View Point

Jan Wallcraft explains why she has resigned from the UK Mental Health Research Network

AS YOU MAY BE AWARE, all the staff that make up the Service User Research Group for England (SURGE), the service user arm of the UK Mental Health Research Network (MHRN),[1] resigned at the beginning of December. When we left we made a public statement to our networks about our reasons for leaving.

I have written this piece to ensure that the leadership of MHRN cannot simply airbrush the former SURGE team out of the picture. Many service user workers in other organisations have faced similar problems, and I think it is time to speak out.

Each of us in the team went through a difficult time personally, and we each made our own decisions to leave. But perhaps the pressures we were under were symptomatic of a national malaise. On the one hand, law and government policy dictate that the public must be involved in health service planning and delivery. On the other, budgets for involvement are constantly eroded, involvement systems that work (eg. patient and public involvement forums) are replaced, and national standards for involvement are non-existent. NIMHE's excellent involvement tools, Making a Real Difference (www.nimhe.csip.org.uk/~mard/), were launched last year, just as the organisation itself was rendered impotent. Instead of real involvement, we get empty rhetoric.

As SURGE manager, I recruited a committed and expert team of service user researchers. Our remit was to work with personnel in and around the MHRN to raise the level of user involvement in large-scale clinical mental health research. We had modest and (we hoped) realistic goals of gradual progress through raising awareness of good practice, networking, and offering training and support to clinical researchers, managers and service users. But the culture of 'information management' that prevails in the MHRN has hampered our work at every turn. Our survey findings about existing involvement were suppressed because of fears that criticism would weaken the organisation and jeopardise its funding position. Most people we spoke to in the MHRN and the UK Clinical Research Network (the overarching body governing all the health research networks) wanted and needed our findings to strengthen good practice, but 'spin' prevailed and genuine communication was curtailed, again and again. Independent involvement of service users, including the SURGE advisory board, was viewed with suspicion.

NIMHE was once pilloried for its concept of service users as 'critical friends'. MHRN went a step further and dropped the 'critical' role. Increasingly, it seems it is only possible to be involved in the MHRN if you toe the party line.

It was never clear to what extent the nervousness of the MHRN leadership was genuinely due to government pressure. Clearly the government leans towards the needs of the pharma industry, who want rapid and unhampered access to patients to take part in large scale clinical trials, and want help from the health research networks to achieve this. If the pharma industry's needs drive the government agenda, this was bound to clash with SURGE's emphasis on quality interactions between researchers and patients/service users, early involvement in initial decisions on research topics, and service user leadership of research wherever possible. Service users call for openness and democratic decision-making, while the academic and commercial sectors are used to top-down, professionally-controlled decision making behind closed doors. No surprises, then, that tensions arose in the MHRN.

When we found ourselves prevented from talking to the people we felt ourselves to be most accountable to – our advisory board, our service user networks, the people who had given us information in our surveys and outreach work, and the people who gave us support, the patient and public involvement systems across the UK Clinical Research Network – we became increasingly unable to carry out the jobs we were recruited to do.

The only choice in such a situation is to give notice. Where people in an organisation are afraid to speak out and share information, what kind of involvement can there be? I have been personally informed that my job was 'to keep a lid on things'. I feel it my public duty to say that this is not service user involvement, and that service user workers should beware of getting themselves into jobs like these, which can destroy their morale and self-esteem.

I think we need to re-assert to the present government that involvement in research and in public services is a form of democracy that can be of immense value in ensuring effective services that are value for money, not to mention the human rights agenda, 'nothing about me without me', and the empowerment factor. People gain a huge amount of self-esteem, learning and improved quality of life from becoming involved in things that personally concern them. We are being sold short if we accept a tame, sanitised, toothless form of government-controlled patient and public involvement. ∎

Jan Wallcraft is a freelance mental health consultant, and was until recently operational manager of SURGE, the service user arm of the UK Mental Health Research Network (MHRN) This is her personal opinion and does not reflect the views of the whole SURGE team.

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1   The UK Mental Health Research Network is funded by the Department of Health to provide the NHS infrastructure to support non-commercial and commercial large scale research in mental health, including clinical trials. The MHRN website states: 'SURGE plays an important part in making sure research across the MHRN is valuable for and makes sense to service users.'