



October 2023

As we bid farewell to the warmth of summer, we find ourselves reflecting on the invaluable contributions that you have made to our research, from feeding back on study documents, to helping guide our research grant applications, your support and insight have been instrumental in enhancing the quality of the research we undertake. We would like to **thank you** for your time and willingness to share your experiences and perspectives with us, we truly value your voice.

Looking forward, we are always eager to have you onboard and, in this newsletter, we will share more details about our ongoing studies and an opportunity to get involved.

Thank you once again for your support of our group.

The PPI Team,
University of Aberdeen Epidemiology Group



iPREPARE

The implementing Patient Research Partner Engagement in Research (iPREPaRe) study will explore the way in which the work of patient research partners (PRPs) in rheumatic and musculoskeletal disease (RMD) research is perceived by the partners themselves and by RMD researchers.

To do this, the iPREPaRe study team will work with patient partners to co-design a questionnaire that will be sent to PRPs and RMD researchers across Europe. The questionnaire will be followed up by interviews with PRPs and RMD researchers.

Patient research partners are the central focus of our study and we're excited that we will be including PRPs on our working group to help co-design the research.

We recently approached the University of Aberdeen Epidemiology PPI group in order to advertise the roles on our working group. We had a fantastic response to our call for partners but we are only able to take forward a limited number of applications to provide a spread of people and experiences across Europe. We are very grateful for the interest that has been shown in our study and hope to be able to share our progress and results with you in the future.

Find out more about the iPREPaRe study [here](#)



While writing up research proposals or results researchers often use technical language which assumes familiarity with scientific jargon in researcher's chosen field. Unfortunately, this language often obscures the meaning and importance of the research from the average or 'lay' reader, making results less accessible to the general public.

Plain language summaries (sometimes called 'lay' summaries) are a way to attempt to bridge the gap between 'academic' and 'everyday' understanding. These are pieces of writing which summarise the key aspects of a research study plan or finding which try to avoid the use of unnecessary complex terminology. They also help package together the key points in a study without going into unnecessary technical detail. They should answer (in a straightforward way) the key questions that show what research is being done and why, including:

- Why is the research important?
- What did the researchers do?
- What did we find out? and
- What does this mean for patients?

Plain language summaries may also include infographics or diagrams which can help to highlight some of the key facts and figures resulting from the research in a clear and engaging way.

Within the Epi group we have made a commitment to producing one of these for every research paper we submit for publication. All of our summaries in the Epi group are reviewed and edited before publication initially by lay members of the group, and are then reviewed by our patient partners and PPI pool to make sure these are clear, readable, and cover the main points which are important *from the patient perspective*.

To give an example, we recently reached out to members of our Core group as well as our academic colleagues to help prepare a summary of an upcoming research collaboration aimed at generating real-world changes from our research results. Comments from our patient partners were vital in helping us to clarify a number of

points and, ultimately create a much more clear and concise description of what the research was about, what it sought to do, and how it would go about achieving this.

We will continue to produce new summaries as and when our research results are written up and submitted for publication, and we hope our PPI members will be available to assist us when it comes to 'taking the academic glasses off' before these are published.

You can view all of our currently published plain language summaries at [our website](#). Of course, we are always looking to improve our communications, so if you have any suggestions for improvements these are always welcome! Email us at epippi@abdn.ac.uk and let us know!



While we know that chronic pain can have a huge impact on a person's working life, at present questionnaires which ask people how their pain affects them at work tend to focus on how this effects the economy and their employer, such as how many days they are off sick, or whether (and how long) they are out of work altogether due to their pain.

The QUantifying the Impact of Chronic pain on work (QUICK) study is a project we have been working on here at the Epi group in conjunction with friends at the Universities of Liverpool, Manchester and Southampton, and King's College London. The goal of QUICK is to develop a new questionnaire tool which captures information on a broader range of impacts people working with chronic pain feel are important to them.

To do this, we first reviewed existing questionnaires and interview studies about chronic pain and work to see what important things might be missing from the existing questionnaires. We then discussed these findings with patients, healthcare professionals, employers, researchers and policy workers, with these discussions informing the design of our first questionnaire focusing on topics that matter to people with pain. We then refined that questionnaire after asking more people with pain and stakeholders to comment on the material we had produced. Our new questionnaire is now ready to be tested via an online survey.

QUICK was designed to include input from people with pain and other stakeholders throughout the study, and so far we have obtained the feedback of over 100 people in the production of the our questionnaire. We also have four fantastic QUICK patient partners, recruited from our PPI Pool, who have helped us immensely, providing review and comment on presentation materials for the study focus groups, and helping us to further refine our draft questionnaire as this went through the stages of development. Our wider PPI pool has also provided fantastic support to the study, giving feedback on our upcoming online survey and providing feedback on general useability and understandability of the online questionnaire.

We are very excited to now be taking forward our final questionnaire for evaluation, and it has been great to see the hard work of the past two years come together to produce something which we hope will help researchers better understand the full range of impacts chronic pain can have on a person's working life. We'd like to extend a massive thanks to everyone who has supported the study so far, and without whom we could not have brought this exciting new questionnaire together!

For further information about QUICK, click [here](#).

Get involved!

The QUICK study team is looking for people to help them evaluate the new questionnaire they have developed. Check out the flyer on the next page for further information, or [click here](#) to find out more!

The logo for 'QUICK' features the word in a bold, black, sans-serif font. A green checkmark is integrated into the letter 'I', with its top bar extending to the left and its bottom bar extending to the right.A photograph showing a close-up of a person's hands typing on a laptop keyboard. The person is wearing a light-colored, textured sweater and has rings on their fingers. The laptop is silver and the keyboard is black.

DO YOU HAVE EXPERIENCE OF CHRONIC PAIN AT WORK?

Researchers at the University of Aberdeen have developed a new questionnaire to measure the impacts that people with chronic pain might experience at work. Our questionnaire has been developed in partnership with patients, healthcare professionals, and employers, and we're now looking to find out what people think about the new questionnaire.

If you are:

- **currently working (either paid or voluntary) and**
- **have experience of chronic pain**

We'd like to hear from you!



TO FIND OUT MORE VISIT: <https://redcap.link/quick-think-aloud>

OR REGISTER YOUR INTEREST BY EMAIL:

quick@abdn.ac.uk



From the very first meeting of our core group in October 2021 training for our patient partners was a key item on the agenda. Being new to the field as PPI coordinators, we initially drew on NIHR INVOLVE's **'Starting Out: Essential information for members of the public getting started in involvement in research'** for guidance, and ensuring adequate training for our patient partners was one of the fundamental issues raised in this document. During this first meeting, and the three subsequent meetings that year, we addressed the issue of PPI training in a relatively informal manner, with different members of the Epidemiology Group kindly providing short talks about their studies, touching upon study methods and research issues in their talks.

During these meetings, we regularly checked in with the group to ask them what training would be useful (either through discussion at the meetings themselves, or via feedback forms issued after the meetings) in the hope we could identify common issues which we would have capacity to deliver. "Since joining the PPI meeting group in October 2021, I have become involved with many other individuals from all walks of life and a variety of academic backgrounds", said group member Diane Smith. "The need to fill in the gaps of knowledge continued to become apparent through our meetings, and needed to be addressed through appropriate training."

Admittedly, it took a while to identify the group's needs (although, as recounted by patient partners and researchers elsewhere, this isn't unusual). The PPI Coordinating Team were also a little hesitant as we didn't want to rush in and deliver training sessions which weren't fit for purpose. We were also aware that we had little training ourselves about patient partner involvement and what this may require, but equally, as the PPI Coordinators we were committed to trying to identify what was needed and figuring out how to deliver it!

By the end of our first year we felt we had collected a significant amount of comments which highlighted a number of key areas where members of the group felt training would improve their patient partner involvement. For example, comments such as 'I am very ignorant of many of the illnesses that are discussed during the calls' or 'I would like to

understand more about the research side of things' were common, and gave us a great steer on how we might shape a more formal training programme.

With this data we applied for, and were able to secure, funding from the University's Public Engagement and Research Unit (PERU) to develop a bespoke PPI training programme, delivered in-house by our clinical and academic colleagues, as well as one of our key patient partners. The programme consisted of a series of monthly seminars and Q&A sessions covering a broad range of topics from research skills and design, information about our group's specialist clinical knowledge, practical skills such as how to review documents, and advice and support from more experienced patient research partners. Topics included:

- An overview of common musculoskeletal conditions
- An introduction to the study of epidemiology
- A guide to research methods (quantitative and qualitative)
- The opportunities and challenges of being a PPI partner
- Reading and reviewing documents
- Overcoming impostor syndrome in research work

Sessions ran from January to July 2023, and our group reported overwhelmingly positive feedback to our first run of training sessions. "Since starting the sessions, it has given the group an opportunity to have greater understanding of the various types of research that are conducted and what they actually mean", said Diane. "This has enabled us to have an understanding that makes reading research papers an easier task to allow effective feedback within the group."

Looking ahead, we hope that this programme has laid a solid foundation for successful engagement with our Core group moving forwards, and to any others who join in the months and years to come. Indeed, as coordinators we have also learned a wealth of information from these sessions, and the series has helped create a greater cohesion amongst patient partners, coordinators and academics working across our research. "I have found that the sessions have refreshed my understanding of research and I have learned more than I already had knowledge of", added Diane. "I also found the sessions have created a better group dynamic of understanding and feel this has benefited everyone and their confidence to speak up and share more within the group meeting. The session on imposter syndrome was for me the most significant as the reactions from every single person in the group (including academic staff) clearly showed we had a commonality in feeling this syndrome in our lives."

We are already thinking of ways to extend the series beyond this initial run, in tandem with ongoing feedback from our partners, and will continue to work with our group to identify areas of need based both on prior sessions as well as emerging issues as our group's work

progresses, and exploring ways in which we might bring some of the lessons learned from these sessions to our wider PPI pool.



Thanks to the support of the Scottish Funding Council (SFC), National Energy Skills Accelerator (NESAs) and Scottish Government, the University of Aberdeen is able to offer a limited number of funded places on a range of online short courses.

These online courses can be used to:

- add in-demand skills to your CV
- gain credits towards postgraduate qualifications
- fit university study around full-time work.

You can apply if you are:

- domiciled in Scotland (Scotland is your primary place of residence).

When to apply for a funded place

- Phase Two – opens in December 2023.
- Phase Three – opens in spring 2024.

Find out more [here](#)



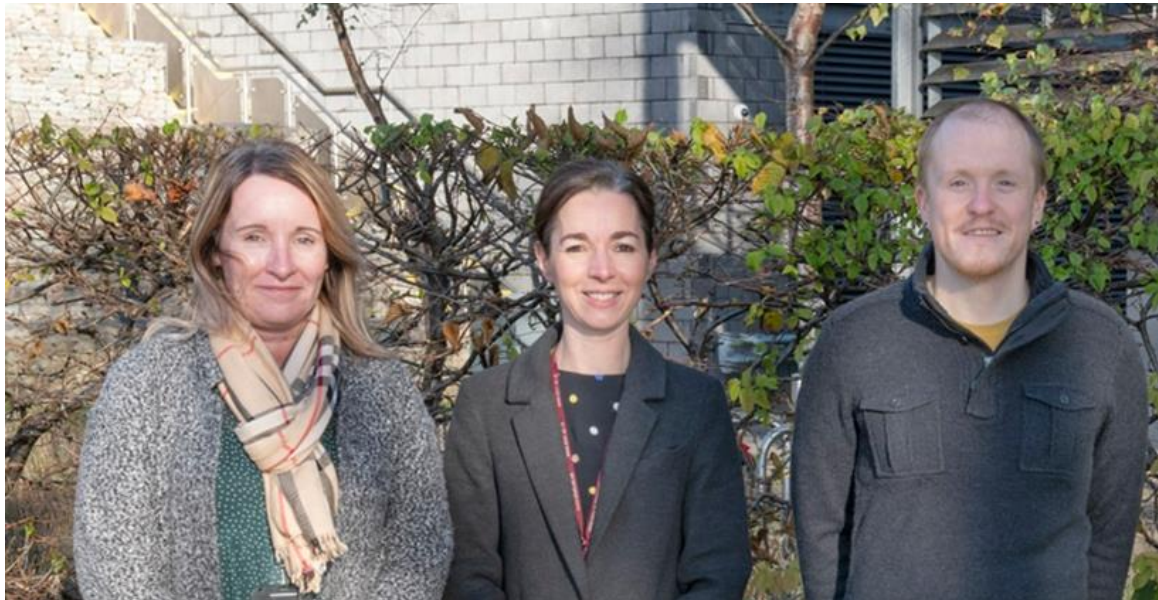
Thank you for taking the time to read this newsletter!

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

