

Part A

What is research and development?

A summary of Part A

Why is Part A important?

Part A describes what research and development activity is. Participants will gain an overview of the six-stage research and development cycle in the NHS - each stage is covered in more detail in Parts B to G. They will also learn about how research and development activity is governed, the different types of research and why user involvement in research and development is important.

What will participants learn by doing Part A?

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

- Understand what research and development is - Activity 1
- Discuss the purpose of research and development - Activity 1
- Understand the six-stage cycle of research and development in the NHS - Activity 2
- Understand the different approaches to research and development - Activity 3
- Understand how research is governed in the NHS - Activity 4
- Discuss why user involvement is important in research and development activity - Activity 5

Skills participants will strengthen or develop

Skills that participants will strengthen or develop include:

- Level 2: Further practice with speaking in large groups
- Level 2: Further practice with thinking about language and meanings
- Level 2: Further practice with thinking about issues
- Level 2: Further practice with developing and presenting an argument

Background information

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

Different tasks in research and development activity

Research and development activity is a cycle. There are six main tasks and user consultants can be involved in **any** of them. User consultants do not usually get involved in every task for a single project but are often involved in one or two. These tasks or stages are:¹⁴

- **Consulting about research** - working out what topics could be researched and what are the priorities
- **Commissioning research** - deciding who gets funded to do the research
- **Doing research** - being involved on the project team who do the research, analyse the information and write it up
- **Managing research** - registering the project within the health or social care organisation, supporting ethics approval and keeping a watch on the research process to make sure it goes smoothly

- **Disseminating research** - getting the research outcomes out to people who need to know about them
- **Evaluating research** - checking how well research was done and also, drawing lots of people's work together to see what we have found out so far

It is a cycle because research outcomes usually tell us other things we need to know, new questions to ask and investigate,

and therefore new issues to research. This takes you back to the 'consulting about research' step where it is decided if these new questions are a priority and you start the process again.

Folk.us is a group who brings together health and social service staff researchers with users, carers and the public to do research work together. They say that:

"Everyone should be involved as early as possible in the research process, so that the direction of the research is clear, everyone knows what they are doing and there is commitment to the project. This is especially important for professionals so that they will be committed to making any necessary changes at the end

TOP TIP

Parts B through G of Unit 5 each focus on one of these six stages in detail. Please see them for more background information and specific training activities.

of the project. It is possible to be involved in ALL stages of the research process, as a researcher or by guiding research on a project steering group." (p.10)¹⁵

Their comments are focused on the **doing** and **managing** of research. But it is also possible to be involved in the other four stages. Some of the case examples in this Unit will explain how that can happen. Importantly, users, carers and the public need to be involved more often in **all** of the research and development activity tasks.¹

Different approaches to research and development

Whenever there is a great deal of interest in an area there is usually going to be many different opinions about it. This is very true for research and development activity. One of the main differences discussed is what type of research is the most valuable and gives you the best information.

Numbers – quantitative research

When people think of research they often start thinking about number and statistics. This is called '**quantitative** research.' In this approach people decide what important things they will look for or do differently in a situation and what they will measure to

see what happens. They are often very specific about the thing they want to find and the measurement and it is usually decided before the research starts. For example, they may do some public education about a health or social problem and then see how many people report having that health or social problem when they visit the GP. They might trial a new blood pressure medication with a group of people and then measure changes in their blood pressure over time. The information they look for or measure is called 'data.' After gathering it, it is analysed in number-based formats. People might be interested in:

- the number of times things do or not happen
- how strong they are
- how often they occur over a certain period of time
- whether they are regular or inconsistent
- how big or small they are, etc.

Statistics is often used in quantitative research to deal with numbers. It is about counting and measuring things once they are made into numbers. We can find out overall percentages, as well as averages, and the amount of difference within or between groups in the research. Quantitative research takes large amounts of information and turns it into clear and simple

categories. The individual detail is lost but an overall 'big' picture is gained. Methods commonly used in quantitative research include:

- Tests
- Surveys where information is turned into numbers
- Measurement of physical and behavioural changes
- Scaling - how little or how much something happens
- Observation and coding behaviour or events

Being number-based data, when people show you the outcomes of quantitative research it is often presented in tables, graphs and lists of figures.

Words - qualitative research

There is another way of doing research. This is where people are interested in experiences and meanings - usually ones that cannot be simply or easily measured. This is called **qualitative** research. The information gathered is people's words, explanations or stories. They analyse the different ideas and meanings so an overall story can be told about the thing being researched.

Qualitative research understands that any piece of research is shaped by people's values. This is often ignored in quantitative work, which believes the researcher can be 'objective.' This means that who you are and what you believe as a researcher does not affect how you decide to do, analyse and write up your research.

Qualitative research usually produces lots of information that is very detailed and complex. It does not neatly fall into pre-decided categories. Researchers need to interpret and re-organise the information as they analyse it. Sometimes graphs and pictures are used. It is less likely to provide definite, clear-cut answers or single solutions, although sometimes the outcomes can be very strong. It certainly gives strong indications of different options or ways of understanding what is happening in a situation. This is powerful and valuable information. Methods commonly used in quantitative research include:

- Surveys or questionnaires
- Interviews
- Focus groups (a small group interview)
- Observation

- Case studies - focusing on one person's story or situation in great detail
- Life histories

When people share the outcomes of qualitative research they still need to reduce the information into a shorter story. It is usually presented through descriptions and stories.

Research governance

The Department of Health invests in research and development to support service quality and improve the knowledge base in health and social issues and services. A considerable sum of money is spent each year and is managed through the Research Governance Framework to make sure research is conducted to high scientific and ethical standards. Research governance:

"Improves research quality and safeguards the public

by:

- Enhancing ethical and scientific quality
- Promoting good practice
- Reducing adverse incidents and ensuring lessons are learned
- Preventing poor performance and misconduct

Is for all those who:

- Participate in research
- Host research in their organisation
- Fund research proposals or infrastructure
- Manage research
- Undertake research"⁴

All people involved in deciding on or running a research project must be aware of research governance issues. The Research Governance Framework sets the standards for conducting research, but also describes the support needed to ensure standards are met and how these standards will be monitored to make sure they are being followed.

What does this mean for an organisation doing research and development? The organisation must demonstrate that it:⁴

- believes that high quality research is important in providing best practice in service delivery
- sets up good support structures for research and development in the organisation
- is committed to doing "good science" by making sure they get independent input on their research and work with partners who are interested in similar research areas

- looks after the wellbeing of people who do the research and all people who are participants in research so that their rights, safety and dignity is protected
- promotes user involvement in research and development
- understands the costs and provides appropriate funds for research
- links its research work to national priorities and needs

User involvement in research and development

A different position for users, carers and the public

For many years, users and carers have usually taken part in research and development activity when they are being researched. The research has usually been developed, done and monitored by health and social service staff. This has started to change in the last 10 years. Users and carers are having more involvement and decision-making in their personal health care. So, it is important they are also involved in researching health and social issues. Research influences decisions about service delivery and management - users and carers have much valuable experience to offer that may not be considered by health and social service staff.^{2,7,12,13,15}

INVOLVE (formerly the Consumers in NHS Research) said:

"The involvement of consumers will lead to research which is more **relevant** to the needs of consumers (and therefore to the NHS as a whole), more **reliable**, and more **likely to be used**. If research reflects the needs and views of consumers, it is likely to produce results which can be implemented." (p.6)⁷

As the experiences and knowledge of most users, carers and the public about research is about 'being done too' rather than 'being done with' this can make people feel like rats in a science experiment. Two user consultants who have been researched and are also researchers decided to let "the rat speak back" (p.280).¹³ This is what they said it feels like when users and carers have no input into why and how research is done:

"I can't say strongly enough that it was this feeling of being led by the nose through a maze - a maze that had been constructed out of the researcher's own bias and interests and funding constraints - that made the image of the rat resonate so strongly in my imagination. That is, this researcher arrived with certain fundamental assumptions and these included ideas about people with particular kinds of so-called mental illness. Her interview technique then consisted of simply plucking

out material, like carrots from vegetable soup, which supported - or at the very least did not run counter to these assumptions - and of collecting meaty little titbits for quotation purposes.... In most people's terms this is not good science but it is allowed to continue in many, many studies." (p.282)¹³

At the same time, this way of doing the work is not always a negative experience. Many people volunteer to be involved in research, but is this about learning the role of being a patient rather than being aware that there is another option?

If provided with another option, some people may choose to be more involved with research. They may want to decide what the priorities are, what work will be done to look into these priorities, which people/group will do the work and how they will do it.¹⁴ Health and social service staff often make assumptions about what they believe are the most important issues and priorities for research. There is no guarantee that users and carers will agree with them or have the same priorities - in fact, they often do not.^{2,7,12,15}

Why user involvement in research and development?

There has been enough user involvement in research and development so far to know that it can and does have positive effects. It improves the quality of services, personal outcomes for users and carers, and leads to empowerment of user consultants.^{2,7,10} For example, a survey was done on user involvement in doing systematic reviews of research - this is where you read all the research in a particular area to find out what it tells us about the issue and write a summary of it. The staff surveyed explained that user consultants:

- offer a 'reality check'
- bring 'an antidote to jargon and pomposity'
- help make reviews relevant to and readable for everyone, not just health care professionals
- assist the dissemination of results to the public (p.14)⁷

Other people experienced in doing user involvement in research argue that user consultants should be involved in research as a political mandate - they are the owners of publicly funded research, therefore they should influence what research is done and how.⁶ Another reason given is that user involvement empowers user consultants.⁶ They also argue that user

involvement improves the quality of research as user consultants can help ensure that research is relevant. User consultants can identify issues that are important to users, carers and the public and prioritise them, as well as identify research topics and questions not considered by researchers.⁷ User consultants also influence how research is designed, including how to ask and what exactly to ask - this can impact the quality and relevance of the information gained.^{2,11} Sometimes user consultants can reach out to people and get them involved in a project in a way that researchers cannot.^{5,9}

User health groups' involvement in research can lead to a shift from making complaints to a clear statement of important needs and creating new directions for mainstream research. For example, women affected by the drug diethylstilboestrol (DES), which led to a rare vaginal cancer, became involved in DES support groups. They gathered information from consumers that identified a link between DES exposure and lupus and asthma. Research was then done in this area that proved the connection and had valuable outcomes.⁸

In examining the outcomes and experience of their collaborative research project, one joint user and staff research group reported that:

"Consumers are the people who can most effectively critique human services work in terms of what **ongoing impact** it has on their lives. It is critical to know what **consumers** believe constitutes a good service experience and a good outcome, rather than assume workers always know what is appropriate for people.... Collaborative research enables the development of 'shared constructions' of good service and outcomes through gaining access to untapped knowledge's and experiences leading to an overall 'expansion of knowledge'." (p.84)²

Opportunities for user involvement

Opportunities in the research area may be in the local area, such as the Research and Development Unit in a Trust, or with a university but they are often at a wider or national level. For example, as part of the overall NHS strategy for research and development different groups were established with one being the Health Technology Assessment Programme.¹¹ It has a national remit and has increased the amount of user involvement it does in recent years. It invites user consultants from throughout the UK to join its advisory panels or review groups.

In contrast the Alzheimer's Society is a user and carer non-government support organisation that has created a 'Consumer Network' to lead their research program - see their website: <http://www.alzheimers.org.uk>. It tries to involve its members in every aspect of its research program. This includes setting strategy, commissioning, reviewing grant applications, grant awards, doing and managing research projects, and disseminating outcomes.

Then there is Folk.us, a user consultant and staff collaborative project at a regional level in Exeter, which is listed as a useful website in this Part. It does work in the local area and also takes up opportunities to do research across a broader geographical region. It has previously done national work for INVOLVE. Folk.us talk about user consultants getting involved at different stages of the research and development activity cycle, with different levels of responsibility, influence and decision-making.

- "Professionals inviting lay people on the steering/advisory group of their research project, from the planning stage onwards

- Lay people asked to advise on the questions that should be asked or help with analysis and interpretation of results
- Lay people doing their own research
- User groups commissioning professionals to do research for them and taking a managerial role
- Lay people and professionals working in equal partnership sharing their knowledge
- There may also be occasions when a project started by laypeople benefits from some professional advice." (pp.6-8)¹⁵

Opportunities for user involvement in research and development need to grow.¹ It is expected that they certainly will grow at both local, regional and national levels.³

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Activity 1

Research and development: What is it? What is its purpose?

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 word web + small group discussion + mini-presentation
- Large group discussion + floor mural + mini-presentation

Things to get ready

- Print the Unit 5 - Part A PowerPoint files 1A - 1F 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 Option 5, cut up sheets of A4 paper into strips (lengthways) - use two different colours

Activity Option 1

Large group word web - What is research and development? (10-15 minutes)

The purpose of the large group word web is to practice skills in thinking about language and meanings:

- Divide the whiteboard in half
- Write the word 'research' in the middle of one half and 'development' in the middle of the other
- Ask participants what immediately comes into their mind when they see or hear these words
- Invite participants to come up to the whiteboard and write these ideas around the two main words - this is how they will create a word web
- Have participants come up in groups, not one person at a time, so this happens quickly and people do not feel like they are being watched
- After they have done this, ring those words that will come up during Part A with a different colour marker
- Facilitate a discussion or explain terms as needed - you can consult the *Glossary of Terms* in the Introduction to this unit and also refer participants to this in their version

Activity Option 2

Large group discussion - Interest in research and development (10-15 minutes)

The purpose of the large group discussion is to practice skills in speaking in large groups:

- Ask participants to work with you in the large group and think about and answer these questions:
 - * Why are you interested in research and development?
 - * Have you had any experience in research and development?
 - * If yes, briefly tell us what it was
- Facilitate a discussion as needed

Activity Option 3

Large group discussion - Purpose of research and development (10 - 15 minutes)

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

- Ask participants to work with you in the large group and think about and answer these questions:
 - * **Why** do you think we do research and development in health and social services?

- * How do you think it **helps** health and social services?
- Write up people's ideas on the whiteboard under the headings of 'purpose' and 'how does it help'

Activity Option 4

Small group discussion - Purpose of research and development (15-20 minutes)

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

- Ask participants to work in groups of 4-5 and think about and answer these questions:
 - * **Why** do you think we do research and development in health and social services?
 - * How do you think it **helps** health and social services?
- Ask them to take notes on flipchart paper under the headings of 'purpose' and 'how does it help' and present this back to the group after 10-15 minutes
- Facilitate further discussion as needed

Activity Option 5

Floor mural – Purpose of research and development (15 – 20 minutes)

The purpose of the floor mural is to practice skills in thinking about issues:

- Ask participants to work individually
- They must write answers to the next two questions on strips of paper (A4 paper cut in half lengthways) in large clear print so it is easy to read from a short distance:
 - * **Why** do you think we do research and development in health and social services?
 - * How do you think it **helps** health and social services?
- They will put their answers to the first question under the heading of 'purpose' and to the second question under the heading of 'how does it help' - you will put these headings at different positions on the floor
- Once they have run out of ideas ask the group to look at everyone's answers and start sorting similar ideas for 'purpose' into groups - do the same for 'how does it help'
- Facilitate further discussion as needed

Activity Option 6

OVERHEADS 1A - 1F

Mini-presentation - What is research and development? What is its purpose? (10-15 minutes)

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

- Definitions of research and development
- The three main roles of research and development
- Examples of these three main roles
- What we learn from the outcomes of research and development
- During or after the mini-presentation, facilitate further discussion as needed

Activity 2

The research and development cycle

There are two 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 A PowerPoint files 2A - 2Q in 'note pages' for you and, where appropriate, 'handouts' (two slides/page) of the presentation material for participants
- Whiteboard and coloured whiteboard markers
- If you choose Activity Option 2 you will need to identify an appropriate presenter who can discuss current examples of research and development in an NHS Trust - meet with them to ensure they understand the task and prepare anything that the guest speaker needs

Activity Option 1

OVERHEADS 2A - 2Q

Mini-presentation with case examples - The research and development cycle (25-30 minutes)

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

- The six main tasks in the research and development cycle and the steps involved in them
- Examples of how users, carers and the public can be involved in the six main tasks
- During or after the mini-presentation facilitate further discussion as needed

Activity Option 2

OVERHEADS provided by guest presenter

Guest presentation with case examples - The research and development cycle (25-30 minutes)

The purpose of the guest presentation with case examples is to gain and extend knowledge and understanding of this area. The presenter will cover these areas drawing on current examples in an NHS Trust:

- The six main tasks in the research and development cycle and the steps involved in them
- Examples of how users, carers and the public can be involved in the six main tasks
- During or after the guest presentation, facilitate further discussion as needed

Activity 3

Different types of 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. Suggested combinations are:

- Stand up/sit down exercise + mini-presentation
- Large group discussion + mini-presentation

Things to get ready

- Print the Unit 5 - Part A PowerPoint files 3A - 3I in 'note pages' for you and, where appropriate, 'handouts' (two slides/page) of the presentation material for participants
- Whiteboard and coloured whiteboard markers

Activity Option 1

Stand up/sit down exercise - Existing knowledge of different types of research and development (15-20 minutes)

The purpose of the stand up/sit down exercise is to build on knowledge and practice skills for speaking in large groups:

- Tell participants that you will call out the names of different types of research - after each name you will ask people to:
 - * Stand up if they have heard of this type of research
 - * Continue standing if they have been involved in this type of research - if they have not, they will sit down
 - * Get all people to sit down and ask those who stood up for either question to share what they know about that type of research with the others
- It is fine if no-one has heard about or been involved with a type of research - answer questions and facilitate discussion as needed
- Here are some different types of research you will go through for this exercise - include others if you like:
 - * Personal interviews
 - * Focus groups
 - * Written questionnaires

- * Health tests where personal ability, blood or a part of the body is measured or observed
- * Case study

Activity Option 2

Large group discussion - Existing knowledge of different types of research and development (15-20 minutes)

The purpose of the large group discussion is to build on knowledge and practice skills for speaking in large groups:

- Ask participants to call out the names of different types of research that they have heard about or been involved in
- Write up the different names on the whiteboard with plenty of space in between them - wait until you have at least 3 or 4 on the whiteboard before moving on
- Ask people who have heard about or been involved in these types of research to share what they know about them with the others - make notes on the whiteboard
- Answer any questions and facilitate discussion as needed

Activity Option 3

OVERHEADS 3A - 3I

Mini-presentation - Different types of research and development (20 minutes)

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

- Different types of research
- What happens in quantitative research
- Methods used to gain data for quantitative research
- What happens in qualitative research
- Methods used to gain information for qualitative research
- During or after the mini-presentation facilitate further discussion as needed

Activity 4

Research governance

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 seesaw exercise and discussion + mini-presentation
- Small group seesaw exercise and discussion + guest presentation

Things to get ready

- Print the Unit 5 - Part A PowerPoint files 4A - 4E in 'note pages' for you and, where appropriate, 'handouts' (two slides/page) of the presentation material for participants
- Whiteboard and coloured whiteboard markers
- If you choose Activity Option 4 you will need to identify an appropriate presenter who can discuss current examples of research governance in an NHS Trust - meet with them to ensure they understand the task and prepare anything that the guest speaker needs

Activity Option 1

OVERHEAD 4A

Large group 'seesaw' exercise and discussion - Managing possible problems in research and development (15-20 minutes)

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

- Draw a large seesaw (like in a children's playground) on the whiteboard with one side weighed down and one in the air
- Ask participants to think about and answer this question:
 - * What do you think could be difficult when doing research that would **stop** the project going ahead or would make people **unhappy** with it?
- 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:
 - * What needs to happen to avoid these problems or help deal with them if they come up?
- 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 other people's ideas: comment that the aim is to keep the issues in balance - this is the role of research governance

Activity Option 2

OVERHEAD 4A

Small group 'seesaw' exercise and discussion - Managing possible problems in research and development (20-25 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 - each group must think about and answer this question:
 - * What do you think could be difficult when doing research that would **stop** the project going ahead or would make people **unhappy** with it?
- They must write their ideas on the 'weighed down' side of the seesaw

- Then they must think about and answer this question:
 - * What needs to happen to avoid these problems or help deal with them if they come up?
- 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 - when the 2nd and 3rd groups present they need to just add **extra** things that the previous groups have not named rather than repeat issues
- Discuss the issues as you go to make sure everyone understands them: comment that the aim is to keep the issues in balance - this is the role of research governance

Activity Option 3

OVERHEADS 4B - 4E

Mini-presentation - What is research governance? (15 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 is research governance?
- What does ethical quality mean in research governance?

- What does scientific quality mean in research governance?
- How do organisations promote good practice as part of research governance?
- During or after the mini-presentation facilitate further discussion as needed

Activity Option 4

OVERHEADS provided by guest presenter

Guest presentation - What is research governance? (15 minutes)

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

- What is research governance?
- What does ethical quality mean in research governance?
- What does scientific quality mean in research governance?
- How do organisations promote good practice as part of research governance?
- During or after the guest presentation facilitate further discussion as needed

Activity 5

Why have user involvement in research and development?

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:

- Debate + small group discussion
- Mini-presentation + pairs and small group discussion

Things to get ready

- Print the Unit 5 - Part A PowerPoint files 5A - 5D in 'note pages' for you and, where appropriate, 'handouts' (two slides/page) of the presentation material for participants
- Whiteboard and coloured whiteboard markers
- If you choose Activity 1 then you will need strips of scrap paper for people to use in the secret ballot

Activity Option 1

Debate - Why should there be user involvement in research and development? (30 minutes)

The purpose of the debate is to practice developing and presenting an argument, and skills for speaking in large groups:

- Divide the group in two - one group will be asked to be the 'for' side of the debate and the other will be the 'against' side of the debate. The question is:
 - * Should there be user involvement in research and development?
- Each group will spend 15 minutes developing an argument for their side of the debate - they must also nominate 3 people to present the argument to the whole group where each person has 1 minute to speak
- Bring the group back together and facilitate the debate - ask the 'for' side to begin with one of their speakers, followed by a speaker from the 'against' side until all have presented
- Hand out strips of paper to all audience members and ask them to do a secret ballot - they must write 'for' or 'against' to indicate which argument they found the most convincing
- Add up the ballot outcomes and announce the results
- Facilitate any further discussion as needed

Activity Option 2

Large group discussion and dotmocracy - Why should there be user involvement in research and development? (20 minutes)

The purpose of the large group discussion and dotmocracy is to practice developing and presenting an argument, and skills for speaking in large groups:

- Ask the group to share their thoughts on why they believe there should be user involvement in research and development
- Put the main points on the whiteboard and any important notes next to them
- Encourage participants to give good explanations for their reasons and encourage them to respond to each other, not just to you
- Once people can think of no further reasons and they have all been discussed, run a dotmocracy (see the Glossary of terms in the Introduction section of Unit 5)
- Each participant can draw 5 stars on the board next to the reasons they think are the most important or convincing
- They can put all 5 stars on the one reason or spread their stars around

- Have participants come up in groups, not one person at a time, so this happens quickly and people do not feel like they are being watched
- After everyone has voted in the dotmocracy then add up the results and identify the most popular or convincing reasons
- Facilitate any further discussion as needed

Activity Option 3

OVERHEADS 5A - 5D

Mini-presentation - Why should there be user involvement in research and development? (10-15 minutes)

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

- Outcomes of user involvement in research and development
- Reasons why user involvement improves the quality of research and development
- Facilitate any discussion as needed in response to the mini-presentation

Activity Option 4

Small group discussion - Why do you want to be involved in research and development? (15 minutes)

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

- Ask participants to work in groups of three
- They will discuss why they personally want to be involved in research and development for ~ 10 minutes
- You may want to leave the room so participants can speak freely
- Return after 10 minutes and invite anyone who wants to share his or her reasons to do so, this is voluntary and not expected of everybody - it is fine if no one shares

Activity Option 5

Pairs and small group discussion - Why do you want to be involved in research and development? (20 minutes)

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

- Ask participants to work in pairs
- They will discuss why they personally want to be involved in research and development for ~ 10 minutes
- You may want to leave the room so participants can speak freely
- Return after 10 minutes and ask each pair to find another pair and share the outcome of their discussion for ~ 10 minutes and discuss anything else that comes up from hearing other people's ideas
- Leave the room again so participants can speak freely - return again and call an end to the discussion
- If wished, invite participants to share anything that came out of these discussions that they want say to the whole group

Personal exercises

Here is an exercise to help participants think about the ideas in Part A.

What interests you the most?

Participants now know more about what research and development activity is. They will think about and answer these questions:

- Are they still sure they want to be involved in research and development?
- Why or why not?
- What stage or stages of the research and development cycle interest them the most?
- Why?
- What steps do they want to take to follow this up? If they have a Link Person, what questions do they need to ask?

There may be an opportunity to do something like this with their service that they have already discussed with a Link Person, but now they need to take this further.

Case examples

1. The Alzheimer's Society

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

Tel: 0191 223 2830

Alzheimer's Society

Gordon House, 10 Greencoat Place

London, SW1P 1PH

Ph: 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 Society aims to involve its members in every aspect of its research program, including strategy setting, commissioning, grant application reviewing, grant awards, project management, implementation and dissemination. It has won national awards for its commitment to user involvement.

2. Sheffield and the North Trent Cancer Research Network

c/- Sheffield Palliative Care Studies Group

Royal Hallamshire Hospital

Sheffield S10 2JF

Contact person: Tony Stevens

E-mail: t.stevens@sheffield.ac.uk

The Sheffield and the North Trent Cancer Research Network was set up to improve the level of involvement of users and carers in cancer related research. There has been a range of activities used to recruit and involve people as user consultants, including three open user conferences to increase awareness of research among users and carers. They used these conferences to directly recruit people with experience of cancer, as users or carers, to sit on individual project steering groups and also a committee that provides a strategic overview of current research. They established a 'Consumer Panel for Research' where reimbursed, trained consumers are able to provide consumer perspective in a range of settings, including steering groups and committees. (See Stevens et al. 2003 listed under the 'Sources used for the material in this part' in the Useful Information section.)

3. SURE: Service User Research Network

SURE

P034

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.)

Useful information for participants

Useful websites

Cochrane Collaboration Consumer Network

<http://www.cochrane.no/consumers/docs.aspx?wfref=Consumer>

This is the website for consumers who are involved in the work of the Cochrane Collaboration. They help review and report on the evidence for health care practices so people can make informed decisions about their health care.

Ease of reading: Average

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 service 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

National Institute for Clinical Excellence (NICE)

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

NICE is part of the National Health Service (NHS). It aims to provide users, carers, health professionals and the public with convincing, clear and reliable guidance on current 'good practice.' This includes information about health assessments and treatments, and the management of specific conditions. The work of NICE will help improve the quality of care that users and carers receive in the NHS.

Ease of reading: Average

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

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 described in this part 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

Bechel, D., Myers, W. & Smith, W. (2000). Does patient-centred care pay off? *Journal of Quality Improvements*, 26(7), 400-409.

Edwards, A., Elwyn, G., Smith, C., Williams, S. & Thornton, H. (2001). Consumers' views of quality in the consultation and their relevance to 'shared decision-making' approaches. *Health Expectations*, 4(2), 151-161.

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Roberts, K. (1999). Patient empowerment in the United States: A critical commentary *Health Expectations*, 2(2), 82-92.

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

Williams, G., Frankel, R., Campbell, R. & Deci, E. (2000). Research on relationship-centred care and healthcare outcomes from the Rochester Biopsychosocial Program: A self-determination theory integration. *Families, Systems & Health: The Journal of Collaborative Family Health Care*, 18(1), 79-90.