

Part B

Consulting about research

A summary of Part B

Why is Part B important?

Before research and development work happens it is important to consult with people on what the focus of this work should be and what are the priority issues. This is called consulting and is the focus of Part B. You will learn about the details of this stage and analyse real examples. You will also consider the practical issues of user involvement in consulting about research to help you decide if you would like to do this work.

What will you learn by doing Part B?

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

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

Skills you will strengthen or develop

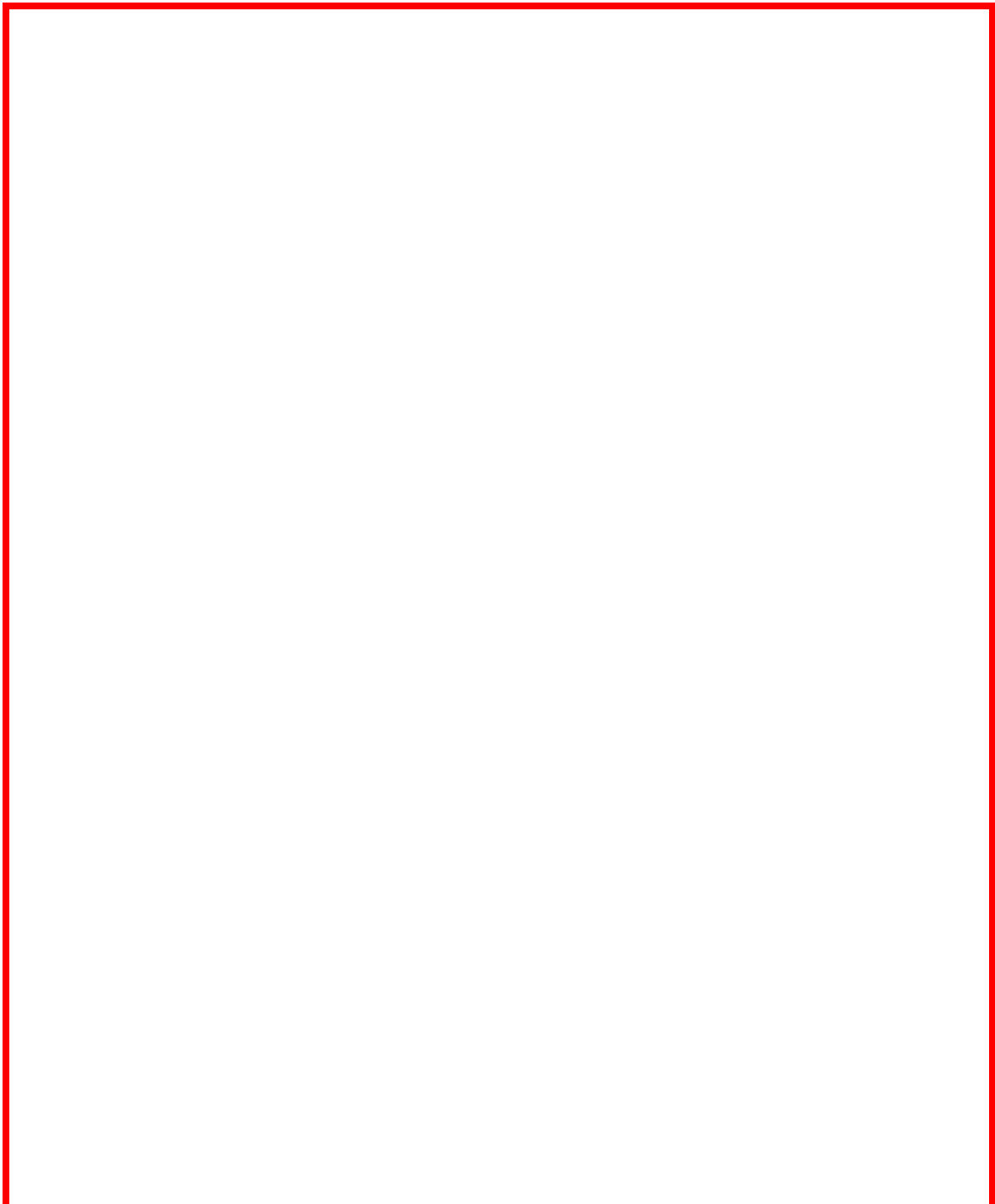
Skills that you will strengthen or develop include:

- Level 2: Further practice with analysing 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 action steps
- Level 3: Demonstrate ability to analyse issues
- Level 3: Demonstrate ability to analyse situations

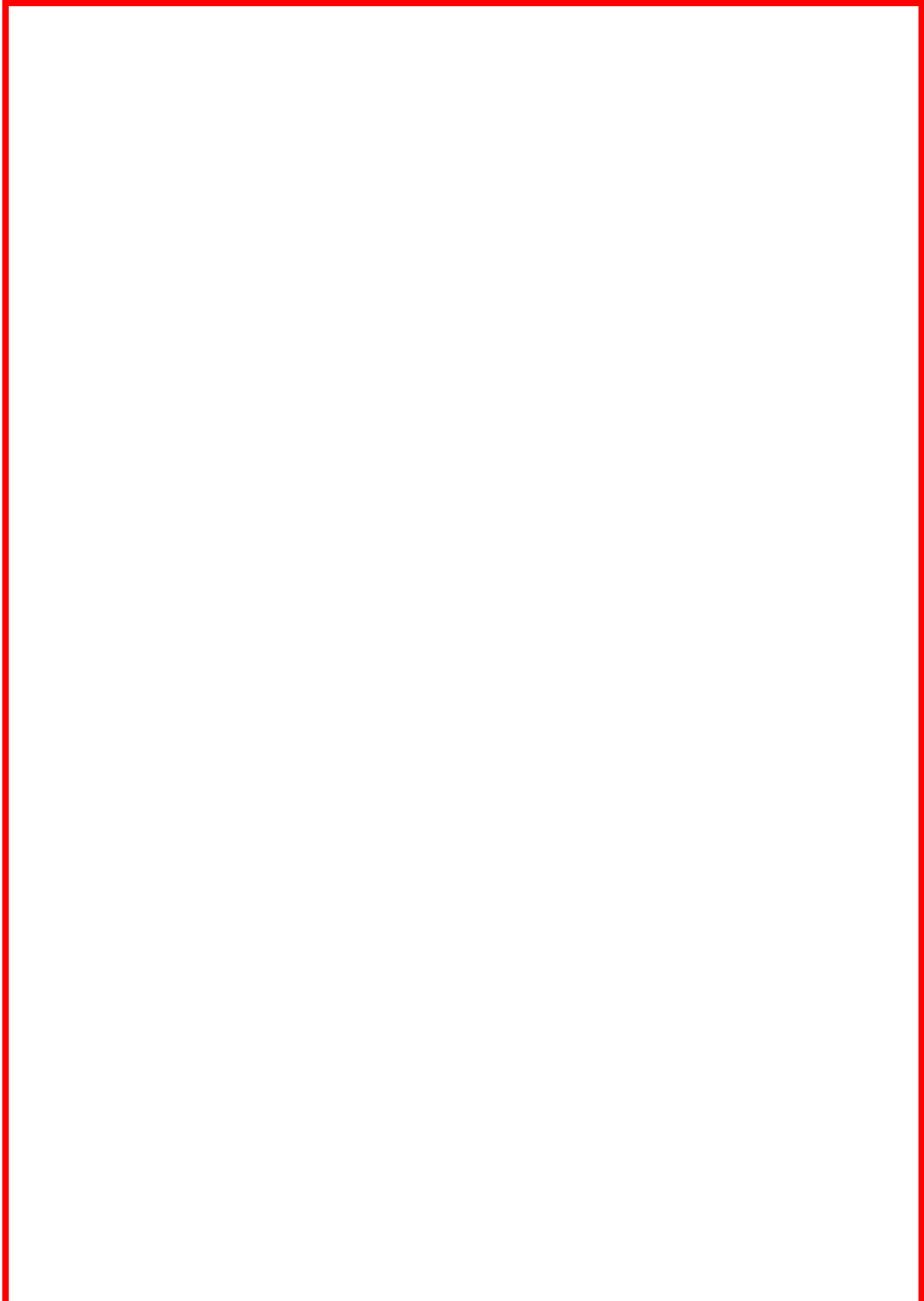
Activity 1

What does consulting about research mean?

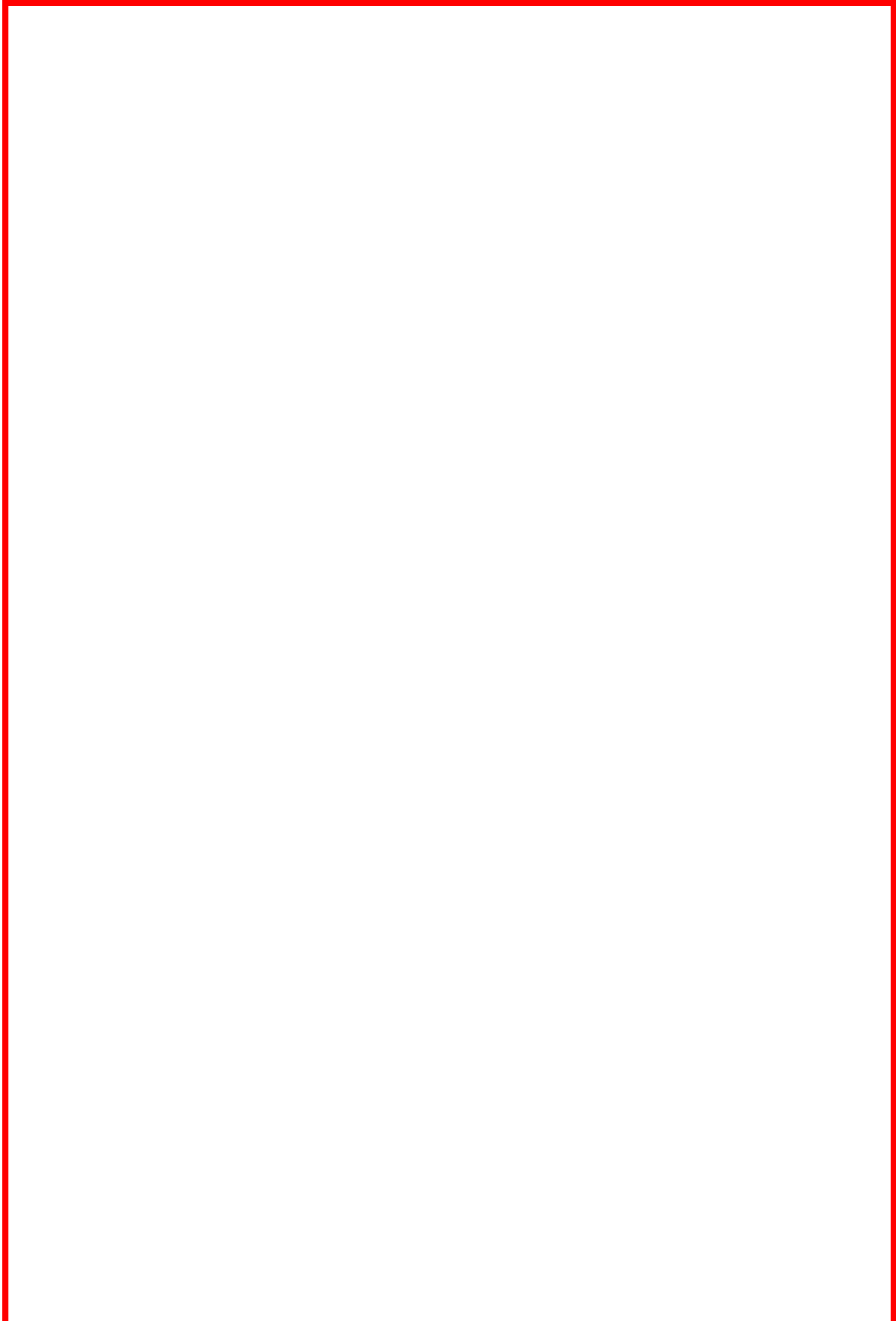
Existing knowledge of consulting about research



**What does consulting about research mean?
What happens in this stage?**



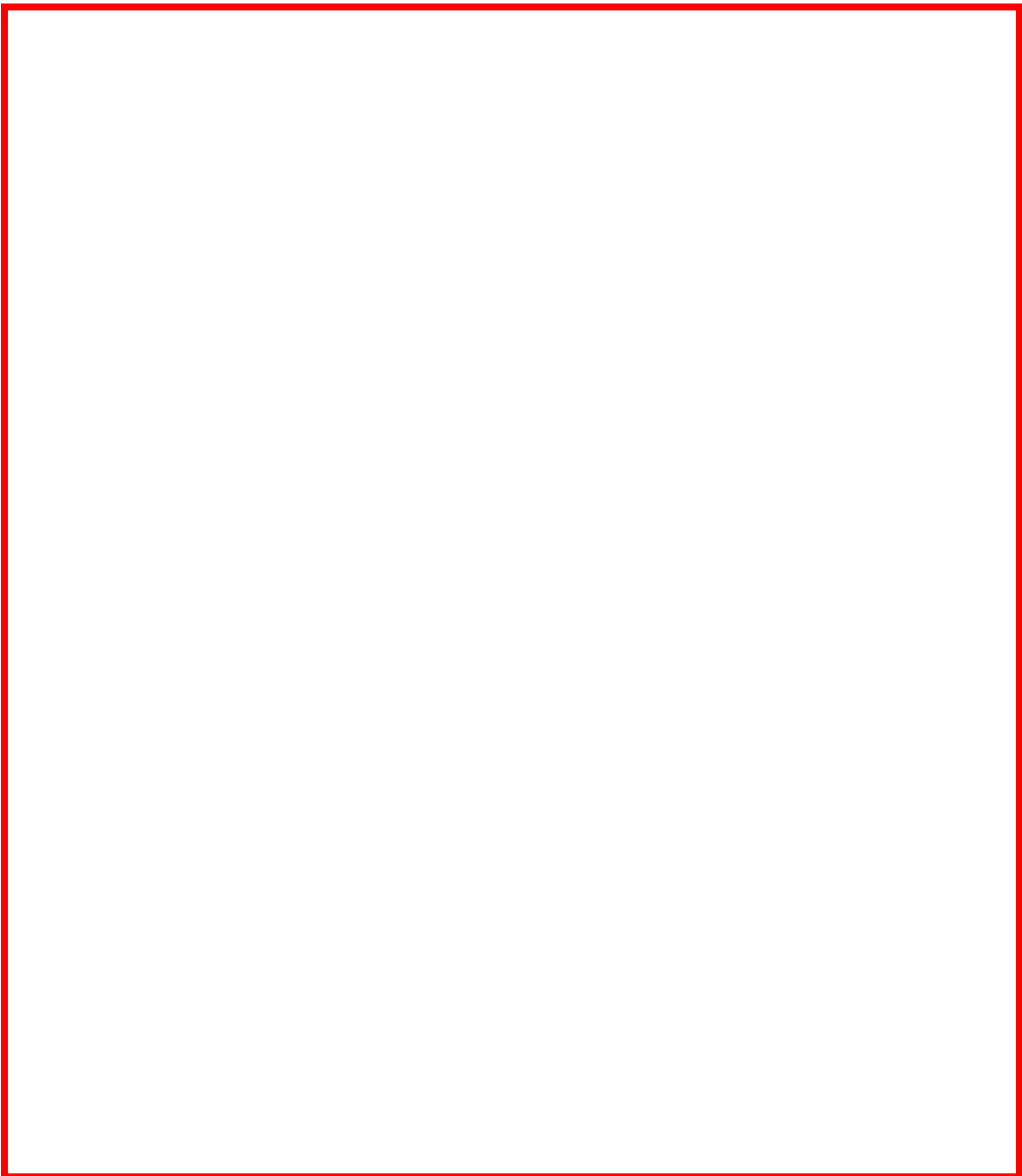
Consulting about research practice

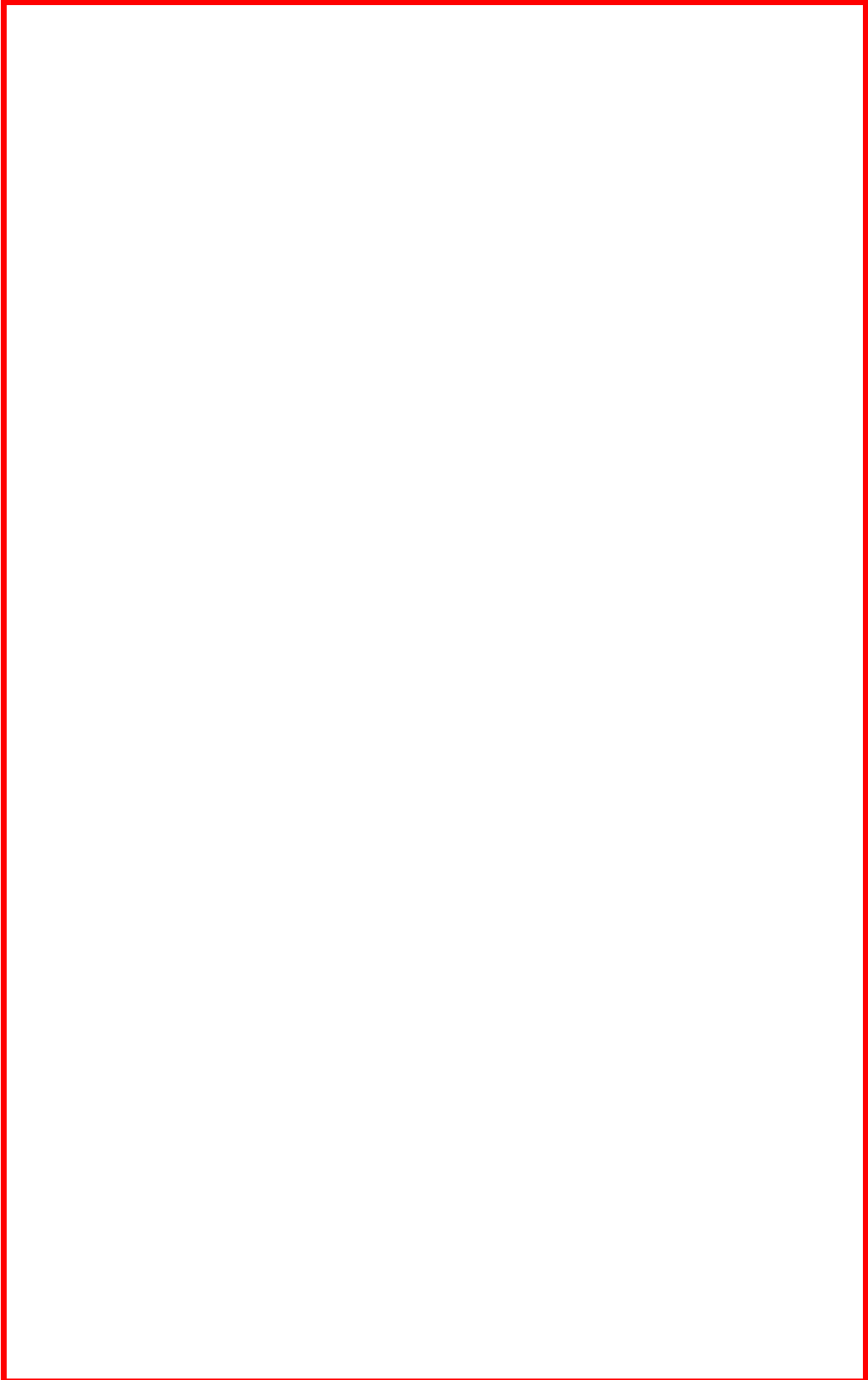


Activity 2

Examples of user involvement in consulting about research

Analysing case examples of user involvement in consulting about research



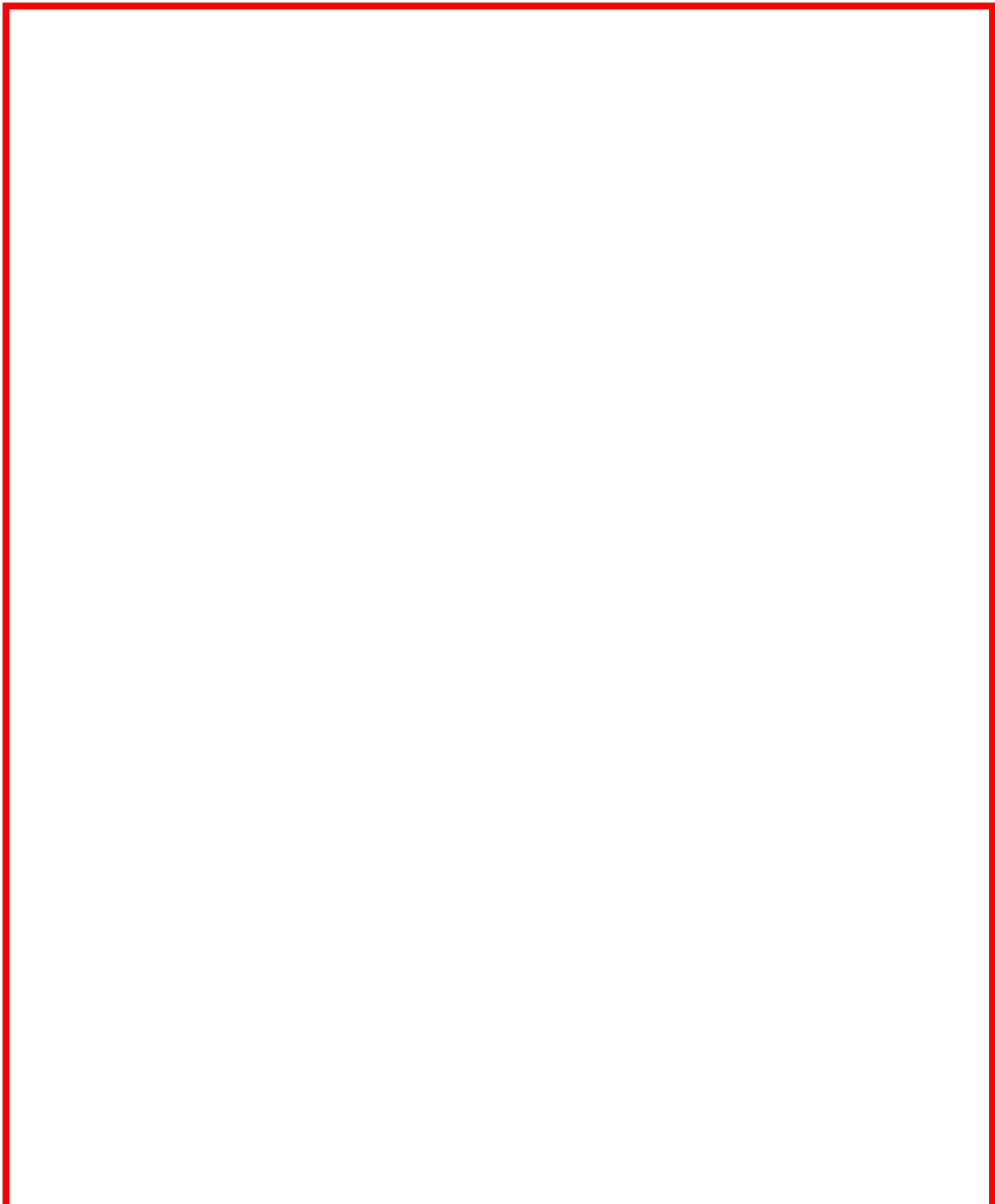


Activities

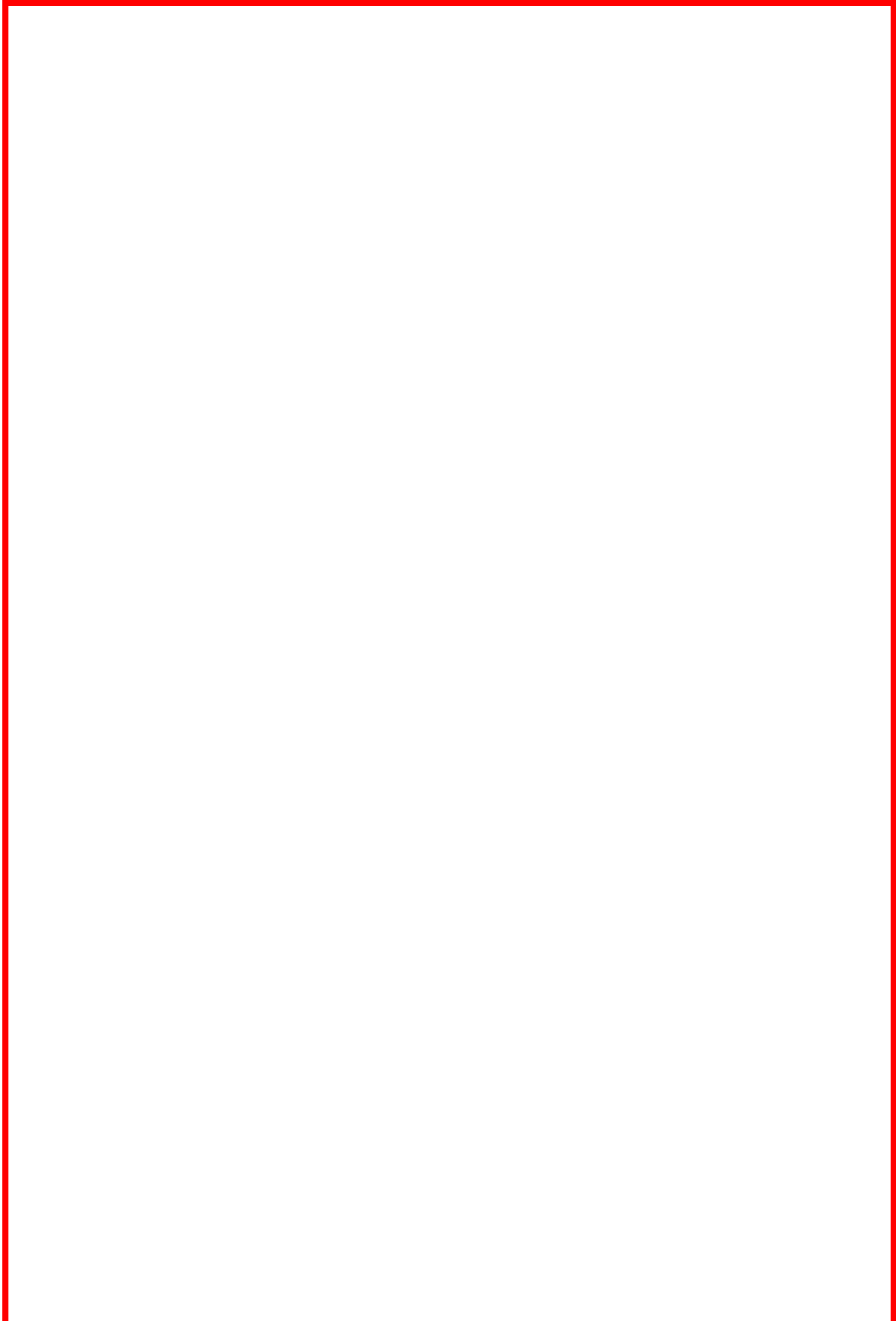
Activity 3

What could user involvement in consulting about research mean for you?

Review practical issues in user involvement work



Plans for dealing with practical issues



Personal exercises

Here are 2 exercises to help you think about the ideas in Part B.

Learning from examples

Think about the example of user involvement for consulting about research in Activity 2 and answer these questions:

- What did you learn from the discussion that will help you in your future user involvement work?

- Is there anything else you want to learn about this stage? If yes, identify who can help you with this. This may be a Link Person in your organisation.

Practical issues in consulting about research

Review the practical issues in consulting about research discussed in Activity 3 and answer these questions:

- Identify which of the issues are of most concern to you

- Do you have enough ideas about how to deal with these concerns?

- If no, identify who you can discuss these issues with further to help you plan what you can do about them

Case examples

1. Involving consumers in a needs-led research program

Oliver, S., Milne, R., Bradburn, J., Buchanan, P., Kerridge, L., Walley, T. & Gabbay, J. (2001). Involving consumers in a needs-led research programme: A pilot project. *Health Expectations*, 4, 18-28.

A service user led this research group. They designed and then evaluated a strategy to involve users, carers and the public in several research tasks for the NHS Health Technology Assessment Program. This included identifying topics, selecting priorities, commissioning and reviewing research. It talks about what they learned and how they will do things differently in the future so that user involvement is better supported and more effective.

Also see the useful website on the Health Technology Assessment Programme.

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 Network - here is the direct link:

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

The Quality Research in Dementia Network identify a range of possible research topics and then participate 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.

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 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: 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 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

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.

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/>

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

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.

Oliver, S., Milne, R., Bradburn, J., Buchanan, P., Kerridge, L., Walley, T. & Gabbay, J. (2001). Involving consumers in a needs-led research programme: A pilot project. *Health Expectations*, 4, 18-28.

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