

# Population-Level Approaches to Supporting Health Living in the Growing Population of Cancer Survivors

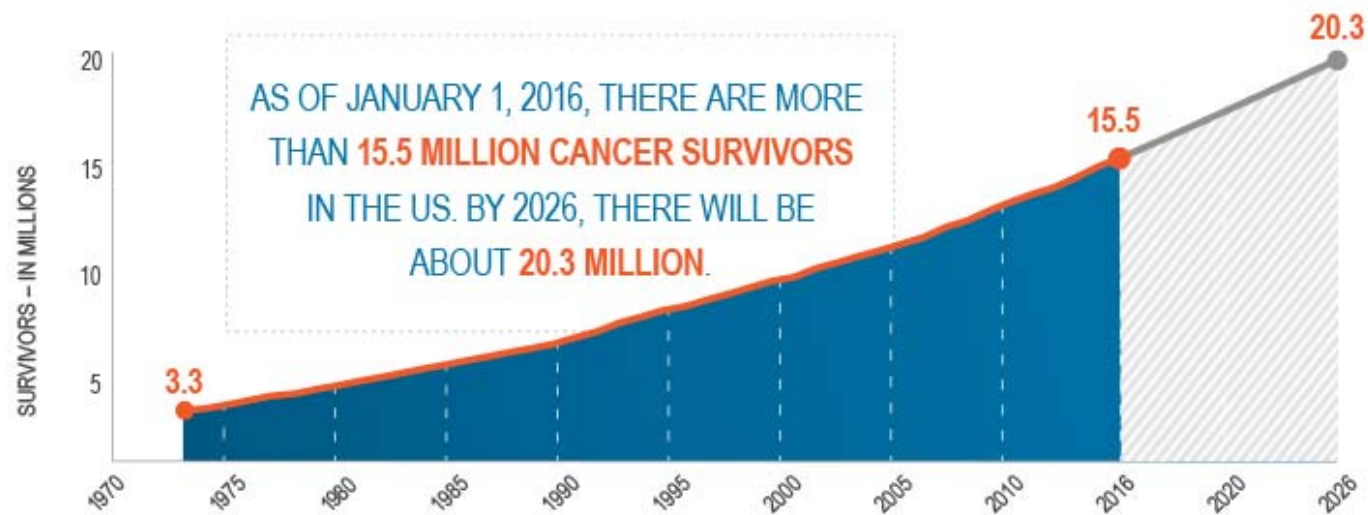
**Catherine M. Alfano, PhD**  
Vice President, Survivorship



## LIFE AFTER CANCER: SURVIVORSHIP BY THE NUMBERS

American Cancer Society // Infographics // 2016

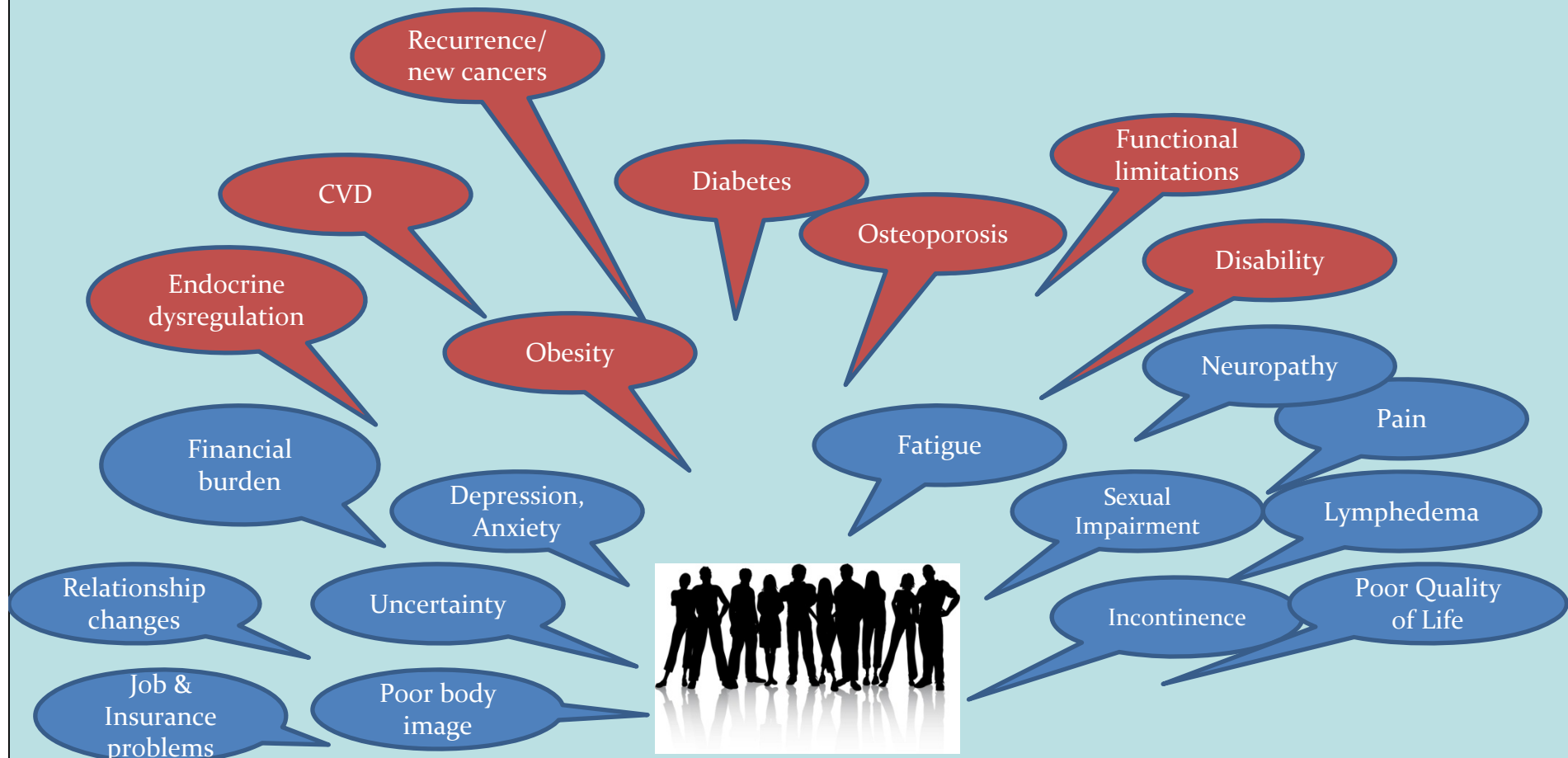
The number of cancer survivors in the United States is increasing, and is expected to grow to about 20.3 million by 2026 according to *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Even though cancer incidence rates are declining in men and stable in women, the number of cancer survivors is rising due to a growing and aging population, as well as earlier detection and better treatments. As this population continues to increase, it will be more important than ever to address this group's unique needs.



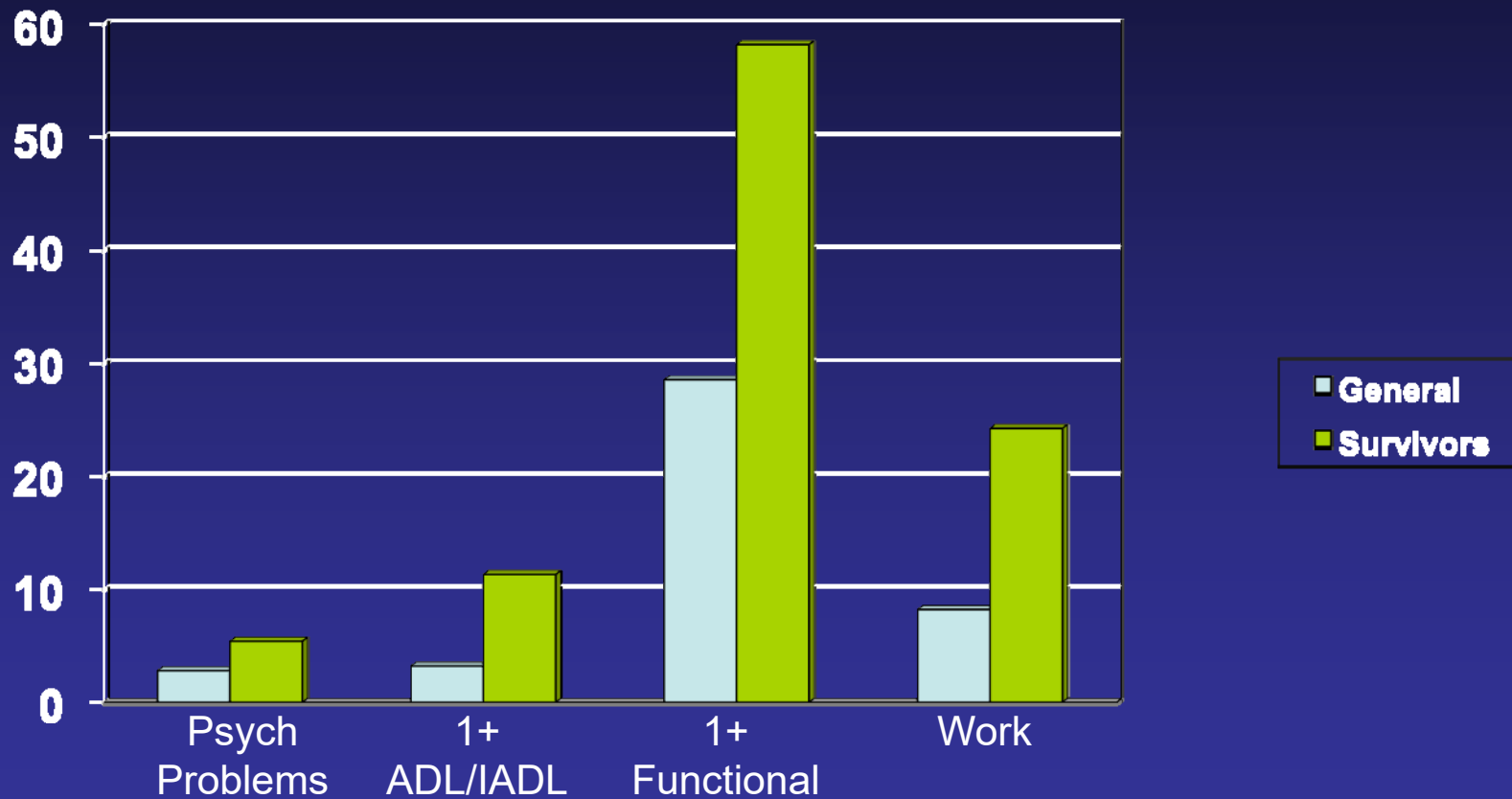
Source: Surveillance, Epidemiology, and End Results Program, National Cancer Institute.



# Cancer Survivors are at risk: Chronic & Late Effects of Cancer

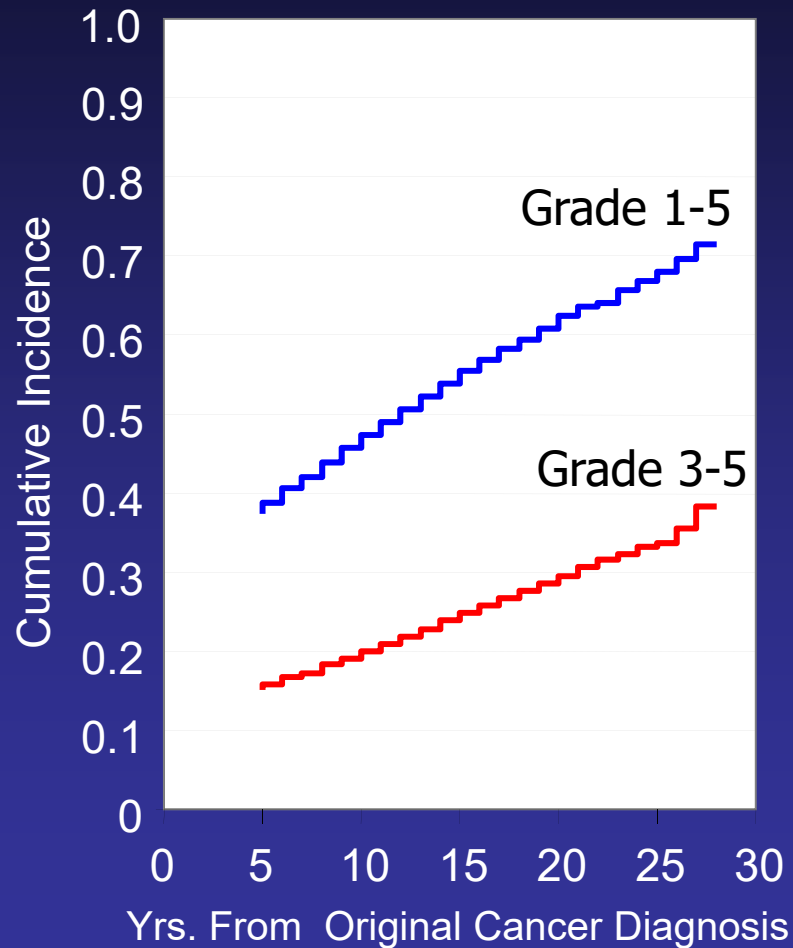


# % with Limitations: Survivors vs. General Population



*Hewitt, Rowland, Yancik. J Gerontol. 58:82, 2003*

## Incidence of Chronic Health Conditions in 10,397 Adult Survivors of Childhood Cancer



Mean age of 26.6 years (18-48 years)

By 30 years post cancer:

- 73% survivors with at least one chronic health condition
- 42% with a Grade 3-5 (severe, life-threatening, death)
- 39% had  $\geq 2$  chronic health conditions

Survivors – 8.2 times more likely to have a severe or life threatening condition compared to siblings

Childhood Cancer Survivor Study

# Many survivors will die of competing causes, NOT cancer...

- Older breast cancer survivors: more likely to die of cardiovascular disease than breast cancer

(Patnaik, *Breast Cancer Research* 2011, 13(3):R64)

- Prostate cancer survivors--15-year mortality
  - 5.3% from prostate cancer
  - 30.6% from non-prostate cancer

(Shikanov, *Prostate Cancer Prostatic Dis.* 2012 Mar;15(1):106-10)

- Young Testicular CA survivors: 1.7 x more likely to die of circulatory disease than general population

(Fossa, *JNCI* 2007 April 4; 99(7), 533-44)



## Focus Care on Creating Healthy Survivors

- ✓ Treat the tumor
- Prevent toxicities, late effects  
...or treat them early





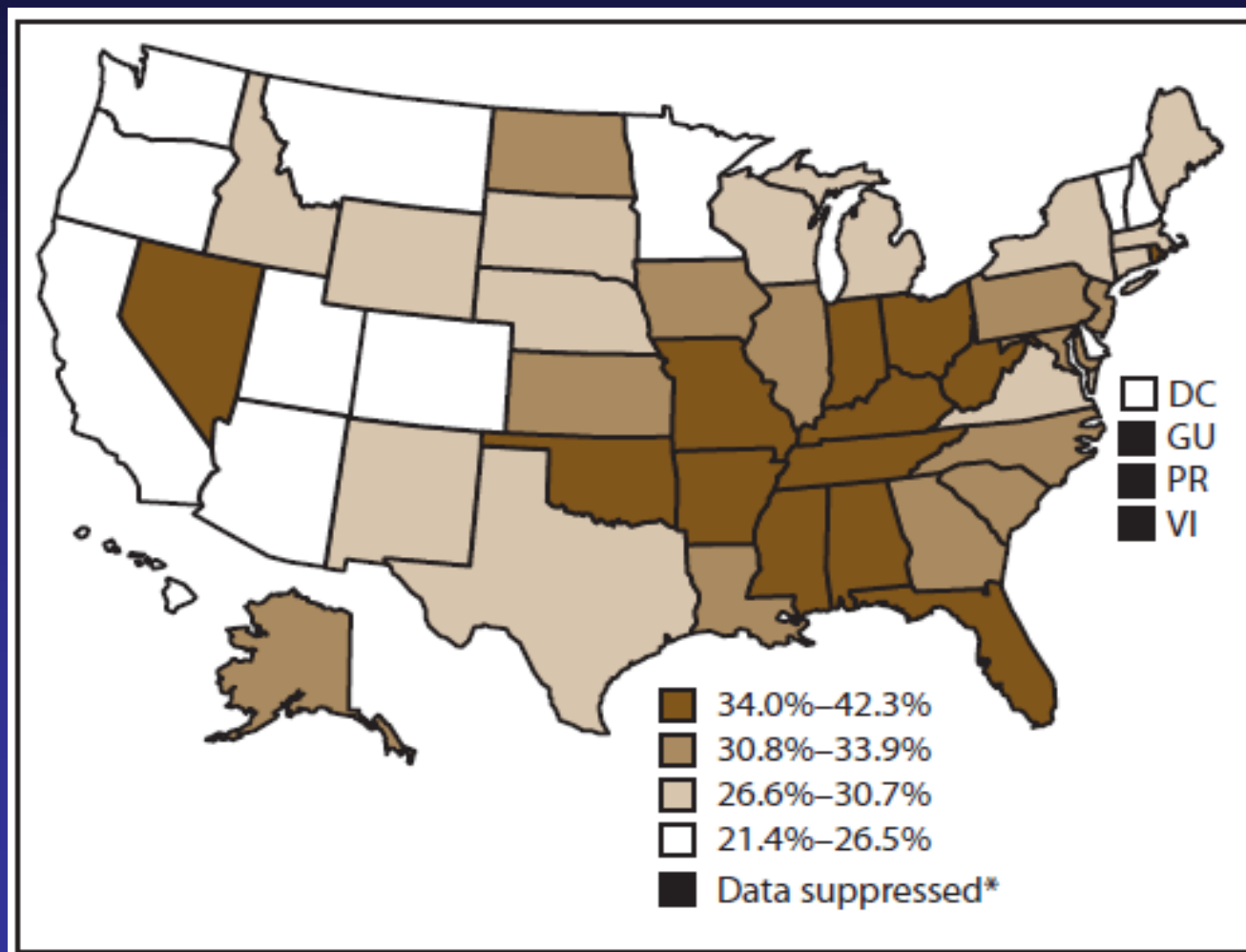
## Exercise & Nutrition

- ✓ Reduce ongoing symptoms like fatigue
- ✓ Improve mood, decrease distress
- ✓ Improve physical functioning and QOL
  - ✓ Prevent spiral into disability
- ✓ Control weight
- ✓ Decrease risk of comorbidities like cardiovascular disease, osteoporosis & diabetes
  - ...and may prevent 1/3 of cancer deaths

# Health Behaviors of Cancer Survivors

(N=45,541; BRFSS data)

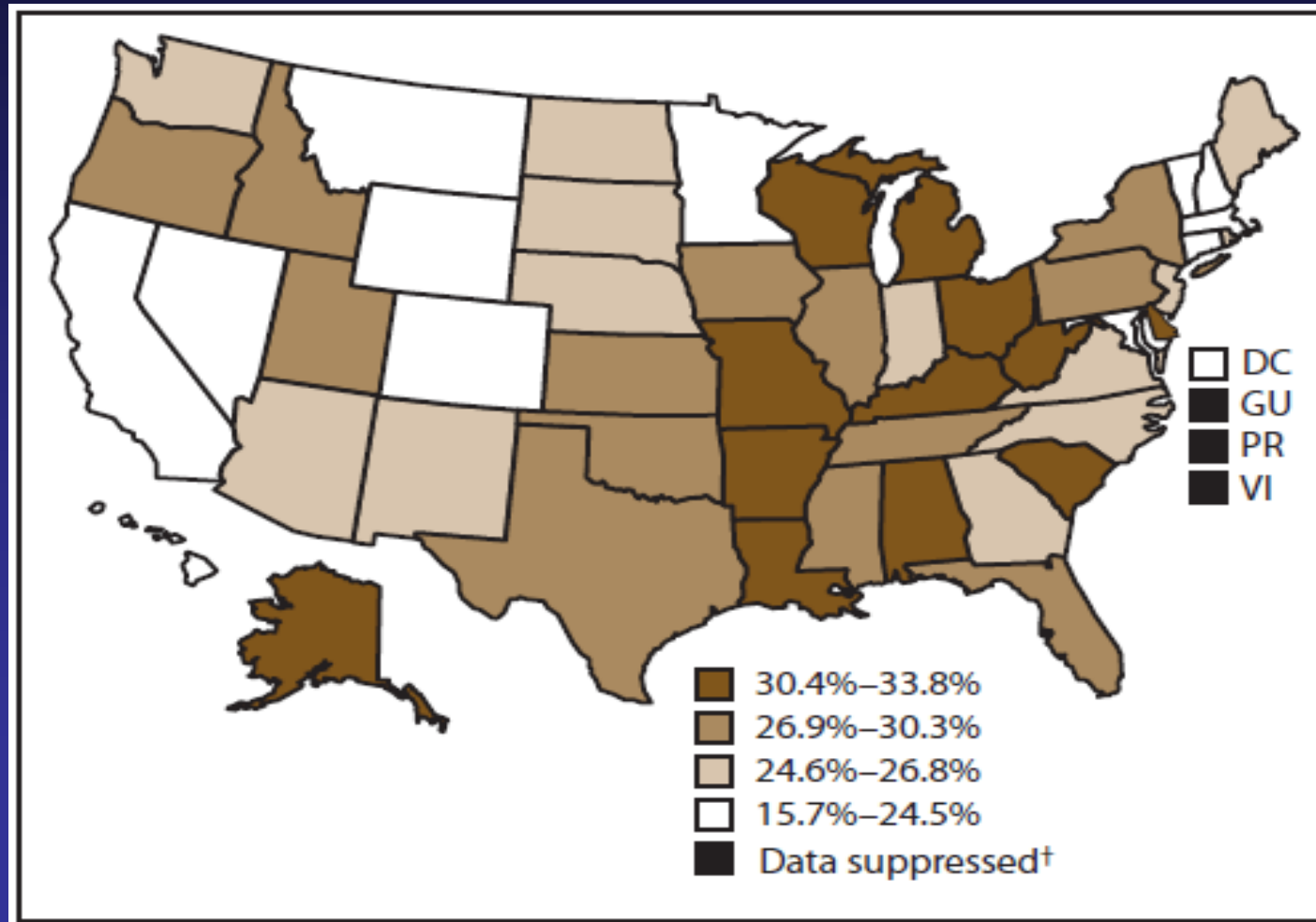
## Sedentary: 31.5%



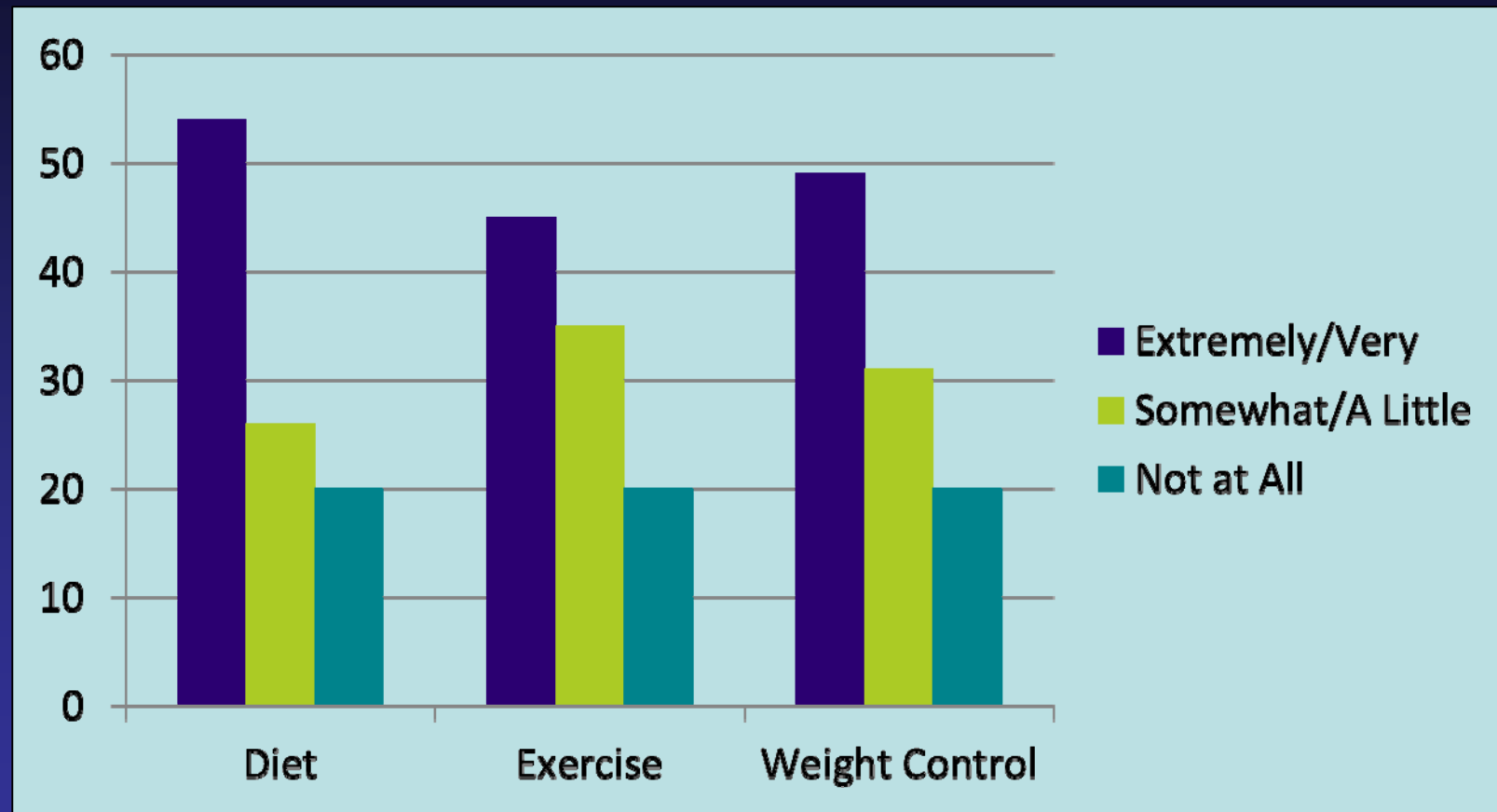
# Health Behaviors of Cancer Survivors

(N=45,541; BRFSS data)

## Obese: 27.5%



# Cancer Survivors Want to Make Healthy Changes



Basen-Engquist, K., Carmack, C., Blalock, J., Baum, G., Rahming, W., & Denmark-Wahnefried, W. (2012, March). Predictors of cancer survivors' receptivity to lifestyle behavior change interventions. Abstract presented at the 36th Annual ASPO Meeting Washington, DC, March 4-6, 2012.

# Do Survivors Talk with their Physicians about Health Behaviors?

(NHIS data)

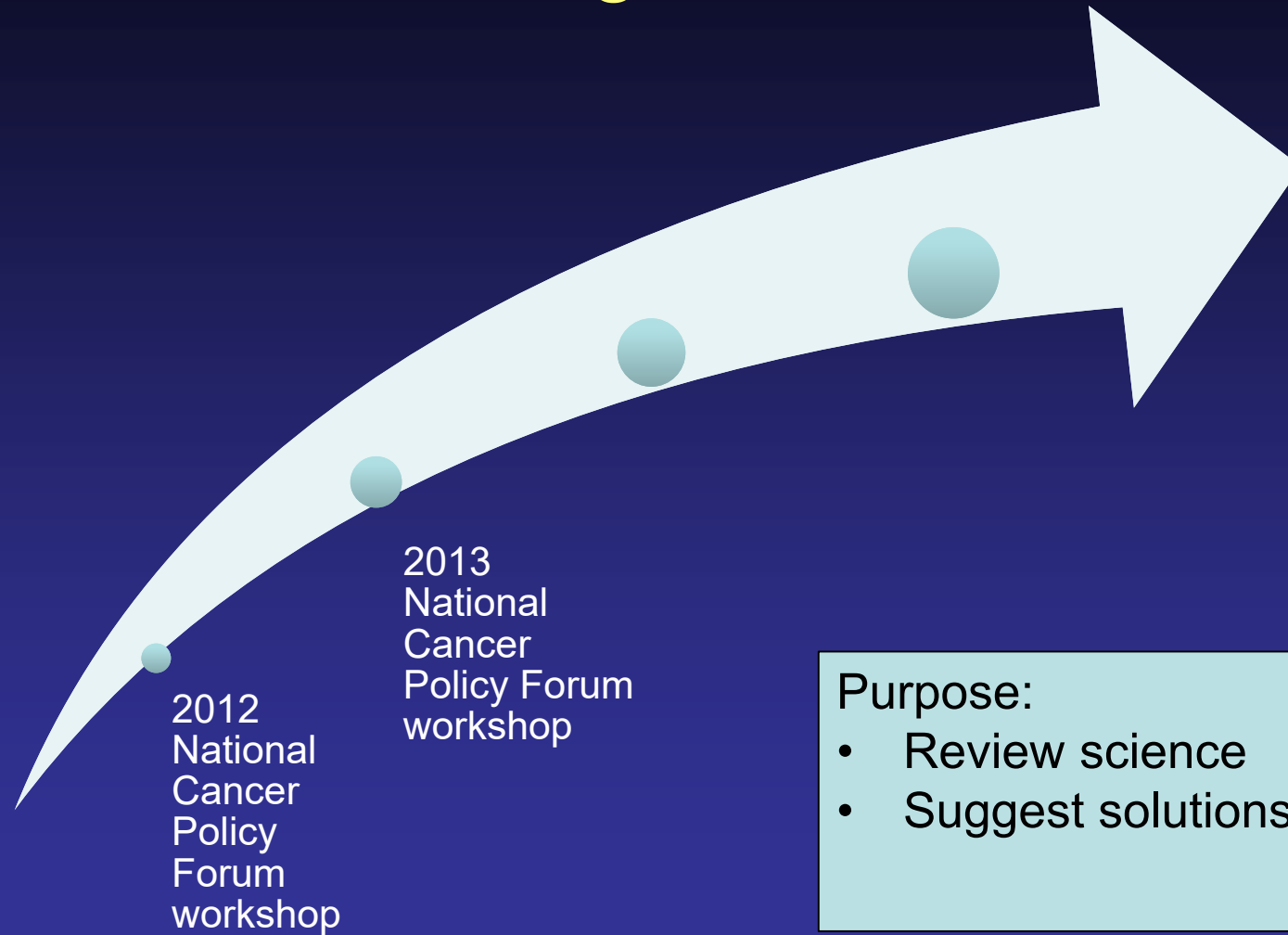
	Cancer Survivors	Adults without Cancer	p
Diet Discussion	30%	23%	<.0001
Exercise Recommendation	26%	23%	<.005
Smoking Assessment	42%	41%	.41

Sabatino et al., 2007, Journal of Clinical Oncology

~~Problems~~  
Solutions

A hand holding a piece of white chalk is visible in the bottom right corner of the chalkboard, pointing towards the word 'Solutions'. The chalkboard is black and the text is written in white chalk.

# Working on Solutions



# Working on Solutions

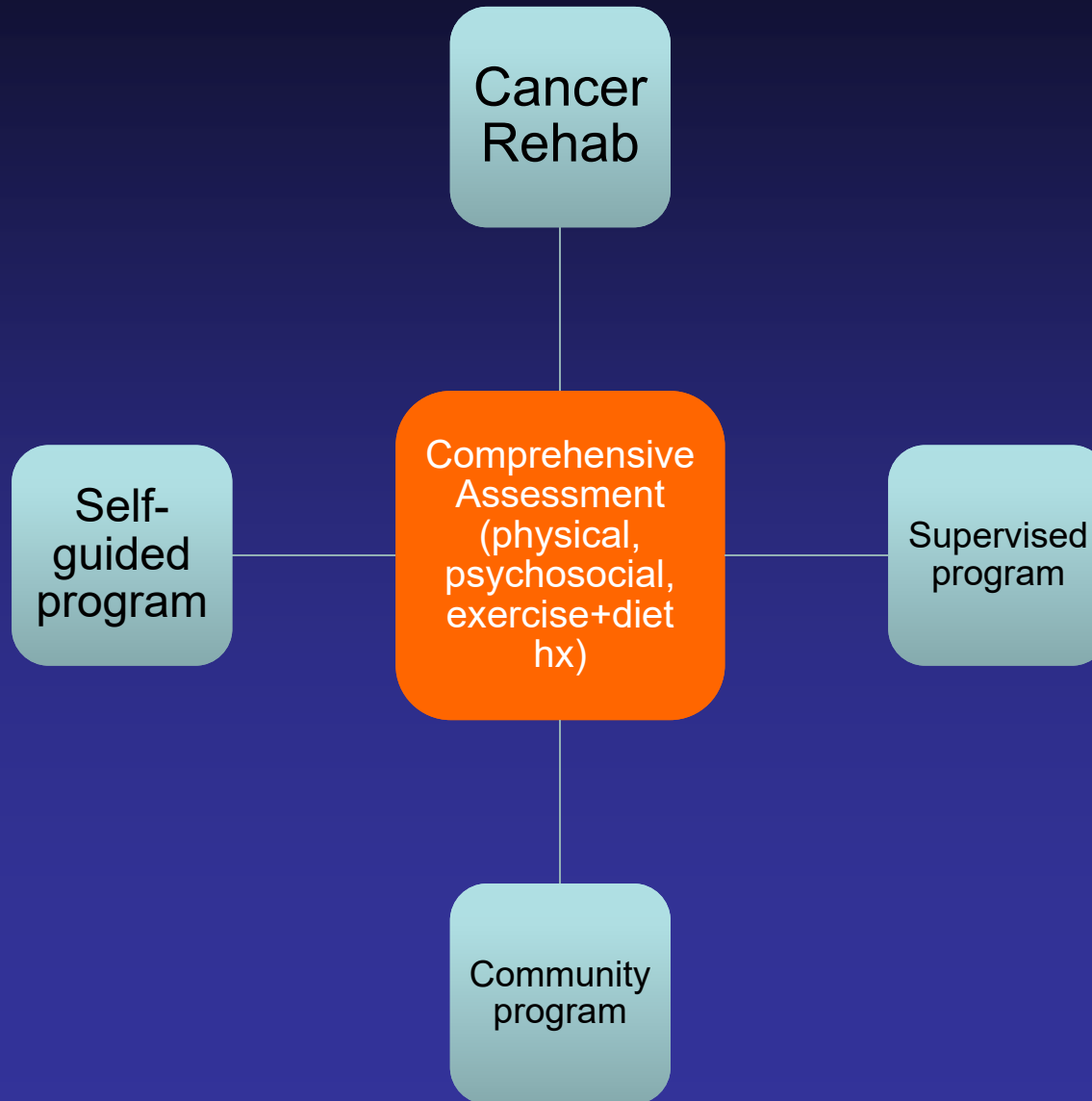
One size  
does NOT fit  
all



2012  
National  
Cancer  
Policy Forum  
workshop



# Need A Personalized Approach



# Population-level Approaches in the US

## 1. Clinical Care Guidelines

# Clinical Care Follow-up Guidelines

**CA**  
A Cancer Journal for Clinicians



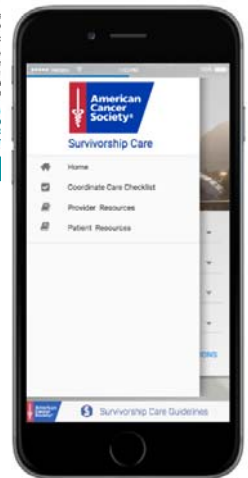
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www.aacr.org

**Cancer Survivorship E-Learning Series for Primary Care Providers**  
Health Care Solutions  
From the American Cancer Society

The National Cancer Survivorship Resource Center offers a free, innovative, online continuing education program to educate primary care providers about cancer survivorship. The Survivorship Center, a collaboration between the American Cancer Society and The George Washington University Cancer Institute, is funded by a five-year cooperative agreement through the Centers for Disease Control and Prevention.

- The Cancer Survivorship E-Learning Series for Primary Care Providers features the following content:
- The role of clinical generalists and specialists in providing follow-up care to survivors of adult-onset cancers
  - Managing long-term and late physical & psychological effects of cancer and its tx
  - Survivorship care planning and care coc
- The series is available at no cost and offers education credits for physicians, physician nurse practitioners, and nurses. New content is added on an ongoing basis. Each webinar includes national experts and features a cancer survivor.
- Visit [cancersurvivorshipcenter.edu](http://cancersurvivorshipcenter.edu) for more information, and help spread the word about this program to your next colleagues, especially those in primary care.



**CA**  
A Cancer Journal for Clinicians

**PATIENT PAGE**

## Prostate Cancer Survivorship Guidelines

**What Are American Cancer Society Survivorship Guidelines?**  
Survivorship guidelines are advice from the American Cancer Society to help you and your healthcare team take care of cancer survivors who have finished their cancer treatment. The survivorship guidelines provide help with care that starts soon after the treatment ends.

**Why Are Prostate Cancer Survivorship Guidelines Needed?**  
• Each year about 300,000 men in the United States are diagnosed with prostate cancer. Most of these men will be treated for their cancer and survive for many years. To help meet your ongoing care needs, we've developed this guide to help you and your healthcare team.

- Finding an oncologist and other health care providers who will provide ongoing care for you.
- Finding out what to expect after your prostate cancer treatment.
- Finding out how to take care of your health and your family.
- Finding out how to manage your symptoms.
- Finding out how to manage your side effects.
- Finding out how to manage your emotional health.
- Finding out how to manage your long-term health.
- Finding out how to manage your late effects.
- Finding out how to manage your quality of life.
- Finding out how to manage your care coordination.
- Finding out how to manage your care planning.
- Finding out how to manage your care delivery.
- Finding out how to manage your care evaluation.
- Finding out how to manage your care improvement.

**What Is Included in These Guidelines?**  
The guidelines address care from diagnosis to the end of life. They cover the following areas:

- General approaches to improve the coordination of care.
- Finding out what to expect after your prostate cancer treatment.
- Finding out how to manage your symptoms.
- Finding out how to manage your long-term health.
- Finding out how to manage your late effects.
- Finding out how to manage your quality of life.
- Finding out how to manage your care coordination.
- Finding out how to manage your care planning.
- Finding out how to manage your care delivery.
- Finding out how to manage your care evaluation.
- Finding out how to manage your care improvement.

**How Should I Use These Guidelines?**  
These guidelines are intended to help you and your healthcare team make decisions about your care. They are not a substitute for your doctor's advice. You should use them as a guide to help you and your healthcare team make decisions about your care.

**American Cancer Society Prostate Cancer Survivorship Care Guidelines**  
Health Care Solutions  
From the American Cancer Society

**CA** A Cancer Journal for Clinicians

**Abstract:**  
Prostate cancer survivors approach 2.8 million in number and represent 1 in 5 of all cancer survivors in the United States. While guidelines exist for timely treatment and surveillance for recurrent disease, there is limited availability of guidelines that facilitate the provision of posttreatment clinical follow-up care to address the impact of long-term and late effects that survivors may face. Based on recommendations set forth by a National Cancer Survivorship Resource Center expert panel, the American Cancer Society developed clinical follow-up care guidelines to facilitate the provision of posttreatment care by primary care clinicians. These guidelines were developed using a combined approach of evidence synthesis and expert consensus. Existing guidelines for health promotion, surveillance, and screening for second primary cancers were referenced when available. To promote comprehensive follow-up care and optimal health and quality of life for the posttreatment survivor, the guidelines address health promotion, surveillance for prostate cancer recurrence, screening for second primary cancers, long-term and late effects assessment and management, psychosocial issues, and care coordination among the oncology team, primary care clinicians, and nononcology specialists. A key challenge to the development of these guidelines was the limited availability of published evidence for management of prostate cancer survivors after treatment. Much of the evidence relies on studies with small sample sizes and retrospective analyses of facility-specific and population databases.

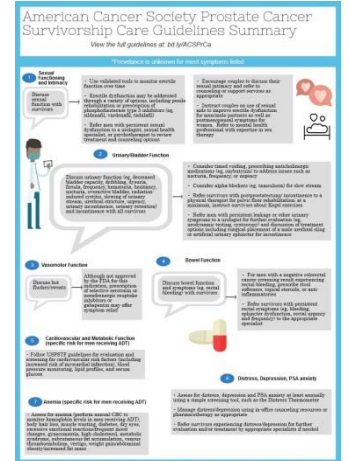
**Reference:**  
Skolaros, T.A., Wolf, A.M.D., Yin, N.L., Brook, D.D., Ryan, B.M., Underwood, W., Sabat, A.L., Zaslavsky, M.J., Aspin, C., Jones, S.J., Williams, D.A., Hest, M.A., Srinivasan, V.L., Chhabra, C., Pruthi-Chaturvedi, M.L., and Cooney, A.M., et al. (2014). American Cancer Society prostate cancer survivorship care guidelines. *CA: A Cancer Journal for Clinicians*, 64, 275-295. doi: 10.3323/caj.2014.01275

**Program Support:**  
The American Cancer Society Prostate Cancer Survivorship Care Guidelines are supported by a cooperative agreement #U59CA000454 from the Centers for Disease Control and Prevention. The Centers for Disease Control and Prevention do not necessarily endorse the clinical advice of the Centers for Disease Control and Prevention.

- **Prostate Cancer** –CA Cancer J Clin on June 10, 2014. ([www.bit.ly/ACSPPrCa](http://www.bit.ly/ACSPPrCa))
- **Colorectal Cancer** –CA Cancer J Clin on September 8, 2015. ([bit.ly/acscolorc](http://bit.ly/acscolorc))
- **Breast Cancer** – Collaboratively developed and released with ASCO. CA Cancer J Clin and JCO on December 7, 2015. ([bit.ly/BrCaCare](http://bit.ly/BrCaCare))
- **Head and Neck Cancer** –CA Cancer J Clin March 22, 2016. ([bit.ly/acsheadneck](http://bit.ly/acsheadneck))

**Describes comprehensive, patient-centered care**

- ✓ Screening, surveillance for new/recurrent cancers
- ✓ Assessment & Management of physical and psychosocial late & long-term effects
- ✓ **Prevention and health promotion**
- ✓ Coordination among specialists and PCPs



# Guidelines on Exercise and Nutrition

CA CANCER J CLIN 2012;62:242-274

## Nutrition and Physical Activity Guidelines for Cancer Survivors

Cheryl L. Rock, PhD, RD<sup>1</sup>; Colleen Doyle, MS, RD<sup>2</sup>; Wendy Demark-Wahnefried, PhD, RD<sup>3</sup>; Jeffrey Meyerhardt, MD, MPH<sup>4</sup>; Kerry S. Courneya, PhD<sup>5</sup>; Anna L. Schwartz, FNP, PhD, FAAN<sup>6</sup>; Elisa V. Bandera, MD, PhD<sup>7</sup>; Kathryn K. Hamilton, MA, RD, CSO, CDN<sup>8</sup>; Barbara Grant, MS, RD, CSO, LD<sup>9</sup>; Marji McCullough, ScD, RD<sup>10</sup>; Tim Byers, MD, MPH<sup>11</sup>; Ted Gansler, MD, MBA, MPH<sup>12</sup>

Cancer survivors are often highly motivated to seek information about food choices, physical activity, improve their treatment outcomes, quality of life, and overall survival. To address these concerns, the American College of Sports Medicine (ACSM) convened a group of experts in nutrition, physical activity, and cancer survivorship to evaluate best clinical practices related to optimal nutrition and physical activity after the diagnosis of cancer. This report summarizes the findings and is intended to present health care providers with the best possible information with which they and their families can make informed choices related to nutrition and physical activity. The report discusses physical activity guidelines during the continuum of cancer care, briefly highlighting important issues during cancer care with advanced cancer, but focusing largely on the needs of the population of individuals who are disease-free following their recovery from treatment. It also discusses select nutrition and physical activity issues, including food choices, food safety, and dietary supplements; issues related to selected cancer sites; and cancer survivorship. CA Cancer J Clin 2012;62:242-274. ©2012 American Cancer Society

Rock et al, 2012

Schmitz et al, 2010

### SPECIAL COMMUNICATIONS

*Roundtable Consensus Statement*

## American College of Sports Medicine Roundtable on Exercise Guidelines for Cancer Survivors

### EXPERT PANEL

Kathryn H. Schmitz, PhD, MPH, FACSM  
Kerry S. Courneya, PhD  
Charles Matthews, PhD, FACSM  
Wendy Demark-Wahnefried, PhD  
Daniel A. Galvão, PhD  
Bernardine M. Pinto, PhD  
Melinda L. Irwin, PhD, FACSM  
Kathleen Y. Wolin, ScD, FACSM  
Roanne J. Segal, MD, FRCP  
Alejandro Lucia, MD, PhD  
Carole M. Schneider, PhD, FACSM  
Vivian E. von Gruenigen, MD  
Anna L. Schwartz, PhD, FAAN

to physical functioning and quality of life are sufficient for the recommendation that cancer survivors follow the 2008 Physical Activity Guidelines for Americans, with specific exercise programming adaptations based on disease and treatment-related adverse effects. The advice to "avoid inactivity," even in cancer patients with existing disease or undergoing difficult treatments, is likely helpful.

In 2009, the American Cancer Society (ACS) estimated that there were nearly 1.5 million new cases of cancer diagnosed in the United States and just more than 500,000 people who died from the disease (76). Currently, there are close to 12 million cancer survivors in the United States, and this number grows each year (66,70,122). Improved prognosis on the basis of earlier detection and newer

New Global  
Effort for  
2017

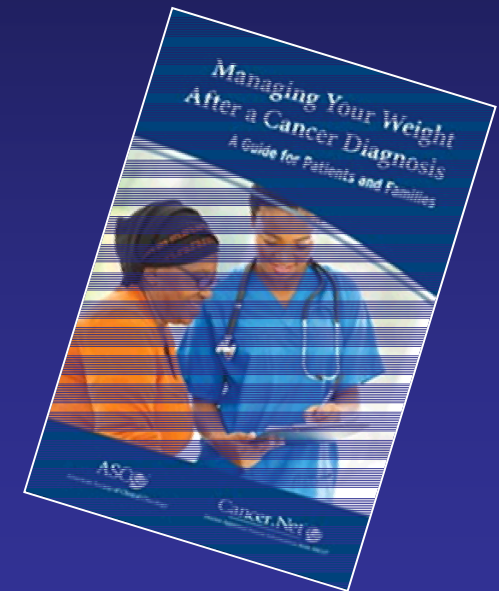
# Population-level Approaches in the US

1. Clinical Care Guidelines

2. Materials & Tools for Survivors

- ACS Materials
- ASCO Guide
- NCI/ACS Springboard Beyond Cancer

<https://Smokefree.gov/springboard/>

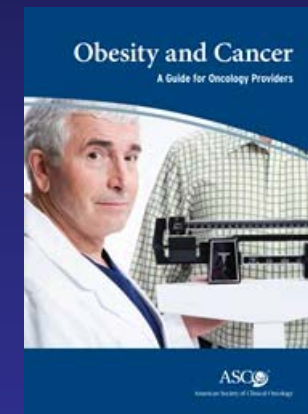


# Population-level Approaches in the US

1. Clinical Care Guidelines
2. Materials & Tools for Survivors & Clinicians
3. Improve access to effective interventions
  - Cancer rehabilitation
  - Supervised programs
  - Community-based programs
    - LIVESTRONG at the Y & the Diabetes Prevention Program
    - Gym-based programs

# Population-level Approaches in the US

1. Clinical Care Guidelines
2. Materials & Tools for Survivors & Clinicians
3. Improve access to effective interventions
4. Train providers
  - ASCO toolkit, position statement
  - Core competencies for MDs
  - Select Medical/ACS International Cancer Rehabilitation Summit
  - ACSM Cancer Exercise Trainer certification
  - APTA Cancer Certification



# Population-level Approaches in the US

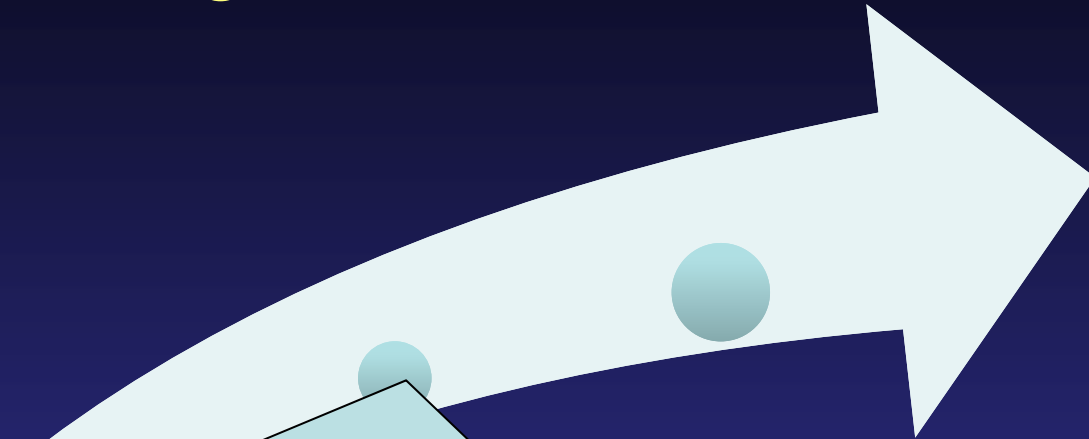
1. Clinical Care Guidelines
2. Materials & Tools for Survivors & Clinicians
3. Improve access to effective interventions
4. Train providers
5. Implement comprehensive assessment of patient needs through and beyond treatment
  - Improved patient-provider communication
  - Refer to the right intervention
  - Currently fielding crowd-sourcing consensus project



# Working on Solutions



# Working on Solutions



ACS

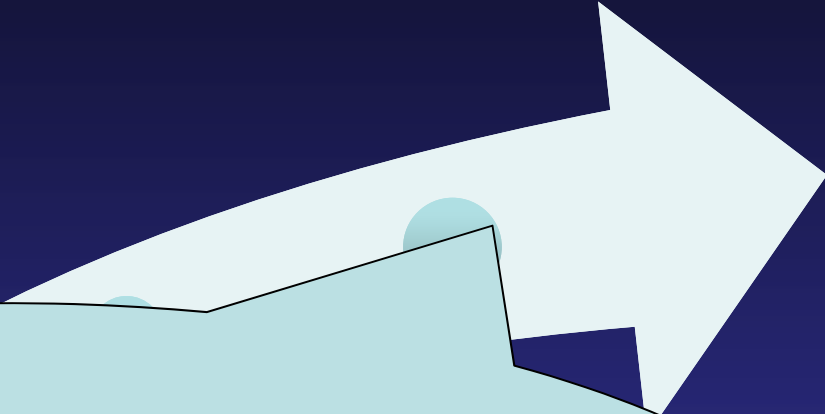
“Cancer survivors face challenges in adopting healthy lifestyle behaviors – personal, family, healthcare system, community/public health levels”

- Need policy solutions **that remove financial, informational, environmental, and other barriers to healthy lifestyles**
- **Stakeholders must work together**

# Working on Solutions



# Working on Solutions

- 
- Harmonizing clinical guidelines
  - Collaborating on provider education/training initiatives
  - Collaborating on public education and patient activation campaigns
  - Collaborating on research efforts
  - Collaborating on a policy agenda including coverage and reimbursement

# Population-level Approaches in the US

1. Clinical Care Guidelines
2. Materials & Tools for Survivors & Clinicians
3. Improve access to effective interventions
4. Train providers
5. Implement comprehensive assessment of patient needs through and beyond treatment
6. Research Agenda to Inform Change

# Research Agenda to Inform Change



*JNCI J Natl Cancer Inst* (2016) 108(1): djv285

doi:10.1093/jnci/djv285

First published online November 7, 2015

Commentary

COMMENTARY

## NCI Funding Trends and Priorities in Physical Activity and Energy Balance Research Among Cancer Survivors

Catherine M. Alfano\*, Shirley M. Bluethmann, Gina Tesauro, Frank Perna, Tanya Agurs-Collins, Joanne W. Elena, Sharon A. Ross, Mary O'Connell, Heather R. Bowles, Deborah Greenberg, Linda Nebeling

Affiliations of authors: Behavioral Research Program (CMA, SMP, CT, EB, TAC, MQ, DC, LN) and Epidemiology and Genomics Research Program (HWF), Division of

# Research Agenda

- Survivor level: create interventions that are feasible for diverse survivors with outcomes meaningful to them
- Clinician-level:
  - A) determine underlying biology of how health behavior interventions improve health and well-being= which survivors to refer for which interventions
  - B) need effective programs in a variety of settings- test models of referral and feedback to clinicians
- Healthcare payer level: collect the data needed to make the case for reimbursement

# Working on Solutions: Next Steps

- 2017 NCPF workshop Feb 13-14





# New US National Initiative



## The Survivorship Roundtable:

- Bring together organizations with a stake in the care of cancer survivors
- Mission: To meet the physical, functional, and psychosocial needs of people living through and beyond cancer and optimize functioning and well-being through enhancing the delivery of services from diagnosis through post-treatment survivorship in clinical, community, and worksite settings in the US
- Tackle agendas that no single organization can do alone



**THANK YOU !**

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