What makes a real patient?

A few years ago I applied for a grant to study my own long term condition. I started out as Ms Snow, ashamed of saying the name of my disease, and ended up Dr Snow, the type 1 diabetic, knowing a lot more about research and academia than I ever thought I would. I realised that patients can see things in research that clinicians can't because we think to look in new places, and we spot discrepancies that doctors take for granted. I became particularly interested in power relations, and then in the things that stop patients having a say in what gets researched in the first place.

I have taken part as a patient in many "patient and public involvement" (PPI) groups. As I changed who I was (from Ms to Dr), I noticed an odd phenomenon. People stopped being sure whether I was a "real" patient.

Until recently, according to the National Institute of Health Research (NIHR), having a doctorate automatically banned me from being part of their PPI reference groups. That was particularly ironic for me, because it was the NIHR that funded me to become a service-user researcher in the first place. The NIHR's Evaluation, Trials and Studies Coordinating Centre (NETSCC) has now reconsidered this policy for future recruitment rounds, but the policy has not yet been changed NIHR-wide. It is still a very familiar concern.

Is it a legitimate concern? Why else might organisations like the NIHR want the pre-doctorate me, but not the post-doctorate me?

Theory 1: Real patients aren't supposed to have knowledge

As Ms Snow, I didn't know much about academia. I knew about living with type 1 diabetes, and had already spotted that much of the research in diabetes is based on flawed assumptions, but I didn't really know how to argue that point. As Dr Snow, I know what a p value is. I know who Foucault and Bourdieu were. I have dug into those flawed assumptions and shaky evidence base for some of the statements made about diabetes, and I can confidently argue those points with anyone. I don't give up as easily as I did when I was Ms Snow; I have the same passion, but I get less frustrated, because now I have the tools to fight my corner. This is in fact the complete opposite from the assumptions the NIHR is making about people like me. Meanwhile, in some organisations, PPI groups are forced to change personnel every couple of years. It's hard not to be cynical about these policies. Is it because if we know stuff, we can argue back?

Theory 2: Real patients don't have the ability to acquire knowledge

From throw away comments by researchers and clinicians, I suspect real patients are supposed to be a bit gormless. I've sat on a lot of PPI groups where healthy researchers provide the structure of the meeting and offer round the biscuits, and the patients provide the naivety. These are the groups

where we end up “commenting on lay summaries” rather than having any useful input on research questions and outcomes. We’re allowed to remind the researchers why they went into the job in the first place, but we’re not supposed to be able to comment on methodology, even if the methodology is flawed because the researchers aren’t aware of their own biases.

Theory 3: Real patients need protecting from academics

At first glance this seems the least unpleasant of the theories: a fear that academics saying “we’re all patients really” would drown out the non-academic patients. I find it nearly as creepy as the other theories, because it gives an uncomfortable insight into the lack of thinking behind their PPI strategy. When people want me to be a patient on a PPI group I always ask “why are you asking me?” If you want “a patient,” I may not be the best person, because it will depend on what you are looking at. I can’t comment on, for example, what it’s like to use palliative care services or what it’s like to be a patient who can’t read or write. If that’s what you want, go and find the right patient. If I have specific experiences that would give you an insight, I’m happy to help. But if you already have an academic with equally relevant lived experience, *and she’s willing to use that experience*, is it really out of the question to ask her? Note the emphasis – that researcher has to be willing. Having a disease can be considered a conflict of interest or a source of bias by those who don’t really understand subjectivity and bias. Those who start off as academics also have to make the uncomfortable move from identifying as “Dr X, the ordinary researcher” to “Dr X, who is going to use his life experience (even his vulnerabilities) to make this research more relevant and effective.” Very few traditional academics I’ve met are willing to do this; but service-user researchers do it all the time.

Perhaps I must just be content with the fact that as far as some academics are concerned, the moment I got through my final exams, I stopped being “real.”

I wish someone would tell my pancreas, mind you. I still don’t seem to be cured.