The Role of Technology in Making Gender Count on the Health Information Highway

Ellen Balka

Abstract
This paper focuses on how gender has been addressed in the health information highway. I examine the accessibility of online health information to women and the question of hip replacements and gender. I conclude that the health information highway obscures the social relations surrounding women's health.

INTRODUCTION
There was rapid growth in the potential of new information technologies in the 1990s, which was also a time of reduced health care expenditures in Canada. Provincial, territorial and federal level cuts led to renewed concern about the state of the Canadian health care system, and an emphasis on more efficient use of health expenditures (Armstrong et al. 1997). Information and communication technologies are increasingly viewed as the means for more efficient and effective delivery of health care services as health budgets shrink.

The following begins with an overview of the emergence and development of the Canadian health information highway. Although women have been lobbying for the collection of data concerned with women's health, and have been working to make sure that the Internet - and the health information it contains - remain accessible and relevant to women, in many respects the Canadian health information highway is a world without women. Women's interests have to date not been adequately represented in the arenas where decisions are made about what fields are created in databases, and what statistics are retrieved about sex and health when data do exist. The brief history of the health information highway below identifies some of the federal institutions that might serve as focal points for feminist interventions in the future, and sets the stage for examining how gender has been...
addressed in the rhetoric and promises of key health information highway documents.

I then discuss how gender issues have been addressed in the reality of the health information highway through two examples. First, I consider what we know and do not know about the accessibility of on-line health information to women. In my second example, I explore the role of technology in the gendering of health information by considering what we know and do not know about people who have had hip replacements. From these two examples I return to the policy processes that seeded the ground for growth of the health information infrastructure, and suggest that if women's needs are to be met, we must intervene in the socio-technical processes that ultimately determine what data are collected and made available, issues that are frequently crystallized in decisions and technical standards, where political and social decisions are often represented as technical problems (Bowker and Star 1999). After considering how technology comes to bear on what data are available about women's health and what data are absent, I end the paper by outlining some strategies that might be used to get women's health on the health information technology agenda.

**THE EMERGENCE OF THE HEALTH INFORMATION HIGHWAY**

As health budgets shrink in Canada, increasingly information and communication technologies are viewed as means for efficient and effective delivery of health care services. This has been fuelled in part by The National Task Force on Health Information, which presented a vision for a nation-wide health information system in 1991. The task force identified several functions needed to ensure public accountability, which included collecting and analysing information, and reporting to the public about health status and health system performance. The need for population health research and evidence-based decision-making were also highlighted by the task force, and echoed in 1994 by the Federal, Provincial and Territorial Advisory Committee on Population Health (Townson 1999). A new policy emphasis on the social determinants of health, for example, income and social status, employment and working conditions, physical environment, biology and genetic makeup (Hamilton & Bhatti 1996), as well as population health and evidence-based decision-making, created fertile ground for increased use of information technology in the health sector.

**POPULATION HEALTH AND EVIDENCE-BASED MEDICINE (EBM)**

McDowell and Edwards (1998) outline four meanings of “population health.” As an academic discipline, it refers to the application of a range of sciences to the study of factors that directly and indirectly influence the health status of a population. As a research field, it “analyses the health status of the entire population, rather than of individuals” (2) and examines the determinants of health status in an effort to develop interventions that can improve the health of a population. “Population health” is a policy concept that seeks “a rational basis for allocating health resources, balancing health protection, health promotion and health care delivery. It seeks to ensure that health expenditures maximize health gains to society as a whole.” As an applied science, population health supports the development of various interventions, including conventional health services, health
promotion, or modifying the socio-economic, physical or political environments, aimed at improving the health of the population.

EBM seeks to increase the degree to which medical care is based on evidence that it is likely to improve health outcomes. Responding to claims "that only 20 percent of medical practices are based on rigorous research evidence" (New York Times Magazine 2001, 68), EBM decision-making "is the systematic application of the best available evidence to the evaluation of options and to decision making in clinical, management and policy settings" (National Forum on Health 1997). In addition to improving health outcomes, EBM seeks to reduce the frequency with which costly health care decisions are based on little or no evidence (National Forum on Health).

THE ROLE OF INFORMATION TECHNOLOGY IN POPULATION HEALTH AND EBM

Realizing the goals of population health and EBM depends upon the availability of nationwide health data that have been extensively analysed. This will require increased use of sophisticated information technologies. Underlying assumptions supporting development of the health information highway in Canada include that it will facilitate collection and analysis of data (e.g., about the social determinants of health), that it will lead to greater utilization of existing data (e.g., from Statistics Canada and provincial ministries of health), and that it will lead to better understanding of factors that influence health. Government documents also suggest that the increased use of information technology will decrease administrative inefficiencies in health, increase the accessibility of health services to Canadians in rural areas, and empower the public by providing increased access to information about health issues (Advisory Council on Health Infrastructure (ACHI) 1998). Information technology is to be the means through which data are collected, stored, combined with other data sources and analysed. Proponents of the health information highway suggest it will make it possible to combine data (such as cost, treatment and health outcome data) that have in the past not been linked, which in turn will lead to more efficient expenditures in the health system by pointing to costly treatments that fail to produce desired results.

THE DEVELOPMENT OF THE CANADIAN HEALTH INFORMATION HIGHWAY: THE FEDERAL CONTEXT

The development, analysis and adoption of health information for different purposes, the communication of information to different users (physicians, nurses, patients), the use of health information to improve health, health care and accountability, and improved communication among various people and groups within the health system, have been cited as the heart of the health information infrastructure (ACHI 1998). The foundation for the development of a national health information infrastructure was laid in the early 1990s. A national task force on health information articulated the need for a national health information structure in 1991. In 1992 the Minister of Health mandated the creation of the Canadian Institute for Health Information (CIHI), which began operation in 1994. CIHI is an independent, not-for-profit organization.
which “collects, processes and maintains a comprehensive and growing number of health databases and registries” (ACHI 1998, 60).

In 1995, the Information Highway Advisory Council (IHAC) advocated the creation of a council to facilitate the development of a health information infrastructure. In 1996, Health Canada consultations assessed health sector needs in relation to the information highway. In 1997, the National Forum on Health called for the establishment of a nationwide population health system to support clinical, policy and health service decisions, as well as assist patients and the public in health decision-making (National Forum on Health, 1997). In that same year, the Advisory Council on Health Info-structure (ACHI) was established, providing strategic advice about the development of the national health info-structure (ACHI 1998).

Progress on information highway initiatives has been rapid. Ample federal, territorial and provincial finances and personnel have been allocated to develop a federal "health info-structure." The 1997 Federal Budget allocated $50 million over three years to Health Canada to develop a strategy for a national health info-structure (ACHI 1998). The Health Transition Fund (also announced in the 1997 Federal Budget) provided $150 million over three years to support provincial, territorial and national pilot and evaluation projects aimed at improving Canada's health system (Lee 1998). The goal of these expenditures is a Canadian health information system that supports health surveillance, population health information and a health information system for Canada's First Nations. Both the range of agencies involved in developing the health information infrastructure and the documents they produced show that development of the Health Infoway has been closely tied to stimulation of the health technology industries.

Developing complex health information systems is costly. Not surprisingly, public-private partnerships have played a significant role in the development of health information technologies. Virtually all federal government funding programs aimed at stimulating the development of health information technologies have required the active participation of industry, which has led to significant concerns about the future of the health information highway. For example, in a 1997 report, members of the National Forum on Health recommended that when preparing model legislation concerning protection of personal data in the private sector, the ministers of Justice and Industry recognize that the interests commercial bodies have for data may differ significantly from the public interest in research (e.g., drug companies may be interested in demographic data about illness for marketing purposes, while researchers may be interested in the development of non-pharmaceutical interventions to improve health). Companies such as IBM have been anxious to gain access to Canada's health data set, which it hopes to use to test and validate software currently being developed in two areas: data mining and decision support systems designed for a clinical setting (Personal Communications, IBM staff, November, 2000).

Recognizing competing interests in the development of the health information highway, Black recommended that health care institutions and governing bodies take the lead in guiding industry in the development of decision support tools (1997). In spite of an awareness of the
hazards of commercial interests in the development of health information technology, it has been argued (Balka 2001; Heeks et al. 1999) that private sector interests remain at odds with a publicly funded health information system, and threats are posed by the imposition of a business model on the management of health systems. Nonetheless, agencies such as CIHI, funded largely through government grants, operate partly on a membership model, where members' fees garner special privileges which include recognition as stakeholders in the national health information standards setting process. CIHI's 100 corporate, individual and student members are invited to sit on expert panels and advisory committees concerned with health informatics, and it is in these arenas that decisions are made about what data are collected and in what format. Increasingly, databases that have been developed and managed with CIHI's assistance are considered the authoritative source for information about health. Although what happens at CIHI occurs at a significant distance from women's health, it is likely to play a significant role in what we do and do not know about women's health.

PUTTING WOMEN IN THE PICTURE: GENDERING THE HEALTH INFORMATION INFRASTRUCTURE

Documents that played a role in the development of the Canadian health information infrastructure acknowledge the necessity of considering the needs of women and other marginalized groups. Women's needs were mostly addressed through a focus on accessibility to the health information highway, and Internet-based health information to women. For example, the 1998 ACHI interim report argues that "it is paramount that there be equitable access throughout Canadian society to the health infostructure." It acknowledges that access to the Internet is an equity issue, and the goal of delivering health information to all Canadians can only be achieved with effective, equal access to the Internet. The ACHI report (19) suggests that "for reasons of equity, policies must take into account the different needs of women and the particular challenges facing people with disabilities or too low an income to have Internet access." Recognizing the heterogeneity of Canadians, the report also suggests that the needs and priorities of Aboriginal communities differ significantly from those of other Canadians.

To the ACHI's credit, access is understood as more than just access to networked computers: the report also suggests that "policies to encourage access must focus not just on delivery technologies but on the format, level of difficulty, language and ethno cultural assumptions that will determine the usefulness and acceptability of information for different groups" (11). Indeed, these issues are among those being addressed by the Canadian Health Network (CHN), a collaboration between major health organizations across Canada, and Health Canada, which provides an electronic gateway to "credible, practical health information on health promotion and disease prevention." Among the goals of the CHN are "to be socially-inclusive and respectful of diversity."

ACCESS AS A GENDER ISSUE

The ACHI recognized that "the speed, reach and cost of a particular technology will always be important, the
mode in which information is presented, the language used, the ethnocultural insensitivity and assumptions underlying it can all present unscalable barriers to use by many Canadians" and that "equity demands the removal of such barriers" (19). Some resources have been dedicated to ongoing monitoring of the accessibility of information technology to Canadians. For example, the Statistics Canada's Household Internet Use Survey asks about household composition. Yet it is not possible to make determinations about gender-based differences in Internet use from the data collected through this instrument because data have been collected on a household level rather than disaggregating households to gendered individuals.

To date no research funds have been dedicated specifically to exploring equity issues related to the consumption and use of online health information. Little is known about the computer-mediated health information behaviours of women, or the health information needs of Canadians who have language proficiency in neither French nor English.

INFORMATION IS POWER: THE COLLECTION AND REPORTING OF DATA AS A GENDER ISSUE

Citing the historical difficulties that many Aboriginal communities have had with researchers which led to mistrust and suspicion, the ACHI interim report noted that a long history of media coverage which stigmatises study results has led to concerns "about privacy that revolve around the portrayal of communities, and not just individual[s], amongst Canada's aboriginal populations" (39-40). Although acknowledging that data can contribute to the stigmatisation of populations, government documents suggest that on-line health information technology will support conditions for empowerment and self-determination of marginal groups. The ACHI interim report indicates that despite concerns about the potential for stigmatised portrayal of Aboriginal Canadians, more widespread collection and dissemination of health information has resulted in a feeling "growing among Aboriginal communities that knowledge is power and the health infostructure, shaped to meet their needs, could provide important tools for self-determination and for identifying how to get on with the job of providing the best of health programs and services" (40). This point is echoed by feminists (Pollack and Sutton 2000).

Although the ACHI acknowledges that various groups "will each have a unique view on the shaping of health policy, a national health infostructure and the information it carries," government documents have framed concerns about the needs of diverse groups largely as a problem of making consumer health information available, and, to a lesser degree, ensuring that information is available that allows us to understand the different health and illness patterns for men and women. Nonetheless, there has been some acknowledgement that "in health and health care, gender counts" (National Forum on Health 1997). The example below illustrates the degree to which data about sex exists, and the limitations of existing data sets in helping us to understand the role of gender as a social determinant of health.
MAKING GENDER COUNT:
THE CASE OF HIP REPLACEMENTS

Gender has been identified as a key determinant of health. Referring to "the array of society-determined roles, personality traits, attitudes, behaviours, values, relative power and influence that society ascribes to the two sexes on a differential basis" (CIHI 2002), gender is reflected in health system practices, many health issues, and health outcomes. In September 2002, Statistics Canada and the CIHI released statistical indicators for fourteen areas of health status, health outcomes, and quality of health services (Statistics Canada 2002). Hip replacements are used as an indicator of health system performance (increasing numbers of hip replacements are equated with improved health system performance). Limitations of existing databases led to the use of joint replacement rates (total hip and total knee replacements) as indicators for health-related quality of life in 2002. However, it should be noted that the outcomes of hip replacements are not being used as an indicator of quality of life - rather, intervention rates (the number of replacements performed per 100,000 population) are used.

Although 94 percent of those receiving a hip replacement reported significant improvement in pain, stiffness and overall functioning, a recent report (CJRR 2002) indicated that 11.4 percent of hip replacements were repeat surgeries (called revisions), performed to repair total hip replacements. Although the majority of patients "experience significant improvement in mobility, pain reduction and quality of life following their initial hip" replacement, "for some patients, their initial hip or knee replacement does not work properly for as long as it should and the patient requires a revision or repeat surgery." The most common reasons for revisions of total hip replacements was a loosening of the implant (65 percent), softening of the bone tissue (34 percent), implant wear and tear (29 percent), and instability (15 percent) (Petrie, cited in CIHI 2002).

What does gender have to do with this? First, the CIHI data indicate that women received 57 percent of all total hip replacements during the study period. Data about the sex of those receiving hip replacements is being collected, which means that a range of people, including orthopaedic surgeons active in research, CIHI and others active in the Canadian Joint Replacement Registry (CJRR), a database that tracks total hip and knee replacement recipients over time in order to monitor outcomes, have all agreed that data about sex should be collected. Unfortunately though, this is all one can easily find about sex or gender and hip replacements.

Although a press release about the joint registry report and executive summary can be viewed for free on the CIHI web site, the complete report must be purchased. The table of contents yields little information about whether gender might be covered in the full report. Somewhat more detailed data (e.g., a breakdown of the number of hip replacements performed annually per 100,000 people for a five year period, for both men and women, by province and territory) can be located online. From this data one learns that women receive more hip replacements than men over time, likely a reflection of the fact that they live longer, and that the population receiving total hip replacements is generally older, but little else.
After a hip replacement, many everyday activities are contraindicated. Activities such as sitting in a normal chair or lifting bags of groceries are prohibited for a few months, while other activities (such as squatting, bending past ninety degrees and crossing one's legs) should never be engaged in after a hip replacement. Depending upon the type of surgery, the total hip recipient may be non-weight bearing for three months, or longer if a complication occurs. An inability to properly look after a total hip replacement can result in the need for a revision.

Following a hip replacement, the hip recipient is quite dependent on others for extended periods of time. Tasks such as retrieving paper from the floor or removing food from a low shelf in a refrigerator cannot be accomplished without help. Cleaning activities (such as washing out a bath tub or cleaning floors) cannot be undertaken without either risk to oneself, or help.

Although Health Canada has identified several key health determinants as important, little data exists about these determinants. If we were to use outcomes of total hip replacements as a surrogate for quality of life rather than using the number of total hip replacements performed, we would expect to see a difference in outcomes between men and women, which might reflect the largely gendered roles that women and men typically fill. We would want to know about several social determinants (e.g., social support, income) which might have either a direct or indirect effect on the ability of replacement recipients to properly look after their hips.

We might surmise that a woman with children or in a traditional relationship (where the woman does the majority of housework) would have a more difficult time looking after her hip replacement than a man (who would be more likely to be looked after by a woman). These effects might be lessened as income rises, which would allow one to purchase food delivery and house cleaning services. Social support networks and social environments, including informal caring, might also lessen the potentially adverse impacts of gender, as members of one's social support network might engage in informal caregiving (e.g., tidying up) that reduces the likelihood of post-operative complications. Finally, if data existed about working conditions - including unpaid work performed in the home - we might be able to gain a better sense of the extent to which men and women engaged in home-based work compromise the integrity of their hip replacements.

Existing data about hip interventions, which includes the number of hip replacements performed, the type of replacement, the initial diagnosis, and the type of prosthetic joint used, can be disaggregated according to sex. The Hospital Morbidity Database and the CJRR both include data about sex. But if we really want to explore quality of life related to hip replacements, we would want much better data than are currently available about health determinants, including social support, etc. In practical terms, in order for us to have good data about gender which might let us determine if total hip replacement outcomes vary in relation to gendered roles, we would need to gain the consent of multiple stakeholders, including surgeons, patients, CIHI, provincial ministries of health, health facilities, and technical support people in multiple locations. We would have to agree on what types of data should be collected in order to better understand the interaction of gender on the outcome of total hip
replacements. For example, this might include collecting data about family composition, and the degree to which a hip recipient had access to support services. Such data would help us understand how behaviours linked to the gendered roles typically filled by women (e.g., as caretaker) come to bear on health outcomes in the case of hip replacements.

Currently, the CJRR and Hospital Morbidity databases can tell us a great deal about prosthetic hips. It is possible to learn how many of which type of prosthetic joint have been used by doctors in a given province, or how long male versus female hip recipients were hospitalised post-operatively. The serial number of joint components used in hip replacements is tracked, but not the effects that home care service reductions have on the outcomes of hip replacements, nor whether these vary according to gendered roles. Although the activities of CIHI and other institutions active in development of the health information highway operate at a distance from women's health, these institutions are influencing what we know and don't know about women's health.

Each time a determination is made about what data are collected and what data are omitted from health databases, options about what we could learn about women's health in the future are foreclosed. In a sense, each decision about database structure freezes the social relations surrounding women's health. Although typically outside of the realm of feminist concerns, as this example demonstrates, database design is political. Health databases can help us to identify adverse events, but they can only give us answers to the questions they have been programmed to answer. As the hip example above indicates, current health databases still lack information about social determinants of health, and thus limit what we can learn about gender.

**CONCLUSION**

Feminists have been vocal about the need to collect data about women's health and gender as a social determinant of health. The brief review of the coverage of gender issues in federal documents about the health information highway indicates that feminists have been somewhat successful at getting issues about gender on the health information highway agenda. Although there is an acknowledgement that the circumstances of women's lives influence access to Internet resources, existing data do not allow us to determine if equitable access to health information is being achieved. Through reviewing available data about hip replacements it is clear that although gender has been identified as an important determinant of health, little data exists that provides insights about gender as a social determinant of health, and that often when data about sex do exist, questions about sex and health outcomes often remain unasked.

Taken together, these two examples underscore the need to insure that feminists remain vigilant in monitoring government programs that extol the virtues of health information technology for women. Although the health information highway can potentially add to what we know about women's health, there is a need to go beyond lobbying for data collection, and to address database design, for it is ultimately decisions about what fields are included and excluded from databases that determine what data are collected. As policy making increasingly turns to health information and evidence-based decision-making, strategically
it would be wise to broaden the scope of feminist critiques of health informatics.

A feminist understanding of health informatics might take as a starting point a strong feminist assessment of technology (Balka 1998) that would include the range of actors involved in the health information highway, the debates about beneficial and adverse effects of health information technology, and an analysis of direct and indirect impacts of health information technology on women. It might include more detailed information about the use of information technologies in the context of health (e.g., online consumption of health information by women), as well as a better understanding of the ways that information systems solidify choices about what data are collected and made available. Finally, a feminist perspective on health informatics might draw our attention to the policy arena. As the brief history of the development of the health information highway above suggests, decisions are often made in the technical arena long before the consequences of those decisions for women become evident.

One factor contributing to this is that the processes that have led to development of the health information infrastructure began over a decade ago. Although concerns about what data existed to describe women in general and women's health in particular were being raised a decade ago, scholars and practitioners raising those concerns were largely unaware of the significance that networked computers would play in organizing those data and ensuring that those data were made accessible. Although feminist scholars have been vocal in raising concerns about the nature of data collection and what constitutes evidence, and have provided continued pressure to insure that data collection concerning health is gender sensitive (Vancouver Richmond Health Board 2001), the role of the underlying technological infrastructure, and those who make decisions about that infrastructure, has been largely taken for granted.

Increasingly, as efforts are made to connect large data sets throughout the country, and decisions are made about the level of aggregation of data made publicly available, these decisions will in all likelihood be worked out nationally under the guise of data standards. As the discussion about the history of the Canadian health information highway suggests, although an awareness of equity issues may filter into planning documents, without continued vigilance as the technological infrastructure of the health information highway evolves and becomes increasingly fixed, it is likely to yield only a limited understanding of women's health. This is partly because decisions about what data are collected reflect numerous factors, including what data are currently available, the challenges and costs associated with
altering existing computer systems or building new systems to accommodate new data collection, and dominant cultural ideas about what constitutes evidence (Armstrong 2001; Grant). Any decisions reached amongst various groups about which data should be collected may be undermined during negotiation of technical standards. Often viewed as a benign technical process, setting technical standards and determining the architecture of computer systems often has important political consequences for women. Social decisions about technology are indeed a feminist issue.

**Endnotes**


2. CIHI receives 27% of its revenues from the sale of its services to provinces, 25% from selling services to individual health institutions, 32% from federal government funding, 15% from sales or user fees, and 1% from other sources. http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=profile_rev_e.


4. Information about member privileges can be found at CIHI Partnership info: http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=partner_e, and information about the cost of memberships and a listing of members can be found at http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=partner_register_e.


7. See CANSIM II table 3580006, for household Internet use at home, by Internet activity, as well as other CANSIM II tables that deal with Internet use. Also see the Statistics Canada Household Internet Use Survey codebook, which contains the questions contained in Statistics Canada’s annual survey concerned with Internet use. This research instrument asks about household composition, but it is not possible to make determinations about any sex or gender-based differences in Internet use from the data collected through this instrument.


11. Although most of the data collected by CIHI is paid for through taxation, much of the analysis CIHI produces comes at a price. Most Canadian health care facilities have access to a set of CIHI information
products and services. These products and services are part of a Core Plan subscription with CIHI or through a bilateral agreement between CIHI and their respective ministry of health. In addition, CIHI offers a number of products and services, at no additional charge, to regional health authorities and ministries of health for jurisdictions covered by a bilateral agreement. Core Plan products are designated with CORE. Facilities under the plan receive the set of products and services for a fixed price.

Clients who use CIHI services less frequently are covered on a price per service basis. Prices are listed in the catalogue as either Price A or Price B. Price A applies to Canadian health care facilities, governments, not-for-profit health agencies, universities, health professionals and researchers from the public sector. Price B applies to private commercial operations (such as, but not limited to, software vendors and consultants), foreign clients and others not qualifying for Price A.

The products in the PDF format are generally offered with unlimited access to Core Plan subscribers via the Web site. Where products are provided outside the Core Plan or to non-Core Plan subscribers, prices for this format will normally represent a discounted price compared to the equivalent paper product.

Acknowledgements
Work on this article was supported by the Social Sciences and Humanities Research Council of Canada.

References


Canadian Institute for Health Information (CIHI). "More than 10% of Total Hip Replacements are for Repeat Surgeries, Reports Canadian Institute for Health Information (CIHI)." Press release, Oct. 9, 2002.


