Part D

Doing research

A summary of Part D

Why is Part D important?

If you are doing research, then you design the project, conduct the research and make sense of what you find out. This is the area of research most people know about. This part will also focus on what it means to be a researcher – what are researcher roles and responsibilities. Participants will see these issues in action through analysing real examples. They will also consider the practical issues of user involvement in doing research to help them decide if they would like to do this work.

What will participants learn by doing Part D?

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

- Understand what doing research means – Activity 1

- Understand what happens in the doing research stage – Activity 1 and 3

- Discuss the role and responsibilities of researchers – Activity 2

- Discuss the practical issues of user involvement when doing research – Activity 4

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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.

User involvement in doing research

When you read reports and articles, or listen to conference presentations on user involvement in research and development, there is a clear message. User involvement can and does have a positive influence on:

- the research process itself and the experience of users, carers and members of the public who take part in it

- where the research directly relates to service delivery, then on the quality of services and improved personal outcomes for people using health and social services

- the sense of worth and personal ability of user consultants who get involved – also known as empowerment of user consultants[6,8,10]

When user consultants influence how research is conducted, as well as how to ask questions and what exactly to ask, the quality and relevance of the information gained is stronger. This

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message comes from health and social service staff who do research, as well as user consultants themselves.[1,3,5,16]

User involvement in research and development has increasingly occurred in the UK. User consultants are more often involved in designing research, as well as doing the research.[1,2,3,4,5.7,9,11,12,14] This needs to grow further, especially in having user consultants involved in the analysis of research outcomes and then writing them up for presentation and publication.[1,2,3,13]

Learning from experience

Designing research

Sometimes user consultants are mainly involved in designing the research and development project, rather than doing it. This occurred in a recent national trial for breast cancer research on hormone replacement therapy (HRT).[11] The researchers worked with the Consumers' Advisory Group on Clinical Trials (CAG-CT) and the health and social service staff who would carry out the medical procedures to develop a way of involving users, carers and the public in the trial. They were the project steering group.

They ran nine focus groups with women from breast cancer support groups nationwide and some patients who had previously

participated in the pilot randomised HRT study. When discussing their decision to participate in a trial the women raised many issues, such as:

- reputation of the hospital and staff who run the trial

- previous experiences with clinical trials

- wanting to give back to the system that has helped them

- needing information about HRT that is written by independent and preferably lay people for a lay audience

- needing clear and honest information about side effects

- having staff respond with respect and interest – to take women's description of their experience seriously

- whether or not there was a placebo group (this group receives no treatment but is still monitored to see if there is any change), as women wanted to know that they were receiving treatment for a disease with life-threatening consequences where the potential of the disease returning was high - they could not afford to do nothing for the sake of the trial

This demonstrates that participants in the trial had a very different perspective from the researchers They raised issues of risk and being fully informed that may not occur to

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researchers who think that they have planned for these things sufficiently. Complex reasons influenced whether or not they would participate in a trial that went beyond research questions. The trial was not their central focus because with or without the trial the women faced decisions about the quality and length of their life.

The project steering group met with representatives from the focus group for a 1-day workshop to debate the focus group outcomes and recommendation. They reached an agreement about how to design the trial so it addressed user needs and the aim of the national HRT trial. Representatives from the CAG-CT and focus groups then went to project steering group meetings to make sure that the final design matched these agreements. A user-friendly summary of the final design was sent to the CAG-CT and all focus group representatives for comment before the trial could gain approval to start. Through this experience the researchers were convinced that it was vital to have user involvement in all stages of research.

Doing research

Here are examples of what people have learned from projects where users, carers and members of the public are on the research team doing hands-on research activities. The Barrow

Community Gym was a gym service for mental health service users.[1] When the gym was evaluated it began as a university researcher-led project. After initial meetings with service users about how to evaluate the gym this changed and a project team was created with 4 gym users, 2 researchers and 1 staff member.

They designed and tested out a questionnaire. When they were happy with it the service users on the project team got other service users to complete it and supported them if that was needed. They then took responsibility for putting the answers on the computer and helped with the analysis. The final outcome was that the gym users took over and continued doing six-monthly evaluations of the expanding gym. They were supported to do this through gaining training and support from the university researchers who were initially involved.

They learned some important things in doing this research:

- it is important to get users involved as early as possible in the research process

- they had to change the way they did the research to make sure it was possible for people to take part, e.g. side effects of medication and fluctuations in mental health symptoms

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could have a negative influence on people's participation, so it was important that there was flexibility and support

- it was very important that researchers built positive, friendly and trusting relationships with the service users to create a strong sense of being on a positive working team

- you need to leave something behind - more than useful information from the research – because you also need to make sure the people involved gained skills that they can continue to use in doing further research work

There are some similarities with what was learned from another research project where the researcher collaborated with breast cancer self-help groups. They learned that user consultants must play a key part in deciding:[7]

- the ideas behind the research agenda and what is the main focus in the project - this needs to happen early when funding is being gained, as well as when the research is designed and conducted

- the approaches and methods that fit the best with the groups of people involved in the research

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- the tasks that user consultants will or will not have in the research, e.g. will user consultants be part of the information collection, analysis, write-up and publication steps

- the communication between the researchers and user consultants during the project – how much information do they get and how often

The most important thing they emphasised was to expect **change** within any project or group, and between different projects and groups. If the lines of communication are open and user consultants have a real stake in what happens – they have decision-making power – then it is usually possible to deal with change or the specific needs of some people.

Other examples of users, carers and the public as co-researchers are presented in Activity 3 and also as case example for this part.[5,12,14] The common learning from all of these projects is having good communication and creating relationships based on trust, respect, openness and honesty so you can directly deal with fundamental issues such as, power, accountability and mutual responsibility.[19]

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User-led research groups

Another development for user involvement in research is setting up user-based research groups where users and carers conduct research themselves, or have an ongoing relationship with health and social service researchers to do. The Suresearch network created in 2000 is a good example (also listed as a case example in this part).[4] It is a partnership between a user-led network of mental health service users in the Midlands and their academic allies at the University of Birmingham. They meet monthly and welcome anyone who is interested in mental health research and education. They have around 80 members, with 65 of them being service users.

Among other activities Suresearch submits proposals and gains funding for research that the members design, conduct, write up and publish together. Members are trained to take on these roles. Suresearch reviewed its work in 2003 and found that service users feel confident, safe and supported. They are treated positively and with respect. It is an opportunity to use and develop their skills, be involved in opportunities that they normally would not have, and make a real impact on what research is done and how in the mental health area.

Folk.us is another example of service users and health and social service researchers working in partnership that aims to have at least 50% of its work user-led. They are listed under the Useful Website section at the end of this part. Folk.us provide support to research work run by NHS, Primary Care and Social Care Trusts, find opportunities to fund research of interest to its user and carer members, and have done work for INVOLVE, the Department of Health unit that supports consumers in NHS research.

TOP TIP

When being a researcher there are important roles and responsibilities to remember. These will be outlined in the mini-presentation activity option for Activity 1 - this is an overview of the issues.

The role of researchers

The role of researchers is not just about knowing about and doing research activities. It is also about being aware of the following things:[17,18]

What is your position?

We do research because we want to **learn** about new things, not because we think we know the answers and simply want some evidence to back them up. If you just concentrate on being in the expert position then you close your eyes and ears to finding new things. You can be an expert because you have a professional qualification and work as a researcher in that area.

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You can also be an expert because as a service user or carer you have first hand experience of the issues being researched. So, this is an issue for **both** health and social service staff and user consultants.

When you only filter things through your 'expert' or 'experience' knowledge, then if something does not fit what you already believe you will dismiss it or see it as a problem or glitch. In fact, you should be looking and listening for these problems or glitches as they can tell you interesting information. If you take a position as a learner, as well as someone with 'expert' and 'experience' knowledge, then you can stay open to the new things and not filter them out.

What is your identity?

Researchers need to be aware of how 'who they are' may influence the research because a person's **identity** shapes how they see the world. Male researchers may have a different perspective than female researchers about doing breast cancer research. White researchers looking at housing issues for Asian people may emphasise different issues than Asian people. Also, within any specific group, there are other group and individual differences. We all have a gender, age, class, cultural/ethnic

identity, level of ability/disability, level of health, etc. All of these things will influence your researcher role.

You cannot be neutral although some researchers still like to believe they are objective. The best you can do is be aware of your identity and how it helps or stops you from seeing things that are important to other people who are a little or much different to you. Sharing a common identity or similar experiences can often be of benefit in a project, as it can increase people's comfort with the researcher. It is important to not assume this will always happen, as there are many other ways in which people are different, including through their values.

What are your values?

Researchers must be aware of their own **values** and that they may come out in research. This affects what research you decide to do, what research questions you ask, how you decide to do the research, and who you include. If you have a negative view of illegal drug users, this may make it difficult for you to hear their point of view in a research interview. When you analyse the outcomes you may ignore some of the things they tell you. Our values influence how we make sense of the research information we gather.

Having the right skills

Researchers must ensure they have the skills to do the job – this is why training for user consultants who do research is vital. This is not just going to courses or reading books and guides. This includes learning by doing where they have another researcher (staff or user consultant) as a mentor and role model. User consultants already come with skills, as described by this research project on mental health service users' satisfaction with the Sheffield primary care service where service users interviewed other users:

"The interviewers had no previous experience of interviewing, but had good listening skills, an ability to be non-judgemental, and a commitment to finding out user's opinions. One of the interviewers' main strengths was their ability to establish rapport with interviewers. The interviewers believe that their experience as mental health service users aided them in this process. Their sensitivity and sympathy put interviewees at ease.

To become a competent interviewer of users it is not enough to be a service user. Interviewing is a skilled job that requires training and support both before and after interviews. Training sessions on how to use the

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questionnaire, conduct face-to-face interviews and overcome communication difficulties are vital. In addition, the interviewer must possess specific skills and qualities, including the ability to concentrate on more than one thing at once, a preparedness to go at the interviewee's pace, an ability to put aside one's own issues and focus on the interview, and the resources to deal with the emotional impact of interviews."[14]

This quote gives an example of the importance of the issues already named about taking a position of wanting to learn, knowing your identity, being aware of your values and gaining the skills that fit with what you have to do in the research project. Obviously these skills will be slightly different depending on what approach to research is taken and what types of research methods are used – as discussed in Part A of Unit 5.

The responsibilities of researchers

Researchers must also follow agreed principles for doing research and development work to make sure that it is of a good quality and people who participate are protected. These principles are called ethics and there is worldwide agreement about what they are. There are nine main issues to concentrate on although they also are linked together:[15,18]

Honesty

This is sometimes called integrity and is about being committed to doing research honestly. This includes giving an honest account of the results, what happened during the research and making sure that you distribute the results to people who need to know about them.

Respect

Researchers must show respect for the people who participate in research. They must respect their personal and physical welfare, rights, beliefs, perceptions, customs and cultural heritage at an individual and group level. This also relates to not discriminating against people who agree to participate in research on the basis of who they are or what they believe. You can only be specific about this if it is essential to the research, e.g. you are looking at differences between specific groups of people. Even if you think that the proposed research offers important knowledge, if it means that you do not respect the people involved then you will not be allowed to do it.

Do no harm

Research and development should not result in physical or emotional harm. It should not lead to a loss of dignity, independence or self-esteem. If there is a risk of harm,

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researchers must clearly outline what they will do to minimise harm, and if there is harm, how they will respond responsibly and quickly.

Benefits or research merit

This is about how worthwhile it is to do the research – can it be justified? You have to be able to answer questions like these, which relate to 'doing no harm' and also to 'justice.'

- What contribution will this make to our pool of knowledge?

- In what way will it build on and expand our current understandings? (It needs to be more than a repeat of what has gone before - it cannot be research for research's sake)

- What contribution will it make to people's lives?

- Will the benefits of doing this outweigh the risks?

- In what way is it a 'public good? (This is something that people would agree would be a good thing for their society)

Justice

There are both benefits and burdens if a person is participating in research. There needs to be a fair distribution of these across the population. If the same group of people are being targeted as participants, they carry more of the burden and

gain less benefit compared to those who are not participating yet benefit from the research. For any single participant there must also be a balance of burdens and benefits – this was highlighted in the example above on women in clinical trials on breast cancer. Another example is people who live in institutions, such as people living in mental health care hospitals who are often seen as readily available for research. However, they may not be the ones to greatly benefit from the outcomes of the research, although they bear the burden and personal costs of involvement.

No deception

This means that there are no surprises. It is connected to honesty. You will be upfront about what is required of the person and what will happen to them in the research and development project. Prior to the 1960s there was frequently deception in research. Even though benefits may be gained from deception in research it has the potential to do harm and disrespects participants. It relates to the next issue.

Informed consent

When people volunteer to participate in research they must be as informed as possible about the purpose, commitment and activities of the research. Whether it is intentional or not,

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researchers must not manipulate people into consenting because they did not know what was going to happen, were afraid of what would happen if they did not agree or simply because they respected the researcher. Participants need accurate and clear written information on what they are being asked to do and what the likely consequences are for them if they choose to participate. This is called informed consent.

Researchers must get the right balance in providing this information and avoid using technical and difficult language. If the information is too overwhelming the person will not read or understand it anyway. They may consent without enough knowledge, or not consent because they were not sure what they were getting into. In most situations people give informed consent in writing. There are times when this is not as easy or possible to obtain, e.g. people are not considered competent because they are young children, comatose, or impaired in a significant way that makes it impossible for them to fully understand what they are being asked to consent to. In these instances an appropriate legal authority or guardian may provide consent.

When people cannot read or write in English, or do not have English as a first language, other ways of fully informing the

person are needed that are acceptable by the community to whom the person belongs. For example, a verbal description in language suitable to the person (i.e. a child), the language of the person's community, or an appropriate legal authority may act on the person's behalf.

As part of informed consent, participants need to understand that they can withdraw from the research at any time without negative consequences. This is vital to emphasise when the request comes from someone on whom the potential participant may be dependent. For example, when the researcher is also someone who provides treatment or service, or when they are their work or study supervisor. In addition, if someone withdraws, the information they provided can only be used if they agree that this can happen.

Confidentiality

This is a major commitment that the researcher must give to participants. Participants need to know how recognisable or not their personal identity will be in the presentation of research outcomes and who has access to the research information. This includes original data and information, such as where it is stored, as well as the information once it is analysed, published and/or presented material. They need to know who else is

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involved in any conversation about the research as it is being done and how their identities will be protected.

In some instances, it may not be possible to protect or disguise people's identities. This happens when working with a very specific group of people who others are likely to know in a local community or even nationally. Researchers must discuss this with participants to check where this will have negative outcomes and if they are willing to still participate.

Privacy

Privacy sounds similar to confidentiality, but it means the personal space that is or is not off-limits for the research to inquire into. Participants must have the right to refuse to discuss or respond to issues/questions about which they are not comfortable or they consider private.

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Activity 1

What does doing 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 + doing practice large group discussion

- Small group discussion + mini-presentation + doing practice small group discussion

Things to get ready

- Print the Unit 5 – Part D PowerPoint files 1A – 1N 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 doing 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 doing 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?

  * How much influence did you have?

  * What difference did this make to the project?

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

- If needed tell participants that doing research is when users, carers and the public are involved on the project team who does the research, analyses the information, and writes up the results and what they mean

Activities

Activity Option 2

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

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

- 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 doing 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 doing research is when users, carers and the public are involved on the project team who does the research, analyses the information, and writes up the results and what they mean

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Activity Option 3

OVERHEADS 1A – 1I

Mini-presentation – What does doing research mean? What happens in this stage? (25 minutes)

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

- What does designing doing research mean?

- What happens in each step of designing and doing research?

- Why is this stage of the research and development cycle important?

- During or after the mini-presentation facilitate further discussion as needed

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Activity Option 4

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

The purpose of the doing research practice exercise is to practice skills in thinking about issues, and developing and presenting an argument:

- Take suggestions from the group about some specific areas in which they could do research to use as practice for designing a research project

- Do a quick vote of hands for which area the group would like to use for the exercise

- Using the steps outlined in the mini-presentation design how you will do the project (leave the relevant slides up to assist)

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

- Point out that if you were doing this in reality then you would spend much more time designing a project than you will today

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Activity Option 5

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

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

- Take suggestions from the group about some specific areas in which they could do research to use as practice for designing a research project – you need to agree on 3

- Do a quick vote of hands for which areas the group would like to use for the exercise

- Ask the group to divide into 3 smaller groups based on the 3 areas chosen

- Using the steps outlined in the mini-presentation each group will design how they will do the project (leave the relevant slides up to assist)

- They need to take notes so they can present their plan back to the larger group – just like they were developing and presenting an argument to a research group

- Ask people to return to the large group and listen to each group's suggested project

- Facilitate further discussion as needed

Activity 2

TOP TIP
If you prefer or if it suits your group better, you can do Activity 3 first and then go on to Activity 2.

Being a researcher

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 + large group seesaw exercise and discussion

- Guest presentation

Things to get ready

- Print the Unit 5 – Part A PowerPoint files 2A – 2H 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 you will need to identify an appropriate presenter who can discuss what it means to be a

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researcher - meet with them to ensure they understand the task and prepare anything that the guest speaker needs

Activity Option 1

OVERHEADS 2A – 2H

Mini-presentation – Being a researcher (15-20 minutes)

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

- What are the roles and responsibilities of being a researcher?

- Ethical principles that researchers must follow

- During or after the mini-presentation facilitate further discussion as needed

TOP TIP
Use the material in the Background Information section to expand on and explain these issues to the group as needed. If you want, copy the section and provide it to participants as a handout.

Activity Option 2

OVERHEAD 2A

Large group 'seesaw' exercise and discussion – Following ethical principles (30 minutes)

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

- Draw a large seesaw (like in a children's playground) on the whiteboard with one side weighed down and one in the air (like on Overhead 2A)

- Go through each area outlined in the Activity Option 1 mini-presentation and ask participants to think about and answer this question for each area:

  * What could cause a problem in doing research for this area?

- Ask them to take the markers and write these ideas on the 'weighed down' side of the seesaw

- Pause and have a brief discussion about the issues to make sure everyone understands other people's ideas

- Then ask people to think about and answer this question for each area:

  * What needs to happen to avoid these problems or manage them if they happen?

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- Ask them to take the markers and write these ideas on the 'in the air' side of the seesaw

- Pause and have a brief discussion about the issues to make sure everyone understands the ideas

TOP TIP
Use the material in the Background Information section to expand on and explain these issues to the group as needed. If you want, copy the section and provide it to participants as a handout.

Activity Option 3

OVERHEAD 2A

Small group 'seesaw' exercise and discussion – Following ethical principals (30 minutes)

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

- Draw a large seesaw (like in a children's playground) on pieces of 3 pieces of flipchart paper with one side weighed down and one in the air

- Divide the group into 3 smaller groups - divide the areas outlined in the Activity Option 1 mini-presentation into 3 lists and give one list to each group

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- Ask participants to think about and answer this question for each area on their list:

  * What could cause a problem in doing research for this area?

- They must write their ideas on the 'weighed down' side of the seesaw

- Then they must think about and answer this question for each area:

  * What needs to happen to avoid these problems or manage them if they happen?

- They must write their ideas on the 'in the air' side of the seesaw

- After 15 minutes bring the group back together and do group presentations

- Discuss the issues as you go to make sure everyone understands them

TOP TIP
Use the material in the Background Information section to expand on and explain these issues to the group as needed. If you want, copy the section and provide it to participants as a handout.

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Activity Option 4

OVERHEADS provided by guest presenter

Guest presentation – Being a researcher and following ethical principles (45 minutes)

The purpose of the guest presentation is to extend knowledge and understanding of this area, and practice skills in thinking about issues. The presenter will cover these areas drawing on current experience in an NHS Trust:

- What are the roles and responsibilities of being a researcher?

- Ethical principles that researchers must follow

- What researchers can do to follow the ethical principles

- Who does ethical quality mean in research governance?

- During or after the guest presentation facilitate further discussion as needed

Activity 3

Examples of user involvement in doing 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 D PowerPoint files 3A – 3J 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 D - 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 doing research - meet with them to

ensure they understand the task and prepare anything that they need

Activity Option 1

OVERHEADS 3A – 3J

Mini-presentation and case example analysis – Analysing case examples of user involvement doing 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 D - 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 D - Appendix 1

Activities

Activities

- 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 D - 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

Activities

Activity Option 2

OVERHEADS provided by guest presenter

Guest presentation and large group discussion - Analysing case examples of user involvement doing 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 doing 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 4

What could user involvement in doing 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 D PowerPoint files 4A – 4B 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

Activities

Activities (vertical, right margin)

Activity Option 1

OVERHEADS 4A – 4B

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 doing 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 doing 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

Activities

Activities

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 doing 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 doing research

Activities

- 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 analysing issues and practice planning action steps:

- 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 'at what stage are user consultants involved' the statement could be: "You accept an invitation to be part of a research project where you will collect some of the research information and help with analysing and writing it up

Activities

When you start asking questions about how the research is designed you are told to not worry, that is already sorted."

- 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 D.

Learning from examples

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

They will review the practical issues in doing research discussed in Activity 4 and answer these questions:

- Identify which 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 what to do next.

Case examples

1. Involving peer interviewers in qualitative research with hard-to-reach populations

Elliott, E., Watson, A. & Harries, U. (2002). Harnessing expertise: Involving peer interviewers in qualitative research with hard-to-reach populations. *Health Expectations*, 5, 172-178.

This research team employed and worked with users to do interviews with people who use and misuse illegal drugs. As this is a very sensitive issue, the involvement of previous drug users was valuable in getting people to be interviewed and in understanding the range of issues that they face. The user consultants helped plan the interviews, found people to be in the research, did many of the interviews and helped analyse the interview information. The paper describes the benefits and challenges in the research, including how researchers learned to work effectively with peer interviewers.

Case examples

2. Suresearch

Institute of Applied Social Studies

The University of Birmingham

Birmingham B15 2TT

Telephone: 0121 414 6223

Contact Ann Davis – email: a.davis@bham.ac.uk

The Suresearch network was created in 2000 following a workshop for service users and academics who were interested in doing mental health research and education work together. It is a partnership between a user-led network of mental health service users in the Midlands and their academic allies at the University of Birmingham. They meet monthly and welcome anyone who is interested in mental health research and education. They have around 80 members, with 65 of them being service users. Together they do the following things:

- develop and provide education and training programmes for its members on research and developing and offering education workshops and courses

- submit proposals to do mental health research projects and education consultancies

Case examples

- write up and disseminate the outcomes of their projects to a range of people who need to hear about them

- educate and share skills with each other to improve quality, ethics and practice in mental health research and education

- link with other regional and national organisations or partnerships in mental health

The group has never received any core funding and are happy to keep their independence. They gain funding through the income they generate from funded research projects. They have attracted ~ £1 million in funding over four years.

When Suresearch reviewed its work in 2003 they found that service users feel confident, safe and supported in the network. It is an opportunity to use and develop their skills, be involved in opportunities that normally they would not have, and make a real impact on what research is done and how in the mental health area.

Case examples

3. SURE: Service User Research Network

SURE

PO34

Institute of Psychiatry

De Crespigny Park

London SE5 8AF

Telephone: 0207 848 5104

http://www.iop.kcl.ac.uk/iopweb/departments/home/default.aspx?locator=300

Established in 2001, SURE is a collaborative project between service user researchers and clinical academics aiming to involve service users in all aspects of research. It is located in the Health Services Research Department at the Institute of Psychiatry. User perspective is central to all of its work and almost all of its staff have been or are service users.

SURE is committed to the involvement of service users in the whole research process: from design to data collection and data analysis to dissemination. At a local level, SURE supports the Consumer Research Advisory Group (CRAG). This group of 12 local service users sends two representatives to the South London and Maudsley Trust, Institute of Psychiatry Research

and Development Steering Group. They have run research skills training courses for local service users.

SURE's national project on Consumers' Perspectives on Electroconvulsive Therapy influenced the new NICE guidelines on ECT. They are building user involvement capacity by registering service user researchers for higher degrees so they can gain relevant qualifications. They organise a weekly 'SURE Clinic' where academics in the Institute can come for advice on how to involve service users in their research projects. SURE publishes papers on collaborative research, including its pitfalls, and on its specific projects.

(Also see the two references by Debra Rose listed under the 'Sources used for the material in this part' in the Useful Information section.)

Case examples

Case examples

4. The Mental Health Foundation: Strategies for Living Project

The Mental Health Foundation

83 Victoria Street

London SW1H 0HW

Telephone: 020 7802 0300

Email: mhf@mhf.org.uk

http://www.mentalhealth.org.uk/page.cfm?pagecode=PBUP0203

'Strategies for Living' has become a nationwide project stretching over 6 years. It began in 1997 with 3 years of funding – this was Phase 1. It then gained further funding in 2000 for another three years – Phase 2. It grew out of a previous Mental Health Foundation project called 'Knowing our own Minds' - a user-led survey of alternative and complementary treatments and therapies in mental health.

Strategies for Living supports many local user-led research projects around the UK. It funds them and provides training and resources on doing research, including a DIY (Do it Yourself) Guide to Survivor Research. It also provides hands-on advice and support through every step of the project, including writing the reports. It publishes them on The Mental Health Foundation website. The Phase 2 projects can be found at:

http://www.mentalhealth.org.uk/page.cfm?pagecode=PISLUNUK

Examples of these projects include:

- A mental health service user who lives with bi-polar disorder decided to interview carers of people with bi-polar disorder. She wanted to highlight the experiences, coping strategies and needs of carers and increase the awareness their needs with mental health services so they receive appropriate support and understanding. She completed all aspects of the project including doing 13 in depth interviews with carers, analysing the outcomes and writing a report. See the reference by Jenkins (2003) listed under the 'Sources used for the material in this part' in the Useful Information section.

- A group of mental health services users explored the impact of losing your job due to mental illness. Several of them had experienced this. They worked together to design and conduct the project, with people taking on different roles. One of the users took the lead on writing the report with contributions and support from the rest of the team. See the reference by Bodman, Davies and others (2003) listed under the 'Sources used for the material in this part' in the Useful Information section.

Case examples

- A conference on user-led research was held in Belfast in May 2003 in collaboration with the local Trust. Users were on the organising committee, were keynote speakers and presented their research, along with contributions from health and social service staff. See the reference by Nicholls (2003) listed under the 'Sources used for the material in this part' in the Useful Information section.

There are more examples of reports on the website and you can also look at previous editions of their newsletter. Some of their resources to support people doing user-led research can be ordered from them for a small cost.

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 meaningfully controlled and influenced by service users, disabled people and informal

Useful information

carers, so that research and implementation reflects the concerns of ordinary folk.

Ease of reading: Good

Consumers for ethics in research (CERES)

http://www.ceres.org.uk/

Or contact at: PO Box 1365, London N16 0BW

CERES is an independent charity set up in 1989 to promote informed debate about research. It helps users of health and social services to develop and publicise their views on health and social care research and on new treatments. CERES believes that everyone asked to take part in research should be able to make an informed, free choice as to whether or not they agree to take part. CERES works to help the voices of patients and research subjects be heard more clearly to improve how research occurs.

Ease of reading: Good

Us as Experts

http://www.mentalhealth.org.uk/page.cfm?pagecode=IZFRUE

The Us As Experts Forum is a free online discussion group. The aim of this forum is to bring together mental health service users and survivors who are undertaking or interested

Useful information

Useful information

in research into mental health issues. By sending and responding to messages to all the other subscribers to the forum you will be able to ask questions, find answers, and share ideas with others doing similar work. It will also provide access to examples of good practice, the latest research, and other expertise. This link will take you to a website where you can get the joining form to be a member.

Ease of reading: Excellent

Useful readings

Hanley, B. (1999). *Research and development in the NHS: How can you make a difference?* Winchester: INVOLVE (Consumers in NHS Research Support Unit). Available online at:

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

This short report is found at the Consumers in NHS Research website – this group is now called INVOLVE. This link takes you to the section that lists all of their publications. This one describes how users, carers and the public can and do make a difference in research and development work.

Ease of reading: Good

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

Thorne, L. Purtell, R. & Baxter, L. (2001) *Knowing how: A guide to getting involved in research*. Exeter: University of Exeter. Accessible online at: http://latis.ex.ac.uk/folk.us/findex.htm

> This is a useful document for anyone who wants to get involved with doing research. It gives examples of what has been learned from projects where user involvement happens. It describes what happens in a research project and what things you need to think about if you do get involved.

> **Ease of reading**: Good

Useful information

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Useful information

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Useful information

Useful information

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