

**Sociological Approaches to the Analysis of the
Informatization of Health and Illness:
Comparisons between the UK and New Zealand**

IHT Fellowships in Comparative and Evaluative Analysis Report

April 2004

Dr Sarah Nettleton (Principal Applicant)

and

Professor Roger Burrows (Co-Applicant)

‘Children, Parents and the Management of Chronic Illness in the Information Age’

ESRC Innovative Health Technologies Programme

Department of Social Policy and Social Work

University of York

May 2004

Introduction

This short report is based on a visit made by Dr Sarah Nettleton and Prof Roger Burrows to Christchurch in Canterbury in New Zealand.¹ The two were hosted by the Social Science Research Centre (SSRC) part of the Department of Sociology and Anthropology at the University of Canterbury in March/April 2004. In April 2004 the University of Canterbury was ranked a close second to the University of Auckland (out of 22 institutions) in the first ever New Zealand research assessment exercise (known as the PBRF). Visits were also made to the Christchurch School of Medicine and Health Sciences, which is part of the University of Otago.

The purpose of the visit was threefold.

- First, to compare and contrast contemporary sociological research on various forms of health informatisation processes in New Zealand and the UK in the light of recently completed work by Nettleton, Burrows and other colleagues at York on the sociology of e-health under the auspices of the ESRC IHT programme (Nettleton, 2004; Nettleton and Burrows, 2003; Nettleton et al., 2004).
- Second, to disseminate the findings of this work (and some of the wider concerns of the IHT programme more generally) via lectures, seminars, meetings and networking events in New Zealand.
- Third, to establish links with colleagues in New Zealand with a view to cultivating future research collaboration in areas covered by the broad IHT programme remit.

¹ This report was made possible through the co-operation of staff at the Social Science Research Centre and the Department of Sociology and Anthropology at the University of Canterbury, Christchurch, New Zealand and the Christchurch School of Medicine and Health Sciences, University of Otago. Particular thanks are due to Professor David Thorns (Director of the SSRC) who both facilitated the visit and allowed us to live in his houses whilst we were in New Zealand. It was carried out following the completion of the York-based research on *Children, Parents and the Management of Chronic Illness in the Information Age* funded by the ESRC Innovative Health Technologies Programme. Travel costs to New Zealand were provided by a fellowship in comparative and evaluative analysis from the ESRC Innovative Health Technologies Programme.

In addition to this the visit also allowed Professor David Thorns (Director of the SSRC and a Panel Chair on the PBRF) to come to York for a month and meet with various colleagues at the University and elsewhere. He met with a number of people in order to discuss common research interests and the differing organisational and financial contexts of social scientific research at both a subject and a programme level in New Zealand compared to the UK.

Background to the Social Science Research Centre

The Social Science Research Centre (SSRC) at the University of Canterbury is a multi-disciplinary centre set up to facilitate a more collaborative approach to social science research within the University and the broader Canterbury region. It includes social scientists from the University of Canterbury departments of history, geography, gender studies, mass communications and journalism, political science, social work, and sociology and anthropology. In addition it also includes social scientists from Lincoln University (based on the outskirts of Christchurch) and the Christchurch School of Medicine, and also some working in the private sector and for the Ministry of Social Development. It is governed by an Advisory Board composed of representatives of the University of Canterbury together with representatives from the Christchurch City Council, the Christchurch School of Medicine, Lincoln University, the Ministry of Social Development, Statistics New Zealand and Taylor Baines and Associates.

The SSRC has five core research areas: sustainable development; social policy; health; technologies; and culture and identity. Between them the research interests of Nettleton and Burrows span all of these themes but the visit to the SSRC was primarily motivated by work being undertaken under the auspices of two of these themes in particular – health and technologies. The Centre's work under the health theme includes research on medicine, medical technologies and organisations, health policy, the body, well-being, and sport and leisure. During our visit we were invited to participate in an inaugural meeting of a new network of researchers from the Canterbury region interested in these areas of work (see below). Work under the technologies theme includes sciences and technologies, material culture,

innovations, technologies and organisational change, ICTs and the digital divide. Whilst in New Zealand we were able to participate in a major project under this theme - *Constructive Conversations: biotechnologies, dialogue and informed decision making* – led by Dr Rosemary Du Plessis, which focuses on science policy and the impacts of new technologies (see details below).

Activities Undertaken

We gave three well-attended formal seminar presentations and attended two networking events where we were able to compare and contrast research and debates in the UK with ongoing work in New Zealand. In addition, we organised meetings with eight individuals all of whom were engaged in various aspects of research on health and informatisation processes.

Presentations

We first presented a paper ‘The emergence of e-scaped medicine’ (based upon a forthcoming article in the journal *Sociology*) to the Department of Sociology and Anthropology Seminar Series on Friday 26th March. The paper was attended by circa. 30 people and generated a lively discussion.

A second presentation - ‘Sorting Places Out? The Social Politics of Neighbourhood Informatisation’ (based upon an article forthcoming in the journal *Information, Communication & Society*) - was made on Tuesday 30th March in the SSRC Seminar series. In addition to staff from Sociology and Anthropology this also attracted staff working in social geography, computer science and from the City Council. The paper was attended by circa. 30 people and again generated a lively discussion.

A third and final presentation - ‘Health eTypes? The Everyday Use of the Internet for Health’ (based upon an article forthcoming in the journal *Information, Communication & Society*) – was presented to the Public Health Group of the

Christchurch School of Medicine and Health Sciences, University of Otago on Thursday 1 April. The paper was chaired by Prof. Peter Davis (see below). Public health academics and practitioners, GPs and health policy analysts attended this presentation. About 20 people attended.

Networking Events

We participated in an afternoon event under the auspices of the *Constructive Conversations* project on Wednesday 31st March 2004. Constructive Conversations/ Kōrero Whakaaetanga is a five-year research project funded by the New Zealand Foundation for Research, Science and Technology (FRST) and it is based within the SSRC at the University of Canterbury. It is primarily concerned with enhancing public participation in discussion and decision-making about new biotechnologies. All components of the research take careful account of appropriate processes for dialogue with Māori, as well as with other New Zealanders.

The research also examines the ethical frameworks New Zealanders bring to discussions about new health biotechnologies, and the implications for public policy of these frameworks. The work is multi-disciplinary and includes social scientists, educationalists, natural scientists and ethicists. As well as academics it includes representatives from research companies and the New Zealand Council for Educational Research (NZCER). Constructive Conversations/ Kōrero Whakaaetanga is one of a number of research projects developed by the New Zealand Institute of Gene Ecology (NZIGE), which is again based at the University of Canterbury.

There were clearly a number of overlaps between the work of the constructive conversations project and elements of the IHT programme. Our own particular interests were in the manner in which the project was using the internet as a mechanism for engaging with public debates and we were able to contribute inputs from our work from both the IHT project on e-health and an earlier project on

‘virtual community care’ funded by an earlier ESRC programme on the Virtual Society? (Burrows *et al.*, 2000). We were also able to introduce the IHT programme work of Ann Kerr and her colleagues on ‘genetic citizenship’ to the project team. The work of the *Constructive Conversations* project group also formed the basis of some of the discussions we had within the context of meetings with individuals (see below).

Rosemary Du Plessis and her colleague Anne Scott from the project are coming to the UK in September/October 2004 and we will meet with them again in York. We also hope to facilitate a meeting between them, Ann Kerr, Andrew Webster and other colleagues at York (and elsewhere from the IHT programme and beyond) interested in the sociology of genetics, ethics and new technologies of public participation.

A second networking event we attended took place on Tuesday 6 April 2004. This was the launch event of a health research network and was attended by about 30 researchers working in the Canterbury area all with interests in the sociology of health and illness. We gave a brief talk on our own work and on the organisation of research funding for medical sociology in the UK. We are maintaining email contact with some members of this group who share interests with us in the informatisation of health and theories of emergence and complexity in social theories of health. Some colleagues from this event will be coming to the UK in the next 12-24 months and intend to visit us in York (see below).

Meetings with individuals

Our most productive time was probably spent in a series of meetings with individuals. In what follows we summarise whom these people were, something of their backgrounds, the nature of our discussions, and any outputs likely to result.



We had a series of meetings with *Victoria Grace* and her post-doctoral fellow *Sarah MacBride-Stewart*. Grace, currently a senior research fellow in the social

sciences in the College of Arts at Canterbury, has a set of research interests that have run in parallel with those of Sarah Nettleton over a number of years – pain; health promotion; undiagnosed illness; and informatisation processes in health and medicine. She is currently doing work on: the epistemology and ontology of medicine in the information age; the meanings of chronic pelvic pain; genetic histories and gamete donation; and applications of the work of Baudrillard. *MacBride-Stewart* is working with Victoria Grace on a chronic pelvic pain project but has more general interests in feminist qualitative methodologies in relation to bodies, health and sexuality. She will be relocating to the UK in the summer of 2004 to work with colleagues working on the sociology of health and illness at Cardiff University. She will be attending the 2004 BSA Medical Sociology conference at York and we will meet with her again then. Our discussions related primarily to two rather different areas of work: a common interest in the sociology of pain and undiagnosed illness (Nettleton, 1992; Nettleton et al., 2004; Grace, 2003a; Hart and Grace, 2000) – a topic that formed the focus of another recent ESRC grant held by Nettleton; and a concern with the ontological and epistemological consequences of informatization processes for medicine (Nettleton, 2004; Grace, 2003b). Since returning to the UK Nettleton has kept in contact with Grace and they are currently planning to write some papers together. Grace hopes to visit the UK (including York) within the next 24 months and we are hopeful that a productive research/publishing relationship will develop.



We also had a series of meetings with both *Anne Scott* and *Rosemary Du Plessis* in relation to issues that emerged from the two networking events (described above). Anne Scott is interested in how new technologies affect women, indigenous peoples, ethnic minorities, and people in developing countries? While lecturing at Bradford University in the UK, she also studied the use of ICTs by community and social activists. Since coming to Canterbury in 2001 she has focused her research on the politics of biotechnology. Her primary role on the *Constructive Conversations* project (described above) is on the development of more democratic ways of making decisions about health biotechnologies. Rosemary Du Plessis has long-term interests in gender, family, work and embodiment but her

current interests are government policy and public debate about the uses of science and technology. She leads the *Constructive Conversations/ Whakaaetanga Korero* project that is exploring people's responses to issues relating to genetic testing. Although not uninterested in the specifics of research on e-health, both Anne and Rosemary were more interested in the remit of the ESRC IHT programme as a whole, viewing it as being broadly homologous to the work they were undertaking in the *Constructive Conversations/ Whakaaetanga Korero* project. This interest was most obviously substantive, but we also discussed the differential organisation of research on similar topics in the UK compared to New Zealand. The work being undertaken as part of the *Constructive Conversations* project is organised and funded more along the lines of what the ESRC might term a *Priority Network* rather than a programme. As we have already noted Anne and Rosemary are coming to the UK in September/October 2004 and we will continue discussions then alongside other colleagues from the IHT programme.



We also met with Professor Peter Davis after our seminar at the University of Otago which he chaired. Prof Davis currently holds a Chair at Christchurch School of Medicine and Health Sciences at the University of Otago. However, from July 2004 he is moving to take up a newly established Chair in the Sociology of Health and Illness in the Department of Sociology at the University of Auckland. He will also be the new HoD of Sociology at Auckland. He is very familiar with the work of Sarah Nettleton and they have corresponded in the past. In the 1980s they were both working on the sociology of dentistry (Nettleton, 1992; Davis, 1980). He has a set of wide ranging interests in medical sociology, health technology assessment and public health policy. We had a wide-ranging discussion with Professor Davis about: the increasingly global character of sociology as a discipline; developments in methodology (he is concerned about the lack of quantitative skills in New Zealand social science and was interested in what the UK ESRC had implemented with the 1+3 PhD scheme); the impact of the UK RAE on medical sociology and what might happen in New Zealand as a consequence of the PBRF; and, more specifically, about the sociology of health informatization processes in the UK in comparison to New Zealand. In particular we discussed the implications of the

‘evidence-based’ turn in health, especially the role of systematic reviews in public health research and how these might usefully be disseminated to consumers of health-care. We also discussed the findings of our work on the lay uses of e-health in the UK and how they might differ in relation to the New Zealand health care system (where GP visits have to be paid for and where prescribed pharmaceuticals are widely advertised).



We also met with *Fiona Coyle* who is currently a postdoctoral researcher in the Agribusiness and Economics Research Unit at Lincoln University. She is a social and health geographer with research interests in: social theory (in particular Virilio, Bakhtin, Hayles and Haraway); posthumanism; biotechnology; complexity theory; environmental health; hybridity; space and place; corporeality and literary geography. She attended our paper on ‘e-scaped medicine’ and we found much in common to discuss as she had applied a broadly parallel analysis to understanding the emergence of environmental illness (Coyle, 2004). We also met to discuss her work on this topic because of new ESRC funded work that Nettleton is undertaking with Potts and Cinderby at York - as part of the Science and Society programme - on perceptions of the environmental risks of breast cancer. Since our return to the UK she has contacted Nettleton to ask for comments on a paper she has prepared for the journal *Space and Society* on the application of complexity theory to the social geography of health and illness in the information age.



Hazel Ashton is a PhD student (supervised by Prof David Thorns) with who Burrows had been in correspondence before the visit in relation to common research interests. She is working on community informatics, social capital and health, drawing upon the work of Scott Lash in particular in order to examine the rhetoric and the reality of ICT-enabled ‘reflexive community’ in a suburb of Christchurch. She was already familiar with the work Burrows had done with Loader and colleagues at CIRA in Teesside on community informatics and health and a useful meeting was held that focussed on methodological and theoretical issues in community informatics research. Contact is being maintained and it is hoped that some comparative work on applications of community informatics in

provincial urban contexts might develop. Hazel is also hoping to submit a paper on her work to the journal *Information, Communication and Society* (Burrows is on the editorial board).



Finally, we also met with *Jamie Pearce*, a lecturer in health and social geography at the University of Christchurch with interests in the social and cultural implications of GIS for health. He is interested in some of the more technical aspects of health-related GIS technologies and he had a detailed discussion with Burrows about some of the dis/similarities between data collection and the spatial measurement of 'health' in New Zealand compared to the UK.

Some Observations

There was a sense amongst many of the people we met that a number of issues had a longer history in the UK and were perhaps more established than in New Zealand. For example, the 'evidence base' movement within health and related areas of social policy was perceived to be less developed. There was also a view that the use of the internet for health issues was not so ubiquitous. However, as yet it remained under researched and so this was more of an impression than an empirically based observation. There was much interest in the IHT programme research on this topic and on the related issues of the (de)regulation of drug advertising. By contrast there seemed to be an established programme of work on public participation and lay involvement in debates on health technologies – most especially biotechnologies and genetics. A widespread policy concern to take account of Māori interests, concerns and perspectives has led to the development of a range of qualitative methodologies designed to elicit their views. These methodologies are now being deployed more generally in the context of debates about both biotechnologies and informatisation processes (Du Plessis, 2003).

Another overlap was the congruence of conceptual thinking around issues of complexity and emergence, and the applicability of these theorisations to issues of bodies, health, technologies and space. Overall it is evident that academics

working on these topics in New Zealand are keen to maintain links and establish networks with academics in the UK. The quality of work in New Zealand seems to be generally high and the literatures and debates drawn upon are broadly similar to those in the UK. The relationship between sociologists and policy makers appears to be far closer New Zealand than in the UK

Future Collaboration

At an individual level Nettleton and Burrows will maintain research contact with a number of people (Thorns, Grace, Scott, Du Plesses, MacBride-Stewart, Ashton and Davis in particular). We will also facilitate meetings between some of these people and colleagues at York and the wider IHT programme when they visit the UK. More generally there may well be scope for more formal links between the SSRC at Canterbury and colleagues at York and elsewhere. The research concerns of SATSU, CHP and SPRU clearly overlap with those of the SSRC as do those of sociologists and social policy analysts at York more generally. A number of highly regarded researchers at Canterbury would be keen to explore the possibilities of academic/home exchanges for short, medium or long term periods with colleagues at York.

References

Burrows, R., Nettleton, S., Pleace, N., Loader, B. and Muncer, S. (2000) 'Virtual Community Care? Social Policy and the Emergence of Computer Mediated Social Support' *Information, Communication and Society*, 3, 1, 95-121.

Coyle, F. (2004) "'Safe space" as counter-space: women, environmental illness and "corporeal chaos"' *The Canadian Geographer* 48,1, 61-74.

Davis, P. (1980) *The Social Context of Dentistry* London, Croom Helm.

Du Plessis, R. (2003) 'Democracy, Participation and "Scientific Citizenship": New Zealand Initiatives', Paper Presented to the *Policy & Politics* Conference on Policy and Politics in a Globalising World, Bristol 24-26 July.

Grace, V.M. (2003a) 'Embodiment and meaning: understanding chronic pelvic pain', *Journal of Consciousness Studies*, 10, 11,: 41-60.

Grace, V. (2003b) 'Medical visualisation: ontological politics and paradoxes' in Grace, V. Worth, H. and Simmons, L (eds) *Baudrillard West of the Dateline*. Dunmore Press: Palmerston North. pp 189-206.

Hart, B. and Grace, V.M. (2000) 'Fatigue in chronic fatigue syndrome: a discourse analysis of women's experiential narratives' *Health Care for Women International*, 21, 3, 187-201.

Nettleton, S. (1992) *Power, Pain and Dentistry* Buckingham, Open University Press.

Nettleton, S. and Burrows, R. (2003) 'E-scaped medicine? Information, reflexivity and health' *Critical Social Policy*, 23, 2, 165-186.

Nettleton, S. (2004) 'The emergence of e-scaped medicine', *Sociology*, 38, 4 forthcoming.

Nettleton, S. O'Malley, L., Burrows, R. and Watt, I. (2004) 'Health E-types': an analysis of the everyday use of the Internet for health' *Information, Communication and Society* Forthcoming in special issue on e-health.