



**2024**  
**2027**

**Patient and Family Experience Strategy:**  
**A Focus on Fundamentals**

# Leadership message

Experience is a challenging thing to define in health care. At a children's hospital, the complexity of what defines experience is deepened by the ripple effects a child or youth's illness can have on siblings, parents, caregivers, and loved ones. For these reasons, developing a deep understanding of what experience means to the community SickKids serves was an essential starting point in the development of our **Patient and Family Experience Strategy**.

We asked you to help us grasp the meaning of experience. After countless hours spent listening, we now have a fuller understanding of what drives experience and what we must do to improve it. Through your inspiring lived experiences and sometimes heartbreaking vulnerability, the following three themes emerged from our conversations:

- Almost everything we do at SickKids, and every member of our team, directly or indirectly impacts experience
- Fundamentals, not cutting-edge innovation, impacts experience most (compassionate communication, listening, making decisions together, comfortable spaces etc.)
- We want to work together to re-imagine experience, every step of the way.

We send a special thank you to our network of child, youth, and family advisors, and our broader community for their time and truth in shaping this strategy. Together, we are on a journey to deliver unprecedented outcomes through Precision Child Health, and we know that unmatched patient and family experiences are the path to take us there.

Sincerely, \_\_\_\_\_



**Ronald Cohn**  
President & CEO



**Karen Kinnear**  
VP Clinical,  
Patient & Family Experience  
Executive Sponsor,  
Patient and Family Experience Strategy



# Why is this strategy important?

Seismic shifts in the health system have impacted patient and family experiences in different ways. Restrictions during the COVID-19 pandemic created both tensions and innovations impacting experience. Patients and families are rightfully demanding more convenience, access, and ease of use from health-care organizations built to serve them. The health-care workforce is stretched and plagued by moral distress in trying to do more with less for the patients and families they have dedicated their lives to care for. Better engagement in research is essential to fuel discovery that will improve the lives of children across the world. Taken together, this

climate necessitates an evolved blueprint to guide our efforts to authentically partner with patients and families in building a SickKids that better meets the diversity of needs and preferences in our community.

With SickKids' vision of **Healthier Children. A Better World.** as our guiding star, this **Patient and Family Experience Strategy** will act as our iterative guide to deliver what every patient and family deserves—unmatched experiences leading to the best possible health outcomes.



**+ EXPERIENCE**

- IMPROVED...**
- Communication, trust, and relationships
  - Engagement and empowerment
  - Treatment adherence
  - Quality and safety
  - Psychological well-being
  - Research and innovation
  - Healthcare utilization



**+ OUTCOMES**



# How we got here



**325**

Patient, Family and Community Survey responses  
(survey fielded in 11 languages)



**134**

New patient, family, and community advisors engaged



### Environmental scans

Experience frameworks, strategies, and tactics  
Customer centric strategies in adjacent industries



**70**

Interviews and focus groups with patients, families, and staff



**536**

SickKids Staff Survey responses



### Literature reviews

Drivers of patient experience  
Relationship between experience and outcomes



# Inspiration from our community

To inspire strategy development, we asked patients, families and staff to tell us about "wow moments" they have experienced in the health system—experiences that exceeded expectations, imprinted on their minds over time...

“

I was 6 years old when I was diagnosed with Tuberous Sclerosis. The first picture is me during my first admission at the hospital. Now here's me at 17 with my Children's Council certificate being given the chance to make changes to the hospital and help patients. Something that I love doing.



“

A wow moment at the hospital for me was waking up from my brain surgery to Harry Styles holding my IV and bravery beads. Thanks to Dianna at the library, who's known me since I started going to SickKids and given me almost every bead I've ever gotten.

## Inspiration from our community

“ While I have created so many WOW moments at SickKids, one that truly stands out to me would involve the healing power of dogs. I had been unable to sit for days on end after one of my spine surgeries, but the minute the therapy dog entered my room, I was finally able to get one step closer to going home!



Gabriella



Ping

“ My wow moment at SickKids isn't a moment, it's a person: Child Life Specialist Katie! She was my rock through so many of the earlier 50+ surgeries I've had. When I was younger, she accompanied me into the operating room, sat with me, and played with me until I was put to sleep, explaining at the right age level everything that was happening. She took away any fear I had. I realize, now that I am older, what an enormous impact she had on my long medical journey. I am forever grateful for everything she has done for me.

# Inspiration from our community



Lily

“ Passing time in the hospital by playing a game with my mom.



“ Feeling strong and proud after getting my feeding tube and PICC line put in with the support of the amazing SickKids nurses!



Sophie

“ A wow moment that I had at SickKids was the night before my surgery. All of the child life specialists were making sure, to the best of their abilities, that I was comfortable. Even though I didn't know what was happening at the time, I remember feeling like I was in very good hands and I wasn't nervous.

## Inspiration from our community



“ In 2021 I had quite a long stay in the hospital. Smack bang in the middle, I celebrated a special birthday; 12 on the 12th. I was desperate to be home but knowing it wasn't an option, the nurses on my unit, along with the Child Life team, threw me the most spectacular birthday. I asked for three things: to breathe some air and feel the grass on my feet, watch a movie and to have a scavenger hunt. They delivered all three and I honestly don't think I could have had a better birthday. They went out of their way to make me feel special and loved on a day that could have felt isolating and sad. It showed me that the staff really do more than just deliver incredible health care, they make sure you can just be a kid enjoying the birthday limelight!

## Inspiration from our community



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Our wow moment is being members of the Children's Council. We share our experiences to improve hospital projects, initiatives, and decision-making. Being a part of the Council allows us to contribute to the SickKids community to ensure patients and family voices are heard and prioritized. We hope this strategy encourages unity, dignity, transparency, community, and commitment. We are excited to see the launch of the Patient & Family Experience Strategy and continue our advisory work!



### Strive for exemplary child, youth, and family centred services

- Ingrain a child, youth, and family focus in our leadership and culture
- Exemplify compassionate service excellence and collaborative decision making
- Ensure consistent communication and coordination across services



### Support families being families and kids being kids

- Infuse play, togetherness, and social interaction
- Scale access to child and family support programs and services
- Expand family and caregiver wellness supports



### Embed partnership in all we do

- Establish an enterprise-wide approach to engagement that centres child, youth, family, and community knowledge and lived experiences in designing the future of SickKids



### Foster healing digital and physical spaces

- Ensure culturally safe, accessible, welcoming, and comfortable campus spaces and amenities
- Create a seamless digital experience



### Establish an experience improvement loop

- Continually capture child, youth, family, and community voices to inform improvement
- Refine the structure and processes accountable for assessing, prioritizing, and actioning opportunities

### Key enablers

Enterprise focus on quality and safety · Healthy and engaged workforce · Equitable, diverse, and inclusive organization

## Strive for exemplary child, youth, and family centred services



- Ingrain a child, youth, and family focus in our leadership and culture
- Exemplify compassionate service excellence and collaborative decision making
- Ensure consistent communication and coordination across services

Child and family-centred care is a philosophy that recognizes the child or patient is at the core of all that we do, and that the family is central in the child's life and therefore central to our work. This philosophy is brought to life through respect, compassionate communication, and partnership.

Modelling this philosophy from the boardroom to the bedside, SickKids will enhance active listening and involvement of patients and families at every step of their journey. We will share information in consistent ways to empower informed decisions and participative planning. We will celebrate the diversity, preferences, and choices of patients and families, adapting services to their unique needs and goals.



## Support families being families and kids being kids



- Infuse play, togetherness, and social interaction
- Scale access to child and family support programs and services
- Expand family and caregiver wellness supports

SickKids will create an environment where children, youth, and families have ample opportunities for play, recreation, and interaction. These activities are crucial for family cohesion and children's growth and development. Play allows children to express their emotions, manage stress, acquire new skills, and most importantly, have fun. Whether it is playing games, creating crafts, listening to music, or reading books, these outlets will help children feel more comfortable, relaxed, and joyful while at SickKids.

SickKids also recognizes the immense challenges faced by siblings, parents, and caregivers when a child is experiencing illness. By providing enhanced access to support programs and services and shining a light on caregiver wellness, SickKids will strive to not only improve the health of children, but also the health of the entire family unit.



## Foster healing digital and physical spaces



- Ensure culturally safe, accessible, welcoming, and comfortable campus spaces and amenities
- Create a seamless digital experience

As we redevelop our campus and upgrade existing buildings for modern medicine, SickKids is dedicated to ensuring that our spaces create a healing environment, designing physical spaces and amenities that are safe, clean, accessible, welcoming, and comfortable for all.

In the era of digital health, SickKids will also strive to create a seamless digital experience, enabling users to easily and conveniently access information, services, and resources. By leveraging the potential of digital technology, we aim to provide more accessible, intuitive, convenient, and personalized care and services for patients and families.



## Establish an experience improvement loop



- Continually capture child, youth, family, and community voices to inform improvement
- Refine the structure and processes accountable for assessing, prioritizing, and actioning opportunities

To ensure continued progress, SickKids will establish an experience improvement loop. We will use a variety of tools such as surveys, focus groups, interviews, storyboards, safety reporting systems, and co-design sessions to capture the diverse voices of our community, then connect this data to develop a better understanding of the full picture of patient and family experiences.

Using a consistent framework to analyze and prioritize opportunities, we will improve the organization's ability to translate needs into action, continuously improving experiences over time.



## Embed partnership in all we do



- Establish an enterprise-wide approach to engagement that centres child, youth, and community knowledge and lived experiences in designing the future of SickKids, including:
  - principles of authentic engagement
  - inclusive, accessible, and representative participation
  - a shared framework, policies, and practices
  - an evolved council and advisory structure
  - centralized intake with simplified onboarding
  - recognition of value
  - a continuum of engagement and co-design

The knowledge that patients, families, and the SickKids community gain from living with their illness, accessing care, or navigating the health system is invaluable to improving experiences. SickKids recognizes the immense value of partnering with patients and families in advancing our mission and is committed to being an authentic partner in everything we do.

Authentic engagement is based on mutual respect, trust, transparency, and shared goals. It values the lived experiences, knowledge, and skills of patients and families alongside those of clinicians, scientists, and staff. By listening to the voices of patients and families, respecting their perspectives, involving them in decision-making, and collaborating to co-design solutions, together we will re-imagine what is possible.





## Our strategy in the words of the Children's Council



Strive for exemplary child, youth, and family-centred services =  
**Making sure patients and caregivers  
have the best possible experience**



Support families being families and kids being kids =  
**Let families be families  
and kids be kids**



Embed partnership in all we do =  
**Equal voices working  
towards the same goal**



Foster healing digital and physical spaces =  
**Easy to use digital tools  
and comfortable spaces**



Establish an experience improvement loop =  
**Share ideas and  
see their results**