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From voice to impact

Capturing and utilising children's experiences of healthcare within Swedish paediatric care

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Abstract

One of the core principles of the United Nations Convention on the Rights of the Child is that children have the right to freely express their views on all matters affecting them. Thus, the paediatric healthcare sector has a responsibility to promote children's participation at both the individual and collective level. An important part of high-quality paediatric care is giving children the opportunity to share views on their experiences.

This thesis explores how children's right to share their views on their healthcare experiences can be facilitated and integrated into Swedish paediatric care. It contains four studies focusing on (I) describing how Swedish paediatric departments encourage children's voices regarding their healthcare experiences and how children's perspectives are taken into account in quality-improvement work; (II) translating, adapting and validating the six versions of the Children and Young People – Patient-reported Experience Measure (CYP-PREM) for use in a Swedish healthcare context; (III) piloting the Swedish versions of the CYP-PREM (Swe-CYP-PREM) questionnaire in paediatric care; and (IV) exploring first-line managers' and quality-improvement workers' perspectives of using PREMs in paediatric units. The findings indicate that integrating children's right to express their views regarding their healthcare experiences into clinical practice requires a systematic, flexible and context-sensitive approach grounded in organisational commitment to listening to children's voices. Swe-CYP-PREM appears to be a valuable tool for facilitating this process, although challenges remain in achieving sustainable and systematic integration of children's perspectives into paediatric care.

Keywords: Children, Healthcare experiences, Instrument development, Paediatric care, PREMs

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ABBREVIATIONS

CVI	Content validity index
CYP-PREM	Children and Young People – Patient-reported Experiences Measure
GOSH	Great Ormond Street Hospital
I-CVI	Item-level – content validity index
IP	Inpatient
ISPOR	International Society for Pharmacoeconomics and Outcomes Research
NPE	National Patient Survey
OP	Outpatient
PREM	Patient-reported experiences measure
SALAR	Swedish Association of Local Authorities and Regions
S-CVI/Ave	Scale-level – content validity index/Average
SPSS	Statistical Package for the Social Sciences
Swe-CYP-PREM	Swedish version of Children and Young People – Patient-reported Experiences Measure
UNCRC	United Nations Convention on the Rights of the Child
WHO	World Health Organisation

List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I. Nordlind, A., Sundqvist, A.-S., Anderzén-Carlsson, A., Almblad, A.-C., Ängeby, K. (2021). How paediatric departments in Sweden facilitate giving children a voice on their experiences of healthcare: A cross-sectional study. *Health Expectations*. https://doi:10.1111/hex.13396

II. Nordlind, A., Anderzén-Carlsson, A., Sundqvist, A.-S., Ängeby, K., Wray, J., Oldham, G., & Almblad, A.-C. (2023). Translation, cultural adaptation and validation of a patient-reported experience measure for children. *Health Expectations*. https://doi.org/10.1111/hex.13924

III. Nordlind, A., Sundqvist, A.-S., Anderzén-Carlsson, A., Almblad, A.-C., Ängeby, K., Wray, J., Oldham, G., & Joffer, J. (2026). The Swedish Children and Young People – Patient Reported Experience Measure questionnaire – A pilot study from paediatric inpatient and outpatient care. *Journal of Pediatric Nursing*. https://doi.org/10.1016/j.pedn.2025.12.021

IV. Nordlind, A., Joffer, J., Almblad, A.-C., Sundqvist, A.-S., Ängeby, K., & Anderzén-Carlsson, A. (n.d.). *Patient-reported experience measures in paediatric healthcare: a qualitative study of first-line managers' and quality-improvement workers' perspectives.* Manuscript in preparation.

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PREFACE

I stepped into the field of paediatrics 20 years ago, after working as a nurse in adult care for almost 10 years. My first employment in paediatrics was in an inpatient ward for children; since 2008, I have been at an outpatient clinic for children aged 0–18 with allergies and lung diseases. When meeting with paediatric patients, it becomes clear that each procedure must be adapted to the individual. Some children give immediate feedback on their experiences, while others are eager to please or more reserved.

My interest in research began during my nursing education. Both my bachelor's thesis and my master's thesis were based on a qualitative approach involving interviews. I find qualitative methods to be closely linked to my clinical work as a nurse. The nursing profession is rooted in a non-academic professional tradition and is informed by numerous theories, as many different aspects must be covered to capture the entire field. My foundation in scientific theory lies primarily in the hermeneutic tradition – a starting point most clearly seen in the qualitative aspects of this thesis. Other areas of this thesis are influenced by positivism (i.e. quantification) and constructivism (i.e. the social context surrounding healthcare visits).

The topic of this thesis stems from a stroke of luck, as I was fortunate enough to be offered participation in a planned doctoral project and was able to be involved in the project's development. The theme of the project, children's opportunity to evaluate their own care, seemed appropriate for the times, and it has given me many insights I can use in my everyday clinical work. The research for this thesis involved various methods through which I have gained a broad education and a desire to continue my research.

INTRODUCTION

Children's treatment in healthcare reflects society's view of children and has evolved over time, alongside developments in medical and nursing knowledge. In the past, paediatric care was characterised by strict routines and limited parental contact. Today, paediatric care in Western countries places great emphasis on the presence and involvement of family. At the same time, healthcare delivery has changed, with shorter hospital stays, increasingly specialised hospital care and expanded outpatient (OP) services (Söderbäck, 2010; Wettergren et al., 2016).

Understanding children's experiences in healthcare requires attention to both a 'child perspective' and 'children's perspectives'. Here, a *child perspective* refers to adults' attempts to understand children's experiences and opinions, which inevitably involves adult interpretation. In contrast, *children's perspectives* represent children's own experiences, perceptions and understandings (Sommer, 2010). The United Nations Convention on the Rights of the Child (UNCRC) emphasises that children have the right to express their views. In particular, Article 12 states that children who can form their own views have the right to express those views in all matters affecting them and that their views should be given due weight in accordance with their age and maturity. The UNCRC, adopted by the United Nations General Assembly in 1989, defines all individuals under the age of 18 as children (UNCRC, 1989); this definition was applied in this thesis, although the participating children were between 8 and 16 years old. Sweden was one of the first countries to ratify the convention. In 2020, the fundamental principles of children's rights were further strengthened when the UNCRC was incorporated into Swedish law (Law (2018:1197) on the United Nations Convention on the Rights of the Child, 2018).

BACKGROUND

Children

Children are a heterogeneous group with varying circumstances, needs and abilities. Their opportunities for participation are influenced by factors such as age, level of understanding, motivation, engagement, cultural background and disabilities (Söderbäck, 2010). What childhood looks like varies across societies and is influenced by factors such as socio-economic conditions, gender and ethnicity. According to the UNCRC, children are regarded as active participants who influence their own lives and society around them, rather than as passive recipients of adult decisions and social structures (Prout, 2015). Attitudes towards children and their role within the family differ across cultures, affecting the extent to which children are encouraged to form and express their own opinions (National Board of Health and Welfare, 2018).

Children's cognitive development progresses through different stages and is closely linked to language development and socialisation. Around the age of 7, intuitive thinking gradually develops into more logical and rational thinking; by approximately 12 years of age, children's thinking becomes increasingly independent (Piaget, 2008). As children develop greater knowledge, self-confidence and responsibility over time, they become increasingly willing to express their own views and participate in decisions regarding their own care (Davies et al., 2025). Although children's preferences for involvement in healthcare decision-making vary, most prefer to be involved (Noteboom et al., 2021).

In paediatric healthcare settings, the child's social context and family relationships are important considerations. Child-centred care emphasises respect for the child as an individual with rights, while acknowledging the child's dependence on and close connection with family (Coyne et al., 2018). Children may perceive their dependence on adults as natural and important for their well-being. At the same time, children's ability to develop their own voice in healthcare can be strengthened through support from healthcare professionals and

child-centred approaches that take children's right to participation seriously (Davies et al., 2025).

The UNCRC

The UNCRC (1989) emphasises children's right to be heard and have their views considered. All children have equal rights without discrimination, and their best interests must always come first in decisions affecting them. They are entitled to guidance as they develop, freedom of expression and access to information, while being protected from all forms of violence, abuse and neglect. Certain key articles from the UNCRC are described below:

Article 2: Children's rights shall apply to every child without any form of discrimination, regardless of the child's or its parents' or guardians' race, skin colour, gender, language, religion, political or other opinions, national, ethnic or social origin, property, disability, birth or other status.

Article 3: The best interests of the child shall be a primary consideration in all actions concerning children, and children shall receive the protection and care necessary for their well-being. This also applies to institutions, services and facilities responsible for the care or protection of children, which must ensure that they meet the standards set.

Article 5: Children have the right to appropriate guidance and counselling in accordance with their level of development in the exercise of their rights under the Convention.

Article 12: Children who can form their own views have the right to express those views freely in all matters affecting them, and their views shall be given due weight in accordance with their age and maturity.

Article 13: Children have the right to freedom of expression, which includes the freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art or through any other media of their choice.

However, the exercise of this right may be subject to restrictions in accordance with respect for the rights of others and for public order.

Article 19: Children shall be protected from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment (UNCRC, 1989).

Organisation of paediatric healthcare in Sweden

Paediatric care varies considerably across countries, reflecting differences in healthcare systems, policies, resources, cultural norms and approaches to children's rights and participation. These variations influence how care is organised and delivered, as well as the extent to which children are involved in decisions about their treatment and care. In Sweden, healthcare for children is provided through child health services, school health services, youth health clinics, paediatric somatic care, habilitation and psychiatrics, as well as through dental care and general primary care. In this thesis, the focus is on the Swedish somatic paediatric care context.

Sweden has 21 county regions responsible for healthcare, and paediatric healthcare is generally financed by public funds. Highly specialised somatic paediatric care is provided at six of the seven public university hospitals, where paediatric wards are located either within the hospital or in a separate children's hospital. At county hospitals, there is usually one neonatal ward and one inpatient (IP) ward for children aged 0–17 years, organised under a single department. Seriously ill children are often cared for in close collaboration with a university hospital. IP care may be required for shorter or longer periods, such as for the treatment of temporary illness, infections and accidents or for the worsening of chronic conditions. OP care can range from regular visits for chronic illnesses to intensive treatment for temporary conditions, as well as emergency visits related to for example infections or accidents (Wettergren et al., 2016).

In Sweden, several laws and regulations provide the foundation for healthcare practice, emphasising quality, patient involvement and safety. The Health and Medical Care Act (2017) stipulates that healthcare must meet the standards of good care and be based on

respect for the patient's autonomy and integrity. Complementing this Act, the Patient Law (2014) requires that healthcare be planned and carried out in consultation with the patient, as far as possible. The Patient Safety Law (2010) further mandates that healthcare providers give patients and their relatives opportunities to participate in patient safety initiatives. Additionally, the National Board of Health and Welfare's regulations and general guidelines on management systems for systematic quality work require that reports, complaints and feedback from patients and their families be collected and analysed to identify patterns or trends indicating areas in need of improvement (National Board of Health and Welfare, 2011).

Quality of care

Feedback from patients and their families is an important part of the effort to provide good quality of care. Donabedian (1980) defines quality of care as the extent to which healthcare maximises benefits while minimising risks. From this perspective, high-quality paediatric care is understood as care that is grounded in evidence-based knowledge and characterised by safety, effectiveness, equity and a child-centred approach. A key aspect of such care is ensuring that children are given opportunities to express their needs and describe their experiences and that their voices are taken seriously. Integrating children's perspectives into care practice enables services to be continuously developed and adapted, thereby strengthening quality in both individual care encounters and the organisation's overall work (World Health Organisation, 2006).

Patient participation in paediatric healthcare

Children have the right to have their views taken into account in decisions that affect them, which places a responsibility on healthcare and other settings to facilitate their involvement at both the individual and collective level (Council of Europe, 2020). The Swedish Patient Law defines participation as enabling patients to be involved in decisions about their care, as far as possible, based on their wishes and individual circumstances – an approach that applies to children (Patient Law, 2014). Patients may act as co-creators at

individual, organisational and system levels, interacting with and shaping their own opportunities for involvement. For example, decisions made at the organisational and system levels can support participation at the individual level (Act for Safer Healthcare, 2025).

Participation entails both rights and responsibilities, and children's ability to engage depends on their circumstances. Without supportive environments that promote freedom of expression and ensure that children's perspectives are taken seriously, there is a risk of children's involvement becoming merely symbolic. Meaningful participation is supported by factors such as an appropriate environment, sufficient time, clear communication and effective collaboration (Davies et al., 2023). Hietanen et al. (2025) emphasises that children's participation in healthcare depends on both individual and contextual factors and encompasses more than participation in decision-making. Supporting children's opportunities to express their opinions and choose their level of participation can strengthen their sense of empowerment. Settings that foster a sense of safety, support and control are particularly important, as are communicative and collaborative practices among staff (Davies et al., 2024; Gilljam et al., 2016). Professionals' attitudes and behaviours also play a key role: children value those who are attentive, provide clear information, offer choices and give emotional support. Opportunities for play, privacy and continuity further enhance engagement. When children feel listened to and involved, they are more likely to share their perspectives during healthcare visits (Ambresin et al., 2013). Perceiving that their views matter and that they can influence decisions about their care may also reduce children's distress during hospitalisation (Coyne, 2006). Understanding children's perspectives is therefore essential for developing child-centred healthcare. However, research indicates that children do not always feel as involved in decisions about their treatment as they would like and that the options presented are not consistently experienced as genuine choices (Davies et al., 2023).

Further development of methods is therefore needed to strengthen children's involvement and co-creation in healthcare – a matter that has been highlighted by the Swedish National Board of Health and Welfare as part of efforts to improve patient safety (National Board of

Health and Welfare, 2025). Existing approaches at the individual level include shared decision-making (Boland et al., 2019; Bosch et al., 2024) and group-level methods such as youth councils (Haesebaert et al., 2020), Photovoice (Schalkers et al., 2015) and participation in working groups (e.g. efforts to incorporate children's perspectives in the development of clinical practice standards) (Bray et al., 2023).

This thesis focuses primarily on children's opportunities to evaluate their healthcare visits through a patient-reported experience measure (PREM), which is described in the following section.

PREMs

PREMs are questionnaires that measure patients' experiences, perceptions and satisfaction with the care they receive, while patient-reported *outcome* measures are questionnaires that measure patients' views of their health status (Kingsley & Patel, 2017). When implementing a PREM, it is essential to ensure that the questionnaire has been validated for the context it will be used in and that the questions are relevant to the individuals evaluating their healthcare visit (McCabe et al., 2023). However, children are rarely involved in the development of PREMs, and very few PREMs have included children as key stakeholders (Bartholdson et al., 2024; Bele et al., 2021; Ferreira et al., 2023). PREM measures can be either generic or tailored to specific patient groups; the PREMs developed for paediatric care vary in terms of content, number of domains and questions (Bartholdson et al., 2024; Bele et al., 2021). Examples of PREMs adapted for paediatric care in the last 10 years are presented in Table 1. The examples include three PREMs validated for the Swedish healthcare context: the Child Participation in Healthcare (ChiPaC) questionnaire (Gilljam et al., 2019), aimed at children aged 6–12 to evaluate participation in healthcare visits, the Visual Consultation and Relational Empathy Measure (VCM) questionnaire (Wiljen et al., 2025), which supports children aged 7–17 (or their parents/carers) in describing their experience of empathy during a healthcare process and the PREM-ped questionnaire (Broström et al., 2026), a short questionnaire to assess experiences of healthcare among children aged 4–15.

Table 1 Examples of PREMs adapted for paediatric care in the last 10 years

Year	Author	Country	PREM	Speciality	Target group
2018/2020	Lunt et al.; McErlane et al.	UK	CAPTURE-JIA[1] PROM[2]/PREM[3]	Juvenile idiopathic arthritis	Child or proxy
2018	Wray et al.	UK	CYP-PREM[4]	Generic Inpatient and Outpatient	8-16 years
2019	Gilljam et al.	Sweden	ChiPaC[5]	Generic	8-12 years
2019	Foster et al.	Australia	NCQ[6]	Generic Inpatient	School-age
2019	Halleran et al.	USA	PREOM-BMP[7]	Constipation and Fecal Incontinence	Proxy
2021	Hu et al.	China	Child HCAHPS[8]	Generic Inpatient	Proxy
2022	Ryberg et al.	Denmark	CYP-PREM[4]	Generic Outpatient	8-17 years
2022	Yeung et al.	Canada	QTAC-PREM[9]	Trauma Acute Care	15–17 years and parents
2023	Azukaitis et al.	Lithuania	PROM[1]/PREM[2]	Kidney and Haematological Disease	<18 years and parents
2023	Pougheon Bertrand et al.	France	CF[10] questionnaire	Cystic fibrosis	All ages or proxy
2024	Hybschmann et al.	Denmark	*MyHospitalVoice	Generic	4-17 years
2024	Nafees et al.	Canada	CYP-PREM[4]	Generic Outpatient	8-16 years
2025	Barr et al.	Australia	*pPREM[11]	Generic	6–11 years
2025	Wiljen et al.	Sweden	VCM[12]	Chronic diseases - procedures	7-17 years or proxy
2026	Broström et al.	Sweden	PREM[3]-Ped Questionnaire	Generic Inpatient and Outpatient	4-15 years
2026	Kocinsky et al.	USA	PACE[13]	Oncology	Parents
2026	Nelson et al.	Australia	AHPEQS[14]	Generic Inpatient	12–17 years

*Study protocol, [1]Juvenile idiopathic arthritis, [2]Patient reported outcome measure, [3]Patient reported experience measure, [4]Children and young people - Patient reported experience measure, [5]Child Participation in Healthcare, [6]The needs of children questionnaire, [7]Patient reported experience and outcome measure - bowel management program, [7]South African Addiction Treatment Services Assessment, [8]Healthcare Providers and Systems Hospital Survey, [9]Quality of teen Trauma Acute Care - Patient reported experience measure, [10]Cystic fibrosis, [11]Pprem: Paediatric Patient reported experience measure, [12]Visual CARE (Consultation and Relational Empathy) Measure, [13]Pediatric Cancer Care Experience, [14]Australian Hospital Patient Experience Question Set

Many European countries have established systems for gathering patients' experiences at the national level, often as part of quality monitoring and healthcare management. However, there are differences in how frequently these are carried out, which patient groups are included and how the results are used. When it comes to children, specific national surveys that directly capture patients' own perspectives are less common. Instead, the experiences of parents/carers are often collected, while children's voices are included to a more limited extent. The National Patient Survey (NPE) in Sweden is co-ordinated by the Swedish Association of Local Authorities and Regions (SALAR). Within the Swedish paediatric healthcare system, the NPE is aimed at children aged 15 and over, as well as at their parents/carers (Swedish Association of Local Authorities and Regions, 2026). SALAR's work on developing an NPE aimed at children under the age of 15, which is currently underway, has been delayed, in part due to the difficulty of ensuring confidentiality when administering the NPE to children. A child impact analysis was therefore initiated with the aim of finding a viable solution that safeguards both children's right to express their views and their right to privacy and protection.

There is a lack of reporting on the use of PREMs in clinical practice and on the application of their results in quality-improvement initiatives within paediatric care, suggesting that the potential of PREMs to improve patient care may be underutilised in this area (Alarilla et al., 2024). The questionnaires used in paediatrics are often developed locally, and satisfaction surveys – which measure overall impressions or satisfaction and are less specific in terms of guiding improvements in healthcare – are more widespread (Ferreira et al., 2023).

In summary, few PREM measures have been developed for and in collaboration with children. Furthermore, children are rarely given the opportunity to share their experiences in national surveys. In Sweden, NPE surveys are currently only available for children aged 15 and over.

The CYP-PREM questionnaire

The Children and Young People – Patient-reported Experiences Measure (CYP-PREM) questionnaire is an example of a PREM questionnaire designed in collaboration with a paediatric target group. The original CYP-PREM was developed in the UK to capture children's views on their experiences of healthcare, in collaboration with children aged 8–16 who had received IP and/or OP care at the Great Ormond Street Hospital (GOSH) in London (Wray et al., 2018). CYP-PREM is a generic questionnaire available in six versions: for three age groups (8–11, 12–13 and 14–16 years) in each of IP and OP settings. It covers three themes – namely, hospital facilities, staff, and treatments and tests – with an additional section for supplementary questions. The different versions of the questionnaire include 31–45 questions with response options on different ordinal scales, such as 'Always', 'Sometimes' and 'Never'. Some questions include response options for when the question is not relevant to the child, such as 'I have been there before and did not need any information' (see Figures 1 and 2 for examples). All versions include an open-ended question where the child can describe what was good and what was bad about the visit in text or by drawing.

In addition to developing questions and response options, children contributed to the graphic design of the questionnaire: the versions for ages 8–11 and 12–13 feature animal-themed designs with animal-related texts (Figure 1), while the version for older children uses a cartoon style (Figure 2). The development process involved four phases, all incorporating children's input. Focus groups identified key issues and guided layout choices; cognitive interviews explored children's understanding of the language and navigation used; and acceptability testing with 41 children, followed by a pilot study with 299 children, assessed the appropriateness of the content (Wray et al., 2018).

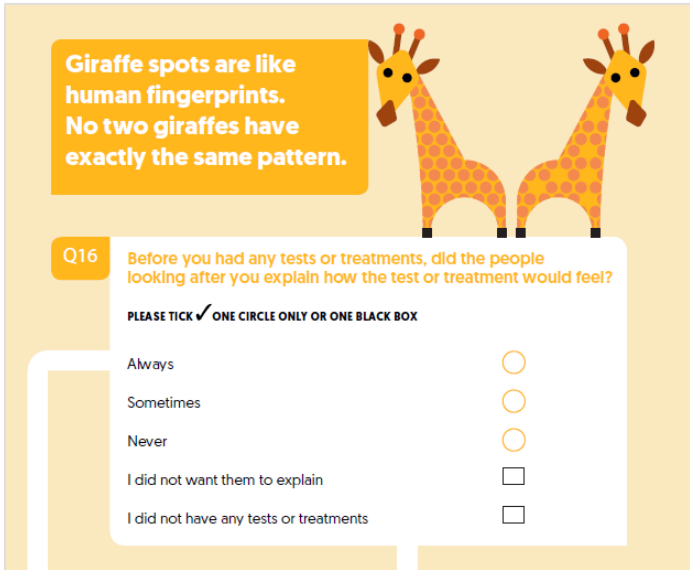


Figure 1 A question in the original CYP-PREM with an animal-themed graphic design (©GOSH).

Figure 2 A question in the original CYP-PREM in a cartoon style (©GOSH).

The OP versions of CYP-PREM have been translated, adapted and validated for new healthcare contexts. For example, these versions have been systematically adapted for Danish and Canadian settings to ensure relevance and validity. This process included linguistic translation, cultural adaptation and alignment with local healthcare practices. Pilot testing with local patient groups assessed clarity, relevance and reliability, alongside consideration of national ethical and data-protection requirements. Together, these measures ensured that the instrument was reliable and useful in both settings and confirmed that CYP-PREM could be used for children in a different healthcare context following appropriate cultural and linguistic adaptation (Nafees et al., 2024; Ryberg et al., 2022). The thorough development process was the reason CYP-PREM was chosen for translation and cultural adaption within this thesis.

Theoretical perspective

In summarising the results of the thesis, the Lundy model was chosen as a framework for the analysis. This model is used herein to understand children's right to voice their opinions of their healthcare experiences and the conditions required to facilitate and integrate children's voices in Swedish paediatric care.

The Lundy model

The Lundy model was originally developed in the UK to facilitate the implementation of Article 12 and children's rights in school settings. Article 12 of the UNCRC contains two important elements: the right of children to express their views and the right of children to have their views taken into account (UNCRC, 1989). The Lundy model for the application of Article 12 (Lundy, 2007) clarifies the need for four separate factors with no hierarchical structure to capture these obligations towards children in decision-making based on articles of the UNCRC. In this thesis, these factors are related to children's right to express their views on their healthcare experiences. The factors in the Lundy model and their relationship to Article 12 are described in the text below, adapted for a paediatric healthcare perspective. The Lundy model is also illustrated in Figure 3, which demonstrates that

there is significant overlap between (1) *space* and *voice* and (2) *audience* and *influence*.

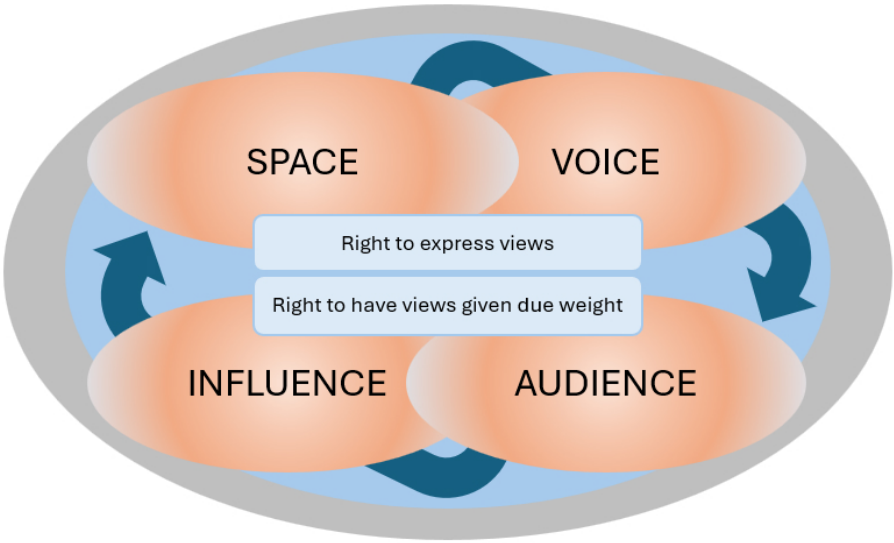


Figure 3 The four factors involved in meeting legal obligations towards children in decision-making, inspired by the Lundy model (Lundy, 2007).

Space – Children must be given opportunities to express their views

Facilitating the provision of space to encourage children to express their opinions is a prerequisite for creating opportunities to integrate children's opinions into development work in paediatric healthcare units. Here, providing *space* involves giving children the right to express their opinions. The first step is to ask children what issues they consider important and how they would like to participate. The space must be inclusive and should seek opinions from a diversity of children, not just those who find it easy to express themselves. The space offered to children for participation must be a safe space where children are given time to express their views without fear of punishment or reprisal. While participation is a right for all children, no child is obliged to share their views (Lundy, 2007).

Voice – Children must be supported in expressing their views

Children should be able to freely express their views of their experiences of healthcare in various forms, including 'orally, in writing or in print, in the form of art, or through any other media of the child's choice'. This right is related to children's right to freedom of expression. Children's right to express their views is not dependent on their ability to express a mature opinion. All children have the same rights and equal value, and none should be discriminated against based on background, gender, religion, disability or parental status. Children may need help to form an opinion, such as information, support and advice from adults, who need to provide guidance in order for children to exercise their rights (Lundy, 2007).

Audience – Children's views must be listened to

Adults must be mindful of their ability to listen to the various verbal and non-verbal ways in which children express their perspectives on healthcare visits. Even when there is no doubt about a child's perspective on an issue, there is no guarantee that the child's views will be communicated to adults who are willing to take these views into account. Therefore, it is necessary to ensure that children's expressed views are received by an identifiable person or body who is responsible for listening (Lundy, 2007).

Influence – Children's views must be appropriately followed up on

Every decision-making process within paediatric healthcare should be based on the principle of looking out for the best interests of the child. The challenge in giving children's views 'due weight' is to find ways to ensure that adults not only listen to children but also take their views seriously. An important part of this work involves ensuring that children are informed about the decisions that have been made and how their views have been taken into account (Lundy, 2007).

RATIONALE

Integrating children's views on their experiences is essential for the development of child-centred healthcare, as it enables care to be adapted and improved based on children's needs and experiences. Children's ability to express their own views can be strengthened through support from healthcare professionals and child-centred approaches. Thus, healthcare providers are responsible for facilitating children's participation at both the individual and collective level. In this way, children's perspectives can contribute to strengthening healthcare quality – both in individual care encounters and in organisational quality-improvement efforts.

PREMs are one way of capturing children's views on the experiences of care they receive. However, research has shown that children are rarely involved in the development of PREMs. Moreover, there is limited knowledge on how PREMs are used in clinical practice and applied in quality-improvement initiatives within paediatric care. This lack of knowledge suggests that children's right to express their perspectives on their healthcare experiences is not yet fully integrated into clinical practice. Thus, further research on how children's voices can be collected and incorporated into paediatric care is crucial.

AIMS

The overall aim of this thesis was to explore how children's right to voice their views of their healthcare experiences can be facilitated and integrated into clinical practice within Swedish paediatric care, with a primary focus on children's opportunities to evaluate their healthcare visits using PREMs.

This aim was addressed through the more specific aims of the following studies, whose aims were

I. To describe how Swedish paediatric departments facilitate children's voices on their healthcare experiences and how their perspectives are taken into account in quality-improvement work.

II. To translate, adapt and validate the six versions of the CYP-PREM for use in a Swedish healthcare context.

III. To pilot the Swedish versions of the CYP-PREM (Swe-CYP-PREM) questionnaire in paediatric care.

IV. To explore first-line managers' and quality-improvement workers' perspectives of using PREMs in paediatric units.

METHODS

Design

This thesis consists of four studies (I–IV). Different methods for data collection and data analysis were used in each study to address the specific aims.

Study I is a cross-sectional questionnaire study, **Study II** focuses on translating, adapting and validating the CYP-PREM questionnaire for use within the Swedish healthcare context, **Study III** is a pilot study using the Swedish version of CYP-PREM and **Study IV** takes a qualitative descriptive approach. Table 2 presents an overview of the designs, participants and applied methods.

Table 2 Overview of the study designs, participants, data-collection methods and analyses used in this thesis

Study	Design	Participants	Data collection	Data analyses
I	Descriptive cross-sectional design	Heads of a paediatric department (*n* = 19) Heads of a paediatric unit/ward (*n* = 3) Quality-improvement worker (*n* = 5) Unknown position (*n* = 1)	Study-specific questionnaire	Descriptive statistics and Burnard's method of coding and categorisation
II	Exploratory sequential mixed-methods design	Children aged 8–16 years (*n* = 62)	Cognitive interviews	Case and cross-case analysis
		Children aged 8–16 years (*n* = 42)	CVI	I-CVI and S-CVI
III	Descriptive cross-sectional design	Children aged 8–16 years (*n* = 176)	Swe-CYP-PREM and a study-specific questionnaire	Descriptive statistics and open-ended answers, which were clustered into positive and negative comments regarding the focus of the content
IV	Qualitative descriptive design	First-line managers (*n* = 8) Quality-improvement workers (*n* = 7)	Focus groups	Qualitative content analysis

CVI: Content validity index; I-CVI: Item-level – content validity index; S-CVI: Scale-level – content validity index; Swe-CYP-PREM: Swedish version of the Children and Young People – Patient-reported Experience Measure

Sample and setting

The participants in **Studies I–IV** were patients or employees at publicly funded paediatric departments with both IP and OP care at the county and university hospital levels, spread across Sweden.

In **Study I**, an e-mail with a link to the questionnaire was sent to all heads of paediatric departments in Sweden ($N = 39$). The heads were informed that the task of completing the questionnaire could be handed over to a co-worker if more appropriate. One of the respondents was excluded because that department did not meet the criterion of providing both IP and OP care. The response rate was 74%. Of the 28 participants in total, 19 were heads of a paediatric department, three were first-line managers of a paediatric unit and five were quality-improvement workers in a paediatric department (the position of one participant was unknown).

The 104 children who took part in **Study II** were recruited during visits to paediatric IP and OP units at one county hospital and one children's hospital in central Sweden. One inclusion criterion was an age between 8 and 16, as the original versions of the CYP-PREM were developed in collaboration with children of these ages. Other criteria were being able to understand the Swedish language and being deemed by healthcare staff as being able to answer the PREM and take part in a cognitive interview or being able to participate in the content validity index (CVI) testing. The cognitive interviews used a convenience sampling including a total of 62 children (37 girls, 24 boys and one child who preferred not to answer). In the CVI testing, a new convenience sample of a total of 42 children (23 girls and 19 boys) was included.

The 176 children who took part in **Study III** were attending IP care or visiting an OP clinic in one of 19 units located at either the county or university hospital level within four central Swedish county regions. All children within the relevant age group (8–16 years) who were discharged from an IP ward or visited an OP unit during the study period were eligible to participate. The potential sample included 480 children, of whom 319 were invited to participate. The

children were asked whether they were willing to participate in the study by staff where they received care. The staff gave several reasons for why some children were not asked to participate, including a lack of time during the visit, language difficulties, medical reasons or simply being overlooked, but these reasons were not systematically recorded in the study. Of those invited, 296 children agreed to participate and 189 returned the questionnaires, corresponding to a response rate of 59.5%. Children who did not provide signed consent ($n = 9$) or who were given the wrong version of Swe-CYP-PREM ($n = 4$) were excluded. Of the 176 children in this study (79 girls, 96 boys and 1 own description), 32 patients were in an IP ward and 144 children were visiting an OP unit.

In **Study IV**, the 15 participants were recruited via an email sent to the heads of departments providing both IP and OP care within paediatric somatic care in Sweden. The email contained information about the study and a request for contact details for first-line managers and quality-improvement workers. Contact details were obtained for a total of 60 potential participants across 14 regions. An invitation was sent to all potential participants via an email, which included information about the study. The aim was to recruit participants purposefully in order to obtain a representative sample comprising both first-line managers and quality-improvement workers with various levels of experience (at least 2 years' experience in this role or equivalent). The intention was to include participants from departments with different subspecialties within paediatric OP and IP care at the county and university hospital levels, in order to gather perspectives from various departments that treat children aged 8–16 with chronic or acute conditions. Ultimately, the selection of participants had to be made more sequentially than expected. Finding interested people was not difficult; however, as the number of potential participants was limited, almost all those who were interested in participating in the study were included. Of the willing potential participants who were not included, three had difficulty finding a suitable time for participation in a focus group, one was unable to attend at the last minute and one did not submit written consent. Of the 60 invited participants, eight first-line managers from

a paediatric unit and seven quality-improvement workers from paediatric departments agreed to participate.

Study I

Data collection

To investigate how children are given the opportunity to voice their views on their experiences of healthcare and how their views are taken into account at Swedish paediatric clinics, a cross-sectional study was carried out at the time the UNCRC became Swedish law – that is, at the turn of the year during 2019–2020. Data were collected via an electronic, study-specific questionnaire consisting of 16 questions. The study-specific questionnaire was developed in collaboration with representatives from SALAR. The questions were both closed and open-ended; the response options were on a nominal or ordinal scale, and the participants had the option to add free text responses to all questions. The focus of the study was to determine whether the paediatric departments gave children the opportunity to share their views on their experiences of care via PREM questionnaires or other sources. There were also questions that focused on how the results from questionnaires (including the NPE) were used.

Data analysis

Descriptive statistics were used in the analysis of quantitative data, where variables were expressed in terms of exact numbers and proportions were expressed as percentages (Altman, 1991). Cross tables were used to describe other approaches to involve children in quality-improvement work, depending on the type of hospital. Statistical Package for the Social Sciences (IBM, 2019) was used to analyse the data. Statistical significance was assumed at a p value of less than 0.05 (Altman, 1991). Burnard's (1991) method of coding and categorisation was used to analyse the qualitative data from the open-ended responses. All open-ended responses were compiled into a single document, and significant words and sentences were coded. These codes were then grouped and categorised based on similar

content. The categories included aspects from more than one open-ended question in the study-specific questionnaire. To ensure the validity of the analysis process, each step was documented in a matrix, making it possible to go back and review the original free-text responses (Burnard, 1991).

Studies II and III

The process of instrument development

The translation, cultural adaptation and validation (**II**) process for the Swe-CYP-PREM was initiated in March 2019, and the first phase of the translation and cultural adaptation of the PREM followed the recommendations of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (Wild et al., 2005) in 10 steps, illustrated in Figure 4. The instrument development included cognitive interviews (**II**), the CVI (**II**) and a pilot study (**III**), all of which are described below. The whole process is illustrated in a timeline in Figure 5.

Data collection

The seventh step in first phase of the translation, cultural adaptation and validation process (Wild et al., 2005) involved cognitive interviews (**II**) (Drennan, 2003; Willis, 2015). Interviews were conducted with representatives from the target group to assess the face validity of their understanding of CYP-PREM. The children were interviewed while answering the questions in CYP-PREM in connection with their healthcare visits. The interviews focused on listening to the children's words to evaluate their understanding of the questions. The children were asked to read the questions aloud, to 'think aloud' to describe their thoughts while answering the questions and to explain their answers so the researcher could assess whether the child understood the questions as intended. The researcher also asked the child to define the meaning of selected words. The interviews followed a structured interview guide based on CYP-PREM and were audio-recorded.

Given that the children found the CYP-PREM too extensive, it was deemed necessary to proceed with content validation of the questionnaire's questions. In the second phase of the validation process, CVI testing (**II**) (Polit et al., 2007) was carried out with representatives from the target group to validate the content of CYP-PREM. The participating children (n = 42) were given the CVI material, which consisted of a stack of sheets of paper, with each question from the age-appropriate CYP-PREM on a separate sheet, and four envelopes labelled 'very important', 'important', 'not so important' and 'not at all important'. The children were instructed to read each question, assess how important the question was for children to express their views on their experiences of a healthcare visit and place the question in the most appropriate envelope. The participating children could choose whether they wanted to complete the CVI during the healthcare visit or at home.

The pilot study (**III**) was conducted as a third phase of the validation process to investigate the acceptance and usability of Swe-CYP-PREM in clinical practice (Kingsley & Patel, 2017). The participating children (n = 176) were asked to complete both the appropriate version of Swe-CYP-PREM and a study-specific questionnaire for the evaluation of Swe-CYP-PREM, where both questionnaires were in paper format. The study-specific questionnaire used response options with different ordinal scales, but the children were also given the opportunity to provide comments in free text. Data collection for the pilot study was conducted over 1–2 weeks at each participating unit. The healthcare staff at each ward recruited children for the study and informed the children and their parents/carers about the study. If there was interest in participating, the healthcare staff handed out envelopes containing age-appropriate information letters, consent forms, Swe-CYP-PREM and the study-specific questionnaire.

Data analysis

The audio files of the cognitive interviews (**II**) were listened to after each interview. Any uncertainties that the children pointed out or occurrences when the child asked for help, had difficulty with words or misunderstood the questions were entered into a case-specific

matrix for each child. After conducting several interviews, all case-specific matrices were compiled for a cross-case analysis (Andersen et al., 2014). The identified problems were coded as follows: (1) *Not relevant or difficult to understand due to the context*, (2) *Difficulty understanding the meaning of the words*, (3) *Difficulty understanding the structure or wording of the question* and (4) *Inconsistent terminology*. The questions were revised in accordance with the issues that emerged during the interviews and were then tested further in new interviews. Interviews, case and cross-case analyses were conducted until the questions were deemed to be understood by the children, resulting in 62 interviews in a total of four rounds.

Data from the *CVI testing* (**II**) were entered into a table in which the responses were coded numerically: '*very important*', 4; '*important*', 3; '*not very important*', 2; and '*not at all important*', 1. The responses were then dichotomised so that higher ratings (3–4) were assigned a value of 1 and lower ratings (1–2) were given a value of 0. The analysis was done separately for each of the six versions of CYP-PREM. The Item-CVI (I-CVI) was calculated for each question by summing the number of '1's and dividing by the number of participants who answered the question, in order to assess the relevance of the questions. The results were used by the research group to jointly determine which questions should be removed. In accordance with the experts' recommendations, questions rated as '*not very important*' or '*not at all important*' by at least three of the seven participating children were excluded. The overall content validity of the questionnaire was assessed using the CVI scale (S-CVI/Ave), calculated as the mean of all I-CVI values. An S-CVI/Ave of ≥0.90 is considered excellent, whilst ≥0.80 is regarded as acceptable (Lynn, 1986; Polit et al., 2007).

Analysis of the cross-sectional data from the questionnaires in the pilot study (**III**) was carried out using descriptive statistics. The chi-square test with a significance level of $p < 0.05$ (Brace, 2016) was used to assess differences between groups and to evaluate differences between potential participants who were not invited to take part and those who were invited but declined to participate or agreed to participate but did not respond. Statistical Package for the Social

Sciences (SPSS) version 29.0.2.0 (IBM, 2021) was used to analyse the quantitative data. The open-ended responses of the children's views on their healthcare visit were sorted into positive and negative comments regarding the focus of the content. Translated quotes were selected to illustrate how the children described their experience of their healthcare visit, in addition to the closed-ended questions.

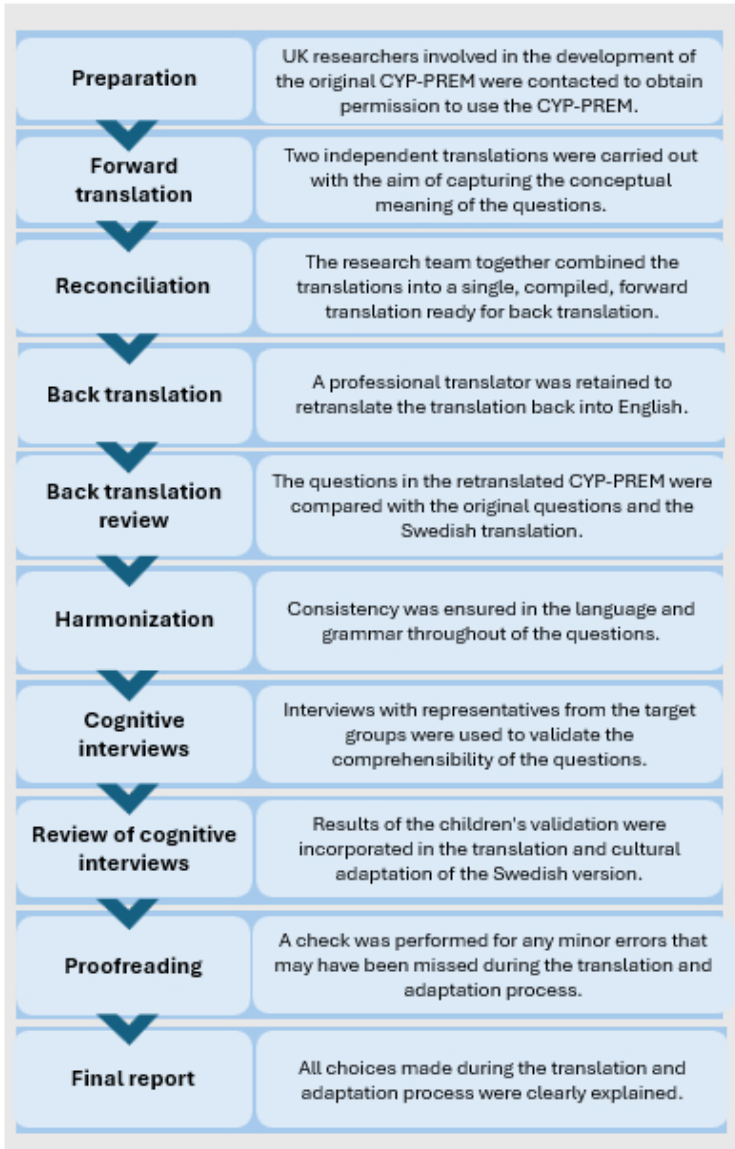


Figure 4 The 10 steps of translation, cultural adaptation and validation based on recommendations from ISPOR (Wild et al., 2005).

Figure 5 Approximate timeline of the development of the Swedish version of CYP-PREM, covering the 10 steps of translation, cultural adaptation and validation, as recommended by ISPOR **(II)** (Wild et al., 2005); the content validity index **(II)** (Polit et al., 2007); and a pilot study in clinical practice **(III)** (Kingsley & Patel, 2017).

Study IV

Data collection

To ascertain management's views on the use of PREMs in paediatric wards, a total of five focus groups (Krueger & Casey, 2014) were conducted, with participants including first-line managers and quality-improvement workers. Each group consisted of two to four participants, and the sessions were arranged progressively throughout the data-collection period between March and May 2024. All focus groups were carried out online and were audio-recorded. Each session included an introduction to the domains (*hospital facilities*, *staff*, and *treatments and tests*) previously identified by children as important in the development of CYP-PREM (Wray et al., 2018), as confirmed in the earlier studies included in this thesis. A structured questionnaire route based on the work of Krueger and Casey (2014) served as a guide for the focus groups. As no significant new insights were emerging and the dataset was considered sufficiently rich, recruitment was discontinued after the fifth session, in line with methodological recommendations (Krueger & Casey, 2014).

Data analysis

An inductive qualitative content analysis of the focus group material was undertaken in accordance with the approach described by Graneheim and Lundman (2004). All focus group recordings were transcribed verbatim by a professional transcription service. The data were organised and analysed using NVivo 14 software (Lumivero, 2023) to support systematic data management. The analytical process was not a strictly linear progression; rather, it moved back and forth between the details and the bigger picture, with ongoing discussions within the research team in which all members contributed alternative perspectives and interpretations to strengthen the findings, in accordance with recommendations by Graneheim and Lundman (2004) and Graneheim et al. (2017). The developed categories were kept close to the manifest content of the codes, albeit at a more abstract and summarised level. At a higher interpretative level, categories were further clustered into sub-themes; ultimately, an

overarching latent theme was constructed (Graneheim et al., 2017; Graneheim & Lundman, 2004).

Collaborations

Initially, the thesis involved collaboration with representatives from SALAR, including a children's rights strategist and statisticians. These individuals were responsible for the development of NPE aimed at children – a project that ran in parallel with the development of the PREM in this thesis. Contact was first established through the initiative of my supervisor, Agneta Anderzén Carlsson, and the representatives contributed to the development of the study-specific questionnaire used in **Study I**, with their expertise regarding national patient surveys, children's participation and questionnaire design.

Before commencing the thesis work, contact was made with Dr Jo Wray and Clinical Governance Manager Geralyn Oldham, the two researchers behind the development of the original CYP-PREM questionnaire, to obtain approval for the development of a Swedish version. Three of my supervisors and I visited GOSH to gain a clear picture of the context and how the original CYP-PREM was developed, as well as to clarify further study planning. Jo Wray and Geralyn Oldham were part of the instrument-development process (**II**) and the pilot study of Swe-CYP-PREM (**III**) as consulting experts.

Ethical considerations

The studies (**I–IV**) included in this thesis were conducted in accordance with national requirements and the principles of the Declaration of Helsinki (World Medical Association, 2024). **Studies II–III** were approved by the Swedish Ethical Review Authority (Nos. 2019-01203, 2020-02350, 2022-00837-02). According to the Swedish Ethical Review Authority, **Studies I and IV** were not covered by the Act on Ethical Approval of Research Involving Humans. **Study I** was described in the first application, but the Swedish Ethical Review Authority assessed that, based on the study design and Swedish law, an ethics review was not required. An advisory approval was obtained for **Study IV** (No. 2023-04203-01). The details of the ethical approvals are outlined in Table 3.

Table 3 Overview of ethical approvals

Study	Ethical approval number	Amendment approval number	Reason for amendment
I	No approval required according to the Ethics Review Act		
II	2019-01203	2020-02350 2022-00837-02	Expansion of study sites Addition of interviewer Addition of CVI testing
III	2019-01203	2022-02365-02 2023-05474-02	Addition of study centres Extended data-collection period for the pilot study Analysis and reporting of cross-sectional data from the pilot study
IV	Advisory approval: 2023-04203-01		

All participants included in the studies (**I–IV**) in this thesis received written information prior to participation. Children (**II–III**) received age-appropriate written and verbal information about what participation entailed, and the instructional guide for completing the CVI was designed with pictures to be more child friendly. It was also clarified that participation was voluntary and could be discontinued at any time. Participants in **Study I** provided consent to participate in the study by completing the questionnaire.

When conducting research involving children, the information must be child friendly; the researcher must also assess the child's ability to understand the information and give consent. Written consent was provided by the participants in **Studies II–IV**; for children younger than 15 years of age, however, the written informed consent of a parent/carer was also required, although the child's own wishes were always respected.

Children within the healthcare system are a vulnerable group due to their position of dependency and structural vulnerability. However, it is important for children to be involved in research that concerns them, and the information sought in the studies for this thesis was deemed to benefit children as a group and to be unobtainable from a less-vulnerable group (UNCRC, 1989; World Medical Association, 2024). Particularly during the cognitive interviews, attention was paid to the child's signals, as recommended in the 'Good Research Practice' report (Vetenskapsrådet, 2024). During the interviews, the interviewer was careful to find the right balance between asking enough follow-up questions to gain as much information as possible from the interview and avoiding putting too much pressure on the child. The interviews did not include any sensitive personal questions, which would have made it even more difficult to determine the right balance.

When inviting children to take part in the studies (**II and III**) for this thesis, there was a risk that the children might feel pressured to participate by staff or by their parents or carers; there was also a risk that staff, parents or carers would perform so-called 'gatekeeping' and prevent the children from taking part (Powell, 2013). Healthcare professionals have a duty to protect their patients, which may in some cases have hindered children from having the opportunity to make their own decisions about participation. Furthermore, parents or carers may have been unable to allow their children to participate due to a lack of time or because they felt it would be too difficult for their child. Neither I nor the other members of the research team were involved in the care of the participants in the cognitive interviews (**II**). I was involved in the care of some of the children who took part in the CVI study (**II**); however, as the children were not asked to answer any questions relating to their actual care, this was not considered to pose any ethical problem. In the pilot study (**III**), members of the research team had been involved in the care of a limited number of children, but had not, in those cases, access to the individual children's responses.

Applying child-friendly research methods involves giving children the opportunity to choose for themselves the time, place and people who

will be present during data collection, as far as possible (Foster et al., 2025). During the cognitive interviews (**II**), many of the children wanted a parent or carer to be present, and some children requested assistance from the researcher or parent/carer in reading the questions to them. The children participating in the CVI testing (**II**) could choose whether they wanted to complete the CVI during the healthcare visit or at home. One participant, whose native language was not Swedish, requested support from a researcher to ensure that the information was understood correctly; the other participants completed the test without anyone from the research team being present. In the pilot study (**III**), it was emphasised that the child's opinions were being sought, rather than the parent's or carer's, but participating children could choose whether they wanted the support of a parent/carer. To further ensure a safe environment, the child and parent/carer could decide whether to complete the questionnaires at the healthcare unit during the visit or take the questionnaires home and complete them at a convenient time within a week.

All participants (**I–IV**) were guaranteed confidentiality. All collected data (**I–IV**) were de-identified, and code keys were created and stored separately from the interview data and questionnaires. Digital data are stored on a password-protected server at the institution of the principal investigator responsible for the data.

RESULTS

The results of **Studies I–IV** are first summarised per study, followed by the synthesised results describing how children's right to express their healthcare experiences can be facilitated and integrated into clinical practice within Swedish paediatric care, based on the Lundy model (Lundy, 2007).

Summarised results of the individual studies

Study I

Monitoring children's perspectives of healthcare was described as an integral part of daily work, where managers and healthcare staff were considered to have a shared responsibility. Variation in the questionnaires used was reported, and examples were given of the use of other methods to capture children's opinions on their experiences.

Questionnaires used

Of the 28 responding departments, 16 had used questionnaires in addition to NPE in the past 3 years, and 12 had used questionnaires aimed at children. These questionnaires varied in content, target group and design. Most were locally developed and were sometimes adapted for specific patient groups, such as a specific ward or children with specific medical diagnoses. The questions mainly concerned treatment, participation and patient satisfaction, but they also included accessibility, co-ordination and quality-improvement work. Two units used validated instruments, one of which had been developed and validated in Sweden.

Other methods to obtain children's perspectives

Half of the participating departments stated that they used methods other than questionnaires to capture children's views on their experiences. Seven departments reported that they had a children's council, which was used to involve children in quality-improvement work and as a reference group for decisions. Other examples of methods included conversations in connection with care contacts and

a recurring 'Question of the Week' with varying themes. Respondents also described café dialogues in which children participated in open conversations about their experiences of the hospital, in-depth interviews carried out with children, and 'safety rounds' in which children of different ages provided feedback through comments and pictures.

Implementing children's rights

Representatives from the departments described how monitoring children's rights was on the agenda of management meetings and was reviewed before decisions were made about changes to premises and within the organisation. Developing a clinical practice based on children's rights was considered a shared responsibility for both the staff working closely with patients and the staff at the management level. Some departments had special representatives for children's rights in all units, and some had a quality-improvement worker. One respondent described an ongoing national project titled 'Child-friendly Care', in which children's departments in Sweden evaluated each other by assessing the extent to which children's rights were being respected. That project will result in a certificate and an action plan showing that departments are working in accordance with the UNCRC.

Opportunities and obstacles using children's perspectives

Some respondents described obstacles to using children's views in clinical quality-improvement work; these mainly included a lack of time, lack of resources and expertise, and uncertainty about how the work should be organised. Some also considered that inviting children's participation needed to be done more systematically and be better integrated into workflows.

It was found to be difficult to involve children in improvement work, especially in overall management issues. Respondents believed that it worked better to involve children in diagnosis-specific issues and that it was easier to involve children with chronic diseases than children with acute conditions. Another obstacle was that participating

children were expected to represent a larger group, rather than providing only their own experiences.

The lack of systematic follow-up systems for children's participation was also emphasised. Thirteen respondents (46%) reported that children's perspectives were taken into account to a 'low' or 'very low' degree in quality-improvement work. One respondent noted that a children's council enabled dialogue between children and management groups, but no relationship between the presence of a children's council and the perceived level of children's participation could be demonstrated ($p = 0.72$).

Study II

During the translation, adaptation and validation of CYP-PREM, issues with clarity and contextual relevance were identified in the Swedish setting. Revisions and deletions were made to improve the questions from a child's perspective. Overall, the children considered the layout easy to understand. Approximately half of the questions were revised as a result of the cognitive interviews. These changes were related to context, wording, question structure, the use of uniform terminology and the adjustment of content in all versions of CYP-PREM. In summary, the translation, cultural adaptation and validation process yielded six Swe-CYP-PREM versions with established face and content validity. The versions of the questionnaire contain 25–34 questions, 12 of which are included in all versions.

Contextual differences

The contextual changes were linked to differences clarified between the specific UK children's hospital GOSH and paediatric care in the Swedish context, where the goal was to make the questionnaire usable regardless of hospital or OP clinic. Difficulties were encountered in finding terms to make it clear which type of room was being referred to in questions about different rooms. This led to questions about the treatment room being removed.

Difficult wording

Most of the words that the children had difficulty understanding were replaced or rewritten to make the questions more understandable. Exceptions included the words 'information' and 'healthcare staff', for which it was considered difficult to find equivalent words. A question regarding 'information' was rephrased in one case, 'Did the healthcare staff tell you why you were in the ward?', but retained in the following question, 'Was the information they gave you about why you were in hospital easy to understand?'. Explanatory text to clarify the meaning of 'healthcare staff' was added the first time this term was mentioned: 'Healthcare staff are those who work in the ward, such as nurses and doctors'.

Issues in question structure

In some cases, the question structure or lack of appropriate response options made it difficult for the children to understand how to answer the questions. Some questions were therefore supplemented with response options based on the child's previous experiences, such as, 'I have done this before, did not need any explanation'.

Inconsistent terminology

Adjustments were also made to achieve as much consistency as possible between the different versions of the questionnaire. For example, in questions about premises, the terms 'playroom' and 'adolecent room' were added as response options in all versions, since it was possible that younger children might use youth rooms and teenagers might spend time in playrooms.

Questionnaire content

In the cognitive interviews, the children reported that CYP-PREM was too extensive. Less-relevant items were therefore removed using the CVI method to enhance the instrument's applicability within Swedish healthcare. As a result of the CVI, a total of three to 10 questions were excluded from the different versions of CYP-PREM. However, some of the questions that the participants gave a low rating to were considered important by the research team based on

children's rights and were therefore not excluded. The adjustments in CYP-PREM improved the relevance and increased the S-CVI/Ave, which now ranges from 0.81 to 0.94 across the six questionnaire versions.

Study III

In the pilot study, no differences in gender or age were found in terms of which children were invited to participate or the response rate. The results showed that the paper-based Swe-CYP-PREM is suitable for clinical use, with high data completeness, few response errors and strong acceptance among children. It was found to capture variations in healthcare experiences despite generally positive responses, and the open-ended question added valuable insight to the closed-ended items.

Opinions and understanding of Swe-CYP-PREM

For about half of the children, the questions in Swe-CYP-PREM took less than 10 minutes to answer, and 91% of the study participants thought it took a reasonable amount of time. No child felt angry or sad about the questions; however, when it came to comprehension, 18 of the children stated that at least one of the questions was difficult to understand. Of the 176 participants, 16 chose to leave written comments to share their opinions about the questions and the answer options. Examples of positive and negative feedback included the following: 'I think it went well, and the questions were good' (IP girl, 12 years old) and 'Some questions were difficult to answer because some questions were about things I was not involved in' (OP boy, 9 years old).

Data completeness and response errors

There were non-responses in 20 of the questions; in eight of these questions, more than one child had omitted an answer. Of the questions with a greater number of missing answers, two were also described as difficult to understand by four children. These two questions were, 'Did the healthcare professional do anything about what you said, if needed?' (missing $n = 5$) and 'Did you (or your

parent or carer) know what to do or who to talk to if you were worried about something when you got home?' (missing $n = 7$).

In a few cases, children had ticked in between options or had found their own answer options, which was possible when the questionnaire was in paper form. Some questions had multiple answers; for example, five children answered that they received an explanation before the test, examination or treatment but also ticked 'I have not undergone any test, examination or treatment'. This question was also reported by four children as difficult to understand.

Children's healthcare experience

The children's responses regarding their experience of a healthcare visit were predominantly positive, but the results show that Swe-CYP-PREM was able to capture differences in experiences. Of the children, 66 answered the open-ended question. Their comments expressed both positive and negative experiences related to all domains of the questionnaire.

Study IV

The analyses of the focus group data resulted in an overarching theme: *Children's perspectives are central for quality improvement - flexibility and resources are needed for clinical use*. The overall theme comprises four sub-themes, each containing two to three categories that represent different aspects of first-line managers' and quality-improvement workers' perspectives on the use of PREMs in paediatric units.

To effectively integrate children's perspectives through PREMs, the participants considered it necessary to adjust their working methods to align with both the children's capacities and preferences and the specific circumstances and needs of individual paediatric units. Furthermore, making use of the results and providing feedback were seen as crucial for sustaining both the children's involvement and the staff's engagement with and commitment to ongoing improvement efforts.

Feedback from children is highly valued – their views need to be sought, but it is not always possible to act on them

The participants' discussions revealed their belief that children can contribute important experiences and that children's views are not always what is expected. Thus, they considered it important to take children's opinions into account, although difficulties were noted in being able to take full advantage of children's views. These difficulties were partly due to limitations (e.g. small premises) but could also occur when different interests were in conflict. The participants recognised the question domains presented in the introduction to the focus groups as issues that children considered important in their healthcare contacts.

Different approaches are needed to give children more equal opportunities to express their opinions

The participants considered PREMs to have many advantages; however, they had experience with a variety of methods for capturing children's opinions and considered these methods to be an important complement to PREMs in order to reach specific groups of children and obtain more in-depth information. They described the advantages of integrating PREMs into the unit's routines. PREM results were considered to be able to capture both positive and negative feedback from children, making it possible to identify areas for improvement. An advantage of PREMs was being able to reach many patients, not just those who usually speak out. The perception that emerged from the focus groups was that children were only willing to answer PREMs with relatively few questions. The participants considered validated questions valuable for ensuring questions were relevant and understandable to children and expressed a desire to have access to select questions from validated questionnaires. Difficulties were described in adapting questions to capture opinions from children with language difficulties, for example. When distributing PREMs, engaging children's interest in order to give them the best opportunity to share their views was found to be challenging.

PREM administration must be adapted to the conditions and needs of different healthcare units

Resources, commitment and flexibility are necessary to be able to adapt questions, administration methods and data compilation to the different circumstances and needs within each unit. Digital questionnaires were considered to be an advantage from the perspective of paediatric departments, as the answers can be more easily compiled and presented. Continuous measurements were considered suitable for units where an evaluation of each visit was desired. However, measurements carried out at recurring periods were considered to facilitate the compilation and use of results, while engaging employees and limiting the additional workload the measurements entailed.

The participants in the focus groups had experience of using PREMs but described the need to take advantage of their own and others' previous experiences in order to work more systematically. Representatives from units with more experience emphasised different areas of responsibility for conducting measurements and acting on the results. For example, the quality-improvement worker could be responsible for measurements and compiling results, while management was responsible for highlighting and acting on the results.

Feedback to children and staff is essential for measurements to be meaningful

Feedback to children and staff was described as essential for measurements to be meaningful. In addition, the participants noted that work was needed to establish methods for providing feedback to the children, which was viewed as important in order to demonstrate the results and actions taken based on the children's views.

Feedback to the organisation was also considered an important part of the work with PREMs. The results from PREMs could be used as a basis for discussion within the relevant unit and for further development and formulation of goals. The participants described feedback as a management responsibility and noted that such

feedback could highlight positive aspects to motivate staff and share good examples.

Synthesis of the results in relation to the Lundy model

The synthesis focuses on understanding how children's right to voice their views on their healthcare experiences can be facilitated and integrated into clinical practice within Swedish paediatric care, with a primary focus on children's opportunities to evaluate their healthcare visits using PREMs. This section explores how children are supported in voicing their views and how these views are received and integrated in clinical practice. The synthesis was interpreted as *facilitating children's right to express their views on their healthcare experiences requires sustainable structures that support equal opportunities and ensure that children's views are systematically taken into account*. This includes providing *space* for children's perspectives, facilitating their *voice*, ensuring that there is an *audience* who listens and integrating opportunities for *influence* (Figure 6). The interpretation of these central aspects is described below, with the key aspects presented as bullet points in the figure and highlighted in italics in the more detailed textual description.

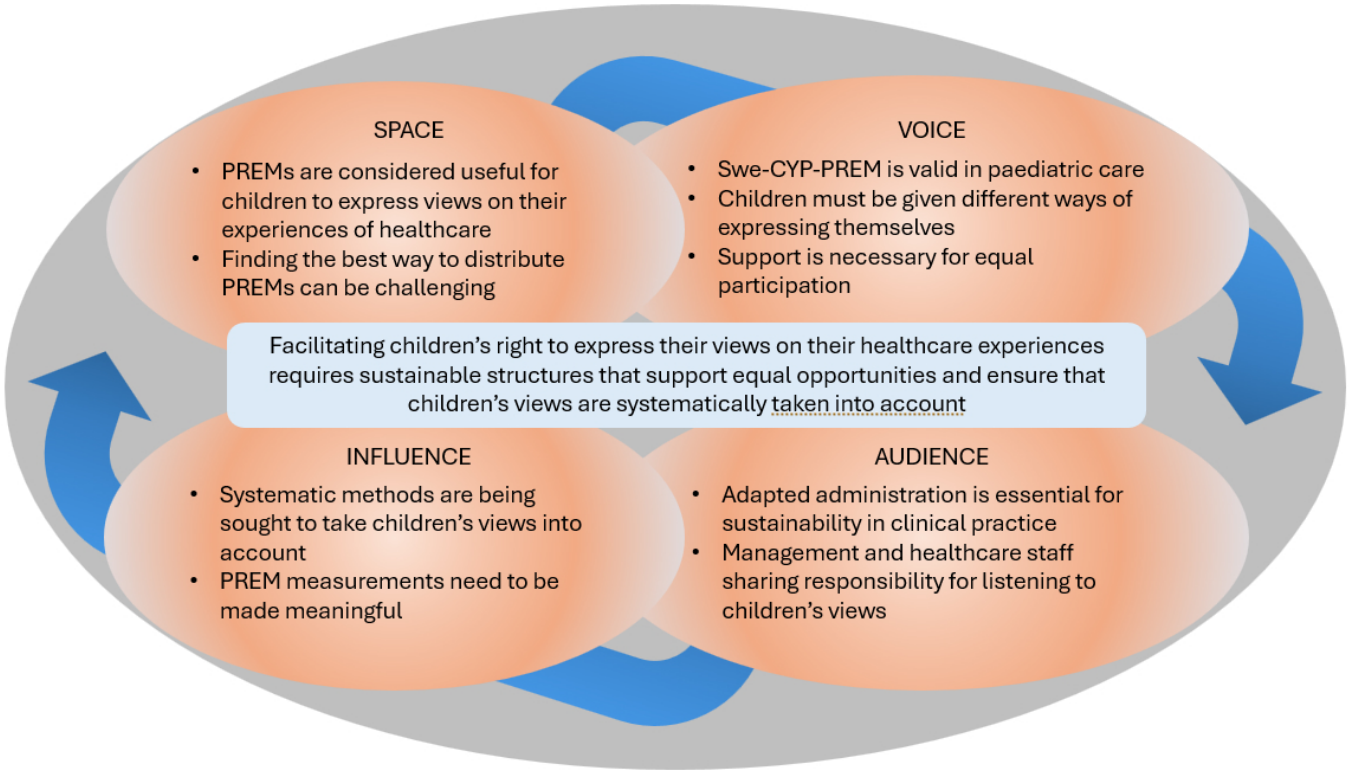


Figure 6 Synthesis of the results in relation to the Lundy model.

Space – Children must be given opportunities to express their views

Space refers to providing opportunities for children to express their views, which is a starting point for participation in all decision-making and thus a prerequisite for children's influence at both the individual and group level (Lundy, 2007). The results of this thesis show that practitioners in Swedish paediatric care have experience with using questionnaires aimed at children (**I and IV**). *PREMs are considered useful for children to express views on their experiences of healthcare*, as they can give many children the opportunity to share their opinions on issues that are important to them (**IV**). Swe-CYP-PREM was rated as a safe method by the participating children in the pilot study, as no one felt angry or upset by the questions. Most of the children were also satisfied with the time it took to answer Swe-CYP-PREM (**III**).

Finding the best way to distribute PREMs can be challenging. The findings reveal challenges in both implementing PREM distribution and adapting to children's preferences. In the pilot study, approximately 33% of the eligible sample of 480 children were not invited to participate, and 107 of the children who agreed to participate did not return the questionnaires (**III**). The focus groups emphasised the importance of adapting PREM distribution to align with children's preferences in order to increase their interest in participating. While the aim was to generate interest so that as many children as possible would want to share their experiences, the best way to achieve high participation was not obvious. Digital solutions were considered to appeal to children, but paper forms were described as easier to use and resulting in a higher level of participation. It was found to be important for staff to directly engage with children and encourage participation, as this emphasised the value placed on the child's views, and as QR codes in waiting rooms did not tend to capture children's interest. It was considered preferable for children to be given the opportunity to answer the PREM in connection with a healthcare visit, both in terms of increased response rates and so that children could relate to the questions more easily (**IV**).

Voice – Children must be supported in expressing their views

Voice concerns children's ability to freely express their views in various forms, including orally, in writing or print, through art or via other media of their choice. This relates to children's right to freedom of expression (Lundy, 2007). The results of this thesis show that *Swe-CYP-PREM is valid in paediatric care* as a means for children to express their views on their healthcare experiences. Specifically, the six versions of the validated Swe-CYP-PREM are deemed to give children the opportunity to share their experiences on issues that are relevant to them. During the translation, adaptation and validation process, the cognitive interviews clarified necessary adjustments based on relevance or difficulty understanding due to context (**II**).

Another aspect of voice is the use of appropriate methods, such as validated instruments. In the focus groups PREMs validated with children were considered to ensure that the questions were understandable for children (**IV**); however, only two of the participating departments in **Study I** reported having validated instruments.

The results also reveal that *children must be given different ways of expressing themselves.* In order to give children different opportunities to express their opinion in the way that suits them best, it was considered important to offer other ways, in addition to PREMs. Methods that worked well to encourage children to make their voices heard included conversations in connection with regular healthcare contacts or time set aside for interviews, and so-called 'safety rounds' in which children reviewed the hospital in the form of photos and comments (**I and IV**). Although the participants in the CVI test gave a low rating to the open-ended free-text question, it was retained to enable children to express their opinions freely by writing or drawing (**II**). Findings from the pilot study supported the relevance of the open-ended question, with 66 children (37.5%) using the question to describe both positive and negative experiences across all domains of Swe-CYP-PREM (**III**). The focus groups also highlighted the importance of open-ended questions to enable children to fully discuss issues they perceived as important and provide detailed

suggestions for improvements, which could not be captured through closed questions alone (**IV**).

The cognitive interviews and pilot study included children with a first language other than Swedish (**II and III**), and a goal when adapting Swe-CYP-PREM was for the language to be as simple as possible (**II**). Nevertheless, some children found certain questions difficult to understand (**III**). *Support is necessary for equal participation* but difficult to enact. Younger children were noted to have difficulty understanding the questions, and children with cognitive difficulties or those with a first language other than Swedish also struggle with questions (**IV**). The experiences of the first-line managers and quality-improvement workers indicated that visual support or simpler questions with 'smiley faces' were sometimes considered helpful. However, the staff had few or no opportunities to translate questions or hire an interpreter, which limited some children's ability to express their opinions. Moreover, it was found to be difficult to maintain anonymity when children needed support from staff or parents/carers in answering questions (**IV**).

Audience – Children's views must be listened to

Audience refers to adults' responsibility to be attentive to the various verbal and non-verbal ways in which children express their perspectives and to ensure that these views are received by an identifiable person or body that is willing to consider them and responsible for doing so (Lundy, 2007).

The focus groups emphasised that *adapted administration is essential for sustainability in clinical practice*. This involved adapting approaches to each unit, based on different needs and opportunities. For example, it was found that continuous measurements could be appropriate in paediatric emergency departments if an evaluation of each visit was desired. However, since the administration of such measures requires staff involvement, it was considered more reasonable to motivate staff to focus on collecting children's views if the measurements were done intermittently (**IV**).

Following up on activities was regarded as part of day-to-day work, with *management and healthcare staff sharing responsibility for listening to children's views* (**I**). The focus groups revealed that issues related to the care environment – such as the children's views on their experiences of the premises and of the activities offered for play and to pass time – were the easiest to work with. Evaluating how children experienced their interaction with care staff was also considered important but was found to be more difficult. The participants showed a clear willingness to act as an audience by seeking and valuing children's views on whether they were treated with respect and whether they felt involved in their own care. The described purposes of using PREMs were not only to find out what children think about their healthcare visits but also to determine children's views before events such as development work and rebuilding. Positive reviews from children were seen as a valuable way of providing good examples and positive feedback to employees (**IV**). A desire to be able to compare the results from PREMs with those of other paediatric care providers also emerged from the data (**I and IV**).

Influence – Children's views must be appropriately followed up on

Influence involves ensuring that the principle of working for the best interests of the child guides decision-making processes and that children's views are given due weight by adults. This includes informing children about the decisions made after eliciting their views and explaining how their views were considered (Lundy, 2007).

Children's perspectives were considered central to quality improvement in paediatric care, although *systematic methods are being sought to take children's views into account* emerged from the analyses (**I and IV**). Participants in the cross-sectional study stated that monitoring children's rights was on the agenda at management meetings and prior to decision-making about changes to premises and within the organisation. However, almost half of the participants rated the consideration given to children's perspectives in their quality-improvement work as '*low*' or '*very low*' (**I**). First-line managers and quality-improvement workers considered it valuable to be able to draw on other organisations' experiences of different

working methods to include children's perspectives more efficiently and systematically. Although it was considered important to act based on children's opinions, the participants emphasised that the possibility of doing so was sometimes limited in terms of the resources and premises available (**IV**).

Feedback of PREM results to children and staff was emphasised as *PREM measurements need to be made meaningful.* The results could be used as a starting point for discussions among staff and were linked to improvement work and goals within the unit, which were viewed as part of the management team's responsibility. Intermittent measurements were found to provide better opportunities for a structured approach, as the measurements were summarised and actions could be planned, implemented and then evaluated at the next measurement. Measurement was also considered relevant when the results were predominantly positive, as children's responses could provide staff with confirmation of their work (**IV**).

DISCUSSION

The overall aim of this thesis was to explore how children's right to voice their opinions of their healthcare experiences can be facilitated and integrated into clinical practice within Swedish paediatric care, with a primary focus on children's opportunities to evaluate their healthcare visits using PREMs. Children's right to have their voices heard and, as far as possible, taken into account is a central aspect of person-centred and high-quality care. It also aligns with the National Board of Health and Welfare's regulations, which state that patients' views should be gathered and analysed in order to identify areas for improvement (National Board of Health and Welfare, 2011). Moreover, the World Health Organisation (WHO) highlights patient involvement as a key prerequisite for quality development and emphasises the need for patients' experiences to be translated into concrete improvement measures (World Health Organisation, 2006). Given this context, it is particularly important for children's experiences and perspectives to be facilitated and integrated in paediatric healthcare.

The Lundy model was applied as a framework to provide a comprehensive and structured approach for understanding children's right to express their views of their healthcare experiences, including the provision of *space*, facilitation of *voice*, presence of an *audience* and potential for *influence*.

Summary of main findings supported by the Lundy model

Regarding *space*, children identified PREMs as an appropriate and safe method for sharing their views on their healthcare experiences. However, difficulties in implementing, distributing, and adapting PREMs to children's preferences limited participation, highlighting the need for flexible and child-centred approaches to facilitate children's engagement.

In relation to *voice*, the validated Swe-CYP-PREM was shown to support children's expression of their views on their healthcare experiences in ways relevant to them. At the same time, the findings

emphasised the importance of integrating multiple forms of expression, including conversations and interviews, to facilitate children's opportunities to communicate freely according to their individual needs. Challenges related to language barriers, cognitive abilities and maintaining anonymity further underscored inequalities in participation.

Concerning *audience*, the findings illustrated an organisational willingness to listen to and value children's views, in relation to care environments, staff interactions and service development. Sustainable implementation seemed to require approaches tailored to local clinical contexts, as well as shared responsibility among healthcare staff and management to ensure that children's perspectives were received, acknowledged and used within quality-improvement processes.

Finally, *influence* was reflected in the recognition that children's perspectives are central to paediatric quality improvement, although systematic methods to integrate their views into decision-making in clinical practice remained limited. PREM results were considered meaningful when linked to feedback, reflection and concrete improvement work, demonstrating the importance of not only facilitating children's participation but also ensuring that their views are acted upon and integrated into organisational development and clinical practice.

The discussion below focus on *choosing questions and distribution method* and *structure and flexibility for sustainable implementation*, which are related to the key findings on facilitating and integrating children's right to voice their opinions of their healthcare experiences, as illustrated in the results and in Figure 6.

Choosing questions and distribution method

Both previous research and the findings of this thesis demonstrate that PREMs are considered useful for children to express their views on their experiences of healthcare regarding issues relevant to them (**II**) and that PREMs offer advantages in reaching many children (**III**) (Foster et al., 2019; Wray at al. 2018). Nevertheless, it is essential to

choose the right PREM for a situation or population group, and paediatric units must ensure that children can understand the questions (Kingsley & Patel, 2017; Shunmuga Sundaram et al., 2022). Bull et al. (2019) emphasise that, when choosing a PREM, it is necessary to consider whether a disease- or environment-specific measure is more appropriate than a general measure. Based on the findings of this thesis, the generic Swe-CYP-PREM is deemed valid for clinical use in the Swedish paediatric care context and was shown to support children's expression of their views on their healthcare experiences in a way relevant to them (**II** and **III**). Other PREMs that have been validated in the Swedish healthcare context are the Child Participation in Healthcare (ChiPaC) measure (Gilljam et al., 2019) for evaluating children's participation in healthcare, the Visual CARE Measure (Wiljen et al., 2025) for assessing children's perceptions of nurses' empathy and PREM-Ped Questionnaire (Broström et al., 2026) a short questionnaire for measuring children's healthcare experience.

Concerning the extent of PREMs, the studies in this thesis produced conflicting results: the focus groups (**IV**) indicated that PREMs needed to be short, whilst most children who took part in the pilot study (**III**) considered the number of questions (25–34 questions) to take just the right amount of time to answer. These findings may indicate that the focus of instrument use should not be on the length of the questionnaire but on its relevance, design and distribution, in order to generate interest in participating among children. The results of this thesis also reveal some uncertainty regarding which PREMs should be used in which contexts, and participants expressed a desire to be able to select questions from validated questionnaires based on what they needed to assess at the time.

Although PREMs validated with children are considered essential to ensure that the questions are comprehensible to children, validated PREMs have not been significantly implemented in paediatric care. This has been demonstrated in previous research (Bele et al., 2021) and was confirmed by the findings of this thesis (**I**), in which most questionnaires aimed at children were described as having been developed locally. This low use of validated PREMs in paediatric care can probably be partly explained by the difficulty of choosing the

right PREM (**IV**). Previous research has shown that validated PREMs are not made available to healthcare units, and there is a lack of awareness of and access to PREMs (Lowry et al., 2024). In the context of this thesis, the dissemination of research findings is an important consideration. Straightforward technical solutions are needed to ensure that the Swe-CYP-PREM questionnaire can be easily implemented and disseminated within Swedish paediatric care. Addressing this issue at the national level, in collaboration with researchers, may help bridge the gap between research and clinical practice.

This thesis also emphasises challenges in finding the best way to distribute PREMs (**IV**). The layout of PREMs and the means of distributing them emerged as central in capturing children's interest. The professionals perceived that children were more motivated to answer the questions when they received a personal invitation from the staff they met during the visit. However, it was unclear whether paper-based or digital questionnaires were better suited to children. Suggestions for improvement included the use of engaging digital solutions, although it was noted that QR codes displayed in waiting rooms generated little or no response. The findings indicate a knowledge gap regarding children's preferences and views on how questionnaires should best be distributed. Shunmuga Sundaram et al. (2022) argue that it is absolutely essential to involve children in the planning and implementation of initiatives in order to encourage them to share their views. To create a safe and inclusive environment where children can form their own views and express their opinions, paediatric departments should actively seek to gather children's opinions on how they would like to be involved (Welty, 2013).

This thesis highlights the difficulties of ensuring that all children have the same opportunity to share their experiences (**III** and **IV**). When using a PREM, it is necessary to pay attention to the risk of excluding certain groups of children. Welty (2013) reports that challenges related to language barriers, cognitive abilities and maintaining anonymity led to inequalities in participation. The participants in the present research included children aged 8 years and older, to align with the age of the children involved in the development of the

original CYP-PREM. Reading and language skills vary among different age groups, and PREMs can be considered unsuitable for children under the age of 7 in terms of both language development and cognitive ability (de Leeuw, 2004; Piaget, 2008). However, Wray et al. (2025) argue that many children with intellectual disabilities are both able and willing to express their views on their experiences of healthcare and emphasise the importance of further adapting PREMs to ensure that as many children as possible are given support for equal opportunities to describe their experiences in hospital in a meaningful way.

Given children's different circumstances and preferences, it is also important that children be offered different ways of expressing their views, so that each child can choose the form that feels most appropriate and accessible. This helps to ensure that more children are given the opportunity to speak up and make their voices heard (Welty, 2013). Based on the UNCRC (1989), Lundy (2007) points out that children's right to express their views is not dependent on their ability to express a mature opinion. The results of this thesis emphasise the importance of integrating multiple forms of expression – including conversations and interviews – to give children sufficient opportunities to communicate freely and according to their individual needs. That said, the choice of method depends on the issue being evaluated (**IV**). Examples of other methods for eliciting children's voices, from both this thesis's findings and previous research, include photovoice (Ekman et al., 2026) and children's councils. Haesebaert et al. (2020) describe how an advisory group comprising patients, relatives, healthcare staff and managers can promote patient-centred working methods.

Structure and flexibility for sustainable implementation

This thesis indicates that children's perspectives are taken into consideration in improvement work and decision-making to a limited or very limited extent and that different groups of children are unequally represented (**I**). This finding highlights the need for systematic methods for integrating children's opinions into healthcare practices. Previous research shows that PREM results can

be used in clinical practice and development work, although there is limited knowledge about whether and how this is done in practice (Alarilla et al., 2024). Research on the implementation of PREMs emphasises that successful implementation depends on several interacting factors. Stover et al. (2021) argue that implementation science provides valuable approaches for introducing PREMs, while acknowledging that no single framework can fully capture the complexity of implementation processes.

The findings demonstrate an organisational willingness to listen to and value children's views in relation to care environments, staff interactions and service development. Still, participants in **Studies I and IV** emphasised the need for a systematic and sustainable approach to ensure that children's views are consistently incorporated into improvement work. They also called for national co-ordination to enable them to benefit from others' previous experiences. Somewhat contradictorily, the focus groups emphasised the importance of customised administration for sustainability in clinical practice and allowing for adaptation to the specific needs of each unit. This finding suggests that sustainability may require not a fixed model but rather a structured overview of the implementation process, including practical tools and examples that can be adapted to different settings.

Several factors identified in the literature align with these findings. Engagement and support among those involved in implementation are consistently highlighted as crucial. Healthcare staff are more likely to adopt new practices when they understand their benefits (National Board of Health and Welfare, 2020), and implementation outcomes are influenced by staff expertise, motivation, available resources and previous experience within the organisation (Kitson et al., 2008). The findings of this thesis make it clear that management and healthcare staff must share responsibility for hearing and implementing children's views (**I** and **IV**). Adequate resources and supportive leadership were viewed as essential prerequisites for implementation, in line with previous research and with the WHO's identification of leadership as a key factor in successful implementation processes (World Health Organisation, 2006). Similarly, Shunmuga Sundaram

et al. (2022) has found that organisational, staff-related and patient-related factors influence the use of PREM data, emphasising the importance of management support, staff training and sufficient resources for collecting, interpreting and acting upon data.

The barriers identified in this thesis – namely, limited time and resources and a lack of committed staff and management – are well documented in previous research. Organisations frequently encounter resource-related constraints, including limited funding, technology, personnel and time (Lowry et al., 2024). According to Fontaine et al. (2026), key individuals must be recruited to drive and maintain an implementation. Fjordkvist et al. (2024) have found that first-line managers play a crucial role in implementing evidence-based care but that their efforts are often constrained by organisational conditions and resource limitations. Although managers strive to facilitate implementation through effective leadership behaviours, implementation can be strengthened by clearer strategies, increased resources and improved organisational support (Fjordkvist et al., 2024).

To ensure that children's views reach those responsible for acting on them, clear structures are needed for receiving, communicating and using children's perspectives. It is vital to identify who the recipients of children's views are and to establish processes that ensure these views are passed on to individuals with decision-making authority. Only then can children's perspectives have a genuine impact on decision-making processes (Welty, 2013).

Practical aspects of PREM implementation must also be considered. Implementing PREMs requires the development of clinical workflows, including decisions about data-collection platforms, patient-recruitment procedures and the presentation of results (McCabe et al., 2023). Alarilla et al. (2024) similarly emphasise the need for a greater understanding of how digital data collection can be integrated into routine clinical practice, including systems that enable compatibility and comparison across healthcare settings. In the present thesis, healthcare staff perceived PREM administration as an additional workload, and periodic rather than continuous assessments were suggested as a more sustainable approach (**IV**). Periodic data

collection was also considered to facilitate the compilation and use of results, although continuous assessments were viewed as providing more opportunities for children to have their voices heard. The challenges addressed in this thesis regarding finding a good way to administer PREMs are similar to those summarised in a recent umbrella review: Fontaine et al. (2026) emphasise that the implementation of PREMs requires a co-ordination of organisational, process-related and technical factors. The involvement of healthcare professionals, managers and patient representatives, together with appropriate measurement instruments, accessible digital solutions and integrated information technology (IT) systems, are highlighted as key prerequisites (Fontaine et al., 2026).

Importantly, the findings of this thesis emphasise that PREM data must be linked to feedback, reflection and concrete improvement activities (**IV**). Facilitating children's participation alone is insufficient if their views are not acted upon and integrated into organisational development and clinical practice, making the measurements meaningful. The meaningfulness of participation depends on visible outcomes. This finding is supported by McCabe et al. (2023), who have reported that patients are more motivated to complete PREMs when they can see how the results contribute to improvements in care.

Finally, the results reveal an ambivalence regarding the solicitation of children's views only on issues relevant to the healthcare development. At the same time, participants described the importance of giving children the opportunity to express their views, even if it was not possible to accommodate their wishes (**IV**). This finding raises questions about the distinction between meaningful and symbolic participation. Symbolic participation occurs when children are invited to express their views without these views being taken seriously, which potentially conflicts with the requirements for genuine influence as outlined in the UNCRC (1989). Lundy (2018) argues that adults sometimes refrain from involving children in decision-making because they fear participation will become tokenistic; however, from a rights-based perspective, this is not a valid justification. Efforts should focus on creating conditions that enable

children's views to be heard, considered and acted upon to the greatest extent possible. The fact that full participation may be difficult to achieve does not negate children's right to be heard.

Methodological considerations

To gain a broad understanding of children's right to voice their views on their experience of healthcare, this thesis included studies using different methods: a cross-sectional study using a study-specific questionnaire (**I**), instrument development including cognitive interviews (**II**), CVI (**II**) and a cross-sectional pilot study (**III**), and qualitative data collected in focus groups (**IV**).

During manuscript preparation, checklists were used to strengthen the credibility of the articles. The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, 2007) was used for **Studies I, II and IV**, and the Child-centred Research Checklist (Foster et al., 2025) was used for **Study III**. The first three studies in the thesis (**I, II and III**) used both qualitative and quantitative approaches, whereas **Study IV** was clearly grounded in qualitative methodology.

Qualitative research relies on the four criteria of credibility, dependability, confirmability and transferability (or generalisability) to evaluate trustworthiness (Lincoln, 1985). The corresponding criteria in quantitative research include internal validity, reliability, objectivity and external validity (Mukherjee, 2019). The studies included in this thesis were conducted within Swedish paediatric healthcare. To facilitate assessments of transferability/external validity, the healthcare context, study settings and participant groups have been described in detail. The dissertation's focus on paediatric care within a specific national healthcare system should be considered when interpreting the findings, however, as organisational structures, legal frameworks and approaches to children's participation may differ between countries and healthcare systems (Morse, 2015).

The strengths and limitations of this thesis are discussed below. The methodological considerations regarding credibility (internal validity), dependability (reliability), confirmability (objectivity) and transferability (external validity) collectively support the quality of the

results, whilst highlighting limitations that should be taken into account when interpreting the results.

Study I

Heads of paediatric departments were selected as participants because they hold overall responsibility for the department's quality of care and for ensuring that children's rights are upheld within healthcare. Their positions provide them with relevant knowledge regarding how children's voices are considered in paediatric care. To further strengthen the relevance of the data, respondents were given the opportunity to delegate completion of the survey to a colleague if that person was considered more suitable. A response rate of 28 out of 38 paediatric departments (74%) was achieved, which is a notable strength of this study and supports the internal validity of the findings.

At the same time, certain limitations should be acknowledged. The reasons for non-response are unknown, making it difficult to determine whether non-participation may have affected the internal validity of the findings. In addition, the depth of responses to the open-ended questions varied considerably, with some participants choosing to answer only the closed-ended items.

The study-specific questionnaire was developed in collaboration with SALAR to ensure that the survey addressed relevant and meaningful aspects of children's participation in healthcare and to avoid common questionnaire design problems described by Creswell and Hirose (2019), such as unclear wording and inappropriate response options. This collaboration, together with the diverse perspectives represented within the research team, is considered a strength that enhances the study's reliability. In addition, respondents were given the opportunity to elaborate on their answers in free-text format for all questions, which enriched the data and provided valuable background information. The collaboration with SALAR, combined with email distribution and online survey completion, may also have contributed to the relatively high response rate.

Individual interviews with heads of paediatric departments might have provided a more detailed understanding of the measures in use, as follow-up questions could have been asked. However, such an approach would likely have reduced the breadth of data that the cross-sectional survey design was intended to provide. Responses from different hospitals at various healthcare levels also strengthen the study's external validity.

Studies II and III

The translation, adaptation and validation of Swe-CYP-PREM was an extensive process, as six versions were handled in parallel. By using a rigorous and systematic approach to ensure dependability and reduce the risk of bias, the questionnaire can be adapted for children with different healthcare experiences. Similar findings have been reported in studies conducted in Canadian and Danish healthcare contexts (Nafees et al., 2024; Ryberg et al., 2022).

Cruchinho et al. (2024) have reviewed 42 guidelines for the cross-cultural adaptation and validation of measurement instruments and have identified considerable variation in recommended procedures. Nevertheless, they recommend that the process should include forward and backward translation, pre-testing with the target population, field testing and psychometric validation. They further suggest two complementary forms of pre-testing: cognitive interviews to assess comprehensibility and an expert panel or focus group to critically evaluate the content of the instrument. Statistical evaluation, such as the calculation of CVI, is also recommended to assess content validity (Cruchinho et al., 2024). The methodology applied in this thesis (Wild et al., 2005) included all these recommended steps except for the use of an expert panel or focus groups and psychometric validation. In retrospect, it is possible that involving focus groups of children during the adaptation process could have provided additional insights into the questionnaire's content and design. The absence of psychometric testing may be considered a limitation. However, psychometric analyses were deprioritised because the questionnaire was developed to capture children's views on healthcare experiences, and the response formats did not permit

certain analyses. For example, test-retest could not be assessed, as it was not possible for children to complete the Swe-CYP-PREM on two strictly comparable occasions. This limitation may otherwise have strengthened the study's reliability, as noted by Mukherjee (2019). Instead, emphasis was placed on ensuring the comprehensibility and content validity of individual questions through cognitive interviews and content validation. This approach can be viewed as a strength, as it allowed each item to be evaluated on its own merits rather than primarily as part of a psychometric scale. At the same time, questions remain regarding how modifications to individual questions or the questionnaire layout might affect the overall relevance and validity of the instrument.

Participants were recruited from the intended target population of the CYP-PREM – namely, children aged 8–16 years with recent healthcare experiences. This age range was consistent with the development of the original instrument and supports the validity of the adaptation process. However, including older adolescents might have provided additional insights regarding the relevance of questionnaire items. The recruitment relied on healthcare professionals and, for younger children, parental consent, which may have limited participation among some groups. Gatekeeping by adults, often motivated by a desire to protect children, is a recognised challenge in paediatric research (Kirk, 2007; Powell, 2013). Nevertheless, the sample included children with diverse healthcare experiences and linguistic backgrounds, strengthening the credibility of the findings.

As information about non-participants was unavailable, the representativeness of the samples in **Studies II and III** cannot be fully assessed. Selection bias may have occurred if children were not invited or chose not to participate due to individual or contextual factors. Regarding the cognitive interviews (**II**), data collection was further affected by the COVID-19 pandemic, resulting in adaptations to the recruitment process. These changes also created opportunities, including recruitment from a children's hospital and the involvement of two interviewers, which increased the reflexivity and objectivity and strengthened the credibility of the study.

Conducting research with children requires careful attention to the power imbalance between adults and children, as previously highlighted by Nilsson et al. (2015), amongst others. Throughout the cognitive interviews and analyses, efforts were made to prioritise children's perspectives and minimise adult influence on their responses. The consistency of children's assessments of item relevance and comprehensibility suggests that this risk was limited. In the presentation of the study's results, quotations are used as a means of verifying confirmability.

Finally, the transferability of the findings should be considered in light of changing healthcare systems and evolving childhood experiences. Although established recommendations for content validation were followed, periodic reassessment of the Swe-CYP-PREM may be necessary to ensure that it continues to reflect contemporary healthcare experiences from children's perspectives.

Study IV

The selection of first-line managers and quality-improvement workers was considered appropriate due to their insight into how PREMs have been – or could be – implemented and used within paediatric care. Although individual interviews might have facilitated participation when scheduling focus groups proved challenging, the focus group methodology offered important advantages. The discussions generated rich reflections and enabled the identification of both shared and divergent perspectives across paediatric units, thereby strengthening the depth and credibility of the findings. Furthermore, the opportunity to discuss these issues with colleagues in similar roles may have contributed to participants' willingness to take part.

The researchers' professional background as paediatric nurses may have influenced both the data collection and interpretation, as described by Morse (2015). At the same time, this background is considered a strength, as it may have facilitated trust and encouraged participants to engage in discussions with researchers who had a thorough understanding of paediatric healthcare and its clinical context. According to Graneheim and Lundman (2004), involving

several researchers in the analysis process can increase dependability by encouraging alternative interpretations and facilitating consensus on the findings. In the present study, the research group's diverse experiences and perspectives strengthened the study's dependability. The researchers' clinical experience, together with insights gained from the preceding studies included in this thesis, likely informed the development of the research questions, the facilitation of the focus groups and the analytical process.

To enhance confirmability, reflexive considerations regarding pre-understanding and potential bias were addressed throughout the research process. By continuously reflecting on how professional experience and prior knowledge might influence interpretations, efforts were made to ensure that the findings remained grounded in participants' accounts rather than the researchers' assumptions. In addition, quotations have been provided when presenting the study's findings for confirmability of the results.

Inclusive research

Research is increasingly conducted in collaboration with users to increase the relevance, quality and impact of research findings. As mentioned above, in studies involving children, children's experiences and views are crucial and cannot be replaced by those of adults (Nilsson et al., 2015). Although children contributed to several stages of the research included in this thesis, they were not involved throughout the entire research process. Future studies should therefore consider involving children more actively in research planning, priority setting and dissemination. At the same time, children's right to participate must be balanced with their need for protection through careful ethical considerations.

Despite growing recognition of the importance of child participation, relatively few studies report activities aimed at ensuring that children's contributions influence research agendas and priorities in paediatric research. Involving children in identifying and prioritising research questions increases the likelihood of research reflecting children's experiences and needs rather than portraying solely adult perspectives (Postma et al., 2024). To support such approaches,

Postma et al. (2025) provide practical guidance on involving children from the earliest stages of paediatric research, including the development of research agendas, which may prove valuable in future research.

Clinical implications and future research

This thesis highlights the need for paediatric healthcare organisations to establish sustainable structures that support children's right to express their views on their healthcare experiences and to ensure that children's views are systematically considered in healthcare development. To achieve this, each healthcare unit must develop clear clinical workflows and patient-recruitment procedures adapted to local conditions and routines. Successful implementation requires the appointment of key individuals responsible for co-ordinating PREM activities, while maintaining shared responsibility between management and healthcare staff.

The findings further suggest that PREMs validated within the Swedish healthcare context should be used to support children in expressing their views on experiences that are meaningful and relevant to them. The relevance of Swe-CYP-PREM has been confirmed by this thesis, but the fact that a questionnaire is validated does not mean it is the only correct one; on the contrary, different PREMs can function as complements to Swe-CYP-PREM. Sustainable implementation depends not only on the content of questionnaires but also on their design, accessibility and methods of distribution. Efforts should therefore focus on creating child-friendly approaches that encourage participation and facilitate the collection of children's views in routine clinical practice. Involving children and local patient representatives, such as children's councils, in the planning, distribution, interpretation and presentation of PREM results may provide valuable insights and should be further explored.

Clear structures are also needed to ensure that children's perspectives are communicated to those with the authority to act on them. Identifying the recipients of children's views and establishing processes for feedback and decision-making are essential if PREM

data are to contribute to meaningful improvements in care. In this context, integrated IT systems may facilitate the collection, management and use of PREM data within healthcare organisations.

National co-ordination could provide important support for a systematic approach to PREM implementation and could contribute to more equitable opportunities for children to have their voices heard, regardless of where they receive care. Such support could include a structured overview of implementation processes, access to validated questions and examples of distribution strategies that can be adapted to different healthcare settings. National co-ordination may also be important for ensuring the continued validity of PREMs, as language, healthcare contexts and children's expectations evolve over time.

Several areas where knowledge remains limited warrant further research. These include children's preferences for digital versus paper-based formats. Future studies should also examine the long-term validity of PREM instruments, how PREMs can be reviewed, updated and maintained over time, as well as exploring other ways of ensuring that children have equal opportunities to voice their opinions of their healthcare experiences.

CONCLUSION

This thesis emphasises that children's participation in paediatric healthcare should be understood as an ongoing process of creating space, facilitating voice, ensuring audience and enabling influence. The results suggest that validated PREMs, such as Swe-CYP-PREM, may facilitate children's participation in paediatric healthcare by providing safe and relevant opportunities to express their views on their healthcare experiences. Although representatives of Swedish paediatric care demonstrated a willingness to listen to children, challenges remain in systematically integrating children's perspectives into decision-making and improvement work. Strengthening children's right to express their opinions on healthcare experiences therefore requires sustainable structures that support equitable participation and ensure that children's views lead to visible actions.

Taken together, the results of this thesis suggest that successful implementation of PREMs is influenced by a combination of child engagement, leadership, staff engagement, organisational readiness and available resources. Sustainable implementation requires not only locally adapted strategies but also sufficient organisational support in terms of co-ordination, processes and technology.

SAMMANFATTNING PÅ SVENSKA (SUMMARY IN SWEDISH)

För att förstå barns upplevelser inom sjukvården behöver både ett barnperspektiv och barnens perspektiv beaktas. Barnperspektiv innebär vuxnas tolkning av barns upplevelser och synpunkter, medan barnens perspektiv utgår från deras egna erfarenheter och uppfattningar. Enligt FN:s konvention om barnets rättigheter har barn som kan bilda egna åsikter rätt att uttrycka dessa i frågor som berör dem, och deras synpunkter ska tillmätas betydelse utifrån ålder och mognad. Barn är samtidigt en heterogen grupp, och deras möjligheter till delaktighet kan påverkas bland annat av ålder, utvecklingsnivå, motivation, kulturell bakgrund och funktionsnedsättning.

En viktig del av en barncentrerad hälso- och sjukvård är att barn ges möjlighet att uttrycka sina behov och upplevelser, samtidigt som deras synpunkter kan tas tillvara i kvalitetsförbättringsarbete. ”Patient Reported Experience Measures” (PREM) är frågeformulär som används för att fånga patienters upplevelser av vården. För att vara användbara behöver PREM vara relevanta och validerade för den målgrupp och vårdkontext där de ska användas. Barn har dock sällan involverats i utvecklingen av PREM. Kunskapen om hur resultaten används i det kliniska kvalitetsarbetet inom svensk barnsjukvård är begränsad. Detta kan innebära att barns möjligheter att påverka vårdens utveckling genom sina egna erfarenheter inte är fullt integrerade i klinisk praxis.

Ett exempel på ett barnanpassat PREM är ”Children and Young People – Patient-reported Experiences Measure” (CYP-PREM), som ursprungligen utvecklades i Storbritannien i samarbete med barn i åldern 8–16 år som hade erfarenhet av slutenvård och/eller öppenvård vid Great Ormond Street Hospital i London. Det övergripande syftet med denna avhandling var att undersöka hur barns rätt att uttrycka erfarenheter av vårdupplevelser kan underlättas och integreras i den svenska barnsjukvården, med särskilt fokus på möjligheten att utvärdera vårdbesök med hjälp av PREM.

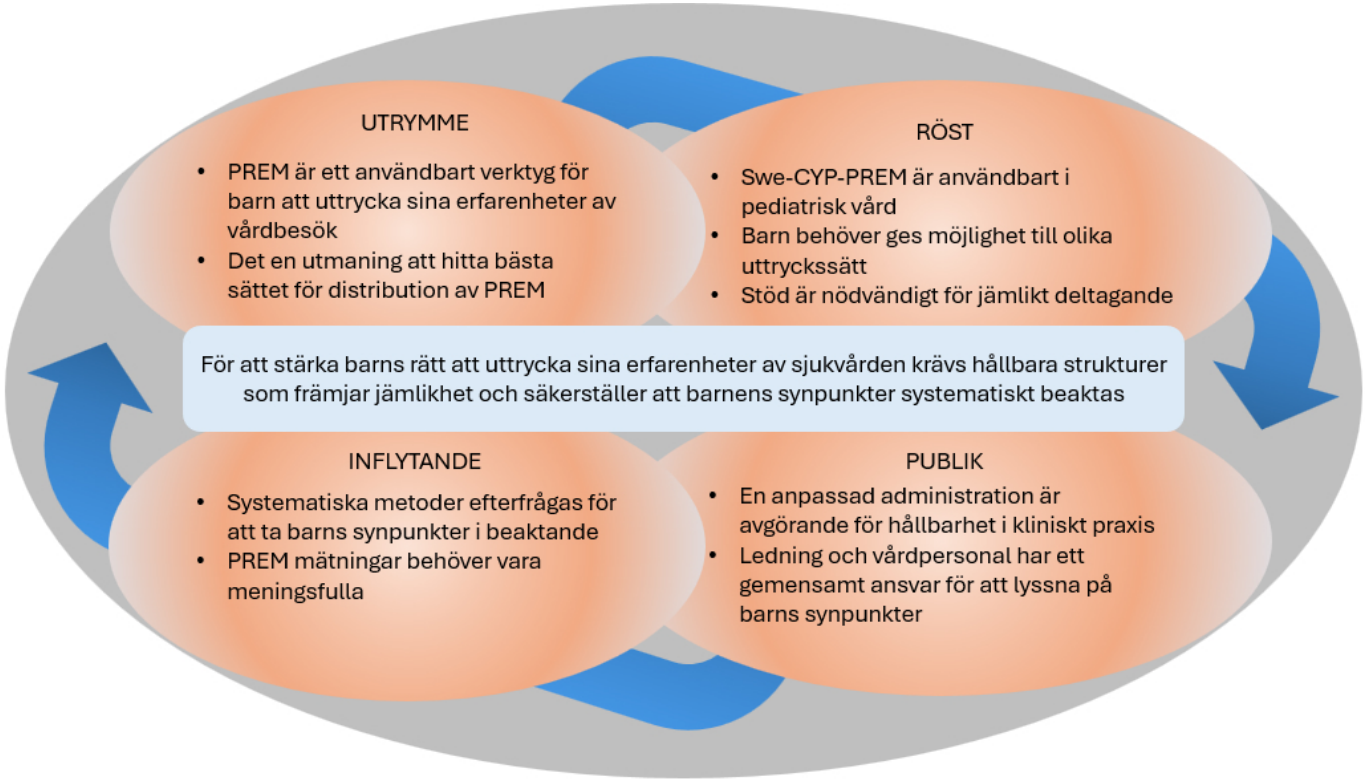
Studie I undersökte hur svenska barnkliniker möjliggör för barn att uttrycka sina åsikter om vården och hur dessa perspektiv används i kvalitetsförbättringsarbete. Resultaten visade att uppföljning av barns erfarenheter uppfattades som en del av det dagliga arbetet och som ett gemensamt ansvar för ledning och vårdpersonal. Samtidigt varierade metoderna för att samla in barns synpunkter. Av de 28 svarande barnklinikerna hade 12 använt frågeformulär riktade till barn. Frågeformulären var ofta lokalt utvecklade och anpassade till specifika patientgrupper. Det framkom också en brist på systematiska strukturer för att följa upp barns delaktighet. Nästan hälften av respondenterna, bedömde att barns perspektiv beaktades i låg eller mycket låg utsträckning i kvalitetsförbättringsarbete.

I **studie II** genomfördes översättning, kulturell anpassning och validering av CYP-PREM i svensk vårdkontext. Kognitiva intervjuer med barn ledde till revidering av omkring hälften av frågorna, avseende kontext, ordval, frågestruktur och enhetlighet i frågorna. Processen resulterade i sex svenska versioner av CYP-PREM (Swe-CYP-PREM) validerade gällande förståelse och relevans. Versionerna innehåller mellan 25 och 34 frågor, varav 12 är gemensamma för samtliga versioner.

I valideringsprocessens tredje fas genomfördes en pilotstudie (**studie III**) för att undersöka acceptansen och användbarheten av Swe-CYP-PREM i klinisk praxis. Resultatet visade få utelämnade svar, låg förekomst av svarsfel och god acceptans bland barnen. Trots att svaren var övervägande positiva kunde instrumentet identifiera variationer i barnens vårdupplevelser. Den öppna frågan gav information som kompletterade och fördjupade resultaten från de slutna frågorna.

Studie IV undersökte avdelningschefers och vårdutvecklares uppfattningar om användningen av PREM inom barnsjukvård. Resultatet synliggjorde att det krävs organisatoriska förutsättningar för genomförande av PREM-mätningar och för att resultaten ska kunna tas om hand och omsättas i förbättringsarbete. Studiens resultat sammanfattas i temat att barnens perspektiv är centrala för kvalitetsförbättring, men att flexibilitet och resurser krävs för att PREM ska kunna användas i klinisk verksamhet.

Sammantaget visar avhandlingens resultat att barns rätt att uttrycka sina synpunkter om sina vårdupplevelser kan stärkas genom strukturerade och barnanpassade metoder, såsom PREM. För att barns perspektiv ska kunna integreras i den kliniska verksamheten krävs dock hållbara strukturer som säkerställer lika möjligheter för barn att uttrycka sina erfarenheter och få sina synpunkter systematiskt beaktade. Detta innebär att skapa utrymme för barns perspektiv, underlätta deras möjlighet att göra sin röst hörd, säkerställa att det finns en publik som lyssnar och skapa möjligheter till inflytande (se figur 7).



Figur 7 Sammanfattning av resultaten i relation till Lundys modell

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