Patient & Public Involvement & Engagement Newsletter
ICR Clinical Trials & Statistics Unit
ICR The Institute of Cancer Research

A warm welcome to all of our new subscribers to the PPIE newsletter!

Inside Issue 5:

Upcoming events

Join us to “Lunch and Learn” together online

Many of us have been involved in writing Patient Information Sheets for ICR-CTSU trials. These are often long and complicated and can be difficult for some people to understand.

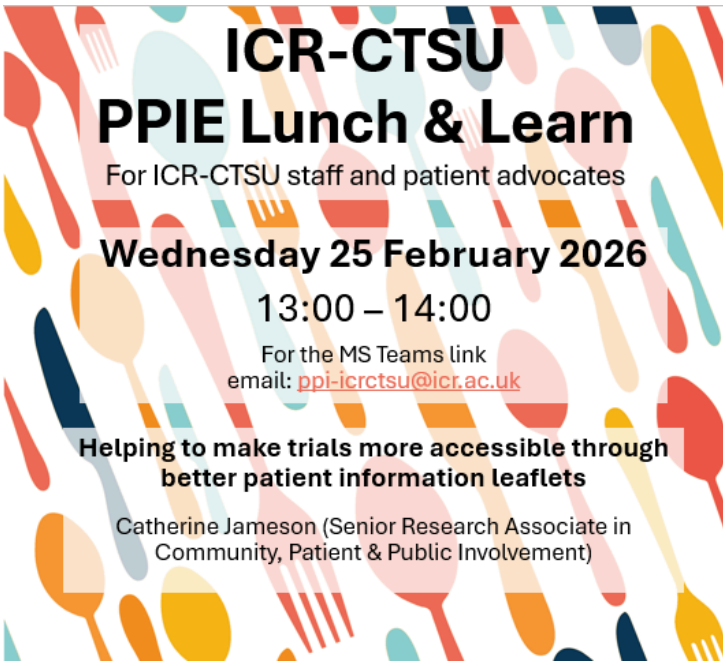
The MAPLE project team based at Bristol University have been working with

marginalised community groups, patients and charity representatives to help researchers to create accessible Patient Information Leaflets for clinical trials. Come along to meet Cat Jameson and learn about all the resources that are now freely available for us to use.

For more the link to join the session, please email ppi-icrctsu@icr.ac.uk.

If you missed the last lunch and learn that Emily Alger presented on Bayesian statistics, you can find that recording here at icr.ac.uk/ctsu-ppi in the password protected section.

Username: ppi-icrctsu@icr.ac.uk
Password: stainless-zoom-doorway



Find out more about MAPLE here

Spotlight on PPI

Advocate blog: “My experience with co-production”

We heard from Araya G, an ICR-CTSU patient advocate to learn about her experiences of co-production. Araya is currently pursuing a Master of Public Health at Queen Margaret University. She is also a research assistant, NIHR Reviewer and Cancer Research UK Panel Member.

Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which

engages groups of people at the earliest stages of service design, development and evaluation.
(Definition from NHS England)

Araya writes: “One of the most positive experiences I have had in co-production happened recently during a committee meeting. The PPI lead created an environment where we genuinely felt valued. She paused the room to make sure we were offered tea and coffee like everyone else, and she repeatedly stopped discussions to ask whether we had anything we wanted to contribute. Each time “PPI” appeared on the slides, she turned towards us with intention, inviting our thoughts. That level of respect, inclusion, and attentiveness made me feel that our presence was not symbolic but essential. It was a powerful reminder of how meaningful co-production can be when lived experience is treated with the same seriousness as academic expertise.

In contrast, I have also experienced situations that were far more challenging. On one occasion, researchers had already completed almost all of a funding application and contacted me only at the last moment, asking for a PPI opinion purely to meet submission requirements. During the meeting, they spoke for most of the time while I nodded along, and afterwards I tried to follow up to hear how the application went. Months passed with no reply. That silence made it clear that my involvement was not valued beyond ticking a box. Experiences like this are disheartening, because they show how co-production can be misused and how easily the purpose improving research for the public gets lost.

From these contrasting experiences, I have learned that co-production is a deliberate and often lengthy process. It requires time, trust, preparation, and genuine curiosity about people’s lived realities. It cannot be rushed or added as an afterthought, and doing so undermines both the research and the people involved. For those considering a co-production approach, I would encourage them to commit fully: create space for voices that are often overlooked, plan early, and treat contributions as central rather than optional. When done well, co-production strengthens research; when done poorly, it risks eroding trust.”

If you are a PPI member interested in contributing to the our next newsletter please email ppi-icrctsu@icr.ac.uk.

Publications and presentations

Recently published: PPI involvement in SPRUCE

We have published our experience of working collaboratively with our patient and public advisors on the SPRUCE study in the journal Research Involvement & Engagement.

People taking part in clinical trials are often asked to complete questionnaires about their treatment side effects and overall quality of life. We normally ask our participants to complete these questionnaires on paper, but they can now be completed electronically over the internet. The SPRUCE study was designed to explore whether electronic questionnaires would be acceptable, or preferable, for trial participants.

The article we published describes how patient and public involvement was integral to the SPRUCE study, the benefits it brought, and the challenges experienced. From starting with one patient advisor, the SPRUCE team managed to hear from 50 people in a survey about their attitudes towards electronic health questionnaires. Eight people went on to join discussion groups to explore issues in more depth, and they formed a Patient and Public Oversight Committee to give PPI advice throughout the study's duration. This was the first time we formed a PPI committee to oversee an ICR-CTSU trial methodology project.

Our patient advocates tested the systems for sending electronic questionnaires, gave advice on the information SPRUCE participants would need, and made sure the electronic system and all documents were easy to understand. They also helped to develop surveys to find out more about the background of participants and their experience of completing questionnaires, as well as a letter to update participants when the planned number of people had joined SPRUCE. They will continue to be involved as results become available in 2026, to advise on next steps and help us share them with our participants.

This article is a great example of how important patient and public involvement is in our work here at ICR-CTSU and how this collaboration can directly shape the way we run our trials.

Our sincere thanks to patient advocates, Diana K, Jacqui G, Andy D, Esme R, Kim W and Franko K for their input and continued support.

You can read the published paper here.

Involvement updates

Thank you for your help with our ePRO project

Clinical trial participants are often asked to complete questionnaires about their treatment side effects and their overall health. Whilst these questionnaires are typically completed on paper, they now can be collected electronically. We refer to these as electronic patient reported outcomes or ePROs. Following on from the results of the SPRUCE study, the ICR-CTSU are using a new clinical trial management system called Medrio that has the ability to collect ePROs. We wanted to make sure that the ePRO module of Medrio is easy to use and works for future trial participants.

With the help of 14 patient advocates we were able to test the ePRO system and confirm that it was a straightforward and easy to use. Patient advocates completed feedback forms and joined discussion groups to give detailed feedback. We were delighted to receive positive feedback in that:

- 85% (11/13) found the ePRO system easy to use.
- 77% (10/13) agreed that they would prefer to use the ePRO system to paper questionnaires.
- 85% (11/13) felt they would be able to complete electronic questionnaires regularly on their own.

With this additional feedback we were able to identify some quick fixes and future updates that could be made to make the system even better. This means that we can confidently introduce ePROs for the first time in our new clinical trials this year.

Thank you so much to all of the advocates that got involved with this project! Your feedback has directly improved the experience for clinical trial participants for all of our studies using ePROs.

Shaping the LOBLOX study together

We've been working closely with people who have experience of invasive lobular breast cancer (ILC) to help design a new clinical trial called LOBLOX.

Unlike the more common type of breast cancer (ductal breast cancer), ILC often grows in a line or as single cells rather than forming a lump. This makes it much harder to spot on scans or during physical examination.

At the moment, people with ILC usually follow the same treatment pathway as those with other types of breast cancer. The LOBLOX trial aims to find out whether a new drug called amsulostat could offer a more effective treatment specifically for invasive lobular breast cancer.

The trial has been developed in partnership with Lobular Breast Cancer UK, who also helped us share the opportunity with people affected by ILC.

We were overwhelmed by the response to our call for involvement. More than 80 people with personal experience of invasive lobular breast cancer (ILC) got in touch which was far more than we expected.
From this group, 28 patients joined three in-depth discussion sessions, sharing their experiences and helping us shape the LOBLOX trial. Across all sessions, patients told us:

- **They welcomed the focus on ILC**, which is often under-researched compared to other types of breast cancer.
- **They supported the trial's approach**, particularly as it had been designed so that the trial wouldn't delay standard treatment.
- **Felt reassured by the early safety data** for the new drug, amsulostat.
- **Most were wiling to undergo additional biopsies and advanced scans**, including whole-body MRI, provided these didn't delay treatment and results were shared quickly. Some patients were more hesitant about additional biopsies and advised the research team of the importance of clearly explaining why they are needed.
- **They highlighted a lack of clear information at diagnosis** about how lobular breast cancer differs from other types. Improving this was seen as important both for patients joining the trial and for people with ILC more generally.

A huge thank you
To everyone who took part: **thank you**. Your experiences and insights have directly shaped the LOBLOX study, we're truly grateful for your time. We also want to thank those who

expressed interest but were not able to join the discussion groups this time. We truly appreciate your enthusiasm and hope to involve you in future opportunities.

What happens next?

The trial has been submitted to the CRUK Clinical Research Funding Scheme. We are hopeful for a positive outcome, although — as with all funding calls — the process is competitive, and we will update you about the outcome in a future edition of this newsletter.

INTERACT social media post

As many of you may be aware from previous newsletters, we are running a study called INTERACT aiming to understand inclusivity in oncology clinical trials.

So we can find out whether cancer studies have been inclusive in the past, NHS England will draw information from NHS records about people's cancer diagnosis, treatment, general health and background. We will share the NHS number, date of birth and trial name of anyone who took part in one of our research studies. NHS England will link the information we provide to the data they hold. The data provided by NHS England to the ICR will not identify individuals but will show if they took part in a trial. We will not be able to identify anyone from the data we receive from NHS England.

It is likely that many of you will have your anonymised data included in this project. We therefore wanted to let you know about this work and share it more widely. The ICR has posted about the INTERACT project on Facebook, Linked-in, and Instagram to raise awareness. For more information on INTERACT and how your data will be used, please see our website: www.icr.ac.uk/interact

The Institute of Cancer Research
6d ·

We are doing a study called INTERACT to find out whether any groups of people have been less likely to take part in cancer studies in the UK.

We'll be using routine data collected by NHS England to find out whether there are any differences between those who joined our clinical trials and those who did not. To do this, we will send NHS England information about our trial participants (NHS number and date of birth).

This will be used by NHS England to note which patients took part in our trials. We will not be able to identify anyone from the data we receive.

To find out more, including how to opt out from your information being shared with NHS England if you took part in one of our trials, head to ⬇️
www.icr.ac.uk/interact

Please note, anyone who has chosen not to allow their NHS health data to be used for research will not be included in the data provided by NHS England. For more information visit the NHS website.

#ICR #CancerResearch #ClinicalTrials #NHS

News

Celebrating Professor Judith Bliss's career

As you may know, Professor Judith Bliss, our long-standing previous Director, will shortly be retiring after

more than 40 years at the ICR. During her remarkable career, Judith founded and led the ICR-CTSU and worked with many of you on national and international trials that have helped improve outcomes for cancer patients. Her leadership, scientific vision, and commitment to methodological rigour have left an enduring legacy across ICR-CTSU and the wider cancer clinical trials research community.

To mark her retirement, we are compiling a **memory book**. If you would like to contribute a tribute, anecdote, reflection, or indeed a photo or two, you can do so here: ***Judith Bliss Memory Book*****.** Please feel free to share this link with others who may wish to contribute.

ICR receives the prestigious Queen Elizabeth Prize

The Institute of Cancer Research (ICR) has been awarded one of the highest national honours in UK further and higher education, recognising its world-leading radiotherapy research and its transformative impact on cancer care.

The Queen Elizabeth Prizes for Higher and Further Education acknowledge the ICR's radiotherapy research programme, which has significantly improved patient outcomes,

reduced treatment costs, and shaped global standards of care. This is the third time the ICR has received this prestigious award.

The prize recognises decades of collaborative laboratory and clinical research that have helped revolutionise radiotherapy, turning it into a highly targeted and personalised treatment. Through pioneering advanced techniques and leading landmark clinical trials, researchers at the ICR, working closely with colleagues at The Royal Marsden NHS Foundation Trust, have delivered tangible benefits for patients and healthcare systems worldwide.

Key achievements highlighted by the award include the development of high-precision radiotherapy techniques; leadership of major clinical trials at ICR-CTSU including CHHiP, PACE-B, PARSPORT and DARS; and the introduction of more efficient treatments that save the NHS more than £28 million each year. The programme has also played a vital role in education, training many of the UK's clinical oncologists and strengthening research engagement among radiographers.

Professor Kevin Harrington, Head of the Division of Radiotherapy and Imaging, said the award recognises "decades of collaborative laboratory and clinical research that have transformed radiotherapy into the highly targeted, personalised treatment that it is today." Professor Kristian Helin, Chief Executive of the ICR, added that the prize reflects the organisation's commitment to ensuring scientific discovery delivers real benefit for patients around the world.

Written by Cecilia Brandt (ICR-CTSU Clinical Trials Assistant)

New Cancer Research UK (CRUK) PPI resources

CANCER RESEARCH UK

Cancer Research UK (CRUK) have recently released resources for patient and public involvement representatives at their clinical trials units. As ICR-CTSU is a CRUK funded clinical trial unit, these resources will be helpful to any patient and public members working with us.

These resources include: induction and training information, bitesize videos (featuring Holly Tovey, a Principal Statistician in our unit), and a roadmap of a clinical trial.

These resources can be found on our website (icr.ac.uk/ctsu-ppi) and we have provided links below where you can access them. Please email ppi-icrctsu@icr.ac.uk if you have any questions or want more information.

Website: Our Clinical Trials Units

Induction and training for PPI representatives

Bitesize videos for PPI representatives

Clinical Trials Roadmap for PPI representatives

Please email ppi-icrctsu@icr.ac.uk if you have any questions.
You can also follow ICR-CTSU on Bluesky @icr-ctsu.bsky.social

For accessibility support, such as needing the newsletter in a different format, please email the PPI team at ppi-icrctsu@icr.ac.uk.

February 2026