



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

Dear all, welcome to the December 2024 edition of our Epidemiology Group Patient and Partner Involvement Newsletter! We are looking forward to telling you all our news as it has been a very busy six months; we have sent out lots of involvement opportunities, submitted grant applications with your help, and organised various events which we outline below.

As always, we would like to extend a huge thank you for your continued interest and involvement with our research!

With warmest wishes,

The PPI Coordinating Team (Karen, Stuart, and Rebecca)



Funding applications

Investigating chronic pain across a person's life course

We are very grateful to those of you who joined our focus group session in early September to discuss a proposed project application to Versus Arthritis investigating chronic or persistent pain across a person's life course. We received some very insightful comments at the session, and are delighted to say this application has now been submitted and we expect to hear from the funder sometime in the first quarter of 2025.

Social prescribing project

Our Core group members were invited to discuss a proposed funding application related to social prescribing. Social prescribing involves referring people to services, groups, and activities in the community which can help with

issues that aren't necessarily addressed in a medical setting. A very constructive discussion took place in late November via Teams and the application has now been submitted. We are keeping our fingers crossed for good news in the New Year!

WORKERS study

Originally called the WORTHWHILE project, this proposed study aims to investigate support for people with knee osteoarthritis who are awaiting surgery. Several of our PPI members reviewed this grant proposal during the summer, and we are happy to say this has now been submitted and has passed the first initial screening phase of the application. The project has also been renamed as WORKERS because it will focus more specifically on work support. We hope to hear about the final outcome of this application soon, and if the project is funded it would aim to start around Easter 2025.

Activities update

Core group

As outlined in our [July newsletter](#), we are lucky to have two forms of patient partner involvement; one via our Core group and the other via our wider Pool collaborators (see our website for more information).

We held an online meeting with our Core members in September to gather in-depth feedback from our partners about a range of issues, including a case study we are developing for Versus Arthritis for their upcoming 'PPIE Hub' web pages (more information to follow in a future newsletter), our PPI documentation, and membership of our group. A few of our Core members have also recently reviewed a [plain language summary from the PACFIND project](#) as the study team have had their [latest paper](#) from this research published in the PLOS ONE journal, and were keen to get feedback on the summary they had written.

Pool group

With regards to the Pool group, there have been many opportunities to get involved with research being undertaken within the Epidemiology Group as well as other external opportunities since our last update. In August we shared an opportunity for those of you based in Scotland to participate in two online focus groups organised by [Research Data Scotland](#). The purpose of each focus group was to gather public and patient views on proposed changes to the way decisions are made about access to regional level healthcare data for research purposes, and the team from Research Data Scotland would like to thank those of you who expressed an interest in and participated in these sessions.

In September we shared the Patient Research Partner Experience Survey (UK) from the PsA HQ – Patient Led Research Project. This patient-led e-survey aimed to explore the experiences and needs of individuals with lived experience of rheumatic diseases in the UK who have participated in a range of research

engagement and involvement activities.

We also contacted you to let you know about the [Alleviate Pain Data Hub's](#) UK National Pain Survey 2024. This follows on from 2023's survey and seeks to gather the experiences of individuals living with chronic pain. Several of you contacted us to let us know you had completed this survey, and you also gave feedback about technical issues which made completing the survey online difficult. This feedback was really helpful, and Alleviate researchers took your feedback on board to address the problems identified, making this year's form more user-friendly, and giving valuable insight for the team when designing next year's survey. Results from the survey should be published towards the end of 2025.

In October we let you know about an opportunity to take part in a short online interview as part of the [PATients' views of Health and WORK advice \(PAThWORK\)](#) study. This study had previously been developed by researchers within the University of Aberdeen's Epidemiology Group before being taken up by the current team at Guy's and St Thomas NHS Foundation Trust. The study team are conducting a series of individual interviews with people who have lived

experience of working with a health issue to find out from their perspective what kinds of support they would like to receive, including where, when and how this support is best delivered. As of time of writing the team are still looking to speak to people, so if you are interested in finding out more please contact either Dr Vaughan Parsons (Vaughan.parsons@gstt.nhs.uk) or Dr Kathleen Lin (Kathleen.lin@gstt.nhs.uk) at Guy's and St Thomas' for further information.

[Centre for Musculoskeletal Health and Work](#) (CMHW) members at University of Salford also asked for your help to test their [WORKWELL](#) programme. WORKWELL is an online toolkit which aims to help people with inflammatory arthritis conditions with the challenges they face in the workplace, with final user-testing and analysis underway. The team at Salford would like to thank those of you who expressed an interest, and hope to officially launch the platform sometime in 2025.

We also let you know about the SUSSED project (Sustainable Self-effective Exercise Development) being run by a team at the University of Dundee. This project gave an opportunity to give your views and share your experiences of how

living with chronic pain impacts your physical activity via a series of online focus group sessions. The research team want to understand the barriers and challenges patients face, and to use these insights as a basis to design a future research study. We have heard back from the SUSSED team that this round of focus groups were fully subscribed, and a further round will be held sometime in early 2025. Keep your eyes peeled for further updates!

Finally, in November the [BRUCES](#) (Building Rural-Urban healthCare Equity for Scotland) study team began assembling a small number of people living in rural areas of Scotland to form the study's PPIE group. This study is being led by members of our research group, and aims to look at important rural health inequalities, how they are caused, and effective ways to address them. The PPIE team will help shape this research and develop action plans from the study key findings. As the study is looking for a very small number of specific people to form the team, invites are being issued on a person-by-person basis, however if you would like to know more, you can contact the BRUCES team at bruces@abdn.ac.uk.

Visit of Versus Arthritis

In early September we were delighted to spend the day with colleagues from one of our key funding partners Versus Arthritis. This research visit enabled the Epidemiology Group and the Aberdeen Centre for Arthritis and Musculoskeletal Health (ACAMH) to showcase our current studies and discuss potential future collaborations with the charity.

This day was a fantastic opportunity to provide examples of the research we undertake in a range of settings, from laboratory science to clinical studies, data health science, health services research and clinical service data. We were also joined by our amazing patient partner Michelle Stevenson, a member of our Core group, who gave a fantastic presentation about how patient partners are integral to our research programme.



Spotlight on studies

British Society for Rheumatology extends support for Psoriatic Arthritis Register until 2027

The BSR recently confirmed continued support for our [Psoriatic Arthritis Register](#) with an extension through to September 2027 now finalised. This means we will now be able to continue our work on behalf of patients and the rheumatology community to investigate the impact of psoriatic arthritis (PsA) on patients' quality of life, and to monitor the effectiveness and safety of treatments. We are also exploring more about how these treatments affect the lives of PsA patients

in areas like work, and why some people respond well to certain drugs and others do not. This is an important time for the register as whilst we continue to recruit participants we are also embarking on an in-depth analysis of the data.

Our Chief Investigator, Professor Gareth Jones commented:

"We're delighted that the BSR's support of the Psoriatic Arthritis Register will be extended until September 2027. The

ability to collect longer-term follow-up data from current participants will be of enormous benefit, allowing us to examine rarer outcome events in these patients and providing a richer, more valuable dataset for research purposes moving forward."

More information on the PsA register can be found [here](#), or you can email bsr-psa@abdn.ac.uk for further information.

BSR-PsA REGISTER STUDY EXTENDED UNTIL 2027

Please email with any questions or to ask for further details



British Society for Antimicrobial Chemotherapy collaboration; the UK Antimicrobial Registry (UKAR) Study.



The [UKAR study](#) is a hospital-based study looking at prescription of last-line antibiotics used to treat infections that are resistant to other, more commonly given antibiotics. The registry study

has been up and running and recruiting participants since May 2023. We're now halfway through the study, which will close for recruitment in May 2026. So far, things are going well, and we will continue working with hospitals from all over the UK to capture as much information as possible on antimicrobial resistance (AMR).

The UKAR team will also be working with patient partners to understand the effect

of AMR on people's lives and make our study as useful and impactful as possible. We are delighted to say that we now have a small group of patient partners who answered our call help shape the project, and we look forward to working with this group throughout the remainder of the study.

You can find out more about UKAR [here](#), or contact the team at ukar@abdn.ac.uk for further details.

Update from Centre for Musculoskeletal Health and Work (CMHW) studies.



centre for
musculoskeletal
health & work

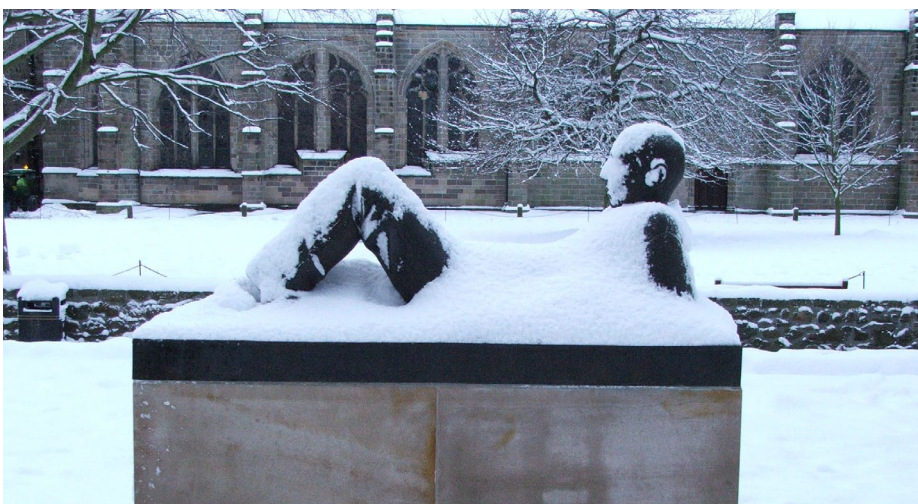
Finally, we have some short updates to give you on two CMHW studies which we spotlighted in our July 2024 newsletter.

You may remember that Making it Work – Scotland™ is an online programme which aims to support people with musculoskeletal conditions to remain working for as long as they wish to do so.

When we last updated you the project team had completed redeveloping and modernising the programme, and it was complete and ready for user-testing. We are now delighted to say that this testing process has been completed in conjunction with 20 patient partners, and some very valuable feedback was received. Based on this feedback the study team are working with e-learning colleagues to incorporate some key final changes and are hoping to officially launch the programme in 2025.

We are also very pleased to say that our finalised questionnaire to measure

the impact of chronic pain on work developed as part of the [QUICK study](#) is now almost ready. This questionnaire has been designed with input and testing from over 1000 people either with lived experience of, or a direct interest in, working with chronic pain. The team have now completed the evaluation phase and analysis and are now making the finishing touches to some outstanding questions alongside QUICK patient partners before hoping to announce a public launch in early 2025!



Thank you

Thank you for taking the time to read our newsletter. All in all, it has been a busy time for patient and partner involvement in the Epidemiology Group this year and we would like to extend our sincere gratitude to you for taking part in any of the studies outlined above. We hope you have a restful festive period and look forward to liaising with you about our research in 2025!

If you would like to contact the team, please feel free to drop us an email at epippi@abdn.ac.uk