Part B

Consulting about research

Introduction

A summary of Part B

Why is Part B important?

Before research and development work happens it is important to consult with people on what the focus of this work should be and what are the priority issues. This is called consulting and is the focus of Part B. Participants will learn about the details of this stage and analyse real examples. They will also consider the practical issues of user involvement in consulting about research to help them decide if they would like to do this work.

What will participants learn by doing Part B?

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

- Understand what consulting about research means – Activity 1

- Understand what happens in the consulting about research stage – Activity 1 and 2

- Discuss the practical issues of user involvement in the consulting about 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

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Background information

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

Consulting about research

This is an area of research and development where there has been a longer history of user involvement. In part this is because it is an 'easy' way of involving users, carers and the public. You can arrange to meet with people, gather in their ideas and then consider how they affect what you were interested in researching. This can end up being very tokenistic as there is no guarantee that people will gain any feedback about their contributions or hear what happens to the research project overall. [4,6]

Learning from failures

Fortunately, more people are making efforts to consult with commitment and genuinely want to hear the perspectives of users, carers and the public. They are continuing to do this even if some of their initial attempts fail.

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One research team did the rare thing of publishing a failure in user involvement.[2] They developed some initial ideas for research in public health and wanted to consult more widely with users to gain their opinions on it. They set up a one-day user and carer workshop where they planned to provide participants with background about the proposed research and engage them in discussion about their concerns and ideas. They hoped they could also identify specific questions for the research and that some of workshop participants would become interested in doing collaborative research.

Questions they wanted to ask users and carers included:

- whether they thought the issues identified by the researchers were relevant to them personally

- what it would be like for them to participate as 'subjects' of the research

- what research methods would work with the different people who may participate

The researchers made contact through community, union and employer organisations. Twenty organisations were directly contacted by phone. Of these, 15 organisations were willing to help identify potential participants for the workshop. Five

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weeks before the workshop a follow-up letter was sent outlining the details of the workshop and offering financial support to cover participants' expenses. When only one application was received prior to the closing date the researchers made a follow-up contact by phone and then asked what the barriers were to participation. The workshop was cancelled when it was apparent that few people planned to attend.

This is what they learned from their experience. It became obvious there were no previous relationships with the users and user groups that they approached – this was a major stumbling block. If there is no prior contact with users or user groups to network and build relationship, and the researchers have no track record in user involvement, then users and user groups will be cautious about involvement.

Users and user groups may have experienced being patronised by 'pseudo-consultation' before and are not interested in lining up for it again.[1] This is when people consult just so they can say they have done it, but have already decided what they want to do and the consultation outcomes will not change these plans. They also found that users wanted more time and resources to be put in to create the rapport, trust and credibility that would fuel a partnership between them and researchers. The research

group concluded: "credibility on consumer consultation must be built up progressively, using not only consultation, but also feedback mechanisms through which progress and results can be communicated" (p.211)[2]

Although they were thoughtful about their process this group realised that all of the above reasons meant that they failed to achieve any user involvement. Fortunately the researchers did not go ahead with their research. They paused to learn from this and decided to try again in a different way.

Learning from successes

There are contrasting examples of real success. The Alzheimer's Society was also used as a case example in Part A of this Unit (see the PowerPoint's for Activity 2 and Case Example 2 in this unit). Unlike the previous example they have credibility because they provide a service to their members and then recruit people from their membership to be involved in research and development work. The people who do this have a high level of concern with research on dementia and a vested interest in what happens. Similarly, the example also provided in Part A on the Sheffield and the North Trent Cancer Research Network is another successful initiative.[5] They have also held user and carer conferences and focused them around research issues,

making sure that people are informed about what is involved in research, what research is happening and why, and how they can get involved. They have done this on the basis of an existing network of people with shared concerns, which always helps you get started more easily. They have used these opportunities to consult people about research topics, as well as including people who become part of their 'Consumer Panel for Research' on groups who prioritise these topics and set the direction for the network's research activities.

What is most important is that whether people fail or succeed in their attempts at user involvement in consulting about research, they reflect on and learn from what happens and use this to improve their efforts in the future.[2,3]

References

1.   Byas, A., Hills, D., Meech, C. Read, L., Stacey, K., Thompson, E. & Wood, A. (2002). Co-researching consumer experiences of child and adolescent mental health services: Reflections and implications. *Families, Systems & Health: The Journal of Collaborative Family Health Care,* 20(1), 75-89.

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2.   Graham, J., Broom, D. & Whittacker, A. (2001). Consulting about consulting: Challenges to effective consulting about public health research. *Health Expectations,* 4, 209-212.

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., 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

5.   Stevens, T., Wilde, D., Hunt, J. & Ahmedzai, S. (2003). Overcoming the challenges to consumer involvement in cancer research. *Health Expectations*, 6, 81-88.

6.   Wilcox, D. (1994). *The guide to effective participation.* Accessible online at:

http://www.partnerships.org.uk/guide/index.htm

Introduction

Activity 1

What does consulting about 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 + consulting about research practice: large group discussion

- Small group discussion + mini-presentation + consulting about research practice: small group discussion

Things to get ready

- Print the Unit 5 – Part B PowerPoint files 1A – 1G 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

Activities

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Activity Option 1

Large group discussion – Existing knowledge of consulting about 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 consulted about a research and development project

- 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 did you find out about the project?

  * How were users, carers or the public invited to be involved?

  * What did you get to do?

  * What did they do with your ideas?

  * What feedback did you get about the project?

- Encourage other participants to ask questions about the process and discuss the issues being raised

- If needed tell participants that consulting about research is when users, carers and the public are asked to identify possible research topics and help select priorities

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Activity Option 2

Small group discussion – Existing knowledge of consulting about research (15-20 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 these questions:

  * What do you think happens if you are being 'consulted about' a research and development project?

  * What opportunities would you want to get?

  * 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 consulting about research is when users, carers and the public are asked to identify possible research topics and help select priorities

Activities

Activity Option 3

OVERHEADS 1A – 1G

Mini-presentation – What does consulting about 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 consulting about research mean?

- Who is involved in consulting about 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

Consulting about research practice: Large group discussion (20 minutes)

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

- Ask the group to suggest 2 areas in which they would personally like to see research occur - if you get more than 2, then agree on which 2 will be discussed

- Focus on one area first and as a large group identify topics and try to be as specific as possible – do not worry about priorities in this exercise

- Point out that obviously you may spend much longer talking and thinking about this if you were in a proper consultation process

- Suggest that they use the questions you provided – you can put Overhead 1E up to help them – and make a list of the topics they identify

- After 10 minutes do the same with the other area

- Encourage participants to give good reasons for their suggestions – just as if they were develop and presenting and argument to a research group

- Facilitate further discussion as needed

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Activity Option 5

Consulting about research practice: Small group discussion (20 minutes)

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

- Ask the group to suggest 3 areas in which they would personally like to see research occur – if you get more than 3, agree on which 3 will be discussed

- Divide the group into 3 or they can choose which area they want to discuss

- Ask them to spend 10 minutes just identifying topics – do not worry about priorities in this exercise – and to be as specific as possible

- Point out that obviously you may spend much longer talking and thinking about this if you were in a proper consultation process

- Suggest that they use the questions you provided, you can leave Overhead 1E up to help them, and make a list of the topics they identify with reasons – just like they were developing and presenting an argument to a research group

- After 10 minutes return to the large group and hear back from people what their ideas are in each area.

- Facilitate further discussion as needed

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Activity 2

Examples of user involvement in consulting about 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 B PowerPoint files 2A – 2K 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 B - 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 consulting about research - meet with

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

Activity Option 1

OVERHEADS 2A – 2Q

Mini-presentation and case example analysis – Analysing case examples of user involvement in consulting about 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 B - 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 B - Appendix 1

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- 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 B - 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

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Activity Option 2

OVERHEADS provided by guest presenter

Guest presentation and large group discussion - Analysing case examples of user involvement in consulting about 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 consulting about 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

Activities (side tab)

Activity 3

What could user involvement in consulting about 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 B 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

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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 asked to consult about 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 consulting about 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

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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 asked to consult about 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 consulting about research

- Tell them to just deal with one point at a time – do 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 'number of user consultants involved' the statement could be: "You get a letter of invitation to attend a group meeting to help identify research topics in the area of stroke management. When you ask who else will be there you

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are told that only a couple of patients and carers who go to your rehabilitation unit have been invited to join the staff."

- 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 B.

Learning from examples

They will think about the example of user involvement for consulting about 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 consulting about research

They will review the practical issues in consulting about 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. Involving consumers in a needs-led research program

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.

A service user led this research group. They designed and then evaluated a strategy to involve users, carers and the public in several research tasks for the NHS Health Technology Assessment Program. This included identifying topics, selecting priorities, commissioning and reviewing research. It talks about what they learned and how they will do things differently in the future so that user involvement is better supported and more effective.

Also see the useful website on the Health Technology Assessment Programme.

Case examples

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 identify a range of possible research topics and then participate 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, grant awards, project management, implementation and dissemination. It has won national awards for its commitment to user involvement.

Case examples

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

Useful information

Useful information

and implementation reflects the concerns of ordinary folk.

Ease of reading: Good

Health Technology Assessment (HTA) Programme

http://www.ncchta.org/ - Main home page

http://www.ncchta.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 reading

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

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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.

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