The Number (and Age) of Cancer Survivors is Increasing

- 2018: 16.5 million cancer survivors in the United States
- 2040: NCI estimates 26 million cancer survivors, with 73% Age 65+, and only 8% under age 50

63% of cancer survivors in the U.S. are age 65 and over

Length of Survivorship

- More than 10 years: 44%
- Less than 5 years: 33%
- 5-10 years: 23%

Sources:
https://seer.cancer.gov/statistics/types/survival.html,
Lost in Transition Recommendations

- Raise Awareness
- **Provide Care Plan**
- Develop Clinical Practice Guidelines
- Define Quality Health Care
- Overcome Delivery System Challenges
- Include as Public Health Concern
- Improve Professional Capacity
- Address Employment-Related Concerns
- Improve Access to Health Insurance
- Invest in Research
Essential Components of Survivorship Care

• **Prevention** of recurrent/new cancers and late effects
• **Surveillance** for cancer spread, recurrence, or 2\textsuperscript{nd} cancers; assessment of late effects
• **Intervention** for consequences of cancer treatment; symptoms such as pain and fatigue; psychological distress; financial concerns
• **Coordination** between specialists and primary care providers to meet the needs of survivors
Models for Survivorship Care

• **Multidisciplinary Clinic:** Patients seen/evaluated by different providers (e.g., oncology, endocrinology, neuropsychology, social work, etc.) (Pediatrics model)

• **Disease/Treatment Specific Clinic:** Survivorship clinic for specific disease category; could be used for psycho-social focus only

• **Integrated Care Model:** Survivorship visit in oncology clinic where the patient was treated; often w/ Nurse Practitioner; ongoing care

• **Shared Care Model Components:** Similar to approach to diabetes management

• **Consultative Model:** One-time visit to establish a plan, make referrals to consultants, identify/return to PCP

• **Tool Kit Visit:** Self-management

Oeffinger & McCabe, J Clin Oncol, 2006; McCabe & Jacobs, *Semin Oncol* 2012
“Finding ways to best follow and support our growing population of long-term cancer survivors – and their families – is the new frontier in survivorship science and care. Negotiating the transition from active treatment to recovery remains a challenge for most. Empowering survivors to ask for, and helping them understand how they can use survivorship care plans to guide their future care, is a key step toward helping them achieve optimal post-treatment health and function. Well implemented, the informed conversations and actions generated by these plans hold the promise of reducing unnecessary morbidity and preventable mortality due to cancer.”

Julia Rowland, PhD
Director, NCI Office of Cancer Survivorship, 1997-2017
NCCS Board member, 2017-present
In Summary...


- Important strides have been made to improve awareness of the transition from active treatment to survivorship and to build new models for survivorship care.

- Significant attention to ensure that cancer patients receive a survivorship care plan.

- Survivors still share that they feel lost in transition, and adoption of survivorship programs and survivorship care plans is uneven.
Creating a Quality Measure for Survivorship

Return to Functional Status (RFS):
Patient-Led Cancer Outcome Measurement

Funded by: American Institutes of Research, with funding from the Robert Wood Johnson Foundation

Goals:
1. Develop conceptual definition of RFS by cancer patients and survivors
2. Evaluate whether any existing tools or measures align with the conceptual definition and, if so, the ability to adapt those within the context of this project
3. Develop patient-centered specifications for RFS outcome measures
Creating a Quality Measure for Survivorship – Patient Committee

Rebecca Esparza  Betsy Glosik  Candace Henley  Allison Rosen

Not Pictured: Allen Hirsch

Susan Strong  Desirée Walker  Dan Weber

NCCS
NATIONAL COALITION FOR CANCER SURVIVORSHIP
Elevating Survivorship (Elevate)

A patient and advocate-led initiative to improve survivorship care in the United States. In partnership with ACCC.

Program Phases:
1. Survey cancer care providers and cancer survivors
2. Develop Elevating Survivorship training toolkit and curriculum
3. Recruit and train Elevate Ambassadors, who will provide hands-on assistance to cancer care providers to improve survivorship care at all levels
4. Conduct Visiting Experts program with Elevate Ambassadors as faculty
5. Provide ongoing support to Elevate Ambassadors through virtual learning collaborative
Survivorship Checklist: A Cancer Survivor’s Guide

Objective: Empower cancer survivors to take charge of their survivorship care with a simple checklist to navigate the complexities of cancer survivorship.
Why a Checklist?

- Checklists have been used successfully in health care
- Simple, practical, to-the-point
- Avoid mistakes and errors
- Our patient-centered innovation – flip the paradigm and create a checklist BY survivors and advocates FOR survivors
- Build on expertise that survivors have and share willingly with other survivors
Survivorship Checklist

• **What is it?** A tool that will empower survivors to take charge of their survivorship care and navigate life after cancer

• **Who will use it?** Our goal will be to put this in the hands of people at the transition to post-treatment survivorship, but the checklist can be used at any point in the cancer journey. The Checklist will be useful for survivors of all ages, all stages, and all types of cancer

• **How will survivors get access to it?**
  • Hard copy from health care provider
  • Advocacy partners
  • Survivorship Checklist website – will include video content that elaborates on topics in checklist
Survivorship Checklist

Topics/Content

• Request survivorship care plan
• Pursue follow-up care
• Transition to primary care
• Monitor health status for co-morbidities or second malignancies
• Find psycho-social support
• Stimulate discussion about exercise, nutrition, and other ways to reduce risk of recurrence