

# **Project ECHO Session One**

## **Introduction and Survivorship 101**

**January 11, 2024**

**Recording: [Project ECHO Session One 1.11.24](#)**

# **SURVIVORSHIP PROJECT ECHO**

## **(Extension for Community Healthcare Outcomes)**



### **Collaborators:**

NYSDOH/NYSCCCP

SUNY Upstate (The Upstate Foundation, Inc.)

NYS Survivorship Action Team

### **Subject matter team leads:**

Maureen Killackey M.D.

Tessa Flores, M.D.

Christina Crabtree-Ide, PhD, MPH

**Funding:** Centers for Disease Control and Prevention

# HOUSEKEEPING ITEMS

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Please type your name (first and last), health center or organization, and your email address into the Chat Box.

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Please mute your line and remain on camera.

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If you have a question, please type it in the Chat Box. Questions will be answered after the speakers' presentations.

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This ECHO session is being recorded and a link will be e-mailed to attendees and posted on the NYS Cancer Consortium Website ([nyscancerconsortium.org](http://nyscancerconsortium.org))

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Do NOT share any personal information about any patient.

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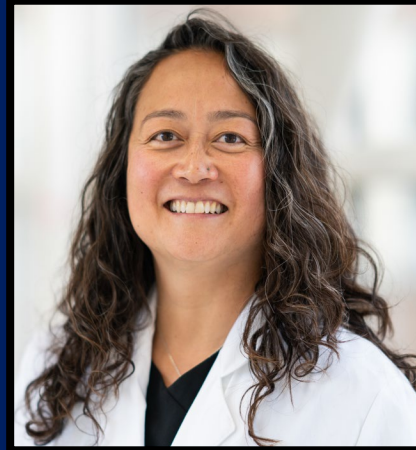
The Session PowerPoint and materials will be sent to attendees after each ECHO Session along with the CME survey.

# INTRODUCTIONS



**Sylvia K. Wood Ph.D., DNP, ANP-BC, AOCNP**

Clinical Associate Professor,  
Director, Ph.D. Program in Nursing,  
Department of Doctoral  
Studies Stony Brook University  
School of Nursing



**Tessa Faye Flores, M.D.**

Medical Director of Cancer Screening  
and Survivorship at Roswell Park  
Comprehensive Cancer Center and a  
board-certified Internist and  
Pediatrician



**Maureen Killackey, MD, FACS,  
FACOG**

Chair, NYS Cancer Advisory Council  
and American College of Surgeons  
Commission on Cancer Site  
Reviewer



**Facilitator: Christina Crabtree-Ide,  
PhD, MPH**

Epidemiologist and Health Services  
Researcher and Implementation  
Scientist at Roswell Park  
Comprehensive Cancer Center

*Speakers have no disclosures or conflicts to report. Crabtree-Ide reports funding support from Genentech, and stock ownership of Danaher, Fortive, Vontier, and Veralto Corps.*

# PARTICIPANT INTRODUCTIONS

Please type your name (first and last), health center or organization, and your email address into the Chat Box.

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# Welcome

Survivorship ECHO Series

Session 1

Introduction and Survivorship 101

## SPEAKERS

Maureen Killackey, MD, FACS, FACOG

Tessa Flores, MD

Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP

**Facilitator:** Christina Crabtree-Ide, PhD, MPH



# What is a Project ECHO?



- Collaborative, hub & spoke model of medical education and care management
- Goal is to form long-lasting partnerships between community-based provider teams and specialized providers to create bi-directional learning networks
- Increases workforce capacity to provide best-practice specialty care to patients wherever they may live; reduces health disparities

**“Moving knowledge, not people”**

# Patient Expectations of High-Quality Cancer Care, 2024

HIGHER HEALTH LITERACY, WELL-INFORMED PATIENT & FAMILY

PRIMARY CARE

CANCER  
PRE-  
VENTION



CANCER  
SCREENING



DIAGNOSIS



CANCER  
TREATMENT



RECOVERY/  
SURVIVORSHIP



END-OF-LIFE  
CARE

PSYCHOSOCIAL & PALLIATIVE CARE

TARGETED NAVIGATION BASED ON NEED

CLINICAL RESEARCH



# SO, HOW ARE WE DOING IN NYS?

- ~70% NYS CoC Cancer sites have Survivorship Programs (required)
- Survivorship Care Plans when developed, <50% routinely share with PCPs
- Barriers: EMR issues, prep time, reimbursement, value?
- <50% coordinate survivorship care with local PCPs
- 50% that do coordinate with PCPs experience challenges such as provider knowledge, confidence
- Bidirectional collaboration and communication lacking
- Few programs provide training or educational opportunities for PCPs, Ob/Gyns and nurses about survivors' cares and needs
- **(How NYS Cancer Programs Implement Survivorship Care: CoC Program Assessment Findings Responses from 55/62 ~90%- Eligible NYS CoC-Accredited Programs)**

# NYS Survivorship ECHO Program Goal



- The goal of the Survivorship ECHO program is to improve knowledge and access to high-quality, evidence-based information related to Survivorship Care for healthcare teams who care for patients with a history of cancer
- The aims are to:
  - Educate Primary Care Teams on issues faced by cancer survivors
  - Develop integration, communication and coordination with the Oncology Team and Patient Navigation services
  - Identify and utilize community resources; Link NYS state-wide expertise

# NYS Survivorship ECHO: Target Participants



Primary care teams providing care to rural and underserved/under-resourced populations in NYS



Any multi-disciplinary teams who care for cancer survivors in NYS

# Goals & Objectives ECHO Series



After participating in this ECHO Session, participants will be able to:

1. Describe the goals, objectives and expectations of this ECHO Series
2. Understand the current landscape of survivorship in New York State
3. Identify available cancer survivorship resources and clinical guidelines.
4. Explain the role of the primary care provider in cancer survivorship care

# Definition of a Cancer Survivor

An individual is considered a cancer survivor from the time of diagnosis, through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer. This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals.



# Timeline: History of Cancer Survivorship

1884

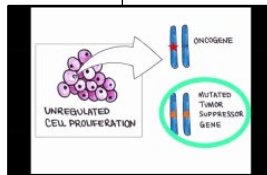


First cancer treatment center in the United States MSKCC.

1938

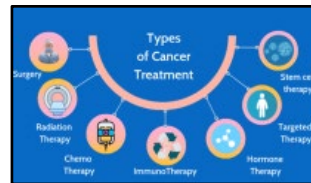


1948-1975



Scientific breakthroughs in oncogenesis  
→ diagnostics & treatment discoveries

1975-2001



Translates into survival benefit

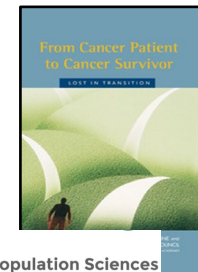
1985-2006



Fitzhugh Mullan  
“Seasons of Survival”



IOM

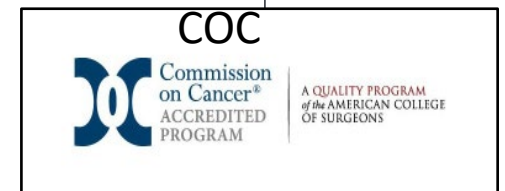


2009-2011



National Stakeholders Conduct Pilot Survivorship Programs

2012



2013



National Organizations Formalize EBP Guidelines in Adults



# What is Cancer Survivorship ?

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In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life.

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This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond.

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The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life.

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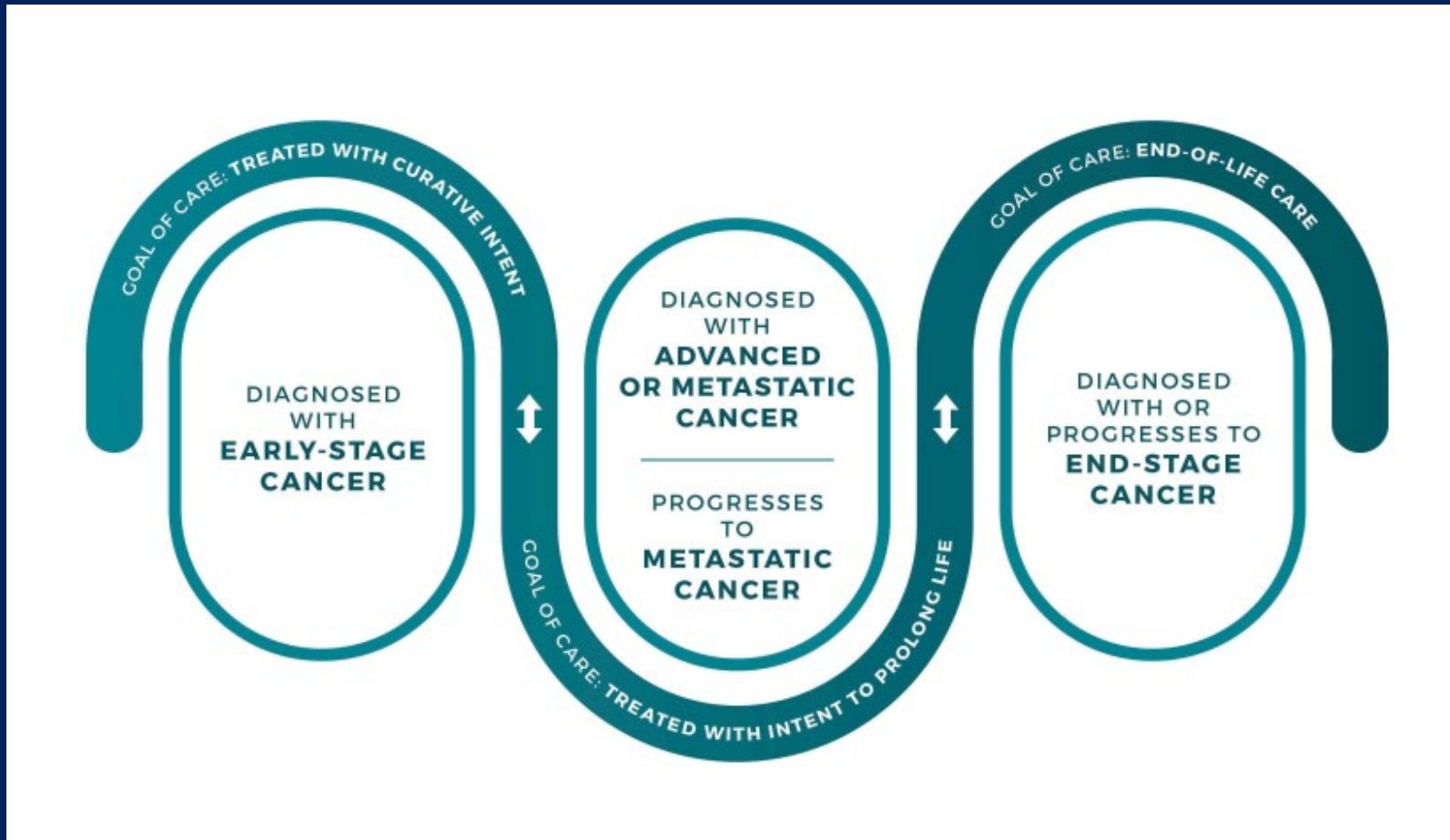
Family members, friends, and caregivers are also considered part of the survivorship experience.

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National Cancer Institute-NCI Dictionary of Cancer Terms. Survivorship  
<https://www.cancer.gov/publications/dictionaries/cancer-terms/>



# Phases of Cancer Survivorship

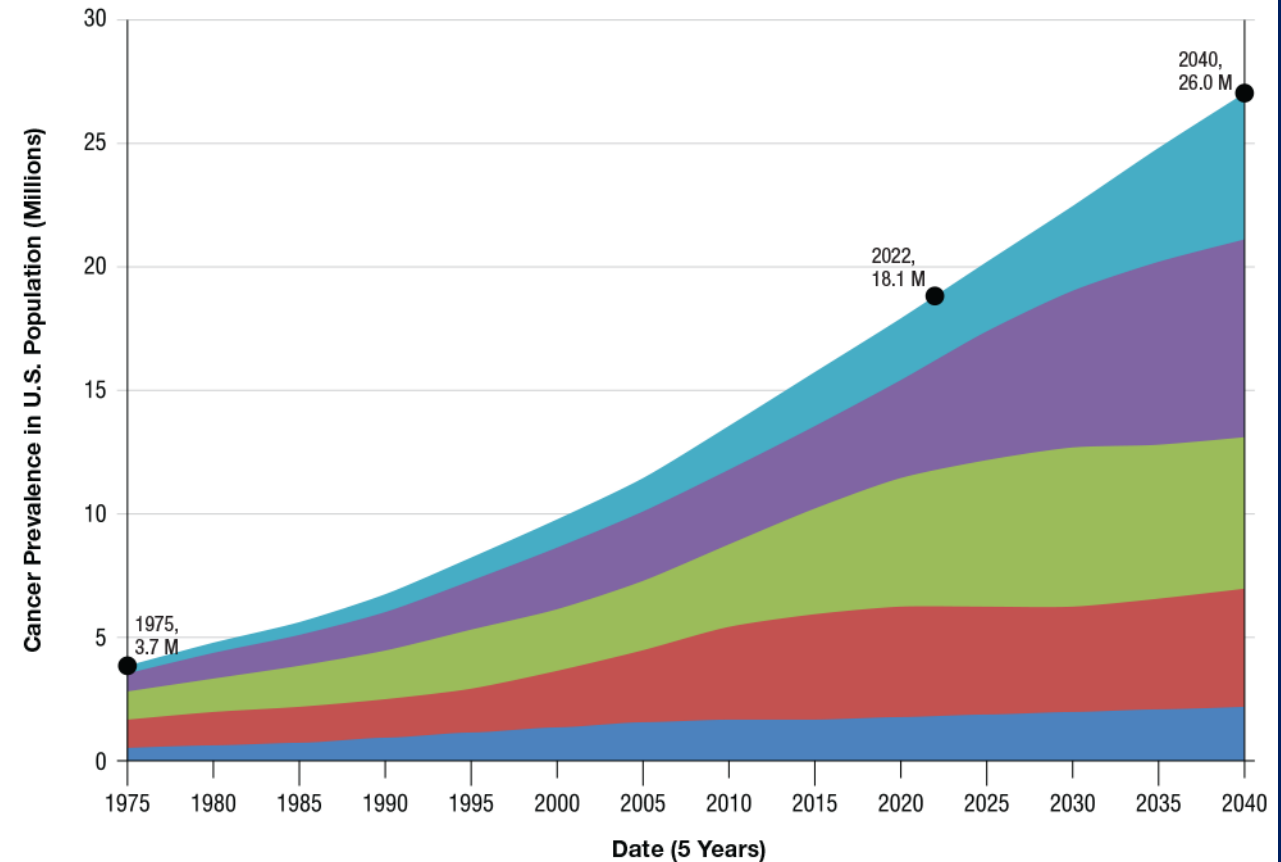


National Cancer Institute-Office of Cancer Survivorship. (2022, February 3). Phases of cancer survivorship. <https://cancercontrol.cancer.gov/ocs/definitions>



# US Cancer Survivors Prevalence and Projections 1975-2040

**Cancer Prevalence and Projections in U.S. Population  
from 1975-2040**



## KEY

### Age

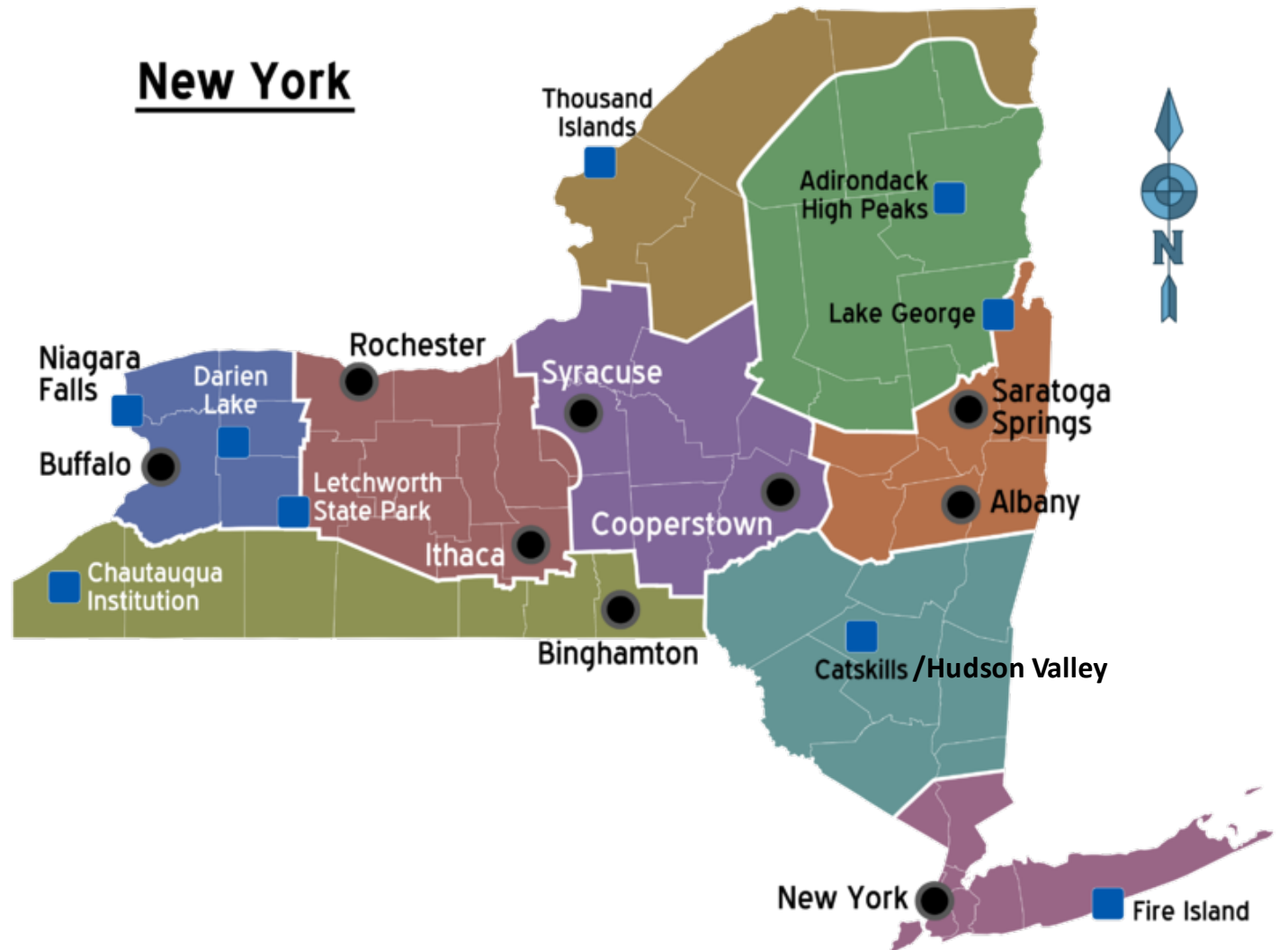
<50 50-64 65-74 75-84 85+

## REFERENCES

Bluethmann SM, Mariotto AB, Rowland JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. *Cancer Epidemiol Biomarkers Prev*. 2016 Jul;25(7):1029-36.

Miller KD, Nogueira L, Devasia T, Mariotto AB, Yabroff KR, Jemal A, Kramer J and Siegel RL. *Cancer Treatment and Survivorship Statistics*. CAA Cancer J Clin. 2022.

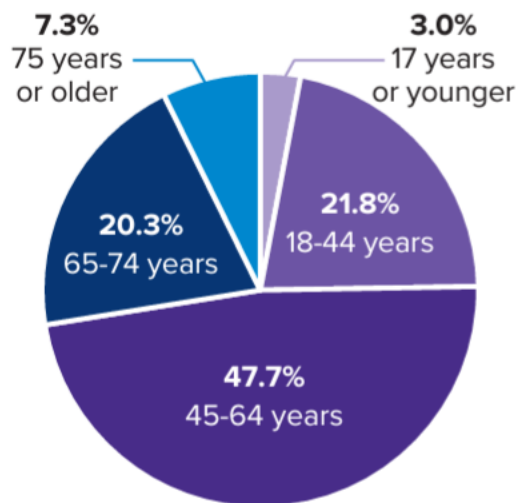
# More than One Million Cancer Survivors Live in New York State



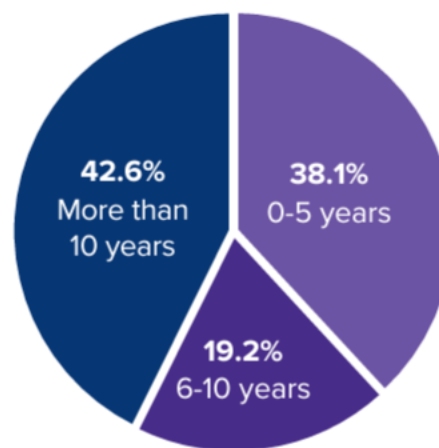
# Cancer Survivors in New York State

## Behavioral Risk Factor Surveillance System (BRFSS)

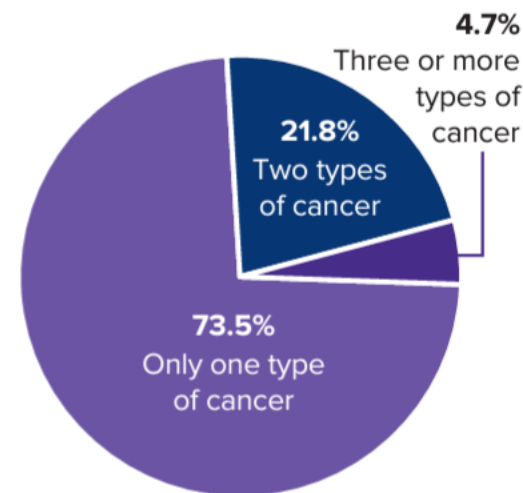
**Figure 1. Age at first diagnosis of cancer (excluding nonmelanoma skin cancer) among NYS adult cancer survivors, BRFSS 2020**



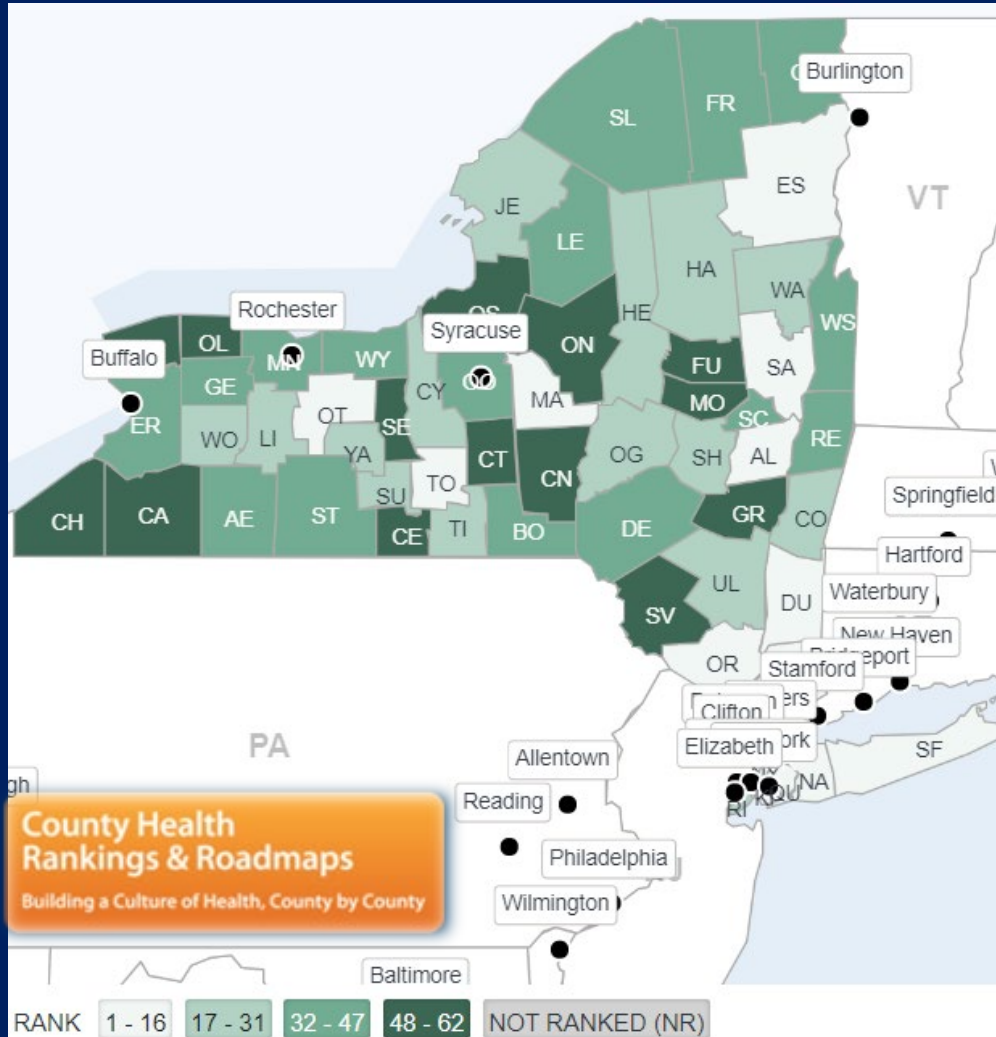
**Figure 2. Years since first cancer diagnosis (excluding nonmelanoma skin cancer) among NYS adult cancer survivors, BRFSS 2020**



**Figure 3. Types of cancer among NYS adult cancer survivors, BRFSS 2020**



# NYS Health Outcomes and Factors Variation



	Number of 5-year cancer survivors: all tumor types	Population/ 1 Primary Care Provider
Niagara	5,121	2,480
Chautauqua	3,255	1,800
Cattaraugus	1,831	2,170
Lewis	506	1,540
Oneida	4,957	1,310
Sullivan	1,481	2,710
<b>NYS County-level Range</b>	<b>400,900 5-year survivors 1.2M survivors</b>	<b>690-13,330 1,170 Average</b>
<b>US Average</b>	<b>18.1M</b>	<b>1,310</b>

Estimates derived from NYS DOH Cancer Registry data for NYS Counties  
[Statistics and Graphs](#) | [Division of Cancer Control and Population Sciences \(DCCPS\)](#)  
[New York](#) | [County Health Rankings & Roadmaps](#)

**Table 1. Prevalence of self-reported cancer type among NYS adult cancer survivors, overall and by sex, BRFSS 2020**

Cancer Type <sup>a</sup>	All Survivors		Male Survivors		Female Survivors	
	%*	95% CI*	%*	95% CI*	%*	95% CI*
Breast	20.8	17.0-24.5	—**	—**	35.6	29.7-41.5
Melanoma	16.8	13.3-20.2	19.1	13.9-24.2	15.0	10.3-19.7
Male reproductive <sup>b</sup>	15.6	12.3-18.9	35.8	29.3-42.4	NA***	NA***
Leukemia/Lymphomas	9.9	6.5-13.3	13.0	7.9-18.2	7.5	3.0-12.1
Other cancer types <sup>c</sup>	7.3	4.7-9.8	8.5	3.8-13.3	6.3	3.7-8.8
Female reproductive <sup>d</sup>	6.7	4.7-8.7	NA***	NA***	11.9	8.5-15.3
Gastrointestinal <sup>e</sup>	5.4	3.5-7.3	5.7	2.7-8.8	5.2	2.7-7.6
Head/Neck <sup>f</sup>	5.1	2.7-7.4	3.0	0.8-5.1	6.7	2.9-10.5
Lung	4.3	2.5-6.0	3.8	1.6-6.0	4.6	2.0-7.3
Urinary tract <sup>g</sup>	2.7	1.4-3.9	3.0	1.3-4.8	2.4	0.6-4.2
Unknown/Refused	5.6	3.9-7.3	6.5	3.7-9.3	4.9	2.7-7.1

\*% = weighted percentage; 95% CI = 95% confidence interval

\*\*suppressed

\*\*\*NA=not applicable

<sup>a</sup> For cancer survivors who reported more than one cancer diagnosis, the cancer type reported was the most recently diagnosed cancer.

<sup>b</sup> Includes prostate and testicular cancers.

<sup>c</sup> Includes bone, brain, neuroblastoma, and other not specified cancer types.

<sup>d</sup> Includes cervical, endometrial, and ovarian cancers.

<sup>e</sup> Includes colon, esophageal, liver, pancreatic, rectal and stomach cancers.

<sup>f</sup> Includes head and neck, oral, pharyngeal (throat), thyroid, and larynx cancers.

<sup>g</sup> Includes bladder and renal cancers.

# Cancer Survivor Needs



## Physical Well-Being

- Functional status
- Fatigue and sleep
- Overall physical health
- Fertility
- Pain
- Food-Quality, Enough?



## Social Well-Being

- Family distress
- Roles and relationships
- Affection/sexual function
- Appearance
- Isolation
- Finances/employment



## Quality of Life



## Psychological Well-Being

- Control
- Anxiety
- Depression
- Fear of recurrence
- Cognition/attention



## Spiritual Well-Being

- Meaning of illness
- Religiosity
- Transcendence
- Hope
- Uncertainty
- Inner strength



## Spectrum of Disciplines Involved in Survivorship Care



## Interdisciplinary Survivorship Care Providers



Diagnosis, screening assessment, treatment, rehabilitation, survivorship or palliative care



Nurses and APNs cut across the whole spectrum of care and survivorship trajectory

# Cancer Survivorship Clinical Practice Guidelines

National Academy  
of Medicine  
Recommendation

## National Comprehensive Cancer Network (NCCN)

Dr. Tessa Flores!

### By Topic:

Anthracycline-induced cardiac toxicity  
Anxiety and depression  
Cognitive function  
Exercise  
Fatigue  
Healthy lifestyles  
Immunizations and infections  
Menopause-related symptoms  
Pain  
Sexual function (female/male)  
Sleep disorders

## The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, & Young Adult Cancers

### By Topic:

Any Cancer Experience

- Psychosocial, Fatigue, Sleep, limitations in healthcare access, subsequent malignancy, malignancy risk offspring

Blood/Serum Products  
Chemotherapy  
Radiation  
Hematopoietic Cell Transplant  
Surgery  
Other Therapeutic Models  
General Health Screening

## American Society of Clinical Oncology (ASCO)

### By Topic:

Anxiety and depression  
Cardiac dysfunction  
Chronic pain  
Fatigue  
Fertility preservation  
Neuropathy  
Palliative care

### By Cancer Site:

Breast (ASCO/ACS)

## American Cancer Society (ACS) Survivorship Care Guidelines for Primary Care Providers

### By Topic:

#### Holistic:

Care coordination  
Health promotion  
Long-term and late effects  
Nutrition and physical activity  
Screening  
Surveillance

### By Cancer Site:

Breast (ACS/ASCO)  
Colorectal  
Prostate  
Head and neck



# Helpful Resources

## HELPFUL RESOURCES

### ASCO Treatment Summary and Survivorship Care Plan (PDF)

Download this survivorship care plan template, treatment summary and follow-up care plan, to enhance communication and coordination of care for the survivor.

### PDQ Cancer Information Summaries: Supportive Care

Find descriptions of the cause and treatment of common complications of cancer, such as pain and nausea/vomiting.

### Coping with Cancer: Supportive and Palliative Care

Find answers to many commonly asked questions about supportive and palliative care.

### Facing Forward Series

Designed to educate cancer survivors, family members, and health care providers about the challenges associated with life after cancer treatment.

### News and Highlights

View recent cancer survivorship news.

### Evidence-Based Cancer Control Programs

Search this database of evidence-based cancer control programs, designed to provide program planners and public health practitioners with access to program materials.

### Support for Caregivers

Providing care and support during cancer treatment can be difficult. Find resources for people who are helping a friend or family member through cancer diagnosis and treatment.

<https://cancercontrol.cancer.gov/ocs/resources/health-care-professionals#helpful>

[All About Cancer](#)[Programs & Services](#)[Get Involved](#)[Ways to Give](#)[Our Research](#)[About Us](#)[Health Care Professionals](#) >

# National Cancer Survivorship Resource Center

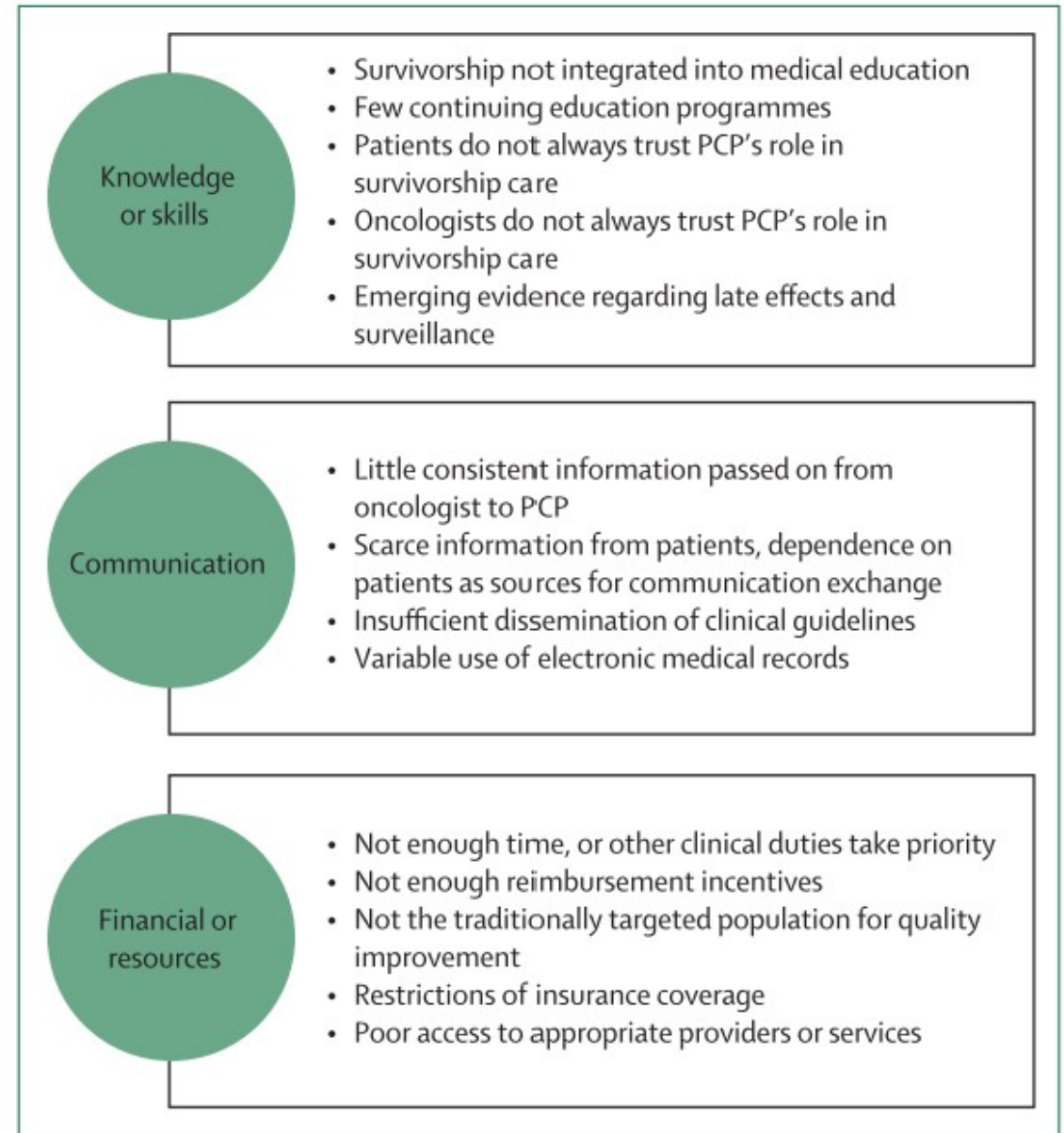
The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaboration between the American Cancer Society and the George Washington University Cancer Institute funded by a 5-year cooperative agreement from the Centers for Disease Control and Prevention.

[www.cancer.org/survivorshipcenter](http://www.cancer.org/survivorshipcenter)

# Challenges in cancer survivorship

- Widespread variation in models of cancer survivorship care delivery
- Lack of clarity in roles and responsibilities, communication and coordination between oncology team and PCPs
- Workforce shortages in oncology, primary care, and cancer survivorship
- Medical education specifically related to Cancer Survivorship is limited and informal
- Rural Patients and special populations:
  - Distance to care, limited options for transportation
  - Digital divide: internet services and health literacy
  - Fewer PCPs, oncologists, and cancer services
  - Social stigma, opiate epidemic, challenges to already stretched resources

# Primary Care Challenges in Transition to Cancer Survivorship



**Figure 3: Examples of barriers to the integration of primary care into the cancer survivorship pathway**  
PCP=primary care provider.

# Current Provider Issues: Cancer Survivorship Care

Limited knowledge of survivorship care needs, late and long-term effects

## Communication

- Oncology –PCP
- Care team-survivors

## Care delivery

- Preventive care-responsible providers not clearly defined
- Duplication/Unnecessary testing
- Insurance restrictions
- Transfer care responsibilities
- Resources
- Access
- Comorbidity management



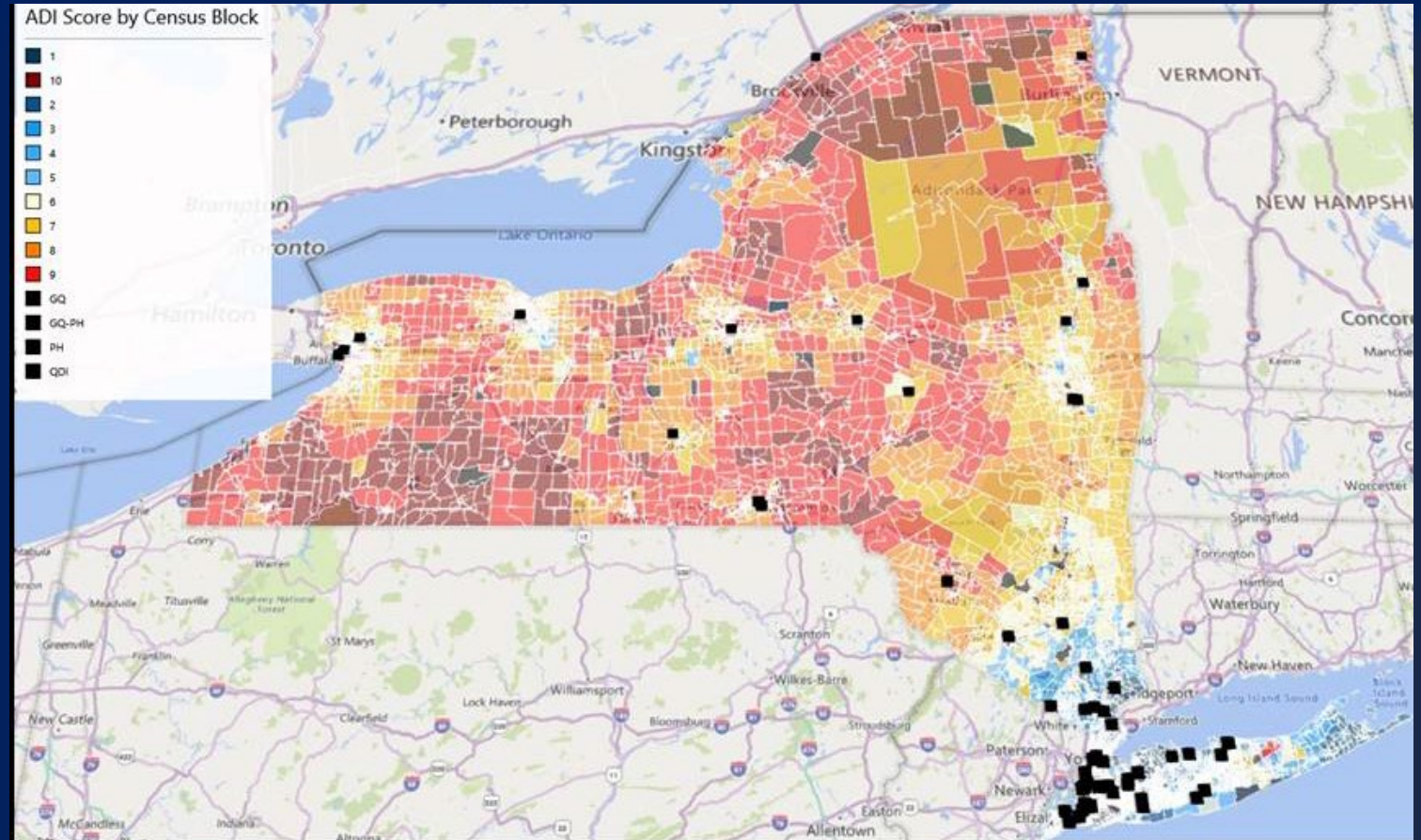
# Few Providers and Limited Oncology Workforce

Understanding How NYS Cancer Programs Implement Survivorship Care

(Responses from 55/62 ~90%-Eligible CoC-Accredited Programs)

Limited workforce, limited availability in rural and underserved regions

[Hospital and Facilities | ACS \(facs.org\)](https://www.facs.org)  
[Neighborhood Atlas - Home \(wisc.edu\)](https://www.wisc.edu)

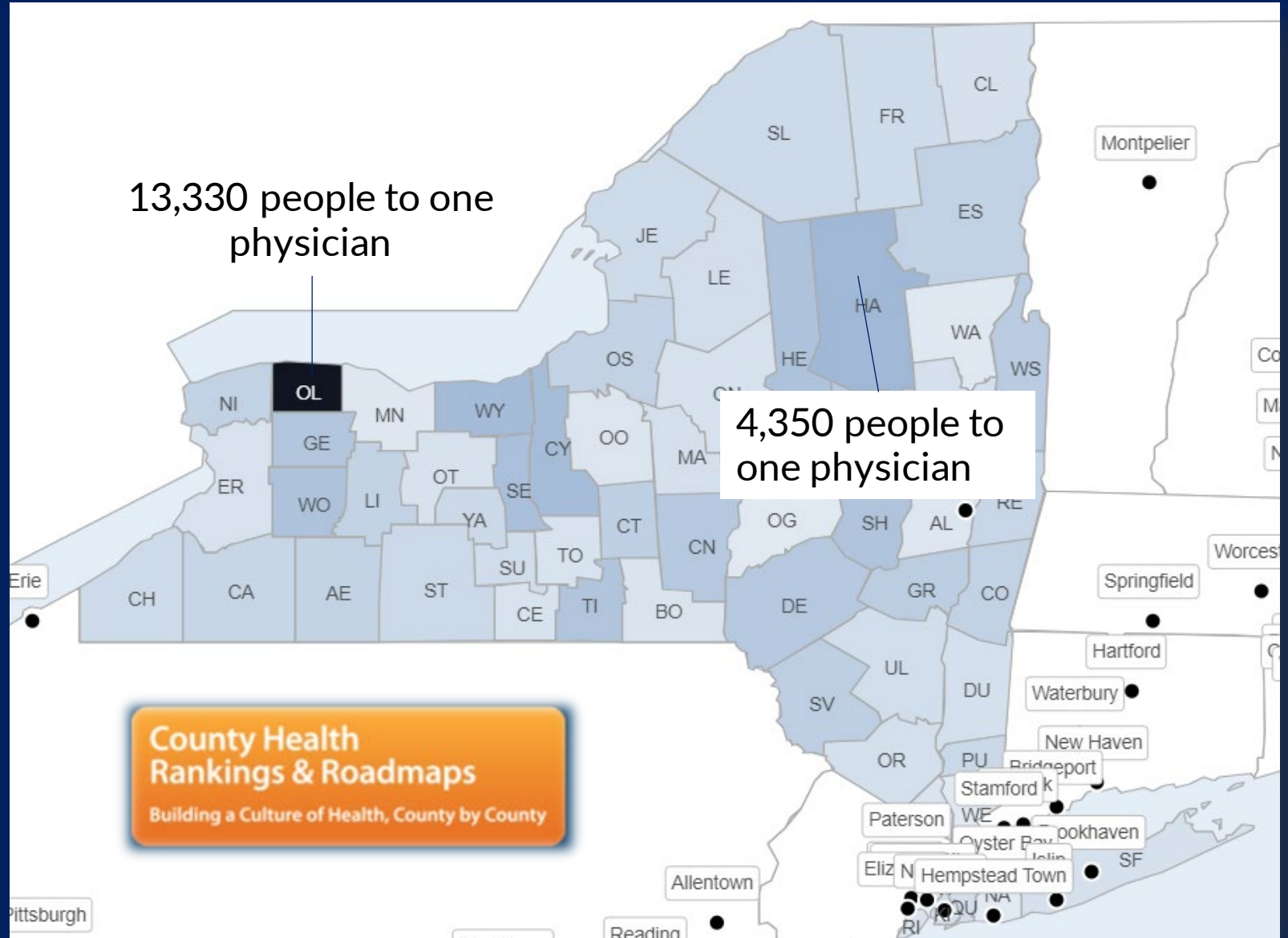


**Map shows distribution of NYS Commission on Cancer-accredited Programs and Area Deprivation Index Score**

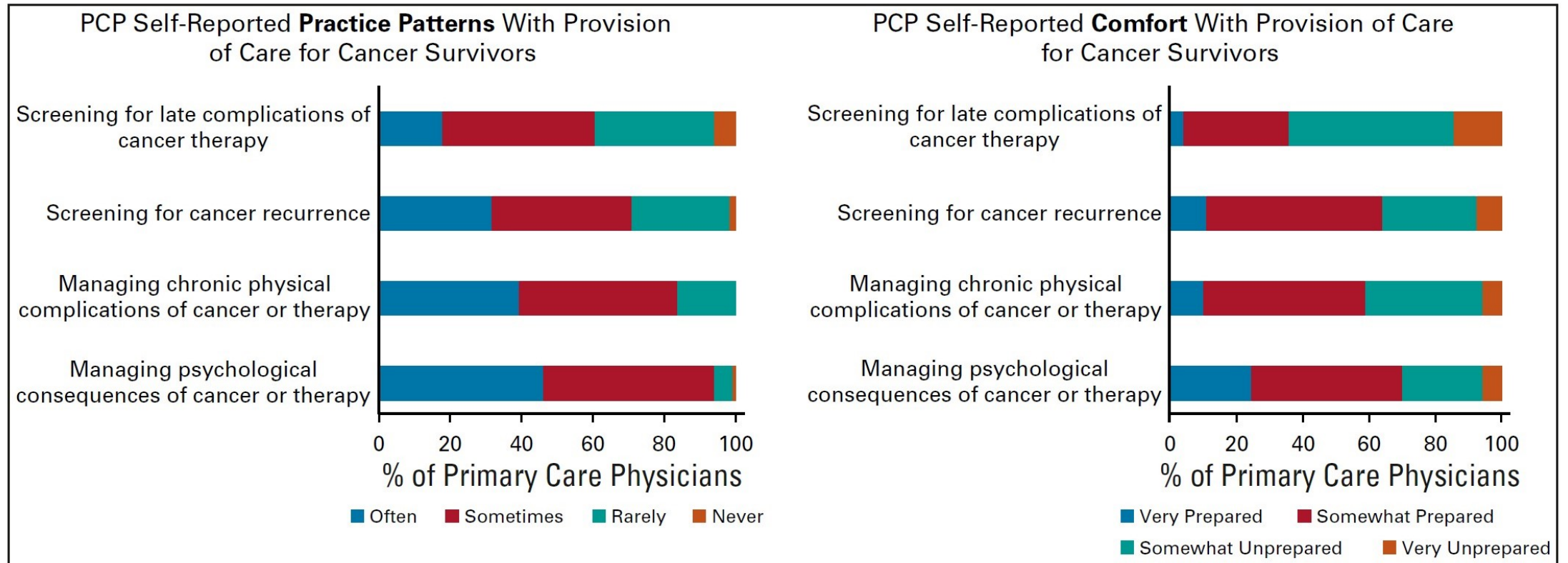
# Few Primary Care Providers and Limited Workforce

Average: 1,170 people per provider

Range: 690-13,330 people per provider



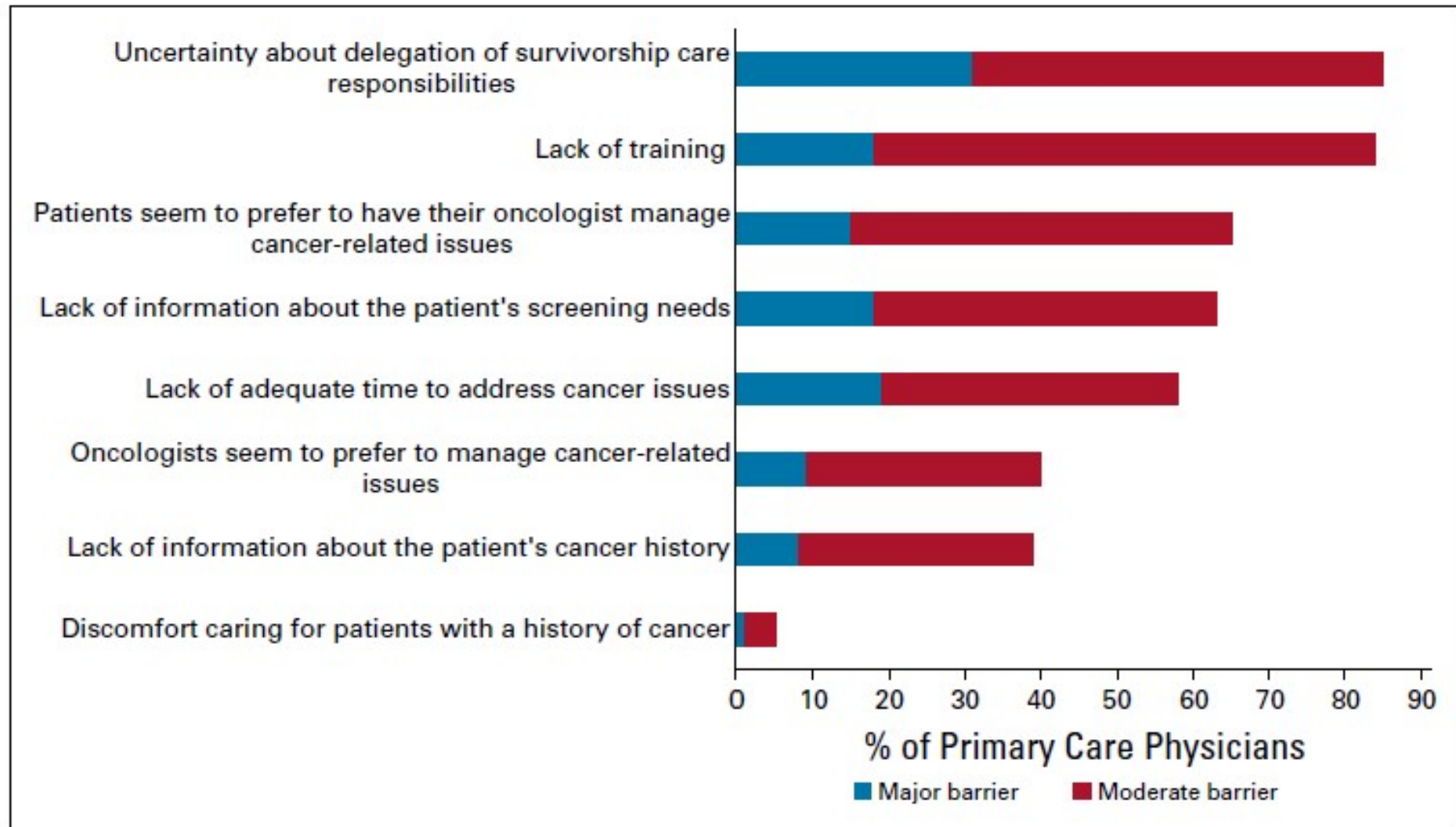
# Current trends



**FIG 1.** Primary care self-reported experience and comfort with providing aspects of cancer survivorship care. PCP, primary care physician.



## Current PCP Self- Reported Barriers



**FIG 2.** Primary care physicians' self-reported barriers to providing cancer survivorship care.

# Cancer Survivorship Care Quality Framework

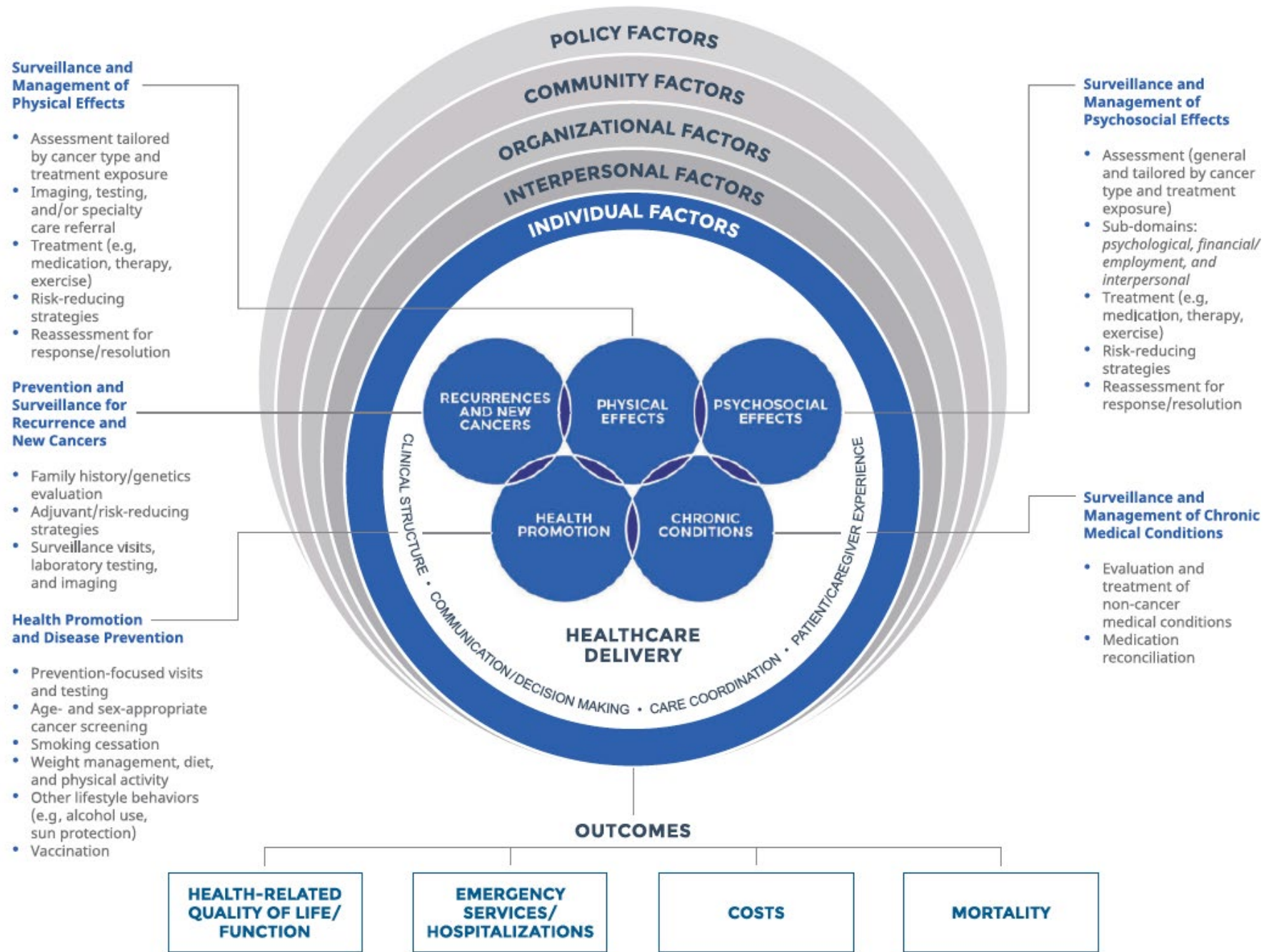


Figure 1. Cancer survivorship care quality framework.

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Brief Report | Brief Report

# Nearly All Cancer Survivors Return to Primary Care

Laura C. Pinheiro, Mangala Rajan, Monika M. Safford, David M. Nanus and Lisa M. Kern

The Journal of the American Board of Family Medicine July 2022, 35 (4) 827-832; DOI: <https://doi.org/10.3122/jabfm.2022.04.220007>

# PCP Role in Cancer Survivorship Care

Surveillance for metastatic disease, recurrence, screening for subsequent primary cancers

Ongoing assessment for long-term effects of cancer & Rx

- Psychological, physical, immunologic

Ongoing assessment & management of cancer-related syndromes or issues

Prevention, healthy lifestyle

Referrals & Coordination of care

# Survivorship Care Plans

- Patient diagnosis and treatment summary
- Best schedule for follow-up tests
- Information on late and long-term effects of cancer treatment
- List of symptoms to look for
- List of support resources

# Components of Survivorship Care Plans

Tissue diagnosis, stage,  
treatment plan and  
dates of treatment,  
toxicities experience

Expected short-and  
long-term side effects of  
therapy

Surveillance plan for  
recurrence and  
secondary cancers

Recommendations for  
late term monitoring

Listing of providers  
responsible for care  
with contact  
information

Evaluation of  
psychosocial needs

Preventative, health  
promotion behaviors

Follow-up care and  
referrals

# Survivorship Care Planning Needs a Personalized Focus

- Consider patient's disease type/stage, age, gender identity, comorbidities, and family history
- Social determinants of health
- Identify risk for recurrence, and/or high-risk factors for the development of secondary cancer or new primary cancer
- Consider needed physical, psychosocial supports & healthy lifestyle modifications
- Communication & Care coordination

# Building a Cancer Survivorship Program at Stanford

Our mission is to improve the experience, and outcomes, of patients and caregivers throughout all phases of their cancer journey by advancing survivorship research, clinical care and education.

Our vision is to give people living with cancer the tools they need to manage their illness with confidence.

We are building interdisciplinary research teams to discover new ways of supporting patients and families, to understand the late effects of cancer therapy, and to integrate survivorship care within primary care.

## Video on Survivorship



<https://med.stanford.edu/aftercancer.html?tab=proxy>



# Advancing Patient-Centered Cancer Survivorship Care

Adapted from the National Cancer Survivorship Resource Center


[www.cancer.org/survivorshipcenter](http://www.cancer.org/survivorshipcenter)

Dr. Maureen Killackey, GWU External Advisory Board, CoC Project

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# Cancer Survivorship E-Learning Series

[GWcanceradmin@gwu.edu](mailto:GWcanceradmin@gwu.edu)



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& Health Sciences

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## Cancer Survivorship E-Learning Series for Primary Care Providers

A program of the National Cancer Survivorship Resource Center®



### GW Cancer Institute

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  - AMA PRA Category 1 Credit
  - NASW, Certified Health Education Specialist/Master Certified Health Education, and more!
- 
- Comprehensive list of disease site topics, clinical issues, supportive services such as navigation, addressing barriers to care, financial issues



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## Working Together, Reducing Cancer, Saving Lives

Achieving cancer control success for all  
New Yorkers

Learn More

### About the New York State Cancer Consortium

The New York State Cancer Consortium is a network of individuals and organizations who work together to reduce the burden of cancer by implementing strategies outlined in the NYS Comprehensive Cancer Control Plan. [Click Here](#) for more information about what we do and how to get involved.

<https://www.nyscancerconsortium.org/>

# References

- Adam, R., & Watson, E. (2018, Sep). The role of primary care in supporting patients living with and beyond cancer. *Current Opinion in Supportive and Palliative Care*, 12(3), 261-267. <https://doi.org/10.1097/spc.0000000000000369>
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# Scheduled sessions and subject matter discussants

## Session 1: Introduction and Survivorship 101

<b>January 11, 2024</b> <b>12-1:00pm</b>	Maureen Killackey, MD, FACS, FACOG Tessa Flores, MD Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP Facilitator: Christina Crabtree-Ide, PhD, MPH
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## Session 2: Survivorship Teams

<b>February 8, 2024</b> <b>12-1:00pm</b>	Tessa Flores, MD Gregory P. Rys, NP Maura Abbott, PhD, AOCNP, CPNP-PC, RN Facilitator: Maureen Killackey, M.D.
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## Session 3: Medical Issues in Survivorship

<b>March 14, 2024</b> <b>12-1:00pm</b>	Craig D Hametz, MD, FACC, FASE, FASNC Tessa Flores, MD Facilitator: Maureen Killackey, M.D.
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## Session 4: Survivorship Lifestyle Behaviors

<b>April 11, 2024</b> <b>12-1:00pm</b>	Mara Ginsberg, Esq. Timothy Korytko, MD Facilitator: Christina Crabtree-Ide, PhD, MPH
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## Session 5: Survivorship and Sexual Health

<b>May 9, 2024</b> <b>12-1:00pm</b>	Kristin Sobieraj, PA Facilitator: Tessa Flores, M.D.
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## Session 6: Supportive Care in Survivorship

<b>June 13, 2024</b> <b>12-1:00pm</b>	Anne Moyer, PhD Robin Eggeling Facilitator: Christina Crabtree-Ide, PhD, MPH
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