

MAKING SPACE IN RESEARCH AND POLICY FOR PEOPLE WITH LIVED EXPERIENCE



By Lucy Holmes

Bringing more people with lived experience into research and policy-making helps us listen, we've concluded in our Listening to Each Other cell. Lucy Holmes shares her experience of this in the homelessness sector.

The first time I accompanied a volunteer peer researcher to an interview, for a project I led at St Mungo's, I learned more about myself than anything else. As I sat in the corner of the room, biting my tongue and sitting on my hands, I reflected on how significant and challenging it is to make space for others to do the listening.

It was hard to watch someone conduct an interview in a way I thought wasn't perfect, wasn't the way I'd been trained to do it, wasn't *quite* the way I had trained her to do it, wasn't the way *I would have done it myself*.

The case for including citizens, patients and service users in designing the systems that govern our lives is well made. From organisations like Involve calling for citizen involvement in civil society to the NHS ambition to embed patient and the public involvement in all of its work, great strides have been made.

Yet properly involving people without professional training in areas of work that have historically been done by 'qualified' experts (like researchers with academic training or policy professionals with detailed technical knowledge) can be difficult and scary.

The charity I now work in, Groundswell, was created – and named – to give power and voice to people experiencing homelessness. To empower a groundswell of feeling, of opinion, of expertise, and to speak out! To speak truth to power. To disrupt and challenge and inspire.

In our earliest days, our Speakout events were a chance for 'people to communicate with and influence people and organisations who make decisions that affect their lives.' In September 2000 more than 2,000 homeless people and 250 support organisations took part in Speakouts.

Since then, Groundswell has grown (we now have staff and volunteers nationwide) but our ethos remains the same. We exist to enable people who have experience of homelessness to create solutions and move themselves out of homelessness – to the benefit of our whole society. Lived experience is central to everything we do, from our Listen Up! peer journalism hub to our national #HealthNow research, partnership and policy programme.

Around two-thirds of our staff team have personal experience of homelessness and around one-third started as volunteers before moving into paid roles. Some team members undergo intensive training. Our Homeless Health Peer Advocates receive several weeks of preparation to support their homeless clients to access healthcare services. We also train volunteers with personal experience of homelessness in research methods. These peer researchers then take the lead on all aspects of a research project. At Groundswell all our research is undertaken by people who have experienced homelessness.

As I sat in on my first peer research interview, silently berating myself and my ego, I missed the most important thing happening in the room. Only when I read the transcript did I realise how much the peer researcher had achieved. The fact that she shared her own experiences, memories and observations helped to elicit data from the participant I never would have got. And that's what matters. When professionals cede power, when organisations give the floor to people with expertise based on experience, the results might be different, but they can be better.

At the March Pathway conference 'Pathways from Homelessness', attended by esteemed clinicians, voluntary sector colleagues and government officials, Debs presented findings from a peer research project, as respected and listened to as any other speaker. Debs also described her experience as a Groundswell peer researcher:

'To be honest it's one of the most amazing experiences I've ever had. Just getting involved, meeting the other volunteers was great fun. [...] My favourite bit was asking people the questions. We did a lot of hours in a day centre and the people there – because I know them, because a lot of them are my friends – they were more willing to answer the questions, because I am one of them. They know I've been through homelessness. [...] They were more willing not just to answer the questions, but to be honest, to trust us researchers. To not just say what they thought we wanted to hear, to give us the real truth.'

Of course I still face dilemmas and questions. I wonder whether, by bringing people in, we're forcing them to mould themselves to a system we should, instead, be challenging or dismantling. Another essay in this collection by Jill Baker captures this neatly: 'I often go back to that question – who am I serving here? The people I am actually here to serve or the authority that oversees the systems?' One of the goals of our Listen Up! project is to support people who've been homeless to hold decision-makers to account. We're explicitly trying to challenge the system, not incorporate our reporters into it.

I also worry that if we pigeonhole people as 'experts by experience' we fail to see their other skills and perspectives. Just because you've been homeless doesn't mean you can't also have *professional* qualifications, expertise and standing. I perceive that in other areas of work (like dementia or mental health research) the lines between types of expertise are blurry and I'd like that to be true in homelessness and complex needs policy areas.

And we have to work hard every day to do the best by our peers, making sure we support them to progress, to develop. Some we help to prepare for paid roles. Others need training or equipment or travel cards to enable them to volunteer. And everyone needs and deserves good management, prompt and efficient work processes, suitable recognition and to understand what happens as a result of their hard work.

If I could impress just one point on anyone who's frightened of bringing people with lived experience into research and policy

roles it is this: there are people who are eager to help you get it right. Yes, it can be scary. Yes, it takes time and patience. Yes, it needs careful consideration before you leap in. But it will change your relationships, your organisation, your power base – for the better. Ask for support. Learn from others' mistakes and missteps. We're all so excited to see you succeed.

Lucy Holmes is Creating Change Director at Groundswell, a charity that works with people with experience of homelessness, offering opportunities to contribute to society and create solutions to homelessness. Groundswell's vision is of an equal and inclusive society, where the solutions to homelessness come from people with experience of homelessness. She previously worked at Alcohol Change UK, St Mungo's, Missing People and the University of Edinburgh.