

Patient and Public Involvement (PPI) Resources & Guidance for Researchers

Background

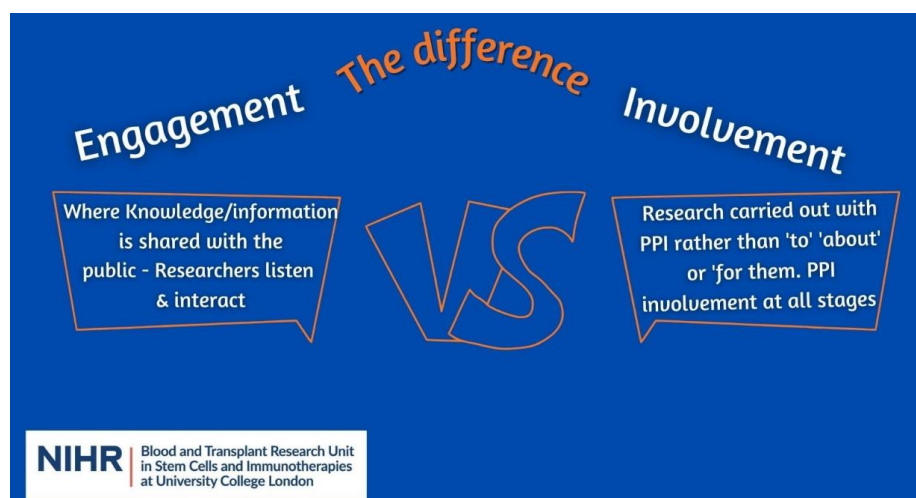
We recently introduced some questions into our grant funding rounds about the **involvement** and **engagement** of people affected by blood cancer in the application and subsequent research being requested for funding. This might be in terms of shaping the research proposal, engaging or involving people within or throughout the research, or post completion of the research.

Blood Cancer UK is a charity predominantly supported through public donations from individuals affected by blood cancer and we want to ensure all research we fund matters most to people affected by blood cancer, through their involvement in the work. Ideally this would be **true involvement**, from the start of the project but we know this isn't possible in all cases and so we want to support researchers in getting closer to this.

PPI does not refer to the recruitment of patients or members of the public as participants in the trial or study. At present, if there are no plans for active research involvement or public engagement, applicants are asked to please explain why.

You are encouraged to investigate and include PPI in your proposal/ project. We understand that developing meaningful PPI in **basic scientific** research can sometimes be challenging. As a result of the challenges, in this document we have collated some resources to help researchers consider this further. Please note, we may ask you to further develop PPI plans before funding is awarded.

The difference between engagement and involvement



There are some key differences between engagement and involvement. Engagement is where knowledge/ information is shared with the public, researchers listen and interact with the public, vs.



involvement is where research is carried out with patient/ public representatives rather than 'to', 'about' or 'for them'. The term involvement refers to an active partnership between patients, members of the public and researchers in the research process. For example, holding a talk for the public to hear about the outputs of a piece of research is 'engagement' and **not** involvement. While we appreciate true involvement may not be possible for all projects, **as a minimum we would expect researchers to involve someone affected by blood cancer in writing of the Plain English summary**, with other ideas detailed below.

Ways you can '**engage**' people affected by blood cancer in your work include:

- Science festivals open to the public with debates and discussions on research
- Open day at a research center or institute where members of the public are invited to find out about the research
- Raising awareness of the research through media such as social media (e.g. Twitter feed)
- Dissemination to research participants, colleagues or members of the public on the findings of a study.

Ways you can '**involve**' people affected by blood cancer in your work include:

- Involving someone affected by blood cancer in the writing and review of the plain English section of the application
- Involvement in identifying research priorities or choice of research topics
- Assisting in carrying out the research (e.g. serving on a 'Steering Committee')
- Asking people affected by blood cancer to feedback on your presentation/ social media content/ video... etc, and work with them to improve these so they can be understood better by these individuals.
- Set up a discussion group for the research project proposed
- Case studies can be found here: <https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/case-studies>
- For clinical research:
 - o Commenting and developing patient information leaflets, consent forms or other research materials for a clinical study
 - o Advising on practical aspects of the study (e.g. checking that the practical arrangements for participants are appropriate and that participation in the study is not overly burdensome)
 - o Undertaking interviews with research participants



Key Resources – for all research

Resource	Description
Briefing notes for researchers - public involvement in NHS, health and social care research	A briefing note for researchers: public involvement in NHS, public health and social care research. Produced by INVOLVE, who were a national advisory body funded by the NIHR to support public involvement in NHS, public health, and social care research.
Why involve members of the public in research?	A briefing note covering why to involve members of the public in research.
INVOLVE top tips when planning and delivering your involvement	For some top tips on ‘What makes good public involvement in research?’ here is a 2 page PDF .
A practical guide to patient and public involvement in lab-based research	<p>This resource was developed by UCLH BRC, Alzheimer’s Society and Parkinson’s UK, in partnership with patients and researchers. It offers a practical guidance about how to involve patients and the public in laboratory based research.</p> <p>A lot of guidance has been written about how to actively involve patients and the public in clinical research, and evidence is growing about the value of this. But there’s very little that is specifically aimed at researchers who work mainly in a laboratory, with very little or no contact with people affected by the condition they are studying.</p> <p>On this website there is a specific section on planning involvement, which may be helpful in considering where it will be most relevant to involvement people and help you to shape your application.</p>
UK Standards for Public Involvement	<p>The UK standards for Public Involvement are:</p> <ul style="list-style-type: none">– A framework for what good public involvement in research looks like and are adaptable to different situations;– Designed to encourage reflection and learning, including where lessons have been learned when public involvement has failed to lead to expected outcomes;– A tool to help people and organisations identify what they are doing well, and what needs improving;– Intended to be used with any method or approach to public involvement in research. <p>A summary of the standards can be found here.</p>
People in Research - sharing your opportunity	<p>A resource to help members of the public find opportunities to get involved in research and for research organisations/researchers to advertise involvement opportunities.</p> <p>If you want people to be involved in your research, then it might be worth sharing the involvement opportunity here.</p>



Cancer Research UK Patient involvement toolkit for researchers	This toolkit provides guidance, tips and templates to help you plan, deliver and evaluate your patient involvement.
ACCELERATE webpage for 'Involving patients and the public in research'	An example from UCL, Engaging patients, public & healthcare professionals in translational research. ACCELERATE has collaborated with UCL Public Engagement, Patient and Public Research Panel Members from the NIHR Blood and Transplant Research Unit, and UCL researchers to develop resources to support you in engaging patients and the public in your translational research projects
Advice on staying connected with Participants	Parkinson's UK found that 80% of respondents to a survey would be more likely to take part in future studies if they received updates from the researchers. This resource provides a series of templates to make communicating with participants easier.
A Field Guide to Public Engagement and Culture Change (example from University of Bath)	The authors hope the guide will prove useful as you navigate and find your way through the process of creating a positive culture of public engagement with research at your university. This resource is likely to be most useful for individuals who want to embed a change what happens at your university. Lessons learned by Bath University in their quest for this, can be found from p38 onwards.
Who should I involve in my research and why? Patients, carers or the public?	An interesting article about who to involve in research and the definitions of patients, carers and the public. A fairly broad article.

Key Resources – for clinical research

Clinical research lends itself to good PPI, although please be reminded PPI does not refer to the recruitment of patients or members of the public as participants in the trial or study.

Resource	Description
Trial Steering Committees (TSCs) / Study Steering Committees (SSCs) Guidance	NIHR's good practice guidelines on the recruitment and involvement of public members on Trial Steering Committees (TSCs) / Study Steering Committees (SSCs). This guidance is for use by researchers, public members and TSC/SSC chairs and members. It provides definitions of research oversight groups including TSC/SSCs, describes the public member role and expectations and outlines good practice for recruitment and involvement of public members on TSC/SSCs.
Trial Forge – the include ethnicity framework	Trial teams need to do everything possible to make their trial relevant to the people for whom the results are intended to apply (often patients) and those expected to apply them (often healthcare professionals).

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	The INCLUDE Ethnicity Framework aims to help trial teams think carefully about which ethnic groups should be included in their trial for its results to be widely applicable, and what challenges there may be to making this possible.
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Key Resources - for 'health data' research

Involving people in 'big data research' is in its infancy, and while we are aware of many resource currently being developed, not many have been published for wider use. Below are some useful links to organisations currently having developed/ developing resources.

Please note: we will continue to review this and update you as such resources are released.

Resource	Description
<u>Crohn's & Colitis Patient and Public Involvement Training in Health Data Research</u>	<p>This training was developed to increase or refresh knowledge, skills and confidence for a patient and public involvement (PPI) representative in Health Data Research and was developed by Crohn's & Colitis UK, Gut Reaction and PPI representatives working in partnership.</p> <p>Although not 'blood cancer specific' this training still provides some material on 'health data research'.</p>
<u>Use MY data</u>	<p>Use MY data began in 2015 at the National Cancer Intelligence Network conference, in Belfast, in response to concerns about how the proposed Care.data programme was causing cancer research to stop and their vision is of "every patient willingly giving their data to help others".</p> <p>Its focus was on how current cancer patients could help turn their data into the best outcomes for future cancer patients. 'Donate your data' was proposed – an organisation where patients would willingly give their data for this purpose.</p> <p>Amongst other things, they host patient data workshops for patients and the public and support organisations who want to collect, store and use patient data for patient benefit, on topics such as consent, audit of clinical practice, security and privacy.</p>
<u>Health Data Research UK (HDRUK)</u>	HDRUK are currently developing a suite of training videos for patient's representatives that will be available online for access by members of the public.
<u>Understanding Patient Data</u>	While no longer funded, 'Understanding Patient Data' give some examples of good practice, tip, and links to useful resources, to support teams thinking about public and patient engagement work that focuses on the way health data is used.



Advice from our Patient Voice Grant Advisory Network

The Patient Voice Grant Advisory Panel are a group of people affected by blood cancer who provide written reviews of each application submitted to Blood Cancer UK for funding.

Two/ three members of the group also represent the feedback from the group as a whole at the [Research Funding Committee](#) meeting or at the relevant governance channel.

They would like to share the following advice with researchers:

Relevance of the work	<p>"We're excited about your research and its potential to help current and future patients. We can help you to amplify your efforts! As well as getting input upfront, also think about how you can keep the broader blood cancer community informed about your projects over its lifetime. Are there obvious project milestones when you could feedback TO blood cancer patients, or seek further input FROM them or do project updates WITH them?"</p> <p>"As a member of the patient review panel, I want to try and understand how transferable the outcome and learnings might be to other blood cancers, so don't miss out this question"</p> <p>"When writing your application, explaining what research has been done already (by you or others) and what you hope to do after it has finished will give patients more perspective"</p>
Language used – PLAIN English	<p>"Please try not to use any technical terms in the Plain English or PPI sections of your applications e.g. "peptides" or "cell lines" can be hard terms for a blood cancer patient to understand. Always ask a blood cancer patient to read your Plain English and PPI sections before submission to help check that it is in easily readable and understandable English (a side benefit is the Plain English summary can then be re-used in your university website to help promote broader understanding of your research projects)"</p> <p>"Please keep the language simple as we are not clinicians"</p> <p>"When writing the plain English section, imagine that you are explaining it to someone you've never met, and they are not from a medical or scientific background. Think about how you'd explain it to a child!"</p>
Patient and Public Involvement	<p>"There were some really good research plans put forward which were exciting to read. Patient involvement was a key factor for me but missing in several submissions"</p> <p>"Patients can be valuable collaborators in the whole research process. Seeking input on research questions or strategic priorities, right from the start is one way of doing this. Identifying and challenging barriers in patient engagement and involvement for research is also important. If one approach doesn't work, can an alternative be used?"</p> <p>"Patients would be very interested to hear about your research; maybe make a short video?"</p> <p>"The value of involving people who have lived with / are living with blood cancers can provide a real insight and help guide the direction of your research, given that they will have unique and personal insights into the whole process from diagnosis, treatments, side effects, and outcomes."</p>