PAEDIATRIC HOSPITAL CARE IN CANADA:

# THE TOP 10 RESEARCH PRIORITIES

Results from the James Lind Alliance Paediatric Hospital Care Priority Setting Partnership

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# FOREWORD

The Canadian Paediatric Inpatient Research Network (PIRN) was launched in 2019 to improve the evidence base and outcomes for hospitalized children in general paediatric inpatient settings. The network's core values include collaboration, inclusivity, and child- and family-centered care. These values inspired us to put patients at the forefront in identifying future research priorities for PIRN by completing a James Lind Alliance (JLA) Priority Setting Partnership (PSP), focused on the care of children hospitalized in general paediatric settings.

This report describes the process undertaken to identify the Top 10 most important, unanswered research questions in paediatric hospital care from the perspectives of parents/caregivers, children/youth, and healthcare providers. Using surveys, we reached out to members of these communities from across Canada, to ask them what matters most to them. The 18-month process, culminating with a final virtual workshop with participants from Yukon to Quebec, generated a list of the Top 10 questions. These questions will help us as paediatricians understand what issues matter to children and families, and as researchers, understand where research is needed to improve outcomes.

This work would not have been possible without key stakeholder partnerships, including: Paediatric Chairs of Canada, Maternal Infant Child and Youth Research Network (MICYRN), Canadian Paediatric Society (CPS) Hospital Paediatrics Section, Canadian Association of Paediatric Nurses (CAPN), Children's Healthcare Canada (CHC), Children's Hospital of Eastern Ontario (CHEO) Patient and Family Advisory Committee (PFAC), CHEO Youth Forum, SickKids Research Family Advisory Committee (RFAC), Ontario Child Health Support Unit (OCHSU), Provincial Council for Paternal and Child Health (PCMCH), Kids Health Alliance (KHA), Section of Child & Adolescent Health – Northern Ontario School of Medicine (NOSM), SPOR SUPPORT Units, and patient and family advisory groups across Canada.

On behalf of the project team, we would like to sincerely thank all the individuals who answered our survey questions, and those who attended the final workshop, which often included sharing personal lived experiences while in hospital. We want to acknowledge the dedication and commitment of the Steering Group, who helped us navigate such a large topic. Lastly, we thank Katherine Cowan, our JLA adviser who played a critical role in our project success.

What next? We urge researchers and research funders, from local charities to national organizations, to ask – what can we do and how can we address these knowledge gaps? What role can we play to improve outcomes for hospitalized children?

Sincerely,

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# EXECUTIVE SUMMARY

The largest population of children cared for in hospital are those with common medical conditions (e.g. chest infections, asthma, the stomach flu) managed in general paediatric inpatient units (GPIUs) (1-3). Despite representing a large inpatient population, there are few research studies that focus on children who are admitted to hospital with these general conditions. To address this evidence gap, the Paediatric Hospital Care Priority Setting Partnership (PSP) was launched.

## PROCESS

The aim of the PSP was to identify the Top 10 most important, unanswered research priorities about the care of hospitalized children in general paediatric settings that are important to patients, parents/caregivers, and the healthcare professionals that support them.

Led by the Canadian Paediatric Inpatient Research Network (PIRN) in collaboration with the James Lind Alliance (JLA), the PSP followed numerous steps to identify the Top 10 and include the patient voice at all stages of the study process, including:

- Developing a Steering Group;
- Developing and launching a Canada-wide online survey;
- Conducting an evidence checking process;
- Completing an interim prioritization survey; and
- Conducting a final priority setting workshop.

## FINDINGS

The Top 10 priorities identified by the PSP reflect the concerns of patients, families, caregivers and healthcare professionals across Canada. These focus on the care of special inpatient populations (e.g. children with medical complexity), communication, shared-decision making, support strategies in hospital, mental health supports, shortening length of stay in hospital, and supporting Indigenous patients, parents and families. Using the Top 10 as a guiding framework, research networks are encouraged to operationalize these priorities in future studies.

## THE TOP 10 RESEARCH PRIORITIES

| | |
|---|---|
| 1 | What best practices and/or care models exist for inpatient care for children and youth with medical complexity on the general paediatric inpatient unit? |
| 2 | What methods of communication are most effective between patients, caregivers and health care providers on a general paediatric inpatient unit? |
| 3 | What are the best practices and support strategies for Indigenous parents, families and children and youth on the general paediatric inpatient unit? |
| 4 | How can we ensure that healthcare delivery in hospital meets the needs of children and youth with developmental disabilities on the general paediatric inpatient unit? |
| 5 | What are effective support strategies for parents, families and children and youth hospitalized on the general paediatric inpatient unit? |
| 6 | What mental health supports can be provided to parents, families and children and youth while hospitalized on the general paediatric inpatient unit? |
| 7 | What mental health supports can be provided to parents, families and children and youth while hospitalized on the general paediatric inpatient unit? |
| 8 | What are effective strategies to mitigate the impacts of prolonged inpatient hospitalizations on the general paediatric inpatient unit? |
| 9 | What are effective alternatives to shorten length of stay for hospitalized children and youth on the general paediatric inpatient unit? |
| 10 | What are the most effective communication methods (e.g. handover, rounds, etc.) between healthcare providers on a general paediatric inpatient unit? |

# BACKGROUND

Admission to hospital can be a vulnerable experience for children and their families, due to both the physical effects of illness and the psychological effects of hospitalization (4,5). In Canada, the largest population of children cared for in hospital are those with medical conditions managed in GPIUs (1-3).

Children admitted to GPIUs may be previously healthy and be hospitalized for acute, common illnesses (e.g. bronchiolitis, gastroenteritis), or for their first presentation of a chronic condition (e.g. epilepsy, asthma). This population may also include children with medical complexity (e.g. cerebral palsy, gastronomy feeding) who are hospitalized for an acute illness or to prevent the further exacerbation of a pre-existing chronic disease (1-3).

## WHY UNDERTAKE A PRIORITY SETTING PARTNERSHIP FOR THIS POPULATION?

Compared to other hospital-based subspecialty areas such as oncology and critical care, there are few research studies that focus on children who are admitted to hospital with general conditions (6-8). Due to this evidence gap, children admitted to GPIUs are at risk of receiving sub-optimal health care, which in turn may hinder their chances of improved health outcomes (9,10).

## ADDRESSING GAPS IN EVIDENCE

In order to fill this evidence gap, a research agenda in hospital paediatrics is needed. A fundamental step in building an agenda is identifying the most important priorities in paediatric hospital care from the perspectives of patients, parents/caregivers, and clinicians.

To identify these priorities, the Paediatric Hospital Care PSP was launched, which sought to answer the following question:

**What are the most important, unanswered research questions in paediatric hospital medicine from the perspectives of children and youth, parents/caregivers, and healthcare professionals?**

## PARTNERS IN RESEARCH

The Paediatric Hospital Care PSP was conducted by the Canadian Paediatric Inpatient Research Network (PIRN) in collaboration with the James Lind Alliance. Using the principles of patient-oriented research, the PSP enlisted the input of paediatric patients, families, and healthcare providers from across Canada at all stages of the research process, to ensure the perspectives of these communities was adequately integrated.

## OVERVIEW OF THE PRIORITY SETTING PARTNERSHIP

The Paediatric Hospital Care PSP was conducted from April 2020 to September 2021, which brought together partners from across Canada including 22 paediatricians, 4 nurses, 4 patient partners, and 13 stakeholder organizations. Together, they identified the Top 10 most important, unanswered research questions about the care of hospitalized children in GPIUs from the perspectives of patients, carers, and clinicians.

These questions provide a roadmap for future research studies on areas deemed most important to children and youth, parents/caregivers, and clinicians with lived experience of paediatric hospital care in general inpatient settings.

### About the Canadian Paediatric Inpatient Research Network

The Canadian Paediatric Inpatient Research Network (PIRN) was established in 2019, for the purpose of addressing the lack of research that focuses on the care of hospitalized children in GPIUs. This Canada-wide hospital-based research network consists of representatives from all 17 academic paediatric hospitals across Canada and four large Ontario community hospitals, who are interested in improving the care of children in hospital. To guide future research priorities in paediatric hospital care and for the network, PIRN works to identify GPIU clinical management questions that are important to paediatric patients, parents/caregivers, and healthcare professionals by conducting multi-centre patient-oriented research.

Supported by the OCHSU in its development as a network, PIRN holds a number of key stakeholder partnerships, with organizations including: the Paediatric Chairs of Canada, the Maternal Infant Child and Youth Research Network (MICYRN), Canadian Paediatric Society (CPS), the Canadian Association of Paediatric Nurses (CAPN), Children's Healthcare Canada, SPOR SUPPORT (Support for People and Patient-Oriented Research and Trials) Units, and patient and family advisory groups. The national team of researchers, clinicians, parents, quality improvement leaders, and stakeholders, positions PIRN well to conduct high-quality research in real-world settings, inform practice guidelines, disseminate findings, and change practice and policy. For more information, please visit **http://www.pirncanada.com**.

### About the James Lind Alliance

Established in 2004, the James Lind Alliance (JLA) is a non-profit making initiative that brings together patients, carers, and clinicians in the execution of PSPs. These PSPs identify and prioritize the evidence uncertainties, or 'unanswered questions' that they agree are the most important for research in their topic area. For further information, please visit **https://www.jla.nihr.ac.uk/**.

PIRN PAEDIATRIC INPATIENT RESEARCH NETWORK | RRPH RÉSEAU DE RECHERCHE EN PÉDIATRIE HOSPITALIÈRE | James Lind Alliance Priority Setting Partnerships

# DETERMINING THE
# TOP 10 RESEARCH PRIORITIES

## STEP 1

**Develop a Steering Group**

A steering group was formed, comprised of patient representatives, clinical representatives, a James Lind Alliance Advisor, and project leads. The Steering Group met monthly to organize the PSP's activities, including defining the study scope, recruiting participants, developing and disseminating surveys, overseeing the analysis and interpretation of study findings, and more.

## STEP 2

**Develop and Launch a Canada-Wide Survey**

A survey was developed by the Steering Group and mass distributed to patients, parents/caregivers, and clinicians with experiences in GPIUs from across Canada, asking respondents to provide the questions they want answered in paediatric hospital care research. Active from August to November 2020, the survey collected 495 questions which were then synthesized by the Steering Group into 75 summary questions.

## STEP 3

**Conduct an Evidence Checking Process**

Highly focused and targeted literature searches were conducted to determine if any of the 75 summary questions had already been answered in published literature.

## STEP 4

**Complete an Interim Prioritization Survey**

Questions considered "unanswered" in published literature were brought forward to an interim prioritization survey, administered online from May to July 2021. In the first part of this survey, participants were asked to select randomly ordered, unanswered questions they thought were important. In the second, once presenting the previously selected questions, participants were asked to select up to 10 questions perceived to be the most important. The Steering Group reviewed responses and reached consensus on which questions to bring forward to the final priority setting workshop.

## STEP 5

**Conduct a Final Priority Setting Workshop**

Two half-day virtual sessions were conducted in August 2021 with 24 participants from across Canada, consisting of 4 paediatricians, 5 nurses, 10 parents, 2 youth, and 3 allied health professionals. Over the course of this workshop, the participants reached consensus on the Top 10 priorities from the perspectives of patients, parents, and healthcare professionals.

# THE TOP 10 RESEARCH PRIORITIES

## FOR PAEDIATRIC HOSPITAL CARE

1. What best practices and/or care models exist for inpatient care for children and youth with medical complexity on the general paediatric inpatient unit?
2. What methods of communication are most effective between patients, caregivers and health care providers on a general paediatric inpatient unit?
3. What are the best practices and support strategies for Indigenous parents, families and children and youth on the general paediatric inpatient unit?
4. How can we ensure that healthcare delivery in hospital meets the needs of children and youth with developmental disabilities on the general paediatric inpatient unit?
5. What are effective support strategies for parents, families and children and youth hospitalized on the general paediatric inpatient unit?
6. What mental health supports can be provided to parents, families and children and youth while hospitalized on the general paediatric inpatient unit?
7. What are effective ways to incorporate shared decision-making with parents and children/youth hospitalized on the general paediatric inpatient unit?
8. What are effective strategies to mitigate the impacts of prolonged inpatient hospitalizations on the general paediatric inpatient unit?
9. What are effective alternatives to shorten length of stay for hospitalized children and youth on the general paediatric inpatient unit?
10. What are the most effective communication methods (e.g. handover, rounds, etc.) between healthcare providers on a general paediatric inpatient unit?

# PRIORITY 1

## What best practices and/or care models exist for inpatient care for children and youth with medical complexity on the general paediatric inpatient unit?

### RATIONALE

Children with medical complexity are characterized as those with functional limitations, substantial family-identified needs, and dependance on medical technologies for activities of daily living (11). Increased health care usage is another common factor among children with medical complexity, whose multiple medical conditions can result in frequent and prolonged hospitalizations which often occur in GPIUs (11). There is a wide variation in how children with medical complexity are managed in hospitals, including how parents/caregivers are involved in their care.

### EVIDENCE GAPS

Children with medical complexity have unique needs, and therefore require diverse and tailored practices of care during their time in the hospital. Existing literature on children with medical complexity addresses medication safety in hospital and parenting skills and interventions for these children, along with the outpatient setting with the development of complex care programs and establishment of a medical home (11-13). However, there is limited evidence on existing best practices and care models for children with medical complexity in hospital (e.g. whether there should be a primary inpatient care team or various consultants), and how to best support parents of these children and integrate them into hospital care. To address this, future research dedicated towards paediatric care for children with medical complexity is needed.

### WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

**Defining Medical Complexity and Care Models**

- How do we categorize medical complexity – is it related to underlying diagnosis, illness severity or safety? How can this categorization be applied in practice?
- Does the "traditional acute care" model on the GPIU need to be modified to meet the needs of children with medical complexity?
- What is the optimal model of care (e.g. consistent/same physician, role of trainees and carers) in the inpatient setting?
- How can children and youth with complex issues that combine mental and physical health concerns be best cared for?
- What is the best model of care to support children with medical complexity who have specific neuro-complexities?
- What are the current models of care for children with medical complexity that exist in Canada? How does it vary by city/province/territory, and by setting of care (children's vs community hospital)?
- If, and how, should children with advanced technology needs (e.g. ventilators) be cared for on GPIUs?
- Are there alternative methods and/or locations of care other than the inpatient setting how and where children with medical complexity with acute health problems can be managed?

**Community and Family Support**

- How can clinicians communicate better with families and parents/caregivers of children with medical complexity, particularly with respect to minimizing medical error and increasing quality of care?
- How can community support be bolstered (e.g. overnight nursing) to ensure children with medical complexity make it home faster?
- Evaluating family perspectives on patient care models, by asking, "what matters to them?"

**Defining "Children with Medical Complexity"**

For more information on how children with medical complexity are defined, check out the following resources:

- (i) Children with medical complexity: an emerging population for clinical and research initiatives
- (ii) Children with medical complexity in Canada

# PRIORITY 2

## What methods of communication are most effective between patients, carers and healthcare providers on a general paediatric inpatient unit?

### RATIONALE

Communication, both verbal and written, is an essential component of paediatric hospital care (14). Furthermore, poor communication can lead to adverse outcomes such as longer hospital stays, incorrect treatments, unsafe patient care, and dissatisfaction among hospitalized patients and their families, weakening collaborative decision making and preventing high-quality care (14,15).

Paediatric patients in GPIUs represent a unique challenge to healthcare professionals and how they communicate health information (14). As these children and youth are often cared for by multi-disciplinary teams, information must be delivered to multiple persons and be communicated in ways that are understandable to all parties involved (14).

### EVIDENCE GAPS

Evidence recognizes several examples of effective communication intervention methods used in paediatric settings. These include visual tools to enhance communication between patients, families and providers and/or improve the communication of medication instructions to patients (e.g. whiteboards and pictures of medical staff) (15,16); traditional face-to-face patient-provider and family interactions (15); email correspondence between families of patients and their providers (17); the “LEARN” (Listen, Explain, Acknowledge, Recommend, Negotiate) model, used in cross-cultural encounters (18); health information technology (HIT), involving the use of various electronic methods to manage information about the health and medical care of paediatric patients (19); and empathetic, compassionate communication from paediatric healthcare professionals to support parents and families of paediatric patients (20-22).

Prior research has shown the effectiveness of some communication interventions in hospital, but the use of these interventions is highly variable and evidence supporting their utility is lacking (15). Additionally, the effectiveness of some communication interventions in hospital has been limited to specific paediatric populations (e.g. pre-term infants), settings of care (e.g. end of life), or those with life-limiting conditions (23-26). It remains unclear which methods of communication are truly effective across GPIUs.

To address this evidence gap, future research is needed to identify the most effective methods of communication between patients, parents/caregivers, and healthcare providers in paediatric care.

## WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

**Informal and Formal Methods of Communication**

- How should clinicians manage synchronous and asynchronous communication with families?
- What measures are relevant to evaluate communication effectiveness between healthcare providers and patients (e.g. parent satisfaction, length of stay, rate of medical errors)?
- What communication strategies are most effective for admission and discharge processes for families?
- Would care be better and would families learn more from informal interactions with other families of children with similar conditions?
- How can clinicians communicate with families in a teaching environment that does not add anxiety for the family or the learner?
- How are linguistic and/or cultural differences accounted for and integrated into communication strategies between patients and their carers on the GPIU?

**Integrating Family into Care**

- What should multi-dimensional meetings between healthcare providers and families of paediatric patients look like?
- How should clinicians tailor communication methods to the preferences of paediatric patients and their families?
- How do families prefer to be given information, and by who (e.g. nurse, physician, trainee)?
- How should confidentiality for adolescent patients be maintained and preserved on the inpatient unit?
- How should families be taught to observe/share in the communication process?

**Length and Frequency of Interactions with Healthcare Providers**

- How frequently should the families of paediatric patients expect to be updated by healthcare professionals?
- How can opportunities be increased for families of paediatric patients to communicate with the team caring for their child?

# PRIORITY 3

## What are best practices and support strategies for Indigenous parents, families and children and youth on the general paediatric inpatient unit?

### RATIONALE

Indigenous children and youth in Canada continue to face significant health and social disparities compared to their non-Indigenous counterparts (27). These include higher rates of hospitalization, injury, suicide, obesity, infant mortality, various respiratory conditions such as tuberculosis, and most recently, increased risk of contracting COVID-19 (27-29).

Studies suggest that these adverse health outcomes are a result of the multigenerational impacts of colonialism and structural violence, which have resulted in inequitable social policies in Canada that place additional challenges for Indigenous communities during health crises (e.g. lack of health information in Indigenous languages, underfunded Indigenous healthcare centers, lack of clean water to maintain effective hygiene, high rates of poverty and food insecurity among Indigenous communities) (27,29,30).

### EVIDENCE GAPS

Existing evidence recognizes that health-related disparities between Indigenous children and youth and their non-Indigenous counterparts prevail on an international scale. In nations such as Australia, Canada, and the United States, Indigenous infants are at substantially higher risk of mortality than non-Indigenous infants (28); and in certain areas of Canada and Australia, Indigenous infants experience substantially higher hospitalization rates (28,31).

Despite these disparities, evidence on existing interventions directed towards Indigenous children have not been tailored to GPIU care, but instead focus on specific areas of care such as treatment for tuberculosis or for a traumatic brain injury (32,33). Furthermore, the existing literature fails to identify the best methods of support for Indigenous children and youth, specifically in the context of GPIU care (e.g. fostering collaborative partnerships with Indigenous patients, clinician attention to local and global Indigenous histories, attention to power differentials) (30).

Therefore, research dedicated towards identifying support strategies of Indigenous children, youth, and their families in paediatric care is needed to ensure these communities may receive better, more culturally-informed and -appropriate care. It is essential that this research be co-created and co-designed with Indigenous communities, in alignment with the **First Nations principles of ownership, control, access, and possession** - more commonly known as **OCAP®** (iii).

## WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

- Empowering Indigenous-led research, by having patient-oriented, participatory research studies conducted by Indigenous communities, for Indigenous communities
- Prioritizing **Indigenous Ways of Knowing** (iv) and a **Two-Eyed Seeing Approach** (v) in exploring the hospitalization experience of Indigenous children and youth
- Exploring the impacts of prolonged hospitalization of Indigenous children and youth on their families (e.g. family separation, isolation, mental health challenges)
- Exploring the impact of medical transport to a paediatric center on Indigenous children, youth and families
- Investigating the average length of hospitalization for Indigenous children and youth, and facts that impact the length of stay
- Exploring the lived experiences of Indigenous children, youth and their families who require hospitalization
- Exploring the positive outcomes that socio-cultural navigators and interpreters may play during the admission and discharge process for Indigenous patients

(iii) **The First Nations principles of OCAP®** establish how data surrounding Indigenous communities should be collected, protected, used, and/or shared. Standing for ownership, control, access and possession, OCAP® asserts that Indigenous communities should alone have control over how data is collected, stored, interpreted, used, or shared in their communities. For more information: **https://fnigc.ca/ocap-training/**

(iv) **Indigenous Ways of Knowing** refers to the diversity of Indigenous worldviews and ways of being, which recognize the whole person (physical, emotional, spiritual, and intellectual components) as interconnected to the land and in relationship to others (families, communities, nations).

(v) **Two-Eyed Seeing** asks that we learn to see things from one eye with the strengths of Indigenous knowledges and ways of knowing, and learning to see from the other eye with the strengths of Western knowledges and ways of knowing. And using both eyes together, working to co-create new learnings that will leave the world a better place and not compromise the opportunities for the next generation.

# PRIORITY 4

**How can we ensure that healthcare delivery in hospital meets the needs of children and youth with developmental disabilities on the general paediatric inpatient unit?**

## RATIONALE

Developmental disabilities refer to a group of conditions due to impairments in physical, learning, language, or behaviour areas (3,4). Usually presenting during the early stages of child development, developmental disabilities include, but are not limited to: autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), cerebral palsy, hearing loss, epilepsy, Down Syndrome, Tourette's Syndrome, intellectual disability, learning disability, and/or vision impairment (34,35).

## EVIDENCE GAPS

Studies show that children and youth with developmental disabilities are much more likely to present with a wide range of child emotional and behavioural problems than their counterparts without such diagnoses (35). As such, literature dedicated towards this population includes programs designed to reduce child emotional and behavioural problems, interventions regarding the education of parents of children born prematurely on best practices for stimulating language development in their child, and guidelines of conduct for health and social care professionals in supporting children and youth with ASD (35-37). However, these resources are not specific to care in general paediatric settings; furthermore, no additional guidelines on the conduct of paediatric care in GPIUs for children with developmental disabilities could be identified in the literature. To remedy this gap, research is needed to help better understand and define the impact of developmental disabilities among children and youth on the care they receive when hospitalized.

## WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

**Fostering Tailored Care**

- How are incorrect assumptions regarding non-neurotypical children among healthcare providers impacting paediatric hospital care?
- How should healthcare providers anticipate which patients with developmental disabilities will require specialized or alternate care in the acute setting?
- What initiatives are available that can help mitigate behavioural challenges among children and youth with developmental disabilities (e.g. in hospital environments and policies)?
- What training is available to hospital staff regarding treating children and youth with developmental disabilities?
- How can hospital staff be equipped with the necessary knowledge needed to treat children and youth with developmental disabilities?

**Inpatient Location and Outpatient Experience**

- Is the inpatient setting the best location of care for children and youth with developmental disabilities?
- What plans are in place to evaluate outpatient programs for children and youth with developmental disabilities once discharged from hospital?
- What physical space amendments can be made in the GPIU to accommodate patients with developmental disabilities (e.g. sensory supports)?

# PRIORITY 5

## What are effective support strategies for parents, families and children and youth hospitalized on the general paediatric inpatient unit?

*(e.g. support groups, private rooms/sleeping arrangements, breastfeeding support, physical activity, making the ward more adolescent-friendly, screen time)*

### RATIONALE

The hospitalization process can be a physically and mentally strenuous experience for paediatric patients and their families. As children and youth are expected to leave their homes and undergo major interruptions to their daily activities and routines, hospitalizations may serve as anxiety-provoking experiences which can affect children's physical growth, personality, and emotional development (38).

In extreme cases, distress among paediatric patients may compromise the completion of a required medical procedure, and in the long term may lead to difficulties in future adherence to medical instructions (38). In efforts to mediate the negative impacts of treatment and hospitalization, supportive care for paediatric patients and their families is essential (39).

### EVIDENCE GAPS

Current literature has identified some promising support strategies for certain groups of paediatric patients. These include physical activity programs that consist of aerobic, strength, and flexibility exercises (39-41), and clown therapy which has proven effective in reducing stress and anxiety levels in children admitted to hospitals as well as their parents (42). However, the most effective strategies for support in general paediatric settings specifically have yet to be identified. Therefore, research is needed to identify and understand what strategies may best assist children and youth hospitalized in GPIUs and their families in coping with the hospitalization process.

### WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

**Caring for Subpopulations of Paediatric Patients**

- How can hospitals become more adolescent-friendly spaces?
- What mental health supports should be made available for hospitalized teens?
- What supports are available for teens and how is supportive care individualized for them?
- What support strategies are available for parents of a child with a recently acquired disability?
- What support strategies are available for new mothers of admitted babies (e.g. Personal Support Workers, lactation consultants)

**Current Best Practices**

- What best practices exist across Canada and can their effectiveness be compared across sites?
- What are the unintended consequences of current best practices (e.g. private rooms, family-centered care)?
- What models of nursing care are in place to support hospitalized children and youth?
- How does the time of day and day of week of an admission affect the extent and quality of a patient's orientation?

**Parental Support**

- What educational supports are available to parents in caring for hospitalized children and youth (e.g. allowing parents to help prepare their children for tests)?
- What is the impact of parent-partner relationships with paediatric clinicians?
- How can educational and supportive care for parents be supported digitally?
- What are the positive health benefits of providing psychosocial interventions to parents/caregivers during their child's hospitalization?

**Accommodations**

- What methods are available to prioritize sleep for inpatients?
- What current day/night cycles are in place and what is the impact of disturbing these cycles in inpatient settings?
- What guidelines, advice and recommendations are in place for safe sleeping by hospitalized infants, children and youth?

**Physical and Mental Health**

- What outlets are available to children to ensure they are leading productive and healthy lives inside hospital wards (e.g. access to outdoor spaces, contact with social network, exercise programs)?
- What psychosocial resources are available for hospitalized children and youth (e.g. mental health services for patients and families)?

# PRIORITY 6

## What mental health supports can be provided to parents, families and children and youth while hospitalized on the general paediatric inpatient unit?

### RATIONALE

The hospitalization process can be a psychologically stressful experience for children, youth and their families in GPIUs. Experiences associated with this period include feelings of stress, anxiety, depression and fear, frustrations with clinician-caregiver communication, disruptions to routine family functioning, separation from family members, and social withdrawals (43,44).

### EVIDENCE GAPS

Evidence has identified interventions demonstrating promise in reducing psychological stresses among paediatric patients and their families (43). These include access to outdoor "green" spaces, referring to areas of grass, trees, or other vegetation set apart for recreational or aesthetic purposes (45); implementing parental support and empowerment programs dedicated towards enhancing parents' knowledge, awareness, and ideas about their hospitalized child (43,46); and music therapy (e.g. auditory stimulation, environmental music therapy) (47,48).

However, most studies are focused on specialized settings of care, such as oncology units, or the Intensive Care Unit (ICU), or evaluate accessing green space outside hospital settings. Furthermore, there are knowledge gaps on the optimal mental health supports that should be provided to parents, families, and children and youth while hospitalized in GPIUs.

### WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

**Patient Support**

- How does hospitalization impact anxiety levels in children and youth in the short and long term?
- How can hospitals meet the mental health needs of children and youth admitted to hospital?
- What mental health supports should be put in place for children and youth before they need it (i.e. before reaching a crisis)?
- How are children and youth socially supported throughout the hospitalization period (e.g. encouraging social groups or friendship formation)?
- What are some strategies that hospital staff may use to help children and youth navigate hospital anxiety?
- How and what mental health practices and resources can be integrated to support patients and families of long-stay patients, both throughout hospitalization and at the time of discharge?

**Parental/Familial Support**

- What help can hospitals provide for parents and families of hospitalized children during the inpatient stay?
- What strategies should be used to reduce the stress of parents when a child is admitted to the hospital?

# PRIORITY 7

## What are effective ways to incorporate shared decision-making with parents and children/youth hospitalized on the general paediatric inpatient unit?

*("Effectiveness" defined as length of stay, caregiver confidence)*

### RATIONALE

Shared decision-making (SDM) refers to the collaborative process between patients, families, and healthcare providers in making informed care and treatment decisions that align with a patient's values, preferences, and treatment goals (49-51). Shared decision-making is considered an effective way to improve person-centered care and quality of health care (50), is associated with increased feelings of preparedness and less anxiety among child and youth patients (52), leads to improvements in provider-patient communication, and improved health outcomes (49). Shared decision-making can be facilitated in paediatric settings by providing and exchanging information; encouraging children and parent(s) to ask questions; and encouraging the expression of preferences (52).

### EVIDENCE GAPS

Available evidence focuses on the unique challenges presented with SDM in paediatrics, such as the varying degrees of patient involvement in accordance with the child's age and level of physical and psychological development (51,53), and the potential for conflicting personal values or preferences among parties involved in patient care (e.g. clinicians, parents/caregivers [50] who are responsible for making medical decisions on the patient's behalf). Few resources were found regarding the implementation of SDM in paediatrics such as Opel's 4-Step Framework (54), and how many interventions focus primarily on parents rather than patients (51). However, the evidence on SDM in paediatric care is limited, particularly for acute illnesses and in the GPIU hospital setting. Prior SDM research is also limited to specific populations, such as children and youth with mental health concerns (55), cancer (50,56), asthma (57), disabilities (58), or cystic fibrosis (52). Future research is needed on how to effectively incorporate SDM in GPIUs.

### WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

- What tools, decision aids, and/or frameworks are available for SDM in GPIUs? How are these being used to address biases and incorporate equity in GPIUs?
- Does SDM improve outcomes of children cared for in GPIUs?
- What is the current state of SDM in GPIUs across Canada?
- How are clinical situations unfolding in GPIUs with SDM? How might a SDM tool improve partnership?

**Inpatient Setting**

- What treatment options do families want explored, whether conventional, complementary, or traditional in origin?
- How are handovers and rounds executed in ways that integrate SDM preferences and values from families and patients?
- How does patient and family inclusion in rounds impact the knowledge and confidence of parents at discharge, and/or help families participate more competently and confidently in the child's care?

**Inclusivity**

- How are linguistic barriers and ethno-cultural factors being incorporated and accounted for in SDM?
- How can SDM be implemented for different sub-populations (e.g. patients and families with limited English proficiency)?

**Experience After Discharge**

- How can parents/caregivers be better engaged in the process of discharge?
- How much do patients understand about their hospitalization and discharge?

# PRIORITY 8

## What are effective strategies to mitigate the impacts of prolonged inpatient hospitalizations on the general paediatric inpatient unit?

*(e.g. addressing unmet needs, prolonged separation from family)*

### RATIONALE

Prolonged inpatient hospitalizations can pose serious emotional and psychological impacts on paediatric patients who are disproportionately impacted by the hospital environment, by for example, missing school (59). Considering their degree of maturity and development, hospitalized children and youth may not fully understand the severity of their illness or be able to fully communicate their needs (59).

### EVIDENCE GAPS

Prolonged inpatient hospitalizations can result in heightened stress and anxiety among children and their families yet there are knowledge gaps on how to mitigate these adverse impacts. One systematic review was identified that focuses solely on the care of children with chronic critical illness in the ICU, who often experience prolonged and recurrent hospitalizations and transfers between ICUs without ever leaving the hospital (60). Because the care these children receive is not specific to the GPIU, several of the learnings identified in this review are not applicable to the current study. These indicate that future research is needed on strategies to mitigate stressors associated with prolonged inpatient hospitalizations in GPIUs.

### WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

**Patient and Familial Support**

- What factors will minimize the fear, guilt, and/or concern of parents/caregivers of children who are hospitalized long-term (e.g. supports to reduce screen time)?
- What perceptions do patients and families have about their inpatient experience after returning home from a prolonged inpatient hospitalization?
- What are the experiences and needs of hospitalized families, especially those who experience multiple hospitalizations?
- How can healthcare providers best limit the negative impact or change hospitalization into a positive experience for children and their families?
- What unmet needs do long-term patients and their families have?

**Current Practices**

- What is the definition of a "long-stay" patient or a prolonged inpatient hospitalization?
- What current practices are in place for long-stay patients?
- What are the models used for discussing long-stay patients with the patient's team of healthcare providers?
- What best practices exist in other care settings (e.g. Newborn Intensive Care Unit [NICU], Paediatric Intensive Care Unit [PICU] regarding prolonged hospitalization, and how can these be applied to the GPIU?
- Does the length of stay affect functional and rehabilitation outcomes for paediatric patients?

**Sub-Populations**

- What is the impact of prolonged hospitalization on Inuit children and youth from northern communities on their families (e.g. family separation due to escort policy, isolation, mental health challenges)?
- What is the impact of prolonged hospitalization of Inuit children and youth from northern communities with developmental disabilities?

**Discharge and Transitioning to At-Home Care**

- What discharge planning practices are currently in place?
- What does transitioning to home-care after long-term stay look like?

**Turnovers of Healthcare Providers**

- How can healthcare providers mitigate the disadvantages of staff turnover?
- What is the impact of continuity versus turnover of care on patients with prolonged hospitalization?

# PRIORITY 9

## What are effective alternatives to shorten length of stay for hospitalized children and youth on the general paediatric inpatient unit?

*(e.g. hospitalization at home, early discharge with close and regular follow-up)*

### RATIONALE

Length of stay in hospital is defined as the time between admission and discharge of a patient (61). While admission to hospital is already a stressful time for patients and families, unnecessarily prolonging time in hospital can pose additional emotional and physical impacts. For children whose emotional and cognitive abilities are limited, this can be an anxiety-provoking and even traumatic experience, characterized by feelings of discomfort, fear, and loneliness (62).

### EVIDENCE GAPS

Prolonged hospitalizations can be stressful for children, youth and their families. While some evidence was identified which speaks to supporting transitional care in neonatal services (63), these studies tend to focus on specific care units such as the NICU and PICU (64). There are specific examples of programs to facilitate early discharge and at home management for neonatal hyperbilirubinemia and bronchiolitis, but implementation is limited to specific settings. To remedy this gap, research is needed to identify ways to shorten the length of stay for hospitalized children and youth in GPIUs.

### WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

- What challenges are associated with evening discharges (e.g. is staying overnight sometimes unnecessary)? How does time of day impact medical disposition decisions?
- What standardized discharge processes can help to reduce length of stay without compromising patient safety (e.g. expected date of discharge, goals for discharge, communication to consultants regarding time of discharge)?
- Which specific conditions managed on GPIUs could be safely and effectively cared for as outpatients with close follow-up care (e.g. neonatal hyperbilirubinemia, bronchiolitis, cellulitis, etc.)?
- What methods of care could be implemented to shorten the length of stay without compromising patient safety (e.g. home hospitalization, late consultations by consultants, transitional care)?
- How can the length of stay for patients with hyperbilirubinemia be decreased?
- What existing home care services and resources could be implemented to facilitate early discharge for children with medical complexity (e.g. nursing/home resources)?

# PRIORITY 10

**What are the most effective communication methods (e.g. handover, rounds, etc.) between healthcare providers on a general paediatric inpatient unit?**

## RATIONALE

Verbal and written communication between healthcare providers are essential components for the effective delivery of care in paediatric settings (64). Numerous barriers in paediatric hospital care exist that may contribute to communication difficulties and/or discrepancies between healthcare providers, including: a lack of structure and standardization for communication, uncertainty about responsibility for specific aspects of the patient's care management, and differences in communication styles (e.g. brief vs descriptive) (64).

## EVIDENCE GAPS

Paediatric patients in GPIUs are cared for by multi-disciplinary teams of healthcare providers. Efficient, effective, and safe communication processes are needed to ensure optimal flow of information between healthcare professionals. While there is some evidence related to specific handover systems (e.g. I-PASS) for physicians and nurses, and interventions for communication with, supporting and providing information for parents of preterm infants (23), evidence that focuses on effective communication methods between provider teams in different GPIU settings and between different allied healthcare professionals were not identified. There is also limited evidence on how to structure consultation requests from general paediatric teams to subspecialty services to reduce duplication and optimize efficiency.

## WHERE TO GO FROM HERE

Potential research questions and/or directions for future studies include, but are not limited to:

- What is the optimal structure (e.g. I-PASS) and method (e.g. verbal, electronic) to provide medical handover between multi-disciplinary teams on the GPIU?
- How should communications related to subspecialty consultations in GPIUs be structured?
- How should team communication regarding patient disposition between the Emergency Department and GPIUs be structured to optimize patient outcomes?
- How are factors such as situational awareness and institutional hospital capacity communicated between healthcare teams?
- How should the lack of communication between healthcare providers (e.g. doctors, nurses, and specialists) be addressed?

# OTHER PRIORITIES

The following questions were also discussed and put in order of priority at the final priority setting workshop:

**11**

**What is the most effective way to conduct medical rounds, including how to involve caregivers and patients in the decision making while on the GPIU?**

Decisions around a child's clinical care are often made during medical rounds. More research is needed to understand the most effective methods of including patients and families during this process.

**12**

**Are ongoing mental health assessments for patients admitted to a GPIU beneficial?**

Mental well-being is important for children, especially when hospitalized. More research is needed to understand if and when ongoing mental health assessments are required for hospitalized children in GPIUs, and what supports can be offered to help.

**13**

**What is the impact of the patient's room/environment on health outcomes on the GPIU? (e.g. noise, lights, private/shared room, window/no window)**

The hospitalization process requires children be removed from their homes, and instead placed in locations or environments which are unfamiliar. As such, more research is needed to understand how a patient's room and surrounding environment can impact their health outcomes.

**14**

**What is the most effective way to obtain and maintain intravenous (IV) access in children and youth hospitalized on the GPIU?**

Obtaining IV access is a common procedure often required when treating hospitalized children, which can cause distress. More research is needed to understand and identify the most effective ways of performing this procedure that result in minimal distress amongst paediatric patients.

**15**

**What are effective methods (e.g. education) to prepare families for discharge from the GPIU?**

The discharge process can be a daunting time for hospitalized children and their families. More research is needed to understand the most effective methods of facilitating this process.

**16**

**When is it appropriate to involve allied healthcare professionals (e.g. occupational therapy [OT], physiotherapy [PT], Child Life Specialists) in the care of children/youth hospitalized on the GPIU?**

Hospitalized children in GPIUs are cared for by multi-disciplinary teams. More research is needed to identify the ideal time to involve different allied healthcare professionals during their stay in the GPIU.

# WHAT'S NEXT?

The Paediatric Hospital Care PSP has identified the Top 10 priorities in paediatric hospital medicine which matter most to paediatric patients, their parents/caregivers, and healthcare professionals who support them.

This partnership has outlined a clear, strategic, patient-oriented research agenda on the management of hospitalized children in general paediatric settings. With the aim of guiding future research priorities and generating evidence for improved outcomes among paediatric hospital medicine patients, research networks (e.g. funders, researchers, organizations working with paediatric patients) are encouraged to operationalize these research priorities in future studies.

## USE THE TOP 10

Patients, parents/caregivers, and clinicians took part in the Paediatric Hospital Care PSP to identify the final Top 10 research priorities. To ensure these efforts are recognized, the following is requested:

### Research Networks

If you are a researcher, funder, or organization working with paediatric patients, include these priorities in future research strategies dedicated towards the management of hospitalized children in GPIUs, and target these topics for research funding. If you will be incorporating these priorities into your work, get in touch with us to tell us how!

### Everyone

Please share this report with your networks and to raise awareness of the need for more research into paediatric hospital care in GPIUs across Canada.

To learn more about this initiative and its progress, visit **www.pirncanada.com/priority-setting.**

For more information on PIRN, get in touch with us at **contact.pirncanada@sickkids.ca**.

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