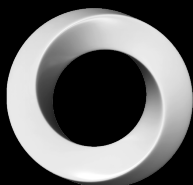


**CANCER
GRAND
CHALLENGES**



Patient Advocate Involvement and Engagement

**Additional information for applicant
teams**

Founded by



**CANCER
RESEARCH
UK**



**NATIONAL
CANCER
INSTITUTE**



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1. Introduction

Cancer Research UK and the National Cancer Institute (NCI) are the founding partners of Cancer Grand Challenges. We have a shared mission to improve health outcomes for cancer patients and the public. We think it is essential to involve in Cancer Grand Challenges those who we want to benefit from our work. Our international, interdisciplinary and team-focused approach to research allows involvement and engagement to be conducted at an unprecedented scale. Cancer Grand Challenges also provides a unique opportunity to continue to pioneer innovative and novel ways to embed people who have been affected by cancer in research, referred to as **patient advocates** from this point forward.

With this in mind, we ask you to think about patient advocate involvement and engagement before you start your application. We have provided more detailed information about patient advocate involvement and engagement and our expectations, below. Please note, this document was developed in partnership with the Cancer Grand Challenges Advocacy Panel (CGCAP) and should be read alongside the main Expression of Interest (EOI) guidelines. If your team is shortlisted and asked to submit a full application by the Cancer Grand Challenges Scientific Committee, you will receive advice and feedback from the CGCAP about your initial patient advocate involvement and engagement plans.

1.1. What are involvement and engagement?

Before starting your EOI we encourage you to learn more about patient advocate involvement and engagement.

Patient advocates provide a unique perspective due to their experience of cancer. They have either faced a cancer diagnosis, had a friend or loved one who has been affected by cancer, and/or have cared for a cancer patient.

Involvement is when patient advocates use their experiences of cancer to help shape research. Involvement is carried out **with** or **by** patient advocates, rather than **to** or **for** them. Involvement enables patient advocates to have a voice that is listened to and reflected in the scientific strategy. This helps to ensure that all research, whether basic or translational, remains focused on patient benefit.



Patient advocates can be involved in research in many ways, including the:

- Development of research questions;
- Design of the research approach;
- Dissemination of research findings.

For example, this may be achieved through:

- Membership of the Management Group that drives the strategic direction of a research programme and/or other groups that oversee the day-to-day progress of each work package;
- Involvement in the design of patient-facing documents such as tissue consent forms and the development of engagement materials to update other patient advocates and the public about the research programme.

Engagement is where information and knowledge about research is shared by researchers or patient advocates with other patient advocates and the public who are not associated with their research programme. The design and delivery of engagement activities provides an opportunity to involve patient advocates.

This can be achieved through the:

- Generation of plain language summaries that can be disseminated through a variety of channels. That includes newsletters, blogs, dedicated websites and social media;
- Hosting of virtual or in-person events such as workshops, seminars, lab tours or open days at research sites.

And there should always be opportunities for those being engaged to ask questions.

It is important not to confuse **involvement** and **engagement** with **participation**. Participation is where a person is part of a research study by providing a sample or takes part in a clinical study or trial but does not work directly with the researcher. The research is being done **to** them, not **with** them.



2. Our guide to involvement and engagement

You must provide a 300-word patient advocate involvement and engagement section as part of your EOI. Please consider consulting patient advocates for this section. We do not require you to have recruited patient advocates to your team at this stage, but you are welcome to do so if you identify patient advocates with the appropriate skills and experiences.

We have listed below areas you might want to consider while drafting your application:

- How you will **involve** patient advocates and **engage** the broader advocacy community and public with your research;
- How these patient advocates will **add value** to your scientific programme. There are no mandatory activities that should be listed;
- Whether your **scientific leadership** has **prior experience** of involvement and engagement, and, if not, how you can learn best practice from others;
- When **recruiting** patient advocates
 - Whether it would be useful to have patient advocates based in **different countries**. Their location may align with where clinical samples are being collected or where members of your research team are based;
 - How you will ensure that you recruit patient advocates from a **diverse range of backgrounds**;

Note that if you are successful at the EOI stage, the full application will include a more detailed advocacy plan, which the office and CGCAP will support you to develop.

2.1. Involvement and engagement resources

This section includes a selection of resources that you may find useful, as recommended by the CGCAP. But this is not exhaustive and there are more available online. You should also contact the relevant office at your institution to utilise the local resources that may be available and to confirm with them any requirements they may have around recruiting patient advocates to your team.

Resource	Description
CRUK's Patient Involvement Toolkit for Researchers	CRUK is the world's largest cancer charity dedicated to saving lives through research. CRUK's vision is to bring forward the day when all cancers are cured, from the most common types to those that affect just a few people. The toolkit provides guidance, tips and templates to help you plan, deliver and evaluate patient advocate involvement. It also includes several case studies that outline how researchers have successfully involved patient advocates in research.



Resource	Description
NCI's Guide to Creating a Culture of Advocate Engagement	The NCI is the US federal government's principal agency for cancer research and training. They have an Office of Advocacy Relations (OAR) which is their principal conduit for engaging the cancer advocacy community. OAR works with the entire cancer advocacy community – from individual research advocates to national advocacy organisations and foundations – to create a culture of advocate engagement at the NCI. This overview provides researchers looking to conduct involvement tips on how to support the right culture as a starting point for working with patient advocates. Although referred to as advocate engagement this is equivalent to patient advocate involvement as described in this document.
European Patients' Academy on Therapeutic Innovation (EUPATI) Guidance Documents	EUPATI's core focus is on the provision of training for patient advocates on the end-to-end process of medicine research and development. They provide guidance on patient advocate involvement that, although targeted towards regulatory agencies, health technology assessment (HTA) bodies, ethics committees and the pharmaceutical industry, is still relevant in the academic research setting. Their toolkit is available in several languages and may be of particular use for teams involving commercial Co-Investigators.
Health and Care Research Wales' Tools and Templates for Public Involvement	Health and Care Research Wales is a networked organisation, supported by Welsh Government, which brings together a wide range of partners across the NHS in Wales, universities and research institutions, local authorities, and others. They provide a number of resources around how to involve the public in research that are also applicable when looking to involve people affected by cancer as patient advocates.
Patient and Public Involvement Toolkit	Julia Cartwright and Sally Crowe's book provides information on how to implement patient advocate involvement. It includes real case scenarios to illustrate the principles of effective approaches, especially when working face-to-face with patient advocates.
Patient-Centred Outcomes Research Institute (PCORI) Engagement Tool and Resource Repository	PCORI, based in the US, was established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information. They provide tools and resources on patient advocate engagement developed and used by PCORI awardees.
Patient Involvement for The Life Sciences	Guy Yeoman and Mitchell Silva's book provides an industry perspective. Described as a practical involvement handbook for anyone striving to incorporate patient value in the delivery of medicines from research and development into a practical healthcare setting. This provides a tangible framework for how this can be achieved with and for patients.



Resource	Description
Journal of Research Involvement and Engagement	An interdisciplinary, open-access health and social care journal focusing on patient advocate and wider involvement and engagement in research, at all stages. The journal is co-produced by all stakeholders, including patient advocates, academics, policy makers and service users.
National Institute for Health Research (NIHR) UK Standards for Public Involvement in Research	NIHR is the largest funder of health and care research in the UK. As part of a UK-wide partnership they developed a set of UK Standard for Public Involvement in Research. The six standards are designed to improve the quality and consistency of involvement in research. Although UK standards, many are transferable internationally.

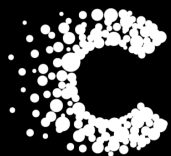
3. Contact us

For more information, please contact Andrea Delgado Garcia, Cancer Grand Challenges patient advocacy manager:

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