Longitudinal adherence to surveillance for late effects of cancer treatment: a population-based study of adult survivors of childhood cancer

Jennifer Shuldiner PhD, Rinku Sutradhar PhD, Cindy Lau MPH, Nida Shah MPH, Emily Lam MSc, Noah Ivers MD PhD, Paul C. Nathan MD MSc

Cite as: *CMAJ* 2024 March 11;196:E282-94. doi: 10.1503/cmaj.231358

Abstract

Background: Adult survivors of childhood cancer are at elevated risk of morbidity and mortality compared to the general population, but their adherence to lifelong periodic surveillance is suboptimal. We aimed to examine adherence to surveillance guidelines for high-yield tests and identify risk factors for nonadherence in adult survivors of childhood cancer.

Methods: In this retrospective, population-based cohort study, we used health care administrative data from Ontario, Canada, to identify adult survivors of childhood cancer diagnosed between 1986 and 2014 who were at elevated risk of therapy-related colorectal cancer, breast cancer, or cardiomyopathy. Using a Poisson regression framework, we assessed longitudinal adherence and predictors of adherence to the Children's Oncology Group surveillance guideline.

Results: Among 3241 survivors, 327 (10%), 234 (7%), and 3205 (99%) were at elevated risk for colorectal cancer, breast cancer, and cardiomyopathy, respectively. Within these cohorts, only 13%, 6%, and 53% were adherent to recommended surveillance as of February 2020. During a median follow-up of 7.8 years, the proportion of time spent adherent was 14% among survivors at elevated risk for colorectal cancer, 10% for breast cancer, and 43% for cardiomyopathy. Significant predictors of adherence varied across the risk groups, but higher comorbidity was associated with adherence to recommended surveillance.

Interpretation: Survivors of childhood cancer in Ontario are rarely up to date for recommended surveillance tests. Tailored interventions beyond specialized clinics are needed to improve surveillance adherence.

Adult survivors of childhood cancer are at elevated risk of late morbidity and premature mortality ("late effects"), resulting from their treatment.[1] As many as 80% of childhood cancer survivors (CCS) will develop a serious or life-threatening late effect by age 45 years.[2] Of these late effects, cardiomyopathy[1] and subsequent malignant neoplasms (including breast and colorectal cancers[3–5]) are among the leading causes of premature mortality. For example, female CCS who received chest radiation have a breast cancer risk comparable with that of females who carry a *BRCA* mutation.[6] The risk of colorectal cancer in CCS is 2- to 3-fold higher than in the general population[7] and as many as 50% of CCS who received anthracycline chemotherapy, radiation involving the heart, or both will develop clinical or subclinical cardiotoxicity.[1]

As risk-adapted surveillance can potentially reduce mortality,[8,9] the Children's Oncology Group offers long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers.[10] Studies have shown the effectiveness and cost-effectiveness of adherence to these surveillance guidelines, hence their broad adoption by North American clinicians who care for CCS.[9,11,12] However, guideline adherence among adult CCS and their health care providers is suboptimal,[8,13–17] placing many CCS at substantial risk for preventable harm.

Our objective was to determine longitudinal surveillance adherence among adult CCS in Ontario, Canada, and to identify survivor and care provider characteristics associated with nonadherence, to inform future targeted interventions.

Methods

Setting

When CCS transition to adult care, they are given a summary of their treatment and the required surveillance testing. All adult CCS in Ontario are eligible to access long-term follow-up clinics (referred by the treating pediatric oncologist, or CCS can self-refer)

located across 5 tertiary or quaternary provincial cancer centres (Appendix 1, available at www.cmaj.ca/lookup/doi/10.1503/cmaj.231358/tab-related-content), but attendance is poor and has been declining.[18,19] Many CCS drop out as they age.[20,21] Some survivors have lifelong annual long-term follow-up clinic visits and others transition to their primary care physician. In the analysis, we included CCS who received a diagnosis between July 1, 1986, and Dec. 31, 2014.

Design

We conducted a retrospective, population-based cohort study of adult CCS in Ontario, Canada. The Reporting of Studies Conducted Using Observational Routinely-collected Health Data (RECORD) checklist is available in Appendix 2 (at www.cmaj.ca/lookup/doi/10.1503/cmaj.231358/tab-related-content).

Data sources

The Pediatric Oncology Group of Ontario Networked Information System (POGONIS)[22] is a registry of all children and adolescents who received a cancer diagnosis before age 18 years and were treated at any of Ontario's 5 pediatric cancer centres since 1986 (Appendix 1). Previous work has shown that POGONIS identifies more than 96% of Ontario children with cancer, younger than 14 years.[22]

We excluded CCS with a less than 5-year event-free period between their last childhood cancer event (latest of primary diagnosis, relapse, or subsequent malignant neoplasm before age 18 yr) and end of study (Feb. 28, 2020). Eligible CCS at elevated risk of cardiomyopathy (anthracycline, radiation to the heart, or both) were aged 18 years or older before the end of study. Eligible CCS at elevated risk of breast cancer (female survivor with radiation to the chest, axilla, or total body irradiation), colorectal cancer (radiation to the abdomen, chest, pelvis, spine, or total body irradiation), or both were age 25 years or older before the end of the study.

We excluded CCS if they had an invalid unique encoded identifier or missing data on sex, a follow-up time of 1 year or less, or emigrated out of Ontario.

We linked patients in POGONIS to population-based administrative databases (Appendix 3, available at www.cmaj.ca/lookup/doi/10.1503/cmaj.231358/tab-related-content) using unique encoded identifiers. Linked data sets were analyzed at ICES, an independent, nonprofit organization that analyzes data collected from administering Ontario's publicly funded health care system. These databases have been validated[23] and used extensively for health services research in Ontario (https://www.ices.on.ca/publications/). Databases capture hospital stays with diagnostic and procedure codes (Discharge Abstract Database), physician claims through the Ontario Health Insurance Plan (OHIP), outpatient ambulatory care visits (National Ambulatory Care Reporting System), cancer cases in Ontario (the Ontario Cancer Registry), basic demographics (Registered Persons Database), and use of breast cancer screening services (Ontario Breast Screening Program).

From POGONIS, we retrieved information on primary cancer diagnosis, diagnosis date, treatment (hematopoietic stem cell transplant, radiation, chemotherapy including anthracyclines), and relapse or subsequent malignant neoplasm before age 18 years. For CCS at elevated risk of colorectal or breast cancer, we categorized radiation as none, abdomen or pelvis only, breast and abdomen or pelvis, or breast only. For CCS at elevated risk of cardiomyopathy, we categorized treatment as anthracycline only, radiation involving the heart only, or radiation involving the heart and anthracycline.

We captured socioeconomic status at index through a composite measure of rurality and neighbourhood income. The Statistics Canada measure included 5 Census-derived neighbourhood income quintiles,[24] with quintile 1 representing the lowest income level. Rural residence was considered a sixth category. We adhered to Statistics Canada's recommendation not to report income quintiles in rural areas, owing to the variation of income within a single rural postal code, an approach that has been adopted by past studies.[25–28]

Using the OHIP database, we identified all primary care physician and long-term follow-up clinic visits in the year before the start date of each surveillance lookback period. We categorized Johns Hopkins' Aggregated Diagnosis Groups (ADG) scores, representing measures of morbidity,[29,30] as none, low (1–5), intermediate (6–9), and high (≥ 10).[31]

Outcomes

Five versions of the Children's Oncology Group Long-Term Follow-Up Guidelines (Table 1 and Appendix 4, available at www.cmaj.ca/lookup/doi/10.1503/cmaj.231358/tab-related-content) have been produced. We assessed guideline adherence to surveillance for colorectal cancer, breast cancer, or cardiomyopathy because these outcomes involve 3 high-yield surveillance tests that are cost-effective in CCS.[12,32]

Current adherence analysis

Current adherence proportions for each surveillance category were calculated as the number of patients adherent on the last day of follow-up (using version 5 [V5] of the guidelines) divided by the total number of patients under follow-up at that time. To assess adherence at the beginning of follow-up, we included a lookback period (pre-index date) based on the surveillance test frequency. We also calculated adherence proportions in 2005, 2010, 2015, and 2019 and examined whether they consistently increased or decreased over time, using the Cochran–Armitage trend test. Proportions adherent for breast and colorectal cancer were compared between survivors newly eligible for the V5 guidelines (no radiation dose criteria for eligibility) and those who had been eligible in versions 1 to 4 (dose criteria for eligibility). Appendix 5 (available at www.cmaj.ca/lookup/doi/10.1503/cmaj.231358/tab-related-content) provides observation window calculations.

Longitudinal analysis

We calculated follow-up time from each survivor's index date, defined as the latter of age 18 years or 5 years after their last childhood cancer event (Appendix 5). We calculated longitudinal adherence based on when each guideline version was applicable. We measured adherence from the index date until an event

Table 1: Children's Oncology Group Long-Term Follow-Up Guidelines, version 5.0[10]

Breast cancer	Colorectal cancer	Cardiomyopathy
Therapeutic exposure Any level of radiation exposure to the chest, axilla, or TBI **Surveillance*** Mammography — Yearly, beginning at age 25 yr or 8 yr post-radiation, whichever occurs last Breast MRI — Yearly, as an adjunct to mammography, beginning at age 25 yr or 8 yr post-radiation, whichever occurs last	**Therapeutic exposure** Any level of radiation exposure to the abdomen, pelvis, spine (lumbar, sacral, whole), TBI **Surveillance*** Multitarget stool DNA test — performed every 3 yr, beginning at age 30 yr or 5 yr after radiation, whichever occurs last. Positive result should be followed up with a timely colonoscopy Colonoscopy — Performed every 5 yr, beginning at age 30 yr or 5 yr after radiation, whichever occurs last.	**Therapeutic exposure** Anthracycline chemotherapy or radiation to a field that involves the heart **Surveillance*** Echocardiogram (or comparable imaging to evaluate cardiac function) starting at the completion of cancer therapy† • Anthracycline dose = none • If radiation dose is < 15 Gy or none, then the recommended frequency is "no surveillance" • If radiation dose is ≥ 15 to < 35 Gy, then the recommended frequency is every 5 yr • If radiation dose is ≥ 35 Gy, then the recommended frequency is every 2 yr. Anthracycline dose ≤ 250 mg/m^2 • If radiation dose is < 15 Gy or none, then the recommended frequency is every 5 yr • If radiation dose is ≥ 15 Gy, then the recommended frequency is every 2 yr. Anthracycline dose is ≥ 250 mg/m^2 • If radiation dose is "any or none," then the recommended frequency is every 2 yr

Note: MRI = magnetic resonance imaging, TBI = total body irradiation.
*Recommendations as per version 5.0 — October 2018.[10]
†Although echocardiographic screening is recommended to start during childhood, for the present analysis we have focused on screening that occurs once survivors become adults at age 18 years.

in adulthood (relapse, subsequent malignant neoplasm), death, emigration out of Ontario, or the end of study.

We organized data as person–period–level, using a Poisson framework. The period reflected the number of surveillance windows during a patient's follow-up. The first period began at the index date. Surveillance windows depended on the frequency of each recommended test (e.g., 1-year windows for a yearly screening test). We created fixed 1-year windows and determined the proportion adherent within each window using our algorithm. Patients could be censored midway through the last year; we used an offset term to account for this. We considered survivors to be adherent for 365 days after completing a test and then nonadherent until next test completion. Within each period, we calculated the proportion of time a patient was adherent as total days adherent divided by total days of follow-up in that period.

Predictors of adherence

Using the Poisson framework, we analyzed predictors of adherence with a Poisson multivariable regression model incorporating generalized estimating equations to account for multiple period data for each patient. The generalized estimating equations model allowed for possible overdispersion.

For each person in every period, we defined the outcome as total days adherent during the period. The regression model offset was the natural log of the patient's follow-up time within that period. We entered variables significant ($p < 0.10$) in the univariate model for each at-risk group into a multivariable model. We added age at diagnosis, sex, and socioeconomic status a priori into the multivariable model regardless of significance; the latter 2 variables affect cancer screening in the general population.[33,34] We included all covariates as baseline measures except for primary care physician and long-term follow-up clinic visits, which were updated over time.

Ethics approval

This study was exempted from ethics review and informed consent under Ontario's *Personal Health Information Protection Act.*

Results

We identified 3241 adult survivors at elevated risk per the V5 guidelines (Figure 1). The number of survivors at elevated risk for 1, 2, or 3 late effects was 2806 (87%), 345 (11%), and 90 (3%), respectively. The number of survivors at risk of colorectal cancer, breast cancer, or cardiomyopathy was 327 (10%), 234 (7%), and 3205 (99%), respectively.

Table 2 describes CCS baseline characteristics by risk type. Median follow-up time was 7.8 years (range 1.41–28.5 yr) and there were 31 476 person-years of follow-up. Median time from diagnosis date until the end of follow-up was 21.0 years (range 5.0–33.6 yr) and there were 79 149 person-years of follow-up. Reasons for censoring were death ($n = 32$), an adulthood cancer event ($n = 149$), or did not meet screening criteria before Feb. 28, 2020 ($n = 205$).

Current adherence

At the end of follow-up, 3241 survivors remained in the cohort, with 13%, 6%, and 53% adherent to colorectal cancer, breast cancer, and cardiomyopathy surveillance recommendations, respectively (Table 3). The Cochran–Armitage trend test indicated that the proportions differed over time for cardiomyopathy, breast, and colorectal adherence ($p < 0.05$, Table 4).

Over time, adherence proportions increased for colorectal cancer and cardiomyopathy but decreased for breast cancer (Table 4). Breast cancer surveillance adherence proportions in 2019 were lower than in previous years. Adherence proportions for mammograms also decreased over time. At last follow-up, only 6% of elevated-risk females had completed both mammogram and magnetic resonance imaging (MRI) and were considered adherent; 10% had completed a mammogram but not an MRI. Breast and colorectal cancer surveillance adherence was not significantly different between those who became newly eligible for the V5 guidelines compared with those eligible in previous versions (Appendix 6, available at www.cmaj.ca/lookup/doi/10.1503/cmaj.231358/tab-related-content).

Longitudinal adherence

The proportion of time adherent to surveillance guidelines was highest for survivors at elevated risk for cardiomyopathy (43%), followed by colorectal cancer (14%) and breast cancer (10%) (Table 5). Table 6, Table 7, and Table 8 describe factors associated with adherence. Greater adherence to colorectal cancer surveillance was associated with older age at diagnosis, female sex, and higher ADG scores. Greater adherence to breast cancer surveillance was associated with older age at diagnosis, more recent period of diagnosis, no transplant, and higher ADG scores. Greater adherence to cardiomyopathy surveillance was associated with younger age at diagnosis, female sex, highest income neighbourhood, more recent period of diagnosis, radiation and anthracyclines, higher anthracycline dose, no autologous transplant, higher ADG scores, more primary care physician visits, and a long-term follow-up clinic visit. Survivors who attended a long-term follow-up clinic in the previous year had generally poor adherence but better than the rest of the cohort: proportion of time adherent was 71% for those at elevated risk for cardiomyopathy, 27% for colorectal cancer, and 15% for breast cancer, compared with 27%, 11%, and 6%, respectively.

Interpretation

In this population-based cohort of 3241 adult survivors of childhood cancer followed for up to 29 years with comprehensive outcome assessments using administrative data, survivors at elevated risk for cardiomyopathy, breast cancer, or colorectal cancer spent a majority of time nonadherent to surveillance guideline recommendations. Although adherence to cardiomyopathy and colorectal cancer surveillance increased over time, adherence to breast cancer surveillance decreased.

These findings mirror the low proportions of adherence in the United States.[35] In Canada, health insurance is rarely a barrier to accessing surveillance, although indirect costs (e.g., time off work, travel) may affect test completion.[36,37] Earlier studies found that a lack of knowledge about late effects risks and surveillance recommendations among survivors,[38,39] family physicians,[40,41] and specialists[42] are substantial barriers to adherence. Our results support this: despite primary care physician visits,

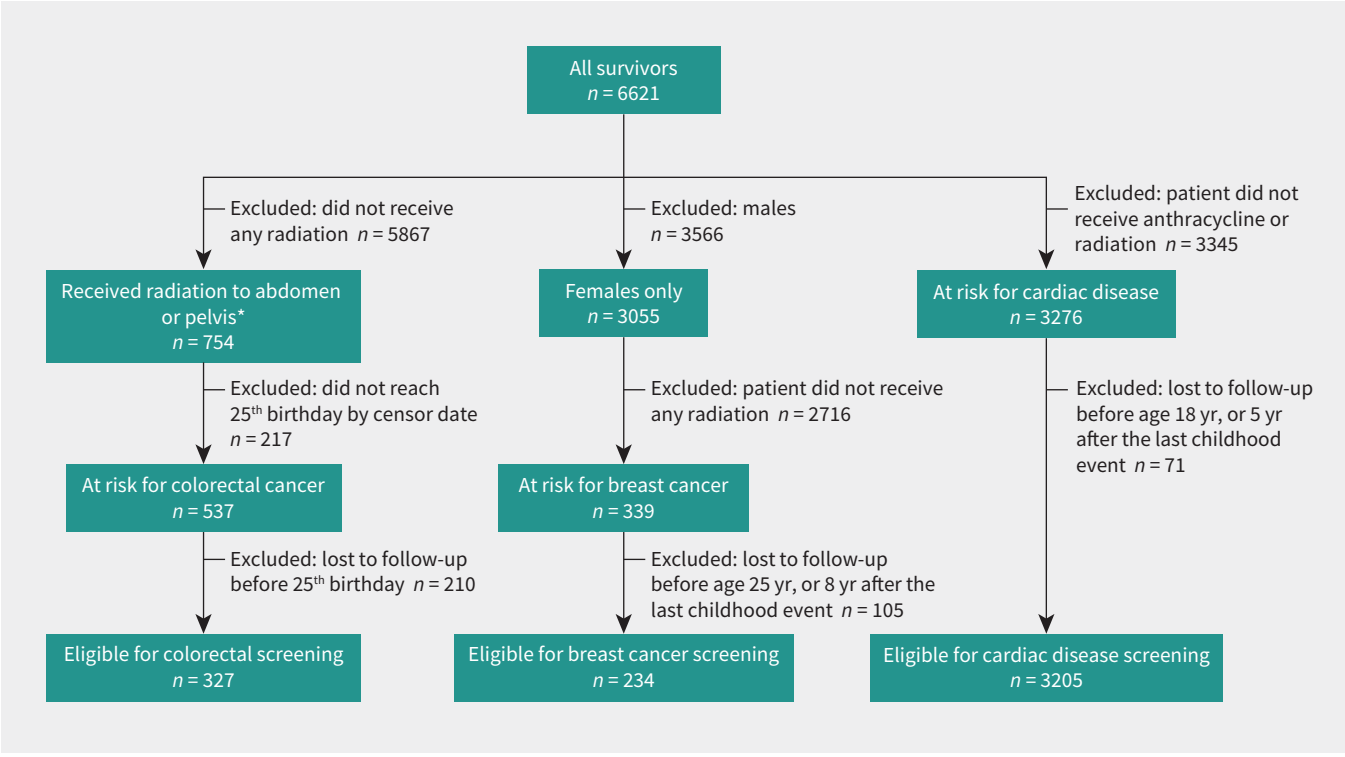

Figure 1: Flow chart for childhood cancer survivors at risk for colorectal cancer, breast cancer, and cardiac complications. Note: A survivor can be in more than 1 group, at risk for cardiac and colorectal cancer. *In earlier versions of the Children's Oncology Group Long-Term Follow-Up guidelines, only patients who received more than the specified amount of radiation were considered at risk for colorectal cancer. In the most recent version, there is no lower radiation dose limit.

Table 2: Distributions of baseline characteristics of high-risk survivors of childhood cancers by risk type, *n* = 3241

Characteristic	No. (%)* of survivors at risk of colorectal cancer *n* = 327	No. (%)* of survivors at risk of breast cancer *n* = 234	No. (%)* of survivors at risk of cardiomyopathy *n* = 3205
Age at first diagnosis, yr			
Median (IQR)	11 (6–14)	13 (8–15)	9 (4–13)
0–4	53 (16.2)	28 (12.0)	930 (29.0)
5–11	115 (35.2)	60 (25.6)	1094 (34.1)
12–18	159 (48.6)	146 (62.4)	1181 (36.8)
Sex			
Female	130 (39.8)	234 (100.0)	1377 (43.0)
Male	197 (60.2)	0 (0)	1828 (57)
Rurality and neighbourhood income			
Rural	33 (10.2)	23 (10.0)	366 (11.5)
Urban and income quintile 1	47 (14.6)	33 (14.3)	406 (12.8)
Urban and income quintile 2	51 (15.8)	41 (17.8)	529 (16.7)
Urban and income quintile 3	69 (21.4)	43 (18.7)	597 (18.8)
Urban and income quintile 4	50 (15.5)	34 (14.8)	593 (18.7)
Urban and income quintile 5	72 (22.4)	55 (23.9)	669 (21.1)
Missing	0 (0)	5 (0.4)	12 (0.4)
Diagnosis			
Leukemias	40 (12.2)	25 (10.7)	1402 (43.7)
Lymphomas	137 (41.9)	149 (63.7)	939 (29.3)
Central nervous system tumours	65 (19.9)	36 (15.4)	138 (4.3)
Solid tumours	80 (24.8)	15 (6.7)	749 (23.2)
Period of diagnosis			
1986–1996	243 (74.3)	117 (50.0)	1309 (40.8)
1997–2007	84 (25.7)	98 (41.9)	1418 (44.2)
2008–2014	0 (0)	19 (8.1)	478 (14.9)
Anthracycline dose†			
None	99 (30.3)	59 (25.2)	216 (6.7)
< 250 mg/m^2	152 (46.5)	136 (58.1)	2148 (67.0)
≥ 250 mg/m^2	76 (23.2)	39 (16.7)	841 (26.2)
Transplant			
Allogenic	25 (7.6)	18 (7.7)	179 (5.6)
Autologous	11 (3.4)	10 (4.3)	149 (4.6)
None	291 (89.0)	206 (88.0)	2877 (89.8)
Radiation			
Breast and abdomen or pelvis	255 (78.0)	151 (64.5)	491 (15.3)
Breast only	0 (0)	83 (35.5)	238 (7.4)
Abdomen or pelvis only	72 (22.0)	0 (0)	171 (5.3)
No radiation to any body region	0 (0)	0 (0)	2305 (71.9)
Follow-up time, yr			
Median (IQR)	1.41 (1.4–1.4)	1.95 (1.41–6.7)	9.33 (4.2–14.6)
Range	0–13.5	0.1–11.4	0.1–17.0
Total person-years contributed	601.8	959.5	29 915.1

Note: IQR = interquartile range.
*Unless otherwise specified. A survivor can be in more than 1 group.
†Doxorubicin equivalents.

survivors' adherence to breast and colorectal cancer surveillance guidance was low. Primary care physician visits were associated only with higher adherence to cardiomyopathy surveillance, although others have found an association with adherence to colorectal surveillance.[16] This may reflect practical barriers; compared with other surveillance tests, echocardiography is more readily available and less restrictive for primary care physicians in Ontario to arrange than a multitarget stool DNA test.

Across the surveillance tests, higher comorbidity was the most robust (rate ratio [RR] > 2) and consistent predictor of better adherence. In the general population, some studies have found higher adherence to cancer screening guidelines among those with self-reported poor health[43] and chronic illnesses,[44,45] but others have reported mixed results.[46] Perhaps survivors with greater morbidity and their medical teams are more motivated to conduct investigations. Rurality and

Table 3 (part 1 of 2): Proportion of high-risk childhood cancer survivors adherent on the last day of follow-up, by risk type (up to Feb. 28, 2020)*

Characteristic	Survivors at risk of colorectal cancer (%) *n* = 327	Survivors at risk of breast cancer (%) *n* = 234	Survivors at risk of cardiomyopathy (%) *n* = 3205
Overall	12.8	6.4	52.7
Age at first diagnosis, yr			
0–4	5.7	0	59.6
5–11	8.7	5.0	54.8
12–18	18.2	8.2	45.3
Age at end of follow-up, yr			
18–24	0	7.5	72.5
25–29	5.4	6.0	54.0
30–34	17.4	4.3	42.0
35–39	21.3	9.7	37.8
40–44	21.1	0	29.9
45–49	–	–	16.9
50–54	–	–	0
Sex			
Female	21.5	6.4	56.9
Male	7.1	NA	49.5
Rurality and neighbourhood income, end of follow-up			
Rural	6.7	0	54.8
Urban and income quintile 1	15.0	0	47.0
Urban and income quintile 2	14.3	8.8	55.5
Urban and income quintile 3	14.3	7.0	55.9
Urban and income quintile 4	16.4	7.3	51.5
Urban and income quintile 5	9.8	14.3	56.5
Diagnosis			
Leukemias	10.0	4.0	57.9
Lymphomas and neoplasms	16.1	8.1	49.6
Solid tumours and other categories	10.7	3.3	47.5
Period of diagnosis			
1986–1996	13.6	6.8	40.6
1997–2007	10.7	4.1	58.9
2008–2014	–	15.8	67.4
Anthracycline dose			
None	8.1	5.1	38.4
< 250 mg/m^2	15.1	5.9	54.8
≥ 250 mg/m^2	14.5	10.3	50.8

Table 3 (part 2 of 2): Proportion of high-risk childhood cancer survivors adherent on the last day of follow-up, by risk type (up to Feb. 28, 2020)*

Characteristic	Survivors at risk of colorectal cancer (%) *n* = 327	Survivors at risk of breast cancer (%) *n* = 234	Survivors at risk of cardiomyopathy (%) *n* = 3205
Transplant			
Allogenic	12.0	5.6	49.2
Autologous	9.1	0	46.3
None	13.1	6.8	53.2
Radiation			
Breast and abdomen or pelvis	13.3	6.6	39.9
Breast only		6.0	51.3
Abdomen or pelvis only	11.1	–	57.3
No radiation to any body region	–	–	55.2
ADG			
None	0	0	8.5
Low, 1–5	9.5	4.2	54.5
Intermediate, 6–9	15.3	8.0	62.0
High, ≥ 10	28.8	9.2	67.9
No. of primary care visits in the yr before end of follow-up			
No visits	1.9	3.5	35.2
1–3	17.2	3.7	59.0
≥ 4	18.5	10.6	60.2
LTFU clinic visit in the yr before end of follow-up			
No	9.2	5.8	39.3
Yes	30.4	8.1	85.5

Note: – = no survivors in these categories, ADG = Aggregated Diagnosis Groups, LTFU = long-term follow-up.
*A lookback period before the last day of follow-up assessed whether the survivor was adherent. We calculated rates by taking the number of patients who were adherent on the last day of follow-up divided by the total number of eligible survivors.

Table 4: Proportion of high-risk childhood cancer survivors adherent by risk type, over time (on the last day of follow-up or end of the year)*

		Colorectal cancer		Breast cancer		Breast cancer (mammography only)		Cardiomyopathy	
Lookback from	*N*	*n* eligible	Proportion adherent (95% CI)	*n* eligible	Proportion adherent (95% CI)	*n* eligible	Proportion adherent (95% CI)	*n* eligible	Proportion adherent (95% CI)
Dec. 31, 2005	1001	–	2.4 (0.1–13.6)	58	19.0 (9.5–33.9)	58	19.0 (9.5–33.9)	980	30.8 (27.4–34.5)
Dec. 31, 2010	1785	42	0 (0)	90	7.8 (3.1–16.0)	90	15.6 (8.5–26.1)	1741	39.2 (36.3–42.2)
Dec. 31, 2015	2544	–	11.9 (3.9–27.8)	125	10.4 (5.5–17.8)	125	16.0 (9.8–24.7)	2490	47.3 (44.7–50.1)
Dec. 31, 2019	3241	323	13.6 (9.9–18.3)	231	5.6 (3.0–9.62)	231	9.5 (6.0–14.4)	3205	53.0 (50.5–55.5)
Feb. 28, 2020	3241	327	12.8 (9.3–17.4)	234	6.4 (3.6–10.6)	234	9.8 (6.2–14.8)	3205	52.7 (50.2–55.2)
p value from Cochran–Armitage trend test			0.003		0.003		0.01		< 0.0001

Note: CI = confidence interval.
*A lookback period before the last day of follow-up assessed whether the survivor was adherent. We calculated proportions by taking the number of patients who were adherent on the last day of follow-up, divided by the total number of eligible survivors. We included data on patients before this date until they were taken out of the analysis, as described in the Methods.

Table 5 (part 1 of 2): Proportion of time that childhood cancer survivors spent adherent from Mar. 1, 2003, to Feb. 28, 2020, by risk type*

Characteristic	Colorectal cancer (%) *n* = 327	Breast cancer (%) *n* = 234	Cardiomyopathy (%) *n* = 3205
Overall	13.9	10.0	42.5
Age at first diagnosis, yr			
0–4	6.4	0	45.5
5–11	11.7	5.0	46.3
12–18	16.3	13.0	37.1
Current age, end of follow-up, yr			
18–24	0	6.2	72.9
25–29	6.6	10.8	56.4
30–34	17.3	2.9	41.2
35–39	17.6	25.6	29.4
40–44	13.1	3.7	20.1
45–49	–	–	16.0
50–54	–	–	0
Sex			
Female	20.9	10.1	46.4
Male	9.5	NA	39.6
Rurality and neighbourhood income			
Rural	16.3	6.0	42.8
Urban and income quintile 1	13.0	2.3	40.5
Urban and income quintile 2	16.1	11.4	45.0
Urban and income quintile 3	11.8	11.6	43.5
Urban and income quintile 4	18.5	15.3	43.7
Urban and income quintile 5	10.4	14.9	44.1
Missing	16.3	6.0	42.8
Diagnosis			
Leukemias	11.5	0.4	48.0
Lymphomas and neoplasms	11.8	14.4	41.0
Solid tumours (and other categories)	15.6	1.9	34.2
Period of diagnosis			
1986–1996	14.4	12.7	32.3
1997–2007	11.0	7.1	55.0
2008–2014	–	1.3	67.4
Anthracycline dose			
None	10.1	3.5	42.0
< 250 mg/m^2	13.2	14.3	45.8
≥ 250 mg/m^2	23.9	10.1	35.2

Table 5 (part 2 of 2): Proportion of time that childhood cancer survivors spent adherent from Mar. 1, 2003, to Feb. 28, 2020, by risk type*

Characteristic	Colorectal cancer (%) *n* = 327	Breast cancer (%) *n* = 234	Cardiomyopathy (%) *n* = 3205
Transplant			
Allogenic	13.7	0.5	38.9
Autologous	10.9	3.5	36.0
None	13.9	10.7	43.1
Radiation			
Breast and abdomen or pelvis	12.6	11.1	30.9
Breast only	–	8.0	43.2
Abdomen or pelvis only	18.9	–	41.9
No radiation to any body region	–	–	44.5
ADG			
None	0.7	1.3	16.8
Low	10.0	9.6	44.7
Intermediate	23.0	13.5	49.0
High	22.6	11.3	51.4
Median no. of primary care visits (in the previous yr) for every follow-up yr			
No visits	3.3	1.5	25.8
1–3	16.9	10.3	47.6
≥ 4	20.8	14.2	47.0
LTFU clinic visit (in the previous yr) for every follow-up yr			
No	10.5	6.5	27.2
Yes	26.7	15.0	71.5

Note: – = no survivors in this group, ADG = Aggregated Diagnosis Groups, LTFU = long-term follow-up, NA = not applicable.
*Proportion of time adherent was calculated by taking the total amount of time that a patient was adherent throughout the follow-up period and dividing by the total days of follow-up starting from when a patient started screening eligibility. Then the value was multiplied by 100 to obtain the final rate in person-days.

income quintile did not significantly predict colorectal and breast cancer surveillance adherence, but with small numbers, there may be undetected differences. For cardiomyopathy surveillance, CCS in the lowest income quintile had lower adherence (RR = 0.93, p = 0.02).

Long-term follow-up clinic attendance was a significant predictor of CCS completing cardiomyopathy surveillance. These specialized clinics often have access to surveillance tests and are staffed by physicians who are unlikely to be more familiar with surveillance recommendations for CCS than the general population of physicians.[18] Survivors who attend such clinics may also be more inclined to seek preventive care, driving higher surveillance rates. However, even survivors who

Table 6: Longitudinal adherence to colorectal cancer surveillance guidelines from Mar. 1, 2003, to Feb. 28, 2020, in 327 survivors of childhood cancer — univariable and multivariable rate ratios and 95% confidence intervals from generalized estimating equations Poisson regression*

Characteristic	Univariable RR (95% CI)	Multivariable RR (95% CI)
Age at diagnosis, yr	1.05 (0.99–1.12)	1.07 (1.01–1.14)
Sex		
Female v. male	2.75 (1.52–4.98)	1.86 (1.05–3.31)
Rurality and neighbourhood income		
Rural v. urban and income quintile 5	0.73 (0.24–2.24)	1 (0.33–3.04)
Urban and income quintile 1 v. urban and income quintile 5	1 (0.48–2.08)	1.25 (0.57–2.73)
Urban and income quintile 2 v. urban and income quintile 5	0.92 (0.47–1.78)	0.93 (0.47–1.83)
Urban and income quintile 3 v. urban and income quintile 5	0.85 (0.41–1.77)	0.94 (0.41–2.18)
Urban and income quintile 4 v. urban and income quintile 5	0.97 (0.47–2.01)	1.07 (0.51–2.21)
Period of diagnosis		
1997–2007 v. 1986–1996	0.76 (0.38–1.52)	–
2008–2014 v. 1986–1996	–	–
Anthracycline dose		
< 250 mg/m^2 v. none	1.39 (0.69–2.78)	1.2 (0.6–2.4)
≥ 250 mg/m^2 v. none	2.18 (1.04–4.58)	1.75 (0.89–3.45)
Transplant		
Allogenic v. none	1.03 (0.35–3.06)	–
Autologous v. none	0.79 (0.12–5.16)	–
Radiation		
No radiation to any body region v. breast and abdomen or pelvis	No patients in this category	–
Abdomen or pelvis only v. breast and abdomen or pelvis	1.21 (0.61–2.38)	–
Breast only v. breast and abdomen or pelvis	No patients in this category	–
ADG, categorical		
High v. none	10.72 (4.65–24.69)	8.58 (2.87–25.59)
Intermediate v. none	9.07 (4.47–18.39)	7.51 (2.99–18.88)
Low v. none	4.29 (1.9–9.66)	3.8 (1.6–9.05)
PCP visits in the past yr		
1–3 PCP visits v. no PCP visits	2.54 (1.42–4.53)	1.3 (0.59–2.85)
≥ 4 PCP visits v. no PCP visits	2.3 (1.09–4.86)	0.93 (0.33–2.63)
LTFU clinic visit in the past yr		
Yes v. no	2.01 (1.29–3.11)	1.33 (0.89–1.98)

Note: ADG = Aggregated Diagnosis Groups, CI = confidence interval, LTFU = long-term follow-up, PCP = primary care physician, RR = rate ratio.
*Age, sex, rurality, anthracycline dose, ADG, PCP visits in the past year.

attended a long-term follow-up clinic had generally poor adherence to all 3 surveillance guidelines. Long-term follow-up clinic physicians can recommend or order tests, but it is up to patients to complete them. Our study did not assess potential barriers to patients' ability to access screening.

Older age at diagnosis was associated with greater adherence to breast and colorectal surveillance, but the inverse was observed for cardiomyopathy surveillance. Perhaps survivors who receive a diagnosis at an older age are more aware of their cancer and are more motivated to complete surveillance. Although female sex was a predictor of greater adherence to cardiomyopathy and colorectal cancer surveillance, the literature is inconsistent regarding sex as a predictor for screening adherence.[35,46–48] A more recent period of diagnosis

Table 7: Longitudinal adherence to breast cancer surveillance guidelines from Mar. 1, 2003, to Feb. 28, 2020, for 234 survivors — univariable and multivariable rate ratios and 95% confidence intervals from Poisson regression*

Characteristic	Univariable RR (95% CI)	Multivariable RR (95% CI)
Age at diagnosis, yr	1.15 (1.05–1.25)	1.09 (1.01–1.18)
Rurality and neighbourhood income		
Rural v. urban and income quintile 5	1.02 (0.38–2.74)	0.85 (0.32–2.25)
Urban and income quintile 1 v. urban and income quintile 5	1.2 (0.51–2.81)	1.09 (0.54–2.23)
Urban and income quintile 2 v. urban and income quintile 5	1.01 (0.36–2.87)	0.95 (0.45–2.03)
Urban and income quintile 3 v. urban and income quintile 5	0.46 (0.14–1.54)	0.51 (0.23–1.13)
Urban and income quintile 4 v. urban and income quintile 5	0.65 (0.26–1.61)	0.59 (0.31–1.12)
Period of diagnosis		
1997–2007 v. 1986–1996	0.71 (0.33–1.52)	0.44 (0.23–0.85)
2008–2014 v. 1986–1996	0.14 (0.02–0.84)	0.09 (0.02–0.39)
Anthracycline dose		
< 250 mg/m^2 v. none	3.36 (0.96–11.73)	2.43 (0.72–8.17)
≥ 250 mg/m^2 v. none	2.8 (0.74–10.63)	2.15 (0.63–7.31)
Transplant		
Allogenic v. none	0.08 (0.01–0.6)	0.14 (0.02–1.18)
Autologous v. none	0.3 (0.08–1.15)	0.13 (0.04–0.41)
Radiation		
No radiation to any body region v. breast and abdomen or pelvis	No patients in this category	–
Abdomen or pelvis only vs breast and abdomen or pelvis	No patients in this category	–
Breast only v. breast and abdomen or pelvis	0.65 (0.31–1.38)	–
ADG, categorical		
High v. none	5.14 (1.5–17.67)	3.21 (1.25–8.25)
Intermediate v. none	5.91 (2.21–15.79)	3.82 (1.9–7.7)
Low v. none	4.52 (1.82–11.25)	2.63 (1.32–5.21)
PCP visits in the past yr		
1–3 PCP visits v. no PCP visits	1.35 (0.9–2.04)	1.15 (0.75–1.74)
≥ 4 PCP visits v. no PCP visits	1.11 (0.63–1.96)	0.95 (0.55–1.65)
LTFU clinic visit in the past yr		
Yes v. no	1.56 (0.66–3.68)	1.59 (0.88–2.89)

Note: ADG = Aggregated Diagnosis Groups, CI = confidence interval, LTFU = long-term follow-up, PCP = primary care physician, RR = rate ratio.
*Age, rurality, period of diagnosis, anthracycline dose, transplant, ADG, PCP visits in the past year, LTFU clinic visit.

was associated with greater adherence to breast and cardiomyopathy surveillance, perhaps because physicians are more aware of the Children's Oncology Group guidelines (first published in 2003).

The low surveillance rates we observed for colorectal cancer are consistent with findings from other at-risk populations.[47,49,50] Fear of bowel preparation is a substantial barrier.[50,51] Other surveillance approaches might be more acceptable to survivors.[52] The V5 guidelines suggest that a fecal immunochemical test is a reasonable alternative to colonoscopy, but it is generally not acceptable to high-risk patients.

Our research suggests that further work on rural residence and lower socioeconomic status as predictors of surveillance adherence can elucidate barriers to screening. There is also a need to evaluate the trade-offs in costs, accessibility, and usability of surveillance tests against accuracy in adult CCS. Our findings demonstrate a need to support patients and clinicians to improve adherence to surveillance guidelines among CCS. This responsibility must be shared between the cancer care system, particularly the provincial pediatric cancer survivor network, as well as the patients themselves, through advocacy and other survivor support groups.

Table 8: Longitudinal adherence — univariable and multivariable rate ratios and 95% confidence intervals from Poisson regression for adherence to cardiomyopathy surveillance guidelines from Mar. 1, 2003, to Feb. 28, 2020, for 3205 survivors*

Characteristic	Univariable RR (95% CI)	Multivariable RR (95% CI)
Age at diagnosis, yr	0.99 (0.98–0.99)	0.97 (0.96–0.97)
Sex		
Female v. male	1.09 (1.03–1.15)	1.03 (0.98–1.07)
Rurality and neighbourhood income		
Rural v. urban and income quintile 5	1.03 (0.97–1.1)	1.02 (0.96–1.09)
Urban and income quintile 1 v. urban and income quintile 5	0.91 (0.86–0.97)	0.93 (0.87–0.99)
Urban and income quintile 2 v. urban and income quintile 5	0.96 (0.91–1.01)	0.97 (0.91–1.02)
Urban and income quintile 3 v. urban and income quintile 5	0.98 (0.93–1.03)	0.98 (0.93–1.03)
Urban and income quintile 4 v. urban and income quintile 5	0.97 (0.92–1.01)	0.96 (0.92–1.01)
Period of diagnosis		
1997–2007 v. 1986–1996	1.79 (1.67–1.91)	1.64 (1.55–1.73)
2008–2014 v. 1986–1996	2.05 (1.9–2.2)	2.16 (2.01–2.32)
Anthracycline dose		
< 250 mg/m^2 v. none	1.52 (1.28–1.81)	0.96 (0.81–1.14)
≥ 250 mg/m^2 v. none	1.11 (0.93–1.34)	0.77 (0.65–0.92)
Transplant		
Allogenic v. none	0.93 (0.82–1.06)	0.99 (0.9–1.09)
Autologous v. none	0.82 (0.7–0.95)	0.9 (0.79–1.03)
Radiation and anthracycline		
Anthracycline only v. radiation only	1.86 (1.5–2.31)	1.97 (1.51–2.55)
Radiation and anthracycline v. radiation only	1.51 (1.21–1.88)	1.64 (1.26–2.15)
ADG		
High v. none	2.84 (2.62–3.06)	2.81 (2.53–3.12)
Intermediate v. none	2.65 (2.46–2.85)	2.63 (2.38–2.91)
Low v. none	2.34 (2.18–2.51)	2.38 (2.16–2.63)
PCP visits in the past yr		
1–3 PCP visits v. no PCP visits	1.16 (1.13–1.19)	1.04 (1.01–1.07)
≥ 4 PCP visits v. no PCP visits	1.22 (1.19–1.26)	1.05 (1.02–1.08)
LTFU clinic visit in the past yr		
Yes v. no	1.4 (1.36–1.44)	1.34 (1.3–1.37)

Note: ADG = Aggregated Diagnosis Groups, CI = confidence interval, LTFU = long-term follow-up, PCP = primary care physician, RR = rate ratio.
*Age, sex, rurality, period of diagnosis, anthracycline dose, transplant, radiation and anthracycline, ADG, PCP visits in the past year, LTFU visit.

Limitations

We examined survivors in a province with survivorship clinics and publicly funded health insurance, which may affect generalizability to other jurisdictions. However, other jurisdictions may have even more barriers to obtaining recommended testing, so these poor adherence proportions may represent best-case scenarios. Importantly, we derived outcomes from administrative data instead of direct patient assessment. They do not capture CCS who emigrated out of the province or the purpose of a test (surveillance or diagnostic). Survivors of childhood cancer who turned 18 years old before 2018 were not discharged from pediatric care with knowledge of the updated guidelines, complicating their ability to adhere to the most recent guidelines. Also, other methods are possible for surveillance (e.g., ultrasound for breast cancer screening), but would not be guideline adherent.

Finally, young adults may avoid or disengage from the health care system owing to the trauma of their cancer experience;[21,53,54] administrative databases cannot capture such factors.

Conclusion

Surveillance for late effects in adult survivors of childhood cancer is poor, placing many survivors at risk for preventable harm. To increase surveillance among this elevated-risk population,

screening recommendations need to consider and address barriers to completing surveillance tests. Surveillance approaches that meet the needs of survivors and their physicians are important to help CCS stay healthy in adulthood.

References

1. Lipshultz SE, Adams MJ, Colan SD, et al.; American Heart Association Congenital Heart Defects Committee of the Council on Cardiovascular Disease in the Young, Council on Basic Cardiovascular Sciences, Council on Cardiovascular and Stroke Nursing, Council on Cardiovascular Radiology and Intervention, Council on Clinical Cardiology, Council on Epidemiology and Prevention, and Council on Nutrition, Physical Activity and Metabolism. Long-term cardiovascular toxicity in children, adolescents, and young adults who receive cancer therapy: pathophysiology, course, monitoring, management, prevention, and research directions: a scientific statement from the American Heart Association. *Circulation* 2013;128:1927-95.
2. Hudson MM, Ness KK, Gurney JG, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA* 2013;309:2371-81.
3. Bhatia S, Yasui Y, Robison LL, et al.; Late Effects Study Group. High risk of subsequent neoplasms continues with extended follow-up of childhood Hodgkin's disease: report from the Late Effects Study Group. *J Clin Oncol* 2003;21:4386-94.
4. Jenkinson HC, Hawkins M, Stiller C, et al. Long-term population-based risks of second malignant neoplasms after childhood cancer in Britain. *Br J Cancer* 2004;91:1905-10.
5. Meadows AT, Friedman DL, Neglia JP, et al. Second neoplasms in survivors of childhood cancer: findings from the childhood cancer survivor study cohort. *J Clin Oncol* 2009;27:2356-62.
6. Moskowitz CS, Chou JF, Wolden SL, et al. Breast cancer after chest radiation therapy for childhood cancer. *J Clin Oncol* 2014;32:2217-23.
7. Teepen JC, Kok JL, van Leeuwen FE, et al.; DCOG-LATER Study Group. Colorectal adenomas and cancers after childhood cancer treatment: a DCOG-LATER record linkage study. *J Natl Cancer Inst* 2018;110:758-67.
8. Nathan PC, Ness KK, Hudson MM, et al. Cancer screening in adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study (CCSS). *J Clin Oncol* 2009;27(Suppl):CRA6501.
9. Hodgson DC, Cotton C, Crystal P, et al. Impact of early breast cancer screening on mortality among young survivors of childhood Hodgkin's lymphoma. *J Natl Cancer Inst* 2016;108. doi: 10.1093/jnci/djw010.
10. *Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers*. Version 5.0. Children's Oncology Group; 2018:1-232.
11. Mulder RL, Hudson MM, Bhatia S, et al. Updated breast cancer surveillance recommendations for female survivors of childhood, adolescent, and young adult cancer from the International Guideline Harmonization Group. *J Clin Oncol* 2020;38:4194-207.
12. Wong FL, Bhatia S, Landier W, et al. Cost-effectiveness of the children's oncology group long-term follow-up screening guidelines for childhood cancer survivors at risk for treatment-related heart failure. *Ann Intern Med* 2014;160:672-83.
13. Yeazel MW, Oeffinger KC, Gurney JG, et al. The cancer screening practices of adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Cancer* 2004;100:631-40.
14. Nathan PC, Ness KK, Mahoney MC, et al. Screening and surveillance for second malignant neoplasms in adult survivors of childhood cancer: a report from the childhood cancer survivor study. *Ann Intern Med* 2010;153:442-51.
15. Oeffinger KC, Ford JS, Moskowitz CS, et al. Breast cancer surveillance practices among women previously treated with chest radiation for a childhood cancer. *JAMA* 2009;301:404-14.
16. Daniel CL, Kohler CL, Stratton KL, et al. Predictors of colorectal cancer surveillance among survivors of childhood cancer treated with radiation: a report from the Childhood Cancer Survivor Study. *Cancer* 2015;121:1856-63.
17. Yan AP, Chen Y, Henderson TO, et al. Adherence to surveillance for second malignant neoplasms and cardiac dysfunction in childhood cancer survivors: a Childhood Cancer Survivor Study. *J Clin Oncol* 2020;38:1711-22.
18. Casillas J, Oeffinger KC, Hudson MM, et al. Identifying predictors of longitudinal decline in the level of medical care received by adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Health Serv Res* 2015;50:1021-42.
19. Kagramanov D, Sutradhar R, Lau C, et al. Impact of the model of long-term follow-up care on adherence to guideline-recommended surveillance among survivors of adolescent and young adult cancers. *Cancer Med* 2021;10:5078-87.
20. Nathan PC, Ford JS, Henderson TO, et al. Health behaviors, medical care, and interventions to promote healthy living in the Childhood Cancer Survivor Study cohort. *J Clin Oncol* 2009;27:2363-73.
21. Nathan PC, Agha M, Pole JD, et al. Predictors of attendance at specialized survivor clinics in a population-based cohort of adult survivors of childhood cancer. *J Cancer Surviv* 2016;10:611-8.
22. Greenberg ML, Barr RD, DiMonte B, et al. Childhood cancer registries in Ontario, Canada: lessons learned from a comparison of two registries. *Int J Cancer* 2003;105:88-91.
23. Williams JI, Young W. Appendix 1: A summary of studies on the quality of health care administrative databases in Canada. In: Goel V, Williams JI, Anderson GM, et al. *The ICES Practice Atlas, 2nd Edition — Patterns of Health Care in Ontario*. Ottawa: Canadian Medical Association; 1996:339-45.
24. *Low income cut-offs for 2005 and low income measures for 2004*. Cat. no. 75F0002MIE — No. 004. Ottawa: Statistics Canada, 2006.
25. Dossa F, Metcalfe K, Sutradhar R, et al. Building the What Comes Next Cohort for *BRCA1* and *BRCA2* testing: a descriptive analysis. *CMAJ Open* 2021;9:E874-85.
26. Baliunas D, Selby P, de Oliveira C, et al. Primary care-based smoking cessation treatment and subsequent healthcare service utilisation: a matched cohort study of smokers using linked administrative healthcare data. *Tob Control* 2023;32:72-9.
27. Paszat LF, Sutradhar R, Gu S, et al. Annual surveillance mammography after early-stage breast cancer and breast cancer mortality. *Curr Oncol* 2016;23:e538-45.
28. Gupta S, Li Q, Kassam A, et al. Specialty palliative care and symptom severity and control in adolescents and young adults with cancer. *JAMA Netw Open* 2023;6:e2338699. doi: 10.1001/jamanetworkopen.2023.38699.
29. Weiner JP, Starfield BH, Steinwachs DM, et al. Development and application of a population-oriented measure of ambulatory care case-mix. *Med Care* 1991;29:452-72.
30. Weiner JP, Abrams C, Bodycombe D. *The Johns Hopkins ACG case-mix system*. Version 6.0 release notes. Baltimore: Johns Hopkins Bloomberg School of Public Health; 2003.
31. *The Johns Hopkins ACG System: excerpt from technical reference guide*. Baltimore: John Hopkins University; 2009.
32. Wong FL, Lee JM, Leisenring WM, et al. Health benefits and cost effectiveness of children's oncology group breast cancer screening guidelines for chest-irradiated Hodgkin lymphoma survivors. *J Clin Oncol* 2023;41:1046-58.
33. Pruitt SL, Shim MJ, Mullen PD, et al. Association of area socioeconomic status and breast, cervical, and colorectal cancer screening: a systematic review. *Cancer Epidemiol Biomarkers Prev* 2009;18:2579-99.
34. Ioannou GN, Chapko MK, Dominitz JA. Predictors of colorectal cancer screening participation in the United States. *Am J Gastroenterol* 2003;98:2082-91.
35. Yan AP, Chen Y, Henderson TO, et al. Adherence to surveillance for second malignant neoplasms and cardiac dysfunction in childhood cancer survivors: a childhood cancer survivor study. *J Clin Oncol* 2020;38:1711-22.
36. Katz SJ, Hofer TP. Socioeconomic disparities in preventive care persist despite universal coverage: breast and cervical cancer screening in Ontario and the United States. *JAMA* 1994;272:530-4.
37. Lofters AK, Kopp A, Vahabi M, et al. Understanding those overdue for cancer screening by five years or more: a retrospective cohort study in Ontario, Canada. *Prev Med* 2019;129:105816.
38. Cherven B, Mertens A, Meacham LR, et al. Knowledge and risk perception of late effects among childhood cancer survivors and parents before and after visiting a childhood cancer survivor clinic. *J Pediatr Oncol Nurs* 2014;31:339-49.
39. Kadan-Lottick NS, Robison LL, Gurney JG, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *JAMA* 2002;287:1832-9.
40. Henderson TO, Friedman DL, Meadows AT. Childhood cancer survivors: transition to adult-focused risk-based care. *Pediatrics* 2010;126:129-36.
41. Nathan PC, Daugherty CK, Wroblewski KE, et al. Family physician preferences and knowledge gaps regarding the care of adolescent and young adult survivors of childhood cancer. *J Cancer Surviv* 2013;7:275-82.
42. Eshelman-Kent D, Kinahan KE, Hobbie W, et al. Cancer survivorship practices, services, and delivery: a report from the Children's Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees. *J Cancer Surviv* 2011;5:345-57.
43. Singh H, Bernstein CN, Samadder JN, et al. Screening rates for colorectal cancer in Canada: a cross-sectional study. *CMAJ Open* 2015;3:E149-57.
44. Ruffin MT, Gorenflo DW, Woodman B. Predictors of screening for breast, cervical, colorectal, and prostatic cancer among community-based primary care practices. *J Am Board Fam Pract* 2000;13:1-10.
45. Richard A, Rohrmann S, Schmid SM, et al. Lifestyle and health-related predictors of cervical cancer screening attendance in a Swiss population-based study. *Cancer Epidemiol* 2015;39:870-6.
46. Wools A, Dapper E, de Leeuw JRJ. Colorectal cancer screening participation: a systematic review. *Eur J Public Health* 2016;26:158-68.
47. Subramanian S, Klosterman M, Amonkar MM, et al. Adherence with colorectal cancer screening guidelines: a review. *Prev Med* 2004;38:536-50.
48. Daskalakis C, DiCarlo M, Hegarty S, et al. Predictors of overall and test-specific colorectal cancer screening adherence. *Prev Med* 2020 Feb. 8 [Epub ahead of print];133:106022. doi: 10.1016/j.ypmed.2020.106022.

49. Bujanda L, Sarasqueta C, Zubiaurre L, et al.; EPICOLON Group. Low adherence to colonoscopy in the screening of first-degree relatives of patients with colorectal cancer. *Gut* 2007;56:1714-8.
50. Denberg TD, Melhado TV, Coombes JM, et al. Predictors of nonadherence to screening colonoscopy. *J Gen Intern Med* 2005;20:989-95.
51. Jones RM, Devers KJ, Kuzel AJ, et al. Patient-reported barriers to colorectal cancer screening: a mixed-methods analysis. *Am J Prev Med* 2010;38: 508-16.
52. Quintero E, Castells A, Bujanda L, et al.; COLONPREV Study Investigators. Colonoscopy versus fecal immunochemical testing in colorectal-cancer screening. *N Engl J Med* 2012;366:697-706.
53. Hobbie WL, Stuber M, Meeske K, et al. Symptoms of posttraumatic stress in young adult survivors of childhood cancer. *J Clin Oncol* 2000;18:4060-6.
54. Zeltzer LK, Recklitis C, Buchbinder D, et al. Psychological status in childhood cancer survivors: a report from the Childhood Cancer Survivor Study. *J Clin Oncol* 2009;27:2396-404.

Competing interests: Jennifer Shuldiner reports receiving a Canadian Institutes of Health Research (CIHR) Health System Impact Postdoctoral Fellowship, in support of the current manuscript. Noah Ivers is supported by a CIHR Tier 2 Canada Research Chair in Implementation of Evidence-based Practice (paid to institution). Paul Nathan is supported by a CIHR Foundation Grant and a grant from the United States Department of Defense (both paid to institution). No other competing interests were declared.

This article has been peer reviewed.

Affiliations: Women's College Hospital Institute for Health System Solutions and Virtual Care (Shuldiner, Ivers), Women's College Hospital; ICES Central (Sutradhar, Lau); the Hospital for Sick Children Research Institute (Shah, Lam, Nathan); Institute of Health Policy, Management and Evaluation (Ivers, Nathan), and Department of Family and Community Medicine (Ivers), University of Toronto; Division of Hematology/Oncology (Nathan), The Hospital for Sick Children, Toronto, Ont.

Contributors: Jennifer Shuldiner, Paul Nathan, and Noah Ivers contributed to the conception and design of the work. Rinku Sutradhar and Cindy Lau acquired the data. Paul Nathan, Noah Ivers, Rinku Sutradhar, Cindy Lau, Nida Shah, and Emily Lam contributed to the analysis and interpretation of data. Jennifer Shuldiner drafted the manuscript. All of the authors revised the manuscript critically for important intellectual content, gave final approval of the version to be published, and agreed to be accountable for all aspects of the work.

Funding: This study was supported by ICES, which is funded by an annual grant from the Ontario Ministry of Health (MOH) and the Ministry of Long-Term Care. This study also received funding from the Canadian Institutes of Health Research. Parts of this material are based on data and information compiled and provided by the Ontario MOH. The analyses, conclusions, opinions, and statements expressed herein are solely those of the authors and do not reflect those of the funding or data sources; no endorsement is intended or should be inferred. This research was facilitated by the Pediatric Oncology Group of Ontario's Networked Information System, financially supported by Ontario's Ministry of Health and Long-Term Care.

Data sharing: The data set from this study is held securely in coded form at ICES. While legal data-sharing agreements between ICES and data providers (e.g., health care organizations and government) prohibit ICES from making the data set publicly available, access may be granted to those who meet prespecified criteria for confidential access, available at https://www.ices.on.ca/DAS (email: das@ices.on.ca). The full data set creation plan and underlying analytic code are available from the authors upon request, understanding that the computer programs may rely upon coding templates or macros that are unique to ICES and are therefore either inaccessible or may require modification.

Accepted: Jan. 24, 2024

Correspondence to: Jennifer Shuldiner, Jennifer.Shuldiner@wchospital.ca