Exploring Pediatric Surgical Journeys through Patient-Reported Outcome and Experience Measures

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For children and their families

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AUTHOR CONTRIBUTIONS

I have made substantial contributions to every co-authored paper contained within this thesis. I developed the original research questions in collaboration with my thesis supervisor Dr. Dan Poenaru. I was responsible for the definition of my thesis objectives, which were reviewed and approved by all members of my research advisory committee. With the guidance of this committee, I developed the study design and methods used in each of the following manuscripts. The contributions of the co-authors of each manuscript within this thesis are detailed below:

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STATEMENT OF ORIGINALITY

I, Zanib Nafees, hereby declare that this thesis, entitled "Exploring Pediatric Surgical Journeys Through Patient-Reported Outcome and Experience Measures," is my original work and has not been submitted, in whole or in part, for any other academic degree or professional qualification. All sources used have been appropriately acknowledged and cited. This thesis represents a significant and original contribution to the field of patient-centered care in pediatric surgery, specifically by introducing a model for assessing patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) that, to the best of my knowledge, is novel within the context of pediatric surgery. While PROMs and PREMs are increasingly used in healthcare, they are less commonly applied or published in the pediatric surgical setting, particularly in Canada. While I gratefully acknowledge the guidance of my supervisors and committee members, as well as the foundational work of other researchers in this field, the data analysis, interpretations, and conclusions presented in the following chapters are my own original work. I have adhered to all ethical guidelines in conducting this research and confirm that this thesis is free from any form of academic dishonesty. I declare no conflicts of interest, and all contributions to this thesis were uncompensated.

This thesis follows the style recommendations set by McGill University. Specifically:

- Spelling and grammar align with the Canadian Press Stylebook (J. McCarten, 2021) and the Canadian Oxford Dictionary (K. Barber, 2004).
- Graphs and tables were constructed according to the American Medical Association (2020) standards.
- Citations adhere to the American Psychological Association style (2020).

I affirm that the statements made in this declaration are true and accurate to the best of my knowledge.

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LIST OF ABBREVIATIONS

CAPS	Canadian Association of Pediatric Surgeons
CDH	Congenital Diaphragmatic Hernia
CHQ	Child Health Questionnaire
CHRIs	Child Health Ratings Inventories
CI	Confidence Interval
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
CYP	Children and Young People
DSII-HSCT	Disease-Specific Impairment Inventory-Hematopoietic Stem Cell Transplantation
EA	Esophageal Atresia
EHR	Electronic Health Record
EQ-5D-Y	EuroQol-5 Dimension (Youth)
ERSD	End-stage Renal Disease
GREAT	Graduate Research Enhancement and Travel
GOSH	Great Ormond Street Hospital
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
HRQoL	Health-Related Quality of Life
ICC	Intraclass Correlation Coefficient
ICF	International Classification of Functioning, Disability and Health
IPCHQE	Integrated Patient-Centered Healthcare Quality and Experience
ISOQOL	International Society for Quality of Life Research
IXTQ	Intermittent Exotropia Questionnaire
KINDL	KINDer Lebensqualitätsfragebogen (Children's QoL Questionnaire)
KIDSCREEN-27	Health-Related Quality of Life Questionnaire
MAX	Muslim Award for Excellence
MCH	The Montreal Children's Hospital
MMAT	Mixed Methods Appraisal Tool
MTL	Montreal

MUHC	McGill University Health Centre
NIS	Narrative Item Set
OxAFQ	Oxford Foot and Ankle Questionnaire
PCC	Patient-Centered Care
PedsQL™	Pediatric Quality of Life Inventory
PeLTQL	Pediatric Liver Transplant Quality of Life
PGI	Patient-Generated Index
PIES	Pediatric Inpatient Experience survey
PODCI	Pediatric Outcomes Data Collection Instrument
pPGI	Pediatric Patient-Generated Index
PREs	Patient-Reported Experiences
PROs	Patient-Reported Outcomes
PROMs	Patient-Reported Outcome Measures
PREMs	Patient-Reported Experience Measures
PREM-UK	Patient-Reported Experience Measures-United Kingdom
PREM-MTL	Patient-Reported Experience Measures-Montreal
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROMIS	Patient-Reported Outcomes Measurement Information System
QoL	Quality of Life
RCT	Randomized Controlled Trial
SDQ	Strengths and Difficulties Questionnaire
SE	Standard Error
SEIQoL	Schedule for the Evaluation of Individual Quality of Life
SR	Systematic Review
SMD	Standardized Mean Differences
SDM	Shared Decision-Making
TAPQOL	TNO-AZL Preschool Children Quality of Life
TQPM	Total Quality Pain Management
WHO	World Health Organization
WMD	Weighted Mean Difference

ABSTRACT

Patient-centered care in pediatric surgery focuses on involving patients and families in decision-making, employing tailored patient-reported measures, and customizing care to meet their unique needs and preferences. This thesis explores the use of Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) to capture the perspectives of pediatric surgical patients and their families, addressing three core questions:

1. How closely do parents' and children's reports of health outcomes and experiences align when using PROMs and PREMs?
    - In this study, a systematic review and meta-analysis were conducted to explore the alignment between children's and caregivers' perspectives on health outcomes and experiences in pediatric surgical settings. The findings indicate that while there is evidence of alignment in many instances, the meta-analysis revealed high heterogeneity in the comparisons, highlighting substantial variability in the results. This variability underscores the importance of caution in generalizing findings and suggests that while parental reports may be a practical proxy in situations where direct data collection from children is challenging, they cannot fully substitute children's input. Therefore, it remains critical to prioritize obtaining children's perspectives whenever feasible to ensure a comprehensive understanding of their experiences.
2. Can existing PREM measures be effectively adapted for use in Canadian pediatric facilities?
    - To explore this, a PREM instrument was culturally adapted and translated with linguistic validation for the Canadian context. This process resulted in a Canadian-specific measure tailored for pediatric outpatient settings for ages 8-16 years, addressing the need for culturally and linguistically appropriate tools, and providing a more precise assessment of patient experiences within the Canadian healthcare system.
3. Can an individualized PROM address gaps in assessing outcomes important to pediatric surgical patients?

- To investigate this, the usability of the pediatric Patient-Generated Index (pPGI) as an individualized PROM was assessed. The evaluation demonstrated that the pPGI effectively captures outcomes defined by patients themselves, uncovering aspects of their health and well-being that standardized measures might miss. This highlights the benefit of using individualized measures alongside standardized ones to gain a more comprehensive understanding of patient outcomes.

This thesis contributes to our understanding of how patient-centered measures can be effectively employed in pediatric surgery. By examining the alignment between child and parent perspectives, adapting measures for various contexts, and exploring individualized tools, it highlights key opportunities for improving care. However, measuring experiences and outcomes alone is not enough. For real impact, these findings must be translated into practice.

Parental reports may be sufficient in some cases, but the newly developed Canadian patient-completed PREM and the pPGI offer a unique opportunity to enhance patient-centered care. Their potential lies in guiding meaningful improvements when systematically applied. Consistently integrating these results into clinical decision-making will be essential for enhancing care quality, patient experiences, and outcomes in pediatric surgery. Future efforts should focus on embedding these measures into routine practice, ensuring their findings lead to actionable changes that benefit both patients and providers.

ABRÉGÉ

Les soins centrés sur le patient en chirurgie pédiatrique visent à impliquer les patients et leurs familles dans la prise de décisions, à utiliser des mesures adaptées rapportées par les patients et à personnaliser les soins pour répondre à leurs besoins et préférences uniques. Cette thèse explore l'utilisation des mesures des résultats rapportés par les patients (PROMs) et des mesures des expériences rapportées par les patients (PREMs) pour recueillir les perspectives des patients chirurgicaux pédiatriques et de leurs familles, en abordant trois questions principales :

1. Dans quelle mesure les rapports des parents et des enfants sur les résultats de santé et les expériences s'alignent-ils lors de l'utilisation des PROMs et des PREMs ?
    - Dans cette étude, une revue systématique et une méta-analyse ont été réalisées pour explorer l'alignement entre les perspectives des enfants et des aidants sur les résultats de santé et les expériences en milieu chirurgical pédiatrique. Les résultats indiquent que, bien qu'il existe des preuves d'alignement dans de nombreux cas, la méta-analyse a révélé une forte hétérogénéité dans les comparaisons, mettant en évidence une variabilité substantielle des résultats. Cette variabilité souligne l'importance de faire preuve de prudence lors de la généralisation des conclusions et suggère que, bien que les rapports parentaux puissent être un substitut pratique dans les situations où la collecte directe de données auprès des enfants est difficile, ils ne peuvent pas remplacer complètement l'apport des enfants. Il reste donc crucial de prioriser les perspectives des enfants chaque fois que cela est possible afin de garantir une compréhension complète de leurs expériences.
2. Les mesures PREM existantes peuvent-elles être efficacement adaptées pour une utilisation dans les établissements pédiatriques canadiens ?
    - Pour répondre à cette question, un instrument PREM a été adapté culturellement et traduit avec validation linguistique pour le contexte canadien. Ce processus a abouti à une mesure spécifique au Canada, adaptée aux milieux ambulatoires pédiatriques pour les enfants de 8 à 16 ans. Cette mesure répond au besoin d'outils culturellement et linguistiquement appropriés, offrant une évaluation plus précise des expériences des patients dans le système de santé canadien.

3. Une PROM individualisée peut-elle combler les lacunes dans l'évaluation des résultats importants pour les patients chirurgicaux pédiatriques ?
    - Pour explorer cette question, l'utilisabilité de l'Index pédiatrique généré par le patient (pPGI) en tant que PROM individualisée a été évaluée. Les résultats ont montré que le pPGI permet de capturer efficacement des résultats définis par les patients eux-mêmes, révélant des aspects de leur santé et de leur bien-être que les mesures standardisées pourraient manquer. Cela met en évidence l'avantage d'utiliser des mesures individualisées aux côtés des mesures standardisées pour obtenir une compréhension plus complète des résultats des patients.

Cette thèse contribue à notre compréhension de l'utilisation efficace des mesures centrées sur le patient en chirurgie pédiatrique. En examinant l'alignement entre les perspectives des enfants et des parents, en adaptant les mesures à divers contextes et en explorant des outils individualisés, elle met en lumière des opportunités clés pour améliorer les soins. Cependant, mesurer les expériences et les résultats ne suffit pas. Pour avoir un impact réel, ces résultats doivent être traduits en pratique.

Les rapports parentaux peuvent être suffisants dans certains cas, mais le nouveau PREM canadien complété par les patients et le pPGI offrent une opportunité unique d'améliorer les soins centrés sur le patient. Leur potentiel réside dans la capacité à guider des améliorations significatives lorsqu'ils sont appliqués de manière systématique. L'intégration cohérente de ces résultats dans la prise de décision clinique sera essentielle pour améliorer la qualité des soins, les expériences des patients et les résultats en chirurgie pédiatrique. Les efforts futurs devraient se concentrer sur l'intégration de ces mesures dans la pratique courante, en veillant à ce que leurs conclusions conduisent à des changements concrets au bénéfice des patients et des prestataires.

1. INTRODUCTION

1.1. Overview of Pediatric Surgery

Pediatric surgery encompasses a diverse range of procedures and interventions aimed at addressing congenital, developmental, and acquired conditions in children (Farmer et al., 2015). Congenital conditions, such as esophageal atresia (EA), where the esophagus does not form correctly, require prompt surgical repair to enable proper feeding and prevent severe respiratory issues (Baldwin & Yadav, 2023). These procedures often involve complex and sensitive operations that require meticulous planning and execution (Ozgediz et al., 2016).

Developmental conditions, including orthopedic abnormalities like scoliosis, characterized by an abnormal curvature of the spine, require ongoing surgical management to correct and improve function, aiming to straighten and stabilize the spine and promote better posture and mobility as the child grows (Block et al., 2022).

Acquired conditions, such as appendicitis—an inflammation of the appendix requiring prompt surgical removal to prevent rupture and severe abdominal infection—or traumatic injuries from accidents or falls, which often necessitate ongoing surgical management to repair tissues, control bleeding, and facilitate recovery, highlight the diverse nature of surgical interventions. These differences in surgical management directly affect patient-reported outcomes and experiences, influencing how such measures are captured and interpreted (Bouassria et al., 2013).

The intricate nature of these surgical journeys necessitates a healthcare approach that not only targets physical healing but also addresses the holistic well-being of pediatric patients (Jasemi et al., 2017). This involves considering the psychological, emotional, and social dimensions of health, which are important for the overall recovery and quality of life (QoL) of the child (Umberson & Montez, 2010). Effective pain management, psychological support, and rehabilitation services are essential components of comprehensive pediatric surgical care, ensuring holistic treatment that minimizes discomfort, addresses emotional well-being, and aids in physical recovery for improved overall outcomes (Trottier et al., 2022).

In recent years, the paradigm of patient-centered care (PCC) has gained prominence in pediatric surgery, advocating for the incorporation of patients' and families' perspectives into clinical decision-making and care processes (Kammerer et al., 2024). This shift represents a

broader movement within healthcare to prioritize the needs and experiences of patients, ensuring that care is tailored to individual circumstances and preferences (Edgman-Levitan & Schoenbaum, 2021).

1.2. Importance of Patient-Centered Care

The shift towards PCC in the context of pediatric surgery reflects a growing recognition of the importance of understanding and addressing the unique needs, preferences, and values of pediatric patients and their families (Kuo et al., 2012). This approach emphasizes shared decision-making, where healthcare providers and families collaborate to make informed choices about the child's care (Jacobs et al., 2023). This collaborative process involves detailed discussions about the risks, benefits, and alternatives of various treatment options, ensuring that the family's values and preferences are integral to the decision-making process (Amuthan & Curtis, 2022).

Effective communication is paramount, ensuring that patients and their families are fully informed and comfortable with the care plan (Kwame & Petrucka, 2021). This includes providing age-appropriate explanations to the child and ensuring that parents understand all aspects of the proposed treatments (Carman et al., 2013). In a concept analysis, family-centered care was regarded as a key component of PCC that highlights the importance of integrating family members as vital members of the care team (Shields et al., 2012). This approach acknowledges their essential role in supporting the child throughout the care process (Seniwati et al., 2023).

This support can range from emotional encouragement, such as providing reassurance and reducing anxiety, to practical assistance with post-operative care, including helping with daily activities, managing medication schedules, and ensuring proper wound care (Kuo et al., 2012).

By fostering shared decision-making, effective communication, and family-centered care, PCC aims to enhance the overall healthcare experience and improve clinical outcomes by involving patients and families in the treatment process and ensuring their needs and preferences are integral to care (Edgman-Levitan & Schoenbaum, 2021).

1.3. Role of Patient-Reported Outcome Measures and Patient-Reported Experience Measures in Pediatric Surgery

The evolution of PROMs (Patient-Reported Outcome Measures) and PREMs (Patient-Reported Experience Measures) has significantly influenced healthcare by enhancing PCC, as demonstrated by their increasing use to capture patients' perspectives and improve clinical outcomes (Weldring & Smith, 2013). Originating in adult medical fields, PROMs initially gained traction as tools to evaluate patients' self-reported health outcomes following various treatments and surgeries. For instance, in the UK, four adult PROMs—covering hip and knee replacements, varicose vein surgeries, and hernia repairs—have been mandated since 2009 to assess recovery outcomes and the effectiveness of care (Appleby et al., 2013). Their success in improving care standards prompted further integration of PROMs into clinical practice across a range of medical disciplines worldwide (Bele et al., 2023). In areas like oncology, rheumatology, and chronic disease management, PROMs have proven valuable in capturing both the physical and psychosocial dimensions of pediatric health (Zigler et al., 2022). Despite this progress, the routine integration of PROMs in pediatric surgery remains relatively underdeveloped compared to adult surgical care (Bele et al., 2023).

In contrast, PREMs focus on capturing patients' experiences with the healthcare system, addressing aspects such as communication with medical staff, accessibility of care, and satisfaction with hospital environments (Shunmuga Sundaram et al., 2022). While PREMs have been widely adopted in adult healthcare to assess service quality, their use in pediatric settings has only recently gained momentum, with healthcare systems recognizing the unique perspectives of children and their families in shaping healthcare delivery (Bele et al., 2023).

Both PROMs and PREMs play pivotal roles in pediatric surgery by capturing the voices of children and their families, offering invaluable insights into health status, QoL and healthcare experiences (Bloemeke et al., 2020). PROMs focus on children's perceptions of their health and well-being, addressing physical, emotional, and social dimensions (Thapa Bajgain et al., 2023). These measures cover areas such as pain, fatigue, emotional distress, and social functioning (Arsiwala et al., 2021). PREMs, on the other hand, assess children's experiences with the healthcare system, focusing on interactions with medical staff, the hospital environment, and overall satisfaction with care (Shunmuga Sundaram et al., 2022). They provide insights into

communication effectiveness, provider responsiveness, and the child's comfort during hospital stays (Bele et al., 2023).

In pediatric surgery, PROMs and PREMs play an important role in supporting patient-centered care by providing insights into children's health outcomes and experiences from their own or their proxies' perspectives (J. Ferreira et al., 2023). Their use helps tailor care to meet the specific needs of pediatric patients (Bele et al., 2023). However, challenges remain in ensuring that these measures are age-appropriate, reliable, and culturally sensitive (Shunmuga Sundaram et al., 2022). Development of pediatric PROMs and PREMs must consider the developmental stages of children and the diversity of their backgrounds. For instance, young children may require simplified language or visual aids to accurately report their experiences, while adolescents might benefit from more detailed and nuanced questionnaires (Churruca et al., 2021). Ensuring the validity and reliability of these measures across various populations is critical for collecting meaningful data that can inform clinical care practices and enhance the patient experience (Gleeson et al., 2016).

By establishing a solid foundation for use of PROMs and PREMs in pediatric surgery, healthcare providers can improve not only the quality of clinical outcomes but also the overall satisfaction and well-being of young patients and their families. As the field continues to evolve, the integration of these measures will be critical to ensuring that surgical care aligns with what matters most to patients and their caregivers.

1.4. Challenges in Implementing Patient Centered Care, Patient-Reported Outcome Measures, and Patient-Reported Experience Measures in Clinical Practice

Despite significant progress in the development and conceptualization of PCC, PROMs, and PREMs, challenges remain in effectively integrating these concepts into daily clinical practice. For instance, advancements in PCC have included a better understanding of how to incorporate patient and family preferences into care planning. Progress in PROMs and PREMs has involved the creation of more refined and diverse measures to capture patient experiences and outcomes comprehensively. However, implementing these tools effectively in clinical settings remains a critical issue. Current literature emphasizes the need for more robust and longitudinal studies to understand the long-term effects of patient-centered approaches and evaluate the effectiveness of these measures in real-world settings (Churruca et al., 2021).

Longitudinal studies are essential for gaining deeper insights into the sustained impacts of surgical interventions and care practices on patients' QoL (Caruana et al., 2015).

Additionally, the development and validation of standardized measures that are sensitive to cultural and linguistic differences are critical for ensuring equitable and high-quality care for all pediatric patients (Çakmak & Uğurluoğlu, 2024). Measures must account for variations in language, customs, and health beliefs to accurately reflect the diverse experiences of children and families (Nair & Adetayo, 2019).

Healthcare providers also need comprehensive training and resources to effectively implement PROMs and PREMs into clinical practice (Panteli et al., 2019). Training programs should aim to enhance providers' skills in administering, interpreting, and integrating these measures into patient care (Shunmuga Sundaram et al., 2022).

Addressing these implementation challenges requires a coordinated effort from researchers, clinicians, and policymakers to develop and promote strategies that facilitate the widespread adoption of PCC principles and the effective use of PROMs and PREMs in clinical settings (Weldring & Smith, 2013).

1.5. Objectives and Structure of the Thesis

The central objective of this thesis is to enhance the way PROMs and PREMs capture what matters most to children and their families, thereby enabling the advancement of patient-centered care in pediatric surgical settings. This goal is pursued through three interconnected studies that explore different aspects of PROMs, PREMs, and individualized measures.

The first study examines the level of agreement between child- and proxy-reported PROMs and PREMs in pediatric surgery, revealing both the alignments and discrepancies in health perceptions. Understanding these differences is important for tailoring interventions that address both the child's and the parent's perspectives, which is a fundamental aspect of PCC.

The second study focuses on adapting and refining a PREM for use in the Canadian pediatric surgical context. This adaptation ensures that the measure is culturally relevant and linguistically appropriate, improving the accuracy and clarity of the information collected. By adapting these measures to reflect the specific needs of Canadian families, we aim to better align

them with the principles of PCC, ensuring they are more responsive to the unique experiences of this population.

The third study investigates the potential of an individualized measure for pediatric surgical follow-up, specifically in the context of EA. The measure captures unique, patient-specific concerns, allowing healthcare providers to address individual priorities in a more precise and personalized manner, which is key to enhancing PCC.

Together, these studies provide a comprehensive approach to improving the way pediatric patients' and their families' experiences and outcomes are measured and addressed in surgical care. By focusing on both standardized and individualized measures, this thesis contributes to a more personalized and responsive healthcare system, ultimately advancing PCC in pediatric surgery.

2. LITERATURE REVIEW

2.1. Gaps in Patient-Centered Care in Pediatric Surgery

PCC has become a fundamental component of modern healthcare, emphasizing the incorporation of patients' and families' perspectives into clinical decision-making (Engle et al., 2021). This approach is especially important in pediatric surgery, where care must account for both the child's unique needs and the family's role in supporting the child through their surgical journey (Nilsson et al., 2023). While advancements such as shared decision-making, effective communication strategies, and family-centered care have improved healthcare experiences for many children and their families (Seniwati et al., 2023), several significant gaps remain that prevent the full realization of PCC in this context.

2.1.1 Lack of Individualized Patient Reported Outcome Measures and Patient Reported Experience Measures

One major gap in current research is the limited focus on individualized PROMs and PREMs. While generalized outcomes such as QoL or satisfaction with care are frequently emphasized, studies often fail to delineate the specific domains of well-being that are prioritized by individual pediatric patients undergoing surgery. For instance, existing measures frequently overlook nuanced concerns such as recovery-related social reintegration or emotional resilience, which are critical to the pediatric population (Coyne et al., 2016).

Similarly, widely used tools like the Patient-Reported Outcomes Measurement Information System (PROMIS) and the EuroQol-5 Dimension (Youth) (EQ-5D-Y) are critiqued for their limited scope in capturing diverse aspects of recovery, such as emotional well-being, peer relationships, and the child's sense of agency (Nilsson et al., 2023). These limitations underscore the need for measures that resonate more closely with the subjective experiences of patients and their families.

Currently, PROMs and PREMs have demonstrated significant benefits in other populations. For example, in adult oncology care, PROMs are used to monitor patient-reported pain and fatigue, enabling timely adjustments to treatment regimens, which has improved patient satisfaction and outcomes (Krist et al., 2017). In pediatric populations with chronic conditions like asthma, individualized PROMs have been shown to improve the alignment of care plans

with patient-specific needs, leading to better disease management and enhanced emotional well-being (Bele et al., 2022).

2.1.2 Variability and Standardization Issues in Patient Centered Care Measurement

Another challenge in pediatric surgery research is the variability in the instruments used to measure PCC. The lack of standardized tools makes it difficult to compare results across different studies or surgical contexts (Engle et al., 2021). For instance, some measures may focus solely on the technical aspects of surgical outcomes, while others may emphasize patient satisfaction or emotional well-being, leading to inconsistent findings and limited generalizability (D. C. Ferreira et al., 2023). Furthermore, this variability can hinder the integration of patient and family perspectives, which are critical for understanding the broader impacts of surgery on QoL (Engle et al., 2021). Wolf et al. (1999) emphasize the need for more rigorous, standardized measures that can be applied across diverse populations and clinical settings (Woolf et al., 1999).

2.1.3 Underrepresentation of Children's Perspectives

Historically, much of the research on PCC in pediatric surgery has prioritized the perspectives of parents or caregivers, often neglecting the child's own experiences and views (Claus et al., 2021). While parents play an essential role in the care process, their perspectives may not always align with those of their children. Studies have shown that discrepancies often exist between parent and child reports on QoL and health outcomes, particularly in areas like pain, emotional health, and social functioning (S. R. Martin et al., 2020). By focusing predominantly on proxy reports, we miss an important opportunity to understand the child's subjective experience, which is critical for delivering PCC. This thesis aims to bridge that gap by exploring the level of agreement between parent and child reports on both PROMs and PREMs, shedding light on discrepancies and areas of alignment.

2.1.4 Lack of Socioeconomic and Cultural Diversity in Patient Centered Care Research

A final gap in PCC research is the underrepresentation of diverse patient populations, particularly in terms of socioeconomic status and cultural background. Groenewald et al. (2022) argue that existing measures often fail to consider the unique needs of children from marginalized or underserved communities, potentially exacerbating healthcare inequities (Groenewald et al., 2022). Cultural norms, language barriers, and socioeconomic factors can all

influence how families experience care and what they prioritize in healthcare settings (Brooks et al., 2019). To address this issue, this thesis adapts a PREM for use in Canadian pediatric surgery settings, ensuring that the measure reflects the specific cultural and socioeconomic contexts of Canadian families, thereby promoting more equitable and inclusive care.

2.2. The Evolution and Importance of Patient-Reported Outcomes and Experiences

Historically, pediatric healthcare relied heavily on proxy reports from parents or caregivers to assess children's health status and QoL (Varni et al., 2007b). Although proxy reports offer valuable insights, they frequently fall short of accurately reflecting the child's objective experience (Lopez et al., 2023). Recognizing these limitations, the 1990s saw a growing awareness of the need for Patient-Reported Outcomes (PROs) and Patient-Reported Experiences (PREs) (Greenfield & Nelson, 1992).

Early efforts focused on adapting adult instruments for pediatric use, but researchers soon realized the necessity for age-appropriate, child-friendly measures that accounted for children's developmental stages and cognitive abilities (Wille et al., 2010). The emergence of pediatric PROs and PREs represented a key breakthrough in pediatric healthcare, enabling clinicians and researchers to fully capture children's health-related quality of life (HRQoL) and their experiences with healthcare services (Varni et al., 2007a).

Various pediatric PROs and PREs instruments have been developed over the years, encompassing a wide range of health domains, including physical functioning, emotional well-being, social interactions, school performance, and patient experiences with care (Detmar et al., 2002; Goldstein, 2008). These measures have been tested across diverse populations, including children with chronic conditions, those undergoing surgery, and in different cultural settings, ensuring their reliability and relevance in a variety of clinical and cultural contexts (Chaudhry & Siddiqui, 2012; Ravens-Sieberer et al., 2010; Varni et al., 2001). For example, the Pediatric Quality of Life Inventory (PedsQL™) has been validated for use in children with asthma, cancer, and diabetes, as well as in different cultural contexts, such as in South Asian and European populations (Amedro et al., 2021; Mustafa & Maqsood, 2024; Sze et al., 2022), while the EQ-5D-Y has been adapted and tested in diverse settings, including in Europe and low- and middle-income countries (Perez-Sousa et al., 2023; Ravens-Sieberer et al., 2010; Wille et al., 2010).

2.3. Measuring Health Outcomes and Experiences in Pediatric Surgery

Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) play a critical role in healthcare, including pediatric surgery, by offering a patient-centered lens to evaluate care. These measures provide insights into specific health outcomes and patient experiences, such as pain management, emotional well-being, functional recovery, and the ease of navigating healthcare systems, from the viewpoints of patients and their families (Bele et al., 2023). Unlike traditional clinical metrics that focus on physiological parameters (e.g., wound healing rates or length of hospital stay), PROMs capture subjective dimensions like physical functioning, psychological distress, and social reintegration, while PREMs assess elements such as communication quality, respect, and shared decision-making (Germain et al., 2019).

In chronic disease management, such as diabetes care, PROMs facilitate regular monitoring of patient-reported issues like activity limitations and emotional well-being, leading to better-informed clinical decisions and improved health outcomes (Terwee et al., 2023).

In pediatric populations, PROMs and PREMs are increasingly applied to assess outcomes that matter most to children and their families. For instance, PROMs in children with chronic illnesses, such as cystic fibrosis, have highlighted unmet needs in emotional support during treatment and transitions in care (Prieur et al., 2021). Similarly, PREMs have revealed gaps in communication between families and care providers in pediatric oncology, prompting the development of more family-centered care models (Harrison, 2010).

2.3.1 Patient-Reported Outcome Measures

PROMs are standardized, validated questionnaires designed to capture patients' perceptions of their health status, symptoms, and overall well-being. Within this broader category, HRQoL represents a specific construct that focuses on the multidimensional impact of health conditions on an individual's physical, emotional, and social functioning (Churruca et al., 2021). Unlike general PROMs, which may assess isolated symptoms or functional domains (e.g., pain intensity, fatigue, or mobility), HRQoL measures integrate these aspects to provide a comprehensive view of how health conditions and treatments influence overall QoL.

HRQoL measures are especially relevant in pediatric care, as they account for the broader developmental and social contexts that shape a child's well-being. For instance, instruments like

the PedsQL™ assess domains such as physical functioning, emotional well-being, school performance, and social relationships, offering insights into how a health condition affects a child's everyday life (Varni et al., 2001). This distinct focus sets HRQoL apart from PROMs that target specific symptoms, such as the Childhood Asthma Control Test (*Welcome to the Asthma Control Test*, n.d.), which evaluates asthma-related symptoms and their impact on daily activities but does not encompass emotional or social dimensions.

In pediatric contexts, HRQoL is often assessed either through self-report by the child or by proxy (e.g., parents or caregivers), particularly for younger children or those with cognitive impairments (Bele et al., 2020). Proxy reporting, however, poses challenges, as research indicates discrepancies between child and parent perceptions. For example, parents may underestimate emotional distress or overestimate social functioning, highlighting the importance of direct child input wherever possible (Cremeens et al., 2006; Galloway & Newman, 2017).

Moreover, in chronic conditions like asthma, diabetes, and cancer, HRQoL measures have been instrumental in tracking long-term outcomes and guiding personalized interventions that address both medical and psychosocial needs (Bele et al., 2022; Kluzek et al., 2022). For instance, children with diabetes benefit from HRQoL tools that capture the emotional burden of disease management, enabling targeted psychosocial support.

In the context of pediatric surgery, the use of PROMs is particularly valuable for understanding both the short- and long-term effects of surgical interventions on a child's HRQoL (Spivack et al., 2024). Studies in surgical populations, such as children undergoing procedures for congenital conditions or major neonatal surgeries, have highlighted the importance of capturing patient perspectives, particularly in complex or ongoing conditions such as EA or congenital diaphragmatic hernia (CDH) (Cullis et al., 2024; Lam et al., 2023). Despite their usefulness, a critique of these measures in pediatric surgery reveals limitations, such as a lack of individualized assessment of domains most relevant to each child's post-operative recovery, which may not be fully captured by standard measures (Kreimeier & Greiner, 2019; Verstraete & Scott, 2022).

PROMs can be generic, applicable across various health conditions, or disease-specific, tailored to particular conditions or treatments (Deighton et al., 2014). One of the most widely used generic PROMs in pediatric surgery is the PedsQL™, which assesses physical, emotional,

social, and school functioning across different age groups (Varni et al., 2001). The PedsQL™ has been validated for use in numerous pediatric conditions and surgical interventions, making it a versatile tool for comparing outcomes across different patient populations (Varni et al., 1999).

Another prominent set of measures is the PROMIS instruments, developed by the National Institutes of Health. PROMIS measures cover various domains such as physical function, pain interference, fatigue, and emotional distress, and have been validated for use in pediatric populations (Aghdaee et al., 2023). These measures use computerized adaptive testing, which allows for more precise measurement with fewer questions, reducing respondent burden (Jacobson et al., 2020).

The EQ-5D-Y, a youth version of the EuroQol-5 Dimension (EQ-5D) measure, is another generic PROM that evaluates health status across five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression (Balestroni & Bertolotti, 2012). This measure also includes a visual analog scale (VAS) for assessing overall health, providing a comprehensive view of a child's HRQoL (Wille et al., 2010). Studies have used the EQ-5D-Y in a range of populations, including children with chronic conditions like asthma, diabetes, and cancer, as well as in those recovering from surgery. For example, the EQ-5D-Y was used to assess health outcomes among primary school children in Malawi (Ngwira et al., 2023), while Ravens-Sieberer et al. (2010) explored its validity in European countries (Ravens-Sieberer et al., 2010). Additionally, in pediatric oncology, the EQ-5D-Y has been used to evaluate long-term survivors' health status, providing insight into their physical and emotional well-being (Horan et al., 2024).

Disease-specific PROMs have emerged as invaluable measures in pediatric surgical care, offering targeted assessments for a wide range of conditions and procedures (Churruca et al., 2021). These specialized measures are meticulously designed to capture the unique challenges, symptoms, and QoL impacts associated with specific pediatric surgical interventions (Field et al., 2004a).

For example, the PedsQL™ Inguinal Hernia Module assesses outcomes specific to inguinal hernia repair in children—a procedure that addresses a protruding intestine through the abdominal wall or groin—by evaluating its impact on physical function, emotional well-being, and overall health (Nazem et al., 2015). For instance, Varni et al. (2002) demonstrated the

reliability of the PedsQL™ in children with asthma and cancer (Varni et al., 2002), while Sze et al. (2022) applied it in a multinational study of children with special educational needs, showing its utility across different cultural contexts (Sze et al., 2022). These studies highlight the versatility of these PROMs in capturing the multidimensional aspects of children's health across various clinical conditions.

Similarly, the CLEFT-Q represents a significant advancement in evaluating outcomes for patients with cleft lip and palate, a congenital condition marked by an abnormal opening or gap in the lip, roof of the mouth, or both, resulting from incomplete fusion of facial tissues during fetal development (Tsangaris et al., 2017). This measure assesses various domains, including facial appearance, speech function, psychological well-being, and social integration – all critical factors in the long-term success of cleft surgeries (Klassen et al., 2018).

Beyond these examples, researchers and clinicians have developed condition-specific PROMs for various other pediatric surgical areas, including appendicitis (inflammation of the appendix), hypospadias (a congenital condition where the urethra does not open at the tip of the penis), and congenital heart defects (structural abnormalities of the heart present at birth) (Brown et al., 2024; Knowles et al., 2014; Stevens et al., 2016). These specialized measures provide healthcare providers with valuable insights into the effectiveness of surgical interventions, potential complications, and their overall impact on a child's QoL (Baker et al., 2015).

By employing these disease-specific PROMs, surgeons and healthcare teams can more accurately monitor patient progress, identify opportunities to refine surgical techniques or post-operative care, and ultimately improve the overall quality of pediatric surgical care (Schifferdecker et al., 2019).

These specialized measures enhance the ability to assess patient-reported outcomes by providing detailed insights into recovery, which can be valuable for evaluating the effectiveness of different treatment methods and healthcare settings. This, in turn, drives evidence-based enhancements in pediatric surgical care (Grandpierre et al., 2022).

2.3.2 Patient-Reported Experience Measures

PREMs deliver critical insights into the healthcare experiences of patients and their families across a wide range of clinical settings (Corazza et al., 2021). Unlike PROMs, which focus on the health status and outcomes from the patient's perspective, PREMs capture patients'

and families' perceptions and satisfaction with the care they receive (Bele et al., 2021). These measures are important for assessing the quality of healthcare delivery, particularly in areas such as communication with healthcare providers, involvement in decision-making processes, and overall hospital experiences (Germain et al., 2019).

PREMs offer several benefits by providing a direct understanding of the experiences of pediatric patients and their families, which are often overlooked in clinical assessments (Wray & Oldham, 2019b). This understanding can lead to improvements in care practices and policies (McKenna, 2011). PREMs can identify specific areas where healthcare services may fall short, providing actionable data for quality improvement initiatives (De Rosis et al., 2020). They also promote PCC by ensuring that the perspectives of children and their families are actively included in healthcare decision-making (Wray & Oldham, 2019a).

One commonly used PREM is the Child Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), which measures inpatient pediatric care experiences (Toomey et al., 2015). The child HCAHPS survey includes questions about communication with doctors and nurses, hospital environment, and overall hospital rating, providing a comprehensive view of the child's and family's hospital experiences (Quigley et al., 2021). It has been used extensively in the U.S. to assess pediatric care quality, allowing hospitals to benchmark performance and identify areas for improvement. However, a critique of the Child HCAHPS highlights that the single open-ended question may not provide enough actionable insights. A study comparing it to the 6-item beta version Narrative Item Set (NIS) found that the NIS elicited more detailed and actionable feedback, with a higher percentage of comments addressing specific areas for improvement in pediatric care (Quigley & Predmore, 2023). The study suggests that a multi-item set like the NIS could provide a more comprehensive view of patient experiences and guide hospital quality improvements more effectively.

Another widely used PREM is the Pediatric Inpatient Experience Survey (PIES), which captures the hospital experiences of pediatric patients and their families across various dimensions, such as communication, care coordination, and the physical environment (Ziniel et al., 2016). The PIES survey is designed to be child-friendly and age-appropriate, ensuring that children's voices are accurately represented (Toomey et al., 2015). It has been lauded for its inclusivity and attention to developmental appropriateness, making it accessible for younger

patients. However, like child HCAHPS, PIES has limitations. Some critics argue that it may not fully capture the complexities of patient experiences in cases of chronic illness or long-term hospital stays, where more nuanced feedback may be needed (Wijlaars et al., 2016). Additionally, both surveys tend to focus on short-term care experiences, offering less insight into the long-term impacts of care on patients' well-being (Ziniel et al., 2016).

2.4. Parent-Child Agreement on Patient Reported Outcome Measures and Patient Reported Experience Measures

The agreement between parent and child reports on PROMs and PREMs is a critical area of research in pediatric healthcare (Ali et al., 2022). Understanding the extent to which parents' and children's perspectives align can provide insights into the validity and reliability of these measures (Eiser & Varni, 2013). However, numerous studies have highlighted discrepancies between parent and child reports, raising questions about the factors contributing to these differences (Van Roy et al., 2010).

2.4.1 Factors Influencing Agreement

Several factors influence the level of agreement between parent and child reports on PROMs and PREMs, including the child's age, the specific domain being assessed, and the health condition in question (McCabe et al., 2023). Younger children may have difficulty articulating their experiences and feelings, leading parents to provide proxy reports that may not fully capture the child's perspective (Ungar et al., 2012). Conversely, older children and adolescents may have a clearer understanding of their health and well-being, resulting in reports that more closely align with their parents' observations (Frosch et al., 2021).

The domains assessed can affect the level of agreement between parents and children. For instance, reports on physical health and functioning often align closely, as these are observable and quantifiable aspects of health (Poulain et al., 2020). In contrast, emotional and psychological well-being may show greater discrepancies, as parents may not be fully aware of their child's internal experiences and struggles (Frosch et al., 2021).

The nature of the child's health condition plays a role in agreement levels. Chronic conditions, where parents are more involved in their child's care, often result in higher agreement

levels (Badour et al., 2023). In contrast, acute conditions or less visible symptoms may lead to greater discrepancies between parent and child reports (Becker-Haimes et al., 2018).

2.4.2 Implications for Research and Clinical Practice

Discrepancies between parent and child reports on PROMs and PREMs have significant implications for both research and clinical practice. In research, understanding these differences is vital for accurately interpreting findings and creating measures that genuinely capture pediatric patients' experiences (McCabe et al., 2023). Researchers need to recognize potential biases in parent reports and incorporate child self-reports whenever possible to obtain a more thorough understanding of the child's health and well-being (Godleski & Ostrov, 2020).

In clinical practice, identifying and addressing parent-child discrepancies is key to ensuring PCC (Seniwati et al., 2023). Healthcare providers should remain mindful of potential differences in perspectives and actively engage in understanding the child's views and experiences (Boelsma et al., 2021). Involving both parents and children in discussions about their health and treatment can help close these gaps, ensuring that care plans are tailored to the needs and preferences of both the child and their family (Hill et al., 2018).

2.5. Cultural Adaptation and Validation of Patient Reported Outcome Measures and Patient Reported Experience Measures

The cultural adaptation and validation of PROMs and PREMs are critical for ensuring that these measures are relevant and reliable across diverse populations (Weldring & Smith, 2013). As healthcare globalizes, it becomes essential to design measures that are culturally sensitive and effectively capture the experiences of patients from varied backgrounds (Nair & Adetayo, 2019).

2.5.1 Importance of Cultural Adaptation

Cultural adaptation involves modifying existing PROMs and PREMs to account for cultural differences in language, values, and health beliefs (d'Agincourt-Canning et al., 2024). This process ensures that the measures are not only linguistically but also culturally appropriate for the target population (Nair & Adetayo, 2019). Cultural adaptation is essential in pediatric surgery, as patients and families from different backgrounds may have diverse expectations, experiences, and perceptions of healthcare (C. B. Smith et al., 2022).

Cultural differences in how pain, emotional distress, and HRQoL are perceived and expressed can significantly impact the validity of PROMs and PREMs (Weldring & Smith, 2013). Without proper cultural adaptation, these measures may not fully capture the true experiences of pediatric patients from diverse backgrounds, resulting in inaccurate assessments and potentially suboptimal care (Okoniewski et al., 2022).

2.5.2 Steps in Cultural Adaptation and Validation

The process of cultural adaptation and validation involves several key steps to ensure that PROMs and PREMs are both culturally appropriate and psychometrically sound (Alrubaiy et al., 2022). These steps include:

1. Translation and Back-Translation: The process begins with translating the original measure into the target language and then back-translating it into the original language to verify accuracy (Tsang et al., 2017). This method helps identify discrepancies and cultural nuances that might not be directly translatable (Lee et al., 2009).
2. Cognitive Interviewing: Following translation, cognitive interviewing is performed with a sample from the target population to evaluate their understanding of the items (Balza et al., 2022). This step ensures that the questions are both culturally relevant and easily comprehensible (Boateng et al., 2018).
3. Expert Review: A panel of experts—including clinicians, researchers, and cultural representatives—evaluates the translated instrument to ensure it is culturally appropriate and accurately preserves the original meaning and intent of the items (Cruchinho et al., 2024).
4. Pilot Testing: The adapted instrument is pilot-tested with a small sample from the target population to assess its reliability and validity within the new cultural context (Bujang et al., 2024). Reliability refers to the consistency of the instrument, which can be evaluated by examining internal consistency (e.g., using Cronbach's alpha) to ensure that items within the instrument measure the same underlying concept (Tavakol & Dennick, 2011). Test-retest reliability may also be assessed by administering the instrument at two different points in time to

evaluate the stability of responses (*Reliability and Validity*, n.d.). Validity, on the other hand, refers to the extent to which the instrument accurately measures what it is intended to measure (Sullivan, 2011). This can be assessed through content validity (ensuring the instrument covers all relevant aspects of the concept being measured), face validity (whether the instrument appears to measure what it should), and construct validity (how well the instrument aligns with theoretical expectations or correlates with other established measures) (Middleton, 2019).

5. Psychometric Evaluation: Finally, the measure undergoes thorough psychometric testing to evaluate its reliability, validity, and sensitivity to cultural variations (Boateng et al., 2018). This step ensures that the adapted PROMs and PREMs are both robust and effective across different cultural settings (Arestad et al., 2017).

2.6. The Role of Individualized Measures in Pediatric Surgery

The Patient-Generated Index (PGI) is a personalized measure that allows patients to identify and rate the aspects of their lives most affected by their health condition (F. Martin et al., 2007; Mayo et al., 2017). Unlike traditional PROMs, which evaluate predefined health domains, the PGI is tailored to each patient's unique experiences and priorities (Weldring & Smith, 2013). This flexibility is particularly advantageous in pediatric surgery, where a child's health and well-being may be impacted by a diverse range of factors not fully captured by standard PROMs (Churruca et al., 2021).

2.6.1 The pediatric Patient-Generated Index (pPGI)

The PGI has been adapted for pediatric populations through the development of the pediatric version (pPGI), which is designed to capture the unique experiences of children and adolescents undergoing surgery (Ow et al., 2022). In the adult PGI, patients can nominate up to six areas and rate the severity of impact on a seven-point scale (Aburub et al., 2016). The pPGI, on the other hand, limits nominations to five areas and uses a more intuitive 0–10 scale for severity ratings, reflecting its adaptation for a younger audience (Ow et al., 2022). Both versions incorporate a weighting process where patients allocate points—translated into physical tokens or "coins" in the pPGI—to signify the priority for improvement across the nominated areas

(Aburub et al., 2016). This prioritization reflects the patient's values and desires for their health outcomes (Lonner et al., 2020).

The pPGI process comprises three key steps. First, the patient identifies significant life areas affected by their condition (Ow et al., 2022). Second, they rate the severity of these impacts on a 10-point scale (Aburub et al., 2016). Finally, they allocate priority weights using "coins" to indicate which areas they most want to improve (Lonner et al., 2020). A composite score is then derived from these severity ratings and priority weights, offering a personalized assessment of HRQoL that reflects the child's most important concerns (Aburub et al., 2016). A diagram detailing this process is available in the *Appendix*.

2.6.2 Benefits and Challenges of Using Individualized Measures

Using individualized measures such as the PGI provides several advantages. These measures help pinpoint patient-specific areas of concern, enabling more targeted and effective interventions (Aburub et al., 2016). For example, the PGI identified a wide range of QoL issues for people with cancer, including fatigue, sleep disturbances, and pain, which were not fully captured by standard QoL measures. This study highlighted that the PGI provided a detailed view of individual patient concerns, facilitating more personalized care (Aburub et al., 2016). Similarly, a study on adolescent idiopathic scoliosis (AIS) revealed that the PGI could distinguish between patient and parent perspectives, identifying distinct concerns such as sports and general function for patients, and physical appearance and sleep for parents (Lonner et al., 2020). This detailed insight enables healthcare providers to address specific patient and family needs more effectively, enhancing the personalization of care.

However, using individualized measures presents several challenges. Their subjective nature can complicate comparisons of outcomes across different patients or studies (Fung & Hays, 2008). This variability makes it difficult to aggregate data and draw broad conclusions, as individual responses can vary widely and lack standardization. Additionally, administering these measures may be more time-consuming and resource-intensive than standardized PROMs. The process of customizing, administering, and interpreting individualized measures requires additional effort from healthcare providers, including longer appointment times and more extensive training (Fung & Hays, 2008; Weldring & Smith, 2013).

Despite these challenges, the benefits of individualized measures in improving patient-centered care emphasize their important role in pediatric surgery (Ow et al., 2022). They offer a comprehensive understanding of patient-specific concerns and contribute to more personalized and effective care. Future research should focus on addressing these challenges by developing methods to standardize the interpretation of individualized measures while exploring ways to streamline their administration to mitigate time and resource burdens.

2.7. Conclusion

Research on PCC in pediatric surgery highlights its substantial benefits, including increased patient satisfaction and improved communication between families and healthcare providers. However, ensuring consistent implementation of PCC across diverse populations remains a challenge, emphasizing the need for further research into culturally inclusive and relevant measures for all pediatric patients.

The development of pediatric PROs and PREMs has significantly advanced pediatric care. While these measures have improved care quality, further refinement—particularly for both general and condition-specific PROMs and PREMs—may be necessary to fully capture the range of pediatric patients' experiences, especially in specialized or under-studied conditions. Exploring both parent and child perspectives adds complexity to pediatric care and emphasizes the need to incorporate these viewpoints to improve the effectiveness of PROMs and PREMs in clinical practice.

Adapting these measures to diverse cultural contexts is essential to ensure their relevance and effectiveness for all patients. As healthcare systems globalize, culturally sensitive instruments are increasingly important, promoting more equitable healthcare and enhancing the accuracy of these measures.

In summary, personalized and culturally sensitive approaches are critical for the future of pediatric care. Research should focus on addressing gaps in cultural relevance, aligning parent and child perspectives, and incorporating individualized measures such as the PGI. This individualized approach ensures care is more closely tailored to each child's unique needs and experiences.

3. THESIS OBJECTIVES

Pediatric surgical patients face complex and multidimensional challenges that require precise measures to accurately capture their health and well-being. While PROMs and PREMs are essential for understanding patient perspectives, it is uncertain whether these measures fully reflect the priorities of pediatric surgical patients and their families. Furthermore, significant differences often arise between the reports of children and their proxies, with parents and children sometimes emphasizing different aspects of health and well-being. Understanding these similarities and differences is critical to ensure that both perspectives are adequately represented in pediatric care.

This thesis seeks to address these gaps by critically evaluating how effectively current PROMs and PREMs capture the concerns and priorities of pediatric surgical patients and their families. It also explores the alignment between child and proxy perspectives, the adaptation of measures for Canadian pediatric populations, and the potential of individualized approaches, like the PGI, to better capture unique patient priorities across various health domains.

The necessity for this research is emphasized by the increasing emphasis on PCC as a cornerstone of high-quality healthcare in Canada (Najafizada et al., 2023) and the country's ratification of the United Nations Convention on the Rights of the Child (Public Health Agency of Canada, 2011). This convention recognizes the right of children to express their views on matters affecting their lives, including healthcare. In pediatric surgery, actively involving children and their families in assessing health outcomes and care experiences ensures that care aligns with their unique needs and expectations.

This research seeks to bridge the gap between current PROMs and PREMs and the lived experiences of pediatric surgical patients. Specifically, it evaluates how well existing measures reflect what pediatric surgical patients and their families consider most important. To achieve this, we employed a multi-faceted approach, including qualitative analyses of interviews with patients and families, item mapping to compare identified priorities with measured content, and direct feedback from clinicians, patients, and families. This comprehensive evaluation ensures that the measures' relevance, comprehensiveness, and alignment with patient and family priorities are thoroughly assessed.

The study is organized around three key objectives, each addressed through a dedicated manuscript:

1. *"Child- and Proxy-Reported Differences in Patient-Reported Outcome and Experience Measures in Pediatric Surgery: Systematic Review and Meta-Analysis"*

This manuscript explores the level of agreement between children and parents on PROMs and PREMs in pediatric surgery. It synthesizes existing literature to identify patterns of concordance and discordance between child and proxy reports, offering insights into how these perspectives can be integrated into clinical assessments.

2. *"Adaptation, Translation, and Validation of a Patient-Reported Experience Measure for Children and Young People for the Canadian Context"*

This manuscript focuses on adapting an existing PREM for Canadian pediatric surgical settings. Through linguistic and cultural adaptation, followed by cognitive interviews with children, the study evaluates the relevance and comprehensibility of the measure to ensure it captures the priorities of Canadian pediatric surgical patients.

3. *"Usability of the Pediatric Patient-Generated Index (pPGI) for Esophageal Atresia Follow-up: Insights from Children and Clinicians"*

This manuscript examines the feasibility of using the pPGI as an individualized measure to capture patient-relevant outcomes in pediatric surgery, specifically in the context of EA follow-up. It gathers insights from both patients and clinicians to evaluate the potential of individualized measures in capturing outcomes often overlooked by standardized PROMs and PREMs.

Together, these manuscripts offer a thorough evaluation of PROMs and PREMs, propose culturally sensitive adaptations, and underscore the value of individualized measures in pediatric surgical care. While this thesis does not include longitudinal studies, it lays the groundwork for future research by identifying where current measures fall short and recommending improvements for more inclusive and relevant patient-reported measures.

4. CHILD-PROXY DIFFERENCES IN PEDIATRIC SURGERY PATIENT-REPORTED OUTCOME AND EXPERIENCE MEASURES

4.1. CONTEXTUAL OVERVIEW

Accurate pediatric healthcare outcome measurement is vital for decision-making and policy. Traditionally reliant on parent-reported assessments, these may not reflect children's experiences, especially in surgery. This study examines the differences between child- and parent-reported health outcomes using PROMs and PREMs.

To address this aim, the study follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. A comprehensive search strategy, designed by an experienced librarian, was employed across eight databases to identify relevant studies published until July 2023. This methodical approach ensured a thorough examination of existing literature, capturing studies that used PROMs and PREMs to assess pediatric surgical outcomes from both child and parent perspectives.

The SR process involved two independent reviewers who screened abstracts and resolved any conflicts with the assistance of senior authors. Quality appraisal of the included studies was conducted using the Mixed Methods Appraisal Tool (MMAT), ensuring the rigor and reliability of the findings. Furthermore, a meta-analysis of the PedsQL™ results was conducted to quantify the differences between child and parent reports.

4.2. CHILD- AND PROXY-REPORTED DIFFERENCES IN PATIENT-REPORTED OUTCOME AND EXPERIENCE MEASURES IN PEDIATRIC SURGERY: SYSTEMATIC REVIEW AND META-ANALYSIS

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This study was presented at the 2024 Canadian Association of Pediatric Surgeons (CAPS) conference, where it received the Best Bilingualism Award. The manuscript is categorized as a systematic review and meta-analysis and has been submitted for publication in the *Journal of Pediatric Surgery*. Previous communication on this topic has not been reported. The authors declare no conflicts of interest. Financial support for this research was provided by CIHR Project Grant #496021.

4.2.1. ABSTRACT

Measuring healthcare outcomes in pediatric populations often relies on proxy assessments, which may not reflect the child's experience accurately. Children with surgical conditions have unique and evolving healthcare experiences. This review estimates the differences between child reports of health status from patient-reported outcome measures (PROMs) and treatment experiences from patient-reported experience measures (PREMs) compared to parent reports.

Following PRISMA guidelines, a librarian-designed search strategy was applied across eight databases until July 2023 to identify studies using PROMs and PREMs to evaluate pediatric surgery outcomes from both child and parent perspectives. Two reviewers independently screened abstracts, resolving conflicts with senior authors. Quality appraisal was conducted using the Mixed Methods Appraisal Tool (MMAT). A meta-analysis of the Pediatric Quality of Life Inventory (PedsQL™) results was also conducted.

After screening 5,415 studies, 53 were included: 50 used PROMs, two used PREMs, and one used both. The PedsQL™ was the most frequently used measure, appearing in 30 studies. Sixteen other quality of life measures were used less frequently. The meta-analysis included 22 studies using PedsQL™, comprising 6,691 child-parent dyads. The pooled effect size of the relationship between child- and parent-reported PedsQL™ scores was 0.98 (95% CI: [-0.81, 2.77], random effects model), with high heterogeneity ($I^2 = 89\%$, $\tau^2 = 11.02$, df = 21, $p < 0.01$).

This systematic review and meta-analysis revealed substantial variability across studies, with little evidence of systematic differences between child and parent reports in pediatric health outcomes assessment. The findings highlight the need for further research to understand the variability and improve the integration of both perspectives in clinical practice.

4.2.2. INTRODUCTION

Patient-reported outcome measures (PROMs) and Patient-reported experience measures (PREMs) play important roles in assessing various aspects of healthcare experience and health status from the patient's perspective (Shunmuga Sundaram et al., 2022; Weldring & Smith, 2013). PROMs evaluate patient-reported outcomes such as health status, treatment impact on health-related quality of life (HRQoL), and functional ability, while PREMs gather insights into a patient's perception of the care they receive (Weldring & Smith, 2013). Together these measures provide valuable evaluations of healthcare quality, symptom burden, and treatment efficacy (Besner et al., 2022b).

Incorporating PROMs and PREMs into healthcare practices allows patients to actively engage in their care, ensuring their primary concerns are addressed in discussions with healthcare providers (Campbell et al., 2022; Solans et al., 2008). When used alongside clinical assessments, these measures also offer a complete understanding of patient care and overall well-being, facilitating quality improvement initiatives (Shunmuga Sundaram et al., 2022; Weldring & Smith, 2013).

Despite the increasing implementation of PROMS and PREMs in clinical settings, their widespread use remains limited, particularly in pediatric surgery (Shunmuga Sundaram et al., 2022; Solans et al., 2008). In this context, existing measures are often generic, lack consistency as well as child-generated elements, and tend to primarily reflect the proxy's perspective, especially in assessments of younger children (Jardine et al., 2014). Moreover, measures that do specifically elicit children's perspectives often lack the children's input during development and validation stages, resulting in a gap in validated outcome and experience measures created *by* children *for* children (J. Ferreira et al., 2023; Jardine et al., 2014).

Furthermore, when PROMs and PREMs are used to capture both child and proxy perspectives in pediatric healthcare settings, discrepancies often arise, particularly within emotional subscales (Jardine et al., 2014). This review aims to identify the extent of these discrepancies in studies comparing child self-reports of PROMs and PREMs in pediatric surgery with parent proxy reports.

4.2.3. METHODS

The study is a systematic review comparing child and parent scores on PROMs and PREMs measures in the context of pediatric surgery, followed by a meta-analysis of the most widely used PROMs. The research was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Stroup et al., 2000) and registered with Prospero (CRD42024539515).

4.2.3.1. Literature Search

A senior medical librarian conducted a comprehensive search of eight databases from inception until July 11, 2023, including Medline (Ovid), Embase (Ovid), CINAHL (Ebsco), Cochrane (Wiley), Global Health (Ovid), Web of Science (Clarivate Analytics), Africa Wide Information (Ebsco), and Global Index Medicus (WHO). The search strategy used variations in text words found in the title, abstract, or keyword fields, along with relevant subject headings, to retrieve articles focusing on the children's perspective in patient-reported experiences and outcomes within pediatric surgery, with no language restrictions. Conference abstracts, books, and book chapters were excluded in Embase. The full search strategy is available in the *Appendix*. References were managed using EndNote X9, with duplicates removed before importing into the online platform Rayyan (Ouzzani et al., 2016) for screening. Two independent reviewers (ZN & SEO) conducted the initial title and abstract screening and the full-text screening, with discrepancies resolved by a third reviewer (JF). The primary reasons for excluding studies are reported in the PRISMA flow diagram Additionally, the PRISMA Checklist and the PRISMA-S Checklist are provided in the *Appendix.*

4.2.3.2. Study selection and eligibility criteria

Studies were included if they used PROMs and/or PREMs to evaluate the self- and proxy-reported health status or experiences with healthcare facilities of pediatric surgical patients up to the age of 18 years. All studies compared child and proxy perspectives on the child's health and surgical experiences.

Exclusion criteria encompassed studies assessing patients above the age of 18 years, unless patients under 18 years were separately analyzed, and studies including patients who undertook only non-interventional treatment, unless a separate analysis of surgically treated

patients was provided. Additionally, studies relying solely on satisfaction surveys, pain scales, or behavioral assessments without using PROMs or PREMs were excluded. Satisfaction surveys were excluded because, while they provide valuable insights into general contentment with care, they do not offer the same depth of information about specific health outcomes, quality of care, or patient and caregiver experiences as captured by PROMs and PREMs. Case reports, conference abstracts, reviews, commentaries, and studies solely focused on instrument validation, development, or translation were also excluded. Furthermore, studies were excluded if they failed to include both patient and parent proxy reports of the PROMs/PREMs or if they lacked statistical analyses comparing patient and proxy-reported results.

4.2.3.3. Data extraction

Data collection was carried out by two reviewers (ZN & SEO). The collected information included study design, publication year, country, scope, operative stage, specialty, condition, procedure, details of the measure(s) used (including name, type, whether generic or disease-specific, and validity status), results of the measure(s), patient-proxy comparison results, and patient characteristics. The validity status of the instruments was verified by conducting a systematic search of the literature for each measure, focusing on studies that provided psychometric evaluations, including reliability, validity, and responsiveness. Specific criteria such as internal consistency (e.g., Cronbach's alpha), construct validity (e.g., comparisons against established benchmarks or gold standards), and test-retest reliability were assessed. Instruments were categorized as valid if they met established thresholds for these criteria in the context of the pediatric population. Measures were then categorized into three main groups: PROMs, HRQoL (a subset of PROMs), and PREMs.

4.2.3.4. Quality and risk of bias assessment

Two independent reviewers (ZN & SEO) used the Mixed-Methods Appraisal Tool (MMAT) to assess the risk of bias. This tool is tailored for evaluating various study methodologies, encompassing qualitative, randomized controlled trials, non-randomized, quantitative descriptive, and mixed methods studies (Hong et al., 2020).

4.2.3.5. Meta-analysis

Mean values of the most used scale and summary scores were pooled and estimated with a random-effects meta-analysis using generalized estimating equations with maximum likelihood estimation. Standardized mean differences (SMDs) were calculated to compare child and parent scores across various HRQoL measures, providing a common metric to evaluate differences. Data for SMD calculations were extracted from included studies, including mean scores and standard deviations for both child and parent groups.

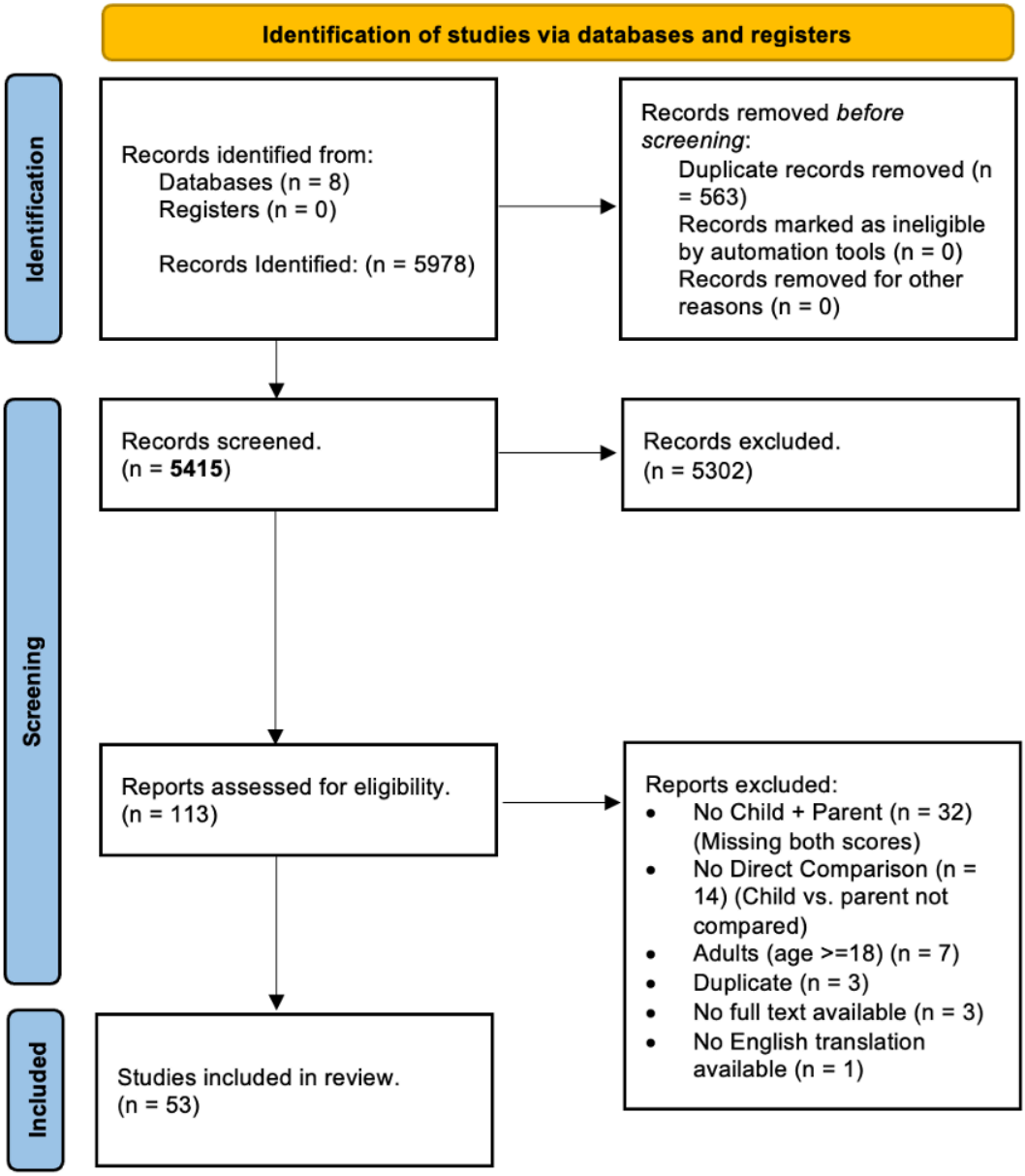
A forest plot was generated to visually represent the SMDs for each HRQoL measure, enabling comparison across instruments. Due to substantial heterogeneity in the included measures and populations, pooled effect sizes were not calculated. Instead, individual effect sizes were presented to highlight variability between child and parent perspectives. Heterogeneity was further evaluated visually through the forest plot and quantified using the I^2 statistic (Higgins & Green, 2008).

All statistical analyses, including the meta-analysis and forest plot generation, were conducted using R (version 4.4.0, R Foundation for Statistical Computing Platform).

4.2.4. RESULTS

Following a preliminary search in the databases, 5978 articles were retrieved, resulting in 5415 articles after duplicate removal. Subsequent title and abstract screening of these articles led to the inclusion of 113 records for full-text review, of which 53 were retained for analysis *(Figure 4.1 & Supplementary File 4.1)*.

Figure 4.1. PRISMA Flow Diagram



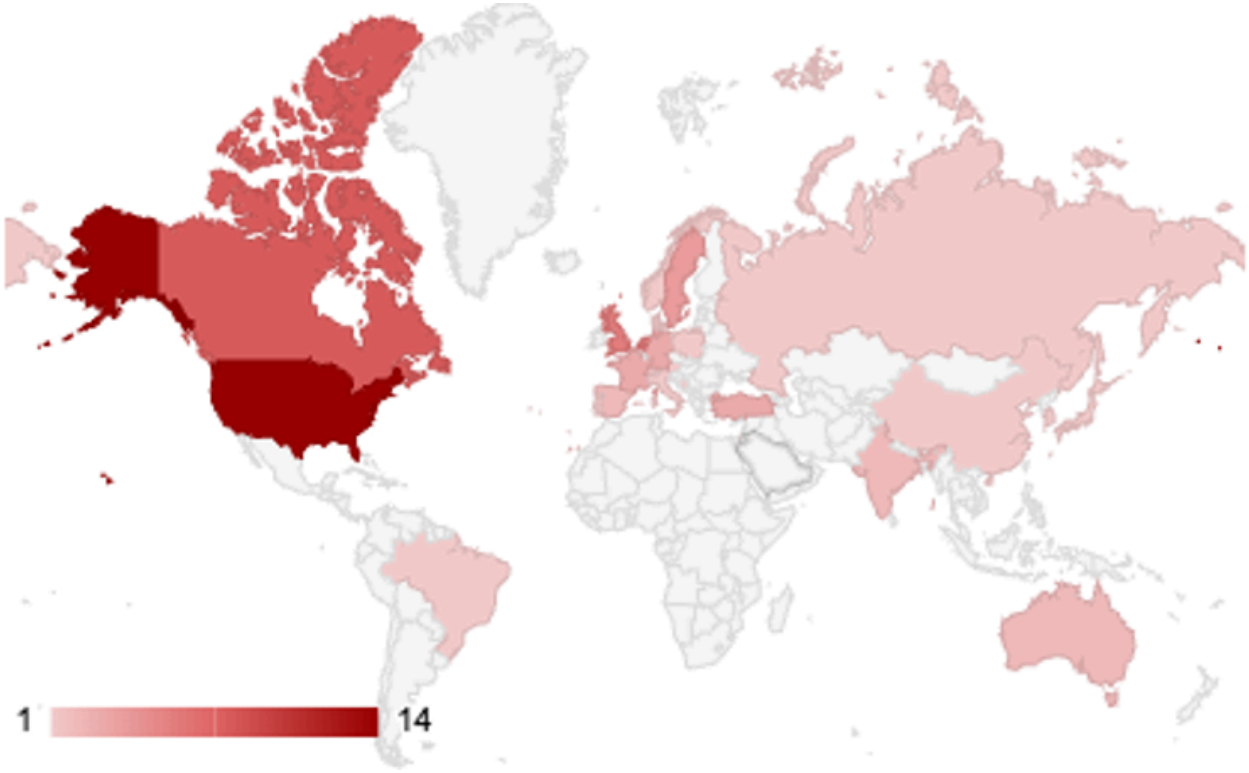
From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n7. For more information, visit: http://www.prisma-statement.org

Abbreviations: PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)

4.2.4.1. Description of studies

Most studies originated from the United States (26%) *(Figure 4.2)*, were single-center (57%), and post-operative (85%) in nature. General surgery was the most common surgical specialty included (25%), followed by ENT (19%) and cardiothoracic surgery (17%). Other specialties included urology (13%), plastic surgery (7%), ophthalmology (6%), anesthesia and neurosurgery (each 2%). Multiple specialties were included in 9% of the studies.

Figure 4.2. Geographic Distribution of Measures Worldwide (SR)



Heat map illustrating the global distribution of measures used in pediatric surgical outcome studies

Abbreviations: SR (Systematic Review)

Regarding outcome measures, HRQoL, a subset of PROMs, was predominant across all studies, with 81% using at least one HRQoL measure. Among these, the PedsQL™ was most often used (75% of studies). PROMIS, a specific HRQoL PROM, was also frequently used, appearing in 22% of studies that utilized PROMs. PREMs were the least used, being present in only 6% of studies.

Analysis of the validation status of the measures used in the studies revealed that the majority were validated (87%), with most being generic (73%). Among validated HRQoL measures, the PedsQL™ Generic Core Scales (Desai et al., 2014) were the most frequently validated (65%). PROMIS (Aghdaee et al., 2023), a specific HRQoL PROM, was also validated and used exclusively among PROMs. Only one validated PREM, the *Information About Pain questionnaire* (*Journal of Clinical Nursing - 2013 - Twycross.pdf*, n.d.), was identified *(Tables 4.1 and 4.2)*.

Table 4.1. Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs)

PROMs	**Description**
PODCI (Pediatric Outcomes Data Collection Instrument)	The PODCI was designed to assess self-reported and parent-reported HRQoL among adolescents.
CHQ (Child Health Questionnaire)	The CHQ is an internationally recognized general HRQoL instrument that has been rigorously translated into more than 78 languages and standardized for use with children ages 5–18 to assess the child's physical, emotional, and social well-being.
PROMIS (Patient-Reported Outcomes Measurement Information Systems)	PROMIS measures evaluate physical, mental, and social health in adults and children. They have been developed and validated with state-of-the-science methods.
CHRIs (Child Health Rating Inventories)	The CHRIs generic core and its DSII-HSCT module are promising measures of health-related quality of life after pediatric hematopoietic stem cell transplant. Both parent and child reports provide complementary perspectives.
SDQ (Strengths and Difficulties Questionnaire)	SDQ is a brief behavioral screening questionnaire for children aged 3 to 16 years. It has been widely used for screening emotional and behavioral difficulties.
PREMs	**Description**
Information About Pain questionnaire: TQPM (Total Quality Pain Management) Instruments	The Information About Pain questionnaire is part of the Child/Parent TQPM Instruments, developed to evaluate the quality of pain management for children in the postoperative period.

Abbreviations: PODCI (Pediatric Outcomes Data Collection Instrument), CHQ (Child Health Questionnaire), PROMIS (Patient-Reported Outcomes Measurement Information Systems), CHRIs (Child Health Rating Inventories), SDQ (Strengths and Difficulties Questionnaire), Health-Related Quality of Life (HRQoL), TQPM (Total Quality Pain Management) Instruments

Table 4.2. Health-Related Quality of Life (HRQoL) Measures, Subset of Patient-Reported Outcome Measures (PROMs)

HRQoL Measures	Description
PedsQL™ Generic Core Scales	The PedsQL™ Generic Core Scales have been validated in the pediatric inpatient setting, demonstrating responsiveness, construct validity, and predictive validity across physical, emotional, and social domains.
PedsQL™ Transplant Module	The PedsQL™ Transplant Module is a specific module designed to measure transplant-specific HRQoL across patient groups with transplants, validated for different age groups.
PedsQL™ end-stage renal disease (ESRD) Module	The PedsQL™ ESRD Module is a disease-specific instrument for measuring health-related quality of life in children with ESRD, validated to identify patients at risk for childhood anxiety and depression.
PedsQL™ Fatigue Scale	The PedsQL™ Multidimensional Fatigue Scale assesses fatigue in pediatric patients, validated to distinguish between healthy children and those with rheumatic diseases.
PeLTQL (Pediatric Liver Transplant Quality of Life)	The PeLTQL questionnaire is a disease-specific HRQoL tool for pediatric liver transplant recipients, offering insights into social, emotional well-being, coping, adjustment, and future health, being the first validated tool for this population.
KINDL	The KINDL questionnaire assesses HRQoL in children and adolescents.
KIDSCREEN-27	The KIDSCREEN-27 is a generic HRQoL instrument for children and adolescents, validated across different cultural contexts and age groups.

Abbreviations: PedsQL™ Generic Core Scales (Pediatric Quality of Life Generic Core Scales), PedsQL™ Transplant Module (Pediatric Quality of Life Transplant Module), PedsQL™ end-stage renal disease (ESRD) Module (Pediatric Quality of Life end-stage renal disease (ESRD) Module), PedsQL™ Fatigue Scale (Pediatric Quality of Life Fatigue Scale), PeLTQL (Pediatric Liver Transplant Quality of Life), KINDL (Quality of Life Questionnaire for Children and Adolescents), KIDSCREEN-27 (KIDSCREEN-27 Health-Related Quality of Life Questionnaire)

The review of studies reveals that 45% of studies concluded disagreement between parent and child reports, 23% concluded agreement, and 32% reported mixed findings. In this context, "mixed findings" refer to studies in which agreement and disagreement between parent and child reports varied across different domains or subscales of the HRQoL measures used. For example, agreement might have been observed for physical health domains, while disagreement was noted for emotional or social domains within the same study. Among the disagreements, underestimation by parents occurred in 54% of cases, overestimation in 25%, and both under- and overestimation in 21%. This categorization reflects overall tendencies in how parent and child scores differ but does not rely on specific cutoff values for defining the magnitude of disagreement (*Supplementary File 4.2*).

4.2.4.2. Results of assessment of bias

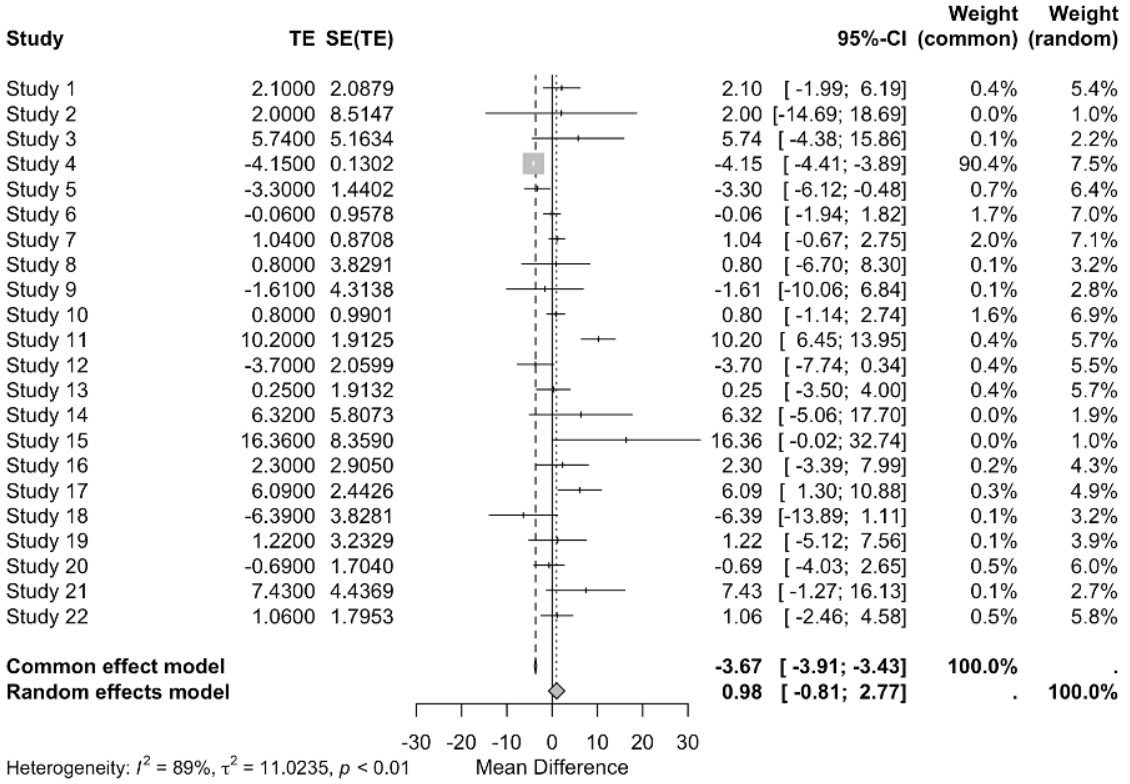
Based on the MMAT assessment outlined in *Supplementary File 4.3*, the included studies varied widely in quality. Qualitative studies generally included clear research questions (100%) and showed coherence between data sources and interpretations (100%). However, some qualitative studies had inadequacies in data collection methods (17%) and substantiation of results (17%). Quantitative randomized controlled trials uniformly included strong randomization (100%) and baseline comparability (100%), but occasionally fell short in blinding methods used (40%) and intervention adherence (20%). Non-randomized studies exhibited a range of quality, with some studies like those by Lifland et al. (2018) and van de Kar et al. (2022) performing well in participant representativeness and measurement appropriateness, whereas others faced issues with confounder management and outcome completeness (Lifland et al., 2018; van de Kar et al., 2022). Descriptive studies also varied, with strengths in sampling strategies and statistical analyses but occasionally revealing risk of nonresponse bias.

4.2.4.3. Meta-analysis - PedsQL™

The meta-analysis was limited to a subset of 6691 children and their parents across 22 studies comparing child and parent scores on the PedsQL™. The random-effects model, which accounts for between-study variability, showed a mean difference of 0.98 (95% CI: -0.81 to 2.77), suggesting no significant difference between child and parent scores. However, the analysis

revealed high heterogeneity ($I^2 = 89\%$), indicating substantial variability among the included studies *(Figure 4.3)*.

Figure 4.3. Meta-Analysis of 22 Studies Comparing Child and Parent Scores in the PedsQL™



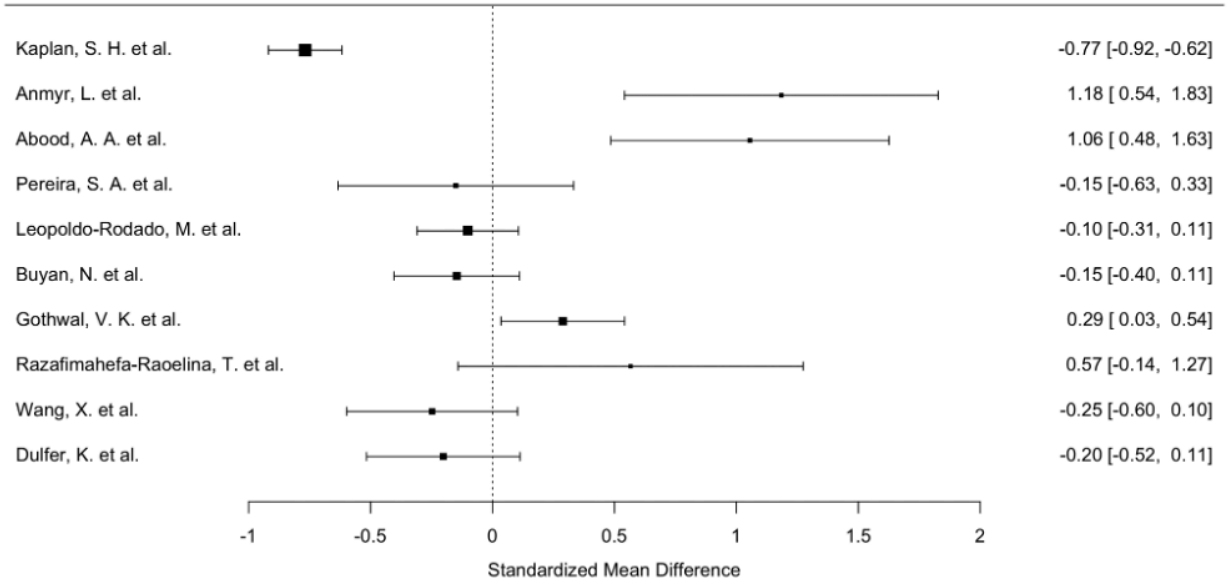
Abbreviations: CI (Confidence Interval), SE (Standard Error), PedsQL™ (Pediatric Quality of Life Inventory™)

The subgroup analysis revealed distinct trends in PedsQL™ scores for small (sample size <100) and large studies (sample size ≥100) (Ioannidis, 2008). For small studies, the weighted mean difference (WMD) was 4.66, with a 95% confidence interval (CI) ranging from 1.69 to 7.63. This positive mean difference indicates that, on average, children scored higher than their parents on the PedsQL™ in smaller studies. Conversely, in large studies, the WMD was -3.73, with a 95% CI from -3.97 to -3.48. This negative mean difference suggests that parents scored higher than their children on the PedsQL™ in larger studies.

4.2.4.4. Forest Plot of Child and Parent Scores with Other Measures

A forest plot was used to compare standardized mean differences (SMD) between child and parent scores across various HRQoL measures. The measures included the TNO-AZL Preschool Children Quality of Life (TAPQOL), Intermittent Exotropia Questionnaire (IXTQ), KIDSCREEN-27 Health-Related Quality of Life Questionnaire for Children and Adolescents (KIDSCREEN-27), KINDer Lebensqualitätsfragebogen (Children's Quality of Life Questionnaire) (KINDL), Oxford Ankle Foot Questionnaire (OxAFQ), Strengths and Difficulties Questionnaire (SDQ), and Children's Health Ratings Interview Schedule (CHRIs) (*Figure 4.4*). The analysis was conducted by extracting mean scores and standard deviations from included studies, calculating SMDs for each measure to facilitate comparison. This was done following the methodology outlined by Cochrane for standardized effect size estimation. However, no pooled effect size was presented in the forest plot. This omission was intentional, as the high heterogeneity in the included measures and populations precluded meaningful aggregation. Instead, the focus was on individual measure comparisons to provide insights into variability in alignment between child and parent perspectives.

Figure 4.4. Forest Plot for SMD for Child Versus Parent Scores Across Various Measures



Abbreviations: SMD **(**standardized mean difference)

Results showed varying patterns of agreement and disagreement between child and parent reports. Some studies, like Kaplan et al. (2022) (Kaplan et al., 2022) using CHRIs, found significantly higher parent scores (SMD -0.77 [-0.92, -0.62]), while others, such as Anmyr et al. (2012) (Anmyr et al., 2012) (SDQ) and Abood et al. (2021) (Abood et al., 2021) (OxAFQ), reported notably higher child scores. Several studies, including those by Grant et al. (2021) (Grant et al., 2021), Pereira et al. (2022) (Pereira et al., 2022), and Gothwal et al. (2018) (Gothwal et al., 2018), found no significant differences.

4.2.5. DISCUSSION

This systematic review and meta-analysis reveals significant variability in child-parent agreement on pediatric surgical QoL. The pooled effect size of 0.98 (95% CI: [-0.81, 2.77]) with high heterogeneity ($I^2 = 89\%$) indicates no consistent differences between child and parent reports. These findings highlight the complexity of assessing pediatric health outcomes and the need to consider both perspectives in clinical practice and research.

Furthermore, this analysis highlights significant challenges in the field, particularly the limitations of predominant cross-sectional study approaches. While our focus was on evaluating current measures, the reliance on cross-sectional data limits the ability to capture changes over time and provide a comprehensive view of patient experiences (Rabbitts et al., 2015). We did not detail study designs and timepoints due to variability and a focus on overall patterns of agreement between parent and child assessments. However, these factors may influence findings and warrant future exploration (Caruana et al., 2015). The lack of longitudinal data creates gaps in understanding long-term outcomes, timely interventions, treatment efficacy, and psychosocial adaptation, while also complicating patient counseling and health economic evaluations (Omahony et al., n.d.). Future research should prioritize longitudinal designs to track patients from pre-surgery through adolescence and adulthood.

The widespread use of validated measures in pediatric surgical QoL research has advanced standardization and comparability across studies. However, frequent discrepancies between parent and child reports highlight deeper complexities in QoL evaluation, reflecting fundamental differences in perception (Feng et al., 2023). Factors influencing these discrepancies include the child's developmental stage, condition visibility, and the parent's psychological state. Cultural influences and family dynamics further complicate the assessment (Oltean et al., 2022). These multidimensional factors emphasize the need to consider multiple perspectives and contextual influences to fully understand surgical outcomes and their impact on children's lives (Fong et al., 2021).

The mixed conclusions in 32% of the studies reflect the complex and multidimensional nature of QoL assessment in pediatric surgical research. This variability highlights the differential impacts of surgery across physical, emotional, and social domains, where improvements in one area may coincide with challenges in others, such as altered body image or

disrupted peer relationships (*Surgical Outcomes*, 2020). Factors like the child's age, developmental stage, family dynamics, and type of surgery further influence outcomes (Maguire & Parkes, 1998). Additionally, the timing of recovery adds complexity, as changes in one domain may occur before or after others (Kuranova et al., 2020). This highlights the need for an assessment framework that captures these nuances, potentially through domain-specific and longitudinal measures.

The reliance on parent proxy reports in pediatric surgical QoL research presents methodological challenges that require careful consideration. While useful for younger children or those with cognitive impairments, proxy reports introduce biases influenced by parental stress, anxiety, and health beliefs, which can affect the validity of findings (Meinzer et al., 2020). Agreement tends to be better for observable aspects, like physical symptoms, but discrepancies are more common for emotional and social dimensions (Rabbitts et al., 2015). The child's age and communication abilities further modulate report accuracy, while evolving parent-child communication adds temporal complexity (Vaughan et al., 2013). These factors underscore the need to approach proxy reports critically and consider supplementing them with observational measures, clinician assessments, or age-appropriate self-report tools (Clark et al., 2023).

The recommendation to combine parent reports with observational methods marks an important step toward a more comprehensive assessment of pediatric QoL. This multi-informant approach leverages the strengths of different data sources: parent reports provide valuable insights into daily experiences, while observational methods offer objective data on interactions and behaviors in natural settings, capturing non-verbal cues and context-specific behaviors that questionnaires may miss (Eiser & Morse, 2001a). This is especially important for assessing less tangible aspects like emotional and social functioning (Oltean et al., 2022). Observational data can validate and contextualize parent reports, revealing consistencies and discrepancies that guide targeted interventions (Flameling & Mesman, 2022). However, environmental factors, such as the hospital setting, must be considered as they may influence behavior and report accuracy (Sawyer et al., 2023). Combining these methods enables a more robust assessment that considers multiple facets of a child's QoL.

The finding that only 23% of studies show parent-child agreement in QoL assessments highlights the complexity of proxy reporting in pediatric surgical research. Higher concordance

in older children may be due to their better cognitive and communication skills, while increased agreement in less severe conditions could reflect reduced parental anxiety and more observable impacts on daily functioning (O'Connor et al., 2020). However, assessing QoL in younger children or those with complex conditions remains challenging. Agreement varies across different populations and clinical contexts, often being higher for physical symptoms than emotional or social aspects (Verdugo et al., 2021). Factors such as social desirability bias, the child's developmental stage, and cultural background can influence responses (Lara et al., 2021). These findings emphasize the need for tailored QoL assessments, age-appropriate self-report measures, and caution in interpreting proxy reports in clinical decision-making.

4.2.5.1. Meta-Analysis

The meta-analysis results *(Figure 4.3)* on parent-child agreement in HRQoL assessments following pediatric surgery reveal a complex picture that warrants deeper examination. The overall mean difference of 0.98 (95% CI: -0.81 to 2.77) between child and parent PedsQL™ scores, while not statistically significant, masks substantial variability across studies as evidenced by the high heterogeneity ($I^2 = 89\%$). This heterogeneity reflects the multidimensional nature of HRQoL perceptions in pediatric surgical contexts. The divergent findings across studies highlight how parent-child agreement can be influenced by factors such as the type of surgery, cultural context, and specific domains of HRQoL being assessed. For instance, the significant negative differences reported by Abassi et al. (2020) (Abassi et al., 2020) and Alonso et al. (2010) (Alonso et al., 2010) suggest that, in some post-surgical scenarios, parents may underestimate their children's QoL. A significant negative difference means that parents' assessments are lower than the children's self-reports. This discrepancy may arise due to heightened concern or lingering anxiety about the surgical intervention, which could lead parents to perceive their child's QoL as worse than the child does themselves. Conversely, the findings of Kljajic et al. (2023) (Kljajić et al., 2023) of parents overestimating HRQoL after neurosurgery could indicate parental relief or optimism following a high-risk procedure. The minimal differences observed by Kikuchi et al. (2018) (Kikuchi et al., 2018) in a single-center study point to the potential for close parent-child alignment in certain controlled settings. Grant et al. (2021) (Grant et al., 2021) presented mixed results across multiple measures and international contexts that emphasize the impact of cultural and methodological factors on HRQoL assessments. These

varied outcomes emphasize the need to consider factors such as the nature of the surgery, recovery trajectory, family dynamics, and cultural background in interpreting parent-proxy reports in pediatric surgical research. The findings also highlight the importance of incorporating both child self-reports and parent-proxy reports in HRQoL assessments to capture a complete picture of post-surgical outcomes and inform tailored interventions and support for pediatric patients and their families.

4.2.5.2. Sub-group Analysis

The sub-group analysis in this meta-analysis reveals a complex interplay of factors contributing to the heterogeneity observed in parent-child agreement on HRQoL assessments following pediatric surgery. The distinction between small (sample size <100) and large studies (sample size ≥100) is particularly important, as it reveals how sample size can influence effect sizes and potentially mask underlying patterns. This phenomenon, where opposing directions in effect sizes between subgroups lead to a non-significant overall effect in a random-effects model, emphasizes the importance of careful interpretation of aggregated data (*Chapter 10: Analysing Data and Undertaking Meta-Analyses*, n.d.). It suggests that the relationship between parent and child reports may be context-dependent, varying based on factors such as study design, patient population, or surgical procedure type (Kolaski et al., 2023). The variability in study quality further complicates the picture, with each methodology presenting its own set of strengths and weaknesses. This diversity in research approaches, while challenging for meta-analysis, reflects the multidimensional nature of HRQoL assessment in pediatric surgery. The forest plots *(Figure 4.4)* for various measures demonstrate substantial variability in child-parent report alignment, with high heterogeneity persisting across different assessment tools. This consistency in inconsistency suggests that the discrepancies between child and parent reports are not merely artifacts of specific measurement instruments, but reflect rather fundamental differences in perception or experience. The lack of a statistically significant pooled effect size in both analyses *(Figure 4.3 & Figure 4.4)* reinforces the notion that these discrepancies are not uniform or predictable across studies. These findings collectively emphasize the critical importance of incorporating both child and parent perspectives in pediatric health outcomes assessment. They highlight the potential limitations of relying solely on either child self-reports or parent proxy

reports and emphasize the value of a multi-informant approach. Moreover, these results point to the need for ongoing refinement of research methodologies in this field.

4.2.5.3. Limitations

This review has several limitations that impact the interpretation and generalizability of its findings. First, the methodological quality of the included studies varied, with many lacking robust designs or sufficient methodological rigor. The predominance of cross-sectional and single-center post-operative studies limits the ability to draw causal inferences or generalize results across diverse populations. The infrequent use of advanced statistical techniques, such as regression methods to explore between-study heterogeneity, further complicates the interpretation of pooled estimates and diminishes the clarity of conclusions regarding factors influencing QoL outcomes.

Additionally, incomplete reporting within the included studies posed challenges. Key details about study settings, design characteristics, and participant demographics were often inadequately summarized, making it difficult to assess the contextual relevance of the findings. This inconsistency in reporting may reduce the applicability of the results to diverse pediatric surgical populations and care settings.

The complexity of interpreting QoL data was further highlighted by discrepancies in reported outcomes, with 32% of studies presenting mixed conclusions. These inconsistencies may arise from methodological differences in the design and execution of QoL assessments, including variations in the tools used, timing of assessments, and the populations studied.

Moreover, the review's inclusion criteria introduced additional limitations. By focusing exclusively on studies that used PROMs and/or PREMs to evaluate self- and proxy-reported health status and compare child and parent perspectives, the review may have excluded studies employing other methodologies or focusing on non-surgical interventions that could provide valuable contextual insights. Similarly, excluding studies solely focused on instrument validation, development, or translation likely limited the scope of findings to a subset of relevant research.

These methodological limitations affect the interpretation and applicability of the findings to the broader pediatric surgical population. They underscore the need for future reviews to address gaps in methodological quality by including longitudinal, multicenter studies with

diverse participant demographics and improved reporting standards. Expanding inclusion criteria to consider a wider range of methodologies and perspectives could enrich the synthesis of evidence and enhance the understanding of pediatric QoL in surgical contexts.

4.2.6. CONCLUSION

This systematic review and meta-analysis revealed high heterogeneity in comparisons between various measures and PedsQL™-specific studies, indicating substantial variability in results. Neither approach showed a statistically significant pooled effect size under the random effects model, suggesting no strong evidence of systematic differences between child and parent reports in pediatric health outcomes assessment. These findings highlight the complexity of interpreting child and parent reports in both PROMs and PREMs.

It is critical to recognize that PROMs and PREMs assess different aspects of health care. PROMs typically focus on the outcomes of health interventions from the patient's perspective, such as symptoms and functional status. In contrast, PREMs assess the patient's experience with the health care process, including aspects such as communication, satisfaction, and care environment. The observed variability in results might be influenced by these fundamental differences.

While both types of measures are valuable, they serve different purposes and may capture different dimensions of health and care experiences. The inconsistency across different measures emphasize the importance of distinguishing between PROMs and PREMs when interpreting findings and integrating them into clinical practice. Future research should aim to better understand how discrepancies between child and parent reports manifest specifically in PROMs versus PREMs, and develop strategies to effectively incorporate both perspectives into a comprehensive assessment of pediatric health outcomes.

BRIDGING TEXT: INTEGRATING CONTRIBUTIONS TO PEDIATRIC SURGICAL OUTCOME ASSESSMENT

The first manuscript, "*Child- and Proxy-Reported Differences in Patient-Reported Outcome and Experience Measures in Pediatric Surgery: Systematic Review and Meta-Analysis*," investigates discrepancies between child and parent reports on health outcomes and treatment experiences in pediatric surgery. This analysis reveals significant differences in perceptions of HRQoL and surgical experiences, emphasizing the challenges clinicians face when relying solely on proxy reports. The review highlights that parents often either underestimate or overestimate their child's health and QoL, underscoring the necessity of incorporating direct child input to achieve a more accurate assessment of the child's well-being. This approach is critical given that HRQoL encompasses physical, emotional, and social dimensions, which may be overlooked if only parental reports are considered. The meta-analysis confirms substantial variability in agreement between child and parent reports, influenced by factors such as study size and context.

Building on these insights, the second manuscript, "*Adaptation, Translation, and Validation of a Patient-Reported Experience Measure for Children and Young People for the Canadian Context*," addresses the practical application of the findings by focusing on the adaptation and validation of a PREM tailored for the Canadian pediatric outpatient setting. This manuscript aims to enhance the accuracy and reliability of capturing children's healthcare experiences by ensuring that these measures are culturally and contextually relevant for Canadian children.

The overarching goal of this thesis is to evaluate and improve how pediatric surgical care is assessed through existing measures. This involves determining whether current PROMs and PREMs adequately reflect the priorities of patients and their families, considering factors like developmental stage and surgical context. By identifying gaps and suggesting improvements, the thesis aims to enhance the relevance and sensitivity of these measures within the Canadian context.

In summary, the first manuscript explores the complexities of pediatric surgical outcome assessment, particularly the variability in agreement between child and proxy (parent or caregiver) perspectives. It highlights how children's self-reported health outcomes and surgical

experiences, assessed through PROMs, PREMs, and HRQoL measures, often differ from parental assessments. For example, parents may underestimate emotional distress or overestimate physical recovery, emphasizing the need to integrate both perspectives to capture a comprehensive view of the child's well-being.

These findings inform the second manuscript's focus on adapting PREMs to ensure cultural and contextual relevance for Canadian children and families. Together, these manuscripts provide evidence to support enhancing patient- and family-centered care in pediatric surgical settings. By addressing gaps in assessment methods and emphasizing the inclusion of children's voices alongside those of their families, this work contributes to improving clinical practices and outcomes in pediatric healthcare.

5. CANADIAN ADAPTATION AND VALIDATION OF A PEDIATRIC PATIENT-REPORTED EXPERIENCE MEASURE

5.1. CONTEXTUAL OVERVIEW

PCC is essential in pediatric healthcare, emphasizing the quality of direct interactions between staff and patients. It seeks to tailor care to individual needs and preferences, enhancing the overall care experience. PREMs, on the other hand, are instrumental in evaluating healthcare quality from the patient's perspective. While PREMs can provide valuable insights into individual experiences, their primary use is often at a more collective level to assess and improve healthcare services broadly. Although PREMs can gather feedback on specific encounters and inform future care planning, their main function is to offer a broader view of service quality and patient satisfaction. This distinction highlights the importance of using PREMs to complement PCC by providing a systematic understanding of care experiences.

Despite their importance, there is a notable lack of PREMs specifically designed for children in North America, leading to a gap in understanding their healthcare experiences. This gap stems not only from the limited availability of child-specific PREMs but also from a shortage of research on their use and effectiveness. Addressing these gaps requires adapting, translating, and linguistically validating existing PREMs, as was done in this study with a measure originally developed at Great Ormond Street Hospital for Children (GOSH) in London for the Canadian context. This process includes cultural adaptation and linguistic validation to ensure the measure's relevance and effectiveness.

Linguistic and cultural adaptation of questionnaires is critical, even between regions that share the same language, such as British and Canadian English. Variations in vocabulary, idiomatic expressions, healthcare terminology, and cultural nuances can affect the clarity, relevance, and interpretability of questionnaire items. For example, words or phrases commonly used in British English may not resonate with Canadian respondents or could lead to misinterpretation. Additionally, healthcare systems, practices, and patient expectations differ between countries, requiring cultural adaptation to ensure that questions accurately reflect the experiences and priorities of the target population. Without these adjustments, the validity and reliability of the questionnaire's results may be compromised.

The significance of this work lies in providing a culturally appropriate measure that accurately reflects the healthcare experiences of children in Canada. By systematically collecting and analyzing patient feedback, this adapted PREM provides healthcare providers with detailed insights into various domains, including communication with healthcare providers, quality of care, coordination of care, and overall satisfaction. These insights are essential for understanding and improving the quality of care from the patient's perspective. Moreover, involving children in the adaptation process ensures that their perspectives are central to the measure, enhancing its validity and empowering young patients to contribute to healthcare improvement. This Canadian PREM will serve as a standardized tool for assessing and improving PCC in pediatric settings, driving quality initiatives and informing policy decisions.

5.2 ADAPTATION, TRANSLATION, AND VALIDATION OF A PATIENT-REPORTED EXPERIENCE MEASURE FOR CHILDREN AND YOUNG PEOPLE FOR THE CANADIAN CONTEXT

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- Critical Revision: Zanib Nafees, Julia Ferreira, Elena Guadagno, Jo Wray, Agneta Anderzén-Carlsson, Dan Poenaru

This study was presented at the 2023 Canadian Association of Pediatric Surgeons (CAPS) conference, where it received the Best Bilingualism Award. The manuscript is categorized as an original article and has been published in the *Journal of Pediatric Surgery*. There is no previous communication on this topic. The authors declare no conflicts of interest. This research did not receive specific grants from public, commercial, or not-for-profit funding agencies.

5.2.1. ABSTRACT

Patient-reported experience measures (PREMs) evaluate children's and young people's (CYP) perceptions of care. An important PREM developed *with* and *for* children was created in London, UK. Given the absence of similar North American instruments, we aimed to adapt, translate, and linguistically validate this instrument for use in a Canadian pediatric outpatient setting.

A qualitative design was used, involving CYP and their parents/caregivers. Phase 1 entailed the English survey adaptation using think-aloud testing, revision, and cognitive testing. Phase 2 involved translation into French, revision and back-translation, and cognitive testing. Phase 3 encompassed a cross-validation of the English and French versions of the adapted instrument.

Fifty-five children in 3 age groups (8-11y, 12-13y, 14-16y) participated in creating the Canadian PREM. In Phases 1 and 2, 41 children participated in reviewing and updating specific questions in the instrument, resulting in adjustments and revisions based on their feedback. In Phase 3, 14 bilingual children linguistically validated the PREM instrument.

This study reports the development of the first Canadian PREM specifically tailored to children. By incorporating the perspectives and preferences of CYP in clinical practice, this approach has the potential to amplify the delivery of patient-centered care for this vulnerable population and ensure that the needs and voices of CYP are acknowledged.

5.2.2. INTRODUCTION

Patient-reported experience (PRE) is an essential element of patient-centered care, frequently evaluated using Patient-Reported Experience Measures (PREMs) (Kingsley & Patel, 2017). PREMs quantify various aspects of the patient's encounters with healthcare services, including communication, respect, care quality, shared decision-making (SDM), and hospital environment perceptions (Morton et al., 2020).

PREMs significance extends to public reporting, benchmarking of institutions, and healthcare planning (Bull et al., 2019). PREM data can also assist practitioners in improving their patients' experiences (De Rosis et al., 2020). More importantly, these instruments encourage patients to reflect on all aspects of their care, providing them with a critical role in the organizational design, management, and policymaking of healthcare services (Bull et al., 2019).

While satisfaction ratings assess whether the care fulfilled patients' expectations, PREMs capture "what" happened during an episode of care and "how" it happened, providing a more comprehensive understanding of the care received (Bele et al., 2021; J. Ferreira et al., 2023). PREMs introduce objectivity by standardizing data collection on healthcare experiences (Shunmuga Sundaram et al., 2022).

Despite the utility of PREs, their use is still limited. In pediatric surgery, PREMs are yet to be used, being typically substituted by satisfaction surveys (J. Ferreira et al., 2023). Efforts are needed to effectively develop and implement PREMs in pediatric surgical care. However, developing PREMs is complex. It requires proper modeling, content generation with patient engagement, correct scaling and testing, and psychometric evaluation (J. Ferreira et al., 2023). Additional challenges arise from resource constraints, such as time, finances, and electronic data collection tools, as well as the imperative of staff training and sustainable resource utilization.

Few PREMs target the pediatric population. To date, only one PREM has been developed *for* and *with* children and young people (CYP). Created at the Great Ormond Street Hospital for Children (GOSH), London, England, this well-designed instrument focuses on child-relevant aspects of the hospital environment, communication, and overall experience (Halleran et al., 2019; Wray & Oldham, 2019b).

In the absence of a PREM that has been developed for use in Canadian settings and in the face of PREM developmental challenges, the aim of this study was to adapt, translate, and linguistically validate the GOSH instrument for use in pediatric outpatient settings in Canada, including surgical patients.

5.2.3. METHODS

5.2.3.1. Study Design

A three-phase qualitative research design was employed, involving the adaptation, translation, and face and linguistic validation of the GOSH PREM instrument for diverse Canadian settings. The study took place at the pediatric surgery outpatient clinic of MCH at McGill University Health Centre in Montreal, Quebec, Canada, approved by the McGill University Health Center Research Ethics Board (2023-8958).

5.2.3.2. Instruments

Our research is based on the outpatient GOSH PREM tools, specifically designed for age groups 8-11, 12-13, and 14-16 years, out of the total set of six GOSH PREM tools (three for inpatient and three for outpatient experiences). The GOSH PREM tool consists of 31 questions for outpatients aged 8-11, 37 questions for those aged 12-13, and 38 questions for those aged 14-16 (Wray et al., 2018). These tools use a Likert scale to assess various aspects of patient experience, such as communication with healthcare providers, coordination of care, and overall satisfaction. Responses are typically scored on a scale from 1 (poor) to 5 (excellent), with higher scores indicating more favorable experiences. The overall score for each tool is often calculated as a sum or mean of the individual item scores, providing an overall assessment of the patient's healthcare experience.

Permission from the lead author of the original questionnaire (JW) was granted to adapt, translate, and linguistically validate the GOSH PREM for use in this study. In order to distinguish between the two instruments, the original GOSH PREM developed in England will be referred to as PREM-UK, while the modified version generated through this study will be denoted as PREM-MTL.

As part of the linguistic and cultural adaptation process, some items may have been excluded or modified to ensure clarity and cultural relevance. While these changes could impact

the number of items and the overall structure of the questionnaire, they do not fundamentally alter the scoring procedure. The modified PREM-MTL continues to use the same Likert scale and summation approach for scoring, ensuring that the integrity of the scoring system is maintained. However, any excluded items were carefully reviewed to ensure that their omission would not distort the overall evaluation of patient experience.

A self-completed instrument, the Face Validation Form QQ-10 (Moores et al., 2012) was used to measure the face validity, feasibility, and utility of the PREM-MTL instrument. The Face Validation Form QQ-10 is a 10-item instrument (Radley et al., 2006) that has been shown to be a valid and reliable measure of assessing patients' views on health-related quality of life (HRQoL), serving as a standardized assessment of face validity and utility of other healthcare instruments (Moores et al., 2012). We modified QQ-10 (Moores et al., 2012) by removing three questions irrelevant to CYP. Adapted questions (*Supplementary File 5.1*) 1-3 and 6-7 were utilized to evaluate the *value score*, which encompasses positive aspects of the questionnaire such as ease of completion, enjoyment, willingness to complete it as part of routine care, inclusion of relevant concerns about the condition, and relevance to the condition. Conversely, questions 4 and 5 were used to determine the *burden score*, as they focused on negative aspects, including the perceived length and complexity of the questionnaire.

5.2.3.3. Study Procedures

Potential participants, both CYP and their parents from the pediatric surgery clinic, were recruited by a clinical team member after expressing their willingness to participate. Information about the study was provided to parents, and children received a pamphlet explaining the significance of their hospital experience. Written informed consent was obtained from recruited parents and children, who were compensated with a $20 voucher for their participation.

We aimed to include approximately 2-3 CYP every week from each of the age groups (8-11, 12-13, 14-16 years of age). In Phases 1 and 3, the aim was to include 4-5 CYP participants in each age group, following the guidelines from the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN), which considers a sample size of 4-6 participants as sufficient (Adler et al., 2019; Gabes et al., 2021). Sessions were tailored to the age of the child, around 30 minutes or more, as recommended in the literature, and parents/caregivers remained nearby throughout to offer support and supervision (Adler et al., 2019).

A member of the research team was assigned to audio-record and take detailed notes during the sessions, which were later transcribed in Phases 1 and 2.

Demographic variables were collected, including the child's age, sex, and language(s) spoken at home. Other data collected included the children's written responses to individual PREM questions, assessing their meaning, clarity, relevance, suggested inclusion or exclusion, and perceived importance.

5.2.3.4. Study Population

The inclusion criteria for all three study phases were: 1. children between 8 -16 years of age; 2. no learning or cognitive disabilities related to reading, writing, and/or comprehension; and 3. fluency in written and spoken English for Phase 1, French for Phase 2, and both English and French for Phase 3. The study also involved the participation of parents/caregivers who had the role of assisting their children in reviewing the study instruments.

5.2.3.5. Phases of Study

5.2.3.5.1. Phase 1 - Local adaptation of the PREM-UK instrument

For this Phase, eligible English-speaking CYP were asked to assess different question subsets in terms of their comprehension and relevance.

Step 1 of Phase 1 involved a think-aloud exercise (Jaspers et al., 2004) with CYP across the three age groups, a process in which participants read aloud the English PREM-UK questions and were asked to voice their understanding and opinion of each question.

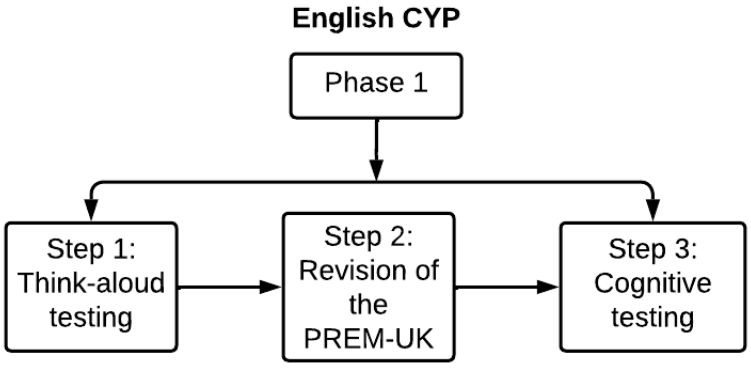
In Step 2, the instrument was revised by the research team based on the reflections and feedback received in Step 1.

In Step 3, cognitive testing was conducted with another set of CYP across the three age groups. To evaluate the CYP's understanding and proficiency in navigating the language and concepts used in the instrument, individual interviews were conducted either in-person or through Zoom (Wray et al., 2018). The assessment process comprised two parts: first, the child was provided with the revised PREM-UK instrument and instructed to answer a set of designated questions chosen by the researcher. Second, the child's responses and interpretations were carefully examined to gain insight into the understanding and comprehension of the instrument items (Alaimo et al., 1999). Detailed records of the children's answers, as well as any additional

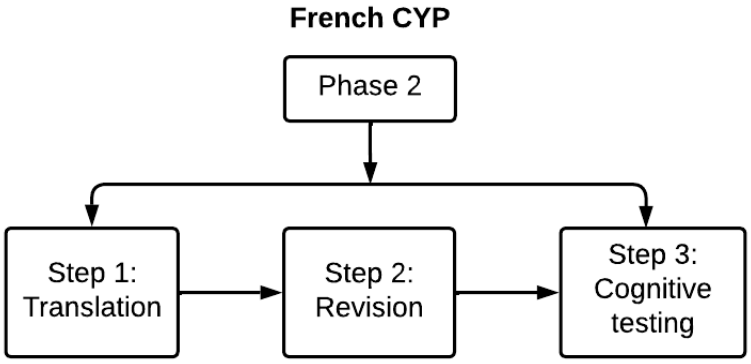
comments or feedback they provided, were recorded by the research team. *Figure 5.1* shows a summary of Phase 1.

Figure 5.1. The Three Study Phases

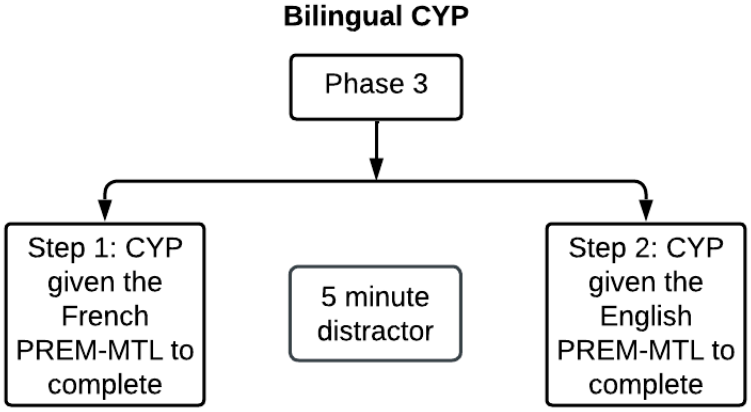
Phase 1



Phase 2



Phase 3



5.2.3.5.2. Phase 2 - Translating instrument from English to French

The process of translating the English-adapted instrument from Phase 1 into French involved several steps. The initial translation from English to French was carried out by the lead author (ZN). Following the initial translation, the translated version underwent two rounds of revisions by a Quebec Francophone patient partner to ensure its accuracy and clarity.

In Step 1 of Phase 2, eligible CYP whose first language/mother tongue was French were recruited and provided with the translated version for review. CYP provided feedback on their understanding and relevance of the questions; all their responses and comments were documented.

In Step 2, to further verify the accuracy of the translation, the French version was subjected to back-translation in England. The back-translation aimed to assess whether the translated version accurately reflected the meaning of the English version without altering its intended message. This included identifying discrepancies, potential issues with phrasing or terminology, and making necessary revisions to enhance clarity and accuracy. All revisions and feedback received were carefully documented (Olson, n.d.).

In Step 3, cognitive testing was conducted with CYP from the three age groups (8-11y, 12-13y, 14-16y). The methodology used in Phase 1, Step 3 was replicated for this step. The research team ensured that all the responses and comments provided by the CYP during the assessment were comprehensively documented (Alaimo et al., 1999). *Figure 5.1* shows a summary of Phase 2.

5.2.3.5.3. Phase 3 - Validating the instrument

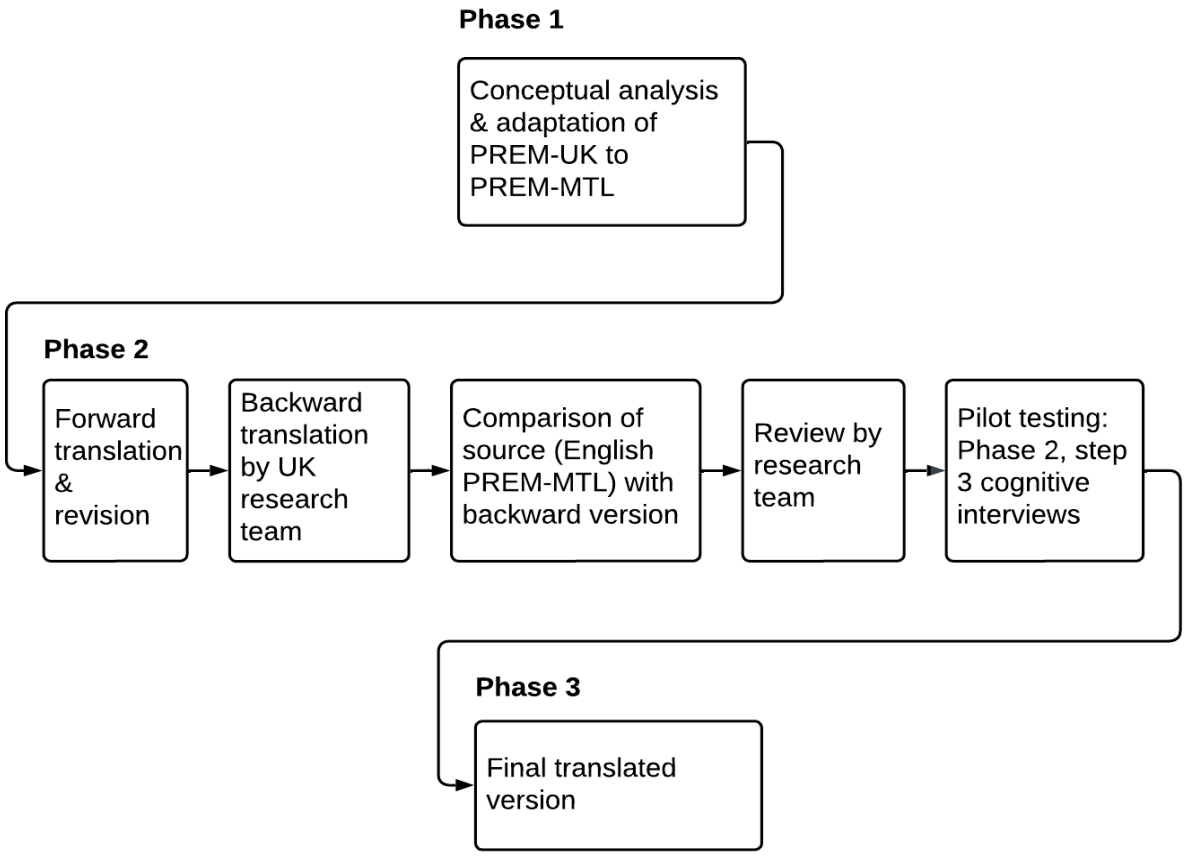
In Phase 3, a linguistic validation was carried out to evaluate the PREM-MTL instrument. This process was guided by the World Health Organization (WHO) Guidelines on Translation and Adaptation of Instruments, which provide a comprehensive framework for ensuring the rigor and consistency of linguistic and cultural adaptation processes. Following these guidelines, the adaptation process included forward translation, expert panel review, backward translation, pre-testing, and cognitive debriefing, ensuring that the instrument was both linguistically accurate and culturally appropriate.

In Step 1, bilingual CYP received the French PREM-MTL instrument and were given 10–20 minutes to complete and answer their age-respective instrument. To avoid recall bias, an

intentional 5–10-minute distractor (e.g., a game of their choice) was provided before the next step (Coughlin, 1990). In Step 2, the bilingual CYP were asked to complete the English PREM-MTL instrument. To mitigate bias, the test versions were administered in a different order, with the French version given first to some individuals and the English version given first to others.

To measure face validity, CYP also completed the Face Validation Form (Moores et al., 2012) to assess whether the PREM-MTL questions effectively probed the specific domains they were designed to evaluate (Tsang et al., 2017). By following the WHO guideline, the process ensured the instrument captured nuanced differences in language and cultural context, minimizing potential biases in responses and maximizing its applicability to the target population. *Figures 5.1* and *5.2* summarize the overall Phase 3 process and the linguistic validation steps, respectively.

Figure 5.2. Description of the Linguistic Validation Process



5.2.3.6. Data Analysis

The analysis of Phases 1 and 2 data focused on qualitative data collected on the PREM-MTL instrument. We used a qualitative coding approach (Chun Tie et al., 2019; J. Smith & Firth, 2011) to analyze the data, identifying patterns and themes. The coding process involved the identification of key concepts related to the hospital experiences of CYP (Chun Tie et al., 2019).

For face validity, the data collected from the Face Validation Form QQ-10 underwent analysis utilizing quantitative and qualitative approaches (Kagaari et al., 2017). As part of the qualitative approach, two questions were presented. The initial question inquired about feedback or recommendations to enhance the questionnaire's quality, including its structure, appearance, or design. The subsequent question was whether there was any additional input to provide (Moores et al., 2012).

5.2.3.7. Statistical Analysis

In Phase 3, intra-rater reliability was estimated using the Intraclass Correlation Coefficient (ICC) (Koo & Li, 2016). The ICC was calculated using mean squares, which estimate population variances based on the variability among a given set of measures obtained through analysis of variance (Koo & Li, 2016). A Two-Way Random-Effects Model was employed to calculate ICC, considering that CYP raters were randomly selected from a larger population with similar characteristics within the same age group (McGraw & Wong, 1996). The measurement protocol followed a single measurement approach, where $k = 1$ (single rater), and the absolute agreement was considered important (Koo & Li, 2016). There are no standard ICC reliability benchmarks, but the literature suggests that values below 0.5 indicate poor reliability, 0.5 - 0.75 moderate reliability, 0.75 - 0.9 good reliability, and above 0.90 excellent reliability (Bobak et al., 2018).

The quantitative analysis involved applying the QQ-10 scoring method, which entailed summing the Likert ratings (ranging from strongly disagree to strongly agree, coded as 0–4) separately for questions 1-3 and 6-7 to compute the value score (Moores et al., 2012). Additionally, the burden score was calculated by summing the Likert ratings for questions 4 and 5 (Gillett-Swan, 2018).

5.2.4. RESULTS

Overall, 52 CYP were included in our study during a nine-month period.

5.2.4.1. Phase 1

Fifteen think-aloud testing sessions (Step 1) were conducted in person, while nine out of 14 cognitive testing sessions (Step 3) were in person, and the remaining five were via Zoom. All approached patients in Phase 1 agreed to participate, totaling 29 children and young people (CYP) – 15 in think-aloud testing (7 females, 8 males) and 14 in cognitive testing (9 females, 5 males).

In think-aloud testing, 50% or more agreement rates led to the retention of 19 out of 21 items in the 14-16y age group, 16 out of 21 in the 12-13y group, and 12 out of 15 in the 8-11y group. Removal decisions were based on consensus, resulting in the deletion of specific questions for each age group (e.g., Questions 4 and 31 in the 14-16y group).

In cognitive testing, significant item changes were made by four out of seven in the 14-16y group, two out of three in the 12-13y group, and two out of four in the 8-11y group. *Table 5.1* reflects modifications based on received feedback during think-aloud testing. *Table 5.2* outlines item changes made during cognitive testing.

Table 5.1. Think-Aloud Testing (Phase 1, Step 1)

This table displays a selection of actual responses obtained from children and young people (CYP) during Think-Aloud Testing in Phase 1.

CYP Profile	**16 year old female**	**13 year old male**	**8 year old male**
Question	Q4: How long did you have to wait for your tests, or treatment and to see a doctor or nurse?	Q35: Which of these is the main language spoken at home?	Q3: How long did you have to wait?
CYP Sample Response	*"Well, I mean, not really for 14-16 years old, I don't think we really need anything to do. I mean, we all have electronics now too. So we don't really need stuff to do. So, yeah. No, I wouldn't include that."*	*"I speak English, French and Spanish. I think it's a good question."*	*"Today not so much, but other times I waited 12 hours. I think it's a good question."*
Analysis	3/7 CYP, 42.9% agreed to keep, this was lower than our 50% threshold so we discarded this question.	4/4 CYP, 100% agreed to keep, this was above the 50% threshold so we kept this question.	1/3 CYP, 33.3% agreed to keep, this was lower than our 50% threshold so we discarded this question.

Table 5.2. Cognitive Interviewing (Phase 1, Step 3)

This table displays a selection of actual responses obtained from children and young people (CYP) during Cognitive Testing in Phase 1.

CYP Profile	**10-year-old female**	**16-year-old female**	**11-year-old male**
Question	Q1 & 2: How nice were each of these places in the hospital? Clinic rooms?	Q23: Did the people working at the hospital do something about what you said if you needed them to?	Q2: Were there enough toys and activities for you in each of these places?
CYP Sample Response	*She did not understand the word clinic, so she suggested using a doctor's room instead.*	*Wanted to simplify it to "Did the people working at the hospital do something if you needed them to?"*	*Revised full (8–11-year-old) questionnaire and thought all the questions were very well done, except Question 2 since he was not looking for toys. It would be okay for younger kids. The father was actively involved in the child's participation, multiple times, the child would talk to the parent in an Asian language.*
Analysis	This change has been implemented.	Taken into account by rewording question	This suggestion was not implemented because it was the only unique one, and all other children either preferred the existing wording or had no comments, so no changes were made to the question.

5.2.4.2. Phase 2

All patients approached for Phase 2 agreed to participate, totaling 12 children and young people (CYP) – eight females and four males. Among five aged 14-16 years, two suggested changes, while none of the three aged 12-13 years proposed modifications. In the 8-11 age group, one out of four children suggested changes. Seven out of the 12 cognitive testing sessions were conducted on Zoom, with the remaining five in person.

5.2.4.3. Phase 3

In this phase, out of 29 patients approached, 14 agreed to participate, comprising five females and nine males. Thirteen of the 14 sessions were conducted on Zoom, with one in person.

Regarding the Face Validation Form (*Supplementary File 5.1*), seven participants gave no qualitative feedback, four answered both questions, and three provided partial responses. The seven rating questions, answered by all participants, resulted in an overall mean value score of 2.89 and a mean burden score of 1.46. Detailed breakdowns by question domains are presented in *Tables 5.3 and 5.4*, with *Figure 5.3* illustrating response distributions.

Table 5.3. Mean Value of Domains Contributing to the Value Score

This table presents the mean values of domains contributing to the Value Score for the Face Validation Form, QQ-10. The analysis is based on 14 responses across all age groups and focuses on questions 1-3 and 6-7 (*Supplementary File 5.1*).

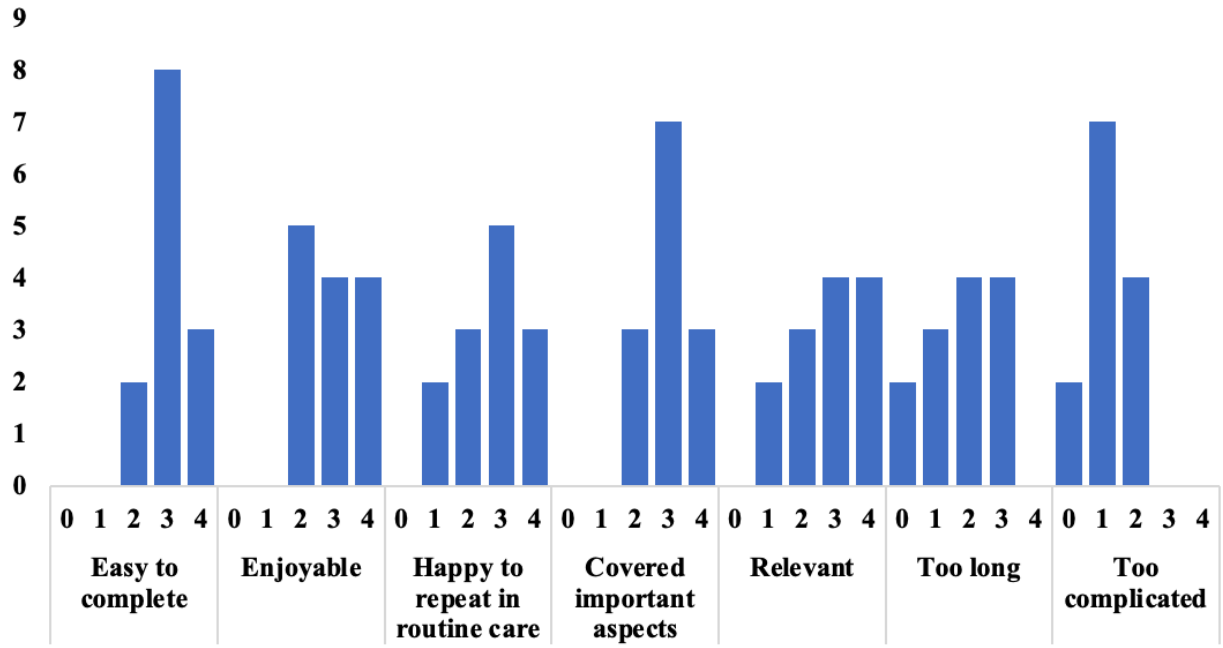
Question theme	Median score on the QQ-10 questionnaire
Easy to complete	3
Enjoyable	3
Happy to repeat in routine care	3
Covered important aspects	3
Relevant	3

Table 5.4. Mean Value of Domains Contributing to the Burden Score

This table presents the mean values of domains contributing to the Burden Score for the Face Validation Form, QQ-10. The analysis is based on 14 responses across all age groups and focuses on questions 4 and 5 (*Supplementary File 5.1*).

Question theme	Median score on the QQ-10 questionnaire
Too long	2
Too complicated	1

Figure 5.3. Frequency Distribution of Scores for All Three Age Groups for each Question in the Face Validation Form, QQ-10



This bar graph depicts the distribution of responses for each question. The y-axis indicates the frequency of children, while the sub x-axis ranges from 0 to 4, corresponding to the following response categories for the Face Validation Form:

4: Strongly agree

3: Mostly agree

2: Neither agree nor disagree

1: Mostly disagree

0: Strongly disagree

The graph reveals that 8 children selected the response "3" (Mostly agree), indicating that a majority of them found the PREM-MTL instrument "Easy to Complete."

Intra-rater reliability analysis showed good reliability for the 8-11y age group (ICC 0.77), moderate reliability for the 12-13y group (ICC 0.73), and good reliability for the 14-16y group (ICC 0.90). Specific question sets from the PREM-MTL instrument were used for ICC calculations, detailed in *Supplementary File 5.2*. Participant characteristics for all phases are in *Supplementary File 5.3*, and images of specific sections from the final PREM-MTL instrument for each age group are available in *Supplementary File 5.4*.

5.2.5. DISCUSSION

The primary objective of the present study was to adapt, translate, and linguistically validate the PREM-UK questionnaire for use in a Canadian pediatric outpatient setting. By undertaking this process, we created a modified version of the original instrument that maintains its core concept while accommodating Canada's cultural context. The comprehensive three-phase approach, incorporating a qualitative research design, allowed for iterative modifications and adjustments based on feedback from CYP.

During Phase 1, the PREM-UK instrument was adapted through think-aloud and cognitive testing. CYP active participation guided the process of adding or removing questions with no interference, and most of the items from the original PREM-UK instrument were retained. This approach allowed the adapted instrument to reflect the CYP experiences in the outpatient setting accurately and empowered them to directly impact the final version of the PREM-MTL.

Phase 2 involved the translation of the adapted instrument into French through several steps. These steps followed the WHO guidelines of forward translation, expert panel evaluation, back-translation, and cognitive interviews (Organization & Others, 2018). Recognizing patients as experts in their health and experiences, the first translated version was revised by a patient partner rather than the usual expert panel. Another important step of this phase was the independent back-translation performed in the UK to assess if the French Canadian version accurately reflected the meaning of the English version. Lastly, CYP provided feedback on the translated instrument and confirmed its comprehensibility and relevance. The meticulous translation process of Phase 2 helped ensure the fidelity of the translated instrument and maintain consistency between the English and French versions.

In Phase 3, the adapted instrument was cross-validated by bilingual CYP, who completed both the English and French versions of the PREM-MTL instrument. The focus shifted to assessing the reliability and validity of the instrument through face validation forms and post-survey feedback. There were varying levels of reliability from moderate to good across different age groups, with the highest reliability predictably observed in the older age group. Regarding face validation, the high mean value score and low burden score suggest that the questionnaire had good face validity and was well-accepted by patients.

Adapting and translating PREMs to diverse ethnic and cultural groups is essential, as a quick translation may not capture CYP unique priorities in their healthcare experiences (Ryberg et al., 2023). Furthermore, the adaptation of an existing and rigorously designed instrument to a new cultural context offers a more efficient and cost-effective approach than developing a new instrument, saving time and resources and further validating the existing instrument (Gjersing et al., 2010). Ryberg et al. and Nordlind et al. translated and culturally adapted the PREM-UK into Danish and Swedish, respectively, recognizing it as the gold standard for assessing CYP healthcare experiences (Nordlind et al., 2024; Ryberg et al., 2023). The successful adaptation, translation, and validation of the PREM-UK for use in pediatric outpatient settings in Canada and Denmark highlights the importance of tailoring PREMs to diverse cultural and linguistic contexts (De Rosis et al., 2020).

The overall impression of the PREM-MTL by the CYP was positive. The participants expressed comfort and ease while completing the PREM-MTL, indicating that the language and concepts used were appropriate for their age group. This affirmative feedback suggests that the PREM-MTL is a valuable instrument for assessing PREs in pediatric outpatient settings, mainly among pediatric surgical patients. The PREM-MTL stands as a pioneering effort, being the first PREM adapted with direct contributions from pediatric surgical patients. This innovative PREM can address significant knowledge gaps in understanding children's experiences after surgery and accelerate the shift from exclusive parental assessments to the inclusion of the unique and evolving perspectives of children. PRE assessments are critical for improving communication and detecting overlooked problems, ensuring better and individualized care. Moreover, the PREM-MTL has the potential to generate credible data for pediatric surgical services improvement, advancing patient-centered care in the field.

The present study aligns with recent publications emphasizing that CYP desire to actively participate, contribute, and share their experiences (Ryberg et al., 2023; Wray et al., 2018). During Phases 1 and 2, all CYP approached agreed to participate in this study and were highly engaged. The participants valued knowing that their opinions, rather than those of their parents', were being sought and heard. Given that CYP's healthcare experiences differ significantly from those of adults - due to challenges in expressing emotions, comprehending medical information, and engaging in their own care - it is imperative to adopt a tailored approach that recognizes their

developmental stage, communication abilities, and emotional well-being (Kwame & Petrucka, 2021).

This study has limitations. Firstly, the findings may be limited in their generalizability due to limited sample size and its focus on a particular pediatric outpatient facility within a single tertiary pediatric institution. The presence of a small sample size, particularly evident in phases 2 and 3 with only three participants in specific age groups, was primarily due to recruitment challenges. Further research in diverse healthcare settings is necessary to assess the applicability of the PREM-MTL instrument. Secondly, a few responses by CYP were conflicting - rendering the understanding of diverse perspectives challenging. Additionally, the lack of qualitative feedback from most participants on the Face Validation Form restricted our understanding of their perspectives. Nevertheless, the quantitative data from the rating questions were completed by all the CYP from Phase 3, and provided a measurable perspective of participants' experiences.

Future research should prioritize and amplify the voices of CYP, granting them a prominent role in shaping healthcare practices and policies. Involving CYP as co-researchers or advisors in the study design and data analysis process can ensure their perspectives are integrated from the outset, thereby enabling the potential transformation of service delivery based on feedback garnered from PREMs (Stover et al., 2021). Moreover, innovative approaches such as digital platforms, interactive workshops, or participatory arts-based methods can be employed to encourage CYP to express their thoughts, experiences, and preferences more creatively and authentically (OECD & World Health Organization, 2019). These methods offer opportunities for CYP to share their narratives, engage in dialogue, and contribute to decision-making processes in a manner that is accessible and engaging for them (Depla et al., 2023).

One of the most challenging aspects of the project was maintaining a balance between linguistic accuracy and preserving the emotional depth of patient responses. Literal translations often fell short in capturing the nuances of certain expressions or sentiments. To address this, investing time in pre-testing and validation with the target audience is recommended. Piloting the translated PREM with the community allows for feedback gathering and necessary adjustments, ultimately refining the instrument for its intended audience. Collaboration with the local community and healthcare professionals proved immensely beneficial. Their insights not only

guided the translation process but also fostered a sense of ownership and trust. Building strong partnerships with local stakeholders from the project's inception is advised. This not only aids in linguistic accuracy but also enhances the overall acceptance and relevance of the translated PREM.

In terms of patient participation, a transparent and respectful approach played a pivotal role. Explaining the survey's purpose, potential impact on healthcare improvements, and assuring anonymity were crucial factors that positively influenced patients' willingness to participate. Additionally, fair compensation for their time and insights contributed to a higher participation rate. While compensation should not be coercive, acknowledging and valuing the participants' contribution is essential. Reflecting on this experience, comprehensive training for the translation team is recommended. This includes linguistic training and cultural sensitivity sessions to foster a deeper understanding of the community's values and beliefs.

In summary, key considerations for those undertaking a similar project include navigating cultural nuances, balancing linguistic accuracy with emotional depth, fostering community partnerships, and adopting a transparent approach with participants. These elements can significantly enhance the effectiveness of translating and adapting patient-reported outcome measures.

5.2.5. CONCLUSION

In this study we successfully adapted, translated, and linguistically validated the PREM-UK instrument for use in a Canadian pediatric outpatient setting. The provision of the PREM-MTL instrument tailored specifically for CYP enhances patient-centered care and ensures that their perspectives and preferences are heard. The findings, while not immediately indicative of this progression, represent the initial stride towards this evolution. They contribute to enhancing healthcare practices through the promotion of patient engagement and the integration of PREMs to steer enhancements in healthcare quality.

BRIDGING TEXT: ADVANCING PEDIATRIC CARE THROUGH CONTEXTUAL AND INDIVIDUALIZED PATIENT-REPORTED MEASURES

The second manuscript, "*Adaptation, Translation, and Validation of a Patient-Reported Experience Measure for Children and Young People in the Canadian Context*," addresses a critical gap in North American healthcare tools by adapting a UK-developed PREM for Canadian children. This study highlights the importance of integrating children's voices in the design process to ensure that the adapted PREM accurately reflects their experiences and needs. The successful adaptation and linguistic validation of this PREM, involving contributions from diverse age groups and bilingual communities, paves the way for a healthcare system that better serves the unique linguistic and cultural landscape of Canada.

Building on the insights from this PREM adaptation, the third manuscript, "*Usability of the Pediatric Patient-Generated Index (pPGI) for Esophageal Atresia Follow-Up: Insights from Children and Clinicians*," explores the application of an individualized PROM within the specific context of EA follow-up. The pPGI allows children to identify and prioritize health domains that are most relevant to their well-being, offering a personalized perspective on health outcomes. This manuscript evaluates the pPGI alongside standard QoL measures like the EQ-5D-Y and PROMIS Short Form Life Satisfaction-8a, assessing its effectiveness in capturing the unique needs of pediatric patients post-EA repair.

The transition from adapting a context-specific PREM to evaluating an individualized PROM illustrates the thesis's broader goal of enhancing patient-centered care. The second manuscript establishes a foundation by ensuring PREMs are culturally relevant, while the third manuscript extends this work by focusing on the personalization of PROMs. Together, these manuscripts address the need for healthcare measures that reflect both overall experiences and individual patient concerns.

This thesis collectively advances patient-centered care in pediatric surgical settings by integrating context-specific and personalized measures. The research aims to evaluate whether current measures align with what matters most to children and families, adapt these measures to meet Canadian needs, and explore individualized tools that reflect each child's unique experiences. The combined findings contribute to improving clinical practices and outcomes,

ensuring that healthcare measures genuinely represent the priorities of children and their families.

6. EVALUATING AN INDIVIDUALIZED PATIENT-REPORTED OUTCOME MEASURE IN PEDIATRIC SURGERY

6.1. CONTEXTUAL OVERVIEW

In pediatric healthcare, particularly for complex conditions like EA, understanding and measuring patient experiences through PREMs and assessing QoL with PROMs are critical for delivering effective PCC.

Traditional PROMs have long been used to assess QoL, but they often rely on predetermined domains that may not fully capture the unique experiences of individual patients.

Recognizing this limitation, there has been a growing interest in developing more personalized assessment tools. The PGI represents an innovative approach in assessing QoL by allowing patients, including adults and children, to identify and prioritize the QoL domains most significant to their personal experience. This method empowers patients to focus on aspects of their well-being that they deem most important, rather than relying solely on predefined domains.

Similarly, the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) provides a framework that also emphasizes patient choice in defining QoL parameters (OBoyle et al., 1995). Like the PGI, the SEIQoL enables patients to select and evaluate the aspects of their lives that they consider important for their overall QoL, thus offering a more personalized and relevant measure of their health status.

Together, these approaches emphasize a shift towards more individualized assessment measures in healthcare, allowing for a nuanced understanding of patient experiences and ensuring that measures of QoL truly reflect what matters most to each individual.

Building on this concept, the pPGI was developed to bring this individualized approach to the pediatric population. This study represents a significant step forward in pediatric patient-reported measures by examining the usability and effectiveness of the pPGI in children who have undergone EA repair. By comparing the pPGI with standard QoL measures and exploring its usability among patients, parents, and clinicians, this research aims to evaluate the potential of this personalized tool in capturing the experiences of pediatric EA patients.

The findings of this study have important implications for how we assess and understand

the impact of complex conditions and their treatments on children's lives. It challenges us to reconsider our approach to measuring QoL in pediatric populations and opens new avenues for more PCC and outcomes assessment in pediatric surgery and beyond.

6.2. USABILITY OF THE PEDIATRIC PATIENT-GENERATED INDEX (pPGI) FOR ESOPHAGEAL ATRESIA FOLLOW-UP: INSIGHTS FROM CHILDREN AND CLINICIANS

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- Drafting of Manuscript: Zanib Nafees
- Critical Revision: Zanib Nafees, Julia Ferreira, Elena Guadagno, Nikki Ow, Nancy Mayo, Dan Poenaru

This study was presented at the Canadian Association of Pediatric Surgeons (CAPS) conference in September 2024 as part of a scientific session. The manuscript is categorized as an original article and has been submitted for publication in the *Journal of Pediatric Surgery*. There is no previous communication on this topic. The authors declare no conflicts of interest. This research received financial support from CIHR Project Grant #496021.

6.2.1. ABSTRACT

Unlike standard patient-reported outcome measures (PROMs) which assess preset quality of life (QoL) domains, the Patient-Generated Index (PGI) is an individualized PROM allowing patients to elicit their personal QoL domains. Here we assess the usability of the pediatric PGI (pPGI, a recent modified version of the adult PGI, *diagram*) alongside other standard measures of QoL in pediatric patients following esophageal atresia (EA) repair.

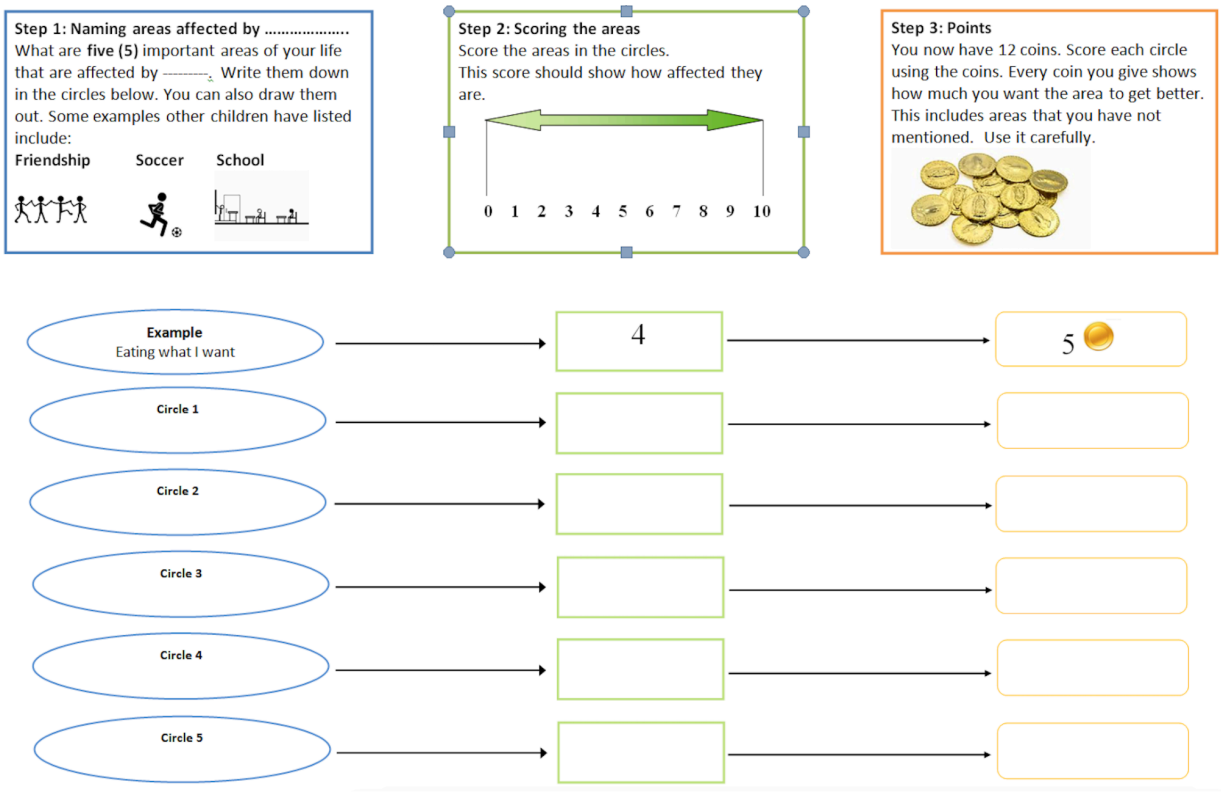
This cross-sectional study used directed and summative content analyses and 3 PROMs: pPGI, EuroQol-5D (Youth, EQ-5D-Y), and the pediatric Patient-Reported Outcome Measurement Information System (PROMIS) Short Form Life Satisfaction-8a-v1.0. Children (ages 0-17 years) with repaired EA completed all three measures. Cognitive interviews with children and their parents assessed pPGI completion experience, while interviews with clinicians explored optimal measures for EA outcomes.

Through 25 interviews of 45 child/parent dyads, the pPGI generated 104 text threads covering 9 unique impairments, 7 activity/participation limitations, 2 environmental factors, and 1 health factor. The most frequently mentioned domain was “looking after one’s health,” emphasizing health management. pPGI QoL scores differed from standardized measures, with correlations of $r = 0.33$ between the pPGI and EQ-5D-Y and $r = 0.19$ between the pPGI and PROMIS Short Form Life Satisfaction-8a-v1.0. The pPGI demonstrated construct validity, aligning with relevant disease-specific QoL measures. In 10 cognitive interviews, feedback on the pPGI was mostly positive: eight patients found it easy to use, but two had difficulty determining the severity of their condition. Three out of 6 clinicians preferred the pPGI over standard measures.

The pPGI effectively captures children’s post-esophageal atresia repair experiences, emphasizing patient-defined QoL domains. Early construct validity and positive feedback support the use of the pPGI in assessing children’s health-related QoL after surgery.

Abstract Diagram

Pediatric Patient-Generated Index



The Pediatric Patient-Generated Index is a self-reported measure that allows patients, including children, to identify and prioritize the specific areas of their life most impacted by their condition or disability. Patients nominate five important life areas, rate each on a scale from 0 to 10, and distribute 12 coins among them, generating an overall score from 0 to 100 that reflects the gap between their current reality and desired state.

This diagram was designed by our co-author Nikki Ow.

6.2.2. INTRODUCTION

Esophageal atresia (EA) significantly affects children's lives, bringing a range of challenges that differ for each person and change over time. EA survivors face multiple sequelae such as gastroesophageal reflux disease, respiratory and feeding difficulties, and growth and development concerns, frequently affecting their quality of life throughout the lifespan (Amin et al., 2018; Durkin et al., 2015; Stolwijk et al., 2016; Uecker et al., 2022).

Quality of life (QoL) assessments have an important role in understanding the overall impact of medical conditions such as EA on patients' physical, social, and psychological well-being (Carr et al., 2001). These assessments not only monitor changes or responses to therapy but also facilitate communication between patients and clinicians (Joyce et al., 1999). While most studies still prioritize medical outcomes, recent studies have focused on EA patients' QoL (Amin et al., 2018; Glinianaia et al., 2012; Jardine et al., 2014; Uecker et al., 2022), demonstrating that it is lower than that of their healthy peers (Dellenmark-Blom et al., 2020). This highlights the need to integrate patient-reported outcomes (PROs) alongside other clinical measures to fully understand the impact of EA and its treatment on children and their families (Capitanio et al., 2021). Moreover, assessing both child and parent perspectives is essential (Bradshaw et al., 2011; Gerharz et al., 2003; Theunissen et al., 1998), given the evidence that children's perception of their QoL often differs from that of their parents (Jardine et al., 2014), and fluctuates as they mature (Glinianaia et al., 2012). As a result, the children's voice, the "gold standard of PROs" (Leahy & Steineck, 2020), is rarely included in outcome studies and is absent following neonatal surgery (Besner et al., 2022a; Glinianaia et al., 2012).

PROs, including measures of health-related quality of life (HRQoL), are increasingly recognized as essential indicators of quality care (Weldring & Smith, 2013). PROs are any information on the outcomes of health care obtained directly from patients, without modification by clinicians or other health care professionals (Cella et al., 2015). PROs are evaluated using specific measures known as patient-reported outcomes measures (PROMs), (Besner et al., 2022a; Cella et al., 2015; Jardine et al., 2014) which enable clinicians to see the disease and treatment impact from the patients' perspective, fostering patient-centered care and shared decision-making (Damman et al., 2020).

Existing PROMs, both generic and disease-specific, are based on pre-selected areas of life ("domains") often chosen without systematic input from patients (Ow et al., 2022). Although these PROMs offer valuable insights, they inherently lack individualization, which limits their ability to fully capture the domains that matter most to individual patients (Ruta et al., 1994). Individualized PROMs, developed on the premise that the patients themselves are best positioned to evaluate their health condition, may address this gap (Joyce et al., 1999). These measures give patients the opportunity to list, rate, and weigh the specific domains of their lives that are most impacted by their condition (Ruta et al., 1994). The patient-generated index (PGI), initially developed for adults (Kuspinar et al., 2020; Mayo et al., 2017), has been recently adapted for pediatric use (pPGI) (Ow, n.d.).

The pPGI may identify important domains of children's lives affected by EA, rate how far from optimal these aspects of life are, and provide a weighing of the importance of possible improvement areas (Ruta et al., 1994). In addition, the pPGI may have overlapping domains with standard pediatric QoL measures, such as the self-report versions of the EuroQol-5D (Youth) (EQ-5D-Y) (Wille et al., 2010) and the pediatric Patient-Reported Outcome Measurement Information System (PROMIS) Short Form Life Satisfaction-8a-v1.0 (NIAMS, 2017). This overlap could offer a valuable opportunity to assess and enhance HRQoL in children (Wille et al., 2010).

In the current study we explore the QoL of children following EA repair using the pPGI alongside standard measures. The study aims to identify patient-valued life domains using the pPGI, compare them with existing QoL measures, and assess the pPGI's relevance and usability. Specifically, the study objectives are to: (i) identify areas of function and health that a sample of target respondents consider important to their QoL; (ii) identify the thought processes that target respondents use to complete the three steps of the pPGI; (iii) identify the extent to which existing measures of pediatric QoL reflect the content considered important by target respondents; and (iv) identify clinicians' perspectives on the usability of these measures for following up their patients.

6.2.3. METHODS

6.2.3.1. Study Design

The study used a cross-sectional, directed, and summative content analysis (Hsieh & Shannon, 2005) to achieve its specific objectives related to measuring the QoL in children (age 0–17 years) following EA repair. Directed content analysis is a method of qualitative research that uses existing theories as a guide (Hsieh & Shannon, 2005). In this study, we applied the International Classification of Functioning, Disability and Health (ICF) framework to identify impairments, limitations, and environmental factors from the domains identified by the pPGI tool. The ICF framework was chosen due to its comprehensive approach to understanding health and disability, capturing biological, functional, and environmental aspects relevant to children's QoL (McDougall et al., 2011). While the ICF includes personal factors as a component, these were not included in this analysis due to the limitations of the available data and the focus on measurable, universally applicable domains. Summative content analysis, which quantifies specific words to explore contextual use and interprets underlying meanings through a combination of manifest and latent content analysis (Hsieh & Shannon, 2005), was used to complement this approach. Using Voyant Tools (version 2024, Stéfan Sinclair & Geoffrey Rockwell, Voyant Consortium, 2024-12-02), we analyzed explicit and euphemistic terms related to the EA condition. This analysis aimed to uncover patterns, word frequencies, and thematic clusters, aligning these findings with patients' interpretations or expectations (Mayo et al., 2023).

The study took place in the pediatric surgery outpatient clinic of the Montreal Children Hospital (MCH) at McGill University Health Centre (MUHC) in Montreal, and was approved by the MUHC Research Ethics Board (#2023-8834).

6.2.3.2. Measures

The pPGI was modified from the adult PGI (F. Martin et al., 2007; Mayo et al., 2017; Ow, n.d.). The main differences between the adult and pediatric versions of the PGI lie in the approach to nomination and rating of affected life areas. The adult version allows for up to six nominated areas and uses a seven-point scale for severity ratings, while the pediatric version limits nominations to five areas and uses a simpler 0–10 scale. Both versions involve distributing points (replaced by coins in the pediatric instrument) among nominated areas to reflect priority for improvement. The pPGI involves identifying significant life areas impacted by the condition, assessing the severity of these impacts on a 10-point scale, and assigning priority weights to

areas where improvement is desired using tokens. A composite score is calculated based on the severity ratings and priority weights assigned to each area (diagram) (Ow, n.d.).

The relevant life areas identified through the pPGI were aligned with items from two generic, non-individualized, PROMs: the EQ-5D-Y (Wille et al., 2010) and the PROMIS Short Form Life Satisfaction-8a-v1.0 (NIAMS, 2017). The EQ-5D-Y measures health-related QoL across five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The questionnaire profiles the respondent's health state, while the EQ VAS provides a self-rating of overall health (Kreimeier & Greiner, 2019). The PROMIS Short Form Life Satisfaction-8a-v1.0 assesses various health-related domains, including physical function, anxiety, depression, fatigue, peer relationships, and pain interference (Wille et al., 2010). Scoring for the PROMIS Short Form Life Satisfaction-8a-v1.0 involves summing the scores across items within each domain, with higher scores indicating better health or functioning (NIAMS, 2017).

6.2.3.3. Study Procedures

Recruitment began by identifying eligible children through medical archives, with consultation to verify eligibility. Families were then contacted and briefed on the study, with an invitation to participate. Upon recruitment, the parents and children provided written informed consent, and all dyads received a $20 voucher as compensation for their involvement. The study lasted 12 months, from January 1, 2023 to December 31, 2023.

We recruited children who underwent surgery for EA in their first year of life between 2005 and 2022 at MCH. With an annual volume of 20 potential participants and an expected 60% recruitment rate (Arulanandam et al., 2022), we anticipated enrolling 12 participants per year. Additionally, a convenience sample of 6 pediatric specialist clinicians (including four pediatric surgeons, one anesthesiologist, and one kinesiologist) from MCH was individually interviewed on the usability of the three measures.

6.2.3.4. Study Population

Three distinct samples contributed data for this study: children aged 0–17 years diagnosed with EA and treated at the MCH between 2005 and 2022, a subset of whom participated in cognitive interviews alongside new patients and their parents, and clinicians who provided insights on the usability of the personalized pPGI tool. Families were initially contacted

by a clinical coordinator, who provided information about the study and assessed their interest in participating. For those who expressed interest, the researcher facilitated the distribution of surveys via email, which parents completed in collaboration with their children. For children below the age of 7, proxy reports from parents were used.

Parents completed surveys and participated in cognitive interviews for children under the age of 7 because younger children may lack the cognitive development and verbal skills necessary to understand and articulate complex health-related questions reliably. Children aged 8 years and older are generally considered capable of self-reporting HRQoL data, as they can better comprehend survey items and express their subjective experiences (Varni et al., 2007a). For children younger than this, parental proxies are a validated approach to capturing relevant health information, as parents are familiar with their child's behavior and well-being, particularly in clinical and everyday contexts (Eiser & Morse, 2001b). This approach ensures the collection of meaningful and representative data while accounting for the developmental limitations of younger participants.

The methods used to assess the usability of the pPGI tool among clinicians were guided by principles from the Technology Acceptance Model (TAM) and user-centered design frameworks (*Technology Acceptance Model - TheoryHub - Academic Theories Reviews for Research and T&L*, n.d.). These theoretical approaches emphasize understanding the perceived usefulness, ease of use, and relevance of a tool within a specific professional context. Clinicians were asked to evaluate the pPGI in terms of its clarity, applicability to clinical practice, and alignment with their workflow. Structured feedback sessions and targeted usability surveys were conducted to capture their insights. This process also incorporated aspects of formative evaluation, where clinicians provided iterative feedback on the tool, allowing for refinements based on their suggestions. These frameworks ensured that the assessment methods were systematically aligned with the goal of optimizing the pPGI's practical implementation and relevance in a clinical setting.

Interviews with parent-child dyads were chosen over individual interviews with children to ensure a comprehensive understanding of the child's experiences, particularly given the variability in children's age, cognitive abilities, and capacity to articulate complex health-related issues. Parents offered valuable contextual and developmental insights, particularly for younger

children or those less able to independently express their thoughts. This approach also helped to bridge any gaps in the child's recall or understanding, thereby enhancing the reliability of the collected data. While parental participation enriched the data by providing supplementary details and interpretations, it also introduced potential biases, such as parental perceptions overshadowing the child's subjective experiences. To mitigate this, the study ensured that survey responses and interview discussions prioritized the child's perspectives whenever possible, with parents acting primarily as facilitators or proxies in cases where direct input from the child was not feasible. Any ambiguities or inconsistencies were addressed through follow-up communication to ensure clarity and accuracy in the data collection process.

The study included children who had no learning or cognitive disabilities related to reading, writing, and/or comprehension, who underwent surgery for EA between 0-12 months of age at MCH from January 1, 2005, to December 31, 2022, along with their parents. Those excluded from the study were children transferred for follow-up elsewhere, children operated on after 12 months of age, those not operated on for EA, and individuals aged 18 years or older.

Clinicians were included if they had provided care for children with EA. Parents completed the surveys and cognitive interviews for children younger than seven years old.

The variables collected included demographic data (age and sex of the child, and diagnosis) along with individualized PROM data. This encompassed important domains of the children's lives impacted by their disease, the associated burden, and their desired improvements in these areas.

6.2.3.5. Phases of Study

6.2.3.5.1. Phase 1 - Identifying Key QoL Factors

In this phase, both children (aged 7 years or older) and their parents (acting as proxies for the younger children) independently completed the pPGI measure via emailed surveys. This approach recognized the importance of capturing complementary perspectives, acknowledging that agreement between self-report and parent proxy assessments is often limited (Eiser & Morse, 2001a; White-Koning et al., 2007).

6.2.3.5.2. Phase 2 - Assessing Alignment of Pediatric Quality of Life Measures

In this phase, we evaluated the alignment of various pediatric QoL measures, including the pPGI, EQ-5D-Y, and PROMIS Short Form Life Satisfaction-8a-v1.0. By comparing the results of these measures, we aimed to assess how well they captured the QoL experiences of children with EA.

6.2.3.5.3. Phase 3 - Cognitive Interviews in Completing pPGI Steps

In this phase, cognitive interviews were conducted to gain deeper insights into the process of completing the pPGI. Children aged 7 years and older answered the pPGI questions independently, while parents acted as proxies for children under 7 years of age. The cognitive interviews provided valuable feedback on how different age groups understand and interpret the pPGI steps. This approach helped identify any challenges or inconsistencies in how the pPGI was completed, offering a better understanding of its usability across various developmental stages.

6.2.3.5.4. Phase 4 - Evaluating Clinicians' Views on Measure Usability

We presented anonymized results of the pPGI, EQ-5D-Y, and PROMIS Short Form Life Satisfaction-8a-v1.0 to several clinicians who follow children with EA. The clinicians only knew the sex and age of the patients, without access to individual patient identities. We then solicited their preferences regarding which measure they found most effective for monitoring the QoL of children with EA. We presented patient ratings on the pPGI (0-10) and their distribution of 12 coins to the most severe domain they generated. For the EQ-5D-Y, we showed ratings on mobility, self-care, usual activities, pain/discomfort, and feelings, as well as their overall health score out of 100. For PROMIS Short Form Life Satisfaction-8a-v1.0, we presented the patient's life satisfaction ratings. Clinicians provided their preferred measure for assessing EA children's QoL, helping us understand the measures' clinical usability and relevance.

6.2.3.6. Data Analysis

In a first step, members of our team mapped the text threads from the pPGI to the ICF (Moriello et al., 2008) by using category coding. This matched areas identified in the pPGI to relevant ICF categories, focusing on functioning and health. Secondly, natural language processing was employed through Voyant Tools (Sampsel, 2018) to analyze the text threads. This

identified recurring words and themes within the pPGI responses, offering a more detailed exploration of the content provided by respondents. The expected end result of using Voyant Tools was to gain insights into the structure and content of the text corpus, including patterns, word frequencies, and thematic clusters (Mayo et al., 2023). These insights can lead to discovering new categories or confirming existing ones, and to see how these categories align with patients' interpretations or expectations (Hsieh & Shannon, 2005).

6.2.3.7. Statistical Analysis

pPGI QoL scores were plotted against QoL scores from the EQ-5D-Y and PROMIS Short Form Life Satisfaction-8a-v1.0 measures. Pearson's correlation coefficient was calculated to assess the strength and direction of the linear relationships between the pPGI and the other PROMs. Specifically, we compared the pPGI domains with corresponding items on the EQ-5D-Y and PROMIS Short Form Life Satisfaction-8a-v1.0 to determine how closely the measures aligned in capturing similar aspects of the patients' experiences and well-being. The coefficient of determination (R-squared) was used to quantify the proportion of variance in pPGI scores that can be explained by the other included measures (Barrett, 2000). Pearson's correlation coefficient ranges from -1 to +1, where values closer to +1 indicate a strong positive relationship, while R-squared ranges from 0 to 1, where 1 indicates that all variance in pPGI scores is explained by the other measures (Nevil, 2009).

6.2.4. RESULTS

6.2.4.1. Phase 1 - Key Quality of Life Factors

Twenty-five patients participated in the study, with a gender distribution of 16 males and 9 females. Their ages ranged from 3 to 17 years. Fifteen patients completed surveys in English and ten in French. The mean age of the children was 9.8 years.

The pPGI generated 104 distinct text threads from the 25 interviews, yielding 58 unique ICF codes categorized into impairments, activity limitations, participation restrictions, and environmental factors. *Table 6.1* displays these threads coded according to the ICF framework.

Table 6.2 outlines 19 themes identified using Voyant Tools, highlighting concerns such as allergies, appearance-related issues, fatigue (within the impairment category), and burden of care (within environmental factors). Activity-related themes emphasized the importance of physical

activities and self-care tasks, while social participation themes highlighted the significance of forming relationships. Health-related themes highlighted the impact of illness and stress, with stigma also playing a significant role. In *Table 6.3*, these themes are condensed into 7 systems affecting various bodily functions, including respiratory, musculoskeletal, gastrointestinal, and immune system concerns, as well as general issues such as fatigue and stress, alongside rehabilitation efforts and family support.

Table 6.1. Summary of Text Threads and Corresponding ICF Classifications

This table presents the text threads of children that are coded according to the ICF.

Text threads	ICF codes	Domain
-	**b**	**Bodily functions**
Fatigue	b1300	Energy and drive
Sleeping	b1348	Sleep functions, other specified
Separation anxiety (being away from parents at daycare), travel (anxiety of being sick when traveling), anxiety at doctor appointment	b152	Emotional functions
Social and emotional impact of scarring, such as bullying, self-consciousness, and potential effects on self-esteem, especially in visible situations like at the pool, wearing dresses without my back scar showing, taking photographs	b1801	Body image
Burning of the throat, headaches	b280	Pain
Back pain	b28013	Pain in back
Speech	b330	Fluency and rhythm of speech functions
Challenges and limitations posed by allergies (food, animals) and the increased susceptibility to illness, such as prolonged colds and seasonal allergies	b435	Immunological system functions
Coughing, including hard coughing, frequent coughing, and the desire for normal coughing without unusual sounds	b450	Respiratory function
Doing sports without being out of breath so often	b455	Exercise tolerance functions
Physical stamina/endurance	b4550	General physical endurance
Wheezing	b460	Cardiovascular and respiratory functions

Constant monitoring (reflux, fluid ingestion, etc.), meals: risk that food gets stuck	b510	Ingesting food
Gained more weight	b530	Weight maintenance functions
Upset stomach	b535	Sensations associated with the digestive system
-	**d**	**Activities and participation**
Challenges with daily medical routines (taking medication)	d230	Carrying out daily routine
Diminish stress	d240	Handling stress and other psychological demands
Managing school responsibilities while dealing with health appointments, explaining these differences to peers and teachers, and balancing studies with necessary time off	d2400	Handling responsibilities
Not being able to speak	d330	Speaking
Gross motor skills	d4	Mobility
Walking	d450	Walking
Activities – running	d4552	Running
Swimming	d4554	Swimming
Not being able to go far	d4602	Traveling long distances
Toileting	d530	Toileting
Eating habits and preferences, such as the ability to eat freely and quickly, meal timing, dietary restrictions, and the need for thickened liquids.	d550	Eating
Drink what I want	d560	Drinking
Frequency and discomfort of medical appointments and procedures (check-ups, surgeries, stool tests), the burden of taking daily medications, and the regular visits to hospitals for various medical needs	d570	Looking after one’s health

Concerns about the genetic risk of passing on conditions to future children and the potential for future health complications related to EA	d5702	Maintaining one's health
Feeling insecure and like an outsider due to different social expectations, facing rejection or feeling isolated in friendships or group settings, and struggling to connect with others who don't share similar behaviors or interests	d7200	Forming relationships
Limit to be respected, need for a lot of personal space (no hugs from friends)	d7204	Maintaining social space
Effect on family, (child) is a twin, takes time away from family, he didn't have mom	d760	Family relationships
Playing with a musical instrument	d920	Recreation and leisure
Engaging in physical movement through dancing and playing sports, and seeking ways to boost energy levels to enjoy these activities to the fullest	d9201	Sports
Going out with friends	d9205	Socializing
-	**e**	**Environmental factors**
Food	e1100	Food
Brace at night for scoliosis	e115	Products and technology for personal use in daily living
Medical procedures (blood tests, endoscopies, x-rays), tracheostomy	e580	Health services, systems and policies
Asthma, scoliosis	hc	ICD
Recovering faster when I'm sick, not being able to be alone, school: autonomy next year, tracheostomy	nc	

Abbreviations: ICF **(**International Classification of Functioning, Disability and Health), hc (Health Condition), ICD (International Classification of Diseases), nc (Not Clear)

Table 6.2. Text Analysis: Themes and Occurrences

This table provides outlines of various themes extracted from text threads, each accompanied by the number of occurrences and their corresponding classification under the ICF.

Content (theme)	Text Thread (*n* occurrences)	ICF
Allergies	Allergies (4)	Impairment
Appearance	Scar (3), Gained weight (1)	Impairment
Breathing	Cough (3), Wheezing (1), Asthma (1)	Impairment
Burden of care	Dislike blood tests (1), Medical appointments (6), Stool tests (1), Surgery (1), Taking medications (2), Waiting list for surgery (2), X- rays (1), Endoscopy (2), Wearing Brace for Scoliosis (1), Not being able to speak (1), Gross motor skills (1), Health: risk that other problems linked to EA will appear in the future (1)	Environment
Eat	Eating (11), Food (1)	Impairment
Fatigue	Fatigue (2), Stamina (1)	Impairment
Forming relationships	Friendship (6), Need for a lot of personal space (no hugs from friends, anxiety at doctor appointment) (1), Not being able to be alone (1)	Participation
Illness	Sick (2), Upset stomach (1), Scoliosis (1), Tracheostomy (1)	Health
Impact on family	Family (1), Outbursts (1)	Participation
Pain	Headache (1), Back pain (1), Throat burning (1)	Impairment
Physical activities	Walking (1), Running (3), Sports (4), Swimming (3), Taking photographs (1), Not being able to go far (1), Dancing (1), Playing with a musical instrument (1)	Activity
Reflux	Reflux (4)	Impairment
Self-esteem	Bullying: risk that other kids will make fun of his scar (1), Self-esteem: risk that he will be self-conscious about his scar (1), Not being like others (1), School: autonomy next year (1)	Participation
Self-care	Toileting (1)	Activity
Sleep	Sleeping (1)	Activity

Stigma	Limit to be respected (1), Genetics: risk that his future kids will have the same or similar conditions (1), Feeling insecure and like an outsider in certain situations due to the EA not allowing the same behavior as everyone else (1)	Environment
Stress	Stress (1), Separating from mommy and daddy at daycare (1), Waiting for the companion (parent/caregiver) (1), Travel (anxiety of being sick when traveling) (1)	Impairment
Studies	Studies (5)	Participation
Talking	Talking (1)	Impairment

Table 6.3. Themes Associated with Each Affected System

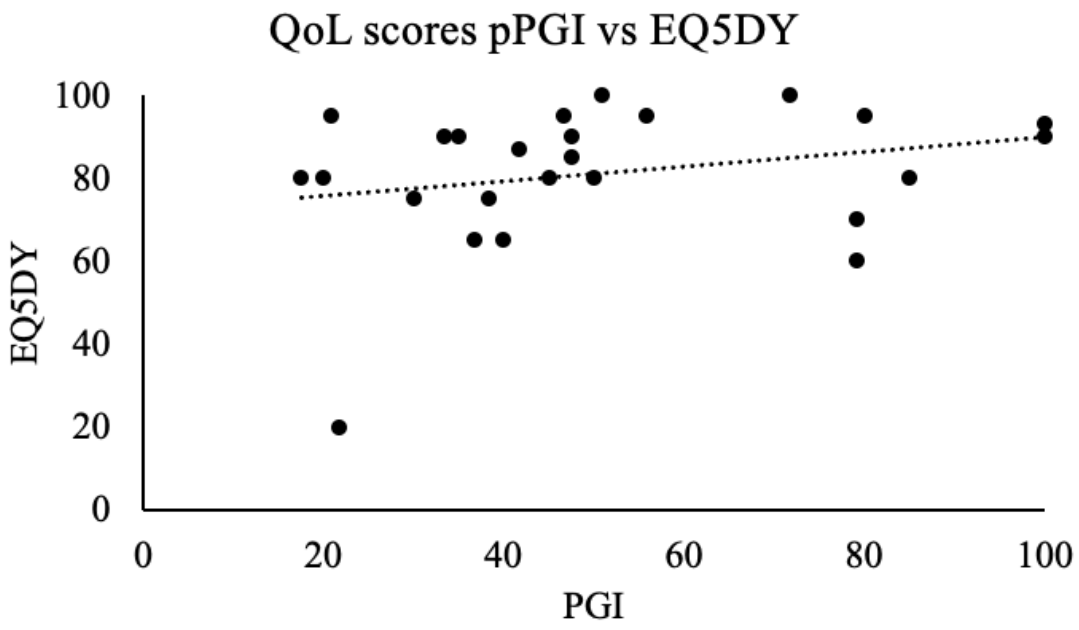
This table provides the 19 themes further condensed to 7 systems affecting various bodily systems.

Affected System	Themes
Respiratory system	Breathing
Musculoskeletal system	Physical activities
Gastrointestinal system	Eat, Reflux
Skin	Appearance
Immune system	Allergies
General	Fatigue, Illness, Pain, Self-esteem, Self-care, Sleep, Stigma, Stress, Studies, Talking
Rehabilitation	Burden of care, Forming relationships, Impact on family

6.2.4.2. Phase 2 - Alignment of Pediatric Quality of Life Measures

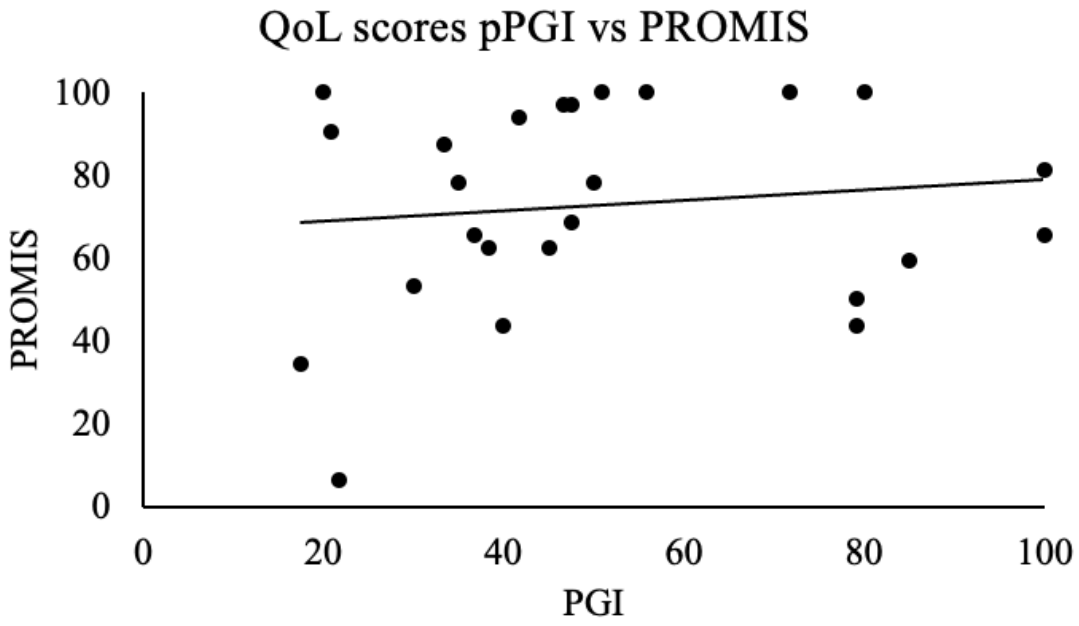
The figures present comparisons of QoL scores across different measures. *Figure 6.1* compares average QoL scores between EQ-5D-Y and pPGI, showing EQ-5D-Y with higher QoL (81.40) and lower variability, and pPGI with lower QoL (50.93) and higher variability. A weak correlation ($r = 0.33$) was observed between pPGI and EQ-5D-Y. In *Figure 6.2*, disparities in average QoL scores and variability between PROMIS Short Form Life Satisfaction-8a-v1.0 and pPGI are highlighted, with PROMIS Short Form Life Satisfaction-8a-v1.0 showing higher QoL (72.75) and lower variability, while pPGI exhibits lower average QoL (50.93) and higher variability. A weak correlation ($r = 0.19$) was also noted between pPGI and PROMIS Short Form Life Satisfaction-8a-v1.0. *Figure 6.3* depicts differences in average QoL between PROMIS Short Form Life Satisfaction-8a-v1.0 and EQ-5D-Y, with EQ-5D-Y reporting higher QoL (81.40) and lower variability compared to PROMIS Short Form Life Satisfaction-8a-v1.0 QoL (72.75) with higher variability. A moderate correlation ($r = 0.84$) was observed between EQ-5D-Y and PROMIS Short Form Life Satisfaction-8a-v1.0.

Figure 6.1. QoL Scores of pPGI and EQ-5D-Y



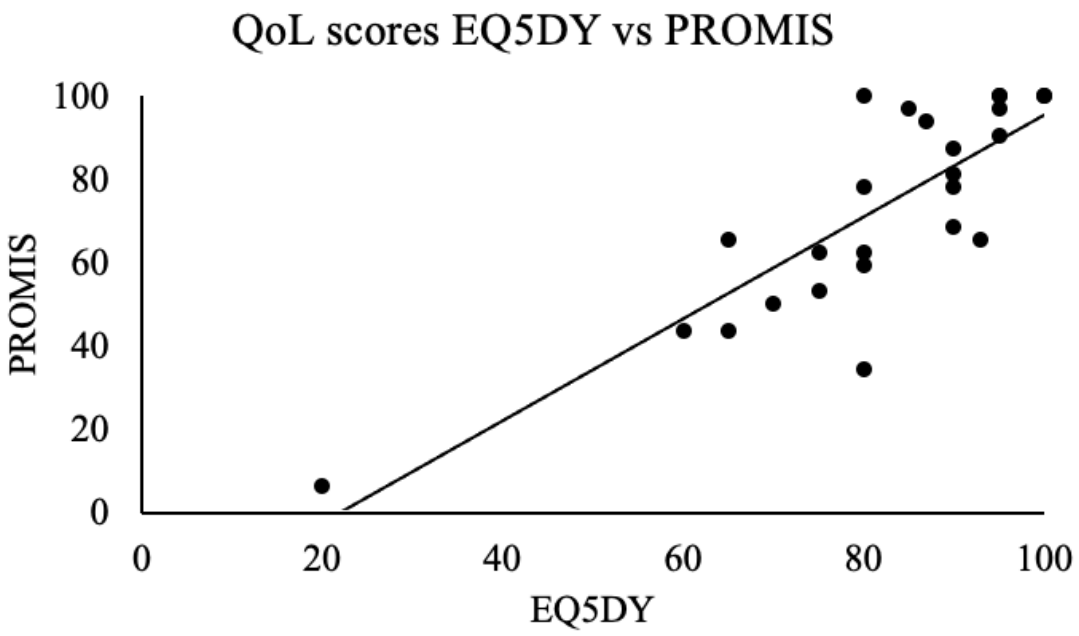
Abbreviations: pPGI (Pediatric Patient-Generated Index), EQ-5D-Y (EuroQol- 5 Dimension (EQ-5D) Youth), QoL (Quality of Life)

Figure 6.2. QoL Scores of pPGI and PROMIS Short Form Life Satisfaction-8a-v1.0



Abbreviations: pPGI (Pediatric Patient-Generated Index), PROMIS (Patient-Reported Outcomes Measurement Information System) Short Form Life Satisfaction-8a-v1.0, QoL (Quality of Life)

Figure 6.3. QoL Scores of EQ-5D-Y and PROMIS Short Form Life Satisfaction-8a-v1.0



Abbreviations: EQ-5D-Y (EuroQol- 5 Dimension (EQ-5D) Youth), PROMIS (Patient-Reported Outcomes Measurement Information System) Short Form Life Satisfaction-8a-v1.0, QoL (Quality of Life)

6.2.4.3. Phase 3 - Thought Processes in Completing the pPGI Steps

A subset of children (n = 3) and new children recruits (n = 3), along with their parents (n = 4), took part in cognitive interview sessions. *Table 6.4* summarizes children's feedback on the pPGI, noting both positive aspects (such as ease of understanding and engagement), and challenges (such as distributing coins in the third step of the pPGI). Suggestions for improvement included alternative formats for the pPGI and more specific questioning.

Table 6.4. Children Feedback Summary with Cognitive Interview Insights

This table summarizes feedback from children regarding their experience with pPGI.

Child	Understanding & Difficulties	Ease of Completion (out of 10)	Coin System Challenges & Suggestions	Emotional Impact & Reflection	Additional Comments
P1	Good; None	8	Positive realization; Discuss coin system	Positive impact; Better than expected	None
P2	Good; None	5	Not motivating; Use scale system	Boredom; Clarity needed	None
P3	Understandable; Life happiness	6	Not helpful; Different system	None	None
P4	Clear; Coin system	5	Difficulty; Provide more space	Concentration; Question wording	Need more space
P5	Clear; None	7	Not motivating; Use different elements	Comfortable; Improvement noticed	N/A
P6	Limited; Coins	5	Not motivating; Simplify format	Frustration; None	None
P7	Easy; None	10	Not applicable; Use editable PDFs	Contentment; QoL improved	N/A
P8 (Mother)	Good; Coin system	8	Frustration; Use single PDF format	Frustration; Child's improvement	Prefer PDF format
P8 (Father)	Difficult; Multiple	N/A	Not helpful; Clearer questions	Confusion; Survey's usefulness	Prefer PDF or web-based
P9	Understandable; Coin system	4	Other approach preferred; Clearer questions	Reflection; Survey's usefulness	Need more clarity
P10	Clear; Coin system	5	Difficulty; Prefer scale system	Tiredness; Reflection on condition	Prefer scale system

6.2.4.4. Phase 4 - Clinicians' Views on Measure Usability

Clinicians' preferences for assessing EA children's QoL varied based on the measures presented. Three clinicians favored the pPGI (Measure A) for its specificity in addressing EA-related issues. Two preferred the EQ-5D-Y (Measure B) due to its clarity and quantitative assessment, while one clinician chose PROMIS (Measure C) for its emphasis on the impact on daily function and relevance in rehabilitation contexts. These preferences, detailed in *Table 6.5*, reflect the clinical usability and relevance of each measure.

Table 6.5. Clinician Perspectives on Measure Preference and Usability

This table indicates clinicians' favored measures for pediatric patient assessment.

Clinician	Age	Specialty	Measure Chosen	Measure Preference and Comments
P1	54	Pediatric Surgeon	B	● Measure A: Found survey overly complicated. ● Measure C: Answers confusing with varied terminology, making interpretation difficult. ● Suggested need for a comprehensive scoring system combining verbal and visual scores for easier interpretation.
P2	67	Pediatric Surgeon	A	● Measure A: Favored specificity to EA patients. ● Measure B: Concerns about broad focus under the "TODAY" heading. ● Suggested merging Measures A and C for comparative analysis across diseases.
P3	59	Pediatric Surgeon	A	● Measure A: Viewed as a better measure of chronicity and specific issues related to EA.
P4	28	Kinesiologist	C	● Measure C: Chosen over others due to focus on daily function impact. ● Emphasized the importance of understanding a patient's well being and satisfaction in a rehabilitation context.
P5	46	Anesthesiologist	A & C	● Measure A & C: Dependent on child's age, mainly clarifying perception of QoL.
P6	34	Pediatric Surgeon	B	● Measure B: Seen as most useful for providing concrete explanations in plain language and offering an overall quantitative assessment. ● Measures A and C are too abstract.

Measure A - pPGI, Measure B - EQ-5D-Y, Measure C - PROMIS Short Form Life Satisfaction-8a-v1.0

6.2.4.5. Voyant Tools

The Voyant Tools' analysis revealed a total of 449 words *(Figure 6.4)*, encompassing 260 unique verb forms. The vocabulary demonstrates diversity, with a density score of 0.579. The Readability Index of 8.57 suggests a moderate level of complexity. The average sentence length is 6.1 words, indicating relatively longer sentences. The analysis highlighted several recurring topics within the document, focusing on eating, school, and reflux. Commonly occurring words included "eat" (8 times), "school" (5 times), and "reflux" (4 times).

Figure 6.4. Voyant Tools Word Cloud

The Voyants Tools analysis helps us understand what aspects of disease bother children the most.

6.2.5. DISCUSSION

This study investigated the QoL in pediatric patients following neonatal repair for EA, using the pPGI alongside standard measures. Twenty-five children identified patient-valued life domains using the pPGI, which generated 104 text threads from 25 interviews. These threads were categorized into 58 unique codes, encompassing themes such as allergies, appearance issues, and fatigue. Results showed that QoL scores were higher and less variable in the EQ-5D-Y and PROMIS Short Form Life Satisfaction-8a-v1.0 compared to the pPGI. Weak correlations were observed between the pPGI and the other measures. Cognitive interviews highlighted that while participants found the pPGI generally easy to understand, they encountered difficulties with distributing coins in the third step of the pPGI. Clinicians had varied preferences for pPGI, EQ-5D-Y, and PROMIS Short Form Life Satisfaction-8a-v1.0 based on different factors. The study confirms that pPGI provides detailed, patient-centered insights not fully captured by other measures, with suggestions for improvement including alternative formats and more precise questioning.

The pPGI exhibited lower correlations with other QoL measures, underscoring the anticipated differences between individualized and standard QoL assessments (Mayo et al., 2017). The observed low correlation can be attributed to the variability in identified domains, highlighting the need for a nuanced understanding of patient-specific challenges. Some areas that were prioritized by patients were not adequately captured by the PROMIS Short Form Life Satisfaction-8a-v1.0 and EQ-5D-Y measures. For instance, the EQ-5D-Y focuses on only five domains—mobility, self-care, usual activities, pain/discomfort, and feelings—while areas such as social interactions, emotional well-being, and specific functional limitations related to EA were not covered. Similarly, PROMIS Short Form Life Satisfaction-8a-v1.0, while comprehensive, may not fully address unique aspects of EA that are critical to patients. This variability underscores the importance of using individualized measures like the pPGI to capture the full spectrum of issues affecting patients' QoL. The lower average QoL scores in pPGI compared to EQ-5D-Y and PROMIS Short Form Life Satisfaction-8a-v1.0 may also result from pPGI's truly individualized approach (Ow et al., 2022). Standardized measures may include unaffected areas of patients' lives, potentially inflating overall QoL scores (Patel et al., 2003).

A directed content analysis was conducted on data from the pPGI, identifying a range of impairments, participation and activity limitations, environmental factors, and health factors significant for individuals with EA. These domains were categorized into 19 themes and further condensed into 7 bodily systems. This categorization aids clinicians in understanding the various systems affected by EA and highlights the areas most impacted by the illness, allowing for more personalized and effective healthcare interventions.

Body structures and personal factors were not included in the domains of *Table 6.1* because the focus of the analysis was on domains that were directly referenced in the children's text threads and could be explicitly mapped to ICF classifications. The body structures component of the ICF, which pertains to anatomical parts of the body (e.g., organs, limbs, and their components), was not explicitly addressed in the text threads provided by participants. It is possible that issues related to body structures were implicitly included in discussions of bodily functions or activities but were not separately coded due to the absence of direct anatomical references in the narratives.

Similarly, personal factors, which encompass individual characteristics such as age, gender, socioeconomic status, personality, and lifestyle, are recognized as an important part of the ICF framework but are not coded in its taxonomy. These factors were not included in the analysis as they were beyond the scope of the current study, which aimed to classify participants' experiences and challenges into the standardized ICF domains for functioning, activities, and environmental factors. While personal factors undoubtedly influence health and functioning, their inclusion would require a different methodological approach focused on subjective and contextual data rather than standardized coding.

In contrast, the Voyant analysis provided a different perspective by visually analyzing and interpreting the frequency and context of terms within the pPGI data. While the ICF mapping offered a structured approach by aligning the identified themes with the ICF framework's classification of health domains, the Voyant analysis highlighted patterns and relationships in the data through visualizations such as word clouds and trend analyses. This complementary approach revealed additional nuances in how patients perceive and articulate their health experiences, offering further insights into the specific challenges faced by children with EA.

The clinical utility of the pPGI is further demonstrated by its effectiveness in identifying patient priorities (Camfield & Ruta, 2007). This person-specific measure allows individuals to express their concerns in their own words and language (Patel et al., 2003). One frequently identified theme, "looking after one's health," underscores its importance to children and highlights the impact of their condition. Additionally, feedback from clinicians reinforced the clinical utility of the pPGI. Clinicians noted that the detailed insights provided by the pPGI into specific areas of concern, such as personal health management, enabled them to better understand and address the unique challenges faced by their patients. This alignment between patient priorities and clinical insights supports the pPGI's role in guiding more personalized and effective healthcare interventions. This emphasizes the patient-centered nature of the pPGI, making it highly relevant for individuals with an illness.

The pPGI demonstrates clear utility as an individualized measure that directly captures what matters most to the person being interviewed. This makes it particularly attractive for use in clinical practice, where tailoring interventions to patient priorities is important (Patel et al., 2003).

Regarding summative content analysis, Voyant Tools provided a clear view of the illness aspects most troubling to young patients by quantifying the frequency of specific terms. It identified that the term "eat" appeared most frequently, 8 times, followed by "school," 5 times, and "reflux," 4 times. This suggests, predictably, that eating is the most affected domain for children with EA. Such insights can guide clinicians and caregivers in prioritizing their attention and support, thereby improving the quality of care delivered. The findings from this analysis deepen our understanding of pediatric patient experiences and highlight the importance of addressing these concerns in both clinical practice and supportive care settings.

The pPGI functions similarly to its original adult version, by facilitating communication between clinicians and patients, and guiding personalized treatment decisions (Ruta et al., 1994). Further comparison with standardized measures reveals that the pPGI captures a diversity of domains not typically addressed by standardized measures, contributing to the low correlations observed (Patel et al., 2003). Both the original PGI and the pPGI effectively identify patient priorities and highlight the lower QoL experienced by individuals with EA (Kuspinar & Mayo, 2013). In addition to revealing individual concerns, the total score of the PGI can also be utilized

similarly to other generic tools to provide an overall assessment of QoL. This dual capability enhances the measure's versatility in both capturing specific patient concerns and providing a comprehensive evaluation of their health status.

In research settings, its provision of a numerical score adds quantitative rigor to qualitative insights, enhancing its usefulness in outcome assessments (Aburub et al., 2016). The scored results serve as a meaningful health index, providing clinicians and researchers with actionable data on areas of personal concern that are essential for optimal patient management (Campos et al., 2024). The PGI thus embodies the ultimate "patient-centered outcome" (Mayo et al., 2017), aligning clinical and research goals with patient priorities.

Some children found the pPGI comprehensible and engaging, while others faced challenges with elements such as the coin system and unclear instructions. Suggestions for improvement included alternative survey formats and more precise questioning. Despite individual differences in experiences and preferences, there was a common realization and reflection on the improvement of children's conditions over time. This reflection aligns with findings in the literature, which emphasize the value of patient-centered tools in tracking and understanding health progression (Tavernier et al., 2011). The feedback from children highlights the importance of continually refining and adapting the pPGI to ensure it remains accessible, relevant, and effective in capturing the nuanced experiences of children treated for EA. This ongoing refinement is important for maintaining the tool's utility and accuracy in clinical settings.

The clinicians' perspectives demonstrate varying preferences for measures used in assessing QoL among pediatric post-surgery patients. The pPGI was favored by three clinicians for its specificity in addressing EA issues, while two preferred EQ-5D-Y due to its clear explanations and quantitative assessment. One clinician opted for PROMIS Short Form Life Satisfaction-8a-v1.0, emphasizing its focus on daily function impact and rehabilitation context. Concerns were raised regarding the complexity of the pPGI and confusion with the score generated by the PROMIS Short Form Life Satisfaction-8a-v1.0 measure, highlighting the importance of clarity and ease of interpretation in assessment tools. One suggestion to complement pPGI and PROMIS Short Form Life Satisfaction-8a-v1.0 indicates a desire for comprehensive analysis across different conditions in pediatric surgery. The kinesiologist's focus

on daily functioning and the anesthesiologist's consideration of age-dependent factors underscore the necessity of a holistic approach to QoL assessment. These insights emphasize the importance of tailoring measures to suit specific patient populations and clinical contexts, ensuring meaningful QoL assessment in pediatric surgical care (Ruta et al., 1994; Tang et al., 2014; K. Turner et al., 2021).

This study has several limitations. While the small sample size is justifiable given the rarity of EA, it may limit the generalizability of the findings to other rare diseases or pediatric surgical conditions. Further research with larger samples is needed to determine whether these findings are applicable across a broader range of rare conditions or different pediatric surgical contexts. Similarly, the clinicians' feedback cannot be generalized due to the limited participant pool and the specific sampling methods used. The small number of participants may not fully represent the broader clinical perspectives needed for comprehensive generalization. The single-center focus may limit the applicability of findings to diverse healthcare settings or cultural contexts. Additionally, there is a potential for response bias in both patient and clinician feedback, as children may have had subjective reasons for their responses and experienced recall bias. Lastly, the study's duration does not fully capture the long-term implications of post-surgery changes in QoL.

Moving forward, similar to the present study, future research should prioritize involving children as patient research partners throughout the study process, integrating their perspectives from the outset (Shunmuga Sundaram et al., 2022). This inclusive approach will ensure effectiveness in addressing children's needs and initiate the development of tailored, patient-centered interventions (Stover et al., 2021). The clinicians' preferences highlighted the pPGI's value in addressing EA-specific concerns, while cognitive debriefing identified challenges with the coin distribution step, suggesting areas for improvement. Additionally, future studies should aim for larger sample sizes for both children and clinicians and explore the use of this measure in other pediatric surgical contexts. This will help validate the measure's applicability and effectiveness across various conditions. Specifically, future research should include examining the consistency between child and proxy scores, which will enhance our understanding of how well proxy reports align with children's own perceptions of their HRQoL.

6.2.5. CONCLUSION

In this study, we have shown the unique value of the pPGI in assessing the QoL of pediatric patients post-EA surgery. Through individualized and patient-centered assessment, the pPGI captured nuanced aspects of QoL that standardized measures missed. The observed differences in QoL scores between the pPGI and standardized measures highlight the importance of integrating patient-generated insights for a thorough understanding of post-surgery experiences. Despite limitations, the study shows the pPGI's potential as a valuable measure for identifying patient-specific concerns and enhancing clinical care.

7. SUMMARY AND CONCLUSIONS

7.1. GENERAL FINDINGS

This thesis investigates the use of PROMs and PREMs in pediatric surgical settings to better understand patient and family perspectives, with the goal of informing and improving PCC. The research addresses three pivotal questions: the alignment between parent and child perspectives on PROMs and PREMs, the adaptation of a PREM for the Canadian pediatric population, and the potential of individualized measures like the pPGI to capture key outcomes for pediatric surgical patients. The results suggest that while there may be some alignment between parent and child perspectives on PROMs and PREMs, significant heterogeneity exists in how both groups perceive these outcomes. This variability highlights the complexity of understanding and measuring the pediatric patient experience and underscores the importance of considering individual differences when using PROMs and PREMs. Additionally, the findings provide promising indications regarding the utility of individualized measures like the pPGI for capturing key outcomes that are specific to pediatric surgical patients, suggesting a more tailored approach could enhance the relevance and accuracy of assessments in this population.

The findings of the first study, which included a SR and meta-analysis, highlight the limitations of relying solely on parental reports to understand a child's lived experience, particularly in emotional and social functioning. The SR revealed frequent discrepancies between parent and child perspectives, with parents often underestimating their child's QoL. This underscores the need for measures that better reflect the child's subjective experiences, as children may perceive their emotional and social well-being differently from their parents.

The pPGI tool, evaluated as part of this research, offers a more effective approach to assessing emotional and social functioning compared to traditional proxy measures. As an individualized measure, the pPGI is specifically designed to capture outcomes that align with the child's unique perspective, including emotional and social well-being. This tailored approach allows for a more accurate representation of how children perceive their experiences, reducing the reliance on parental interpretations.

Emotional and social aspects of QoL are central to the pediatric experience. Children often prioritize social interactions, emotional regulation, and peer relationships as key components of their overall well-being, particularly in contexts such as pediatric surgery.

Accurate assessment of these domains is crucial to understanding the child's true lived experience.

The findings further indicate that parents frequently underestimate their child's emotional and social functioning. This aligns with broader research showing that parents may struggle to capture the nuances of a child's emotional life, especially when children are reluctant or unable to fully articulate their feelings. By focusing directly on the child's perspective, the pPGI aims to address this gap, providing a more reliable and nuanced assessment of emotional and social well-being from the child's viewpoint.

The second study focuses on adapting, translating, and validating a PREM specifically for the Canadian pediatric surgical context. The development of this culturally and linguistically tailored measure shows promise in addressing the specific needs of Canadian pediatric surgical patients. However, further research is required to fully assess its effectiveness across different patient populations and healthcare contexts. This adapted PREM aims to offer healthcare providers a more contextually relevant measure for assessing patient experiences, reflecting the cultural and linguistic nuances of the Canadian healthcare environment. However, further validation is needed to determine its applicability across diverse pediatric outpatient settings throughout the country. This process emphasizes the importance of contextualizing patient-reported measures to enhance their validity and reliability across different healthcare settings.

The third study evaluates the usability of the pPGI, introducing a novel approach to capturing patient-defined outcomes in pediatric surgery. The pPGI allows patients to identify and prioritize the aspects of their lives most impacted by their surgical experience, offering a personalized account of their QoL. This individualized approach complements standardized tools and is particularly valuable in pediatric surgery, where patient experiences can vary widely. The findings suggest that the pPGI has the potential to capture unique and meaningful outcomes, offering healthcare providers valuable insights for developing more tailored and effective treatment plans.

Together, these studies provide valuable knowledge that can contribute to enhancing PCC in pediatric surgical settings. The alignment between child and parent perspectives, the culturally adapted PREM, and the individualized pPGI create a multidimensional approach to

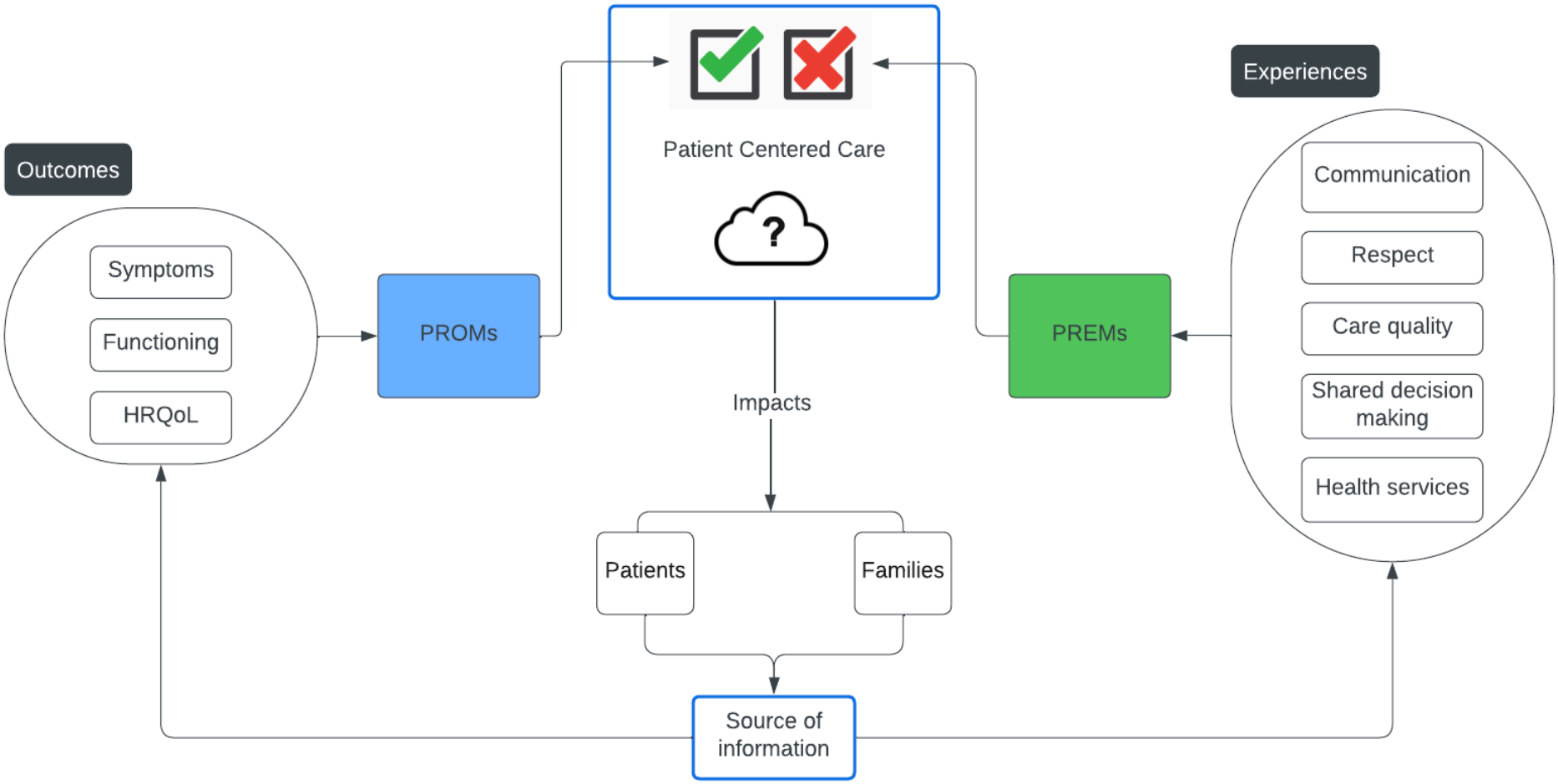
understanding and improving patient experiences. This holistic framework integrates both quantitative outcomes and qualitative experiences, leading to a more complete and accurate assessment of healthcare quality.

The implications of these findings are significant for healthcare policy and practice. While parental reports provide valuable insight, they should complement, not replace, direct child input whenever possible, as both perspectives contribute to a fuller understanding of patient experiences. The development of culturally adapted measures ensures that patient-reported data are relevant and meaningful, providing a foundation for more informed decision-making in clinical care. Moreover, the introduction of individualized measures like the pPGI highlights the need to tailor care to each patient's unique needs, with the ultimate goal of using these insights to inform service delivery and improve the quality of care in a patient-centered manner.

7.2. PROPOSED MODEL FOR INTEGRATING PROMs AND PREMs

To synthesize the findings of this thesis and provide a structured approach to enhancing PCC in pediatric surgical settings, I propose the Integrated Patient-Centered Healthcare Quality and Experience (IPCHQE) model. This model is designed to bridge clinical outcomes with patient experiences through the integration of PROMs and PREMs. Below, I explain the key elements of this model, which serves as a visual representation of the framework established by the three studies in this thesis.

Figure 7.2. The Integrated Patient-Centered Healthcare Quality and Experience (IPCHQE) Model



The IPCHQE model serves as a conceptual framework for integrating PROMs and PREMs to enhance PCC in pediatric surgical settings. This model is visually represented by two key symbols. The cloud symbol represents the central question of how integrating PROMs and PREMs can provide a broader view of care quality, capturing both health status and patient experiences. The check mark and red X represent the validation process in this model. PROMs and PREMs are used in practice to "test" whether PCC is achieved. The check mark signifies areas where PCC has been validated through positive outcomes and impacts, while the red X shows areas where improvements are still necessary. This reflects our ongoing efforts to assess and ensure that care delivery aligns with patients' and families' reported needs and experiences.

Together, these elements of the model illustrate how combining PROMs and PREMs offers a more comprehensive perspective on patient care, as informed by the findings of this thesis and the broader research literature (Churruca et al., 2021). The development and refinement of these measures involve extensive literature reviews, meta-analyses, cultural adaptations, psychometric testing, and pilot studies, all designed to ensure that the measures are reliable, valid, and suitable for diverse patient populations (Uman, 2011).

A key feature of the IPCHQE model is the conceptual dynamic feedback loop between PROMs and PREMs. This loop illustrates how insights gained from PROMs and PREMs can inform and refine each other to enhance PCC. While this feedback loop is an integral part of the model, its application and effectiveness should be further explored in future research to fully validate its practical utility based on the findings of this thesis. This interaction allows clinical outcomes to influence patient experiences and vice versa, fostering a continuous cycle of improvement. For instance, effective pain management has been shown to lead to higher patient satisfaction (Weldring & Smith, 2013), while improved communication with healthcare providers can enhance treatment adherence (Kynoch et al., 2022). Although this thesis did not specifically investigate these relationships, prior research supports the notion that such factors play an important role in patient outcomes and experiences (Tawil et al., 2018). Future studies could explore how integrating PROMs and PREMs might further elucidate these connections. This feedback loop promotes a deeper understanding of patient needs and drives ongoing improvements in care (Bombard et al., 2018).

The model also considers the influence of patient characteristics and healthcare system factors on the implementation and effectiveness of PROMs and PREMs. While this thesis primarily focused on adapting and evaluating these measures, it is important to recognize that individual patient factors (such as age, health status, and cultural background) and systemic factors (such as healthcare provider practices and resource availability) can significantly affect how PROMs and PREMs are applied and their overall impact (*Data Collection Systems Integrating PROMs and PREMs to Support Value-Based Decisionmaking*, n.d.). These considerations are informed by broader literature and underscore the need for context-sensitive application of these measures in real-world settings (Shunmuga Sundaram et al., 2022). Demographics, health literacy, and organizational culture are all factors that influence how patients report their experiences (Andrulis & Brach, 2007). By considering these variables, the model supports personalized healthcare delivery tailored to individual patient needs.

The ultimate goal of the IPCHQE model is to improve healthcare quality and promote value-based care in pediatric surgery. By integrating PROMs and PREMs, the model facilitates a more comprehensive understanding of both clinical outcomes and patient experiences. This holistic view allows healthcare providers to tailor interventions more effectively, address specific patient needs, and enhance overall care. For example, using PROMs to track health status alongside PREMs to assess patient experiences can help identify gaps in care, improve communication between patients and providers, and ensure that treatment plans are aligned with patients' preferences and expectations (*Data Collection Systems Integrating PROMs and PREMs to Support Value-Based Decisionmaking*, n.d.).

The use of PROMs and PREMs in routine clinical care is gaining momentum. PROMs have been shown to influence individual care by enabling healthcare providers to monitor health outcomes over time, adjust treatments based on reported symptoms and QoL, and engage patients in shared decision-making (Kynoch et al., 2022). Similarly, PREMs provide insight into patient experiences with healthcare services, allowing organizations to assess communication effectiveness, the quality of provider-patient relationships, and overall satisfaction with care (Shunmuga Sundaram et al., 2022). These insights can lead to organizational improvements by informing policy decisions, resource allocation, and the development of PCC models (Weldring & Smith, 2013).

In a broader context, the integration of PROMs and PREMs can drive organizational change by providing data that is used for quality improvement initiatives. For instance, healthcare organizations can analyze aggregated PROM and PREM data to identify trends, uncover areas where services may be underperforming, and implement changes that address these gaps (Weldring & Smith, 2013). This approach not only improves individual patient care but also enhances service delivery on a systemic level (Krist et al., 2017). By aligning care processes with patient needs and outcomes, PROMs and PREMs contribute to more responsive and effective healthcare systems, as outlined in value-based care principles (Teisberg et al., 2020).

This integration supports the delivery of more personalized and effective care, ultimately contributing to higher quality and more value-driven healthcare (Bhati et al., 2023). By combining these measures, the model ensures that healthcare is both effective and responsive to patient needs. It also helps identify areas for improvement and guide resource allocation, fostering a holistic approach to enhancing pediatric surgical care (Teisberg et al., 2020).

Moreover, the IPCHQE model emphasizes the importance of continuous data integration and stakeholder engagement to drive quality improvement (Norris et al., 2017). By incorporating PROMs and PREMs into electronic health records and patient feedback systems, healthcare providers can monitor outcomes in real-time, enabling prompt responses to patient needs (Casaca et al., 2023). Engaging all stakeholders—including patients, families, and healthcare providers—ensures transparency and shared decision-making in quality improvement efforts (Heckert et al., 2020).

In addition, while the IPCHQE model integrates PROMs and PREMs to enhance PCC, it explicitly acknowledges the strengths and limitations of patient-reported measures. The model demonstrates the value of these measures in offering comprehensive insights into patient outcomes and experiences, but also highlights their limitations, such as the potential for missing individualized concerns or difficulties in capturing nuanced experiences. For instance, while PREMs effectively assess healthcare interactions and overall patient experiences (Shunmuga Sundaram et al., 2022), they may overlook specific, individual challenges that more personalized measures like the pPGI capture (Aburub et al., 2016). This balance of strengths and limitations is critical for informing healthcare policy and guiding the development of more tailored

interventions that meet the diverse needs of pediatric surgical patients, as presented in the literature and findings discussed throughout this thesis. The model serves as a framework for both optimizing patient care and identifying areas where further refinement of PROMs and PREMs is necessary to address gaps in PCC.

In summary, the IPCHQE model emphasizes the value of integrating patient-reported data into healthcare policy and practice. By leveraging insights from PROMs and PREMs, healthcare providers can enhance communication, optimize care pathways, and foster truly patient-centered practices (McCabe et al., 2023). This approach has the potential to not only improve patient satisfaction and clinical outcomes but also contribute to the overall efficiency of the healthcare system, offering a pathway to more effective and satisfying care for young patients and their families. Although this thesis did not directly assess the effectiveness of the approach, existing literature suggests that integrating PROMs and PREMs can positively impact these areas (Bhati et al., 2023). Future research could further explore the specific effects of this approach on healthcare efficiency and outcomes.

7.3. STRENGTHS & LIMITATIONS

7.3.1. Child-Proxy Differences in Pediatric Surgery Patient-Reported Outcome and Experience Measures

The SR and meta-analysis of pediatric QoL assessments reveal a complex landscape with both strengths and significant limitations. A key strength of this review is its focus on synthesizing existing evidence on child-proxy differences in patient-reported outcome and experience measures. By including diverse studies, this review offers valuable insights into the variability in parent and child perspectives, which are critical for shaping PCC in pediatric surgery. The use of meta-analytic techniques, despite inherent variability across studies, also strengthens the evidence base, allowing for a more structured comparison of these perspectives.

However, several limitations also need to be acknowledged. The omission of details about study settings, design characteristics, and participant demographics in many included studies impairs the ability to contextualize findings and assess their broader applicability. This lack of detailed reporting undermines transparency, limits the potential for meaningful subgroup analyses, and challenges reproducibility (Estoque et al., 2019). Without such details, it becomes

difficult for clinicians and researchers to determine the relevance of findings to specific patient groups or healthcare settings, which could lead to misapplication of results or missed opportunities for targeted interventions (Balogh et al., 2015). Additionally, the predominance of cross-sectional studies rather than longitudinal designs limits insights into how QoL changes over time in pediatric patients.

A further limitation concerns the types of studies included in this review. The reliance on published, peer-reviewed literature means that grey literature, such as unpublished studies, conference abstracts, or reports, was not considered. The exclusion of grey literature could have restricted the comprehensiveness of the review by potentially omitting important findings that could provide additional context or support for the conclusions drawn. Additionally, the restriction to English-language studies may have excluded relevant research from non-English-speaking regions, limiting the generalizability of the findings, particularly in multicultural or non-Western healthcare settings.

One of the key challenges in this field is the high degree of heterogeneity observed across studies. The use of different QoL measures, patient populations, and follow-up periods introduces variability that complicates the ability to draw consistent conclusions across studies. In particular, heterogeneity among studies focused on the PedsQL™ measure demonstrates the inherent challenges in synthesizing pediatric QoL research. Although we used a random-effects model to account for this variability, the lack of a statistically significant pooled effect size suggests that systematic differences between child and parent reports may be obscured by this heterogeneity.

Another limitation is related to the methodologies used in the included studies. The meta-analysis was limited to specific measures such as the PedsQL™, which, while widely used, may not fully capture the diversity of patient-reported outcomes across different pediatric surgical conditions. Additionally, the relatively small number of studies available for certain patient groups, particularly rare conditions, limits the generalizability of the results. It is important to note that our review was constrained by the methodological quality of the original studies, which varied in terms of design, sample sizes, and follow-up times, further limiting the precision of our pooled estimates.

Despite these limitations, our review suggests that proxy reports provided by parents remain a useful source of information when child self-reports are unavailable or impractical, particularly for younger children or those with cognitive or communication limitations. However, it is important to balance this with the recognition that parent reports may differ from children's self-reports, as highlighted by the significant discrepancies noted in nearly a third of the studies reviewed. These differences emphasize the need for healthcare providers to consider both perspectives to gain a complete understanding of pediatric health outcomes (Lifland et al., 2018). The variability in findings across studies not only complicates the formulation of clear clinical guidelines but also raises questions about the reliability and validity of current QoL assessment tools (Bullinger & Quitmann, 2014).

Overall, while the inclusion of proxy reports is justified in many cases, as discussed throughout the thesis, this review highlights the importance of addressing these limitations through more rigorous, standardized research. Future studies should aim to include larger, more diverse patient populations, use longitudinal designs to track QoL changes over time, and ensure greater transparency in reporting study details. By addressing these gaps, future research can better inform clinical practice and contribute to more nuanced understandings of pediatric surgical outcomes.

7.3.2 Canadian Adaptation and Validation of a Pediatric Patient-Reported Experience Measure

The study successfully adapted and piloted a pediatric PREM for the Canadian context, offering insights into how healthcare experiences are perceived by young patients. One of the key strengths of this research is the incorporation of bilingual materials, ensuring inclusivity for both French and English speakers in Montreal. The use of face validation and cognitive debriefing also provided some level of insight into how well children understood and interpreted the measure. Additionally, the engagement with clinicians and patient advocacy groups helped to facilitate recruitment and mitigate some challenges, although these efforts were limited by the scope of the research site.

However, the study faces significant limitations, particularly in terms of generalizability. The small sample size, especially in phases 2 and 3, where only three participants were included in specific age groups, raises concerns about the statistical power of the findings. With such a

limited number of participants, the results may not reflect broader trends or experiences among children in pediatric surgical settings across Canada (Faber & Fonseca, 2014). Furthermore, conducting the research at a single pediatric outpatient facility within a tertiary institution constrains the applicability of the findings to other healthcare settings. The demographics of the Montreal population, with its high proportion of immigrant families and non-native French or English speakers, may introduce biases that are not representative of other regions in Canada.

The recruitment challenges that contributed to the small sample size also limited the scope of the study. Parental consent, children's willingness to participate, and logistical hurdles are common in pediatric research (Kilicel et al., 2023). Although efforts were made to address these issues, the small and relatively homogeneous sample limited the ability to conduct subgroup analyses that could reveal variations in patient experiences across different age groups or healthcare settings (Nass et al., 2009). This limitation underscores the need for future research to adopt broader recruitment strategies, including multicenter studies, to ensure a more diverse and representative participant pool (Alvis et al., 2023).

Another limitation lies in the lack of qualitative feedback on the Face Validation Form. While the study used quantitative measures, such as Likert scales and numerical rating systems, to collect data on patient experiences, the absence of detailed qualitative feedback reduces the depth of understanding regarding the participants' perspectives. Qualitative data could have provided richer insights into the reasoning behind children's ratings, offering context that is essential for interpreting their experiences (Sutton & Austin, 2015). Without this qualitative layer, the findings are limited to surface-level insights, which may overlook more nuanced aspects of patient experiences.

In future studies, addressing these limitations could involve more robust participant engagement strategies, expanding recruitment across multiple healthcare settings, and incorporating a balanced mix of quantitative and qualitative data collection. These steps would improve the study's generalizability and offer a more comprehensive understanding of pediatric patient experiences across diverse healthcare contexts.

7.3.3. Evaluating an Individualized Patient-Reported Outcome Measure in Pediatric Surgery

This study offers valuable insights by evaluating the pPGI, an innovative, individualized measure in pediatric surgery. A key strength is its focus on capturing unique, patient-centered

outcomes, which generic PROMs often miss. The use of both child and clinician feedback, despite the small sample size, provided important perspectives on the pPGI's practical application and usability in real-world settings. Additionally, the study's pioneering use of an individualized measure in a rare condition like EA offers a strong foundation for future research, encouraging broader validation in diverse healthcare contexts.

This study, while providing valuable insights, is subject to several significant limitations that warrant careful consideration when interpreting and applying its findings. These limitations span various aspects of the research design and execution, potentially impacting the generalizability and broader applicability of the results.

One of the primary limitations is the small sample size employed in the study. This constraint substantially restricts the ability to extrapolate the findings to a broader population of patients treated for EA. The limited number of participants may not adequately represent the diverse range of experiences and outcomes typically observed in EA treatment (Shea et al., 2022). Consequently, the results should be viewed as preliminary or indicative rather than definitive, necessitating further research with larger cohorts to validate and expand upon these initial findings.

The feedback obtained from clinicians, while valuable, is similarly constrained by the limited participant pool. The fact that all participating clinicians were male introduces a significant gender bias (Samulowitz et al., 2018), potentially overlooking important perspectives that female clinicians might offer. This homogeneity in the clinician sample raises questions about the comprehensiveness of the professional insights gathered and may fail to capture the full spectrum of clinical experiences and observations in EA treatment (Donabedian, 2005).

The study's focus on a single center presents another notable limitation. Healthcare practices, resources, and patient populations can vary significantly across different institutions and geographical regions (Swift, 2002). As a result, the findings from this single-center study may not be readily applicable to diverse healthcare settings or cultural contexts. This limitation highlights the need for multi-center studies that can account for variations in treatment approaches, patient demographics, and healthcare system characteristics (Rotter et al., 2019). Nevertheless, despite the limitations of conducting a single-center study, valuable insights into the usability and effectiveness of the pPGI were obtained. The data gathered provided

meaningful information about how the pPGI functions in a real-world setting, offering preliminary evidence that it can capture individualized, patient-centered outcomes in pediatric surgical contexts. These findings, though specific to one institution, still contribute to the growing understanding of how individualized measures like the pPGI can be implemented and adapted in healthcare settings. Further research across multiple centers will help to validate these insights and ensure broader applicability.

While it is true that asking participants for their views is central to understanding their subjective experiences, the potential for response bias remains relevant. Even when directly soliciting children's perspectives, factors like their relationship with caregivers, mood, or recall ability can shape their responses (McCoy & Raver, 2011). These subjective influences may affect how children interpret and respond to questions, leading to variations in the accuracy or consistency of their answers (Hassan, 2006). Acknowledging this bias is essential in studies involving PROs, as it helps frame the findings within the context of potential limitations inherent in subjective self-reporting.

7.4. FUTURE DIRECTIONS

Building upon the insights gained from the three studies conducted, future research should prioritize robust, multidimensional designs that capture the dynamic nature of children's experiences across diverse populations and healthcare settings (Lakind et al., 2022). For the first study, it is essential to address the issue of missing data in systematic reviews to reduce heterogeneity in meta-analyses and improve the reliability of the findings (Germain et al., 2019). This approach should be considered both at the level of SRs and individual studies. The second study highlights the need for innovative recruitment strategies to enhance patient participation (Brockman et al., 2023). By improving recruitment and ensuring broader participant inclusion, these strategies can lead to more representative data and a more comprehensive understanding of pediatric QoL. The third study highlights the importance of multi-site collaborations to increase sample sizes, particularly for conditions like EA (Patil et al., 2023). Together, these improvements will contribute to a more nuanced and accurate understanding of pediatric QoL.

To further advance the field, researchers should explore innovative methodologies such as digital platforms, virtual reality, and participatory arts-based methods to encourage more authentic expression from children (Nathan et al., 2023). These approaches can enhance

engagement by making data collection more interactive and enjoyable for children, thus improving the quality and accuracy of the information gathered. Additionally, integrating these innovative methods into routine clinical practice requires thoughtful consideration of how data are captured, managed, and utilized.

Standardizing reporting protocols, adopting cutting-edge statistical techniques, and implementing longitudinal research designs will be critical in tracking changes in children's experiences over time (Caruana et al., 2015). Furthermore, there is a pressing need to involve children as active research partners throughout the study process, expand sample sizes for both children and clinicians, and explore the consistency between child and proxy scores (Field et al., 2004b). To maximize the impact of collected data, it is essential to integrate data capture methods into electronic medical records systems. This integration facilitates real-time access to patient-reported outcomes and experiences, enabling more personalized and responsive care.

By enhancing data capture methods and ensuring effective integration into medical records, researchers and healthcare providers can use this data at patient, service, and organizational levels. At the patient level, this means tailoring interventions to individual needs; at the service level, improving care delivery based on aggregated data trends; and at the organizational level, informing policy and resource allocation decisions. By integrating these advancements, researchers can develop a better understanding of pediatric QoL, paving the way for the creation of innovative assessment tools and targeted interventions (Robichaud et al., 2024). These efforts will significantly enhance the well-being of children globally and equip healthcare providers with actionable, evidence-based strategies to improve outcomes across the full spectrum of pediatric health challenges.

7.5. CONCLUSION

The research objectives of this thesis were achieved through a rigorous methodological approach. A systematic review and meta-analysis confirmed the accuracy of parental reports in capturing patient experiences, effectively addressing the first research question. The adaptation of a PREM for the Canadian pediatric population produced a culturally relevant measure for assessing patient experiences. Additionally, the evaluation of the personalized pPGI demonstrated its effectiveness as an individualized measure, capturing outcomes that matter most to pediatric surgical patients.

These findings hold significant potential for enhancing PCC in pediatric surgical settings. By integrating PROMs and PREMs, this research provides a comprehensive approach that prioritizes patient perspectives, enhances the relevance of collected data, and supports the development of personalized treatment plans. The ultimate goal is to improve patient experiences, health outcomes, and the overall quality of healthcare delivery. Future research should focus on implementing these measures in clinical practice and assessing their long-term impact on patient outcomes and healthcare quality, ensuring that the insights gained continue to drive meaningful advancements in pediatric surgical care.

8. SUPPLEMENTARY FILES

Supplementary File 4.1. Included Articles

Author	Year	Country	Condition	Measure	Study Aim
(Abassi et al., 2020)	2020	France	Cardiothoracic	HRQoL PedsQL™	To compare the HRQoL between children with congenital heart disease and typically developing children of the same age range, using PedsQL™
(Abrão et al., 2021)	2021	Brazil	Urology	HRQoL PedsQL™ (ESRD module)	To assess HRQoL and behavioral problems of children and adolescents with chronic kidney disease stages 3–5, and HRQoL and mental health of their parents, comparing the differences between the results according to each stage of the disease.
(Abood et al., 2021)	2021	Denmark & UK	Ophthalmology	PROMs Oxford Foot and Ankle Questionnaire (OxAFQ)	To report PROM data using the OxAFQ from children and their proxies after resection of tarsal coalition, and to correlate the data gathered from the children to the data from their proxies.
(Alekseenko & Karpishchenko, 2020)	2020	Russia	ENT	HRQoL SNOT-20	To compare the efficiency and safety of two surgical approaches used to treat chronic rhinosinusitis in children.
(Alonso et al., 2010)	2010	USA	General	HRQoL PedsQL™	To compare the HRQoL of pediatric liver transplant recipients with two reference groups (healthy children and pediatric cancer patients), and to evaluate specific domains of HRQoL while examining the alignment between parent and self-reported assessments of HRQoL.

(Alonso et al., 2013)	2013	USA	General	HRQoL PedsQL™	To compare various demographic and medical variables to the levels of HRQoL in pediatric liver transplant recipients, identifying predictors or factors associated with lower HRQoL from both child and parent perspectives.
(Anmyr et al., 2012)	2012	Sweden	ENT	PROMs SDQ	To explore and compare how children with cochlear implants, their parents, and their teachers perceive the children's mental health in terms of emotional and behavioral strengths and difficulties.
(Çavuşoğlu et al., 2012)	2012	Turkey	General	HRQoL PedsQL™	The first aim of the study was to compare the QoL of 2–12-year-old children who had undergone surgical correction of their congenital abnormality at least 24 months ago with healthy children. The secondary aim was to evaluate whether there were differences between the QoL perception of parents and children.
(Buyan et al., 2010)	2010	Turkey	Urology	HRQoL KINDL	To compare the QoL scores of Turkish children who are dialysis patients, renal transplant recipients, and age-matched healthy controls, and to compare child-self and parent-proxy scores.
(Dalton et al., 2022)	2022	UK	Plastics	PROMs Child Health Questionnaire (CHQ)	To use the child and parent versions of the CHQ to compare outcomes of synostosis surgery or status before surgery, such as how noticeable the child's head shape is and how bothered they are by this.
(De Bruyne et al., 2023)	2023	Belgium	Urology	HRQoL PedsQL™	To compare child self-reports of quality of life (QoL) to parent proxy reports of QoL for children with kidney diseases, and to explore the relationship between the

					QoL of the children and the level of parental stress experienced.
(Dulfer et al., 2016)	2016	Netherlands & Israel	Cardiothoracic	HRQoL TAPQOL	To assess the impact of various medical history and present medical status variables on both physical and psychosocial domains of health-related quality of life in children who have undergone EA repair.
(A. D. Turner et al., 2024)	2017	USA	Cardiothoracic	HRQoL PedsQL™	To compare long-term outcomes and quality of life in children who were previously supported by extracorporeal membrane oxygenation for cardiac reasons, and to identify potential associations with patient characteristics.
(Flieder, 2019)	2018	Germany & Sweden	General	HRQoL PedsQL™	To compare the HRQoL of patients who have undergone EA repair across several dimensions, including severity of EA, associated conditions, and nationality.
(Gothwal et al., 2018)	2018	India	Ophthalmology	HRQoL KIDSCREEN -27	To compare parent-child agreement regarding child's HRQoL in children operated for congenital glaucoma.
(Grant et al., 2021)	2021	Canada, Australia & UK	General	HRQoL PeLTQL, PedsQL™ (Transplant module), PedsQL™	To compare parent-proxy and self-reported HRQoL in children who have undergone liver transplantation.
(Green et al., 2009)	2009	USA	Cardiothoracic	HRQoL Adaptation of	To compare the QoL of school-age heart transplant recipients from the perspectives of both parents and children.

				an interview guide	
(Hager et al., 2021)	2021	Canada	General	HRQoL PeLTQL	To conduct a longitudinal study examining HRQoL in pediatric liver transplant recipients and identifying key determinants affecting HRQoL over a four-year period.
(Hao et al., 2013)	2013	Canada	ENT	HRQoL GCBI	To compare the preoperative and postoperative states of pediatric patients who undergo otoplasty and assess changes in health-related quality of life and patient satisfaction.
(Hartman et al., 2015)	2015	Netherlands	General	HRQoL mean HRQoL Child report	To compare parent proxy reports with self-reports of children with anorectal malformations or Hirschsprung disease and healthy siblings in terms of health-related quality of life assessments.
(Haukedal et al., 2020)	2020	Norway & Sweden	ENT	HRQoL PedsQL™	To compare the self-reported HRQoL between children with cochlear implants and children with normal hearing, focusing on domains such as school functioning and social functioning.
(Hendriksma et al., 2020)	2020	Netherlands	ENT	HRQoL PedsQL™	To evaluate the QoL agreement between children and their parents following cochlear implantation and determine which factors lead to increased agreement.
(Howard et al., 2010)	2010	Australia	Anesthesia	HRQoL PedsQL™	To compare the quality of life and behavioral changes in children undergoing day case surgery at three different time points: Baseline (pre-anesthesia), 7 days following anesthesia, and 30 days following anesthesia.

(Huber, 2005)	2005	Austria	ENT	HRQoL KINDL	To assess the HRQoL of Austrian pupils with cochlear implants across two key dimensions: differences between age groups and the degree of agreement between self-reported HRQoL assessments by children and assessments provided by their parents.
(Ingerski et al., 2010)	2010	USA	Multiple	HRQoL PedsQL™	To compare the HRQoL among children and adolescents diagnosed with different pediatric chronic conditions and to examine the convergence or disparities between self-reports provided by the youth themselves and reports made by their parents.
(Jolley, 1992)	1992	UK	ENT	PREMs Hospital Experience Questionnaire	To compare the reported likes and dislikes of being in the hospital between parents and children undergoing tonsillectomy or adenoidectomy, including aspects such as the salience and positive evaluation of hospital staff by both parents and children, and to highlight the divergence in experiences.
(Kaplan et al., 2022)	2022	USA	Multiple	PROMs CHRIs	To examine the contributions of parents' health and distress to parents and children's assessments of children's health.
(Kikuchi et al., 2018)	2018	Japan	General	HRQoL PedsQL™ (Transplant module)	To evaluate and explore the factors of generic and transplant-specific HRQoL in Japanese pediatric and adolescent patients with biliary atresia after living donor liver transplant and to compare parent and child reports.
(Kljajić et al., 2023)	2023	Sweden	Neurosurgery	HRQoL PedsQL™	To compare the HRQoL of patients with treated sagittal synostosis and metopic synostosis and examine the

					impact of different surgical methods on HRQoL outcomes in the SS group.
(Lambert et al., 2009)	2009	USA & Canada	Cardiothoracic	PROMs CHQ	To compare functional health status as reported by children and their parents following the Fontan procedure.
(Lazor et al., 2017)	2017	Canada	Cardiothoracic	PedsQL™	To examine the impact of liver transplantation on QoL of pediatric recipients. Secondary objective: To explore similarities or differences in agreement between child and parent ratings of child QoL.
(Leopoldo-Rodado et al., 2021)	2021	Spain	Plastics	KINDL	To evaluate HRQoL in 4–7-year-old children treated for cleft lip and/or palate compared to healthy controls and to estimate a possible association with cleft type, gender, age, and surgical re-interventions.
(Lifland et al., 2018)	2018	USA	Multiple	Rating scales for pain intensity, PedsQL™	To compare parent reports and child self-reports of pain intensity and HRQoL in children who have had inpatient surgery, and to determine how well parent reports align with child self-reports.
(Mavis et al., 2015)	2015	USA	General	HRQoL SF-12, PROMs SF-36	To compare parents' and children's perceptions of vulnerability and wellness in children who have received a kidney or liver transplant.
(Miserachs et al., 2019)	2019	Canada, Spain, Italy, Poland, Germany, France & Switzerland	General	HRQoL: PeLTQL; PedsQL™	To assess HRQoL among pediatric recipients of liver transplantation due to a primary diagnosis of biliary atresia using disease-specific and generic measurement tools and compare their HRQoL with healthy controls.

(Palabiyik & Demir, 2021)	2021	Turkey	Post-op General	HRQoL: PedsQL™	To compare the presence and effects of chronic post appendectomy pain (CPAP) in children who have undergone open appendectomies, examining its impact on daily life activities and differences in quality of life between children with CPAP and those without CPAP based on self-reports from the children and reports from their parents.
(Parekh et al., 2008)	2008	USA	Multiple stages Urology	HRQoL: PedsQL™	To evaluate health-related quality of life in patients with ureteropelvic junction obstruction undergoing pyeloplasty and document differences between parent and child assessments at given intervals.
(Parekh et al., 2006)	2006	USA	Multiple stages Urology	HRQoL: PedsQL™	To study health-related quality of life, reporting differences between parents and children.
(Park et al., 2012)	2012	South Korea	Post-op Urology	HRQoL: PedsQL™ (ESRD module)	To assess HRQoL in children and adolescents with end-stage renal disease (ESRD) using the Korean version of PedsQL™ ESRD, comparing child self-reported and parent proxy HRQoL.
(Pereira et al., 2022)	2022	Portugal	Post-op ENT	HRQoL: KINDL; CI-specific HRQoL questionnaire	To compare HRQoL questionnaire scores among children with cochlear implants, normal-hearing age-peers, and parents of children with CI, using both generic and CI-specific HRQoL questionnaires.

(Petersen et al., 2019)	2019	Germany	Post-op General	HRQoL: PedsQL™ (Fatigue Scale); PedsQL™	To investigate the occurrence of fatigue in pediatric liver transplant recipients and its effect on their HRQoL, exploring the influence of various factors on HRQoL and comparing fatigue levels and HRQoL between recipients and healthy peers.
(Razafimahefa-Raoelina et al., 2016)	2016	France	Post-op ENT	HRQoL: KIDSCREEN-27	To assess QoL in children fitted with cochlear implants using combined self- and parental assessment.
(Reiter et al., 2023)	2023	USA	Multiple stages General	PROMs: Postoperative survey (not validated); PROMIS; PREMs: Preoperative survey (not validated)	To assess agreement between pediatric patients undergoing elective gastrointestinal surgery and their parents on perioperative education, expectations, comprehension, milestones, and PROMIS measures.
(Rijke et al., 2021)	2019	Netherlands	Post-op ENT	PROMs: Child self-report	To compare the post-implant capabilities of deaf children who have received cochlear implants and are undergoing rehabilitation to those of age-matched peers with normal hearing.
(Sabapathy et al., 2021)	2021	India	Post-op Plastics	PROMs: PODCI; PROMIS; MHQ	To evaluate the outcomes of nonvascularized free toe phalangeal transfer in the reconstruction of congenital short fingers with redundant soft tissue and assess radiological, functional, and patient/parent-reported outcomes.

(Sorensen et al., 2015)	2015	USA & Canada	Post-op Urology	HRQoL: PedsQL™	To compare the neuropsychological functioning and HRQoL of pediatric patients who have experienced acute liver failure with established norms and healthy samples.
(Tahirović et al., 2011)	2011	Bosnia and Herzegovina	Post-op Cardiothoracic	HRQoL: PedsQL™	Evaluate the HRQoL of children after surgery for congenital heart defects.
(Ten Kate et al., 2021)	2021	Netherlands	Post-op General	HRQoL: PedsQL™; DUX-25	To compare self-reported and proxy-reported health status and QoL of school-aged children born with EA at two different time points and evaluate changes in health status and QoL over time.
(Twycross & Finley, 2013)	2012	UK & Canada	Post-op Multiple	PREMs: Information About Pain questionnaire	To compare children's and parents' perceptions of the quality of postoperative pain management, exploring factors such as pain intensity, communication about pain, use of pain medication, and satisfaction with care.
(Uzark et al., 2012)	2012	USA	Post-op Cardiothoracic	HRQoL: PedsQL™	To examine self- and parent-reported QoL outcomes in pediatric heart transplant recipients.
(van de Kar et al., 2022)	2021	Netherlands	Post-op Plastics	HRQoL: PedsQL™	To assess the impact of severe hand injuries caused by fireworks on adolescents and their parents, focusing on pain, activities and participation problems, quality of life, self-esteem, and psychological distress among parents.
(Wang et al., 2015)	2015	China	Post-op Ophthalmology	HRQoL: IXTQ	To evaluate the impact of strabismus surgery on the HRQoL assessment scores of children with intermittent exotropia and their parents.

(Wray et al., 2012)	2012	UK	Post-op Cardiothoracic	HRQoL: PedsQL™	To compare the QoL of children who required bridging to transplant with that of children transplanted without mechanical support, and to assess correlations of parent and child reports.

Supplementary File 4.2. Summary of Measures and Discrepancies in Pediatric Surgery Studies

Measure	Frequency (*n*)	Percentage (%)
Discrepancies Between Patient and Parent Proxy Reports		
Disagreement	24	45.3
Agreement	12	22.6
Mixed (more than one conclusion)	17	32.1
Types of Disagreements		
Underestimate	13	54.2
Overestimate	6	25.0
Both	5	20.8
Type of Measures		
Validated	61	87.1
Not Validated	9	12.9
Specificity of Measures		
Not Disease-specific	51	72.7
Disease-specific	19	27.1
Types of Measures Used		
Patient-Reported Outcome Measures (PROMs)	67	95.7
Patient-Reported Experience Measures (PREMs)	3	4.3
Studies Using at Least One Type of Measure		
PROMs	51	96.3
PREMs	3	5.7
Total (including articles using multiple types):	54	102.0

Supplementary File 4.3. Risk of Bias Assessment Mixed Methods Appraisal Tool (MMAT)

Qualitative studies (Ethnography, Phenomenology, Narrative research, Grounded theory, Case study, Qualitative description)							
Reference	Are there clear research questions?	Do the collected data allow to address the research questions?	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?
(Twycross & Finley, 2013)	Y	Y	Y	Y	Y	Y	Y
(Green et al., 2009)	Y	Y	Y	Y	Y	Y	Y
Quantitative randomized controlled trials - Methodological quality criteria - Randomized control							
Reference	Are there clear research questions?	Do the collected data allow to address the research questions?	Is randomization appropriately performed?	Are the groups comparable at baseline?	Are there complete outcome data?	Are outcome assessors blinded to the intervention provided?	Did the participants adhere to the assigned intervention?
(Wang et al., 2015)	Y	Y	Y	Y	Y	N	CNT
Quantitative non-randomized (non-randomized controlled trials, cohort study, case-control study, cross-sectional analytic study)							

Reference	Are there clear research questions?	Do the collected data allow to address the research questions?	Are the participants representative of the target population?	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Are there complete outcome data?	Are the confounders accounted for in the design and analysis?	During the study period, is the intervention administered (or exposure occurred) as intended?
(Lifland et al., 2018)	Y	Y	Y	Y	Y	Y	N
(van de Kar et al., 2022)	Y	Y	Y	Y	N	Y	N
(Hao et al., 2013)	Y	Y	Y	Y	Y	Y	N
(Howard et al., 2010)	Y	Y	N	Y	Y	Y	N
(Rijke et al., 2021)	Y	Y	Y	Y	N	N	Y
(Dulfer et al., 2016)	Y	Y	Y	Y	Y	CNT	Y
(Hartman et al., 2015)	Y	Y	Y	Y	Y	Y	N
(Palabiyik & Demir, 2021)	Y	Y	Y	Y	Y	Y	N
(Alonso et al., 2013)	Y	Y	N	Y	N	N	N
(Alonso et al., 2010)	Y	Y	N	Y	Y	CNT	CNT

(Petersen et al., 2019)	Y	Y	N	Y	Y	Y	N/A
(Flieder, 2019)	Y	Y	CNT	Y	Y	Y	N/A
(Hager et al., 2021)	Y	Y	Y	Y	Y	Y	Y
(Ingerski et al., 2010)	Y	Y	CNT	Y	Y	Y	N/A
(Pereira et al., 2022)	Y	Y	Y	Y	Y	Y	Y
(Abassi et al., 2020)	Y	Y	Y	Y	Y	Y	Y
(Miserachs et al., 2019)	Y	Y	CNT	Y	Y	Y	N/A
(Huber, 2005)	CNT	CNT	CNT	Y	Y	Y	N/A
(Kljajić et al., 2023)	Y	Y	CNT	Y	Y	Y	CNT
(Haukedal et al., 2020)	Y	Y	Y	Y	Y	Y	CNT
(De Bruyne et al., 2023)	Y	Y	Y	Y	Y	Y	N/A
(A. D. Turner et al., 2024)	Y	Y	CNT	Y	Y	CNT	N

(Ten Kate et al., 2021)	Y	Y	Y	Y	Y	Y	N/A
(Sorensen et al., 2015)	Y	Y	CNT	Y	Y	CNT	N/A
(Sabapathy et al., 2021)	Y	Y	CNT	Y	CNT	Y	Y
(Lambert et al., 2009)	Y	Y	Y	Y	CNT	N	Y
(Gothwal et al., 2018)	Y	Y	Y	Y	CNT	N	Y
(Wray et al., 2012)	Y	Y	Y	Y	CNT	Y	Y
(Parekh et al., 2008)	N	Y	Y	Y	Y	N	Y
(Parekh et al., 2006)	N	Y	Y	Y	Y	N	Y
(Hendriksma et al., 2020)	Y	Y	Y	Y	Y	N	Y
(Kikuchi et al., 2018)	Y	Y	Y	Y	CNT	N	Y
(Tahirović et al., 2011)	Y	Y	Y	Y	Y	N	Y
(Buyan et al., 2010)	Y	Y	Y	Y	N	N	Y

(Park et al., 2012)	Y	Y	Y	Y	CNT	N	Y
(Leopoldo-Rodado et al., 2021)	Y	Y	Y	Y	CNT	N	Y
(Uzark et al., 2012)	Y	Y	Y	Y	CNT	N	Y
(Lazor et al., 2017)	Y	Y	Y	Y	Y	N	Y
(Abood et al., 2021)	Y	Y	Y	Y	CNT	N	CNT
(Razafimahefa-Raoelina et al., 2016)	Y	Y	Y	Y	N	N	Y
(Anmyr et al., 2012)	Y	Y	Y	Y	CNT	N	Y
(Abrão et al., 2021)	Y	Y	Y	Y	CNT	N	Y
(Grant et al., 2021)	Y	Y	Y	Y	CNT	N	Y
(Çavuşoğlu et al., 2012)	Y	Y	Y	Y	CNT	N	Y
(Kaplan et al., 2022)	N	Y	Y	Y	N	N	Y

(Mavis et al., 2015)	Y	Y	Y	Y	CNT	N	Y
Quantitative descriptive studies (Incidence or prevalence study without comparison group, survey, case series, case report)							
Reference	Are there clear research questions?	Do the collected data allow to address the research questions?	Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?
(Alekseenko & Karpishchenko, 2020)	Y	Y	Y	N	Y	N	N
(Jolley, 1992)	Y	Y	Y	Y	Y	Y	N/A
(Dalton et al., 2022)	N	Y	Y	Y	Y	Y	Y
(Reiter et al., 2023)	N	Y	Y	Y	Y	CNT	Y

Abbreviations: “N” means "No", “Y” means "Yes", and “CNT” means “Can Not Tell,” following MMAT predetermined answer

Supplementary File 5.1. Face Validation Form (Moores et al., 2012)

Please circle the answers below each of the following 7 statements that best fit your feelings about the questionnaire that you recently completed. Please use the boxes at the bottom of the page to make additional comments.

The questionnaire was easy to complete				
Strongly agree	Mostly agree	Neither agree or disagree	Mostly disagree	Strongly disagree
I enjoyed filling in the questionnaire				
Strongly agree	Mostly agree	Neither agree or disagree	Mostly disagree	Strongly disagree
I would be happy to complete the questionnaire again in the future as part of my routine care				
Strongly agree	Mostly agree	Neither agree or disagree	Mostly disagree	Strongly disagree
The questionnaire was too long				
Strongly agree	Mostly agree	Neither agree or disagree	Mostly disagree	Strongly disagree
The questionnaire was too complicated				
Strongly agree	Mostly agree	Neither agree or disagree	Mostly disagree	Strongly disagree
The questionnaire covered things that were important to me about my hospital visit				
Strongly agree	Mostly agree	Neither agree or disagree	Mostly disagree	Strongly disagree
The questionnaire was relevant to my hospital visit				
Strongly agree	Mostly agree	Neither agree or disagree	Mostly disagree	Strongly disagree

Do you have any comments or suggestions on how the questionnaire you used could be improved (e.g., its structure, appearance, or design)?

Is there anything else that you want to add?

Adapted from: Moores KL, Jones GL, Radley SC. Development of an instrument to measure face validity, feasibility and utility of patient questionnaire use during health care: the QQ-10. Int J Qual Health Care 2012;24:517–24.

Supplementary File 5.2. Sample ICC Calculations for Within-Rater Reliability

Detailed Steps

- Data Analysis. Then, Anova: Two-Factor Without Replication
- Input Range box: Dataset for Patient 45 (French) & (English)
- Output Range box: Cell S2 as the starting cell of the output range
- Alpha: 0.05

Sample calculations

Question	P45 (FR)	P45 (EN)
1.a	2	2
1.b	2	2
2.a	2	2
2.b	2	2
3.a	2	2
3.b	2	2
4.a	1	1
4.b	1	2

Source of Variation	*SS*	*df*	*MS*	*F*	*P-value*	*F crit*
Rows	53.22	44	1.21	7.65	2.188E-10	1.65
Columns	0.04	1	0.04	0.28	0.60	4.06
Error	6.96	44	0.16			
Total	60.22	89				

ICC = 0.77168273

Supplementary File 5.3. PREM Instrument Revision (Phases 1, 2, 3) - Participant Characteristics

Sample participants

ID	Outpatient	Age	Sex	Consent	Setting	Consent for next steps (Email)	Questions of PREM asked	Gift Card given	Phase	Step
P1	Yes	14	F	Yes	In clinic	No*	1-2, 36-38, 32-35, 3-6, 29-30	Indigo	1	1
P2	Yes	12	F	Yes	In clinic	Yes	1, 7, 30-37, 23, 25	Cineplex	1	1
P3	Yes	16	M	Yes	In clinic	Yes	1-5, 32-38	Cineplex	1	1
P4	Yes	16	M	Yes	In clinic	Yes	1-6, 32-38, 29-30	Indigo	1	1
P5	Yes	12	F	Yes	In clinic	Yes	28-37, 1-6	Cineplex	1	1

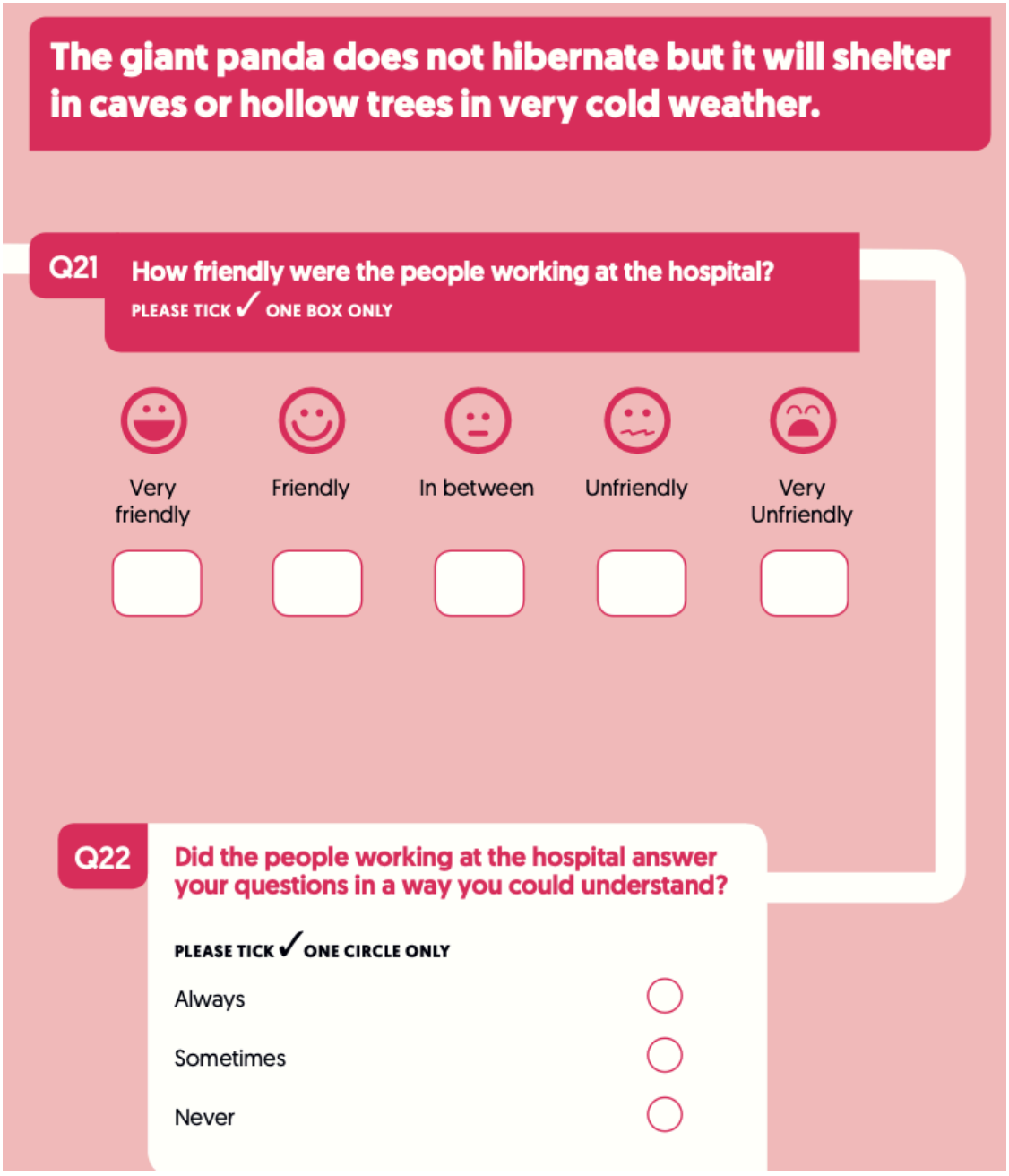
Sample (14-15 Think-Aloud testing)

Original Instrument (PREM-UK)	Modified Instrument (PREM-MTL)	Collate	Agreement to keep question	Conditions	Phase	Step
Question 1: How would you rate each of these places in the hospital on noise?	General consensus: good question. keep	5/7	71.4%	Not understood (1), not relevant (1)	1	1
Question 2: How would you rate each of these places in the hospital on space?	General consensus: good question. keep	7/7	100.0%	None	1	1
Question 3: How would you rate each of these places in the hospital on temperature?	General consensus: good question. keep	5/7	71.4%	Not understood “treatment room” (1), not relevant (1)	1	1

Supplementary File 5.4. PREM-MTL Images for Each Age Group (8-11, 12-13, 14-16)

Sample

The following image displays the finalized versions of the PREM-MTL after the completion of our study. The image is specifically designed for the age groups of 8-11 and is presented in English.



9. APPENDICES

Appendix 2.1. Complete Search Strategy Developed for Systematic Review and Meta-Analysis

Databases Searched

Africa-Wide Information [EBSCO] (July 11, 2023)

#	Query	Results
S26	S19 OR S24 OR S25	110
S25	TI((child* or teen* or youth* or adolescen* or boy* or girl*) N1 experienc* N7 (surg* or preop* or perioop* or perop* or postop*)) OR AB((child* or teen* or youth* or adolescen* or boy* or girl*) N1 experienc* N7 (surg* or preop* or perioop* or perop* or postop*))	17
S24	S23 AND S15	34
S23	S20 OR S21 OR S22	670
S22	TI((child* or teen* or youth* or adolescen* or boy* or girl*) and (PROM or PROMs or PREM or PREMs or (report* N0 (outcome* or experience*))))	13
S21	TI((child* or teen* or youth* or adolescen* or boy* or girl*) N0 (centr* or center*))	136
S20	TI((child* or teen* or youth* or adolescen* or boy* or girl*) N1 (perspectiv* or view? or voice* or opinion* or empower* or advoca*))	525
S19	S14 AND S15 AND S18	64
S18	S16 OR S17	257,354
S17	SO(child* or adolesc* or paediatr* or pediatr*)	38,472
S16	TI(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*) OR AB(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*)	244,426
S15	TI(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*) OR AB(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*)	222,429
S14	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13	930
S13	TI((child* or teen* or youth* or adolescen*) N2 (self-report*)) OR AB((child* or teen* or youth* or adolescen*) N2 (self-report*))	224

S12	TI((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and (self*)) OR AB((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and (self*))	57
S11	TI((child* or teen* or youth* or adolescen*) and ((PRO or PROs) N2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))) OR AB((child* or teen* or youth* or adolescen*) and ((PRO or PROs) N2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)))	12
S10	TI(((((health or pediatric* or paediatric*) N0 "quality of life") or HRQoL) N1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*) OR AB(((((health or pediatric* or paediatric*) N0 "quality of life") or HRQoL) N1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*)	39
S9	TI((functional* N2 "health status") and self*) OR AB((functional* N2 "health status") and self*)	7
S8	TI((child* or teen* or youth* or adolescen*) N1 feedback) OR AB((child* or teen* or youth* or adolescen*) N1 feedback)	7
S7	TI((child* or teen* or youth* or adolescen*) N0 (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) N1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)) OR AB((child* or teen* or youth* or adolescen*) N0 (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) N1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*))	101
S6	TI((child* or teen* or youth* or adolescen*) N3 lived N2 (experienc* or outcome* or satisf* or "health status" or prefer* or care)) OR AB((child* or teen* or youth* or adolescen*) N3 lived N2 (experienc* or outcome* or satisf* or "health status" or prefer* or care))	65
S5	TI((child* or teen* or youth* or adolescen*) N1 voice*) OR AB((child* or teen* or youth* or adolescen*) N1 voice*)	136
S4	TI((child* or teen* or youth* or adolescen*) N2 (outcome* or report*) N1 measure*) OR AB((child* or teen* or youth* or adolescen*) N2 (outcome* or report*) N1 measure*)	139
S3	TI((child* or teen* or youth* or adolescen*) N3 ("health status" or satisf* or recover*) N1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) OR AB((child* or teen* or youth* or adolescen*) N3 ("health status" or satisf* or recover*) N1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*))	11
S2	TI((child* or teen* or youth* or adolescen*) N3 (perceived or perception* or important* or value*) N1 (experienc* or satisf* or outcome* or care)) OR AB((child* or teen* or youth* or adolescen*) N3 (perceived or perception* or important* or value*) N1 (experienc* or satisf* or outcome* or care))	128

S1	TI((child* or teen* or youth* or adolescen*) N1 (report* or centered or centred or focused) N1 (experienc* or outcome* or satisf* or "health status" or prefer* or care)) OR AB((child* or teen* or youth* or adolescen*) N1 (report* or centered or centred or focused) N1 (experienc* or outcome* or satisf* or "health status" or prefer* or care))	84

CINAHL Plus [EBSCO] (July 11, 2023)

#	Query	Results
S27	S19 OR S24 OR S25	472
S26	S19 OR S24 OR S25	110
S25	TI((child* or teen* or youth* or adolescen* or boy* or girl*) N1 experienc* N7 (surg* or preop* or perioop* or perop* or postop*)) OR AB((child* or teen* or youth* or adolescen* or boy* or girl*) N1 experienc* N7 (surg* or preop* or perioop* or perop* or postop*))	17
S24	S23 AND S15	34
S23	S20 OR S21 OR S22	670
S22	TI((child* or teen* or youth* or adolescen* or boy* or girl*) and (PROM or PROMs or PREM or PREMs or (report* N0 (outcome* or experience*))))	13
S21	TI((child* or teen* or youth* or adolescen* or boy* or girl*) N0 (centr* or center*))	136
S20	TI((child* or teen* or youth* or adolescen* or boy* or girl*) N1 (perspectiv* or view? or voice* or opinion* or empower* or advoca*))	525
S19	S14 AND S15 AND S18	64
S18	S16 OR S17	257,354
S17	SO(child* or adolesc* or paediatr* or pediatr*)	38,472
S16	TI(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*) OR AB(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*)	244,426
S15	TI(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*) OR AB(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*)	222,429

S14	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13	930
S13	TI((child* or teen* or youth* or adolescen*) N2 (self-report*)) OR AB((child* or teen* or youth* or adolescen*) N2 (self-report*))	224
S12	TI((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and (self*)) OR AB((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and (self*))	57
S11	TI((child* or teen* or youth* or adolescen*) and ((PRO or PROs) N2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))) OR AB((child* or teen* or youth* or adolescen*) and ((PRO or PROs) N2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)))	12
S10	TI(((((health or pediatric* or paediatric*) N0 "quality of life") or HRQoL) N1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*) OR AB(((((health or pediatric* or paediatric*) N0 "quality of life") or HRQoL) N1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*)	39
S9	TI((functional* N2 "health status") and self*) OR AB((functional* N2 "health status") and self*)	7
S8	TI((child* or teen* or youth* or adolescen*) N1 feedback) OR AB((child* or teen* or youth* or adolescen*) N1 feedback)	7
S7	TI((child* or teen* or youth* or adolescen*) N0 (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) N1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)) OR AB((child* or teen* or youth* or adolescen*) N0 (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) N1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*))	101
S6	TI((child* or teen* or youth* or adolescen*) N3 lived N2 (experienc* or outcome* or satisf* or "health status" or prefer* or care)) OR AB((child* or teen* or youth* or adolescen*) N3 lived N2 (experienc* or outcome* or satisf* or "health status" or prefer* or care))	65
S5	TI((child* or teen* or youth* or adolescen*) N1 voice*) OR AB((child* or teen* or youth* or adolescen*) N1 voice*)	136
S4	TI((child* or teen* or youth* or adolescen*) N2 (outcome* or report*) N1 measure*) OR AB((child* or teen* or youth* or adolescen*) N2 (outcome* or report*) N1 measure*)	139
S3	TI((child* or teen* or youth* or adolescen*) N3 ("health status" or satisf* or recover*) N1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) OR AB((child* or teen* or youth* or adolescen*) N3 ("health status" or satisf* or recover*) N1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*))	11

S2	TI((child* or teen* or youth* or adolescen*) N3 (perceived or perception* or important* or value*) N1 (experienc* or satisf* or outcome* or care)) OR AB((child* or teen* or youth* or adolescen*) N3 (perceived or perception* or important* or value*) N1 (experienc* or satisf* or outcome* or care))	128
S1	TI((child* or teen* or youth* or adolescen*) N1 (report* or centered or centred or focused) N1 (experienc* or outcome* or satisf* or "health status" or prefer* or care)) OR AB((child* or teen* or youth* or adolescen*) N1 (report* or centered or centred or focused) N1 (experienc* or outcome* or satisf* or "health status" or prefer* or care))	84

Cochrane [Wiley] (July 11, 2023)

#1	((child* or teen* or youth* or adolescen*) NEAR/1 (report* or centered or centred or focused) NEAR/1 (experienc* or outcome* or satisf* or "health status" or prefer* or care)):ti,ab,kw	65
#2	((child* or teen* or youth* or adolescen*) NEAR/3 (perceived or perception* or important* or value*) NEAR/1 (experienc* or satisf* or outcome* or care)):ti,ab,kw	74
#3	((child* or teen* or youth* or adolescen*) NEAR/3 ("health status" or satisf* or recover*) NEAR/1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)):ti,ab,kw	49
#4	((child* or teen* or youth* or adolescen*) NEAR/2 (outcome* or report*) NEAR/1 measure*):ti,ab,kw	290
#5	((child* or teen* or youth* or adolescen*) NEAR/1 voice*):ti,ab,kw	20
#6	((child* or teen* or youth* or adolescen*) NEAR/3 lived NEAR/2 (experienc* or outcome* or satisf* or "health status" or prefer* or care)):ti,ab,kw	8
#7	((child* or teen* or youth* or adolescen*) NEAR/0 (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) NEAR/1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)):ti,ab,kw	28
#8	((child* or teen* or youth* or adolescen*) NEAR/1 feedback):ti,ab,kw	42
#9	((functional* NEAR/2 "health status") and self*):ti,ab,kw	70
#10	(((((health or pediatric* or paediatric*) NEAR/0 "quality of life") or HRQoL) NEAR/1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*):ti,ab,kw	232

#11	((child* or teen* or youth* or adolescen*) and ((PRO or PROs) NEAR/2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))):ti,ab,kw	123
#12	((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and (self*)):ti,ab,kw	898
#13	((child* or teen* or youth* or adolescen*) NEAR/2 (self-report*)):ti,ab,kw	811
#14	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13	2576
#15	(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*):ti,ab,kw	611921
#16	(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*):ti,ab,kw	307654
#17	(child* or adolesc* or paediatr* or pediatr*):so	490277
#18	#16 OR #17	322780
#19	#14 AND #15 AND #18	398
#20	((child* or teen* or youth* or adolescen* or boy* or girl*) NEAR/1 (perspectiv* or view? or voice* or opinion* or empower* or advoca*)):ti,kw	94
#21	((child* or teen* or youth* or adolescen* or boy* or girl*) NEAR/0 (centr* or center*)):ti,kw	44
#22	((child* or teen* or youth* or adolescen* or boy* or girl*) and (PROM or PROMs or PREM or PREMs or (report* NEAR/0 (outcome* or experience*)))):ti,kw	12
#23	#20 OR #21 OR #22	150
#24	#23 AND #15	21
#25	((child* or teen* or youth* or adolescen* or boy* or girl*) NEAR/1 experienc* NEAR/7 (surg* or preop* or perioop* or perop* or postop*)):ti,ab,kw	32
#26	#19 OR #24 OR #25	442

Embase [Ovid] (July 11, 2023)

Embase Classic+Embase 1947 to 2023 July 10

1	exp patient reported outcome/	55573
2	*self report/	10379
3	((child* or teen* or youth* or adolescen*) adj1 (report* or centered or centred or focused) adj1 (experienc* or outcome* or satisf* or "health status" or prefer* or care)).tw,kf.	522
4	((child* or teen* or youth* or adolescen*) adj3 (perceived or perception* or important* or value*) adj1 (experienc* or satisf* or outcome* or care)).tw,kf.	572
5	((child* or teen* or youth* or adolescen*) adj3 ("health status" or satisf* or recover*) adj1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)).tw,kf.	114
6	((child* or teen* or youth* or adolescen*) adj2 (outcome* or report*) adj1 measure*).tw,kf.	1200
7	((child* or teen* or youth* or adolescen*) adj1 voice*).tw,kf.	632
8	((child* or teen* or youth* or adolescen*) adj3 lived adj2 (experienc* or outcome* or satisf* or "health status" or prefer* or care)).tw,kf.	370
9	((child* or teen* or youth* or adolescen*) adj (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) adj1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)).tw,kf.	367
10	((child* or teen* or youth* or adolescen*) adj1 feedback).tw,kf.	110
11	((functional* adj2 "health status") and self*).tw,kf.	361
12	(((((health or pediatric* or paediatric*) adj2 quality of life) or HRQoL) adj1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*).tw,kf.	2875
13	((child* or teen* or youth* or adolescen*) and ((PRO or PROs) adj2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))).tw,kf.	565
14	((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and self*).tw,kf.	4933
15	((child* or teen* or youth* or adolescen*) adj2 self-report*).tw,kf.	6738
16	or/1-15	80914
17	exp surgery/	627952
18	exp surgeon/	211020

19	(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*).tw,kf.	6966876
20	or/17-19	9242253
21	exp pediatrics/ or exp child/ or exp adolescent/ or "minor (person)"/	4504658
22	(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*).tw,kf.	3193751
23	(child* or adolesc* or paediatr* or pediatr*).jw.	1120274
24	or/21-23	5485747
25	16 and 20 and 24	3727
26	((child* or teen* or youth* or adolescen* or boy* or girl*) adj1 (perspectiv* or view? or voice* or opinion* or empower* or advoca*)).ti,kf.	1920
27	((child* or teen* or youth* or adolescen* or boy* or girl*) adj (centr* or center*)).ti,kf.	950
28	((child* or teen* or youth* or adolescen* or boy* or girl*) and (PROM or PROMs or PREM or PREMs or (report* adj (outcome* or experience*)))).ti,kf.	1090
29	*"quality of life"/ and ((exp *pediatrics/ or exp *child/ or *adolescent/ or "minor (person)"/) not exp adult/)	1525
30	or/26-29	5444
31	20 and 30	707
32	((child* or teen* or youth* or adolescen* or boy* or girl*) adj1 experienc* adj7 (surg* or preop* or perioop* or perop* or postop*)).tw,kf.	260
33	25 or 31 or 32	4470

("30857849" or "33183312" or "25834278" or "35959939" or "33347651" or "30676202" or "28668970" or "20223595" or "33196410" or "34924864" or "36975119" or "31094614" or "33830343" or "24148211" or "28569451" or "29852258" or "29655778" or "25058258" or "29972067" or "27896941" or "33218361" or "29800373" or "34632153" or "29384815" or "26286444" or "36507905" or "35106917" or "30925497" or "36497690" or "31559491" or "36419027" or "20145479" or "33125739" or "26360141" or "25665957" or "26192881" or "32522194" or "17527105" or "28798984" or "34262668" or "26878499" or "34229473" or "28610795" or "33581300" or "11875145" or "28041938" or "24894777" or "34569040" or "31665824" or "28635157" or "30975368" or "33948419" or "31614242" or "3842878" or "33773755" or "29409229" or "31211431" or "1625173" or "37229839" or "28417237" or "29664849" or "35708575" or "37257855" or "35897063" or "24715422" or "28784616" or "33205735" or "28815308" or "30066816" or "28746153" or "19846110" or 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"29562769" or "30675727" or "18703884" or "35674414" or "15793401" or "33151295" or "28472844" or "31000205" or "29853236" or "26577763" or "36587742" or "23622312" or "29309443" or "25987795" or "30081742" or "28425579" or "30284250" or "24612889" or "36470745" or "32732798" or "33175563" or "31261259" or "30587304" or "34718670" or "30696346" or "26907509" or "35123787" or "31837149" or "30483946" or "27994796" or "28416023" or "31900764" or "28643117" or "2269802" or "33559860" or "28856395" or "28727858" or "28968597" or "28538570" or "31236635" or "31225999" or "35183928" or "30349946" or "10802791" or "30180088" or "30284240" or "30321323" or "32229096" or "32020725" or "10887859" or "30900033" or "11516601" or "22369219" or "31167738" or "29958793" or "19937049" or "29678170" or "24273949" or "29479900" or "26564782" or "9042118" or "32935239" or "29956493" or "28233519" or "33622957" or "27402215" or "34636795" or "30879100" or "6514917" or "16496558" or "22921164" or "34269996" or "19338463" or "23389579" or "25063368" or "32116083" or "34561660" or "29282576" or "15714787" or "30531327" or "26460499" or "19653296" or "36064983" or "26575179" or "30004245" or "25053126" or "10493648" or "23644629" or "22284837" or "26612631" or "34245258" or "25765162" or "31516047" or "21520396" or "17873814" or "20713751" or "29644385" or "32353623" or "36866431" or "23760529" or "27699557" or "24867742" or "29358019" or "27693732" or "14552306" or "30642456" or "30885335" or "12900310" or "2303552" or "33486062" or "19350642" or "25014326" or "34438097" or "11658543" or "28772342" or "30066452" or "31222392" or "19132711" or "18226154" or "12460132" or "31584227" or "33608901" or "24634396" or "30900820" or "29076746" or "26519666" or "29191095" or "5618302" or "32880193" or "30569754" or "25544993" or "34916887" or "25159223" or "33581301" or "35614427" or "31070677" or "20383649" or "29124379" or "23470447" or "24355601" or "28678998" or "30891883" or "16430410" or "28841271" or "3591505" or "4041707" or "25847977" or "9681909" or "19201559" or "32698983" or "27544638" or "27894229" or "26476972" or "28371501" or "33845659" or "20870029" or "31345179" or "25998878" or "27720200" or "25277096" or "36582933" or "2384703" or "9654836" or "33321175" or "27020377" or "36728498" or "21150731" or "32501927" or "25420921" or "36520301" or "33588763" or "33165267" or "32356375" or "26847141" or "32368935" or "30028421" or "24279218" or "20536377" or "15035240" or "21942232" or "29481599" or "28556426" or "24712721" or "32475156" or "33226845" or "24761801" or "14527704" or "10506669" or "35197205" or "18942300" or "28763701" or "25216809" or "30426663" or "35670761" or "28413130" or "30612775" or "27045086" or "32473825" or "29384973" or "21618413" or "27716318" or "36622514" or "17960770" or "30062942" or "26929181" or "31363830" or "26545589" or "24724780" or "29234838" or "21119994" or "31931397" or "30991007" or "29135288" or "33348302" 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"1383246" or "32667271" or "36216218" or "24570124" or "33526294" or "23350828" or "37100216" or "36661250" or "27429076" or "31521557" or "32444340" or "33966936" or "31489051" or "25501834" or "30396204" or "26473103" or "22529273" or "31524348" or "33591084" or "37347378" or "30194684" or "35171893" or "35972573" or "35254862" or "29244525" or "17719362" or "29103840" or "29273254" or "25088308" or "17960520" or "32184312" or "34941059" or "29878815" or "28098707" or "25589231" or "33781995" or "32299401" or "36872135" or "34131211" or "18184244" or "8424069" or "23486145" or "32389774" or "29847149" or "31990822" or "26879522" or "30855093" or "28138779" or "23582573" or "27511830" or "26312229" or "11553696" or "34002631" or "29373171" or "24360746" or "27816198" or "28205363" or "25937470" or "30091490" or "33730219" or "11444337" or "21600599" or "30501422" or "34057093" or "33197821" or "30933364" or "12122400" or "29218777" or "22750038" or "34323063" or "28600107" or "24785269" or "26501967" or "34529078" or "29179907" or "31535881" or "31307495" or "30571607" or "30869964" or "33300448" or "12402728" or "36856281" or "27007130" or "7014810" or "31198119" or "33609398" or "27518928" or "31620947" or "25799814" or "19781433" or "28889654" or "30182745" or "31901394" or "26017600" or "26095521" or "25563196" or "28817182" or "35053644" or "24585511" or "15867023" or "28592374" or "32688373" or "28248017" or "23470119" or "32562131" or "23863412" or "23870201" or "8707210" or "30846560" or "25174276" or "2046222" or "31307212" or "11137909" or "31493368" or "21563897" or "9188115" or "26034245" or "31252237" or "32013624" or "3586273" or "24411681" or "23959332" or "30482439" or "24135645" or "18307667" or "31387803" or "33765519" or "26447007" or "30688017" or "28298194" or "35181126" or "34723192" or "23981730" or "28439659" or "18992169" or "30064840" or "25733230" or "24445753" or "33618847" or "26625504" or "30667569" or "20815921" or "27085637" 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"29334933" or "25623517" or "14597017" or "32376752" or "31558420" or "26580680" or "31155885" or "33652139" or "26275239" or "30476003" or "25820683" or "19489807" or "28823623" or "31466514" or "18584473" or "7432802" or "29368686" or "30742831" or "36459394" or "26637684" or "26198707" or "30343864" or "26192378" or "34550072" or "25221969" or "33885342" or "30855342" or "23169073" or "36948934" or "31281929" or "28089292" or "33345919" or "32203873" or "32442292" or "28976287" or "24414115" or "23746866" or "17391138" or "23519958" or "31590628" or "11167100" or "23544222" or "34242161" or "28252219" or "29134251" or "30018121" or "31924236" or "31526609" or "15205550" or "28318932" or "29754980" or "25449584" or "28574124" or "32283983" or "27522440" or "21299450" or "34165630" or "33408270" or "30647200" or "24955077" or "33525923" or "31685391" or "30126743" or "29330019" or "23743433" or "28085146" or "33105055" or "34187822" or "19756730" or "22397273" or "28128793" or "23937796" or "35678489" or "25082002" or "29117822" or "33724977" or "28471432" or "32532651" or "24686151" or "23918236" or "29955931" or "12220745" or "34128745" or "27103414" or "17111941" or "25539308" or "20345615" or "30608305" or "10728255" or "26269203" or "25799142" or "34508046" or "36197603" or "28202302" or "30962109" or "27184100" or "28545727" or "16136349" or "35974718" or "27097631" or "30336742" or "25077941" or "34230203" or "30074844" or "28153861" or "30865918" or "26424196" or "27289276" or "31119906" or "26883504" or "27114076" or "30481475" or "35178463" or "26321830" or "21832888" or "34991868" or "2694857" or "21958060" or "33404808" or "32567173" or "33827692" or "21281416" or "27519274" or "32993614" or "28990491" or "36260134" or "1464058" or "26908699" or "8047560" or "33802114" or "15655186" or "35940937" or "31888370" or "33334640" or "25397366" or "22140642" or "32450557" or "11700336" or "23667428" or "24079098" or "32482958" or "25186101" or 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"27820384" or "35088747" or "34711395" or "3650597" or "28797872" or "29775379" or "30878328" or "29696317" or "8935312" or "9575010" or "31384981" or "29100774" or "4754548" or "32621064" or "31426703" or "15543218" or "24577640" or "23168102" or "32037234" or "23679811" or "29781716" or "27898605" or "24849913" or "27072024" or "32584926" or "26657571" or "12836995" or "28661082" or "11818762" or "17145490" or "24673603" or "34166262" or "2087407" or "27744499" or "32759066" or "19383176" or "24658445" or "17465390" or "29980545" or "24708535" or "16467664" or "24334369" or "29447822" or "28077415" or "31246826" or "29437508" or "34670677" or "36378509" or "8736472" or "36287352" or "26448622" or "20698962" or "21709820" or "21660203" or "21744648" or "23121073" or "31318611" or "15976152" or "34029267" or "35584396" or "26991402" or "35246063" or "21372703" or "27265024" or "24491360" or "1617472" or "26886672" or "33533570" or "36238262" or "24726124" or "27846610" or "33317436" or "31627759" or "15867109" or "21315631" or "24443894" or "28153429" or "23807064" or "28340017" or "27175631" or "27907053" or "31895236" or "24724715" or "32956254" or "33907079" or "31381468" or "32243495" or "22703807" or "31530206" or "31679676" or "31889572" or "33090474" or "25455529" or "24880925" or "34351688" or "32871911" or "31395159" or "26842312" or "10865553" or "32031200" or "31549203" or "33208669" or "28586587" or "35012837" or "28935397" or "36394207" or "36737707" or "30569480" or "30182063" or "26740165" or "35267237" or "28207575" or "28424633" or "31670610" or "31512920" or "29576119" or "3527691" or "32032087" or "34292310" or "26092232" or "25774054" or "16585310" or "15536221" or "30295594" or "24952003" or "31061436" or "35538806" or "31256354" or "29514373" or "31096459" or "31797022" or "30369354" or "33170758" or "29798163" or "36285720" or "35466902" or "32911007" or "32707553" or "33381560" or "33104394" or "34076625" or "32842115" or "17544126" or "30472892" or "29411068" or "30157124" or "17046072" or "34483476" or "33749731").pm. [Remove Medline UI]	
35	33 not 34	2868
36	limit 35 to (books or chapter or conference abstract or conference paper or "conference review" or editorial or letter)	1219
37	35 not 36	1649
38	remove duplicates from 37	1609

Global Health [Ovid] (July 11, 2023)

Global Health 1973 to 2023 Week 26, Database Field Guide Global Health Archive 1910 to 1972

1	((child* or teen* or youth* or adolescen*) adj1 (report* or centered or centred or focused) adj1 (experienc* or outcome* or satisf* or "health status" or prefer* or care)).ti,ab,id.	80
2	((child* or teen* or youth* or adolescen*) adj3 (perceived or perception* or important* or value*) adj1 (experienc* or satisf* or outcome* or care)).ti,ab,id.	118
3	((child* or teen* or youth* or adolescen*) adj3 ("health status" or satisf* or recover*) adj1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)).ti,ab,id.	13

4	((child* or teen* or youth* or adolescen*) adj2 (outcome* or report*) adj1 measure*).ti,ab,id.	343
5	((child* or teen* or youth* or adolescen*) adj1 voice*).ti,ab,id.	68
6	((child* or teen* or youth* or adolescen*) adj3 lived adj2 (experienc* or outcome* or satisf* or "health status" or prefer* or care)).ti,ab,id.	56
7	((child* or teen* or youth* or adolescen*) adj (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) adj1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)).ti,ab,id.	49
8	((child* or teen* or youth* or adolescen*) adj1 feedback).ti,ab,id.	10
9	((functional* adj2 "health status") and self*).ti,ab,id.	38
10	(((((health or pediatric* or paediatric*) adj2 quality of life) or HRQoL) adj1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*).ti,ab,id.	236
11	((child* or teen* or youth* or adolescen*) and ((PRO or PROs) adj2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))).ti,ab,id.	46
12	((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and self*).ti,ab,id.	131
13	((child* or teen* or youth* or adolescen*) adj2 self-report*).ti,ab,id.	1054
14	or/1-13	2144
15	(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*).ti,ab,id.	3903 93
16	paediatrics/ or exp adolescents/ or exp children/	4427 75
17	(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*).ti,ab,id.	5634 39
18	(child* or adolesc* or paediatr* or pediatr*).jx.	1283 62
19	or/16-18	6149 56
20	14 and 15 and 19	70

21	((child* or teen* or youth* or adolescen* or boy* or girl*) adj1 (perspectiv* or view? or voice* or opinion* or empower* or advoca*)).ti,id.	318
22	((child* or teen* or youth* or adolescen* or boy* or girl*) adj (centr* or center*)).ti,id.	256
23	((child* or teen* or youth* or adolescen* or boy* or girl*) and (PROM or PROMs or PREM or PREMs or (report* adj (outcome* or experience*)))).ti,id.	20
24	or/21-23	593
25	15 and 24	33
26	((child* or teen* or youth* or adolescen* or boy* or girl*) adj1 experienc* adj7 (surg* or preop* or perioop* or perop* or postop*)).ti,ab,id.	13
27	20 or 25 or 26	115
28	remove duplicates from 27	115

Global Index Medicus [WHO] (July 11, 2023)

1	tw:((tw:(child* OR teen* OR adolescen*)) AND (tw:((reported*) AND (experienc* OR outcome*))) AND (tw:(self*)) AND (tw:(surger* OR surgic* OR operation? OR postop*)))	**38**

Medline [Ovid] (July 11, 2023)

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to July 10, 2023>

1	exp patient reported outcome measures/	13698
2	patient outcome assessment/	5984
3	*self report/	7577
4	((child* or teen* or youth* or adolescen*) adj1 (report* or centered or centred or focused) adj1 (experienc* or outcome* or satisf* or "health status" or prefer* or care)).tw,kf.	417
5	((child* or teen* or youth* or adolescen*) adj3 (perceived or perception* or important* or value*) adj1 (experienc* or satisf* or outcome* or care)).tw,kf.	463
6	((child* or teen* or youth* or adolescen*) adj3 ("health status" or satisf* or recover*) adj1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)).tw,kf.	80
7	((child* or teen* or youth* or adolescen*) adj2 (outcome* or report*) adj1 measure*).tw,kf.	863
8	((child* or teen* or youth* or adolescen*) adj1 voice*).tw,kf.	509

9	((child* or teen* or youth* or adolescen*) adj3 lived adj2 (experienc* or outcome* or satisf* or "health status" or prefer* or care)).tw,kf.	301
10	((child* or teen* or youth* or adolescen*) adj (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) adj1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)).tw,kf.	278
11	((child* or teen* or youth* or adolescen*) adj1 feedback).tw,kf.	78
12	((functional* adj2 "health status") and self*).tw,kf.	284
13	(((((health or pediatric* or paediatric*) adj2 quality of life) or HRQoL) adj1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*).tw,kf.	1859
14	((child* or teen* or youth* or adolescen*) and ((PRO or PROs) adj2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))).tw,kf.	278
15	((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and self*).tw,kf.	2359
16	((child* or teen* or youth* or adolescen*) adj2 self-report*).tw,kf.	5398
17	or/1-16	38212
18	exp Specialties, Surgical/	219627
19	exp Surgical Procedures, Operative/	353961
20	exp Surgeons/	16801
21	su.fs.	225473
22	(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*).tw,kf.	481810
23	or/18-22	665292
24	exp pediatrics/ or exp child/ or adolescent/ or minors/	339053

25	(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*).tw,kf.	231103 8
26	(child* or adolesc* or paediatr* or pediatr*).jw.	835006
27	or/24-26	435355 9
28	17 and 23 and 27	2358
29	((child* or teen* or youth* or adolescen* or boy* or girl*) adj1 (perspectiv* or view? or voice* or opinion* or empower* or advoca*)).ti,kf.	1549
30	((child* or teen* or youth* or adolescen* or boy* or girl*) adj (centr* or center*)).ti,kf.	719
31	((child* or teen* or youth* or adolescen* or boy* or girl*) and (PROM or PROMs or PREM or PREMs or (report* adj (outcome* or experience*)))).ti,kf.	766
32	*"Quality of Life"/ and ((exp *pediatrics/ or exp *child/ or *adolescent/ or *minors/) not adult/)	152
33	or/29-32	3162
34	23 and 33	362
35	((child* or teen* or youth* or adolescen* or boy* or girl*) adj1 experienc* adj7 (surg* or preop* or perioop* or perop* or postop*)).tw,kf.	192
36	28 or 34 or 35	2787
37	remove duplicates from 36	2784

Web of Science [Clarivate Analytics] (July 11, 2023)

Indexes= Web of Science Core Collection (IC, CCR, SCI, AHCI, BHCI, BSCI, ESCI, ISTP, SSCI, ISHP), Timespan=All years

#	Search Query	Results
1	TI=((child* or teen* or youth* or adolescen*) NEAR/1 (report* or centered or centred or focused) NEAR/1 (experienc* or outcome* or satisf* or "health status" or prefer* or care)) OR AB=((child* or teen* or youth* or adolescen*) NEAR/1 (report* or centered or centred or focused) NEAR/1 (experienc* or outcome* or satisf* or "health status" or prefer* or care))	3847
2	TI=((child* or teen* or youth* or adolescen*) NEAR/3 (perceived or perception* or important* or value*) NEAR/1 (experienc* or satisf* or outcome* or care)) OR AB=((child* or teen* or youth* or adolescen*) NEAR/3 (perceived or perception* or important* or value*) NEAR/1 (experienc* or satisf* or outcome* or care))	2256

3	TI=((child* or teen* or youth* or adolescen*) NEAR/3 ("health status" or satisf* or recover*) NEAR/1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) OR AB=((child* or teen* or youth* or adolescen*) NEAR/3 ("health status" or satisf* or recover*) NEAR/1 (questionnair* or scor$1 or scoring or assessment* or survey* or interview*))	280
4	TI=((child* or teen* or youth* or adolescen*) NEAR/2 (outcome* or report*) NEAR/1 measure*) OR AB=((child* or teen* or youth* or adolescen*) NEAR/2 (outcome* or report*) NEAR/1 measure*)	2881
5	TI=((child* or teen* or youth* or adolescen*) NEAR/1 voice*) OR AB=((child* or teen* or youth* or adolescen*) NEAR/1 voice*)	2559
6	TI=((child* or teen* or youth* or adolescen*) NEAR/3 lived NEAR/2 (experienc* or outcome* or satisf* or "health status" or prefer* or care)) OR AB=((child* or teen* or youth* or adolescen*) NEAR/3 lived NEAR/2 (experienc* or outcome* or satisf* or "health status" or prefer* or care))	2546
7	TI=((child* or teen* or youth* or adolescen*) NEAR/0 (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) NEAR/1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*)) OR AB=((child* or teen* or youth* or adolescen*) NEAR/0 (report* or measur* or questionnair* or scor$1 or scoring or assess* or survey* or interview*) NEAR/1 (outcome* or experience* or symptom* or progress* or satisfaction* or activit* or "health status" or recover*))	2040
8	TI=((child* or teen* or youth* or adolescen*) NEAR/1 feedback) OR AB=((child* or teen* or youth* or adolescen*) NEAR/1 feedback)	570
9	TI=((functional* NEAR/2 "health status") and self*) OR AB=((functional* NEAR/2 "health status") and self*)	291
10	TI=(((((health or pediatric* or paediatric*) NEAR/0 "quality of life") or HRQoL) NEAR/1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*) OR AB=(((((health or pediatric* or paediatric*) NEAR/0 "quality of life") or HRQoL) NEAR/1 (measure* or questionnair* or scor$1 or scoring or assessment* or survey* or interview*)) and self*)	1826
11	TI=((child* or teen* or youth* or adolescen*) and ((PRO or PROs) NEAR/2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*))) OR AB=((child* or teen* or youth* or adolescen*) and ((PRO or PROs) NEAR/2 (measure* or questionnair* or score$1 or scoring or assessment* or survey* or interview*)))	402
12	TI=((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and (self*)) OR AB=((PedsQL or PROM or PROMs or PREM or PREMs or PREOM? or PROMIS) and (self*))	2192

13	TI=((child* or teen* or youth* or adolescen*) NEAR/2 (self-report*)) OR AB=((child* or teen* or youth* or adolescen*) NEAR/2 (self-report*))	8319
14	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13	26992
15	TI=(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*) OR AB=(surger* or surgic* or surgeon? or procedure* or operate? or operation? or preop* or perioop* or perop* or postop* or postsurg* or reoperat* or bypass* or by-pass* or resect* or re-sect* or transplant* or biopsy or biopsie* or debridement* or laparoscop* or laparotom*)	5649200
16	TI=(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*) OR AB=(child* or paediatr* or pediatr* or toddler* or kid or kids or boy* or girl* or juvenile* or adolesc* or teen* or youth* or pubescen* or preadolesc* or prepubesc* or preteen*)	2946748
17	SO=(child* or adolesc* or paediatr* or pediatr*)	421748
18	#16 OR #17	3136044
19	#14 AND #15 AND #18	1493
20	TI=((child* or teen* or youth* or adolescen* or boy* or girl*) NEAR/1 (perspectiv* or view? or voice* or opinion* or empower* or advoca*))	6991
21	TI=((child* or teen* or youth* or adolescen* or boy* or girl*) NEAR/0 (centr* or center*))	1382
22	TI=((child* or teen* or youth* or adolescen* or boy* or girl*) and (PROM or PROMs or PREM or PREMs or (report* NEAR/0 (outcome* or experience*))))	576
23	#20 OR #21 OR #22	8916
24	#23 AND #15	298
25	TI=((child* or teen* or youth* or adolescen* or boy* or girl*) NEAR/1 experienc* NEAR/7 (surg* or preop* or perioop* or perop* or postop*)) OR AB=((child* or teen* or youth* or adolescen* or boy* or girl*) NEAR/1 experienc* NEAR/7 (surg* or preop* or perioop* or perop* or postop*))	365
26	#19 OR #24 OR #25	2093
27	PMID=(0* OR 1* OR 2* OR 3* OR 4* OR 5* OR 6* OR 7* OR 8* OR 9*)	27605335
28	#26 NOT #27	408

Appendix 2.2. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist and the PRISMA-S Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Pg.43
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg.44
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg.45
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg.46
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg.46
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg.46 & included in the Appendix
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Included in the Appendix
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg.47
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg.47

Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Pg.47
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Pg.47
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg.48
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/A
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Pg.48
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pg.48
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg.48
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Pg.48
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Pg.48
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			

Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Pg.48
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Pg.48 and *Figure 4.1* (pg. 54)
Study characteristics	17	Cite each included study and present its characteristics.	Pg.49 and *Supplementary File 4.1* (pg. 58)
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Pg.50 and *Supplementary File 4.3* (pg.68)
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarize the characteristics and risk of bias among contributing studies.	Pg.49
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Pg.50
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Pg.50
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Pg.50
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pg.74
	23b	Discuss any limitations of the evidence included in the review.	Pg.81
	23c	Discuss any limitations of the review processes used.	Pg.81

	23d	Discuss implications of the results for practice, policy, and future research.	Pg.82
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	National Institute for Health-PROSPERO (CRD#42024539515)
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg.46
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg.43
Competing interests	26	Declare any competing interests of review authors.	Pg.43
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

PRISMA-S Checklist

Section/topic	#	Checklist item	Location(s) Reported
INFORMATION SOURCES AND METHODS			
Database name	1	Name each individual database searched, stating the platform for each.	Pg.46 and included in the *Appendix*

Multi-database searching	2	If databases were searched simultaneously on a single platform, state the name of the platform, listing all of the databases searched.	Pg.46 and included in the *Appendix*
Study registries	3	List any study registries searched.	N/A
Online resources and browsing	4	Describe any online or print source purposefully searched or browsed (e.g., tables of contents, print conference proceedings, web sites), and how this was done.	Conference proceedings included primarily within Embase (Ovid) as well as other databases.
Citation searching	5	Indicate whether cited references or citing references were examined, and describe any methods used for locating cited/citing references (e.g., browsing reference lists, using a citation index, setting up email alerts for references citing included studies).	N/A
Contacts	6	Indicate whether additional studies or data were sought by contacting authors, experts, manufacturers, or others.	N/A
Other methods	7	Describe any additional information sources or search methods used.	N/A
SEARCH STRATEGIES			
Full search strategies	8	Include the search strategies for each database and information source, copied and pasted exactly as run.	*Appendix*
Limits and restrictions	9	Specify that no limits were used, or describe any limits or restrictions applied to a search (e.g., date or time period, language, study design) and provide justification for their use.	Pg.46
Search filters	10	Indicate whether published search filters were used (as originally designed or modified), and if so, cite the filter(s) used.	MUHC pediatric filter used
Prior work	11	Indicate when search strategies from other literature reviews were adapted or reused for a substantive part or all of the search, citing the previous review(s).	N/A
Updates	12	Report the methods used to update the search(es) (e.g., rerunning searches, email alerts).	N/A
Dates of searches	13	For each search strategy, provide the date when the last search occurred.	Pg.46

PEER REVIEW			
		Describe any search peer review process.	Used PRESS (McGowan J, Sampson M, Salzwedel DM, Cogo E, Foerster V, Lefebvre C. PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. J Clin Epidemiol. 2016 Jul;75:40-6. doi: 10.1016/j.jclinepi.2016.01.021). Reviewed by the McConnell Resource Centre of the MUHC.
Peer review	14		
MANAGING RECORDS			
Total Records	15	Document the total number of records identified from each database and other information sources.	*Appendix*

Deduplication	16	Describe the processes and any software used to deduplicate records from multiple database searches and other information sources.	Initial deduplication done via Endnote X9.3.3 using modified version of Bramer WM, Giustini D, de Jonge GB, Holland L, Bekhuis T. De-duplication of database search results for systematic reviews in Endnote. Journal of the medical library association: JMLA. Further deduplication manually performed in Endnote then in Rayyan online software.

PRISMA-S: An Extension to the PRISMA Statement for Reporting Literature Searches in Systematic Reviews Rethlefsen ML, Kirtley S, Waffenschmidt S, Ayala AP, Moher D, Page MJ, Koffel JB, PRISMA-S Group. Last updated February 27, 2020.

Appendix 2.3. Meta-Analysis of Eligible Studies Comparing Child and Parent Scores in PedsQL™

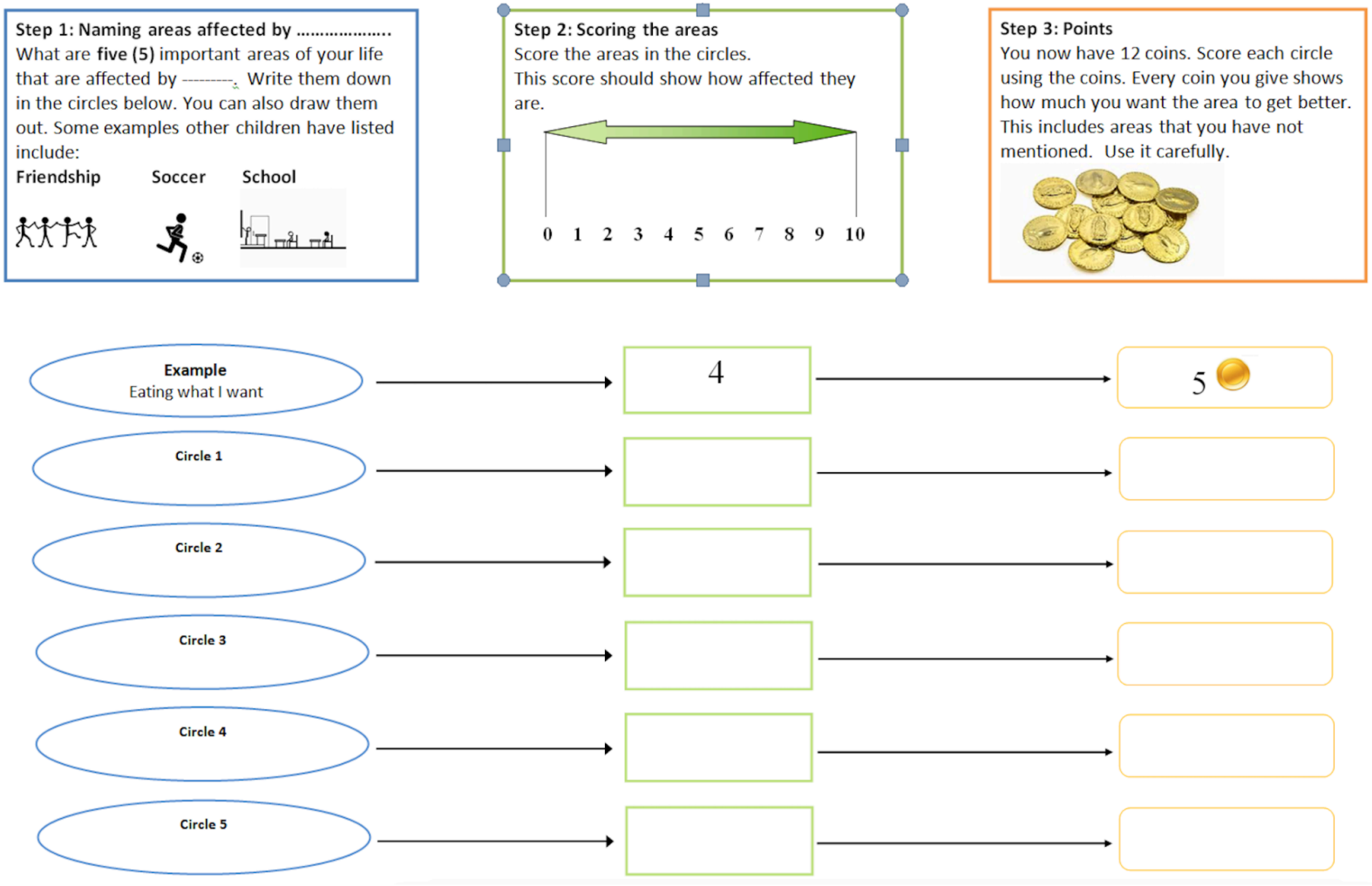
Meta-analysis of eligible studies comparing child and parent scores in PedsQL™

					Child			Parent			SD. Mean difference, Random, 95% CI				
#	Article (Ref)	Measure	N	Disease	Mean	SD	Total	Mean	SD	Total	Weight (%)	SMD	SE	CI_lower	CI_upper
1	van de Kar et al., 2021	PedsQL™	16	Firecracker-Induced Severe Hand Injuries	81.0	18	8	79	16	8	0.2%	0.2	8.5	-15.4	15.7
2	Grant et al., 2021	PedsQL™	20	Liver Transplant Patients	70.4	19.6	10	54.0	17.8	10	0.3%	1.0	9.7	-18.6	20.6
3	Ingerski et al., 2010	PedsQL™	40	Pediatric Chronic Illnesses.	81.4	12.2	15	74.0	15.6	25	0.6%	0.6	5.3	-9.4	11.0
4	Tahirovic et al., 2011	PedsQL™	50	Congenital Heart Disease	80.9	19.2	25	74.6	21.8	25	0.7%	0.3	7.3	-13.9	14.6
5	Parekh et al., 2006	PedsQL™	59	Reconstructive Urological Surgery	76.8	15.0	13	71.1	20.6	46	0.9%	0.4	3.2	-5.8	6.7
6	Miserachs et al., 2019	PedsQL™	60	Biliary Atresia	75.5	14.4	16	77.1	15.8	44	0.9%	-0.1	2.1	-4.3	4.1
7	Uzark et al., 2012	PedsQL™	70	Heart Disease	72.2	14.5	34	78.6	17.5	36	1.0%	-0.4	3.0	-6.3	5.6
8	Sorensen et al., 2015	PedsQL™	78	Pediatric Acute Liver Failure	71.6	14.4	32	70.8	19.4	46	1.2%	0.1	3.7	-7.2	7.4
9	Flieder et al., 2018	PedsQL™	135	Esophageal Atresia	84.3	12.5	67	88	11.4	68	2.0%	-0.3	1.3	-2.9	2.3
10	Abrao et al., 2021	PedsQL™	149	Chronic Kidney Disease	86.0	11.0	75	75.8	12.3	74	2.2%	0.7	1.3	-1.9	3.3
11	Wray et al., 2012	PedsQL™	160	Heart Transplantation	71.7	9.5	80	75	8.7	80	2.4%	-0.4	1.6	-3.6	2.8
12	Lifland et al., 2018	PedsQL™	171	Surgery (Multiple)	81.0	13.4	71	74.9	18.5	100	2.6%	0.3	1.5	-2.6	3.3
13	Ten Kate et al., 2021	PedsQL™	184	Esophageal Atresia	48.0	22	92	45.7	17.1	92	2.7%	0.1	2.4	-4.6	5.0

14	Palabiyik and Demir, 2021	PedsQL™	192	Appendectomy	87.3	27.1	96	86.1	16.4	96	2.9%	0.1	3.4	-6.6	6.8
25	Alonso et al., 2010	PedsQL™	252	Pediatric Liver Transplant Recipients	80.5	14.3	126	79.4	14.2	126	3.8%	0.1	1.3	-2.5	2.6
16	Lazor et al., 2017	PedsQL™	294	Pediatric Lung Transplantation	82.4	17.9	147	80.3	17.9	147	4.4%	0.1	1.5	-2.1	2.3
17	De Bruyne et al., 2023	PedsQL™	309	Kidney Diseases	75.5	14.6	137	76.2	15.3	172	4.6%	-0.04	1.4	-2.8	2.7
18	Park et al., 2012	PedsQL™	316	Renal Disease	75.1	16.6	158	74.9	17.4	158	4.7%	0.02	1.3	-2.6	2.7
19	Hendriksma et al., 2020	PedsQL™	372	Cochlear Implants	73.5	1.2	124	77.6	1.1	248	5.6%	-0.14	0.2	-0.5	0.2
20	Kikuchi et al., 2018	PedsQL™	1091	Liver Transplant for Biliary Atresia	72.6	15.4	508	71.8	17.3	583	16.3%	0.05	0.8	-1.4	1.6
21	Parekh et al., 2008	PedsQL™	1232	Ureteropelvic Junction Obstruction	77.2	14.2	363	77.3	17.6	869	18.4%	-0.004	0.4	-0.7	0.7
22	Ã‡avusoglu et al., 2012	PedsQL™	1441	Congenital Anomaly	77.1	14.3	444	76.1	17.2	997	21.5%	0.05	0.4	-0.661	0.8
	Total (95% CI)		6691				2641			4050	100.0%	0.04	0.2	−0.4	0.5

Abbreviations: PedsQL™ (Pediatric Quality of Life Inventory), CI (Confidence Interval), SMD (Standard Mean Difference), SE (Standard Error), SD (Standard Deviation), N (Sample Size)

Appendix 2.4. Pediatric Patient-Generated Index (pPGI)



Designed by Nikki Ow

Appendix 2.5. Research Ethics Board Approvals and Consent Forms

Research Institute of the McGill Health Centre approval

Centre universitaire de santé McGill  McGill University Health Centre

2022-10-31

Dr Dan Poenaru
Pediatric Surgery
c/o: Elena Guadagno
Pediatric Surgery
1001 Décarie Boulevard Montréal, Québec Canada H4A 3J1 email: elena.guadagno@muhc.mcgill.ca

Re: MUHC Authorization

Adaptation and translation of the Patient Reported Experience Measure for Children and Young People (PREM-CYP) at The Montreal Children's Hospital **(PREM CYL MTL / 2023-8958)**

Dear Dr Poenaru,

We are writing to confirm that the study mentioned above has received research ethics board approval and all required institutional approvals.

You are hereby authorized to conduct your research at the McGill University Health Centre (MUHC) as well as to initiate recruitment.

Please refer to the MUHC Study number in all future correspondence relating to this study.

In accordance with applicable policies it is the investigator's responsibility to ensure that staff involved in the study is competent and qualified and, when required, has received certification to conduct clinical research.

Should you have any questions, please do not hesitate to contact the support for the Personne mandatée at personne.mandatee@muhc.mcgill.ca.

We wish you every success with the conduct of the research.

Sincerely,

Kassandy Kowalyk

Kassandy Kowalyk for:
Keith Woolrich
Personne Mandatée
Centre universitaire de santé McGill

Signed on 2022-10-31 at 11:59

Centre universitaire de santé McGill | McGill University Health Centre

2022-10-31

Dr. Dan Poenaru
c/o: Elena Guadagno
email: elena.guadagno@muhc.mcgill.ca

Re: Final REB Approval of a New Research Project (PREM CYL MTL / 2023-8958)

Adaptation and translation of the Patient Reported Experience Measure for Children and Young People (PREM-CYP) at The Montreal Children's Hospital

MUHC REB Co-Chair for the Pediatrics (PED) Panel: Mr. Carlo Cicero Oneto, MD, PhD

Dear Dr. Poenaru,

Thank you for submitting your responses and corrections for the research project indicated above, as requested by the McGill University Health Centre (MUHC) Research Ethics Board (REB).

The MUHC REB, more precisely its PED Panel provided conditional approval for the research project after a delegated review provided by its member(s).

On 2022-10-31, a delegated review of your responses and corrections was provided by member(s) of the MUHC REB. The research project was found to meet scientific and ethical standards for conduct at the MUHC.

The following documents were approved or acknowledged by the MUHC REB:

- Initial Submission Form (F11-98625)
- REB Conditions & PI Responses Form(s) (F20-102253, F20-103651)

Research Protocol

- PREM CYP MTL_V1_EN_Protocol_October 12 2022.docx [Date: 2022-10-12, Version: 1]
- PREM CYP MTL_V1_FR_Protocol_October 25 2022.docx[Date: 2022-10-25, Version: 1]

Approval of the Department / Division Head

- PREM CYP MTL_Approval of department head_JP Farmer_ July 19 2022.pdf [Date: 2022-07-11]

Questionnaire - Study Material

-]14-16 Outpatient_EN_Oct_22.pdf [Date: 2022-10-22, Version: 1]
- 12-13 Outpatient_EN_Oct_22.pdf [Date: 2022-10-22, Version: 1]
- 8-11 Outpatient_FR_Oct_24_REBapproved.pdf [Date: 2022-10-31]
- 12-13 Outpatient_FR_Oct_25_REBapproved.pdf [Date: 2022-10-31]
- 14-16 Outpatient_FR_Oct_22_REBapproved.pdf [Date: 2022-10-31]
- 8-11 Outpatient - v5_REBapproved.pdf [Date: 2022-09-26]
- 12-13 Outpatient (animal) - v5_REBapproved.pdf [Date: 2022-09-26]
- 14-16 Outpatient - v5_REBapproved.pdf [Date: 2022-09-26]
- PREM CYP MTL_EN_V1_Face Validation Form_August 4 2022_REBapproved.docx [Date: 2022-09-26]
- PREM CYP MTL_FR_V1_Face Validation Form_October 25 2022_REBapproved.docx [Date: 2022-10-31]

Participant Information

- PREM CYP MTL_V1_Pamphlet_July 22 2022.docx)[Date: 2022-07-22, Version: 1]
- PREM CYP MTL_V1_FR_Pamphlet_July 22 2022.docx [Date: 2022-07-22, Version: 1]

ICF approved by the REB

- CYP-PREM_MTL_Assent form_8-13_V1-October 11, 2022_REBapproved.pptx
- CYP-PREM_MTL_Formulaire d'assentiment_8-13_V1_FR_October 21, 2022_REBapproved.pptx
- PREM CYP MTL_EN_V1_Consent_October 12 2022_REBapproved.docx
- PREM CYP MTL_FR_V1_Consent_October 25 2022_REBapproved.docx

Additional documents

- 2022_07_12_CYP PREM Copyright Statement_Final version.pdf

This will be reported to the MUHC REB and will be entered accordingly into the minutes of the next PED Panel meeting. Please be advised that you may only initiate the study after all required reviews and decisions are received and documented and you have received the MUHC authorization letter.

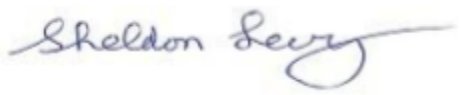
The approval of the research project is valid until 2023-10-31.

All research involving human subjects requires review at recurring intervals. To comply with the regulation for continuing review of at least once per year, it is the responsibility of the investigator to submit an *Annual Renewal Submission Form* (F9) to the REB prior to expiry. Please be advised that should be protocol reach its expiry before a Continuing review has been submitted, the data collected after the expiry date may not be considered valid. However, should the research conclude for any reason prior to approval expiry, you are required to submit a *Completion (End of Study) Report* (F10) to the board once the data analysis is complete to give an account of the study findings and publication status.

Furthermore, should any revision to the project or other development occur prior to the next continuing review, you must advise the REB without delay. Regulation does not permit initiation of a proposed study modification prior to its approval by the REB.

The MUHC REB is registered and works under the published guidelines of the *Tri-Council Policy Statement 2*, in compliance with the *Plan d'action ministériel en éthique de la recherche et en intégrité scientifique* (MSSS, 1998) and the *Food and Drugs Act* (2001.06.07), acting in conformity with standards set forth in the (US) *Code of Federal Regulations* governing human subjects research and functioning in a manner consistent with internationally accepted principles of good clinical practice.
We trust this will prove satisfactory to you. Thank you for your consideration in this matter.

Best Regards,



Sheldon Levy
MUHC REB Coordinator for MUHC REB
Co-chair mentioned above
Signed on 2022-11-08 at 12:17

Centre universitaire de santé McGill
McGill University Health Centre

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L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

PEDIATRIC RESEARCH INFORMATION AND CONSENT FORM

Title: Adaptation and translation of the Patient Reported Experience Measure for Children and Young People (PREM-CYP) at The Montreal Children's Hospital

Persons responsible:

Dan Poenaru, Pediatric Surgeon, RI Investigator, Department of Pediatric Surgery, Harvey E. Beardmore Division of Pediatric Surgery, The Montreal Children's Hospital, McGill University Health Centre
Zanib Nafees, MSc, PhD Candidate, Department of Experimental Surgery, McGill University Health Center
Julia Ferrera, MD, MScC, Department of Pediatric Surgery, Harvey E. Beardmore Division of Pediatric Surgery, McGill University Health Center
Elena Guadagno, MLIS, Project Manager, Department of Pediatric Surgery, Harvey E. Beardmore Division of Pediatric Surgery, McGill University Health Center
Jo Wray, PhD, Senior Research Fellow in the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID), Health psychologist in the Heart and Lung Directorate at Great Ormond Street Hospital for Children (GOSH)
Agneta Anderzén Carlsson, RN, Associate Professor, University Health Care Research Centre, Region Örebro Count

Funding Source: N/A

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS SESSION?

The Harvey E. Beardmore Department of Pediatric Surgery participates in research studies to try to improve the experiences of children and young people at the Montreal Children's Hospital. Today, we are inviting you to take part in a research study session. Please read this information to help you decide if you want to participate in this research project's session. It is important that you understand this information. We encourage you to ask questions! Please take all the time you need to make your decision.

We encourage parents to include their child in the discussion and decision-making to the extent that the child is able to understand.

In this research information and consent form, "you" means you or your child.

WHY IS THIS STUDY SESSION BEING DONE?

Context and importance of the research

It is important to improve the experiences of children and young people as patients. The first step is to find out what children and young people think about their hospital experience. Our goal is to collect all the information from children and young people about their hospital experience and use the collected information to adapt and translate the existing Patient Reported Experience Measures (PREMs) for use at the Montreal Children's hospital. These existing English questionnaires were created at Great Ormond Street Hospital for Children (GOSH), London, United Kingdom. It looks at different points of care and children's hospital experiences which are important to children themselves.

WHAT ARE THE OBJECTIVES OF THE RESEARCH?

You are being invited to participate in this research that aims, 1) to make sure that the voices of children and young people are heard regarding their experiences at the hospital; (2) to help make this PREM available to more people by translating it from English to French; and (3) to make sure PREMs are clear and understood by children and young people at the Montreal Children's Hospital.

HOW MANY PEOPLE WILL TAKE PART IN THIS SESSION?

Around 12-15 patients in the age groups (8-11, 12-13, 14-16) at the pediatric surgery clinics will take part in each session.

WHAT WILL HAPPEN ON THIS RESEARCH SESSION?

Session 1:

If you decide to participate in this session, you will be asked to read the English questions while you tell us what you think, out loud. You will be asked about what parts of care are important to you that had an impact on your experience while you received the care. Your doctor will tell you about the study and invite you to join. You will then come to the researcher and look at a few questions. The researcher will ask you to think out loud whatever comes to mind while you read the questions. This should take about 10 minutes. The researcher will ask to audio-record your answers.

Session 2:

If you decide to participate in this session, we will have a one-on-one interview with you to see how you understand the questions. You will complete a questionnaire and we will go over with you the language and concepts that are used in the questionnaires. This will take around 30-60 minutes.

Session 3:

If you decide to participate in this session, you will read the questionnaire in French or English and answer some questions about it. This should take about 10 minutes. Then you will take a 5- or 10-minute break to play a game. After this, you will read the same questions in the second language that you did not read before and answer some questions again. This should take about 10 minutes. For example, if the first questions you read were in French, then you would read the English the next time. You will then tell us about the questions that you read in both languages, and we will also ask you about your experience completing the questions.

FOR HOW LONG WILL YOU PARTICIPATE IN THIS SESSION?

You will participate in person for 10 minutes in session 1, or 30-60 minutes in session 2, or less than 30 minutes in session 3. Parents can stay with their children. If you agree to participate in phase 1, but do not have enough time to complete the study before or after your appointment, a member of the research team will request a caregiver's email. In this case, we will email the caregiver to set up a time to complete the study.

WHAT ARE THE RISKS?

A possible risk associated with this session is a breach of confidentiality. To limit this risk, we will take the steps to protect your confidentiality described in a section below.

IS ANY COMPENSATION BEING OFFERED?

For your time participating in this session, you will be given a 20$ gift card.

SHOULD YOU SUFFER ANY HARM

Should you suffer harm of any kind following any procedure related to this research study session, you will receive all the care and services required by your state of health.
By agreeing to participate in this research session, you are not waiving any of your rights nor discharging the doctor in charge of the study session, the sponsor, or the institution of their civil and professional responsibilities.

HOW IS PRIVACY ENSURED?

During your participation in this session, the study session doctor and their team will collect and record information about you in a study session file. They will only collect information required to meet the scientific goals of the study session.

The study session file may include information about yourself that you provide us directly, including your age, gender, language(s) spoken at home, and your diagnosis.

All the information collected during the research project will remain confidential to the extent provided by law.

To ensure your safety, a copy of this information and consent form will be placed in a locked cabinet in the office of the principal investigator. We will also store the data on the MUHC Next Cloud server database authorized by the MUHC.

The study session data will be stored for 7 years by the study session doctor.

The data may be published or shared during scientific meetings or presentations; however, it will not be possible to identify you.

For monitoring, safety, and security, your study file which could include documents that may identify you may be examined by a person mandated by the institution, or the Research Ethics Board. All these individuals and organizations will have access to your personal data, but they adhere to a confidentiality policy.

You have the right to consult your study session file in order to verify the information gathered, and to have it corrected if necessary.

Throughout the program, the research team will be recording each session. All audio-recordings will be transcribed (your words will be written down) in a de-identified fashion (i.e. your name will not appear in the transcripts). **The audio-recordings will be destroyed after transcription.** It is possible that direct quotes of what you said will be presented in publications and/or conferences. However, precautions will be taken to ensure that it will not be possible to identify you. The questionnaires and pictures of your written material/drawings will be destroyed 7 years after the completion of the research project.

No patient results/data will be shared with the external collaborator. Only the adapted English version of the PREM-CYP_MTL questionnaire and the French translated version of the PREM-CYP_MTL questionnaire will be shared with the external collaborator to obtain feedback on the comprehensiveness of the questions. This has been added to the protocol

IS YOUR PARTICIPATION VOLUNTARY AND CAN YOU WITHDRAW?

Yes. Your participation in this research project is voluntary. Therefore, you may refuse to participate. You may also withdraw from the project at any time, without giving any reason, by informing the study session doctor or a member of the research team.

Your decision not to participate in the study session, or to withdraw from it, will have no impact on the quality of care and services to which you are otherwise entitled, or on your relationship with the study session doctor or clinical team.

The study session doctor, the Research Ethics Board, or the funding agency may put an end to your participation without your consent. This may happen if new findings or information indicate that participation is no longer in your interest, if you do not follow study session instructions, or if there are administrative reasons to terminate the project.

If you withdraw or are withdrawn from the study session, the information collected during the study session will nonetheless be stored, analyzed, or used to protect the scientific integrity of the research project.

Any new findings that could influence your decision to stay in the research project session will be shared with you as soon as possible.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have any questions about this research project session or if you suffer any problems, you believe are related to your participation in this research session, you can call the researcher responsible for the project in your hospital:

Dr. Dan Poenaru at (514) 412-4400 ext. 22498.

In case of emergency, please go directly to the closest emergency room.

If you would like information about your rights related to your participation in the research, you may contact the hospital Ombudsman (Patient Representative) at 514-412-4400, poste 22223

WHERE CAN I GET MORE INFORMATION?

You may ask to receive a copy of the results of this research project session; these will only be available after the entire project has been completed.

You will receive a signed copy of this form. You may ask the research team questions at any time.

RESEARCH ETHICS COMMITTEE

The Research Ethics Board of the McGill University Health Center approved this study session and is responsible for monitoring it at all participating institutions in the health and social service network in Quebec.

CONSENT AND ASSENT FORM

Research Study: [Adaptation and translation of the Patient Reported Experience Measure for Children and Young People (PREM-CYP) at The Montreal Children's Hospital]

I have reviewed the Informed Consent Form. Both the research study session and the Informed Consent Form were explained to me. My questions were answered, and I was given sufficient time to decide. After reflection, I consent to participate, or that my child will participate in this research study session in accordance with the conditions stated above, including the use of all personal data collected.

E-mail:

_____

Name of participant	Assent of minor, capable of understanding the nature of the research (signature) or Verbal assent of minor obtained by:	Date	(Print)

Name of parent(s) or legal guardian	Signature	Date	(Print)

Name of participant (18 years +)	Signature	Date	(Print)

I have explained the research study session and the terms of this Informed Consent Form to the research participant, and I answered all questions asked.

Name of the person obtaining consent Signature Date

SIGNATURE OF WITNESS

YES □ NO □

A witness' signature is required in the following cases:

Reading disability or inability to read – The witness (impartial) signing below attests to the fact that they read the Informed Consent Form, that the research study session was precisely explained to the participant, and that the participant seems to have understood it.

Foreign language (participant does not understand the language in which the Informed Consent Form was written) – The signatory attests to acting as interpreter for the participant throughout the consent process.

Name of witness Signature Date

Addendum to consent form (*Where applicable)*

Participant who has now become an adult (18)

Research Study: [Adaptation and translation of the Patient Reported Experience Measure for Children and Young People (PREM-CYP) at The Montreal Children's Hospital]

Today, I reviewed the informed consent form that my parents signed on my behalf when I enrolled in this research project session and a copy of that signed consent was given to me.

I agree to continue my participation in this research project session.

I understand that my participation is free and voluntary and that I can stop participating in this research project session at any time I choose.

I authorize the research team to use the information relevant to this project.

Name of participant	Signature	Date

Name of person obtaining consent	Signature	Date

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X HME MCH X HGM MGH X HRV RVH
X HNM MNH X ITM MCI X CL LC

FMU-9997

L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT POUR LA RECHERCHE PÉDIATRIQUE

Titre : Adaptation et traduction d'expérience rapportée par les patients pour les enfants et les jeunes (PREM-CYP) à l'Hôpital de Montréal pour enfants.

Personnes responsables :
Dan Poenaru, chirurgien pédiatrique, investigateur RI, Département de chirurgie pédiatrique, Division de chirurgie pédiatrique Harvey E. Beardmore, L'Hôpital de Montréal pour enfants, Centre universitaire de santé McGill
Zanib Nafees, MSc, candidat au doctorat, Département de chirurgie expérimentale, Centre universitaire de santé McGill
Julia Ferrera, MD, MScC, Département de chirurgie pédiatrique, Division de chirurgie pédiatrique Harvey E. Beardmore, Centre universitaire de santé McGill
Elena Guadagno, MLIS, Chef de projet, Département de chirurgie pédiatrique, Division Harvey E. Beardmore de chirurgie pédiatrique, Centre universitaire de santé McGill
Jo Wray, PhD, chercheur principal au Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID), psychologue de la santé au sein de la Direction du cœur et des poumons à l'hôpital pour enfants Great Ormond Street (GOSH).
Agneta Anderzén Carlsson, RN, Associate Professor, University Health Care Research Centre, Region Örebro Count

Source de financement : N/A

POURQUOI ÊTES-VOUS INVITÉ À PARTICIPER À CETTE SESSION ?

Le département de chirurgie pédiatrique Harvey E. Beardmore participe à des études de recherche pour tenter d'améliorer les expériences des enfants et des jeunes à l'Hôpital de

Montréal pour enfants. Aujourd'hui, nous vous invitons à prendre part à une séance d'étude de recherche. Veuillez lire ces informations pour vous aider à décider si vous voulez participer à la session de ce projet de recherche. Il est important que vous compreniez ces informations. Nous vous encourageons à poser des questions ! Prenez tout le temps dont vous avez besoin pour prendre votre décision.

Nous encourageons les parents à inclure leur enfant dans la discussion et la prise de décision dans la mesure où l'enfant est capable de comprendre.

Dans ce formulaire d'information et de consentement à la recherche, le terme "vous" désigne vous ou votre enfant.

POURQUOI CETTE SESSION D'ÉTUDE A-T-ELLE LIEU ?

Contexte et importance de la recherche

Il est important d'améliorer l'expérience des enfants et des jeunes en tant que patients. La première étape consiste à savoir ce que les enfants et les jeunes pensent de leur expérience à l'hôpital. Notre objectif est de recueillir toutes les informations auprès des enfants et des jeunes sur leur expérience à l'hôpital et d'utiliser les informations recueillies pour adapter et traduire les mesures d'expérience rapportées par les patients (PREM) pour les utiliser à l'Hôpital de Montréal pour enfants. Ces questionnaires anglais existants ont été créés à l'hôpital pour enfants Great Ormond Street (GOSH), à Londres, au Royaume-Uni. Ils portent sur différents points de soins et expériences hospitalières des enfants qui sont importants pour les enfants eux-mêmes.

QUELS SONT LES OBJECTIFS DE LA RECHERCHE ?

Vous êtes invité à participer à cette recherche qui vise, 1) à s'assurer que les voix des enfants et des jeunes sont entendues en ce qui concerne leurs expériences à l'hôpital ; 2) à aider à rendre ce PREM disponible à plus de gens en le traduisant de l'anglais au français ; et 3) à s'assurer que les PREM sont clairs et compris par les enfants et les jeunes à l'Hôpital de Montréal pour enfants.

COMBIEN DE PERSONNES PARTICIPERONT À CETTE SESSION ?

Environ 12 à 15 patients des groupes d'âge (8-11, 12-13, 14-16) des cliniques de chirurgie pédiatrique participeront à chaque session.

QUE SE PASSERA-T-IL LORS DE CETTE SESSION DE RECHERCHE ?

Session 1 :

Si vous décidez de participer à cette session, on vous demandera de lire les questions en anglais pendant que vous nous direz ce que vous pensez, à haute voix. On vous demandera quelles sont

les parties des soins qui sont importantes pour vous et qui ont eu un impact sur votre expérience pendant que vous receviez les soins. Votre médecin vous parlera de l'étude et vous invitera à y participer. Vous vous présenterez ensuite devant le chercheur et examinerez quelques questions. Le chercheur vous demandera de penser à voix haute à tout ce qui vous vient à l'esprit pendant que vous lisez les questions. Cela devrait prendre environ 10 minutes. Le chercheur vous demandera d'enregistrer vos réponses sur un support audio.

Session 2 :

Si vous décidez de participer à cette session, nous aurons un entretien individuel avec vous pour voir comment vous comprenez les questions. Vous remplirez un questionnaire et nous passerons en revue avec vous le langage et les concepts utilisés dans les questionnaires. Cet entretien durera environ 30 à 60 minutes.

Session 3 :

Si vous décidez de participer à cette session, vous lirez le questionnaire en français ou en anglais et répondrez à quelques questions à son sujet. Cela devrait prendre environ 10 minutes. Ensuite, vous ferez une 5 ou 10 minutes pause pour jouer à un jeu. Après cela, vous lire les mêmes questions dans la deuxième langue que vous n'avez pas lues auparavant et vous répondrez à nouveau à quelques questions. Cela devrait prendre environ 10 minutes. Par exemple, si les premières questions que vous avez lues étaient en français, vous lirez l'anglais la fois suivante. Vous nous parlerez ensuite des questions que vous avez lues dans les deux langues, et nous vous demanderons également comment vous avez répondu aux questions.

PENDANT COMBIEN DE TEMPS ALLEZ-VOUS PARTICIPER À CETTE SESSION ?

Vous participerez en personne pendant 10 minutes en session 1, ou 30-60 minutes en session 2, ou moins de 30 minutes en séance 3. Les parents peuvent rester avec leurs enfants. Si vous acceptez de participer à la phase 1, mais que vous n'avez pas assez de temps pour compléter l'étude avant ou après votre rendez-vous, un membre de l'équipe de recherche demandera le courriel d'un soignant. Dans ce cas, nous enverrons un courriel à l'aidant pour fixer un moment où il pourra compléter l'étude.

QUELS SONT LES RISQUES ?

Un risque possible associé à cette session est la violation de la confidentialité. Pour limiter ce risque, nous prendrons les mesures de protection de votre confidentialité décrite dans une section ci-dessous.

UNE COMPENSATION EST-ELLE OFFERTE ?

Pour votre temps de participation à cette session, vous recevrez une carte cadeau de 20$.

SI VOUS SUBISSEZ UN PRÉJUDIC

Si vous subissez un préjudice de quelque nature que ce soit à la suite d'une procédure liée à cette session de recherche-étude, vous recevrez tous les soins et services requis par votre état de santé. En acceptant de participer à cette session de recherche, vous ne renoncez à aucun de vos droits et ne déchargez pas le médecin responsable de la session d'étude, le promoteur ou l'institution de leurs responsabilités civiles et professionnelles.

COMMENT LA CONFIDENTIALITÉ EST-ELLE ASSURÉE ?

Pendant votre participation à cette session, le médecin de la session d'étude et son équipe recueilleront et enregistreront des informations vous concernant dans un dossier de session d'étude. Ils ne recueilleront que les informations nécessaires pour atteindre les objectifs scientifiques de la session d'étude.

Le dossier de la session d'étude peut inclure des informations vous concernant que vous nous fournissez directement, notamment votre âge, votre sexe, la ou les langues parlées à la maison et votre diagnostic.

Toutes les informations recueillies au cours du projet de recherche resteront confidentielles dans les limites prévues par la loi.

Pour assurer votre sécurité, une copie de ces informations et du formulaire de consentement sera placée dans une armoire verrouillée dans le bureau du chercheur principal. Nous stockerons également les données sur la base de données du serveur Next Cloud du CUSM autorisée par le CUSM.

Les données de la session d'étude seront conservées pendant 7 ans par le médecin de la session d'étude.

Les données peuvent être publiées ou partagées lors de réunions ou de présentations scientifiques ; toutefois, il ne sera pas possible de vous identifier.

Pour des raisons de contrôle, de sûreté et de sécurité, votre dossier d'étude, qui peut contenir des documents permettant de vous identifier, peut être examiné par une personne mandatée par l'institution ou par le comité d'éthique de la recherche. Toutes ces personnes et organisations auront accès à vos données personnelles, mais elles adhèrent à une politique de confidentialité.

Vous avez le droit de consulter votre dossier de session d'étude afin de vérifier les informations recueillies, et de les faire rectifier si nécessaire.

Tout au long du programme, l'équipe de recherche enregistrera chaque session. Tous les enregistrements audios seront transcrits (vos paroles seront écrites) de manière dépersonnalisée (c'est-à-dire que votre nom n'apparaîtra pas dans les transcriptions). Les **enregistrements audios**

seront détruits après la transcription. Il est possible que des citations directes de vos propos soient présentées dans des publications et/ou des conférences. Toutefois, des précautions seront prises pour s'assurer qu'il ne sera pas possible de vous identifier. Le site des questionnaires et des photos de votre matériel écrit/dessins seront détruits 7 ans après la fin du projet de recherche.

VOTRE PARTICIPATION EST-ELLE VOLONTAIRE ET POUVEZ-VOUS VOUS RETIRER ?

Oui. Votre participation à ce projet de recherche est volontaire. Par conséquent, vous pouvez refuser d'y participer. Vous pouvez également vous retirer du projet à tout moment, sans donner de raison, en informant le médecin de la séance d'étude ou un membre de l'équipe de recherche.

Votre décision de ne pas participer à la session d'étude ou de vous en retirer n'aura aucune incidence sur la qualité des soins et des services auxquels vous avez droit par ailleurs, ni sur votre relation avec le médecin de la session d'étude ou l'équipe clinique.

Le médecin de la session d'étude, le comité d'éthique de la recherche ou l'organisme de financement peuvent mettre fin à votre participation sans votre consentement. Cela peut se produire si de nouvelles découvertes ou informations indiquent que la participation n'est plus dans votre intérêt, si vous ne suivez pas les instructions de la session d'étude ou s'il existe des raisons administratives de mettre fin au projet.

Si vous vous retirez ou êtes retiré de la session d'étude, les informations recueillies au cours de la session d'étude seront néanmoins stockées, analysées ou utilisées pour protéger l'intégrité scientifique du projet de recherche.

Toute nouvelle découverte qui pourrait influencer votre décision de rester dans la session du projet de recherche sera partagée avec vous dès que possible.

Aucun résultat/donnée sur les patients ne sera partagé avec le collaborateur externe. Seule la version anglaise adaptée du questionnaire PREM-CYP_MTL et la version française traduite du questionnaire PREM-CYP_MTL seront partagées avec le collaborateur externe afin d'obtenir un retour sur l'exhaustivité des questions. Ceci a été ajouté au protocole.

QUI DOIS-JE APPELER SI J'AI DES QUESTIONS OU DES PROBLÈMES ?

Si vous avez des questions sur cette session de projet de recherche ou si vous souffrez de problèmes qui, selon vous, sont liés à votre participation à cette session de recherche, vous pouvez appeler le chercheur responsable du projet dans votre hôpital :

Dr Dan Poenaru au (514) 412-4400, poste 22498.

En cas d'urgence, veuillez-vous rendre directement aux urgences les plus proches.

Si vous souhaitez obtenir des informations sur vos droits relatifs à votre participation à la recherche, vous pouvez contacter l'ombudsman de l'hôpital (représentant des patients) au 514-412-4400, poste 22223.

OÙ PUIS-JE OBTENIR PLUS D'INFORMATIONS ?

Vous pouvez demander à recevoir une copie des résultats de cette session de projet de recherche ; ceux-ci ne seront disponibles qu'après la fin du projet.

Vous recevrez une copie signée de ce formulaire. Vous pouvez poser des questions à l'équipe de recherche à tout moment.

COMITÉ D'ÉTHIQUE DE LA RECHERCHE

Le Comité d'éthique de la recherche du Centre universitaire de santé McGill a approuvé cette session d'étude et est responsable de son suivi dans tous les établissements participants du réseau de la santé et des services sociaux du Québec.

FORMULAIRE DE CONSENTEMENT ET D'ASSENTIMENT

Étude de recherche : [Adaptation et traduction d'expérience rapportée par les patients pour les enfants et les jeunes (PREM-CYP) à L'Hôpital de Montréal pour enfants].

J'ai examiné le formulaire de consentement éclairé. La session de recherche et le formulaire de consentement éclairé m'ont été expliqués. On a répondu à mes questions et on m'a laissé suffisamment de temps pour prendre une décision. Après réflexion, je consens à participer, ou à ce que mon enfant participe, à cette session de recherche conformément aux conditions énoncées ci-dessus, y compris l'utilisation de toutes les données personnelles recueillies.

Courriel: _____

Nom du participant (Imprimer)	Assentiment du mineur, capable de comprendre la nature de la recherche (signature) ou Consentement verbal du mineur obtenu par :	Date

Nom du/des parent(s) ou du tuteur légal (Imprimer)	Signature	Date

Nom du participant (18 ans et +) (Imprimer)	Signature	Date

J'ai expliqué la session d'étude de recherche et les termes de ce formulaire de consentement éclairé au participant à la recherche, et j'ai répondu à toutes les questions posées.

Nom de la personne qui obtient le consentement Signature Date

SIGNATURE DU TÉMOIN

OUI □ NON □

La signature d'un témoin est requise dans les cas suivants :

Handicap de lecture ou incapacité à lire - Le témoin (impartial) qui signe ci-dessous atteste qu'il a lu le formulaire de consentement éclairé, que la session d'étude de recherche a été expliquée précisément au participant et que ce dernier semble l'avoir comprise.

Langue étrangère (le participant ne comprend pas la langue dans laquelle le formulaire de consentement éclairé a été rédigé) - Le signataire s'engage à servir d'interprète au participant tout au long du processus de consentement.

Nom du témoin Signature Date

Addendum au formulaire de consentement (*le cas échéant)*

Participant qui est maintenant devenu adulte (18 ans)

Étude de recherche : [Adaptation et traduction d'expérience rapportée par les patients pour les enfants et les jeunes (PREM-CYP) à L'Hôpital de Montréal pour enfants].

Aujourd'hui, j'ai examiné le formulaire de consentement éclairé que mes parents ont signé en mon nom lorsque je me suis inscrit à cette session de projet de recherche et une copie de ce consentement signé m'a été remise.

J'accepte de poursuivre ma participation à cette session de projet de recherche.

Je comprends que ma participation est libre et volontaire et que je peux cesser de participer à cette session du projet de recherche à tout moment de mon choix.

J'autorise l'équipe de recherche à utiliser les informations pertinentes pour ce projet.

_____

Nom du participant Signature Date

_____

Nom du participant Signature Date
Obtention du consentement

CYP PREM Project Assent Form

L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

COMMISUR

Tick if you agree with the sentence ☑

Cross if you don't agree with the sentence ☒

START

1. I have read the information leaflet ☐

2. I was able to ask questions about the study ☐

3. I was told what I wanted to know ☐

4. I know I can stop helping with this project at any time and it won't affect my time in the hospital and my doctors or nurses will not mind at all. ☐

5. I want to take part in the CYP PREM_MTL project ☐

Your name: _____

Your signature: _____

Date: _____

END

CYP PREM Project Assent Form

Tick if you agree with the sentence ☑ Cross if you don't agree with the sentence ☒

☐ I know that the things I say will be recorded.

I know that the things I write and draw will be photographed

☐

I know that the the voice recordings and photographs of my work will be used only by the Montreal Children Hospital (MCH) staff for the CYP PREM_MTL project and that all of the audio files and photographs will be destroyed once the project is finished. ☐

I agree to the recording of the things I say and I agree to the photography of the things I write and draw. ☐

L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

Formulaire d'avis conforme du projet CYP PREM

L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

Cochez si vous êtes d'accord avec la phrase ☑

Croix si vous n'êtes pas d'accord avec la phrase ☒

DÉPART

1. J'ai lu la brochure d'information  ☐

2. J'ai pu poser des questions sur l'étude  ☐

3. On m'a dit ce que je voulais savoir  ☐

4. Je sais que je peux cesser de participer à ce projet à tout moment sans que cela n'affecte mon séjour à l'hôpital et que les médecins et les infirmières n'y verront aucun inconvénient.  ☐

5. Je veux participer à la Projet CYP PREM_MTL  ☐

Votre nom : _____

Votre signature _____

Date : _____

FIN

Formulaire d'avis conforme du projet CYP PREM

Cochez si vous êtes d'accord avec la phrase ☑ Croix si vous n'êtes pas d'accord avec la phrase ☒

☐ Je sais que les choses que je dis seront enregistrées.

Je sais que les choses que j'écris ou que je dessine seront photographiées.  ☐

☐ Je sais que les enregistrements vocaux et les photographies de mon travail seront utilisés uniquement par le personnel de l'Hôpital de Montréal pour enfants (HME) pour le projet CYP PREM_MTL et que tous les fichiers audio et les photographies seront détruits une fois le projet terminé.

☐ J'accepte l'enregistrement de ce que je dis et j'accepte la photographie de ce que j'écris et dessine.

L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre

Centre universitaire de santé McGill | McGill University Health Centre

2022-09-29

Dr Dan Poenaru Pediatric Surgery c/o: Julia Loyola Ferreira Pediatric Surgery
email: juloyola7@hotmail.com

Re: MUHC Authorization

A cross-sectional survey of individualized PROs after congenital surgery **(PROPS - PGI / 2023-8834)**

Dear Dr Poenaru,

We are writing to confirm that the study mentioned above has received research ethics board approval and all required institutional approvals, namely:

- Access to health records

You are hereby authorized to conduct your research at the McGill University Health Centre (MUHC) as well as to initiate recruitment.

Please refer to the MUHC Study number in all future correspondence relating to this study.

In accordance with applicable policies it is the investigator's responsibility to ensure that staff involved in the study is competent and qualified and, when required, has received certification to conduct clinical research.

Should you have any questions, please do not hesitate to contact the support for the Personne mandatée at personne.mandatee@muhc.mcgill.ca.

We wish you every success with the conduct of the research.

Sincerely,

Kassandy Kowalyk

Kassandy Kowalyk for:
Keith Woolrich
Personne Mandatée
Centre universitaire de santé McGill

Signed on 2022-09-29 at 14:34

Centre universitaire de santé McGill | McGill University Health Centre

2022-09-28

Dr Dan Poenaru
Pediatric Surgery
MUHC-Montreal Children's Hospital

email: juloyola7@hotmail.com

RE: Final REB Approval of a New Research Project
A cross-sectional survey of individualized PROs after congenital surgery **(PROPS - PGI / 2023-8834)**

MUHC REB Co-Chair for the PED panel: Carlo Cicero Oneto

Dear Dr Poenaru,

Thank you for submitting your responses and corrections for the research project indicated above, as requested by the McGill University Health Centre (MUHC) Research Ethics Board (REB).

The MUHC REB, more precisely its Pediatric (PED) panel provided conditional approval for the research project after a delegated review provided by its member(s).

On 2022-09-28, a delegated review of your responses and corrections was provided by member(s) of the MUHC REB. The research project was found to meet scientific and ethical standards for conduct at the MUHC.

The following documents were approved or acknowledged by the MUHC REB:

Initial	Submission Form (F11-NIR-96063)
REB	Conditions & PI Responses Form(s) (F2099263 & 98644)
Research	**protocol**
(PGI	proposal_V1July19_REBapproved.docx) [Date: 2022-07-26]
Approval	**of the Department / Division Head**
(Approval	of department head _PROPS PGI (2023-8834) JP Farmer_June 7
	2022.docx.pdf) [Date: 2022-06-07]

ICF approved by the REB
(MYMOP_REBapproved.docx) [Date: 2022-07-26]
(PGI_REBapproved.docx) [Date: 2022-07-26]
(MYMOP_FR_V1_Sept 26 2022_REBapproved.docx)
(PGI_FR_V1_Sept 26 2022_REBapproved.docx)

This will be reported to the MUHC REB and will be entered accordingly into the minutes of the next PED meeting. Please be advised that you may only initiate the study after all required reviews and decisions are received and documented and you have received the MUHC authorization letter.

The approval of the research project is valid until 2023-09-27.

All research involving human subjects requires review at recurring intervals. To comply with the regulation for continuing review of at least once per year, it is the responsibility of the investigator to submit an *Annual Renewal Submission Form* (F9) to the REB prior to expiry. Please be advised that should be protocol reach its expiry before a Continuing review has been submitted, the data collected after the expiry date may not be considered valid. However, should the research conclude for any reason prior to approval expiry, you are required to submit a *Completion (End of Study) Report* (F10) to the board once the data analysis is complete to give an account of the study findings and publication status.

Furthermore, should any revision to the project or other development occur prior to the next continuing review, you must advise the REB without delay. Regulation does not permit initiation of a proposed study modification prior to its approval by the REB.

The MUHC REB is registered and works under the published guidelines of the *Tri-Council Policy Statement 2*, in compliance with the *Plan d'action ministériel en éthique de la recherche et en intégrité scientifique* (MSSS, 1998) and the *Food and Drugs Act* (2001.06.07), acting in conformity with standards set forth in the (US) *Code of Federal Regulations* governing human subjects research and functioning in a manner consistent with internationally accepted principles of good clinical practice.

We trust this will prove satisfactory to you. Thank you for your consideration in this matter.

Best Regards,

Ms. Elizabeth Craven, Coordinator, MUHC REB
MUHC REB Coordinator for MUHC
Co-chair mentioned above

Signed on 2022-09-28 at 19:59

Centre universitaire de santé McGill | McGill University Health Centre

INFORMATION AND CONSENT FORM

Research Study Title:	A cross-sectional survey and validation of the patient-generated index (PGI) following neonatal surgery
Nagano number:	PGI 2023-8834
Researcher responsible for the research study:	Dr. Dan Poenaru
Co-Investigator(s)	Zanib Nafees, MSc, PhD(c) Sherif Emil, MD Julia Ferrera, MD, MSc(c) Elena Guadagno, MLIS Gowree Tillousing Gobin, DIP HE, BScN, M.Mgmt Nikki Ow, PhD Nancy Mayo, PhD Montreal Children's Hospital

INTRODUCTION

You are invited to take part in this research study aimed at understanding the perspectives and experiences of clinicians involved in the follow up of paediatric patients who had surgery for Esophageal Atresia.

Before deciding whether to participate, it is important that you understand the purpose of the study, what your participation will involve, and your rights as a participant.

Please take the time to read this consent form carefully. If you have any questions, feel free to ask the research team member before deciding whether to participate.

BACKGROUND

We are evaluating three Patient-Reported Outcome Measures (PROMs) in assessing health outcomes for esophageal atresia patients, incorporating perspectives from both clinical staff and

patients/families.

STUDY PROCEDURES
If you agree to participate, you will be asked to engage in an interview with a member of the research team. The interview will be conducted either in person, over the phone, or via video conferencing, depending on your preference and availability. The interview is expected to last approximately 5-10 minutes and will involve questions related to the surveys completed by the families.

PURPOSE OF THE RESEARCH STUDY
This purpose of this study is to determine if a PROM measure effectively measures the concerns of children and young people (CYP) who have had surgery for Esophageal Atresia. We seek to achieve this by identifying important aspects of their health and function, understanding how they approach the measure's process, assessing the alignment of existing pediatric quality of life measures with their priorities, and gathering clinicians' perspectives on the usability of these measures.

BENEFITS ASSOCIATED WITH THE RESEARCH STUDY
There is no direct benefit to you for participating in this research. However, we hope that the study results will contribute to the advancement of scientific knowledge in the study field.

RISKS ASSOCIATED WITH THE RESEARCH STUDY
A possible risk associated with this study is a breach of confidentiality or use of your personal information by a third party. To limit this risk, we will take the steps to protect your confidentiality described in the Confidentiality section, below.

We do not foresee any other risks associated with this study.

INCONVENIENCES LINKED TO STUDY PROCEDURES
These are the only foreseeable inconveniences that may result from study participation.

VOLUNTARY PARTICIPATION AND THE RIGHT TO WITHDRAW
Participation in this study is entirely voluntary. Your decision to participate or not will not affect your professional standing, employment status, or relationships within the workplace. You have the right to decline participation or withdraw from the study at any time without consequences. If you choose not to participate or withdraw, you will not be penalized in any way.

If you withdraw or are withdrawn from the study, you may also request that the data already collected about you be removed from the study. If you request that your data be removed and the

information already collected about you can be identified as yours it will be destroyed. If the data has been anonymized or was always anonymous (i.e. does not contain any information that can be used to identify you), the data will continue to be used in the analysis of the study.

CONFIDENTIALITY
During your participation in this study, the researcher and his/her team will collect information about you. They will only collect information necessary for the study such as age, gender, and surgery specialty.

All the information collected during the research project will remain confidential to the extent provided by law. You will only be identified by a code number. The key to the code linking your name to your study participant number will be kept by the researcher on a secure MUHC drive.

All information will be collected in a de-identified fashion (i.e. your name will not appear in the transcripts). It is possible that direct quotes of what you said will be presented in publications and/or conferences.

The study data will be stored for 7 years by the researcher responsible for the study.

The data may be published or shared during scientific meetings; however, precautions will be taken to ensure that it will not be possible to identify you.

For auditing purposes, the research study files which could include documents that may identify you may be examined by a person mandated by the McGill University Health Center or the Research Ethics Board. All these individuals and organizations adhere to policies on confidentiality.

CONFLICT OF INTERESTS
The researchers have no conflict of interest to declare.

COMPENSATION
You will not receive financial compensation for participating in this research study.

SHARING STUDY RESULTS
Results from this study will be presented at conferences and published in journals.

SHOULD YOU SUFFER ANY HARM
By agreeing to participate in this research project, you are not waiving any of your legal rights nor discharging the researcher, the institution, of their civil and professional responsibilities.

CONTACT INFORMATION

If you have questions or if you have a problem, you think may be related to your participation in this research study, or if you would like to withdraw, you may communicate with the researcher, Dr. Dan Poenaru, at the following number (514) 412-4400 ext. 22498.

For any question concerning your rights as a research participant in this study, or if you have comments or wish to file a complaint, you may communicate with the local service quality and complaints commissioner at: 514-412-4400, poste 22223.

OVERVIEW OF ETHICAL ASPECTS OF THE RESEARCH

The Research Ethics Board of the McGill University Health Centre has given ethics approval to this research study and is responsible for the ongoing ethics oversight of the study.

Research Study Title: A cross-sectional survey and validation of the patient-generated index (PGI) following neonatal surgery

SIGNATURES

Signature of the participant

I have reviewed the information and consent form. Both the research study and the information and consent form were explained to me. My questions were answered, and I was given sufficient time to make a decision. After reflection, I consent to participate in this research study in accordance with the conditions stated above.

1) I authorize a member of the research study to contact me in the future to ask if I am interested in participating in other research.

   Yes ☐ No ☐ If yes, please provide contact information: _____

_____

Name of participant Signature Date

Signature of the person obtaining consent

I have explained the research study and the terms of this information and consent form to the research participant, and I answered all his/her questions.

_____

Name of the person obtaining consent Signature Date

Centre universitaire de santé McGill | McGill University Health Centre

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

Titre de l'étude de recherche :	Une enquête transversale et la validation de l'index généré par le patient (PGI) suite à une chirurgie néonatale
Numéro Nagano :	PGI 2023-8834
Chercheur responsable de l'étude de recherche :	Dr. Dan Poenaru
Co-chercheur(s)	Zanib Nafees, MSc, PhD(c) Sherif Emil, MD Julia Ferrera, MD, MSc(c) Elena Guadagno, MLIS Gowree Tillousing Gobin, DIP HE, BScN, M.Mgmt Nikki Ow, PhD Nancy Mayo, PhD Hôpital de Montréal pour enfants

INTRODUCTION

Vous êtes invité(e) à participer à cette étude de recherche visant à comprendre les perspectives et les expériences des cliniciens impliqués dans le suivi des patients pédiatriques ayant subi une chirurgie pour une atrésie de l'œsophage.

Avant de décider de participer, il est important que vous compreniez le but de l'étude, ce que votre participation impliquera, ainsi que vos droits en tant que participant.

Veuillez prendre le temps de lire attentivement ce formulaire de consentement. Si vous avez des questions, n'hésitez pas à les poser à un membre de l'équipe de recherche avant de décider de participer.

CONTEXTE

Nous évaluons trois Mesures de Résultats Rapportés par les Patients (PROMs) dans l'évaluation des résultats de santé des patients atteints d'atrésie de l'œsophage, en intégrant les perspectives tant du personnel clinique que des patients/familles.

PROCÉDURES DE L'ÉTUDE
Si vous acceptez de participer, vous serez invité(e) à participer à une entrevue avec un membre de l'équipe de recherche. L'entrevue se déroulera soit en personne, par téléphone, ou via une visioconférence, selon vos préférences et disponibilités. L'entrevue devrait durer environ 5 à 10 minutes et comportera des questions liées aux enquêtes complétées par les familles.

OBJECTIF DE L'ÉTUDE DE RECHERCHE
L'objectif de cette étude est de déterminer si une mesure PROM mesure efficacement les préoccupations des enfants et des jeunes (CYP) ayant subi une chirurgie pour une atrésie de l'œsophage. Nous cherchons à le faire en identifiant les aspects importants de leur santé et de leur fonctionnement, en comprenant leur approche du processus de mesure, en évaluant l'alignement des mesures existantes de qualité de vie pédiatrique avec leurs priorités, et en recueillant les perspectives des cliniciens sur l'utilisabilité de ces mesures.

AVANTAGES LIÉS À L'ÉTUDE DE RECHERCHE
Il n'y a aucun avantage direct pour vous à participer à cette recherche. Cependant, nous espérons que les résultats de l'étude contribueront à l'avancement des connaissances scientifiques dans le domaine d'étude.

RISQUES LIÉS À L'ÉTUDE DE RECHERCHE
Un risque possible associé à cette étude est une violation de la confidentialité ou l'utilisation de vos informations personnelles par un tiers. Pour limiter ce risque, nous prendrons les mesures nécessaires pour protéger votre confidentialité comme décrit dans la section Confidentialité, ci-dessous.

Nous ne prévoyons aucun autre risque associé à cette étude.

INCONVÉNIENTS LIÉS AUX PROCÉDURES DE L'ÉTUDE
Ce sont les seuls inconvénients prévisibles pouvant résulter de la participation à l'étude.

PARTICIPATION VOLONTAIRE ET DROIT DE RETRAIT

La participation à cette étude est entièrement volontaire. Votre décision de participer ou non n'affectera pas votre position professionnelle, votre statut d'emploi ou vos relations dans le milieu de travail. Vous avez le droit de refuser de participer ou de vous retirer de l'étude à tout moment sans conséquences. Si vous choisissez de ne pas participer ou de vous retirer, vous ne serez en aucun cas pénalisé(e).

Si vous vous retirez ou êtes retiré(e) de l'étude, vous pouvez également demander que les données déjà collectées à votre sujet soient supprimées de l'étude. Si vous demandez la suppression de vos données et que les informations déjà collectées à votre sujet peuvent être identifiées comme les vôtres, elles seront détruites. Si les données ont été anonymisées ou étaient toujours anonymes (c'est-à-dire qu'elles ne

contiennent aucune information permettant de vous identifier), les données continueront d'être utilisées dans l'analyse de l'étude.

CONFIDENTIALITÉ
Pendant votre participation à cette étude, le chercheur et son équipe collecteront des informations vous concernant. Ils ne collecteront que les informations nécessaires à l'étude telles que l'âge, le sexe et la spécialité de la chirurgie.

Toutes les informations collectées pendant le projet de recherche resteront confidentielles dans la mesure prévue par la loi. Vous ne serez identifié(e) que par un numéro de code. La clé reliant votre nom à votre numéro de participant à l'étude sera conservée par le chercheur sur un lecteur sécurisé du CUSM.

Toutes les informations seront collectées de manière dé-identifiée (c'est-à-dire que votre nom n'apparaîtra pas dans les transcriptions). Il est possible que des citations directes de ce que vous avez dit soient présentées dans des publications et/ou des conférences.

Les données de l'étude seront conservées pendant 7 ans par le chercheur responsable de l'étude.

Les données peuvent être publiées ou partagées lors de réunions scientifiques ; cependant, des précautions seront prises pour garantir qu'il ne sera pas possible de vous identifier.

À des fins de vérification, les dossiers de l'étude de recherche qui pourraient inclure des documents pouvant vous identifier peuvent être examinés par une personne mandatée par le Centre universitaire de santé McGill ou le Comité d'éthique de la recherche. Toutes ces personnes et organisations adhèrent à des politiques de confidentialité.

CONFLIT D'INTÉRÊTS
Les chercheurs n'ont aucun conflit d'intérêts à déclarer.

COMPENSATION
Vous ne recevrez pas de compensation financière pour votre participation à cette étude de recherche.

PARTAGE DES RÉSULTATS DE L'ÉTUDE
Les résultats de cette étude seront présentés lors de conférences et publiés dans des revues.

EN CAS DE PRÉJUDICE
En acceptant de participer à ce projet de recherche, vous n'abandonnez aucun de vos droits légaux ni ne déchargez le chercheur, l'institution, de leurs responsabilités civiles et professionnelles.

COORDONNÉES

Si vous avez des questions ou si vous rencontrez un problème que vous pensez être lié à votre participation à cette étude de recherche, ou si vous souhaitez vous retirer, vous pouvez communiquer avec le chercheur, le Dr Dan Poenaru, au numéro suivant : (514) 412-4400, poste 22498.

Pour toute question concernant vos droits en tant que participant à la recherche dans cette étude, ou si vous avez des commentaires ou souhaitez déposer une plainte, vous pouvez communiquer avec le commissaire local à la qualité des services et aux plaintes au : 514-412-4400, poste 22223.

APERÇU DES ASPECTS ÉTHIQUES DE LA RECHERCHE

Le Comité d'éthique de la recherche du Centre universitaire de santé McGill a donné son approbation éthique à cette étude de recherche et est responsable de la surveillance éthique continue de l'étude.

Titre de l'étude de recherche : Une enquête transversale et la validation de l'index généré par le patient (PGI) suite à une chirurgie néonatale

SIGNATURES

Signature du participant

J'ai examiné le formulaire d'information et de consentement. L'étude de recherche ainsi que le formulaire d'information et de consentement m'ont été expliqués. Mes questions ont été répondues, et j'ai eu suffisamment de temps pour prendre une décision. Après réflexion, je consens à participer à cette étude de recherche conformément aux conditions énoncées ci-dessus.

1) J'autorise un membre de l'étude de recherche à me contacter à l'avenir pour savoir si je suis intéressé(e) à participer à d'autres recherches.

   Oui ☐ Non ☐ Si oui, veuillez fournir vos coordonnées: _____

_____

Nom du participant Signature Date

Signature de la personne obtenant le consentement

J'ai expliqué l'étude de recherche et les termes de ce formulaire d'information et de consentement au participant à la recherche, et j'ai répondu à toutes ses questions.

_____

Nom de la personne obtenant le consentement Signature Date

Centre universitaire de santé McGill | McGill University Health Centre

Title of Study: A cross-sectional survey and validation of the patient-generated index (PGI) following neonatal surgery.

Dear [Participant],

The Harvey E. Beardmore Department of Pediatric Surgery participates in research studies to try to improve the experiences of children and young people at the Montreal Children's Hospital. Today, we are inviting you to take part in a research study session. Please read this information to help you decide if you want to participate in this research project's session. It is important that you understand this information. We encourage you to ask questions! Please take all the time you need to make your decision. We encourage parents to include their child in the discussion and decision-making to the extent that the child is able to understand.

We invite you to participate in our research study: A cross-sectional survey and validation of the patient-generated index (PGI) following neonatal surgery. The study will be conducted by the following investigators: Dr. Dan Poenaru, MD PhD, Department of Pediatric Surgery; Sherif Emil, MD, Department of Pediatric Surgery; Julia Ferrera, MD, MSc(c), Department of Pediatric Surgery; Elena Guadagno, MLIS, Department of Pediatric Surgery; Zanib Nafees, MSc, PhD(c), Department of Experimental Surgery; Nikki Ow, PhD, Occupational Science and Occupational Therapy; Nancy Mayo, PhD, School of Physical & Occupational Therapy.

This study is aimed at improving the quality of care for children with conditions requiring surgery such as esophageal atresia. The goal of our project is to understand how children with this condition are faring in the long-term, from their own perspective and that of their family. We aim to identify and measure important factors that matter to the child.

To achieve this, we need your help to complete three short questionnaires online. The surveys include the Patient-Generated Index (PGI), the PROMIS life satisfaction survey, and the EQ-5D-Y. These surveys have been designed to be easy to complete and should take no more than 30 minutes of your time. We have chosen to conduct the surveys online, so you do not have to come in person.

A possible risk associated with this study is a breach of confidentiality. To limit this risk, we will take the steps to protect your confidentiality described below.

Only data relevant to this study will be collected by the research team. All the information collected during the research project will remain confidential to the extent required and provided by law. Patient data will be deidentified and coded. The code will be kept by the principal investigator in a password-protected digital file behind the MUHC firewall. Data will be kept for 7 years after the end of the study.

Your input from these surveys is critical and will help us improve the quality of care for children with conditions requiring surgery such as esophageal atresia. Your participation in this study is voluntary, and you can withdraw at any time without any consequences. By completing the questionnaire, you are consenting to take part in this project. Your responses will be kept confidential, and no identifying information will be collected.

Should you suffer harm of any kind following any procedure related to this research study session, you will receive all the care and services required by your state of health.

By agreeing to participate in this research session, you are not waiving any of your rights nor discharging the doctor in charge of the study session, the sponsor, or the institution of their civil and professional responsibilities.

Thank you for your time and consideration. Your participation will make a significant contribution to improving the lives of children with conditions requiring surgery and you will be compensated with a 20 $ gift card.

If you have any questions about this research project session or if you suffer any problems, you believe are related to your participation in this research session, you can call the researcher responsible for the project in your hospital: Dr. Dan Poenaru at (514) 412-4400 ext. 22498.

In case of emergency, please go directly to the closest emergency room.

If you would like information about your rights related to your participation in the research, you may contact the hospital Ombudsman (Patient Representative) at 514-412-4400, poste 22223.

Sincerely,

Dan Poenaru, MD, MHPE, MA, PhD, FRCSC, FACS
Harvey E. Beardmore Division of Pediatric Surgery
The Montreal Children's Hospital
McGill University Health Centre
Professor of Surgery and Pediatrics, McGill University

Senior Scientist, RI-MUHC
Scientific Director, CommiSur Lab
dan.poenaru@mcgill.ca

Centre universitaire de santé McGill | McGill University Health Centre

Titre de l'étude : Enquête transversale et validation de l'index généré par le patient (IGP) à la suite d'une chirurgie néonatale.

Cher [participant],

Le département de chirurgie pédiatrique Harvey E. Beardmore participe à des études de recherche pour tenter d'améliorer l'expérience des enfants et des adolescents à l'Hôpital de Montréal pour enfants. Aujourd'hui, nous vous invitons à participer à une séance d'étude de recherche. Veuillez lire ces informations pour vous aider à décider si vous souhaitez participer à la session de ce projet de recherche. Il est important que vous compreniez ces informations. Nous vous encourageons à poser des questions ! Prenez tout le temps nécessaire pour prendre votre décision. Nous encourageons les parents à faire participer leur enfant à la discussion et à la prise de décision dans la mesure où il est capable de comprendre.

Nous vous invitons à participer à notre étude de recherche : Une enquête transversale et la validation de l'index généré par le patient (IGP) après une chirurgie néonatale. L'étude sera menée par les chercheurs suivants : Dan Poenaru, MD PhD, Département de chirurgie pédiatrique ; Sherif Emil, MD, Département de chirurgie pédiatrique ; Julia Ferrera, MD, MSc(c), Département de chirurgie pédiatrique ; Elena Guadagno, MLIS, Département de chirurgie pédiatrique ; Zanib Nafees, MSc, PhD(c), Département de chirurgie expérimentale ; Nikki Ow, PhD, Sciences du travail et ergothérapie ; Nancy Mayo, PhD, École de physiothérapie et d'ergothérapie.

Cette étude vise à améliorer la qualité des soins prodigués aux enfants atteints de maladies nécessitant une intervention chirurgicale, comme l'atrésie de l'œsophage. L'objectif de notre projet est de comprendre comment les enfants atteints de cette pathologie s'en sortent à long terme, de leur propre point de vue et de celui de leur famille. Nous souhaitons identifier et mesurer les facteurs importants pour l'enfant.

Pour ce faire, nous avons besoin de votre aide pour remplir trois courts questionnaires en ligne. Il s'agit de l'index généré par les patients (IGP), de l'enquête PROMIS sur la satisfaction de la vie et de l'EQ-5D-Y. Ces enquêtes ont été conçues pour être faciles à remplir et ne devraient pas prendre plus de 30 minutes de votre temps. Nous avons choisi d'effectuer les enquêtes en ligne, de sorte que vous n'avez pas besoin de vous déplacer.

Un risque possible associé à cette étude est la violation de la confidentialité. Pour limiter ce risque, nous prendrons les mesures décrites ci-dessous pour protéger votre confidentialité.

Seules les données pertinentes pour cette étude seront collectées par l'équipe de recherche. Toutes les informations recueillies au cours du projet de recherche resteront confidentielles dans la mesure où la loi l'exige et le prévoit. Les données des patients seront dépersonnalisées et codées. Le code sera conservé par le chercheur principal dans un fichier numérique protégé par mot de passe derrière le pare-feu du CUSM. Les données seront conservées pendant 7 ans après la fin de l'étude.

Votre participation à ces enquêtes est essentielle et nous aidera à améliorer la qualité des soins prodigués aux enfants atteints de maladies nécessitant une intervention chirurgicale, telles que l'atrésie de l'œsophage. Votre participation à cette étude est volontaire et vous pouvez vous retirer à tout moment sans aucune conséquence. En remplissant le questionnaire, vous consentez à prendre part à ce projet. Vos réponses resteront confidentielles et aucune information permettant de vous identifier ne sera recueillie.

Si vous subissez un préjudice quelconque à la suite d'une procédure liée à cette session de recherche, vous recevrez tous les soins et services requis par votre état de santé.

En acceptant de participer à cette session de recherche, vous ne renoncez à aucun de vos droits et vous ne déchargez pas le médecin responsable de la session de recherche, le promoteur ou l'institution de leurs responsabilités civiles et professionnelles.

Nous vous remercions de votre temps et de votre attention. Votre participation contribuera de manière significative à l'amélioration de la vie des enfants atteints de maladies nécessitant une intervention chirurgicale et vous serez récompensé(e) par une carte-cadeau d'une valeur de 20 dollars.

Si vous avez des questions sur ce projet de recherche ou si vous souffrez de problèmes que vous pensez liés à votre participation à cette session de recherche, vous pouvez appeler le chercheur responsable du projet dans votre hôpital : Dr Dan Poenaru au (514) 412-4400 poste 22498.

En cas d'urgence, veuillez vous rendre directement à l'urgence la plus proche.

Si vous désirez obtenir de l'information sur vos droits liés à votre participation à la recherche, vous pouvez communiquer avec l'ombudsman de l'hôpital (représentant des patients) au 514-412-4400, poste 22223.

Je vous prie d'agréer, Madame, Monsieur, l'expression de mes sentiments distingués,

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