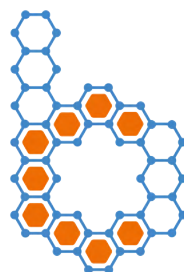




# PATIENT AND PUBLIC INVOLVEMENT IN RESEARCH

## GUIDANCE FOR RESEARCHERS



**BONE  
CANCER**  
RESEARCH TRUST  
UNTIL THERE'S A CURE

# 1. INTRODUCTION

## 1.1. PURPOSE OF THIS HANDBOOK

The aim of this handbook is to outline the Bone Cancer Research Trust's, patient and public involvement in research programme and explain the benefits this will have for applicants' grant proposals and their research projects going forward. We are excited to introduce the Patient and Public Involvement Panel or PPIP for short.



**ENSURING PATIENT AND PUBLIC NEEDS ARE  
AT THE HEART OF OUR RESEARCH**

We encourage applicants for all our funding schemes to engage as fully as possible with PPIP as it provides a unique opportunity to gain insight into primary bone cancer research from a patients' perspective and offers the opportunity to receive valuable feedback on your application. A list of all the available funding opportunities can be found on the Bone Cancer Research Trust website.

Communicating the benefits and potential impact of research to a non-scientific audience is hard. However, if you can involve people affected by primary bone cancer in the development of your application it will make your research more meaningful.

**We support all researchers,  
regardless of who they are funded by  
or applying for funding from.**





We have developed this guidance document for applicants to explain what our PPI network offers is and how to make effective use of this unparalleled resource.

Through our patient and public involvement programme, the Bone Cancer Research Trust aims to support researchers to carry out meaningful involvement that will add value to their research into primary bone cancer.

From August 2021, the Primary Bone Cancer PPI Network will be involved in assisting the Independent Scientific Advisory Panel with their funding decisions by commenting constructively on the following aspects:

- **Is this research important, from the point of view of a person affected by Primary Bone Cancer?**
- **Was the lay summary sufficiently clear?**
- **Did the applicants demonstrate engagement with the Primary Bone Cancer community when they planned their research?**
- **Did the applicants show an intention to remain engaged with the Primary Bone Cancer community and communicate outcomes?**
- **Is the proposal aligned with the priorities of Primary Bone Cancer patients and the charity?**

If you have any further questions about our PPI programme, please contact the research team at [research@bcrt.org.uk](mailto:research@bcrt.org.uk).



“Despite being the primary benefactors of medical research and experts in their disease, patients have historically been regarded passive objects in research. It is now widely recognised that patients should be research partners rather than recipients. Ensuring that patients are actively involved in the design, conduct and dissemination of trials, patient participation has been shown to significantly enhance the quality of research. The Bone Cancer Research Trust recognises patient-centricity as an absolute priority. By putting patients at the heart of their work, BCRT empowers the individuals that fund their research, to directly influence the outcome.

**Dr Phil Green, General Practitioner, PPIP Representative and Bone Cancer Research Trust Trustee**

## 2. PUBLIC AND PATIENT INVOLVEMENT

### 2.1. DEFINING PATIENT AND PUBLIC INVOLVEMENT



“ Patient and Public Involvement that our research is carried out "with" patients and members of the public, rather than "to", "about" and "for" them. It ensures that the research questions we ask, and the outcomes we achieve, truly matter to patients. It also provides perspectives that complement or challenge those of researchers and offers ISAP a different point of view, enriching their recommendations for funding. Ultimately, PPI improves the quality and the relevance of the research we fund

**Dr Viqui Vinader, Research Manager, Bone Cancer Research Trust**

Patient and public involvement in research means including people affected by primary bone cancer and/or their families in the various stages of research. We are eager to ensure our community has the opportunity to participate in planning, evaluating and/or sharing the research funded by the Bone Cancer Research Trust.

We want all primary bone cancer researchers to work in partnership with the community wherever possible.

Involving the people affected by primary bone cancer will help the researchers to produce higher quality and more relevant research focusing on the problems that matter most to the Bone Cancer Research Trust community. This programme will allow researchers to write more competitive grant applications that are more likely to be successful in achieving funding. PPI also helps break down the barriers between academic and lay communities which will help to build public trust in science and research.

Through our PPI programme we are committed to support all primary bone cancer researchers involving the Bone Cancer Research Trust community in their projects. We aim to:

- Help researchers understand how PPI can benefit their work and how they can involve people affected by primary bone cancer in their work
- Bring together researchers and our PPI network to work collaboratively and develop relationships
- Plan and deliver meaningful involvement and engagement opportunities

## 2.2. INVOLVEMENT, ENGAGEMENT AND PARTICIPATION

There is an important distinction between patient and public **involvement** in research and patient and public **participation and engagement** in research.

Patient and public **involvement** in research is a partnership between the researcher and the community affected by primary bone cancer. This partnership includes, for example, asking for feedback when developing a funding application or working with the community to design research that will answer the questions most important to them.

Involvement, engagement and participation are intrinsically linked and often overlap.

**Engagement** is the sharing of information and findings from your study by presenting at lay research meetings, such as the Bone Cancer Research Trust Conference and/or by writing or filming blog posts about your research to keep the community up to date on progress.

Patient **participation** in research is defined as people taking part in research, such as being recruited as participants on a clinical trial. In the case of 'Basic' and 'Translational' research, patient participation is less applicable.

The primary bone cancer community can be involved at all stages of the research cycle:





## 3. APPROACHES TO PPI

There is no singular approach to PPI in research. We are eager to ensure our community can be included wherever possible but recognise that it is not always practical. In the following section we describe the different ways in which patients' and the public can be included in research before detailing our expectations for involvement in different grant applications.

How you chose to involve people will depend on numerous factors including: the level of input you want, the nature of project and the stage of research.

### 3.1. CONSULTATION

Consultation involves asking members of the primary bone cancer community for their views and to use their responses to inform decision making when shaping research proposals. Examples of consultation involve asking those affected by primary bone cancer:

- What it is like to live with the disease and the consequences of treatment
- Their feelings about certain areas of research e.g., biomarkers, indicators of prognosis and treatments
- The priorities and aims of the research project

Consultation can take place during any part of the research project planning, from identifying topics of research through to how it might be best to share findings of and potential outcomes of your work.

PPI consultations can be incredibly valuable for exploring sensitive and difficult issues with those most affected by them. It is also a great opportunity to engage people in discussions and debate about your research and gain a wide range of views.

Working closely, and developing relationships, with members of the PPI network will take you closer to establish collaborations.

### 3.2. COLLABORATION

Working in collaboration is about forming a true partnership with people affected by primary bone cancer and sharing research decisions. For example, members of the PPI network might collaborate with the researcher to develop grant applications, e.g., providing feedback on lay grant application summaries, how a project is managed and disseminating the research.

Like consultation, collaboration with the PPI network can take place at any point throughout the project and requires commitment, openness and flexibility. The benefits of collaboration include:

- Help ensuring the project remains focused and relevant
- Patients can provide skills and perspectives that complement the researcher

You can talk through your ideas with people and give them the opportunity to contribute thoughts and suggestions. Collaboration is an iterative process and will allow you to continue to gain insight from patients.

### 3.3. CO-PRODUCTION

The essence of co-production is sharing control and responsibility throughout the project. Researchers and people affected by primary bone cancer have an ongoing dialogue. In this style of PPI, the assumption is that those for whom the research is most relevant are the best placed to help design and deliver it in partnership with the with professionals and have skills, knowledge and experience that is of equal importance. Co-production is largely the same as collaboration but it differs in the ethos of shared expertise that underpins it. Co-production requires that all relationships are valued and nurtured, and that people are supported and enabled to realise their potential whilst carrying out their responsibilities as part of the project. Examples of co-production include having someone affected by primary bone cancer as a co-researcher on the project or working with people affected by primary bone cancer to design a new resource.

Co-production allows:

- The inclusion of all perspectives and skills of a diverse team
- Reciprocity in that everybody benefits from working together

In practice, PPI in research projects can include a combination of these elements as the boundaries are not strict.

It is important to remember that PPI in research is a two-way process, everyone is a valued and respected member of the team. Please note that we expect researchers participating in PPI to consider all views and opinions and provide feedback on exchanges for our PPI network as this is a learning experience for everyone involved.



## 4. ENGAGING WITH PPIP

You can involve people affected by primary bone cancer at all stages of research:

- Commenting on research applications prior to their submission – helping identify research priorities relevant to people affected by primary bone cancer, developing the grant application, including making sure that the research is relevant to people affected by primary bone cancer and the lay summary is communicated well.
- As co-applicants on a research project
- As members of a project advisory or steering group throughout the research process
- Reviewing materials such as leaflets, posters, webpages, and questionnaires prior to their use in research
- Offering suggestions to you about the suitability of proposed methods
- Contributing to the design and management of your research study
- Undertaking your research, including helping to create leaflets or completing questionnaires
- Disseminating your research findings to lay audiences
- Guiding the translation of your research findings, for example into altering clinical practice or guiding further research
- Evaluating its impact for people affected by primary bone cancer



Once you have decided the stage at which you plan to involve people affected by primary bone cancer, you will need to think about the level of involvement you would like from PPIP

**Will their involvement be consultation, collaboration, or co-production?**

“It’s easy to forget that scientific and medical research is paid for by all of us – be it through philanthropy or as a tax payer. Yet there sometimes seems to be a ‘division’ between scientists and non-scientists. We may play different roles in the research process but we are one community. It’s important that we all feel ownership and be proud of the scientific achievements that we make together. It’s superb that the creation of a PIPP panel will formally recognise this; putting the PBC community (i.e. scientists, patients, families, friends) together in the drawing room when designing the studies of the future.

**Dr Darrell Green, Primary Bone Cancer Researcher,  
Bone Cancer Research Trust Trustee**





## 4.1. THINGS TO CONSIDER BEFORE CONSULTING PPI

Are you looking to gain an insight into a specific type of primary bone cancer? Do you want to know for example, what the community thinks about genomic research? Do you want to know how relevant is your research and how it aligns with the priorities of patients? Or do you simply want feedback on your grant application lay summary?

It is important to know what you want the PPI network to help you achieve, so you can plan your consultation appropriately.

Things to consider when planning PPI in research:

### 4.1.1. What stage of the research process are you at?

In the early stages of the research process, you could consult the PPI network to gain a broad perspective on the issues at the forefront of those affected by primary bone cancer. This could help you shape your research questions, develop new ideas, inform approaches you could take and decide how/if you want to involve the PPI network going forward. Later on in the research process, if appropriate, you can collaborate with a narrower more focused group of PPI contributors to develop the project further.

### 4.1.2. Who should you involve?

It is imperative to ensure the group you involve is representative of the area you are researching. Whilst researchers may suggest who they want to involve in their discussions, the Bone Cancer Research Trust, as the conduit of PPI network and researcher meetings, will bring the most suitable groups together. Therefore, the first step is to contact the Bone Cancer Research Trust research team and discuss your requirements.

### 4.1.3. Inclusivity

You need to consider how you will work with the PPI network and ensure barriers to involvement are minimised. PPI activities should be inclusive as possible to achieve maximum engagement and benefit.

### 4.1.4. Time investment

When considering getting involved with PPI contributors, you must carefully consider how much time you really have. This opportunity has the potential to be incredibly beneficial to your work but will also mean a considerable time investment. As outlined earlier in this guidance, PPI can happen on many levels, consultation is relatively simple and efficient to carry out, whereas collaboration and co-production will require a more significant allocation of time to plan and build relationships.



### 4.1.5. Capturing and sharing impact

As described before, a member of the Bone Cancer Research Trust's research team will attend PPI meetings to moderate and take minutes. In addition to this, it is important for the researcher to document feedback and suggestions from their meetings so in the future, when discussing their project(s) they can describe how their research was influenced and the impact of PPI.

#### Key points

Once you know who you are going to involve, and what you are going to do, it's important to:

- Clearly communicate the questions you would like people to answer and what you would like them to contribute
- Be clear on deadlines
- If a difficult situation arises, be prepared to be flexible on the method of involvement
- Think of some of the barriers you may face in a meeting, such as keeping the conversation focused

**We understand that PPI may seem daunting, but we want to reassure you that the Bone Cancer Research Trust is committed to helping you however we can. You will have the full support of our team, every step of the way.**

## 4.2. COMMUNICATING WITH THE PPI

### Meeting in person

Face-to-face meetings are a great way to build relationships with PPI contributors, and they can also help people focus and think creatively.

### Communicating via email

When PPI contributors are commenting on study documents, or answering specific questions, it may be easiest to liaise with them over email. This enables people to contribute at a time that suits them. Note that it's best practice to give people deadlines for when you'd like them to provide feedback.


### Meeting remotely

Remote meetings are also an excellent way to communicate with PPI contributors. They offer more flexibility and can enable you to involve a wider range of people. Some people are more at ease when they can contribute from the comfort of their home. Video



# 5. HOW TO ACCESS PPIP

Whilst we are keen for all our researchers to take advantage of the opportunity to involve PPIP in their work, please note that under no circumstances is it acceptable for researchers to contact primary bone cancer patients, their families, or friends directly.



**The Bone Cancer Research Trust, research team will always act as an intermediary between you and PPIP.**

**We will facilitate the organising of meetings, bringing you and PPIP together.**

To begin your journey with patient and public involvement in your research please complete the 'PPI Support Request Form for Researchers' which can be found on our website. Once completed, please return the form to [research@bcrt.org.uk](mailto:research@bcrt.org.uk). Your request will be assessed by the research team and you will be contacted to discuss your request further and begin planning your meeting with members of PPIP.

If you have any questions about this process, please contact [research@bcrt.org.uk](mailto:research@bcrt.org.uk) and we will do our best to support you.





# 6. PPI IN RESEARCH GRANT APPLICATIONS

We are keen to involve PPIP at every step of the research journey starting at the very beginning, with research grant applications. As PPIP grows over the coming years we hope to achieve our ambition of a integrated research process where patients and the public have a guiding hand in the research they fund.

## 6.1. GETTING STARTED

As part of our research funding strategy, we are asking lay reviewers to participate in the evaluation of research proposals submitted as part of this grant application. Please note that members of PPIP that help researchers to write their lay grant summaries will not be asked to review the same project to avoid bias.

During the planning process, we encourage those wanting to involve the patient community to email [research@bcrt.org.uk](mailto:research@bcrt.org.uk) to discuss setting up a meeting with PPIP.

## 6.2. LAY SUMMARY REVIEW

Once you have completed your lay grant summary, we ask that you send us this in isolation from the rest of your application. Lay summaries will be anonymised and passed on to PPIP. Once we have received completed review forms from the lay reviews, these will be compiled into a single feedback document for the applicant.

## 6.3. HOW WILL PPI BENEFIT MY LAY SUMMARY?

### 5.3.1. Written communication

Writing a lay summary is challenging. Researchers often fall into the trap of using jargon and technical language when describing their work, but this is often difficult for non-experts to understand. The Primary Bone Cancer Patient Network will help you communicate the themes, ideas and potential impact of your work in a clear and effective way.

### 5.3.2 Context

Involving people with a lived experience of primary bone cancer will help put your research into context. Basic and translational research, while focused on and crucial for the development of new treatments, may sometimes seem detached from the real world. The Primary Bone Cancer Patient Network will help you think about your research in a wider context and the long-term impacts it could have. When you have received your feedback, we encourage you to act on it as much as possible. This is valuable information that will benefit your final application. As noted previously, PPI is a two-way commitment and we trust that you will reflect on how the Primary Bone Cancer Patient Network has helped you and take the time to let them know.

## 6.4. STAYING INVOLVED

We hope that the successful 'Early Career Fellowship' applicant will have found engaging with the Primary Bone Cancer Patient Network rewarding and that they are eager to continue working with them during the fellowship. We do not expect the applicant to adopt a full collaboration/co-production approach to PPI but there are several ways the Primary Bone Cancer Patient Network can help you going forward.

### 5.4.1. Sharing your findings

Sharing your findings is a pivotal stage of the research process. Once you have completed your experiments and made a discovery, everyone needs to know what has been achieved; research institute you reside in, the fundraisers who made your project possible and the primary bone cancer patients who will benefit. The Primary Bone Cancer Patient Network can help you share your findings with a lay audience by helping you prepare presentations and blog posts.

**If you have any questions about involving PPIP in you research grant application, please contact [research@bcrt.org.uk](mailto:research@bcrt.org.uk) for a discussion about your ideas and how we can help!**



# 7. PPI IN CLINICAL RESEARCH

## 7.1. AT WHAT STAGES CAN I INVOLVE PEOPLE IN CLINICAL RESEARCH?

Patients and their friends and family can be involved in numerous stages of the clinical research cycle. Involving those directly affected by primary bone cancer in the design and development of your study can have a significant impact on the quality and success of your research.

## 7.2. HOW CAN PPI BENEFIT MY CLINICAL RESEARCH?

### 7.2.1. Helping maximise recruitment and retention

The PPIP can help you design your study protocol to ensure maximises recruitment and retention of patients. It is paramount that any clinical study is feasible and accessible to all prospective patients. PPI contributors can provide key insights into the practicalities to study and help you overcome any barriers to involvement in your clinical research.

### 7.2.2. Identifying relevant and meaningful outcomes

Study outcome measures need to be robust and meaningful; nobody is better placed to help you identify these measures than someone with a lived experience of primary bone cancer. Including outcome measures that matter to patients will directly benefit your clinical research, increasing your chance of finding significant outcomes.

### 7.2.3. Addressing ethical considerations

People directly affected by primary bone cancer can greatly benefit the process of achieving ethical approval by helping to identify and address potential issues. This in turn can lead to more straightforward and faster approval.

### 7.2.4. Designing essential documents

The first thing a patient sees before getting involved in clinical research are the documents containing all the necessary information. First impressions count! The PPIP can help you ensure that all patient-facing documents are written in plain, accessible English so prospective participants have all the details they need to make an informed decision about joining the study.





## 7.3. INVOLVING PPI THROUGHOUT THE STUDY

Involvement does not have to be limited to be before and after data collection. People with primary bone cancer can be involved throughout the study. A strong partnership between researchers and the patient and public will ensure the study remains focused on the most relevant questions from beginning to end.

### 7.3.1. Collecting data

In some circumstances, it might be appropriate to involve people affected by primary bone cancer in data collection. For example, the PPIP could conduct interviews with research participants. As people living with and beyond primary bone cancer, the PPIP understand the anxiety of those getting involved in clinical research and are therefore ideally placed to ask sensitive questions and gain the most insight.



### 7.3.2. Interpreting and presenting findings

Even for the initiated, understanding the data from clinical research can be a challenge. Imagine a patient with a non-scientific background trying to navigate that information loaded minefield, incredibly difficult!

Involving PPI contributors when interpreting findings can give you a unique insight into the results, they can help you think about your results in a wider context and relate the findings to aspects of primary bone cancer you may not have considered.

**If you have any questions about involving PPIP in clinical research, please contact [research@bcrt.org.uk](mailto:research@bcrt.org.uk) to discuss your ideas and how we can help!**

