

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.

Why establish a group?

- Perspectives of people that use NHS services and the perspectives of people who have a 'professional role' in health may be different
- Involvement in research encompasses getting service users actively involved in the research process itself rather than being the participant or subjects of the research

Aim of our group

- To introduce and facilitate service user involvement in research within WWL
- To advise and potentially work as co-researchers on WWL initiated research projects
- To promote the benefit of public involvement in research for professional staff and researchers in areas, which include funding applications and study design

Objectives of the group

- To help to identify which research questions are important to fund
- To influence the way that research is planned by working on research projects
- To improve the experience of people who take part in research by influencing the way it is carried out
- To influence the choice of outcome measures in research by suggesting measures that may be more important to people who use the services
- To increase the number of people who take part in research by making sure that good quality information is given and that people are treated with respect
- To ensure that research findings are provided in user friendly ways and publicised widely to people who need to know about it

Essential qualities for group members

- Be a good communicator with a practical approach and confidence to voice your opinions
- Be able to read and assimilate information about research proposals
- Be available to attend meetings
- Understand the requirement for confidentiality
- Be willing to undertake training to equip you to carry out your role
- Have a strong personal commitment to ensuring the highest standards for clinical research
- Become a lay member of Wrightington, Wigan and Leigh NHS Foundation Trust

Desirable qualities

- Live in, or close to Wrightington, Wigan and Leigh NHS Foundation Trust
- Have experience as a carer or user of the NHS
- Have experience serving in the voluntary sector, in education or community organisations
- Have an understanding and experience of the public, private or voluntary sectors

Examples of our work

- Contribution to a successful grant application on how to measure fatigue associated with Ankylosing Spondylitis (AS) in collaboration with Warwick University. Direct involvement with the Principle Researcher on methodology, the interview schedule and ultimately with the analysis
- Design of an interview schedule for patients undergoing hip surgery as part of a Masters Research study
- Writing a patient information leaflet on how to 'ask' to be involved in a research study within our Trust
- Providing constructive help and feedback to a study looking at flare in Ankylosing Spondylitis conducted by the University of Aberdeen
- Contribution to the design and implementation of a study on disclosure of diagnosis in inflammatory arthritis
- Guidance and lay representation for an application for an NIHR Clinical Research Fellowship - Developing a novel Disclosure Needs Assessment Tool for people with inflammatory arthritis in the workplace

Our members tell us:

What are the highlights of being part of the group?

'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.'

What do you feel you have achieved?

'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.'

Our Researchers tell us:

How have you benefitted from seeking the group's advice?

'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'

Why did you join the group?

'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.'

Training Objectives

Ensure that a study will have sufficient funding to pay for the expenses of those who participate
Validate if the research question is 'good' and it is relevant to patients
Ensure that people taking part can do so without being over burdened by the amount of time and effort that they are expected to give

2 day programme

What is Research (NHS) and Why we need research

Who does research

Understanding the implications that patients are experts in their own experience

'Bringing your knowledge and experience as a service user of health services to the research process'

Different stages of research

Importance of ethical approval

Importance of the governance process

Sharing the findings and putting research into practice