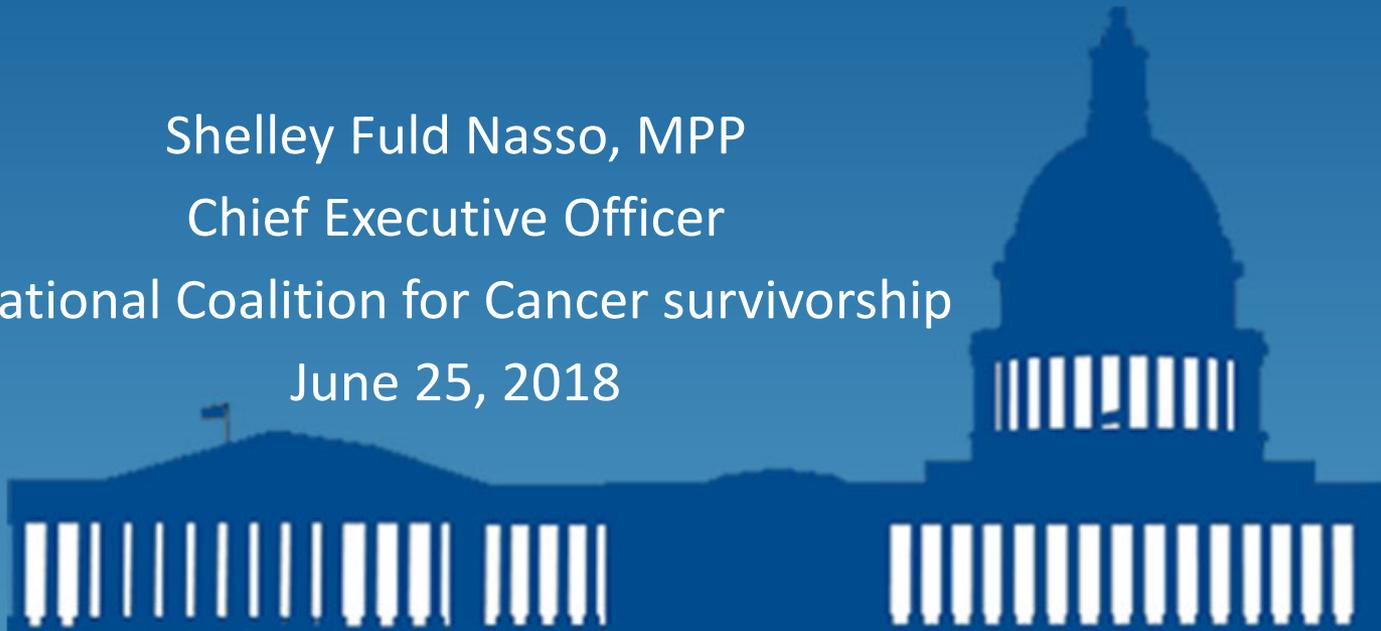
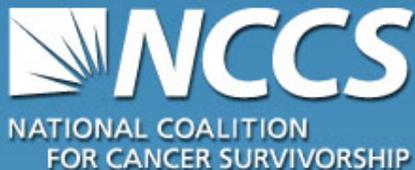


# Survivorship: Today and Tomorrow

Shelley Fuld Nasso, MPP  
Chief Executive Officer

National Coalition for Cancer survivorship  
June 25, 2018



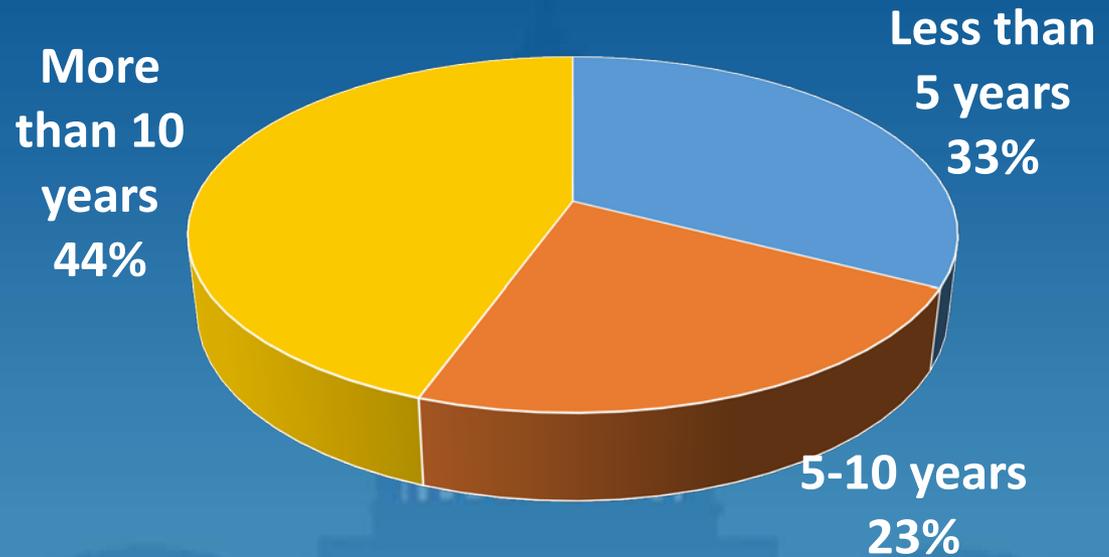
# The Number (and Age) of Cancer Survivors is Increasing

- 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

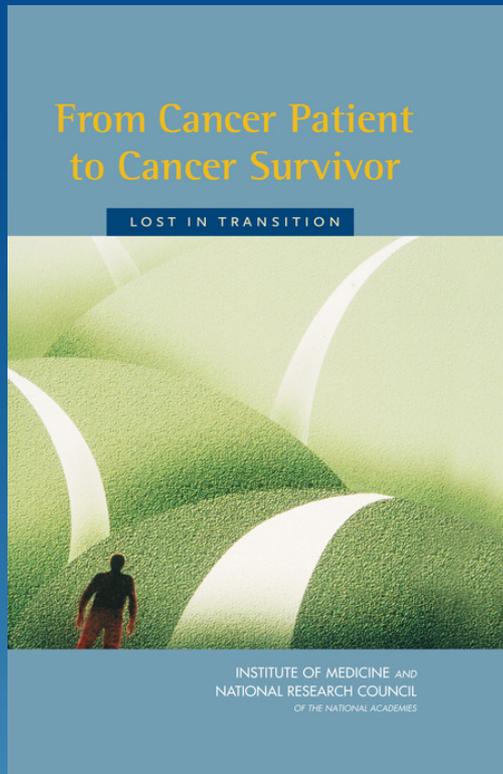
**63%** of cancer survivors in the U.S. are **age 65 and over**



## Length of Survivorship



# 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<sup>nd</sup> 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

*“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.**”*



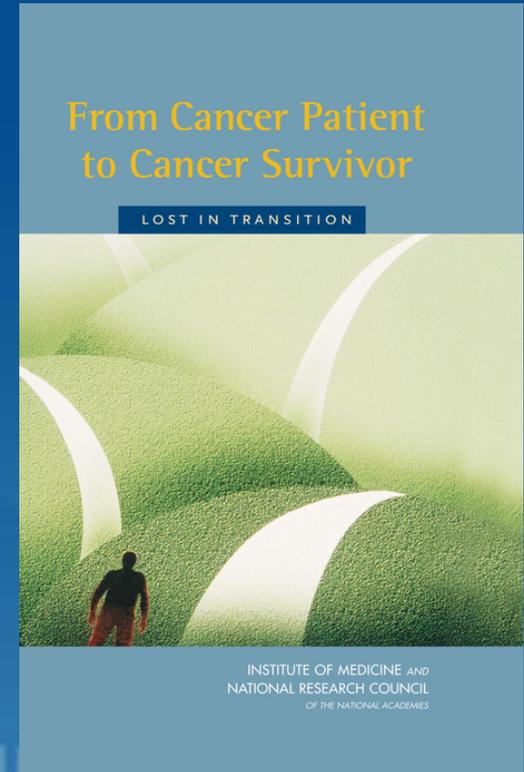
*Julia Rowland, PhD*

*Director, NCI Office of Cancer Survivorship, 1997-2017*

*NCCS Board member, 2017-present*

# In Summary...

- 2005 Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, built evidence base for issues cancer survivors face and standards for quality care
- 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

# 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

**Surgical Safety Checklist**

World Health Organization | Patient Safety

**Before induction of anaesthesia**  
(with at least nurse and anaesthetist)

- Has the patient confirmed his/her identity, site, procedure, and consent?  
 Yes
- Is the site marked?  
 Yes  
 Not applicable
- Is the anaesthesia machine and medication check complete?  
 Yes
- Is the pulse oximeter on the patient and functioning?  
 Yes
- Does the patient have a:
  - Known allergy?  
 No  
 Yes
  - Difficult airway or aspiration risk?  
 No  
 Yes, and equipment/assistance available
  - Risk of >500ml blood loss (7ml/kg in children)?  
 No  
 Yes, and two IV/central access and fluids planned

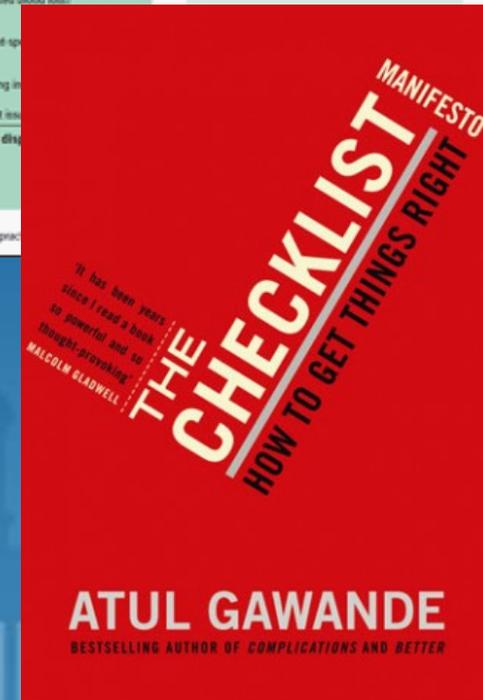
**Before skin incision**  
(with nurse, anaesthetist and surgeon)

- Confirm all team members have introduced themselves by name and role.
- Confirm the patient's name, procedure, and where the incision will be made.
- Has antibiotic prophylaxis been given within the last 60 minutes?  
 Yes  
 Not applicable
- Anticipated Critical Events**  
To Surgeon:
  - What are the critical or non routine steps?
  - How long will the case take?
  - What is the anticipated blood loss?To Anaesthetist:
  - Are there any patient-specific concerns?To Nursing Team:
  - Has stability (including inotropes) been confirmed?
  - Are there equipment issues?- Is essential imaging done?  
 Yes  
 Not applicable

**Before patient leaves operating room**  
(with nurse, anaesthetist and surgeon)

- Nurse Verbally Confirms:**
  - The name of the procedure
  - Completion of instrument, sponge and needle counts
  - Specimen labelling (read specimen labels aloud, including patient name)
  - Whether there are any equipment problems to be addressed
- To Surgeon, Anaesthetist and Nurse:**
  - What are the key concerns for recovery and management of this patient?

This checklist is not intended to be comprehensive. Additions and modifications to fit local practice are encouraged.



# 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**