

Evidence-Based Series 26-1 Version 2 IN REVIEW

A Quality Initiative of the  
Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)

## Models of Care for Cancer Survivorship

*The Expert Panel on Models of Care for Cancer Survivorship*

An assessment conducted in February 2026 placed Evidence-Based Series (EBS) 26-1 Version 2 IN REVIEW. This means it is undergoing a review for currency and relevance. It is still appropriate for this document to be available while this updating process unfolds.

The PEBC has a formal and standardized process to ensure the currency of each document ([PEBC Assessment & Review Protocol](#))

EBS 26-1 Version 2 is comprised of 4 sections. You can access the summary and full report here:

<https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/246>

Section 1: Guideline Recommendations (ENDORSED)

Section 2: Evidentiary Base

Section 3: Development Methods, Recommendations Development and External Review Process

Section 4: Document Assessment and Review

March 28, 2017

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## Guideline Report History

GUIDELINE VERSION	SYSTEMATIC REVIEW		PUBLICATIONS	NOTES and KEY CHANGES
	Search Dates	Data		
Original 2012	2000 to Week 13 2012	Full Report	Web publication	N.A.
Current Version 2 March 28, 2017	2000 to September 2016	New data found in <a href="#">Section 4</a> : Document Summary and Review Tool	Updated web publication	2012 Recommendations are ENDORSED

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Evidence-Based Series 26-1 Version 2: Section 1

A Quality Initiative of the  
Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)

**Models of Care for Cancer Survivorship**

*J. Sussman, L.H. Souter, E. Grunfeld, D. Howell, C. Gage, S. Keller-Olaman, and M. Brouwers*

March 28, 2017

These guideline recommendations have been ENDORSED, which means that the recommendations are still current and relevant for decision making. Please see [Section 4: Document Review Summary and Tool](#) for a summary of updated evidence published between 2012 and 2016, and for details on how this Clinical Practice Guideline was ENDORSED.

**OBJECTIVES**

1. What are the models described in the literature for the follow-up care of adults with cancer who have completed treatment and are clinically disease free?
2. Are certain models favoured for survivors of specific cancer types in terms of the following:
  - a. Clinical outcomes (e.g., surveillance, recurrence)
  - b. Survivor quality of life outcomes (e.g., quality of life, patient satisfaction)

**TARGET POPULATION**

Adults without evidence of disease after primary, curative treatment for any stage of cancer comprise the target population. Both clinical outcomes (recurrence, surveillance) and quality of life (QoL) outcomes (quality of life, patient satisfaction) from follow-up strategies reported for patients at all levels of risk of recurrence are of interest.

**INTENDED USERS**

This guideline is targeted for:

1. Health professionals who are responsible for the care of adults with cancer who are clinically disease free after receiving curative treatment.
2. Health professionals engaged in the care of adults with cancer who are clinically disease free after receiving curative treatment and who would make referrals to the appropriate care team.
3. Administrative and system leaders responsible for implementing high-quality evidence-informed survivorship services for adults with cancer who are clinically disease free after receiving curative treatment.

**RECOMMENDATIONS AND KEY EVIDENCE**

For Objective 1, the Working Group (Section 2, [Appendix 2-1](#)) produced a framework that describes and organizes the core models of survivorship follow-up care from five landmark papers (1-5) (Table 1-1). This framework was then used to evaluate the studies investigating models of care that were reviewed to answer the Objective 2 questions.

**Table 1-1. Framework of models of care identified in the literature.**

Setting	Options: coordinator of follow-up care
Institution <ul style="list-style-type: none"> <li>• Hospital</li> <li>• Cancer centre</li> </ul>	<ul style="list-style-type: none"> <li>• Specialist                             <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, general practitioner in oncology (GPO)</li> </ul> </li> <li>• Nurse                             <ul style="list-style-type: none"> <li>◦ Nurse specialist, nurse practitioner, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>
Community <ul style="list-style-type: none"> <li>• Family Physician’s office</li> <li>• Specialist’s office (outside hospital)</li> </ul>	<ul style="list-style-type: none"> <li>• Family Physician</li> <li>• Specialist                             <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, GPO</li> </ul> </li> <li>• Nurse                             <ul style="list-style-type: none"> <li>◦ Nurse specialist, nurse practitioner, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>
Shared Care	Any combination of: <ul style="list-style-type: none"> <li>• Specialist                             <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, GPO</li> </ul> </li> <li>• Family Physician</li> <li>• Nurse                             <ul style="list-style-type: none"> <li>◦ Nurse specialist, nurse practitioner, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>

The review of the models of care in survivorship yielded few studies involving randomized comparisons between two distinct model types, and the quality and completeness of reporting is very uneven. Although shared care has been shown to be beneficial for other diseases, no studies were found that explicitly studied shared care compared to another model in cancer. The most common comparison in published studies looks at care coordinated in an institutional setting by a specialist (considered the control arm) versus community-based family physician care, involving discharge from the cancer system. In studies with breast cancer populations, community based family physician care appears reasonable from the perspectives of the patient and health system in that there has been no significant difference found between the models in terms of surveillance for recurrence and medical outcomes. No conclusions could be made regarding an optimal primary care configuration with the patient’s own provider as this was not described in the studies. Across studies, there is some suggestion that patient satisfaction and costs with family physician-led care are as good as or better than specialist-coordinated models located within institutions. The role of nurses as the coordinating provider (but not necessarily the most responsible clinical provider) has been studied in the context of breast, colorectal, and prostate cancer. The expert opinion is that these cancers follow a

similar trajectory in terms of initial diagnosis, treatment, and follow-up care. In these studies, the nursing model was tested within the setting of an institution, where nurses were able to order the appropriate follow-up tests. These studies suggest that a nursing lead model alternative may be reasonable to consider within the context of ongoing follow-up within an institution. The review found no studies with nursing models situated in a community setting, meaning that no conclusions can be made.

This review included both clinical and survivor QoL outcomes, and so the recommendations are based on all these studies. However, the working group decided that studies that did not include clinical outcomes provided insufficient evidence to support strong recommendations. Currently in Ontario, the most common standard practice for follow-up survivorship care involves specialist-coordinated care within an institution. The overall recommendations from this review support the alternative options below.

***Added to the 2017 Endorsement:***

The reader is also referred to other PEBC/CCO documents on follow-up care for colorectal cancer, lung cancer, prostate cancer, gynecologic cancers, melanoma, sarcoma, and lymphoma listed at the end of this section.

**Breast Cancer**

1. For cancer survivors with breast cancer, if no ongoing treatment issues are observed after the completion of primary therapy (though hormonal therapy may still be ongoing), their discharge from specialist-led care to community-based family physician-led care is a reasonable option.

***Key Evidence***

Studies indicate that the transfer of breast cancer survivor care to the patient's usual community-based family physician does not result in an increase in the time to the diagnosis of recurrence (5,6). Additionally, when breast cancer survivors are followed by community-based family physicians, there is no difference in recurrence-related serious clinical events or any physical, psychosocial, or QoL components compared to when survivors are followed by a specialist (5,6). The evidence for this recommendation comes from both a randomized controlled trial (RCT) (5) and an RCT with a non-inferiority design (6). In terms of survivor QoL, patient satisfaction was greater in the family physician-led community-based care group (4).

2. In cancer survivors with breast cancer, if no ongoing treatment issues are observed after the completion of primary therapy (though hormonal therapy may still be ongoing), their discharge from specialist-led care to nurse-led care within an institutional setting is a reasonable option.

***Key Evidence***

An equivalence trial found that breast cancer survivors followed by nurse-coordinated care showed no differences in time to detection of recurrence, number of clinical investigations ordered, or psychological morbidity when compared to breast cancer survivors followed by specialist-coordinated care (7). In addition, women who received telephone nurse-coordinated follow-up were not more anxious as a result of foregoing hospital contact and clinical examinations (7). An RCT testing non-inferiority between nurse-coordinated and specialist-coordinated care found that nurse-led telephone follow-up could replace specialist-led institutional visits after breast cancer treatment without adversely affecting health-related QoL, emotional functioning, or anxiety levels (8).

***Qualifying Statements***

The working group acknowledges that the RCTs included in the evidence for the recommendations were completed before the routine use of aromatase inhibitors. For patients in whom a change in hormonal therapy is anticipated, a planned visit with the oncology team may be necessary and should be clearly arranged between the specialist and the nurse or family physician.

**Colorectal Cancer**

3. In cancer survivors with colorectal cancer who have completed all treatment, discharge from specialist-led care to community-based family physician care is a reasonable option.

***Key Evidence***

The evidence suggests that when colon cancer survivors were followed by a community-based family physician, there were no significant differences for rates of recurrence; time-to-detection of recurrence; death rates; or physical, psychosocial or QoL components compared to when survivors were followed by an institution-based specialist (9). This finding can reasonably be applied to both colon and rectal cancer populations as the treatment trajectories are very similar.

4. In patients with colorectal cancer who have completed all treatment, the transition to nurse-led care within an institution may be a reasonable option, based on a similar disease follow-up care trajectory to breast cancer. However, there is insufficient data to inform whether nurse-coordinated care is equivalent to specialist-led.

***Key Evidence***

The working group was unable to find comparative studies investigating the role of nurse-coordinated follow-up of colorectal cancer survivors. The recommendation that colorectal cancer survivors may be followed by nurses is based on the success of nurse-coordinated follow-up of breast cancer survivors (7,8,10) and on the similarity in the follow-up care trajectory between colorectal and breast cancers, where guideline recommended visits and testing can be organized by physicians or nurses within the institutional setting.

**Prostate Cancer**

5. In patients with prostate cancer who have completed primary treatment (radiation or surgery, but with hormonal therapy possibly still ongoing), the transition to nursing-led care within an institution is a reasonable option. Insufficient data exist to inform whether a discharge to primary care is equivalent, but, based on the disease trajectory, the expert opinion is that this is a reasonable option.

***Key Evidence***

Prostate cancer survivors receiving follow-up care coordinated by a nurse, but still within an institutional setting, showed no differences from those followed by a specialist when the amount of hospital care and the lag time between diagnosed symptoms and intervention was studied (11). In addition, there were no observed differences between the survivor groups in terms of depression or anxiety (11). The working group did not find any studies examining family physician-led follow-up care of prostate cancer survivors; however, given the similar disease trajectory to breast cancer (expert opinion), there is evidence that this model should be further studied for prostate cancer survivors.

**Other Cancer Types**

6. In patients with melanoma and esophageal cancer, follow-up outside specialist care appears to be acceptable to patients, but without clinical outcomes data, no model of care recommendations can be made.

***Key Evidence***

Melanoma survivors receiving family physician-led follow-up care were more satisfied with their care than were survivors followed by specialists (12). However, this trial did not include any clinical outcomes (12), and so no recommendation can be made about the effectiveness of the medical care. Similarly, esophageal or gastric cardia cancer survivors followed by nurse-led home visits were equally satisfied with nurse-led compared to specialist-led care after a one-year period (13). Once again, no recommendation can be made about the effectiveness of medical care from this trial as no clinical outcomes were included in the trial (13). As survivors appear to be open to alternative care, further studies with survivors of these two cancer types should be undertaken.

7. No recommendation can be made about models of care of other disease types based on the currently available published literature.

***Key Evidence***

The working group was unable to find sufficient studies that investigated survivorship models of care for cancer beyond those mentioned in the above recommendations.

**Nursing Models within Community Setting**

8. Nursing models of care within a community care setting appear to be of interest but have not been explicitly evaluated to date.

***Key Evidence***

All studies that evaluated nurse-coordinated care obtained for this systematic review were still within the institutional setting. Given the success of these studies, further research into the efficacy of nurse-coordinated care within a community-based setting are warranted.

**Shared Care Models**

9. No recommendation about the role of shared-care models can be made at this time based on the currently published literature.

***Key Evidence***

Although shared care has been shown to be beneficial in other disease sites, in the cancer setting, there is not a formalized shared-care model. Due to this lack of formalization, no studies were found that explicitly studied shared care compared to another model in cancer, and thus no recommendation can be made in relation to shared care for survivorship follow-up.

**Added to the 2017 Endorsement:**

A recently published small randomized trial in Australia<sup>1</sup> tested sharing visits during the first year of follow up for patients with low risk prostate cancer. Two hospital visits were

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<sup>1</sup> Emery JD, Jefford M, King M, Hayne D, Martin A, Doorey J, et al. ProCare Trial: a phase II randomized controlled trial of shared care for follow-up of men with prostate cancer. *BJU Int.*

replaced by visits with the general practitioner. Short term outcomes were encouraging in terms of surveillance and quality of life outcomes.

## FUTURE RESEARCH

A comprehensive literature search focusing on comparisons between two models of survivorship care returned few studies. The published comparative literature included in this guideline involved primarily breast, prostate, or colorectal cancer survivors. The expert opinion is that the follow-up care trajectories of breast, prostate, and colorectal cancer are similar, allowing recommendations for all three to be created based on family physician- and nurse-led follow-up care studies. However, studies to investigate family physician-led follow-up of prostate cancer survivors are warranted, as are studies looking at nurse-coordinated care of colorectal cancer survivors. Patient satisfaction with follow-up care outside the institutional setting has been investigated in melanoma and esophageal cancer, with non-inferior results. Studies looking at the clinical outcomes of alternative follow-up models of care in melanoma and esophageal cancers are warranted. Finally, further studies in cancer types that follow a different care trajectory than do breast, prostate, and colorectal cancers should be conducted. While shared-care models are often suggested as alternatives to exclusive care by one provider group, more research is needed to define the configuration of such models in order to study their efficacy within the context of cancer survivorship care.

### ***Added to the Endorsement:***

There is also emerging interest in using a stratified approach to survivorship care that includes more formal assessment of risk to inform the model of care. Risk-stratified pathways of care have been studied by the National Cancer Survivorship Initiative (NCSI) UK, with plans to phase them starting with breast cancer in 2017 (<https://www.england.nhs.uk/cancer/living/>).

Finally, given the success of nurse-coordinated follow-up care within the institutional setting, studies to investigate the effectiveness of community-based nurse-coordinated follow-up care models should be considered.

## RELATED GUIDELINES

### ***Added to the Endorsement:***

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  - Fung-Kee-Fung M, Dodge J, Elit L, Lukka H, Chambers A, Oliver T, et al. Follow-up after primary therapy for endometrial cancer. Toronto (ON): Cancer Care Ontario; 2006 Jan 10; in review 2015 Nov; cited 2016 Oct 26. Program in Evidence-Based Care Guideline No.: 4-9 In Review. Available at: <https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/616>. 2006.
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  - Le T, Kennedy EB, Dodge J, Elit L, Ovarian Follow-up Guideline Expert Panel. Follow-up of patients who are clinically disease-free after primary treatment for fallopian tube, primary peritoneal, and epithelial ovarian cancer. Toronto (ON): Cancer Care Ontario [2015 Nov 11; cited 2017 Jun 13]. Program in Evidence-Based Care Guide No.: 4-22. Available at: <https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/186>. 2015.
  - Ghert M, Yao X, Corbett T, Gupta A, Kandel A, Verma S, Werier J, et al. Optimal treatment options and follow-up strategies in patients with desmoid tumours. Toronto (ON): Cancer Care Ontario [2013 Nov 25; cited 2017 Jun 14]. Program in Evidence-Based Care Guide No.: 11-3. Available at: <https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/37806>. 2013.
  - Rajagopal S, Souter L.H., Baetz T, McWhirter E, Knight G, Rosen C.F., et al. Follow-up of patients with cutaneous melanoma who were treated with curative intent. Toronto (ON): Cancer Care Ontario [2015 Nov 3; cited 2017 Jun 14]. Program in Evidence-Based Care Guide No.: 8-7. Available at: <https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/31776>. 2015.

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#### *Updating*

All PEBC documents are maintained and updated as described in the PEBC Document Assessment and Review Protocol at <http://www.cancercare.on.ca/>.

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*Contact Information*

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*J. Sussman, L.H. Souter, E. Grunfeld, D. Howell, C. Gage, S. Keller-Olaman, and M. Brouwers*

**Report Date: October 26, 2012**

**OBJECTIVES**

1. What are the models described in the literature for the follow-up care of adults with cancer who have completed treatment and are clinically disease free?
2. Are certain models favoured for survivors of specific cancer types in terms of the following:
  - a. Clinical outcomes (e.g., surveillance, recurrence)
  - b. Survivor quality of life outcomes (e.g., quality of life, patient satisfaction)

**INTRODUCTION**

In Ontario, the incidence of new cancer diagnoses was projected to be approximately 66,900 people in 2011. Due to improvements in screening and treatment, there is a 62% likelihood of surviving for at least five years after diagnosis, compared to the general population of the same age and sex (based on 2004-2006 estimates (1)). With such a large proportion of cancer patients transitioning to survivorship, a clear model for surveillance and follow-up care needs to be developed. For the purposes of this document, a definition for survivorship is adapted from the Institute of Medicine's (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* (2) and will refer to the interval following the completion of primary treatment until treatment is needed again or until death. In Ontario, where most survivors are typically followed by a cancer specialist, a large burden is placed on the cancer care system (3, 4), and the projection is that this model is not sustainable (5). However, there is evidence with some cancers that survivorship care can be provided by primary care practitioners or nurses, or by sharing the care of survivors among a team of professionals.

The survivorship phase is multifaceted, encompassing physical, psychosocial, and economic issues (6,7). Depending on the cancer type, treatment, and circumstances, individuals vary in terms of their clinical and quality of life (QoL) requirements for follow-up care. However, follow-up care typically includes screening for new primary tumours, as well as recurrence; detecting and managing the impact of long-term and late effects; addressing rehabilitation and psychological needs; and reviewing the treatment, including assessing new therapies (8). According to Earle (9), the lack of evidence on best practices and clear models for what care oncologists should provide contributes to wide variations in the provision of care. The need to reduce this variation has gained momentum recently with several prominent cancer organizations publishing major reports containing recommendations for action. The most notable being the Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor:*

*Lost in Transition* (2). The IOM recommendations include raising the awareness of cancer survivorship, developing and testing models of care, and providing patients with a care plan. Survivorship follow-up care plans are purported to facilitate continuity of care (2,10,11), since care plans may minimise adverse outcomes as survivors transition from their oncologist back to their family physician (2,10,11). Currently care plans have not been extensively evaluated; however, early evidence has indicated that many cancer survivors are not satisfied with their follow-up care (2,12-14). Thus, survivor cancer care plans under development must address the clinical issues as defined by healthcare providers and the general QoL parameters deserved by survivors.

There is evidence that various models of survivorship care can be provided by specialists, family physicians, or nurses, or by sharing the care of survivors among a team of professionals. *For this document, a model of care is defined as a conceptual object or diagram that provides an outline of how to plan all current and future facility and clinical services (15).* Depending on the clinical context, a particular model of care may be more or less appropriate for a particular clinical situation or disease model. Critical elements of any model include a clear identification of a specific health professional ultimately responsible for the planning and coordination of care, as well as the location in which the care will be provided. While a variety of survivorship care initiatives and programs have begun in Canada, there has not been a systematic review of the literature to inform the development and implementation of survivorship care models. The examination of models of care provides a foundation for the development of disease-specific follow-up care guidelines, focusing on the provider of follow-up care, as has previously been demonstrated in pediatric oncology (7,16,17).

The purpose of this document is to provide guidance on rigorously evaluated models of care for the long-term follow-up of adult cancer survivors in Ontario. This document is intended to be used by policymakers, clinicians, support groups, and administrative staff in Ontario but may be extended to other provinces and/or countries.

## **METHODS**

The evidence-based series (EBS) guidelines developed by the PEBC, CCO, use the methods of the Practice Guidelines Development Cycle (18). This guidance document was developed under the leadership of the PEBC and the Models of Care for Cancer Survivorship Working Group. The working group consisted of clinical oncology experts, health service researchers, and methodologists ([Appendix 2-1](#)).

### **Overview of Approach**

The methods of approach comprised three parts. To address Objective 1 of the guideline, the working group agreed that an initial framework should be created to inform the development of appropriate models of care for the Ontario setting. A targeted scan was used to identify landmark papers that outlined the core models of survivorship care. These core models were used to develop the framework, which was then used to organize the evidence obtained for Objective 2.

For Objective 2, the core methodology was a systematic review to identify an evidentiary base that addressed appropriate outcomes of the core models of care. The systematic review is a convenient and up-to-date source of the best available evidence on models of care for survivorship. The body of evidence in this review is restricted to randomized controlled trial (RCT) data, comparing at least two models of follow-up care. The appraisal of evidence was conducted by a research methodologist (SKO). It was audited, reviewed, and evaluated by the clinical experts in the working group. The appraisal assessed methodology, clinical applications, and feasibility.

The third and final part of the methods involved determining the appropriateness of each model in various cancer types and developing recommendations about potential options for the Ontario setting. The evidentiary foundation from Objective 2 formed the basis of the recommendations developed by the PEBC Models of Care for Cancer Survivorship Working Group (see [Section 1](#)).

The systematic review and companion recommendations are intended to promote evidence-based practice in Ontario, Canada. The PEBC is supported by the Ontario Ministry of Health and Long-Term Care. All work produced by the PEBC is editorially independent from the Ontario Ministry of Health and Long-Term Care.

### **Objective 1: Framework Development**

The working group reviewed selected articles on the delivery and organization of survivorship care from a targeted scan of documents from leading researchers, specific journals (e.g., *Journal of Cancer Survivorship*) and from web sites of organizations concerned with survivorship care (the Canadian Partnership Against Cancer, <http://www.partnershipagainstcancer.ca/>; National Cancer Survivorship Initiative (UK); National Institute of Health <http://www.nih.gov/>; and National Cancer Institute: Office of Cancer Survivorship, <https://cancercontrol.cancer.gov/ocs/>). The working group came to a consensus on several landmark papers that outlined models of care relevant to current professional knowledge within the Ontario context. These core models were used to develop the framework by which the studies defined in Objective 2 could be described and organized.

### **Objective 2: Literature Review**

#### ***Search Strategies***

##### ***Electronic***

OVID was used to systematically search the MEDLINE (R) and EMBASE databases for articles assessing the impact of model(s) of care for post-treatment cancer survivors, published between 2000 and week 13 of 2012. Key terms were purposely broad and included: cancer, survivor, follow-up care and after care, with a subsequent RCT and systematic review filter. The literature search strategy is reproduced in [Appendix 2-2](#).

##### ***Other Sources***

Reference lists of primary articles were scanned for potentially useful studies, and selected journals were hand-searched (e.g., *Journal of Cancer Survivorship*). Websites relevant to care for cancer survivors were searched for evidence-based practice and/or institutional guidelines (e.g., BC Cancer Agency: Cancer Management Guidelines) and recommendations (see [Appendix 2-3](#)). The main searches were supplemented by material identified by individual members of the working group. This strategy ensured that pioneering studies published before 2000 were considered.

##### ***Outcomes***

Both clinical and QoL outcomes were considered. The primary clinical outcomes related to the impact of a model or service on disease-free survival, mortality (cancer-related and all cause), morbidity (late effects), and time to recurrence. The outcomes related to survivor QoL included the impact of a model on health-related quality of life and patient satisfaction. Models reporting only psychosocial outcomes were not included because a PEBC framework to guide psychosocial care in Ontario for cancer patients and their families already exists (EBS 19-3), and future PEBC guidelines will address this area.

### **Study Selection Criteria**

Eligible sources of information had to include the following:

1. Peer-reviewed published full reports with information on follow-up care models for adult cancer survivors or examining elements of such models. Follow-up had to be beyond 12 weeks to be considered relevant. The coordinating provider(s) had to be identified and the model(s) clearly defined and, at minimum, include some aspect of medical care and/or surveillance (rather than merely support). If a trial was not explicit in terms of the model(s) being researched, the evidence was still initially considered if the data and results were relevant to the research objectives.
2. Reports published in English.
3. RCTs, expecting a comparison between a model or elements of a model with another approach. If a trial was not explicit in terms of the model(s) being researched but there were sufficient descriptions to ascertain model or defining feature of survivorship care, the evidence was still considered if the data and results were relevant to the research questions.
4. Systematic reviews identified by the systematic search.
5. Additional sources provided by the working group (such as pioneering studies) if they were relevant to the topic.

The most common reasons for excluding articles were when the articles were not oncology-related, pertained to the active treatment phase, or did not include the target population (e.g., pediatric), or if metastatic disease was diagnosed or the article was not relevant to the present topic (e.g., aspect of support rather than care provision; survivorship focus but not evaluating models of care such as an adjunctive lifestyle program).

### Literature Selection

Citations and brief records identified by the search strategy were downloaded electronically into a bibliographic management package (EndNote X5). A research coordinator (SKO) studied the titles from all the searches to identify which abstracts should be obtained. The list of titles was reviewed by a working group member (MB). Following this, two reviewers (JS and SKO) independently reviewed all the eligible abstracts to assess whether the full-text article should be retrieved. Assessments were based on the selection criteria noted. All abstracts categorised as “yes” or “maybe” were then selected for full-text screening.

Studies eligible for full-text screening were saved in PDF format wherever possible; otherwise paper records were kept. Two reviewers (JS and SKO) independently reviewed the full texts for eligibility. The reasons for excluding studies at this full-text stage included the following: a lack of information about who was providing the overall care, treatment included in the follow-up period being studied, a focus on an adjunctive lifestyle program, and an incomplete final data collection. Two members of the working group reviewed the studies to be included and finalized the list of articles and sources included in the evidentiary base. The studies that met the criteria were retained, and data extraction and analysis followed.

### Critical Appraisal and Data Extraction

Data were extracted by one reviewer, using a predefined form, and audited by a second reviewer independently ([Appendix 2-4](#)). Study quality was independently assessed by two reviewers. For RCTs, no specific instrument was used, but pre-determined criteria included: method of randomization clearly described; whether blinding was employed; power calculations stated; sample size adequate in relation to outcome(s); length of follow-up stated; details of statistical analyses, withdrawal and other losses to follow-up described; and sources of funding declared. The working group members recognised that, due to the nature of the studies being examined, blinding of the model of care was not always possible, and therefore, lack of blinding was not considered a significant weakness in the study design. The

methodological quality ratings of the included RCTs are presented in [Appendix 2-5](#). A formal assessment of systematic review quality was not conducted; however, checks were made to ensure the systematic reviews were explicit in how studies were selected (clear inclusion and exclusion criteria) and assessed and clear about attempts to minimize biases and how studies were integrated to form the conclusions.

### Synthesizing the Evidence

Due to the anticipated large variation in the outcomes measured and/or how they were reported, pooling the data was not planned but would be considered if the data were to allow.

We grouped the studies analyzed in Objective 2 as best we could, based on the framework created in Objective 1. Outcomes were reported to have a positive effect if there was a significant difference between the models of care ( $p \leq 0.05$ ).

## RESULTS

### OBJECTIVE 1

#### Core Survivorship Models of Care

Five published articles from the literature were selected as a foundation on which to organize models of survivorship care (4,7,16,19,20). In addition and although it was in the palliative arena, a report by CCO that described recommendations on the organization and delivery of palliative care in Ontario (21), was included.

Within the landmark articles, the working group identified multiple models of care, which were described with inconsistent terminology, making it difficult to group and compare the models. For this document, a framework was created that defined the models by two key domains: the setting where the care is provided and the coordinator of the care (Table 2-1). Within the setting domain, care can be provided at an institution, in the community or shared between the two locations. For this report, an institution setting refers to a cancer centre or hospital, while a community setting refers to a family physicians' or specialist's office, outside the hospital setting. The coordinator of the follow-up care may be a specialist, a family physician, or a nurse, or the care may be patient-directed. A specialist is defined as a medical oncologist, surgeon, radiation oncologist, or other specialist involved in cancer care management (e.g., endocrinologist). A general practitioner in oncology (GPO) is a family physician who is able to provide specialized cancer care, typically within an institution setting, under the mentorship of an oncologist (22), and is included within specialist-coordinated care in the framework. In contrast, a general practitioner or family physician, practicing in the community out of his/her own office, was considered a family physician. In the context of this report, a nurse may include a nurse specialist, nurse practitioner, or family practice nurse. In addition, nurse navigators are included within the nurse heading in the framework. The nurse navigator project is a pilot program organised through the Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers. In this system, registered nurses have been trained to provide individualized assistance to patients, families, and caregivers to help them understand the healthcare system, overcome barriers, and facilitate timely access to quality health and psychosocial care from pre-diagnosis through all phases of the cancer experience (23). When care is self-directed, patients have point-of-need access to the cancer care team. A belief is that relatively complex models can be described in terms of the two domains within the created framework (Table 1). The models of care for cancer survivorship described in the landmark papers were grouped and compared based on the framework.

**Table 2-1. Framework of models of care identified in the literature.**

Setting	Options: coordinator of follow-up care
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<b>Institution</b> <ul style="list-style-type: none"> <li>• Hospital</li> <li>• Cancer Centre</li> </ul>	<ul style="list-style-type: none"> <li>• Specialist <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, general practitioner in oncology (GPO)</li> </ul> </li> <li>• Nurse <ul style="list-style-type: none"> <li>◦ Nurse specialist, nurse practitioner, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>
<b>Community</b> <ul style="list-style-type: none"> <li>• Family Physician’s office</li> <li>• Specialist’s office (outside hospital)</li> </ul>	<ul style="list-style-type: none"> <li>• Family Physician</li> <li>• Specialist <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, GPO</li> </ul> </li> <li>• Nurse <ul style="list-style-type: none"> <li>• Nurse specialist, nurse practitioner, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>
<b>Shared Care</b>	Any combination of: <ul style="list-style-type: none"> <li>• Specialist <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, GPO</li> </ul> </li> <li>• Family Physician</li> <li>• Nurse <ul style="list-style-type: none"> <li>◦ Nurse specialist, nurse practitioner, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>

**Models within an Institutional Setting**

In the institutional setting, care is coordinated by a specialist or nurse, or may be self-directed by the patient. Typically, when care is based in an institution, the specialist is the foremost care provider; however, the services may differ in focus and organisation. In this model, a specialist may continue to see their original patients indefinitely, a situation described as ongoing care and based on the pediatric model (16). Within our framework, this model would be described as being within the institutional setting with care coordinated by the specialist. Alternatively, using the same parameters within the framework, a survivor may attend a multidisciplinary disease-specific outpatient clinic that is directed by a specialist, and the follow-up care is provided by a range of professionals (7). Of note, a survivor can transition between these different configurations within an institutional-based model of care. For example, a survivor may transition from specialist follow-up care to a multidisciplinary disease-specific outpatient clinic (21). Upon completion of treatment, patients may be supported by nurse specialists. This nurse-coordinated care may be provided in a clinic setting as part of a program that is disease specific (e.g., breast cancer follow-up clinic) or general for all adult survivors (7); however, it is still within the institutional setting. When a nurse is responsible for providing care for survivors, the nurse may not always be the coordinator of care. For example, the plan for follow-up may be developed by a group of disease-specific oncologists, and therefore, the specialist is the coordinator (7). Alternatively, a nurse practitioner may be responsible for coordinating continued follow-up care under the auspices of the survivor program and assisted by the survivor program team (7). Depending on the survivor’s needs, a nurse specialist clinic may provide information, emotional support, symptom management, and referrals to oncologists, a palliative team, social worker/care, and primary health care. With

this option, the nurse practitioner may also play a role in re-establishing communication with the family physician to initiate a shared-care model for the survivor.

### **Models within a Community Setting**

In a community setting, care is organized and directed by a family physician, the specialist who provided treatment, a nurse, or the patient. Generally, the responsibility for follow-up care falls to the patient's usual family physician. This model is described in the Grunfeld et al studies (4,19,20) and fits within the community setting of our framework, with the family physician predominantly being the coordinator of the follow-up care. In the community family physician-led model, the survivor is transitioned from the oncology setting to their usual community-based family physician entirely at a pre-determined point (e.g., one to two years after treatment is completed) (24). The family physician only contacts the specialist if concerns arise (24). A community-based family physician may include a group practice (family health team) and may involve a community clinic setting (24). Even though a family physician is responsible for the follow-up care in this model, the care may be coordinated by a nurse-specialist (similar to within an institution setting), the original treating specialist, or the family physician. When the follow-up care is self-coordinated, the adult cancer survivor accesses community resources and programs as directed or needed (e.g., support groups, pastoral care, occupational therapy, rehabilitation services) (24). The survivor initiates cancer-related follow-up with their family physician if they have any concerns (24). Direction is therefore provided about community resources and accessing oncology services for routine surveillance (e.g., annual mammogram for breast cancer survivors) and primary care if concerns arise (24). Typically the family physician is the point of entry back to the cancer care system for the survivor (24).

### **Models with a Shared Setting**

In a shared model, the responsibility for care is shared between two providers. Most commonly, these two providers are an institution-based specialist and a community-based family physician. The coordination of this care is directed by the specialist, family physician, or nurse, or patient-directed. Shared-care models have been applied in the management of a range of chronic conditions such as diabetes and arthritis, and in palliative care (25). The term shared care can encompass a broad range of definitions, providers, and settings (26), but for this document, we are referring to a model that involves shared responsibility for predominantly medical care between two providers (i.e., two leads), typically an institution-based specialist and a community-based family physician. According to Oeffinger et al (16), depending on the risk of problems, the survivors are transferred back to the community-based family physician one to two years after the completion of therapy. The community-based family physician is responsible for routine health maintenance, management of co-morbid diseases, and ongoing management of the physical and emotional needs of the survivor. The specialist provides the community-based family physician with a survivorship care plan and is available for ongoing consultation regarding areas of uncertainty. The survivor may be referred back to the specialist for specific problems, surveillance, and recurrence. The survivor is therefore monitored by both the specialist and the family physician, with both having a clear picture of what care they are responsible for providing. This model is strongly endorsed and also provides a role for nurse practitioners in the transition (16). As noted above, a specialist nurse may provide care (coordinated by a specialist) and also re-establish communication with the family physician to initiate the shared care of the survivor. Shared care continues with transitioning of care to the community-based family physician, and there is ongoing communication between the nurse practitioner and the family physician in the planned delivery of care (16).

We also note that shared care may be ongoing between an institutional specialist and a community family physician (no transition), or the survivor may transition (discharge) from specialist to family physician when appropriate with rapid access back to the specialist for the treatment of disease progression (see Models with a Community Setting).

### **Model Overlap**

As seen in Table 2-1, various follow-up care coordinators can be part of any configuration, and the models are not mutually exclusive (21). Shared care, for example, can involve an approach where both providers monitor the survivor, or a tiered approach that essentially involves a discharge from specialist care to primary care. The community-based family physician model is therefore equivalent to a shared-care model (with transition). Additionally, within the institutional setting, care can be specialist led or nurse led, which will result in differences in the team monitoring the survivor and what emphasis will be placed on QoL or non-medical aspects of care.

In addition, any model can potentially be augmented with allied care such as physiotherapy, nutrition intervention, or social work, which clearly places a different emphasis on non-medical versus medical aspects of care. For the purposes of this document, we are not including allied care as part of a shared care model, because there is no co-leadership of medical care.

## **OBJECTIVE 2**

### **Systematic Literature Search**

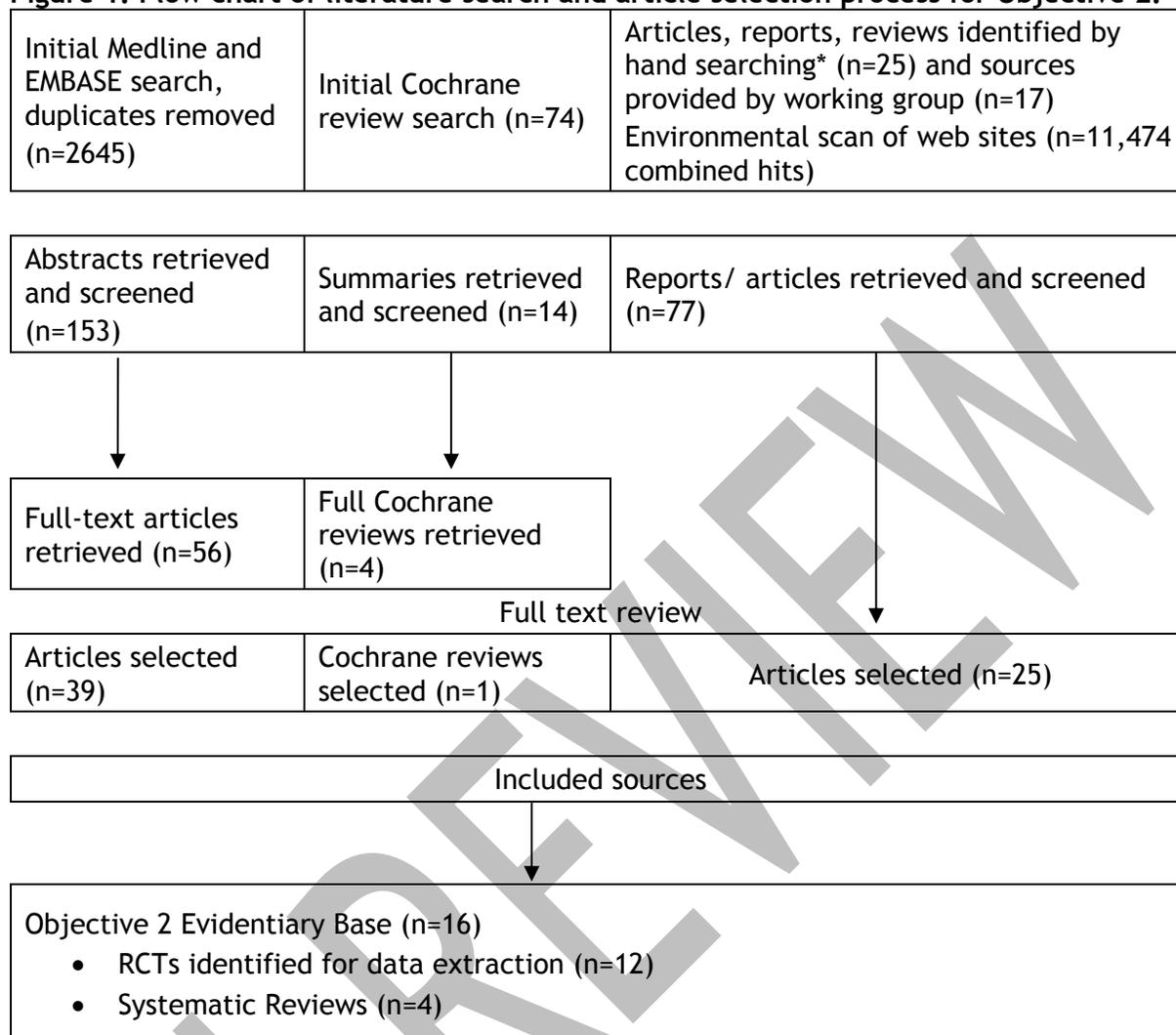
The systematic literature search yielded a total of 2645 articles. Of the 2645 articles, 153 were highlighted as potentially relevant to Objective 2. The abstracts of the 153 articles were examined, and 56 full documents were subsequently obtained and assessed. A search for Cochrane reviews found 74 potentially relevant sources, of which 14 were eligible to be screened, and the full-texts of four were assessed. The hand-searching, back-searching and web site searches yielded 163 sources that were considered potentially useful for this guidance document.

Of all the source material retrieved and examined, a total of 25 were retained, primarily for background, and the following 16 sources were retained for the evidentiary base:

- Twelve RCTs that addressed different providers or aspects of follow-up care
- Four systematic reviews that looked at different providers or methods of follow-up care

The 16 studies included in the evidentiary base are summarized in [Appendix 2-4](#). A flow chart of sources searched, the number of texts reviewed in full, and the number of source texts retained is presented in Figure 1.

**Figure 1. Flow chart of literature search and article selection process for Objective 2.**



\*Journal of Cancer Survivorship included in hand-search count

**Outcomes: Are Certain Models Favoured for Specific Types of Cancer Survivors?**

The systematic literature search identified 12 RCTs (19,20,27-36) and four systematic reviews (37-40) that examined models of follow-up care. Clinical and QoL evidence was reviewed from these 16 sources about surveillance, prevention, quality of life, psychological morbidity, and patient satisfaction. Eight of the 12 RCTs (67%) plus the Cochrane review involved breast cancer survivors.

As either primary or secondary outcomes, nine of the 16 sources reported patient satisfaction (19,27-29,31,34,37,39,40). Eleven sources measured and reported on quality of life (20,27,28,30,32-35,37,39,40). Eight sources reported on psychological morbidity such as anxiety and depression (20,29,30,33,35,37,38,40), and three sources reported costs (34,38,40). The studies have been organized in relation to how they fit into our framework from Objective 1 (Table 2-2a and 2-2b) and evaluated based on the Objective 2 outcomes.

The methodological quality of the RCTs was assessed on the basis of predetermined areas. Methodological quality overall among the studies in the evidentiary base was good (see [Appendix 2-5](#)). To evaluate the quality of RCTs, the working group focused on the method of randomization, if blinding was utilized; the use of power calculations, if the sample size was

adequate in relation to the outcomes, the length of follow-up, if details of the statistical methods were described, if withdrawal and losses to the study were described, and the agency providing the funding for the study. For systematic reviews, the working group ensured that the reviews were explicit about how the studies were chosen and analyzed, as well as being clear about attempts to minimize biases and the inclusion of studies in the conclusion.

**Table 2-2a. Simplified models of care framework.**

Setting	Options: Coordinator of follow-up care
Institution <ul style="list-style-type: none"> <li>• Hospital</li> <li>• Cancer centre</li> </ul>	<i>A</i> Specialist <i>B</i> Nurse <i>C</i> Patient-directed
Community <ul style="list-style-type: none"> <li>• Family Physician’s office</li> <li>• Specialist’s office</li> </ul>	<i>D</i> Family Physician <i>E</i> Specialist <i>F</i> Nurse <i>G</i> Patient-directed
Shared Care	Any combination of: <i>H</i> Specialist <i>I</i> PCO <i>J</i> Nurse <i>K</i> Patient-directed

**Table 2-2b. Models of care compared and cancer type by RCTs.**

Study	Model Comparison	Cancer Type
Beaver 2009 (29)	<i>A</i> vs. <i>B</i>	Breast
Grunfeld 1996 (20)	<i>A</i> vs. <i>D</i>	Breast
Grunfeld 1999 (19)	<i>A</i> vs. <i>D</i>	Breast
Grunfeld 2006 (30)	<i>A</i> vs. <i>D</i>	Breast
Helgesen 2000 (36)	<i>A</i> vs. <i>B</i>	Prostate
Kimman 2010 (31)	<i>A</i> vs. <i>B</i>	Breast
Kimman 2011 (32)	<i>A</i> vs. <i>B</i>	Breast
Koinberg 2004 (28)	<i>A</i> vs. <i>C</i>	Breast
Murchie 2010 (27)	<i>A</i> vs. <i>D</i>	Melanoma
Sheppard 2009 (33)	<i>A</i> vs. <i>C</i>	Breast
Verschuur 2009 (34)	<i>A</i> vs. <i>B</i>	Esophageal or gastric cardia
Wattchow 2006 (35)	<i>A</i> vs. <i>D</i>	Colon

Note: vs. =, versus.

### **Institution-Based Specialist-Led versus Community-Based Family Physician-Led Setting**

Four studies and one review investigated institutional-based specialist-led versus community-based family physician-led follow-up care (20,27,30,35,38) (Table 2-2b). Two of the trials were with breast cancer survivors (20,30), while the third examined colon cancer survivors (35) and the fourth, melanoma survivors (27). The review (38) included three of the trials plus three studies examining the formal involvement of family physicians in conventional hospital-based follow-up. Details of the studies can be found in [Appendix 2-4](#).

In the breast cancer sector, Grunfeld et al have performed two RCTs, a smaller trial in the United Kingdom (UK) (20) and then a larger one in Canada (designed to test non-inferiority) (30). Both trials followed patients who were randomized to either follow-up care with their usual family physician or routine follow-up with a specialist at least three months after treatment completion (20) and within 12 months after diagnosis (30). In the UK trial, the family physicians were provided with a discharge letter and educational booklet on breast cancer (20). In the Canadian trial, family physicians were provided with a one-page follow-up guideline (30). Several factors were examined, including time to recurrence, quality of life, psychological

morbidity, and recurrence-related serious clinical events (SCE; defined as spinal cord compression, pathological fracture, hypercalcemia, uncontrolled local recurrence, brachial plexopathy, or poor functional status at the time of diagnosis of recurrence) (20,30). Both studies concluded that the transfer of care to community-based family physicians did not result in an increase in the time to the diagnosis of recurrence (Table 2-3) (20,30). In addition, there was no difference in recurrence-related SCE or any physical or mental components, and patient satisfaction was greater in the community-based care group (Table 2-3) (20,30).

Similarly, in another trial it was found that survivors of colon cancer did not experience inferior outcomes if they received community-based family physician follow-up care (35). Wattchow et al performed an RCT in Australia in which colon cancer survivors were randomized to either routine specialist-led care within a hospital setting or a community-based family physician four to six weeks after treatment completion (35). No significant differences were found for rates of recurrence, time to detection of recurrence, death rates, or physical and mental components between the two groups (35) (Table 2-3). The only difference noted was in the follow-up tests requested by the care providers. Family physicians tended to order more fecal occult blood tests than did surgeons, whereas surgeons ordered more colonoscopies and ultrasounds (35). The trial authors concluded that, while patterns of investigation were different, there was no significant difference in outcomes between the groups (35).

A systematic review by Lewis et al (38) included the above three studies and concluded that there were no statistically significant differences between institutional-based and community-based follow-up care of breast and colon cancer patients in terms of patient QoL, psychological morbidity, and patient satisfaction (38). However, the reviews also concluded that the lack of difference may be due to the duration of follow-up and sample size rather than to the interventions being equivalent (38).

**Table 2-3. Results of recurrence and survival: Institutional specialist-led compared to community family physician-led follow-up.**

Study Details	Recurrence	Survival
Grunfeld, 1996 (20). Community-based family physician (n=148) versus hospital-based specialist (n=148). 18 months follow-up (breast cancer survivors).	n=10 (6.8%) family physician-led group versus n=16 (10.8%) hospital-based group. Distant recurrence: n=6 (4.1%) family physician-led group versus n=13 (8.8%) in the hospital-based group (difference 4.7%; 95% CI, -0.8 to 10.3). No difference in diagnostic delay (days): family physician-led mean 22 days, hospital-based mean 21 days. Mean difference 1.5 days (95% CI, -13 to 22).  No comprehensive review at end of trial to identify missed recurrences.	Deaths (breast cancer): family physician-led n=2 (1.4%), hospital-based n=7 (4.7%); difference: 3.3%*
Grunfeld, 2006 (30). Community-based family physician (n=483) versus hospital-based specialist (n=485). Median 3.5 years follow-up (breast cancer survivors).	Recurrence-related serious clinical events: family physician n= 17 (3.5%), hospital n=18 (3.7%); difference: 0.19% (95% CI, -2.26 to 2.65). Recurrence or new contralateral breast cancers: family physician n=54 (11.2%), hospital n=64 (13.2%); difference: 2.02% (95% CI, -2.13 to 6.16). Comprehensive review at end of trial found no missed recurrence.	Deaths (all cause): family physician n=29 (6.0%), hospital n=30 (6.2%); difference: 0.18% (95% CI, -2.90 to 3.26)

Wattchow, 2006 (35). Community-based family physician (n=97) versus conventional hospital with surgeon (n=106, from state-based cancer registries). 24 months follow-up (colon cancer).	Recurrence rate (per 1000 months on trial): family physician n=7.1, hospital=8.0; p=0.92, Fisher's exact test. Median time to detection (months): family physician n=9.5, hospital n=8.0; p=0.76, log rank test.	Death rates (per 1000 months on trial): family physician n=6.6, hospital n=5.4; p=0.67, Fisher's exact test. Median survival (months): family physician=31, hospital=20; p=0.69
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Note: n = sample size; CI = confidence interval; p = probability.  
\* Author's calculation

An RCT conducted in Scotland investigated family physician follow-up of melanoma survivors, but only looked at survivor QoL outcomes (27). Melanoma survivors were randomized to receive either traditional follow-up at a melanoma clinic or family physician-led follow-up. The family physicians involved in providing the care received a training session and manual on the presentation of new and recurrent melanomas. Additionally, survivors in the family physician-led group received a booklet with information on melanoma and self-examination. Both groups were seen by the respective care giver at three- or six-monthly intervals depending on the thickness of melanoma and time since diagnosis (27). The trial determined that survivors followed by family physicians were significantly more satisfied with their follow-up care than was the control group (p<0.001) (27). Additionally, the RCT looked at adherence to care guidelines in both groups and found that family physician-led care was more guideline compliant than was specialist-led (98.1% of survivors in family physician-followed group seen according to local guidelines; 80.9% of specialist-followed group; p=0.02) (27). There was no significant difference between the groups in terms of health status when Short Form - 36 (SF-36) and Hospital Anxiety and Depression Score (HADS) scores were examined (27). The trial authors concluded that the family physician-led follow-up of melanoma survivors provided greater care satisfaction, allowed for closer adherence to care guidelines, and did not adversely affect health status or anxiety and depression when compared to specialist-led follow-up.

The evidentiary base that compared community-based family physician care to the typical specialist-led care within an institutional setting illustrates that, for breast and colon cancer survivors, family physician-led follow-up does not adversely affect clinical or QoL outcomes. For melanoma patients, community-based family physician care does not adversely affect QoL outcomes.

### **Nurse-Led versus Specialist-Led Follow-Up within Institutional Setting**

Four randomized trials and one randomized equivalence trial focusing on nurse-led models were included in the evidentiary base (29,32,34,36) (Table 2-2b). In addition, one systematic review was included that examined nurse-led telephone follow-up (37). Another systematic review combined nurse-led follow-up with community-based family physician follow-up versus specialist-led care (39). A third systematic review looked at the effectiveness of nurse-led compared to specialist-led follow-up care (40). Two studies examined breast cancer follow-up (29,32), another followed prostate cancer survivors (36), and one examined specialist-led versus nurse-led follow-up in esophageal or gastric cancer (34). The systematic reviews included all cancers (37,39,40). Study details are summarized in [Appendix 2-4](#).

Several of the nurse-led RCTs involved nurse care provided via the telephone. Within these models, the care was still technically within the institutional setting, but the nurse was the coordinator of care. An equivalence trial following breast cancer survivors randomized to either receive routine physician-led follow-up in an outpatient clinic (typically provided by junior medical staff, supervised by a specialist), or nurse care follow-up via telephone at the

usual appointment times (29). Breast care nurses underwent training on the administration of the telephone intervention (29). It was found that there was no difference between the groups when the time-to-detection of recurrence (39.0 days for nurse-led versus [vs.] 60.5 days for specialist-led;  $p=0.228$ ), the number of clinical investigations ordered (40% for specialist-led, 43% for nurse-led at end of trial;  $p=0.574$ ) or psychological morbidity were examined (29). As for satisfaction, the nurse-led telephone group rated higher levels of satisfaction with the information received and with helpfulness in dealing with concerns than did the hospital group (29). These differences were not observed at the start of the trial but became significant at the middle and end of the trial, with a higher proportion of the telephone group providing positive responses than did the hospital group (49% positive for specialists-led vs. 80% for nurse-led;  $p\leq 0.001$ ) (29). The trial researchers concluded that the women who received telephone follow-up were not more anxious as a result of foregoing hospital contact and clinical examinations (29).

A similar RCT following breast cancer survivors also supported the use of nurse-led follow-up. Breast cancer survivors who had completed treatment less than six weeks prior were randomized to one of four arms; hospital follow-up with a specialist, nurse-led telephone follow-up, hospital follow-up plus an educational group program, or telephone follow-up plus an educational group program (32). Hospital follow-up (usual) care was provided by a specialist and/or a trained breast care nurse (BCN) and involved medical history taking and a physical examination over five outpatient clinic visits (32). Telephone follow-up was provided by a hospital-based BCN and included screening for treatment side effects, physical and psychological symptoms, compliance with hormone therapy, and open discussion of issues via the telephone plus one outpatient clinic visit at 12 months combined with an annual mammogram (32). An additional hospital appointment was scheduled if the patient or BCN was not reassured. The educational group program consisted of two interactive sessions with a BCN and a health psychologist and covered the aims of follow-up and possible physical and psychological sequelae of breast cancer treatment. The trial found that there were no differences between the four arms in health-related QoL ( $p=0.42$  specialist vs. nurse;  $p=0.86$  follow-up with or without educational group program;  $p=0.50$  nurse-led vs. educational group), role ( $p=0.28$ ), and emotional functioning ( $p=0.24$ ) or anxiety levels ( $p=0.40$ ) (32). The authors concluded that nurse-led telephone follow-up could replace face-to-face specialist-led hospital outpatient visits in the first 12 months after breast cancer treatment without adversely affecting HRQoL, role, and emotional functioning or anxiety levels (32).

In prostate cancer, an RCT that compared on-demand contact with a specialist nurse versus traditional follow-up by an urologist (specialist) for survivors was conducted (36). The survivors were contacted by the nurse every six months by telephone for three years, or the patient could initiate contact if they had concerns (36). As well, the specialist nurse could consult directly with an urologist or other specialists if a patient had signs and symptoms of progressive disease (36). The researchers determined that there was no difference between groups when looking at lag time between diagnosed symptoms and intervention and amount of hospital care (545 days specialist-led; 403 days nurse-led) (36). There were also no significant differences between the groups in terms of HADS (depression, anxiety) (36).

An additional trial looked at nurse-led follow-up, but instead of telephone-based visits, the nurses visited the survivors at home (34). Three weeks after curative surgery for esophageal or gastric cardia (upper gastrointestinal) cancer, patients were randomized to standard follow-up with surgeons at a hospital outpatient clinic or to regular home visits by a specialist nurse (34). If specific symptoms and medical problems occurred, the specialist nurse referred patients to the hospital outpatient clinic for medical evaluation (34). All patients showed an improvement in quality of life over the trial on the EQ-5D index and the EQ-VAS for overall self-rated health (34). Although more improvement was seen at four and seven months for the

nurse-led group compared to the specialist-led group, this difference was not significant (34). Weight loss in the specialist-led group (73.2 kg at randomization, to 71.2 and 69.6 kg at six and 12 months, respectively;  $p=0.04$ ) compared to the nurse-led group (74.5, 74.2, 75.5kg, respectively;  $p=0.19$ ) was slightly increased (34). There was no difference in patient satisfaction between the two groups (nurse-led mean 8.3, 1.2 standard deviation (SD) vs. specialist-led mean 7.9, 1.2 SD;  $p=0.14$ ) (34). However, when spouses were questioned, they were generally more satisfied with nurse-led follow-up than with specialist-led (mean 8.1 vs. mean 7.4;  $p=0.03$ ) (34). Patients and spouses in the nurse-led group indicated that they received more advice regarding disease management than did the specialist-led group (patients:  $n=45$  vs.  $n=37$ ,  $p=0.04$  and spouses:  $n=27$  vs.  $n=20$ ;  $p=0.03$ ), while patients and spouses in the specialist-led group more often indicated that the visits did not fulfill their expectations ( $p=0.04$  and  $0.03$ , respectively) (34). Cost was also examined in this trial and showed an overall lower cost in the nurse-led follow-up than in the specialist-led follow-up care group, but the differences were not statistically significant due to the large amount of variation (34). The authors concluded that nurse-led follow-up at home did not adversely affect the quality of life or satisfaction of esophageal or gastric cardia (upper gastrointestinal) cancer survivors (34). When compared with follow-up by clinicians at an outpatient clinic, nurse-led service at home may also help to reduce waiting lists in hospitals and/or reduce the workload of physicians (34). Additionally, the authors speculated that this type of care could also be an attractive alternative to the standard follow-up of patients with other types of cancer, particularly in patients in whom no curative treatment option is available for recurrent or metastatic malignancy (34).

Three systematic reviews have been conducted to examine the efficacy of nurse-led follow-up care within an institutional setting. One, conducted by Cusack and Taylor (37) evaluated RCTs and patient questionnaires, investigating whether nurse-led telephone follow-up met the needs of patients and the consequences of the use. Based on the synthesized evidence, Cusack and Taylor concluded that telephone follow-up conducted by an experienced nurse specialist was accepted by the majority of patients and provided a safe method of delivering care (37). The second systematic review, by Ouwens et al (39), included interventions aimed at improving the integration of care for adults affected by cancer in hospital or in an out-patient setting (39). These interventions were focused on patient needs (patient centeredness), optimal collaboration among the professionals involved (multidisciplinary care), and continuous care with optimal coordination and organization of the total-care process (organization of care) (39). Ouwens et al (39) concluded that intervention outcomes, satisfaction, and subjective health outcomes (depression, anxiety, quality of life) can be equal or better with nurse-led follow-up rather than with specialist-led follow-up. The Lewis et al review (40) aimed to compare the effectiveness and cost effectiveness of nurse-led follow-up to specialist-led follow-up. Outcomes included survival and recurrence rates, psychological morbidity and quality of life, patient satisfaction and resource use. The reviewers concluded that there was no difference between the intervention groups in terms of the outcomes investigated; however, they pointed out that, although there were no differences found, that did not mean the interventions were equivalent, only that the sample size and length of follow-up may have been insufficient to detect differences (40).

Based on the literature, it appears that nurse-coordinated follow-up is as efficient as specialist-coordinated when comparing clinical outcomes. Moreover, nurse-led care may be beneficial for survivor QoL outcomes

### **Shared-Care Models**

The shared-care model for the long-term follow-up of adult cancer survivors is based on the pediatric model (16). One systematic review was identified that examined shared-care

approaches (38) ([Appendix 2-4](#)). The review compared institution-based specialist-led and a shared-care model of care. It considered the effectiveness and cost-effectiveness of primary versus secondary care follow-up and the effectiveness of the integration of primary care in routine hospital follow-up, and evaluated the impact of patient-directed follow-up on primary care (38). Interventions were complex but were essentially ongoing shared care between community-based primary providers and institution-based secondary-care providers (38). With relation to our framework from Objective 1, the parameters would include a specialist coordinator from the institutional setting and a family physician coordinator from the community setting. The review looked at RCTs following survivors of breast, prostate, colorectal, gastric, gastrointestinal, germinal cell, head and neck, bladder and kidney, ovarian and cervix, sarcoma, malignant melanoma, brain, lung, and miscellaneous cancers (38). The review concluded that, overall, medical outcomes and patient satisfaction measures are consistent between a shared-care model and usual specialist-led care (38).

### **Patient-Directed Follow-Up Care**

Two RCTs and one systematic review provide the evidentiary base for patient-directed follow-up care (28,33,38). Details for these studies are summarised in [Appendix 2-4](#).

One RCT examined the effectiveness of point-of-need access to specialist care via a nurse specialist compared to routine hospital-based six-monthly clinical reviews in breast cancer survivors two years post-treatment (33). This care is considered patient directed, since survivors chose if they needed access to medical care. Survivors randomized to the point-of-need access group were given information about how to contact a trained hospital nurse specialist by telephone if concerned (33). Mammograms continued on an annual basis for both groups. At 18 months, there was no difference between the groups in relation to quality of life (FACT-G,  $p=0.952$ ), psychological morbidity (GHQ12,  $p=0.767$ ), recurrence (endocrine scores,  $p=0.388$ ), or fear ( $p=0.066$ ) (33). When the trial was completed, all survivors in the point-of-need access group were given the option of returning to six-monthly clinical review, and less than 5% chose this option (33). Thus, the authors concluded that, for the majority of patients, point-of-need access is acceptable (33). Additionally, point-of-need access via a trained specialized nurse may offer a more personalized level of care based on patient need and appears to create a rapid, efficient, and responsive management system for potential recurrence (33).

The second RCT examined the effectiveness of point-of-need access to a nurse specialist via telephone compared to routine follow-up with a specialist for breast cancer survivors (28). Survivors randomized to the nurse-group met with an experienced nurse three months after curative surgery and were instructed on how to recognize recurrence. Survivors were requested to contact the nurse if they had any questions about symptoms that could be attributed to breast cancer. Both the specialist and the nurse point-of-need groups were scheduled for mammograms on an annual basis (28). Quality of life, care satisfaction, access to medical care, and medical safety were measured twice a year over a three-year period through a questionnaire. A final questionnaire was mailed to the survivor at the end of five years. Additionally, the measurements of the number of contacts with healthcare services, number of diagnostic procedures, and time-to-recurrence were obtained over the five-year follow-up. The trial found no significant difference between groups regarding anxiety and depression (measured by HAD scale) or satisfaction with care (measured by a satisfaction and accessibility scale designed for the trial) (28). It was found that the specialist group required 21% more primary contacts than did the nurse group (28). Alternately, the nurse group requested more mammograms than did the specialist group (28). Other than mammograms, all other imaging and laboratory evaluations were similar between the two groups (28). Locoregional recurrences were higher in the nurse group by 3%; however, there were no other significant differences

regarding types of events (time to locoregional recurrence, metastases, death) according to Kaplan Meier estimates at three and five years (28). The authors concluded that their trial added to the evidence that nurse-led outpatient clinics are a reasonable alternative to specialist follow-up but did not comment specifically about the implications of a patient-initiated approach.

A systematic review compared specialist-led, community family physician-led and patient-directed community care (38). The review included three small RCTs examining patient-directed follow-up care. One included breast cancer survivors who were advised to telephone a nurse if they had problems, while a second advised the breast cancer survivors to request an immediate appointment with their family physician if they had any problems (38). Finally the third RCT included colorectal cancer survivors advised to see their family physician if they had any abdominal pain or change in bowel habits lasting more than two weeks (38). The control group for all three studies received routine hospital follow-up (38). The outcomes investigated the number of family physician visits made by the survivors and the number of referrals family physicians made to hospitals (38). Lewis et al (38) reported no differences between groups for the number of family physician visits or cancer-related family physician referrals.

### Patient Satisfaction with Care Models

Although some RCTs had patient satisfaction as an outcome, only two were designed to test patient satisfaction primarily. Both the RCTs identified examined patient satisfaction with follow-up for breast cancer survivors (19,31).

A trial by Grunfeld et al (19) compared patient satisfaction with community family physician-led follow-up versus specialist-led hospital outpatient clinic follow-up. This trial was a secondary outcome of the authors' earlier RCT (20). Patients answered questionnaires on their satisfaction with care at the beginning, mid-way, and end of the 18-month trial. The responses were summarized under three key areas: service delivery, quality of consultation, and continuity of care. The group followed by community family physicians showed higher levels of satisfaction (mid-trial data) in all key areas compared to the hospital follow-up group (Table 2-4) (19). The community family physician-led group also demonstrated a significant increase in satisfaction from baseline to mid-trial in all areas, apart from two items that had a ceiling effect (19). Alternately, the institution-based group were relatively static in their satisfaction ratings from baseline to mid-trial (19). The authors concluded that patients should be given appropriate information and choices when developing a survivorship care plan (19). Patients for whom good communication is part of their cancer care feel more involved in the decision-making process and experience better psychosocial adjustment (19).

**Table 2-4. Patient satisfaction at mid-trial by group (19).**

Question	Agree* GP, n (%)	Agree* Hospital, n (%)	Difference (95% CI)	p-value
<b>Service Delivery</b>				
If it's urgent you can see a doctor on the same day	116 (84.1)	61 (50.8)	33.2 (22.4 to 44.1)	<.001
You are usually seen by the doctor within 20 min of appointment time	134 (97.1)	111 (91.0)	6.1 (0.3 to 11.9)	.009
There is not enough times to discuss your problems with your doctor	38 (27.9)	56 (47.1)	-19.1 (-30.8 to -7.4)	.005
<b>The consultation</b>				
You get good advice about how to keep yourself healthy	112 (81.2)	77 (63.6)	17.5 (6.8 to 28.3)	.001

It is sometimes difficult to discuss your concerns with the doctor	39 (28.7)	48 (39.7)	-11.0 (-22.6 to 0.57)	.175
The doctor explains clearly what is wrong	126 (91.3)	103 (85.8)	5.5 (-2.3 to 13.3)	.321
The doctor examines you thoroughly when necessary	136 (98.6)	119 (98.3)	0.2 (-2.8 to 3.2)	.507
Sometimes you feel the doctor should listen more to what you say	36 (26.5)	52 (43.7)	-17.2 (-28.8 to -5.6)	.004
The doctor should tell you more about your problem and treatment	63 (46.7)	76 (63.9)	-17.2 (-29.3 to -5.1)	.001
The doctor encourages you to talk about your problem and treatment	126 (92.0)	91 (75.8)	16.1 (7.2 to 25.0)	.009
<b>Continuity of care</b>				
You see a doctor that knows you well	124 (89.9)	65 (53.7)	36.1 (25.9 to 46.3)	<.001
If you need to see a doctor, you have to wait too long for an appointment with the doctor you want	54 (39.7)	31 (26.3)	13.4 (2.0 to 24.9)	<.001

Note. Table adapted from (19). CI = confidence interval; GP= general practitioner; min = minute; n = sample size; p = probability.

Another RCT, by Kimman et al (31) compared satisfaction with nurse-led (institution-based) telephone follow-up to satisfaction with usual institution follow-up (specialist-led) among breast cancer survivors. Data on patient satisfaction were collected at baseline, three, six and 12 months after treatment. Satisfaction measures included general satisfaction, scores for technical competence, interpersonal aspects, and access of care. At 12 months, there were no significant differences between the groups in terms of general satisfaction, satisfaction with technical competence, and satisfaction with interpersonal aspects (31). However, access to care was rated higher for the telephone follow-up group, but the authors deemed this difference not clinically relevant because it was less than half a standard deviation (Table 2-5) (31).

**Table 2-5. Patient satisfaction scores at 12 months follow-up (31).**

Satisfaction item	Nurse-led telephone (n=150), Mean (SD)	Hospital follow-up (n=149), Mean (SD)	Difference	95% CI	p-value
General satisfaction	76.4 (19.7)	75.3 (19.6)	1.86	-2.30 to 6.03	0.379
Interpersonal aspects	80.5 (17.6)	78.7 (18.5)	0.91	-3.18 to 5.00	0.662
Access to care	76.4 (15.6)	73.3 (15.7)	3.10	0.71 to 6.70	0.015
Technical competence	75.8 (16.8)	73.7 (17.9)	2.13	-1.51 to 5.77	0.249

Note: Table adapted from (31). n = sample size; SD = standard deviation; CI = confidence interval; p = probability.

Four additional RCTs mentioned in previous sections examined patient satisfaction, although not as the primary outcome (27-29,34). Results from these studies have been described in the appropriate sections; however for completeness, the patient satisfaction data is also summarized here. In the Beaver et al breast cancer survivor trial (29), survivors in the nurse-led telephone group rated higher levels of satisfaction than did the hospital group. The Murchie et al trial (27), which followed melanoma survivors, also found survivors more satisfied with the intervention care (family physician-led) compared to institutional specialist-led care. Alternately, both the Verschuur et al study (34) with esophageal cancer survivors and the Koinberg et al trial (28) with breast cancer survivors found no satisfaction differences between

the intervention group (both nurse-based) and usual specialist-led survivor follow-up. These studies demonstrate at least equivalent, or greater, patient satisfaction with care models that do not involve specialist-led components.

## **DISCUSSION**

### **Objective 1. Models of Care Framework**

There is general recognition that all adult survivors of cancer should receive follow-up care after their treatment (2-5,7-9). The aim of Objective 1 was to describe the current models of care for follow-up care of adults with cancer who have completed treatment and are clinically disease free. The literature discussing models of survivorship care is limited, and the studies examining the delivery of models of care in adult cancer survivors are varied in their approaches and measures. The PEBC Models of Care for Cancer Survivorship Working Group selected six landmark reports to inform a framework of models for this area of care (7,16,19-21,30). A framework was defined by two domains by which models within the literature could be described (Table 2-1). The domains were the setting where the care is provided and the professional responsible for coordinating the care. The framework was used to help describe the evidence from the systematic literature search. We grouped the studies as best we could according to the setting in which follow-up care was provided, acknowledging that at times there was overlap.

### **Objective 2. Are Certain Models Favoured for Specific Types of Cancer Survivors?**

The aim of Objective 2 was to determine whether certain follow-up care models are favoured for survivors of specific cancer types. Based on the evidence reviewed, follow-up care led by a community-based family physician does not adversely affect survival outcomes or psychosocial or quality-of-life outcomes compared with a specialist-led (institution-based) model of follow-up care for breast and colorectal cancer survivors after the completion of adjuvant therapies (20,30,35). The systematic review by Lewis et al (38) grouped the same three RCTs when they examined studies of family physician follow-up. Lewis et al (38) reached the same conclusion; that regular specialist-led hospital based follow-up has no survival benefit over family physician-led follow-up. There is evidence that breast cancer patients are more satisfied with family physician-led follow-up compared with receiving care by a specialist in a hospital setting (19). There is also evidence that melanoma survivors are more satisfied when followed by family physicians than by specialists; however, no clinical outcomes have been examined (27).

There is evidence suggesting that nurses can also play a major role in follow-up care of breast and prostate cancer survivors. From the articles reviewed, there was no evidence of physical or psychological disadvantage with nurse-coordinated telephone follow-up care compared to the more conventional specialist-led care within an institutional setting. Indeed, the reviewed evidence indicates that nurse-led follow-up is associated with higher levels of satisfaction with care versus conventional institution-based specialist-led care (31). In addition, nurse-coordinated follow-up is associated with reduced use of other services such as diagnostic tests and hospital-based consultations (34). Results from the Verschuur et al (34) trial also demonstrate that nurses can perform follow-up of patients by home visits after esophageal or gastric cardia resection surgery for cancer treatment, with no disadvantage in quality of life. However, this trial involved only immediate postoperative care, and so no conclusions can be made regarding long-term follow-up care.

Shared care is the joint participation of specialists and family physicians in the planned delivery of care, a follow-up approach common within pediatric oncology and other chronic disease contexts (16,25). A systematic review investigating shared care reported positive feedback in terms of medical and non-medical outcomes compared to a hospital-based

specialist-led model (38). However, within cancer care, a shared-care model has not been well defined or formalized, making it difficult to draw conclusions about the effectiveness of a shared-care plan. Further to this point, the review (38) that discussed a shared-care model with positive outcomes for cancer survivors actually included studies (20,30) that by this document have been defined as community-based family physician-coordinated care.

For patient-directed care, the evidence shows that patients are accepting of self-initiated follow-up, and that routine institutional (specialist-led) follow-up is not associated with increased benefits for breast cancer survivors compared to patient-directed follow-up (28,33). Engaging the survivor in the follow-up care process is, therefore, another way to address individual needs.

### **Care Plans to Support Provider Transition**

While comparative studies have demonstrated in a number of contexts that survivorship care transition is possible between providers, there is little evidence from these studies to inform the process of how to optimally facilitate this transition. Much has been written about the use of survivorship care plans to facilitate the transfer of care between providers based on face validity but with little empiric evidence to support their use. One recent large RCT has been completed to address this question directly. In the trial by Grunfeld et al (14), survivors with breast cancer who were planned to be discharged to their family physician were randomized between a usual discharge control arm including a discharge letter, which may or may not have summarized follow-up recommendations, and a group that additionally received a specific survivorship care plan and an educational session with a nurse. This trial did not find any differences on patient reported outcomes between the groups; however, outcomes were favourable in both groups (14). The adherence to guidelines or provider's perspectives on transition data from the trial have yet to be published (14). This research suggests that within the Canadian health care context, a survivorship care plan may not improve the transition from the patient's perspective. Further research is needed to clarify this finding and to determine what the effects might be at the provider and health system level.

### **Timing of Transition to Primary Care Provider**

Few of the studies included in this review explicitly inform the question of when care was transitioned after completion of therapy. It is recognized that there may be a period of time necessary to establish the stability of the patient prior to the transition of care from that led by an oncology team. A Canadian trial by Del Giudice et al (24) does address this question. In a survey of nearly 330 family physicians from across Canada, it was determined that the median acceptable time to accept exclusive care of patients was 2.4 years for prostate cancer, 2.6 years for colorectal cancer, 2.8 years for breast cancer, and 3.2 years for lymphoma (24). Family physicians indicated that certain elements would assist them in assuming exclusive care for cancer survivors. The modalities included a patient-specific letter from the specialist, printed guidelines on follow-up care, expedited referral routes back to the cancer system as well as expedited access to clinical tests if recurrence is suspected (24). Two US studies also surveyed family physicians and similarly discovered that family physicians are willing to assume the follow-up care of cancer survivors but want specific follow-up guidelines from the treating oncologist (41,42), as well as more preparation and training (42). This information should be taken into consideration by programs planning care transitions from oncology care to primary care.

Factors that would facilitate shared care between institution-based specialists and community-based family physicians were investigated in a RCT (43). Community-based GPs were randomized to receive either a one-page standard letter from the cancer treatment centre or the standard letter plus an additional one-page information sheet tailored to the

specific type of chemotherapy the patient was given. This correspondence was sent by the patient's oncologist to the community-based family physician after the patient completed the chemotherapy regimen. The tailored sheet included information about the chemotherapy (e.g., regimen, intent, name of treating doctor), potential adverse effects, and recommended management. Baseline and follow-up surveys were administered to measure the community-based family physician's confidence in managing adverse effects, unprompted recall of knowledge, satisfaction with shared care, satisfaction with the communication received, and perceptions of the correspondence (e.g., usefulness, extent to which understanding and knowledge increased). Family physicians assigned to the intervention reported significantly greater levels of confidence in treating adverse effects and greater levels of satisfaction at follow-up than did family physicians receiving the usual correspondence (43). The perceptions of the usefulness of the correspondence, usability, right length, and instructiveness were significantly more positive in the intervention group compared to the control (43). The authors concluded that the confidence of community-based family physicians in managing adverse effects and their satisfaction with the shared care of their patients is improved when standard information relevant to the specific patient was provided (43). This trial adds credence to the family physician survey studies (24, 41, 42) and also indicates that family physicians require specific assistance from specialists when assuming follow-up care responsibilities.

### **Limitations of the Body of Evidence**

The evidence available to determine whether certain models of follow-up care are favoured for survivors of specific cancer types (Objective 2) included systematic reviews and RCTs. The complete evidentiary base was appraised, but we acknowledge various limitations.

Few studies examining models of follow-up care for adult cancer survivors were identified. More specifically, few studies about shared care and studies of certain populations (e.g., men with cancer) were identified, which influences the external validity of findings. The majority (eight out of 12, 67%) of the RCTs in the evidentiary base were conducted with breast cancer survivors. The assumption cannot be that the evidence from the breast cancer follow-up care RCTs generalizes to other disease sites, although some suggestions can be made based on common trajectories of cancer similar to breast cancer. At present, more research is needed to build on the knowledge about feasible models of follow-up care, because evidence in cancer populations other than women with breast cancer is limited (e.g., men with cancer, marginalized populations). Of note, no follow-up care research was found pertaining to geographic dispersion and tertiary versus community hospitals (i.e., the opportunity to implement some of the recommendations may be limited due to local circumstances and the availability of resources).

Many of the studies reported few or no differences between their intervention and control groups. Non-significant findings do not always mean equivalence, however, and in some cases could be due to insufficient follow-up duration or small sample size, particularly when considering relatively infrequent outcomes such as recurrence or mortality (e.g., (20,33)).

Inconsistent findings are also a limitation, largely due to a lack of standardization. Several studies may examine a common model of care, for example, but follow different designs (e.g., varying sample characteristics, outcome measures, length of follow-up). Due to the range of measures, populations, and follow-up approaches, it was not possible to pool data.

### **CONCLUSIONS**

A thorough search of the literature found few studies of randomized comparisons between two distinct survivorship models of care. In the studies that were found, the control arm was almost always specialist-coordinated care within an institutional setting, while the alternate model was either family physician-coordinated care in a community setting or nurse-

coordinated care within the institutional setting. For community-based family physician care, it is implied that the survivors are discharged from the cancer system, while with the nurse-coordinated model, the survivors are retained within the system. Discharge from specialist care to family physician care appears to be a reasonable alternative to the usual specialist-coordinated care in breast cancer and colorectal cancer. Studies involving breast cancer survivors indicate that this approach is reasonable from the perspectives of the patient and the health system in that there has been no significant difference found between models in terms of surveillance for recurrence and medical outcomes. Additionally, across several studies, there is some suggestion that patient satisfaction and costs are equivalent to, if not better than, specialist-coordinated models within institutions. The success of family physician-based models may extend to prostate cancer for early stages of disease, given the similarities to breast cancer in terms of care trajectories and care characteristics during the survivorship period (i.e., high cure rates, well-established guidelines for follow-up that are not provider dependent, and testing that can be organized within the community). The role of nurses as the coordinators of follow-up care, but not necessarily the most responsible clinical providers, has been studied in the context of breast, colorectal, and prostate cancer. These cancers follow a similar trajectory in terms of initial diagnosis, treatment, and follow-up care, and studies suggest that a nurse-coordinated model may be reasonable to consider within the context of ongoing follow-up within an institution. Future research, particularly studying the role of community-based models that involve nursing coordination components, and especially in colorectal and prostate cancers, could further inform the development of models in these cancer types.

#### **CONFLICT OF INTEREST**

The conflict of interest details are shown at the end of [Section 3](#).

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**Appendix 2-1. Members of the Models of Care for Cancer Survivorship Guideline Development Group.**

Name	Contact Information	Role in Guideline Development	Conflict of Interest
Jonathan Sussman, MD, FRCPC Director, Supportive Cancer Care Research Unit	Juravinski Cancer Centre 699 Concession Street Hamilton, ON L8V 5C2	Working Group member	None
Lesley Souter, PhD Research Coordinator, Cancer Care Ontario's Program in Evidence-based Care	Department of Oncology, McMaster University, Juravinski Hospital Site, 711 Concession Street Hamilton, ON L8V 1C3	Working Group member	None
Eva Grunfeld, MD, DPhil, FCFP Clinical Scientist, Ontario Institute for Cancer Research	Department of Family and Community Medicine 500 University Avenue Toronto, ON M5G 1V7	Working Group member	Published several RCTs on follow-up care of breast cancer survivors, as well as editorials/commentaries on the subject.
Doris Howell, RN, PhD Scientist, Ontario Cancer Institute	Princess Margaret Hospital 610 University Avenue Toronto, ON M5G 2M9	Working Group member	Received a grant to research survivorship models of care, as well as published a review on the subject.
Cristina Gage Clinical Research Manager	Juravinski Cancer Centre 699 Concession Street Hamilton, ON L8V 5C2	Working Group member	None
Melissa Brouwers, PhD Provincial Director, Cancer Care Ontario's Program in Evidence-based Care	Department of Oncology, McMaster University, Juravinski Hospital Site, 711 Concession Street Hamilton, ON L8V 1C3	Working Group member	None
Laurie Elit, MD, MSc, FRCS(C) Lead Scientist, Ontario Cervical Screening Program and Division of Gynecologic Oncology	Juravinski Cancer Centre 699 Concession Street Hamilton, ON L8V 5C2	Report Approval Panel member	None
Eric Winqvist, MD, MSc Medical Director, Clinical Cancer Research Program and Leader, Lawson Translational Cancer Research Team	London Health Sciences Centre 790 Commissioners Road E London, ON N6A 4L6	Report Approval Panel member	None

## Appendix 2-2. Literature search strategies.

### EMBASE < 2000 to 2012, week 13 >

1. exp meta analysis/ or exp systematic review/
2. (meta analy\$ or metaanaly\$).tw.
3. (systematic review\$ or pooled analy\$ or statistical pooling or mathematical pooling or statistical summar\$ or mathematical summar\$ or quantitative synthes?s or quantitative overview).tw.
4. (systematic adj (review\$ or overview?)).tw.
5. exp review/ or review.pt.
6. (systematic or selection criteria or data extraction or quality assessment or jadam scale or methodological quality).ab.
7. (study adj selection).ab.
8. 5 and (6 or 7)
9. or/1-4,8
10. (cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or cinhal or science citation index or scisearch or bids or sigle or cancerlit).ab.
11. (reference list\$ or bibliograph\$ or hand-search\$ or relevant journals or manual search\$).ab.
12. exp randomized controlled trial/ or exp phase 3 clinical trial/ or exp phase 4 clinical trial/
13. randomization/ or single blind procedure/ or double blind procedure/
14. (randomi\$ control\$ trial? or rct or phase III or phase IV or phase 3 or phase 4).tw.
15. or/12-14
16. (phase II or phase 2).tw. or exp clinical trial/ or exp prospective study/ or exp controlled clinical trial/
17. 16 and random\$.tw.
18. (clinic\$ adj trial\$1).tw.
19. ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3 or dummy)).tw.
20. placebos/
21. (placebo? or random allocation or randomly allocated or allocated randomly).tw.
22. (allocated adj2 random).tw.
23. or/18-22
24. practice guidelines/
25. practice guideline?.tw.
26. practice guideline.pt.
27. or/24-26
28. 9 or 10 or 11 or 15 or 17 or 23 or 27
29. (editorial or note or letter or erratum or short survey).pt. or abstract report/ or letter/ or case study/
30. 28 not 29
31. limit 30 to english
32. animal/
33. human/
34. 32 not 33
35. 31 not 34
36. cancer.mp.
37. neoplasm.mp.
38. carcinoma.mp.
39. oncology.mp.
40. 36 or 37 or 38 or 39
41. care.mp.
42. continuity.mp.
43. follow up.mp.
44. shared care.mp.
45. (after care or aftercare).mp.
46. 41 or 42 or 43 or 44 or 45
47. survivo\$.mp.

48. 40 and 46 and 47
49. 48 and 35
50. limit 49 to yr="2000-2012"
51. (childhood or pediatric).ti.
52. 50 not 51

Ovid MEDLINE < 2000 to 2012, week 13 >

1. meta-Analysis as topic/
2. meta analysis.pt.
3. (meta analy\$ or metaanaly\$).tw.
4. (systematic review\$ or pooled analy\$ or statistical pooling or mathematical pooling or statistical summar\$ or mathematical summar\$ or quantitative synthes?s or quantitative overview).tw.
5. (systematic adj (review\$ or overview?)).tw.
6. (exp Review Literature as topic/ or review.pt. or exp review/) and systematic.tw.
7. or/1-6
8. (cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or cinhal or science citation index or scisearch or bids or sigle or cancerlit).ab.
9. (reference list\$ or bibliograph\$ or hand-search\$ or relevant journals or manual seach\$).ab.
10. (selection criteria or data extraction or quality assessment or jadad scale or methodological quality).ab.
11. (study adj selection).ab.
12. 10 or 11
13. review.pt.
14. 12 and 13
15. exp randomized controlled trials as topic/ or exp clinical trials, phase III as topic/ or exp clinical trials, phase IV as topic/
16. (randomized controlled trial or clinical trial, phase III or clinical trial, phase IV).pt.
17. random allocation/ or double blind method/ or single blind method/
18. (randomi\$ control\$ trial? or rct or phase III or phase IV or phase 3 or phase 4).tw.
19. or/15-18
20. (phase II or phase 2).tw. or exp clinical trial/ or exp clinical trial as topic/
21. (clinical trial or clinical trial, phase II or controlled clinical trial).pt.
22. (20 or 21) and random\$.tw.
23. (clinic\$ adj trial\$1).tw.
24. ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3 or dummy)).tw.
25. placebos/
26. (placebo? or random allocation or randomly allocated or allocated randomly).tw.
27. (allocated adj2 random).tw.
28. or/23-27
29. practice guidelines/
30. practice guideline?.tw.
31. practice guideline.pt.
32. or/29-31
33. 7 or 8 or 9 or 14 or 19 or 22 or 28 or 32
34. (comment or letter or editorial or note or erratum or short survey or news or newspaper article or patient education handout or case report or historical article).pt.
35. 33 not 34
36. limit 35 to English
37. animal/
38. human/
39. 37 not 38
40. 36 not 39
41. cancer.mp.
42. neoplasm.mp.
43. carcinoma.mp.

44. oncology.mp.
45. 41 or 42 or 43 or 44
46. care.mp.
47. continuity.mp.
48. follow up.mp.
49. shared care.mp.
50. (after care or aftercare).mp.
51. 46 or 47 or 48 or 49 or 50
52. survivo\$.mp.
53. 45 and 51 and 52
54. 40 and 53
55. limit 69 to yr="2000-2012"
56. (childhood or pediatric).ti.
- 57.54 not 55

IN PREVIEW

### Appendix 2-3. Websites searched: Models of Care for Cancer Survivorship.

Source/ database	Date searched	No# of hits	Full-text review	Retained
Keywords used: cancer, survivor, follow up, care				
<b>Canadian organizations</b>				
Canadian Partnership Against Cancer (www.cancerview.ca SAGE)	Feb 2011	133 included duplicates	Site specific (e.g., ESMO)	0
BC Cancer Agency - Cancer management guidelines ( <a href="http://www.bccancer.bc.ca/">http://www.bccancer.bc.ca/</a> ) "follow up care"	Feb 18, 2011	5062	2 reviewed: 1 env scan; 1 prostate guideline	0
Alberta Health Services (http://www.albertahealthservices.ca/) - Cancer.	March 2011	64	2 guidelines	0
Saskatchewan Cancer Agency - Follow up guidelines (www.saskcancer.ca)	Feb 2011	10	Site specific	0
Cancer Care Manitoba (www.cancercare.mb.ca)	Feb 2011	23	Telehealth, moving forward	0
Cancer Care Nova Scotia (http://www.cancercare.ns.ca/) - Guidelines	Feb 2011		Site specific	0
Canadian Cancer Society (Canada-wide)	Feb 2011	12	0	0
CMAJ infobase: "cancer follow up care" with "adult" filter	June 2011	0	0	0
<b>U.S. organizations</b>				
National Guideline Clearing House (www.guidelines.gov)	Feb 2011	33	1 nutrition (ACS)	0
AHRQ HTA (www.ahrq.gov)	Feb 2011	33	0	0
ASCO guidelines (www.asco.org)	Feb 2011	1	1 fertility preservation (consensus)	0
NCCN ( <a href="http://www.nccn.org/">http://www.nccn.org/</a> ) "follow up"	Feb 2011	100		0
NIH and NCI, Office of Survivorship ( <a href="http://www.cancercontrol.cancer.gov/ocs/">www.cancercontrol.cancer.gov/ocs/</a> ) "clinical practice guidelines"	June 2011	856	0 (Link to ASCO and NCCN)	0
NCI, Cancer Survivorship Research	Feb 2011	780	0	0
Livestrong: Lance Armstrong Foundation (www.livestrong.org)	Feb 2011	10	0	0
American Cancer Society (ACS) (www.cancer.org)	Feb 2011	2850	1 nutrition	0
Dana Farber (www.dana-farber.org)	Feb 2011	128	0	0
National Coalition for Cancer Survivorship (www.canceradvocacy.org)	June 2011	28	3: Journey forward; IOM info; ONS care plan tool.	0
<b>U.K. organizations</b>				
Cochrane Collaboration database ( <a href="http://www.cochrane.org">www.cochrane.org</a> ) - Reviews: "cancer follow up care"	Mar 17, 2011	74	14 (including protocols)	0
NHS (www.nhs.uk)	March 2011			
National Cancer Survivorship Initiative (www.ncsi.org.uk) - risk stratified pathways of care prototype, assessment and care plans	Feb 6, 2011	17	1 rapid review	0

NHS Improvement - Cancer. ( <a href="http://www.improvement.nhs.uk">www.improvement.nhs.uk</a> )	March 2011	69	1 review	1
NICE ( <a href="http://www.nice.org.uk">www.nice.org.uk</a> ) "guidance by topic - cancer"	June 2011	221,	0	0
		included		
		guidelines		
		with		
		aspects of		
		follow-up		
SIGN ( <a href="http://www.sign.ac.uk">www.sign.ac.uk</a> ) guidelines -Cancer.	Jun 2011	18	3	0
Cancer UK ( <a href="http://www.canceruk.org">www.canceruk.org</a> ) -	June 2011	10	0	0
Researchers menu				
<b>New Zealand organizations</b>				
NZ Guidelines group ( <a href="http://www.nzgg.org.nz">www.nzgg.org.nz</a> )	Feb 2011	0	0	0
NZ Cancer Control Trust ( <a href="http://www.cancercontrol.org.nz">www.cancercontrol.org.nz</a> )	Feb 2011	1	0	0
<b>Australian organizations</b>				
National Health & Medical Research Council ( <a href="http://www.nhmrc.gov.au">www.nhmrc.gov.au</a> ) Guidelines and Publications by Subject - Cancer	March 2011	22	Site specific (e.g., lung, colorectal, localised prostate).	0
Cancer Forum Journal - Cancer Council Australia ( <a href="http://www.cancerforum.org.au">www.cancerforum.org.au</a> ) "survivor follow up care"	June 2011	806	6 articles: Nov 2009 vol 33 (5 reviewed) ; 1 exercise article	0
Cancer Council Victoria ( <a href="http://www.cancervic.org.au">www.cancervic.org.au</a> ) research projects. "survivor follow up care"	June 2011	113	0	0
Peter MacCallum Cancer Centre/ ( <a href="http://www.petermac.org">www.petermac.org</a> ) -Research	March 2011	57	0	0
Medical Oncology Group of Australia ( <a href="http://www.moga.org.au">www.moga.org.au</a> )	March 2011	0	0	0
Cancer Australia ( <a href="http://www.canceraustralia.gov.au">www.canceraustralia.gov.au</a> ); amalgamated with the National Breast and Ovarian Cancer Centre (NBCC)	March 2011	19	0	0
National Breast and Ovarian Cancer Centre <a href="http://www.nbcc.org.au/bestpractice/mdc/">www.nbcc.org.au/bestpractice/mdc/</a> "follow up"	March 2011	50	1 CPG, supplementary guideline recommendation 25 re: follow-up care in the CPG for the management of early breast cancer, 2nd ed. 2001.	0
<b>Obtained through other resources (e.g., grey literature search, papers and reports forwarded by working group members, hand searching)</b>				
Journal of Cancer Survivorship (from volume 1/ 2007 to volume 5/ 2011). "follow up care" with no filters*	June 2011	149	7 (2007): Baravelli, Earle, Blaauw- broek et al; (2008): Jefford et al, Pisu et al, Winters et al, Findley et al.	4
SIGLE (grey literature): "cancer care"	Mar 2011	497	0	0
<b>TOTAL</b>		<b>11,474</b>	<b>43</b>	<b>5</b>

Note: Duplicates removed; env = environmental; ESMO = European Society for Medical Oncology; vol = volume; *Journal of Cancer Survivorship* included in hand-search count

IN REVIEW

#### Appendix 2-4. Models of Care for Cancer Survivorship: included RCTs and systematic reviews.

Study and country	Study type	Population	Comparison, including setting and lead provider(s)	Key outcomes	Results
<b>Randomised controlled trials (RCT)</b>					
Beaver, 2009; England	Randomised equivalence, Two centres North England.	Breast cancer (grade I-III), n=374. After treatment. Low to mod risk recurrence.	Hospital clinic (physician-led) vs. nurse specialist (hospital-clinic based) phone follow-up at intervals consistent with hospital policy; mean follow-up 24 months. All continued to receive routine mammography.	Psych morbidity (STAI, GHQ-12), Patient need for information, Patient satisfaction, tests ordered, time to detection of recurrence.	No difference in psych morbidity, No. tests ordered, time to recurrence and days in hospital between nurse-led and physician-led. Telephone (nurse-led) group more satisfied with the information they received and reported higher levels of helpfulness in how their concerns were dealt with than physician-led care. Direct evidence that nurse-led telephone follow-up is no different in terms of medical outcomes than physician-led care (low- to moderate-risk breast cancer). Direct evidence nurse-led phone group no more anxious as a result of foregoing clinical examinations and face-to-face contact (low- to moderate-risk breast cancer).
Grunfeld, 1996; UK	RCT, randomised by phone, 18-month follow-up	Breast cancer (stage I, II, III)(mean age 59.1 yr), n=296, treatment completed at least 3 months prior	Routine follow-up with either community-based family physician (n=148) or conventional hospital follow-up (out-patient clinic) n=148	Time from symptoms first presented to diagnosis of recurrence, no. of recurrences, no. of deaths, Quality of life (EORTC QLQ-C30), and HADS	In family physician group - no delay in diagnosing recurrence, no increase in anxiety, or reduced health-related quality of life.  Evidence that community-based family physician follow-up is no different than hospital-based out-patient clinic setting. "Most recurrences are detected by women as interval events and present to the general practitioner, irrespective of continuing hospital follow-up".
Grunfeld, 1999; UK	RCT (data collected during 1996 RCT) randomised by phone, 18	Breast cancer (stage I, II, III)(mean age 59.1 yr), n=296, treatment	Routine follow-up with either community-based family physician (n=148) or conventional hospital follow-up (out-patient clinic) n=148	Patient satisfaction (questions related to service delivery, continuity of care, the consultation). Measured	Generally high levels of satisfaction for all patients. However, family physician group more satisfied at follow-up than baseline (compared with the hospital

	month follow-up	completed at least 3 months prior		at baseline, mid-trial and end of trial	group) and more satisfied mid-trial and end of trial than the hospital group.  Direct evidence that patients are as satisfied or more satisfied with family physician follow-up than with hospital out-patient clinic follow-up.
Grunfeld, 2006; Canada	RCT, non-inferiority of family physician follow-up, multi-centre. long-term follow-up for early-stage breast cancer	Breast cancer I, II, III, (mean age 61 yrs), median follow-up 42 months, n=968	Patients family physician (community-based) (n=483) versus usual (specialist care, cancer centre) (n=485). Patients observed for 5 years after randomisation or until June 30 <sup>th</sup> 2003, whichever came first.	Rate of recurrence-related serious clinical events; Health related Quality of life via HADS and also SF-36 physical & mental health	No increase in health-related quality of life or serious clinical events (overall survival, detection of recurrence) with family physician group versus usual cancer centre follow-up  Direct evidence that follow-up with community-based family physician is no different than specialist care based at a cancer centre
Helgesen, 2000; Sweden	RCT, multi-centre, closed-envelope randomization, 36 months follow-up	Prostate cancer (less expectancy of at least 3 months), n=400	Traditional follow-up with urologist group versus urology-trained nurse. Nurse follow-up by telephone. Nurse would consult urologist if suspicion of progressive disease.	Questionnaire - accessibility of services, confidence and satisfaction. Also questions about social network and if he/she wanted to change follow-up routine. Anxiety and depression measured via HADS. Cost of medical intervention also calculated.	No difference between groups on HADS, and absolute levels generally low. No difference in accessibility of urological services, but tendency for men in nurse group to rank accessibility higher than in urologist group. No difference in satisfaction. Time to symptoms and lag time from diagnosed symptoms to intervention not different between groups. No difference between groups in total amount of hospital care and hospital-supported home care. Cost of care less in nurse group.
Kimman, 2010; Holland	RCT. Multi-centre.	Breast cancer (post-treatment), n=299, mean sample age 56F years, randomised by phone. 12 months follow-up.	In first year after treatment, either (4 arms): 1) Hospital out-patient clinic visits (specialist care) every 3 months including annual mammogram; 2) Nurse-led telephone follow-up by trained breast care nurse every 3 months plus hospital	Patient satisfaction ratings 12 months after treatment, PSQ III questionnaire (e.g., access to care, general satisfaction, perceptions of care including technical competence)	Arms 1 and 3 hospital follow-up combined (n=149) and compared to arms 2 and 4 telephone follow-up (n=150).  General satisfaction, satisfaction regarding technical competence and satisfaction with interpersonal aspects were not significantly different

			out-patient clinic visit and annual mammogram; 3) arm 1 plus education group; 4) arm 2 plus education group.		between the hospital and telephone follow-up groups. Patient satisfaction regarding access to care was significantly higher in the telephone group than in the hospital group (but not considered clinically relevant) Indirect evidence that nurse-led telephone follow-up is as satisfying for patients than is face-to-face hospital-based follow-up.
Kimman, 2011; Holland	RCT, non-inferiority, multi-centre, stratified by institute and treatment modality (surgery/ radiation/ chemotherapy)	Breast cancer, n=320. Recruited within 6 weeks of end of final treatment. 18-month follow-up.	Randomised to 4 arms: 1) Hospital out-patient clinic visits (Specialist care) every 3 months for 18 months and mammogram at 12 months; 2) Nurse-led telephone follow-up by trained breast care nurse every 3 months, hospital out-patient clinic visit and mammogram at 12 months; 3) arm 1 plus two interactive group education sessions; 4) arm 2 plus two interactive group education sessions.	Health-related quality of life at 12 months (EORTC QLQ-C30). Secondary outcomes include: role, emotional functioning, perceived feelings of control and anxiety, number of visits to hospital, family physician, number of phone contacts with nurse, and specialists.	Although improvements seen over time, no significant difference between hospital and nurse-led groups at 12 months in terms of quality of life, role, emotional functioning, feelings of control and anxiety. No significant difference in quality of life or secondary outcomes between groups with or without education component. Indirect evidence that breast cancer patients do not benefit from relatively frequent and/or intensive follow-up. i.e., models defined by less-intensive follow-up are fine.
Koinberg, 2004; Sweden	Randomised, longitudinal, multi-centre study	Breast cancer, n=264. 5-year follow-up	Routine follow-up by specialist (oncologist or surgeon) (SG) compared to on demand nurse telephone intervention (NG). SG was examined 4 times per year for the first 2 years after surgery, then bi-annually for up to 5 years, and annually after 5 years. Mammograms were performed yearly. NG met with nurse 3 months after surgery and given information on how to recognize recurrence and	Health-related quality of life via HADS. Patient satisfaction via satisfaction and accessibility scale (SaaC), developed for the study.	Levels of reported problems were low and there was no significant difference in relation to anxiety and depression between the groups. Patients were generally satisfied with both interventions, with no significant difference between the groups. Study was not designed to explore differences in survival, but observations were provided. Nurses requested more mammograms than specialists, but use of other imaging and laboratory evaluations were similar between the groups. Kaplan Meier estimates for time to loco-

			instructed to contact nurse with questions or symptoms. Mammograms were performed annually.		regional recurrence, distance metastases or death at 3 and 5 years similar, with no significant differences between the groups.
Murchie, 2010; Scotland	Open cluster randomised trial, multi-centre	Melanoma, n=142, 12-month follow-up	Patients were randomised to receive usual melanoma clinic (specialist-led) care or family physician-led care. Family physicians received a training session and manual on the presentation of new and recurrent melanomas. Patients in family physician group also received a booklet about melanoma and self-examination. Patients in both groups were seen at 3- or 6-monthly intervals depending on thickness of melanoma and time since diagnosis.	Primary outcome: patient satisfaction via a questionnaire. Secondary outcomes: adherence to local guidelines and health status via SF-36 and HADS	Patients in the family physician group were significantly more satisfied than was the control group. Family physician-led care was also more guideline compliant than was specialist-led care. There was no difference between the groups when SF-36 and HADS scores were examined.
Sheppard, 2009; England	RCT, measures at baseline, 9 and 18 months	Breast cancer, 2 years post-diagnosis, n=237 enrolled. Mean age 57 years.	Setting is a hospital-based breast unit. Comparison of point-of-need access model (given information regarding how to contact a breast care nurse if concerned) versus regular 6-monthly clinical review appointments at breast unit (control). Both groups received annual mammogram. All seen by clinical nurse on completion of study to assess unreported symptoms.	Psychological morbidity via GHQ-12 and Quality of Life via FACT-B, at 9 and 18 months. Secondary outcomes included assessment of fear of recurrence, isolation (at 9 and 18 months), extent of telephone contact and/or requests for a clinical review. Recurrence, serious clinical events.	No significant difference in psychological morbidity, Quality of life, fear, isolation between the two groups. In terms of clinical outcomes, no significant difference in early detection of recurrence. More than 95% of point-of-need group did not want to return to 6-monthly review after completion of trial. Indirect evidence that many (low risk) breast cancer survivors may be willing to forego routine follow-up for patient-led point-of-need access ("No follow-up") and are not disadvantaged by this type of model of care.
Verschuur, 2009; Holland	RCT. Measures at baseline, 6 weeks and 4, 7, 13 months.	Oesophageal or gastric cardia cancer, randomised 3 weeks after hospital discharge	Standard follow-up with surgeon at out-patient clinic versus regular home visit by specialist nurse.	Health-related quality of life (EORTC - generic & health-related quality of life), patient satisfaction, costs	Quality of life scores similar (improved during follow-up for all patients); No significant difference in patient satisfaction. Patient family more satisfied however with nurse-led (& lower costs).

		(curative intent) n=109			Indirect evidence that nurses can perform follow-up of patients at home (following upper gastrointestinal cancer surgery).
Wattchow, 2006; Australia	RCT, multi-centre, across 4 Australian states, (random numbers), Measures at baseline, 12 & 24 months	Colon, n=203, 57.6% male. Randomised and recruited after completing treatment.	Post-treatment follow-up with family physician (n=97) versus conventional hospital follow-up (n=106) with surgeon (primary versus secondary care)	Primary outcome Quality of life; HADS (depression, anxiety); Patient satisfaction. Secondary at 24 months: number and types of tests, recurrence, mortality.	No significant differences in quality of life and HADS for follow-up with family physician rather than surgeon. Similar recurrence and mortality. Differences in types of tests ordered only.  Direct evidence that follow-up with community-based family physician is no different than hospital-based follow-up with surgeon.
<b>Systematic Reviews</b>					
Cusack and Taylor, 2010	Systematic lit search. Databases searched from inception to 2008. 4 RCTs, 1 literature review and 6 observational studies included.	Cancer type, study type, frequency and duration of follow-up varied between studies.	Examined if telephone use meets needs of patients, methods of telephone follow-up (set-up and who delivers) and consequences of telephone follow-up	Outcomes included: depression, anxiety, quality of life, no. of investigations requested, patient need for information, duration of consultation, waiting time, patient satisfaction, patient preferences.	Nurse specialists carried out phone follow-up in most studies. No difference in reassurance, anxiety and depression for telephone rather than traditional clinic-based follow-up.  Indirect evidence that majority of patients find the telephone an acceptable method of follow-up and a positive experience (e.g., home comfort for those end-of-life, more convenient in general and less stressful).
Lewis, 2009	Systematic review including 7 RCTs, comparative, economic evaluations, qualitative studies. Databases searched from	All cancers. Survivors after treatment, free of active disease.	Primary versus secondary follow-up (e.g., family physician versus conventional hospital). Elements of shared care also examined (e.g., formal involvement of community family physician in conventional follow-up; specialist care and nurse home visits; different frequency of appointments).	Outcomes included: survival, psychological wellbeing, effectiveness and cost effectiveness; Patient and healthcare professionals views of follow-up, irrespective of setting or provider.	No significant difference between primary and secondary follow-up groups (breast or colon cancer) for survival, recurrence rates, quality of life, psychological morbidity (3 RCTs). One RCT showed significantly higher levels of satisfaction in the family physician rather than hospital groups. 3 RCTs examined elements of shared care (type of cancer varied; one intervention started at time of diagnosis). Length of follow-up 6

	inception to Feb 2007.				months. No significant differences between the intervention groups in terms of hospital admissions, outpatient visits, patient wellbeing and satisfaction. Indirect evidence that follow-up using primary care is no different than follow-up using secondary care. Indirect evidence that improved integration between primary and secondary care led to increase in patient contact with primary care.
Lewis, 2009	Systematic review, databases searched from inception to Feb 2007	Patients of any age who had received treatment for any cancer, at any disease stage.	Any study or economic evaluation comparing nurse-led follow-up with specialist-led hospital follow-up of patients with cancer	Outcomes included: survival and recurrence rates, psychological morbidity and quality of life, patient satisfaction and resource use.	Aim was to compare the effectiveness and cost-effectiveness of nurse-led follow-up to specialist-led. No statistically significant differences found between the intervention groups in terms of survival, recurrence rates and psychological morbidity.
Ouwens, 2009	Systematic review, Medline and Cochrane databases 1996-Oct 2006.	Adults with cancer (42% of the studies involved breast cancer survivors). RCTs and controlled before-after studies. Narrative analysis.	Interventions to improve integrated care (hospital or out-patient setting), specifically evaluations of patient-centeredness, organization of care, and/or multidisciplinary care. Seven studies investigated follow-up care.	Outcomes included: morbidity, mortality, quality of life, anxiety, patient satisfaction.	Indirect evidence that the way care is organised impacts objective and subjective outcomes. (e.g., Follow-up by nurse or family physician reported better than or as good as specialist follow-up in terms of depression, anxiety, satisfaction).

Note: EORTC = European Organization for Research and Treatment of Cancer; FACT = Functional Assessment of Cancer Therapy; GHQ = General Health Questionnaire; HADS = Hospital Anxiety and Depression Scale; n = sample size; no. = number; PSQ III = Ware's Patient Satisfaction Questionnaire III; RCT = randomised control trial; SF-36 = Short Form-36; UK = United Kingdom; vs = versus; yrs = years.

Appendix 2-5. Methodological quality rating of included studies.

Study	Method of randomisation	Blinding	Power calculation	Summary of key outcomes	Adequate sample size in relation to outcome	Length of follow-up	Withdrawal & other losses to follow-up explained	Sources of funding
Beaver, 2009	By phone, computer generated	Allocation blind, analyst blind to group allocation.	95% required 162 per group.	Psych morbidity, patient satisfaction, tests ordered, time to detection of recurrence.	Enrolled n=183 hospital and n=191 phone (total n=374)	Mean 24 months (only 17 recurrences, but sample low-mod risk)	8.8%* (33 of 374)	Medical Research Council, UK and Rosemere Cancer Foundation, UK
Grunfeld, 1996	Phone	Group allocation masked as best possible, time to diagnosis of recurrence blinded.	90%, $\alpha=0.05$	Time from symptoms first presented to diagnosis of recurrence, no. of recurrences, no. of deaths, quality of life	n=300 required (data complete from n=296)	18 months	Withdrawal and losses explained	Department of Health for England and Wales, contributions from Ballakermean School on the Isle of Man, General Practice Research Group of the Imperial Cancer Research Fund
Grunfeld, 1999	Phone	Article refers to the 1996 RCT for information about methods	90%, $\alpha=0.05$	Patient satisfaction	n=300 required (data complete from n=296)	18 months	Withdrawal and losses explained	Department of Health for England and Wales, contributions from Ballakermean School on the Isle of Man, General Practice Research Group of the Imperial Cancer Research Fund
Grunfeld, 2006	Phone, computer generated	A committee blinded to group allocation adjudicated all clinical events.	Risk difference assumed and 95% CI determined using Wilson (score) method, power analysis NR	Rate of recurrence-related serious clinical events, health related quality of life mental health	Calculated n=1045, assuming 4% serious clinical events (and 1.5% margin). (enrolled 968; n=483 family physician group, n=485 cancer centre group)	Median 42 months (identical for both groups)	Withdrawal and losses explained	Canadian Breast Cancer Research Alliance (CBCRA)

Study	Method of randomisation	Blinding	Power calculation	Summary of key outcomes	Adequate sample size in relation to outcome	Length of follow-up	Withdrawal & other losses to follow-up explained	Sources of funding
Helgesen, 2000	Sealed envelope	NR	95%, $\alpha=0.05$	Patient satisfaction, anxiety and depression, cost of medical intervention	n=400 between both groups	36 months	Number of patients lost and deceased reported	Dagmar-50 project of Swedish government, Orebro Medical Centre Research Foundation and Orebro County Council Research Committee
Kimman, 2010	Computer generated	Patients not blind to different groups before agreeing to participate	90%, $\alpha=0.05$	Patient satisfaction	n=320 enrolled, n=299 data available	12 months	7% (n=21) dropped out for various reasons, explained.	Dutch Organization for Health Research and Development (grant 945-04-512)
Kimman, 2011	Computer generated	Patients not blind to different groups before agreeing to participate	80%, $\alpha=0.05$	Health-related quality of life	enrolled 320, data reported from n=299	12 months	7% (n=21) dropped out for various reasons, explained.	Netherlands Organization for Health Research and Development (grant 945-04-512)
Koinberg, 2004	Computer generated	Patients given no study info prior to consent.	90%, $\alpha=0.05$	Health-related quality, patient satisfaction	n=264 from 2 centres, originally n=400 but third centre not included in analysis	60 months	Withdrawal and losses explained	CTRF, Sweden (cancer and traffic federation) and County Council of Halland, Sweden
Murchie, 2010	Computer generated after allocation within practice strata	Patients not blinded to group allocation	80%, $\alpha=0.05$	Patient satisfaction, adherence to local guidelines, health status	n=142 total	12 months	Withdrawal and losses explained	Cancer Research UK (grant C10673/A3912)
Sheppard, 2009	Sealed envelopes & computer generated	Prior to randomisation participants and research staff blind	90%, $\alpha=0.05$	Psychological morbidity, quality of life, recurrence, serious clinical events.	Intended accrual n=120 per arm.	18 months	10.7%* loss, n=214 completed. Not a great deal of demographic	Wessex Cancer Trust

Study	Method of randomisation	Blinding	Power calculation	Summary of key outcomes	Adequate sample size in relation to outcome	Length of follow-up	Withdrawal & other losses to follow-up explained	Sources of funding
		to group allocation					data collected from eligible that declined	
Verschuur, 2009	Computer generated	NR	80%, $\alpha=0.05$	Health-related quality of life, patient satisfaction, costs	Intention to treat. Intended accrual n=50 per arm, n=109 enrolled	13 months	Explained. 13% died.	Health Care Research Program Erasmus MC Rotterdam, Dutch Digestive Disease Foundation
Wattchow, 2006	Computer	Researchers blind	80%, $\alpha=0.05$ .	Quality of life, patient satisfaction, number and types of tests, recurrence, mortality.	Intended accrual 100 per arm. N=203 agreed to participate. Adequate power for outcomes SF-12, HADS, PSVQ. Not powered to measure differences in recurrence and mortality at 24 months.	24 months, n=157	Losses explained. Patient flow through study provided	National Health and Medical Research Council and Anti-Cancer Foundation of South Australia

Note: CI = confidence interval; n = total sample size; NR = Not reported; RCT = randomised controlled trial; UK = United Kingdom.

\* Author's calculation.

## Evidence-Based Series 26-1 Version 2: Section 3

### A Quality Initiative of the Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)

## Models of Care for Cancer Survivorship: Development Methods, Recommendations Development and External Review Process

*J. Sussman, L.H. Souter, E. Grunfeld, D. Howell, C.Gage, S. Keller-Olaman, and M. Brouwers*

Report Date: October 26, 2012

### THE PROGRAM IN EVIDENCE-BASED CARE

The Program in Evidence-based Care (PEBC) is an initiative of the Ontario provincial cancer system, Cancer Care Ontario (CCO) (1). The PEBC mandate is to improve the lives of Ontarians affected by cancer, through the development, dissemination, implementation, and evaluation of evidence-based products designed to facilitate clinical, planning, and policy decisions about cancer care.

The PEBC supports a network of disease-specific panels, termed Disease Site Groups (DSGs), as well as other groups or panels called together for a specific topic, all mandated to develop the PEBC products. These panels comprise of clinicians, other health care providers and decision makers, methodologists, and community representatives from across the province.

The PEBC is well known for producing evidence-based guidelines, known as Evidence-based Series (EBS) reports, using the methods of the Practice Guidelines Development Cycle (1, 2). The EBS report consists of an evidentiary base (typically a systematic review), an interpretation of and consensus agreement on that evidence by our Groups or Panels, the resulting recommendations, and an external review by Ontario clinicians and other stakeholders in the province for whom the topic is relevant. The PEBC has a formal standardized process to ensure the currency of each document, through the periodic review and evaluation of the scientific literature and, where appropriate, the integration of that literature with the original guideline information.

### The Evidence-Based Series

Each EBS is comprised of three sections:

- [\*Section 1: Guideline Recommendations\*](#). Contains the clinical recommendations derived from a systematic review of the clinical and scientific literature and its interpretation by the Group or Panel involved and a formalized external review in Ontario by review participants.
- [\*Section 2: Evidentiary Base\*](#). Presents the comprehensive evidentiary/systematic review of the clinical and scientific research on the topic and the conclusions reached by the Group or Panel.

- [Section 3: Development Methods, Recommendations Development and External Review Process](#). Summarizes the EBS development process and the results of the formal external review of the draft version of [Section 1: Guideline Recommendations](#) and [Section 2: Evidentiary Base](#).

## DEVELOPMENT OF THIS EVIDENCE-BASED SERIES

### Development and Internal Review

This EBS was developed by the Models of Care for Cancer Survivorship Guideline Development Group of the CCO PEBC. The series is a convenient and up-to-date source of the best available evidence on models of care for cancer survivorship developed through review of the evidentiary base, evidence synthesis, and input from external review participants in Ontario. The Models of Care for Cancer Survivorship Working Group was comprised of clinical oncology experts, health service researchers and methodologists. A consensus process was employed for development of the recommendations from the evidentiary base.

### Report Approval Panel Review and Approval

Prior to the submission of this EBS draft report for External Review, the report was reviewed and approved by the PEBC Report Approval Panel, a panel that includes oncologists and whose members have clinical and methodological expertise. The PEBC Report Approval Panel usually consists of three reviewers, including Dr. Melissa Brouwers (MB); however, since MB is an author of this guideline, the panel consisted of only two reviewers. Key issues raised by the Report Approval Panel included the following:

1. There was an issue raised that, given the variability in the terminology used for survivorship care, some RCTs may have been missed. The reviewer found a recent RCT that was not included in the original literature search.
2. A reviewer raised a concern about stating that there is a similar disease trajectory between breast, colorectal and prostate cancer. The reviewer believed that these statements were not supported by evidence.

### *Actions/Modifications*

1. The trial found by the reviewer was more recent than was the original literature search conducted for this guideline document. The literature search was updated to week 13, 2012 in order to include the trial. In addition, the search strategy was examined to ensure the terminology was as efficient as possible. From the updated search, two RCTs and a systematic review were added to the evidentiary base. In addition, two studies were added to [Section 2](#), Discussion.
2. It is expert opinion that breast, prostate, and colorectal cancers follow a similar trajectory in terms of disease diagnosis, treatment, and follow-up care. To address the concern posed by the reviewer, the recommendations were formatted to ensure that the care trajectories were explained as being similar by expert opinion.

### External Review by Ontario Clinicians and Other Experts

The PEBC external review process is two-pronged and includes a targeted peer review that is intended to obtain direct feedback on the draft report from a small number of specified content experts and a professional consultation that is intended to facilitate dissemination of the final guidance report to Ontario practitioners.

Following the review and discussion of [Section 1: Recommendations](#) and [Section 2: Evidentiary Base](#) of this EBS and the review and approval of the report by the PEBC Report Approval Panel, the Models of Care for Cancer Survivorship Guideline Development Group circulated Sections 1 and 2 to external review participants for review and feedback. Box 1

summarizes the draft recommendations and supporting evidence developed by the Models of Care for Cancer Survivorship Guideline Development Group.

**BOX 1:**

**DRAFT RECOMMENDATIONS** (approved for external review May 25, 2012)

**OBJECTIVES**

1. What are the models described in the literature for the follow-up care of adults with cancer who have completed treatment and are clinically disease free?
2. Are certain models favoured for survivors of specific cancer types in terms of:
  - a. Clinical outcomes (e.g., surveillance, recurrence)
  - b. Survivor well-being outcomes (e.g., quality of life, patient satisfaction)

**TARGET POPULATION**

Adults without evidence of disease after primary, curative treatment for any stage of cancer comprise the target population. Both clinical outcomes (recurrence, surveillance) and life well-being outcomes (quality of life, patient satisfaction) from follow-up strategies reported for patients at all levels of risk of recurrence are of interest.

**INTENDED USERS**

This guideline is targeted for:

1. Health professionals who are responsible for the care of adults with cancer who are clinically disease free after receiving curative treatment.
2. Health professionals engaged in the care of adults with cancer who are clinically disease free after receiving curative treatment and who would make referrals to the appropriate care team.
3. Administrative and system leaders responsible for implementing high-quality evidence-informed survivorship services for adults with cancer who are clinically disease free after receiving curative treatment.

**RECOMMENDATIONS AND KEY EVIDENCE**

For Objective 1, the Working Group created a framework to describe and organize core models of survivorship follow-up care from five landmark papers (3-7) (Table 1-1). This framework was then used to evaluate studies investigating models of care that were reviewed to answer the questions of Objective 2.

**Table 1-1. Framework of models of care identified in the literature.**

Setting	Options: coordinator of follow-up care
Institution <ul style="list-style-type: none"> <li>• Hospital</li> <li>• Cancer centre</li> </ul>	<ul style="list-style-type: none"> <li>• Specialist                             <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, general practitioner in oncology (GPO)</li> </ul> </li> <li>• Nurse                             <ul style="list-style-type: none"> <li>◦ Nurse specialist, nurse practitioner, physician assistant, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>
Community	<ul style="list-style-type: none"> <li>• Primary care practitioner (PCP)</li> </ul>

<ul style="list-style-type: none"> <li>• Primary care practitioner’s (PCP) office</li> <li>• Specialist’s office (outside hospital)</li> </ul>	<ul style="list-style-type: none"> <li>• Specialist             <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, GPO</li> </ul> </li> <li>• Nurse             <ul style="list-style-type: none"> <li>◦ Nurse specialist, nurse practitioner, physician assistant, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>
<p>Shared Care</p>	<p>Any combination of:</p> <ul style="list-style-type: none"> <li>• Specialist             <ul style="list-style-type: none"> <li>◦ Medical oncologist, surgeon, radiation oncologist, GPO</li> </ul> </li> <li>• PCP</li> <li>• Nurse             <ul style="list-style-type: none"> <li>◦ Nurse specialist, nurse practitioner, physician assistant, family practice nurse, nurse navigator</li> </ul> </li> <li>• Patient-directed</li> </ul>

The review of models of care in survivorship yielded few studies of randomized comparisons between two distinct model types. Although shared care has been shown to be beneficial in other diseases, no studies were found that explicitly studied shared care compared to another model in cancer. The most common comparison in published studies is care coordinated in an institutional setting by a specialist (considered the control arm) versus community-based primary care practitioner (PCP) care, involving discharge from the cancer system. In studies in breast cancer populations, it appears that community based PCP care is reasonable from the perspectives of the patient and health system in that there has been no significant difference found between models in terms of surveillance for recurrence and medical outcomes. No conclusions could be made regarding an optimal primary care configuration with their own provider, as this was not described in the studies. Across studies, there is some suggestion that patient satisfaction and costs with PCP-led care are as good or better than specialist-coordinated models located within institutions. The role of nurses as the coordinating provider (but not necessarily the most responsible clinical provider) has been studied in the context of breast, colorectal, and prostate cancer. The expert opinion is that these cancers follow a similar trajectory in terms of initial diagnosis, treatment, and follow-up care. In these studies, the nursing model was tested within the setting of an institution. These studies suggest that a nursing lead model alternative may be reasonable to consider within the context of ongoing follow-up within an institution. The review found no studies with nursing models situated in a community setting, and thus, no conclusions can be made in this setting.

This review included both clinical and survivor well-being outcomes, and as such, the recommendations are based on all these studies. However the Working Group deemed, studies that did not include clinical outcomes insufficient to support strong recommendations. Currently in Ontario, the most common standard practice for follow-up survivorship care involves specialist-coordinated care within an institution. The overall recommendations from this review support the following alternative options:

**Breast Cancer**

1. In cancer survivors with breast cancer, if no ongoing treatment issues are observed after the completion of primary therapy (hormonal therapy may still be ongoing), discharge from specialist-led care to community-based PCP care is a reasonable option.

***Key Evidence***

Studies indicate that the transfer of breast cancer survivor care to the patient's usual community-based PCP(s) does not result in an increase in the time to the diagnosis of recurrence (7,8). Additionally, when breast cancer survivors are followed by community-based PCPs, there is no difference in recurrence-related serious clinical events or any physical, psychosocial, or quality-of-life components compared to when survivors are followed by a specialist (7,8). The evidence for this recommendation comes from both a randomized controlled trial (RCT) (7) and an RCT with a non-inferiority design (8). In terms of survivor well-being, patient satisfaction was greater in the PCP-led community-based care group (6).

2. In cancer survivors with breast cancer, if no ongoing treatment issues are observed after the completion of primary therapy (hormonal therapy may still be ongoing), discharge from specialist-led care to nurse-led care within an institutional setting is a reasonable option.

***Key Evidence***

An equivalence study found that breast cancer survivors followed by nurse-coordinated care showed no differences in time to detection of recurrence, number of clinical investigations ordered, or psychological morbidity when compared to breast cancer survivors followed by specialist-coordinated care (9). In addition, women who received telephone nurse-coordinated follow-up were not more anxious as a result of foregoing hospital contact and clinical examinations (9). An RCT testing non-inferiority between nurse-coordinated and specialist-coordinated found that nurse-led telephone follow-up could replace specialist-led institutional visits after breast cancer treatment without adversely affecting health-related quality of life, emotional functioning, or anxiety levels (10).

**Colorectal Cancer**

3. In cancer survivors with colorectal cancer who have completed primary surgery and who have not received adjuvant chemotherapy, discharge from specialist-led care to community-based PCP care is a reasonable option.

***Key Evidence***

The evidence suggests that when colon cancer survivors were followed by a community-based PCP, there were no significant differences for rates of recurrence; time-to-detection of recurrence; death rates; or physical, psychosocial or quality-of-life components compared to when survivors were followed by an institutional-based specialist (11). This finding can reasonably be applied to both colon and rectal cancer populations as the treatment trajectories are very similar.

4. In patients with colorectal cancer who have completed adjuvant therapy, the transition to nurse-led care within an institution may be a reasonable option, based on a similar disease trajectory to breast cancer. However, there is insufficient data

to inform whether nurse-coordinated care is equivalent to specialist-led, and this option should be considered within the context of a trial at this point.

***Key Evidence***

The Working Group was unable to find an evidentiary base that investigated nurse-coordinated follow-up with colorectal cancer survivors. This recommendation is based on the expert opinion that disease trajectories of breast and colorectal cancer are similar and on the success of nurse-coordinated follow-up of breast cancer survivors (9,10,12).

**Prostate Cancer**

5. In patients with prostate cancer who have completed primary treatment (radiation or surgery, but with hormonal therapy still possibly ongoing), transition to nursing-led care within an institution is a reasonable option. Insufficient data exist to inform whether discharge to primary care is equivalent, but, based on the disease trajectory, the expert opinion is that this is a reasonable option.

***Key Evidence:***

Prostate cancer survivors receiving follow-up care coordinated by a nurse, but still within an institutional setting, showed no differences from those followed by a specialist when the amount of hospital care and the lag time between diagnosed symptoms and intervention was studied (13). In addition, there were no observed differences between the survivor groups in terms of depression or anxiety (13). The Working Group did not find any studies examining PCP-led follow-up care of prostate cancer survivors; however, given the similar disease trajectory to breast cancer (expert opinion), there is evidence that this model should be further studied for prostate cancer survivors.

**Other Cancer Types:**

6. In patients with melanoma and esophageal cancer, follow-up outside specialist care appears to be acceptable to patients, but without clinical outcomes data, no model of care recommendations can be made.

***Key Evidence***

Melanoma survivors receiving PCP-led follow-up care were more satisfied with their care than were survivors followed by specialists (14). However, this study did not include any clinical outcomes (14), and so no recommendation can be made about the effectiveness of medical care. Similarly, esophageal or gastric cardia cancer survivors followed by nurse-led home visits were equally satisfied with nurse-led compared to specialist-led care after a one-year period (15). Once again, no recommendation can be made about the effectiveness of medical care from this trial as no clinical outcomes were included in the study (15). As survivors appear to be open to alternative care, further studies with survivors of these two cancer types should be undertaken.

7. No recommendation can be made about models of care of other disease types based on the currently available published literature.

**Key Evidence**

The Working Group was unable to find sufficient studies that investigated survivorship models of care for cancer beyond those mentioned in the above recommendations.

#### **Nursing Models within Community Setting**

8. Nursing models of care within a community care setting appear to be of interest but have not been explicitly evaluated to date.

##### ***Key Evidence***

All studies that evaluated nurse-coordinated care obtained for this systematic review were still within the institutional setting. Given the success of these studies, further research into the efficacy of nurse-coordinated care within a community-based setting are warranted.

#### **Shared Care Models**

9. No recommendation about shared care can be made at this time based on the currently published literature.

##### ***Key Evidence***

Although shared care has been shown to be beneficial in other disease sites, in the cancer setting, there is not a formalized shared-care model. Due to this lack of formalization, no studies were found that explicitly studied shared care compared to another model in cancer, and thus no recommendation can be made in relation to shared care for survivorship follow-up.

#### ***Methods***

***Targeted Peer Review:*** During the guideline development process, 12 targeted peer reviewers from Ontario considered to be clinical and/or methodological experts on the topic were identified by the working group. Several weeks prior to completion of the draft report, the nominees were contacted by email and asked to serve as reviewers. Eight reviewers agreed and the draft report and a questionnaire were sent via email for their review. The questionnaire consisted of items evaluating the methods, results, and interpretive summary used to inform the draft recommendations and whether the draft recommendations should be approved as a guideline. Written comments were invited. The questionnaire and draft document were sent out on May 25, 2012. Follow-up reminders were sent at two weeks (email) and at four weeks (telephone call). The Models of Care for Cancer Survivorship Working Group reviewed the results of the survey.

***Professional Consultation:*** Feedback was obtained through a brief online survey of health care professionals who are the intended users of the guideline. All nurses, primary care practitioners and oncologists in the PEBC database were contacted by email to inform them of the survey. Six hundred two individuals in Ontario were contacted versus thirty-three outside Ontario. Participants were asked to rate the overall quality of the guideline ([Section 1](#)) and whether they would use and/or recommend it. Written comments were invited. Participants were contacted by email and directed to the survey web site where they were provided with access to the survey, the guideline recommendations ([Section 1](#)) and the evidentiary base ([Section 2](#)). The notification email was sent on May 25, 2012. The consultation period ended on July 9, 2012. The Models of Care for Cancer Survivorship Working Group reviewed the results of the survey.

### Results

**Targeted Peer Review:** Seven responses were received from eight reviewers. Key results of the feedback survey are summarized in Table 3-1.

**Table 3-1. Responses to nine items on the targeted peer reviewer questionnaire.**

Question	Reviewer Ratings (N=7)				
	Lowest Quality (1)	(2)	(3)	(4)	Highest Quality (5)
1. Rate the guideline development methods.	0	0	0	4	3
2. Rate the guideline presentation.	0	0	0	3	4
3. Rate the guideline recommendations.	0	0	0	5	2
4. Rate the completeness of reporting.	0	0	0	3	4
5. Does this document provide sufficient information to inform your decisions? If not, what areas are missing?	0	0	2	2	3
6. Rate the overall quality of the guideline report.	0	0	0	5	2
	Strongly Disagree (1)	(2)	Neutral (3)	(4)	Strongly Agree (5)
7. I would make use of this guideline in my professional decisions.	0	0	0	5	2
8. I would recommend this guideline for use in practice.	0	0	0	5	2

**9. What are the barriers or enablers to the implementation of this guideline report?**

**Barriers**

- Convincing patients that they can be discharged from the Cancer Centre.
- Ingrained culture in oncology treatment.

**Enablers**

- Share early successes with the health care team/patients/families.

### Summary of Written Comments

The main points contained in the written comments were:

1. In relation to Table 1-1, it was pointed out that the Physician Assistants role is not usually held by a nurse and that GPOs are not unique to Ontario.
2. Several reviewers raised concerns that some of the RCTs included in the evidentiary base did not reflect current follow-up practice for breast cancer survivors on aromatase inhibitors following primary therapy.
3. Several reviewers raised concerns about the document not discussing the common practice of intense follow-up of colorectal survivors.
4. One reviewer felt it would be beneficial to include information on comparability of cost between the models of care.
5. One reviewer thought that the authors should have emphasized the importance of further trial into what follow-up might entail for each individual tumour type.

6. One reviewer pointed out that nurse practitioners are PCPs in the primary care setting.
7. In relation to [Appendix 2-5](#), which detailed the quality analysis of the included studies, one reviewer requested that the power calculation column be moved next to a key outcome column. In addition, this reviewer believed that the trials were well presented, but felt it would be beneficial to insert study limitation within the text, and not just in [Appendix 2-5](#).

**Modifications/Actions**

1. The Physician Assistant role was not only removed from the Nurse category of Table 1-1, but also removed entirely from the table, as this role was never discussed in the text. The explanation for GPO was altered in the text to reflect that this role is common throughout Canada.
2. A Qualifying Statement section was added to the recommendations for breast cancer survivors to address the needs of patients on aromatase inhibitors.
3. A guideline on colorectal cancer survivor follow-up has been published by the PEBC. This guideline summarizes the appropriate follow-up care and surveillance of survivors. A Related Guidelines section was added to [Section 1](#) of this guideline that links to the colorectal follow-up guideline.
4. Although the working group agrees that a cost is important when implementing a change in care, cost analysis is beyond the scope of PEBC guidelines.
5. Future PEBC EBS guidelines will discuss follow-up care of individual tumour types in detail. As such, these guidelines will discuss what further study is warranted for the specific cancer.
6. When discussing PCPs, the working group was referring only to family physicians. The working group agrees that Nurse Practitioners serve as PCPs in the community setting and have changed “PCP” to “Family Physician” in the guideline.
7. [Appendix 2-5](#) has been altered to add a column with a summary of the key outcomes beside the power calculation column. Although the working group agrees that a discussion of the study limitations may be beneficial within the text, it is believed that this addition will add considerable length to the document and reduce readability.

*Professional Consultation:* Forty-four responses were received. Key results of the feedback survey are summarized in Table 3-2.

**Table 3-2. Responses to four items on the professional consultation survey.**

	Number (%)				
	Lowest Quality (1)	(2)	(3)	(4)	Highest Quality (5)
<b>General Questions: Overall Guideline Assessment</b>					
<b>1. Rate the overall quality of the guideline report.</b>	0	6.8	18.2	54.5	20.5
	Strongly Disagree (1)	(2)	(3)	(4)	Strongly Agree (5)
<b>2. I would make use of this guideline in my professional decisions.</b>	0	9.1	9.1	40.9	40.9
<b>3. I would recommend this guideline for use in practice.</b>	0	11.4	15.9	34.1	38.6

4. **What are the barriers or enablers to the implementation of this guideline report?**  
Barriers

- Funding base to establish nurse led clinics.
- Knowledge translation to community care providers and patients.
- Adequate numbers of specialized oncology nurses and family physicians.
- Reluctance of some patients to be discharged back into primary care.

Enablers

- Positive outcome from the breast studies should pave the way for the other site groups.
- Providing patient care closer to home and in a less stressful environment would promote patient satisfaction

***Summary of Written Comments***

The main points contained in the written comments were:

1. Several typos were pointed out, as well as sentences that were confusing.
2. There were questions raised about adherence to guidelines, rural versus urban community settings, psychosocial issues and cost.
3. Several respondents mentioned the use of aromatase inhibitors in breast cancer patients, which was not discussed in the document.
4. One respondent brought up the concern that study populations represent a very small percent of all eligible patients and that this phenomenon should have been discussed in the document.

***Modifications/Actions***

1. Identified typos were corrected, and flagged sentences were rewritten for clarity.
2. Although the working group agrees that these topics are of important, they were out of scope for this document.
3. As was mentioned in the Targeted Peer Review section, follow-up care of breast cancer patients on an aromatase inhibitor are discussed in the Qualifying Statements section of the Breast Cancer recommendations.
4. The working group admits that there is a selection bias inherent in all RCTs. This situation has been well documented and the group accepts this limitation to the threat to internal validity.

**CONFLICT OF INTEREST**

In accordance with the PEBC Conflict of Interest (COI) Policy, the guideline authors and internal and external reviewers were asked to disclose potential conflicts of interest. All authors and reviewers, except for EG and DH reported that they had no conflicts of interest. EG reported that she has conducted and published several RCTs on follow-up care of breast cancer survivors, as well as editorials/commentaries on the subject. DH reported that she has received a grant to research models of survivorship care and has published a review on the subject.

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Evidence-Based Series #26-1 Version 2: Section 4

A Quality Initiative of the  
Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)

**Models of Care for Cancer Survivorship**

March 28, 2017

*The 2012 guideline recommendations are*

***ENDORSED***

*This means that the recommendations are still current and relevant for decision making.*

**OVERVIEW**

The original version of this guidance document was released by Cancer Care Ontario's Program in Evidence-based Care in 2012.

In May 2016, this document was assessed in accordance with the PEBC Document Assessment and Review Protocol and was determined to require a review. As part of the review, a PEBC methodologist conducted an updated search of the literature. One clinical expert reviewed and interpreted the new eligible evidence and proposed the existing recommendations could be endorsed. The Expert Panel on Models of Care for Cancer Survivorship ([Appendix 4-1](#)) endorsed the recommendations found in [Section 1](#) (Clinical Practice Guideline) on March 28, 2017, with a suggestion there be addition of a few explanatory comments.

**DOCUMENT ASSESSMENT AND REVIEW RESULTS**

**Question Considered**

1. What are the models described in the literature for the follow-up care of adults with cancer who have completed treatment and are clinically disease free?
2. Are certain models favoured for survivors of specific cancer types in terms of the following:

- a. Clinical outcomes (e.g., surveillance, recurrence)
- b. Survivor quality of life outcomes (e.g., quality of life, patient satisfaction)

#### **Literature Search and New Evidence**

MEDLINE and Embase were searched from 2000 to September 26, 2016. This overlapped the original search from 2000-2012 (week 13) due to refining of the search strategy for the concept of survivorship. A description of the literature review and its results is given in the following pages.

#### **Impact on the Guideline and its Recommendations**

The Expert panel agreed that no new recommendations are required and that the 2012 recommendations cover all relevant subjects areas identified in the new evidence; therefore, the Expert Panel ENDORSED the recommendations on Models of Care for Cancer Survivorship.

The Expert panel suggested that some commentary be added to some of the recommendations/qualifying statements to point the reader to some ongoing work and other relevant issues.

<b>Number and Title of Document under Review</b>	26-1 Models of Care for Cancer Survivorship
<b>Current Report Date</b>	October 26, 2012
<b>Clinical Expert</b>	Jonathan Sussman
<b>Research Coordinator</b>	Glenn Fletcher
<b>Date Assessed</b>	May 9, 2016
<b>Approval Date and Review Outcome (once completed)</b>	March 28, 2017 Endorse
<p><u>Original Question(s):</u></p> <ol style="list-style-type: none"> <li>1. What are the models described in the literature for the follow-up care of adults with cancer who have completed treatment and are clinically disease free?</li> <li>2. Are certain models favoured for survivors of specific cancer types in terms of the following: <ol style="list-style-type: none"> <li>a. Clinical outcomes (e.g., surveillance, recurrence)</li> <li>b. Survivor quality of life outcomes (e.g., quality of life, patient satisfaction)</li> </ol> </li> </ol> <p><u>Target Population:</u> Adults without evidence of disease after primary, curative treatment for any stage of cancer comprise the target population. Both clinical outcomes (recurrence, surveillance) and quality of life (QoL) outcomes (quality of life, patient satisfaction) from follow-up strategies reported for patients at all levels of risk of recurrence are of interest.</p> <p><u>Study Section Criteria:</u> A targeted scan was used to identify landmark papers that outlined the core models of survivorship care. The working group came to a consensus on several landmark papers that outlined models of care relevant to current professional knowledge within the Ontario context. A systematic review was used to identify an evidentiary base that addressed appropriate outcomes of the core models of care. It was restricted to RCTs comparing at least 2 models of follow-up care, and excluded models with only psychosocial outcomes.</p> <p><u>Search Details:</u> Original Guideline: OVID was used to systematically search the MEDLINE (R) and EMBASE databases for articles assessing the impact of model(s) of care for post-treatment cancer survivors, published between 2000 and week 13 of 2012. Key terms included: cancer, survivor, follow-up care and after care, with a subsequent RCT and systematic review filter.</p> <p>Note: the original search strategy required all hits to have the term survivor*, and therefore may have missed some articles where this exact word or MESH heading was not used.</p>	

Document Assessment and Review Search: MEDLINE and Embase were search for documents published in 2000 or later (up to September 26, 2016; see [Appendix 4-2](#) for search strategy). Publications from the 2012 version of this document were excluded.

More details of the literature search and a summary of new evidence are given following this tool.

Clinical Expert Interest Declaration: none

**Questions as part of the assessment**

1. Does any of the newly identified evidence contradict the current recommendations? (i.e., the current recommendations may cause harm or lead to unnecessary or improper treatment if followed)	No
2. Does the newly identified evidence support the existing recommendations?	Yes
3. Do the current recommendations cover all relevant subjects addressed by the evidence? (i.e., no new recommendations are necessary)	Yes
4. Is there a good reason to postpone updating the guideline? (e.g., new stronger evidence will be published soon, changes to current recommendations are trivial or address very limited situations)	Yes, new evidence is currently limited and some trials are ongoing.
<b>Review Outcome as recommended by the Clinical Expert</b>	Endorse
<b>Sponsor Commentary</b>	

## Literature Search Methodology

During planning for a revised literature search, key references were reviewed and entered into the Endnote database. It was noted that the search strategy previously reported had some deficiencies, most notably that included publications had to have both the exact term survivorship (i.e., survivor, survivors, survivorship) with no allowance for alternative terminology, as well as the concept of care or follow-up. The reported number of results could not be reproduced. A broader search was conducted (see [Appendix 4-2](#)) on September 26, 2016 using the Embase and Medline databases, for publications from 2000-2016. Publications included in the original report were noted and not reviewed again. A search for additional guidelines was conducted on October 24-26, 2016 using the websites listed in [Appendix 2-3](#) of the original Evidentiary Base. In situations where the website was no longer in existence, a search was made for a new website of the same organization.

## Results

The literature search on MEDLINE and Embase, after removing duplicates, resulted in 10,060 publications. An additional 26 publications were found from references lists and 18 from the original guideline (which may or may not have been found by the search). The guideline search using specific websites found 48 additional guidelines.

During screening of the search results it was noted that many publications dealt with identification of patient needs arising from the cancer or its treatment (including adverse effects or monitoring recurrence, n=219) or symptom management (n=915). While extremely relevant to follow-up care, they are of indirect relevance to the model of care, and did not meet the inclusion criteria. An additional 8653 papers were excluded as being non-relevant, and 192 as being of interest but only on related topics (e.g., patient education or support, care plans, inter-professional communication, physician needs, definitions of survivor or supportive care, palliative care, non-randomized trials of care models, and non-systematic reviews of survivorship/follow-up). Some of these related publications might be referred to as background if the guideline is eventually updated. Of the publications for inclusion there were 17 publications on models of care [1-17] (see [Table 4-1](#)), 23 publications of randomized controlled trials [18-40] (see [Table 4-2](#)), 8 meta-analysis [41-48], and 24 systematic reviews [49-70]. The models of care publications included several reports on specific models of care and several more general reviews which often discussed multiple models.

There were 68 guidelines identified from the databases and website searches. It was noted that guidelines were searched for but not discussed in the 2012 report. In the current search, guidelines were noted that mentioned coordination of follow-up or who should conduct it. Most of these were on either management or follow-up of a specific type of cancer, and did not specifically focus on models of care, with the exception of two reports by ASCO [71,72]. However, as the current guideline makes specific recommendations for different cancers, these are considered of relevance. References for various cancers are as follows and the reader can review them as required; no additional details have been extracted: bladder [73], breast [74-85], colorectal [86-93], gynecologic [94-106], head and neck [107], hematologic [108-114], lung [115-118], melanoma [119-122], prostate or testicular [123-132], sarcoma [133,134]. In addition to the ASCO guideline on models of long-term follow-up care there are three guidelines on survivorship [135-137] and one on the role of advance practice nurses [138].

Survivorship care plans (SCP) have become standard of care in several jurisdictions. In the United States, such plans are a requirement for cancer programs to be accredited by the Commission on Cancer of the American College of Surgeons [139,140]. The 2012 version required these plans by 2015, but the 2016 document revised the timeline to phase in the use. A general template as well as several disease-specific ones are available from ASCO (<http://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention->

[survivorship/survivorship-compedium](#)), while LiveStrong and OncoLink provide an online tool (<http://www.livestrongcareplan.org/> or <http://www.oncolink.org/oncolife/>). Care plans are mentioned briefly, but are not part of the models in the 2012 PEBC/CCO guideline.

The 2012 guideline is primarily focused on models evaluating by whom and in what physical location survivorship care should be provided. RCTs only on this aspect are limited in number and quality. Other models incorporate patient education, interdisciplinary support, SCPs, training of follow-up personnel. Several models have been implemented either on a pilot basis or as current practice (See [Table 4-1](#) for some examples), though generally not evaluated in a randomized fashion.

Provision of patient education, support, and counselling prior to or during transfer of care may also affect patient outcomes. An important component of survivorship care is patient follow-up, and the essential components vary depending on cancer type and stage. Several guidelines and publications on survivorship focus on this area instead of survivorship models; however, in determining what model to use, the patient needs are crucial. It therefore appears remiss to consider models without follow-up needs, especially for the second question dealing with most appropriate models for specific cancer types. Some common problems or symptoms due to cancer or treatment that may need to be addressed are sexual (function or infertility: prostate, breast, gynecologic, anal/rectal cancers); cognitive (chemotherapy, brain radiation); menopausal symptoms, hot flashes, vaginal problems (gynecological cancers, endocrine treatment); pain, fatigue, depression, sleep disturbance, fear, anxiety (may be associated with any cancer, sometimes these are considered psychosocial); cardiovascular (anthracyclines, trastuzumab, radiotherapy); pneumonitis, pulmonary fibrosis, respiratory failure (radiation to heart or lungs, bleomycin); recurrence (any); secondary cancers (radiotherapy, chemotherapy); diarrhea (pelvic, endometrium, cervical irradiation); lymphedema (breast, gynecologic, melanoma, genitourinary, sarcoma, head/neck, pelvic dissection, lymph node dissection, radiation); oral problems, oral mucositis, serostomia (chemotherapy, endocrine therapy, radiotherapy); eating, drinking, or swallowing (head and neck radiotherapy, gastrointestinal cancer); immune suppression (hematologic, transplants); urinary incontinence (bladder, prostate, gynecologic); bone or skeletal (endocrine therapy, androgen-deprivation); various symptoms of androgen-deprivation from prostate cancer (sexual, hot flashes, gynecomastia, changes in body composition/metabolism/cardiovascular system; osteoporosis, anemia, psychiatric and cognitive, fatigue, QoL).

As indicated in [Table 4-1](#), reports of several models of follow-up care were found from the literature search. Risk-Stratified Pathways of Care, being studied by the National Cancer Survivorship Initiative (NCSI) UK, is probably the most important model that was not included in the 2012 guideline. The NCSI website is currently being updated and therefore several supporting documents could not be accessed. The Prospective Surveillance Model (PSM) [12,16,17] is another model that does not really fit into the current framework. ASCO [71,72] has listed eight models, of which several are based on various types of survivorship clinics.

Most of the RCTs were small and without the long-term outcomes of recurrence or survival. Some of the RCTs did not really fit within the models of the original guideline, and may not meet strict inclusion criteria. As the purpose of this assessment was to determine whether or not the guideline should be updated, the level of data extraction was only enough for the assessment, and not for a complete revision of the guideline. As such, the data in the tables is primarily for the user to be aware of the extent of new studies but not to give a full evaluation.

Table 4-1. Models of Care

Citation	Group or Model	Description	Implementation Evaluation or	Other
Grant, 2015 [4]	Cancer Care Ontario	Survivorship care plan + a) direct to primary care; or b) transition clinic; or c) shared care	Patient experience surveys. Not RCT	
Houlihan, 2010 [14] Oeffinger, 2014 [5]	Memorial Sloan-Kettering (MSKCC). Also see reviews by Mary McCabe who is the director  Fort Worth Program for Community Survivorship (ProComS)	<b>Survivorship clinic (Academic Cancer Centres).</b> Nurse practitioners with intensive training in survivorship care creates care plan and provides disease- and treatment-specific care and counseling with a focus on assisting optimal recovery and transition to wellness. NP facilitates communication with primary care provider; makes interdisciplinary referrals. Five-year goals [5] include establishing a multidisciplinary Survivorship Management Team and implementation of risk-stratified plan for all new patients  <b>Survivorship Care Services in Community Cancer Centres (community hospitals)</b> Multidisciplinary services consolidating survivorship care previously fragmented; includes oncology nurses, social workers, exercise specialists, dietitians, clinical psychologists, an genetics counselors	In use since 2005; were evaluated after one year pilot programs	
Jefford, 2015 [3]	Victorian Cancer Survivorship Program (VCSP), state of Victoria, Australia	<b>Shared models of care</b> across acute (hospital) and primary care sectors; studied alongside usual models of posttreatment care 1. Shared care, discharge to GP, 2 appointments with nurse-led clinic 2. Shared care with GP (breast cancer pts), 1 appointment with nurse-lead clinic 3. Discharge to GP (melanoma pts) 4. Specialist care (adolescent and young adults), 7 reviews with allied health professional and nurse	Six 2-y demonstration projects, not RCT. Community of practice shared experiences.  Recommend multidisciplinary or interdisciplinary leadership, education of health care workforce, risk stratification, active discharge planning, preparation (education) of	

		<p>5. Self-management with specialist follow-up and GP support for chronic diseases, 4 reviews with nurse</p> <p>6. Physical activity and nutrition program + late effects clinic specialist follow-up + GP for chronic disease</p>	survivors for GP care and self-management	
<p>Jefford, 2013 [10]</p> <p>Maier, 2013 [9]</p>	<p>National Cancer Survivorship Initiative (NCSI) UK; supported by NHS Improvement</p>	<p><b>Risk-stratified pathways of care</b>  Tailored support; personalized information and care planning based on assessment of individual risks, needs, and preferences. All pts offered treatment summary and personalised care plan, supported by information and education. Rapid re-access to appropriate part of health-care system if concern about recurrence or need for other specialized cancer care. Includes remote monitoring of tests (e.g. blood work) and care coordination.</p> <p>Model incorporates (1) self-care with support and open access, (2) shared care, (3) complex case management through MDT. This goes from low to high requirement for intervention and professional care.</p>	<p>Piloting models of improved care and support at test sites throughout England</p>	<p>NHS Improvement site undergoing revision and several documents referred to cannot be located</p>
Frew, 2012 [13]	NHS Improvement: prostate cancer only	Patients stratified to pathway that meets their individual needs	Pilot project in urology at 4 sites	Results not reported
Trotter, 2013 [6]	A comprehensive cancer centre in the southeastern United States (Duke University?), adapted from Centering Healthcare Institute model of group care	<p><b>Group Medical Appointments (Shared Medical Appointments)</b>  Bring together pts with similar health issues in group facilitated by nurse practitioner and including dietitian, physical therapist, social worker, offering peer support, education, and one-on-one assessment</p>	Survey of pts about their experience; not RCT; unclear if one-time or ongoing	
Reed, 2015 [1]		<p><b>Shared Medical Appointments</b>  Have been used in non-cancer care  Generally include group visit with 8-12 patients with a coordinated medical team (physician, nurse practitioner or physician assistant; other</p>		

		professions depending on visit intent), about 90 minutes long May include an individual assessment portion Includes education		
Jiwa, 2008 [15]	Integrated Primary Care Hub, Australia	<b>Integrated Primary Care Hub</b> Multidisciplinary team of professionals, peer support groups, and primary health practitioners within a primary care hub Coordination by GP and nurse practitioner, with management by specialists during treatment (acute phase of cancer treatment), and multidisciplinary care at other times. Includes a strong link to peer support services.		Model proposal, not implemented
Gerber, 2012 [12] Stout, 2012 [16,17]	Based on a Roundtable Meeting on a Prospective Model of Care for Breast Cancer Rehabilitation, February 24-25, 2011, American Cancer Society, Atlanta, Georgia	<b>Prospective surveillance model (PSM) - breast cancer</b> Interval assessment from the point of diagnosis through survivorship to promote early identification and intervention for physical impairments. Includes education about toxicities, ongoing health maintenance care, periodic functional tests, and referral to specialists as needed. Two key components are identification and management of impairment, and health-promoting skills and behaviours.		
Bugos, 2015 [141]	Blood cancers	<b>Embedded Nurse Practitioner</b> Provides care in parallel with treatment at start of maintenance therapy or post-treatment surveillance		
ASCO, 2014, 2016 [71,72]	Various models of follow-up care	<ol style="list-style-type: none"> <li>1. Oncology Specialist Care</li> <li>2. Multi-Disciplinary Survivorship Clinic</li> <li>3. Disease/Treatment Specific Survivor Clinic</li> <li>4. General Survivorship Clinic (may not have expertise in particular disease/treatment)</li> <li>5. Consultative Survivorship Clinic (on-time visit without follow-up; idea of creating treatment summary and care plan)</li> <li>6. Integrated Survivorship Clinic (embedded in treatment-focused oncology setting; specialist is part of the team)</li> </ol>		Guideline/resource, lists advantages and disadvantages of each model but no recommendations

		7. Community Generalist Model (Primary care physician or nurse) 8. Share-Care of Survivor		
McCabe, 2013 [8]	ASCO statement	Approaches: 1. Exposure-based: based on specific chemotherapy, radiation dose and volume, and surgical procedure 2. Disease-based: focuses on therapeutic modalities and health concerns related a specific cancer 3. Organ-system: focuses on specific organ or organ system affected by cancer or therapy (e.g., cardiovascular or pulmonary) 4. Symptom-based: e.g., fatigue, sleep disturbance Academic Centers: clinic focused on specific diseases or survivor of different cancers; either longitudinal or consultative clinics Community Practice (community hospitals): survivorship clinic Shared Care: ideally using risk-stratified approach; PCP provides non-cancer related care throughout		
NCCN, 2016 [142]	NCCN	For adolescent and young adults: 1. Cancer centre (primary treatment team or specialized long-term follow-up clinic) 2. Primary care physician 3. Shared care For shared care, consider risk stratification based on current medical issues and prior treatment to determine level of follow-up required. If low risk for late effects may transition to primary care physician soon after completion of therapy. Moderate risk may alternate between oncology team or primary care physician. Those at high risk for late effects should be followed annually by the oncology team and continue follow-up with the primary care physician		
NCCN, 2016 [137]		1. Survivorship clinic within academic or community cancer centre		

		<p>2. Community survivorship clinic by primary care clinicians</p> <p>3. Care in the primary care setting</p> <p>In all cases, care by either physicians or advanced practice clinicians such as nurse practitioners.</p>		
Kinahan, 2015 [2]		Discusses models of NCCN AYA guide [142] as well as Risk-Stratified Shared Care (see McCabe 2013 [7])		
McCabe, 2013 [7]		<p>Formal multidisciplinary follow-up is resource intense and most suitable for survivors with complex health care needs</p> <p>Disease-specific clinics (e.g. breast cancer)</p> <p>Intervention-specific clinics (e.g. bone-marrow transplant)</p> <p>Consultative model: one-time consultation at survivorship clinic and development of treatment plan then ongoing care by oncologist or primary care physician</p> <p>Longitudinal model for survivorship clinic: patient transitioned from oncologist to clinic when risk of recurrence is decreased and immediate adverse effects of therapy resolved (1-5 years).</p> <p><b>Risk-stratified survivorship</b> care involves a personalized systematic plan of periodic screening, surveillance, and prevention. This approach can be used in various survivorship care models. Addresses questions of who needs to be followed, by whom, for how long, and by what methods.</p>		
McCabe, 2012 [11]		<p>Shared Care</p> <p>Care shared between specialist and generalist providers with clearly delineated roles and ongoing communication</p> <p>a) Pediatric Long-term Follow-up Model</p> <p>Includes late effects clinic, not usually disease-specific; may be multidisciplinary or with NP-run in collaboration oncologist or primary care provider who refers to other specialists as needed</p>		

		<p>b) Adult Follow-up Clinic model Nurse Practitioner is key provider, sometimes as part of multidisciplinary team</p> <ul style="list-style-type: none"> <li>• Disease-Specific Model</li> <li>• General Survivorship Clinic Model</li> <li>• Consultative clinic model</li> <li>• Multidisciplinary clinic model</li> <li>• Integrated care model: located in same place treatment is received, and patients transitioned to nurse practitioner for ongoing care</li> <li>• Transition to primary care: may be directly after treatment ends or once at low risk of recurrence and late effects</li> </ul>		
Halpern, 2015 [56] Viswanathan, 2014 [57]	Review on models of care	<p>Survivorship clinics, either integrative (with treatment facility) or separate (setting other than where treatment received) Type of Clinician: led by physician, nurse, or nurse practitioner, or care team, or shared care Purpose: e.g., transition clinic model (focus on transition from oncologist to PCP)</p>		
Howell, 2012 [65]		<p>Standard care by oncologist in a cancer centre Care by primary care physicians or nurses Conventional vs on-demand or patient-initiated follow-up</p>		
Boogaard, 2016 [42] Kim, 2015 [43] McCorkel, 2011 [143]		<p>Self-management Interventions that support patient empowerment of independent health behaviours; interventions designed to help survivors manage their symptoms and side effects of cancer treatment; interventions that enable patients and families to participate in managing their care</p>		

Table 4-2. Randomized Controlled Trials

Author, Citation	Year,	Trial name or location; Disease	Study details and comparison	Outcome
Ruddy, 2016 [18]		Massachusetts-based hospital network; Breast	Phase 2 trial (n=200) Coordinated follow-up care (included SCP and patient navigator calls every 3 months) vs standard care (no SCP or patient navigator)	Unnecessary breast exams in both groups
Jefford, 2016 [19]		SurvivorCare; Colorectal	N=217 Usual care plus SurvivorCare vs usual care. SurvivorCare included educational materials, needs assessment, survivorship care plan, end-of-treatment session, 3 telephone calls	SurvivorCare patients were more satisfied with care; SurvivorCare did not have beneficial effect on distress, supportive care needs, or QoL
Emery, 2016 [20]		ProCare; prostate	Shared care vs usual care, n=88 Shared care entailed substituting 2 hospital visits with 3 visits in primary care + survivorship care plan, recall and reminders + screening for distress and unmet needs	Shared care is feasible; appears to produce similar outcomes at lower cost
Visser, 2015 [21]		Netherlands; breast	N=38 Single group medical consultation vs control (individual outpatient visits)	Group consultation scored high on feasibility, both groups equally satisfied, distress and empowerment were equal, costs were similar
Aktas, 2015 [22]		Turkey; gynecologic	N=70 Home care nursing service vs control Nursing care through hospital and home visits (1 <sup>st</sup> and 12 weeks; included nursing care and consultancy for sexual problems) vs control (hospital routine protocols (1 <sup>st</sup> and 12 <sup>th</sup> weeks)	Patients with home care experienced fewer sexual problems
Wulff, 2013 [23]		Denmark; colorectal	N=280 Case management (CM) vs control CM group provided by experienced and specially trained nurses who were part of the MDT. CM nurses provided needs assessment at initiation and at any transition of care, phoned patient to assess and facilitate patients' bio-psycho-social well-being and ensure informed about diagnosis and treatment plans, continued for 4 weeks after completion of CRC treatment; kept GP informed	Survey of GPs found CM associated with more positive GP evaluations
Bergholdt, 2013 [24,25] Bergholdt, 2012 [27]		Denmark, NCT01021371 Incident cancer (43% breast, 15% lung, 8% malignant melanoma)	N=955 Patient interview about rehabilitation with rehabilitation coordinator + compressive information to GP about individual needs + encouragement to proactively contact the patient vs control	No effect on patient or GP reported extent of GP proactivity, no effect on patient participation in rehabilitation activities during 14-month follow-up period

Author, Citation	Year,	Trial name or location; Disease	Study details and comparison	Outcome
Augustad, 2013 [26]		Norway, NCT00572143. Colon	N=110 GP vs surgeon organized colon cancer surveillance for 24 months	No difference in QoL, time to recurrent cancer diagnosis, or metastases surgeries performed; GP follow-up was more cost-effective
Beaver, 2012 [28]		UK, Colorectal	N=65, exploratory RCT Telephone (colorectal nurse practitioner) vs hospital (consultant surgeons, registrars, junior doctors, or colorectal nurse practitioner) follow-up after colorectal cancer Follow-up at 5 weeks post-treatment then every 6 months for 2 years, then annually for a further 3 years then discharged to GP unless complex or unresolved problems were evident	Telephone appointments were longer (median 29 min vs 14 min); pts in telephone arm more likely to raise concerns
Strand, 2011 [29]		Sweden, Colorectal	N=110 Follow-up by nurse (trained by colorectal surgeon) vs surgeon. Evaluation by patient questionnaire	Patient satisfaction high in both groups, no significant difference. More blood samples with nurse; no difference in detection of distant metastases. No difference in total cost.
<b>Publications before 2011*</b>				
Gall, 2007 [30]		Australia colon	N=203 randomized, plus additional 135 patients who chose their follow-up (patient preference arm) GP vs surgeon follow-up HR QoL outcomes	No difference found in physical or psychologic HR QoL
Nielsen, 2003 [31]		Denmark	N=248 Shared care (knowledge transfer from oncologist to GP, communication channels, active patient involvement) vs normal care (usually a discharge summary letter to GP at end of treatment) Evaluation at 0, 3 m, 6 m of patients' attitudes towards healthcare services, HR QoL, performance status, contacts with GP	More GP contact in intervention group, positive effect on patient evaluation of cooperation between healthcare sectors, no difference in QoL or performance status
Johansson, 2003 [32] Johansson, 2001 [36]		Uppsala	N=485 Intensified primary health care (GP and home care nurses) vs control (standard care)	More follow-up contacts in intervention group and less days at specialist clinics
Moore, 2002 [33]		Southeastern England Lung cancer	N=203 Nurse-led follow-up of outpatients (clinical nurse specialists in lung cancer assessed monthly by phone or in clinic plus as needed) vs conventional follow-up (outpatient appointments after treatment and then at 2-3 month intervals to monitor disease progression and also on basis of need)	Less dyspnoea at 3 m; better emotional functioning and less peripheral neuropathy at 12 m; better satisfaction. No differences were seen in survival or rates of objective progression, although nurses recorded progression of symptoms sooner than doctors (P=0.01). Intervention patients were more likely to die at home rather than in a hospital or hospice (P=0.04), attended fewer

Author, Citation	Year,	Trial name or location; Disease	Study details and comparison	Outcome
				consultations with a hospital doctor during the first 3 months (P=0.004), had fewer radiographs during the first 6 months (P=0.04), and had more radiotherapy within the first 3 months (P=0.01).
Brown, 2002 [34]		UK Breast (stage 1)	N=61 Patient-initiated follow-up (written information on signs and symptoms of recurrence, and advised to contact breast care nurse by phone if a problem) vs standard clinic follow-up (examined by doctor) Assessed cancer and breast cancer-specific quality of life, and psychological morbidity at recruitment, 6 months and 1 year	No major difference in QoL or psychological morbidity
Rutherford, 2001 [35]		Australia Gynecologic	N=200 Personal invitation for GP to contact hospital during patients admission and payment vs no invitation	Increase in GP contact rates; no difference in patient satisfaction and confidence in future management by their GPs
McCorkle, 2000 [37]		Pennsylvania Elderly (age 60-92); solid cancers	N=375 Standard assessment and management post-surgical guidelines + instructional content + schedules of contact (3 visits + 5 phone calls over 4 weeks by advanced practice nurses) vs usual care (out-patient clinic) Follow-up until death or end of study (maximum 44 m)	Deaths 22% vs 28%, p=0.002 stratified log-rank test] No difference for early-stage pts Improved survival for late-stage pts (2-y OS 67% vs 40%)
<b>Ongoing Studies</b>				
Taylor, 2016 [38]		Large tertiary cancer centre in Western Australia; Lymphoma	Pilot RCT(n=100) Nurse-led lymphoma survivorship clinic compared to usual post-treatment care	Not complete
Huntingdon, 2016 [39] Schofield, 2013 [40]		PeNTAGOn trial, Australia Gynecologic, with treatment including radiotherapy	N=3-6 Usual care plus 4 specialist nurse led consultations plus 4 phone calls from a peer support volunteer throughout disease trajectory (pre-treatment, mid-treatment, treatment completion, post-treatment) vs usual care Outcomes of psychological distress, QoL, symptom distress, unmet supportive care needs, psychosexual function, vaginal stenosis	Ongoing

\*Several RCTs published prior to 2011 were found in the literature search. While not reported in the 2012 version of this guideline, it was not possible to determine whether these were missed due to limitations in the literature search used or that these were found but excluded during the literature review process.

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#### Appendix 4-1. Members of the Expert Panel

Name	Affiliation
Jonathan Sussman, MD, FRCPC	Chair, CCO Survivorship Advisory Committee Radiation Oncologist, Hamilton Health Sciences Hamilton, Ontario
Paula Doering, BScN, MBA	Regional Vice President, Champlain Regional Cancer Program Ottawa, Ontario
Esther Green, BScN, MSc(T)	Director, Person Centred Perspective Canadian Partnership Against Cancer Toronto, Ontario
Andrea Eisen, MD FRCPC	Ontario Breast Cancer Lead, Cancer Care Ontario Medical Oncologist, Sunnybrook Odette Cancer Centre Toronto, Ontario
Craig Earle, MD, MSc	Director, CCO Health Services Research Program Medical Oncologist, Sunnybrook Health Sciences Centre Toronto, Ontario

**APPENDIX 4-2. Final 26-1 Document Assessment and Review Search Strategy, September 26, 2016**

Database(s): Embase 1996 to 2016 Week 39, Ovid MEDLINE(R) without Revisions 1996 to September Week 2 2016, Ovid MEDLINE(R) Daily Update September 23, 2016, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations September 23, 2016, Ovid MEDLINE(R) Epub Ahead of Print September 23, 2016

Search Strategy:

#	Searches	Results	Annotations
1	exp Neoplasms/ or exp tumor/ or exp cancer/ or (cancer: or neoplasm: or tumo?r: or carcinom: or malignan: or oncolog:).mp.	5893981	
2	limit 1 to yr="2000-current"	5252726	
3	exp phase 3 clinical trial/ or exp "phase 3 clinical trial (topic)"/ or exp clinical trial, phase iii/ or exp clinical trials, phase iii as topic/ or exp phase 4 clinical trial/ or exp "phase 4 clinical trial (topic)"/ or exp clinical trial, phase iv/ or exp clinical trials, phase iv as topic/ or exp randomized controlled trial/ or exp "randomized controlled trial (topic)"/ or exp controlled clinical trial/ or exp randomized controlled trials as topic/ or exp randomization/ or exp random allocation/ or exp double-blind method/ or exp single-blind method/ or exp double blind procedure/ or exp single blind procedure/ or exp triple blind procedure/ or exp placebos/ or exp placebo/ or ((exp phase 2 clinical trial/ or exp "phase 2 clinical trial (topic)"/ or exp clinical trial, phase ii/ or exp clinical trials, phase ii as topic/ or exp clinical trial/ or exp prospective study/ or exp controlled clinical trial/) and random\$.tw.) or (((phase II or phase 2 or clinic\$) adj3 trial\$) and random\$.tw. or ((singl\$ or doubl\$ or treple\$ or trebl\$ or tripl\$) adj3 (blind\$ or mask\$ or dummy)).tw. or placebo?.tw. or (allocat: adj2 random:).tw. or (random\$ control\$ trial? or rct or phase III or phase IV or phase 3 or phase 4).tw. or (random\$ adj3 trial\$).mp. or "clinicaltrials.gov".mp.	1750758	
4	exp meta analysis/ or exp "meta analysis (topic)"/ or exp meta-analysis as topic/ or exp "systematic review"/ or exp "systematic review (topic)"/ or ((exp "review"/ or exp "review literature as topic"/ or review.pt.) and ((systematic or selection criteria or data extraction or quality assessment or jaded scale or methodologic\$ quality or study) adj selection).tw.) or meta-analysis.mp. or (meta-analy: or metaanaly: or meta analy:).tw. or (systematic review or systematic overview).mp. or ((cochrane or medline or embase or cancerlit or hand search\$ or hand-search\$ or manual search\$ or reference list\$ or bibliograph\$ or relevant journal\$ or pooled analys\$ or statistical pooling or mathematical pooling or statistical summar\$ or mathematical summar\$ or quantitative synthes?s or quantitative overview\$ or systematic) adj2 (review\$ or	569578	

	overview\$).tw. or (medline or med-line or pubmed or pub-med or embase or cochrane or cancerlit).ab.		
5	exp evidence based practice/ or exp practice guideline/ or exp consensus development conference/ or guideline.pt. or practice parameter\$.tw. or practice guideline\$.mp. or (guideline: or recommend: or consensus or standards).ti. or (guideline: or recommend: or consensus or standards).kw.	1546068	
6	2 and (3 or 4 or 5)	504295	
7	(abstract or note or editorial or letter or comment or historical).pt.	5080578	
8	6 not 7	415193	
9	(survivor: and (care or continuity or follow up or aftercare)).mp.	74864	
10	limit 9 to yr="2012-current"	33812	
11	10 or (9 and ((2012: or 2013: or 2014: or 2015: or 2016:).ed. or (2012: or 2013: or 2014: or 2015: or 2016:).dd. or (2012: or 2013: or 2014: or 2015: or 2016:).em.))	54770	
12	11 and 8	3705	
13	remove duplicates from 12	2925	
14	meta-analysis as topic/ or meta analysis.pt. or exp meta analysis/ or exp systematic review/ or (meta analy\$ or metaanaly\$).tw. or (systematic review\$ or pooled analy\$ or statistical pooling or mathematical pooling or statistical summar\$ or mathematical summar\$ or quantitative syntheses or quantitative overview).tw. or (systematic adj (review\$ or overview?)).tw. or ((exp review/ or review.pt.) and (systematic or selection criteria or data extraction or quality assessment or jadad scale or methodological quality or (study adj selection)).ab.) or ((exp Review Literature as topic/ or review.pt. or exp review/) and systematic.tw.) or (cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or cinhal or science citation index or scisearch or bids or sigle or cancerlit).ab. or (reference list\$ or bibliograph\$ or hand-search\$ or relevant journals or manual search\$).ab. or exp randomized controlled trials as topic/ or exp clinical trials, phase III as topic/ or exp clinical trials, phase IV as topic/ or (randomized controlled trial or clinical trial, phase III or clinical trial, phase IV).pt. or random allocation/ or double blind method/ or single blind method/ or exp randomized controlled trial/ or exp phase 3 clinical trial/ or exp phase 4 clinical trial/ or randomization/ or single blind procedure/ or double blind procedure/ or (randomi\$ control\$ trial? or rct or phase III or phase IV or phase 3 or phase 4).tw. or (((phase II or phase 2).tw. or exp clinical trial/ or exp prospective study/ or exp controlled clinical trial/) and random\$.tw.) or (clinic\$ adj trial\$1).tw. or ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$3 or mask\$3 or dummy)).tw. or placebos/ or (placebo? or random	2552418	Used in previous version

	allocation or randomly allocated or allocated randomly).tw. or (allocated adj2 random).tw. or practice guidelines/ or practice guideline?.tw. or practice guideline.pt.		
15	14 not ((editorial or note or letter or erratum or short survey).pt. or abstract report/ or letter/ or case study/)	2351388	
16	limit 15 to english	2170344	
17	animal/	3924884	
18	human/	21691524	
19	17 not 18	2573390	
20	16 not 19	2091169	
21	((cancer or neoplasm or carcinoma or oncology) and (care or continuity or follow up or shared care or (after care or aftercare)) and survivo\$.mp.	27338	
22	20 and 21	4381	
23	22 not (childhood or pediatric).ti.	4025	
24	limit 23 to yr="2000-2011"	1458	
25	24 not ((2012: or 2013: or 2014: or 2015: or 2016:).ed. or (2012: or 2013: or 2014: or 2015: or 2016:).dd. or (2012: or 2013: or 2014: or 2015: or 2016:).em.)	644	in original search
26	remove duplicates from 25	637	
27	9 and 8	4326	
28	27 not 25	3912	
29	28 not 12	207	
30	exp Survivors/ or exp Patient Care Planning/ or (survivor: or aftercare or (care adj2 (followup or follow up or after or model: or plan: or continuity or setting or transfer))).mp. or ((exp oncologist/ or exp Medical Oncology/ or exp Radiation Oncology/ or exp specialties, surgical/ or exp hospitals/) and (exp community medicine/ or exp general practice/ or exp general practitioner/ or exp physicians, family/ or exp physicians, primary care/ or exp primary health care/))	455198	
31	(30 and 8) not (9 or 25)	9361	
32	limit 31 to yr="2012-2016"	4622	
33	31 not 32	4739	
34	remove duplicates from 32	3583	
35	remove duplicates from 33	3762	
36	34 or 35	7345	

## DEFINITIONS OF REVIEW OUTCOMES

- 1. EDUCATION AND INFORMATION** – EDUCATION AND INFORMATION means that a Clinical Expert and/or Expert Panel has reviewed new evidence pertaining to the guideline topic and determined that the guideline is out of date or has become less relevant. The document will no longer be tracked or updated but may still be useful for academic or other informational purposes. The document is moved to a separate section of our website and each page is watermarked with the words “EDUCATION AND INFORMATION.”
- 2. ENDORSED** – ENDORSED means that a Clinical Expert and/or Expert Panel has reviewed new evidence pertaining to the guideline topic and determined that the guideline is still useful as guidance for clinical decision making. A document may be endorsed because the Expert Panel feels the current recommendations and evidence are sufficient, or it may be endorsed after a literature search uncovers no evidence that would alter the recommendations in any important way.
- 3. UPDATE** – UPDATE means the Clinical Expert and/or Expert Panel recognizes that the new evidence pertaining to the guideline topic makes changes to the existing recommendations in the guideline necessary but these changes are more involved and significant than can be accomplished through the Document Assessment and Review process. The Expert Panel advises that an update of the document be initiated. Until that time, the document will still be available as its existing recommendations are still of some use in clinical decision making, unless the recommendations are considered harmful.