

# PUBLIC INVOLVEMENT IN RESEARCH

This information pack summarises what public involvement in research entails, what you can expect if you get involved in research, and what you can expect from the research team at Bone and Joint Health.

# Public Involvement in Research

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## 1.0 Bone & Joint Health

- We are a new clinical academic group based at the Blizard Institute, Queen Mary University London & Barts Health NHS Trust.
- Our purpose is to transform research, education and care for people with bone & joint disorders and injuries.
- Our vision is to be the global leader in bone & joint disorders and injuries.

## 2.0 Who are “the public”?

- The public can be defined as
  - Patients or potential patients
  - Informal or unpaid carers
  - Parents, caregivers, or guardians
  - People who/that use health and social care services
  - People who are living with a condition, disease, or disability
  - People from organisations that represent people who use services
  - Anyone who is not employed as a healthcare professional or academic

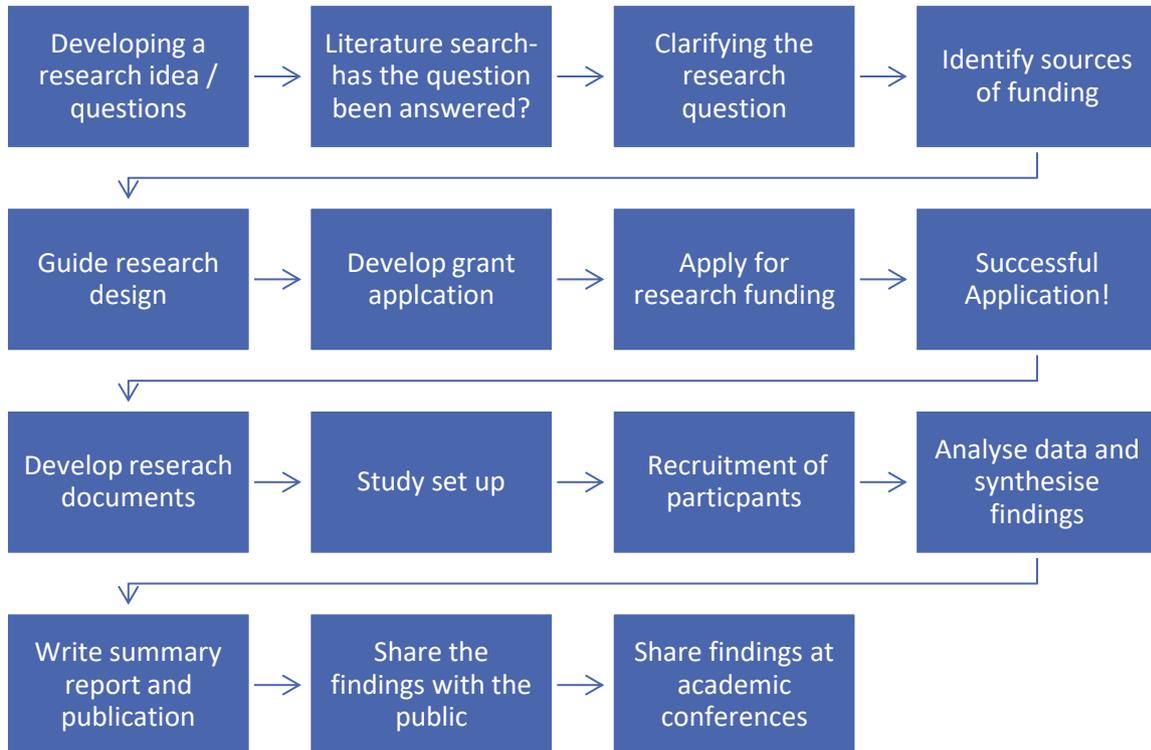
## 3.0 What is patient and public involvement (PPI) in research?

Unless a healthcare professional or researcher has lived through a condition there will be gaps in their knowledge and understanding about a certain condition. This is where a public member can help to fill those gaps.

- Research that is carried out “with” and “by” members of the public rather than research carried out “to” “for” or “about” the public
- Providing a different perspective on a condition or on the research process
- Your lived experience of living with or caring for someone with a specific, condition, disease or disability can help to shape the research being undertaken which can improve the research as well as patient care and outcomes
- Being actively involved in the design and conduct of research

### 3.1 The Research Pathway

The diagram below outlines the research pathway. Members of the public can be involved at any stage of this process.



### 4.0 What might I do if I am a public member of a research project?

There are lots of different opportunities and ways to be involved in research such as: working with funders to prioritise research areas, offering advice as members of a steering group, commenting on and developing research materials.

Each of these will be described in more detail below.

## 4.1 Involvement

Members of the public are actively involved in a partnership with researchers that directly influences and shapes research

### 4.1.1 Prioritising Research Areas

- Work with funders and researchers to identify areas of research that are a priority for researchers to investigate
- Using your personal experience, you can help to identify research areas that are important to you as someone living with a specific condition or caring for someone with a condition of which the outcomes may help to improve the life or management of those living with the condition
- Helps researchers to better understand the lived experience and what is important to people living with the condition as well as research the most important and relevant questions which will lead to improved care

### 4.1.2 Steering Group Member

- Steering groups are part of the research process and provide input and direction to the person leading the research
- Members of the steering group are researchers, academics, and members of the public
- The steering group meets at key stages of the research project such as before the project starts, at regular periods during the project, and again at the end of the project to discuss the findings and how best to share these with the public.

### 4.1.3 Research Material Development

- Many research projects have information that are provided to individuals who may want to take part in the research called Participant Information Sheets (PIS). These describe what the research is about and what would happen if they take part in the research
- A public member involved in the research can help with making sure that this information is clear and easily understood by people who come from different backgrounds.

#### 4.1.4 Research Co-applicant

- Public members can be involved from the beginning of the research idea development and be a co-applicant on a grant application
- A co-applicant is involved in every stage of the research process from developing the research idea, developing the research methods used to answer the research question, help writing up the research proposal and submitting the grant application
- If the project gets funded the co-applicant would then be involved in the research helping to developing information for the public, collecting data, writing up the findings, and sharing (disseminating) the findings with the public

#### 4.2 Engagement

Information and knowledge about research can be shared by the public

##### 4.2.1 Science Festivals

- Public members can share and take part in local and national science festivals where they will help to raise awareness about research and share the findings of current research studies they have been involved in

##### 4.2.2 Media

- Members of the public can help to raise awareness of research and different conditions through sharing their experiences and research findings with the public
- Helping us sharing study findings on social media (Twitter, Facebook, Instagram) creating an informational video or poster, taking part in interviews (TV, radio, newspapers).

##### 4.2.3 Research Centre Open Days

- Members of the public can be part of Research Centre open days where they can share their experiences of research
- Public members can also share their experience of being part of and contributing to research

### 4.3 Participation

Taking part in a research study.

- Members of the public can take part in the research project themselves such as being involved in a clinical trial, taking part in interviews, or completing a questionnaire
- Taking part in research helps healthcare professional to better understand different conditions, diseases, and disabilities to improve health and social care for those people living with the condition.

### 5.0 What to expect as a member of Bone & Joint Health's public advisory group

We are building a network of people from the public who can provide us their views and input in a number of ways. All the ways you can get involved are outlined below. We will contact you when we are working on a new idea to see if you would like to get involved.

If you do get involved in a project we will give you all the information you need about the project and we will let you know from the start of the project where we would really appreciate your input.

### 5.1 The team

You will be provided information about the team that is working on the research project. This may be names, job description, role in the project, emails, telephone numbers, and photographs to help you remember who everyone is.

### 5.3 Glossary

Within research there are many different medical terms used as well as acronyms and abbreviations. It can feel overwhelming at the beginning and takes a while to remember them. The team have created a separate glossary of medical terms that are commonly used within research and grant applications.

This glossary will help you to better understand what the team is discussing as it can sometimes feel like a secret code. With time you will become familiar with these words

and if at any point you want to check the meaning of something you can contact a member of the team.

#### 5.4 Policies and Procedures

The team will share with you policies and procedures that are specific to the research project you are going to be involved in. General procedures and common questions are:

- Disability Access
- Parking
- Travel

#### 5.6 Payment and Reimbursement

- As a public contributor you may be offered payment for the tasks you are requested to do such as attending a meeting or reviewing documents.
- Please refer to the separate Payment and Reimbursement for Public Involvement document for complete details.

#### 5.7 Training and learning opportunities

- The team have resources and training guides available to you
- If you think you would benefit from any specific training just ask the team
- Over time you could develop a CV of the skills you have developed

#### 5.8 How will my involvement be acknowledged?

- Your involvement may be acknowledged through payments and reimbursement for your contribution to the research project
- Your involvement will be acknowledged through how your contributions has impacted on and changed the research for the better
- You will be offered learning opportunities to help to develop your skills, and you may receive certificates for this learning
- Your contribution will be acknowledged through project reports (internal and external), publications, conferences: posters and presentations

## 6.0 What can I expect from the research team?

Standards have been developed to set out what you as a public member can expect from the research team. These standards are the: UK Standards for Public Involvement, there are six key standards:

1. Inclusive opportunities – researchers offer public involvement opportunities that are accessible and that reach people and groups according to research needs
2. Working together – work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
3. Support and learning – you are offered support and learning opportunities that build your confidence and skills for public involvement in research
4. Governance – research teams involve the public in research management, regulation, leadership and decision making
5. Communication – plain language is used for well-timed and relevant communications, as part of involvement plans and activities
6. Impact – researchers will improve their practices by identifying and sharing the difference that public involvement makes to research

## 7.0 What does the team expect from me?

- Respect other team members views and ideas
- Ensure that anything that is said or shared during meetings, public involvement discussion groups, and when speaking with potential participants is considered confidential and not shared outside the meeting
- Be punctual
- Share your lived experience
- There are no “silly” questions
- Challenge the team if you think something could be done differently
- Always provide constructive feedback to other members of the team

## References

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