Limited evidence of non-response bias despite modest response rate in a nation-wide survey of long-term cancer survivors – Results from the NOR-CAYACS study.

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Abstract

Purpose: Declining response rates threaten the generalizability of health surveys. We investigate 1) the effect of item-order on response rate, 2) characteristics of early-, late- and non-responders, and 3) potential non-response bias in a population-based health survey of childhood, adolescent and young adult cancer survivors (CAYACS).

Methods: We mailed a questionnaire-survey to 5361 eligible CAYACS identified by the Cancer Registry of Norway (CRN), representing a range of cancer diagnoses. The 302-item questionnaire included a range of survivorship-related questions and validated patient-reported-outcome-measures. To investigate item-order effects on response rates, we constructed two versions of the questionnaire presenting cancer-related or socio-demographic items first. The CRN provided demographic and clinical information for the total population. Risk of non-response bias was estimated by 1) comparing outcomes between early- and late-responders (answered after a reminder), and 2) by applying inverse probability of participation-weights to construct a total population (with 100% response) and then compare 21 *a priori* selected outcomes between early responders, all responders (early + late) and the total population (all eligible).

Results: Survey item-order did not affect response rates (cancer-first: 49.8% vs sociodemographic-first: 50.2%). Shorter time since diagnosis, male gender and a malignant melanoma diagnosis remained significant predictors of non-response in a multivariable multinomial regression model. There were no significant differences on 16/21 survey-outcomes between early- and late-responders, and 18/21 survey-outcomes between early responders, all responders and the total population.

Conclusion: Despite a modest response rate, we found little evidence for a response bias in our study.

Implications for Cancer Survivors: Surveys of survivor-reported outcomes with low response rates may still be valuable and generalizable to the total survivor population.

Introduction

Health surveys are commonly used in cancer survivorship research. They represent a cost-effective way of obtaining important data, including patient-reported outcomes not available in public registries or medical records [1], to inform survivorship care. Adverse health and psychosocial effects of the cancer and its treatment are well documented for childhood cancer survivors [2-5], but to a lesser extent for survivors of cancer during the adolescent and young adult years [6, 7]. Large-scale health surveys among childhood cancer survivors have been conducted in the USA [8], Canada [9], the Netherlands [10], the Great Britain [11] and Switzerland [12], with the British and Swiss studies representing national population-based cohorts. Similar nation-wide, population-based health surveys among survivors of young adult cancers (e.g. diagnosed between the ages of 19 and 39 years) are scarce.

A challenge for health surveys in general is the continuing decline in response rates over the last 30 years [13, 14]. It increases the risk of non-response bias and thus the potential usefulness of surveys to inform clinical practice and policies [15]. The risk of non-response bias depends not on the response rate *per se*, but to what extent respondents differ from non-respondents on characteristics that are associated with the outcomes under survey. Male gender, younger age, lower education and ethnic minority background are typically underrepresented among respondents to surveys [16, 1, 17, 18]. Those with better health and health behaviours are expected to be overrepresented [16] but this is not always the case [19, 20]. However, recent research suggests that such differences do not necessarily translate into biased outcomes in general population surveys [21, 20] or among childhood cancer survivors [18]. With average response rates to population-based surveys approaching 30-40% [22, 23], we need a better understanding of factors affecting both motivation to participate, and of the risk of non-response bias, to ensure generalisability and usability of findings to inform survivorship care.

In Norway, the entire population of cancer survivors can be identified through the Cancer Registry of Norway (CRN). The CRN can provide basic demographic and clinical information for the entire population of survivors, thus allowing an examination of potential non-response bias. Capitalising on this

rare opportunity [21, 17], we launched a nation-wide survey among Norwegian Childhood, Adolescent and Young Adult Cancer Survivors (CAYACS) in 2015, the NOR-CAYACS study. The overall aim of the study is to investigate a wide range of outcomes associated with being treated for cancer at a young age, including health, quality of life and health care- and information needs.

In this study, we aimed to:

- a. Investigate the effect of item-order on survey response by constructing two survey versions: One starting with demographic background items (lower perceived relevance) and with cancer history items (higher perceived relevance).
- b. Compare basic characteristics of early (before reminder), late (after reminder) and non-responders, and investigate socio-demographic and clinical factors associated with responding early or late compared to not responding.
- c. Examine the potential for non-response bias on selected outcomes by:
 - a. Comparing observed prevalence estimates between early and late responders based on the assumption that late responders are more similar to non-responders than early responders, and
 - b. Calculating expected outcomes for the total population using inverse probability of participation weights based on available data on all eligible survivors and compare these to the observed outcomes in early responders and all responders (early + late).

Methods

Study cohort

Participants eligible for the NOR-CAYACS study were identified through the CRN, which contains information on all cancer cases diagnosed in Norway since 1953. Reporting cancer cases to the CRN is required by law, ensuring a high degree of completeness [24]. Study inclusion criteria were: ≥ 18 years at time of survey, diagnosed between 1985 and 2009, with a minimum of five years since the initial cancer diagnosis of: any childhood cancer (CC, excluding central nervous system (CNS) tumours) at ages

0-18 years; or breast cancer (BC, ICD-10: C50, stages $\leq$ III), colorectal cancer (CRC, ICD-10: C18-20), non-Hodgkin lymphoma (NHL, ICD-10: C82-85), acute lymphatic leukaemia (ALL, ICD-10: C91-96) and a random subsample of malignant melanomas (MM, ICD-10: 43), diagnosed at ages 19-39 years (Supplemental Table S1). Except for the MM group, the diagnostic groups were chosen due to their good prognosis, long life expectancy and high risk of late effects. Further, we chose diagnostic groups not included in other on-going studies at our institution at the time of the survey (e.g. Hodgkin lymphoma, testicular and cervix cancer). The MM group was included to serve as a reference-group because 5-year survivors primarily received surgical treatment only, with none or minimal oncological treatment. Of 2873 registered five-year survivors of MM, 960 were randomly selected for study inclusion.

Available information on responders and non-responders

Basic clinical information was provided by the CRN for all eligible participants. Extended clinical information was obtained from participant who provided permission for linkage with the CRN's data files. The extended clinical information included: date of diagnosis, age at diagnosis, diagnosis (morphology, histology and location), metastatic status, diagnostic certainty, and number of malignancies.

Number of malignancies was calculated as any malignancies of different diagnoses regardless of time of occurrence. For the non-responders, de-identified extended clinical information was made available from the CRN. Time since diagnosis was calculated as number of months from date of primary diagnosis to May 2015. Age at survey was calculated as age in May 2015.

The NOR-CAYACS study questionnaire

The NOR-CAYACS questionnaire included validated patient-reported outcome measures and questions constructed for the specific aims of this survey (Supplemental **Figure S1 and Table S2**). It consisted of 302 items of which 162 were compulsory. In brief, the following topics were covered: Socio-demographic background, late effects, health care use and needs, information needs, work ability and financial burden, physical health, mental health, fatigue, life-style, health-related quality of life and health literacy .

According to the “Tailored Design Method”, placing items of high apparent relevance at the beginning of the survey, not neutral items, could increase motivation to respond [25]. Two versions of the CAYACS questionnaire were constructed to test for any effect of item-order on response rates: One version presented cancer history-related items first (higher apparent relevance) and the other version presented demographic background items first (lower apparent relevance).

Procedures

Survivors were mailed an invitation to participate from the Oslo University Hospital including the study information, an informed consent form, the questionnaire and a pre-addressed pre-paid return envelope. Informed consent was collected for both participation in the survey and for data-linkage to information in the CRN. No incentives were offered. A reminder including a brief personalised letter, the questionnaire, an informed consent form and a pre-paid return envelope was sent to survivors who had not responded after five months.

Survivors were randomly allocated to receive one of the two questionnaire versions..

Statistical analyses

Statistical analyses were performed with Stata 15.0 (Stata Corporation, Texas). Item-order effects on the probability to respond according to questionnaire version (cancer vs social first) was examined using univariable multinomial regression models (across the three groups of responders as described next). The study population was divided into three groups: early responders (answered before the reminder), late responders (answered after the reminder), and non-responders. We used descriptive statistics to present the group characteristics. Univariable and multivariable multinomial regression models were used to identify factors predicting the probability of responding early or late compared to not responding. The following predictor variables were tested individually, and included in the multivariable model if significant at $p \leq 0.10$: Gender, age at survey, age at first diagnosis, time since first diagnosis, diagnostic group (CC, BC, CRC, NHL, ALL, MM) and multiple malignancies. Stratified analyses were performed for each diagnostic group in case of significant interaction ($p < 0.05$) between the above-mentioned variables and diagnostic group.

We used the methods described by Rueegg et al [18] to investigate the potential of non-response bias. We selected 21 outcomes *a priori* that could be dichotomised in a meaningful way and that represented all topics under survey (Figure 2 and Supplemental Table S4). We then compared these 21 outcomes between the early and late responders using chi-square statistics.

Next, we compared the 21 outcomes between early responders (29%), all responders (early and late responders pooled, 39%) and a constructed total population (representing 100% response) using inverse-probability of participation weights (IPW). Based on information for the total population provided by the CRN, population characteristics that are underrepresented among the responders can be determined and statistically adjusted for using IPW (see appendix I for a detailed explanation). The constructed total population was constructed to be representative of the total eligible CAYACS population in terms of its marginal distribution (i.e. the probability distribution of the group of variables) of age at survey (2 year intervals), gender, diagnostic group, number of malignancies (1 vs. more than one), and age at diagnosis (5 year intervals). We generated the weights by estimating the probability of responding to the questionnaire from a logistic regression model (see Appendix I) with being a responder vs. non-responder as outcome. The weights were then applied to the prevalence estimates of the 21 selected outcomes to simulate the total population with a 100% response [26, 19].

Ethical consideration

The study was granted concession by The Norwegian Data Protection Authority (15/00395-2/CGN), and approved by the Regional Committee for Medical Research Ethics (2015/232 REK sør-øst B), and the Data Protection Officer at Oslo University and the Norwegian Cancer Registry.

Results

Study population and data completeness

Of 5494 survivors identified in the CRN, 68 were not eligible due to unknown address, diseased or inability to respond. In addition, 65 survivors completed and returned the questionnaire but declined

consent to link their data to further information from the CRN. They were subsequently excluded because their extended clinical information could not be obtained (Figure 1). As a result, 5361 survivors were eligible for study inclusion of which 2104 (39.3%) responded. Of these, 1552 (29.0%) responded before the reminder (early responders) and 552 (10.3%) after the reminder (late responders). Data completeness for the questionnaire items was excellent. Mean number of completed items was 159.4 (of 162 compulsory items, SD=7.2), representing an average of 1.1% missing items.

Participant characteristics are provided in Table 1. In brief, respondents were 31.1% males, with a mean age at survey of 43 years, diagnosed on average at the age of 26 years with an average of 16.5 years since diagnosis.

Item-order effect on response

Item-order did not have a significant effect on the proportion of responders to the two versions of the questionnaire: with response rates of 49.8% and 50.2% for the cancer-first and the social-first questionnaire, respectively ($p=0.736$; Table 1).

Characteristics of early, late and non-responders and associated factors

Compared to early and late responders, non-responders were slightly younger at survey and older at the time of diagnosis, had shorter time since diagnosis, and were more likely to be male and diagnosed with malignant melanoma (Table 1). In the multivariable, multinomial regression model, shorter time since diagnosis, male gender and a diagnosis of malignant melanoma remained significant predictors of non-response (Table 2). Given the large ranges of age at survey and time since diagnosis, we re-ran the models using them as categorical variables (divided in 5-year interval categories). As this did not alter the results, we kept the continuous variables in the model to avoid potential loss of power or any spurious effects.

There were significant interactions between diagnostic group and the following variables: age at survey, time since diagnosis, age at diagnosis (all p -values < 0.037). Supplemental Table S3 shows the univariable and multivariable multinomial models for response status stratified by diagnostic group. In brief, there were no significant differences when comparing early and late responders to non-responders

within the breast cancer, colorectal cancer and malignant melanoma groups. Marginal differences were observed for age at survey, gender, and time since diagnosis between early, late and non-responders within the remaining diagnostic groups.

Examination of potential non-response bias

a. Comparison of observed survey outcomes between early and late responders. Compared to early responders, late responders were less likely to report receiving follow-up care (24.7% (95%CI: 22.7-27.0) vs 19.4% (95%CI: 16.3-22.9), $p=0.011$ and to suffer from late effects (65.0% (95%CI: 62.6-67.3) vs 59.6% (95%CI: 55.4-63.6), $p=0.023$). Compared to early responders, the late responders were more likely to report being unsatisfied with GP-care (44.1% (95%CI: 41.4-46.9) vs 51.0% (95%CI: 46.4-55.7), $p=0.012$), to smoke (17.7% (95%CI: 15.9-19.7) vs 21.6% (95%CI: 18.4-25.3), $p=0.043$) and to having ever sought help for depression (21.4% (95%CI: 19.4-23.5) vs 25.5% (95%CI: 22.1-29.4), $p=0.45$) (Figure 2 and Supplementary Table S4). The differences were, however, small and would not withstand corrections for multiple comparisons.

b. Comparison of observed vs expected survey outcomes between early, all and total population. Figure 3 and Supplementary Table S5 illustrate the expected changes in prevalence estimates associated with a stepwise increase in the proportion of responders. They show the observed prevalence estimates on the 21 survey outcomes for early responders (29.0%) and all responders (39.3%), and the corresponding predicted prevalence estimates for the constructed total population (100%). The marginal changes of the observed estimates between early responders to all responders, and to the expected estimates for the constructed total-population indicate no apparent clinically relevant differences between the groups. Early responders were slightly more likely to report attending follow-up care (24.7%, 95%CI: 22.7-27.0) than expected in the total population (22.6%, 95%CI: 20.9-24.5). A higher proportion of early responders (65.0%, 95%CI: 62.6-67.3) and all responders (63.6%, 95%CI: 61.5-65.6) reported suffering from late effects than expected in the total population (61.0%, 95%CI: 58.8-63.1). Lastly, a higher proportion of early responders reported a comorbid musculoskeletal disease (45.4%, 95%CI: 43.0-47.9)

than expected in the total population (43.1%, 95%CI: 40.9-45.3). There was no difference between the groups on the remaining 18 of 21 survey outcomes.

Discussion

This is to our knowledge the first study to both investigate item-order on survey response and assess the risk of non-response bias in a population-based health survey among survivors of childhood, adolescence and young adulthood cancers. In brief, we found no effect of item-order on response rates and, despite modest response rates, we found low risk of non-response bias in our data.

Item-order effect on survey response

Item-order effects have been suggested as a cost-effective way of increasing response rates to surveys [25], but have to the best of our knowledge not previously been tested in a population of cancer survivors. Contrary to our expectation, there was no evidence of an item-order effect on the probability to respond. Including items of presumed high relevance for participants at the beginning of the surveys did not increase response probability [25, 26]. The lack of an item-order effect may partially be due to the study-invitation letter. It described the purpose of the study in details, thus potentially priming willingness to respond and thereby reducing any effect of item-order.

Factors associated with probability of response

To our knowledge, only three previous health surveys of CAYACS have assessed potential selection bias or response behaviour [28, 17, 18]. In our study, as in previous research, non-responders tended to be male, of younger age at survey, older age at diagnosis and to have had shorter time since diagnosis compared to responders [16, 17]. Shorter time since diagnosis, male gender and a diagnosis of malignant melanoma remained significant predictors of non-response in the multivariable analysis. Important for long-term survivorship research, the findings that responders were older at survey and had longer time since diagnosis can ease concerns that survivors may lose interest in participating in survivorship research with increasing time since diagnosis [29].

Rather, according to the tailored design method of surveys, we would expect higher participation rates among older and longer-term survivors if the survey appeared to be more relevant for them compared to the younger survivors [25]. Survivors' health and functioning is expected to decline over time due to the occurrence of late-onset late effects and increasing frailty [30], thus potentially increasing the perceived relevance of health surveys like the current one. This assumption is also congruent with the observed lower response rate for both the malignant melanoma group, who were mainly exposed to local surgery and thus at low risk of developing late effects, and the childhood cancer survivors, who were on average younger at survey compared to the other diagnostic groups. Similarly, Rueegg et al [18] found lower response rates among survivors who had received surgery only compared to survivors who had received chemotherapy and/or radiotherapy. Future research could consider ways to increase the perceived relevance of the survey, and investigate whether different survey formats elicit higher response rates, including the use of pre-notifications, telephone reminders and electronic survey versions [1].

Non-response bias

Non-response bias can affect the generalizability of survey results. The risk of non-response bias, however, depends not on the response rate *per se*, but to what extent respondents differ from non-respondents [31, 32, 23, 33]. This can only be investigated if information is available for both responders and non-responder [17], which is rarely the case due to ethical and legal restrictions regarding use of personal data without informed consent. Without such information, one can compare the characteristics and outcomes of survey participants who responded before (early) the use of a reminder to those responding after (late) the reminder. Assuming that late responders are more similar to non-responders, any differences in outcomes or exposure-outcome associations between the two groups are indicative of potential response bias in the survey data. [19, 18]. Alternatively, non-response bias can be assessed by examining changes in the prevalence of outcomes before and after including late responders in the sample [34, 18, 20].

In our study, there were few substantial differences between the observed prevalence estimates of the 21 survey outcomes among the early and late responders. Similarly, there were few differences

between the early- and all-responders compared to the predicted prevalence estimates for the constructed total population. This suggests a low risk of over- or underestimation for a wide range of study outcomes in the NOR-CAYACS cohort. As such, our study adds to the growing literature demonstrating that response rates alone are not accurate markers of the data quality and scientific usefulness of survey data [21, 32, 23, 18].

Our findings mirror those reported by Rueegg et al [18] in a Swiss national population-based survey of adult survivors of childhood cancers with a response rate of 69%. In both studies, the prevalence estimates in the domains of physical and mental health, medical care and health behaviours were similar across the groups of early responders, all responders and a constructed total population representing a 100% response rate. Similar conclusions have been made in surveys among the general population. For example, a Norwegian population-based survey found high data quality and representativeness even with a response rate of four percent [23]. Additionally, a large-scale follow-up survey of mothers in the Danish national birth cohort (53% response rate) compared respondents to the non-respondents using available base-line information and health outcomes available from Danish population registries [21]. The participants tended to be older, healthier and report healthier lifestyle on several factors than the non-responders, but the authors found limited risk of non-response bias on the observed registry-based outcomes when adjusting for factors likely to influence selection using IPW [21]. Other large-scale studies investigating predictors of attrition from longitudinal surveys also report no bias on important variables, including demographic factors and physical and mental health, despite attrition through refusal [35-37]. Thus, non-responders may not necessarily represent subsamples that systematically vary from the rest of the cohort on important base-line variables. In sum, these results highlight the inadequacy of using response rates to assess the quality of survey data, and emphasize the importance of assessing the risk of non-response bias when evaluating the generalisability of studies.

Limitations and strengths

A major strength of our study is the nation-wide, population-based cohort consisting of all 5-year survivors of several diagnostic groups of CAYA cancers for whom basic demographic and clinical data is

available from the CRN. This provided us with the rare opportunity to assess the risk of non-response bias using weighted analysis with IPW to construct a total population of 100% response. A limitation of this procedure is the possibility that factors not included in the weights could influence participation and thus outcomes of interest, e.g. physical functional status or mental health issues. This can be a problem regarding the assumption underlying this analysis, namely that specific subgroups of responders are representative for all eligible participants who share the same characteristics. In other words, we assume that the outcome in a specific substratum of participants is observed at random (for example, males, aged <40 years, with low education, diagnosed with ALL and low BMI). However, our constructed weighted population was built based on the marginal distribution of gender, age, age at diagnosis, diagnosis and number of malignancies which are known to co-vary with the load of late effects, thus likely to capture risks of late-effects.

A general concern of health surveys is the selection of responders based on health status, with individuals of low health likely underrepresented. In our study, however, early responders were more likely to report suffering late effects compared to late responders. Moreover, several population based studies have found little evidence of bias due to differences in health status on prevalence estimates and exposure-disease associations [20, 21, 37]. Lastly, we cannot rule out bias in other outcomes not analysed in the current study. We tried to reduce this risk by choosing *a priori* 21 outcomes covering all the topics investigated in the questionnaire. In sum, despite modest response rates, the low risk of non-response bias and the low rates of missing items in our survey data speak to the quality and representativeness of the collected data.

Conclusion

In our questionnaire survey, varying the item-order of the survey did not lead to higher response rates for the survey starting with items of presumed high apparent interest (cancer related items). Although there were small differences on some socio-demographic and clinical variables between responders and non-responders, we found no evidence of a non-response bias when comparing the prevalence estimates of a wide range of outcomes for the responder samples and the constructed total population. This, combined

with the low proportion of missing items in the current study, reduces the risk of bias in the observed survey estimates. Results from the NOR-CAYACS study can therefore be generalized with confidence to the underlying Norwegian population of five year CAYACS and the resulting data appears suitable for informing the clinical care and policy making in the area of cancer survivorship.

Implications for survivors

Survey studies are the backbone of survivorship research, providing detailed patient-reported information about life after cancer not available elsewhere (e.g. registries and medical records) that can be used to tailor clinical practice and policy making to meet the needs of the survivors. Facing the reality of rapidly declining response rates to health surveys in general and in survivorship research, our study adds to the growing body of evidence that surveys with low response rates can yield useful, representative and high quality data of scientific value that can inform clinical practice to improve survivors' long-term health and well-being.

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Figure 1. **Flow chart illustrating the study design and response behaviour in the NOR-CAYACS study.** NCR=Norwegian Cancer Registry; CC=childhood cancer, BC=breast cancer, CRC=colo-rectal cancer, NHL=Non-Hodgkin Lymphoma, ALL=Acute lymphatic leukaemia, MM=malignant melanoma.

Figure 2. **Comparison of a selection of self-reported binary outcomes between early and late responders.** The x-axis depicts outcomes of interest with early responders in blue and late responders in red. Error bar represents 95% CIs. The y-axis represents proportions and 95% confidence intervals for typical self-reported outcomes for education level, health care, follow-up care, information needs, somatic health, mental health, and health behaviors. Statistically significant differences are indicated with an * (Supplementary Table S4).

Figure 3. **Comparison of a selection of self-reported outcomes between early responders, all responders and the constructed total population of cancer survivors.** The total population responses were modelled by calculating inverse probability of participation weights (Supplemental Table S5). Proportions and 95% confidence intervals for typical self-reported outcomes for education level, health care, follow-up care, information needs, somatic health, mental health, and health behaviors, comparing the observed prevalence from early responders (blue bar) and all responders (red bar) with the expected prevalence in the representative complete population (designated with a green bar, Supplemental Table S5).

Table 1. Characteristics of early, late and non-responders from univariable multinomial regression models with non-responders as reference category.

	<u>Response category</u>				RR early (95% CI) ⁴	RR late (95% CI) ⁵	<i>p</i>
	Total Mean (SD, range)	Early ¹ Mean (SD, range)	Late ² Mean (SD, range)	Non ³ Mean (SD, range)			
n	5361	1552	552	3257			
Age at survey (years)	42.0 (11.9, 18-65)	43.7 (11.6, 18-65)	43.2 (11.3, 18-64)	41.0 (12.0, 18-64)	1.02 (1.01-1.02)	1.02 (1.01-1.02)	<0.001
Time since first diagnosis (years)	16.1 (6.8, 5-30)	16.5 (1.0, 5-30)	16.5 (7.0, 5-30)	15.8 (6.7, 5-30)	1.02 (1.01-1.03)	1.02 (1.00-1.03)	0.018
Age at diagnosis (years)	25.4 (11.9, 0-39)	26.6 (11.5, 0-39)	26.1 (11.7, 0-39)	24.7 (12.1, 0-39)	1.01 (1.01-1.02)	1.01 (1.00-1.02)	0.006
	n (%)⁶	n (%)⁶	n (%)⁶	n (%)⁶	RR early (95% CI)	RR late (95% CI)	<i>p</i>
Questionnaire version							0.736
Cancer first	2714 (50.6)	797 (51.4)	282 (51.1)	1635 (50.2)	1.05 (0.93-1.18)	1.04 (0.87-1.24)	
Social first	2647 (49.4)	755 (48.6)	270 (48.9)	1622 (49.8)			
Gender							<0.001
Female	3373 (62.9)	1096 (70.6)	354 (64.1)	1923 (59.0)	1.67 (1.47-1.90)	1.24 (1.03-1.50)	
Male	1988 (37.1)	456 (29.4)	198 (35.9)	1334 (41.0)			
Diagnostic group⁷							<0.001
CC	1803 (33.6)	453 (29.2)	163 (29.5)	1187 (36.4)	1.06 (0.88-1.28)	0.89 (0.68-1.16)	
BC	1257 (23.4)	463 (29.8)	134 (24.3)	660 (20.3)	1.95 (1.61-2.37)	1.31 (0.99-1.74)	
CRC	380 (7.1)	109 (7.0)	46 (8.3)	225 (6.9)	1.35 (1.02-1.77)	1.32 (0.90-1.94)	
NHL	623 (11.6)	184 (11.9)	69 (12.5)	370 (11.4)	1.38 (1.10-1.75)	1.21 (0.86-1.68)	
ALL	338 (6.3)	115 (7.4)	42 (7.6)	181 (5.6)	1.77 (1.34-2.33)	1.50 (1.01-2.23)	
MM	960 (17.9)	228 (14.7)	98 (17.8)	634 (19.5)			
Multiple malignancies							0.082
No	5002 (93.3)	1433 (92.3)	510 (92.4)	3059 (93.9)	0.78 (0.62-0.98)	0.79 (0.57-1.11)	
Yes	359 (6.7)	119 (7.7)	42 (7.6)	198 (6.1)			

Notes:

¹Early responders: Survivors responding before the reminder was sent²Late responders: Survivors responding after the reminder was sent³Non-responders: Survivors who did or respond or declined participation (reference category)⁴RR early: Risk ratios from univariate multinomial regression models comparing early responders with non-responders.⁵RR late: Risk ratios from univariate multinomial regression models comparing late responders with non-responders.⁶Column percentages are reported⁷The diagnosis of non-Hodgkin lymphoma and ALL may occur in both the CC and AYA diagnostic groups of NHL and ALL respectively depending on whether they were diagnosed before or after the age of 19 years.

CC=childhood cancer, BC = breast cancer, CRC = Colorectal cancer, NHL = non-Hodgkin lymphoma, ALL = Acute lymphoblastic leukemia, MM = Malignant melanoma.

Table 2. Factors associated with early and late response compared to non-response from multivariable multinomial regression model.

	RR early responder (95% CI)	RR late responder (95% CI)	p
Age at survey	1.01(1.00-1.02)	1.00(0.98-1.02)	0.242
Time since first diagnosis	1.02(1.01-1.04)	1.02(1.00-1.05)	0.004
Gender			<0.001
Female	1.55(1.34-1.80)	1.19(0.96-1.47)	
Male			
Diagnostic group			<0.001
CC	1.40(1.02-1.91)	0.91(0.58-1.42)	
BC	1.84(1.50-2.26)	1.35(1.00-1.82)	
CRC	1.53(1.16-2.03)	1.45(0.99-2.14)	
NHL	1.65(1.30-2.09)	1.32(0.94-1.88)	
ALL	2.20(1.65-2.93)	1.69(1.13-2.54)	
MM			
Multiple malignancies			0.871
No	0.97(0.76-1.24)	0.91(0.64-1.30)	
Yes			