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## **Rural women's health information needs: Are technology-based services the answer?**

**Abstract:** Various models of community health information delivery exist in Canada. Spiralling health care costs have many governments seeking to promote more judicious (and presumably more cost-effective) use of health care by consumers. One such method is through centralized, government-run health information services that rely heavily on information and communication technologies (ICTs). These services have evolved with little apparent awareness of the role that might be played by existing information infrastructures, such as public libraries. This lack of awareness is especially true at the policy level, where decisions and resource-allocations are made for a variety of reasons, few of which seem based on an understanding of how ordinary citizens seek help and information, especially those who have special needs or face barriers to access. Recently introduced programs in Ontario, including TeleHealth Ontario and HealthyOntario.com, as well as the federal Canada Health Portal, suggest considerable faith on the part of policy makers in ICT-based strategies for providing health and wellness information to Canadians. Presented in this paper are the preliminary results of research involving members of three groups, health policy makers, public librarians, and rural women, each with a different perspective on how consumer health information should be delivered. The results of this research are discussed in the larger context of the ICT-based health information infrastructures that are being developed across the country.

**Résumé:** Il existe au Canada de nombreux modèles de systèmes communautaires qui permettent la distribution de l'information sur la santé. Face à la hausse des coûts de santé, beaucoup de gouvernements ont cherché à promouvoir une utilisation plus judicieuse (et vraisemblablement plus rentable) des soins médicaux par les consommateurs. Une telle façon de faire entraîne l'étatisation et de fait, la centralisation des services d'information médicale qui utilisent les technologies d'information et de communication (TIC) en particulier le téléphone et l'internet. Il semblerait que ces services aient évolué sans accorder une grande importance au rôle que pourraient jouer les infrastructures d'information déjà existantes. Le manque d'attention envers ces infrastructures et leur non-intégration sont particulièrement notables au niveau politique où une variété de raisons préside à la prise de décisions et d'attributions de ressources financières sans que l'on tienne le plus souvent compte des citoyens ayant des besoins particuliers ou des handicaps. Comme l'ont clairement montré les récents programmes ontariens tels que le TéléSanté Ontario et les services SantéOntario.com, ainsi que le Portail Santé Canada à l'échelle fédérale, un crédit considérable est accordé à la capacité d'internet de fournir aux canadiens de l'information sur la santé et le bien-être.

Cette communication présentera les résultats préliminaires d'entrevues qualitatives semi-préparées avec les membres de trois groupes de gens (des responsables des politiques de santé, des bibliothécaires publiques et des femmes de la communauté rurale à la recherche d'information sur la santé). Ces trois groupes distincts offrent des perspectives différentes quant à la façon d'utiliser des TIC afin de résoudre des problèmes liés à la santé. Ces expériences sont replacées dans le contexte plus large des infrastructures d'information sur la santé faisant appel aux TIC, infrastructures qui ont été développées autant au niveau provincial que fédéral au Canada. Beaucoup d'entre elles:

- a) Ignorent le rôle potentiel d'intermédiaires professionnels distribuant de l'information.

- b) Négligent des infrastructures d'information déjà existantes dont la capacité de distribution de l'information est largement avérée.
- c) Se développent sans remarquer qu'elles se copient mutuellement.
- d) Ont souvent pour résultat un déplacement massif des ressources publiques vers le secteur privé, les gouvernements achetant par exemple des bases de données de santé à des vendeurs du privé, et finalement
- e) Ne tiennent pas compte des difficultés d'accès à cette information des citoyens ruraux, en particulier les femmes.

## 1. BACKGROUND

*Canadians have established one of the best health systems in the world and have set themselves the objective of developing the healthiest population in the world. To achieve this goal, several key service and program challenges must be addressed. Among those challenges, all jurisdictions have recognized the need to improve the use of health-related information at all levels, i.e. governments, institutions, professionals, and consumers (Arlington Consulting Group, 1997).*

The preceding quote is the opening paragraph of a background paper developed for Health Canada prior to the 1998 National Conference on Health Info-structure. It draws attention to several issues: the diffuse and broad-ranging nature of "health information," the multi-jurisdictional nature of a "health info-structure," the presumed link between better health information and better health, and the recognition that health information is generally not well used. In this paper, we explore these issues from the perspective of health information users, providers, and policy decision-makers.

### 1.1 Consumer Health Information

Consumer health information (CHI) is "information on health and medical topics provided in response to requests from the general public, including patients and their families" (CAPHIS/MLA Policy Statement, 1996). Broadly defined, CHI includes information about diseases and treatments as well as health promotion and protection, preventive health care, determinants of health, and access to health care. Although supporting evidence is limited, a pervasive assumption in the rhetoric surrounding CHI, including "patient education" and "patient empowerment," is that better-informed patients will make more judicious (and presumably more cost-effective) use of health care services (Coiera, 1998). In private health models, this notion is explicit, and managed care organizations actively seek to educate patients in order to reduce costs (Egger, 1999; Bartlett, 1986; Bartlett, 1988). As various Canadian jurisdictions consider introducing public-private blended health care models and undertake primary care reform<sup>1</sup>, "health info-structures" are being developed in which it is assumed that informed, even "expert" (Smith, 2002), patients will be actively involved in shared decision-making about their health (Weston, 2001; Elwyn, Edwards, Gwyn, and Grol, 1999; Towle, Godolphin, Greenhalgh, and Gambrill, 1999).

At present, several models of CHI delivery co-exist in Canada. These include a variety of local "resource centres" that may be located in hospitals, community health settings, or specific

agencies, and which provide information specific to certain diseases or conditions, special populations, and/or a broader range of topics (health and non-health) to the general public. Advocacy groups, often national or provincial in scope, such as the Canadian Cancer Society, the Ontario March of Dimes or local community chapters of the Alzheimer Society of Canada, also provide information about specific health conditions. In addition to these programs, provincial health ministries may also be involved with CHI delivery and there is a growing trend to establish centralized, government-run health information services. These services, which are designed to provide around-the-clock access to health information, have evolved with seemingly little awareness of the role that might be played by existing information infrastructures, such as public libraries. A prominent feature in the design of these initiatives is that they rely on information technologies, especially the Internet, to enable citizens self-service, i.e., they are designed to allow members of the public to find their own answers to health questions. Although “live” interactions are possible with triage nurses through telephone dial-in programs, the new approach to CHI does not assume a role for trained information intermediaries and the “health reference interview” does not appear to be recognized as an important component of the information exchange process.

## **2. DELIVERY OF CHI**

The growing interest in the electronic delivery of CHI is driven by a recognition that the volume of information about health is growing at an enormous rate, that sources of health information are ubiquitous and extremely variable in quality, and that health care delivery systems, at least in countries such as Canada, the United States and Great Britain, are overburdened. As a result, policy makers at various levels of government, as well as public providers of health care and information services, consumer groups, and private, for-profit providers of health-related services are working, sometimes at cross-purposes, to find ways to exploit the potentially lucrative opportunities of “e-health.”

To understand how CHI is developed, delivered and used, we have undertaken a series of research initiatives to examine these issues from the perspectives of policy makers, information providers, and users. In this paper, we report a summary of some of the key literature in this area, as well as the preliminary results of our own research which is focused primarily on Ontario government health policy makers, public libraries as potential health information intermediaries, and rural women as health information users.

## **3. POLICY PERSPECTIVES ON CHI DELIVERY**

*There's innovation in New Brunswick at the telephone triage centre that I visited in Moncton last Sunday where trained and experienced nurses offer frontline advice over the telephone to people who call to inquire. And those telephone triage services have taken the pressure off emergency rooms at local hospitals. (excerpt from a speech by then Federal Minister of Health, Allan Rock, October 2000).*

The Health Minister's statement, reflected in federally-funded CHI initiatives such as the Canadian Health Network, highlights the policy emphasis on CHI delivery mediated by

telecommunications networks, as well as cost-effectiveness as a primary goal in developing these services. Our exploratory review of the various models of consumer health information delivery available at the provincial level reveal a similar orientation, namely:

- a) Many of the provinces have a poorly articulated vision of their role in the delivery of health information directly to consumers. This could be because Ministries of Health do not regard CHI as part of their mandate and expect regional or municipal-level structures to fulfill this role. In some cases this expectation is met, although often in an ad hoc fashion.
- b) The provinces that claim direct information services as part of their health mandates appear to have various systems, at various levels, to deliver these services, although it is unclear how the public becomes informed about them, or whether intermediaries are required in order for the public to gain access to the systems.
- c) "Telehealth" programs differ from province to province. For example, Ontario and British Columbia include consumer information provision in this service whereas other provinces regard telehealth primarily as a means to link primary care providers in remote areas with specialists in larger centres.
- d) Although there are one or two notable exceptions, such as Nova Scotia, the provinces that mention consumer health information in the context of provincial health systems do not make explicit links to public libraries as mediators to provide this information.

### **3.1 Preliminary Research Findings**

In 2002, we conducted qualitative semi-structured interviews with five senior staff members involved in health policy from different branches of the Ontario Ministry of Health and Long-term Care. The interviews revealed that, beyond a few marketing-style focus groups to evaluate pilot programs, in developing "e-health" initiatives, not only is there little reference to specific consumer health outcomes that might support such programs, but in designing such programs, little consideration is given to how ordinary people go about seeking help and information for their own or their family members' health concerns.

None of the interview respondents mentioned libraries as part of the CHI response and, even when prompted, libraries were described only as possible sites in which telephone or Internet access might be available. In other words, none of the respondents imagined libraries as gatekeepers through which health information could be retrieved, assessed for quality, organized and prepared for users. Instead, the responsibility for gatekeeping, i.e., controlling the quality of the information, was repeatedly described as something to be taken on, in an unspecified manner, by a cadre of 'experts,' described variously as health professionals, ministry employees, or academics.

The policy interviews suggest that Ministry personnel in Ontario work from a rather broad understanding of "consumer health information" that includes not only the information that citizens might want when making health decisions, but also incorporates information through which voters can be "educated" about how the government is delivering health care. The intertwining of government promotion with CHI was a thread throughout the interviews, regardless of the area of Ministry operations the respondents represented. Indeed, some respondents do not regard the Ministry as directly responsible for the delivery of health services, let alone health information, because these functions are distributed, with funds, to regional and

local authorities, hospitals and agencies. According to one of the interviewees, the Ministry's main information function is to ensure that people get information about provincial health services, not about health topics, per se. The interview participants indicated that the Ministry's recent forays into direct CHI provision via initiatives such as TeleHealth Ontario and HealthyOntario.com are, in part, an effort to "make[s] people more confident that the system is working for them" and to position the Ministry as a gatekeeper of "information about health that people would want at every stage in their lives."

The respondents were somewhat vague about the factors that give rise to policy development in this area. Indeed, it appears that policy often arises as a result of an interest on the part of political leaders rather than in response to evidence of a community need. For example, one respondent commented, "It is out of initiatives that tend to come policy." In other words, a political announcement may give rise to a flurry of activity, rather than from a carefully planned response to a well-studied public need.

The interviews also suggest that the creation of health information initiatives may be undertaken, at least in part, to reassure the public about the availability of access to health care providers, however indirect the access, as in the case of the TeleHealth dial-a-nurse service. Such reassurances are intended to deflect public concern that the health system is in crisis and that access to professional help is limited. The policy of linking CHI to government promotion is evident in a series of recently televised advertisements that showcase Ontario government health initiatives, such as the flu shots program, the recruitment of international physicians, the expansion of enrolment in nursing education programs, as well as TeleHealth Ontario and HealthyOntario.com.

#### **4. LIBRARY PERSPECTIVES ON CHI DELIVERY**

The public demand for consumer health information is enormous and the possibilities for linking to sources of health information have increased dramatically through initiatives such as the 1997 decision by the American National Library of Medicine (NLM) to make its major databases, including MEDLINE and the more consumer-oriented MEDLINEplus, available on its website and to waive all fees for users who connect to NLM databases via the Web. "Since that time, the number of MEDLINE searches has exploded from seven million to more than 220 million per year, of which an estimated one-third are members of the public" (Wood et al., 2000, p. 315).

The potential for responding to the need for consumer health information services in the public library has been recognized since the late 1970s (Baker and Manbeck, 2002). In Baker and Manbeck's (2002) book, *Consumer Health Information for Public Librarians*, Robert Braude writes

*Growth in the demand for consumer health information has increased the pressure on public libraries. As the source for information, self-education, and self-improvement, the local public library has been the one institution viewed by the community as accessible, neutral, and concerned. It is natural for individuals to expect that their local public library will be as responsive to their needs for health information as it has been for the myriad other information needs they have had in the past. Public libraries can no longer*

*avoid meeting these expectations, any more than the medical profession can expect to control them ... Many patients will come to the public library for that information. And they will expect the same expert guidance in appropriate health information resources that they receive in other subject areas (p. viii).*

The American Library Association reports that public libraries in the U.S. respond to an estimated 52 million health-related inquiries per year (Deering and Harris, 1996). In a report prepared for the American Association for the Advancement of Science, Chobot (2002) reinforces the importance of public libraries' role in providing access to health information, noting that "consumers continue to require assistance in sifting through the sheer volume of information available and in selecting reliable sources" (p. 8), a particular challenge when providing services for those with limited literacy or language comprehension skills. Despite this enthusiasm for the role of public libraries in the provision of CHI, Baker and Manbeck (2002) note that "the majority of people in a community are not seeking health information in their public library" (p. 23), apparently because they do not believe the library keeps relevant information or that it will retrieve such information on behalf of patrons, nor do they believe that librarians can be of much help in locating health information.

Although it is not clear that access to CHI reduces demand on health care systems, as politicians might wish, there is some evidence to suggest that health information does affect those who seek it. American "health surfers" use the Internet to locate information on diseases, women's health, nutrition, fitness and pharmaceuticals and are most likely to be "married, college-educated Caucasian women" who describe the Internet as "convenient, current, available, and anonymous" (Calabretta, 2002, p. 32). Webseekers of health information report that the information they locate affects "their health care decisions and interactions with their doctors" (Calabretta, p. 33). According to Calabretta, this phenomenon reflects a paradigm shift in health care "toward a cultural belief in personal responsibility for one's health and away from the attitude that physicians can use pharmaceutical therapy, advanced surgical techniques, or modern technology to 'fix' any health problems that arise" (p. 33). As a result, "as consumers increase their involvement in health issues, physicians will have to be drawn into new 'partnerships' with patients who are more responsible for their own care" (p. 33-34).

Consistent with Calabretta's observations are the results of a study by Bunn (1993) in which people were asked how they perceive sources of medical information. The respondents indicated that the most important features of the sources from which they sought information are, in order, that it be current/up-to-date, accurate; easy-to-understand; credible; easy-to-get; exactly-what-I-want; and confidential. While physicians were perceived to be the most credible and accurate sources of medical information, they were also ranked lowest in the "easy-to-understand" and "easy-to-get" categories, while "mass media" are easiest to access and understand, but lowest in credibility, accuracy and "exactly-what-I-want." A more recent study by Quintana et al. (2000) revealed that health care consumers consider credibility and trust in the information source to be critical in the provision of preventive health information on the Internet. And, while consumer advocate groups such as the Canadian Cancer Society or well-known organizations such as the Mayo Clinic were identified as credible sources, corporate websites, especially those of drug companies, were not.

The challenge of providing up-to-date, understandable, and credible information is one that public libraries are mandated to meet. As Baker and Manbeck point out, “unlike their competitors, libraries are one-stop shops for both historic and current health information. In public libraries, consumers have access to lay-oriented, medical, and alternative or complementary therapy books and periodicals; videos; pamphlets; lay magazines; CD-ROM products that provide access to nursing, medical, and consumer health information; and the Internet” (Baker and Manbeck, 2002, p. 60). Baker and Manbeck argue that librarians have an important role to play in mediating between information seekers and information resources because of their knowledge of source credibility and their ability to deliver appropriate information efficiently. As they point out, “people have an overwhelming choice of resources” for CHI but it can be “out-of-date, of questionable authority or quality, and in general, confusing. Healthcare consumers may frequently find information that is conflicting, misleading or unreadable.” Furthermore, while “finding health information on the Internet is fairly simple for many healthcare consumers .. understanding how to evaluate it is considerably more difficult” (p. 62-63).

There are a number of examples of library systems that have responded to the need for CHI, generally in collaboration with other partners, particularly those in the health sector. For instance, the Access Colorado Library and Information Network and the Colorado State Library have created a virtual library for the residents of Colorado, including a Best Web sites service that covers several subject areas, one of which is health and medicine. “Librarians from public, academic and special libraries in Colorado have worked together to evaluate and select these sites to assist consumers in finding reliable online health information” (p.12, Chobot).

Another model for CHI service that incorporates libraries is Ohio’s NetWellness program. Health sciences faculty members from three Ohio universities “create and evaluate consumer health content for the site and staff its Ask and Expert service, where consumers can ask questions and view responses directly on the Web” (Guard et al., 2000, p. 375). The program enables Ohio residents to visit any public library to reach all NetWellness resources and is being extended to enable public library cardholders to use a dial-in service. The purpose of the NetWellness program is to provide “easy, equitable, and widespread access to health-related information resources to the general public in the Ohio Valley region, particularly rural Appalachian and urban minority populations,” “use the existing telecommunications infrastructure to extend health information resources to as many citizens of the Ohio Valley Region as possible,” “contribute to extending the information superhighway to all citizens of the Ohio Valley Region” and “contribute to the health education and awareness of citizens of the Ohio Valley” (Guard et al., p. 375). Unlike in other jurisdictions in which librarians appear to be only bit players in CHI, Ohio’s librarians play an integral role in this program, likely because of the state’s history of supporting shared information services such as OCLC (the well known acronym for the Online Computer Library Center).

In Canada, the Nova Scotia Health Network is an example of a “grass-roots” service developed by librarians in response to the needs of their users and the limitations of their existing resources. The initiative is based on the idea that “the public library delivers consumer health information through its branch libraries and its public Internet access computers while the health centre library provides back-up for inquiries beyond the capability of public librarians and assures the

quality control of the information being offered” (<http://www.nshealthnetwork.org/background.cfm>). The project operates province-wide to provide a web-based consumer health information service through a collaboration between public libraries, health sciences libraries, the provincial library, several health-related organizations and the University. As noted on its website, the objectives of the network include providing citizens “with a quality source for local and general consumer health information,” facilitating “cooperation among the various organizations presently providing consumer health information in the province,” providing “a portal to reliable sites on many aspects of health and wellness,” and increasing “the public’s awareness of the role of libraries .. as sources of health information.”

Based on these examples, one might expect public libraries, and consequently, librarians, to play a major role in the delivery of consumer health information across Canada. However, our investigation suggests that this is not always the case.

#### **4.1 Public Library Responses to Health Inquiries**

As part of an ongoing investigation of library reference interactions, Catherine Ross and her colleagues (see, for example, Ross, Nilsen and Dewdney, 2002; Dewdney & Ross, 1994) have shown that the exchange between library patrons in search of information and the librarians who assist them is not always fruitful. For several years, students enrolled in a reference course have been asked to visit libraries to ask a reference question on a subject that is personally meaningful to them. Ross and her colleagues have compiled a collection of more than 250 descriptions of the students’ encounters in the library, of which 41 involve requests for health information (73% in public libraries and 27% in academic libraries). The 37 students who completed a rating form about their experiences, expressed a relatively high level of satisfaction with their reference encounters ( $M = 5.14$  on a 7-point scale,  $SD 1.75$ ), even though the descriptions of the exchanges suggest that very few met the standard of reference service that we might expect. Few included an inquiry on the part of the librarian as to the intended use of the information, a thorough search for the relevant material, and careful follow-up to ensure that the information located actually met the user’s needs. Instead, many of the responses by library staff were perfunctory, led to out-of-date materials, and there were minimal attempts to ascertain whether the information retrieved actually met the student’s need. For instance, in 2000, one of the students asked a public librarian “if you could help me find some information on diabetes. Books, but as well, articles on the recent breakthroughs in research.” The librarian advised the student that while the library had “a good selection of books on diabetes, .. the new discoveries in diabetes research will only be found in periodicals. We do have a catalogue here, but it has not been updated for a year. Your best bet would be to go to the central library where their catalogues are more recent.” The librarian used the computer to look up a call number for a book on diabetes and showed the student to the location in the collection. The most recent book on the shelves was published in 1995. The student, who described the librarian as “very helpful and friendly,” commented that it was strange that the librarian did not direct her/him to more recently published material or to other sources, such as the Canadian Diabetes Association. Not only is it disappointing that the librarian made no effort to find out why the student wanted the information or how she/he intended to use it, but it is also peculiar that the librarian did not steer the student to relevant sites on the Web.

In a 1999 interview, a student visited a public library and asked a librarian seated in the main reference area for “information on alcoholism and the elderly.” The librarian did not ask the student for any additional information but turned immediately to the computer, typed in some subject searches in the catalogue and gave the student the call number for a book published in 1992. Subsequently, the student noticed an area in the library in which community groups are able to distribute information packages. Here, she/he located information about consumer health and found pamphlets related to substance abuse, some specifically targeted at seniors. The student was disappointed that the librarian didn’t alert her/him to these resources, nor did the librarian suggest consulting with any community organizations, such as Senior Centres, that might be able to provide information and support for the student’s alcoholic grandparent.

If the exchanges described by the respondents in Ross’s data set are typical of the quality of response public library patrons can expect in response to requests for CHI, considerable staff development will be essential if these libraries are to respond to the consumer health information challenge. The problem is further illustrated in a quick survey we undertook of the Ontario public libraries’ response to the health emergency posed by Sudden Acute Respiratory Syndrome (SARS).

The SARS outbreak in Ontario was acute in the last week of March and the first weeks of April 2003, prompting the provincial government to declare a public health emergency. The crisis provided an opportunity to assess the response of the public library systems in the province. In the early part of April, a research assistant (a recent MLIS graduate) contacted each of the larger public library systems in Ontario, the main county libraries, and a random sample of public libraries serving smaller communities to ask for information about SARS. When probed, she said she was making the inquiry on the part of a family member living in the area of the library who was concerned about travelling elsewhere in the province. The research assistant also visited the websites of these libraries (for those who have them) to search for information about SARS on these sites, and she made email reference inquiries to the libraries that offered electronic reference services.

A preliminary analysis of the results of this project reveals that, in general, even during a declared health emergency, public library staff do not necessarily see themselves as providers of even basic forms of information, such as the telephone number for the public health unit (the research assistant placing the calls was told by one library staff member to look up the number herself in the phone book), or the numbers for local and provincial hotlines set up specifically to deal with SARS. Some library personnel contacted in this fashion had not even heard of the outbreak, or suggested that our research assistant check the newspaper. On a brighter note, the exploration of the libraries’ websites and electronic reference services yielded somewhat more helpful responses, including referrals to the Health Canada website, etc.

## **5. USER PERSPECTIVES ON CHI DELIVERY: RURAL WOMEN AS CASE STUDY**

Different groups in the community may approach their health care needs in distinct ways. For instance, women tend to be the primary seekers of health information for their children and other

family members, as well as for themselves (Stoller, 1993), and they represent the majority of health information seekers (Hibbard et al., 1999). There are also notable differences in the way urban and rural dwellers seek and use health services. Some survey findings indicate that people living in rural areas may be less likely to use certain types of health services, including "advice nurses" available via telephone hotlines (Hibbard et al., 1999; Wagner and Hibbard, 2001). These differences suggest a possible "policy divide," that is, a gap in the way policy is currently being developed for delivery of health information and the realities of consumer needs and information-seeking behaviours by members of different groups.

A review of morbidity and mortality data in Australia suggests that rural women are more vulnerable in a number of respects than their urban neighbours. For instance, rural women die or are hospitalised more often as a result of ischaemic heart disease, traffic accidents, injury and poisoning, diabetes, pneumonia/influenza, asthma, cervical cancer and malignant melanoma (Wainer, 1998). According to Wainer, factors that have an adverse effect on rural women's health include: lack of access to health services and information, transport cost and availability, experiences with lack of confidentiality and privacy, lack of counselling and education on issues such as stress management and woman abuse, lack of consultation by governments, and lack of access to female doctors. Interestingly, there is some indication that urban and rural women may also define health differently, with rural women placing greater emphasis on self-reliance and self-help in dealing with health matters. Wainer suggests that some of the components of best practice with respect to rural women's health are participation by women in the allocation of health resources in their communities, access to female health care providers, *the provision of high quality information*, accessible services, and "an emphasis on well-being, as well as illness management." She argues that in order to improve rural women's health it is essential to "*continue to ask women what they want.*"

### 5.1 Preliminary Research Findings

One aspect of our research program involves individual interviews with 40 women living in the large and sparsely populated County of Huron, located in southwestern Ontario. The women who are participating in the study responded to ads placed in community agencies and local newspapers inviting them to take part in a study of rural women's healthcare experiences. Respondents are asked to respond to one of two scenarios, one in which they or a member of their family woke up in the night feeling ill with symptoms more serious than the flu or a second scenario in which they or a member of their family needed information about a chronic health problem, e.g., a nagging pain in the shoulder. They are also asked to describe their own experiences in seeking help and information from the health care system.

The participants have been eager to share their experiences. Active health information seekers, they frequently refer to the importance of key informants in their personal networks, such as relatives or friends who work in health care, particularly nurses, as well as favorite resources, such as self-help or home-healing books. They also turn to various "alternative" health care and health information providers, such as chiropractors, homeopaths, massage therapists, practitioners of Chinese medicine, and health food stores. Contrary to some of the respondents in Catherine Ross' study, a number of the women in this study commented on the valuable sources of information available in the public library. Few mentioned using the province's

Telehealth service or searching provincial or federal health websites for information. Indeed, if they have a computer and use the Internet, some search sites focused on specific conditions, such as cancer, or particular issues, such as parenting. A few of the women had heard “good things” about the Telehealth dial-a-nurse service but others expressed scepticism, one woman didn’t think she could “learn much from them” and another referred to the service as “too impersonal and a waste of money.” Generally, when these women consult with the formal help system, the family doctor or the emergency department is their first point of contact, with the emergency department emerging as a particular favourite because “you don’t have to wait as long.”

Consistent with some of Wainer’s observations above that rural women may have a unique, self-reliant perspective on health care, a farming woman who participated in our study told us that *“people have to be responsible for their own health and the whole system is inappropriately called health care. We’re in charge of our health care. The other people are in charge when we get sick. It’s sick care.”*

## 6. DISCUSSION

The role of consumer-oriented health information in the everyday lives of citizens is emerging as an important field of study. As health care providers come to expect knowledgeable patients to engage in a process of shared decision-making (Smith, 2002; Weston, 2001; Elwyn, et al., 1999; Towle et al., 1999), and as resource-strapped health systems place an increasing premium on citizens knowing and understanding ways to prevent disease and maintain their own good health, there is an increasing demand for public access to high quality, timely, and useful health information. However, the sheer volume of CHI available from a variety of sources can be overwhelming. Continuing to develop delivery mechanisms for CHI without first understanding the needs of various types of users, and the role of information systems and professionals as part of the delivery system, only exacerbates the problem. Studies of the types reviewed and reported above will begin to build an evidence base on which both future research, as well as practice and policy can build.

From the perspective of the information professions, especially librarianship, it is becoming clear that, despite what appears to be the obvious desirability of initiatives involving public libraries, such as the Nova Scotia Health Network, the lack of development of organized consumer health responses in public libraries may be due, in part, to a lack of leadership within the public library community in identifying CHI as a service priority, as well as a lack of dedicated funding (within the libraries and from external, government sources) for this purpose. The lack of funding is significant in view of public libraries’ mandate to provide access to a very broad spectrum of information and to serve a diverse clientele. The failure to make such an investment is regrettable since public libraries are already located in most communities of any size across the country. To date, libraries have not been included systematically in the development of the country’s health information structures. Instead, considerable sums of public money are being directed to create new entities that, to a large extent, are redundant with existing library infrastructures. Furthermore, some of these funds are being directed to private commercial interests rather than being invested to develop and enhance public institutions.

In the end, what matters most with respect to CHI is that citizens in need of health information are able to find what they need. If access to information is compromised by lack of availability, affordability or credibility, there is a failure of social responsibility. In a period in which most Western governments are concerned about rising health care costs, it seems unwise to overlook public institutions with a well-established mandate to provide equitable access to information, staffed by professionals who are trained to locate, organize and retrieve information relevant to users' needs. Yet, with one or two notable exceptions, this is precisely what is happening with virtually no reaction, either on the part of libraries, librarians or members of the public.

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