

NCCN Cancer Survivorship Guidelines: Development and Clinical Use **A Primary Care Perspective**

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Disclosures

- NCCN Survivorship Guidelines Panel
- Springer Publishing



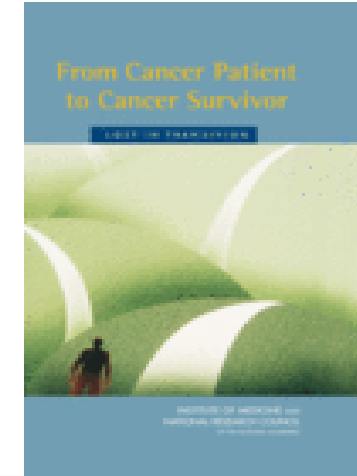
Objectives

- Introduce the NCCN Cancer Survivorship Guidelines for those who may not be familiar
- Discuss the role of the NCCN Cancer Survivorship Guidelines in the clinical care of individuals with a history of cancer, with special focus on the primary care setting

The call for survivorship care clinical guidance

By 2013:

- A growing evidence base around the unmet needs of individuals living beyond a cancer diagnosis
- Most individuals with a history of cancer follow up in primary care settings over time
 - includes rural areas/community health centers
- Growing numbers of long-term cancer survivors projected to overwhelm the oncology workforce
- But how to develop and implement guidelines in a way that supports truly coordinated care?



¹Institute of Medicine and National Research Council. 2006. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/11468>.

²Available at: <https://www.livestrong.org/sites/default/files/what-we-do/reports/essentialelementsbrief.pdf>

New NCCN Guidelines® for Survivorship Care

Presented by Jennifer A. Ligibel, MD, and Crystal S. Denlinger, MD

- In 2013, new cancer survivorship guidelines from the National Comprehensive Cancer Network (NCCN) were presented
 - Intended to serve as guidance for clinicians to address post treatment sequelae more **comprehensively** and **systematically**
 - Cross-cuts any one specific cancer type
 - Serve as “...a companion to the disease guidelines”^{*,+}
- Treatment summaries/Survivorship Care Plans may not always be available to clinicians; these guidelines can still be helpful
- Available at www.nccn.org

^{*}Ligibel JA, Denlinger CS. New NCCN guidelines for survivorship care. *J Natl Compr Canc Netw*. 2013 May;11(5 Suppl):640-4. PMID: 23704233.

⁺Denlinger CS, Ligibel J. A work in progress: developing the new NCCN guidelines for survivorship. *J Natl Compr Canc Netw*. 2014 Jan;12(1):1-4. PMID: 24453287.

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- Survivorship Assessment tool
 -with Provider Key to refer to specific sections within the guidelines
 - Not validated but includes validated questions when possible
 - Periodic reassessment is recommended
- Designed for providers/care teams from oncology, other subspecialty care settings and primary care who care for individuals once active treatment is completed
- Intended for those diagnosed and treated as adults
- Intended for those in clinical remission or living with chronic form of cancer

*Ligibel JA, Denlinger CS. New NCCN guidelines for survivorship care. *J Natl Compr Canc Netw*. 2013 May;11(5 Suppl):640-4. PMID: 23704233.

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New NCCN Guidelines® for Survivorship Care

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- Anxiety and Depression
- Cognitive function
- Exercise
- Immunizations/Infection prevention
- Fatigue
- Pain
- Sexual Function
- Sleep Disorders

*Ligibel JA, Denlinger CS. New NCCN guidelines for survivorship care. *J Natl Compr Canc Netw*. 2013 May;11(5 Suppl):640-4. PMID: 23704233.

+Denlinger CS, Ligibel J. A work in progress: developing the new NCCN guidelines for survivorship. *J Natl Compr Canc Netw*. 2014 Jan;12(1):1-4. PMID: 24453287.

Evolution of topics over time

- Member institutions invited to review and provide feedback annually
- Subcommittees formed and meet regularly as needed in between annual meetings
 - Healthy Lifestyles (physical activity, nutrition, supplement use, weight management)
 - Cardiovascular disease
 - Fatigue
 - Lymphedema
 - Second primary neoplasms
 - Employment/Return to work
 - Hormone related symptoms

Evolution of the panel over time

Multidisciplinary expertise:

Medical Oncology, Gynecology, Cardiology, Clinical Psychology/Psychiatry, Nursing, Cancer Survivor/Advocates, Gynecology, Primary Care (Internal Medicine), Radiation Oncology, Epidemiology, Nutrition and Exercise Science, Surgical Oncology, Bone Marrow Transplantation, Supportive Care, Hematologic Oncology, Pediatric Oncology

← → ↻ nccn.org/profile#

NCCN's First Patient Webinar Presented in Spanish Will Focus on Invasive Breast Cancer. Learn More >

NCCN National Comprehensive Cancer Network®

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Guidelines

- COVID-19 Resources
- Treatment by Cancer Type >
- Detection, Prevention, and Risk Reduction >
- Supportive Care >**
- Specific Populations >
- Guidelines for Patients >
- Guidelines With Evidence Blocks
- NCCN Framework For Resource Stratification
- Harmonized Guidelines

Adult Cancer Pain

Antiemesis

Cancer-Associated Venous Thromboembolic Disease

Cancer-Related Fatigue

Distress Management

Hematopoietic Cell Transplantation

Hematopoietic Growth Factors

Management of Immunotherapy-Related Toxicities

Palliative Care

Prevention and Treatment of Cancer-Related Infections

Smoking Cessation

Survivorship

https://www.nccn.org/guidelines/category_3 tions and

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National Comprehensive
Cancer Network®

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Survivorship

Version 1.2022 — March 30, 2022

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Healthy living

Cancer survivors can improve their health and quality of life with healthy living. For some cancers, healthy living lowers their risk of recurrence and death. NCCN encourages all survivors to adopt a healthy lifestyle.

There are many parts to healthy living. In the next chapters, there is detailed information on physical activity, food, supplements, weight, and metabolism. A list of basic goals for healthy living is in [Guide 2](#).

Healthy living can be hard to do. Your care providers can be supportive. They may work with you so you can make changes on your own. At times, they may refer you to a counselor. Through counseling, you can learn about barriers to achieving goals and how to overcome them.

Guide 2

Goals of healthy living

Be physically active and avoid inactivity

Eat healthful foods

Limit or avoid drinking alcohol

Achieve and maintain a normal body weight

Don't smoke, chew, or sniff tobacco

Practice sun safety by using sunscreen and do not use tanning beds

Get enough sleep

See your primary care provider on a regular basis

Follow health guidelines as appropriate

How are the guidelines being used?

- Observational study of individuals referred to a survivorship clinic within a cancer center*:
 - **Less than 8 percent** of survivors met all NCCN Healthy Behavior Guidelines prior to attending the clinic
 - Assessed: smoking, weight management, alcohol, physical activity, sun safety, PCP visits
 - Non-adherence to guidelines was significantly associated with higher levels of distress

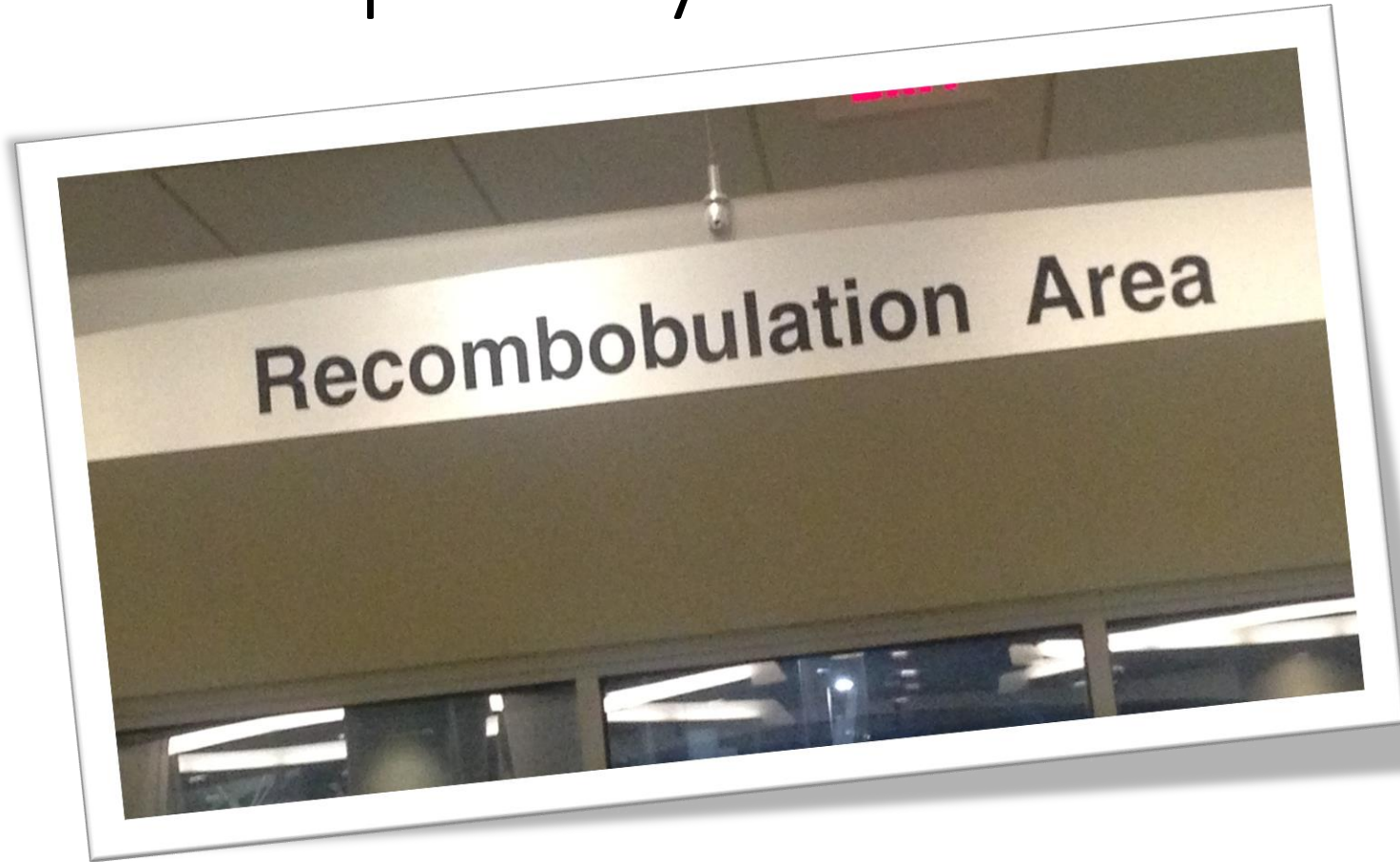
**Hyland, K. A. et al. (2018). Are cancer survivors following the national comprehensive cancer network health behavior guidelines? An assessment of patients attending a cancer survivorship clinic. Journal of psychosocial oncology, 36(1), 64-81.*

How are the guidelines being used?

- 2017 systematic review of patient-provider communication around sexual concerns of survivors*
 - NCCN Guidelines pertaining to sexual health and function helped provide context for categorizing types of communication
 - advising on potential effects of treatment (sexual function, fertility)
 - assessing/screening for concerns
 - managing concerns (offer treatments, provide referrals)
 - Most common type of communication was advising on potential effects
 - Confirms that few studies assess communication around assessing for or managing concerns, and average prevalence of each was low

**Reese JB, Sorice K, Beach MC, et al. Patient-provider communication about sexual concerns in cancer: a systematic review. J Cancer Surviv. 2017;11(2):175-188. doi:10.1007/s11764-016-0577-9*

Perspective from primary care



recombobulate. Verb. (third-person singular simple present **recombobulates**, present participle **recombobulating**, simple past and past participle **recombobulated**) (uncommon) To cause to think clearly again; to reorient; to put back into working order.

www.yourdictionary.com/recombobulate

Perspective from primary care

- Health promotion, healthy lifestyle assessment and counseling are daily conversations
- Cardiovascular disease, psychosocial morbidity, functional concerns are common
 - Quality metrics/targets identified and help drive population-based care
- Cancer screening, infection prevention are expected activities
 - Guidelines that address how we may need to adapt screenings/counseling are particularly helpful
 - Resources may be lacking that are ***survivorship specific***
 - *This is meaningful to patients*
- Survivorship guidelines can help with symptom triage (pre-test probability)

Perspective from primary care

- Guideline development has/continues to be in context of a need to promote shared care
- Communication between PCPs and specialists has been (2011) and continues to be (2017) problematic (*Potosky et al, JGIM, 2011; Dossett et al, CA Cancer J Clin, 2017, 67:156-169*)
 - PCPs seek to address knowledge gaps; could benefit from resources endorsed by specialists “in a format that meets their needs”
 - ?Disconcordant preferences and expectations

Perspective from primary care

- Not just surveillance for recurrence of disease
 - Messages can be consistent, reinforced from multiple care teams
- Lack of “discrete, actionable” guidance/guidelines cited as a barrier to provision of survivorship care in primary care practices/shared care*

**Rubenstein et al, JAMA Internal Medicine 2017; Lisy K, Kent J, Piper A, Jefford M. Facilitators and barriers to shared primary and specialist cancer care: a systematic review. Support Care Cancer. 2021 Jan;29(1):85-96.*

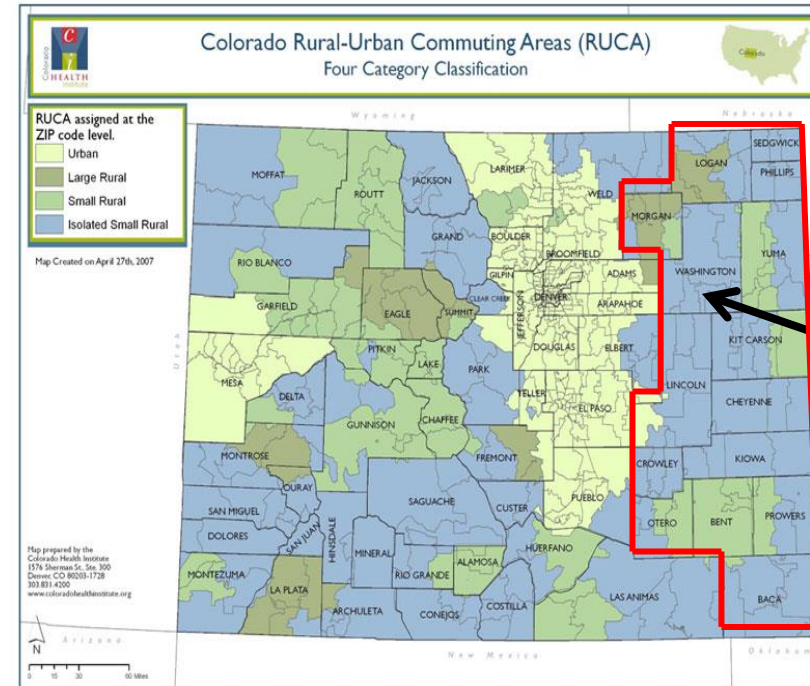
Are guidelines enough?

- Clinical practice guidelines are **necessary**, but maybe **not sufficient** to implement comprehensive survivorship care
- Just like TS/SCP, they are a tool
- Need to better understand how clinical guidelines can be incorporated into ***clinical care delivery***
 - “...strategies and approaches that engage implementation science are vital.”*

**Gallicchio L, Tonorezos E, de Moor JS, et al. Evidence Gaps in Cancer Survivorship Care: A Report From the 2019 National Cancer Institute Cancer Survivorship Workshop. J Natl Cancer Inst. 2021;113(9):1136-1142.*

Lessons learned in CO: iSurvive

- A multi-component practice-based cancer survivorship curriculum
- iSURVIVE, was created and implemented over **four visits** in rural primary care practices
- Geared towards primary care practices (not just providers)



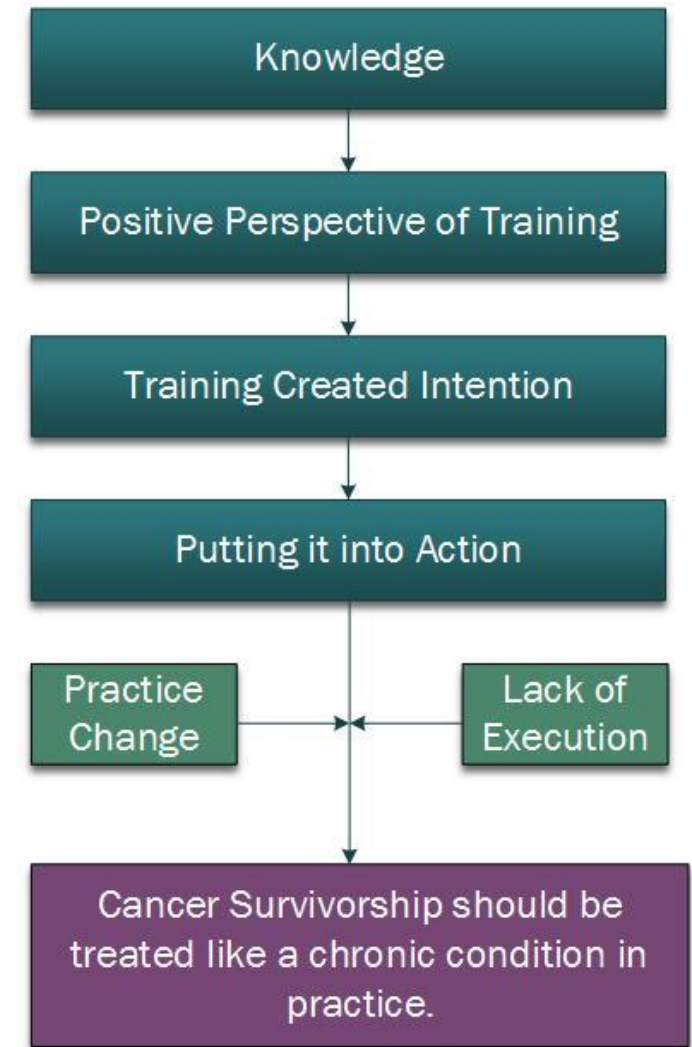
- 16 counties (8 are MUA/HPSA)
- 30,000 square miles
- 150,000 Coloradoans
- 56 primary care practices
- 16 hospitals

Risendal et al, Impact of Cancer Survivorship Care Training on Rural Primary Care Practice Teams: a Mixed Methods Approach, Journal of Cancer Education, 2020

iSurvive results

Four main themes:

1. Immediate/positive impact of training
2. Created intention to change cancer/survivorship care delivery
3. Ways participants put knowledge into practice
4. **There are contextual factors that contribute to lack of execution of survivorship care**



Risendal et al, Impact of Cancer Survivorship Care Training on Rural Primary Care Practice Teams: a Mixed Methods Approach, Journal of Cancer Education, 2020

Practice Change	Execution
Facilitators	Barriers
<p>Actionable next steps</p> <p>Personal attributes of staff</p> <p>Patient initiation</p> <p>Reminders (similar to chronic disease practices)</p> <p>Continuity of care in rural practices to observe long-term effects</p>	<p>Limited established workflow</p> <p>Lack of actionable items</p> <p>Practice/organization readiness</p> <p>Internal capacity</p> <p>External policy factors</p> <p>Competing priorities</p>

Risendal et al, Impact of Cancer Survivorship Care Training on Rural Primary Care Practice Teams: a Mixed Methods Approach, Journal of Cancer Education, 2020

Potential gaps

- Financial toxicity---survivorship care/visits can be expensive!
- Ever expanding array of treatments available---what are the long-term consequences of treatment?
- The role of telehealth
- Care for underrepresented populations
- Delivering care in under-resourced communities
- How to address multi-morbidity/interactions
 - Nutrition counseling, physical activity, prescriptions



Thank you!

