A National Expansion of the STEP-1 Pilot Initiative – Supporting Travel for Pediatric and Adolescent Patients to Access Academic Phase I/II Trials in Canada

Spotlight Presentation – ACCESS Annual Meeting 2025

Sarah Cohen-Gogo, Norman Cook & Lisa Goodyear

STEP
Supporting Travel for Pediatric and adolescent patients to access academic phase 1/2 studies in Canada

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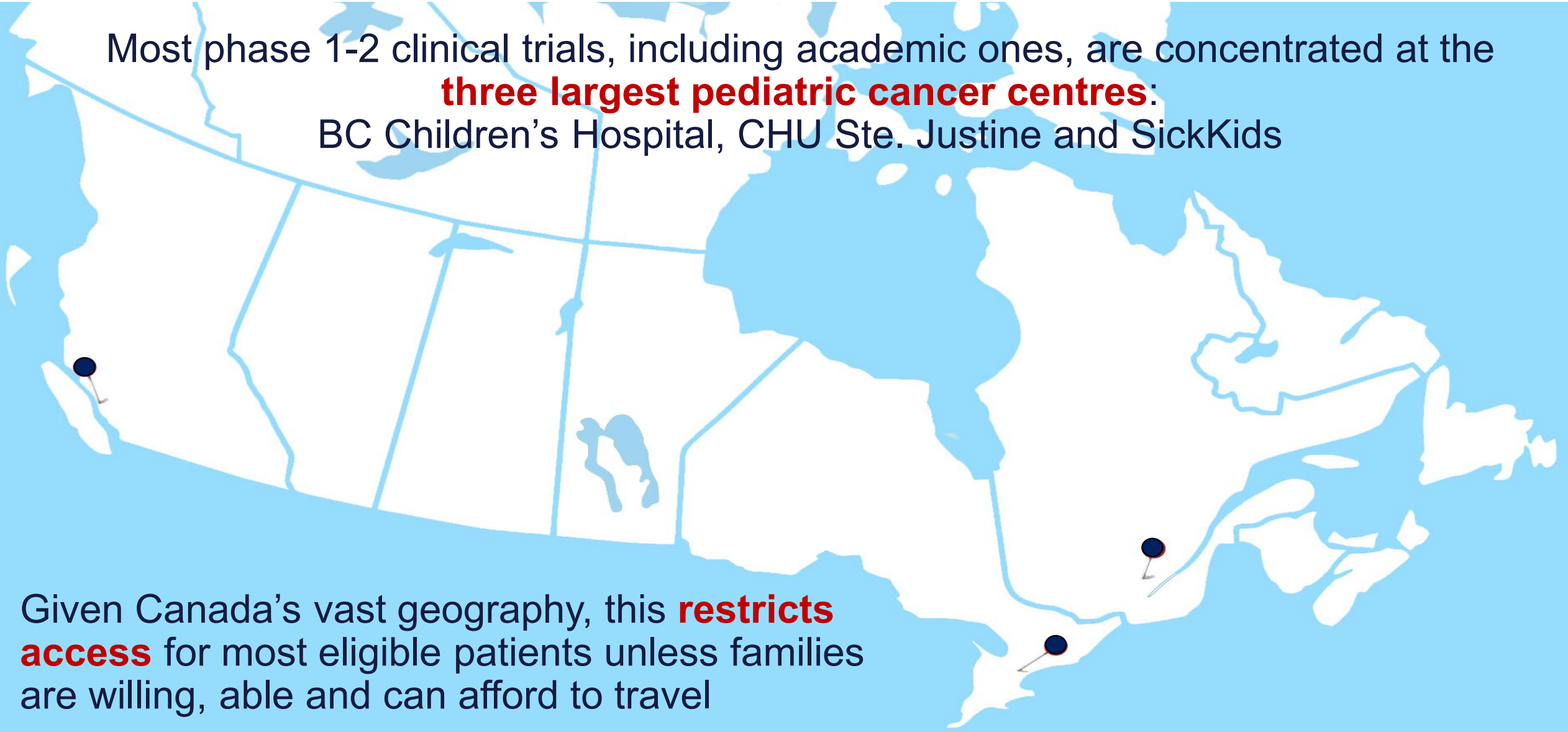
Enrollment In Pediatric Oncology Clinical Trials In North America

- Enrollment in pediatric oncology clinical trials is limited in North America
  - A Canadian population-based study found that **27.5%** of pediatric cancer patients in Canada enrolled in a clinical trial at the time of initial diagnosis (2001-2012)
  - **19.9%** of estimated US cancer patients 0 to 19 years enrolled on COG trials (2004-2015)
    - Younger patients were more represented across diseases and races/ethnicities
    - Patients with hematologic malignancies were more represented compared to solid and central nervous system (CNS) tumors

Pole *et al.*, BMC Cancer 2017
Faulk *et al.*, PLoS One, 2020

Pediatric Oncology Early Phase Academic Trials In Canada

Most phase 1-2 clinical trials, including academic ones, are concentrated at the **three largest pediatric cancer centres**:
BC Children's Hospital, CHU Ste. Justine and SickKids



Given Canada's vast geography, this **restricts access** for most eligible patients unless families are willing, able and can afford to travel

Separate work within ACCESS is on-going, to increase trial availability across Canada

Pediatric Oncology Early Phase Academic Trials in Canada

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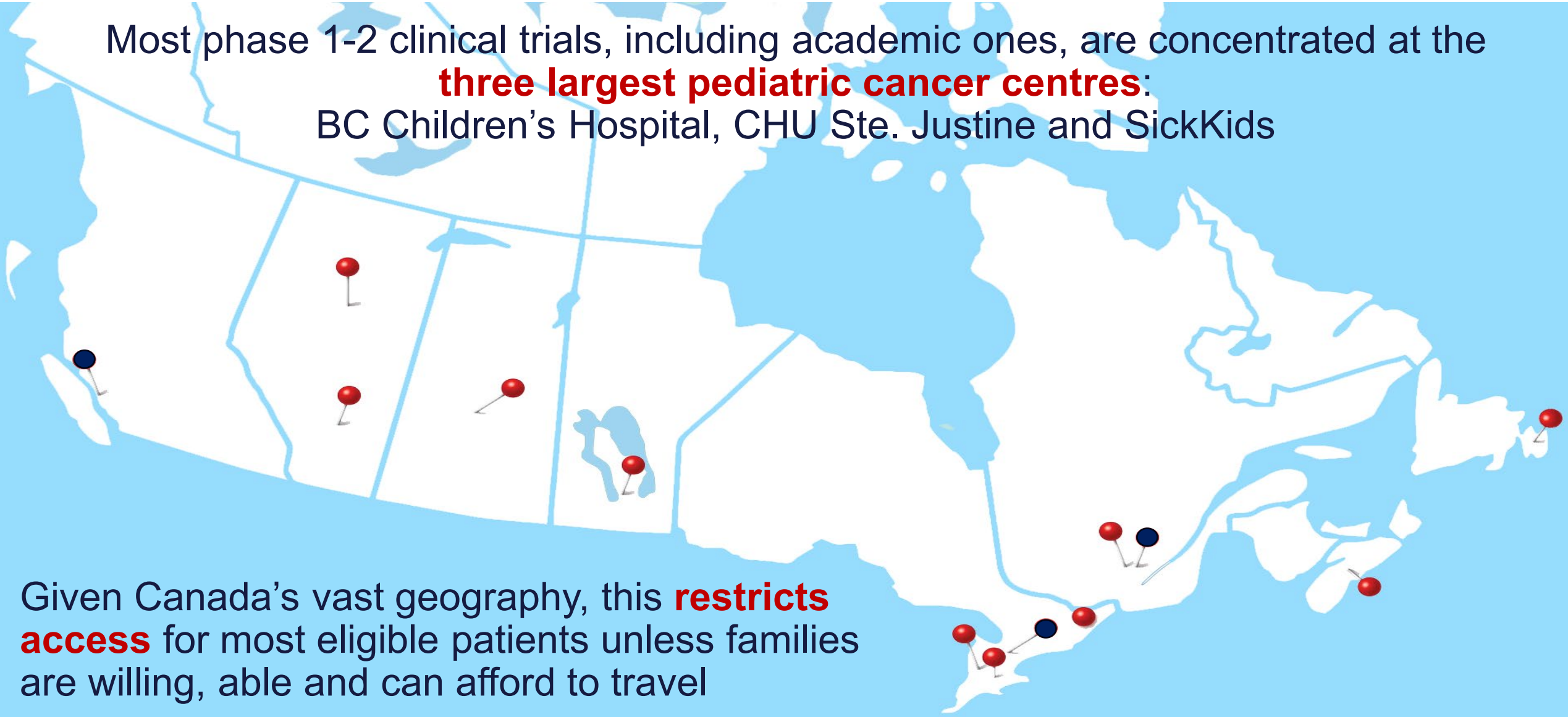


Given Canada's vast geography, this **restricts access** for most eligible patients unless families are willing, able and can afford to travel

Separate work within ACCESS is on-going, to increase trial availability across Canada

Financial Support for Patients in Early Phase Academic Trials in Canada

Social workers or patient navigators from referring and welcoming teams collaborate with families and their care team to identify and **submit applications** to **other potential funding sources** to offset some of the travel-related costs

However, families still experience the **financial and resulting emotional challenges related to the uncertainty of funding as well as potentially having to cover the upfront travel costs*

National Expansion of the STEP-1 Pilot Initiative – Approved Late December 2024

access acces

Access to Innovative Therapies & Optimal Care

- **Where?** Three regional hubs: BCCH, CHU-SJ and SickKids
- **Who?** Children and adolescents with hard-to-treat cancer, eligible for a study in the STEP-1 portfolio, from anywhere in Canada, no income based-criteria
- **Which studies?** Academic-sponsored early phase interventional trials, with novel therapies, and withOUT built-in funding
- **What?** Travel, accommodation, meals, ground transportation, parking for the patient and ONE caregiver
- **How?** A STEP-1 coordinator in each hub, supported by a lead MD and a lead clinical research professional at each site (CRA/RN), in collaboration with Hope Air

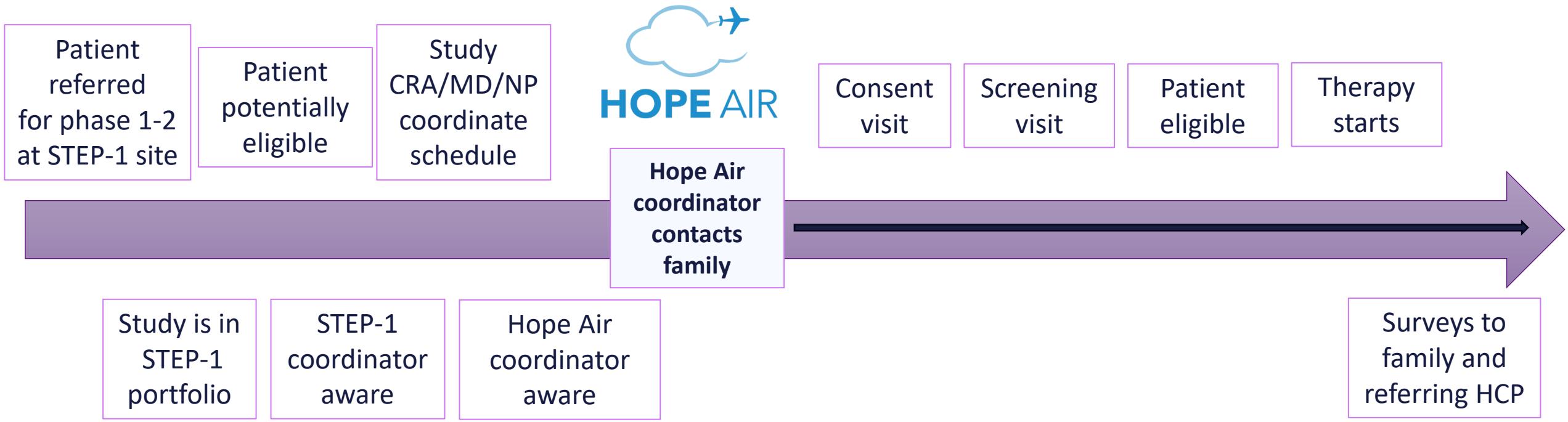
National Expansion: Collaboration With Hope Air

- National Canadian program that coordinates **non-emergency medical travel and accommodations** for patients and / or caregivers in financial need in Canada
  - Provides free flights, accommodations, airport ground transportation and meal vouchers for patients + one caregiver for individuals who must travel for medical care
- Recently partnered with the Centre for Living Organ Donation at UHN to ensure full support for individuals who need to travel to donate a kidney or portion of their liver (non-standard of care medical travel)

HOPE AIR

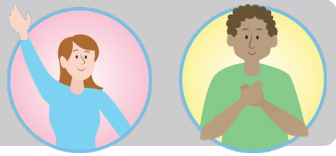
National Expansion: Coordination Of Travel And Accommodations

- Collaboration with national medical travel program (**Hope Air**) to coordinate travel for all patients



National Expansion : Finessing Our Approach

- **Knowledge Mobilisation** plan "*the process of making research results available and useful to people and organizations*"
- Collection of **potentially sensitive information** – ACCESS guidance document
- **Psychosocial support** at the STEP-1 centre
- Expand our QI initiative to our two new centres – ***en français aussi***
- Engage additional **PWLE** in our initiative!



Thank you!
Merci!

STEP
Supporting Travel for Pediatric and adolescent patients to access academic phase 1/2 studies in Canada

SickKids

Nathalie Costie
Shaherose Nanji
Norman Cook
Aiman Siddiqi
Ashley Doka
Karen Fung
Vijay Ramaswamy
Jim Whitlock
Daniel Morgenstern

access acces

Tricia Schneider
Helen Petropoulos

SickKids
Garron Family Cancer Centre

BC CHILDREN'S HOSPITAL

Rebecca Deyell
Hina Johnstone

Access to Innovative Therapies & Optimal Care

Norman Cook
Geoffrey Cuvelier
Paul Gibson
Lisa Goodyear
David Mitchell
Vijay Ramaswamy
Patrick Sullivan
Derek Tsang

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant
Université de Montréal

Henrique Bittencourt
Linda Hershon

U-LINK CANADA
ENSEMBLE AGISSONS POUR GUÉRIR LES CANCERS DES ENFANTS, ADOLESCENTS ET JEUNES ADULTES
TOGETHER, LET'S TAKE ACTION TO CURE CANCERS IN CHILDREN, ADOLESCENTS AND YOUNG ADULTS

Cielle Stapleton, **Ashley Doka**, Lucie Pecheux, Pauline Tibout, Aiman Siddiqi Kathy Brodeur-Robb, Jim Whitlock Daniel Morgenstern

HOPE AIR

Mark Rubinstein
Stephanie Aldridge

Our first cohort of STEP-1 supported patients, their families, their referring teams

Family And Healthcare Provider Feedback

“We are very appreciative of the program as it takes a load off, financially, and mentally by providing for our stay. So far, the process has been smooth and the communication from our coordinator has been great.”

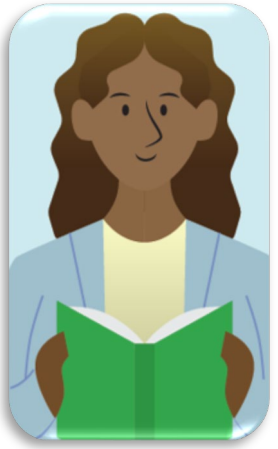
- Family member

“It's a great program and is helpful to families to remove one barrier. Reduction in worry/stress, I can put more focus and energy to my child.”

- Family member

"Great experience. It is wonderful to have something that families can receive financial support for various aspects when treated outside of their primary institution as this may serve as a barrier for some families to participate in clinical trials."

- Referring physician



"STEP-1 is covering most of the medical related expenses for the study which alleviates a lot of the financial stress for the family, especially study that requires frequent whole day visit and living far away from the hospital.“

- Social worker from referring team

Approaches to policy & health system implementation for innovative diagnostics in childhood cancer

ACCESS Meeting, January 2025.

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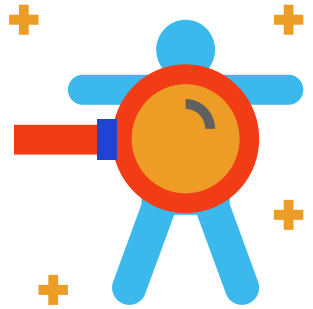
Introduction

- **Research Context**
  - Molecular diagnostics offer incredible promise for precision oncology
  - Substantial uncertainty of benefit + high costs
  - No consensus on regulation and policy that can address the clinical implementation
  - Policy void is especially relevant for CAYA (clinical, economic, ethical needs)
  - Need for good health technology governance



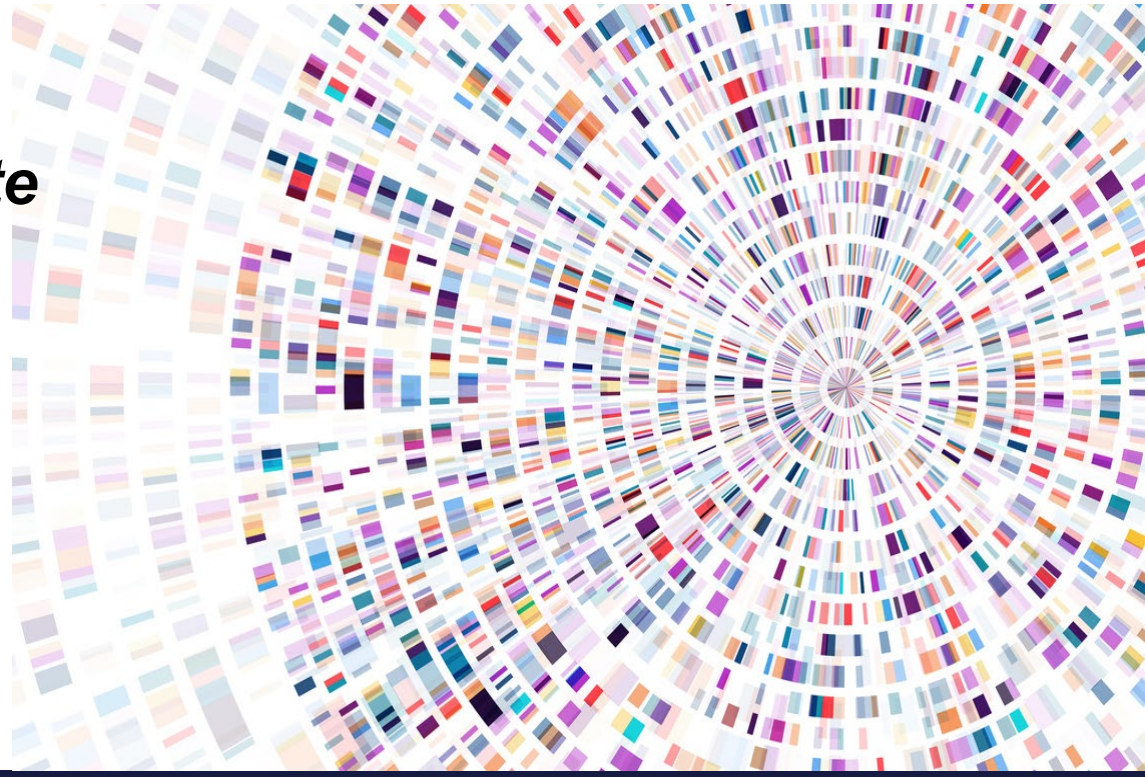
Introduction

- **Project Aims**

(i) Understand the ***current state*** of policy and system implementation for innovative diagnostic technologies in childhood cancer in Canada and comparator countries

(ii) Generate lessons for an ***ideal future state***

- Focus on
  - exemplar technologies
  - access and equity
  - Canadian setting



Methods & Design

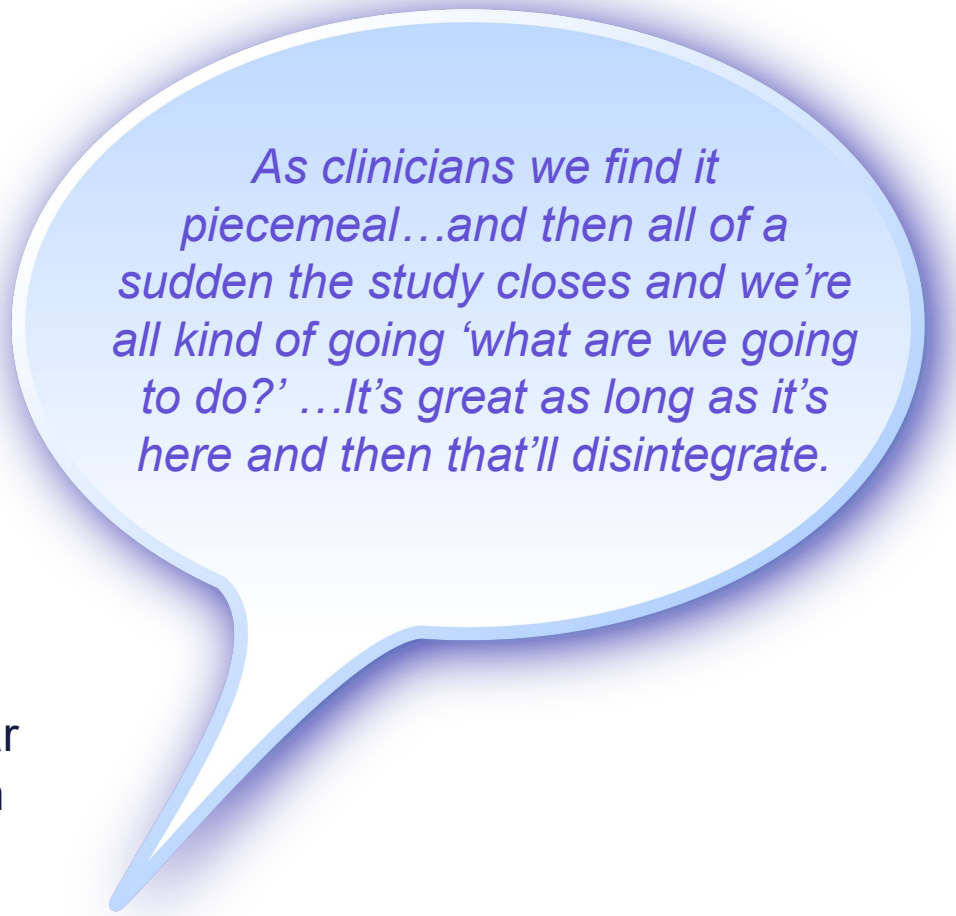
1. **Semi-structured key informant interviews** with clinicians and decision-makers, exploring:
   - Experience accessing molecular diagnostics for pediatric oncology
   - Opportunities and barriers to access
   - Ideal future state

2. **Survey** of genome sequencing availability for oncology at children's hospitals
   - Map genome testing access (somatic + germline) through standard clinical pathways and research pathways, comparing source of funding (research/hospital/provincial), location of testing (in-hospital/in province/out-of-province) and turn-around times across sites

3. **Document analysis** to map the policy environment
   - Implementation of innovative diagnostics for pediatric oncology in Canada and comparator jurisdictions (UK, Sweden, Australia)

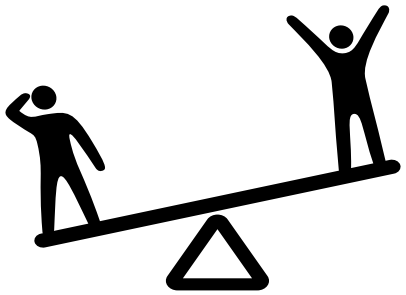
Preliminary Results

- **Key informant interviews**
  - N=25, oncology, pathology, bioinformatics, policymakers
  - Current state themes:
    - An evolving space
    - Complex patchwork of access
    - Absence of standards
    - Variable overlap with adult genome sequencing in oncology→ gaps and omissions
    - Shifting clinical trials landscape (e.g. COG molecular characterization initiative in US, methylation classifier in Germany)



Preliminary Results

Disparities



- Quebec vs rest of Canada
  - Routine testing at diagnosis vs only for sub-populations via research pathways
- Urban vs rural
  - Available expertise (e.g., pediatric pathologists)
- Differences based on type and stage of cancer
- Provider knowledge of testing options and current research opportunities

Exemplars

- Quebec
- Centralized laboratory
- Distributed model with regional centres for high-complexity testing
- Clarity re: testing pathway

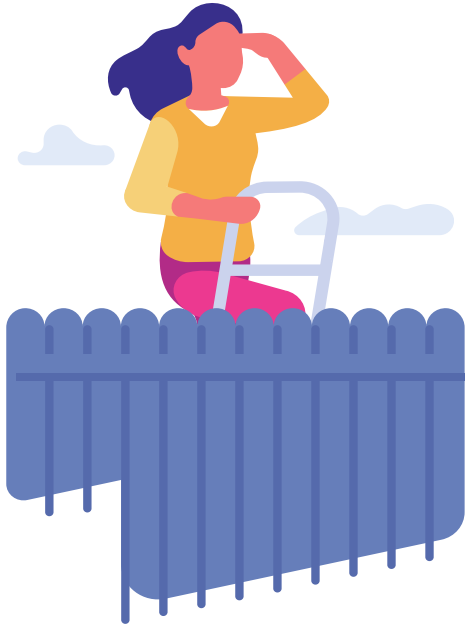
Preliminary Results

- **Ideal future state**
  - Clinical standards for testing algorithms
  - Resources for funding, infrastructure, personnel across the health system (e.g., bioinformaticians, nurse navigators, genetic counsellors, patient + provider education)
  - Debate about the relative merits of broad vs. targeted testing
    - Many want comprehensive testing (WGS/WES/WGTA) of tumour and germline at diagnosis, and repeated at relapse
    - Some see more value in sequenced approach

The challenge, with all of this is, do you work up tumors by doing an individual test for A and then a test for B and then a test for C? And then a test for D? Or do you just test the whole alphabet on everything? And which is the more efficient both in time, in tissue and money?

Future Directions

- Ongoing data collection and analysis
- Next steps:
  - Identify exemplar technologies and policy processes
  - Synthesize lessons from different approaches to policy implementation
  - Cross-case comparison: Canadian findings vs. select countries where there has been broad adoption of NGS for pediatric oncology (e.g. Zero Childhood Cancer in Australia, Genomic Medicine Sweden, UK 100,000 Genomes Project/NHS WGS)
- → *We hope to offer lessons that can help harmonize access pathways across Canada*



Acknowledgements

Project Team

Avram Denburg
Celine Cressman
Anita Villani
Robin Hayeems
Adam Shlien
Rebecca Deyell
Valerie McDonald
Keith McIntosh
Yvonne Bombard
Beverly Essue
David Malkin

Special thanks to our key informants and PROFYLE clinical site leads who have facilitated data collection.

Thank you
Merci

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Persons With Lived Experience in ACCESS

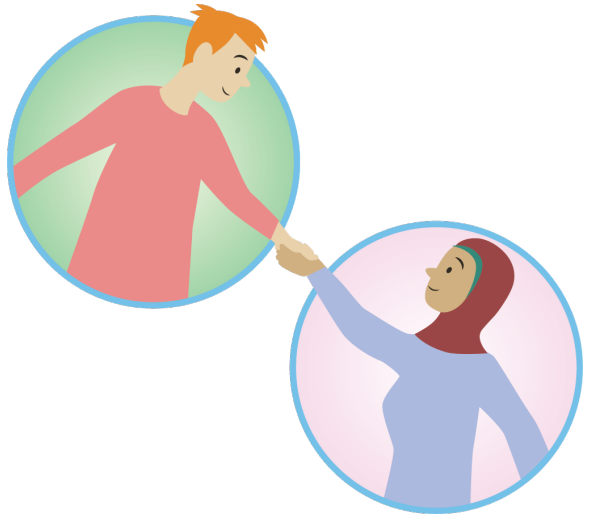
Highlighting the many important ways Persons With Lived Experience (PWLE) contribute to ACCESS

Chiquita Hessels, PWLE, Education and Training Theme Co-Lead, SJII Committee

Dawn Pickering, PWLE, Education and Training Theme Co-Lead

Persons With Lived Experience in ACCESS

ACCESS recognizes the importance of including diverse perspectives and insights of people who have been directly affected by pediatric cancer, to drive meaningful improvements through research, policies, practices, processes, and programs at all levels of ACCESS



Persons With Lived Experience Community

- The PWLE Community is an internal group of PWLE, which aims to supports those who participate in ACCESS Theme(s)/Group(s) as a co-lead or member and/or a collaborator on a project

- The PWLE Community aims to:
  - Create a safe, supportive and social space
  - Foster collaboration and leverage the unique insights and experiences of individuals who have lived through various healthcare challenges
  - Provide advocacy development and learning opportunities
  - Maintain ongoing communication between PWLE and ACCESS

Persons With Lived Experience Network

- The PWLE Network aims to create an inclusive space for all People With Lived Experience of pediatric cancer
  - By joining the Network, PWLE are provided with broad communication from ACCESS, such as e-Updates, Newsletters, and PWLE-specific opportunities that is available to them
  - The PWLE Network is invited to join centrally organized events such as virtual Town Halls, educational sessions/webinars, and other ACCESS events

Persons With Lived Experience Advisory Committee

The PWLE Advisory Committee was created through a self-nomination process from members of the PWLE Community

The main functions of the PWLE Advisory Committee include to:

- assist the Senior Leadership Committee by helping ACCESS understand how its work impacts families, children and AYA living with pediatric cancer
- provide feedback and recommendations on strategic priorities
- advise on the scope and direction of ACCESS scientific activities, organizational development, consortium growth and long-term sustainability
- provide a link to the broader PWLE network and pediatric cancer community and serve as ambassadors for ACCESS by communicating ACCESS' contributions to their PWLE/Advocacy networks

Persons With Lived Experience Subsidy

- One of the Education and Training theme's objective is to improve access for Persons With Lived Experience to educational resources

- We recognize the importance of supporting PWLE to learn more about pediatric cancer to in turn better advocate for their child, themselves, and others they are supporting

- The PWLE Subsidy is designed to help offset the costs of attending national and international online and in-person workshops, seminars, single courses, and conferences to further PWLE knowledge of, and advocacy efforts in, childhood cancer

Persons With Lived Experience Subsidy

- This subsidy is intended to complement existing opportunities in Canada and expand the pool of resources available to support PWLE learning

- Any person who has been directly impacted by pediatric cancer through lived experience as a patient or caregiver in Canada is welcome to apply

Persons With Lived Experience Subsidy

To date, ACCESS has received:

- 8 PWLE Subsidy Applications to attend education and training events
- 3 applications currently under review
- 4 approved and funded

"Applying to the PWLE subsidy allowed me to attend the 7th International Li-Fraumeni Syndrome Symposium, an invaluable opportunity I would not have had a chance to attend without the subsidy…. This experience has helped strengthen my understanding and advocacy abilities within the pediatric cancer community. I feel better equipped to navigate and support others facing the unique challenges of Li-Fraumeni syndrome.“

-E.H., PWLE, British Columbia

Persons With Lived Experience Subsidy

To apply to the PWLE Subsidy, please use the QR code, or visit:

https://redcap.link/PWLE_Subsidy_Application

Please contact Jenna Craig (jenna.craig@sickkids.ca)
if you have any questions about the PWLE opportunities shared today

Thank you
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Scoping Review of Psychosocial Screening Measures in Pediatric Oncology

Fiona Schulte, PhD RPsych

Associate Professor, Department of Oncology, University of Calgary

Co-Lead, Psychosocial and Survivorship

January 28, 2025

Survivorship and Psychosocial Theme Co-Leads



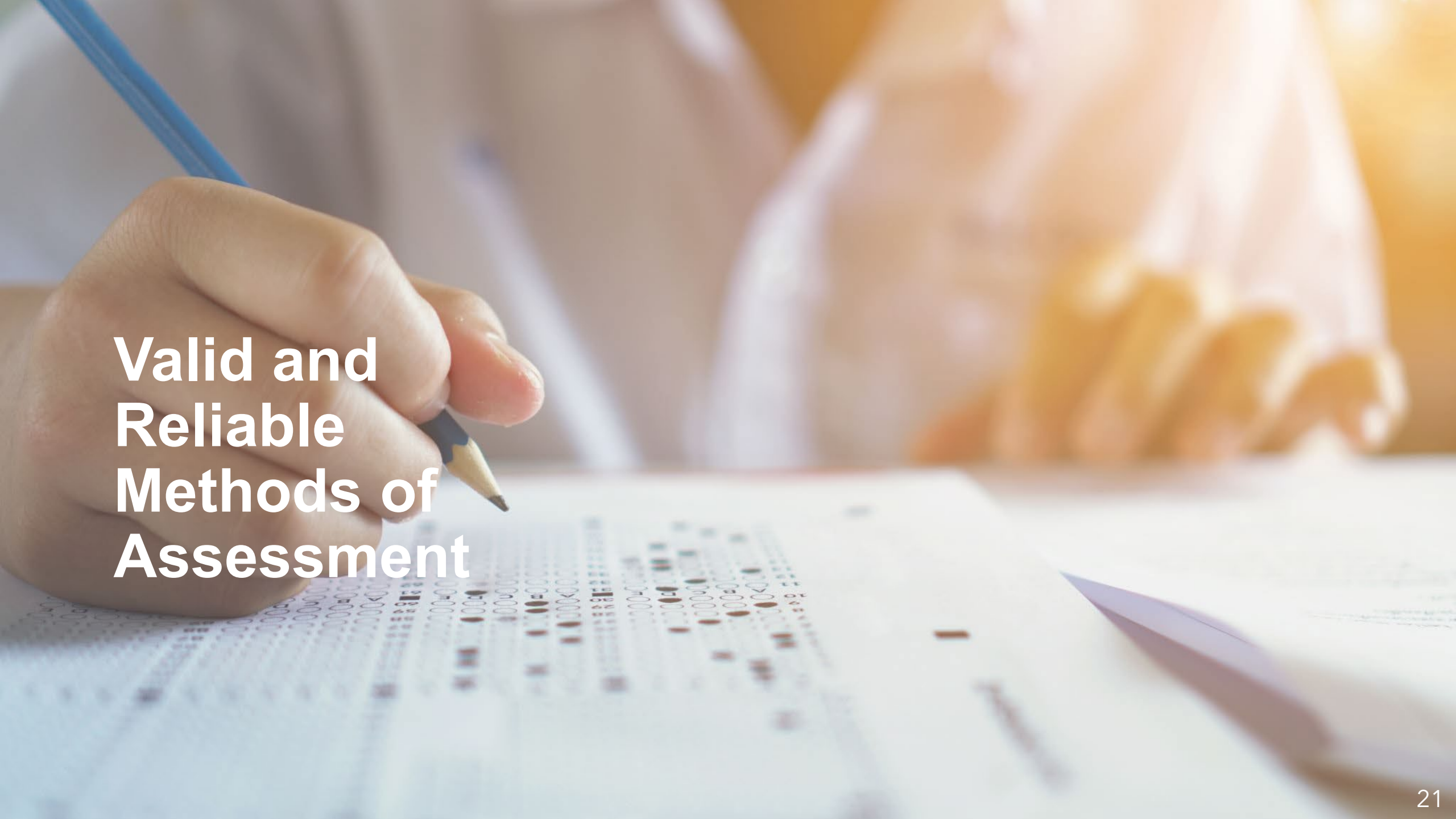




Distress should be measured as the 6th vital sign after temperature, blood pressure, pulse, respiratory rate, and pain

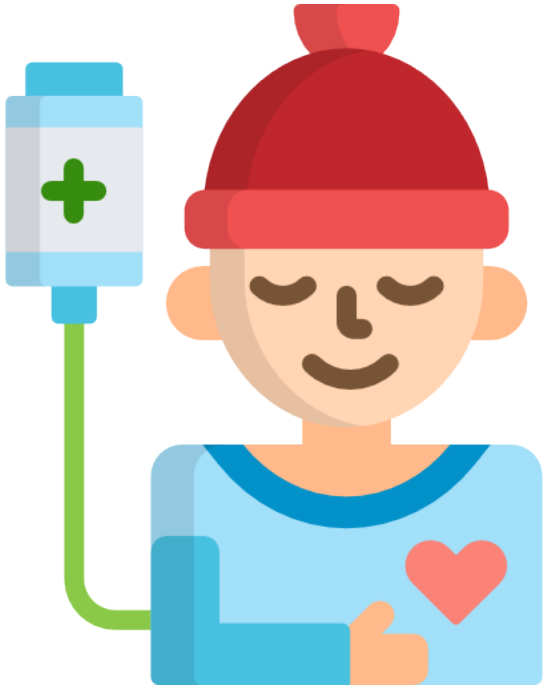
Standards of Care in Pediatric Psychosocial Oncology

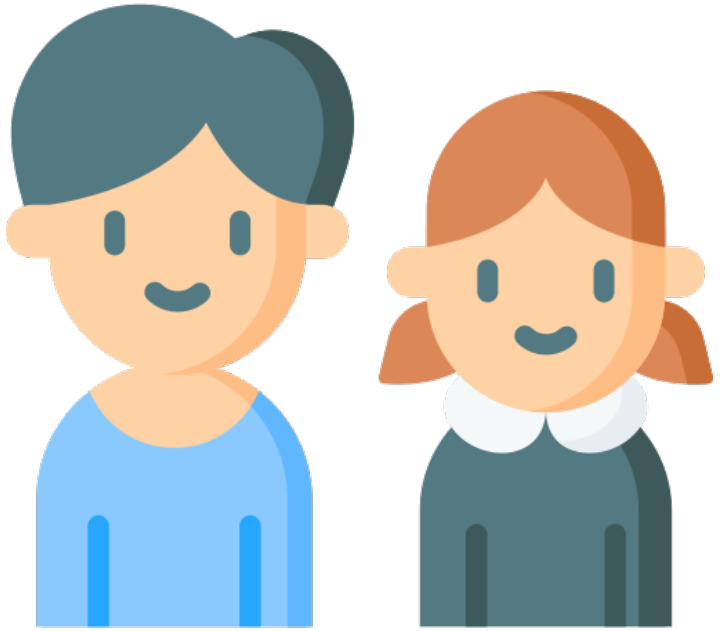
1. **Psychosocial Assessment**
2. Monitoring of neuropsychological outcomes
3. Psychosocial follow-up in survivorship
4. Psychosocial interventions and therapeutic support
5. Assessment of financial burden
6. Standards of psychosocial care for parents
7. Anticipatory guidance and psychoeducation
8. Procedural preparation and support
9. Providing opportunities for social interaction
10. Supporting siblings
11. Academic continuity and school reentry support
12. Assessing medication adherence
13. Palliative care
14. Bereavement follow-up
15. Communication, documentation and training standards



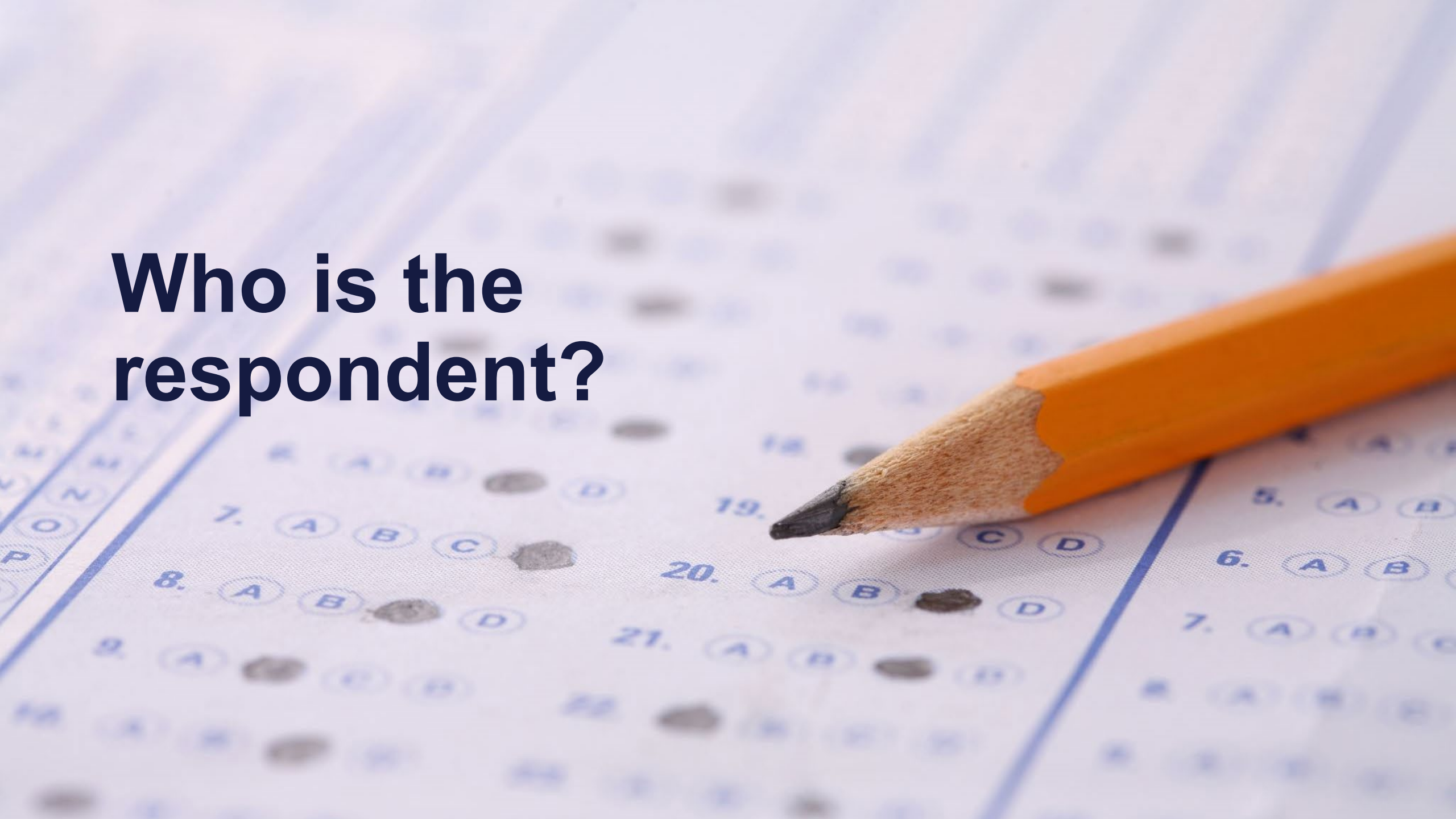
Valid and Reliable Methods of Assessment

Who is the patient?





Who is the respondent?



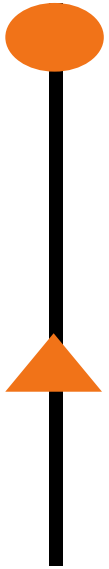
Identify and pilot the implementation of a comprehensive means to assess patient-reported psychosocial health outcomes in children and in psychosocial screening in their family.

Scoping review (underway)

Provide national recommendation on behalf of ACCESS

Implement screening protocol in pilot sites across Canada

Scoping Review Aims



What instruments are available to enable **psychosocial distress screening** in children with cancer, survivors of childhood cancer, and family members with cancer?

What instruments are available to enable **psychosocial needs assessments** in children with cancer, survivors of childhood cancer, and family members with cancer?

Inclusion

1. Children who have cancer or have had cancer, the majority (>50%) of which are between the ages of 0-21 years
   - *Note: survivors must have a mean or median age between 0-21 years.*

2. The family caregivers (e.g., parents) of such children.
   - *Note: siblings are not included.*

3. Patient-reported outcome (PRO) tools which yield a direct index of distress (e.g., depression, anxiety) or ≥ 2 related cancer symptoms (e.g., pain, fatigue)
   - *Can include parent-reported outcomes (e.g., parent's distress)*

4. Patient-reported outcome (PRO) tools which yield a direct index of need. Tools may assess a single domain of need (e.g., information needs).

5. Participants from any geographic location

6. Tool intended for use in any setting where cancer care may occur (e.g., hospital, clinic, home)

7. Systematic reviews

Exclusion

1. Children without cancer or their family caregivers make up >20% of the study sample.

2. Studies that include participants from a single diagnosis group.
   - *E.g., only CNS tumors.*

3. Studies that include only one measure of a physical cancer-related symptom.
   - *E.g., only nausea; only fatigue; only pain.*

4. Studies where no quantitative data are presented.

5. Tools which assess satisfaction with care.

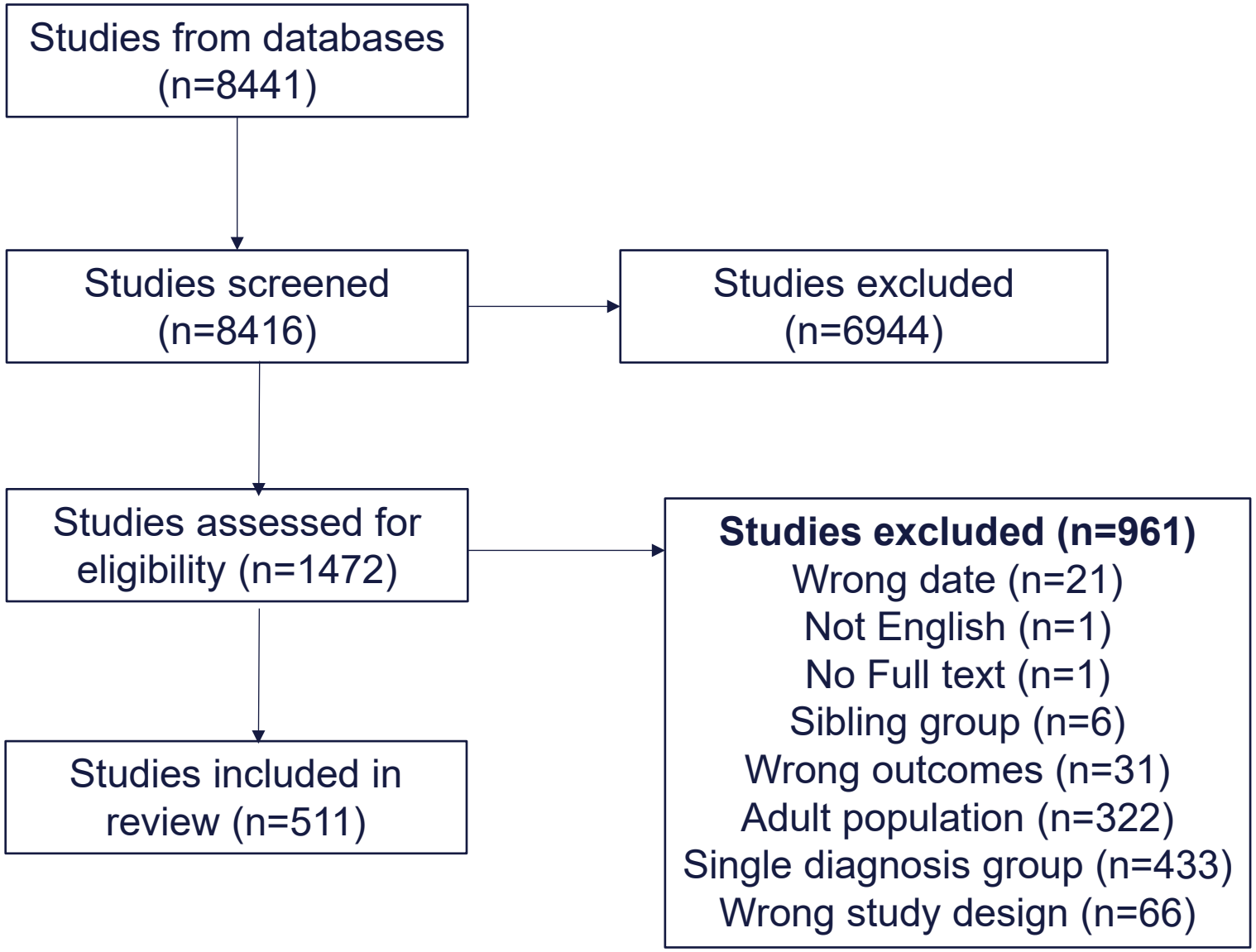
6. Case reports and case studies (i.e., less than 10 patients included)

7. Grey literature, dissertations, and conference proceedings.

8. Outcomes involving (a) positive psychosocial constructs (e.g., hope, coping, resilience) OR (b) neurocognitive functioning OR (c) behavioral functioning.

9. Studies published before 1990.

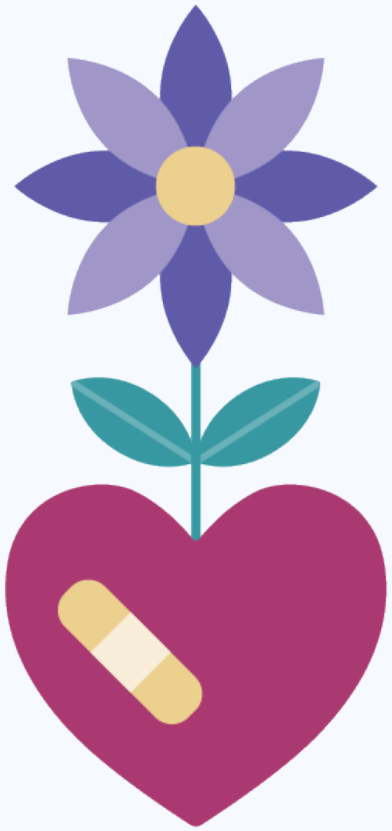
Scoping Review Results



Scoping Review Results

266

patient and caregiver screening tools in total were identified



Highly Cited Patient Screening Tools

	Number of times cited	Number of items	Free	Does not require scoring algorithm	Self-Report Available	Parent-Proxy Report Available	Used across age ranges	Translations available	Used in screening study for this population
PedsQL	208	23	✗	✓	✓	✓	✓	✓	✓
PROMIS-25	75	25	✓	✗	✓	✓	✓	✓	✓
MSAS 10-18	50	30	✓	✓	✓	✓	✓	✓	✗
Distress Thermometer	13	1	✓	✓	✓	✓	✓	✓	✓
SF RAND 36	30	36	✓	✗	✓	✗	✗	✓	✓

Highly Cited Patient Screening Tools (Cont'd)

	Number of times cited	Number of items	Free	Does not require scoring algorithm	Self-Report Available	Parent-Proxy Report Available	Used across age ranges	Translations available	Used in screening study for this population
BSI-18	20	18	✗	✓	✓	✗	✓	✓	✓
BDI-II	26	21	✗	✓	✓	✗	✓	✓	✓
HUI-2	25	15	✗	✗	✓	✓	✓	✓	✓
SSpedi	6	15	✓	✓	✓	✓	✓	✓	✓
CHQ	22	87	✓	✗	✓	✓	✓	✓	✓

Future Directions

- Review of criteria for caregiver tools
- Consensus meeting to finalize recommendations
- POGO funded a feasibility study to explore the use of electronic health records to support psychosocial screening - SSPedi (SickKids & CHEO)
- CIHR submitted grant to explore implementation of the PAT (St. Justine)

Takeaways

Screening for distress has been recognized as a priority in pediatric oncology

There are challenges to screening including identifying the correct tool

ACCESS provides an opportunity to implement screening across the country

Thank you
Merci

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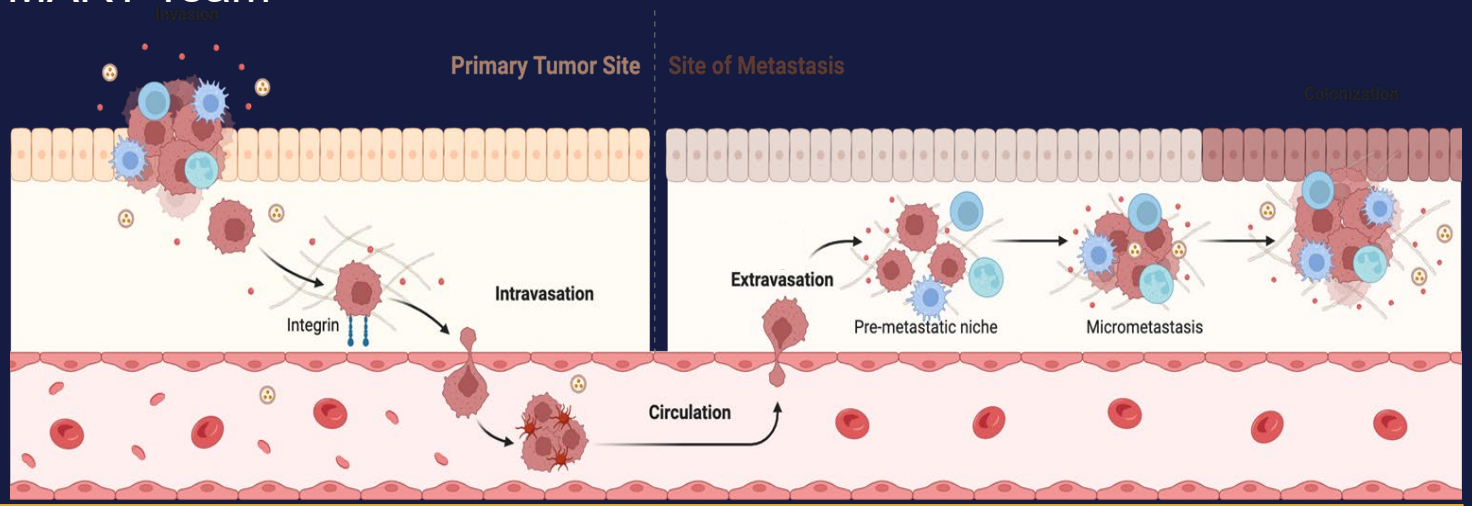
Sarcoma MetAstasis Research Taskforce (SMART)

Livia Garzia and Rebecca Gladdy for the SMART Team



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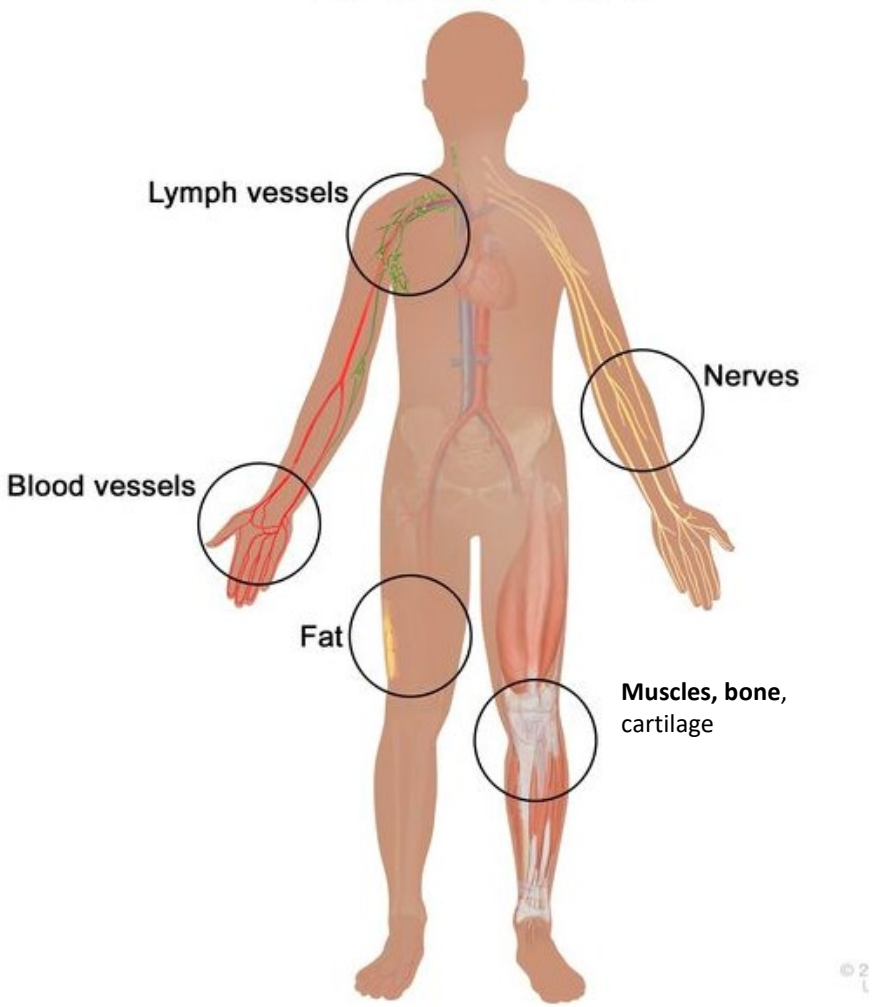
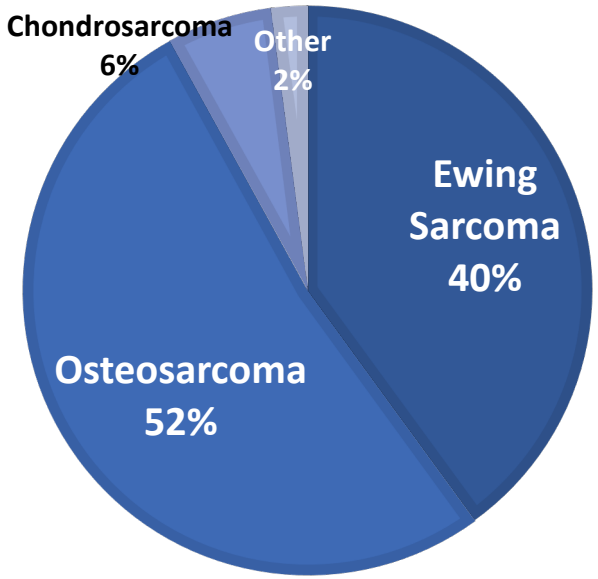
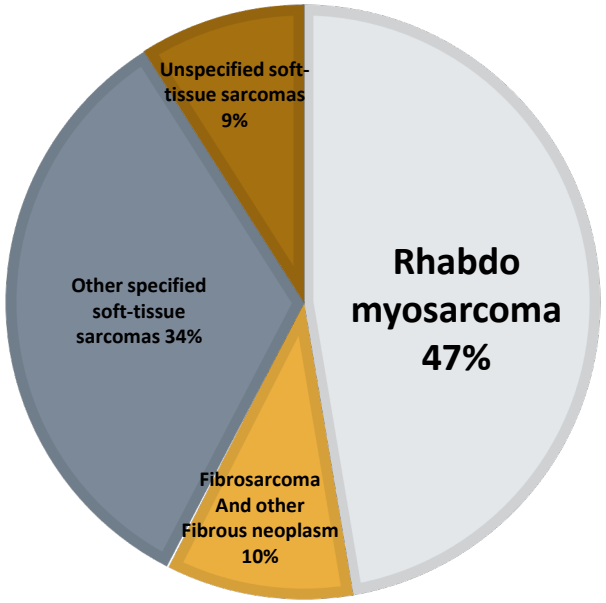
Pediatric Sarcoma







Sarcomas can occur everywhere in the body.

Up to 170 children are diagnosed with sarcoma each year in Canada.

For most of them upfront treatment hasn't changed in 40 years.

Osteosarcoma, Ewing sarcoma and Rhabdomyosarcoma are the most common.

Osteosarcoma, Ewing Sarcoma and Rhabdomyosarcoma often metastasize to a secondary site and become hard to treat.

The SMaRT Team

The Challenge

"To improve the outcome of high risk pediatric sarcomas by understanding and targeting the biology of metastatic disease"









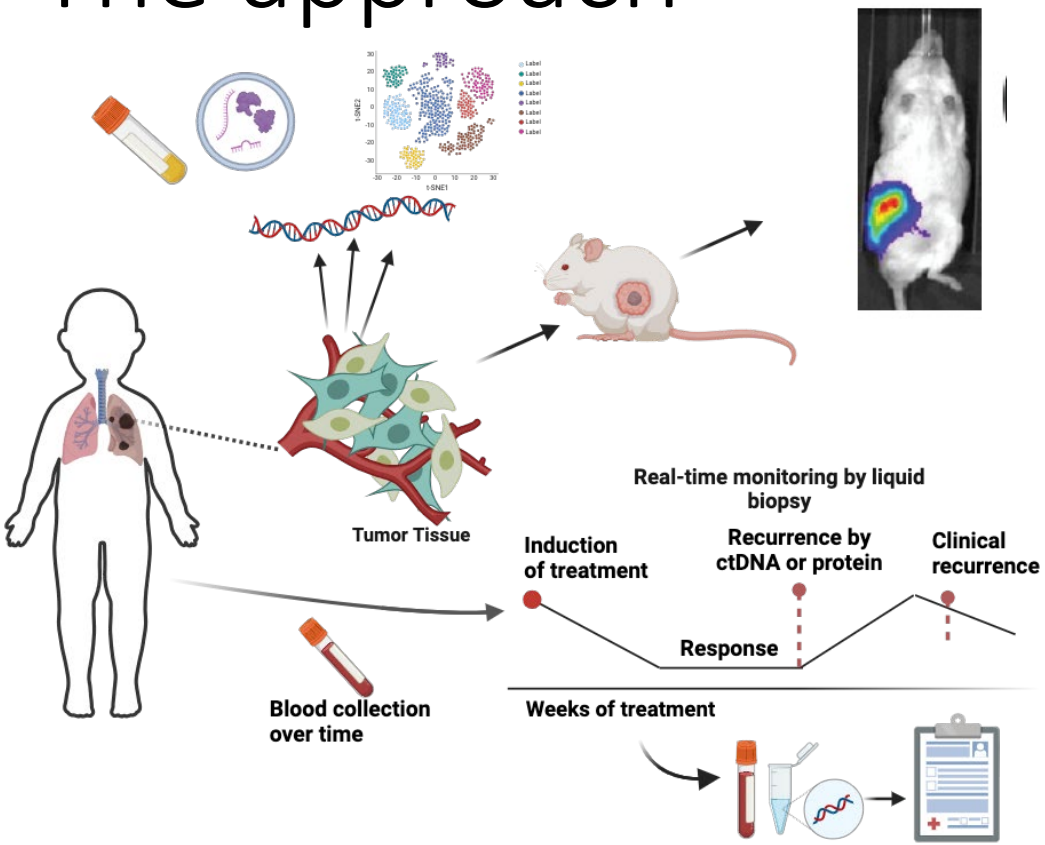









The approach



Samples selection and prioritization

- Osteosarcoma
- Ewing Sarcoma
- Rhabdomyosarcoma

Refractory and metastatic tumors

Baseline Profiling of tumors and Validation of models
Bulk level

Aim 1

Intratumoral complexity -> spatial and single-cell omics

cfDNA features -> genetics and epigenetics

Plasma EVs features -> Proteomics

Aim 2

Hits validation -> In vitro

Hits validation -> In vivo

Aim 3

Prospective studies-> cfDNA and EV based longitudinal sampling

Surfaceome, immunopeptidome -> Novel immunotherapy targets

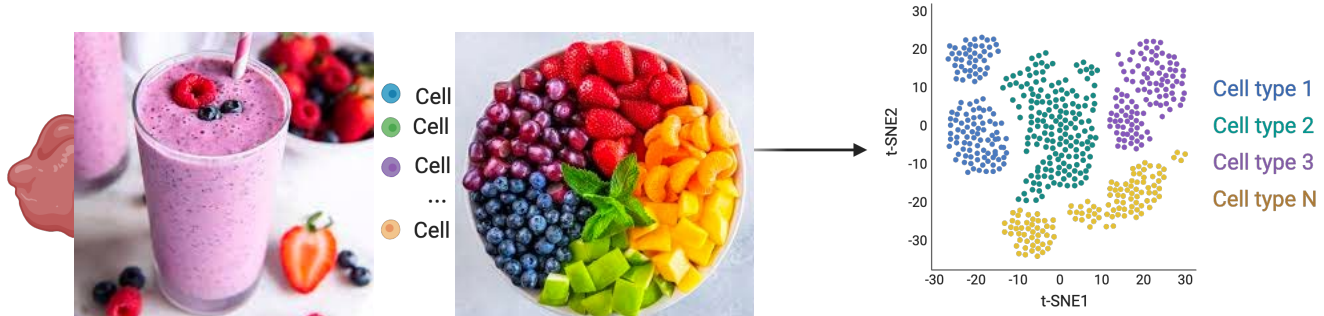
Osteosarcoma metastasis at high-resolution

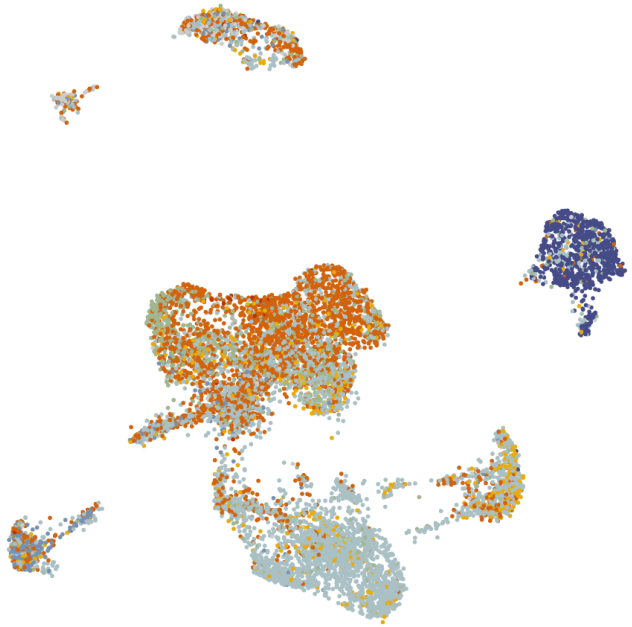
Aim 1

Intratumoral complexity -> spatial and single-cell omics

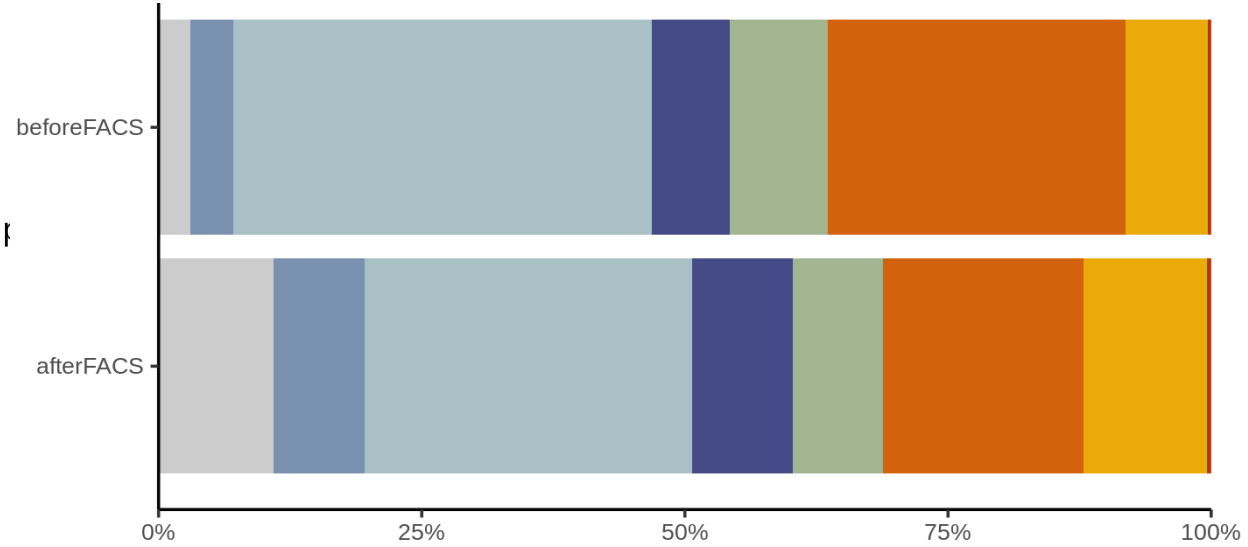
cfDNA features -> genetics and epigenetics

Plasma EVs features -> Proteomics



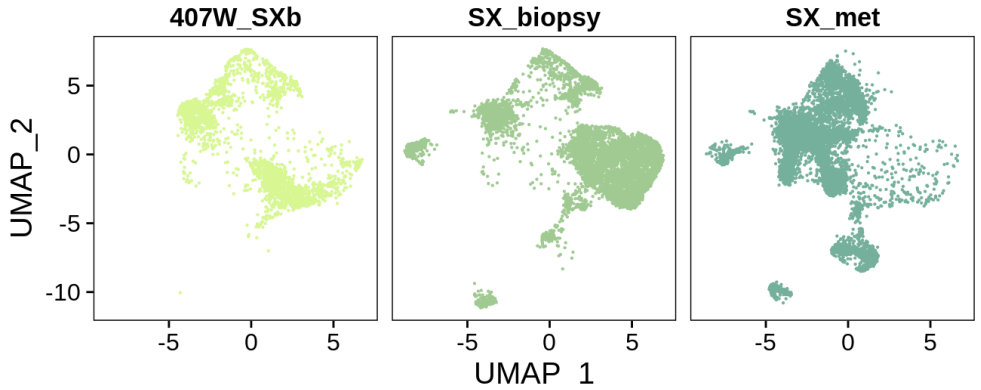


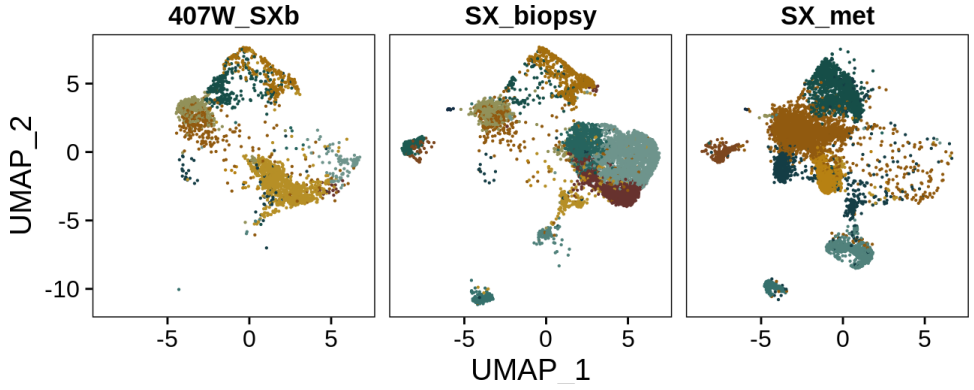
Osteoblasts
Osteo-CAR
Adipo-CAR
Ng2+ MSCs
Fibro/Chondro p
Endothelial
Fibroblasts
Myofibroblasts
Immune

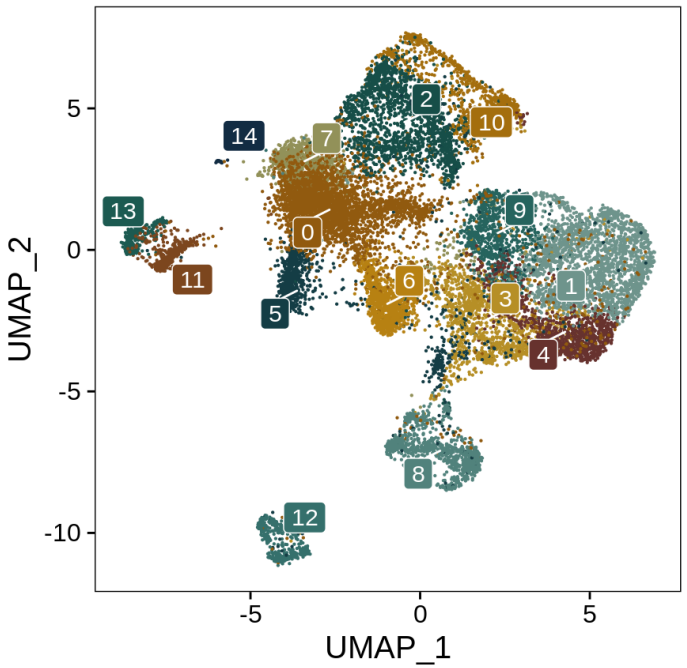


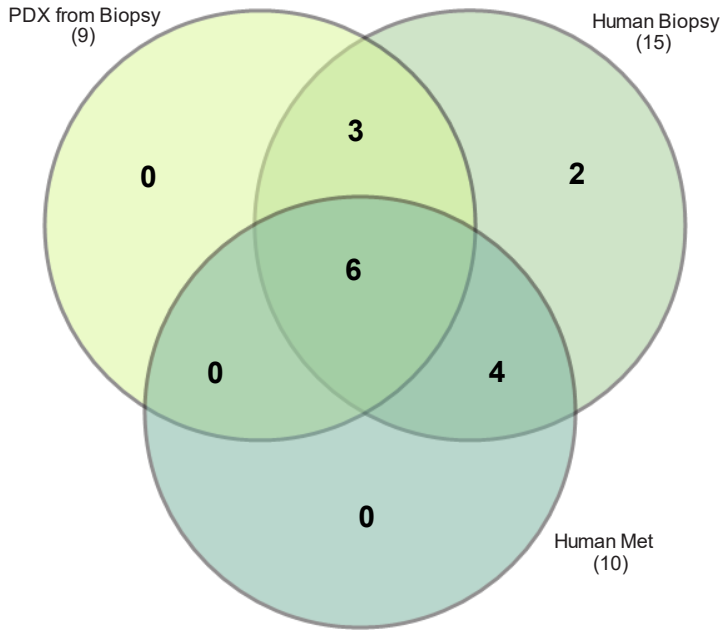
Garzia lab and Kleinman lab

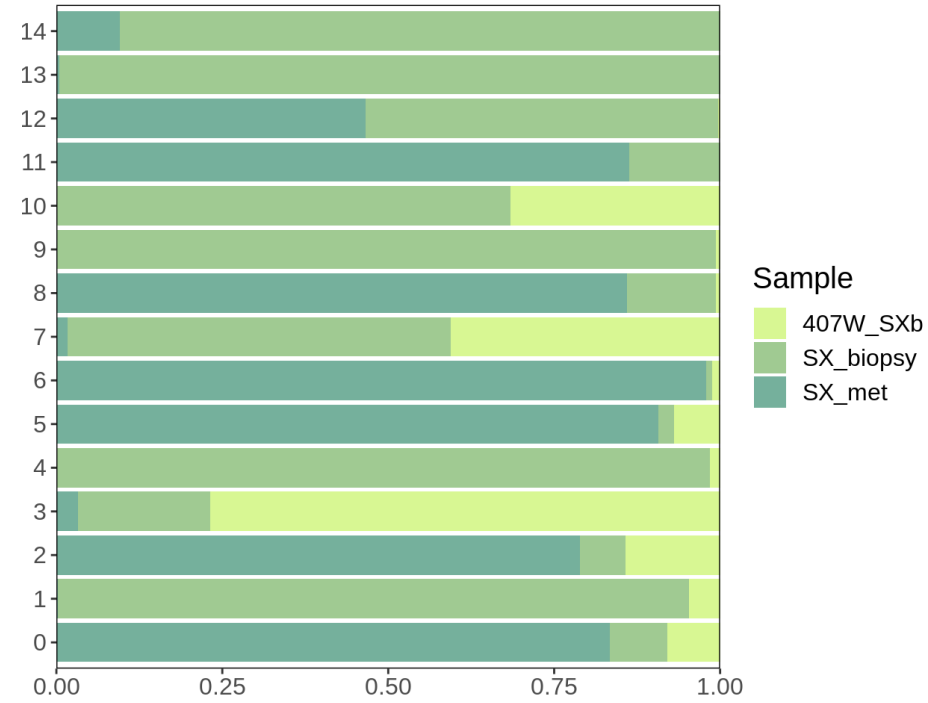
Osteosarcoma metastasis at high-resolution











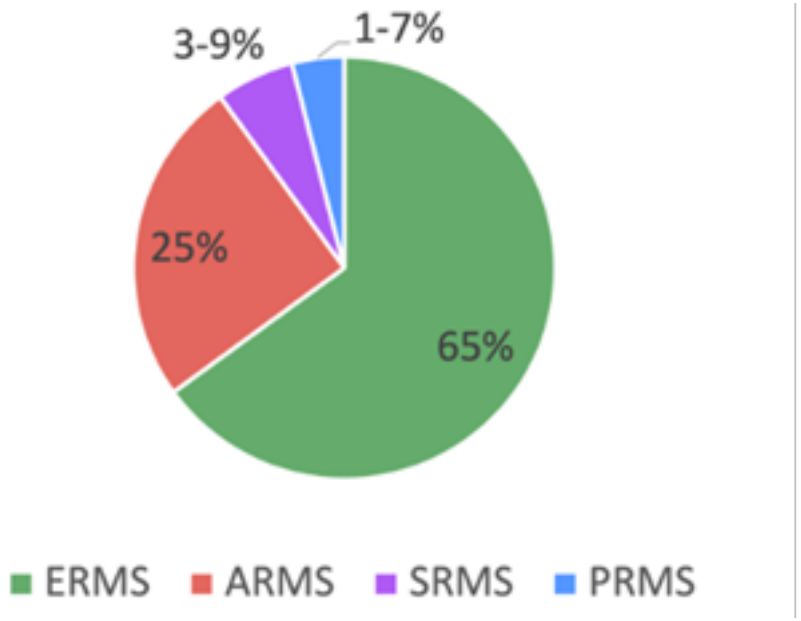
Garzia lab and Kleinman lab

Creation of Pre-Clinical RMS Models to prevent or treat metastasis and relapse

Aim 2

Targets validation -> Ex vivo

Targets validation -> In vivo



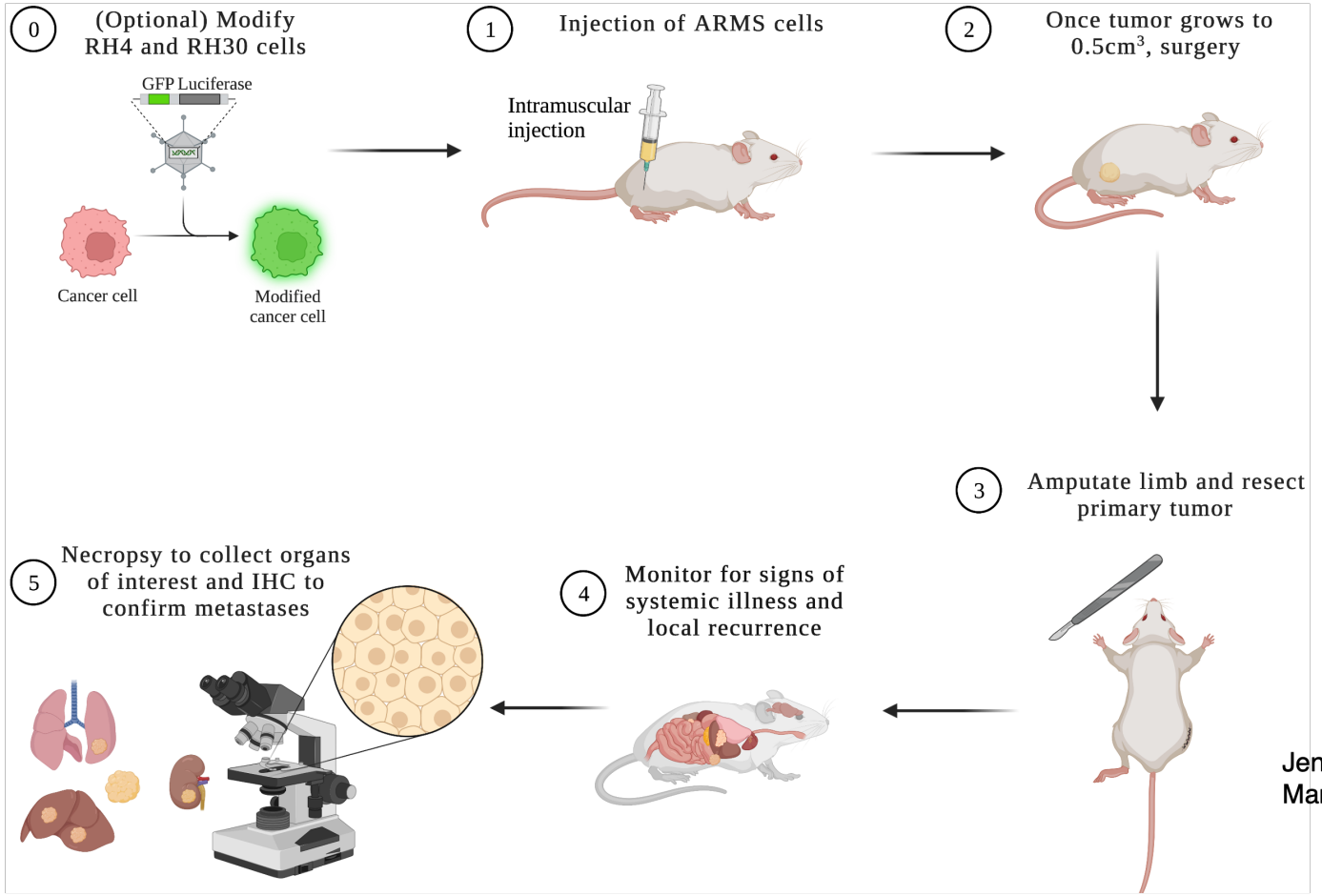
Unmet need: Effective systemic therapies for advanced/metastatic disease

Goals of ACCESS Sarcoma MetAstasis Research Taskforce:

1. Characterize the heterogeneity in RMS patients via genomics (Shlien)

2. Develop RMS model systems that recapitulate human disease;
   - Hone to common sites of metastasis
   - Understand how similar/disparate primary vs metastatic disease
   - Create models of SRMS and PRMS: do not respond to current standards of care

DEVELOPING A SURGICAL METASTATIC MOUSE MODEL OF ARMS



Anna Mandel, PhD Student

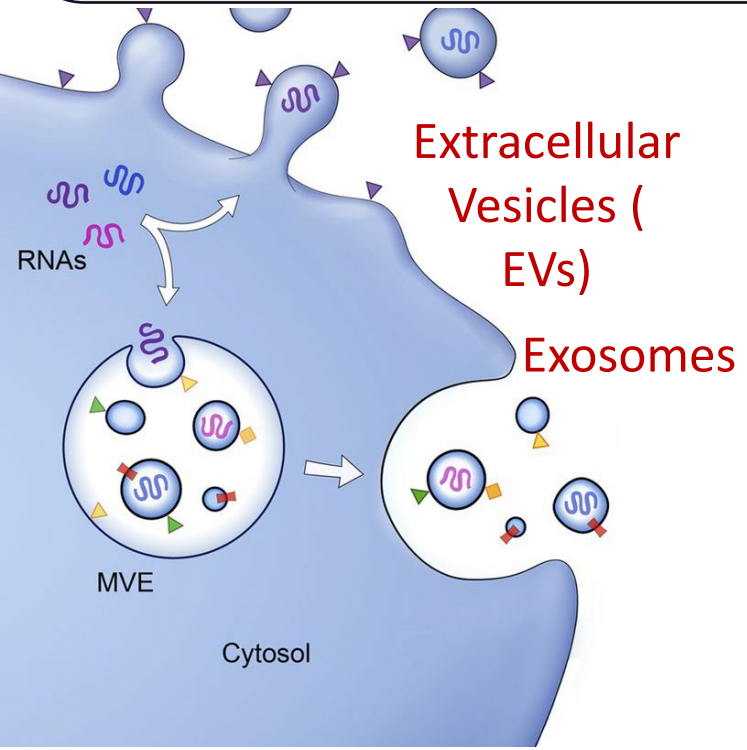
Jen Dorsey, Claire Wunker, Maryam Siddiqui, Julia Nomikos

Searching for unique secreted RNAs that can be used as diagnostic biomarkers in Ewing sarcoma

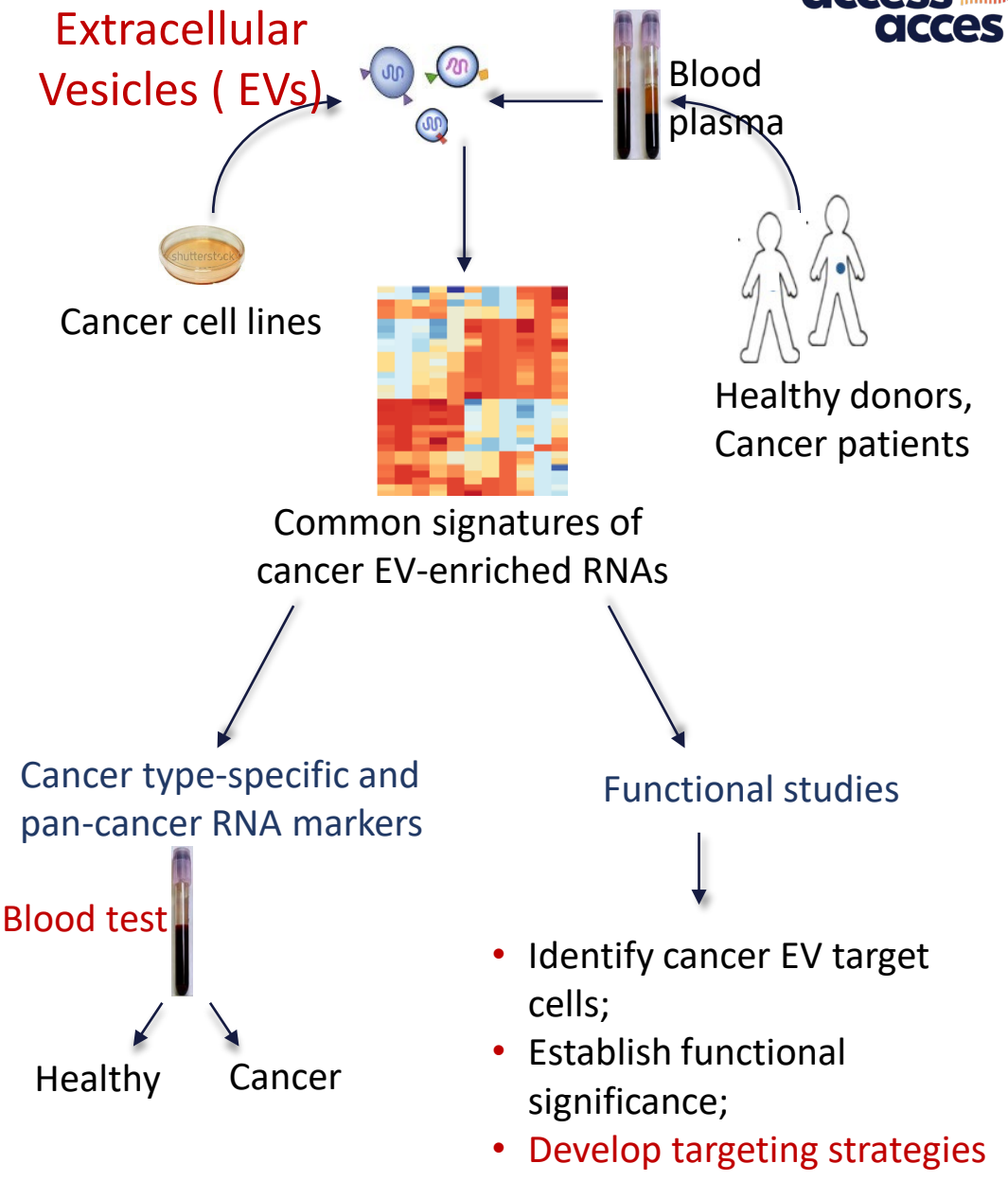
Aim 3

Prospective studies-> cfDNA and EV based longitudinal sampling

Surfaceome, immunopeptidome -> Novel immunotherapy targets



J Cell Biol 2013;200:373-383

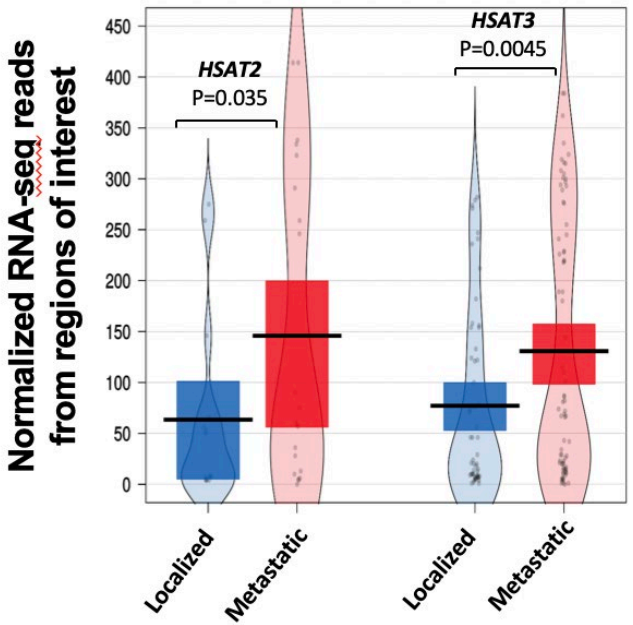


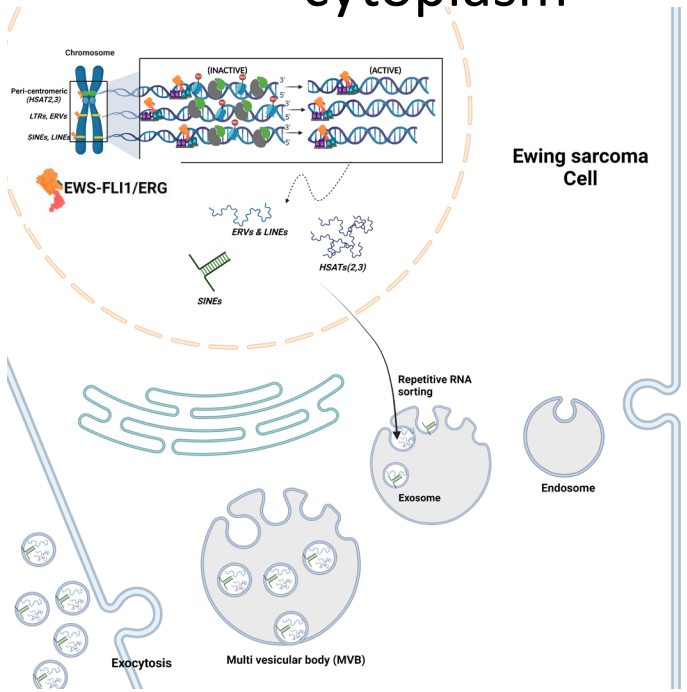
JCI The Journal of Clinical Investigation

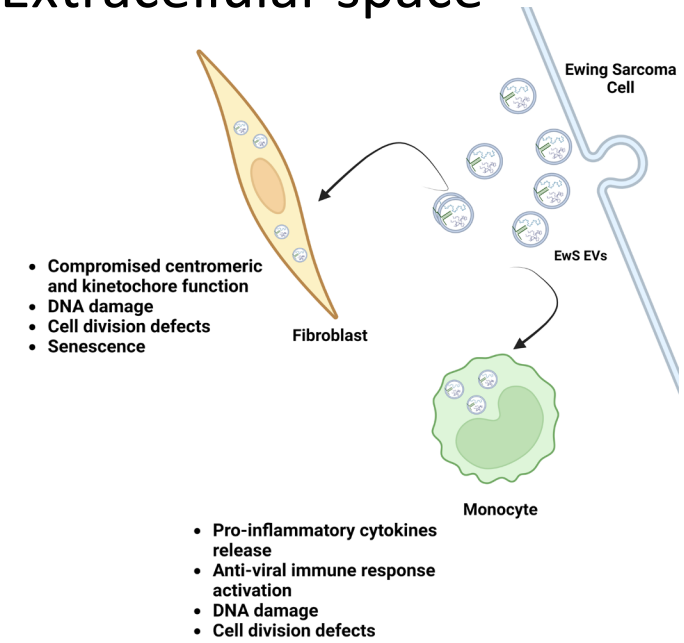
Research Article | Inflammation | Open Access | 10.1172/JCI169470

Oncogenic ETS fusions promote DNA damage and proinflammatory responses via pericentromeric RNAs in extracellular vesicles

Peter Ruzanov,[1] Valentina Evdokimova,[1] Manideep C. Pachva,[2,3] Alon Minkovich,[1] Zhenbo Zhang,[1] Sofya Langman,[2,3] Hendrik Gassmann,[4] Uwe Thiel,[4] Marija Orlic-Milacic,[1] Syed H. Zaidi,[1] Vanya Peltekova,[1] Lawrence E. Heisler,[1] Manju Sharma,[5] Michael E. Cox,[5] Trevor D. McKee,[6,7] Mark Zaidi,[7,8] Eve Lapouble,[9] John D. McPherson,[1,10] Olivier Delattre,[9,11] Laszlo Radvanyi,[1,12] Stefan E.G. Burdach,[2,4,13,14] Lincoln D. Stein,[1,15] and Poul H. Sorensen[2,3]



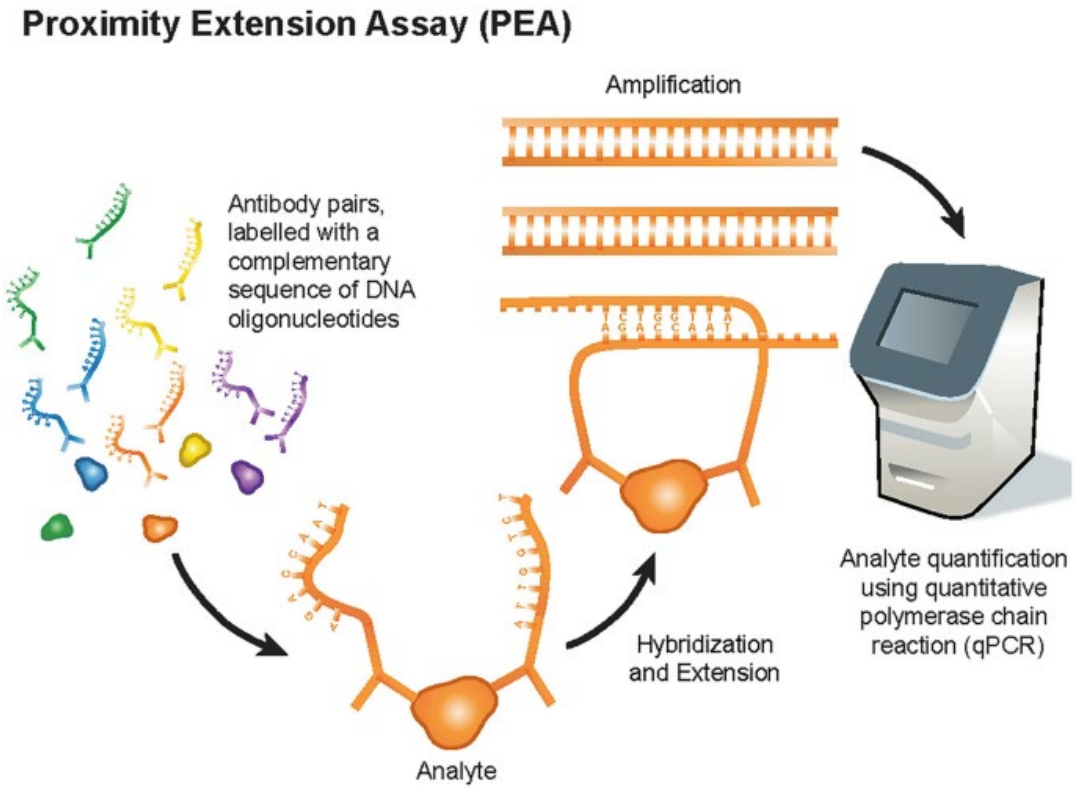


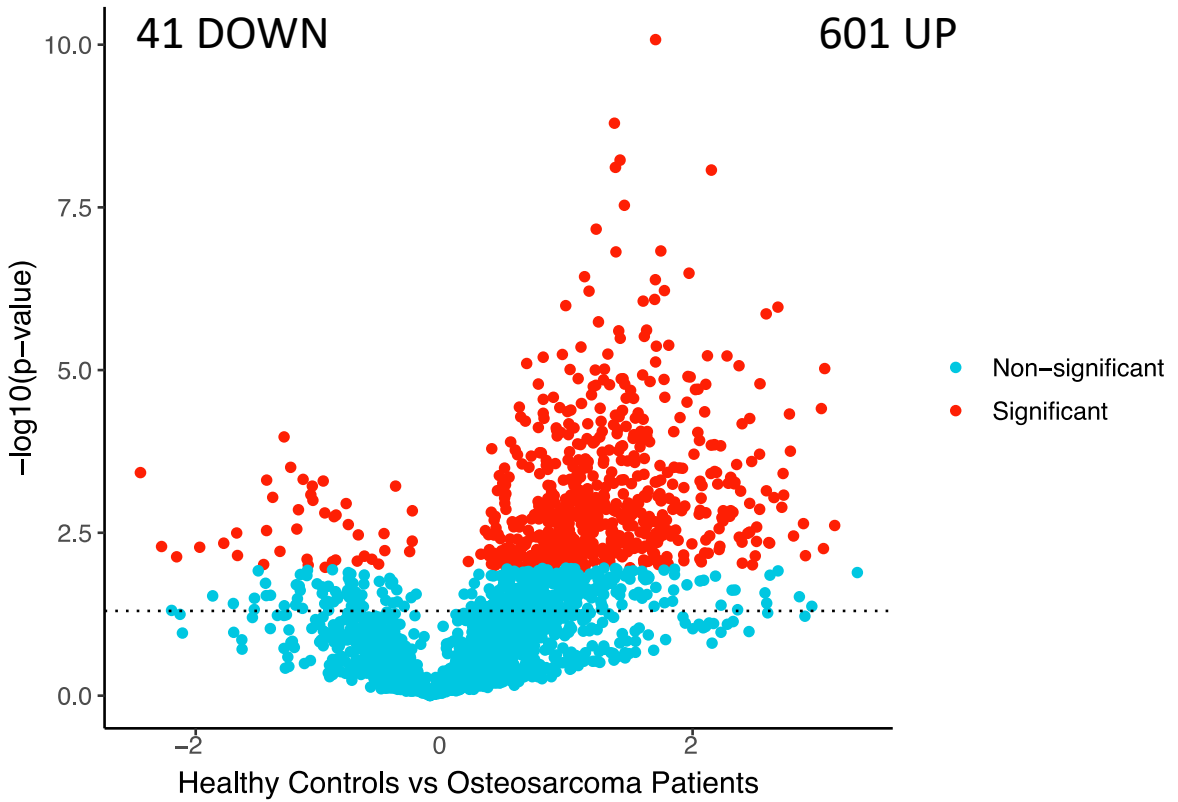


- EVs cargo molecules modulate the tumor microenvironment
- Both biomarkers and targets in pediatric sarcomas
- Easily accessible by liquid biopsy approaches

Soluble and particle proteome of pediatric osteosarcoma

Cohort composition:
14 CTL plasma
62 Osteosarcoma plasma
12 EVs fractions from OS longitudinal plasma

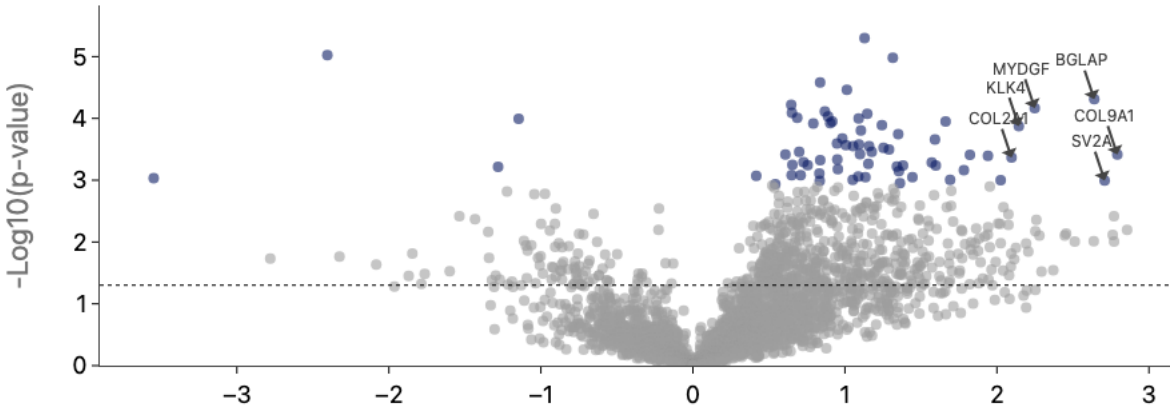




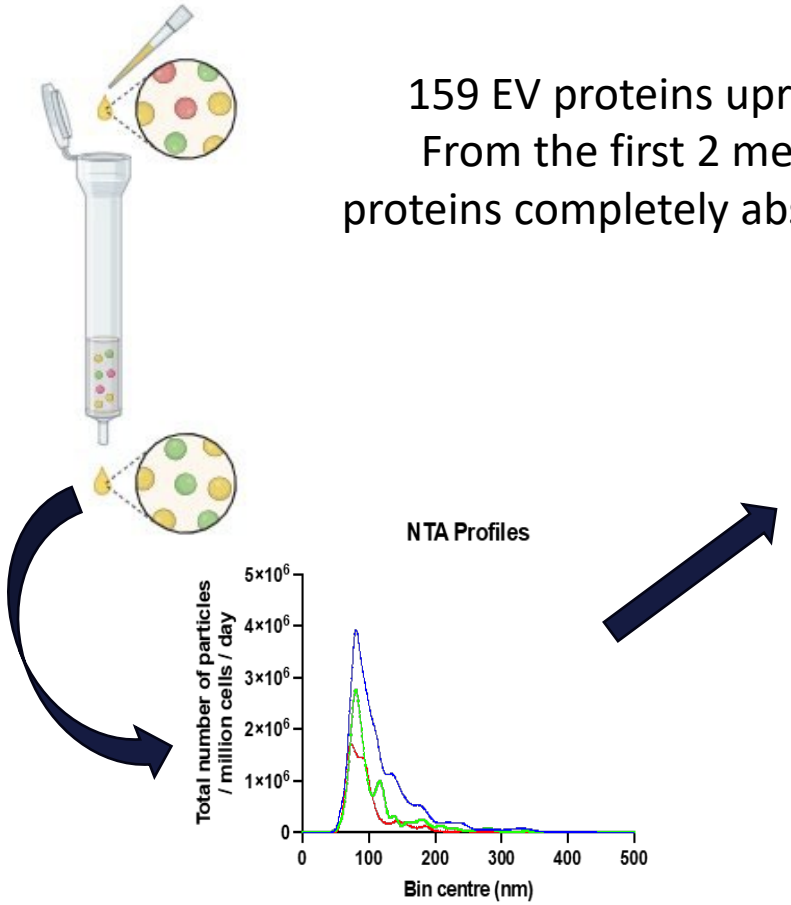
3,000 proteins
The method used by the Human Proteome Atlas

Cases only, biopsies (N20) = vs progressive (N=19)

69 DEG, 40 Higher progressive (NPX diff >1).



Targeted proteomics of blood derived EVs in patients with longitudinal collection, initial results.



159 EV proteins upregulated in blood EVs
From the first 2 metastatic patients four proteins completely absent at the time of biopsy

Aim 3
Prospective studies-> cfDNA and EV based longitudinal sampling

Surfaceome, immunopeptidome -> Novel immunotherapy targets

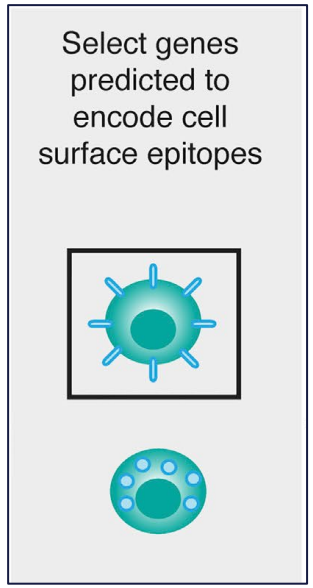
Why should we care about surface protein expression in childhood sarcomas?

1. Discover new targets for immunotherapy

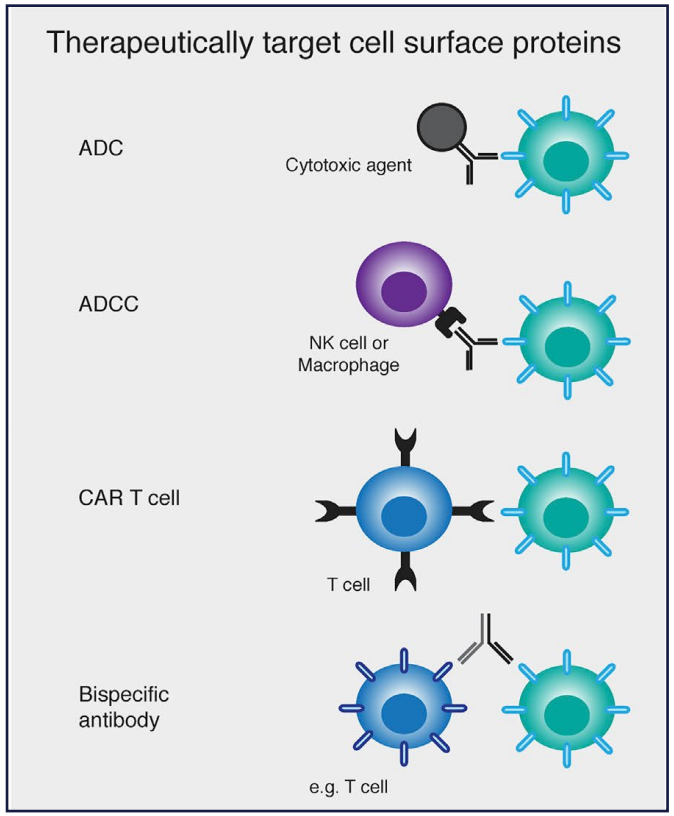
2. Uncover novel vulnerabilities

Focus on targetable surface proteins that confer critical functions to sarcoma cells, to avoid potential immune escape:

- Adaptation to new microenvironments
- Metabolic reprograming in the TME
- Cell-cell interactions in the TME
- Activation of essential cell signaling
- Metastatic competence



Identification of candidate targets for immunotherapy



Phage display biopanning to select binders for clinical development

Future directions

To expand on our investigation of the intratumoral heterogeneity of sarcoma metastasis

To develop clinically relevant models to study sarcoma metastasis for pre-clinical studies

To nominate targets for targeted approaches, based on surface proteins and metastases-enriched biological processes

Thank you to the The SMaRT Team

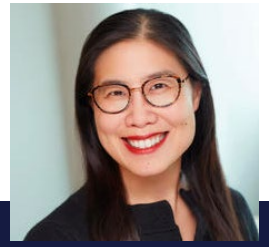
The Challenge

"To improve the outcome of high risk pediatric sarcomas by understanding and targeting the biology of metastatic disease"











Thank you
Merci

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Advancing Childhood Cancer Experience, Science & Survivorship
Agir contre le cancer des enfants avec succès

CIHR IRSC Canadian Institutes of Health Research Instituts de recherche en santé du Canada

Leveraging Human Rights to Clarify the Risk of Genetic Discrimination in Pediatric Oncology

Diya Uberoi, PhD

Genetic Discrimination Observatory, Associate Director, McGill University

January 28, 2025

Advancing Childhood Cancer Experience, Science & Survivorship
Agir contre le cancer des enfants avec succès

CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

Outline

1. Background
2. Aim
3. Research Questions & Methods
4. Going Forward

Human Rights and Pediatric Research

Informed Consent and Autonomy

Conducting **pediatric scientific research** poses a unique set of **ethical challenges**, particularly as it concerns informed consent and autonomy in a population with limited decision-making capabilities.

For example, minors may not fully comprehend the privacy implications associated with participating in genetic research and be more vulnerable to inducement.

Right to Science

However, we know that we need **data that is representative** of children in order to advance research for the benefit of children's health.

→ Right of the child?

What is Genetic Discrimination?

Defining Genetic Discrimination (GD):

“Genetic discrimination involves an individual or a group being negatively treated, unfairly profiled or harmed, relative to the rest of the population, on the basis of actual or presumed genetic characteristics”
(Kaiser et al. 2024)

Why is the Genetic Discriminatory Observatory Interested?

The Genetic Discrimination Observatory (GDO)

- Multidisciplinary network of scholars from around the globe
- Monitoring instances of GD and the creation of/changes to related legislation
- Creation of educational and legislative tools to address the phenomenon

Genetic Discrimination in Pediatric Research

Perceived Risk vs Actual Occurrence of GD

- GD is a concerning ethical issue. However, increasingly, evidence suggests that the perceived risk of GD heavily outweighs its actual occurrence.
- Canada has adopted the Genetic Non-Discrimination Act (GNDA)

In Pediatric Research

Researchers have an obligation to make potential participants aware of any associated risks. However, is it possible that overly-protective consent clauses are limiting participation in pediatric research? And what are the implications for the Rights to Health and Science, among others, which depend so heavily on the availability of relevant data?

Our Aim – Finding a Balance

Use human rights to see how we can promote the best interest of children, while also bringing forward principles that adequately protect them against the real ethical issues that arise in research.

Part I – In the Literature

Research Questions I & II

1. What is the real risk of GD in the context of pediatric oncology research?

2. How can human rights be leveraged to promote the best interest of the child in pediatric oncology research?

Methods

- Systematic literature review of empirical studies on GD in Canada

- Thorough exploration of human rights documents applicable to children in the health research context at the provincial, national, and international level

- Comparative analysis of research consent forms across Canada, France, and the UK

Part II – The Impacts of GD & Human Rights Awareness

Research Question III

3. Can research participation be improved by adopting consent clauses with nuanced language around GD that reflects the real risk of GD?

Methods

- Focus groups with parents and researchers to assess how knowledge of GD and human rights protections affect perceptions and concerns about the risks and benefits of participating in genetic research on pediatric cancers

Putting the Pieces Together

Informed by existing literature and the perspectives of affected community members, this project will allow for:

1. Further clarification of the real risk of GD
2. The development of informative guides for research ethics committees
3. The formulation of a model consent clause which reflects the actual risk of GD and ensures the adequate protection of participants' rights and data

gdo.global

company/genetic-discrimination-observatory/

/DGenetique

Interested to know more about our project?
Want to share your perspective with the team?
Don't hesitate to reach out to diya.uberoi@mcgill.ca!

CIHR IRSC Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Thank you
Merci

A big thank you to our sponsors and to all of you for making this possible!

AALL2131/EsPhALL2022:

An international pilot study of chemotherapy and tyrosine kinase inhibitor with blinatumomab in patients with newly-diagnosed Philadelphia chromosome-positive or ABL-class Philadelphia chromosome-like B-cell acute lymphoblastic leukemia

28 January 2025

Advancing Childhood Cancer Experience, Science & Survivorship
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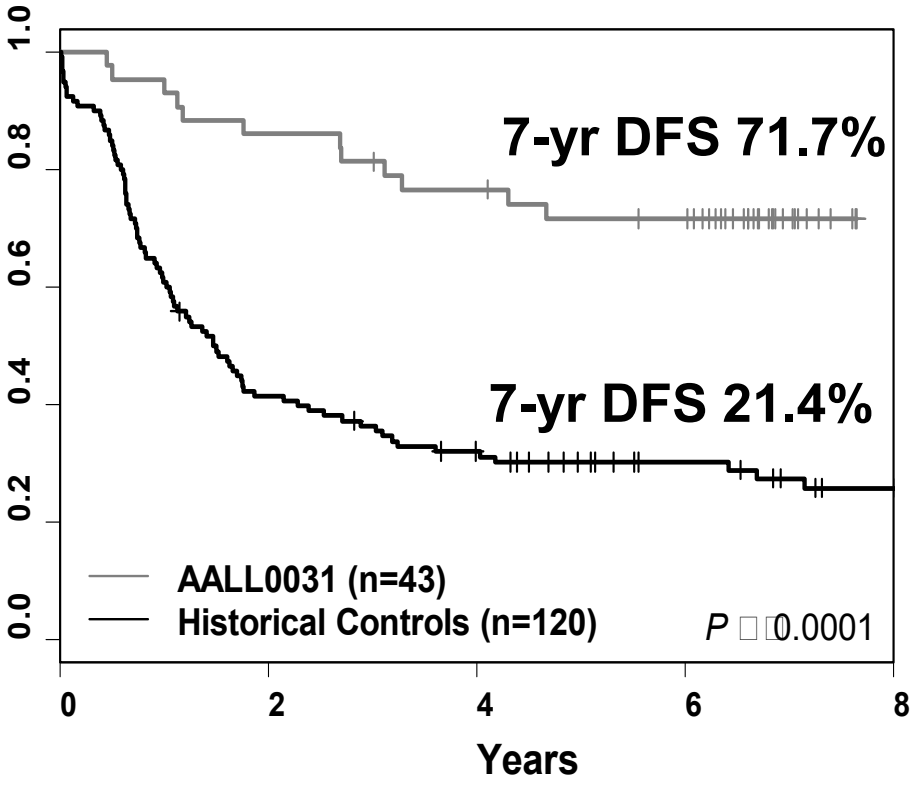
Ph+ and ABL-class Ph-like ALL are rare subtypes of B-ALL

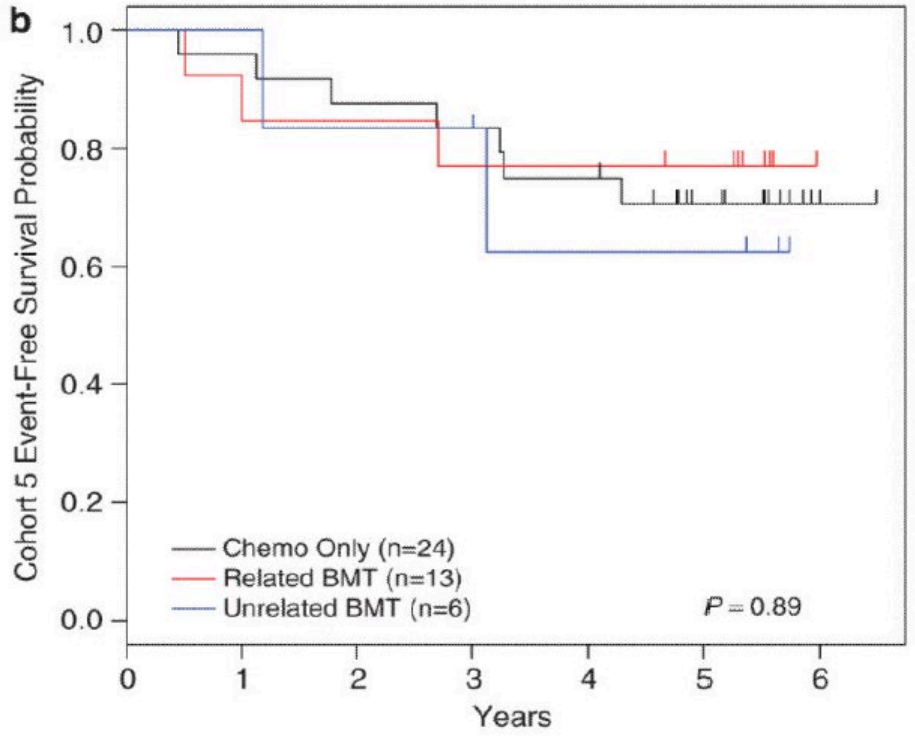
	NCI SR[1]	NCI HR[2]	16-39 yo[3]
N = total # of B-ALL	1023	1389	542
Ph+ ALL (%)	6 (**0.6**)	46 (**3.3**)	37 **(6.8)**
ABL-class Ph-like ALL (%)	2 **(0.2)**	40 **(2.9)**	11 **(2.0)**

3' kinase genes	5' fusion partner genes
ABL1	***CNTRL***, *CENPC*, ***ETV6***, *FOXP1*, ***INPP5D***, *LSM14A, NUP153*, ***NUP214***, *RANBP2*, ***RCSD1***, *SFPQ, SHIP1, SNX1, SNX2, SPTNA1, ZMIZ1*
ABL2	***EZR***, *PAG1*, ***RCSD1***, *ZC3HAV1*
CSF1R	*MEF2D*, ***NUMA1***, ***SSBP2***, *TBL1XR1*
PDGFRB	*ATF7IP, CD74*, ***EBF1***, *ETV6, GOLGA4*, ***PACSIN2***, *SNX29, SSBP2, TNIP1, ZEB2, ZMYND8, ZNF608*

[1] Roberts KG et al, **Blood**, 2018 [2] Reshmi SC et al, **Blood**, 2017 [3] Roberts KG et al, **NEJM**, 2014

Combination of chemotherapy and TKI improved the outcome of pediatric Ph+ALL





Schultz K et al., **Leukemia**, 2014

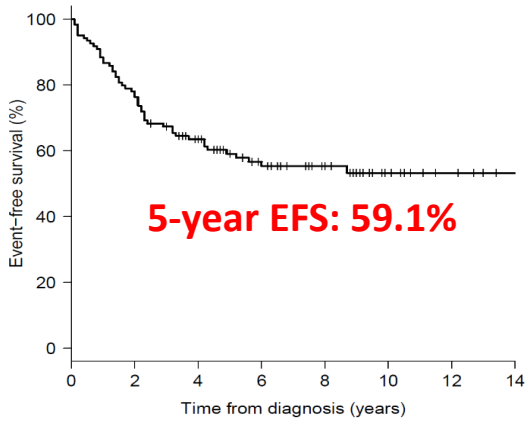
Relapses and treatment-related mortality in pediatric Ph+ALL remain significant in the TKI era

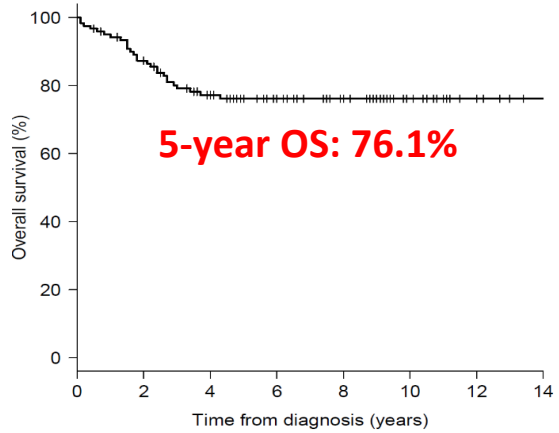
Ph⁺ALL trials	Years (# Pts)	Chemotherapy backbone	TKI	CRT	CR1 HSCT	CI of relapses	CI of remission deaths	EFS	OS
COG AALL0031[1] Cohort 5	2002-06 (49)	AALL0031	Imatinib 340 mg/m²	All	41%	5-yr: 21%	5-yr: 10%	5-yr: 68%	5-yr: 81%
EsPhALL 2004[2]	2004-09 (178)	BFM HR	Imatinib 300 mg/m²	All	81%	5-yr: 31%	5-yr: 9%	5-yr: 60%	5-yr: 72%
COG AALL0622[3]	2008-12 (60)	AALL0031	Dasatinib 60 mg/m²	CNS3 only	32%	5-yr: 35%	5-yr: 3%	5-yr: 60%	5-yr: 86%
EsPhALL 2010[4]	2010-14 (155)	BFM HR	Imatinib 300 mg/m²	All	38%	5-yr: 27%	5-yr: 16%	5-yr: 57%	5-yr: 72%
CA180-372/AALL1122[5]	2012-14 (106)	BFM HR	Dasatinib 60 mg/m²	CNS3 only	14%	5-yr: 36%	5-yr: 9%	5-yr: 55%	5-yr: 82%
CCCG-ALL-2015[6]	2015-18 (92)	Modified Total XV-XVI	Dasatinib 80 mg/m²	None	1.1%	4-yr: 20%	4-yr: 6%	4-yr: 71% 5-yr: 60%	4-yr: 88% 5-yr: 74%
	2015-18 (97)	Modified Total XV-XVI	Imatinib 300 mg/m²	None	3.1%	4-yr: 34%	4-yr: 4%	4-yr: 49% 5-yr: 39%	4-yr: 69% 5-yr: 72%

[1]Schultz KR et al., **Leukemia**, 2014
[2]Biondi A et al., **Haematologica**, 2019
[3]Slayton WB et al., **JCO**, 2018
[4]Biondi A et al., **Lancet Haematology**, 2018
[5]Hunger SP et al., **Lancet Haematology**, 2023.
[6]Shen SH et al., **JAMA Oncology**, 2020

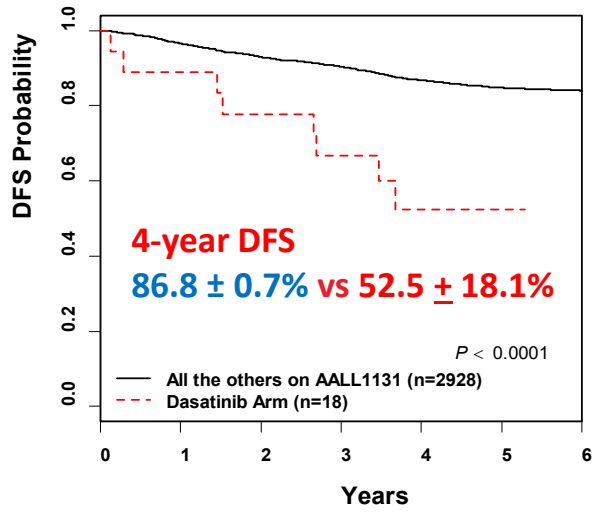
Poor outcomes of ABL-class Ph-like B-ALL despite the addition of dasatinib to chemotherapy

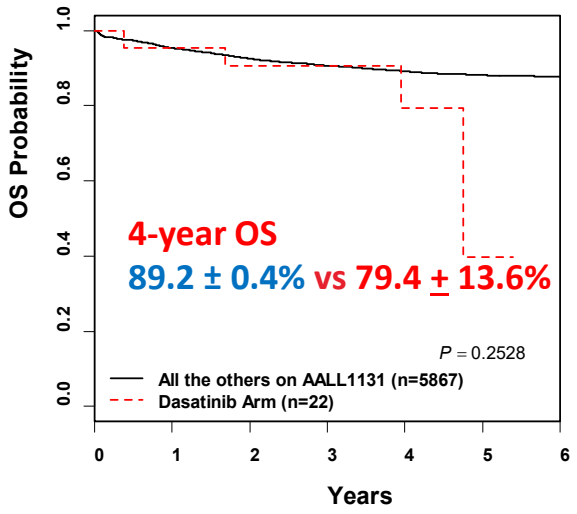
Chemotherapy alone[1]





Chemotherapy + Dasatinib[2]



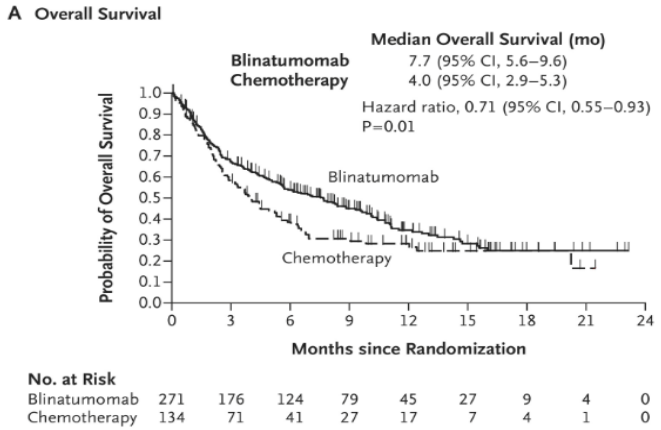


[1]Den Boer ML et al., **Lancet Haematology**, 2021 [2]Salzer W et al., **ASH Annual Meeting**, 2023

Blinatumomab improves survival in Ph-negative B-ALL across the age and disease spectrum

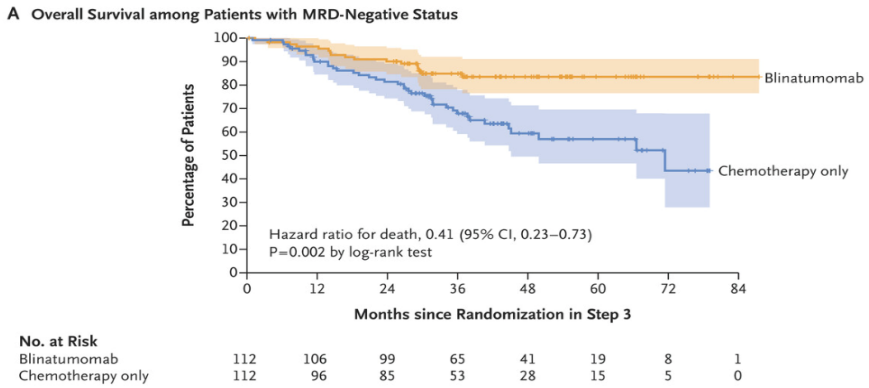
ADULTS

RELAPSED



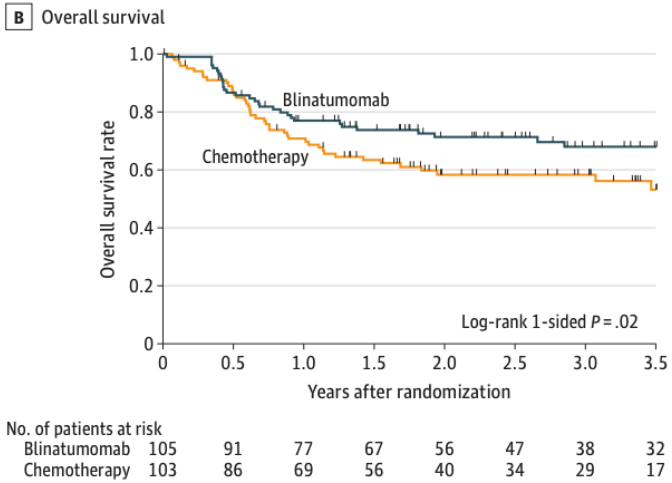
Kantarjian H et al., NEJM, 2017

NEWLY-DIAGNOSED

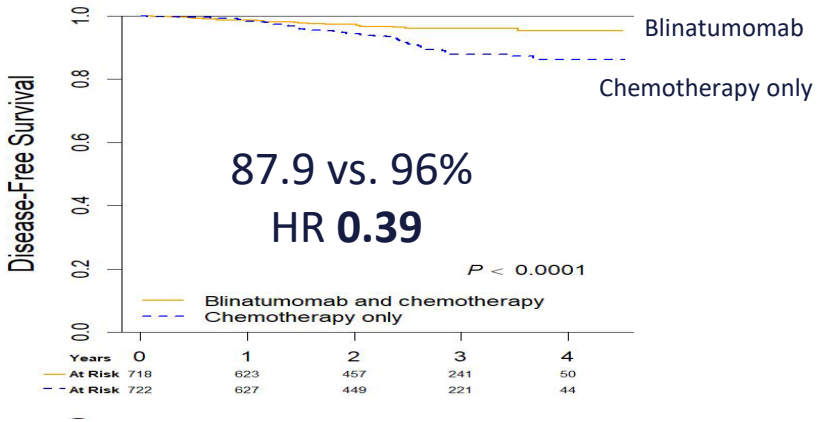


Litzow MR et al., NEJM, 2024

CHILDREN



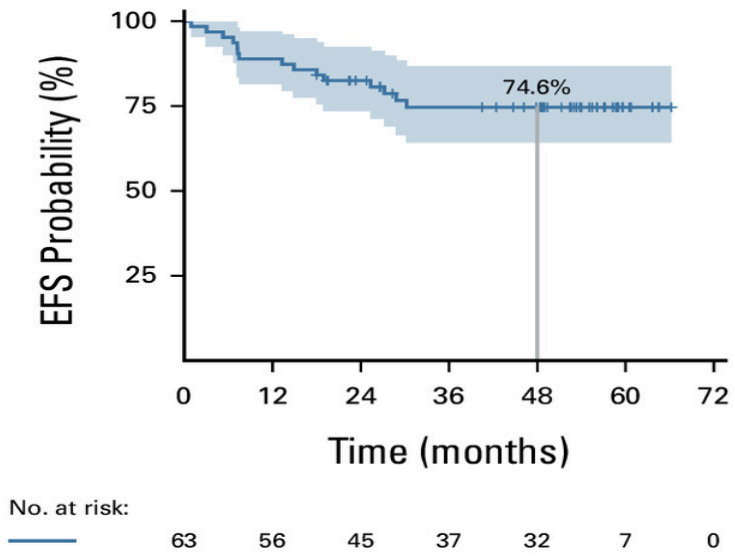
Brown PA et al., JAMA, 2021

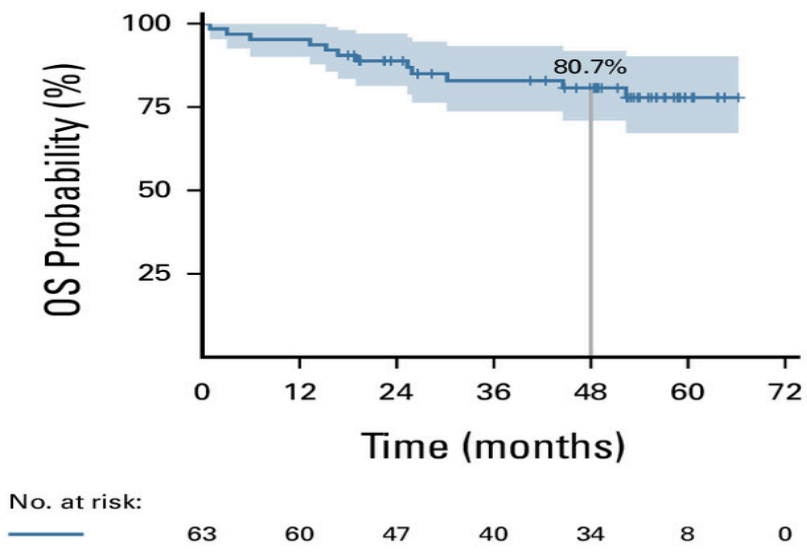


Gupta S et al., NEJM, 2024

Chemotherapy-free approach with blinatumomab + TKI in *de novo* adult Ph+ALL is feasible and results in favorable outcomes

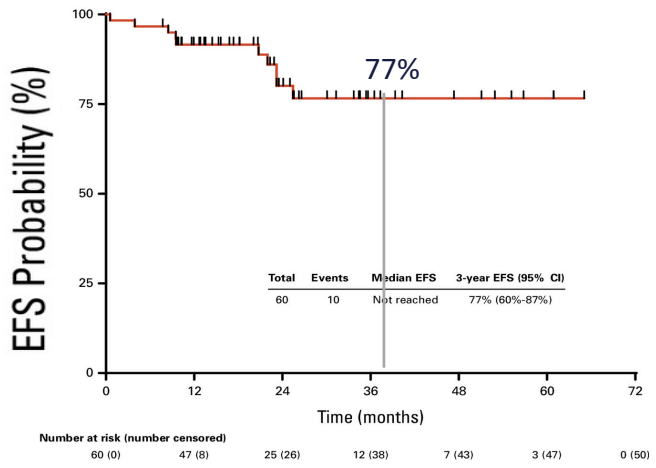
Blinatumomab + dasatinib

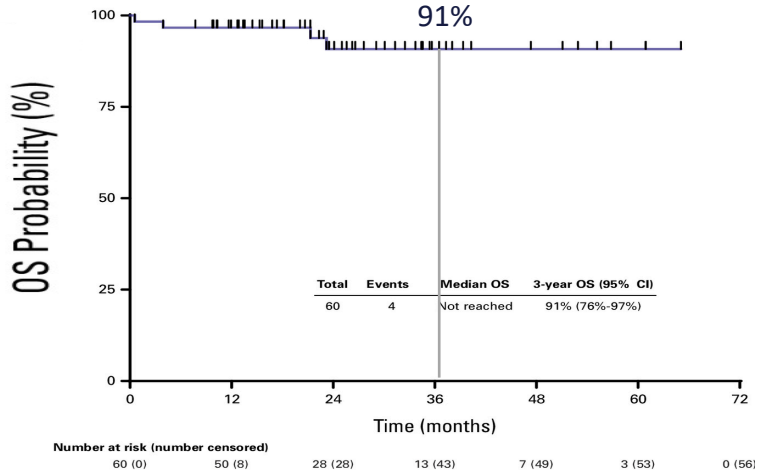




Foà R et al., JCO, 2024

Blinatumomab + ponatinib

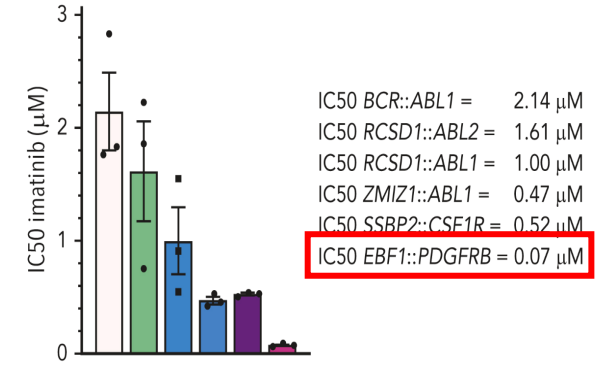




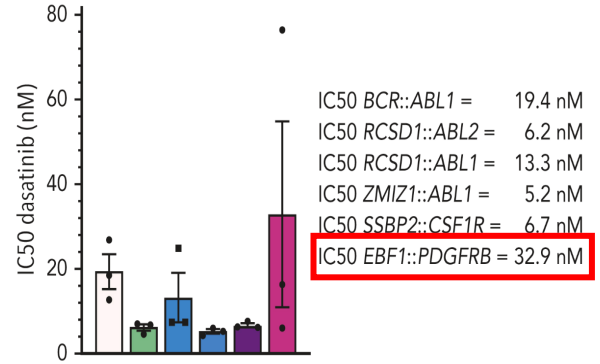
Kantarjian H et al., JCO, 2024

Rationale for imatinib in *PDGFRB*-rearranged Ph-like B-ALL

in vitro[1]

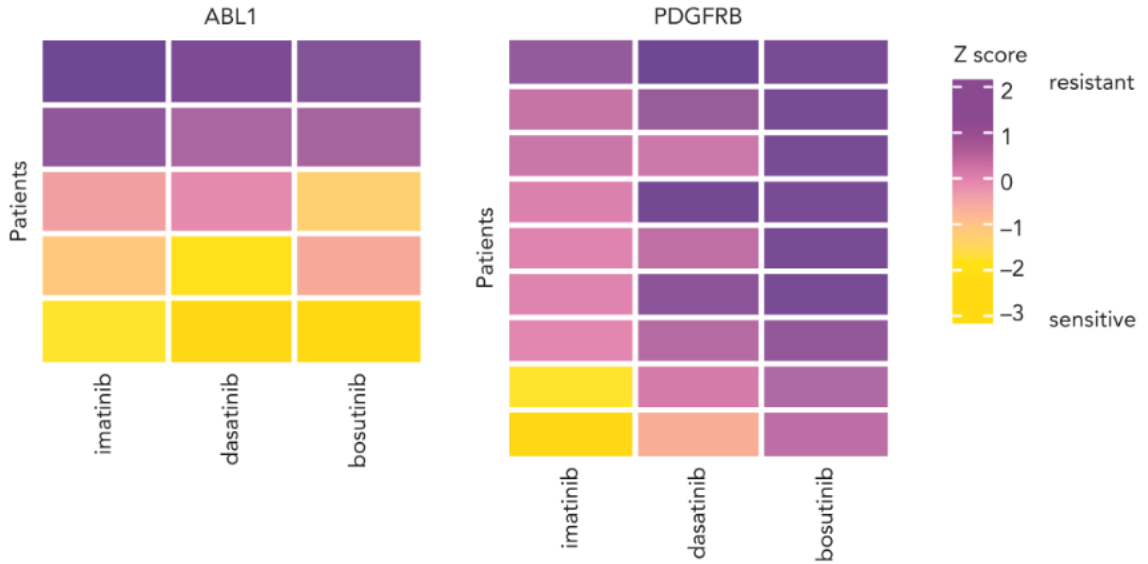


Imatinib



Dasatinib

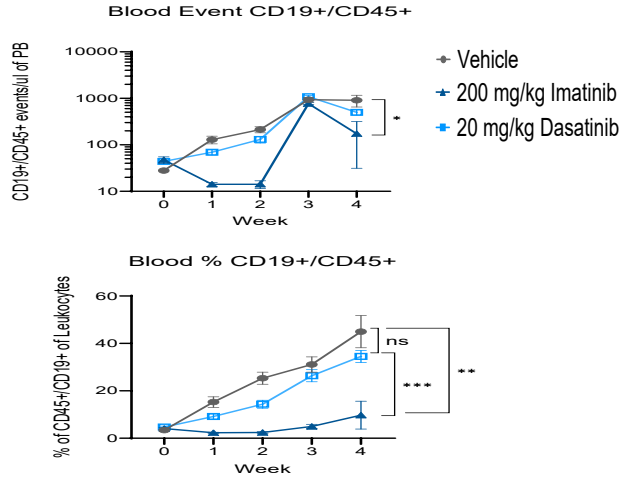
ex vivo[1]



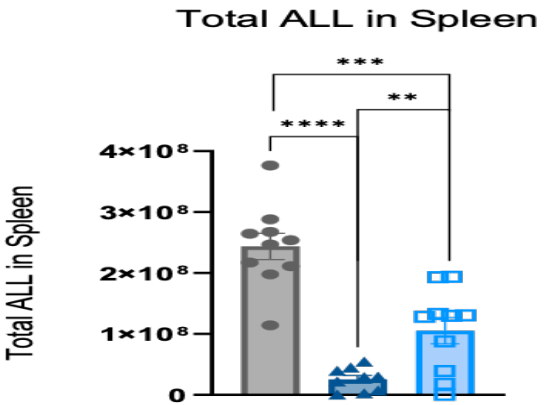
ABL1	Rho	*P*-value
ima-dasa	1	.02
ima-bosu	0.9	.08
dasa-bosu	0.9	.08

PDGFRB	Rho	*P*-value
ima-dasa	0.68	.05
ima-bosu	0.84	.004
dasa-bosu	0.7	.03

in vivo[2]

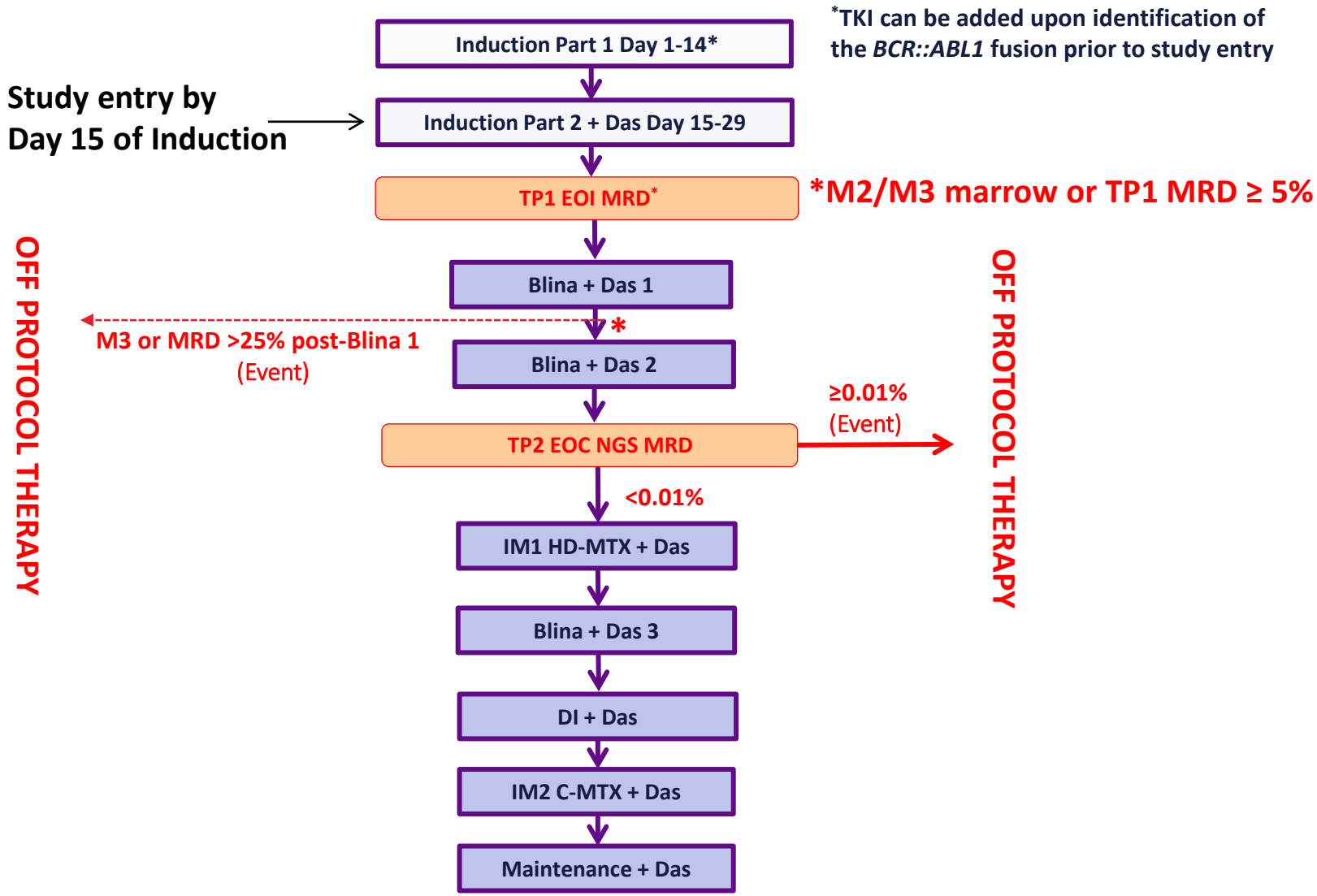


NL432 (*EBF1::PDGFRB*)

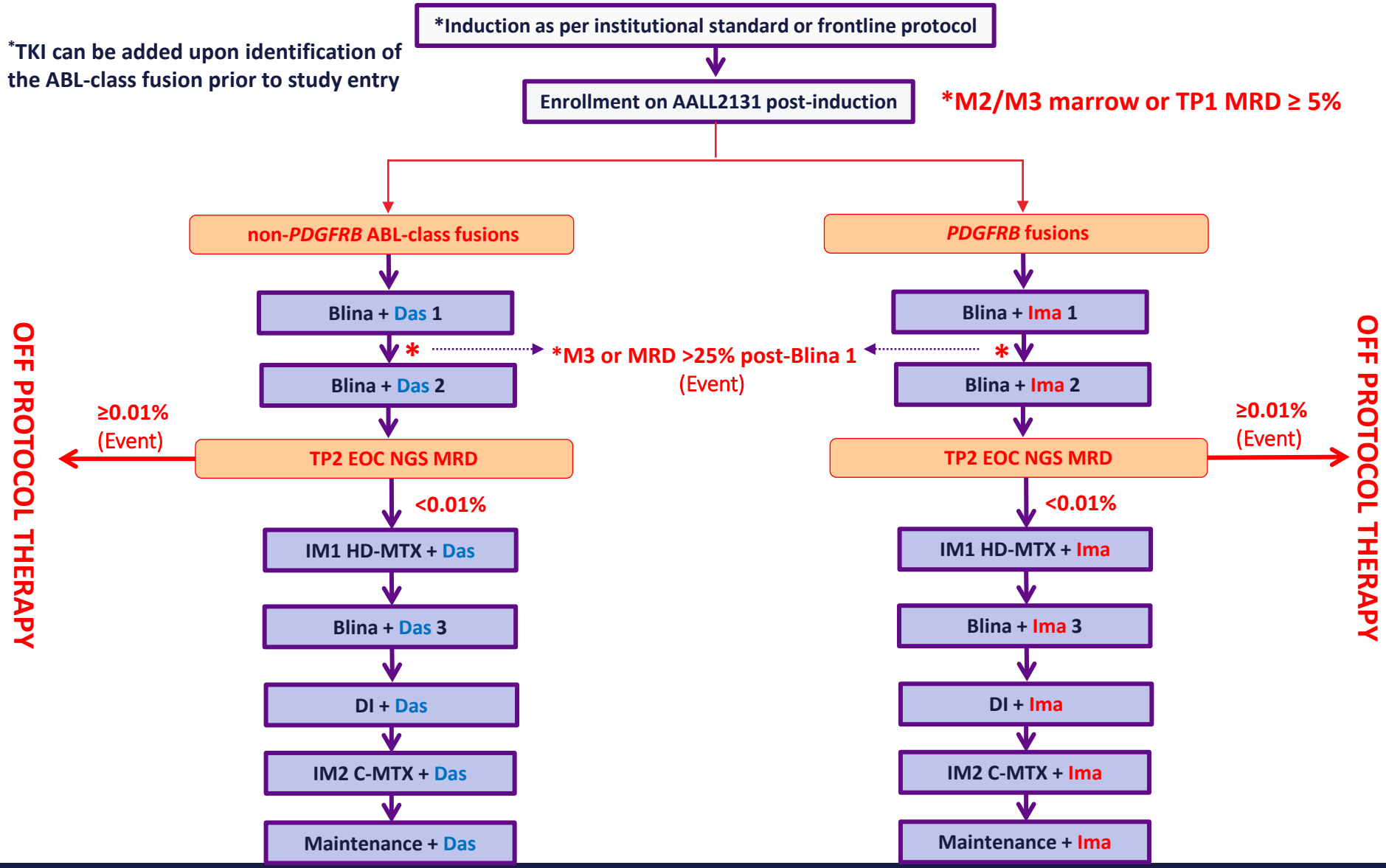


[1]Van Outersterp I et al., **Blood**, 2024. [2]Unpublished data, Tasian Lab

Ph+ALL


*TKI can be added upon identification of the BCR::ABL1 fusion prior to study entry
Study entry by Day 15 of Induction
Induction Part 1 Day 1-14*
Induction Part 2 + Das Day 15-29
TP1 EOI MRD*
*M2/M3 marrow or TP1 MRD ≥ 5%
OFF PROTOCOL THERAPY
Blina + Das 1
*
M3 or MRD >25% post-Blina 1
(Event)
Blina + Das 2
≥0.01%
(Event)
TP2 EOC NGS MRD
OFF PROTOCOL THERAPY
<0.01%
IM1 HD-MTX + Das
Blina + Das 3
DI + Das
IM2 C-MTX + Das
Maintenance + Das

ABL-class Ph-like B-ALL



Key eligibility criteria

- **Age**: >365 days to <22 years (for COG sites) and up to <46 years (for the ALLTogether Consortium)
- **Disease**: newly-diagnosed CD19-positive B-ALL
- **Other key requirements**: ABL-class gene rearrangements involving *ABL1* (including *BCR::ABL1*), *ABL2, CSF1R,* or *PDGFRB*) should be confirmed prior to study entry. Confirmation of the 5' fusion partner gene is not required for study enrollment.
- Previous treatment with either imatinib or dasatinib is permitted prior to study entry
- Adequate organ function obtained within 7 days prior to enrollment

Primary aims

- To estimate the 3-year EFS of newly-diagnosed patients with Ph^+ B-ALL
- To estimate the 3-year EFS of newly-diagnosed patients with ABL-class Ph-like B-ALL
- To describe the safety and toxicity profile of this new chemo-immunotherapy regimen with continuous TKI in patients with newly-diagnosed Ph^+ and ABL-class Ph-like ALL

Statistical plan

- Two separate strata
  - 100 Ph^+ B-ALL
  - 100 ABL-class Ph-like B-ALL
  - Enrollment anticipated to take 2 to 2.5 years
- With 100 Ph^+ B-ALL patients, we can estimate 3-year EFS with a maximum standard error of 4.8%.
- With 100 ABL-class Ph-like B-ALL patients, we can estimate 3-year EFS with a maximum standard error of 4.8%.

Current status

- Initial full concept approved by:
  - COG Scientific Council – October 2021
  - NCI PLLSC – July 15, 2022
- Protocol development and submission:
  - CTEP – approval-on-hold on February 16, 2024
  - Pediatric CIRB – February 22, 2024
  - FDA – July 11, 2024
- Amendment summary approved by:
  - COG Scientific Council – August 8, 2024
  - NCI PLLSC – September 16, 2024
  - CTEP protocol submission – December 5, 2024
- Anticipated study activation – Q1 of 2025

ACCESS support to AALL2131

- Cover the costs for NGS MRD for all Canadian patients enrolled on the trial
  - Provide ACCESS to Canadian patients to:
    1. Most sensitive MRD assay
    2. Innovative trial

- Provide research support to CHU Sainte-Justine's Clinical Pharmacology Team to lead a trial-embedded correlative study evaluating treatment response/toxicities by measuring TKI levels in the blood and cerebral spinal fluid
  - Support and promote Canadian investigator-initiated projects

Acknowledgments

COG AALL2131 Study Committee

- Sarah Tasian (Vice-Chair)
- Lewis Silverman (Vice-Chair)
- Mini Devidas (Senior Statistician)
- Mignon Loh
- Dave Teachey
- Steve Hunger
- Lia Gore
- Elizabeth Raetz
- Kirk Schultz
- Loretta Li
- Maureen O'Brien
- Sarah Alexander
- Tamara Miller
- Jessica Stiefel
- Mary Shago
- Drew Carroll
- Fady Mikhail
- Shalini Reshmi
- Laura Ramsey
- Derek Tsang
- Natalie Logie
- Shelby Smith
- Allison Lam
- Kim Derr
- Rachel Vasquez
- Charlotte Wood

AIEOP-BFM

- Andrea Biondi
- Valentino Conter
- Gunnar Cario
- Maria Grazia Valsecchi
- Paola de Lorenzo
- Veronica Leoni

ALLTogether

- Rob Pieters
- Mats Heyman
- Ajay Vora
- Andre Baruchel
- Kjeld Schmiegelow
- Cecilie Rank
- Inge van der Sluis
- Virginie Gandemer

PATIENTS & FAMILIES!

Thank you
Merci

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Advancing Childhood Cancer Experience, Science & Survivorship
Agir contre le cancer des enfants avec succès

CIHR IRSC Canadian Institutes of Health Research Instituts de recherche en santé du Canada

Collection of Sensitive Sociodemographic Information in Canada

Stacey Marjerrison, MD, MSc, FRCPC

On behalf of the ACCESS SJII Committee

January 28, 2024

Advancing Childhood Cancer Experience, Science & Survivorship
Agir contre le cancer des enfants avec succès

CIHR IRSC Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

Overview

- Current landscape of sensitive SD data collection in Canada
- An ACCESS proposal example – American vs. Canadian differences in data standards
- Mapping a path forward

Current Landscape of Collection of Sensitive Sociodemographic Data in Canada

What is Potentially Sensitive Sociodemographic Information?

Information including but not limited to:

- Sex
- Gender
- Sexual orientation
- Race
- Ethnicity
- Indigenous identity
- Ability/disability
- Genetic diagnoses
- Family structure
- Finances
- Employment
- Education, Immigration, etc.

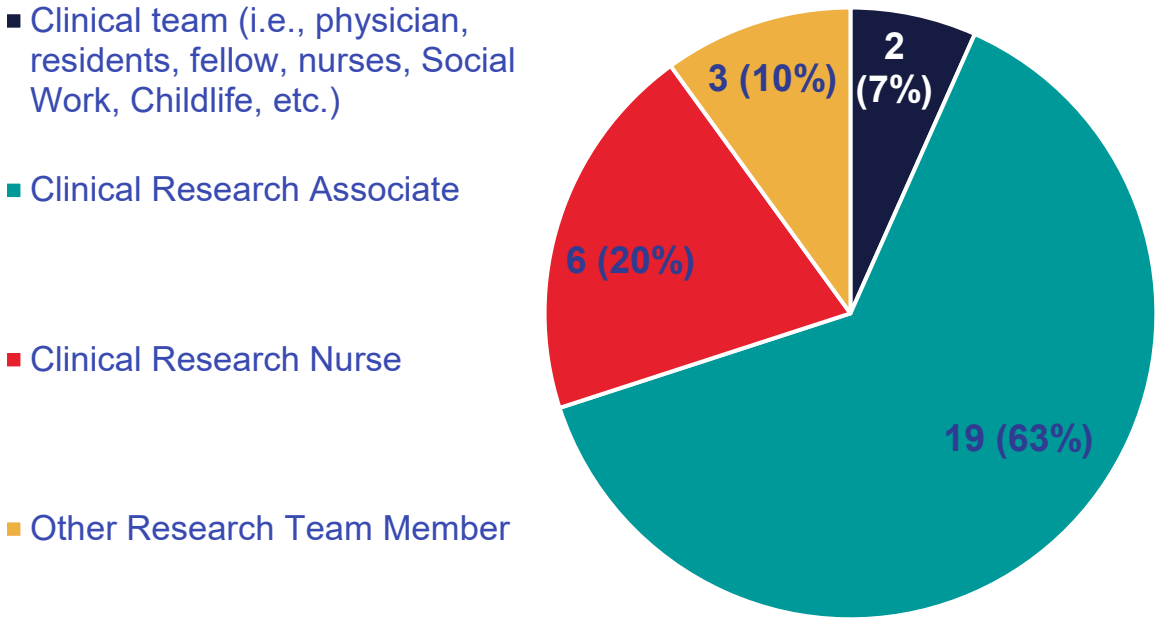
Canadian Childhood Cancer Data Sources

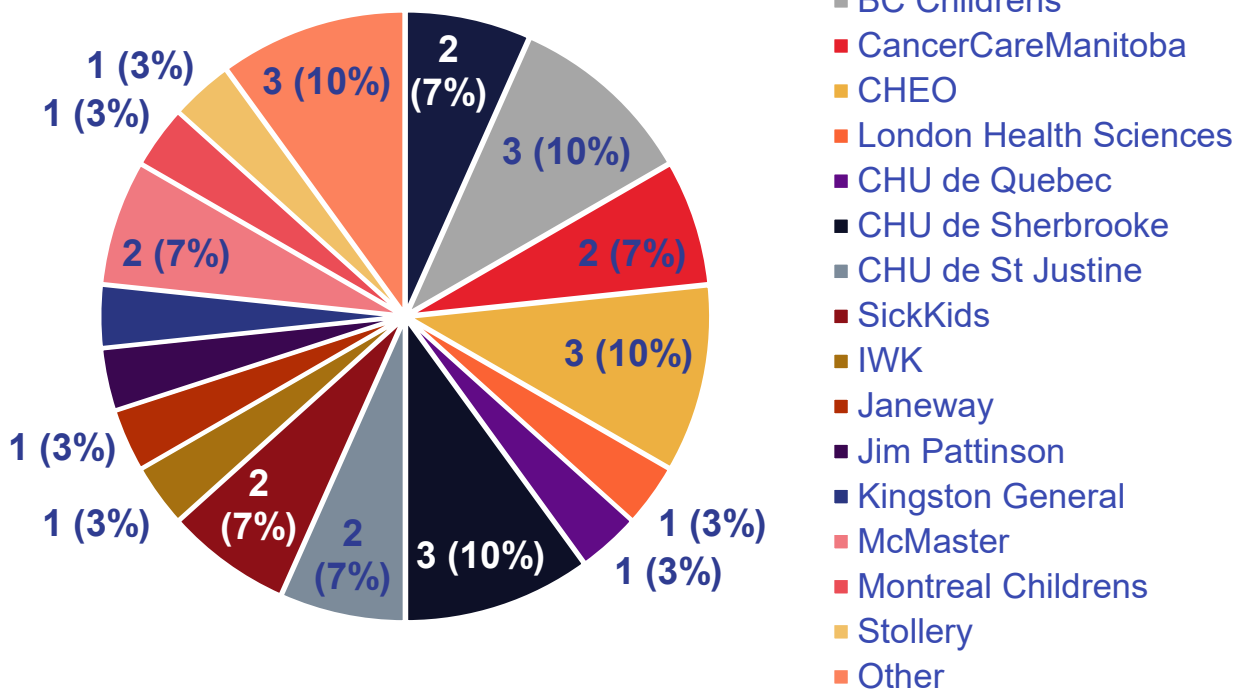
Administrative & Billing Data	• Ex: ICES, StatsCan • Difficult patient identification, linkages possible, limited individual socio-demographics
Cancer Registry Data	• Ex: CYP-C, POGONIS • Comprehensive patient enrolment, linkage possible, limited socio-demographics
Clinical Trial Data	• Ex: Children's Oncology Group (COG) • Individual-level data, limited to study questions, only those who choose to enroll
Institutional Data	• Ex: McMaster, SickKids, Alberta Children's, IWK… • Permits detailed analysis, but limited sample size & generalizability

Adapted from: https://ascopubs.org/doi/pdf/10.1200/EDBK_320499

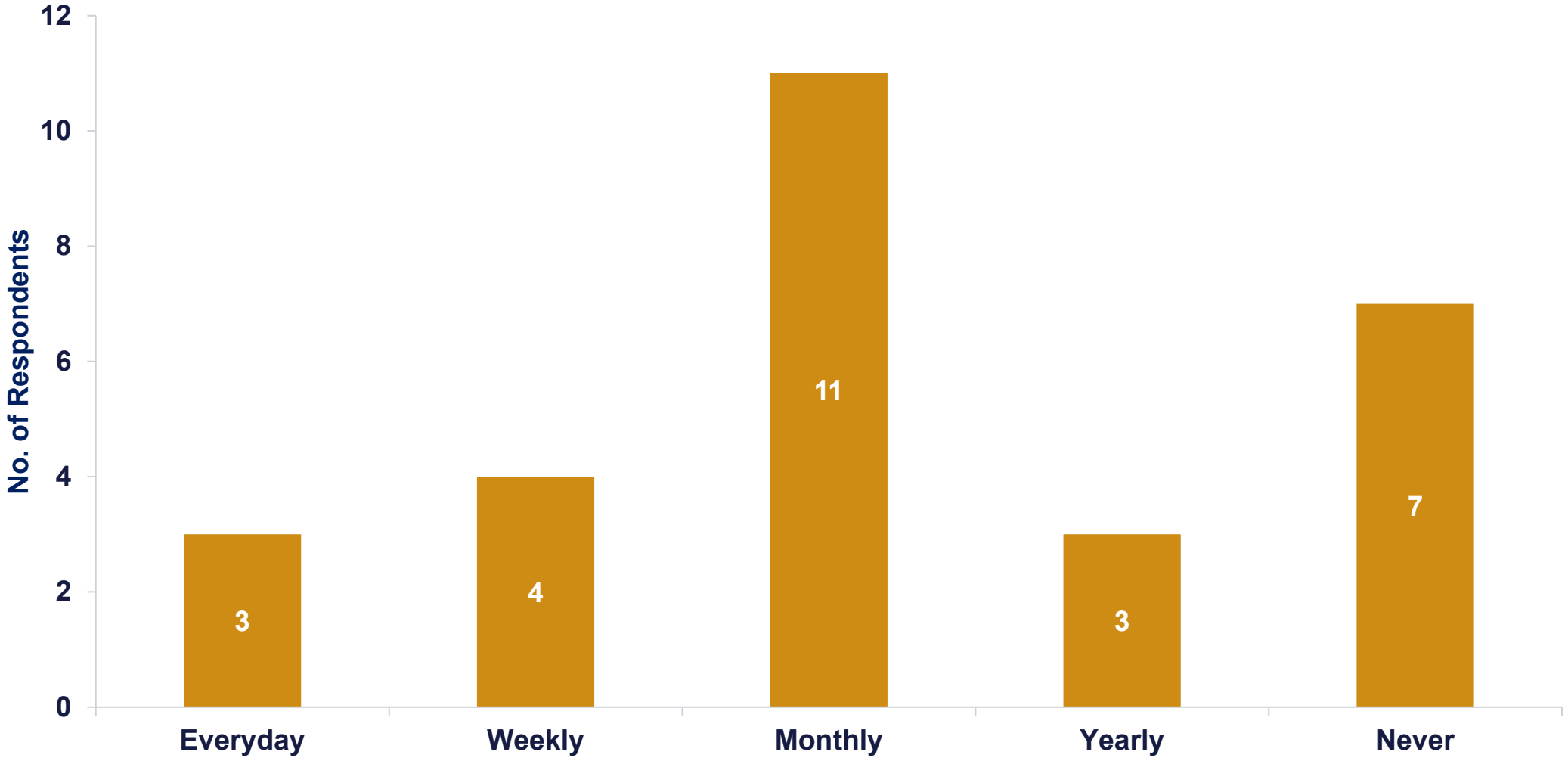
Canadian Survey of Research Staff

30 research staff in spring 2024 asked about collection of sensitive sociodemographic information

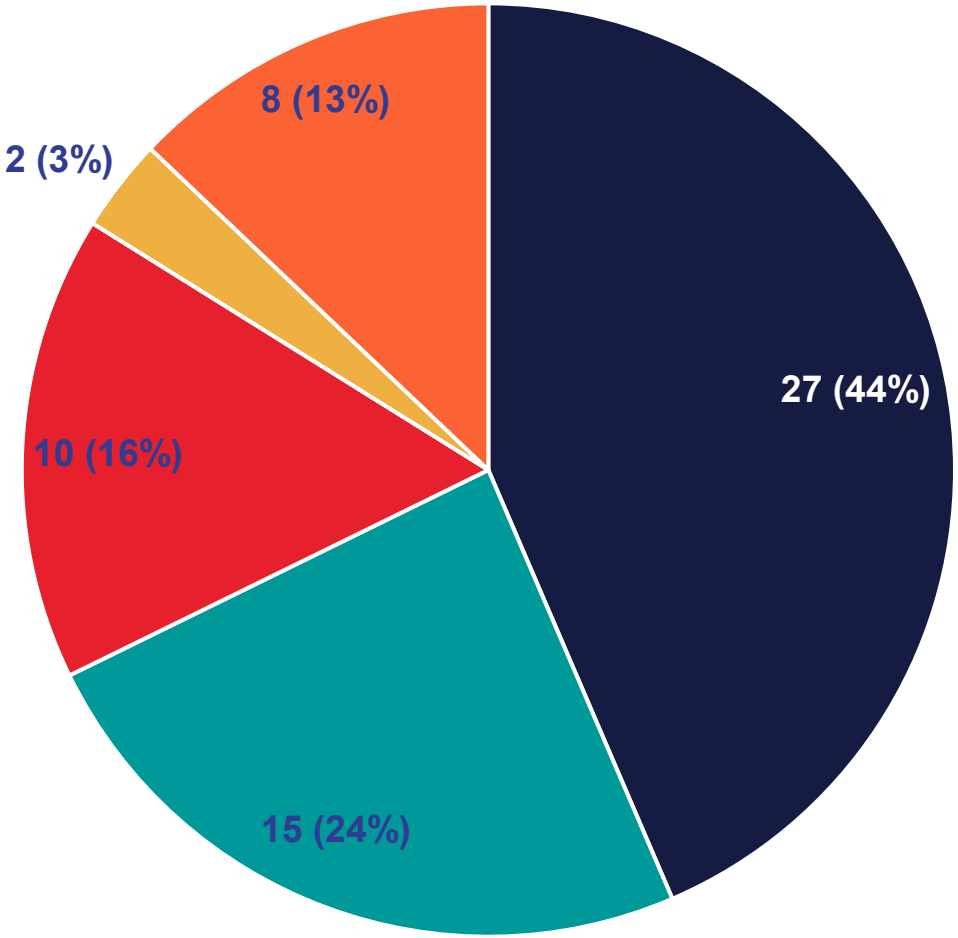




How often does your team ask this information?

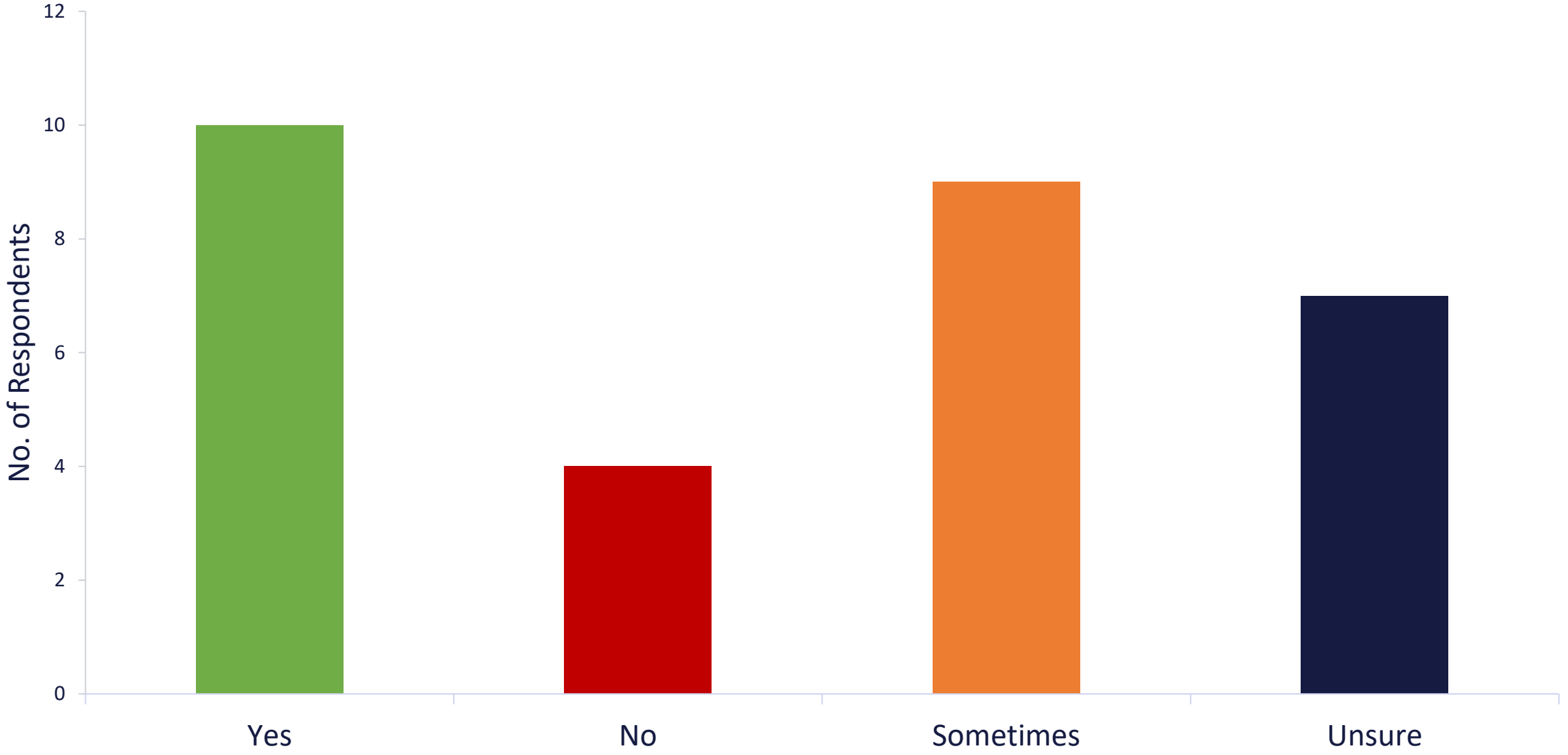


Who collects this information?



- Clinical team (i.e., physician, residents, fellow, nurses, Social Work, Childlife, etc.)
- Clinical Research Nurse
- Clinical Research Associate
- Other research team member
- Self-Reported by patient

Is this information self-reported?

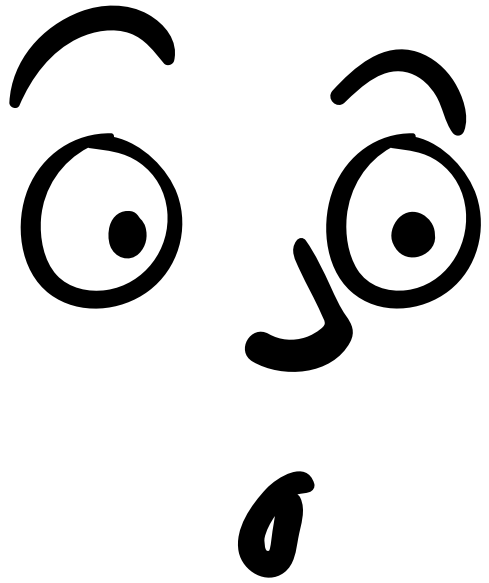


ACCESS Project Proposal – Harmonizing Canadian & American Data Standards for Race/ethnicity

Background: AALL2131 Proposal to ACCESS

- Request was to fund NGS sequencing to allow Canadian sites to participate in a study of Dasatinib +/- Blinatumumab in Ph+ ALL patients

- Racial categories to be collected based on NCI:
  - American Indian/Alaska Native
  - Asian
  - Native Hawaiian or Other Pacific Islander
  - Black or African American
  - White
  - More than one Race



Canadian Categorizations

POGO
PEDIATRIC ONCOLOGY GROUP OF ONTARIO
FOR KIDS WITH CANCER
FOR NOW, FOR LIFE.

Children's Cancer & Blood Disorders

access acces

Based on CIHI

CIHI ICIS

Canadian Institute for Health Information

Institut canadien d'information sur la santé

access acces

CIHI Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada

What are important considerations when using or interpreting race and Indigenous identity data?

"The most important consideration when interpreting disaggregated data by race and Indigenous identity is clarity on what is being measured. Disaggregated data is a critical tool that helps make visible the ways in which structural racism, systemic white supremacy and social exclusion both harm Indigenous and racialized peoples and sustain unearned privilege for white settlers. By collecting race and Indigenous identifiers, and ensuring they are used in a good way in partnership with BIPOC [Black, Indigenous and People of Colour] collectives, we can take collaborative actions towards our fully realized health and wellness through evidence-based and self-determined policies, programs, and services."

— Dr. Danièle Behn Smith, Deputy Provincial Health Officer, Indigenous Health, Ministry of Health, Government of British Columbia

Indigenous Identity Data Standard

Table 1 Indigenous identity question and responses*

Question: Do you identify as First Nations, Inuk/Inuit and/or Métis?

Response categories (select all that apply)
Yes, First Nations
Yes, Inuk/Inuit
Yes, Métis
No
Do not know
Prefer not to answer

Note

* The implementation of the Indigenous identity data standard should include data governance agreements, engagement with Indigenous groups, and processes related to culturally safe and appropriate data collection.

Race-Based Data Standard

Table 2 Race-based question and responses*

Question: In our society, people are often described by their race or racial background. These are not based in science, but our race may influence the way we are treated by individuals and institutions, and this may affect our health. Which category(ies) best describes you? Check all that apply:†

Response category	Examples
Black	African, African Canadian, Afro-Caribbean descent
East Asian	Chinese, Japanese, Korean, Taiwanese descent
Indigenous (First Nations, Inuk/Inuit, Métis)‡	First Nations, Inuk/Inuit, Métis descent
Latin American	Hispanic or Latin American descent
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish)
South Asian	South Asian descent (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan)
Southeast Asian	Cambodian, Filipino, Indonesian, Thai, Vietnamese, or other Southeast Asian descent
White	European descent
Another race category *Optional* — please specify: [open text]	Includes values not described above
Do not know	Not applicable
Prefer not to answer	Not applicable

Notes

* The collection of race-based and Indigenous data should involve community engagement to mitigate the risk of harm to individuals and communities, and to ensure the safe and appropriate use of the data.

† Individuals who identify as mixed race can select all categories that apply.

‡ Distinctions-based approaches — that is, separately identifying First Nations, Inuit and Métis Peoples — may be preferred.

COG Racial & Ethnic Categorizations

CHILDREN'S ONCOLOGY GROUP

Based on NIH

National Institutes of Health

NIH Definitions (OMB Directive 15)

- **American Indian or Alaska Native**: A person having origins in any of the original peoples of North and South America, and who maintain tribal affiliations or community attachment
- **Asian**: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent
- **Black or African American**: A person having origins in any of the black racial groups of Africa
- **Hispanic or Latino**: A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture origin regardless of race
- **Native Hawaiian or Other Pacific Islander**: A person having origins in any of the original peoples of Hawaii, Guam, Samoa or other Pacific Islands
- **White**: A person having origins in the original peoples of Europe, the Middle East or North Africa

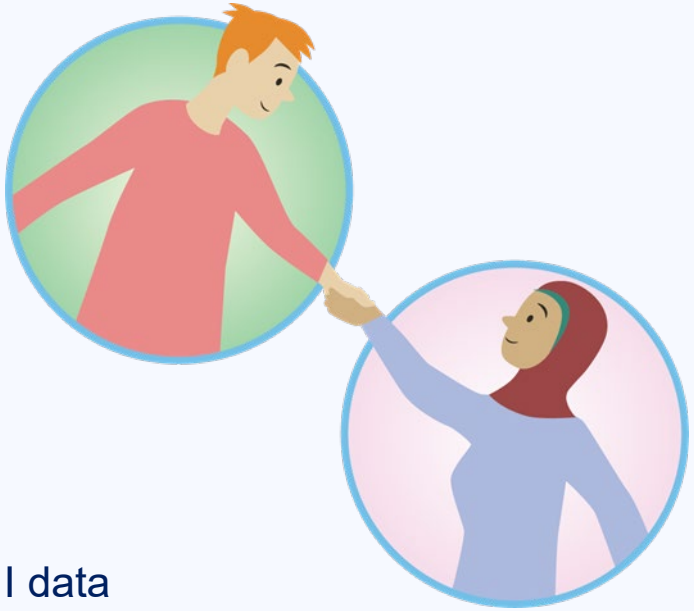
Household Sociodemographic Surveys

- However – some studies are collecting more broad and inclusive information as part of the individual studies
- This information is self-reported and contains broader racial and ethnic data, as well as other sociodemographic information

Mapping a Path Forward

Discussions at the COG Meeting & Since

- Within the Canadian contingent:
  - How do we collect this information standardly?
  - Who should ask the questions? Required training?
  - Where should the data be held?

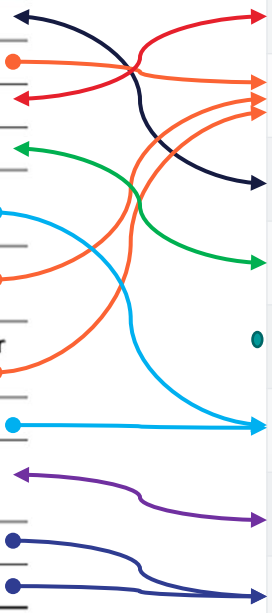


- With American counterparts:
  - Diversity & Disparities Community:
    - How to include appropriate categories for Canadian Families → Shared CIHI data
    - How to approach consolidating American & Canadian categories??? Mapping vs. consolidating?
    - For future state – new more inclusive names?
  - Registration community:
    - Remains a challenge since collection of this data in this format is US government mandated

Mapping Race/Ethnicity

Canadian

Response category	Examples
Black	African, African Canadian, Afro-Caribbean descent
East Asian	Chinese, Japanese, Korean, Taiwanese descent
Indigenous (First Nations, Inuk/Inuit, Métis)[‡]	First Nations, Inuk/Inuit, Métis descent
Latin American	Hispanic or Latin American descent
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish)
South Asian	South Asian descent (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan)
Southeast Asian	Cambodian, Filipino, Indonesian, Thai, Vietnamese, or other Southeast Asian descent
White	European descent
Another race category *Optional* — please specify: [open text]	Includes values not described above
Do not know	Not applicable
Prefer not to answer	Not applicable



American

Race/ethnicity
American Indian/Alaska Native
Asian
Black or African American
Hispanic or Latino
Native Hawaiian/Pacific Islander
White
Another
Unknown

Lots of work remaining…

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Agir Contre le Cancer des Enfants avec Succès

CHILDREN'S ONCOLOGY GROUP

CANADIAN PARTNERSHIP AGAINST CANCER

Children's Cancer & Blood Disorders

Public Health Agency of Canada | Agence de la santé publique du Canada

Canadian Cancer Clinical Trials Network

CANCER IN YOUNG PEOPLE IN CANADA PROGRAM
PROGRAMME CANCER CHEZ LES JEUNES AU CANADA

CIHR IRSC

… but many partners in this work

Thank you
Merci

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Knowledge Mobilization Group Spotlight Projects

ACCESS Book Club & Special ACCESS Collection of Frontiers for Young Minds

Presented by Stephanie Reid and Karen Haas

ACCESS Annual Meeting

January 28, 2025

Stephanie Reid

- Knowledge Mobilization Group Co-Lead & PWLE

- Qualifying 4th year Bachelor Social Work Student at Trent University

Karen Haas

- **Knowledge Mobilization Group Co-Lead & PWLE**

ACCESS Book Club

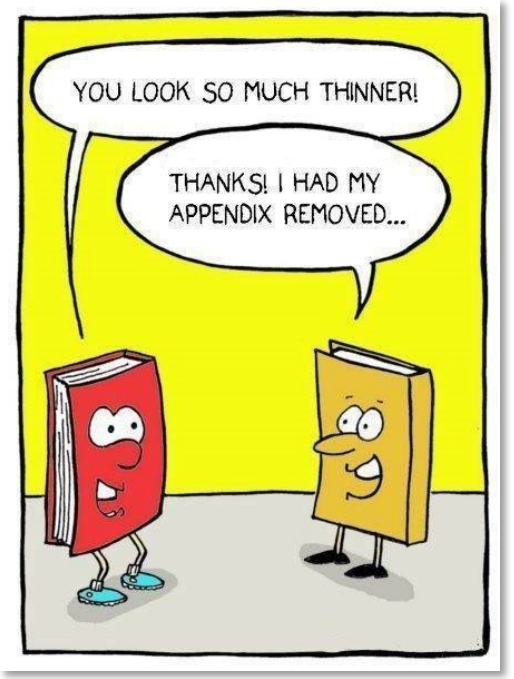
Advancing Childhood Cancer Experience, Science & Survivorship
Agir contre le cancer des enfants avec succès

CIHR IRSC Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

Introducing the **ACCESS Book Club**

Not your **average** Book Club…

The ACCESS Book Club will increase the amount, and improve the quality, of child-focused literature related to childhood cancer.



The ACCESS Book Club

WHAT?

A Community of Practice comprised of authors and illustrators, as well as aspiring authors and illustrators, of children's books on pediatric cancer.

The Book Club will:

- Offer guidance and opportunities to share knowledge
- Provide and receive insight and feedback on story development

We will collaboratively problem solve issues regarding the authorship, illustration and publication processes.

The ACCESS Book Club

HOW?

- Provide opportunities for experienced authors to provide **mentorship** to others who are not as far along in the writing and publication journey
- Share knowledge, perspectives, expertise and support
- Share and receive information on relevant aspects of the **publication process**
- Virtual, interactive **workshops** on key topics identified by our members
- Webinars delivered by **experts**

The ACCESS Book Club

WHY did we create the ACCESS Book Club?

We know the process of writing, illustrating, and publishing can be challenging.

We endeavour to rescue numerous stories, like *Toby's Tumour Tale*, from living forever on computer hard drives.*

A tall doctor with kind eyes came into Toby's hospital room the next day.

"Hello, my name is Dr Stitches." He explained to Toby and his Mommy and Daddy that Toby would have to have an **MRI**, followed by an **operation**.

While watching a movie, Mommy said, "Toby, one day soon, you might have less or no hair. The chemo medicine must be so yucky that your hair will jump out!" "Mommy, I think that already started to happen." said Toby. "Look at my pillowcase. This is strange!"

Ten days later, Toby and his Mommy and Daddy were back at the hospital to see the doctor. "Toby, you've been so brave during all your treatments. You deserve this medal!" said Dr Onco as he put a Bravery Medal around Toby's neck.

"And here is a special toy truck for you!" said Dave, the social worker.

"You've been such a good patient!" they all exclaimed.

*Toby's Tumour Tale was written prior to 2007 and remains unpublished in any format.

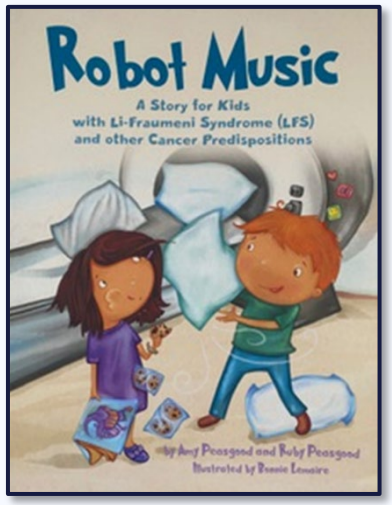
The ACCESS Book Club

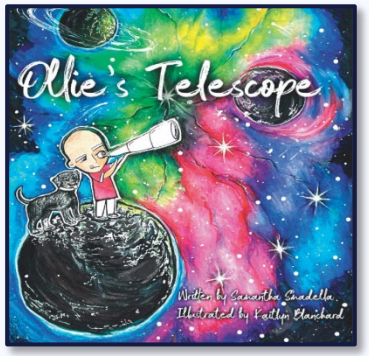
WHEN?

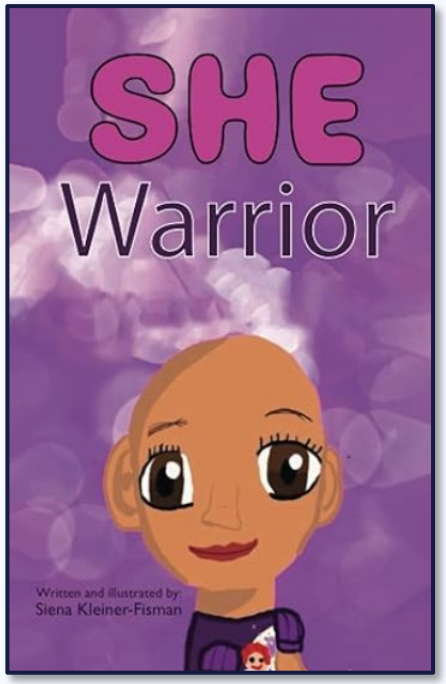
We aim to have our first meeting in **February 2025**

The ACCESS Book Club

We seek to help authors and aspiring authors create engaging books that are written at age-appropriate levels and which will provide information and comfort to help young readers and their parents /caregivers make sense of their childhood cancer journeys.







The ACCESS Book Club

WHO should join the ACCESS Book Club?

PWLEs, Nurses, Doctors, and Researchers who have just started, or completed and published (or somewhere in between) a children's book about childhood cancer.

We can learn from each other

Note: ACCESS funding will support Book Club activities; funds will not be used to publish or illustrate books.

The ACCESS Book Club

Steering Committee: We will strive to include members from across Canada, and from diverse cancer types, in the Steering Committee.

Brain Tumours

Sarcomas

Rhabdomyosarcoma

Leukemias

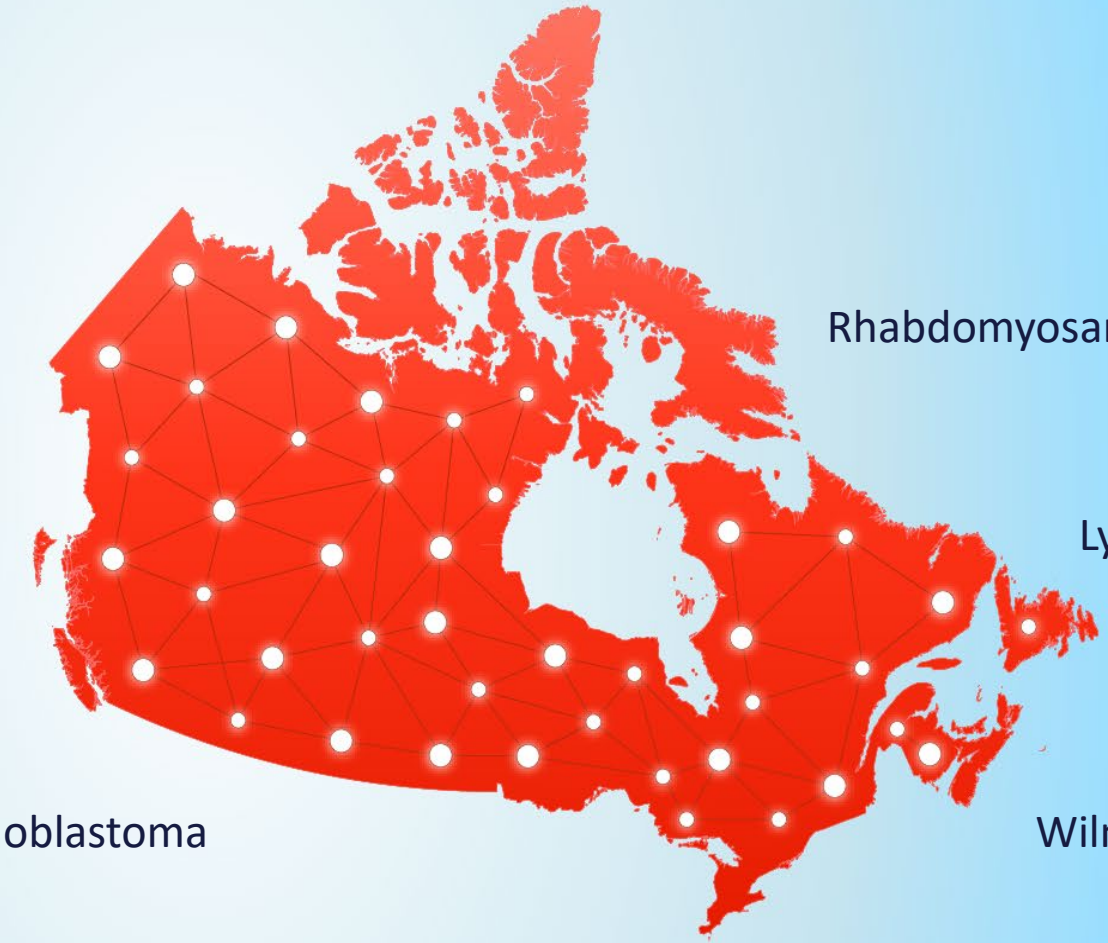
Neuroblastoma

Lymphomas

Osteosarcoma

Retinoblastoma

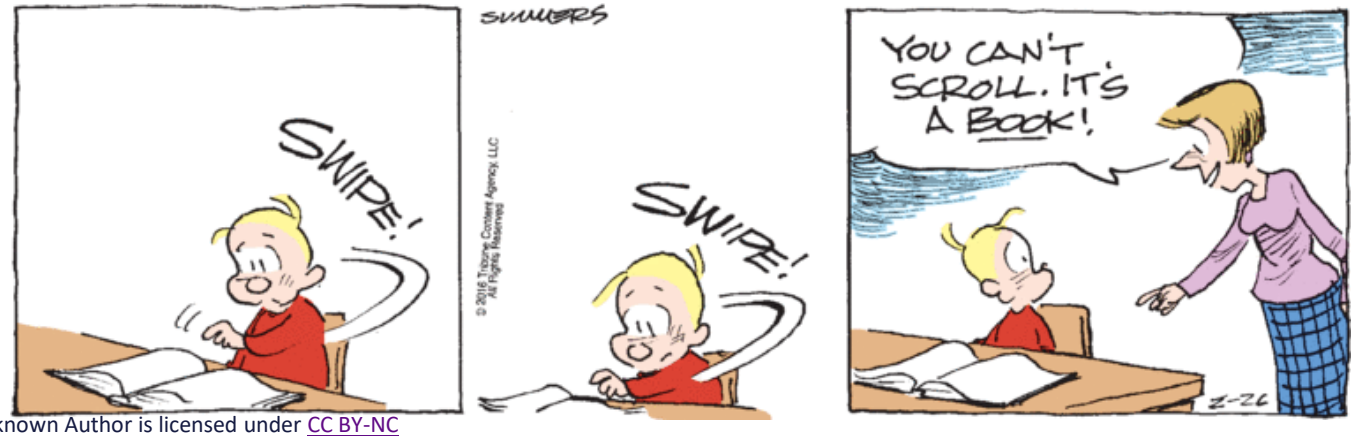
Wilms Tumour



The ACCESS Book Club

In Summary:

- The aim of the ACCESS Book Club is to **increase the impact, volume, quality, distribution, and implementation** of children's books about childhood cancer.
- The ACCESS Book Club will **enable the national and international reach** of the children's literature stemming from our community
- We intend for the work of the ACCESS Book Club **to amplify the impact of the children's books** present in our pediatric cancer community.



The ACCESS Book Club

Call to Action

- You had me at 'Book Club'.
- I would like to know more.
- This isn't for me, but I have a friend who might be interested.

Frontiers for Young Minds (FYM)

A Special ACCESS Collection Dedicated to Childhood Cancer Research

Advancing Childhood Cancer Experience, Science & Survivorship
Agir contre le cancer des enfants avec succès

CIHR IRSC Canadian Institutes of Health Research Instituts de recherche en santé du Canada

Committee of Collection Editors

Dr. Michel Duval

Ms. Adrienne Co-Dyre

Ms. Karen Haas

Dr. Argerie Tsimicalis

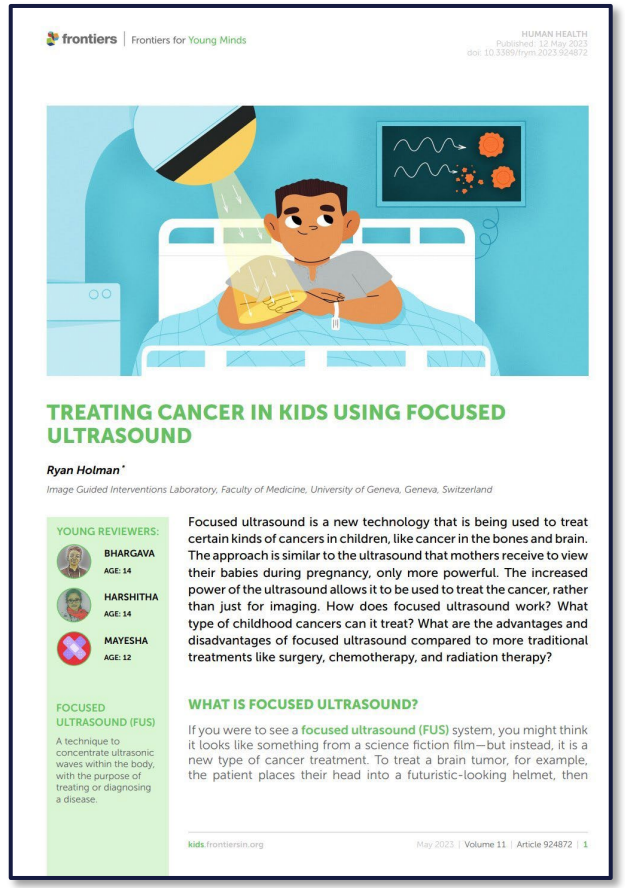
Dr. Christine Williams


frontiers | Frontiers for Young Minds

Rationale

When we **amplify the focus and voices of children** affected by pediatric cancer through **child-centered communication,** we can:

- Help children gain a **clearer understanding** of their condition
- **Foster trust** in healthcare providers
- Enhance **adherence** to treatments
- Promote feelings of **respect, security** and **autonomy**
- Reduce **anxiety** and **depression** (Høeg, 2023)
- **Motivate survivors** to attend long-term follow-up care (Syed et al., 2016)


frontiers | Frontiers for Young Minds

HUMAN HEALTH

TREATING CANCER IN KIDS USING FOCUSED ULTRASOUND

Ryan Holman*

Image Guided Interventions Laboratory, Faculty of Medicine, University of Geneva, Geneva, Switzerland

YOUNG REVIEWERS:

BHARGAVA AGE: 14

HARSHITHA AGE: 14

MAYESHA AGE: 12

Focused ultrasound is a new technology that is being used to treat certain kinds of cancers in children, like cancer in the bones and brain. The approach is similar to the ultrasound that mothers receive to view their babies during pregnancy, only more powerful. The increased power of the ultrasound allows it to be used to treat the cancer, rather than just for imaging. How does focused ultrasound work? What type of childhood cancers can it treat? What are the advantages and disadvantages of focused ultrasound compared to more traditional treatments like surgery, chemotherapy, and radiation therapy?

FOCUSED ULTRASOUND (FUS)

A technique to concentrate ultrasonic waves within the body, with the purpose of treating or diagnosing a disease.

WHAT IS FOCUSED ULTRASOUND?

If you were to see a focused ultrasound (FUS) system, you might think it looks like something from a science fiction film—but instead, it is a new type of cancer treatment. To treat a brain tumor, for example, the patient places their head into a futuristic-looking helmet, then

kids.frontiersin.org

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"To improve communication, we must move beyond a focus on the individual-level and account for the other factors that shape the way clinicians and families communicate" (Sisk et al., 2023 pp. 9)

Special ACCESS Collection on Pediatric Oncology

Child-centric knowledge mobilization resource dedicated to the pediatric cancer community in Canada and abroad.

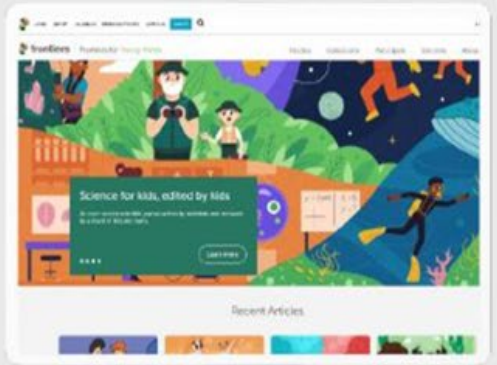
Frontiers for Young Minds

Frontiers For Young Minds (FYM) is an **award-winning, peer-reviewed science engagement journal for children aged 8-15.**

- Open Access
- Available in **five languages** (English, French, Chinese, Hebrew and Arabic)

The primary aim of *FYM* is to inspire young audiences by providing them with **scientific information** to evoke critical thoughts and questions about real science relevant to their lives.

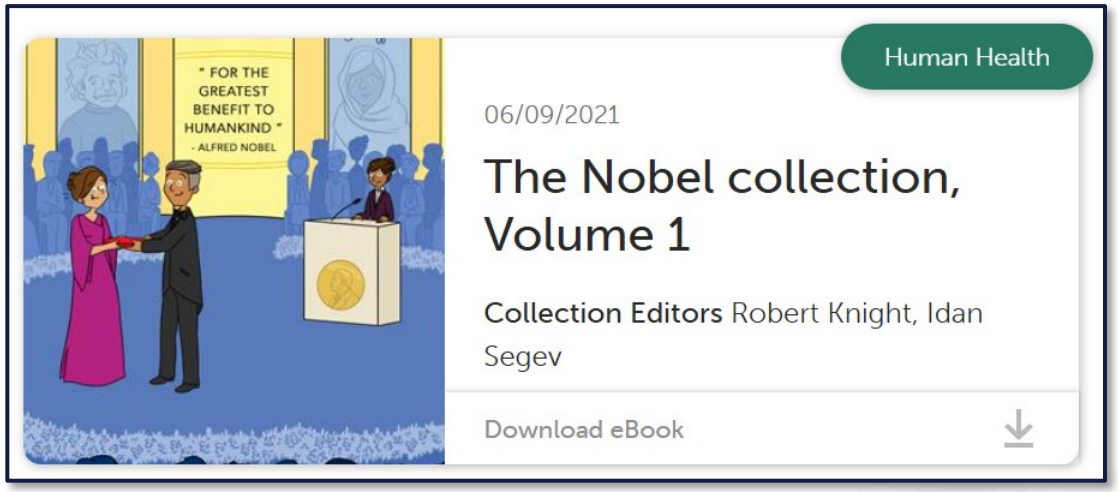
Global impact expansion for everyone



29K average views per article

46M article views from

230 countries and territories



Nobel-level impact

Our Nobel collection continues to attract today's most distinguished scientists to connect with our young minds community and showcase their groundbreaking research

30 Nobel Prize winners

195M social media impacts

2M collection views

gairdner
LES PRIX CANADA GAIRDNER AWARDS

Criteria for Article Submission & Author Guidelines

*For this special ACCESS collection, articles submitted **do not** need to stem from an ACCESS-supported project.*

Types of Articles Permitted:

- ***Core Concepts:*** Cover a foundational idea that is still relevant
- ***New Discovery:*** Highlight groundbreaking research and/or innovative findings and showcase the latest developments

Author Guidelines:

- Written by at least one **ACCESS member**
- Based on **one research topic** (Core Concept or New Discovery) related to pediatric oncology
- Already peer-reviewed and **published (or accepted)** in an academic journal
  - *No restrictions on publication date*
- Ideally no more than **1,500 words**
- Synthesized/distilled down into **language that can be understood by children and/or youth** (ages 8 to 11 years or 12 to 15 years)
  - *Sweet spot: 10 to 11-year age range*

(At Least) One Article from each ACCESS Theme/Group

Cancer Biology

Clinical Trials

Access to Innovative Therapies & Optimal Care

Regulation, Policy & Economics

Education & Training

Ethical, Legal, Societal Issues & Implementation Science

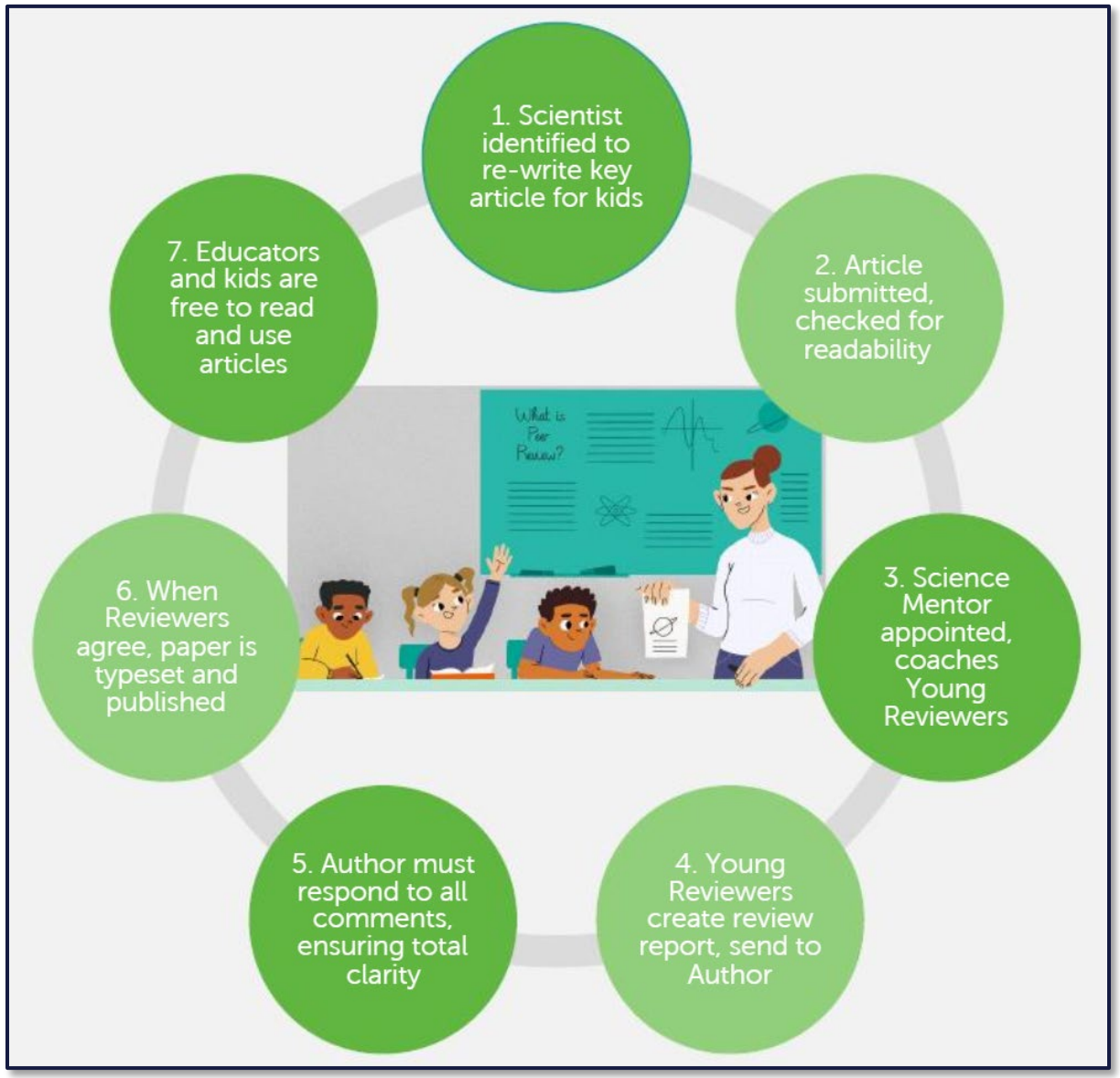
Psychosocial & Survivorship

Social Justice, Indigenization & Inclusion

Knowledge Mobilization

Driver Projects

The Process


1. Scientist identified to re-write key article for kids
2. Article submitted, checked for readability
3. Science Mentor appointed, coaches Young Reviewers
4. Young Reviewers create review report, send to Author
5. Author must respond to all comments, ensuring total clarity
6. When Reviewers agree, paper is typeset and published
7. Educators and kids are free to read and use articles
What is Peer Review?

Step 1: Extend a Call for Nomination of Articles to Include in Special Collection

Self-nominate an article for inclusion by completing the Nomination Form on REDCap™

Step 2: Recruit Scientific Stakeholders to Serve as Science Mentors

Interested individuals can apply to be a Science Mentor by completing the Science Mentor Expression of Interest Form on REDCap™

Who can apply to be a Science Mentor?

- ✓ Must have experience in the peer review process and/or typically have or are close to completing their doctoral degree;
- ✓ Those without a doctoral degree but with a science background and significant experience in scientific outreach may also be eligible

Step 3: Recruit Pediatric Members to Serve as Young Reviewers

Interested individuals can apply to be a Young Reviewer by completing the Young Reviewer Expression of Interest Form on REDCap™

Who can apply to be a Young Reviewer?

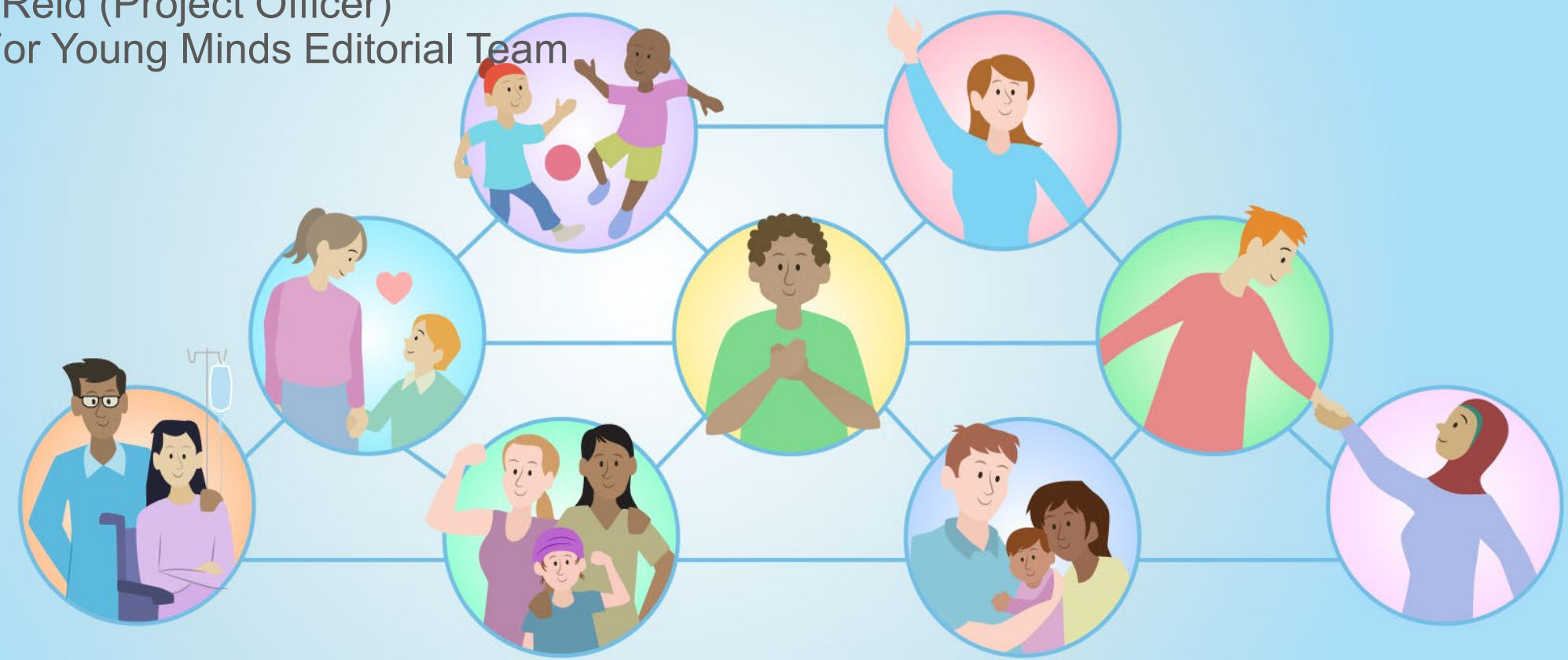
Youth aged 8 to 15 years who are:

- ✓ Pediatric cancer patients and survivors, or their siblings
- ✓ Bereaved siblings
- ✓ Friends or classmates of pediatric cancer patients and survivors

Parental consent will be needed to participate

Support Throughout the Process

- ✓ Committee of Collection Editors
- ✓ Stephanie Reid (Project Officer)
- ✓ Frontiers For Young Minds Editorial Team



Call to Action

Nomination of Articles for Inclusion Form

Science Mentors Expression of Interest Form

Young Reviewers Expression of Interest Form

Thank you
Merci

accessforkidscancer.ca

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Advancing Childhood Cancer Experience, Science & Survivorship
Agir contre le cancer des enfants avec succès

CIHR IRSC Canadian Institutes of Health Research Instituts de recherche en santé du Canada