



University of  
Nottingham

UK | CHINA | MALAYSIA

Winter 2023

# School of Medicine PPI Newsletter

Showcasing the contribution of patients,  
carers and members of the public in the work  
and research of the School of Medicine



## Stroke Research Showcase

Back by popular demand following a pause during COVID, the Stroke Research Showcase conference was held on 31 August at the Nottingham City Hospital.

The event proved a resounding success, with the participation of 85 stroke survivors, carers, members of the public and researchers. Presentations covered key topics including electrical stimulation to treat swallowing difficulties, fatigue after stroke, psychological care for TIA (trans-ischaemic attack) and minor stroke and home-based rehabilitation for stroke survivors with severe disability.

The event brought opportunities for participants to hear details of some of the latest stroke research and share their valuable experiences with researchers to help shape future research directions. Feedback from the delegates at the event was positive, including “The presentations were really amazing – lots of information. And I felt people listened to me.”

**If you have been impacted by stroke and would be interested in feeding into stroke research topics at the University of Nottingham, please contact Helen Taylor on 07970 555001 or [h.taylor@nottingham.ac.uk](mailto:h.taylor@nottingham.ac.uk).**



## Every part of me

Mental health masks the sound of the physical signs,  
Saying this hurts often is dismissed.

But why not check out my history in my physical health before you say it seems to be in your head?

Mental health masks the signs,  
Of hi please I'm here.  
It brings out the past dismissals so no more questions now.

Mental health masks my pleas,  
I'm a human too.  
And just because my mental health shows from time to time, I am not often heard.

But thanks to those of you that do understand and make me feel heard,  
it is after all every part of me.  
Thank you.

Debbie Butler

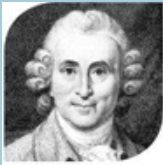


## BATH-OUT 2 at the Global Ageing Network Conference

The BATH-OUT-2 PPI group have been busy recently presenting our work at the Global Ageing Network Conference in Glasgow. We were invited to present our work as an example of best practice within Patient and Public Involvement in older people's research.

The poster was co-designed by the BATH-OUT 2 PPI group and created to be accessible for everyone, moving away from the more traditional academic poster styles. Our poster was very well received, and we are exploring other opportunities for presenting together again next year.

Download the poster in [Landscape](#) or [Portrait](#).



## James Lind Alliance

Priority Setting Partnerships

### Patients and public setting research priorities

Research on the effects of treatments hasn't always considered the shared interests of patients, carers and clinicians.

The [James Lind Alliance \(JLA\)](#) was established to address this. Priority Setting Partnerships (PSPs) follow methods set out by the JLA where clinicians, patients and carers work together to identify and prioritise unanswered research questions. Over 150 such Partnerships on a range of topics have been supported.

Major research funders store much value in addressing questions prioritised by PSPs. The National Institute for Health Research has a [rolling call](#) to fund such research.

A tool is now available to highlight emerging themes or "overarching topics" across PSPs. This may help in addressing similar priorities together. Researchers with non-condition specific remit may be interested in common priorities.

These have been grouped under seven topics:

- Quality of life
- Caregivers and families
- Causes and prevention
- Screening and diagnosis
- Treatment and management
- Services and systems
- Social influences and impacts

[Read more about identifying the themes](#) and [download the full report](#).

### Shaping future research about dementia and hearing conditions

A new survey has been launched to guide future research about dementia and hearing conditions, given some people can experience both conditions together.

The survey aims to collect people's main questions about the connection between dementia and hearing conditions (e.g. hearing loss, tinnitus, hyperacusis, balance disorders). People over the age of 18 who are interested in the topic can take part.

The survey takes around 10 minutes and involves telling us your main concerns or questions about dementia and hearing conditions.

If you or someone you know might like to take part, or you want to find out more, please [complete the online survey](#) (BSL version of the survey is available).

If you have any questions or want the survey in a different format (e.g., larger font) please get in touch with Sian at [sian.calvert@nottingham.ac.uk](mailto:sian.calvert@nottingham.ac.uk).



Photo by Peter Kindersley via Centre for Ageing Better



Researching Rare Diseases



University of Nottingham  
UK | CHINA | MALAYSIA



### Successful launch of RECORDER's Public Partnership

On 18 November, 11 patients and two carers attended the online launch event of RECORDER's Public Partnership.

First, an experienced patient partner and two researchers shared their perspectives on what public involvement means to them. Then, attendees experienced a flavour of involvement activities through two short workshops.

Feedback was overwhelmingly positive. Public partners were hearteningly supportive of one another, and one said a highlight was: "The focus on people first. The science and education possibilities. The hope."

The RECORDER team is now energised with project and engagement ideas for the future.

The [RECORDER team](#), led by rheumatologist Dr Fiona Pearce, aims to benefit people with rare diseases through research primarily using electronic health records. Their focus is on autoimmune conditions such as lupus, scleroderma, myositis, and vasculitis.

Live in the East Midlands and interested to get involved? Please [complete the online signup form](#), email [RECORDER@nottingham.ac.uk](mailto:RECORDER@nottingham.ac.uk) or call 0115 823 1357.



### Centre of Evidence Based Dermatology (CEBD) Patient Panel Day

Ten patient panel members attended our most recent annual meeting at Jubilee Conference Centre, Nottingham in early October.

CEBD hold two annual meetings (one online and one face to face) each year to help our patient panel who support PPI input into CEBD research. The panel is comprised of a group of 40+ patients and

carers from across the UK affected by a variety of skin diseases.

The day included learning sessions on systematic reviews, research impact and the [Include Ethnicity Framework](#). Workshops considered areas for future dermatology studies in primary care and patient facing materials for an acne study. We got some great feedback from those attending, with many indicating they get a lot more out of these meetings than just learning about research.

Huge thanks to the [NIHR School for Primary Care Research](#) for sponsoring the event.

## PPI doesn't stop at patients! Employer engagement in research

Rehabilitation research includes improving support for people returning or staying in work following injury or long-term illness. Interventions are frequently targeted at both the 'patient' and their employer.

In addition to our patient and public partners with lived experience of stroke, MS, or [serious injury](#), we are working with employer stakeholders

to shape our research and inform its dissemination. This includes representatives from human resources, large and small companies. We are creating an Employer Community Engagement and Involvement (CEI) group, to work with us. Can you help?

Our 'employer' definition is broad and includes company directors and line managers with experience of supporting employees returning or staying in work following injury or illness. Also, professionals who specialise in supporting people to stay in work or education.

If you, or someone you know meets meet this definition and would be

interested in advising on our research, please contact [Kate.radford@nottingham.ac.uk](mailto:Kate.radford@nottingham.ac.uk).

Feel free to pass on this request. Thank you.



Research Skills Sessions

## Sharing PPI skills within the Lifespan and Population Health (LPH) Unit

The LPH Research Forum has launched its skills session programme to enhance shared learning across the unit.

The inaugural session, held on 14 November 2023, was hosted by the Centre of Evidence Based Dermatology (CEBD) and focused on "doing PPI well". It kicked off with a series of 'flash talks' explaining the different types of research they do and how PPI is done, including:

- co-ordinating the CEBD patient panel
- analysing large patient databases
- co-ordinating systematic reviews
- analysing qualitative data

Amanda Roberts, who lives the condition she helps others study, also spoke about user led research. This was followed by a small group activity planning PPI for a new project.

Key themes arose on including PPI at all research stages, from start to finish, challenges on involving different populations and the diversity of researchers including PPI.

For information on further LPH Research Forum skills sessions, please contact [MS-LPHResearchForum@nottingham.ac.uk](mailto:MS-LPHResearchForum@nottingham.ac.uk)

## Lived experience centre stage in disability awareness training

Disability Recognition Month at the University of Nottingham celebrates disabled history, culture, and achievements.

It opened on the 16 November with disability awareness training held by the School of Medicine. The session centred on attendees chatting with public research partners who all live with different disabilities. Fred Higton, Claire Klauza and Stevie Vanhegan generously shared their insights and experiences of disability.

Attendee Jo Taylor said "The training provided a great opportunity to understand how different disabilities can

impact individuals' ability to take part in meetings and events. In particular, the ways that we can adapt our approach to better suit individual's needs."

Attendee Mengfan Wu said "The invited speakers are all very friendly, kind and well-spoken to share their experience as well as to discuss any related topics from the audience."



## Equality, Diversity and Inclusion Training

Equality, Diversity and Inclusion (EDI) is about ensuring equal opportunities, embracing and valuing people's differences including their beliefs, abilities, preferences, backgrounds, values, and identities. Building this into academic culture will lead to research that is developed by a broad mix of people and designed around the needs of our diverse population. PPI members play a vital role in this.

The Nottingham Stroke Research Partnership Group (NSRPG) members have personal experience of stroke and regularly advise researchers. They were keen to know more about EDI, so on 30 October, Dr Adele Horobin and Claire Klauza shared their knowledge around current legislation, how stroke may affect groups of people differently, what this means for stroke research and how PPI can advocate for more inclusive research.

The event was positively received and, as was stated by a group member "The more we know about EDI compliance, the more knowledgeable we are as a group to offer well-informed advice".



## 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.

You are free to unsubscribe at any time.



Scan the QR code to subscribe

## What is Patient and Public Involvement (PPI) in research?

Involvement, Engagement and Participation in research all have specific definitions in the UK. Read more at: [What is public involvement in research?](#), and [Briefing notes for researchers - public involvement in NHS, health and social care research.](#)

### Support and information

- [British Association of Dermatologists - Patient Support Groups](#)
- [Dementia UK](#)
- [Mind](#)
- [Rare Diseases](#)
  - [British Sjögren's Syndrome Association \(BSSA\)](#)
  - [Fibromyalgia UK](#)
  - [Hidden Disabilities Sunflower Scheme](#)
  - [Lupus UK](#)
  - [Myositis UK](#)
  - [The Wren Project](#)
  - [Vasculitis UK](#)
  - [Scleroderma and Raynaud's UK](#)
- [RNID - National Hearing Loss Charity](#)
- [Stroke Association](#)

## 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](mailto: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



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 needs, 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](#) 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](mailto:MS-ResOps@nottingham.ac.uk).