COMMUNITY REPORT

2026

Co-Designing Paediatric Sickle Cell Disease Care at Trillium Health Partners

Presented By:

Family & Child Health Initiative

www.familychildhealth.ca

SICKLE-CELL
AUGUST 9TH
SUMMER EVENT

Trillium Health Partners | INSTITUTE FOR BETTER HEALTH | Family and Child Health INITIATIVE

LAND ACKNOWLEDGEMENT

We acknowledge that Trillium Health Partners (THP) and the communities engaged in this project are situated on the traditional territories of the Mississaugas of the Credit, the Haudenosaunee, the Huron-Wendat, and the Anishinaabe Peoples.

Today, this land continues to be home to many diverse First Nations, Inuit, and Métis communities. We recognize the enduring presence of Indigenous Peoples and reaffirm our collective responsibility to work toward reconciliation in healthcare, community, and research practices.

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RECOGNITIONS & ACKNOWLEDGEMENTS

We want to acknowledge our partners.

This initiative was made possible through the support and collaboration with caregivers, youth, community partners, health providers, and organizations committed to advancing equitable care for Sickle Cell Disease (SCD).

We thank the Sickle Cell Awareness Group of Ontario (SCAGO), the SCD Clinical Team at THP, our Peer Research Assistants (PRAs), and Karen Fleming, RN, MN, MSHS, a sickle cell activist, whose leadership, advocacy, and lived expertise strengthened this initiative and guided this work.

Executive Summary

Sickle Cell Disease in Our Community

Sickle cell disease (SCD) is an inherited blood disorder that alters the shape and function of red blood cells. It is most prevalent among people with ancestry from malaria-endemic regions, such as sub-Saharan Africa, the Caribbean, Latin America, the Mediterranean, the Middle East, and South Asia (1). In Ontario, more than 3,500 people live with SCD, with many families based in Peel Region and the Greater Toronto Area (2). Even though the condition is well known, families still face challenges getting timely, high-quality, and culturally safe care, meaning care that is grounded in respectful engagement, recognizes power imbalances, and supports patients and families to feel safe and respected while receiving care.[3]

Working Together for Better Care

To help improve care, Trillium Health Partners (THP) – through the Institute for Better Health and the Family and Child Health Initiative – partnered with the Sickle Cell Awareness Group of Ontario (SCAGO), The Hospital for Sick Children, Ontario Health, and local organisations. Together, they worked to plan a new paediatric SCD clinic at THP.

The project used community-based participatory research and human-centred design approaches, meaning that caregivers, youth and healthcare providers all helped shape the ideas and recommendations for the clinic.

Community Engagement

- April to May 2025: Virtual workshops were held with healthcare providers to discuss care gaps, share experiences and imagine what an ideal paediatric SCD clinic should look like. These sessions included hands-on activities to design possible clinic models together.
- August 2025: A community event and workshops were held with caregivers and children. These gatherings included storytelling, wellness activities, and interactive discussions about challenges, possible solutions, and priorities for the new clinic.

Executive Summary

Key Findings

Children and **youth** shared detailed personal experiences in hospital settings. They reported long wait times, discomfort in cold clinical environments, and distress associated with frequent needle procedures. Many also described hospital layouts as confusing and intimidating. Participants emphasized that child-friendly, warm, and welcoming environments could help reduce fear and improve the overall care experience.

Caregivers talked about how hard it can be to get consistent care for their children. They described the challenges of moving between different hospitals or clinics, long waits in emergency rooms, and the need for more compassionate and well-coordinated support.

Healthcare providers recognized challenges in the healthcare system, including a lack of training on SCD among general staff and difficulties helping youth move from paediatric to adult care. They also emphasized the need for stronger partnerships with community organisations and dedicated staff, such as system navigators, to help families find and access the right care.

Across all groups, findings highlighted that improving SCD care requires going beyond clinical treatment to address the emotional, social, and logistical realities faced by families. Four key themes stood out as central to improving care: **equity**, **trust**, care **navigation**, and **education**.

Executive Summary

Impact and Next Steps

The co-design process showed an urgent need for services that address both the clinical and everyday challenges of living with SCD, including stronger education, coordination, and support systems. What we heard will directly shape the new paediatric SCD satellite clinic at THP.

The next steps include:

- Embedding equity and cultural safety in all parts of care, so families feel respected and understood.
- Expanding education for healthcare staff, caregivers and youth to increase knowledge, confidence and advocacy.
- Creating navigation supports to help families move more easily through the healthcare system.
- Strengthening community-healthcare partnerships to build trust and improve health outcomes throughout people's lives.

This new clinic will not only support families in Peel Region but also help drive system-wide change across Ontario. It will build on and expand the Ontario Health Quality Standard for Sickle Cell Disease (4) to make care more equitable and effective for everyone.

Project Background

Sickle cell disease (SCD) is one of the most common inherited blood conditions worldwide. It affects Black, African, Caribbean, and other racialized communities at higher rates.[1] In Ontario, more than 3,500 people live with SCD, with many families based in Peel Region and the Greater Toronto Area.[2]

In Canada, children and youth with SCD often face unfair differences in the care they receive. Many families experience long wait times in emergency departments, gaps between services, and difficulty accessing paediatric care that truly understands their needs. Access to specialized, high-quality, and culturally safe care remains limited.[3]

Recognizing these gaps, Trillium Health Partners (THP), through the Institute for Better Health (IBH) and the Family and Child Health Initiative (FCHI), partnered with community organisations and families to co-design a new paediatric SCD satellite clinic at THP.

The goal of this clinic is to improve timely, coordinated, and equity-focused care for children and families living with SCD in Peel Region, guided by patient and caregiver priorities identified through SCAGO.[4]

Project Objectives

THE PROJECT AIMED TO:

1. Engage children, youth, caregivers, and clinicians to identify the main challenges and support related to SCD care.

2. Work together to develop recommendations that will guide the design and implementation of the new paediatric SCD satellite clinic at THP.

3. Strengthen the healthcare system by connecting community perspectives with existing standards, policies and models of integrated care.

4. Create a strong foundation for ongoing learning and collaboration between families, providers and the health system.

Community Engagement Process

APPROACH AND GUIDING FRAMEWORKS

The project used Community-Based Participatory Research (CBPR) and Human-Centred Design (HCD) approaches.

These approaches centre the voices of caregivers, youth, and clinicians across all stages of the project, from identifying challenges to shaping solutions.

Participants were engaged through collaborative workshops and discussions to share experiences, identify priorities, and inform recommendations. This approach placed lived and living experience at the centre of the work and reflects[5] equity-focused, community-driven research practices.

Partnerships & Collaborators

Partnerships were central to this project.

This project brought together several key partners, each playing an important role:

- **Peer Research Assistants (PRAs):** Brought lived/living experience and helped ensure the project was grounded in the real experiences of families affected by SCD.
- **Sickle Cell Awareness Group of Ontario (SCAGO):** Offered advocacy, caregiver support, and community expertise.
- **Family and Child Health Initiative (FCHI):** Focused on promoting equity in child and family health.
- **Institute for Better Health (IBH):** Provided research and implementation expertise.
- **Trillium Health Partners (THP):** Will host the new paediatric SCD clinic and bring together multidisciplinary clinical expertise to deliver comprehensive paediatric SCD care.

Community Engagement **Activities**

In April and May 2025, virtual workshops were held with clinicians using the Future Workshop method (critique, fantasy, implementation).[6] These sessions were guided by a community-based participatory research (CBPR) approach, which emphasizes shared decision-making and collaboration between community members and researchers throughout the research process.[7]

Participants used interactive online tools, including shared whiteboards, to reflect on current gaps in SCD care and imagine what an ideal paediatric clinic could look like.

These sessions helped surface system-level challenges while supporting creative, solution-focused thinking to strengthen care for children and families living with SCD.

In August 2025, an in-person community event was held for caregivers and children. The event created a welcoming space for families to share experiences and ideas. Activities included:

- **Workshops** where caregivers and children discussed challenges in current care, imagined what ideal services could look like, and worked together to create practical solutions.
- **Wellness** activities like massages and art supported healing, relaxation and community connection.
- **Community** booths hosted by local organizations that shared resources, information and support.
- **Interactive** discussions on topics like navigating the healthcare system, building trust, reducing stigma and finding support networks.

How the Workshops **Worked**

(Future Workshop Method)

PHASE 1: CRITIQUE

"WHAT IS NOT WORKING"

PHASE 2: FANTASY

"WHAT COULD BE POSSIBLE"

PHASE 3: IMPLEMENTATION

"WHAT CAN WE DO NEXT"

Who Attended

7 YOUTH & CHILDREN

13 CAREGIVERS

9 CLINICIANS

HOW PARTICIPANTS SHARED

- Spoken Discussions
- Chat Responses
- Collaborative Whiteboards

WHY WE ENGAGED

To ensure the clinic reflects lived experience, caregiver priorities, and provider insights.

ETHICAL CONSIDERATIONS

The project followed the ethical standards of THP and IBH. Community members were compensated for their time, expertise and lived and living experience. Throughout the process, the team made sure that respect, dignity, and cultural safety were upheld in every interaction.

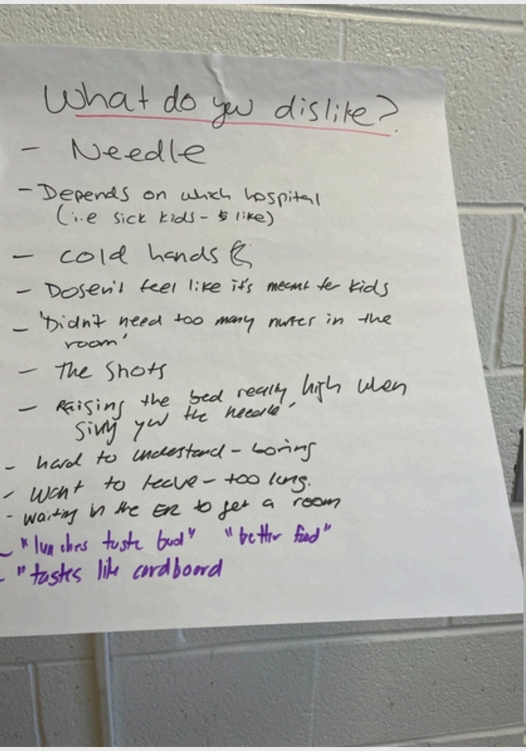
CHILDREN'S PERSPECTIVES

Children living with SCD were candid about how care spaces influence their experiences, emotions, and sense of safety. Children see care extending well beyond medical treatment to include welcoming environments, open communication, and feeling genuinely seen, understood, and protected. Youth also pinpointed exactly what falls short and suggested practical ways to improve it.

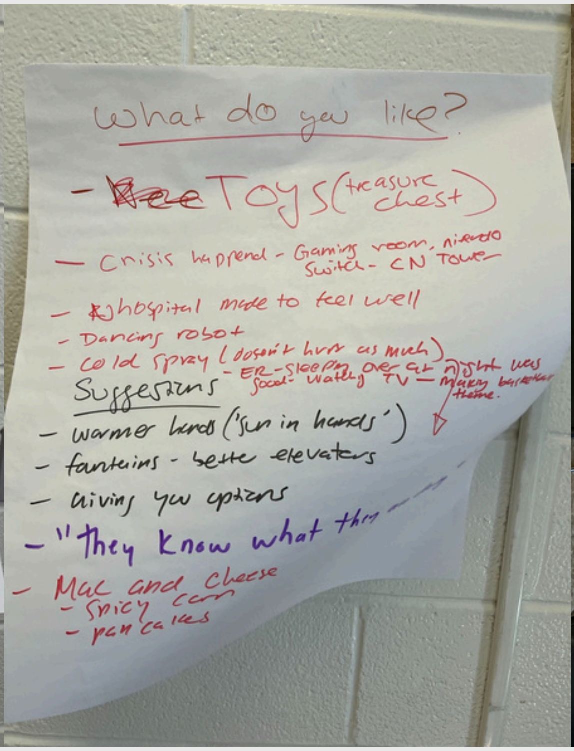
Workshops with youth highlighted four main themes:

- **Experiencing the Health System:** Children described long wait times, travel to appointments, and waiting in clinic spaces. They also highlighted the stress associated with frequent needle procedures. These experiences often built stress before care even started and shaped their views on accessing health care.
- **Sensory Experiences and Memory:** Youth described care spaces using all five senses, including feeling cold, sounds, lighting, and movement. These sensory experiences shaped how youth remembered care, linking hospital spaces with feelings of comfort, fear, or safety. Care environments were places that hold stories and memories.
- **Safety, Familiarity, and Comfort:** Safety lies at the heart of children's experiences. They described emotional and physical safety, including feeling overwhelmed when too many providers were present. Familiar elements, such as recognizable views, elevators, or child-friendly features, created comfort and reassurance across different care settings.
- **Communication and Being Met Where They Are:** Youth called for straightforward, age-appropriate communication that skips medical jargon and matches their level of understanding. Youth stressed that care teams should see the whole family unit and account for cultural contexts shaping their care experiences.

CHILDREN & YOUTH
WORKSHOP

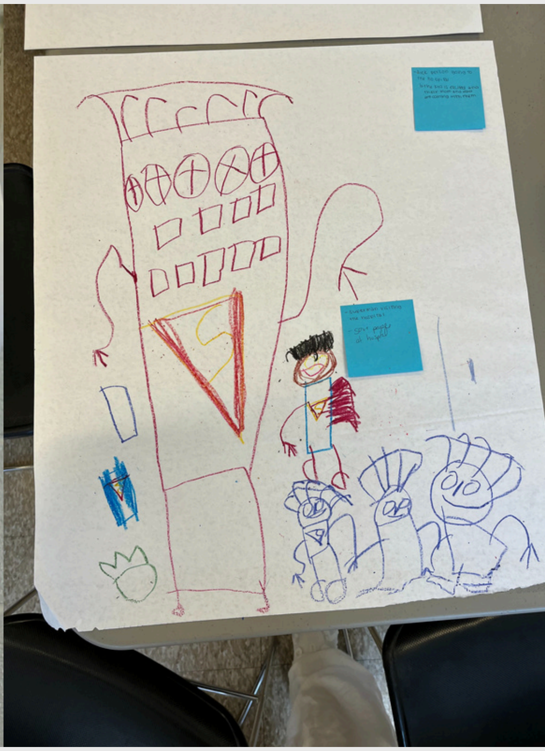


What do you dislike?
- Needle
- Depends on which hospital (i.e sick kids - $ like)
- cold hands
- Dosen't feel like it's meant for kids
- 'Didn't need too many nurses in the room'
- The shots
- Raising the bed really high when siving you the needle'
- hard to understand - boring
- want to leave - too long.
- waiting in the ER to get a room
- "lunches taste bad" "better food"
- "tastes like cardboard



What do you like?
- ~~Nee~~ Toys (treasure chest)
- crisis happend - Gaming room, nintendo Switch - CN Tower
- hospital made to feel well
- Dancing robot
- cold spray (dosen't hurt as much)
- ER - sleeping over at night was good - watching TV - Making basketball theme.

Suggestions
- warmer hands ('sun in hands')
- fountains - better elevators
- giving you options
- "They know what they
- Mac and cheese
  - spicy corn
  - pancakes



A snapshot from the children and youth workshop showing participant-generated reflections through drawings, notes, and group activities. Youth shared experiences of current care, including what feels challenging or supportive, and identified ideas for more welcoming, comfortable, and child-friendly clinic environments.

> *I wish that they [nurses] had a sun in their hands.*
>
> *— Youth participant*

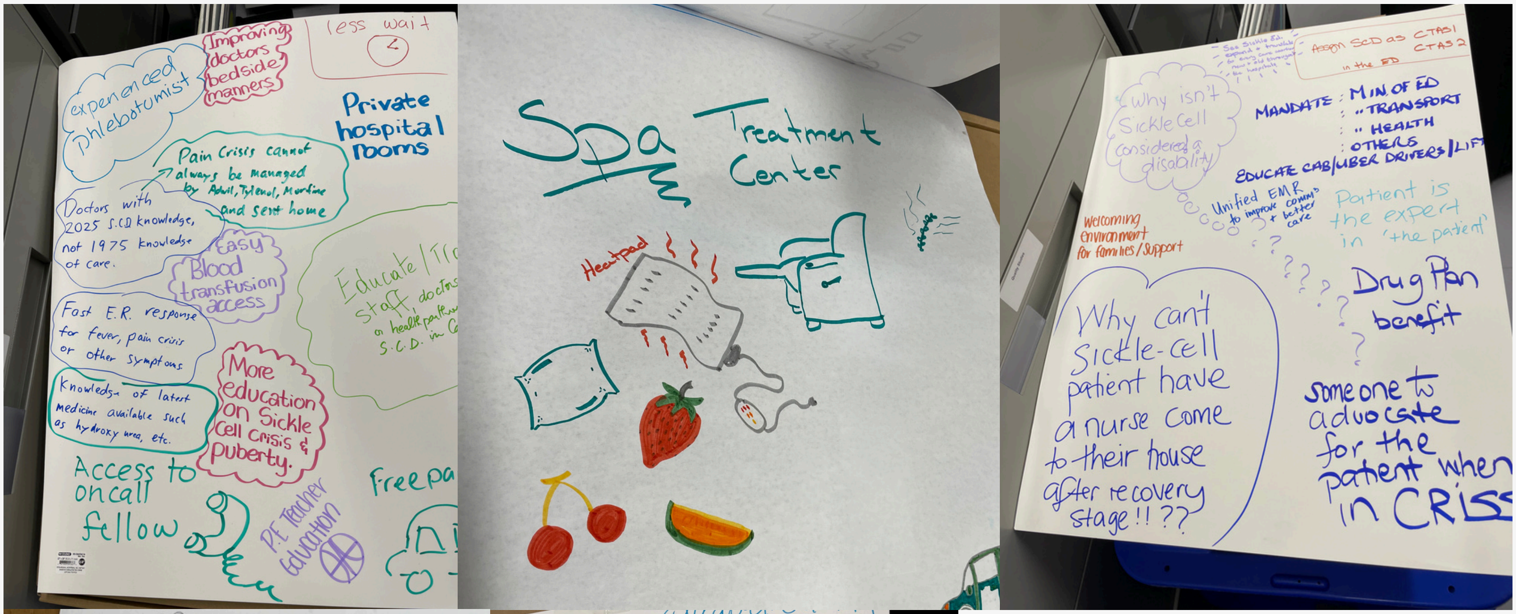
CAREGIVER'S PERSPECTIVES

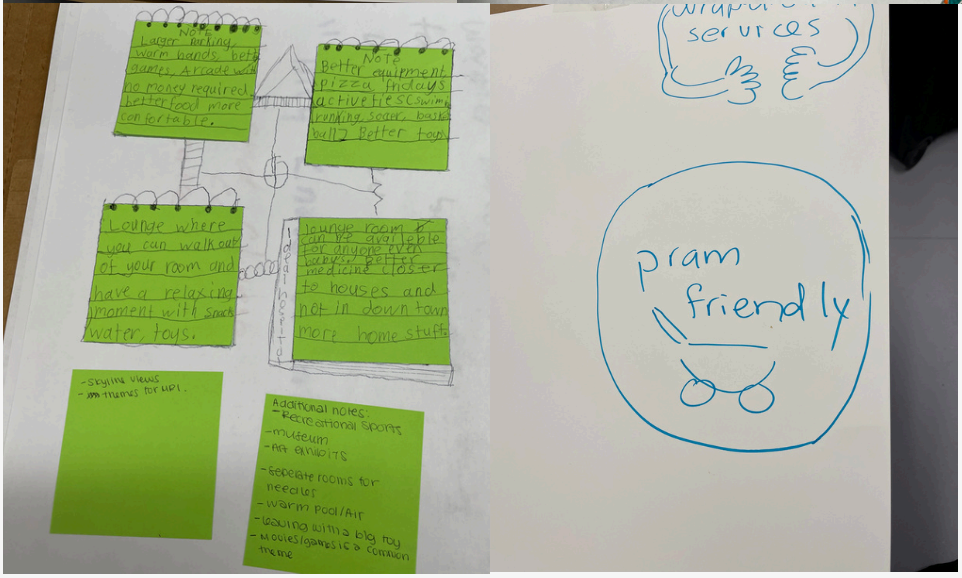
Caregivers spoke openly about the physical exhaustion, emotional strain, and logistical difficulties of managing care. Their accounts revealed gaps in access, communication, and continuity that place an unfair load on families. Caregivers identified key shortcomings in the system and described the supports required to better integrate care in clinical, educational, and community contexts.

Workshops with caregivers highlighted four main themes:

- **Access to Timely and Reliable Care:** Caregivers described long wait times in emergency departments, inconsistent triage, and uneven application of pain management protocols. These experiences frequently led families to delay seeking care until symptoms were severe. They noted that care quality depended heavily on location, time of day, and individual providers rather than on standardized systems.
- **Advocacy as Ongoing and Unrecognized Labour:** Caregivers described constantly having to advocate for their children across hospitals, schools, and social service settings. This required repeatedly educating providers and teachers about sickle cell disease, managing care plans, and navigating school boards. Although essential, participants viewed this advocacy as exhausting and unsupported.
- **Impact on the Whole Family:** SCD care impacts entire households through missed workdays, lost income, transportation challenges, and out-of-pocket costs such as tutoring during prolonged school absences. Caregivers stressed that health systems often overlook the broader family context shaping care experiences.
- **Loss of Continuity During Transitions:** Caregivers described transitions from paediatric to adult care as abrupt and destabilizing. Care plans, records, and accumulated knowledge were frequently lost, forcing families to start over. Caregivers emphasized the need for coordinated, lifelong care models that maintain continuity and support youth into adulthood.

CAREGIVER **WORKSHOP**





A snapshot from the caregiver workshop showing participant-generated ideas and reflections through drawings, notes, and group activities. Caregivers shared priorities for an ideal paediatric SCD clinic, including timely pain management, better communication and education, stronger care coordination, and family-friendly supports.

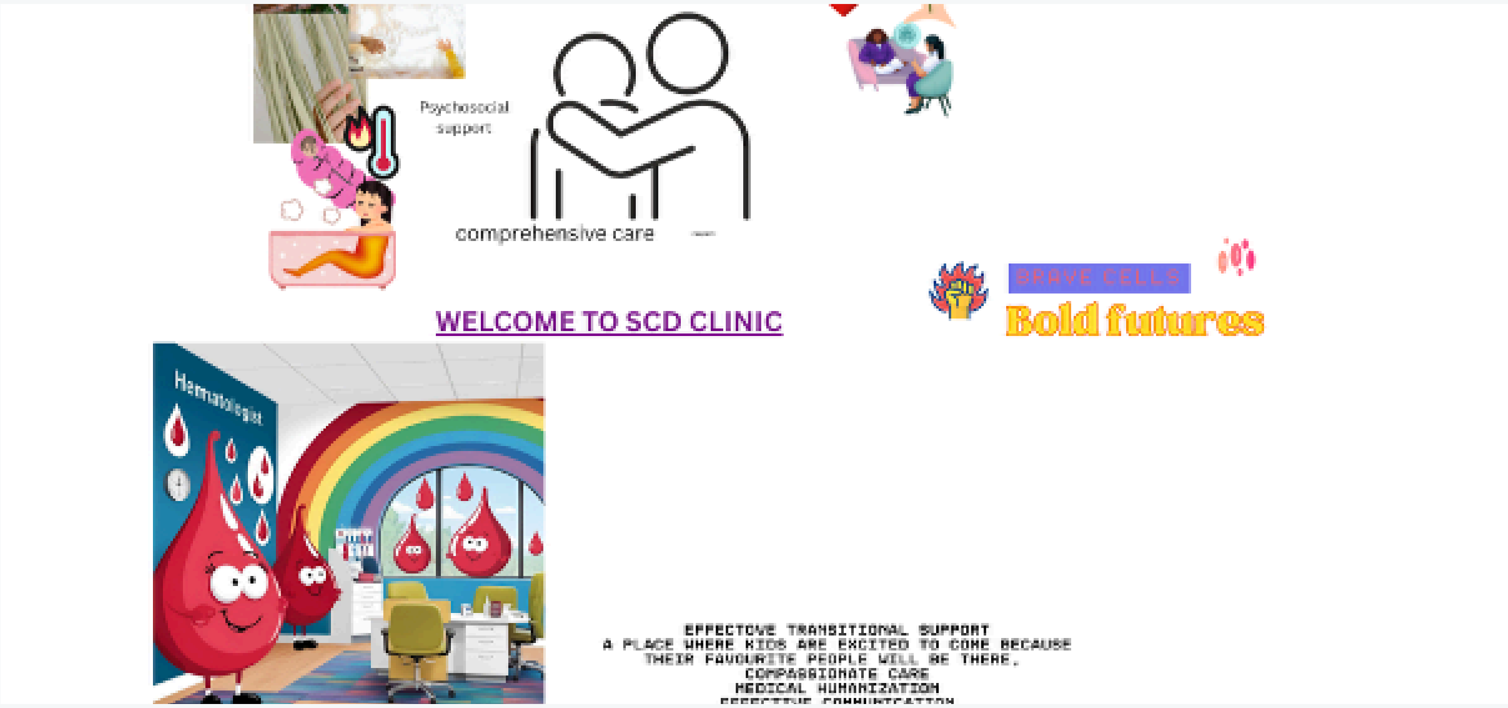
> We have to explain ourselves over and over.
>
> — Caregiver

CLINICIAN PERSPECTIVES

Service providers, including clinicians and health system partners, recognized that families face many gaps in care. They spoke about the challenges young people experience when moving from children's to adult health services. They also noted that many general healthcare staff do not get enough training about SCD. Providers said there needs to be better communication and coordination between hospitals and community services. Many also said that working closely with community organisations can help build trust and improve care for people with SCD.

Workshops with service providers highlighted four main themes:

- **Importance of Presence:** Providers said that good SCD care is not just about clinical treatment - it is about treating people with respect and dignity. Patients need to feel seen, heard and cared for. Providers also said that faster care in emergency rooms and more education and training are needed to reduce stigma.
- **Disempowerment and Empowerment:** Providers spoke about how racism, stigma and disbelief of patients' pain can make people feel powerless. They said care should focus on empowerment by helping patients and families feel strong and supported through advocacy, education, mentoring and positive messages that children and families can relate to.
- **Lifespan Approach to SCD Care:** Providers emphasized that SCD affects people throughout their lives, so care must be ongoing and age-appropriate. They noted that more support is needed when young people move from children's to adult care. Topics like sexual and reproductive health and using modern tools (like apps and games) for health education should also be included.
- **Prioritizing SCD in the System:** Providers said that the health system needs to give more attention and resources to SCD care. This includes better emergency department responses, creating system navigator roles and working with community organisations to provide support beyond hospitals.



CLINICIAN **WORKSHOP**

A snapshot from the clinician workshop showing participant-generated ideas through a collaborative whiteboard activity. Clinicians used images and keywords to visualize an ideal paediatric SCD clinic, highlighting priorities such as safety, trust, culturally safe care, welcoming environments, and comprehensive support.

> People with sickle cell disease have been traumatized in some way or form by the healthcare field.
>
> — Clinician

ACROSS ALL GROUPS WE HEARD:

1. **Equity:** Caregivers, children and healthcare providers want care that understands the unique challenges of SCD and actively works to address systemic racism and inequities in the health system.

2. **Trust:** Because of past negative experiences, many families have lost trust in the system. Rebuilding that trust means providing culturally safe care, being accountable and building stronger partnerships with the community.

3. **Consistency:** People want care that is clear and reliable with standard procedures, good communication and smooth transitions between hospitals and from child to adult care.

4. **Support:** Families need help beyond hospital care, including better training for schools, peer support networks, advocacy roles and community-based resources.

5. **Child- & Family-Centred Care:** Children want safe, welcoming spaces where their voices matter. Caregivers and healthcare providers also emphasized the importance of respectful, people-focused care that treats every patient and family with dignity.

Visibility Through Lived Experiences

November 15 Knowledge Mobilization Event

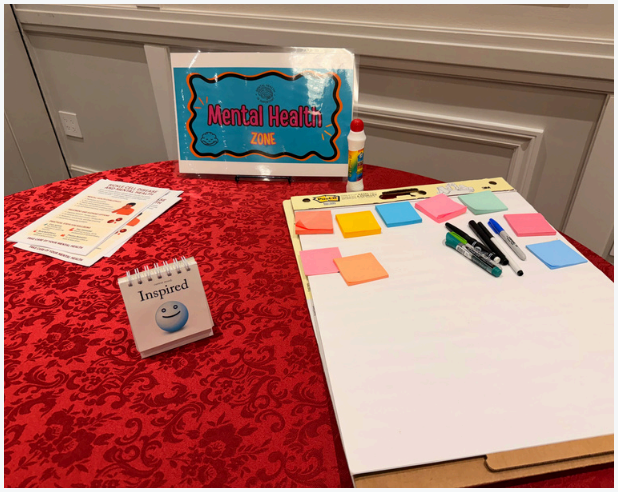
This community gathering brought together children, youth, caregivers, service providers, families, clinical partners, and community organisations to share and reflect on the results of the co-design workshops conducted throughout the year. The event provided a space for individuals living with SCD and their families to see their insights reflected in the findings and to contribute to next steps for the new paediatric satellite clinic at THP.

1. Share key findings from children, caregiver, and service provider workshops in clear and accessible ways.
2. Create opportunities for engagement through storytelling, lived/living experience sharing, and interactive learning.
3. Strengthen cross-sector dialogue among healthcare providers, researchers, policymakers, and community organisations.
4. Gather community feedback to help refine the clinic model, identify priorities, and guide future evaluation.

AGENDA HIGHLIGHTS

- **Welcome, introductions, and opening remarks**
- **Reflections from caregivers and youth**
- **Summary of co-design workshop findings**
- **Rotation zones with interactive sessions**
- **Group discussion and reflections**
- **Closing remarks and next steps**

ROTATION ZONES



Sickle Cell and Mental Health
Facilitated by Dr. Lance Archer
Psychologist (Supervised Practice)
Person Living with Sickle Cell Disease
Member, Board of Directors SCAGO
1st Vice Chair, Patient Advisory & Advocacy Council (PAAC) SCAGO

Affirmation Building and Storytelling
Facilitated by Simone Wright
PsychoHairapist & Certified ISO-30415 Diversity & Inclusion Professional
Community Facilitator
Community Advocate
Person with Lived Experience
Program Lead, Parting The Roots

Participants rotated through four interactive learning spaces designed to reflect major themes of the co-design work.

These zones encouraged dialogue, creativity, and shared learning. Youth and caregivers highlighted the value of hands-on activities and safe spaces to express their experiences.

SCD in Action
Facilitated by Lystra Beausoleil, RN and Jennifer Siove
Peer Research Assistants, Family and Child Health Initative, Institute for Better Health, Trillium Health Partners

Arts-based learning
Facilitated by Josephine Fosuwaa
Person with lived experience/advocate

Visibility Through Lived Experiences

November 15 Knowledge Mobilization Event

COMMUNITY PARTNERS

The Honourable Jean Augustine
Trailblazer – Educator – Community Champion

The **November 15 event** was deeply enriched by the presence of The Honourable Jean Augustine. As the first African Canadian woman elected to Canada’s Parliament and appointed to Cabinet, her lifelong leadership has shaped national conversations on equity, education, and community well-being.

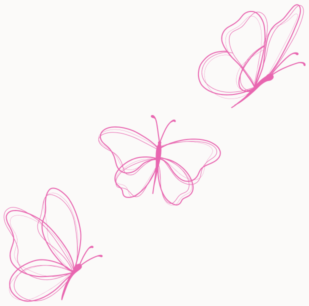
Her reflections reminded us that the work of building culturally safe and equitable health care is rooted in collective action, historical struggle and the unwavering commitment of community. Attendees shared that her words were inspiring, grounding, and a powerful affirmation of the importance of centring lived and living experience in transforming sickle cell care.

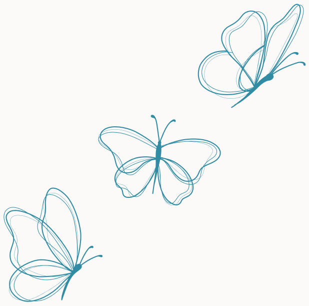
“Sickle Cell is not just a health issue; it is a community issue and that is why we are all here”.

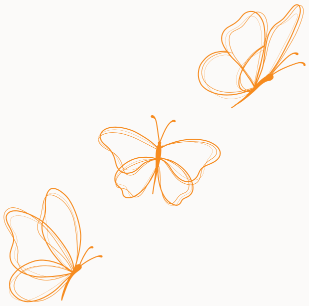
Her presence honored the community and reinforced the significance of this work for generations to come.

Word Cloud
Participant Survey

The word cloud below reflects the most common words participants used to describe how they felt after the event.







WHAT WE HEARD

This page summarizes what participants shared through feedback forms and reflections collected during the knowledge translation (KT) event. These insights build on earlier workshop findings and will inform both the paediatric satellite clinic and future community engagement efforts.

What Stayed with Participants

Participants were deeply impacted by the personal stories shared throughout the event, including experiences with misdiagnosis, delayed care, and navigating the emotional realities of sickle cell disease. Many described the storytelling as powerful, motivating, and necessary for understanding the full picture of SCD care.

Key Learnings

Attendees reported learning about:

- Different SCD genotypes and their symptoms
- The distinction between trait and disease
- How SCD affects organs and body systems
- The mental health impacts of SCD
- The importance of community resilience and shared advocacy

These insights reinforce the need for clinical, educational, and psychosocial supports within the new clinic.

CONNECTING FINDINGS TO QUALITY STANDARDS AND SYSTEMS CHANGE

Alignment with Ontario SCD Quality Standard

The experiences and voices of children, youth, caregivers and clinicians closely align with the Ontario Health Quality Standard for SCD. Families called for timely assessment and treatment of pain, consistent access to knowledgeable providers and clear care pathways. Our engagement work confirmed that these expectations remain critical benchmarks for improving the experiences of patients and their families.

Extending Beyond the Standards

Families and youth emphasized that lived and living experiences go beyond policy documents, even though the Quality Standard is a good starting point. They said challenges like stigma at school, limited peer support and the emotional and mental health strain on families are not fully covered by the standard. They also emphasized the need for culturally safe care and better education for all service providers. These points show the importance of taking a broader, community-informed approach to SCD care.

Contributions to Broader Health Systems Change

This project also connects to broader health system priorities related to continuity and transitions in care. Youth and caregivers highlighted concerns about changes in support as patients move from paediatric to adult services, underscoring the importance of early planning, shared decision-making, and coordinated transitions that prepare young people and families for long-term care needs.[8]

Lessons from this engagement can help inform:

- **Integrated care** planning to make sure children and youth move smoothly from child to adult services.
- **Education and training** that build cultural safety and increase awareness of SCD across all parts of the health care system.
- **Partnerships between communities** and the health system to strengthen trust, improve access and better support families living with SCD.

In this way, the project not only responds to the current needs of families in Peel and the GTA but also adds to the broader effort to make Ontario's healthcare system more fair, inclusive and responsive for everyone.

RECOMMENDATIONS FOR POLICY & PRACTICE

Based on the findings, the following recommendations are proposed:

1. **Improve** health care provider education through regular training on SCD care, anti-racism and patient-centred communication.
2. **Develop** peer support networks for children, youth and caregivers to reduce isolation and build resilience.
3. **Integrate** mental health supports into SCD care pathways, recognizing the emotional and psychological impact of living with a chronic illness.
4. **Strengthen** school-based awareness initiatives to better support students living with SCD.
5. **Add** advanced system navigation supports, such as patient navigators or dedicated coordinators, to help families move more easily through the health care system.

NEXT STEPS:

THP’S SICKLE CELL DISEASE PAEDIATRIC SATELLITE CLINIC

The insights from families, youth and providers will help guide the ongoing development of THP’s paediatric SCD satellite clinic.

- **Integrate Clinical and Social Needs:** Conduct a community needs assessment to identify the daily challenges families face.
- **Develop a Multidisciplinary Team:** Schedule regular interdisciplinary meetings for collaborative patient care discussions.
- **Enhance Partnerships with Community Organisations:** Identify and collaborate with local organisations to co-host educational events for families.
- **Establish Ongoing Evaluation and Feedback Mechanisms:** Implement a feedback system, such as surveys, for families to share their experiences.
- **Continuous Professional Development:** Offer training for staff on family engagement and holistic care practices.
- **Utilize Data for Improvement:** Regularly analyze feedback data to identify trends and areas for adjustment in services.

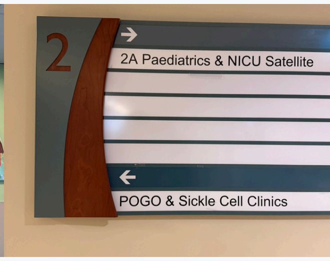
Credit Valley Paediatric Satellite Clinic

A **satellite clinic** is a specialized clinic embedded within a community hospital to bring expert care closer to the community it serves.

In a shared care model with SickKids Hospital, children living with Sickle Cell Disease can receive coordinated, consistent care closer to home at Credit Valley Hospital in Mississauga. The Credit Valley site is one of six dedicated paediatric sickle cell disease satellite centres in Ontario.

This outpatient clinic is located in a welcoming, colourful, child-friendly space designed to support children and families. The care team includes **paediatricians**, a **registered nurse**, a **nurse practitioner**, a **social worker**, a child life specialist, and administrative support.

Members of the clinical team have collaborated with families and the Family and Child Health Initiative (FCHI), contributing their expertise, time, and commitment to co-design. This collaboration has helped shape a model of care that prioritizes trust, continuity, and meaningful engagement while ensuring evidence-based best practice.



Key Insights and Practical Implications

The engagement process showed that families affected by SCD face barriers that go beyond medical treatment. Caregivers described the emotional and logistical burden of coordinating care, while children highlighted the need for peer connection and understanding in hospital settings. Healthcare providers identified challenges related to limited awareness and resources. Together, these insights underscore that improving SCD care requires both clinical excellence and strong support systems that address the social and emotional realities of living with the disease.

Educational Components for Staff, Caregivers, and Youth

Education emerged as one of the most consistent priorities across groups:

- Health care providers require training in SCD-specific care, pain management, and cultural safety to ensure families receive timely, respectful, and appropriate treatment.
- Caregivers expressed interest in structured education sessions on navigating the health care system, advocating for their children, and understanding treatment options.
- Children and youth could benefit from tailored education around self-advocacy, transition to adult care, and coping strategies for school and social environments.

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“It feels good when I’m seen.”

Workshop Participant

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Family and Child Health INITIATIVE