

**Research-user workshop: Project Initiated Programme Event, Research
Beehive, Newcastle University, Friday 5th May 2006**

Background

In the last decade, there has been an increased interest in the biomolecular and epidemiological characterization of pre-clinical dementia. It is argued that early diagnosis of dementia will facilitate the prevention of dementing processes and lower the prevalence of the condition in the general population. In this context, Mild Cognitive Impairment (MCI) – a concept being proposed to describe the transitional stage between normal cognitive ageing and dementia – has been the object of intense debate and controversy.

The research project 'Boundary Work, Normal Ageing and Brain Pathology' had as its main objectives:

- A. To understand how biomedical definitions of the boundaries between 'normal' and 'abnormal' cognitive ageing processes are changing with the emergence of Mild Cognitive Impairment.
- B. Understand how these changes affect culturally embedded knowledge about the experiences of older citizens.

Topic

In the research project we explored how the MCI controversy encapsulates important transitions and uncertainties in the scientific and clinical understanding of dementia as well as in the social organisation of dementia care and its political framing. We identified the main areas of debate as relating to:

- a) the relation between the commercialisation and evaluation practices of pharmaceuticals and the emergence of new diagnostic categories,
- b) the relations between the level of scientific and clinical uncertainty that is ascribed to new diagnostic criteria and changes in the organisation of dementia care,
- c) possible outcomes and scenarios for dementia health research and health care policies.

The workshop

This one day workshop was designed to bring together researchers, a selected panel of members of the public and other stakeholders with the results of the project. The workshop was attended by older people, advocates of older people, informal carers, clinicians, dementia researchers and social scientists. The panel was invited to discuss changes in the understanding of cognitive ageing, possible scenarios for dementia research and care coming out of various debates identified in the research and to reflect on the role the diverse stakeholders could play in the debate.

The workshop format was as follows:

1. Introduction: overview of the findings of 'Boundary Work, Normal Ageing and Brain Pathology' research project
2. Parallel discussion groups
3. Feedback from group and discussion
4. Reflective account from research team and conclusion

Three parallel workgroups were given extracts from the study interviews grouped into the following areas:

- Mild Cognitive Impairment: Clinical use of MCI
- Mild Cognitive Impairment: Commercialisation of science
- Mild Cognitive Impairment: Scientific uncertainties

The workgroups with the aid of a facilitator were then asked to look at the following questions/tasks:

1. Reflect on the diversity of views in selected extracts
2. Voice their own view on the positions expressed?
3. Identify the possible implications of these positions for older members of the public
4. In light of these implications, decide future research topic priorities
5. Highlight potential public policies.

In plenary discussion the participants concluded that MCI was of limited utility for clinicians and older people and that there was an important role for existing carers in formulating research and policy on early diagnosis and prevention of cognitive impairment. Participants also highlighted the dangers of propagating ageist attitudes through awareness campaigns about the risks associated with dementia and memory loss.

The workshop was innovative in attempting to involve different users of the research in the interpretation of the study findings. Our aim was to engage participants with some of the data from the study with the purpose of widening the potential interpretation of our results.

Outputs

We intend to produce a report of the proceedings of the workshop based on the transcripts of the event (including parallel groups), for which we have the participants' consent.