

Clinical Research and Innovation Office Public Involvement Newsletter

DECEMBER 2023

HELLO AND WELCOME

FROM LUCY WASINSKI, RESEARCH COORDINATOR
AND KATIE GRAY, RESEARCH ADMINISTRATOR - CRIO



Lucy Wasinski



Katie Gray

Welcome to the latest edition of the **Patient and Public Involvement Newsletter**.

As the end of the year fast approaches, we are looking forward to sharing a round up of activities, news and updates from the course of the year. Thanks to everyone who has contributed to this newsletter; we hope you enjoy it!

Contents

[News and Updates from the Panels](#)

[Feedback from researchers](#)

[Shaping the Future Event](#)

[Meet the Team](#)

[BISTRo Project](#)

[Goodwill to Goodwin: Diabetes Podcast](#)

[Participant in Research Experience Survey](#)

[Research Updates](#)

[Contact us](#)

News and Updates from the Panels

Thanks to everyone who has got in touch to tell us about the innovative and exciting projects you have been involved in over the past year, particularly as lay advisers to researchers and as co-applicants. It comes as no surprise to hear how active and engaged you have been! Here are a selection of some of your news stories.

Appearing in an ITV news item about exciting research into the treatment of diabetic foot ulcers – by Brenda Riley (Lay ADvice for Diabetes & Endocrinology Research (LADDER) PPI Group)

“In September I had the opportunity to give my diabetes patient perspective about some exciting new research by Professor Graham Stafford on the treatment of diabetic foot ulcers (DFUs) which was shown on the ITV news. When I arrived, and while we were waiting for the TV crew, he explained his project to me further, and patiently answered my questions about it.

When the ITV film crew, consisting of one interviewer and one cameraman, arrived, we went into Professor Stafford’s lab where the filming took place. I had never been into a real lab before, so I found these surroundings very interesting, and quite different from the type of lab usually shown in films.”

Read more about Brenda’s experience of being interviewed [here](#) (and see the item as it appeared on ITV News)

My involvement with the CONNECTED Study – by Linda Abouzeid (Sheffield Emergency Care Forum)

“I feel very privileged, over the last few years, to have been involved in the CONNECTED Study. This research led by Dr Richard Bourne (ICU Consultant Pharmacist), has been looking at the complex and high-risk point when patients are transferred from the ICU to a ward. Some of the patients’ long-term medicines will have been discontinued on admission to the ICU and other new medicines will have been started. On transfer to the ward, more changes to the patients’ medications will be needed with some medicines restarted and others discontinued, and all the relevant information will need to be communicated to all the various stakeholders. The complexity of this process is difficult to appreciate, and many medication errors can occur at this point resulting in as many as one in four emergency readmissions within 90 days and increased mortality rates.

As a massive oversimplification - through thorough analysis of the transfer process and the involvement of all relevant ICU and ward-based staff, patients, and families, and overcoming many obstacles, an intervention has been developed. This has been shown to have real impact on reducing medication errors and improving patient outcomes. PPI has been valued and meaningfully involved throughout this research and from my perspective it has been a very worthwhile and rewarding experience.”

NEWS2 Research Study: our experience as co-applicants – by Enid Hirst and Linda Abouzeid (Sheffield Emergency Care Forum)

“For the last couple of years, we have been involved in the Pre-Hospital Early Warning Scores (PHEWS) study as PPI co-applicants from Sheffield Emergency Care Forum (SECF). The findings from the PHEWS study led to a further piece of work and we were invited to be co-applicants. This recently funded National Institute for Health and Care Research (NIHR) study is investigating the triage scoring system called National Early Warning Score version 2 (NEWS2) and hopes to establish the accuracy of the scores (or limitations) when used with patients who presented at the Emergency Department (ED) in 2022.

NEWS2 is an early warning system to identify acutely ill patients in emergency departments and is mandated for use by the ambulance services and in emergency departments

It is a simple scoring system measuring respiration rate; oxygen saturation; systolic blood pressure; pulse rate; level of consciousness and temperature

High score may identify patients who need urgent treatment

Linda and I felt that, as co-applicants, we needed to re-visit the Emergency Department at the Northern General Hospital (NGH), to update and clarify our knowledge of the triage system and NEWS2 in particular. We were invited to visit the ED last month to widen our knowledge before embarking on the NEWS2 study.

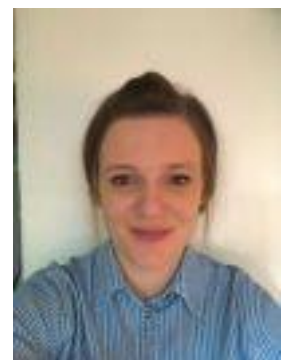
We arrived at the ED at 3 p.m. – a quiet time, we were told. The waiting room was very full. Professor Goodacre came out to greet us and took us into the “green” area behind reception. Over the next hour we were taken into each of the different “colour” areas and were able to ask questions about how NEWS2 triage is used at NGH ED. Each of the areas seemed calm and quiet at the time. We were taken into the area where the ambulances arrive. The area outside was busy with parked ambulances, possibly waiting new calls, and one vehicle just arriving. The reception area, where ambulance patients are booked in, was busy but seemed quiet and efficient.

Linda and I take our PPI roles as co-applicants very seriously. It is so worthwhile to take part in research studies as a representative of the patient. We are all potential/past patients and our role is to help to get the best possible benefit for each patient.”

Read more about Enid and Linda’s visit to the Emergency Department and their roles as co-applicants [here](#).

Introducing Hannah Roddie, the new PPI Coordinator – OGN Panel

“I completed my PhD in Molecular Cell Biology at the University of Sheffield in 2018, before working as a PostDoctoral Research Associate in Cardiovascular Science at the University from 2018-2021. I then took up the role of Directorate Research Facilitator for Diabetes and Endocrinology, where I assisted Sharon Caunt in the set-up and delivery of clinical research studies, before taking up the position of Directorate Research Coordinator for OGN and MIMP. I have two children, George who is three and a half and Hazel who just turned one, both of whom were born at Jessops! Most of my spare time is spent with my family but I do enjoy the odd artistic venture, and gardening. I’ve just taken over the role of PPI coordinator and I hope to bring a down-to-earth and friendly attitude to the OGN panel, and to continue to support and nurture the women who put so much effort into providing vital feedback on research studies.”



FEEDBACK FROM RESEARCHERS

As regular attendees at many different public involvement meetings, it is always striking to hear how incisive and constructive panel members' feedback to the researchers can be, and how well-prepared members are for the discussion. Here is a selection of some of the positive comments we have received from researchers recently which demonstrate just how valuable they find the PPI process to their work – 90% said they had made changes to their project because of the panels' feedback:

“The panel showed great curiosity towards the project. They have asked very relevant and interesting questions. In future projects, I would like to engage the panel at the early study design stage and will certainly receive valuable suggestions from the panel.”

“It is very valuable and I would be happy to talk to the panel again and get their input on the draft application that I write. I found it really useful to get their perspective. I was also pleasantly relieved that they liked the idea of the project.”

“This is a particularly good panel due to the range of people on it and their amount of lived experience. They are very vocal and honest and have really helped to inform how we present information about the trial.”

“I would always want to involve groups like this in my research and tell everyone how valuable this has been to the research process.”

“The panel give rich insight into their lived experience with stroke and what could have made things easier along the way.”

“I felt fortunate to have opportunities to engage with the group and to learn more about their perspectives.”

“The panel has not only pointed out potential weaknesses but also provided suggestions of how to correct/improve them. This is super helpful. Also we are very appreciative that the panel has asked very relevant scientific questions and provided suggestions.... Please keep doing this so there will be two-way engagement.”

Shaping The Future – Celebrating 75 years of the NHS and the NIHR Be Part of Research Campaign

On a rainy Saturday afternoon in July, the Sheffield Winter Garden was a hive of activity as researchers and the public gathered to celebrate the 75th anniversary of the National Health Service (NHS) and the National Institute for Health and Care Research (NIHR) Be Part of Research campaign. The "Shaping the Future" event brought together researchers from across Sheffield to celebrate past, present and future healthcare innovations.

We were very glad to have chosen an indoor venue as the rain came down in true British summer time fashion, and the exotic setting of the Winter Garden meant everyone kept warm and dry as visitors of all ages browsed the stands and interactive activities, including active hands-on and even on the floor participation! It was great to see some of you there on the day taking advantage of the opportunity to engage directly with researchers and hear about their current projects – we hope you enjoyed the event.



Read more about the event [here](#)

Meet the Team

Lisa Watson – Research Coordinator

I am a research coordinator working within Respiratory Medicine directorate. My role is to support the portfolio of research studies in the department, this includes a wide range of responsibilities including: helping develop our research strategy, tracking recruitment and progress of open studies, setting up hosted research studies and supporting researchers with developing grants and study documentation and supporting patient and public involvement and engagement.



In October the Pulmonary Hypertension Association hosted TogetherSheffield at Quays Hotel in Sheffield. This was a patient focused day for pulmonary hypertension (PH) patients and their families who are treated at the Sheffield Pulmonary Vascular Disease Unit at the Royal Hallamshire Hospital (part of respiratory medicine). At this event there were a series of expert talks from clinicians, nurses, pharmacists, nutritionists and physios about PH in the morning, followed by a research-focussed session in the afternoon. I chaired the afternoon research session.

As well as research fellows giving an update on their current specific research projects, we integrated a PPI session into this event. We used Wooclap, an audience participation app to collect answers from the audience on various topics. This was well received and most attendees were happy to take part and vote on a selection of questions. We asked people about symptoms that bother them the most, and what they thought key priorities would be for research. It was a unique opportunity to also get the view of carers and family members.

I am interested in making sure we keep in touch with our research participants during research studies to let them know about study progress and disseminate the results of research at the end of the study. We asked a selection of

questions to our attendees about how important “keeping in touch” is for them, and how they wish to be contacted about results and study updates. What we learned from our attendees is helpful for us planning our research studies and how we run them operationally. Finally, we asked for expressions of interest from attendees about joining study specific PPI panels so we can ensure our future research is patient-centred. TogetherSheffield was a great day for me, allowing me to meet people who are affected by the research that we do in Sheffield and we learnt as much from attendees as they did from us.



BISTRO Project

Lucy and I were pleased to attend an event celebrating the completion of Natalie Jones’ BISTRO project at St Mary’s Church in Sheffield over the summer, along with members of the Stroke and Aphasia Patient and Public Involvement group. Both the event and the project itself were great examples of the importance of involving not just healthcare professionals in research but also the patients and carers it affects, and it was inspiring to see such an emphasis placed on sharing the findings of the project with all of those involved.

Natalie is a clinical academic researcher, NIHR Fellow and Occupational Therapist. She worked in Sheffield Teaching Hospitals for 23 years and for the last three years, she was studying for a PhD at the University of Sheffield. Her research study Breakfast Group Interventions in Stroke Rehabilitation (BISTRO) involved stroke survivors and their families in the study design and enabled those who would deliver and receive the intervention to co-produce a prototype intervention for testing in three Stroke Services in South Yorkshire. Co-producing a research project is an approach that sees researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project.



Early engagement with patients and the public in study design:

Natalie is enthusiastic about collaboratively producing research. Her involvement with stroke survivors and informal carers began before the BISTRO study was funded. She was successful in securing funding for the development of her NIHR Clinical Doctoral Research Fellowship application. Natalie travelled to stroke services in four counties to:

- 1) explore how eating and drinking interventions were being delivered in stroke rehabilitation wards
- 2) to consult with stroke survivors and their families about their lived experience of eating and drinking difficulties.

Public involvement during the study:

Natalie regularly involved the Sheffield Teaching Hospitals Stroke & Aphasia Patient and Public Panel as well as recruiting stroke survivors and informal carers to take part in the intervention design group. Natalie made several films with stroke survivors, carers and healthcare professionals to show the intervention design group the particular problems that stroke survivors experienced.

These trigger films were used to generate ideas about how eating and drinking interventions could be improved. A breakfast group intervention brings together stroke survivors in a social dining group to receive physical and psychosocial (having both psychological and social elements) interventions to help them gain independence with eating and drinking activities. Stroke survivors prepare and eat their breakfast during the group and whilst socialising with other stroke survivors.

This study found that breakfast groups were feasible to deliver and acceptable to patients, carers, and health care professionals. The research highlights the importance of involving patients and carers in research to ensure it benefits those it is aiming to help. One of those who advised Natalie on the design of the intervention was Kate Sudworth, whose husband is a stroke survivor. She provided a valuable carer's perspective:

"I became involved in the BISTRO project with Nat when she brought the idea to a Stroke and Aphasia PPI Advisory Group Meeting.

My husband had a stroke and while he was in hospital he struggled with breakfast as he was unable to open packets one handed and didn't always have enough food to eat, not realising he could have larger portions. I advised Nat on accessible options for patients to help themselves to their own breakfast, the benefits of eating in a social environment and producing the patient booklet. It's been a great project to be involved in and fantastic that the patients have improved during their time on the BISTRO project."

We would also like to congratulate Natalie on receiving this year's UK Stroke Forum Conference prize for her participatory research methods involving those who would deliver and receive the intervention as equal partners in the research. Participatory research engages those who may not be trained in research but belong to or represent the interests of the people who are the focus of the research to ensure their voice is heard. Her abstract was one of 400 submitted to this year's conference. The prestigious Patient, Carer and Public Involvement Award was sponsored by a stroke survivor. Well done Natalie - fantastic achievement!

If you would like to know more about the study findings, please see:
<https://youtu.be/b4vGBdhDpLA?si=FbaWpbWDBhu7ZKBk> (12.27mins)

To find out more about the study design scan the QR code:



Disclaimer:

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Goodwill to Goodwin: Diabetes and the UK's first clinical trial of insulin

The Overend-Knight Medical History Podcast

Some of you may be aware that Sheffield played a crucial role in the first clinical trials of insulin in the 1920s, and continues to be at the forefront of innovative diabetes research to this day. Hear more about this fascinating story in the first episode of the Overend-Knight Medical History Podcast, featuring a discussion between Professor Solomon Tesfaye from Sheffield Teaching Hospitals and Dr Jackie Elliott, University of Sheffield:

<https://open.spotify.com/episode/5P0JdVQqw7yqNyFAWTRsKC?si=w7bgT8c8RRy7Nvg8sygx3A>

Participant in Research Experience Survey

The Participant in Research Experience Survey (PRES) gives participants in research an opportunity to share their experience of taking part. By using this feedback, research teams can identify the factors that impact on a participant's experience of research participation, and then use them to design and deliver research that will be more appropriate, accessible and meaningful for participants.

The reasons people get involved are varied but many people who have been involved in studies during and in the time after the COVID-19 pandemic, report feeling like they are making a valued contribution to medical research that will make a difference to many others.

There were lots of positive comments from participants who had taken part including *"I believe the information I received from the beginning of the trial was helpful and informed all of my decisions."* There were also constructive comments about what could be better, and three of the most common themes were:

- Communication
- Practicalities of participation
- Trial procedures

The above feedback highlights the importance of involving the public in research, particularly around ensuring appropriate information is included in participant information, and that the proposed research and procedures are suitable for prospective participants.

If you'd like to find out more about PRES at STH, please visit our website here: [Participant in Research Experience Survey - Sheffield Clinical Research](#)

Clinical Trials Regulations

Last year, some of you may have shared your views in a public consultation conducted by the Medicines and Healthcare products Regulatory Agency (MHRA) Health Research Authority (HRA), the MHRA and the Department of Health in Northern Ireland about clinical trial legislation. [New measures will be introduced](#) to make it faster and easier to gain approval and to run clinical trials in the UK.

One of these measures is around public involvement in clinical trials. The HRA is supporting the development of guidance on patient and public involvement to ensure patients are meaningfully involved in designing and delivering clinical trials, and that diversity in trials is achieved in a proportionate manner.

Along with members of the public and other stakeholders, we are pleased to be sharing our views as part of a group that will make recommendations on ensuring suitable resources are available for those setting up and running clinical trials.

HRA Quality Standards and Design and Review Principles

On 1st December, the Health Research Authority (HRA) introduced mandatory Quality Standards and Design and Review Principles. The aim is to **improve information** given to people who are invited to be a participant in research, and to show researchers and Research Ethics Committees (RECs) what the **important ethical considerations** are for participant information. RECs will check the participant information complies with the Quality Standards and share their findings as part of the outcome of ethics review meetings.

The Trust have advised researchers and research support staff about these new Standards and Principles so that they can design information in line with these new requirements. As members of public involvement panels you can contribute to helping researchers meet these standards by raising the topic with them at meetings and when carrying out reviews of study paperwork, so we can make sure the message is getting through.

You can read more about the Quality Standards [here](#) and Design and Review Principles [here](#).

Public involvement opportunities

Many of our groups always welcome new members. You can find details of many of the groups at STH along with details of how to get involved here: [How to get involved - Sheffield Clinical Research](#)

Many external opportunities for members of the public wishing to get involved in research can be found here: [Home - People in Research](#)

Contact us in the Clinical Research & Innovation Office

We hope you have enjoyed reading this newsletter – we are grateful to all of those who have contributed to it. If you have any questions, comments or suggestions you can contact us in the following ways:

Website: [Sheffield Clinical Research](#)

Telephone: 0114 271 3260 (Katie)

General enquiries: sth.getinvolved@nhs.net

X/Twitter: @Shef_Research

Finally, a big thank you for all your valued contributions and involvement over the past year – we look forward to continuing to work together with you in 2024!