HHS Public Access

Author manuscript

Am J Prev Med. Author manuscript; available in PMC 2016 December 01.

Published in final edited form as:

Am J Prev Med. 2015 December ; 49(0): S528–S535. doi:10.1016/j.amepre.2015.08.026.

Connecting the Dots:

Linking the National Program of Cancer Registries and the Needs of Survivors and Clinicians

A. Blythe Ryerson, PhD, MPH[1], **Christie Eheman, PhD, MSHP**[1], **Timothy Styles, MD, MPH**[1], **Randi Rycroft, MSPH, CTR**[2], and **Claire Snyder, PhD**[3,4]

[1]Division of Cancer Prevention and Control, CDC, Atlanta, Georgia [2]Colorado Central Cancer Registry, Colorado Department of Public Health and Environment, Denver, Colorado [3]Division of General Internal Medicine, Johns Hopkins School of Medicine; Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland [4]Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore, Maryland

Abstract

Cancer survivors, the medical community, public health professionals, researchers, and policymakers all need information about newly diagnosed cancer cases and deaths to better understand and address the disease burden. CDC collects cancer data on 96% of the U.S. population through the National Program of Cancer Registries. The National Program of Cancer Registries routinely collects data on all cancer occurrences, deaths, and the types of initial treatment received by the patients, and recently CDC has made advances in its cancer surveillance activities that have direct applicability to cancer survivorship research and care. This Special Article examines CDC's innovative uses of the National Program of Cancer Registries infrastructure and data as a recruitment source for survivorship research studies and behavioral interventions; comparative effectiveness and patient-centered outcomes research; and for the collection, consolidation, and dissemination of treatment summaries for cancer survivors and their providers. This paper also discusses long-term, idealistic plans for additional data linkages and sharing among public health, providers, and the cancer survivor through innovative concepts such as patient portals and rapid-learning health care.

Introduction

As the second leading cause of death, cancer poses a significant public health challenge in the U.S. in terms of both mortality and morbidity.[1] However, continuing progress in early diagnosis and treatment has improved survival for many cancer patients.[2] In 1977, fewer than 4 million people in the U.S. were living with a diagnosed cancer; in 2012, this increased to about 13.7 million, and is expected to rise to 18 million by 2022 because of improved survival as well as the growth and aging of the population.[3]

Address correspondence to: A. Blythe Ryerson, PhD, MPH, CDC, 4770 Buford Highway NE, MS F-76, Atlanta GA 30341. aryerson@cdc.gov..

No financial disclosures were reported by the authors of this paper.

With an increasing number of cancer survivors, addressing the needs and health outcomes of cancer patients beyond treatment is imperative. Focus can now shift beyond preventing cancer mortality to long-term well-being. Cancer survivors, like the general population, need to manage their health by participating in preventative care; however, they also have unique needs related to their diagnosis of cancer and its treatment. In 2005, IOM released "From Cancer Patient to Cancer Survivor: Lost in Transition," a consensus report that highlights the fact that many survivors finish their primary cancer therapy unaware of their heightened health risks and ill-prepared to manage their future healthcare needs.[4] Furthermore, delivery of recommended follow-up care is lacking, and many of the unique psychosocial needs of survivors are not routinely addressed.

Leveraging existing information on patient diagnosis and care may help to address some survivorship needs. Unbeknownst to most patients, cancer is a notifiable disease, and collection of cancer registry data for public health surveillance is mandated by law in all U.S. states or jurisdictions. Hospitals, physicians' offices, pathology laboratories, and other medical facilities submit data on new cancer diagnoses to a central cancer registry at the state or territorial level. Both the data routinely collected through cancer registries and the existing data collection infrastructure are uniquely poised to address many needs of cancer survivors, their physicians, and researchers.

The Dots: National Program of Cancer Registries in Practice and Research

In 1992, Congress established the National Program of Cancer Registries (NPCR) by enacting the Cancer Registries Amendment Act, Public Law 102-515.[5] Before NPCR was established, ten states had no registry, and most states with registries lacked the resources and legislative support they needed to gather complete data. Administered by CDC, NPCR funds 45 states, the District of Columbia, Puerto Rico, and the U.S. Pacific Island Jurisdictions, which covers 96% of the U.S. population.[6] These central cancer registries collect data on the occurrence of cancer, which includes the type, extent (stage), and anatomic origin (primary site) of the cancer (Table 1). Together, NPCR and the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program[7] collect data for the entire U.S. population. Both NPCR and SEER use North American Association of Cancer Registries standards and work together to ensure compatibility and comparability of U.S. cancer incidence, regardless of funding source.[8] Using these data, CDC and the National Cancer Institute publish annual data from both NPCR and SEER in the U.S. Cancer Statistics Incidence and Mortality Web-based Report.[9] Although this online report hosts the official federal cancer statistics of the U.S., NPCR and SEER data are also made available through other online tools, including CDC-WONDER,[10] CDC's Environmental Public Health Tracking Network,[11] and State Cancer Profiles.[12] Additionally, NPCR analytic data are available to researchers free through CDC's National Center for Health Statistics Research Data Center.[13]

Data collection occurs at the healthcare facility or central cancer registry through medical record abstraction or electronic reporting. Incident cases from all hospitals, physicians' offices, pathology laboratories, treatment facilities, and other medical facilities are reportable to the central cancer registry. The goal of the central cancer registry is to collect a

standard set of data on all cancer patients. Consequently, the data in the state or territorial central registries represent everyone diagnosed or treated for cancer, regardless of race, age, insurance status, or geography and are submitted to NPCR or SEER on an annual basis. Because patient populations and the infrastructure needs of each state and territory are unique, central cancer registries vary in the amount of funding they receive. A recent study looking at five NPCR programs revealed that the cost per cancer case ranged from $24 to $96 while the cost of data enhancements and analysis ranged from $2.91 to $9.31 per case.[14] However, despite these costs, the information captured in the central registry are invaluable to cancer surveillance and research and reflects real-world clinical experiences of diverse populations in all medical care settings.

A brief summary of the data items collected by all central cancer registries is shown in Table 1. Because these data items may come from different sources, and patients often visit various healthcare providers during their course of diagnosis and treatment, multiple health facilities may be reporting information on the same incident cancer. Although the central cancer registry is responsible for case consolidation, CDC has several surveillance informatics initiatives underway to identify better ways to use emerging technology to incorporate automated processes and electronic data exchange in cancer reporting. Examples of these initiatives include the automated transmission of pathology information to central cancer registries using the encoded College of American Pathologists Cancer Checklists and Health Level Seven messages, and cancer reporting from ambulatory providers to registries in a new public health objective for Stage 2 Meaningful Use.[15]

Additionally, the central cancer registry conducts data linkages with state and national databases to supplement or improve the data. Every central cancer registry routinely links cancer data with that of its state death files, the National Breast and Cervical Cancer Early Detection Program, the National Death Index, and the Indian Health Service. Some registries optionally link with other data sources, such as Medicare and Medicaid claims files to address gaps identified in their data or improve the usefulness of the data for local cancer control activities.

Together, NPCR and SEER form one of the most sophisticated public health surveillance systems in the U.S. and are the basis for nearly all cited cancer statistics and projections, including the Annual Report to the Nation on the Status of Cancer[16-18] and the American Cancer Society's Cancer Facts & Figures.[19] These routine cancer surveillance activities are paramount to all cancer research, including cancer survivorship research. In addition to the routine cancer surveillance activities of NPCR that provide incidence, mortality, and cancer prevalence estimates for the majority of the U.S., CDC has a number of initiatives underway specifically designed for cancer survivorship research and care.

Using Cancer Registries for Study Recruitment

Central cancer registries are uniquely capable of providing population-based lists of all patients diagnosed with a particular cancer for the purposes of research and health interventions. Cancer registries strive to include all cancer patients regardless of their SES, where they live, and whether or not they received the best clinical care. These real-world

populations are invaluable in evaluating the effectiveness of interventions, whether they are new cancer treatments or behavior changes. Though state and jurisdictional laws and regulations designed to protect patient privacy dictate the availability and specific uses of cancer registry data for research purposes, CDC has undertaken a number of activities to help understand the potential that NPCR registries have for such activities.

Early Case Capture for Pediatric Cancer

Because of the complexity of cancer reporting and required follow-up, reports to the central cancer registry are often delayed beyond 6 months for reporting facilities to capture all diagnostic and treatment information on a particular case. This delay at the registry level can often limit the utility of such data for identification and recruitment of patients into clinical trials. In response to this issue, and to the Carolyn Pryce Walker Act (2008)[20] that sought to improve the completeness and timeliness of pediatric cancer tracking, CDC is piloting an Early Case Capture project for pediatric cancer cases. Seven NPCR registries are asking reporting facilities to submit pediatric cases to them within 30 days of diagnosis through this pilot, which has the potential to lead to increased clinical trial enrollment and to accelerate other surveillance and research activities across the cancer care continuum.[21]

Behavioral Interventions

The use of population-based cancer registries for study recruitment is a common practice in some states.[22-30] However, for others, use of cancer registries for research recruitment purposes is limited. Thus, CDC has recently undertaken a number of initiatives to understand how it can work at the federal level to facilitate and promote use of cancer registries in these ways. In 2012, CDC funded a 3-year project through its Prevention Research Centers to explore new ways that registry data could be used to improve cancer screening among breast and colorectal cancer survivors and their relatives. Funding was awarded to three Prevention Research Centers to collaborate with their state cancer registries to accomplish this goal: Emory School of Public Health, Michigan School of Nursing, and the University of California at Los Angeles. Each center took a unique approach and is currently analyzing its findings. Overall, CDC found that although recruitment of survivors was efficient and effective using cancer registry data, there were challenges to recruiting the family members of the survivors into studies. To continue use of cancer registries in the identification and recruitment of people at high-risk of negative health outcomes, CDC has released an announcement to fund an additional project in 2015 that would use cancer registry data to promote proactive tobacco cessation (RFA-DP-15-008, SIP 15-003).

Comparative Effectiveness and Patient-Centered Outcomes Research

In 2010, CDC was awarded funding to support Comparative Effectiveness Research through the American Recovery and Reinvestment Act of 2009. This project established ten Specialized NPCR Registries to collect enhanced data for people diagnosed in 2011 with breast (n>48,000), colon (n>18,00), or rectum (n>7,000) cancer or with chronic myeloid leukemia (n>700).[31] Information collected included all typically required NPCR data elements and more-detailed information on specific treatments, biomarkers/prognostic markers, comorbid conditions, Census Tract–level SES measures, and personal

characteristics such as height and weight at diagnosis (used to dose chemotherapy), smoking status, and occupation as available. One goal of this project was to examine population-based treatment patterns in comparison to treatment guidelines. Over time, survival will be compared between patients receiving different treatments. These unique data will educate both providers and cancer survivors on treatment options, practices, and potential barriers to delivery and receipt of standards of care. Multiple analyses of these data are currently underway by CDC and its state partners to explore critical issues in cancer care, including guideline-concordant use of biomarker testing and type of treatment for breast and colorectal cancer by stage. As with all NPCR data, these Comparative Effectiveness Research data are available to researchers with the appropriate human subject protection approvals through CDC's Research Data Center.

In 2013, CDC obtained additional support through a Patient-Centered Outcomes Research Trust Fund award via the Assistant Secretary for Planning and Evaluation to collect intermediate outcomes such as progression, recurrence, and vital status, as well as subsequent therapy information on the same 2011 breast, colon, and rectum cancer cases in five of the ten Specialized NPCR Registries. A minimum of 32 months of follow-up will be completed for these cases. Through active patient follow-up, this effort will capture those with more consistent aftercare visits versus those lost to follow-up and better describe disease-free periods and time to recurrence or progression. This information will provide data on intermediate outcomes that are important to cancer survivors and their providers, as well as traditional survival statistics. In addition, these data will illustrate real-world outcomes in a population that is more varied in age and comorbid conditions than patients normally included in clinical trials. On a population level, this will give researchers a better understanding of disease course by site and stage after completion of first-course therapy. Once collected, these data will also be made available through CDC's Research Data Center to improve the cancer community's understanding of population-level outcomes such as progression and recurrence for these specific cancers.

Treatment Summaries and Care Plans

In response to the 2005 IOM report,[4] a number of expert organizations have recommended that patients, along with their primary care providers, receive from the oncology team a summary of treatment provided as part of a comprehensive survivorship care plan. Despite limited evidence of their effectiveness, these plans are now included in a number of cancer quality initiatives.[14, 32-34] Even with the increasing interest in survivorship care plans, few recently diagnosed survivors report receiving treatment summaries and written follow-up instructions, and receipt of these documents varies widely by subgroup.[35, 36]

There are a number of challenges to cancer survivorship care plan implementation. Provider barriers include limited staff, time, and technologic resources to develop and deliver the plans, lack of reimbursement and information, and communication systems failing to optimize communication and coordination of care.[37] Patients with cancer often require treatment by multiple specialists (surgeons, radiation oncologists, medical oncologists) as part of multimodal therapies. As a result, there is seldom a single integrated medical record, and there may be limited formal written communication between specialists.

To help reduce provider barriers to delivering cancer survivorship care plans, CDC in collaboration with the Colorado Central Cancer Registry recently developed a secure, web-based application that allows individual hospitals or providers to use previously collected cancer surveillance data from the central cancer registry to pre-populate and semi-automate care plans. The Web Plus Survivorship Module includes templates for breast and colorectal cancers, a generic template for all other cancers, and a collection of static resource documents covering general cancer information, physical activity, nutrition, stress management, sexual health, and smoking cessation. The module includes Spanish versions of all templates and materials. The Colorado registry conducted a pilot project with four hospital-based survivorship programs and their staff oncologists to create survivorship care plans using this tool. Oncology providers who developed and delivered the plans reported high satisfaction with the web-based application in focus groups. Patients also reported high satisfaction with the care plans they received. CDC continues to work with the Colorado Central Cancer Registry to integrate the tool into Registry Plus™, a suite of publically available free software programs developed and supported by CDC for collecting and processing cancer registry data.[38] Though the Web Plus Survivorship Module is still in the final stages of beta testing, CDC is exploring expanding use of the module to other NPCR cancer registries as well as development of new content for additional cancer types.

Although the completeness and timeliness of data collected through cancer registries may limit the availability of some data for populating survivorship care plans, at least some of the data needed by the clinician compiling a care plan will be available in the registry. This project demonstrates innovative use of routinely collected registry data to inform cancer survivors about their cancer diagnosis, the care they have received, and expectations for their next steps and future care. It also helps healthcare providers develop and deliver survivorship care plans that meet requirements of initiatives meant to improve the quality of cancer care. This project leverages resources, using previously collected data from the central cancer registry to reach out to community oncologists and primary care providers to illustrate how the registries can help them improve communications and efficiencies in meeting the needs of cancer survivors. The multidirectional sharing of health information as demonstrated in this project has tremendous potential and applicability for not only cancer registries and survivorship care, but also other disease registries. CDC plans to continue this initiative with the goals of facilitating the integration of this system into existing physician workflows for interested hospitals or vendors, exchanging structured data across systems, and leveraging existing tools to allow patients to access all their health information, treatment summary, and survivorship care plan electronically.

Connecting the Dots to Create a Picture of Quality Survivorship Care for Patients and Populations—A Vision for the Future

The NPCR cancer registries are faced with a number of barriers and challenges to collecting, maintaining, and disseminating the most useful data for public health surveillance and research. Existing legal and regulatory requirements often dictate the availability and use of certain data. Registry data collection is traditionally limited by the type of data available in medical records. Finally, the availability of resources (e.g., financial, personnel, information

technology) at the national, state/territorial, and local levels also constrain the capabilities of cancer registries. However, if cancer registries can find ways to overcome these barriers, they have tremendous potential to improve quality cancer survivorship care.

Applying Registry Data for Quality Assessment and Improvement

Given the registry systems and processes that form an infrastructure for cancer surveillance, the potential to link these "dots" to promote quality survivorship care and research is promising. Take the data for a given breast cancer patient, "Ms. P." Information about Ms. P and her cancer diagnosis is reported to a central cancer registry. These data are available for epidemiologic and population surveillance studies—the traditional applications of the registry system. However, the Web Plus Survivorship Module project demonstrates how these data can also be used to improve Ms. P's care directly by facilitating completion of her survivorship care plan. This contributes to her care by making it possible, or at a minimum easier, to provide her with a cancer survivorship care plan.

In addition to being used directly in an individual patient's care, the registry data aggregated across patients provide useful information on patterns of care and outcomes. For example, the American Society for Clinical Oncology piloted a registry for survivorship care plan data in which 20 practices entered data on 2,014 newly diagnosed breast cancer patients.[39] These data were used to populate treatment plans and summaries and could be used to produce practice-specific and aggregate quality measures (e.g., the proportion of eligible women prescribed adjuvant hormone therapy). The comparative effectiveness and patient-centered outcomes work conducted by CDC through NPCR is another example of how registries can be used to evaluate quality of care through collection and consolidation of treatment data and outcomes.

Evaluations of care quality can, in turn, guide quality improvement initiatives. Though not a registry, per se, the Quality Oncology Practice Initiative (QOPI) provides an example of how this could work.[34] QOPI is a voluntary system for oncology practices to report their performance on a number of quality indicators, and as illustrated by Blayney et al.,[40] the reporting and benchmarking information helped inform quality improvement at the University of Michigan Comprehensive Cancer Center. The QOPI data showed that an above-average percentage of cancer patients at the University of Michigan were receiving chemotherapy during the last 2 weeks of life. After these data were provided to the faculty oncologists, this number decreased from approximately 50% to 20%.

Linking Registry Data With Patient-Reported Outcomes to Make Care and Research More Patient-Centered

Although clinical data abstracted from medical records provide important information on patterns of care and outcomes, these data become more powerful when linked with the patient perspective, measured via patient-reported outcomes (PROs).[41] PROs are reports directly from the patient about health, disease, or treatment, without amendment or interpretation by a clinician or anyone else. PRO is an umbrella term that can refer to symptoms, functioning, treatment satisfaction, and health-related quality of life, among

other measures.[42, 43] PROs are increasingly being incorporated in electronic health records,[44] expanding their availability for clinical care and research.

Imagine that throughout her cancer treatment, Ms. P completed a brief questionnaire that covered her functioning, well-being, and symptoms. This PRO reporting system might help her clinician identify and address Ms. P's anxiety due to her cancer. This information could be included in her survivorship care plan to advise her primary care provider that this issue requires monitoring and potential management. In fact, quite a few electronic systems have been developed for this purpose of assessing PROs in practice.[45] Again, these data become more powerful when linked with other clinical information, such as an electronic health record, a cancer registry, or clinical trials.[41] For example, QOPI is planning to pilot PRO quality indicators to make its quality reporting system more patient-centered.[46] Similarly, the SEER registry data for Medicare Advantage beneficiaries has been linked with the Medicare Health Outcomes Survey, thereby linking registry data with PRO data.[47] Rather than linking the PRO and registry data after data have been submitted, patient portals, such as the electronic PRO reporting systems described above, could be used to enter the PRO data directly into the registry database. Though many significant challenges exist for collecting PROs through cancer registries, such as limitations in local legislation, working toward enabling a more fluid data exchange process among patients, clinicians, healthcare facilities and the central cancer registry would allow for better health communication and immediate outcomes, as well as improving the timeliness of cancer research and surveillance.

Connecting the dots of the PRO and clinical information creates a powerful platform for a learning healthcare system. In IOM's 2013 publication, "Best Care at Lower Cost: The Path to Continuously Learning Health Care in America," a learning healthcare system is one that uses advances in computing, information science, and connectivity to improve communication between the patient and clinician, point-of-care guidance, the capture of experience, population surveillance, planning and evaluation, and the application of real-time knowledge.[48] Though not necessarily population-based, such a system would enable examination of cancer survivorship issues such as the rates of moderate/severe nausea associated with different chemotherapy regimens under real-world practice conditions, the long-term impact on cognitive function of different doses of radiation to the brain, or the impact of treatments on sexual function. The American Society for Clinical Oncology's CancerLinQ is being developed for this purpose.[49] Its long-term goal is to provide real-time quality feedback and decision support while analyzing patterns of care.[50] When PROs are linked to, or included in, electronic health records or registries, they provide essential information from the patient perspective to these learning health systems, enabling new information from the cancer care experience to inform the biomedical knowledge base.

Conclusions

Cancer surveillance data remain the core of cancer epidemiology and outcomes in clinical cancer research. Cancer registries are among the most sophisticated and standardized surveillance systems in the U.S. and have been used as a reputable source of surveillance, epidemiology, or comparative effectiveness/patient-centered outcomes research data for

decades. Whether for repurposing public health surveillance data to directly aid in patient care or for contributing to the understanding of how cancer treatments influence population health, cancer registries are uniquely poised to serve as a source of critical data for cancer survivors, clinicians, and researchers.

As a leader in the development of policies and methodologies for collecting complex clinical data more rapidly through electronic advances, CDC manages NPCR in a health data environment that is swiftly changing. To remain at the forefront of clinical and epidemiologic research, NPCR registries will continue to expand their usefulness to cancer survivors, providers, and researchers—and enhance the infrastructure for rapid reporting of incident cancer cases while simultaneously acknowledging the importance of capturing more-complete treatment data.

Acknowledgments

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of CDC.

References

1. Hoyert DL, Xu J. Deaths: preliminary data for 2011. Natl Vital Stat Rep. 2012; 61(6):1–51. [PubMed: 24984457]
2. Surveillance, Epidemiology, and End Results (SEER) Program SEER*Stat Database: Incidence - SEER 18 Regs Research Data + Hurricane Katrina Impacted Louisiana Cases, Nov 2013 Sub (1973-2010 varying), National Cancer Institute, DCCPS, Surveillance Research Program, Surveillance Systems Branch, released April 2013, based on the November 2013 submission. Available at www.seer.cancer.gov. Accessed June 30, 2015
3. de Moor JS, Mariotto AB, Parry C, Alfano CM, Padgett L, Kent EE, et al. Cancer survivors in the United States: prevalence across the survivorship trajectory and implications for care. Cancer Epidemiol Biomarkers Prev. 2013; 22(4):561–70. doi: 10.1158/1055-9965.EPI-12-1356. Epub 2013 Mar 27. [PubMed: 23535024]
4. National Research Council. From Cancer Patient to Cancer Survivor: Lost in Transition. The National Academies Press; Washington, DC: 2005.
5. Fisher, R.; Haenlein, M. State cancer legislative database update. Vol. 8. US Department of Health and Human Services, Public Health Service, National Institutes of Health. National Cancer Institute; Bethesda, MD: 1991. Legislative authorizations for cancer registries; p. 15National Cancer Institute, National Institutes of Health
6. Centers for Disease Control and Prevention. NPCR: Contact a Local Regsitry website. http://nccd.cdc.gov/dcpc_Programs/default.aspx?NPID=3. Accessed June 30, 2015
7. National Cancer Institute. SEER Program-Official website. http://seer.cancer.gov/. Accessed June 30, 2015
8. Howe HL, Wingo PA, Thun MJ, Ries LA, Rosenberg HM, Feigal EG, et al. Annual report to the nation on the status of cancer (1973 through 1998), featuring cancers with recent increasing trends. J Natl Cancer Inst. 2001; 93(11):824–42. [PubMed: 11390532]
9. U.S. Cancer Statistics Working Group. United States Cancer Statistics: 1999-2011 Incidence and Mortality Web-based Report. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; Atlanta: 2014. Available at: www.cdc.gov/uscs
10. United States Cancer Statistics: 1999 - 2011 Incidence, WONDER Online Database. 2014. United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer InstituteAvailable at http://wonder.cdc.gov/cancer-v2011.html. Accessed June 30, 2015

11. Centers for Disease Control and Prevention. National Environmental Public Health Tracking Network Cancer Data website. http://ephtracking.cdc.gov/showCancerMain.action. Accessed June 30, 2015
12. National Cancer Insitute. State Cancer Profiles website. http://statecancerprofiles.cancer.gov/. Accessed June 30, 2015
13. Centers for Disease Control and Prevention. National Center for Health Statistics, Research Data Center website. http://www.cdc.gov/rdc/index.htm. Accessed June 30, 2015
14. Tangka F, Subramanian S, Beebe MC, Trebino D, Michaud F. Economic assessment of central cancer registry operations, Part III: Results from 5 programs. J Registry Manag. 2010; 37(4):152–5. [PubMed: 21688745]
15. Centers for Disease Control and prevention. NPCR Meaningful Use and Electronic Health Records website. http://www.cdc.gov/cancer/npcr/meaningful_use.htm. Accessed June 30, 2015
16. Edwards BK, Noone AM, Mariotto AB, Simard EP, Boscoe FP, Henley SJ, et al. Annual Report to the Nation on the status of cancer, 1975-2010, featuring prevalence of comorbidity and impact on survival among persons with lung, colorectal, breast, or prostate cancer. Cancer. 2014; 120(9): 1290–314. doi: 10.1002/cncr.28509. Epub 2013 Dec 16. [PubMed: 24343171]
17. Eheman C, Henley SJ, Ballard-Barbash R, Jacobs EJ, Schymura MJ, Noone AM, et al. Annual Report to the Nation on the status of cancer, 1975-2008, featuring cancers associated with excess weight and lack of sufficient physical activity. Cancer. 2012; 118(9):2338–66. doi: 10.1002/cncr.27514. Epub 2012 Mar 28. [PubMed: 22460733]
18. Jemal A, Simard EP, Dorell C, Noone AM, Markowitz LE, Kohler B, et al. Annual Report to the Nation on the Status of Cancer, 1975-2009, featuring the burden and trends in human papillomavirus(HPV)-associated cancers and HPV vaccination coverage levels. J Natl Cancer Inst. 2013; 105(3):175–201. doi: 10.1093/jnci/djs491. Epub 2013 Jan 7. [PubMed: 23297039]
19. American Cancer Society. Cancer Facts & Figures 2015. American Cancer Society; Atlanta: 2015.
20. H.R. 1553: Caroline Pryce Walker Conquer Childhood Cancer Act. 110th Congress. 2008. 2nd Session. edAvailable at https://www.congress.gov/bill/110th-congress/house-bill/1553/actions. Accessed June 30, 2015
21. Aldrich TE, Vann D, Moorman PG, Newman B. Rapid reporting of cancer incidence in a population-based study of breast cancer: one constructive use of a central cancer registry. Breast Cancer Res Treat. 1995; 35(1):61–4. [PubMed: 7612905]
22. Andrykowski MA, Steffens RF, Bush HM, Tucker TC. Disparities in mental health outcomes among lung cancer survivors associated with ruralness of residence. Psychooncology. 2014; 23(4): 428–36. doi: 10.1002/pon.3440. Epub 2013 Nov 11. [PubMed: 24217966]
23. Ashing K, Rosales M. A telephonic-based trial to reduce depressive symptoms among Latina breast cancer survivors. Psychooncology. 2014; 23(5):507–15. doi: 10.1002/pon.3441. Epub 2013 Nov 11. [PubMed: 24217994]
24. Ashing K, Rosales M, Lai L, Hurria A. Occurrence of comorbidities among African-American and Latina breast cancer survivors. J Cancer Surviv. 2014; 8(2):312–8. doi: 10.1007/s11764-014-0342-x. Epub 2014 Jan 29. [PubMed: 24473830]
25. Brasky TM, Neuhouser ML, Cohn DE, White E. Associations of long-chain omega-3 fatty acids and fish intake with endometrial cancer risk in the VITamins And Lifestyle cohort. Am J Clin Nutr. 2014; 99(3):599–608. doi: 10.3945/ajcn.113.070524. Epub 2014 Feb 5. [PubMed: 24500149]
26. Le D, Holt CL, Pisu M, Brown-Galvan A, Fairley TL, Lee Smith J, et al. The role of social support in posttreatment surveillance among African American survivors of colorectal cancer. J Psychosoc Oncol. 2014; 32(3):245–63. doi: 10.1080/07347332.2014.897293. [PubMed: 24611486]
27. Lewis C, Xun P, He K. Physical activity in relation to quality of life in newly diagnosed colon cancer patients: a 24-month follow-up. Qual Life Res. 2014; 23(8):2235–46. doi: 10.1007/s11136-014-0679-7. Epub 2014 Apr 5. [PubMed: 24706291]
28. Osann K, Hsieh S, Nelson EL, Monk BJ, Chase D, Cella D, et al. Factors associated with poor quality of life among cervical cancer survivors: implications for clinical care and clinical trials. Gynecol Oncol. 2014; 135(2):266–72. doi: 10.1016/j.ygyno.2014.08.036. Epub 2014 Sep 3. [PubMed: 25192629]

29. Rosales M, Ashing K, Napoles A. Quality of cancer follow-up care: a focus on Latina breast cancer survivors. J Cancer Surviv. 2014; 8(3):364–71. doi: 10.1007/s11764-014-0343-9. Epub 2014 Feb 22. [PubMed: 24563169]
30. Warner EL, Montenegro RE, Stroup A, Kinney AY, Kirchhoff AC. Health care concerns of rural childhood cancer survivors. J Health Care Poor Underserved. 2014; 25(2):901–12. doi: 10.1353/hpu.2014.0095. [PubMed: 24858893]
31. Chen VW, Eheman CR, Johnson CJ, Hernandez MN, Rousseau D, Styles TS, et al. Enhancing Cancer Registry Data for Comparative Effectiveness Research (CER) Project: Overview and Methodology. J Registry Manag. 2014; 41(3):103–12. [PubMed: 25419602]
32. Ligibel JA, Denlinger CS. New NCCN guidelines for survivorship care. J Natl Compr Canc Netw. 2013; 11(5 Suppl):640–4. [PubMed: 23704233]
33. NCI. The National Cancer Institute Community Cancer Centers Program (NCCCP): Translating Science into Care. NCCCP Chronicle 2007-2014, http://ncccp.cancer.gov/NCCCP_Chronicle_2007to2014_final.pdf
34. Neuss MN, Desch CE, McNiff KK, Eisenberg PD, Gesme DH, Jacobson JO, et al. A process for measuring the quality of cancer care: the Quality Oncology Practice Initiative. J Clin Oncol. 2005; 23(25):6233–9. Epub 2005 Aug 8. [PubMed: 16087948]
35. Jabson JM, Bowen DJ. Cancer treatment summaries and follow-up care instructions: which cancer survivors receive them? Cancer Causes Control. 2013; 24(5):861–71. doi: 10.1007/s10552-013-0163-7. Epub 2013 Feb 6. [PubMed: 23385334]
36. Sabatino SA, Thompson TD, Smith JL, Rowland JH, Forsythe LP, Pollack L, et al. Receipt of cancer treatment summaries and follow-up instructions among adult cancer survivors: results from a national survey. J Cancer Surviv. 2013; 7(1):32–43. doi: 10.1007/s11764-012-0242-x. Epub 2012 Nov 21. [PubMed: 23179495]
37. Dulko D, Pace CM, Dittus KL, Sprague BL, Pollack LA, Hawkins NA, et al. Barriers and facilitators to implementing cancer survivorship care plans. Oncol Nurs Forum. 2013; 40(6):575–80. doi: 10.1188/13.ONF.575-580. [PubMed: 24161636]
38. Centers for Disease Control and Prevetion. Registry Plus. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion; Atlanta (GA): 2015. Available at: http://www.cdc.gov/cancer/npcr/. Accessed June 30, 2015.; Available from: http://www.cdc.gov/cancer/npcr/tools/registryplus/index.htm
39. Partridge AH, Norris VW, Blinder VS, Cutter BA, Halpern MT, Malin J, et al. Implementing a breast cancer registry and treatment plan/summary program in clinical practice: a pilot program. Cancer. 2013; 119(1):158–63. doi: 10.1002/cncr.27625. Epub 2012 Nov 29. [PubMed: 23197186]
40. Blayney DW, McNiff K, Hanauer D, Miela G, Markstrom D, Neuss M. Implementation of the Quality Oncology Practice Initiative at a university comprehensive cancer center. J Clin Oncol. 2009; 27(23):3802–7. doi: 10.1200/JCO.2008.21.6770. Epub 2009 Jun 1. [PubMed: 19487377]
41. Snyder CF, Jensen RE, Segal JB, Wu AW. Patient-reported outcomes (PROs): putting the patient perspective in patient-centered outcomes research. Med Care. 2013; 51(8 Suppl 3):S73–9. doi: 10.1097/MLR.0b013e31829b1d84. [PubMed: 23774513]
42. Acquadro C, Berzon R, Dubois D, Leidy NK, Marquis P, Revicki D, et al. Incorporating the patient's perspective into drug development and communication: an ad hoc task force report of the Patient-Reported Outcomes (PRO) Harmonization Group meeting at the Food and Drug Administration, February 16, 2001. Value Health. 2003; 6(5):522–31. [PubMed: 14627058]
43. U.S. Food and Drug Administration. Guidance for Industry: Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims. Dec. 2009 Federal RegisterAvailable at: http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf. Accessed June 30, 2015
44. Wu, AW.; Jensen, RE.; Salzburg, C.; Snyder, C. Advances in the use of patient reported outcome measures in electronic health records: including case studies. Landscape review prepared for the PCORI National Workshop to Advance the Use of PRO Measures in Electronic Health Records; Atlanta, GA. Nov 19-20. 2013

45. Jensen RE, Snyder CF, Abernethy AP, Basch E, Potosky AL, Roberts AC, et al. Review of electronic patient-reported outcomes systems used in cancer clinical care. J Oncol Pract. 2014; 10(4):e215–22. doi: 10.1200/JOP.2013.001067. Epub 2013 Dec 3. [PubMed: 24301843]

46. Basch E, Snyder C, McNiff K, Brown R, Maddux S, Smith ML, et al. Patient-reported outcome performance measures in oncology. J Oncol Pract. 2014; 10(3):209–11. doi: 10.1200/JOP.2014.001423. Epub 2014 Apr 22. [PubMed: 24756142]

47. National Cancer Institute. SEER-Medicare Health Outcomes Survey (SEER-MHOS) Linked Database website. http://appliedresearch.cancer.gov/seer-mhos/. Accessed June 30, 2015

48. Institute of Medicine. Best care at lower cost: The path to continuously learning health care in America. the National Academies Press; Washington, DC: Sep 6. 2012 Available at http://www.iom.edu/Reports/2012/Best-Care-at-Lower-Cost-The-Path-to-Continuously-Learning-Health-Care-in-America.aspx. Accessed June 30, 2015

49. ASCO. CancerLinQ website. http://cancerlinq.org/. Accessed June 30, 2015

50. ASCO Institute for Quality, LLC. CancerLinQ™ website. http://www.instituteforquality.org/cancerlinq. Accessed June 30, 2015

Table 1

Summary of Data Items Collected by All Central Cancer Registries

Data type	Examples of data items collected
Record ID	Registry identification
	Patient name[a]
Demographics	Patient address[a]
	Race
	Spanish/Hispanic origin
	Sex
	Date of birth
Cancer identification	Primary site
	Histologic type (ICD-O-3)
	Behavior code (ICD-O-3)
	Grade
	Date of diagnosis
Stage/Prognostic factors	Stage Tumor size
Treatment	Type of first course of definitive treatment
	Date of first course of definitive treatment
Follow-up/Recurrence/Death	Date of last contact
	Date of death
	Underlying cause of death

[a] CDC does not receive patient identification information.