

The Wrightington Wigan and Leigh Patient Research Advisory Group

INVOLVE defines public involvement in research as research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.

What do we do?

At WWL we believe that patient and public involvement in research is extremely important. As with the INVOLVE organization (<https://www.involve.org.uk/>) we believe that people should be at the heart of decision making about research. To facilitate this, we have established the WWL Patient Research Advisory Group

Aim of our group

- To involve lay people, for example patients and service users, to work in collaboration in research at WWL as we work towards a common vision.
- To try to ensure that the work that we do meets the values of the INVOLVE organisation which shares the belief that everyone in society has an equal right to be listened to and participate in decisions that affect their lives.
- To help to develop research questions and design ways to answer them by working alongside clinicians.
- Promote and champion the benefit of public involvement in research.
- To act as Patient Partners working as members of teams to develop grant applications to secure funding to carry out research.
- To improve patient outcomes

Objectives of our group

- To help to identify which research questions are important to fund
- To shape the way that research is planned by working on research projects together with WWL clinicians alongside experts from Academic Institutions and Clinical Trials Units.
- To improve the experience of people who take part in research by influencing the way it is carried out
- To influence the choice of the design and the way that research should be carried out by suggesting measures that are acceptable for people who use the services
- To increase the number of people who take part in research making sure it is of good quality and is easy to understand. We aim to ensure that research information and findings are provided in user friendly ways and shared as widely as possible.
- To try to reach out into our community to overcome the barriers of being involved in research ensuring that we address issues of both inequality and diversity.
- To try to alleviate fears of taking part in the research studies by giving clear and understandable explanations e.g. when new methods of treatment or new medications are involved

Our members tell us:

"I feel that my contributions were valued. I have enjoyed and learnt from hearing the life lessons of my fellow volunteers, prompted by the research topics under discussion. I feel that barriers to conversations with clinicians are broken down. This has given me an excellent insight into the process of the whys and the wherefores for research and barriers to gaining funding for research projects."

"I try to bring an open non-medical mind and patient's point of view by clarification of the why and how the research will benefit the patients".

"I know speaking to family and friends about research most do not understand what it entails and how much work and time is involved in the process. I personally find that the meetings are very interesting and that we can be involved in a variety of subjects. I feel my opinion matters."

"I really enjoy meeting and working with people with a range of different backgrounds and conditions. Everybody has something different to contribute and are all really friendly and supportive. I feel I have learnt something new after every meeting and also have a greater insight into my own condition. It has also been interesting to meet medical staff and researchers from both within the Trust and from other establishments'.

"It is early days, but I feel we are increasingly being seen as a resource which can provide support and add value to a range of research proposals and ongoing projects. Hopefully our discussions have given researchers a greater insight into their work from a patient's perspective."

"I am an ordinary member of the public with no specific medical knowledge. I come to each task with an open mind and look at the proposals from a lay persons view point. I ask questions about things I do not understand so the researchers can see if clarification needs to be added to their proposal."

Our researchers tell us:

"The patient research advisory group is a great asset to the Trust. I am an early career researcher and have been guided by them at various stages of research. I have approached the group for developing multiple research projects and they have been kind enough to read through research documents and provide valuable feedback. Their feedback ensures that the research projects at WWL Trust as easily understandable and accessible for potential participants.'

"Following a lengthy consultation with the group, I was able to modify interview questions to make them easier to understand, relevant and comprehensible. The group helped me to refine my thinking around the interviews, ensuring that I was capturing the most important aspects for patients regarding their fatigue experiences'

"I would like to extend my thanks to the patient research partner group for their interest, support and enthusiasm for our project. Particularly, I am extremely grateful for the relationship we have been able to develop over the last 4 years and their warm welcome and engagement during and after our meetings. I would also like to thank all the patients and healthcare professionals who participated in my research studies.'

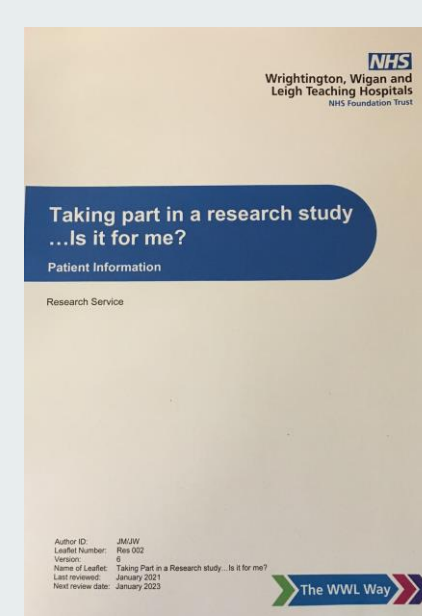


Examples of our work:

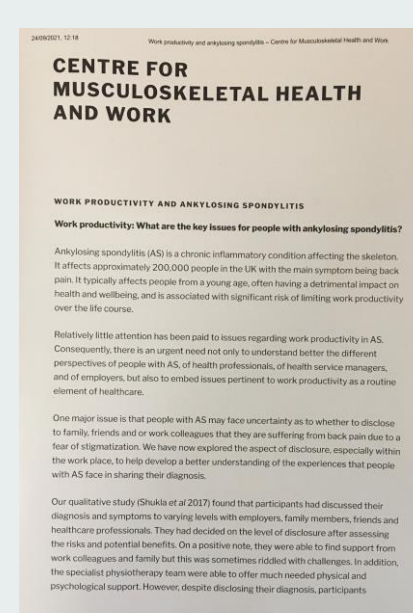
We have supported a large grant application to the National Institute of Research (NIHR) and are continuing to work collaboratively with the study team on the SOFFT trial. One of our members acts as a Patient Partner for this study.



We have written a patient information leaflet on how to 'ask' to be involved in a research study within our Trust.



We have contributed to the design and implementation of a study on disclosure of diagnosis in inflammatory arthritis



We contributed to a successful grant application which led to the completion of a PhD study for Dr. Nathan Pearson.

The aim of the research was to understand and measure the impact of fatigue associated with axial Spondyloarthritis and was in collaboration with Warwick University.

To validate the questionnaire our two patient partners have helped to win a Research for Patient Benefit grant to complete the research and ensure this questionnaire is adopted into clinical practice.

