RESEARCH EXAMPLES: LAY USER PROJECTS

The ACTION for Health program is concerned, in part, with the use of Internet-based health information by lay users. Through collaboration with community groups and health care professionals, particularly in rural and remote areas, our research seeks to:

- Identify obstacles encountered by lay users searching for health information;

- Identify mechanisms that facilitate effective information location, retrieval and use;

- Explore how informal information-exchange networks operate within different communities;

- Explore how information received through these networks and other sources, especially the Internet, affects interactions between lay users and health care professionals;

- Examine the unintended consequences of Internet based information systems, including government-supported health portals;

- Develop technology-aided systems to facilitate lay users' access to timely, relevant and useful health information;

- Develop technology-aided systems that integrate into a system of community care in which users' needs for personal relationships and emotional support is recognized.

Following are specific projects within this area of the **ACTION for Health** program.

Rural Women's Health Information Seeking

- Explores the health-information seeking practices of women living in rural communities.

- Preliminary results:

    o Women rely heavily on their own resources, using information and advice from various sources (e.g., the Internet or home remedy books), especially in the case of non-urgent health concerns.

    o Many women look for emotional support and caring relationships with 'providers' outside the formal health system (e.g., health food stores, pharmacists and sources of alternative medicine).

    o Some women appear to self-diagnose and self-treat as a result of information they have found on their own.

- A model of health care delivery that relies on lay users finding health information on their own (often from the Internet) is sometimes flawed and may lead to unanticipated or unintended consequences, such as reliance on sources of information, advice or 'care' outside the formal health system. This research is concerned with addressing these issues.

Rural HIV/AIDS Information Networks Study

- Examines how HIV/AIDS information is exchanged in rural communities among people with HIV/AIDS (PHAs), their friends and family members, and health care providers.

- Few studies have addressed the support systems available for PHAs. In many rural communities, HIV/AIDS is a hidden problem and PHAs are isolated and sometimes are forced to re-locate to larger centres in order to receive support and treatment.

- This study is currently underway in Ontario and will be expanded to sites in Newfoundland and the Kootenays region of British Columbia *(pending additional funding)*.

The Impact of a Nurse Intermediary in e-Health Support for Rural Youth

- Involves the development of an Internet-based health chat exchange for rural youth that will be mediated by a public health nurse.

- This pilot initiative will be evaluated, in collaboration with community partners, the Medical Officer of Health and the Director of Public Health of Huron County, Ontario, to assess the impact of supporting the health information needs.

A Comparison of Consumer Health Information Websites

- Evaluates a selection of Canadian government (federal and provincial), Canadian private, US private, international private, and major search engine Internet sites. Evaluations include:

  o Overall quality – Each site is being evaluated with two instruments used in other website analysis research.

  o Content – Each site is being assessed based on a series of questions specific to various medical conditions and rated according to how well the site leads the inquirer to an answer, the accuracy and detail of the answer provided, and the effort required to locate an answer.

- This research intends to address the underlying assumption that the provision of consumer health information via the Internet is enhancing the availability and accessibility of health information to the average consumer and will increase their ability to take responsibility for their own health.

Implications:

Our research will provide a critical examination of the needs and uses of health information by the public, the role of health care providers in decision-making, and the assumptions about the role of health information held by those making resource allocation and program delivery decisions. A more comprehensive analysis of the role of health information and its various delivery mechanisms, including information technologies, will enable more informed decision making among key stakeholders in Canada's health system.

For additional information on these projects:
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