Guide to Grand Challenge
Public and Patient Involvement

These guidelines were developed in partnership with the Grand Challenge Patient Advisory Panel.

Jump to...
INTRODUCTION ......................................................................................................................... 2
1.1 Public and Patient Involvement at Cancer Research UK ......................................................... 2
1.2 Definition of Public and Patient Involvement ............................................................................ 2
1.3 Public and Patient Involvement in the Grand Challenge .......................................................... 3
1.4 Expectations for Public and Patient Involvement and Engagement in applications ............ 3
GUIDANCE ............................................................................................................................................ 4
1.5 Use of the Patient Advisory Panel .......................................................................................... 4
1.6 Use of Cancer Research UK’s Patient Involvement and Communications Team ................. 4
1.7 Writing about involvement and engagement ......................................................................... 4
RESOURCES ....................................................................................................................................... 5
1.8 Recruitment ................................................................................................................................. 6
1.9 Budgets and Costs ..................................................................................................................... 6

For queries related to Public and Patient Involvement in your application please contact Involvement@cancer.org.uk including ‘Grand Challenge’ in the subject line.
INTRODUCTION
This document is intended to support you in completing the public and patient involvement/engagement sections of your funding application. It contains additional information and resources and can be used alongside the Grand Challenge Funding Guidance.

If, after reading this, you have questions about how to answer the public and patient involvement and engagement (PPI/PPE) sections of your application please contact involvement@cancer.org.uk including “Grand Challenge” in the subject line.

Public and Patient Involvement at Cancer Research UK
Cancer Research UK is committed to developing and supporting meaningful and high quality public and patient involvement, where it adds value and benefit across the work of the charity. We firmly believe that people affected by cancer have valuable insight to offer through their personal experiences of cancer and that by working in partnership with them we can achieve our ambition of bringing forward the day when all cancers are cured sooner.

From working with us to develop our health and patient information, consulting on our policies and strategies, participating in our research funding committees and co-delivering training for staff and researchers we have found that involving people affected by cancer provides us with invaluable insights that will help us accelerate our progress.

We are increasing our focus on PPI/PPE in research and require all applicants to the Grand Challenge award to complete the PPI/PPE sections of the application form.

Definition of Public and Patient Involvement
We differentiate between participation, engagement, and involvement in research. Participation in research is not the same as involvement in research and, whilst we recognise the value that engagement activities have, we encourage you to move beyond engagement and to build involvement opportunities throughout your research.

Participation: Taking part in research as the object of study. A person affected by cancer may be the subject of research but does not work with the researcher.

Engagement: An opportunity for two-way interaction between researchers and the public aimed at increasing public understanding of research. This could include, but is not limited to, researchers hosting lab tours, holding open days at research sites, and providing lay-friendly information about research using newsletters/blogs. There should be opportunities for the public/patients being engaged to ask questions.
Involvement: INVOLVE, a national advisory group for public involvement in research, describe ‘patient and public involvement’ as an active partnership between patients, members of the public and researchers in the research process. This could include, but is not limited to, involvement in the development of research question, planning/design of research, recruitment, monitoring progress, evaluation and/or dissemination of research findings, offering advice as members of a project steering group, commenting on and developing research materials.

Public and Patient Involvement in the Grand Challenge

People affected by cancer have been at the core of the Grand Challenge from its conception. This is because we believe that high quality PPI will ensure that patient benefit is always at the heart of the Grand Challenge, keeping research grounded in the needs of patients and ensuring that all our work has a clear and significant benefit for patients.

The seven Grand Challenges, and our Grand Challenge PPI strategy, were developed in collaboration with people affected by cancer. This includes the creation of our Grand Challenge Patient Advisory Panel, who have worked in partnership with us to develop the involvement and engagement questions in your research application, create these guidelines, and will be responsible for reviewing and giving feedback on the involvement and engagement sections of your funding application.

Grand Challenge awards are the most ambitious cancer research grants in the world. We want to see the innovative spirit of the Grand Challenge carried through to the patient involvement plans within your funding proposal. We encourage all applying teams to design and trial new ways of working with people affected by cancer in order that a new benchmark for public and patient involvement can be set.

Expectations for Public and Patient Involvement and Engagement in applications

Please refer to the Funding Guidance for information outlining the expectations for public and patient involvement in Grand Challenge applications. The document outlines the minimum requirements around public and patient involvement and engagement, as well as details about how this information will be assessed.
GUIDANCE
You should use the following guidance to support you to develop your public and patient involvement and engagement plans.

Use of the Patient Advisory Panel
You will have received feedback about your initial PPI plans from the Patient Advisory Panel; this feedback contained questions and suggestions to support you in building PPI/PPE into your application.

- In your full application you should evidence that those comments/suggestions/questions received following review of your expression of interest have been addressed.

- You will have the opportunity to consult the Grand Challenge Patient Advisory Panel during the build phase. This check point can be used by your team to gain feedback on your proposed involvement/engagement plans; to ask questions around involvement/engagement methods; to seek advice on additional involvement/engagement opportunities that there may be for your area of research. Teams should submit questions 2 weeks in advance of meeting and where questions are generic, the responses will be compiled to create a FAQ document for the Grand Challenge website.

Use of Cancer Research UK’s Patient Involvement and Communications Team
You are able to seek support from Cancer Research UK’s Patient Involvement and Communications Team at any point during the build phase of your application. This team are able to advise you on recruitment of people affected by cancer and may be able to advertise opportunities for people affected by cancer to be involved in your application development/future involvement activities through Cancer Research UK’s Involvement Network.

The Patient Involvement and Communications Team are able to give you further advice around payments and expenses for involvement in accordance with the relevant Cancer Research UK policies.

Writing about involvement and engagement
We do not mandate specific involvement or engagement activities; however you may like to address the following prompt questions when writing about your involvement and engagement plans in your application.
You are not required to follow this format, or to address all of these questions in your application.

- What is the proposed involvement/engagement activity?
- What is the rationale for the involvement/engagement activity?
- What number of people will you aim to recruit to the engagement/involvement activity?
- How do you propose to recruit to the engagement/involvement activity?
- How will you support those who you involve in your research?
- What is the proposed budget required for your engagement/involvement activity?
- How has public and patient involvement impacted on the development of your application/study design?
- How could involvement be used to support the dissemination of your research?

RESOURCES
The following links provide you with a range of involvement resources. This is not an exhaustive list.

**INOLVE Briefing notes for researchers:** contains information on how to involve members of the public in research, case studies, and template documents such as terms of reference for steering groups.

**NIHR Research Design Service:** can offer application specific support and advice on appropriate public and patient involvement methods.
[http://www.rds-london.nihr.ac.uk/Patient-Public-Involvement.aspx](http://www.rds-london.nihr.ac.uk/Patient-Public-Involvement.aspx)
[http://www.rds-sc.nihr.ac.uk/public-patient-involvement/the-research-process/](http://www.rds-sc.nihr.ac.uk/public-patient-involvement/the-research-process/)

**Healthtalk.org:** host a series of videos which include patient experiences of public and patient involvement. There are also a range of resources around involvement methods and information around barriers to involvement which you may want to consider when planning your involvement activities.
Recruitment
Below are some options to support you in recruiting people affected by cancer to be involved in your research. It is important to ensure that the people you involve understand their roles and responsibilities and what they can expect from the research team in way of support.

**Cancer Research UK’s Involvement Network:** Our Involvement Network is a group of people affected by cancer who have expressed an interest in being involved in the research policy, an information work of Cancer Research UK. **We advertise external opportunities to our network on a case by case basis and Grand Challenge teams** may be able to advertise your involvement opportunities to this network in our monthly Involvement Network newsletter or more broadly on the CRUK website. Please contact the Patient Involvement and Communications team when planning your involvement for advice on this. We are also able to provide templates for role descriptions/terms of reference, and examples of briefing documents. Contact: involvement@cancer.org.uk and include “Grand Challenge” in the subject heading.

**People In Research:** can be used to advertise involvement opportunities and recruit people. [http://www.peopleinresearch.org/](http://www.peopleinresearch.org/)

**NCRI Consumer Liaison Forum:** Many forum members also act as patient representatives in their local area or for other national bodies such as the Department of Health or Public Health England. Contact: consumer@ncri.org.uk

**Budgets and Costs**
It is important not to under-estimate costs when budgeting for involvement activities.

**Cancer Research UK:** have an internal Reward and Recognition policy which outlines recommended payments for people who are involved in our work. If you would like to know more about this policy in order to apply any of the principles to your proposal please contact: involvement@cancer.org.uk including “Grand Challenge” in the subject heading.