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Summer 2023

School of Medicine PPI Newsletter

Welcome to our first issue of the School of
Medicine Patient and Public Involvement
newsletter



Rapid Eczema Trials – creating research together



What are we doing?

We are members of the public working with researchers to design and run clinical trials that answer questions that people have about living with eczema. If you have questions about how best to manage your eczema, then this project is for you. Come and join us – together we can improve the lives of people living with eczema.

How can you help?

We are looking for people with experience of eczema from all over the UK who would like to get involved. No matter what your skills or experiences in life, we would love to hear your views.

Find out more about this National Institute for Health & Care Research (NIHR) flagship citizen science project at:
rapideczematrials.org



Welcome message from Dr Adele Horobin

Hello! The School of Medicine appointed me in the new role of Senior Patient and Public Involvement and Engagement Manager in September 2022. I am a member of the School's Research and Knowledge Exchange team. We work with researchers in planning research, developing and submitting funding bids and managing processes before and after funding has been won.

An essential part of research is including the voices of people who have personal, or 'lived' experience of the topic in question. Involving patients, carers and people who have a non-researcher's perspective on healthcare can be invaluable, making research more in tune with patient needs. In the UK, this is known as Patient and Public Involvement (PPI).

Since I started my post, I have been working with Claire, Colleen, Fred, Michael and Stevie, who have all done a lot of PPI with the School. We first met in my previous role with the Hearing theme of the Nottingham Biomedical Research Centre. There, we established a PPI and public engagement strategy steering group. We want to do the same for the School of Medicine, but we want to make this open to everyone in the School. **So, if you are a patient or public member of a research team, or a researcher experienced in PPI and public engagement, and you have an interest in developing strategy, please do get in touch. We would love to hear from you!**

It is clear that there is some great PPI happening across the School of Medicine. But it may not be well known outside of the project groups. People are missing out on learning more.

We want to change that. We would like this newsletter to highlight the fantastic work that is already happening and to inspire others to PPI. Spreading good practice and creating a school-wide community who all have a shared interest in PPI will be key successes.



The Nottingham Stoke Research Partnership Group

Nottingham healthcare and research is recognised for its success in treating and rehabilitating from stroke. Much is due to the calibre of the specialists, researchers and medics, but part is from patients, carers and the public, who guide studies to areas that benefit patients most.

History of our group

The Nottingham Stroke Research Partnership Group was established in 2004 as an independent organisation of stroke researchers from the University of Nottingham and stroke survivors and their carers. Run by lay chair the late Ossie Newell and academic chair Prof Marion Walker for many years, it is now led by joint lay chairs Philip Johnson and Fred Higton, and joint academic chairs Prof Nikola Sprigg and Dr Niki Chouliara. Helen Taylor co-ordinates.

What we do

Stroke survivors, carers, and interested public meet once a month to talk with researchers. Together, we input into all areas of projects, including defining research questions, assisting with grant applications and wording patient-facing literature. The aim is to help, and many members have several years' experience. Before they attend, researchers provide a written outline and any questions for the group. They have 30 minutes for presenting and discussing. They receive a summary of discussions.

How do we know it works? Researcher feedback is normally very positive, and they come back for extra support throughout the project. This is, in our opinion, one way of supporting researchers and ensuring that projects are developed in a way that will benefit stroke survivors.

Fred Higton Joint lay chair

P	Patient focused
A	Accountable
R	Responsive
T	True partners
N	Non-confrontational
E	Equal
R	Respectful
S	Seamless

The Nottingham Stroke Research Partnership Group's philosophy is summarised in the acronym PARTNERS.



Dementia, frail older person and palliative care PPI group

The 'Dementia, frail older person and palliative care PPI group' is a dynamic and passionate group of people with dementia, carers and those interested in the healthcare of older people. Members of the group have collaborated with us on many funded research and PhD studies over the past 10 years to ensure our research is focused on the needs of service users and that our research methods are appropriate. They have worked with us to co-design, conduct, interpret and disseminate research.

The group currently meets once a month (except December, April and August) on the third Friday of the month between 10.30 and 12.30 in the Medical School. By joining the meeting presenters will get to hear about research studies going on across the faculty and understand how PPI contributes to research.

PPI members of this group are experienced and supportive, providing a valuable platform to share ideas with the public and practice communicating in 'lay' terms. They offer feedback on patient information materials and can provide guidance on study progress and disseminating findings.

"And the winning researcher is..." The Institute of Mental Health New Researchers Day

I and another PPI colleague, Fred, judged the presentations given by new researchers on the second 'New Researchers' Day at the Institute of Mental Health. As the judging panel, we used a sheet with guide criteria covering five elements of presentation skills and were asked to give an overall mark between 1 – poor, up to 5 – excellent, in each area, across six presentations.

This is the first time I have personally undertaken judging researchers' presentations, and not only did I thoroughly enjoy the experience, I felt that I was helping researchers to develop their presentation skills to a mixed academic/lay audience; I was also improving my evaluation abilities, therefore gaining further transferable skills!

A 'question and answer' session was also led during the day by two other PPI colleagues, and Fred and I supported them in answering questions from the audience to give as broad, 'lay' perspective as possible. Overall, a very informative day for all attendees, both professional and non-professional.

Claire Klauza PPI representative





BATH-OUT-2

What are we doing?

BATH-OUT-2 is a national randomised control trial that is on-going. The aim is to find out the effectiveness of installing accessible showers for older people who need them, and doing this quickly, compared with using waiting lists.

Championing PPI

From the earliest ideas through to having public members as co-applicants, the [BATH-OUT-2](#) study has a long history of PPI. The PPI members have experience of accessing social care services. One took part in the BATH-OUT feasibility trial led by University of Nottingham and wished to continue supporting the study. The group meet in person and online, and we value their input as much as any other member of the study team.

BATH-OUT-2 is funded by NIHR School for Social Care Research, led by University of Newcastle, with University of Northumbria at Newcastle, Care & Repair England, University of Nottingham, Nottingham City Council, University of York, University of Salford.

PPI informing PhD Fellowship applications

Rehabilitation is a process that starts with an interview with the patient to understand the problem, before goal setting and developing an intervention plan. As an Occupational Therapist, and Professor of Rehabilitation Research, doing anything other than this would seem nonsensical.

I lead the NIHR/ Health Education England funded Pre-Doctoral Bridging Programme. We select five non-medical healthcare professionals from NHS Trusts in the East Midlands each year, match them with an academic mentor and support them to develop

competitive PhD fellowship applications. We stress the importance of Patient and Public Involvement and Engagement (PPIE) from day one, reiterating that failure to embed PPIE throughout an NIHR proposal is the most commonly reported failings (NIHR Doctoral Clinical and Practitioner Academic Fellowship Chair's Report, 2023). In preparation for fellowship submission/interview we host mock funding panels, comprising academics, fellowship recipients and PPIE partners. We are blessed with outstanding, highly-skilled PPIE and NIHR panel members in the School of Medicine. They ask the questions that matter, shaping our fellows research projects, learning and fellowship applicant success (89%).

Professor Kate Radford
Professor of Rehabilitation Research

Training for PPI

Learning about PPI is vital for building confidence in involving public members and spreading good practice. Public partners Debra Dulake, Trevor Jones, Michael Prior, Amanda Roberts and Stevie Vanhegan, with Dr Joanne Stocks and Dr Adele Horobin have all shared their perspectives in the Grant Writing Programme for early career researchers led by Dr Paul Leighton.

The Focus on Fellowships course includes an overview of PPI for clinical and discovery science researchers with Dr Adele Horobin, Colleen Ewart and Claire Klauza. While the Nottingham

Clinical Trials Unit offers insights for trial staff and researchers through the Fundamentals of Clinical Trials course. The Researcher Academy at the University includes a Patients, Carers & Public Involvement in Research course, led by Andy Wragg under the umbrella of the NIHR Nottingham Biomedical Research Centre, supported over the years by Prof John Gladman, Kate Frost, Dr Jane Horne and public members Karen Andrews, Debra and Richard Dulake, Michael Prior, John Shaw, Stevie Vanhegan, Richard Winning. And the Research and Knowledge Exchange team deliver seminars throughout the year, some of which focus on PPI.



Public partner Michael Prior talking with medical students

Teaching the next generation

Second-year BMedSci students have the opportunity to choose an optional module in their Spring term and we were delighted that 17 chose our module 'Patient and Public Involvement in Research: "No research about me, without me"' Set up by Dr Rebecca Fisher in 2019 and co-designed

and co-delivered with public partners, the course introduces students to the role of PPI in research. The course is now convened by Dr Joanne Stocks and co-delivered by School of Medicine and Nottingham University Hospital (NUH) staff Dr Adele Horobin, Andy Wragg, Dr Shirley Thomas and Becky Woodcock, and has received positive student feedback.

Though many students admitted they weren't previously aware of the involvement of patients in research, students appreciated the opportunity to be taught and engage with our public partners as collaborating participants and not just as a patient. They fed back how listening to Jeff discuss his experience with dementia made them reflect on their own assumptions about patients and stereotypes.

Debbie Butler's discussions on triggering brought about considerations on topics that hadn't previously thought about. Claire's sharing of bad experiences of PPI and Michael's suggestions on consideration when running a session and why PPI is important to them all helped enthuse the students to not only carry out, but also involve patients and the public in future research, and also reflect on how learning from the module could influence their practice as future clinicians. Thank you also to Julie Bryant and Claire Klauza who helped in the online assessment where the students ran their own PPI session with module team members as the participant.

Dr Joanne Stocks
Assistant Professor of Sport and Exercise Medicine



Keep in touch and get involved

We are setting up a mailing list to make it easier for people to find out about PPI activities and new opportunities to get involved. Whether you are a member of the public, staff or student, please join our mailing list to:

- Receive future issues of this newsletter
- Be notified of new opportunities to get involved in research

Sign up at: bit.ly/3DY44KH. You are free to unsubscribe at any time.



Scan the QR code to subscribe

GLOSSARY

Feasibility trial: A feasibility study asks whether something can be done, should we proceed with it, and if so, how.

Randomised Controlled Trial (RCT): A study in which a number of similar people are randomly assigned to 2 (or more) groups to test a specific drug, treatment or other intervention.

Involvement, Engagement and Participation in research all have specific definitions in the UK. Read more at: Briefing notes for researchers - public involvement in NHS, health and social care research (tinyurl.com/NIHRNotesforResearchers).

Website links:

BATH-OUT study: www.sscr.nihr.ac.uk/projects/p151/

Rapid Eczema Trials: rapideczematrials.org

Atastroke: <https://atastroke.com/about-us/about-us>

PPI Subscription form: <https://r1.dotdigital-pages.com/p/5IL5-HSO/ppi-newsletter-subscribe-form>

Attention all researchers!

Has this newsletter whetted your appetite to find out more?

- Please visit our [School of Medicine's PPI SharePoint](#) to access guidance on PPI
- Need some pre-grant funding for PPI? Visit [Research and Knowledge Exchange fund for Grant Development, Impact and Patient and Public Involvement \(GrIP\) fund page](#).
- Identified a training need? Let us know and we'll see what we can do.

- Do you have responsibility for PPI and/or public engagement in your work? Want to meet others with similar responsibilities? The PPI Operations group of staff members meet to share experiences, highlight issues and recommend solutions. Join us for peer support and to input into processes relating to PPI e.g. payments and expenses, employment considerations, safeguarding, communications

For any of the above, email us at MS-ResOps@nottingham.ac.uk.



Share your feedback

The newsletter

We have developed this newsletter with public members as a pilot and we welcome your feedback. We want to make this work for you!

- Do you find the articles engaging? Do you like the way the newsletter looks?
- Do you prefer paper copies over electronic?
- Want articles that give guidance on doing PPI?
- Want to know more about the impact of PPI?
- Anything else you want to share?

Please tell us!

Submit newsletter articles

Want to share your experiences of PPI? Are you working with a local community? Got an interesting story to tell?

Whether you are a patient, public, student or staff, please contact us about submitting an article for future editions.

Our website



Get involved

Patients, carers, and members of the public can get involved in our world-leading research in many ways. Involving patients and carers in our research helps us to identify research questions that are most relevant. It also makes sure that the needs of patients, carers and anyone else affected by the research, are central throughout the research process so that we answer these questions in the right way.

What is Patient and Public Involvement?

Patient and public involvement (PPI) is about people sharing their lived experience as a patient, carer, or member of the public to make sure research is based on reality, is relevant, and addresses patient needs and priorities.

Who can get involved in our research?

Medical research done well is a joint effort involving a broad range of members of the public and other interested groups. The School of Medicine welcomes all contributions of patients, carers, and the public in our research with different levels of involvement depending on experience, interests, and availability.

We have redesigned the School webpages about getting involved. Please do take a look at our website by clicking the link nottingham.ac.uk/medicine/research/get-involved.aspx or scan the QR code and let us know what you think.



Scan the QR code to view Get Involved web page

For any of the above, email us at MS-ResOps@nottingham.ac.uk.