

The Ottawa Hospital's Consultations on Cancer Program Transformation



Final Report June 2011
Prepared for The Ottawa Hospital by MASS LBP



The Ottawa Hospital | L'Hôpital
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Foreword

I want to take this opportunity to once again thank all those who participated in the stakeholder engagement process for the significant contribution they made to helping The Ottawa Hospital Cancer Program begin its transformational process. In order to truly demonstrate our commitment to improving the patient and family experience, we needed to begin by engaging our stakeholders — patients, family members, physicians and staff— to find out what the issues were, and where improvements needed to be made.

Staff and physicians participated in open, honest discussions in an effort to articulate the changes they would like to see implemented to improve the patient experience. The patients and family members sharing of their experiences in cancer care and their journeys through the cancer system touched me on both a professional and personal level.

We were pleased to hear that the majority of patients and family members consulted as part of the process felt that they received high quality clinical care. However, we recognize that there are a number of areas within the care journey that need our attention. The time and energy invested by all stakeholders in this process resulted in an incredible list of values and recommendations that The Ottawa Hospital will use to make the necessary changes that will impact the experience for future cancer patients and their families across the Champlain Region.

I also want to assure you that, as promised, the Cancer Program will provide regular updates on our progress as we move forward with implementation. We recognize that while some changes can be made rather quickly, many others will require significant investment of time and resources, but we are confident that we will be successful in reaching our goal of becoming a leader in the delivery of patient- and family-centred care.

I look forward to continuing to lead this important process and can't wait to see the results of this work come alive within our organization.



Paula Doering
Vice President, Clinical Programs, Surgery/Cancer/Medical Imaging
Regional Vice President, Cancer Services, Champlain
Regional Cancer Program

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Introduction

In January 2010, The Ottawa Hospital's Cancer Program (TOHCP) embarked on an innovative and largely unprecedented effort to engage their patients in a frank discussion about improving patient experience and adopting a more patient- and family-centred approach to care.

The fruits of this effort will only be realized over the year ahead as the advice the Cancer Program received is refined, tested and ultimately adopted by program staff. What this means is that soon the Cancer Program will have new ways of working and interacting with patients and their families — new practices that have been developed in partnership with the patient and family members the program serves.

Too often, organizations pay lip service to the advice and recommendations offered by their constituents. Engagement means periodic surveys, evening information sessions and comment boxes.

The commitment made by The Ottawa Hospital's Cancer Program to patient and family engagement goes far beyond any of this. The program contacted 15,000 recent patients and their family members. Hundreds of volunteers were recruited and ultimately 36 panellists were randomly selected to participate in an intensive learning and dialogue exercise: A process now known as the Patients' Reference Panel on Cancer Program Transformation.

The Patients' Reference Panel was designed to combine the direct experience of patients and their family members with a balanced and detailed view of the operational abilities of the Cancer Program. It also drew together doctors, nurses and other program staff in a broader conversation to identify those priorities that could have the most dramatic effect on the experience of patients and family members.

Overall, the members of the Panel were highly complimentary regarding the quality of care they or their family members received from the Program. They frequently acknowledged the hard work of

staff and the high calibre of their clinical skills. They also noted that the expectations of patients have changed dramatically.

Today, an increasing number of cancer patients are beating cancer to return to their lives and families. Cancer treatment is rightly described as a journey. Along that journey, they:

- Stressed the heightened importance of improving access to information and enhancing communication, ensuring that it is both “proactive” and “two-way”;
- Identified the need for more assistance navigating what all acknowledge is a complex and sometimes circuitous diagnosis and treatment regimen;
- Highlighted the economic realities of patients, stressing the serious financial strain many patients experience as they undergo treatment;
- Noted the importance of a more holistic, or total body approach to care, that would provide more nutritional, psycho-social, and restorative therapies and services;
- Asked for more opportunities to be included and regarded as an essential member of the care team; and
- Suggested a renewed focus on relationships among medical staff so that care becomes more fully team-based; between the program and other health practitioners so that there is greater consistency across the continuum of care and between the program and its many stakeholders, patients and family members first among them.

Ultimately, the panel put forward 108 recommendations categorized according to the four stages of care. Their recommendations were discussed and further refined during a joint session of patients, physicians and staff. A list of these shared priorities also appears in this report.

The Panel Process

The first phase of the Transformation Project was comprised of a series of six meetings. First, physicians and staff met separately to learn about the Patients' Reference Panel, and to consider what the adoption of a patient- and family-centred care model would mean for The Ottawa Hospital's Cancer Program. Physicians and staff also discussed whether there were gaps in the patient experience that needed to be addressed.

The Patients' Reference Panel met during three Saturdays in March and April 2011. The Panel had four tasks:

1. Share their experience of the Cancer Program and learn from the experiences of others;
2. Suggest values and a vision for patient- and family-centred care at The Ottawa Hospital Cancer Program;
3. Identify the major issues affecting the patient and family experience in each of the four stages of cancer care (prevention and screening, diagnosis and assessment, managing treatment, support and follow-up) and provide advice on how they can be made more patient- and family-centred; and
4. Draft a final report to The Ottawa Hospital (TOH), which will help to guide the next phases of the Cancer Program Transformation Project.

The first phase of the Transformation Project concluded with a special day long session that brought together physicians, nurses, staff as well as many of the members of the Patients' Reference Panel. Together, they worked to understand each other's concerns and reach agreement on the priorities that would set the agenda for the second phase of the Transformation Project.



THE CIVIC LOTTERY

The Patients' Reference Panel members were selected through a process known as a "civic lottery". In an unprecedented effort, The Ottawa

Hospital (TOH) sent 15,000 invitations to the households of patients who had sought treatment at the centre in 2010. The invitation letters informed recipients about the Transformation Project and asked them to volunteer to be a part of the Panel.

Remarkably, 1,083 people responded to the invitation. Of those, 629 declined the offer to be on the Panel, but requested updates about the process. Several responded to the invitation with personal letters, regretting their inability to participate on the Panel but applauding the efforts to reach out so widely to the patient community. Ultimately, from among the 1,083 respondents, 403 patients and family members volunteered to serve on the Patients' Reference Panel.

From the pool of volunteers, 36 were randomly selected to be panelists. This included 24 current or former patients, as well as 12 family members. Consideration was given to ensure gender parity, and to ensure that the Panel was broadly representative of the age, geography, and language profile of the community. The lottery also produced a Panel that was broadly representative of the distribution of cancer types among the Cancer Program's patient population.

Physician and Staff Sessions

March 9 and 11, 2011

Physician and Staff sessions were held the week preceding the Patients' Reference Panel. The two groups met separately during similar three-hour sessions.

Each group received a briefing about the Panel process and had a short discussion about what they expected to hear from patients and family members, as well as what they hoped the process would achieve. They conducted two activities, both of which were also completed by the Patients' Reference Panel.

"We're busy and understaffed. When there's a long list of things to do, compassion and sensitivity can get lost. It's unfortunate...but the other stuff is about saving lives."

—CANCER PROGRAM NURSE

The first activity compared the values they felt characterized the current care provided in the Cancer Program to those they thought defined a patient- and family-centred model of care. The second evaluated the strengths and weaknesses of four phases of cancer care according to the impact on patient experience.

The physicians initially expressed doubt about the Transformation Project, and the notion of patient- and family-centred care. Many felt that their input into previous consultations had produced few results. They questioned whether the concepts of *transformation* and *patient-centred care* were really about marketing rather than medicine, and insisted that the care they provide is already *patient-centred*. Though they were cautious about the terminology, there was strong agreement among the physicians that patient experience could and should be improved. They were curious about the Panel process and hopeful that the results would be comprehensive and result in the administration taking action.

The staff group, which included volunteers, was less wary of the idea of transformation, or patient- and family-centred care. Staff discussed barriers to effective communication and interdisciplinary teamwork, as well as the gaps between family doctors and the Cancer Program during a patient's diagnosis and post-treatment. Like the physicians, they also felt as though previous consultations had gone nowhere, and hoped that this time would be different.

Panel Day One

Saturday March 19th, 2011

Despite being mid-March, the temperature neared 20 below as Panellists arrived at the Cancer Centre on Saturday morning. The Panel sessions were held in the main atrium of the Cancer Centre, where many patients wait for their appointments. The Panellists knew this place well, except that this time as they walked into the atrium, shaking off the cold, it looked different.

The reception chairs had been cleared away, replaced by round tables covered in craft paper. Huge white umbrella canopies had been set up amongst the tables, and flip charts were scattered throughout the room. Music was playing. Panellists removed their coats and began to chat in small groups. The feeling was immediately warm and informal.

The program began promptly at 9:30am. Dr. Jack Kitts, president and CEO of The Ottawa Hospital, welcomed Panellists to the first day of the Patients' Reference Panel. He expressed his gratitude for their time and volunteer effort, assuring them that their advice and recommendations would be taken seriously and used in concrete ways to improve the experience of care in the Cancer Care Program.



Vice President Paula Doering spoke next, encouraging the Panel members to speak openly and honestly about their experiences, noting that Cancer Program staff and executives want to hear “the good, the bad, and the ugly” of the patient and family experience.

Greg Dorion, Clinical Director of the Cancer Centre, also assured the Panel that their work would not be censored, and that their advice would be invaluable. He walked Panel members through the timeline and process of the Transformation Project, explaining how the Panel's work would contribute to the broader project.

MEETING ONE ANOTHER

After the Panel host explained the Panel process, Panellists were invited to stand up and spread out across the room as if it were a large map of the region, standing in the approximate location of their hometown.





Panellists introduced themselves and briefly talked about why they had volunteered to be a part of the Panel.

Here is what some of them had to say:

“I had breast cancer in 2004. It changed my life so dramatically that I wanted to stay involved.”

“I’m 21, the baby of the pack. I was diagnosed with Hodgkin’s in November. I just finished my last treatment on Friday. I’m going to the University of Ottawa. I’m here to voice my opinion and talk about my journey. Talking with others will help me.”

“I represent my son who passed away in November. He spent a lot of time here where he was an in-patient. I have lots of ideas I know he’d like me to pass on.”

“I am the mother of a 10-year-old boy. In 2005, I was diagnosed with thyroid cancer, which is the best cancer to have. They operated, took it out, and it’s gone. I’m here to give back.”

Panel members shared their experiences as patients and as the family members of patients. Some had been living with cancer for decades, some were survivors, and others were at the beginning of their cancer journey. Though their experiences varied widely, all of the Panel members expressed an eagerness to learn more about how the Cancer Program worked as well as a desire to play a part in improving cancer services for future patients and their families.

AN INSIDE LOOK AT CANCER SERVICES

The Panel members spent the remainder of the morning and half of the afternoon getting a behind the scenes look at the Cancer Program and hearing directly from hospital staff and physicians.

One nurse and one physician came to represent their peers and tell the Panel about the gaps they see in patient care as well as their hopes for the Panel process. Heather Lloyd-Easy, a nurse in the diagnostic clinic, told the Panel about the challenges for both patients and staff in navigating between silos in cancer care, and bridging the gulf between family physicians and the Cancer Program. Dr. Shail Verma, a medical oncologist, spoke about the history of the Cancer Centre and noted that logistical problems remain from the amalgamation of the Cancer

Program with The Ottawa Hospital in 2004. He also stressed the importance of patient advocacy.

The Panel also toured the Cancer Program at TOH, to see all the areas of the hospital where cancer services are provided and hear firsthand from the people who work there. Half a dozen staff members had volunteered their Saturday to show the panellists around their department and explain what they do.

At the Cancer Assessment Clinic, Panelists visited the new patient resource library and learned about the development of a decision-making tool to help patients and their families decide which prostate cancer response was right for them. In Module L, where physicians and staff work in small teams to treat patients, the Panellists had many questions about team organization and coordination. In the new Cancer Centre participants were impressed at The Ottawa Hospital's investment in cutting-edge technology, such as the Cyber-Knife, capable of administering radiation therapy with sufficient accuracy to treat eyes and lungs.



Panellists asked many questions of all their guides, and groups often looked to a Panel member who had first-hand experience in that area to answer questions about the patient experience. They probed into the rationale of some operating procedures, such as visitor limits, and looked to popular initiatives as the Bell of Hope, a bell patients ring to signify their final treatment, for ideas that could be replicated or expanded.

SELECTING VALUES

Back at their tables in small groups, the Panel turned to its last activity of the day. Just as the physicians and staff had done in their sessions, the Patients' Reference Panel selected from a list of 100 values the eight values that define the current state of care, and eight more that define a patient- and family-centred model of care.

Once each table made their selections, they shared their chosen values in a final plenary session. The two sets of values revealed the difference that a patient- and family-centred model might achieve.

The current care values were generally seen to describe a system geared for excellent clinical care. All groups agreed care is efficient and precise and that caregivers are dedicated and well-meaning.

The patient- and family-centred care values retain these qualities, but described a more integrated system in which the patient is more

involved. Such values as *accessible, accountable, collaboration, equity, holistic, and supportive* were common among groups considering patient- and family-centred care, though largely absent from current care. *Specialized, effective, established, and confident* were among the current values but absent from patient- and family-centred care.

The Panel had narrowed a list of 100 possible patient- and family-values to 31. Before the Panel adjourned for a week long break, they were tasked with homework. Each member was asked to interview one or more friends, neighbours or colleagues who had experienced cancer to discuss their experience and describe the values they felt characterized the care they had received. The Panellists left the first session eager to reach out to others.

Panel Day Two

Saturday March 26, 2011

One week later, the Patients' Reference Panel began their second session by sharing their findings from their homework interviews. Every Panellist had spoken to at least one person, and many who were members of support groups and community organizations had asked their peers for input at meetings, and several Panel members sent group emails to solicit more voices. Between them, Panel members had spoken to more than 200 people about patient- and family-centred care. Panellists brought these views to bear on their conversations throughout the day.

Panel members revisited the values they had selected the previous Saturday. They were each given a large chart that compared the physician, staff and patient and family member values.

The Panel compared each group's elections. Some were surprised to find there was greater alignment on the values for patient- and family-centred care values than on current values. Current care had only two values in common among all three groups: *expertise* and *commitment*. There were twice as many shared values describing patient- and family-centred care: *accountability, compassion, quality, and support*.

The Panel was challenged to take their aggregated list of 31 values and narrow their selection. In small groups and then in plenary, Panellists considered which of their selected values were most integral to achieving a patient- and family-centred model of care. The group agreed on 10, but decided to take them up again the following week to further refine and define their values.

Next, Panellists mapped their cancer care experience from the beginning to the present day. Each Panellist was given a long chart designed to resemble an 'electrocardiograph'. On it they were asked to mark the high and low points of their patient experience. Panellists spread out around the room, some speaking quietly to each other, others working from notes that they had prepared at home. All took great care to give the hospital a clear understanding of what the cancer journey is like



from the patient and family perspective and how certain policies, or the actions of individuals, affect the patient experience.

PERSPECTIVES ON CANCER CARE

Three speakers presented to the Panel on facets of cancer care.

Dr. Gad Perry, Interim Head of the Division of Radiation Oncology, spoke about the immense amount of coordination required among many professionals to give patients the best possible care. Dr. Perry also noted that because all people process information and emotions differently, physicians often struggle to give patients the right amount of information at the right time.

Amber Killam, a registered nurse with the outpatient program, identified the transitions between care providers or phases of care as the moments when communication is most likely to break down, just when patients and their families need it most.

Carrie Liska, a care facilitator with the Champlain Regional Cancer Program, acknowledged the communication gaps, noting that patient involvement in decision making and tighter response-time protocols for health staff would improve these gaps. She also stressed the importance of patient advocacy and liaising among the Cancer Centre, the community, and the satellite programs.



MAPPING THE ISSUES IN FOUR STAGES OF CARE

After lunch, Panel members switched tables and shared their *experience maps* with their new tablemates. During their conversations, panellists identified common instances when the care they received exceeded their standards, and times when the system did not perform up to standard. They looked systematically at their experiences to find the root causes of why some were better than others.

Each table received four charts, one for each stage of cancer care: Screening & Prevention, Diagnosis & Assessment, Managing Treatment, and Support & Follow-up. Panellists spent the next 30 minutes listing the strengths and weaknesses of each stage according to their experiences.

The room was reorganized again, this time into four large groups, one for each stage of care. Panellists selected the stage of care that interested them the most. The new groups were tasked with combin-

ing the six charts for that phase of care, creating one master list that also ranked the strengths and weaknesses according to which would have the greatest impact on patient and family experience. Panellists engaged in heated discussions over how different patient populations would experience each issue.

They shared their results in a concluding plenary session. Some began to brainstorm recommendations to alleviate the weaknesses they had identified. The following week the Panel would return to their issues charts and produce recommendations for all of the identified issues.

In preparation for their final task, the Panel was given their homework assignment for the week. The Ottawa Hospital had been running an online Patient and Family Survey for over a month. The survey was open to everyone who had first hand experience in the Cancer Program, and had received hundreds of responses. Panellists were asked to study the results of the Patient and Family Survey and compare the responses to the interviews they had conducted, as well as their own experience.

Panellists left the meeting with a shared sense of pride and a feeling of accomplishment. The Panel adjourned for the week long break before the final session.





Panel Day Three

Saturday April 2, 2011

The Panellists arrived for the third and final session to find the atrium of the Cancer Centre once again transformed. The experience maps from the previous week had been put up on display, covering one entire wall of the meeting space.

Paula Doering and Greg Dorion opened the Panel session by remarking on the experience maps. Paula called them “unbelievable,” acknowledging how difficult it must have been for some people to revisit their experiences. Both Paula and Greg were enthused about the effect the Panel process was having in the hospital.

“Staff and physicians are revved up. We have the momentum we need to put your recommendations forward.” The Panel was invited to return to the hospital the following Saturday to present their recommendations to a joint session of staff and physicians.

The Panel had a brief conversation comparing their reflections on the Patient and Family Survey results, and then set to work. The Panel was given their most important task: producing final recommendations for how to improve the patient and family experience of cancer care.



DRAFTING THE REPORT

Panellists returned to the four topic tables from the week before: Screening & Prevention, Diagnosis & Assessment, Managing Treatment, and Support & Follow-up. Each table reviewed the issues they had identified the previous week and received a series of discussion questions to guide their deliberation. Panellists worked in these groups to draft their recommendations, sometimes moving between tables to another topic to which they wanted to contribute. At intervals, the Panel returned to plenary, and each group reported to the others and gathered feedback or revisions.

In the afternoon, two new topic tables were opened; a ‘Wild Card’ table for recommendations that didn’t fit neatly into any one of the four categories, and a ‘Vision and Values’ table. The Vision and Values table worked to define each of the 10 values the Panel had previously selected

and craft a statement of purpose for patient- and family-centred care at TOH. Panellists continued to move among the tables, sometimes sending a delegate to take an important recommendation or consideration to another group.

By 3:30pm, the Panel had completed their work. The tables assembled their recommendations into a large multi-page report, with each table topic forming a chapter. From the podium, each table took turns presenting their chapter of the report. Some tables sent a single speaker, while others chose to come up together and to take turns. A round of applause from fellow Panellists followed each presentation. They had produced a statement of purpose for patient- and family-centred care, defined a set of guiding values and generated 108 recommendations to improve the patient and family experience.



Paula Doering received the Panel’s recommendations on behalf of The Ottawa Hospital. She commended the Panel for their clear, detailed, and enlightening recommendations. “You today...were unbelievable. We could not have come up with a better 36 to come up with these recommendations.”

Panellists finished by gathering for a group photo. As they left, each was presented with a framed certificate from The Ottawa Hospital in recognition of their commitment and hard work. The Panel adjourned satisfied with the completion of a momentous task. As one Panellist remarked, “I have been asked several times about the sacrifice I’ve made for the last three Saturdays, but it hasn’t been a sacrifice it’s been a privilege.”

Joint Session Saturday April 9, 2011

One month after the Panel process began, the final joint session of staff, physicians and Panellists was held at The Ottawa Hospital. By now spring was in bloom, but despite the temptation of a sunny Saturday, 90 people convened that morning to contribute to the Transformation Project. The group included physicians and staff from virtually every department in the Cancer Program at TOH. Sixteen members of the Patients' Reference Panel joined them.

Jack Kitts opened the proceedings. He thanked the Panellists for having committed to four Saturdays in a row, some of them having travelled a considerable distance to do so. He also thanked the physicians and staff for agreeing to meet, listen and discuss the recommendations that the Panel had put so much work into producing. Paula Doering followed, commending the Panel's results and encouraging the staff and physicians to build on their work.

The session host followed with a presentation of the Patients' Reference Panel process including pictures from each Panel session and videos of the Panellists explaining their work.

PRESENTATIONS AND RECOMMENDATIONS

Next, everyone took a moment to introduce themselves and ensure that there was an even mix of physicians, staff and patients at each table. Then two members of the Patients' Reference Panel presented the Panel recommendations. They read out the Panel's statement of purpose for patient- and family-centred care, the guiding values, and the recommendations for each stage of care.

The remainder of the morning was devoted to small group discussions evaluating the 108 recommendations put forward by the Panel. Each recommendation had been printed on a card, colour coded by stage of care. Every table was given a complete deck, and charged with selecting three recommendations from each stage of care that the group felt were most important.

For the next hour, physicians and staff of all specialties worked alongside patients and family members to reach consensus. Though



there were many instances of heated discussion, many participants were surprised at how easy it was to reach agreement.

At the end of the morning, each table presented their list to the room. Each group recounted their discussion and the decisions they had made. It became clear there were many points of overlap across the groups. On behalf of his team, Kitts thanked the Panellists for their contribution. Over the lunch break, the patients and family members departed, leaving the shortlist of recommendations the physicians and staff would use in the afternoon.

AFTERNOON: SETTING PRIORITIES

After lunch, the groups were reorganized into five large tables, each devoted to one phase of care, with one table for the Wild Card recommendations. The selected recommendations were redistributed across the five tables. Participants sat at whichever table topic interested them the most, and though they were invited to move from table to table, few chose to do so.

Each table surface (covered with paper) was divided into quadrants with two intersecting lines. The line from top to bottom represented the continuum from *Easy* to *Hard*, while the line from left to right represented the continuum of *Convinced* to *Not Convinced*. Each topic table was tasked with assigning their stack of recommendations to a location along the two continuums. They had to decide as a group which recommendations they were most committed to, and which they felt were simplest to accomplish.



Once every recommendation had been assigned, participants took a tour around the room to review each table and hear a summary of the discussion from each group. The presentations were followed by questions and brief conversations so each group could gather feedback to revise their decisions.

Returning to their tables, the participants embarked on their final task: to provide specific advice for each of their chosen recommendations. For each recommendation on the *Convinced* side of the spectrum, the groups advised the next steps to be taken in the second phase of the Transformation Project. For those recommendations the group assigned to the *Not Convinced* side of the spectrum, participants were asked to provide the rationale for their decision.

In a final plenary, each table took a few minutes to present their work. They offered concrete, practical actions TOH could take to realize the

recommendations, with detailed descriptions of possible challenges. They considered financial implications, scheduling, infrastructure, and expressed confidence that many recommendations were both achievable and necessary.

In the concluding discussion, the room expressed cautious optimism for the next stages of the Transformation Project. One physician praised the Panel's recommendations for their "sophistication and insight," and others expressed their admiration for the Panel's results. Many said that despite their initial skepticism that the process would be "another smoke and mirrors thing that will come and go with nothing done," they now felt that "they [the administration] really do want to go down this path together with us."

Themes and Observations

“Hearing their recommendations was one of the best experiences I’ve had in more than 28 years.”

—PAULA DOERING, VP, CLINICAL PROGRAMS, SURGERY/
CANCER/DIAGNOSTIC IMAGING, REGIONAL VP, CANCER
SERVICES, CHAMPLAIN REGIONAL CANCER PROGRAM

Throughout the consultation process, all groups praised The Ottawa Hospital’s commitment to excellence in clinical care. Patients and family members above all value the Cancer Program’s ability to treat and cure. The 108 recommendations are intended to help TOH improve patient and family experience, and be more responsive to the individual needs of patients throughout their journey. Across all 108 recommendations there were many common themes.

IMPROVING SYSTEM NAVIGATION

Patients and family members, staff and physicians all acknowledged that cancer care is challenging, both in terms of understanding treatment as well as physically finding one’s way around the hospital. Many recommendations focus on orienting patients to their treatment plan, their care team, and their surroundings. Increased navigational assistance is particularly needed at points of transition between caregivers or stages of care. Navigation recommendations include:

- Provide tours of the Cancer Program, both in person and online so patients can orient themselves to their surroundings before beginning treatment;
- Expand the CAC’s cancer journal program, so all patients can document their journey and receive helpful information that they can access at their own pace;
- Connect the patient to former patients or a trained Navigator to tell them what to expect from each stage of treatment;



- Institute a joint appointment process so the patient can meet all the members of their care team at once; and
- Consider a designated patient Navigator to guide the patients throughout their journey.

Both patients and TOH personnel agreed the navigator function is important and needed. The staff and physicians felt that all care providers could be better equipped to orient patients, diminishing the necessity for a designated navigator position. This is true, but patients were adamant about the necessity of consistent personal contact.

ENHANCING COMMUNICATION AND INFORMATION

The recommendations stressed the heightened importance of improving access to information and enhancing communication, ensuring that it is both *proactive* and *two-way*. This includes communication within the Cancer Program, between the Cancer Program and care providers in the community, and between care providers and patients and family members.

- Expand staff access to scheduling information across departments, to improve patient services and streamline the appointment process;
- Adopt a single system to manage patient records and data across the Cancer Program;
- Institute a double-appointment process for diagnosis so patients and their family members can prepare in advance;
- Consider a permission system so patients can allow designated individuals to access information and discuss a patient with care providers;
- Provide information that is clear, concise and in laymen's terms. Include a glossary of medical terms;
- Research an online patient portal, where patients and designated care providers or family members can access and update the patient's treatment information; and
- Develop an information program and system to educate patients on clinical trials.

Panellists, staff and physicians were mindful that any online or shared system must be secure, private, and patient-initiated. Staff and physicians had further reservations about the risks of patients learning possibly traumatic information through an online record. Further research into a patient portal would have to include restrictions, particularly around diagnoses and assessment.

ADDRESSING FINANCIAL PRESSURES

Combating cancer can be costly, and for low-income or fixed-income patients it can be devastating. Many patients struggle not only with treatment but also with supporting themselves during the journey. Acknowledging and responding to the economic situation of patients will diminish patient stress and preserve their dignity.

- Inform patients of their prescription options, including the costs of various drugs;
- Invest in transportation services for patients to and from the Cancer Program: limit the number of passengers per vehicle and coordinate rides with patient treatment schedules to prioritize time and convenience;
- Consider alternate parking rates for low-income or fixed-income patients;
- Inform patients of the range of parking options at the outset of treatment, and provide advice as to which option would best suit their treatment needs; and
- Simplify and streamline the process for collecting supporting documents for patients applying to Ontario Disability Support Program (ODSP).

ADOPTING A WHOLE-PATIENT APPROACH TO HEALTH

“You’ve got cancer’ has got to be one of the worst things a person could ever hear. Every person reacts differently... but one thing that is a ‘given’ is that all hospital staff — from the cleaner to the nurses and doctors — should treat patients with respect, dignity and understanding while imbuing hope.” —PRP MEMBER

Many recommendations noted the importance of a more holistic, or total body approach to care that would provide more nutritional, psycho-social, and restorative therapies and services. These include:

- Create a rehabilitation and wellness clinic that would include exercise, physiotherapy, massage therapy;
- Develop program seminars to provide info and training to patients and family members on nutrition and exercise;
- Research best practices in other cancer centres and develop an approval process for naturopathic oncology; and
- Expand psycho-social support.

The physicians were extremely cautious about recognizing — much less promoting — any form of alternative or complimentary medicine. They admitted, however, that most patients practice some form of alternative therapy, and agreed on the importance of making patients feel comfortable sharing that information with their care team. Physicians, staff and patients all declared TOH approval of alternative therapies would have to be based on evidence, though some physicians doubted that this was possible.

INCREASING PATIENT PARTICIPATION

“When I was lying on a flat hard slab getting X-rays, I never thought that I would ever be involved with 35 of you guys coming up with recommendations for how this hospital could possibly do any better. I’ve been listening to all of you with different treatments and points of view and it has been an enlightening experience, to say the least.” —PRP MEMBER

All groups recognized the patient as an integral member of their care team, and many recommendations focused on methods of expanding or improving the quality of patient participation. These include:

- Create patient-friendly charts and teach patients how to read them;
- Conduct training sessions with patients and caregivers to inform them about symptoms and side-effects (both physical and mental) and provide instruction on how to administer care;
- Consult with patients regarding The Ottawa Hospital Cancer Program budgeting and program changes before decisions are made;
- Institute a regular patient audit of the patient and family experience; and
- Develop decision-making tools (like that for prostate cancer) to help patients and their families understand their diagnosis and choose the treatment that's right for them.

BUILDING RELATIONSHIPS

“There were successes when there was empathy, compassion, and it was felt there was a high degree of competence. We identified failures when mistakes were made, when expertise was lacking, and when the treatment wasn't timely.” —PRP MEMBER

The Panellists emphasized the importance of strengthening relationships: among medical staff so that care becomes more fully team-based; between the Cancer Program and other health practitioners so that there is greater consistency across the continuum of care; and between the Cancer Program and its many stakeholders, patients and family members first among them, including:

- Partner with public health, business, and local schools to educate and raise awareness about cancer prevention and screening;
- Develop information sessions for GPs to learn about the specific cancer profile of the catchment demographics and understand how the Cancer Program works for their patients and increasing GP access to their patient's files at TOH;

- Integrate surgeons into the cancer care team and involve them in face-to-face meetings with the patient, pre- and post-treatment;
- Encourage frequent face-to-face contact between the patient and their oncologist during treatment — this contact can be brief and informal, but is very powerful;
- Allow exceptions of visitor limits so younger patients can have both parents present during treatment; and

Both physician and patient groups identified the need to improve the follow-up appointment process for recovering patients. Many patients continue with follow-up appointments as long as possible — as opposed to as long as necessary — simply to maintain contact with the Cancer Program.

Report of the Patients' Reference Panel

STATEMENT OF PURPOSE

A patient and family-centred Cancer Care program will:

Live up to its values. We are a leader at the centre of the community meeting the needs of patients and their loved ones: mind, body and spirit.

We encourage The Ottawa Hospital and the Cancer Program to:

Embrace change; act on our recommendations; encourage patient advocacy; reach out to community care providers; continue to involve patients and their loved ones in the decisions and the evaluation of their care.

VALUES

Accountable: We are all accountable. We are responsible for our actions as they affect ourselves and others. We are in this together.

Accessible: We will ensure that our services are accessible to all people regardless of their background, location, language, gender or age.

Advocacy: We support patient advocacy and recognize the need to act as a compass points throughout the journey.

Caring: Patients should be treated with the compassion and respect that we would want for our loved ones.

Timely: We meet patients and family and caregivers needs in a prompt and responsive manner.

Collaboration: A coordinated team that works together in the delivery of services with TOH and within the broader community.

Clarity and Communication: Information and choices are presented consistently using clear and simple language.

Holistic: The complete needs of the patient and their loved ones are met: mind, body and spirit.

Transition: We recognize the importance of providing seamless continuity throughout the stages of care and treatment.

Quality: We are committed to providing excellence in every aspect of care.

RECOMMENDATIONS

Prevention and Screening

How can we support people to be more proactive and responsible for prevention and screening?

1. Utilize the experiences of cancer centre patients and family members by sending them out as volunteers to schools, community groups, youth groups, universities/colleges and similar partnerships should be fostered in workplaces. As spokespeople representing the CP their mandate is to: spread cancer awareness, diminish fear and stigma about cancer, reinforce the cancer program's role in the community; and
2. Recommend that that CP partner with area schools to develop education awareness programs regarding the benefits of health and wellness for cancer prevention.

What do GPs need to know to be full and effective partners in the prevention, detection and screening of cancer?

1. Produce detailed information by way of the internet, particularly the CP website, so that General Practitioners (GP) patients and family members can gain access to the specialist's knowledge;
2. Encourage GPs to visit and familiarize themselves with the cancer program's people, services and approach; and
3. Develop information sessions so GPs can learn from the CC about the cancer risks and profile of the Ottawa area's specific demographic.

How can the CP promote access to its screening programs?

1. Expand the role and scope of the CP to allow direct access to screenings without referrals;
2. Provide clear concise bilingual information on the hospital's website about the availability of screening; and

3. Establish a CP hotline with information about available screening programs can be acquired. Call it 1-800-I-screen/1-800-Cancer1. Promote this hotline through public service announcements, community newspapers, and municipal handouts.

How can the CP be more responsive to the needs of different patient groups?

1. Extend hours of operation;
2. Implement a mobile screening program in marginalized or less accessible communities; and
3. Reach more marginalized segments of the population through multilingual and multicultural media, community centres and other possible partnerships.

How can the CP better coordinate patient care?

1. Establish patient advocate (Navigator);
2. Create secure online resources which allow patients to access their medical records; and
3. Create a videoconferencing system for patients to limit the number of trips to the hospital.

Assessment & Diagnosis

How can the Cancer Program support patients and families during wait times for testing and diagnosis?

1. Provide access to online 'profile' with treatment plans, including wait times, appointments, test results, long range plans, that is up to date. There must also be an option for personal contact who is always available to share with the patient this profile by telephone; and
2. Provide access to a health professional Navigator to explain timeframes and delays, look into delays, contact patients promptly if there are delays.

What do patients and families need to better understand their diagnosis and the information they receive?

1. Provide access to translator as needed to make sure you understand diagnoses;
2. Create a two-appointment process for diagnosis: a short initial meeting with the physician followed by a longer meeting after the patient has had a chance to confer with others and draft questions;

3. Connect patients to a former patient volunteer and provide a professional Navigator to consult with patients;
4. Provide a list of frequently asked questions and answers that are created in consultation with former/current patients and families;
5. Provide information that is clear, concise and in layperson's terms. Include a glossary or medical terms;
6. Provide access to medical records (at the ready); and
7. Tell patients about monthly parking options and other resources available.

What do patients and family members need to know and need to do to better recognize, report and manage their symptoms?

1. Provide a reference/ journal with step by step information and space for patients to record symptoms, questions, test results, appointments — develop an online option;
2. Give patients clear instructions about what to look for in terms of symptoms and side-effects of diagnostic tests, both physical and psychological;
3. TOH should report back about the diagnosis to the GP and ask GP to provide relevant information to TOH; and
4. Electronic records should be accessible to all parties — TOH, GP and patient.

What does the CP need to do to help patients and family members negotiate the 'firsts' of their cancer journey?

1. Professional Navigator available to explain outside supports such as social worker, legal support, financial advice, and support groups and set them up with the necessary appointments;
2. Family or support person present at first meetings;
3. Provide access to a trained survivor volunteer for patient and family support about what to expect;
4. First contact, front-line staff should be exceptionally compassionate and empathetic but still be competent;
5. Provide a tour of the Cancer Centre;

6. It should be advertised that TOH is patient and family-centred and that they are all committed partners in the cancer journey; and
7. It should be stated that patients and family are partners in the cancer journey.

Management and Treatment

What are the elements of a patient- and family-centred care plan?

1. Patient Care Navigator:
 - a. Explain diagnosis, prognosis, treatment in plain language;
 - b. Single point of contact 7 days a week;
 - c. Coordinate scheduling;
 - d. Liason between care professionals, patients, care givers (flow of medical records continuity of care);
 - e. Provide patients and families with information (specific to patient: age, gender, culture); and
 - f. Proactive approach including visiting patient at the hospital.
2. Integrate Active Support Programs for patients and their caregivers;
3. Service standard — respond to all patient inquiries within 24-hours, inform patient of interpretation of test results within 24-hours of receipt;
4. Train nurses to draw blood from PORT; and
5. Develop and provide cancer and patient profile specific decision-trees outlining treatment options, possible outcomes, potential complications.

What can the CP do to better support family members and caregivers?

1. Release form filled out by patient to allow specified family access to patient information;
2. Online information sharing through a secure website with access to treatment plan, appointments, results and medical charts (with access to care givers with patient permission) updated within 24 hours;

3. Develop seminar program to share info about psychosocial support and care giver support;
4. Institute Navigator or medical team during treatment; and
5. Allow two care givers for younger patients during treatment (especially for younger patients).

Follow-up and Support

How can the CP help family members assist and support patients following treatment?

1. Information about support and follow-up services should be made available via brochures, pamphlets, guides on TV screens in waiting rooms, on posters, and on both CC website and TOH website (Did You Know? Format);
2. Ensure the GP receives the patient's transfer summary status report following treatment upon transfer. These should include a one to two page document provided to patients and GP for review together;
3. Create a CD-ROM that includes the complete patient history; and
4. Ensure that a customized palliative care plan is developed between TOH and GP as well as the LHIN or CCAC as necessary.

What can the CP do to be sensitive and support patients handling the impact of important life changes during recovery?

1. A dedicated point person to relay info about existing internal & external resources and support groups; and
2. Referral to individual psychological therapy;
3. Create support groups for children and youth of cancer patients, younger patients (18-30) and patients going through extreme life changes;
4. Promote awareness about financial assistance available for the re-integration into employment and education; and
5. Modify financial barriers, such as transfer and/or administrative fees not covered under existing health or insurance plans.

How can psychosocial care be more effective and better integrated?

1. Follow-up pain management must be available over the long term (referral to pain clinic); and

2. Create an inclusive rehabilitation program from diagnosis to reintegration (these may include psychologists, occupational therapist, physiotherapist, gym, massage therapist).

How can follow-up programs and scheduling be improved?

1. Service standard: all follow-up appointments should be made in person prior to leaving the office after each appointment;
2. Appointment options should be more flexible to accommodate patient and family needs and schedules;
3. Coordinate same-day appointments when it makes sense for patients to see multiple doctors in one day and/or have a single appointment with the whole care team; and
4. Provide patients with follow-up reminder options such as phone call, email or mail.

What do patients and families need to achieve or sustain healthy lifestyles post-treatment?

1. Patients must receive a list of possible symptoms and side-effects to watch for and it should include all information available. List should be reviewed by patient, doctor and nurse;
2. Create point-person to contact should side-effects occur; and
3. Guide doctors to provide clear information about prescriptions, potential side-effect and hazardous combinations.

Wildcard (Additional Recommendations)

Navigator Role:

- Meets with the patient upon initial diagnosis and conducts needs assessment, including transportation, caregivers, lifestyle and lifecycle (age, etc.);
- Creates patient profile (medical and whole patient);
- Assigned to patient throughout entire cancer journey;
- Orients patients to diagnosis, treatment;
- Orients patients to each stage of cancer care; and
- Teaches patients about symptoms, how to assess their progress.

Training:

- Must be recognized by medical team (not a volunteer); and
- Social worker ++, must have medical knowledge.

Transportation:

- Increase funding and recognition;
- Coordinate pick-ups to align with treatment type; and
- Limit number of passengers.

Hospital Computer Systems:

- Integrate a single system throughout TOH;
- Create internal reminders between departments to ensure timely follow-up on test results;
- Research the creation of an online patient file;
- Secure, patient-initiated, password protected, coordinated between Patient, TOH and GPs; and
- Contains test results, appointments, prescriptions, etc.

Complimentary medicine:

- Review best practices nationally and internationally;
- Develop approval process for naturopathic oncology (evidence-based only);
- Take leadership position, inviting complimentary practitioners in dialogue with TOH; and
- Integrate complimentary medicine in all phases of cancer treatment.

Coordination of medication

- BMT model – GP part of medical team; and
- Investigate role of physician assistants.

Clinic Hours:

- Extend clinic hours to accommodate ‘real people’ schedule; and
- Investigate BMT model – smaller teams within the cancer clinic.

Preventing Recurrence and Clinical Trials:

- Education for patients and GPs on unique risks to former patients;
- Create outreach position (possibly through patient library) to connect patients to clinical trials; and
- Trials (eg: Avon Army of Women).

Scheduling

- Inform patients of estimated wait time on arrival;
- Respect that appointments involve more than just the patient; and
- Involve patients in a review of scheduling procedures.

Create rehabilitation and wellness clinic

- Nutritional info;
- Exercise, physiotherapy, massage therapy;
- Complimentary medicine; and
- Program seminars, lectures, workshops to provide info and training to patients and family members.

Walk the Talk

If TOH strives for excellence in the patient and family experience, then it must continue to involve patients and families:

- Ongoing surveys;
- Consult with patients regarding budgeting and program changes;
- Institute regular patient audit of the patient and family experience;
- Increase awareness and education to the public about the PRP process; and
- Involve the volunteers NOT chosen for the Panel to advise the next phases of the Transformation Project.

Appendix A

The physicians, staff and the Patients' Reference Panel respectively selected the values that they believed best described the current state of care at The Ottawa Hospital Cancer Program, and those they felt would ideally describe a patient and family-centred model of care. The following chart compares the responses of each group.

- Patients' Reference Panel Values Worksheet (broadside)

PATIENTS' REFERENCE PANEL VALUES WORKSHEET

Table #1	Table #2	Table #3	Table #4	Table #5	Table #6	Staff	Physicians
Compassion Efficient Humane Quality Respectful Responsive Trustworthy Warm	Capability Commitment Credibility Dedicated Expertise Friendly Individual (Silo) Integrity	Confident Dedicated Effective Efficient Expertise Safe Specialized Timely	Caring Diverse Efficient Evidence-based Friendly Supportive Timely Truthfulness	Compassion Established Expertise Innovation Responsiveness Supportive Timeliness Truthfulness	Cleanliness Cutting-edge Dedicated Dignity Efficient Evidence-based Quality Respectfulness	Compassionate x2 Teamwork x2 Accessible Accountable Advocate Commitment Dedicated Dignity	Caring Collaboration Commitment Credibility Effective Evidence-Based Expertise Practicality

Current Values

Table #1	Table #2	Table #3	Table #4	Table #5	Table #6	Staff	Physicians
Accessible Coordinated Cutting-edge Empathetic Instructive Safe Synergy Timely	Accessible Caring Community Excellence Leadership Streamlined Synergy Timely	Accessible Accountability Collaboration Compassionate Consistency Holistic Quality Timely	Accessible (Equity) Advocate Confidence Coordinated Cutting-edge Holistic Humane Quality	Attentiveness Compassionate Decisiveness Expertise Future Holistic Humane Simplicity	Accessible Clarity Collaboration Consistency Heart Responsiveness Supportive Timeliness	Accountable x3 Compassionate x2 Evidence-Based x2 Responsive x2 Streamlined x2 Coordinated Clarity Equity Inclusive	Accountable Accessible Compassionate Efficient Expertise Supportive Teamwork Quality

Patient- and Family-Centred Values

Values identified by patients, staff and physicians as Patient- and Family-Centred Values

Combined Patients' Reference Panel Patient- and Family-Centred Values	Values identified by patients, staff and physicians as Patient- and Family-Centred Values
Accessible x5 Timely x4 Holistic x3 Humane x2 Coordinated x2 Compassionate x2 Collaboration x2 Cutting-Edge x2	Compassionate Quality Supportive
Consistency x2 Synergy x2 Quality x2 Attentiveness Accountable Advocate Caring Clarity	Compassionate Quality Supportive
Confidence Community Decisiveness Expertise Excellence Empathetic Future Heart	Compassionate Quality Supportive
Instructive Leadership Safe Streamlined Supportive Simplicity Responsive	Compassionate Quality Supportive

Appendix B

The physicians, staff, and the Patients' Reference Panel respectively assessed the strengths and weaknesses of each phase of care in terms of the patient and family experience. The following pages represent the complete list of strengths and weaknesses per phase of care generated by each group.

- Stages of Care Findings: Patients' Reference Panel (broadside)
- Stages of Care Findings: Physicians and Staff (broadside)

STAGES OF CARE FINDINGS: PATIENTS' REFERENCE PANEL

Screening and Prevention

Strengths

Public Awareness: Cancer-related publicity from both government (LHIN/CAC) and non-profit sectors. Self-assessment information is useful (when accessed)

Professional Development: Hospital staff has good training on identifying and addressing risk factors and using appropriate technology to address problems early. GPs can handle biopsies, systems are becoming more focused on prevention/screening. Doctors know about new programs, how they're funded, CAC, etc.

Education: Public sector education is effective, from nutrition to behavioural factors that impact health throughout life stages

Patient focus: Family history is taken, time is taken to inform family members - in the hopes to educate and promote screening/prevention

Weaknesses

Accessibility: Several barriers to care, including socioeconomic status, no primary GP, geography, age, social support. Referrals can take a long time, potential beneficiaries fall through cracks

Stigma: More education is needed (Canada-based, most comes from U.S.). Improved advertising needed on symptoms, like stroke-related commercials (important resource)

Unreliability of follow-ups: Lacking in early stages (identifying crucial early steps). This increases risk of falling through cracks, missing out on essential care

Sensitivity: More training is needed for non-diagnostic staff

Financial barrier: Free screening should be available (cost is \$30)

Access: Difficult to gain access to specialists, people to consult about concerns

Dealing with stigma: Disincentive, barrier to access screening, treatment

Denial: Develop further efforts to reach out to those people who 'don't think it will happen to me'

Age: Limitations of reach acc. to age. Younger patients not targeted as much as they should

Assessment and Diagnosis

Strengths

Timeliness: Once problems are identified, entering the system is well facilitated. Logistics (tests, appointments) are well-managed. Developing a care plan fast is reassuring for patients.

Clear information: First appointments booked immediately, care plan is mapped (what steps to take), tailored to patient history. Referral to specialists (as needed) is prompt.

Empathy/Compassion: Making and delivering diagnosis is appropriate. Manner of speaking, behaviour is respectful, considerate

Informative: Available resources are made known, facility tour is available to familiarize with surroundings, procedures. Literature (books, pamphlets, videos) available for patient and family

Accessibility: The Learning and introduction to hospital setting is well handled, facilitated by social workers. Hospital environment is clean, welcoming, made less intimidating by staff.

The physical tour is helpful, welcoming. AGES is an excellent program

Atmosphere: light, welcoming, clean, bright — all good for introduction

Integration: putting general health and specialties in closer physical proximity is helpful

Weaknesses

Timing: Getting 'into the system' can take a long time. Tests and their analysis can take a long time

Accountability: What if someone gets it wrong? What recourse do patients have? What resources are available to patients?

Communication: Family and friends often need much more information. Medical records are inaccessible. Lacking coordination between services, phases of care. Much help is needed to navigate system and advocate for patient needs. Phone diagnoses are bad. Impersonal diagnosis leads people to not take symptoms seriously

Timeframe: Whirlwind induction: from diagnosis to treatment, much information and agency is lost in the patient perspective. These quick transitions must be helped by attention to patient and family needs

Information overload: Patients and family need more education on what resources are available. Complex voicemails are unhelpful and difficult to respond to. This diminishes accessibility, feeling of powerlessness

Attitude: patients sometimes feel they're not taken seriously, don't know how to address/handle symptoms.

Coordination: More is needed to coordinate between physical locations (as applicable).

Management and Treatment

Strengths

Timeliness: Care is regimented during treatment phase and follows a timeline

Compassionate/Caring: Care plans are detailed, comprehensive, treatment options are offered as well as their limitations and side-effects. Face-time with whole care team is very helpful. Recognizing patients and family by name is especially welcome - personalizing what can be an impersonal space

Access/visitation: Family members, friends, support groups can easily access patients and provide valuable resources/support

Referral: Automatic referral to specialists, and other relevant staff, including palliative care and home care

Communication/Services: Seminars are very useful to access support, become educated about groups (for families, patients),

Sometimes only way to learn is the hard way. Constantly dealing with strangers results in duplication, frustration, miscommunication

Quality: Patients benefit from cutting-edge research.

Weaknesses

Silo effect: Lack of coordination and inconsistency within certain phases of care (esp. surgical oncology). Patients and family need resources to address other needs (non-medical).

Financial burden: both direct and indirect (secondary costs - including parking). These are often overlooked, though remain important. Some required medications are not covered by insurance, patients can't afford them.

Face time: More time needed with entire care team: physicians, nurses, caregivers. Family needs information in order to advocate for patient. Improve access to health care staff

Accessibility: 'How-to' visit is unclear for family, friends, supporters. Can be very rushed.

Appropriateness: ex. mastectomy is not a day surgery. Side-effects, unknown consequences become large burden for family and friends.

Quality control: incorrect reading of charts, medical bracelets, lacking consistency creates big problems. ER staff should be more educated about complications of cancer care

Communication: More is needed between phases of treatment, e.g. surgery and oncology departments

Inflexible: care plan implementation often not flexible to accommodate other needs/ family schedules

Support and Follow-up

Strengths

Support Groups: Available within and outside of hospital. They make patients look good, feel better. Psychosocial oncology and survivor rehabilitation services are highly valued/appreciated.

Pain management: Education is available for dealing with pain after hospital, both individually and coordinated with caretakers and other resources

Follow-up appointments: Flexible and automatic to accommodate patient/family needs and schedules. Reminder calls, logistical support is very helpful. Personalized treatment - patient's case is known by caller, support staff.

Support: Family, friends, support groups are aided by hospital resources. Information from essential groups is available from hospital.

Information: Long-term plans are developed and discussed with patients and family. Secondary prevention is covered, as well as the identification of symptoms of treatment. Resources available: who to call for help.

Survivor Program: Good access to survivor rehabilitation plan (post-treatment)

Weaknesses

Family member needs: Extreme life challenges (divorce).

Younger patients have no help with employment, lifestyle needs (differ greatly from older patients' needs). Caregiver skills are overestimated

Financial information/support: Transfer fees, parking fees need to be modified

Volunteers & extras: Sympathy and support letters are helpful but vary depending on case. Small things count

Age consideration: support groups lacking for younger patients

Symptoms ID: list of symptoms to look for post-treatment not available, uncertainty about follow-up if symptoms show

Coordination: Should be improved for testing

Social workers: Often not as effective or well-trained as needed.

Some sort of quality control needed

Medicine: more information needed on medicines regiment, instructions

Follow-up: limited for GP, can be superficial when unfamiliar with case, consider complementary options, emphasize secondary prevention

Timeliness: unexplained delays are frequent. why?

STAGES OF CARE FINDINGS: PHYSICIANS AND STAFF

Screening and Prevention

Staff: Access to breast/colorectal screening (referral)
 Timeliness
 Good follow-up to a positive FOBT
 Automatic recall for breast and colorectal screening
 Provincial prevention initiatives - smoking cessation
 Earlier detection leads to more effective treatment
 WBHC - high risk
 PAP screening

Physicians: Dependent on Family Practitioner
 Expertise
 Free
 Reassuring

Staff: Teamwork between CAC, WBHC
 Hematology - quick to get into system on referral
 Small professional to patient ratio
 Decision making and counselling support
 Short wait times after patients have seen specialists in Hem/CAC/WBHC
 ESAS

Physicians: Teamwork between CAC, WBHC
 Timeliness improving
 Small professional to patient ratio
 Wide range of expertise
 Access to electronic charting

Staff: Patients information, education and ESAS
 Proactive management of S/E, chemo/rads
 Confidence in staff expertise
 Wait times are good
 Good, comfortable environment
 State of the art equipment/Reliability of equipment
 ISMP, PSLs to improve overall patient/staff safety

Physicians: Management of side-effects of treatment
 Prevention
 Follow-through on side effects and supportive care
 Efficiency of appointments
 nurses and physicians accessible
 Quality of facilities
 Good community support, CCAC

Staff: Access to expertise to symptom management problems (home care nurse, etc)
 Access to PSOP and interdisciplinary care available on out/inpt services
 community resources (wellspring, CCS, volunteers)
 access to long term f/u expertise at TOHCC

Physicians: Good range of services in supportive and palliative care, psychosocial oncology, complex pain clinic, pleurx and dyspnea clinic
 Systematic screening of symptoms (ESAS)

Management and Treatment

Support and Follow-up

Strengths

Screening and Prevention

Staff: Lack of access to GPs
 Limited public awareness of screening
 PSA tests
 Over-saturation of information, lack of clarity
 Limited access for most vulnerable demographics
 Inconsistency of referrals from GPs
 GPs don't have full information/knowledge
 Lack of PAP testing

Physicians: Not accessible
 Lack of information on tests, patients often confused
 No central coordination of screening
 Anxiety created by false positives, repeated tests for benign findings
 Lack of understanding regarding the limitations of testing/screening

Assessment and Diagnosis

Staff: GPs:
 Lack of access to GPs
 GPs lack knowledge of the system
 CAC is not located inside TOHCC
 Financial burden of multiple appointments, travel and parking
 Lag in biopsy/pathology results
 Diagnosis in ER is sometimes traumatic
 Lack of standard of care for diagnosis and assessment
 Access to specialists/ ESAS if not in the system
 Patients don't know what to ask

Physicians: "The worst part of the experience"
 Information not integrated
 Patients don't know what to ask
 Serial thinking - need for parallel processing
 Lag in biopsy results
 Wait time until treatment
 GP referrals to correct area
 Multiple databases - lack of results to make treatment decisions

Management and Treatment

Staff: Waiting in clinic - wait times not communicated
 Two-site model difficult to navigate
 Accessibility, continuity and consistency of team (PDIN)
 Scheduling logistics
 More efficient transfer of PT information and access to information (unconnected info systems)
 Relying on patients to transfer their info
 two-tiered system in pharmacy and daycare
 financial burden .parking and social support
 patient past experience with health care

Physicians: Waiting for chemo to be prepared and administered
 Financial Burden: Cost of some medications/care
 timeliness, efficiency in scheduling appointments.
 Multiple appointments
 Long wait in emergency
 Coordinated investigations
 Transcription slow
 Interdepartmental communication and paperwork vs electronic
 Waiting for consult
 Communication uneven with the community
 Communication: patients want a clear pathway but aren't getting one
 Palliative care an after-thought

Support and Follow-up

Staff: guidelines for physicians to guide patients
 lack of knowledge that community programs exist
 lack of coordinated care when patient is discharged
 Lack of GPs to discharge to (patients don't have GP)
 Lack of community programs (knowledge of)
 re-entry into the system
 Disconnect between cancer centre and community
 Communication and transition between cancer centre and community.
 RE-entry back to cancer center can be challenging
 No formal survival plans to guide follow-up at cancer center and/or community
 Patients not always directing their care

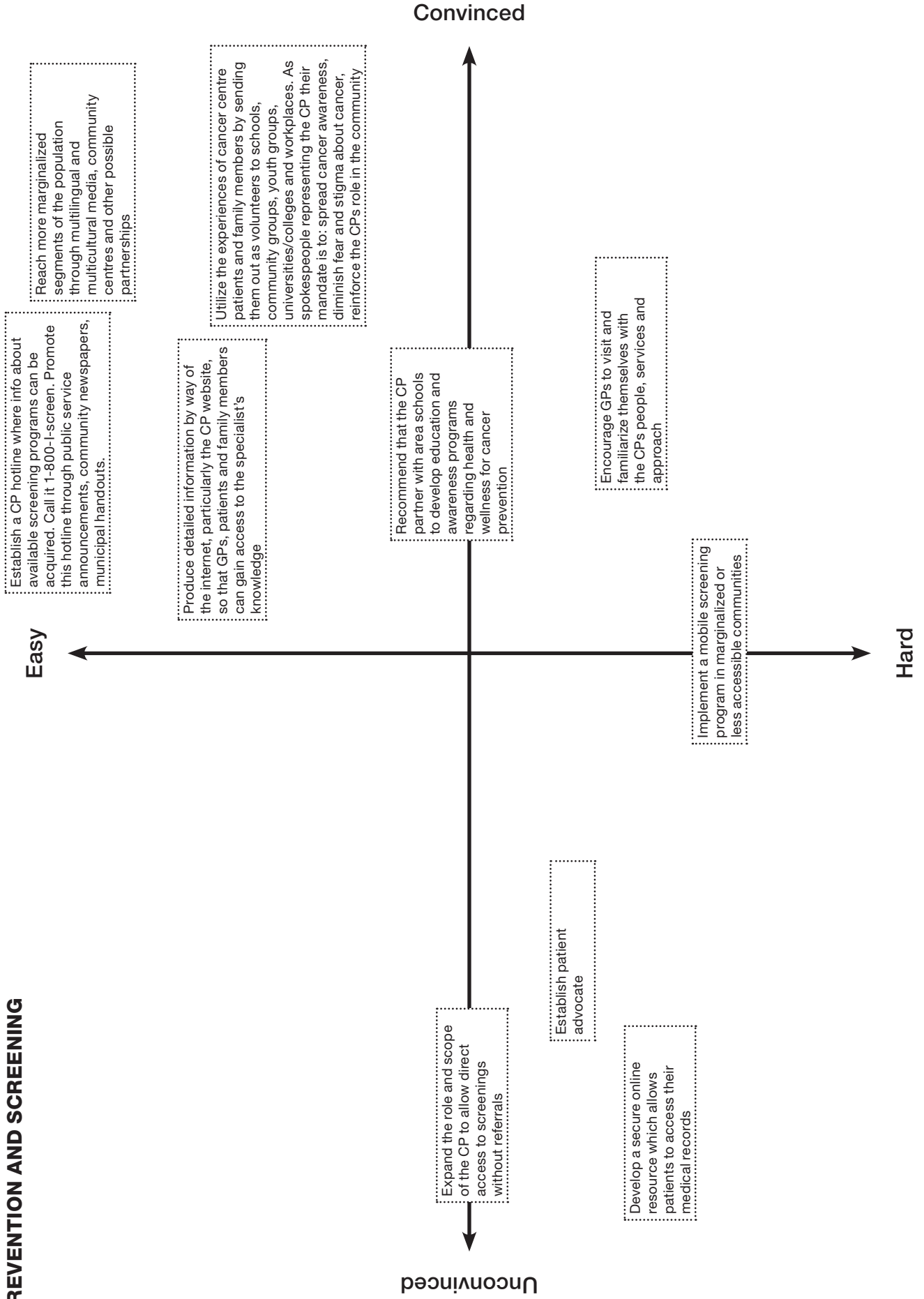
Weakness

Appendix C

At the final joint session, staff and physicians worked in groups according to phase of care to assign selected recommendations a designation along two continuums, with the X-axis representing *Convinced* to *Unconvinced* and the Y-axis representing *Easy* to *Hard*. The following pages illustrate the results according to each stage of care.

- Prevention & Screening (broadside)
- Assessment and Diagnosis (broadside)
- Managing Treatment (broadside)
- Support and Follow-Up (broadside)
- Wildcard (broadside)

PREVENTION AND SCREENING



ASSESSMENT AND DIAGNOSIS

Easy

Ensure patients have family or support person present at all meetings

Provide information that is clear, concise and in laymen's terms. Include a glossary of medical terms

Give patients clear verbal and written instructions about what to look for in terms of symptoms and side-effects of diagnostic tests, both physical and mental

State that patients and family are partners in the cancer journey

Connect patients with a trained survivor volunteer for patient and family support about what to expect

Unconvinced

Convinced

Provide a reference journal with step by step information and space for patients to record symptoms, questions, test results, appointments. Develop online option

Provide access to a professional Navigator to explain timeframes & delays, look into delays, contact patients promptly if there are delays

Professional Navigator available to explain supports such as social worker, legal support, financial advice and support groups, and help patients make initial appointments

Electronic records should be accessible to all parties - TOH, GP, patient

Hard

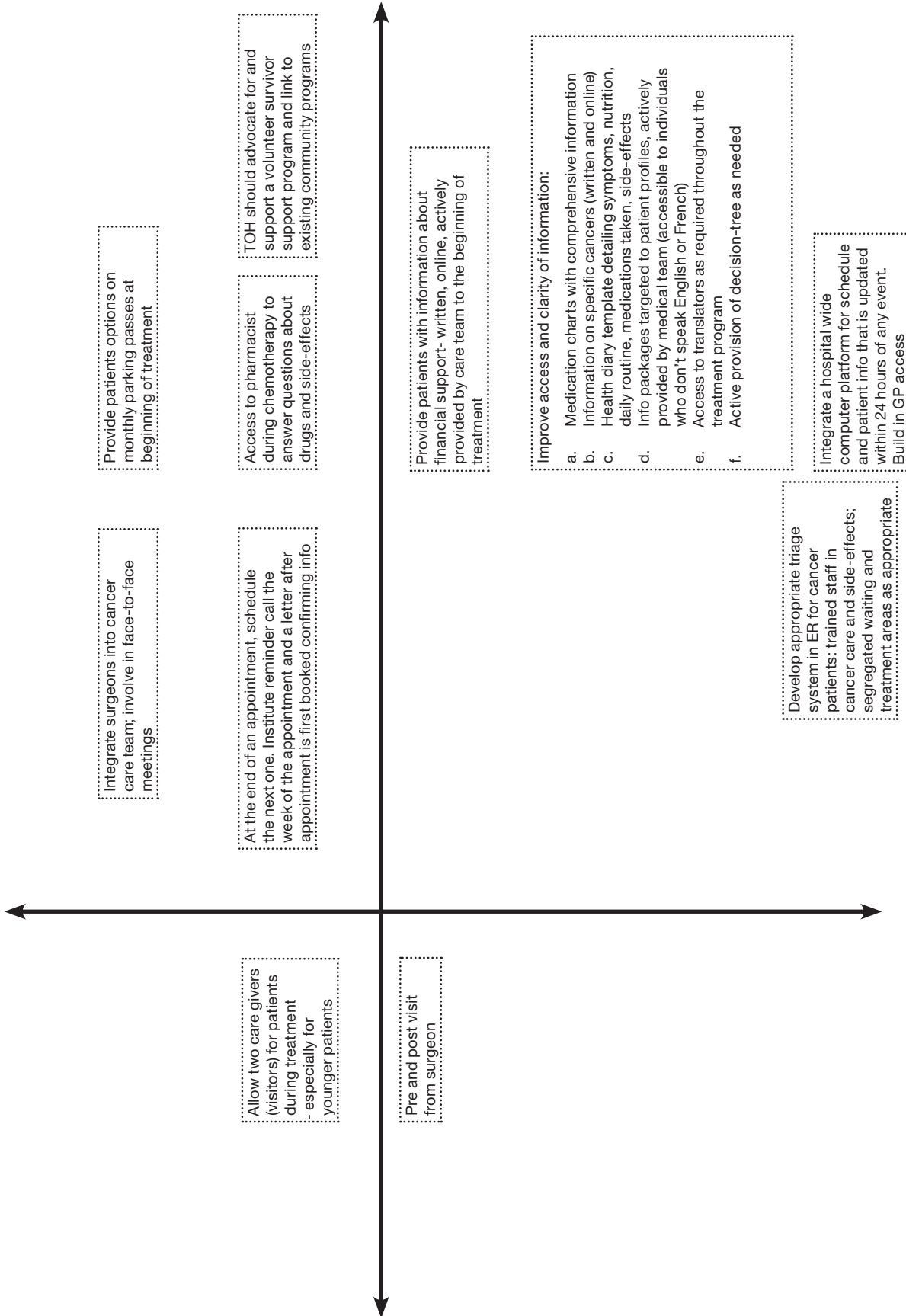
MANAGING TREATMENT

Easy

Hard

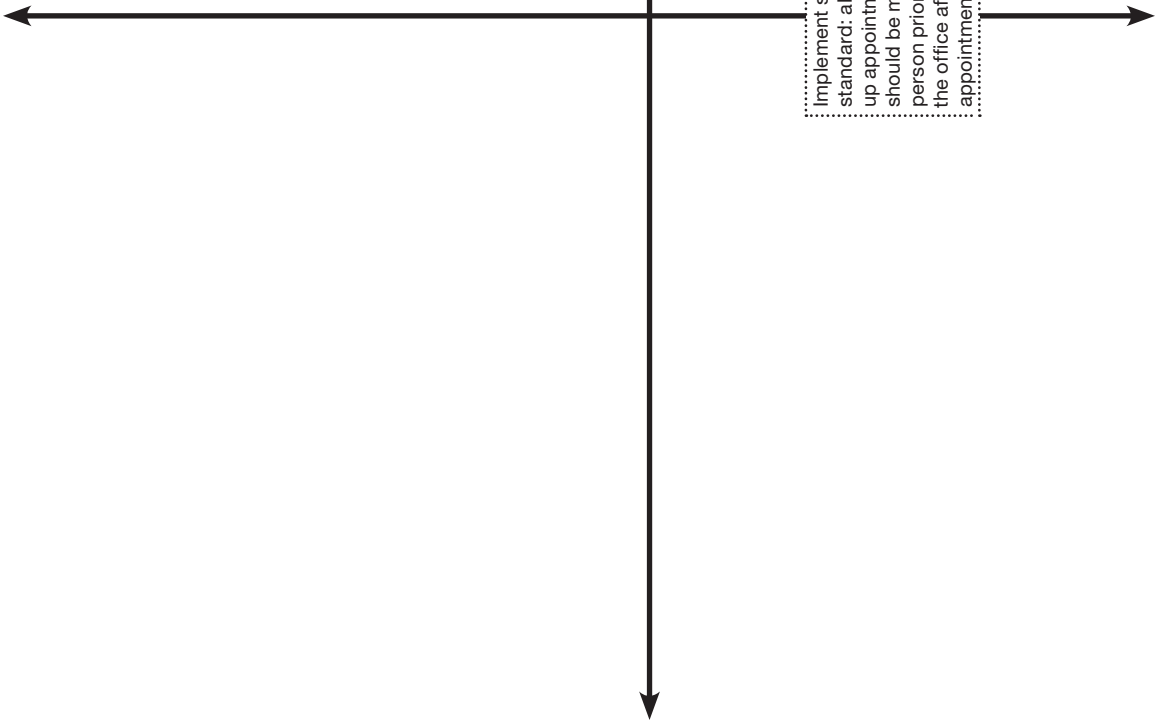
Unconvinced

Convinced



SUPPORT AND FOLLOW-UP

Easy



Engage a dedicated point person to relay information about existing internal and external resources and support groups.

Create support groups for children of cancer patients, younger cancer patients (18-30) and patients going through extreme life changes

Create an inclusive rehabilitation program from diagnosis to reintegration (this may include psychologists, occupational therapists, physiotherapist, gym, massage therapist)

Information about support and follow-up services should be made available via brochures, pamphlets, waiting rooms TV, posters, and on both CC website and TOH website (Did You Know? format)

Promote awareness about financial assistance available for the re-integration into employment and education

Ensure that a customized palliative care plan is developed between TOH and GP as well as the LHIN or CCAC as necessary

Co-ordinate same day appointments when it makes sense for patients to see multiple doctors in one day and/or have a single appointment with the whole care team

Implement service standard: all follow-up appointments should be made in person prior to leaving the office after each appointment

Ensure the GP receives the patient's transfer summary status report following treatment. These should include a one to two page document provided to patients and GP for review together

Unconvinced

Convinced

WILDCARD

Easy

Unconvinced

Convinced

Hard

Create rehabilitation and wellness clinic:

- Nutritional information
- Exercise, physiotherapy, massage therapy
- Complimentary medicine
- Program seminars, workshops, lectures to provide info. and training to patients and family members

Walk the Talk: Involve patients and families in the next phases of the Transformation Project through:

- Ongoing surveys
- Increase awareness and education to the public about the PRP process
- Involve the volunteers NOT chosen for the Panel to advise the next phases of the Transformation Project

Create outreach position (possibly through patient library) to connect patients to clinical trials (eg: Avon Army of Women)

Investigate extending the BMT model of smaller teams to the cancer clinic

Integrate a single computer system across TOH

Prevent recurrence and Promote Clinical Trials. Educate patients and GPs on unique risks to former patients

Take leadership position inviting complementary practitioners in dialogue with TOH (goal is to integrate complimentary medicine into all phases of cancer treatment)

Review best practices - nationally and internationally - on how other centres are integrating complimentary medicine into all phases of cancer care

Transportation: Co-ordinate pickups to align with treatment type and care schedule

Extend clinic hours to accommodate 'real people' schedule

Navigator Training: Must be recognized by medical team (not a volunteer); Social worker ++, must have medical knowledge

Appendix D

For the final task of the joint session, physicians and staff suggested next steps for TOH to take in the subsequent phases of the Transformation Process. They put forward specific actions to address each of the Patients' Reference Panel recommendations they supported. For those recommendations they did not support, they provided a rationale explaining their concerns.

- Prevention and Screening
- Assessment and Diagnosis
- Managing Treatment
- Support and Follow-Up
- Wildcard

Prevention & Screening	
PRP Recommendations	Next Steps/Rationale
Establish a CP hotline where info about available screening programs can be acquired. Call it 1-800-I-screen. Promote this hotline through public service announcements, community newspapers, municipal handouts	<p><i>Note:</i> Priorities were integrated into a broad programmatic recommendation; the PSPP seeks to address all of these Priorities</p> <p>Prevention & Screening Partnership Projects (PSPP) (Ministry of Public Health and TOHCC)</p> <ol style="list-style-type: none"> 1. Paula Doering to name project lead 2. Project lead to setup steering committee, consisting of community partners, general practitioners, TOHCC, public health 3. Environmental scan of existing services, jurisdictions and funding 4. Draft recommendations with patient consultation: <ul style="list-style-type: none"> • Stakeholders and possible participants (patients, nurses) • Role of public health, of TOH — guidance, ‘champion’ • Propose a funding plan (role of province?) • Program development • Outcome measures, program evaluation, research opportunities • Education of GPs • Exploring mobile screening options for marginalized groups • Exploring screening without GP referral/request • Website TOH for education • Program for orphan patients (those who don’t have GPs) 5. Final report back to TOHCC Transformation Project with suggestions for implementation <p><i>Note:</i> Role of Patient Navigator is unclear at this early stage. It is possible that Navigation is a role carried out by several people throughout the process, and not necessarily a ‘navigator person’</p>
Reach more marginalized segments of the population through multilingual and multi-cultural media, community centres and other possible partnerships	
Produce detailed information by way of the internet, particularly the CP website, so that GPs, patients and family members can gain access to the specialist’s knowledge	
Utilize the experiences of cancer centre patients and family members by sending them out as volunteers to schools, community groups, youth groups, universities/colleges and workplaces. As spokespeople representing the CP their mandate is to: spread cancer awareness, diminish fear and stigma about cancer, reinforce the CPs role in the community	
Recommend that the CP partner with area schools to develop education and awareness programs regarding health and wellness for cancer prevention	
Encourage GPs to visit and familiarize themselves with the CPs people, services and approach	
Implement a mobile screening program in marginalized or less accessible communities	
Establish patient advocate	
Expand the role and scope of the CP to allow direct access to screenings without referrals	
Develop a secure online resource which allows patients to access their medical records	

Assessment and Diagnosis	
PRP Recommendations	Next Steps/Rationale
Ensure patients have family or a support person present at first meetings	<ol style="list-style-type: none"> 1. When appointments are made, strongly encourage patients and family that a family member or other support person should be present at the meeting 2. Inform the person who makes the appointment (at the hospital) of the role of this 'support person' – so they may be recognized 3. ISIT to make paper changes
Provide information that is clear, concise and in laymen's terms. Include a glossary of medical terms	<ol style="list-style-type: none"> 1. Medical glossary would be included in the general info upon entry into TOHCC. Alternatively, a kind of journal with important information 2. All information could be in a journal that is site specific 3. Add multilingual options to this journal or glossary
Give patients clear verbal and written instructions about what to look for in terms of symptoms and side-effects of diagnostic tests, both physical and mental	<ol style="list-style-type: none"> 1. Look at current practices to see where lapses are 2. Recognize that current written and oral information might not be sufficient to accommodate language skills and level of education 3. Add online information – easily navigable 4. Specific TOH/TOHCC information sheets and phone numbers/contact information (customizable to services and care type) <ul style="list-style-type: none"> • Include what it is, what to expect, how you will feel, and what to do
State that patients and family are partners in the cancer journey	<ol style="list-style-type: none"> 1. Promote a culture shift within TOHCC 2. Use advertising, incorporate into mission statement, vision
Connect patients with a trained survivor volunteer for patient and family support about what to expect (after diagnosis)	<ol style="list-style-type: none"> 1. Review current knowledge, practice and existing programs 2. Find and train volunteers 3. Match accordingly with volunteers who have similar disease or stage of treatment

Assessment and Diagnosis	
PRP Recommendations	Next Steps/Rationale
Provide a reference journal with step by step information and space for patients to record symptoms, questions, test results and appointments. Develop online options	<ol style="list-style-type: none"> 1. Models exist already – investigate where they do, what are their characteristics, as well as what they lack 2. Transition from service to service – capitalize on what works, discourage what doesn't 3. Online development – cost, privacy considerations 4. Implementation – consistently getting out to patients
Provide access to a professional Navigator to explain timeframes & delays, look into delays and contact patients promptly if there are delays	<p><i>Note:</i> There is a lack of specificity on what should be addressed here. First, define:</p> <ol style="list-style-type: none"> 1. Roles 2. Does it resolve the problem? 3. Symptomatic of a problem 4. Are we just addressing the symptoms of underlying gap? 5. Need clearer description of systemic issues that we are trying to address 6. Identify what is being done in other centres, emulate best practice
Create a two-appointment process for diagnosis: a short initial meeting with the physician followed by a longer meeting after the patient has had a chance to confer with others and draft questions	<ol style="list-style-type: none"> 1. Create the opportunity for patients to have a follow-up visit after they receive diagnosis to ask questions as necessary <ul style="list-style-type: none"> • Recognition that people absorb information and require more information and appointments than are generally available • Improve ability to be flexible in making appointments • Offer to the patient at appointment or instruct how to book them in the future
Professional Navigator available to explain supports such as social worker, legal support, financial advice and support groups, and help patients make initial appointments	<ol style="list-style-type: none"> 1. Identify and correct process and systemic issues underlying the problems that we think require a Navigator role 2. Identify the appropriate person or professional for this role

Assessment and Diagnosis	
PRP Recommendations	Next Steps/Rationale
TOH should report back about the diagnosis to the GP and ask GP to provide relevant information to TOH	<ol style="list-style-type: none"> 1. Develop an integrated platform to ensure a timely two-way communication with TOH and GP 2. Considerations: Cost, Privacy 3. Engagement of GPs - what are their issues and processes, challenges to participate 4. If IT/IS support on both ends (integrate for consistency)
Electronic records should be accessible to all parties – TOH, GP, patient	<ol style="list-style-type: none"> 1. Provide value-specific information (tailored to target audience, i.e. GP, TOH, patient) 2. Considerations: <ul style="list-style-type: none"> • Privacy, cost, workload (increases as patients have more information, especially when there are concerns, misunderstanding, not agreed upon) • Sensitive results (biopsy shows cancer, CT shows new metrics) • Lack of mediator prior to visit, for sensitization, etc. 3. Look for best practice models that already exist

Managing Treatment	
PRP Recommendations	Next Steps/Rationale
TOH should advocate for and support a volunteer survivor support program and link to existing community programs	<ol style="list-style-type: none"> 1. Incorporate existing programs within cancer society 2. Create a database of points willing to be 'buddied' 3. Challenges: IT involved in setting up; navigator, nurse, other clinical staff roles? Part of discharge process? 4. CP already has database of 220 volunteers – expand this
Provide patients options on monthly parking passes at beginning of treatment	<ol style="list-style-type: none"> 1. Integrate with parking and security services 2. Make pay per use packs available (i.e. \$40/10 parking pass with no timeframe for expiration)
<p>Improve access and clarity of information:</p> <ol style="list-style-type: none"> a. Medication charts with comprehensive information b. Information on specific cancers (written and online) c. Health diary template detailing symptoms, nutrition, daily routine, medications taken, side-effects d. Info packages targeted to patient profiles, actively provided by medical team (accessible to individuals who don't speak English or French) e. Access to translators as required throughout the treatment program f. Active provision of decision-tree as needed 	<ol style="list-style-type: none"> 1. Translator: Model available for 24hr phone translating 3-way line 2. Consider navigator role to help with many of these issues
Integrate a hospital wide computer platform for schedule and patient info that is updated within 24-hours of any event. Build in GP access	<p>Challenges:</p> <ul style="list-style-type: none"> • Appropriate information, PAD approved - too time consuming, IT challenge. • Complexity of screening accessible vs. non accessible information? • Send 'acknowledgments' – i.e. 'we have received your message'

Managing Treatment	
PRP Recommendations	Next Steps/Rationale
Develop appropriate triage system in ER for cancer patients: trained staff in cancer care and side-effects; segregated waiting and treatment areas as appropriate	<p>Challenges:</p> <ul style="list-style-type: none"> • Barriers from outlying hospitals • Financial barriers • ER resources already strained <p>Solutions:</p> <ul style="list-style-type: none"> • Staff training in ER • Decision tree/algorithm • Committee needed to create this
Access to pharmacist during chemotherapy to answer questions about drugs and side-effects	<ol style="list-style-type: none"> 1. This is already done at multiple sites 2. Provide information on the web, part of a patient passport 3. May also be within navigator role to refer
Integrate surgeons into cancer care team; involve in face-to-face meetings	<ol style="list-style-type: none"> 1. This has been done in many places, with few exceptions (in some select disciplines)
At the end of an appointment, schedule the next one. Institute reminder call the week of the appointment and a letter after appointment is first booked confirmation the information	<ol style="list-style-type: none"> 1. This should be integrated into the online system, so that automated messages could be sent when appointments are made, as they approach, etc. (reminders)
Allow two care givers (visitors) for patients during treatment - especially for younger patients	<ol style="list-style-type: none"> 1. This is already done where possible 2. Improve communications with patients in cases where visitation is restricted (managing expectations), i.e. where safety is an issue
Pre and post visit from surgeon	<ol style="list-style-type: none"> 1. This is already done in many cases 2. There is a program in place to ensure surgeon sees patient following an operation, but it would be difficult, if not unnecessary for a surgeon to provide follow-up immediately following surgery
Institute Navigator to team during treatment	<p>Challenges:</p> <ul style="list-style-type: none"> • Clear definition of this role is needed • Training for navigator consists of what? • Who is the navigator? social worker? RN? clerk? • Financial: more staff needed for this? • Multidisciplinary model • See Sunnybrook model, BC
Initiate face-to-face seamless transfer of patient in all aspects of care	<p><i>Note:</i> Instituting Navigator may reduce the need for the patient to have as much face time with professionals; however, it remains key for the patient to see the GP regularly</p>

Support and Follow-up	
PRP Recommendations	Next Steps/Rationale
Create support groups for children and youth of cancer patients, younger patients (18-30) and patients going through extreme life changes	<ol style="list-style-type: none"> 1. Many of these already exist. We simply need to focus resources to identify them and direct patients appropriately
Information about support and follow-up services should be made available via brochures, pamphlets, waiting rooms TV, posters, and on both CC website and TOH website (Did You Know? format)	<ol style="list-style-type: none"> 1. Focus on HOW and WHY: Calling vs. mail; Explain roles and limitations 2. Create a “master schedule” – more transparent and open schedules 3. Breakdown existing barriers to access, i.e. certain services and programs (TOH vs. Queensway)
Ensure that a customized palliative care plan is developed between TOH and GP as well as the LHIN or CCAC as necessary	<ol style="list-style-type: none"> 1. Develop more “supportive and palliative care” support in the psychosocial oncology unit 2. Begin these services earlier in illness trajectory, not just “end of life” <ul style="list-style-type: none"> • Integrate earlier: quality of life palliation of symptoms • Change attitudes of health professionals • Initiatives to improve understanding of patients and families • Integrate into other clinics (tumor clinics) so that it is integrated from the beginning (in site groups) • Refer to the service or team, not an individual staff member/Dr. • Make supportive and palliative care part of the vocabulary: on signage, pamphlets from psychosocial oncology • Systemic screening of symptoms: respond to symptom issues (oncologist+PDN+scientist collaborating) • Palliative Navigator to help patients access resource in community and fully engage family physicians/primary care • Supportive Pathways

Support and Follow-up	
PRP Recommendations	Next Steps/Rationale
<p>Ensure the GP receives the patient's transfer summary status report following treatment upon transfer. These should include a one to two page document provided to patients and GP for review together</p>	<p>This includes:</p> <ol style="list-style-type: none"> 1. List of symptoms 2. Contact number for GPs and patient 3. "Discharge Pathway" 4. Review the content of this package with the GP 5. Encourage the patient to continue to see GP 6. Create more focused goals for follow-up care (questions to ask; things to look for re: needs), create questionnaire on needs 7. Ensure the treatment summary is electronic, if patient moves, etc. 8. Include treatment summary, drugs used, symptom management, psychosocial support, screening guidelines, triage number to call, access for re-entry 9. Patient education: what to do, what to expect, etc. 10. Carry out focus groups with GPs to hear their suggestions about communication 11. Develop guidelines for family MDs for regular visits while patient is treated 12. Develop a written call map at start of treatment and share with patient and GP 13. Provide GP w information on how to reach TOHCC MD or services 14. Develop survivorship, discharge summary to MD and patient for each disease site. Include frequency of follow-up, treatment to report, how to access TOHCC 15. Develop standardize letter/report for GP, highlight potential side effects of treatment and how to contact oncologist
<p>Promote awareness about financial assistance available for the re-integration into employment and education</p>	<ol style="list-style-type: none"> 1. Improve the access to a vocational counsellor ➡ links to vocational rehabilitation program need to be established from TOHCC 2. Occupational therapist and other members of PSOP have developed programs to assist with return to work challenges and financial counseling 3. Wellspring to be offering a Return to Work educational component

Support and Follow-up	
PRP Recommendations	Next Steps/Rationale
Coordinate same day appointments when it makes sense for patients to see multiple doctors in one day and/or have a single appointment with the whole care team	<ol style="list-style-type: none"> 1. Encourage health care professionals to check patient appointments when they make them and coordinate with professionals' schedules where possible 2. Refer to the service <p><i>Note:</i> Because of the rigidity of physician clinics, this can be difficult to coordinate as it may not be possible</p>
Engage a dedicated point person to relay information about existing internal and external resources and support groups	<ol style="list-style-type: none"> 1. Fits under the “Navigator” umbrella, but would also be served well by more comprehensive information network (website, brochures, etc.)
Implement service standard: all follow-up appointment should be made in person prior to leaving the office after each appointment	<ol style="list-style-type: none"> 1. In original FAQ package to manage expectations; explain time/space constraints/jobs to patient - explain roles. Use videos online, waiting room TV 2. Ask which way patient would prefer to receive information about their appointments - mail, email, phone calls. Many appointments are “after CT/MRI test” in which case we cannot make the appointment until DI gives us the appointment time, which takes a few weeks. 3. Alternative: Make patients feel more at ease when appointment are made - let them know the time as well as mailing an appointment slip. This gives more human approach, make patients feel more included
Make appointment options more flexible to accommodate patient and family needs and schedules	<p><i>Note:</i> Great in theory, almost impossible in practice.</p> <ol style="list-style-type: none"> 1. Many physicians only hold clinics 1 or 2 times per week and each day is site specific. So for a patient to see both or all physicians on the same day would require the physicians to hold more clinics. Even more of a problem at IGFCC, where most Dr.s only go one day a week. 2. Give patients more information as to why this would be very difficult to achieve

Wildcard	
PRP Recommendations	Next Steps/Rationale
<p><i>Walk the Talk:</i> Involve patients and families in the next phases of the Transformation Project through:</p> <ul style="list-style-type: none"> • Ongoing surveys • Increase awareness and education to the public about the PRP process • Involve the volunteers NOT chosen for the PAnel to advise the next phases of the Transformation Project 	<ol style="list-style-type: none"> 1. Develop and expand existing programs 2. Communication between senior management and front line staff regarding programs and new initiative implementation (small group format) 3. Establish Town Hall meetings video taped and available on InfoNet with online resources to ask questions (blog?) 4. Address problems by treatment sites
<p>Create rehabilitation and wellness clinic:</p> <ul style="list-style-type: none"> • Nutritional information • Exercise, physiotherapy, massage therapy • Complimentary medicine • Program seminars, lectures, workshops to provide information and training to patients and family members 	<ol style="list-style-type: none"> 1. Advertise current programs available in the community 2. For example: Wellspring, Maplesoft house disease specific associates
<p>Investigate extending the BMT model of smaller teams to the cancer clinic</p>	<ol style="list-style-type: none"> 1. Preserve and Protect the small multidisciplinary teams that already exist within the hospital 2. Start developing, using above system models, other disease site group
<p>Integrate a single computer system across TOH</p>	<ol style="list-style-type: none"> 1. Expertise is there but insufficient resources 2. Need: Money, IT development, implementation, research
<p>Create outreach position (possibly through patient library) to connect patients to clinical trials (e.g. Avon Army of Women)</p>	<ol style="list-style-type: none"> 1. Appointment slots for D.I. allocated and managed by disease sites within hospital 2. Use of ESAS as admission tool to refer patients to appropriate area 3. These systems should be used more - they are available, but aren't currently used enough
<p>Prevent recurrence</p>	<ol style="list-style-type: none"> 1. Promote GP refresher courses 2. Acknowledge capacity gap
<p>Navigator training:</p> <ul style="list-style-type: none"> • Must be recognized by medical team (not a volunteer) • Social worker ++, must have medical knowledge 	<ol style="list-style-type: none"> 1. Navigator is a resource person, not necessarily medical — he/she knows who will answer the patient's questions 2. Challenges: Funds, resources, location, integration in team, being accepted

Wildcard	
PRP Recommendations	Next Steps/Rationale
Extend clinic hours to accommodate the needs of ‘real people’	<ol style="list-style-type: none"> 1. Start with “Well follow-up” point 2. Extend hours into the evening to begin with 3. Ensure that if there are changes made that other supplementary services also available (e.g. DI, labs, communication with GP)
Transportation: Coordinate pick-ups to align with treatment type and care schedule	<ol style="list-style-type: none"> 1. Optimize patient and family participation 2. Manage expectations 3. More access to information for patients: internet, navigating information session immediately following diagnosis 4. Resource sheet (by PSOP SW) on its way 5. Parking validation with clinic appointment, attached to capture of visit <ul style="list-style-type: none"> • Decreases transportation problems • Decreases anxiety over wait time (i.e. parking gets more expensive with time)
Take leadership position inviting complimentary practitioners in dialogue with TOH (goal is to integrate complimentary medicine in all phases of cancer treatment)	<i>Note:</i> Very difficult to have medical teams be either knowledgeable and partnering with complimentary medical services (i.e. naturopath). Particularly with med onc/gyn onc, complimentary medicines may adversely interact with medicines we are prescribing. We do not have the training or capacity to address this expectation, perhaps we can address this expectation and align with our medical and care realities.
Review best practices - nationally and internationally — on how other centres are integrating complimentary medicine into all phases of cancer care	Specialist guidance for patients: should be unbiased, focus on managing expectations
Walk the Talk: Institute regular patient audit of the patient and family experience	Develop and expand exiting programs as appropriate
Improve coordination of medication: <ul style="list-style-type: none"> • BMT model — GP part of medical team • Investigate role of physician assistants 	One Stop Shop Model <i>Note:</i> Geographic barriers are problematic, organize disease-specific groups

Wildcard	
PRP Recommendations	Next Steps/Rationale
<p>Navigator Role:</p> <ul style="list-style-type: none"> • Meets with patient upon initial diagnosis and conducts needs assessment, including transportation, caregivers, lifestyle and lifecycle (age, etc.) • Creates patient profile (medical and whole patient) • Assigned to patient throughout entire cancer journey • Orients patients to diagnosis, treatment • Orients patients to each stage of cancer care • Teaches patients about symptoms, how to assess their own progress 	<p><i>Note:</i> Some dissent, many questions about this role</p> <ol style="list-style-type: none"> 1. Oversight and resource person, not active medical role? 2. Reduce the cost to hire navigators 3. Extensive knowledge of different resources available during patient journey 4. Someone with knowledge to ID patient needs and give resources based on this – screening for diseases, education class online for navigators

Patient Panellists

Everett Arthurs: No biography provided.

Catherine Birch: I am a breast cancer patient. I am a wife and mother to a 15 month old son named Liam. I was diagnosed when my son was 7 months old. I was the first in my family to receive a diagnosis of breast cancer. I work for the federal government in labour relations but I was on maternity leave when I was diagnosed. I was diagnosed July 19, 2010 and have been in treatment ever since. I am also participating in a clinical trial.

Wilma Burton: I live in Renfrew and am in my 3rd year of total recovery from colon rectal cancer. I work at Trinity St. Andrew's United Church as an administrative secretary. I have one son and a beautiful granddaughter.

Maria Conti: I was diagnosed with leukemia in August 2010 and had a stem cell transplant in November 2011. I am now spending my days recuperating from the barrage of chemo and radiation, hoping that my body decides to calm down and accept my sister's stem cells (she always was a little brat!).

Richard Currie: No biography provided.

Carmen DeCarufel: My name is Carmen. I'm a 39 year old woman living with NF1 and NF2. Neurofibromatosis was a name I had never heard or understood until I was approximately 16 years old. It was at this stage I started to notice tumors appearing on my body. It wasn't long after this that I was diagnosed with neurofibromatosis at Toronto Sick Kids Hospital. I'll never forget that day, coming home on the train wondering how this was going to change my life and what I could expect in the future. Fear was one of many emotions I felt at this time. For many years I was in denial; I didn't want to think about it or allow it to be real in my life. At this time this was easily done as I was not badly affected. I went on with my teenage years and tried to feel normal and knew it was only a matter of time before it would manifest into something that could be seen by all.

There came a time in my 20s that I wanted to understand NF more and be informed of the various aspects of this condition. I was beginning to realize that I could not continue to live in denial, and at that the time

had come for me to accept the condition and find positive ways to cope. This did not come easily and I still had a long way to go.

From that point on, I gathered as much information as I could from New York, as there was nothing in Ontario at the time. Once the NFSO was formed it was a huge comfort to realize I was not alone. To go to the meetings and talk with others who had NF was one way of coping.

With this condition, I was no longer in denial. But I still found it hard to cope. I met my husband in 1991 and this was the first time I realized that for those who choose to look within, I could be loved and accepted, and this gave me comfort. I began to realize that for all those strangers who were not accepting, there would be many who would be able to look past appearances and see the person within.

At this time, I decided I would have to accept the fact that not everyone would be kind or take the time to get to know the person within, but I would treasure those who did. God gave me the gift to work with special needs children and they have taught me many life lessons. They have so much love to give and they give it unconditionally. I knew that my condition was not near what they could have to cope with in their lives. I realized I had to do something positive with my life and be grateful for the blessings that I had been given.

I'm now 39 years old and have noticed a great deal of progression with my tumors. This is the turning point for me, not it is really here. People have begun to stare at me when I look in the mirror I no longer see the person I did years ago. As when I found out I had brain cancer and 3 brain tumors. This was depressing and I knew I had to do something, as I was determined not to allow my condition to rob me of the blessings in my life or stop me from living but the surgery made me more depressed as when I woke up I was deaf and blind and my face was paralyzed. Three years later I got cervical cancer, and then had ovarian cancer.

Most days are great. However, some days I still feel down but I think this is normal. I have NF and cancer but this is just one aspect of my life. I'm also a wife, a mother, with a son with NF too and ADHD. I have a sister and friends and coworkers and my spirit has chosen to enjoy all those people who can see what God sees - and that is my heart, not my outward appearance. My husband's love and encouragement

allows me to pick myself up when I am down and I know that I can go through another day.

There will be a cure, and in the meantime, I have chosen to live life to the fullest.

God bless you all, Carmen.

Daniela Decceco: I was born in Ottawa and am a management consultant. I do reviews and evaluations.

Pat Durr: I was born in the United States and went to the University of Kansas and graduated with honors with a Bachelor of Art Education, minor in English Literature. On a scholarship I did post-graduate studies in England. I met my future husband, married and moved to Canada. I taught in Montreal, then Ottawa at Algonquin College. At the same time, I established a career as a visual artist, first showing at the National Gallery of Canada and then across Canada and then in the United States. I was elected to the Royal Canadian Academy of the Arts and as a Chair of CARFAC, the National Organization of professional artists in Canada. The recipient of numerous grants and honors, my art is in public, private, and corporate collections across Canada, the U.S. and private collections in England and Israel. I have served on committees for the federal government and the City of Ottawa, dealing with the arts, arts policy, taxation and health hazards. A retrospective exhibition of my artwork will be shown at the Ottawa Art Gallery in 2012. I just celebrated my 48th anniversary and have two grown children and three grandchildren.

Edgar Godin: No biography provided.

Denise Gratton: Je suis née en 1941, fille de Gérard Racine et Eva Gagné à Casselman. J'ai un diplôme École secondaire de Casselman (1959). En 1963, je me suis inscrit un diplôme de l'Université d'Ottawa en Diététique et Science Domestique. De 1963-65, j'ai été une professeure à l'école secondaire de Casselman, puis à l'école André Laurendeau, Eastview. En 1969, je me suis mariée à Gilles Gratton Embrun. J'a trois enfants: Phillippe, Mathieu et Anne-Marie. En 1969-1996, j'ai été ue administrateure de la Clinique Vétérinaire Embrun. En 2010, j'ai soutenu ma mère de 97 ans qui a un cancer de la bouche et nécessite des traitements de radiation à la clinique du cancer de l'Hôpital Général d'Ottawa.

Josée Groleau: I was born in Montréal and moved to Sudbury at the age of one. I remember the smell of sulfur in the air in Sudbury. I remember when they had the heart institute with the best doctors as well as when they built the cancer center in Sudbury. Many people were diagnosed with one or the other illness (My aunt, lots of people who worked in the mines) I am the eldest of 4 siblings. (2 brothers and a sister) I graduated from Laurentian University and could not find work in my hometown that was the case for many of us. (At the time, the mine industry was still a major part of the economy so a lot of my generation moved out of Sudbury.) I started my career in Iroquois Falls and then with budgets cuts (the Bob Ray Days) moved to the Outaouais Ottawa region. I have always worked in Ontario as a teacher and consider myself as a French Canadian, a Franco-ontarienne. In 2000, I had a son Pascal. In 2004, I went to my annual physical like I usually do and my family doctor noticed a lump in my neck. It was news to me. I had never noticed it before. My family doctor sent me to for more testing. My thyroid gland was working normally but I was feeling tired. Was that normal? At the time I was teaching JK and Kindergarten and at the end of the day, I was tired. During all the testing all the doctors could tell me was that they had found cells that normally are neighbours to cancer cells but could not find the cancer cells. The best option was to get an operation and remove the lump. They would check to see if it had cancer cells. During the operation, they found cancer cells and the cancer had spread to the other side of my neck. They took my whole thyroid out. The operation was a day surgery. The doctors also suggested that I needed one nuclear treatment and so I did. For the treatment, I had to have a special iodine free diet. I was isolated for almost 3 days. The doctors, the nurses, the receptionist were all wonderful. I had a treatment and when I received an acceptable level of radioactive, I took a walk in the hallway. Someone died of cancer as I was taking my walk around the floor. I was going home, my cancer was all gone. I only realized then, that I was on the cancer floor. I saw pictures and paintings thanking the hospital staff. I was going home, my cancer was gone. I felt very lucky and blessed at the same time. The only doctor that had truly prepared me for the eventual cancer diagnosis was my oncologist Dr. El Sayed. The biggest problem I had was that I was misinformed about possible side effects that could happen after my surgery and before my treatment. I had lots of pain in my legs and had trouble walking. I thought then I might have developed another cancer in my legs but it was only a side effect of my missing thyroid. Today I have thyroid medication and only need to see my oncologist once a year. So being part of the panel was an honour and a way to give back. I also had the privilege to meet wonderful people who have stories worse than mine.

Jean A. Hamelin: I am sixty nine years old and a lover of wide open space, fresh air and sunshine. I still live with my wife in the house on the 100 acre farm that my grandfather bought in 1916. I had a dairy farm that I sold at age 51 on account of thyroid gland problems. A year later, after a much needed rest, I felt that I was healthy enough to buy a beef herd, then I did that until I was diagnosed with prostate cancer. Since then, I do carpentry and cabinet-making, reading and working into my fresh-lot, cutting fire wood and logs.

Dave Henry: I am qualified as a professional engineer with a career in heavy engineering. I am now retired. I have been married 42 years and have 2 children and 3 grandchildren. I have lived in Ottawa since 1979.

Nadia Herrera: I am the youngest of three daughters and am bilingual. I attended primary and secondary school in Kingston and moved here to study at Ottawa University. Ever since, I have been a resident of Ottawa and I do not plan to relocate in the near future.

Kenneth Hills: No biography provided.

Huguette Hurley: My name is Huguette Hurley, a mother of 3 children and wife of John Hurley for 59 years. I am a grandmother to five and have 3 grandsons and 2 granddaughters. I am a great grandmother to a sweet baby girl born April 30 2010. I was born in 1934 in the General Hospital in Ottawa, 1 of a family of 10 (6 girls, 4 boys). I have 4 living sisters and one living brother. My mother died in 1949 of cancer and 3 of my brothers have passed on due to cancer. The first brother passed at age 44, the second at 56 and the third at 82. I am a cancer survivor and so is my twin sister. Although I have a lot of medical issues, I'm still active and still enjoy life. Unfortunately, my twin sister has been diagnosed with incurable peritoneal carcinoma and is now living on borrowed time. I had a cardiac implant in 1981 and last February 2008 had a replacement pacemaker following an open heart surgery by Dr. Wilbur Keon. In 1999 the aortic and mitral valves were replaced with artificial ones and the pulmonary tricuspid valve was repaired. In 2005, I was diagnosed with breast cancer and due to being a poor risk, I was offered an oral treatment (ARiMiDEX) of which I still benefit. I am diabetic and treated with insulin since 1993. It caused a few more little snags as I had to be treated for renal failure and then was asked to submit to injections of Aranesp followed by infusions of iron. Since then, I have kept well in spite of being diabetic, having heart issues and cancer. I wish to offer to the whole medical team who have cared for me, their patient for all of those years, since 1993. All the doctors, cardiologists, family physicians, endocrinologists, surgeons, nurses, nephrologists, lab technicians, etc. I am hoping to atone for all of the trouble I have brought on to you all and this is a big reason for my wish to be

part of the Panel on which I can give something in return. I have been on the receiving end since 1993 and I believe that when you receive something with love and are something has to be returned. I hope that I will not disappoint you. Thanks a million.

Chris Judge: I was born in England and first lived in Canada between 1993 and 1995. I moved to Canada on a permanent basis in 1998 and became a (proud) Canadian citizen in 2005.

I have a wife who works at Carleton University and two “children” (aged 19 and 21). One is graduating from Western University (Health Sciences) this year and the other is still navigating through the “university of life.”

I have worked in Human Resources most of my career. We have lived in Toronto, Belleville and Ottawa, although Ottawa is by far the location we have felt most settled in. In the 25 years of marriage, it is the longest we have stayed in any one location.

I am a keen cyclist (I clocked 3,600 km last year) but also enjoy recreational activities such as curling and fishing. I also “learned” to cross country ski this year. I’m also a volunteer advocate with Citizen’s Advocacy.

The rest of our extended family (parents, brothers/sisters and their families) all live in England. We have no immediate extended family in Canada. I think Canada, and Ottawa in particular, is a wonderful place to live.

John F. Keddy: I was born in 1952 into a military family, so moved around a lot. I spent 8 years in France and Germany. I’ve been in 32 countries. In 1970, I joined the military myself and served just over 12 years in the Air Force, Army and Navy as Logistics and also Air Craft Safety Systems. I have flown Supersonic once in the CF 101 VOODOO and have flown in the T33 Silver Star in the back seat. I was in Golan Heights in Israel and Ismailia Egypt for almost a year. In 1988, the United Nations was awarded the Nobel Peace Prize and in 1998 the Governor General and the Queen commissioned the Canadian Peacekeeping Service Medal for those who had served in a Peacekeeping Role which is our little part of the Nobel Peace Prize. I retired from the Government after 32.5 years in 2008. In July, 2008 I got bit by a mosquito and that was right where I had the cancer which

was discovered a couple months later. Just over 2 years later, I'm still cancer free, living one day at a time.

Karl Koch: I was born in Europe, the youngest of five children. I immigrated to Canada in the early 1950s. I settled in the upper Ottawa Valley until the early 1960s, when I moved to Ottawa proper. I attended elementary school in Ottawa west and then Ottawa south. I graduated from Glebe Collegiate Institute and then from Carleton University. I was married in 1975 and had one daughter who was born in the late 1970s and now resides in California. I began a federal public service career in 1978 and retired in 2008. My hobbies include old MGs, motor-cycles and travel and I speak three languages.

Jan Langevin: My name is Jan, I am 55 years young and a very proud grandmother. In 2007, I was diagnosed with breast cancer. My parents taught me a life lesson that really motivated me...you have to take the good with the bad and work through the challenges. With the help of my wonderful husband, family and friends, co-workers and the great staff at all the General Hospital campuses, I went through three surgeries, chemo and radiation. Happily, I became a grandmother a week before I was diagnosed with cancer, and my greatest joy was visiting my new grandson when I was feeling well enough. Between treatments, I also spent time bicycling, working in my garden and taking photographs of nature and my flowers. These activities helped me through the challenging times and I realized that having cancer changed my life for the better. It made me slow down, take one day at a time and appreciate everyone and everything in my life. It has been a very positive experience for me and I believe that it made me a better person. I am sharing my experiences in the hopes of supporting others through their own personal challenges.

Dennis Lewis: No biography provided.

Don McCause: I was born in Montréal July 24, 1951, the eldest son of Donald R. McCause (sales & marketing executive with McLean Hunter) and Elizabeth R. Ferguson (graduate nurse from McGill), both in Montréal. I have two brothers, Kenneth and Stephen. I moved to Toronto in 1962 and later to Ottawa in 1981. I am the former vice president of sales for DGW Electronics (1981-2006) retiring in 2006. I was married to Suzanne Casfagne in September 1987 in Ottawa. Our only son Derek was born in February 1989 and he presently attends the University of Ottawa in his fourth year. Suzanne passed away in July from Ovarian Cancer. I'm presently a widower, involved as a cottager, art dealer/collector, stamp collector and support for my son. Some accomplishments include Queen's Scout Award, Ontario Junior Golf

Champion, President of Student Council, RSM award 1986-1991, and the Charlotte Whitton Award.

Dan Murphy: I am a 61 year old retired lawyer. I have one daughter (Megan). I was married for 38 years to Suzanne (Sue), who passed away on September 19, 2010 from a mysterious cancer of the brain.

Courtney O'Halloran: I am a 22 year old University of Ottawa graduate currently working toward the completion of the Bachelor of Education program. In the fall, I will begin my Masters in Education in hopes of one day becoming a kindergarten teacher. During the summers, I work as a lifeguard on the beaches in Barrie. In November, 2010, I was diagnosed with Hodgkin's Lymphoma, stage 2A and finished my last chemotherapy treatment on March 11, 2011. I am the first person in my family to undergo chemotherapy treatments for cancer.

Michael Street: I have been married 15 years to my wife Michelle. We have two children, Travis and Daniel. I am retired from the Pembroke Police Service. I am an avid boater and traveler and I had cancer.

Mildred (Midge) Morrison: I met my handsome husband who was a young Lieutenant just home from Korea in 1953. We were married in 1954 and had three beautiful children, one girl and two boys. We had a very interesting army life when Scott rose to the rank of Colonel commanding the Black Watch Royal Highland Regiment and then the RCR. We moved 18 times, the most interesting being sent to India where I had 5 servants. It sounds great but they were most necessary at that time! We were married for 55 years. Dear Scott died just this past April 3rd from lung cancer. He had excellent care at TOH Cancer Centre and then home care for nearly four years. After all that time, I learned many good nursing skills. There were times when I felt I could have written my RNs and probably passed with a B+.

Patti Murphy: I remain free from breast cancer after diagnosis and treatment of early stage breast cancer in 2006. The cancer journey my family and I experienced was unexpected, as I was young and had no known risk factors for breast cancer. My hope is that my participation in the Patients' Reference Panel was to have an opportunity to share her experiences to better the journey for those to come and to validate the experience with those who have already taken.

Serge Laflèche: No biography provided.

Monica Lega: I am married and have 2 children. I am a city clerk employee. I had breast cancer at age 51 and now am 6 years cancer free. The emotional aftermath never ends and psychosocial support is necessary especially after treatments.

Denis Richardson: Since returning to the hospitals Cancer Centre with my wife Karen after reference panel we have seen very much improvement already especially in the physio-oncolgy section in cancer center reception and rehab are immaculate in there explanation and attempts to bring patients physical and mental stability back to as best that can be for their individual situations.

Guy Roy: I was born in Sherbrooke, Québec and spent 37 years in the Canadian Military raising my family in many different parts of Canada and Europe. I retired from the Army in 2005 and I presently work as a Manager for Volcom Consulting Group Inc. here in Ottawa. I am married and have three children (2 girls, 1 boy) and my wife Francine and I have one grandson. I was diagnosed with prostate cancer in December 2007 and thanks to the excellent care I received from this Cancer Centre, I continue to live a normal and happy life. I am still an outpatient of the Centre and I have follow-ups every 6 months.

Catherine Searson: I am the mother of four wonderful children: Jack (10), Andrew (9), Ben (7), and Sadie (4). I have the best job in the world. I teach kindergarten. I was diagnosed with cancer in 2009. I am living well with cancer now.

Sharon Shea: I'm 51 years old and a mother of 2: Eric and Ian. Sadly, Eric passed away from cancer this past November after a 3 year battle. He was 25 years old. His brother, Ian, is 23 year old student of Carleton University of Ottawa. My husband and I live in Carleton Place, 45 minutes away from Ottawa. We will celebrate our 30th anniversary this year.

I am the Welcome Wagon representative, a national marketing and public relations service in Carleton Place, in my 21st year. I also work part time at a garden centre. We've lived in Carleton Place for 26 years, but I'm originally from Ottawa. Both my husband and I have close family there.

I enjoy cooking, gardening, renovating and reading, although those things have been on hold for the last 3 years. My son was diagnosed with a brain tumor during Christmas of 2007, with surgeries, complications, and cancer treatment lasting the first 7 months of 2008. His cancer recurred in July of 2009, with triple stem cell transplants taking him through to March 2010. His case was unique and trial

chemotherapy cocktails lasted through the summer and fall of 2010. I have been his primary caregiver; staying with him throughout each hospital stay, driving him to his appointments, as mu husband tried to work and maintain our household. With Eric's tragic passing, we're slowly going back to work.

I hope to advocate on Eric's behalf for a few changes in patient care, although his medical care was excellent.

Karen Vallieres: No bio provided

The Ottawa Hospital's Consultations on Cancer Program Transformation

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