

A Research Program for Cancer Survivor Care and Control

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Survivorship Issues and Priorities

- The majority of cancer patients in Western countries now survive their cancer.
- Quality of life and late effects are emerging issues for survivors. There is a need to:
 - Document effects and assess long term care needs;
 - Develop evidence-based strategies and translate to policy, programs and care;
 - Evaluate interventions; monitor change over time; and educate stakeholders

Late Effects

- a term used to describe the broad range of *post-therapeutic disabilities, mostly treatment-related*, that are seen in survivors of cancer
- Types of late effects:
 - physical, psychosocial, cognitive conditions;
 - educational difficulties;
 - vocational difficulties
 - marriage, social adjustment

Childhood, Adolescent, and Young Adult Cancer Survivorship Research Program (CAYACS)

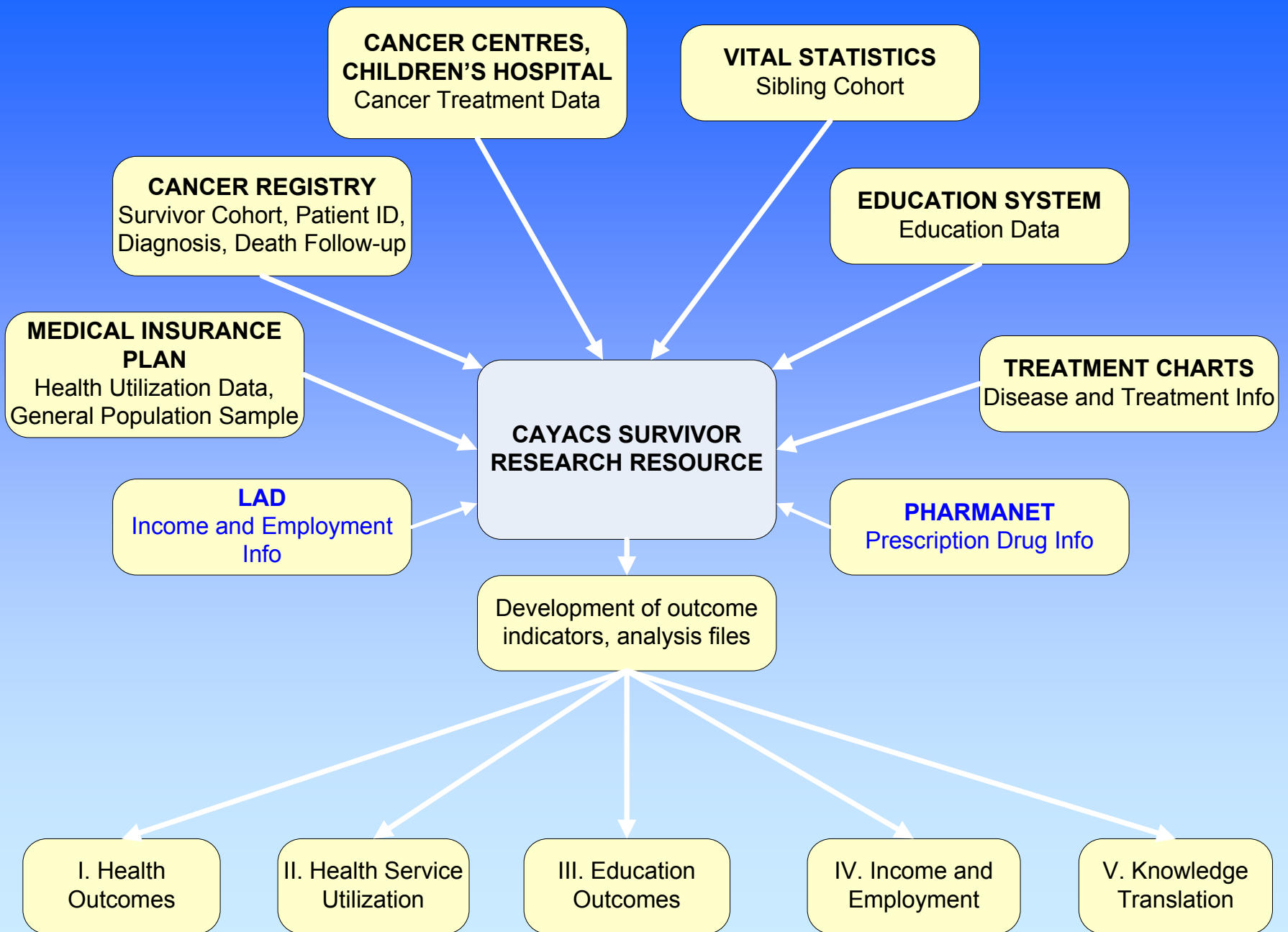
For all five year survivors of a cancer or tumour diagnosed under age 25 years in British Columbia, Canada, from 1970, using population registers and record linkage, the CAYACS Program aims to:

- 1) Develop an ongoing survivor research resource;
- 2) Examine late effects in multiple domains;
- 3) Examine long term care in relation to these effects;
- 4) Develop tools for translation of evidence to policy and practice;
- 5) Expand capacity for survivorship research

with the goal of maximizing survivor quality of life.

Core Hypotheses

- What is the distribution of (survivor or health services) outcome in survivor population?
- What are the factors (sociodemographic, clinical, system-related, temporal) affecting the outcome in the survivor population?
- What is relative risk of the outcome compared to a similar population without cancer?

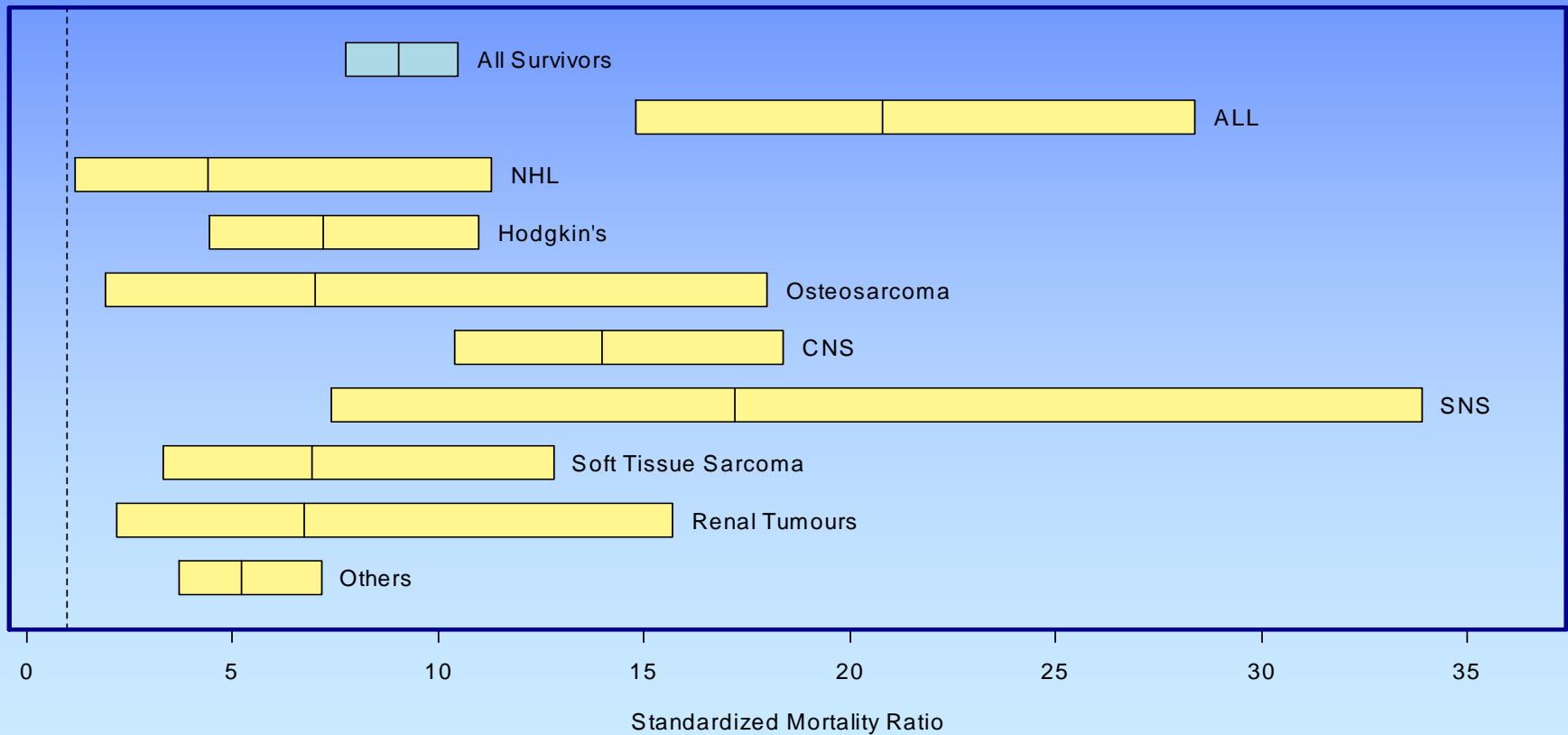


Primary Diagnosis of CAYACS Cohort Diagnosed Age 0-19

	Survivors (N=2345)
ICCC groups	
Leukemia	491
Lymphoma	388
CNS	439
Sympathetic nervous system	85
Retinoblastoma	57
Renal tumours	125
Hepatic tumours	10
Malignant bone tumours	111
Soft tissue sarcomas	145
Germ cell cancers	163
Carcinomas and others	331

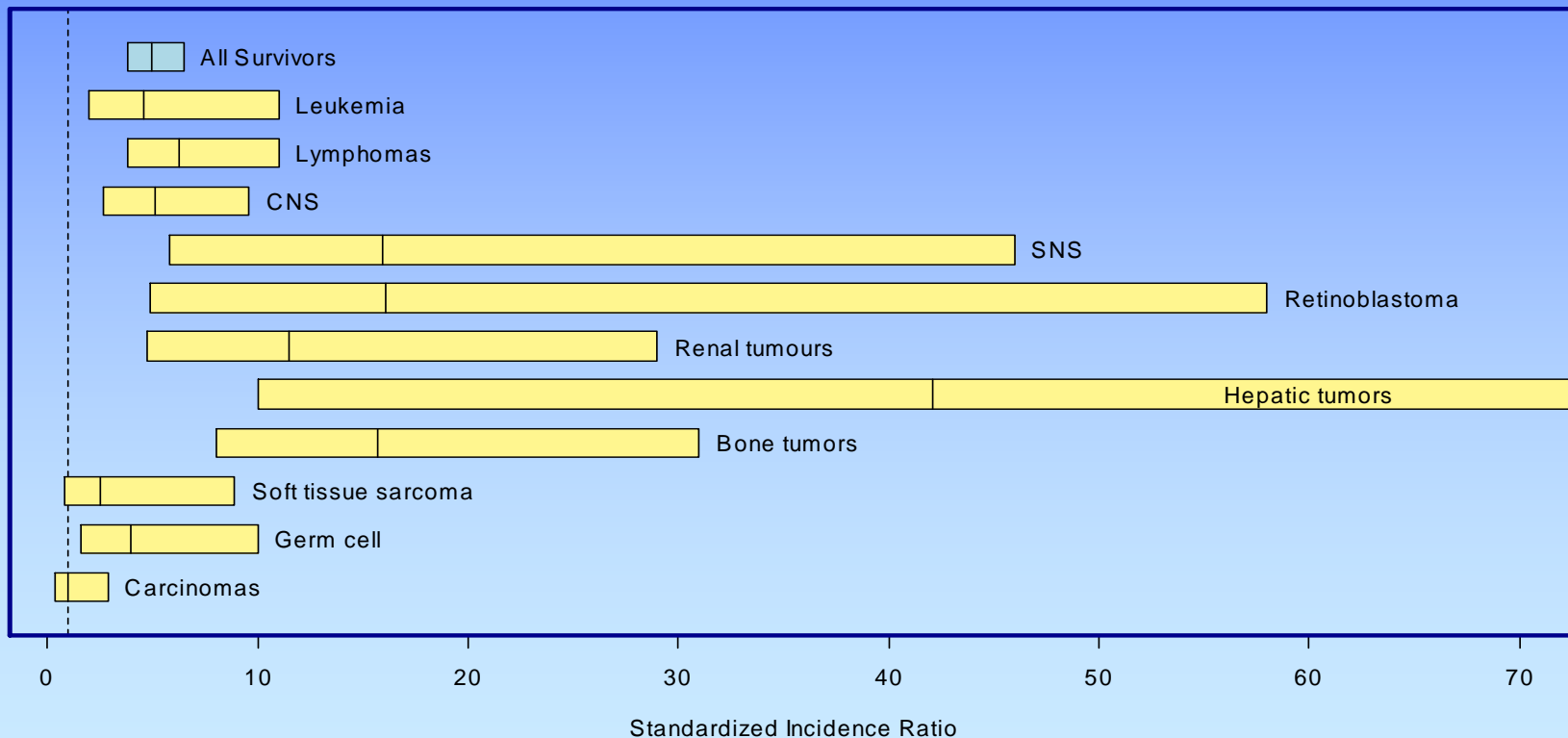
Late Mortality

Relative Mortality - Survivors vs BC Population

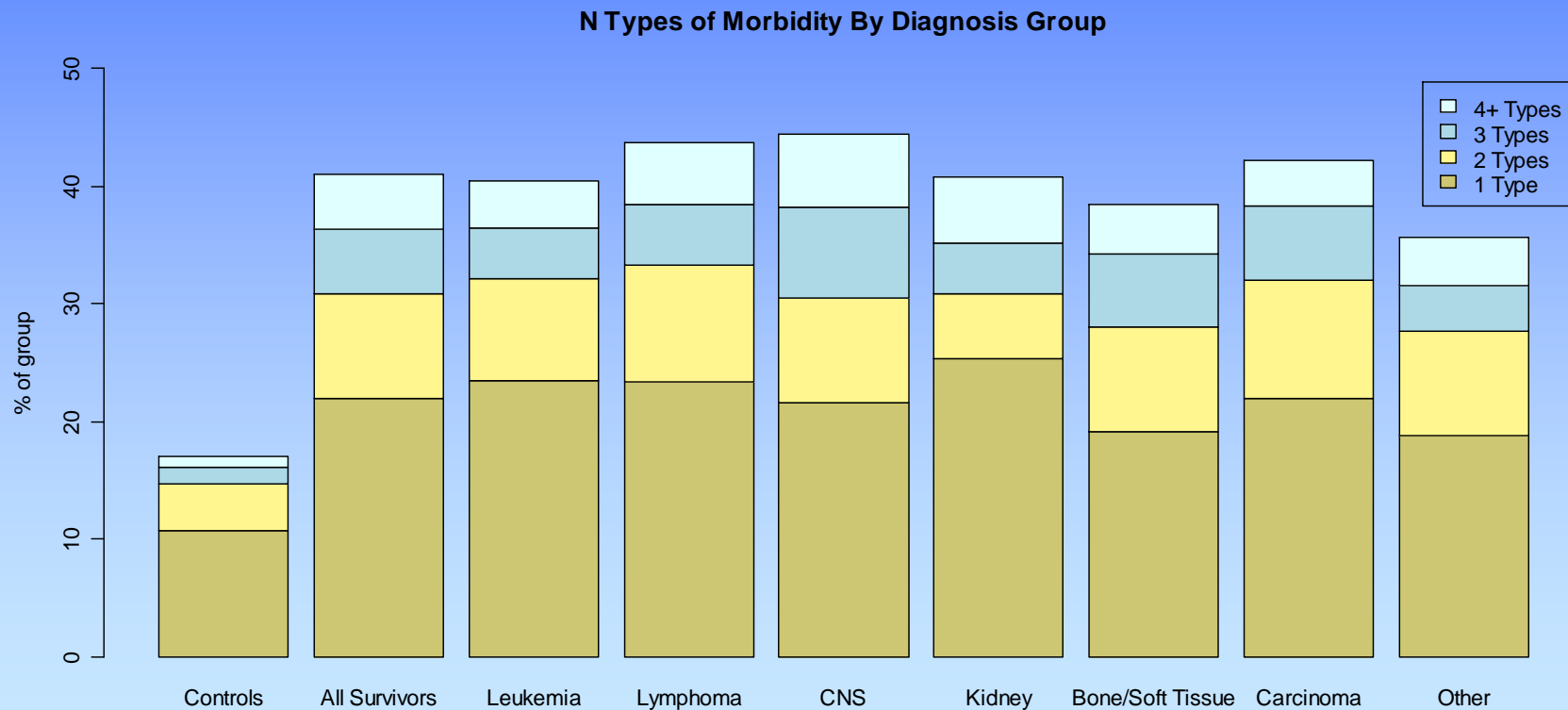


Second Cancers

Relative Cancer Incidence - Survivors vs BC Population

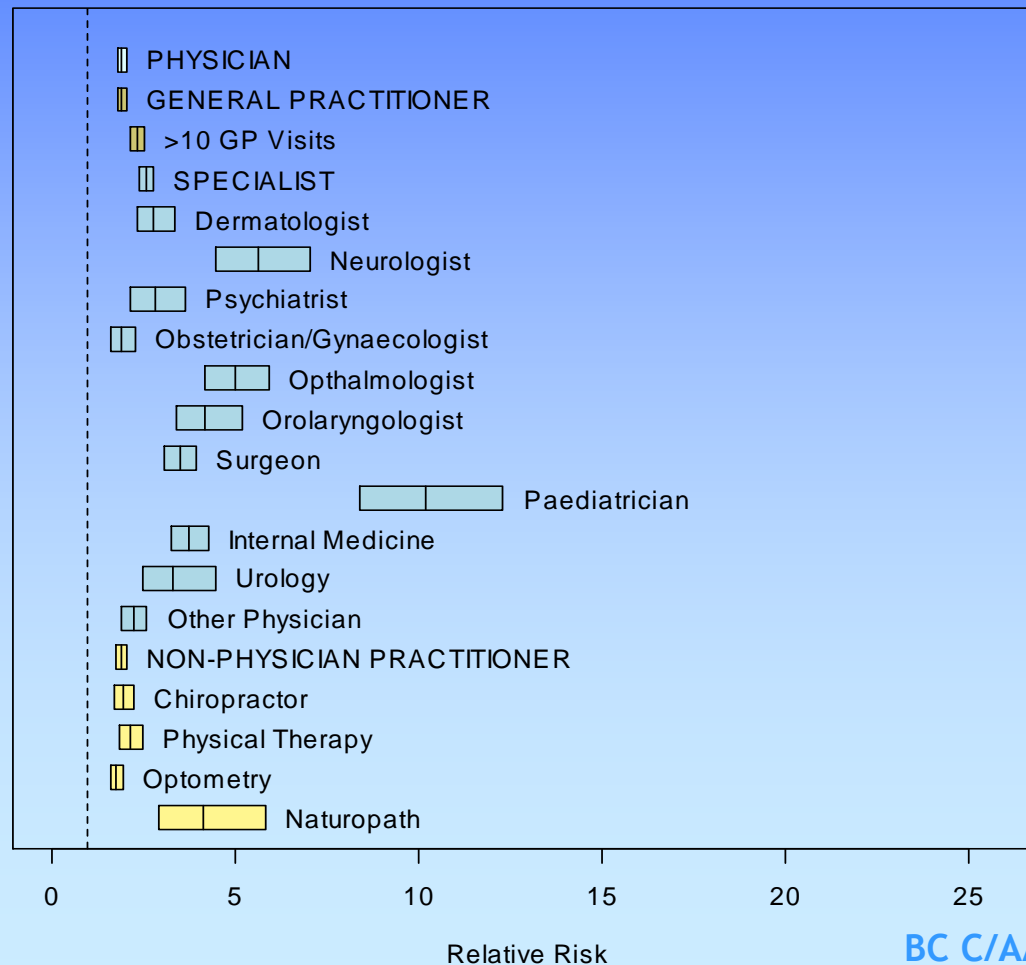


Hospital-related Late Morbidity



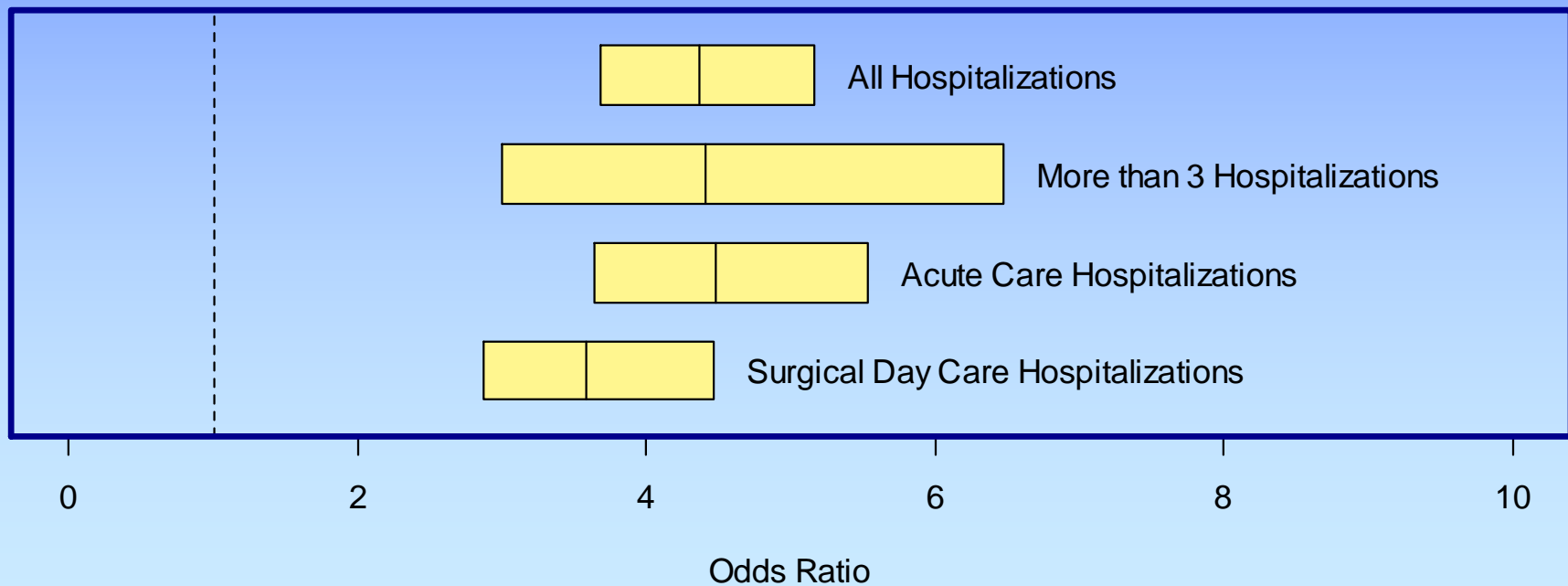
Physician Visits 1998-2000

Relative Risk of Physician Visit - Survivors vs Comparison Group



Hospitalizations 1998-2000

Risk of Hospital Admission - All Survivors



Continuity of Care

In a longitudinal analysis of continuity of primary care, survivors were found to experience a drop in continuity of care (COC) as they aged and transitioned into adult care from paediatric follow-up.

The drop in continuity was most dramatic in survivors diagnosed in pre- and early adolescence (age 10-14).

Educational Achievement

Outcome	Controls (n=8386)		CNS Tumours (n=166)			Leukemias (n=270)			Remaining Survivors (n=346)		
	No.	%	No.	%	OR _{adj} ^a	No.	%	OR _{adj} ^a	No.	%	OR _{adj} ^a
FSA meets expectations											
Numeracy Gr 4	836	68.2	5	29.4	0.2*	26	53.1	0.5*	41	59.4	0.7
Numeracy Gr 7	1255	66.1	13	38.2	0.3*	41	54.7	0.6*	53	58.9	0.7
Numeracy Gr 10	1024	52.6	9	25.0	0.3*	30	43.5	0.7	50	58.8	1.3
Reading Gr 4	799	65.2	5	29.4	0.2*	27	55.1	0.6	45	65.2	1.1
Reading Gr 7	1233	64.9	13	38.2	0.3*	40	53.3	0.6*	54	60.0	0.8
Reading Gr 10	1029	52.8	11	30.6	0.4*	32	46.4	0.7	42	49.4	0.9
Writing Gr 4	1006	82.1	9	52.9	0.2*	40	81.6	1.0	53	76.8	0.8
Writing Gr 7	1419	74.7	18	52.9	0.4*	52	69.3	0.8	65	72.2	0.9
Writing Gr 10	1212	62.2	16	44.4	0.4*	47	68.1	1.3	54	63.5	1.1

*significant at p=0.05

Knowledge Translation

- **Decision-makers:** evidence-based policy change, system change; planning and monitoring of cost-effective care
- **Program managers:** development of follow-up care models; monitoring of compliance and effectiveness of surveillance, interventions
- **Health practitioners, education, welfare providers:** development of care guidelines
- **Clinicians:** assessment of cost-benefits of treatments; outcome in clinical trials
- **Survivors:** awareness for self-management of health

Program Strengths and Synergies

Strengths:

- Population-based; longitudinal
- Multiple outcome domains (health services, education, future - income, employment)
- Availability of a comparison group for calc of relative risks
- Methodologic strengths of use of registries, admin datasets and record linkage methodology (cost-effective and timely; high level of completeness and accuracy of data, cohort recruitment and retention)

Synergies:

- Same at-risk population, patient group, exposure (treatment) data, outcomes, analytic methods
- Sequential inquiry from effects to resource use to effectiveness
- Use of results from some studies for other studies
- Use of results and Program infrastructure for knowledge translation

Future

- Update cohorts, follow-up
- Additional outcomes and domains
- Parallel studies using different methodologies
- Evaluate interventions
- Monitor change over time
- Collaborate to extend research value
- Use methodology to evaluate other at-risk groups of cancer survivors

CAYACS Research Program

Currently funded by Canadian Cancer Society (CCS) Research Institute and CCS BC and Yukon Division (2008-2013)

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