



March 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. 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.

In this newsletter we will update you on our UKAR study with an opportunity to get involved, some training information, and a really interesting article from Debra Dulake. Debra is one of our patient partners on the [PACFiND](#) Study, and in this short piece, she shares her thoughts on why PPI is so important to her.

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

Our group recognises that collaborating with patients, carers, community and charitable organisations, and individuals with relevant experience positively impacts on all stages of our research. Patient and public involvement helps us to identify the most relevant research priorities, allows for better design and management of our research projects and improves interpretation and dissemination of our findings.

The Epidemiology Group currently runs a number of research studies which focus on rheumatic and musculoskeletal conditions. You can find out more about our current studies here:

<https://www.abdn.ac.uk/iahs/research/epidemiology/studies-1285.php>

All of our studies have PPI input. This will vary from study to study. Some studies have patient partners as part of their study management group, this is where PPI members come along to monthly meetings and are part of the management of the study, while others have either PPI advisors or a study specific PPI group who they reach out to on a regular basis for feedback.

Within the group we also have a core PPI group and a pool PPI group:

- The core PPI group consists of 10 individuals with a wide range of experiences of living with different musculoskeletal conditions. This group meet quarterly and discuss current and upcoming research.
- The pool PPI group consists of people who has expressed an interest in our research and kindly volunteered to be contacted when something that matches their preferences arises. This is a large group of people with a wide range of experience in living with musculoskeletal conditions, along with age, location, and other life experiences.

All researchers within the Epidemiology group can make requests (through the Epi PPI Team) for feedback from either the core, or pool PPI group. Our last group PPI meeting discussed and provided feedback on our BSR PsA and UKAR studies, along with discussions on potential new research studies. We have also recently reached out to the pool PPI group for recruitment to our Move and Snooze, RHEUMAPS and PACFiND studies. In addition, we also receive requests from external researchers for PPI feedback, and where appropriate we share these with the core or pool PPI group.

Focus on our research studies



UK Antimicrobial Registry

The University of Aberdeen is working with The British Society for Antimicrobial Chemotherapy to develop a UK-wide Antimicrobial Registry (UKAR). Antimicrobial medications are used to stop the growth of microorganisms that cause disease. Antimicrobial medications include antibiotics (such as penicillin which can be used to treat chest infections), antivirals (such as Tamiflu which is used to treat the flu), and antifungals (such as clotrimazole, which is used in the treatment of athlete's foot).

The Registry will look at novel antimicrobials, with a particular focus on those that are used to treat multi-drug resistant organisms. The aim of the Registry is to increase our understanding of how widely these novel antimicrobials are used across the UK, and how effective they are.

The Registry will also be used to help monitor the safety of antimicrobials. Sharing knowledge gained from the Registry will help guide future research into these medications.

Currently the UKAR team in the Epidemiology Group is busy working to set up the Registry. Amongst other things, we are putting together documents that need approval from Research Ethics and Research Governance committees. Once approved, these documents will be used to recruit patients, which we hope will start in October 2022. You can find out more about the study here: <https://www.abdn.ac.uk/iahs/research/epidemiology/ukar-2091.php>

Patient and Partner Stories



Debs Dulake is a patient partner on our PACFiND Study and a mentor to our core PPI group. At our first core PPI group meeting Debs described why patient and public involvement is important to her.

You can watch the full video: <https://www.youtube.com/watch?v=gTYFCQvu0aY>

Debs Dulake

"I think for me, I'm not backwards at going forward, and not a lot of people have the ability to be able to stand up and make themselves understood and heard. I feel very privileged to be able to say that I can put everybody's point of view across; for me, research, for it to be relevant to people on the ground, it needs to be patient centred. It needs to have patient involvement from beginning to end, even if it's just an idea from a researcher... it needs to be run past a group of patients to say, what do you think about this? How do you think this would work? Are there any changes that you think we should be making? I've been in so many meetings in different rooms with different organisations where I've stated something that happens in my day to day, and I've had professors and scientists look at me and they had never even thought of that point of view, it hadn't even entered into their minds that that could be relevant to a patient.

So, for me, it's all about letting them know that we are on the same team that we can fight these horrible, horrible diseases together and get our voices out there to make changes at the top where it really matters, with the NHS with government, with benefit systems. Making diseases that are really not heard of heard - and giving them time; where people are able to say you're not going mad, it is real, that it can, it can be looked at. It can be researched. Let's try and help you. You know that light when you're in a very, very dark room of feeling not well and not right, and you're in pain, that light is worth all the weight in gold. "

Get involved with our research

We currently have the following patient and public involvement opportunity:

UK Antimicrobial Register Feedback Requested



As described above the UK Antimicrobial registry is being set-up to look at how widely novel antimicrobials (antibiotics, antifungals and antivirals) are being used across the UK. We plan to look at how safe and effective they are and use this data to guide future research into these medications.

Any patient in hospital who has been prescribed one of these novel anti-microbials of interest will be eligible to be part of the study.

All potential participants in the study will be given details about the study (participant information sheet) and what being part of the study means to them. Potential participants will then be asked to give consent to be part of the study. Consent to take part in the study can only be taken if the potential participant is informed of the nature, significance, implication, and risks of the study.

Two different options are being considered for completing the consent process:

1. Paper consent: participants receive a physical paper copy of both the participant information sheet and consent form
2. Electronic consent (or E-consent) For this option the participant would still receive a physical paper copy of the participant information sheet, but the consent would be done via smart-phone or tablet.

There would always be the option of paper PIS/consent forms for those without access to a smartphone or tablet.

We would like to ask for your feedback regarding the use of e-consent.

We would like you to consider how you would feel about using your smartphone or tablet to consent to being part of the study for yourself or a member of your family.

If you would like to give us your thoughts, or if this is something you have personal experience of, please click on the link below to take you to our feedback form:

[Microsoft Online Form](#)

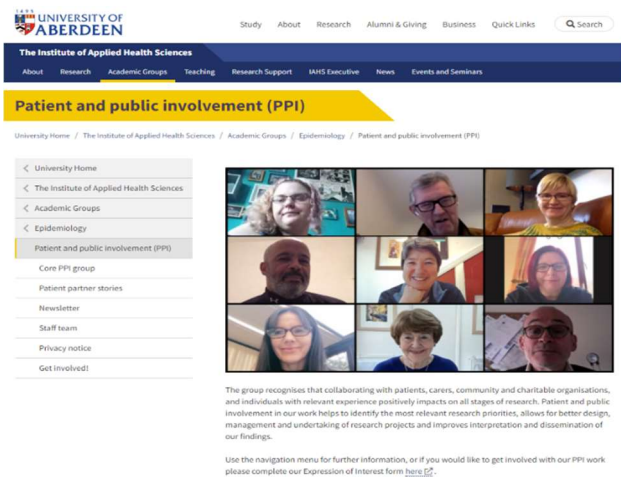
Or scan the code below on a phone or tablet to access the form:



All responses are anonymous.

Thanks in advance for your time.

Epidemiology Patient and Public Involvement Website



We now have a dedicated website for all the latest updates and information about PPI activities within the Epidemiology group! On these pages you can find more details about the PPI work done within the group, access back issues of our newsletters, read bios of our Core PPI Group members and patient partners and find out about ongoing opportunities to get involved in our research.

The website sits within the wider Epidemiology group web pages, and you can navigate here to read more about the work

we do in the group, our research specialties, ongoing studies, links to papers and research summaries and much more.

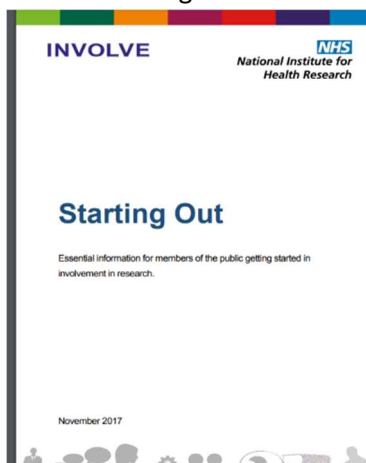
These pages are under ongoing development, so make sure to check back from time-to-time for the latest updates. If you know of others who would like to get involved in our PPI work, the easiest way is to direct them to the website at: <http://www.abdn.ac.uk/epippi>

PPI Training Resources

Training for Patient and Public Involvement in Research – for researchers and patients

It has been over six months now since the EPIPI Team (Laura, Elaine, Karen and Stuart) was formally established in order to help develop and embed patient and public involvement (PPI) within our Epidemiology research group. Whilst we brought some experience of PPI to our team (mainly from Laura and Elaine) we were acutely aware of how little formal knowledge we had about PPI in research. In order to address this, we tried to find out about best practice in PPI and have begun to build a list of resources to read, reflect upon, and learn from other's experiences.

Prior to holding our first meeting with our core PPI group, we found the INVOLVE 'Starting Out'



document very helpful (see <https://www.invo.org.uk/wp-content/uploads/2018/01/Induction-public-v3.pdf>). This short document raised 12 key points – see the contents page – which was a great starting point and helped us to think about what you may need to know about us and some things we hadn't considered. During that initial period, we also sought advice from colleagues at the University with a lot of PPI experience and patient partners already involved with our research.

Since last summer we have identified a range of training and resources aimed at researchers and patient partners on 'how to do PPI' but we have also discovered there are many ongoing debates and discussions (e.g., over language, the meaning of involvement and engagement) and, unsurprisingly, that there is a huge amount for us still to learn from the literature and from yourselves! To that end, we will endeavour to add to our growing depository of resources and will share anything which may be useful via the newsletter (and at core group meetings).

We are also aware that many of you have significant experience in PPI and would maybe like to share your experiences of 'what works' with us all and any pitfalls to try and avoid. Please feel free to get in touch via our epippi@abdn.ac.uk email address if you would like to contribute a piece in future newsletters, or at one of our core group meetings. On a final note, from our perspective, we have found the following modules developed by HealthTalkOnline particularly helpful and illuminating:

Patient and public involvement in research: What is patient and public involvement ('PPI') in research? Why does it matter?

<https://healthtalk.org/patient-and-public-involvement-research/what-is-patient-and-public-involvement-ppi-in-research-why-does-it-matter>

Researchers' experiences of patient & public involvement

<https://healthtalk.org/patient-public-involvement-researchers/overview>

Watch this space for future information and discussion!

**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