

Patient and Public Involvement:

A vital part of healthcare research

Patient and Public Involvement, or PPI, is an essential part of modern healthcare research. Patients are the only ones who truly understand what it is like to live with their condition and can therefore offer a uniquely valuable contribution to research. At the University of Nottingham, Professor Roshan das Nair and his colleagues have established a successful PPI group for multiple sclerosis research. The group ensures that service users, including patients and carers, are involved at every stage of the research process, from project planning to communicating results to the public.

Modern healthcare research is centred on the patient. Rather than the traditional approach, where research has been about doing things “to” or “for” the patient, investigators increasingly try to make patients a part of the research process, so that it is carried out “with” or “by” members of the public. This idea is reflected in the concept of Patient and Public Involvement (PPI), which is now an integral aspect of much healthcare research.

PPI in clinical studies allows service users – who can include patients, carers, family members and members of the public – to be involved in research that could directly affect their healthcare. Patients and the public can potentially be involved in all stages of the research process, from planning and designing the study to communicating the results of the project. Most large funders now require researchers to consider PPI as a key part of their project planning. Many research grant funding panels include PPI members on an equal basis with

healthcare professionals and scientists.

PPI: AN INTEGRAL PART OF THE RESEARCH PROCESS

Although PPI is an essential part of modern healthcare research, it can still be difficult for researchers to work out exactly how to incorporate PPI into their projects. Unfortunately, this can lead to only token attempts to address PPI. Given the significance of PPI to patients, and the potential benefits to clinical research, it is important that investigators have the tools to properly include PPI in their work.

At the University of Nottingham, Professor Roshan das Nair and his colleagues carry out research into multiple sclerosis (MS). MS is a disease that can affect the brain and spinal cord, causing symptoms ranging from fatigue and muscle stiffness to problems with vision, cognition, and walking. MS is a chronic condition that is most commonly diagnosed in younger adults in their 20s and 30s. There is currently no cure.

Professor das Nair and his team have established a PPI group that specifically focuses on MS research. The group is chaired by Dr Clare Bale. Dr Bale was herself diagnosed with MS in 2007, and also has family members with the condition. As well as chairing the PPI group, Dr Bale is a co-investigator on several important research projects.

The approach taken by Professor das Nair and his colleagues, of making PPI an integral part of the research process, has received excellent feedback. In particular, numerous research grant



Consultation meetings chaired by a PPI facilitator allow researchers to focus their work and make it more relevant.



The team use focus groups to collect feedback.

reviewers have commented on the policy. For example, one reviewer said that, “the team in Nottingham have clearly established an excellent working relationship with their PPI group and their endorsement of this proposal is clearly evident.” A member of another committee was so impressed by the study that they planned to alert their own institution’s PPI team to the work done at Nottingham, as they felt that it was an excellent example of how PPI could successfully be integrated into research. A third reviewer noted that, “with some grant applications, the PPI plans feel no more than box ticking. That is certainly not the case with this study.”

PATIENT-FOCUSED RESEARCH

One particular example of Nottingham’s PPI work is a project called PrEliMS (PRoviding Emotional support In MS diagnosis.) This project, funded by the MS Society, is led by Professor das Nair, with Dr Bale and Dr Topcu as co-investigators. PPI is a key focus at every stage of the research, from developing the funding proposal to evolving the intervention and monitoring progress of the study.

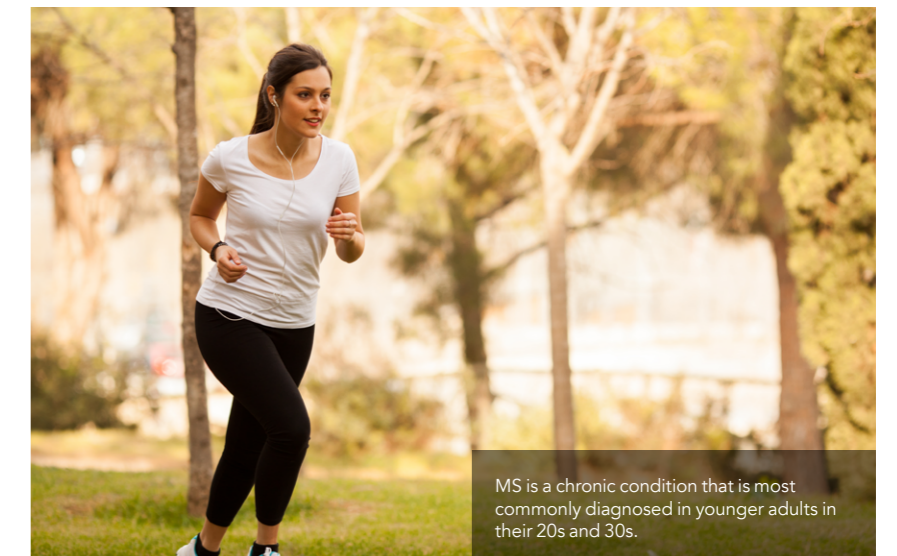
Feedback from people living with MS helped to shape the research questions addressed by the project;

for example, patients expressed the belief that providing emotional support at the point of diagnosis is extremely important. The team were then able to consider this factor in their research design.

To develop the PrEliMS emotional support intervention, the team received input from 29 people with

MS, 12 carers/family members, and 24 clinicians and MS Society volunteers. These consultation meetings were facilitated by Dr Bale. The research team provided the group with information they had collected from other international research studies and from their clinical colleagues, but it was

Patient and Public Involvement (PPI) is now an integral aspect of much healthcare research.



MS is a chronic condition that is most commonly diagnosed in younger adults in their 20s and 30s.



Patient and Public Involvement allows a wider range of voices to be directly involved in research.

Involving patients in the development of research helps ensure that it is relevant.



the PPI group that enabled the team to make it relevant for people with MS in the UK. The draft intervention was then taken to another smaller PPI group to refine it further. This shows the active, rather than passive, role allocated to PPI at all stages of the research process.

Dr Bale provided advice and guidance at all stages of the PrELiMS project.

The real-life experience of living with MS is something only the patient can truly understand and describe.

Her role included attending research team meetings, helping to identify useful research materials, providing feedback on all patient-facing material (like information sheets) and preliminary findings, and co-ordinating communication with other service users.

In an interview with BBC Radio Nottingham, Dr Bale summed up the importance of the involvement of patients and other service users in PPI. "If you are a lay person, an individual, part of the public, involved in these projects, you can help the researchers to hold a mirror up to themselves and just check whether they've got a grasp on the real experience of people and whether things are useful," she said. It is important that, as in the PrELiMS project, service users are

invited to give feedback at various stages of the project, so that PPI is not neglected as the study evolves.

AN ONGOING COMMITMENT TO THE PATIENT

For those patients and their families who choose to participate in PPI, the experience does not end as a particular project concludes. Rather, Professor das

Nair and his team aim to continue to build close, ongoing relationships with MS patients, their families and carers. Indeed, PPI members are trained to share the research findings more widely. Through their own MS PPI group and via the MS Society, they aim to produce useful findings that can one day be put into practice, either through the MS Society or the NHS.

Patients are always encouraged, and very welcome, to become involved in PPI. Understandably, some might be hesitant, perhaps wondering what value they can offer to academic research. Dr Bale hopes to reassure patients that their unique perspective on living with MS is essential to successful research. "You can ask anything, you can say

anything, there's no right or wrong, you don't have to have a PhD in neurology, everybody's contribution is really useful," said Dr Bale.

Dr Bale also encourages patients to seek out good quality information from organisations such as the MS Society. This will help patients to have confidence in the value of their own knowledge and experience, which could be an important contribution to research through PPI. "You're the expert on you," says Dr Bale. "Find out what your options are, ask questions, and be prepared to say no – or not yet – and be prepared to look for information out there."

REAL-LIFE EXPERIENCE IS IRREPLACEABLE

The real-life experience of living with MS, or any other health condition, is something only the patient can truly understand and describe. For this reason, PPI is now, and will continue to be, a crucial part of healthcare research. The effort devoted to ensuring PPI is integral to the research process by Professor das Nair and his colleagues has already proven to be worthwhile. This is reflected in the positive response from service users, as well as from grant reviewers and others with a stake in healthcare research. As one grant reviewer commented, the team at Nottingham have thoroughly embraced the value of PPI.

Behind the Research



Roshan das Nair



Clare Bale



Gogem Topcu

E: roshan.dasnair@nottingham.ac.uk T: +44 (0) 115 82 30589 W: <https://www.nottingham.ac.uk/medicine/people/roshan.dasnair>
W: www.neuroms.org

Research Objectives

The Patient and Public Involvement group at University of Nottingham focus on multiple sclerosis research.

Detail

Roshan das Nair
B19, Institute of Mental Health
Jubilee Campus
University of Nottingham
Nottingham NG7 2TU
UK

Bio

Roshan das Nair is professor of Clinical Psychology & Neuropsychology at the University of Nottingham and Institute of Mental Health. His clinical trials focus on evaluating the effectiveness of psychological and neuropsychological therapies in neurological conditions. He has over 100 publications and research grants of over £13 million.

Clare Bale is the PPI Lead for the Nottingham MS PPI group. She was diagnosed with MS in 2007 and also has family members with MS. She had been actively involved in PPI activities for a number of years and has contributed towards several grant applications and research projects.

Gogem Topcu is a Research Fellow at the University of Nottingham and has expertise in health psychology. Her research mainly includes developing and evaluating complex interventions by using a person-centred approach to improve health and wellbeing of people with MS and their carers/family members.

Funding

- University of Nottingham Institute for Policy and Engagement <https://www.nottingham.ac.uk/policy-and-engagement/home.aspx>
- Nottingham Impact Accelerator <https://www.nottingham.ac.uk/research/knowledge-exchange/nottingham-impact-accelerator.aspx>
- MS Society
- National Institute for Health Research

Collaborators

- Nottingham Multiple Sclerosis Research Group, University of Nottingham, Institute of Mental Health, & Nottingham University Hospitals NHS Trust
- Dr Nikos Evangelou, Division of Clinical Neurosciences, University of Nottingham & Nottingham University Hospitals NHS Trust

References

Das Nair, R., Topcu, G., Evangelou, N., Bale, C., Drummond, A., Moghaddam, N., Fitzsimmons, D., Vernon, K. (2018). Providing emotional support around the point of Multiple Sclerosis Diagnosis (PrELiMS): A feasibility randomised controlled trial. *ClinicalTrials.gov* NCT03735056. Available from: <https://clinicaltrials.gov/ct2/show/NCT03735056>

Topcu, G., Griffiths, H., Bale, C., Drummond, A., Fitzsimmons, D., Vernon, K., Rose, A., Evangelou, N. & dasNair, R. (2017). A meta-synthesis of qualitative studies on experiences of multiple sclerosis diagnosis. PROSPERO CRD42017067703. Available from http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42017067703

Topcu, G., Griffiths, H., Bale, C., Drummond, A., Clarke, S., Trigg, E., Martin, K. J., Fitzsimmons, D., Vernon, K., Rose, A., Evangelou, N. & dasNair, R. (2017). A meta-review of systematic reviews on psychosocial adjustment in multiple sclerosis. PROSPERO CRD42017067697 Available from http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42017067697

Tallantyre, E. C., Evangelou, N., Bale, C., Chaudhry, B. Z., Gray, E. H., LaRocca, N., Pavitt, S., Miller, D. M., Planchon, S. M., Ontaneda D., Manzano, A. (2019). Achieving effective patient and public involvement in international clinical trials in neurology. *Neurol Clin Pract*, DOI: 10.1212/CPJ.0000000000000739

Personal Response

In your experience, how has PPI in MS research benefited the patient?

/// Patient benefit is at the heart of all our research. To achieve this goal, we start and end with patient involvement, because without their input, research risks asking irrelevant questions resulting in meaningless outputs. There are clear cost and ethical implications for such endeavours. The Nottingham MS Research Group has enabled over 50 people with MS to better engage in research. The MS PPI group gets to learn about all the new projects that they may wish to participate in, which may lead to direct patient benefit. They also get to shape the research they want to take part in, which they recognise may not directly benefit them, but they feel is vital to improved patient care for the future. If anyone would like to be involved in our MS PPI group, they can email msppi@nottingham.ac.uk. ///