

A Model of Consumer Participation: The Canadian Breast Cancer Initiative

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RÉSUMÉ

La question de l'établissement d'un lien entre la recherche et les politiques n'est pas unique au secteur des soins de santé des aînés; elle a été mise de l'avant par de nombreux groupes d'intervenants, y compris ceux chargés de maladies bien précises comme le cancer du sein. Une façon d'améliorer ces liens fait présentement l'objet d'une étude systématique entreprise dans le cadre de l'Initiative canadienne sur le cancer du sein avec l'apport de femmes ayant le cancer du sein. L'initiative comprend un certain nombre de volets et se veut un modèle de participation du consommateur, à divers paliers, à l'établissement du programme de recherche et d'élaboration de politiques, et partant, permet d'améliorer la responsabilité en matière de transformation des constatations de la recherche en politiques. Cette notion de participation du consommateur à l'établissement d'un lien entre la recherche et les politiques peut être appliquée à d'autres maladies et à d'autres groupes démographiques, dont les aînés.

ABSTRACT

The issue of linking research and policy is not unique to health care of the elderly; it has been articulated by numerous stakeholder groups, including those with specific diseases, such as breast cancer. A method of enhancing these links is now being systematically addressed in the Canadian Breast Cancer Initiative with the input of women with breast cancer. The Initiative consists of a number of components and demonstrates a model of consumer participation at multiple levels in setting the agenda for research and policy development, thus enhancing accountability in the transfer of research findings into policy. The concept of consumer participation in linking research and policy is transferable to other diseases and other population groups, such as seniors.

Key Words: Breast Cancer, Consumerism, Models, Research, Policy.

Mots clés: Cancer, consumérisme, modèles, recherche, politiques.

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Introduction

“What must be done to better link research and policy for the benefit of Canada’s seniors?” is one of the questions common to the focus of all the manuscripts in this Special Joint Issue. This question assumes that research influences policy and vice versa and that improvement in this relationship can have a beneficial impact on Canada’s seniors. This issue of forging links between research and policy is not unique to this age group; it has been articulated by numerous stakeholder groups, including those affected by specific diseases, and is now being addressed systematically through the Canadian Breast Cancer Initiative with consumer participation.

Although the Canadian Breast Cancer Initiative does not focus specifically on the age group which is the focus of this Joint Special Issue, the relevance of using the example of cancer, and specifically breast cancer, in a collection of papers on bridging research and policy on aging in Canada can be seen in the following statistics: in 1996 it was estimated that 72 per cent of the new cases and 81 per cent of the deaths from cancers of all types would occur in the age groups over 60 and for breast cancer the respective figures were 59 and 70 per cent. In addition, as women predominate in the older age groups, breast cancer is obviously an issue that concerns older women.

This paper will describe the current policy development and research activities, which are being undertaken by Health Canada and its partners, under the umbrella of the Canadian Breast Cancer Initiative. These activities will have an impact on the health and health care of elderly women with breast cancer, as well as of those in younger age groups. Indeed, the model of consumer participation at multiple levels of all parts of the Initiative is one that bears description at the very least and emulation in future efforts in other areas of health care. The paper will highlight the aspects of consumer participation that facilitate the linkage between research and policy and will describe potential impediments to such participation.

Consumer Involvement in Health Care

Policy Development

In a review of the literature on public participation, commissioned by Health and Welfare Canada, and related to the elements of the Health Promotion Framework presented in the document *Achieving Health for All*, Powell et al.¹ used the following working definition: “public participation means the individual and collective action of people to be involved and improve their community”. The authors suggest that participatory actions are generally directed at three goals: social or recreational ends, individual, community or group betterment or to influence government decision-making. To the same end, Zakus and Hastings² were also commissioned to review the literature as it specifically pertained to public involvement in health pro-

motion and recommended two broad areas for future study: clarification of the appropriateness of different research methodologies and approaches to public involvement in decision-making and research directed at a clearer definition of the basic assumptions, concepts, issues, questions, methodologies and models related to public involvement in decision-making.

A number of frameworks or theories for analysing consumer participation in policy-making and in health care specifically have been developed.^{3,4,5,6} Much of the early literature grew out of the consumer movement of the 1960s and 1970s; particularly challenging to traditional elites were the women's liberation movement and the minority rights movement. A more informed public with greater awareness of the high cost of health care in Canada and the need for more accountability in the health care system are factors that have led to an increase in involvement in activism and advocacy. Rachlis and Kushner⁷ suggest that the time is ripe for governments in Canada to cultivate a consumer coalition for health reform by setting up participatory forums for health debate.

Regionalization of health administration and consumer involvement in health policy planning have been central themes of the health reform activities in several Canadian provinces over the past decade.^{8,9,10,11} This is predicated on the assumption that consumer participation ensures accountability of health care providers in meeting the needs of the community. However, the most appropriate role of the consumer in the context of a universal, publicly-funded health care system, and particularly in the increasingly complex environment of health care delivery, has not been defined. In a review of different models of consumer involvement, Sullivan and Scattolon¹² identified three main barriers to effective consumer involvement. Firstly, the imbalance of power between professionals and consumers leads to professional authority and consumer complacency. Secondly, consumers lack ties with the local support networks in health care institutions and organizations, thereby having less ability to influence health care issues. Finally, lack of access to information and skills necessary for making decisions related to health policy planning undermines the success of consumer participation. The authors suggest that more attention needs to be paid to the social psychology of professional-consumer interactions, particularly in relation to traditional power hierarchies and organizational ties and skill level, if consumers are expected to participate as equal partners with professionals and administrators in health policy planning.

Research on patient involvement in decision-making has focussed on treatment decisions and how best to involve patients in making these choices.^{13,14} However, in an editorial on incorporating patients' preferences into medical decisions, Kassirer¹⁵ pointed out the necessity for research into the types of decisions that require the most patient participation and for developing reliable ways of assessing patients' preferences. On the other hand, consumer participation in policy development and resource allocation decisions, as recommended by the provincial health reform reports, has not

been articulated clearly in terms of specific roles for consumers and the expected outcomes of such participation. Certainly, such participation has not been well studied.

Participation in Research

In a report prepared for The Royal Society of Canada, Green et al.¹⁶ emphasize the integration of research, education and action in the definition of participatory research and describe it as a process rather than a specific methodology. The authors describe the distinguishing characteristics of participatory research as: "(a) extensive collaboration between traditionally defined researchers and the community in each stage from identifying the problem to applying and disseminating results; (b) a reciprocal educational process between community and researchers; and (c) an emphasis on taking action on the issue under study". In this context, "community" is any group of individuals sharing a given interest, who may or may not share a geographic association; thus, individuals with a specific disease or within a particular age group may constitute the community with whom the researchers collaborate.

How has the Canadian Breast Cancer Initiative involved consumers? Has the Initiative overcome the barriers to effective consumer participation in health care planning and does it truly reflect the distinguishing characteristics of participatory research described above? An understanding of what the Initiative is and how it came about is an essential first step before those questions can be answered.

History of the Canadian Breast Cancer Initiative

In September 1991, the Sub-Committee on the Status of Women of the Standing Committee of the House of Commons on Health and Welfare, Social Affairs, Seniors and the Status of Women initiated a study of breast cancer and produced a report in June 1992 to the Standing Committee entitled "Breast Cancer: Unanswered Questions".¹⁷ A campaign of writing by women with breast cancer provided much of the public advocacy needed to reach the attention of top-level policy-makers.

In December 1992, in response to this report, the Government announced a federal commitment of \$25 million over five years to the Canadian Breast Cancer Initiative to:

- support breast cancer research;
- develop information exchange models for breast cancer;
- hold a national consensus workshop;
- continue support and co-ordination of provincial breast screening activities (begun in 1987);
- support activities to foster uniform high standards of care; and,
- support activities in the area of professional education.

The Breast Cancer Initiative thus consists of a number of components. The National Forum on Breast Cancer was held in November 1993 and

resulted in a number of recommendations for action and research which are currently being addressed by the other parts of the Initiative, namely the Canadian Breast Cancer Screening Initiative; the Steering Committee for Care and Treatment Guidelines; the Canadian Breast Cancer Research Initiative; five regional Breast Cancer Information Exchange Pilot Projects and the Professional Education Strategy.

Consumer Involvement in the Breast Cancer Initiative

Women with breast cancer are participating in the process of identifying issues for research and policy development, in the various committee structures addressing these issues and in the dissemination of potential solutions to the identified problems.

The National Forum on Breast Cancer, held in November 1993, was the first major activity carried out under the Initiative. Women affected by breast cancer were involved on the Organizing Committee and on the various subcommittees and working groups developing background information and materials for the Forum. The Forum was organized around four major themes, namely, *Research, Prevention and Screening, Treatment and Care and Support, Advocacy and Networking*. The task of the working groups was to summarize existing knowledge, seek input from all parties involved (including women with breast cancer and the general public) and recommend the priorities and directions that should guide the activities of research agencies, universities, governments, advocacy groups, volunteer agencies and health care institutions. A pre-Forum survey of women with breast cancer by the Sub-Committee on Support, Advocacy and Networking highlighted the lack of attention to the psychological dimensions of breast cancer in research and in the design and delivery of treatment and care services. To ensure that this would be addressed in the future, the sponsoring organizations supported the attendance of women with breast cancer at the Forum.

The Forum was unique in that approximately one-quarter of the 650 invited participants were women with breast cancer and their families. Clinicians, researchers, representatives of non-governmental agencies and policy-makers were among the remainder of the participants. The concerns of women dealing with the day-to-day reality of breast cancer were articulated clearly in presentations by breast cancer survivors in the plenary sessions as well as in the small group discussions, in which all participants reviewed and refined the initial sub-committee recommendations. Thus the "community" made its voice heard.

The Report on the Forum made numerous recommendations for action and research based on the discussions at the Forum and the involvement of women and families affected by breast cancer in all phases of the Initiative was strongly advocated.¹⁸ Areas of research that were strongly identified at the Forum included: the psychosocial support of women with breast cancer and their families; the study of potential environmental causes of breast

cancer; and the effectiveness of alternative therapies. Many of these areas for investigation have not received major attention from traditional funding sources in the past and the influence of the consumer can be seen in bringing these issues forward.

The Canadian Breast Cancer Network (CBCN) came into existence as a direct outcome of the recommendations of the survivors attending the Forum. This non-profit, charitable organization is a survivor-driven, national network of organizations and individuals which seeks to promote education and communication about breast health; to increase awareness of breast cancer as a major national health issue; to increase openness and accountability in the research process; to sustain a national network of breast cancer groups and survivors and to help survivors develop support systems that meet their unique needs. It is to this group that the Breast Cancer Initiative looks for representation on its various committees.

The majority of Canadian Breast Cancer Initiative funding has been allocated to the Canadian Breast Cancer Research Initiative (CBCRI), which is a partnership between the Medical Research Council of Canada, the National Cancer Institute of Canada, the Canadian Cancer Society and Health Canada, through the National Health Research and Development Program. The administration of the CBCRI is carried out by the National Cancer Institute of Canada on behalf of the partners. Women affected by breast cancer are involved as members of the Management Committee of the CBCRI and have been included in the review process for proposals submitted to the CBCRI. It has been recognized that training of lay representatives in such activities is essential to increasing their effectiveness.

There are three strategic areas to which the CBCRI has given priority: alternative therapies research, communications research and health services research. These respond to the areas identified at the National Forum as needing to be addressed by the research community. Involvement of women as members of research teams was a stated criterion for a recent Request for Applications on communication research, an issue which was given high priority for action and research at the Forum.

Women affected by breast cancer are also represented on each of the other committees of the Breast Cancer Initiative to give input and to help set priorities. The Professional Education Strategy on Breast Cancer consists of medical educators and communication experts; practising family physicians, surgeons and other medical specialists caring for patients with breast cancer; other health professionals and consumers. The decision to focus on communication skills of practising physicians emanated from discussions at the National Forum which resulted in a recommendation

To give high priority to the development and evaluation of communication skills training that targets practising health professionals – particularly oncologists and surgeons – and health sciences students. Such training should be based on respect for individual rights and choices and the importance of shared decision-making.

Strategic alliances with the Royal College of Physicians and Surgeons of Canada and with the College of Family Physicians of Canada assist with the dissemination of the need to enhance the communication skills of physicians and of educational interventions to meet this objective. A workshop "Communication Skills and Breast Cancer – A Forum to Develop Strategies to Enhance Physician-Patient Interactions" was recently held under the sponsorship of the Professional Education Strategy and was attended by influential medical educators; practising physicians; researchers in communication research; representatives of non-governmental organizations such as the Canadian Cancer Society and the Pharmaceutical Association of Canada; and by women affected by breast cancer. The presentation of her story by a woman with breast cancer provided a focus on the whole person instead of the disease; within the small group discussions the women were able to keep this focus ever-present. Dissemination of the need to enhance the communication skills of physicians in their interaction with women with breast cancer and the "buy-in" by others with the capacity to develop local or national activities appears to have been achieved. As a result of this networking event, it is hoped that links between researchers, clinicians and educators will be forged. The need for the input of the consumer in the development of educational programs has also been recognized.

The Steering Committee on Care and Treatment Guidelines is also responding to the recommendations of the Standing Committee and of the Report of the National Forum on Breast Cancer. The need for these guidelines has also been identified as a result of studies on the variations in practice with respect to treatment for breast cancer in Ontario.¹⁹ Complementary guidelines for patients will also be disseminated as a means of influencing change in practice.

The five regional Breast Cancer Information Exchange Projects have as their objective the development of networks of easily accessible information for women with breast cancer, their families, the public and professionals. Women affected by breast cancer constitute 50 per cent of the membership of the Advisory Committees which provide direction to each project and participate in the evaluation of whether the projects are meeting the needs of the local community and the target audience. To this end, consumers participating in these projects may or may not represent the CBCN, but certainly represent the local community.

In order to respond to the numbers of women developing breast cancer and dying from this disease as identified by the Canadian Cancer Registry, and in light of the increasing evidence in support of mammographic screening for women aged 50 to 69, provincial breast cancer screening programs were being developed in a number of provinces prior to the announcement of the Breast Cancer Initiative. Ideas were exchanged through meetings supported by the Disease Prevention Division; these meetings have resulted in the formalization of the Canadian Breast Cancer Screening Initiative. Through this Initiative, Health Canada supports the collection of core data elements to evaluate the processes and outcomes of the screening programs

Table 1

Consumer participation

Macro-level

Issue identification and priority setting

- National Forum on Breast Cancer
- CBCRI
- Professional Education Strategy
- Information Exchange Projects

Input to potential solutions

- Professional Education Strategy
- Information Exchange Projects
- Guideline development and review

Meso-level

Review of CBCRI proposals

Micro-level

Participants as members of research teams for CBCRI RFA on communication research

Participants as research subjects

Participants in Cancer Registry and Screening Database

in increasing screening uptake and reducing incidence and mortality. Data currently being collected will allow each provincial program to identify the uptake of screening by the target group and to identify trends in mammographically-detected lesions. In the long run, these databases, in combination with the cancer registry data will be able to identify whether the screening programs have had an impact on the incidence and mortality of breast cancer in Canadian women.

Thus, the Breast Cancer Initiative demonstrates a model of consumer participation at multiple levels in setting the agenda for research and policy development in an area of direct relevance to them (Table 1). Women have been and continue to be involved in all aspects of the components of the Breast Cancer Initiative; this involvement is at multiple levels. At the macro-level, they have been involved in identifying issues that need to be addressed either by research or policy development and in giving priority to those issues of importance to them. This was seen at the National Forum and continues to be so in the CBCRI, the Professional Education Strategy and the Information Exchange Projects. They also participate by giving their input in the development of solutions; in the guideline development process they will be active reviewers of draft documents directed at the public.

Women with breast cancer have been actively involved as reviewers of a number of research proposals, a process that is amongst those being evaluated by the CBCRI. At a micro-level, women have been involved as members of research teams for communication research proposals; obviously, they participate as research subjects and by consenting to their information being collected for the Cancer Registry and the Screening Database. The involvement of consumers as participants in research goes without saying; their involvement in developing the design of research studies is new.

Has the Initiative overcome the barriers to effective consumer participation? To date, the response to this question can only be answered anecdotally. Those women involved on the various committees have expressed an appreciation that they are at the table and their input is valued by the rest of the membership. This is one aspect of the planned evaluation of the Initiative which will contribute to knowledge in this area and respond to the recommendations by Zakus and Hastings² for more research into the specific factors contributing to effective participation.

Translating the Model

The key aspects of the Breast Cancer Initiative that are likely to contribute to the effectiveness of consumer participation include: involvement of all key stakeholders, including the consumers, at a very early stage of the planning process without pressure from above; being and being seen to be responsive to the identified needs of the consumers in a meaningful way; and including those stakeholders who can assist in implementing the final products of the Initiative. Challenges are those organizational pressures that influence the political will to involve and respond to consumers; the sublimation of science to the pressures of advocacy; and the reality that the health of consumers involved in committees and other areas of commitment may deteriorate at critical points during the process. However, access to alternative dedicated consumers through the CBCN facilitates consumer participation.

The above facilitators and challenges equally apply in other arenas, such as aging; the major difference is that in the Breast Cancer Initiative, a single disease is the focus of interest. Aging policy and research are directed at individuals with a wide spectrum of health states ranging from those in perfect health to the frail elderly. On the one hand, this allows for a larger population pool from which to select participants; on the other, criteria for selection of consumers may have to be determined dependent on the issue or health condition targeted for discussion.

The dissemination of research findings and implementation of the policy implications of these findings are issues that have received much attention in recent years. The SIRP symposium and this Special Joint Issue pose the question of how to link research and policy for the benefit of Canada's seniors; the model of the Breast Cancer Initiative is one that should be explored. Setting priorities and accountability in the transfer of recommendations from the National Forum on Breast Cancer and the translation of research findings into policy continues to be enhanced by the participation of the consumers at all levels of the Initiative.

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