

The patient inside and 'outside' the committee

By Jennifer Bostock

There's a lesson to be learnt from my first day on the National Institute for Health Research (NIHR) Research for Patient Benefit Programme (RfPB) committee – never carry a cup of coffee if you're also carrying a large bag and a pair of crutches.

This lesson was unexpected, but it was the first, the worst, and one of many. For on that day I nervously arrived at the RfPB committee meeting as an observer, wearing best suit, carrying thoroughly examined papers and negotiating crutches and coffee. A beautiful building awaited, and with vim and vigour I announced my arrival by falling into the majestic room – coffee, crutches and papers everywhere. The stunned, serious and seemingly less than amused faces stared from around the table – the patient had arrived!

Fortunately it could not get any worse, in fact it got a lot better – the stony faces soon turned to smiles and the stern conversations to light hearted and welcoming chat. I had survived the observation at least. From then on it's been a pleasure to be a part of the committee. I must say it's hard work, with tons of papers and lots to get my head around from methodology and statistics to complex medical and surgical research. But such is the stimulation of the committee, the approachability of the 'experts', and the value placed upon the patient perspective, that I genuinely feel a valuable and valued member. I have now been given lead assessor duties which means that I introduce studies to the rest of the committee and keep track of and feedback the salient points to the Chair.

I certainly still have lessons to learn in terms of getting my head around the subject matter, for example the differences between feasibility and pilot studies, and what would prevent an application being recommended at the end of the assessment. I suppose one of the most important lessons for me is to take a more laidback approach, to realise that I do not have to read and understand every word of every application, nor do I need to comment on every aspect – no one else does.

I feel that as a lay person I am expected to comment more than other people who sit on the committee as they have their own area of expertise, whereas I see the projects as a whole. But it is not expected – and probably not a good use of the short time we have for assessing each application – for me or anyone else to dissect every aspect and critique every word.

So it is still a learning curve for me but I like that, as it keeps the work interesting and challenging. As a patient, I suppose my biggest contribution to the committee is to ask the simple and somewhat naïve questions, for example why is this research, how exactly will patients benefit from this study or can't the money be better spent elsewhere? I don't always get an answer, I don't really expect to, but I'll keep asking because sometimes I find that others agree with my innocent questions.

As patients, we don't often feel powerful, but in a strange way being a lay person on a committee like the RfPB allows us to relax and ask all the questions that the 'experts' would like to but dare not ask, and that puts us in quite a powerful position.

I did not expect to learn the coffee and crutches lesson at the committee, and the committee certainly did not expect to learn that patients can make just as much noise once inside the committee as they can coming in.

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Health Research (NIHR) Research for Patient Benefit (RfPB)
Regional Advisory Committee for London. For further details
on the programme and to enquire about joining an RfPB
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