Guidelines for incorporating lay & service user representatives

Note: These guidelines are intended to advise researchers who are involving mental health service users on steering and advisory committees for research projects. These guidelines have been developed in collaboration between researchers and service users. Nonetheless, this is intended to be an evolving document. So if you have any potential corrections or helpful tips please feel free to contact us using the contact details at the bottom of the document.

Planning

1. **Work out how service users are going to be involved at an early stage**

   Everyone should have clear expectations about service user involvement. It is good to involve service users as early as possible within your project cycle. You don't need to have a plan written down for the whole of the trial period, but you need to have some idea about initial tasks you want the service user representatives to provide input on – for example, looking over participant information sheets, commenting on methodology/measures, practising all aspects of patient facing activity with a researcher. Service users can also suggest ways they could be involved – for some research projects, taking the draft project proposal to the Service User Advisory Group (SUAG) or the virtual FAST-R service before it goes to the funder is one way of doing this.

   You also need some idea about your budget for user involvement and how to access these funds.

   Everyone needs to have clear expectations about their involvement before the project is approved. Be clear about what you can gain from hearing the user perspective and including this in your trial. The funder will need to know about this, and it needs to be achievable so the service user representatives can deliver their side of the work.

Recruitment

2. **Find the right people**

   If you are a researcher or a clinician, you may be able to recruit service user representatives from among your own current and former participants or

patients. This has the advantage that they know you and can speak from personal experience about the condition being studied and the treatment process.

You may also be able to recruit other experienced service user representatives from the SUAG or elsewhere within the college. Although they may not have personal experience of the condition being studied, they will be used to participating in meetings and discussions on other research projects and can comment generally from the patient perspective.

It may be most helpful to have representatives from both of the groups above, providing a mixture of experience.

Recruit representatives who will be comfortable and confident in playing the role in the trial that you are looking for. Do not recruit people who are overtly antagonistic to your research area or to the ethos of your study. For example, if you're funded by a drug company or using a medical model (two things which are potentially controversial) – then state these as soon as possible, so that potential representatives can make up their own minds. These factors can be assessed by meeting prospective members for an initial chat before recruiting them. Most user representatives will be supportive of research which will ultimately help other patients in future.

Consultation with SUAG members has provided the recommendation that, while carers are also an important group who can offer a useful perspective, they are not substitutes for service user representatives. You may wish to include one or more carers in your group, but they would need to be in addition to users with direct patient experience, rather than instead of them.

3. **Recruit a minimum of two user representatives**
Having more than one service user representative means they can support each other and feel more comfortable challenging jargon, practices, and governance in a group dominated by professionals. Where one service user might feel unable to address one issue, another often can. It also gives the committee the benefit of different patient perspectives.

You may wish to recruit a pool of people who can help with different tasks on the project. If someone is not available to come to a meeting, another user representative may be able to stand in for them.

4. **Manage expectations**

What are service user reps realistically going to be able to influence over the course of their participation? Acknowledge this upfront and speak to potential service user representatives before you recruit them. Don't make vague promises that you can't keep – if you have low expectations of how much influence service user representatives can have on certain aspects of trial management, it is better to state this up front and focus on what people can influence.

Make sure the prospective service user representatives are aware not only of the work involved in their role but also the timescale of their involvement, which may vary from one brief consultation on a leaflet to participation in a management committee for the duration of a trial. Some users may make an open-ended commitment to membership of an internal committee. Different people may be involved in different tasks, so if you are able to offer options, users can choose a type of involvement that suits them.

It is also important to discuss payments and expenses in advance, see point 10 below.

5. **Plan to meet service user representatives' needs**

The trial manager or the meeting organiser is ultimately responsible for the experience of the service user representatives. It is their job to make sure people have the support to be able to understand and contribute.

As part of the recruitment, establish each user's needs and any adjustments needed for meetings or other work on account of their mental health condition or other disabilities. It is important to be aware that users may have more than one health issue or disability.

The Trial Manager should be responsible for pointing out where necessary, the parts of documents and/or supplementary material that service user can influence. Make sure these documents arrive in a timely manner (i.e. in good time before the meeting and in an appropriate format). Remember, some people find it easier to read printed documents, so make sure you have enough printed copies at the meeting.

6. **Provide training**

It is good practice to provide training (or at least a good comprehensive briefing) to both the user representatives and the professionals who will be involved in the trial or committee. This is because user involvement places additional responsibilities on all those involved to ensure it works effectively.

Meetings and other work

7. **Interaction between professionals and user representatives**

The very process of having lay or service user members on a committee should be enough to encourage all members think twice about how they say and present things. In line with this, make sure all members know that lay/service user members will be present at the meetings. Professionals may want to adjust the way they word things (use more sensitive or less jargon heavy language).

Service users usually have a different relationship to this process than researchers or clinicians and it's important to be aware that they may have had bad previous experience of something which is being discussed at the meeting. Provide support, as the users' perspective is invaluable to making sure the trial runs effectively.

8. **Offer support and adjustments**

Ensure that any adjustments needed are planned in advance.

Acknowledge that trial meetings can sometimes be long and tedious for everyone, including service user representatives. For large multi-disciplinary meetings such as a trial steering group, most attendees (professionals and lay members) are not expected to follow and understand the whole meeting. Instead, people will be able to speak for one or two items on the agenda. Often, large amounts of paperwork are generated in advance of meetings. Ensure that you highlight the most relevant parts for service users to look at, rather than expecting them to read it all.

The speed or length of time of the meeting might be an issue. In longer meetings, add in a small break for everyone. Advise representatives that they can step out or leave the meeting if they need to.

If service user reps have not had a chance to feed back or have their say during the meeting, then offer them a chance to debrief on the phone or somehow after the meeting – and feed their comments back into the next meeting.

Offer pre- and post-meeting debriefing and support to users in any case, as they may be affected by the issues discussed at the meeting. To fulfil their role, they need to connect with memories of their own patient experience, which may often be upsetting. The organisation is responsible for providing adequate support.

9. **Produce a glossary of terms and acronyms**

Update this at every meeting as any questions arise about a term. This is useful for everyone, not just service user reps! Be prepared to write a short description of acronyms, it's not enough to just spell it out. An example of a glossary entry could be something like *"NIHR = National Institute of Health Research – a part of the health service which funds health research"*

10. **Payments and expenses**

This is the most complicated aspect of involvement (feel free to speak to a member of the BRC Service User and Carer Participation theme for advice, details below).

Determine remuneration in advance. All members of the project are being paid to bring their expertise, and this should be no different with service user representatives. There are standard scales of payment for user representatives, such as those available on the INVOLVE website (invo.org.uk).

Agree in advance what expenses you will be paying (e.g. travel, parking, and childcare). Always ask individuals that you will need them to bring **receipts** to meetings in order to pay the expenses. Some people prefer to use their own transport and this can make the payment of expenses more different. Ask the person in advance if they intend to use their own car to get to the meetings, and if so, work out the mileage claim in accordance with the college expenses policy.

If the university pays expenses via BACS with a significant delay, inform representatives in advance. It may sometimes be appropriate to pay expenses in petty cash (for example, when payment of late expenses would cause people to be out of pocket). Whichever method you use, make sure the individual receiving the payment **signs** for any expenses/payments received. Create/adapt a receipt form (two copies) for this purpose, this should state the date, name of meeting/task, and give space for you both to sign. Give one copy of this to the service user rep. Keep the other copy for your own project records.

Finally, payments may affect individuals' benefits claims, so speak to the individual if they have any concerns about this. (Bear in mind that benefits is a

complex and ever-changing issue, if you need any advice speak to the BRC Service User and Carer Participation theme for more details).

11. **Confidentiality**

Don't assume that service user representatives want to be known as 'service user representatives' to anyone outside the project. People have their own private lives and careers and these can be quite different to the roles they wish to adopt in the meeting. There is still considerable stigma attached to mental illness (and other illnesses) in the wider community, which can unfortunately affect work prospects, relationships and other areas of life. Consider this in your email and other communications. You may need to tailor your subject lines, and always use 'BCC' for emails to user reps unless you have permission from the service user to do otherwise.

Don't 'out' anyone as a service user in public. Let the person choose whether they wish to do this, in their own time and at their own pace.

12. **Further contact:**

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KCL also has a disability advice service which may be able to help. For enquiries or to make an appointment email disability@kcl.ac.uk or call 0207 848 7018