

***Maximizing Patient Voices***  
**Phase 2, Final Report**

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## List of Acronyms

CBCF	Canadian Breast Cancer Foundation
CBCI	Canadian Breast Cancer Initiative
CCAN	Canadian Cancer Action Network
CCCSCP	Canadian Childhood Cancer Surveillance and Control Program
CCNS	Cancer Care Nova Scotia
CCO	Cancer Care Ontario
CCS	Canadian Cancer Society
CED	Committee to Evaluate Drugs (Ontario)
CIHR - ICR	Canadian Institutes of Health Research – Institute of Cancer Research
CPAC	Canadian Partnership Against Cancer
CPFN	Cancer Patient Family Network
CPP	Cancer Partnership Project (UK)
CQCO	Cancer Quality Council of Ontario
CRS	Cancer Research Society
FRSQ	Fonds de la recherche en santé au Québec
IAB	Institute Advisory Board of the ICR
JOACC	Joint CCO Aboriginal Cancer Committee
NCIC	National Cancer Institute of Canada
NHS	National Health Service (UK)
OICR	Ontario Institute of Cancer Research
PGs	Partnership Groups (UK)
PPI	Public and Patient Involvement
SAC-OT	Scientific Advisory Committee on Oncology Therapies
SCNs	Supportive Care Networks (Ontario)

## **Executive Summary**

Although the importance and usefulness of patient involvement on cancer-system committees and decision-making bodies has been widely recognized, less is known about how patient representation in Canada has actually been implemented. Phase 2 of the *Maximizing Patient Voices Project* draws on qualitative interviews with official representatives of committees and decision-making bodies with patient voice representation in order to provide greater depth and detail as to the nature of patient involvement in the Canadian cancer system. This study also helps clarify the value of patient representation by drawing on interview data with patient voice representatives. The key themes covered are the definition of the “informed patient voice” and the rewards and challenges of patient voice representation.

### ***The academic literature***

A review of the academic literature on patient involvement in the cancer-system suggests there is value to having patient representation on committees and decision-making bodies related to health-system planning and coordination. The key benefits of including patient representation are the way in which it:

- Integrates a unique patients’ perspective into cancer-system decision-making.
- Allows cancer-patients to have a direct impact on cancer-system policy, service delivery, and research.
- Provides cancer-patient representatives with a positive and empowering experience.
- Improves communication between the cancer-system and its users.

The academic literature also identifies a number of conditions for success in patient voice involvement. When implementing cancer-patient/survivor/family member representation, the most important conditions for success are:

- A clear definition of the nature and purpose of patient involvement.
- Sufficient information and training for patient representatives.
- Good communication between health professionals and patient representatives.
- Providing for more than one patient representative per committee and ensuring continuity of committee membership.

Finally, the academic literature suggests that several factors may serve as barriers to meaningful patient involvement in cancer-system committees and decision-making bodies. Among the potential obstacles are:

- The lack of adequate resources to ensure long-term funding stability for patient involvement.
- The lack of clearly defined roles for patient voice representatives.
- Power imbalances between patients and health professionals.

- The lack of adequate training and information resources for patient representatives.
- The lack of sufficient ties between patient representatives and the patient/survivor community.

### ***Key findings***

The findings of this report are divided into two parts: 1. the responses of officials from cancer-system committees and decision-making bodies, and 2. the responses of patient voice representatives on the “informed” patient voice.

The nature and extent of patient representation and the types of committees/decision-making bodies on which patient representatives serve are summarized in Table 2 (Appendix A). Patient voice representatives serve on a wide variety of committees, including both decision-making and advisory bodies. In almost all cases, patient voice representatives serve as equal and full participants. The exception is on some research funding peer review committees, where patient representatives participate in deliberations but do not vote.

Officials from cancer-system organizations and committees were asked to comment on the value of patient representation as well as on the challenges and obstacles of trying to include patient voices. Respondents emphasized that the value of patient representation is:

- To provide a ‘reality check’ on the work of cancer-system organizations and committees based on the direct experience of those affected by cancer.
- To help the cancer-system become more responsive to the needs of patients and families.
- To allow for better communication between the cancer-patient/survivor/family member community and the cancer-system.

There are a number of potential obstacles and barriers to patient involvement, according to officials from cancer-system organizations and committees, including the ‘steep learning curve’ required on some technical committees, the challenge of balancing one’s personal experience with a broader perspective, and some practical constraints (e.g., time) on patient involvement. When asked about how their organizations and committees tried to ensure that patient involvement was meaningful and effective, these respondents emphasized that:

- Patient representatives must be fully involved in the work of the committee or decision-making body.
- That the roles and expectations of patient representatives be very clearly presented.
- That patient voice representatives receive adequate training, orientation, and support in their roles.

The second set of key findings relates to the views of current patient voice representatives. When asked about the value of patient representation, respondents emphasized that the patient voice:

- Is essential for achieving a more accountable and responsive cancer-system and for pursuing positive system change.
- Offers a unique perspective that can have a significant impact on the nature and outcome of conversations in cancer-system committees/decision-making bodies.
- Provides the perspective of someone who has directly experienced the illness and the cancer-care system.

Current patient voice representatives have also helped clarify the definition and parameters of the ‘informed’ patient voice. Aside from being someone with first-hand experience of the cancer journey, the informed patient voice is someone who has a good understanding of:

- The committee/decision-making body on which they are to serve, its role in the broader cancer-system, and the role envisioned for the patient representative.
- Patient needs and priorities, as reflected by the broader cancer community.
- The knowledge content of the committee or decision-making body’s work.

The notion of the informed patient voice encompasses a number of crucial skills and abilities. Patient voice representatives must have good communication skills, including the ability to speak up, to listen, and to engage in constructive dialogue. They must also be able to manage large volumes of sometimes technical information while maintaining a patient-centred perspective. Finally, they must be able to adopt a broad perspective, informed by a desire to represent cancer-patient needs and priorities in general. When defining the roles and functions of the informed patient voice, respondents emphasized above all that patient representatives should serve as a full and equal participant.

According to current patient voice representatives, the most rewarding aspects of serving in this capacity are the sense of being listened to and the possibility of positive system change. There are nonetheless some challenges and obstacles to meaningful patient voice involvement. The learning demands of serving on technical committees can be challenging. Another potential obstacle encountered only in some cases is the resistance of health care professionals and scientific experts, which can be manifested as paternalism or a fear that the patient representative is pursuing a narrow personal or advocacy-based agenda.

Current patient voice representatives also identified key conditions for meaningful participation. Respondents emphasized the importance of better recruitment, training, and orientation for patient voice representatives. Training and orientation should be tailored specifically to the needs of patient voice representatives and must include both a basic orientation to the cancer-system as well as skill building components. Part of the training and orientation needs could be fulfilled through mentoring relationships between experienced and new patient voice representatives.

In light of these findings, we offer the following recommendations as priority areas for action:

1. That CCAN advocate for more targeted and formalized orientation and training for patient voice representatives in the cancer-system.
2. That CCAN explore how best to incorporate mentorship of new patient voice representatives in patient voice training and orientation.
3. That CCAN explore ways of providing on-going support to patient voice representatives.
4. That CCAN engage in a conversation with cancer-system committees and decision-making bodies on how best to divide the responsibility for patient voice training, orientation, mentorship, and support.

## 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. In Phase 1 of the *Maximizing Patient Voices Project*, an environmental scan was conducted to determine the state of patient representation on federal, provincial, and territorial cancer-specific/cancer-related decision-making bodies and committees, as well as on committees within the eight major cancer research funding agencies. Though data were difficult to obtain in some cases, a number of such committees and decision-making bodies were identified as having patient voice representation.

Having identified the committees/decision-making bodies that include patient voice representation, there is a need for qualitative data on the nature, extent, and value of patient involvement. Phase 2 of the *Maximizing Patient Voices Project* draws on qualitative interviews with official representatives of such committees and decision-making bodies in order to provide greater depth and detail as to the nature of patient involvement in the Canadian cancer-system. There is also a need to clarify the value of patient representation from the perspective of current patient voice representatives. Phase 2 of this project will do so by drawing on interview data with patient voice representatives dealing with the definition of the "informed patient voice" as well as the rewards and challenges of patient voice representation.

The key objectives guiding Phase 2 of this project are:

1. To determine the level of participation of patients on those committees/decision-making bodies identified in Phase 1 as having patient representation;
2. To determine the function of the committees/decision-making bodies identified in Phase 1 as having patient representation;

3. To provide plain language statements, derived from the academic literature, on the value of patient representation in the cancer-system;
4. To clarify the definition of the “informed” patient voice, including the necessary skills, abilities, roles and functions, through interviews with current patient voice representatives.

## Methodology

Organizations with committees/decision-making bodies confirmed to have some patient voice were identified based on the results from Phase 1 of the *Maximizing Patient Voices Project* (Table 1). We also solicited the participation of some of the cancer research funding agencies from which we had received no response during Phase 1 of the project. In all, 13 organizations were contacted, of which 9 provided either a full telephone interview or confirmation that they do not have any patient representation (Table 1). A recruitment and information letter (Appendix B) outlining the purpose and scope of Phase 2 of the project was sent by email to key contacts in each organization. We followed-up with prospective respondents by email or telephone one week after the initial letter, and at least twice more if no response was received. Telephone interviews were based on an interview guide (Appendix C) covering specific committee-level information as well as general questions related to the value of patient representation and the challenges and obstacles organizations encountered when including patient voices.

In order to obtain a sample of current patient voice representatives, CCAN provided a list of CCAN provincial representatives and current patient voice representatives on CPAC Action Groups (13 contacts). CCAN also recommended we interview Dr. Margaret Fitch (PhD), a long-time academic researcher on patient involvement, and current chair of the Rebalance the Focus Action Group of CPAC as someone with insight on the “informed” patient voice. Prospective participants were sent an information and recruitment letter (Appendix D) outlining the purpose and scope of Phase 2 of the project. In all, 11 interviews were conducted. The interview guide (Appendix E) focused on respondents’ experiences as a patient voice representative, the rewards and challenges of serving as patient voice representatives, and the definition of the “informed” patient voice.

Qualitative interview data were coded and analyzed using NVIVO qualitative analysis software. From the data analysis, a synthesis of key themes emerging from each set of respondents (representatives of cancer system committees and decision-making bodies and patient voice representatives) was compiled. The results of the data analysis are presented in the Key Findings section of this report.

## Literature review

There is an extensive academic literature on patient and public involvement in health system planning, coordination, and research. A subset of this literature deals specifically with patient involvement in the cancer-system. Focusing on experiences with cancer-patient involvement in Canada and the UK, the purpose of this brief review of the

literature is to highlight the value of patient representation and identify the conditions for success and potential barriers to meaningful patient involvement. At the end of each subsection there is a list of statements summarizing the key findings of the literature in plain language.

### ***The value of patient representation***

Academic studies suggest that there is value to having patient representation on committees and decision-making bodies related to health-system planning and coordination. Much of this literature focuses on the question of public/citizen participation in health-care policy in general, while some of it focuses specifically on patient representation in the cancer care system.

The purpose of including public involvement in health systems governance involves 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). In Canada, initiatives for public involvement in the health system have relied mostly on public communication and consultation rather than full citizen participation (19). Where they have been studied, initiatives that directly involve lay people and patients in priority-setting committees demonstrate that such participation is valuable and can increase the legitimacy of decision-making (Martin et al. 2002).

A number of studies have examined patient involvement in cancer-system planning and coordination. In the UK, there have been substantial efforts to increase patient/lay involvement in the cancer system. In the cancer system, Partnership Groups (PGs) involving patient representatives were to be established in each of 34 regional cancer networks (Sitzia et al. 2006). The key goals of the PGs were to help shape cancer service delivery and policy in the interests of patients and to ensure that a patient perspective was central to service development. Most participants in the PGs indicated that they felt the groups had a significant impact on service delivery and planning. Among the successes of the PGs were the establishment of a 'nucleus' for patient involvement in the health region, the ability to design and implement patient information and communication initiatives, and the ability to directly influence service delivery and policy (Sitzia et al. 2006, 64). 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).

The Canadian experience is reflected by several studies that examined questions of patient involvement in cancer-system planning and coordination. Perhaps the first initiative to include substantial patient/survivor involvement was Cancer 2000, a national cancer system coordination task force operating from 1989 to 1991 (Gray et al. 1995, 27). In Ontario, the Life to Gain cancer strategy launched in 1991 involved cancer survivors, family members and general community representatives in a major cancer system planning initiative (27). Gray et al. summarize the experience of patient/survivor/community representatives in this way:

*Most patients/survivors and family members saw their participation as critical to the success of the process and felt strongly that all future planning exercises should involve consumers in a major way. They felt they had made a real difference. It would seem, then that the envisioned promise of consumer participation was, from their perspective, largely realized. It provided an “insider’s” perspective, allowed a voice in the process which was free of professional vested interests, and was mostly experienced by consumers as empowering. (31)*

Parboosingh and colleagues examined an early effort to involve cancer patients in health research and policy planning, the Canadian Breast Cancer Initiative (CBCI) (1997). The CBCI emerged in the early 1990s in response to concerns about a lack of government initiative in tackling breast cancer. 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 CBCI provides a model of patient/survivor involvement for its success in the early involvement of all stakeholders and its responsiveness to consumer needs (185). In this instance, the value of patient representation results from the ability to link breast cancer research and policy in ways that reflect patient needs.

Martin et al. (2002) conducted a study of patient and public participation on two committees involved in priority setting for new cancer and cardiac care technologies in Ontario. The study suggested that one of the key roles of patient representatives is to provide first-hand knowledge of patient needs and experiences, including, for example, the potential impact of a particular treatment (2002, 226). As one patient representative put it: “Hopefully I’m able to express that patient’s desires, fears, and wishes, to the extent that I can put myself in his or her shoes” (226).

The following statements summarize the key findings in the literature:

**The academic literature suggests that there is value in including patient/survivor/family-member representation in cancer-system planning, coordination and research. Among other things, patient voice representation:**

- **Integrates a unique patient’s perspective, drawn from personal experience as a cancer-system user, into cancer-system decision-making.**

- **Provides the potential for cancer-patients to have a direct impact on cancer-system policy, service delivery, and research.**
- **Generally provides cancer-patient representatives with a positive and empowering experience.**
- **Improves communication between the cancer-system and its users, for example, by designing patient-centred information.**

### ***Conditions for success***

Experiences in Canada and the UK reveal both opportunities and obstacles to implementing meaningful participation of cancer-patient representatives. Researchers have defined broad criteria for successful public participation initiatives as well as more specific recommendations related to patient involvement.

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.

Participants in Ontario's Life to Gain initiative helped identify the key skills and assets required of patient voice representatives in such a context (Gray et al. 1995). The most important of these was "the ability and willingness to speak up in an environment that may sometimes be intimidating" (Gray et al. 1995, 29). In order to ensure meaningful participation, patient voice representatives also emphasized the importance of sufficient orientation and training, particularly familiarization with the overall functioning of the cancer system and some introduction to terminology (30). Patient, survivor and community participants in priority-setting committees for new health technologies in Ontario identified two key conditions for the success of the involvement (Martin et al. 2002). First, participants emphasized the need for continuous involvement over a long period of time in a group with consistent membership as a key condition for developing good working relationships with other committee members and becoming familiar with the issues (224). Second, participants felt that having more than one patient/survivor/community representative on a committee provided for a 'critical mass' that helped to address feelings of intimidation brought on by knowledge and power differentials between health professionals and lay members (224-5).

Evans et al. (2003) studied the perception of UK cancer service users on the issue of patient involvement. Among the key findings, they found that key conditions for meaningful patient involvement were access to adequate information and good communication between patients and health professionals.

The following statements summarize the key findings in the literature:

**When implementing cancer-patient/survivor/family member representation, the most important conditions for success are:**

- **A clear definition of the nature and purpose of patient involvement.**
- **Sufficient information and training for patient representatives.**
- **Good communication between health professionals and patient representatives.**
- **Providing for more than one patient representative in order to prevent the isolation of a single representative.**
- **Ensuring continuity of committee membership in order to facilitate learning and relationship building among members.**

***Potential barriers to involvement***

Sullivan and Scattolon (1995) identify three key barriers to effective patient involvement: often implicit power differentials between patients and health professionals, a lack of ties between patient representatives and support networks linked to their constituency, and the challenge posed by patients' lack of information and technical skills in relation to health professionals (319). In fact, the barrier posed by the lack of adequate information and training for patient representatives is a common theme in both the UK and Canadian literature. 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 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). The study documents challenges and barriers in establishing regional Supportive Care Networks, which were to help ensure cancer-patient involvement in the new cancer care delivery system implemented in 1997. Among the key problems were a lack of clear direction for the networks, which 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). This problem is also reflected in the UK experience, where researchers found that conflicting views about the purpose of patient involvement could pose a barrier to meaningful participation (Daykin et al. 2004; Tritter et al. 2003; Evans et al 2003).

The following statements summarize the key findings in the literature:

**Among the potential obstacles to meaningful cancer-patient/survivor/family member participation are the:**

- **Lack of adequate resources to ensure long-term funding stability for patient involvement.**
- **Lack of clearly defined goals for patient involvement and roles for patient voice representatives.**
- **Power imbalances between patients and health professionals.**
- **Lack of adequate training and information resources for patient representatives.**
- **Lack of sufficient ties between patient representatives and supportive networks linked to the patient/survivor community.**

## **Key Findings**

The findings are divided into two parts. Based on the interview responses of officials from cancer-system committees and decision-making bodies, the first section focuses on clarifying the nature and extent of patient participation on various bodies. This section also includes an analysis of the views of officials from cancer-system committees and decision-making bodies on the value of patient representation, the potential obstacles and barriers to effective patient involvement, and making participation meaningful.

The second section of the findings reports on the interview responses of patient voice representatives and other key informants on the “informed” patient voice. This section is divided into subsections highlighting the following key themes: the value of patient representation, the definition of the “informed” patient voice, the rewards and challenges of serving as patient voice representatives, and the conditions for success for patient involvement.

### ***Cancer-system committees and decision-making bodies***

#### **Nature and extent of patient participation**

The committees and decision-making bodies for which patient representation was confirmed in Phase 1 of the project were asked to provide more detail on the nature of patient representation and the types of committees/decision-making bodies on which patient representatives serve. The results are summarized in Table 2.

In defining the nature of patient involvement, the distinction was made between full-voting participation and observer status. In order to specify the type and role of the committees/decision-making bodies on which patient representatives serve, we asked respondents to distinguish between committees with an advisory function and those with a decision-making function. Because the nature and governance structures of the various

organizations/committees differs considerably, defining the terms ‘advisory’ and ‘decision-making’ is not always straightforward. For instance, in a provincial cancer agency, committees may have decision-making power, but because the agency reports to the Minister of Health, their actions could potentially be overridden by the provincial government. Where necessary, footnotes have been used to provide more detail than could be included in the table.

In Phase 1 of the project, we received no survey response from four of the major cancer research funding agencies: the Terry Fox Foundation, the Cancer Research Society (CRS), the Canadian Breast Cancer Foundation (CBCF), and the Fonds de la recherche en santé du Québec (FRSQ). In Phase 2, we attempted to contact each of these organizations once again, but were only successful in obtaining a response from the CRS. An official with the CRS confirmed that the organization’s board of directors and other committees do not include any patient representation. There is no information on whether or not the Terry Fox Foundation, the CBCF, or the FRSQ include any patient voice representation on their committees and decision-making bodies.

Two cancer research funding organizations – the National Cancer Institute of Canada (NCIC) and the Institute of Cancer Research (ICR) of the Canadian Institutes of Health Research (CIHR) – participated in in-depth telephone interviews for Phase 2. Information on the NCIC’s committees was supplied by Stuart Edmonds, Director of Research Programs, and is presented in more detail in Table 2. There are patient representatives on the NCIC’s board of directors, Advisory Committee on Research, and on each of 17 Review Panels. While there is no specific provision for cancer-patient representation on the NCIC Nominating Committee, this committee normally includes one Canadian Cancer Society division president. Patient representatives on the board of directors and the Advisory Committee on Research are full-voting members. On the NCIC’s Review Panels, the patient voice is represented by 1 or 2 positions filled by ‘community representatives’, defined as someone who has had direct experience with cancer. These representatives are active participants in the research review process, but ultimately do not vote on approvals for research grants and personnel awards. There is no information currently available on patient representation on the Steering Committee on Cancer Statistics.

Information on the ICR was supplied by Dr. Benoit Lussier, Assistant Director. The ICR is governed by an Institute Advisory Board (IAB), which sets the strategic direction of the agency and guides the design of its funding programs. Although a provision for patient representation is not written into the terms of reference for the IAB, including at least one patient voice representative has been the standard practice. IAB members are appointed on the recommendation of the CIHR according to gaps that must be filled on the committee, one of which is understood to be cancer-patient/survivor representation. Patient voice representatives are full-voting members of the ICR’s IAB.

Two federal government cancer committees/decision-making-bodies – the Canadian Childhood Cancer Surveillance and Control Program (CCCSCP) and the Scientific Advisory Committee on Oncology Therapies (SAC – OT) -- participated in Phase 2 of

this project. Because funding for the program ended in 2000, the CCCSCP has not been active in recent years. The CCCSCP has recently begun the process of re-launching the program and has established a Steering Committee to guide the restructuring process. Though the Steering Committee does not yet include a patient voice representative, it is actively soliciting advice on including patient voice representation and recruiting suitable representatives. Under the CCCSCP's new structure, the Steering Committee will set the strategic direction for the program while the Management Committee will oversee operational matters. Patient voice representation on the Management Committee as well as on any Working Groups established by the CCCSCP will be decided by the Steering Committee.

SAC-OT is an advisory committee that provides advice to the federal government on the regulation of oncology therapies in Canada. While the committee does not evaluate particular drugs, it provides advice on drug regulation policy and guidelines. SAC-OT currently includes two patient voice representatives who serve as full-voting, core members of the committee.

Three provincial cancer agencies were confirmed to include patient voice representation in Phase 1 of the project. We received no response from CancerCare Manitoba with respect to our invitation to participate in Phase 2 of the project. Both Cancer Care Ontario (CCO) and CancerCare Nova Scotia (CCNS) participated in Phase 2 of the project through telephone interviews and written submissions providing additional detail on committee-specific information. Many of CCO's committees, councils and working groups include patient voice participation. The role and function of each of these is described in Table 2. Patient voice representatives are full-voting participants on each of these. Although patient representation is not stipulated in the terms of reference for the CCO board of directors, several board members are family members of cancer patients and survivors. The same situation is true of the 5 committees of the board listed in Table 2.

A brief telephone interview with an official with the Joint CCO Aboriginal Cancer Committee (JOACC) helped clarify the status of patient representation on this committee. All lay members of the committee are appointed by aboriginal political/territorial organizations. There are no provisions for patient voice representation per se, but there have been lay members in the past with a direct experience of cancer. Patient voice participation sometimes occurs through ad hoc consultations about JOACC initiatives.

CancerCare Nova Scotia has extensive provisions for patient voice representation. One of CCNS's key initiatives for seeking patient input into improving the cancer system is the Cancer Patient Family Network (CPFN). The CPFN is overseen by a full-time Coordinator and is comprised of over 700 individual members who are 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 CPFN offers a mechanism for recruiting and placing patient voice

representatives in CCNS committees. The CPFN Coordinator plays a key role in supporting patient voice representatives in their roles.

The role and function of the various committees and decision-making bodies on which patient voice representatives serve is summarized in Table 2. CCNS patient voice representatives serve as full-voting members on each of the committees and decision-making bodies. The Satellite Oncology Evaluation Committee deals with technical matters and does not include any patient voice representation. However, the Satellite Oncology Evaluation Committee consults regularly with Cancer Patient Family Network.

## The value of patient representation

Officials from cancer-system organizations and committees raised a number of common themes on the value of patient representation. Each respondent emphasized that patient voice representation was important to the way in which their organization or committee operates.

One of the most common themes was the idea that patient voice representation provides a necessary ‘reality check’ to the work of these organizations and committees. Respondents used several different ways of expressing this idea, including the notion that patient voice representation helps the organization/committee stay ‘grounded’ or ‘make it real’.

*We’re all here because we’re trying to make care better for patients and their families so in many ways it’s really just bringing some depth to the work that we’re all doing and grounding us in reality.*

- Janine Hopkins, CancerCare Ontario

For cancer research funding agencies, this aspect of patient voice representation contributes by posing the ‘So what?’ questions that connect the research agenda to

*It’s sometimes very easy to get caught in the weeds really and thinking about a research question, where actually what we’re thinking about is how to prevent and cure cancer and ... providing better support for patients with cancer. So it really is a case of having that bigger picture view on cancer and I think that’s something that is broader at many different levels in our organization having patient advisors, care givers on our committees.*

- Stuart Edmonds, NCIC

concrete implications for cancer patients. Patient voice representation can help ensure that cancer research funding agencies are doing the research that is most meaningful to patients, their families, and the Canadian public in general.

Officials from the provincial cancer agencies (CCO and CCNS) emphasized the importance of patient voice representatives for cancer-system quality and effectiveness. Including patient voice representation in the governance of these agencies allows the cancer-system to be more responsive to the needs of patients and families.

*We believe that it's absolutely essential that we include patients and families in the process. If we didn't, the health care system really would not be able to respond to the real needs and concerns of those who we are supposed to be serving. ... Their participation is essential to the design and delivery of care and services.*  
-Emmie Luther-Hiltz, CCNS

One of the key roles of patient voice representatives, according to Janine Hopkins of CCO, is to provide patient and family feedback on aspects of cancer-system

performance that cannot be measured. The quality and appropriateness of the information supplied to cancer patients, for example, is one of the areas in which patient voice representatives can provide valuable feedback to the provincial cancer agency.

Most organizations and committees also emphasized that, having directly experienced the illness and the whole spectrum of care in the cancer-system, cancer survivors provide a unique perspective to the work of committees and decision-making bodies. This point was especially relevant for a committee such as SAC-OT, which deals with regulating cancer treatment technologies. This first hand experience leads cancer patients/survivors to exhibit “a real passion and commitment” that allows them “provide valuable insight based on their experience” (Emmie Luther-Hiltz, CCNS).

Another benefit of patient voice representation cited by officials from cancer-system organizations and committees is that it allows those working in the cancer-system to be better connected to the broader survivor community.

### **Obstacles and barriers in patient representation**

Officials from cancer-system organizations and committees identified several potential obstacles to effective patient voice representation. One important theme emerged around the knowledge gap that can exist between health professionals and patient voice representatives, especially when the committee involved is technical in nature. This is most true of patient voice involvement on committees in the cancer research funding agencies, where there can be a ‘steep learning curve’ for lay people with no scientific or clinical background. One approach used to address this problem is to encourage, as much as possible, health professionals to use plain language when explaining their research to lay people as well as other professionals outside their field (Stuart Edmonds, NCIC).

Another challenge several respondents raised is the need for patient voice representatives to be able to adopt a broader, ‘big picture’ perspective on the cancer-system. There are several ways in which this can pose a problem. First, it can be a challenge for cancer patients/survivors/family members whose experience with cancer is very recent not to allow their personal experience to dominate their role as a patient voice representative. Second, it can also be a challenge to come to terms with the fact that change can take a long time and must proceed through the proper channels. Cancer patients/survivors/family members who recognize the need for system change may come at the issue with a sense of urgency that is difficult to reconcile with the reality that change takes time. Third, some respondents raised the issue of patient voice

representatives identifying too strongly with the agenda of an advocacy group they may be representing. Respondents emphasized the need for patient voice representatives to be able to draw on their personal experience as well as their ties to the survivor and advocacy community, but not allow a personal or advocacy agenda to drive their participation.

*People who are living with cancer or who have experienced cancer ... [have] got very valuable experiences to bring. They don't want to be wasting their time, they want to be feeling that there is some way that they can contribute ... . If they're sitting on a committee and they don't feel that they are making any contribution other than consuming the lunch sandwiches, that's not very meaningful.*  
- Emmie Luther-Hiltz, CCNS

Some respondents highlighted the danger of tokenism, i.e., involving patient voice representatives only superficially, as a barrier to meaningful involvement.

Another common theme from these interviews was that patient voice representatives may face constraints on their participation that are practical in nature. Several respondents mentioned that the time commitment involved in serving on various committees and decision-making bodies can pose a barrier to participation. Likewise, participation is more difficult for those cancer patients/survivors/family-members who live far away from major centres.

## **Making patient involvement meaningful**

Respondents were asked how their organization or committee ensured that patient voice representation was meaningful. Among the most common responses was the idea that patient voice representatives must be fully engaged in order to participate meaningfully.

For some respondents, this meant very clearly defining the objectives, roles and expectations of patient voice representation.

*We try and be very thoughtful about where we do involve them and then when we do, we try and make sure that their role and expectations are very clear. ... We don't involve patients or care givers ... on every committee just as a matter of practice because we ... have some kind of a policy that says that patients must be on every committee. ... We involve them in committees where they really will have a meaningful role.*

- Janine Hopkins, CCO

Another key to meaningful involvement, emphasized most strongly by CCNS, is appropriate training, orientation, and support for

patient voice representatives. New patient voice representatives must receive the training/orientation necessary to learn about the cancer-care system, the functioning of the committee they are to serve on, and their role on the committee. CCNS has a dedicated staff person, the Director of the Cancer Patient Family Network, responsible for recruiting, orienting and supporting patient voice representatives.

The personal qualities of the representative can also be important, as participation is likely to be more meaningful if the patient voice representative is someone confident

enough to speak up and participate in discussions. Some respondents also mentioned the importance of procedural issues such as good chairing and an openness and respect for others as key to successful patient voice involvement.

## ***Patient voice representatives***

### **The value of patient representation**

There is a significant overlap between the themes raised by patient voice representatives and those raised by officials from cancer-system organizations and committees on the value of patient representation. In general, current patient voice representatives emphasized that including patient/survivor/family-member representation is essential for achieving a more accountable and responsive cancer-system. Patient involvement, for instance, plays a key role in system change.

*I think that to get the attention of policy makers, government, providers, etcetera, the consumer voice has been extremely important. I think without it the process either doesn't occur or it occurs far more slowly.*

- Dr. Gene Vayda, M.D., and cancer survivor,

Patient voice representation also helps the cancer-system strive towards becoming truly patient/family-centred, more accountable, and more transparent.

Most respondents emphasized the idea that patient voice representatives offer a unique perspective that can have a significant impact on the nature and outcome of conversations in cancer-system committees/decision-making bodies. For some, the patient voice provides a necessary balance to discussions that would otherwise be dominated by health care professionals. Cancer patients/survivors/family-members may have different priorities from health care professionals, and adding their voices can significantly change the agenda of a group's work. As Steve Phillipow, patient voice representative on the ICR's Institute Advisory Board, puts it, the patient voice is "a voice that speaks to the other side of the equation".

One effect of having patient voice representation is to add a human dimension into discussions that otherwise might focus only on priorities of the health care system such as efficiency and cost-effectiveness. Cancer-system committees and decision-making bodies must keep in mind that:

*... they are not dealing with automatons or robots or automobiles that can be put on a hoist and called in and left alone and done whatever overnight. You're dealing with human beings, living human beings, who are vitally interested in what's happening to them, would like to know, [and] would like to be treated with respect.*

- Herold Driedger, patient voice representative on the Surveillance Action Group, CPAC

*... it's terribly important that there be some balancing of the professional input with people who are actually living with the disease, living with the condition and bring that viewpoint.*

- Dr. Gene Vayda, M.D., and cancer survivor, Primary Prevention Action Group, CPAC

Another key contribution of patient voice representatives is that they can provide the perspective of someone who has directly experienced the illness and the cancer-care system. In this regard, the patient perspective can help address the potential problems of paternalism and disconnect on the part of the cancer-care system.

*The ones who are being treated and going through the ministrations ... are the users of the system and without their perspective, then we don't have a full picture about the impact of the disease, the impact of the treatment or the impact of the way we've got our system organized. It's far too easy as a health care professional being in the situation day by day by day to become a little numb to some of the situations. For the person who is coming in as newly diagnosed cancer patient, the family member, everything is new. It's like being in a foreign land and everybody's speaking a foreign language and to understand what that's like and understand where we can make changes as health care professionals and as cancer system policy decision makers, I think we have to be informed by the people who are actually going through the experience.*

- Dr. Marg Fitch, PhD, patient voice advocate and researcher

## **The “informed” patient voice**

Current patient voice representatives were asked to provide their views on the notion of what constitutes an ‘informed’ patient voice. Being an informed patient voice could be considered a precondition for effective and meaningful patient involvement in cancer-system planning, coordination and policy-making. As such, it is perhaps best understood as an ideal to be pursued, rather than an existing state of affairs.

### *Definition of the informed patient voice*

Interview respondents were asked to provide a definition of the informed patient voice. Several respondents suggested that the concept is complex and therefore inherently difficult to define. Patient voice representatives face a wide range of situations in their work on committees and decision-making bodies and the requirements of those situations can vary considerably.

One aspect of the informed patient voice emphasized by some respondents is first-hand experience with the cancer journey, from diagnosis through treatment and care. This notion is tied to the idea that direct experience of the disease is among the most important contributions made by patient voice representatives. It allows patient voice

representatives to speak with authority on matters related to the patient/survivor experience.

In defining the informed patient voice, others highlighted three specific knowledge requirements. First, patient voice representatives must have a good understanding of the committee/decision-making body on which they are to serve, its role in the broader cancer-system, and the role envisioned for the patient representative. Without a basic understanding of the parameters for the body on which they serve and its role in the system, patient voice representation cannot be effective.

Second, the patient voice representative must have a good understanding of patient needs and priorities. In order to act as an effective patient advocate, the patient voice representative must be able to adopt a broad perspective encompassing the needs of patients in general. The effect should be to ensure that conversations are patient-centred. For those patient voice representatives representing particular patient/survivor organizations (e.g., site-specific survivor organizations), it is important to understand the group's key messages and priorities.

Third, patient voice representatives must develop an understanding of the knowledge content of the committee or decision-making body's work. This requires a willingness to prepare for meetings ahead of time, read prepared materials, and absorb sometimes technical information. Respondents emphasized that patient voice representatives cannot be expected to completely master technical information, but that what is important is a willingness to learn and understand the basic parameters of the discussion.

### *Skills and abilities of patient voice representatives*

Respondents were asked to identify some of the key skills and abilities required of effective patient voice representatives. The key themes identified here fall under three categories: communication skills, learning and managing information, and the ability to adopt a broad perspective.

Respondents emphasized a number of communication skills that are essential to serving as an informed patient voice. Among the most important of these is for the patient voice representative to have the confidence to speak up and fully participate in the proceedings of the committee or decision-making body on which they serve. This can be a challenge when considering that in many cases the patient voice representative will be the only layperson (or one of a small number of laypeople) around a table of scientific or medical experts. The confidence to speak up may involve not being afraid to "ask the dumb questions" (Archie McCullough, patient voice representative, Screening Action Group, CPAC). Sometimes the so-called 'dumb question' may help raise an issue from a new perspective, or shift the conversation in significant ways. It also involves the ability to communicate clearly and to do so with passion and conviction. In some cases, the patient voice representative may be at odds with health care professionals on an issue, and the ability to present the patient perspective with confidence becomes essential.

Another key communication skill respondents identified is the ability form open and collegial relationships with other people around the table. To a large degree, this requires that patient voice representatives develop good listening skills. It also involves presenting the patient perspective in a constructive, diplomatic, and reasonable way.

The ability to manage large volumes of sometimes technical information was also seen as one of the most important skills and abilities of an informed patient voice representative.

*... if you're going to be an informed patient or consumer voice in a policy arena then you also have to have the capacity to understand evidence, to understand the current status of knowledge in a field, at least to the point of recognizing what's good or what's bad, what you need to pay attention to.*

- Dr. Marg Fitch, PhD, patient voice advocate and researcher

There can be a very steep learning curve involved with joining a new committee or decision-making body, but the key is a desire to learn. This involves an ability to synthesize complex information and view it with a critical eye. Several respondents emphasized the need for patient representatives to be well prepared for meetings, e.g., by having read prepared materials and conducted some independent research. To some extent, this comes naturally with the desire of new patient representatives to be effective participants.

The third essential skill identified by current patient voice representatives in their responses is the ability to adopt a broad perspective. This can be an effective way of countering the perception that the patient representative has a narrow, 'single-issue'

*There are over 200 types of cancers so somebody has to start looking outward and start speaking out on behalf of those people who cannot speak out ... for themselves. ... There are some rare cancers that do not have support groups. So essentially you need to find generalists who are able to look beyond their own site and look to the general cancer population, and are able to react as a cancer patient, period.*

- Liz Whammond, CCAN Vice-Chair and patient voice representative on the Rebalancing the Focus Action Group, CPAC

focus. One aspect of this broader perspective is for the patient voice representative to keep in mind the needs of cancer patients in general. While one's personal experience always informs the patient

voice, it is important to go beyond personal circumstances and consider the perspective of patients as a collective. In other words, a patient voice representative must learn to 'speak with many voices'. One dimension of this is to look beyond the particular kind of cancer a survivor may have experienced and to consider the wider cancer field.

Aside from considering the needs and priorities of patients in general, adopting a broader perspective requires being able to consider the views of other types of actors around the table. This type of attitude helps foster a sense of cooperation and common-purpose

between the patient voice representative(s) and other actors such as health care professionals and researchers.

*The patient's voice is terribly important. For a long time it wasn't there, but it's not the only voice. In other words it still has to be seen in conjunction with the researcher, with the person who looks after the patient, both the health professional and the family members, etcetera.*

- Dr. Gene Vayda, M.D., and cancer survivor, Primary Prevention Action Group, CPAC

### *Roles and functions of patient voice representatives*

When asked about the roles and functions they thought patient voice representatives should play, respondents emphasized, first of all, that patient voice representation should be seen as an essential precondition for achieving a patient-centred cancer-system. In other words, patient voices should be included as much as possible in cancer-system planning, coordination and policy-making.

The second key theme was that, where patient involvement exists, the patient voice representative needs to be included as a full and equal participant. The patient voice representative should be invited to participate fully and to contribute meaningfully to decisions and their implementation. Where voting is involved, patient voice representatives should also be assigned a vote.

Another important aspect of full involvement is for patient voice representatives to be involved at the earliest stage possible of any initiative. This helps ensure that the patient perspective has an influence on setting the framework for discussions, intervening in the discussions themselves, and has an impact on the dissemination of the group's work.

### **Rewards and challenges of serving as a patient voice representative**

Respondents were asked to reflect on the rewards and challenges of serving in their roles as patient voice representatives. For some, the most rewarding aspect of their work as a patient voice representative was to know that their participation has led to positive system change. Some respondents mentioned specific instances of positive change. Others suggested that any change, however small, makes participation worthwhile.

For others, the most rewarding aspect is the sense that their perspective is valued and that they are listened to. The sense of being listened to is closely related to the sense that, as a patient voice representative, they are considered

*... it was just seeing the effect of having a patient voice at the table, where people would just stop and take a second look at you and say, "I hadn't thought of it from that perspective."*

- Deanna Silverman, patient voice representative on the Standards Action Group, CPAC

*What's rewarding is when your perspective is listened to and incorporated into [the work of the committee].*

- Diana Ermel, patient voice representative on the Cancer Guidelines Action Group, CPAC

equals in the work of the committee or decision-making body. At the same time, some respondents suggested that simply bringing a patient perspective to a conversation that might not otherwise have had one was the most rewarding aspect of their participation.

Respondents listed a number of challenges they encountered in their work as patient voice representatives. Serving as a patient voice representative – especially on a board or committee dealing with technical matters – can be very demanding. The volume and technical nature of the information with which patient representatives must become familiar can be daunting. Although it is not usually necessary that they master all of the technical information, some familiarity with the issues is important for meaningful participation.

Resistance to patient voice involvement on the part of health care professionals and scientists was a theme raised by several respondents. Most respondents emphasized that they encountered this type of resistance only occasionally and with particular individuals. There are a few different forms this type of resistance can take. For some respondents, the challenge was to convince health care professionals that the patient voice can make a credible and legitimate contribution to the work of the committee or decision-making body. In some cases, resistance was a product of the idea that the patient voice representative would slow down deliberations in the group, thereby making it less efficient.

Another common type of resistance encountered was the fear that the patient voice representative would ‘highjack’ the proceedings of the committee. The sense was that some health care professionals assume that patient voice representatives will only advocate for narrow, single-issue interests. If they tend to see the patient representative as the ‘squeaky wheel’ or ‘single-issue nut’, health care professionals may resent the patient voice perspective.

In other cases, respondents expressed this resistance as a form of paternalism. Some health care professionals may feel they know what is best for patients by virtue of their medical expertise. In cases where health professionals feel that patient representatives

*Sometimes there is lip service paid to having a patient voice but then that lip service does not really translate into strong listening.*

- Jack Shapiro, CCAN chair, and patient voice representative on the Research Action Group, CPAC

are they only because they have to be, the patient voice tends to get “patted on the head” (Pam Del Maestro, CCAN executive). The danger in this scenario is that patient involvement becomes tokenistic, where the patient voice serves as a ‘place-holder’.

The sense can be that, despite patient involvement, the major decisions have already been taken.

*There’s a sense of paternalism that still exists and a sense sometimes that, ‘We’ll figure it all out and we’ll put it down on paper and then we’ll ask for a response,’ as opposed to saying, ‘Let’s talk about this all together and put whatever we need to do down on paper ourselves as a collective’.*

- Dr. Marg Fitch, PhD, patient voice advocate and researcher

## Conditions for success

There are a number of factors that have an important impact on the success of patient involvement. These differ from the skills and abilities listed above in that they are external or contextual factors that serve as important conditions for success.

For some respondents, it is important for patient voice representatives to be connected to a broader cancer-patient constituency. This allows the patient voice representative not only

*It's good for a patient to have some kind of a patient constituency so that they have a group to whom they are responsible, to whom they report or with whom they discuss. And having that constituency gives them more bona fides when they are participating in discussions.*

- Jack Shapiro, CCAN chair and patient voice representative on the Research Action Group, CPAC

to better reflect the patient community, but also to engage in two-way communication between their network and the cancer-system committee or decision-making body with which they are involved. Being connected to a network of cancer-survivor organizations also can provide support and validation in a person's role as a patient voice representative.

On a similar note, some respondents suggested that having more than one patient voice representative on a given committee improves the chances of meaningful involvement. Here the idea is that patient voice representatives can provide support for each other. In the case where one individual has more experience than the other, there can be a mentoring relationship between the 'senior' and 'junior' patient voice representatives.

The importance of good committee chairing was an issue raised by a few respondents. A good chair can help ensure that the patient voice representative is given an adequate opportunity to express themselves and that they are not left behind in highly technical discussions.

Finally, an important theme raised by many respondents was the need for better recruitment, training and orientation for patient voice representatives. In many cases, recruitment occurs in a haphazard way, according to the availability of volunteers. More focused recruitment could help match individual skills with particular committees and decision-making bodies. At the same time, for most patient voice representatives, there was no formal training, or only a brief training and orientation session. Training and orientation specifically tailored to the needs of patient voice representatives might focus on explaining the basic workings of the cancer system, the specific role and function of the committee or decision-making body, and the role of the patient voice representative. Other respondents noted that training and orientation could also focus on skills building, for example, in communication or evaluating information. Partly, the training and orientation needs could be fulfilled through mentoring by experienced patient voice representatives.

## Conclusions

This study contributes significantly to understanding the current state of patient representation as well as the perspectives of current patient voice representatives. There is a significant overlap between the findings of this study and the academic literature on patient involvement reviewed above. Many of the key themes from the academic literature are borne out by the qualitative data collected from officials of cancer-system organizations and committees and patient voice representatives.

More in-depth information on the nature and extent of patient representation in cancer-system committees and decision-making bodies was sought from provincial cancer agencies, cancer research funding agencies, and federal cancer-related committees. In almost all cases, patient voice representatives serve as full-voting participants on these committees and decision-making bodies. The exception is on some peer review research committees, where patient voices participate in deliberations, but ultimately do not vote on research funding decisions. The information collected suggests that patient voices are included on a wide range of committees, including both advisory and decision-making bodies.

Officials from cancer-system organizations and committees that do include patient voice representation see patient involvement as valuable. Many of these officials expressed the idea that patient voice involvement made their work more grounded and more relevant to the ultimate beneficiaries of the cancer-system: patients, survivors, and their families. They nonetheless also recognized that there can be barriers to effective patient representation. Among the most important of these is the knowledge gap between lay people and health care professionals, the balance that must be struck between patient advocacy and adopting a broader perspective, and the practical constraints of volunteering one's time to serve on boards and committees. In terms of key conditions for success, most officials of cancer-system organizations and committees stressed that patient voice representatives must be fully involved, have a good understanding of their role, and must receive adequate support and training in their role.

Current patient voice representatives and other actors with insight on patient voice involvement provided their perspectives on a wide range of issues related to the informed patient voice. The value of patient representation is the unique, patient-centred perspective that it brings to discussions within cancer-system committees and decision-making bodies. This perspective can play an important role in achieving positive system change as well as in improving the transparency and openness of the cancer-system. Respondents also commented on the definition and key attributes of the 'informed' patient voice. The informed patient voice is someone with a good understanding of the cancer-system, of the committee on which they serve, and of their role as a patient representative. The most important skills and abilities of the informed patient voice are good communication skills, the ability to learn and manage information, and the ability to adopt a broad perspective. Respondents emphasized that the informed patient voice should be a full and equal participant in cancer-system committees and decision-making bodies on which they serve.

Patient voice representatives identified a number of rewards and challenges associated with their roles on committees and decision-making bodies. The most rewarding aspects include a sense of being treated as an equal, listened to, and allowed to participate fully. Some of the most challenging aspects are the steep learning curve associated with patient voice involvement and instances of resistance to patient involvement on the part of health care professionals. Finally, respondents commented on other conditions for the meaningful participation of patient voice representatives. Here the key themes were being connected to a broader patient constituency and the importance of adequate training, orientation, and mentorship for new patient voice representatives.

With a better understanding of the value of patient involvement a clearer definition of the ‘informed’ patient voice, it is hoped that the data from this study will contribute to further strengthening the role of patient voice representatives in the cancer-system. There are a few priority areas of action that should be considered for further improvement. One priority should be to seek more targeted and formalized orientation and training for patient voice representatives. An important element of this training and orientation could be provided through mentorship by more experienced patient voice representatives. Another priority might be to explore ways to provide on-going support to patient voice representatives. The model employed by Cancer Care Nova Scotia, with a dedicated staff person and Cancer Patient Family Network, is one successful example of this support. Finally, CCAN and other cancer-patient organizations should explore how the responsibility for patient voice training, orientation, and mentorship should be divided between their own organizations and the cancer-system committees and decision-making bodies on which their members serve. Based on these priority areas for action, we offer the following recommendations:

1. That CCAN advocate for more targeted and formalized orientation and training for patient voice representatives in the cancer-system.
2. That CCAN explore how best to incorporate mentorship of new patient voice representatives in patient voice training and orientation.
3. That CCAN explore ways of providing on-going support to patient voice representatives, with the model offered by Cancer Care Nova Scotia’s approach as a guide.
4. That CCAN engage in a conversation with cancer-system committees and decision-making bodies on how best to divide the responsibility for patient voice training, orientation, mentorship, and support.

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## Appendix A – Tables

**Table 1 - Research Status of Cancer-Specific and Cancer-Related Organizations and Committees with Patient Representation**

<b>Organization</b>	<b>Status</b>
<i>Cancer Research Society</i>	Brief telephone interview completed.
<i>Canadian Breast Cancer Foundation</i>	Did not participate.
<i>National Cancer Institute of Canada</i>	Interview completed.
<i>Ontario Institute for Cancer Research</i>	Did not participate.
<i>Fonds de la recherche en santé du Québec</i>	Did not participate.
<i>Canadian Institutes of Health Research - Institute of Cancer Research</i>	Interview completed.
<i>Canadian Childhood Cancer Surveillance and Control Program</i>	Interview completed.
<i>Health Canada - Scientific Advisory Committee on Oncology Therapies</i>	Interview completed.
<i>CancerCare Manitoba</i>	Did not participate.
<i>Cancer Care Ontario</i>	Interview completed.
<i>Joint CCO Aboriginal Cancer Committee</i>	Brief telephone interview completed.
<i>CancerCare Nova Scotia</i>	Interview completed.
<i>Ministerial Advisory Council on Tobacco Control (Health Canada)</i>	Email response indicated that the Council is under restructuring and that no new details are available.

**Table 2 - Cancer-system organizations and committees with patient voice representation**

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees/ Decision-making bodies</i>	<i>Committee Role</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Current Patient/Survivor/ Family Member Representatives</i>	<i>Nature of Patient Voice Involvement</i>
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	Decision-making	Yes	1	Full voting
		Advisory Committee on Research	Advisory	No <sup>1</sup>	1	Full voting
		Finance and Audit Committee	Advisory - Provides financial oversight	No	0	-
		Nominating Committee	Decision-making -Nominates NCIC Board and Committee Chairs	No	?	-
		Review Panels (17)	Decision – making - Reviews research grants to individuals and personnel awards	Yes	1 or 2 on each	Active participants/ Non-voting
		Steering Committee on Cancer Statistics	-	-	-	-
Canadian Institutes of Health Research – Institute of Cancer Research	Virtual research institute within CIHR devoted to cancer research.	Institute Advisory Board	Advisory body. Sets the strategic direction of the ICR, including appropriateness of funding programs	No	1	Full voting

<sup>1</sup> The terms of reference do not specify patient representation per se, but a lay member who is able to represent a cancer community perspective. In practice this position has been filled by a cancer patient/survivor/family-member.

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees/ Decision-making bodies</i>	<i>Committee Role</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Current Patient/Survivor/ Family Member Representatives</i>	<i>Nature of Patient Voice Involvement</i>
Canadian Childhood Cancer Surveillance and Control Program	The CCCSCP operates a national surveillance system for childhood cancer. Collects and disseminates information on incidence, mortality, clinical trials, etc.	Steering Committee	Sets strategic direction for CCCSCP	Yes		Full voting
		Management Committee	Will oversee operational matters. Decision-making. <sup>2</sup>	-	-	-
Health Canada – Scientific Advisory Committee on Oncology Therapies	Provides HC with advice on regulating oncology therapies in Canada.	Committee	Decision-making	No <sup>3</sup>	2	Full voting
		Working Group for the Scientific Advisory Committee on Oncology Therapy	-	-	0	-

<sup>2</sup> Terms of reference for this committee have not yet been established.

<sup>3</sup> Patient representation is not specified in the terms of reference, but is a function of the nominating process.

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees/ Decision-making bodies</i>	<i>Committee Role</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Current Patient/Survivor/ Family Member Representatives</i>	<i>Nature of Patient Voice Involvement</i>
Cancer Care Ontario	Provincial cancer agency coordinating treatment, research and fundraising.	Board of Directors	Decision-making	No	0 <sup>4</sup>	-
		Executive Committee	Decision-making	No	0	-
		Finance and Audit	Committee of Board	No	0	-
		Cancer System Planning, Performance and Research	Committee of Board	No	0	-
		Provincial Clinical Standards, Guidelines and Quality	Committee of Board	No	0	-
		Corporate Governance/ Nominating	Committee of Board	No	0	-
		Communications and Stakeholder Relations	Committee of Board, Advisory	Yes	1	External (non-board) member of the committee
		Cancer Quality Council of Ontario (CQCO)	Expert advisory group to CCO	Yes	2	Full-voting
		CQCO Signature Event Steering Committee	Decision-making	Yes	1	Full-voting

<sup>4</sup> 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/ Decision-making bodies</i>	<i>Committee Role</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Current Patient/Survivor/ Family Member Representatives</i>	<i>Nature of Patient Voice Involvement</i>
		Prevention and Screening Council	Advisory group to CCO, composed of external experts and stakeholders	Yes	1	Full-voting
		Disease Management Steering Committee Subgroups <sup>5</sup>	Decision-making	Yes	1-2 <sup>6</sup>	Full-voting
		Regional Cancer Patient Education Advisory Committees (reports to the CCO Patient Education Committee)	Advisory	Yes	Varies, according to each committee	Full-voting
		Ontario Cervical Screening Collaborative Group	-	Yes	1	Full-voting.
		Ontario Cervical Screening Recruitment, Education and Communications Committee	-	Yes	1	Full-voting.
		Ontario Breast Screening Program Committees	-	No	0	-

<sup>5</sup> The disease management steering committee is a new operation group. Each year a disease-specific team will be established that will include at 1-2 patient representatives. The Colorectal Cancer Team is the first that has been created.

<sup>6</sup> 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/ Decision-making bodies</i>	<i>Committee Role</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Current Patient/Survivor/ Family Member Representatives</i>	<i>Nature of Patient Voice Involvement</i>
Joint CCO – Aboriginal Cancer Committee	Provides advice and guidance to CCO in cancer control among aboriginal populations.	Committee	Advisory	No	-	
CancerCare Nova Scotia	Provincial cancer agency coordinating treatment, research and fundraising.	Board of Directors	Advisory	Yes	3	Full voting
		District Cancer Committees (9)	Decision-making	Yes	2 (?)	Full voting
		Nova Scotia Cancer Patient Education Committee	Decision-making	Yes	3	Full voting
		Cancer Systemic Therapy Policy Committee	Decision-making	Yes	2	Full voting
		Cancer Research Training Program Management Committee	Decision-making	Yes	1	Full voting
		Satellite Oncology Evaluation Committee	Decision-making			-
		Cancer Survivorship Roundtable Planning Committee	Advisory.	Yes	2	Full voting

<i>Organization/ Agency</i>	<i>Description</i>	<i>Committees/ Decision-making bodies</i>	<i>Committee Role</i>	<i>Patient Representation in Terms of Reference?</i>	<i>Current Patient/Survivor/ Family Member Representatives</i>	<i>Nature of Patient Voice Involvement</i>
		Norah Stephen Scholarship Awards Committee	Decision-making.	Yes	2	Full voting.
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. <sup>7</sup>	Decision-making	-	2 <sup>8</sup>	Full voting.

<sup>7</sup> Terms of reference are under revision by the Ministry of Health and Long-Term Care, which intends to add patient representation.

<sup>8</sup> There are two patient representatives on the Committee to Evaluate Drugs.

## Appendix B - Information and Recruitment Letter, Organizations/Committees with Patient Representation



Dear Sir or Madam,

We are writing to invite you to participate in **Phase II** of the *Maximizing Patient Voices* study 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 objective of this study is to identify the extent of patient/cancer-survivor representation in cancer-specific and cancer-related organizations and committees. In Phase II of the study, we are following up with organizations that indicated cancer-patient representation on one or more committees in order to obtain further information on the nature and extent of cancer-patient participation.

We would like the opportunity to interview someone with a good knowledge of the current state of patient representation in your organization/ committee. The interview will consist of a short telephone conversation based on a list of prepared questions about the extent and nature of cancer-patient participation on the organization's committees. We have identified you as our principle contact during the first phase of the project for your organization/committee. If there is someone else who would be better suited to participate in the interview, please let us know, and we will contact them.

For further information, or to arrange an interview time that is convenient for you, please contact us at the coordinates given below. Should you have general questions about the study's goals and objectives, feel free to contact Liz Whamond (CCAN Co-Chair) at [liz.whamond@gmail.com](mailto:liz.whamond@gmail.com), Diana Ermel (CCAN Council Member) at [dianaermel@accesscomm.ca](mailto:dianaermel@accesscomm.ca), or Deanna Silverman (CCAN Council Member) at [dfsilvcslt@rogers.com](mailto:dfsilvcslt@rogers.com).

Sincerely,

Erin Knuttila and  
André Magnan  
Consultants  
knuttila@sasktel.net  
(306) 584-1497

## Appendix C - Interview Guide, Organizations/Committees with Patient Representation

**Informant Name:** \_\_\_\_\_

**Date of Interview:** \_\_\_\_\_

**Interview ID #:** \_\_\_\_\_

### *Introduction:*

In Phase I of the Maximizing Patient Voices Project, you indicated that cancer-patient/survivor/family members participate in one or more of your organization's committees. Today I'd like to get more detail on patient involvement on these committees. Specifically, I would like to get a better sense of the *type* of committees on which there is some cancer patient/survivor/family member involvement, as well as the extent and nature of patient involvement on each. Finally, I would like to ask you a few questions about the value of patient involvement in your organization.

### *Part A:*

In your survey response in Phase I, you indicated that \_\_\_\_\_ committee(s) include(s) cancer-patient/survivor/family-member representation.

1. How would you describe the role of this committee in the organization (prompt: decision-making, advisory)? What are the committee's most important responsibilities?

\_\_\_\_\_  
\_\_\_\_\_

2. What role do(es) the cancer-patient/survivor/family member participant(s) play on this committee (prompt: full-voting participation, observer only)?

\_\_\_\_\_  
\_\_\_\_\_

### *Part B:*

3. What are the most significant **benefits** of cancer-patient/survivor/family-member participation in the governance of your organization/committee?

\_\_\_\_\_  
\_\_\_\_\_

4. What are the most important **strengths of cancer-patient/survivor/family-member representatives** on your organization's committee(s)?

- 
- 
5. What are the most significant **challenges** associated with including cancer-patient / survivor/ family-member representation in your organization/on your committee?

- 
- 
6. What are the most important **barriers** to the participation of cancer-patient/ survivor/ family-member representatives on this/these committee(s)?

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7. In what ways does your organization/committee try to **ensure that cancer-patient/ survivor/ family-member participation is meaningful and effective?**
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## Appendix D – Information and Recruitment Letter, Patient Voice Representatives



Dear Sir or Madam,

We are writing to invite you to participate in **Phase II** of the *Maximizing Patient Voices* study being conducted for the Canadian Cancer Action Network (CCAN). Because of your close involvement with CCAN, you may already be familiar with this project, the primary goal of which is to identify the extent of patient/cancer-survivor representation in cancer-specific and cancer-related organizations and committees. In Phase II of the study, we would like to obtain a better understanding of how patient representatives on such committees/decision-making bodies understand their roles.

We would like the opportunity to interview you regarding your role as a CCAN representative to a CPAC Action Group and/or as a CCAN provincial representative. Among the themes we would like to cover are your experiences representing the patient voice, your understanding of what constitutes an “informed patient voice” and the rewards, and challenges of acting as a patient representative. The interview will consist of a short telephone conversation based on a list of prepared questions. Your input will be very valuable in compiling a final report for Phase II of the project.

For further information, or to arrange an interview time that is convenient for you, please contact us at the coordinates given below. Should you have general questions about the study’s goals and objectives, feel free to contact Liz Whamond (CCAN Co-Chair) at [liz.whamond@gmail.com](mailto:liz.whamond@gmail.com), Diana Ermel (CCAN Council Member) at [dianaermel@accesscomm.ca](mailto:dianaermel@accesscomm.ca), or Deanna Silverman (CCAN Council Member) at [dfsilvcslt@rogers.com](mailto:dfsilvcslt@rogers.com).

Sincerely,

Erin Knuttila and  
André Magnan  
Consultants  
[knuttila@sasktel.net](mailto:knuttila@sasktel.net)  
(306) 584-1497

## Appendix E – Interview Guide, Patient Voice Representatives

**Informant Name:** \_\_\_\_\_  
**Date of Interview:** \_\_\_\_\_  
**Interview ID #:** \_\_\_\_\_

### *Introduction:*

You have been asked to participate in this interview because of your role as a cancer-patient/survivor representative on an Action Group of the Canadian Partnership Against Cancer and/or as a provincial CCAN representative. The goal of this interview is clarify the value of cancer-patient representation and the definition of “informed” patient voices from the perspective of current cancer-patient/survivor representatives.

Because I would like to make an accurate transcript of this interview, I would like your permission to record our conversation. Depending on your preference, I can attribute your words to your name, or simply to a generic reference to your role as a CCAN representative.

### *Part A: Background Questions*

8. In what capacity have you served as a cancer-patient representative?

\_\_\_\_\_

\_\_\_\_\_

9. What types of committees/decision-making bodies have you served on?

\_\_\_\_\_

\_\_\_\_\_

10. How long have you served in this/these role/s?

\_\_\_\_\_

\_\_\_\_\_

### *Part B: Opportunities and Challenges*

11. In your view, what is **the value** of including patient voice representation on cancer system committees and decision-making bodies?

\_\_\_\_\_

\_\_\_\_\_

12. In your experience, what have been the most **rewarding aspects** of your role as a cancer-patient representative?

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13. In your experience, what have been the most **challenging aspects** of your role as a cancer-patient representative?

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*Part C: The Informed Patient Voice*

14. How would you **define** the notion of the ‘informed patient voice’?

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15. When thinking of the notion of the ‘informed patient voice’, what are the most important **abilities and skills** required of a patient-representative to ensure meaningful participation on a committee/decision-making body?

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16. When thinking of the notion of the ‘informed patient voice’, what types of **roles and functions** do you think patient representatives should play on committees/decision-making bodies?

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17. In your view, what are the most important **obstacles** to the inclusion of informed patient voices on cancer-related committees and decision-making bodies?

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18. In your experience, what factors **enabled you to participate** as an informed patient voice on the committees/ decision-making bodies identified above?

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19. In your experience, what factors **limited your ability to participate** as an informed patient voice on the committees/ decision-making bodies identified above?

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