



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



**Patient and Public Involvement Panel
Volunteer Job Description**

The charity

In 2004, a group of families who had lost children and young people to primary bone cancer came together. At that time, there was virtually no accessible information and practically no funding for research into this disease. Determined not to accept the *status quo*, the families pooled funds they had already raised, and together with guidance from Professor Ian Lewis, a consultant paediatrician and adolescent oncologist at St James's University Hospital, Leeds, the Bone Cancer Research Trust was registered in 2006. Today, the Bone Cancer Research Trust is the leading charity dedicated to saving lives and fighting primary bone cancer.

As of December 2022, we have funded 128 grants, totalling a research investment of over £7.9 million. This makes the Bone Cancer Research Trust the largest, dedicated funder of research into primary bone cancer in the UK.

Patient and Public Involvement in Primary Bone Cancer Research - Patient and Public Involvement Panel PPIP

Patient and Public Involvement (PPI) ensures 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 our Independent Scientific Advisory panel (ISAP) a different point of view, enriching their recommendations for funding. Ultimately, PPI improves the quality and the relevance of the research we fund.

We are always looking for enthusiastic individuals whose lives have been affected by primary bone cancer and are excited at the prospect of supporting BCRT in putting PPI into practice by becoming voluntary members of our **Patient and Public Involvement Panel (PPIP)**. As a member of this panel, you will be networking with researchers and other patient representatives, shaping research proposals and assisting the Independent Scientific Advisory Panel (ISAP) with their funding decisions. These activities recognise that people with lived experiences contribute additional expertise and give valuable, novel insights.

Key responsibilities

1. To participate in discussions with researchers during the planning stages of their research proposals and make recommendations to the Independent Scientific Advisory Panel (ISAP) regarding research funding, by commenting constructively on the following aspects:
 - The importance of the research from the point of view of a person affected by primary bone cancer
 - The clarity of the lay summary
 - The applicants' engagement with the primary bone cancer community during the research planning
 - The applicants' intention to remain engaged with the primary bone cancer community and communicate outcomes
 - The alignment of the proposal with the priorities of primary bone cancer patients and the charity
2. To contribute to the design and management of clinical studies, by:
 - Ensuring the design of the clinical study is practical and has relevant outcome measures
 - Providing patients' feedback during clinical studies and helping identify and overcome problems
3. To help the charity communicate outcomes, by sharing the information we present to lay audiences and increase the dissemination of our findings.
4. To define priorities by helping identify those key research areas/questions that are important for people affected by primary bone cancer.

What can you expect from us?

- Full training and support in all aspects of the role
- Informative guides to support independent work
- Being part of our dedicated and enthusiastic research team
- The Bone Cancer Research Trust's Research Team will coordinate grant applications and the dissemination of the accompanying documentation. BCRT's Research Team is also responsible for organising teleconferences and meetings.

Frequency

- It is initially anticipated that members of the Patient & Public Involvement Panel (PPIP) will meet up to 3 times a year to discuss grant applications.

- Assessment of research proposals and planning discussions with researchers will be alternated among the PPIP members, to make their involvement more manageable.
- These meetings will be in most cases *via* teleconference or video meeting.
- A panel representative may also be asked to meet face to face, where feasible, once a year to undertake interviews (travel expenses will be paid).

The role will suit you if you...

- Are passionate about primary bone cancer research progress and new developments
- Can work independently and enjoy interacting with others
- Have good communication skills
- Would like to contribute your lived experiences to define priorities in primary bone cancer research

Requirements

- Applicants must have access to a computer and internet
- Applicants must be over the age of 18
- Applicants will be expected to read applications for research and accompanying documentation and prepare their own feedback on supplied document templates for sharing as part of PPIP discussions

The impact you will make

- You will help create a positive and motivating primary bone cancer research network
- You will ensure that the research we fund, and the outcomes we achieve, truly matter to patients
- You will provide perspectives that complement or challenge those of researchers and clinicians
- You will offer ISAP a different point of view and enrich their recommendations
- You will help us disseminate research outcomes

How to apply

Please complete the volunteer application form for this role and send it to the Research Team at PPIP@bcrt.org.uk

If you would like more information or to discuss the role before applying, please contact us at PPIP@bcrt.org.uk or by calling 0113 259 5934.