Taking the Cue: Elements of a Well-championed Survivorship Program

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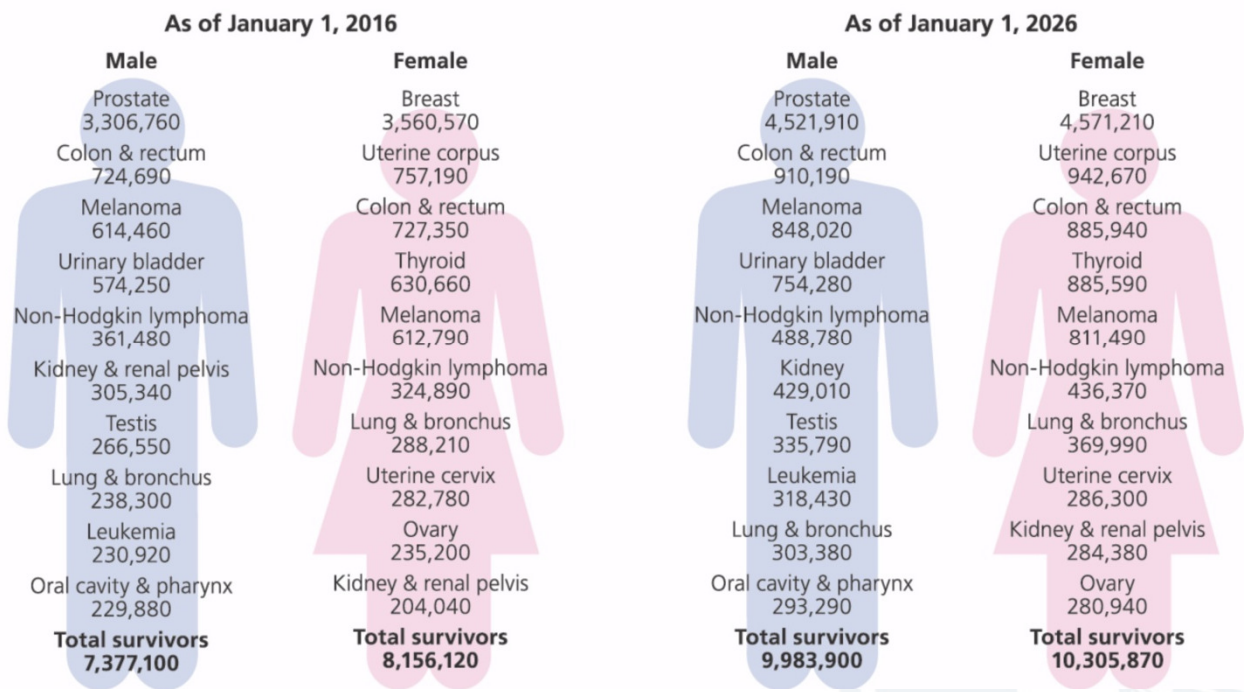
Outline

- Epidemiology of cancer survivorship
- Late effects of cancer treatment
- Models of survivorship care
- Key components of survivorship clinics
- Survivorship care plans

Cancer Survivors in the United States



>15.5 million in 2016

>20 million by 2026

Miller et al, Ca Cancer J Clin 2016

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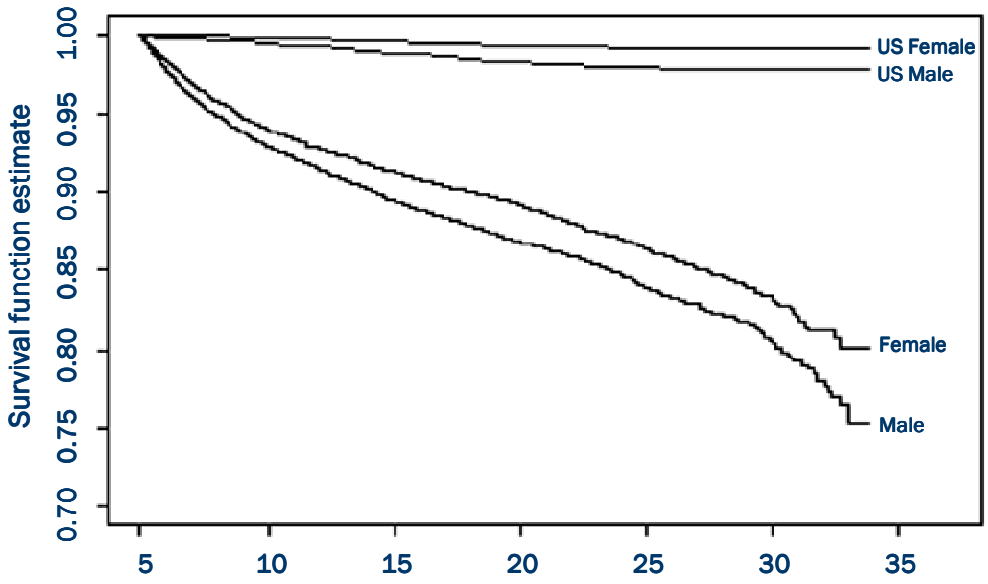
Survival Estimates



Mertens et al, *J Natl Cancer Inst* 2008

- Childhood cancer survivors experience increased mortality risk compared to the U.S. population

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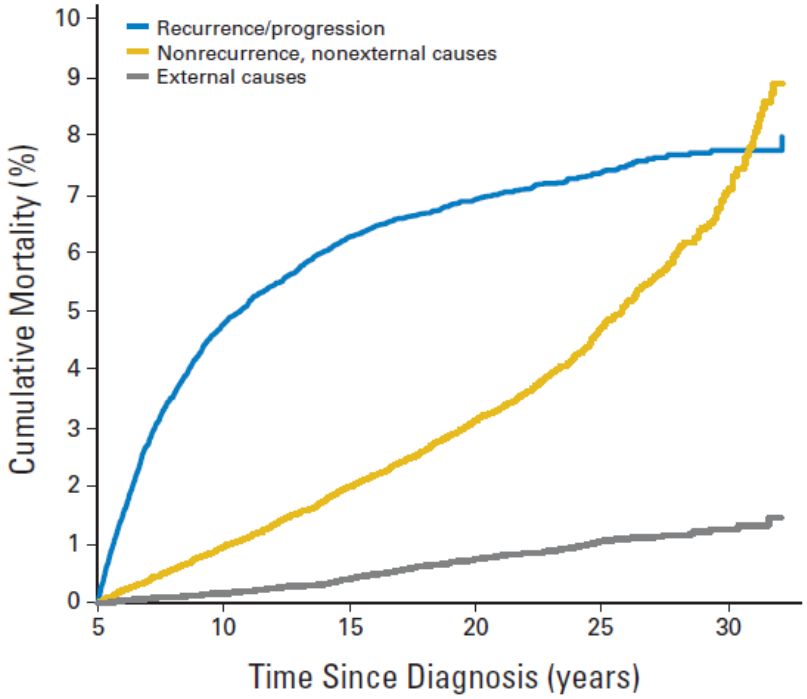

Armstrong et al, *J Clin Oncol* 2009

- Childhood cancer survivors experience increased mortality risk compared to the U.S. population
- By 30 years from diagnosis, chronic health conditions surpass recurrent or progressive disease as the leading cause of death

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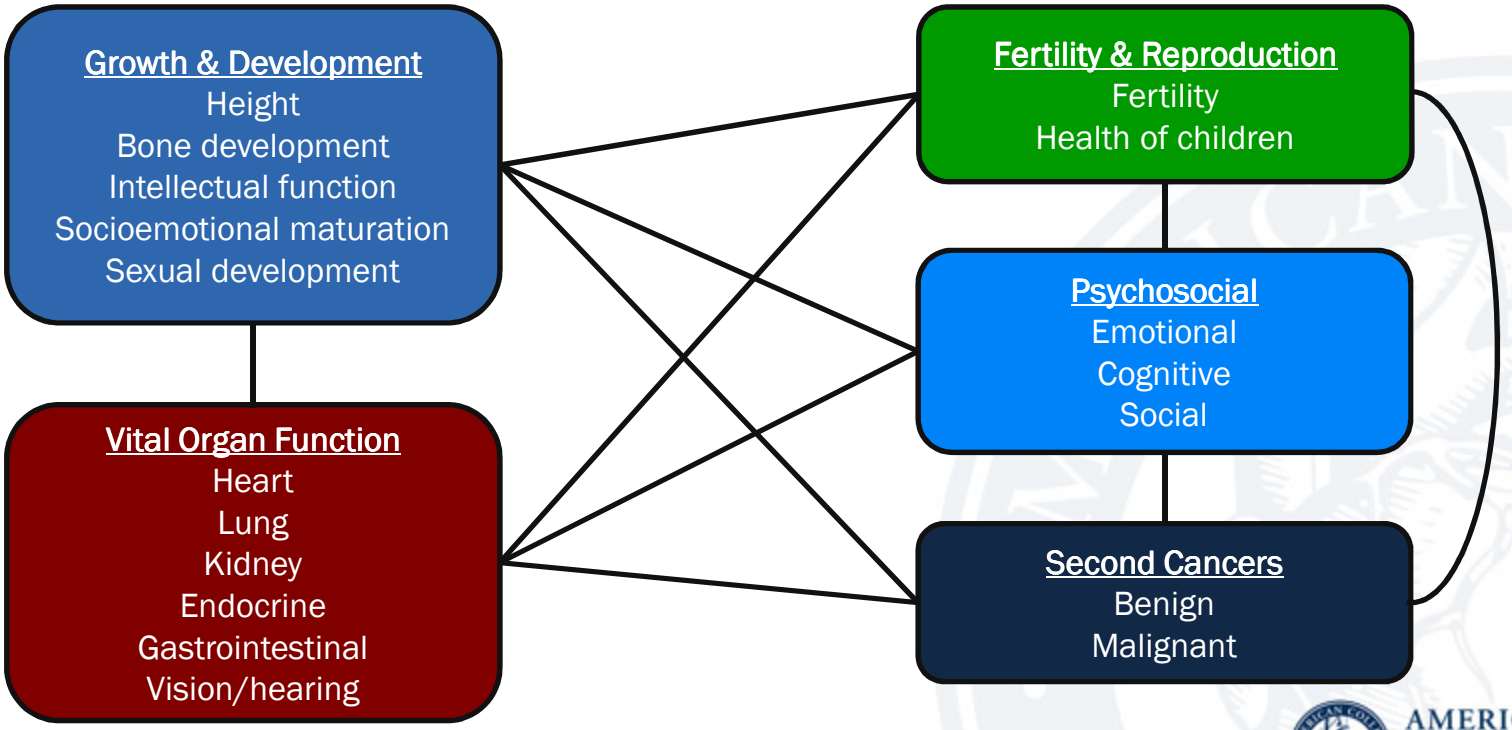
Adverse Effects of Therapy



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Chronic Conditions in Childhood Cancer Survivors

Table 3. Relative Risk of Selected Severe (Grade 3) or Life-Threatening or Disabling (Grade 4) Health Conditions among Cancer Survivors, as Compared with Siblings.

Condition	Survivors (N = 10,397)	Siblings (N = 3034)	Relative Risk (95% CI)
	percent		
Major joint replacement*	1.61	0.03	54.0 (7.6–386.3)
Congestive heart failure	1.24	0.10	15.1 (4.8–47.9)
Second malignant neoplasm†	2.38	0.33	14.8 (7.2–30.4)
Cognitive dysfunction, severe	0.65	0.10	10.5 (2.6–43.0)
Coronary artery disease	1.11	0.20	10.4 (4.1–25.9)
Cerebrovascular accident	1.56	0.20	9.3 (4.1–21.2)
Renal failure or dialysis	0.52	0.07	8.9 (2.2–36.6)
Hearing loss not corrected by aid	1.96	0.36	6.3 (3.3–11.8)
Legally blind or loss of an eye	2.92	0.69	5.8 (3.5–9.5)
Ovarian failure‡	2.79	0.99	3.5 (2.7–5.2)

Oeffinger et al, *N Engl J Med* 2006

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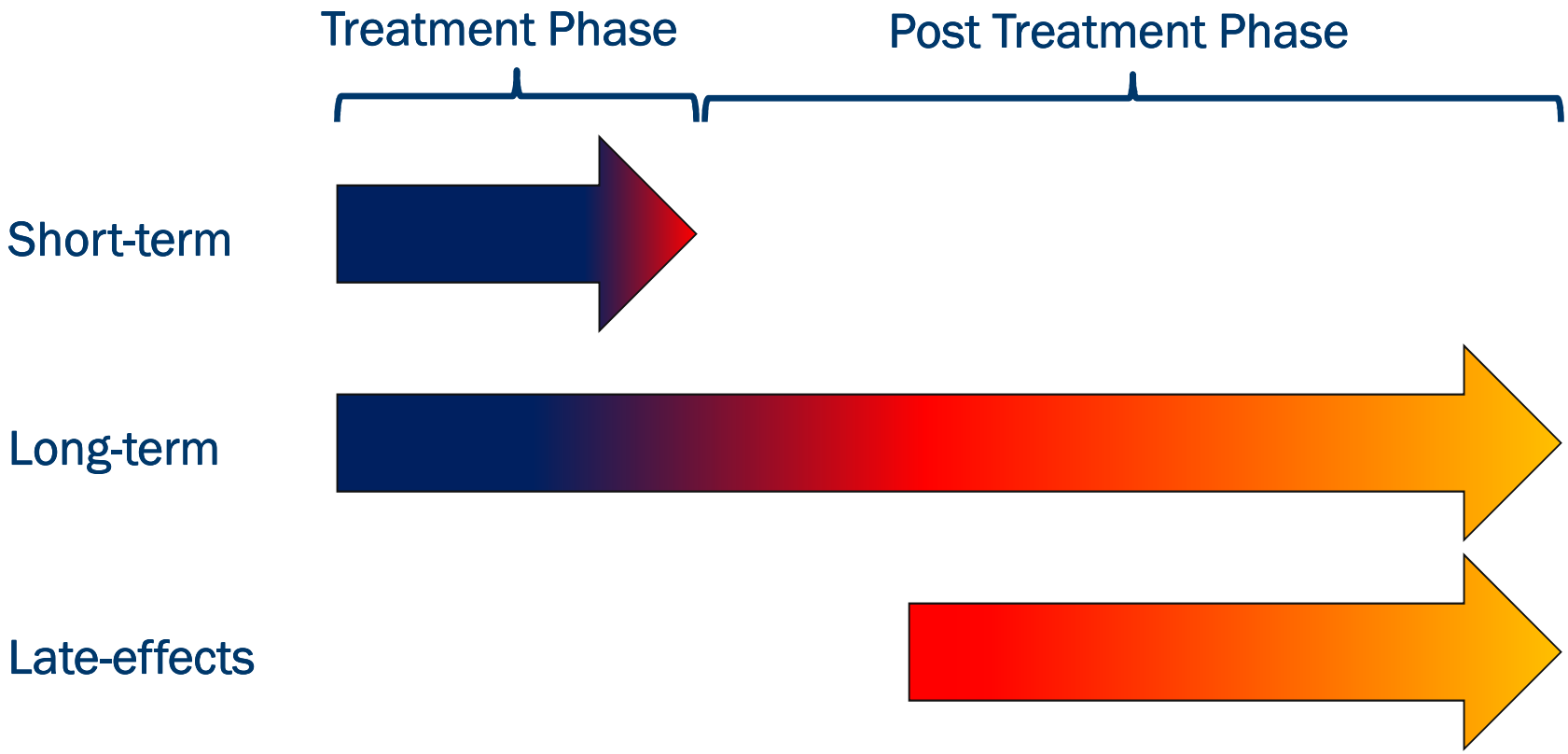
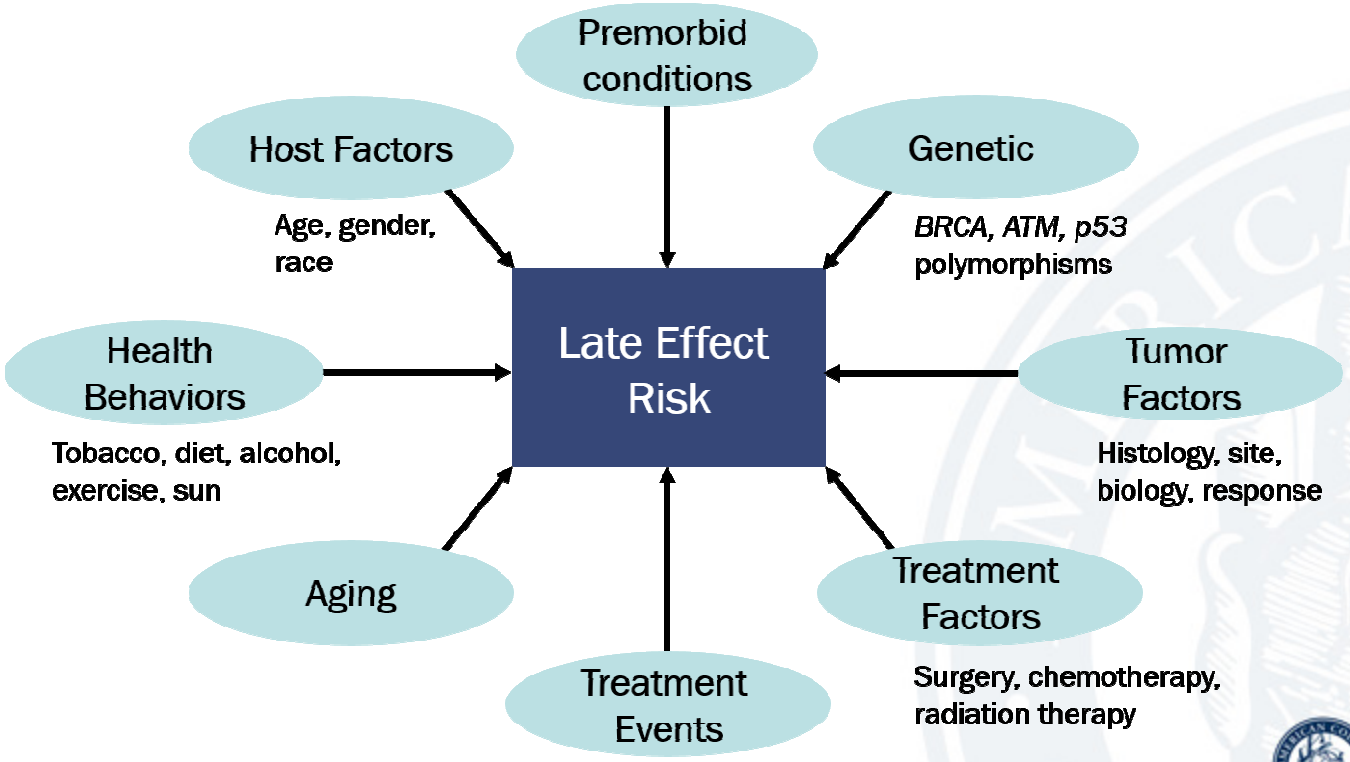
Timing of Adverse Effects of Therapy



Risk-Based Survivor Care



Hudson, *Cancer* 2005

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Essential Components of Survivorship Care

- Prevention of recurrent/new cancer and late effects
- Surveillance for cancer (progression, recurrence, or secondary)
- Assessment of medical and psychosocial late effects
- Intervention for consequences of cancer and its treatment
- Coordination between specialists and primary care providers to ensure survivor's health needs are met

Hewitt et al, IOM and NRC 2005

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Models of Care

- Multidisciplinary
  - A variety of providers present same day
  - Resource intense
- Disease specific
  - Individual clinics for each primary malignancy
- Consultative
  - Single survivorship visit (general or disease specific)

Jacobs et al, *Lancet Oncol* 2017

Models of Care

- Integrated care model
  - Survivorship-focused extension of the cancer care continuum
  - Nurse practitioners and physician assistant visits
- Risk-stratified and shared care
  - Care based upon low, moderate, and high risk for late effects
  - Coordination between oncology and primary care with eventual transition to primary care

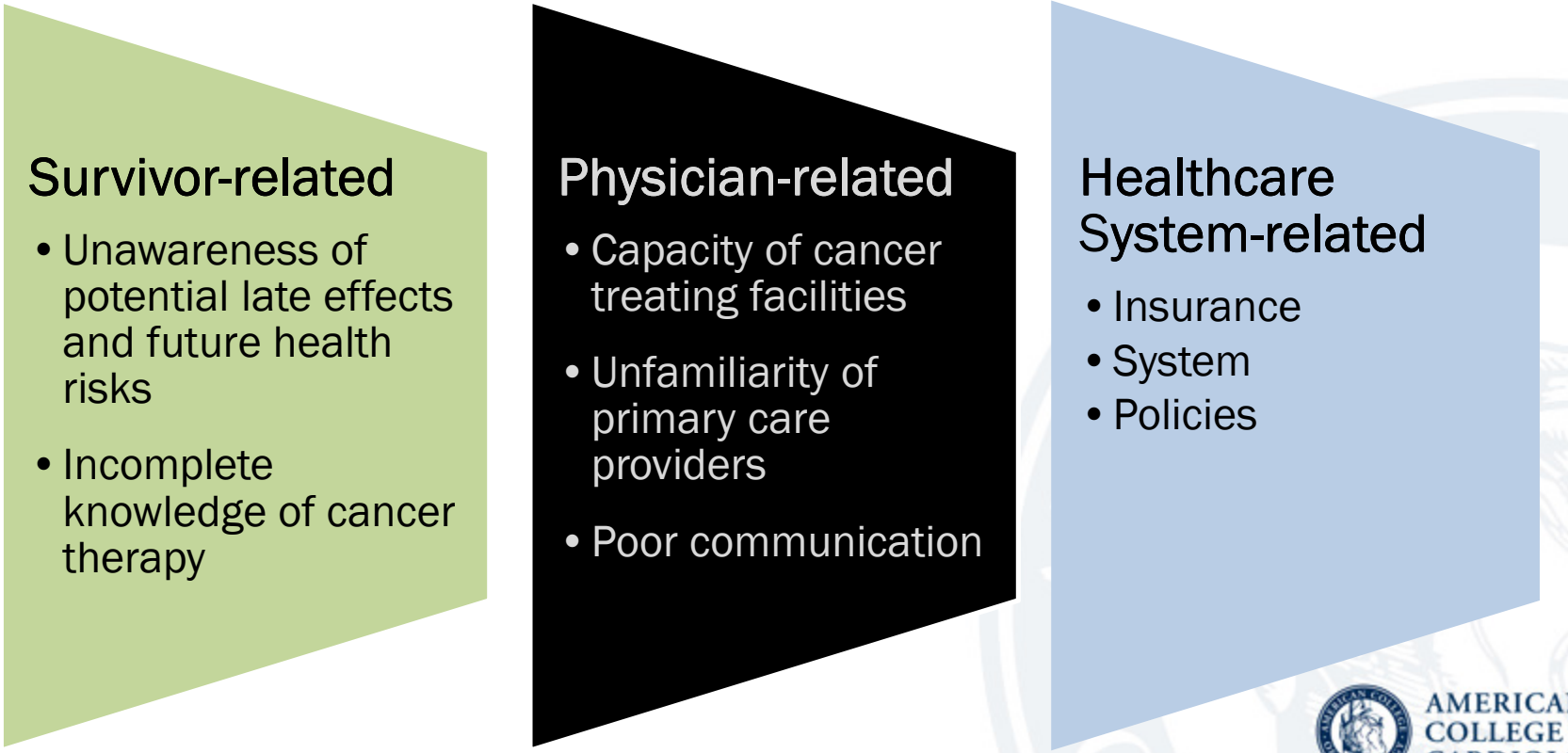
Jacobs et al, *Lancet Oncol* 2017

Logistical Considerations

- How many survivors are active in follow-up?
- Mechanisms of identification and recruitment?
- How will clinical evaluations be funded?
- Are there limitations on attained age of recruited survivors?
- Availability of clinicians with appropriate expertise?
- Follow-up of abnormalities identified by evaluation?

Jacobs et al, *Lancet Oncol* 2017

Barriers to Survivor Care



Oeffinger, *Curr Probl Cancer* 2003

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St. Jude After Completion of Therapy Clinic

Mission: To improve quality of life by facilitating access to resources that optimize physical and emotional health, social functioning and educational and vocational achievement during and after transition to community care.

Admission to ACT

- Cancer free
- 5 years from cancer diagnosis
- 2 years after completion of therapy
- 5 years from completion of salvage therapy

Alumnus Discharge

- 10 years from diagnosis of cancer
- 10 years from completion of relapse therapy
- At least 18 years old
- High school graduate

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St. Jude Social Work Assessment

- Comprehensive psychosocial assessment
- Health and wellness evaluation
- Family and interpersonal relationships
- Insurance and medical care access
- Educational progress/vocational plans
- Scholarship opportunities
- Information/referral to local resources

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IOM Guide to Development of Adult Cancer Survivor Programs

- Recommendation 1
  - Raise awareness of survivors' needs, establish survivorship as a distinct phase of cancer care, and ensure delivery of appropriate survivorship care
- Recommendation 2
  - Provide patients with a clearly explained, survivorship care plan
- Recommendation 3
  - Use systematically developed, evidence-based clinical practice guidelines, assessment tools, and screening instruments to identify and manage late effects of cancer and of its treatment

Hewitt et al, IOM and NRC 2005

IOM Guide to Development of Adult Cancer Survivor Programs

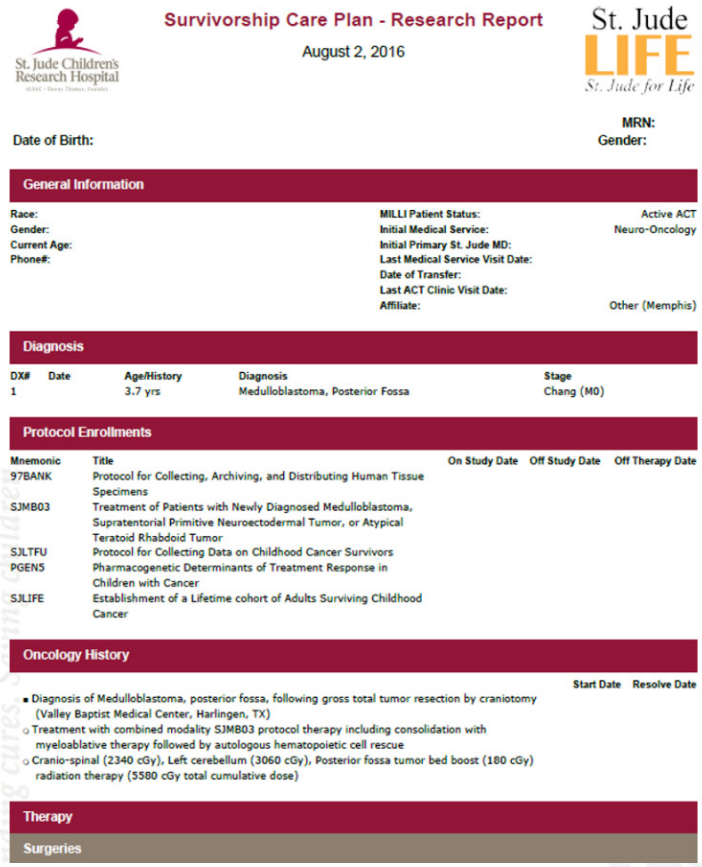
- Recommendation 8
  - Eliminate discrimination and minimize adverse effects of cancer on employment while supporting survivors with short-term and long-term work limitations
- Recommendation 9
  - Ensure that all cancer survivors have access to adequate and affordable health insurance

Hewitt et al, IOM and NRC 2005

Survivorship Care Plan

- Diagnostic information about cancer
- Treatment modalities/cumulative dose
- Clinical events and status
- Transfusion history
- Family history
- Cancer-related health risks
- Risk-based screening recommendations
- Health behaviors modifying cancer risks

Survivorship Care Plan (Example)



St. Jude Children's Research Hospital

Survivorship Care Plan - Research Report

August 2, 2016

St. Jude LIFE — St. Jude for Life

Date of Birth:

MRN:
Gender:

General Information

Race:		MILLI Patient Status:	Active ACT
Gender:		Initial Medical Service:	Neuro-Oncology
Current Age:		Initial Primary St. Jude MD:	
Phone#:		Last Medical Service Visit Date:	
		Date of Transfer:	
		Last ACT Clinic Visit Date:	
		Affiliate:	Other (Memphis)

Diagnosis

DX#	Date	Age/History	Diagnosis	Stage
1		3.7 yrs	Medulloblastoma, Posterior Fossa	Chang (M0)

Protocol Enrollments

Mnemonic	Title	On Study Date	Off Study Date	Off Therapy Date
97BANK	Protocol for Collecting, Archiving, and Distributing Human Tissue Specimens			
SJMB03	Treatment of Patients with Newly Diagnosed Medulloblastoma, Supratentorial Primitive Neuroectodermal Tumor, or Atypical Teratoid Rhabdoid Tumor			
SJLTFU	Protocol for Collecting Data on Childhood Cancer Survivors			
PGEN5	Pharmacogenetic Determinants of Treatment Response in Children with Cancer			
SJLIFE	Establishment of a Lifetime cohort of Adults Surviving Childhood Cancer			

Oncology History

	Start Date	Resolve Date
▪ Diagnosis of Medulloblastoma, posterior fossa, following gross total tumor resection by craniotomy (Valley Baptist Medical Center, Harlingen, TX)		
○ Treatment with combined modality SJMB03 protocol therapy including consolidation with myeloablative therapy followed by autologous hematopoietic cell rescue		
○ Cranio-spinal (2340 cGy), Left cerebellum (3060 cGy), Posterior fossa tumor bed boost (180 cGy) radiation therapy (5580 cGy total cumulative dose)		

Therapy

Surgeries

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Survivorship Care Plan - Research Report

August 2, 2016

MRN:

Date of Birth:

Gender:

General Information

Race:
Gender:
Current Age:
Phone#:

MILLI Patient Status: Active ACT
Initial Medical Service: Neuro-Oncology
Initial Primary St. Jude MD:
Last Medical Service Visit Date:
Date of Transfer:
Last ACT Clinic Visit Date: 1/27/2016
Affiliate: Other (Memphis)

Diagnosis

DX#	Date	Age/History	Diagnosis	Stage
1	7/12/2004	3.7 yrs	Medulloblastoma, Posterior Fossa	Chang (M0)

Suggested Evaluations Related to Your Specific Treatment for Childhood Cancer

Laboratory Tests

Screening Recommendations	Screening Frequency
ALT, AST, bilirubin, ferritin	Baseline, then as clinically indicated
BUN, creatinine, Na, K, Cl, CO2, Ca, Mg, PO4	Baseline, then as clinically indicated
Fasting blood glucose or HgbA1c, and lipid profile	Every 2 years, or as clinically indicated
Free T4, TSH	Yearly
FSH, LH, Estradiol	Baseline, at age 13, then as clinically indicated
Serum cortisol (8 am)	Yearly
Urinalysis	Yearly

Diagnostic Studies

Screening Recommendations	Screening Frequency
Abdominal x-ray	At pubertal growth spurt for patients with shunts to assure appropriate placement of distal shunt tubing in peritoneum
Audiogram or brainstem auditory evoked response (ABR, BAER)	Yearly
Bone density evaluation	Baseline, then as clinically indicated
ECHO (2D and m-mode) or MUGA	Every 2 years, or as clinically indicated
EKG for evaluation of QTc interval	Baseline, then as clinically indicated
Neuropsychological testing	Baseline, then as clinically indicated (based on age, specific treatment, and evidence of impaired educational or vocational progress)

Therapy

Radiation

Start Date	Stop Date	Radiation Type	Source Type	Site	Cumulative Site Dose (cGy)	Boost Site Dose (cGy)
		Conformal	Linear Acceleration	Flank, Left	1050	
		Conformal	Linear Acceleration	Lung, Bilateral	1260	
		Conformal	Linear Acceleration	Lung, Right	2500	

Chemotherapy - Cumulative Dosage Summarization

Drug Name	Drug Route	Dose /m2
Carboplatin	Intravenous	4570
Cyclophosphamide	Intravenous	12993
Dactinomycin	Intravenous	5
Doxorubicin - Adriamycin	Intravenous	490
Etoposide	Intravenous	3852
Ifosfamide	Intravenous	63000
Melphalan	Intravenous	177
Topotecan	Intravenous	35
Vincristine	Intravenous	17

Major Medical Events

	Start Date	Resolve Date	Evaluation Date
Cardiovascular (arrhythmia/general)			
■ Cardiac dysfunction associated with congenital heart disease, requiring surgical intervention (sub-aortic membrance and aortic coarctation)			
■ Congenital cardiovascular disease, (bicuspid aortic valve)			
■ Pulmonary hypertension, requiring medical intervention, (PAP 38 mmHg, TR gradient 40.26 mmHg or TR Vmax 3.17 m/s)			
■ Conduction abnormality, (intraventicular conduction delay, QRS 144 ms, First degree heart block, PR 198 ms)			
■ Cardiomyopathy requiring surgical intervention, (bilateral ventricular assist devices, heart transplant)			
■ Congestive heart failure requiring medical/surgical intervention, (Lasix, Carvedilol, and Lisinopril)			
■ Ventricular diastolic dysfunction, left			
■ Dyslipidemia requiring medical intervention, counseled regarding need for dietary fat restriction and for regular exercise, (Pravastatin)			
■ Heart block, recommend follow-up with local physician, (right bundle branch block, QRSD 134 ms)			
■ Borderline left ventricular systolic function, (EF 54%)			

Key Survivorship Clinic Components

- Clinicians (including subspecialists) experienced in long-term follow-up care
- Comprehensive survivorship care plan
- Resources to address psychosocial concerns
- Effective communication between survivorship clinic, primary care, and patient

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