

Example of user involvement in consulting about research

User consultants on the NHS HTA Program panels¹

Purpose: The HTA Program wanted to trial ideas for creating stronger user involvement within the NHS Health Technology Assessment (HTA) Program. They involved people at several stages of the research and development cycle, but here we will concentrate on the consulting about research stage, in particular, prioritising identified topics.

Setting up the project: The HTA program decides on what the national research priorities are and who will get funded to do research in the health technology area. They employed a person who was a service user with strong research experience to set up and run the user involvement project and evaluate how it went - this was Sandra Oliver. They also had two users on the project advisory group. As the program manager, Sandra invited users to be involved in several ways for the five main tasks for the HTA program. We will concentrate on one task - user involvement on the HTA Program advisory panels where

they prioritise and select what topics should be researched.

The program manager identified user consultants by:

- public information campaigns about the HTA program
- informing self-help or patients' representative groups and national charities (with a health focus)
- contacting health information services
- telling journalists

Users registered their interest and then two users joined three of the HTA Advisory Panels (six users in total). Each panel had 15-18 health and social service staff members.

Roles of the user consultants: User consultants were full members of the three panels that met twice a year. They had to read up to 15 brief summaries about research needs to help them with prioritising topics between the first and second meetings held each year. These 'vignettes' were 3-4 pages long. The researchers who prepared the summaries had to consult users about how they wrote them before they could send them out to panel members. So, at the first panel meeting the user consultant panel members recommended other people to be consumer experts that the researchers could talk to based on their networks. These consumers were asked to comment on

the vignettes to highlight issues that are important to patients or people using services with a particular focus on:

- whether the research question is the right one and matters to consumers
- whether it is looking at the right aspects of the health condition or problem
- what are the important areas where the research topic should make a difference

After the user consultants read the summaries they went to the second meeting and discussed all the research topics, then voted for their priorities.

Support provided to user consultants: The user consultants received training through an induction day along with other new non-user panel members. They had panel observers from INVOLVE, the Consumers in NHS Research Group, there as well. Equal partnership was modelled by having users take lead roles during the day. User consultants got support from the Chair of each panel, and also administrative support from the HTA Program for managing the paperwork involved. They were not paid an honorarium during this trial of user involvement.

Level of influence or decision-making: User consultants were seen as equal team members of the panels who could discuss ideas, influence other people's opinions and vote like any other member. There were more health professionals (8) than user consultants (2) on the panels.

Activities that happened: Each panel met twice a year to consider the information about research priorities, discuss the issues and then vote on what the priorities would be. The panels do not select who gets to do this research - that is called commissioning. That was a different task involving reviewers across the country including users, carers and/or their organisations.

Outcomes achieved: The HTA program learned many things through their trial of user involvement strategies. They plan to improve their user involvement work based on the trial. The learning about user consultants involved on panels included:

- they need to make sure there are adequate resources for user involvement, including payment for honorariums and staff time
- they need to provide more support for user consultants, including more training, mentoring, debriefing and giving a clearer understanding of their and all panel members' roles

- they need to support health service staff to become more 'bilingual' in discussing research with users so that it is easier to understand and discuss

Strategies for success:

- Training user consultants, support from HTA program staff - particularly those running the user involvement project
- Preparing the panel chairs for the project and getting their cooperation and willingness to support users as panel members

Problems that occurred:

- Heavy workload for user consultants - they received advice and support from panel chairs to help manage this
- Feeling isolated in their role - this was not addressed, but user consultants recommended that in future an experienced panel member mentors them in their role
- Different levels of support for user involvement by other panel members - this was managed by the panel chairs, but more support from HTA staff to help them look after group dynamics may help
- User consultants and professionals being uncomfortable with each other - mistakes and difficulties were discussed openly to reduce the tension

Benefits achieved:

- User perspectives did influence what the final research priorities were as they could see different knowledge gaps to health professionals
- Other panel members learned about user involvement and became more positive about it
- The HTA has continued with a strong commitment to user involvement and this process is outlined in detail on their website²
- The HTA has now set up a mentoring program for all new user consultant panel members, clear job descriptions, briefing papers for tasks and appropriate remuneration²

References

1. Oliver, S., Milne, R., Bradburn, J., Buchanan, P., Kerridge, L., Walley, T. & Gabbay, J. (2001). Involving consumers in a needs-led research programme: A pilot project. *Health Expectations*, 4, 18-28.
2. Health Technology Assessment (HTA) Programme: Main home page: <http://www.nchta.org/>; Consumer home page: <http://www.nchta.org/consumers/index.htm>

Case example analysis

Use what you have learned so far about user involvement to decide if what happened in this example was:

Poor

OK

Good

Excellent

Rate the 7 areas below. For some areas you may wish you had more information. Just do the best you can with what you have. After you rate each area give brief reasons for your decision.

- If you liked something, say why
 - If you think something was missing, then say what it was
 - Someone must record your decision and reasons for each area - another person must be your group representative when we return to the large group
1. A good **range** of users, carers or the public were involved
 2. User consultants had meaningful **roles**
 3. There were realistic **expectations** of what they would do
 4. They received strong **support**
 5. They had strong **influence** in the decisions
 6. Their involvement had **benefits** for the organisation
 7. Their involvement had **benefits** for other users, carers, and/or members of the public