McMaster University | HEALTH FORUM

Rapid Synthesis Appendices

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

13 October 2023

[MHF product code: RS 112]

Appendix 1: Methods

Background to the rapid synthesis

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum's Rapid Response program. Whenever possible, the rapid synthesis summarizes evidence drawn from existing evidence syntheses and from single research studies in areas not covered by existing evidence syntheses and/or if existing evidence syntheses are old or the science is moving fast. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The rapid synthesis does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

The Forum produces timely and demand-driven contextualized evidence syntheses such as this one that address pressing health and social system issues faced by decision-makers (see our website for more details and examples). This includes evidence syntheses produced within:

- days (e.g., rapid evidence profiles or living evidence profiles)
- weeks (e.g., rapid syntheses that at a minimum include a policy analysis of the best-available evidence, which can be requested in a 10-, 30-, 60- or 90-business-day timeframe)
- months (e.g., full evidence syntheses or living evidence syntheses with updates and enhancements over time).

This rapid synthesis was prepared over a 30-business day timeframe and involved five steps:

1) submission of a question from a policymaker or stakeholder (in this case, Canadian Partnership Against Cancer)
2) identifying, selecting, appraising and synthesizing relevant research evidence about the question
3) conducting and synthesizing a jurisdictional scan of experiences about the question from other countries and Canadian provinces and territories
4) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence
5) finalizing the rapid synthesis based on the input of at least two merit reviewers.

Identification, selection, quality appraisal and synthesis of evidence

For this rapid synthesis, we searched Health Systems Evidence (Search 1 and 2), PubMed (Search 1) for:

1) guidelines (defined as providing recommendations or other normative statements derived from an explicit process for evidence synthesis)
2) evidence syntheses
3) protocols for evidence syntheses that are underway
4) single studies (when no guidelines or evidence syntheses are identified or when they are older).

In Health Systems Evidence, we searched for evidence syntheses on 21 August 2023 using the terms "cancer care pathway" and "cancer care transition". In PubMed, we searched for evidence syntheses and primary studies on 21 August 2023 using cancer AND (transition or pathway) AND primary care AND (access OR coordination).

Additional handsearching was conducted through an evidence brief on cancer care transitions and by searching for relevant CanIMPACT studies.

Each source for these documents is assigned to one team member who conducts hand searches (when a source contains a smaller number of documents) or keyword searches to identify potentially relevant documents. A final inclusion assessment is performed both by the person who did the initial screening and the lead author of the rapid synthesis, with disagreements resolved by consensus or with the input of a third reviewer on the team. The team uses a dedicated virtual channel to discuss and iteratively refine inclusion/exclusion criteria throughout the process, which provides a running list of considerations that all members can consult during the first stages of assessment.

For any included guidelines, two reviewers assess each guideline using three domains in the AGREE II tool (stakeholder involvement, rigour of development and editorial independence). Guidelines are classified as high quality if they were scored as 60% or higher across each of these domains.

For each evidence synthesis we included, we documented the dimension of the organizing framework (see Appendix 3) with which it aligns, key findings, living status, methodological quality (using AMSTAR), last year the literature was searched (as an indicator of how recently it was conducted), availability of GRADE profile, and equity considerations using PROGRESS PLUS.

For AMSTAR, two reviewers independently appraise the methodological quality of evidence syntheses that are deemed to be highly relevant. Disagreements are resolved by consensus with a third reviewer if needed. AMSTAR rates overall methodological quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. High-quality evidence syntheses are those with scores of eight or higher out of a possible 11, medium-quality evidence syntheses are those with scores between four and seven, and low-quality evidence syntheses are those with scores less than four. 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 those pertaining to health-system arrangements or to economic and social responses. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, an evidence synthesis that scores 8/8 is generally of comparable quality to another scoring 11/11; both ratings are considered 'high scores.' A high score signals that readers of the evidence synthesis can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the evidence synthesis should be discarded, merely that less confidence can be placed in its findings and that it needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1): S8.)

For primary research (if included), we documented the dimension of the organizing framework with which it aligns, publication date, jurisdiction studied, methods used, a description of the sample and intervention, declarative title and key findings, and equity considerations using PROGRESS PLUS. We then used this extracted information to develop a synthesis of the key findings from the included syntheses and primary studies.

During this process we include published, pre-print and grey literature. We do not exclude documents based on the language of a document. However, we are not able to extract key findings from documents that are written in languages other than Chinese, English, French, Portuguese or Spanish. We provide any documents that do not have content available in these languages in an appendix containing documents excluded at the final stages of reviewing. We excluded documents that did not directly address the research questions and the relevant organizing framework. All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Identifying experiences from other countries and from Canadian provinces and territories

For each rapid synthesis, we work with the requestor and a subject matter expert to collectively decide on what countries (and/or states or provinces) to examine based on the question posed. For other countries we searched relevant government and stakeholder websites, including ministries of health, other government agencies and cancer care or primary-care organizations working to strengthen cancer care. In Canada, a similar approach was used, which involved searching the websites of ministries of health, other government agencies and organizations and networks working to strengthen cancer care. While we do not exclude countries based on language, where information is not available in English, Chinese, French, Portuguese or Spanish, we attempt to use site-specific translation functions or Google Translate.

Appendix 2: Key findings from highly relevant jurisdictional experiences on transitions into and out of cancer care systems for patients who do not have a primary-care provider

Table 1: Experiences in other countries on transitions into and out of cancer care systems for patients who do not have a primary-care provider

Jurisdiction	Summary of findings

Australia	• In Australia, patients are not registered with a specific general practice and may choose which practice to attend on each occasion and information about individual's health and previous use of health services is contained within the Australian My Health Record system
	• Cancer Australia is working on the expansion of multidisciplinary teams run out of regional cancer centres that involve many different professionals; select pilots of this approach have involved a representative from the local Division of General Practice, who can support planning for care transitions for patients
	  ○ Changes during the pandemic to virtual multidisciplinary team meetings have improved the attendance of primary-care providers
	  ○ The pandemic has also spurred an 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 support greater involvement of primary-care providers in cancer care (and ultimately the transition out of cancer care), Cancer Australia developed evidence-based guides for select cancer types that detail roles for different health professionals

Denmark	• None identified
France	• None identified
Germany	• None identified

New Zealand	• No relevant findings directly related to the transitions into and out of cancer care systems for patients without primary-care providers were identified; however, some key features were noted with respect to primary and cancer care:
	  ○ The Medical Oncology National Implementation Plan brought forth a new model of care that emphasized the role of primary-care clinicians in cancer care and treatment
	  ○ In New Zealand, cancer care navigators provide residents and their families with support to help with the coordination of care between primary-care facilities and hospitals
	  ○ The health system in New Zealand has a 'hub-and-spoke' model that helps to deliver palliative care in rural and remote areas; a feature of this model is that it connects primary healthcare teams with oncology specialists

Sweden	• None identified
United Kingdom (U.K.)	• In the U.K., primary care networks (PCNs) consist of GP practices working together with mental health, social care, pharmacy, hospital and voluntary services in their local areas as multidisciplinary group practices, collectively responsible for the health and well-being of the communities they serve • The Additional Roles Reimbursement Scheme was introduced in England in 2019 to help improve access to general practice, allowing PCNs to claim reimbursement for salaries of 17 new roles within primary-care multidisciplinary teams to meet local population needs ○ Many PCNs leverage this 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 • Some cancer centres in the U.K., 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 centres

Jurisdiction	Summary of findings
	o Patients meet monthly 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
United States (U.S)	• The ACS CARES™ (Community Access to Resources, Education, and Support) developed by the American Cancer Society provides newly diagnosed individuals with access to customized guidance, 24/7 over-the-phone support, and both virtual and in-person support from trained community volunteers o They also provide resources for finding a cancer navigator • George Washington University developed the Patient Navigation Barriers and Outcomes Tool (PN-BOT™) that helps with data management and reporting for oncology patient navigation programs in the U.S. • The Association of Community Cancer Centers developed a cancer care patient navigation program toolkit • The Mayo Clinic Comprehensive Cancer Center provides free navigation services for patients enrolled at their clinics, which includes navigators who can provide information on cancer care, employment, financial assistance, insurance, local community resources, lodging options, support resources and transportation options • The 2005 Institute of Medicine report From Cancer Care to Cancer Survivor: Lost in Transition indicated four components for cancer care transition models: prevention, surveillance, interventions for treatment, and care coordination between specialists and primary-care providers

Table 2: Experiences across Canadian provinces and territories on transitions into and out of cancer care systems for patients who do not have a primary-care provider

Jurisdiction	Summary of findings
Pan-Canadian	• None identified
British Columbia	• BC Cancer plans, coordinates and evaluates cancer care in partnership with health authorities throughout British Columbia o The goal is to ensure equitable and cost-effective healthcare for individuals living with or impacted by cancer o BC Cancer offers a Survivorship Nurse Practitioner Program for cancer patients without a primary-care provider in the Lower Mainland ▪ Nurse practitioners with specialized cancer care training provide complete primary healthcare to those who already have a cancer diagnosis, including diagnosis follow-up, treatment, test orders, medication prescriptions, specialist consultations, monitoring of cancer effects, referrals and cancer screenings ▪ These services are covered by the BC Medical Services Plan, ensuring accessible care for patients
Alberta	• Alberta Health Services aims to increase holistic supports to support persons transitioning in and out of cancer treatment o Alberta Health Services intends to provide community-based supports to augment cancer care pathway supports in diagnosis o Community supports include mobile screening and follow-up care in marginalized communities (e.g., Indigenous peoples and people in rural and remote areas), and cultural specialists to help Indigenous peoples maintain cultural connectedness during cancer care ▪ Information regarding this program's mobile care and consideration of cultural factors can be used to improve care coordination between primary-care services and cancer centres • Alberta Cancer Foundation is an independent organization supporting cancer research and access to cancer treatment

Jurisdiction	Summary of findings
	o Alberta Cancer Foundation's patient navigator program connects patients with a recent cancer diagnosis, especially those outside of Edmonton and Calgary, to a social worker or clinical assistant who can assist with navigating care systems o Patient Navigators in rural Alberta help patients navigate complex cancer care systems to access services and follow-up care o While the program does not connect patients to primary-care providers, it allows patients to access services in their communities to avoid unnecessary visits to general practitioners and emergency rooms, ensuring that all patients, including those who may be unattached, access appropriate services
Saskatchewan	• None identified
Manitoba	• CancerCare Manitoba serves as Manitoba's provincial authority, directing strategic planning for cancer and blood disorder care o CancerCare Manitoba offers support services, including counselling, support groups, educational programs and Telehealth o CancerCare Manitoba's Cancer Navigation Services offer personalized support during transitions into and out of cancer care for patients without primary-care providers, utilizing specialized teams such as Nurse Navigators, Psychosocial Oncology Clinicians, and Community Engagement Liaisons to aid in diagnosis comprehension, emotional assistance, practical problem-solving and community education on cancer prevention
Ontario	• In July 2023, the Thunder Bay Regional Health Sciences Centre announced a new partnership with Lakehead Nurse Practitioner Led Clinic to support 'unattached patients' with breast cancer screening follow-ups o 'Unattached patients' receiving care at this facility will be assigned a nurse practitioner that can help to facilitate necessary care o Prior to this partnership, unattached patients would have to visit a walk-in clinic or emergency department of a hospital for mammogram follow-ups
Quebec	• A partnership between an oncology centre (CHU de Québec-HDQ) and a community cancer care organization (OQPAC) was orgainzed to help improve access to services and bridge for cancer survivors through the Cancer Transitions program o The Cancer Transitions program consists of seven group meetings led by clinicians and designed for patients who recently completed primary cancer treatment ▪ Meetings consist of 30 minutes of physical exercise adapted to participants' needs, followed by two hours of various support and information activities related to exercise, nutrition, medical monitoring, distress management and other health-related concerns post-treatment o Findings from the pilot project found significant improvement in participants who completed the group in terms of: ▪ empowerment and feelings of personal effectiveness ▪ emotional well-being ▪ self-perceived health and quality of life ▪ skills to manage illness and its symptoms ▪ health behaviours and ▪ maintaining a positive attitude • Across Quebec, many cancer centres have integrated a nurse navigator to help bridge the gap between primary care and oncology care for cancer patients o Nurse navigators are responsible for assessing the needs of cancer patients, providing resources, information and support throughout their cancer journey, and working to coordinate services across primary-care providers and cancer centres
New Brunswick	• None identified

Jurisdiction	Summary of findings
Nova Scotia	- None identified

Prince Edward Island	- PEI Cancer Patient Navigation provides non-medical holistic supports for persons with cancer in Prince Edward Island
	  ○ This program provides supports to augment the cancer care pathway and help patients understand their screening results, connect to supplementary care and prepare for their appointments
	  ○ Specialized supports are available for Indigenous peoples to promote cultural connectedness
	  ○ Patients can reach out directly at any point during the cancer care continuum, enabling unattached patients to become connected to a PEI cancer patient navigator who can provide support, education, advocacy and referrals to relevant programs and services

Newfoundland and Labrador	- Support for unattached patients is broadly provided by the Patient Connect NL program, in which unattached patients register online or by phone on a provincial list of individuals who have identified as lacking a Primary Care Provider (Family Physician or Nurse Practitioner)
	  ○ The goal of Patient Connect NL is to connect individuals to a Family Care Team or Primary Care Provider (PCP) as soon as one becomes available in their area
	  ○ Although the province currently offers a Cancer Patient Navigators program, accessing this program still necessitates a referral from a family physician, care provider, cancer specialist or another healthcare professional
	  ○ As a result, patients must first connect to the Patient Connect NL program to be referred to the Cancer Patient Navigators program

Yukon	- None identified

Northwest Territories	- From the suspicion of a cancer diagnosis to palliation and survivorship, the Cancer Navigation Program is available to all residents in the NWT to help cancer patients navigate the healthcare system during their cancer journey
	  ○ Even without referral, a person living with cancer may directly contact (self-refer to) the Cancer Navigation Team by phone or email, at which time a Cancer Navigator (nurse, social worker or both) will 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
	  ○ They will also provide information and resources to help the patient prepare for appointments, tests and treatments and connect the patient with valuable community resources

Nunavut	- None identified

Appendix 3: Detailed data extractions from evidence syntheses about transitions into and out of cancer care systems for patients who do not have a primary-care provider

Table 1: Detailed findings from systematic reviews about transitions into and out of cancer care systems for patients who do not have a primary-care provider

Dimension of organizing framework	Declarative title and key findings	Relevance	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations

• Approaches to enhance discharge supports from cancer care for patient without a primary-care provider
• Priority populations
  ○ Indigenous peoples
  ○ People in rural and remote areas
	Shared care and transition clinics aim to slowly transition cancer patients from oncology teams to primary-care providers while enhancing collaboration and communication, potentially providing opportunities to improve access to primary care follow-up care services for unattached patients
	• Four models of follow-up cancer care were identified: 1) primary care, 2) oncology care, 3) shared care and 4) transition clinics
	• Shared care, sometimes facilitated through transition clinics, aims to transition patients between oncology and primary care by creating individualized survivorship care plans
	  ○ Rural/remote and Indigenous patients reported that it was difficult to access resources and programs supporting their follow-up care needs
	• Across Canada, survivorship care is delivered inconsistently, 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
		Low	No	5/9	2021	No	• Place of residence
							• Race/ ethnicity/ culture/ language

• Approaches to enhance discharge supports from cancer care for patient without a	There is large variations in survivorship care due to its adaptability to different settings and the lack of consensus on core components of care programs, which poses a risk to understanding the benefits and risks of survivorship care models	Low	No	6/10	Not reported	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
primary-care provider							
- Approaches to enhance discharge supports from cancer care for patient without a primary-care provider	There is a limited evidence base to draw conclusions on the most effective or preferred model to improve care coordination between primary healthcare and oncology care providers, largely due to conceptual and methodological challenges within the field	Low	No	8/10	2015	No	None identified
- Approaches to augment the cancer care pathway to account for what is missed in primary care	The authors of a Cochrane review were not able to conclude on the effectiveness of interventions (e.g., patient-held records, follow-ups, care coordination, change in medical record system, care protocols) that aimed to improve continuity of cancer care on patient, provider and process outcomes due to the lack of clear evidence on whether the interventions improved or worsened health outcomes - Case management models, shared care models and interdisciplinary team models were all used to improve continuity of cancer care between specialty and primary-care providers	Low	No	7/9	2009	Yes	None identified
- 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 patient without a	For people without a connection with primary care, patient navigators may be useful across healthcare settings for improving access to primary care, including for cancer patients - The studies included in the scoping review contained elements of a patient navigation framework that may be generalizable to the task of connecting vulnerable individuals without a primary-care provider, including unattached cancer patients ○ Almost every study included at least one of the three patient-centred care factors: (1) an	Medium	No	9/10	2016	None	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
primary-care provider • Outcomes ○ Improved care experiences	informed and involved patient, (2) receptive and responsive health professionals and (3) a coordinated, supportive healthcare environment ○ A relationship-based approach, informing and involving patients in connecting them to care, is a critical element of patient navigation to facilitate access to primary care • A study of patient navigator activities in breast cancer navigation programs revealed that they are commonly aligned with individual-level principles such as removing barriers, prioritizing patient-centred care and integrating care ○ However, there was inconsistency between programs regarding program-level principles such as navigators' skill levels, their scope of practice and how well they coordinated within the healthcare system						
• Approaches to enhance discharge supports from cancer care for patient without a primary-care provider • Outcomes ○ Improved care experiences	Follow-up care for childhood cancer survivors has proven to be beneficial for patients in different models of care, including shared care, problem-oriented and informal care, multidisciplinary clinics and late effects pediatric and hospital-based clinics • The multidisciplinary survivorship clinic appeared to have provided the most valued follow-up service for patients when compared to other models of care, but given that the included studies were largely observational, more reliable sources of evidence are needed	Low	No	6/10	2010	No	None identified
• Approaches to augment the cancer care pathway to account for what is missed in primary care	While the evidence suggests that nurse-led navigation programs may not lead to a better quality of life for cancer patients undergoing treatment, it does indicate that patient satisfaction may significantly increase as a result of these programs	Low	No	8/10	2014	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
• Outcomes ○ Improved care experiences							
• 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 patient without a primary-care provider • Outcomes ○ Improved health outcomes ▪ Cancer-specific outcomes	Patients who do not have a primary-care provider may receive informational and well-being supports from cancer case managers to improve health outcomes and quality of life • Across numerous studies in different countries, supports from community, virtual or clinical-based cancer case managers (e.g., patient navigator, nurse specialist) were reported to reduce cancer-related symptoms and improve quality of life in persons newly diagnosed, currently undergoing and leaving cancer care • Supports provided by case managers included emotional support, symptom management, referral support and social care • The supports from patient navigators and nurse specialists could be modified to help connect patients to primary-care givers	Low	Not living	5/10	2009	Not available	• Place of residence
• Approaches to enhance discharge supports from cancer care for patient without a primary-care provider • Outcomes	Survivorship cancer plans provide minimal benefits to enhance discharge supports form cancer care • The purpose of this systematic review was to review the utility of survivorship care plans (SCPs) to enhance discharge supports from cancer care • SCPs typically included treatment history and instructions for discharge support • When an SCP was used appropriately, primary-care providers reported improvements to care	Low	Not living	5/9	2017	Not available	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
○ Improved provider experiences	experiences, such as increased confidence and improved care coordination with cancer specialists • Given the variability of information provided in SCPs and the lack of recommendations on how to best utilize them, they overall had minimal benefits on improving care coordination • The limitations of this intervention could be considered when creating models to improve communication and care coordination for unattached patients						

Table 2: Summary of findings from primary studies about transitions into and out of cancer care systems for patients who do not have a primary-care provider

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations
• Approaches to enhance discharge supports from cancer care for patient without a primary-care provider • Outcomes ○ Improved care experiences	*Focus of study:* To evaluate the implementation of a proactive survivorship care pathway *Publication date:* 2023 *Jurisdiction studied:* France *Methods used:* Mixed-methods process evaluation	Medium	Patients with early breast cancer at the end of primary treatment phase A pathway manager screened and flagged eligible patients to an assisting physician with a reminder of pathway eligibility one day before the end of the primary treatment visit Pathways enabled patients to receive individualized survivorship care plans, in-person and at-home patient education and self-management, health	A proactive survivorship care pathway for breast cancer survivors demonstrated high patient satisfaction but encountered challenges in reaching all eligible patients, highlighting the importance of multidisciplinary collaboration and digital solutions to connect at-risk patients to survivorship care • Administrative data from a total of 154 seminars delivered during 17 transition days showed high intervention fidelity (96%) • During the first 6 months of the pathway, 288 physical and psychosocial domains and 72 unhealthy conditions were detected in patients during their personalized consultations, which	None identified

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations
			promotion supports, and connections to community services and primary-care physicians	subsequently helped inform individualized care plans	
- Approaches to enhance discharge supports from cancer care for patient without a primary-care provider	*Focus of study:* To summarize results of intervention studies implementing these elements in transitioning survivors from oncology to primary-care providers for long-term follow-up care *Publication date:* 2015 *Jurisdiction studied:* United States *Methods used:* Conceptual overview	Low	N/A Risk-stratified care for cancer survivors, coordinated between oncology and primary-care providers	The development of user-friendly assessment tools and effective communication methods is essential for improving survivorship care collaboration between oncology and primary-care providers - Models of survivorship generally consist of multidisciplinary follow-up programs, including: o Disease- or intervention-specific clinics that leverage specific expertise o 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 provider - Risk-stratified aspects of these models address questions of who needs to be followed, by whom and for what duration, and with which modalities and frequency - Survivorship care plans should ideally be concise and specific, with details about the patient's treatments, recommendations for follow-up, and identification of providers, with options ranging from generic templates for provider-populated communication to web applications allowing patient input and comprehensive plans that	None identified

Dimension of the organizing framework	**Study characteristics**	**Relevance**	**Sample and intervention description**	**Declarative title and key findings**	**Equity considerations**
				provide educational information, links to resources, and detailed summaries, ensuring patient-oriented and informed care	
- Approaches to enhance discharge supports from cancer care for patient without a primary-care provider	*Focus of study:* To explore cancer survivors' views about share care, including enablers and barriers *Publication date:* 2017 *Jurisdiction studied:* Australia *Methods used:* Focus groups	Low	11 cancer survivors, two family caregivers and eight clinicans/researchers Shared-care models of care that promote early re-engagement of primary-care providers to support transition from acute oncology back to primary care	Patients reported that effective shared care required shared electronic health records, key individuals as care coordinators, muldisciplinary case conferences, shared decision-making, preparation for self-management and improving general practitioners' skills in providing cancer care - Patients expressed a burden in being responsible for navigating information sharing and communication processes, stressing the need for care coordinators	None identified
- Approaches to augment the cancer care pathway to account for what is missed in primary care - Priority populations ○ People in rural and remote areas	*Focus of study:* To explore healthcare provider perspectives on the coordination of cancer care between cancer specialists and family physicians *Publication date:* 2016 *Jurisdiction studied:* Canada *Methods used:* Qualitative semi-structured interviews	Low	21 family physicians, 15 surgeons, 12 medical oncologists, six radiation oncologists and four general practitioners in oncology Care coordination efforts between cancer specialists and family physicians	Cancer care coordination between cancer specialists and primary-care providers requires fostering stronger interdisciplinary relationships and improving the availability of patient information to help coordinate care efforts - System-level barriers included delays in medical transcription, lack of access to patient information and physicians not having access to patient reports - Individual-level barriers consisted of lack of rapport between primary-care providers and oncology specialists and a lack of coordination in terms of clearly defined and communicated roles - Patients living in rural and remote areas often face additional challenges to care coordination, as cancer care typically required travel to larger centres	- Place of residence

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations

- Approaches to enhance discharge supports from cancer care for patient without a primary-care provider
- Outcomes
  - Improved care experiences
  - Improved provider experiences
	Focus of study: To evaluate the process of survivorship care plan (SCP) completion and describe the challenges in implementing Cancer SCPs
	
	Publication date: 2015
	
	Jurisdiction studied: Vermont, United States
	
	Methods used: Telephone survey and telephone interviews
		Low	58 patients (48 with stage 0-III breast cancer, and 10 stage II-IV with colorectal cancer)
			
			16 oncology staff members, including oncologists, advanced practice practitioner (either nurse practitioner or physician assistant), and nurses
			
			Following the first or second post-therapy visit, an advanced practice practitioner (either a nurse practitioner or physician assistant) prepares a written survivorship care plan (SCP) that includes a comprehensive care summary, recommended follow-up care, secondary prevention, and a list of national and local health promotion resources, which is then discussed with patients at the next follow-up clinic visit
			
			If late or long-term side effects are discovered, the patient is referred to the appropriate specialty
				In a shared-care model of optimal wellness, increased communication and coordination between oncologists, survivors and other healthcare providers via a SCP regarding not only what has been done but also what must be done in the future may help to more clearly delineate and facilitate the role of the primary-care physician in survivorship care
				
				- Key recommendations for SCP implementation included the following:
				  - It is suggested that oncology nurse practitioners are well-positioned to develop and implement SCPs, thereby facilitating the transition of patients from oncology care to primary care
				  - Since access to complete medical records is a barrier to completing SCPs, incorporating SCPs into electronic medical records may facilitate patient identification, staff scheduling and SCP creation in a timely manner
				  - Developing and delivering SCPs within three to six months following the conclusion of treatment may be optimal for patients and providers of care
				  - Including information in the SCP concerning late and long-term effects and standard monitoring tests may increase the utility of SCPs
					None identified

- Approaches to enhance discharge supports from	*Focus of study:* To understand current transition practices	Low	Childhood cancer survivors (CCS) who recently transitioned out of pediatric	Before the childhood cancer survivor (CCS) leaves pediatric care, a site visit with the healthcare provider who will provide	- Place of residence

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations

cancer care for patient without a primary-care provider
- Priority populations
  - People in rural and remote areas
- Outcomes
  - Improved care experiences
	and barriers to transition through the experiences of childhood cancer survivors entering adult-focused aftercare
	Publication date: 2021
	Jurisdiction studied: Newfoundland and Labrador
	Methods used: In-person and telephone semi-structured interviews
			care and healthcare providers who provide care for CCS in Newfoundland and Labrador
			No intervention
				the CCS's adult aftercare is needed to facilitate the transition
				- Other significant findings and recommendations concerning their transition to adult-focused aftercare include:
				  - Increasing CCS awareness of available resources is a challenge that must be considered when improving transition support
				  - The CCSs interviewed for the study were unaware of existing tools such as patient navigators as resources for navigating the healthcare system
				  - A more formalized approach must begin before a patient's last pediatric visit that includes educating the CCS about their past cancer, developing plans to help them navigate the adult healthcare system and meeting with the receiving adult healthcare practitioner
					- Time-dependent relationships

- Approaches to enhance discharge supports from cancer care for patient without a primary-care provider
- Outcomes
  - Improved health outcomes
  - Improved care experiences
	Focus of study: To evaluate survivorship models/interventions regarding effectiveness, sustainability and transferability to different settings
	Publication date: 2015
	Jurisdiction studied: Australia
		Low	Sample of the study included managers of the Victorian Cancer Survivorship Program (VCSP) pilot projects, lead clinicians, key stakeholders and general practitioners
			The VCSP pilot projects included six two-year demonstration projects on cancer survivorship post-treatment shared models of care across acute (hospital), primary care and/or cancer-
				The optimum mode of delivery of survivorship care remains uncertain
				- The following are common system-level enablers for implementing post-treatment care models for cancer survivors:
				  - Workforce education and training, including mentoring of nurses in motivational interviewing, providing education about adolescent and young adult survivorship
					None identified

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations
	Methods used: Semi-structured interviews		related nongovernment cancer organizations (NGO) The projects explored different models of delivery including shared care, nurse-led care and self-management, while seeking to incorporate many key principles of survivorship care including risk stratification, needs assessment, the use of survivorship care plans (SCPs), education for providers and improved care coordination	experiences and linking with GP education programs o Involvement of primary-care organizations and GP representative bodies throughout project development, implementation and evaluation o Partnerships with community-based organizations • In terms of outcomes: o Some participants experienced improved well-being as one of the health-related outcomes o In terms of care experiences, the interventions resulted in improved understanding and management of issues that survivors may face (by survivors, health professionals and NGO partners), and improved access to community-based services for survivors o System-level evaluations of shared care indicate that these models may ensure rapid access to specialist care when needed	
• 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 patient without a primary-care provider	*Focus of study:* To assess Canadian strategies to improve coordination of care between primary-care physicians and oncology specialists and identify barriers, facilitators and success indicators for this process	High	Sample included in the telephone interviews were individuals who represented the eligible Canadian initiatives The initiatives had to be designed to support coordination and collaboration between primary-care physicians and oncology specialists; related	British Columbia's Survivorship Nurse Practitioner Program was the only initiative noted to provide survivorship and primary care to unattached patients after treatment as they transition to follow-up care • The high level of primary-care engagement in this model can be attributed to the nurses' and physicians' daily interaction and collaboration	• Time-dependent relationships

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations
	Publication date: 2016 *Jurisdiction studied:* Canada *Methods used:* Pan-Canadian environmental scanning and telephone interviews		to diagnosis, treatment, survivorship care or personalized medicine (i.e., individualized diagnostic, prognostic and therapeutic care); and inclusive of breast or colorectal cancer or both This article documented a total of 24 initiatives that were identified as part of the CanIMPACT casebook project	• In terms of impact, it was difficult to identify the most effective interventions or care models due to the lack of evaluation data • While the other models did not specifically target unattached patients, they used transitional approaches to help patients progress through different stages of cancer care, such as facilitating coordination between primary-care providers and oncology specialists ○ Nursing navigation was commonly incorporated in most of the initiatives • Barriers to implementation of the initiatives included lack of care standardization and incompatibility with electronic systems, while facilitators included financial support, skilled program leads and public support	
• Approaches to augment the cancer care pathway to account for what is missed in primary care • Outcomes ○ Improved care experiences	*Focus of study:* Integrated care model for palliative cancer care *Publication date:* 2017 *Jurisdiction studied:* Italy *Methods used:* Descriptive statistics	Low	Patients eligible for palliative care (often in their last month of life) may be referred by a palliative care specialist to receive service at home in lieu of a hospice An integrated care plan is developed in efforts to keep transitions between hospital and home at a minimum between all providers including a palliative care specialist, a general	Integrated care plans reduced the number of transitions between care settings and the number of days spent in hospital during the final days of life	• Time-dependent relationships

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations
			practitioner and a palliative care nurse		
- Approaches to enhance discharge supports from cancer care for patient without a primary-care provider	*Focus of study:* Risk-stratified survivorship care models to enable coordination between specialized and primary care *Publication date:* 2021 *Jurisdiction studied:* Quebec *Methods used:* Deliberative dialogue	Low	Stratified pathway based on an individual's risk according to the type of cancer treatment, potential late treatment–related effects and risk of recurrence The study reports on findings from a deliberative dialogue of 24 patients and clinicians describing the views on the core components and implementation of risk-stratified cancer pathways	Additional clarity and improved information transition between specialty and primary care is required prior to the implementation of risk-stratified models - Suggestions for laying the groundwork for the development and implementation of risk-stratified models includes: ○ Offering continuing education to primary-care providers to keep their understanding of oncology practice ○ Opening up participation in oncology sector committees to better understanding the role that primary-care providers could play in care for cancer survivors ○ Enhancing the capacity of the cancer survivor to determine how involved primary care will be in their cancer care and follow-up (however, there are concerns that this places too much burden on the survivor)	None identified
- Approaches to enhance discharge supports from cancer care for patient without a primary-care provider - Outcomes ○ Improved care experiences	*Focus of study:* Survivorship follow-up *Publication date:* June 2015 *Jurisdiction studied:* Alberta, Canada	Low	Study participants were women with stage I-III invasive breast cancer diagnosed June 2006 to September 2009 Eligible participants who consented completed a structured telephone interview and had their chart data reviewed	After at least one year post-diagnosis, women with stage I–III invasive breast cancer who had transferred to primary care for survivorship follow-up were found to have adhered well to follow-up guidelines for mammograms but were still very interested in a telephone survivorship clinic - Younger, fatigued women living in nonurban settings were found to use a telephone clinic more, suggesting that	None identfied

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations
	Methods used: Mixed methods – interview and chart review			integrated care options could fill gaps in access to care and resources while reducing health care costs - However, ongoing symptoms and psychosocial needs of survivors should be considered when developing telephone clinics and similar care strategies	
- 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 patient without a primary-care provider - Outcomes ○ Improved care experiences	*Focus of study:* Investigating the importance of shared leadership in cancer care transitions *Publication date:* 2016 *Jurisdiction studied:* Not reported *Methods used:* Case study	Low	This case study examined a 47-year-old woman undergoing primary therapy with curative intent for breast cancer	The transfer of information and responsibilities from oncology to primary care has historically experienced a myriad of challenges; however, shared leadership can help to coordinate pathways from treatment to follow-up and management - Shared leadership is effective in helping to overcome barriers to survivorship transition, including attitudes, knowledge and professional organizational boundaries	None identified

- Approaches to augment the cancer care pathway to account for what is missed in primary care
- Outcomes
  ○ Improved care experiences
  ○ Improved provider experiences
	Focus of study: Examining the findings of the CanIMPACT project
	Publication date: 2016
	Jurisdiction studied: Canada
	Methods used: Qualitative methods
		Low	This study describes the use of primary-care providers supporting routine follow-up through the CanIMPACT project	Clinical guidelines and cancer programs encourage the use of primary-care settings for routine follow-up, as it has been proven to be a safe, alternative form to cancer care centres
				- The CanIMPACT project features a multidisciplinary group of health professionals (e.g., primary-care physicians, nurses, oncologists, researchers) that strive to improve the integration and quality of care of patients as they transition between primary-care providers and oncologists in the cancer care continuum
					None identified

Dimension of the organizing framework	**Study characteristics**	**Relevance**	**Sample and intervention description**	**Declarative title and key findings**	**Equity considerations**
• 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 patient without a primary-care provider • Outcomes ○ Improved health outcomes ▪ Cancer-specific outcomes ○ Improved care experiences ○ Improved provider experiences	*Focus of study:* Examining the cancer care experiences and perspectives of patients *Publication date:* 2016 *Jurisdiction studied:* Canada *Methods used:* Qualitative methods; semi-structured telephone interviews	Low	A total of 38 breast and colorectal cancer survivors one- and four-years post-diagnosis; 32 female cancer survivors (of which, 20 had breast cancer, 10 had colorectal cancer and 2 had both breast and colorectal cancer), and six male colorectal cancer survivors	Communication, patient and provider relationships, health care provider roles, access to care, and timely information are key themes affecting participants' cancer care experiences and perspective on continuity of care • The primary factor underlying cancer care experiences appeared to be communication processes, as effective communication from health care providers reportedly led to positive feelings and improved health outcomes among patients	None identified
• Approaches to augment the cancer care pathway to account for what is missed in primary care • Outcomes ○ Improved provider experiences	*Focus of study:* Challenges and successes of communication and care coordination programs for primary-care providers and oncologists in Canada *Publication date:* April 2017 *Jurisdiction studied:* Canada *Methods used:* Casebook analysis	Low	A total of 24 casebooks were collected from the Canadian Team to Improve Community-Based Cancer Care Along the Continuum (CanIMPACT) project was analyzed	Structured and well-defined methodological frameworks and accessible electronic communication systems can be used to improve access to care and communication for unattached patients • The purpose of this study was to analyze casebooks from the CanIMPACT project to support continuity of patient care between primary-care providers and oncologists • Approaches to augment the cancer care pathway and decrease workload for primary-care providers included: 1) establishing provider responsibilities to minimize duplication of workload and 2) accessible electronic communication systems that contain comprehensive	None identified

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations
				information regarding a patient's condition, history and treatment plan • Recommendations to ensure the success of a communication model between primary-care providers and oncologists included having a clear methodological framework and protocol, seeking input from patient advisory committees, and considering feasibility • This communication model could be scaled up to improve communication and care coordination for unattached patients	
• Approaches to augment the cancer care pathway to account for what is missed in primary care	*Focus of study:* To explore the experiences of primary-care providers in using an online communication and coordination of care platform to connect with cancer specialists *Publication date:* March 2023 *Jurisdiction studied:* Canada *Methods used:* Qualitative survey	Low	A total of 34 primary-care providers who used eOncoNote participated in this qualitative survey eOncoNote is a free online communication platform that allows primary-care providers to directly communicate with their patients' cancer specialist	Online communication and coordination of care platforms for primary-care providers and cancer specialists may have minimal benefits • The results of this study concluded that 71% of participants did not engage with cancer specialists and reported that the platform had minimal benefits • Participants reported that the platform may be more useful if it was integrated with patients' electronic medical records • The limitations of this communication model could be considered when creating models to improve communication and care coordination for unattached patients	None identified
• Approaches to augment the cancer care pathway to account for what is missed in primary care • Outcomes	*Focus of study:* To examine the utility of an online communication and coordination of care	Low	A total of 173 patients were randomized into two groups: 1) eOncoNote and usual methods of communication	Online communication and coordination of care platforms for primary-care providers and cancer specialists may improve patient anxiety	None identified

Dimension of the organizing framework	Study characteristics	Relevance	Sample and intervention description	Declarative title and key findings	Equity considerations
○ Improved health outcomes	platform for primary-care providers and cancer specialists *Publication date:* January 2023 *Jurisdiction studied:* Canada *Methods used:* Pragmatic randomized control trial		and 2) usual methods of communication only eOncoNote is a free online communication platform that allows primary-care providers to directly communicate with their patients' cancer specialist	• This study concluded that patients in the intervention condition (eOncoNote and usual methods of communication) reported significant improvements in anxiety in comparison to the control condition (usual methods of communication only) • This study did not report an increase in communication or coordination of care between primary-care providers and cancer specialists • Findings from this study may be utilized to develop communication and coordination of care programs that include unattached patients	
• Approaches to augment the cancer care pathway to account for what is missed in primary care	*Focus of study:* To understand how patients using the eOncoNote system perceive their role in utilizing the platform and to understand healthcare providers experiences in implementing the platform into their practice *Publication date:* 28 October 2022 *Jurisdiction studied:* Canada *Methods used:* Qualitative	Low	A total of 18 patients were interviewed and 12 healthcare professionals were interviewed. The occupations of healthcare professionals included program management, oncology nurses, oncologists and primary-care providers eOncoNote is a free online communication platform that allows primary-care providers to directly communicate with their patients' cancer specialist	Online communication and coordination of care platforms for primary-care providers and cancer specialists may reduce communication burden on patients; however, improvements in platform usage and feasibility are needed • The results of both patient and healthcare provider interviews concluded that patients were often unaware of the communication between their healthcare team and were required to coordinate their care between their cancer specialists and primary-care providers • Some patients accepted their role in coordination, while others felt unprepared and uncomfortable with this responsibility • Results from the healthcare provider interviews reported minimal	None identified

Dimension of the organizing framework	**Study characteristics**	**Relevance**	**Sample and intervention description**	**Declarative title and key findings**	**Equity considerations**
				communication between cancer specialists and primary-care providers - Recommendations to improve the use of OncoNote was the integration of the platform onto existing electronic medical records databases	
- 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 patient without a primary-care provider - Outcomes ○ Improved care experiences	*Focus of study:* Transition process of childhood cancer survivors from pediatric to adult healthcare services *Publication date:* 2013 *Jurisdiction studied:* Do not specify a particular jurisdiction *Methods used:* Literature review with qualitative and quantitative methods	Low	Participants in these studies are childhood cancer survivors The main goal is to assist these survivors as they move from pediatric to adult healthcare services by establishing shared care models, providing education to survivors, addressing psychological factors and considering social elements like insurance and education	Successful transition for childhood cancer survivors is more challenging for those with complex medical conditions, cognitive or mental health impairments, and social issues like lower incomes and lack of access to health insurance, emphasizing the need for closer cooperation with adult healthcare providers	Personal characteristics associated with discrimination (e.g. age, disability)

Appendix 4: Documents excluded at the final stage of reviewing

Document type	Hyperlinked title
Single study	Variation in suspected cancer referral pathways in primary care: Comparative analysis across the International Benchmarking Cancer Partnership
Singly study	Referring patients with suspected lung cancer: A qualitative study with primary healthcare professionals in Ireland
Singly study	CASNET2: evaluation of an electronic safety netting cancer toolkit for the primary care electronic health record: Protocol for a pragmatic stepped-wedge RCT
Full systematic review	Interventions to reduce primary care delay in cancer referral: A systematic review
Full systematic review	Patient and primary care delays in the diagnostic pathway of gynaecological cancers: A systematic review of influencing factors
Single study	Team-Based Surgical Scheduling For Improved Patient Access In A High-Volume, Tertiary Head And Neck Cancer Center
Singly study	Improving regional lung cancer optimal care pathway compliance through a rapid-access respiratory clinic
Singly study	Improving the colorectal cancer care pathway via e-health: A qualitative study among Dutch healthcare providers and managers
Single study	the colocation model in community cancer care: A description of patient clinical and demographic attributes and referral pathways
Singly study	The role of family physicians in cancer care: Perspectives of primary and specialty care providers
Single study	Primary care and cancer: Facing the challenge of early diagnosis and survivorship
Singly study	Cancer specialist perspectives on implementing an online communication system with primary care providers
Singly study	Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA

DeMaio P, Waddell K, Bain T, Alam S, Dass R, Cura J, Ali A, Bhuiya A, Wilson M. Rapid synthesis: Approaches to support transitions into and out of cancer care systems for patients who do not have a primary-care provider. Hamilton: McMaster Health Forum, 13 October 2023.

The rapid-response program through which this synthesis was prepared is funded by the Canadian Partnership Against Cancer. The McMaster Health Forum receives both financial and in-kind support from McMaster University. The views expressed in the rapid synthesis are the views of the authors and should not be taken to represent the views of the Canadian Partnership Against Cancer or McMaster University. The authors would like to thank Naheed Dosani and Sian Shuel for their feedback and insightful comments.