Part H

Preparing for user involvement in research and development

A summary of Part H

Why is Part H important?

This part is designed for people who have been invited to or identified a user involvement opportunity in research and development that they want to take. In this part you review the top tips that support positive user involvement in research and development work. You focus on getting ready for the user involvement activity you want to join, and the real and practical issues that you will need to negotiate.

Only choose this Part H if you have a clear idea about what you will be doing and have a link or support person that you 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 you learn by doing Part H?

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

▪ Discuss the top tips that support positive user involvement in research and development work – Activity 1

▪ Negotiate the research and development role you want to have and support you need from your organisation – Activity 2

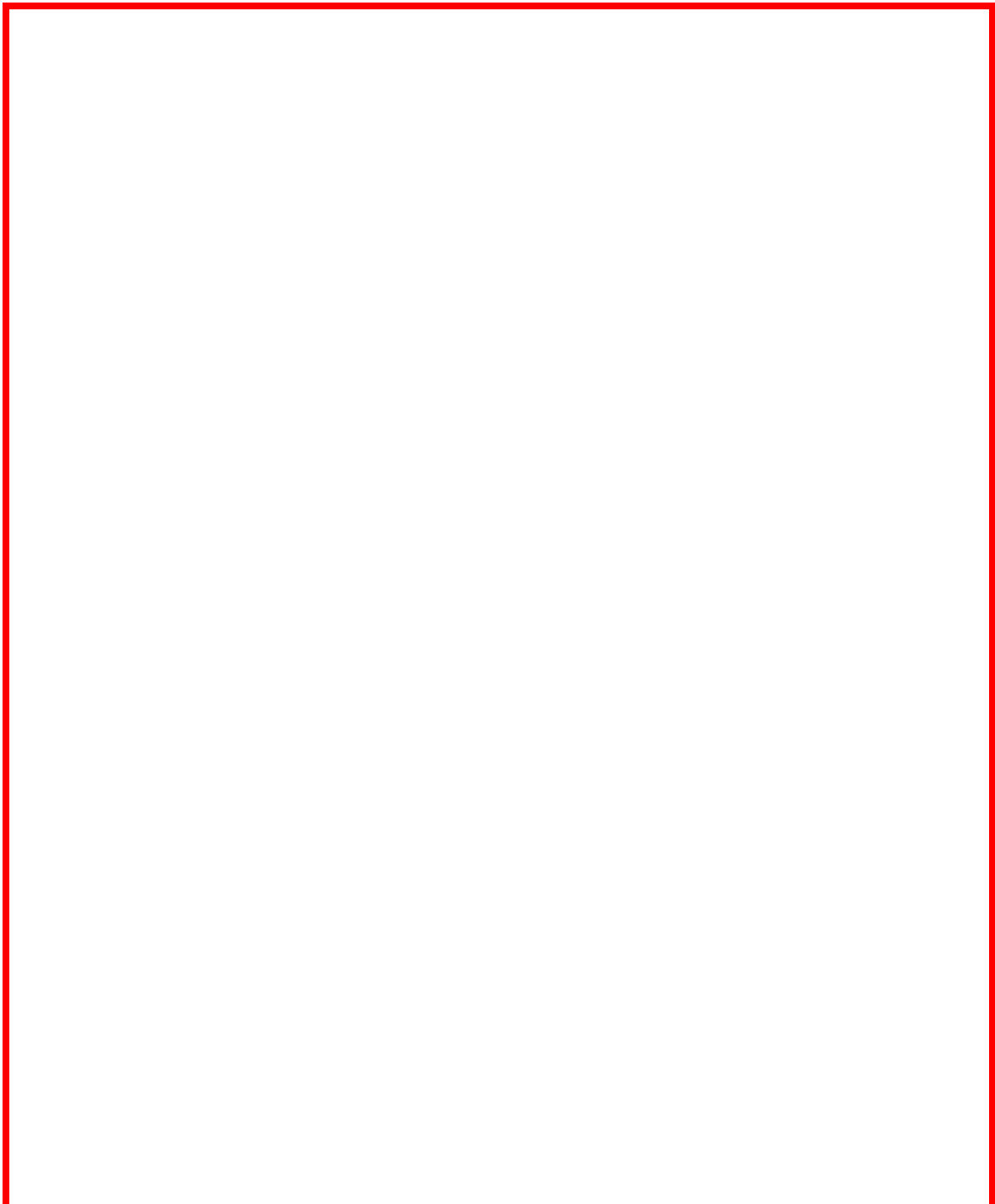Introduction

Skills you will strengthen or develop

Skills that you will strengthen or develop include:

- Level 2: Further practice with thinking about issues

- Level 2: Further practice with setting goals

- Level 3: Demonstrate ability to think about case examples

- Level 3: Demonstrate ability to plan what to do next

Introduction

Activity 1

Top tips for positive user involvement in research and development

Top tips for positive user involvement

Activities

Activities

Activity 2

Getting ready for user involvement

Questions to guide your discussion

1. What is the research and development **activity** in which you will be involved?

    * Which stage or stages of the research and development cycle does it involve?

    * Are you happy with this or do you want to be involved in more or less of the stages? Why?

    * If you are not happy who do you need to discuss this with?

Activities

2. What **role** will you have?

   * What exactly do you need to do in this role?

   * What things will be your responsibility to look after?

Activities

3. How fair are the **expectations** for that role?

   * Are you happy with this role?

   * Do you feel ready to take on these responsibilities?

   * What things do you need to negotiate?

   * Who do you need to do this with?

4. What **support** are your receiving?

   * What introduction to the project will you get?

   * What information will you receive?

   * What training will you receive?

   * Will you have a support person or mentor?

Activities

* What payments will you receive for costs and/or your time?

* Are you happy with this support or do you need something more or different? Why?

* If you are not happy who do you need to discuss this with?

Activities

5. What **influence** will you have on decisions?

 * Are you being consulted, are you collaborating with health and social service researchers, or is it a user-controlled project where health and social service researchers may work under the guidance of user consultants?

 * Is this satisfactory or not? Why?

 * If you are not happy who do you need to discuss this with?

Activities

6. What are you planning to do to help yourself be **successful**?

   * How are you going to keep a user perspective?

   * What personal family or friend support do you have?

   * Does what you want to do fit within the time you can give?

   * How will you give feedback to the people you represent?

Activities

Activities

7. What **problems** do you think there might be?

   * Are there problems for you or problems for the health and social service researchers?

   * If problems for you how should you deal with them?

   * If problems for the health and social service researchers how do you think they should deal with them?

Personal exercises

Here is an exercise to help you think about the ideas in Part H.

Preparing for research and development work

In Activity 2 you discussed what research and development activity you are planning to join. Your group members gave you feedback and ideas to think about. Go back over your notes from this activity and do this planning:

- Review your answers to each of the seven questions and score it on how ready you are. Are you:

  * Not at all, a little, fairly or completely ready?

- Identify all the things you need to discuss or negotiate about the project and make a plan:

  * When will you do this?

  * Who will you discuss this with?

Personal exercises

* What do you want to achieve in this discussion?

■ Identify all the things that you personally need to do to be ready for the project and make a plan:

* When will you do this?

* How will you do this?

Personal exercises

Case example

1.Successful involvement of users in research

Rosemary Telford, Lead Researcher

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Community Health Sheffield NHS Trust (CHS)

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The full name of this project is 'A qualitative evaluation of influential factors in promoting successful involvement of consumers in research' and a report was published in 2002. The project aimed to find out what factors promoted successful involvement of users, carers and the public in NHS research and why. The researchers interviewed users, researchers and research commissioners from a research project that successfully involved consumers.

In doing the research they also involved users. They held a focus group at the beginning of the project to share their ideas with consumer representatives interested in the consumer involvement concept. Consumers shaped the aim of the research, came up with the key questions to address and through focus

group discussions contributed to the design of the interview schedule. The findings have created greater interest about user involvement in research in Sheffield, and influenced the strategy on consumer involvement in the Community Health Sheffield NHS Trust (CHS). It is hoped that the findings will be implemented both locally and nationally.

2.   Consumers for ethics in research (CERES)

PO Box 1365

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E-mail: info@ceres.org.uk

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

CERES is an independent charity set up 1989 to promote informed debate about research. It helps users of health services to develop and publicise their views on health research and on new treatments. CERES believes that everyone asked to take Part Hn 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 to be heard more clearly to improve how research occurs.

Case examples

Case examples

3. Matrix Research Group

Matrix Service User Group and Middlesex University

Contact: Brigid Morris, Project Coordinator

Email: brigidm@morrisb.fslife.co.uk

Morris, B. & Holmshaw, J. (2004). *Doing service user-led research in mental health: Matrix Service User Group and Middlesex University*. Paper presented at the User Involvement in Health and Social Care Practice, Education and Research Conference, Middlesex University.

The Matrix Research Group are looking at the experience of care on acute mental health wards at the Middlesex Hospital from the perspective of both current inpatients and staff. The Research Group is made up of members from the Matrix Service User Group and a Middlesex University researcher. They have had previous experience in doing audits and evaluations of local mental health services. Service users have been involved in all stages of the design, funding proposal and doing the research. They personally interviewed 60 inpatients, organised to survey staff on 6 wards, and personally interviewed a range of staff from different disciplines and levels. At the time of presenting the above conference paper they were analysing the information and planning a report.

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 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

Folk.us

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

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

Useful information

and implementation reflects the concerns of ordinary folk.

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 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 information

Useful readings

Beresford, P. (2003). *It's Our Lives: A short theory of knowledge, distance and experience.* London: Citizen Press.

Peter is a service user and has a long history of doing user involvement work. He the Professor of Social Policy and a User/Researcher. He was a key person in the Shaping our Lives project that helped create a national network (see the case example in Unit 1: Part A). If you want to read a sample of his ideas go to this website:

http://www.shapingourlives.org.uk/Peter%20Beresford%20Presentation%20Launch.htm

Ease of reading: Good

You can contact Peter at:

Open Services Project, Tempo House,

15 Falcon Road, London. SW11 2PJ

Ph: 0207 228 0085

Email: peter.beresford@brunel.ac.uk

Useful information

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 you can be involved. If you go to the website you will find 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 very useful document for anyone who is involved in doing and disseminating research. It outlines the skills and abilities that users, carers and members of the public can bring to the review process and outlines the five main steps in disseminating a review.
>
> **Ease of reading**: Good

Useful information

Strategies for Living Project (2003). *Surviving user-led research: Reflections on supporting user-led research projects.* London: The Mental Health Foundation.

This report describes the realities of supporting user-led research as experienced by the Strategies for Living II team, at the Mental Health Foundation. It includes the achievements and challenges of this process in relation to issues of: power, roles and relationships, ethics, resources and training. The report also outlines the lessons learned from these experiences, using examples and stories to illustrate points, and includes tips and recommendations. It is intended as a valuable resource for anyone who has some familiarity with the field, and is considering carrying out or supporting user-led research.

Price £30 (£15 for service users): Pages 156

Available from: The Mental Health Foundation

83 Victoria Street, London SW1H 0HW

Telephone: 020 7802 0300

Email: mhf@mhf.org.uk

Ease of reading: Good

Useful information

Sources used for the material in this part

Baxter, L., Thorne, L. & Mitchell, A. (2001). *Small voices, big noises: Lay involvement in health research: lessons from other fields*. Exeter, UK: Washington Singer Press.

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

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

Epstein, M. & Shaw, J. (1997). *Developing effective consumer participation in mental health services: The report of the Lemon Tree Learning Project*. Melbourne: Victorian Mental Illness Awareness Council.

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

Useful information