

The patient voice can shape our research. Is your voice being heard?

Did you know that as a patient, carer, family member or member of the wider community you could become involved in our cutting-edge cancer research?



What is patient and public involvement in research?

Patient and public involvement (PPI) is where patients, carers, family members and the community work with researchers to explore new or improved cancer treatments.

PPI is vital to our research at the Clinical Trials & Statistics Unit at The Institute of Cancer Research (ICR-CTSU), it provides valuable lived experience and opinions from a patient's perspective.

Why get involved in cancer research?

- To work with research teams to advance and improve the understanding and treatment of cancer.
- To use your lived experience of cancer treatment to improve how we do clinical trial research.
- To shape the quality of care for people with cancer in the future.
- To join the network of over 50 patients and carers who regularly work with us.

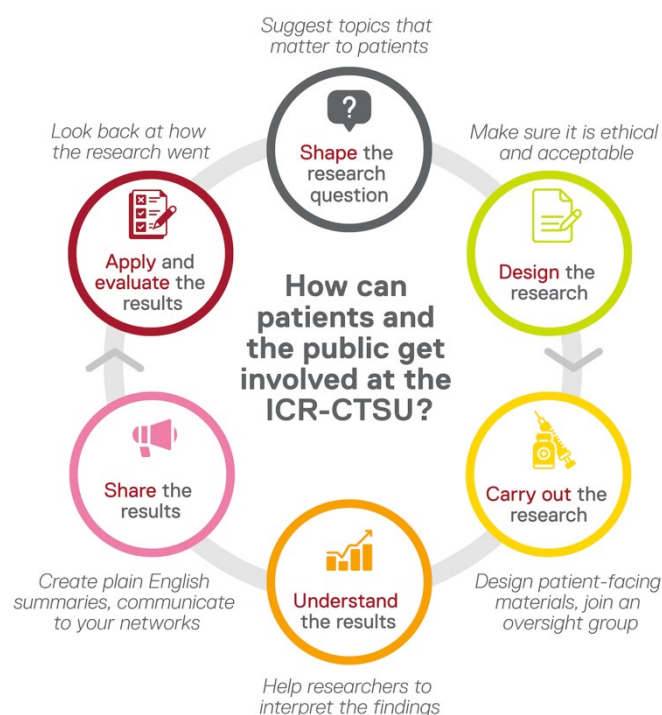


We would like your thoughts on our research

Your opinions and thoughts, whatever your background and experience, can help us develop new or better ways to treat cancer.

Your perspectives are valuable and can help design research that includes and benefits everyone who will receive future treatments. You can be involved as much or as little as you wish. For instance, you could join us for an online discussion when we are designing new research or become a patient advocate, advising us about a clinical trial over months and years. Everyone who helps us in these ways is offered reimbursement for their time and expenses.

When and how do we involve members of the public in our research?



What is a clinical trial?

A clinical trial checks whether new treatments are safe and effective. People taking part in trials should be representative of those affected by cancer in the wider population.

Clinical trials should be designed so that anyone can join them, as long as it is safe for them to do so.

How our patient and public advocates have improved research

Some examples of their work with the ICR-CTSU

A patient or public advocate helps make sure that patient perspectives and needs are considered. They may have had cancer themselves or be a carer or family member. They could also be a member of the public who represents people affected by cancer.

Deciding what's acceptable for patients



The [POETIC trial](#) was for people recently diagnosed with breast cancer. Taking part meant having multiple tumour biopsies before and after surgery.



Hospital teams were concerned that patients would find this unacceptable, as it could add stress at a difficult time.

Patient Advocates:



Persuaded the researchers and NHS staff that people should have the choice to donate the tumour biopsies for research.



Helped to create leaflets. These explain why the biopsies were needed and the risks involved, so that people could make their decision.

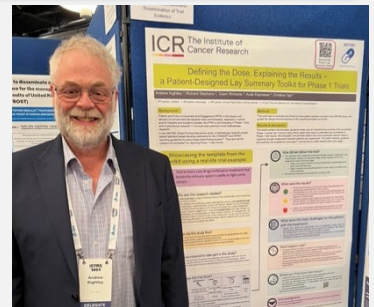
Thanks to this input, **over 4,400 people joined the POETIC trial**. The results showed that having the extra tumour biopsy meant many patients were able to have **better, more targeted treatment**.

Researchers are still learning from this valuable biopsy tissue and data collected within the trial. It also led to other trials adopting a similar approach.

You can read more about how patient advocates influenced this research [here](#).

Shaping the future of research communication

Andrew, one of our patient advocates, has been working with an international team to improve the way results of early-stage clinical trials are shared.



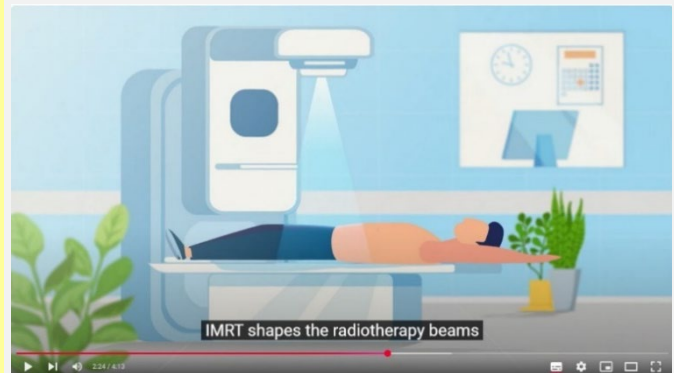
Early-stage trials involve giving a new treatment to people for the first time.

Andrew worked alongside other patient advocates. They developed a template to help researchers produce easy-to-understand summaries of the results of these clinical trials.

Creating videos to help explain research

Patient advocates have helped create videos that explain individual trials. The videos are shared with patients and their family and friends to support the written information they receive.

Patient advocates advise on the script and the look and feel of each video. They work with a professional video company to create short, easy to understand animations.



Below are links to videos about:

- [A prostate cancer trial called PEARLS](#)
- [A breast cancer trial called POETIC-A.](#)

Want to find out more?

If you would like to find out more about how you can be involved in our research, please visit our [website](#) or get in touch by email: ppi-icrctsu@icr.ac.uk

This leaflet was produced by the Clinical Trials and Statistics Unit at the Institute of Cancer Research (ICR-CTSU), Sutton in collaboration with patient advisors.