

Becoming 'them' and remaining 'us' ... or the road to ruin?

By Rosie Davies and Kath Maguire



We are both service user researchers studying public involvement in research for a PhD, and this sometimes feels like a road to confusion. Taking the journey to become a research professional can feel in opposition to our identities as a service user and carer and poses difficult questions about who we are and our place in the world of involvement. Some professionals seem to feel it is wrong for members of the public to take on researcher roles, describing such people as 'amateur' researchers; some researchers want 'naive' service users, patients and carers, not people with involvement experience. Where do such perspectives leave us? Can we retain our identities as people who feel changed by our encounters with health services and gain an identity where we are accepted as professional researchers, or are we on a journey that makes us unacceptable as both researchers and members of the public? These questions are at the heart of a workshop that we will be running at the INVOLVE Conference in November.

These are real questions which we continue to explore, but some of the issues we have identified already are:

- It seems to us that public involvement in research describes a very wide variety of roles and that members of the public are therefore likely to need different experiences and skills to do them. Some involvement jobs need people who have the skills to engage in strategic discussions in national research funding committees while others need people who have recently used

particular health services.

- Doing a PhD is the route for almost everyone who wants to become a professional researcher, so in what sense might we still be amateurs if we get our PhDs? Does the term not apply to us? If it does, is it a means of undermining our credibility, making us suspect as not fully socialised in a professional identity?
- Criticism of 'professional' service users and carers in public involvement seems to be about the need to emphasise the key place of lived experiences in relation to health problems and use of health and social care services. We agree that such experiences are at the heart of all involvement. But if it was only about experience of a particular health condition and use of services it would be just as good to have a professional researcher or clinician – who had, for example, been treated for cancer – as having an 'ordinary' member of the public involved in a cancer research study. So perhaps a key aspect of public involvement means both having relevant lived experience and coming from a social and structural position that is different from professional researchers and clinicians. It seems to us that while everyone's experiences of using health services must be acknowledged as legitimate, having a different perspective is also important.
- Can we continue to bring a different perspective while becoming professional insiders too? Both of us have had experiences with health and social care services which changed our lives and identities in significant ways and which are an ongoing part of our lives and work. We think we can continue to draw on such experiences in public involvement roles, but we think we are not suitable for all roles. To remain useful as both a service user and carer perhaps we need to learn to hold and draw on different aspects of our identities and be aware of how they interact, sharing different parts of ourselves in different situations and bringing outsider

parts of us in to insider situations.

- Another question is whether or not we have been empowered by our involvement experiences to become professionals. This seems to suggest that someone else has given us power which we lacked. While we have been given opportunities by others we have taken up and used those opportunities in a particular way, a way that many people would not be interested in. The focus on empowerment within public involvement in research suggests that patients, service users and carers as a group lack power, and while having health conditions clearly affects the control we have over our lives and our choices and abilities, it does not make sense to us to see all patients as powerless; would the Prime Minister need empowerment if he became a patient? In involvement situations we have both experienced professionals behaving in ways that disempower service users and carers, and situations where service users and carers have behaved in ways that disempower professionals and researchers. So, while professionals, particularly doctors, have more structural power than others in society, such power is resisted by service users and carers. Whether or not we are involvement 'successes' as newly empowered citizens, and how power is used and resisted in public involvement activities are questions we continue to think about, alongside the question of whether we risk being disempowered by occupying an ambiguous position as both 'us' and 'them'.

Our challenge is to both remain 'us' and become 'them' and avoid being marginalised and disempowered! We plan to develop our thinking about these tangled issues in the hope of finding a deeper understanding.

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