

Why we should conduct research in collaboration with people who use alcohol and other drugs

Collaborative research is more than a list of involvement activities; it is a mindset requiring receptiveness to new ideas, trust, respect, effort and resources. There are utilitarian, ethical, epistemological and consequentialist arguments for taking the time to do it well.

If you have ever struggled to recruit participants to your trial, discovered that the results of your survey are compromised by missing data, wondered why interviewees in a qualitative study did not grasp the point of your questions or been disappointed that your research findings were not embraced enthusiastically by the treatment sector, then this editorial—on conducting research in collaboration with people who use substances—might be for you.

Terminology used to describe the concept we are discussing is confusing. We refer here to ‘collaborative research’, meaning researchers working ‘with’ members of the group being studied throughout the research process. We distinguish this from: (i) participation in research (where members of the group studied are involved as research participants), (ii) engagement in research (where information about research is shared with members of the group studied) and (iii) user-led research (where those directing the research are members of the group studied; e.g. people in treatment researching that treatment for themselves) [1,2].

The term ‘collaborative research’ is often used interchangeably with ‘service user involvement in research’, ‘patient and public involvement in research’ and ‘community involvement in research’. Language is crucial, and the best form of words to use will depend upon context and political perspective [3]. For a treatment study, ‘patient involvement’ may seem appropriate, yet be offensive to those who do not consider themselves to be ‘sick’. ‘Service user’ may capture those in treatment, but exclude those who are not currently accessing services. Even the word ‘involvement’ is challenging, as it refers to a continuum of activities, e.g. advising, assisting and being equal partners in the research process [4,5].

In this editorial, we focus upon the principles and practices of collaboration rather than semantics. Common strategies are asking people who use substances to identify topics requiring further study, join a project advisory group, help design a study intervention, comment on the feasibility of using particular research methods, suggest appropriate outcome measures, co-write participant information sheets, prepare lay summaries, advise on interview topic guides, recruit study participants, assist with

data collection and analyses and contribute to dissemination activities [3,6–11]. Piloting is not generally viewed as involvement, but can be if feedback is collated and used to inform the study going forward.

Collaboration is, however, much more than a list of ‘involvement’ activities. It is a mindset, requiring all parties to trust, respect and value each other and to function as a team. People who use substances need to recognize that there are rules and conventions of research, including deadlines, over which researchers may not have control. Researchers must be willing to change their views and amend study designs depending on what people who use substances tell them. Addiction studies are conducted routinely by multi-disciplinary teams of scientists who have different perspectives and knowledge. Just as health economists, statisticians or qualitative researchers bring distinct but valued understanding to any study, so people who use substances have their own expertise (they are ‘experts by experience’). Furthermore, just as statisticians do not need to comprehend qualitative research or qualitative researchers do not need to be proficient in health economics, so people who use substances do not need to understand all aspects of the study to contribute meaningfully.

Within collaborative research, there is no place for tokenism. Tokenism might include inviting the same person onto every project advisory group, asking someone for his or her views and then ignoring the responses, or treating involvement as an afterthought (e.g. designing the study intervention and then asking a person who uses substances to ‘approve’ or ‘sanction’ what has already been decided). Good collaborative research requires effort and resources. Researchers need to ensure that people who use substances have all the information they need, but are not overloaded with unnecessary information. Payment needs to be discussed and, if payment is not available, alternative forms of compensation or reciprocity should be considered.¹ It is also important to ask people who use substances how they prefer to collaborate (e.g. doing what activities, when, where, for how long and using what communication media). Additionally, researchers must offer support, mentoring or training when asking people to participate in activities that may be unfamiliar to them.

This, of course, leaves an important question. Why should researchers collaborate, given the evident effort and costs required? This seems pertinent, given that there is actually no good evidence quantifying the benefits of involving people who use substances in conducting research. To begin,

¹In our own collaborations, researchers who did not have budgets have, for example, offered to mentor service users applying for jobs, college places or student bursaries.


there is a (somewhat mercenary) utilitarian argument: research funders often expect and request collaboration. Then there is an ethical and moral argument: people who use substances have a right to be involved in research that affects them. Next, there is an epistemological argument: people who have used services or experienced particular life circumstances have valuable first-hand information that researchers tend not to have but need to know [3,12–16].

Our own experiences of research collaboration during the last 4 years have also highlighted consequentialist arguments. We alluded to some of these in our opening paragraph, but expand here. First, collaboration can bring credibility to a study, so increasing recruitment and trust in the findings. Secondly, collaboration forces researchers to learn how to explain their studies clearly to those whom they want to participate, so increasing interest and engagement. Thirdly, collaboration can help to minimize the chances that study documentation, questionnaires and research reports inadvertently use language that is stigmatizing, offensive or overly technical. Fourthly, collaboration can prevent researchers from making naive judgements about how interventions will work in the real world. Fifthly, collaboration enables researchers to report their results more confidently, knowing that the study population shares some responsibility for the findings. Sixthly (and we appreciate that this is not a scientific justification, but it seems important to mention all the same), we genuinely enjoy working together, have learnt much from each other and believe that everyone has gained something personally from the process.

Declaration of interests

J.N. is part-funded by, and J.S. is supported by, the National Institute for Health Research (NIHR) Biomedical Research Centre for Mental Health at South London and Maudsley NHS Foundation Trust and King's College London. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. J.N. receives honoraria and some expenses from *Addiction* journal in her role as Commissioning Editor and Senior Qualitative Editor. J.S. is a clinician and researcher and has worked extensively on clinical trials and wider research and has contributed to clinical guidelines on treatment types and provision. J.S.'s employer (King's College London) receives, connected to his work, project grant support and/or honoraria and/or consultancy payments from government agencies, charitable sources and also from pharmaceutical companies, including funding for clinical trials and research studies (for fuller information see www.kcl.ac.uk/ioppn/depts/addictions/people/hod.aspx).

Keywords Alcohol and other drugs, collaborative research, patient and public involvement, research, service user involvement, user-led research.

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References

- Rose D. The contemporary state of service-user-led research. *Lancet Psychiatry* 2015; 2: 959–60.
- Involve. What is public involvement in research? National Institute for Health Research; 2017. Available at: <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/> (accessed 12 September 2017) (Archived at <http://www.webcitation.org/6tQQ557Zo>).
- Trivedi P., Wykes T. From passive subjects to equal partners: qualitative review of user involvement in research. *Br J Psychiatry* 2002; 181: 468–72.
- Arnstein S. R. A ladder of citizen participation. *J Am Inst Plann* 1969; 35: 216–24.
- Poulton B. C. User involvement in identifying health needs and shaping and evaluating services: is it being realised? *J Adv Nurs* 1999; 30: 1289–96.
- Elliott E., Watson A., Harries U. Harnessing expertise: involving peer interviewers in qualitative research with hard-to-reach populations. *Health Expect* 2002; 5: 172–8.
- Angell K. L., Kreshka M. A., McCoy R., Donnelly P., Turner-Cobb J. M., Graddy K. *et al.* Psychosocial intervention for rural women with breast cancer. *J Gen Intern Med* 2003; 18: 499–507.
- Hewlett S., Cockshott Z., Byron M., Kitchen K., Tipler S., Pope D. *et al.* Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. *Arthritis Rheum* 2005; 53: 697–702.
- Goberman-Hill R., Horwood J., Calnan M. Citizens' juries in planning research priorities: process, engagement and outcome. *Health Expect* 2008; 11: 272–81.
- Oliver S., Armes D. G., Gyte G. Public involvement in setting a national research agenda: a mixed methods evaluation. *Patient* 2009; 2: 179–90.
- Boote J., Baird W., Sutton A. Public involvement in the design and conduct of clinical trials: a review. *Int J Interdiscip Soc Sci* 2011; 5: 91–111.
- Fudge N., Wolfe C., McKevitt C. Assessing the promise of user involvement in health service development: ethnographic study. *BMJ* 2008; 336: 313.
- Ward P. R., Thompson J., Barber R., Armitage C. J., Boote J. D., Cooper C. L. *et al.* Critical perspectives on 'consumer involvement' in health research: epistemological dissonance and the know-do gap. *J Sociol* 2010; 46: 63–82.
- Gibson A., Britten N., Lynch J. Theoretical directions for an emancipatory concept of patient and public involvement. *Health* 2012; 16: 531–47.
- Goodare H., Lockward S. Involving patients in clinical research. *BMJ* 1999; 319: 724–5.
- School of Health and Related Research (SchHARR). Patient and public involvement in research. The University of Sheffield, School of Health and Related Research, PPI; 2017. Available at: <https://www.sheffield.ac.uk/scharr/ppi> (accessed 12 September 2017) (Archived at <http://www.webcitation.org/6tQQHkUgV>).