

THEME 2

Unit 5

Introduction

Involvement in research and development activity

A summary of Unit 5

Why is this unit important?

Research and development activity is very important in guiding health and social service work. It checks to see if the work that is done leads to good outcomes. It also identifies whether new ideas are helpful and should be put into practice. All of these things have a direct affect on users, carers and the public.

User involvement in research and development means more than just taking part in research and development activities. For example, answering the surveys, participating in interviews or agreeing to do tests. It includes deciding on the priorities for research and development activity - what are the most important things to be investigating and who will get the money to do this? It involves deciding how the research and development activity will be run, and being involved on the team that does the direct work. It includes making sense of what is found out and writing this up to share with other people. In short, user involvement can happen at any point in the research and development cycle. Unit 5 takes participants through all of these areas. There are eight parts to Unit 5:

- **Part A: What is research and development?** - This part 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.
- **Part B: Consulting about research** - Before research and development work happens, it is important to consult with people on what the focus of this work should be and what are the priority issues. This is called consulting. Participants will learn about the details of this stage and analyse real examples. They will also consider the practical issues of user involvement in consulting about research to help them decide if they would like to do this work.
- **Part C: Commissioning research** - Once people have decided to research a specific area they need to gain funds for the project. They submit proposals to research funding groups who have the job of deciding who gets the money. This is called commissioning. Participants will learn about the details of this stage and analyse real examples. They will also

consider the practical issues of user involvement in commissioning research to help them decide if they would like to do this work.

- **Part D: Doing research** - 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.

- **Part E: Managing research** - In the NHS, all research and development must be managed. During this stage of the research cycle a number of procedures take place:
 - ω The research will be subject to external and internal peer review
 - ω The research will be approved and registered within the trust's research and development department
 - ω The research will be assessed by a research ethics committee for ethical approval

Throughout the research cycle the research managers and project board will also support and guide the project through all of its stages and provide advice where needed. In Part E participants will learn about the details of this stage and analyse real examples. They will also consider the practical issues of user involvement in managing research to help them decide if they would like to do this work.

- **Part F: Disseminating research** - After completing a research and development project it is important to share what was learned. There are several ways of sharing this through writing and speaking - this is called disseminating research. Participants will learn about the details of this stage and analyse real examples. They will also consider the practical issues of user involvement in disseminating research to help them decide if this work interests them.

- **Part G: Evaluating research** - Evaluation of research can happen in several ways. Research and development projects are evaluated for a number of reasons - to see if:
 - ω the aims of the research have been fulfilled
 - ω they have been done well
 - ω it helps tell us more about a specific issue

- ω the results are accurate
- ω the results suggest a change in practice or services

In Part G participants will learn about these ways of evaluating research and analyse real examples. They will also consider the practical issues of user involvement in evaluating research to help them decide if this work interests them.

- **Part H: Preparing for user involvement in research and development** - This part is designed for participants who have been invited to or identified a user involvement opportunity in research and development that they want to take. In this part participants review the top tips that support positive user involvement in research and development work. They focus on getting ready for the user involvement activity they want to join, and the real and practical issues that they will need to negotiate. **Only** choose this part if your participants have a clear idea about what they will be doing, and have a link or support person that they are working with to discuss and clarify this. That person may be a health and social service researcher or an experienced user/carer researcher.

What will participants learn by doing Unit 5?

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

- Understand what research and development is - Part A
- Discuss the purpose of research and development - Part A
- Understand the six-stage cycle of research and development in the NHS - Part A
- Understand the different approaches to research and development - Part A
- Understand how research is governed in the NHS - Part A
- Discuss why user involvement is important in research and development activity - Part A
- Understand what consulting about research means - Part B
- Understand what happens in the consulting about research stage - Part B
- Discuss the practical issues of user involvement in the consulting about research stage - Part B
- Understand what commissioning research means - Part C
- Understand what happens in the commissioning research stage - Part C
- Discuss the practical issues of user involvement in the commissioning research stage - Part C

- Understand what doing research means - Part D
- Understand what happens in the research stage - Part D
- Discuss the role and responsibilities of researchers - Part D
- Discuss the practical issues of user involvement when doing research - Part D
- Understand what managing research means - Part E
- Understand what happens in the managing research stage - Part E
- Discuss the practical issues of user involvement in the managing research stage - Part E
- Understand what disseminating research means - Part F
- Understand what happens in the disseminating research stage - Part F
- Discuss the practical issues of user involvement in the disseminating research stage - Part F
- Understand what evaluating research means - Part G
- Understand what happens in the evaluating research stage - Part G
- Discuss the practical issues of user involvement in the evaluating research stage - Part G

- Discuss the top tips that support positive user involvement in research and development work - Part H
- Negotiate the research and development role they want to have and the support they need from their organisation - Part H

Summary of parts and content of Unit 5

Theme Two	
PART A What is research and development?	1. Research and development: What is it? What is its purpose?
	2. The research and development cycle
	3. Different types of research
	4. Research governance
	5. Why have user involvement in research and development?
PART B Consulting about research	1. What does consulting about research mean?
	2. Examples of user involvement in consulting about research
	3. What could user involvement in consulting about research mean for you?
PART C Commissioning research	1. What does commissioning research mean?
	2. Examples of user involvement in commissioning research
	3. What could user involvement in commissioning research mean for you?

Theme Two	
PART D Doing research	1. What does doing research mean?
	2. Being a researcher
	3. Examples of user involvement in doing research
	4. What could user involvement in doing research mean for you?
PART E Managing research	1. What does managing research mean?
	2. Examples of user involvement in managing research
	3. What could user involvement in managing research mean for you?
PART F Disseminating research	1. What does disseminating research mean?
	2. Examples of user involvement in disseminating research
	3. What could user involvement in disseminating research mean for you?

Theme Two	
PART G Evaluating research	1. What does evaluating research mean?
	2. Examples of user involvement in evaluating research
	3. What could user involvement in evaluating research mean for you?
PART H Preparing for user involvement in research and development	1. Top tips for positive user involvement in research and development
	2. Getting ready for user involvement

Glossary of terms

- **Adverse incidents:** When someone is poorly affected or harmed by an action taken by a health and social service staff member while providing assessment and care, or by a researcher in carrying out a research project.
- **Clinical guidelines:** Recommendations for the care of service users by health and social service professionals. These statements are developed in a systematic way by consulting the published evidence, and health and social service staff, users, carers and the public about their experiences and opinions. They assist staff and service users to make decisions about appropriate care for specific health and social issues, eg coronary heart disease, cancer, diabetes, mental illness, etc.
- **Clinical trial:** In order to see whether a medical treatment or procedure has real and positive effects a large research project is carried out. It is usually set up as a 'randomised control trial.' This is where you recruit a large group of people and randomly divide them into two or more groups. One group receives the treatment or procedure, one group receives nothing and one or more other groups may have a different treatment or procedure. The progress of all

groups is tracked, e.g. before, during and after the trial, to see if there are any changes and if this differs between the groups.

- **Development:** In the term 'research and development', development means testing and evaluating new ways of doing things in health and social services. It focuses on how well new ideas actually work in practice, including ideas that have been identified through research.
- **Dotmocracy:** This is a training term and is a fun way of voting. Everyone is given 5 dots or stars - 5 votes - and then can spread their votes across as many options as they like. If there are 4 options to vote on they can put all their stars on one option, or 2 stars on one option and 3 on another, etcetera.
- **Empowerment:** The process that helps people feel that they are important, capable and valuable, and have the ability and confidence to do things for themselves - they feel empowered. It can also include having permission and the confidence to do things or speak on behalf of others. In short, empowerment is when a person feels they can stand up for him/herself, be heard and get things done.
- **Ethical and scientific quality:** Ethical quality means the degree to which a health and social service activity meets

the agreed ethical standards (see 'ethics' below). Scientific quality means the degree to which a health and social service activity follows the standards for good science. For example, it includes clearly explaining what you are doing and why, communicating clearly with people involved, following appropriate procedures and reporting your results honestly.

- **Ethics:** These are agreements for making sure that health and social service practice and research is done to high standards, and that there are benefits, safety, respect, privacy and care for the people involved.
- **Good and best practice:** Both of these terms are used. 'Best practice' means the very best way of providing health and social services or an aspect of them. Because there is not always a single best way the term 'good practice' is used to mean a high quality or excellent way of providing services or an aspect of them.
- **Infrastructure:** This refers to the basic things you need to run a health and social service, including the 'bricks and mortar,' furniture, computing and medical equipment, funds for stationery or medicines, and many other similar things.
- **Misconduct:** Poor and unprofessional behaviour by a health and social service staff member or researcher. This is behaviour that does not meet the ethical standards.

- **Outcomes:** This is used in several ways in health and social services, including:
 - ω what happens because of an action by a health and social service staff member
 - ω the results of an assessment
 - ω the results of a research project
 - ω the results of a change in service delivery
- **Qualitative:** In research this means gathering information that focuses on words, experiences, stories and meanings and then analysing this information. You cannot easily turn this information into numbers. If you do you lose a lot of the important meanings.
- **Quantitative:** In research this means gathering information that focuses on numbers, or things that can be turned into numbers, then analysing these numbers through a set of mathematical procedures called statistics.
- **Research:** The NHS defines research as work that aims to provide new knowledge. This knowledge should be:
 - ω potentially of value to those facing similar problems elsewhere
 - ω open to critical examination
 - ω accessible to all who could benefit from it.⁸

- **Research and development cycle:** There are six main stages to this cycle:
 - ω **Consulting about research** - working out what topics could be researched and what are the priorities
 - ω **Commissioning research** - deciding who gets funded to do the research
 - ω **Doing research** - being involved on the project team who does the research, analyses the information and writes it up
 - ω **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
 - ω **Disseminating research** - getting the research outcomes out to people who need to know about them
 - ω **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
- **Review:** When you read a research proposal or report and then give your opinion on how good it is and how well it fits with user perspective.

- **Stakeholders:** People, groups or organisations that have an interest in the research and development because it affects them in some way.
- **Values walk:** This is a training term. When people listen to a statement about an issue, e.g. "user involvement improves the quality of services," or a situation, e.g. "you are asked to be a user consultant on a planning committee but are not offered any training for the role - are you happy with this?" They must take a position on how much they agree with or are happy with it. They are given options that are written on posters and put at points around the room, for example:
 - ω Definitely agree
 - ω Possibly agree, but could be persuaded
 - ω Do not agree, but could be persuaded
 - ω Definitely do not agree

Other options may be a scale of 1 to 10, or Poor, OK, Good and Excellent. People choose the position that fits and then stand or sit at that poster. The trainer asks people from each position their reason for being there while the others listen. The trainer may invite a group discussion on the issue.

Background information

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

The importance of research and development

Research and development activity is highly valued because it helps health and social services know what is working and not working, and what new ideas they can use to create better health and social services. There are many groups involved with research and development activity in health and social services.^{3,6,8} Since the emphasis on patient and public involvement in the 2000 NHS Plan they have needed to consider how to create meaningful and substantial opportunities for user involvement. This has occurred at individual Trust level and also in sections of the Department of Health that are set up to support research across the NHS.

The interest in user involvement in research and development has led to the creation of groups such as INVOLVE, formerly, Consumers in NHS Research.⁶ Their work is listed as case examples throughout this unit and several of their documents are used or recommended throughout the resource.⁸

Shifting to user involvement in research and development

User involvement in research and development is growing, although it still presents many challenges to health and social services. Many are used to thinking of users, carers and the public as people who participate in research and development that is run by health and social service staff, not as key people involved in the different stages of the research and development cycle.⁴ This even occurs when the research project is evaluating a user involvement activity.^{1,2} Some consult users, carers and the public about research or include them on committees, but it is only in fairly recent times that user consultants have gained influential, decision-making and/or team member positions.³

It will become obvious in each part of this unit that user involvement in research and development means questioning what is often 'taken for granted' by health and social service researchers. They will need to think again and discuss with user consultants matters such as:

- how to start the research and development process
- how to argue for why the topic is important
- how to ask questions

- how to conduct the research and development work
- who will be involved and in what way
- what the appropriate research methods are for the different groups of people involved
- what issues to look for
- what researchers may see or not see based on their different experiences and personal identity
- how to analyse the outcomes of what is found, heard or seen
- what sense to make of the outcomes
- how to explain the outcomes
- how to judge whether or not the project was done well
- what further steps should be taken to build on the research

Although it is always important to think carefully about these issues, reviewing them through a user involvement process in research and development can positively influence the quality and relevance of the information gained.^{5,7} Examples of user involvement in the research and development cycle will be given throughout Parts B to G so participants have the opportunity to analyse them and decide for themselves if user involvement has a positive influence.

References

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