Patient and Public Involvement and Engagement (PPIE) in Blood Cancer Research

A Practical Guide for Researchers

Introduction

At Blood Cancer UK, we believe research is strongest when it is shaped by the people it is ultimately intended to benefit.

People affected by blood cancer bring unique experiences, perspectives and expertise that can help researchers ask better questions, design more relevant studies, improve communication and maximise the impact of their work.

We are committed to ensuring that the voices of people affected by blood cancer are embedded throughout the research process. We encourage all researchers applying for funding from Blood Cancer UK to consider how people affected by blood cancer can be involved in shaping, delivering and sharing their research.

This guide has been developed to support researchers at all stages of their careers and across all types of blood cancer research, from laboratory discovery science and translational research through to clinical trials, health data research and implementation studies.

Whether you are new to PPIE or looking to strengthen existing approaches, we hope this guide provides practical ideas, inspiration and support.

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What is PPIE?

Patient and Public Involvement and Engagement (PPIE) describes the ways in which researchers work alongside patients, carers, family members and members of the public throughout the research process.

PPIE consists of two distinct but complementary activities: involvement and engagement.

Public Engagement

Public engagement is about sharing information and creating opportunities for dialogue between researchers and the public.

Examples include:

- Public talks and events
- Blogs and articles
- Social media activity
- Podcasts and videos
- Laboratory open days
- Sharing research findings with patient communities

Patient and Public Involvement

Patient and public involvement means carrying out research *with* or *by* people affected by blood cancer rather than doing research to, about or for them.

Involvement means that people with lived experience actively contribute to decisions about research.

Examples include:

- Helping identify research priorities
- Contributing to grant applications
- Reviewing Plain English Summaries
- Joining advisory groups
- Sitting on steering committees
- Reviewing participant information materials
- Helping interpret findings
- Supporting dissemination activities

A simple test

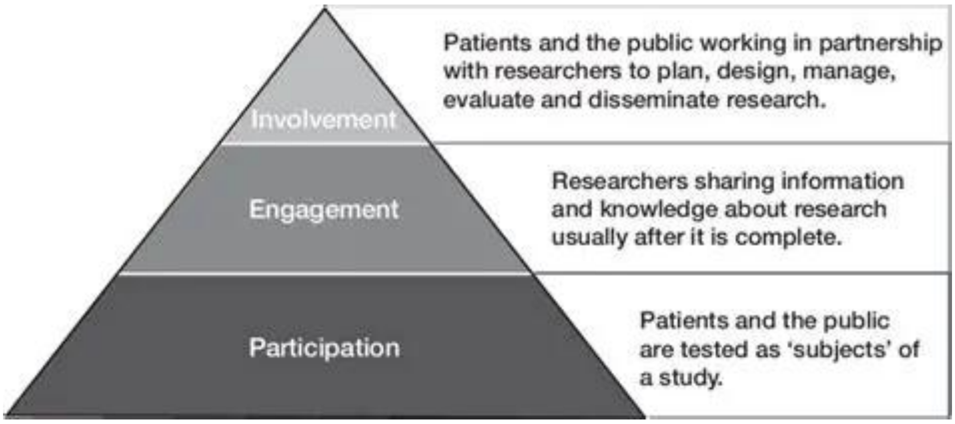
Ask yourself:

"Can people affected by blood cancer influence decisions about this research?"

If the answer is yes, it is likely involvement.

If the answer is no, but you are sharing information or creating opportunities for discussion, it is likely engagement.

Both are important and both can strengthen blood cancer research.



Patients and the public working in partnership with researchers to plan, design, manage, evaluate and disseminate research.

Researchers sharing information and knowledge about research usually after it is complete.

Patients and the public are tested as 'subjects' of a study.

Why Involve People Affected by Blood Cancer?

Researchers are experts in science. People affected by blood cancer are experts in living with blood cancer. Both forms of expertise are valuable.

People living with blood cancer, carers and family members bring insights that cannot be gained from laboratory experiments, datasets or scientific literature alone.

Their experiences can help researchers:

- Focus on questions that matter most
- Improve the relevance of research
- Understand treatment burden and quality of life issues
- Improve communication and accessibility
- Identify barriers to participation
- Strengthen dissemination and impact
- Build trust and accountability

Meaningful involvement helps ensure that research remains connected to the needs and priorities of the people it is intended to benefit.

What Blood Cancer UK Looks For

We recognise that involvement will look different depending on the type of research being undertaken. We do not expect every project to involve people in exactly the same way.

Instead, we encourage researchers to consider:

- Why involvement is important for their project
- Who should be involved
- When involvement should happen
- How involvement will influence decisions
- How contributors will be supported
- How impact will be evaluated

Strong applications often include:

✓ Early involvement

✓ Clear plans throughout the project

✓ Appropriate budgeting

✓ Realistic and proportionate approaches

✓ Feedback mechanisms

✓ Dissemination plans

Common pitfalls

✗ Confusing participation and engagement with involvement

✗ Involving people only at the end of the project

✗ Providing no evidence of influence

✗ Tokenistic approaches

✗ No plans for feedback

Working with Blood Cancer UK's Research Involvement Network

One of the most common challenges researchers face is identifying people with relevant lived experience who can contribute to research.

Blood Cancer UK's Research Involvement Network brings together people affected by blood cancer who help shape research and funding decisions.

Members include:

- People living with blood cancer
- Family members
- Carers
- People who have supported loved ones through diagnosis and treatment

The network contributes to:

- Reviewing funding applications
- Assessing research relevance
- Reviewing Plain English Summaries
- Focus groups and discussion activities
- Strategic discussions within the charity
- Research priority setting
- Involvement and engagement activities

Their feedback helps ensure that research remains focused on issues that matter most to people affected by blood cancer.

Working with the Network

Researchers may wish to involve members of the network in:

- Developing research ideas
- Preparing funding applications
- Reviewing participant materials
- Advisory groups
- Dissemination planning
- Public engagement activities

Researchers interested in involving people affected by blood cancer should contact Blood Cancer UK's Research Involvement Manager, Lisa Whittaker, as early as possible lisa.whittaker@bloodcancer.org.uk Lisa can help to connect you with people with relevant lived experience, facilitate small group sessions and capture feedback.

Early involvement often leads to stronger applications and more meaningful partnerships.

Getting Started

If you are new to PPIE, start small.

Meaningful involvement does not need to be complicated.

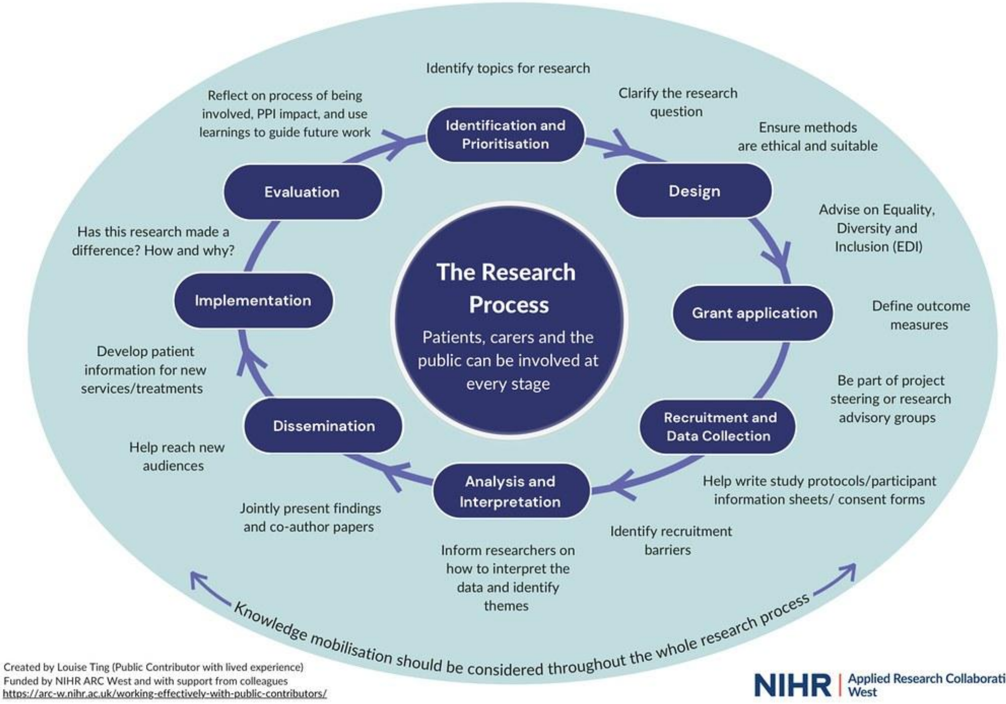
Five questions to ask

1. Who could benefit from this research?
2. Who might bring valuable lived experience?
3. What decisions will need to be made?
4. How could lived experience help inform those decisions?
5. How will I know whether involvement made a difference?

First steps

- Review your research idea with patients
- Ask for feedback on your Plain English Summary
- Attend PPIE training
- Connect with patient organisations
- Speak to Blood Cancer UK

PPIE Across the Research Cycle



Created by Louise Ting (Public Contributor with lived experience)
Funded by NIHR ARC West and with support from colleagues
https://arc-w.nihr.ac.uk/working-effectively-with-public-contributors/

NIHR | Applied Research Collaboration West

Identifying Research Priorities

Examples:

- Priority-setting workshops
- Focus groups
- Advisory discussions
- Surveys

Developing Funding Applications

Examples:

- Reviewing proposals
- Testing relevance
- Reviewing Plain English Summaries

Study Design

Examples:

- Outcome measures

- Recruitment approaches
- Participant information materials

Conducting Research

Examples:

- Steering groups
- Advisory panels
- Governance activities

Analysis and Interpretation

Examples:

- Discussing findings
- Interpreting results
- Identifying key messages

Dissemination

Examples:

- Videos
- Podcasts
- Blogs
- Public talks
- Conference presentations
- Co-authored papers

Future Research

Examples:

- Identifying unanswered questions
- Prioritising next steps
- Developing future applications

PPIE in Laboratory and Discovery Research

Many researchers working in laboratory-based research worry that involvement may not be relevant to their work. However, meaningful involvement is possible at every stage of discovery science.

Common misconceptions

"My research is too technical."

People affected by blood cancer do not need to understand every experimental method to contribute valuable insights.

"The impact is years away."

Many people affected by blood cancer are highly motivated by contributing to future improvements in care and treatment.

Practical Ideas

Before funding

- Discuss priorities
- Review research aims
- Review Plain English Summaries

During research

- Advisory groups
- Research update sessions
- Laboratory visits
- Discussions about future applications

At project completion

- Plain English outputs
- Blogs
- Videos
- Public engagement activities

PPIE in Translational Research

Translational research sits between discovery science and patient benefit.

Examples include:

- CAR-T research
- Precision medicine
- Biomarker development
- Drug development

Opportunities for involvement include:

- Discussing acceptability
- Exploring priorities
- Reviewing communications
- Understanding patient perspectives

PPIE in Clinical Research

Clinical research provides many opportunities for involvement.

Examples include:

- Developing participant information sheets and consent materials
- Recruitment approaches
- Trial oversight
- Outcome measures
- Dissemination activities

Researchers should remember that recruiting participants is not the same as involving patients in research decisions.

PPIE in Health Data Research

Health data research depends on public trust.

People affected by blood cancer can help researchers understand:

- Expectations

- Concerns
- Transparency needs
- Governance priorities

Examples of involvement include:

- Reviewing communications
- Discussing consent
- Advising on data access
- Supporting public engagement

Inclusive Involvement

There is no single patient perspective. Researchers should consider involving people from a range of backgrounds and experiences. You should try to avoid overburdening 1 or 2 people.

This may include:

- Relevant blood cancer diagnoses
- Different ethnic communities
- Younger adults
- Older adults
- Carers
- Bereaved relatives
- Rural communities
- People with disabilities

Questions to ask

Who is represented?

Who is missing?

What barriers exist?

How can they be reduced?

Budgeting for Involvement

Meaningful involvement requires time and resources. Researchers should budget appropriately to reimburse people for their time, ideally in line with NIHR guidelines, and cover any expenses. It’s also worth thinking about costs associated with:

Accessibility

- Interpreters
- Captioning
- Accessible materials

Practical support

- Childcare
- Carer replacement costs
- Accommodation

Delivery costs (for example if working with a charity)

- Facilitation support
- Training
- Online platforms
- In person meeting costs e.g. catering, printing etc

Appropriate budgeting demonstrates that involvement is valued and respected.

Top Tips from People Affected by Blood Cancer

Start early

Don't wait until all major decisions have been made.

Use Plain English

Avoid unnecessary jargon.

Use a readability checker e.g. https://www.thefirstword.co.uk/readabilitytest/

Be honest

Explain what can and cannot be influenced.

Close the feedback loop

Tell contributors what changed as a result of their involvement

Build relationships

Good involvement is based on partnership.

Think beyond your current study

People are often interested in where the research may lead next.

Be prepared to learn

Keep an open mind and don't aim for perfection

Quotes from researchers

"I have found involving blood cancer patients and their carers in my research hugely valuable, both scientifically and personally. Scientifically, discussing research plans with the people directly affected by blood cancer helps to make our research questions more focused on the issues that have greatest impact. Ultimately, the purpose of our work is to improve the quality and quantity of life of people with blood cancer - and the people living with blood cancer are best placed to comment on their needs and where the gaps are that research must fill. As well as helping to frame the overall research direction, blood cancer patients have a unique perspective to offer on clinical trial design features such as patient information and consent documents and study protocol tolerability. On a personal level, speaking with patients who have been diagnosed and treated for blood cancer has been very moving and one of the most rewarding parts of my scientific career. I am indebted to them for their time and input." Will Hamilton, University of Cambridge

"Last night I had the honour of being part of an introductory patient involvement/engagement session for childhood leukaemia research.

Hearing so openly and honestly from people who had leukaemia as children, and from parents who had watched their child go through it, was genuinely moving. I filled a full page of notes. Some of what they shared aligned with what I might have expected - but some of it genuinely surprised me and has made me begin to reflect on how we frame our research priorities. The clinician favourite of finding drugs to use as a bridge to transplant looks very different when you're sitting across from adults who have spent 20+ years living with the after-effects of that transplant. Delivery methods are another area where I can see research has a lot of catching up to do: a cure would be fantastic, but a cure without yet another IV for a toddler would be better.

Ultimately, the themes that emerge from these conversations map directly onto what our research is trying to achieve: kinder, safer, more effective treatments. It's easy to lose sight of why that matters when you're tied to a lab bench and analysing data, but sessions like this are such an important reminder that there is a person behind those numbers." Sophie Kellaway, University of Nottingham

"Speaking to patients in focus groups is challenging but in a positive way; some are almost professional PPI and want to understand the detail or have already drafted changes to the lay section, while others may be joining for the first time and need to be guided through the core reasons for conducting the research. Regardless, I am yet to be involved in a focus group session that hasn't provided me with some enlightenment or one that hasn't made me reflect on why patient input throughout the entire grant application process adds huge value." Dr Mark Bishton, University of Nottingham

"I went into this feeling slightly that it might be a box ticking exercise, but came out having enjoyed the interaction [with patients] and feeling that the proposal had been strengthened as a result. And there was the significant bonus of being forced to think about the scientific problem from someone else's perspective, which allowed us to devise a new experiment!" Colin Adrain, Queen's University Belfast

Evaluating the Impact of PPIE

Patient and public involvement should be evaluated just like any other aspect of research.

Evaluation helps researchers understand what worked well, what could be improved and what difference involvement made.

Why evaluate?

Evaluation can help:

- Demonstrate value
- Improve future involvement activities
- Share learning
- Recognise contributor impact
- Meet funder expectations

What difference did involvement make?

Impact on research

Did involvement influence:

- Research priorities?
- Study design?

- Recruitment plans?
- Communication materials?
- Dissemination plans?

Impact on researchers

Did involvement:

- Challenge assumptions?
- Improve understanding?
- Influence future plans?

Impact on contributors

Did contributors:

- Feel heard?
- Feel valued?
- Understand their role?
- Want to be involved again?

Simple Evaluation Questions

Ask contributors:

- What worked well?
- What could be improved?
- Did you feel able to contribute?
- Did you understand how your feedback was used?

Ask yourself:

- What changed because of involvement?
- What would have happened without involvement?
- What have we learned?

PPIE Planning Checklist

Before submitting your application, have you considered:

☐ Why involvement is needed

☐ Who should be involved

☐ How they will influence decisions

☐ How they will be supported

☐ Accessibility requirements

☐ Budget requirements

☐ Feedback mechanisms

☐ Evaluation plans

☐ Dissemination plans

Further Resources

General PPIE

- UK Standards for Public Involvement https://sites.google.com/nihr.ac.uk/pi-standards/home
- NIHR guidance https://www.nihr.ac.uk/get-involved/public-involvement
- Cancer Research UK Patient Involvement Toolkit (there are hundreds of toolkits about PPIE if this one doesn't help, try another one) https://www.cancerresearchuk.org/for-researchers/how-we-deliver-research/patient-and-public-involvement-in-research/our-toolkit

Laboratory Research

- NIHR Practical Guide to PPI in Lab-Based Research https://www.learningforinvolvement.org.uk/content/resource/a-practical-guide-to-patient-and-public-involvement-in-lab-based-research/

Clinical Research

- Trial Steering Committee Guidance https://www.learningforinvolvement.org.uk/content/resource/good-practice-guidelines-on-the-recruitment-and-involvement-of-public-members-on-trial-steering-committees-tscs-study-steering-committees-sscs/
- INCLUDE Ethnicity Framework https://www.trialforge.org/trial-diversity/include/

Health Data Research

- Health Data Research UK https://www.hdruk.ac.uk/
- Use MY Data https://www.usemydata.org.uk/

Finding People to Involve

- Blood Cancer UK's Research Involvement Network https://bloodcancer.org.uk/get-involved/give-time/research-involvement-network/
- People in Research https://www.peopleinresearch.org/
- Voice Network https://voice-global.org/why-join-voice

Final Thoughts

Good PPIE is not about ticking a box. It is about building meaningful relationships with people affected by blood cancer that improve the quality, relevance and impact of research.

Researchers do not need to be experts in involvement before they begin. The most important step is to start early, listen well and be open to learning from the expertise that lived experience brings.

Together, researchers and people affected by blood cancer can help ensure that blood cancer research addresses the questions that matter most and delivers meaningful benefits for current and future generations.