

Patient & Public Involvement (PPI) opportunities across the NCRI Partnership



NCRI Partners

NCRI is a UK-wide partnership between research funders working together to maximise the value and benefits of cancer research for the benefit of patients and the public. A key strength of the NCRI is our broad membership with representation across both charity and government funders as well as across all four nations in the United Kingdom.



1. National Cancer Research Institute (NCRI)

Our work to advance cancer research puts cancer patients and carers at its heart, by inviting patients, carers and others affected by cancer (also known as '[consumers](#)') to participate in all aspects of our work.

All NCRI activities have direct input from patients and carers, who are experts in the experience of cancer. Patients and carers shape actions at the national level as part of an [NCRI Group](#), or as part of our [pathology](#) or [radiotherapy](#) initiatives. Patients and carers are also represented on the [Strategy Advisory Group](#) and NCRI's [Board of Trustees](#), contributing to setting NCRI's strategy and governance.

If you have been affected by cancer and have a strong interest in cancer research, you could help shape its development through the work of NCRI. We are committed to increasing the diversity of our consumer representation and encourage individuals based throughout the UK, from all ethnic groups, all age groups, and from people with experience of all kinds of cancer, become involved in cancer research.

Vacancies for consumer membership of NCRI Groups and initiatives are advertised on the [jobs and opportunities](#) page. If there are not currently any consumer vacancies, you are encouraged to register your interest: <https://www.ncri.org.uk/get-involved-consumers/>

For any general queries, or to find out more please email consumers@ncri.org.uk

2. Brain Tumour Research

We involve patients and their families in our campaigning work, which strives to increase national investment in brain tumour research and improve options and outcomes for brain tumour patients. To this end we undertake surveys, start petitions, write case studies and encourage patient attendance at meetings of the All Party Parliamentary Group on brain tumours – for whom we provide the secretariat.

We work with patients and carers to share their case studies with the media, to grow awareness of the disease and the research that is being undertaken at our Centres.

We have a patient advocate on [our Scientific and Medical Advisory Board](#) and they are part of the panel when we review the partnerships at these Centres.

As research at our Centres develops, we will engage a network of patients and carers to inform this research, and to support applications for NIHR and other funding.

We keenly encourage our supporters to meet with the researchers they fundraise for at supporter events, and they can also join [lab tours at our research centres](#) where they can provide challenge, and a new perspective for the scientists to consider.

3. Breast Cancer Now

Breast Cancer Now has two insight and involvement networks and works with patient representatives across our organisation to make sure we keep people affected by breast cancer at the heart of everything we do. Our two insight and involvement networks are made up of people whose lives have been changed by breast cancer, who want to help shape and improve our work.

These include:

- **Breast Cancer Voices:** a quarterly email newsletter with opportunities to use your experience to get involved in campaigning, media, surveys, patient panels, and fundraising
- **Insight and Experience Panel:** a more ad hoc way for us to contact you about ways you can use your experience to shape our work and contribute to the wider field of breast cancer

The opportunities we share through both networks may take the form of surveys, invites to focus groups, or reviewing and 'testing' materials across any areas of our work, from campaigns, services and policy to corporate partnerships, fundraising and research.

You don't have to comment on every piece of work we do – just let us know if and when you want to get involved. You can read about [Clover's experience of being a Patient Advocate](#), and [Lin's story of why she gets involved](#) with the Insight Panel in their blogs.

Whether you've been diagnosed, or somebody close to you has, your feedback and involvement will help to ensure we're acting on the issues most important to those affected by breast cancer. If you are interested in joining one of our insight and involvement networks, you can find out more and register here: [Breast Cancer Voices sign-up](#) [Insight and Experience Panel sign-up](#)

We also have several patient representatives sitting on our funding and advisory committees – for example our Science Strategy Committee. You can read about the [impact of patient representation](#) on the committee in our blog, or [hear first-hand from our patient representative](#), Anna.

Although we do not have any current vacancies, if you would be interested in any future opportunities that arise please get in contact with Eleanor at Eleanor.garrattsmith@breastcancer.org, or join one of our networks above.

4. Cancer Research UK (CRUK)

At Cancer Research UK, we actively involve people affected by cancer in our work. Your Involvement Network at Cancer Research UK is a group of people from across the UK who want to make a real difference to the lives of other people facing cancer, now and in the future. Whether as a patient, carer or as a loved one, they share their experiences of diagnosis, treatment and care through a range of involvement opportunities. The insight they provide shapes our work as it develops, helping us to better meet the needs of people affected by cancer.

We try to ensure that our opportunities are accessible to everyone and offer support to members when they get involved. You'll be sent our bi-weekly newsletter which lists all the latest opportunities to get involved. You'll also get regular updates on the work people have already been involved with. You don't need to have taken part in involvement opportunities before joining the network or getting involved. Your experience of cancer, and your general experience can add real value to our work from your very first activity.

To find ways that suit you and to use your experience of cancer to make a real difference please visit our web pages <https://www.cancerresearchuk.org/get-involved/volunteer/patient-involvement>

5. National Institute for Health Research (NIHR) *(funded by Dept. of Health & Social Care)*

Patients, carers and the public can get involved with NIHR research. Visit the '[I want to help with research](#)' pages on NIHR.ac.uk to find out how you can:

- [suggest a research question](#)
- [give your opinion on potential research](#)
- [join one of our decision-making committees](#)
- [become a public Research Champion.](#)

Members of the public interested in working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking

research with research participants can find opportunities on [People in Research](#).

Patient Organisations with an interest in working with the life sciences industry, and who could contribute to the recruitment of patients to help shape and improve the design and delivery of commercial clinical research, can sign up to the [Patient Engagement in Clinical Development Service](#).

6. Health & Care Research Wales

Health and Care Research Wales has a dedicated team who help support the public to get involved in all health and social care research. They also support researchers or health and social care professionals to involve the public throughout the whole research cycle from the development of a research idea through to the dissemination of research finding. All information can be found under the public tab of the Health and Care Research Wales website <https://healthandcareresearchwales.org/>

The team provide:

- [Information and resources](#)
- Advertisements on the website and on social media for [opportunities](#) to get involved in research
- [Registration](#) to join a research involvement community
- Training and guidance
- Communication channels including weekly bulletins

7. HSC Public Health Agency

In Northern Ireland, patients and public can find out more about involvement in research on the PPI pages of the HSC R&D website <http://www.research.hscni.net>. This includes information about the role of its public panel, 'Public Involvement Enhancing Research', (PIER), NI.

People with a specific interest in involvement in Cancer Research, can join the NI Cancer Research Consumer Forum (NICRCF). <http://www.nicrn.hscni.net/information-for-patients-public/>

People can also express an interest in 'Being Part of Research' by becoming a member of the Patient Client Council's membership scheme www.patientclientcouncil.hscni.net

More general opportunities for involvement in HSC services are advertised on www.engage.hscni.net

8. Marie Curie

The Marie Curie Research Voices is a group of individuals who have personal experiences of living with terminal illness. The group supports research activities across the charity in a number of ways including by providing their opinion on research proposals, talking about research at external events or conferences (currently virtually), and helping the team to plan workshops. Opportunities for involvement and input are also sent to the Marie Curie Research Voices Group and these may include requests to review lay summaries, and requests to join suitable advisory groups for a research project. Members are able to choose which opportunities they respond to and can be as involved as they would like/suits their current circumstances. We also make sure to send opportunities for webinars that might be of interest. To find out more about the Marie Curie Research Voices please click [here](#), and/or email research.info@mariecurie.org.uk

9. Prostate Cancer UK

Our Patient Representative Network (PRN) supports the research community by offering advice and involvement of people who have direct experience of prostate cancer. The PRN partakes in building, critiquing and improving research applications and representing the views of people living with prostate cancer within the development and management of research projects.

We also have Patient and Public Involvement (PPI) representatives that sit on our [Research Advisory Committee](#) (RAC). The RAC considers research proposals submitted to the charity for funding and make recommendations as to which applications should be funded by Prostate Cancer UK. The purpose of the PPI representatives is to ensure that the voice of the patient is central to the discussions and recommendations of the clinical studies proposed for funding. Find out more about our involvement opportunities [here](#).

10. Prostate Cancer Research

We are committed to ensuring our work and research is informed by the people it matters most to – people affected by prostate cancer.

In particular, it is crucial that we involve and work with patients at every stage of the research process. There are many ways for you to get involved, from helping us decide what research we fund, to reviewing our communications, to sharing your story.

No specialist knowledge, medical or otherwise, is required to take part in any of our Patient Voice activities. This is an opportunity for those affected by prostate cancer to use their own experiences to help us help other people and families who will be affected by the disease.

If you would be interested in taking part in Patient Voice, please visit our website www.pcr.org.uk/patient-voice to find out more.

11. Tenovus Cancer Care

Our Research Advisory Group (RAG), formed in 2011, is made up from people affected by cancer who review and make decisions regarding our community-based iGrant scheme. Though supported through scientific peer review, the panel ultimately make the call as to who is funded with the central question, “how does this research benefit the person affected by cancer?” central to any decision making. Unfortunately, due to the COVID pandemic, we are unable to make funding calls for the foreseeable future. However, we are working on some great ideas to involve patients and the public in new opportunities, running throughout the charity, which we will be announcing shortly.

We also have a Research Network with a strong cohort of approximately 500 members. This is a group who receive information regarding research with opportunities to get involved in ongoing research projects. This might include chances to be participants in the research, but also opportunities to be involved in activities as patient/public representatives. For example, this could include checking information sheets, giving advice on research questions, discussing the potential impact of selected data collection methods or assisting to disseminate findings. We have very recently launched a page on our website which provides up to date opportunities. If you are a patient, member of the public or researcher who wants to know more please take a look [here](#) or contact us on research@tenovuscancercare.org.uk

12. Pancreatic Cancer UK

Our Research Involvement Network is a group of over 170 people who each have a personal connection to pancreatic cancer, through being patients, carers, loved ones and survivors. The group has a diverse range of views and experiences and can provide researchers with insights that inform and shape their work, as well as help Pancreatic Cancer UK to determine which research we should support with the funds raised by our supporters. In a nutshell, members are welcome to opt-in to as many or as few opportunities to comment and review research from their own perspective. Opportunities come out in a monthly bulletin and range from feeding into the development of patient information sheets, sitting on trial

steering committees, reviewing funding applications and attending virtual focus groups. Find out more about joining the network [here](#).

If you have any queries about any of the information included in this booklet, please feel free to get in touch by emailing consumers@ncri.org.uk



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