

Part E

Managing research

A summary of Part E

Why is Part E important?

In the NHS, all research and development must be managed. During this stage of the research cycle a number of procedures take place:

- The research will be subject to external and internal peer review
- The research will be approved and registered within the trust's research and development department
- 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 you will learn about the details of this stage and analyse real examples. You will also consider the practical issues of user involvement in managing research to help you decide if you would like to do this work.

What will you learn by doing Part E?

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

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

Skills you will strengthen or develop

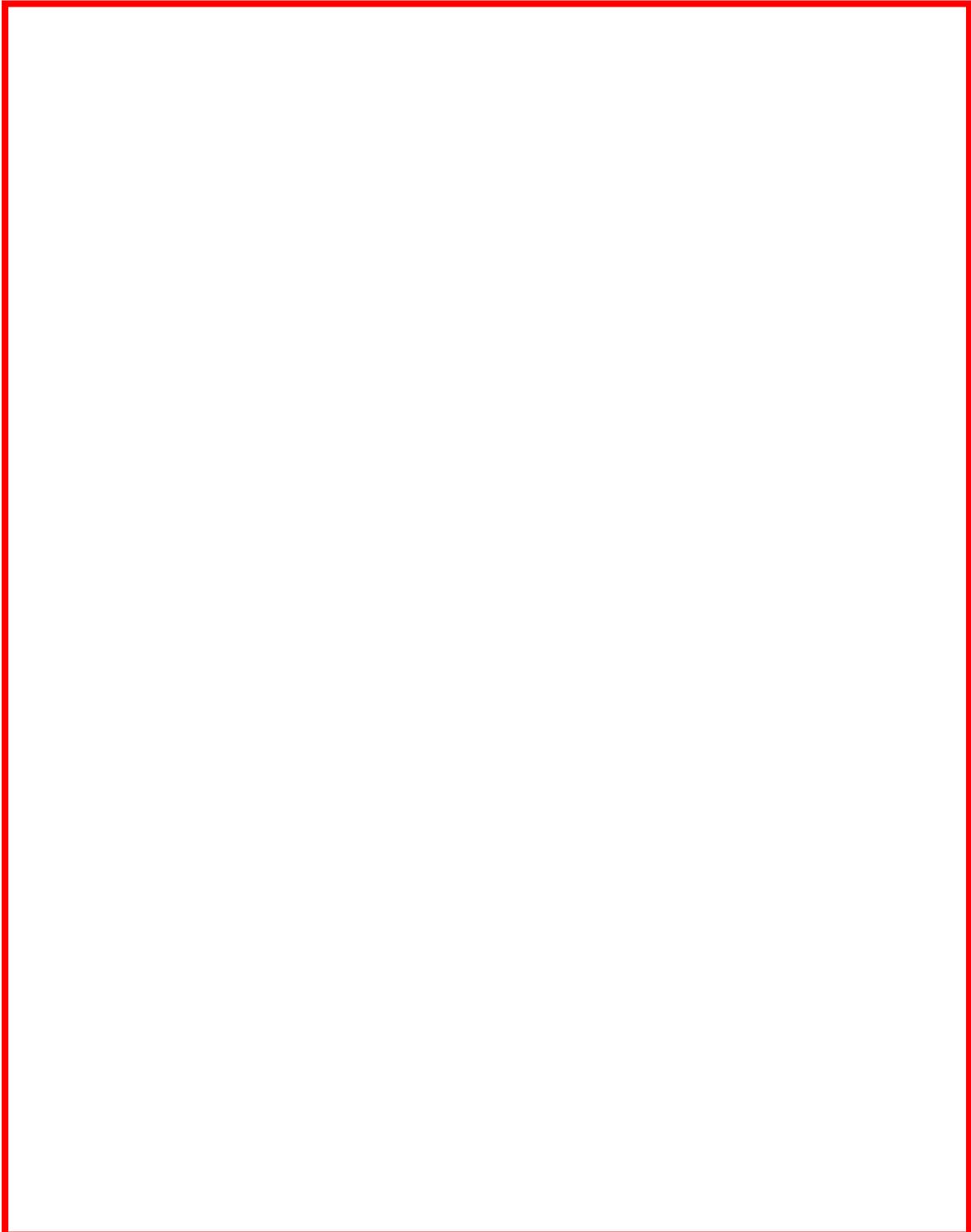
Skills that you will strengthen or develop include:

- 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

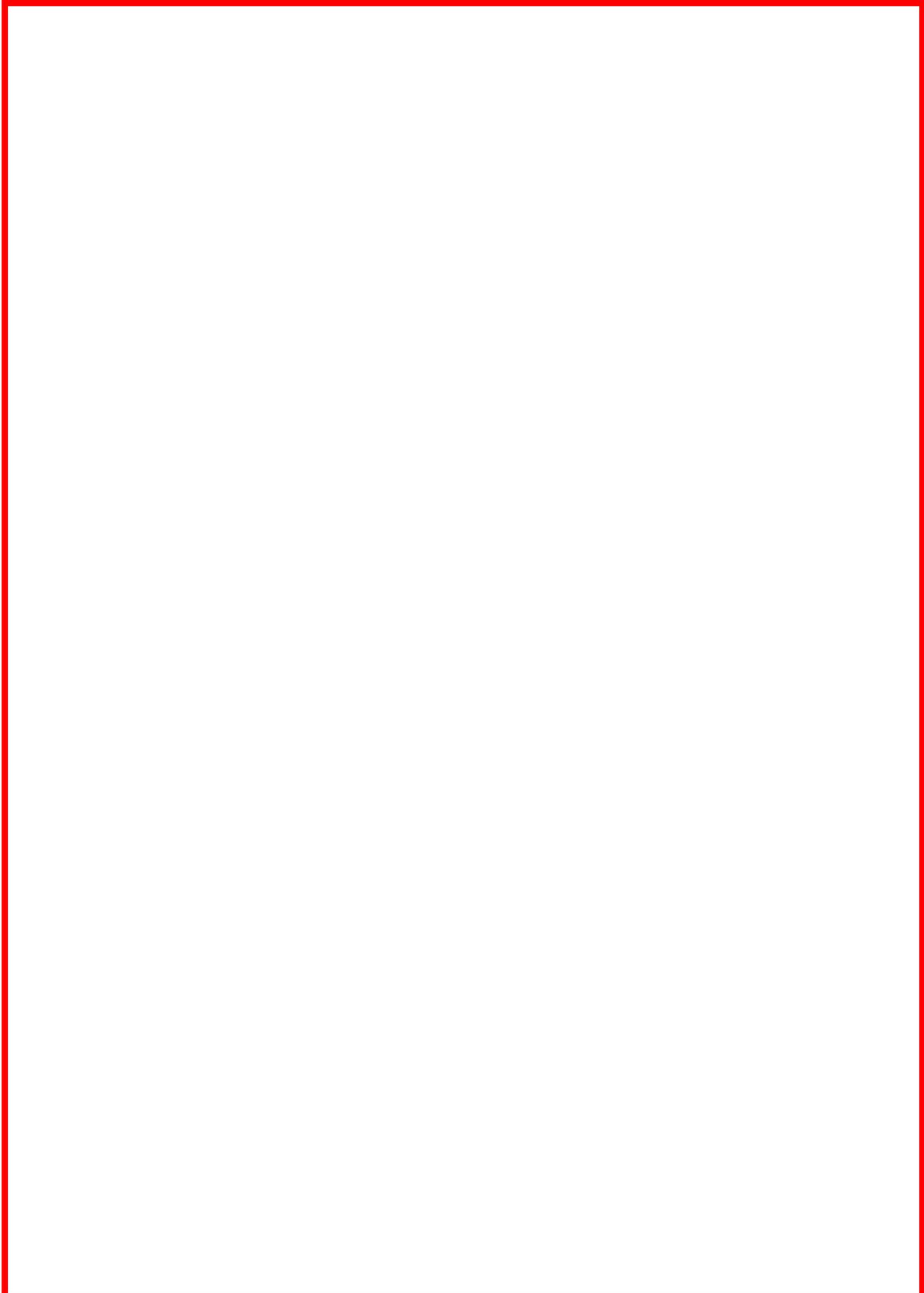
Activity 1

What does managing research mean?

Existing knowledge in managing research



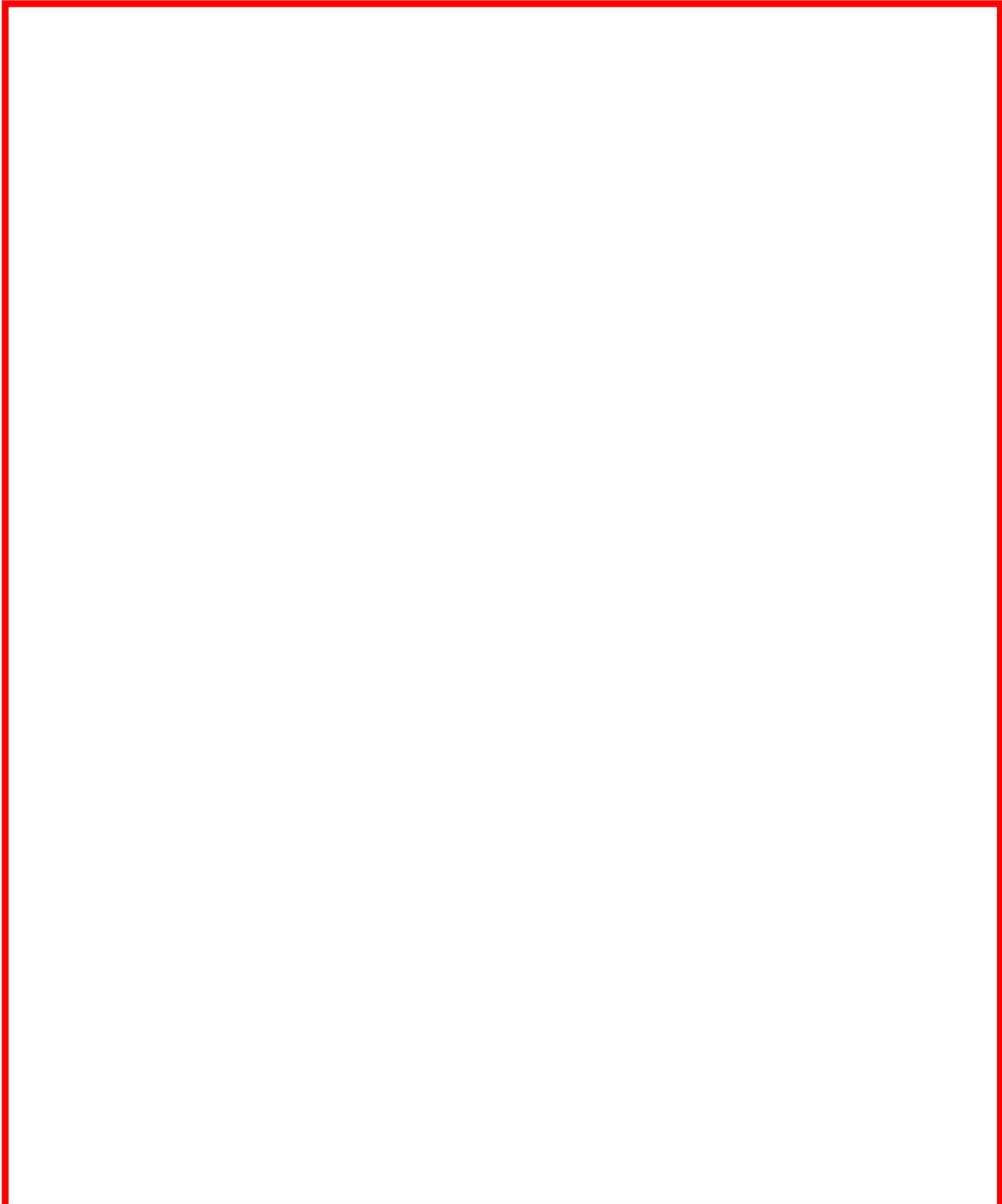
What does managing research mean? What happens in this stage?



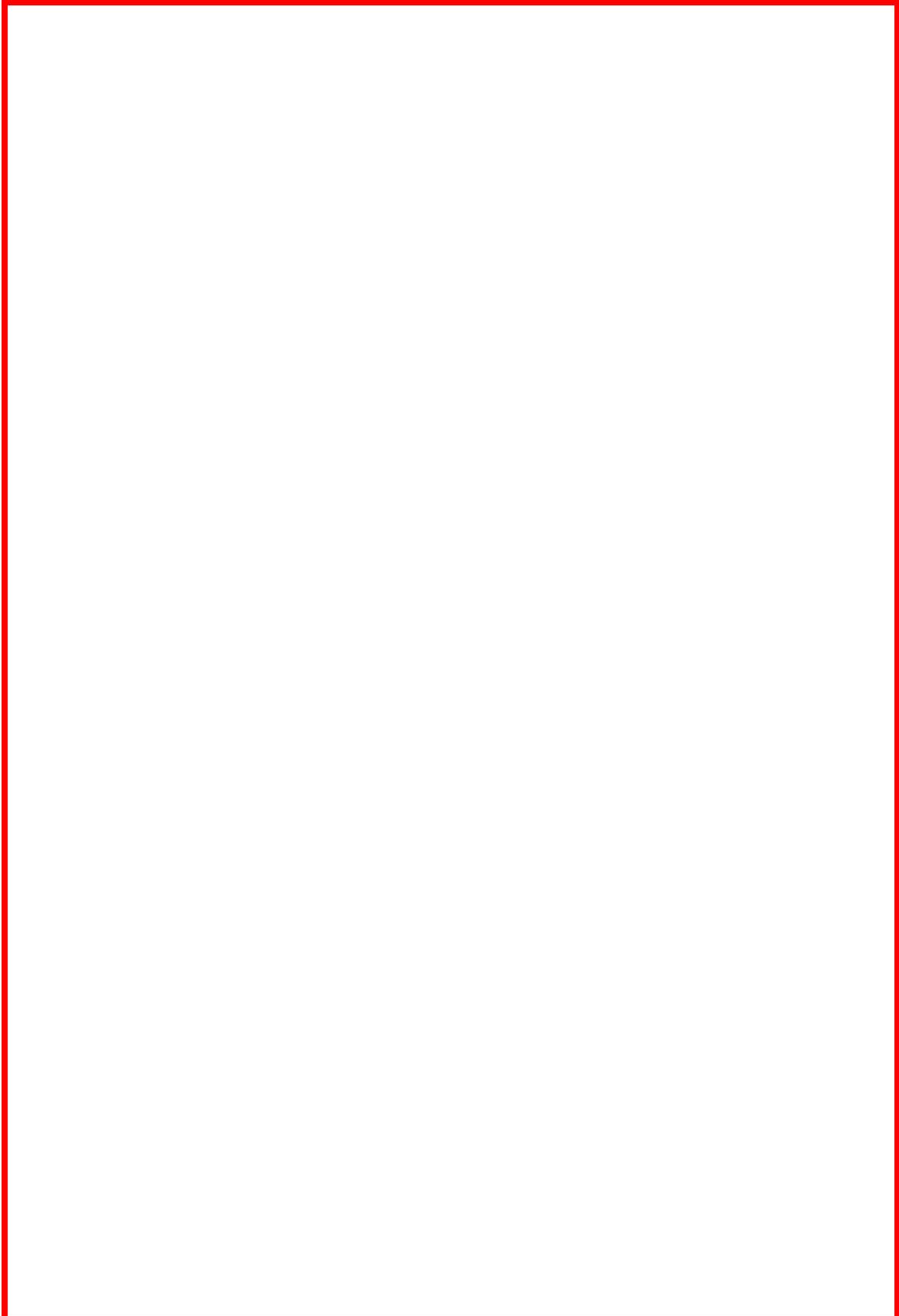
Activity 2

Examples of user involvement in managing research

Analysing case examples of managing research



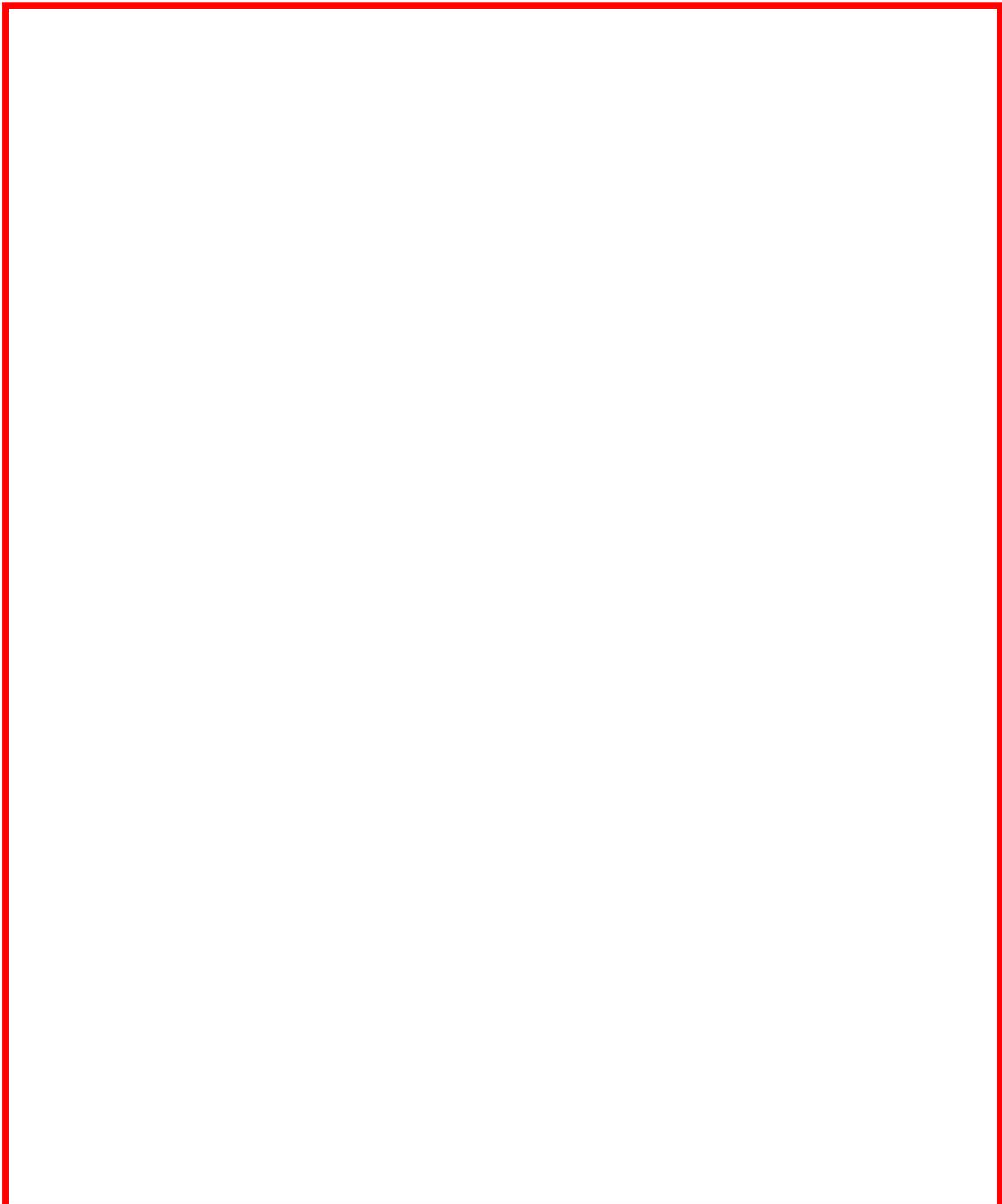
Managing research practice



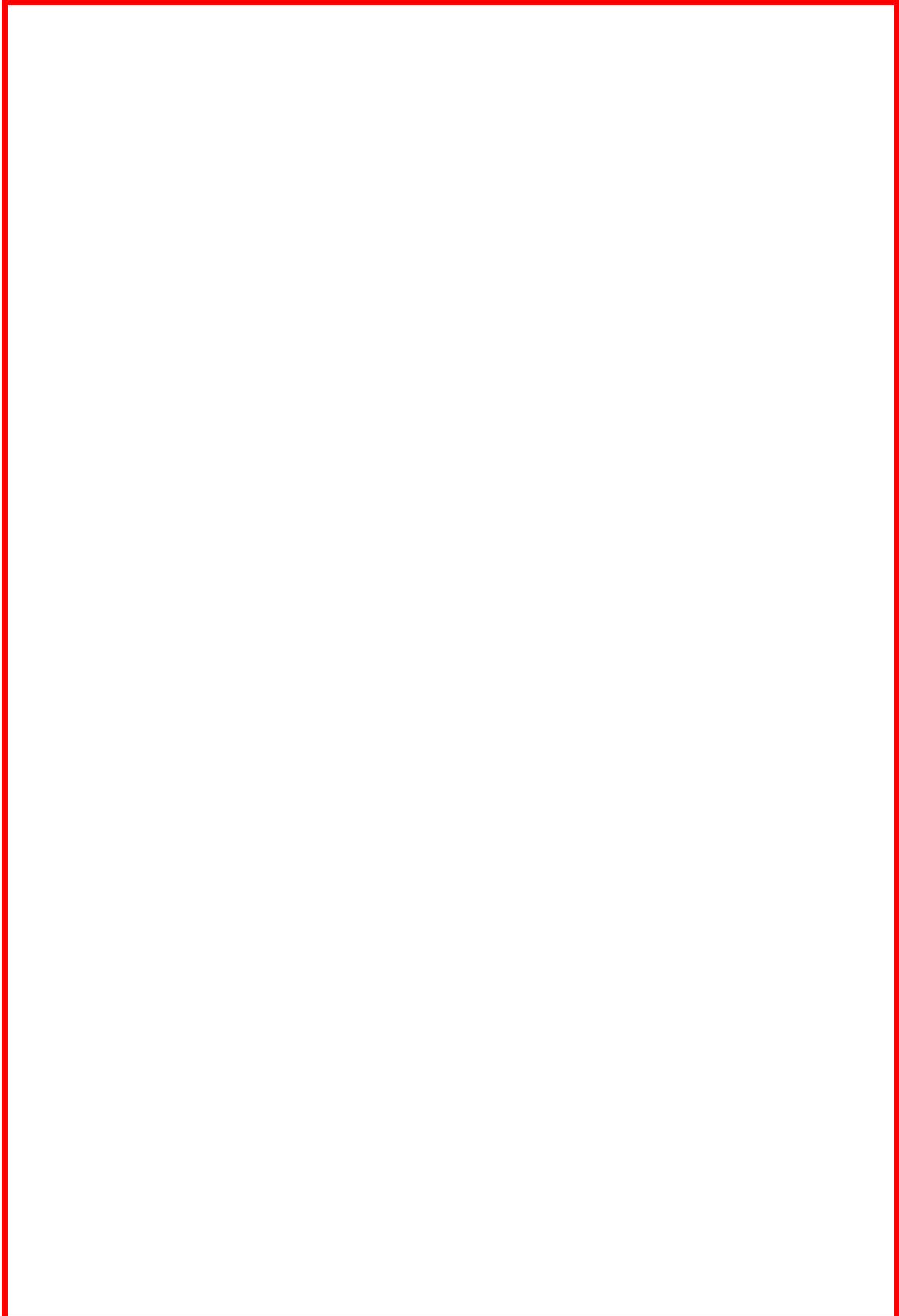
Activity 3

What could user involvement in managing research mean for you?

Review practical issues in user involvement work



Plans for dealing with practical issues



Case examples

1. The Alzheimer's Society

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

Tel: 0191 223 2830

Alzheimer's Society

Gordon House, 10 Greencoat Place

London, SW1P 1PH

Ph: 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 Network - here is the direct link:

http://www.qrd.alzheimers.org.uk/qrd_advisory_network.htm

The Quality Research in Dementia Network identifies a range of possible research topics and then participates in processes that select the priorities. The Society uses this as the basis for commissioning research. In addition, The Society aims to involve its members in every other aspect of its research program, including commissioning, grant application reviewing, grant awards, project management, implementation and dissemination.

It has won national awards for its commitment to user involvement.

2. Review and Reference Group - Involving Users, Carers and the Public as Equal Partners: A Learning and Development Resource

Dr Sandy Herron-Marx (Project Manager)

School of Health Sciences

University of Birmingham

52 Pritchatts Road

Birmingham, B15 2TT

Tel: 0121 414 3571

Email: s.herronmarx@bham.ac.uk

'Involving Users, Carers and the Public as Equal Partners: A Learning and Development Resource' was a pilot project to develop a training mechanism for health and social service staff in engaging service users and carers. The review and reference group consisted of a group of health and social service professionals and service users and carers from the pilot organisations (Birmingham Heartlands and Solihull NHS Trust and South Worcestershire PCT and Social Services). Their role was to continually monitor, support and give guidance to the project. They reviewed and commented on the development of

the training resource and ensured that it was fit for the purpose and that user perspective was embedded in it. They were also involved in overseeing the evaluation of the resource during its first trial, and made recommendations for change based on the outcomes of the evaluation.

3. Consumers for ethics in research (CERES)

PO Box 1365

London N16 0BW

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 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 to be heard more clearly to improve how research occurs.

Useful information for participants

Useful websites

Central Office for Research Ethics Committees (COREC)

www.corec.co.uk

This useful website is the department of Health's website for Local and Multi-centre Ethic committees. All protocols and national guidelines are stored on this website and are easy to download.

Ease of reading: Average

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: Average

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

Health Technology Assessment (HTA) Programme

<http://www.nchta.org/> - Main home page

<http://www.nchta.org/consumers/index.htm> - Consumer home page

The HTA programme is a national research programme funded by the Department of Health. Its job is to ensure that high quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most effective way for those who use, manage and provide care in the NHS. There is a consumer home page for users, carers and the public to learn about how user involvement occurs in the HTA programme. The HTA identifies and prioritises

research topics, then commissions research, monitors its progress and evaluates it when finished.

Ease of reading: Average

Useful reading

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

Sources used for the material in this part

Birmingham Heartlands and Solihull NHS Trust (undated).

Example Peer Review Form. UK: Research and Development Department, Birmingham Heartlands and Solihull NHS Trust.

Department of Health (2001). *Governance Arrangements for NHS Research Ethics Committees*. Found at:

<http://www.dh.gov.uk/assetRoot/04/05/86/09/04058609.pdf>

Department of Health (2003). *Research Governance Framework*. Available online at:

<http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/ResearchAndDevelopmentAZ/ResearchGovernance>

Herron-Marx, S., Stacey, K., Dunn, L., Miles, B. & Williams, A. (2004). *Involving Users, Carers and the Public as Equal Partners: A Learning and Development Resource for Health and Social Care Staff - Project Report*. UK: Birmingham and Black Country Strategic Health Authority.

Premila, T. Wykes, T. (2002) From passive subjects to equal partners: Qualitative review of user involvement in research. *British Journal of Psychiatry*, 181, 468-472.