# 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



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

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WORK PRODUC	TIVITY AND ANKYLOSING SPONDYLITIS
Work productiv	ity: What are the key issues for people with ankylosing spondylitis?
It affects approx pain. It typically a	dylitis (AS) is a chronic inflammatory condition affecting the skeleton, imately 200,000 people in the UK with the main symptom being back affects people from a young age, often having a detrimental impact on eing, and is associated with significant risk of limiting work productivity se.
Consequently, the perspectives of p	ttention has been paid to issues regarding work productivity in AS. ere is an urgent need not only to understand better the different people with AS, of health professionals, of health service managers, s, but also to embed issues pertinent to work productivity as a routine neare.
to family, friends fear of stigmatizi the work place, to	is that people with AS may face uncertainty as to whether to disclose and or work colleagues that they are suffering from back pain due to a store. We have now explored the aspect of disclosure, especially within help develop a better understanding of the experiences that people varing their diagnosis.
diagnosis and syn healthcare profes the risks and pote work colleagues a	udy (Shukla et al 2017) found that participants had discussed their riptoms to varying levels with employers, family members, friends and sisterals. They had decided on the level of discloaure after assessing trial benefits. Or a positive note, they were able to find support from and family but this was sometimes riidided with challenges. In addition, softmary fearm were able to offer sum, needed physical and the second

We contributed to a succe application which led to th PhD study for Dr. Nathan

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.

#### 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.

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e completion of a	
Pearson.	

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Pre-testing the Warwick Axial Spo Description scale (WASTED): a co-pro			
Background	Res	ults	
Axial Spondyloarthritis (axSpA) is rheumatic disease that primarily manifests as inflammation in the spine and pelvis [1]; resulting in pain, functional impairment and reduced spinal mobility [2]. Fatigue has been reported as one of the most important symptoms to patients in a UK-wide survey [2]. However, it is poorly understood and measurement is limited to a single-item on fatigue severity [4] taken from the Bath AS Disease Activity index [5]. Research has highlighted the impact of fatigue on daily living, relationships, mental health [6] and self- management [6,7]. The WASTED is a co-produced patient-reported questionnaire, developed following extensive qualitative work. This study pre-tests the WASTED.	Ten male patients were interviewed in a secondary care setting (five per round). Their mean age was 52.8 years (range 28-75), mean AS duration was 16.4 years (range 1-32). Mean interview duration was 80.24 minutes (range 34-132 minutes). <b>Round 1: Cognitive Interviews (n=5)</b> Interviews confirmed that energy and fatigue were interpreted as distinct concepts at the point of completion. Nine items were added to further distinguish between fatigue and energy for testing in round 2. Two items were removed due to significant variation in interpretation (not fatigue or energy-specific).		
Methods	Round 2: Three-Step Test Interv Interviews supported the selection of item		
Participants and patient and public involvement Ten asSpA patients (five per round) were recruited from three rheumatology departments across England. The study patient and public involvement (PPI) group highlighted items they thought needed particular scrutiny and co-produced interview probes to address the concerns raised. The PPI group also reviewed the questionnaire after rounds 1 and 2.	Interviews supported the selection of items that were either energy or fatigue- specific, leading to removal of seven items. The most common modifications were: standardisation of item stems; addition of examples to improve clarify; and minor wording changes to improve item precision and minimise the risk of unintended interpretations. Proposals for questionnaire formatting and presentation were discussed.		
Eligibility criteria Inclusion: aped 18+ years with a clinical diagnosis of axSpA.	PPI group The PPI group were actively involved in all changes to the questionnaire, including decisions pertaining to the addition or removal of items. Following round 2, the group recommended dividing the questionnaire into two sections to improve the		
Exclusion: could not read or speak English or primary diagnosis was not axSpA.	flow' of the questionnaire.		
Procedure Patients were approached by a consultant rheumatologist within their local interunatology department and, if interested, were contacted by the lead author to explain and schedule the interview. A second consent form was completed immediately prior to interview. After the interview, patients were invited to complete three questionmaines: Bath AS Disease Activity Index (15): Bath AS Functional Index (1): and Hospital Anxiety and Depression Scale (19). Two rounds	Figure 1: Procedure for each pre-tests Round 1: Cognitive Interview (n<5) Pre-interview training: "Think shoe"	ng interview round per participant Round 2: TSTI method (n=S) Pre-interview training: "Think about"	
of interviews with five participants each were completed, interviews were recorded and summaries generated.	a. Interview block: think aloud	TSTI Step 1: Observation of participant completing questionnaire	
Round 1: cognitive interviews [10] (using think aloud and verbal probing techniques) were used to explore the concept of energy as a distinct but related	•	•	
component of fatigue experience. A pilot interview confirmed the topic guide and probes. To ensure that participants were able to recall their thought processes for items, the 32-tem tong-form questionnaire was divided into five blocks: blocks 1-4.	b. Interview block: retrospective probing	TSTI Step 2: Follow-up using fieldnotes (observation data only)	
consisted of six items; block 5 consisted of eight items. An iterative cycle of think		•	
aloud and verbal probing was performed until questionnaire completion for each participant (see Figure 1).	repeat a and b through to block S	TSTI Step 3: Semi-structured interview and probing	
Round 2: this round used the Three-Step Test Interview (TSTI) method which was specifically designed to pre-test patient self-reported questionnaires [11] (Figure			
1). There were three steps: i) observation of participant completing questionnaire; ii) Follow-up using fieldnotes; iii) semi-structured interview and probing.	Administration of demographic questionnaires	Administration of demographic questionnaires	
Data analysis	Discussion		
The Question Appraisal System (QAS-99) [12] was used as a framework to categorise participant responses [13]. The QAS-99 consists of 6 categories: 1. Clarity (wording, technical terms, vague, reference periods) 2. Assumptions (inappropriate assumptions, double-barrelled) 3. Knowledgel memory (knowledge, attitude, recal) 4. Sensitivity/ Bias (sensitive content, wording, socially acceptable) 5. Response categories (open-ended, mismatch, technical terms) 6. Other problems	This research demonstrates the value of working closely with a PPI group to co- produce a questionnaire that is relevant, acceptable and captures what matters to patients. Equally, this research shows how using two methods of questionnaire pre-testing: cognitive interviews [10] and TSTI [11] can complement one another. Cognitive interviews were effective in further elucidating the distinction between fatigue and energy items, whist TSTI enabled a more naturalistic completion that focused on the wider questionnaire. This process confirmed the content of the long-form WASTED questionnaire in advance of psychometric evaluation.		
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