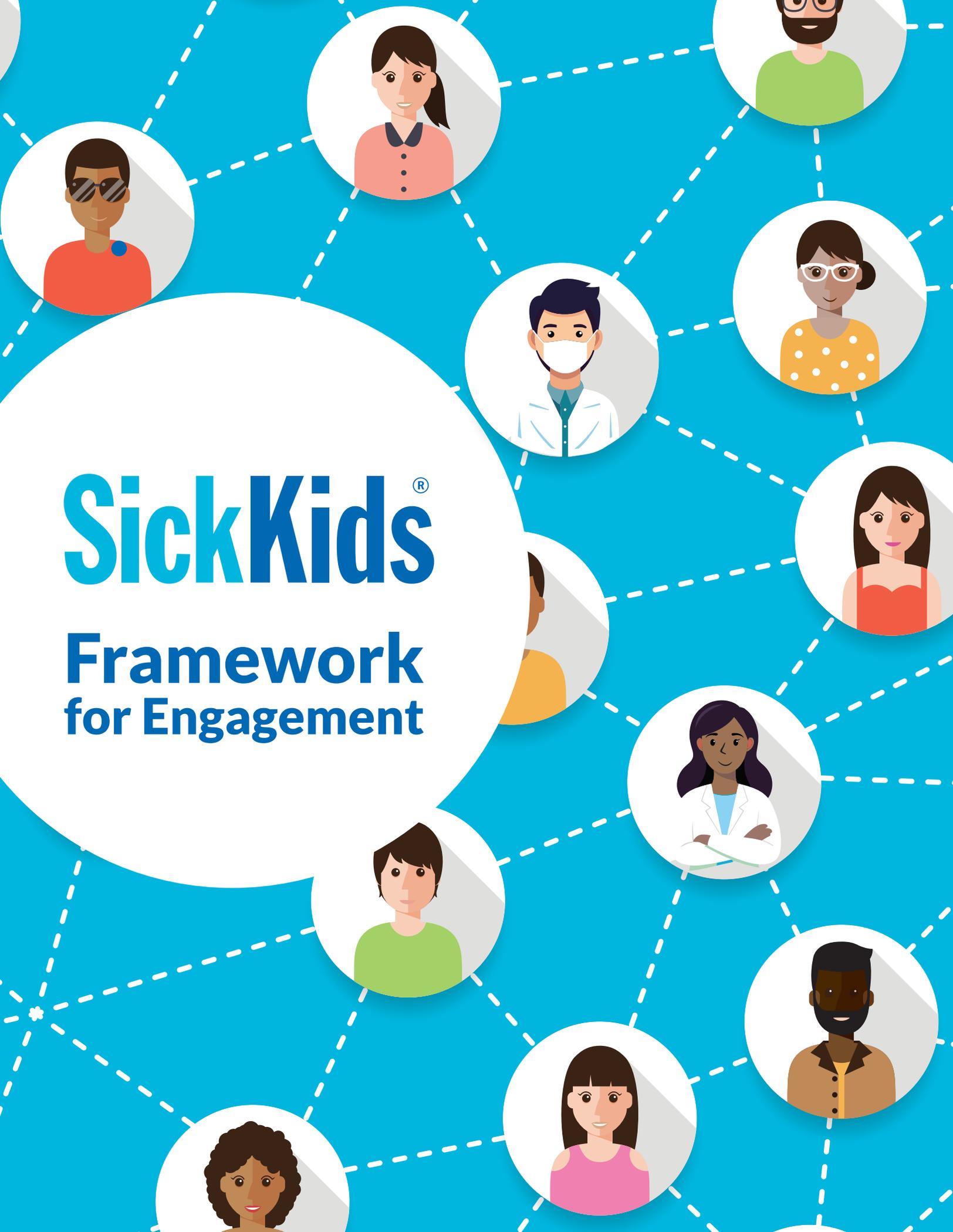


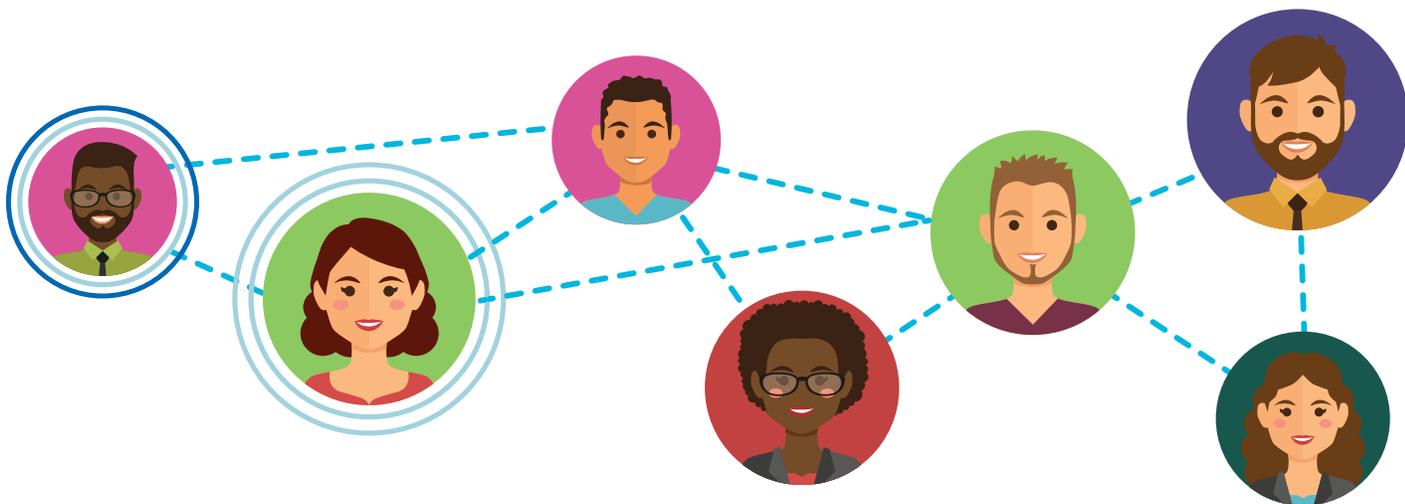


SickKids[®]



**Framework
for Engagement**





INTRODUCTION

At SickKids, we believe the best health systems are built by listening to the voices of the people they serve. Patients, families, and communities hold the stories, wisdom, and lived experiences that can transform health systems to truly reflect the needs of patients and their families.

The *SickKids Framework for Engagement* is a call to action. Co-created with lived experience advisors and staff across care, research, and education, it is both a guide and a promise: to build meaningful partnerships, to ground decisions in lived experience, and to keep learning as we advance our vision of *Healthier Children. A Better World.*

The framework is designed to guide meaningful engagement—from planning and implementation to evaluation—so that our programs, services, and research initiatives reflect what matters most to patients and families. It is a living resource that will evolve as our partnerships grow and as we continue learning together.

To put this framework into action, we have developed a companion guide for staff, with practical tips and considerations to support you in embedding meaningful engagement into your work. If you have questions, ideas, or feedback, we encourage you to contact us at aSK.engagement@sickkids.ca. Together, we can ensure that every voice shapes a stronger, better SickKids.

SickKids gratefully acknowledges the members of the framework co-design group (Kameeza Ali, Saima Azhar, Barbara Couper, Kimberley Dionne, Tamara Greaves, Karen Haas, Melissa Jones, Lawrence Ng, Margaret Schwan, Sandra Tomassini) for their perspectives, input, and commitment to producing the framework; the Patient Advisory Council, lived experience advisors, and staff who provided additional feedback; and lastly, the Office of Engagement team (Brooke Allemang, Cindy Alves, Francine Buchanan, Lisa Howlett, Anitha Ithayalingam, Clara Jordan, Dalya Kablawi, Priscilla Medeiros, Alexa Petta, Michelle Quinlan, Jennifer Rosart, Julie Rose, Harprit K. Singh, Rita Visconti) for their contributions to developing and refining the framework.

DEFINITIONS



ENGAGEMENT

Engagement is the intentional, impactful and authentic involvement of people with lived experience in the design of clinical programs, research, and education. The goal of engagement is to ensure that the health system reflects the lived experiences of those who use it.

The terms below describe the diversity of experiences that we can learn from at SickKids. They recognize that we must look within and outside our walls, as we advance care, research and education.

SickKids ADVISOR

A patient*, caregiver or family member**, who holds wisdom, knowledge and expertise based on their lived experience at SickKids.

COMMUNITY ADVISOR

An individual with knowledge and expertise rooted in lived experience in their community, with valuable insights that inform and advance the work at SickKids.

SickKids STAFF

Anyone working at SickKids who could benefit from engaging with patients, caregivers/family members and the broader community. This includes staff in clinical, administrative, research, or educational roles.

** Age 12+ (SickKids works with patients under 12 in ways that are distinct from advisory work happening at SickKids. This is to ensure that the voices of younger patients are captured in emotionally safe, developmentally appropriate ways.)*

*** 'Family' is defined as the individuals to whom a patient is connected whether through biology, legal ties, or intentional choice.*

FRAMEWORK

Purpose Statement: The Framework for Engagement sets out best practices for patients, families, community members, and SickKids staff to work together to make changes to the health system that reflect the lived experiences of those who use it. It also guides our efforts to evaluate and ensure ongoing meaningful engagement.

CORE VALUES

We aim to embed partnership in all we do across SickKids by adopting the following values:



TRANSPARENCY

We openly share our goals, plans, concerns, expectations and opportunities for impact when working together.



MUTUAL RESPECT

We listen to and consider each other's ideas, lived experiences, worldviews, cultural beliefs, and knowledge.



SAFETY

We work collaboratively to build trust, acknowledge trauma, and prevent unintentional harm to any person with whom we are working by fostering physically and emotionally safe environments. We acknowledge the inherent power imbalances that exist between healthcare professionals and users of the healthcare system, and actively take steps to address those imbalances.



INCLUSIVITY

We foster welcoming and accessible environments which enable everyone to participate to their fullest potential. We prioritize inclusion, equity and diversity across cultural backgrounds, diagnoses, education, socioeconomic status, age, family structure, religion, gender, and ability.



CO-LEARNING

We approach engagement activities with an openness to learning and growth, and an acknowledgment of the mutual benefits of exchanging knowledge, experiences, and skills when working together.



FACILITATORS

Facilitators are organizational factors that create an environment in which safe and impactful engagement can occur. These include foundational beliefs, policies, resources, and practices that allow an institution to achieve its goals. Key facilitators for engagement are:

- A culture that champions lived experience as an invaluable form of expertise.
- Clear, timely, and consistent communication to support equitable and transparent engagement.
- Ongoing research and evaluation of engagement activities to support continuous improvement.
- Adequate resources (e.g., time, budget, people, training, etc.) to support the right engagement approaches and ensure that engagement goals are met.

ENGAGEMENT APPROACHES

SickKids defines four approaches to engaging patients, families, and community members, each with their own corresponding roles and expectations of advisors and staff: **Inform, Consult, Involve, and Shared Leadership**^{1,2}. The table and wheel below describe the four engagement approaches, their goals, and example activities related to each. Different approaches may be used at different times, and engagement opportunities can range from ad hoc (i.e., one-time) to long-term initiatives. All approaches have the potential to be highly impactful – the key is ensuring that the engagement approach aligns with the overall goal, and that the appropriate facilitators are in place. In one project, you may utilize more than one approach to engagement. For example, an advisor may join a patient and family advisory council (PFAC) to receive information (Inform), to provide feedback on policies/tools (Consult), to co-design tools and training (Involve), or to co-lead the council and actively partner in decision-making (Shared Leadership). For this reason, it is critical to align advisor and staff goals and expectations to ensure meaningful and impactful engagement.

¹International Association for Public Participation. *Spectrum of Public Participation*. 2024.

https://iap2.org.au/wp-content/uploads/2020/01/2018_IAP2_Spectrum.pdf

²Health Quality Ontario. *Ontario's Patient Engagement Framework*. 2017.

<https://www.hqontario.ca/portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>

Aligning Engagement Approaches, Goals, Activities, and Resources

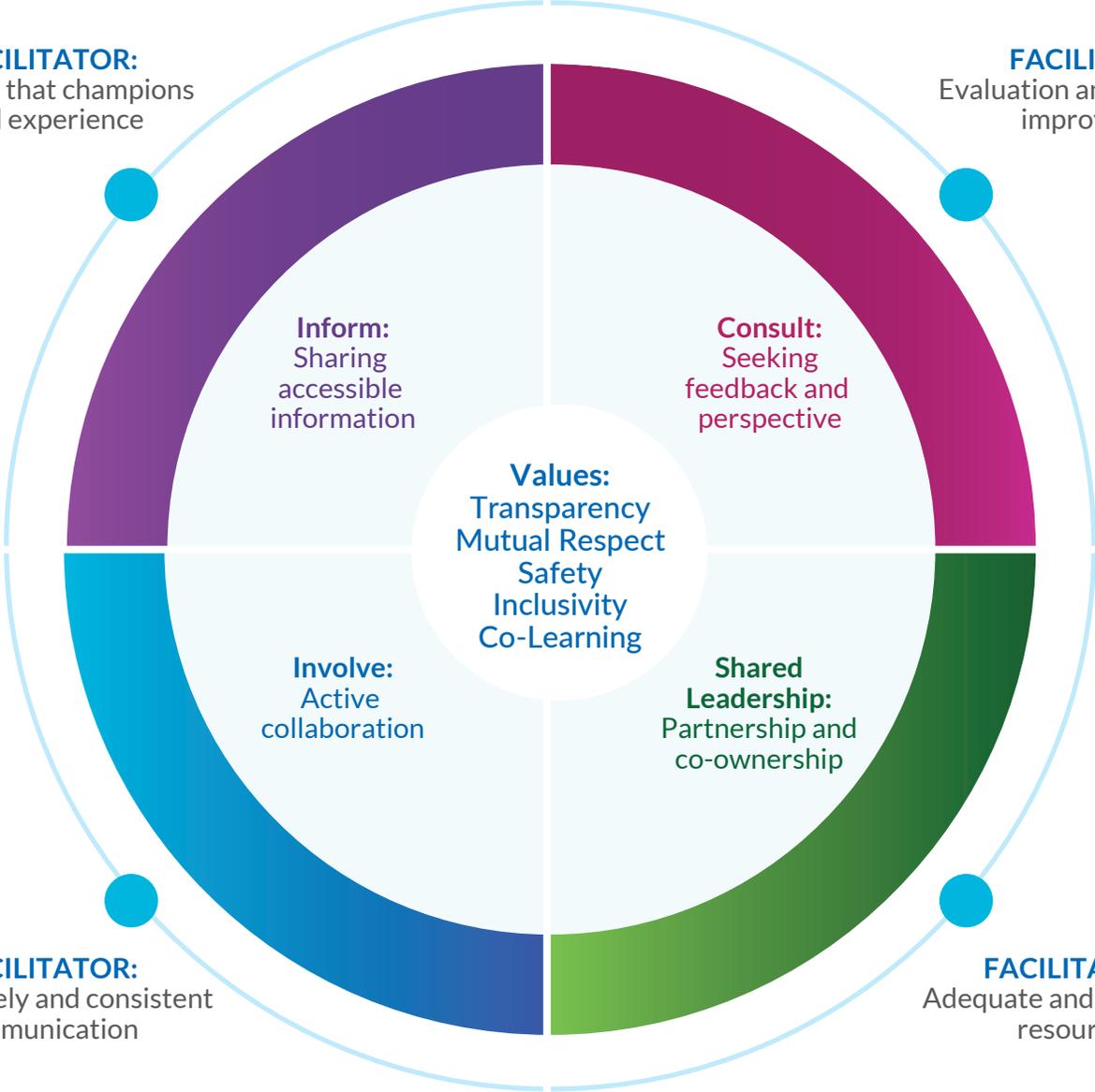
ENGAGEMENT APPROACHES	ADVISOR GOAL	STAFF GOAL	EXAMPLE ENGAGEMENT ACTIVITIES
INFORM	To share or receive accessible information that increases awareness and understanding.		<ul style="list-style-type: none"> • Advisors receive information about engagement work happening at SickKids via a newsletter, website, or webinar • Staff attend a learning event featuring speakers with lived experience
CONSULT	To share feedback and perspectives based on lived experience to guide decisions.	To learn from the lived experiences of advisors and apply these learnings to improve the health system.	<ul style="list-style-type: none"> • Advisors complete surveys or share their perspectives via an interview or focus group • Advisors complete a document review to ensure that content for patients and families is accessible, easy to understand and relevant to their needs and experiences • Advisors provide feedback to staff on clinical, educational, or research tools
INVOLVE	To actively collaborate with staff and other advisors to co-develop solutions to improve the health system.	To learn from the lived experiences of advisors and apply these learnings to improve the health system.	<ul style="list-style-type: none"> • Advisors and staff work together to co-design a clinical, educational, or research tool through regular communication or meetings • Advisors actively participate in hospital accreditation activities • Advisors and staff collaborate to develop and deliver a presentation or training
SHARED LEADERSHIP	To partner in decision-making to improve the health system.		<ul style="list-style-type: none"> • Advisors and staff co-lead a PFAC, project or working group • Advisors assume co-investigator roles on research studies or grant applications • Staff and advisors partner to lead and sustain initiatives that involve patients and families in decision-making

Note: The examples included in this table are not an exhaustive list.

ENGAGEMENT WHEEL

FACILITATOR:
A culture that champions lived experience

FACILITATOR:
Evaluation and continuous improvement



About the Office of Engagement at SickKids

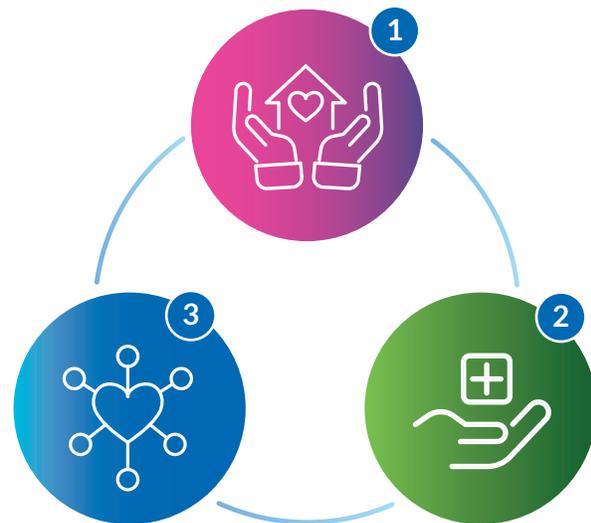
The Office of Engagement at SickKids is dedicated to fostering meaningful partnerships among patients, families, community members, staff, researchers, and educators. Our office serves as a central resource to support and advance engagement practices across the organization.

Through leadership, guidance, and resources, the Office empowers SickKids staff, researchers, and educators to engage effectively and inclusively, strengthening the hospital's mission to provide world-class care, research, and education.

What We Do

Our mandate is to support a culture that embeds partnership in all we do at SickKids. We are here to help staff and advisors, with a focus on:

- 1 Building and fostering a community of individuals with lived experiences in diverse healthcare journeys.
- 2 Supporting advisors and staff with guidance and tools to participate in partnerships that are safe, welcoming and impactful.
- 3 Connecting people with lived-experience to staff across SickKids to improve the design of care, education and research.



To learn more, email aSK.engagement@sickkids.ca