Cancer Patient Navigation Evaluation

Final Report

Confidential

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Prepared for:

Cancer Care Nova Scotia

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Introduction

In Nova Scotia, more than 24,000 people are living with cancer, and approximately 5,200 new invasive cancers are being diagnosed each year.ⁱ Nova Scotia has one of the highest incidence rates of cancer in Canada² making it a predominant health issue for the province. A public opinion survey, conducted in 2001³ for Cancer Care Nova Scotia (CCNS) indicates that cancer has touched most Nova Scotians directly or indirectly and is considered a primary health concern.

Across Canada, the development of an integrated, coordinated cancer system that insures optimum access and continuity has been identified as a serious challenge for cancer control.⁴ There is a need to re-orient the system to comprehensive and coordinated care, improve continuity of care throughout the disease trajectory, integrate institutional and community based approaches, develop community resources to inform and support patients and balance patient and provider perspectives. Health service leaders are being challenged to develop an integrative model of care that provides access to a continuum of services, improves quality of care and reduces costs. Cancer Patient Navigation has been identified as an approach that may address problems related to integration, coordination and continuity in cancer care.

Cancer Care Nova Scotia identified the concept and need for Cancer Patient Navigation early in its mandate and commissioned research in 2000 to seek input from all stakeholders. The findings of the research⁵ confirmed that patients and health professionals saw the need for a service coordinator like a Cancer Patient Navigator. The patient navigation study and round table discussions enabled CCNS to tailor its cancer patient navigation program to meet the expectations of patients, families and health professionals.

Background

In February 2002 in collaboration with three “early adopter” health authorities, CCNS launched a Cancer Patient Navigation program. The three “early adopter” sites were: South West Health Authority (District 2), Pictou County Health Authority (District 6), and Guysborough Antigonish Strait Health Authority (GASHA, District 7).

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Cancer Patient Navigators are health professionals who are working in consultation with patients, families, physicians and the cancer centres to ensure cancer patients needs are appropriately and effectively addressed. They are assisting patients and their support networks by addressing challenges that may be unique to their particular situation or community. Patient Navigators strive to ensure both patients and their families have access to timely care and receive maximum community support.

Program Goals and Objectives

The goals of the Cancer Patient Navigation Program are to:

- Ensure cancer patients and their families have the information, knowledge, and support they need as they journey through the cancer system;
- Assist family physicians, surgeons, community-based specialists, oncologists, and other health professionals provide optimal cancer care; and
- Enhance district health authorities capacity to care and support people with cancer and their caregivers.

The objectives of the program are to:

- Develop structures and processes necessary for timely access to patient navigators in the community;
- Better prepare cancer patients and families for their cancer journey by providing information and education about their disease;
- Decrease anxiety for patients/families with cancer;
- Coordinate access to care at the provincial cancer centres;
- Increase access to supportive, rehabilitative, and palliative care services for cancer patients and families in their own communities;
- Strengthen and support the role of family physicians and community-based specialists in cancer care;
- Improve collaborative/consultative relationships among cancer team members;
- Provide a single focus point for coordination and integration of cancer services;
- Provide cancer-related expertise to health professionals in the community;
- Gather evidence to make informed decisions about improvements to the patient navigation system; and
- Improve cancer education strategies and access to cancer services for a number of diverse communities.
Evaluation Overview

An evaluation framework was developed early in the design of the program. Stakeholders were consulted to determine their expectations of the evaluation. In February 2003, the framework was peer reviewed by a panel of experts. In June 2003, Capital District Health Authority Research Ethics Board and ethic committees in two of the participating districts approved the study. Districts where ethic committees were not fully functioning, accepted the Capital District Health Authority Ethics Committee report. Following a competitive process, CCNS commissioned Corporate Research Associates Inc. (CRA) to conduct the evaluation.

The evaluation was a retrospective study conducted to:

- Clarify the role of Cancer Patient Navigator and best approaches to improve coordination and continuity of care;
- Determine effectiveness of processes used in navigation;
- Measure the impact cancer patient navigation has had on patients/families and health professionals particularly the family physician and medical oncologist;
- Measure the impact on the development, organization, and utilization of cancer services within the “early adopter” sites; and
- Describe issues relevant to implementation that should be considered as cancer patient navigation is phased into remaining health districts.

The evaluation had two key components. A process evaluation focused on understanding how Cancer Patient Navigation was implemented and operates. This involved an in-depth assessment of program activities during the development stages and operation of patient navigation during its first 18 months. The effectiveness of the structures, communication plan, referral process, orientation and continuing education schedule and reporting mechanisms that support patient navigation were reviewed.

An impact evaluation was also conducted to address whether patient navigation achieved its goals and objectives. It measured the value added to patients and families, health professionals and district cancer program development and utilization.

Methodology and Analysis

Both qualitative and quantitative research methods were used to address the process and impact evaluation questions posed in this study. Multiple stakeholder groups participated in the evaluation, including patients and families, community partners, such as continuing care services, Canadian Cancer Society staff/volunteers, physicians, other community health professionals, staff at the three tertiary cancer centers, Patient Navigators, senior leaders in the “early adopter” districts, and key CCNS staff. The evaluation incorporated both
qualitative and quantitative research methods. Data for the evaluation was collected through 16 focus groups, 57 one-on-one interviews, 162 patient surveys, and a review of 808 records in the patient navigation database.

The mixture of qualitative and quantitative data sources strengthened the overall research design by allowing for in-depth insight in the qualitative components and more precise statistical measurement in the quantitative components. Multiple data sources allow for the determination of consistency, which strengthened the evaluation’s conclusions.

Focus group discussions and in-depth interviews allow for in-depth probing with participants on a subject matter. This qualitative research method allows for more complete understanding of the segment in that the thoughts or feelings are expressed in the participants’ “own language” and at their “own level of passion.” Qualitative research is used as a means of developing insight and direction, rather than collecting quantitatively precise data or absolute measures. Due to the inherent biases in the technique, the data should not be projected to other populations.

Conversely, quantitative data is able to provide more absolute measures. The survey was conducted with a random sample of participants, which permits projection to the population of patients under study. Review of the patient navigation database, which consisted of records from all referrals, allowed for absolute measures.

The methodology and analysis is divided into several key sections including:

- Focus groups with patients and families;
- Focus groups with community partners;
- Health professional interviews (community-based specialists, family physicians, medical oncologists, community health care workers, and staff of the provincial cancer programs);
- Cancer Patient Navigators, DHA senior leaders, and CCNS staff interviews;
- A patient survey; and
- A review of the cancer patient navigation database.

To ensure all pertinent information was collected, focus group guides, interview protocols, and a survey questionnaire were developed by CRA in consultation with CCNS. Details on these different methodological components and the accompanying analysis follow.

**Ethics Review**

In June 2003, Capital District Health Authority Research Ethics Board approved a peer reviewed evaluation protocol for scientific validity and ethical acceptability. Ethics reviews were also conducted in two of the “early adopter” sites where regional ethics committees
were established. In districts without formal ethics committees, the Capital District Health Authority Research Ethics Board review was accepted.

**Focus Groups with Patients and Families**

**Design**

Focus groups were held with patients and families in each of the “early adopter” sites. These focus groups investigated patients and families’ experiences with the cancer care system, including their issues, sources of support, and their experiences with patient navigation. Two focus groups were held in a comparison district without a Patient Navigator. The comparison focus groups examined patients and families’ experiences with the cancer system, including their issues and sources of support.

A total of seven focus groups were held in the “early adopter” sites during June and July 2003. The location of the patient focus groups is as follows: two in Pictou County Health Authority, three in South West Health, and two in GASHA. Three family focus groups were also held in “early adopter” sites. In the comparison site, one patient focus group and one family focus group were held in September 2003. Table 1 provides a summary of where the patient and family focus groups were conducted by group type.

<table>
<thead>
<tr>
<th>DHA</th>
<th>Community</th>
<th>Group Type</th>
<th>Number of Groups</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pictou County Health</td>
<td>New Glasgow</td>
<td>Patient</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>New Glasgow</td>
<td>Family</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pictou</td>
<td>Patient</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>South West Health</td>
<td>Digby</td>
<td>Patient</td>
<td>1</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Yarmouth</td>
<td>Patient</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yarmouth</td>
<td>Family</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>GASHA</td>
<td>Port Hawkesbury</td>
<td>Patient</td>
<td>1</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Antigonish</td>
<td>Patient</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Antigonish</td>
<td>Family</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Comparison District</td>
<td>-</td>
<td>Patient</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Family</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td></td>
<td><strong>12</strong></td>
<td><strong>71</strong></td>
</tr>
</tbody>
</table>
Recruitment

Patients in “early adopter” sites were recruited through lists generated from the patient navigation database. Patients were sent a letter from CCNS informing them of the study and requesting that they notify their patient navigator if they did not want to participate. Patients not wanting to be recruited were removed from the list. Family members in the “early adopter” sites were recruited through a mixture of referrals from the navigators, patients and local advertisements. Patients and family members in the comparison site were recruited through referrals from community health professionals and advertisements. CRA developed a screener (Appendix B) and recruited all participants.

Participants came from a variety of communities throughout the district. They were presented with background information on the research study and required to sign a consent form. Patient and family participants attending focus groups were given a $50 honorarium to cover any expenses, such as travel or babysitting.

Altogether, 49 people participated in patient focus groups, 22 in family focus groups. Table 2 summarizes the demographic characteristics of patients who participated.

<table>
<thead>
<tr>
<th>Table 2. Patient Demographic Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Age</td>
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<td></td>
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<tr>
<td>Type of Cancer</td>
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<td></td>
</tr>
<tr>
<td>When Diagnosed</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
</tbody>
</table>
Table 3 summarizes the demographic characteristics of family members who participated.

| Table 3. Family Members Demographic Characteristics |
|-----------------|----------------|
| Gender          | Male | Female |
|                 | 23%  | 77%    |
| Age             | 18-30| 0%     |
|                 | 31-40| 10%    |
|                 | 41-50| 5%     |
|                 | 51-64| 62%    |
|                 | 65 plus| 24%   |
| Type of Cancer  | Breast| 27%   |
|                 | Lung  | 23%   |
|                 | Brain | 9%    |
|                 | Throat/Larynx| 9% |
|                 | Colorectal| 5%  |
|                 | Melanoma| 5%   |
|                 | Kidney | 5%    |
|                 | Bone   | 5%    |
|                 | Lymphoma| 5%   |
|                 | Leukemia| 5%   |
|                 | Other  | 5%    |
| When Family Member Diagnosed | Less than 1 year| 45% |
|                           | 1 to 2 years | 27%  |
|                           | 2 or more years| 27%  |
| Relationship to Person With Cancer | Spouse| 55% |
|                                | Parent  | 18%  |
|                                | Child   | 9%   |
|                                | Other   | 18%  |

**Analysis**

All focus groups were tape recorded and later reviewed by focus group moderators. The tapes were reviewed to identify emerging themes, which were subsequently classified into specific categories. Once reviewed in their entirety, the proceedings from the focus groups were then compared with the same group type (patient or family) to identify consistent themes, and determine differences. To validate these findings, two senior researchers independently analyzed focus group proceedings and where differences in interpretation occurred, discussions were held until consensus was achieved. Interpretations are supported by direct quotes from focus group proceedings throughout the key findings.
Community Partner Focus Groups

Design

Community partners are organizations involved in providing services to cancer patients. These include various organizations such as the Canadian Cancer Society (CCS), other charities, Victorian Order of Nurses (VON), Community Health Boards, and support groups. In order to obtain the opinions of community partners, focus groups were held in each “early adopter” site. A focus group was held with staff of the Canadian Cancer Society in Halifax.

These focus groups investigated community partners’ perspectives on the cancer care system in general, and more specifically on patient navigation. Participants were questioned on how the cancer patient navigation program has impacted patients and family members and their organization. Three community partner focus groups were held during June and July 2003. Each group was approximately two hours in duration. Differences in views or experiences between CCS and other focus group participants are noted in the report.

Recruitment

The Cancer Patient Navigators in each of the “early adopter” sites provided CRA with a list of potential community groups and organizations along with contact names and numbers that would be suitable for participation. Invitations were extended to these organizations via telephone. Participants were presented with background information on the research study and were required to sign a consent form.

Participants included a mixture from different organizations. Altogether, 31 people participated in community partner groups.

Analysis

Focus group proceedings were tape recorded and later reviewed by focus group moderators. In addition, participants were asked to complete a written exercise to independently record their views on the patient navigation program. The same process of identifying common themes and subsequently developing categories was undertaken. Findings of each focus group were compared with one another and commonalities and differences noted. Where differences in interpretation occurred between the two researchers, discussions were held until consensus was achieved. Interpretations are supported by direct quotes from focus group proceedings throughout the key findings.
Health Professional Interviews

Interviews were conducted with 40 health care professionals who provide services and care to cancer patients and their families in the districts. Input was received from health care professionals who provide care and services at the three provincial cancer centres; Nova Scotia Cancer Centre, Queen Elizabeth Health Science Centre, IWK Health Centre and the Cape Breton Cancer Centre. CRA recruited for the interviews from a list of potential participants provided by CCNS.

These interviews focused on health professionals’ experiences and perceptions of the patient navigation program. It examined the program’s impact on health care providers, the utilization and organization of cancer care services at the district level, and its ultimate influence on patient care and satisfaction.

Interviews were conducted in person when possible, otherwise they were conducted via telephone by one of two senior researchers at CRA. All interviews were conducted between June and September 2003. The interviews were generally between 10 and 20 minutes and were completed with a wide range of health professionals across “early adopter” sites. Table 4 provides a summary of health care professionals by occupational type.

<table>
<thead>
<tr>
<th>Area</th>
<th>Type</th>
<th>Number</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provincial Cancer Centres</td>
<td>Oncologists, Nurse, Manager/Other</td>
<td>3, 1, 6</td>
<td>10</td>
</tr>
<tr>
<td>Pictou County Health</td>
<td>General practitioner, Specialist/Surgeon, Nurses/Other health professional</td>
<td>2, 2, 8</td>
<td>12</td>
</tr>
<tr>
<td>South West Health</td>
<td>General practitioner, Nurses/Other health professional</td>
<td>3, 8</td>
<td>11</td>
</tr>
<tr>
<td>GASHA</td>
<td>General practitioner, Specialist, Nurses/Other health professional</td>
<td>2, 1, 4</td>
<td>7</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>40</strong></td>
<td></td>
</tr>
</tbody>
</table>

All interviews were tape recorded with consent of participants and later reviewed. Additionally, notes were recorded from interviews. The review of these tapes and notes permitted identification of commonalties and differences between different health care professionals, as well as between districts. Findings from all interviews were compared to identify similarities and differences. Two senior researchers reviewed the tapes and notes and where differences in interpretation occurred, discussions were held until agreement was achieved. In order to demonstrate the conclusions derived from this evaluation, direct
comments expressed by those who were interviewed are included in the detailed findings of this report.

Cancer Patient Navigators, District Senior Leaders, and CCNS Interviews

Interviews were conducted with patient navigators and senior leaders in “early adopter” sites. In addition, interviews were held with CCNS personnel involved in patient navigation. The purpose of these interviews was to understand how each district handled communications about the program and how patient navigation program had been implemented. Participants were also asked their opinions on the impact and success of the program to date, and its limitations and challenges.

Where possible, interviews were conducted in person; otherwise they were conducted via telephone. A senior researcher at CRA conducted all interviews during June and August 2003. Interviews with Cancer Patient Navigators and the Project Manager took approximately two hours per interview, while those with senior leaders and other CCNS staff ranged between 30 minutes to an hour. Table 5 provides a summary of district personnel interviews conducted.

<table>
<thead>
<tr>
<th>Table 5. District Personnel Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GASHA</strong></td>
</tr>
<tr>
<td>• Cancer Patient Navigator</td>
</tr>
<tr>
<td>• VP Community</td>
</tr>
<tr>
<td>• VP Patient Care</td>
</tr>
<tr>
<td>• Manager CA &amp; SC /PC HITH, Manager/MED Team, Coordinator of Cancer and Support Care Services</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pictou County Health Authority</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cancer Patient Navigator</td>
</tr>
<tr>
<td>• VP Community</td>
</tr>
<tr>
<td>• VP Patient Services</td>
</tr>
<tr>
<td>• VP Medicine</td>
</tr>
<tr>
<td>• Head Nurse</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>South West Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cancer Patient Navigator</td>
</tr>
<tr>
<td>• VP Community</td>
</tr>
<tr>
<td>• VP Continuing Care</td>
</tr>
<tr>
<td>• Site Manager-Shelburne</td>
</tr>
<tr>
<td>• Site Manager-Digby</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CCNS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Chief Operating Officer</td>
</tr>
<tr>
<td>• Coordinator, Education and Patient Navigation</td>
</tr>
<tr>
<td>• Cancer Patient Navigation Project Manager</td>
</tr>
</tbody>
</table>
All interviews were taped recorded and later reviewed by a senior researcher and notes recorded for the interviews. The same analysis procedure was employed for interviews with health professionals, senior leaders and CCNS staff. Direct quotes obtained during this analysis are presented in the body of this report to demonstrate the conclusions drawn.

Patient Survey

The survey consisted of 162 telephone interviews with patients, conducted between September 15 and October 2, 2003.

Questionnaire Design

The questionnaire was designed by CRA in consultation with CCNS. Prior to being finalized, the survey was pre-tested on a small number of respondents to ensure the appropriateness of the questions and response categories.

Sample Design and Selection

The sample was drawn from a list provided to CRA by CCNS from the patient navigation database. The list consisted of all patients who had received the services of a patient navigator from program initiation to June 30, 2003. Patient Navigators reviewed the lists and excluded patients who have since deceased, were identified as seriously ill or had indicated they were unwilling to participate in the study. In total, 361 eligible records were provided.

An overall sample of 162 drawn from the population would be expected to provide results accurate within plus or minus 5.7 percentage points in 19 out of 20 samples. The margin of error would be larger for analysis by subgroups (i.e., analyzing the findings by health district, age, gender, etc.) due to the smaller sample size for these subgroups.

Survey Administration

The survey was conducted by telephone from Corporate Research Associates’ data collection facilities in Halifax. Fully trained and supervised interviewers conducted all interviewing, and a minimum of ten percent of all completed interviews was subsequently verified. Up to eight callbacks were used to reach selected respondents who were not available at the time of the call to ensure an appropriate representation of patients. The average length of time required to complete an interview was 17 minutes.

Completion Results

Among all eligible respondents contacted during the interview period, the response rate was 81 percent. This represents an exceptionally high response rate. The response rate is
calculated as the number of completed interviews (162), divided by the total number of numbers dialed (361) minus ineligible numbers (25), those respondents who could not be reached during the interview period (118), and non-qualifying respondents (18). The final disposition of all telephone numbers dialed is shown in Table 6. Please note that 6 pre-test interviews were excluded, after a change was made in the questionnaire design.

<table>
<thead>
<tr>
<th>Table 6. Completion Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A. Total Numbers Attempted</strong></td>
</tr>
<tr>
<td>Not in service</td>
</tr>
<tr>
<td>Fax/Modem</td>
</tr>
<tr>
<td>Wrong number</td>
</tr>
<tr>
<td>Duplicate/Blocked number</td>
</tr>
<tr>
<td><strong>TOTAL INELIGIBLE NUMBERS</strong></td>
</tr>
<tr>
<td><strong>B. Total Eligible Numbers</strong></td>
</tr>
<tr>
<td>Busy</td>
</tr>
<tr>
<td>Answering machine</td>
</tr>
<tr>
<td>No answer</td>
</tr>
<tr>
<td>Language</td>
</tr>
<tr>
<td>Illness/incapable</td>
</tr>
<tr>
<td>Qualified respondent not available/call-backs</td>
</tr>
<tr>
<td><strong>TOTAL RESPONDENTS THAT COULD NOT BE REACHED DURING THE PERIOD</strong></td>
</tr>
<tr>
<td><strong>C. Total asked</strong></td>
</tr>
<tr>
<td>Household refusal</td>
</tr>
<tr>
<td>Respondent refusal</td>
</tr>
<tr>
<td>Mid-Terminate</td>
</tr>
<tr>
<td><strong>TOTAL REFUSALS</strong></td>
</tr>
<tr>
<td><strong>D. Cooperative Contacts</strong></td>
</tr>
<tr>
<td>Not familiar with navigator</td>
</tr>
<tr>
<td>Deceased</td>
</tr>
<tr>
<td>No cancer</td>
</tr>
<tr>
<td><strong>TOTAL NON-QUALIFYING RESPONDENTS</strong></td>
</tr>
<tr>
<td><strong>Completed interviews</strong></td>
</tr>
<tr>
<td><strong>Response Rate</strong></td>
</tr>
</tbody>
</table>
Analysis

Analysis was conducted using SPSS. In addition to overall percentages, results were compared across key characteristics. Any demographic differences are noted throughout this report. However, these differences are not necessarily statistically significant, but may be directional in nature. These differences have been highlighted because, while they may not be statistically significant, they demonstrate important trends and differences that warrant mention.

Except where noted, all results are presented in percentages and have been rounded to the nearest whole number (in some cases, the total percentage may not add up exactly to 100 percent).

Cancer Patient Navigation Database Review

At the beginning of the patient navigation program, CCNS developed a database to track all referrals made to the Navigators. Referrals tracked included those directly related to patients, as well as requests for assistance from non-patients such as family members, health professionals, support groups, or community organizations like schools. Information tracked included details on reasons for referral, the referral source, date of referral and diagnosis, cancer site, ICD oncology diagnostic code, patient characteristics (age, gender, location, address), family physician, and specialist. Issues were classified as one of three types information/education, coordination/integration or continuity. The actions taken to resolve issues was a check off box and more than one action could be taken to resolve an issue. The length of time to resolve issues was noted for workload purposes.

A data dictionary was developed and a data entry clerk completed data entry. Patient Navigators submitted completed patient data and issue logs to the Project Manager. Patient data logs recorded all pertinent demographic information about the client including reason for the referral and referral source. Issue logs tracked issues and actions required on initial referral as well as any follow up visits.

In total, 808 records were in the database provided to CRA for analysis. The analysis was conducted by CRA using SPSS. The database review covered the period from January 2002 to June 2003. In reviewing the analysis from the database, it is important to note some limitations of the database. Foremost, due to a data collection error in South West Health, non-patient client counts are inaccurate. Most non-patients were classified as patients. Furthermore, there were some inconsistencies noted during the analysis, which suggested there might be inconsistencies in the record keeping. Where problems appeared, the data was classified as missing. For some variables, namely patient type, issue type and referral type, design did not allow for multiple categorizations when multiple categorizations would have been appropriate. Therefore, these variables did not capture the full extent of the issues presented.
Report Overview

The remainder of this report includes an executive summary, summary of key findings, conclusions and recommendations. The detailed findings of the Cancer Patient Navigation Evaluation are broken down into the following sections:

- Focus groups with patients and families;
- Focus groups with community partners;
- Health professional interviews (community-based specialists, family physicians, medical oncologists, community health care workers, and staff of the provincial cancer programs);
- Cancer Patient Navigators, district senior leaders and CCNS staff interviews;
- Patient survey; and
- Cancer patient navigation database review.
Executive Summary

Results of the Cancer Patient Navigation Evaluation confirm that the program has significantly benefited cancer patients and their families in dealing with the emotional turmoil, informational needs and logistical challenges associated with having cancer. It has resulted in more efficient use of clinical time for physicians and more appropriate use of community health professionals. The program has contributed to overall improvements in the cancer care system itself by addressing problems related to integration, coordination and continuity of care. There is strong evidence to support the implementation of Patient Navigation in the remaining health districts.

This evaluation integrated information from a variety of different sources. It included 16 focus groups, 57 one-on-one interviews, 162 patient surveys, and a review of 808 records in the patient navigation database. Multiple stakeholder groups participated in the evaluation, including patients and families, community partners, such as, home care, Canadian Cancer Society staff/volunteers, physicians, other health professionals in the districts and at the cancer centers, Patient Navigators, senior leaders in the “early adopter” districts, and key Cancer Care Nova Scotia (CCNS) staff.

The evaluation confirmed that Patient Navigators have significant knowledge and awareness of the provincial cancer system and community supports and resources. Using this knowledge has played a key role in improving overall quality and consistency of cancer care in the district which has resulted in; more awareness and utilization of community supports, identification of community service gaps, increased collaboration among health care members, improved coordination between community services and tertiary centres, more consistency in cancer care, earlier referrals to oncologists and providing a new source of oncology expertise to the community. In addition to the introduction of the patient navigation program, many felt that the establishment of district cancer committees and CCNS’ direct involvement within both of these programs has served to give cancer care a high priority at the district level.

The program is meeting the expectations of health professionals, community partners, and senior leaders in the district. Patient Navigators are described as providing consistency in care by having one person from their area that is a constant for patients, health professionals and community partners throughout the cancer journey. This fulfils a supportive role for the patient, and helps provide better coordination and consistency of care in the district. Most district health professionals cannot imagine cancer care in the districts without a Patient Navigator and there is widespread support from senior leaders, health professionals and the community for the program’s continuation.

The consistently recognized benefits of navigation for patients and families include; providing emotional support, preparing them for their cancer journey, referrals to
appropriate health professionals, increasing their knowledge about cancer, helping with coordinating appointments, referral to community supports, assisting with the logistics of getting to cancer centers and finding sources of funding for medications and supplies. The results show that the Patient Navigators have become, for many patients and their families, a central contact and this assistance is highly valued. A comparison between patients’ expectations and satisfaction with the services provided indicates that the Navigators are closely matching expectations in assisting patients and families with multiple issues.

Health professionals value the patient navigation program and credit the program with; better patient preparedness, providing more support for patients, improved collaboration among health professionals, more efficient clinical involvement with patients, and identification of service gaps. Navigators have become one of the primary sources of assistance for patients, along with family doctors, oncologists, and staff at the cancer centres. It was identified that the Patient Navigator does not replace other sources of support, but rather complements and reinforces the support, information and education provided especially by physicians.

Patient Navigators were acknowledged as a source of information for health professionals, and patients and families. Navigators are identified as the linkage among different components of the health and cancer system and as educating the cancer team to be more aware of services and actions other team members are providing. This is reducing duplication of services resulting in efficient and cost effective care. The increased collaboration that has occurred was attributed to the Navigator role and physicians noted that further strengthening these linkages would serve to improve efficiencies in patient care.

Various factors have contributed to the program’s success. These include; commitment of district senior leaders, health professionals and all those involved in cancer care, extensive communications and having the right professionals in the Navigator positions. Patient Navigators need to have an understanding of cancer, extensive people skills, and be self-directed. The Navigators must also have or be able to develop an in-depth knowledge of the multitude resources available to assist cancer patients. Additionally, support from Cancer Care Nova Scotia was considered instrumental by district staff to the success of the program. CCNS’s role includes not only financial support, but also the overall vision and direction for the program, providing and directing orientation and continuing education opportunities for Navigators and coordinating the network among them.

There are a number of challenges to be addressed by the program including; encouraging a greater number of referrals; increasing the timeliness of the referrals received; and more continuous communication about navigation with health professionals. For the districts with large geographical areas, strategies to ensure equal access to the navigator should be considered. As the program moves forward, careful monitoring of the roles and priorities of Patient Navigators, along with their workloads is recommended.
Navigation has been successful at integrating institutional and community based care and effective at balancing health professional and patient perspectives. Navigators have been able to improve patients’ ability to cope with a critical illness which research has concluded is ultimately more cost effective care. Patient navigation has met its goals and the findings provide strong evidence to support cancer patient navigation implementation in the remaining health districts. All key processes and structures are in place to ensure program success and CCNS is prepared to take the program forward.
Key Findings

Key Finding 1

Cancer Patient Navigation has improved the quality and consistency of cancer care in the districts.

Community partners reported that having one person from their area that is a constant for patients, health professionals and community partners has improved consistency and quality of cancer care. This fulfils a supportive role for the patient, and helps to provide better coordination of care for health professionals. Patient Navigators serve as a linkage or interface between patients and families and the cancer care system. Community partners indicated that having a Navigator results in appropriate and timelier referrals to services for patients. They also indicated the Navigator is often the linkage for patients with provincial services.

A number of district service providers reported that their level of involvement with patients has increased especially for nurses working in continuing and palliative care settings. They reported being more aware of cancer patients’ needs and thereby providing more services to a greater number of patients.

“I have seen an improvement in care and communication with cancer patients and families from several points of view: 1) They have access to someone who will provide them with information and support as they go through their illness; 2) The Navigator has an excellent knowledge of available resources and has been providing good follow-up and referrals to appropriate people.” Community Partner

Most community partners, senior leaders and health professionals, noted Navigation has improved development and utilization of cancer care in the districts. All participants who had the opportunity to work with Patient Navigators indicated they could not imagine the district without such a position. Improvements to the district cancer system as the result of navigation include; better awareness and utilization of community supports, greater consistency and coordination of care, increased and earlier referrals to oncology, increased contact between district and cancer centre, and more referrals to home care and palliative care.

“Because she is there we are delivering better cancer care, we are providing more services to patients and there is an increased use of services.” Senior Leader

Findings from Patient Navigators, senior leaders, and CCNS staff indicate that Navigators are identifying needed community cancer resources and services, such as patient education materials, counseling, home care and palliative care. Patient Navigators bring their
knowledge and experiences to various committees and clinical rounds, extending the knowledge about quality cancer care to the community team. Findings also indicate that the Patient Navigator has become the cancer professional with the most centralized knowledge of available community resources and services. This has facilitated appropriate referrals to other health professionals and services in the community. The database confirmed 92 new referrals made to home care, 62 referrals to palliative care, 134 referrals to CCS, and 124 referrals to support groups during the first 18 months.

Senior leaders and a number of health professionals indicated, that since the establishment of patient navigation, they perceive a greater awareness and collaboration among health professionals at the district level. Health professionals are referring patients to the right resources.

“I find I am more involved than ever since the Patient Navigator because we are more aware now of all the new cancer diagnoses. The Patient Navigator has helped a lot…It has opened our eyes to the fact that these people have needs that are not being met, so we have looked at that, I have brought that up to my supervisor and the Patient Navigator and I meet with them and now we are offering supportive visits through home care Nova Scotia. The way that we do it is we give them teaching visits regarding their new cancer diagnosis. Before they weren’t offered that.” Nurse

**Key Finding 2**

*Cancer Patient Navigation is viewed as an integral component of district cancer services and there is widespread support for the program among health professionals, patients and families, and administrators.*

Participants overwhelmingly supported the continuation of the patient navigation program. In fact, when asked to rate how important it is to continue with a patient navigation program on a scale of 1 to 10 where 1 was not at all important and 10 was very important, community partners almost exclusively gave ratings of 10 (although some indicated 10 plus), while a few individuals indicated a rating of 9. The program is now viewed as an integral component of cancer services in the “early adopter” districts bringing considerable benefits to cancer patients, their families and health professionals working with cancer patients. Patient navigation is viewed by the senior leaders and health professionals in the districts not only as essential, but critical.

“*It (Patient Navigation) is so fundamental to the goals of quality, evidence-based cancer services, client satisfaction and improved primary health care in the community.*” Senior Leader
“A Patient Navigator is extremely essential to this area. Patients need this one on one support to go through their cancer journey. She relieves a lot of stress that most patients don’t need. The Patient Navigator pilot project is the best thing that has happened in this area for cancer patients.” Community Partner

Key Finding 3

Cancer Patient Navigation is fostering collaboration and communication among health professionals and reducing duplication of services, which is attributed with more efficient and cost effective care.

Forty interviews conducted with a wide range of health professionals working in the districts and at the cancer centers in Halifax and Sydney, found that the Navigators have met the majority of their expectations and in many ways have exceeded them. Health professionals expect Patient Navigators to provide assistance to cancer patients and their families as they journey through the cancer system, as well as foster communication and collaboration among health professionals. Health professionals indicated that the impacts of Patient Navigation include: better patient preparedness, more support for patients, improved collaboration among health professionals, and more efficient clinical involvement with patients.

Patient Navigators were acknowledged as a source of information for health professionals, as well as for patients and families. According to the database, health professionals and community groups looking for oncology information or education made up 24 percent of the 208 non-patient requests for assistance from the Navigators. A number of health professionals talked about Patient Navigators linking together the different components of the health and cancer system. Most felt that the cancer team was more aware of the services and actions other team members are providing. This helps to ensure that all members of the patient treatment team are aware of the patient’s status and treatments each member is providing. This can help avoid duplication of services resulting in efficient and cost effective care. This increased knowledge was attributed to the Navigator role and the physicians interviewed noted that further strengthening these linkages would serve to improve efficiencies in patient care.

“Basically I see them as a liaison between myself, the family doctor and other health professionals ensuring that the patient has a smooth ride through the cancer system and when necessary arranging transitions to other services such as palliative care.”
Oncologist

Another positive outcome of the patient navigation program is the increased collaboration and communication that has taken place between health professionals, cancer patients and their families. A number of participants referred to the Navigator as the link among health professionals, especially the family physician and the staff at the cancer centres. Each
Navigator serves as part of a cancer care team in their respective district and attends clinical rounds as part of that team. Nursing staff and other professionals including home care staff, dietitians, physiotherapists, and occupational therapists are essential contacts for the Patient Navigators to gain information and to refer patients to when required. In turn, these health professionals are sources of referrals for Navigators. Health professionals expressed the view that when a patient’s treatment team is aware of the patient’s status and the services or treatments each team member is providing, there is reduced duplication of services and more optimal care. As the program continues, collaboration and communication can be further developed.

“There is a lot more talk among health care professionals, between doctors and the staff with the Patient Navigator, there is more communication that way.” Nurse

Navigators are viewed by many as the centralized source of cancer information and education that has resulted in better use of clinical time for physicians and reduced anxiety and distress for patients/families. Family physicians and specialists reported that patient navigation has allowed family physicians and oncologists to focus on the medical issues, knowing that someone else is looking after the logistical issues.

“Since it started there is more coordination between surgeons, patients, family physicians, oncologists the whole team. There is more information sharing and families are more involved.” Nurse

Key Finding 4

Cancer Patient Navigation has become an important source of support for patients and families in dealing with the emotional turmoil, informational needs and logistical challenges associated with cancer.

Ten focus groups were held with patients/families in the “early adopter” districts to: discuss issues and challenges faced by cancer patients, identify their key supports, and share their knowledge and experiences with patient navigation. Two focus groups were also held in a comparison district, where patient navigation is not available, to identify patient and family issues and sources of supports. All patient/family focus groups identified the same issues and similar sources of supports. Patients in the comparison group felt their cancer journey might have been better if they had access to a central contact. These issues were confirmed by 162 patient surveys and findings from four focus groups held with community partners. The top four issues and concerns identified were (a) emotional impact/fear and stress, (b) dealing with physical symptoms/complications, (c) getting to cancer centers in Halifax and Sydney, and (d) coping with financial impacts.

Patient Navigators were identified as significantly benefiting patients and families by providing emotional support, preparing them for their cancer journey, increasing the
knowledge about their disease, helping with coordination of appointments, referring to community supports, assisting with the logistics of getting to cancer centers and finding sources of funding for medications and supplies. In the district without navigation, the comparison group identified the need for a central contact person as important. The database recorded 873 issues with a 94 percent successful resolution rate. The most common issues not resolved were financial assistance (25 percent) and emotional support (18 percent). No other specific issue comprised more than six percent. Patients and health professionals reported that those who were in contact with the Navigators were often better informed and less stressed. Database results indicate that 41 percent of actions taken by Patient Navigators in assisting patients involved the provision of information.

“If we had had a Navigator, it would have taken some of the pressure off because here you are trying to get information and you don’t know what avenues you have open to you, you don’t know where to go and you don’t know what’s available.” Patient, Comparison Site

“I went through it (cancer diagnosis) without the Navigator and with a Navigator and definitely with the Navigator it is easier to get through. The first time there was no support, no Navigator or anything, fear takes hold of you and you can’t get a lot of your questions answered and it is a lot more stressful, not only on the patient, but on the family and everyone.” Patient

Patients and health professionals reported that patients who were in contact with Navigators were often better informed, knowledgeable and supported. The patient survey and patient and family focus group discussions indicate that for many, the Patient Navigator has become one of the primary sources of assistance, along with family doctors, oncologists, and staff at the cancer treatment centres. It was identified that the Patient Navigator does not replace these other sources of support, but rather complements and reinforces the support, information and education provided especially by physicians.

“She’s such an advocate for people, such a vital part of care of the patients.” Nurse

“I think patients who had come to see me having already worked with the Navigator were much better prepared...because a lot of the emotional, valid concerns had been aired to some degree. They were much more ready to listen, hear, and accept the treatment plan because they had done that work already and quite frankly, they can do that work with an oncologist, that is not the problem. The problem is a cost effective one.” Oncologist
Key Finding 5

The referral process is open ended and flexible and is progressively moving forward as an automatic contact for patients with cancer.

The program developed a written referral process with options remaining open for verbal referrals. Referral sources included patients themselves, family members and health professionals. Referrals came from different sources, which indicates program awareness is spreading across key groups. As indicated by the database reviews 63 percent of referrals came from health professionals, including family physicians, 20 percent were self-referrals while family members referred 13 percent. While not all cancer patients will need a Navigator or want to see a Navigator, it is an objective of the Navigation program to have all cancer patients aware of the service. Several health professionals report that they are progressively looking toward the Patient Navigator as the automatic contact for cancer-related issues.

Navigators reported satisfaction with the referral process, indicating that as long as they get the referrals it does not matter if it is written or verbal. The ability for patients or their families to self refer is an important aspect of the referral process. In the period reviewed one-third of all referrals were made by patients or their families.

Key Finding 6

Communication initiatives about the Navigator role must be continuous and hard-hitting to ensure all are aware of cancer patient navigation.

There were extensive communication efforts undertaken to inform the public and health professionals about navigation and its services including letters to (a) all physicians, (b) community presentations, (c) one-to-one contacts, (d) an official launch in each district, and (e) development of branding materials including a logo for patient brochures and posters.

Health professionals, particularly physicians, indicated that more continuous information about the role of Patient Navigators is needed. Physicians interviewed indicated they recalled seeing information early in the program. However, most family physicians have small numbers of newly diagnosed patients per year and do not automatically think of patient navigation.
“The nature of the role (patient navigation) is such that it does require continuous advertising and you have to recognize that the average family doctor only has one to three cancer patients in their practice at any given time, so they may hear about or use the Patient Navigator service in February, but then not have any occasion to think about it for a year and so when out of sight out of mind. You can’t do a one off advertising/education process, it has to be continuous.” Specialist

“Substantial progress has been made in building program awareness. While the initial efforts were indeed intensive, this process needs to be ongoing and hard hitting to ensure it remains top of mind to everyone.” Family Physician

A key challenge is to increase program awareness so all cancer patients can experience this support. Continuous communications will be required to health professionals in particular to ensure that all cancer patients and their families are aware of Patient Navigation and are accessing the program.

**Key Finding 7**

**Comprehensive orientation and ongoing educational opportunities are necessary for the success of the program.**

The Navigator’s orientation plan is considered to be a key element in the ability of Navigators to better assist and support patients. Navigators reported it provided them with a better understanding of the process patients go through during their cancer experience and thus they are better able to provide necessary assistance to patients. The comprehensive orientation and ongoing education program established for the Navigators provided them with the opportunity to increase their oncology expertise and knowledge of the cancer system and process needed for coordination. It was an important way to be kept up to date on treatment protocols, care paths and establish credibility with the cancer team. The navigators presence at the cancer centres facilitated positive relationships with oncology staff and established buy in for the program.

**Key Finding 8**

**A network of Cancer Patient Navigators, coordinated by CCNS, is collectively a strong asset to the cancer system.**

Consensus among district personnel was that patient navigation was effective in each district. They indicated that patient navigation has been one of the most effectively implemented programs. Strong commitment from the district and appropriate support and guidance from CCNS is integral to its success.
“It is one of the most successful programs that I have ever been involved in…we thought it was going to be good, but it is better than our anticipated goals and objectives. Any other program that we have tried to do, there has been a catch, and there is a gap, or we haven’t been able to recruit the right people. In this case, none of that happened.” Senior Leader

District personnel considered the connection and support from CCNS as an essential component. They unanimously desired a strong involvement on the part of CCNS. The role of CCNS ensures that standards of practice are established and followed in each district and that accountability within each district continues. CCNS coordination and management ensures quality of care, standards of practice, and access to provincial expertise and resources to the districts. A network of Patient Navigators, coordinated by CCNS, is collectively a stronger asset to the cancer system. CCNS can assist the Navigators with education and problem solving. Navigators rely on this support network in performing their job. Education of Patient Navigators was also considered a part of CCNS’ role and one that the Navigators personally thought was particularly valuable. The guidance and standards provided by CCNS and linkages to other districts was felt to help keep the program consistent throughout the province. Having the support of CCNS staff, the other Navigators, and district staff is an important source of support to Navigators. As a provincial body, CCNS should synthesize information from each district in order to provide evidence of issues in the cancer care system that need to be addressed by government.
Conclusions

The following conclusions have been made relevant to each of the five key evaluation questions. The conclusions are supported by key findings.

Conclusion 1

The current role is matching expectations of patients, families, physicians and health professionals and there is a high level of satisfaction with the role.

Expectations for Patients and Families

In the view of patients, families, physicians, health professionals, district leaders, community partners and the Navigators, the top priority for the patient navigation role is providing education, assistance and support to patients and families. Patients/families expect Navigators to; provide emotional support, increase the understanding about their disease, inform them on what to expect, coordinate and improve access to treatment, help with the logistics of getting to appointments and finding accommodations, and assist with dealing with financial impacts such as the costs of drugs and loss of income. The patient and family focus group discussions, patient survey, and database review, consistently identify the Patient Navigator as providing support in meeting these needs. Many patients report that the Navigator’s support resulted in decreased anxiety, stress and fear.

“While I was waiting to find out whether I had to have chemo, the Navigator contacted me…. Gave me information as to what will happen, came to my home. It was very satisfactory. The literature was up to date, very informative and basic to what I needed...My contact with her was reassuring I knew that there was someone to reach out to, someone to give me information if I needed it or wanted it.” Patient
Figure 1 demonstrates the variety of assistance patients received from the Patient Navigator, as outlined by the patient survey. The survey results, along with findings from the focus groups, indicate that actual assistance received is meeting expectations.

In the survey, patients were asked to evaluate the importance of various aspects of assistance from Patient Navigators. This is presented in figures 2 and 3 below. It is clear that patients expect the Patient Navigator’s role to be multi-dimensional. The high level of satisfaction further supports that the current role is matching expectations of patients. However, dealing with financial issues and logistical arrangements are areas where assistance is not rated as strong. These are areas where Patient Navigators have little control.
Expectation of Health Professionals

The Cancer Patient Navigator role also encompasses assistance to health professionals. Based on the evaluation findings, health professionals’ expectations for the Navigator position have a high correlation with the role. The role is credited with; better preparing patients for their visits to cancer centres, helping patients with logistical issues, allowing physicians to make more efficient use of time, working with cancer centres to coordinate patients’ appointments and tests, and assisting with coordinating follow-up appointments locally. Because the role is a central contact person, health professionals have an expectation that the role could foster collaboration and communication among health professionals. Health professionals report that they are progressively looking toward the Patient Navigator as the automatic contact for cancer-related issues.

Health professionals frequently reported that patients who have received the services of the Patient Navigator were more prepared for their treatment visits. They reported that patients appear to be more aware of what to expect and what questions they should be asking. This required knowledge was seen as equipping patients with the skills and confidence they require navigating the cancer care system. Participants interviewed felt having this awareness prior to medical appointments and procedures helped to relieve some of the stress and anxiety patients frequently experience. Participants reported that navigated patients who wanted to take an active role in the selection of their treatment process appeared to be more knowledgeable. Simply knowing they have a specific person to turn to if any issues arise or if they have questions provided patients with an important sense of being supported.

“Patients and families feel they are well supported in terms of accessing the system from initial diagnosis right through.” Nurse

“I think patients are definitely more aware of what to expect, what they should be looking for, what they should be asking for, time frames for various things that should happen. I think the patients overall are much better informed.” Community Health Professional

Navigators felt their roles matched the intended functions of the position, however, a number of spin-off expectations had evolved. Navigators are frequently requested to be a member of any cancer related committee or initiative, both within the district and provincially. As the cancer care system in the districts gain momentum this could mean additional demands on Navigators’ time for activities other than direct patient care. The program needs to be a balance between committee work and patient care, given that patient care is considered the most important component of the role.
The evaluation has concluded that the Navigator role is viewed as integral to the district cancer team. The role is seen as complementary and not a duplication. Key challenges for the role are heavy workload, burnout and covering extensive geographic areas. The database information suggests that proximity to the Patient Navigators’ offices is linked to the likelihood of receiving referrals. Innovations that allow the Navigator to partner with community resources in more remote areas need to be formalized.

**Conclusion 2**

**Appropriate processes have been established in the cancer patient navigation program.**

The key processes involved in patient navigation are: communications, referrals, orientation/education, project management, data collection, and reporting. All of these processes were developed during the early stages of the program, in collaboration with CCNS, the districts and the Patient Navigators.

**Communications**

A broad program communication plan is fundamental to establish broad awareness, uptake, acceptance and credibility. Interviews with Patient Navigators, senior leaders, and CCNS staff confirm that communication was a key priority. There were extensive communication efforts undertaken to inform the public and health professionals about navigation and its services including letters to (a) all physicians, (b) community presentations, (c) one-to-one contacts, (d) an official launch in each district, and (e) development of branding materials including a logo for patient brochures and posters. Both community partners and health professionals report they felt well informed of the program, having learned of it through various and sometimes multiple avenues.

“The information is very well presented, it is very well written, it is very easy to understand for families and patients and it kind of gives them, especially when they are in crisis, it gives them something that is written that shows them that they are not alone nor will they be through this whole process.” Nurse

**Referral Process**

The program developed a written referral process with options remaining open for verbal referrals. Referral sources included the patients themselves or their families, health professionals, and community partners. Family physician referral was encouraged to enable the navigators to better support the family physician role. Patient Navigators indicated that most referrals are verbal. Attendance at various clinical rounds and chemotherapy clinics help Navigators identify potential patients. In some cases referrals sources are clinic nurses who notify navigators at the request from surgeons for automatic referral of all cancer
patients. Eighty-four percent of the 598 patients referred were newly diagnosed; fifteen percent had a recurring cancer, one percent was for other reasons. The Navigators have reached patients with various cancer types, however, patients with certain cancers are accessing the Navigators more often. Patients with breast cancer accounted for 28 percent of referrals, cancer of the digestive system 22 percent, and respiratory cancers 12 percent. Patients with genitourinary cancer appear least likely to be referred to the patient navigation program.

The average number of days between diagnosis and referral was 49. This remained relatively unchanged over the 18 months. Efforts to stabilize the consistency and timeliness of referrals are warranted. Patients reported in the focus groups they could have benefited even more from the service had they been in contact with the Patient Navigator at the time of diagnosis.

**Orientation and Education**

Patient Navigators and senior leaders view the orientation and educational opportunities for the Navigators as both comprehensive and important. The orientation included an introduction to the cancer centres, a two-day oncology workshop at the QEII, and an overview of CCNS directions in cancer care. Ongoing education includes an eight-month continuing education program in oncology through the University of Alberta, participation in conferences, and ongoing sharing of current material, primarily through CCNS.

**Program Management**

In terms of program management and accountability, each of the districts established different reporting structures. It was noted the Patient Navigators are generally self-directed and independent regardless to whom they report. They turn to various senior staff in their districts for consultation depending on particular issues and concerns. They also work closely with various medical and oncology staff to ensure appropriate care. The channels of reporting do not limit the role and working relationships. The role should be integrated with acute care, medical care and continuing care.

It is evident that there are multiple demands on Navigators’ time. Workload and time management is important and there appears to be room for efficiencies. The Navigators in each district indicated the amount of paperwork required in their role is a frustrating aspect of their job, as there is a lot of duplication. Their suggestion is to reduce duplication or to have appropriate clerical assistance.
Database

A database was developed for the program to track information on referrals and actions taken to resolve issues. This database provides an important source of continuous information that can be used for quality improvement for the program over time. The lessons learned from the early stages of the database design and use should be used to develop a more robust system.

Conclusion 3

Cancer Patient Navigators have had a positive impact on patients/families, health professionals and has resulted in improved community cancer care.

Survey and focus group results confirm that patients are experiencing a multitude of challenges following a cancer diagnosis. The emotional impact and fear of the diagnosis are the primary concerns. Other issues and concerns identified through the patient telephone survey and focus groups include physical symptoms/complications, travel to cancer centres, and financial concerns, among others. Figure 4 captures the issues and concerns of patients, as outlined in the patient survey.

![Figure 4. Issues and Concerns During Cancer Experience](image)

Source: Patient Survey

Health professionals identified a number of improvements that have occurred with the implementation of patient navigation. These include: (a) better patient preparedness, (b) more patient support, (c) improved communication and collaboration among professionals, (d) more efficient physician involvement with patients, and (e) identification of service gaps.

A number of family physicians and oncologists reported that the patient navigation program has helped them focus on cancer patients’ medical issues. They explained that they are
not necessarily more or less involved with a patient, but rather the focus of their involvement has changed. They can focus more on the medical aspects of cancer patients’ diagnosis and spend less time discussing logistics such as how to book appointments or where to go for tests. These physicians indicated Navigators help patients deal with the psychological aspects of having cancer, as well as assists them with such things as booking appointments, finding transportation and accommodations, and finding financial aid where necessary. This allows physicians to focus specifically on their medical area of expertise and was seen as being significantly more cost and time effective.

“It hasn’t changed the level of involvement. What it has changed is the nature of the involvement of a given visit. So the involvement may be more focused on treatment related issues or relapse specific issues or disease specific issues, as opposed to practical issues. I can sit there and talk to them about how to arrange a drive to their appointment, but that is a very, very expensive use of my time.” Specialist

“It certainly has eased the amount of time that I have to spend with a patient on non-clinical issues and my secretarial time with patients having to describe where to go, when to go, procedures for follow-up with the specialists. It’s been a boom in terms of time efficiency.” Family Physician

The Navigators are the central linkage when dealing with concerns outside of the cancer diagnosis and treatment. Patient Navigators, with their extensive knowledge of the cancer care system, can better coordinate care for patients, eliminating unnecessary trips to the province’s cancer centres. This has decreased the burden patients face in arranging transportation and accommodations when they must travel to receive treatment.

The financial impact of a cancer diagnosis is identified as an issue needing patient navigation assistance. Patient and family focus groups, patient surveys, and interviews conducted with health professionals and community partners identified that Patient Navigators have been effective in helping many patients and their families access available funding sources and lobbying on behalf of patients. They are credited with discovering methods of accessing financial assistance that were previously not known to health professionals and the general public. The patient survey, found that 67 percent of patients were satisfied with the level of assistance the Navigator provided with financial issues. According to the database, Navigators were unable to resolve financial issues 25 percent of the time.

The findings of this evaluation indicate that patient navigation has also helped increase access to supportive, rehabilitative, and palliative care services for cancer patients and families in their own community. The Patient Navigators referred 62 patients to palliative care, largely in Pictou County Health and in GASHA where formal palliative care programs are established. South West Health did not have a formal Palliative Care Program during the evaluation period.
Findings indicate Patient Navigators are effective at coordinating the logistics of accessing the cancer system. Results indicate physicians, in particular family physicians and oncologists, do not have the time to do so nor are they fully aware of all the resources which can assist patients.

**Conclusion 4**

*The program has been successful at bringing notable benefits to the development and utilization of cancer care in the “early adopter” districts.*

The evaluation considered the impact patient navigation has had on the development, organization, and utilization of cancer services. Those who participated in the community partner focus groups, along with district personnel, and health professionals indicated the program has been successful at bringing notable benefits to overall cancer care in their districts, including more awareness and utilization of community supports, identification of service gaps, increased collaboration among health care members, improved coordination of community services, and a new source of oncology expertise to the community. In addition to the introduction of the patient navigation program, many felt that establishment of district cancer care committees and CCNS’ direct involvement within both of these programs has served to give cancer care a higher priority at the district level.

A spin-off benefit of patient navigation, highlighted by a number of health professionals and leaders, was the identification of service gaps that exist at the district level. Service gaps frequently cited by participants included the financial burden, from the cost of prescription drugs and medical supplies to the cost associated with travel and accommodations and lack of support groups and in one district the lack of a formal palliative care program. While many acknowledged that the Patient Navigators have been very resourceful in addressing these issues, it was felt that more system-wide attention is needed to address patient financial burdens and palliative care services. The districts have begun to explore identified service gaps and are working on solutions to address them.

“They have been able to feed back into those district cancer committees some of the gaps in their own districts and from the general discussions that we have had at different venues, you can see where these districts are taking this information and trying to move forward in improving things within their district. So I think they have been very instrumental in their districts in identifying the gaps and the things they need to improve.” Community Health Professional

Health professionals, senior leader participants as well as those who participated in the community partner focus groups acknowledged that the patient navigation program was still in the early stages. While many improvements have taken place in terms of the development and organization of cancer care services at the district, participants felt that as
the program grows, more services will be established to meet the needs identified and as a result, the system will become more cohesive.

Conclusion 5

**CCNS leadership, district commitment and good communication are needed for successful implementation across the province.**

The evaluation has served to highlight important considerations as the patient navigation program is implemented in other health districts. There is widespread support for continuation of the patient navigation program among district staff, health professionals, community partners, and patients and families. The patient navigation program is now viewed as an integral component of cancer care services in each of the districts that were involved in early implementation.

There are a number of key elements identified for program success. These elements include:

- Strong commitment from the district to the program including commitment from clinical, continuing care and medical services;
- Recruiting a professional with the right skills and personality;
- Ongoing communication;
- Good working relationships and linkages with health professionals;
- Comprehensive orientation and ongoing educational opportunities; and
- **CCNS** leadership and expertise.

District personnel explained that support for the program has to be established among senior leaders and the board. They indicated it is important to build support from various community partners, citing that buy-in contributes to program success. A number of district personnel observed that more champions for the program, in the physician community, would facilitate greater awareness and buy-in from this key target audience.

Finding the appropriate person to fill the position was also deemed critical. Patient Navigators need to have the right knowledge and skills to be effective in the position, but they also need to have the right personality fit and level of dedication to make the program effective. They also need to be knowledgeable about community resources, about cancer and its treatment and be an effective educator. The position requires the ability to be self-managing in terms of the potential workload issues.

There needs to be linkages and working relationships with others in the district involved in cancer care. Patient Navigators must understand other health professionals’ roles and make appropriate referrals. Good relationships and familiarity with the Patient Navigator will facilitate referrals.
District personnel considered the connection and support from CCNS as an essential component. District personnel unanimously desired a strong involvement on the part of CCNS. This ensures the continued coordination and management of quality of care, standards of practice, and access to provincial expertise and resources to the districts. A network of Patient Navigators, coordinated by CCNS, is collectively a stronger asset to the cancer system. CCNS can assist the Navigators with education and problem solving. Navigators rely on this support network in performing their job. Education of Patient Navigators was also considered a part of CCNS’ role and one that the Navigators personally thought was particularly valuable.

Key challenges for the program include increasing the number and timeliness of referrals. The flexible referral process from multiple sources reduces the chances of patients being missed. More automatic referrals are also recommended to circumvent this issue. For GASHA and Southwest Health, the sheer geographical size of their district is a challenge. Strategies to ensure access across districts to patient navigation services should be considered. As the program moves forward, careful monitoring of the roles and priorities of Patient Navigators, along with their workloads, is recommended.
Recommendations

The following recommendations are put forth based on the findings from the Cancer Patient Navigation Evaluation.

- The Cancer Patient Navigation Program should be implemented in the remaining health districts taking into account the key issues identified.
- CCNS should continue to take the lead in supporting and coordinating the patient navigation network.
- The responsibilities and priorities of the Cancer Patient Navigator must be clearly defined.
- The workload of the Cancer Patient Navigator must be continuously measured to determine appropriate balance, reduce administrative duplication, and provide appropriate clerical support where possible.
- The Cancer Patient Navigation Program should continue to address the spectrum of patient concerns and issues.
- Actions to increase the referrals rates should be undertaken.
- Consideration should be given on how to increase access to patient navigation services that ensures availability across all areas within districts.
- Ways in which patients with less frequently referred diagnoses can be reached should be considered by identifying particular sources (e.g., clinics, support groups, etc.) that could be targeted to better inform patients with different cancer types.
- The database should be redesigned to be more robust.
- Data entry by the Navigators should be considered to ensure consistent classification and data entry and to reduce the paper work.
- Communications about patient navigation with family physicians, community-based specialists and oncologists should be an ongoing process to ensure all cancer patients are aware and can benefit from the services of a Navigator.
- There is a need to work closely with community groups, organizations and agencies to ensure that access to cancer care resources at the district and provincial level are being utilized to their maximum capacity.
- Information gathered through the patient navigation program about gaps in required services and assistance in cancer care should be compiled and shared with the appropriate authorities.
Patient and Family Focus Groups
Detailed Findings

This section describes the findings from the 12 focus groups conducted with patients and families. In the “early adopter” sites, seven groups were held with patients and three with family members. In the comparison site, one group was held with patients and one with family members.

In “early adopter sites” participants were asked about their own or their family member’s experiences throughout their journey with cancer from the time of diagnosis to the present. They were asked to discuss the issues and challenges they faced, the key supports and their knowledge and experiences with patient navigation. Comparison site focus groups were asked to discuss issues and challenges and key supports.

Issues and Challenges

**Patients not only face challenges of emotional distress and physical discomfort during their cancer experience, but also challenges of financial burden, difficulty finding information, and coordination of their care.**

Patients and their families indicated there are a number of issues and challenges they encountered during their cancer experience. These included the emotional impact associated with cancer, lack of information, financial difficulties, wait times for appointments, and coordination of their care. These issues and challenges were similar across districts, both in the “early adopter” and comparison sites.

The **emotional impact** associated with a cancer diagnosis was a key issue for participants. Participants commonly described their reaction to their initial diagnosis as one of shock and numbness. They indicated it often took them some time to process information after initial diagnosis due to the intensity of their emotional reactions. For some, the emotional distress was such that they reported feeling depressed and had thoughts of suicide.

"When you hear the word cancer it is like a two-by-four hits you and your doctor is talking to you, but you don’t know what she is saying.” Patient

"That was one of the worst days of my entire life.” Patient

The anxiety also continued throughout the journey for many participants. They commented they often experienced fear in anticipation of various procedures such as surgery and chemotherapy. Some reported they experienced emotional distress after active treatment, as they tried to readjust to “normal” life. For family members, there is also the stress of being a primary care provider. They explained that sometimes providing care could be very exhausting.
“Like they tell you, you have cancer and there was no support at the start, there was support afterwards.” Patient

“You’re so busy handling the cancer…when that is over they say just go back to your life…well I quit most of my life.” Patient

The approach of health professionals in informing patients about their diagnosis added additional distress for some patients and family members. Some felt that they were not told of their diagnosis in a compassionate way, as the health professional used blunt language and did not offer them any hope. Some were also told of their diagnosis over the telephone rather than face-to-face. Others commented that doctors did not seem to know how to address the distress experienced by their patients nor did they understand the impact that the diagnosis had for individuals. In some cases, participants felt health professionals were trying to remain emotionally uninvolved from their patient, perhaps because it was difficult for health professionals to deal with someone who may be dying. Other participants indicated their doctors were exceptional supports for them, taking the time to ensure they understood their diagnosis, being very compassionate toward them, and indicating they were available at any time.

“There’s a fear of giving you false hope, so they take away all hope.” Patient

“Some doctors have a better bedside manner than others, you don’t have to sugar coat it. I like to be told upfront, but have some sympathy for you, some compassion.” Patient

The physical pain and discomfort associated with cancer and its treatment were also issues that patients and family members had to deal with. Participants explained that the pain and side effects associated with treatment including hair loss, swelling, and weight loss had to be endured. Some patients required surgery, which in some cases led to physical disfigurement, which they had to cope with. Breast cancer patients in particular indicated that the loss of a breast was difficult to accept. Family members were sometimes not prepared for the physical changes of loved ones, especially after major surgery and this was distressing for them and the patient.

Many participants also indicated that lack of information was a critical and frustrating issue for them. Some participants felt they lacked information on their diagnosis and what to expect in the cancer journey. In many cases, participants indicated that things were not really explained to them until they had their first visit with their primary cancer care provider, for example the oncologist or surgeon. However, in the “early adopter” sites patients had often received assistance from the Patient Navigator prior to their visit to their primary cancer care provider.
Some participants who had a diagnosis of breast cancer cited the pink rose package as a useful resource for them. However, such a resource does not exist for many other types of cancers, and participants with other types of cancers commented they felt they would have benefited from such a resource.

“It would have been helpful to have a little bit more information about it.” Patient

“I don’t think I was prepared for what was going to happen.” Patient

“I found the first time I was diagnosed (1984) there was no information and support, the second time I was diagnosed that was in place. I knew what to look for.” Patient

Participants were mixed in terms of whether they were given information on treatment options. Some participants indicated their physician explained the treatment options to them and included them in the decision making process. Others indicated they were simply told what treatment they would have, albeit some acknowledged that there was only one treatment option available to them. Some participants also commented that their physicians seemed reluctant to share negative information with them, which was frustrating, as they wanted to fully understand their diagnosis and prognosis. Others indicated their physicians were mostly upfront and forthcoming with information.

“I had no discussions. There was a real lack of communication [with doctor], and the suggestions I made were totally ignored. I was simply told what I was having…we later found out that the procedure I had was totally inappropriate for me.” Patient

“I was told what I had and that was it.” Patient

“You don’t know what you are supposed to do.” Family member

“There are things that I would like to tell other people, like don’t go and have the breast removed. I know it is shocking and scary, but I don’t believe it is always the thing to do. There are new ways and they don’t always do them.” Patient

Some patients did not feel prepared for treatment despite having been informed about what to expect. They explained that they still experienced a great deal of anxiety and fear about what would happen. It was also indicated that while the doctor may explain to them what would happen, they would have liked to have had more written information to refer back to when they went home. Participants explained that it was difficult to absorb all the information during their visit.

“They try to make sure you understand, but you need something to refer back to sometimes, when you are sitting at home.” Family member
“He is a good doctor, he has been good to me. But I would have liked to talk to other health care professionals or even have concrete information that I could read myself and at that time, there was really nothing available.” Patient

While many recognized they could call health professionals if they had any questions, there was a sense that health professionals were very busy. Those who had been in contact with the Patient Navigator at this point indicated they were more comfortable contacting her. They recognized that her job involved helping patients find information and they did not feel that they would be bothering her, as they would other health professionals.

“They sat down and explained everything to me, what would happen, and all the side effects, but I was still scared to death.” Patient

In contrast, individuals in the comparison site indicated they did not have a local person to contact for questions. They felt this was a much-needed resource.

“I can’t say that anywhere I wasn’t treated well, but it left you sort of disconnected…if I had a question, the nurses in Halifax are so busy…if I had somebody here that I could talk to, it would be much easier.” Patient, Comparison Site

Many participants felt they lacked information on logistical aspects. This includes who to contact to find out about next steps or appointments and where to go to obtain assistance for things such as financial support, accommodations during treatment, and transportation to health facilities. Participants indicated they often found out about some of the assistance available to them haphazardly through conversations they had with other patients or with health professionals.

“The biggest problem I had was finding information on financial support, information on the disease.” Patient

“You get frustrated running around trying to find out things.” Family member

“It’s unfortunate that all these resources are out there and you are not consistently told about them.” Patient

For many participants, the financial worries associated with cancer placed considerable additional stress on their cancer experience. Participants described how the cost of drugs was often way beyond their means. Travel was an additional expense that posed a financial challenge for some participants. Participants who had to give up their jobs experienced a loss of income. They explained that financial implications could, in some cases, be more traumatic than the actual diagnosis. Participants indicated the criteria for qualifying for assistance are too restrictive. As a result, many people fall through the cracks and are unable to obtain assistance.
“It wasn’t something we were prepared for financially, we just didn’t know.” Patient

“Treatment is the easy part, it’s dealing with all the other stuff, financial, that is the hardest.” Patient

The lack of coordination among various health professionals was identified as an issue. Some felt that all professionals involved in their care did not seem to know what the others were doing. Participants commented they often had several appointments in Halifax that were not necessarily on the same day. They also indicated that not all professionals involved in their care were fully informed of what was happening with them. This is particularly the case when it comes to their family doctors, who some indicated were often not kept up-to-date after the initial diagnosis.

“My family doctor was the last person to know what happened to me.” Patient

“I think it starts with the family doctors, there is a major loophole. I feel like my husband’s doctor is now in Halifax, it shouldn’t be that way.” Family member

“I was sent home from the hospital with no post-operative care, no appointments.” Patient

Some patients experienced confusion once their treatment was completed regarding whom they should be in contact with and what to expect. A few participants indicated they did not have a family doctor. They felt this presented additional problems in terms of getting an initial diagnosis, getting referrals to specialists, and in follow-up treatment. Some also indicated they did not always see the same oncologist, which led to challenges in building a rapport with one health professional.

Distance from major cancer care facilities is also a major challenge for people, particularly those in districts further from Halifax. While access to chemotherapy services in local health facilities helped reduce the burden associated with traveling for care for some, many participants explained that the drive to Halifax, and to Sydney in the case of GASHA participants, could be difficult. Some participants expressed the drive could be difficult when they just had surgery or were receiving treatment, as they were often uncomfortable. Many participants indicated that frequent trips to Halifax for treatment could be very trying due to the length of the drive, while others had challenges in finding transportation. Due to the distance, many participants were required to find lodgings in Halifax during their stay. The Lodge that Gives and Point Pleasant Lodge were found to be very helpful. Several participants indicated they did not know how to access these facilities and some did not even know they existed when they were mentioned during the groups.

“Going to Halifax, they think you live next door. I think they can schedule your appointments later on rather than 9 o’clock in the morning.” Patient
“The hardest part for me was being away from my family, because I had three small children and I had to be in Halifax Monday through Friday. It was very difficult to be away from home and they were afraid and it was really hard.” Patient

In relation to travel, many participants were not familiar with Halifax and found it stressful to find their way around. This also pertained to finding their way around the QEII Health Centre.

“It’s sort of daunting going round and round.” Patient

Wait times are also an issue, both leading up to treatment and waiting for appointments at the cancer centre. Waits for diagnostic testing were a predominant concern. Many felt that if the appropriate tests were done at an earlier stage then perhaps the cancer would not have progressed to the point it did.

Table 7 summarizes the key issues and challenges identified by patients.

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<thead>
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<th>Table 7. Key Issues and Challenges</th>
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<tr>
<td>➢ Emotional impact</td>
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<td>➢ Approach of health professionals</td>
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<td>➢ Physical pain and discomfort</td>
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<td>➢ Lack of information</td>
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<td>➢ Financial impact</td>
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<td>➢ Coordination of services</td>
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<td>➢ Distance/Travel/Accommodations</td>
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<td>➢ Wait times</td>
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Key Supports in the Cancer Journey

*Cancer Patient Navigators were identified as a key support for patients and families during their experience with cancer.*

Participants indicated that they had a great deal of support from various sources, with family and friends being the primary source of support typically identified. The difficulty family and friends sometimes had in coping with the diagnosis of their loved one provided additional stress for the cancer patient. Participants commented that it was nice to have someone who is a little more distant from them personally who can provide more objective support.

People who had similar cancers were key supports for many participants. They were often identified as a valuable source of not only emotional support, but also in terms of information on various services and what to expect as their treatment progressed. Some patients who had less common cancers indicated they were in contact with people across North America. Some participants reported attending support groups, those with less common cancers were unable to find local support groups specific to their type of cancer.
Cancer Patient Navigators were a source of support for many participants in the “early adopter” sites. In some cases it was just in terms of dealing with the emotional impact of the diagnosis. For others it was helping to deal with the confusion they were experiencing in understanding what was to happen and in trying to find out information regarding various things including appointments and potential supports. Many participants reported that, while their family and friends provided a great deal of support, it was nice to have a support, such as they found in the Navigator, who they knew was knowledgeable about the system, was a little more objective, and would be there when they needed her.

“You don’t know what to ask. When you don’t know what to expect, the Patient Navigator can lead you through it.” Patient

“With the Patient Navigator and people like that to help you, it takes a lot of stress away from you that you don’t actually need, because these little things are taken care of, you can lean on them for that.” Patient

“To me she was like someone who cared about you, as an individual, and was concerned about what type of treatment, and everything about you.” Patient

“I found her (the Navigator) a wealth of information, whatever an individual needed, whether it be directions as to where to get this information or putting you in touch with a person who has been through this. Whatever it was, the Navigator was like the 911 number. If she couldn’t help she could put you in touch with someone who did.” Patient

Health professionals and support staff participants encountered during their experience both at their local facilities and the cancer centres were found to be supportive. This pertained to providing information on what to expect as well as helping to address the anxiety that they were experiencing during procedures. Some participants noted hospital staff is often very busy and perhaps unable to provide as much support as they would like.

“I couldn’t say enough about the staff.” Patient

For some participants, the Lodge That Gives was viewed as a key support. Participants explained that, often to their surprise, it is a fairly upbeat place and they were able to speak with others who were going through the same thing. The Canadian Cancer Society and the VON were also noted as providing valuable assistance.

Participants were mixed regarding whether their family doctor was a source of support. Some participants indicated that their family doctor was a key source of support they could speak to regarding their diagnosis. In a few cases, participants reported their doctors showed a great deal of empathy and were very responsive to both their emotional and information needs. Many others, however, indicated their family doctor had little
involvement once they were diagnosed and their contact post-diagnosis was mostly with health professionals who were working specifically in the oncology setting. In other cases, some participants indicated they or their family member did not have a family doctor. Some participants hold the perception that physicians do not have the time to explain things to them and feel they would be imposing on them. Turning to Patient Navigators and sometimes to other health professionals made some people more comfortable, as they were viewed as having more time to address their questions and concerns.

“He (family doctor) got me through the initial first part of it, the shock of it, and he was the one who suggested that I contact this person, that person, to give me literature, so I knew what these doctors were talking about. Before I went in I knew what to expect.” Patient

“My doctor called me that night. She called me at home after I got the news, after supper to see how I was and if I needed anything, and I said, ‘no, I’m okay’, and the next morning she called me again to see how I got through the night and if I needed anything to help me sleep…she was very supportive.” Patient

“The family doctor is so hard to get to see.” Patient

“Physicians can’t take an hour and just talk you through this.” Family member

The broader community was also a support to many who provided assistance in several ways from fundraising, providing food, or emotional support. Some participants also indicated they derived spiritual support from their faith and clergy members.

An occasional participant indicated they had turned to professional counselling services. Such services were sought to deal with the emotional aspects of diagnosis and also for dealing with post-treatment issues, namely, going back to a life where cancer is no longer the primary focus. This professional counselling support was viewed as essential in dealing with the emotional issues.

“Seeing a psychologist, that mentally, was the best thing because everybody, your family, your friends try to give you as much support as they can, but they really don’t know what to do for you. Husbands, mothers, and sisters don’t know what to do and there is really not a lot of support for them.” Patient
Table 8 outlines the key supports identified by patients.

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<th>Table 8. Key Supports</th>
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<td>Ø Family and friends</td>
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<td>Ø People who had similar cancers</td>
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<td>Ø Cancer Patient Navigators</td>
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<td>Ø Health professionals and support staff</td>
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<td>Ø Canadian Cancer Society</td>
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<td>Ø Lodge That Gives</td>
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<td>Ø Family doctor</td>
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<td>Ø Broader community</td>
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<td>Ø Faith/Church members</td>
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<td>Ø Professional counselors</td>
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Patients in the comparison site felt they would have benefited from a central contact. There was some familiarity with the patient navigation program and participants commented this would be a valuable source of support for themselves and other cancer patients.

“It would be nice to pick up the phone and hear, ‘hi, I’m so and so, and I’m here to help you.’” Patient, Comparison Site

“If we had had a Navigator, it would have taken some of the pressure off because here you are trying to get information, and you don’t even know what avenues you have open to you, you don’t know where to go, you don’t know what’s available.” Patient, Comparison Site

Communication Regarding Cancer Patient Navigation

Many patients did not learn of the Cancer Patient Navigators until directly contacted by them.

Participants in the “early adopter” sites were asked how they found out about patient navigation. Most did not have any general awareness of the program until they were in their cancer journey. This may be a consequence of the newness of the program and also of a tendency to learn of services when the need presents. Some participants did recall seeing newspaper articles regarding the program.

“I think a lot of people know of the Navigator through the Women Alike Program and the women are very close and they (the Navigator) are in the newspaper a lot.” Patient

Patients learned about the Patient Navigator from a variety of sources. The primary source, however, seems to be Patient Navigators themselves. Participants explained they were often not aware of the Patient Navigator until she contacted them. This contact mostly seemed to occur while participants were in hospital for surgery or treatment. Patient Navigator’s attendance at support groups was the point of contact for occasional participants, primarily for those who had gone through treatment before implementation of the patient navigation program. Only a few participants indicated their contact with the Patient Navigator was before they had surgery or treatment.
“While I was waiting to find out whether I had to have chemo, the Navigator contacted me…and gave me the information as to what will happen, and came to my home. It was very satisfactory; the literature she gave me was up-to-date and very informative. It was the basic information that I needed. She checked with me later to see if I had been assigned a time or a location for a chemo treatment. My contact with her was reassuring in that I knew there was somebody there that I could reach out to, somebody that was available to give me information about the system if I needed it and wanted it.” Patient

“I had surgery in January and then the Navigator came in to see me. She was very helpful to me. She’s like a lifeline when you are in the middle of the ocean. She knows where to get answers for you.” Patient

“I had not heard anything about the Patient Navigator until she came.” Patient

Many patients reported not receiving any information from the family doctor regarding the availability of the Patient Navigator. Several patients were unaware of how the Patient Navigator came to know of their diagnosis, and it is possible these referrals might have come from the family doctor. One participant did recall her family doctor providing information on the Patient Navigator, although at the time she did not want to discuss her diagnosis at that time and therefore did not use the contact information provided.

Other sources of communication regarding the patient navigation program included oncology staff, surgeons, and other hospital staff, and in some cases family and friends. Another participant indicated he was unaware of the patient navigation program until he saw a poster while in the social services office.

Participants strongly felt more communication regarding the availability of a Patient Navigator needs to occur. They felt patients should be informed of the Patient Navigator or a referral made more expediently after diagnosis.

“Patient Navigator is the first place they [doctors] should send you.” Patient

“All my treatments were at the QEII. They didn’t tell me anything.” Patient

“By the time I found out about the Patient Navigator, I had most of the information I needed. If I had known that she was there before, it would have saved me a whole lot of headaches…but what she could do for me she did and I am grateful for that, but there wasn’t a whole lot at that point. I had taken care of most of it myself. If I had access earlier I would have saved myself a lot of running around…nobody mentioned it…it was totally by accident that I stumbled across it.” Patient
Participants understood the role of Patient Navigator. They described the role as helping to navigate the cancer system or steering patients in the right direction. They further explained the Navigator is there to explain to patients what to expect and to help them find information and assist them with things like finding financial assistance, transportation, appointments, and accommodations. A few participants indicated they thought the Navigator was for those patients who were in the hospital only. Some also indicated they were unaware they could contact her for logistical things such as arranging appointments or helping to find financial assistance.

“She’s there to steer you in the right direction.” Family member

“It’s just the fact that knowing she is there, knowing what the function is, knowing she can talk you through the process. If she doesn’t have an answer she can get the answer.” Patient

“I just figured that for anything that I needed, for tests, for appointments, for reservations, she would help me do it.” Patient

As more and more patients receive the services of the Patient Navigator, patients themselves will likely increasingly become a source of referrals for others diagnosed with cancer. For example, some participants indicated they had already referred family members or friends who are newly diagnosed with cancer to the Patient Navigator, and in some cases these patients are from outside the district.

“I have referred three people to the Patient Navigator.” Patient

**Assistance Provided by Cancer Patient Navigators**

*Patients received varying types of assistance from Cancer Patient Navigators.*

Participants in the “early adopter” sites were asked about their contact with the Patient Navigator. Contact with the Navigators varied both in terms of the amount of contact and whether it was by phone, in the home, at the Navigator’s office, or while in the hospital. Participants indicated the contact was suitable to the needs.

Participants indicated the Navigator had assisted them in various ways depending on their individual needs. For example, some participants noted the Navigator provided assistance in **dealing with emotional problems** to both patients and family members. In other instances the Navigator provided **supportive care** in terms of providing reassurance that someone was concerned about what they were going through and would be there to assist them if they needed it. Some participants indicated that while they did not have any concrete needs to be taken care of, simply knowing the Navigator was there was a source of relief for them.
“My wife broke down and the nurse went and got the Patient Navigator.” Patient

“My husband and I knew that if anything came up, she was just a phone call away. That took a lot of stress away.” Patient

“She was contacting us throughout it to see how things were moving along. That was a support.” Patient

“Anything you wanted to ask, she was there.” Patient

“After the day I met her in the hospital I felt so much better, and now I know even just someone is there to talk to, that there is someone here now.” Family member

Several patients had begun their cancer journey before the patient navigation program was initiated. In a few cases, patients had experienced a reoccurrence of their cancer after the Navigator was in place. These participants felt their initial experience with cancer would have been vastly different if they had the assistance of the Navigator initially.

“I went through it without the Navigator and with the Navigator and definitely with the Navigator there it is definitely easier to get through. The first time when there was no support group, no Navigator or anything, fear takes hold of you and you can’t get a lot of your questions answered and it is a lot more stressful. Not only on the patient, but on the family and everyone else.” Patient

Some participants indicated the Navigator helped them with learning about their diagnosis, treatment, and what to expect. They explained that she provided them with information, both verbal and written, and also directed them to other resources such as websites where they could obtain further information. Navigators also provided assistance in terms of information on other aspects of care including explanation of medications and nutritional recommendations. As noted previously, the time after active treatment was described as confusing by some participants, as it was unclear what they should expect from this point onward. Some participants noted the Patient Navigator was able to provide them with information on what to expect after treatment.

“I spoke to the Patient Navigator and she told me what to expect from the time I went into the operating room, to the time of chemotherapy. That was a positive experience, because there wasn’t any surprises. That’s what got us through it.” Patient

“I didn’t know what the next step was. When she came out of the hospital, I didn’t know where I was going to go, and she let me know this is what could happen, you can go get help from here, if you need to get a nurse to come to your home, stuff like that.” Family member
Several participants also indicated the Navigator provided them with assistance in terms of logistics. This included arranging accommodations and transportation when they were going for treatment and finding out about appointments. Many also noted the Navigator called to arrange appointments at a more convenient time than originally scheduled, especially when a patient had appointments with multiple professionals in Halifax. Participants also noted the Navigator seemed to be able to get things moving in terms of having appointments set when they had been waiting for a period of time.

“She arranged for me a place to stay in Sydney, it was great to have that done. You have so much to think about, when they do these things for you, it is one less thing you have to worry about.” Patient

“She’s just helped us through some of the red tape, because quite frankly I don’t know what to do.” Family member

“She helped me find out about my appointments for radiation and my accommodations while in Halifax.” Patient

“The ball started rolling instantly, we were waiting for the call every day, but the specialist didn’t know we existed, but once we went to her (Patient Navigator), we had an appointment within 24 hours.” Family member

For many participants, the Navigator was instrumental in helping them find financial assistance. They indicated they did not know what avenues were available to them or were turned down for financial assistance because they were above the low-income cut off point. The Navigator was able to identify sources where they could obtain funding to pay for their medications.

“She arranged to have my last chemo drug paid for.” Patient

“She got me appointments and she got my medications paid for.” Patient

It was also noted that the Navigators helped arrange access to other care providers. For example, one family member noted the Navigator found a family doctor for their relative. Other referrals were also made including to palliative care coordinators (GASHA), nutritionists, and home supports.

In describing the support provided by the Navigators, participants indicated they felt comfortable contacting the Navigator because the desire to assist them was so evident. They indicated the Navigator was responsive in returning calls and in being open to assisting them whatever their needs. Participants commented that simply knowing the Navigator was there was a huge relief for them, as they had a clear source to turn to during different stages of the cancer journey.
“She’s the only person in the system who will return your call.” Family member

“If the position was not here, where would we go?” Family member

“She called me at 9:00 pm on Friday because she did not want to leave my question for four days.” Patient

“We’re a small community and 90 percent of the people diagnosed with cancer go off to the city, and really she’s the only anchor for you here.” Family member

While the Navigator was not able to help in all cases, particularly in terms of arranging financial assistance or other supports, participants recognized that she did try to help. It was noted that when the Navigator was unable to help, she tried to make a referral to someone who might be able to do so. Participants described the Navigator as knowledgeable about where to go in the cancer system to obtain information and as having a lot of contacts within the cancer system that facilitated the journey.

“Patient Navigator couldn’t help me herself, but she sent me to someone who could.” Patient

“She can pick up a phone, she’s known by name.” Patient

“There is a lot of lack of information all the way around, the hospital, Cancer Society, anyone who deals with cancer patients doesn’t have all the necessary information, not in my experience, but the best resource so far has been the Patient Navigator.” Patient

Table 9 outlines the types of assistance received from Cancer Patient Navigators.

<table>
<thead>
<tr>
<th>Table 9. Types of Assistance From Cancer Patient Navigators</th>
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<tbody>
<tr>
<td>- Dealing with emotional problems</td>
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<tr>
<td>- Supportive care</td>
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<tr>
<td>- Learning about their diagnosis, treatment, and what to expect</td>
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<tr>
<td>- Logistics</td>
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<tr>
<td>- Finding financial support</td>
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<tr>
<td>- Arranging access to other care providers</td>
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Areas in Need of Improvement

*Patients and families felt that referrals to Cancer Patient Navigators need to be more consistently done and Navigators need appropriate supports to ensure workloads are manageable.*

Participants identified a number of areas of cancer care services in need of improvement, with most of their suggestions relating to the issues and challenges they had noted in their experience with the cancer care system. They included better coordination of services,
shorter waiting periods, easier access to professionals and services, services closer to home, and more information.

In terms of information, participants indicated that patients need more information in a number of areas including on their diagnosis, what to expect in terms of treatment, and what to expect following treatment. They also thought there should be more ready information on what types of assistance and supports are available. Even more commonly, participants felt a need for greater awareness of Patient Navigators among the general public and health professionals.

“Lack of information is a huge gap, no one talks to anyone.” Patient

There was also some criticism of the programs and regulations in place, particularly as it related to obtaining financial and logistical assistance. Participants explained that there are many barriers and obstacles to obtaining assistance. Participants were very grateful for the Navigator’s assistance in overcoming some of these obstacles, but they also recognized some changes are needed in the system in order to remove these obstacles altogether.

“It’s the programs that are in place that are the problem.” Family member

“It’s like you’re fighting city hall.” Family member

In terms of the patient navigation program specifically, the predominant issues identified as requiring improvement included earlier referral and workload. Participants questioned how initial referrals were supposed to work, as some people appear to be finding out about the availability of the Patient Navigator, while others were not. It was felt referral to the Patient Navigator should be made earlier, preferably at the time of diagnosis, and they should be more automatic. It was also suggested more communications could be done around the program.

Participants expressed concern about the workload of Navigators and the potential of burnout that might put the program in jeopardy. For South West Health and GASHA, it was noted the Navigator had a huge geographical distance to cover. Additionally, in all three districts participants indicated there are a considerable number of individuals with cancer. Participants felt the Navigators need more assistance, either through additional navigators or through administrative support.

“Our Navigator has three counties to see to, she’s going to burn out. She needs an assistant or something. That part worries me, that we are going to lose out because there is too many to look after.” Patient

“It is a heavy load for one person.” Patient
“I don’t know how she does what she does!” Patient

“You know how busy she is and you don’t want to tie her up more than you have to.” Patient

Other participants felt Navigators could play a role in providing information on new treatments, distribution of a map of services in the cancer centres, and initiating support groups. In addition, it was felt that something akin to a reference guide for patients with a list of resources or answers to questions could be developed.

“On the financial end of it, she should have more information on where you go, have the answers before there are any questions, she couldn’t really help me in that aspect of it…but it was understandable because it was a new program. With the phone calls we went back and forth and she did point me in a few directions and I did get answers.” Patient

“The answers to all the questions we have should be put together and not asked for, but given to all patients.” Patients

Some participants noted it would be good if the Navigators had a pool of patient volunteers who would be willing to talk to other patients regarding their journey. Participants would like for the Navigator to provide the link between the volunteers and new patients.
Community Partner Focus Groups
Detailed Findings

This section details the findings from the four community partners’ focus groups. One focus group was held with community partners in each of the three “early adopter” sites and one with Canadian Cancer Society (CCS) staff in Halifax.

Issues in Navigating Cancer Care System

**Community partners felt patients faced a number of challenges including financial burden, stress and fear, lack of information and coordination, wait times, and accessing transportation and accommodations.**

Participants were asked to identify the greatest issues or challenges patients face in navigating the cancer system. They cited a variety of such challenges, which were consistent with those identified by patients and families themselves. These included stress and anxiety, financial burden, lack of information, wait times, and lack of resources.

Community partners consistently felt that one of the predominant challenges associated with a diagnosis of cancer is often not the cancer itself, but the **financial burden** associated with cancer in terms of being able to afford medications, supplies, transportation, and accommodations. They explained that many families, not just those with lower income levels, experience financial burden when they lose a significant portion of the family income and are faced with the costs of medications and supplies. They further described how the ability to afford drugs impacts on patients’ compliance with treatment. Community partners stated the current allowances for financial assistance are problematic and need to be changed in order to be able to provide needed assistance to more cancer patients. The CCS staff shared this opinion.

“That cut off amount [for financial assistance] is just ridiculous.” Community Partner

“People are skipping or limiting their drugs.” Community Partner

“When you take time off from work you can’t draw EI.” Community Partner

“I think that there are people who have chosen to die, to not continue their fight against cancer, because of the financial burden on their families. They come to a point that maybe they could have been survivor, but because of all the burdens and the fears they face they take this route that it would be better for my family.” Community Partner
“Thirty percent of Nova Scotians have no health insurance at all, so they find themselves in a catastrophic situation and they are unable to pay for their treatments. We have some governmental programs, but your annual income has to be pretty darn low to qualify for these programs, and even those programs don’t cover all the supplies and supports that a patient would need. For instance, nutritional supplements, they are not covered by any of the government programs.” Community Partner

For some cancer patients, their diagnosis is just one aspect or challenge of their life. In some instances, pre-existing health issues or events in their life may actually overshadow their diagnosis.

“Sometimes cancer is just one more thing that folks are dealing with and we have a lot of people in very difficult life circumstances or perhaps they have a mental health issue, perhaps they have a learning disability, maybe they have been abused. Whatever the case may be, cancer is just one more thing in their life so when you try to support them it is not just the cancer.” Community Partner

Community partners frequently indicated stress and fear are common among patients and families, because not only do they have a diagnosis of cancer, they also often do not know what to expect or where to turn. They described how patients face challenges in terms of understanding how the system works and the terminology involved and in finding information. They described how this could be a particular challenge among older cancer patients, those with lower levels of education, and those whose first language is not English. Furthermore, patients face continuity of care issues after discharge, with not all patients fully prepared for what to expect after treatment.

“It is not that they (the patients) do not have the cognitive ability, but the stress of the situation impedes their ability to take information in.” Community Partner

“When you are in a situation that is very stressful, I am not sure how much information you absorb at the information given to you and how much you filter out.” Community Partner

“There is a fear of diagnosis, loneliness, fear of the unknown, fear of the direction that this illness will take them. There are personal losses, not only the loss of life, but the loss of independence, perhaps the family income.” Community Partner

“Some of our seniors have only one language, and are not comfortable with the English language and especially in stressful situations you go to your first language that you learned.” Community Partner
“A lot of people will not speak up for themselves. I deal with that, especially with seniors. They really need someone to speak for them and to advance the process. When the level of education is also limited, that understanding or what they can comprehend is another factor as well.” Community Partner

Community partners indicated communication issues within the system often contribute to the lack of understanding and confusion experienced by patients. They explained that various health professionals, including the family physicians, are not always aware of patients and their needs. Therefore, patients may not be getting referred to all the services they need or receiving the appropriate coordination of care. Community partners also pointed out the situation is further compounded by how busy health professionals are, which makes it more difficult for them to give adequate attention to all patients. They felt patients need a single contact person to go back to for information and support as required. In relation to this, community partners commented that given that family physicians do not appear to be referring patients, then the patients do not benefit from having the single contact point of Patient Navigator.

“Everybody is so busy with tasks that there is nobody there to help the person.” Community Partner

“Family physicians are not always notified [about diagnosis].” Community Partner

“We wondered just what leadership potential there should be in relation to physicians in the office, because it has been the experience of at least some of us that an individual diagnosed with cancer has to be directed to the Patient Navigator by someone other than the family physician.” Community Partner

Wait times for appointments and treatment are also a frequent challenge according to community partners. They commented that wait times can be a frustrating experience for patients, particularly given that often patients are unsure of how long they should expect to wait for specialist appointments, diagnostic tests, and treatments to begin.

“The wait times are longer, it can pose some challenges for the person diagnosed in terms of reassurance.” Community Partner

“If there is one constant in cancer, it is waiting.” Community Partner

Community partners also indicated that for patients and families in rural areas, arranging transportation and accommodations in Halifax and Sydney can be difficult. Participants explained that some people, especially those who are older, have not visited these places frequently and doing so can be a very stressful and intimidating experience. Participants indicated some patients simply have difficulty finding their way around hospitals.
Community partners also indicated it is sometimes confusing for patients to understand the roles of the various health care professionals involved in their care.

“There are many people that play a role in the health care team and the patient doesn’t necessarily know who to call first.” Community Partner

“I think a lot of people are diagnosed and then they are sent home.” Community Partner

Additionally, some commented people are also confused about the palliative care role, believing it is for end-of-life care only.

“There’s still a belief that palliative care is only for the end stages and for people diagnosed with certain types of cancer.” Community Partner

“There is a lack of understanding what the role of palliative care is. People just assume that it is only to do with death, they don’t realize that there are a lot of issues such as pain relief that can be dealt through with palliative care and they not using that as a resource or they are trying to avoid that resource because they think that is what it means.” Community Partner

Table 10 summarizes the issues and challenges identified by community partners.

<table>
<thead>
<tr>
<th>Table 10. Issues and Challenges</th>
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<tbody>
<tr>
<td>➢ Financial burden (affording medications/supplies, transportation, accommodations)</td>
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<tr>
<td>➢ Access to transportation</td>
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<tr>
<td>➢ Wait times</td>
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<tr>
<td>➢ Stress and fear</td>
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<tr>
<td>➢ Access to information</td>
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<tr>
<td>➢ Understanding terminology and how the system works</td>
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<tr>
<td>➢ Hospital discharge issues</td>
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<tr>
<td>➢ Follow-up</td>
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<tr>
<td>➢ Human resources to help patients</td>
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<tr>
<td>➢ Community awareness/understanding of cancer</td>
</tr>
<tr>
<td>➢ Not being referred to resources</td>
</tr>
<tr>
<td>➢ Cultural differences and beliefs/languages</td>
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<tr>
<td>➢ Education levels/understanding</td>
</tr>
<tr>
<td>➢ Travel to unfamiliar places/hospitals</td>
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<tr>
<td>➢ Access to doctors</td>
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<tr>
<td>➢ Clarity of roles of health care team</td>
</tr>
<tr>
<td>➢ Understanding palliative care role</td>
</tr>
<tr>
<td>➢ Gap in physician referral to Navigator</td>
</tr>
<tr>
<td>➢ Caregiver burden</td>
</tr>
</tbody>
</table>
Communication about Cancer Patient Navigation

*Community partners felt they were appropriately informed about cancer patient navigation, but thought there was a lack of broader community awareness.*

Community partners have learned of the cancer patient navigation program in a variety of ways, and often through multiple channels. Some had been told by CCNS directly, while others learned about it through the Canadian Cancer Society, and yet others through various health professionals with whom they interact or through announcements at their health facility. Some indicated the Patient Navigator or another representative did a presentation to their organization. Some people indicated they had previously worked or interacted with the Navigators before they assumed their new positions, so they were aware of the change in roles. In some cases there was written information with some having the patient navigation pamphlets and referral forms.

“We had her do a presentation, and it was wonderful. It reached out to those that were interested.” Community Partner

“The Navigator came and spoke to all nurses on staff so we knew what her job was, and what people could expect from her.” Community Partner

The CCS staff felt they had received a great deal of communication regarding the patient navigation program. This was in part due to the fact that members of the CCS were members of CCNS’s Patient Navigation Working Group. These participants felt their involvement from the very early stages of this program provided them with an immense understanding of the program and its mandate. The collaboration that took place between CCS and CCNS regarding the development of the patient navigation program was seen as being very productive and worthwhile.

“The Canadian Cancer Society actually advocated for such a system, without using that language, patient navigation. The Society is actively involved with the creation of Cancer Care Nova Scotia and in the framing of Cancer Care Nova Scotia and identifying this issue of key concern, individuals from the society really advocated to have such a role as the Patient Navigator. So we were involved in the creation of the role, we were involved in the patient navigation-working group.” Community Partner

Participants felt they had been well-informed about the project personally, and there were not any ways in which they could have been better informed. However, participants felt there were limitations in the awareness of the public regarding the patient navigation program, but recognized that people often do not pay attention to information regarding a particular service until the time comes that they actually need that service.
“Even community leaders are not aware of what this resource is.” Community Partner
“I have never heard much talk about it in the community.” Community Partner

“There are a lot of people out there that doesn’t know [about patient navigation]. They are not getting the information from their doctors and I know there are people, when you speak patient navigation to them, they’re like, ‘What are you talking about?’ …We have got to get more education out there, that the Patient Navigator is there.” Community Partner

In terms of CCNS’s role, a number of community partners were not sure of their role, while others indicated it was in terms of setting the parameters of the program and providing funding for the program.

“They did a terrific job in identifying the need.” Community Partner

“They got the ball rolling.” Community Partner

As previously mentioned, the CCS perceived their organization to be a key partner with CCNS within the development and implementation of the patient navigation program. While staff at the provincial level acknowledged they had adequate information and were supportive of the patient navigation program, CCS volunteers at the district level were initially not receptive to the patient navigation program. In many cases, volunteers felt the patient navigation program would somehow duplicate the work they were doing at the district level. However, communication and reassurance from CCS staff at the provincial level served to alleviate these fears.

“Their (rural volunteers) initial reaction was, ‘Well, this is what we do…we spent a fair amount of time working with our volunteers dissuading their concerns and that has completely turned around’.” Community Partner

**Ongoing Contact with Cancer Patient Navigator**

Participants had various levels of contact with Navigators. In some cases, it was sitting on the same committees, while others availed of her as a resource for the patients they deal with. Referrals seem to be a two-way process, with the Navigator making a referral to them when appropriate and they, in turn, making referrals to the Navigator. Participants made referrals for a number of reasons including general support and accessing resources such as assistance with drugs, accommodations, and transportation.

“The Navigator does the initial flag, she does rounds on the floors every day or every other day to check and see who is in, what diagnoses are being made, and then makes sure the right professionals are becoming involved, are being identified, and the appropriate referrals are being made.” Community Partner
In describing contact with the Navigator, community partners in all three districts commented on the willingness of the Navigator to provide assistance to patients and the lengths they would go to do so. They explained that the Navigators were keen on learning as much as possible in order to assist patients with understanding their diagnosis, accessing resources, and navigating the cancer system. In some cases, they commended the willingness of the Navigator to travel great distances in order to meet in person with particular patients.

“Her personality, her disposition, her approachability is there...these are key issues when you are dealing with individuals and that openness to look at possibilities and her willingness to adapt and do what she can with those tools that she has, we have to congratulate that effort as well.” Community Partner

“It is quite a learning process for anyone in that role, it is a fairly new role, and I think the person that took on that job is continuing to learn from it.” Community Partner

Participants from CCS indicated that to date they have played a role in Patient Navigators’ orientation process. Similarly, whenever Patient Navigators meet in Halifax for training, there is always time set aside for them to meet with the staff of CCS.

“The Society was very pleased that the role (Cancer Patient Navigator) was created because it was something that people had been telling us for some time that they needed and in terms of receptivity to an ongoing relationship, there was no question that we would be involved with the orientation of the folks coming onboard.” Community Partner

**Understanding of Role**

Community partners felt the Cancer Patient Navigator role was to support patients and help them navigate the system, with an expectation that Navigators have extensive knowledge about cancer, the system, and resources.

Community partners have clear expectations of the Cancer Patient Navigator’s role. The role was described as helping patients navigate the system and to support patients and families. In this manner, the title of the role was deemed to be very pertinent.

“The choice of the words were excellent, because navigation explains the role.” Community Partner

Participants also described the role in more specific ways. This included being knowledgeable about cancer, the cancer care system, and resources available to patients. In this regard, the Navigators were expected to refer patients to the appropriate resources, to educate them about their diagnosis, and outline the steps of the journey. They were also
expected to advocate on patients’ behalf in terms of accessing resources and dealing with other health care professionals. Some also indicated they expected the role to make a significant contribution in terms of the cancer care program in the district. They explained that the Navigator has a large role to play in coordinating services in the district and bringing together the various people involved in the cancer care system in terms of sharing information and identifying needs.

“The Navigator can help the patient make decisions, i.e., treatment choices, she can help clarify information that is received from the doctor’s office, i.e., appointments, drugs, even the terminology. And really you look at the major benefits, it is the Navigator being able to take the client step-by-step in an individual manner through what has happened, what is happening, and what will likely happen later in the process.” Community Partner

“It brings the idea across that it is a way to live with cancer.” Community Partner

“The individual meets with each patient in hospital, starts to identify where the needs or concerns may be and helps to point them in the right direction to finding resolution to some of those concerns.” Community Partner

“To coordinate, bring all the different people together, provide information for individuals, both volunteers working with other cancer patients and health providers.” Community Partner

Some stakeholders in Antigonish felt assistance with logistics such as arranging financial assistance, accommodations, and transportation was beyond the scope of a Patient Navigator. They explained that the substantial amount of time required to deal with these issues detracts from the one-on-one educational and emotional support they believe is the focal point of this role. While they felt these were important issues that require attention, they believed that either these resources should be more easily accessible or that the Navigator should have appropriate administrative support in identifying and accessing these resources on behalf of patients.

When speaking of their expectations of the Patient Navigator role, community partners recognized that a certain amount of time was required for the individuals to become oriented to the role. They indicated it has been a steep learning curve for some of the Patient Navigators given that they have worked in a hospital setting and not a community setting. They explained that there is a significant amount of knowledge and information required by Navigators in order to be successful in their position. As such, they were unfamiliar with the resources available at the community level and how to access them. Therefore, the time required for orientation is a much-needed component.
“There is a maze of information out there, that’s what makes it tough for patients. The person who is going to be the Navigator has to know what’s out there and how all that needs to be used so that he or she can point people in the right direction.” Community Partner

“She needs to compile a lot of information since this is new. There is getting the networking, getting the connections, just that process of starting this program up and working with volunteers…it is an effort all in itself, it is a lot of work.” Community Partner

A couple of individual participants felt the position should only be filled by someone with a nursing background, as the support provided to patients often required discussions of medical related information.

“I feel that a nursing background is essential because you have had patients that have had cancer and you know what they go through and all the personal experiences you have had over the years through your work. It gives you a deeper insight into the problems.” Community Partner

Table 11 summarizes community partners’ understanding and expectations of the patient navigation role.

<table>
<thead>
<tr>
<th>Table 11. Understanding/Expectations of Role</th>
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<tbody>
<tr>
<td>➢ Help patients navigate system</td>
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<tr>
<td>➢ Refer patients to resources</td>
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<tr>
<td>➢ Be knowledgeable and provide information on resources</td>
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<tr>
<td>➢ Advocate on patients’ behalf</td>
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<tr>
<td>➢ Outlining steps of journey</td>
</tr>
<tr>
<td>➢ Education of public and health professionals on role</td>
</tr>
<tr>
<td>➢ Support patients and families</td>
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<tr>
<td>➢ Nursing background</td>
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Benefits of Cancer Patient Navigation

Community partners agreed the cancer patient navigation program has many benefits including reducing the anxiety experienced by patients, helping patients be better prepared and access resources, and improving the continuity of care.

Community partners consistently believed the patient navigation program has brought numerous benefits, not only to patients and families, but also to the district cancer care overall. One of these benefits is the reduction in stress and anxiousness experienced by patients and families. They explained that this comes from patients having a support person who is available to provide information and assistance to them. Community
partners indicated that when patients have their concerns addressed, their overall cancer journey becomes smoother and they can concentrate on becoming well.

“I’ve seen a definite difference in patients out in the community who have been diagnosed with cancer. They are more comfortable and they have someone they know they can contact.” Community Partner

“The patient navigation program has been crucial in guiding patients through a very anxious, complex, and extremely difficult journey.” Community Partner

“Patients do not spend their energy on being anxious about what is next. They can focus on themselves and moving on to wellness.” Community Partner

“Patients I’ve talked to simply couldn’t have faced what they did without her. This program is indispensable.” Community Partner

“There is often a question when a person passes on, should we have done this or that or they’ll hear from someone else maybe you should have done this. I think by having a Patient Navigator, someone who is educated, and they see the role and the link, it’s between the system and the family, it allows for better closure if the person passes on. You have all the information you could get. It allows for the whole journey to be a lot better.” Community Partner

Community partners explained that a navigator is a person patients and families can turn to for any questions they may have, and in many cases patients develop a better understanding of their diagnosis and what to expect in terms of their cancer experience. They commented that the initial diagnosis is an emotional experience and patients often do not fully take in what they are being told and are unable to articulate the questions running through their minds. Having the Patient Navigator available provides a resource patients can turn to if they feel they need to have information clarified. The Navigator, in some cases, can help patients think through their options when it comes to making decisions regarding treatment. Community partners indicated the extensiveness of the Cancer Patient Navigator’s knowledge regarding cancer, the system, and resources is a critical component in being able to provide patients and families with the assistance they need.

“Another benefit would be the Patient Navigators’ knowledge of the drugs, the process of the health care system itself, just relaying what the client can likely expect as she progresses through her journey.” Community Partner

“The Navigator is able to take the client step-by-step, and do it in a personalized way. The Navigator is knowledgeable about what has happened, what is presently happening, and what will happen later in the process.” Community Partner
“The Navigator is able to fill in the gaps, what the individual did not or forgot to ask the doctor...because of her experience she is able to clarify some of the information.”
Community Partner

Community partners commonly indicated the Navigator has often been able to help patients and families access resources they might have otherwise not been able to access. This includes financial assistance for medications and transportation, as well as arranging transportation and accommodations when patients are required to go to Halifax or Sydney for treatment. They also described the Navigator as an advocate for patients when in comes to accessing resources and in dealing with the cancer care system, such as in arranging appointments and follow-up.

Community partners also described Patient Navigators as providing consistency of care in terms of one person from their area who is a constant throughout their cancer journey. This not only fulfils a supportive role to the patient, but also helps to provide better coordination of care. Patient Navigator serves as a linkage or interface between patients and families and the cancer care system. Community partners indicated that having a Navigator results in appropriate and timelier referrals to services for patients. They also indicated the Navigator is often a go between for patients and provincial services.

“I have seen an improvement in care and communication with cancer patients and families from several points of view: 1) They have access to someone who will provide them with information and support as they go through their illness; 2) The Navigator has an excellent knowledge of available resources and has been providing good follow-up and referrals to appropriate people.” Community Partner

“I’ve been with the support group before the Navigator and since, and we have a lot of people that have been referred to us by the Navigator.” Community Partner

Community partners felt that the Patient Navigator, along with the patient navigation community liaison, can also be an important linkage to diverse communities. By working with members of diverse communities, these communities can also benefit from improved coordination of care.

“Whenever the Navigator came to the community, I could introduce her, that I knew her well enough, what her role is, and for me to go to one of my culture and say, this is the Navigator, this is what she can do for you, it interacted better than a phone call, or getting a message saying, ‘there is a Patient Navigator.’ I found that the community links are a lot better. That gives them a link of trust. If I trust the person, then so will they…and also with Donna [community liaison] who is of our culture, and with her coming, it was really good. It met a lot of our expectations.” Community Partner
Table 12 summarizes the key benefits of the patient navigation program identified by community partners.

<table>
<thead>
<tr>
<th>Table 12. Benefits</th>
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<tbody>
<tr>
<td>• Having someone in community</td>
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<tr>
<td>• Accessibility</td>
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<tr>
<td>• Access to information/resources</td>
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<tr>
<td>• Patients/families less anxious/stressed</td>
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<tr>
<td>• Patient/families feel supported/comforted</td>
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<tr>
<td>• Early referrals</td>
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<tr>
<td>• Consistency of one person</td>
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<tr>
<td>• Advocacy for patients</td>
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<tr>
<td>• Helps with understanding of diagnosis/treatment</td>
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<tr>
<td>• Leadership for direction and information</td>
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<tr>
<td>• Connection/communication between system and individuals/families, community</td>
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<tr>
<td>• Improves patient experience</td>
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<tr>
<td>• Allows for closure</td>
</tr>
<tr>
<td>• Equitable system (across cultures, geographic areas, diagnosis)</td>
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<tr>
<td>• Assist patients in making decisions</td>
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Limitations of Cancer Patient Navigation

*Community partners considered the widespread geographical areas covered by Cancer Patient Navigators, along with the large caseload, to be major limitations of the program.*

While positive about the benefits of patient navigation overall, community partners indicated the program had certain limitations. The most significant limitations were felt to be the extensive geographical area (particularly in the South West Health and GASHA) covered by Navigators, along with the potentially excessive caseload in terms of the number of patients affected by cancer in each district. Community partners felt these limitations posed challenges for the Navigator in being able to reach and address the needs of all patients. They felt there was a risk of Navigators burning out, and therefore, a risk of potentially losing such a valuable resource. They clearly indicated the navigation program needs additional resources in terms of Navigators or other types of supports. In particular, they felt Patient Navigators spend a great deal of time on administrative tasks and assistance with some of these tasks would enable Patient Navigators to spend more time on direct supportive care for patients.

“How can one person do all that for this district?” Community Partner

“We have five hospitals in this district. When you look at the number of patients diagnosed coming through the system, no one person can handle all that.” Community Partner
“There is no way that the Patient Navigator can have a one-to-one with all of those people, it just can’t happen. There’s people who are going to be on the sidelines...when it is up and starting and there is so many other things that have to be done.”
Community Partner

“With all those things coming towards her, how much longer can a person not be burned out?” Community Partner

“As the position becomes better known, there will be more demand on it and at some point it is not going to be possible for one person to meet those expectations.”
Community Partner

Some community partners in GASHA also felt the **breadth or scope of the role** was a limitation. They explained that the Navigators have an extensive role from providing support to patients, accessing resources for them, sitting on numerous committees, and paperwork. They felt that greater efficiencies needed to be achieved in the role in order that the primary function of providing support and education to patients received sufficient time allocation. Some participants felt that not all patients were able to access a Navigator because some of her time is required for other activities, for example, community involvement and paperwork.

“The role should be more assisting clients (education, information) as opposed to finding resources.” Community Partner

“Even the ones that know about it [patient navigation] can’t access it.” Community Partner

“We have been lucky to have been chosen for the pilot project, and I think it has been overwhelmingly proven of value. Those that use it, it is wonderful, but then for those few, there are others with tears in their eyes.” Community Partner

“We are not looking to separate it, we are looking to have something in place to support the Navigator, that provides the information to the client, that speaks to the resource needs, the child care needs, the day care needs, the transportation needs, the drug cost needs.” Community Partner

Some community partners were concerned that in cases where Patient Navigators are not able to access financial assistance for patients who require it, it might impair patients’ receptivity to the Patient Navigator providing them with other assistance and support.

“When you get into financial things, then if they don’t meet the requirements, those emotions may be transferred to the relationship established with the Navigator. They may be angry at her, and therefore, the whole process of navigation is lost.”
Community Partner
Community partners indicated system problems with financial support for patients limits the program to some extent. They explained that lack of financial supports results in Navigators’ time being consumed too much by this one aspect of care, limiting the time available to provide education and emotional support to more patients.

“She should not have to look for financial support for medication, she should have more time to spend with people.” Community Partner

“If the Department of Health were more generous in supporting the drug program, then the Navigators would have more time to do their job of navigating the patient through the system.” Community Partner

Community partners did not feel acceptance of the program by health professionals was a major limitation. While they recognized that there might have been some initial resistance and questions regarding the role on the part of some health professionals, over the course of the program they believe most have become accepting and supportive of the role.

“Early on I would have said the challenge was acceptance by the rest of the medical community, but I would say that that hurdle has almost been overcome.” Community Partner

Since there is only one Navigator assigned to a specific district, CCS staff questioned what would happen if the Navigator became ill or was on vacation. This was seen as somewhat of a difficult situation, as the Navigator is the person the cancer patient or their family members have come to rely on during their cancer journey. It was felt that too much responsibility for patient care was being assigned to one individual. In the absence of the Navigator, patients and their family members may not be as comfortable with or accepting of the temporary Navigator. Similarly, the Navigator’s replacement may not be familiar with the specific details of each patient.

Table 13 summarizes the key limitations of the patient navigation program identified by community partners.

<table>
<thead>
<tr>
<th>Table 13. Limitations/Challenges</th>
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<tbody>
<tr>
<td>➢ Excessive case load</td>
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<tr>
<td>➢ Not available across province</td>
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<tr>
<td>➢ Breadth of role/Expectation that Cancer Patient Navigators do everything</td>
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<tr>
<td>➢ Coverage for vacation/illness</td>
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<tr>
<td>➢ Some Patient Navigators came to role without full understanding of system, resources, and cancer</td>
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<tr>
<td>➢ Different cultures/languages</td>
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<tr>
<td>➢ Time spent on finding resources</td>
</tr>
<tr>
<td>➢ Need more awareness of program</td>
</tr>
<tr>
<td>➢ Limited access to other health professionals/doctor shortage</td>
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Moving Forward

Participants felt very strongly that the cancer patient navigation program should continue.

Participants overwhelmingly supported the continuation of the patient navigation program. In fact, when asked to rate how important it is to continue with a patient navigation program on a scale of 1 to 10 where 1 was not at all important and 10 was very important, participants almost exclusively gave ratings of 10 (although some indicated 10 plus), while a few individuals indicated a rating of 9. Their reasons pertained to the numerous benefits they identified, as described previously.

“The massive amount of information that is out there, a patient by themselves will never sort things out by themselves. The Navigator is like finding an angel on a rainy night in the dark.” Community Partner

“A Patient Navigator is extremely essential to this area. Patients need this one on one support to go through their cancer journey. She relieves a lot of stress that most patients don’t need. The Patient Navigator pilot project is the best thing that has happened in this area for cancer patients.” Community Partner

“Individuals have such tremendous trust and faith in the system and are unable to speak for themselves and do not have someone to advocate for them, those individuals don’t have the knowledge in how to access the system, that trust is all that they have got…it is extremely overwhelming for an individual. When we look at the challenges, much of it could be mediated in a way if the physicians, at the specialist level and at the family practice level really take a leadership role in making sure that the client is directed in the appropriate way, given the fact that we do have a Navigator system in now and it is working.” Community Partner

“The Navigator is a sign that something really useful is happening.” Community Partner

“I think even in my community, if someone would need that resource, I would know where to direct them to, I think that makes me feel great to know that she is there.” Community Partner
Health Professional Interviews
Detailed Findings

In this section, the results of the 40 interviews conducted with health professionals are presented.

Communication on the Cancer Patient Navigation Program

*Health professionals felt well informed of the program.*

Initial communications around the program have suitably introduced it to health professionals. Most health professionals felt they were well informed with respect to the patient navigation program’s introduction. In some cases, they indicated they played some role in the development and implementation of the program and, as a result, felt they had an intimate understanding of the program’s intended objectives. Others indicated they attended roundtable discussions held by Cancer Care Nova Scotia, which provided them with an understanding of the program prior to its implementation.

Some participants indicated they had the opportunity to attend a presentation or information session on the patient navigation program. Most who attended such a session found it to be a valuable and worthwhile experience. In a couple of instances, participants noted they were aware such sessions were being held, but they were unable to attend because of work conflicts or heavy caseloads. These latter individuals suggested that such information sessions be held outside of working hours so more people would be able to attend. In addition, it was recommended the general public be invited to attend these sessions so they too could learn of what the program has to offer.

Some participants recalled receiving written documentation on the program, with most describing this channel of communication as satisfactory. Others noted they receive so much written information and their workloads are such that they often do not have the time to read information in great detail. Many of these individuals would have preferred to attend a presentation where they could learn about the role of Patient Navigator. This was particularly true of physicians.

“I believe it has been explained in a nice concise explanation, naming the role and the contact.” Community Health Professional

“The information is very well presented, it is very well written, it is very easy to understand for families and patients and it kind of gives them, especially when they are in crisis, it gives them something that is written that shows them that they are not alone nor will they be through this whole process.” Nurse
“The information is helpful. The difficulty is sitting down with a lot of paper and reading through it…I’m better learning through an oral presentation or word-of-mouth.” Specialist

Similarly, a number indicated they would have liked a little more detail as to the specific duties and responsibilities of the Navigator. They recognized the program was in its infancy and the information might have been limited because the program implementers were uncertain how this position would unfold. Many suggested future publications provide greater detail on the current functions of Patient Navigators as they have evolved.

“If they addressed more specifics. Stating exactly what they wanted the navigation role to be. They just sort of skimmed the surface and I am not saying that was a bad thing, I don’t think they really knew how this was going to work because this was a brand new system set up.” Community Health Professional

“Initially their job description was vague and the Patient Navigators themselves had to let the program evolve and identify the needs.” Nurse

“I would have liked more in-depth information on what the Patient Navigator actually does for patients.” Nurse

Moving forward, many participants indicated they would like to have the opportunity to talk with the Navigator in an informal setting to learn more about the Navigator’s role and the services she provides to patients, their families, and health care professionals.

**Expectations of the Cancer Patient Navigation Program**

*Health professionals expect Cancer Patient Navigators to provide assistance to cancer patients and their families as they journey through the cancer system, as well as to foster communication and collaboration among health care providers.*

Health professionals have clear expectations of the patient navigation program. Participants perceive the Navigator to be the person who guides patients and their families through the cancer system and attempts to make the transition between different sectors of the system as smooth as possible. Many described the Navigator as filling a “liaison” function between the cancer care system, the patient, and their family. Referring patients to the Patient Navigator immediately following diagnosis was seen as key, as during their initial stage of the cancer journey, patients have a host of needs and concerns. Participants noted that once in contact with the Navigator, patients have an opportunity to ask questions and learn about the support services available to them. This serves to alleviate some of the misgivings and fears patients have in a non-intimating environment.
“Basically I see them as a liaison to interact between myself, between the family physician, between other health care professionals, and ensuring the patient has the smoothest possible ride through the cancer system and, if necessary, arranging transitions to other services, such as palliative care or whatever.” Specialist

“I expect the Patient Navigator to guide a patient through his illness as far as appointments with doctors, helping them to understand what their illness is all about…kind of like a liaison between the doctor and the patients.” Nurse

In addition to guiding patients through the cancer care system, a number of participants noted the patient navigation program links together the different components of the health and cancer care systems. Many felt the team of health care professionals providing services to any one cancer patient were more cognizant of the services and actions other members of the team were providing. This increased knowledge was attributed to Patient Navigators and a few physicians noted that further strengthening these linkages within the system would serve to greatly improve efficiencies in patient care.

“I think my expectation is that the support of the Navigator really should be directed at the practitioner. If your long-term goal is to build community capacity. If your long-term goal is simply to have happy patients then the Navigator can support patients, but really, in terms of maximizing the ability of the community to take care of patients, they have got to work with the practitioners not just the patients, they have got to make those linkages.” Specialist

Participants were quick to point out that Patient Navigators provide a great deal of functional or logistical support for patients and their families. For instance, Patient Navigators were often credited with assisting patients in scheduling their appointments so they were not making several trips to Halifax for tests and procedures. Similarly, Navigators were ascribed with assisting patients and families in arranging transportation and finding accommodations where needed. Participants indicated that often when patients are having difficulty dealing with the financial aspects of paying for the costs of medications, Navigators would explore avenues on the patients’ behalf to seek financial assistance.

“I understand that the Patient Navigator is basically there to navigate patients through the system when they are receiving therapy. It is the contact person to help them (the patients) out with money, places to stay, where they have to go when they have appointments in Halifax, anything linked to treatment as far as cancer goes.” Nurse

“I know that the Patient Navigator has dug up ways that people can access funds that nobody knew about, things like that. She knows all the criteria for accessing them…she knows how to access funding, transportation, places to stay in Halifax.” Nurse
“The other role they have taken on to some extent is to assist in finding ways of obtaining reimbursement for drug costs and so on, and finding ways to arrange money through MSI or through the hospital.” Specialist

Many participants also perceived Navigator as not only an **information source for patients and their families, but also for health professionals**. When health professionals, especially nurses, have questions about new treatments or protocols, it is the Patient Navigator they have come to rely on to obtain this information. The Patient Navigators also pass on to health professionals in the district any new and relevant information regarding cancer treatment and protocols. Similarly, if a patient comes to them with a question they are not able to answer, they will often consult with the Patient Navigator or they will refer the patient to the Navigator directly.

“In this area, because I get the early referrals I do all the navigating myself, but the Navigator is a great resource to me. Since she has been there if I run into any problems or if I have any questions, I will consult her or if I have any patients going for tests and I need information looked up, she is good at that.” Nurse

“It has made things be pulled together a little tighter. As a health care professional if I am trying to find out something, the Patient Navigator is the person to call and I don’t have to start calling everybody in the book. She is a single source to do the leg work.” Nurse

Without exception, stakeholders felt the Navigators have met their expectations and in many cases they have exceeded them.

“My expectations have been meet 110 percent. In the tri-county area, since the Patient Navigator started, I am not getting all these calls with panicking families like I used to, saying, we have no money and my mother is on Xolphrine and we can’t afford it. That is all being taken care of by the Patient Navigator now.” Nurse

“What I expected the person to do was to have a personal role with the person diagnosed with cancer. The Patient Navigator does a very good job of connecting with these people, and connects them readily with other resources.” Community Health Professional

**Referral Process**

*Participants who have used the referral process believe it is working well, however, not all general practitioners are referring their patients to the Navigator.*

Given that participants play different roles in the treatment and care of cancer patients, it is to be expected that there is a fair degree of discrepancy with respect to referrals. For
example, oncologists and those working in the cancer centre in Halifax made very few referrals. These participants indicated that often the patient has already seen or been in contact with the Patient Navigator by the time they see the patient. In contrast, a number of general practitioners indicated they refer most, if not all, of their patients who receive a cancer diagnosis to the Patient Navigator. Some general practitioners are not referring patients to the Patient Navigator because they do not seem to have a clear understanding of the Navigator’s role in relation to patient care. In other instances, some general practitioners indicated they are often so busy with their practice they forget to make the referral.

“I haven’t made any referrals because I don’t think of it.” General Practitioner

“I don’t know enough about the program.” General Practitioner

One cancer specialist pointed out that most general practitioners do not have a high percentage of cancer patients in their practice. Given that cancer makes up a small percentage of their patient population, it is quite likely that general practitioners may forget to refer their cancer patients to this service. As such, it was seen as essential that general practitioners be given regular updates regarding the work of the Patient Navigator and the services the position can provide to keep the general practitioners aware of the role.

“The nature of the role (cancer patient navigation) is such that it does require continuous advertising and you have to recognize that the average family doctor only has one to three cancer patients in their practice at any given time, so they may hear about or use the Patient Navigator service in February, but then not have any occasion to think about it for a year and so when out of sight out of mind. You can’t do a one off advertising/education process, it has to be continuous.” Specialist

Most district nurses involved in the care of cancer patients are referring their patients who have a cancer diagnosis to the Navigator. Nurses at the district level work very closely with the Navigator and have a relatively high level of contact. In fact, the referral process tends to work both ways with regular discussions on caseloads and identifying the most appropriate services for patients occurring between the Navigator and the district nurses.

In some cases, health professionals do not necessarily refer all their patients to the Navigator. These latter participants indicated they would assess the patient’s situation and make a judgment call as to whether or not the patient or their family will benefit from the Navigator’s services. The criteria these participants frequently cited included difficulty in obtaining financial assistance in terms of medications, transportation, or accommodations. Others indicated they would refer a patient to the Navigator if they or their family were having difficulty coping emotionally with the diagnosis. One general practitioner noted that he offers the services to all his cancer patients and has had a few decline the service, as these patients felt they had sufficient supports to navigate the system on their own.
Overall, those who have used the referral process believe it is working well. When asked to provide suggestions for improvement, those who have used the process were unable to make any recommendations.

Contact With Cancer Patient Navigators

*Many participants have a high degree of in-person and telephone contact with the Navigators in their districts.*

Regular contact between the Patient Navigators and other health professionals has been largely established. As previously mentioned, district nurses have a high degree of contact with the Patient Navigator. Most of them indicated this contact tends to be face-to-face, as the Navigators attend medical rounds as well as other meetings that take place within the hospital setting. With the Navigators in the hospital, they often work in close physical proximity and will discuss patient issues on a case-by-case basis, as needed. In addition, nursing staff in the district, especially those working in palliative and continuing care, will contact the Navigator by phone as needed.

“She does keep us up-to-date with a lot of different things, meetings are ongoing and she was the facilitator on getting me oncology orientation at the QE11. She drops into the unit every so often and brings updates and asks about patients.” Nurse

Staffs at the cancer centre in Halifax also have a great deal of contact with the Navigators. It was noted by one participant working in the cancer centre in Halifax that since the Navigators have been in place, the information they receive to process a patient and arrange an appointment is much more likely to be complete. This individual also noted the Navigators will frequently follow-up with them to make sure they have all the information they require. This, in turn, has relieved some of the confusion and delays experienced in the past.

“The vast majority of our dealings have been with the Patient Navigator, and she is just awesome in ensuring that the physicians there provide the cancer centre with all the necessary information on these patients because prior to that the information we received was minimal and I think that the physicians up there have come to rely on her greatly and I know they will contact her who in turn contacts us to see if a referral is here, what the status is and she knows our system very well and knows what is required at this end before an appointment can be processed for a patient and she will forward information or ensure that the physicians forward everything that is necessary.” Community Health Professional

Physicians who have had some experience with the patient navigation program indicated most of their contact with the Navigator is via telephone. Saying that, one oncologist noted
he has also had contact with the Navigator in the form of emails and faxing of lab reports. When it comes to receiving written information from the Navigators since the program has been implemented, participants most do not recall receiving any written information from the Patient Navigator. However, a few, especially those in the nursing field, have requested and received specific information from the Navigator, mostly pertaining to new treatment protocols, travel, and accommodation issues.

The biggest information gap identified is detailed information pertaining to the specific duties and responsibilities of the Navigator. A number of participants indicated they would like to receive some feedback on service gaps the Navigators have identified so they could take appropriate steps to address these gaps. Consequently, Navigators would not have to deal with the same problems again and again if they are addressed at the source.

“It would be nice to receive some sort of report or some sort of feedback. If there are areas or gaps commonly identified for a particular service, then it can be brought to that service’s attention in a formalized manner. For example, if a Patient Navigator in Yarmouth has had 15 issues with trying to organize lodging for patients coming to Halifax then that type of feedback can be appropriately funnelled back to somebody who could appropriately address those issues, versus them having to constantly address and muddy through an issue that there be some venue for that feedback so we may be able to resolve some of these issues.” Nurse

**Benefits of the Cancer Patient Navigation Program**

The implementation of the cancer patient navigation program is viewed as having a positive impact on cancer patients and their families, as well as on overall cancer care in the districts.

From the perspective of health professionals, the impacts of the patient navigation program have been positive and the benefits to patients many. These include patient preparedness, patient support, communication and collaboration among professionals, more efficient involvement with patients, and identification of service gaps.

Participants felt patients who have received the services of the Patient Navigator were more prepared for what their treatment would entail. They reported that when patients go to appointments or for treatments they appear to be more cognizant of what to expect and what questions they should be asking. Having this resource person and obtaining this required knowledge was seen as equipping patients with the skills and confidence they require to navigate the cancer care system. In many cases, participants felt having this awareness prior to medical appointments and procedures helped to relieve some of the stress and anxiety patients so frequently experience. In addition, some participants reported that patients who wanted to take an active role in the selection of their treatment process appeared to be better informed and knowledgeable if they had received the
services of the Navigator. Furthermore, simply knowing they have a specific person to turn to if any issues arise or if they have questions in itself provided patients with a sense of being supported.

“She’s such an advocate for people, she’s such a vital part to care of the patients.”
Community Health Professional

“Patients and families feel they are well supported in terms of accessing the system from initial diagnosis right through.” Nurse

“It has given them (patients) one less thing to worry about, peace of mind, a number and name to call even if they are not in a problematic situation right the. They can contact her and find an answer to a problem.” Community Health Professional

“I think patients are definitely more aware of what to expect, what they should be looking for, what they should be asking for, time frames for various things that should happen. I think the patients overall are much better informed.” Community Health Professional

“I think patients who had come to see me having already worked with the Navigator were much better prepared…because a lot of the emotional, valid concerns had been aired to some degree. They were much more ready to listen, hear, and accept the treatment plan because they had done that work already and quite frankly, they can do that work with an oncologist, that is not the problem. The problem is a cost effective one.” Specialist

Another positive outcome of the patient navigation program is the collaboration and communication that has taken place between the various health professionals cancer patients and their families rely on. The Navigator was commonly referred to as the “liaison” or “link” among health professionals, especially between the general practitioners and the staff at the cancer centres. Ensuring that all members of a patient’s treatment team are aware of what the patient’s status is and what services or treatments each team member is providing was seen as avoiding duplication of services and ensuring that the patient was receiving optimal care.

“There is a lot more talk among health care professionals, between doctors and the staff with the Patient Navigator, there is more communication that way.” Nurse

“Since it started there is more coordination between doctors, patients, the family doctor, oncologists, the whole team. There is more information sharing, and families are more involved.” Nurse
Some participants felt less progress has been made in this area due to the infancy of the patient navigation program. They did note that as the program matures and becomes more established, the sharing of information among health professionals will be more fully realized.

“Although I don’t think it is fully matured yet, another strength is the ability to provide feedback to district cancer committees and the district process as well as to people in the tertiary care areas to improve service. I really see great potential once the patient navigation project reaches its maturity.” Community Health Professional

A number of participants made reference to the fact that implementation of the patient navigation program have brought some of the inadequacies that exist in the health care system to the forefront. This was not seen as a criticism of the program, but rather makes the inadequacies more difficult to ignore. These participants acknowledged that working in a system where such service gaps exist makes it difficult for the Patient Navigators to meet their mandate. Where gaps exist, the districts have been able to look at these service gaps and many have started working towards finding solutions to address them.

“They have been able to feed back into those district cancer committees some of the gaps in their own districts and from the general discussions that we have had at different venues, you can see where these districts are taking this information and trying to move forward in improving things within their district. So I think they have been very instrumental in their districts in identifying the gaps and the things they need to improve.” Community Health Professional

“There has been a lot more recognition of the burden of cancer and the financial burden that families face.” Nurse

“What the Patient Navigators, unfortunately or fortunately, do provide, depending on your perspective, is illumination on what services that really aren’t there. So one of the biggest frustrations, it is not a criticism of the Patient Navigator, but they can’t navigate what doesn’t exist.” Specialist

“You can’t navigate what doesn’t exist, so many of the services patients need over and above simply the core medical services are either non-existent or exist in such a rudimentary form that you can navigate all you want, but they are still not sufficient.” Specialist

Having Navigators identify these service gaps was seen as positive, as health care funders would have to address these issues that are brought to light.
For a number of participants, especially general practitioners, the patient navigation program has helped them focus on cancer patients’ medical issues. They can focus more on the medical aspects of cancer patients’ diagnosis and spend less time discussing logistics such as how to book appointments or where to go for tests. These physicians indicated the Navigator helps patients deal with the psychological aspects of having cancer, as well as assists them with such things as booking appointments, finding transportation and accommodations, as well as seeking out financial aid for medical coverage where necessary.

“It hasn’t changed the level of involvement. What it has changed is the nature of the involvement of a given visit. So the involvement may be more focused on treatment related issues or relapse specific issues or disease specific issues, as opposed to practical issues. I can sit there and talk to them about how to arrange a drive to their appointment, but that is a very, very expensive use of my time.” Specialist

“It certainly has eased the amount of time that I have to spend with a patient on non-clinical issues and my secretarial time with patients having to describe where to go, when to go, procedures for follow-up with the specialists. It’s been a boom in terms of time efficiency.” General Practitioner

“The physician has to make less phone calls. My time is now spent more on patients, rather than trying to find information for them.” General Practitioner

A few other district service providers indicated their level of involvement with patients has increased. This is especially true for nurses working in continuing and palliative care settings. This is commonly in terms of being more aware of patients’ needs and thereby providing services to a greater number of patients.

“I find I am more involved than ever since the Patient Navigator because we are more aware now of all the new cancer diagnoses. The Patient Navigator has helped a lot...It has opened our eyes to the fact that these people have needs that are not being met, so we have looked at that, I have brought that up to my supervisor and the Patient Navigator and I meet with them and now we are offering supportive visits through home care Nova Scotia. The way that we do it is we give them teaching visits regarding their new cancer diagnosis. Before they weren’t offered that.” Nurse

Others commented that their involvement did not change since the patient navigation program. Most of these did not expect it to change, given the patient navigation program would not change their own role with patients.

There is some sense the patient navigation program has had an impact on the utilization of services, more so than on the organization. Patient Navigators have identified the various
supports available to people in their communities. Through their work with patients and health professionals, Navigators have created greater awareness in both these groups of the available supports. While such services may have been available prior to the introduction of the Navigator’s position, many people were unaware of the full range of services available. With the greater awareness, services in the district are not being used more to their capacity.

“It all really comes back to utilization of resources in community. I know that the Patient Navigator has dug up ways that people can access funds that nobody knew about, things like that, she knows all the criteria for accessing them.” Nurse

“The services are being used better, more effectively. She is also pulling the resources, like before there were resources that weren’t being used to their fullest potential, like continuing care.” Nurse

“Somebody is now able to tell you who to call if you have to sort something out. There is also increased utilization of services.” Community Health Professional

“People are pleased to find out that they can access things locally that they didn’t know about, being isolated geographically, we’re all kind of very used to having to go to Halifax, we automatically assume that if someone says that we have to go to Halifax…it is true. We are finding out about the resources we have either right in our own community or closer than Halifax. I think it is helping people that way.” Community Health Professional

Many others were unable to provide a definite response regarding whether the program had an impact on the organization or utilization of services or indicated they had not noticed any dramatic impact. Some of these felt they were not in a position to comment on the organization and utilization of cancer care services at the district level because it is not something they deal with on a daily basis. Many felt that over time both health professionals and patients will become more cognizant of what services are available locally and many will avail of them.

“This is going to end up forging linkages. The more awareness we have, the more chance of using programs efficiently and effectively.” Nurse

“I think the really key point is they are not just there in the community, they have a relationship with the community, that the people trust them.” Specialist

“It has shortened the distance between access and expertise, even though the distance is exactly the same. Patients feel more confident, they feel more connected to the system and therefore reduces their anxiety and ultimately. That’s a good thing.” Specialist
Table 14 outlines the key benefits of the Patient Navigation Program as outlined by health professionals.

<table>
<thead>
<tr>
<th>Table 14. Benefits of the Cancer Patient Navigation Program</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ø Patients more prepared</td>
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<tr>
<td>Ø Relieves patients’ stress and anxiety</td>
</tr>
<tr>
<td>Ø Patients more supported</td>
</tr>
<tr>
<td>Ø Patients informed and knowledgeable</td>
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<tr>
<td>Ø Improved utilization of services</td>
</tr>
<tr>
<td>Ø Collaboration and communication between health professionals</td>
</tr>
<tr>
<td>Ø Identified gaps in services and supports</td>
</tr>
<tr>
<td>Ø Enabled physicians to focus on medical issues</td>
</tr>
</tbody>
</table>

**Weaknesses of the Program**

*Not having a Navigator in every district and heavy workloads were seen as the program’s two shortcomings.*

In contrast to identifying the strengths of this program, participants had much more difficulty identifying the weaknesses. Weaknesses identified included program coverage, workload, geographic scope, and system gaps.

With respect to program coverage, many participants, especially those working in the Capital District Health Authority, felt all nine district health authorities in the province would benefit from the services of a Navigator. Many participants who made such comments were aware that over the course of time there would be Patient Navigators in the remaining district health authorities.

Given the nature of the Patient Navigator role, many questioned the burn-out rate. The Navigators were perceived as carrying very heavy workloads with no support staff. In addition, the geographic area the Navigators have to cover was also seen as daunting. Several participants felt there was an argument to be made for having more than one Navigator in their district or at least a nursing staff underneath the Navigator to provide assistance with patient assessments or secretarial support to help with the paperwork.

In addition to direct patient support, many participants indicated Navigators are also expected to participate in committees and working groups. These activities, again, were seen as contributing to an unrealistic workload.

“She is overworked, she is expected to be involved in every step of cancer care. She seems to be the one that everyone is asking to sit on committees and working groups. I am not sure about her actual caseload itself, whether that is manageable.”  Community Health Professional
“My concern is that her workload will become so great she will be spread too thin. If the numbers increase as they are they will need to increase the number of Navigators down the road.” Nurse

Many felt the work of the Navigator, while challenging and rewarding, can also be very frustrating. These participants noted there are unavoidable gaps within the system. As Navigators try to assist patients through the cancer care system it is inevitable they will encounter obstacles they cannot overcome. In a few instances participants indicated Navigators were trying to eliminate some of these service gaps and as such were taking on roles beyond their mandate. This was seen as putting Navigators at an even greater risk of burn out.

“Because there are gaps in the system the Navigators are taking on roles that are beyond what the objective of the Navigator is and there is responsibility and pressure falling on a Navigator to deal with issues beyond what their scope is intended to be and I think that is a significant risk.” Community Health Professional

“The Navigator can’t create services that don’t exist, they cannot reduce wait times that are inevitable, so a big risk of the system is that you are asking people to deal with a system that in itself is insufficient. So you are setting them up for some degree of failure and also you are setting the public up for some degree of misaligned expectations and I think that this is a key issue that will not go away.” Specialist

Moving Forward

While the Cancer Patient Navigator is seen as an indispensable member of the cancer treatment team, their role needs to be carefully defined and communicated.

Since they have had the opportunity to see the actual works of Patient Navigators, most participants cannot imagine the district cancer programs without such a position. The Navigator is seen as an instrumental member of the cancer treatment team who serves as a common link among health professionals involved in cancer care, in addition to providing the support and guidance patients and their families require. Participants felt that to remove or discontinue the patient navigation program would be a mistake and would result in backlash at the district level. When responding to this question regarding the continuation of the patient navigation position, most stakeholders indicated this position is “essential” if not “crucial” to maintain.

“The program has been a huge step forward, and to go backward would be a huge disservice, especially in the type of community environment we are in now.” Community Health Professional
“Now that we have had a Patient Navigator, I can’t imagine not having one. I think it would be a great loss for cancer patients in the tri-county if we lost our Patient Navigator. She is the one person who knows everything or almost everything there is to know about navigation when you are receiving treatment. Like before, we all know little bits, but this is her specialty and it is a resource for the clients and it is somebody they can talk to when they have questions or if they need help or whatever, and I don’t even want to think about her not being there.” Nurse

“It is very important because of the links that they provide with the patients to the health care system without them. So many people get lost in the health care system in general.” Community Health Professional

“It’s big time important. It would be awful to go back to the old way where people are left floundering.” Nurse

Given that most participants perceive the Patient Navigators as having heavy caseloads, many were unable to offer a definite response when asked what other services they believe the Patient Navigators should provide. If anything, participants suggested that the Patient Navigator be given some type of supports such as an administrative assistant or another health professional. Making the Navigators’ workloads more realistic and manageable was the most frequently identified change to the current role.

“She needs help. Probably another person to help with referrals or some secretarial help.” Nurse

“I don’t think the role of the Patient Navigator needs to change. I think we need to ensure that there are enough resources to allow the Navigator to fulfill that role, so I think we really need to look at volume per Navigator and I think the Navigator role is something that needs to be rolled out across the province.” Community Health Professional

“She has probably got her hands full doing exactly what she is doing.” Nurse

At the present, many feel the Navigators’ role is all encompassing and as such, these individuals are spreading themselves too thin. Having a more defined role and communicating the role to other health professionals was seen as being a positive step.

“I think one of the difficulties is it is very easy when her role is not well defined, that she could get overwhelmed. I think her role should be limited and clear on her responsibilities. Right now she encompasses everything.” Specialist
One area identified as problematic and requiring attention is the communication regarding the program and getting health professionals, especially family doctors, to refer their patients. On this matter, it was felt that communication needs to be ongoing to increase understanding of the patient navigation program.

“Whether that be a quarterly newsletter to medical staff in each distinct hospital combined with a quarterly mail-out to the community or even a advertisement in the community based paper once every three or four months in the Saturday paper with a little block saying we exist. I think they can’t make a one off investment in communication, I think it has to be on-going, about four times a year and it has to be formal.” Specialist

“They need to be more visible and they need to get the family doctors to start referring their patients.” Nurse

“Education of the medical staff, there is definitely a need.” Nurse

“There doesn’t need to be too many changes, it seems to be working well. Maybe if there was some way of reaching the family doctors.” Nurse
Cancer Patient Navigators, DHA Senior Leaders, and CCNS Interviews
Detailed Findings

This section of the report presents the detailed findings for the three interviews conducted with Navigators, eleven interviews conducted with other district personnel, and three with CCNS staff.

Cancer Patient Navigation Program Initiation

There was strong support for the cancer patient navigation program in each of the three districts.

Participants indicated various people were involved in the implementation of the patient navigation program in each district. A variety of stakeholders were responsible for advocating for the role during the proposal stage, including medical staff and other community supports. In South West Health, the support of the Chief of Staff was considered particularly important. Support from other sources including the district cancer care committee, the oncology unit, and the nursing staff (both in hospitals and physicians’ offices), VON, and Continuing Care Nova Scotia were also key supports. In Pictou County Health Authority, key supports were the palliative care physician and palliative care coordinator, along with the palliative care, medical care, and surgical care teams. In GASHA, the palliative care network along with a local surgeon and the oncology clinic nurse were key advocates for the program. These types of supports from key groups involved in cancer care were viewed as important to the districts obtaining the program. From CCNS personnel perspective, the commitment of each district to the success of the program was evident.
Table 15 summarizes the key supports identified for each district.

<table>
<thead>
<tr>
<th>Table 15. Key Supports in Program Initiation</th>
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<tbody>
<tr>
<td><strong>GASHA</strong></td>
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<tr>
<td>• Palliative care nurses network</td>
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<tr>
<td>• Local surgeon</td>
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<tr>
<td>• Palliative Care Physician</td>
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<td>• Oncology clinic nurse</td>
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<tr>
<td>• Community Health Boards</td>
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<tr>
<td>• Cancer and Supportive Care Coordinator and</td>
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<tr>
<td>staff</td>
</tr>
<tr>
<td>• Continuing Care and VON</td>
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<tr>
<td>• CCNS Board member</td>
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<tr>
<td>• CCS units</td>
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<tr>
<td>• Cancer Resource Room Volunteers</td>
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<tr>
<td>• Hospice/Palliative Care volunteers</td>
</tr>
<tr>
<td>• CEO, VPs Community, Patient Care, Medical</td>
</tr>
<tr>
<td>Director</td>
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<tr>
<td>• Community Volunteers</td>
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<tr>
<td>• Multidisciplinary Team</td>
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<tr>
<td>• Community physicians</td>
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<tr>
<td>• District Cancer Committee</td>
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<td></td>
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<tr>
<td><strong>Pictou County Health</strong></td>
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<tr>
<td>• Palliative care physician</td>
</tr>
<tr>
<td>• Palliative care coordinator</td>
</tr>
<tr>
<td>• Other palliative care team members (including VON and home care)</td>
</tr>
<tr>
<td>• Medical care team</td>
</tr>
<tr>
<td>• Surgical care team</td>
</tr>
<tr>
<td>• Oncology outreach clinic nurse</td>
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<tr>
<td>• Woman Alike groups</td>
</tr>
<tr>
<td>• CCS Volunteers</td>
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<tr>
<td>• Senior leadership</td>
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<tr>
<td>• District Cancer Committee</td>
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<tr>
<td></td>
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<tr>
<td><strong>South West Health</strong></td>
</tr>
<tr>
<td>• Chief of Staff</td>
</tr>
<tr>
<td>• CEO, VP Continuing Care</td>
</tr>
<tr>
<td>• District Cancer Care Committee</td>
</tr>
<tr>
<td>• Yarmouth oncology unit</td>
</tr>
<tr>
<td>• Nurses (hospital and physicians’ offices)</td>
</tr>
<tr>
<td>• VON</td>
</tr>
<tr>
<td>• Continuing Care Nova Scotia</td>
</tr>
<tr>
<td>• CSS units</td>
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<tr>
<td>• Surgical Units</td>
</tr>
</tbody>
</table>

District senior leaders spearheaded the implementation in each district, with the program falling under the responsibility of one specific district senior leader. Once Navigators were hired, they did much of the legwork, especially in terms of creating awareness and receptivity to the program. However, key supporters helped promote and distribute materials on the program. District cancer care committees and the CCNS were commended for its considerable support in program implementation, not only in terms of funding, program design, and training/orientation, but also for their ongoing availability for consultation and assistance.

“As things were uncovered we needed to do it. You start taking steps and realizing what you need, and our group worked together to make it happen.” Senior Leader

“The palliative care networking group was spokespersons for using the program.” Senior Leader
District personnel mostly felt the implementation was fairly inclusive with many different parties having been provided an opportunity for input. More input from certain groups was desired, but it was a challenge to encourage their involvement. This is particularly the case with respect to the input of physicians and the community as a whole.

“There are groups that you try to include, but they don’t easily take part. Like physicians or whatever.” Senior Leader

“We would have had more community involvement.” Senior Leader

Program Communications

Intensive efforts undertaken to create awareness and understanding of the Cancer Patient Navigator’s role were felt to be hugely effective.

Overview

It is clear that across districts similar comprehensive communication efforts took place to build program awareness. Patient Navigators were in place for three to four months in each of the districts before the navigation component actually began, which provided not only an opportunity for training and orientation of Navigators, but also time to ramp up awareness of the program. Many actions were taken to create awareness and program receptivity. Letters/memos were sent to various health professionals to inform of the program. Navigators and senior leaders undertook speaking engagements to various partners including VON, family physicians, hospital staff, community health boards, municipalities, the Canadian Cancer Society, and support groups. There was also a considerable amount of one-on-one contact in each district, with Navigators speaking with family physicians, other health professionals, and community partners on a one-on-one basis.

“We had a working group. It was a new concept so we understood that there was a need for a lot of awareness and promotion. We needed to tell people about the referral process. We made a list of who needed to know what.” Senior Leader

“The Patient Navigator did a number of speaking engagements. She went to all units in all three sites. She sold herself very well. She went out into the community, she met with physician groups and talked to doctors, she talked to doctors’ secretaries. She put her name out there to be invited to everything.” Senior Leader

“She has worked hard to network with physicians. They were given information packages, she met with them privately. She let them know what services she can offer as the doctor cares for the patient.” Senior Leader
“There were two or three months of orientation before the role and [Patient Navigator] did much of the introduction. She spoke to a lot of community groups, she called to get herself invited. She went to the CME meeting.” Senior Leader

“The Patient Navigator came to the hospital to introduce herself, sitting down and explaining how it would work in terms of the community, in terms of referrals, information families would need, and other professionals would need.” Senior Leader

Other efforts more directly encompassed the public, in addition to health professionals and community partners. There was an official launch of the program in each district to which the general public along with health professionals and community partners were invited. This event received media attention in each district, with a MLA present. The program posters and brochures were also distributed to increase public awareness. These efforts also included (and continue to do so) articles in the paper about the patient navigation program.

“People needed to know they could come in on their own [to see Navigator], so not only did we get to community people, but we also got to the public as much as we could.” Patient Navigator

In terms of keeping senior leaders and the board informed about patient navigation activities, personnel in each district indicated the senior leader responsible for the program kept other senior leaders and board members updated. No issues were identified in keeping either party informed, with both formal and informal channels being utilized. The senior leader responsible for patient navigation would report on the program’s progress to other senior leaders during their regular meetings and would include an update on the patient navigation program in the report to the board. One Patient Navigator also did a presentation to the board. From a more informal perspective, feedback comes to senior leaders and the board from clients, families, and staff regarding the patient navigation program.

“The VP responsible reports at senior leadership each month.” Senior Leader

“The VP responsible is the vehicle to let people know.” Senior Leader

“In the beginning patient navigation was on the [senior leaders] agenda every week since it was a new program. It is now less frequent because it is an ongoing program.” Senior Leader

“Key information on the program is submitted to the board in the board report.” Senior Leader
Effectiveness

Respondents mostly felt the communications around the program were effective. The extent to which the Navigators and program supporters went to reach the broad array of stakeholders was considered to be more comprehensive than many other initiatives in the past. It was positively viewed for its inclusiveness and recognition of various stakeholder groups.

“I think really effective. We are constantly surprised by who has found out about it. We had a really good plan in the beginning to get the word out. People are using it and seeing the value of it.” Senior Leader

“Of all the programs in our district, I can’t think of too many programs that got as much publicity.” Senior Leader

“The communications were quite effective. We have had other initiatives, which have not been as effective. There was a real conscious effort to include the district in this program, of being part of the district, of being more community-based. I would rank it as fairly inclusive.” Senior Leader

They recognized that initial communications would not create complete awareness of the program. In particular, a number felt that informing the public about patient navigation or any health service is challenging, as people tend to not retain information about services until they actually require them. Therefore, the referral from health professionals rather than reliance on public awareness was perceived as essential to ensuring program uptake. There was consensus across districts that awareness of the patient navigation service continues to grow as more and more patients avail of the service. Some respondents commented that patients themselves are often the best sellers of the program, as they tell others who might need the service and health professional they come into contact with about the value of the service to them.

“Those most vulnerable are always the most difficult to reach. Mail-outs and things don’t reach them. It means we have to inform our staff and they have to keep it up-front. It means we have to keep it in the doctors’ offices because it is the one-to-one communication that you benefit from the most. But in this case no more of a challenge than any other time.” Senior Leader

“Unless people need the service they don’t retain it.” Senior Leader

“Even if it is publicized, it may not hit them that it is available. It creates a level of awareness, but it’s the actual time to make the referral that impacts the uptake.” Senior Leader
Cancer Patient Navigators, DHA Senior Leaders, and CCNS Interviews

“It [awareness] is improving all the time.” Senior Leader

“I find that you have to keep bringing things back to people and keeping it fresh or they forget.” Patient Navigator

The one-on-one approach was seen as a key component to building program awareness among health professionals. However, there was not always clear comprehension initially on what the program could offer to health professionals and their patients until they saw the role in action. There was resistance to patient navigation among some health professionals or other groups involved in cancer care, as they viewed patient navigation as part of their own role. Respondents indicated awareness and receptivity of the program has improved over the course of the implementation, as health professionals have seen patient navigation in practice and realize it is a complement rather than a threat to their own role. In some cases, they have received feedback from patients on how the Patient Navigator has assisted them. Nonetheless, participants felt that referrals by family physicians continue to remain a challenge, as they feel notable numbers do not refer. However, district personnel felt this will take time. Ongoing communications, along with Navigators’ presence in the facilities and participation in different committees and in hospital rounds are viewed as actions that will help build awareness of the role among health professionals.

“Even some of the family physicians, which had some questions about why they are not the Navigators, are now referring to the Patient Navigator. It is really coming into its own and it is seen as a complementary resource to family practice.”

“I think it has become clearer over time.” Senior Leader

“There was a challenge in family physicians accepting the role that has become better as they have seen it work. People also have their own ideas about what they want the role to do. It’s an ongoing thing. The Patient Navigator has been clarifying.” Senior Leader

“When we first started, doctors didn’t refer much at all, the referrals came from chemotherapy, support groups, people you had contacts with before. Now I find that physicians trust you a little more and it is a credible service, so they don’t hesitate to send their patients.” Patient Navigator

“There weren’t any barriers they built. They might not have understood what she did, but there was no threat to them and no challenges. It’s gone from no harm done, send a referral, to a necessary part of good cancer care.” Senior Leader

Navigators all had previous positions in their district. With this history, it took a little bit of time for some to understand their new role. For Navigators in South West Health and
GASHA there was the challenge of reaching the rural areas. It was easier to build an understanding of their role through day-to-day contact in the communities where they lived. This was not as easily done in communities in which they did not have a daily presence. Furthermore, the Navigator in South West Health noted her office location posed somewhat of a challenge, as it was not located in an area that would experience heavy “traffic” of cancer patients.

Looking back, senior leaders, Patient Navigators, nor CCNS personnel felt they would have taken a significantly different approach to communications regarding the program. Some indicated they would have made some modifications or additions. This included more physician-to-physician selling of the program, as physicians might be more inclined to appreciate the perspectives of other physicians in similar work environments. It was also suggested to have more emphasis on staff in the physicians’ offices, as they are often the ones who find out about patients’ issues while in the waiting room. Another suggestion was more assistance with doing one-on-one contact with physicians, as it required a significant amount of time on the part of the Navigator to make this individual contact. It was also indicated that more publicity to the media might have been beneficial.

“In all the conversations we have had about patient navigation, I have never heard anyone say we wish we had done this.” Senior Leader

“When you have one person responsible for starting up the program, it would have been nice to have more help for her to do those orientations for physicians.” Senior Leader

“If an oncologist or physician that is local was seen to be a leader or champion in promoting the program, that would be very effective.” Senior Leader

When asked the challenges were for patients in accessing the patient navigation system, each Navigator indicated awareness of the program and lack of referrals as the predominant challenges. These challenges are being worked on. Through various mechanisms, including featuring articles on navigation in local papers and establishing relationships with the community health boards. It is felt that over time patients will become more aware of the program through word of mouth and it will also be more readily thought of by health professionals.
Program Implementation

Program implementation was consistent across districts. However, there are some differences in delivery due to varying resources and working relationships.

District Context

District personnel were questioned on the programs in place in the district related to cancer care and any characteristics of the district that might have impacted the program. The program was not reported to be significantly modified for each district, with the key focus remaining on providing support to patients and families. However, due to variations in the district there are some differences in delivery reported. In South West Health, the Navigator has taken on more palliative care coordination than the other two Navigators due to the absence of a palliative care program. In GASHA, the Navigator has been able to rely on the palliative care nurses for coordination of some patients in the rural areas, as this was a function the nurses were performing prior to the patient navigation program. In turn, the Navigator provides assistance to the palliative care nurses in supporting patients, rather than direct patient support. In Pictou County Health Authority, providing direct patient support is not as much of a challenge, as the area is much smaller. However, the lack of psychological supports, namely social workers, similar to those available in GASHA was identified as a limitation.

“One thing that is different here is that there is no palliative care program to pick up the palliative care people. We have taken a different approach here. She really isn’t navigating them anymore. She’s just providing support because you can’t drop people.” Senior Leader, South West Health

“This district is unique in its remoteness, the challenges of the people are different.”
Senior Leader, GASHA

“The integrated palliative care and home care certainly plays a role.”
Pictou County Health Authority

Table 16 identifies the services identified for each district. Each district has a number of cancer care services that support the cancer patient navigation program.
Table 16. Services Related to Cancer Care in Each District

<table>
<thead>
<tr>
<th>GASHA</th>
<th>Pictou County Health Authority</th>
<th>South West Health</th>
</tr>
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<tbody>
<tr>
<td>• Surgery @ St. Martha’s</td>
<td>• Surgery</td>
<td>• Surgery</td>
</tr>
<tr>
<td>• Oncology outreach clinic</td>
<td>• Oncology outreach clinic – visiting oncologist</td>
<td>• Diagnostic Dept</td>
</tr>
<tr>
<td>• Chemotherapy</td>
<td>• Chemotherapy</td>
<td>• Yarmouth Oncology outreach clinic</td>
</tr>
<tr>
<td>• Palliative care network</td>
<td>• Palliative care program (palliative care and home care together)</td>
<td>• Yarmouth chemo unit</td>
</tr>
<tr>
<td>• Hospice Palliative Care Program take early referrals on diagnosis</td>
<td>• Diagnostic services</td>
<td>• Continuing care</td>
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<td></td>
<td>• Bronchoscopy, cat scan,</td>
<td>• VON</td>
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<tr>
<td></td>
<td>• Canadian Cancer Society</td>
<td>• District Cancer Patient and Family resource room</td>
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<tr>
<td></td>
<td>• Support groups (breast, prostate, and brain)</td>
<td>• Digby Hospice</td>
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<td></td>
<td>• VON</td>
<td>• Look Good Feel Good Program</td>
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<tr>
<td></td>
<td>• Palliative Care Doctor</td>
<td>• Canadian Cancer Society</td>
</tr>
<tr>
<td></td>
<td>• Home care</td>
<td>• Support groups (General-Yarmouth; Barrington -Breast-Clare; Plans underway for 3 more)</td>
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<tr>
<td></td>
<td>• Well women’s clinic</td>
<td>• Reach to Recovery Volunteers-Yarmouth</td>
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<td></td>
<td>• Mobile breast clinic</td>
<td>• Well women’s days in Shelburne County</td>
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<td></td>
<td>• Mental health addictions services</td>
<td>• Breast screening program</td>
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<tr>
<td></td>
<td>• Enterostomy therapists</td>
<td>• Titz and glitz funds</td>
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<tr>
<td></td>
<td>• Wound management therapist</td>
<td>• Bikers Memorial fund</td>
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<td></td>
<td>• 2 nurse practitioner pap screening</td>
<td>• Tobacco reduction coordinator</td>
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<tr>
<td></td>
<td>• Ortho specialist for bone Mets</td>
<td>• Supportive care coordinator</td>
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<td></td>
<td>• Gyn backup</td>
<td>• Social Worker</td>
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<tr>
<td></td>
<td>• Designated pastoral program for cancer pts providing grief support</td>
<td></td>
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<tr>
<td></td>
<td>• Homeopathic medicine and lymphedema specialist</td>
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<td></td>
<td>• Pre admission and cancer teaching clinic</td>
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<td></td>
<td>• Look good feel good program</td>
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<tr>
<td></td>
<td>• Titz and glitz funds</td>
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<tr>
<td></td>
<td>• Bikers Memorial fund</td>
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<tr>
<td></td>
<td>• Primary health coordinator</td>
<td></td>
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<td></td>
<td>• Tobacco reduction coordinator</td>
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<tr>
<td></td>
<td>• Look Good Feel Good Program</td>
<td></td>
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<tr>
<td>• CT scan, mammography, bone scan, plastic surgeon</td>
<td>• District Cancer Patient and Family resource room</td>
<td></td>
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<tr>
<td>• Hospital in the Home St. Martha’s</td>
<td>• Breast screening program</td>
<td></td>
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<tr>
<td>• Mental health and addictions services</td>
<td>• Titz and glitz funds</td>
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<tr>
<td>• Tobacco reduction coordinator</td>
<td>• Bikers Memorial fund</td>
<td></td>
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<tr>
<td>• Titz and glitz funds</td>
<td>• Tobacco reduction coordinator</td>
<td></td>
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<tr>
<td>• Bikers Memorial fund</td>
<td>• Social Worker</td>
<td></td>
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<tr>
<td>• Look Good Feel Good Program</td>
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Accountability

In each district the Patient Navigator reported to a specific senior leader. In Pictou County Health Authority, this is the Vice President Patient Services, with the direct manager being the Head Nurse at the hospital. In South West Health, the Patient Navigator reports to the Vice President Community Health and in GASHA it is the Vice President Community through the Manager of Cancer and Supportive Care for the hospital.
District personnel felt the current reporting structure would also be appropriate after the “early adoption” phase. It was noted Patient Navigators are mostly self-directed and independent regardless of reporting structure. They turn to various senior leaders for consultation depending on particular issues and concerns, and work closely with the various medical and oncology staff to ensure appropriate care. Therefore, the role and working relationships are not limited by the channels of reporting and overlap both medical and community based settings.

“She works pretty independently. I think it is fine here this way.” Senior Leader

“The Patient Navigator reports to VP Community Health, but also works with the acute care people.” Senior Leader

Referral Process and Triage

The CCNS Patient Navigation Project Manager in conjunction with the Navigators developed the referral process. A written referral form was developed along with a toll-free number.

The proportion of referrals received in written form varies across districts from about one-half in South West Health to virtually none in GASHA and Pictou County Health Authority. This may be due in part to the location of the Navigator’s offices. In GASHA and Pictou County Health Authority, the Navigators’ offices are located in close proximity to other professionals providing cancer care and thus verbal referrals come in through professionals who drop by. Referrals are also picked up in the districts through participation in rounds and committees. The Navigators are satisfied with the referral process, indicating that getting the referrals, whether they are written or verbal, is most important.

The primary challenge in terms of referrals from the Cancer Care centers is the cancer centre staff knowing which districts have Patient Navigators. Patients often do not know what health district they are in and the staff do not always know all the communities that are covered in the District.

A triage system was also established in the districts, with written criteria set out to help Navigators prioritize cases. The Navigators indicated it is helpful to be able to determine urgency and prioritize accordingly, although one Navigator noted there is not always enough information with verbal referrals to determine priority. Another noted the criteria serve as useful guidelines, but it would be too time consuming to complete the written triage form.
Cultural, Language, and Literacy Issues

Considerable efforts have been made to address cultural, language, and literacy issues. CCNS has established a Patient Navigation Community Liaison role, which serves as an important driving force in addressing these issues. The Community Liaison has introduced Patient Navigators to the local African Nova Scotian communities. In GASHA, it was noted the district cancer care committee has a working group to address some of the issues regarding the Francophone and African Nova Scotian communities. It is acknowledged that there is still a long way to go and inroads also need to be made with the Aboriginal community. Using educational materials always requires being cognizant of whether the materials are culturally sensitive.

“She [Patient Navigation Community Liaison] met with them [members of the African Nova Scotian community]. She introduced me to some people and I have had some referrals after that.” Patient Navigator

“She [Patient Navigation Community Liaison] is a constant reminder to us of cultural sensitivity and that we need to look at what we are giving out in literature and making sure it is culturally sensitive, it isn’t to bring it forward to the source of the literature.” Patient

It was noted that literacy is a difficult thing to address with people, requiring considerable sensitivity. A Navigator noted much of the educational materials is above the reading level of some patients.

“Part of my assessment had to include approaching that in a gentle way, and offering alternatives when people are illiterate. Not only recognizing it but being able to continue on with patient teachings or guidance to services, that it doesn’t stop because people are not literate.” Patient Navigator

CCNS Support

CCNS is viewed as providing exceptional support and guidance.

The involvement of CCNS was viewed as critical to the district patient navigation programs. District personnel indicated CCNS’s involvement helped ensure quality programming and accountability, explaining that CCNS has taken an evidence-based approach to developing the program. Clearly, CCNS’s funding of the program was an important component, as the districts would not have been able to put the program in place without it. Beyond funding, the provincial coordination provided to the districts was perceived as instrumental in ensuring a consistent focus for the program and the required support to work through program details at the district level. District personnel commented on how available and supportive CCNS staff are and how they are willing to assist in many different ways.
District personnel could not identify ways in which CCNS’s support could have been better or any aspect of their support that was not valuable. One respondent commented on the expense of the branding materials, but the value of these was seen in the long run.

“I think that CCNS’s support is absolutely critical. Only CCNS understands the standards and the impact of cancer and they also have the history and evidence to support that people do need navigation.” Senior Leader

“It was amazing. I don’t know what we would have asked for that they wouldn’t have helped us with.” Senior Leader

“CCNS has been phenomenal in terms of the support they have given from a planning and operational perspective.” Senior Leader

“From the beginning all the way through, I can’t think of anything that shouldn’t have been doing or they could do more. They were there to support us every step of the way. Yet they weren’t dictatorial, they didn’t say you must do this or that. It was simply providing support, orientation, Sandra’s [project manager] coordination from the provincial point of view, the weekly conference calls. All of the things put in place were never to go in a direction that the district did not want to go in.” Senior Leader

From the Patient Navigators’ perspective, the support provided to them from CCNS, along with the other Navigators, has helped them feel confident they are carrying out the role as intended. It has also helped them feel supported when they have issues pertaining to particular patient cases. Through their regular discussions, their expertise grows and they become more effective and efficient in their role.

“I use the other two Navigators when there is a patient issue or Sandra [project manager].” Patient Navigator

“I don’t think they could have been any better. We became part of a team, the three of us and Sandra. The weekly conference calls built up confidence over time that you were doing what you were supposed to be doing.” Patient Navigator

“The openness about the program and cancer care in general has really been respected in the district. CCNS is very forthcoming with information and willing to share resources. Their availability to other people in the district as well as the Patient Navigator.” Patient Navigator
Team Fit

Navigators have become central players in the cancer care teams, with linkages to various individuals and groups involved in cancer care.

The Patient Navigator role has become well-integrated and integral to the district cancer care team. There were some concerns in the beginning regarding whether the Patient Navigator role overlapped or was redundant with existing roles. In GASHA there was some concern that the Patient Navigator role replicated activities already being performed by palliative care nurses in various communities. The palliative care nurses have long histories in their communities and established relationships with family physicians. This concern has been resolved through the Patient Navigator and palliative care nurses working closely together and determining who provides the best fit for a patient. The Navigator noted that palliative care nurses would best know the local community resources. Conversely, the Patient Navigator knows the provincial cancer care system and other resources, and can often assist palliative care nurses in addressing issues for patients. Furthermore, the Navigator indicated she often provides early referrals to palliative care after clarifying with patients exactly what palliative care is. There was also some initial question in GASHA whether the role overlapped with the nurse consultant role in the hospital.

“People were saying we need nurses here. I think there may have been some people who thought ‘why do we need this position?’ That is what some of the palliative care nurses are doing, we need more time for some of them, not a new position.” Patient Navigator

“I think there is some overlap in some of our more rural areas with the palliative care nurses. Because of the way the physicians use their services some nurses would have seen their role as already doing patient navigation. It wasn’t a major influencing piece, but there was a working through, ‘well, how do we fit and when do we refer to the Patient Navigator.’ They worked it out among themselves.” Senior Leader, GASHA

In South West Health and Pictou County Health Authority, there were also some questions about redundancy with existing community services. However, clarity of the role was achieved once in operation.

“I think there may have been some hesitancy as to why I was a Patient Navigator and not a palliative care coordinator.” Patient Navigator
“The only thing I have ever heard is that we have a hospice group, which is volunteers...It was felt that there was a tendency to rebuild and not recognize some of the strengths we had in the community, and that’s the only comment I have ever heard. I do see members of the district cancer care committee are active in the district and I think some of that has been worked out.” Senior Leader

“I wondered where the Navigator’s expertise in oncology was growing, would it evolve into an oncology nurse. One of her closest working relationships is with the oncology clinic, but they are not the same. There is no overlap.” Senior Leader

There is consensus the Patient Navigator role complements the roles of other health providers in the district. While there may be some degree of overlap in certain instances, it is not viewed negatively, but rather as helping ensure patients are not missed.

“She’s on committees. She works as part of the oncology clinic and on various cancer care team committees. There is an overlap sometimes with the oncology nurse coordinator, but we view that as positive because it ensures there is teamwork and collaboration. She is not a silo, she is part of the oncology experience.” Senior Leader

“Other team members understand her role because they refer to her.” Senior Leader

In each district, it was noted that the Patient Navigator is an integral part of the cancer care services. Respondents explained that the Navigators sit on various committees and teams related to cancer care. The Navigator in Pictou County Health Authority is a member of the medical, surgical, and palliative care teams, with participation in the latter involving rounds.

In GASHA, the Navigator is linked to surgical and medical care teams through representation on the district cancer care committee and through participation in rounds. The Navigator also participates in clinical discussions in the oncology clinic and palliative care rounds and is part of the palliative care nurses network meeting about once a month.

In South West Health, the Navigator participates in inpatient hospital rounds through open invitation. She also participates in telehealth oncology weekly rounds with the cancer centre. During rounds, Navigators typically speak with patients and determine if there are issues they can assist with. Furthermore, the Navigator noted integration into the team has been more effective at the hospital in Yarmouth because of the day-to-day contact with other team members dropping by on a fairly informal basis. Visits to Shelburne and Digby tend to be more focused on a specific task, therefore, it is more challenging to develop the relationships.
All Navigators have leadership roles in the district cancer care committees. They view membership on these teams as appropriate, as this membership provides a two-way mechanism of sharing information and they have an important contribution to make. There is concern that taking a leadership role in these committee in the future could be challenging if the workload increases.

“She’s a very integral part of the team.” Senior Leader

Program Identity

*Cancer Patient Navigator is viewed as an appropriate term for the role, but there is uncertainty regarding the program’s branding.*

Use of the word “Patient Navigator” appears to be appropriate. Most district personnel were of the opinion it did not pose any problems and many felt the term accurately described the nature of the role. They also indicated that if there is any confusion clarity is achieved through the Navigator explaining her role.

“I never heard any negative connotations with it and she would always explain it to people.” Senior Leader

“It’s a self-explanatory term. There’s no confusion.” Senior Leader

“Because we are a Maritime province, people understand what a Navigator does. It just seems to fit the role very well.” Patient Navigator

“In the beginning people were wondering what it was. Once we talked about what it was, people understood, but they didn’t always quite see how it fit. But the minute it started and connections were made and people saw the benefits, they got it.” Senior Leader

Most were uncertain about the effectiveness of the visual identities of the program. They were not able to comment on whether people associate the visual identities such as the maze with patient navigation. They did indicate that Navigators themselves are achieving recognition as people who can assist cancer patients.

“Presence and action needs to be there for recognition.” Senior Leader

“After a while, when there is one person that does something, it’s her that’s recognized more than anything else. It’s like that in a small town. She’s done a good job of selling it.” Senior Leader
Orientation and Education

The orientation and educational opportunities for the Navigators are viewed as both exceptional and important to the role.

The orientation and ongoing education of the Patient Navigators is viewed as very comprehensive by Navigators and senior leaders. The orientation and education included:

- An orientation to the cancer centres, which encompassed the various departments and provided an opportunity for Patient Navigators to meet many of the people patients would interact with and see first hand the processes patients would go through at the centers;
- A two-day oncology workshop at the QEII covering cancer and treatment procedures;
- An orientation to the direction the cancer system is taking;
- An eight-month continuing education program in oncology through the University of Alberta;
- Participation in conferences including an international one in psychosocial oncology and a national one in palliative care along with provincial workshops, conferences, and telehealth sessions; and
- Various written materials that are shared with them, primarily through CCNS.

Patient Navigators felt orientation was exceedingly useful to them. They commented that it was very thorough in providing them with an understanding of the cancer care system. In particular, time spent at the cancer centres was viewed as an integral component. The flexibility of the orientation was also cited as a valued component. The Navigators appreciated the opportunity to have input into the orientation and what they would need both as a group and as individuals.

“It helped me to understand the system and to go through the system as a cancer patient would, to go to the centre, see the radiation centre, all that learning to be able to effectively tell people what it is all about…and to be there and meet the people the patients are actually going to be talking to. Sometimes I can give them a name of a patient, to give people a more personal feeling. Orientation to the different aspects of cancer care, to see the palliative care ward, to see the bone marrow transplant unit, to see clinics and how they operate, the referral centre, just the overall bigger picture of the provincial system.” Patient Navigator

Navigators indicated they would not change anything about the orientation process. The one limitation noted of the orientation is being away from the district for an extended period of time, as there is a backlog of work when the Navigators return to their district. One Navigator noted that perhaps the orientation period would be shorter for Navigators...
coming on, given that they worked out some of the details during the initial orientation process.

The Navigators did not feel anything was missing in their orientation process or continuing education opportunities. They felt it important to have an ongoing focus on education with Navigators being kept up-to-date on new processes, treatments, and changes in the cancer care system.

The Navigators indicated they are kept informed of current cancer guidelines and standards. This comes through CCNS, typically through the cancer site teams. The Navigators identified the medication sheets/drug protocol are among the most useful guidelines for them currently. Other mentions included the breast cancer guidelines, physicians’ statement on prostrate cancer, and colorectal cancer screening guidelines. The visiting oncologist was also noted as a source of information when it comes to new medications.

### The Cancer Patient Navigator Role

**Navigators' primary focus is on assisting patients, but encompasses other responsibilities related to cancer care in the district. Navigators are becoming a central point of contact for cancer care in the district.**

Patient Navigators were asked to describe their responsibilities and activities. Clearly, the primary activity is to assist and support patients in their cancer journey. The role also encompasses activities designed to build the overall capacity and quality of care in the district, through support and education to other health professionals and participation in cancer-related committees.

“The foremost activity is to guide patients through the cancer system, through all stages of their illness.” Patient Navigator

“It is to be there for patients when they are first diagnosed, to support and guide and to coordinate their care, to give them resource material. It is more of a constant liaison for all the activities that go on.” Patient Navigator

“Introducing patients to the concept of patient navigation, providing information about their disease, about resources, helping to support patients, families, and other health care professionals in the community.” Patient Navigator
Assistance to Patients and Families

Cancer Patient Navigators perform numerous activities related to the multitude of issues patients face during their cancer journey. Patient Navigators indicated financial issues are the most common issues for patients, particularly cost of medications. Navigators indicated financial issues are most difficult to address, and they cannot find assistance for all patients. They explained that people who do not have private health coverage or do not qualify for MSI seniors pharmacare, community service social assistance, or meet the financial requirements of the provincial cancer drug assistance program are the ones most difficult to find financial aid for. A number of community-based funds can be accessed but they have limitations and are not consistently available throughout the districts. With time and experience, Navigators have become more familiar with the available financial resources, both provincially and within the district.

“There’s limited finances available and for some of the drugs, costs are so high. These small amounts in charitable funds just won’t cover the costs.” Patient Navigator

“I have made contacts in those different departments, MSI, drug billing. There’s a particular person that I call and I don’t have to go through all that I did when I first started.” Patient Navigator

Other common issues included coordination (appointments, tests, reports), education on diagnosis, overview of referral process and cancer care system, and psychosocial support.

When they are able to make contact with patients soon after diagnosis, Navigators indicated they provide patients with information on their type of cancer and answer questions. If appropriate, they speak about the referral process and provide an overview of the facility they will be visiting. Navigators commonly share standard information such as the Pink Rose package for breast cancer patients and the Reef Knot package for prostate cancer patients. They also have print information from the Canadian Cancer Society and the Living Well with Cancer Series. Other resources include British Columbia medication guidelines available on their Website, QEII booklets on treatment, QEII information on specific units at the hospital, and information from the Ovarian Cancer Association. For patients who are familiar with the Internet, they sometimes refer them to particular websites they feel are credible.

“We can provide them with written material that is standardized across Canada. It is good credible written information.” Patient Navigator

“Usually when I meet with them, I tell them a little bit about what the referral process will be like and if they have specific questions about the type of cancer they have or what types of treatment they might encounter, I answer those.” Patient Navigator
With respect to treatment, Navigators will sometimes reinforce teachings provided by the oncology staff including treatment options and what each entails. They help prepare patients for future visits in terms of reviewing information and helping them identify any questions to ask. During the treatment phase, Navigators help with coordination issues, for example, ensuring all necessary tests and procedures are done prior to the oncologist’s visit to avoid potential delays. Where possible, they try to avoid patients having to make multiple trips back to the cancer centres by rearranging different appointments to the same day. Side effects are also an issue during treatment and Navigators sometimes put patients in contact with appropriate supports, such as VON for management of these symptoms. They will also speak with patients about logistical issues as required including transportation and accommodations. Where necessary, Navigators assist with arrangements or finding funding to cover transportation, medications, and other medical supplies.

"Tell them what to expect by way of appointment. Once they find out the type of treatment maybe going over and reinforcing what the oncology nurses have told them about therapy, radiation, those options." Patient Navigator

"Lots of times when they return back from an oncologist, they don’t hear much from a visiting oncologist, so they come back for interpretation of what treatments they may have had or are going to have." Patient Navigator

After treatment, the Navigators often assist with coordinating follow-up appointments and where possible, they arrange follow-up locally. They also assess patients’ needs for symptom management. Often it involves just providing reassurance to patients about what is normal in terms of symptoms and follow-up appointments. They will also try to introduce patients to community supports such as support groups, rehabilitative care, and places to get things like wigs and prosthesis. They try to be available to patients if they have any questions, noting that patients often feel lost at this point in their cancer journey after having such extensive contact with professionals during treatment.

"Patients experience anxiety when leaving someone who they are familiar with, that has cared for them throughout the treatment phase. I’m speaking mostly about oncology nurses they have become close to. Although the door is still open for them and they are told that, they don’t have the regular contact they had throughout the treatment. And later on once they have finished with the oncologist, and the care is handed back to the family doctor there is some anxiety there." Patient Navigator

"They get lost in the system. We have a lack of family physicians. Once you are finished with the specialist, you may not have anybody to go back to." Patient Navigator
“General support when people are unsure of themselves, to let them know that it is quite normal to feel that way and usually anxiety diminishes. And also recognizing when they don’t seem to be progressing normally and discussing a mental health referral if that seems appropriate, if someone is really having a difficult time coping after treatment.” Patient Navigator

“They’ve been surrounded by so many professionals for so long, they get the lost in the system feeling again. So what is appropriate follow-up care is to try to explain to them things to look for, what they should expect. It relieves them to know what is appropriate, for example, a year follow-up is fine.” Patient Navigator

When it comes to palliative care, there are differences in the level of assistance Navigators, as the palliative care structure varies across districts. In GASHA, there are palliative care nurses in several communities and the Navigator works closely with them. In Pictou County Health Authority, the Navigator is part of the palliative care team, which meets weekly to discuss all cases. The Navigator can refer patients to the appropriate palliative care team members. In South West Health, in the absence of a coordinated palliative care program, the Navigator has taken on a more direct role of managing individual palliative care cases and arranging necessary supports.

It was noted it can be a challenge to follow up with all patients after treatment, given the caseloads associated with assisting patients who are newly diagnosed. This suggests that as the number of new referrals to the program increases it will become more difficult to provide post-treatment care as so much time is being afforded to addressing the needs and concerns of those entering the cancer care system.

**Working Relationships with Other Cancer Care Providers**

Cancer Patient Navigators were also asked about their work with various professionals in the district and the cancer care centres. Patient Navigators have built relationships and continue to do so. When it comes to family physicians, the Navigators indicated some family physicians regularly refer patients to them. Referrals are commonly made to address a specific issue (e.g., financial or transportation needs) rather than general care. Ideally, they want referrals coming in for more general assistance as well, as Navigators can support patients in ways other than just specific financial or logistical issues. Referrals seem to be more widely received from surgeons and specialists. With respect to the outreach oncologist, the Patient Navigators have established good working relationships with them, attending the outreach clinic on the days the oncologist is visiting. This provides an opportunity for Navigators to come into contact with a large number of patients, as well as keeping oncologists cognizant of the Navigator.
As previously noted, each Navigator serves as part of a cancer care team in each district and attend rounds as part of that team. Nursing staff and other professionals including home care staff, dieticians, physiotherapists, and occupational therapists are essential contacts for Patient Navigators. Patient Navigators can refer patients to these sources and they can refer patients to Navigators. In GASHA, the Navigator has frequent contact with the oncology chemotherapy nurse and the palliative care nurses. This contact usually involves coordinating care of particular patients. The Navigator also participates in the palliative care nurses network meetings. The Patient Navigator in Pictou County Health Authority also noted the use of a homeopathic doctor in instances where patients were seeking alternative treatments. In GASHA and South West Health, the Navigators also used the cancer resource rooms in navigating patients, while the Navigator in GASHA reported using the social worker. Clergy, volunteer groups, and charitable organizations are also common contacts used for supporting patients, with the Canadian Cancer Society being a particularly regular contact. Community pharmacies are also a frequent contact, as Navigators work with them to help address situations where patients have challenges paying for medications and other medical supplies.

The Navigators in South West Health and Pictou County Health Authority typically only have contact with the QEII in Halifax whereas the Navigator in GASHA tends to have contact with both, perhaps more so with Sydney. This variation in contact with the province’s cancer care centres is due to the geographical location of these districts. Regardless, a lot of the contact with the cancer care centres pertains to coordination of care including checking on the status of referrals and trying to help patients schedule appointments at convenient times. On these matters contact is with the referral office. Patient Navigators indicated they also have contact with specific people or departments including the oncology staff, chemotherapy department, radiation department, palliative care unit, and the care clinics, with this contact typically being in relation to checking on specific issues for patients. For the Patient Navigator in GASHA, there is also contact with the oncology social worker in Sydney who helps deal with financial and psychosocial issues. Contact with the IWK in Halifax has been minimal for all the Navigators, but for the contact they have had it is mostly with family coordinators or pediatricians and involves sharing information or helping with coordination of care.

The Navigators sometimes provide linkages between community-based health professionals and the cancer care centres. It was noted that Navigators have become recognized as knowing whom to directly contact at the cancer care centres, and other care providers in the district will come to them to determine the most appropriate contact. One Navigator also noted she would sometimes discuss the need for cancer centre referrals with family physicians, as currently not all patients are referred to an oncologist.
“I’ve been to the cancer care centres, I have met the people, I have the numbers. Sometimes they [district health professionals] go through me, sometimes I offer to do it, knowing that I can do it.” Patient Navigator

“I’m sort of the link for who’s the most appropriate person to refer to…it helps to make the link a little better, if there is an issue, e.g., making sure patients gets to radiation.” Patient Navigator

When it comes to sharing information on available supports, the Navigators noted that they have a list of supports they use, but there is not yet a formalized one that has been distributed. Information is shared with others through interactions on district cancer care committees, other teams, and a one-on-one basis. The Navigators indicated that producing a list for distribution is a challenge in light of their workload. It is also a challenge for the Navigators covering a broad geographical area to be continuously aware of all the supports available in other parts of the district. It was noted that the Canadian Cancer Society also has a resource list, but that it needs to be updated for the regions. The Navigators noted that over time they have made considerable progress in identifying resources for patients.

**District Support**

There are a number of avenues available to Patient Navigators for support in their work. All three districts have a cancer care committee in place, and while the mandate of these committees pertains to the whole spectrum of cancer care rather than as an advisory group to patient navigation, they offer valuable linkages to Navigators for obtaining advice and feedback with respect to their work. These committees have representation from the various organizations involved in cancer care as well as cancer survivors. They provide important linkages to the community and community-based health professionals, as well as acute care based professionals.

“She co-chairs the district cancer care committee. This is another formal link and this would offer her community input into the role.” Senior Leader

“The patient navigation program is now a program of the district cancer committee, and I’m part of the leadership group of that committee…so that is a forum that I use to discuss issues.” Patient Navigator

“The district cancer group is certainly one of the biggest supports. All cancer issues can be brought up to that.” Patient Navigator
Patient Navigators also have access to other DHA senior leaders to discuss various issues. Senior leaders also provide a linkage to other organizations, for example, Community Health Boards.

“Senior leadership have been very supportive of the role.” Patient Navigator

“Our VP is on the district cancer care committee. She’s our link with the board in taking our issues to the board.” Patient Navigator

“She [Navigator] has access to the VPs, her office is located in nursing administration, and all the district cancer care committee as support to her. She has a great network.” Senior Leader

“Senior leadership meets every week. We also see each other on a daily basis.”
Senior Leader

“If she needed to talk about an issue, she has senior leadership.” Senior Leader

In South West Health, there was an initial working group for the patient navigation program that met frequently to discuss issues, but less so now that the program is up and running. There is also the palliative care-working group driving the initiative to establish a palliative care program, which can also provide feedback to the Navigator.

One respondent noted it would not be appropriate for the patient navigation program to have its own advisory committee. If it is to be part of the district organization then it needs to work with the linkages and infrastructure that is already in place in the district.

“We wouldn’t want the position to have its own advisory committee if it is to be part of the organization.” Senior Leader

Alignment with Intended Function

Navigators felt their roles largely matched the intended functions of the position. However, it was noted the number of spin-off roles were not realized in terms of the various cancer care committees and initiatives in the district. As the cancer care system in the districts gain momentum, this means more demands on Navigators’ time for activities other than direct patient care and there will be a need to ensure the program remains focused on its intended function of directly supporting patients. While it is important for Navigators to be involved in key committees that contribute to coordination of and improvements to cancer care, each additional initiative should be carefully examined for its potential impact on workload.
In addition, one Navigator noted they may not be supporting family physicians to the point originally set out. However, this is largely a function of physicians’ own reluctance. There is also a clause in the job description about arranging diagnostic testing, which it was pointed out Navigators have no power to order, but can only encourage.

**Work Issues**

Patient Navigators were asked to describe the issues they face due to the nature of their work. Key issues for the Navigators include the amount of travel required, dealing with barriers or challenges in the cancer care system, workload, time management, and lack of backup in the districts.

For GASHA and South West Health, Navigators could potentially spend a considerable amount of time traveling within their district in order to meet with patients. Moreover, all three Navigators have spent considerable amounts of time away from their district for training. While the training is a valued piece the time away does pose some challenges in terms of juggling work. This is compounded by the lack of back up or coverage they have in the district.

> “The travel time [in the district], it is kind of a waste of time, but sometimes it is best to meet face to face. You try to see as many people as you can when going to an area, but I don’t know if people in outlying areas get the same service as people coming into the regional centre.” Patient Navigator

> “The geographic area, I could spend a whole day going from one end of the district to the other then the next day, I feel behind.” Patient Navigator

Navigators can also become frustrated when trying to assist patients and are faced with limitations in the current system. These limitations, which include things like lack of financial assistance, wait times, and lack of psychological supports, are a difficult aspect of the job, as the Navigators cannot find appropriate resources for all patients. In addition, there is a feeling they may be missing some patients who need assistance because the referrals are not automatic. This can be frustrating for the Navigators to try to address.

> “There are some issues that need to be addressed on a much higher level, and the two that pop into my mind are the drug cost and the referral issue – people not being referred to an oncologist or not being offered that option.” Patient Navigator

When it comes to workload and time management, there are multiple demands on Navigators’ time. This includes not only direct patient contact, but also participation in
activities in the district aimed at improving cancer care. As previously noted, additional responsibilities would have to be assessed carefully.

“It is not always easy when dealing with this type of a job. Things happen unexpectedly, patients drop in sometimes. You can’t turn them away. It is difficult to juggle sometimes. I feel I could be a better Navigator if I didn’t have this large a caseload. I feel I could get deeper into issues with more time.” Patient Navigator

The Navigators in each district indicated the amount of paperwork required in their role is a frustrating aspect of their job, even though they understand some of the rationale for it. They indicated there was a lot of duplication and hoped eventually they would only enter the information once and/or there would be clerical assistance to help with that part of the job.

“It [paperwork] takes away from patient time for me.” Patient Navigator

The Patient Navigators unanimously agreed that being able to assist patients is the most positive and valuable aspect of their jobs.

“Dealing with patients, it gives you a whole feel of your worth…anytime that you feel you are helping someone.” Patient Navigator

“What I hear from patients, the feedback I get, that my role has been helpful.” Patient Navigator

“Being able to help and support people.” Patient Navigator

Having the support of CCNS staff, the other Navigators, and district staff is important to Navigators for dealing with the stressors they experience in their role.

“The support I get through CCNS is definitely needed. I don’t think I could do this without that support, and the support of the other Navigators because nobody in the district understands the program to that level so it is very supportive to have someone at least recognize and be able to relate some of the stresses you are feeling.” Patient Navigator

**Required Skill Set**

Patient Navigators were asked what in their education or experience has been the most helpful to them in performing their job and what skill set they believe is important for a Navigator to have. Whether it was a palliative care background, a community background in home care, or an oncology background, all felt their prior training provided them with
a solid basis for fulfilling their role. Even though they had different health care
experience they all had extensive nursing experience and experience with cancer patients.

In terms of the required skill set, all agreed experience in working with cancer patients is
essential. Other things noted included being self-directed, having good communication
skills (particularly in terms of being able to speak about difficult issues and dealing with
physicians), and being knowledgeable in terms of finding information or resources. It was
also noted that a medical background in terms of understanding oncology is important for
the job, and to this effect all the Navigators are enrolled in an eight-month oncology
program regardless of their previous experience. It was noted it would be difficult for
someone without a medical background to fulfill the job, as a key component is
discussing medical issues with patients. It is also recognized there is a huge psychosocial
component, and in this regard some expertise in social work would be an asset.

Overall Effectiveness of the Program

The program is viewed as being very effective with district commitment, CCNS
support and guidance, and having the right professionals in the position key to
effectiveness.

District personnel agreed that the program was effective in each district. Indeed, several
commented the patient navigation program has been one of the most effectively
implemented programs with a strong commitment from the district and appropriate
support and guidance from CCNS integral to its success.

“It is one of the most successful programs that I have ever been involved in…we
thought it was going to be good, but it is better than our anticipated goals and
objectives. Any other program that we have tried to do, there has been a catch, and
there is a gap, or we haven’t been able to recruit the right people. In this case, none
of that happened.” Senior Leader

“It is very successful. It’s used. It’s such an asset to the community, to the public.”
Senior Leader

“It is very successful. We now have the CEO advocating for it who was concerned
about the cost of the resource. We have more people accessing it. It’s growing. The
oncology clinic is asking that we look at a new model with the Patient Navigator and
oncology nurse partnering more formally.” Senior Leader

“It is very successful. I am certainly aware of very positive comments from users of
the services, through the Navigator, and reports.” Senior Leader
Navigators and CCNS personnel felt the program objectives had been addressed. The process is considered ongoing and increasing referrals is one area that needs improvement.

District personnel described several strengths of the program contributing to its effectiveness. This includes:

- The commitment by the districts to the program;
- The skills, knowledge, and personal qualities of the persons in the Navigator roles;
- The support from CCNS;
- The focus of the program on the patient; and
- The linkages the program makes among services.

“It is totally dedicated to patients, it works from the patient out. It is totally related to the strategic plan, values, and vision. It exists to improve services. It helps us examine care, for example, the need for a social worker dedicated to palliative and cancer care and other high risk problems.” Senior Leader

“Communication between the Patient Navigator and all the people involved in the treatment, the families and patients, oncologists, surgeons, and family physicians.” Senior Leader

In contrast, district personnel found it more difficult to identify any major weaknesses of the program in terms of either design or implementation. It was recognized there are several challenges for the program, which are discussed in detail in a following section.

Senior leaders were also asked whether the funds allocated in their district were sufficient to implement the program as intended. There is clear recognition that patient navigation would not have been possible without the funding provided by CCNS. One senior team member indicated they would have reduced the position to half-time in the second year if there were not additional funding from CCNS. With another year passing, most recognize that the position is integral for their district and they would work to find funding for the position within the district. Additional funding will be required not only for sustaining the current Navigator position, but also in terms of ensuring coverage throughout regions. Team members in both GASHA and South West Health indicated the geographic size of their districts is a challenge and they need to find ways to increase accessibility particularly in rural areas.

“I don’t think we are ever going to give up the Patient Navigator no matter what.” Senior Leader
“I would suspect that there would need to be additional resources so there was actually a presence in rural communities too.” Senior Leader

“Cancer Care has covered the cost of one Navigator, but that is simply the beginning. We could have two easy. There would never be an end to what you would put in place if you had money. There are always more people that we can do more for…but that is not necessarily a CCNS role.” Senior Leader

“We have identified [need for] how in the more rural areas, how we can increase accessibility, especially as referrals increase.” Senior Leader

Benefits of the Program

The program is viewed as making the journey easier for many patients in terms of preparedness and resolving challenges and as helping districts improve overall cancer care.

It is clear respondents felt the program has resulted in numerous benefits, both for patients and families and for the districts overall. The cancer journey for many patients has been made easier by the assistance received from the Navigator, while the Navigators’ activities in that role has contributed to an enhanced insight on cancer care in the district. While these benefits have been identified throughout this section, they are outlined specifically here.

Patient Benefits

Respondents indicated one of the key benefits to patients is being better informed and prepared for what to expect. They now have someone who can reinforce information they were given by their family physician, surgeon, oncologist, or other health professionals. It was noted that patients are often very stressed when they are given information and do not remember everything told to them. Therefore, having someone available to reiterate that information is very helpful in ensuring they do understand their diagnosis and treatment options and are prepared for treatment components. Patient Navigators can also provide additional information and resources for clients on their type of cancer.

Another key benefit identified for patients is the assistance with logistical issues. This takes different forms for patients depending on their individual needs. This includes:

- Assistance with coordinating appointments and tests, ensuring everything is in place (i.e., all the necessary tests have been done) prior to seeing the oncologists or surgeons;
• Scheduling appointments with various professionals on the same day to avoid multiple trips to the cancer centres.
• Arranging transportation or accommodations for those who require them when they are going to the cancer centres for treatment.
• Determining where their referral is in the entire process, for example, whether appointments have been made, and in some cases ensuring the appointments are set in a timely manner.

Assistance with these types of issues is felt to have resulted in better coordination of care and improved access to services for patients.

“It has brought a little more timely access and better quality of cancer care to patients and families.” Senior Leader

“I never thought that, she is almost a social worker too. I never thought she would take it to the extent she did, helping them out until there was nothing else she could do for them. She does more than I thought a Navigator would do.” Senior Leader

Patient Navigators have also been able to help many patients deal with financial issues, albeit they are not able to help all patients. When the Patient Navigator is able to identify funding to assist them with some of the costs of things like medication and transportation, it eases a considerable burden for patients.

“Patients are more well-informed. They are not going without as much as they were before.” Patient Navigator

“There has been an increase in early palliative care referrals. Some patients are better informed about the cancer system. For some of them their care is better coordinated or avoids duplication of appointments or tests. They have support and encouragement. They have information available to them.” Patient Navigator

District personnel indicated the assistance provided by the Navigator across these areas has helped reduce the level of stress for patients and families and enabled them to better cope with their cancer experience. They explained that this is important in order for patients to have the best possible outcomes.

**Overall District Benefits**

The patient navigation program was cited with bringing considerable benefits to overall cancer care in the district. This is in conjunction with other cancer care initiatives, most notably the establishment of the district cancer care committees and the attention on cancer care afforded by the direction of CCNS. There is little doubt among respondents
that the patient navigation program along with these other initiatives has brought an **increased attention** to cancer care in each district.

“I never saw the Navigator as alone. CCNS has a whole new way of approaching cancer care. There’s more, they meet with us more, they work closely with our oncology department. We have expanded our oncology department a little bit since our Navigator has been in place, and she is an important part of that.” Senior Leader

Respondents felt there is **greater awareness and collaboration** among health professionals in the district. Health professionals are more cognizant of referring patients to the right resources. The Patient Navigator is often viewed as the central link to finding the right resources for people.

Other benefits included increased and earlier referrals to oncologists, increased contact with cancer care centres, increased referrals to services such as VON, home care, and public health, and an increase in early palliative care referrals.

“I think the navigation program has become the central point for different services to see themselves as part of the team. In community, there are partners who know of the program, they see the Navigator as a source of information, and a common link between community partners.” Senior Leader

“Because she is there we are delivering better cancer care, we are providing more services to patients, and there is increased utilization of services.” Senior Leader

“I think health professionals in general are more aware of the cancer referral process and cancer system.” Patient Navigator

“Patient Navigation has suggested we need to be preventative, to encourage people to participate in screening, describing family history to family physicians, advocating at the care team level to be more focused on health promotion for people who come to use our services for other reasons.” Senior Leader

“The oncology service has increased, there is more than one nurse. That is partly due to the increased oncology expertise the Patient Navigator has brought and the connection to the Halifax cancer centre.” Senior Leader

A Navigator also explained that patient navigation has helped increase awareness of and adherence to cancer care standards.
“It has helped us understand that all people with cancer need to be referred onto the cancer care program at QEII, everyone with cancer should see an oncologist. It has improved how we use evidence, for example, we no longer have someone prescribing chemo who shouldn’t. It is in part due to the cancer care program, but also to the Patient Navigator empowering people to know what is right and what they should be asking.” Patient Navigator

Respondents pointed out patient navigation has brought to light gaps in service at the district level. One of the largest gaps is the burden placed on patients to pay for drugs and other costs, as described previously. Through the contact with patients, the Patient Navigators have been able to identify that as an extremely prevalent problem. They have identified several resources that have been able to assist patients, such as local charitable funds, including the Biker’s Fund and Titz and Glitz. However, they have also identified that these sources are limited in being able to address all problems, and that wider systematic attention needs to be given to the financial burden of cancer.

“It has clearly documented challenges patients experience…we have documented statistics, and real anecdotal situations.” Senior Leader

Another issue identified is traveling to the cancer care centres. Not only does this encompass the cost of travel, which is a problem for some patients, but also the anxiety of traveling to unfamiliar places.

“The distance here, how much it costs for people to go, that’s been identified. Some of them are terrified to think of driving there. Some don’t have the money.” Senior Leader

In South West Health, it was noted that patient navigation has helped to not only illuminate the need for, but also to partially fill the lack of a coordinated palliative care program, which is in place in the other two districts. It was explained that the Navigator has taken on part of the function of coordinating palliative care. However, given the extra demands this places on the position, it would be difficult to do this for all patients or on a long-term basis without interfering with the intended functions of the patient navigation role. Additionally, attention has also been placed on bringing the various cancer supports, including the Patient Navigator, Canadian Cancer Society, and the resource room closer together in the hospital to provide easier access to patients.

Many also felt the program has identified the need for more volunteer resources for things such as support groups, staffing of the Canadian Cancer Society office, and other programs. As referrals increase, the requirement for volunteer resources will undoubtedly also increase.
“We have brought a lot of problems to the forefront, financial problems, cultural ones, educational issues—the level of educational materials.” Patient Navigator

“It has brought new issues to light that have been buried a bit, which isn’t a negative thing, but it has impacted on workload, VON says workload has increased and support group attendance has increased.” Patient Navigator

Other gaps in services the patient navigation program has highlighted include the long wait times experienced by patients, reports not reaching the appropriate people, and a lack of family physicians. In Pictou County Health Authority, it was noted that the lack of family physicians has been addressed at least in part by some family physicians agreeing to take on cancer patients.

Another benefit is the advocacy role fulfilled by the program. This is not only on an individual patient level, but also for the district overall. This covers various issues such as the need for increased financial support to patients, additional services for cancer patients in the district, establishment of support groups for patients, and preventative care, for example, advocating for the breast screening bus to stop in more communities.

Table 17 summarizes the key benefits of the program, identified by Patient Navigators, DHA senior leaders, and CCNS staff.

<table>
<thead>
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<th>Benefits</th>
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<tbody>
<tr>
<td>Ø Patients better informed and prepared</td>
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<td>Ø Patients logistical issues addressed</td>
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<td>Ø Helps patients deal with financial issues</td>
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<td>Ø Patients able to better cope</td>
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<tr>
<td>Ø Increased attention on cancer care in the district</td>
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<td>Ø Increased collaboration among professionals</td>
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<tr>
<td>Ø Identified gaps in service</td>
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<td>Ø Information for advocating for improving services</td>
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Limitations/Challenges of the Program

Key challenges for the program is increasing the number of referrals while simultaneously addressing the increasing demands for service associated with the program’s success.

Respondents noted that there are some challenges for the program including: 1) awareness and receptivity, 2) referrals, 3) impact on demand for services, 4) workload, 5) geographical dispersion, and 6) funding. These have been discussed previously but are outlined in this section.
As it was a new program, it was necessary to build **awareness and receptivity** to the program. Intensive communication efforts around the program were undertaken to address these challenges.

There is also the challenge of **encouraging referrals**. This is being addressed through communications and regular contacts. As the reputation of the program grows, referrals should become more standard.

“There was some conflict with family physicians as the point person for clients. It wasn’t big, but we still have some outliers. We believe it is evolutionary, they need to see the benefits of having this role and then there will be buy in.” Senior Leader

“Uptake by physicians and others. Making sure they understand the role and encourage them to refer. Those are just things you expect when you have new programs. People need to understand and trust it.” Senior Leader

“I think having physicians and providers understand, to have a good understanding of what the position could offer. It will always remain a challenge to some degree.” Senior Leader

“Patients are better informed but because many patients are not referred early enough, it could be a lot better.” Patient Navigator

Although increased referrals to the program are desired, it was recognized this comes hand in hand with the challenge of an **increasing demand for services**. Respondents explained that as services are more coordinated and appropriate referrals are made district services including VON, home care, and palliative care, along with community resources such as support groups are increasingly accessed. While this is considered a positive outcome of the program, it is also recognized that it may become a challenge as demand for services increase. An increased focus on cancer care in each district through the patient navigation program and other conjoint activities such as the district cancer care committee has served to heighten awareness of the cancer care available at the district level as well as the limitations. This awareness results in increased pressure to work towards improving cancer care services within the districts.

“The only challenge is resource offshoots. They all take money. There is heightened sensitivity around a palliative care program. There is more pressure on the district to provide more services. A lot of these components require funding, but it is good pressure because it needs to be done.” Senior Leader

As awareness of the patient navigation program spreads along with referrals to the program, the **workload of the Patient Navigators** will also increase. There is a concern
across all districts that there will be a point where the workload in each district becomes too much for the Patient Navigator to address. There is recognition that the functions of the role will have to be periodically re-evaluated to ensure the Navigators’ workload permits the role to be fulfilled successfully and does not result in burnout. Another limitation noted was coverage when Patient Navigators are away.

For GASHA and South West Health, geography is felt to be a challenge in implementing the program. This is in terms of initial communications about the program, which involved a lot of one-on-one contact. It’s also in terms of overall visibility and reach of the program since the Navigator is based in one particular community. Therefore, there was some question whether access to navigation is the same throughout the district.

“Our district is big. It took a toll on the Patient Navigator to travel.” Senior Leader

Finally, some district personnel indicated ongoing funding would be a challenge as that provided by CCNS comes to an end.

“Our biggest worry is funding the role. We believe the role is critical to patient care.” Senior Leader

Moving Forward

Support for continuing the program is resounding. An ongoing role for CCNS is not only desired, but also viewed as essential.

Both Patient Navigators and senior leaders agree it is important to continue to have a Patient Navigator in the district cancer program. Indeed, they commented it would be difficult to remove the program now that benefits have been realized and people have developed expectations of the role.

“I think it is very important. It has been a great link for nurses and other health professionals to the cancer system and to the regional hospital and most patients are very appreciative of the services, the ones you are able to help.” Patient Navigator

“It is very important because there are still an awful lot of barriers. It has become part of the way we are doing our work with people. At this point if it was pulled away it would be a bigger gap then it was before.” Senior Leader

“It is so fundamental to the goals of quality evidence-based cancer services, client satisfaction, and improved primary health services in the community.” Senior Leader
“It is absolutely essential because of the distance, the services we lack, the challenges for people in our district.” Senior Leader

“I strongly support continuing with the role. Patients are more confident, they know what is coming next.” Senior Leader

Most felt that patient navigation was well designed and required little modification. Where the program needs improvement however, is in increasing referrals, as described previously. A need to improve available supports, such as financial assistance and support groups, was considered necessary in assisting the Navigators to fulfill their roles. Other required improvements were identified for specific districts. In South West Health, it was felt a palliative care program was necessary, as the Navigator has been covering many aspects of palliative care not part of the intended role of a Navigator. The need for a social worker was also mentioned in South West Health. In Pictou County Health Authority, it was stated that the Navigator needs to be more community based through participation in wellness initiatives or sitting on community health boards. It was also noted that the Navigator should be part of an interdisciplinary team in hospital and not just the palliative care team. In GASHA, it was mentioned that ways to improve access in rural areas need to be considered.

Role of CCNS

When asked what they saw as the role of CCNS, district personnel unanimously desired a strong involvement on the part of CCNS in the future of the program. There is recognition that the level of current support, particularly in terms of financial support, is not realistic to expect from CCNS. The role of CCNS is viewed as particularly critical, ensuring that standards of practice are established and followed in each district.

“CCNS should always be attached to the delivery of cancer care services in districts. They (CCNS) should tell us what and how we should deliver, they should evaluate how we are doing like an accreditor would.” Senior Leader

CCNS was also viewed as having an important role in ensuring coordination among districts and linking Patient Navigators so Patient Navigators can support and learn from one another. This was viewed as particularly important to Navigators as they rely on this support network in performing their job.

“We don’t expect them to continue to coordinate. It has to be a district program, but it would be great to still pull together all the Navigators, so to me it would be great if they continued to do that, to share.” Senior Leader
Education of Patient Navigators was also considered a part of CCNS’s role and one that the Navigators personally thought was particularly valuable to them. It was also felt, that as a provincial body, CCNS would be able to synthesize the information from each district in order to provide evidence of issues in the cancer care system that need to be addressed by government.

“I feel I need them there to back me. We need the coordinator of the program. We need someone you can bounce ideas off.” Patient Navigator

“I think that an identical role to what they have been playing would be ideal, although that probably isn’t possible. I think they need to play as big as role as possible. I think the more support and expertise the program has, the better it will do.” Patient Navigator

“To continue to support and nurture it. I would hope that there would be support for education and ongoing promotion of the role and I think the networking part of it is important for continuity of standards.” Patient Navigator

“I think the expertise is with CCNS. The encouragement and enthusiasm that we get from them and the focus on cancer. It can become very dilute in the district when you are dealing with so many different illnesses, but to keep cancer in the forefront, there needs to be a real drive and some support to do that. Plus the educational needs of the Navigators. As the systems change and cancer care changes, we need to be up-to-date.” Patient Navigator

**Considerations for Other Districts**

Respondents clearly saw several factors as important for other districts to consider in implementing their own patient navigation program. One of these factors was having a commitment from the district. They explained that this support needs to come from the senior leaders and the board. As well, they indicated it is important to build support from various community partners, citing that buy-in contributes to program success. Along these lines, communication with family physicians and others was viewed as an integral component to establishing this receptivity.

“It was supported by the community and enough providers. Having those kinds of champions and hiring the right people.” Senior Leader

“You need to promote yourself. That is the key because if you don’t promote yourself to all these people and they don’t use the service, it is not going to work. It is going out to community groups, community health boards, and physicians’ offices. It has to be sold first.” Senior Leader
“Keep focus on what it was set out to be, to support patients and families, while supporting physicians and others, but I think we have to keep the patients and families first.” Patient Navigator

The connection and support from CCNS was considered an essential component. The guidance and standards provided by CCNS along with the orientation/education and linkages to other districts was highly regarded and felt to help keep individual districts on track. It was noted that to be successful, Navigators need to continually be up-to-date with new evidence in cancer care. The district cancer committees were also seen as a beneficial supplement to the Navigator’s role, providing a source of support and information for the Navigators. It was also suggested that to achieve maximum success, the district needs to ensure there is a team approach to cancer care, with the Navigators serving as part of multidisciplinary teams on both the acute care and community sides. Finding the appropriate person to fill the position was also deemed critical. Respondents explained that a Patient Navigator needs to have the right knowledge and skills to be effective in the position, but they also need to have the right personality fit and level of dedication to make the program effective.

“When you are starting a system, not hiring the right person could end a good opportunity.” Senior Leader

Finally, it was noted that districts need to be prepared for the level of commitment required for the program. Respondents explained that implementing a program like this brings additional scrutiny to cancer care in the districts and will illuminate gaps in service. Districts need to be prepared for the commitment involved in addressing these gaps.

“They need to understand that it will be a well-utilized resource by health professionals and the community equally. It will demonstrate the gaps in service at the DHA level. It will offer strengths and support and improve the delivery of service, but it will demonstrate your gaps and you have to strive to do better. It will cost, it will require you to advocate to those who might see the role as a conflict to others. You need to have strong support for the role at the management level.” Senior Leader
Patient Survey
Detailed Findings

This section presents the detailed results of the 162 interviews conducted with patients.

Cancer Background

*A profile of respondents’ cancer experiences suggests Navigators are reaching patients with various cancer types and who are at different points in their cancer journey.*

Seven in ten (70%) patients were diagnosed with cancer in the last three years, with most being diagnosed in 2002. Less than two in ten (15%) received their diagnosis between 1996 and 2000, while ten percent were diagnosed prior to 1996. The remaining five percent were unable to recall when they received their diagnosis. This profile is expected, since Navigators began seeing patients early in 2002. Only 25 percent of patients had a diagnosis prior to implementation of the patient navigation program. Figure 1 outlines the year the patient received their cancer diagnosis.

![Figure 1. First Cancer Diagnosis](image-url)
As Figure 2 indicates the types of cancer reported by respondents were: breast (35%), colorectal (20%), prostate (7%), lymphoma (7%), ovarian/uterine (6%), lung (4%), and liver (4%). No other specific type of cancer was identified by more than three percent.

At the time of the survey, six in ten (59%) have completed their treatment regime, while one-quarter (26%) were currently receiving treatment. Of the remainder, one in ten (10%) did not require treatment, and (4%) were waiting to commence treatment.

Among those patients who had completed or were currently receiving treatment, chemotherapy (50%) and radiation (45%) were the two treatment types most frequently identified, followed by surgical intervention (29%). Less frequently identified types of treatments included hormone therapy (19%) and oral medications (16%). The types of treatment are outlined in Figure 3.

Six in ten patients (61%) received all or part of their treatment at the Cancer Centre in Halifax and four in ten received all or part of their treatment at their local hospital (47%). One in ten patients (12%) reported receiving all or some of their treatment at the Cancer Centre in Sydney. (Only patients from GASHA would be likely to go to Sydney for treatment). No other location was mentioned by more than six percent of respondents.
Home location influences where patients go for treatment. Patients in South West Health and Pictou County Health Authority were more likely to receive their treatment at the Cancer Centre in Halifax, whereas patients in GASHA were more likely to visit the Cancer Centre in Sydney. Also in terms of regional differences, patients in Pictou County Health Authority (59%) were more likely to have received all or part of their treatment at their local hospital in comparison to those in South West Health (41%) and GASHA (38%).

While the number of visits to the cancer centres ranged from one trip to more than 20, the average number of trips is 12. Patients in Pictou (15 trips) and GASHA (13 trips) made slightly more trips than patients in South West Health (8 trips).
Overall Cancer Experience

Primary Issues

_The emotional consequence of having cancer is the primary concern of patients._

When asked unaided, what their primary issue or concern was during their cancer experience four in ten (40%) identified emotional impact, stress or fear associated with cancer. This was followed distantly by physical symptoms or side effects of treatments (15%). No other specific issue or concern was identified by more than seven percent of patients. Patients in Pictou County Health Authority (50%) were most likely to identify the emotional impact as their greatest issue, while patients in South West Health (30%) were least likely.

In addition to the unprompted questioning of issues during their cancer experience, patients were asked whether each of nine specific issues had been a concern to them, if they had not identified the issue during the unprompted question. These issues included emotional impact, lack of information on diagnosis, lack of information on what to expect during treatment, lack of coordination among those involved in their care, financial concerns, distance to travel to cancer centres, accommodations during treatment, waiting times, and physical symptoms or complications. Figures 4 and 5 outline both the unaided mentions and the total aided mentions. Considering those who identified an issue either unprompted or when prompted, the emotional impact of having cancer was the most frequently identified issue, with two-thirds (67%) identifying it as an issue for them.

As shown in Figure 5, other frequently identified issues or concerns included physical symptoms or complications (44%), distance to cancer centres (40%) and financial concerns (38%). Two in ten (22%) patients identified waiting times or lack of information upon diagnosis (18%) as issues. Other mentions included a lack of information on what to expect during treatment (16%), lack of coordination among those involved with their care (12%), and finding accommodations during treatment (10%).

![Figure 4. Issues and Concerns During Cancer Experience](image)

![Figure 5. Issues and Concerns During Cancer Experience](image)
As outlined in Table 18, there are some regional differences. Patient in GASHA (21%) were most likely to report difficulties with finding accommodations as opposed to those in South West Health (8%) and Pictou County Health Authority (3%). Patients in GASHA (48%) and South West Health (45%) were more likely to report having issue with the distance they had to travel to the cancer centre than those in Pictou County Health Authority (28%). This latter finding may be a consequence of Pictou County Health Authority’s proximity to Halifax relative to the other regions. In terms of financial assistance, patients in GASHA (55%) were most likely to have experienced financial concerns whereas those in Pictou County Health Authority (25%) were least likely.

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<thead>
<tr>
<th></th>
<th>GASHA</th>
<th>South West Health</th>
<th>Pictou County Health</th>
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<tr>
<td>The emotional impact, stress, or fear</td>
<td>74%</td>
<td>60%</td>
<td>70%</td>
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<tr>
<td>Lack of information on diagnosis</td>
<td>21%</td>
<td>15%</td>
<td>18%</td>
</tr>
<tr>
<td>Lack of information on what to expect</td>
<td>17%</td>
<td>20%</td>
<td>12%</td>
</tr>
<tr>
<td>Lack of coordination among those involved</td>
<td>12%</td>
<td>13%</td>
<td>10%</td>
</tr>
<tr>
<td>Financial concerns</td>
<td>55%</td>
<td>40%</td>
<td>25%</td>
</tr>
<tr>
<td>Distance to travel to cancer centers</td>
<td>48%</td>
<td>45%</td>
<td>28%</td>
</tr>
<tr>
<td>Finding accommodation during treatment</td>
<td>21%</td>
<td>8%</td>
<td>3%</td>
</tr>
<tr>
<td>Waiting times</td>
<td>19%</td>
<td>23%</td>
<td>23%</td>
</tr>
<tr>
<td>Physical symptoms or complications</td>
<td>45%</td>
<td>43%</td>
<td>45%</td>
</tr>
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In addition, men were almost twice as likely (57%) to report experiencing financial difficulties than women (30%). Those most likely to experience difficulties with wait times included those with higher levels of education and those who were in contact with the Navigator before or during treatment. A relationship was also observed between frequency of contact with the Navigator and wait times. Those having more frequent contact with the Navigator experienced fewer difficulties in this area.

Aside from difficulty with wait times, patients with higher levels of education were also more apt to express concern with the lack of information they received regarding treatment and the coordination of their care.

**Sources of Support**

*Family members are by far the greatest source of support for patients.*

Patients were asked to identify their main source of support during their cancer experience, without the aid of a list of options. In analyzing the results, a distinction is made between first mentions and total mentions. First mentions are those answers supplied first by patients, while total mentions
include first as well as other responses given. First mentions are shown in Figure 6 and total mentions in Figure 7.

In total mentions, family members, excluding spouses/partners, were the most frequently reported source of support (72%), while spouses/partners were identified by close to one-half (47%) of respondents. In first mentions, spouses/partners were the most frequently mentioned source of support (38%) closely followed by other family members at (36%).

Other total mention sources of support included friends (20%), family doctor (14%), Patient Navigator (12%), oncologist (10%) and other cancer center staff (10%). No other source of support was identified by more than nine percent of respondents.

Those most likely to identify the Navigator as a support included those who had contact with the Navigator prior to their treatment and those who see the Navigator more frequently.

Those who were diagnosed in 2002 or after (42%) were more likely to identify a family member, other than their spouse/partner, as their first mention for their primary source of support than those diagnosed prior to 2002 (25%).

Assistance in Journey Preparation

*Family doctors, oncologists, Cancer Patient Navigators and staff at the cancer centres are most often attributed with helping patients prepare for their cancer journey.*

Patients were asked to identify, without the aid of a list of options, who helped them understand their diagnosis and what to expect with treatment and recovery. Again, a distinction is made between first mentions and total mentions, with first mentions being those answers supplied first by patients, while total mentions include first as well as other responses. Looking at total mentions, three in ten patients (30%) identified their family doctor and the same proportion (30%) identified
their cancer specialist as the individual who helped prepare them the most. In addition, another two in ten (20%) identified each of the Patient Navigator or staff at the cancer centre as the person who assisted them in this process. Other common mentions included surgeons (15%) and other health care professionals (16%). Figures 8 and 9 outline first and total mentions, respectively.

Patients in GASHA were more likely to identify their family doctor as the individual who helped prepare them than those in other districts, while patients in Pictou County Health Authority were more likely to identify the Patient Navigator than those in other districts. Patients who were introduced to the Navigator earlier in their journey were more likely to report the Navigator provided them with assistance in this area, as are those who have regular contact with the Navigator.
Satisfaction with Care

Patients expressed high levels of satisfaction with their cancer care overall.

Patients’ satisfaction with four aspects of cancer care was ascertained. These four aspects included the assistance of health professionals, the coordination of care, access to health professionals for questioning, and availability of supports, such as home care and transportation. As demonstrated in Figure 10, almost all patients express satisfaction with the assistance of health professionals in helping them understand their diagnosis and what to expect, the coordination of care among health professionals, and having a health professional to whom they could turn to if they had any questions or concerns.

The aspect of care that received the lowest satisfaction rating pertains to the availability of supports, such as home care and transportation, albeit it is still quite high with close to seven in ten (68%) very or somewhat satisfied with this aspect of care. Only eight percent (8%) were not satisfied. Two in ten (21%) indicated that this aspect of care was not applicable to them and another three percent (3%) were unable to provide a definite response to this question.

Patients in GASHA and South West Health were more likely to require home care and transportation support, however they reported satisfaction with the support. Patients in Pictou County Health were unlikely to require this support and therefore did not provide a satisfaction rating.
Cancer Patient Navigation

Sources for Initial Contact

*A variety of sources were identified for initiating contact between patients and Navigators.*

As outlined in Figure 11, patients found out about the Patient Navigator in a variety of ways. About two in ten patients reported being contacted by the Patient Navigator while they were in hospital (22%) or being referred or informed by hospital/cancer centre staff (19%). Others reported their family or friends told them about the Patient Navigator (13%) or the Patient Navigator contacted them at home (12%). Less than one in ten (7%) reported their family doctor referred or informed them. However, in cases where the navigator contacted them directly, patients may not be aware their family doctor had referred them. Other mentions by 6 percent or less included ads/articles in newspapers, posters/pamphlets, and previous experience with the Navigator.

![Figure 11. Means of Finding out About the Cancer Patient Navigator](image)

There were some variations across districts. Patients in GASHA followed by those in South West Health were more likely to be contacted by the Patient Navigator at home, compared with patients in Pictou County Health Authority, where no patients reported being contacted at home. Conversely, patients in Pictou County Health Authority were the most likely to be referred to or informed about the Patient Navigator by hospital or cancer centre staff.

Patients diagnosed prior to the patient navigation program being put in place were more likely than patients diagnosed more recently to find out about the Navigator through articles in the paper or posters and pamphlets.
Contact with Cancer Patient Navigator

**Initial timing and ongoing frequency of contact with Navigators varied and most patients did not have any trouble in reaching their Navigator.**

Most patients (76%) recalled having contact with the Patient Navigator. Patients in Pictou County Health Authority (82%) and South West Health (77%) were more likely to recall contact with the Navigator than those in GASHA (67%). GASHA’s Patient Navigator often assists patients indirectly by providing assistance to the rural palliative care nurses who interact with the patients in their local area. In these cases, the Patient Navigator has no direct contact with the patients. Close to one-half indicated they were in contact with the Navigator before treatment. Another one-quarter was in contact during treatment and the same proportion was in contact after treatment. Less than one in ten were unsure when their initial contact took place. Figure 12 shows the time of first contact with the Navigator.

**Figure 12. Time of First Contact With the Cancer Patient Navigator**

Don't know/ Not sure

Before treatment 47%

During treatment 24%

After treatment 24%

Patients in Pictou County Health Authority were more likely to be in contact with the Patient Navigator before treatment than those in GASHA or South West Health, while the latter two districts had higher proportions of patients first coming into contact with the Navigator during treatment. Men were also more likely to indicate first contact was during treatment. Those diagnosed in 2002 or later were more likely than those diagnosed prior to that time to have contact with the Navigator before beginning their treatment, while those diagnosed prior to 2002 were more likely to have first contact during treatment.
As shown in Figure 13, frequency of contact with the Navigator varied. Two in ten (22%) indicated they were regularly in contact with the Patient Navigator, while close to one-half (46%) reported occasional contact. Just over one-quarter (27%) indicated they were rarely in contact with the Patient Navigator, while a few were unsure.

Patients in South West Health were less likely to report regular contact than those in the other two districts. Patients in Pictou County Health Authority were less likely to indicate that contact was rare. Patients were also more inclined to indicate their contact was regular if they were in contact with the Navigator before treatment, if they were older, and if they had household incomes less than $16K.
Most participants (66%) reported they never had any trouble contacting the Navigator or did not try to contact the Navigator. Patients in GASHA and South West Health, women, and those with household incomes less than $16K were more likely to indicate they had not tried to contact the Navigator. Those whose contact with the Patient Navigator was rare were also more likely to not have tried to reach the Navigator. A few (15%) did report they sometimes or often had trouble contacting the Navigator. Of those reporting difficulty (n=18), the difficulty in reaching the Patient Navigator pertained to not being able to reach the Navigator (answering machines, busy signals, etc.) and the Navigator not being available or being away. An occasional participant indicated the Navigator did not return their call or there was no one at the office when they went there. Figure 14 outlines the frequency of difficulty in reaching the Patient Navigator.

Figure 14. Frequency of Difficulty in Reaching the Cancer Patient Navigator

- Never had trouble: 66%
- Sometimes had trouble: 13%
- Often had trouble: 2%
- Did not try to reach navigator: 18%
- Don't know/No answer: 2%
Assistance from Cancer Patient Navigator

Patients have received various types of assistance from Navigators.

As demonstrated in Figure 15, the assistance provided by Patient Navigators is multi-faceted. Patients commonly indicated the Patient Navigator had provided emotional support (63%) and information on what to expect from treatment and its side effects (62%). One-half also indicated that the Patient Navigator helped them understand their diagnosis (54%), helped book or coordinate their appointments (50%), and helped them access support groups (50%). Fewer than one-half (45%) reported the Patient Navigator helped prepare them for their visit to the cancer treatment center. One-third indicated their Navigator helped them with arranging follow-up care in their community after treatment (35%), while three in ten indicated they received help finding funding for drugs or supplies (31%). One-quarter reported receiving assistance with finding accommodations during treatment (24%). Some patients also received help arranging transportation (15%).

![Figure 15. Assistance Received From the Cancer Patient Navigator](image)

Patients in Pictou County Health Authority were more likely to report receiving each type of assistance than those in the other districts, except finding accommodations and transportation. Patients in GASHA were somewhat more likely to indicate they received help in finding funding for drugs or supplies.

There were other demographic variations. More women than men were inclined to report receiving support in several areas including emotional support, understanding their diagnosis, booking or coordinating appointments, and arranging follow-up care. Men were somewhat more inclined to require assistance with accommodations and transportation arrangements. Across age groups, younger patients were more likely than older patients to report receiving assistance in preparing them for their visit to the cancer treatment center, booking or coordinating appointments and
arranging follow-up care. Older patients were more likely than younger patients to report assistance finding funding for drugs and supplies.

In terms of income, those with lower household incomes were less likely than those with higher household incomes to report receiving assistance with preparation for their visit to the cancer centre, but were more likely to report assistance with funding for drugs and supplies and arranging transportation. Additionally, patients were more inclined to report assistance with accessing support groups if their household incomes were between $16K and $50K while those with household incomes of at least $25K were more likely to report assistance with follow-up care. Considering education, those with lower education levels were more likely than those with higher education levels to report assistance with funding for drugs and supplies, finding accommodations, and arranging transportation.

Those who had contact with the Navigator before treatment were more inclined to indicate they received a variety of supports as opposed to those who had contact at a later point in time. This is as would be expected, given that the earlier the contact, the more opportunity Navigators would have had to be aware of issues and provide assistance. Also, as would be expected, those who reported more frequent contact with the Navigator were more inclined to report receiving various types of assistance. Those diagnosed prior to 2002 were more likely to indicate they received help understanding their diagnosis and in arranging follow-up care of treatment. While the latter would perhaps be expected given that these patients were more likely to be finished treatment, the former seems to be reflective of a portion of patients having unresolved issues regarding understanding their diagnosis, which once in place, the Navigators have been able to provide assistance with.

Nine in ten (89%) reported they did not have any issues or concerns that the Navigator was unable to help them with. While only two percent indicated the Navigator was unable to help with finding funding for drugs or supplies, all of these patients had household incomes in the range of $16K to $25K. While these numbers are small, it does suggest that these patients falling around the cut-off levels for financial assistance are the ones most at-risk financially.

**Evaluation of Care**

*Patients consider various aspects of care provided by Cancer Patient Navigators very important and most are satisfied with the service they have received.*

Patients were asked to indicate how important they considered each of ten aspects of care Patient Navigators can potentially provide. Almost all considered each factor to be at least somewhat important. Looking at the proportion considering the factors to be very important reveals some differences in rankings. The highest proportion (93%) considers the Navigator being understanding and caring as very important. This is followed by the Navigator sharing information in a way they are able to understand (90%), being available when they need her (88%), trying to identify and address any issues they have (85%), helping them feel less anxious (84%), and being sensitive to their personal beliefs (81%). Somewhat further down the list in terms of being considered very
important include: assistance in dealing with financial issues (76%), helping with arrangements such as transportation, accommodations, and appointments (74%), and trying to meet with them at times that are convenient for them (73%). Two-thirds consider the Navigator spending enough time with them as very important (66%). Figure 16 shows the importance ratings of aspects of care.

![Figure 16. Important Aspects of the Cancer Patient Navigator](image)

 Patients were also asked to indicate how satisfied they were with the Patient Navigator on those same factors. Satisfaction was examined excluding those who indicated that aspect of patient navigation as not applicable to them. As evident in Figure 17, satisfaction levels were high. At least eight in ten were very satisfied that the Patient Navigator had tried to meet or talk with them at times that were convenient for them (86%), had been understanding and caring (85%), shared information with them in a way they were able to understand (85%), identified and addressed needs (83%), had been sensitive to their personal beliefs (81%), had spent enough time with them (80%), and helped them feel less anxious (79%). Satisfaction levels were somewhat lower for help with arranging transportation, accommodations, and appointments (73%) and for help dealing with financial issues (67%).

![Figure 17. Satisfaction With Aspects of the Cancer Patient Navigator](image)
For the purpose of comparison, CRA performed a gap analysis on patients’ perceptions to determine the difference (i.e., the “gap score”) between what aspects of the care provided by Navigators they consider as very important, on the one hand, and how satisfied they are with the Navigator’s performance on these aspects, on the other hand. A gap analysis consists of identifying the percentage of patients that both view an aspect of care as very important and indicate they are very satisfied with the Navigator in terms of this aspect of care. This type of analysis can be a powerful indicator of those aspects requiring the most attention in program improvement.

The gaps observed in this study were notably small. It is not uncommon when it comes to public sector services for gaps to be as high as 50 and 60 percent. In the present study, most gaps were under 15 percent. The largest gap is for help in dealing with financial issues, which stands at 23 percent. This is to be expected given that it is beyond the control of the Navigators to secure financial assistance for all patients. The gap scores are presented in Figure 18.

The gaps were considerably smaller as frequency of contact with the Navigators increased. They were also smaller in Pictou County Health Authority, among women, younger patients, and those with higher household incomes. Gaps were largest among patients who first came into contact with Patient Navigators during treatment.
Overall Level of Assistance

Patients were very positive about the overall level of assistance they received from the Navigator.

Seven in ten (70%) patients rated the overall level of assistance they received from the Navigator as excellent, while another two in ten (19%) rated it as good. Less than one in ten (8%) rated it as only fair or poor. Patients were more likely to provide excellent ratings if they had been in contact with the Navigator before treatment, and had more frequent contact with the Navigator. Figure 19 shows the ratings for overall level of assistance.

![Figure 19. Rating of Overall Level of Assistance Provided by the Cancer Patient Navigator](image)

Those who indicated that the overall level of assistance was only fair or poor were asked how this assistance could be improved. While this represents only nine patients, most felt there should be more involvement, follow-up, or information.
The relationship between perceptions of aspects of care provided by the Patient Navigators and the rating of overall level of assistance was examined. To do so, correlations were calculated between overall level of assistance and each factor. Correlations can range from 0 to 1. Results indicate that all ten aspects of care are significantly correlated to overall level of assistance, indicating that all factors contribute a great deal to patients’ experience with patient navigation. Correlation scores are presented in Table 19.

<table>
<thead>
<tr>
<th>Table 19. Correlation with Overall Level of Assistance</th>
<th>$r^2$ (out of 1.0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared information with you in a way that you were able to understand</td>
<td>.75</td>
</tr>
<tr>
<td>Spent enough time with you</td>
<td>.75</td>
</tr>
<tr>
<td>Helped you feel less anxious</td>
<td>.72</td>
</tr>
<tr>
<td>Tried to meet or talk with you at times that were convenient for you</td>
<td>.72</td>
</tr>
<tr>
<td>Been sensitive to your personal beliefs</td>
<td>.70</td>
</tr>
<tr>
<td>Tried to identify and address any needs that you had</td>
<td>.67</td>
</tr>
<tr>
<td>Been available when you needed her</td>
<td>.67</td>
</tr>
<tr>
<td>Helped you with arrangements such as transportation, accommodations, and appointments</td>
<td>.66</td>
</tr>
<tr>
<td>Been understanding and caring</td>
<td>.63</td>
</tr>
<tr>
<td>Helped you deal with financial issues</td>
<td>.59</td>
</tr>
</tbody>
</table>
Cancer Patient Navigation Database Review
Detailed Findings

This section presents the analysis from the patient navigation database review. There are two types of clients recorded in the database. One is patient, when the referrals are directly for patients. The other is a non-patient referral, which could comprise request for assistance from health professionals, family members, or community groups. In many cases, these referrals were relevant to individual patients, but were not a direct referral for the patient. As outlined in the methodology, in South West Health, referrals that related to a non-patient group were categorized as patient referrals even though the patients were not contacted. It is important to keep this in mind when examining differences across district health authorities.

Referral Overview

Referrals were a mixture of direct referrals for patients and referrals not directly for patients.

In total, 808 referrals were made. Overall, three-quarters (74%, n=598) of the referrals were classified as patient referrals. The remaining one-quarter (26%, n=210) of contacts was classified as a non-patient referral. Given the difference in classification, it is as expected that most referrals in South West Health (97%, n=231) were classified as patient referrals. In Pictou County Health, seven in ten (69%, n=247) were direct patient referrals and three in ten (31%, n=111) were not. In GASHA, close to six in ten (57%, n=118) were patient referrals, while more than four in ten (43%, n=90) were not. This higher proportion of non-patient referral is in GASHA, where the Patient Navigator is often behind the scenes, providing indirect support to the patient through the palliative care nurses located throughout the district. Figure 20 below outlines the client breakdown across districts.

Figure 20. Cancer Patient Navigation Clients

<table>
<thead>
<tr>
<th>District</th>
<th>Patient %</th>
<th>Non-patient %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>74%</td>
<td>26%</td>
</tr>
<tr>
<td>South West Health</td>
<td>97%</td>
<td>3%</td>
</tr>
<tr>
<td>Pictou County Health</td>
<td>69%</td>
<td>31%</td>
</tr>
<tr>
<td>GASHA</td>
<td>57%</td>
<td>43%</td>
</tr>
</tbody>
</table>
Patient Contacts

Referrals appear to be increasing, however, there is a higher proportion of referrals in the counties where Navigators are present.

A jump in referrals in the last six-month period suggests referrals may be on an upward trend, although further tracking is required to confirm that this is the case. This increase noted in the last six-month period followed a slight decrease in the number of patient referrals from the first six-month period to the second six-month period. This pattern was observed in both Pictou County Health and GASHA, whereas the number of referrals remained relatively stable in South West Health. Figure 21 below outlines the number of patient referrals.

Figure 21. Number of Patient Referrals
In South West Health and GASHA there are several counties in each district. An analysis was conducted to determine if there is any geographic pattern in the referrals to the program. Results indicate there was a strong tendency for a greater number of referrals within the counties where the Patient Navigators are located. This is Yarmouth County in South West Health and Antigonish County in GASHA. In South West Health, this may have leveled off but further tracking is required to confirm this. In GASHA, most direct patient referrals come from Antigonish County, but this is as expected given that in other areas, the Patient Navigator is providing indirect support through the palliative care nurses. Figures 22 and 23 outline the number of referrals by county for South West Health and GASHA, respectively.

Only two referrals were made for patients outside the district. One of these was from Colchester County and the other from Cumberland County.
Patient Characteristics

Patients referred to the patient navigation program most commonly had a new diagnosis and were at least 50 years of age.

Patients fit into one of two categories: new diagnosis or recurrent diagnosis. Overall, 84 percent of referrals were classified as a new diagnosis. Less than two in ten (15%) were classified as a recurrent diagnosis. Pictou County Health had a slightly higher proportion of recurrent diagnoses than South West Health or GASHA. The categories of patient referrals are outlined in Figure 24.

As evident in Figure 25, there were also some changes over time. In particular, the number of referrals for recurrent diagnoses dropped.
As outlined in Figure 26, patients referred to the Patient Navigators had varying types of cancer. Overall, three in ten (28%) were breast cancer patients. Two in ten (22%) had cancer in the digestive system (includes esophagus, stomach, colorectal and pancreas). One in ten (12%) had cancer in the respiratory system (includes larynx, lung, trachea, and bronchus). Other types of cancer included male genital organs (includes prostate and testes) (6%), blood and lymph tissue, urinary tract (includes kidney and bladder) (6%), female genital organs (includes cervix and ovary) (2%), brain (2%), and liver/gallbladder (1%). The types of cancer did not differ substantially across districts, albeit there were some small fluctuations.

More than eight in ten (86%) patients were 50 years or older at the time of referral. More specifically, one-half (51%) were 50 to 69 years of age and another one-third (34%) were 70 years of age or more. Overall, the age distribution was fairly consistent across districts and over time. However, slightly more patients in Pictou County Health were aged 20 to 49 years and slightly fewer were aged 50 to 69 years, in comparison with the other districts. Figure 27 outlines the age distribution of patients.
Patients were more often female than male. This is consistent across districts and over time. (see Figure 28)

The cancer patient navigation database is updated for patient death statistics on an ongoing basis, as an index of the number of patients in palliative stages. One-quarter (n=143) of the referred patients have since deceased. In GASHA, patients in palliative stages would be more likely to be referred to the palliative care nurses than to the Navigator. Figure 29 shows the proportion of referred patients who have since deceased.
Timeliness of Patient Referrals

There was considerable variability in the timeliness of referrals.

Information on diagnosis dates was transferred from OPIS and comparisons made with referrals dates. For this analysis, patients diagnosed more than a year before the start of the program were excluded to control for more extreme cases. Patients who have had a recurrence (based on the recurrence data field) were also excluded in looking at new diagnoses. The analysis showed that the average number of days between diagnosis and referral was 49 days, which remained relatively steady over the eighteen months. The trend was slightly different across districts. South West Health had a decreasing trend, whereas GASHA exhibited an increasing trend. Pictou County Health experienced a declined after a rise in the second quarter. Altogether, the average length of days between diagnosis and referral was lower in Pictou County Health (42 days) than South West Health (50 days) and GASHA (59 days). The mean number of days between diagnosis and referral are outline in Figure 30.

Figure 30. Mean Number of Days From Diagnosis to Referral to Cancer Patient Navigator

n=332

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Overall</td>
<td>49.3</td>
<td>51.3</td>
<td>53.4</td>
</tr>
<tr>
<td>South West Health</td>
<td>48.5</td>
<td>60.3</td>
<td>58.1</td>
</tr>
<tr>
<td>Pictou County Health</td>
<td>41.7</td>
<td>34.2</td>
<td>48.1</td>
</tr>
<tr>
<td>GASHA</td>
<td>50.4</td>
<td>53.7</td>
<td>35.7</td>
</tr>
</tbody>
</table>
From another perspective, the proportion of patients (of all new diagnoses referred) seen within thirty days of diagnosis was also examined. Overall, one-half of patients were referred within 30 days of diagnosis. This proportion was slightly higher in Pictou County Health than South West Health and GASHA. This proportion increased substantially in South West Health over the 18 months from one-third percent in the first six months to two-thirds percent in the last six months. In contrast, GASHA and to a lesser extent Pictou County Health saw a decline in the proportion of patients seen within 30 days from the first diagnosis date. Figure 31 outlines the proportion of patients seen within 30 days.

Figure 31. Proportion of Patients With New Diagnosis Referred Within 30 Days of Diagnosis Date

n=353
Considering those patients who had a recurrence, the average number of days between the date of recurrence (as determined from registration data in OPIS) and referral to the Navigator was 86 days. This analysis excluded those with a recurrence date more than a year prior to the program start. The comparison showed that the average number of days was higher in South West Health (110 days) than Pictou County Health (69 days) and GASHA (65 days). The average number of days increases over the 18 months, which again may be reflective of a certain amount of catch-up during the early stages of the program. (Figure 32)

![Figure 32. Mean Number of Days From Recurrence to Referral to Navigator](image)

The proportion of patients (of all those with a recurrence) referred within 30 days of recurrence was also examined. Overall, one-third of patients with a recurrence were referred to a Navigator within 30 days. This proportion was slightly higher in South West Health and GASHA than Pictou County Health. There were also fluctuations over time, but no clear pattern has stabilized. (Figure 33)

![Figure 33. Proportion of Patients With Recurrence Referred Within 30 Days of Reoccurrence Date](image)
Patient Referral Patterns

The majority of patients received a single referral for a particular issue.

The number of referrals per patient, the number of issues addressed per referral, and the broad categorization of issues were examined. As outlined in Figure 34, more than eight in ten patients had one referral. Slightly more than one in ten (13%) had two referrals, while 4 percent had more than two referrals (4%). The proportion of patients having one referral increased over the patient navigation program timeframe. Patients in GASHA were more inclined to have multiple referrals than patients in the other two districts. However, in the most recent six months of the program the proportion of patients with only one referral was similar across all three districts.

Figure 34. Percentage of Patients With One Referral

For most referrals, patients were at home (73%). Two in ten patients were in hospital (20%) and (6%) were at a clinic. This pattern is consistent across districts.

As shown in Figure 35, eight in ten referrals pertained to one issue only (80%), 15 percent covered two issues (15%), while 6 percent covered more than two issues (6%).

Figure 35. Number of Issues Per Patient Referral
For each referral, a primary reason for the referral was identified. These reasons fit into three broad categories including information/education (40%), continuity of care (40%), and coordination of care or referral to appropriate resources (18%). There were some slight differences across districts. The Patient Navigator in Pictou County Health had a lower proportion of referrals for continuity of care than the other two districts, but slightly more for each of information/education and coordination/referral. The primary reasons for referrals are shown in Figure 36.

Close to seven in ten referrals (68%) did not require further follow-up, while one-third (32%) did require further follow-up. This was more likely to be the case earlier in the program than later. (Figure 37)
Source of Patient Referrals

*Health professionals were a key source of referrals and have become increasingly so over the course of the program.*

Referrals came from a number of primary sources, as outlined in Figure 38. Health professionals (including family physicians) were by far the most common source of referrals (63%). Family members (13%) were also a source of referrals along with self-referrals (20%). Referral sources were consistent across districts.

![Figure 38. Source of Patient Referrals](image-url)
Across time, there was a change in the number of referrals from particular sources. There was an increase in referrals from health professionals in GASHA in the last six months. Self-referrals decreased in South West Health and GASHA, but increased in Pictou County Health. Table 20 outlines the number of referrals from various sources.

<table>
<thead>
<tr>
<th>Table 20. Number of Referrals From Each Source</th>
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</thead>
<tbody>
<tr>
<td>Health professional</td>
</tr>
<tr>
<td>----------------------</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
</tr>
<tr>
<td>Jan 2002 to Jun 2002</td>
</tr>
<tr>
<td>Jul 2002 to Dec 2002</td>
</tr>
<tr>
<td>Jan 2003 to Jun 2003</td>
</tr>
<tr>
<td><strong>South West Health</strong></td>
</tr>
<tr>
<td>Jan 2002 to Jun 2002</td>
</tr>
<tr>
<td>Jul 2002 to Dec 2002</td>
</tr>
<tr>
<td>Jan 2003 to Jun 2003</td>
</tr>
<tr>
<td><strong>Pictou County Health</strong></td>
</tr>
<tr>
<td>Jan 2002 to Jun 2002</td>
</tr>
<tr>
<td>Jul 2002 to Dec 2002</td>
</tr>
<tr>
<td>Jan 2003 to Jun 2003</td>
</tr>
<tr>
<td><strong>GASHA</strong></td>
</tr>
<tr>
<td>Jan 2002 to Jun 2002</td>
</tr>
<tr>
<td>Jul 2002 to Dec 2002</td>
</tr>
<tr>
<td>Jan 2003 to Jun 2003</td>
</tr>
</tbody>
</table>
Patient Issues Categorization and Resolution

*Cancer Patient Navigators addressed a wide variety of issues, and most issues were addressed within the same day.*

A portion of the database collects information according to each issue raised. As mentioned previously, while most referrals pertained to one issue, 873 separate issues were identified and 909 actions were taken to address these issues.

Close to one-half of the issues (45%) involved either continuity of care, while close to four in ten (36%) involved information and education needs. Close to two in ten (18%) of the issues were coordination/referrals. Similar to primary referral issues, information/education and coordination/referral issues were identified more so in Pictou County Health than in GASHA and South West Health. South West Health had the highest proportion of continuity of care issues, followed by GASHA. Figure 39 outlines the categories of patient issues.
Looking at the types of issues more specifically, the most common issues for patients were a need for emotional support (17%), information on their cancer (13%), financial issues (13%), coordination with the cancer center (11%), general information on cancer (9%), and a need for homecare (7%). No other specific issue made up more than four percent. (Table 21)

<table>
<thead>
<tr>
<th>Table 21. Specific Types of Issues for Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Overall</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Continuity of Care</strong></td>
</tr>
<tr>
<td>Emotional support</td>
</tr>
<tr>
<td>Home care</td>
</tr>
<tr>
<td>Palliative care</td>
</tr>
<tr>
<td>Hospital discharge issues</td>
</tr>
<tr>
<td>Lack of family doctor</td>
</tr>
<tr>
<td><strong>Information/Education</strong></td>
</tr>
<tr>
<td>General info on cancer</td>
</tr>
<tr>
<td>Prescription plan</td>
</tr>
<tr>
<td>Site specific info</td>
</tr>
<tr>
<td>Chemotherapy</td>
</tr>
<tr>
<td>For patient’s family</td>
</tr>
<tr>
<td><strong>Coordination/Referral</strong></td>
</tr>
<tr>
<td>Coordination to cancer centre</td>
</tr>
<tr>
<td>Diagnostic</td>
</tr>
<tr>
<td>Appointments</td>
</tr>
<tr>
<td>Surgery</td>
</tr>
<tr>
<td><strong>Cancer system</strong></td>
</tr>
<tr>
<td>Finance</td>
</tr>
<tr>
<td>Drugs</td>
</tr>
<tr>
<td>Lodging</td>
</tr>
<tr>
<td>Transportation</td>
</tr>
<tr>
<td>Insurance</td>
</tr>
<tr>
<td><strong>Symptom Management</strong></td>
</tr>
<tr>
<td>Pain</td>
</tr>
<tr>
<td>Lymphadema</td>
</tr>
<tr>
<td>Hair loss</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Nausea</td>
</tr>
</tbody>
</table>
Table 21. Specific Types of Issues for Patients

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>South West Health</th>
<th>Pictou County Health</th>
<th>GASHA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Volunteer/Support Group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>0%</td>
<td>0%</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>RR</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>1%</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unusual circumstances</td>
<td>1%</td>
<td>1%</td>
<td>0%</td>
<td>1%</td>
</tr>
</tbody>
</table>

These were the top issues across districts, although there were some variations. In South West Health, homecare was more often an issue than for the other two districts. Financial issues presented more so in South West Health and GASHA than in Pictou County Health. Conversely, in Pictou County Health, issues more often pertained to education on the type of cancer and coordination with the cancer center.

Almost all issues are resolved (94%). This is consistent across districts and over the course of the program. Most issues (84%) were resolved within the same day. Another 5 percent took one to three days, while 3 percent took longer. Resolution times are not available for eight percent. Across all three districts the proportion of issues resolved within the same day increased from the first six months and remained consistent across the last 12 months. Resolution times are presented in Figure 40.

![Figure 40. Resolution Time for Patient Issues](image)

The issues not resolved most commonly were financial (25%) and emotional issues (18%). No other specific issue comprised more than six percent of unresolved issues.
As mentioned, the Patient Navigators can take various actions to resolve issues, and in some cases more than one action is appropriate. Most commonly, these actions included provision of information (41%) and provision of support (30%). To a lesser extent the actions were arrangement of referrals (14%) and coordination of appointments (11%). The overall pattern is consistent across districts, although there were some minor fluctuations. The types of actions are presented in Figure 41.

**Figure 41. Types of Actions Taken**
For many of the actions, further detail on these broader categories was obtained. One-third (32%) of the actions involved providing cancer information, while two in ten (18%) involved provision of kits or brochures and close to two in ten (17%) involved the provision of emotional support. In terms of coordination and referrals, the most common actions included arranging referrals to the Canadian Cancer Society (15%), arranging referrals to support groups (14%), arranging referrals to home care (10%), and coordination of appointments (10%). No other action comprised more than seven percent of the total actions. The details of the specific actions taken are presented in Table 22.

<table>
<thead>
<tr>
<th>Table 22. Specific Actions Taken to Resolve Patient Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Provided Information</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Provided cancer info</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Provided kits/brochures</td>
</tr>
<tr>
<td>Provided information (general)</td>
</tr>
<tr>
<td>Teaching one-on-one</td>
</tr>
<tr>
<td>Provided 1-800 line</td>
</tr>
<tr>
<td>Community group education session</td>
</tr>
<tr>
<td>Provided Website information</td>
</tr>
<tr>
<td>Provided Support</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Provided emotional support</td>
</tr>
<tr>
<td>Provided support (general)</td>
</tr>
<tr>
<td>Provided social support</td>
</tr>
<tr>
<td>Coordination and Referral</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Arranged referral to CCS</td>
</tr>
<tr>
<td>Arranged referral for support group</td>
</tr>
<tr>
<td>Arranged referral for home care</td>
</tr>
<tr>
<td>Coordinated appointments</td>
</tr>
<tr>
<td>Arranged referral for palliative care</td>
</tr>
<tr>
<td>Arranged referral (general)</td>
</tr>
<tr>
<td>Coordinated appointments education session</td>
</tr>
</tbody>
</table>

There are some fluctuations across districts. Provision of cancer information and kits/brochures were somewhat more common in Pictou County Health. At the same time, referrals to home care were at least twice as frequent in South West Health as in the other districts.
The actions often involved contact with others in order to resolve the issue. In the majority of cases (81%) it included contact with the patients themselves. A variety of other contacts were also initiated, but most commonly included contact with health professionals (21%), relatives (17%), spouses (17%), the cancer clinic (15%), the family doctor (11%), and the Canadian Cancer Society (11%). Palliative care (8%), home care (8%), and oncologists (8%) were each contacts in the actions taken to resolve issues. While results are mostly consistent across districts, in Pictou County Health the actions involved contact with the cancer clinic more often than in the other two districts, but contact with health professionals less often. Table 23 outlines the actions taken to resolve issues.

<table>
<thead>
<tr>
<th>Table 23. Contacts Made to Resolve Patient Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Overall</td>
</tr>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>Health professional</td>
</tr>
<tr>
<td>Relative</td>
</tr>
<tr>
<td>Spouse</td>
</tr>
<tr>
<td>Cancer clinic</td>
</tr>
<tr>
<td>Family doctor</td>
</tr>
<tr>
<td>Canadian Cancer Society</td>
</tr>
<tr>
<td>Palliative care</td>
</tr>
<tr>
<td>Home care</td>
</tr>
<tr>
<td>Oncologist</td>
</tr>
<tr>
<td>Support group</td>
</tr>
<tr>
<td>Diagnostic agencies</td>
</tr>
<tr>
<td>Client</td>
</tr>
<tr>
<td>Friend</td>
</tr>
<tr>
<td>Not stated</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

The time taken to complete each action is within one and a half hours (mean=1.2). This is consistent across districts.
Non-Patient Contacts

Overall, referrals from non-patient sources increased.

As previously noted, one-quarter (24%) of the referrals were for non-patient clients. The number of contacts from non-patients increased substantially over the course of the patient navigation program in both districts (GASHA and Pictou County Health), where referrals not directly for patients were recorded as non-patients. As noted previously, referrals in South West Health were recorded differently and therefore it is not possible to determine the change over time. Figure 42 outlines the number of non-patient referrals.

Figure 42. Number of Non-Patient Referrals
These referrals were from a variety of sources, with nurses being the most frequent contact (29%). The number of referrals in GASHA from nurses was much higher because of palliative care nurses use of the Patient Navigator. Other referrals included support groups (12%), other community groups (11%), physicians (9%), other health care professionals (10%) and family (7%). Contact was rarely declined (1%). Table 24 below outlines the categories of non-patient referrals. Caution should be used given that Southwest represents a count of only 8.

<table>
<thead>
<tr>
<th>Table 24. Categories for Non-Patient Referrals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Nurse</td>
</tr>
<tr>
<td>Support group</td>
</tr>
<tr>
<td>Physician</td>
</tr>
<tr>
<td>School</td>
</tr>
<tr>
<td>Spouse</td>
</tr>
<tr>
<td>Child</td>
</tr>
<tr>
<td>Friend</td>
</tr>
<tr>
<td>Business</td>
</tr>
<tr>
<td>Other patient related</td>
</tr>
<tr>
<td>Other community group</td>
</tr>
<tr>
<td>Other Health Care Professional</td>
</tr>
<tr>
<td>Contact declined</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

There were some differences across districts. In GASHA, over one-half of the non-patient contacts were with nurses compared (50%), with only one in ten in Pictou County Health (10%). In Pictou County Health, the non-patient referrals were more spread across different sources. In particular, Pictou County Health saw a higher percentage of contacts with physicians than GASHA. Comparisons are not made with South West Health given the low number and difference in classification.

Similar to patient referrals, the number of referrals per non-patient contacts, the number of issues addressed per referral, and sources of referrals were examined. The majority of non-patient referrals (95%) were one-time referrals. Another five percent had two referrals. In addition, almost all referrals (99%) involved a single issue.
The sources of referrals for non-patient contacts varied. The most common referral source was health professionals (43%). Other sources include community group or support groups (16%), family members (14%), and family physicians (8%). There were some differences across districts. GASHA had a higher proportion of referrals from health professionals than the other districts. Sources for non-patient referrals are presented in Figure 43.

Figure 43. Source of Non-Patient Referrals
Non-Patient Issues Categorization and Resolution

Most non-patient issues pertained to provision of information and education and were addressed within the same day they were presented.

Similar to patients, one main reason for each referral was identified. Six in ten (59%) referrals for non-patient contacts primarily pertained to information/education. Continuity of care and coordination or referral accounted for 14 percent and 12 percent respectively. One in ten were unknown (12%) and 3 percent were for another reason. Across districts, Pictou County Health had fewer referrals for information/education, but more classified as unknown. Most non-patients did not require further follow-up (96%). Referral reasons for non-patients are presented in Figure 44.

![Figure 44. Non-Patient Referral Reasons](image)

In addition to examining the primary issue for each non-patient referral, all of the issues presented for each non-patient case were examined. A similar pattern was observed as when examining the primary reasons. Most of the issues for non-patient referrals were for information or education (67%). This was followed by continuity of care (17%) and coordination/referral (14%).

When looking at the types of issues in more detail, there was considerable variation. No one issue was identified by more than 13 percent. The most commonly identified issues included information on the specific cancer type (13%), general information on cancer (11%), and financial issues (9%). No other issue made up more than six percent of the total issues.

Similar to patient issues, the majority of issues for non-patients were resolved (94%). Most (92%) were resolved on the same day as they are presented. For 7 percent of issues, the resolution time was not recorded.

The actions taken to resolve issues for non-patient contacts involved providing information in most cases (68%). Other actions involved providing support (12%), arrangement of referrals (7%),
education sessions (5%), or coordination of appointments (5%). This was consistent across
districts.

More detailed information on the actions was also recorded. The actions taken included providing
cancer information (38%), provision of general information (29%), provision of kits/brochures
(14%), provision of Website information (9%), arranging referrals to support groups (8%), and
arranging referrals to the Canadian Cancer Society (7%). The full list of actions taken is presented
in Table 25.

<table>
<thead>
<tr>
<th>Table 25. Specific Actions Taken to Resolve Non-Patient Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall</strong></td>
</tr>
<tr>
<td><strong>Provided Information</strong></td>
</tr>
<tr>
<td>Provided cancer information</td>
</tr>
<tr>
<td>Provided information (general)</td>
</tr>
<tr>
<td>Provided kits/brochures</td>
</tr>
<tr>
<td>Provided Website information</td>
</tr>
<tr>
<td>Provided 1-800 line</td>
</tr>
<tr>
<td>Community group education session</td>
</tr>
<tr>
<td>Teaching one-on-one</td>
</tr>
<tr>
<td>Provided bereavement support</td>
</tr>
<tr>
<td>Education session</td>
</tr>
<tr>
<td><strong>Provided Support</strong></td>
</tr>
<tr>
<td>Provided emotional support</td>
</tr>
<tr>
<td>Provided support (general)</td>
</tr>
<tr>
<td>Provided social support</td>
</tr>
<tr>
<td><strong>Coordination and Referral</strong></td>
</tr>
<tr>
<td>Arranged referral for support group</td>
</tr>
<tr>
<td>Arranged referral to CCS</td>
</tr>
<tr>
<td>Arranged referral for palliative care</td>
</tr>
<tr>
<td>Coordinated appointments</td>
</tr>
<tr>
<td>Arranged referral for home care</td>
</tr>
<tr>
<td>Arranged referral (general)</td>
</tr>
<tr>
<td>Coordinated appointments education session</td>
</tr>
</tbody>
</table>
While most actions involved contact with the client (the person for whom the referral was made) (81%), many also involved contact with other sources. This included health professionals (10%) and patients (7%) among others. No other specific contact was mentioned by more than five percent of actions. Table 26 outlines the various contacts made for these referrals.

<table>
<thead>
<tr>
<th>Table 26. Contacts Made to Resolve Non-Patient Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Client</td>
</tr>
<tr>
<td>Health professional</td>
</tr>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>Cancer clinic</td>
</tr>
<tr>
<td>Family doctor</td>
</tr>
<tr>
<td>Canadian Cancer Society</td>
</tr>
<tr>
<td>Palliative care</td>
</tr>
<tr>
<td>Relative</td>
</tr>
<tr>
<td>Support group</td>
</tr>
<tr>
<td>Home care</td>
</tr>
<tr>
<td>Diagnostic agencies</td>
</tr>
<tr>
<td>Spouse</td>
</tr>
<tr>
<td>Oncologist</td>
</tr>
<tr>
<td>Not stated</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Resolution time was within one and a half hours (mean =1.3 hours).