

Part A

What is research and development?

A summary of Part A

Why is Part A important?

Part A describes what research and development activity is. You will gain an overview of the six-stage research and development cycle in the NHS - each stage is covered in more detail in Parts B to G. You will also learn about how research and development activity is governed, the different types of research and why user involvement in research and development is important.

What will you learn by doing Part A?

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

- Understand what research and development is - Activity 1
- Discuss the purpose of research and development - Activity 1
- Understand the six-stage cycle of research and development in the NHS - Activity 2
- Understand the different approaches to research and development - Activity 3
- Understand how research is governed in the NHS - Activity 4
- Discuss why user involvement is important in research and development activity - Activity 5

Skills you will strengthen or develop

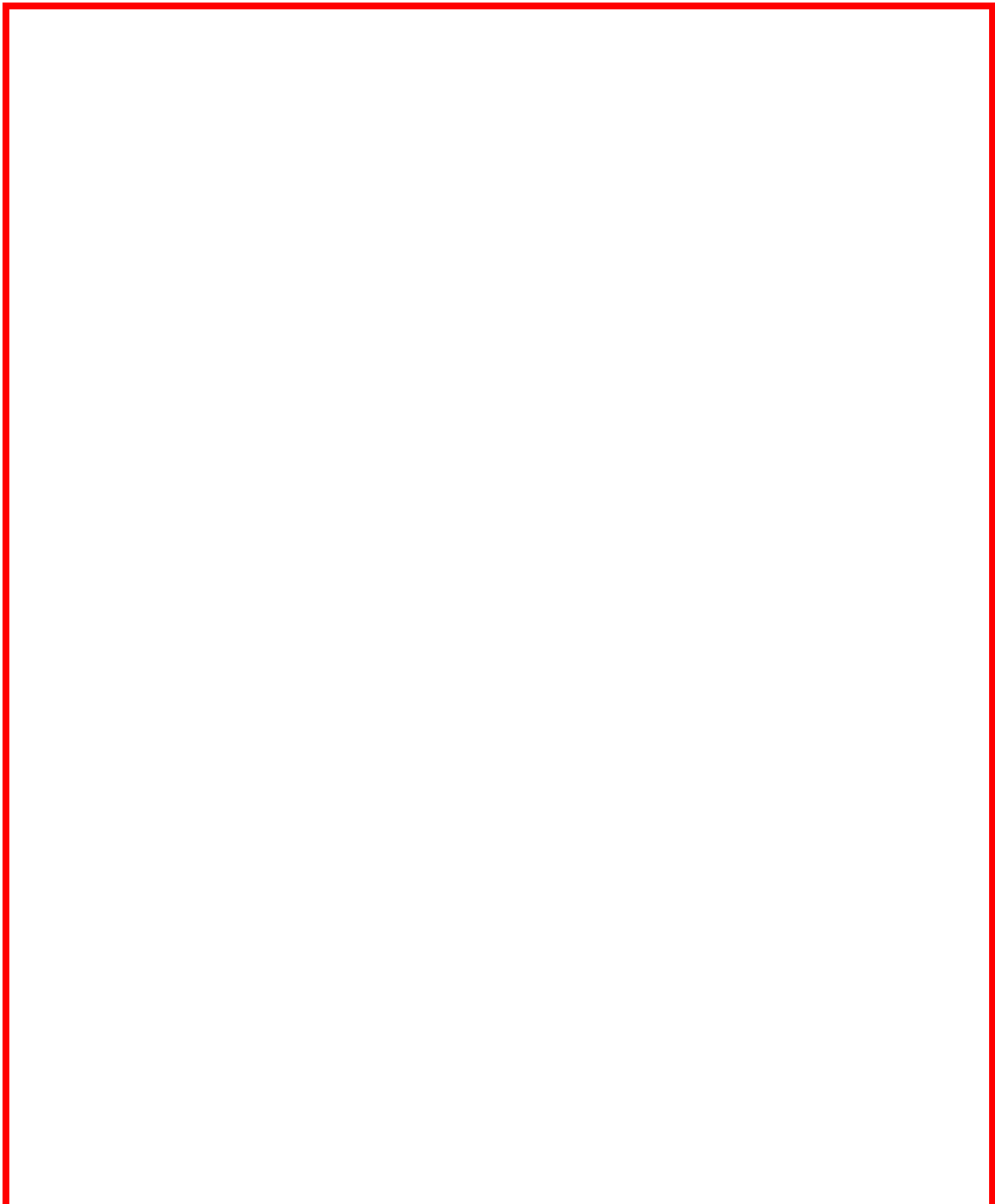
Skills that you will strengthen or develop include:

- Level 2: Further practice with speaking in large groups
- Level 2: Further practice with thinking about language and meanings
- Level 2: Further practice with thinking about issues
- Level 2: Further practice with developing and presenting an argument

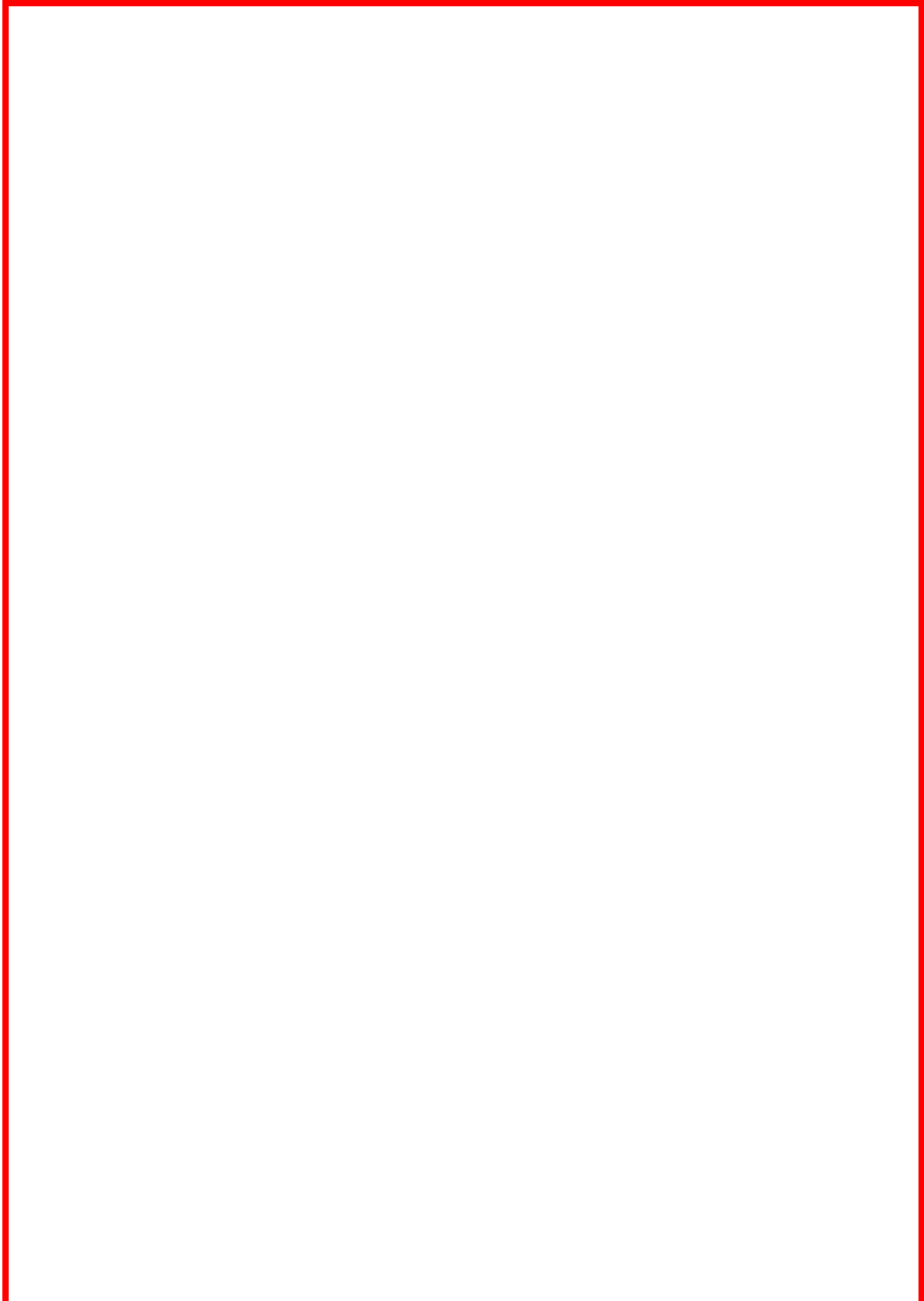
Activity 1

Research and development: What is it? What is its purpose?

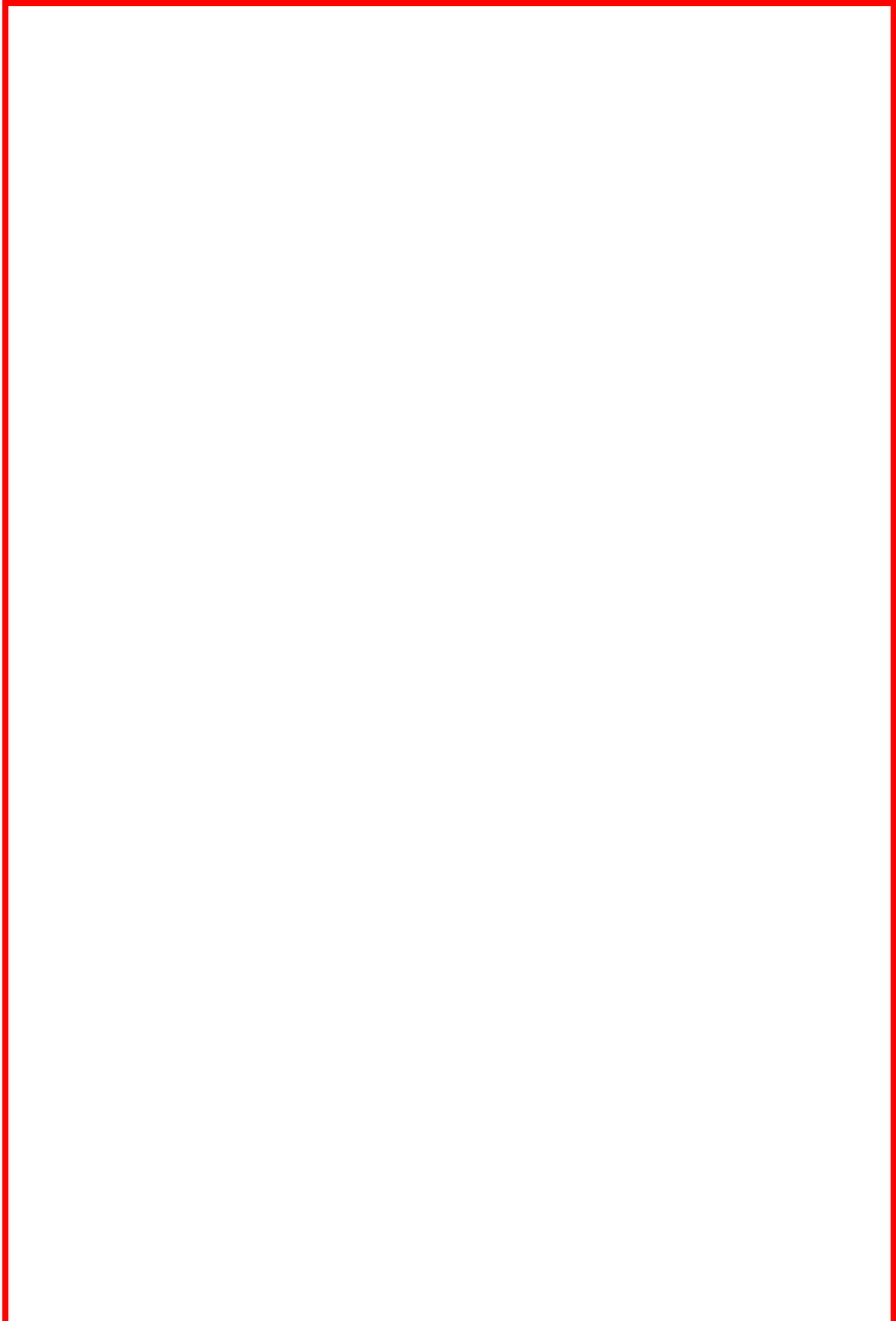
What is research and development?



What is your interest in research and development?



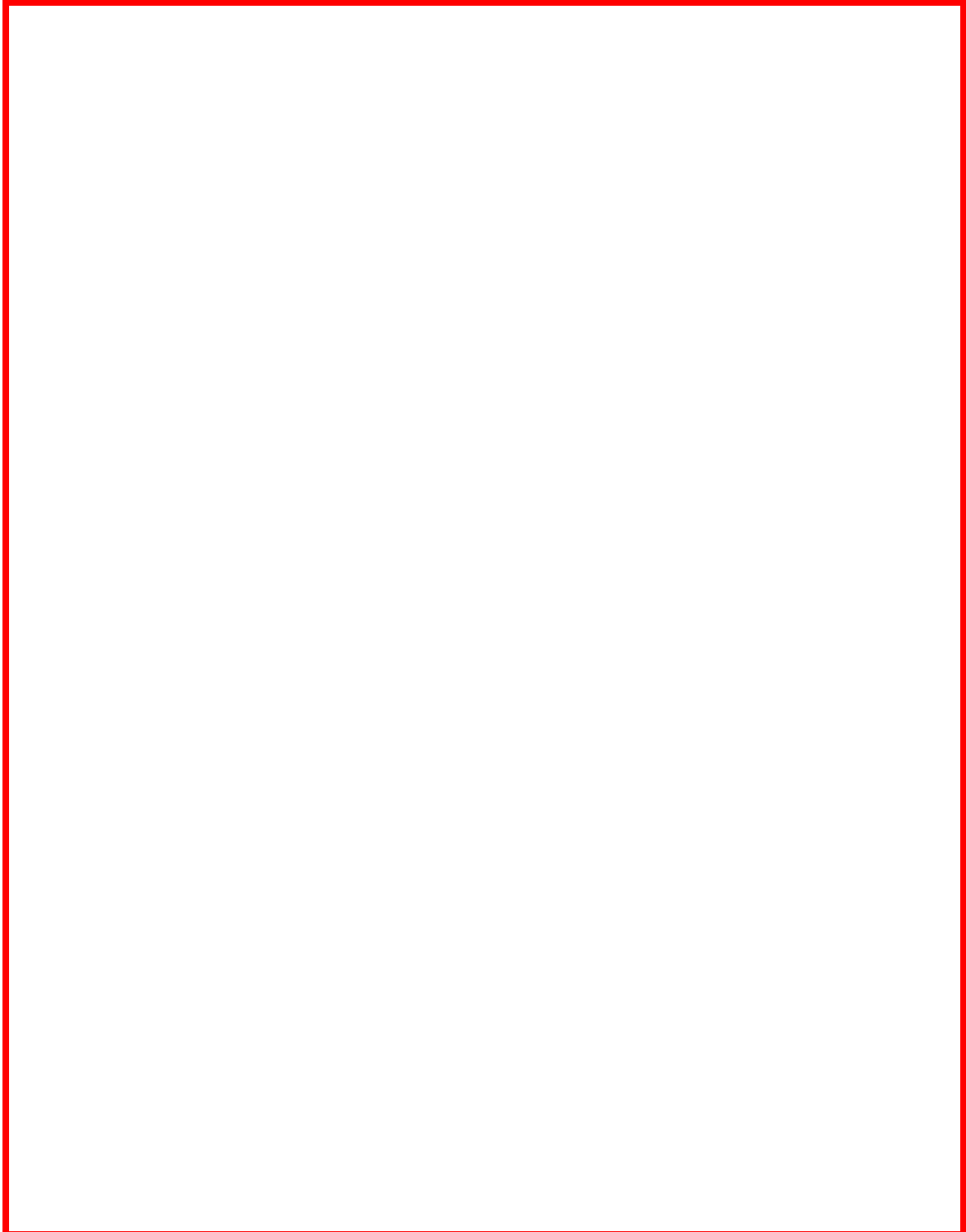
The purpose of research and development



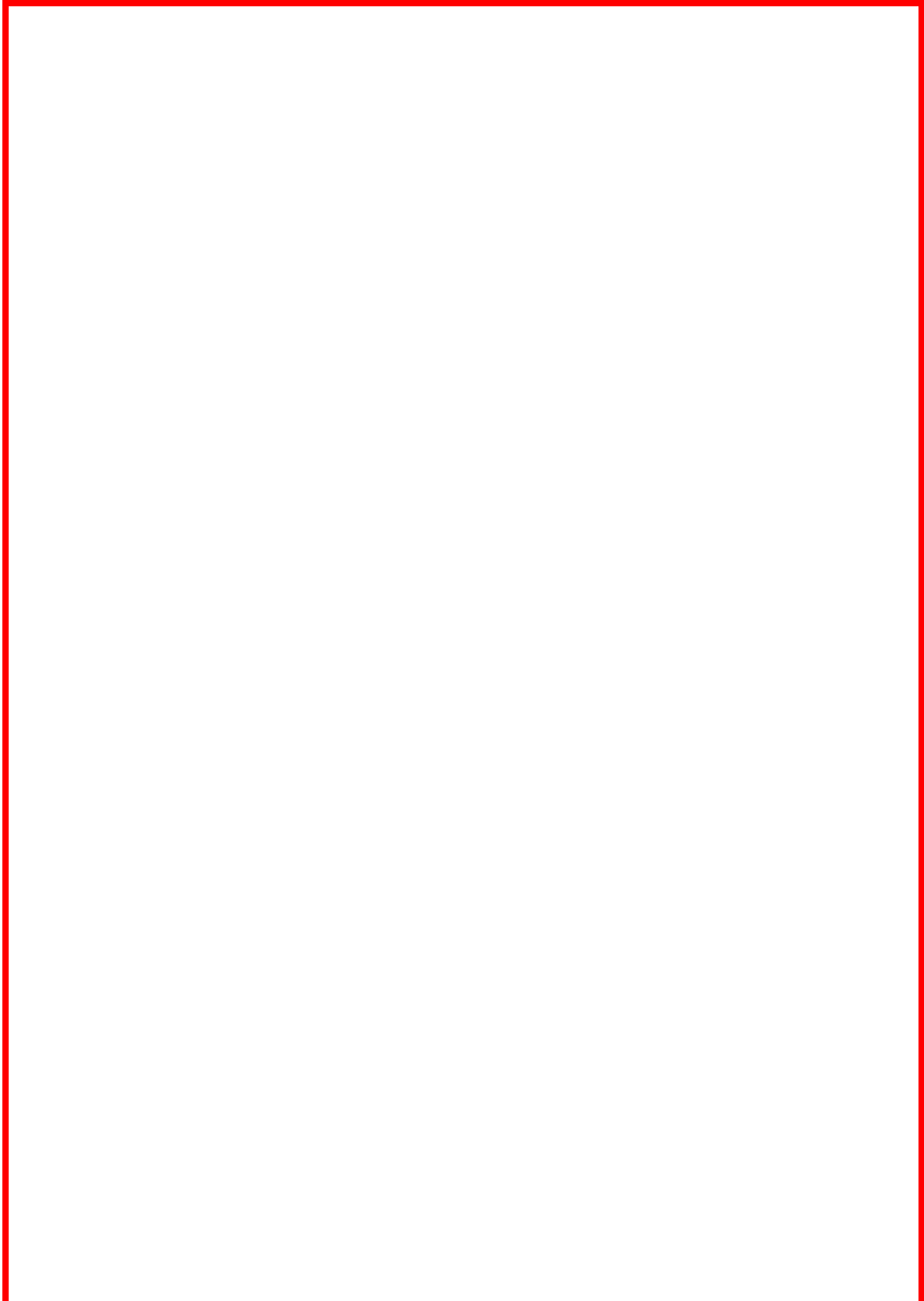
Activity 2

The research and development cycle

The research and development cycle



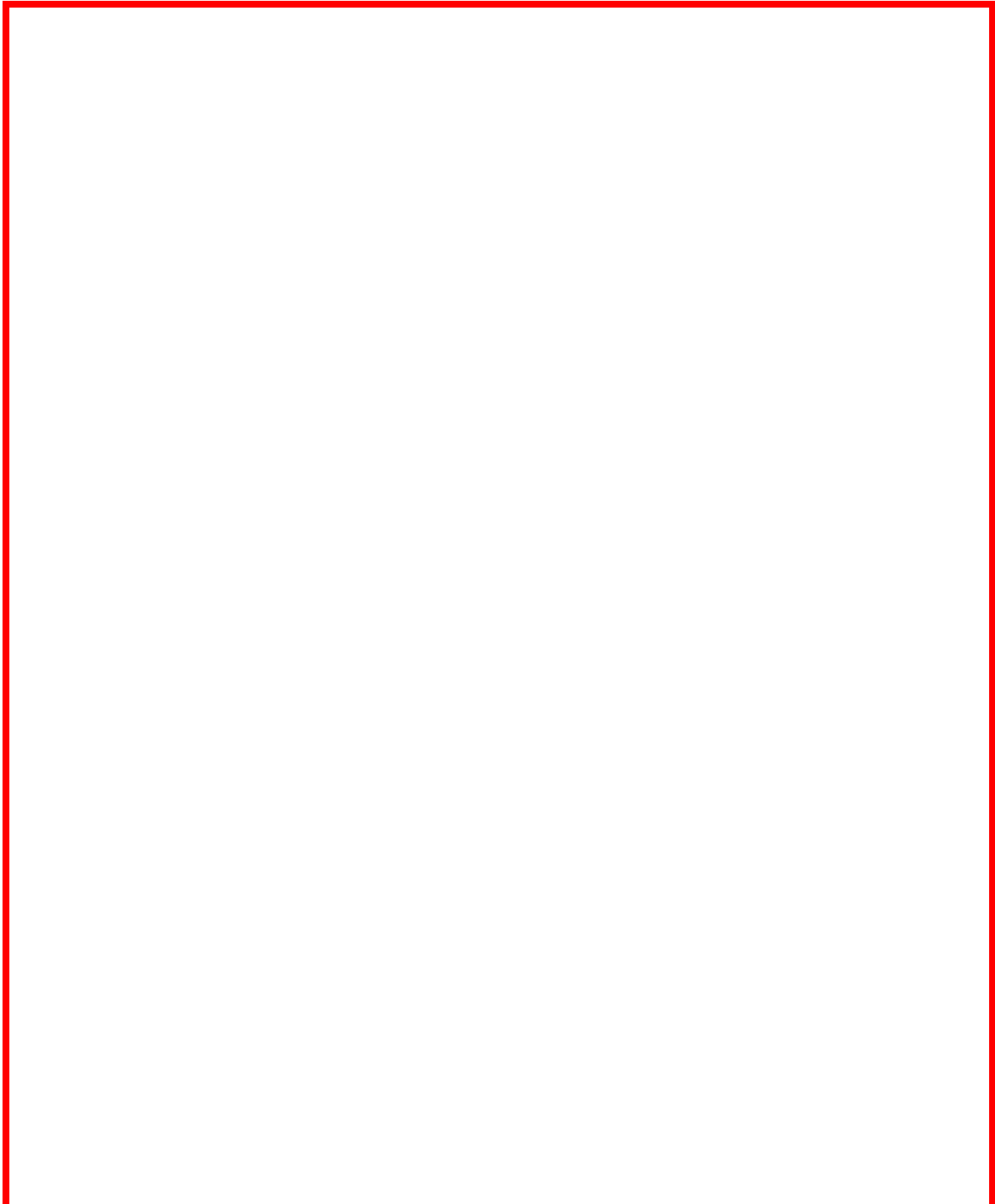
Ways you can be involved in the research and development cycle



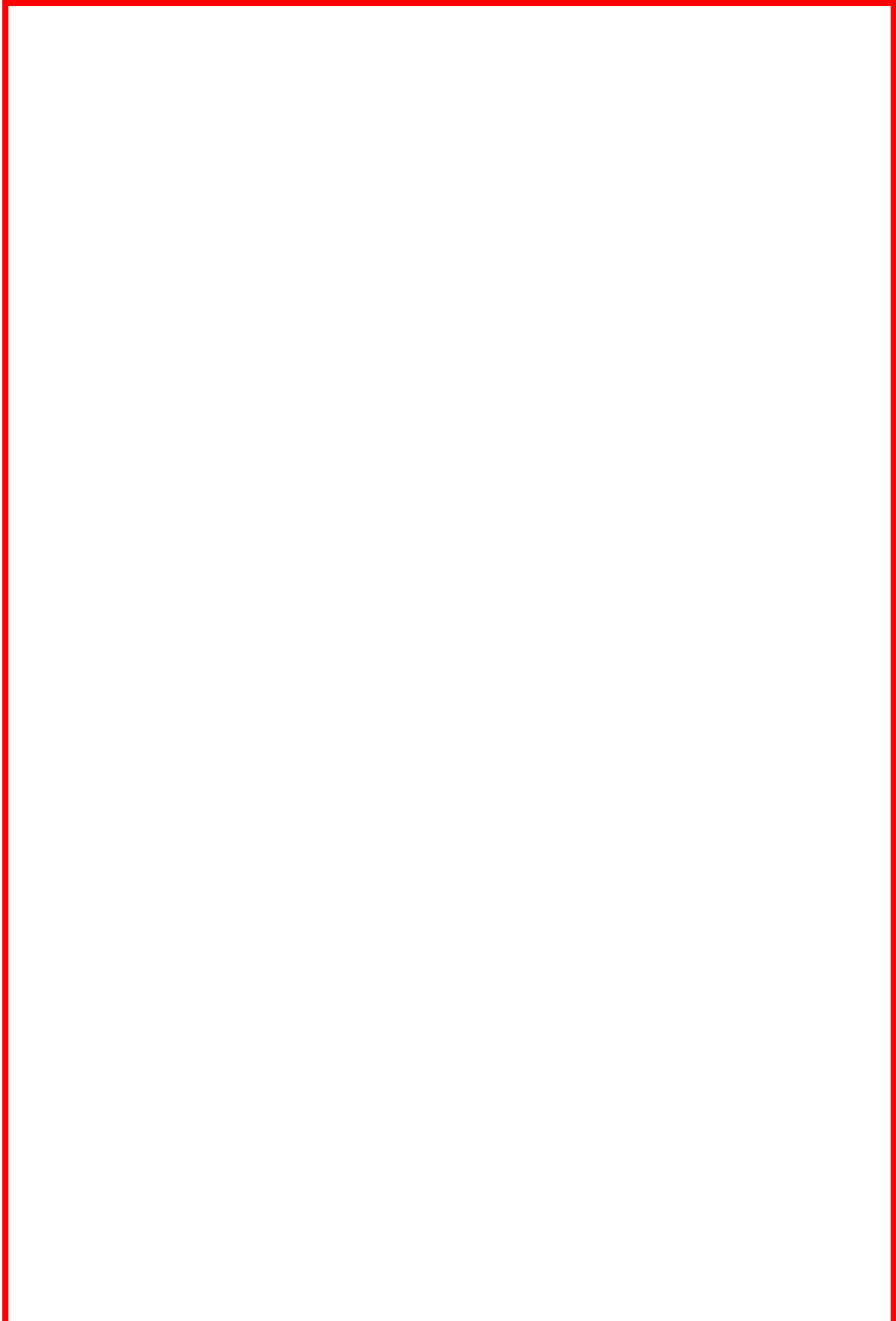
Activity 3

Different types of research

What do you know about different types of research and development?



Different types of research and development

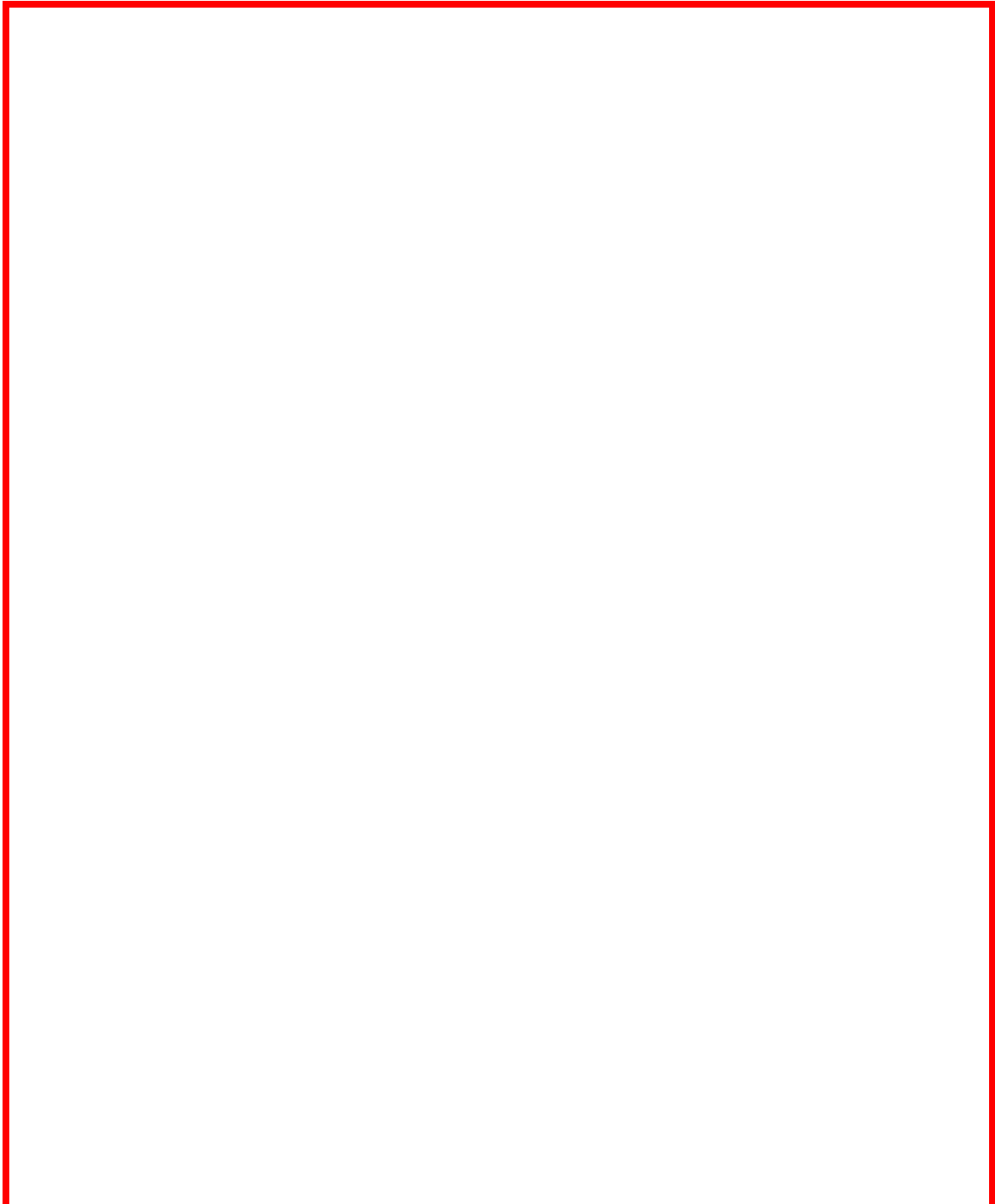


Activities

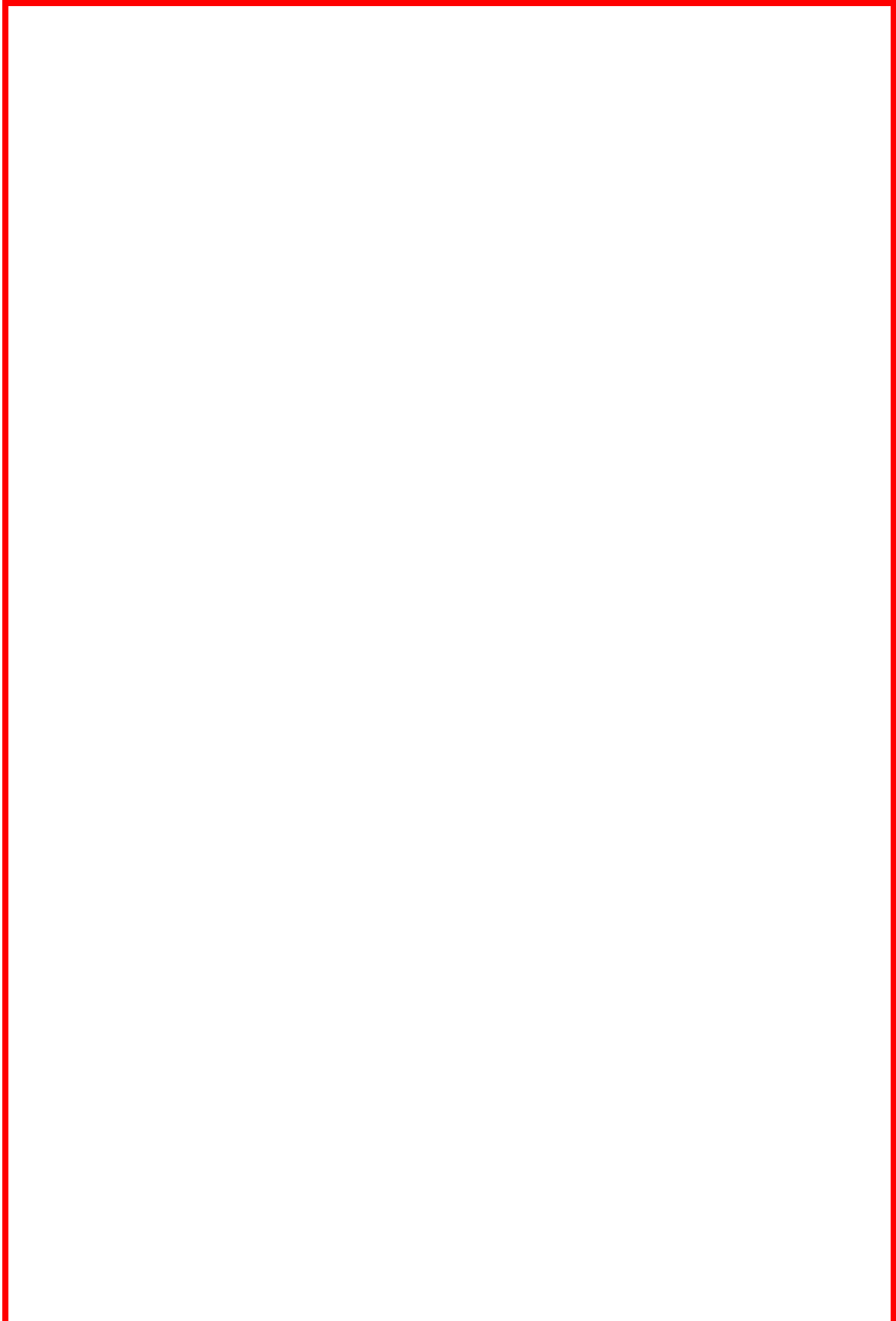
Activity 4

Research governance

Managing possible problems in research and development



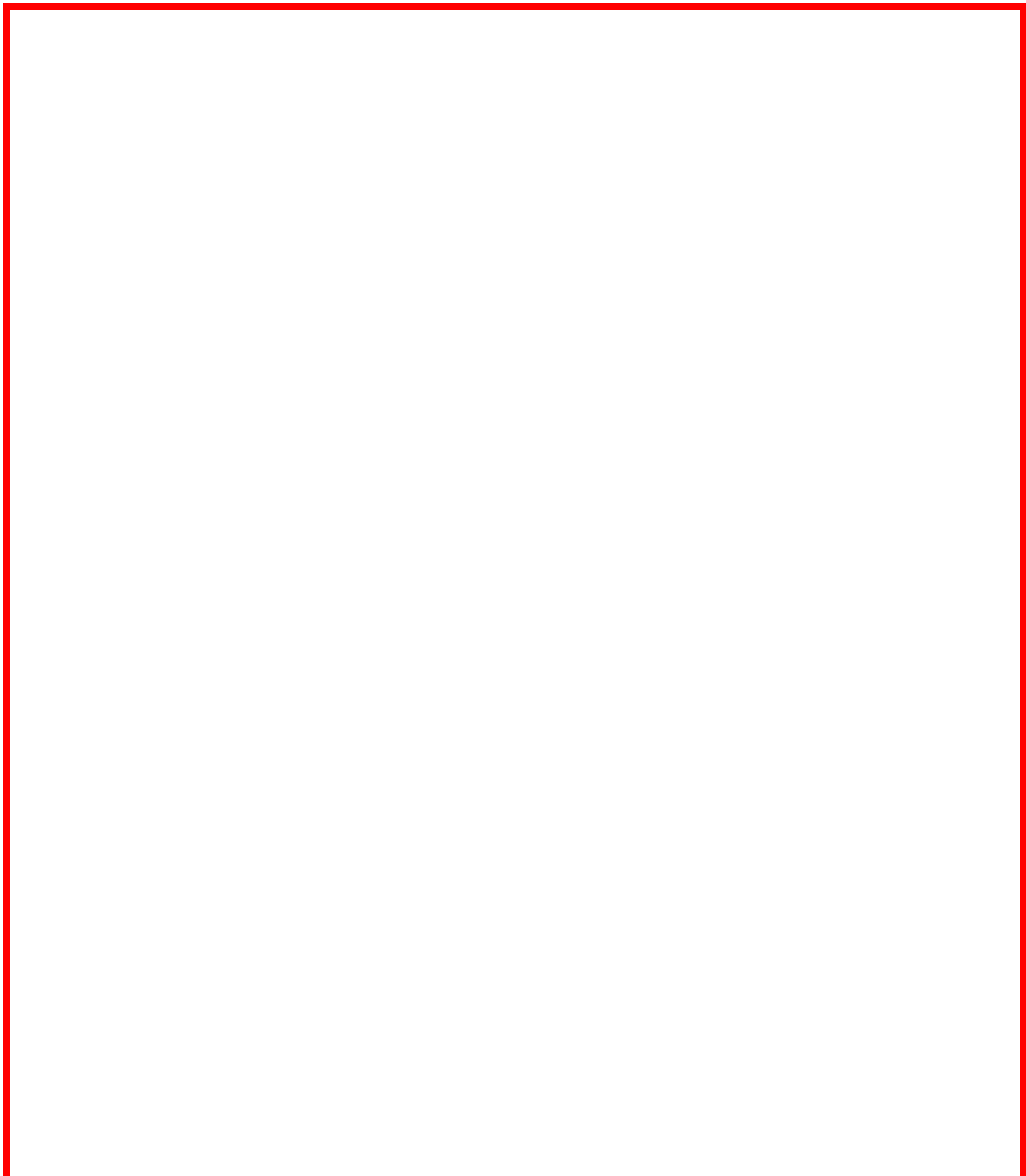
What is research governance?



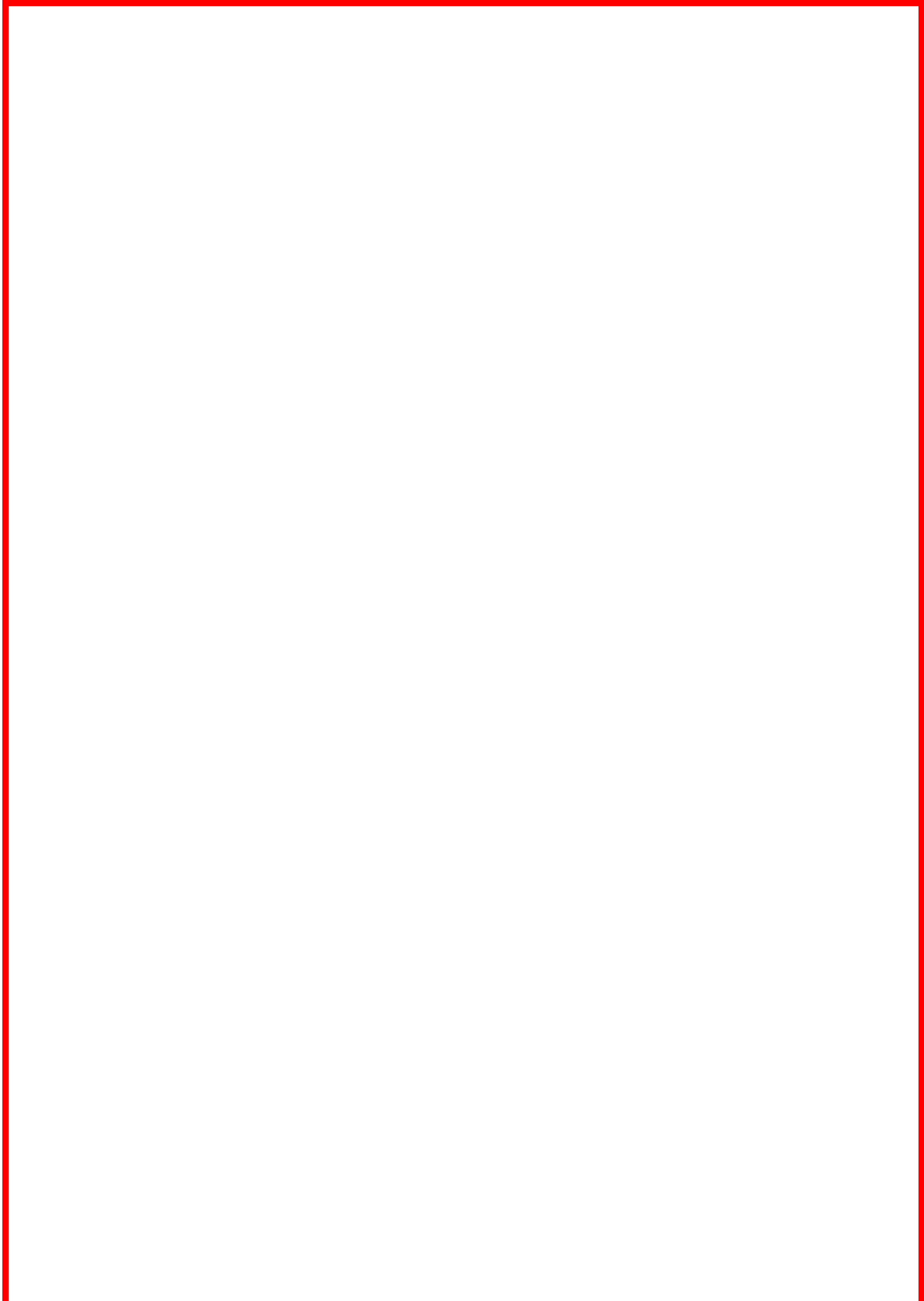
Activity 5

Why have user involvement in research and development?

Why should there be user involvement in research and development?



Why do you want to be involved in research and development?



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

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 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.

2. Sheffield and the North Trent Cancer Research Network

c/- Sheffield Palliative Care Studies Group

Royal Hallamshire Hospital

Sheffield S10 2JF

Contact person: Tony Stevens

E-mail: t.stevens@sheffield.ac.uk

The Sheffield and the North Trent Cancer Research Network was set up to improve the level of involvement of users and carers in cancer related research. There has been a range of activities used to recruit and involve people as user consultants, including three open user conferences to increase awareness of research among users and carers. They used these conferences to directly recruit people with experience of cancer, as users or carers, to sit on individual project steering groups and also a committee that provides a strategic overview of current research. They established a 'Consumer Panel for Research' where reimbursed, trained consumers are able to provide consumer perspective in a range of settings, including steering groups and committees. (See Stevens et al. 2003 listed under the 'Sources used for the material in this part' in the Useful Information section.)

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 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.)

Useful information for participants

Useful websites

Cochrane Collaboration Consumer Network

<http://www.cochrane.no/consumers/docs.aspx?wfref=Consumer>

This is the website for consumers who are involved in the work of the Cochrane Collaboration. They help review and report on the evidence for health care practices so people can make informed decisions about their health care.

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 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

National Institute for Clinical Excellence (NICE)

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

NICE is part of the National Health Service (NHS). It aims to provide users, carers, health professionals and the public with convincing, clear and reliable guidance on current 'good practice.' This includes information about health assessments and treatments, and the management of specific conditions. The work of NICE will help improve the quality of care that users and carers receive in the NHS.

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

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 you learned about in this part 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

Bechel, D., Myers, W. & Smith, W. (2000). Does patient-centred care pay off? *Journal of Quality Improvements*, 26(7), 400-409.

Edwards, A., Elwyn, G., Smith, C., Williams, S. & Thornton, H. (2001). Consumers' views of quality in the consultation and their relevance to 'shared decision-making' approaches. *Health Expectations*, 4(2), 151-161.

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.

Roberts, K. (1999). Patient empowerment in the United States: A critical commentary *Health Expectations*, 2(2), 82-92.

Rose, D. (2001). *Users' voices: The perspective of mental health service users on community and hospital care*. London: Sainsbury Centre for Mental Health.

Rose, D. (2002). *Sure thing*. Openmind, July/August, 116.

Roter, D. (2000). The medical visit context of treatment decision-making and the therapeutic relationship. *Health Expectations*, 2(1), 17-25.

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>

Stevens, T., Wilde, D., Hunt, J. & Ahmedzai, S. (2003). Overcoming the challenges to consumer involvement in cancer research. *Health Expectations*, 6, 81-88.

Williams, G., Frankel, R., Campbell, R. & Deci, E. (2000). Research on relationship-centred care and healthcare outcomes from the Rochester Biopsychosocial Program: A self-determination theory integration. *Families, Systems & Health: The Journal of Collaborative Family Health Care*, 18(1), 79-90.