



¹ Barnsley Hospital NHS Foundation Trust

Cite this as: *BMJ* 2022;378:o2310
<http://dx.doi.org/10.1136/bmj.o2310>
 Published: 23 September 2022

Patients and healthcare professionals in priority setting partnerships: two very different sides of the same coin

Adewale Adebajo *professor associate medical director and consultant rheumatologist*¹

It is easily forgotten that healthcare professionals are frequently patients themselves, but potentially with very different power dynamics. I recently had cause to reflect on this issue, due to my involvement in two separate James Lind Alliance priority setting partnerships.¹ The purpose and methodology of these partnerships are well established and well documented. In brief, the JLA methodology involves setting up a steering group to oversee the project and inviting patients, carers, and clinicians to participate in the project, gathering treatment and intervention uncertainties from surveys and from the literature and then ranking these uncertainties into a top 10, through discussion and voting by patients, carers and clinicians as equal partners.

My involvement in both of these partnerships was unusual in two respects. Firstly, as with many other health related activities, the meetings of these priority setting partnerships were conducted online, rather than the usual in person meetings. Secondly, and even more uniquely, I was involved in the first partnership (stroke PSP) in my role as a stroke patient and then within a six month period, I was involved in a second partnership (psoriatic arthritis PSP) in my role as a consultant rheumatologist.

What struck me most was the difference in confidence and vulnerability that I found in the two roles. Psoriatic arthritis is a special interest of mine, as a rheumatologist, and well within my comfort zone. I felt that I knew the condition inside out and I was in no doubt as to what the research priorities and unmet needs were for this condition. With the stroke priority setting partnership, I found myself being more hesitant and looking to the healthcare stroke specialists for tacit guidance. By coincidence, both priority setting partnerships were facilitated by the same individual who was amazingly supportive and helpful during both priority setting partnerships. However, I found myself even more appreciative of her input, during the stroke priority setting partnerships. In particular, I saw her as an advocate for those of us who were patient participants, ensuring that we had an equal voice with the stroke professionals.

Despite substantial progress in the adoption of patient centred care in recent years, which I believe has led to less paternalistic attitudes among healthcare professionals and greater shared decision making with patients, I still hear of complaints from patients and public contributors involved in health research. They still experience a persisting and pervasive power differential between them and researchers and talk of an unwillingness for researchers to share or relinquish this power. They have also expressed the view that the health research

systems still greatly favour researchers. On reflecting on my contrasting feelings of control and security, based on my two different roles for the two priority setting partnerships, I began to have greater insight into this issue of a very real power differential. This was further evident in the degree of my understanding of the language and the terms used in the two priority setting partnerships. With the stroke priority setting partnerships, my feelings bordered on imposter syndrome, while with the psoriatic arthritis priority setting partnerships, I felt like a master of my speciality.

As healthcare professionals (even those who are sensitive and welcoming to patient and public contributors) we can take our power for granted and not recognise the power problem. Interestingly, during the stroke priority setting partnerships, I found myself being attracted towards choosing support and rehabilitation priorities, which are often the issues considered to be most important to patients. However, with the psoriatic arthritis priority setting partnerships, I gravitated towards pathogenetic, diagnostic, and treatment priorities. I suspect that this was as a direct result of my being in healthcare professional mode.

I would like to commend the James Lind Alliance for its pioneering role in bringing together patients, carers, and healthcare professionals in an egalitarian manner with a robust methodology, in order to achieve mutually agreed research and unmet need priorities resulting in the provision of a roadmap for research and other funders to take forward.

However, I believe that much more still needs to be done to ensure that health research and research systems are equally accessible to patients and members of the public. Simple measures like arranging research meetings in community centres rather than in university board rooms, can often make patients and members of the public feel more comfortable when attending research steering group meetings. Underplaying professional titles and academic qualifications together with emphasising the fact that patients are experts in their own right, with important knowledge gained from the lived experience of their condition is central to the JLA narrative, and one that I think should be more widely applied.

Interestingly, the online nature of the priority setting partnerships meetings, may have helped in reducing the power differential, although I recognise that holding only virtual meetings has the potential to exclude people with fewer digital skills or those who do not have the requisite digital hardware and software.

I believe that as researchers, we need to realise that by relinquishing power to patient and public contributors, we facilitate an enrichment of our research endeavours, so that everyone benefits. It has been said that by giving away power, everyone gets more power!

Competing interests: Adewale Adebajo is a professor and an associate medical director and consultant rheumatologist at Barnsley Hospital NHS Foundation Trust. He is also an external representative on the contract management board of the NIHR Centre for Engagement and Dissemination and Hon Chair of Rheumatology and Health Services Research, University of Sheffield. No competing interests declared.

Provenance and peer review: not commissioned, not peer reviewed.

1 James Lind Alliance. <https://www.jla.nihr.ac.uk/>