

Patient Perspectives on Post-treatment Surveillance

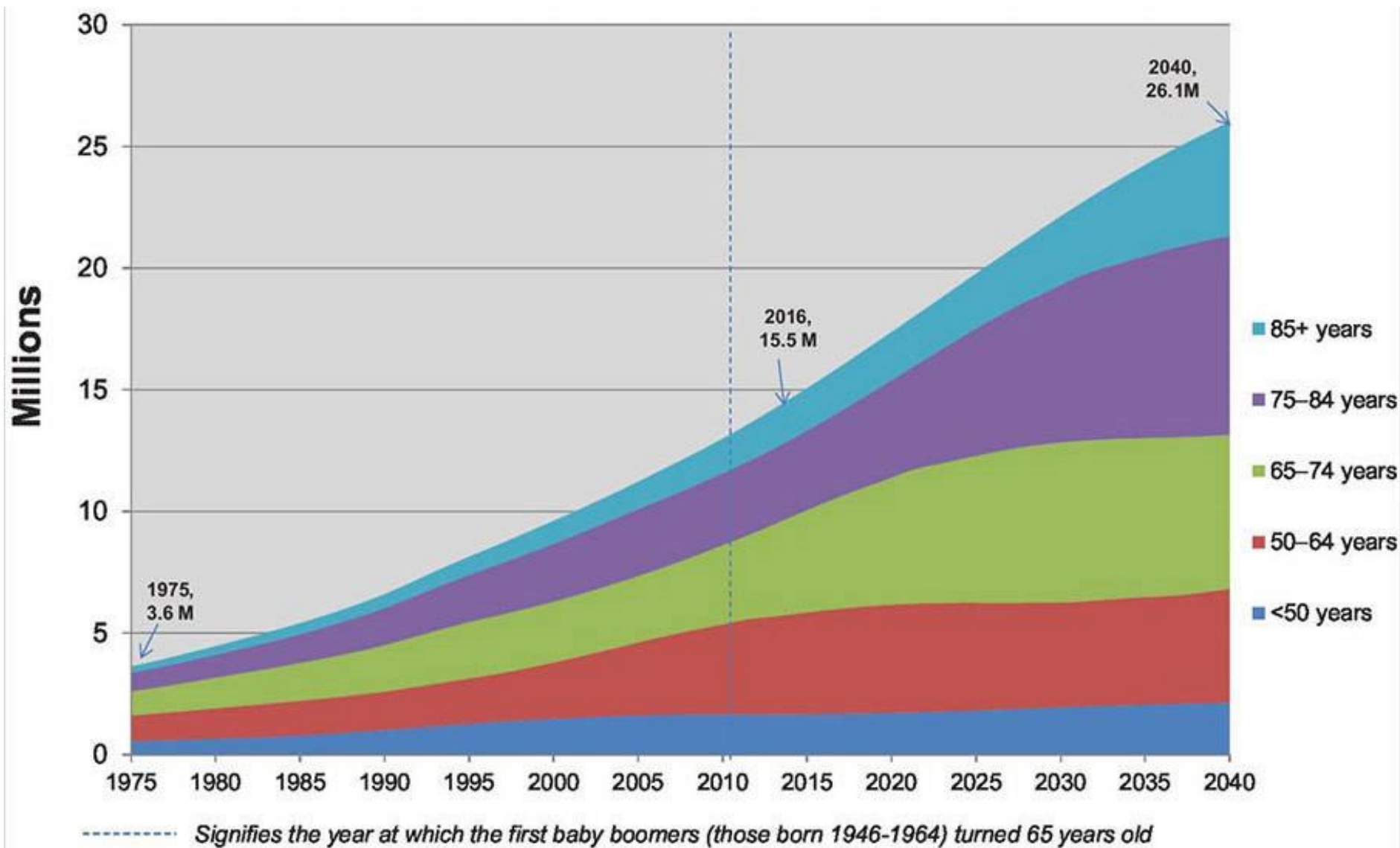
Overview of Follow-up Care for Cancer Survivors

Paul Jacobsen, PhD

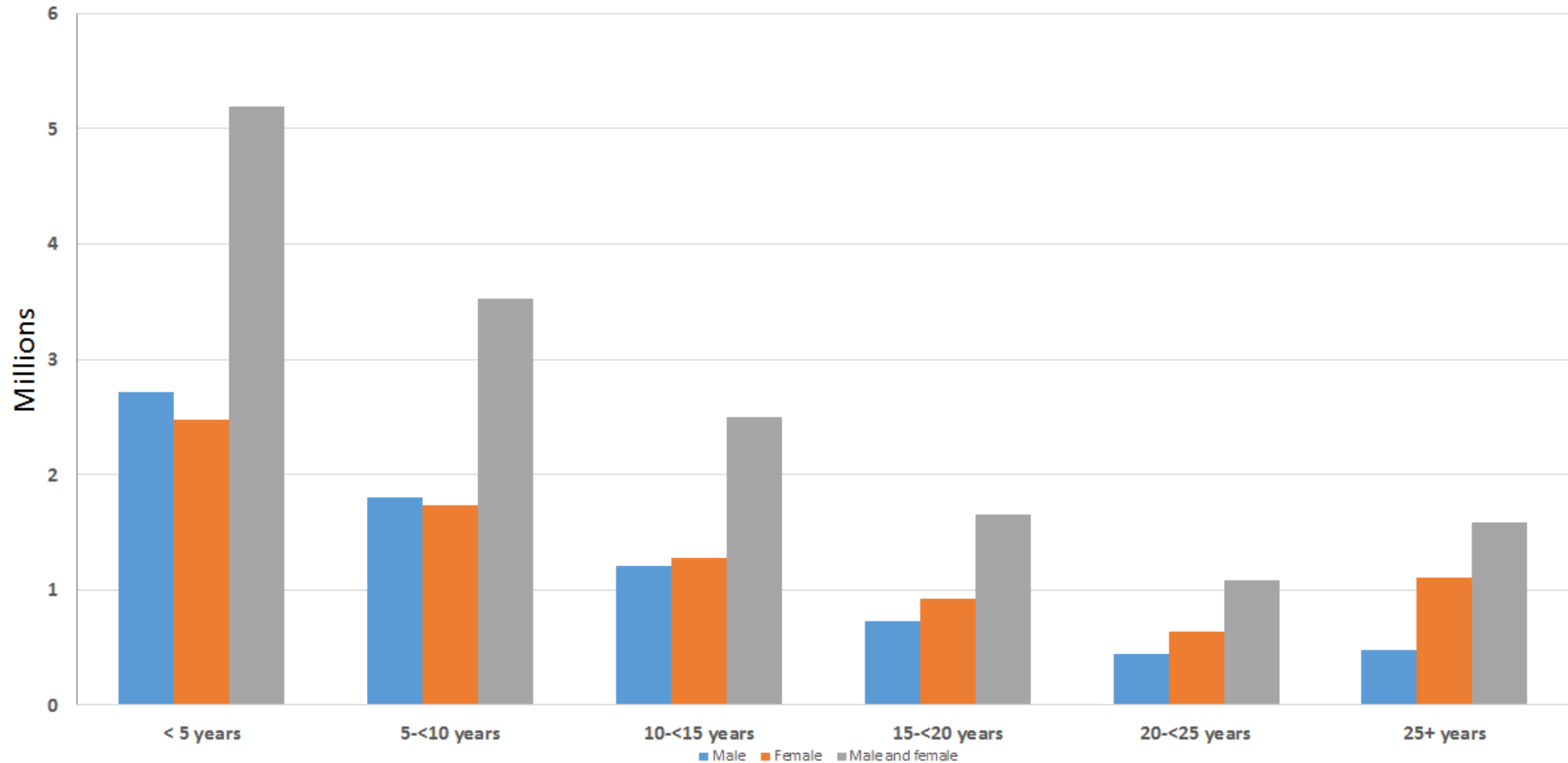
Healthcare Delivery Research Program

Division of Cancer Control and Population Sciences

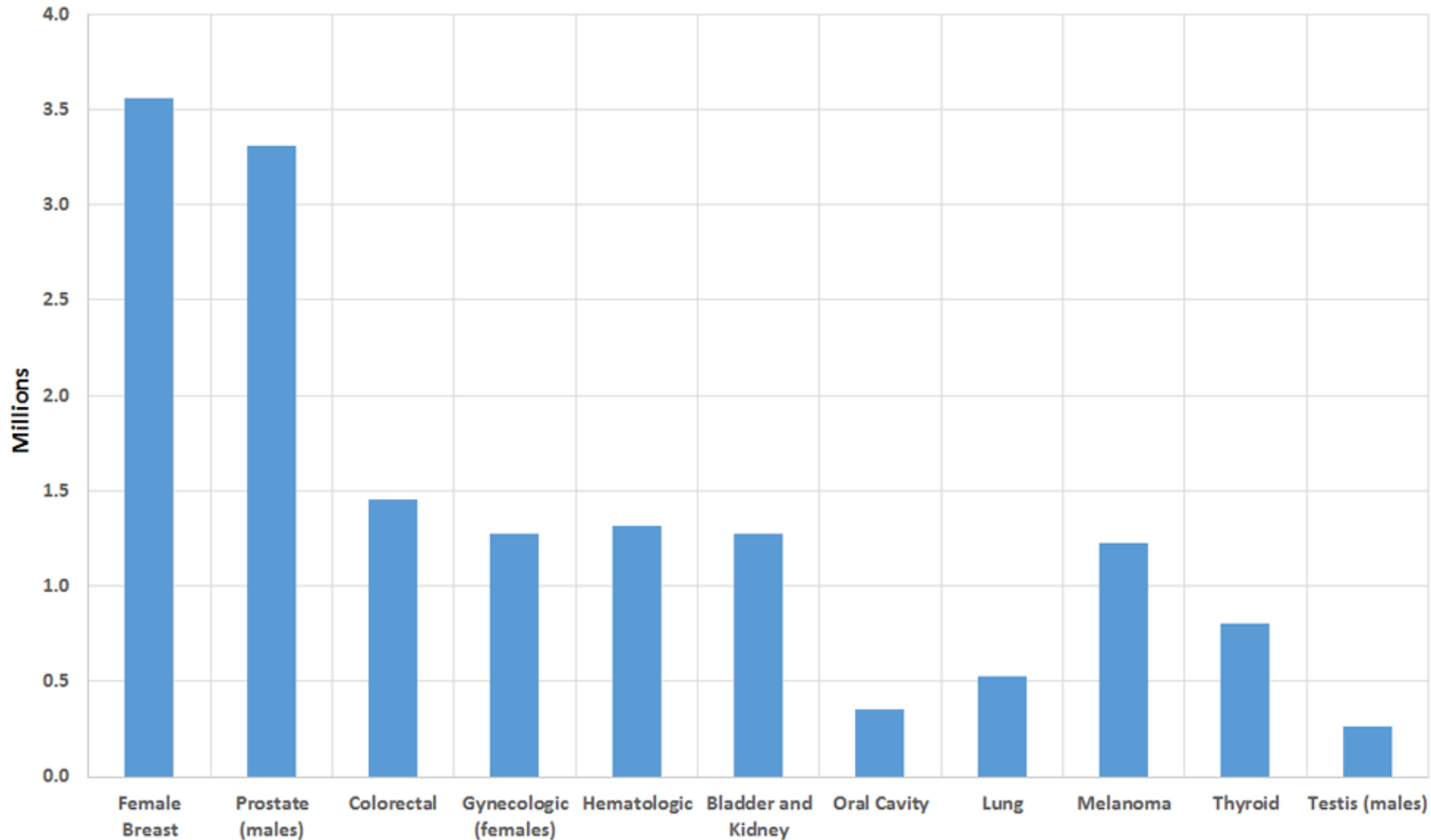
Estimated and Projected Number of U.S. Cancer Survivors



Estimated Number of U.S. Cancer Survivors By Years Since Diagnosis



Estimated Number of U.S. Cancer Survivors by Site



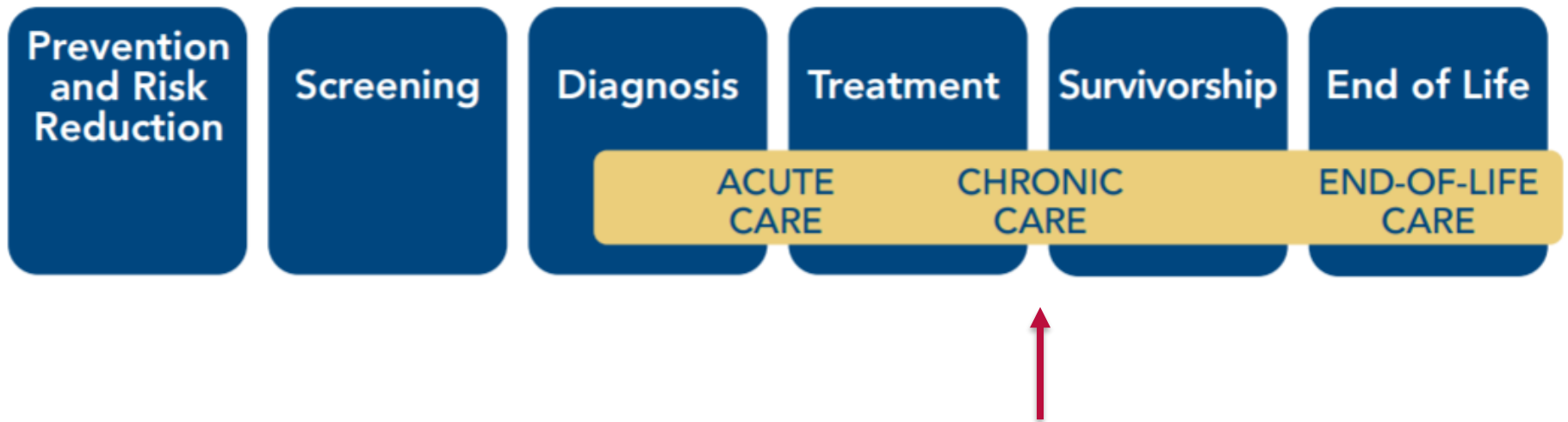
Different Ways of Defining Cancer Survivor

- Individuals living with a cancer diagnosis
- Individuals surviving 5 years or more post-diagnosis (long-term survivors)
- Individuals who have completed active treatment (surgery, chemotherapy, radiotherapy, transplantation)

Different Ways of Defining Cancer Survivor

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- Individuals surviving 5 years or more post-diagnosis (long-term survivors)
- Individuals who have completed active treatment (surgery, chemotherapy, radiotherapy, transplantation)
- Individuals receiving extended treatment to control disease

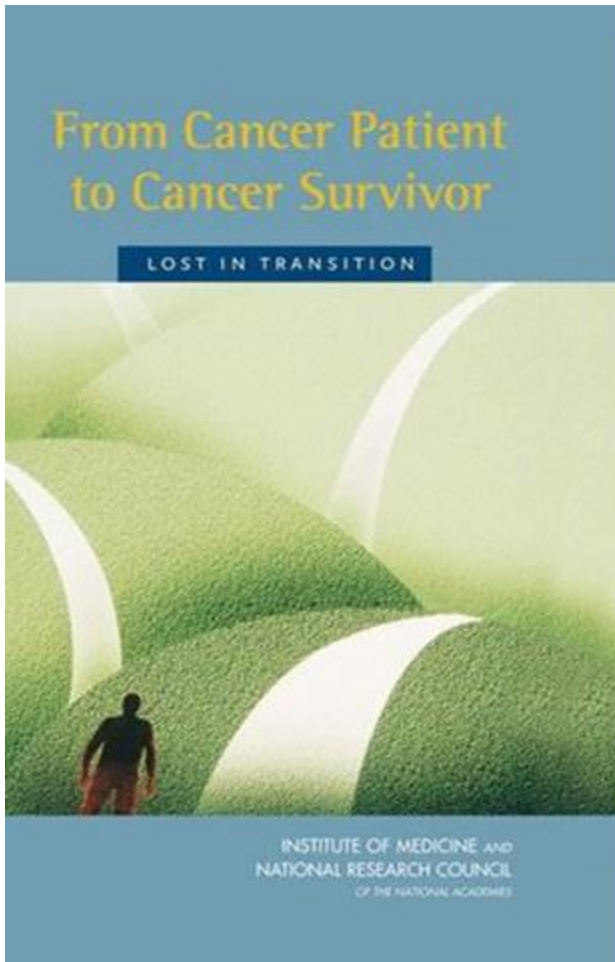
Cancer Prevention and Control Continuum



Cancer Survivorship Research

- Rise in publications
 - 2000: 23
 - 2016: 488
- Lines of Research
 - Disease recurrence
 - Late effects
 - Quality of life
 - Delivery of care

Lost in Transition



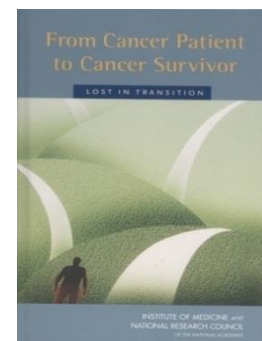
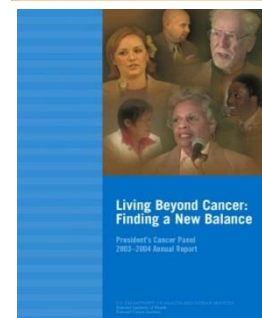
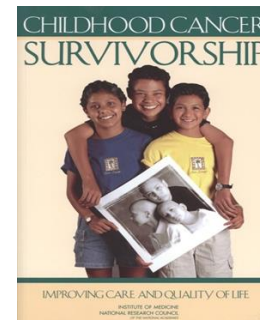
- Transition from active treatment to post-treatment care is critical to the long-term health of cancer survivors
- Unfortunately, many patients are “lost in transition” and do not receive the care they should

Institute of Medicine, 2006

Recommendations from the President's Cancer Panel and IOM Reports

- When treatment ends, all survivors should receive a summary record that includes important disease characteristics and treatments received
- In addition, they should be provided with a follow-up care plan incorporating available evidence-based standards of care

**Treatment summary + Follow-up care plan
= Survivorship Care Plan (SCP)**



Follow-up Care Plan

- **Prevention of recurrent and new cancers and late effects**
- **Surveillance for disease progression or recurrence and for second cancers; screening for medical and psychosocial late effects**
- **Intervention for consequences of cancer and its treatment** (e.g., lymphedema, pain, fatigue, employment, and financial issues)
- **Coordination of care** (e.g., frequency of visits, tests, and who is performing these)

Surveillance Among Colorectal Cancer Survivors

- Recommended surveillance first 12-18 months post-treatment
 - Colonoscopy: 18% - 61%
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- **Correlates of adherence**
 - Focus largely on nonmodifiable (e.g., socio-demographic and disease/treatment) factors
 - Younger, White, fewer comorbidities, insured
 - Colonic site of disease, adjuvant chemotherapy
 - Limited research on provider or organizational factors

Patient Perspectives on Surveillance After Cancer Treatment

- Patient perceptions of routine surveillance

- Positive: High rates of overall satisfaction
Stress and anxiety acceptable in relation to benefit
Evaluation for recurrence most important reason for follow-up
- Negative: Unmet expectations for information exchange
Anxiety and stress related to follow-up visits and tests

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- Patient preference for delivery by provider type

Open to nurse follow-up as long as specialist is involved
Willingness to have PCP assume a larger role
Concerns about losing contact with specialists
Satisfaction generally high regardless of provider

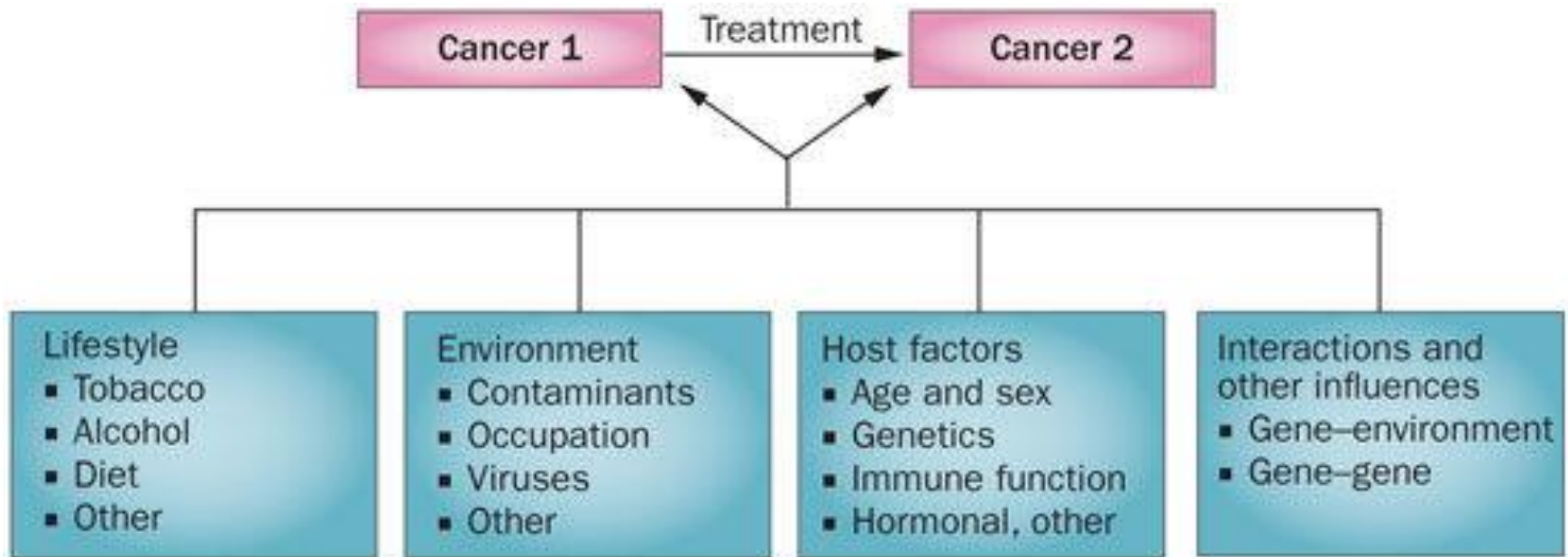
Prevalence of Prior Cancer Among Persons Newly Diagnosed with Cancer

- Of incident cancers diagnosed 2009-2013, 18.4% represented a second order or higher primary cancer
- 25.2% of older (≥ 65 years) adults and 11% of younger adults newly diagnosed with cancer had prior history of cancer

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- Of incident cancers diagnosed 2009-2013, 18.4% represented a second order or higher primary cancer
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- Prevalence of prior cancer varied by incident cancer type, ranging from 3.5% to 36.9%, with most in a different cancer site
- $\geq 30\%$ of older adults with tobacco or HPV related cancers had a prior cancer
- 36.9% of older adults with myeloid leukemia had a prior cancer

Risk Factors for Second Cancers



Models of Survivorship Care

- Acknowledgement of limitations of “one-size-fits-all” approach
- Growing interest in models that provide more tailored and coordinated care
- Evolving international consensus on potential merits of risk-stratified survivorship care models

United Kingdom: National Cancer Survivorship Initiative¹

Canada: Cancer Care Ontario²

Australia: Clinical Oncology Society of Australia³

United States: American Society of Clinical Oncology⁴

¹england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf

²cancercare.on.ca/common/pages/UserFile.aspx?fileId=258056

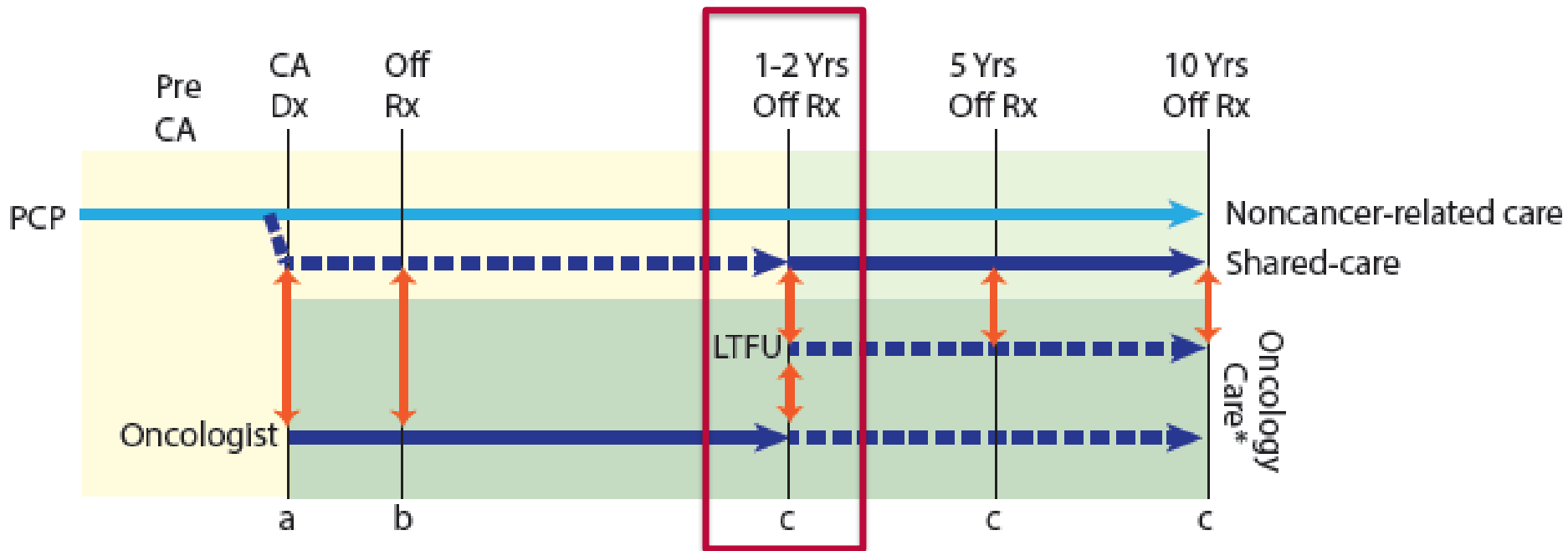
³cosa.org.au/media/332340/cosa-model-of-survivorship-care-full-version-final-20161107.pdf

⁴McCabe et al, J Clin Oncol 2013;31:631-40

Risk-Stratified Shared Care Model

Low Risk

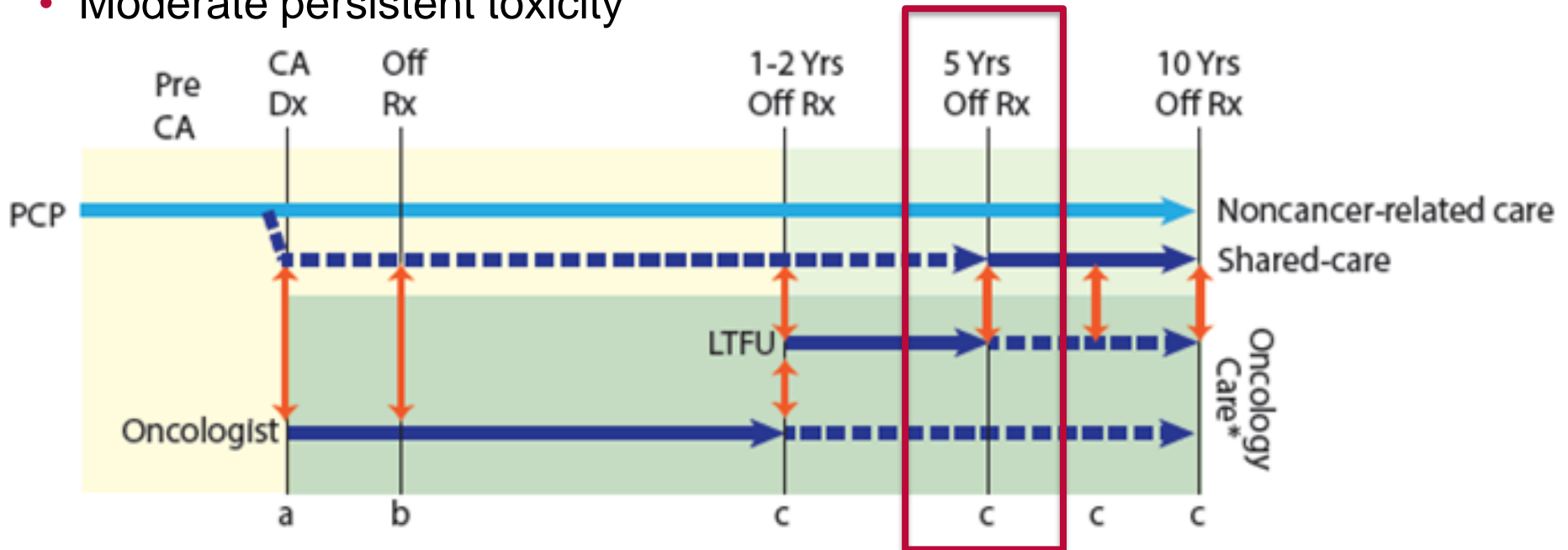
- Surgery only or chemotherapy that did not include agents such as anthracyclines and alkylators
- Low risk of recurrence
- Mild or no persistent toxicity



Risk-Stratified Shared Care Model

Moderate Risk

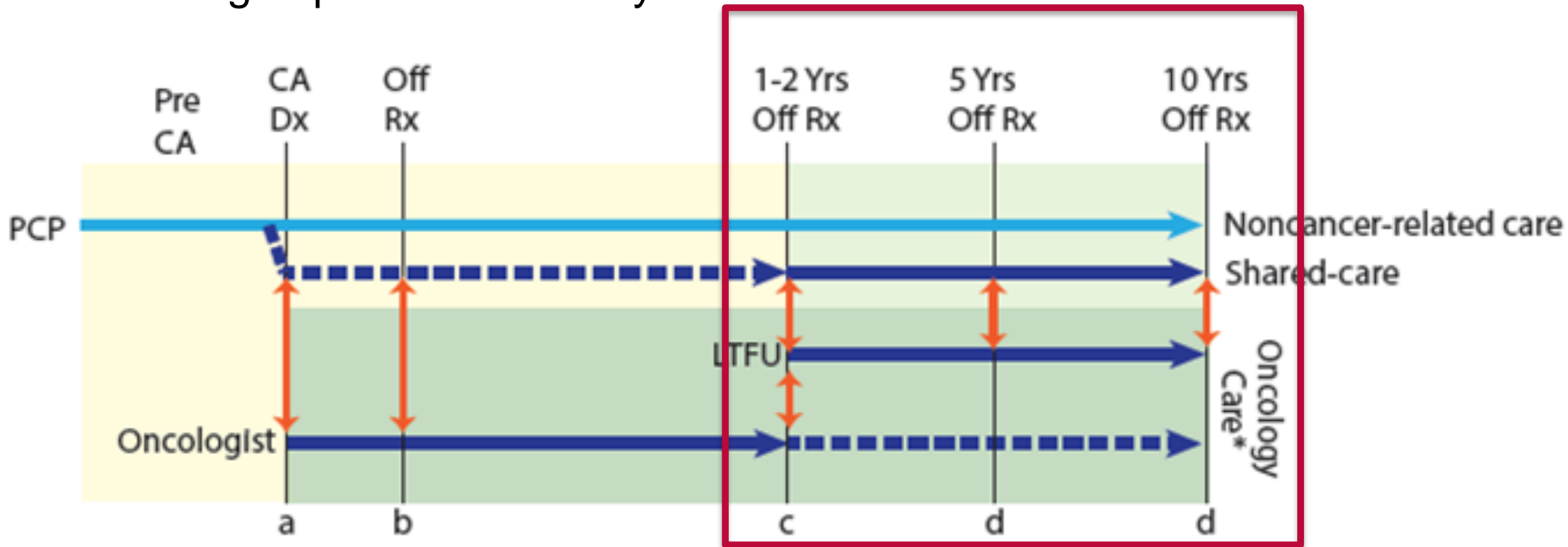
- Low/moderate dose radiation therapy
- Low/moderate dose of agents such as anthracyclines and alkylators
- Autologous transplant
- Moderate risk of recurrence
- Moderate persistent toxicity



Risk-Stratified Shared Care Model

High Risk

- High dose radiation therapy
- High dose of agents such as anthracyclines and alkylators
- Allogeneic transplant
- High risk of recurrence
- Multi-organ persistent toxicity



Summary

- Growing evidence base on risk factors for recurrence, second primary cancers, and late effects
- Initial development of clinical practice guidelines for survivorship care
- Follow-up care remains suboptimal for many cancer survivors
- Efforts to tailor follow-up care to survivors' risks and needs are in their infancy
- Limited evidence to support effectiveness of care models that have been described
- Limited progress in integrating primary care providers into survivorship care

Future Directions

- Develop comprehensive evidence-based risk stratification models
- Fill evidence gaps and refine existing clinical practice guidelines for survivorship care
- Understand and influence mechanisms that can promote better coordination of care for cancer survivors
- Design and conduct studies to evaluate different survivorship care delivery models
- Conduct research, based on implementation science, to promote widespread adoption of effective care models

Paul.Jacobsen@nih.gov



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