National Survivorship and QoL Research:
Impact on Interventions, Guidelines, and Resources

Kevin D. Stein, PhD, Vice President, Behavioral Research, Director, Behavioral Research Center, American Cancer Society, Adjunct Associate Professor, Rollins School of Public Health, Emory University, Atlanta, GA
Co-Author & Acknowledgements

Co-Authors

• Lee Westmaas, PhD, American Cancer Society
• Corinne Leach, PhD, American Cancer Society
• Rachel Cannady, American Cancer Society
• Tenbroeck Smith, MA, American Cancer Society
• Elizabeth Fallon, PhD, American Cancer Society
• And many other external collaborators...

Acknowledgements:

• Intramural Funding from the American Cancer Society
• SEER and NPCR state cancer registries (study sampling frame)
• Participation of thousands of cancer survivors across the USA
Outline of Presentation

- Organizational structure of the American Cancer Society
- Integration of research and cancer control programs at ACS
- Exemplar findings from the ACS Studies of Cancer Survivors
- Translation of findings into evidence-based interventions, guidelines, and resources
- What’s next?
The American Cancer Society was founded in 1913

The ACS Research program was founded in 1946 under the leadership of Mary Woodard Lasker

Since then, the ACS has invested more than $2.8 billion in Cancer Research

ACS dedicates more money to Cancer Research than any other private, non-profit, non-governmental funding organization in the US
The American Cancer Society, Inc. Organizational Chart

ACS Board of Directors

Chief Executive Officer

Chief Operating Officer

ACS Divisions

President, ACS CAN
Federal Advocacy
Grassroots Advocacy
Government Relations
Policy Analysis
State & Local Campaigns

Chief Medical & Scientific Officer
Intramural Research
Extramural Grants
External Medical / Scientific Partnerships

Chief Cancer Control Officer
Patient and Caregiver Support
Health Systems
Global Health
Prevention and Early Detection
Programs and Services

Chief Revenue Officer
Core Revenue
Grass Tops Engagement

NVP, Communications
Strategy/Implementation
Organizational Communications
Media Relations
Brand Management
Issue/Reputation Management
Operations

Planned Giving

Core Revenue
Grass Tops Engagement

NVP, Communications
Strategy/Implementation
Organizational Communications
Media Relations
Brand Management
Issue/Reputation Management
Operations

Planned Giving

The critical need of our healthcare system is...
The ACS Intramural Research Department

ACS Intramural Research Department

- Behavioral Research
- Epidemiology Research
- Economic and Health Policy Research
- Statistics & Evaluation
- Surveillance & Health Services Research
The ACS Intramural Research Department

ACS Intramural Research Department

- Behavioral Research
- Epidemiology Research
- Economic and Health Policy Research
- Statistics & Evaluation
- Surveillance & Health Services Research
The ACS Intramural Research Department

- Behavioral Research
- Epidemiology Research
- Economic and Health Policy Research
- Statistics & Evaluation
- Surveillance & Health Services Research
Mission of the ACS Behavioral Research Center

To support the mission of American Cancer Society by conducting quality, high impact original behavioral research to reduce cancer disparities, modify cancer risk behaviors, and improve cancer outcomes and quality of life among cancer survivors, caregivers, and the general population

1. **Build the Evidence**: Increase our understanding of behavioral and psychosocial aspects of cancer

2. **Use the Evidence**: To improve cancer outcomes, through behavior change and risk modification
How Behavioral Research Can Improve Outcomes

Knowledge, attitudes, & beliefs
• Obesity causes cancer?
• I don’t have time for cancer screening!

Health behaviors & coping
• Diet, exercise, tobacco use
• Compliance with cancer screening guidelines
• Depression, anxiety, distress

PROs and Clinical outcomes
• Quality of life (QoL)
• Risk for cancer diagnosis
• Risk for cancer recurrence
• Risk for mortality

Social, Contextual & Environmental Factors
• Family and community
• Social determinants
The ACS Studies of Cancer Survivors (SCS)

**SCS-I (n = 6,307)**
- Longitudinal design; follows a single cohort of cancer survivors over 10-years
- Monitor changes in quality of life and health behaviors over time

**SCS-II (n = 9,105)**
- Cross-sectional design; includes 3 separate cohorts: short-medium- and long-term survivors
- Immediate data on long-term survivors QoL & health behaviors

**SCS Caregiver (n = 1,635)**
- Caregivers nominated by SCS-I participants to complete a separate survey

Rationale:
• 20 million survivors by 2026, with continued health needs after cancer treatment ends

Methods Brief:
• Nationwide – over 15,000 survivors
• Population-based sampling methods
• Over-sampling of minority and younger cancer survivors

Major outcomes of interest:
• Physical and mental health
• Lifestyle behaviors
• Quality of life (QoL)
SCS Findings: Top Cancer-Related Problems
“Top Five” Cancer-Related Problems

SCS combined dataset. Cancer Problems in Living Scale (CPILS).
“Top Five” Cancer-Related Problems

Percentage with Problem

- Fearful Illness Will Return: 65%
- Fatigue/Loss of Strength: 60%
- Concern about Relapsing: 60%
- Fears about the Future: 55%
- Sleep Difficulties: 50%

SCS combined dataset. Cancer Problems in Living Scale (CPILS).
“Top Five” Cancer-Related Problems by Time Since Diagnosis

<table>
<thead>
<tr>
<th>Percentage with Problem</th>
<th>1-YR Survivors</th>
<th>3-YR Survivors</th>
<th>6-YR Survivors</th>
<th>11-YR Survivors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fearful Illness Will Return</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue/Loss of Strength</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concern about Relapsing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fears about the Future</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep Difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SCS combined dataset. Cancer Problems in Living Scale (CPILS).
SCS Findings: Tobacco Use amongst Survivors
Percentage of survivors still smoking 9 years after diagnosis

[Bar graph showing the percentage of survivors still smoking 9 years after diagnosis by cancer type, with the legend indicating Never smokers, Former smokers (quit before Dx), Former smokers (quit after Dx), and Current smokers.]

ACS Study of Cancer Survivors-I (n=2,938)
Mean Quality of Life = 50

- **Met none**
- **Smoke only**
- **Met 2**
- **Met all 3**

SCS Findings: Problems Obtaining Information
I needed information regarding:

- Experience of other patients
- Clinical trials
- Cancer doctors
- Support groups
- Long-term side effects

Information Barriers Experienced by Survivors

Survivors’ Ratings of Physician Communication

My Doctor did NOT:

- Explain things understandably
- Provide enough emotional support
- Make decisions collaboratively
- Seem informed about my other cancer care
- Provide clear instructions about side effects

SCS Findings

Cancer-related problems (physical & emotional)

ACS Interventions

Online Self-Management Springboard Beyond Cancer
5 Steps to Take Action for Better Self-Management

1. **Step One: Identify your goals**
2. **Step Two: Create a Plan**
3. **Step Three: Identify potential challenges**
4. **Step Four: Monitor your progress**
5. **Step Five: Re-assess the plan**
Manage Cancer—Your Way

Cancer can bring many challenges. Springboard Beyond Cancer gives you information and resources to help you cope and be in control.

Springboard Beyond Cancer Can Help

Want to take control of your health?
Learn about Self-Management and the steps you can take to actively manage your health.

Are you struggling with side effects?
Explore the Symptoms section for information on Fatigue, Nausea, and more.

Need help from doctors and loved ones?
Learn to make the most of your support system in the Get Support section.

https://smokefree.gov/springboard
What Are Action Decks?

Action Decks are collections of information related to a cancer topic or treatment.

1. Create or choose a action deck
2. Download and print your action deck
3. Use the action deck to help manage your symptoms
4. Come back for more help when you need it

Use the action decks to get information, tips, and resources that address what you are going through. These decks will help you build skills, tackle challenges, and move forward along your cancer journey.

1. Pick or create the deck that suits your needs
2. Download or print the deck for future reference
3. Come back and find your next deck as your symptoms change

Browse Available Cards
Action Decks: Create Your Own

Use the action decks to get information, tips, and resources that address what you are going through. These decks will help you build skills, tackle challenges, and move forward along your cancer journey.

Select a Topic Area

Select Symptom Cards to Add to Your Deck

- Anemia & Bleeding
- Appetite Changes
- Bladder Control Problems (Incontinence)
- Chemo-Brain & Memory Problems
- Constipation
- Diarrhea
- Fatigue
- Hair Loss
- Infections
- Hot Flashes & Night Sweats
- Sleep Problems

Cards in Your Action Deck

Symptoms Cards
- Fatigue
- Sleep Problems

Stress & Mood Cards
Fatigue

Fatigue is a very common side effect of cancer treatment that can disrupt your ability to do everyday things. Here’s what you can do to help deal with fatigue.

Try This

Ask for help. Reach out to friends and family to help you with chores and errands.

Set priorities. Identify the most important tasks each day, and then focus your energy on those tasks.

Keep a schedule. Wake up, go to bed, and rest at the same times each day.
SCS Findings

Cancer-related problems (physical & emotional)

Continued smoking among survivors

ACS Interventions

Online Self-Management Springboard Beyond Cancer

Online Smoking Cessation Intervention

Translational Research
Tailored Email Smoking Cessation Intervention

Rationale:
- Advances in digital technology create new opportunities for widespread dissemination of cessation assistance to smokers.

Methods Brief:
- The **ACS Tailored Email Study** was posted on the ACS Great American Smoke Out site
- 3 Arm study, participants randomized to:
  1) **Deluxe Arm** with 27 **tailored** emails
  2) **Basic Arm** with 3-4 emails
  3) **Control Arm** with 1 email with resources

Major outcomes of interest:
- Abstinence Rates
- Cessation Aid Use
SCS Findings

- Cancer-related problems (physical & emotional)
- Continued smoking among survivors
- Poor compliance with ACS healthy lifestyle recommendations

ACS Interventions

- Online Self-Management Springboard Beyond Cancer
- Online Smoking Cessation Intervention
- Community-based Physical Activity Intervention via RTR

Translational Research
Physical activity intervention delivered to BR CA Survivors through ACS Reach to Recovery

- RCT 2-arm study design
  - ARM 1 (intervention): standard RTR + Exercise
  - ARM 2 (control): standard RTR Program alone
- 12-week phone-based exercise intervention
Physical Activity Intervention

Major Finding:

Reach to Recovery + peer-led physical activity coaching leads to greater changes in physical activity


- Supported by the National Cancer Institute (Grant R01 CA132854).
Nutrition and Physical Activity Guidelines for Cancer Survivors

Cheryl L. Rock, PhD, RD¹; Colleen Doyle, MS, RD²; Wendy Demark-Wahnefried, PhD, RD³; Jeffrey Meyerhardt, MD, MPH⁴; Kerry S. Courneya, PhD⁵; Anna L. Schwartz, FNP, PhD, FAAN⁶; Elisa V. Bandera, MD, PhD⁷; Kathryn K. Hamilton, MA, RD, CSO, CDN⁸; Barbara Grant, MS, RD, CSO, LD⁹; Marji McCullough, ScD, RD¹⁰; Tim Byers, MD, MPH¹¹; Ted Gansler, MD, MBA, MPH¹²

Cancer survivors are often highly motivated to seek information about food choices, physical activity, and dietary supplements to improve their treatment outcomes, quality of life, and overall survival. To address these concerns, the American Cancer Society (ACS) convened a group of experts in nutrition, physical activity, and cancer survivorship to evaluate the scientific evidence and best clinical practices related to optimal nutrition and physical activity after the diagnosis of cancer. This report summarizes their findings and is intended to present health care providers with the best possible information with which to help cancer survivors and their families make informed choices related to nutrition and physical activity. The report discusses nutrition and physical activity guidelines during the continuum of cancer care, briefly highlighting important issues during cancer treatment and for patients with advanced cancer, but focusing largely on the needs of the population of individuals who are disease free or who have stable disease following their recovery from treatment. It also discusses select nutrition and physical activity issues such as body weight, food choices, food safety, and dietary supplements; issues related to selected cancer sites; and common questions about diet, physical activity, and cancer survivorship. CA Cancer J Clin 2012;00:000-000. © 2012 American Cancer Society.
ACS Nutrition & Physical Activity Guidelines for Cancer Survivors

• Achieve a diet that emphasizes plant foods, including vegetables, fruit and whole grains.

• Engage in regular physical activity.

• Achieve and maintain a healthy weight.
ACS Resources for Healthy Living

I Can Cope
Nutrition during cancer treatment
Translational Research

SCS Findings

- Cancer-related problems (physical & emotional)
- Continued smoking among survivors
- Poor compliance with ACS healthy lifestyle recommendations
- Difficulties obtaining cancer information

ACS Interventions

- Online Self-Management Springboard Beyond Cancer
- Online Smoking Cessation Intervention
- Community-based Physical Activity Intervention via RTR
- Cancer Survivorship Resource Center
Survivorship-focused Web pages on cancer.org

Life After Treatment Guide

Chronic Disease Self-Management Program

Rx for Survivorship

Program Evaluation Guide

Provider e-learning series

Survivorship Care Guidelines for Primary Care Providers

www.cancer.org/survivorshipcenter
Cancer Survivorship E-Learning Series for Primary Care Providers

A program of the National Cancer Survivorship Resource Center

According to the American Cancer Society, there are nearly 14.5 million cancer survivors in the U.S., many of whom face physical, psychological, practical, informational, and spiritual challenges after the completion of cancer treatment. Primary care providers play a critical role in providing much-needed follow-up care for cancer survivors.

The Cancer Survivorship E-Learning Series is a free continuing education program that provides a forum to educate primary care providers (PCPs) (e.g., general medicine physicians, geriatricians, gynecologists, physician assistants, nurse practitioners, nurses) who may have patients who are cancer survivors about how to better understand and care for survivors in the primary care setting. Continuing education credits (CEs) are available at no cost to participants for each 1-hour module.

This program is available through the National Cancer Survivorship Resource Center (The Survivorship Center), 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.

The audience will learn about caring for survivors of adult-onset cancers, including:

- Module 1: The Current State of Survivorship Care and the Role of Primary Care Providers
- Module 2: Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers
- Module 3: Late Effects of Cancer and its Treatment: Meeting the Psychosocial Health Care Needs of Survivors
- Module 4: The Importance of Prevention in Cancer Survivorship: Empowering Survivors to Live Well

cancersurvivorshipcentereducation.org
Cancer Survivorship E-Learning Series: Now up to 10 Modules!

Module 1: Current Status of Survivorship Care and the Role of Primary Care Providers
Module 2: Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers
Module 3: Late Effects of Cancer and its Treatments: Meeting the Psychosocial Health Care Needs of Survivors
Module 4: The Importance of Prevention in Cancer Survivorship: Empowering Survivors to Live Well
Module 5: A Team Approach: Survivorship Care Coordination
Module 6: Cancer Recovery and Rehabilitation
Module 7: Spotlight on Prostate Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
Module 8: Spotlight on Colorectal Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
Module 9: Spotlight on Breast Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
Module 10: Spotlight on Head and Neck Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

Cancer Survivorship E-Learning Series for Primary Care Providers
cancersurvivorshipcentereducation.org
Advancing Survivorship Care Through the National Cancer Survivorship Resource Center

Developing American Cancer Society Guidelines for Primary Care Providers

Rebecca Cowens-Alvarado, MPH; Katherine Sharpe, MA; Mandi Pratt-Chapman, MA; Anne Willis, MA; Ted Gansler, MD, MBA, MPH; Patricia A. Ganz, MD; Stephen B. Edge, MD; Mary S. McCabe, RN, MA; Kevin Stein, PhD

The National Cancer Survivorship Resource Center (The Survivorship Center) began in 2010 as a collaboration between the American Cancer Society and the George Washington University Cancer Institute and was funded by the Centers for Disease Control and Prevention. The Survivorship Center aims to improve the overall health and quality of life of posttreatment cancer survivors. One key to addressing the needs of this ever-growing population is to develop clinical follow-up care guidelines that emphasize not only the importance of surveillance for cancer recurrence, but also address the assessment and management of the physical and psychosocial long-term and late effects that may result from having cancer and undergoing cancer treatment as well as highlight the importance of healthy behaviors that can reduce the risk of cancer recurrence, second primary cancers, and other chronic diseases. Currently, The Survivorship Center is coordinating the work of experts in oncology, primary care, and other health care professions to develop follow-up care guidelines for 10 priority cancer sites. CA Cancer J Clin 2013;000:000–000. © 2013 American Cancer Society.

Keywords: survivorship, primary care, public health, guidelines

Introduction
Cancer survival rates have improved over the past several decades due to advances in treatment and screening. Nearly 13.7

...
Survivorship care guidelines now available for:

- Prostate cancer
- Colorectal cancer
- Breast cancer
- Head and neck cancers
ACS Cancer Survivorship Care Guidelines: Clinician Mobile App

To learn more, visit cancer.org/survivorcareapp
CA Patient Pages help patients talk to their doctors about the guidelines.

Available free online: bit.ly/CAPatientPages
Where are we headed?

• Dissemination and Implementation Science
  • What works for whom, under what conditions, via what delivery channel, at what time in the continuum ...and WHY?

• Use of E-health technologies in research & interventions

• Cancer Survivorship Roundtable – its time!
  • Joint effort between the ACS and ASCO
  • To be launched in 2017
To learn more about survivorship research at ACS
Email: kevin.stein@cancer.org

To learn more about The ACS Survivorship Center
Visit: cancer.org/survivorshipcenter

To Learn more about the E-Learning Series
Email: gwci@gwu.edu