

# Welcome!

## 2019 Monthly Webinar Series

**Network** without  
leaving your desk.



# Welcome!

- ▶ Sarah Kerch, MPH
- ▶ Program Director



# This Month's Topic: Survivorship

## ► Agenda:

- Survivorship At-A-Glance
  - Growing need for cancer survivorship efforts
  - Cancer survivorship in Wisconsin
- 2019 WI Cancer Summit
  - Date, Location, Theme, Objectives
  - Planning Update
  - Discussion

# Evidence-based Approaches for Survivorship Care: Where are the Research Gaps?

- ▶ National Cancer Institute expert meeting held earlier 2019
  - ▶ In attendance:
    - ▶ Dr. Melinda Stolley, PhD
    - ▶ Associate Director Prevention and Control, Cancer Center
    - ▶ Medical College of WI
    - ▶ Chair, WI Cancer Council



# Growing Need

CA CANCER J CLIN 2019;69:35–49

## Equitably Improving Outcomes for Cancer Survivors and Supporting Caregivers: A Blueprint for Care Delivery, Research, Education, and Policy

Catherine M. Alfano, PhD<sup>1</sup>; Corinne R. Leach, PhD, MPH<sup>2</sup>; Tenbroeck G. Smith, MA<sup>2</sup>; Kim D. Miller, MPH<sup>3</sup>;  
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doi: 10.3322/caac.21548. Available online at [cancerjournal.com](http://cancerjournal.com)

**Abstract:** Cancer care delivery is being shaped by growing numbers of cancer survivors coupled with provider shortages, rising costs of primary treatment and follow-up care, significant survivorship health disparities, increased reliance on informal caregivers, and the transition to value-based care. These factors create a compelling need to provide coordinated, comprehensive, personalized care for cancer survivors in ways that meet survivors' and caregivers' unique needs while minimizing the impact of provider shortages and controlling costs for health care systems, survivors, and families. The authors reviewed research identifying and addressing the needs of cancer survivors and caregivers and used this synthesis to create a set of critical priorities for care delivery, research, education, and policy to equitably improve survivor outcomes and support caregivers. Efforts are needed in 3 priority areas: 1) implementing routine assessment of survivors' needs and functioning and caregivers' needs; 2) facilitating personalized, tailored, information and referrals from diagnosis onward for both survivors and caregivers, shifting services from point of care to point of need wherever possible; and 3) disseminating and supporting the implementation of new care methods and interventions. **CA: Cancer J Clin** 2019;69:35–49. © 2019 American Cancer Society.

**Keywords:** cancer survivors, disease management, evidence-based practice, health policy, survivorship

### Rising Numbers of Cancer Survivors

More than 1.7 million Americans are expected to be diagnosed with cancer in 2018 (Fig. 1).<sup>1,2</sup> This number of new cancer cases in America continues to increase each year despite declining incidence rates in men and stable rates in women<sup>3</sup> as a result of population growth and aging. The rising cancer case burden as well as advances in early detection and treatment<sup>4</sup> all contribute to an unprecedented and continuing rise in the number of Americans living with a history of cancer, a group referred to as *cancer survivors*. Although 5-year survival rates vary substantially by type of cancer (Fig. 1),<sup>1,2</sup> many survivors are living years beyond their disease. Of the nearly 15.5 million cancer survivors, 67% were diagnosed 5 or more years ago, and 17% were diagnosed 20 or more years ago.<sup>4</sup>

Demographic shifts are expected to shape the numbers of survivors dramatically in the near future. With population aging and growth, the number of American cancer survivors is projected to rise to 20.3 million in 2026 and to 26.1 million by 2040.<sup>5</sup> The aging US population also will result in increases in the number of older cancer survivors: 73% of survivors will be age 65 years or older by 2040, up from 62% in 2016.<sup>5</sup> The increase in the number of older adults with cancer has implications for the delivery of oncology and posttreatment follow-up care, because older adults are likely to need management of multiple comorbid conditions concurrent with their cancer-specific care.<sup>5</sup>

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# Growing Need

- ▶ 1.7 million Americans expected to be diagnosed with cancer in 2018
- ▶ Americans living with history of cancer growing due to population growth, aging, advances in early detection and treatment
  - ▶ 20.3 million in 2026 to 26.1 million in 2040
- ▶ Changing demographics
  - ▶ Aging: 73% of cancer survivors will be 65+ by 2040, up from 62% in 2016
  - ▶ Race and ethnicity: 125 million in 2016 to 157 million in 2030
    - ▶ non-Hispanic white to stay relatively flat
    - ▶ Mortality gap continues to be high for racial/ethnic minorities younger than 65 years

## Equitably Improving Outcomes for Cancer Survivors and Supporting Caregivers: A Blueprint for Care Delivery, Research, Education, and Policy

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# Growing Need

## ► Implications:

- Older cancer survivors have several comorbidities making delivery of active and post treatment cancer care more challenging
- Racial and ethnic minority cancer survivors face informational, structural, financial barriers to quality cancer care and post treatment care
- Survivorship care research and practices must consider these issues

## Equitably Improving Outcomes for Cancer Survivors and Supporting Caregivers: A Blueprint for Care Delivery, Research, Education, and Policy

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# Opportunities to Address Growing Need

## ► The Blueprint's 3 Priority Areas:

1. Implementing routine assessment of survivors' needs and functioning and caregivers' needs
  - A process for communication between clinicians, survivors and caregivers
  - Comprehensively and routinely assess symptoms and limitations to refer to multidisciplinary teams
  - Patient-reported outcomes (PRO) becoming more widely used to aid in these assessments
2. Facilitating personalized, tailored, information and referrals from diagnosis onward for both survivors and caregivers, shifting services from point of care to point of need wherever possible
  - Use PRO information to facilitate personalized multidisciplinary referrals
3. Disseminating and supporting the implementation of new care methods and interventions
  - Value-based care model and activities to support this model
  - Clear and digitized clinical care guidelines accompanied with regulatory and policy reforms to support new care methods/interventions
  - Work with payers to address under- and unreimbursed care

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# Opportunities to Address Growing Need

## REVIEW

### Survivorship Science at the NIH: Lessons Learned From Grants Funded in Fiscal Year 2016

Julia H. Rowland, Lisa Gallicchio, Michelle Mollica, Nicole Saiontz, Angela L. Falisi, Gina Tesaro

JNCI J Natl Cancer Inst (2019) 111(2): dty208

doi: 10.1093/jnci/dty208  
Advance article

See the Notes section for the full list of authors' affiliations.  
Correspondence to: Julia H. Rowland, PhD, Smith Center for Health and the Arts, 1632 U St NW, Washington, DC 20009 (e-mail: julia@smithcenter.org).

#### Abstract

Federal investment in survivorship science has grown markedly since the National Cancer Institute's creation of the Office of Cancer Survivorship in 1996. To describe the nature of this research, provide a benchmark, and map new directions for the future, a portfolio analysis of National Institutes of Health-wide survivorship grants was undertaken for fiscal year 2016. Applying survivorship-relevant terms, a search was conducted using the National Institutes of Health Information for Management, Planning, Analysis and Coordination grants database. Grants identified were reviewed for inclusion and categorized by grant mechanism used, funding agency, and principal investigator characteristics. Trained pairs of coders classified each grant by focus and design (observational vs interventional), population studied, and outcomes examined. A total of 215 survivorship grants were identified; 7 were excluded for lack of fit and 2 for nonresearch focus. Forty-one (19.7%) representing training grants ( $n = 38$ ) or conference grants ( $n = 3$ ) were not coded. Of the remaining 165 grants, most (88.5%) were funded by the National Cancer Institute, used the large, investigator-initiated (R01) mechanism (66.7%), focused on adult survivors alone (84.2%), often breast cancer survivors (47.3%); were observational in nature (57.3%); and addressed a broad array of topics, including psychosocial and physiologic outcomes, health behaviors, patterns of care, and economic/employment outcomes. Grants were led by investigators from diverse backgrounds, 28.4% of whom were early in their career. Present funding patterns, many stable since 2006, point to the need to expand research to include different cancer sites, greater ethnoculturally diverse samples, and older (>65 years) as well as longer-term (>5 years) survivors and address effects of newer therapies.

It is now over two decades since the National Cancer Institute (NCI) established the Office of Cancer Survivorship (OCS), heralding the intent of NCI leadership to invest in research to better understand and address the long-term consequences of surviving a cancer diagnosis (1). The unique purview of the OCS was—and remains—to support and direct research designed to enhance quality of life, and not simply length of survival, for all those diagnosed with cancer, and to champion studies that examine, as well as intervene, to improve the health and function of those post definitive treatment for cancer. In the years since OCS was created, five national reports have been released, two produced by the Institute of Medicine (2,3), two led by the President's Cancer Panel (4,5), and one sponsored by the

Centers for Disease Control and Prevention, in partnership with the Lance Armstrong Foundation (6), highlighting the gaps in our knowledge regarding the challenges of cancer survivorship and necessary steps to address these. Among the handful of key recommendations cited in each of these documents was the need for more research.

Considerable progress has been made since publication of the *Lost in Transition* report in 2006, considered by many as the benchmark review of the state of survivorship science and care (7). This has included steady growth in survivorship research funding and publications (8,9). As the field matures into young adulthood, however, it is imperative to understand the direction that current research is taking, to evaluate this in the context of

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Published by Oxford University Press 2018. This work is written by US Government employees and is in the public domain in the US.

## COMMENTARY

### Long-Term Survivorship Care After Cancer Treatment - Summary of a 2017 National Cancer Policy Forum Workshop

Ronald M. Kline, Neeraj K. Arora, Cathy J. Bradley, Eden R. Brauer, Darci L. Graves, Natasha Buchanan Lunsford, Mary S. McCabe, Shelley Fuld Nasso, Larissa Nekhlyudov, Julia H. Rowland, Rebekkah M. Schear, Patricia A. Ganz

JNCI J Natl Cancer Inst (2018) 110(12): dty176

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Correspondence to: Ronald M. Kline, Medical Officer, Patient Care Models Group, Center for Medicare & Medicaid Innovation, WB 09-01, 2000 Lord Baltimore Drive, Baltimore, MD 21244 (e-mail: Ron.Kline@cms.hhs.gov).

#### Abstract

The National Cancer Policy Forum of the National Academies of Sciences, Engineering and Medicine sponsored a workshop on July 24 and 25, 2017 on Long-Term Survivorship after Cancer Treatment. The workshop brought together diverse stakeholders (patients, advocates, academicians, clinicians, research funders, and policymakers) to review progress and ongoing challenges since the Institute of Medicine (IOM)'s seminal report on the subject of adult cancer survivors published in 2006. This commentary profiles the content of the meeting sessions and concludes with recommendations that stem from the workshop discussions. Although there has been progress over the past decade, many of the recommendations from the 2006 report have not been fully implemented. Obstacles related to the routine delivery of standardized physical and psychosocial care services to cancer survivors are substantial, with important gaps in care for patients and caregivers. Innovative care models for cancer survivors have emerged, and changes in accreditation requirements such as the Commission on Cancer's (CoC) requirement for survivorship care planning have put cancer survivorship on the radar. The Center for Medicare & Medicaid Innovation's Oncology Care Model (OCM), which requires psychosocial services and the creation of survivorship care plans for its beneficiary participants, has placed increased emphasis on this service. The OCM, in conjunction with the CoC requirement, is encouraging electronic health record vendors to incorporate survivorship care planning functionality into updated versions of their products. As new models of care emerge, coordination and communication among survivors and their clinicians will be required to implement patient- and community-centered strategies.

Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one basic fact. (1)

—June Goodfield as cited in *The Emperor of All Maladies: A Biography of Cancer* by Siddhartha Mukherjee

N.A. is a 48-year-old male diagnosed with aggressive non-Hodgkin's Lymphoma at age 25 years while pursuing his PhD studies. He received chemotherapy for three years and radiation to the head and neck. Treatment was deemed successful and he has been in remission for 23 years. But the road through survivorship continued. About 13 years postdiagnosis, he developed

congestive heart failure and then three years later experienced a near cardiac arrest leading to the placement of an implantable cardioverter defibrillator. Numerous other treatment-related complications ensued, each leading to a new specialist. Despite being an educated researcher, throughout his cancer journey, N.A. has had questions about his diagnoses and has been challenged in trying to understand complex medical information. He has needed help making decisions, longed for emotional support, and faced the daunting task of navigating the health care system, often by himself. He was not a patient treated in a patient-centered, primary care-based medical home, but one in several homes belonging to multiple specialists, not knowing

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Published by Oxford University Press 2018. This work is written by US Government employees and is in the public domain in the US.

# Opportunities to Address Growing Need

- ▶ Conducted a portfolio analysis in 2016 to describe NIH funded survivorship projects between 1996 and 2016:
  - ▶ Nature of research
  - ▶ Establish a benchmark
  - ▶ Clarify future direction
- ▶ Findings and conclusion:
  - ▶ 215 grants on survivorship science
  - ▶ Need to expand research on:
    - ▶ Older, longer-term survivors and caregivers
    - ▶ More diverse sociocultural and geographic backgrounds
    - ▶ Neglected topics: sexual dysfunction, financial toxicity, competing comorbid conditions

## REVIEW

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# Opportunities to Address Growing Need

- ▶ National Cancer Policy Forum of the National Academies of Sciences, Engineering, and Medicine sponsorship a workshop on July 24 and 25, 2017
  - ▶ Diverse stakeholders
  - ▶ Review progress and challenges since IOM's report on adult cancer survivors in 2006
- ▶ Workshop themes:
  - ▶ Progress made since 2006 but many recommendations still need to be fully implemented
  - ▶ Progress includes:
    - ▶ CoC survivorship requirement for survivorship care planning
    - ▶ CMS Innovation's Oncology Care Model requiring psychosocial services and survivorship care plans for beneficiaries

## COMMENTARY

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Julia H. Rowland, Rebekkah M. Schear, Patricia A. Ganz

# Opportunities to Address Growing Need

## ► Recommendations:

1. Workforce education
2. Address all aspects of survivor and caregiver needs
3. Improve data collection on diverse survivor populations
4. Integrate evidence-based psychosocial services into medical standard of care
5. Develop and implement quality measures for survivorship care plans
6. Assessment and interventions at diagnosis through follow up for tailored care
7. Increase primary prevention, early detection, and chemoprevention for prevention of secondary cancers
8. Improve precision in oncology (right treatment to the right person at the right time)
9. Delivery of high-quality survivorship care
10. Promote accessibility and affordability of care for all survivors

### COMMENTARY

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### Box 1. Recommendations to improve survivorship care

1. A healthcare workforce sufficiently educated and trained in the needs of cancer survivors, including changes in medical practice and education through existing accrediting organizations.
2. Increased focus on the physical, psychological, and socioeconomic needs of survivors and caregivers across the cancer care continuum, with the tools necessary to provide coordinated care.
3. Improved collection of outcomes data on diverse populations with cancer who have not been adequately represented in research studies on cancer survivors.
4. Better integration of evidence-based psychosocial services into the medical standard of care, and the elimination of services for which no evidence exists.
5. Development and implementation of quality measures for survivorship care (if you cannot measure it, you cannot evaluate it).
6. Risk assessment and intervention at diagnosis and follow-up so that clinicians can better understand how cancer treatment may affect a patient's life as a survivor and tailor treatment accordingly.
7. Address the high risk for second malignant neoplasms in the survivor population by primary prevention, increased screening, and chemoprevention when available.
8. Improved precision in oncology (giving the right therapy to the right person at the right time), with the goal of delivering appropriate, risk-adapted, individualized therapies to reduce morbidity, minimize late effects, and optimize health care resources.
9. Delivery of high-quality survivorship healthcare focusing on palliation of symptoms, prevention of late effects, and health promotion.
10. Promotion of efforts to ensure that care is accessible and affordable for all cancer survivors.

# Cancer Survivorship in Wisconsin

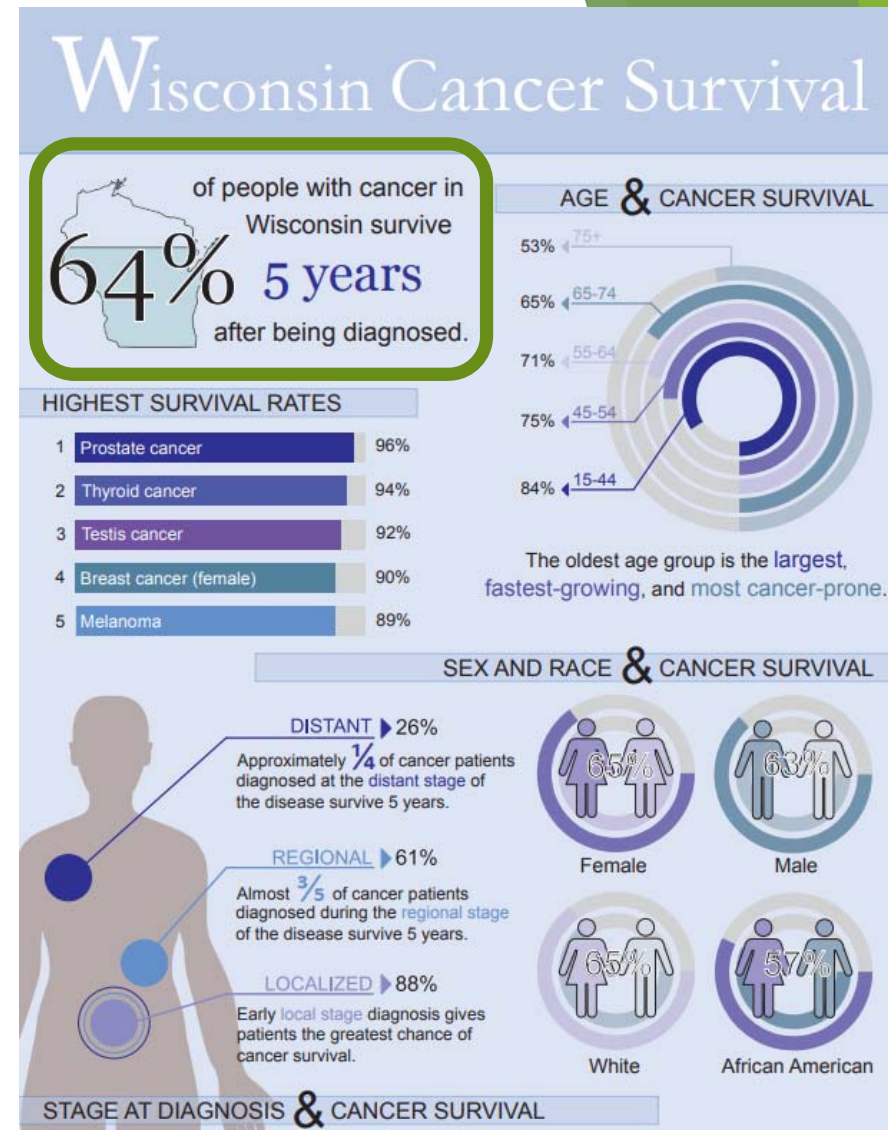
- ▶ September 2016 Report on WI Cancer Survival
- ▶ WI Cancer Reporting System





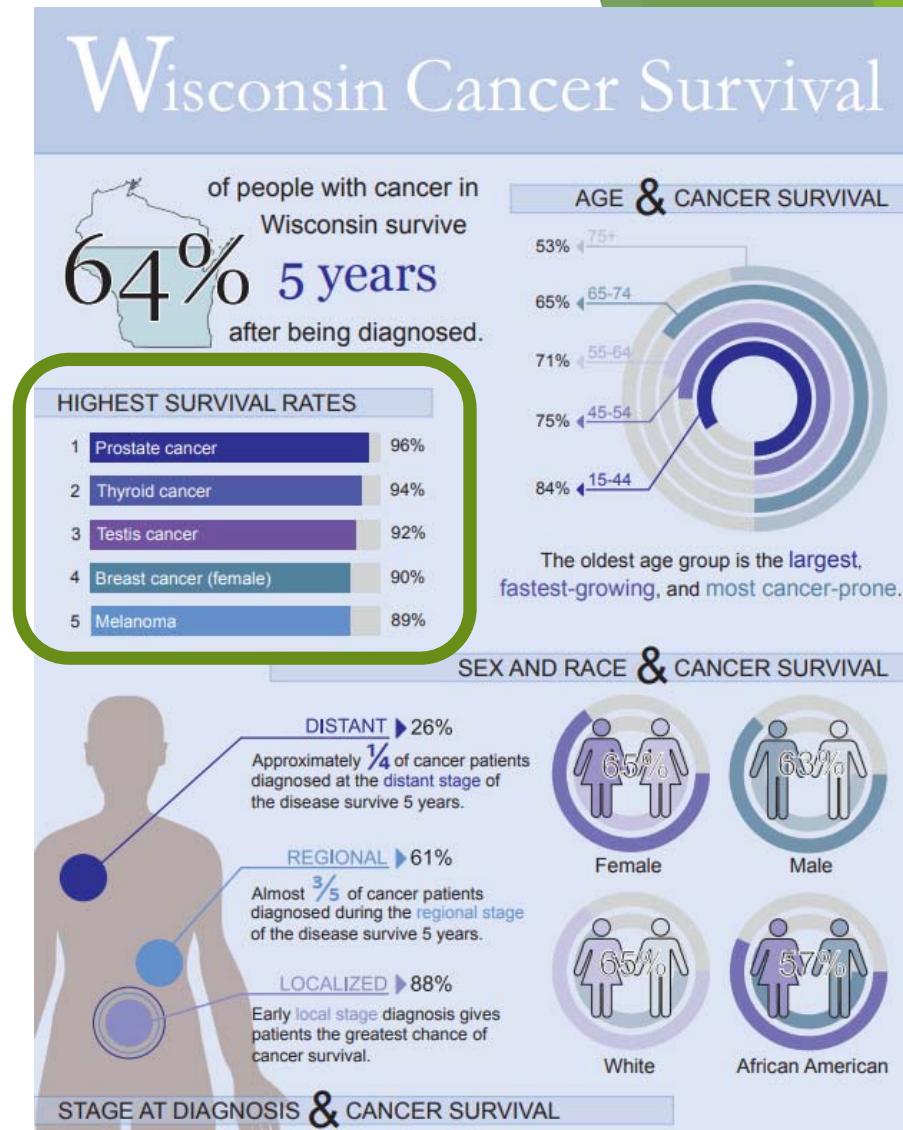
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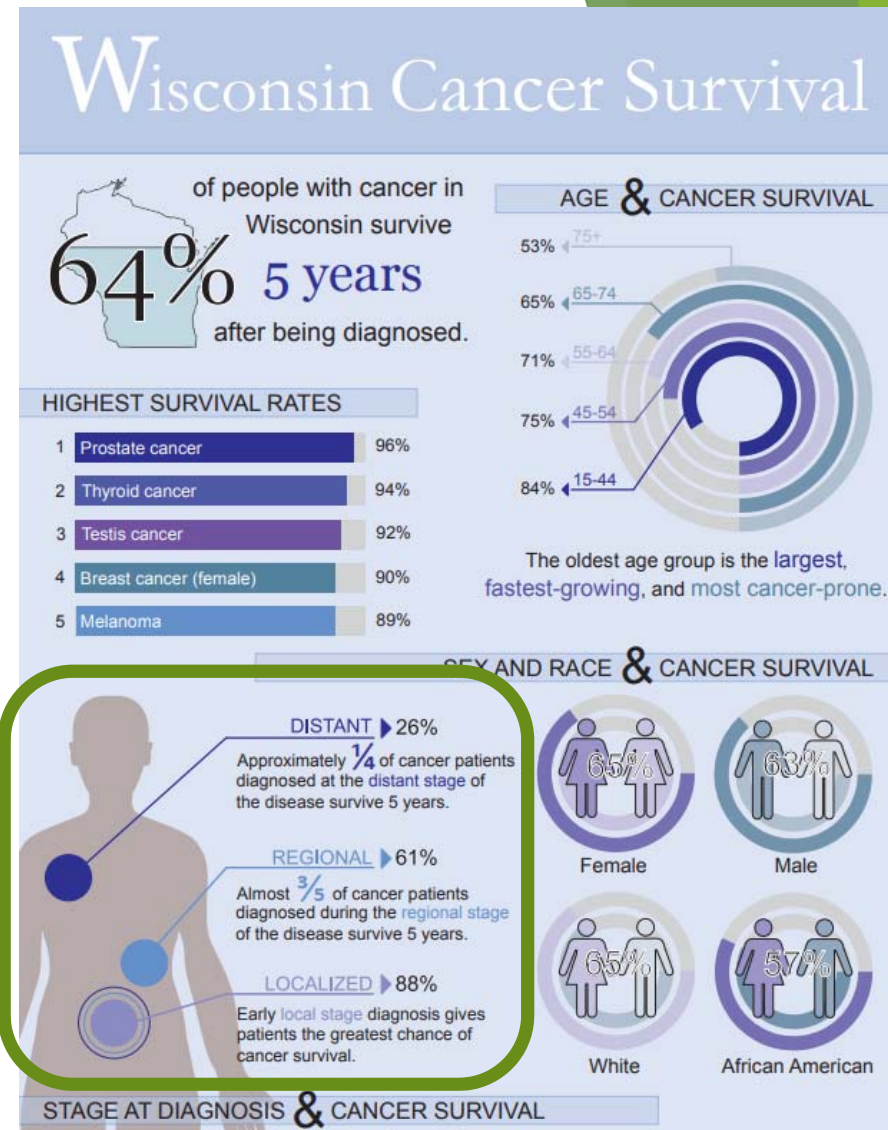
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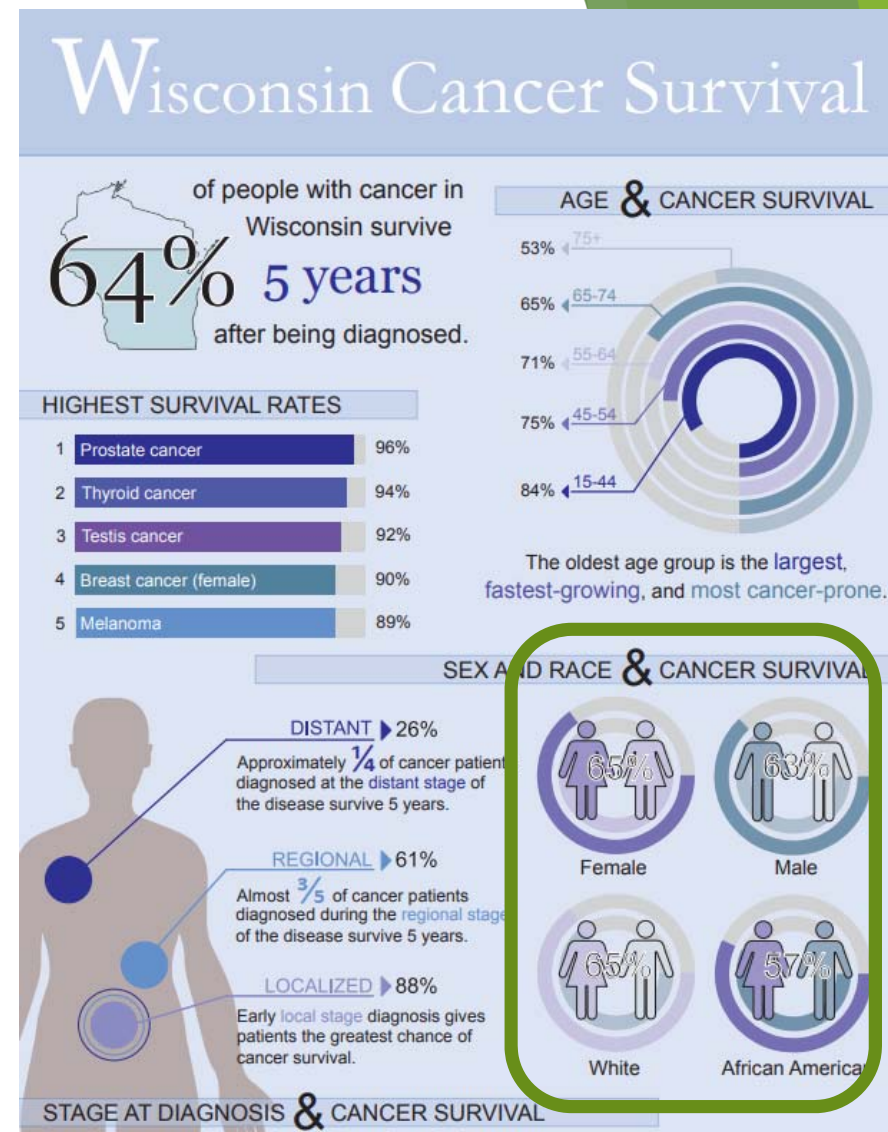
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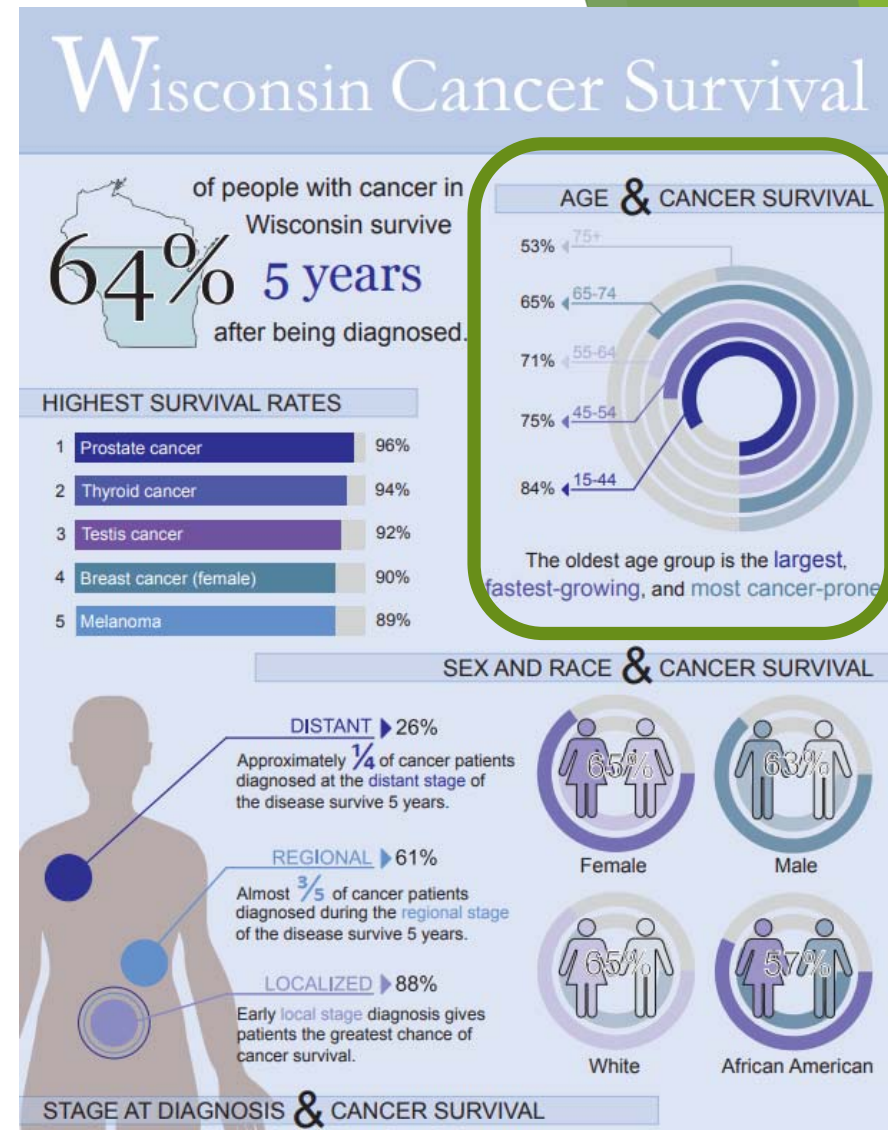
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# Cancer Survivorship in Wisconsin

- ▶ September 2016 Report on WI Cancer Survival
- ▶ WI Cancer Reporting System



# Cancer Survivorship in Wisconsin

- ▶ Behavioral Risk Factor Surveillance System (BRFSS) - 2010, 2012, 2014
  - ▶ Survivorship module examined:
    - ▶ Receipt of health care services
    - ▶ Health insurance coverage
    - ▶ Enrollment in clinical trials
    - ▶ Pain management

# Cancer Survivorship in Wisconsin

- ▶ Behavioral Risk Factor Surveillance System (BRFSS) – 2010, 2012, 2014
  - ▶ 16,708 responses over three rounds of data collection
  - ▶ Results:
    - ▶ 28.3% did not receive instructions from health professional regarding where to receive routine cancer check-ups
    - ▶ 35.9% received a written summary of all cancer treatments
    - ▶ 94.4% had insurance for cancer treatment
    - ▶ 7.2% denied insurance coverage due to cancer diagnosis
    - ▶ 7.0% participated in a clinical trial
    - ▶ 7.3% reported current pain from cancer or treatments
    - ▶ 80.5% had pain under control

# Cancer Survivorship in Wisconsin

## ► Areas of Focus to Date

- WI CCC Plan
- Survivorship Forums in 2010, 2011, 2012, 2014, 2016
- Survivorship funding opportunities
  - 2012-2014 Patient Navigation and Survivor Care Plans
  - 2014-2015 Transitions in Care
- Data:
  - BRFSS 2010, 2012, 2014

## PRIORITIES OF THE WI CCC PLAN 2015-2020

- |   |   |    |   |
|---|---|----|---|
| 1 | Decrease tobacco use and exposure to tobacco  | 8  | Increase access to cancer genetic risk assessments and counseling       |
| 2 | Increase healthy, active lifestyles           | 9  | Increase access to quality cancer care and services                     |
| 3 | Decrease high risk alcohol consumption        | 10 | Increase awareness and knowledge of issues relevant to cancer survivors |
| 4 | Increase HPV vaccine completion               | 11 | Increase advance care planning  |
| 5 | Decrease exposure to ultraviolet radiation    | 12 | Increase participation in cancer clinical trials                        |
| 6 | Decrease exposure to radon                    | 13 | Improve WI specific cancer related data collection and use              |
| 7 | Increase use of recommended cancer screenings |    |   |

# Cancer Survivorship in Wisconsin

- ▶ Areas of Future Exploration
  - ▶ WI CCC Plan 2020-2030
  - ▶ Supplemental Project from CDC
    - ▶ Data Surveillance via BRFSS Survivorship Module & SHOW Survey
    - ▶ Patient Navigation
    - ▶ Care Plans
    - ▶ Primary Care Education
    - ▶ Dissemination
  - ▶ 2019 WI Cancer Summit

# Cancer Survivorship in Wisconsin

- ▶ Discussion Questions:

- ▶ What are you doing to address cancer survivorship in your work and region?
- ▶ What seems to be working?
- ▶ What could you use assistance with?

- ▶ To respond:

- ▶ Unmute your phone to share
- ▶ OR
- ▶ Use the chat feature

# 2019 WI Cancer Summit

- ▶ Tina Pap
- ▶ Program Specialist





## This month's topic:

# 2019 WI Cancer Summit - SURVIVORSHIP

### When:

Wednesday, October 16, 2019: WI CCC Plan meetings and  
Pre-Summit Reception

Thursday, October 17, 2019: WI CCC Summit

### Where:

The Wilderness Resort – Wisconsin Dells, WI



# Objectives, Tagline, and About

## Objectives

- ▶ Hear from survivors and caregivers to understand their experiences
- ▶ Develop and identify solutions based on their experiences
- ▶ Apply these solutions in practice

## Tagline

- ▶ “Lessons from the Front Lines”

## About

- ▶ Join us for the 2019 WI Cancer Summit, where we will explore the theme of Cancer Survivorship. What do cancer survivors and caregivers want us to know? What does research tell us about survivor and caregiver well-being? How can we apply these lessons to improve outcomes and experiences for survivors, caregivers, and their families? When we position survivors and their stories at the center of our work, new ways of approaching cancer control and prevention can emerge.

# 2019 WI Cancer Summit

## ► Updates:

1. Invited Governor Evers
  2. Invited Joe Lee (Caregiver)
  3. Our Afternoon Discussion - “Sisters We Thrive, Stories We Tell” - Dr. Alice Yan, UW Milwaukee Zilber School of Public Health
- This film includes voices from survivors, researchers, and healthcare professionals on issues related to racial/ethnic health disparities on breast cancer outcomes among Young African American Breast Cancer Survivors in Southeast Wisconsin.

# Tentative Agenda

October 17, 2019

- We still need SIX Breakout session topics to be filled!



Time	Session
7:30-8:30	Registration & Networking Breakfast
8:30-8:45	Welcome & Purpose of the Day (TBA)
8:45 – 9:00	Introduction (Governor Evers)
9:00-10:00	Opening Session
10:00-10:30	Caregiver Voice (Joe Lee)
10:30-10:45	Networking Break
10:45-11:45	Breakout Sessions A-C A: B: C:
11:45-12:45	Networking Lunch
12:45-1:45	Afternoon Plenary Session ("Sisters We Thrive, Stories We Tell" Documentary & Dr. Yan/Deb Nevels Q&A)
1:45- 2:00	Break
2:00-3:00	Breakout Sessions D-F D: E: F:
3:05-4:00	Closing Session (TBA)

## Survivorship Must Center Around the Patient!



What can we do to help Survivorship Care?

**POLL QUESTION:** What topics do you want to learn more about at the Summit? Pick your top three.

Five Common Topics:

- ▶ Survivorship Care Plans
- ▶ Caregiver Support
- ▶ Patient Navigation
- ▶ Financial Toxicity
- ▶ Sexual Health

These topics were all chosen based on previous summit feedback, highlighted research, and trending survivorship topics.

# Let's Discuss....

- Suggestions for speakers or professionals in these topics to deliver useful and credible tools and resources to our attendees?
- Are there any topics that we might have missed that would be helpful to present at the Summit?
- Does anyone have any policy related topics to include for the Summit?

## Survivorship Must Center Around the Patient!



# Thank you!


- ▶ The recording, slides and links to resources will be distributed after the call



## Upcoming Webinars & Topics

- ▶ No June webinar will be held to make time for you all to join the June 20<sup>th</sup> WI CCC Plan input meeting!

**Join us**  
for a statewide  
Feedback Session  
to create the  
WI Cancer Plan  
2020-2030




Hosted by the  
WI Cancer Council

You can guide the future of  
cancer control in Wisconsin

**JUNE 20**  
**Wisconsin Dells**

Learn more online



[www.wicancer.org/GuideTheFuture](http://www.wicancer.org/GuideTheFuture)

# Upcoming Webinars & Topics

- July 11 – 2018/2019  
Implementation Grantees

*Have a topic that you'd like to learn more about or something you feel passionate about that you'd like to share with others? Let us know!*

