

Part F

Disseminating research

A summary of Part F

Why is Part F important?

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.

What will participants learn by doing Part F?

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

- Understand what disseminating research means - Activity 1
- Understand what happens in the disseminating research stage - Activity 1 and 2
- Discuss the practical issues of user involvement when disseminating research - Activity 3

Skills participants will strengthen or develop

Skills that participants will strengthen or develop include:

- Level 2: Further practice with thinking about issues
- Level 2: Further practice with developing and presenting an argument
- Level 2: Further practice with speaking in large groups
- Level 2: Further practice with planning what to do next
- Level 3: Demonstrate ability to think about issues
- Level 3: Demonstrate ability to think about case examples

Background information

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

Issues in disseminating research

Disseminating research means getting the message about research and development projects and their outcomes out to people who need to know about it. When disseminating you need to think about methods, audience and levels of user involvement.

There are as many ways of disseminating research as there are ways of communicating with each other. They range from common or 'standard' ways such as writing reports, book chapters or articles for professional journals and magazines, to presenting at conferences and seminars. There are also more imaginative ways that can make the research and its outcomes easier to read or understand, so they are important to think about for user involvement. For example, they could range from: writing a leaflet or creating a poster that gives a summary of the project using words and pictures, through to running community forums, speaking at Patient Forums, user/carer

associations or self-help groups, creating a drama performance or using the media.

How you decide to disseminate the research and development outcomes will depend on who you think the audience is. The audience for research outcomes includes many groups of people. This is more than just health and social service staff and researchers, or users, carers and the public. It may include private companies, particular industries (restaurant/catering, mining, agricultural) or schools and childcare centres. You need to work out the audience depending on what the research and development project was about, and which people or groups you believe will be affected by it.

User involvement in disseminating research

A recent project identified, discussed and agreed on good principles and indicators of successful user involvement in research and development work.^{6,13} Several of them apply directly to disseminating research - see the table on the next page.

This work highlights some of the different ways that users, carers and the public can be involved in disseminating research. It also identifies the importance of thinking about your

audience and putting it in a form that they can use, such as other languages or communication systems (eg Braille).^{1,8}

Principle	Indicators
Researchers respect the differing skills, knowledge and experience of consumers	* The contribution of consumers skills, knowledge and experience were included in research reports and papers
Consumer involvement is described in research reports	* The involvement of consumers in research reports and publications was acknowledged * Details were given in research reports and publications of how consumers were involved in the research process
Research findings are available to consumers in formats and in language they can easily understand	* Research findings were disseminated to consumers involved in the research in appropriate formats (e.g. large print, translations, audio, Braille)

Here is a list of possible options:

- co-writing or independently writing drafts or final versions of documents
- reading and providing comments on drafts or final versions of the documents by writing a review or talking to the authors

- joining meetings or workshops to discuss the drafts of final versions with other people - including health and social service staff, researchers and other users, carers and the public - and how you want them to be disseminated
- co-presenting or presenting the outcomes at conferences, seminars, community forums or invited workshops
- talking on radio or appearing on TV alone or together with a health and social service staff researcher
- co-designing or designing posters
- co-developing or developing drama performances - possibly also being involved in performing them

Learning from experience

Not doing it well

Cath Roper is an Australian¹ who has a user consultant academic position at a university. She said:

"It is ironic that consumer participation, which holds involvement of consumers at its heart, is almost always written about, researched, run and controlled by

¹ The term 'consumer' is used in Australia, rather than user.

providers, academics and researchers, and not by consumers." (p.19)¹²

She speaks to the heart of an ongoing issue for user involvement in health and social services. Although interest in doing and evaluating user involvement work is growing, what is lagging behind is how often user consultants are involved in writing and reporting on user involvement work and to what level. She gave an example of an Australian project where users were included on the project reference group, helped develop interview guides, trained as interviewers and then conducted interviews.¹⁴ Roper commented that the "researchers regarded their own approach as being an embodiment of consumer participative principles" (p. 21).¹² However, all authors of the article were non-users so consumers' position and power in the process was limited when it came to the interpretation and reporting of the findings. No comment or attention was paid to this in the article - it was a 'non-issue.'

Doing it well

Fortunately this is beginning to change, especially since the late 1990s. The mental health sector has been one of the leaders in this area. An excellent example is from The Mental Health Foundation who has funded the Strategies for Living project

since 2000.⁷ It has supported many local user-led research projects around the UK. It funds them and provides training and resources on doing research, including a Do it Yourself, DIY Guide to Survivor Research. It also provides hands-on advice and support through every step of the project, including writing the reports, then publishes them on The Mental Health Foundation website: <http://www.mentalhealth.org.uk>

Users and carers have played a key role in all aspects of the project, including reporting and presenting the findings. Here are three examples (also used as case examples in this part):

- 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.¹⁰
- A group of mental health services users explored the impact of losing a 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.³

- 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.¹¹

Other examples are provided during Activity 2 and in the case example section. There is the work of SURE from the Institute of Psychiatry in London, which is a collaborative project between service user researchers and clinical academics aiming to involve service users in all aspects of research and development cycle. This includes disseminating outcomes of their research.

Suresearch is based at the University of Birmingham and is also a collaboration between user and carer researchers, academics and health and social service staff. They gain funding to run projects, and then write up reports and disseminate the results. They make sure that all user consultants are trained to carry out the different tasks they want to do.

There are other examples from outside the UK. An Australian group of child and adolescent mental health (CAMH) workers and consumers designed a research project on consumer's experiences of CAMH services from the ground up.⁴ They presented their work at conferences,⁹ including what it was like to be in the project, and published two articles in an international journal.^{4,5} One of the articles focused on what they learned about doing collaborative research and what needs to be dealt with if it is going to work well.⁴

Being realistic

All of these developments are very encouraging. However, Peter Beresford, a service user who has been at the forefront of user involvement work for several years, points out that we have to be careful to not overestimate the achievements. He speaks from experience in the mental health sector and asks:

“How can we make sure that user involvement in research is not tokenistic, as it often has been in mental health policy and practice: a tick-box exercise where mental health service users are merely used to legitimate traditional research approaches and agendas, and research funding continues to stay mainly with traditional stakeholders? How do we make sure that we

are not only involved in the generation of data but also its interpretation, ownership and follow-up action?"²

Being involved in dissemination increases users, carers and the public's ownership of research, and recommending and advocating for the follow-up action that is needed.

References

1. 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.
2. Beresford, P. (2002). Turning the tables. *Openmind*, 116, July/August.
3. Bodman, R., Davies, R., Frankel, N., Minton, L., Mitchell, L., Pacé, C., Sayers, R., Tibbs, N., Tovey, Z. & Unger, E. (2003). *Life's labours lost: A study of the experiences of people who have lost their occupation following mental health problems*. The Mental Health Foundation: London. Available online at:
<http://www.mentalhealth.org.uk/page.cfm?pagecode=PBBR MH#lost>

4. Byas, A., Hills, D., Meech, C. Read, L., Stacey, K., Thompson, E. & Wood, A. (2002). Co-researching consumer experiences of child and adolescent mental health services: Reflections and implications. *Families, Systems & Health: The Journal of Collaborative Family Health Care*, 20(1), 75-89.
5. Byas, A., Hills, D., Meech, C. Read, L., Stacey, K., Presland, E. & Wood, A. (2003). From the ground up: Collaborative research in child and adolescent mental health services. *Families, Systems & Health: The Journal of Collaborative Family Health Care*, 21(4), 397-413
6. Cooper, C., Telford, R. & Boote, J. (2003) Developing principles and indicators of successful consumer involvement in NHS research: Results of a consensus study. *Research for Health in Primary Care: Reality, Impact and Future Conference*. Fielder Centre, University of Hertfordshire, May 21st-22nd, 2003.
7. Faulkner, A. & Layzell, S. (2000). *Strategies for Living: A report of user-led research into peoples' strategies for living with mental distress*. The Mental Health Foundation: London. Summary available online at:

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

8. Hanley, B., Bradburn, J., Gorin, S., Barnes, M., Evans, C., Goodare, H., Kelson, M., Kent, A., Oliver, S. & Wallcraft, J. (2003). *Involving the public in NHS, public health and social care: Briefing notes for researchers (2nd edition)*. Winchester: INVOLVE (Consumers in NHS Research Support Unit). Available online at:
<http://www.invo.org.uk/pub.htm>
9. Hills, D., Stacey, K. & Thompson, E. (1998). *Collaborative Research in Action*. Paper presented at the 3rd National Child & Adolescent Mental Health Conference, Sydney, Australia.
10. Jenkins, L. (2003). *The 'ups and downs' of bipolar carers: An investigation into the coping strategies and needs of bipolar carers*. The Mental Health Foundation: London. Available online at:
<http://www.mentalhealth.org.uk/page.cfm?pagecode=PBBR MH#bipolar>

11. Nicholls, V. (2003). Getting together in Northern Ireland. *Strategies for Living Newsletter*, 19(Summer), 2. Available online at:
http://www.mentalhealth.org.uk/html/content/s4newsletter_jun03.pdf
12. Roper, C. (2003). Consumer participation in mental health: We want it! *Health Issues*, 74(March), 19-22.
13. Telford, R., Boote, J. & Cooper, C. (2003). What makes consumer involvement in research successful? Towards a consensus. *Consumers in NHS Research: Making a difference Conference*. Harrogate International Conference Centre, November 7th, 2002.
14. Tobin, M., Chen, L. & Leathley, C. (2002). Consumer participation in mental health services: Who wants it and why?' *Australian Health Review*, 25(3), 91-100.

Activity 1

What does disseminating 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 + disseminating practice large group discussion
- Small group discussion + mini-presentation + disseminating practice small group discussion

Things to get ready

- Print the Unit 5 - Part F PowerPoint files 1A - 1I 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

Activity Option 1

Large group discussion - Existing knowledge of disseminating 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 disseminating 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?
 - * What did they do with your ideas?
 - * What feedback did you get about the final document?
- Encourage other participants to ask questions about the process and discuss the issues being raised
- If needed tell participants that disseminating research is when users, carers and the public are asked to help get the research outcomes out to people who need to know about them through writing or speaking about them

Activity Option 2

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

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

- Divide people into groups of 3-4. Give them a few minutes to think about and discuss this question
 - * What do you think happens if you are involved in disseminating the outcomes of a research and development project?
 - * 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 disseminating research is when users, carers and the public are asked to help get the research outcomes out to people who need to know about them through writing or speaking about them

Activity Option 3

OVERHEADS 1A - 1I

Mini-presentation - What does disseminating research mean? What happens in this stage? (15 minutes)

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

- What does disseminating research mean?
- Who is involved in disseminating research?
- Why is this stage of the research and development cycle important?
- During or after the mini-presentation facilitate further discussion as needed

Activity Option 4

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

The purpose of the disseminating research practice large 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 want to do research - for this activity they need to imagine that they **did** do the project and they now want to disseminate the outcomes
- Do a quick vote of hands for which two areas the group would like to use for the exercise
- For each topic go through the three main issues to consider when disseminating (leave the slides up from the mini-presentation to assist):
 - * Audience: Who do they need to reach? Who needs to know?
 - * Methods: In how many different ways will they get the message out? Which methods will they choose for the different audiences? Why are they doing it that way?
 - * Level of user involvement: What tasks would you want to take on? What support would you want or need to do this?

- Encourage participants to give good reasons for their suggestions - just as if they were developing and presenting and argument to a research group
- Point out that if you were doing this in reality then you would spend more time discussing these issues than you will today.
- Facilitate further discussion as needed

Activity Option 5

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

The purpose of the disseminating 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 want to do research - for this activity they need to imagine that they did do the project and they now want to disseminate the outcomes
- Do a quick vote of hands for which 3 areas the group would like to use for the exercise
- Ask them to divide into 3 smaller groups, one for each area - they will go through the three main issues to consider when disseminating (leave the slides up from the mini-presentation)

to assist):

- * Audience: Who do they need to reach? Who needs to know?
- * Methods: In how many different ways will they get the message out? Which methods will they choose for the different audiences? Why are they doing it that way?
- * Level of user involvement: What tasks would you want to take on? What support would you want or need to do this?
- 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
- After 15-20 minutes ask people to return to the large group and listen to each group's dissemination plans
- Point out that if you were doing this in reality then you would spend more time discussing these issues than you will today.
- Facilitate further discussion as needed

Activity 2

Examples of user involvement in disseminating 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 F PowerPoint files 2A - 2D 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 look up the Internet links for the case examples (listed in the case example section at the end of this part) and print off copies of them where possible. Further instructions are given in the 'Trainer Notes' section of the PowerPoint slides. You need at least 3 actual examples - preferably different ones. Feel free to choose others that you know from personal knowledge or involvement

- If you choose Activity Option 2 you will need to identify an appropriate presenter who can bring in and discuss current examples of user involvement in disseminating research - meet with them to ensure they understand the task and prepare anything that they need

Activity Option 1

OVERHEADS 2A - 2D

Mini-presentation and case example analysis - Analysing case examples of user involvement in disseminating 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 different case examples
- Once you have presented the case examples, give out the three or four actual examples of the reports, newsletter articles, conference papers, etc
- Ask participants to divide into three or four groups - the same number as your examples

- Each group will look through the example and discuss the following things
 - * How user-friendly do you find the example?
 - * What do you like or not like about it?
 - * If you were one of the user consultants involved, what role could you imagine yourself playing in creating this example?
 - * What support do you think you would need to do that?
- 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 work together and be available to answer questions as needed
- After 20 minutes ask people to return to the large group and listen to each group's comments on their dissemination examples
- Facilitate further discussion as needed

Activity Option 2

OVERHEADS provided by guest presenter

Guest presentation and large group discussion - Analysing case examples of user involvement in disseminating 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 disseminating research
- Roles of user consultants, support provided and level of involvement in decision making for user consultants
- What has been learned from user involvement in the disseminating stage - 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 3

What could user involvement in disseminating 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 F PowerPoint files 3A - 3B in 'note pages' for you and, where appropriate, 'handouts' (two slides/page) of the presentation material for participants
- Whiteboard and coloured whiteboard markers
- Flipchart paper and markers

Activity Option 1

OVERHEADS 3A - 3B

Mini-presentation - Review practical issues in user involvement work (5-10 minutes)

The purpose of the mini-presentation is to build on knowledge and support skills in thinking about issues. Cover these areas using the PowerPoint slides:

- Review the practical issues that are important to think and ask about before taking on user involvement work

TOP TIP

If this group has done Core 2 - Unit 2: Part C then they have covered this material. Remind them that they have already discussed these issues. If the group has not done this part of the training, it may be useful to go back and do Activity 1 and 2 with them first.

Activity Option 2

Large group discussion - Plans for dealing with practical issues (30 minutes)

The purpose of the large group discussion is to demonstrate skills in thinking about issues and practice planning what to do next:

- As a large group go through the 15 points in the mini-presentation **one at a time** using the following steps
- On the whiteboard draw a picture of a hot air balloon with a basket at the bottom
- Ask participants to name any practical issues that would concern people if they were involved in disseminating 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 disseminating 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

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 disseminating 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 disseminating research

- 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 thinking about issues and practice planning what to do next:

- As a large group, go through the 15 points in the mini-presentation **one at a time** doing a values walk for each one based on a 'situation statement' that you create and read out
- For example, for 'mentoring' the statement could be: "You have agreed to write up a part of a research project that you have designed and done with other user consultants as a research group. The group organise for you to be linked to an

experienced researcher, who is also a user, who is happy to be your mentor."

- 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 F.

Learning from examples

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

They will review the practical issues in disseminating research discussed in Activity 3 and answer these questions:

- Identify which of the issues are of most concern to them: Do they have enough ideas about how to deal with these concerns? If no, they will identify who can discuss these issues with them further and help them plan action steps.

Case examples

1. 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.

- 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.

2. The Alzheimer's Society

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

Tel: 0191 223 2830

Alzheimer's Society

Gordon House, 10 Greencoat Place

London, SW1P 1PH

Tel: 020 7306 0606

The Alzheimer's Society is a user and carer non-government support organisation. It has created a consumer network to lead its research program called the Quality Research in Dementia (QRD) 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. They produce a monthly QRD Newsletter, which has many examples of progress reports or summaries of research they commissioned and are involved in disseminating. Take note of the 'bumper research issues.' Here is the link: <http://www.qrd.alzheimers.org.uk/newsletters.htm>

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 users in all aspects of research. It is located in the Health Services Research Department at the Institute of Psychiatry in London. 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.

If you click on the link above, you will find their research work listed on the top right-hand side of the page. Click on 'Research' to find out about their approach to research and their future projects. Click on one of the project names directly under 'Research' and you can read a summary about the progress of each of these projects. For example, there is one on young people, mental health and primary care located at:

<http://www.iop.kcl.ac.uk/iopweb/departments/home/default.aspx?locator=569>

4. 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

- 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.

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

and implementation reflects the concerns of ordinary folk.

Ease of reading: Good

Useful readings

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

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.

Beresford, P. (2002). Turning the tables. *Openmind*, 116, July/August.

Bodman, R., Davies, R., Frankel, N., Minton, L., Mitchell, L., Pacé, C., Sayers, R., Tibbs, N., Tovey, Z. & Unger, E. (2003). *Life's labours lost: A study of the experiences of people who have lost their occupation following mental health problems*. The Mental Health Foundation: London. Available online at:

<http://www.mentalhealth.org.uk/page.cfm?pagecode=PBBRMH#lost>

Bowl, R. (1996). Involving service user consultants in mental health services: Social Services Departments and the National Health Service and Community Care Act 1990, *Journal of Mental Health* 5(3), 287-303.

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

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/>

Entwistle, V., Renfrew, M., Yearley, S., Forrester, J. & Lamont, T. (1998). Lay perspectives: Advantages for health research. *British Medical Journal*, 316, 463-466.

Epstein, M. & Wadsworth, Y. (1996). *Understanding and involvement: Consumer evaluation of acute psychiatric hospital practice - A project unfolds*. Melbourne: Victorian Mental Illness Awareness Council.

Hanley, B. (1999). *Involvement Works: The second report of the Standing Group on Consumers in NHS Research*. Winchester: Consumers in NHS Research Support Unit. Available online at: <http://www.invo.org.uk/pub.htm>

Hanley, B. (2000). *Working partnerships: Consumers in NHS Research third annual report*. Winchester: Consumers in NHS Research Support Unit. Available online at: <http://www.invo.org.uk/pub.htm>

Jenkins, L. (2003). *The 'ups and downs' of bipolar carers: An investigation into the coping strategies and needs of bipolar carers*. The Mental Health Foundation: London. Available online at: <http://www.mentalhealth.org.uk/page.cfm?pagecode=PBBRMH#bipolar>

Macaulay, A., Commanda, L., Freeman, W., Gibson, N., McCabe, M., Robbins, C. & Twohig, P. (1999). Participatory research maximises community and lay involvement. *British Medical Journal*, 319: 774-778.

Nicholls, V. (2003). Getting together in Northern Ireland. *Strategies for Living Newsletter*, 19(Summer), 2. Available online at:

http://www.mentalhealth.org.uk/html/content/s4newsletter_jun03.pdf

Oliver, S. (1999). Users of health services: Following their agenda (pp. 139-153). In S. Hood, B. Mayall & S. Oliver, *Critical issues in social research: Power and prejudice*. Open University Press: Buckingham.

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>