



January 2023

As we start 2023, we would like to take the time to thank you for being part of the Epidemiology Patient and Public Involvement Group. 2022 was a busy year and we really appreciate all the feedback this group has provided.

Thank You

Introduction

In this newsletter you will find a recap about some of the studies the Epidemiology Group is involved with as well as information about the website HealthTalk.org and two of the modules we have developed. We are also delighted to begin our newsletter by telling you about the award-winning PPI undertaken by our VOICES study team.

Award Winning PPI within the Epidemiology Group



In July 2022 the VOICES Study team gave a presentation at the Health Sciences Research UK Conference. This was a filmed conversation about how they worked together, the productive tensions experienced, and the trusting relationships that were formed. The conversation was framed around thinking about the ethics of responsibility to each other, to other patients, to NHS colleagues and to the quality of research. See the full recorded presentation [here](#).

They were delighted to win an **Innovation in Health Services Research award** supported by the Health Services Research National Specialty Group in the NIHR Clinical Research Network. You can read more about this in an accompanying blog - [Frankly speaking](#) - conversations about PPI – where Professor [Louise Locock](#) reflects on their experiences.

Healthtalk.org: Real People. Real life experiences



Have you heard about Healthtalk.org? At Healthtalk.org you can find out about what it is like to live with a health condition by watching other people share their stories, in their own words. Healthtalk.org contains hundreds of real people's stories, collected by academic researchers, in their own homes, using their own words.

Researchers and participants in our PACFiND and VOICES Studies have been instrumental in developing pages for this website. Our PACFiND study was involved in the development of the pages about the experience of living with fibromyalgia ([click here](#)) while our VOICES study developed a section about experiences of systemic vasculitis and healthcare ([click here](#)).

Healthalk.org has helped millions of people each year to feel better prepared, informed and less alone in what they are going through. We feel privileged as a research group to be able to play a small part in this.

Focus on our Research Studies

Consortium Against Pain Inequality (CAPE) - The impact of adverse childhood experiences on chronic pain and responses to treatment



At our August core group PPI meeting Dr Kate Timmins shared with us details about the Consortium Against Pain Inequality (CAPE) study:

The aim of the study is to improve our understanding of how adverse childhood experiences (ACEs) might lead to chronic pain in adulthood. Having a traumatic experience as a child – for example, abuse, neglect, violence, physical or emotional trauma, or living with hardship (such as severe financial difficulties) – can have a lifelong impact. Research has found that people who report having several adverse childhood experiences, are more likely to have health problems later in life. CAPE, which is part of the Advanced Pain Discovery Platform ([APDP](#)), will approach this topic from a variety of angles, piecing together different types of evidence.

CAPE will develop a new questionnaire to better capture these adverse experiences, bring together data from current studies to rigorously evaluate the evidence of a link, collect new data on young people with arthritis, and investigate biomarkers that may be associated with people being at high risk of developing chronic pain.

Investigators at the University of Aberdeen will lead the work which will use epidemiological methods to analyse the relationship between ACEs and chronic pain in existing large-scale data sets.

Making it Work™ – Scotland



Making it Work™ is a programme which was developed in Canada to support individuals with inflammatory arthritis (such as rheumatoid arthritis, psoriatic arthritis, or spondyloarthritis) to stay in work for as long as they wish to do so. The Making it Work™ - Scotland study is tasked with adapting this programme to make it suitable for a wider range of inflammatory and non-inflammatory conditions, as well as making changes to make it fit for the Scottish health and social context, and the wide variety of different working situations people find themselves in the modern work environment. In order to make the required changes to the programme, our

first step was to conduct a series of focus groups with both patients and healthcare professionals in order to get their input into the changes we would need to make to fit this wider context.

Thanks to our PPI pool, we were able to advertise, interview, and recruit patient partners to this study back in May, and they have already provided excellent feedback and advice on our progress in the study so far. For our focus groups we needed to be able to present the existing programme in a concise manner before getting feedback on the content changes which might need to be made. Through email and online consultation sessions, our partners were key in shaping a series of key presentation videos, helping our researchers tailor these to ensure that these gave as accurate an impression of the existing material as possible. We also followed this with a 'dry-run' of the focus group sessions themselves, in order to make sure the planned conduct of these were fit for purpose before inviting our research participants to the study focus group sessions. Whilst making changes to the content, we are also keen to modernise the look and feel of the programme, and we have also held consultations with our patient partners to get their feedback on the visual and audio presentation elements so that we can make sure the adapted version looks as good as possible for a more modern audience.

We plan to use this feedback, in conjunction with the findings of our focus groups, to start making our initial changes to the programme in early 2023 and all the team are very excited about the way things are shaping up, in no small part thanks to the great input we have received from our excellent PPI representatives. We are looking forward to working further with our patient partners in the New Year (as well as the wider Epi PPI pool) as we start to make our changes to the programme.

University of Aberdeen Events



The Alan Turing Institute - Interdisciplinary Data & AI Talk (Teams Live Event)

Overview of Data Science for Science and Humanities at The Alan Turing Institute & the University Partner Network

Join us in conversation this Friday, 20th January at 10am as Dr Georgios Leontidis, Interdisciplinary Director of Data & AI, Dr Donna Brown, Director of Academic Engagement at the Alan Turing Institute, and Programme Director Professor Jonathan Rowe discuss the Alan Turing Institute's Data Science for Science and Humanities programme. Professor Rowe and Dr Brown will provide an overview of the programme challenges and impact, as well as the Alan Turing Institute's University Partnership Network.

[Data science for science and humanities | The Alan Turing Institute](#)

[LINK TO TEAMS LIVE EVENT](#)

Professor Jonathan Rowe Biography

Jon Rowe is Professor of Natural Computation in the School of Computer Science, and Deputy Pro-Vice Chancellor (Strategic Projects) at the University of Birmingham. He is Programme Director for the Data Science for Science and Humanities programme at The Alan Turing Institute and is PI and Chair of the Strategic Priorities Fund (SPF) for Science and Government project. He is an Associate Editor for Theoretical Computer Science journal. He joined the University of Birmingham in 2000 and his PhD in Artificial Intelligence is from the University of Exeter. Jon's research encompasses the theoretical analysis of nature-inspired algorithms, such as evolutionary algorithms and other randomised search heuristics, along with a range of interdisciplinary applications from modelling social crowd dynamics to chemical reaction networks to medical imaging techniques.

Get Involved In Our Research

GET INVOLVED

The University of Aberdeen Epidemiology Group is interested in the effects that musculoskeletal (MSK) conditions have on a person's daily life, and you can find out more about our current research studies [here](#)

We are always looking for ways to improve our research studies and are therefore reaching out to you to ask about your experience of being involved in research. What makes you want to be part of a research study, and what stops you getting involved? What opportunities have you had, and what has motivated to take part?

Please click here (<https://forms.office.com/e/ePiMvsibs9>) to complete a short questionnaire

Contact Us



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



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