

Amanda Roberts talks to Alison Ford about her involvement with NIHR research

AF: Amanda, you're a public panel member in HTA, could you tell us a little bit about how you found out about that panel role?

AR: Well it's a bit like being a pass the parcel really! I got involved initially because I was on a NICE guideline [group] and having learnt all the jargon I felt it would be a waste if I didn't use it... So then I got onto a different NIHR panel called the 'Research for Patient Benefit' Panel and after a few years at that I met some other patients who said "why don't you look at applying to go on the HTA panels?", I thought that sounded like a good idea and that's how I managed to fool everybody into letting me come onto the panel!

AF: Can you tell me what's involved in being a public member on a panel?

AR: Being involved in a panel is a bit like sitting an exam, but without getting any award at the end of it! So there's no real pressure, except that you feel as a patient that you have loads of reading to do. It could sound all very stuffy, but actually it's a fabulous experience. You learn about all sorts of interesting things that are probably outside your sphere. My particular interest is eczema and occasionally I've seen a paper/research proposal about eczema, but normally it's about completely odd things that I'd probably never come across. Then the really interesting thing is then you can 'Google' it, or talk to your friends and find out a little bit more, so you're a better informed person for a start-off. It just makes it so interesting to read around the subject, the bonus is that at the end of it there's all these really intelligent people who'll stop what they're saying and listen to you! Amazing!

AF: So it sounds very rewarding; are there also challenges involved in it?

AR: It is, it's extremely rewarding, of course you do have to find the time to prepare well, and the other problem is knowing when to put your oar in and when not to put your oar in. The way I do it is; if I like a paper/proposal and it's going well then I tend to shut up, because we're only the first hurdle – this isn't the final thing [the funding decision]. And if it's going badly and I don't like it equally I shut up – but if I think there's an important point to be made, that I could change the way the discussion is going; then I make it. And so it's being aware of what's going on around you.

AF: And you've talked there about the panel role, but I believe you also do reviewing for NIHR?

AR: I do! I get my red pen out and I grump and groan over them and then I send them back, which is fab. I really like that because you can do that in your own time, at your own speed and you're never asked to do something which is outside your sphere of experience. There's no need to 'Google' things, unless it's something

which is in your experience, but perhaps you just need to check something or whatever. In a way it's an easier thing, but the really important thing, and the privilege, is trying to represent patients in as broader way as possible, as opposed to just your own experiences; sometimes as a patient you can get carried away with *your* experiences being the only thing which matters, and of course they do but equally they don't.

AF: So what advice would you give to a patient or a member of the public who hears about this and thinks about getting involved in research in this way?

AR: If you've time, you've got computer skills and you enjoy doing a bit of reading around a subject and health turns you on, give it a go. It's incredibly rewarding, I find it fun, and being listened to by very intelligent people gives you a hell of a boost of self-esteem!
