RETHINKING FOLLOW UP CARE WHILE ADDRESSING BLADDER CANCER SURVIVORS NEEDS

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Disclosures

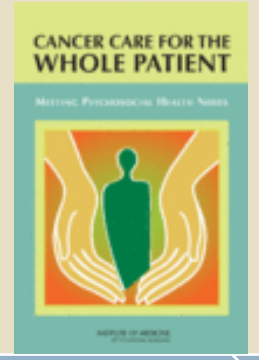
- I am a stockholder and advisor to Carevive Systems
- I will not discuss any drugs during this presentation

Objectives

- Examine cancer statistics
- Define cancer survivor and survivorship care
- Appraise survivorship issues bladder cancer survivors face
- Reframe follow-up care for bladder cancer survivors
- Describe needed survivorship research

Survivorship Over Time

"War" → "Competition" → "Journey"



National Cancer Institute

OFFICE OF CANCER SURVIVORSHIP

Dedicated to enhancing the length and quality of life of survivors and addressing their unique needs.

PART OF NCI'S DIVISION OF CANCER CONTROL AND POPULATION SCIENCES

1950 5-yr survival = 30%

1975 5-yr survival = 48%

1986

1996

2005

2007

2019 5-yr survival = 68%

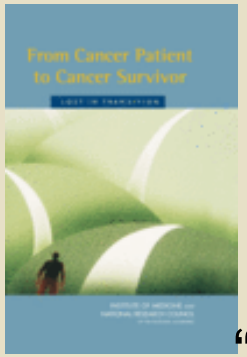
3m

16.9 m

NCCS

NATIONAL COALITION FOR CANCER SURVIVORSHIP

WE ADVOCATE FOR QUALITY CANCER CARE FOR ALL INDIVIDUALS TOUCHED BY CANCER



"Good Patient"

"Victims" → "Empowered Patient"

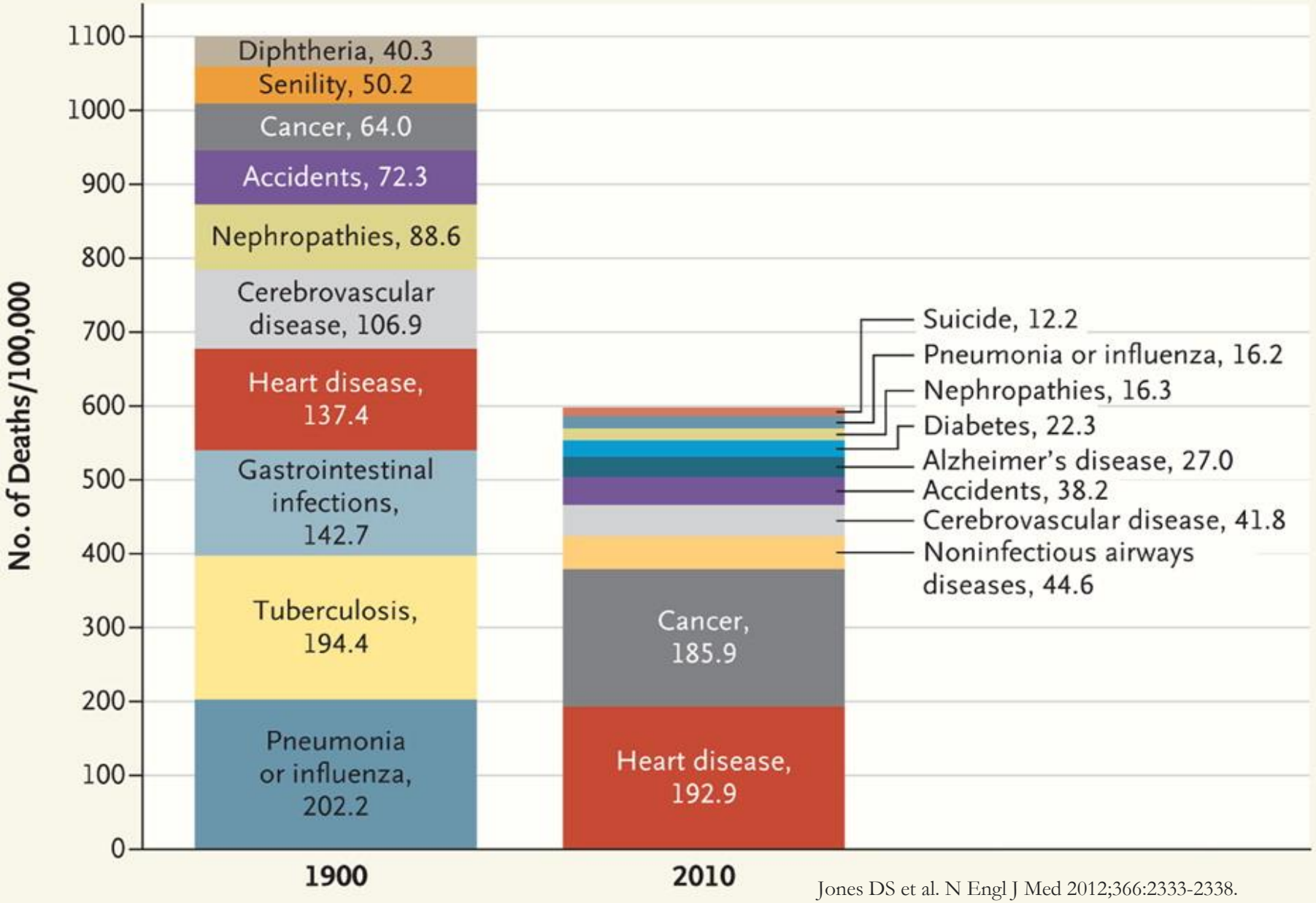
"Survivors"

CANCER IN THE US

More Than a Statistic

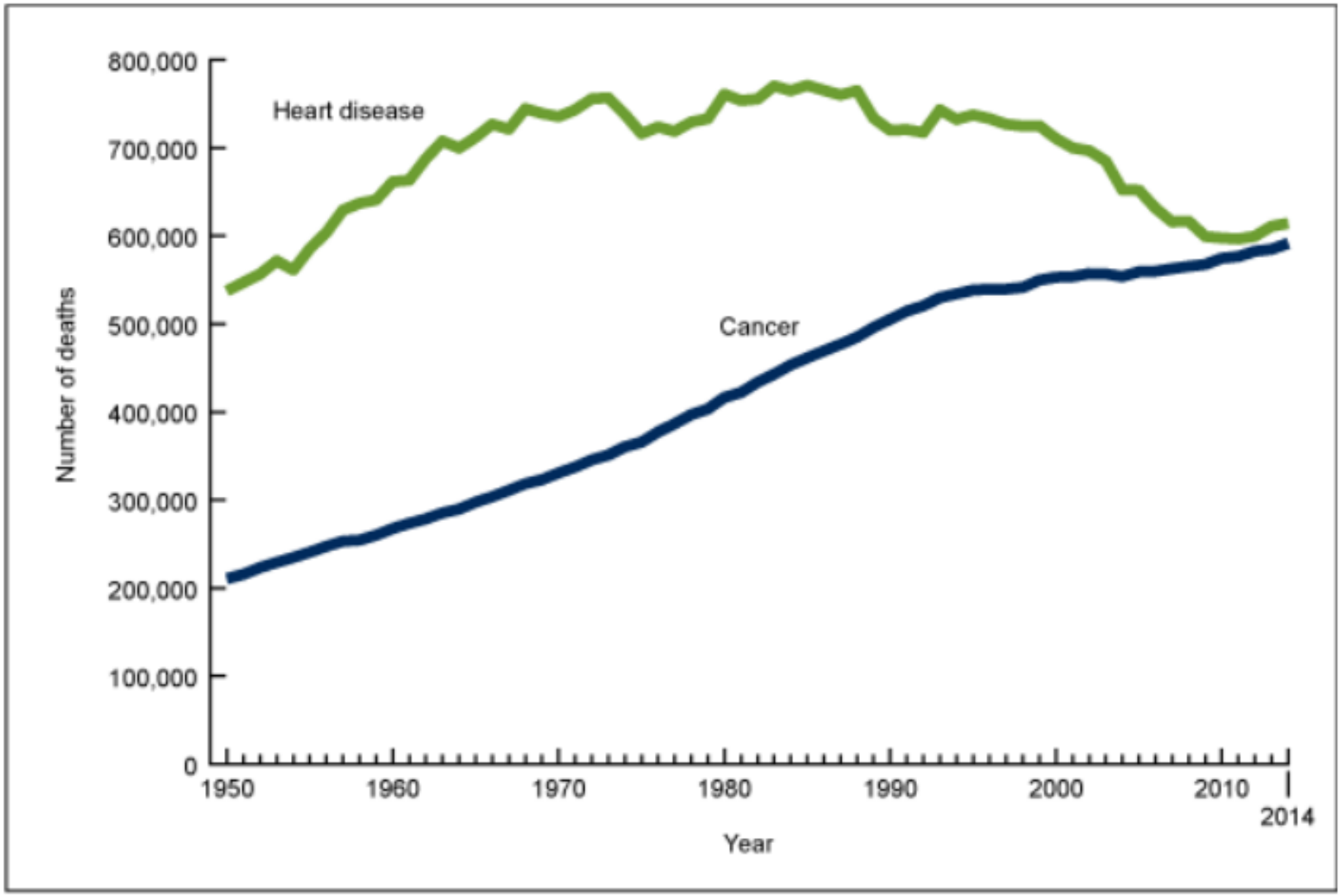
Oncology On Canvas
Expressions of a Cancer Journey

Top 10 Causes of Death: 1900 vs. 2010



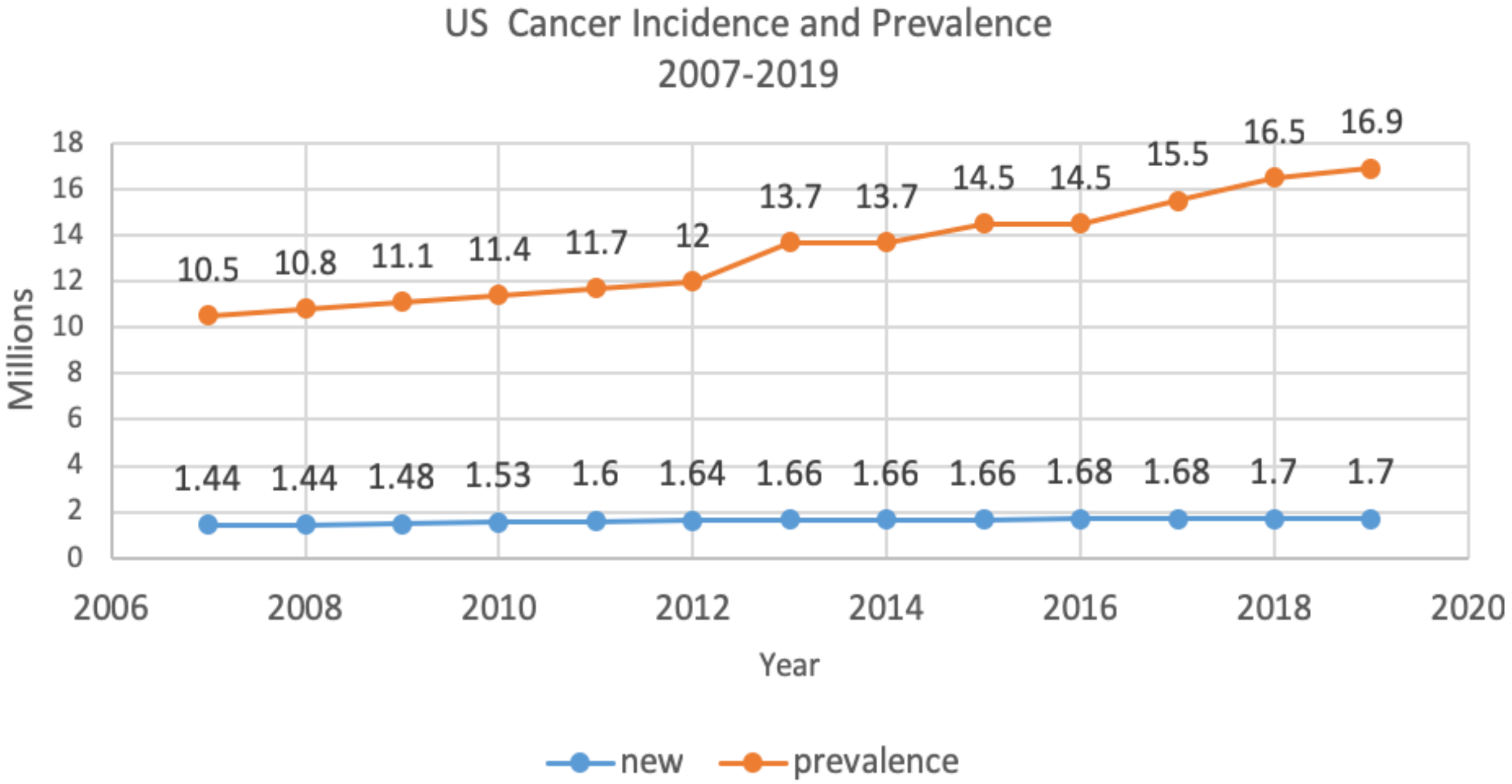
Jones DS et al. N Engl J Med 2012;366:2333-2338.

Figure 1. Number of deaths due to heart disease and cancer: United States, 1950–2014



NOTES: Leading cause is based on number of deaths. Access data table for Figure 1.

SOURCE: NCHS, National Vital Statistics System, Mortality.


US Cancer Incidence and Prevalence
2007-2019
Millions
18
16
14
12
10
8
6
4
2
0
10.5
10.8
11.1
11.4
11.7
12
13.7
13.7
14.5
14.5
15.5
16.5
16.9
1.44
1.44
1.48
1.53
1.6
1.64
1.66
1.66
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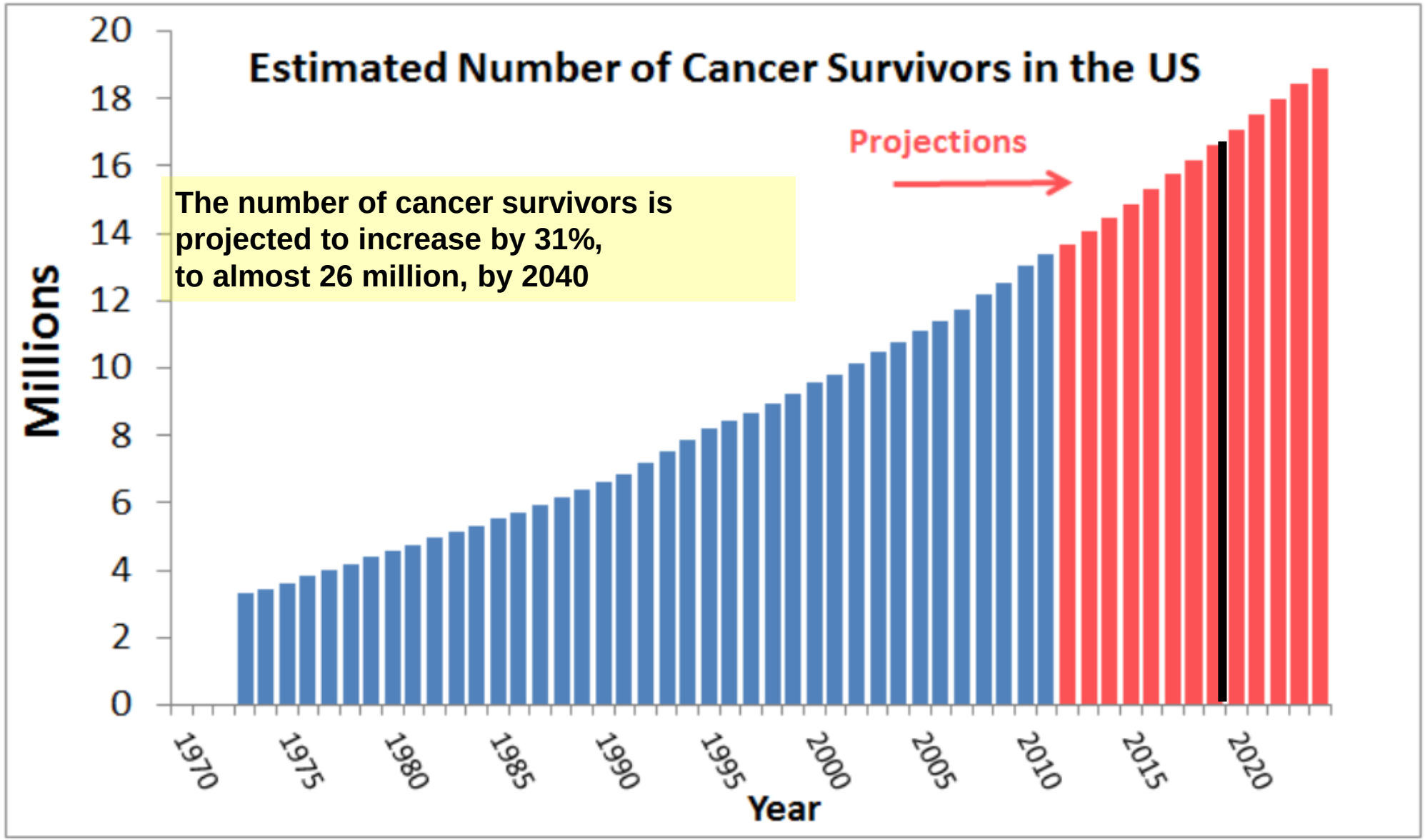
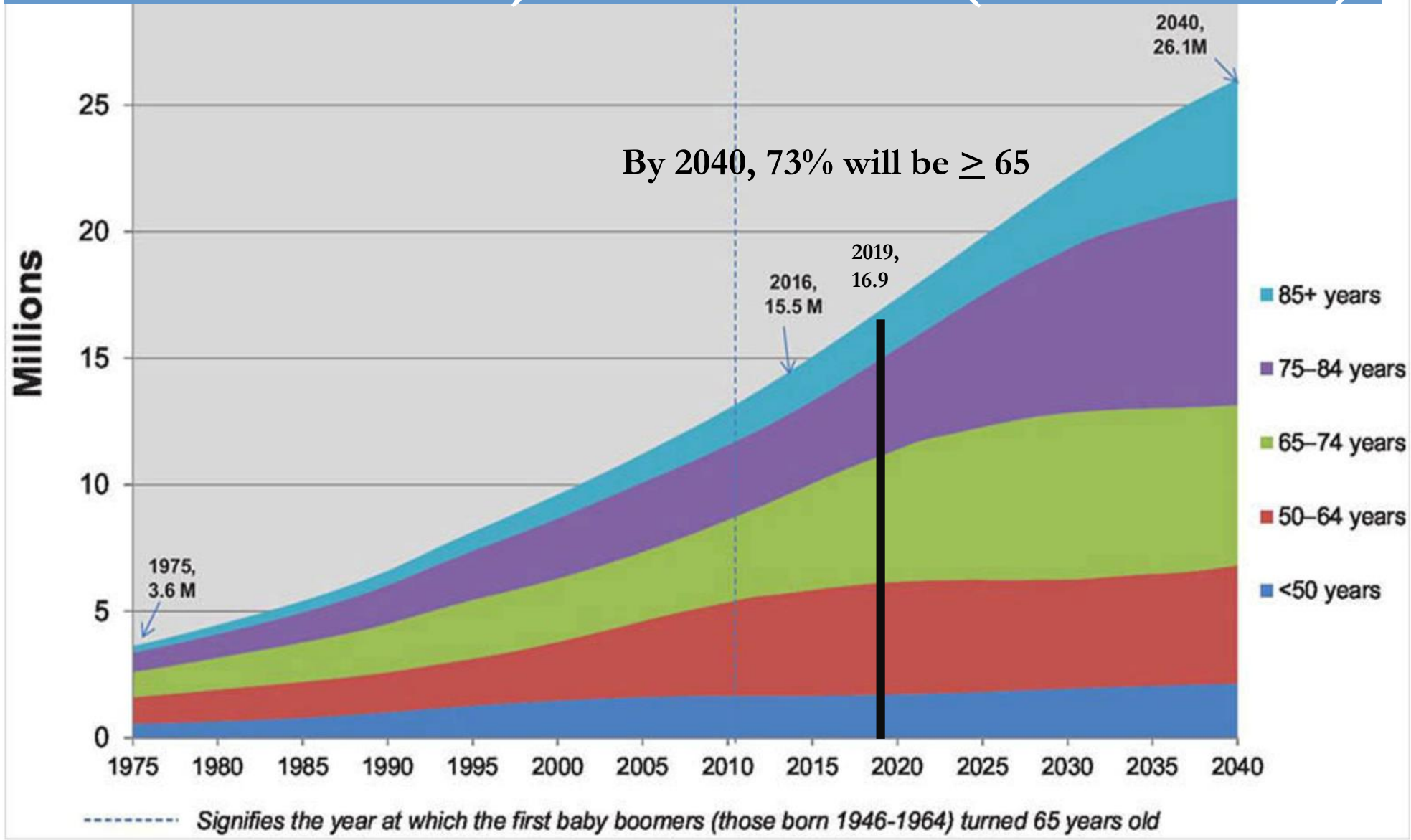
2006
2008
2010
2012
2014
2016
2018
2020
Year
new
prevalence



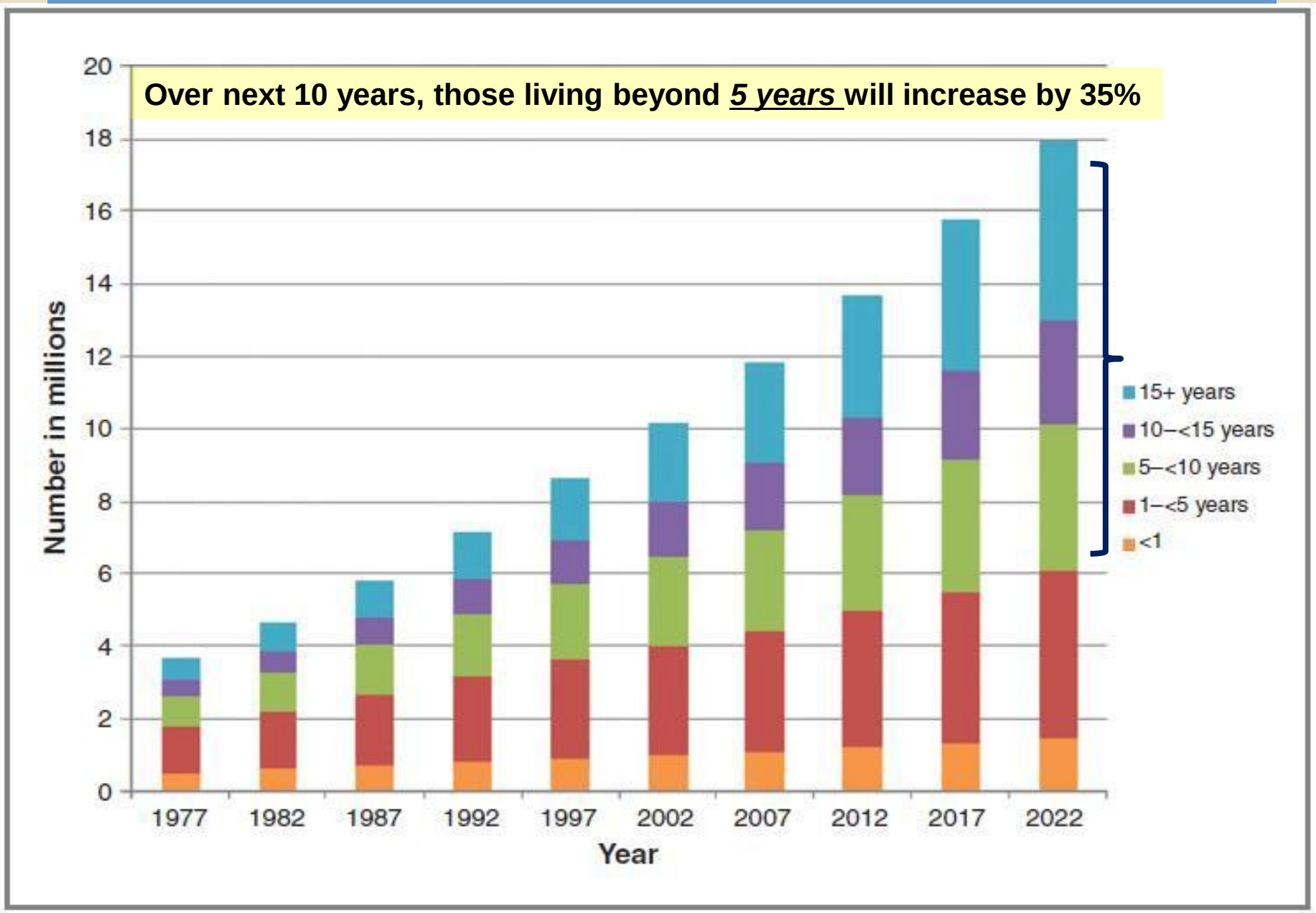
[1] DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press.

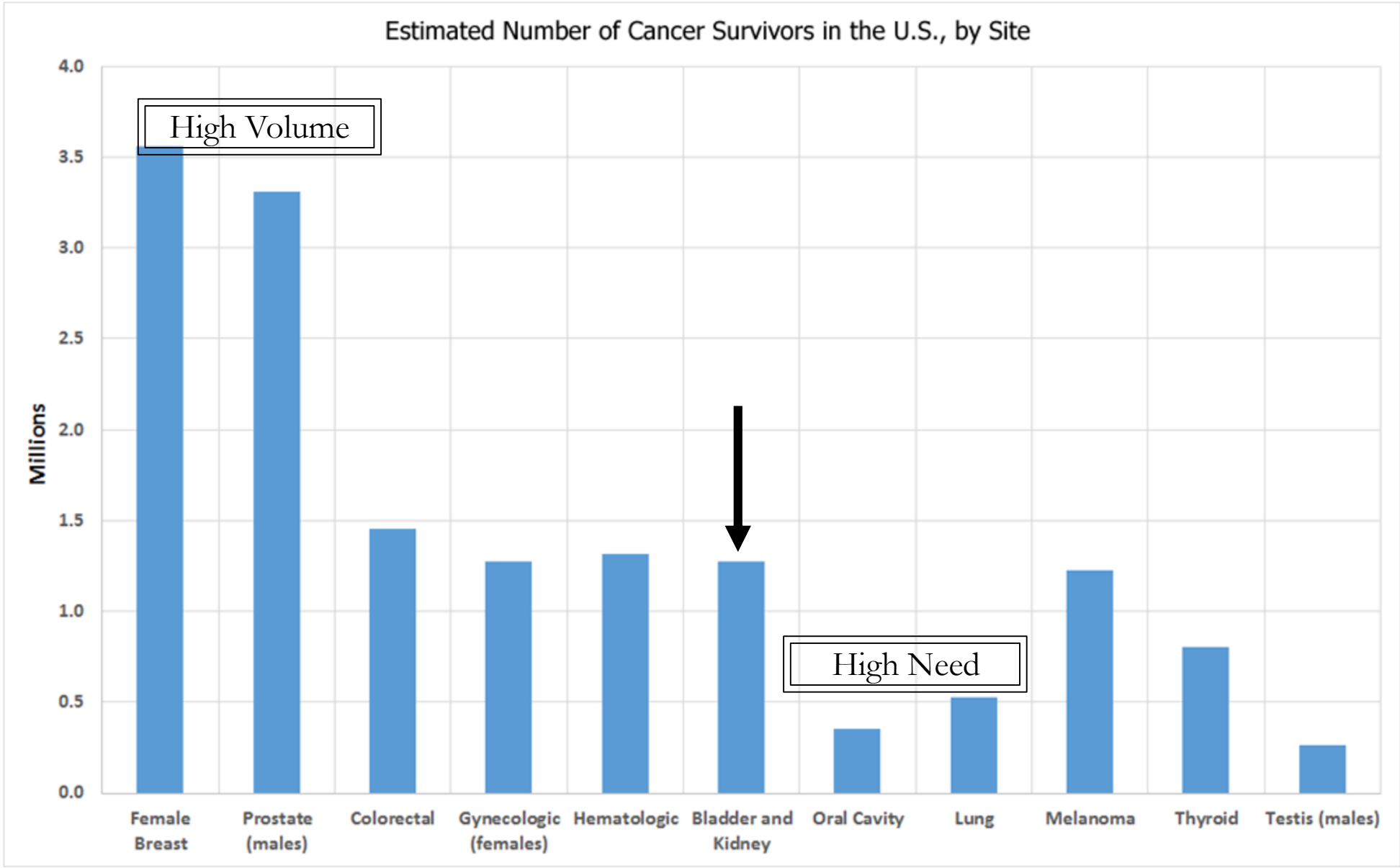
Survivors Projected in US (1975- 2040)



Bluethmann SM, Mariotto AB, Rowland, JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. Cancer Epidemiol Biomarkers Prev. 2016;25:1029-1036.

Survivors Projected in 2022





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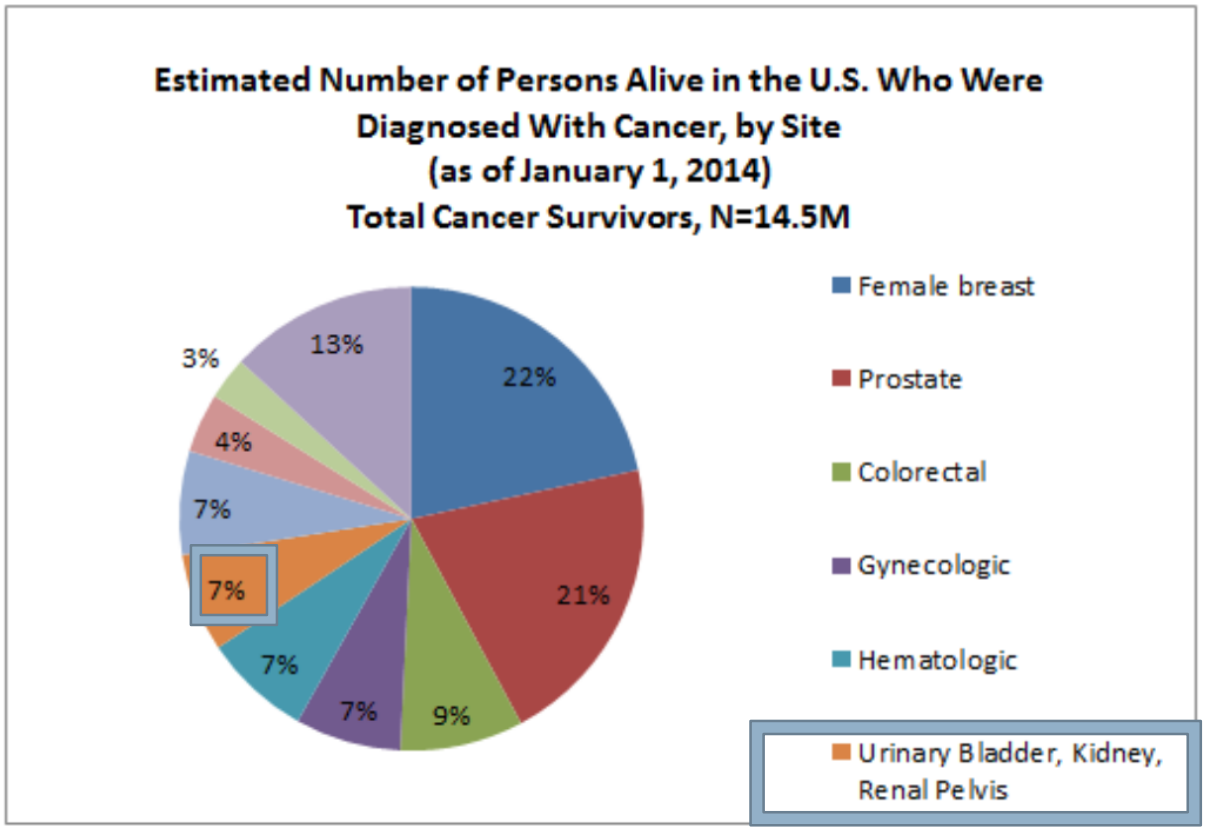

[1] DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press.

Bladder Cancer

BCAN
Bladder Cancer Advocacy Network

Statistics at a Glance

At a Glance

Estimated New Cases in 2019	80,470
% of All New Cancer Cases	4.6%

Estimated Deaths in 2019	17,670
% of All Cancer Deaths	2.9%

Percent Surviving 5 Years

77.1%

2009-2015

Five-year Relative Survival Rates (%) by Race, 2007-2013

Site	White	Black	Absolute Difference
All Sites	70	63	7
Breast (female)	92	83	9
Colorectum	67	59	8
Esophagus	22	12	10
Non-Hodgkin lymphoma	74	67	7
Oral cavity & pharynx	69	49	20
Ovary	46	39	7
Prostate	>99	97	3
Urinary bladder	79	65	14
Uterine cervix	71	58	13
Uterine corpus	85	65	20

In 2016, there were an estimated 699,450 people living with bladder cancer in the United States.

Trends in Five-year Relative Survival Rates (%), 1975-2012

Site	1975-1977	1987-1989	2006-2012
All sites	49	55	69
Breast (female)	75	84	91
Colorectum	50	60	66
Leukemia	34	43	63
Lung & bronchus	12	13	19
Melanoma of the skin	82	88	93
Non-Hodgkin lymphoma	47	51	73
Ovary	36	38	46
Pancreas	3	4	9
Prostate	68	83	99
Urinary bladder	72	79	79

5-year relative survival rates based on patients diagnosed in the 9 oldest SEER registries from 1975-1977, 1987-1989, and 2006-2012, all followed through 2013.
Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2016.

Defining Survivors and Survivorship

The Face of Cancer

Lilly Oncology On Canvas
Expressions of a Cancer Journey

NCI Survivor and Survivorship Definitions

Cancer Survivor: An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. There are many types of survivors, including those living with cancer and those free of cancer. This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals.

–Adapted from the National Coalition for Cancer Survivorship

Survivorship Defined

- **Living cancer free**
  - For remainder of life
  - Experiences ≥ 1 treatment complication
  - But dying after a late recurrence
  - But develops another cancer

- **Living with cancer**
  - Intermittent periods of active disease on/off treatment
  - Continuously without disease free period

Survivorship Definition and Attributes

- Defined as those who have lived through a potentially deadly or life altering event.
- It is a dynamic process
- It involves uncertainty
- It is a life changing experience
- It has duality of positive and negative aspects
- It is an individual experience with universality

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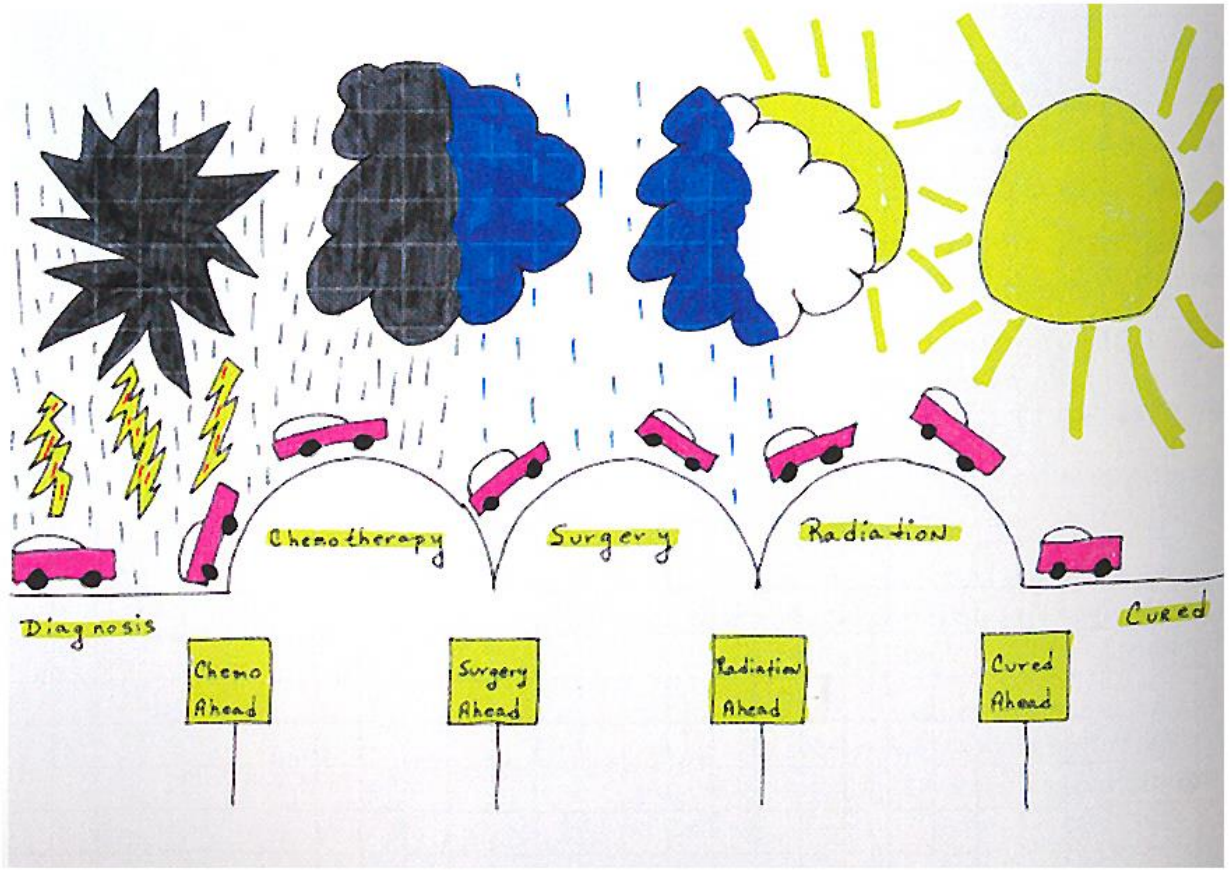
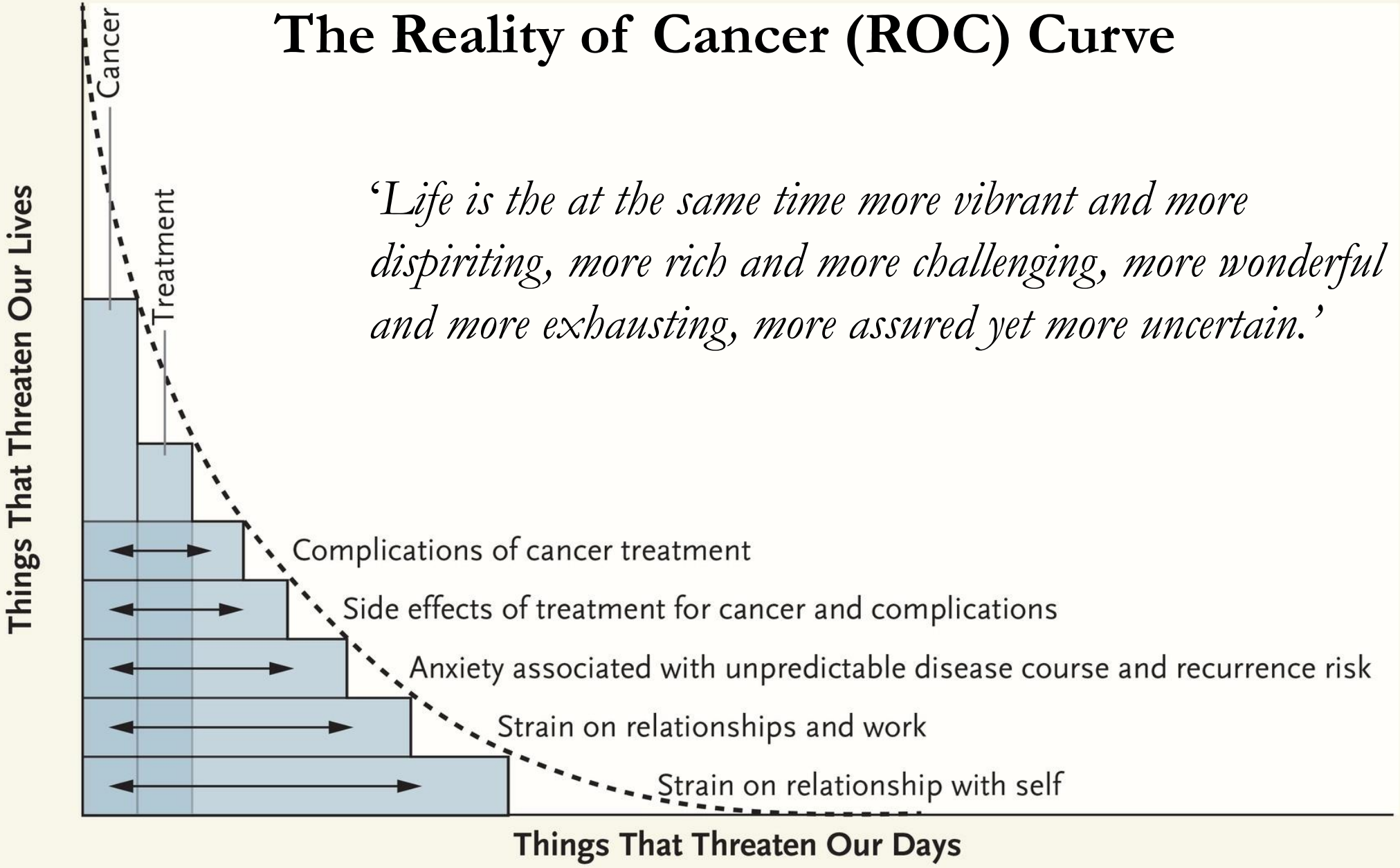


BUMPS ON THE ROAD OF LIFE

Lilly ONCOLOGY On Canvas
Expressions of a Cancer Journey

The Reality of Cancer (ROC) Curve

'Life is the at the same time more vibrant and more dispiriting, more rich and more challenging, more wonderful and more exhausting, more assured yet more uncertain.'



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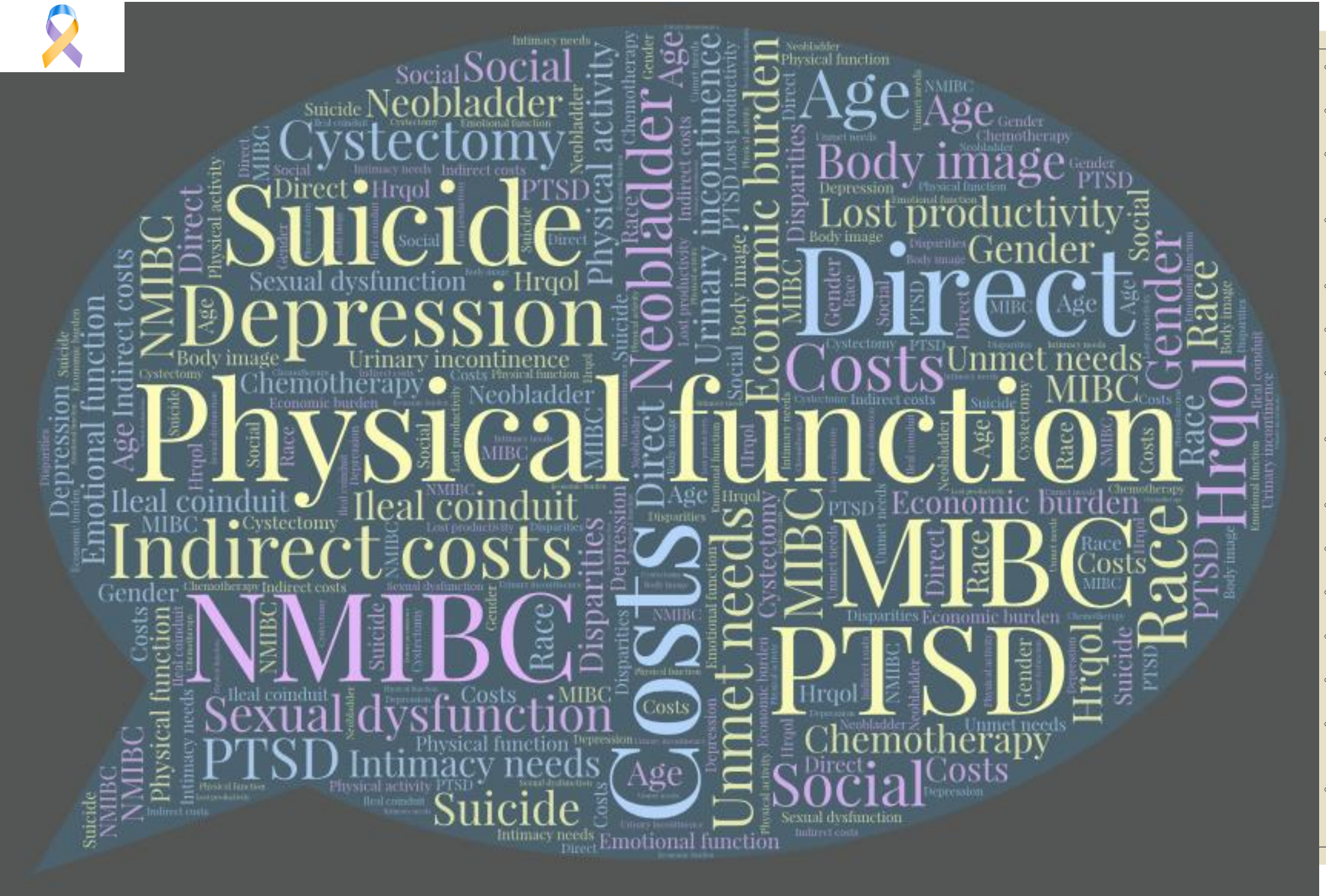

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Models of Survivorship Care

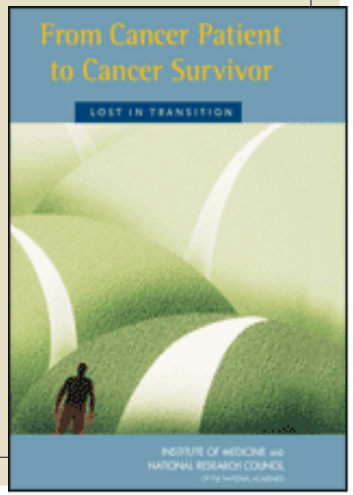
UNCHARTED

Oncology On Canvas

Expressions of a Cancer Journey

Essential Components of Survivorship Care

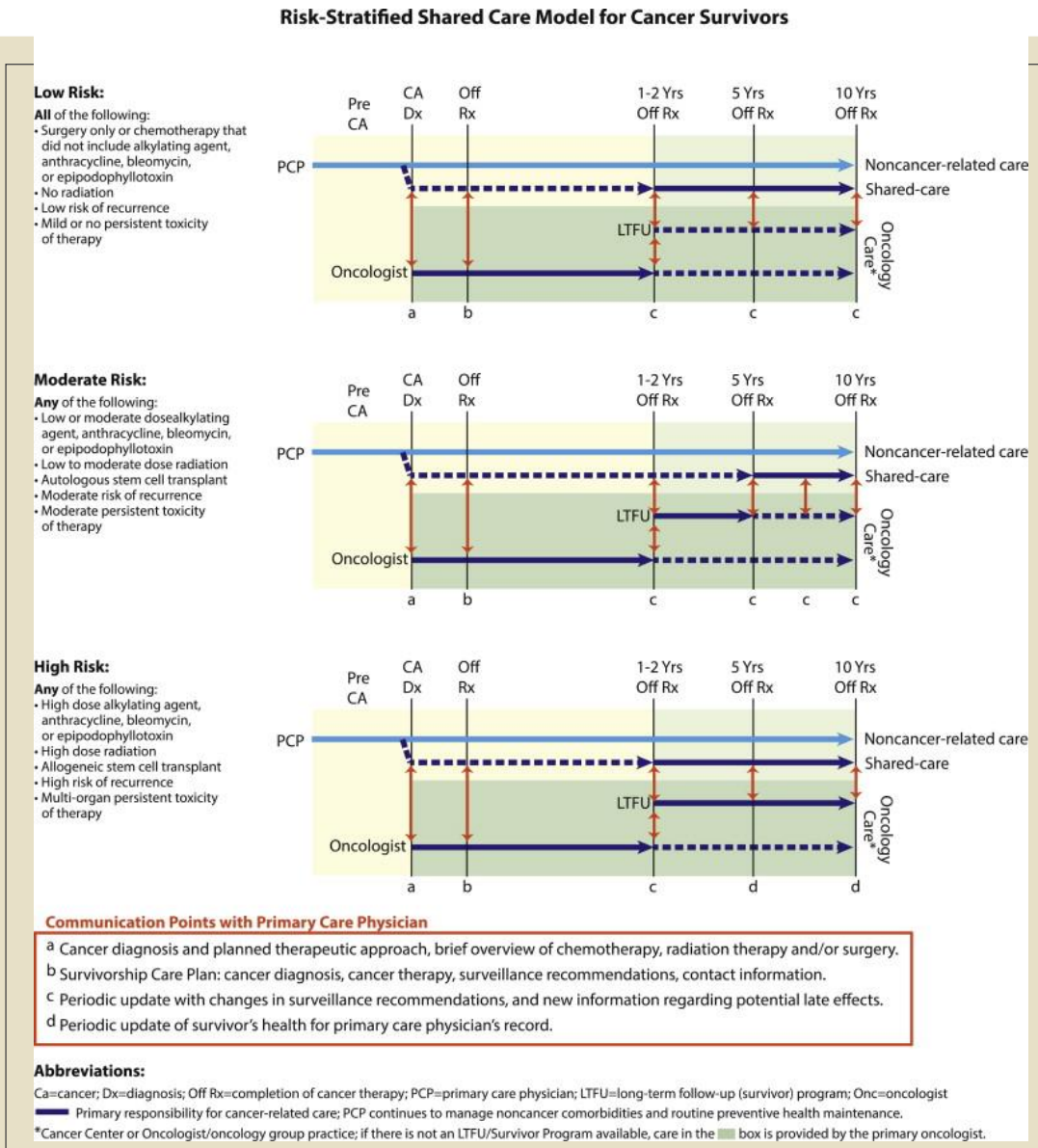
- Prevention of recurrent and new cancers and other late effects
- Surveillance for cancer spread, recurrence or new cancers and assessment and mitigation of physical and psychosocial late effects
- Health Promotion
- Coordination between specialists and primary care providers to ensure that the survivors health needs are met



Adult Follow-up Care Models

- Multidisciplinary
- Disease specific
- Consultative service
- Integrated care model
- Risk-stratified and shared care

Jacobs & Shulman (2017) *Lancet Oncol*; 18: e19-29.



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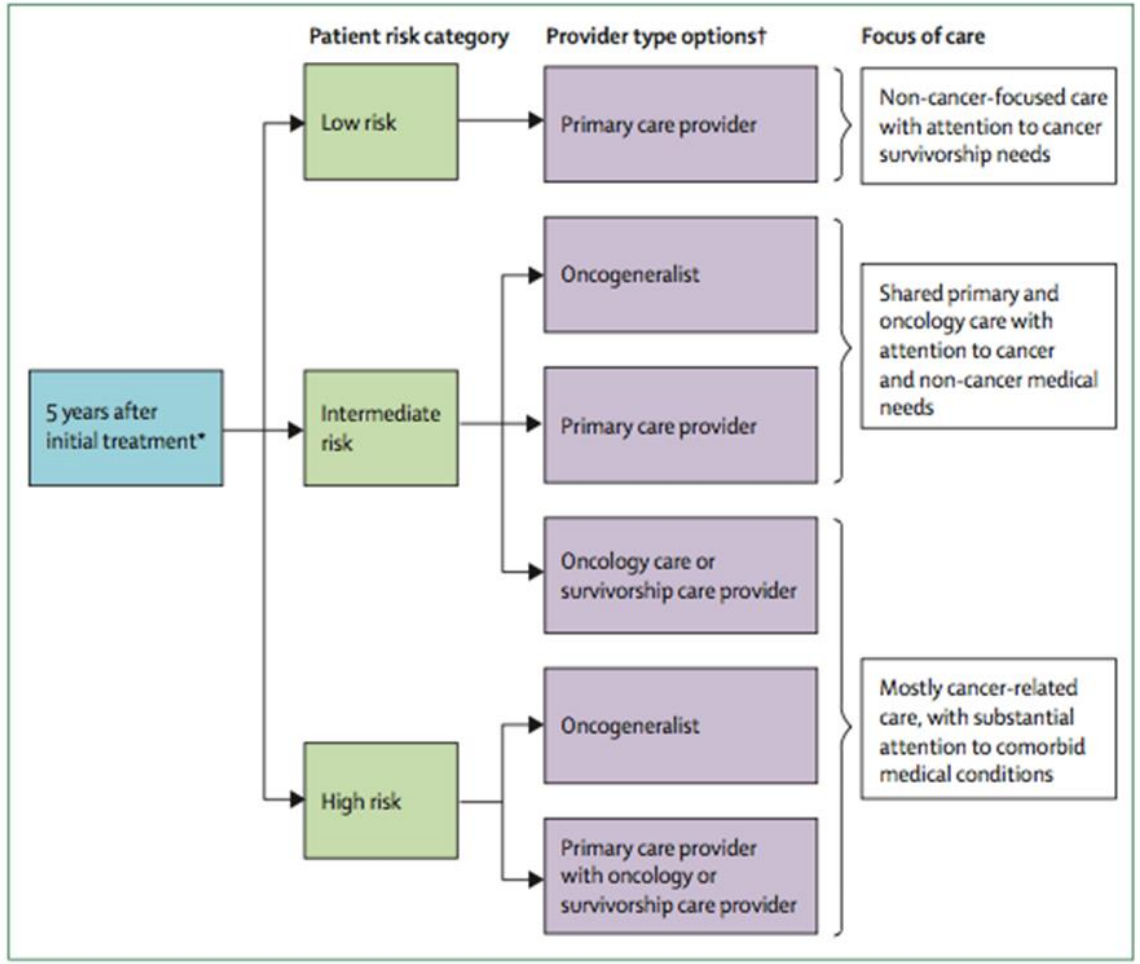


***Figure 2:* Survivorship care strategies**
*5 years is based on general recommendations in the cancer community; transition of care might vary. †Any of these models might be appropriate for nurse practitioner or physician assistant involvement.

Nekhlyudov L, O'Malley D., Hudson SV. (2017). *Lancet Oncology*, 18: e30-e38

Risk Stratified Model National Cancer Survivorship Initiative

Supported self-management (patients at low risk for developing long-term and late effects of treatment):
- Patients are given the knowledge and skills to self-manage their care

Shared care (patients at moderate risk for developing long-term and late effects of treatment):
- Patients have regular contact with health-care professionals

Complex case management (patients at high risk for developing long-term and late effects of treatment):
- Patients need intensive support from health-care services to meet their needs

Risk Stratified Shared Care Model

Patients at low risk of developing long-term and late effects of treatment
All of the following:
- Surgery only
- Non-alkylating chemotherapy
- No radiotherapy
- Low risk of recurrence
- Mild or no persistent toxicity of therapy

Patients at moderate risk of developing long-term and late effects of treatment
Any of the following:
- Low or moderate-dose alkylating agent
- Low or moderate-dose radiotherapy
- Autologous stem-cell transplantation
- Moderate risk of recurrence
- Moderate persistent toxicity of treatment

Patients at high risk of developing long-term and late effects of treatment
Any of the following:
- High-dose alkylating agent
- High-dose radiotherapy
- Allogeneic stem-cell transplantation
- High risk of recurrence
- Multi-organ persistent toxicity of therapy

Jacobs & Shulman (2017) *Lancet Oncol*; 18: e19-29.

Risk Stratified Model of Care

- *Breast 70-80%*
- *Colorectal 50%*
- *Prostate 40-50 %*

http://www.evidence.nhs.uk/qipp

WE ARE MACMILLAN. CANCER SUPPORT

NHS England

Lessons from Other Countries

- England and Northern Ireland(National Cancer Survivorship Initiative or NCSI)
  - Triage to one of three pathways based on risk of recurrence, subsequent cancers and late effects; severity of ongoing treatment sequalae; functional ability; psychosocial issues; health literacy and ability to self-manage:
    - Supported self-management
    - Shared care with self-management on provider (either PCP or Oncologist)
    - Complex care management
  - 14 sites in England for CRC, breast and prostate cancers
    - 50% CRC, 80% Breast and 50% prostate patients treated with curative intent → supported self-management
    - Projected savings of £90m/5 years with 58% breast patients supported self-management

https://www.macmillan.org.uk/_images/sustainable-cancer-service-redesign_tcm9-298128.pdf

Sustainable Cancer Redesign

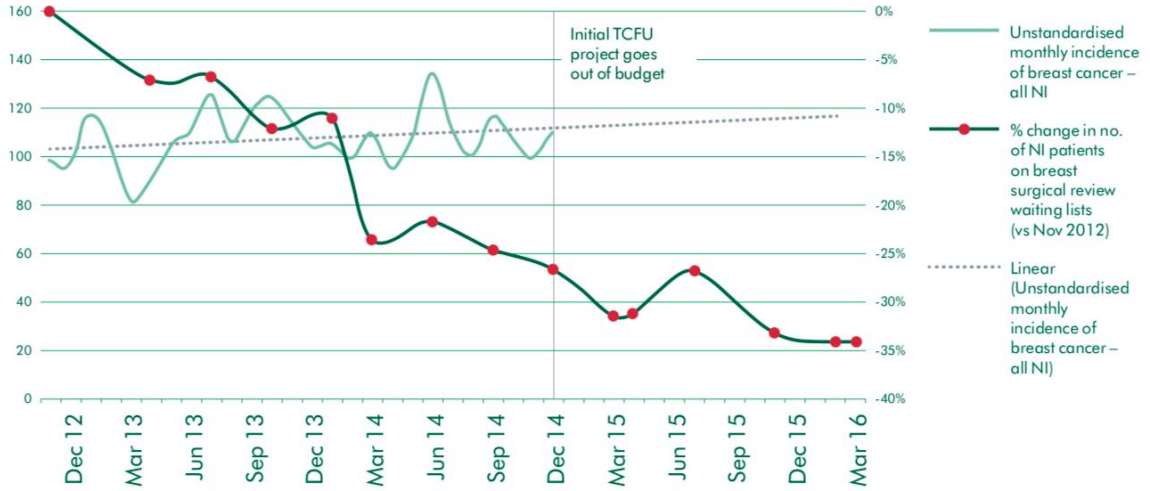
Figure 1: The Recovery Package

Figure 3: Key breast cancer follow-up findings from the TCFU evaluation

Enhance coordination and integration of care	Improve cancer patients' aftercare experience	Improve resource utilisation
1,000 fewer patients receiving dual speciality follow-up (39% reduction)	Patients satisfied with the timing of appointments: 70%→90%	Release of almost 3,000 review appointments
More patients feeling various aspects of their care were well coordinated: 71%→78%	More patients feeling supported to manage the emotional impacts of their cancer: 44%→67%	2,724 fewer patients on surgical review waiting lists (28% reduction)
	More patients feeling supported to manage the practical impacts of their cancer: 40%→65%	228 fewer patients on oncology review waiting lists (4% reduction)
	More than 1,000 patients had received an HNA	

Adapted from Macmillan Cancer Support and PwC. *Evaluation of the Transforming Cancer Follow-up Programme in Northern Ireland, Final Report*. Available from: http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/ourresearchpartners/tcfufinalreportfeb2015.pdf

Figure 6: % change in breast cancer surgical review waiting lists versus monthly incidence, Nov 12–Mar16



Source: Monthly incidence figures courtesy of the N. Ireland Cancer Registry. Incidence data are only available to December 2014.

https://www.macmillan.org.uk/_images/sustainable-cancer-service-redesign_tcm9-298128.pdf
https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Stratified-Pathways-of-Care.pdf
https://www.nice.org.uk/savingsandproductivityandlocalpracticeresource?id=2632

Clinical Oncology Society of Australia

Stratified pathways of care will be influenced by:

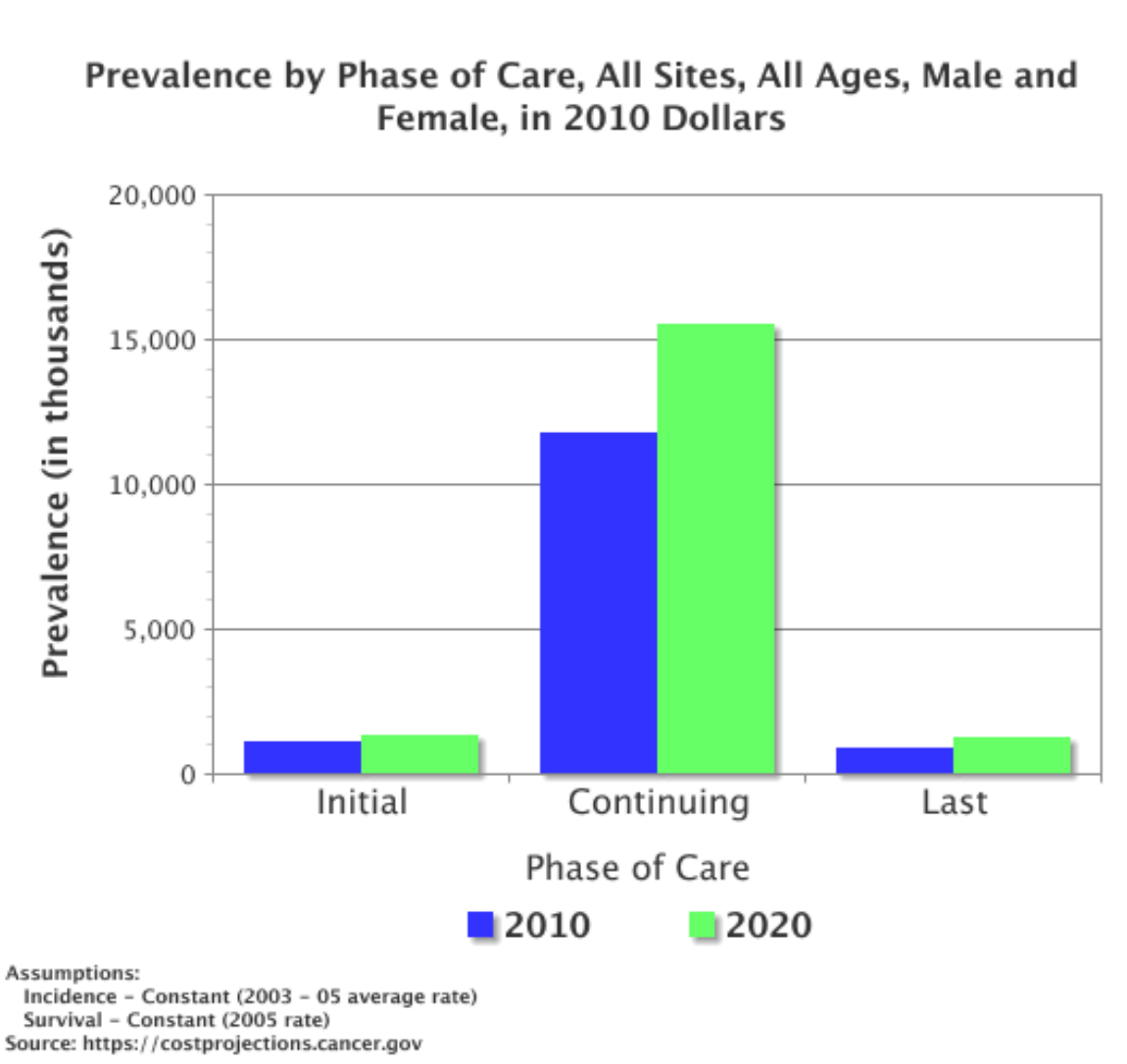
- Assessing the level of risk for disease related comorbidity and recurrence, dependent on the tumour type;
- Short, medium and long-term treatment sequelae;
- Existing comorbidities;
- Survivor ability and motivation to engage and self-manage;
- Level of professional involvement required.

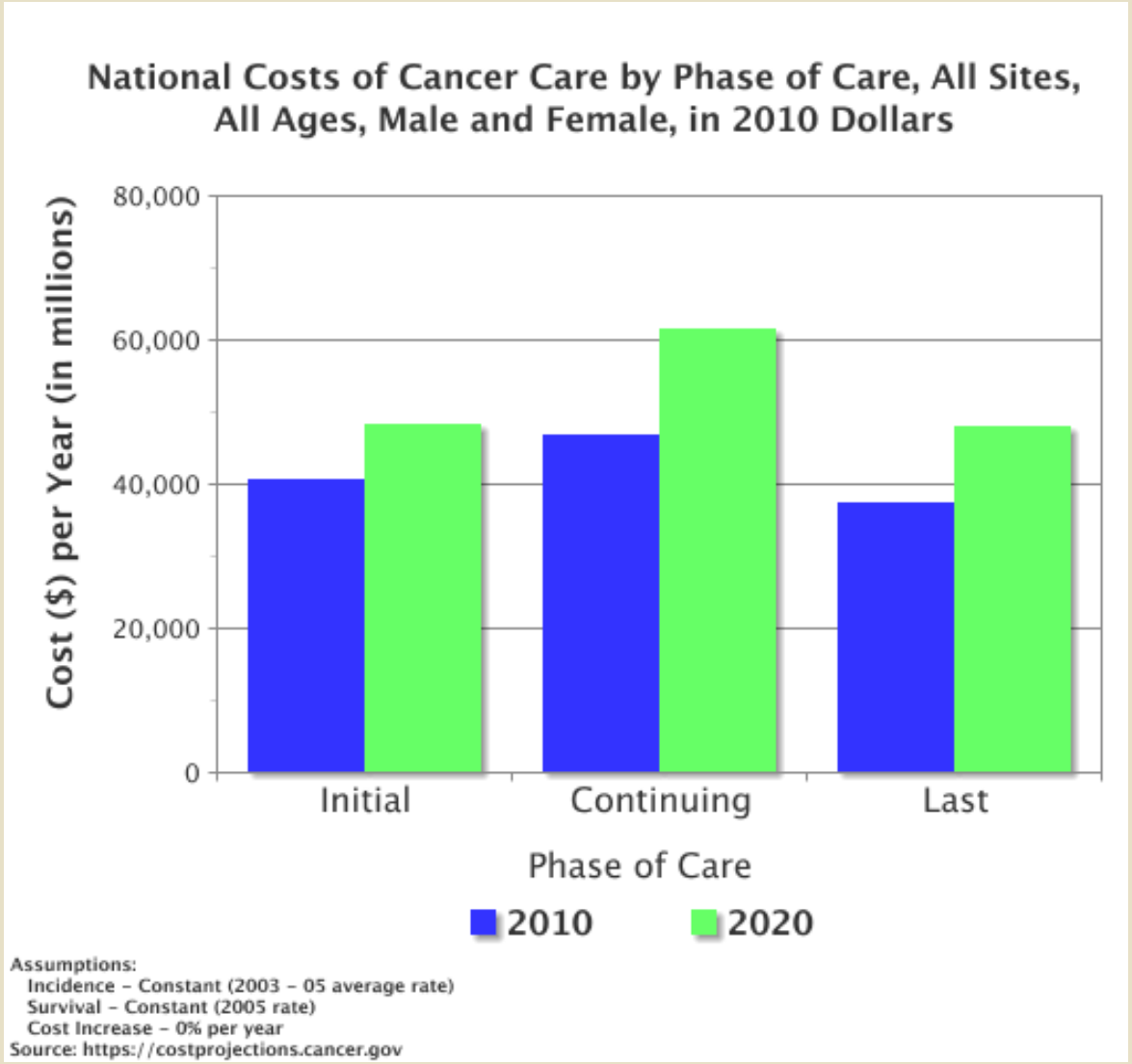
https://www.cosa.org.au

Principles of Personalized Follow-up Care Pathways

- Triage into care pathways is influenced by more than risk of recurrence, subsequent cancers or late effects.
- Patient-identified issues should guide the delivery of care.
- Remote monitoring should be used to imbed a survivor in a surveillance system to monitor them for the exacerbation of ongoing cancer-related symptoms or functional limitations, and for early recurrence, new cancer, or late effects detection.
- Shifting patients to supported self-management and reducing face-to-face clinic visits is critical for improving clinic utilization and cost outcomes.
- Coordination and information exchange among oncology, primary care, specialists and patients is essential.
- Engaging all stakeholders, securing their buy-in, and using change management and continuous improvement principles are critical for successful follow-up care transformation.

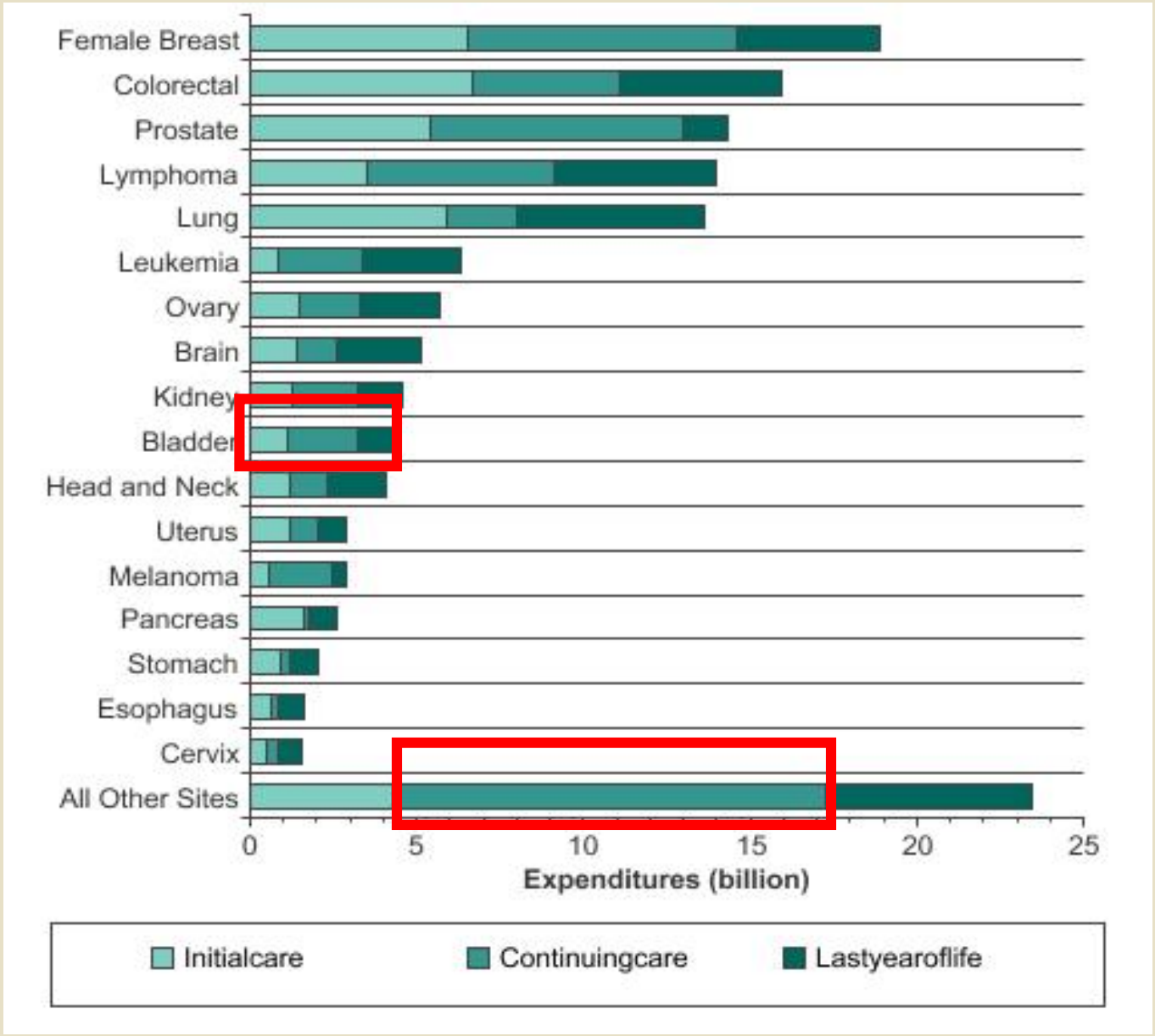
Continuing Care for Cancer Survivors





https://costprojections.cancer.gov/

Estimates Of National Expenditures For Cancer Care, By Site



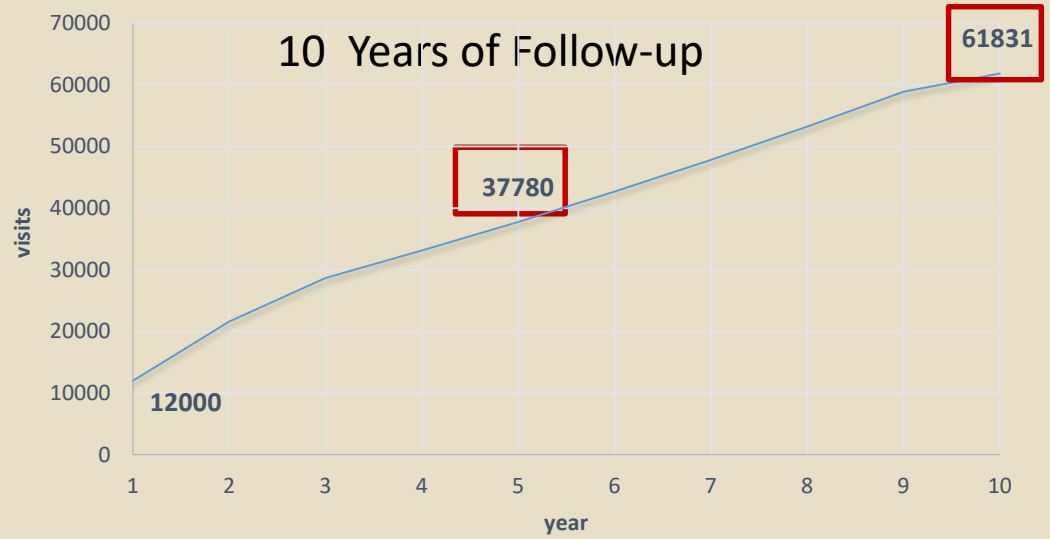
Cancer Survivors at Duke

January 1, 2016 – June 30, 2017 (18 months), the following unique patients were seen:

	Interval from Cancer Diagnosis 0-2.9 y	3-4.9 y	5-9.9 y	10-20 y	Total
Brain	3143	826	1092	747	5808
Breast	4175	1713	2487	**1972**	10347
Cell Therapy	2826	1036	1523	976	6361
Endocrine	1250	352	394	238	2234
Eye	182	52	59	30	323
GI	5041	1099	1250	526	7916
GU	4495	1641	2635	**1696**	10467
Gyn	2160	772	968	467	4367
H&N	1023	304	430	229	1986
Melanoma	1471	504	644	471	3090
Other sites	252	29	42	24	347
Sarcoma	563	201	269	152	1185
Thoracic	4658	827	925	367	6777
Grand Total	**31239**	**9356**	**12718**	**7895**	**61208**

Source: Kevin Oeffinger, MD, Duke 4.19

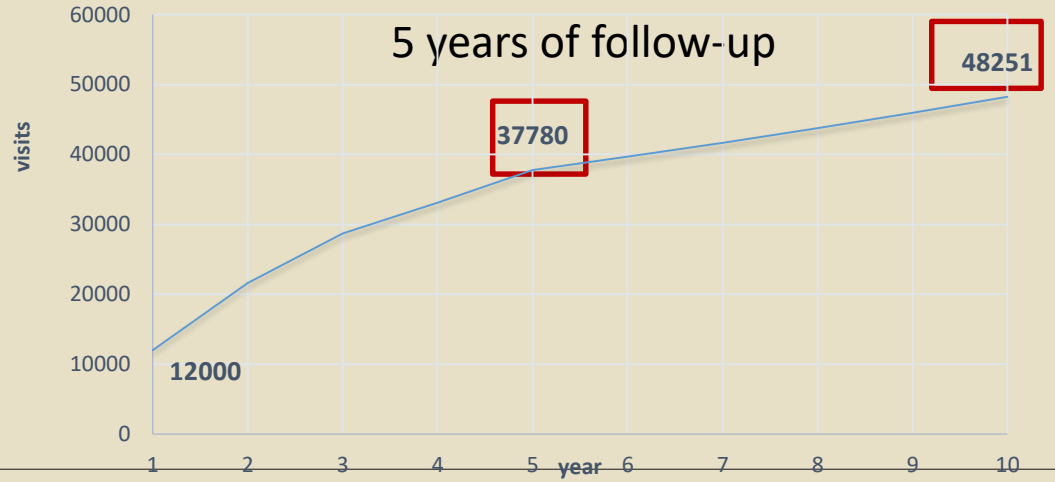
UNC Follow-up Visits



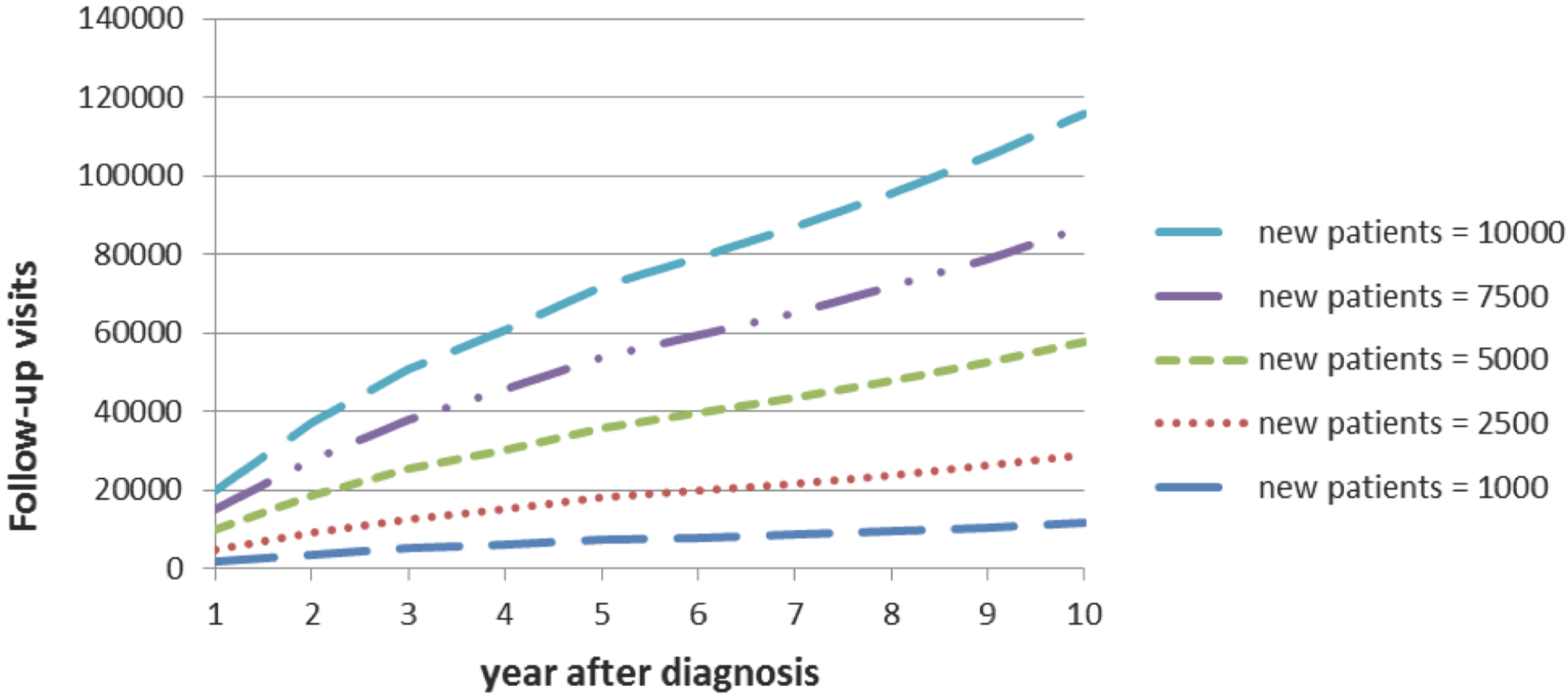
Total Visits						
	Fiscal Year 2016		Fiscal Year 2017		Fiscal Year 2018	
	New	Return	New	Return	New	Return
Total New/Return	13005	59820	13683	66800	14561	84260
Total Encounters	72825 (82%)		80483 (83%)		84260 (83%)	

Assumptions:

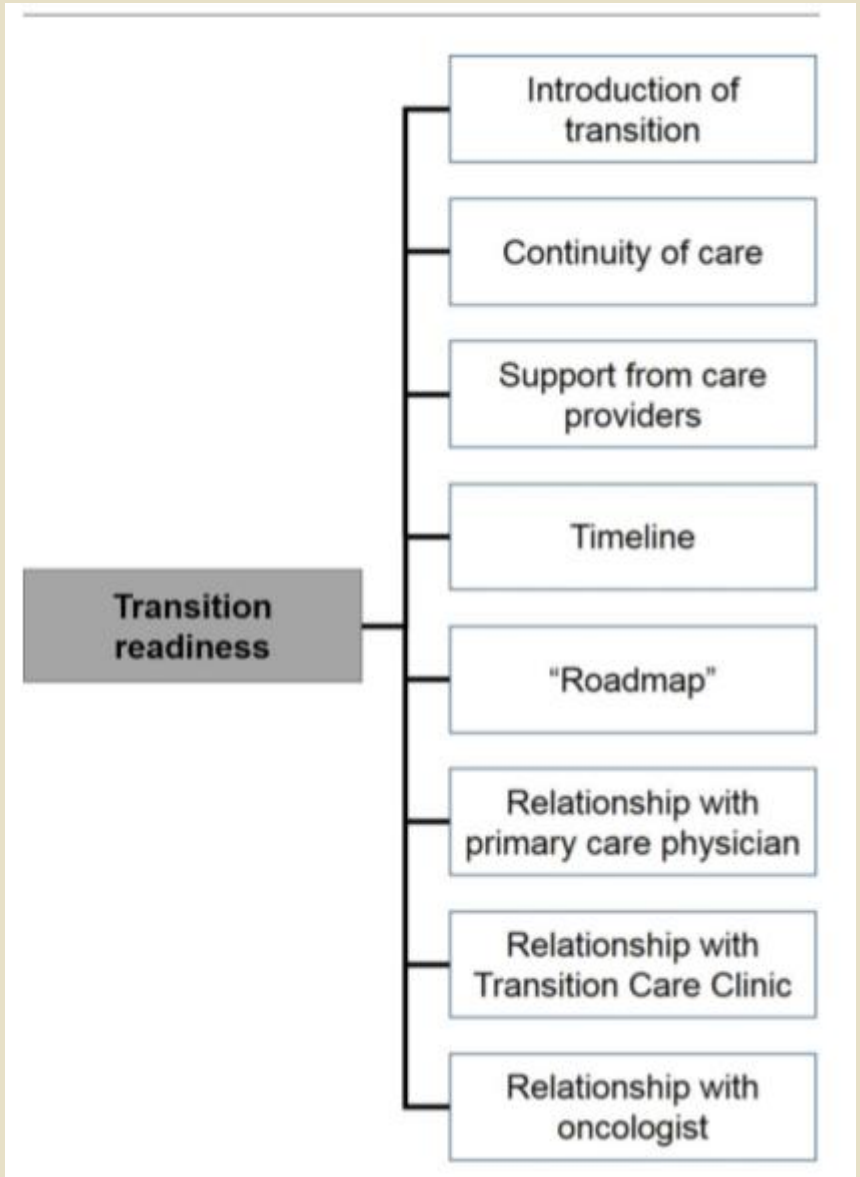
- 5% new cases/year
- **50%** of all new cases will be followed long term.
- Follow-up begins year 2 with 4 visits, year 3=3 visits, year 4=2 visits, year 5-10=1 visit or 0 visits



Follow-Up Visit Growth by New Cancer Cases/Year



Follow-up of 50% of new cases starting year 2 after diagnosis with 4 visits year 2, 3 visits year 3, 2 visits year 4 and annually thereafter.



CURRENT ONCOLOGY
A Canadian Cancer Research Journal

ORIGINAL ARTICLE

The experiences of cancer survivors while transitioning from tertiary to primary care

B.B. Franco,* L. Dharmakulaseelan,* A. McAndrew BA RAP,* S. Bae MPH,* M.C. Cheung MD MSc,*,a and S. Singh MD MPH*,a

ABSTRACT

Purpose In current fiscally constrained health care systems, the transition of cancer survivors to primary care from tertiary care settings is becoming more common and necessary. The purpose of our study was to explore the experiences of survivors who are transitioning from tertiary to primary care.

Methods One focus group and ten individual telephone interviews were conducted. Data saturation was reached with 13 participants. All sessions were audio-recorded, transcribed verbatim, and analyzed using a qualitative descriptive approach.

Results Eight categories relating to the main content category of transition readiness were identified in the analysis. Several factors affected participant transition readiness: how the transition was introduced, perceived continuity of care, support from health care providers, clarity of the timeline throughout the transition, and desire for a "roadmap." Although all participants spoke about the effect of their relationships with health care providers (tertiary, transition, and primary care), their relationship with the primary care provider had the most influence on their transition readiness.

Conclusions Our study provided insights into survivor experiences during the transition to primary care. Transition readiness of survivors is affected by many factors, with their relationship with the primary care provider being particularly influential. Understanding transition readiness from the survivor perspective could prove useful in ensuring patient-centred care as transitions from tertiary to primary care become commonplace.

Key Words Primary care, transitions in care, patient-centred care, qualitative research, survivors

Curr Oncol. 2016 Dec;23(6):378-385 www.current-oncology.com

Actions *Oncology Clinicians* Can Pursue Now

- Clearly communicate to patients from the time of diagnosis that they will be expected to continue to be followed by their primary care provider and likely will transition back to predominately primary care after treatments ends.
- Examine current patient rosters, clinic utilization patterns, and new patient visit slots →consider how shifting care of low-risk/low-need survivors to primary care or advanced practice practitioners would affect these factors.

Alfano, C. et al. *CA Cancer J Clin*. 2019;69(3):234-247

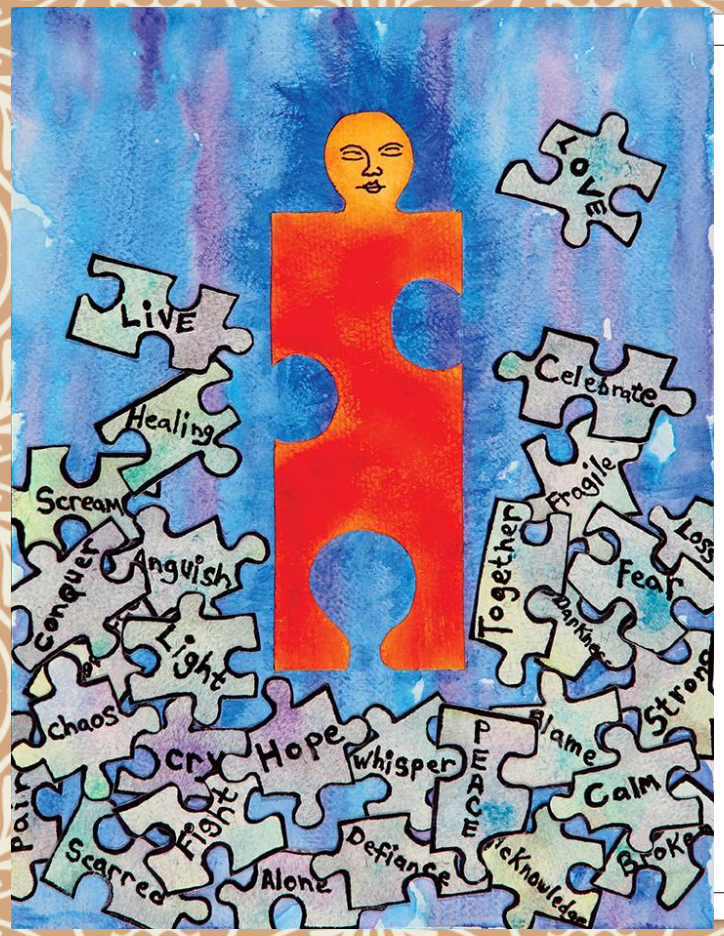
Actions *Oncology Clinicians* Can Pursue Now

- Reinforce expectations about follow-up by ongoing communication throughout cancer treatment.
- Shift follow-up appointments for patients off treatment so they are clustered.
- Support patients who are doing well in self-managing their health.
- Build bridges with primary care.

Alfano, C. et al. *CA Cancer J Clin*. 2019;69(3):234-247

Challenge

- Reorganize your follow-up of patients off treatment to their own follow-up clinics→ first integrate and then move fully to APP → transition to PCP over time.
- Get your institution to provide the numbers of follow-up visits by time since diagnosis.
- Identify PCP interested in taking care of survivors in your area.
- Discuss long-term plans of care with new patients throughout their care.



Survivorship Research

Picking up my pieces

Oncology On Canvas
Expressions of a Cancer Journey

NCI Survivorship Research Definitions

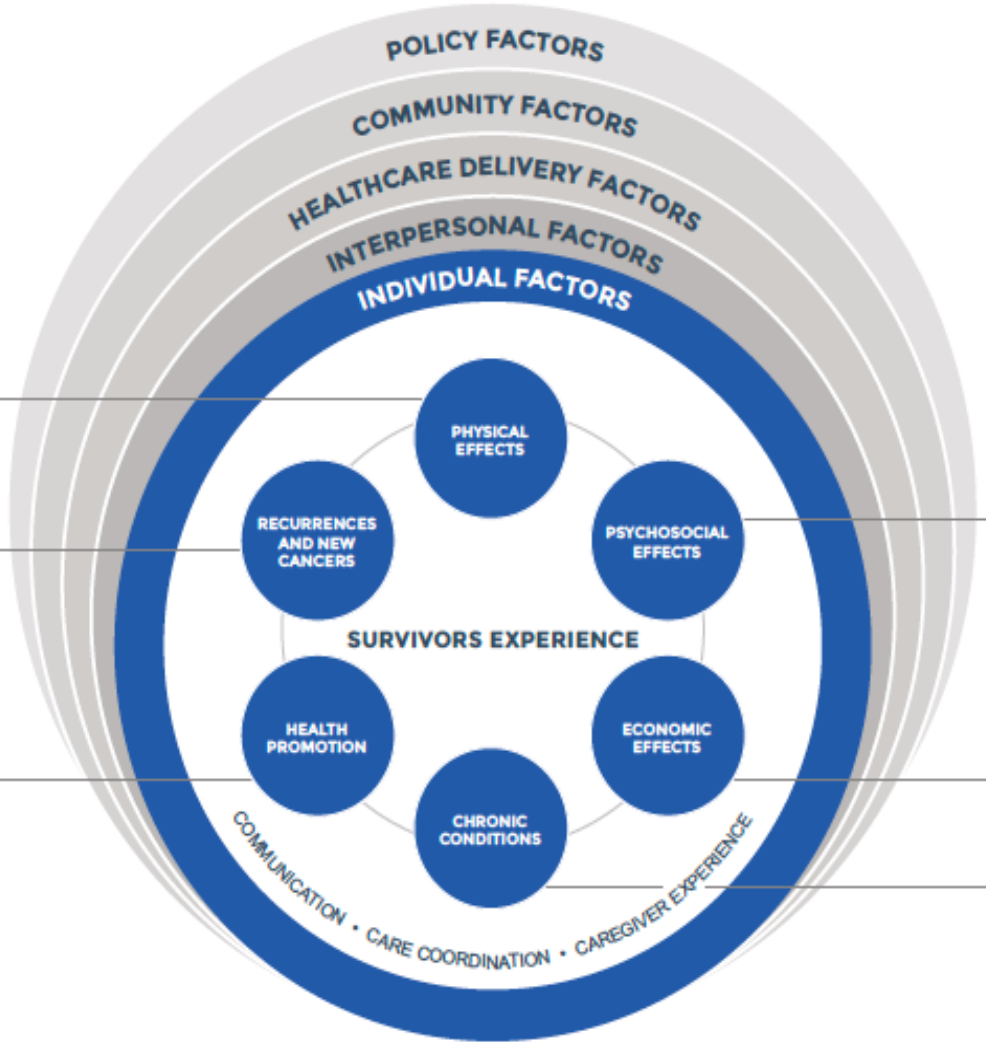
Cancer Survivorship Research: *Cancer survivorship research seeks to improve the health and well-being of cancer survivors and caregivers providing care to survivors.*

It aims to improve understanding of the sequelae of cancer and its treatment and to identify methods to prevent and mitigate adverse outcomes, including functional, physical, psychosocial, and economic effects.

This research also includes and informs the design, delivery, and implementation of evidence-based strategies and the coordination of healthcare services to optimize survivors' health and quality of life from the time of diagnosis through the remainder of the survivor's life.

Any cancer survivorship research should clearly identify the type of survivor being studied (e.g. age, type and stage of cancer, time since diagnosis) and the outcomes of the research (e.g. function, quality of life, health care utilization, costs, survival).

Cancer Survivorship Research



Surveillance and Management of Physical Effects

- Assessment (general and tailored by cancer type and treatment exposure)
- Imaging, testing, and/or specialty care referral
- Management (e.g. medication, therapy, exercise)
- Risk-reducing strategies

Prevention and Surveillance for Recurrence and New Cancers

- Family history/genetics evaluation
- Adjuvant/risk-reducing strategies
- Surveillance visits, laboratory testing, and imaging

Health Promotion and Disease Prevention

- Prevention-focused visits and testing
- Age- and gender-appropriate cancer screening
- Smoking cessation
- Weight management, diet, and physical activity
- Lifestyle behaviors (e.g., alcohol use, sun protection)
- Vaccination

Surveillance and Management of Psychosocial Effects

- Assessment (general and tailored by cancer type and management exposure)
- Treatment (e.g. medication, therapy, exercise)
- Risk-reducing strategies

Surveillance and Management of Economic Effects

- Financial hardship
- Access to treatment and survivorship care
- Employment limitations and concerns
- Health care costs

Coordination and Management of Chronic Conditions

- Evaluation and treatment of non-cancer medical conditions
- Medication reconciliation

Adapted from Nekhlyudov, L, Mollica, M., Jacobsen, P., Mayer, DK, Shulman, LN, Geiger, AM. (2019). Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research and Policy. *JNCI*, epub ahead of print

NIH Survivorship Research Portfolio Analysis (2016)

Review of 165 eligible grants:

- 88.5% were funded by the National Cancer Institute followed by NINR, NIH OD, and NIA
- 85.6% of NCI studies funded by DCCPS
- 66.7% were investigator-initiated (R01) mechanism
- 84.2% focused on adult survivors
- 47.3% focused on breast cancer survivors
- 64.2% focused on <2 years since diagnosis
- 57.3% were observational in nature (57.3%)
- 4.8% older adults and 3% rural populations
- Topics included:
  - 75.8% physiologic outcomes
  - 37.6% psychosocial outcomes
  - 35.7% health behaviors
  - 35.7% patterns of care
  - economic/employment outcomes


OXFORD

JNCI J Natl Cancer Inst (2019) 111(2): djy208

doi: 10.1093/jnci/djy208
Review

REVIEW

Survivorship Science at the NIH: Lessons Learned From Grants Funded in Fiscal Year 2016

Julia H. Rowland, Lisa Gallicchio, Michelle Mollica, Nicole Saiontz, Angela L. Falisi, Gina Tesauro

NIH Survivorship Research Portfolio Analysis (2016)

Research recommendations:

- Increase diversity of cancer sites
- Greater ethnoculturally diverse samples
- More older (>65 years) and longer-term (>5 years) survivors
- Need to address effects of newer therapies

NCI Future Directions in Cancer Survivorship Research: Workshop priorities and Webinar endorsements

- Identify and present the research gaps in the recommended components of survivorship care and important next steps that were identified at a recent NCI meeting; and

- Gather feedback on the identified strategic research priorities (SA-SD).

Survivorship Research Priorities

Prevention and Surveillance

(87% Agree)

- Surveillance schedules
  - Testing optimal frequency, risks and benefits and bundled screening
  - Evidence-based guidelines consistent across organizations
- Reducing disparities among different populations
- Adding longer surveillance for existing, relevant clinical trials
- Enhancing SEER, State Registries and National Cancer Databases

Physical Late/Long-term

(91% Agree)

- Measurement of symptoms, functional impairments, comorbid conditions and needs as core measures by disease
- Profiles of natural history of late/long-term effects in prevalent cancers
- Frame intervention development using chronic disease model (CDM) as it is multilevel and is patient and family focused at its core and spans risk reduction, rehabilitation and self-management support

Survivorship Research Priorities

Psychosocial Late/Long-term
(89% Agree)

- Implementation of psychosocial interventions in real-world settings (e.g. community oncology, primary care)→integration of psychosocial services into existing community systems.
- Prevention and mitigation strategies that include risk-stratification

Health Behaviors
(87% Agree)

- Mechanisms and biomarkers for health behaviors
- Integration of exiting and emerging technologies for health promotion in cancer survivorship care
- Multi-level research studies addressing health behaviors in cancer survivors

Survivorship Research Priorities

Care Coordination

86% Agree

- Identify key outcomes to assess quality care coordination
- What are optimal models to promote risk-based care coordination?
  - What are key strategies to support vulnerable populations?
- How to engage IT in care coordination

Economic

90% Agree

- Longitudinal studies to understand risk factors for financial hardship, employment limitations and other economic effects.
- Studies to understand the impact of financial hardship, employment limitations and other economic effects on functioning, clinical outcomes, quality of life and healthcare utilization.
- Conduct new interventions to address economic effects and leveraging implementation science to ensure effective interventions are disseminated.
- Leverage data infrastructure, linkages, and methods
- Leverage technology to collect data and deliver interventions.

Conclusions

- **Current cancer cancer can not be sustained**
- More survivorship research to help prevent or mitigate long term and late effects
- There is no one solution to address this issue but all require culture change in cancer care delivery.
- Projections for staff and facilities must go beyond # new cases and beyond the next 1-2 years.
- ***Shifting model for follow-up survivorship care is part of the solution but needs to be based on risk stratification, collaboration between PCP and Oncologists, team based care, and supported self-management.***
- Multiple strategies need to be tested.
- We need to develop ***and implement*** a range of evidence-based programs that do not require 1:1 face-to-face interventions.

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When Life Is
Sewn Back
Together,
It Has Changed

Libby Oncology On Canvas
Expressions of a Cancer Journey