

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. You will learn about the details of this stage and analyse real examples. You will also consider the practical issues of user involvement in disseminating research to help you decide if this work interests you.

What will you learn by doing Part F?

At the end of this part you 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 you will strengthen or develop

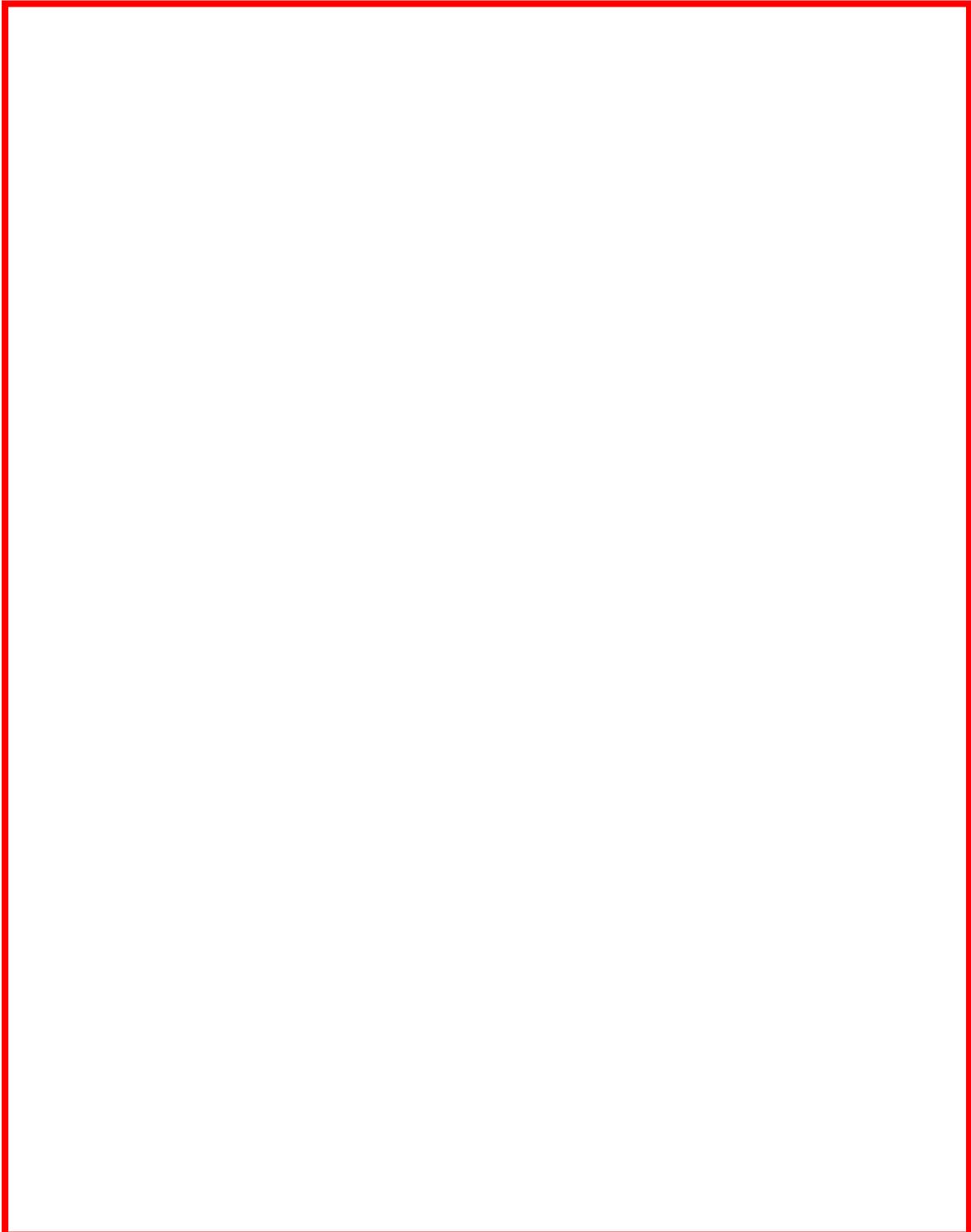
Skills that you will strengthen or develop include:

- Level 2: Further practice with thinking about issues
- Level 2: Further practice with 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

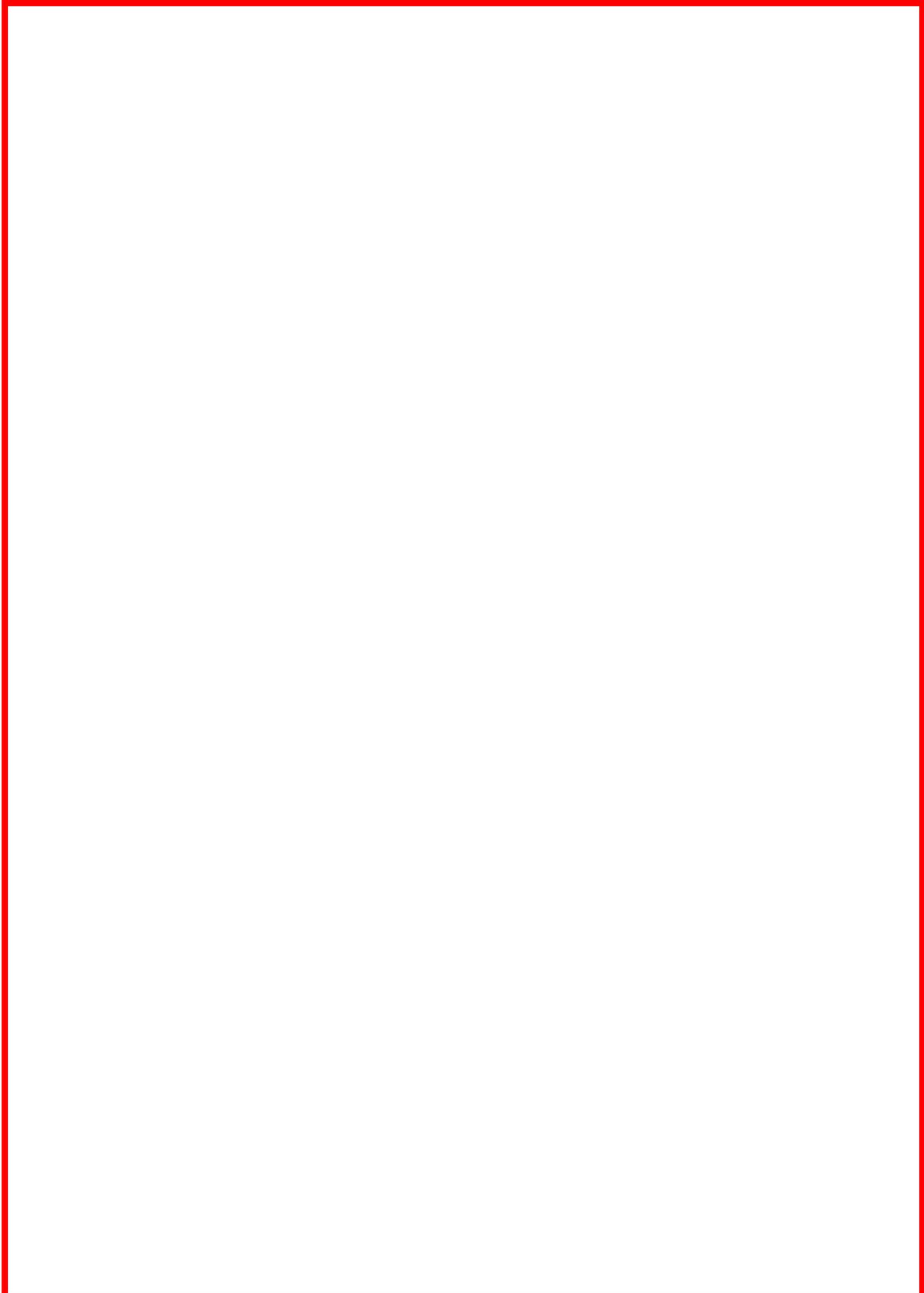
Activity 1

What does disseminating research mean?

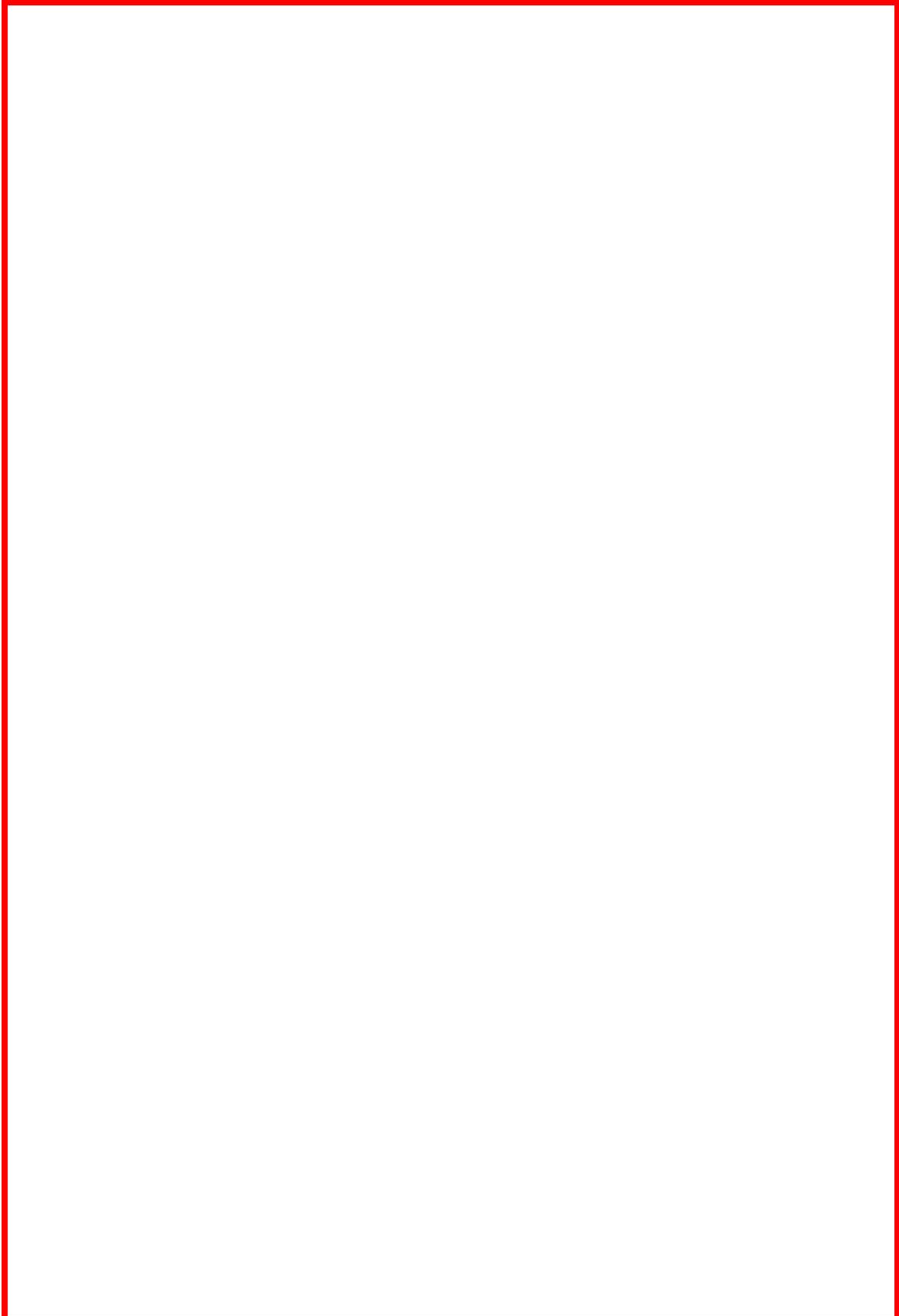
Existing knowledge of disseminating research



What does disseminating research mean? What happens in this stage?



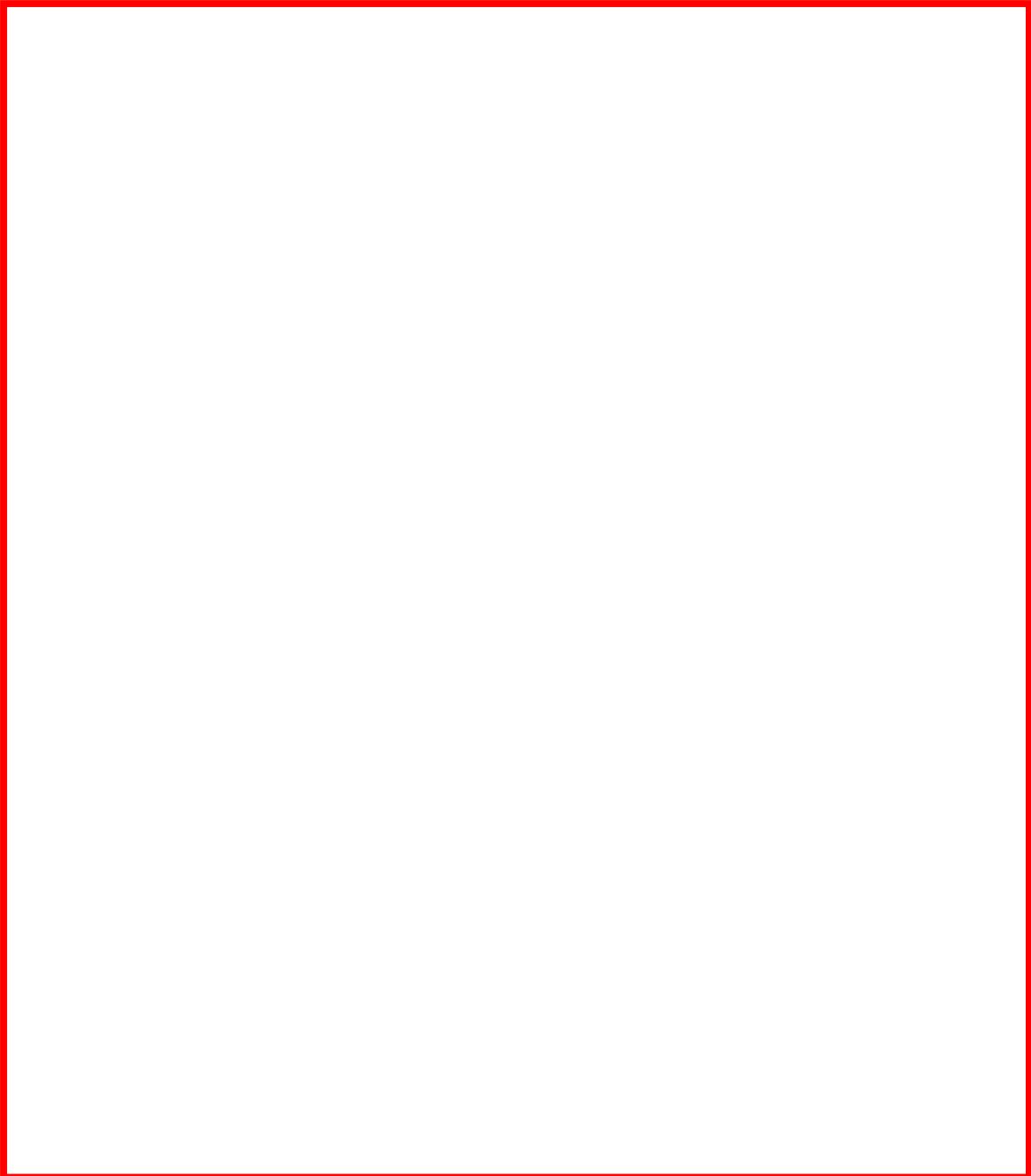
Disseminating research practice



Activity 2

Examples of user involvement in disseminating research

Analysing case examples of user involvement in disseminating research



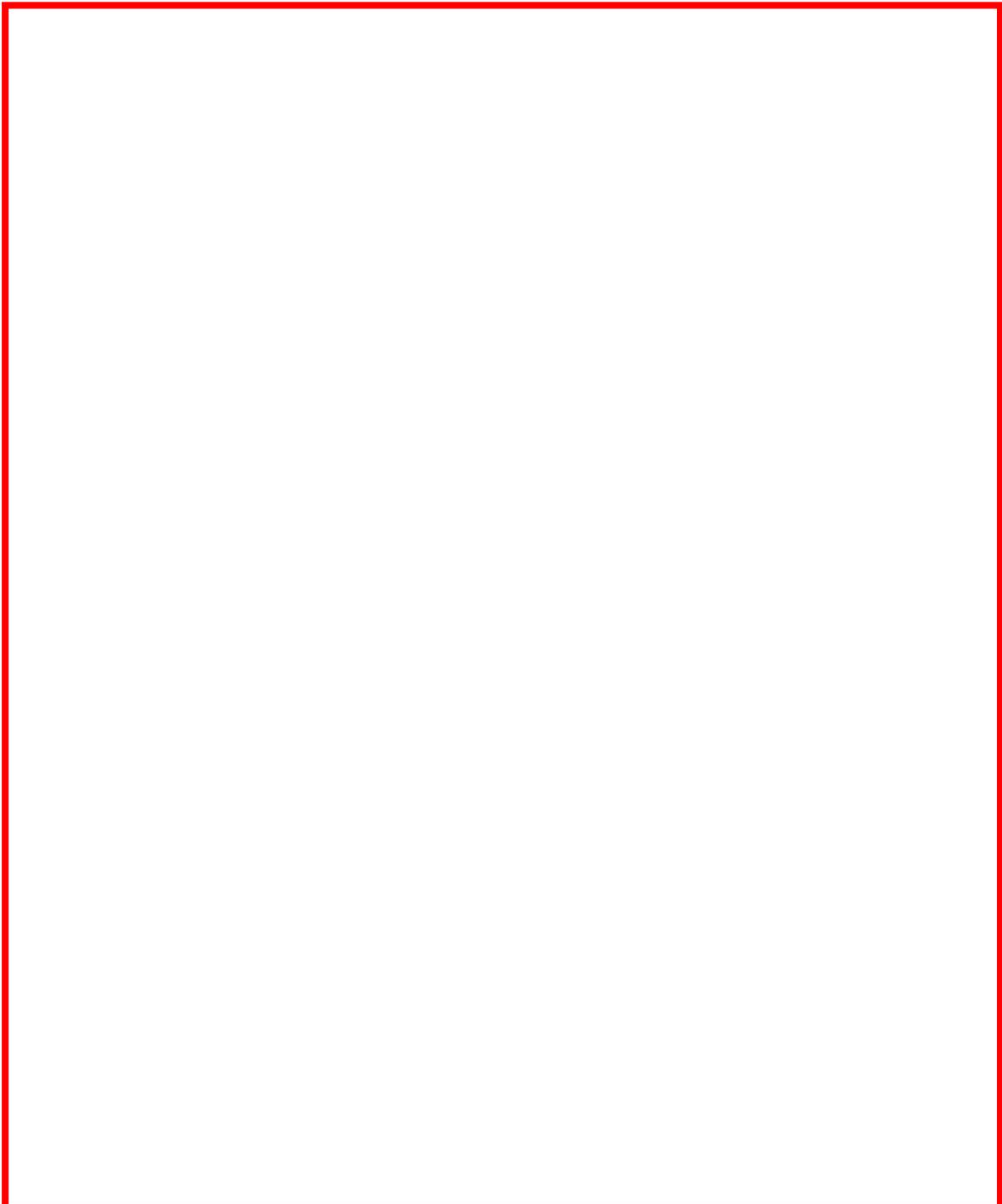


Activities

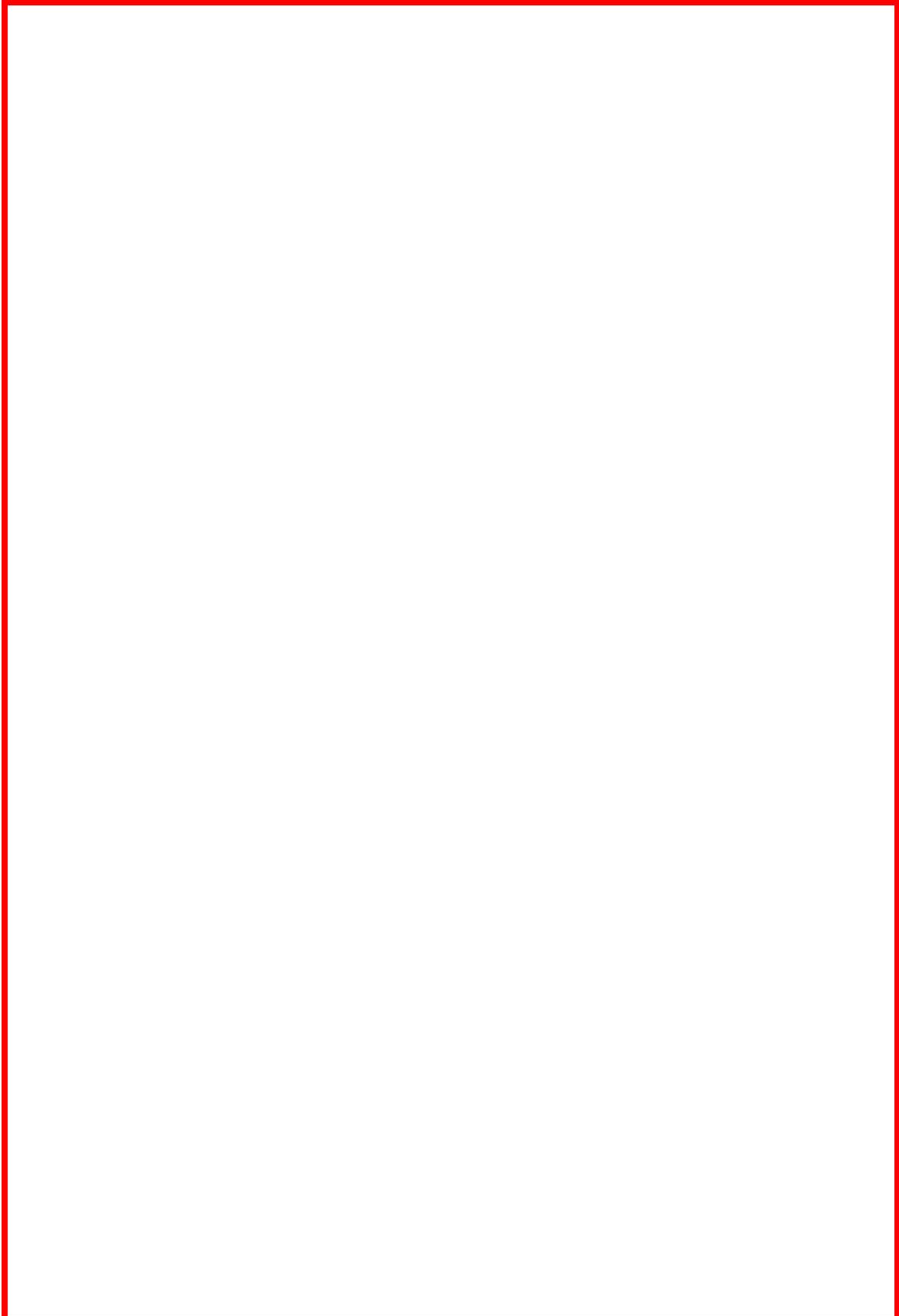
Activity 3

What could user involvement in disseminating research mean for you?

Review practical issues in user involvement work



Plans for dealing with practical issues



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 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

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>