**Role of the community in health and social care research – some thoughts**

*17 July 2018*

**Savitri Hensman**

savitri.hensman@kcl.ac.uk

Patient and Public Involvement Coordinator, Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London

(and long-time voluntary sector board member, carer and NHS patient)

I'm an enthusiast about the role of the community in health and social care research and beyond. The word community has been in my job title or the name of the organisation I work for, for most of the past twenty years or so. Whether we are talking about a local community, LGBT community, ethnic minority community, maybe even the community of skateboarders in a particular park (though that's not one I've ever been part of), there is that sense of being connected, having some level of shared identity and maybe the ability to make a difference together.

However, to begin with, it's useful to be clear about what community is not.

Community is not a substitute for involvement by service users or people with a particular condition and their carers. For instance, even if almost everyone in my neighbourhood agrees that children with epilepsy should be well cared for by the NHS, those children and their caregivers have to be asked what that might mean in practice.

It does not mean that relationships are always harmonious or that everyone thinks the same. Even a faith community which utters beautiful words about loving one another can end up quarrelling fiercely about matters such as seating or hymn-tunes. Apparently the atheist online community can be as bad or worse. As many of us who work or are active in the voluntary sector know all too well, humans can be cooperative one moment, argumentative the next (though arguments also have their place).

Nor does it mean that everyone in a community is equal. In many communities for example, those with less money or education, ethnic minorities, women, young people tend to have less say, though norms vary. For instance, it might be the people who fight hardest or who are best at sports who dominate. It doesn't mean that others in that community have no power, but it may be harder to exercise.

All the same, communities have much to contribute to health and social care research, whether that’s engaging with or helping to shape research, leading it or carrying it out. To understand why, it's useful to look more at a variety of community roles in health and social care.

These include amplifying the voices of people with health needs or carers or acting as a gateway so that they can find out about involvement opportunities. For instance, local Healthwatch often carries out that work; and other bodies as well, for instance pensioners’ forums, may do so too.  Last year, I went through a range of reports from South London organisations and fed back some key points to researchers in my immediate network and beyond. The reports highlighted how variable services were and that those facing disadvantage and discrimination, often with high levels of health need, received inconsistent treatment and care, which could increase inequalities. The reports also highlighted the impact of factors such as housing, benefits and poor access to services generally on people's health and wellbeing. This helped to inform other activities such as our Active Involvement in Research Day – more about that later.

Communities may also take action to prevent illness or injury or reduce harm in a direct or indirect way. For instance, about thirty years ago, I was working for the Black Lesbian and Gay Centre project during the height of the HIV/AIDS crisis. Organisational activities included running a helpline with support from one of black and minority ethnic volunteers at, and one-time chair of, London Lesbian and Gay Switchboard. From what I recall, we adopted a Switchboard policy which was that any caller who sounded male was asked by our volunteers or staff if they knew about safer sex. And if they said they didn't, they’d get a very brief description. That was fine if the callers weren't male too; but it was a rough and ready attempt to reach those most at risk of infection.

I'm not sure whether researchers ever studied how effective this was; I think some Switchboard volunteers are asking around as to whether anyone knows of any research on this matter. But it was one of quite a few interventions at community level, in addition to those that were statutory sector-led, that I believe collectively worked, probably saving a fair number of lives. Sometimes in stories about health and social care and activities designed to tackle particularly serious problems, those kinds of initiatives get overlooked by researchers, among others.

Taking action can include resourcing mutual support among people with shared health needs, for instance offering meeting space; and can also involve alleviating the impact of poverty and minority stress on health and wellbeing, about which there has been an increasing amount of research. At a direct level, for instance, I'm the link to the local foodbank for a congregation of which I’m part. So last Sunday and next, I've been helping to organise a collection of food and toiletries, since 21st century Britain, rather as in Victorian times, seems to rely on volunteers to prevent mass starvation.

Less directly, communities can help people to feel valued, including those who often get messages from society that may have the opposite effect, help to give them a sense of identity, enable them maybe to make contact with others and share something of their experiences, views and concerns and enable them to achieve change in themselves or their environment that otherwise would not be possible - though communities can also have negative effects, it's not always sunny. For instance, this might include stigmatising unemployed and disabled people, reinforcing racism, sexism, homophobia or transphobia, prejudice against immigrants or refugees or enforcing silence around child abuse and domestic violence.

It would be good perhaps if more health researchers who are working on the impact of economic hardship and the effects of being part of a minority on particular aspects of health could learn from, work with, some of the voluntary sector researchers or other researchers doing work on communities and their actions and activities, including research on the role and influence of volunteers, and perhaps also involve some of those taking action at a collective level.

Communities also have a contribution to make in observing what affects health and care, gathering knowledge and ideas. This may be especially important for people, families and networks who have multiple health conditions or are at risk of developing these and in addressing social problems which further affect health. Sometimes health research is fairly narrow in focus for understandable reasons – it can be important to look very carefully at particular interventions, particular kinds of action, to see what difference these make. But this can end up with a very fragmented view of what happens to people who may often be dealing with a range of different issues in their lives and different threats to, or challenges to, their health. Humans are more than a collection of body parts, some of which are not working properly, or a bundle of care needs. And working with communities can help to offer a bigger picture.

For example, in CLAHRC South London, for the past few years we've been running an annual Active Involvement in Research Day. We held this in March 2018, in terms of the most recent one, a day with unexpected snowfall - that wasn't something that we had particularly planned for. We did however get a fair number of people along. These days bring together researchers, service users, carers and members of local communities, all of whom have perhaps different perspectives, all of whom have something unique to contribute.

This year there was a particular focus on people with, or at high risk of developing, multiple long-term conditions or who are facing social and health inequalities and the range of factors that can assist or hinder health, including taking into account what goes on within communities that may have a negative impact on health, or the strengths and assets within communities that can help to keep people healthy.

The day included presentations, a feeding in of what we’d found out from looking at those reports by local organisations and a couple of outreach visits, including one talking to some young people as well as to a Healthwatch, to try to make sure that some of those voices were reflected as well, who aren't as likely to turn up to an event of this kind. To some teenagers a day meeting on a Saturday might appeal but not to every one. Different methods may be needed to bring in different views from within communities.

And in the afternoon there was a session of mapmaking. There will be a report on AIRD 2018 coming out fairly soon so, if anybody would like to find out more, I and my team can share this with them. But it involved groups of people from different backgrounds getting together, working around maps, so to speak, which mapped out factors that might influence people’s health, both negatively and positively, and came up with some potential research questions that might arise. Jurgen was at that day as well. It was noteworthy I think, surprising even me, that a lot was achieved in a relatively short space of time as people spoke from their experience and brought those different perspectives together, in ways that researchers spending much longer together might not have achieved without that participation from service users, carers and a wide range of local people.

So these are just a few examples of ways in which communities, with all their complexities and flaws, and not taken as some substitute for service users and carers, nevertheless have a rich contribution to make to health and social care research.