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# **On a scale of 1–5 how satisfied are you with the healthcare service you receive?**

*Paul Godin and Jacqueline Davies*

The recent trend towards involving service users in research poses a number of ethical issues, particularly in the area of forensic mental healthcare. There is a propensity for traditional researchers to involve service users in a rather perfunctory, minimal and even tokenistic manner. They might consider asking service users' advice about what questions to include in a questionnaire or interview schedule and might even pay some service users to survey or interview their peers. But, if you were a forensic mental healthcare service user, how would you feel about someone, albeit a fellow service user, shoving a Likert-type scale satisfaction questionnaire through the bars of your cage? What could you convey about your experiences of forensic mental healthcare through the few boxes you ticked? How actively involved or empowered would it make you feel? We contend that such putative user involvement research is morally objectionable as it encourages service users to retain a largely passive, "done to" role. Furthermore, it stands in the way of more genuinely participatory research that can give voice to service users and enable them to bring about change for the better in themselves and the world around them.

Elsewhere, we have given a detailed account of one of the first Department of Health funded research projects to involve forensic mental health service users in the evaluation of their care (Banongo et al 2005). We have also explained how the project adhered to core principles of participatory research and went some way towards facilitating what Habermas (1984) calls "communicative action" (Godin et al 2007). In short, communicative action might be described as free open debate between people concerned to understand and change the world for the better; the basis for deliberative democracy. In this brief account of the project, we reflect on some of the ethical problems and issues that it posed for us as we facilitated it. We hope that our reflections are of use to those who share our values about involving

service users in research and aim to advance participatory research in the world of forensic mental healthcare.

As forensic mental healthcare service users are often incarcerated in highly secure environments, they and the people who attempt to undertake research with them inevitably face considerable restraint on what they can do. For this reason, the research project we facilitated recruited forensic mental health service users who were at liberty to come and meet with us at City University to participate in the project.

We were determined that the service users we recruited would be maximally involved in all stages of the research project, from setting the research questions to gathering and analysing data, to disseminating their findings. There was to be no cleavage between the researchers and researched as exists in traditional studies. The service users researched themselves and each other as they gave accounts of their experiences of using forensic mental health services, which they then analysed. As we (academics and service users) talked as a group, sharing our experiences of forensic mental healthcare, we (academics, some with mental health nursing backgrounds) too became subjects within the research.

We, the academics on the project team, attempted to place our expertise at the disposal of the service user researchers to use as they wished in order to evaluate the services they had received. This ideal was never fully realised, not least because it was us who employed the service users rather than the other way around. To obtain funding and ethical approval, the project proposal had to be explained in very open-ended terms, speculating what the service user researchers might wish to do. Fortunately our funders (the National Forensic Mental Health Research and Development Programme) and the ethics committee understood our intention and approved our proposal.

When we began the project, the first task was to recruit service users to it. This posed a number of ethical questions. Were we to be so mindful of their forensic histories that we were to invite psychiatric experts to screen and select a number of “their” patients that they deemed safe and suitable for the project? We thought not and resolved to recruit the service users as other hourly paid researchers. After advertising we interviewed people who contacted us and then sought a reference from somebody that knew the candidate well, usually their key worker. How were we to pay our recruits? Were we to dole out cash to them as a reward each time they came to the group or were we to treat them as proper hourly paid employees of the university receiving a contract of employment and a pay cheque at the end of the month? We went for the second option as we believed that this afforded respect for the service users as employees engaged in a proper job.

As we have explained elsewhere (Banongo et al 2005), recruitment proved difficult as applicants were not readily forthcoming and those that there were

proved to be very ambivalent about joining the project. The seven service users that eventually joined came to us largely as a result of encouragement from their key workers. Although we were of course extremely grateful for the efforts of key workers, in one case it appeared that the encouragement was too much. We had contacted, interviewed and accepted one candidate, introduced to us by his key worker. After attending the group a couple of times the service user, an intelligent and thoughtful man, stopped attending. His key worker then phoned us to find out how his client was getting on in the group. On telling the key worker of his client's non-attendance, the key worker expressed disappointment, telling us that he and the consultant psychiatrist had written in the service user's care plan that he should attend the group. We were determined that the group should not be regarded as formal therapy, far less that service users should be compelled to attend. Thus when we next met the service user we explained that although we did not want to lose him we were quite happy for him to discontinue coming to the group if he so wished.

Although we made it clear to the service users that the purpose of the group was to enable them to conduct research rather than for them to receive therapy, there were moments when the service users sought or clearly needed help from us. One of the service users often asked our advice about his health. We listened sympathetically and made suggestions as to from whom he could receive help. Although most meetings were largely convivial, service users often disagreed with each other in group discussion.

At the end of one of the group meetings a service user threatened violence towards another. Fortunately one of the academics managed to mediate between the two to defuse the situation. Just like any research managers, we had a duty of care to the researchers. Perhaps this responsibility is greater when employing people that are users of health services.

Although the project was to be led by the service users, they found it difficult to take the initiative to direct the project. In the early meetings the service users asked us: "What do you want us to do?" We shared our expertise and knowledge of research and explained that we were available to help them undertake any service evaluation research that they wished to do. They then responded by asking us: "So what do you want us to want to do?" Ironically we had to be very directive in getting them to be self-directive.

After a number of meetings the service users set their research questions. The main question they wished to ask was: "Why are services so bad?" With our expertise and knowledge of social science research, we suggested that their question was inappropriately phrased as a leading question. We advised that the normal and recommended style for questions was something more balanced. We suggested they ask what was good and not so good about services. They unanimously agreed that it was quite obvious to all users of forensic mental healthcare that the services they received were inadequate.

In their view, satisfaction questionnaires would only establish what was already known by service users.

Progressively the focus of our weekly meeting shifted from discussion about what research the service users wanted to do and how to do it, towards actually doing the research. In short, the service users converted our meetings into focus groups, which they analysed and recreated in filming. This was complemented by a number of the service users also producing written accounts of their experiences of using services. This material was put together in a glossy report with an accompanying DVD (which can be obtained free of charge on request by e-mail from p.m.godin@city.ac.uk) (Banongo et al 2005). As the service users were actively involved in the research it was only correct that they, along with the academics, claimed authorship of the report. Thus it bears the names, in alphabetical order, of all those involved in its production. The service users also played a very full and active part in disseminating the research in a number of seminar and conference presentations.

Reactions to presentations of the research and the report have particular importance in relation to the ethics of such participatory research in the area of forensic mental healthcare. In one way or another, some people criticised us for ignoring the “elephant in the room”. We were told that we were blind to the fact that our service user researchers were “difficult”, “manipulative” people with “challenging behaviours”, which rendered their voices suspect if not untrustworthy. Furthermore, some critics questioned whether it was right to allow people who had committed serious crimes to have a voice as they had curtailed the freedom of their victims. Lastly, other critics condescendingly suggested that the service users might find the freedom and responsibility of leading the research too much to handle. In essence, all of these criticisms serve to mute or disregard the voice of forensic mental health service users and deny the possibility of open democratic debate with them. In conclusion we suggest that if we (academics and clinicians) really want to involve forensic mental health service users in research then we must be prepared to listen to their voices as they wish to express them, rather than to merely record and add up the ticks they place on satisfaction surveys.

## References

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