

## Approaches to Support Transitions into and out of Cancer Care Systems for Patients Who Do Not Have a Primary-Care Provider

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### Context

- Cancer systems are complex and require considerable communication and coordination across providers to ensure patients receive optimal care.(1)
- Due to this complexity, many patients face a significant burden in navigating cancer systems and facilitating communication across providers, which can result in emotional distress and impede access to care.(2)
- These challenges may be especially pronounced for those who do not have a regular primary-care provider or team (i.e., who are unattached to primary care) as they transition into and out of cancer care systems, given the absence of consistent case management and coordination of care.
- For the purposes of this rapid synthesis, we considered primary care to include the health provider or team of providers who acts as the patient's first point of contact with the health system when ill, diagnoses and treats most conditions, refers complex cases to specialists when needed, and ensures continuity of care.
- This rapid synthesis aims to examine approaches that have been used to support cancer patients who are unattached to primary care transition into and out of cancer systems and improve access to appropriate services across the cancer care continuum.

### Question

- What are the features and impacts of approaches to support transitions into and out of cancer care systems for patients who do not have a primary-care provider?

### High-level summary of key findings

#### Research evidence

- We identified nine evidence syntheses and 19 primary studies that addressed the question, of which one was deemed highly relevant to the question (a primary study focused on shared care and interdisciplinary models supporting cancer care in Canada), two were of medium relevance, and the remaining 25 were assessed as low-relevance to the question due to lack of explicit focus on patients unattached to primary care.
- The included evidence that provided implications for patients unattached to primary care largely focused on nurse navigation approaches and interdisciplinary team and shared care models.
- Heterogeneity in the way these models are implemented, the fact that the models were often used in tandem with each other, and the lack of rigorous comparative evaluation studies limits our ability to draw conclusions about each model in relation to the question.
- Equity considerations addressed by these approaches largely focused on rural/remote communities and those in time-dependent relationships (e.g., those coming out of hospital or receiving palliative care), for whom the approaches were sometimes tailored to or provided additional supports for; some approaches also provided additional supports for Indigenous populations.
- Overall, both models appear to show promise in supporting cancer patients who are unattached to primary care to transition into and out of cancer care systems.

## Jurisdictional scan

- We also conducted a jurisdictional scan to examine experiences with approaches to support transitions into and out of cancer care systems for patients unattached to primary care in eight countries (Australia, Denmark, France, Germany, New Zealand, Sweden, United Kingdom and the United States), as well in all 13 provinces in territories in Canada.
- Due to differences in the way primary care is structured across countries, we included approaches supporting transitions that could be utilized to support patients unattached to primary care (i.e., did not rely on primary care provider referrals).
- Referral mechanisms that enabled patients with suspected cancer to access approaches to support transitions into and out of the cancer care systems included self-referral and referral from emergency departments, while those with recently diagnosed cancer gained access through these as well as referrals from oncology specialists or cancer clinics.
- Across countries and Canadian provinces and territories, the jurisdictional scans echoed findings from the evidence documents in highlighting nurse navigation and interdisciplinary team models as the most promising approaches to supporting cancer care transitions for patients unattached to primary care.
- In British Columbia, in particular, the Survivorship Nurse Practitioner Program supports unattached cancer patients already diagnosed with cancer from diagnosis follow-up to survivorship, including organizing specialist consultations and referrals while monitoring patients' symptoms.
- Considering the findings from the jurisdictional scans, both the nurse navigator and interdisciplinary team approaches may be able to leverage existing health system infrastructure and trends in Canada that can be optimized to achieve the goal of supporting transitions into and out of cancer systems for patients unattached to primary care.

## Framework to organize what we looked for

We organized our findings using the framework below.

- Approaches to accelerate the process for patients with suspected or recently diagnosed cancer to get a primary-care provider
- Approaches to augment the cancer care pathway to account for what is missed in primary care
- Approaches to enhance discharge supports from cancer care for patients without a primary-care provider
- Priority populations
  - New immigrants
  - Refugees
  - Indigenous peoples
  - People in rural and remote areas
  - People who face language barriers
- Outcomes
  - Improved health outcomes
    - Cancer-specific outcomes
  - Improved care experiences
    - Attachment to a primary-care provider
  - Improved provider experiences
  - Keeping per-capita costs manageable

## What we found

We identified nine evidence syntheses and 19 primary studies that addressed the question, of which one was deemed to be highly relevant to the question, two were of medium relevance, and the remaining 25 were assessed as low relevance to the question due to lack of explicit focus on patients unattached to primary care. The highly relevant evidence document was a primary study focused on shared care and interdisciplinary models supporting cancer care transitions in Canada.

We outline in narrative form below our key findings related to the question from the evidence documents and based on experiences from the jurisdictional scan of eight countries and all 13 Canadian provinces and territories (see Box 1 for more details).

A summary of the evidence organized by type of approach is provided in Table 1, while a summary of the experiences from other countries and from Canadian provinces and territories is provided in Appendix 2. Detailed data extractions from each of the included evidence documents is provided in Appendix 3, and hyperlinks for documents excluded at the final stage of reviewing in Appendix 4.

## Key findings from evidence sources

Fourteen evidence documents (four evidence syntheses and 10 single studies) provided insights about approaches to augment the cancer care pathway to account for what is missed in primary care, and 20 documents (seven evidence syntheses and 13 single studies) provided insights about approaches to to enhance discharge supports from cancer care for patients without a primary-care provider (note that some addressed both topics). It should be noted that none of the included documents focused on the first category in the organizing framework about accelerating the process for patients with suspected or recently diagnosed cancer to get a primary-care provider.

### Box 1: Approach and supporting materials

We identified evidence addressing the question by searching PubMed and Health Systems Evidence to identify evidence syntheses, protocols for evidence syntheses, and primary studies. All searches were conducted on 21 August 2023. The search strategies used are included in Appendix 1. We identified jurisdictional experiences by hand searching government and stakeholder websites for information relevant to the question from eight countries (Australia, Denmark, France, Germany, New Zealand, Sweden, U.K. and the U.S.) and all Canadian provinces and territories.

In contrast to our rapid evidence profiles, which provide an overview and insights from relevant documents, this rapid synthesis provides an in-depth understanding of the evidence.

We appraised the methodological quality of evidence syntheses that were deemed to be highly relevant using AMSTAR. Note that quality appraisal scores for evidence syntheses such as rapid syntheses/reviews are often lower because of the methodological shortcuts that need to be taken to accommodate compressed timeframes. AMSTAR rates overall quality on a scale of 0 to 11, where 11/11 represents an evidence synthesis of the highest quality. It is important to note that the AMSTAR tool was developed to assess evidence syntheses focused on clinical interventions, so not all criteria apply to evidence syntheses pertaining to delivery, financial or governance arrangements within health systems or to broader social systems.

This rapid synthesis was prepared in a 30-business day timeline.

A separate appendix document includes:

- 1) methodological details (Appendix 1)
- 2) a summary table of experiences from other countries and select Canadian provinces and territories (Appendix 2)
- 3) findings from each evidence document, organized by document type, and sorted by relevance to the question (Appendix 3)
- 4) documents excluded at the final stages of reviewing (Appendix 4)

The single study that we deemed to be of high relevance to the question analyzed approaches for improving support and coordination from diagnosis follow-up to survivorship, including British Columbia's Survivorship Nurse Practitioner Program that explicitly targets patients unattached to primary care. This study and other supporting evidence identify the following two broad and often overlapping approaches (see Table 1) for supporting transitions into and out of the cancer care system and improving access to services across the cancer care continuum:

- **nurse navigation approaches**, in which nurses support patients' cancer journey by providing services that may include clinical consultations, advocacy, coordination and scheduling of services, and monitoring
- **interdisciplinary team and shared care models** that aim to improve communication, care coordination and case management across oncology specialists and primary-care providers.

Cancer care navigation approaches often utilize specialized nurses trained in cancer care and may operate as part of interdisciplinary teams that include oncology specialists and primary-care providers, or act as a care coordinator across these different types of providers. Limited evidence about these models of care suggest that they may play a role in improving patient satisfaction, but do not appear to increase quality of life.(3) Lack of standardization across electronic communication of information systems (including electronic medical records) pose a barrier to these models, while potential facilitators include financial support, skilled program leads and public support.(4)

Interdisciplinary teams and shared care models supporting transitions into and out of cancer care systems consist of teams with both oncology specialists and primary-care providers working in settings such as transition clinics that are accessible by patients unattached to primary care, as well as shared care networks or communication strategies that aim to better support case management and coordination of care across providers. Many of the included studies focused on facilitating survivorship and follow-up care through these approaches, and often took the form of individualized survivorship care plans, workshops, counselling, education and health promotion resources, care coordination across oncology specialists and primary-care providers, and monitoring to ensure survivorship care services provided. These approaches generally consist of disease- or intervention-specific clinics that leverage specific expertise, or consultative or longitudinal models providing consultations for a broad range of cancer survivors and care plans to be carried out by oncologists or primary-care providers.(5) Additionally, they might include risk-stratification approaches to ensure survivorship models are tailored to patients' needs and that at-risk populations are followed.

In terms of outcomes, some studies have suggested that these approaches have demonstrated high satisfaction,(6) are perceived as useful among patients,(7) may produce minimal benefits to enhance discharge supports,(8) and might help reduce patients' anxiety (9) and communication burden.(10) However, given the heterogeneity of types of models and the program elements used in these models, the ability to draw conclusions about the effectiveness of these programs is limited.(11)

Key implementation considerations include system-level barriers consisting of delays in medical transcription, lack of access to patient information, and physicians not being able to access patient reports, while individual-level barriers consist of lack of rapport between primary-care providers and oncology specialists.(12) Additionally, enhancing primary-care providers' skills, supporting access to and use of shared electronic health records, engaging designated care coordinators (e.g., nurse navigators), and monitoring patients in relation to their survivorship care plans were identified as key factors contributing to successful shared care models.(4; 13-16)

## Key findings from jurisdictional scans

In addition to our literature search, we undertook a jurisdictional scan of Canadian provinces and territories as well as Australia, Denmark, France, Germany, New Zealand, Sweden, the United Kingdom and the United States to examine experiences of approaches to supporting cancer care transitions for patients unattached to primary care.

## Experiences identified from other countries

Internationally, we did not identify any approaches to support transitions in cancer care systems specifically for patients unattached to primary care. This appeared to be largely due to the interrelated issues of differences in how primary care is organized in different countries, as well as less concern over ‘unattached’ patients when primary-care networks are responsible for a specific jurisdiction or population rather than individual patients. In response to these initial findings, we identified and included approaches supporting transitions into and out of cancer care systems that were likely to help support unattached patients, and then analyzed these approaches based on the primary care and cancer care contexts in which they were implemented. Across these approaches, we identified similar approaches to those identified in the Canadian context, specifically nurse navigators and interdisciplinary teams or approaches to improve communication among oncology specialists and primary-care providers that help improve transitions into and out of cancer care systems and improve access to care services across the cancer continuum.

In terms of nurse navigators, New Zealand’s cancer care [navigators](#) provide residents and their families with support to help with the coordination of care between primary-care facilities and hospitals. In the U.K., [primary care networks](#) (PCNs) in England are leveraging the [Additional Roles Reimbursement Scheme](#) to hire [cancer care coordinators](#) who assist patients with personalized care planning and support throughout the cancer pathway, helping to ensure that patients receive required cancer care from PCNs. Additionally, care coordination efforts undertaken by the Leeds Teaching Hospitals include monthly patient meetings with a [Macmillan nurse](#) (specialist cancer nurses) to [update and communicate shared treatment plans](#), including to local primary-care providers that can help support cancer care.

Interdisciplinary teams and networks promoting communication across oncology specialists and primary-care providers were often emphasized as a key to improving transitions into and out of cancer care and improving timely access to services across the cancer care continuum. In Australia, patients are [not registered with a specific general practice](#) and may choose which practice to attend on each occasion, and Cancer Australia is working on the [expansion of multidisciplinary teams](#) run out of regional cancer centres that involve many different professionals. These efforts, largely prompted by the pandemic, include the use of [virtual multidisciplinary team meetings](#), which have improved the attendance of primary-care providers and the [expansion of shared care](#) (as some patients were unable to visit a cancer centre) between a specialist and a general practitioner using telehealth services and shared online consultations. To improve palliative cancer care communication and coordination among primary health teams and oncology specialists in rural and remote areas, New Zealand uses a ‘[hub-and-spoke](#)’ model that leverages a centralized hospice as a ‘hub’ for palliative care expertise that provides expert guidance to primary health provider ‘spokes’ within community and regional hospitals. In the U.K., some cancer centres, such as the [Children’s and Teenage Oncology and Haematology Unit](#) at the Leeds Teaching Hospitals, [coordinate with local hospitals, children’s community nursing teams and general practitioners](#) to enhance access to cancer care services that need not be provided at specialist centre.

## Experiences identified from Canadian provinces and territories

In Canada, other than approaches that support access to cancer screening services (which was not included in the scope of the request for this synthesis) the approaches we identified aimed to support access to primary-care services specifically during cancer care transitions or to improve coordination between oncology specialists and primary-care providers. These approaches either explicitly targeted patients unattached to primary care, included patients unattached to primary care, or were broader efforts to better connect patients unattached to primary care that are relevant to cancer care. Similar to the models identified in the literature, relevant Canadian approaches to supporting transitions for patients unattached to primary care in and out of cancer care systems generally consisted of one or both of the following types of interventions: 1) assigning patients to a cancer care navigator, usually provided by a nurse with specialized cancer training, or 2) interdisciplinary teams models that connect oncology



specialists with primary-care providers, thereby improving communication and facilitating joint action to improve patients' cancer care transitions and access to relevant services.

Nurses working as cancer care navigators provide patients with personalized support during transitions into or out of cancer care systems. Referral mechanisms that enabled patients with suspected or recently diagnosed cancer to access cancer care navigators included self-referral, referral from oncology specialists, or referral from cancer clinics or emergency departments. The types of services provided through these approaches include connecting patients to primary-care providers or oncology specialists to access appropriate care (but not necessarily to 'attach' a patient to a primary-care provider for the long-term), as well as consultations, workshops and various support services provided either through the cancer care navigator or through a larger interdisciplinary team of which the cancer care navigator is a part. BC Cancer, for example, aims to improve access to cancer care services across the cancer care continuum by connecting [cancer patients without a primary-care provider](#) in the Lower Mainland to a nurse practitioner with specialized cancer training that provides complete primary healthcare, cancer treatment, referrals for specialist consultations and care, and monitoring of cancer effects. It is worth noting, however, that this initiative faces potential challenges with sustainability and equity in accessibility, as many nurse practitioners are unable to take on new patients and the program is only available to those living in the Lower Mainland. Similarly, CancerCare Manitoba's [Cancer Navigation Services](#) offer personalized support during transitions into and out of cancer care for patients without primary-care providers through self-referral, utilizing specialized teams such as Nurse Navigators, Psychosocial Oncology Clinicians and Community Engagement Liaisons to aid in diagnosis comprehension, emotional assistance and care coordination. In July 2023, the Thunder Bay Regional Health Sciences Centre in Ontario announced a [partnership](#) with Lakehead Nurse Practitioner Led Clinic to support 'patients unattached to primary care' with breast cancer. Following diagnosis, patients unattached to primary care are assigned nurse practitioners to facilitate necessary follow-up care. Across Québec, many cancer centres have integrated a [nurse navigator](#) to help [bridge the gap between primary care and oncology care](#) for cancer patients, including those who may be unattached. Finally, in the Northwest Territories, the [Cancer Navigation Program](#) is available to all residents, including patients unattached to primary care without a referral, to receive support from a Cancer Navigator (nurse, social worker or both) to guide the patient through the cancer care system and can serve as the primary point of contact to answer questions and coordinate care among all healthcare team members. Very few approaches targeted patients with suspected but not diagnosed cancer, highlighting an important gap to be considered for future approaches.

Despite the paucity of literature and experiences of jurisdictions focusing explicitly on supporting transitions into and out of cancer care systems for patients unattached to primary care, there appears to be potential to leverage existing infrastructure to better support this population in Canada. [Health Care Connect](#) in Ontario and centralized waitlists ([GAME/GACO](#)) in Quebec, for example, both provide systems that aim to connect patients unattached to primary care to primary-care providers, prioritizing patients based on urgency/greater needs. Although these programs did not meet inclusion criteria as they do not explicitly focus on cancer patients, such programs could build in specific protocols for cancer patients to ensure they can access appropriate cancer services across the continuum of care. Nurse navigator programs such as British Columbia's [Survivorship Nurse Practitioner Program](#) provide an example of one possible way these existing systems might be expanded to better accommodate unattached cancer patients' needs. Specifically, unattached cancer patients accessing broader programs to become attached to primary-care providers could be assigned nurse navigators during the interim as they wait to be attached, allowing transitions into or out of cancer systems to begin immediately without having to wait for attachment and allowing the navigator to provide support, service coordination and case management to the unattached patient.

**Table 1: Outcomes and implementation considerations of approaches to support transitions into and out of cancer care systems**

Type of approach and description of elements	Outcomes	Implementation considerations
<p><b>Nurse navigation approaches</b></p> <ul style="list-style-type: none"> <li>• These initiatives often utilize specialized nurses trained in cancer care who act as case managers and care coordinators</li> <li>• They may act as coordinators across oncology specialists and primary-care providers or be integrated as part of interdisciplinary teams</li> </ul>	<ul style="list-style-type: none"> <li>• Nurse-led cancer navigation programs may improve patient satisfaction, but might not lead to better quality of life (3)</li> </ul>	<ul style="list-style-type: none"> <li>• Relationship-based approaches and informing and involving patients in connecting them to care were identified as key factors supporting nurse navigation programs (17)</li> <li>• Potential barriers to implementing nurse navigation approaches include lack of standardization and incompatibility with electronic health record systems, while facilitators included financial support, skilled program leads and public support (4)</li> </ul>
<p><b>Interdisciplinary teams and shared care models</b></p> <ul style="list-style-type: none"> <li>• These approaches often facilitate survivorship and follow-up care models and transition clinics that help patients transition between oncology and primary care</li> <li>• They consist of interdisciplinary teams that include both oncology specialists and primary-care providers and/or communication pathways that help coordinate care across providers</li> <li>• They are often guided by individualized survivorship care plans and/or nurse navigators</li> </ul>	<ul style="list-style-type: none"> <li>• Limited observational data suggests that follow-up care is perceived as useful by patients, even those who did not perceive this as a need (7)</li> <li>• An evidence synthesis of survivorship care plans (SCPs) found minimal benefits to enhance discharge supports from cancer care (8)</li> <li>• Proactive survivorship care pathways for breast cancer survivors demonstrated high patient satisfaction and were able to successfully identify patient needs and conditions, but encountered challenges reaching all eligible patients (6)</li> <li>• A Cochrane review could not draw any conclusions about the effectiveness of specific program elements such as changes to care coordination, care protocols, change in medical record systems, and follow-ups that aimed to improve the continuity of cancer care between oncology specialists and primary-care providers (11)</li> <li>• Online communication and coordination of care platforms may have minimal benefits in terms of improving communication between primary care and oncology specialists, and improving patients' anxiety and communication burden (9; 10; 18)</li> </ul>	<ul style="list-style-type: none"> <li>• Indigenous patients and patients living in rural and remote areas report difficulty in accessing resources and programs supporting their follow-up care needs (20)</li> <li>• Survivorship care is delivered inconsistently across Canada and the extent to which models implement guidelines by Cancer Care Ontario (CCO) and the Canadian Association of Psychosocial Oncology/Canadian Partnership Against Cancer (CAPO/CPAC) are varied (19) <ul style="list-style-type: none"> <li>○ The lack of consensus on core components of these programs and their adaptability to different settings makes it difficult to understand their benefits and risks (1; 19; 20)</li> </ul> </li> <li>• Information communications systems infrastructure such as shared electronic health records are crucial for successful survivorship and follow-up care (4; 6)</li> <li>• Enhancing primary-care providers' skills, supporting access to and use of shared electronic health records, engaging designated care coordinators (e.g., nurse navigators), and monitoring patients in relation to their survivorship care plans were identified as key factors contributing to successful shared care models (4; 13-16)</li> </ul>

Type of approach and description of elements	Outcomes	Implementation considerations
		<ul style="list-style-type: none"> <li>• Younger, fatigued women living in non-urban settings who transferred to primary care for survivorship follow-up after primary breast cancer treatment appear to use telephone clinics more, suggesting the potential usefulness of such clinics for improving follow-up care in hard-to-reach populations (21)</li> <li>• Risk stratification to inform individualized care pathways based on patient needs may help ensure proactive survivorship care (6)</li> <li>• Barriers to cancer care coordination between oncology specialists and primary-care providers include: <ul style="list-style-type: none"> <li>○ system-level barriers such as delays in medical transcription, lack of access to patient information, and physicians not having access to patient reports</li> <li>○ individual-level barriers such as lack of rapport between primary-care providers and oncology specialists and a lack of coordination in terms of clearly defined and communicated roles</li> <li>○ patients living in rural and remote areas who face long travel times to access certain forms of cancer care (12)</li> </ul> </li> <li>• Establishing provider responsibilities to minimize duplication of workload and accessible electronic communication systems containing comprehensive information regarding a patients' condition, history and treatment plan can help strengthen continuity of care efforts between oncology specialists and primary-care providers (6; 9; 10; 18)</li> </ul>



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