EVALUATING ICTS IN HEALTH CARE

‘Fellowship in Comparative and Evaluative Analysis’ Report

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1. INTRODUCTION

The fellowship to Canada was undertaken between 24 November and 7 December 2003 and was hosted by Professor Ellen Balka. Professor Balka holds a joint position as Director of the Assessment of Technology in Context Design Lab (ATIC-DL) in the School of Communication, Simon Fraser University, BC and as Research Scientist at The Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health, based at Vancouver General Hospital. Balka has recently been awarded $3 million by the Canadian Social Sciences and Humanities Research Council (SSHRC), under their Initiative on the New Economy (INE) programme to look at ‘Technology and Health Information in the New Economy’. This is discussed further on p.7 In this report, we first provide a short description of the Canadian health care system so that the reader has some idea of the context in which the research about health and ICT takes place. We then present the teams we met and projects we discussed. We conclude with a brief discussion of some of the main research issues which emerged as well as our observations on the approaches to evaluation adopted by the researchers whom we met.

2. CANADIAN HEALTH CARE SYSTEM

National level

Canada is a federal country (ten provinces and three territories; total population approximately 31.5 million) with a complex division of responsibilities between federal, provincial and local governments. In terms of health, the federal government (based in Ottawa) raises revenues and establishes the basic framework in which health care must be delivered but actual delivery is conducted at provincial level. The Canadian health care system evolved into its present form during the latter half of the twentieth century. The province of Saskatchewan was the first to establish public, universal hospital insurance in 1947. By 1961, all provinces and territories had schemes for insuring universal access to hospital services. In the late 1950s, the federal government had already passed legislation in which it shared in the costs of these services. The Canada Health Act (1984) established the conditions related to insured and extended health care services[1] that the provinces and territories must meet in order to received the full federal contribution. This Act replaced two earlier acts. The Health Act occupies a similar place in the Canadian political memory as the Beveridge Report in the UK. The Health Act introduced universal health care, based on five principles:

- Universality
- Accessibility
- Comprehensiveness
- Portability
- Public administration (meaning not-for-profit)

These principles continue to guide health care policy across Canada and have recently been re-asserted in the so-called Romanow Report (2002), a royal commission about the future of health care in Canada.

For many years, the federal government gave funds to provincial governments specifically earmarked for health. This changed in 1995 when health budgets were integrated with other social services (Health and Social Transfer Payment), allowing provincial governments greater discretion in deciding how much of these total funds would go towards healthcare. This change was prompted both by growing concern at increased healthcare costs and by long-standing debates within Canada about the balance of power between federal and provincial governments.

While Canadians often re-assert their commitment to the five principles enshrined in the Canada Health Act, there is growing dissatisfaction with the health care system due to the increased costs associated with an ageing population, growing waiting lists and pressure to cut costs. From the late 1970s, the federal government started reducing its contributions towards health care costs. In Canada, these issues similar to those in the UK and elsewhere in the EU, are compounded by the federal-provincial relationship. There is growing concern that healthcare is not equal in different provinces. For example, during our visit, we read in the newspapers that the province of Quebec is the first province to provide PET scans. The Canadian Medical Association expressed concern that cancer patients in Quebec will have significantly better care than patients in other provinces, some of which claim that PET scans are still at an experimental stage

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[1] Insured health care services are defined as medically necessary hospital, physician and surgical-dental services. Extended health care services include long-term residential care, health aspects of home care and ambulatory care services.

and thus cannot be supported with public funds. Cuts in health care expenditure together with a greater policy emphasis on the social determinants of health and evidence-based decision-making in health care have contributed to the development of both new health information technologies and a Canadian health information infrastructure (Balka, in press).

Information and Communication Technologies

Information and communication technologies (ICTs) did not receive much explicit attention from Health Canada (equivalent to the UK Department of Health) until the 1990s. The Canadian Institute for Health Information (CIHI), an independent, non-profit organisation, began its work in 1994 to collect, process and maintain the growing number of health databases. Between 1995-7, the Information Highway Advisory Council (IHAC) met to discuss Canada's response to the 'information society'. One of their recommendations was that information should be deployed to serve health needs. In 1997, Health Canada established CHIPP (Canadian Health Information Partnership Program – now discontinued) and HISP (Health Information Superhighway Program).

Canada Health Information Way has recently been establised as a private, not-for-profit organisation to develop electronic health records. It was originally given C$500million and in February 2003 was given an additional C$600million by the federal government. This organisational structure is designed so that the funds cannot be taken away by a future government. Its main task is to develop infrastructure for electronic health records but it is also concerned with emerging health technologies.

These and other initiatives (for more detail, see Balka, no date) have all contributed to developing an information infrastructure for Canada's health system and to supporting a variety of projects aimed at improving the management and delivery of health care. As in the UK, these projects have mixed success, with some running significantly over budget. From the patients' perspective, the most visible of these projects are about health promotion and patient navigation.

British Columbia

British Columbia (BC) is Canada's western-most province, with a population of 4.141 million. 35,000 new immigrants arrive each year. Vancouver is the largest city though the provincial government is based in Victoria. Throughout most of the 1990s, the BC legislature was run by the New Democratic Party (NDP) which has its origins in a collectivist, farming tradition but would now feel comfortable with New Labour. There has never been a federal majority NDP government (though they have sometimes been a minority partner in a Liberal government), but the NDP has often been the majority party at provincial level, especially in the western provinces and Ontario.

The NDP government of BC in the 1990s attempted to bring healthcare closer to the people. The province was organised into over 50 health authorities, most of which were geographically based but some large hospitals were independent health authorities. The Liberal Government (elected 2001 – quite conservative by UK political classifications) has reduced the number of health authorities to just six.

The province is planning to spend over $10 billion on health care in 2003-4. This represents approximately 42% of the provincial budget. Health and education are the two largest areas of provincial expenditure and activity.

3. RESEARCH CENTRES, RESEARCHERS AND PROJECTS

3.1 Centre for Clinical Epidemiology and Evaluation, Vancouver General Hospital
(www.vch.ca/c2e2/)
&
ATIC (Assessment of Technology in Context) lab, Simon Fraser University
(www.sfu.ca/~aticdl/)

Professor Ellen Balka works in both of these locations, managing a complex array of academic and community projects. The Centre for Clinical Epidemiology and Evaluation is based in Vancouver General Hospital which employs 23,000 staff and was until the recent 'rationalisation' its own health authority. It began relatively early to develop its own ICT infrastructure via public-private partnerships. The ATIC Lab, based at SFU, brings together faculty and graduate students interested in social approaches to technological change. The projects discussed below involve collaborations between these two groups/institutions.

ACT for Health (Applied Communication Technologies for Health) project
This four year research programme has been awarded C$3million by SSHRC (Social Science and Humanities Research Council) . The programme was formally announced in December 2003, but funding began in October 2003. The programme is led by Professor Balka, and includes Canadian and international academic partners and collaborators as well as a variety of 'community' partners. (Community here means non-academic, and in this case includes many healthcare organisations such as Vancouver Coastal Health Authority, the BC Cancer Agency, Planned Parenthood.) International co-investigators are from the UK, the Netherlands, Austria and Australia and include both Flis Henwood and Sally Wyatt (joint holders of this travel fellowship) as well as Eileen Green and Frances Griffiths, also researchers on the IHT programme. The goal of the programme is to understand the complex ways that health information is produced, consumed and used by lay people and produced and used by health care professionals in order to inform the design of policies and information systems. A major focus of the programme is to investigate the sociotechnical constraints in realising Canada's vision of the new economy through the application of ICTs in the health sector. As mentioned above, ICT is viewed as a way of making an expensive healthcare system more efficient while at the same time maintaining the five principles of the Canada Health Act. Studies of everyday use of health information technologies by both patients and professionals are one of the gaps identified in the research proposal. The programme provides funding mainly for MA and PhD students and postdoctoral researchers. This fellowship enabled Henwood and Wyatt, acting as representatives of the UK/Netherlands team, to meet with Balka and members of her team in Canada to begin to plan collaborative projects as well as graduate student training, a core component of the overall programme.

Evaluation of BC Health Guide project (Allan Best, Irving Rootman and Judith Krajnak)
BC Health Guide is similar to NHS Direct, but is operated provincially. Some but not all other provinces have something similar. The BC Health Guide has five elements:

1. *BCHealthGuideOnline* is a secure database containing medically approved information. It is only available to BC residents, or anyone with access to a BC postcode. We were able to gain entry by typing in Sally Wyatt's parents' postcode, which is hardly top secret information.

2. *BCNurseLine* is a 24 hour, 7 day service available via a freephone number. It is staffed by nurses and promises availability for deaf people and translation into 130 languages.
3. *BCHealthFiles* are one page fact sheets on a range of common health problems as well as environmental and health and safety issues.
4. *BCHealthGuide* is a book delivered to all BC households containing advice and information on nearly 200 common health concerns. It is basically a self-help book, but also contains information and checklists for patients to use when visiting their doctors. There is a special supplement to this book focusing on health concerns for First Nations (native peoples) individuals and communities.
5. *BCHealthGuideResourceCentre* provides additional information for health care professionals

The evaluation of this initiative began in July 2003 and is to last for four years. It is funded (C$500,000) by the BC Government. Like many projects we encountered, this will be a 'multi-method' evaluation, using a range of both quantitative and qualitative evaluation tools. One key issue is, of course, cost-effectiveness and an economic evaluation will therefore be a central part of the overall project. Other issues to be covered are the ergonomic ones, examining working practices in the call centre itself (and specific health issues such as RSI amongst nurses who answer the phones); and, user issues from the point of view of both health care professionals and the public. The evaluation team is also interested in issues of non-use and plan to explore this issue through a population survey of households. An on-going monthly 'patient satisfaction' survey will be used as a vehicle for exploring the public's views on *BCHealthGuide* and to locate its use in a wider health context. The design of the project also enables an examination of the ways in which the different aspects of *BCHealthGuide* are used together and which media are preferred for specific types of health information and/or advice seeking by different social and cultural groups.

We had an interesting discussion about the software for the *BCHealthGuide's* 'knowledge base' which is of US origin and the significant 'teething problems' faced by nurses having to convert units of measurement for drugs, etc. to Canadian metrics.

Partners in Community Health Research Training Program

This project is funded by CIHR (Canadian Institute for Health Research) for six years. It is now at the beginning of Year 2. 50 similar projects have been funded across Canada. This is primarily a program for developing skills and competences in research, especially amongst those working in community health. It seeks to achieve this through academic-community linked projects which offer training to both academic and practitioner researchers. In Vancouver, three areas of work have been identified:

1. Marginal populations
2. Workplace health
3. Community health services

Each of the three areas is co-facilitated by a community health person and an academic. These are the 'mentors'. Each area also has associated 'learners' from both academia and community. Ellen Balka is the academic mentor/co-facilitator for the third area about community health services and we attended one of their weekly meetings whilst in Vancouver. All projects under this strand of work are associated in some way with evaluating approaches to primary health care reform. The funding enables support for graduate students and for community learners to be seconded for one day a week to work on their projects. Examples of projects include:

- how to engage physicians in primary health care research
- inter-professional communication in primary health care – identifying models and barriers
- how to take 'difference' into account in evaluations

This Program is formally part of Balka's SSHRC/INE-funded 'ACT for Health' project. It provides a very innovative and exciting approach to developing research expertise in community health whilst at the same time bringing academics and what the ESRC would term 'users' closer together. Community learners gain support and advice from more senior researchers in their own area of work (the community mentors) whilst also gaining access to academic expertise and guidance (the academic mentors). Those we spoke to (both mentors and learners) agreed that the collaboration was extremely fruitful, with each partner acquiring a deeper understanding of each others' approaches to community health research and practice.

'From Work Practice to Public Policy: Case Studies of the Canadian Health Information Highway' project.

This project is funded by the SSHRC and is being undertaken by Balka in collaboration with colleagues Karen Messing, Université de Québec à Montréal and Pat Armstrong, York University, Toronto. The overall objectives of the project are to consider the interaction of the micro, meso and macro contexts in influencing technology design and implementation issues. For the purposes of this project and related work, the micro context is defined as work practice issues, the meso context as organisational factors and the macro context as policy and broader political-economic factors. This is a framework for study that was first mapped out by Balka (in press). It is a useful methodological 'framing' device for identifying the ways in which organisational goals and priorities mediate actions and initiatives undertaken at both macro and micro levels.

There are several linked cases studies, two of which we were able to hear about in some depth during our visit. These were the 'Tower Move' and 'Data Sharing equals Patient Caring' projects, each of which is described below.

The 'Tower Move' project (Ellen Balka and Nicki Kahnamoui)

The Tower Move Project was initiated six months prior to the opening of a new building at Vancouver General Hospital (VGH). The overall objective of this project was 'to ensure the timely, efficient and successful move of identified clinical areas into the tower at the VGH site with minimal disruption in the care and workflow, while ensuring patient and staff safety' (Balka and Kahnamoui, 2003, 6). Balka became involved in her capacity as member of the Professional Practice Leadership Team, responsible for evaluation at VGH. The particular aspect of the move that interested Balka and her Research Assistant (Kahnamoui) was what they defined as the 'technology issues'. The objectives of their action research initiative were 'to quickly identify problems with technology, communicate the problems to the directors responsible, and develop solutions that work, from a staff perspective' (Balka and Kahnamoui, 2003, 7). Following Reinharz (1992), their research was designed as one in which action and evaluation proceed simultaneously, which is particularly suitable to research that has problem solving and improvement as its goals (Hart and Bond, 1996). Their methods included 'being seen' (the researchers wore T-shirts with 'Technology Trouble? Talk to Us!' printed clearly on the front), observations of work and informal interviews with staff both during the move itself and for a period of several months afterwards. The visibility of researchers and the opportunities for face-to-face communication about technology problems as they occurred proved very fruitful in ensuring that staff were able to verbalise their frustrations, as well as providing a valuable conduit for such complaints back to the team coordinating the Tower Move. An ‘issues log’ was set up to record all technology-related problems as they were reported and problems were tracked through from report through to resolution with staff being kept informed at all stages. The main technologies studied were the automated drug dispensing system (Omnicell), the wireless nurse call system (Rauland) and the ceiling lifts (Lieko) but as the research progressed, other technology-related problems came to the fore: including with newly designed keyboard trays and the pneumatic tube system. The research revealed a number of problems with the ways in which the key technologies under study had been implemented resulting in disruptions to work flow.

The innovative aspect of this project was the way in which the research team was invited to share their expertise and enable ‘technology problems’ to be reinterpreted, early on in the move process, as ‘sociotechnical problems’, requiring appropriate managerial action. The project highlighted the importance of the ‘meso’ or organizational level in preventing and solving problems, particularly those related to infrastructural technologies. The team concluded that ‘rapid response evaluation can play an important role in problem identification and resolution, and lead to economic savings’ (Balka and Kahnamoui, 2003, 38). The methods used in this project offer an interesting approach to evaluation and could usefully be developed in joint ESRC/DH/EPSRC projects in the UK.

‘Data sharing equals patient caring?’ project (Zena Sharman)

This Masters project examined the implementation of PCIS (Patient Care Information System) into the emergency department at VGH. The title for the project was taken from the slogan written in the form a statement of fact on the mouse mats issued with the PCIS and observed in use in the hospital and was imaginatively converted into a research question. The mats were considered a ‘potent artefact’, conveying a strong organisational message. The project examined nurses’ experiences of the PCIS in relation to this assumed relationship between data sharing and patient caring. For her MA thesis, Sharman examined the relationship between gender, technology and nurses’ caring work. She concluded that nurses do not see the relationship between data sharing and patient caring as so straightforward and unproblematic. Sharman drew on the work of Karen Messing (Messing, 1999) and others in the tradition of Francophone ergonomics to examine both the ‘capacities’ and ‘constraints’ offered by the new technology. Her research methodology also incorporated elements of ‘institutional ethnography’, following the work of Dorothy Smith (Smith, 1987). As with similar work in Europe (for example, Wagner 1995, Berg 1997 and 1998 and Timmons, 2001), Sharman identified ways in which nurses adopted ‘work arounds’ to make the system better meet their needs. In addition to a gender analysis, identifying the importance of recognizing the invisibility of much ‘feminised’ caring work, the thesis identified the problems users had trying to adopt and adapt a system designed and built for the US health care system, an issue which arose repeatedly in our discussions about the Canadian experiences of ICT use in health care.

Best Practices for Healthy Midlife

This project is funded by CAHR (Community Alliance for Health Research). It is another multi-method evaluation, consisting of three subprojects:

1. randomised trial of people at risk of cardiovascular disease – treatment group receives report card and lifestyle counselling

2. interventions aimed at reducing diabetes amongst low socio-economic status communities
3. integration of the two programmes, focusing on the measurement of community empowerment

Office of Learning Technology project
This project is funded by the Office of Learning Technologies and is concerned with the development of web-enabled self-learning training materials for those wishing to undertake outcome and evaluation research across the local health authority (Vancouver Coastal Health). This is directly linked to Balka's formal responsibility to VCH which is provide support for evaluation research across the authority.

3.2 The Division of Continuing Medical Education (CME), Faculty of Medicine, University of British Columbia, Vancouver (www.cme.med.ubc.ca)

The key task of this group is to provide continuing education for practising health care professionals. There are three permanent staff and about 30 researchers on external funding. They are involved in many fascinating projects, of which several are described below. It is intended that Kendall Ho, the Director of CME, become a collaborator in the ACT for Health programme. We met him together with two of his colleagues, Sandra Jarvis-Selinger (Director of Research) and Brandi Bell (Researcher).

Technology-enabled knowledge translation (TEKT): Current Best Practice in Innovation, Evaluation and Future Directions
TEKT is a concept that underlies much of the work of this group. They are concerned with the time it takes for new evidence/knowledge to be translated into changes in medical and health practices. In particular, they are keen to identify where, when and how ICTs can be used to help accelerate what they call this 'knowledge translation cycle'. A TEKT workshop was held in Vancouver in March 2003 (details on the wesbsite, see also Ho et al, 2003).

Connecting Rural and First Nation Communities in British Columbia: Amplifying Access of Service and Education in Health
This project is funded by a UBC-TELUS grant and builds on previous expertise in the area of telehealth for rural and First Nation communities, where specific projects have included one that provided real time access to nursing and medical trauma emergency care for rural health professionals combined with 'just-in-time' learning opportunities at the point of care using telehealth technologies. The new project will examine the telehealth 'readiness' of rural and First Nations communities, identify appropriate telehealth applications, evaluate how such initiatives can help health professionals in their practice, provide health educational opportunities for professionals and assess the impact of telehealth connectivity on professionals' satisfaction and on the health outcome of the community. Early emphasis will be on wireless infrastructures but both landwire and wireless approaches will be explored.

Broadband Program Evaluation
In 1995, Industry Canada (equivalent to the UK Department of Trade and Industry) funded twelve 'smart' communities across Canada. For obvious geographical reasons, Canada has been a world leader in trying to develop community access to ICTs in remote areas and especially by First Nations communities. This evaluation project

examined these smart communities and sought to construct and develop a framework for ‘early success indicators’ of these broadband applications.

Methodologically, this evaluation again used a range of techniques which involved user ‘needs assessment’ and the development of a range of community access programmes based on these needs. In particular, they sought to identify the ‘killer applications’ that would bring local communities online. The approach was described to us in discussion as ‘foresight as opposed to hindsight evaluation’ and as setting out to ‘positively contaminate’ the field, in the tradition of action research.

Technology-Enabled Health Care projects

One project under this heading examines the use of Personal Digital Assistants (PDAs) in medical training. The pilot study has been about chronic disease management and the use of PDA-based tools for physicians in the management of patients with diabetes. In the first stage, they have looked at the ways medical students use PDAs in their recording of cases for subsequent educational use. Forty students kept paper records and 40 students used PDAs. The first group kept 60 logs and the second over 1200. They will shortly also be looking at the differences in exam performance of the two groups.

Community Learning Centres

This project evaluates the implementation and uses of community learning centres in remote areas. These centres have been established to promote community engagement in health, education and training. Both infrastructural and content issues are addressed Some interesting new social linkages have been developed through these centres: for example, encouraging young people to help their elders with ICT whilst older people assist younger people to understand and contextualise health information. They are also attempting to promote the integration of western approaches to health with the traditional medicine of native people.

Overall, the UBC research group deploys a wide variety of quantitative and qualitative research and evaluation tools. They are also involved with a wide variety of community groups in the Vancouver area and in northern BC. They are clearly committed to using their research results in the education of both HCPs and policymakers and they offer a distributed Masters award in Health Informatics in collaboration with Frances Lau, Health Information Sciences, University of Victoria (see below).

3.3 School of Health Information Science, University of Victoria, Victoria

http://hinf.uvic.ca

Francis Lau, the Director of this School, is one of the academic partners in the ACT for Health programme. His School provides academic education, post-qualification training and research in the application of ICTs in health care. At present the School is quite small, with just three permanent academic staff. However, the University of Victoria will be starting a medical school in September 2004, and the School of Health Information Science is heavily involved in that. The medical school development will provide the Health Information Science School with the opportunity to employ more staff. Lau is also involved in the development of a PhD/postdoctoral training program, using distance learning technologies and involving eight universities across Canada. The Continuing

Medical Education division of the Faculty of Medicine at UBC (see above) is one of the eight.

PDAs and Palliative Care (Craig Kuziemsky)

One of the first projects based here which is to be funded by 'ACT for Health' is the PhD work of Craig Kuziemsky about the development of computer-based strategies for pain management in palliative care. The project is in two parts. Phase 1 will study and analyse retrospective data on PDA use in the Victoria Hospice Society (VHS). The PDAs were introduced in 2000 but use was halted in 2002 because of resistance of the part of nurses who felt that the use of computers conflicted with the 'person-centred' approach favoured in palliative care. Phase 2 will consist of a prospective study using a participatory design approach which will involve working with health professionals (physicians, nurses counselors) to develop an assessment tool for severe pain management. The overall goal is to computerise this tool and have it accessed via PDAs in palliative care. Particular attention will be paid to how the technology affects approaches to inter-professional communication and practitioner-patient relationships.

Francis Lau and Craig Kuziemsky came to Vancouver to meet with us, Professor Balka and Dr Ho and his team. Sally Wyatt also visited Lau and his team in Victoria.

3.4 Centre for Global eHealth Innovation, University of Toronto

www.uhnres.utoronto.ca/ehealth

This centre started in 2000, as a joint initiative of three large Toronto hospitals (University Health Network) the University of Toronto. It is physically located within the Toronto General Hospital. It is a multidisciplinary team whose main aim is to test, develop and evaluate e-health innovations. There are currently about 35 staff from a range of social science, technical and health backgrounds. conductich undertakes evaluations and usability studies. They see themselves as contributing to the improvement of healthcare on a global level and feel Toronto is a good place in which to do that. There are 150 different ethnic communities in Toronto, a city with a population of 2 million, 45% of whom were not born in Canada.

They are in the process of developing state-of-the-art usability labs which should be in place in early 2004. These facilities will give them many possibilities for conducting elaborate usability trials and evaluations. They have the potential to capture huge amounts of data, including video material. It is proposed to make them a partner in the 'ACT for Health' programme, thus enabling an interesting mix of approaches to developing and evaluating health information technologies.

Three examples of current projects are discussed briefly here. More details about these and other projects can be found on their website.

Levelling the playing field, Developing Innovative Educational Program Strategies to Help Underserved Populations Understand, and Access, Supportive Care Services

This study is developing a strategy to help underserved cancer patients gain information about, understand, and use supportive care services. An intervention called the Personal Coach Program was developed whereby people are trained in the role of 'coaches', under the direction of a senior health professional and supported by a collection of multimedia information resources. The aim is to provide tailored information and support to cancer patients who face economic, cultural, social or educational barriers to supportive care. Development and evaluation is being conducted in tandem. The first phase, funded by the Ontario Ministry of Health and Long Term Care, was a formative evaluation completed in January 2002. Through structured interviews with cancer patients and supportive care providers in the Toronto area, the Personal Coach Program idea was found to be feasible to develop, acceptable and desired by both patients and providers. The model was perceived to be beneficial to the physical and emotional health of under-served cancer patients and would facilitate equitable access services meant to provider information and services that support cancer patients when dealing with their illness. The second phase of the project will implement and evaluate the pilot phase of five coaches with approximately 80 cancer patients. An anonymous philanthropic donor provided the funds to develop training and resource materials for coaches and patients. Public/private partnerships are being developed to support the activities of the coaches so that the pilot phase can be extended.

eGUIDES (Electronic Guideline Usability and Information Design Evaluation Study)

This study is funded by CIHR (Canadian Institute for Health Research), and will be completed in 2005. Its purpose is to assess, improve and test various formats of electronic clinical guidelines and to make design recommendations to enhance knowledge transfer between HCPs and between HCPs and patients. This project uses different qualitative research methods, including focus groups, comparisons between different formats and video-taping people accessing guidelines and reviews online to identify any problems during their interaction. The aim is to develop a checklist of design features for those creating guidelines and reviews for both the healthcare provider and the consumer.

SUSHI-Q (Standardized Usability and Satisfaction with Health Information Questionnaire) and the Canadian Health Network

SUSHI-Q is the development of a standardised usability and satisfaction questionnaire for use by people using health information websites. The *Canadian Health Network* is mandated to build health information websites for Canadians. Eysenbach is developing the former and on the board of the latter. The idea behind the Canadian Health Network (funded and evaluated by Health Canada) is to develop a ‘health network you can trust’. It supports a network of organisations developing content, but it needs to evaluate the content. Eysenbach wants them to use SUSHI-Q for that. The Canadian Health Network is fundamentally a health promotion organisation, but the problem is that people do not normally actively seek health promotion information. Most people only look for health information when they have a health problem. This raises the interesting question of how far websites are the appropriate medium for health promotion messages, given that they need to be accessed first.

4. OTHER COLLABORATIVE WORK UNDERTAKEN

Special Issue of *Information, Communication and Society* on ‘e-Health’.
This is being co-edited by Flis Henwood and Ellen Balka. The intention was to use a special issue to bring together research findings and discussion the use of ICTs in healthcare, with a particular focus on the public’s use of the Internet for accessing and sharing health information. The ‘call for papers’ (see Appendix 2) highlighted issues of Internet and information access and use, with questions of information quality and patient/consumer empowerment to the fore. These themes are highly visible both within the informatics cluster of the IHT programme and within Ellen Balka’s INE Project: ‘ACT for Health’, thus making the editorial team ideally placed to produce the Special Issue. The travel fellowship enabled the co-editors to meet face-to-face to discuss the articles submitted by the November deadline, to make some initial prioritisation of papers and to identify suitable referees. The opportunity of a face-to-face meeting was also used to begin to produce a book proposal for an edited collection that would enable a larger number of papers submitted to the Special Issue to be published, alongside some additional chapters to cover gaps identified by the editors. Both the Special Issue and the edited book can be seen as early output from the IHT/informatics cluster and Balka ‘ACT for Health’ collaboration.

5. CONCLUDING REMARKS

As can be seen from the preceding pages, we experienced an introduction to a wide range of fascinating research topics and approaches in the area of innovative health information technologies. Amongst the research issues to emerge are the following:

- Use of ICTs by remote communities, a particularly Canadian perspective on issues associated with digital and social exclusion
- Relationship between the Canadian health care system as a user and the US ICT industry as a supplier
- A focus on everyday life and work experiences
- A continued commitment on the policy-side at least to viewing ICT as a technical fix to wider social problems

The fellowship has also enabled us to reflect on a number of key issues concerning approaches to evaluation of health care ICTs. Overall, the hosting of our visit by Professor Ellen Balka means that we were necessarily introduced to research and researchers that shared her approach to evaluation which incorporates one or more of the following aspects: multidisciplinary teams, multi-method evaluations, action-oriented research.

Multidisciplinary teams

Especially important here are the academic-community partnerships, which exist in most of the projects described in this report. Here, ‘community’ is defined broadly to mean ‘non-academic’. In practice, this is often health practitioners but there is also widespread involvement of geographical communities or communities-of-interest as and when this is appropriate to the research goals. As much of the research is action-oriented (see below) with a heavy emphasis on stakeholder engagement, the identification of relevant stakeholders (be they academic, health practitioner or community groups) to act as team members is a key aspect of many projects.

The involvement of practitioners in many projects ensured not only a closer link with health care practice throughout the projects (offering the opportunity to identify and access appropriate field sites, for example) but, in several cases, also ensured that research would have an impact on practice via the development of appropriate continuing professional development (CPD) curricula.

Multi-method evaluations

We have reported upon a number of projects that were extremely successful in taking a multi-method approach to evaluations. The range of different tools and techniques employed include:

- Surveys (demographics, satisfaction surveys etc.)
- Administrative data (re: staffing, costs etc.)
- Ethnographic observation of work
- Interviews and focus groups
- Elite (expert) interviews
- Participant observation
- Policy mapping techniques

In some cases qualitative research techniques were used in one part of a project and a quasi-experimental technique in another. The success of such combined approaches depends crucially on the ability of the team to manage the epistemological and ontological tensions that such a strategy brings to the fore.

Action-oriented research

Many projects were interventionist- they were designed to make a change, not merely evaluate one. In many cases, an action-oriented approach was taken to facilitate a more ‘inclusive’ approach to the implementation of new systems and to encourage the participation of as many stakeholders as possible in that change. The aim here is to achieve a better ‘fit’ between new technologies and everyday work practices/ everyday life, from a range of user perspectives. Such approaches were variously described to us as ‘rapid response evaluation’, as ‘proactive rather than reactive’ evaluation, as using ‘foresight as opposed to hindsight’ approaches and as setting out to ‘positively contaminate the field’. Where systems design and implementation projects are concerned, this approach has much in common with the ‘co-production’ and ‘co-design’ approaches advocated by Hartswood et al (2001) and Proctor and Williams (1996) who, along with Berg (see, for example, Berg, 1997 and 1998) and others have long advocated the importance of user involvement in such processes.

In conclusion, the networking opportunities offered by the travel fellowship were found to be enormous and offered much inspiration for future research in the UK (and the Netherlands). In particular, we recommend that the multidisciplinary, multi-method, action research-oriented approaches to evaluation undertaken by many of the projects we have reported on here be used as a model for projects funded by any future joint Department of Health/ESRC/EPSRC research initiative.

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APPENDIX 1: PEOPLE MET (BY INSITITUTIONAL AFFILIATION)

1. Centre for Clinical Epidemiology and Evaluation, Vancouver Coastal Health
Ellen Balka
Allan Best
Judith Krajnak

Members of ATIC lab, Department of Communication, Simon Fraser University
Ellen Balka
Patrick Feng
Katrina Peddle
Zena Sharman
Kelsey Nutland
Kaye Buchholz
Nicki Kahnamoui

Participants in Partners in Community Health Research Training Program
Ellen Balka
Yuriko Araki, Department of Gerontology, Simon Fraser University
Joanne Douglas, Vancouver Coastal Health
Nicki Kahnamoui, Interdisciplinary Studies, Simon Fraser University
Ann Dauphinee, Vancouver Coastal Health
Lynn Buhler, Vancouver Coastal Health
Brian Evoy, Vancouver Coastal Health

2. University of British Columbia - Continuing Medical Education
Kendall Ho, Director
Sandra Jarvis-Selinger, Research Director
Brandi Bell

3. University of Victoria - School of Health Information Science
Francis Lau, Director
Craig Kuziemsky

4. University of Toronto - Centre for Global eHealth Innovation,
Alex Jadad, Director
Gunther Eysenbach
Joanne Hohenadel

5. Other (while in Toronto)
Andrew Clement, Faculty of Information Studies, University of Toronto
Lucy Suchman, Department of Sociology, University of Lancaster

APPENDIX 2: INFORMATION, COMMUNICATION AND SOCIETY- SPECIAL ISSUE ON E-HEALTH, CALL FOR PAPERS

The area of e-Health is now huge and covers a wide range of sociotechnical innovations in health service delivery and organisation. This Special Issue will explore just *one key area of e-Health*- the use of information and communication technologies (ICTs) in the communication of health information and advice - both to patients/public and between members of the public.

Health policy documents in many countries suggest that the greater availability of health information via the Internet will necessarily lead to the emergence of more informed patients who are better able to assess the risks and benefits of different treatments for themselves. The now widely used notion of ‘informed choice’ is indicative of the greater agency and sense of empowerment said to be experienced by such patients. Such thinking exists within sociology, too, where, following Giddens’ notion of the ‘reflexive consumer’, there is some support for the idea that the overall expansion in medical knowledge via new media technologies such as the Internet will empower patients.

This Special Issue of iCS seeks to explore the assumptions embedded in this ‘informed patient’ discourse through empirically-based papers which explore the extent and nature of Internet use in a range of settings and its relationship to patient empowerment and more equitable practitioner-patient relationships.

Topic areas we hope to cover include:

- Creation and use of health information websites by both health care professionals and the public
- Use of the Internet in consultations between practitioners and patients
- Online health chat and self-help groups

Key cross-cutting themes we hope to examine include:

- Access and equality issues
- Information quality
- Practitioner-patient relations
- Information and empowerment

Deadline for submission of papers: Monday 17th November 2003.
Co-editors: Flis Henwood, Brighton University, UK and Ellen Balka, SFU, Canada.
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