

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). 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 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?



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. In Canada, the largest population of children cared for in hospital are those with medical conditions managed in GPIUs.

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, gastroenteritis) who are hospitalized for an acute illness or to prevent the further exacerbation of a pre-existing chronic disease.

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. 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.

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 (MICRYN), 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/>.



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

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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.