

# Long-term Surveillance of Exposed Patient Populations: Experience with Pediatric/Adolescent Cancer Survivors



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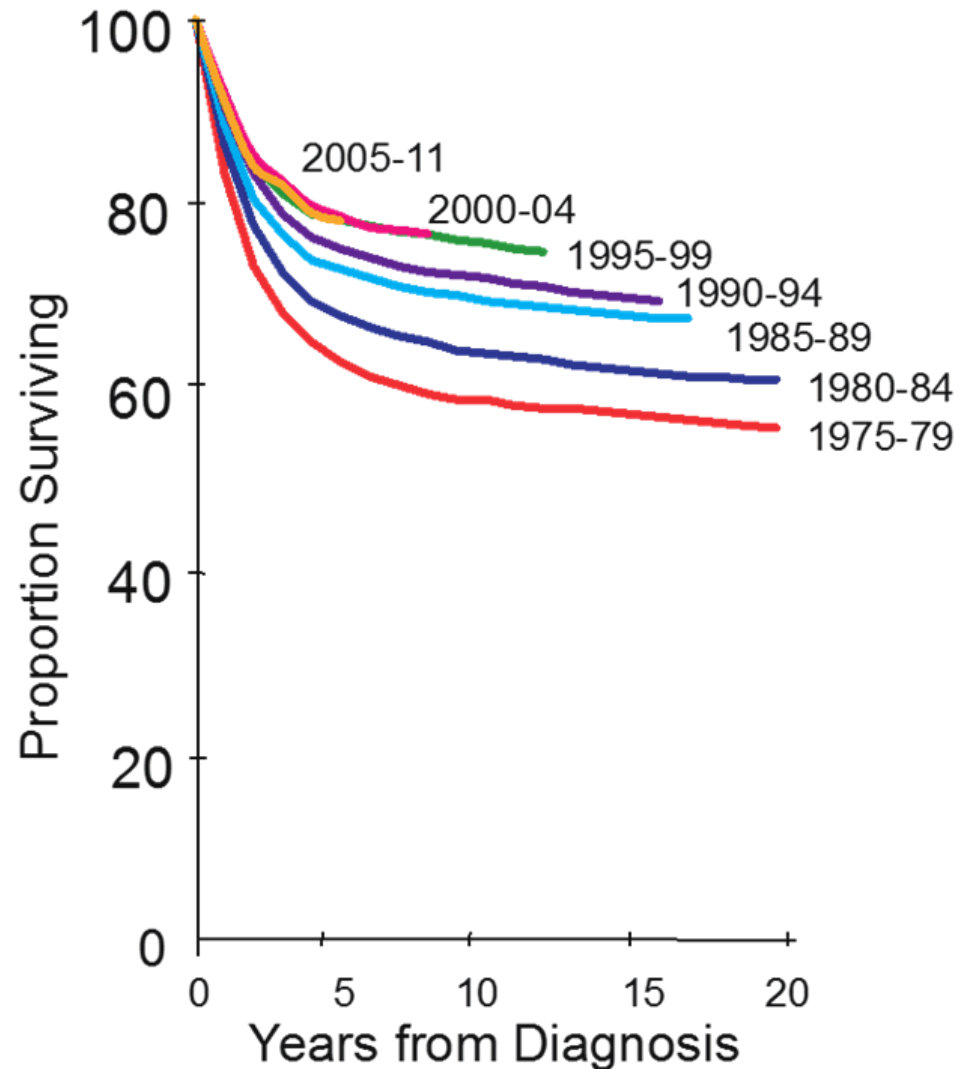
# Long-term Surveillance of Exposed Patient Populations: Experience with Pediatric/Adolescent Cancer Survivors

- Childhood Cancer Survivor Cohorts
- Prospective vs. Retrospective
- Ascertainment of Long-term Outcomes
  - Patient-reported vs. Clinical Assessment
  - Cumulative Burden
  - Record Linkage
  - mHealth

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# Childhood Cancers in the US: Survivorship Statistics



- Estimate 13,500 newly diagnosed cases annually
- >83% achieve five-year survival
- End of 2013, estimated number surpass 420,000
- 1 in 750 in the US is a childhood cancer survivor
- Number of survivors will approach 500,000 by 2020

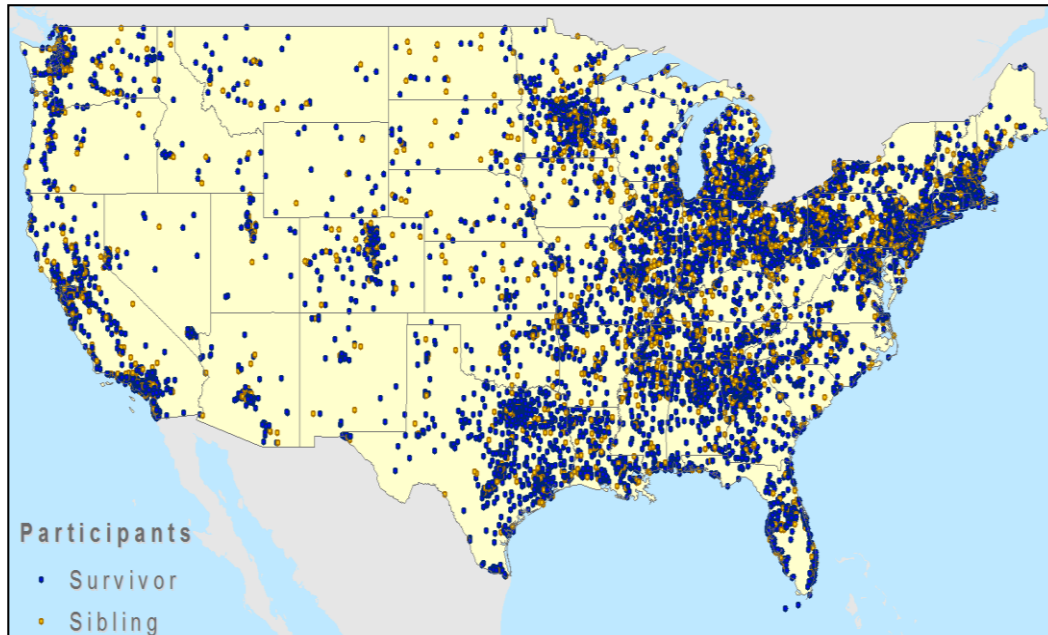
# Pediatric Cancer Survivor Cohorts

CCSS

Childhood Cancer Survivor Study Cohort

U24 CA55727 (PI: Armstrong)

35,937 Survivors (24,500+ participants)

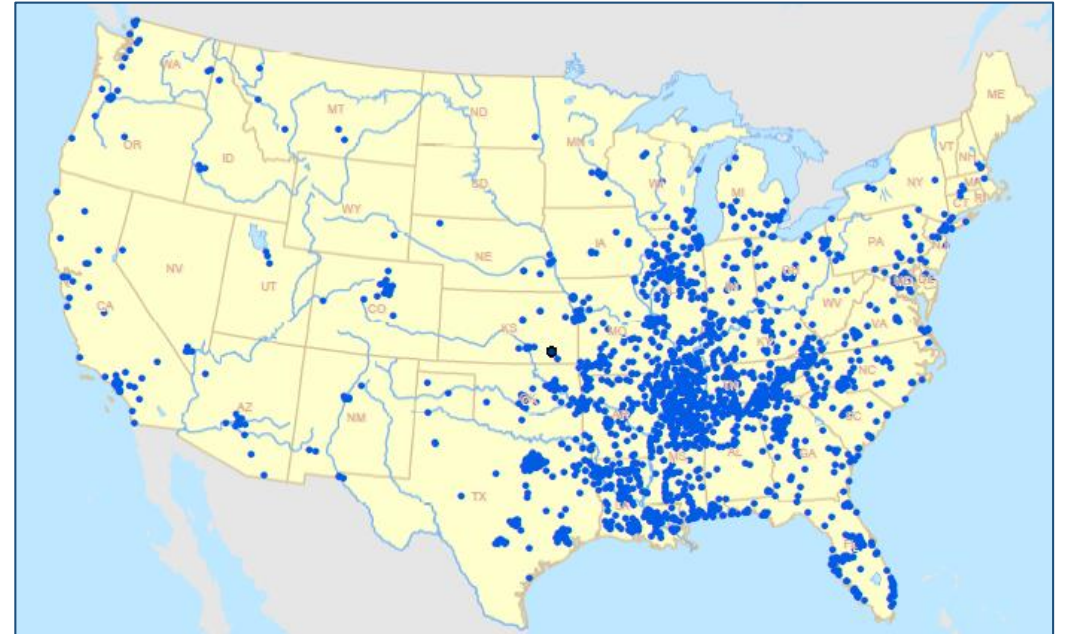


SJLIFE

St. Jude Lifetime Cohort

U01 CA195547 (MPI: Hudson/Robison)

8245 Survivors (6000+ clinically assessed)



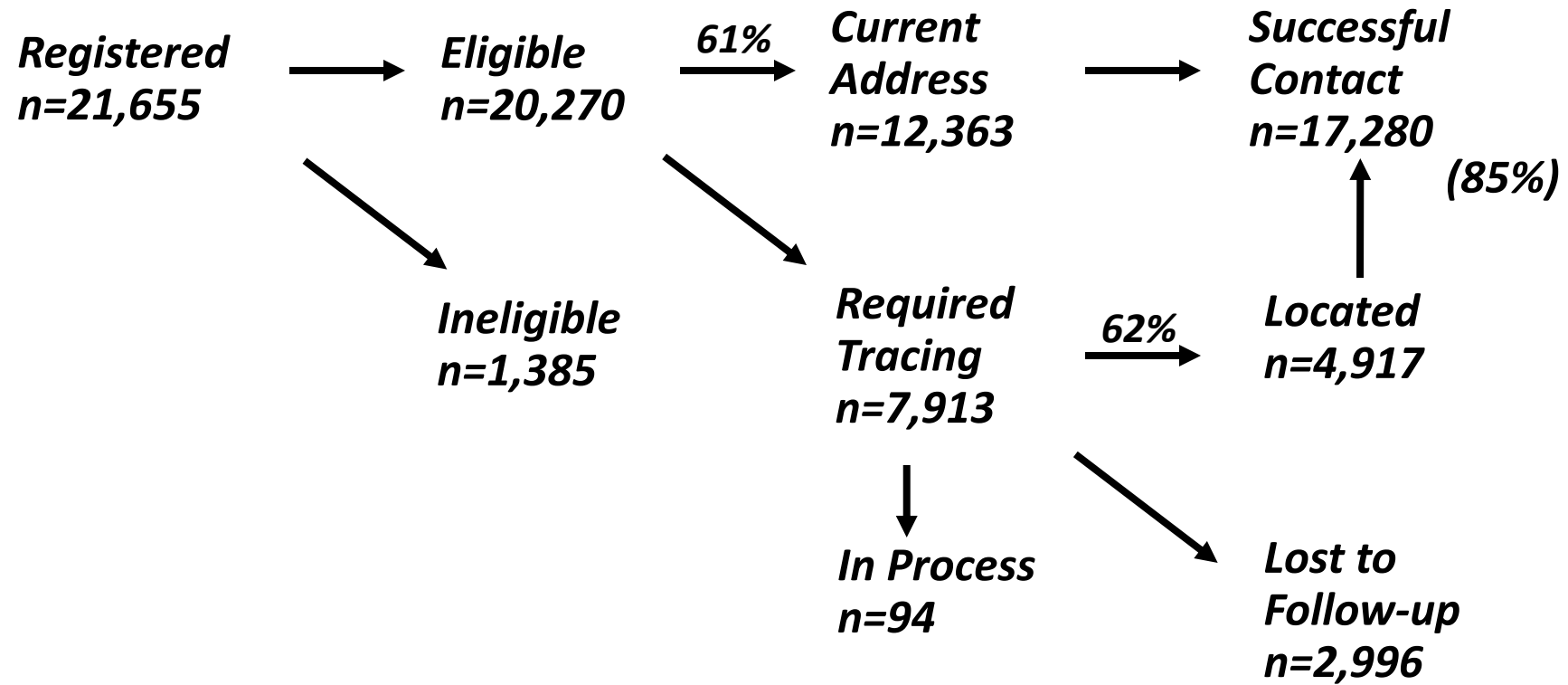
# Pediatric Cancer Survivor Cohorts

Characteristic	CCSS (Dx 1970 - 1999)	SJLIFE (Dx 1962 - 2012)
Cohort size	35,937 (24,000+ active participants)	8,245 (4,688 participants to date)
Entry criteria	≥5 years from diagnosis	≥5 years from diagnosis
Age at cancer diagnosis	<21 years	<25 years
Cancers	Leukemia, CNS, HL, NHL, neuroblastoma, soft tissue sarcoma, Wilms, bone tumors	All diagnoses
Study design	Retrospective cohort with prospective follow-up, hospital-based	Retrospective cohort with prospective follow-up, hospital-based
Methods of contact	Surveys	Clinic visits and surveys
Comparison population	Siblings, general population	Frequency-matched community controls, general population
Therapeutic exposures	>90%	100%
Ascertainment methods	Self-report, pathology reports, NDI	Med. assessment, self-report, med. record, NDI
Collection of germline DNA	>60%	>95%

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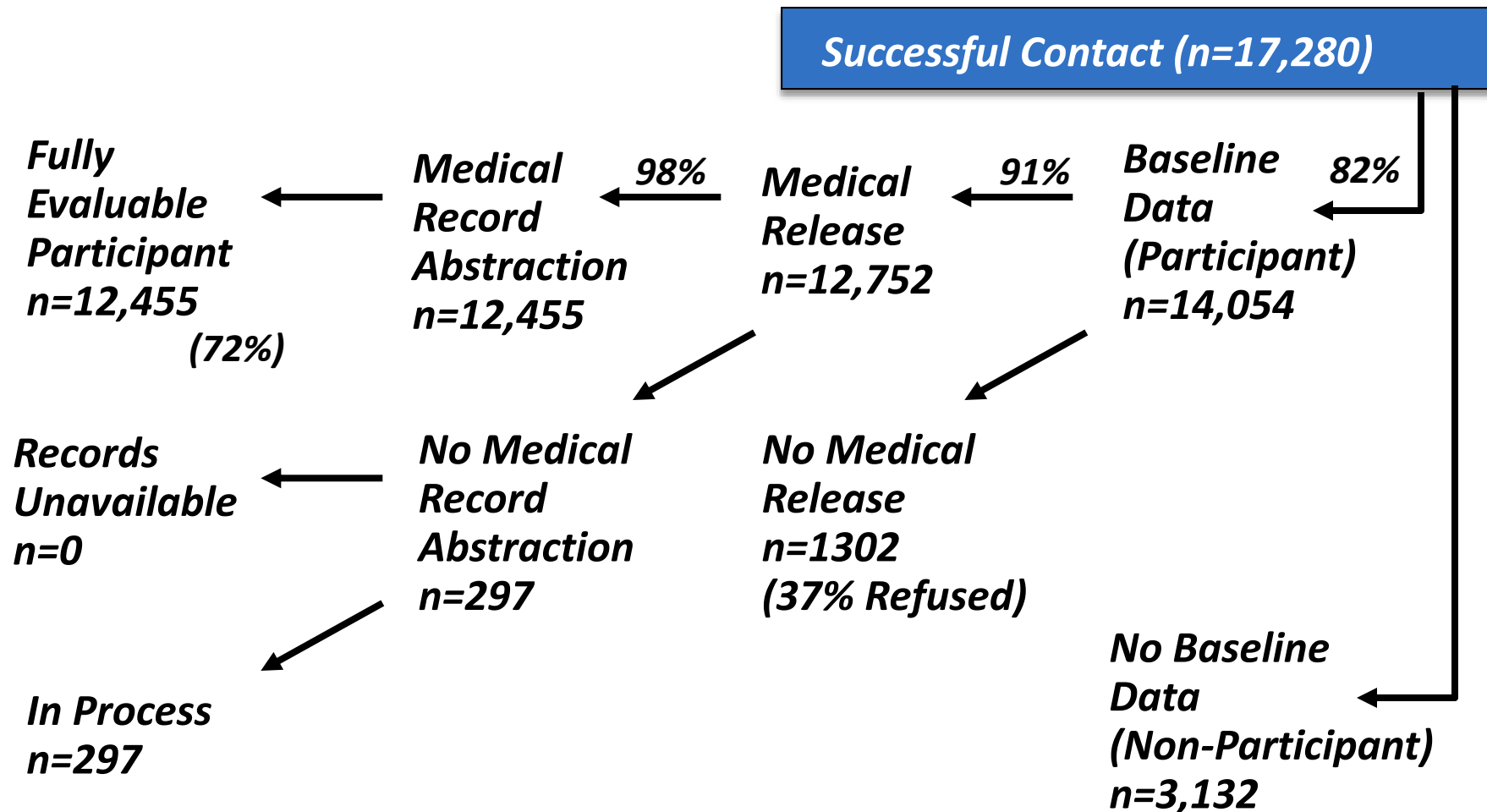
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# Recruitment of the Initial CCSS Cohort





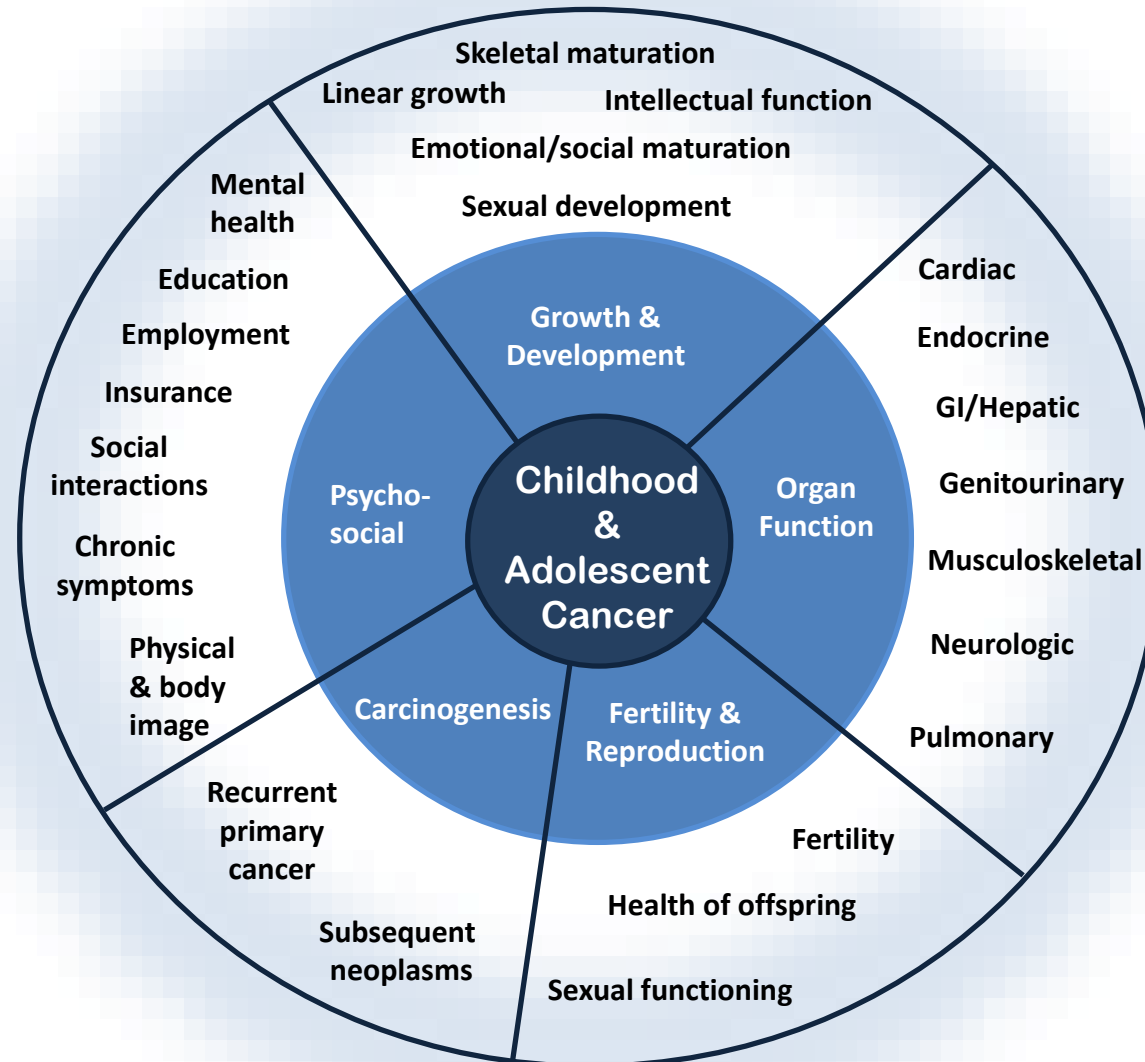
# Recruitment of the Initial CCSS Cohort



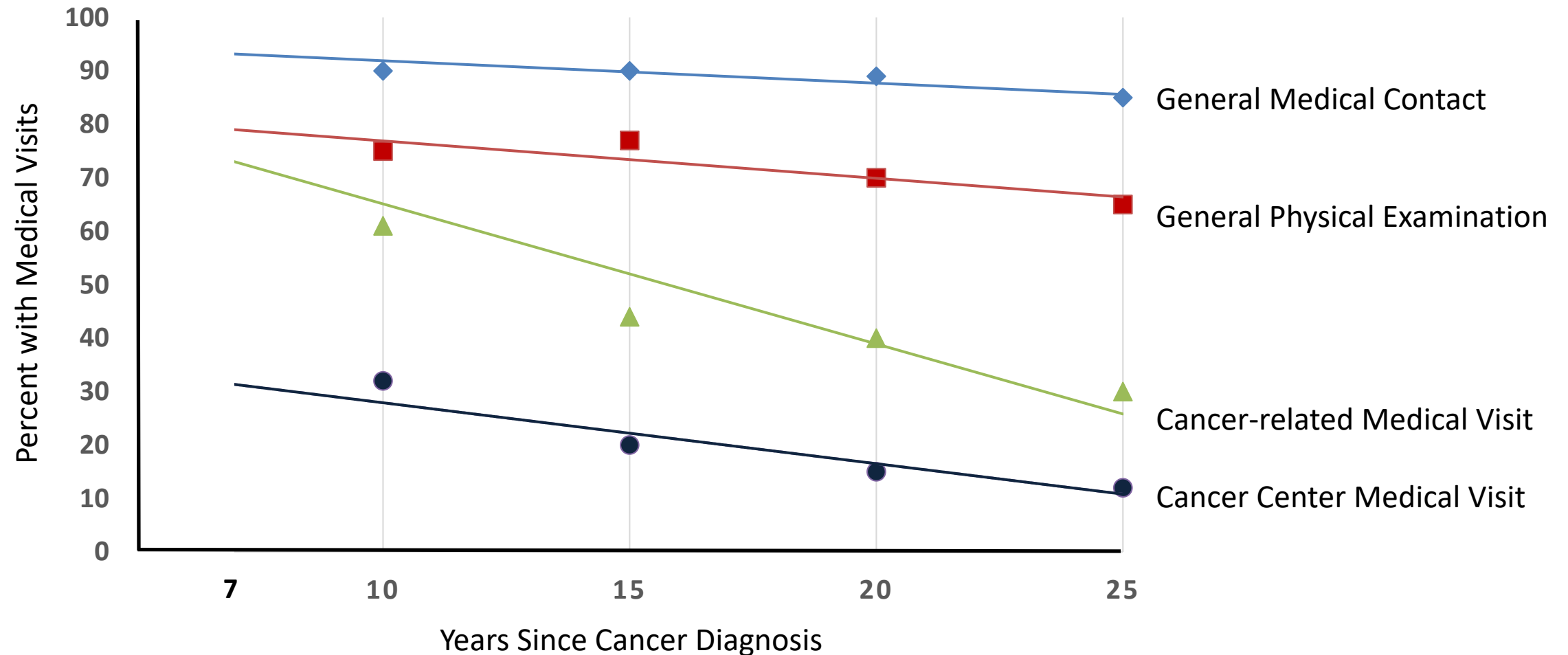
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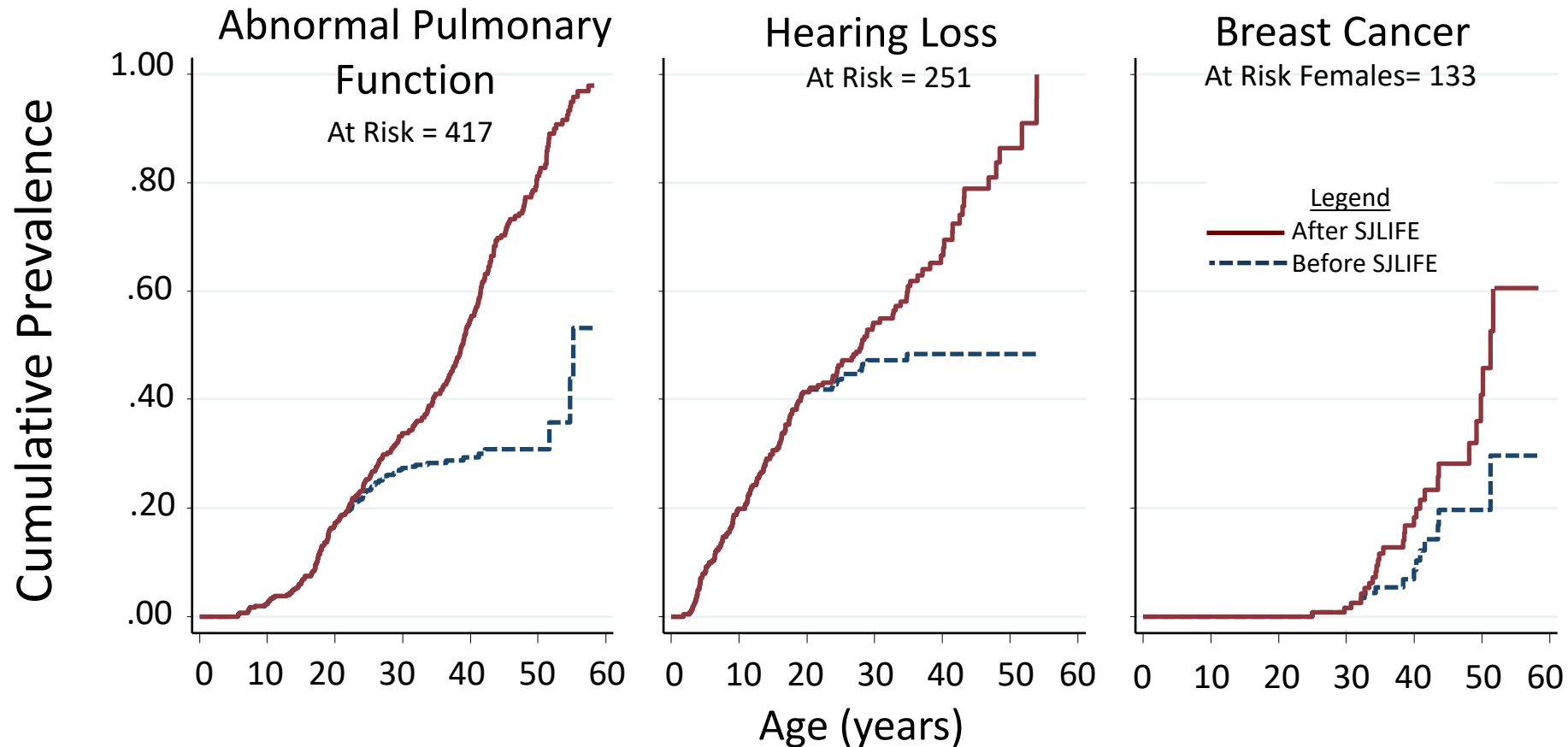
# Spectrum of Health-related and Quality of Life Outcomes



# Engagement with Medical Care within Past 2-Years



# Prevalence - Yield of Risk-based Screening



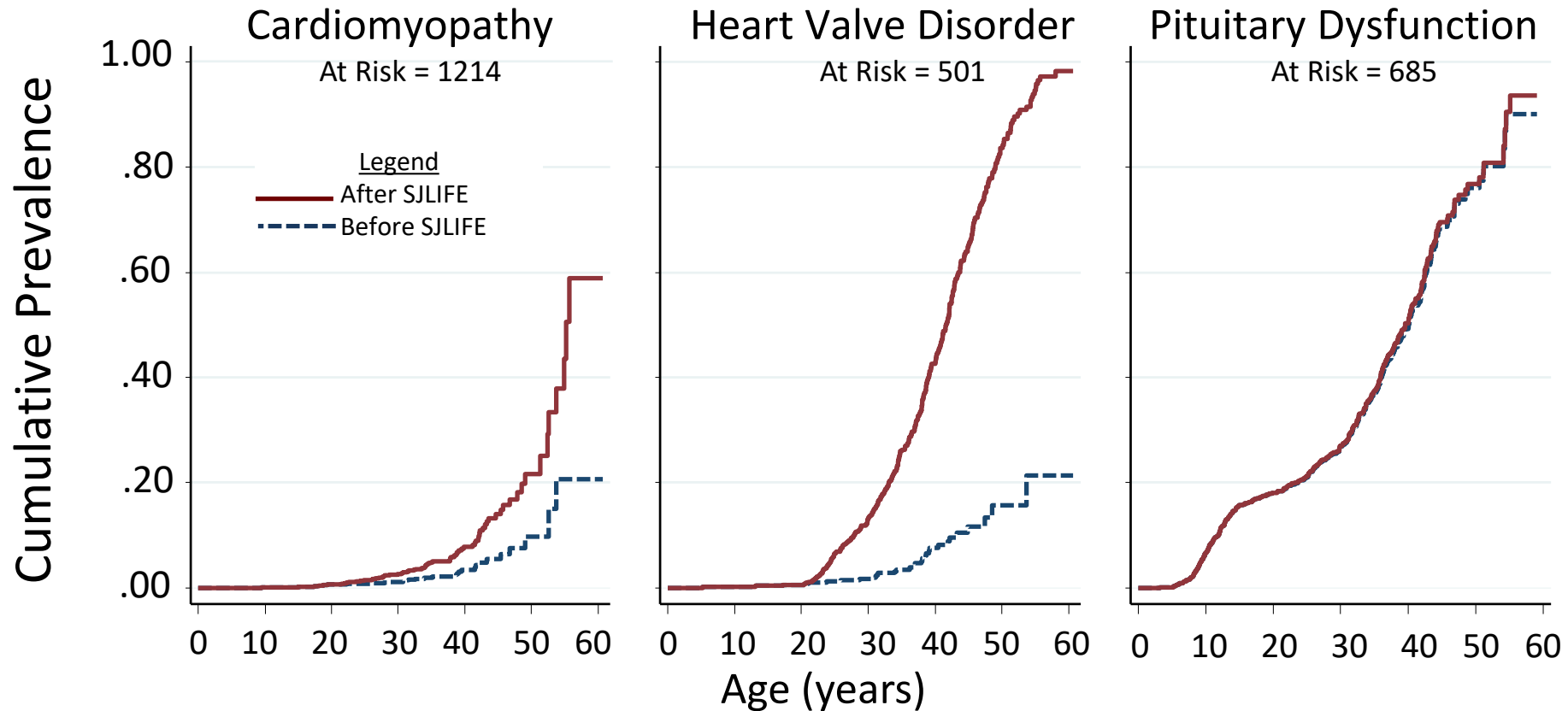
At Risk Criteria

Bleomycin, Carmustine/Lomustine,  
Busulfan, Lung RT, or thoracotomy

Cisplatin/Carboplatin or Ear RT

$\geq 20$  Gy RT to the breast

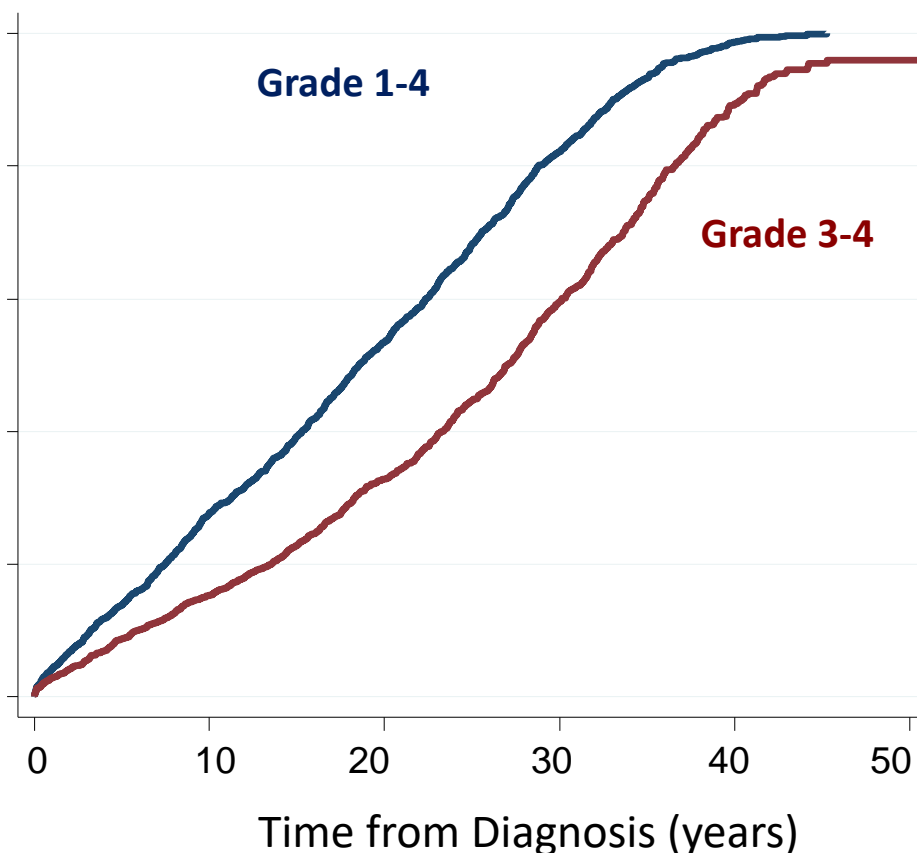
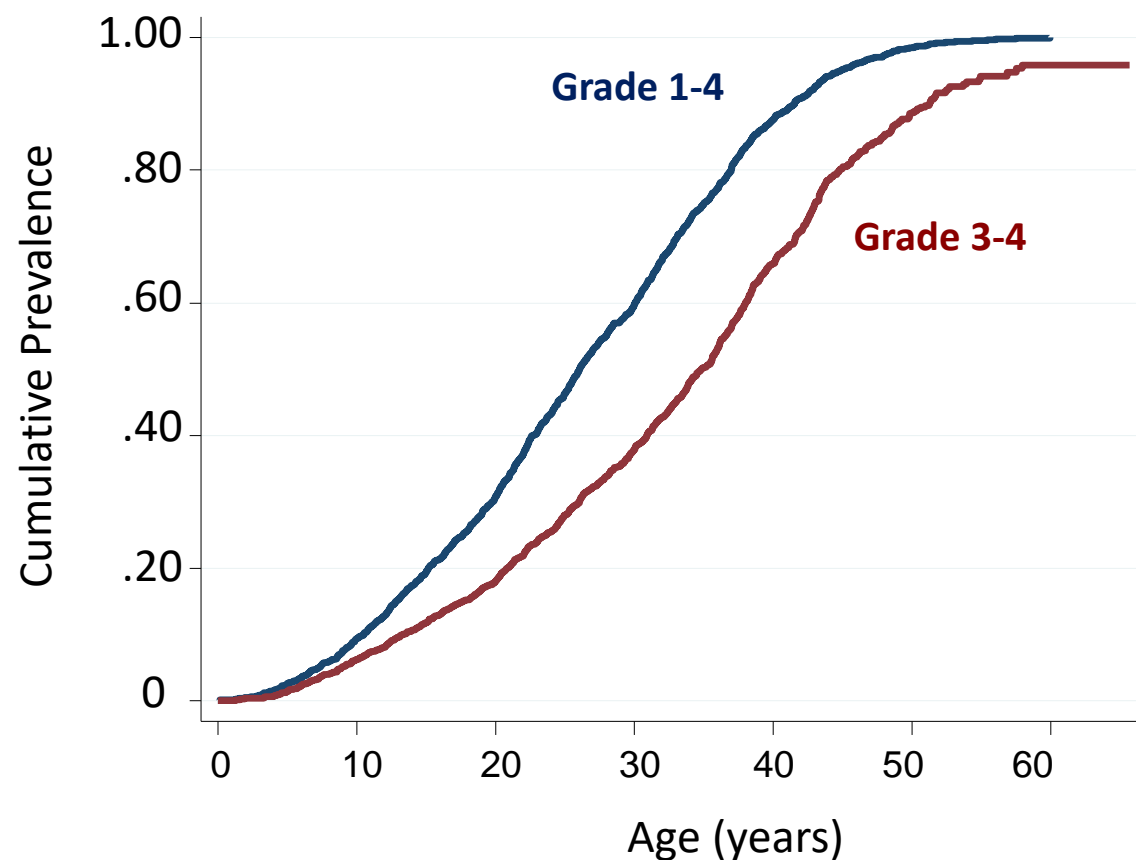
# Prevalence - Yield of Risk-based Screening



At Risk Criteria	Anthracycline/Anthraquinone or heart RT	Heart RT	$\geq 18$ Gy RT hypothalamus-pituitary
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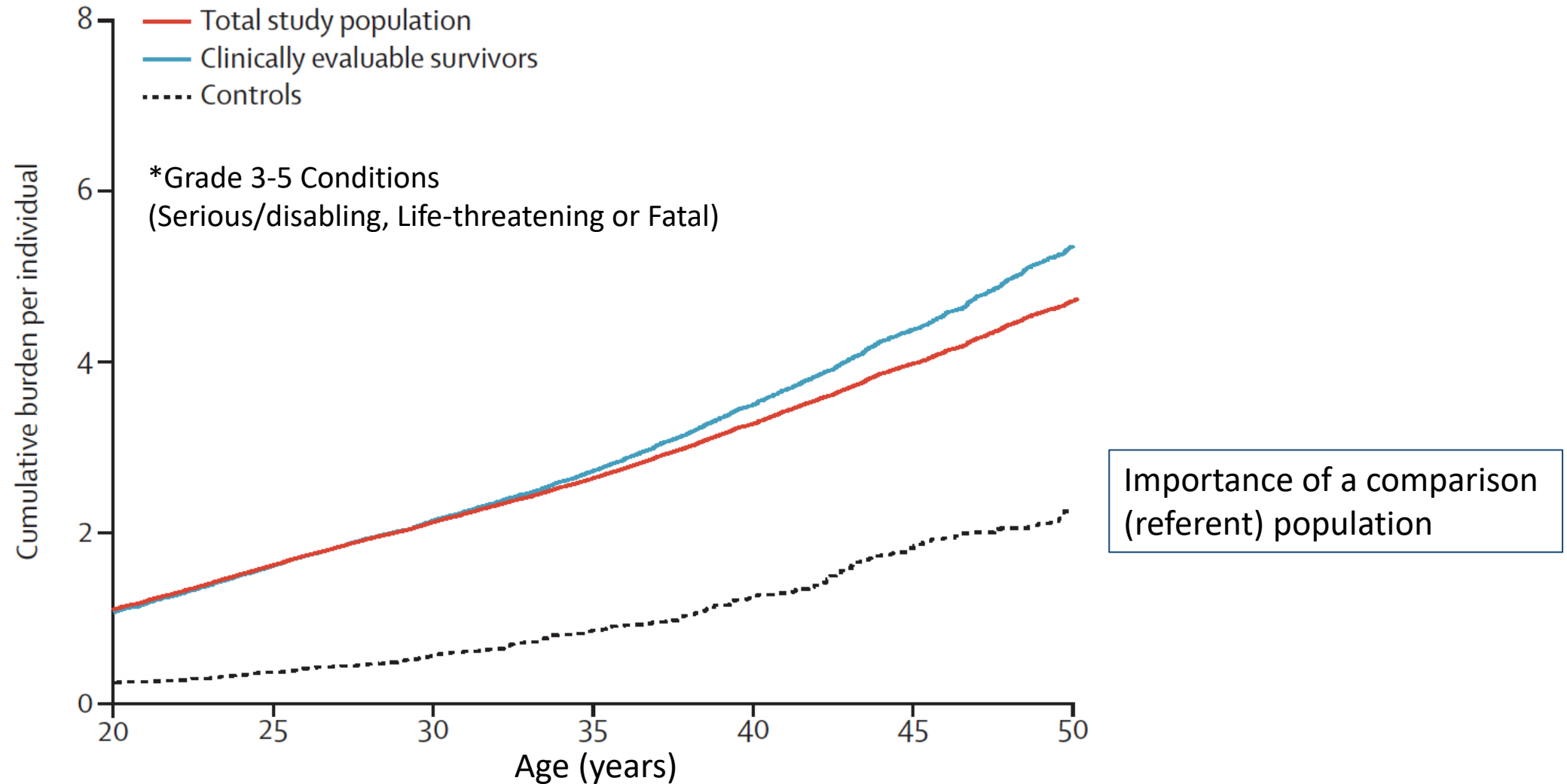
# Cumulative Prevalence of Chronic Health Conditions

Common Terminology Criteria, Version 4.03



# Long-term Survivors of Childhood Cancer

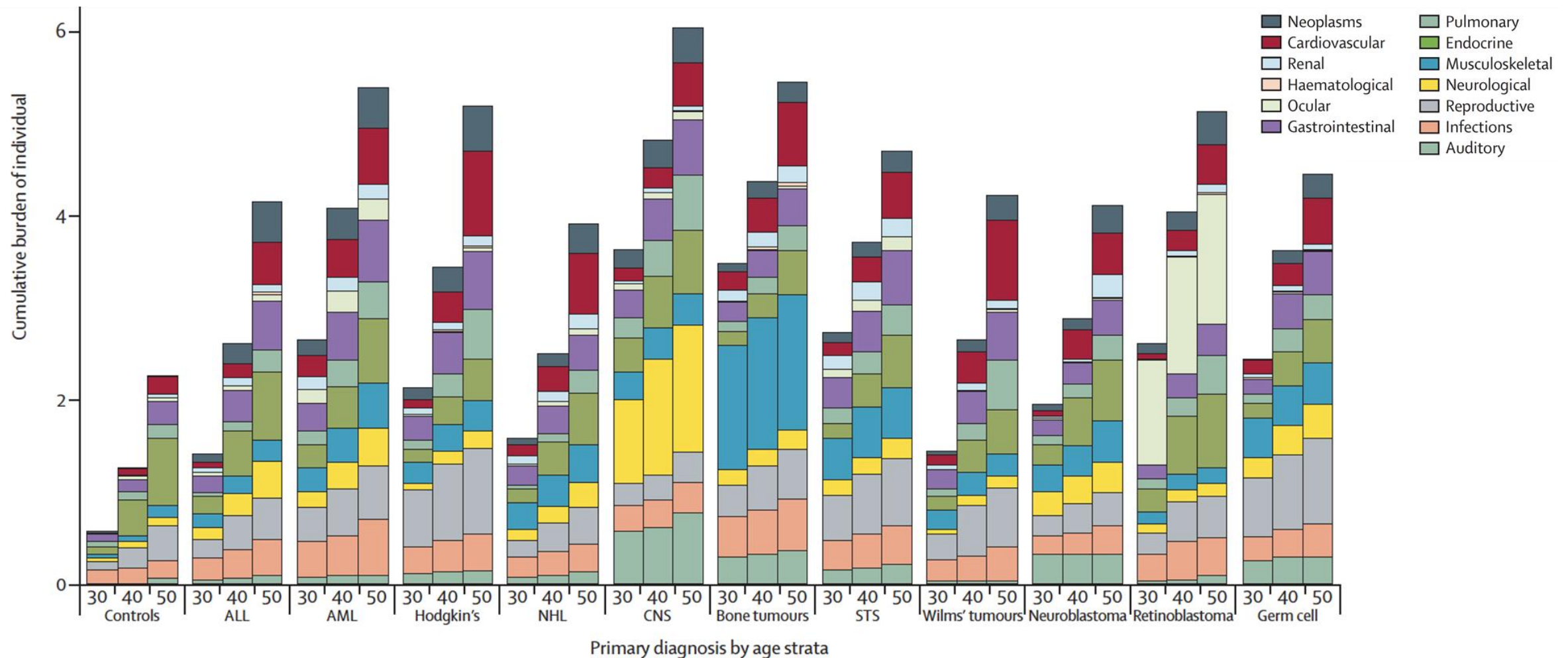
## Cumulative Burden of Grade 3-5\* Chronic Health Conditions





# Long-term Survivors of Childhood Cancer

## Grade 3-5 Cumulative Burden By Organ System



# Record Linkage

- National Death Index
- Virtual Pooled Cancer Registry
- Administrative (Medicare, Medicaid)
- Others (Organ transplant, Assisted Reproduction)

# Mobil Health (mHealth) Approaches

10:07 [status bar icons] 78%

**SAM**

0%

Welcome on Board

Let's get started by learning more about symptoms you may have had. This study is about checking your symptoms on a regular basis, which will help us design a better way to collect symptom data and find ways to help improve your symptoms.

Your Past Symptoms & Treatments

This section asks about how you have managed symptoms you may have experienced in the past. For each symptom, please select any treatment strategy you have used in the past 3 months.

Have you experienced ANY of these symptoms in the past 3 months? [\(Mark all that apply\)](#)

Welcome & Consent

10:19 [status bar icons] 80%

**SAM**

Check Here for Things to Do

Great job! You're caught up on your activities. We'll contact you when you have new things to do.

**Month 1 Amazon Gift Code**

Month 1 Amazon Gift Code: 1234-5678-91011

Go here to redeem: <https://www.amazon.com/gc/redeem>

**Check Your Profile**

We have your cell phone number as . If that is

Daily Assignment

10:08 [status bar icons] 78%

**SAM**

symptoms you may have experienced in the past. For each symptom, please select any treatment strategy you have used in the past 3 months.

Have you experienced ANY of these symptoms in the past 3 months? [\(Mark all that apply\)](#)

- ☐ Headache
- ☒ Body Aches/Pains
- ☐ Fatigue
- ☐ Difficulty Falling or Staying Asleep at Night
- ☒ Anxiety
- ☐ Poor Memory
- ☐ Lack of Concentration
- ☐ None

Next

Symptom Checklist

10:09 [status bar icons] 78%

**SAM**

97%

How severe was your poor coordination over the past 24 hours?

- ☐ Mild
- ☒ Moderate
- ☐ Severe

Previous

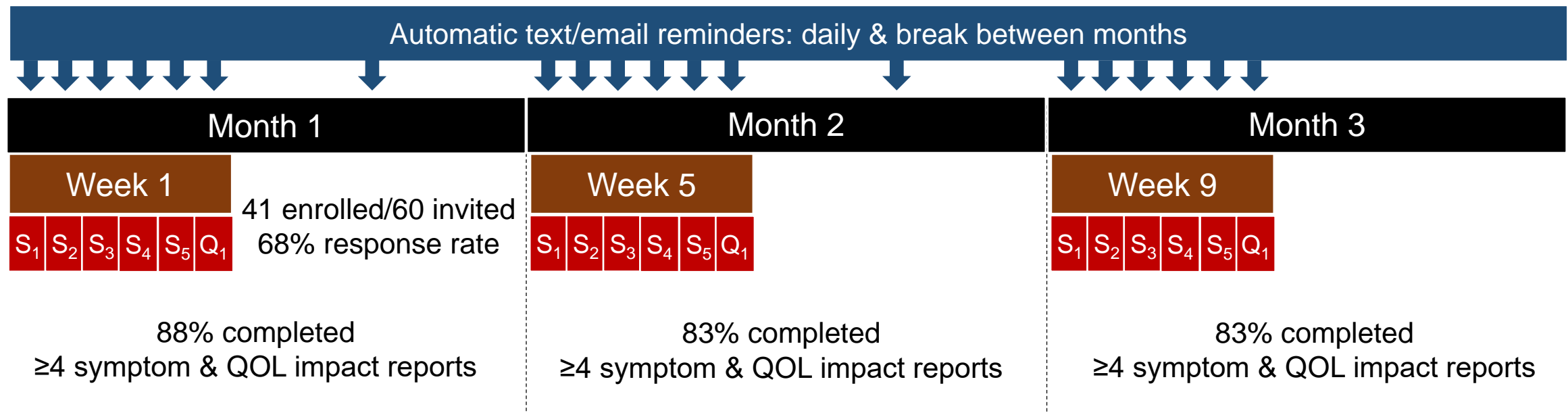
Submit

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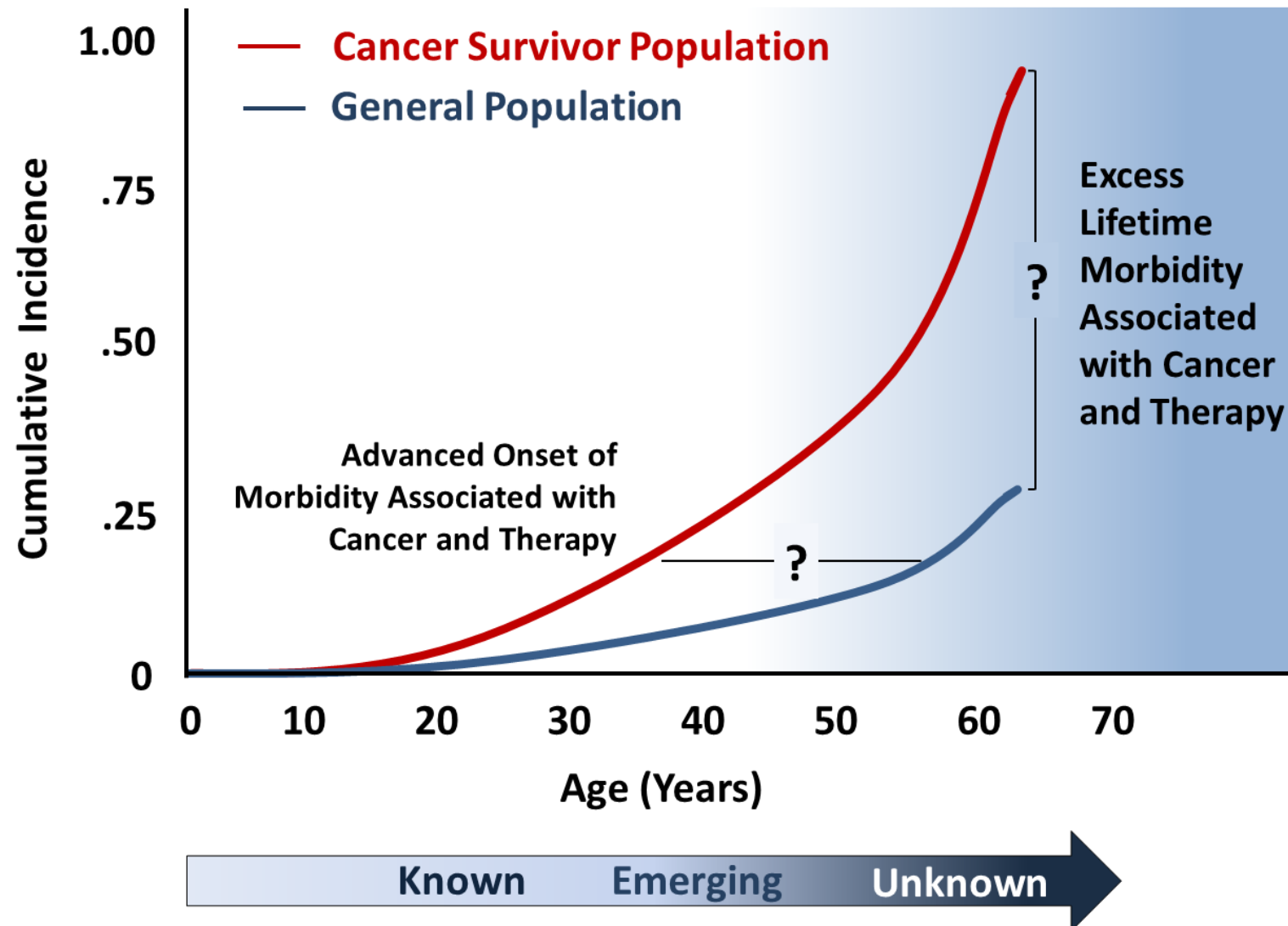
Symptom Severity

# Mobil Health (mHealth) Approaches

- CCSS SAM Pilot Design and Response Rate
  - Collect real-time PRO data via mobile phone, tablet & computer
  - Daily symptom (1 minute) & monthly QOL impact (5 minutes) report



# Gaps in Knowledge Regarding Long-term Outcomes: Theoretical Framework



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