IMPACCT

IMProving care & outcomes Across the Childhood Cancer Trajectory

Small voices, big impact: turning symptom screening into better care



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Pediatric Cancer

A Medical Success Story



Treatment

- Survival rates have improved, making **patient burden** a central indicator of care.
- Treatment can lead to physical symptoms, poor quality of life, and distress

Survivorship

- 3 out of 4 children will develop one or more **late effect** from their treatment
- Late effects can impact physical, mental, or social health

85%

SURVIVAL RATE

High-income settings (up from 58% in 1970s)



Screening helps us

- See symptoms that might otherwise go unnoticed
- Measure the burden and impact on everyday life
- Identify children who may need additional support
- Monitor changes over time
- Match children and families with appropriate interventions



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

Alberta Children's HOSPITAL FOUNDATION

Research Program

1. Distress Screening During Treatment

- Choosing the right screening tool
- Implementing routine distress screening across Alberta

2. Monitoring Neuropsychological Outcomes

- Support implementation and collection of neuropsychological outcome data in **clinical trials**
- Developing a neurocognitive screening program at the Alberta Children's Hospital

3. Symptom Burden During Survivorship

- Routine screening for survivors of childhood cancer
- Development of a research database with patient-reported psychosocial outcomes
- Creation of a mHealth platform for survivors of childhood cancer

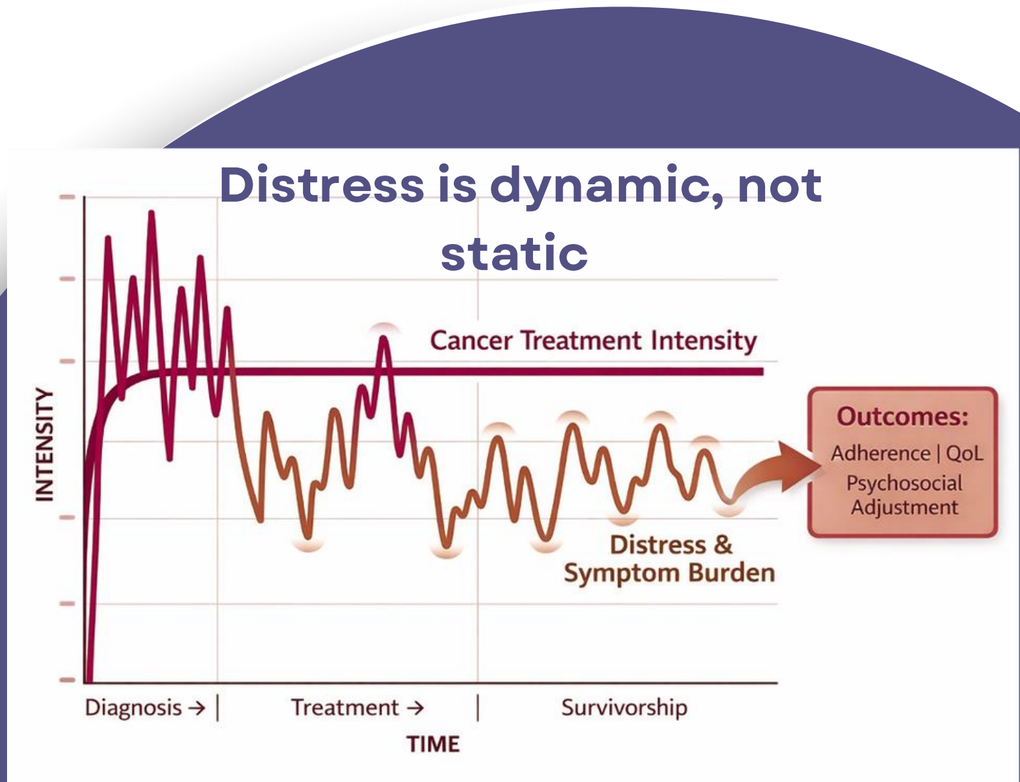
1. Distress Screening

Distress should be measured as the 6th vital sign after temperature, blood pressure, pulse, respiratory rate, and pain. Consistent screening can support earlier identification, triage, and referral for symptom burden.

Choosing the right tool

Assessing readiness and developing an implementation plan

Implementation and evaluation



ACCESS

Advancing Childhood Cancer Experience, Science & Survivorship









Survivorship and Psychosocial Matrix Co-Leads

Aim: To advance the wellbeing and quality of life of patients, survivors, and their families through the identification, prevention, and management of long-term physical, emotional and/or cognitive effects of disease and treatment.

Distress Screening Measures

Aim: To select a tool that is both psychometrically sound and feasible for routine use.

- Cost
- Ease of administration
- Used across age ranges
- Translations available
- Used in pediatric cancer populations
- Self-report and Parent-Proxy

1. Distress Screening

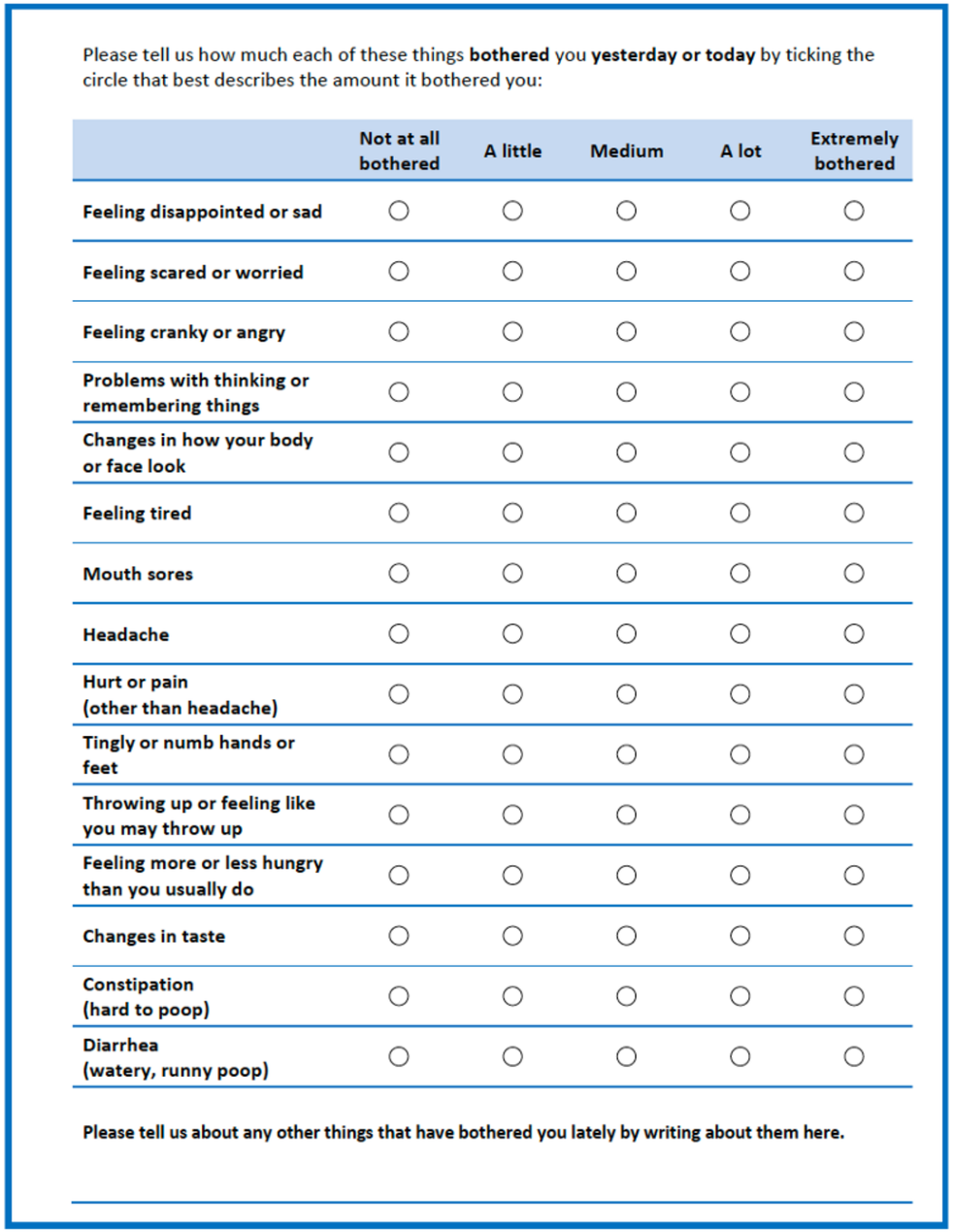
Systematic Review of Distress Screening Tools in Pediatric Oncology

266

patient and caregiver screening tools in total were identified

1. Distress Screening

Systematic Review of Distress Screening Tools in Pediatric Oncology



SSPedi: Symptom Screening in Pediatrics

Please tell us how much each of these things **bothered** you **yesterday or today** by ticking the circle that best describes the amount it bothered you:

	Not at all bothered	A little	Medium	A lot	Extremely bothered
Feeling disappointed or sad	○	○	○	○	○
Feeling scared or worried	○	○	○	○	○
Feeling cranky or angry	○	○	○	○	○
Problems with thinking or remembering things	○	○	○	○	○
Changes in how your body or face look	○	○	○	○	○
Feeling tired	○	○	○	○	○
Mouth sores	○	○	○	○	○
Headache	○	○	○	○	○
Hurt or pain (other than headache)	○	○	○	○	○
Tingly or numb hands or feet	○	○	○	○	○
Throwing up or feeling like you may throw up	○	○	○	○	○
Feeling more or less hungry than you usually do	○	○	○	○	○
Changes in taste	○	○	○	○	○
Constipation (hard to poop)	○	○	○	○	○
Diarrhea (watery, runny poop)	○	○	○	○	○

Please tell us about any other things that have bothered you lately by writing about them here.

1. Distress Screening

Next Steps



Planning

Champions from the **Alberta Children's Hospital** and **Stollery Children's Hospital** are working with the Shared Health Services team to develop a successful workflow through ConnectCare



Pilot

Routine screening with the SSPEDI will begin in **early 2027**



Feedback and Improvements

Feedback from patients and families, healthcare providers, and administrators will support a successful implementation across all patients



Full Launch

Routine distress screening will be standard for all oncology patients across Alberta.

2. Monitoring Neuropsychological Outcomes

- Memory , learning, school achievement
- Attention and concentration
- Processing speed
- Executive functions
- Mental health (ex., depression, anxiety, suicidality)

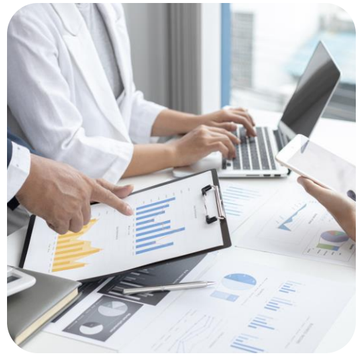


2. Neuropsychological Outcomes

Clinical Trials

Working with the Clinical Research Unit (CRU) and clinical leads at the Alberta Children's Hospital, our team supports the implementation and collection of Quality of Life (QOL) and neurocoginitve data in clinical trials.







- **30 Trials with QOL and Neurocognitive assessments**
- **250 Participants**
- **768 assessments**

2. Neuropsychological Outcomes

Neurocognitive Screening Program

Dr. Stephen Nicolas is the recipient of the Kids Cancer Care Clinical Research Fellowship. In addition to his clinical work, he will be supporting the development of a **neurocognitive screening program** for children receiving brain-directed therapy for cancer.



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3. Psychosocial Follow-Up in Survivorship

CHILDREN'S ONCOLOGY GROUP

ANY CANCER EXPERIENCE

Sec #	Therapeutic Exposure	Potential Late Effects	Periodic Evaluation	Health Counseling/ Further Considerations
1	**Any Cancer Experience**	**Adverse psychosocial/quality of life effects** Social withdrawal Educational problems Relationship problems Under-employment/ Unemployment Dependent living	**HISTORY** **Psychosocial assessment with attention to:** - **Educational and/or vocational progress** - **Social withdrawal** Yearly	**HEALTH LINKS** **Introduction to Long-Term Follow-Up** **Emotional Issues** **Educational Issues** **RESOURCES** 'Childhood Cancer Survivors: A Practical Guide to Your Future,' by Nancy Keene, Wendy Hobbie & Kathy Ruccione, Childhood Cancer Guides, 2012 'Educating the Child with Cancer: A Guide for Parents and Teachers' edited by Ruth Hoffman, American Childhood Cancer Organization, 2013 **POTENTIAL CONSIDERATIONS FOR FURTHER TESTING AND INTERVENTION** Psychological consultation in patients with emotional difficulties related to cancer experience, including physical deformities or chronic disabilities. Social work consultation. Refer as indicated to school liaison in community or cancer center (psychologist, social worker, school counselor) to facilitate acquisition of educational or vocational resources. Refer as indicated for neuropsychological evaluation. **SYSTEM = Psychosocial** **SCORE = 1**

Additional Information

Consider patient and cancer/treatment factors, pre-morbid/co-morbid health conditions, and health behaviors, as appropriate, that may increase risk.

- Patient factors: Female sex, younger age at diagnosis, family history of depression, anxiety, or mental illness, lower household income, lower educational achievement, failure to graduate from high school
- Cancer/Treatment factors: Bone tumor, CNS tumor, CNS-directed therapy, history of hematopoietic cell transplant
- Pre-morbid/Co-morbid medical conditions: Neurocognitive problems, depression, physical limitations, seizures, scarring or disfigurement, vision loss, hearing loss, premorbid learning or emotional difficulties

References

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Bernard F, Auquier P, Herrmann I, et al: Health status of childhood leukemia survivors who received hematopoietic cell transplantation after BU or TBI: an LEA study. Bone Marrow Transplant 49:709-16, 2014

Boman KK, Lindblad F, Hjern A: Long-term outcomes of childhood cancer survivors in Sweden: a population-based study of education, employment, and income. Cancer 116:1385-91, 2010

Brinkman TM, Bass JK, Li Z, et al: Treatment-induced hearing loss and adult social outcomes in survivors of childhood CNS and non-CNS solid tumors: Results from the St. Jude Lifetime Cohort Study. Cancer 121:4053-61, 2015

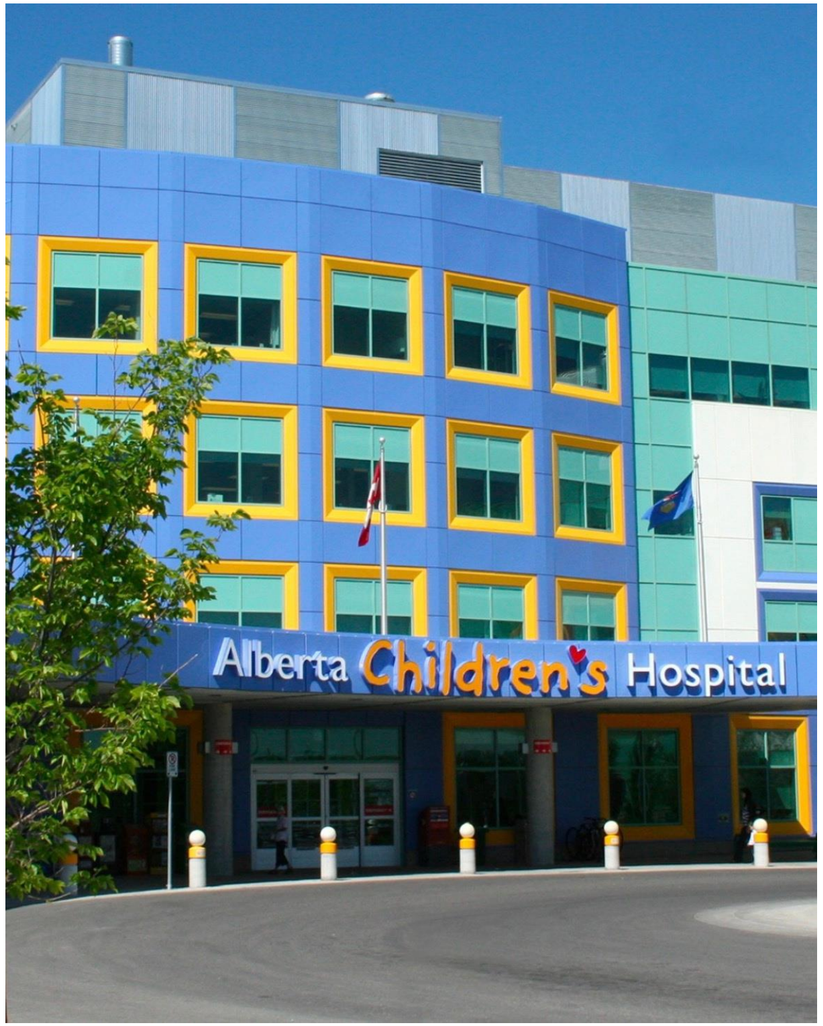
Brinkman TM, Krasin MJ, Liu W, et al: Long-term neurocognitive functioning and social attainment in adult survivors of pediatric CNS tumors: results from the St Jude Lifetime Cohort Study. J Clin Oncol 34:1358-67, 2016

Long-Term Survivor Clinic

Questionnaires

The Long-Term Survivor Clinic at the Alberta Children's Hospital follows survivors over their lifetime.

- Over 1000 patients in the clinic. They are seen every 1, 2, or 3 years based on their risk profile
- They receive surveillance according to the Children's Oncology Group screening guidelines
- Patients complete a screening questionnaire at every appointment



3. Survivorship

Psychooncology. 2025 Dec;34(12):e70344. doi: 10.1002/pon.70344.

Attending Childhood Cancer Follow-Up Care: Travel Time, Disparities and Health-A Canadian Cohort Study

Martina Ospelt [1 2], Jenny Duong [2], Caitlin Forbes [2], Miranda M Fidler-Benaoudia [3 4], Kathleen Reynolds [5 6], Gisela Michel [1], Fiona S M Schulte [2 6]

Cancer. 2026 Feb 15;132(4):e70281. doi: 10.1002/cncr.70281.

Fear of recurrence, secondary cancers, and health problems in long-term survivors of childhood cancer: Findings from a Canadian cohort

Perri R Tutelman [1 2], Jenny Duong [2], Caitlin Forbes [2], Oluwaseyi A Lawal [2], Miranda Fidler-Benaoudia [3 4], Kathleen Reynolds [5 6], Jennifer Giles [5], Gregory M T Guilcher [7 8], Brooke Russell [9], Sophie Lebel [9], Fiona S M Schulte [2 5]

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Associations Among Health Behaviors and Psychosocial Outcomes in Adolescent and Young Adult Cancer Survivors

Julie M Deleemans [1 2], Hailey M Zwicker [2], Kathleen A Reynolds [3 4], Fiona S M Schulte [2 4]

Cancer. 2026 Aug 15;132(16):e70560. doi: 10.1002/cncr.70560.

Sexual health behaviors and contraceptive practices among Canadian childhood, adolescent, and young adult cancer survivors and controls

Ismay A E de Beijer [1], Selina R van den Oever [1], Oluwaseyi A Lawal [1], Amanda Button [1], Jenny Duong [1], Heide Adham [1], Jennifer Giles [2], Kathleen Reynolds [2 3], Fiona S M Schulte [1 2]

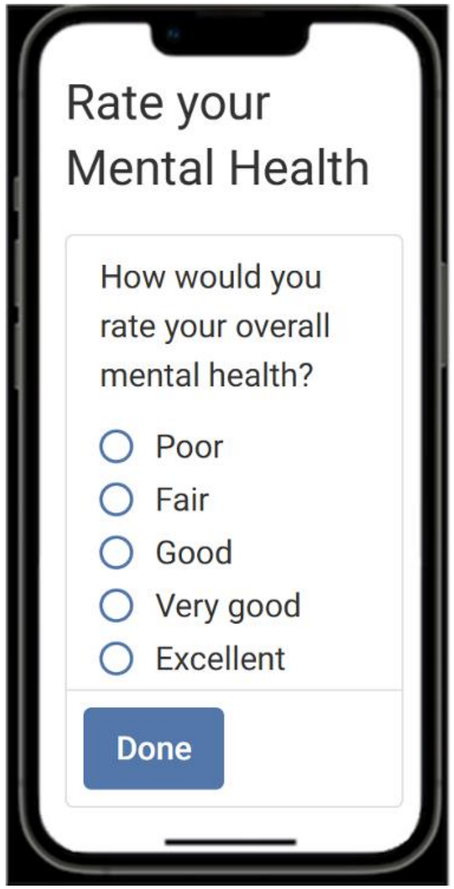
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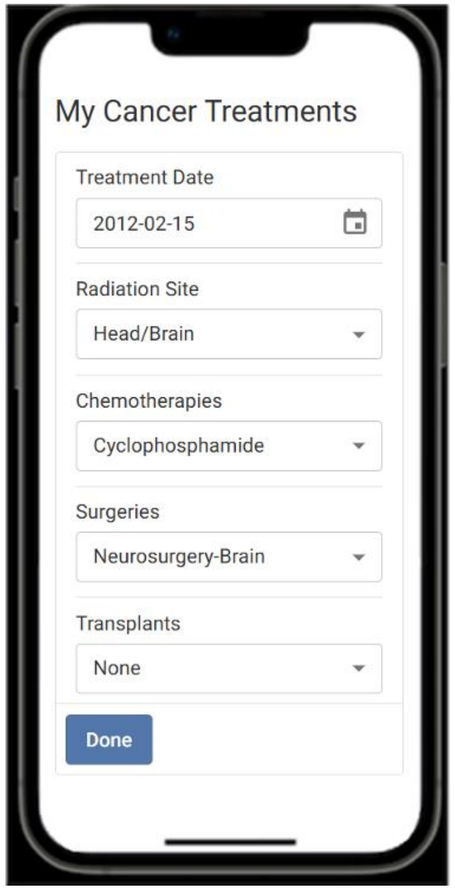
Fertility-Related Concerns in Survivors of Childhood Cancer: A Systematic Review

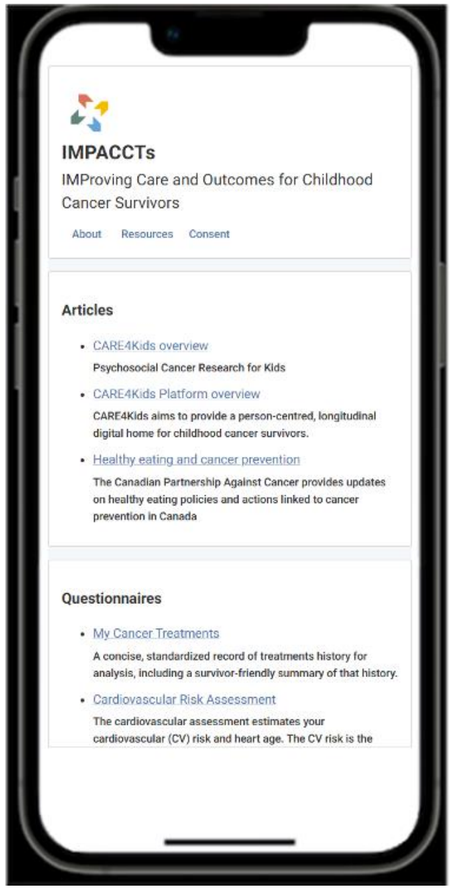
Pauline Holmer [1 2 3 4 5], Martina Ospelt [1], Gisela Michel [1], Vicky Lehmann [2 3], Fiona S M Schulte [4]

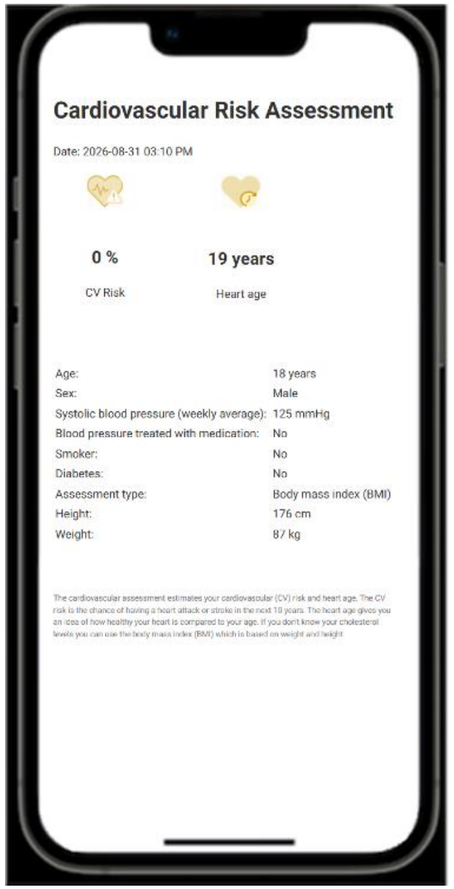

CODESIGN with SURVIVORS, CAREGIVERS, HEALTHCARE PROVIDERS and RESEARCHERS
features?
WHO ARE the USERS?
empowered by the platform
Accessible NATION-WIDE
We need many different VIEW POINTS
COMMUNICATION with PROVIDERS
Peer to Peer SUPPORT
Easy access
HEALTH SUMMARY
DIAGNOSIS
DATE
TREATMENT
MENTAL HEALTH RESOURCES
RESEARCH OPPORTUNITIES
SHARE FINDINGS
FAMILY MEMBERS
PEOPLE WHO HAVE OR HAVE HAD CANCER
SIBLINGS
Can donate to cancer INITIATIVES
DONORS with access
Separate Platforms?
COORDINATE CARE
SURVIVORS AT THE CORE
Access to TRAINING and EDUCATION
keep PRIVACY TOP of MIND
chat functions
stop working in SILOS

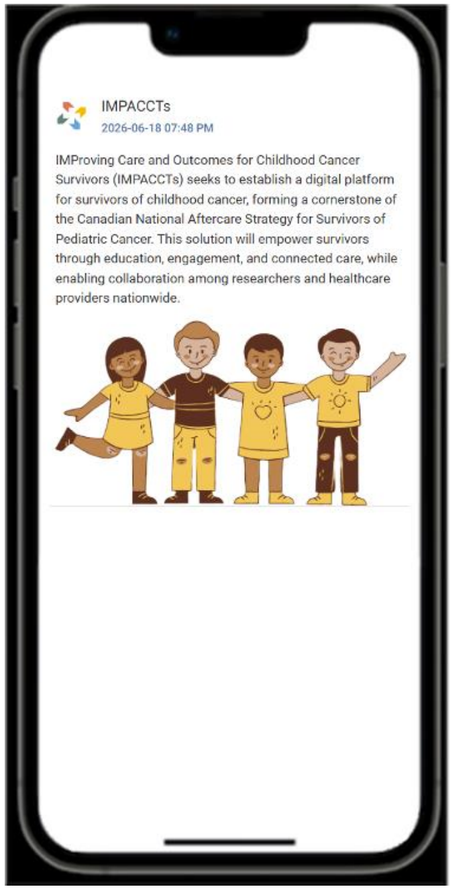
#. Survivorship











Conclusions & Next Steps

Next Steps

Expand our screening program to include:

- Siblings
- Parents and Caregivers

Our team is upholding standards of care in pediatric oncology through:

1. Distress Screening During Treatment

- Implementing the SSPEDi across Alberta for all pediatric oncology patients
- This will allow for timely supports for families as well as a better understanding of the psychosocial resources required

2. Monitoring Neuropsychological Outcomes

- By collecting QOL and neurocognitive outcomes in **clinical trials,** we will support the development of treatment protocols that minimize burden
- Routine neurocognitive screening will help us better support the needs of patients receiving brain-directed therapy

3. Symptom Burden in Survivorship

- Routine screening for survivors of childhood cancer ensures survivors get the support they need
- Our research database provides insight to the unique needs of survivors of childhood cancer

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- Patient and Family Advisors

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