

# Making Caregiver Distress Visible: Pre-implementation of Digital Psychosocial Screening in Pediatric Oncology

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## Background

- Caregiver distress in pediatric oncology is common, clinically significant, and associated with child and family outcomes, yet remains inconsistently identified in routine care.
- Psychosocial assessment typically relies on informal, time-limited clinician judgment rather than standardized screening approaches.
- Electronic screening (e-screening) offers a scalable, systematic strategy for earlier identification of caregiver distress and improved family-centered care.
- Understanding feasibility, usability, and sustainability across multiple pediatric oncology programs is critical to inform national implementation and equitable access to psychosocial support

## Aim

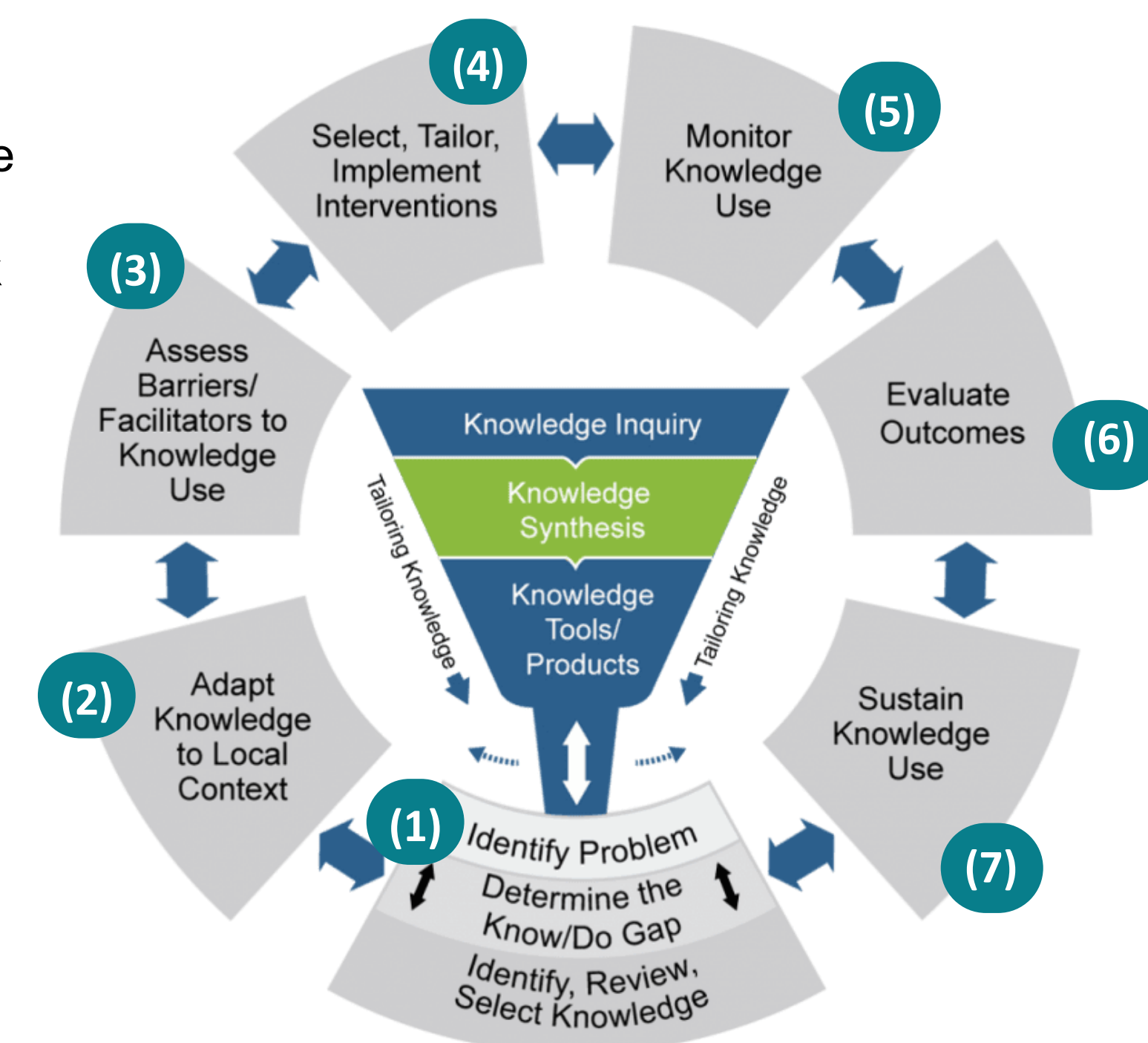
We aimed to assess the acceptability, clarity, and perceived usability of psychosocial e-screening and implementation process through qualitative feedback from parents and clinical team members prior to implementation

## Methods

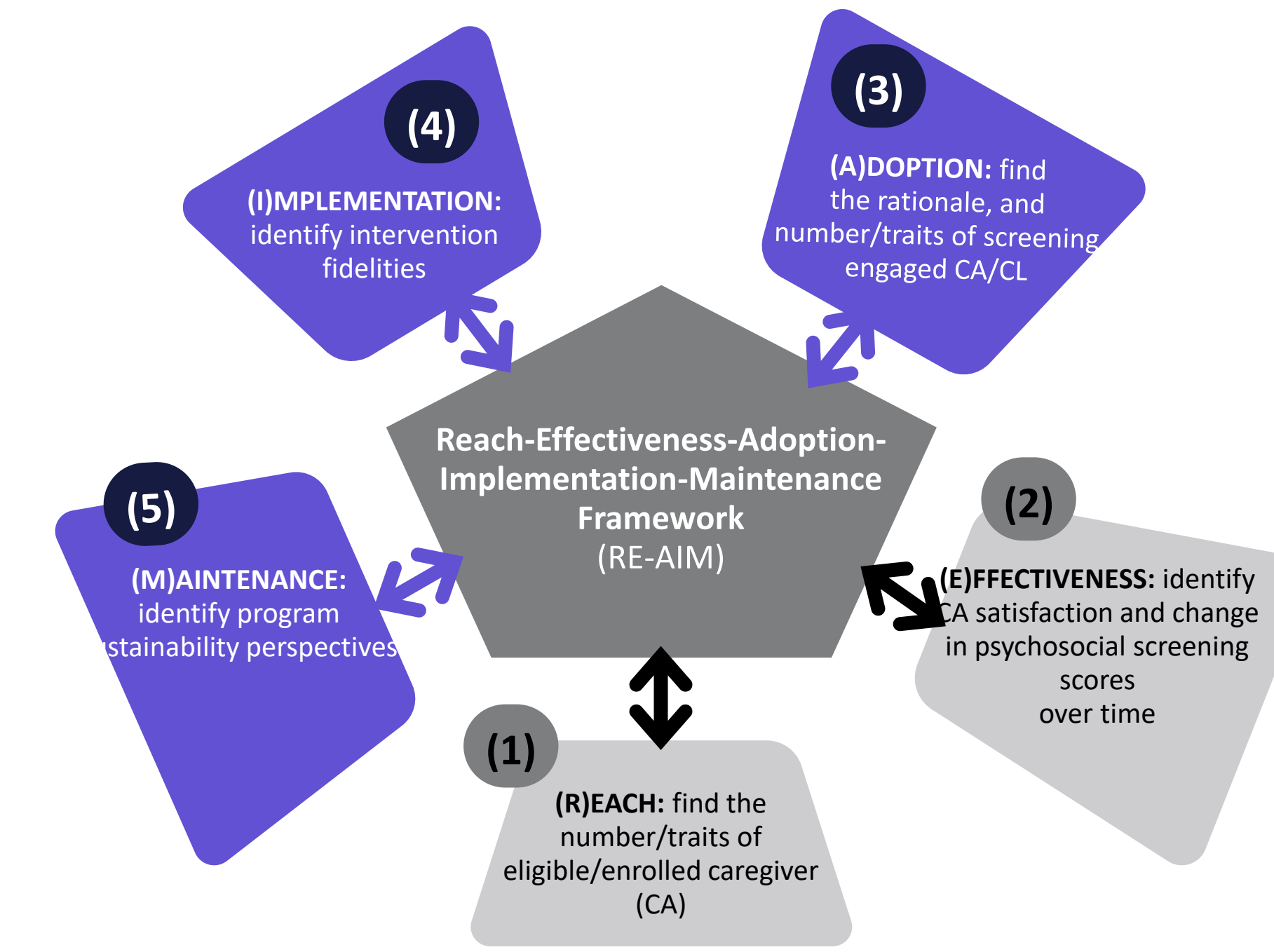
- Design:** Pre-implementation qualitative pilot phase to assess acceptability, usability, and contextual fit of the screening tool and workflow prior to broader rollout.
- Participants:** A convenience sample of 10 parents of children receiving care in the leukemia and lymphoma clinic at SickKids and 10 clinical team members representing diverse professional roles.
- Recruitment:** Parents identified in clinic and approached by a trained research assistant to participate in a structured feedback exercise. Clinical team members invited via secure SickKids hospital email. Written informed consent was obtained. Participants received a \$20 gift card in recognition of their time.
- Data Collection:** Individual semi-structured interviews (25-60 min in length) were conducted at a time convenient for participants. Interviews were audio-recorded and transcribed using Microsoft Teams transcription software. Identifying information was redacted prior to analysis.
- Data Analysis:** De-identified transcripts were uploaded into NVivo15.0 for qualitative analysis. Two co-investigators reviewed transcripts to enhance rigor. Data were analyzed deductively using the Knowledge-to-Action (KTA) framework, with reference to the RE-AIM model, focusing on adaptation to local context and identification of barriers and facilitators to implementation.

## Implementation Theory Underpinnings

**Figure 1.** Knowledge to action framework



**Figure 2.** RE-AIM framework with utilized domains highlighted



## Discussion

- Findings from this pre-implementation phase highlight strong acceptability of caregiver e-screening among both families and clinicians, alongside critical considerations for successful integration into routine care. Participants emphasized that screening must be embedded within existing workflows, supported by timely alerts, and linked to clear, coordinated triage pathways with visible clinical follow-up.
- Importantly, sustainability depends on reducing—not increasing—clinical burden and ensuring flexible, low-effort completion aligned with treatment phases. Parents underscored that screening is meaningful only when responses lead to actionable support delivered within a trusted, family-centered care team.
- Together, these findings inform context-sensitive refinement prior to broader implementation and provide practical guidance for scalable, sustainable integration of caregiver distress screening across pediatric oncology settings.

## Next Steps

- Implementation Phase** at SickKids CHEO, Alberta Children's and CHU Ste-Justine: Systematic identification of eligible caregivers through weekly review of divisional databases and clinic schedules. Reasons for refusal will be explored through an optional brief survey, ongoing refinement at CHEO, Alberta Children's and CHU Ste-Justine.
- Post-Implementation Evaluation:** We will evaluate reach (enrollment and screening completion), effectiveness (changes in distress scores, referral escalation, parent satisfaction), adoption (clinician engagement), implementation fidelity (workflow adherence), and maintenance (program acceptability and sustainability). A purposive parent and clinician sample (~12 each per site) will participate in interviews to explore real-world acceptability, feasibility, and impact.
- Knowledge Translation:** Findings will inform refinement of triage pathways, workflow integration, and sustainability planning to support broader scale-up across Canadian pediatric oncology programs.

KTA Phase	RE-AIM Domain and Study Focus	Central Implementation Themes	Quotations	
			Parent	Clinician
<b>Phase 1</b> • Review knowledge + identify 'know-do gap'  <b>Phase 2</b> • Adapt knowledge to context	<b>Adoption</b> • Barriers/facilitators to meeting psychosocial needs • Clinic openness to change • Elements needed for implementation	1. Psychosocial assessment in routine care relies on informal, narrative clinician judgment rather than standardized screening tools. 2. Parents strongly value systematic psychosocial screening. 3. A clear <b>know-do gap</b> exists between parents' lived distress and what is routinely identified in standard care.	"Sometimes I feel like... I can't answer this honestly because it might impact something else... custody battles."  "The scale does not meet the needs of all demographics... for some cultures it's all or nothing."	"I think some of the staff who have been here for a really long time have a difficult time adjusting to change especially when it comes to tech-change. They're used to paper-charting... hard to jump into new tech platforms... feels scary to use something you've never used before"
<b>Phase 3</b> • Assess barriers/facilitators to knowledge use  <b>Phase 4</b> • Tailored method selection  <b>Phase 5</b> • Knowledge monitoring	<b>Implementation</b> • 'Easiness' of tool use • 'User-friendliness' of tool • Clinician level of knowledge/skill needed for implementation • Hindering/helping policies, procedures, or practices	1. Successful e-screening requires workflow integration, real-time flagging, and coordinated triage with visible clinical action. 2. Both clinicians and parents view e-screening as usable; however, meaningful benefit depends on actionable resources and trusted, team-based follow-up.	"This is definitely user-friendly... I don't see people having necessarily problems filling out."  "It would be nice to have all the resources... in one place... instead of different emails."  "It has to be somebody whose sole job is to take care of the family."	"...because then it means something to the parents to complete, right? It's valuable to complete it because somebody's following up on it. It doesn't just go into the abyss and nothing happens."  "if it was prompted by the front desk or something... and then they sit down and have their phone, and if it's straightforward, takes a couple moments... then I feel it will work"
<b>Phase 6</b> • Intended use + outcome evaluation  <b>Phase 7</b> • Assess long-term/daily-life integration feasibility	<b>Maintenance</b> • Perceived impact on care practices • ...on clinic performance • ...on personal job performance • Perspective on fit into day-to-day life	1. E-screening strengthens family-centered care via earlier distress detection. 2. For sustainability, implementation must decrease clinical burden and integrate efficiently into workflows. 3. Parents perceive e-screening as validating and beneficial, but long-term uptake depends on flexible, low-burden completion timed to treatment.	"I think that the people that could benefit the most are probably people that aren't going to fill it out as often as the—as they truly need to. As—as bad as that is, right?"	Initiative importance? "The top, the top."