

Maximizing Patient Voices

Final Report

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Table of Contents

Table of Contents	1
List of Tables	3
List of Acronyms	4
Executive Summary	6
Introduction	8
<i>Project Background and Scope</i>	8
Review of the literature	9
Key Findings	15
<i>Results of the Environmental Scan</i>	15
<i>Representation of cancer patients/survivors/family members</i>	16
Major Cancer Research Funding Agencies	16
Federal Cancer-Specific Committees and Decision-Making Bodies	17
Provincial Cancer-Specific Committees and Decision-Making Bodies.....	17
Federal Cancer-Related Committees and Decision-Making Bodies	19
Provincial Cancer-Related Committees and Decision-Making Bodies.....	20
<i>Training and recruitment of patient representatives</i>	21
Conclusions and recommendations	22
<i>Gaps in patient representation</i>	22
<i>Gaps in training of patient representatives</i>	23
<i>Transparency in governance</i>	24
<i>Recommendations</i>	24
<i>Need for further research</i>	25
Bibliography	26

Appendix I – Recruitment and Information Letter.....	28
Appendix II – Survey Instrument (English).....	29
Appendix III – Survey Instrument (French).....	38
Appendix IV - Tables.....	47

List of Tables

Table 1 – Cancer Research Funding Agencies	47
Table 2 - Federal Cancer Specific Decision Making Bodies	51
Table 3 - Provincial/territorial cancer specific decision-making bodies	53
Table 4 - Federal cancer-related agencies/bodies	60
Table 5 - Provincial/Territorial cancer-related committees and decision-making bodies	63

List of Acronyms

ACBF	Alberta Cancer Board and Foundation
BCCA	British Columbia Cancer Agency
CADTH	Canadian Agency for Drugs and Technologies in Health
CBCF	Canadian Breast Cancer Foundation
CBCI	Canadian Breast Cancer Initiative
CCAN	Canadian Cancer Action Network
CCCSCP	Canadian Childhood Cancer Surveillance and Control Program
CCMB	CancerCare Manitoba
CCMF	CancerCare Manitoba Foundation
CCNS	Cancer Care Nova Scotia
CCO	Cancer Care Ontario
CCRA	Cancer Research Alliance
CCS	Canadian Cancer Society
CCTC	Canadian Council for Tobacco Control
CDR	Common Drug Review
CED	Committee to Evaluate Drugs (Ontario)
CIHR - ICR	Canadian Institutes of Health Research – Institute of Cancer Research
COMPUS	Canadian Optimal Medication Prescribing and Utilization Service (CADTH)
CPAC	Canadian Partnership Against Cancer
CPFN	Cancer Patient Family Network
CPP	Cancer Partnership Project (UK)
CQCO	Cancer Quality Council of Ontario
CQLC	Conseil québécois de lutte contre le cancer
CRS	Cancer Research Society
CSCC	Canadian Strategy for Cancer Control
CSM	Conseil du médicament
CTFPHC	Canadian Task Force on Preventive Health Care
DLCC	Direction de la lutte contre le cancer
FPT-CPMP	Federal/Provincial/Territorial Committee on Pest Management and Pesticides
FPT-RPC	Federal/Provincial/Territorial Radiation Protection Committee
FRSQ	Fonds de la recherche en santé au Québec
MACTC	Ministerial Advisory Council on Tobacco Control
MANTRA	Manitoba Tobacco Reduction Alliance
NBCN	New Brunswick Cancer Network
NCIC	National Cancer Institute of Canada
NCTRF	Newfoundland Cancer Treatment and Research Foundation
NHS	National Health Service (UK)
OICR	Ontario Institute of Cancer Research
PGs	Partnership Groups (established by UK regional cancer networks)
PHSA	Public Health Services Authority (BC)
PMAC	Pest Management Advisory Council
PPI	Public and Patient Involvement

REPOP Comité des représentants de la population atteinte de cancer et des proches
 au Québec
SAC-OT Scientific Advisory Committee on Oncology Therapies
SCA Saskatchewan Cancer Agency
SCNs Supportive Care Networks (Ontario)

Executive Summary

Although the importance of patient involvement in the cancer system has been widely recognized, less is known about how patient representation in Canada has actually been implemented. This report aims to fill this knowledge gap through a comprehensive assessment of the state of patient representation in cancer-specific and cancer-related government committees/decision-making bodies. The key objectives guiding the project are to assess the present status of patient representation on Canadian federal, provincial and territorial government committees and decision-making bodies, to assess the present status of patient representation in the major Canadian cancer funding research agencies, and to assess training initiatives made available to current patient representatives on such bodies.

Data were collected via an extensive web search for all of the relevant committees/decision-making bodies and by administering an on-line survey or phone survey to key respondents in the organizations/committees identified. In part because of issues of project timing, response rates were lower than expected among larger target organizations such as provincial cancer agencies and the research funding bodies. Where possible, gaps in data were filled by information these organizations supplied on-line regarding their governance structure, terms of reference, and levels of patient representation.

An analysis of the findings yielded a number of provisional conclusions that can be drawn about the state of patient representation in the cancer-specific and cancer-related fields. Three of four research funding agencies for which enough data were available had some patient representation, though this tended to be limited to a single position on the board of directors. Federal cancer-specific committees/decision-making bodies each had some provision for patient representation, but one did not currently have a patient representative, suggesting difficulties in finding or recruiting patient representatives.

Because of different governance structures, direct comparisons between provincial cancer agencies are difficult. Cancer agencies range from those that have extensive and fully integrated patient representation (e.g., Cancer Care Nova Scotia), those with substantial patient representation (Cancer Care Ontario), and others (Saskatchewan Cancer Agency, CancerCare Manitoba) with more limited/less formalized patient representation. The restructuring of the cancer care program in Quebec has eliminated an important mechanism for patient representation in the Comité des représentants de la population atteinte de cancer et des proches. There is no indication that a similar mechanisms exists under the new structure.

Conclusions about federal cancer-related committees/decision-making bodies were limited by the fact that several of them are currently undergoing restructuring. Of the provincial cancer-related committees/decision-making bodies examined, most operate as coalitions of organizations (e.g., anti-tobacco and sun safety coalitions) that tend to include provincial chapters of the Canadian Cancer Society, but not survivor/patient

organized groups. The Joint Oncology Review, a pilot project for nationally coordinated cancer drug evaluation, is a key cancer-related initiative for which the terms of reference are currently being reviewed in order to incorporate patient representation.

There are significant gaps in the training provided to cancer patient representatives on cancer-specific committees/decision-making bodies. Among those committees/decision-making bodies confirmed to have patient representation, only one organization indicated that patient representatives had received targeted training for their role in the governance of the organization. Likewise, only one committee-decision-making body had conducted a formal evaluation of patient representation.

The report concludes by offering a number of recommendations for strengthening patient involvement in cancer-specific and cancer-related committees/decision-making bodies:

1. Efforts to increase and/or formalize cancer patient representation in the governance of provincial cancer agencies should be a priority area of action.
2. Cancer Care Nova Scotia's approach to patient representation and outreach might be considered a model for comprehensive patient representation and effective recruitment of patient representatives for provincial cancer agencies.
3. Efforts should be made to increase the participation of cancer patient/survivor advocacy organizations within provincial anti-tobacco, sun safety, and healthy living coalitions.
4. Given the importance of the Joint Oncology Review, ensuring patient representation on the CED/CCO Joint Subcommittee should be a priority area of action.
5. CCAN should consider advocating for cancer patient representation on federal cancer-related committees/decision-making bodies currently undergoing restructuring.
6. CCAN should consider advocating for some role for cancer organizations on the Health Canada Pest Management Advisory Council.
7. CCAN should seek Cancer Care Nova Scotia's cooperation in sharing training material targeted specifically to cancer patient representatives undertaking governance roles.
8. Cancer-specific agencies should be encouraged to provide better access to comprehensive information on their governance structures, including provisions for patient representation/consultation, committee structure, and terms of reference.

Introduction

The Canadian Cancer Action Network (CCAN) is a unique, national coalition dedicated to ensuring patients interests are at the top of the national cancer agenda. CCAN brings together patient-family focused cancer groups from across Canada to ensure that the patient's voice is heard as the Canadian Partnership Against Cancer (CPAC) moves forward. CCAN's membership consists of 28 patient-oriented cancer groups representing all national cancer-sites, aboriginal groups and CCAN provincial affiliates in several provinces. CCAN strives to build and sustain a health care and research model that is successful in the fight against cancer. CCAN works with federal and provincial decision-makers to build a national system that optimizes care and treatment outcomes through all phases of the cancer control continuum from prevention through treatment and palliation. CCAN's purpose is to make patient voices heard, recognized and understood.

Project Background and Scope

Although the importance and usefulness of patient involvement and the role of patient representatives on cancer-specific/cancer-related committees and decision-making bodies has been widely recognized, less is known about how patient representation in Canada has actually been implemented. This report aims to fill this knowledge gap through a comprehensive assessment of the state of patient representation in such bodies. The report draws on data collected between July and October, 2007 by means of an extensive web search and an on-line survey and telephone follow-up administered to relevant cancer-specific and cancer-related bodies (please see below for a detailed methodology). For the purposes of this study, voluntary organizations operating in the cancer field were excluded in order to focus exclusively on government decision-making bodies and committees and the major Canadian cancer research funding bodies.

The key objectives guiding the project were:

1. To assess the present status of patient representation on Canadian federal, provincial and territorial cancer-specific/cancer-related government committees and decision-making bodies;
2. To assess the present status of patient representation on the major Canadian cancer funding research agencies (Terry Fox Foundation; Canadian Breast Cancer Foundation; Research Action Group of the Canadian Partnership Against Cancer; Cancer Research Society; Canadian Institute of Health Research – Institute for Cancer Research; National Cancer Institute of Canada; Ontario Institute of Cancer Research; and Fonds de la recherche en sante du Quebec).
3. To assess training initiatives made available to current patient representatives.

The research strategy deployed included first, an environmental scan to identify all of the relevant cancer-specific and cancer-related government decision-making bodies and

committees, and second, web research and an on-line questionnaire to collect relevant information on patient representation from each of the decision-making bodies and committees. In order to assess the status of patient representation on each decision-making body and committee, data were collected on:

- The number of patient representatives on the main governing body (Board of directors, Steering Committee, etc.);
- The number of patient representatives on each of the organization's/committee's subsidiary bodies (committees/subcommittees, action groups, working groups);
- The process by which patient representatives were chosen;
- The training provided to patient representatives; and
- The outcome of any evaluations of patient representation.

The results of the data analysis provide a snapshot of the state of patient representation in Canada. Key trends identified in the data suggest a number of gaps in the implementation of patient representation that are outlined in this report's Key Findings.

Review of the literature

The purpose of this review is to briefly summarize the academic literature on patient participation in health-system planning and coordination, with a focus on the cancer system. This literature is situated in a much broader field of enquiry that has emerged around the question of public/citizen participation in health-care policy and planning in general, of which we can provide only a snapshot. This review of the literature will provide some context in assessing the level and effectiveness of current efforts to include cancer patient representation in key government committees/decision-making bodies.

The increasing attention given to questions of public/citizen participation in health-care policy and planning in Canada have emerged from a number of key social trends over the last twenty or thirty years. Among the most important of these are declining levels of trust in decision-makers, major health-care reforms, including regionalization and program cuts, and emerging notions of deliberative and participatory democracy. In Canada, there is a well-developed academic literature on public/citizen engagement in health-care reform and coordination. A number of studies have evaluated particular cases of public involvement, with a strong emphasis on the process of regionalization (Frankish et al. 2002, Church and Barker 1998, Abelson and Forest 2000) as well as the citizen engagement process used in the Romanow Commission on the Future of Health Care (Maxwell et al. 2003).

The literature has helped clarify different types and levels of citizen engagement, as well as their purpose. The three key types of public involvement are public communication, public consultation, and public participation, ranging from passive to more active forms of involvement (Gauvain and Abelson 2006). The purpose of including public involvement in health systems governance may involve a number of overlapping objectives including strengthening democracy in general, improving the legitimacy of

decision-making, contributing to a more active and engaged citizenry, and resolving conflicts among stakeholders (Gauvain and Abelson 2006, 12). The importance of public involvement in the health system may be less a matter of increasing the efficiency of the health care system than of enhancing democratic values and accountability in the health sector (Abelson and Eyles 2004).

General overviews of public engagement in the health system over the last two decades underline key opportunities, challenges, and conditions for success (Church et al. 2002; Abelson et al. 2002; and Gauvain and Abelson 2006). The major risks in any initiative for including citizen participation include how to define 'participation', deciding who should participate, and deciding what level of input the public will provide and which types of decisions will be taken (Church et al. 2002). Church et al. (2002) express some skepticism as to whether most efforts to include citizen participation have been effective at truly enhancing accountability in the health system (25). Other key challenges that have been confronted in major Canadian initiatives of this type include motivating citizen participation, political interference, the complexity of policy issues, unrealistic expectations, and lack of resources (Gauvain and Abelson 2006, 19). There also exist significant barriers to consumer/patient involvement, the most important of which are power imbalances between health consumers and professionals and, given the complexity of the technical and policy issues involved, the relative lack of skills and expertise of health consumers in these areas (Sullivan and Scattolon 1995).

Assessing past experiences has also allowed researchers to define broad criteria for more successful public participation initiatives. Initiatives that are better focused, involve clearly defined objectives, and that have built-in mechanisms for evaluation are more likely to be successful (Abelson et al. 2002). Gauvain and Abelson (2006) identify seven essential conditions for successful public involvement: representativeness, independence, early involvement, ability to significantly influence policy decisions, access to sufficient information, adequate resources, and a transparent and structured decision-making process (17-18). Importantly, Gauvain and Abelson (2006) conclude that any successful attempt at citizen engagement ought to include a means of formally evaluating the success of the process.

Some attention has also been devoted to better understanding the way that lay/patient participants in health policy/planning evaluate and understand their role in the process. A study of public/patient participation in health-care priority setting revealed that all participants (lay/expert) tend to agree that public/patient representatives serve a useful role in representing community interests and patient perspectives (Martin et al. 2002). The conditions under which public/patient participants are likely to assess such exercises as successful include establishing some consistency of membership and duration to the committee/body and having a 'critical mass' of lay/patient representatives (2 or more) that prevents the isolation of a single lay/patient member (Martin et al. 2002, 224). Hogg and Williamson (2001) argue that understanding the different interests that lay members can represent is crucial to understanding lay participation in health decisions. Without properly establishing the definition and purpose of lay representation, 'lay' positions risk

being captured by representatives that advance the established interests of medical professionals and managers rather than those of patients (Hogg and Williamson 2001, 8).

Though there exists a very large literature on cancer patient involvement in treatment decisions (not reviewed here), there are fewer studies of patient involvement in cancer-system planning and coordination. We begin with a number of studies based in the UK, where there have been substantial efforts to increase patient/lay involvement in the cancer system. As part of the generalized reform of the National Health Service (NHS), the UK has sought to make Patient and Public Involvement (PPI) a priority. In the cancer system, this has involved the launch of the Cancer Partnership Project (CPP) through which Partnership Groups involving patient representatives were to be established in each of 34 regional cancer networks (Sitzia et al. 2006). By 2004, Partnership Groups (PGs) had been established in 30 of the 34 regional networks. In 27 networks, the PGs supplied patient representatives (usually 2) to the board of directors of the regional cancer network (Sitzia et al. 2006, 63). The establishment of PGs has involved a number of successes as well as tensions. Key successes included establishing the PGs (a significant achievement in itself), providing a reference group for NHS consultation, providing a 'nucleus' for user involvement, successful patient information and communication initiatives, and modest influences on service delivery (Sitzia et al. 2006, 63). Among the important challenges encountered were the different motivations of health care professionals in participating in the PGs (some of whom felt obliged to participate in the initiative), the sensitive nature of disclosing personal health status among patient representatives, and the lack of social/ethnic diversity among patient members (Sitzia et al. 2006, 64-70). Though it is difficult to assess the concrete impact of PGs on policy, participants have generally evaluated their experiences positively, indicating a belief that the initiatives made a difference in the provision of cancer services (Richardson et al. 2005, 218-9).

Other studies have explored the perspectives of health professionals and service users (patients) in efforts to increase user involvement in the UK cancer system (Daykin et al. 2004, Tritter et al. 2003). Daykin et al. (2004) found that some health professionals tended to define users according to a 'deficit model', emphasizing their limited knowledge, the difficulty in motivating their participation, or perceptions of their vulnerability in ways that potentially limit the usefulness of their involvement (292). Tritter et al. (2003) concluded that there exist different understandings of the purpose and definition of user involvement between health care providers and service users and that many forms of user involvement consist of passive exercises such as collecting data through consultations rather than direct involvement (447-8). Likewise, in a study of cancer service users with varying degrees of involvement in treatment decisions or cancer service planning/policy, Evans et al. (2003) found that many users tended to define user involvement exclusively in terms of participating in treatment decisions. The authors likewise highlight the importance of greater access to information and better communication between users and health professionals as essential to successful user involvement. In a comprehensive review of the literature on patient involvement in cancer system policy and planning in the UK, Hubbard et al. (2007) found that many studies identified the lack of training and resources for participants as a major barrier to effective patient involvement (27).

A search of the literature identified four studies that examined questions of patient involvement in cancer system planning and coordination in the Canadian context. Gray et al. (1995) interviewed cancer survivors, family members and general community representatives involved in cancer system planning activities. Participants tended to evaluate their participation positively, but raised issues about fair representation and empowerment. Others have examined the value of the Canadian Breast Cancer Initiative (CBCI) in better linking health research and policy by means of consumer (patient/survivor) participation (Parboosingh et al. 1997). The CBCI emerged in the early 1990s in response to concerns about a lack of government initiative in tackling breast cancer and included several mechanisms for involving breast cancer patients and survivors. In particular, patients/survivors were included on the Organizing Committee of the National Forum on Breast Cancer in 1993 and played a key role in setting strategic policy and research directions for breast cancer initiatives in Canada. One result of the National Forum was the establishment of the Canadian Breast Cancer Network, a network of survivors' organizations from which representation on various committees of the CBCI would be drawn. Women affected by breast cancer were involved in the CBCI at many levels, including representation on CBCI committees/action groups and representation in the Canadian Breast Cancer Research Initiative as members of the Steering Committee and as reviewers (Parboosingh et al. 1997, 180-4). The authors consider patient/survivor involvement in the CBCI a model worth applying to other circumstances for its success in the early involvement of all stakeholders and its responsiveness to consumer needs (185).

A study of efforts to include patient representation in the establishment of regional cancer care networks in Ontario revealed “a significant gap between intentions to involve patients in health planning and their actual involvement” (Tedford Gold et al. 2005, 195). Ontario introduced a new structure for cancer care service delivery in 1997, with the establishment of Cancer Care Ontario. The reforms included the establishment of 8 regional councils responsible for setting up Supportive Care Networks that would include patient involvement (197). Though it did not define patient involvement at the beginning of the process, the province later developed a comprehensive *Policy on Patient/Survivor Participation in Cancer Care Ontario Planning and Evaluation* in 2001-2002. The study documents challenges and barriers in establishing regional SCNs, including a lack of clear direction for the networks that left the purpose and means of patient involvement ill-defined, the dominance of Regional Cancer Centres in the process, and lack of resources for network development (200). The authors conclude that the failure of some regions to establish viable SCNs as vehicles of patient representation resulted from ‘benign neglect’ rather than direct resistance: “While the provincial agency mandated patient involvement it did little to encourage it” (206).

Experiences in the UK and Canada highlight both opportunities and challenges in increasing patient involvement in cancer system planning and coordination. A clear definition of the nature and purpose of patient involvement, sufficient information and training for patient representatives, commitment from cancer system professionals and

managers, and adequate resources are among the most important conditions for success in the studies reviewed.

Methodology

Research for this project proceeded in two steps. First, an environmental scan was conducted in order to identify all of the relevant federal, provincial and territorial cancer-specific/cancer-related government committees and decision-making bodies. *Cancer-specific* government committees and decision-making bodies are those directly involved in providing cancer care services and support or that play a significant role in cancer-system coordination, planning, and monitoring. In defining *cancer-related* committees and decision-making bodies, the net was cast quite widely. Web research was conducted to identify government decision-making bodies and committees with at least the potential for public/patient representation in the following areas: tobacco control, preventive health, sun safety, radiation safety, pesticide regulation, and drug review.

Second, data were collected from each of the relevant committees and decision-making bodies via extensive searches of each organization's website as well as by means of an on-line questionnaire. The survey instrument (Appendix II) allowed for data to be collected on the number of patient representatives on the main governing body and subsidiary bodies (committees/subcommittees/action groups/working groups) of each organization or committee, the means by which patient representatives were chosen, the training provided to patient representatives, if any, and an evaluation of patient representation on such decision-making bodies and committees. For the purposes of the survey, patient representation was defined broadly to include cancer patient/survivor/or family member representation.

Each organization/committee was sent an information letter (Appendix I) on CCAN letterhead outlining the purpose and nature of the study. Participants in the on-line questionnaire were recruited by means of contacting each organization/committee by email and/or phone and requesting a suitable survey contact. Having identified a suitable survey contact, an email invitation was sent to each prospective participant. We allowed for up to 3 reminder invitations to be sent over the course of several weeks in cases where prospective participants had not yet responded.

The response rate for the on-line questionnaire varied considerably between size and type of organization. Unfortunately, response rates were lowest among larger target organizations such as provincial cancer agencies and the research funding bodies. From correspondence with prospective participants, the timing of the project contributed to some extent to low response rates. Information letters were mailed during August, which meant that many potential respondents were away on vacation. More active recruiting for the questionnaire took place in September, but a common response was that prospective respondents were very busy, especially those involved in annual fundraising events (e.g., Run for the Cure). The questionnaire deadline was extended to try to accommodate these questions of timing. Ultimately, the questionnaire was closed on October 5th when it was felt that all reasonable possibilities for reminders and follow-ups had been exhausted.

Together, survey data and web research allowed for crosschecking key information on patient representation in the targeted committees and decision-making bodies. Some limitations to the data occur where either one type of information or the other was not available for a particular committee or decision-making body. Depending on the organization, web material sometimes provided detailed information on an organization/body's terms of reference and committee structure. However, web material alone was limited in the extent to which it provided information about the current state of committee membership and patient representation. The questionnaire was designed to allow for very detailed information to be collected on patient representation within an organization/committee and its subsidiary bodies. Because of the level of detail required, however, not all respondents were able to provide all of the information requested. The data from both sources were compiled to create tables (Appendix IV) specifying for each organization/committee the number of patient representatives 1. specified in the terms of reference, and 2. currently sitting on the main governing body and on each of the subsidiary bodies identified.

Other survey data was used to assess the provision of training to patient representatives, assessments of training initiatives, and respondent attitudes towards patient representation.

Key Findings

Results of the Environmental Scan

The purpose of the environmental scan was to identify all of those cancer-specific and cancer-related government committees/decision-making bodies with some possibility of non-governmental participation (lay/patient/expert). The results of the environmental scan yielded the list of agencies/committees/decision-making bodies listed in Tables 1-5 for which web material was collected and on-line survey participation was sought. The tables organize the results according to the following categories: cancer research funding agencies (Table 1); federal cancer-specific committees/decision-making bodies (Table 2), provincial cancer-specific committees/ decision-making bodies (Table 3), federal cancer-related committees/ decision-making bodies (Table 4) and provincial cancer-related committees/decision-making bodies (Table 5). Since the list of cancer research funding agencies to be examined in this study was supplied by CCAN in its project proposal, the environmental scan focused on establishing a comprehensive list of committees/action groups/working groups for each of these agencies.

The key federal cancer-specific committees/decision-making bodies are the Canadian Partnership Against Cancer (CPAC), which was established in 2006 to move forward on the agenda laid out in the Canadian Strategy for Cancer Control (CSCC), the Canadian Childhood Cancer Surveillance and Control Program and the Health Canada Scientific Advisory Committee on Oncology Therapies. At the provincial level, the key cancer-specific committees/decision-making bodies are linked to the provincial cancer agencies. In those provinces that do not have provincial cancer agencies, as well as in the territories, cancer control, treatment, and research are coordinated by departments of health. In those cases, there is no formal opportunity for patient representation on committees/decision-making bodies, though governments may seek opportunities to consult with patient/survivor representatives and organizations.

While identifying relevant cancer-specific bodies was fairly straightforward, identifying relevant cancer-related bodies was more difficult. A search for relevant committees/decision-making bodies in the cancer-related fields of tobacco control, preventive health, sun safety, radiation safety, pesticide regulation, and drug review yielded more results at the federal than at the provincial level. Federal consultative initiatives exist in several of these areas (tobacco control, radiation safety, pesticide regulation), therefore providing at least a potential vehicle for patient representation. A federal initiative on preventive health care (the Canadian Task Force on Preventive Health Care), which had included a role in providing recommendations for cancer screening, is no longer active as it is undergoing a process of revitalization. Two organizations listed under federal cancer-related bodies are not strictly government decision-making bodies, but involve either government funding (the Canadian Council for Tobacco Control) or the participation of government agencies/departments (the Intersectoral Healthy Living Network).

There tends to be provincial government initiatives for each of the cancer-related fields (tobacco control and healthy living, in particular), but few examples of committees/decision-making bodies with the potential for patient/survivor participation. Many provinces have tobacco control coalitions that, while strictly speaking are not government decision-making bodies, include representation from government departments/agencies as well as non-governmental organizations. Because membership in the coalitions is by organization, the potential for cancer patient/survivor representation exists through the participation of cancer patient/survivor advocacy organizations. This posed a challenge in data collection, however, since the survey was designed to collect information on individual patient/survivor representatives. Only two provinces – Ontario and Nova Scotia – have comparable sun safety coalitions, but there is very little information available on either. With the exception of Newfoundland and Labrador, none of the provincial healthy living initiatives have any committees/decision-making bodies that would be relevant for the study.

A search of the cancer-related field of government drug review revealed one federal agency, the Canadian Agency for Drugs and Technologies in Health (CADTH), and provincial/territorial drug review committees. Since March 1, 2007, most provinces have participated in a pilot-project for Joint Oncology Drug Review led by a joint committee of the government of Ontario's Committee to Evaluate Drugs (CED) and Cancer Care Ontario. The result is that many provincial drug review committees do not directly evaluate cancer drugs. Survey data was nonetheless collected from these committees, providing some information on lay/community participation in the general process of drug review.

Representation of cancer patients/survivors/family members

Major Cancer Research Funding Agencies

Of the eight major cancer research funding agencies included in the study, 3 were confirmed to have some patient representation. The Canadian Cancer Research Alliance, which, as well as existing as an independent body, constitutes the Research Action Group of CPAC, has one patient representative on its board of directors. The patient representative is CCAN co-chair Jack Shapiro and was appointed in consultation with CCAN. Data compiled from both the on-line survey and extensive web material allowed for a fairly detailed account of lay/patient representation within the National Cancer Institute of Canada (NCIC). There are currently 3 lay representatives and one patient representative on the NCIC's board of directors. Patient representation is specified in the terms of reference for the NCIC's Joint Advisory committee on Cancer Control, but no data was available on whether or not that position was currently filled. None of the NCIC's other committees/subsidiary bodies have any patient representation.

The Canadian Institutes of Health Research Institute of Cancer Research (ICR) currently has one patient representative on the Board of Directors. According to our survey data, there is no provision for patient representation in the terms of reference for the Ontario Institute for Cancer Research's (OICR) Board of directors, nor in any of its

committees/subsidiary bodies. There is however lay/community representation on 3 of its operational committees and all four of its peer review committees.

Little information was available to assess levels of cancer patient representation in the four other cancer research funding agencies (the Terry Fox Foundation, the Cancer Research Society, the Canadian Breast Cancer Foundation, and the Fonds de la recherche en santé du Québec).

Federal Cancer-Specific Committees and Decision-Making Bodies

All three of federal cancer-specific committees/decision-making bodies studied for this report had some provision for patient representation. The Canadian Partnership Against Cancer (CPAC) has the most comprehensive approach for patient representation with provisions for patient representation on the Board of Directors as well as on the Advisory Council and each of its 9 Action Groups. There is currently one patient representative on the Board of Directors (CCAN co-chair Liz Whamond). Membership on the Advisory Council and each of the Action Groups has not yet been formalized, though chairs have been appointed.

While there is a provision for cancer-patient representation on the Canadian Childhood Cancer Surveillance and Control Program (CCCSCP's), the CCCSCP's survey response indicated that there is currently no patient representative. The CCCSCP has not conducted any formal evaluation of patient representation for the initiative. Health Canada's Scientific Advisory Committee on Oncology Therapies (SAC-OT) currently includes 2 patient representatives, as specified in their terms of reference (defined there as 'consumer' representatives).

Provincial Cancer-Specific Committees and Decision-Making Bodies

Survey participation was sought for each provincial cancer agency or provincial/territorial cancer control program. In total, 5 organizations (including 4 provincial cancer agencies) responded. A representative of the Saskatchewan Cancer Agency (SCA) answered several survey questions in a phone interview. Unfortunately, there is little web material on the governance of provincial cancer agencies.

The BC Cancer Agency (BCCA) provided a survey response outlining its unique governance structure. The BCCA is a branch society of the provincial government's Public Health Services Authority (PHSA), and is thus governed by the Board of Directors of the PHSA. For this reason, there is neither lay/community nor patient representation on the BCCA Strategic Leadership Council. However, the BCCA does solicit community/client input via regular consultations, ad hoc consultations, and surveys/questionnaires. The Board of Directors for the fundraising wing of the BCCA, the BC Cancer Foundation, currently includes three 'community volunteers'.

A representative of CancerCare Manitoba (CCMB) provided a survey response, though the survey was only partly completed. The data indicate that there is a provision for patient representation on the CCMB Board of Directors, but that there are currently no

sitting patient representatives. Survey data from the CancerCare Manitoba Foundation (CCMF) (CCMB's fundraising wing) indicated that there is no provision for patient representation on the CCMF's Board of Directors. Information obtained from a phone interview with a representative of the SCA revealed that there is no formal provision for patient representation on the board of directors, though cancer survivors have been members of the board in the past.

Cancer Care Ontario provided a written submission with detailed information on levels of patient representation. The Charter governing appointments to CCO's board of directors does not include any formal provision for patient representation. There are, however, currently 3 board members with family members who have or have had cancer. Likewise, there is no provision for patient representation on CCO's board committees, but there is at least one member on each that qualifies as a cancer patient/survivor/ or family member. Several of CCO's subsidiary bodies do have formal provisions for patient representation, including the Communications and Stakeholder Relations Committee, the Cancer Quality Council of Ontario, and the Prevention and Screening Council. There do not seem to be any vacancies with respect to positions reserved for patient/survivor/family member representatives. At the regional level, there is patient representation in each of Ontario's Regional Cancer Patient Education Advisory Committees, which report to CCO's Patient Education Committee. Aside from representation on the committees/decision-making bodies listed above, CCO seeks patient involvement through a variety of forms of consultation and outreach, including surveys and focus groups, CCO events and forums, and the Patient Education Program.

The survey response from the Joint CCO Aboriginal Cancer Committee indicated that there is a provision for patient representation on this body, though no information was supplied as to whether there currently are any patient/survivor/family member representatives on the committee. The committee includes significant lay representation (with 8 lay members). One of the Joint CCO Aboriginal Cancer Committee's working groups (the Cancer Video Project Working Group) includes 5 cancer patient representatives.

CancerCare Nova Scotia provided comprehensive information on its initiatives for patient representation. The data, which are summarized in Table 3, highlight CCNS's strong commitment to patient representation. There are provisions for patient representation on its Board of Directors (3 members), as well as on all of its subsidiary committees/advisory groups (1 or 2 members on each). In addition, the province's 9 District Cancer Committees each include up to two patient representatives. One of CCNS's key initiatives for seeking patient input into improving the cancer system has been to establish a provincial Cancer Patient Family Network (CPFN) comprised of over 700 individual members who are either cancer patients, survivors, family members or friends. The purpose of the CPFN is to maintain regular communication with patients/survivors/family members (e.g., through a regular newsletter) and inform them of on-going opportunities to provide input to system improvement in the province (e.g., through roundtables, consultations, focus groups, etc.).

The other province for which there is a provincial cancer agency is Alberta. There is no information on patient representation on the main governing bodies/subsidiary bodies of the Alberta Cancer Board and Foundation.

In the remaining provinces, as well as the territories, cancer treatment, research and service delivery are organized directly by government departments of health/health and social services. Survey responses were sought from representatives of these departments in order to obtain information on general initiatives for consulting with patient advocates. In Québec, the Direction de la lutte contre cancer (DLCC), an agency of the Ministry of Health and Social Services provides cancer system coordination and service delivery. In 2003-4, the DLCC replaced its predecessor organizations, the Conseil québécois de lutte contre le cancer (CQLC) and the Centre de coordination de la lutte contre le cancer. The CQLC had included at least one patient representative, and had struck a committee to examine the needs of cancer patients/family members called the Comité des représentants de la population atteinte de cancer et des proches (REPOP) au Québec. No information was available on how the province's new structure provides for patient representation, if at all. The New Brunswick Cancer Network indicated that it consults with cancer system stakeholders through ad hoc consultations and roundtables. No response was obtained from the Newfoundland Cancer Treatment and Research Foundation, the PEI Department of Health, or the respective Departments of Health and Social Services of the Yukon, North West Territories, and Nunavut.

Federal Cancer-Related Committees and Decision-Making Bodies

The results of data collection on federal cancer-related committees/decision-making bodies are summarized in Table 4. The Canadian Task Force on Preventive Health care is currently undergoing a revitalization process led by a Stakeholders' Advisory Committee. No information on the membership of the Advisory Committee is available on-line, nor did correspondence with the chair of the committee (Dr. John Feightner) yield any information on the composition of the committee. Likewise, the only information available on the Intersectoral Healthy Living Network, an initiative of the Public Health Agency of Canada, was web material, the most recent of which dates from 2005. Attempts to contact the Intersectoral Healthy Living Network through their street address posted on-line were unsuccessful.

The federal government's key advisory body on tobacco policy, the Ministerial Advisory Council on Tobacco Control (MACTC), is also currently being restructured. Health Canada representatives involved in the restructuring were not prepared to provide any information on the composition of the new advisory body. Three other federal government advisory committees were examined in this study. Though none of these provided survey feedback, web research provided some information on the composition of these bodies. The Federal/Provincial/Territorial Radiation Protection Committee consists of government representatives exclusively, and therefore includes no lay representation. The Federal/Provincial/Territorial Committee on Pest Management and Pesticides likewise only includes representatives from each respective government. The Pest Management Advisory Council of the Pest Management Regulatory Agency is, by

contrast, a multi-stakeholder group whose terms of reference include provisions for representation by non-governmental organizations in the environmental, consumer and health sectors. The Council's membership currently does not include any organizations linked to the cancer field.

The Canadian Council for Tobacco Control is a national coalition of non-governmental organizations devoted to tobacco control that receives funding from the governments of Ontario and Quebec as well as its members. According to the survey data collected, the CCTC does not provide for either lay or patient representation on its board of directors/subsidiary bodies, though it does have one lay member on its Executive Committee.

In the area of drug review, the Common Drug Review of the Canadian Agency for Drugs and Technologies in Health (CADTH) provides a crucial role in advising governments on the adoption and best-use of new drugs. While there is no provision for lay or patient representation on the board of directors of the CADTH, there is lay representation on two key committees, the Canadian expert Drug Advisory Committee, and the COMPUS Expert Review Committee.

Provincial Cancer-Related Committees and Decision-Making Bodies

The key cancer-related fields in which relevant committees/decision-making bodies were identified as targets for survey participation were the provincial anti-tobacco coalitions (which often include provincial government agencies/departments as participants), two provincial sun safety initiatives, and provincial drug review initiatives.

None of the six provincial anti-tobacco coalitions that participated in the survey reported any designated patient representation on their main governing bodies/subsidiary bodies, though one reported some lay representation (the Newfoundland and Labrador Alliance for the Control of Tobacco). These data must be qualified by the fact membership in these coalitions is by organization and most coalitions include representation from provincial/territorial divisions of the Canadian Cancer Society, and, in some cases, from provincial cancer agencies. However, neither web material nor survey responses indicated the participation of any patient/survivor advocacy organizations in the provincial anti-tobacco coalitions.

The two provincial sun safety initiatives identified were Sun Safe Nova Scotia and the Ontario Sun Safety Working Group. Sun Safe Nova Scotia is chaired by a representative of Cancer Care Nova Scotia, and includes participation from provincial government departments, the Canadian Dermatology Association, as well as Canadian Cancer Society (CCS) Nova Scotia Division. The membership of the Ontario Sun Safety Working Group includes CCS Ontario division, as well as Cancer Care Ontario. Unfortunately, the most recent web material available for the Ontario Sun Safety Working Group is from 2004.

Of the provincial drug review committees, only Québec's Conseil du médicament (CSM) provided a full survey response. The CSM has fairly extensive lay representation, including 4 lay members on the governing council, and lay membership on at least one

committee. Two provincial drug review committees declined to participate because oncology drug review fell outside of their mandate and was instead handled by the provincial cancer agency. Since March 2007, a joint committee of the Ontario Committee to Evaluate Drugs (CED) and Cancer Care Ontario has been responsible for administering a Joint Oncology Drug Review process for all Canadian provinces except Québec. In its submission, the CCO indicated that the terms of reference for the CED/CCO Joint Subcommittee are being revised with the intention of formally incorporating patient representation.

Training and recruitment of patient representatives

Of the committees/decision-making bodies that indicated some patient representation, the OICR, CCNS, and CCO indicated that patient representatives had received training for their participation in the organization's governance. CCNS indicated that the training included written orientation materials and a training session both designed specifically for patient representatives. None of these organizations reported having conducted any formal evaluation of the training provided to cancer patient representatives. No training was provided to current patient representatives on SAC-OT.

Survey data indicates that patient representatives were appointed to committees/decision-making bodies in a number of different ways, including nomination by other organizations, nomination by the government, and recruitment by existing board members. Patient representatives on CCNS's board of directors/committees are recruited through the Cancer Patient Family Network, CCNS's outreach and communications initiative for cancer patients, survivors, and family members.

Only one organization, SAC-OT, reported having conducted a formal evaluation of patient representation. The committee was not, however, prepared to share the results of that study with us.

Conclusions and recommendations

Gaps in patient representation

This study contributes significantly to understanding the current state of patient representation in cancer-specific and cancer-related government committees/decision-making bodies. It is clear, however, that there are obstacles to a truly comprehensive picture of the situation. A lower than expected response rate to our on-line survey, combined with a dearth of information on governance structures for some types of committees/organizations means that the conclusions drawn from this report must be understood as provisional. A number of conclusions regarding gaps in patient representation can nevertheless be drawn from the data.

There is only enough data to draw conclusions about the state of patient representation among four of the major cancer research funding agencies. Three of these agencies (NCIC, CCRA, and ICR) have some provision for patient representation (though this tends only to be at the level of the board of directors) and one (OICR) indicated that it does not. Web research suggests that OICR has in the past had patient representatives. The federal cancer-specific committees/decision-making bodies studied all have some provision for cancer patient representation, though for at least one of them (CCCSCP), there is currently no patient representative. The lack of current patient representation on CCCSCP could indicate problems finding/recruiting suitable representatives, a problem worthy of further study. The comprehensive approach to providing patient representation within CPAC is an encouraging sign for realizing better levels of patient participation in the implementation of the Canadian Strategy for Cancer Control.

Differences in the governance structures of provincial cancer agencies/programs make direct comparisons of levels of patient representation difficult. Of those provinces with cancer agencies, Cancer Care Nova Scotia (CCNS) and Cancer Care Ontario (CCO) confirmed that they have current patient representation. The lack of a current cancer representative on the board of directors of CancerCare Manitoba, despite provisions for such representations, may suggest a gap in CCMB's ability to find/recruit suitable cancer patient representatives. Two cancer agencies (the Saskatchewan Cancer Agency, and the BC Cancer Agency) cited the particularities of their governance structures as reasons for which there is no current cancer patient representation. While SCA has had cancer patient representation in the past, its members are appointed by the Minister of Health, and there is no formalized provision for such representation. CCO has implemented patient representation on a number of its committees and other subsidiary bodies. It does not, however, have any formal provisions for patient representation on its board of directors or on board committees. Unfortunately, no conclusions can be drawn regarding levels of patient representation at the Alberta Cancer Board and Foundation since little information was available on-line and the agency did not participate in the on-line survey.

Among provincial cancer agencies, CCNS might be considered a model for implementing strong patient outreach and patient representation at all levels of the organization. Aside from significant patient representation on the CCNS board of directors and committees,

the CCNS Cancer Patient Family Network (CPFN) provides for on-going communication with cancer patients, survivors, friends and family members regarding opportunities to provide input to cancer system improvement. The CPFN also provides a unique mechanism for ensuring CCNS is able to recruit interested cancer patients/survivors for positions on the CCNS board of directors/committees.

Changes in the last 4 years to the provincial cancer control program in Quebec raise questions about the potential reversal of gains with respect to patient representation in the cancer system. In 2004, the establishment of the Direction de la lutte contre cancer (DLCC) replaced the two organizations previously charged with overseeing the provincial cancer program, the Conseil québécois de lutte contre le cancer (CQLC) and the Centre de coordination de lutte contre le cancer. The CQLC had included one designated cancer patient representative, and had struck an advisory committee of cancer patients/survivors and family members called the Comité des représentants de la population atteinte de cancer et des proches (REPOP). It is unclear whether there is any formal mechanism for patient representation in the DLCC.

Several of the federal cancer-related committees/decision-making bodies examined for this study are currently undergoing periods of restructuring. This period of change could present an opportunity to have decision-makers consider the value of including cancer patient representation in the new structures (e.g., on the Ministerial Advisory Council on Tobacco Control, the Canadian Task force on Preventive Health Care). Since cancer organizations are not currently represented on the Health Canada Pest Management Advisory Council, there exists an opportunity for CCAN or some other cancer organization to advocate for such a role. The Joint Oncology Review being coordinated by the CED/CCO Joint Subcommittee is a key cancer-related initiative for which adequate patient representation should be assured. The terms of reference for the Joint Subcommittee are currently under review and it is expected that some mechanism for patient representation will be incorporated.

The important provincial cancer-related bodies identified in this study include provincial anti-tobacco and sun safety coalitions. Provincial divisions of the Canadian Cancer Society as well as some provincial cancer agencies are represented in these coalitions, but there do not seem to be any cancer patient/survivor advocacy organizations represented.

Gaps in training of patient representatives

Survey results indicate that there are significant gaps in the training provided to cancer patient representatives on cancer-specific committees/decision-making bodies. Among those committees/decision-making bodies confirmed to have patient representation, only one organization (Cancer Care Nova Scotia) indicated that patient representatives had received targeted training for their role in the governance of the organization. CCNS's experience with training patient representatives, depending on the agency's willingness to cooperate, could form the basis of a set of guidelines and best practices for training patient representatives for roles in governance.

Transparency in governance

Many of the organizations/decision-making bodies examined in this study go to some length to provide public information on their governance structures on their websites. Given the increasing importance placed on public participation in health care policy, planning and governance (including patient representation), it is important to make information on public/patient participation more easily accessible. In many cases, committees/decision-making bodies for which there are provisions for patient representation did not make that information available on-line, even in instances where a significant amount of information was available on governance in general. The level of public prominence given to initiatives to include patient representation in cancer system policy and planning is an important goal in and of itself. In other words, part of effective patient representation must also be clearly highlighting initiatives for patient representation as a part of organizational communications and transparency.

Recommendations

1. Efforts to increase and/or formalize cancer patient representation in the governance of provincial cancer agencies should be a priority area of action for CCAN.
2. Cancer Care Nova Scotia's approach to patient representation and outreach, including its Cancer Patient Family Network, ought to be considered as a potential model for comprehensive patient representation and effective recruitment of patient representatives for provincial cancer agencies.
3. Efforts should be made to increase the participation of cancer patient/survivor advocacy organizations within provincial anti-tobacco, sun safety, and healthy living coalitions.
4. Given the importance of the Joint Oncology Review in coordinating the national drug review process for cancer drugs, ensuring patient representation on the CED/CCO Joint Subcommittee should be a priority area of action for CCAN.
5. CCAN should consider advocating for some mechanisms of cancer patient representation on federal cancer-related committees/decision-making bodies that are currently undergoing restructuring, particularly the Ministerial Advisory Council on Tobacco Control and the Canadian Task force on Preventive Health Care.
6. CCAN should consider advocating for some role for cancer organizations on the Health Canada Pest Management Advisory Council.
7. CCAN should seek Cancer Care Nova Scotia's cooperation in sharing training material targeted specifically to cancer patient representatives undertaking governance roles.
8. Cancer-specific agencies should be encouraged to provide better access (e.g., on-line) to comprehensive information on their governance structures, including provisions for patient representation/consultation, committee structure, and terms of reference.

Need for further research

1. More research is needed to determine levels of patient representation on the major cancer research funding agencies.
2. More research is needed to determine levels of patient representation in one key provincial cancer agency, the Alberta Cancer Board and Foundation.
3. More research is needed to determine obstacles to finding/recruiting suitable cancer patient/survivor/family member representatives among agencies for which patient representative positions are currently vacant.

Bibliography

- Abelson Julia, Pierre-Gerlier Forest, Patricia Smith, John Eyles, Elisabeth Martin, Francois-Pierre Gauvin. 2002. "Obtaining public input for health-systems decision making: Past experiences and future prospects." *Canadian Public Administration* 45(1) Spring: 70-97.
- Abelson, Julia and John Eyles. 2004. "Public participation and citizen governance in the Canadian health system." In *Changing Health Care in Canada: The Romanow Papers*, edited by Pierre-Gerlier Forest, Tom McIntosh and Gregory Marchildon. Toronto: University of Toronto Press, 279-311.
- Abelson, Julia and Pierre-Gerlier Forest. 2000. "Towards more meaningful, informed and effective public consultation: A comparative study of regional health authorities in Canada." Canadian Health Services Research Foundation.
- Church, J. and P. Barker. 1998. "Regionalization of health services in Canada: A critical perspective." *International Journal of Health Services* 28:467-486.
- Church, John, Duncan Saunders, Margaret Wanke, Raymond Pong, Carol Spooner and Marlene Dorgan. 2002. "Citizen participation in health decision-making: Past experience and future prospects." *Journal of Public Health Policy* 23 (1): 12-32.
- Daykin, N., Sanidas, M., Tritter, J., Rimmer, J., Evans, S. 2004. "Developing user involvement in cancer services: professionals' and users' perspectives". *Critical Public Health*. 14 (3): 1-18.
- Evans, S., Tritter, J., Barley, V., Daykin, N., McNeill, J., Palmer, N., Rimmer, J. Sanidas, M., and Turton, P. 2003. "User involvement in UK cancer services: Bridging the policy gap". *European Journal of Cancer Care* 12 (4): 331-338.
- Frankish, James, Brenda Kwan, Pamela Ratner, Joan Wharf Higgins, Craig Larsen. 2002. "Challenges of citizen participation in regional health authorities." *Social Science and Medicine* 54: 1471-1480.
- Gauvain, Francois-Pierre and Julia Abelson. 2006. *Primer on Public Involvement*. Health Council of Canada.
- Gray, Ross, Margaret Fitch, Marlene Greenberg, and Sharon Shapiro. 1995. "Consumer participation in cancer system planning." *Journal of Palliative Care* 11 (4): 27-33.
- Hogg, Christine and Charlotte Williamson. 2001. "Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees." *Health Expectations* 4:2-9.

- Hubbard, Gill, Lisa Kidd, Edward Donaghy, Charlotte McDonald, and Nora Kearney. 2007. "A review of literature about involving people affected by cancer in research, policy and planning and practice." *Patient Education and Counselling* 65: 21-33.
- Martin, Douglas, Julia Abelson, and Peter Singer. 2002. "Participation in health care priority-setting through the eyes of the participants." *Journal of Health Services and Research and Policy* 7 (4) 222-229.
- Maxwell, Judith, Steven Rosell, and Pierre-Gerlier Forest. 2003. "Giving citizens a voice in healthcare policy in Canada." *British Medical Journal* 326: 1031-1033.
- Parboosingh, Jean, Sylvie Stachenko, and Suzanne Inhaber. 1997. "A Model of Consumer Participation: The Canadian Breast Cancer Initiative." *Canadian Public Policy / Analyse de Politiques* 23: 177-86.
- Richardson, Allison., John Sitzia, and Phil Cotterel. 2005. "'Working the system' – Achieving change through partnership working: an evaluation of cancer partnership groups." *Health Expectations* 8: 210-220.
- Sitzia, John, Phil Cotterell, and Alison Richardson. 2006. "Interprofessional collaboration with service users in the development of cancer services: The Cancer Partnership Project." *Journal of Interprofessional Care* 20 (1): 60-74.
- Sullivan, J and Y Scattolon. 1995. "Health policy planning: A look at consumer involvement in Nova Scotia." *Canadian Journal of Public Health* 86(5):317-20.
- Tedford Gold, Sara, Julia Abelson, Cathy Charles. 2005. "From rhetoric to reality: including patient voices in supportive cancer care planning." *Health Expectations* 8: 295–309.
- Tritter J.Q., Barley V., Daykin N., Evans S., McNeill J., Rimmer J., Sanidas M., Turton P. 2003. "Divided care and the Third Way: user involvement in statutory and voluntary sector cancer services." *Sociology of Health & Illness* 25 (5): 429-456.

Appendix I – Recruitment and Information Letter



Dear Sir or Madam,

I am writing to notify you of an important study, entitled *Maximizing Patient Voices*, being conducted for the Canadian Cancer Action Network (CCAN). CCAN is a national coalition devoted to raising the profile of cancer patient interests in the Canadian cancer system. The principle objective of this study is to identify the extent of patient/cancer-survivor representation in cancer and cancer-related organizations. The study will also collect information on the training provided to patient/survivor representatives appointed to committees and decision-making bodies within such organizations.

Given [organization name]'s important role in [cancer research, coordinating provincial cancer treatment and research, federal cancer policy, etc.], your organization's participation is very important to this study. In the coming weeks, I will be contacting your office to obtain contact information for suitable study participants. Typically, this would be someone with a good knowledge of the organization's governance structure and recruitment procedures (e.g., CEO/President, Board Chair). Participants in the study will be asked to complete a short on-line questionnaire distributed by email.

In addition, I will be collecting information on participating organizations' governance structure including committee structure, terms of reference, and nominating procedures.

Should you require any further information, please do not hesitate to contact me at the coordinates given below. For general questions about the study's goals and objectives, feel free to contact Jack Shapiro, Chair of CCAN at j.shapiro@sympatico.ca or Diana Ermel, at dianaermel@accesscomm.ca.

Sincerely,

Erin Knuttila
Consultant
Maximizing Patient Voices Project

Appendix II – Survey Instrument (English)¹

Questions marked with a * are required

Dear respondent,

You have been invited to participate in the Maximizing Patient Voices project sponsored by the Canadian Cancer Action Network. The objectives of this study are to identify the extent of cancer patient/survivor representation in federal, provincial and territorial cancer-specific and cancer-related decision-making bodies and committees in Canada.

You have been asked to participate because of your leadership role in a cancer-specific or cancer-related body. This survey, which should take approximately 15 minutes to complete, asks you to provide information about your organization's governance, including the extent of lay or patient representation in decision-making bodies and committees.

Your participation in this project is very valuable, and we are grateful for the time you have set aside to complete this survey. Your participation is completely voluntary and there are no foreseeable risks associated with this project. However, if you feel uncomfortable answering any questions, you can withdraw from the survey at any point.

If you have any questions about the survey or the procedures, you may contact Erin Knuttila at 306-584-1497 or by email at knuttila@sasktel.net. Should you have any general questions about the project objectives and goals, please do not hesitate to contact Liz Whamond (CCAN Co-Chair) at liz.whamond@gmail.com, Diana Ermel (CCAN Council Member) at dianaermel@accesscomm.ca, or Deanna Silverman (CCAN Council Member) at dfsilvcslt@rogers.com.

Thank you very much for your time and support. Please start with the survey now by clicking on the Continue button below.

¹ Please note, the formatting presented here is different from that in the on-line version of the survey. I have indicated skip patterns in the text of this version, whereas the on-line version skipped respondents according to programmed skip patterns.

Personal/Organizational Information

1. Please provide your name in the space below (Last Name, First Name). *

Which cancer/cancer-related organization do you represent? *

2. What position do you currently hold in this organization?

- President/CEO
- Executive Director
- Chair
- Vice-Chair
- Other (Please specify) _____

Organizational Structure

3. A variety of governance models exist. How would you characterise your organization's board/main governing body? *

- Traditional Board (Board and committees oversee at high level with delegation of operations to management)
- Operational Board (No permanent staff so board members involved in actual operations of organization)
- Policy Governance Board (Based on Carver model with Board focused on aims and relationship with CEO)
- Management Board (Board-managed finances, service delivery etc. with the aid of a small staff reporting directly to board on all matters)
- Stand-alone Committee (e.g., Advisory Committee/Council)
- Government Department/Initiative
- Other (Please specify) _____

4. How are members of the board/main governing body selected? (Select all that apply)

- Named by other organizations
- Appointed by government
- Volunteer
- Recruited by existing board members
- Recruited through media and other campaigns
- Other (Please specify) _____

5. The membership of boards and committees sometimes includes representation by lay members, community members, clients (including, but not limited to patients) or other special stakeholders. Does your organization's board/main governing body or any of its committees/working groups/action groups include any lay/community/client representation? *

- Yes (Skip to 10)
- No
- Don't Know (Skip to 10)

6. What are the most important reasons there is no lay/community/client representation on your organization's board/main governing body, committees, or working groups?

7. Does your organization solicit any lay/community/client input with respect to its operations or program delivery?

- Yes
- No (Skip to end)
- Don't know (Skip to end)

8. What kind of lay/community/client input has your organization sought? (Select all that apply)

- Regular consultations/roundtables
- Ad hoc consultations/roundtables
- Surveys/questionnaires
- Other (Please specify) _____

9. Please describe the initiative(s) your organization has used to collect lay/community/client input.

(Skip to end).

Main Governing Body

The following questions ask for information about your organization's main governing body. Depending on the case, this will refer to your board of directors, governing council, or, for stand-alone committees, the committee itself.

10. Do the terms of reference for your main governing body/board of directors mandate lay/community representation?

- Yes
- No (Skip to 12)
- Don't Know (Skip to 12)

11. How many lay/community member representatives currently sit on your main governing body/board of directors? _____

12. Do the terms of reference for your main governing body/board of directors mandate cancer patient/survivor/family member representation specifically?

- Yes
- No (Skip to 14)
- Don't Know (Skip to 14)

13. How many cancer patient/survivor/family member representatives currently sit on your main governing body/board of directors? _____

Committees, Working Groups, Action Groups

The following questions ask for information about your organization's subsidiary bodies/committees. Depending on your governance model, this might include board committees, subcommittees, working groups, or action groups.

14. How many of each of the following are there in your organization?

- Committees
- Working Groups
- Action Groups
- Other Subsidiary Bodies

15. How many of each of the following include lay/community representation in their terms of reference?

- Committees
- Working Groups
- Action Groups
- Other Subsidiary Bodies

16. How many of each of the following include cancer patient/survivor/family member representation in their terms of reference?

- Committees
- Working Groups
- Action Groups
- Other Subsidiary Bodies

17. In the table below, please list all of your organization's committees/subcommittees and the number of lay/community and cancer patient/survivor/family member representatives currently sitting on each:

Committee Name	Number of current lay/community representatives	Number of current cancer patient/survivor/family member representatives
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

18. In the table below, please list all of your organization’s Working Groups or Action Groups and the number of lay/community and cancer patient/survivor/family member representatives currently sitting on each:

Working Group/Action Group Name	Number of current lay/community representatives	Number of current cancer patient/survivor/family member representatives
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

Recruitment and Training

The following questions ask for information about the methods by which cancer patient/survivor/family member representatives were chosen for participation in your organization as well as the training provided, if any, to cancer patient/survivor/family member representatives.

19. Thinking of all cancer patient/survivor/family member representatives on the main governing body/board of directors or committees/working groups/action groups, which of the following best describes how these members were chosen?

- Appointed by government
- Named by other organizations
- Volunteer
- Recruited by existing board members
- Recruited through media and other campaigns
- Don’t know
- N/A
- Other (Please specify) _____

20. Was any training provided to cancer patient/survivor/family member representatives on the main governing body/board of directors or committees/ working groups/action groups?

- Yes
- No (Skip to 24)
- Don't Know (Skip to 24)
- N/A (Skip to 24)

21. What type of training was provided? (Choose all that apply).

- General written training/orientation materials
- Written training/orientation materials specifically designed for cancer patient/survivor/family member representatives
- General training/orientation session
- Training/orientation session specifically designed for cancer patient/survivor/family member representatives
- Other (Please specify)

22. Thinking of the general training/orientation session(s) provided to cancer patient/survivor/family member representatives, approximately how many hours of training/orientation were provided? _____

23. Thinking of the training/orientation session(s) specifically designed for cancer patient/survivor/family member representatives, approximately how many hours of training/orientation were provided? _____

24. Has your organization conducted any formal evaluation of the training provided to cancer patient/survivor/family member representatives on your main governing body/board of directors or subcommittees/working groups/action groups?

- Yes
- No (Skip to 27)
- Don't Know (Skip to 27)

25. What were the most important findings of this evaluation?

26. Would your organization be willing to share the results of this evaluation for the purposes of the CCAN Maximizing Patient Voices project?

- Yes
 No

27. Thinking about your experiences with cancer patient/survivor/family member or lay/community participation in your organization, please select the answers that most closely correspond to your view:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Don't Know	N/A
Including cancer patient/survivor/family member representation is worthwhile							
Including lay/community representation is worthwhile							
Patient/survivor/family member representatives contribute positively to the work of the organization							
Lay/community representatives contribute positively to the work of the organization							
Patient/survivor/family member representatives have the skills necessary to participate meaningfully in the organization							
Lay/community representatives have the skills necessary to participate meaningfully in the organization							
Patient/survivor/family member representatives receive the training they need to contribute positively to the organization							
Lay/community representatives receive the training they need to contribute positively to the organization							

28. Has your organization conducted any formal evaluation of patient/ survivor/ family member or lay/ community participation in your organization?

- Yes
- No (Skip to 31)
- Don't Know (Skip to 31)

29. What were the most important findings of this evaluation?

30. Would your organization be willing to share the results of this evaluation for the purposes of the CCAN Maximizing Patient Voices project?

- Yes
- No

31. This concludes the survey. We value your all of your insights on the topic of lay or cancer patient/survivor/family member representation in the cancer field. If you have any additional comments you would like to make, please do so in the box provided below:

Please contact knuttila@saskatel.net if you have any questions regarding this survey.

Appendix III – Survey Instrument (French)

Questions marked with a * are required

Cher/Chère participant.e,

Vous êtes invité à participer au projet Maximizing Patient Voices mené par le Réseau d'action de lutte contre le cancer. Ce projet vise à identifier le taux de participation des gens qui sont ou ont été atteints du cancer au sein d'organismes liés directement ou indirectement au champ du cancer au Canada.

Nous vous avons invité à participer en vue de votre rôle de leadership au sein d'un organisme directement ou indirectement lié au champ du cancer. Ce questionnaire, qui devra se compléter en environ 15 minutes, vous demande de nous fournir des renseignements ayant rapport à la gouvernance de votre organisme, y inclus le degré de représentation communautaire au sein de l'organisme.

Votre participation nous est très importante, et nous sommes reconnaissant du temps que vous avez réservé pour compléter le questionnaire. Votre participation est volontaire et nous ne prévoyons aucun risque ressortant du projet. Cependant, si vous vous ne sentez pas confortable de répondre à une question quelconque, vous êtes libre de terminer votre participation.

Si vous désirez de plus amples renseignements, n'hésiter pas de me rejoindre aux coordonnées fournis ci-bas. Pour de renseignements généraux au sujet des objectifs du projet, s'il vous plaît contacter Liz Whamond (liz.whamond@gmail.com), Co-Présidente du RALC, Diana Ermel (dianaermel@accesscomm.ca) ou Deanna Silverman (dfsilvcslt@rogers.com), membres du conseil d'administration du RALC.

Nous vous remercions de votre participation. Pour débiter le questionnaire, s'il vous plaît cliquez sur le lien ci bas.

Reseignements Personnels/Organisationnels

1. S'il vous plaît nous fournir votre nom (Nom, prénom) *

Quel organisme représentez-vous? *

2. Quel est votre poste au sein de cet organisme?

- Président et directeur général
- Président du conseil d'administration
- Vice-président du conseil d'administration
- Administrateur
- Autre (Veuillez préciser) _____

Structure Organisationnel

3. Comment décririez-vous votre organisme? *

- Organisme à but non-lucratif
- Conseil/comité consultatif
- Division d'un ministère gouvernemental
- Programme/initiative gouvernementale
- Autre (Veuillez préciser) _____

4. Comment sont les administrateurs du conseil d'administration/membres du comité sélectionnés?

- Nommés par d'autres organismes
- Nommés par le gouvernement
- Bénévoles
- Recrutés par administrateurs/membres du comité actuels
- Recrutés par annonces publicitaires
- Autre (Veuillez préciser) _____

5. La composition des conseils d'administration et des comités inclut parfois de représentants communautaires/sociétaux. Est-ce que votre organisme fait preuve de telle représentation, soit au niveau du conseil d'administration/comité de gestion ou au niveau des comités du C.A.? *

- Oui (Skip to 10)
- Non
- Incertain (Skip to 10)

6. Quelles sont les raisons les plus importantes pour lesquelles il n'y a aucune représentation communautaire/sociétale au sein de votre organisme?

7. Est-ce que votre organisme tente consulter le publique/groupes sociétaux afin d'améliorer l'organisation des services et la gestion de vos programmes et initiatives?

- Oui
- Non (Skip to End)
- Incertain (Skip to End)

8. Quelle sorte(s) de consultation(s) avez-vous tenter? (Plusieurs réponses peuvent-être sélectionnées)

- Consultations à intervalles réguliers
- Consultations ad hoc
- Questionnaires
- Autre (Veuillez préciser) _____

9. S'il vous plaît nous décrire les initiatives de consultation communautaire/sociétale achever par votre organisme.

Direction générale de l'organisme

Les questions suivantes vous demandent de nous fournir des renseignements au sujet de la direction générale de l'organisme, soit par un conseil d'administration ou autre forme de direction.

10. Est-ce que les modalités de la composition de votre conseil d'administration/direction générale spécifient la participation de représentants communautaire/sociétaux?

- Oui
 Non (Skip to 12)
 Incertain (Skip to 12)

11. Combien de membres communautaires/sociétaux siègent actuellement au conseil d'administration/ à la direction générale? ____

12. Est-ce que les modalités de la composition de votre conseil d'administration/direction générale spécifient la participation de représentants des personnes atteintes du cancer ou de leurs proches ?

- Oui
 Non (Skip to 14)
 Incertain (Skip to 14)

13. Combien de représentants des personnes atteintes du cancer ou de leurs proches siègent actuellement au conseil d'administration/à la direction générale? ____

Comités, Groupes de Travail, Groupes d'Action

Les questions suivantes vous demandent de nous fournir des renseignements au sujet des comités, sous-comités, groupes d'action et groupes de travail de votre organisme.

14. Combien y a-t-il de chacun des suivants dans votre organisme?

- Comités
Groupes de travail
Groupes d'action

15. Combien des suivants ont des modalités de composition qui spécifient qu'il y ait de la représentation communautaire/sociétale?

Comités

Groupes de travail

Groupes d'action

16. Combien des suivants ont des modalités de composition qui spécifient qu'il y ait de la représentation des personnes atteintes du cancer et de leurs proches?

Comités

Groupes de travail

Groupes d'action

17. Dans le tableau qui suit, s'il vous plaît nous faire la liste de tous les comités/sous-comités dans votre organisme et le nombre de représentants communautaires/sociétaux ainsi que le nombre de représentants des personnes atteintes du cancer et de leurs proches qui siègent actuellement sur chacun :

Nom du comité	Nombre actuel de représentants communautaires/sociétaux	Nombre actuel de représentants des personnes atteintes du cancer et de leurs proches
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

18. Dans le tableau qui suit, s'il vous plaît nous faire la liste de tous les groupes d'action/groupes de travail dans votre organisme et le nombre de représentants communautaires/sociétaux ainsi que le nombre de représentants des personnes atteintes du cancer et de leurs proches qui siègent actuellement sur chacun :

Nom du groupe de travail/groupe d'action	Nombre actuel de représentants communautaires/sociétaux	Nombre actuel de représentants des personnes atteintes du cancer et de leurs proches
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

Recrutement et Formation

Les questions suivantes vous demandent de nous fournir des renseignements au sujet des méthodes par lesquelles les représentants des personnes atteintes du cancer et de leurs proches ont été sélectionnés pour votre organisme ainsi que la formation avec laquelle vous les avez fournis :

19. Lesquelles des méthodes suivantes ont été utilisé pour recruter les représentants des personnes atteintes du cancer et de leurs proches dans l'organisme?

- Nommés par le gouvernement
- Nommés par d'autres organismes
- Initiative du représentant
- Recrutement par administrateurs/membres actuels
- Annonces médiatiques/publiques
- Incertain
- Sans objet (S.O.)
- Autre (Veuillez préciser) _____

20. Est-ce que les représentants des personnes atteintes du cancer et de leurs proches ont part à un processus de formation en tant que nouveaux membres de l'organisme?

- Oui
- Non (Skip to 24)
- Incertain (Skip to 24)
- Sans objet (S.O.) (Skip to 24)

21. Quelle(s) sorte(s) de formation a (ont) été fournis? (Plusieurs réponses peuvent être sélectionnées)

- Matériaux écrits en voie d'orientation/formation générale
- Matériaux écrits conçus spécifiquement pour les représentants des personnes atteintes du cancer et de leurs proches
- Session d'orientation/de formation générale
- Session d'orientation/de formation conçue spécifiquement pour les représentants des personnes atteintes du cancer et de leurs proches
- Autre (Veuillez préciser) _____

22. Par référence à la/aux session(s) d'orientation/de formation générale offerte(s) aux représentants des personnes atteintes du cancer et de leurs proches, combien d'heures d'orientation/ de formation ont été fournis? _____

23. Par référence à la/aux session(s) d'orientation/de formation conçue(s) spécifiquement pour les représentants des personnes atteintes du cancer et de leurs proches, combien d'heures d'orientation/ de formation ont été fournis? _____

24. Est-ce que vous avez tenter une évaluation quelconque de la formation fournie aux représentants des personnes atteintes du cancer et de leurs proches au sein de l'organisme?

- Oui
- Non (Skip to 27)
- Incertain (Skip to 27)

25. Quels ont été les constatations les plus importantes de cette évaluation?

26. Seriez-vous prêts à nous faire parvenir les résultats de cette évaluation en fonction de nos recherches pour le projet Maximizing Patient Voices?

- Oui
 Non

27. D'après vos expériences avec la participation des représentants des personnes atteintes du cancer et de leurs proches au sein de l'organisme, sélectionnez les réponses qui correspondent le mieux à vos opinions:

	Fortement d'accord	D'accord	Neutre	En désaccord	Fortement en désaccord	Incertain	Sans objet (S.O)
La représentation des personnes atteintes du cancer et de leurs proches est importante							
La représentation communautaire/sociétale est importante							
Les représentants des personnes atteintes du cancer et de leurs proches contribuent de façon importante au mandat de l'organisme							
Les représentants communautaires/sociétaux contribuent de façon importante au mandat de l'organisme							
Les représentants des personnes atteintes du cancer et de leurs proches ont les cométences nécessaires pour participer de façon significative à l'organisme							
Les représentants communautaires/sociétaux ont les compétences nécessaires pour participer de façon significative à l'organisme							
Les représentants des personnes atteintes du cancer et de leurs proches reçoivent la formation qu'il leur faut pour pouvoir participer de façon significative à l'organisme							
Les représentants							

communautaires/sociétaux reçoivent la formation qu'il leur faut pour pouvoir participer de façon significative à l'organisme							
--	--	--	--	--	--	--	--

28. Est-ce que vous avez tenter une évaluation quelconque de la participation des représentants des personnes atteintes du cancer et de leurs proches ou des représentants communautaires/sociétaux au sein de l'organisme?

- Oui
- Non (Skip to 31)
- Incertain (Skip to 31)

29. Quels ont été les constatations les plus importantes de cette évaluation?

30. Seriez-vous prêts à nous faire parvenir les résultats de cette évaluation en fonction de nos recherches pour le projet Maximizing Patient Voices ?

- Oui
- Non

31. Ceci termine le questionnaire. Nous vous remercions sincèrement d'y avoir participé. Si vous avez de commentaires ou de suggestions additionels, veuillez nous les communiquer dans l'espace fourni ci-bas.

SVP contacter knuttila@saskatel.net si vous désirez de plus amples renseignements au sujet du questionnaire.

Appendix IV - Tables

Table 1 – Cancer Research Funding Agencies

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees/ Decision-making bodies</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Terry Fox Foundation	Charitable foundation devoted to raising funds for cancer research. All funds are contributed to the National Cancer Institute of Canada.	Board of Directors	-	-	-	-
Canadian Cancer Research Alliance	A stand-alone body as well as a CPAC action group with the mandate to foster research networks focused on translating knowledge into more effective cancer treatment/detection and on cancer prevention.	Board of Directors	-	-		1
Cancer Research Society	Not-for-profit organization devoted to providing 'seed' money for basic cancer research.	Board of Directors	-	-	-	-

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees/ Decision-making bodies</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Canadian Breast Cancer Foundation	National volunteer-based organization that raises funds for breast cancer research and engages in advocacy and awareness programs.	Board of Directors	-	-	-	-
National Cancer Institute of Canada	National research fund granting agency, with major funding from Terry Fox Foundation and Canadian Cancer Society. Also trains cancer research personnel.	Board of Directors	Yes	Yes	3	1
		Joint Advisory Committee on Cancer Control	-	Yes	3	?
		Advisory Committee on Research	Yes	No	-	-
		Finance and Audit committee	No	No	0	0
		Nominating Committee	No	No	1	
		Strategic Advisory Council			-	-
		Steering Committee on Cancer Statistics	-	-	-	-
		CCS Portfolio Council	-	-	2	-

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees/ Decision-making bodies</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Ontario Institute for Cancer Research	Not-for-profit corporation funded by the government of Ontario, dedicated to cancer research.	Board of Directors	?	No	-	-
		Scientific Advisory Board	-	-	-	-
		Audit and Finance	-	-	1	-
		Governance	-	-	1	-
		Human Resources	-	-	1	-
		Four Peer Review Committees	-	-	1 on each	-
Fonds de la recherche en santé du Québec	Non-profit provincial funding body for health research. Awards \$80 million per year in research funds.	Board of Directors	-	-	-	-
		Executive Committee	-	-	-	-
		Finance Committee	-	-	-	-
		Ethics Committee	-	-	-	-
		Student Committee (Ad hoc)	-	-	-	-

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees/ Decision-making bodies</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
		Clinical Research Committee (Ad hoc)	-	-	-	-
		Peer review committees	-	-	-	-
Canadian Institutes of Health Research – Institute of Cancer Research	Virtual research institute within CIHR devoted to cancer research.	Institute Advisory Board	-	-	-	1

Table 2 - Federal Cancer Specific Decision Making Bodies

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Canadian Partnership Against Cancer	Announced November, 2006. Established to help accelerate action on the CSCC. Role in providing knowledge to patients, governments, health professionals, and others on prevention, screening, treatment, diagnosis and research.	Board of directors	-	Yes	0	1
		Advisory Council	-	Yes	-	-
		Action Groups (9)	-	Yes	-	-
Canadian Childhood Cancer Surveillance and Control Program	Founded in 1992, the CCCSCP operates a national surveillance system for childhood cancer. Collects and disseminates information on incidence, mortality, clinical trials, etc.	Management Committee	Yes	Yes	0	0
		Treatment and Outcome Surveillance Working Group	No	No	0	0
		Late Effects Study Working Group	No	No	0	0
		Etiology Working Group	-	-	-	-

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Health Canada – Scientific Advisory Committee on Oncology Therapies	Provides HC with advice on regulating oncology therapies in Canada. Contributes to drug review process.	Committee	-	Yes	0	2
		Working Group for the Scientific Advisory Committee on Oncology Therapy	-	-	0	0

Table 3 - Provincial/territorial cancer specific decision-making bodies

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
BC Cancer Agency	Provincial cancer agency coordinating treatment, research and fundraising.	BCCA Strategic Leadership Council	No	No	0	0
		BC Cancer Foundation Board of Directors	-	-	3	-
Alberta Cancer Board and Foundation	Provincial cancer agency coordinating treatment, research and fundraising.	Board of Directors	-	-	-	-
		Alberta Cancer Foundation (ACF) Board of Trustees	Yes	No	6	-
		ACF Audit and Finance Committee	-	-	3	-
		ACF Nominating Committee	-	-	3	-
		ACF Fundraising Cabinet	-	-	8	-

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Saskatchewan Cancer Agency	Provincial cancer agency coordinating treatment, research and fundraising.	Board of Directors	-	No	-	-
CancerCare Manitoba	Provincial cancer agency coordinating treatment, research and fundraising.	Board of Directors	No	Yes	-	0
		Planning	-	-	-	-
		Finance and Audit	-	-	-	-
		Quality Improvement	-	-	-	-
		Community Advisory Committee	-	-	-	-
		Inter-organizational Relations	-	-	-	-
		Medical Advisory	-	-	-	-
		Nomination and Governance	-	-	-	-
		CancerCare Manitoba Foundation Board of Directors	No	No	-	-

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Cancer Care Ontario	Provincial cancer agency coordinating treatment, research and fundraising.	Board of Directors	-	No	-	3 ²
		Executive Committee	-	No	-	1
		Finance and Audit	-	No	-	1
		Cancer System Planning, Performance and Research	-	No	-	3
		Provincial Clinical Standards, Guidelines and Quality	-	No	-	1
		Corporate Governance/Nominating	-	No	-	1
		Communications and Stakeholder Relations	-	Yes	-	1
		Cancer Quality Council of Ontario (CQCO)	-	Yes	-	2
		CQCO Signature Event Steering Committee	-	Yes	-	1
		Prevention and Screening Council	-	Yes	-	1

² Though there is no formal provision for patient/survivor/family member representation in the Charter for CCO's board of directors, 3 current members are family members of someone diagnosed with cancer.

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
		Disease Management Steering Committee Subgroups	-	Yes	-	2 ³
		Regional Cancer Patient Education Advisory Committees (reports to the CCO Patient Education Committee)	-	Yes	-	?
		Ontario Cervical Screening Collaborative Group	-	Yes	-	1
		Ontario Cervical Screening Recruitment, Education and Communications Committee	-	Yes	-	1
		Ontario Breast Screening Program Committees	-	No	-	0
Joint CCO – Aboriginal Cancer Committee	Provides advice and guidance to CCO in cancer control among aboriginal populations.	Committee	Yes	Yes	8	-
		Aboriginal Tobacco Strategy Working Group	-	-	8	-

³ CCO has established the Disease Management Steering Committee as a new operations group. Disease specific teams will be established each year, and CCO anticipates that when these groups are operational, they will each have 2 patient representatives.

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
		Aboriginal Research Working Group	-	-	2	-
		Cancer Video Project Working Group	-		8	5
Ministère de la santé et des services sociaux – Direction de la lutte contre le cancer	Division of the MSSS coordinating provincial cancer programs. In 2003-4, replaced the Conseil québécois de lutte contre le cancer and the Centre de coordination de lutte contre le cancer.		-	-	-	-
Fondation québécoise du cancer/ Quebec Cancer Foundation	Provincial organization coordinating cancer support services patients/family members.	Board of directors	-	-	-	-
New Brunswick Cancer Network	Division of NB Department of Health.	No relevant committees, since the NBCN is a government department. The NBCN consults with stakeholders via ad hoc consultations and roundtables.	-	-	-	-

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
CancerCare Nova Scotia	Provincial cancer agency coordinating treatment, research and fundraising.	Board of Directors	Yes	Yes	3	3
		District Cancer Committees (9)	Yes	Yes	2 (?)	2 (?)
		Nova Scotia Cancer Patient Education Committee	Yes	Yes	3	3
		Cancer Systemic Therapy Policy Committee	Yes	Yes	2	2
		Cancer Research Training Program Management Committee	Yes	Yes	1	1
		Education Advisory Group	Yes	Yes	1	1
		Satellite Oncology Evaluation Committee	Yes	Yes	2	2
		Cancer Survivorship Roundtable Planning Committee	Yes	Yes	2	2
		Norah Stephen Scholarship Awards Committee	Yes	Yes	2	2

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
PEI Department of Health	Government department overseeing provincial cancer treatment/research programs.	No relevant committees, since it is a government department.	-	-	-	-
Newfoundland Cancer Treatment and Research Foundation	Provincial health organization overseeing prevention, treatment, research and fundraising.	Cancer Care Foundation Board of Directors	-	-	-	-
Yukon Department of Health and Social Services	Government department overseeing provincial cancer treatment programs.	No relevant committees, since it is a government department.	-	-	-	-
North West Territories Department of Health and Social Services	Government department overseeing provincial cancer treatment programs.	No relevant committees, since it is a government department.	-	-	-	-
Nunavut Department of Health and Social Services	Government department. No information on cancer treatment in the territory.	No relevant committees, since it is a government department.	-	-	-	-

Table 4 - Federal cancer-related agencies/bodies

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Canadian Task Force on Preventive Health Care	Up until 2005, provided evidence-based advice to health care providers, consumers and planners on preventive health intervention, including recommendations for cancer screening.	Stakeholders Advisory Committee – Currently charged with guiding the revitalization process for the CTFPHC.	-	-	-	-
Intersectoral Healthy Living Network	Charged with developing and implementing the Pan-Canadian Healthy Living Strategy.	Coordinating Committee	-	-	-	-
		Working Groups (4)	-	-	-	-
Health Canada Tobacco Control Programme	Federal government tobacco control program.	Ministerial Advisory Council on Tobacco Control. Currently undergoing restructuring.	-	-	-	-
Canadian Council for Tobacco Control	National coalition of organizations devoted to tobacco control. Receives funding from the Ontario Ministry of Healthy Living, Québec's Ministère de la Santé et des Services sociaux, the	Board of Directors	No	No	-	-
		Executive Committee	No	No	1	0

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
	Canadian Cancer Society, and the Heart and Stroke Foundation.	Conference Organizing Committee	No	No	0	0
Federal Provincial Territorial Radiation Protection Committee	Coordinates harmonization of F/P/T standards and practices for radiation protection	Committee	-	-	-	-
Health Canada (PMRA) - Federal, Provincial Territorial Committee on Pest Management and Pesticides	Serves as forum for discussing F/PT approaches to pest management/pesticides. Provides advice to governments.	Committee	No	No	-	-
		Working Groups	Yes	-	-	-
Health Canada (PMRA) - Pest Management Advisory Council	Multi-stakeholder group providing advice to/communicating with Pest Management Regulatory Agency.	Advisory Council	Yes	No	-	-
		Low Risk Pesticides Working Group	-	-	-	-
		Communications Working Group	-	-	-	-

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
Canadian Agency for Drugs and Technologies in Health – Common Drug Review	Independent, non-profit agency funded by federal, provincial, and territorial governments. Provides advice to governments on drugs and health technologies. Program includes the Common Drug Review that assesses new drugs based on cost and effectiveness and makes recommendations for formulary listing.	Board of Directors	No	No	-	-
		Canadian Expert Drug Advisory Committee	Yes	No	2	-
		COMPUS Expert Review Committee	Yes	No	2	-
		COMPUS Advisory Committee	No	No	-	-
		Advisory Committee on Pharmaceuticals	No	No	-	-
		Devices and Systems Advisory Committee	No	No	-	-
		Scientific Advisory Panel	No	No	-	-

Table 5 - Provincial/Territorial cancer-related committees and decision-making bodies

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees</i>	<i>Lay Representation in Terms of Reference?</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Lay/Community Representatives Currently Sitting on Body</i>	<i>Patient/Survivor/Family Member Representatives Currently Sitting on Body</i>
BC Aboriginal Tobacco Strategy	Provincial government aboriginal tobacco control strategy.	Tobacco Working Group	-	-	-	-
Clean Air Coalition of BC	A coalition between the Heart and Stroke Foundation of BC and Yukon and the BC Lung Association devoted to tobacco reduction.	No steering committee or board.	-	-	-	-
Campaign for a Smoke-Free Alberta	Coalition of health organizations, including CCS, AB/NWT Division and Alberta Cancer Board, dedicated to tobacco reduction.	No information available.	-	-	-	-
Saskatchewan Coalition for Tobacco Reduction	Coalition of organizations promoting anti-tobacco education and advocacy. CCS Saskatchewan Division withdrew from coalition in 2005.	Board of directors	No	No	-	-
		Working Groups (4): Best Practices/ Advocacy Working Group, Tobacco Free Schools Working Group, Website Working Group, Smoke-Free Workplaces Working Group.	No	No	0	0

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Manitoba Tobacco Reduction Alliance (MANTRA)	Provincial coalition devoted to tobacco reduction in Manitoba. Membership includes CancerCare Manitoba,	Board of Directors (composed of representatives of participating organizations)	No	No	-	-
Ontario Campaign for Action on Tobacco	Provincial lobby effort targeted at anti-tobacco legislation. Membership includes CCS Ontario Division.	No information available.	-	-	-	-
Coalition Quebeoise pour le controle du tabac	Provincial coalition of over 700 organizations devoted to tobacco reduction in Quebec.	No information available.	-	-	-	-
Newfoundland and Labrador Alliance for the Control of Tobacco	Government/non-governmental partnership of organizations devoted to tobacco control.	Board of Directors	Yes	No	3	-
		Executive Committee	No	No	0	0
		Implementation Committee	No	No	1	0
		Advocacy Working Group	Yes	No	1	-
		Cessation Working Group	Yes	No	3	-
		School Communities Working Group	Yes	No	3	-

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Coalition for a Smoke Free Nova Scotia	Coalition of organizations devoted to tobacco reduction in NS. Membership includes CCS Nova Scotia Division and Cancer Care Nova Scotia.	No information available.	-	-	-	-
PEI Tobacco Reduction Alliance	Government/non- governmental partnership committed to tobacco control. Members include CCS, PEI Division.	Board of Directors	No	No	-	-
New Brunswick Anti-Tobacco Coalition	Coalition devoted to implementing goals of the National Strategy for Tobacco Control. Membership includes CCS – NB Division.	Implementation Committee	-	-	0	0
		Cessation Working Group.	-	-	-	-
Newfoundland and Labrador – Go Healthy	Provincial preventive health/health promotion initiative.	Provincial Wellness Advisory Council – Membership includes CCS, Newfoundland and Labrador Division	-	-	-	-

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SunSafe Nova Scotia	Coalition of governmental/non – governmental organizations devoted to sun safety. An initiative of Cancer Care Nova Scotia.	Membership includes the Department of Health Promotion and Protection, Canadian Dermatology Association, and the Canadian Cancer Society - Nova Scotia division	-	-	-	-
Ontario Sun Safety Working Group	Established in 1997 as a partnership between government and non-governmental organizations to promote sun safety in Ontario.	Membership includes CCS, Ontario Division and Cancer Care Ontario. Unclear whether Working Groups is still active.	-	-	-	-
BC Pharmacare Drug Benefit Committee	Evaluates drugs not eligible for review by the federal Common Drug Review.	Committee	-	-	-	-
Alberta Expert Committee on Drug Evaluation and Therapeutics	Reviews drugs not eligible for the federal Common Drug Review. Includes assessment of scientific and socio-economic factors.	Committee	-	-	0	0
Saskatchewan Formulary Committee	Part of drug approval process in Sask. Mandated with assessing value of new drugs to consumers and health system.	Committee	-	-	-	-

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Manitoba Drug Standards and Therapeutics Committee	Provincial review process for adding new drugs for Pharmacare coverage. Does not assess applications for cancer drugs.	Committee	-	-	-	-
Ontario Committee to Evaluate Drugs (CED)	Expert advisory group that makes recommendations on drug submissions to the Ontario Drug Benefit Formulary/Comparative Drug Index.	CED/Cancer Care Ontario Subcommittee – Responsible for administration of the Joint Oncology Drug Review. ⁴	-	-	-	-
Conseil du médicament (Québec)	Provides advice to the Quebec Ministry of Health and Social Services on drug adoption and best-practices.	Council	Yes	No	4	-
		Comité scientifique d'inscription	No	No	-	-
		Comité scientifique de suivi et usage optimal	No	No	-	-
		Table de concertation	Yes	No	2	-
		Comité d'éthique et déontologie	No	No	-	-
Atlantic Common Drug Review	Drug review body for the four Atlantic provinces, advising on drug listing, cost, etc.	Atlantic Expert Advisory Committee	-	-	-	-

⁴ Terms of reference are under revision by the Ministry of Health and Long-Term Care, which intends to add patient representation.

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Yukon Formulary Working Group	Advises on inclusion of drugs in the Territorial formulary.	-	-	-	-	-
Nunavut Pharmacy and Therapeutic Committee	Advises on inclusion of drugs in the Territorial formulary.	-	-	-	-	-