

Enhancing Capacity for Primary Care Research in Cancer Survivorship: A Workshop for Action

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Executive Summary

Introduction

Cancer survivorship care includes surveillance for recurrence and new malignancies, screening and management of physical and psychosocial effects of cancer and its treatment, care coordination, and health promotion and preventive care. Survivors also may require other care: addressing chronic conditions (not related to cancer), optimizing psychosocial functioning, practicing preventive care, and supporting positive health behaviors. Many of these components of care are managed by primary care providers (PCPs).

Given the important role that PCPs have in this care, it is critical to ensure that they are prepared to address the needs of all survivors. Although many PCPs currently provide or are interested in providing high-quality care for survivors, they experience substantial barriers. For example, cancer survivors are not a distinct clinical category, and providers may not have access to actionable information on diagnosis, treatment history, or recommendations for follow-up care. The challenge of delivering high-quality survivorship care is exacerbated by a shrinking and overburdened PCP workforce, a fragmented health system, patient-level factors such as variability in health insurance coverage and issues with language and health literacy, contextual barriers stemming from organizational policies, and neighborhood or community factors such as the availability of affordable transportation.

Evidence-based strategies to deliver survivorship care in the primary care setting, however, are limited. While there have been efforts to improve PCP capacity and knowledge regarding care for survivors, these initiatives have not resulted in widespread change. Previous efforts have included training programs for interested PCPs, interventions targeting individual PCPs (not practices or health systems), or survivorship care plans, which often focus on documentation rather than the ongoing process of coordination in survivorship care.

There are challenges to conducting research focused on primary care and cancer survivorship. To further elucidate research needs for addressing the intersection between these two fields, the Office of Cancer Survivorship at the National Cancer Institute (NCI) held a virtual workshop to discuss actionable opportunities to develop capacity in this area of science. The meeting goals included identifying the key challenges and facilitators influencing the development and implementation of research on primary care and survivorship, and how best to incorporate different perspectives and disciplines to create new opportunities for impact.

The workshop began with a presentation of the challenges of conducting this type of research, followed by a discussion of specific topics that are essential to this work, such as system-level interventions, methods and measurement, and mentoring/team building.

Key Takeaways

Below we summarize challenges and opportunities that are essential to consider when working to build capacity for research on primary care and survivorship.

Setting the Stage

Shawna Hudson, PhD

- Cancer survivors are often not a visible and clinically defined population in primary care, yet they have distinct needs.
- Current information systems are insufficient to support survivorship care.
- PCPs receive limited information or follow-up guidance on patients' cancer care.
- There is a need for health system buy-in for patient, practice, and system-level interventions.
- There is often limited infrastructure to conduct primary care research.
- There is limited organizational support to test models of care and practice-level interventions.
- It is often difficult to engage PCPs who are in clinical care, as many do not have dedicated time for research.
- High-quality primary care is integrated, accessible, and equitable across settings, requiring sustained relationships with individuals, families, and communities.

Advancing Systems-Level Research

Moderated by Erin Hahn, PhD, MPH

Presentations by Youngjee Choi, MD; Bijal Balasubramanian, MBBS, PhD; and Simon Craddock Lee, PhD

- Barriers to system-level interventions in primary care and survivorship include time, appropriate resources, and clinician knowledge and self-efficacy.
- For health systems to see the value of interventions, primary care research must be aligned with the objectives of PCPs.
- There is a need to find mutually meaningful questions and alignment of goals to engage both PCPs and researchers without simply asking primary care to "do more."
- There is also a need to identify and work with champions at all levels and areas, including executives and administrators as well as clinical care teams (e.g., nurses, social workers, navigators, physicians, advanced practice providers) in primary and oncology care.
- Both primary care *and* oncology teams should be engaged concurrently when developing and testing system-level interventions to ensure primary care clinicians are actively involved throughout the cancer care journey.
- For ease of referral to survivorship services, appropriate educational programs and electronic tools should be accessible to primary care clinicians at the point of care.

Methods Challenge: Identifying Cancer Survivors Within Primary Care Practices

Moderated by Jennifer Klemp, PhD, MPH, MA

Presentations by K. Allen Greiner, MD, MPH; Kimberly Kaphingst, ScD; and Urmimala Sarkar, MD, MPH

- Identifying survivors within primary care is a challenge across multiple geographical areas and health systems.
- Patients and families believe providers should have all of their medical and treatment history, but providers do not always have this information easily accessible or in a usable form.
- Structured data within the Electronic Health Record (EHR) designed for billing purposes and to track clinical care needs could be useful for research but require additional cleaning, structure, and manipulation to answer research questions with appropriate data analytics.
- Registries are useful to identify cancer survivors, but researchers need to navigate the capabilities, legislation, and restrictions, as well as delays with availability of data.
- Identifying survivors within primary care practices is one example of a methods challenge; there are likely others that this community of practice needs to discuss.

Mentoring and Team Building for Research Success

Moderated by Shawna Hudson, PhD

Fireside Chat with Deborah Cohen, PhD; Alexander Krist, MD; Larissa Nekhlyudov, MD, MPH; Denalee O'Malley, PhD, MSW; and Archana Radhakrishnan, MD, MHS

- It is essential for researchers in this area to be active in establishing and re-establishing relationships and connections, including asking questions and offering collaboration opportunities.
- To build teams with clinicians, researchers need to appeal to the work that is germane to clinical care.
- Community-based participatory research approaches can be effective in working with primary care providers, but it can take time to establish relationships.
- Mentoring is not routinely supported by grant funding and is difficult to do without protected time, and this is true for early, mid-, and senior-level researchers.
- To build a team and be successful conducting research in primary care and cancer survivorship, you likely need multiple mentors who can champion your work, challenge your thinking, and help bridge clinical and research disciplines.

Cross-Cutting Ideas

- Researchers must actively engage with primary care providers where they gather and meet, including engaging at their conferences, to understand the PCPs' needs and challenges.
- Survivors and people with lived experience need to be partners throughout this research.
- To advance research on primary care and survivorship, researchers need to engage with people who have diverse perspectives and voices.

A key outcome of this workshop will be the development of a community of practice to facilitate collaborations that span different research areas, disciplines, and organizations. From this initial conversation, we will build an ongoing agenda of critical topics to address together in our future community of practice.

Co-chairs

Shawna Hudson, PhD

Rutgers Robert Wood Johnson Medical School
Rutgers Cancer Institute of New Jersey
New Jersey Alliance for Clinical and Translational Science

Erin Hahn, PhD, MPH

Kaiser Permanente Southern California
Kaiser Permanente Bernard J. Tyson School of Medicine

Jennifer Klemp, PhD, MPH

University of Kansas Medical Center
University of Kansas Cancer Center

In Collaboration with the NCI Office of Cancer Survivorship

Emily Tonorezos, MD, MPH

Michelle Mollica, PhD, MPH, RN, OCN

Crystal Reed, MHA