

## Evidence-Based Series 26-1 Version 2

# 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 March 2025 deferred the review of Evidence-Based Series (EBS) 26-1 Version 2. This means that the document remains current until it is assessed again next year. 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	SYSTEMATIC REVIEW		PUBLICATIONS	NOTES and
VERSION	Search	Data		KEY CHANGES
	Dates			
Original	2000 to	Full Report	Web publication	N.A.
2012	Week 13			
	2012			
Current	2000 to	New data found in	Updated web	2012
Version 2	September	Section 4: Document	publication	Recommendations
March 28,	2016	Summary and Review		are ENDORSED
2017		Tool		

## 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

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## 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	Specialist		
<ul> <li>Hospital</li> </ul>	<ul> <li>Medical oncologist, surgeon, radiation oncologist,</li> </ul>		
Cancer centre	general practitioner in oncology (GPO)		
	• Nurse		
	<ul> <li>Nurse specialist, nurse practitioner, family</li> </ul>		
	practice nurse, nurse navigator		
	Patient-directed		
Community	• Family Physician		
<ul> <li>Family Physician's office</li> </ul>	• Specialist		
<ul> <li>Specialist's office</li> </ul>	<ul> <li>Medical oncologist, surgeon, radiation oncologist,</li> </ul>		
(outside hospital)	GPO GPO		
	Nurse		
	<ul> <li>Nurse specialist, nurse practitioner, family</li> </ul>		
	practice nurse, nurse navigator		
	Patient-directed		
Shared Care	Any combination of:		
	Specialist		
	<ul> <li>Medical oncologist, surgeon, radiation oncologist,</li> </ul>		
	GPO GPO		
	• Family Physician		
	Nurse		
	<ul> <li>Nurse specialist, nurse practitioner, family</li> </ul>		
	practice nurse, nurse navigator		
	Patient-directed		

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 specialistcoordinated 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.

#### Kev 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

<sup>&</sup>lt;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:

- Earle C, Annis R, Sussman J, Haynes AE, Vafaei A, Colorectal Cancer Survivorship Group. Follow-up care, surveillance protocol, and secondary prevention measures for survivors of colorectal cancer. Toronto (ON): Cancer Care Ontario [2012 Feb 3; assessed 2014 and endorsed 2016 Mar 10; cited 2016 Oct 24]. Program in Evidence-Based Care Evidence-Based Series No.: 26-2 Version 2. Available at: <a href="https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/256">https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/256</a>. 2012.
- Ung YC, Souter LH, Darling G, Dobranowski J, Donohue L, Leighl NB, et al. Follow-up and surveillance of curatively treated lung cancer patients. Toronto (ON): Cancer Care Ontario [2014 Aug 29; cited 2016 Oct 26]. Program in Evidence-Based Care Guideline No.: 26-3. Available at: <a href="https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/261">https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/261</a>. 2014.
- Matthew A, Souter LH, Breau RH, Canil C, Haider M, LJamnicky L, et al. Follow-up care and psychosocial needs of survivors of prostate cancer. Toronto (ON): Cancer Care Ontario [2015 June 16; cited 201 Jun 13]. Program in Evidence-Based Care Evidence-Based Series No.: 26-

2016;19:19.

- 4. Available at: <a href="https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/266">https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/266</a>. 2015.
- Sussman J, Varela N, Cheung M, Hicks LJ, Kraftcheck D, Mandel J, et al. Folllow-up care for survivors of lymphoma who have received curative-intent treatment. Toronto (ON): Cancer Care Ontario [2016 Apr 12; cited 2017 Jun 13]. Program in Evidence-Based Care Evidence Summary No.: 26-5. Available at: <a href="https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/471">https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/471</a>. 2016.
- 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: <a href="https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/616">https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/616</a>. 2006.
- Elit L, B. KE, Fyles A, Mestser U, PEBC Gynecologic Cancer Disease Site Group. Follow-up for cervical cancer. Toronto (ON): Cancer Care Ontario [2015 May 12; cited 2016 Oct 26]. Program in Evidence-Based Care Guideline No.: 4-16 version 2. Available at: <a href="https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/476">https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/476</a>. 2015.
- 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: <a href="https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/37806">https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/37806</a>. 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: <a href="https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/31776">https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/31776</a>. 2015.

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#### **REFERENCES**

- 1. Oeffinger KC, McCabe MS. Models for delivering survivorship care. J Clin Oncol. 2006;24(32):5117-24.
- 2. Leigh SA. The changing legacy of cancer: issues of long-term survivorship. Nurs Clin North Am. 2008;43(2):243-58; vi.
- 3. Grunfeld E. Looking beyond survival: how are we looking at survivorship? J Clin Oncol. 2006;24(32):5166-9.
- 4. Grunfeld E, Fitzpatrick R, Mant D, Yudkin P, Adewuyi-Dalton R, Stewart J, et al. Comparison of breast cancer patient satisfaction with follow-up in primary care versus specialist care: results from a randomized controlled trial. Br J Gen Prac. 1999;49(446):705-10.
- 5. Grunfeld E, Mant D, Yudkin P, Adewuyi-Dalton R, Cole D, Stewart J, et al. Routine follow up of breast cancer in primary care: randomised trial. BMJ. 1996;313(7058):665-9.
- 6. Grunfeld E, Levine MN, Julian JA, Coyle D, Szechtman B, Mirsky D, et al. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. J Clin Oncol. 2006;24(6):848-55.
- 7. Beaver K, Tysver-Robinson D, Campbell M, Twomey M, Williamson S, Hindley A, et al. Comparing hospital and telephone follow-up after treatment for breast cancer: randomised equivalence trial. BMJ. 2009;338:a3147.
- 8. Kimman ML, Dirksen CD, Voogd AC, Falger P, Gijsen BC, Thuring M, et al. Economic evaluation of four follow-up strategies after curative treatment for breast cancer: results of an RCT. Eur J Cancer. 2011;47(8):1175-85.
- 9. Wattchow DA, Weller DP, Esterman A, Pilotto LS, McGorm K, Hammett Z, et al. General practice vs surgical-based follow-up for patients with colon cancer: randomised controlled trial. Br J Cancer. 2006;94(8):1116-21.
- 10. Sheppard C, Higgins B, Wise M, Yiangou C, Dubois D, Kilburn S. Breast cancer follow up: a randomised controlled trial comparing point of need access versus routine 6-monthly clinical review. Eur J Onc Nurs. 2009;13(1):2-8.
- 11. Helgesen F, Andersson SO, Gustafsson O, Varenhorst E, Goben B, Carnock S, et al. Follow-up of prostate cancer patients by on-demand contacts with a specialist nurse: a randomized study. Scand J Urol Nephrol. 2000;34(1):55-61.
- 12. Murchie P, Nicolson MC, Hannaford PC, Raja EA, Lee AJ, Campbell NC. Patient satisfaction with GP-led melanoma follow-up: a randomised controlled trial. Br J Cancer. 2010;102(10):1447-55.
- 13. Verschuur EM, Steyerberg EW, Tilanus HW, Polinder S, Essink-Bot ML, Tran KT, et al. Nurseled follow-up of patients after oesophageal or gastric cardia cancer surgery: a randomised trial. Br J Cancer. 2009;100(1):70-6.