding these aims better will help us design ways to connect people with relevant programmes, and to develop pathways to make it easier for specialist NHS care to link with community support.

We hope this work will help more people stay involved in the activities and communities that matter to them.

Later this year we plan to hold a workshop to better understand issues around the acceptability of social prescribing interventions.

Please keep an eye on your inbox for opportunities to get involved in this phase of the work.

Prioritising Early Detection of Knee Osteoarthritis

We are excited to be launching our new study, [Prioritising early detection of KNEE osteoarthritis \(PIOKNEER\)](#). This Arthritis UK funded project is an interdisciplinary study being led by the University of Aberdeen in collaboration with the University of Edinburgh and NHS Grampian.

Currently, there are no treatments that can slow or stop osteoarthritis once joint damage is visible. Detecting changes earlier could open the door to effective new therapies and prevent progression.



PRIORITISING EARLY DETECTION OF KNEE OSTEOARTHRITIS

PIOKNEER builds on the FRESKO pilot study, working towards this major gap in care identified by people living with knee osteoarthritis. PIOKNEER is in line with the global effort to improve early diagnosis of osteoarthritis.

One of the most exciting aspects of PIOKNEER is the innovative Field

Cycling Imaging (FCI) scanner, pioneered in Aberdeen and the only one of its kind anywhere in the world. The FCI works like multiple scanners in one, giving more information than standard MRI scans.

The PIOKNEER team is delighted to be working with a study-specific PPIE group, with members joining us from the Epidemiology Core group, the pool, and the University of Aberdeen.

So, watch this space for more info and the opportunity to get involved in this ground-breaking research in 2026.

Patient-centred Care for Fibromyalgia; New Pathway Design

Improvements to services that better support people with fibromyalgia are needed

Fibromyalgia is a common condition with symptoms of pain, fatigue and sleep disturbance, affecting an estimated 1.5 - 2.5 million people in the UK. Despite this, there is not much existing evidence on the best way to organise health services for people living with the condition.

We setup the [Patient-centred Care for Fibromyalgia: New pathway Design \(PACFiND\) study](#) in order to better understand existing services, patient experiences, and preferences for care, and ultimately to use this evidence to shape more supportive health and work systems. PACFiND surveyed over 2,700 patients and professionals, analysed health records from nearly 100,000 people, and worked closely with patient partners to understand what actually works for people living with fibromyalgia.

With the study now complete, findings from PACFiND revealed significant gaps and challenges in how fibromyalgia is currently diagnosed and supported in the UK. Most people wait around 3 years for a diagnosis, many cycling through repeated appointments and unnecessary tests. Many healthcare professionals don't feel confident diagnosing fibromyalgia, and support varies dramatically depending on where you live.

People described a frustrating "revolving door" of referrals between different services, and patients wanted earlier diagnosis, more consistency across the UK, and a more holistic approach, with less focus on medication, and more emphasis on personalised, compassionate support. Community groups are invaluable but often aren't formally recognised as part of care.

As with all of our studies, the experience of people living with fibromyalgia was instrumental in helping the direction and conduct of the PACFiND study. Debs Dulake, one of our key PACFiND patient partners, gave her thoughts on being involved with the study:

"Working on PACFiND has been educational, confidence building and inclusive, and working with the whole team which has led to further opportunities to get involved with other research. It even led me to returning to work - only for 12 hrs a week, working from home, but a massive step. I found out more about fibromyalgia from this research, discovering that there were many others like me, and I was no longer alone. The team became my friends, and they championed me throughout the project. Our relationship was symbiotic and all verbalised that they had also learnt from me. I will always say that my experience was the 'gold standard' of involving patients in research and I am so privileged to have been along for the journey."



Based on findings from the study we now have a set of core evidence-based principles for better fibromyalgia care. We are currently developing a practical toolkit of guidance for various groups, including clinicians, policymakers, and people living with fibromyalgia.

These recommendations focus on supporting earlier diagnosis and patient-centred pathways that reduce unnecessary tests and improve support across the NHS.

We are also busy developing video resources to accompany these recommendations, and to highlight the key issues around providing better fibromyalgia care for patients, healthcare providers, and people involved in delivering fibromyalgia policy. We hope to make these publicly available during the second half of 2026.



Listening, Involving and Forging Trust

We are very excited to share that [LIFT \(Listening, Involving and Forging Trust in Musculoskeletal Research\)](#), a major new five-year UK-wide research programme looking to better support PPI infrastructure for arthritis research in the UK, is now underway.

Funded by [Arthritis UK](#) in partnership with [Orthopaedic Research UK](#) and the [Kennedy Trust](#), the LIFT network is led by the Universities of Keele, Aberdeen and Leeds. The programme aims to transform how people living with musculoskeletal conditions can better shape the research that affects them.

Our team, comprised of academics, and key patient and public involvement partners, and led by Dr Rosemary Hollick and Dr Elaine Wainwright will deliver a key aspect of this project. We will lead the programme's work on the Four Nations Hub across Scotland, Wales, and Northern Ireland, with a focus on building inclusive, community-driven networks and improving access for rural and underserved populations.

Michelle Stevenson is one of our key patient and public involvement (PPI) partners who helped us bring this project together. Michelle lives in rural Scotland and faces unique challenges living in this area with her MSK condition on a daily basis.

Michelle said: *"I didn't realise that vital research was happening on my doorstep until the team in Aberdeen reached out to me in 2019. LIFT matters — not just for me, but for the thousands across Scotland, Wales and Northern Ireland who don't yet know that their voice is wanted, and that research can work for them too."*

Dr Hollick said: *"Many people living with arthritis face barriers to taking part in PPI activities, including geography, lack of support, or limited awareness of opportunities. Through LIFT, we will strengthen and support PPI in ways that recognise the different health systems, infrastructures, geographies and communities across these nations."*

Stay tuned for updates on this exciting new research programme!



The new Scottish Centre for Work and Health seeks to better understand work and health challenges across Scotland and beyond

We're delighted to announce the official launch of the [Scottish Centre for Work and Health \(SCWH\)](#), a new research collaboration funded by the Colt Foundation which brings together people interested in advancing work and health research across Scotland.

The UK is currently experiencing high levels of economic inactivity, particularly among young people and older workers. Ill-health is a major reason, especially mental health and musculoskeletal conditions. The Scottish Centre for Work and Health aims to better understand how to keep people healthy and in work, with a particular focus on the issues which affect Scotland and a view to how these findings can be translated more widely.

SCWH's research programme will explore four main themes:

1. How work is changing and what that means for health
2. Supporting people through key life transitions (starting work, managing long-term conditions, aging)
3. Helping people with long-term health conditions stay in employment
4. Preventing ill-health at work

Our research group is at the forefront of this new initiative, with Epidemiology Group Lead Professor Gary Macfarlane taking on a role as Centre Director, and Dr Rosemary Hollick leading the theme on supporting people with long-term conditions in work.

Of course, patient and public involvement will be at the heart of the Centre's work. We aim to work closely with employers, clinicians, and, crucially, people with lived experience of work and health challenges to make sure that the Centre's research is aligned with the needs and concerns of those affected by work and health challenges across Scotland and further afield.

The Centre recently held its inaugural meeting in Glasgow in June 2026, and several of our patient partners were in attendance on the day to find out more about the Centre and help shape early research project ideas.

We were also delighted to welcome three of our fantastic Epi Core PPI Group members, Abdul Menan, Diane Smith, and Michelle Stevenson, who helped provide a vital lived-experience perspective on our early research plans and discussions.

Michelle also gave a fantastic and impactful presentation to our members on what good, effective PPI looks like, and to give her own experiences of work and health challenges faced, particularly to those living in rural areas of Scotland.

The SCWH will be looking to develop specific patient and public involvement structures for those interested in work and health issues more broadly.

Please watch this space for further information on how you can get involved!



PPI Training Resources

We would like to highlight a **free** resource from the National Institute for Health and Care Research (NIHR); [A how-to guide for patient engagement in research](#). This is a self-directed course that you can complete in your own time, should you wish to learn more.

Developed by the Canadian Institutes of Health Research's Institute of Musculoskeletal Health and Arthritis, the course aims to help patient partners, researchers, trainees, and

others in research teams, to do patient engagement in research.

You'll learn:

- Module 1: What is patient engagement?
- Module 2: The research process: Understanding the research process for patient
- Module 3: Setting up a research project for successful partnership
- Module 4: Patient engagement for research teams: Being part of a research team for patient partners

After completing each module, you will receive a certificate of completion.

We hope you find this free resource helpful!

If you've come across any other training resources you think might be useful to your fellow PPI contributors, please share them with the Epi PPI Coordination Team via email at epippi@abdn.ac.uk and we'll include them in the next newsletter.

PPI Team Updates

We have a few personnel changes to tell you about in our PPI Coordination Team. Firstly, we would like to say a huge thank you and farewell to [Rebecca Parr](#) who is now co-ordinating two large studies within the Epidemiology Group, the [UK Antimicrobial Registry \(UKAR\)](#), and [PIOKNEER](#) and needs to concentrate her energy on these! Rebecca has kindly written a few words about the time she spent in the PPI Coordinating Team.

Rebecca said: *"I am honoured to have been a part of the Epidemiology Group Patient and Public Involvement and Engagement team. My time with the group has had a lasting impact on my understanding of PPIE. I now appreciate the time and energy involved in infusing lived experience throughout our research. My thanks to the patient partners for making me feel so welcome and included, and to the co-coordinating team for sharing their knowledge and approach. I am looking forward to being part of the [PIOKNEER](#) study-specific PPIE group. We are only at the start of the project and already I*



Rebecca Parr

am eager to find out what our team will achieve over the course of the 5-year study and beyond."

Given Rebecca's commitment to PPI and all she has learnt, we look forward to hearing how this will be taken forward in her new role.

Whilst we are sad to say goodbye to Rebecca as she brought a wealth of enthusiasm and new ideas, we are delighted to welcome [Claire Hunter](#) to the PPI Coordinating Team. Claire is a PhD student about to embark on the second year of her studies. Her research interests include rheumatic disease,

chronic pain, health disparities, and the intersection of these topics. Claire's PhD aims to identify whether men and women with psoriatic arthritis (PsA) have different rates and lived experience of diagnosis, treatment response, and associated health, social and economic outcomes.

Before starting her PhD, Claire completed an MSc in Clinical Nutrition at the University of Aberdeen. Outside of her studies and PPI coordinating duties, Claire enjoys exploring Scotland, skiing, and attempting to grow fruits, vegetables and cut flowers in her garden.



Claire Hunter



Thank you for taking the time to read our newsletter. If you have any questions or would like any further information about our PPI activities, please get in touch via our dedicated email epippi@abdn.ac.uk and one of the coordinating team will reply.

We hope you all had a lovely summer, and we look forward to telling you more about our PPI activities in 2027.

[Elaine](#), [Stuart](#), [Karen](#) and [Claire](#)

The Epidemiology Group PPI
Coordinating Team