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Cancer survivor perspectives on sharing patient-generated health data with central cancer registries

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Abstract

Purpose Central cancer registries collect data and provide population-level statistics that can be tracked over time; yet registries may not capture the full range of clinically relevant outcomes. Patient-generated health data (PGHD) include health/treatment history, biometrics, and patient-reported outcomes (PROs). Collection of PGHD would broaden registry outcomes to better inform research, policy, and care. However, this is dependent on the willingness of patients to share such data. This study examines cancer survivors' perspectives about sharing PGHD with central cancer registries.

Methods Three U.S. central registries sampled colorectal, non-Hodgkin lymphoma, and metastatic breast cancer survivors 1–4 years after diagnosis, recruiting them via mail to participate in one of seven focus groups ($n = 52$). Group discussions were recorded, transcribed, and thematically analyzed.

Results Most survivor-participants were unaware of the existence of registries. After having registries explained, all participants expressed their willingness to share PGHD with them if treated confidentially. Participants were willing to provide information on a variety of topics (e.g., medical history, medications, symptoms, financial difficulties, quality of life, biometrics, nutrition, exercise, and mental health), with a focus on long-term effects of cancer and its treatment. Participants' preferred mode for providing data varied. Participants were also interested in receiving information from registries.

Conclusions Our results suggest that registry-based collection of PGHD is acceptable to most cancer survivors and could facilitate registry-based efforts to collect PGHD/PROs. Central cancer registry-based collection of PGHD/PROs, especially on long-term effects, could enhance registry support of cancer control efforts including research and population health management.

Keywords Patient-reported outcome measures · Focus groups · Cancer survivors · Quality of life · Patient generated health data · Registries

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Introduction

Population health concerns health outcomes in groups of individuals over time, including outcomes such as quality of life and functional status [1–3]. The systematic, repeated assessment of health outcomes is intended not only to describe population health, but also to provide data that can be used to identify determinants of health, identify health disparities and, ultimately, inform efforts to improve health [3]. Select cancer outcomes are monitored in most countries by population-based central cancer registries [4], which are often supported by laws or regulations requiring that incident cancers be reported to them [5]. Central cancer registries can provide high-quality, population-based data on cancer incidence, survival, and cancer-related care around the time of diagnosis. These outcomes play an essential role in informing cancer control and cancer research efforts [4, 5], but registries' lack of quality of life and functional health data inhibits their ability to fully describe the burden of cancer on population health.

Increasing the scope of data captured by registries to include patient-generated health data (PGHD) would parallel the overall trend in research to assess patient-centered outcomes (e.g., symptom burden, health-related quality of life) [6], in addition to traditional biomedical outcomes (e.g., survival time, tumor size), thereby providing important population-level data about cancer survivors' health and well-being. Concepts such as quality of life, symptom burden, functioning, and patient experiences of care are typically measured using patient-reported outcomes (PROs) [7]. PROs are collected directly from patients via standardized questions administered in a variety of ways, including paper-and-pencil, face-to-face, telephone interviews or, increasingly, via internet and computing platforms (e.g., smartphones, tablets).

Guidelines for cancer symptom management published by leading organizations recommend the use of PRO measures for routine symptom assessment [8–13]. Inclusion of PROs in clinician performance measures is recommended by organizations such as the National Quality Forum [14], the American Medical Association [15], and the Centers for Medicare and Medicaid Services [16].

In research, the United States (US) Food and Drug Administration and the European Medicines Evaluation Agency have acknowledged the essential role of PROs in clinical trials [17, 18]. Further, the National Institutes of Health and the National Cancer Institute have funded the development of measurement tools intended for research such as the Patient-Reported Outcomes Measurement Information System (PROMIS) and the PRO version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) [19, 20].

While some PRO data are collected in US national health surveys [21], their utility for informing cancer control efforts is limited by the relatively small number and heterogeneity of cancer survivors included in such general population samples, and reliance on self-reporting of cancer diagnosis and treatment. Central cancer registries ascertain all cases in a geographic region and possess valuable clinical data on cancer diagnosis and treatment, making them an excellent platform for population health PRO measurement. Indeed, many one-off studies have sampled survivors from cancer registries and collected their PROs [22], but these do not allow for the ongoing, systematic monitoring of population health trends. Another approach is to link national quality-of-care surveys and registries [23, 24]. However, the surveys used in these linkages are designed for the general population, so they lack PROs that are most relevant to cancer patients/survivors, and the samples tend to include an idiosyncratic subset of survivors.

These limitations could be surmounted by adding PROs to the data routinely collected by central cancer registries. Further, routine PRO data collection by registries could address the recommendation of the White House Cancer Moonshot Task Force to systematically collect such data to inform "the development of guidelines for routine monitoring and management of patient-reported symptoms in all care settings, throughout the cancer continuum" [25]. The Agency for Healthcare Research and Quality suggests that PROs could substantially enhance registries' ability to characterize the natural history of cancer, measure harm, and gauge the effectiveness of treatments (i.e., comparative effectiveness research) [26].

The scope of registry data collection could also be expanded by new technologies for remote monitoring and digital/passive data collection [27]. Wearable activity trackers, home blood pressure monitors, and other wearable devices enable patients to collect and track their own biometric data, while smartphone applications and websites allow people to record and track other personal health data. These PGHD include domains such as vital signs (e.g., temperature, blood pressure, and blood glucose), lifestyle data (e.g., caloric intake, diet, exercise, medication adherence, and ability to perform activities of daily living), and PRO data (e.g., mood, sleep quality, and pain) [28]. The utility of PGHD data has been demonstrated in diseases like diabetes, and has potential to improve cancer care [27], but is not included in cancer registries.

Little is known about the types of data that cancer patients and survivors would be willing to share with central cancer registries, and under what conditions and stipulations they would do so. No prior studies have systematically explored survivors' concerns in this area. One qualitative study noted that cancer survivors did not want to be approached about providing data to registries close to the time of diagnosis or while making treatment decisions [29]. A quantitative study found that most survivors preferred to be contacted directly about opportunities to share data rather than having their physician be contacted first [30].

Given the limited knowledge about survivor preferences for information sharing with cancer registries, the objective of this study was to explore cancer survivors' perspectives about providing PROs and other PGHD to central cancer registries in the US. Using focus group methodology, we addressed three research questions:

1. What information would cancer survivors be willing to provide to a central cancer registry to assist in understanding cancer outcomes?
2. What methods would be acceptable and preferable to survivors for providing this information (e.g., mailed questionnaire, patient portal, website, phone app)?
3. What information would survivors be interested to receive back from cancer registries?

Methods

We conducted seven focus groups with cancer survivors from three central cancer registries: 2 focus groups in Atlanta, Georgia; 3 in New Mexico; and 2 in New Orleans, Louisiana. The focus groups in Atlanta and New Orleans were conducted in-person (8–9 participants per group) while those in New Mexico were conducted via telephone conference call (5–6 participants per group). Overall study approval was provided by the Westat Institutional Review Board (IRB), and each registry obtained local IRB approval. In Georgia and Louisiana, informed consent was obtained just prior to the in-person focus groups. In New Mexico, consent forms were included with mailing packets sent to potential participants, and only those returning signed consent forms were scheduled for the telephone-based focus groups.

Eligibility, sampling, and recruitment

Eligible participants were survivors of localized colorectal cancer (representing nonmetastatic solid tumors), non-Hodgkin lymphoma (representing nonsolid tumors), and metastatic breast cancer (metastatic disease). Survivors were 12–48 months from diagnosis at the time of sampling. This represents a typical window for registry-based PRO/PGHD data collection efforts, since it allows survivors to complete initial treatment, and registries to ascertain cases completely. In Atlanta and New Orleans, survivors resided within driving distance of registry offices. In New Mexico they resided within the state. All participants were fluent in English.

Since cancer is a reportable disease [5], participating registries have a census of cancer cases. Each registry randomly sampled eligible survivors, checked their vital status, and recruited with a single mailing. The introductory letter described the study, indicated that not all those expressing interest would be selected, and that those completing the focus groups would receive a $100 gift. A response form allowed respondents to indicate their availability for specific focus group times, and their level of education and internet use. A total of 1688 survivors were mailed an invitation; recruitment was closed after several weeks and 147 survivors responded for a yield of 8.7% (i.e., including those with invalid addresses). A comparison of respondents and nonrespondents (Appendix A in Electronic Supplementary Material) found differences on age, sex, and cancer type were not statistically significant; differences on race and ethnicity were significant, but the effect sizes were negligible [31]. A subset of respondents was selected to achieve a mix of demographic characteristics by over-selecting minorities and those with less education or internet use.

Focus group procedures

A semistructured focus group facilitator guide (see Appendix B in Electronic Supplementary Material) including questions and probes led the conversation and addressed the research questions. The guide was refined slightly after the first two focus group sessions. All groups included a facilitator (KL), one or two note-takers (MD, TS), and were audio-recorded. De-identified verbatim transcripts were produced for data analysis.

Data analysis

The analysis used a grounded theory approach, allowing themes to emerge from the transcripts as we reviewed them [32]. A single analyst (ST) conducted the initial distillation and review of the data to ensure consistent implementation of the study's goals and uniform comparison of results across the groups. The facilitator (KL) and note-taker (MD) provided close review, oversight, and quality control to ensure the analytic process was systematic and reproducible. The group met at each step of the analysis process to discuss and review findings, agree on key themes, address gaps, and resolve inconsistencies. Transcript data were organized by topic area and then by question asked for each of the three states. Since we did not find any notable state-level differences, the data were combined and summarized across states. The analysis process resembled the "constant comparative method" [32]. Review and discussion of codes, questions, and themes assigned to each data point with the moderator and note-taker provided a consistency check as well as quality assurance. Finally, (TS) reviewed all transcripts, confirming the analysis.

Results

Seven focus groups were conducted with a total of 52 participants. Focus group participants had a mean age of 60.4 (SD = 12.1) years, 75% Caucasian, 98% non-Hispanic, 54% women, 60% had a college degree or higher, and 85% were daily internet users (Table 1). Participants were 1–4 years from diagnosis of localized colorectal cancer (48%), non-Hodgkin lymphoma (35%) or metastatic breast cancer (17%).

Willingness to provide information to medical personnel

As a warm up, the participants were asked about information they typically provide to medical personnel. Participants reported sharing all types of medical and personal information with their doctors and other medical staff, including medical history, vital signs (e.g., pulse, temperature), family history, allergies, current medications, symptoms, insurance, financial and employment issues, self-report of physical and mental health and quality of life, functional status, and behavioral and lifestyle issues such as nutrition, exercise patterns, and use of recreational drugs. When asked about information they might not be comfortable providing, few topics arose. Several participants mentioned not wanting to discuss sexual issues and another participant preferred not discussing personal financial information. Soliciting information about sensitive topics such as depression and recreational drug use was not identified as problematic by most participants. Overall, participants had few reservations about providing medical personnel with personal information.

Table 1 Participant characteristics

Age	Mean 60.4, SD 12.1
Race/ethnicity	Caucasian 75% (39), Black 25% (13)
Ethnicity	Non-Hispanic 98% (51), Hispanic 2% (1)
Gender	Women 54% (28), men 46% (24)
Education	High school 13% (7), some college 27% (14), college grad 31% (16), post grad 29% (15)
Internet use	Never 2% (1), less than once a month 2% (1), weekly 12% (6), daily 85% (44)
Cancer type	Metastatic breast 17% (9)
	Local colorectal 48% (25)
	Non-Hodgkin lymphoma 35% (18)
Time since diagnosis	Mean 2.3 years, SD 0.3

Willingness to provide information to registries

Although the study recruitment materials briefly described cancer registries, many participants were unclear about the functions and purpose of cancer registries. For example, some participants did not consistently differentiate between healthcare personnel and the registries. Therefore, the facilitator made further efforts to clarify the role of registries during the discussions. Based on the description of the purpose and role of a cancer registry provided by the facilitator, all participants expressed a willingness to share the same data they provided to healthcare professionals with registries, expressing the altruistic notion that their data could be compiled and shared to benefit others (see Table 2 for quotes). One participant noted benefiting from information cancer patients submitted 50 years ago "when the treatment of cancer was a death sentence … Today it's not." A few participants noted that they had become more accustomed to providing information of all sorts since their diagnosis and treatment. In the context of these discussions, some participants expressed an assumption that their data would be or a desire for their data to be kept confidential (Table 2). A few participants expressed a preference to be able to control what data were shared (Table 2).

Table 2 Willingness to provide data to registries

Themes	Quotes
Altruistic desire to share data to help others	Anything that would help somebody else, I would.
	I would feel like I was making [a] contribution by filling out a questionnaire or whatever.
Assumption that data is held confidential	[With an assurance of..] confidentiality, I wouldn't have problems responding to any question if the information would help someone else.
Desire to control how data are used	I do feel more private about my information, … I would like to know how information is being used and where it's going. I would like to OK something and say, "Yes, you can share this, or, no, not," rather than just a blank check. I would like to share information. It doesn't mean I don't want to, but I would like a say in the process. I would like to be able to check it.

Table 3 Most important information for registries to collect

Themes	Quotes
Long-term effects of cancer and cancer treatment	1. You mentioned earlier, chemo brain, and I think that was, after the chemotherapy, that was really weighing heavily on me because at my age I was associating it with early Alzheimer's. … I was now the age that my dad was when we noticed changes so I think chemo brain really has to be addressed more and talked about because we really internalize fears.
	2. We really don't find out about those issues until you're going through them. I didn't know what to expect. I think those things are so critical. [would be great to] have access to that information from actual patients that are going through it, that are dealing with it… I could read up on and … then make an informed decision based on your medication, based on your chemo…"
	3. Quality of life things, in the longer term … might be something that could be useful in setting state policy and stuff. Moderator: Break down quality of life for me. Participant: First of all, the ability to take care of yourself. Your mental status would be another thing. Are you depressed? Are you lonely? What is your situation? Can you go back to work? Can you start enjoying things that you used to enjoy?… Are you able to get back to having, maybe not the same life, but a life that's as rewarding as it was before the diagnosis?
Cancer incidence, treatment and survival	4. My dad had mesothelioma … They say it's one of the rarest forms of cancer but the gentleman next door to us passed away at 55 with it, my dad 59 and the man across the street at 49, from mesothelioma. I'd like the registry to really reflect the truth about the numbers and particular areas that they're most common that people have these cancers.
	5. I had insurance problems… You've got to have almost below fixed income to get co-payment insurance. I think insurance is a major. We talk like most of us are covered but I just wonder every time, those people who don't have the insurance, and they're on the registry, how they're treated.
	6. Now, the question I asked my oncologist, and have asked for over the past few visits, "Is there any data on what happens if a person stops taking this medication after having had a positive result?" Of course, she says, "Well, no. We don't have any data. It's too new. There are studies going on." … I asked the next question the last visit. "Am I part of that study? Is my data being reported?" Only answer to that is, "No, you're not enrolled in a study." I think that's kind of information that could be sent to the registry and maybe it would be helpful in guiding some patients as to what they want to do.
Other biomedical or health data	7. I think the registry ought to reflect if a patient has a cancer and other kinds of major health challenges.
	8. I think there should be some discussion about family history. My mom had non-Hodgkin's at the same age that I was diagnosed.
Quality of care	9. I know that there are certain rating systems that are used by hospitals, …different hospitals and post-operative infections, and different hospital's ability to handle this treatment, whether a hospital specializes in heart or cancer or whatever, to have some sort of cross reference statistics of hospitals, doctors, whatever, as far as the long-term outcome for patients.
Nutrition	10. *Nutrition* They gave me 6 months to live. I did a lot of alternative treatments, supplements, became a vegan. That's the kind of information I think that needs to be spread around, but even my doctors at Emory don't want to talk about it… when I saw my last appointment with the oncologist, He looked at me and says, "I don't know why you're still here."… Why don't you want to know about it? Something's working here.

Most important information for registries to collect

When asked what type of information would be important for registries to collect, participants had many suggestions. Often, they seemed to think about the kinds of information they would like to receive. The most common suggestions had to do with the long-term effects of cancer and its treatment, including symptoms, side-effects, quality of life, and functioning (Table 3, quotes 1–3). One participant noted not being able to find useful information about medication and treatment side-effects and suggested that the registry could become a repository for such information. Another participant expanded on this theme, indicating that information on side-effects of treatment could affect treatment decisions for patients. Several participants thought that it was critical that information on cancer patients' quality of life and functioning be collected, suggesting it could inform policy (Table 3, quote 3).

Some participants suggested that registries should collect data on cancer incidence, treatment and survival. A number of participants expressed the importance of tracking cancer incidence by geographic region or 'hot spots' (Table 3, quote 4). A participant who had experienced health insurance issues wondered if the registry had data that could describe how lack of insurance affects cancer patient treatment (Table 3, quote 5). Another participant thought it would be important to collect information on outcomes for survivors who stop treatment early (Table 3, quote 6). Other types of biomedical information suggested by participants included the importance of major, noncancer health challenges, or comorbidities that often accompany a cancer diagnosis (Table 3, quote 7), and family history of cancer (Table 3, quote 8).

Comments about quality of care, both positive and negative, were offered as survivors described their experiences, and a number of survivors recommended that registries collect quality of care data (Table 3, quote 9). Many participants felt registries should collect data on nutrition. Several participants felt strongly about this, arguing that changes they had made to their diets were contributing to their recovery. They also noted that this type of information was generally not elicited by their doctors and nurses (Table 3, quote 10).

Preferred methods for providing information to registries

Expressing the altruistic desire to help others, many participants indicated they would be willing to provide data via any mode of collection (Table 4, quote 1). While many participants expressed a preference for a specific mode of data collection, no consensus about a preferred or best method was reached within groups or across participants. Some respondents preferred traditional mail or phone approaches (Table 4, quotes 2–3). Others preferred online approaches, often expressing a preference for receiving an email survey (Table 4, quote 4–5). Some participants did not want to have another website to log onto or another portal specifically for registry data collection (Table 4, quote 5). Others suggested integrating data collection into their healthcare provider patient portals (Table 4, quote 6). A few noted that allowing for multiple data collection methods, sufficient response time, receiving reminders, and assurances of confidentiality would all contribute to increasing response rates. Finally, a number of participants expressed frustration about frequent and lengthy surveys often received from many difference sources, highlighting the issue of respondent burden, and the importance of minimizing survey length and/or the frequency of data collection.

Information survivors want from registries

Some participants felt they were entitled to receive a summary of the information being collected by registries. As one participant said, "I think we, as a participant, need to know what the registry found to be beneficial to us and to our families, for the future." A few participants expressed distress about not having easy access to clinical information on topics such as treatment options, side-effects or survival times to inform their cancer experiences. Participants wanted information from registries on topics that overlapped with and expanded upon their suggestions for data that registries should collect. For example, information about symptoms and side-effects of cancer and cancer treatment were common requests (Table 5, quotes 1–3). One participant asked if there was a way for cancer patients to be notified when they should be examined for possible cancer-related comorbidities and treatment side-effects. There were also requests for information about data registries already track, for example, cancer survival statistics, cancer hot spots and the contribution of environmental factors to cancer outcomes (Table 5, quotes 4–5). Participants also wanted information about new treatments and clinical trials (Table 5, quotes 6–7). Some participants expressed the desire for quality of care ratings about specific physicians or cancer centers (Table 5, quote 8).

Nutrition emerged as an important theme, with some respondents wanting to receive information about diet and nutrition during chemotherapy. A broader theme of strategies for cancer prevention also emerged including nutrition, physical activity, screening and general cancer awareness. One participant hoped that data on diet, physical activity and cancer remission might be provided to survivors to promote

Table 4 Preferred method for providing information to registries

Themes	Quotes
Willing to provide data using any mode	1. I would give the information any way. If they said go to website, fill out this information, or mail in something, or I'll call you and let's talk about it. I'm just interested in getting information out so that people can benefit from it. I'm not holding out.
Survey mode preferences	2. I prefer a paper and pen.
	3. I'd rather talk to them, so maybe phone.
	4. I don't have any problem doing an on-line survey. Just as long as it's anonymous and confidential.
Patient portals	5. I have enough portals at work. I don't want to go online to do anything, unless it was an email that was sent to me. That would be OK.
	6. It gets really technical at some point but if somehow, we could tie it into our portal, and if it's a portal that we're well aware of, then that may be an avenue for us to do that [provide data].

Table 5 Information survivors want from registries

Themes	Quotes
Long-term effects of cancer and its treatment	1. I would like to see a back list broken up into types of cancers so you could go and find what possible effects you're going to see as you're being treated. 2. So I guess a percentage of people who definitely do have [neuropathy], because I was told it may never go away. –this gets at the idea of wanting to know which persistent effects might go away and which are likely to stay for life. 3. The other thing is, 'what are the long-term effects?' We took some pretty serious poisons. I have no idea, 10 years from now…"
Cancer incidence, treatment and survival	4. if the registry could inform the public as to the environment, do they gather data on the pollutants and the chemicals and so on and so forth that have affected the environment, which will in turn affect humans? 5. What are the general chances of surviving what you've got? How much is the improvement if you make it two years? 6. Is there a newer, better medication that's out there? Is there a better, newer chemo? I only know the chemo that I went through, but now I hear that people are doing chemo with pills.
Other biomedical concepts	7. For us, just having somebody to talk to – to find out what's the 360 when it comes to clinical trials. That's useful information that the registry could maybe provide.
Quality of care	8. I wish there's something connected with registries to more registries that would more like help rate surgeons and physicians that treat cancers. You're really blessed that you get the best surgeon or you did a [inaudible] surgery, and you're not lucky if you get someone who is in over their heads. Other than having to search all the places where health grades and ratings, it'd just be nice to know what surgeons and oncology doctors, how they stack up in the state.
Screening and prevention	9. There might be some benefit to having [the registry] communicate that to you at some point. The people who ate healthier did that, or the people who exercised more did that. That might encourage people to take up a healthier lifestyle. 10. I think the registry could be more instrumental in cancer awareness. I had no idea I even needed that test and if I had, I could've prevented all of this. Now they have that little mailing package for detection of colon cancer but I still think, during those 10 years, if it had been advertised more, I would've noticed it and had that test.
Information and support	11. For me, support groups that are around for your particular diagnosis. 12. Transportation to and from a doctor and chemo. 13. The people who live by themselves, resources … somebody to come in and walk your dog a few times a day, and do your laundry, and bring in your mail. 14. My insurance tried to dispute me getting the port taken out. They said it was not medically necessary … [my surgeon said] "It's a necessity. If we leave it in there, he could clot and then die." … a letter coming from the registry, like, "This was a cancer-based port. It needed to be there. It needs to be taken out." 15. How often [a claim] is turned down initially and how long it takes to [process]. 16. People … who still have a desire to still work or need to work, if it would help us find locations that would understand our needs in terms of working with us through our disabilities or what have you. 17. There's no information at all about what kind of financial programs, assistance, etc., are state provided. 18. My husband is self-employed, so our deductible is very high. We say, "We get a bill every January for still being alive for $10,000." 19. If the registry could address issues with our families also? I think that while we're going through the treatment and while going through the surgeries, or whatever we're going through, they're going through a lot of issues also, and I think a lot of times they are left out.

healthy behaviors (Table 5, quote 9). Others suggested that the registry might promote cancer screening or awareness of cancer to the general public (Table 5, quote 10).

Several novel topics emerged as participants thought about the kinds of help they would like to receive to address issues they were facing. Perhaps the most common request was for access to support groups that matched one's type of cancer and were close to home (Table 5, quote 11). Participants also mentioned the need for transportation to treatment, help with household chores, and preparing meals (Table 5, quotes 12–13). Financial issues were also raised by participants, including difficulties with treatment-related insurance claims (Table 5, quotes 14–15), finding insurance in survivorship, returning to work, and long-term debt resulting from cancer treatment (Table 5, quotes 14–18). Others wanted registries to address their family members' need for psychosocial support (Table 5, quote 19).

Preferred formats for receipt of registry information

Participants offered several recommendations about the formats they would prefer when receiving information back from a cancer registry. They indicated the optimal approach would vary with the type of information being provided and no clear consensus emerged. Some would prefer access to a searchable database or a website, while others would like to participate in seminars or receive reports, pamphlets, newsletters or literature.

Discussion

We conducted focus groups with cancer survivors one to three years after diagnosis to understand their perspectives on providing data to central cancer registries. Most participants were unfamiliar with cancer registries; while laws require incident cancers be reported to central registries, requirements for notifying cancer patients vary [4, 5]. After having registries explained, participants expressed consistent and unequivocal willingness to share a wide range of data, including PROs, PGHD, experiences of care, and other issues such as financial concerns. Their willingness to provide these data was based primarily on the altruistic belief that the data could benefit others. Some participants assumed such data would be kept confidential, while others explicitly required confidentiality as a condition of sharing. Their high level of willingness to share data for altruistic reasons and concerns about confidentiality align with patient attitudes about sharing health record data, genomic data, and secondary analysis of data [33–36]. Our results support the acceptability of registry-based collection of PGHD/PROs to cancer survivors, describe which types PGHD/PROs survivors prioritize for collection, and provide survivor preferences regarding collection methods and receiving data back from registries.

In describing the types of data that participants believed registries should capture, they confirmed the importance of the biomedical outcomes registries already collect—incidence, treatment and survival data. Other biomedical data domains suggested by participants included comorbidities, family history of cancer, and quality of care ratings for hospitals and doctors. The role of nutrition during treatment and recovery was noted by many participants.

The most common theme was that registries should collect data on the long-term effects of cancer and its treatment, including symptoms, side-effects, quality of life, and functioning. Participants' suggestion that registries collect these data reflects their desire for information on the prevalence and persistence of side-effects through the phases of survivorship, by cancer type and treatment, as well as their suggestion that this information could inform treatment decisions and ongoing adjustment to cancer. These results align with survivors' high need for information on side-effects [37] and reaffirm the value of collecting PRO data in clinical practice and research settings [6, 7, 18]. This suggests side-effects should be central to future registry efforts to collect PGHD. To optimize the utility of treatment side-effect data, registries might improve the granularity of their treatment data (e.g., capturing specific chemotherapeutic agents) and capture side-effects based on both medical records and PROs.

With respect to registry-based data collection methods, participants' preferences varied, and included mail, telephone, and web-based. Regarding web-based approaches, some preferred to receive a link to the survey and did not want to have to establish a new log in or password. Participants also provided advice on survey design elements that aligned with best practices [38]—assure confidentiality, use multiple modes and allow respondents to choose their preferred mode, provide multiple reminders, and keep questionnaires brief.

Participants' suggestions for information they would like to receive from registries recapitulated and expanded upon the topics that they identified as important for registries to collect. For example, respondents underscored the importance of receiving information about nutrition and expanded that topic to include physical activity and the overall effects of a healthy lifestyle on cancer outcomes. They also suggested the registry might facilitate cancer prevention by promoting screening and awareness. Participants asked for help with finding support groups, transportation to treatment, household chores, and meals, reflecting common needs of cancer patients and survivors. They also wanted help with the financial burden of cancer, health insurance, and the impact of cancer on employment, reflecting the increasing recognition of the importance of financial toxicity among cancer survivors [39, 40].

Our findings should be interpreted in the light of several study limitations and strengths. The generalizability of our sample is unknown. As respondents to our study invitation, participants likely overrepresented those who were well educated and inclined towards providing data to registries. By design, participants were English-speaking US residents, and almost entirely non-Hispanic, limiting generalizability to other populations. Strengths of this study include medico-demographic similarity between respondents and nonrespondents; sampling and recruitment methods that enhance the generalizability of these results to respondents who might in the future participate in registry-based PGHD/PRO collection efforts; and, participant diversity with respect to cancer diagnosis and geographic region.

The rich data from our focus groups provide a basis for selecting outcomes and designing methods by which cancer registries might capture PGHD/PROs as part of their standard operating procedures. Adding PGHD/PROs (e.g., side-effects, functioning, and quality of life) to registries would allow patients to directly report experiences that are important to them, and to provide data that are not readily available to the registry from another source. Collection of these data is permitted within the current or slightly expanded legal mandates of registries [41, 42], which vary by geopolitical region. Such efforts should be supported by guidelines on selection of measures and optimal methods for registry-based PGHD/PRO collection [26] that can build upon publications providing guidance on the use of PROs in comparative effectiveness research and clinical trials [7, 43–46].

The addition of PGHD/PROs to central cancer registries would provide a more complete set of cancer outcomes better describing the impact of cancer and its treatment on cancer survivor population health. These data could provide population-based estimates of these outcomes, describing the scale of problems to inform prioritization and resource allocation. Ongoing registry-based collection of PGHD/PROs would enable tracking of longitudinal population-level trends; for example, changes in the prevalence of side-effects as new cancer treatments emerge and become standard practice. These data could enable observational studies identifying risk factors for or health disparities in these outcomes, as well as real-world comparative effectiveness research contrasting symptom burden among those receiving different cancer treatments. Thus, adding PGHD/PROs to central cancer registries could inform cancer control efforts including research, policy, population health management, and care intended to improve survivors' patient-centered outcomes.

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Compliance with ethical standards

Conflict of interest The authors have no conflicts of interest with regard to this paper.

Ethical approval All procedures performed in this study were approved by the Westat institutional review board (Project Number 6153.44), and performed in accordance with the ethical standards of the 1964 Declaration of Helsinki and its later amendments or comparable standards.

Informed consent Informed consent was obtained from all study participants.

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