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

Welcome to the new edition of our newsletter!

Inside Issue 4:

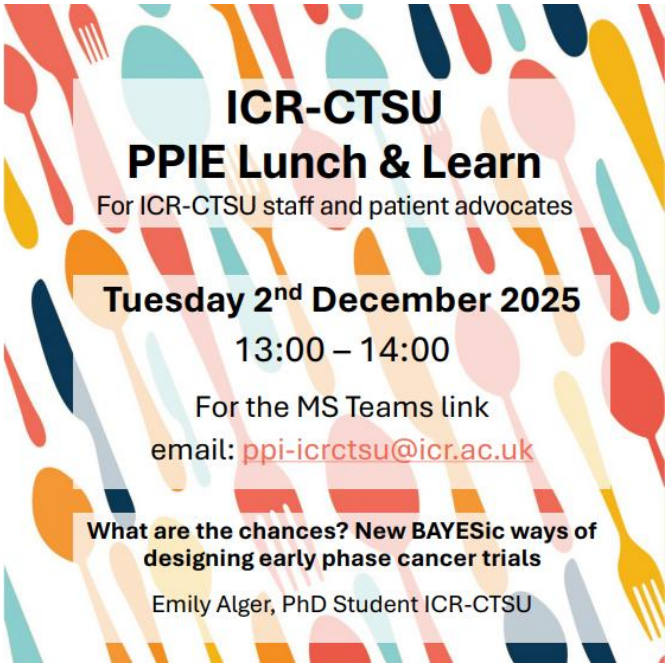
Join us to "Lunch and Learn" together online

Lunch & Learn sessions bring together patient advocates and ICR-CTSU staff to learn together in a virtual informal session. At our second Lunch & Learn event (24 July) Georgiana Synesi (PhD student) presented her work exploring underrepresented groups in bladder and head & neck cancer trials to 15 patient advocates and 20 staff.

Georgiana's work included three projects. The first involved reviewing the demographic data of trial participants in six ICR-CTSU trials recruiting during 2003-2023 and comparing these against NHS data of people treated for these cancers to identify underrepresented groups. The second project reviewed the eligibility criteria for all 68 UK multi-centre randomised clinical trials in head & neck and bladder cancer over 2013-2023. This demonstrated how trial inclusion criteria can inadvertently and disproportionately exclude some people (such as those with other health conditions such as heart problems, or HIV). Georgiana shared her insights from the third project (REPRESENT study) where she observed and interviewed 10 staff and 30 patients at an NHS Hospital Trust. If you missed this session, you can watch it back here (login ppi-icrctsu@icr.ac.uk, password: stainless-zoom-doorway).

It is always a pleasure to see you all. Please come and join us at our next Lunch & Learn event on **Tuesday 2 December 2025, 13.00-14.00**.

Come and hear Emily Alger talk about how we apply statistics to our every day lives. Emily will introduce “Bayesian Statistics” to show how our decisions change and become more accurate as we gain information, and what this means when the stakes are high.
We’ll follow a group of patients in a simulated trial design to see how drug dose recommendations change as we observe each cohort of patients on the trial.
For more the link to join the session, please email ppi-icrctsu@icr.ac.uk

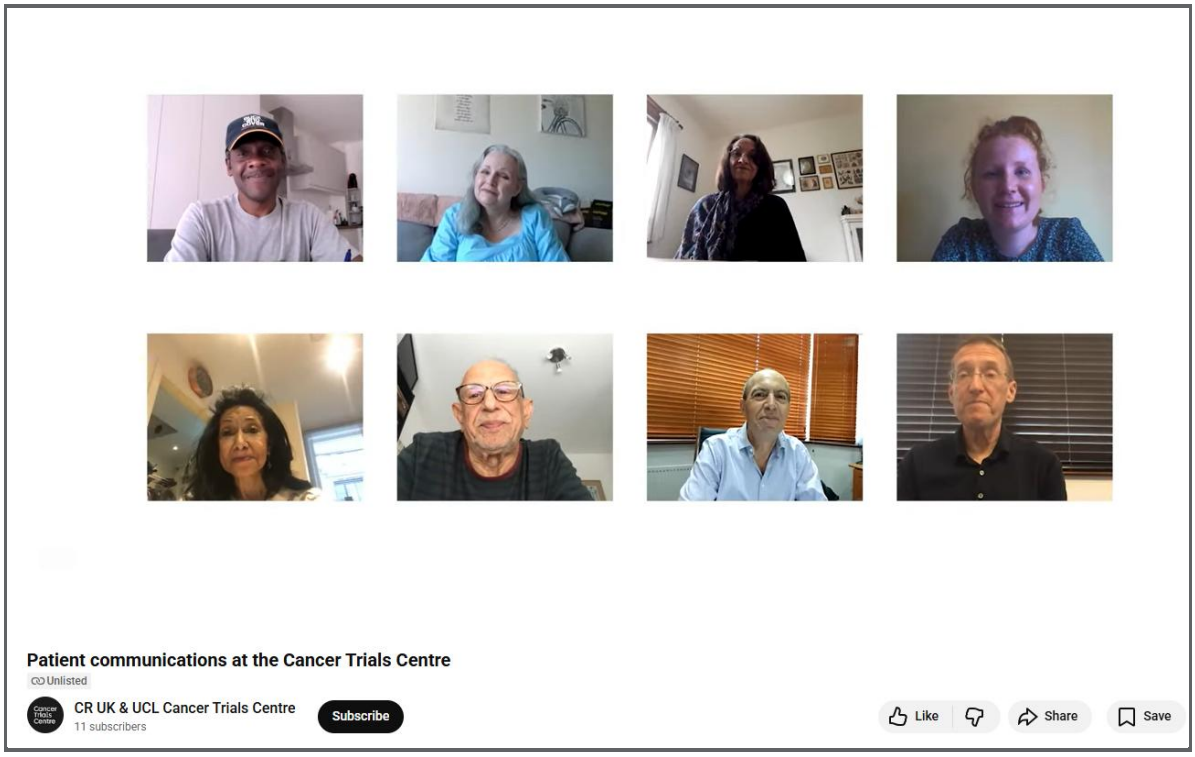


Would you like to be involved in a video about radiotherapy trials?

We are looking for volunteers to participate in a joint project between the Cancer Research UK & UCL Cancer Trials Centre and the Institute of Cancer Research (ICR). The teams are working together to create a series of videos for people who are considering taking part in a research study or who want to learn more about research.

As part of this project, we are looking to speak with individuals who have been involved in radiotherapy research studies, as patients or carers and who are willing to share their experiences and contribute their voices to the project. More on the project can be seen here.

If you would like to take part please email ppi-icrctsu@icr.ac.uk for more information!



Opportunity to get involved: the REDEFINE study

Finding better ways to run clinical trials: the REDEFINE study

REDEFINE

Cancer clinical trials often require participants to have extra tests and assessments which involve extra hospital visits. This can be inconvenient for patients and add pressure on NHS staff. Since COVID-19, healthcare has changed to include video calls, home testing kits and other remote methods, but trials need to keep up.

Many people with cancer find it hard to join clinical trials due to travel, finances, caring responsibilities, or other barriers. The REDEFINE Study is not a clinical trial itself. Instead, it aims to understand how trials can become more flexible and accessible for everyone, no matter their situation.

The study involves interviews, focus groups, and workshops with people affected by cancer, their caregivers, and healthcare professionals. It will explore how technology, like video appointments, online questionnaires, GP blood tests, and home treatment kits, might help people take part more easily.

By gathering views from a wide range of people, the REDEFINE Study hopes to find better ways to run cancer trials, improve access for underserved groups, support the NHS, and speed up progress in cancer treatment.

If you would like to register your interest in taking part please email redefine@icr.ac.uk or scan the QR code.

INTERACT-R Survey: thank you for your feedback

On the 15th August we sent you an email to request your input on the INTERACT-R project, which aims to assess the inclusivity of our research. For more information on INTERACT, see our website. www.icr.ac.uk/interact

A huge thank you to everyone who took part in the survey. Out of 87 patient advocates invited, we received 27 responses – a response rate of **31%**. All responses were anonymous.
We're pleased to share that:

- **22 respondents (81%)** said they ***strongly support*** the aims of INTERACT
- **4 respondents (15%)** said they ***mostly support*** the aims
- **1 respondent** was ***unsure*** and requested more information
- No one expressed disagreement with the project's aims

Feedback received:
We have also received some suggestions from patient advocates that we have taken on board and included in the project:

- **Including what matters to you:** You highlighted the importance of capturing a wide range of characteristics, such as disability, other health conditions, and whether someone lives in a rural or urban area. We're making sure these are included in the data we request.
- **Sharing the findings:** You told us how important it is to communicate the results back to patients and the public. We completely agree — we plan to sharing what we learn as widely and clearly as possible.
- **Keeping your data safe:** Some of you asked about data security. We want to reassure you that the data we receive from NHS England will not include any information that could identify individuals. It will be stored securely and only accessed by essential staff at ICR-CTSU. Once the project is finished and the findings are summarised, we'll permanently delete the data from our systems.

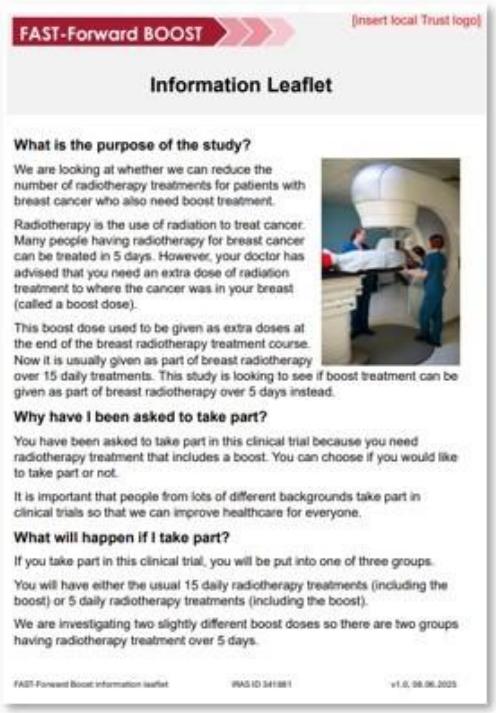
Next steps: We're pleased to share that we now have ethics approval for the project. The next step is preparing our application to request the data from NHS England. Our Patient and Public Advisory Group which consists of 6 advocate members will continue to advise on the project as it progresses.

Improving patient information leaflets

Making trials more accessible in FAST-Forward BOOST

Patient Information Sheets used in clinical trials are often long and complicated. Six patient advocates working with the FAST-Forward Boost trial team at ICR-CTSU helped to create a two-page information leaflet to be a clear introduction and the first part of a layered approach to help people to decide if they want to know more. The six patient advocates together with Professor Anna Kirby (Chief Investigator) and Karen Poole (PPI Lead) met online and worked together to agree the wording and produce the leaflet design. The leaflet has been approved by the Research Ethics Committee and is now being used across the NHS by hospital staff offering the FAST-Forward Boost trial to their patients. If people would like to know more, they are then given the longer Patient Information Sheet. A huge thanks to Vicky G, Fiona K, Sheridan L, Sarah M, Lorna McH and Nerys W for helping to create this leaflet!

This work was inspired by work done by the “Making trials more Accessible through better Patient information LEaflets” (MAPLE) project in Bristol, who have been working with community groups, patients and charities to help researchers to create accessible information. Click here to read more about the MAPLE project and the MAPLE team will join us at a Lunch & Learn event in 2026.



FAST-Forward BOOST

[insert local Trust logo]

Information Leaflet

What is the purpose of the study?

We are looking at whether we can reduce the number of radiotherapy treatments for patients with breast cancer who also need boost treatment.

Radiotherapy is the use of radiation to treat cancer. Many people having radiotherapy for breast cancer can be treated in 5 days. However, your doctor has advised that you need an extra dose of radiation treatment to where the cancer was in your breast (called a boost dose).

This boost dose used to be given as extra doses at the end of the breast radiotherapy treatment course. Now it is usually given as part of breast radiotherapy over 15 daily treatments. This study is looking to see if boost treatment can be given as part of breast radiotherapy over 5 days instead.

Why have I been asked to take part?

You have been asked to take part in this clinical trial because you need radiotherapy treatment that includes a boost. You can choose if you would like to take part or not.

It is important that people from lots of different backgrounds take part in clinical trials so that we can improve healthcare for everyone.

What will happen if I take part?

If you take part in this clinical trial, you will be put into one of three groups.

You will have either the usual 15 daily radiotherapy treatments (including the boost) or 5 daily radiotherapy treatments (including the boost).

We are investigating two slightly different boost doses so there are two groups having radiotherapy treatment over 5 days.

FAST-Forward Boost information leaflet IRAS ID 341881 v1.0, 08.06.2025

Boost radiotherapy over **15** days

Boost radiotherapy over **5** days

Boost radiotherapy over **5** days at a slightly different dose

People will be put into a group randomly, so that each person has an equal chance of being in one of these three groups (but a 2 in 3 chance of being allocated treatment over 5 days). We do this so that we can test whether the shorter treatments work in the same way as the longer treatment.

What will I need to do?

You will be asked to fill out a questionnaire about your health before your treatment, during your radiotherapy treatment and then 3 months later.

You will then be asked to complete a questionnaire every year for 5 years.

Your doctor will see you to check that your breast cancer has not returned 1 year after your radiotherapy treatment, and again at 3 years and 5 years.

How will this help?

We will compare findings in the groups that had radiotherapy over 5 days with those in the group that had radiotherapy over 15 days. This will mean that we can find out if all the treatments are as good as each other at stopping cancer from coming back. It also allows us to compare the side-effects of each treatment.

What happens next?

If you are interested in taking part in this clinical trial, there are more details in the longer information booklet.

You can contact us if you have questions about this study or your radiotherapy treatment

[insert local researcher name and contact details]

Thank you for reading this information sheet.

FAST-Forward Boost information leaflet IRAS ID 341881 v1.0, 08.06.2025

Results from NIHR Research Participant Voices Survey 2024/5

NIHR | National Institute for Health Research

The National Institute of Health Research conducts an annual national survey across England to understand the participant experience in health and care research. The results of the 2024/2025 survey were released on 16 October. There were 32,268 respondents (29,664 adults and 2,604 young

people). Those taking part in cancer studies accounted for the largest share of responses (16%, 5321). 91% of adults taking part in cancer studies, would consider taking part again, 94% felt that the information that they had received before taking part prepared them for their study experience, and 93% felt their contribution was valued by researchers. However, 32% said that they didn't receive enough updates during their participation journey and 30% didn't know how to access the results of their study. You can read more about the survey and the results here.

The findings are particularly informative given the Health Research Authority "#Make it Public" strategy. This initiative involves people and organisations across the community to improve transparency in health and social care research. It aims to simplify the process of making information public, make transparency easy and make it the norm.

Research transparency to become UK law in 2026

From 28 April 2026, the new Clinical Trials Regulations and Good Clinical Practice Standards will come into force. For the first time in the UK, it will be a legal requirement to:

- Register clinical trials involving medicines in a public registry
- Publish a summary of trial results within 12 months of completion
- Offer to share a summary of results with participants (or other relevant people) in a way that they can easily understand.

All ICR-CTSU trials are registered on public registries (such as the UK's Clinical Study Registry, ISCRTN, and the USA's National Institute for Health Clinical Trial Registry Clinical Trials.gov). The results of completed ICR-CTSU trials are also hosted on these registries, as well as on our website here with links to summaries. We will be prioritising our work on trial summaries and sharing results with research participants in 2026.

Please email ppi-icrctsu@icr.ac.uk if you have any questions or if you would like to be added to our mailing list!

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

View email in browser

The Institute of Cancer Research - Clinical Trials and Statistics Unit
32 Oakleaf Avenue · Sutton, SM2 5GP · United Kingdom

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