

Part D

Doing research

A summary of Part D

Why is Part D important?

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. You will see these issues in action through analysing real examples. You will also consider the practical issues of user involvement in doing research to help you decide if you would like to do this work.

What will you learn by doing Part D?

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

- Understand what doing research means - Activity 1
- Understand what happens in the doing research stage - Activity 1 and 3
- Discuss the role and responsibilities of researchers - Activity 2
- Discuss the practical issues of user involvement when doing research - Activity 4

Skills you will strengthen or develop

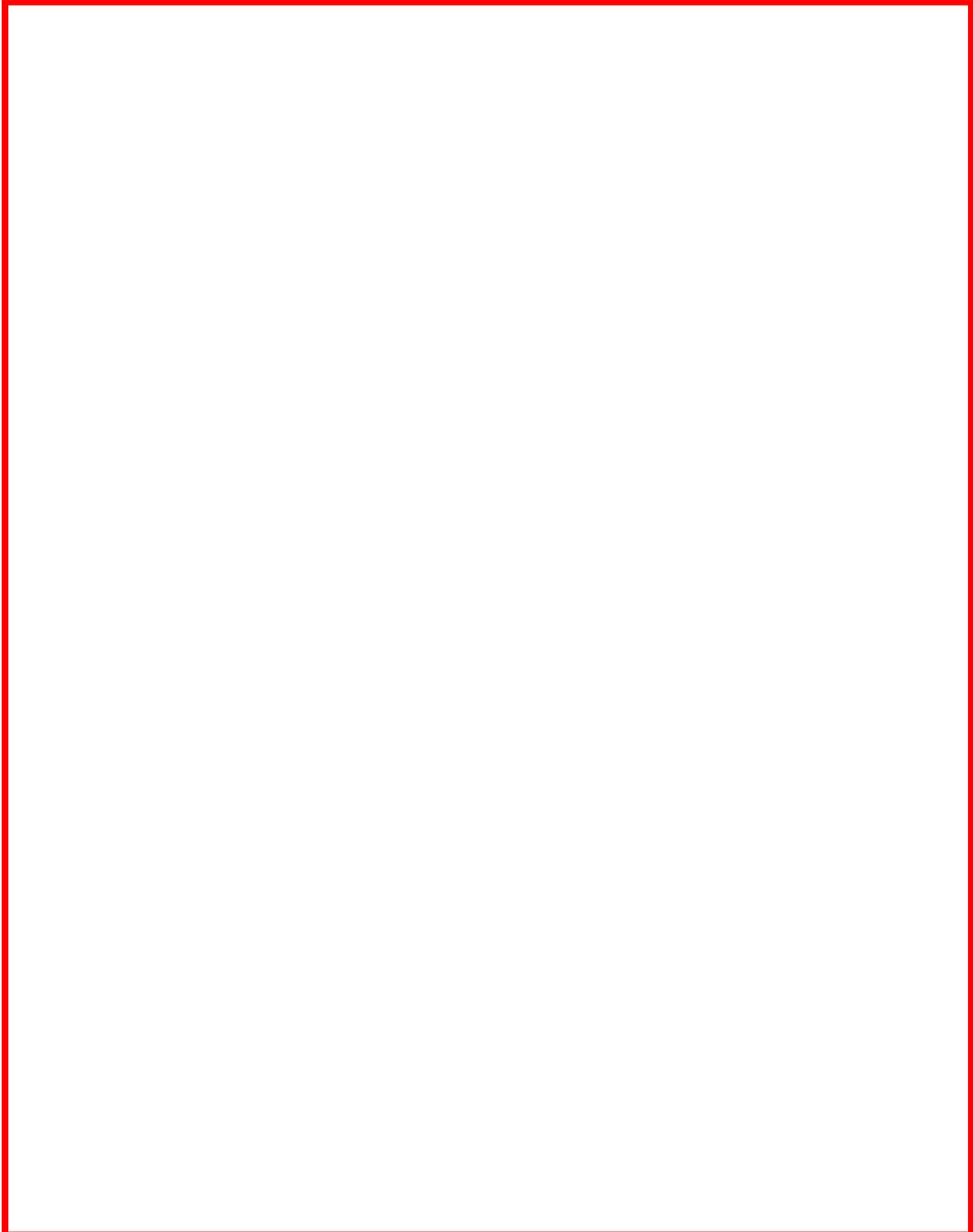
Skills that you will strengthen or develop include:

- 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

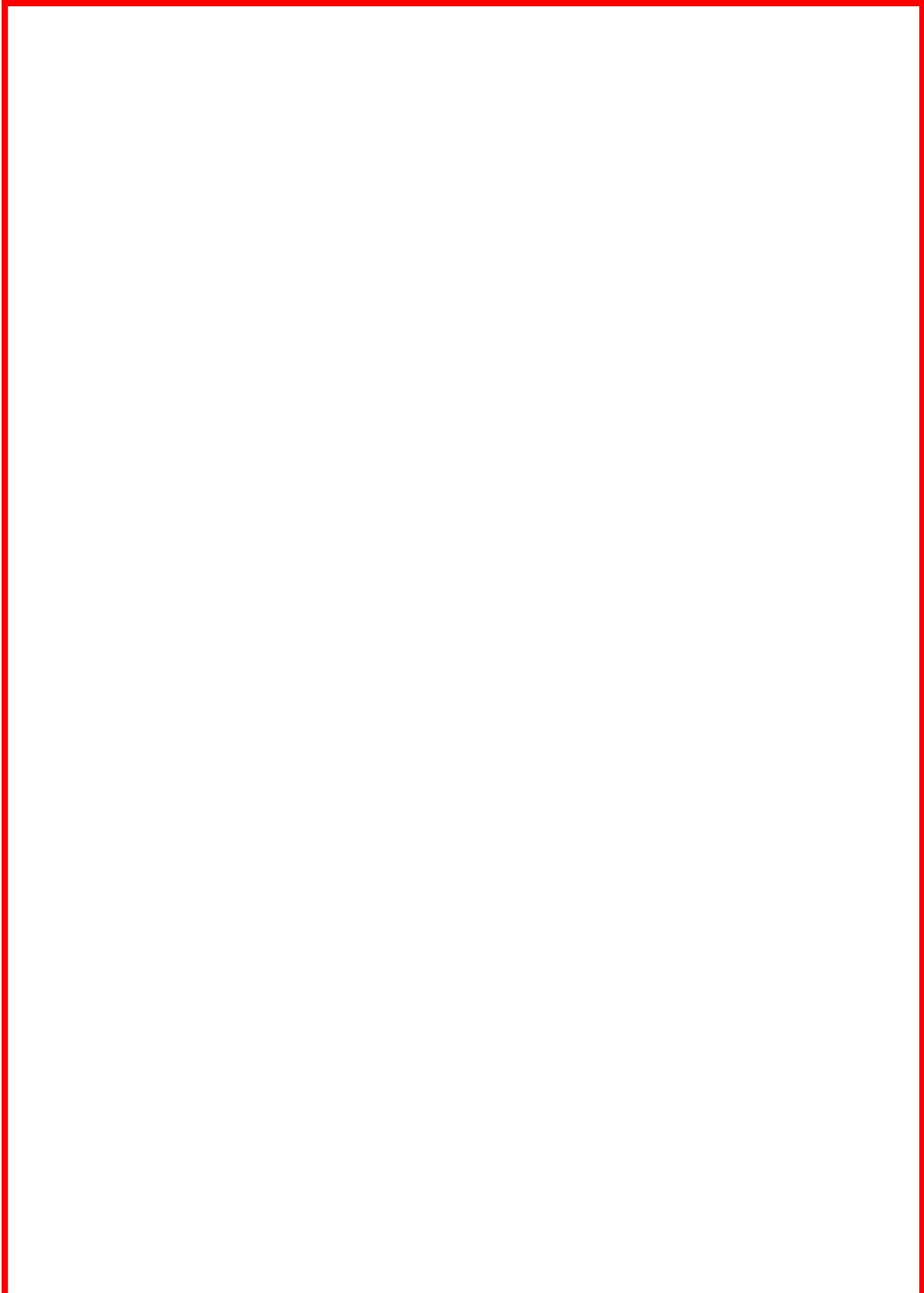
Activity 1

What does doing research mean?

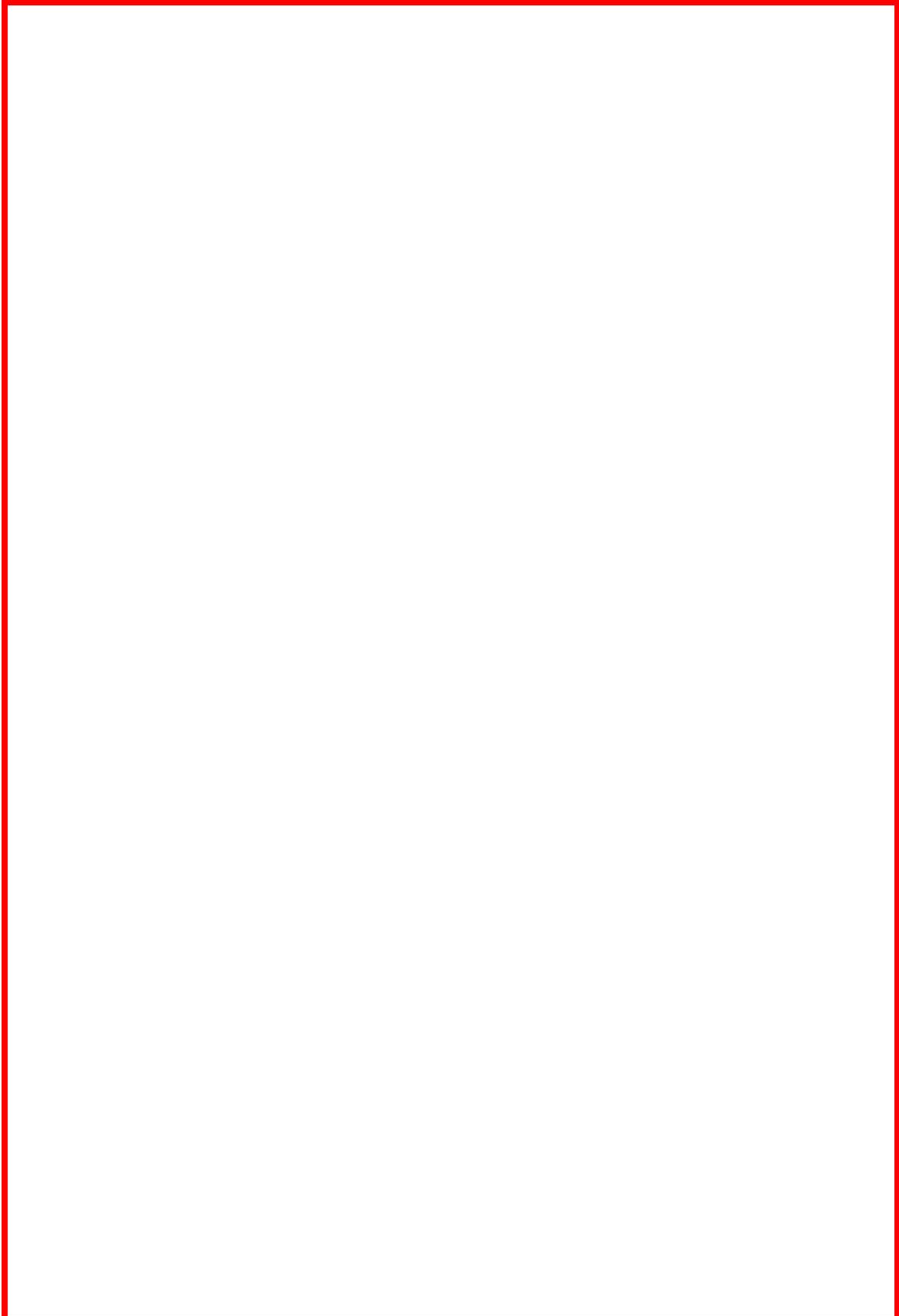
Existing knowledge in doing research



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



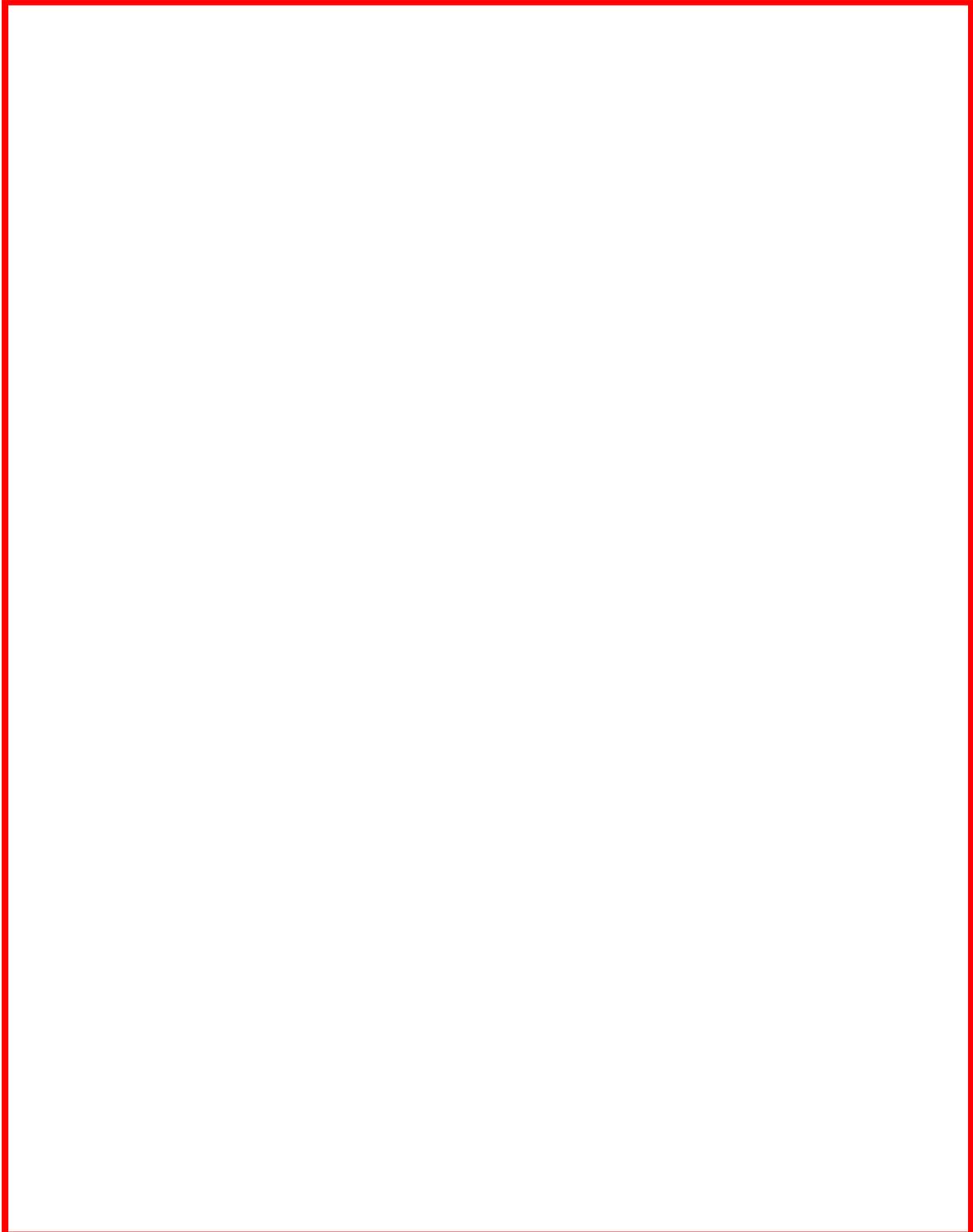
Doing research practice



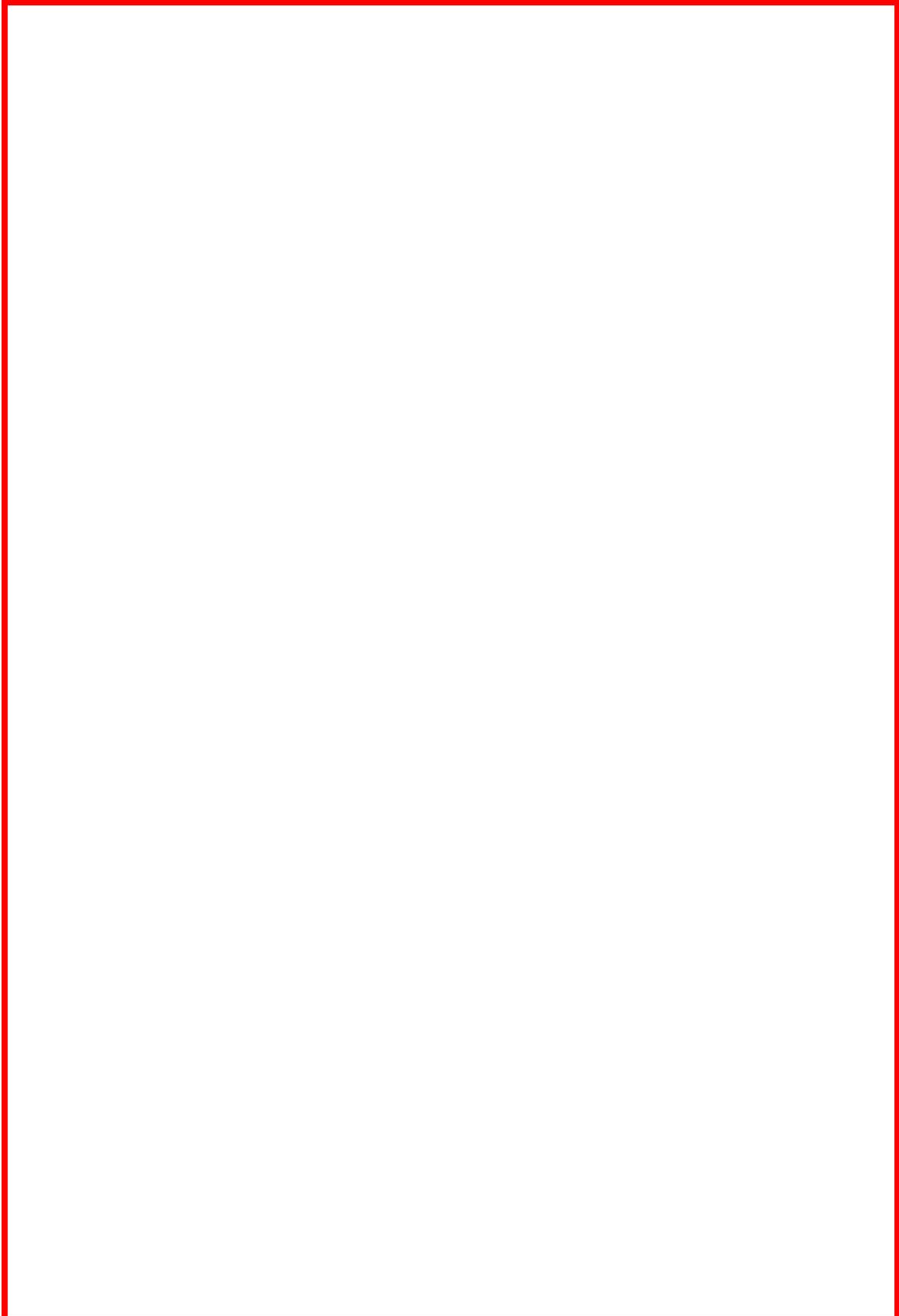
Activity 2

Being a researcher

Being a researcher



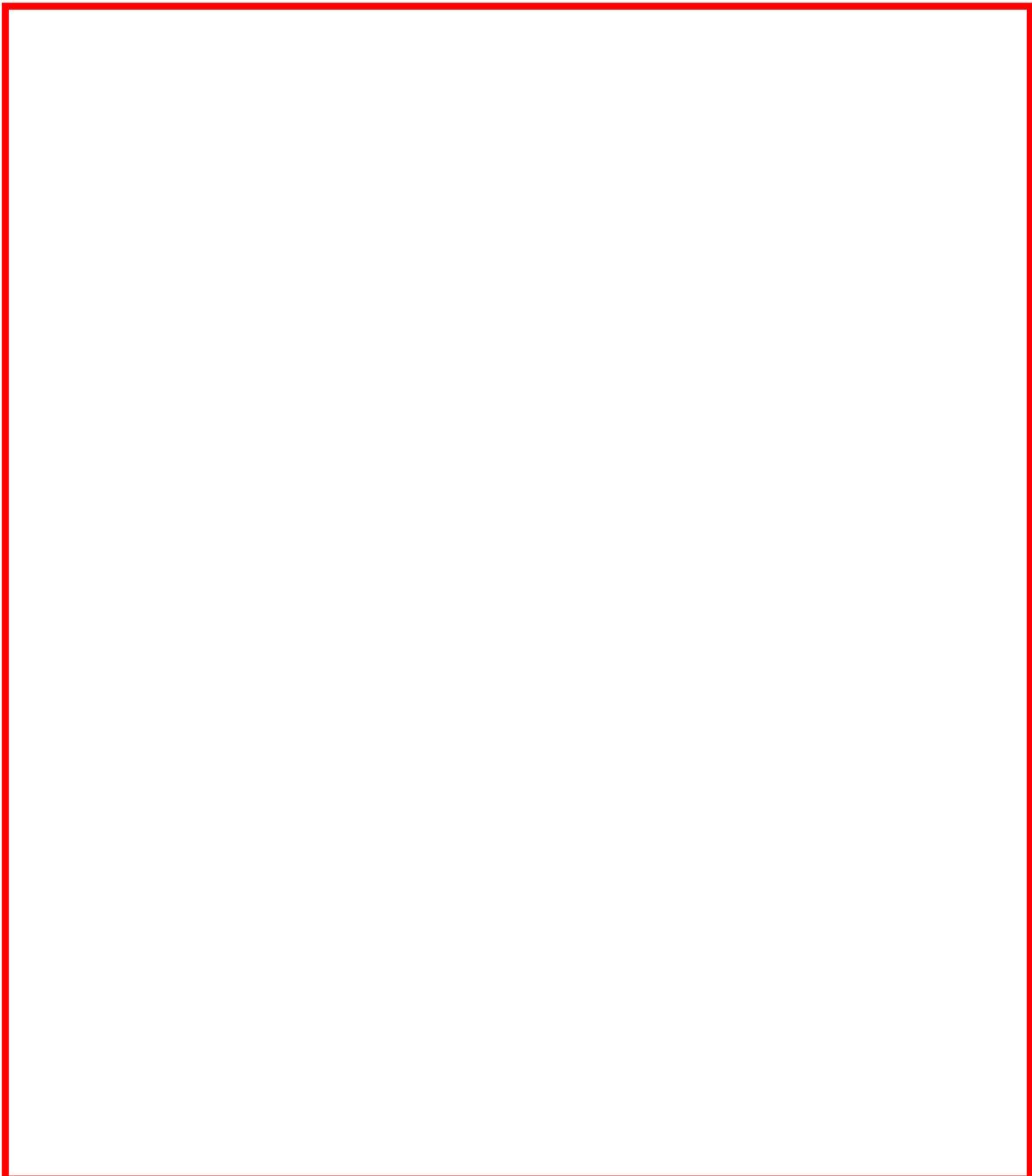
Following ethical principles

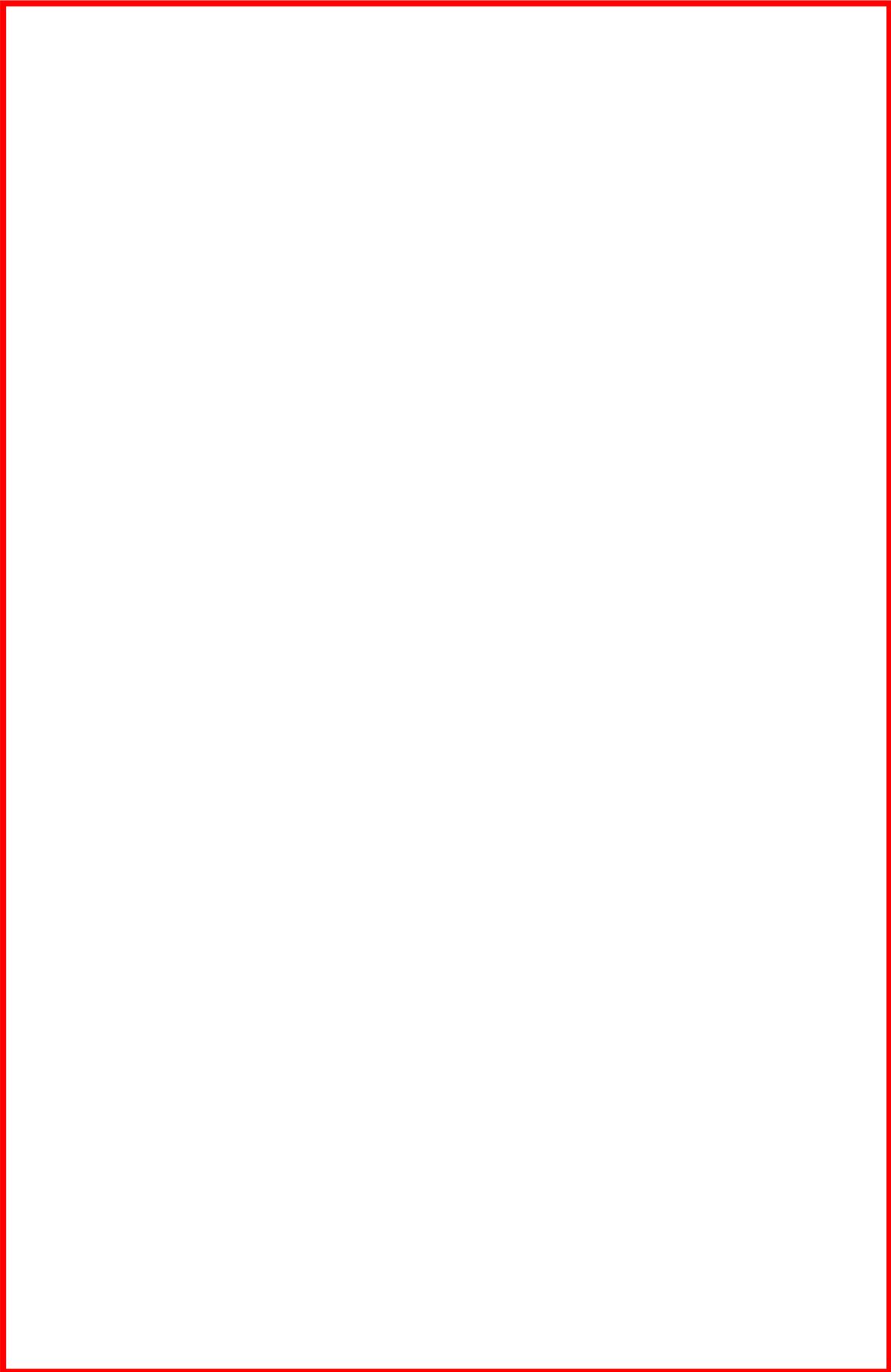


Activity 3

Examples of user involvement in doing research

Analysing case examples of user involvement in doing research



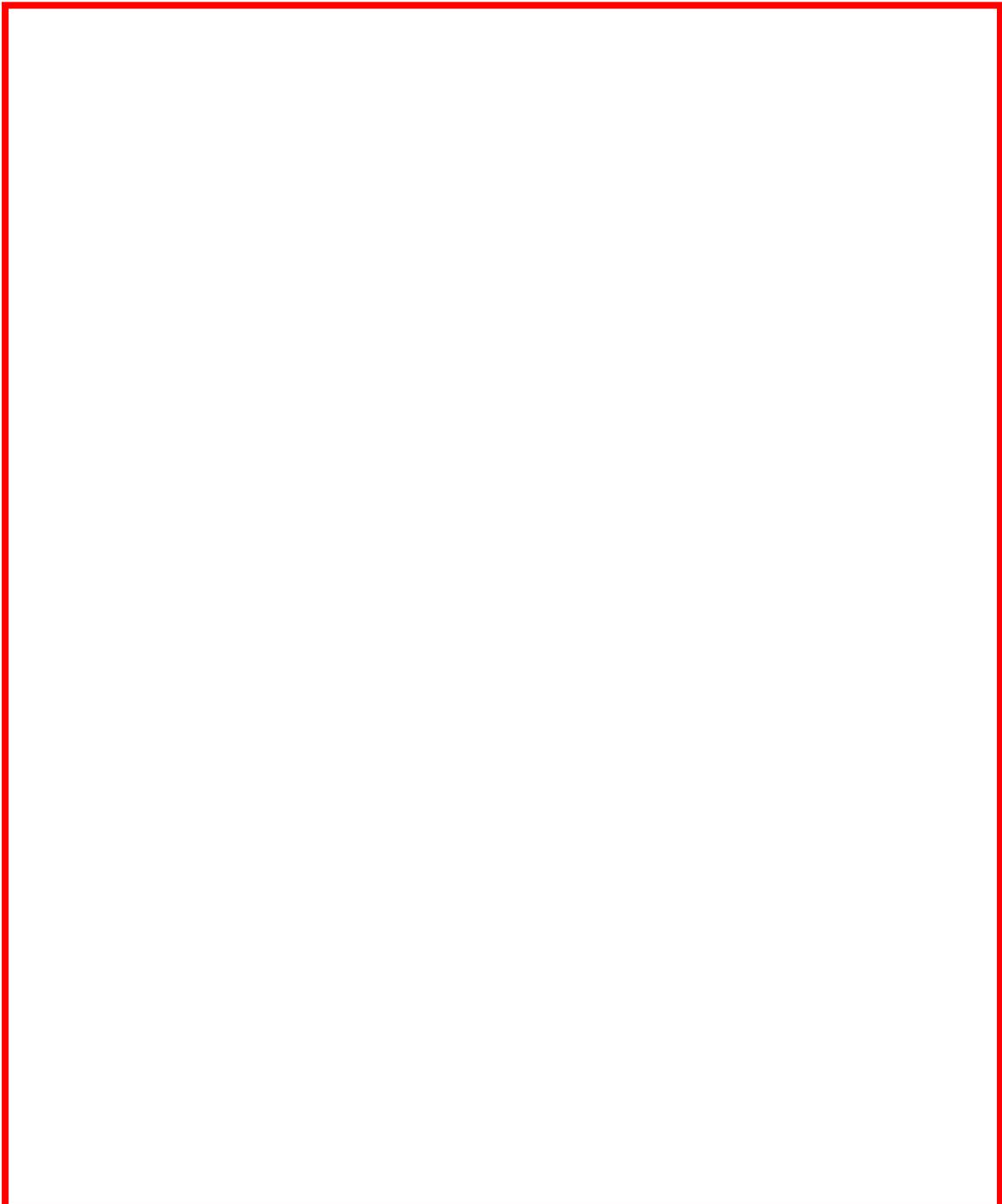


Activities

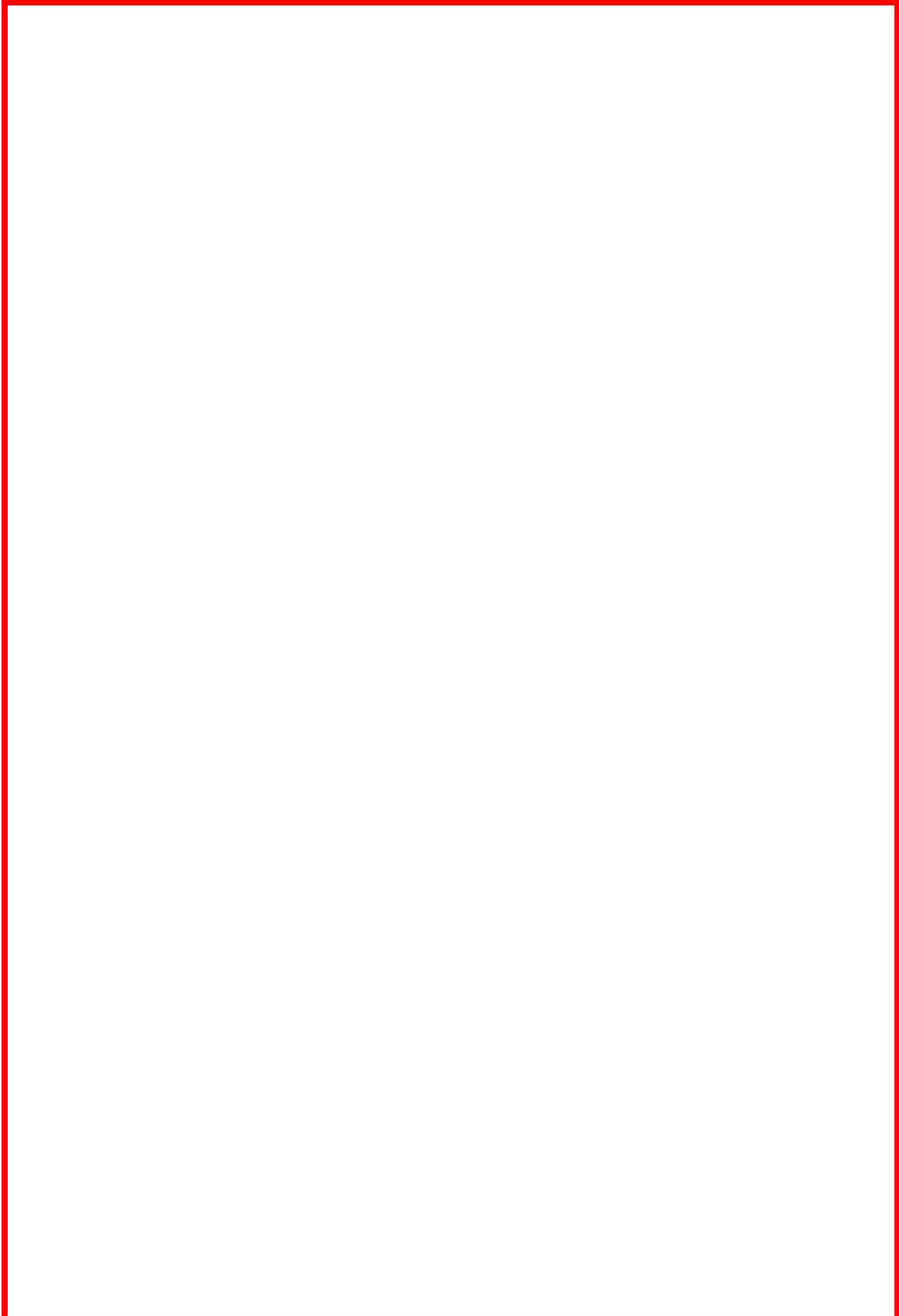
Activity 4

What could user involvement in doing research mean for you?

Review practical issues in user involvement work



Plans for dealing with practical issues



Case examples

1. Involving peer interviewers in qualitative research with hard-to-reach populations

Elliott, E., Watson, A. & Harries, U. (2002). Harnessing expertise: Involving peer interviewers in qualitative research with hard-to-reach populations. *Health Expectations*, 5, 172-178.

This research team employed and worked with users to do interviews with people who use and misuse illegal drugs. As this is a very sensitive issue, the involvement of previous drug users was valuable in getting people to be interviewed and in understanding the range of issues that they face. The user consultants helped plan the interviews, found people to be in the research, did many of the interviews and helped analyse the interview information. The paper describes the benefits and challenges in the research, including how researchers learned to work effectively with peer interviewers.

2. Suresearch

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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.

3. SURE: Service User Research Network

SURE

P034

Institute of Psychiatry

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London SE5 8AF

Telephone: 0207 848 5104

<http://www.iop.kcl.ac.uk/iopweb/departments/home/default.aspx?locator=300>

Established in 2001, SURE is a collaborative project between service user researchers and clinical academics aiming to involve service users in all aspects of research. It is located in the Health Services Research Department at the Institute of Psychiatry. User perspective is central to all of its work and almost all of its staff have been or are service users.

SURE is committed to the involvement of service users in the whole research process: from design to data collection and data analysis to dissemination. At a local level, SURE supports the Consumer Research Advisory Group (CRAG). This group of 12 local service users sends two representatives to the South London and Maudsley Trust, Institute of Psychiatry Research

and Development Steering Group. They have run research skills training courses for local service users.

SURE's national project on Consumers' Perspectives on Electroconvulsive Therapy influenced the new NICE guidelines on ECT. They are building user involvement capacity by registering service user researchers for higher degrees so they can gain relevant qualifications. They organise a weekly 'SURE Clinic' where academics in the Institute can come for advice on how to involve service users in their research projects. SURE publishes papers on collaborative research, including its pitfalls, and on its specific projects.

(Also see the two references by Debra Rose listed under the 'Sources used for the material in this part' in the Useful Information section.)

4. 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.

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 services 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 meaningfully controlled and influenced by service users, disabled people and informal

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

Ease of reading: Good

Consumers for ethics in research (CERES)

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

Or contact at: PO Box 1365, London N16 0BW

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

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 readings

Hanley, B. (1999). *Research and development in the NHS: How can you make a difference?* Winchester: INVOLVE (Consumers in NHS Research Support Unit). Available 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 useful document for anyone who wants to get involved with doing research. It gives examples of what has been learned from projects where user involvement happens. It describes what happens in a research project and what things you need to think about if you do get involved.

Ease of reading: Good

Sources used for the material in this part

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