



**Health Communication Research
Centre
Cardiff University
PO Box 94
Cardiff CF10 3XB**

Tel: (029) 2087 6325
Fax: (029) 2087 4242
<http://www.cf.ac.uk/encap/hcrc/>

Project Synopsis:

Communicative frames in counselling for predictive genetic testing

The Health Communication Research Centre (HCRC), as an interdisciplinary initiative within Cardiff University, co-ordinates communication and discourse based research in areas of health and social care. This project in genetic counselling is funded by The Wellcome Trust (2001-2004) under their *Medicine and Society* programme.

Predictive genetic testing for some late-onset Mendelian disorders can identify unaffected individuals who are at risk of developing a genetic disease in later life. Examples of such late onset neurodegenerative disorders include Huntington's disease (HD), and the familial (Mendelian) cancer disorders such as familial breast cancer (FBC), ovarian cancer and colon cancer. What makes these conditions even more complex is the variability associated with their treatment regimes. This means that counselling for different predictive tests will rely on how geneticists and clients interactively negotiate decisions in the clinical setting.

This research project aims to investigate the genetic counselling process, opening it up to more systematic description and evaluation. It aims to produce a detailed structural and interactional analysis of HD and FBC clinics as they lead up to predictive genetic testing. The analytic focus is to identify elements of pre-test counselling which have the most important influences on client decisions about testing and on the clinical outcomes of those who are tested.

The study will mainly gather data on the communicative processes within counselling sessions during the clinical encounters and supplement these with ethnographic interviews of clients and the notes from medical files.

We are interested in the following set of questions:

- How do genetic counsellors manage the balance between information-giving and advice-giving? How do they communicate indirectness and professional neutrality in the face of patient-centred health care?
- How are treatment/testing options endorsed, rejected or contested by clients and clinicians?
- How are uncertainties and knowledge claims accomplished interactionally through shifts in positions of speaking and by recruiting other voices?
- What rhetorical and persuasive strategies (e.g. contrast, listing) are used for communicating risk?
- How is individual risk compared to population risk and how are future events compared to present action plans?
- How are medical, ethical and social aspects negotiated in a session?

It is hoped that the research findings will assist in the development of professional practice, based on the linkage between localised communicative patterns and clinical outcomes. In a modest way the study will inform future policy decisions about counselling services in relation to predictive testing for a wide range of genetic disorders.

Research team: Dr Srikant Sarangi (Project Coordinator); Dr Kristina Bennert (Research Associate); Ms Lucy Howell (Research Assistant); In association with the Institute of Medical Genetics, University of Wales College of Medicine (Prof Angus Clarke, Prof Peter Harper, Dr Ruth Harper and Dr Jonathon Gray).

For further information, please contact Lucy Howell <HowellL@cardiff.ac.uk> or Kristina Bennert <bennert@cardiff.ac.uk>