

## The Empowerment Model and Using E-Health to Distribute Information

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Prepared by:

**Roma Harris**

**Tiffany Veinot**

The University of Western Ontario

Document Contact:

**Ellen Balka**

Centre for Clinical Epidemiology & Evaluation

828 West 10<sup>th</sup> Avenue

Vancouver, B.C., Canada V5Z 1L8

**tel:** +1.604.875.4111 ext. 66240

**email:** act4hlth@sfu.ca

**website:** www.sfu.ca/act4hlth/



## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

‘Empowerment’ is a construct that is growing in popularity and application.<sup>1 2 3</sup> For example, Perkins notes that a computer search found that the root word “empower” was used in 360 different White House press releases, speeches, and policy statements from January 1992 through August 1994 in the United States.<sup>3</sup> Despite its popularity, ‘empowerment’ is often inadequately conceptualized and loosely defined.<sup>1</sup>

‘Patient empowerment’ focuses on control in individuals’ experiences of health, disease and illness, as well as the roles of health care organizations, communities and the broader health care system. The term health care ‘consumer’ is commonly used, and refers to people who are healthy and those who are ill<sup>4</sup> in addition to connoting a market-type relationship that extends beyond health settings.

The popularity of the idea of ‘patient empowerment’ has emerged in the context of several significant social trends including an explosion of patient-focused self-help and mutual aid programs, a growth of health care ‘consumerism,’ increased patient activism and organization, along with the rise of complementary and alternative medicine. The most systemic trends include the growth of the Internet and a reduction in health care spending in most Western countries. Significantly, the latter trend has resulted in widespread transfer of responsibility for health care onto individual citizens.

Approaches to increase ‘patient empowerment’ in the health system are numerous, from training patients to ask their doctors more questions to patient ‘self-management’ programs to promoting patient involvement in treatment decision-making to provision of consumer health information. ‘Patient empowerment’ and its applications in health care settings, however, have shown mixed results. Furthermore, the ‘patient empowerment’ discourse is based on numerous assumptions that require further

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

examination. These assumptions include the idea that patients want to be in control of their health care, and that such control will yield benefits for patients. In addition, it presumes that health care providers support patient control of their health care.

Furthermore, it is suggested that information empowers patients, and that ‘informed’ and ‘empowered’ patients take better care of their health. In this paper, we examine some of the evidence for these assumptions and discuss the relevance of this concept to dissemination and exchange of HIV/AIDS information in rural communities.

### Definitions of ‘Empowerment’

The concept of ‘empowerment’ has been used in many different disciplines<sup>3</sup>, most notably: community psychology, mental health, nursing, medicine, social work, education and organizational development. Across these domains, definitions of ‘empowerment’ vary considerably. Some overarching features, however, include the idea that ‘empowerment’ occurs on different levels: individual, organizational, community and societal/political, and may refer to both processes and outcomes.

The most influential and relevant definitions of empowerment for health care include definitions by Zimmerman in the field of community psychology, and Gibson in the field of nursing. Zimmerman argues that empowerment is:

*“the ability of individuals to gain control socially, politically, economically and psychologically through access to information, knowledge and skills, decision-making, individual self-efficacy, community participation and perceived control”<sup>5,6</sup>.*

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

Gibson defines empowerment as follows:

*“empowerment is a process of helping people to assert control over the factors which affect their lives. This encompasses both the individual responsibility in health care and the broader institutional, organizational or societal responsibilities in enabling people to assume responsibility for their own health.”<sup>7</sup>*

The essential component that these definitions share is the notion of personal control, although they differ in its scope. While Zimmerman emphasizes social, political, economic and psychological control, Gibson emphasizes individual responsibility for health care and the institutional facilitators of this responsibility. In addition, Zimmerman emphasizes the outcome of empowerment, whereas Gibson stresses the process of empowerment. The notion of personal control, common to these definitions, will frame our discussion of ‘patient empowerment’.

### **The Social Context of ‘Patient Empowerment’**

The concept of ‘patient empowerment’ and its applications have been developed in a particular social context, and the concept’s popularity can, in part, be understood by examining this context. Aspects of this context include trends that have been initiated by patients, as well as those initiated by the health system.

#### Self-Help and Mutual Aid

The rise of ‘patient empowerment’ as an area of interest and activity is seen to have roots in the traditions of self-help and mutual aid<sup>2</sup>. The number of self-help groups in Western countries have grown since the 1970s,<sup>8 9</sup> to the extent that self-help/mutual aid is viewed as a new social movement<sup>8</sup>. It is estimated that 2.4% of Canadians have attended self-

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

help groups in one year<sup>9</sup>, and in Ontario alone, there are more than 3,000 self-help groups in existence.<sup>10</sup>

Development of self-help/mutual aid is often attributed to the breakdown of traditional support networks, such as family and neighbourhoods.<sup>9</sup> Borkman also argues that rapid technological and social changes in society have led to a decreased ability for younger generations to turn to older generations for guidance.<sup>9</sup> This leads to greater reliance on peers for guidance. Borkman also argues that the rapid changes faced by younger generations include the greater number of diseases and social conditions that have been identified, longer life expectancies and treatments – which creates conditions for which an individual’s social network may have little up-to-date information to provide.<sup>9</sup> It has also been suggested that deinstitutionalization in mental health, reduction of medical and clinical practice, the growth of alternative medicine, and the awareness of some users of stigma they experience<sup>2</sup> have also contributed to the growth of self-help.

### Health Care ‘Consumerism’

Historically, some of the primary issues for the health care consumer movement have been patient’s rights to privacy and confidentiality, informed consent to medical treatment and disclosure of information.<sup>4</sup> ‘Consumerism’ has led to widespread introduction of Patient’s Bills of Rights,<sup>4</sup> entrenchment of informed consent to treatment in law<sup>11,12</sup>, introduction of patient representatives in hospitals,<sup>4</sup> hospital ‘report cards’,<sup>13</sup> advanced directives for treatment decisions should a patient become incapacitated,<sup>13</sup> and increases in malpractice litigation.<sup>4</sup> Consumerism also advocates the right of people to who can afford it to choose the goods and services they purchase.<sup>2</sup> Consumerism has

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

played a great role in health policy development in Western countries, such as Britain<sup>2</sup> <sup>14</sup> and Germany.<sup>13</sup>

An even greater influence of ‘consumerism’ may be a widespread change in attitudes of patients. Michael Decker<sup>13</sup> argues that around the world, users of health care in developed nations are thinking less like recipients and more like consumers. He states that consumers in every nation want: quality, speed, choice, appropriateness of care, and affordability.<sup>13</sup> He suggests that this results in a move away from a “one size fits all” model to more individualized services and consumer choice.<sup>13</sup> He argues that consumers are demanding options, such as selection of their surgeon or doctor or complementary therapists, and they also want to choose additional types of care, such as complementary therapists.<sup>13</sup>

### Rise of Complementary & Alternative Medicine (CAM)

In most Western countries, there has been a significant increase in usage of CAM. According to the National Population Health Survey (NPHS), use of alternative practitioners among Canadians increased from an estimated 15 percent in 1994/95 to an estimated 19 percent in 1998/99.<sup>15</sup> In 1998/99, this meant that about 3.8 million people used an alternative practitioner.<sup>15</sup> In 2001, it was found that the proportion of people who had used one or more natural health products in the previous six months grew from 70 percent in 1999 to 75 percent in 2001, with the greatest increase being in use of herbal remedies.<sup>16</sup> Overall, it is suggested that 30-40% of the North American population has used at least one complementary approach.<sup>17</sup> In fact, it has been argued that Americans made more visits to complementary therapists than they did to primary care physicians.<sup>17</sup>

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

In one Canadian study,<sup>16</sup> people who used CAM do so for the following reasons:

- they believed that using alternative medicine together with conventional medicine was better than using either alone (72%);
- they thought that alternative practitioners spent more time with them than physicians (37%); and
- they thought that alternative practitioners were better listeners (31%).

Similar to the relational emphasis above, an Australian study also found that it was alternative therapies offered individuals an empathic connection with a health care provider that doctors were not inclined or able to provide them with, given limitations on their time and their focus on the disease state rather than the whole person.<sup>18</sup>

Use of CAM can also give people with life-threatening and/or chronic illnesses a sense of control. For example, people living with HIV/AIDS (PHAs) identify that use of CAM provides them with a greater sense of control over their health and health care,<sup>17 19</sup> and cancer patients state that use of CAM gives them a sense of control over their destiny.<sup>20</sup>

### Patient organizations and activism

The rise of patient organizations and activism is also a key social context of ‘patient empowerment.’ Like self-help/mutual aid initiatives, the numbers of patient groups in the West have rapidly proliferated. For example, in Britain in 1999, the College of Health had 2,500 patient organizations in its database, compared to 800 in the database in 1984.<sup>21</sup> Patient organizations/activists often inform, involve, represent, advocate for and provide support for patients.

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

Several aspects of the work of patient organizations are particularly relevant to the idea of 'patient empowerment', including the involvement of patients in services,<sup>22 23</sup> and the role of patient organizations in advocacy and health service planning.<sup>22</sup> Patient activism has also reached new levels in Canada and other Western countries around the issue of HIV/AIDS, where a newfound treatment activism led to greater patient involvement in clinical trials, dissemination of treatment information, and changes in drug approval processes.<sup>24</sup> This activism also led to the establishment of many community-based AIDS Service Organizations in Canada. Patient organizations can also be significant players in the political process.<sup>22 25</sup>

### Growth of the Internet

It is widely argued that access to health information via the Internet empowers patients<sup>26</sup> and equalizes the physician-patient relationship because it diminishes the knowledge asymmetry that has historically marked that relationship. This access to information is believed to increase the control that patients can exert in the health care setting. While this notion is supported by limited evidence, as will be discussed later in this paper, the impact of the Internet on health care is indisputable.<sup>13</sup> The Pew Internet and American Life Project in the United States found that 52 million American adults, or 55% of those with Internet access, have used the Web to get health or medical information<sup>27</sup>.

Additionally, in a telephone survey of a nationally representative sample of the American public, with oversample of people in poor health, 31% had looked for health information on the Internet in the past 12 months<sup>28</sup>. Additional studies have also shown high levels of Internet usage amongst those facing a serious illness, such as patients with breast

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

cancer,<sup>29 30</sup> and patients of children facing cardiac surgery.<sup>14</sup> However, it is important to recognize that access to the Internet is by no means universal.<sup>31</sup>

An important phenomenon enabled by the Internet, also widely cited as ‘empowering’, is the growth of virtual communities and electronic support groups.<sup>8 32 33</sup> These online resources provide participants with international, free, 24-hour access to health information and referral, advice and emotional support on a broad range of topics.<sup>8</sup> It has been suggested that they “support self education and self responsibility, encourage patients' initiative and assertiveness, and provide members with an opportunity to help others.”<sup>34</sup> Several studies have found high levels of support in online communities,<sup>8 35 36 37 38 39 40 41</sup> and one study demonstrated the use of virtual communities as a form of adult learning.<sup>42</sup> Thus, this technology has become a significant facilitator of self-help/mutual aid. Additionally, a potentially radical changes brought about by the Internet is the transformation of patients into producers, as well as consumers, of health information.<sup>43</sup>

### Reduction in health care spending

In Western countries, escalating health care costs have led to a variety of cost-cutting and management-oriented initiatives. These escalating costs are also projected to increase due to demographic shifts, including the aging population and a shift from acute to chronic illness as the predominate disease pattern in the West.<sup>21</sup>

In Canada, there have been expenditure caps in Ontario, Alberta, British Columbia, and other provinces.<sup>44</sup> As a result, there have been caps on the number of new physicians, limits on the practices of new physicians, and a limits in the growth of physician fees.<sup>44</sup> Among the consequences of these policies are severe physician

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

shortages in most areas of Canada, with the reality that many individuals are unable to secure a family physician. For example, in Ontario, there are 142 communities designated as under-serviced for general/family physicians<sup>45</sup> and almost 1 million people do not have timely access to a family physician.<sup>46</sup>

One of the important features of the current climate in health care has been a shift in the responsibility for much health care to the patient.<sup>47 48</sup> Examples of this include increased drug costs paid by patients, inability of individuals to find a physician, encouragement of chronically ill patients to ‘self-manage’ their illnesses and increased outpatient medication therapy for even the most serious conditions.<sup>49</sup> In addition, because of fragmented services and the variety of types of care used, patients are increasingly becoming their own ‘care integrator,’<sup>13 50</sup> because they may be the only persons with a complete and integrated view of their care.<sup>13</sup> The end result of these trends is that individuals are becoming less able to rely on formal health care to meet all of their health care needs.

While the relationship of cost containment to ‘patient empowerment’ is complex, this does illuminate an important issue: ‘patient empowerment’ has received widespread support at the same time that health care spending has been reduced in most Western countries, and ‘patient empowerment’ can potentially be used as a justification for cost-cutting<sup>51</sup> as a part of transfer of responsibility for care to individual citizens. This transfer of responsibility to patients has been described as a cost-cutting measure in the health system.<sup>48</sup> In this way, ‘patient empowerment’ can be used to serve the interests of institutions rather than directly serve those of the patients.

### **Critical perspectives on ‘patient empowerment’**

The idea of ‘patient empowerment’ is based on underlying assumptions that bear further examination. These include the ideas that:

- patients want to be in control of their health and health care;
- it is good for patients to have choice and control;
- health care providers support patient efforts to gain control;
- providing health information to patients ‘empowers’ them; and
- ‘informed’ and ‘empowered’ patients take better care of their health.

### ***Assumption #1: Patients want to be in control of their health and health care***

#### Physician-Patient Relationship

The doctor-patient relationship is potentially both a site of healing and a site of disempowerment for people experiencing illness. It has been suggested that patients feel a continual tension in the medical encounter between wanting to avoid dependency and an equally strong desire to take on a ‘passive patient’ role and invest their trust and faith in health professionals.<sup>18</sup> This creates a central paradox when considering ‘empowerment’ in the physician-patient relationship, and potentially exposes some of the limits to the applicability of this concept: sometimes, particularly at times of great vulnerability, people may not want the control that ‘patient empowerment’ purports to provide.

#### Treatment Decision-Making

Shared decision-making and patient involvement are often forwarded as the ideal models of treatment decision-making in medicine,<sup>11 52</sup> and this concept has received much attention in research and clinical practice literature. However, there is a great deal of

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

variability in patients' desires for involvement in treatment decision-making.<sup>53</sup> For instance, individuals diagnosed with a life-threatening illness are more likely to want physicians to make treatment decisions on their behalf and less likely to want to take an active role in decision-making.<sup>54</sup> Paradoxically, patients who do not want an active role occasionally have this thrust on them.<sup>55 56</sup>

### *Assumption #2: It is good for patients to have choice and control*

The assumption that choice and control in health care benefits patients has primarily been tested through interventions aimed at increasing patient choice and control. To date, the results of these interventions have been contradictory,<sup>57</sup> with some interventions reporting benefits, and some interventions reporting neutral or negative effects.

The benefits ascribed to choice and control in health care may not be as great as has been assumed<sup>58</sup> and may well be related to other factors, such as feelings of support or safety.<sup>59</sup> For example, one extensive review of studies that examined the association of psychosocial issues and cancer relapse and survival found no relationship between coping styles associated with 'patient empowerment', such as a 'fighting spirit' and relapse and survival. Similarly, a measure of perceived control, the multidimensional health locus of control, showed no relationship to prognosis.<sup>60</sup>

A number of interventions to increase control in patients have led to unintended effects, some of which actually undermine the experience of 'control'. For example, a study of the use of a question prompt sheet with cancer patients increased patient anxiety, unless the doctor specifically addressed the questions on the prompt sheet.<sup>61</sup> Additionally, it has become increasingly common to give patients patient-controlled analgesia (PCA) after surgery, where patients themselves decide how much analgesia they will use.

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

However, in evaluations of this approach, patient's freedom to control their pain was limited by their fears of overdosing and side effects, ambivalent feelings towards pain, and mistrust of technology.<sup>62</sup> To the extent that patients like PCA, it is because it makes it unnecessary to 'bother' the nurse with their requests.<sup>62</sup> Salmon argues that this in fact disempowers patients, as their ability to assert their needs to health care providers is diminished.<sup>58</sup>

Importantly, 'patient empowerment' in the health care context usually focuses on the individual patient, rather than system level factors as suggested by the definition of 'empowerment.'<sup>63</sup> However, it is important to consider the purported benefits of 'patient empowerment' in the context of systemic factors, notably the increased transfer of responsibility for health care to individual citizens in Western countries as described above. Patients are increasingly being required to do more of the work of their care, whether or not they want this.<sup>48</sup>

### *Assumption #3: Health care providers support patient efforts to gain control*

'Patient empowerment' often refers to some aspect of the physician-patient relationship, such as increased involvement in clinical consultations or medical decision-making. However, little research has focused on how physicians actually respond to 'empowered patients.'<sup>63</sup> What research has been done, however, suggests a gap between ideal and reality. For example, in one study, informed decision-making occurred in only 9% of outpatient visits, and doctors asked patients if they have questions in less than half of visits.<sup>64</sup> In addition, this research shows serious constraints on patient 'empowerment'.

One of the greatest systemic barriers to patient involvement and control in health care in Canada is lack of access to a physician. With 142 communities medically under-

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

serviced for family or general practice physicians in Ontario<sup>45</sup> alone, and with 88% of primary care practices in Ontario partially or completely closed to new patients,<sup>46</sup> citizen ability to choose a health care provider, or even enter into a therapeutic relationship, is currently compromised. In addition, general and family physicians in Ontario have an increased workload,<sup>46</sup> with approximately 35% of physicians having “too many” patients relative to their desired patient load.<sup>46</sup> In order to facilitate informed decision-making, it is recommended that the doctor and patient engage in dialogue – however such dialogue is rare in clinical practice.<sup>65</sup> Doctors usually spend less than one minute out of a 20-minute visit discussing treatment and planning.<sup>64</sup> In addition, patients may be hesitant to challenge their doctor’s authority.<sup>26 18 66</sup>

There is also evidence that physician receptiveness to ‘patient empowerment’ is variable. For instance, one study involving 800 post-medical visit interviews with mothers of children with medical problems<sup>67</sup> found that one in four mothers did not ask their most pressing question, because they were not given the opportunity or encouraged to raise their concern.<sup>12</sup> Patients who present with difficult or medically controversial problems may be viewed negatively by their doctors.<sup>68-70</sup> Thirty-eight percent of American physicians felt that patients bringing Internet information into the consultation makes the consultation less efficient because patients may want something inappropriate, or the physician may feel challenged.<sup>28</sup>

### *Assumption #4: Providing health information to patients ‘empowers’ them*

Physicians frequently do not meet their patients’ information needs fully. For example, in one study, 48% of persons with cancer reported that they had insufficient information,<sup>71</sup>

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

and in a Canadian survey of oncology patients, 54% felt that they had not received enough information.<sup>72</sup>

For those who have access and requisite technical and information literacy skills, does their use of health information on the Internet result in them becoming ‘empowered’ in their health care? Again, the evidence is mixed. Patients do report that accessing health information increased their confidence in asking questions<sup>35</sup> and feeling more in control and confident.<sup>28</sup> Conversely, some patients do not feel comfortable bringing health information to their doctor due to concerns about challenging physician authority.<sup>26</sup> Also, physicians vary in their receptiveness to patients bringing Internet health information to the consultation, and may indeed ‘act challenged’ in response.<sup>27</sup>

Additionally, not all patients want to look for information. Patients may also avoid further information about their illness because to seek further information would feel contrary to believing in the doctor’s expertise.<sup>66</sup> They may also want to avoid feeling confused by additional information,<sup>66</sup> and to protect their sense of hope.<sup>66</sup>

### *Assumption #5: ‘Informed’ and ‘Empowered’ patients take better care of their health.*

Numerous studies suggest that information alone rarely changes health behaviour.<sup>73-75</sup>

### **Summary: the Patient Empowerment Paradox**

A critical analysis reveals many inaccurate or poorly supported assumptions behind the notion of ‘patient empowerment’. These include the ideas that: patients want to be ‘empowered’, ‘empowerment’ is good for patients, health care providers support patient efforts to become ‘empowered,’ ‘informed’ patients are ‘empowered’ patients, and that ‘informed’ and ‘empowered’ patients take better care of their health. Additionally, the popularity of the concept of ‘patient empowerment’ has been located within a social



## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

context of diminished health care spending and increased transfer of responsibility for health care to individual citizens.

However, the popularity of the idea of ‘patient empowerment’ also occurs at a time of patient-directed trends that involve patients being active in matters of their own health. These trends include the growth of self-help/mutual aid, increased consumerism, more engaged patient activism, the increasingly prevalent use of CAM, and widespread patient use of the Internet and other sources to inform themselves, connect with others, and share their personal knowledge. However, the reasons for and benefits of these activities have generally not been concretely linked to a process or outcome ‘empowerment’, although on the surface it may appear that this is so. Benefits may equally be related to patient’s wishes to develop supportive relationships with others or to reduce their health-related anxiety. Growth of these activities may also be an adaptation to diminished availability of health care in Western countries.

### **Rural HIV/AIDS Information Networks Study**

#### *Background: HIV/AIDS Treatment Information in Canada*

HIV/AIDS has a significant impact on the health of Canadians. As of 2002, there were an estimated 56,000 people living with HIV/AIDS (PHAs) in Canada,<sup>76</sup> with 2,800-5,100 new infections per year.<sup>76</sup> Information on HIV/AIDS treatment is a critical resource for PHAs and their caregivers.<sup>77,78</sup> Treatment information is used for: health decision-making; providing care, support and treatment to PHAs; patient education; treatment advocacy; and other community-based activities. Factors that affect development, dissemination and exchange of HIV/AIDS treatment information in Canada include:<sup>77-79</sup>

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

- PHAs prefer *personalized* treatment information delivered face-to-face by local sources, including personal physicians, friends/acquaintances and local AIDS Service Organizations (ASOs).
- HIV/AIDS affects diverse communities, such as: gay men, injection drug users, Aboriginal peoples and prisoners. Each group has unique treatment information needs and social contexts for treatment. Many of these communities have less access to support services, health care and health information.
- Many PHAs find it difficult to obtain treatment information in an accessible format and appropriate literacy level. PHAs want to be supported in understanding and using treatment information.
- Discrimination and stigma are barriers for individuals in seeking treatment information and support.
- Many PHAs do not actively seek information, but there are many self-taught “treatment experts”.
- Treatment decision-making amongst PHAs is social in nature. PHAs value informal learning and observation of their peers, and institutional relations of power affect their decision-making.
- Treatment information is exchanged by diverse individuals and groups in Canada with varying needs and issues: ASOs; PHAs and their networks; physicians, nurses and other health care providers; HIV clinics; community health centers; informal caregivers; support workers and volunteers.

These factors demonstrate the importance of a community-level (meso-level) approach to treatment information delivery, rather than a sole focus on individual PHAs as recipients

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

of treatment information. However, much remains poorly understood about HIV/AIDS treatment information exchange and treatment information networks in Canada: what they look like, how they function and their current capacity. We are in the early phases of a developing a project to address some of these questions.

### *Background: HIV/AIDS in Rural Communities*

Rural communities face many challenges with regard to health care, including geographic isolation, lack of services, lack of anonymity, and a necessity to travel for health care. As previously described, there are 142 medically under-serviced communities in Ontario, the majority of them rural and/or northern.<sup>45</sup>

Within the context of HIV/AIDS, initial consultations with rural communities reveal particular challenges. In rural communities, anonymity of HIV testing can be a particular worry as a result of the discrimination and stigma associated with HIV/AIDS. However, most small communities do not provide anonymous testing. Low income people in such communities may not have the ability to travel to anonymous testing sites in larger cities, and thus may not be tested for HIV. Conservatism in some rural areas also isolates at-risk populations, such as lesbian, gay, bisexual and transgendered youth and injection drug users. Additionally, for people living with HIV/AIDS in rural areas, there is a real lack of routes to HIV/AIDS treatment information.<sup>80</sup> For example, many people do not have Internet access at home, and public Internet access sites often do not afford the privacy that PHAs would want when seeking HIV/AIDS information. PHAs also experience challenges with health care. For those who have a family physician in their community, their physician may not have enough PHA patients to develop needed knowledge of HIV treatment. Some PHAs have physicians who refer them to other

## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

providers, or refer their patients' HIV-related health issues to specialist HIV care available in other centres. Also, in order to receive specialist care, most PHAs need to travel. This alone can be a significant barrier to accessing such care.

### *Rural HIV/AIDS Information Networks Study*

Our research will be undertaken in two rural settings in Ontario, Huron and Perth counties. Community partnerships have been formed with local organizations, including AIDS Service Organizations, libraries and public health units. The study will involve interviews with PHAs, people at risk of HIV infection, friends and family members, health care providers, as well as staff and volunteers in community agencies, such as libraries. We will also conduct an analysis of access to health services through asset mapping and policy analysis techniques.

### **Conclusion**

In this paper we've outlined a broad context for a study of HIV/AIDS information exchange in rural communities, including: a critical and historical examination of the 'patient empowerment' model in health care, a discussion of what is known about HIV/AIDS treatment information exchange in Canada, and the context of HIV/AIDS in rural communities. This examination suggests reasons to be skeptical about the applicability of an 'empowerment' model as a framework for disseminating health information to patients. As a result, this study will start from a different location, looking at how HIV/AIDS information flows through communities, and with what impact. The research seeks to increase our understanding about the ways in which HIV/AIDS information flows through and affects rural communities in order to develop new approaches to providing useful and timely information. Through this, we aim to increase



## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

the capacity of these communities to support persons living with HIV/AIDS, as well as their family and friends, and to facilitate the work of service and health care providers.

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## The Empowerment Model and Using E-Health to Distribute Information

Roma Harris and Tiffany Veinot

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