Positive Patient and Public Involvement (PPI) in Research at Leeds
Acknowledgements

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Introduction

What is Patient and Public Involvement?

Patient and Public Involvement (PPI) is “research that is done with or by the public, and not to, about or for the public.”

PPI can be a range of activities, from the public proposing their own research projects to providing input for researchers’ projects. It can be as much or as little of a time commitment you can give.

*Ok to Ask* event at the Leeds City Market, May 2016
Why is Patient and Public Involvement Important?

The National Institute of Health Research (NIHR) defines PPI as “members of the public actively involved in research projects and research organisations”.

The NIHR states that patients and the public must be actively involved in planning and reviewing research activities as “involving patients and members of the public in research can lead to better research, clearer outcomes and faster uptake of new evidence.”

Patient and public involvement ensures that research remains focused on the needs of the users of health and social services in the NHS.

What are the LCRF and the LMBRU?

The Leeds Clinical Research Facility (LCRF) and the Leeds Musculoskeletal Biomedical Research Unit (LMBRU) are dedicated to providing the resources to conduct world-class research. The LCRF focuses on delivering ground breaking early phase clinical trials. The LMBRU focuses on the translation of research from bench to bedside.
Musculoskeletal Research

Musculoskeletal conditions are estimated to affect one in six people in the UK and can lead to chronic pain and disability. They include osteoarthritis and inflammatory conditions such as rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, scleroderma and lupus.

Musculoskeletal research at Leeds focusses on improving the diagnosis and optimising the treatment of these conditions in order to improve outcomes for patients. This includes studies to identify factors which influence progression of disease, clinical trials to investigate medicines, development of devices such as joint replacements, and studies which evaluate patient experience.

Patient and Public Involvement is key to this work. Leeds Musculoskeletal Biomedical Research Unit has had a PPI group since 2009. Members can receive regular newsletters and updates and attend public engagement events such as “Ask the Researcher”. Members also support the research in a number of ways:

• Shaping the kind of research we do to ensure it always has a patient based focus.
• Reviewing information for patients and the public to ensure it uses unambiguous language and can be easily understood.
• Helping to increase public awareness of our research.
• Providing advice to researchers to improve their projects and make them more acceptable to patients.
• Advising on the conduct of ongoing studies.
Musculoskeletal Research

The Impact of Patient and Public Involvement

Researcher Laura Horton describes how PPI enhanced her research project:

“My study required the development of a patient information booklet. I circulated an early draft to the members of the Leeds Musculoskeletal Biomedical Research Unit PPI group and received many constructive and detailed replies to my request for feedback on the content and style of the booklet. In response to the suggestions, I changed the font, font size, added some pictures, got rid of jargon and clarified some sentences which were previously slightly ambiguous. As well as this I re-ordered some of the sections of the booklet in order to make the text flow more intuitively. Without the input of the PPI group, the booklets would not have been as well received and easily understood by the participants of my study. The patient information booklets are essential in the process of informed consent, so it is of paramount importance to get them right”.

PPI members at the Yorkshire & Humber NIHR Voices regional event, November 2016
Musculoskeletal Research
Sue Watson

**Being a member of a PPI Group**

I think the PPI group is great because it is open to anyone, it’s just for ordinary people with an interest in health research. You don’t need medical or formal training to be involved in the group. Anyone can give as much or as little time as they can, and everyone is welcomed no matter what their background. I get to meet others with the same interests as me, and I have the knowledge that our help today will benefit those with similar musculoskeletal conditions in the future (I have rheumatoid arthritis). This really helps the group as a whole to gain confidence in our involvement, and really feel that we are making a positive difference.

**Why PPI is important and what it involves**

PPI gives patients and the public the opportunity to be more involved and make real change. The PPI group really helps to de-mystify the research process; so many people think of research as just taking drugs, but there is so much more to it. One of the ways I have been involved is at the “OK to Ask” event (held yearly in May). In 2015 I spent some time at a stall at Leeds market talking to people about the different types of research available. I also attend “Ask the Researcher” events and focus group meetings where researchers come and talk about their projects and we provide feedback.
Musculoskeletal Research

Sandra Purdy

It is important for researchers to be ‘grounded’ to the patient’s needs and not just think about the academic or scientific requirements of their studies. It is good for patients/public to have a say in how trials are conducted to protect the interests of the patients and ultimately improve recruitment rates by raising any concerns about the study that would be off putting to patients and thereby present a problem to recruitment.

Initial motivation was to re-pay something back as I had personally benefited from taking part in a clinical trial in the past. Now I have more understanding of the role I want to be involved to ensure research is continued and is successful in the hope that better treatment will be available in the future for my children and grandchildren who have a likelihood of getting the disease Ankylosing Spondylitis. I have also met new people and gained a broader understanding of all aspects of Rheumatology and treatments.

We meet about every two months. In between meetings I may be asked to review literature to ensure it is understandable to a patient and not too technical. This can take up a couple of hours to read/digest and comment but it is time well spent to make sure patients get the right information in a manner that they can understand.
Cardiovascular Research

Christine Thompson

My name is Christine Thompson, my husband Ian is taking part in a clinical trial for a new cholesterol reducing drug. I attend his appointments at the hospital and I also administer his injection every two weeks. As a result of his involvement in the trial we were invited to join the “PPI Group” and we attend the quarterly meetings where we meet members of staff and other volunteers.

We receive excellent presentations by members of the senior staff within the organisation covering not only the clinical trials being run at the LGI but also additional medical information. I find these extremely interesting and very informative. We are given the opportunity to chat to members of staff, to feedback our experiences and ask any questions that may be bothering us. Although I am not a patient I feel that I am part of the team and value being part of such a great group. I would whole heartedly recommend joining the “PPI Group”.

Anyone can do PPI
Cardiovascular Research

Julie Corrigan

Leeds Clinical Research Facility Operations Manager

Before becoming the Leeds Clinical Research Facility Manager, my background is as a Cardiac Physiologist specializing in non-invasive investigations with an interest in education, training and research. I organise the Cardiovascular Patient Group meetings on the Leeds General Infirmary site and I try to ensure a varied programme of speakers along with high quality and plentiful refreshments!

The patient, carer and public group is integral to the success of the research taking place as we absolutely value the opinions of our volunteers and involve them in important decision making, particularly during the set-up stage of new studies.

As I am now generally ‘desk-based’ I look forward to every meeting greeting old friends and ensuring that the patient perspective is central to everything that we plan and carry out. We welcome new members all of the time and there is a lovely atmosphere at each meeting of friendship and teamwork. The Cardiovascular Patient group meets generally every three months with email or postal correspondence in between these meeting dates.
Cardiovascular Research

Ian Thompson

I was happy to take part in a five year trial for a cholesterol lowering drug. I felt pleased that in a small way I could be helping future generations reduce the risk of heart attacks. The trial required me to visit the LGI every three months. I really enjoyed these visits. The Clinical Research Facility staff are great and made me feel one of the team. When the trial period ended I was devastated. I then heard about the PPI group and asked to join. I’ve been to a number of meetings and met other volunteers. I’ve had easy to understand details of future studies being told by professors! I get involved in producing documentation and I hope to be able to spread the word at events on just how good it feels to be a volunteer trialling new drugs and methods within the research taking place at Leeds General Infirmary!
Anyone can do PPI

Yorks region PPI event in Leeds, November 2016

LCRF showcase event at Leeds Market, December 2016
Oncology Research

Dr Maria Jove

Research Fellow

I am a Medical Oncologist from Spain, trained in Institut Catala d’Oncologia, and now a Clinical Research Fellow in Phase I clinical Trials. I started working in Leeds Clinical Research Facility in April 2014, working with Prof Chris Twelves in the Phase I clinical trials team and Breast Cancer clinics, and with Prof Susan Short in a specific phase I clinical trial of a cannabinoid derivate and the Brain tumours clinics. After the first year, I won a grant from the Spanish Medical Oncology Society to continue my work in phase I clinical trials unit and to do a laboratory research project of Intratumoral Drug Penetration with the Pharmacokinetics Team (the team who looks at what our body does to the cancer drugs) of the Institute of Cancer therapeutics in Bradford University under the supervision of Prof Chris Twelves and Prof Paul Loadman.

I visit patients on Wednesdays in the early phase clinical trials clinics where most of the patients have been through all standards of care therapies. Therefore, as well as to give the patients the opportunity to participate in a clinical trial, it is very important we ensure they maintain their quality of life and have all the Gold Standard of Care Framework in place.

Since the first day I started working here I have felt part of the team. Team work in these circumstances is essential and I would describe our team as a friendly and lovely place to work. Moreover, my PhD research in Bradford will hopefully help to increase the understanding of cancer and aid in the development of a better drug delivery for this complex disease.
I became involved in PPI whilst on chemotherapy for breast cancer in 2010 when I joined the Leeds PPI.

I was offered the opportunity to sit on a National Clinical Studies Group for Breast cancer. This has lead to many other opportunities to provide a patient perspective. Including inviting to join Trial Management Groups.

My input has been actively sought and welcomed, and often resulted in changes to design of trials, content of patient information leaflets and even decisions on funding.

My involvement as also provided the opportunity to connect to other patient groups and researchers across the country and learn more about the actual research work including getting the opportunity to perform some of the laboratory techniques used.

I have learnt many things about patients contribution to research. Involvement can range from small studies where only consent is needed to use tissue donated following completion of diagnostic use through to longer term studies involving new treatments.
I am a passionate graphic designer and as part of my research whilst undertaking an MA Creative Practice I investigated opportunities for effective collaboration between art practitioners and healthcare professionals, creating new mechanisms to develop change and narratives for the future. The PPI group meetings give an invaluable insight into the work involved within clinical trials. I felt my personal and professional experience could be of value to the group and felt my contributions may help in the future.
Case study of how the PPI group influenced future research

“As we were developing our application to become an NIHR Diagnostic Evidence Co-operative (DEC), we met with the NIHR Leeds Musculoskeletal Biomedical Research Unit (LMBRU) PPI Group for advice on how to effectively incorporate patients and the public in our programme. The LMBRU PPI Group invited us to join one of their forums so we could see how their group ran. The PPI members advised us on how to incorporate patients and the public into the different levels of DEC governance and shared their PPI Group Terms of Reference, policies and forms with us, allowing us to adapt these documents for our own group. As our plans for the DEC also covered the Musculoskeletal clinical theme, a few of the LMBRU PPI members also volunteered to join our group and help with our work. We incorporated the advice from the LMBRU PPI Group into our proposal, which was successful in securing £999,255 NIHR Infrastructure funding”.

Principles of Good PPI

• Building on people’s existing capabilities
• Promoting mutuality and reciprocity
• Developing peer support networks
• Breaking down boundaries
• Facilitating as well as delivering

NIHR Going the extra mile
If you would like more information, please visit:

**INVOLVE**, the NIHR’s PPI resource for the public and researchers:  
invo.org.uk

The Leeds Musculoskeletal Biomedical Research Unit:  
lmbru.leeds.ac.uk

The Leeds Clinical Research Facility (LCRF): leedscrf.nihr.ac.uk
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