Receipt of cancer treatment summaries and follow-up instructions among adult cancer survivors: results from a national survey

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Abstract

Purpose—The purpose of this study is to examine reporting of treatment summaries and follow-up instructions among cancer survivors.

Methods—Using the 2010 National Health Interview Survey, we created logistic regression models among cancer survivors not in treatment (n= 1,345) to determine characteristics associated with reporting treatment summaries and written follow-up instructions, adjusting for

sociodemographic, access, and cancer-related factors. Findings are presented for all survivors and those recently diagnosed (4 years). We also examined unadjusted associations between written instructions and subsequent surveillance and screening.

Results—Among those recently diagnosed, 38 % reported receiving treatment summaries and 58 % reported written instructions. Among all survivors, approximately one third reported summaries and 44 % reported written instructions. After adjustment, lower reporting of summaries was associated with cancer site, race, and number of treatment modalities among those recently diagnosed, and white vs. black or Hispanic race/ethnicity, breast vs. colorectal cancer, >10 vs. 5 years since diagnosis, no clinical trials participation, and better than fair health among all survivors. For instructions, lower reporting was associated with no trials participation and lower income among those recently diagnosed, and increasing age, white vs. black race, lower income, >10 vs. 5 years since diagnosis, 1 vs. 2 treatment modalities, no trials participation, and at least good vs. fair/poor health among all survivors. Written instructions were associated with reporting provider recommendations for breast and cervical cancer surveillance, and recent screening mammograms.

Conclusion—Many recently diagnosed cancer survivors did not report receiving treatment summaries and written follow-up instructions. Opportunities exist to examine associations between use of these documents and recommended care and outcomes, and to facilitate their adoption.

Implications for cancer survivors—Cancer survivors who have completed therapy should ask their providers for treatment summaries and written follow-up instructions, and discuss with them how their cancer and therapy impact their future health care.

Introduction

The cancer survivor population is large and growing with nearly 12 million U.S. adult cancer survivors [1, 2]. As survivors live longer, increasing attention has focused on long-term care. Survivors are at risk for recurrence, second primary cancers [3], and late and long-term effects of cancer and treatment [4]. Because health risks vary, individualized risk assessment and management is needed [5].

Health problems among survivors may not develop for years [6, 7]. Given concerns about the sustainability of the cancer specialist workforce providing long-term follow-up care [8, 9], and that follow-up may be provided by primary care providers (PCPs) [10, 11], coordinated care is important [5, 12]. However, there may be suboptimal communication between PCPs and oncologists [13, 14], who may have discordant perceptions of their roles [15], leaving some PCPs with inadequate knowledge of survivors' health history and risks [16], and many survivors unsure which provider is in charge of their follow-up care [17].

A recent Institute of Medicine (IOM) report noted that many survivors get lost to follow-up during the transition from active treatment to posttreatment care [12]. In response,

survivorship care plans have been developed to summarize cancer and treatment history, needed screening, surveillance and preventive care, and specify providers responsible for follow-up [5, 12, 18]. Treatment summaries and written follow-up instructions are recommended care plan components [12, 19]. Care plans are recommended or supported by many expert organizations [12, 19, 20], with delivery of treatment summaries, a key component of plans, endorsed by the American Society of Clinical Oncology (http://qopi.asco.org/Documents/QOPISpring2011MeasuresSummary_000.pdf), the Physician Consortium for Performance Improvement (http://www.ama-assn.org/ama/pub/physician-resources/clinical-practice-improvement/clinical-quality/physician-consortium-performance-improvement/pcpi-measures.page), and the Commission on Cancer (http://www.facs.org/cancer/coc/programstandards2012.html). However, little is known about how frequently plans are used among adult cancer survivors, and national estimates of care plan use are lacking.

National estimates would provide information about current care plan use and which survivors are least likely to receive plans. This information would be valuable to cancer clinicians, survivors, and decision makers in raising awareness about delivering care plans and survivors' long-term care needs. This information would also be useful to researchers and others in evaluating the impact of plans on morbidity and mortality, developing interventions to promote care plan use, and identifying a national baseline for future monitoring. We examined the extent to which survivors of adult-onset cancers report having received treatment summaries and follow-up instructions, variations in receipt, and whether follow-up instructions are associated with subsequent care. We present findings for those diagnosed within 4 years, who were diagnosed after the release of reports in 2004–2005 calling for delivery of these documents to survivors (http://www.nap.edu/catalog.php?record_id=11468) [12, 19]. We also separately present findings for all survivors. Although many survivors in this group were diagnosed prior to release of these reports and therefore may not have been expected to have received these documents, findings among all survivors may identify groups who may benefit and/or whose providers may benefit from further education about their treatment history and future care needs.

Methods

We used data from the 2010 National Health Interview Survey (NHIS) [21], a nationally representative sample of the civilian, non-institutionalized U.S. population. NHIS is an annual survey administered by the Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS) through in-person interviews. The final sample adult response rate was 60.8 % [21].

Our sample included adult cancer survivors (*n*=2,333), except those whose most recent cancer was non-melanoma skin cancer, skin cancer of uncertain type, or unknown type (*n*=549); who were in active treatment (*n*=108); did not report treatment (*n*=98); and had unknown information about whether treatment was received (*n*=173) or active (*n*=14). Because our focus was on survivors of adult-onset cancers, we also excluded 46 respondents whose age at diagnosis was before age 18 or unknown.

Primary dependent variables included self-reported receipt of a treatment summary and follow-up instruction as determined by: "At the completion of your cancer treatment(s), did your doctor give you a single written document describing ALL the treatments you actually received? This would NOT include general pamphlets about cancer treatments or individual lab results" and "Have you EVER received advice from a doctor, nurse, or other health care professional about where you should return or who you should see for routine cancer check-ups after completing treatment for cancer? Not including appointment cards or reminders, was this information written down, printed on paper, or provided in an electronic format for you?" We categorized follow-up instructions as written/textual, unwritten or none. We categorized written and unwritten instructions separately because the IOM report indicates that such information should be provided to survivors in a written format [12]. Other dependent variables included use of recent surveillance to monitor for recurrence, other cancer screening, provider recommendations for surveillance and screening, and having a usual provider.

Surveillance and screening definitions were based on National Comprehensive Cancer Network guidelines (www.nccn.org) and U.S. Preventive Services Task Force recommendations (http://www.uspreventiveservicestaskforce.org/recommendations.htm), respectively (Table 1). To examine associations of instructions with subsequent cancer screening, we excluded screening tests prior to diagnosis and limited analyses to survivors 1 year post-diagnosis. We did not report lung cancer surveillance or provider recommendations for colorectal cancer surveillance because of small cell sizes and/or large relative standard errors. For provider recommendations, NHIS respondents aged 40 with no recent colorectal cancer test were asked whether a healthcare provider recommended one within the prior year. Provider recommendation questions for Pap and mammography pertained to the prior year and were asked of respondents who did and did not report receiving recent tests.

Independent variables included age, sex, race/ethnicity, education, income measured as percentage of federal poverty thresholds (FPL), insurance, health status, clinical trial participation, and cancer site, age at diagnosis, time since diagnosis, number of treatment modalities received, and recency of treatment for the most recent cancer. Insurance was categorized as any private or military insurance ("private"), public insurance only, and no insurance or only single service plan coverage (n=3, all excluded cancer care). For time since diagnosis, we subtracted age at diagnosis from age at interview. Treatments included surgery, radiation, chemotherapy, hormonal treatments, bone marrow/stem cell transplants or other. Because NHIS inquired about receipt of summaries of *all* treatments received, we categorized treatment by number of modalities. Treatment recency included whether non-hormonal treatments were received within 1 year.

To examine the proportion of survivors who report having received these documents among those diagnosed after recommendations for their use were issued, we present findings for those diagnosed within 4 years. To examine the proportion of all survivors who report not having received these documents and may benefit from additional information about their treatment history and future care needs, we separately present findings for all survivors. Pearson chi-square tests were used to test differences in weighted percentages. Multivariable

logistic regression models were created to determine characteristics independently associated with reporting treatment summaries and written follow-up instructions. The linearity assumption for continuous predictors (age and income) was assessed using restricted cubic spline functions [22]. Relationships with each outcome were linear. P values reflect simultaneously testing that all regression coefficients for a given variable equal zero.

NCHS imputes missing data for income using multiple imputation [21]. Missing data for time since diagnosis were multiply imputed (five imputations) using the aregImpute function from the Hmisc [23] package in R [24]. Of 74 survivors with incomplete time since diagnosis due to age truncation in NHIS or missing data, 52 had minimum times available. Partial timing information was used in imputation with imputed values defined as the maximum of observed minimum times since diagnosis and predicted times from the imputation. All independent variables, outcome variables, and sampling weights were included in the imputation. We weighted all statistics and used SUDAAN version 10.0.1 (Research Triangle Institute, Research Triangle Park, NC) and SAS version 9.2 (SAS Institute Inc, Cary, NC) to account for the complex survey design.

Results

Of 1,345 survivors, 52 % were younger than 65 (range, 20–85+; Table 2). Most were female, white, privately insured, and had at least some college education. Breast cancer survivors predominated. Approximately 40 % reported diagnosis ≤5 or >10 years prior. Most survivors reported one treatment modality, no recent treatments, no clinical trials participation, and at least good health.

Among recently diagnosed survivors (within 4 years), 29.4 % reported receiving both treatment summaries and written follow-up instructions and 33.1 % reported neither. Among all survivors, 22 % reported receiving both documents, while 45 % reported neither. Among those recently diagnosed, 38 % reported summaries, and no factors in unadjusted analyses were significantly associated with recalling having received a treatment summary, although findings by cancer site were of borderline significance (p=.059; Table 3). Among all survivors, 32 % reported receiving treatment summaries. Survivors with age ≥80, white race, cancers other than prostate, colorectal or cervical, diagnosis >10 years prior, no trials participation, and better than fair health status were less likely to report summaries than survivors with age 50–64 years, black race or Hispanic ethnicity, prostate or colorectal cancer, diagnosis within 5 years, trials participation, and fair/poor health status, respectively.

Written follow-up instructions were reported by 58 % of recently diagnosed survivors (Table 4). In this group, those who did not participate in clinical trials were less likely to report written instructions. Among all survivors, 44 % reported receiving written follow-up instructions. Survivors with age ≥80 years, white race, no college education, income <250 % FPL, no insurance, diagnosis >10 years prior, no recent treatment, and no trials participation were less likely to report written instructions than those with age <80, black race, at least some college, income ≥400 % FPL, private insurance, diagnosis within 10 years, recent treatment, and trial participation, respectively. Uterine cancer survivors were least likely to report written instructions (<20 vs. >50 % of prostate or colorectal cancer survivors).

Survivors reporting one treatment modality were more likely to report not having received any follow-up instructions. Among survivors with age 80, no insurance, uterine cancer, or diagnosis >10 years prior, 40–50 % reported no instructions at all.

After adjustment, race/ethnicity, cancer site, and number of treatment modalities were significantly associated with reporting having received treatment summaries among those recently diagnosed (Table 5). Black survivors were more likely than white survivors and colorectal cancer survivors were more likely than breast cancer survivors to report having received a summary. More than one treatment modality was associated with a lower likelihood of reporting a summary than one modality. Among all survivors, differences between colorectal and breast cancer survivors, and by race, time since diagnosis, clinical trial participation, and health status retained significance after adjustment.

For written instructions, after controlling for other factors, clinical trials participation was a strong predictor of reporting having received written instructions among recently diagnosed survivors. Income also achieved significance, with higher income survivors more likely to report written instructions. Among all survivors, lower reported receipt was associated with increasing age, white vs. black race, decreasing income, >10 vs. 5 years since diagnosis, one treatment modality, no clinical trials participation, and better than fair vs. fair/poor health.

Written instructions were associated with reporting recent provider recommendations for breast and cervical cancer surveillance, although not test use (Table 6). For prostate cancer, unwritten instructions were associated with greater PSA surveillance. For screening, written instructions were associated with recent mammography use.

Discussion

Major reports recommending that providers deliver treatment summaries and written follow-up instructions to cancer survivors upon completion of treatment were released in 2004–2005 (http://www.nap.edu/catalog.php?record_id=11468) [12, 19]. Our analysis of survivors diagnosed after that time suggests that reported receipt of these documents was low with 40–60 % not reporting having received them. Not surprisingly, when examining all survivors, including those diagnosed before issuance of these reports, rates were even lower. Findings for the full sample are important however, not necessarily as a measure of quality of care, since most of this group was diagnosed prior to release of these reports, but rather as a baseline measure and an indication of the proportion of survivors who might benefit from additional information about their diagnosis, treatment history, and future care needs. More than one quarter of survivors did not recall any follow-up instructions, including 40–50 % of the oldest survivors, those uninsured, diagnosed >10 years prior, or surviving uterine cancer. This is important given many survivors are unsure who manages their follow-up [17], are insufficiently aware of their continuing health risks [25, 26], and may lack regular follow-up for possible late effects and recommended services [25, 27–29]. We are unaware of previous national estimates of these measures. Findings for these documents are consistent with reports and assertions that care plans and treatment summaries are not implemented widely [5, 30], and with gaps reported by survivors regarding treatment information received [30].

Some survivors were less likely to report receiving these documents, including those with no clinical trials participation or diagnosed >10 years prior. This is not surprising given the recent emergence of care plans and attention to treatment summaries, and the increased documentation and healthcare system contact with clinical trials. However, findings indicate that these groups and providers delivering their long-term care may need further education about their treatment history and best course of follow-up. Greater reported receipt of treatment summaries by colorectal vs. breast cancer survivors both overall and among those recently diagnosed is somewhat surprising given the relatively early promotion of breast cancer care plan templates. Potential contributing factors might include differences in treatment modalities, facilities, or providers. Breast cancer survivors were more likely to report receiving radiation (44 vs. 19 %), hormonal treatments (26 vs. <1 %), and chemotherapy (39 vs. 33 %). Racial/ethnic differences in reporting treatment summaries also existed in both groups of survivors, even after adjusting for socioeconomic and cancer-related factors. It is not clear why this is the case. Potential factors that may contribute in part to such differences could include differences in healthcare settings or systems [31, 32], comorbidity burden [32], or interpretation of or response to survey questions. Confirmation of these findings is needed. A lower likelihood of reporting treatment summaries among those with more than one treatment modality could reflect more difficulty compiling treatment history for those who received different forms of treatment from multiple providers.

For follow-up instructions, we examined written instructions separately because the IOM report states instructions should be in writing [12]. Among recently diagnosed survivors, increasing income was associated with likelihood of reporting having received written instructions, and clinical trials participation was a strong predictor of reporting written instructions. Although reporting written instructions was greater among survivors diagnosed <4 vs. >4 years for both trials, participants and non-participants, differences by participation were greater for recently diagnosed survivors (not shown). Among all survivors, age, race, time since diagnosis, number of treatment modalities, and health status were associated with reporting of written instructions in addition to income and trials participation. Decreased life expectancy among older survivors may prompt discontinuation of surveillance and screening, leading to less detailed follow-up planning. However, some older survivors were likely diagnosed at younger ages when life expectancy was longer. Greater recall for those in fair/poor health may reflect increased healthcare system contact.

Studies examining the impact of these documents are few given the nascency of research in this area [8, 33]. The IOM concluded that care plans "have strong face validity and can reasonably be assumed to improve care unless and until evidence accumulates to the contrary" [12]. Among childhood Hodgkin's lymphoma survivors, care plans may lead to completion of recommended surveillance [34]. We found that written follow-up instructions may be more highly associated with some recommended surveillance than screening, most notably provider surveillance recommendations. Except for prostate cancer surveillance, compared with no instructions significant increases in recommending or completing surveillance or screening were driven by written rather than unwritten instructions. However, findings for surveillance and screening were based on small numbers and unadjusted, so confirmation is needed.

Study limitations include that NHIS data are self-reported and do not necessarily reflect actual document delivery. Inquiring about treatment summaries and follow-up instruction may not reflect use of comprehensive survivorship care plans. Recall may be an issue, particularly for survivors farther from diagnosis, and interpretation of findings for those diagnosed more than 4 years prior should consider that recommendations for use of these documents were not in place at that time. However, findings may indicate survivors and their providers who may benefit from additional information about their history and future recommended care. NHIS does not provide information about stage at diagnosis. Thus, it is possible that patients with metastatic disease could be in our sample. However, in order to focus our analysis on survivors not undergoing cancer treatment, we excluded survivors actively receiving treatment for whom treatment summaries and follow-up instructions may have been inappropriate. Furthermore, approximately 90 % of survivors reported being > 1 year beyond completion of treatment. These factors likely reduce the chance that such patients were included. Our sample also may not reflect all cancer survivors. Compared with U.S. prevalence data [2], a smaller proportion of our sample was older than 65 (60 vs. 47 %), male (46 vs. 41 %), or had prostate cancer (19 vs. 14 %), and more reported cervical cancer (2 vs. 9%) or melanoma (7 vs. 11%). Overreporting cervical cancer and underreporting other cancers, including prostate, in national surveys have been documented [35]. Younger age in our sample may have contributed to the lower proportion of prostate cancer survivors. NHIS data also are limited to noninstitutionalized individuals; therefore, findings for institutionalized survivors are not incorporated, nor are those for survivors who died after treatment or were too ill to participate. Finally, some variables such as insurance are as of time of interview and not diagnosis.

Among recently diagnosed cancer survivors, many did not report receiving treatment summaries and written follow-up instructions, key components of survivorship care plans, with repotted receipt even lower for some groups. Although care plans may not be appropriate for all cancer survivors, this would likely not explain why so many recently diagnosed survivors did not report receiving these documents. Findings suggest that implementation of these documents is in a relatively early stage of adoption, and that opportunities exist to educate providers and survivors about their recommended use to help them understand care received, and identify current and future needs. For researchers and others, findings indicate a need to examine further the impact of these documents on recommended health services use and outcomes, identify key barriers [5, 8] to. their delivery, develop effective interventions to facilitate their use, and monitor progress from the baseline established by these findings.

Acknowledgments

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Table 1

Cancer surveillance and screening definitions

Surveillance[a,b]	
Breast cancer survivors	Mammogram within 1 year
Colorectal cancer survivors[c]	Colonoscopy within 5 years
Cervical cancer survivors	Pap within 1 year
Prostate cancer survivors	PSA within 1 year
Lung cancer survivors	Chest CT within 1 year
Screening[d]	
Mammogram	Mammogram within 2 years among female survivors aged 50–74 without breast cancer
Colorectal cancer	FOBT within 1 year, flexible sigmoidoscopy within 5 years, and FOBT within 3 years, or colonoscopy within 10 years among survivors aged 50–75 without colorectal cancer
Pap test	Pap test within 3 years among female survivors aged 21–65 without cervical cancer or hysterectomy

PSA prostate-specific antigen, *FOBT* fecal occult blood test

[a]Monitors for disease recurrence

[b]Among survivors not treated within 1 year

[c]Because guidelines for survivors <5 years post-diagnosis are conditional on timing and findings of previous tests, we limited analysis to 5 years post-diagnosis

[d]Monitors for new cancers. Limited to survivors >1 year post-diagnosis

Table 2

Characteristics of survivors of adult-onset cancers not in active treatment, NHIS 2010

	All survivors, N= 1,345 N (%)	Diagnosis 4 years[b], N=407 N (%)
Age		
<50	258 (20.0)	100 (24.5)
50–64	409 (32.1)	141 (36.3)
65–79	450 (33.9)	142 (34.4)
80	228 (14.0)	24 (4.7)
Sex		
Male	494 (40.9)	180 (48.4)
Female	851 (59.1)	227 (51.6)
Race/ethnicity		
Hispanic	123 (5.7)	46 (6.8)
Non-Hispanic White	989 (83.1)	290 (81.2)
Non-Hispanic Black	180 (8.4)	56 (8.8)
Non-Hispanic Other	53 (2.9)	15 (3.1)
Education		
High school	575 (41.2)	163 (37.6)
Some college	766 (58.8)	241 (62.4)
Income (% FPL)		
<250 %	608 (37.9)	172 (34.6)
250–<400 %	295 (23.8)	92 (25.8)
400 %	441 (38.2)	142 (39.6)
Insurance		
Any private/military	882 (69.1)	270 (69.8)
Public only	378 (24.8)	110 (23.9)
Single service/none	85 (6.1)	27 (6.3)
Diagnosis[a]		
Breast	307 (20.4)	81 (19.1)
Prostate	188 (14.4)	73 (19.5)
Cervix	123 (8.7)	20 (3.7)
Melanoma	125 (11.0)	36 (10.1)
Colorectal	113 (8.1)	37 (9.4)
Uterus	71 (4.5)	11 (1.9)
>1 Recent diagnosis	30 (1.9)	8 (1.8)
Other	388 (31.0)	141 (34.6)
Age at diagnosis[a]		
<50	532 (39.8)	117 (28.5)
50–64	446 (34.2)	144 (37.2)
65	367 (26.0)	146 (34.3)
Time since diagnosis[a]		

	All survivors, N= 1,345 N (%)	Diagnosis 4 years[b], N=407 N (%)
5	503 (40.5)	
6–10	299 (21.4)	
>10	543 (38.1)	
Treatment modalities[a]		
1	854 (63.1)	252 (61.2)
2	329 (25.4)	97 (25.5)
3	162 (11.6)	58 (13.3)
Treatment recency[a]		
12 months	147 (11.2)	112 (26.7)
>12 months	1198 (88.8)	295 (73.3)
Clinical trial participation		
Yes	119 (9.1)	44 (10.5)
No	1212 (90.9)	360 (89.5)
Health status		
Excellent/very good/good	988 (75.4)	296 (75.4)
Fair/poor	355 (24.6)	111 (24.6)

FPL federal poverty level

[a]Most recent cancer

[b]Survivors diagnosed after recommendations for use of treatment summaries and written follow-up instructions were issued

Table 3

Unadjusted associations of demographic, access, and health factors with reported receipt of treatment summaries, 2010 NHIS

	All survivors		Diagnosis 4 years[a]	
	% (95 % CI)	P	% (95 % CI)	P
Total	32.2 (29.2–35.4)		38.3 (33.0–43.9)	
Age		0.0259		0.6131
<50	33.2 (27.3–39.7)		36.7 (26.7–47.9)	
50–64	36.9(31.4–42.8)		43.0 (33.9–52.7)	
65–79	30.5 (25.5–35.9)		34.9 (26.4–44.4)	
80	24.0(17.8–31.6)		35.1 (18.5–56.2)	
Sex		0.0512		0.3347
Male	35.6 (30.8–40.6)		41.1 (33.1–49.6)	
Female	29.9 (26.5–33.6)		35.6 (28.6–43.3)	
Race/ethnicity		<0.0001		0.0762
Hispanic	49.5 (38.4–60.7)		47.1 (31.0–63.9)	
Non-Hispanic White	28.7 (25.3–32.4)		35.5 (29.2–42.3)	
Non-Hispanic Black	51.3 (43.0–59.5)		57.6 (43.2–70.9)	
Non-Hispanic Other	45.1 (27.8–63.6)		41.2 (16.8–70.9)	
Education		0.3937		0.7900
<High school	30.6 (26.2–35.3)		37.3 (29.3–46.0)	
Some college	33.3 (29.2–37.7)		38.8(31.7–46.5)	
Income (%FPL)[b]		0.4707		0.5765
<250 %	34.4 (29.7–39.4)		39.4 (30.8–48.8)	
250–<400 %	29.3 (23.3–36.2)		33.2(23.1–45.1)	
400 %	31.8(26.7–37.4)		40.6(31.6–50.2)	
Insurance		0.2733		0.2905
Any private/military	31.8(28.3–35.4)		38.4 (32.0–45.3)	
Public only	31.1 (25.5–37.2)		34.3 (24.1–46.1)	
Single service/none	42.3 (30.2–55.5)		52.3 (33.4–70.5)	
Diagnosis[c]		0.0006		0.0592
Breast	30.0 (24.3–36.5)		36.4 (25.7–48.7)	
Prostate	41.9(33.3–51.1)		41.1 (28.4–55.1)	
Cervix	35.2 (25.6–46.2)		51.3 (25.9–76.1)	
Melanoma	25.1 (17.4–34.6)		30.0 (16.7–47.9)	
Colorectal	48.5 (37.4–59.7)		65.7 (46.8–80.7)	
Uterus	25.1 (15.7–37.5)		59.7 (27.2–85.4)	
>1	12.9(4.5–32.1)		9.5(1.2–47.0)	
Other	29.0 (24.3–34.2)		31.9(23.5–41.7)	
Age at diagnosis[c]		0.5804		0.5354
<50	30.9 (26.5–35.6)		36.2(27.4–46.1)	

	All survivors		Diagnosis 4 years[a]	
	% (95 % CI)	P	% (95 % CI)	P
50–64	34.4 (29.5–39.7)		42.1 (33.2–51.7)	
65	31.3(25.8–37.4)		35.7(27.3–45.1)	
Years since diagnosis[b,c]		0.0005		
5	38.3 (33.3–43.5)			
6–10	32.6 (26.5–39.4)			
>10	25.3(21.2–29.8)			
Treatment modalities[c]		0.7189		0.1227
1	33.1 (29.4–37.0)		42.8 (36.0–49.9)	
2	31.6(26.1–37.6)		30.1 (21.0–41.2)	
3	29.2(21.2–38.7)		33.6 (19.9–50.8)	
Treatment recency[c]		0.2334		0.6456
12 months	37.4 (29.0–46.7)		36.2 (26.2–47.5)	
>12 months	31.6(28.4–34.9)		39.1 (32.9–45.6)	
Clinical trial participation		0.0421		0.3203
Yes	43.0 (32.2–54.4)		45.9 (30.3–62.3)	
No	31.0(28.0–34.2)		37.4 (32.0–43.1)	
Health status		0.0463		0.5700
Excellent/very good/good	30.4 (27.0–34.0)		37.4(31.1–44.1)	
Fair/poor	37.8(31.6–44.3)		41.2(30.7–52.5)	

FPL federal poverty level

[a] Survivors diagnosed after recommendations for use of treatment summaries and written follow-up instructions were issued

[b] May not sum to total due to rounding across multiple imputations

[c] Most recent cancer

Table 4

Unadjusted associations of demographic, access, and health factors with reported receipt of follow-up instructions, 2010 NHIS

	All			Diagnosis 4 years[a]		
	Written %	Unwritten %	None %	Written %	Unwritten %	None %
Total	44.4 (41.3–47.5)	28.1 (25.2–31.2)	27.5 (24.8–30.5)	58.5 (52.7–64.0)	27.9 (22.9–33.5)	13.7 (10.5–17.7)
Age		p=0.0035			p=0.5215	
<50	49.6 (41.6–57.5)	25.1 (18.5–33.1)	25.3 (19.1–32.8)	55.5 (43.5–66.9)	29.3 (19.3–41.8)	15.2 (8.6–25.4)
50–64	46.3 (40.7–51.9)	30.9 (25.8–36.4)	22.9 (18.6–27.8)	60.0 (49.9–69.3)	30.1 (21.7–40.0)	9.9 (6.1–15.9)
65–79	44.7 (39.9–49.7)	28.6 (24.1–33.5)	26.7 (22.2–31.7)	61.0 (51.5–69.8)	24.6 (16.8–34.6)	14.4 (9.4–21.4)
80	31.6 (24.6–39.5)	24.9 (18.9–32.0)	43.5 (35.7–51.7)	43.0 (24.2–64.0)	26.8 (11.0–51.9)	30.3 (13.5–54.7)
Sex		p=0.0839			p=0.9148	
Male	47.2 (41.9–52.5)	28.9 (24.3–34.0)	23.9 (19.7–28.6)	58.0 (50.0–65.5)	27.6 (20.9–35.4)	14.4 (9.8–20.8)
Female	42.4 (38.8–46.2)	27.5 (24.0–31.4)	30.0 (26.7–33.6)	58.9 (51.3–66.2)	28.1 (21.3–36.1)	13.0 (9.0–18.2)
Race/ethnicity		p=0.0173			p=0.2440	
Hispanic	48.9 (38.0–60.0)	19.4 (12.3–29.1)	31.7 (23.3–41.5)	60.1 (43.1–75.0)	27.0 (14.5–44.5)	12.9 (5.3–28.2)
NH White	43.0 (39.4–46.6)	29.7 (26.5–33.2)	27.3 (24.2–30.6)	57.3 (50.7–63.6)	29.2 (23.6–35.6)	13.5 (10.0–18.1)
NH Black	57.4 (48.1–66.2)	16.3 (10.8–23.9)	26.2 (18.9–35.3)	74.7 (61.8–84.3)	12.7 (6.2–24.0)	12.7 (6.4–23.5)
NH Other	39.4 (24.0–57.3)	314 (17.5–49.7)	29.2 (15.7–47.8)	41.9 (17.9–70.5)	36.3 (13.3–67.8)	21.8 (7.2–49.9)
Education		p=0.0028			p=0.0711	
High school	37.7 (33.0–42.8)	30.5 (25.8–35.7)	31.7 (27.1–36.8)	50.8 (42.1–59.5)	32.1 (23.7–41.9)	17.0 (11.3–24.8)
Some college	49.0 (44.8–53.1)	26.5 (22.8–30.6)	24.5 (21.2–28.2)	63.1 (55.8–69.8)	25.6 (19.4–32.9)	11.4 (7.8–16.2)
Income (% FPL)		p=0.0007			p=0.0898	
<250 %	37.9 (33.4–42.5)	27.5 (23.0–32.4)	34.7 (30.0–39.6)	51.5 (42.4–60.4)	29.9 (21.7–39.6)	18.7 (13.0–26.2)
250–<400 %	43.5 (36.8–50.4)	30.6 (24.3–37.6)	25.9 (20.9–31.7)	54.2 (42.7–65.3)	34.4 (24.1–46.3)	11.4 (6.3–19.8)
400 %	51.3 (46.1–56.5)	27.2 (22.8–32.2)	21.5 (17.6–26.0)	67.2 (58.3–75.1)	21.9 (15.2–30.5)	10.9 (6.6–17.4)
Insurance		p=0.0100			p=0.3780	
Any private	47.1 (43.3–50.9)	28.2 (24.9–31.8)	24.7 (21.7–27.9)	60.7 (53.8–67.2)	27.2 (21.7–33.6)	12.0 (8.5–16.7)
Public only	40.4 (34.7–46.4)	27.4 (22.2–33.4)	32.2 (26.7–38.1)	57.6 (46.4–68.0)	25.6 (16.2–37.8)	16.9 (10.1–27.0)
None	30.4 (20.1–43.3)	29.3 (18.9–42.4)	40.3 (29.2–52.4)	37.2 (18.9–60.1)	43.3 (21.2–68.4)	19.5 (7.5–41.8)
Diagnosis[b]		p=0.0046			p=0.7088	
Breast	45.0 (38.5–51.8)	29.1 (22.8–36.4)	25.9 (20.9–31.6)	56.1 (43.1–68.3)	31.2 (19.8–45.5)	12.6 (6.5–23.1)

	All			Diagnosis 4 years[a]		
	Written %	Unwritten %	None %	Written %	Unwritten %	None %
Prostate	52.7 (44.8–60.4)	25.2 (19.0–32.7)	22.1 (16.4–29.1)	63.2 (50.5–74.3)	22.5 (13.7–34.6)	14.3 (7.6–25.2)
Cervix	35.9 (26.3–46.9)	27.5 (18.9–38.2)	36.5 (26.9–47.4)	32.0 (14.4–56.8)	41.0 (17.6–69.2)	27.1 (10.3–54.5)
Melanoma	38.4 (30.2–47.2)	29.8 (22.2–38.9)	31.8 (23.3–41.6)	58.0 (40.6–73.6)	27.4 (14.6–45.3)	14.7 (7.0–28.1)
Colorectal	50.9 (40.1–61.6)	23.2 (15.1–33.8)	25.9 (17.4–36.6)	70.9 (51.5–84.9)	20.0 (8.8–39.5)	9.0 (2.8–25.5)
Uterus	19.6 (11.9–30.7)	30.8 (18.7–46.4)	49.5 (35.9–63.2)	42.2 (15.5–74.4)	55.2 (23.9–82.9)	2.5 (0.3–17.3)
>1	38.6 (21.7–58.8)	33.9 (17.5–55.4)	27.4 (13.0–48.8)	56.0 (20.8–86.0)	22.7 (4.6–64.2)	21.3 (3.1–69.5)
Other	46.8 (41.4–52.3)	28.8 (24.0–34.1)	24.4 (19.8–29.6)	57.6 (48.7–66.1)	28.8 (21.1–37.8)	13.6 (8.4–21.3)
Age at diagnosis[b]		$p=0.1561$			$p=0.3002$	
<50	41.4 (36.4–46.5)	27.0 (22.5–32.1)	31.6 (27.0–36.5)	54.2 (44.0–64.0)	29.3 (20.9–39.4)	16.5 (10.0–26.0)
50–64	45.9 (40.9–51.0)	30.4 (25.6–35.7)	23.7 (19.4–28.5)	61.8 (52.1–70.6)	29.0 (20.9–38.8)	9.2 (5.9–14.0)
65	47.0 (41.1–52.9)	26.7 (21.8–32.2)	26.4 (21.4–31.9)	58.5 (49.1–67.3)	25.3 (17.7–34.9)	16.2 (10.6–24.1)
Years since diagnosis[b]		$p<0.0001$				
5	55.0 (49.8–60.1)	28.8 (24.3–33.9)	16.2 (13.0–20.0)			
6–10	46.5 (39.6–53.5)	26.5 (20.9–32.9)	27.0 (21.4–33.5)			
>10	31.8 (27.2–36.7)	28.2 (23.6–33.4)	40.0 (35.2–45.0)			
Treatment modalities[b]		$p=0.0064$			$p=0.1881$	
1	40.7 (37.0–44.6)	28.1 (24.5–31.9)	31.2 (27.6–35.1)	56.2 (49.4–62.8)	27.5 (21.6–34.3)	16.3 (12.0–21.8)
2	50.2 (42.8–57.5)	26.8 (21.2–33.4)	23.0 (18.1–28.8)	60.4 (48.7–71.1)	27.9 (18.6–39.6)	11.6 (6.1–21.2)
3	51.3 (42.2–60.4)	31.1 (22.4–41.3)	17.6 (11.6–25.9)	65.0 (47.7–79.1)	29.5 (16.2–47.4)	5.5 (1.9–15.0)
Treatment recency[b]		$p=0.0033$			$p=0.3361$	
12 months	57.9 (48.0–67.2)	25.5 (17.7–35.2)	16.6 (10.9–24.4)	64.0 (53.0–73.7)	21.2 (13.4–32.0)	14.7 (8.8–23.7)
>12 months	42.7 (39.4–46.0)	28.4 (25.3–31.8)	28.9 (25.9–32.2)	56.5 (49.5–63.2)	30.2 (24.0–37.3)	13.3 (9.7–18.0)
Clinical trial participation		$p<0.0001$			$p=0.0019$	
Yes	65.4 (54.5–74.9)	24.9 (16.9–35.1)	9.7 (5.4–16.9)	84.9 (71.0–92.8)	11.6 (4.9–25.2)	3.5 (1.0–12.1)
No	42.2 (38.7–45.7)	28.6 (25.4–31.9)	29.2 (26.2–32.4)	55.1 (48.7–61.4)	29.9 (24.3–36.2)	14.9 (11.4–19.4)
Health status		$p=0.2207$			$p=0.8697$	
Excellent/very good/good	43.4 (39.7–47.2)	29.6 (26.3–33.0)	27.0 (23.9–30.3)	57.6 (50.5–64.5)	28.6 (22.5–35.6)	13.7 (10.0–18.5)
Fair/poor	47.2 (41.1–53.5)	23.8 (18.5–30.0)	29.0 (23.6–35.1)	61.0 (50.2–70.9)	25.5 (17.0–36.4)	13.4 (7.9–21.9)

FPL federal poverty level

[a]Survivors diagnosed after recommendations for use of treatment summaries and written follow-up instructions were issued

[b]Most recent cancer

Table 5

Adjusted associations of demographic, access, and health factors with reported receipt of treatment summaries and written follow-up instructions, by time since diagnosis, 2010 NHIS

	Treatment summary				Written follow-up instructions			
	Total		Diagnosis 4 years[a]		Total		Diagnosis 4 years[a]	
	OR (95 % CI)	P	OR (95 % CI)	P	OR (95 % CI)	P	OR (95 % CI)	P
Age		0.2018		0.8477		0.0445		0.8300
Per 5-year increase	0.96 (0.91–1.02)		1.01 (0.90–1.13)		0.94 (0.89–1.00)		0.99 (0.90–1.09)	
Sex		0.9316		0.8467		0.8364		0.2888
Male	Reference		Reference		Reference		Reference	
Female	0.99 (0.72–1.36)		1.07 (0.53–2.17)		1.04 (0.73–1.47)		1.38 (0.76–2.50)	
Race/ethnicity		<0.0001		0.0327		0.0313		0.0813
Hispanic	2.35 (1.37–4.04)		1.93 (0.83–4.47)		1.31 (0.78–2.18)		1.54 (0.63–3.78)	
Non-Hispanic White	Reference		Reference		Reference		Reference	
Non-Hispanic Black	2.43 (1.60–3.68)		2.57 (1.19–5.54)		1.81 (1.15–2.84)		2.35 (1.10–5.00)	
Education		0.5674		0.3689		0.1378		0.4621
High school	Reference		Reference		Reference		Reference	
Some college or higher	1.10 (0.78–1.56)		0.76 (0.42–1.38)		1.28 (0.92–1.76)		1.24 (0.70–2.18)	
Income (% FPL)		0.4944		0.0685		0.0063		0.0256
Per 50 % increase	1.01 (0.98–1.04)		1.05 (1.05–1.11)		1.03 (1.01–1.06)		1.07 (1.01–1.13)	
Insurance coverage		0.0765		0.1026		0.1594		0.4722
Any private/military	Reference		Reference		Reference		Reference	
Public only	0.82 (0.57–1.19)		0.77 (0.39–1.52)		0.85 (0.61–1.18)		1.03 (0.56–1.91)	
Single service/none	1.71 (0.95–3.07)		2.39 (0.96–5.94)		0.55 (0.28–1.05)		0.50 (0.15–1.62)	
Most recent cancer diagnosis		0.0024		0.0256		0.1200		0.1679
Breast	Reference		Reference		Reference		Reference	
Prostate	1.71 (0.92–3.17)		1.08 (0.36–3.24)		1.65 (0.93–2.91)		2.03 (0.73–5.64)	
Colorectal	2.32 (1.27–4.24)		4.09 (1.45–11.55)		1.75 (0.95–3.23)		3.99 (1.16–13.66)	
Other	0.94 (0.61–1.46)		0.96 (0.46–1.97)		1.05 (0.71–1.56)		1.47 (0.71–3.04)	
Years since diagnosis		0.0181				<0.0001		

	Treatment summary				Written follow-up instructions			
	Total		Diagnosis 4 years[a]		Total		Diagnosis 4 years[a]	
	OR (95 % CI)	P	OR (95 % CI)	P	OR (95 % CI)	P	OR (95 % CI)	P
5	Reference				Reference			
6–10	0.79 (0.53–1.18)				0.79 (0.54–1.15)			
>10	0.60 (0.42–0.85)				0.44 (0.32–0.61)			
Treatment modalities received		0.1852		0.0296		0.0116		0.4679
1	Reference		Reference		Reference		Reference	
2	0.80 (0.57–1.11)		0.54 (0.31–0.94)		1.52 (1.10–2.10)		1.22 (0.72–2.07)	
Recency of treatment		0.8890		0.4910		0.3482		0.4712
12 months	0.97 (0.61–1.54)		0.82 (0.46–1.45)		1.26 (0.78–2.03)		1.23 (0.70–2.17)	
>12 months	Reference		Reference		Reference		Reference	
Clinical trial participation		0.0265		0.1431		0.0045		0.0034
Yes	1.73 (1.07–2.81)		1.76 (0.82–3.76)		2.15 (1.27–3.63)		4.48 (1.65–12.15)	
No	Reference		Reference		Reference		Reference	
Overall health status		0.0386		0.6521		0.0071		0.0715
Excellent/very good/good	0.69 (0.48–0.98)		0.88 (0.49–1.56)		0.64 (0.46–0.88)		0.56 (0.30–1.05)	
Fair/poor	Reference		Reference		Reference		Reference	

[a]Survivors diagnosed after recommendations for use of treatment summaries and written follow-up instructions were issued

Table 6

Associations of receipt of follow-up instruction with having a usual provider, recent cancer surveillance and screening test use, and provider recommendations for surveillance and screening

| | Received follow-up instruction | | | | | | |
| | Written | | Unwritten | | None | | p value |
	N	Weighted % (95 % CI)	n	Weighted % (95 % CI)	n	Weighted % (95 % CI)	
Total	577	100	349	100	385	100	
Usual provider[a]	577	96.0 (93.8–97.4)	349	95.2 (92.5–97.0)	385	92.0 (88.7–94.4)	0.0711
Cancer surveillance[b]							
Recent test[c]							
Mammogram	128	72.0 (62.1–80.2)	75	67.6 (53.2–79.4)	78	60.3 (47.6–71.7)	0.2910
Colorectal cancer test	31	79.7 (59.7–91.2)		–[g]		–[g]	0.7770
Pap test	40	59.4 (42.1–74.6)	36	48.8 (32.2–65.7)	50	43.1 (29.1–58.3)	0.3886
PSA	81	73.7 (61.4–83.1)	48	89.3 (78.9–94.9)	42	78.0 (60.2–89.3)	0.0455
Provider recommendation[d]							
Mammogram	125	78.5 (69.3–85.5)	72	72.7 (59.7–82.8)	74	58.4 (45.5–70.3)	0.0271
Pap test	36	86.6 (71.8–94.3)	31	73.4 (50.4–88.3)	41	48.3 (31.3–65.8)	0.0069
Cancer screening[b]							
Recent test[e]							
Mammogram	71	82.1 (70.3–89.9)	59	72.2 (57.5–83.2)	74	62.4 (49.5–73.7)	0.0464
Colorectal cancer test	191	67.4 (60.0–73.9)	138	58.2 (48.1–67.6)	133	67.6 (59.0–75.2)	0.2930
Pap test	95	88.2 (80.1–93.2)	43	92.1 (77.1–97.6)	46	80.1 (62.3–90.7)	0.3865
Provider recommendation							
Mammogram	67	79.3 (66.9–87.9)	57	68.0 (52.8–80.1)	69	64.3 (49.3–76.9)	0.1672
Colorectal cancer screening test[f]	68	11.6[h] (5.0–24.7)	51	15.5[h] (6.7–32.1)	42	7.8[h] (1.9–27.0)	0.6149
Pap test	91	63.6 (52.7–73.3)	41	65.2 (46.0–80.4)	44	64.2 (45.2–79.6)	0.9893

PSA prostate-specific antigen

[a] Usual provider for preventive care

[b] Cancer surveillance tests monitor for disease recurrence. Cancer screening tests monitor for development of new cancers

[c] Defined as a mammogram within 1 year among breast cancer survivors not treated in the past year; colonoscopy within 5 years among CRC survivors diagnosed ≥5 years ago and not treated in the past year; Pap test within 1 year among cervical cancer survivors not treated in the past year; PSA within 1 year among prostate cancer survivors not treated in the past year; chest CT within 1 year among lung cancer siuvivors not treated in the past year

[d] Unlike the survey items for breast and cervical cancer, the NHIS survey item about provider recommendation for colorectal cancer testing was asked only of those respondents aged ≥40 who had not received a recent test (a colonoscopy in the past 10 years, sigmoidoscopy in the past 5 years, CT colonography in the past 5 years, or home blood stool test in the last year). There were too few colorectal cancer survivors not up-to-date with surveillance testing to examine provider surveillance recommendations

[e] Defined as a mammogram within 2 years among female survivors aged 50–74 with no breast cancer history and >1 year post-diagnosis; FOBT within 1 year or flexible sigmoidoscopy within 5 years or colonoscopy within 10 years among survivors aged 50–75 with no colorectal cancer history and >1 year post-diagnosis; and Pap test within the prior 3 years among female survivors aged 21–65 with no cervical cancer history, no prior hysterectomy, and >1 year post-diagnosis. Cancer screening tests excluded recent tests done prior to diagnosis

[f] NHIS survey item asks respondents aged 40+ who have NOT had a colonoscopy in the past 10 years, sigmoidoscopy in the past 5 years, CT colonography in the past 5 years, or home blood stool test in the last year, whether a doctor or other health professional recommended within the prior year that they be tested to look for problems in their colon or rectum. Provider recommendation questions for Pap and mammography testing were asked of respondents who reported receiving recent tests as well as those who did not

[g] Estimates based on n<30 or with a relative standard error >50% are indicated, but are not shown

[h] Estimates have a relative standard error of >30 and ≤50% and do not meet the standards of reliability or precision