

Unite in the fight to beat cancer



Everyone can play a part in helping us find better treatments for cancer. The more people get involved the faster we will get there.

But we need to have representation from more groups of our diverse society (across age, gender, race, religion or disability).

This will bring a wider viewpoint to our research and help us to develop new treatments that are suitable for a wider range of patients.

How can I help?

What is public involvement in research?

Public involvement in research means **research that is done 'with' or 'by' the public, not 'to', 'about' or 'for' them.**

It means that patients or their carers will help researchers to design and carry out the research. It does not refer to patients taking part in a study.

Why do members of the public get involved in research?

- A desire to bring about change in the quality of care
- To try to improve treatment either for themselves or for others in the future
- A way to have a voice and influence the decisions which affect people's lives
- To shape research by 'giving something back'

Patient advocates are vital because they provide valuable opinions on our cancer research from the patient's perspective, ensuring our research best accounts for the needs of participants.

Why is public involvement in research so important?

- Identifying what research is important to the patient
- Influence how the research is carried out—will it be acceptable to patients?
- Improving the process of informed consent ie making the research easier for patient to understand
- Improving the communication of findings to patients and the wider public.

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

- As early as possible— i.e. during funding application or during the design of the study, to comment if the study design is acceptable from the perspective of the patient
- To be involved in shared decision making either by joining the Trial Management Group, a Focus group, or a Patient Advocate Group.

See next page for some frequently asked questions about public involvement in research.

"I became a patient advocate initially because I felt so grateful for the life-saving care and treatment I had received that I wanted to give something back, whatever that may be.

"The more involved I become, the more I see that having been through the 'process' of getting rid of cancer, I am in a good position to offer useful advice to the experts who may not appreciate what it looks like from the patient's point of view. I also feel my contribution is valued, which helps."

Want to find out more?

How to contact us

If you would like to find out more about how you can be involved in our research please email

The Institute of Cancer Research Clinical
Trials and Statistics Unit Patient and Public
Involvement Group

ppi-icrctsu@icr.ac.uk

Useful Links

NCRI Consumer Forum

A group of people affected by cancer participating in, and providing input to, the work of the National Cancer Research Institute.

www.ncri.org.uk/patient-and-public-involvement

The patient voice can shape our research.

Is your voice being heard?

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

Frequently Asked Questions

Will I receive guidance in my role?

Yes. We provide training for patient advocates so that they can get the most out of their contribution.

Can I speak to other patient advocates before I decide to contribute?

Yes. We can arrange this at a time to suit you.

What if I decide it is not for me?

You can choose how you would like to take part and how much you would like to contribute.

You can change your mind at any time.

Will I be reimbursed for my expenses?

The level of reimbursement will vary according to your contribution but all patient advocates should receive reimbursement for their participation.

Is it possible for me to contribute if I cannot attend meetings?

YES. You can join a virtual meeting and/or be contacted by email.