At the beginning of the twenty first century, research has come to be seen as a necessary part of clinical activities. Research studies are used to supplement dwindling clinical budgets, provide services, develop the evidence base, generate income for pharmaceutical companies and improve clinicians’ career prospects and so on. Despite increasing regulation and governance of research activities, clinical research still generates a number of ethical and practical issues for those involved in this activity.

In this symposium, we will explore some of the issues that arise while undertaking clinical research, such as the ways in which research protocols may be adapted to meet professional and institutional agendas and the increasingly pressing ethical issue of what to do with clinically relevant results that may emerge during the course of research. In the first of two presentations, we will look at patient and staff experiences of taking part in a clinical trial where protocol ‘adaptations’ became evident after clinical endpoints were not attained. The second presentation discusses some of the ethical issues emerging from the generation of incidental information in research. Interview data from research participants who have received genetic test results following their research participation in the Australian Ovarian Cancer Study will be presented.

Nina is a Senior Lecturer in Health Services Research at Newcastle University, UK. Nina has formerly worked at Edinburgh and Cambridge Universities and the Institute of Cancer Research in London. She has undertaken a number of projects which look at the implementation of high technology medicine in clinical practice. She is particularly interested in patients’ and healthcare professionals’ understandings of research activities and has published widely in this area.

Julia is a Senior Research Fellow in the Centre of Population Health Sciences at Edinburgh University. She leads a programme of qualitative research concerned with the understandings, experiences and views of patients who have type 1 and type 2 diabetes and their health care providers. Her broader research interests include: barriers and facilitators to diet, physical activity and medication adherence, trial participation, evaluation of structured education programmes; and, end of life care. Julia has a background in Social Anthropology and Medical Sociology, and, prior to taking up her post at Edinburgh in 2001, was a Research Fellow at Newnham College, University of Cambridge.

Associate Professor Marilys Guillemin is the Director of the Centre for Health and Society. Marilys teaches courses at postgraduate level in qualitative research design and research methods, social health and health ethics. With Lynn Gillam, Marilys has been awarded the Carrick Australian Award for University Teaching in 2007 and the University of Melbourne David White Teaching Award in 2005. Marilys is an established health researcher whose strengths are in qualitative health research methods. She has completed a number of key research projects that include: the management of menopause within specialised clinic settings, mid-age women and heart disease particularly focusing on women’s understanding of risk and prevention of heart disease. Marilys is currently undertaking research on how ethics committee members and health researchers understand research ethics and how they address ethical issues in practice.