

ICR-CTSU PPI/E NEWSLETTER

Clinical Trials and Statistics Unit at the Institute of Cancer Research (ICR-CTSU)

Translating cutting-edge science into quality clinical trials that can transform cancer care

Welcome to Issue 3 of the ICR-CTSU Patient and Public Involvement and Engagement (PPI/E) Research Advisory Group (RAG) Newsletter, updating Patient Advocates, staff, members of the public, carers and our community about PPIE in the ICR-CTSU. This Newsletter is co-produced by the ICR-CTSU (RAG) team and patient advocates who support us.

Issue 3, 2025



NATIONAL NEWS UPDATES



CRUK programme to help assess individual cancer risk

Funding of £10m for The Cancer Data Driven Detection Programme was announced in January jointly by CRUK, the NIHR and the Engineering and Physical Sciences Research Council (EPSRC).

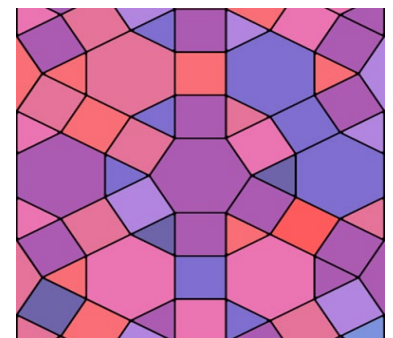
The programme aims to generate new statistical models that could be used to help predict who is most likely to get cancer in the future, by accessing and linking data from different sources, including health records, genomics, family history, demographics and behaviour data.

The programme will also develop powerful new tools which use artificial intelligence (AI) to analyse the data and calculate an individual's risk of cancer throughout their lifetime:

<https://news.cancerresearchuk.org/cancer-driven-detection-programme>

Introducing PEDRI - Good Practice Standards for Public Involvement and Engagement (PIE) in research

The Public Engagement in Data Research Initiative (PEDRI) unites UK organisations working with data and statistics to improve how the research community work with the public. The initiative creates guidance for better public involvement and engagement (PIE) in data research, co-produces projects and engagement tools with the public, and provides learning opportunities for organisations working with data to improve their PIE skills.



The latest version of the PEDRI Good Practice Standards have recently been made available in a downloadable format. These standards are designed to support researchers, PIE professionals, and all those involved in data-related projects, ensuring that the public voice is an integral part of the data community. Researchers are encouraged to consider factors such as equality and diversity, transparency and data literacy to ensure effective public engagement.

For more information about PEDRI and how to get involved, visit:

<https://www.pedri.org.uk/get-involved/>

Sign up now for the VOICE 2025 course for patient advocates

Independent Cancer Patient's Voice (ICVP) is a patient advocate group led by patients for patients, bringing the lived experience of cancer patients, their family and carers to the cancer research community. Founded in 2009 by a group of breast cancer patients whose vision was a patient-led organisation forum for learning and debate through which patients can have an effective independent voice in research, ICPV have now grown to cover all cancer groups, with members as the advocates involved with clinical and scientific research nationally and internationally.

The 1st VOICE course was in September 2013, designed for advocates to learn and understand the biology and science of research so they can be more involved within research. The format worked first time and continues today as a successful course for advocates, led by patients in partnership with the Barts Cancer Institute team. 2024 saw the 9th VOICE course attended by 16 advocates (in total 114 advocates have joined the course since 2013).

Course members meet on the Sunday afternoon to check into the student rooms on the Mile End campus at Queen Mary University of London and then have a meet and greet meal in the local Pizza pub, it is a true back to university experience for many. After a short tube ride to Charterhouse Square, we start on Monday morning with lectures explaining the biology of cancer. After lunch we move to the training labs for our lab experience, which involves pipette training on the first day. We follow the same format of morning lectures and afternoons in the labs, working with researchers and students. Patient advocates get to experience work in the lab and lab students gain experience networking with advocates, often the first time they have had this opportunity. We plan the morning lectures around the advocates, bringing in speakers to ensure every advocate has a session about their own cancer. Afternoons are in the labs, from pipetting on day one, PCR testing and growing on cancer cells to give a truly unique experience.

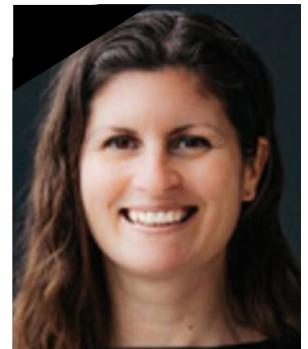
The course is open to any patient advocate from anywhere in the world. VOICE 2025 will run from 31st August to 5th September and is being planned now, so far 10 advocates have signed up, many funded by a charity or patient organisation. For more information about VOICE 2025, please contact: info@icpv.org.uk

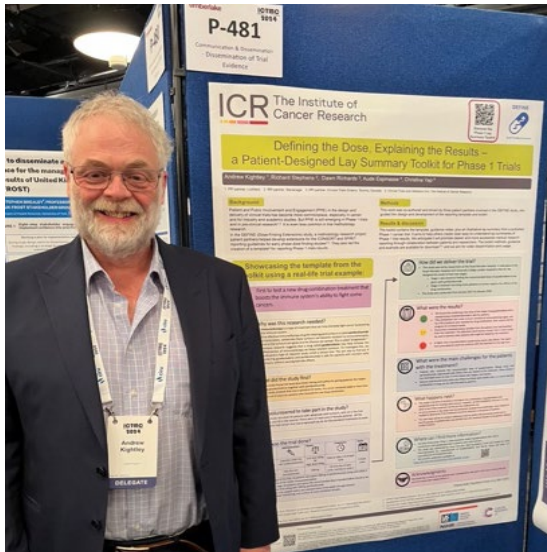
Dear sceptics of patient engagement in research

In an article published in the **BMJ**, Canadian scientist Dawn P Richards, patient engagement consultant and author, challenges researchers who are not convinced about patient engagement in research. Dawn believes that the expertise that patients bring to a research project comes from their experiences of living daily with a condition or disease and makes them worthy of being included in a research team, and she asks researchers to do just that!

The full article can be found here:

[Dear sceptics of patient engagement in research | The BMJ](#)





Being a PPI Rep in a Roomful of Experts (Andrew Kightley, ICR-CTSU PPI RAG member)

I've spent the past few years working with an international team to improve reporting guidelines for early-stage clinical trials (trials which involve giving a new treatment to people for the first time) - the **DEFINE** project. These guidelines provide researchers with recommendations for what information about the trial should be reported to make sure research is transparent, complete, and easy for other researchers to understand. My role was to provide a public and patient perspective as the team identified gaps and proposed improvements. Even without a clinical research background, I was fully included as an equal member of the team.

DEFINE brought together global experts to vote on changes to these guidelines. However, incorporating PPI proved challenging due to the complexity of early-stage trials.

Instead, we created an additional document—the **Lay Summary Toolkit**—to help researchers communicate their findings more clearly. This toolkit was published in the **British Medical Journal** in late 2023.

In 2024, I presented it as a poster at the **International Clinical Trials Methodology Conference (ICTMC)** in Edinburgh, where over 1,300 delegates engaged with more than 528 posters. The experience was intense but rewarding, generating significant interest. As a result, I have been invited to give talks at Cambridge and Sheffield Universities later this year, helping medical statisticians use the toolkit to make their research more accessible to the wider public.

Useful Links:

- [Toolkit for lay summary of early phase dose-finding clinical trial results](#)
- [Enhancing quality and impact of early phase dose-finding clinical trial protocols: SPIRIT Dose-finding Extension \(SPIRIT-DEFINE\) guidance | The BMJ](#)
- [Enhancing reporting quality and impact of early phase dose-finding clinical trials: CONSORT Dose-finding Extension \(CONSORT-DEFINE\) guidance | The BMJ](#)
- [The need for reporting guidelines for early phase dose-finding trials: Dose-Finding CONSORT Extension – Nat Med](#)

ICR-CTSU PPIE Lunch & Learn

We were excited to hold our first ICR-CTSU Patient and Public Involvement and Engagement (PPIE) online 'lunch and learn' session on 11th March 2025. At this session CTSU PhD Student Morgaine Stiles presented her work that explored public views on collecting data to monitor inclusivity of cancer clinical trials (the DISTINCT project).

We had a great turn out with 14 patient advocates and 32 ICR-CTSU staff members. It was a fantastic opportunity for both staff and patient advocates who work with us across the UK to learn together and get to know one another in an informal online setting. Given the success of our first event, we are hoping to hold another PPIE lunch and learn session early summer. Please keep an eye out for our invitation, it would be lovely to see you there!

If you could not attend the first session and would like to watch the recording, please contact: ppi-icrctsu@icr.ac.uk and we can send you the details.

PARABLE

A patient's experience

PARABLE is a research study looking at Proton Beam Therapy (PBT) to treat breast cancer. PBT is a type of radiotherapy that uses protons rather than x-rays. People eligible for the study are those who have been diagnosed with early or localised breast cancer. They will have had their tumour removed by surgery and now need to have radiotherapy to their breast.

To share her experiences with patients considering the trial, one of the PARABLE participants who received PBT at the NHS proton centre in London has documented her time on the trial: <https://www.icr.ac.uk/A-PARABLE-participant's-experience>

More information about the PARABLE study can be found on the trial web page: <https://www.icr.ac.uk/PARABLE>

CURRENT OPPORTUNITIES



ICR The Institute of
Cancer Research

Clinical Trials & Statistics Unit (ICR-CTSU)



Patient & Public Involvement and Engagement

Click here for more
information about PPIE at
the ICR-CTSU:



www.icr.ac.uk/patients-and-public

OPEN DAY

Date to be confirmed

The ICR-CTSU are busy planning our second celebration of Patient and Public Involvement and Engagement. An opportunity to invite our patient advocates and public contributors to join us in person at the ICR in Sutton or online.



Join us to learn and discuss how patient and public involvement and engagement (PPIE) improves our research. This is your opportunity meet your fellow patient advocates and the ICR-CTSU trial teams. Look out for more details arriving in your mailbox. Refreshments will be available.

CONTACTS and LINKS

Webpage: [https://www.icr.ac.uk/research-and-discoveries/centres-and-strategic-collaborations/clinical-trials-and-statistics-unit-icr-cts/our-research-at-icr-cts/patients-and-public](https://www.icr.ac.uk/research-and-discoveries/centres-and-strategic-collaborations/clinical-trials-and-statistics-unit-icr-ctsu/our-research-at-icr-cts/patients-and-public)

Email: ppi-icrcts@icr.ac.uk

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