HHS Public Access

Author manuscript

Cancer Epidemiol Biomarkers Prev. Author manuscript; available in PMC 2021 March 01.

Published in final edited form as:

Cancer Epidemiol Biomarkers Prev. 2020 September ; 29(9): 1699–1709.

doi:10.1158/1055-9965.EPI-20-0153.

Utilizing SEER cancer registries for population-based cancer survivor epidemiologic studies: a feasibility study

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Abstract

Background: While the primary role of central cancer registries in the United States is to provide vital information needed for cancer surveillance and control, these registries can also be leveraged for population-based epidemiologic studies of cancer survivors. This study was undertaken as a pilot project to assess the feasibility of using the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) Program registries to rapidly identify, recruit, and enroll individuals for survivor research studies and to assess their willingness to engage in a variety of research activities.

Methods: In 2016–2017, six SEER registries recruited both recently diagnosed and longer-term survivors with early age-onset multiple myeloma or colorectal, breast, prostate, or ovarian cancer.

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Conflict of interest statement: The authors declare no conflicts of interest.

Potential participants were asked to complete a survey, providing data on demographics, health, and their willingness to participate in various aspects of research studies.

Results: Response rates across the registries ranged from 24.9% to 46.9%, with sample sizes of 100 to 239 enrolled by each registry over a 12- to 18-month period. Among the 992 total respondents, 90% answered that they would be willing to fill out a survey for a future research study; 91% reported that they would donate a biospecimen of some type. Approximately 82% reported that they would consent to have their medical records accessed for research.

Conclusion/Impact: This study demonstrated the feasibility of leveraging SEER registries, and possibly other population-based cancer registries, to recruit and engage a geographically- and racially-diverse group of cancer survivors across cancer types and lengths of time since diagnosis.

Keywords

biospecimens; cancer registries; cancer survivors; epidemiologic research; Surveillance; Epidemiology and End Results (SEER) Program

Introduction

The current U.S. cancer survivor population of about 17 million is expected to grow to over 20 million by 2026 (1) as a result of advances in the screening, diagnosis, and treatment of cancer. These cancer survivors face an uncertain future with the possibility of a myriad of physical, psychological, financial, and social consequences, some predictable and others unknown. Information on long-term effects of newer therapies is sparse, especially for vulnerable populations under-represented in clinical trials such as the elderly, minorities, young adults, and those with multiple co-morbid conditions. Population-based research is needed to characterize the long-term effects of cancer, including the impact of evolving cancer treatments, and to identify strategies to mitigate the adverse effects of cancer and its treatment.

Observational studies provide critical information to address gaps in knowledge concerning the long-term survivor experience. Leveraging the existing resources of central cancer registries can improve the efficiency in the conduct of studies while ensuring adequate representation of diverse populations. While the primary role of cancer registries is to provide vital information for cancer surveillance and control (2), they provide an opportunity to perform population-based observational studies (3). Because cancer is a reportable disease, central cancer registries capture data about persons diagnosed with cancer, including patient demographics, primary tumor site, tumor morphology and stage at diagnosis, first course of treatment, and follow-up for vital status (4). Furthermore, the adoption of e-Path reporting in many cancer registries enables rapid case identification.

Depending on the research questions, participant involvement in a study can range from completing a survey to intensive in-person examinations, donation of biological specimens, and the sharing of personal health information. Since 1973, the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) Program has provided high quality, authoritative cancer incidence and survival data for specific states, regions and population groups (5). This study was undertaken as a pilot project to assess the feasibility

of using SEER registries to rapidly identify, recruit, and enroll individuals for population-based survivor research studies and to assess the extent of their willingness to engage in a variety of potential research activities.

Methods

In 2016, six SEER cancer registries were selected among those responding to a request for proposals for a pilot study to determine the feasibility of obtaining patient reported outcomes from cancer survivors to enhance SEER registry data: the Louisiana Tumor Registry at Louisiana State University School of Public Health-New Orleans; the Iowa Cancer Registry; the Metropolitan Detroit Cancer Surveillance System; the New Jersey (NJ) State Cancer Registry; the Los Angeles (LA) Cancer Registry; and the Utah Cancer Registry. The Institutional Review Board at each site approved that site's study protocol and materials.

Study sample

The target populations in this study were individuals diagnosed at any stage with early age-onset multiple myeloma or colorectal, breast, prostate, or ovarian cancer. Early age-onset was defined as under 50 years of age at time of diagnosis for breast or colorectal cancer, under 55 years of age for prostate cancer, and under 65 years of age for multiple myeloma or ovarian cancer. Cancer stage was defined using SEER summary stage 2000 or derived SEER summary stage 2000 (6). Two groups, defined by time since diagnosis, formed the sampling frame for each cancer type. The first group included those recently diagnosed (within one year of diagnosis) and the second group included longer-term survivors, diagnosed more than three years prior to the study start date for ovarian cancer or multiple myeloma cases or more than five years prior to the start date for breast, prostate, and colorectal cancer cases. The expectation was that each participating registry would recruit a minimum of 10 cases in each category of time since diagnosis for each cancer type. Overall target sample sizes ranged from 100 (Iowa) to 200 (NJ). Identification of sampling frames occurred in either late 2016 (Utah) or early 2017 (Louisiana, LA, Detroit, NJ, Iowa). The total number of individuals sampled from each SEER registry ranged from 320 (Iowa) to 1301 (NJ) (Table 1).

Participant diversity was encouraged; three registries had recruitment strategies to increase the representation of certain subgroups in their study sample. Utah oversampled Hispanics and residents of rural counties for the longer-term survivors and Iowa oversampled non-Whites. Detroit limited recruitment to White and Black survivors and oversampled Black survivors.

Recruitment methods

All of the registries sent initial recruitment mailers for the study, some containing the paper questionnaire or a link to access the survey online if that option was available for that registry. The procedures for follow-up of cancer survivors who did not respond to the initial mailing varied by registry (Table 1). For all registries, multiple attempts were made by mail and/or phone to request study participation if there was no response to the first mailing or the mailer was not returned as being undeliverable. Email was not used to initiate

recruitment, as email addresses are not routinely collected by SEER registries. An incentive for participation was not part of the protocol at any of the study sites.

Questionnaire

The questionnaire was developed by NCI staff in collaboration with key personnel at each SEER registry. The questionnaire consisted of 28 items and included questions on demographics (sex, current employment, education), current health (co-morbid conditions), and willingness to participate in various aspects of research studies, with slight variations for state-specific information (e.g. health insurance options vary by state).

The primary outcome variables were those pertaining to the respondent's willingness to participate in research studies and various aspects of studies; for example, whether the respondent would complete a single survey and/or multiple surveys, share their medical records, attend a clinic visit, or donate certain types of biospecimens. Other outcome variables included modality preference for completion of surveys (response choices: phone, paper, computer, smart phone or tablet, and other) and main reasons that they would be interested in participating in a research study (response choices: giving back to the medical community and helping those with cancer; learning more about cancer and relevant resources (including clinical trials); compensation; and other). For the modality preference for survey completion and reasons for participating in a research study, some registries allowed multiple responses while the other registries asked the respondent to select only one choice.

Different methods were used to administer the questionnaire across registries (Table 1); these methods included paper questionnaires sent through the mail (all registries except Detroit), a web-based platform (Iowa, LA, Utah, NJ, Detroit), and telephone (Iowa, LA, Utah, Detroit, NJ). Utah conducted a randomized trial within this study in order to assess the response rate when offering a web-based versus paper survey; potential respondents, thus, were offered only the survey type associated with the experimental arm to which they were assigned (7). At NJ, LA, and Utah, the questionnaire was available in Spanish.

SEER data

Data on diagnosis date, age and stage at diagnosis, sex, and cancer type were abstracted from the SEER registry file and linked to each participant's questionnaire data by each registry. Cancer stage data were analyzed using the American Joint Commission on Cancer 6th edition staging manual categories (8), collapsed as 0 (*in situ*), I, II, III, and IV. Stage data in this format were not available for the analysis for the NJ and Detroit registries.

Statistical analysis

Response rates were calculated excluding individuals sent a mailing who were later determined to be ineligible. Personnel from each site abstracted and analyzed data for a limited set of SEER variables to compare enrollees to non-respondents (excluding those determined to be ineligible) using chi-square tests for categorical variables and Student's t-tests or Wilcoxon signed-rank tests for continuous variables. Data for each selected variable

may not be comparable across the registries and results are show by registry (with the exception of LA, for which results were not available).

The associations between the willingness to participate variables and participant characteristics were examined using chi-square tests. Analyses were carried out initially within study site strata, and Breslow-Day tests were conducted to examine effect modification of each association by study site. All associations were similar across the study sites; thus, combined results are presented. Multivariable logistic regression analyses were conducted to examine the associations between each of the participant characteristics and the willingness to participate variables adjusted for the other participant characteristics variables; the results were similar to the bivariate analyses and, thus, only the bivariate analyses results are shown.

All analyses were conducted using SAS v9.4. A p-value of less than 0.05 was considered statistically significant.

Results

The registries used a variety of methods to recruit participants, follow-up with non-responders, and survey survivors, with varied response rates from 24.9% (NJ) to 46.9% (Utah) (Table 1). . Five of the registries compared SEER data from those enrolled to non-respondents (Table S-1); there were few statistically significant differences that were observed consistently among the registries. In Louisiana, Iowa, and Utah, the enrolled participants were more likely to be white than the non-respondents; in contrast, in Detroit, the enrolled cancer survivors were more likely to be black than their non-respondent counterparts. For other variables (e.g. age at diagnosis, cancer type, sex), there were no statistically significant differences, or inconsistent directions of association, between enrollees and non-responders.

Five registries exceeded their overall sample size target; Louisiana achieved 98% of their overall sample size goal. Among the 992 total participants, the majority completed paper surveys at five of the registries; in Utah, the randomized trial conducted within the study showed that offering a paper survey only yielded a non-statistically significant higher response rate than offering the web survey only (7). At Detroit, the majority of participants (66.9%) completed the survey via a phone interview with a registry staff member.

The majority of the study participants at each registry were female, were in good or very good health, and reported 0 or 1 comorbidities (Table 2). For the remaining characteristics, there were variations across the registries. For example, there were greater percentages of Black participants in the Detroit (36.6%) and Louisiana (22.8%) samples, and a greater percentage of Asians in the LA (14.4%) and NJ (13.0%) samples, compared to the other registry sites. Similarly, there were greater percentages of Hispanic participants in the LA (32.5%) and NJ (14.2%) samples compared to the other four registry sites. The majority of participants across the registries had at least some college education [range: 68.1% (LA) to 82.4% (Detroit)], with low percentages at each registry not having a high school degree [range: 1.4% (Detroit) to 15.0% (LA)]. Approximately half of respondents at all registries

were employed full-time [range: 40.6% (Detroit) to 57.4% (Utah)]. There were some differences in the distribution of cancer types, cancer stage, and the time since diagnosis categories between the registries due to different initial sample size targets and varying success in recruiting within these strata.

Overall, a high percentage of respondents were willing to participate in various aspects of research studies (Tables 3 and 4). Approximately 90% of participants answered that they would be willing to fill out a survey (Table 3). At four registries, the majority of respondents selected paper as the preferred survey type (Table S-2); at Utah, participants preferred computer-based, and in Detroit, the majority preferred delivery of the survey by phone. Of note, at all registries, a minority listed smart phone or tablet as the preference for survey delivery. Among those who preferred an electronically delivered survey, the majority at all registries selected a home computer as the preferred device with the exception of those in Louisiana, whose participants' most frequently stated preference was a mobile device.

Approximately 87% of the respondents were willing to undergo a clinical exam at their regular doctor's office and 56.2% stated their willingness to take part in a clinic-based study at a doctor's office other than their own (Table 3). Eighty-two percent reported that they would consent to have their medical records accessed for research.

Over 91% of respondents were willing to donate a biospecimen of some type (i.e. either blood, saliva, urine, stool or tissue) (Table 4). Overall, 77.8% percent of participants stated that they were willing to donate a blood sample for research and 83.5% were willing to donate their tumor tissue (Table 4). In contrast, only about half of the participants responded that they would be willing to donate a stool sample.

Regarding the reasons to participate in research, over 78% of the total respondents at each registry stated that they would participate to give back to the medical community [range: 78.1% (LA) to 93.7% (Detroit)] (Table S-2). The second most common reason for participating in research was to learn more about cancer and relevant resources such as clinical trials [range: 36.9% (LA) to 54.3% (Louisiana)].

Tables 3 and 4 show the associations, across the registries, for the demographic and health characteristics and selected willingness to participate variables. Those who had previously participated in a research study, were more educated, or were employed full-time, were significantly more likely to indicate a willingness to participate in a future study that required a biospecimen donation, requested medical record access, or included a clinic visit. Race and ethnicity were also significantly associated with the willingness to participate variables; White cancer survivors were the most likely, and Asian cancer survivors the least likely, to report willingness to participate in future studies that involved completion of a survey, accessing medical records, a clinic visit, or donation of biospecimens. Cancer survivors of Hispanic ethnicity were less likely than non-Hispanic cancer survivors to indicate willingness to participate in a future study involving survey completion, a clinic visit at their regular doctor's office, or donation of DNA; in contrast, Hispanic cancer survivors were more likely than their non-Hispanic counterparts to indicate a willingness to donate a stool sample.

By cancer site, breast cancer survivors were significantly less likely to report being willing to donate a stool sample for a future research study, and multiple myeloma survivors less likely to report willingness to donate a tissue sample, compared to participants with the other cancer types. Time since diagnosis and cancer stage was not significantly associated with any of the willingness to participate variables.

Discussion

SEER and state cancer registries represent the most complete enumeration of cancer survivors in the U.S. population (3). While cancer registries have been successfully used to recruit research participants for studies in the past (examples: (9–12)), there have been research and societal changes that may affect use of registries for population-based research (13–17). For example, there is an increasing demand by researchers for biospecimen collection and access to all health records, as well as increasing awareness of privacy concerns and changes in technology communication patterns such as switch to cell phones and use of caller-ID (3). Further, the growth in rapid reporting mechanisms to cancer registries may open the door for registries to efficiently recruit recently diagnosed cancer survivors. For these reasons, this pilot study was conducted to assess the impact on and feasibility of leveraging SEER resources to recruit and engage both long-term and newly diagnosed cancer survivors in population-based research.

The results of this study showed that, across six SEER registries, using various recruitment methods, it is feasible to rapidly recruit a geographically- and racially-diverse group of cancer survivors over a short time period to participate in a research study. In this pilot study, almost 1,000 cancer survivors (615 recently diagnosed and 377 longer-term survivors) were successfully contacted and responded to a survey during a 12- to 18-month study period. Similar to previously conducted survey-based studies that utilized central cancer registries for recruitment, response rates ranged from 24.9% to 46.9% (10,11). Additional effort by the registry staff at each site to recruit for this study ranged from as little as an additional one-third full time equivalent (FTE) to as much as two FTE depending on the goal number to enroll as well as the protocol (e.g. survey modality offered, number of follow-up contacts for non-responders). Novel approaches for recruiting participants through SEER registries in this study included the use of multiple options for survey completion, such as a web-based option at five of the six registries, as well as a Spanish version of the survey, which was available at three registries.

To assess the generalizability of the results, a comparison of enrollees to non-respondents was conducted for a limited set of SEER variables. In general, there were few statistically significant differences between enrollees and non-responders in the registry-specific analyses, and for some of the significant associations, the directions of the associations varied by registry, possibly reflecting regional population differences, variations in recruitment methods, or chance effects. It should be noted that this study focused on the recruitment of early-age onset cancer cases, as this is a NCI area of interest; thus, no statement can be made about the generalizability of these results to older cancer survivors, who may differ in their willingness to participate in a research study. The benefit of utilizing registries is that they provide a well-defined source population, allowing investigators to

assess how well a study sample reflects the population of interest, and, thus, the external validity of the results (3).

Successful recruitment using SEER or other central cancer registries depends on knowing how best to reach and engage the targeted ‘local’ population. Each SEER registry used their own methods of contacting and recruiting participants that was informed, in part, by previous studies carried out by these registries. Most used multiple modalities for survey administration: five offered paper surveys, five allowed phone completion of the survey, and five had a web-based survey option. However, even in an era where tasks are increasingly done electronically, it is interesting to note that five out of the six registries received most of the completed surveys via paper, which is consistent with what has been found in the survey methods literature (18–22); in addition, at four of the six registries, participants stated paper as their preferred mode of survey delivery. The stated preference results should be interpreted with caution, as there is some evidence that participants tend to prefer the survey modality that they just completed (23). The one study registry that received most of their surveys using a modality other than paper was Detroit, where most surveys were completed by phone, informed by their experience developing the Detroit Research on Cancer Survivors (ROCS) study, which is recruiting newly diagnosed African American breast, prostate, colorectal, and lung cancer patients through the Detroit-based cancer registry (9). At all registries, only a small percentage of enrollees listed smart phone or tablet as the preference for survey delivery, which may reflect either lack of access to or experience with the devices or past difficulty with completing surveys on small devices. For those registries offering both a web-based option and a paper option of the survey, most participants completed the paper version which may reflect that the initial contact was via a mailed (paper) letter since SEER registries do not routinely collect e-mail addresses for contact. In Utah, where potential participants were randomized to receive either the paper survey or web-based survey only, there was a non-statistically significant higher response rate for the paper versus web-based survey (7).

Among the respondents, 90% indicated that they were willing to participate in at least some aspect of a research study, and the majority were willing to participate in aspects of research associated with a higher participant burden, such as a clinic visit or biospecimen donation. However, as seen prior studies (24–28), those with lower education and those who had not participated in research studies in the past were less willing than others, speaking to the need for additional outreach efforts to engage certain populations.

Across all races and ethnicities, the majority of respondents were willing to participate in research but Black and Asian respondents (as well as those who were of Hispanic ethnicity) were less likely than their White counterparts to report willingness to participate in certain components, including survey completion, a clinic visit, or collection of a biospecimen. Similar differences have been observed in the Breast Cancer Family Registry study where enrollment rates and biospecimen collection among the breast cancer patients and her family member(s) were considerably lower among Asian Americans compared to non-Hispanic whites and other race and ethnic subgroups (29). Differences in the relationships between race and ethnicity with the willingness to participate variables highlight the importance of understanding how to engage underrepresented populations in research, which includes

recognizing community members as partners in research, building trust between the community and investigators, being transparent regarding risk of research to participants and community, and establishing a line of communication between the researcher and the community during all phases of research (30).

There were few differences in the willingness to participate in various aspects of research by cancer type. Individuals diagnosed with multiple myeloma were less likely than individuals diagnosed with the other cancer types to be willing to donate a tissue sample for research; further, the percentage of respondents overall who were willing to donate a stool sample was lower than those who were willing to donate the other biospecimen types, with breast cancer survivors being the least likely to report being willing to donate a stool sample. We did not assess the underlying reasons for the choices associated with these cancer types, but the results speak to the need to clearly communicate issues about research, such as the type of tissue required for donation, use of existing tissue samples, and the importance of collections that are perceived more negatively (e.g. stool collections) for the relevant research.

Previous research has shown that altruism is one of the primary reasons that individuals participate in research (31,32) – this was echoed by the participants in this study as well. While altruism is a major driving force for study participation, most of the sites noted that use of an incentive, which was not provided here, has helped in other studies. In their analysis of data from the 17 studies conducted from 2007–2016 that utilized the Utah SEER registry for recruitment, Millar et al. (33) found that the odds of recruitment increased by 62% with an incentive. Interestingly, all of the Utah SEER studies from 2007–2017 used a post-incentive (33) – those promised at the end of study completion – which has been shown to be less effective than unconditional pre-incentives (34,35). Other recommendations from the registries after the completion of this study included building an informational website for participants; offering multiple modality options for completing a survey, with consideration of the sequence on how the modalities are offered (36); providing information on how the study results will be used (i.e., ensure that they know the importance of the research); minimizing participant burden; and sharing study results and providing study updates to engage survivors in continued study participation.

Cancer survivors in this pilot study reported willingness to participate in all aspects of research studies, including an in-person visit, blood collection, and access to medical records. Caveats are that these results reflect those who were willing to take part in this study in the first place and, intention does not always lead to the intended behavior. However, the response rates observed here are commensurate with several other survey-based studies conducted using central cancer registries for recruitment (10,11). It is unknown whether a research study requiring multiple surveys, biospecimen donation, clinical exams, or medical record abstraction would have similar response rates as are reported in this manuscript, although in the analysis of the 17 Utah registry-based studies, results showed that having a biospecimen donation component did not affect response rates (33).

Overall, this study demonstrated the feasibility of leveraging population-based cancer registries to recruit and engage a geographically- and racially-diverse group of cancer

survivors across cancer types and lengths of time since diagnosis. SEER registries represent 35% of the US population (5) and state cancer registries cover the remaining population, making these resources an invaluable network for recruiting cancer survivors into research studies and utilizing the data collected within these registries.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Financial Support:

Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under contract numbers HHSN261201300020I, HHSN261201300011I, HHSN261201300017I, HHSN261201300016I, HHSN2612013000021I, HHSN2612013000004I.

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Table 1.

Study sample and recruitment methods, by registry

	Iowa	Louisiana	Los Angeles
Sample size target (n)	100	130	130
Cancer patients/survivors contacted (n)	320	420	500
Cancer patients/survivors enrolled (n)	115	127	160
Response rate[a] (%)	36.6	35.4	35.4
Follow-up protocol[b]	The first 70–75 cancer survivors received four follow up phone calls (morning, afternoon, evening and weekend); two messages were left for the four phone calls. The rest of the participants received two follow-up phone calls (am and pm). A reminder letter was sent to participants who had not refused or completed a survey three weeks after the initial letter.	Cancer survivors who did not return the mailed packet was contacted by phone during daytime hours (9am-3pm) and a message was left on his/her voicemail. Two weeks after this phone call, a second packet was mailed.	Cancer survivors received a minimum of three follow up phone calls (morning, afternoon, evening and weekend) and reminder postcards (two versions) after the initial mailing. If there was no response, a second mailing was sent. Tracing was conducted to locate survivors with bad addresses and phone numbers. For Hispanic surnames, a letter and survey were sent in both English and Spanish.
Reasons for non-response	Passive refusal/unable to contact (85.4%) Active refusal (14.6%) Not interested	Passive refusal/unable to contact (97.1%) Active refusal (2.9%) Too sick	Passive refusal/unable to contact (80.1%) Active refusal (19.2%) Not interested No time
Survey administration method (%)			
Paper/mail	73.9	100.0	75.0
Web	21.7	0.0	8.1
Phone	4.3	0.0	16.9
	Utah	**Detroit**	**New Jersey**
Study sample goal (n)	130	130	200
Cancer patients/survivors contacted (n)	464	495	1301
Cancer patients/survivors enrolled (n)	209	142	239
Response rate[a] (%)	46.9	29.4	24.9
Follow-up protocol[b]	Cancer survivors who had not refused or completed the survey after four mailers (prenotice, invitation with survey or survey link, reminder letter, second invitation with survey or survey link) were also contacted by phone, with up to three attempts (weekday, weeknight, and Saturday). For cancer survivors identified as Hispanic in SEER, a	Cancer survivors who did not respond to the initial mailed invitation letter after two weeks were contacted by phone up to nine times on a variety of days and times (if the survivor did not actively refuse participation). Voicemails were left after each follow-up attempt if the voicemail option was available.	Cancer survivors who did not respond to the first survey mailing after one week were contacted by phone up to three times (weekday, weeknight, and weekend). A voicemail was left after each call attempt; there was a one-week interval between each call. All study materials (including the survey) were

	bilingual letter was sent for both the pre-notice and the survey mailing noting that a Spanish version of the survey was available upon request.		translated into Spanish and were available for Spanish-speaking cancer survivors.
Reasons for non-response	Passive refusal/unable to contact (91.1%) Active refusal (8.9%) Not interested Questions too personal Not feeling well	Passive refusal/unable to contact (44.5%) Active refusal (55.5%) Not interested Not feeling well (chemo) Too busy No compensation	Passive refusal/unable to contact (83.7%) Active refusal (16.3%) Not interested Not much time to live
Survey administration method (%)			
Paper/mail	52.9	0.0	87.0
Web	45.2	33.1	10.9
Phone	1.9	66.9	2.1

[a] excludes those determined to be ineligible

[b] after identified in SEER registry and sent initial mailing

Table 2.

Participant characteristics by registry

	Iowa	Louisiana	Los Angeles	Utah	Detroit	New Jersey
Sample size	115	127	160	209	142	239
Sex (%)						
Male	39.1	33.1	42.5	39.7	28.9	32.6
Female	60.9	66.9	57.5	60.3	71.1	67.4
Age at diagnosis (%)						
<40	9.6	15.0	13.8	17.7	12.7	7.9
40 to 49	53.9	40.2	58.1	45.9	57.7	45.2
50 to 59	20.9	44.9	17.5	27.3	16.2	18.0
60+	15.7	0.0	10.6	9.1	13.4	28.9
Race (%)						
White	91.3	73.2	57.5	91.4	60.6	64.0
Black	3.5	22.8	8.1	1.9	36.6	16.7
Asian	2.6	0.8	14.4	1.0	0.0	13.0
Other	2.6	1.6	15.0	4.8	2.8	2.1
Missing	0.0	1.6	5.0	1.0	0.0	4.2
Ethnicity (%)						
Hispanic	2.6	1.6	32.5	9.1	0.7	14.2
Non-Hispanic	93.9	92.9	63.8	90.9	98.6	82.0
Missing	3.5	5.5	3.8	0.0	0.7	3.8
Education (%)						
Less than high school degree	5.2	7.1	15.0	1.9	1.4	7.1
High school graduate	20.9	22.8	13.1	20.1	15.5	18.0
Some college	19.1	25.2	22.5	31.6	38.7	24.3
College graduate or more	54.8	44.1	45.6	45.9	43.7	49.4
Missing	0.0	0.8	3.8	0.5	0.7	1.3
Type of cancer (%)						
Breast	24.3	29.1	22.5	22.0	41.5	26.4
Colorectum	21.7	16.5	14.4	24.4	13.4	21.3

	Iowa	Louisiana	Los Angeles	Utah	Detroit	New Jersey
Multiple myeloma	23.5	19.7	22.5	15.8	16.9	20.5
Ovary	17.4	17.3	20.0	17.7	14.8	15.9
Prostate	13.0	17.3	20.6	20.1	13.4	15.9
Time since diagnosis (%)						
Longer-term survivor	45.2	25.2	47.5	37.3	51.4	28.0
Newly diagnosed	54.8	74.8	52.5	62.7	48.6	72.0
Cancer stage (AJCC 6 category) (%)[a]						
0 (in situ)	0.0	3.2	0.0	6.7	-	-
I	21.7	19.7	20.0	17.7	-	-
II	22.6	21.3	30.6	27.3	-	-
III	23.5	17.3	11.9	16.3	-	-
IV	8.7	12.6	6.9	3.8	-	-
Not applicable	23.5	21.3	26.3	19.6	-	-
Unknown/missing	0.0	4.7	4.4	8.6	-	-
Number of comorbidities (%)						
None	44.3	47.2	39.4	46.4	33.1	47.7
One	27.8	26.8	31.3	32.1	37.3	31.0
Two	14.8	9.4	11.9	13.9	21.1	10.5
Three	8.7	7.9	6.9	5.3	4.2	6.7
Four or more	4.3	3.9	3.1	2.4	4.2	4.2
Missing	0.0	4.7	7.5	0.0	0.0	0.0
Self-reported health (%)						
Poor	4.3	3.9	5.6	2.4	4.2	1.7
Fair	16.5	20.5	19.4	17.7	19.7	16.7
Good	38.3	27.6	40.6	40.2	37.3	43.1
Very Good	34.8	34.6	19.4	30.6	26.8	27.2
Excellent	6.1	11.0	11.9	8.6	12.0	11.3
Missing	0.0	2.4	3.1	0.5	0.0	0.0
Employed full-time (%)						
Yes	54.8	51.2	48.1	57.4	41.5	40.6
No	45.2	47.2	47.5	42.6	58.5	59.0

	Iowa	Louisiana	Los Angeles	Utah	Detroit	New Jersey
Missing	0.0	1.6	4.4	0.0	0.0	0.4

AJCC = American Joint Commission on Cancer

[a] AJCC 6 stage data were not provided by the Detroit or NJ registries for analyses

Table 3.

Associations between participant characteristics and willingness to participate variables

	Willing to…											
	Complete a survey			Provide access to medical records			Attend a clinic visit at regular doctor's office			Attend a clinic visit at another doctor's office		
Characteristic	**n**	**%[c]**	**p-value**	**n**	**%[c]**	**p-value**	**n**	**%[b]**	**p-value**	**n**	**%[c]**	**p-value**
Overall	972	90.3		966	82.2		977	86.9		981	56.2	
Missing	20			26			15			11		
Cancer type			1.0			0.06			0.08			0.3
Breast	267	89.9		263	78.3		267	91.4		266	56.4	
Prostate	166	89.8		164	80.5		168	82.7		169	52.7	
Colorectum	189	90.9		186	85.0		185	85.9		188	61.7	
Ovary	163	90.8		167	88.6		167	87.4		168	57.7	
Multiple myeloma	187	90.9		186	80.7		190	84.7		190	52.1	
Time since diagnosis			0.7			0.8			0.04			0.2
Longer-term survivor	372	90.9		373	81.8		376	84.0		374	53.5	
Newly diagnosed	600	90.0		593	82.5		601	88.7		607	57.8	
Cancer stage (AJCC 6 category)[a,b]			0.7			0.6			0.8			0.1
0-I	136	89.0		134	79.1		135	87.4		134	57.5	
II	156	87.2		155	82.6		156	87.2		156	56.4	
III	99	90.9		102	84.3		101	91.1		102	61.9	
IV	43	93.0		43	86.1		45	88.9		45	75.6	
Sex			0.3			0.6			0.4			0.5
Male	352	88.9		349	81.4		354	85.6		354	54.8	
Female	620	91.1		617	82.7		623	87.6		627	56.9	
Race[a]			0.003			<0.0001			0.007			0.004
White	712	91.9		708	86.3		713	88.9		715	59.0	
Black	137	89.8		134	71.6		141	84.4		142	50.7	
Asian	60	78.3		58	74.1		59	83.1		59	37.3	
Other	45	84.4		48	60.4		46	73.9		47	48.9	
Ethnicity[a]			0.03			0.3			<0.0001			0.1

	Willing to…											
	Complete a survey			Provide access to medical records			Attend a clinic visit at regular doctor's office			Attend a clinic visit at another doctor's office		
Characteristic	**n**	**%[c]**	**p-value**	**n**	**%[c]**	**p-value**	**n**	**%[b]**	**p-value**	**n**	**%[c]**	**p-value**
Hispanic	109	84.4		109	78.9		109	74.3		110	49.1	
Non-Hispanic	842	91.1		836	83.1		846	89.0		848	57.4	
Education[a]			<0.0001			0.005			<0.0001			<0.0001
Less than high school	59	81.4		61	77.1		60	81.7		62	40.3	
High school graduate	176	82.4		175	73.7		179	73.7		181	40.9	
Some college	265	92.1		265	85.3		266	89.1		268	57.1	
College graduate or more	464	93.8		457	84.5		464	91.8		462	64.1	
History of research participation[a]			<0.0001			0.002			0.0007			0.0003
Yes	252	97.6		252	88.5		251	93.2		253	66.0	
No	720	87.8		713	79.9		725	84.8		727	52.8	
Employed full-time[a]			0.2			0.3			0.3			0.06
Yes	475	91.8		476	83.8		477	88.3		480	59.4	
No	494	89.1		486	80.1		496	86.1		497	53.3	
Number of comorbidities[a]			0.7			0.6			0.08			0.1
Zero or one	427	90.4		423	81.6		428	84.8		429	53.4	
Two or three	433	90.8		430	83.7		435	89.9		438	59.6	
Four or more	99	87.9		99	80.8		100	86.0		100	53.0	
Self-reported health[a]			0.04			0.6			0.7			0.2
Fair or poor	212	87.3		212	80.2		213	86.4		213	52.1	
Good	376	89.1		371	83.3		377	85.9		381	55.1	
Excellent or very good	378	93.1		377	82.0		381	87.9		381	59.1	

AJCC = American Joint Commission on Cancer

[a] Frequency counts do not always sum to overall available count because of further missing data for specific variable

[b] AJCC 6 stage data were not provided by the Detroit or NJ registries; stage analysis does not include not applicable code (multiple myeloma)

[c] Row percent

Table 4.

Associations between participant characteristics and willingness to donate biospecimen variables

	Willing to donate…											
	At least one type of biospecimen[c]			Blood			Saliva			Urine		
Characteristic	**n**	**%[d]**	**p-value**	**n**	**%[d]**	**p-value**	**n**	**%[d]**	**p-value**	**n**	**%[d]**	**p-value**
Overall	958	91.2		973	77.8		975	82.0		974	80.0	
Missing	34			19			17			18		
Cancer type			0.7			1.0			0.5			1.0
Breast	265	91.3		267	78.3		267	83.5		265	80.4	
Prostate	162	92.0		167	78.4		167	82.0		167	80.8	
Colorectum	185	92.4		185	76.8		186	80.1		186	79.0	
Ovary	165	92.1		167	76.7		166	84.9		166	81.3	
Multiple myeloma	181	88.4		187	78.6		189	78.8		190	78.4	
Time since diagnosis			0.5			0.5			0.4			0.6
Longer-term survivor	367	90.5		371	76.6		372	80.7		370	79.2	
Newly diagnosed	591	91.7		602	78.6		603	82.8		604	80.2	
Cancer stage (AJCC 6 category)[a,b]			0.7			0.7			0.7			0.5
0-I	136	90.4		136	78.7		136	83.1		134	78.4	
II	154	90.9		156	80.8		156	84.6		155	83.2	
III	100	94.0		101	84.2		101	86.1		101	85.2	
IV	44	93.2		42	83.3		42	90.5		43	86.1	
Sex			0.8			0.2			0.4			0.7
Male	344	91.6		354	75.7		354	80.5		354	79.4	
Female	614	91.0		619	79.0		621	82.8		620	80.3	
Race[a]			0.0002			0.0003			0.0001			0.002
White	703	93.6		711	81.3		713	85.3		713	82.9	
Black	134	85.8		138	72.5		139	77.0		139	73.4	
Asian	58	81.0		60	60.0		59	66.1		58	65.5	
Other	47	85.1		46	71.7		46	71.7		46	78.3	
Ethnicity[a]			0.3			0.9			0.4			0.3

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	Willing to donate…											
	At least one type of biospecimen[c]			Blood			Saliva			Urine		
Characteristic	**n**	**%[d]**	**p-value**	**n**	**%[d]**	**p-value**	**n**	**%[d]**	**p-value**	**n**	**%[d]**	**p-value**
Hispanic	110	89.1		110	79.1		110	80.0		110	84.6	
Non-Hispanic	827	92.3		840	78.6		842	83.3		841	80.4	
Education[a]			0.0002			<0.0001			0.0001			0.0007
Less than high school	61	83.6		61	68.9		61	77.1		61	70.5	
High school graduate	171	84.8		179	65.4		179	71.0		180	71.1	
Some college	260	95.4		263	82.9		265	85.3		265	81.9	
College graduate or more	460	92.4		463	81.0		463	85.1		461	83.7	
History of research participation[a]			0.01			0.0005			<0.0001			0.0005
Yes	249	95.2		252	85.7		253	90.1		251	87.7	
No	708	89.8		720	75.1		721	79.2		722	77.4	
Employed full-time[a]			0.048			0.002			0.01			0.009
Yes	472	93.2		477	82.2		477	85.3		474	83.5	
No	482	89.6		493	73.8		495	79.0		497	76.9	
Number of comorbidities			0.8			0.2			0.4			0.2
Zero or one	419	90.5		427	75.2		428	80.1		427	77.8	
Two or three	431	91.9		436	79.1		437	83.5		436	81.2	
Four or more	94	91.5		97	82.5		97	83.5		97	84.5	
Self-reported health			0.5			0.9			0.7			1.0
Fair or poor	209	89.5		213	78.9		213	83.6		213	79.8	
Good	371	91.1		378	77.8		379	81.8		379	80.0	
Excellent or very good	372	92.2		377	76.9		377	80.9		376	79.8	

	Willing to donate…								
	Stool			Tissue			DNA		
Characteristic	**n**	**%[c]**	**p-value**	**n**	**%[c]**	**p-value**	**n**	**%[c]**	**p-value**
Overall	974	56.4		862	83.5		977	85.0	
Missing	18			130			15		
Cancer type			0.02			0.0001			0.3

	Willing to donate…								
	Stool			Tissue			DNA		
Characteristic	**n**	**%[c]**	**p-value**	**n**	**%[c]**	**p-value**	**n**	**%[c]**	**p-value**
Breast	266	48.5		259	83.0		266	86.5	
Prostate	167	60.5		147	86.4		169	85.8	
Colorectum	187	58.8		181	86.7		184	85.9	
Ovary	164	54.9		159	88.7		169	86.4	
Multiple myeloma	190	62.6		116	69.0		189	79.9	
Time since diagnosis			0.8			0.6			0.2
Longer-term survivor	372	55.9		322	82.6		372	83.1	
Newly diagnosed	602	56.6		540	84.1		605	86.1	
Cancer stage (AJCC 6 category)[a,b]			0.6			0.8			0.7
0-I	135	57.0		134	88.1		136	87.5	
II	155	55.5		149	86.6		156	89.1	
III	100	61.0		99	90.9		100	92.0	
IV	44	65.9		43	88.4		44	88.6	
Sex			0.02			0.6			0.4
Male	354	61.3		301	84.4		355	83.7	
Female	620	53.6		561	83.1		622	85.7	
Race[a]			0.3			<0.0001			<0.0001
White	715	58.0		636	87.3		713	89.5	
Black	138	52.9		116	69.8		140	72.1	
Asian	57	50.9		53	75.5		58	70.7	
Other	46	45.7		44	77.3		48	75.0	
Ethnicity[a]			0.049			0.2			0.04
Hispanic	110	65.5		94	79.8		111	79.3	
Non-Hispanic	841	55.6		750	84.7		843	86.5	
Education[a]			0.07			0.006			<0.0001
Less than high school	61	65.6		54	70.4		62	79.0	
High school graduate	180	48.9		150	78.7		179	74.9	
Some college	265	55.5		234	87.2		265	89.8	
College graduate or more	461	58.4		420	85.0		464	87.3	

	Willing to donate…								
	Stool			Tissue			DNA		
Characteristic	**n**	**%[c]**	**p-value**	**n**	**%[c]**	**p-value**	**n**	**%[c]**	**p-value**
History of research participation[a]			0.02			0.1			0.02
Yes	250	62.8		224	87.1		251	89.6	
No	723	54.2		637	82.3		725	83.3	
Employed full-time[a]			0.1			0.1			0.02
Yes	474	58.9		441	85.5		478	87.9	
No	497	54.1		417	81.8		495	82.4	
Number of comorbidities			0.1			0.5			1.0
Zero or one	425	53.2		387	82.1		427	84.8	
Two or three	438	56.9		379	85.2		436	85.3	
Four or more	97	65.0		82	81.7		99	84.9	
Self-reported health			0.4			0.2			0.2
Fair or poor	213	60.1		183	82.5		212	80.7	
Good	379	55.9		331	81.3		381	85.8	
Excellent or very good	376	54.3		343	86.0		378	86.2	

AJCC = American Joint Commission on Cancer

[a]Frequency counts do not always sum to overall available count because of further missing data for specific variable

[b]AJCC 6 stage data were not provided by the Detroit or NJ registries; stage analysis does not include not applicable code (multiple myeloma)

[c]includes blood, saliva, urine, tissue, and stool

[c]Row percent