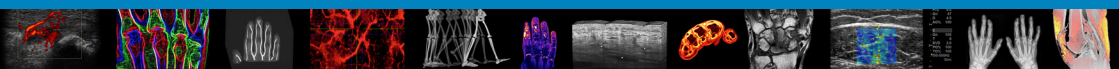




NIHR LEEDS BIOMEDICAL RESEARCH CENTRE
WELCOME GUIDE

FOR **PATIENTS AND THE PUBLIC** WHO WANT
TO BE INVOLVED IN **ADVISING ON RESEARCH**



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INTRODUCTION AND DEFINITIONS

WELCOME

Thank you for showing an interest in Patient and Public Involvement and Engagement (PPIE) at Leeds Biomedical Research Centre (Leeds BRC).

This guide has been written to help answer any questions you may have about getting involved.

ABOUT NIHR LEEDS BIOMEDICAL RESEARCH CENTRE

Leeds BRC is a world leading centre for research to improve treatment for musculoskeletal diseases.

We are one of only 20 Biomedical Research Centres in the country - recognising our excellence in research and innovation.

We are a partnership between Leeds Teaching Hospitals NHS Trust and the University of Leeds and are the only musculoskeletal dedicated Biomedical Research Centre in the UK.

Our predecessor, Leeds Musculoskeletal Biomedical Research Unit was originally established in 2008 and funded by the National Institute for Health Research (NIHR - the national research arm of the NHS) to support research in priority areas



of high disease and clinical need.

The **vision** for Leeds BRC is to improve outcomes for patients with musculoskeletal conditions through understanding the factors underlying disease and developing and evaluating individually targeted treatments.

Musculoskeletal conditions (everything bones and muscles) include:

- inflammatory arthritis (rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis)
- connective tissue diseases (such as scleroderma and lupus)
- osteoarthritis.

Musculoskeletal conditions are the single most common cause of chronic pain and disability and one of the most expensive to treat, estimated to affect 1 in 6 people in the UK.

Our long term goal is the early diagnosis and prevention of musculoskeletal disease.

WHAT IS PATIENT AND PUBLIC ENGAGEMENT (PPE) IN RESEARCH?

Public engagement is where information and knowledge about research is provided and disseminated.

This can be through events, media coverage, social media and newsletters. It is aimed at people who have an interest in finding out more about research.

PPE AT LEEDS BRC EVENTS

We hold regular 'Ask the Researcher' events which are an opportunity to hear from our researchers and learn about particular conditions, what research is being planned and to ask questions of researchers.

We also annually celebrate International Clinical Trials Day and hold a range of events to raise awareness about the research we conduct at the Leeds BRC details of which can be found

on our website: <http://leedsbrc.nihr.ac.uk/events/>, through our twitter account or by accessing our Facebook group (details on page 18).

Events are also publicised in our quarterly newsletter which is sent to all members of the PPI Network.

WHAT IS PATIENT AND PUBLIC INVOLVEMENT (PPI) IN RESEARCH?

NIHR explain PPI as '*where members of the public are actively involved in shaping research projects in research organisations.*' Examples of these types of activity include reviewing patient literature, undertaking interviews with research participants or sitting on project advisory boards.



PPI Members volunteering at the I Am Research Open Day with Professor Emery and Professor Conaghan

PPI AT LEEDS BRC

The PPI network has been active since 2009 and was established to guide, assist and promote research.

We now have a group of over 150 PPI Members and we aim to put the patient at the heart of all the research we do.

There are lots of opportunities to get involved depending on what you are interested in and how much time you would like to give.

Involvement can be attending a one off focus group or a more regular commitment to attend our PPI Core Steering Group for example.

"Patient and Public Involvement is central to how we plan and develop our research, it ensures we keep patients at the heart of everything we do and makes sure our research makes a real difference to people's lives"

**Professor Paul Emery,
Director of Leeds
Biomedical Research
Centre**



HOW YOU CAN GET INVOLVED

Involvement is on a voluntary basis with reasonable expenses provided. Below is a list of some of our current opportunities for involvement:

REVIEWING RESEARCH INFORMATION

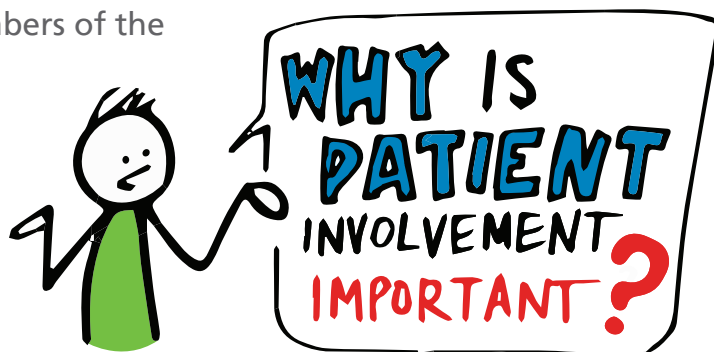
You can help review and comment on information for research participants to ensure that the information provided by researchers is easily understood without lots of medical jargon.

Other documents that you may be asked to review include summaries of studies aimed at members of the

public, study plans, funding applications and information about specific condition areas.

For some research areas we have opportunities to feedback via email or through an online survey. This is a great option for people with limited time.

We will provide you with either questions or a prompt sheet for reviewing literature or reviewing grant applications to help you understand the types of feedback that are valuable to researchers.



FOCUS GROUPS

We hold regular focus groups for individual research studies to gain feedback from a patient's perspective. This can include advising on the early stages of research ideas such as when researchers are planning an application for funding, feedback on the design of a study before it starts and reviewing feasibility of studies.

You will find out about focus groups by signing up to be a member of the PPI mailing list. You will receive an email with a summary of the research, the time of the focus group and any additional supporting documentation that may be relevant.

We ask that you read supporting information in advance of the meeting as the focus group will discuss the content of this summary. Sometimes the researcher is seeking people with experience of a specific condition, whilst other times

the researcher may want to speak with a more general group of patients, the public and carers. This will be made clear in the essential requirements when we contact you.

Any personal information shared during the focus group will be kept confidential, we will ask you to respect others personal information and you will be asked to abide by our 'Code of Conduct' sheet (Appendix 1).



**NO PATIENTS,
NO RESEARCH!**

THE PPI CORE STEERING GROUP

The vision of the Patient and Public Involvement Core Steering Group is:

'To create a community of impassioned, informed and determined people to support and provide advice through involvement in the development and conduct of research at NIHR Leeds BRC.'

The group meet every two months and work with Leeds BRC to support researchers to ensure that they are always focussed on the needs of patients and that patient voice is at the heart of research.

The group sometimes forms subgroups for specific areas of activity and attend events to publicise the PPI activities of Leeds BRC.

New members are welcome to attend a meeting to see if they would be interested in joining.

PRESENTING AT CONFERENCES AND AS PART OF TRAINING

PPI Members may get the chance to present at conferences, meetings or as part of training our emerging researchers.

This is a valuable opportunity to share the lived experiences of patients with clinical staff and ensure that the patient voice is influencing research throughout our organisation.

MEMBERSHIP OF PROJECT AND ORGANISATIONAL STEERING COMMITTEES

We have opportunities for patients to sit on Leeds BRC's board and other meetings such as research steering committees and study management groups.

This is a chance for patient voices to be represented as part of our research and strategic planning teams.

How to get involved

For all PPI activities contact the Patient and Public Involvement Manager on:

email: PPIBRC@leeds.ac.uk

Phone: **(0113) 392 4474.**

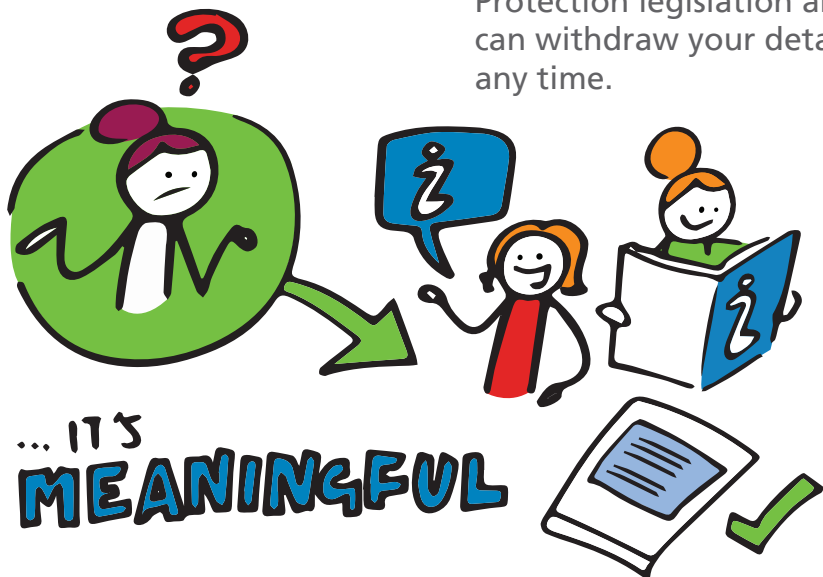
They will explain how you can sign up to the PPI Network through which you can receive information via email or post.

You will hear about all new opportunities for involvement such as focus groups, review of patient literature and new involvement roles through this network.

You will also receive our newsletter which features what is happening at Leeds BRC as well as information about new staff, opportunities for involvement and research updates.

Please ensure that we have up to date contact details for you by advising the Patient and Public Involvement Manager if any of your details change. We will manage your information in line with Data Protection legislation and you can withdraw your details at any time.

PEOPLE NEED
TO **KNOW** WHAT
RESEARCH IS...



'Hello, my name's Lynne and I Chair the BRC PPI Steering Group. Our group are passionate about involving members of the public in research. We have developed this guide to let you know about the different opportunities that are available. If you need more information we have a dedicated PPI Manager who would be happy to speak to you or put you in touch with one of our members if you would like to hear more'

Lynne Lister, Chair of BRC PPI Steering Group



WHAT PPI MEMBERS CAN EXPECT

EXPENSES

When volunteering we will strive to ensure that you are not out of pocket as a result of your involvement.

We will reimburse travel expenses incurred to a limit of £50 for a return trip. Mileage is paid at 40p per mile. Car parking costs will be covered.

We can only provide reimbursement with a complete expenses form accompanied by an appropriate receipt.

Expenses will be reimbursed through cheque or paid directly to your bank account through BACS.

You will be provided with an expenses claim form and a prepaid envelope (if required).

Reimbursement can take between 4-6 weeks. We can book a taxi for members if preferred within the £50 return limit - please advise in advance of the meeting if you require this.

We **do not** provide expenses for attendance at engagement events such as Ask the Researcher unless you are volunteering to support the event.

ACCESSIBILITY

We are committed to ensuring our opportunities are accessible and no one is excluded. If you have any access requirements please let us know prior to any meetings.

Our building and toilets are accessible and we have a hearing loop. Carers are welcome and encouraged to attend.

REFRESHMENTS

You can expect hot drinks and biscuits at meetings which last for up to 3 hours.

If meetings are for a full day or span the full lunch period we will provide either a lunch or reimbursement (through BACS or Cheque on receipt of a completed expenses claim form) for food and a drink up to £6.00.

TRAINING AND SUPPORT

For most PPI activities no specialist knowledge is required. In some instances such as being a member of the PPI Core Steering Group or sitting on a strategic panel / project steering group you may feel you need training to support you to fulfil your role.

We are committed to support you to do this and will identify the skills you need and provide training to support you to develop these.

A POSITIVE AND LISTENING ENVIRONMENT

As a PPI Member you bring expertise of your condition area and experience of being a patient to our research.

Meetings should be enjoyable, positive and your views should be listened to by both researchers and other PPI Members.



EXPECTATIONS OF PPI MEMBERS

CODE OF CONDUCT

PPI is essential to our research activity. In order to provide active and positive engagement between researchers and PPI Members, the Leeds BRC PPI group have agreed a code of conduct when reviewing, advising and consulting with researchers.

We ask that PPI Members make themselves aware of the code of conduct and ensure that they follow this during meetings and in their communications with staff and other PPI Members. A copy of the code of conduct is included at the end of this booklet.



ROLE OF PPI MEMBER

The role of PPI Members is to provide advice from a patient's perspective to ensure research is relevant to those living with MSK conditions.

PPI activities are an opportunity to share your ideas and thoughts as an expert through your own experiences of your condition/s.

Meetings are focussed on how these experiences can influence our research. The meetings are a great opportunity to meet others with shared experiences but are not support groups.

There are a range of support groups in Leeds and nationally that we can help you find information about. If you are going to be late for or unable to attend PPI meetings please inform the Patient and

Public Involvement Manager if possible, especially if we have organised transport for you.

There may be times that they cannot include the suggestions of patients due to these requirements.

ROLE OF THE RESEARCHER

The researcher will lead discussions and keep them on track and relevant to the research areas discussed. They will consider feedback and how this impacts on their research.

It is the responsibility of the researcher to ensure technical and scientific excellence and to make sure the design and conduct of the research meets legal and regulatory requirements.

RESEARCH MAKES A DIFFERENCE



The Leeds BRC team, PPI members and partners celebrating the launch of Leeds BRC

FREQUENTLY ASKED QUESTIONS

1 Do I need any qualifications / experience to be involved?

We want to hear from people from a range of experiences and backgrounds. You do not need any specific qualifications or understanding of medical research.

Some focus groups will require you to have experience of a certain condition, however this will be made clear when you are told about the opportunity.

2 How often do I need to be involved?

There are no requirements about the length of involvement or how regularly you are involved.

3 Can carers / family members get involved?

Carers / family members will often have an interest in and an appreciation of the lived experience of conditions and we encourage them to also get involved.

4 What do I do if I have a bad experience during a meeting or involvement opportunity?

We always strive to address any concerns immediately. If you are unhappy with your experience and would like an informal discussion please contact The Patient and Public Involvement Manager (details on page 19) However if you are not satisfied or would like to raise a formal concern you can contact:

Medina Inamdar
Business Operations Manager

email: medina.inamdar@nhs.net

Phone: **0113 3924485**

5 Why should I get involved?

There are many reasons to become involved. You will be contributing to improving how we do research, making it a better experience for research participants, and ultimately contributing to the advancement of health care in the future.

You will meet new people. You will be able to provide a valuable insight into the lived experience of a condition and help us prioritise research which makes a real difference to the lives of people with your condition.

6 Can I leave at any time?

Involvement in PPI activities is voluntary and you can leave at any time during the meeting.

7 Where are meetings held?

Most meetings will be held at Leeds BRC, at Chapel Allerton Hospital (directions on page 18).

On occasion we run events in different locations and this will be made clear on the poster or information provided.

8 I receive benefits, how will being involved affect this?

INVOLVE have a Benefits Advice Service which is specifically set up for people who are involved in research PPI activities.

They can be contacted by email: involve@nihr.ac.uk
phone: **02380 595628**

You will need to tell them you are involved with NIHR Leeds BRC.

They will give you an email address (or telephone number) so that you can contact the Benefits Advice Service directly.

They will also give you a code. Please give this code to the service when you contact them.

FURTHER INFORMATION AND CONTACTS

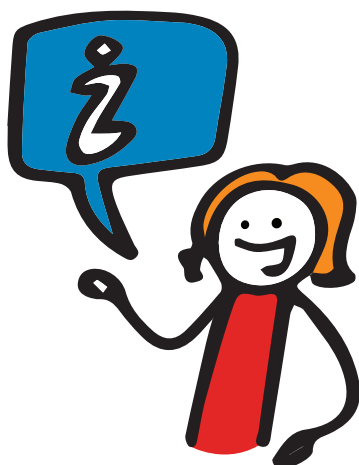
LOCATION OF PPI ACTIVITIES

PPI activities are held at Leeds BRC, which is located in the Clinical Research Centre at Chapel Allerton Hospital.

The centre has its own entrance by the hospital car park or can be accessed through the main reception area.

Further directions can be found online at

<http://leedsbrc.nihr.ac.uk/get-in-touch/>



More information about getting to Chapel Allerton Hospital such as bus routes and car parking can be found here:

<http://www.leedsth.nhs.uk/patients-visitors/our-hospitals/chapel-allerton-hospital/how-to-find-us/>

CONTACT

NIHR Leeds Biomedical Research Centre,
Clinical Research Centre,
First Floor,
Chapel Allerton Hospital,
Chapeltown Road,
Leeds, LS7 4SA



(0113) 392 4474



leedsth-tr.LMBRUnit@nhs.net



<http://leedsbrc.nihr.ac.uk/>



Twitter @LeedsBRC

You can call or email the Public Involvement Manager at any time to discuss PPI activities, sign up to our mailing list or for any other questions relating to events and PPI activities.



PPIBRC@leeds.ac.uk



(0113) 392 4485

Or you can sign up to our mailing list directly at:



<http://leedsbrc.nihr.ac.uk/keeping-touch-leeds-biomedical-research-centre/>



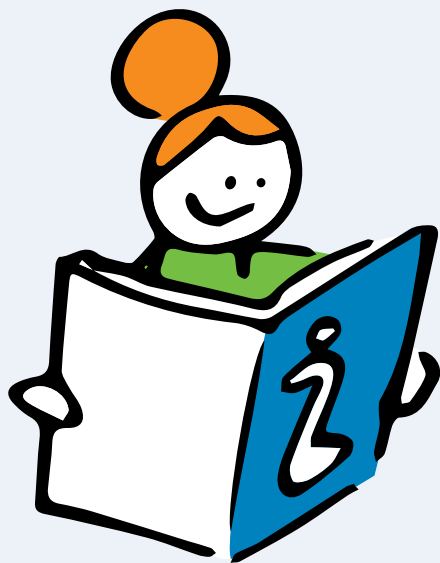
Professor John Fisher with PPI representative – we want to co-create the right technology solutions

CODE OF CONDUCT

Leeds BRC PPI Members

In order to provide active and positive engagement between researchers and PPI Members, the Leeds BRC PPI Core Steering Group have agreed a code of conduct when reviewing, advising and consulting with researchers.

This document sets out the standards of behaviours expected by PPI Members when consulting on research.



The Code of Conduct is to be signed by volunteers participating in PPI activities such as focus groups or reviewing confidential information such as grant applications.

The purpose is to:

- Give assurance to PPI volunteers
- Give credibility to the group and ensure a professional understanding of the confidential nature of the material to be discussed and reviewed
- Give assurance to researchers

PPI Members agree to work in partnership with researchers to identify, design, prioritise, conduct and disseminate patient focussed research that is relevant, ethical and will make a difference to patient care.

EQUALITY AND DIVERSITY

We are strongly committed to the promotion of equality and diversity for PPI Members and staff.

PPI Members' behaviour and attitudes must be consistent with the aims of the BRC PPI Group to support inclusion, diversity and equity for all.

RESPECT

PPI Members must treat each other, researchers and others they come into contact with when volunteering in their role with respect and courtesy at all times.

PPI Members must respect different opinions and experiences - listening to and recognising the value of others' contributions to discussions.

We ask that feedback is constructive and conducive to improving the quality of our research.

CONFIDENTIALITY

PPI Members must respect the status of confidential issues they read and discuss. They are bound to maintain the status of this material and any information shared by researchers or other PPI Members.

INTEGRITY

PPI Members are required to use their knowledge, expertise and experience to give the best advice they can.

PPI Members should act in an individual capacity and not as a representative of any group, organisation or individual.

PPI Members must not accept gifts or hospitality which are aimed at compromising their neutrality.

COMMITMENT

PPI Members should prepare for meetings to ensure they add value to any PPI activities and should inform the PPI Manager if they are unable to attend.

CONFLICTS OF INTEREST

PPI Members should identify and promptly declare any actual, potential or perceived conflicts affecting them.

If you hear something within a focus group which you feel would be a conflict of interest for you, please make the researcher aware.

A conflict of interest could be working for or having involvement in activities, organisations or funders related to the research or being involved as a participant in a research trial directly related to the research you are discussing.

If you are unsure please raise this with the Patient and Public Involvement Manager or the researcher.

OPENNESS AND ACCOUNTABILITY

PPI Members must be open, responsive and accountable to each other, members of staff and other stakeholders about their involvement, actions and work, including their use of PPI group resources.

NOTES

