

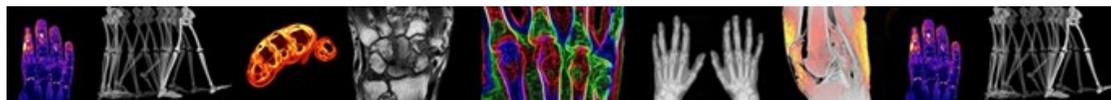


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Patients Matter

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The Leeds Musculoskeletal Biomedical Research Unit
Patient and Public Involvement Newsletter



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Welcome

Welcome to the newsletter of the Leeds Musculoskeletal Biomedical Research Unit Patient and Public Involvement Group.



Chapel Allerton Hospital where our Patient and Public Involvement Group is based.

Who we are...

The PPI group of the NIHR Leeds Musculoskeletal Biomedical Research Unit (LMBRU) was established in 2009 to guide, assist, direct and promote research within the LMBRU. Our mission is to create a successful partnership between patients, carers, members of the public, and researchers in order to ensure that the research undertaken within the LMBRU makes a difference to improve patient care.

What we do...

The group is comprised of volunteer patients, carers and members of the public who have an interest in advising and shaping musculoskeletal research.

Our members...

- Engage with researchers
- Provide feedback on research proposals
- Advise on content and presentation of patient literature
- Communicate with the general public
- Contribute to planning the strategy for research
- Advise on issues such as recruitment and publicity



Recent News



The LMBRU would like to congratulate Anne-Maree Keenan on being awarded the prestigious title of Professor from the School of Healthcare at The University of Leeds in August 2015.

This position and title recognises the extensive work completed by Anne-Maree in the field of musculoskeletal research and as a champion of non-medic research

participation.

Those of you who know Anne-Maree will recognise that she is not a native of Yorkshire. Her cultural roots, sense of humour and love of sport originate from the other side of the world in Australia. After qualifying as a podiatrist at Lincoln Institute of Health Sciences in Melbourne, Australia, Anne-Maree worked in both the public and private sector as a podiatrist. Alongside her podiatrist role, Anne-Maree also taught part-time. Not satisfied with sun and sand, Anne-Maree decided to leave Australia to seek out the cooler climes of Yorkshire and came to work in Leeds in 2002. With the cold affecting her faculties, she embarked on studying a PhD looking at the effects of osteoarthritis on quality of life. The title of Dr was awarded in 2008 with the completion of her PhD.

The newly acquired skills obtained from her PhD resulted in being appointed Assistant Director of the LMBRU, and the rest as they say, is history.

Anne-Maree has been invaluable and integral in the setting up, running of and acquiring new funding for the LMBRU. She always has a smile and an open door for everyone, except when there is room for discussion of the qualities of a certain National team's performance in the rugby or cricket.

The Patient and Public Involvement Group would also like to add their thanks for all the help and support Anne-Maree has given them since the start of 'Ask The Researcher' events and look forward to hearing all about her new role.

Anne-Maree will still be around so don't worry; her never ending list of skills are required to help write the NIHR funding bid for the LMBRU.

Thank you Anne-Maree for everything you have done (and are about to do) for the LMBRU. We wish you every success for the future, but don't forget the patients and the staff you leave behind.

[You can read more about Anne-Maree on our new and](#)

Upcoming News

The LMBRU Website is being updated

Watch this space for our new and improved website which will provide information about the LMBRU, patient and public involvement and the research which is taking place. It will have recent news stories as well as upcoming events, so keep a look out for the new design during March!



What We Do

The LMBRU was awarded £6.2 million to support translational clinical musculoskeletal research in 2008. Funding awarded by the NIHR must be patient centred and show benefit to patients within 5 years of the award. In order for grants to be successful, it is essential to involve both the public and patients to ensure that the research is patient focused. The LMBRU respects and encourages interactions with our extensive PPI group and value their inputs into it's projects. Here are some examples...

Richard Wilkins has been successful in his application to the NIHR and will start a clinical doctoral research fellowship in April 2016. Richard works as a hospital specialist podiatrist for Leeds Teaching Hospitals NHS trust and is a member of the Foot and Ankle STudiEs in Rheumatology (FASTER) group lead by Professor Anthony Redmond. Richard's project is titled; Haemarthrosis of the ankle in haemophilia A and B: prevalence, impact and intervention. Over the course of the 5 year project Richard will establish the impact and prevalence of blood in the ankle joint, explore the mechanical properties of a new boot design, and explore the feasibility of conducting a national study providing footwear and orthoses to patients with damage cause by blood in the ankle joint. Richard has presented to the PPI group and his last presentation was circulated to members of the PPI group with the recommended changes receiving positive feedback.

Gui Tran recently came to the PPI group for involvement with his application for an NIHR Doctoral Research Fellowship. Gui intends to understand how ultrasound scans of shoulders can help with the management of shoulder pain. He hopes to explore if people with different ultrasound findings have different outcomes. These findings may guide the way for the best therapy for people with shoulder pain. The PPI group thought that this was a great idea, and after a few suggestions to his project, think this will have a great chance of succeeding. Good Luck Gui!

What We Do



Medical Education
Leeds

The Leeds Teaching Hospitals NHS Trust

Volunteer Patient Community

Would you like to contribute to the education of our future doctors?

The Leeds Teaching Hospitals Trust, Medical Education Undergraduate Team are looking for patient volunteers to give a little of their time to be involved in the education of our healthcare professionals.

We would be really grateful if you would allow our students to talk to, examine and learn from you about your medical history, the care that you are receiving, and how your illness impacts on your life and your family. This would allow our students to learn from your experience of illness and is a vital contribution to our medical training programmes.

Who can be a volunteer patient?

We are looking for adults of any age with a medical condition they can discuss with undergraduate medical students.

How to get involved?



New Research Projects

Research around Rheumatoid Arthritis: R4RA

There are a number of options for treatment following on from anti-TNF therapy, however there is currently no clear rationale for deciding which treatment is superior in patients who have initially failed anti-TNF therapy. This study aims to investigate whether the choice of drug treatment may be influenced by different cell types in synovial tissue (tissue which lines joints and becomes inflamed in people with RA). This will hopefully provide evidence for stratifying patients into different treatment groups following anti-TNF therapy. The ultimate aim is to provide a tailored approach to treatment decisions in patients at this stage of their disease, in order to maximise their potential to respond to therapy.

Research around Osteoarthritis: STROPP

This study looks at pain arising from the kneecap joint to identify groups of people with similar causes for their pain. The study hopes to be able to improve the groupings of people with kneecap pain by using different testing methods on one study group, alongside a group of people having physiotherapy. Hopefully they can find a sub-group of people who can be treated better if the treatment is more targeted

Research around Connective Tissues Disease: Sjogrens Access to Care

Participation of this study is through a questionnaire. The purpose is to find out what it is like to live with Sjogrens, experiences of accessing care when symptoms of Sjogrens first began, and the risks associated with this illness. The questionnaire will take about 30 minutes.

You can read more about our current research on our new and improved website later this month: www.lmbru.leeds.ac.uk

Upcoming events

OK To Ask—International Clinical Trials Day

Friday 20th May

Last years Ok to Ask Campaign was a huge success and we are pleased to announce that we will be holding another open day this year at Chapel Allerton Hospital. The Event will run between 10am and 3pm and aims to raise awareness of research and encourage people to ask about research opportunities that could be available to them or their families.

Planned activities on the day include:

- Tours of the MRI unit
- Demonstrative ultrasound scans
- Gait Lab analysis tours
- Tai Chi Beginner's session
- Presentations by study participants and PPI members of their personal research experience
- Interactive stalls with researchers
- Refreshments and light lunch



An Interview with Kirste Mellish

LMBRU Director of Operations

What is your background?

I started out my career as a biochemist. I did a degree in Nottingham and then a PhD at the Institute of Cancer Research in London. I spent a few years doing postdoctoral lab based cancer research at universities in the USA, Liverpool and then came to Leeds. I liked Yorkshire so much I have never left! I worked for a University of Leeds spin out company called Photopharmica for 6 years organising and running clinical trials of new medicines and medical devices. I then joined the NHS working at Bradford Institute for Health Research, first managing a national NIHR stroke research programme, followed by setting up a care home research network across West Yorkshire and then working on healthcare service improvement projects as part of the Yorkshire and Humber Academic Health Science Network. I spent the last year working for the three Leeds clinical commissioning groups (CCGs) on “Discharge to Assess”, a project to help people leave hospital sooner for further assessment and support in their own home. I’ve also been a volunteer on Bradford-Leeds Research Ethics Committee for a number of years.

What brought you to LMBRU?

The work I was doing for the CCGs was challenging and interesting, but I missed being in a research environment so I jumped at the opportunity when I saw the Director of Operations role at LMBRU advertised. The LMBRU has an excellent reputation for translational research and I felt I could use my experience and knowledge to support research that makes a real difference to patients. Fortunately I was successful and I started the role in January 2016. My job is to make sure that all of the LMBRU functions are operating effectively to support the research. This includes imaging activities, PPI group,

information systems and administrative processes. My role also involves communication with NIHR, prioritisation of research activities, oversight of budget and developing future plans for LMBRU.

What involvement have you had in research and PPI before?

I started my clinical research career at Photopharmica, a small inexperienced company at the time, and it’s fair to say that we didn’t really understand the importance of PPI. My first real involvement in PPI was when I started working in stroke research. We were developing ways of supporting stroke survivors and helping them to adjust in the months and years after the stroke, so it was crucial to find out their perspective. We involved stroke survivors and carers in management of clinical trials, development of new research ideas, and review of documents. I learnt how valuable this contribution is and how keen many people are to share their experiences. PPI (or “resident and relative” (R&R) involvement) was more challenging when I was involved in care home research and mostly involved relatives rather than care home residents themselves who were often too ill to participate. In my last role I was involved in the Leeds West CCG Patient Leader programme. We had two patient leaders on the Discharge to Assess Steering Group who also supported us to conduct focus groups and semi-structured interviews to find out the views of patients and the wider public on the Discharge to Assess service.

What do you look forward to in the future of the LMBRU?

It is an exciting time for the LMBRU. We are in the process of applying for funding to continue our work from April 2017 to March 2022. If successful, this will see us linking up with cardiovascular research to become a Biomedical Research Centre. We are also hoping to get the funds to buy a second MRI scanner and build an extension to house it in 2017, so I am looking forward to putting into practice everything I have learned from watching Grand Designs ...



An Interview with Barbara Hartley

PPI Member

1. How did you get involved with the PPI Group?

I was involved in a study of Dr Tran's 5 years ago, and I heard about the PPI group through one of the research nurses. I attended the next Ask the Research Event and put my name on the mailing list, and Sue Smith emailed me about the upcoming events which I then attended regularly.



Barbara (right) with fellow PPI member Val Davies

2. Why do you think PPI is important?

If people didn't get involved in research and share their knowledge as patients then research would not progress. The events are great because people who attend them sometimes become more interested in taking part in research. Sometimes what you read about a subject doesn't give you the same information as when you hear it directly from a researcher. Many people who have illnesses feel too unwell to want to leave their house, but by coming to the events you can speak to others and share experiences; it's like comradeship—a support network. You can also speak to doctors who present at the event to find out more information about research around different diseases.

3. What do you gain from being a part of the PPI group?

You feel as though you are giving something back. We help to give

researchers ideas of how to get people involved, and by doing this we help the research be more reflective of what patients need. Sometimes researchers are closed to technicalities, and we can provide patient feedback – things that they may not have realised from our point of view. You get a good vibe when you walk into the research unit with Tracy on the door and you really feel valued. It's a great boost.

4. What can others gain from being involved in research?

We take information, disseminate it, and pass it back out. We're a platform for both researcher and patients to get the message out there to take part. In the past patients have become upset about having MRI as they don't know what to expect. Our group can help patients to understand what will happen and explain the use of the scan.

5. Can you tell us a bit about a research study which you have been involved in.

I was on a steering group for a study called AKI (Acute Kidney Injury) which was developed due to findings during war and conflict. On the battlefield they found men with kidney complaints and realised if they treated them quickly, they would recover better. I was able to give a different viewpoint towards their study and helped with their milestones as they were missing deadlines. I was able to help them to see why they were missing them.

6. What's been your favourite Ask the Research Event?



Spotlight Tracy Hulland

Radiographer Assistant

Background

Tracy was a radiographer assistant at Cookridge Hospital in Leeds. After a few years in this role she decided to complete an access course at Park Lane College in order to gain a place at university to become an oncology assistant practitioner. After two years she gained a diploma, but due to illness had to stop her studies before she could finish the final year. She returned to work but her illness caused her to take a step back in the type of work she could do. After a few years Tracy decided that she missed the patient contact too much and motivated herself to push through her illness in order to get back into the type of work she enjoyed. It was at this point she applied for a radiographer assistant position at the LMBRU, and became a major part of our team.



Research

As well as ME, Tracy had a mild form of Psoriatic Arthritis, which was exacerbated when she had her son. Fortunately, whilst she was on maternity leave, Chapel Allerton Hospital gained a dermatology department which meant she had advice on hand! She was recommended to take part in a research study which helped with her condition. Tracy is grateful towards research as she wouldn't be where she is now without it. And more than this, she sees so many patients coming out the other side of illnesses,

and sees their improvements.

Her own experiences of research contribute to Tracy being an asset of the unit. She has a lot of understanding towards what patients are feeling, alongside her full knowledge of what they can expect. Furthermore she has been on similar medication to many patients and can be supportive about how they are feeling, and how it is helping them. She can explain to patients how valuable they are towards the research and actively show them the reward of taking part.

Your date with Tracy

If you come to the LMBRU, Tracy will be the first person you meet when you come to our reception. She will welcome you with a big smile and have a chat to make sure you're feeling OK about your appointment over a cup of tea. She is there with patients throughout their whole journey in the research unit; she helps patients to complete safety checks, chaperones patients to their different scans, cannulates and takes bloods, positions patients on the scanner and sits with them if they are claustrophobic. She makes sure patients are in a fit state before they leave the unit and answers any questions they may have.

[You can read more about Tracy on our new and improved website later this month](#)





Patient and Public Involvement Group



*Some of the PPI core members at a recent PPI
planning meeting in LMBRU*

Want to be involved?

You can get involved with LMBRU PPI in a number of ways.

- Come along to our ask the researcher event
- Get involved with the PPI group we have meetings every two months
- Volunteer to be on a PPI study focus/PPI advisory group
- Review grant applications

Contact **Susan Smith** or **Emma Rice** for more details:

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Telephone: 0113 3924474 / 01133924485

Visit: <http://lmbu.leeds.ac.uk>

