

Part C

Commissioning research

A summary of Part C

Why is Part C important?

Once people have decided to research a specific area they need to gain funds for the project. They submit proposals to research funding groups who have the job of deciding who gets the money. This is called commissioning. In Part C participants will learn about the details of this stage and analyse real examples. They will also consider the practical issues of user involvement in commissioning research to help them decide if they would like to do this work.

What will participants learn by doing Part C?

At the end of this part participants will be able to:

- Understand what commissioning research means - Activity 1
- Understand what happens in the commissioning research stage - Activity 1 and 2
- Discuss the practical issues of user involvement in the commissioning research stage - Activity 3

Skills participants will strengthen or develop

Skills that participants will strengthen or develop include:

- Level 2: Further practice with thinking about issues
- Level 2: Further practice with developing and presenting an argument
- Level 2: Further practice with speaking in large groups
- Level 2: Further practice with planning what to do next
- Level 3: Demonstrate ability to think about issues
- Level 3: Demonstrate ability to think about case examples

Background information

The background information provides trainers with additional information that prepares them for issues that may be discussed during the training.

User involvement in commissioning research

User involvement in commissioning research is becoming more commonplace, particularly in national programs funded by the Department of Health such as the Health Technology Assessment (HTA) Programme that is listed as a case example in this Part as well as Part B. User and carer associations may also have research funds and want to commission research in the priority areas they have identified. This happens with The Alzheimer's Society, which was listed as a case example in Parts A and B, and again here but in much more detail.

Learning from experience

In 1998 the HTA program decided to extend user involvement into all aspects of their work, developing a pilot study and reporting on its outcomes.³ They found that users and carers tended to highlight issues about patients' views, social contexts, and information and support needs. They also focused on long-term outcomes and how research findings are disseminated to

consumers.⁴ It became obvious that the initial process they put in place was not sufficient to support users, carers and the public's active and meaningful involvement in the program. In their initial process training was provided, along with support from staff and other member of the HTA panels. They have since developed additional support structures, including:

- a mentoring program for all new user consultant panel members
- clear job descriptions so people can understand their role and the expectations
- briefing papers for specific tasks so people have a step-by-step guide to follow²
- appropriate remuneration for significant tasks, as well as travel costs where relevant

This has resulted in a program where the HTA now supports significant levels of user involvement (they use the term 'consumers' in their programme):⁴

- Between 30 and 45 consumers each year comment on what they believe the specific research needs are for identified topics - this contributes to brief summary papers or vignettes on research topics to assist with prioritising topics

- Six consumers attend 7-8 research topic prioritisation meetings a year to determine what work will be advertised in the commissioning
- Thirty consumers a year comment on research proposals that are submitted for funding in the commissioning stages
- After research has been commissioned and monitored, 20 consumers a year comment on the research reports before they are finalised for publication and dissemination

The peer reviewing task

The HTA's guidelines on peer reviewing for consumers are an excellent resource for outlining the steps in doing this task.

Rather than summarise this here please refer to this guide.²

The key steps will be outlined in Activity 1, however, there are some other issues to note if people are facilitating user involvement or being user consultants.

Different users, carers and members of the public will bring varied perspectives. For example, single users or carers may focus on areas specific to their own experience. This is vital and must be heard, but it is also useful to hear the range of experience, which may be gained through people involved in

specific national or local user/carer organisations. But there will also be a difference there as well:

“Recognise that consumers from national organisations may have different expertise than those from local groups. National organisations may employ researchers or research managers with particular expertise in this area. Local groups will often be dependent on volunteers.” (p.20)¹

When users, carers or members of the public are reviewing research proposals they offer fresh perspectives and ideas for researchers to consider. They can do this through several or all of the following ways:²

- thinking creatively based on their own experience
- knowing a lot about their subject, which may be based on their personal experience and that of other consumers
- thinking logically and seeing if the research proposal has clear aims and methods, a convincing rationale (its reason for doing it and in particular ways) or if there is bias that has not been identified
- gaining more information by asking personal questions from a user or carer's point of view

- applying ethical principles, such as how well the proposal meets human rights and civil rights, ensures personal safety and support
- making sure the language is can be understood and other ways of representing the information are included, such as illustrations or graphs
- encouraging authors by identifying what they think is good and why
- making practical suggestions for change and explaining why this would be helpful
- commenting on the overall value of the research

Without the input of users, carers and the public, research may be well intended but not contribute to issues that make a meaningful and visible difference in their lives. There are limitations on research dollars and research groups usually compete with each other to gain funds. The commissioning process is critical in making sure that researchers have a clear commitment to and understanding of user perspective and user involvement, as well as the technical and professional skills needed to do the research.

References

1. Hanley, B., Bradburn, J., Gorin, S., Barnes, M., Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver, S. & Wallcraft, J. (2003). *Involving the public in NHS, public health and social care: Briefing notes for researchers (2nd edition)*. Winchester: INVOLVE (Consumers in NHS Research Support Unit). Available online at:
<http://www.invo.org.uk/pub.htm>
2. Oliver S. (2000). *Guidelines for consumers peer-reviewing research 2*. HTA Programme. Available online at:
<http://www.nchta.org/consumers/index.htm>
3. 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.
4. Royle, J. & Oliver, S. (in press). Consumer involvement in the health technology assessment programme. *Journal of Health Technology Assessment*.

Activity 1

What does commissioning research mean?

There are several activity options. Each one has a suggested time allocation. This is a rough guide and can be extended according to the programme you have set up. Combine different activity options depending upon your chosen programme and your participants' needs. Suggested combinations are:

- Large group discussion + mini-presentation + commissioning practice large group discussion
- Small group discussion + mini-presentation + commissioning practice small group discussion

Things to get ready

- Print the Unit 5 - Part C PowerPoint files 1A - 1I in 'note pages' for you and, where appropriate, 'handouts' (two slides/page) of the presentation material for participants
- Whiteboard and coloured whiteboard markers
- Flipchart paper and coloured markers
- If you choose Activity 4 or 5 speak to the Research and Development Unit of your local NHS Trust or PCT. Ask them for an example of a 3 page research proposal written as a

'lay summary' that you can use. For confidentiality reasons, they will provide a project that has already been commissioned and can be publicly known

- If you choose Activity 4 then you will need strips of scrap paper for people to use in the secret ballot

Activity Option 1

Large group discussion - Existing knowledge of commissioning research (10-15 minutes)

The purpose of the large group discussion is to practice skills in thinking about issues and speaking to large groups:

- Ask if any participants have ever been involved in commissioning research and development projects
- If no, move on to the mini-presentation
- If yes, ask these people to share their experience with the group if they are willing. Here are some prompt questions to help facilitate the story:
 - * How were you invited to be involved?
 - * What did you get to do?
 - * What did they do with your ideas?
 - * What feedback did you get about whether the project was funded?

- Encourage other participants to ask questions about the process and discuss the issues being raised
- If needed tell participants that commissioning research is when users, carers and the public are asked to review research proposals to see if they like and support them, and then make decisions about whether they get funded

Activity Option 2

Small group discussion - Existing knowledge of commissioning research (10-15 minutes)

The purpose of the small group discussion is to practice skills in thinking about issues:

- Divide people into groups of 3-4. Give them a few minutes to think about and discuss this question
 - * What do you think happens if you are involved in commissioning research and development projects?
 - * What opportunities would you want to get to do this?
 - * What support would you like to get?
- Ask them to write key points about their answers for each question on flipchart paper and identify a person to present this to the wider group

- Listen to the feedback from all groups - facilitate further discussion as needed
- If needed tell participants that commissioning research is when users, carers and the public are asked to review research proposals to see if they like and support them, and then make decisions about whether they get funded

Activity Option 3

OVERHEADS 1A - 1I

Mini-presentation - What does commissioning research mean? What happens in this stage? (15 minutes)

The purpose of the mini-presentation is to gain knowledge in this area. Cover these areas using the PowerPoint slides:

- What does commissioning research mean?
- Who is involved in commissioning research?
- Why is this stage of the research and development cycle important?
- During or after the mini-presentation facilitate further discussion as needed

Activity Option 4

Commissioning research practice large group discussion (20-30 minutes)

The purpose of the commissioning research practice large group discussion is to practice skills in thinking about issues, and developing and presenting an argument:

- Give out copies of the research proposal 'lay summary' to all participants
- Read through the proposal with the group
- Using the steps outlined in the mini-presentation review the proposal (leave the relevant slides up to assist)
- Point out that if you were doing this in reality then you would spend more time reviewing a proposal than you will today
- When you reach the final step hand out the strips of paper to all members of the audience and ask them to do a secret ballot
- They must write their score and description on the strip of paper to indicate whether or not they support the proposal
- Add up the ballot outcomes and announce the results
- Facilitate further discussion as needed

Activity Option 5

Commissioning research practice small group discussion (20-30 minutes)

The purpose of the commissioning practice small group discussion is to practice skills in thinking about issues, and developing and presenting an argument:

- Give out copies of the research proposal 'lay summary' to all participants
- Ask the group to divided into 3 smaller groups and read out the proposal in that group
- Using the steps outlined in the mini-presentation they will review the proposal (leave the relevant slides up to assist)
- When they get to the last point see if they can reach a consensus as a group as to how they will score the proposal - they need to note down their reasons for this score
- Ask people to return to the large group and listen to each group's score and reasons
- Facilitate further discussion as needed, particularly on why there were differences or similarities between the groups' decisions

Activity 2

Examples of user involvement in commissioning research

There are several activity options. Each one has a suggested time allocation. This is a rough guide and can be extended according to the programme you have set up. Combine different activity options depending upon your chosen programme and your participants' needs, although for this activity you will probably choose one option or the other.

Things to get ready

- Print the Unit 5 - Part C PowerPoint files 2A - 2J in 'note pages' for you and, where appropriate, 'handouts' (two slides/page) of the presentation material for participants
- Flipchart paper and coloured markers
- If you choose Activity Option 1 then make sufficient copies of Unit 5: Part C - Appendix 1 for all participants - also create 'posters' on A4 paper by writing in clear large writing the following ratings: Poor, OK, Good, Excellent
- If you choose Activity Option 2 you will need to identify an appropriate presenter who can discuss current examples of user involvement in commissioning research - meet with them

to ensure they understand the task and prepare anything they that they need

Activity Option 1

OVERHEADS 2A - 2Q

Mini-presentation and case example analysis - Analysing case examples of user involvement in commissioning research (40 minutes)

The purpose of the mini-presentation and case example analysis is to build on knowledge in this area and demonstrate the ability to think about case examples.

- Using the PowerPoint slides provide a description of the case example
- Once you have presented the case example give out Unit 5: Part C - Appendix 1 which has a written version of the PowerPoint slides and the steps needed to do the case example analysis
- Ask participants to divide into four groups
- Each group will follow the steps for analysing the case example that are listed at the end of Unit 5: Part C - Appendix 1

- They need one person to record the answers of the group for each question and another to be a representative to share their decisions with the large group
- Allow time for the small groups to do this analysis and be available to answer questions as needed
- When all groups have got through the questions ask the representatives of each group to come to the front
- Go through each of the questions listed at the end of Unit 5: Part C - Appendix 1 - ask the representatives to stand next to the poster that matches their group's answer
- For each question check the spread in answers between the groups and then invite people from the groups to explain why they chose that answer, for example, if two chose 'OK' and two chose 'Good', then ask the groups who chose OK to give their reasons, and then the groups who chose 'Good' to explain why they gave a higher rating
- Continue until all questions have been discussed

Activity Option 2

OVERHEADS provided by guest presenter

Guest presentation and large group discussion - Analysing case examples of user involvement in commissioning research (40 minutes)

The purpose of the guest presentation and large group discussion is to build on knowledge in this area and demonstrate the ability to think about case examples. The presenter will cover these areas:

- Case examples of commissioning research
- Roles of user consultants, support provided and level of involvement in decision making for user consultants
- What has been learned from doing this work - outcomes achieved, strategies for success and benefits gained
- What is happening to improve or expand this work - problems that occurred and how they were or could be addressed
- During and after the guest presentation encourage questions from participants to facilitate a discussion about the examples and issues raised

Activity 3

What could user involvement in commissioning research mean for you?

There are several activity options. Each one has a suggested time allocation. This is a rough guide and can be extended according to the programme you have set up. Combine different activity options depending upon your chosen programme and your participants' needs. Suggested combinations are:

- Mini-presentation + small group discussion
- Mini-presentation + values walk

Things to get ready

- Print the Unit 5 - Part C PowerPoint files 3A - 3B in 'note pages' for you and, where appropriate, 'handouts' (two slides/page) of the presentation material for participants
- Whiteboard and coloured whiteboard markers
- Flipchart paper and markers
- If you choose Activity Option 4 then you need to create a situation statement for each of the 15 practical issues as explained in the activity

Activity Option 1

OVERHEADS 3A - 3B

Mini-presentation - Review practical issues in user involvement work (5-10 minutes)

The purpose of the mini-presentation is to build on knowledge and support skills in thinking about issues. Cover these areas using the PowerPoint slides:

- Review the practical issues that are important to think and ask about before taking on user involvement work

TOP TIP

If this group has done Core 2 - Unit 2: Part C then they have covered this material. Remind them that they have already discussed these issues. If the group has not done this part of the training, it may be useful to go back and do Activity 1 and 2 with them first.

Activity Option 2

Large group discussion - Plans for dealing with practical issues (30 minutes)

The purpose of the large group discussion is to demonstrate skills in thinking about issues and practice planning what to do next:

- As a large group, go through the 15 points in the mini-presentation **one at a time** using the following steps
- On the whiteboard draw a picture of a hot air balloon with a basket at the bottom
- Ask participants to name any practical issues that would concern people if they were involved in commissioning research - write them in the basket - these are the things that weigh the balloon down and stop it from flying
- Then ask participants to suggest ways of dealing with these issues - write them in the hot air balloon - these are the things that make the balloon rise and lead to a good experience of user involvement in commissioning research
- Assist participants with suggestions as needed for either concerns or ways of dealing with issues
- Make sure that there is a positive response to all of the concerns raised
- If you run out of room draw another hot air balloon on a piece of flipchart paper and continue

Activity Option 3

Small group discussion - Plans for dealing with practical issues (30 minutes)

The purpose of the small group discussion is to demonstrate skills in thinking about issues and practice planning what to do next:

- Ask participants to divide into 4 groups - each group will have 3-4 of the 15 points in the mini-presentation to discuss using the following steps
- On the whiteboard draw a picture of a hot air balloon with a basket at the bottom - ask each group to copy this drawing on a piece of flipchart paper
- For the points their group are given they must name any practical issues that would concern people if they were involved in commissioning research - write them in the basket - these are the things that weigh the balloon down and stop it from flying
- Then, for each of these same points they must suggest ways of dealing with these issues - write them in the hot air balloon - these are the things that make the balloon rise and lead to a good experience of user involvement in commissioning research

- Tell them to just deal with one point at a time - doing the concerns and then the suggestions
- Circulate among the groups and assist participants with suggestions as needed for either concerns or ways of dealing with issues
- After 20 minutes bring the group back together and ask them to share their ideas - facilitate a discussion
- Make sure that there is a positive response to all of the concerns raised

Activity Option 4

Values walk - Plans for dealing with practical issues (30 minutes)

The purpose of the values walk is to demonstrate skills in thinking about issues and practice planning what to do next:

- As a large group, go through the 15 points in the mini-presentation **one at a time** doing a values walk for each one based on a 'situation statement' that you create and read out
- For example, for 'handling confidential information' the statement could be: "You are part of a User Research Network at your NHS trust and are asked to review a research proposal about alternative medications for treating

heart disease. When you ask if you can discuss it with other user consultants, you are told to keep it confidential."

- Ask participants to decide how concerned they would be about this situation, where 1 = not at all concerned and 10 = extremely concerned - make the line for this go from one side of the room to the other
- After participants stand on the line, check what range of numbers there are - ask people from different areas of the line to explain why they are there and what should happen to deal with the concern
- Assist participants with suggestions as needed or ask other participants to offer ideas for ways of dealing with issues
- Make sure that there is a positive response to any concern raised
- Repeat this process for the other 14 points using a situation statement that you have created that is relevant to your group
- Facilitate further discussion as needed

Personal exercises

Here are two exercises to help participants think about the ideas in Part C.

Learning from examples

They will think about the example of user involvement for commissioning research in Activity 2 and answer these questions:

- What did they learn from the discussion that will help them in their future user involvement work?
- Is there anything else they want to learn about this stage? If yes, they will identify who can help them with this. This may be a Link Person in their organisation.

Practical issues in commissioning research

They will review the practical issues in commissioning research discussed in Activity 3 and answer these questions:

- Identify which of the issues are of most concern to them: Do they have enough ideas about how to deal with these concerns? If no, they will identify who can discuss these issues with them further and help them plan action steps.

Case examples

1. Health Technology Assessment Programme: Consumers as peer reviewers

Health Technology Assessment (HTA) Programme

Mailpoint 728, Boldrewood

University of Southampton

Bassett Crescent East

SOUTHAMPTON SO16 7PX

Tel: 023 8059 5586

Email: hta@soton.ac.uk

<http://www.nchta.org/> - Main home page

<http://www.nchta.org/consumers/index.htm> - Consumer home page

The HTA programme is a national research programme funded by the Department of Health. It has developed a system of user involvement in all areas of its activities, including consumer reviewing of research as part of the commissioning process.

Consumer reviewers have a job description, receive training, use guidelines for the review process, have access to personal support and, where appropriate, have their costs covered. Also see the papers by Royle and Oliver (in press) and Oliver et al. (2001) in the 'Sources used for the material in this part.'

2. The Alzheimer's Society

<http://www.alzheimers.org.uk>

Tel: 0191 223 2830

Alzheimer's Society

Gordon House, 10 Greencoat Place

London, SW1P 1PH

Tel: 020 7306 0606

The Alzheimer's Society is a user and carer non-government support organisation. It has created a consumer network to lead its research program called the Quality Research in Dementia Network - here is the direct link:

http://www.qrd.alzheimers.org.uk/qrd_advisory_network.htm

The Quality Research in Dementia Network identifies a range of possible research topics and then participates in processes that select the priorities. The Society uses this as the basis for commissioning research. In addition, The Society aims to involve its members in every other aspect of its research program, including commissioning, grant application reviewing, and grant awards, project management, implementation and dissemination. It has won national awards for its commitment to user involvement.

Useful information for participants

Useful websites

INVOLVE (formerly Consumers in NHS Research)

<http://www.invo.org.uk>

INVOLVE believes that members of the public should be involved at all stages of the R&D process. This means users, carers and the public are active participants, not just 'subjects' of research. INVOLVE supports and advocates for this to happen through working with the NHS, and providing training materials and guidebooks for health and social services staff, and users, carers and the public. They also monitor and assess the effects of public involvement in NHS, public health and social care research.

Ease of reading: *Good*

Folk.us

<http://latis.ex.ac.uk/folk.us/findex.htm>

This is the website of a user/carer and health and social service staff collaborative project. It aims to promote a research culture that is controlled and influenced by service users, disabled people and informal carers, so that research

and implementation reflects the concerns of ordinary folk.

Ease of reading: Good

Health Technology Assessment (HTA) Programme

<http://www.nchta.org/> - Main home page

<http://www.nchta.org/consumers/index.htm> - Consumer home page

The HTA programme is a national research programme funded by the Department of Health. Its job is to ensure that high quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most effective way for those who use, manage and provide care in the NHS. There is a consumer home page for users, carers and the public to learn about how user involvement occurs in the HTA programme. The HTA identifies and prioritises research topics, then commissions research, monitors its progress and evaluates it when finished.

Ease of reading: Good

Useful readings

Oliver S. (2000). *Guidelines for consumers peer-reviewing research 2*. Health Technology Assessment Programme.

Available online at: <http://www.nchta.org/consumers/index.htm>

The specific link is:

<http://www.nchta.org/consumers/importedDocuments/guidelines-2.pdf>

This is a very useful document for anyone who is involved in peer reviewing research proposal to assist with commissioning research. It outlines the skills and abilities that users, carers and members of the public can bring to the review process, and the five main steps in doing a review.

Ease of reading: Good

Royle, J., Buckland, S. & Hayes, H. (2003). *Report of the commissioning workshops*. Winchester: Consumers in NHS

Research Support Unit. Available online at:

<http://www.invo.org.uk/pub.htm>

This report gives a summary of the presentations and workshops that occurred at a workshop on user involvement in commissioning research. User consultant speakers talked about their experience of being involved in commissioning,

what they learned and what needs to be improved. Health and social service researchers and users, carers and the public then took part in workshops to discuss the challenges of user involvement in commissioning, and share ideas for what works and what could be improved.

Ease of reading: Excellent

Royle, J., Steele, R., Hanley, B. & Bradburn, J. (2001). *Getting involved in research: A guide for consumers*. Winchester: Consumers in NHS Research Support Unit. Available online at: <http://www.invo.org.uk/pub.htm>

This is an excellent document with valuable information for users, carers and members of the public who want to become more involved in research. It describes the different stages in the research process and how people can be involved. On the website there is also a document for health and social service staff called 'Involving the public in NHS, public health and social care: Briefing notes for researchers.'

Ease of reading: Good

Sources used for the material in this part

Bowl, R. (1996). Involving service user consultants in mental health services: Social Services Departments and the National Health Service and Community Care Act 1990, *Journal of Mental Health* 5(3), 287-303.

Consumer Focus Collaboration (2000). *Improving health services through consumer participation: A resource guide for organisations*. Canberra: Commonwealth Department of Health & Aged Care. Available online at:

<http://www.participateinhealth.org.au/clearinghouse/>

Epstein, M. & Wadsworth, Y. (1996). *Understanding and involvement: Consumer evaluation of acute psychiatric hospital practice - A project unfolds*. Melbourne: Victorian Mental Illness Awareness Council.

Oliver, S. (1999). Users of health services: Following their agenda (pp. 139-153). In S. Hood, B. Mayall & S. Oliver, *Critical issues in social research: Power and prejudice*. Open University Press: Buckingham.

Oliver S. (2000). *Guidelines for consumers peer-reviewing research 2*. HTA Programme. Available online at:

<http://www.nchta.org/consumers/importedDocuments/guidelines-2.pdf>

Royle, J., Steele, R., Hanley, B. & Bradburn, J. (2001). *Getting involved in research: A guide for consumers*. Winchester:

INVOLVE (Consumers in NHS Research Support Unit). Available online at: <http://www.invo.org.uk/pub.htm>