



**BC Cancer Agency**

CARE + RESEARCH

*An agency of the Provincial Health Services Authority*

# Use of linked health administrative data to support policy change for child cancer survivor care

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- No conflicts of interest

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## Data Sources

BC Cancer Registry  
BC Cancer Agency  
BC College of Pharmacists  
Ministry of Health  
Population Data BC  
Ministries of Education  
Statistics Canada

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# Cancer Survivor Health/Healthcare Priorities

- Advances in cancer diagnosis, treatment and supportive care, have increased survival rates, *most dramatically among children.*
- Cancer survivors are at increased risk for long-term morbidity and premature mortality, related directly to the cancer itself, to ... comorbidities, and to exposure to therapy (ASCO 2013), *most notably among childhood cancer survivors.*
- There is a lack of guidance for care providers on the clinical management of cancer survivors, due to:
  - Lack of long-term follow-up and research to provide *high-quality* comprehensive, long-term risk estimates of medical issues and their predictors, to inform guidelines for follow-up care, AND
  - Lack of models of comprehensive, coordinated care that meet those needs.

# Childhood Cancer Survivor Issues

- Small numbers, but survivors constitute second-largest years of life saved after breast cancer
- Heterogeneous group; dramatic increase in survival; multimodal toxic treatments; therapy delivered while body is still developing -> variable risks of multiple late-occurring and chronic health problems.
- Studies to date have limitations wrt representativeness of population ; limitations of case identification, recruitment, retention; lack of appropriate comparison group, potential bias from self-report survey outcome data; lack of information on healthcare demand that could inform models of quality care

# Situational Assessment and Strategy Development

## **Current State**

- Follow-up of adult-age child cancer survivors occurs mainly in the primary care setting, with little coordination and support

## **Strategy**

- Spring 2015: Provincial government requested recommendations for strategies and models of care to meet the needs of this patient population
- Multi-stakeholder Provincial Oncology Adult Childhood Cancer Survivors Task Group (POACCS) was formed to develop recommendations and a business case

## **Activities**

- Define and describe: the population of interest, measurable outcomes
- Review of the BC research, best practice guidelines, models of care
- Environmental scan of current strategies to support this patient population
- Identify gaps in care
- Identify and advise on potential strategies to improve outcomes for defined population
- Identify who is responsible for next steps

# Comments from Stakeholders

- *“I don’t really have any knowledge of my medical history... they didn’t tell me. They could have just given me a record of it, like a paper record, and given me a copy of the file of everything that happened to me, because maybe then I could read it when I was older” (Cancer Survivor)*
- *“I think the impact has actually been stronger as an adult than as a teen... I find it harder to process things. Like, it just takes me a little bit longer; I’m a little bit slower than the average student” (Cancer Survivor)*
- *“And so with cancer survivorship for children, you kind of run into the same challenge. The difference is it’s even more complicated, because they’re not only moving from being a child into an adult—which is a whole different kettle of fish in terms of how you treat someone—but they also have some very specific chronic conditions related to the treatment. And not every GP, or even specialist, knows how to deal with that” (Health Authority Executive)*
- *“So whether it’s a kid who has had cancer and who is now cured of the cancer but has some ongoing, lingering chronic issues, or whether it’s a severely disabled child that can be seen at Children’s until 18 or 19 and then all of the sudden they’re out adrift in a health authority that may have hardly any paediatricians, let alone any kinds of specialists to be able to deal with their issues... we’ve got a challenge” (Health Authority Executive)*

# CAYACS

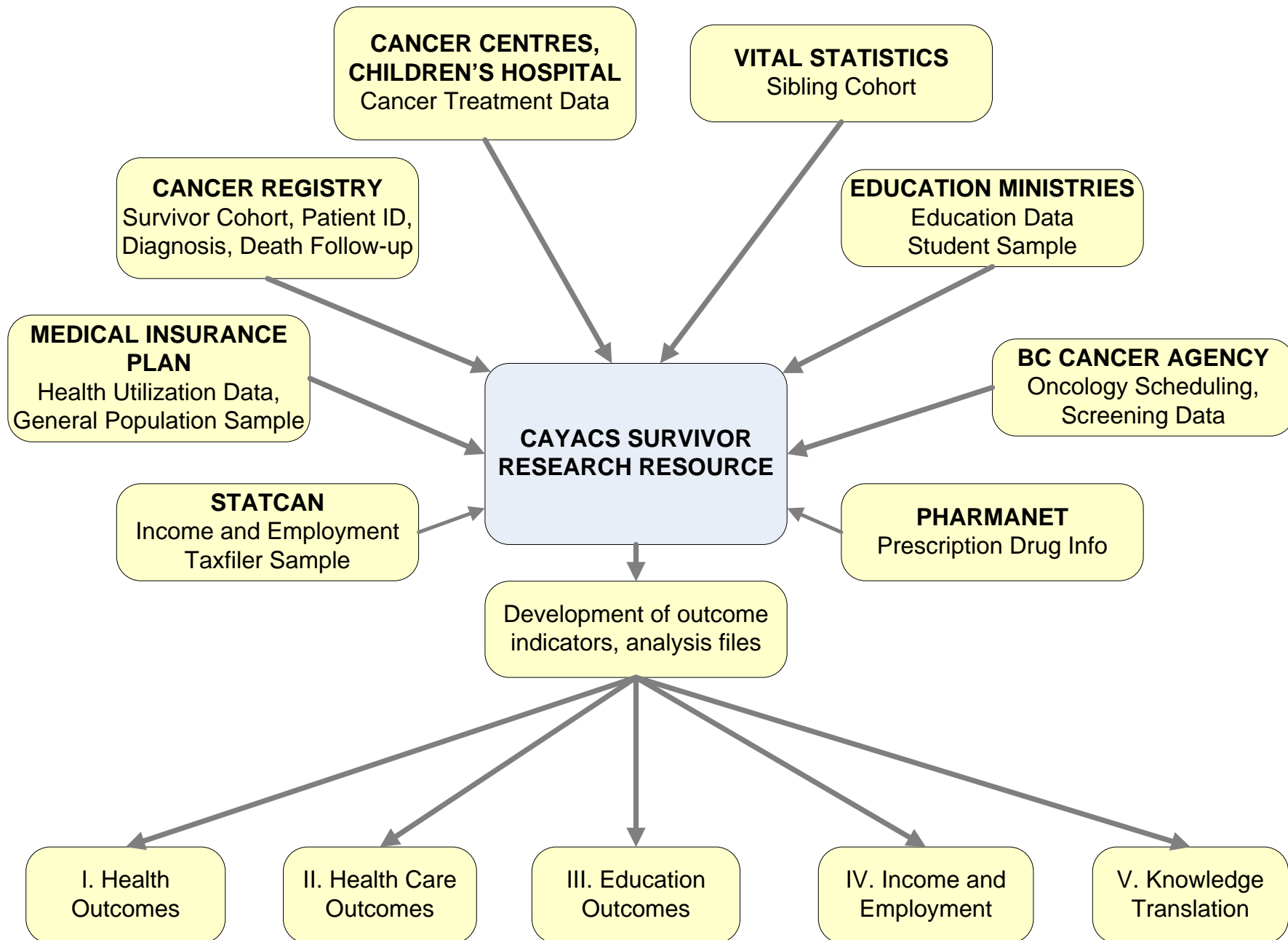
Childhood, Adolescent, and Young Adult Cancer Survivor Program

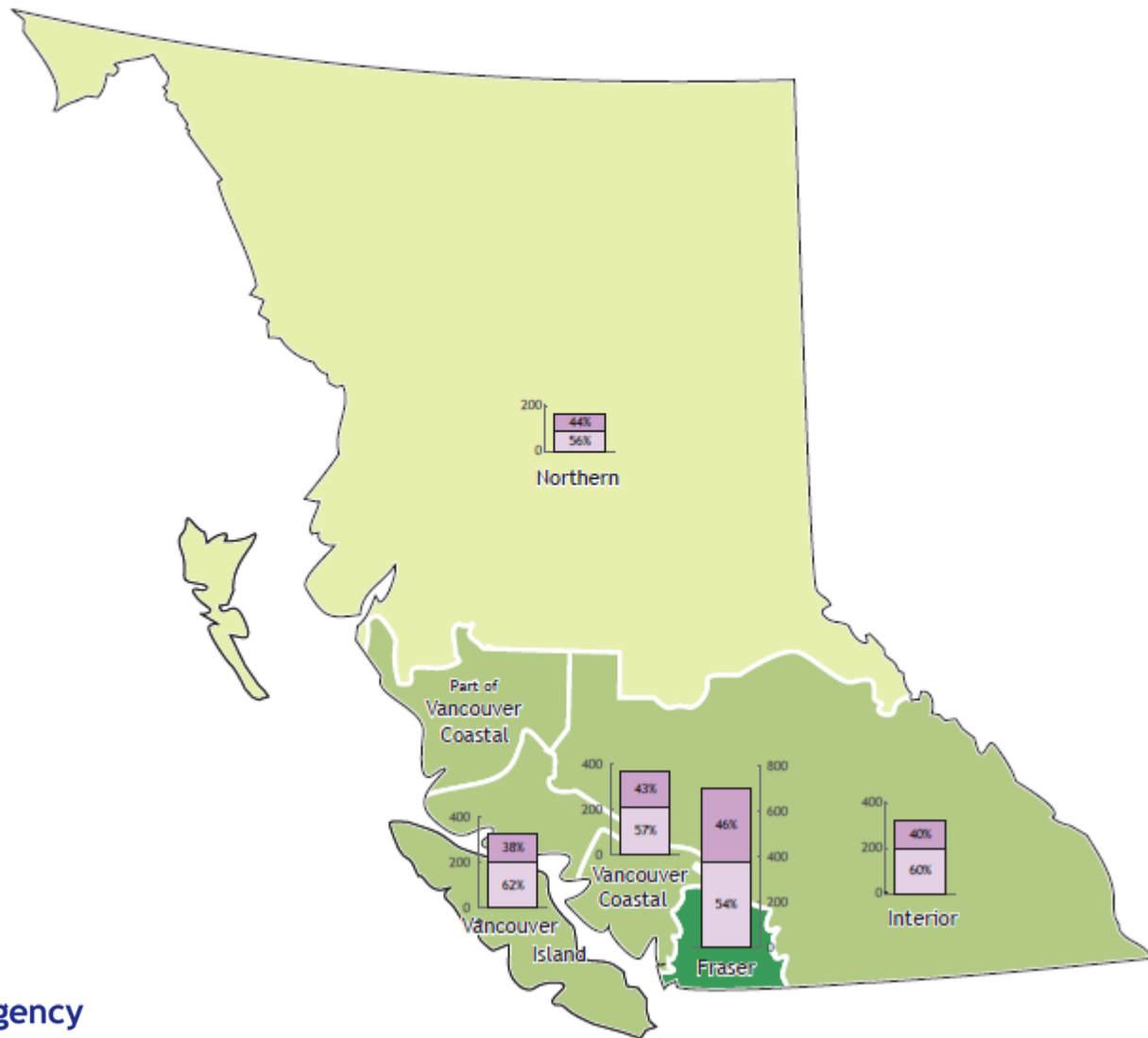
For all BC residents diagnosed with a cancer under age 25 years from 1970, surviving five years or more from diagnosis, using population registers and linked databases, the Program aims to:

- Develop a resource for childhood, adolescent, and young adult cancer survivorship research
- Determine risks of late-occurring and long term medical problems
- Examine patterns and quality of (health) care in relation to these risks
- Generate and transfer knowledge for change in (health) care policy and practice

**Goal: to inform care for health outcomes and quality of life**







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# Health Outcomes

Childhood and adolescent cancer survivors had:

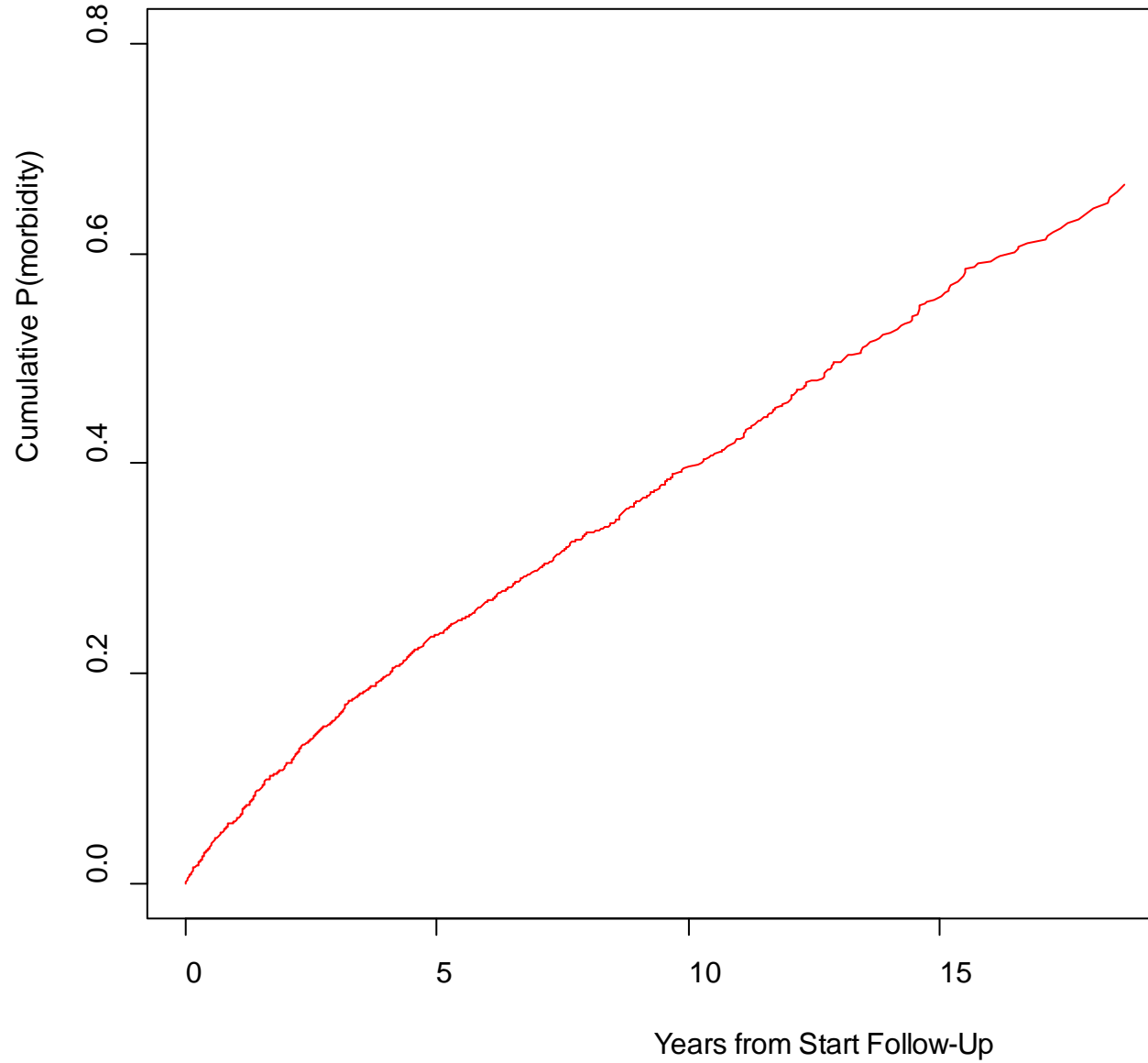
- 8% mortality from 5-25 years post-diagnosis
- Nine times excess risk of **late death**
- Five times excess risk of a **second cancer**

Among these survivors:

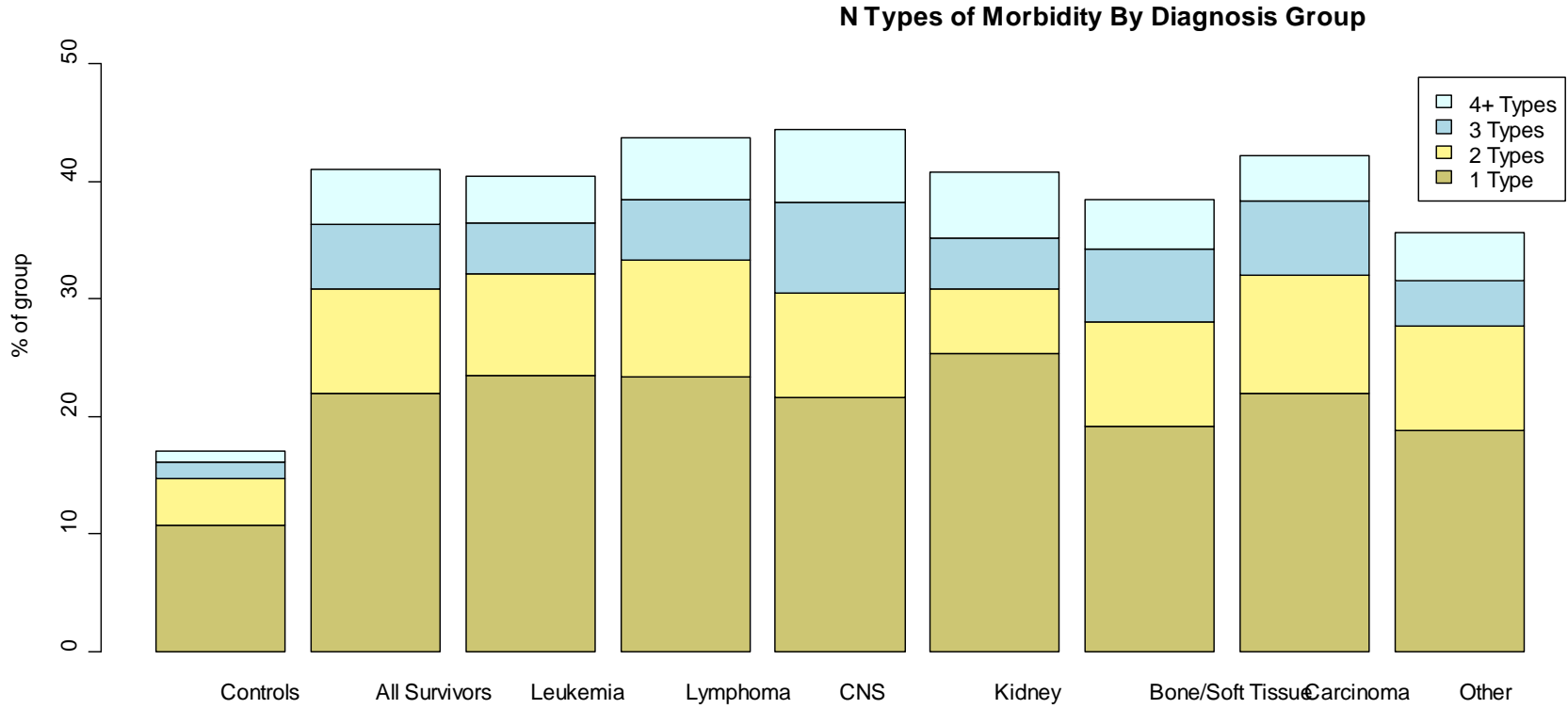
- 40% had conditions leading to hospitalization
- Nearly twice the excess risk of hospital-related morbidity (RR 1.8, 95% CI 1.7-1.9)
- Excess risk of all types of conditions assessed

***Diagnosis and treatment affected risk***

# Cumulative Probability of Hospital-Childhood Survivors Dx 0-19



# Hospital-related Types of Late Morbidity by Index Diagnosis



# Healthcare Utilization

In a three-year period:

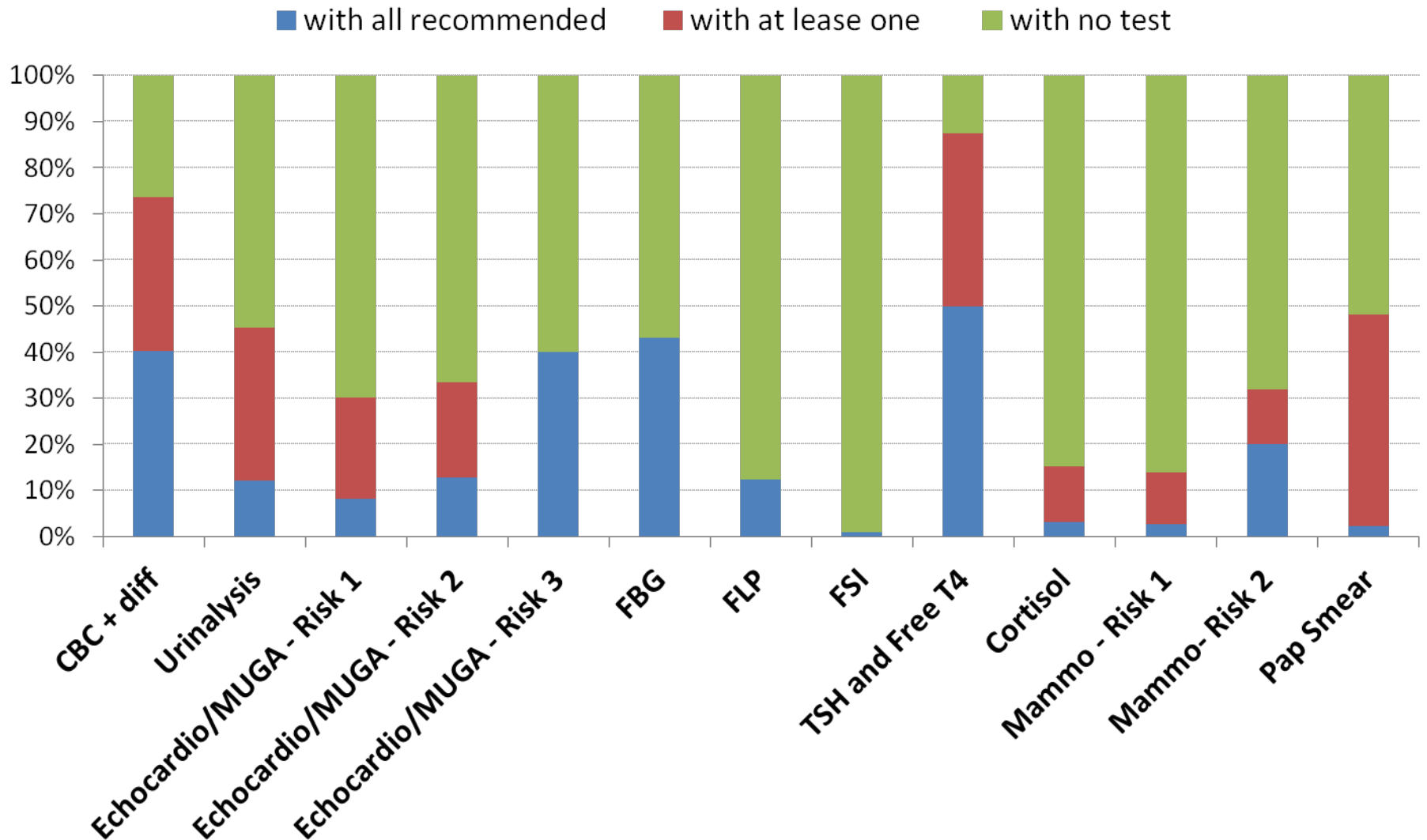
- Over **90%** of survivors saw a family physician/services; **49%** more outpatient physician visits/services than general population; **51%** increased frequency of specialist visits (particularly pediatrics, neurology, internal medicine and ophthalmology)
- **40%** of survivors had at least one hospital admission; twice as often as general population; **40%** more hospitalizations per survivor; **70%** longer stays than the general population
- About **90%** of survivors received at least one prescription; overall, survivors were more likely to use more prescription drugs and to have higher numbers of prescriptions than the general population

***Diagnosis and treatment affected utilization; region of residence, urban/rural residence, and socioeconomic status did NOT affect utilization in general***

# What is Quality Care?

- Appropriate care (evidence-based care)
- Accessible care (equal utilization by underserved groups)
- Equitable care (equal utilization by vulnerable/risk groups)
- Efficient care (no inappropriate care)
- Patient-centred care (seamless care: coordinated and continuous care; acceptable care)
- Safe care

# Adherence to Recommended Follow-up Tests





# Risk-stratified Approach to Follow-up Care

There is general recognition that some survivors of childhood cancer should be followed up for life, and that different survivors have different risk profiles.

- **Low risk:** surgery only, low-risk chemotherapy (18% in BC)
  - **Moderate risk:** anthracyclines, alkylators (31% in BC)
  - **High risk/high needs:** brain tumours, bone cancers, leukemia other than ALL; intensive chemotherapy, cranial irradiation, combination high-dose chemotherapy and radiation, combination surgery with chemotherapy and radiation, bone marrow transplant (BMT) (51% in BC)
- > **Risk-based tiered care where care and setting matches risk**

# Implementation

January 2015: BC government announces support for program.

- Van Sun newspaper article

# Risk-Stratified Care



Where are we going?



## **TIER 4**

**Subspecialized Services**  
Provincial one-of-a-kind services

## **TIER 3**

**Regional Specialized Services**  
Complementing community-level services

## **TIER 2**

**Community-Based Services**  
"Home team" for children and youth  
focused on children and youth

## **TIER 1**

**"Broad Reaching" Service Providers**  
Public health nurses, family doctors,  
social workers

# Conclusions

- It is imperative to address the gaps identified in care of both current and new survivors of (childhood) cancer:
  - The incomplete evidence for late-occurring and ongoing risks of later problems, and
  - the lack of a sustainable model of survivor care *appropriate for the health system*
- The linked registries, clinical, and administrative databases in British Columbia are a uniquely valuable tool to address both of these issues

