



Annual Interdisciplinary Workshop – May 2006

Health Care Work, Technologies and Places: Concepts, Methods & Practices

Annual Interdisciplinary Workshop
May 4 & 5, 2006
St. Andrew's Club & Conference Centre
Toronto, Ontario

Welcome to the Fourth Annual Workshop. *Health Care, Technology, and Place* (HCTP) is a CIHR Strategic Research and Training Program and Collaborative Doctoral Program, launched at the University of Toronto in 2002. In 2003, HCTP was awarded an Interdisciplinary Capacity Enhancement (ICE) Team Grant to support collaborations among HCTP faculty, mentors and fellows. HCTP's aim is to develop humanistically-informed biomedical and social scientists and scientifically-informed humanists and, to generate new lines of scholarship about geographically dispersed, technologically-mediated health care. Visit the website to learn more about the HCTP Program, Doctoral and Post-Doctoral Fellowships, and Partnership Opportunities. www.hctp.utoronto.ca

Handwritten signature of Patricia McKeever in black ink.

Patricia McKeever, PhD
HCTP Co-Director

Handwritten signature of Peter C. Coyte in black ink.

Peter C. Coyte, PhD
HCTP Co-Director

Sponsors:

CIHR Institute of Health Services and Policy Research/Institute of Gender & Health/Knowledge Translation

The Change Foundation



CIHR IRSC





Table of Contents

Workshop Overview	1
Thursday May 4th – Technologically-Mediated Health Care Work Evaluation Form – page 4	2
Friday May 5th – Health Care Work and Places Evaluation Form – page 7	5
Session Abstracts In Order of Agenda	8
Speaker & Facilitator Biographies Alphabetical	17
Participant Contact Alphabetical	29
Appendix Reference Article for HCTP Fellows' Session	32



Health Care Work, Technologies and Places: Concepts, Methods & Practices

Workshop Overview

To an unprecedented extent health care work is technologically-mediated, spatially and temporally modified, and geographically dispersed.

The 2006 workshop assembles scholars, researchers, clinicians, and designers from the health and biomedical sciences, the social sciences, and humanities to engage in dialogue about the clinical, political, and cultural significance of technologically-mediated health care organization and provision. The workshop provides opportunities to grapple with a range of clinical, aesthetic, social, economic, technological, political and ethical issues that arise from relationships among established and emerging health care technologies, the range of settings where care takes place, and health care work.

This two-day invitational workshop consists of a mix of plenary sessions with facilitated discussion, concurrent research methods sessions, and a HCTP Fellows' interactive session.



Technologically-Mediated Health Care Work

Thursday May 4, 2006 (8 am – 12 pm)

Registration & Breakfast (8:00 – 8:20 am St. Andrew's Lounge)

Welcome, Opening Remarks & Introductions (8:20 – 8:30 am St. Andrews Hall)

Patricia McKeever

Welcome & Opening Remarks

Kirstin Borgerson

Kiran van Rijn Award

Plenary Session I (8:30 – 10:00 am)

Joel Howell

Medicine in Cyberspace: Does Place (still) Matter?

Alberto Cambrosio

Biomedicine's Epistemic and Transnational Spaces and Networks: Conceptual and Methodological Issues

Elizabeth D. Harvey

Facilitated Discussion

Break (10:00 – 10:30 am)

Plenary Session I (continued 10:30 – 12:00 pm)

Jack Dowie

Decision Technologies in Health: Balancing Analysis and Intuition

Jane Sandall

Making Babies: The Routinisation of New Reproductive Technologies and Parental 'Decision Making'

Pascale Lehoux

Facilitated Discussion

Lunch (12:00 – 1:00 pm)



Technologically-Mediated Health Care Work
Thursday May 4, 2006 (1 pm – 5 pm)

Concurrent Methodology Sessions (1:00 – 2:00 pm)

Katherine Boydell (St. Andrew's Lounge)

Advancing Qualitative Methods: A Framework for Focus Group Analysis

Jeffrey Hoch (St. Andrew's Hall)

Decisions Based on Cost-Effectiveness Analysis: How Much More Are We Willing to Pay for Equity?

Pia Kontos (Edinburgh Room)

Dramatizing Data

Break (2:00 – 2:30 pm)

Plenary Session II (2:30 – 4:30 pm)

Thomas Schlich

Technology and the Body: How the Rise of Surgery has Changed Modern Body Concepts

Carl May

Theorizing the Recalcitrant Professional: How Research Makes Sense of Intention and Diffusion

Alex Mihailidis

Artificial Intelligence and Healthcare

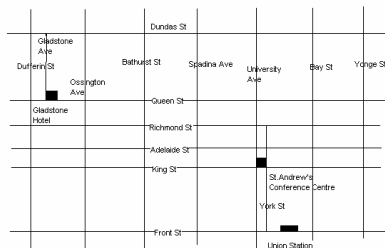
Eric Mykhalovskiy

Facilitated Discussion

Closing Remarks & Evaluation (4:30 – 5:00 pm)

Dinner & Music (6 pm – 10 pm)

Gladstone Hotel, 1214 Queen Street W





Thank you for participating in the 2006 HCTP Annual Workshop. We need your opinions about the quality of the workshop for planning and program evaluation purposes. Please complete this form, remove it from your Program and it will be collected shortly. Feel free to provide additional feedback about the workshop program, communication and/or administration.

a) Comment on the content of today's sessions. Our goals were to enable participants to engage with scholars from different backgrounds and to identify content relevant to their own scholarship. To what extent were we successful? Please give examples.

b) Comment on the format of the workshop (plenary sessions and concurrent session).

c) How would you describe the 2006 Workshop for a Report to The Canadian Institutes for Health Research?

d) Additional comments:

e) We would like your permission to use your comments from this evaluation for insertion in our reports and communication materials regarding the workshop. Permission Granted:

Thank you!



Health Care Work and Places

Friday May 5, 2006 (8 am – 12 pm)

Registration & Breakfast (8:00 – 8:30 am St. Andrew's Lounge)

Plenary Session III (8:30 – 10:00 am St. Andrew's Hall)

Blake Poland

Healthcare Settings and the Social Context of Practice: Unpacking How Place Matters

Julia Twigg

When Care Comes into the Time and Space of Home

Jim Dunn

Facilitated Discussion

Break (10:00 – 10:30 am)

Plenary Session III (continued 10:30 – 12:00 pm)

Sarah Whyte

Creating Space for Inter-professional Communication in the Operating Room: Design and Implementation of a Preoperative Team Checklist

Tilda Shalof

The World of the Intensive Care Unit: A Nurse's Story

Ellen Hodnett

Facilitated Discussion

Lunch (12:00 – 1:00 pm)



Health Care Work and Places

Friday May 5, 2006 (1 pm – 5 pm)

Concurrent Methodology Sessions (1:00 – 2:00 pm)

Donald Boyes (St. Andrew's Lounge)

More than Mapping: An Introduction to Geographic Information Systems

Pamela Hudak (St. Andrew's Hall)

Conversation Analysis and Patient-Provider Communication

Liza McCoy/Eric Mykhalovskiy (Edinburgh Room)

Texts, Time and Place: Using Institutional Ethnography in Health Research

HCTP Fellows' Panel (2:00 – 3:00 pm St. Andrews Hall)

Farah Ahmad, Kirstin Borgerson, Jill Cameron, Valorie Crooks, Andrea Stone

Shared Decision Making and Health Care Work: Interdisciplinary Perspectives

(Please see Appendix for Reference Article)

Break (short break with refreshments available during session)

Plenary Session IV (3:00 – 4:30 pm)

Anne Carlyle

Bloorview Kids Rehab: Purpose and Participation in Design

Annmarie Adams

Collapse and Expand: Design for Tuberculosis, 1909-1956

Shelley Wall

Facilitated Discussion

Closing Remarks & Evaluation (4:30 – 5:00 pm)

Peter C. Coyte

Acknowledgements



Medicine in Cyberspace: Does Place (still) Matter? Joel Howell (MD, PhD) University of Michigan

Over the past century or so, Western medical practice has become dominated by the use of medical technology. Some of that technology was initially placed in hospitals, serving to create and justify the centralization of care. Yet technology has increasingly been used to span distance, often great distance. Sick people, healers, bodily fluids, and medical information all move rapidly and almost seamlessly about the globe. In this talk I will ask whether the long-running and pervasive technological revolution has done more to erase or to emphasize spatial differences in health care. I will ask who is doing the work of the new technology, and who is bearing the associated costs. I will also make a few tentative suggestions about the changing role of hospitals over the next few decades.

Biomedicine's Epistemic and Transnational Spaces and Networks: Conceptual and Methodological Issues Alberto Cambrosio (PhD) McGill University

The evolution of Western medicine since World War II may be described as a realignment of biology and medicine that has resulted in the emergence of new practices based on the direct interaction of biology and medicine. The post-war realignment of biology and medicine has in turn been accompanied by the emergence of a new type of objectivity - regulatory objectivity - that is based on the systematic recourse to the collective production of evidence. The term "collective" refers to the kind of evidence that is produced, for instance, by inter-laboratory studies, multi-center clinical trials and research consortia that develop collective devices such as mouse models of disease, genetic maps or clinical and laboratory guidelines. Indeed, collaborative forms of work such as extended networks, expert groups and consortia increasingly structure biomedical activities. The collaboration often extends beyond the border of nations and accelerates the globalization or international standardization of biomedical activities which increasingly distinguish western biomedicine from other types of medical practices. They are particularly prominent in the cancer field, where procedures such as multi-center clinical trials have been instrumental in establishing the specialty of oncology, and even more so in subfields such as cancer genetics, where bio-clinical activities - e.g., testing for breast and ovarian cancer genes and follow-up interventions - are predicated upon the articulation of a number of tasks performed by bio-clinical collectives. In addition to discussing substantive issues, the presentation will address the methodological challenge of analyzing the new collective configurations of biomedical work and the thick web of (textual, discursive, virtual, material, etc.) entities they generate and circulate.

Decision Technologies in Health: Balancing Analysis and Intuition Jack Dowie (PhD)
London School of Hygiene and Tropical Medicine

Numerous confusions characterise the contemporary discourses in both clinical medicine and public health and in the increasing number of bodies around the world that impact on the clinical-public interface (e.g. through influencing reimbursement policies within public health services). These confusions reflect - in addition to those intentionally promoted by self-serving stakeholders of all kinds - failure to clarify and locate the distinctions between:

- Knowledge, valuation and decision technologies
- More analytical and more intuitive modes of inquiry, valuation and choice
- Coherence-focused and correspondence-focused approaches to the assessment of quality and validity
- Bayesian and non-Bayesian conceptualisations of knowledge and uncertainty
- Absolutist/deontological and consequentialist/utilitarian approaches to ethics.

A new map of the world of health decision making, locating alternative disciplines and practices in terms of these distinctions, is offered as the basis for clarifying the meta-issue of deciding how to decide - given we accept (as Kenneth Hammond argues) that we are engaged in the unenviable task of allocating the unavoidable injustices that will follow from the inevitable errors that we will make as a result of the irreducible uncertainties under which decisions must be made. Four basic Decision Technologies relevant to both clinical medicine and public health emerge: the biological, the intuitive, the verbal TIABIM ('Taking into Account and Bearing In Mind') and the decision analytical. Their characteristics in terms of the above distinctions are identified and the methodology for their comparative evaluation considered in the light of the decision task and decision makers' responsibilities. Since powerful interests and passions are involved in the comparative evaluation of Decision Technologies in the health arena, we emphasise the need for evaluation go well beyond prescriptive technical or procedural requirements to address the fundamental issue of how transparent equitable efficiency is to be best achieved.

Making Babies: The Routinisation of New Reproductive Technologies and Parental 'Decision Making' Jane Sandall (PhD) King's College London

Risk is a pervasive concept in perinatal services, as women & their unborn babies are being reconfigured as objects of surveillance, rather than recipients of care. The findings of this study come at an important time when current UK screening policies are advocating for the first time, that the offer of screening for foetal abnormality and particularly Down's syndrome become a routine part of antenatal care for all women, combined with the move to first trimester screening technologies, which achieve the greater level of accuracy required. It has been argued that women welcome the increased knowledge and control such technologies bring. However, there is concern that this introduces a new level of surveillance and medicalisation into pregnancy, of how choice is constructed, and of the organisational, social, ethical implications for service delivery and public policy. Data is drawn from a study funded by the ESRC/MRC Innovative Health Technologies Programme of the first UK NHS Hospital offering such screening. Using a range of qualitative and quantitative methods, this study explored the social, ethical and organisational implications of new screening technology implementation in the clinic. We discuss how this new technology has shaped maternal health services delivery, and how clinicians, women and their partners view these developments.

Our findings explore how non-directiveness and informed decision-making are constrained within a context where an innovative screening technology is conflated with routine care. The latest report from the Human Genetics Commission states that an ethical screening policy is built on such concepts, however our findings show that the implementation of new technologies which routinise first trimester screening may erode such practices, which already have been more rhetoric than reality in maternal health services. The pace at which first trimester screening is being introduced and the potential consequences for an ethical screening policy require wider policy debate, and a focus on the intended and unintended consequences of new health technologies are crucial in informing future developments in this field.

Advancing Qualitative Methods: A Framework for Focus Group Analysis Katherine Boydell (PhD) Hospital for Sick Children

The value of qualitative focus group research lies in its exploratory and explanatory power, achievable with methodological rigor at all stages of the research process; including design, fieldwork, and analysis. The first two stages, design and fieldwork, are reasonably straightforward and are described fully in the extant literature. It is the third area, analysis, which suffers from lack of attention. Current research outlines the organization and conduct of focus groups; however, a critical gap exists regarding issues of data analysis, such as reporting in detail the approach to analysis that was used in a particular study. Empirical studies of alternative modes of analysis that focus on group interaction are essential, wherein the focus group is not simply a forum for the emergence of thematic content. This presentation focuses on analysis and addresses the current need for an analytic framework in qualitative focus group research by disclosing the process of interpretation undertaken, documenting interaction, and attending to analytic details such as transcription, and the resources and time taken to perform such analyses. This represents an important contribution to qualitative focus groups as a method.

Decisions Based on Cost-Effectiveness Analysis: How Much More Are We Willing to Pay for Equity? Jeffrey Hoch (PhD) University of Toronto

The goal of this session is to discuss how decisions based on cost-effectiveness analysis (CEA) rely on value judgments and how these might be related to equity. To prepare participants for this discussion, I will introduce core concepts of CEA and explain their relationship with decision making and equity. Topics that we will discuss as a group will include:

1. Is it ethical to use cost-effectiveness analysis to influence health care decisions (Are economic concerns ethical in health care, technology and place?)?
2. Is inferior care ever worth it (Should we blame or thank Jack Dowie?)?
3. Are some people worth more than others (Does Mary have a little lambda?)?
- 4.

Famous health economists have had their say. Using CEA concepts, what do you think?



Dramatizing Data Pia Kontos (PhD) Toronto Rehabilitation Institute

This paper discusses our use of research-based drama as an alternative method of knowledge translation to explore with health care practitioners in focus groups how the notion of embodied selfhood – the idea that despite severe dementia selfhood can continue to be expressed through movements and gestures of the body – could enhance person-centred dementia care. The appeal of dramatic performance as an alternative medium for the translation of research is that it provides an accessible presentation of research to audiences of diverse disciplinary backgrounds, it recovers the experiential immediacy of the body present in the original data gathering setting, and it can foster critical awareness and engage audiences to envision new possibilities. Kontos, P. and Naglie, G

Technology and the Body: How the Rise of Surgery has Changed Modern Body Concepts Thomas Schlich (PhD) McGill University

In the twentieth century individual bodies became the locus for dealing with issues that had previously belonged to other realms of social life and culture, such as politics, morals or religion. By defining problems as belonging to the bodily sphere, they became amenable to medical treatments in the form of a circumscribed and controlled intervention into the body of individual, in other words to a technological fix. In my talk I will focus on the strategy of the technological fix and analyze its significance for concepts of the body. More specifically, I will use the example of surgery and describe how the use of the technical fix strategy in areas like traumatology, brain surgery, cosmetic surgery and genital surgery has resulted in a positive feedback loop which is shaping modern culture in many areas. As a result, the body has become more significant as a place of problem solving and manipulation. At the same time, the body is increasingly seen as an object, separate from the person as such (who owns a body rather than is a body).

Theorizing the Recalcitrant Professional: How Research Makes Sense of Intention and Diffusion Carl May (PhD) University of Newcastle

Agencies that fund research on health, health services and health technologies are often explicit in their expectation that such work will have an evaluative element and will be carried out by multi- or inter-disciplinary teams of researchers. The policy assumption that underpins these expectations is that combining and co-ordinating the methodological and analytical perspectives of different disciplines adds a significant value to this kind of work. But the emphasis placed on methodology in current debates about interdisciplinary evaluations raises interesting questions about how actors are understood in such contexts. This paper explores these problems with reference to two studies: (i) of researchers at work in two domains: 'quality improvement' research (researchers in six European countries working to close the gap between routine and evidence-based clinical practice), and (ii) telemedicine research (British researchers working to use new technologies to make services more responsive over distances). This paper will explore the problems of 'territory' and 'governance' that stem from interdisciplinarity: such problems increasingly form features of the terrain over which social science studies of health and health care are accomplished.

***Artificial Intelligence and Healthcare*** Alex Mihailidis (PhD) University of Toronto

Canada's healthcare system is currently faced with the challenge of caring for an increased number of elders who are living with various life-style related and chronic diseases and impairments, while dealing with a shortage in the number of available clinicians, nurses, and other caregivers. This has resulted in an increased need for new treatment options and solutions that are robust and easily scalable to deal with this growing problem. In particular, researchers have been looking at the use of new healthcare technologies as a potential solution.

These technologies have included the development and use of physiological monitoring devices, emergency response systems, and other tele-health/rehabilitation systems. However, while the majority of these devices have had a positive effect on the healthcare of the user, they have also resulted in an increase burden and workload on nurses, caregivers, and family members who are required to interact with these technologies to ensure that they work properly and effectively. Many of these systems require someone to initially set them up and to program them for a specific user. Further programming is then often required to ensure that the technology will remain appropriate as the user's condition(s) and needs change with time.

In response to the above challenges, we have been focusing on the development of healthcare technologies that use artificial intelligence. Such a device would be able to automatically learn about the user and environment, continuously collect data and information, and use this contextual information to autonomously make considered and rational decisions— i.e., without the need for manual interaction with the user or caregiver. It is thought that the use of artificial intelligence will not only allow us to develop more robust healthcare technologies, but will also reduce the burden and workload on nurses, caregivers, and family members.

This talk will present work that has been completed by the Intelligent Assistive Technology and Systems Lab on the use of artificial intelligence in healthcare. It will focus on two intelligent systems across two healthcare settings— in the home and in a long-term care facility. The first technology that will be described is an intelligent system for monitoring the level of health and well-being of an older adult in the home. This system can learn and monitor a user's pattern of living and identify irregularities in these patterns, which may signify a change in the person's health. In addition, this system can monitor and detect spontaneous adverse events such as a fall. The second technology will be an intelligent powered wheelchair that allows older adults with cognitive impairments to maintain their mobility in long-term care facilities. Using techniques from robotics this chair helps to prevent collisions between the user and other people (and objects), and attempts to motivate the user exploration of the environment using automated feedback and prompting techniques.

Healthcare Settings and the Social Context of Practice: Unpacking How Place Matters Blake Poland (PhD) University of Toronto

The devolution of care into nontraditional community-based settings has led to a proliferation of sites for health and social care. Despite recent (re)formulations of 'evidence-based' approaches that stress the importance of optimizing interventions to best practice by taking into account the uniqueness of place, there is relatively little guidance in the literature and few attempts to systematically 'unpack' key dimensions of settings most relevant to policy, practice and research. In this presentation, I explore how place matters for health and social care. The presentation will draw on 3 primary sources:

1. Cultural studies, Foucault and STS literatures to elucidate some of the complex interrelationships between power, technology, culture, and place
2. Critical realist approaches to program evaluation
3. Settings approach in health promotion, by way of a framework for analyzing settings for intervention

When Care Comes into the Time and Space of Home Julia Twigg (PhD) University of Kent

The presentation explores the intersection of time and space in the constitution of home care, discussing the multi-layered and conflicting ways in which these two fundamentals of social order impact upon and structure care at home. Home care centres on the management the body, but it is a body located within a specific space – home – and specific time – domestic life. The coming of formal care into this setting can challenge its spatial and temporal ordering, imposing on it alien logics that derive from the globalised world of work and economic production. The session explores the nature of these different rationalities and their implications for the provision of care.

Creating Space for Inter-professional Communication in the Operating Room: Design and Implementation of a Preoperative Team Checklist Sarah Whyte
University of Toronto

Strong interprofessional communication is essential for safe and effective health care, and proven strategies are needed to support the best possible communication among members of health care teams. Experience in other safety-conscious domains, such as aviation, suggests that communication can be made safer through the use of communication routines that are standardized within a team or organization. Our research team implemented a change in communication practices in the operating room at one hospital by designing and implementing a routine "team checklist", which was used to structure a briefing among surgeons, nurses, and anesthesiologists prior to each surgical procedure. Ethnographic observations and participant surveys were used to evaluate the effectiveness of the team checklist briefings. This presentation will provide an overview of the study, exploring two questions in particular: What does it mean to create space for communication in an environment that is not "geographically dispersed"? What are the effects of "mediating" communication that is traditionally autonomous and independent?



The World of the Intensive Care Unit: A Nurse's Story Tilda Shalof (RN) Toronto General Hospital/Author

The Intensive Care Unit (ICU) is a place-world unto itself, with its own culture, mores, language, and most of all, stories. Many of these stories, for various reasons, have never before been documented, only shared privately, behind closed doors. In the ICU, where patients are treated for life-threatening, catastrophic illness, nurses with specialized knowledge and skills are the main caregivers. In her memoir, "A Nurse's Story: Life, Death and In-Between in an Intensive Care Unit" the author tells of her 20-year experience as an ICU nurse through true, personal narratives working in this high-tech environment, providing direct, hands-on care, much of which is mediated and guided by technology. The author will show the many ways in which the particularities of the place-world of the ICU world have a bearing upon the nurse who is to be found at the very nexus between the patient's body and technologies, both standard and novel.

More than Mapping: An Introduction to Geographic Information Systems Donald Boyes (PhD) University of Toronto

A geographic information system (GIS) is a powerful tool for mapping the locations of objects and incidents over geographic space, and then analyzing them to uncover geographic patterns and relationships. This session will provide an introduction to GIS, including an overview of hardware, software, data sets, types of analysis, and avenues for further instruction. Attendees are invited to participate in a discussion of how GIS might be applied to their particular area of interest.

Conversation Analysis and Patient-Provider Communication Pamela Hudak (PhD) St. Michael's Hospital

Conversation analysis attempts to describe and explicate the collaborative practices speakers use and rely upon when they engage in intelligible interaction. Both the production of conduct and its interpretation are seen as the accountable products of a common set of methods or procedures. It is through these procedures that the intelligibility of the social world is made evident.

Texts, Time and Place: Using Institutional Ethnography in Health Research Liza McCoy (PhD) University of Calgary/Eric Mykhalovskiy (PhD) York University

This session introduces institutional ethnography as a method of inquiry particularly suited to studying the social organization of health care work and the deployment of text-based medical knowledges in actual settings. It covers the central analytic project of institutional ethnography and common ways of conducting research, drawing on examples of institutional ethnographic research in the health and human services. Workshop participants will have an opportunity to discuss how they might use institutional ethnography in their areas of research interest.



Shared Decision Making and Health Care Work: Interdisciplinary Perspectives Farah Ahmad MD (U of Toronto), Kirstin Borgerson (U of Toronto), Jill Cameron PhD (Toronto Rehabilitation Institute), Valorie Crooks PhD (York University), Andrea Stone (U of Toronto)

Researchers and health care experts are increasingly calling for shared decision-making between health care professionals and patients. Yet the benefits and drawbacks of this model of care delivery are not always evident. Nor are the implications for those involved in providing health care work. In this panel session we will critically examine the turn toward shared decision-making and patient self-management while specifically considering the impact of the altered roles of both patients and health care professionals on the delivery of health services. We use the term 'health care professionals' here in its broadest sense to refer to those health workers and caregivers who perform primary, secondary, tertiary, non-conventional, community-based, and even unpaid care. While considering an editorial by Holmes-Rovner (2005), the HCTP themes, and a clinical case study, panelists will propose answers to some of the following questions:

1. What is at the core of this issue;
2. What role(s) do health care professionals play in shaping shared decision-making or self-management;
3. What are the implications of shared decision-making or increasing patient self-management for how we deliver health services or for how we conceptualize health; and
4. What are the pressing research questions we must investigate in order to address these concerns?

Each presenter will address these questions based on her unique disciplinary and research background. A facilitated discussion period following the presentations will allow workshop attendees to respond to the presentations and will provide an opportunity to further critically examine the issue of shared decision-making and health care work from a variety of interdisciplinary perspectives. (Please see Appendix for Article, page 32 in Program.)

Bloorview Kids Rehab: Purpose and Participation in Design Anne Carlyle (ARIDO) Carlyle Design Associates

Bloorview Kids Rehab, a pediatric rehabilitation and complex continuing care centre serving children and their families from across Ontario, opened the doors to its new 350,000 square foot facility in Toronto in February 2006. There is a buzz. A remarkable new place has been created. What makes it remarkable and in what ways did the multi-year process of planning and design contribute to the success? The presentation includes a review of the workshop and site visits process that launched design work, bringing the project team together for the first time – clients, family members, staff and designers – and helping to articulate guiding principles and overall goals. It explores how this foundation, along with user consultations and collaborative design thinking, informed ensuing phases of work. Where did inspiration come from? What issues developed over competing/conflicting needs, visions, place for kids verses workplace, and how were decisions made? What spaces reflect “missed opportunities” to significantly improve the experience of clients and staff and what learning opportunities do these present? How do specific kinds of spaces in the new building – public and circulation spaces, client care team centres, and staff offices for example – differ from those in the two replaced buildings? And, briefly, how do these changes reflect the evolution of design thinking around children's health care facilities as observed and experienced by the designer over 25 years.



Collapse and Expand: Design for Tuberculosis, 1909-1956 Annmarie Adams (PhD) McGill University

This paper explores the complex reflexive relationships between technologies associated with the care and treatment of tuberculosis: the fresh air cure, surgical collapse therapy, architecture (in particular building programmes intended to expand the number and kind of people treated by hospitals), and chemotherapy.

Technology in this sense is a set of resource-using practices marshalled to eradicate tuberculosis. The rest-cure prevalent at the beginning of the twentieth century started a tradition, lasting until the age of antibiotics, where architecture (or more generally the patient's material setting) was one of the physical agents of TB treatment. The increasing use of surgical collapse theories from pneumothorax to lung resections, however, did not displace the importance of the rest cure. Instead, the architecture (with its porches, balconies, and sunning galleries) provided crucial material (spatial) continuity for physicians, surgeons, public health officials and patients, even after the successes of chemotherapy (the first therapy to directly target the tubercle bacillus) augured the end of specialized TB settings.

In order to track contemporary notions of therapy and space, we contrast the medical and architectural images of collapse/renovation and expansion/addition. We review the architectural histories of the Royal Edward Laurentian Hospital in Montreal, looking at the changing design guidelines for tuberculosis care, in the context of changing treatment of tuberculosis patients as a social practice, and not merely a medical one: prevailing cultural and lay beliefs about modern medical care inspired and conditioned the adoption of leading-edge therapeutic advances.

The paper is part of "Design and Practice," a SSHRC-funded that explores the relationship of tuberculosis and space at four key moments in Montreal between 1880 and 2002. This multi-disciplinary investigation, involving researchers from architecture, urban planning, geography, and medicine, situates *design* as a fulcrum at which various *practices* come to bear on defining the problem of tuberculosis and the practical remedies called for in its solution.

Annmarie Adams (School of Architecture, McGill University); Kevin Schwartzman (Respiratory Epidemiology Unit, Montreal Chest Institute, and Department of Medicine, McGill University); David Theodore (School of Architecture, McGill University)



Anmarie Adams (PhD) McGill University, *Collapse and Expand: Design for Tuberculosis, 1909-1956* (HCTP Mentor)

Anmarie Adams is Professor at the School of Architecture, McGill University. She was educated as an architect (M.Arch. 1986) and architectural historian (Ph.D. 1992) at the University of California at Berkeley, following undergraduate studies at McGill (B.A. 1981). Her major areas of research are healthcare architecture and gendered space. Her first book, *Architecture in the Family: Doctors, Houses, and Women, 1870-1900* (McGill-Queen's University Press, 1996), combined both these interests. The book won the 1999 Jason Hannah Medal, given by the Royal Society of Canada, as an outstanding contribution to the history of medicine. Adams co-authored *Designing Women: Gender and the Architectural Profession* (UTP, 2000) with McGill sociologist Peta Tancred. This study of Canadian women architects is the first national overview of women in the profession. Prof. Adams' current research is supported by a Health Career Award given by the Canadian Institutes for Health Research. Entitled, "Medicine by Design: A Hospital for the 21st Century," the project explores contemporary issues in Canadian hospital design.

Farah Ahmad (MD) University of Toronto, *HCTP Fellows' Panel: Shared Decision Making and Health Care Work: Interdisciplinary Perspectives* (HCTP Fellow)

Farah Ahmad is a Doctoral Fellow at the HCTP program. She also holds CIHR Institute of Gender and Health Fellowship Award since 2004. Farah has training in medicine from Punjab University, and in Public Health from Harvard University. Currently, she is in 4th year of her doctoral studies at the Institute of Medical Sciences, University of Toronto. Farah describes herself as a public health researcher with interests in areas of primary healthcare services, women's health and socio-cultural determinants of health. Her research focuses on the healthcare access and utilization at the intersections-of- marginality. Her current examines the effectiveness and feasibility of computer-assisted screening for partner abuse among Canadian women visiting family physicians.

Kirstin Borgerson University of Toronto, *HCTP Fellows' Panel: Shared Decision Making and Health Care Work: Interdisciplinary Perspectives* (HCTP Fellow)

Kirstin Borgerson is a doctoral candidate in the Department of Philosophy at the University of Toronto and a CIHR Strategic Research and Training Doctoral Fellow in Health Care, Technology and Place. Her research interests include philosophy of medicine, philosophy of science, social epistemology, bioethics and feminist philosophy. Kirstin's thesis project draws upon feminist social epistemology in order to propose an answer to the question, 'How should we determine standards of evidence in medicine'? Kirstin aims to clarify the requirements of 'good evidence' in medicine through an in-depth investigation into the nature of evidence and a critical analysis of the more recent writing done on the subject of evidential standards from within the medical community as well as from the alternative medical community. She has presented her work at a variety of national and international conferences and was recently the guest editor for a special issue of the journal *Perspectives in Biology and Medicine* on evidence-based medicine (Autumn, 2005). Kirstin is also a Research Associate with the Comparative Program on Health and Society at the Munk Centre for International Studies and an Ontario Graduate Scholar.



Katherine Boydell (PhD) Hospital for Sick Children, *Advancing Qualitative Methods: A Framework for Focus Group Analysis* (HCTP Mentor)

Dr. Katherine Boydell is a health systems research scientist in the Community Health Systems Resource Group, and scientist in Population Health Sciences at the Hospital for Sick Children. She is also an associate professor in the Departments of Psychiatry and Public Health Sciences at the University of Toronto. Katherine received her Master of Health Science in Community Health and Epidemiology at the University of Toronto and her Doctorate in Sociology at York University. She conducts theoretically based, collaborative, mixed method research in the children's mental health system that is relevant and useful for individuals involved in health and social services at the community level - so that evidence will have an impact and will guide positive change. Her program of research in children's mental health systems focuses on the pathways to mental health care for children and youth, youth with first episode psychosis, paediatric telepsychiatry, the impact of informal support on families of those with mental illness, knowledge translation and exchange in children's mental health, and qualitative methods. She has published many articles in peer-reviewed journals and has presented her research widely, both nationally and internationally.

Donald Boyes (PhD) University of Toronto, *More than Mapping: An Introduction to Geographic Information Systems*

Don Boyes is a Senior Lecturer in the Department of Geography, University of Toronto, specializing in the theory and application of geographic information systems (GIS). He teaches a number of GIS courses at the undergraduate and graduate level. Past research has focused on studying the evolution of arctic river deltas. Current interests include the use of GIS in non-profit organizations, and the emerging field of location-based services. Don has also worked as a consultant in the Northwest Territories, Nunavut, and Ontario.

Alberto Cambrosio (PhD) McGill University, *Biomedicine's Epistemic and Transnational Spaces and Networks: Conceptual and Methodological Issues*

(PhD, University of Montreal, 1984). Professor, at McGill University since 1990. Professor Cambrosio's area of expertise lies at the crossroads of medical sociology and the sociology of science and technology. His work focuses on the "material culture" of biomedical practices, and in particular on the study of the application of modern biological techniques to the diagnosis and the therapy of cancer, the comparative (North-America - Europe) development of cancer clinical trials, and the role of visual imagery in the development of immunology. Professor Cambrosio's most recent project (supported by grants from the Social Sciences and Humanities Research Council of Canada, the Fonds Québécois de Recherche sur la Société et la Culture and the Canadian Institutes of Health Research) examines how modern medicine has come to grips with the multiple and ubiquitous cultural, social and practical differences and variations with which it is increasingly confronted. He is especially concerned with the creation of institutions and instruments to manage these differences and generate consensus, however partial or temporary in nature, and thus with the social and historical dynamics of biomedical regulation, objectification and standardization. His most recent book (*Biomedical Platforms*, co-authored with Peter Keating) analyzes the transformation of medicine into biomedicine and its consequences since the end of World War II, ranging from the recasting of hospital architecture to the redefinition of the human body, disease, and therapeutic practices. The book has been awarded the 2005 Ludwik Fleck Prize by the Society for Social Studies of Science (4S).



Jill Cameron (PhD) Toronto Rehabilitation Institute, HCTP Fellows' Panel: Shared Decision Making and Health Care Work: Interdisciplinary Perspectives (HCTP Fellow)

Jill Cameron is a CIHR and HCTP funded post-doctoral fellow at the Toronto Rehabilitation Institute. She will be joining the faculty of Occupational Science and Occupational Therapy at the University of Toronto in September 2006. Her primary research interest is to examine the experiences of family members who assume the role of informal caregiver for individuals with disability. She has conducted research in the area of advanced cancer, critical illness, mental health, heart failure and her doctoral and post-doctoral research specifically focuses on informal care post-stroke. Jill's aim is to understand caregivers' needs and develop timely and relevant programs to assist them with their care-giving activities and pursuit of other valued activities and interests. Funded by an Interdisciplinary Capacity Enhancement Grant from HCTP, she is currently studying changing caregiver needs across care environments including acute care, rehabilitation, and the community. Jill and her colleagues are developing an intervention to support caregivers as they move across these care environments.

Anne Carlyle (ARIDO) Carlyle Design Associates, Bloorview Kids Rehab: Purpose and Participation in Design

Anne Carlyle is a professional interior designer with extensive experience in planning and design for public, institutional and health care environments. Since 1984, her firm *Carlyle Design Associates* has provided design consulting services for clients in Canada and the United States. She has earned a reputation for innovation in developing strategies for collaboration and for facilitating participation in design. Involvement of client representatives, staff, public stakeholders, design professionals and artists has been used to create thoughtful solutions that meet user needs, enhance quality of life and work, and express the purpose and character of a client organization or community. Over the years, health care project work has included new construction and renovations for clients such as the Mayo Clinic in Rochester, Minnesota, The Children's Inn at the National Institutes of Health in Bethesda, Maryland, Children's Seashore House in Philadelphia, the Hospital for Sick Children in Toronto, The Ottawa Hospital Shirley E. Greenberg Women's Health Centre, Alberta Children's Hospital, the Children's Hospital of Eastern Ontario, Montreal Children's Hospital and several community health centres. For the past six years, Anne has been a consulting member of the design team for the new Bloorview Kids Rehab which opened in February this year.

Anne graduated from the University of Toronto (BA) and from the Ontario College of Art and Design (Environmental Design). She is an award-winning member of the Association of Registered Interior Designers of Ontario, the Interior Designers of Canada, and the American Society of Interior Designers. She just completed a three year term serving on the ARIDO board and currently serves on the Advisory Committee for the Algonquin College Interior Design Program and on the Ottawa Women's Health Centre Advisory Board. In 2005, she was elected to membership in the Royal Canadian Academy of Arts.

Peter C. Coyte (PhD) University of Toronto, *Closing Remarks* (HCTP Co-Director)

Peter C. Coyte is Co-Director of the Doctoral Collaborative Program in Health Care, Technology, and Place (HCTP) and Professor of Health Economics in the Department of Health Policy, Management, and Evaluation, University of Toronto. He publishes widely in the areas of health economics, health policy and health services research. His studies have included the measurement of regional variations in health service utilization, evaluations of the cost-effective provision of health care services, and assessments of health service finance, delivery and organization. Dr. Coyte holds a Chair in Health Services Research from the Canadian Health Services Research Foundation in partnership with the Canadian Institutes for Health Research. Dr. Coyte's chair is designed to advance health services research, training, and linkage and exchange activities. Health service restructuring and rapid technological developments have triggered a dramatic shift towards the delivery of ambulatory, home-based, and more recently, internet-based health care. This dispersion of health care services to the places where Canadians live, work, and attend school will have major social and health services repercussions. However, while restructuring has been rapid and ubiquitous, research and research capacity to assess the implications of such change has been lacking. The CHSRF/CIHR Chair, with its links to the program in HCTP, has been designed to address this gap. In the past four years, the Chair has generated a body of research evidence and a network of colleagues, students, and industry and policy partners who use evidence to inform decision-making in the financing, delivery, and organization of home and community care.

Valorie Crooks (PhD) York University, *HCTP Fellows' Panel: Shared Decision Making and Health Care Work: Interdisciplinary Perspectives* (HCTP Fellow)

Valorie Crooks, BA hon., MA, PhD, completed her doctoral degree in the School of Geography and Earth Sciences at McMaster University in the fall of 2005. Her dissertation research was conducted with women living with fibromyalgia syndrome, a contested chronic illness, and examined their negotiations of health services and the doctor-patient relationship. This work was primarily supported by SSHRC, the Centre for Health Economics and Policy Analysis, the Northern Scientific Training Program, and the Arthritis Health Professions Association. Dr. Crooks is currently a CHSRF/CIHR postdoctoral fellow at the York Institute of Health Research (York University) and a CIHR strategic training postdoctoral fellow in Health Care, Technology and Place (University of Toronto). She is also a Course Director in the Critical Disability Studies program at York University where she will be instructing a course she has recently developed entitled *Experiences & Politics of Multiple Identities: Disabled Bodies and Chronic Illness* this summer. At present, her primary focus is on understanding the implications of a lack of interpersonal continuity of care for women managing complex chronic illnesses. In the fall of 2006 she will take up a faculty position in the Department of Geography at Simon Fraser University specializing in health geography.



Jack Dowie (PhD) London School of Hygiene and Tropical Medicine, *Decision Technologies in Health: Balancing Analysis and Intuition*

Jack Dowie took up the newly-created chair in Health Impact Analysis at the London School of Hygiene and Tropical Medicine in 2000, leaving The Open University where he had been a member of the Faculty of Social Sciences since 1976. While at the OU he designed and ran the BBC transmitted multi-media courses on RISK (from the late seventies) and PROFESSIONAL JUDGMENT AND DECISION MAKING (from the late eighties). His early qualifications were in history and economics at the University of Canterbury, New Zealand and he went on to merge these disciplines in doctoral work (at the Australian National University) and subsequent research and teaching in economic development and economic history (first at ANU and then the Universities of Kent and Durham in the UK). What had been side interests in risk phenomena such as entrepreneurship, accidents, gambling and health eventually took over and led to his full time involvement with risk and judgment in health decision making and to research and teaching in both clinical decision analysis and cost-effectiveness analysis in health care. His current focus is on the evaluation of alternative 'decision technologies' in the health context and he has a particular interest in promoting decision-focused approaches within professional education and exploring the way they relate to 'knowledge technologies' and 'valuation technologies'. He is involved in the development of user-friendly software which can raise the analytical level of decision making and policy formation in relation to health, both in the clinical setting of the doctor-patient consultation, and the wider context of health-related policies, programmes and projects. He was a founder member of the Health Economists Study Group and currently serves as a member of the Appraisals Committee of the National Institute for Health and Clinical Excellence, which advises on reimbursement policy within the National Health Service.

Jim Dunn (PhD) St. Michael's Hospital, *Plenary Facilitator* (HCTP Mentor)

Dr. Jim Dunn is a Research Scientist at the Centre for Research on Inner City Health at St. Michael's Hospital, Toronto and an Assistant Professor in the Department of Geography and Planning at the University of Toronto, and an HCTP Mentor. Jim is a social geographer by training, and his research program focuses on spatial aspects of the social and economic determinants of health and the influence of economic and social policies and programs on health inequalities.

Elizabeth D. Harvey (PhD) University of Toronto, *Plenary Facilitator* (HCTP Mentor)

Elizabeth D. Harvey has extensive experience managing and teaching cross-disciplinary graduate programs and supervising research that bridges the humanities and health sciences. She is Professor of English and Director of Graduate Studies. She is the author of *Ventriloquized Voices: Feminist Theory and Renaissance Texts*, (Routledge, 1992), co-editor of *Women and Reason* (University of Michigan Press, 1992), *Soliciting Interpretation: Literary Theory and Seventeenth-Century English Poetry* (University of Chicago Press, 1990), *Luce Irigaray and Premodern Culture: Thresholds of History* (Routledge, 2004), and editor of *Sensible Flesh: On Touch in Early Modern Culture* (University of Pennsylvania Press, 2003). She is completing a book on early modern literature, memory, imagination, the passions, and medicine: *Inscrutable Organs: Gender, Medicine, and Literature in Early Modern England*, and she has started working on a new book (supported by a SSHRCC research grant) on the history and theory of touch: *Sensational Subjects: The Rhetoric of Touch in Early Modern England*.



Jeffrey Hoch (PhD) University of Toronto, *Decisions Based on Cost-Effectiveness Analysis: How Much More Are We Willing to Pay for Equity?*

Jeffrey Hoch received his PhD in health economics from the Johns Hopkins Bloomberg School of Public Health. Dr. Hoch has taught Health Economics and Economic Evaluation classes in Canada and internationally. Currently, Dr. Hoch is pursuing research on the statistical methodology and application of health economics. Special interests include health services research related to mental health and other health issues affecting poor and vulnerable populations. Dr. Hoch is an award-winning teacher and is the recipient of a Career Scientist Award from the Ontario Ministry of Health and Long Term Care.

Ellen Hodnett (PhD) University of Toronto, *Plenary Facilitator* (HCTP Mentor)

Ellen Hodnett is Professor and Heather M. Reisman Chair in Perinatal Nursing Research in the Faculty of Nursing, University of Toronto. Her research program involves rigorous evaluations of forms of care for childbearing women, through large, international, randomized controlled trials. As a result of her association with HCTP (and Pat McKeever in particular), she has embarked on an exciting new program of research to evaluate the effects of ambient technologies in a variety of hospital patient care environments, including labour rooms, MRI suites, and psychiatric seclusion rooms.

Joel Howell (MD, PhD) University of Michigan, *Medicine in Cyberspace: Does Place (still) Matter?*

Joel D. Howell, MD, PhD, is the Victor Vaughan Professor of the History of Medicine at the University of Michigan, where he is also a professor in the Departments of Internal Medicine (Medical School), Health Services Management and Policy (School of Public Health), and History (College of Literature, Science, and the Arts). He received his MD at the University of Chicago, and stayed at that institution for his internship and residency in internal medicine. At the University of Pennsylvania he was a Robert Wood Johnson Clinical Scholar and received his PhD in the History and Sociology of Science. Dr. Howell has been a faculty member at the University of Michigan since 1984. He is Co-Director of the University of Michigan Robert Wood Johnson Clinical Scholars Program and Director of the University of Michigan Program in Society and Medicine. He has written widely on the use of medical technology, examining the social and contextual factors relevant to its clinical application and diffusion, analyzing why American medicine has become obsessed with the use of medical technology. His current research is an attempt to analyze the implication for health policy of factors that have both contributed to and slowed the diffusion of medical technology into clinical practice. His most recent book is *Technology in the Hospital: Transforming Patient Care in the Early Twentieth Century* (Baltimore: Johns Hopkins University Press, 1995). Dr. Howell's research has been supported recently by a Robert Wood Johnson Foundation Investigator Award in Health Policy Research and by a Burroughs Wellcome Foundation Award in the History of Medicine. Recently, he was named to the University of Michigan Society of Fellows.

Pamela Hudak (PhD) St. Michael's Hospital, *Conversation Analysis and Patient-Provider Communication* (HCTP Mentor)

Pamela Hudak BScPT, PhD, is a Research Scientist in the Department of Medicine at St. Michael's Hospital and Assistant Professor at the University of Toronto. She trained originally as a physical therapist before completing a MSc in Clinical Epidemiology and PhD in Medical Sciences. She is interested in how persons with musculoskeletal disorders and surgeons make decisions regarding surgery, in patient satisfaction with treatment outcome, and on the interactive space between surgeons and patients. She is currently using conversation analysis to explore whether ethnic/racial differences in communication between older patients and orthopaedic surgeons may help to explain racial disparities in the rates of surgical procedures.

Pia Kontos (PhD) Toronto Rehabilitation Institute, *Dramatizing Data* (HCTP Fellow)

Dr. Kontos obtained her PhD from the University of Toronto, Department of Public Health Sciences. She is presently a Postdoctoral Fellow at Toronto Rehabilitation Institute, a teaching hospital of the University of Toronto. Her research interests are embodiment, personhood, Alzheimer's disease, and ethnodrama. She has published her research in *Ageing and Society*, *Journal of Aging Studies*, *Dementia: The International Journal of Social Research and Practice*, and *Philosophy in the Contemporary World*. She has also contributed to several edited volumes including *Old Age and Agency*, *Ageing and Place: Perspectives, Policy and Practice*, and *Thinking About Dementia: Culture, Loss and the Anthropology of Senility*.

Pascale Lehoux (PhD) University of Montreal, *Plenary Facilitator* (HCTP Mentor)

Pascale Lehoux obtained her Ph.D. in Public Health from University of Montreal (Quebec, Canada) in 1996. She is Associate Professor with the Department of Health Administration, and Researcher with the Groupe de Recherche Interdisciplinaire en Santé (GRIS) at University of Montreal. She obtained a National Scholar from the NHRDP (1998-2003) and a New Investigator Award from the CIHR-IHPSR (2003-2008). She was a consultant researcher for the Quebec Health Services and Technology Assessment agency (AETMIS) between 1994 and 2004. Pascale Lehoux holds a Canada Research Chair on Innovations in Health (2005-2010). Her research interests lie with the sociology of innovation, the production and use of Health Technology Assessment (HTA), and knowledge utilization. She published more than 40 papers examining the use of computerized medical records, telemedicine, scientific knowledge, home care equipment and mobile and satellite dialysis units. She published papers in *Social Science and Medicine*, the *International Journal of Technology Assessment in Health Care*, the *Journal of Health Politics, Policy and Law* and the *Canadian Medical Association Journal*. Her first book, *The Problem of Health Technology*, was published in April 2006 by Routledge. She is the Canadian Director of an International Master's Program in Health Technology Assessment and Management, involving seven Universities (Univ. of Montreal, McGill Univ., Univ. of Ottawa, Univ. of Barcelona, International Univ. of Catalonia, Catholic Univ. of Rome, Univ. of Toronto) and five HTA agencies in Canada and Europe. She is a Board Member of the Canadian Association of Health Services and Policy Research and editor for *Healthcare Policy*.

Carl May (PhD) University of Newcastle, *Theorizing the Recalcitrant Professional: How Research Makes Sense of Intention and Diffusion*

Carl May is an ESRC research fellow and professor of medical sociology at the University of Newcastle, UK, where he leads the *health technologies and human relations* research programme in the Institute for Health and Society. Carl's first degree is in Social and Economic history (Wales, Aberystwyth) and his PhD is in Social Policy (Edinburgh). Beginning with doctoral research on the structure and organization of nurse-patient relationships in terminal care, continuing through postdoctoral research on adolescent alcohol problems, and early research on the social organization of genetic counseling and the boundaries of professional-patient relations in primary care, Carl's research work has come to be concerned with two key scholarly questions:

- *How does the production and organisation of professional knowledge lead to particular forms of clinical practice?*
- *How are professional knowledge and practice shaped by, and mediated through, new technologies and treatment modalities?*

Since the mid-1990s, these questions have been addressed through comparative studies of physicians, nurses and patients, working mainly in primary care and associated settings at the interface between primary and secondary care, in the UK National Health Service – although his work has also included studies in North America and Europe. Carl's current methodological interests are focused on developing integrative analyses of qualitative data and building middle range models and theories which can extend sociological analyses into clinical research and practice. His research mainly uses discourse analytic and ethnographic research techniques (although it also includes trials, surveys and systematic reviews). Carl's sociological research interests focus on the social organisation of professional knowledge, practice and technologies in health care. His current work includes research on the social shaping of Health Technology Assessment.

Liza McCoy (PhD) University of Calgary, *Texts, Time and Place: Using Institutional Ethnography in Health Research*

Liza McCoy is Assistant Professor in the Department of Sociology at the University of Calgary. She has been conducting institutional ethnographic research for the past fifteen years, primarily in the areas of health, employment, and education. With Eric Mykhalovskiy and other researchers, she studied the institutional and discursive relations shaping the health work of people living with HIV/AIDS. She is currently working on two research projects examining polices and services for immigrant women in Calgary experiencing difficulties with employment, health, housing and domestic violence.

**Patricia McKeever (PhD) University of Toronto** *Welcome and Opening Remarks* (HCTP Co-Director)

Patricia McKeever is Co-Director of the Doctoral Collaborative Program in Health Care, Technology, and Place (HCTP) and a Professor in the Faculty of Nursing. She is a health sociologist whose teaching and research focuses on persons (especially children) who have severe chronic illnesses or disabilities, the technologies they use, their care providers and the places where their care takes place. Her expertise in contemporary social theory, transdisciplinary scholarship, long-term care policy and qualitative research methods are recognized locally, nationally and internationally. Since 2002 she has co-directed HCTP with Peter Coyte, health economist in the Department of Health Policy, Management and Evaluation, Faculty of Medicine. HCTP is the first research training program in the world designed to advance understanding of geographically-dispersed, technology-mediated 21st century health care. The health care landscape is characterized by unprecedented flows of information; mutable coalitions of traditional, alternative, and even robotic care providers; new configurations of physical settings and cyberspaces; and technology-informed and monitored work processes. Based at the University of Toronto, with Faculty Mentors and Fellows from across Canada and abroad, this doctoral and post-doctoral program emphasizes transdisciplinary approaches to complex problem solving, mentorship across disciplines and career levels, and knowledge transfer with decision-maker constituencies. In 2002, HCTP was designated as a Collaborative PhD Program at the University of Toronto and in 2003, McKeever and Coyte were awarded a CHIR Interdisciplinary Capacity Enhancement Grant to further support the program.

Alex Mihailidis (PhD) University of Toronto, *Artificial Intelligence and Healthcare* (HCTP Mentor)

Dr. Mihailidis is an Assistant Professor in the Department of Occupational Science and Occupational Therapy (University of Toronto) with cross appointments in Biomedical Engineering and Computer Science. He has been conducting research in the field of pervasive computing and intelligent systems in healthcare for the past eight years, having published or submitted over 30 publications. He has specifically focused on intelligent systems for elder care and wellness. He currently holds several major research grants from internationally recognized funding agencies and industrial partners to support this work, including the Canadian and American Alzheimer Associations, Intel Corporation, NSERC, and CIHR.

Eric Mykhalovskiy (PhD) York University, *Texts, Time and Place: Using Institutional Ethnography in Health Research & Plenary Facilitator* (HCTP Mentor)

Eric Mykhalovskiy is a sociologist and Assistant Professor in the Department of Sociology, York University. His programme of research focuses on the social organization of health knowledge and is conceptually influenced by institutional ethnography, anthropology of biomedicine, and foucauldian research. His recent work includes studies of formal discourses of health knowledge, in particular health services research and evidence-based medicine, published in such journals as *Social Science & Medicine* and *Health* as well as studies of the interface of biomedical and experiential knowledges in the context of HIV/AIDS, published in *Critical Public Health*, *Social Theory & Health* and elsewhere. He is currently principal investigator of a SSHRC-funded study on the gap between lay and biomedical knowledge in HIV/AIDS, is co-investigator of a SSHRC-funded interdisciplinary (anthropology, history, sociology) study on interspecies health with Melanie Rock (PI) and Thomas Schlich, and very recently received a CIHR New Investigator Award. He is also currently working with Lorna Weir on a study of global public health governance.



Blake Poland (PhD) University of Toronto, *Healthcare Settings and the Social Context of Practice: Unpacking How Place Matters* (HCTP Mentor)

Blake is Director of the MHS Program in Health Promotion in the Department of Public Health Sciences. He teaches courses in health promotion and in community development. Blake has several foci of research, including community development as an arena of practice for health professionals, hospital-community collaboration, settings for public health practice, and the social context of collective lifestyle practices. In most of his research, critical social theory and qualitative methods are employed. Blake has also published several papers on theory and method in health promotion and qualitative research.

Jane Sandall (PhD) King's College, London, *Making Babies: The Routinisation of New Reproductive Technologies and Parental 'Decision Making'*

Jane Sandall is Professor of Midwifery and Women's Health and co-leads the Women and Family Health Research Group at King's College, London. She is a midwife and has an academic background in sociology and social policy. Her research explores two themes: 1) the social shaping of, and impact of maternity policy for providers and women both in the UK and internationally including: a Cochrane Review on midwifery led care, evaluation of a range of midwifery-led care programmes and access to care projects, the impact of continuity of care on the NHS workforce, the training and role of maternity assistants in Europe, the development of maternity policy in Northern Europe and North America 2) exploring the social and ethical implications of reproductive technologies for women and health professionals including: midwives' attitudes and practice on prenatal screening in UK and Europe; ethnic minority women's experiences of prenatal screening; the social and organisational implications for women and health professionals of the implementation of an innovative one stop clinic offering first trimester prenatal screening technology for Down's Syndrome. She was a member of the Expert Maternity Working Group and the Research Group of the Children's NSF and is a member of the MRC National Stem Cell Bank Steering Committee. She is emeritus co-chair of the Research Standing Committee of the International Confederation of Midwives for whom she runs the Midwifery-Research e-list

<http://www.jiscmail.ac.uk/lists/MIDWIFERY-RESEARCH.html>

Thomas Schlich (PhD) McGill University, *Technology and the Body: How the Rise of Surgery has Changed Modern Body Concepts*

Thomas Schlich is Associate Professor and Canada Research Chair in History of Medicine at the Department of Social Studies of Science at McGill University. After working as a physician at the University Hospital in Marburg, Germany, he pursued his historical interests in different research and teaching positions in Cambridge, England, Stuttgart, Germany and Freiburg, Germany. Before moving to Montreal in September 2002 he held a Heisenberg Fellowship of the German Research Council (DFG). He has worked on surgery's connections to science and industry in the twentieth century, the history of organ transplantation, bacteriology, disease concepts in modern medicine, physiology and the relation of medicine and Judaism. His most recent books are *Surgery, Science and Industry. A Revolution in Fracture Care 1950s-1990s* (2002) and *The Risks of Medical Innovation: Risk Perception and Assessment in Historical Context*, edited with Ulrich Tröhler (London and New York: Routledge, 2005). His current research is focused on the rise of surgery, 1800-2000. This work aims at examining how surgery became built into the fabric of modern society and culture, thus providing a new and better basis for understanding surgery's current status as the most important but least questioned technique of body manipulation.



Tilda Shalof (RN) Author, *The World of the Intensive Care Unit: A Nurse's Story*

Staff Nurse, Toronto General Hospital. Graduated from University of Toronto, Faculty of Nursing in 1983. Specialized in critical care nursing since 1987. Tilda is the author of the bestselling memoir, "A Nurse's Story: Life, Death, and In-Between in an Intensive Care Unit." Now in French, Chinese and Japanese, published by McClelland and Stewart, Canada, 2004.

Andrea Stone University of Toronto, *HCTP Fellows' Panel: Shared Decision Making and Health Care Work: Interdisciplinary Perspectives* (HCTP Fellow)

Andrea Stone, BA, BEd, MA, is currently completing her PhD in English at the University of Toronto and holds an HCTP Doctoral Fellowship. Her thesis is titled, "Rule and Regulation: The Body in Early New World African Literature". It interrogates how medical and legal theories informed notions of humanness in the early nineteenth century in Canada, the United States and the Caribbean as the New World attempted to define rights according to race and gender. Such theories influenced and were influenced by literature written by blacks and whites. Andrea's primary aim is to uncover the way in which medical, legal and literary conceptions of race intersected and shaped the practical lives of enslaved New World peoples. Andrea has presented papers on physiology and internalized racism on the "Body of Medicine and Literature" panel at the annual Congress of the Humanities and Social Sciences Federation of Canada (Winnipeg, MB, 2004); on juridical discourse in antebellum medical literature at the Law, Culture and Humanities annual meeting (Austin, TX, 2005), and on Canadian abolitionist publishing at the Modern Language Association annual conference (Washington, DC, 2005). This summer she will be participating in a six-week seminar on "Black Intellectuals" at The School of Criticism and Theory at Cornell University.

Julia Twigg (PhD) University of Kent, *When Care Comes into the Time and Space of Home*

Julia Twigg is Professor of Social Policy and Sociology, University of Kent, UK. She has written extensively on social care, on the support of informal, family carers, and on the caseworker workforce. She has particular interest in questions of the body and its management in care, and in 2000 published *Bathing - Body and Community Care* (Routledge) This year she published *The Body in Health and Social Care* (Palgrave). She is currently working on the subject of clothing and ageing.

Shelley Wall (PhD) University of Toronto, *Plenary Facilitator* (HCTP Mentor)

Shelley Wall is a medical illustrator specialising in web-based patient education. She divides her time between The Hospital for Sick Children, where she develops clinical teaching resources for the Child Physiology Web Project, and the University of Toronto, where she lectures in health communication and biomedical visualisation in the Biomedical Communications program. Her education includes a PhD in English from McMaster University; a four-year diploma in studio art from the Ontario College of Art and Design, and a professional Master's degree in biomedical communication from the Institute of Medical Science, Faculty of Medicine, University of Toronto. Practising as she does at the intersection of art and science, Shelley is delighted to be involved with the larger transdisciplinary exploration that HCTP represents.



Sarah Whyte *University of Toronto, Creating Space for Inter-professional Communication in the Operating Room: Design and Implementation of a Preoperative Team Checklist*

Sarah Whyte earned a Bachelor's degree in Biomedical Science at the University of Guelph and a Master's degree in English at the University of Waterloo. She worked as a Medical Writer and Editor before beginning her current position as a Senior Research Coordinator at the Wilson Centre for Research in Education. She has worked for the past four years with Dr. Lorelei Lingard to conduct qualitative and mixed-method research related to health care team communication, patient safety, and health professional education. Her experience includes hundreds of hours of research observations in the operating room. Sarah looks forward to beginning her doctoral degree in English this year at the University of Waterloo, where she plans to bring a linguistic and rhetorical perspective to the study of knowledge translation in health care.



Anmarie Adams

School of Architecture
McGill University
anmarie.adams@mcgill.ca

Gina Agrawal

Faculty of Medicine
McMaster University
agarg@mcmaster.ca

Farah Ahmad

Institute of Medical Sciences
University of Toronto
ahmadf@smh.toronto.on.ca

Hugh Armstrong

Political Economy and Social
Work
Carleton University
hugh_armstrong@carleton.ca

Pat Armstrong

Sociology
York University
patarmst@yorku.ca

Jana Bajcar

Faculty of Pharmacy
University of Toronto
jana.bajcar@utoronto.ca

Kirstin Borgerson

Philosophy
University of Toronto
kirstin@chass.utoronto.ca

Katherine Boydell

Community Health Systems
Resource Group
Hospital for Sick Children
katherine.boydell@sickkids.ca

Donald Boyes

Department of Geography
University of Toronto
boyes@geog.utoronto.ca

Jack Butler

HCTP/Visual Artist
University of Toronto
fatemaps@interlog.com

Alberto Cambrosio

Department of Social Studies of
Medicine
McGill University
alberto.cambrosio@mcgill.ca

Jill Cameron

Research - Optimizing
Rehabilitation Team
Toronto Rehabilitation Institute
cameron.jill@torontorehab.on.ca

Anne Carlyle

Interior Designer/Consultant
Carlyle Design Associates
Limited
anne@carlyledesign.ca

Andrea Charise

English
University of Toronto

Angela Colantonio

Department of Occupational
Health
University of Toronto
angela.colantonio@utoronto.ca

Peter C. Coyte

HCTP Co-Director
Health Policy, Management, and
Evaluation
University of Toronto
peter.coyte@utoronto.ca

Jack Dowie

Health Impact Analysis, London
School of Hygiene and Tropical
Medicine
University of London UK
jack.dowie@lshtm.ac.uk

Jim Dunn

Centre for Research on Inner
City Health
University of Toronto
jim.dunn@utoronto.ca

Gillian Einstein

Centre for Research in Women's
Health
University of Toronto
gillian.einstein@utoronto.ca

Joshua Evans

Geography & Earth Sciences
McMaster University
evansjd@mcmaster.ca

Caroline Fusco

Faculty of Physical Education
and Health
University of Toronto
c.fusco@utoronto.ca

Barbara Gibson

Medical Science and
Collaborative Program in
Bioethics
University of Toronto
barbara.gibson@utoronto.ca

Julie Gilbert

Manager Knowledge Translation
The Change Foundation
jagilbert@changeofoundation.com

Iona Gocool

HCTP Program Coordinator
University of Toronto
iona.gocool@utoronto.ca

Enza Gucciardi

Public Health Sciences
University of Toronto
enza.gucciardi@uhn.on.ca

Elizabeth D. Harvey

English
University of Toronto
elizabeth.harvey@utoronto.ca

Jeffrey Hoch

Health Policy, Management, and
Evaluation
University of Toronto
hochj@smh.toronto.on.ca

Ellen Hodnett

Faculty of Nursing
University of Toronto
ellen.hodnett@utoronto.ca

Joel Howell

Department of Internal Medicine
University of Michigan
jhowell@med.umich.edu

Pamela Hudak

St. Michael's Hospital
University of Toronto
hudakp@smh.toronto.on.ca

Sarah Jarmian

Department of Medicine
University of Western Ontario
Sarah.Jarmain@sjhc.london.on.ca



Sandra Knol

HCTP Manager
University of Toronto
sandra.knol@utoronto.ca

Pia Kontos

Toronto Rehabilitation Institute
University of Toronto
kontos.pia@torontorehab.on.ca

Pascale Lehoux

Département d'administration
de la santé, GRIS
Université de Montréal
pascale.lehoux@umontreal.ca

Meredith Lilly

Health Policy, Management &
Evaluation
University of Toronto
meredith.lilly@utoronto.ca

Jeffrey Masuda

Geography
McMaster University
masudaj@mcmaster.ca

Carl May

School of Population and Health
Sciences
University of Newcastle UK
C.R.May@newcastle.ac.uk

Liza McCoy

Sociology
University of Calgary
mccoy@ucalgary.ca

Patricia McKeever

HCTP Co-Director
Faculty of Nursing
University of Toronto
p.mckeever@utoronto.ca

Alex Mihailidis

Department of Occupational
Therapy
University of Toronto
alex.mihailidis@utoronto.ca

Alexandra Mihailovic

Health Policy, Management &
Evaluation
University of Toronto
alex.mihailovic@utoronto.ca

Kaveh Momen

IBBME
University of Toronto
kaveh007@yahoo.com

Md Moniruzzaman

Anthropology
University of Toronto
monir.moniruzzaman@utoronto.ca

Eric Mykhalovskiy

Sociology
York University
ericm@yorku.ca

Joy Parr

Faculty of Information and
Media Studies
University of Western Ontario
jparr@uwo.ca

Blake Poland

Public Health Sciences
University of Toronto
blake.poland@utoronto.ca

Brandi Row

Centre for Studies in Aging
University of Toronto
Brandi.Row@swri.ca

Jane Sandall

Florence Nightingale School of
Nursing and Midwifery
King's College, London UK
jane.sandall@kcl.ac.uk

Bart Sarsh

Public Health Sciences
University of Toronto
b.sarsh@utoronto.ca

Thomas Schlich

History of Medicine
McGill University
thomas.schlich@mcgill.ca

Tilda Shalof

ICU Nurse & Author
Toronto General Hospital
TShalof@Rogers.com

Mark Skinner

Geography
University of Toronto
mwskinne@uoguelph.ca

John Steven

Principal
Stantec Architecture
jsteven@stantec.com

Andrea Stone

English
University of Toronto
gogostone@sympatico.ca

Julia Twigg

School of and Social Policy,
Sociology and Social Research
University of Kent UK
J.M.Twigg@kent.ac.uk

Shelley Wall

Institute of Medical Science
University of Toronto
shelley.wall@utoronto.ca

Lorna Weir

Department of Sociology
York University
lweir@yorku.ca

Sarah Whyte

Centre for Research in
Education, Faculty of Medicine
University of Toronto
sarah.whyte@utoronto.ca

Holly Witteman

Mechanical and Industrial
Engineering Department
University of Toronto
holly@mie.utoronto.ca

Josephine Wong

Public Health Sciences
University of Toronto
jph.wong@utoronto.ca

Jiahui Wong

Research Manager
The Change Foundation
jwong@change.foundation.com

Mike Wu

Computer Science/Dynamic
Graphics Project
University of Toronto
mchi@dgp.toronto.edu

Nicole Yantzi

Faculty of Nursing
University of Toronto
nicole.yantzi@utoronto.ca

Hilde Zitzelsberger

Faculty of Nursing
University of Toronto
h.zitzelsberger@utoronto.ca



Editorial

Likely consequences of increased patient choice

As policy makers begin to embrace patient choice as a tool of healthcare reform, it is important to ask several critical questions: (i) What are the drivers of the policy? (ii) What are the likely outcomes? (iii) How can the policy be shaped to maximize the likelihood that patient choice will support better health and health care for more people?

The main drivers of the policy to embrace patient choice in the interest of healthcare reform are to contain cost and utilization of health services and please the public simultaneously. This is well articulated in the future planning report produced for the UK Treasury.¹ The assumption underlying this approach is what Wennberg has called the 'rational agency view of the role of patients.'² Under this assumption, doctors may be driven by self-interest and professional bias to perform interventions which some may deem unnecessary. Further, the corollary is that it is in the best interest of well-informed patients to balance this bias by doing only what is necessary for their health. The result, under these assumptions, will be that demand for health services will decrease, as patients will demand only what is truly necessary. Shared decision-making and self-management, under these assumptions, will rationalize the system. This, perhaps we hope, is driven by an emancipatory impulse that presumes that the old oppressive, paternalistic system can be liberated by engagement of patients in decision making. Critical social theory has dominated radical thought in the 20th century. It has given intellectual support for the important work in education of Freire³ and other social reformers. It has been applied analytically to health care by Paley.⁴ From this point of view, the logical antidote to oppression or unequal power is the increased knowledge, autonomy and self-esteem necessary to overcome restricted choices. That impulse has fuelled the shared decision making and evidence-based patient choice movement. If knowledge is power, and

self-reaction can lead to action through evaluating outcomes, then patient decision aids should lead to rational choices. From this perspective, patient decision aids, if they improve the match between patient values for outcomes, should help patients make free and autonomous treatment choices.^{5, 6} Research to date shows that decision support tools or 'decision aids' are, in fact, well received by patients, and that they improve informed consent.⁷ But how likely is shared decision-making to constrain cost? Should shared decision-making and self-management be inexorably linked as the best road to either reduced health care cost or improved health status?

The evidence to date is that patient involvement in decision-making has been shown to decrease demand in only a few clinical conditions. Screening and treatment for prostate cancer,⁸ and use of hysterectomy are examples.^{9, 10} Use of a decision aid for the choice between mastectomy and breast conserving treatment is another.¹¹ These are informative, if unusual, examples. Prostate cancer is a rare example where the harms of treatment, in the aggregate, occur in the face of no improvement in mortality. The recently reported breast cancer trial is interesting for several reasons. Not all previous decision aids have moved patient choices towards breast-conserving therapy, as is advocated by many guidelines. Further, the decision board used as a decision aid is unusual in being used by surgeons during the routine clinical encounter leading to a clinical decision. Most prior decision aids for this problem have been implemented outside the clinical encounter as patient information tools.¹² However, in most circumstances, patient involvement in choice has produced better informed patients making the same choices their doctors would make without involving them. Why is this? One clue from the literature is that patient satisfaction with



information is high, whether or not knowledge is high.

Patient satisfaction with their own doctors is also consistently high, even while patients desire more control over what doctor and what hospital they visit.¹³ While disappointing, this behaviour is not unprecedented. It is reminiscent of the early introduction of British Primary School methods to the United States. When progressive teachers involved grade 3 children in arranging their classrooms, they produced exactly the same configurations of furniture they had experienced the year before. But they liked it much better. The same is likely to occur in health care. In addition, the countervailing force to patients as *_rational agents_* is that the entire culture is driven by the technological imperative. We all actually want *_bigger, better, more_*, and we want it faster and more efficiently. Liberated patients are most likely to have higher, not lower, demands for quality and for new technology. Further, since the 1950s, communication science has devoted itself to persuasive advertising. In health communication, the focus has been on effective health campaigns, meaning getting more people to attend health screenings. Health media, perhaps responding to the twin imperatives of technology and public health campaigns, consistently tout *_medical breakthroughs_*

_. If choice is socially constructed, these countervailing forces promise to swamp potential decreases in use of medical technologies produced by decision aids. The largely failed example of attempting to decrease the use of antibiotics is a case in point. Decreasing use of antibiotics does harm, has medical and public health support, and even is supported by advertising. Where choices produce no obvious harm, but simply cost money, the chance that shared decision making will decrease cost is highly unlikely. Gore Vidal observed, as far back as 1982 that *_democracy is supposed to give you the feeling of choice, like Painkiller X and Painkiller Y. But they're both just aspirin._* But who can be against democracy, choice, or a medical intervention that has a chance to make one feel better?

If shared decision making and self-management, by itself, is unlikely to control

cost, does this mean that increased patient choice is still the right public policy? I believe the answer is *_yes – but_*. Increasing patient choice has the potential to decrease utilization and, therefore, cost.

However, patient choice with this desired outcome must be guided by technology assessment data, framed to explicitly compare one treatment or screening option against the other, and against watchful waiting, or no treatment. These choices have to be presented accompanied by explicit data showing how much improvement in outcomes can be obtained at what cost in terms of pain and inconvenience from procedures, and in terms of money. These data are rarely made available in conventional patient health information.¹⁴ However, decision aids that show patients the actual probabilities of symptom relief and life extension, do produce more realistic expectations.⁷ As patients' expectations become more realistic, and the limitations of known, patient choice could decrease utilization, and/or more appropriate use of medical intervention and may also decrease litigation. To date, patients have been taught to believe that medical interventions will cure completely whatever is wrong. Evidence suggests they can learn differently when they engage in evaluating the evidence.

In summary, decision aids that support patients in using evidence to make informed choices, perhaps including cost, have the potential to provide a bridge to cost-effective health care. The caveats are that much more research needs to be carried out to fully develop the best use of evidence-based decision aids inside the clinical encounter. This is no small endeavour, as it requires physicians and nurses to consider benefit to society as well as benefit to the individual patient. Similarly, research is needed to learn the best way to encourage treatment and diagnostic decisions that produce the best outcomes for the least cost. This reform challenge is large, and contentious. It may attract accusations of cost-cutting. However, the feel-good approach of leaving the whole job to consumers is destined to fail. The first foray into this task is to recognize that the

32



production of a greater number of decision aids is a public health imperative. Producing publicly available, high quality evidence-based decision aids, using techniques already available¹⁵ requires international collaboration. Such collaboration may produce a large enough set of evidence-based decision aids to move patients and providers in a cost-effective direction. We are entering an era in which technologies, including those arising from the mapping of the human genome, promise to provide an explosion of choice opportunities. Providers and patients must be prepared to understand the uncertain nature of the information, and realistically evaluate the chance that new treatments will improve health. Simultaneously, health systems in many nations need to conduct research into incentives and healthcare organizational strategies that support use of technologies in ways that produce the best outcomes for the least cost. This task will require increasing the analytic and regulatory power of health systems. This is a hugely challenging undertaking.

Margaret Holmes-Rovner

Associate Editor

References

- 1 Wanless D. Securing our Future Health: Taking a Long Term View. London: HM Treasury, 2002 (.nal report).
- 2 Wennberg JE. Improving the medical decisionmaking process. *Health Affairs (Millwood)* 1988; 7: 99–106.
- 3 Freire P. *Pedagogy of the Oppressed*. New York: The Continuum International Publications, 1970.
- 4 Paley J. Misinterpretive phenomenology: Heidegger, ontology and nursing research. *Journal of Advanced Nursing* 1998; 27: 817–824.

- 5 Holmes-Rovner M, Wills CE. Improving informed consent: insights from behavioral decision research. *Medical Care* 2002; 40(9 Suppl.):V30–V38.
- 6 Holmes-Rovner M, Rovner DR. Measuring improved patient choice. *Journal of Evaluation in Clinical Practice* 2000; 6: 263–272.
- 7 O'Connor AM, Rostom A, Fiset V et al. Decision aids for patients facing health treatment or screening decisions: systematic review. *BMJ* 1999; 319: 731–734 (review).
- 8 Volk RJ, Spann SJ, Alvab R, Cass AR, Hawley ST. Patient education for informed decision making about prostate cancer screening: a randomized controlled trial with 1-year follow-up. *Annals of Family Medicine* 2003; 1: 22–28.
- 9 Barry MJ. Health decision aids to facilitate shared decision making in o.ce practice. *Annals of Internal Medicine* 2002; 136: 127–135.
- 10 Kennedy ADM, Sculpher MJ, Coulter A et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs. *JAMA* 2002; 288: 2701–2708.
- 11 Whelan T, Levine M, Willan A et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *JAMA* 2004; 292: 435–441.
- 12 Holmes-Rovner M, Charles S. The mammography screening controversy: who and what is heard in the press? *Patient Education and Counseling* 2003; 51: 75–81.
- 13 Coulter A. What price choice. *Health Expectations* 2004; 7: 185–186.
- 14 Fagerlin A, Rovner D, Stableford S, Jentoft C, Wei JT, Holmes-Rovner M. Patient education materials about the treatment of early-stage prostate cancer: a critical review. *Annals of Internal Medicine* 2004; 140: 721–728.
- 15 <http://decisionaid.ohri.ca/AZinvent.php>. Last accessed 26 November 2004.

Editorial

_ Blackwell Publishing Ltd 2005 *Health Expectations*, 8, pp.1–3
3