Acta Psychologica 267 (2026) 106821

Contents lists available at ScienceDirect

Acta Psychologica

journal homepage: www.elsevier.com/locate/actpsy

# Paediatric patient experience during hospitalisation stays: Developing paediatric PREMS questionnaires through a collaborative Delphi study

Sabina De Rosis [a,b,*], Veronica Spataro [a], Jan A. Hazelzet [c], Elisa Peruzzo [a], Manila Bonciani [d]

[a] *Sant'Anna School of Advanced Studies, Pisa, Italy*
[b] *University "Mediterranea" of Reggio Calabria, Italy*
[c] *Department of Public Health, Erasmus University Medical Center, Rotterdam, the Netherlands*
[d] *Meyer Center for Health and Happiness, Meyer Children's Hospital, Florence, Italy*

ARTICLE INFO

*Keywords:*
Patient-centered care
Paediatric hospitalisation
Collaborative consensus-building process
Delphi study
Patient reported experience measures (PREMs)
Stakeholder engagement

ABSTRACT

Children and adolescents may experience vulnerability when accessing healthcare services. Despite patient-centered care is a core principle of healthcare, a notable gap remains in systematically integrating their perspectives into healthcare management. Part of the VoiCES European project, this study explored the construct of paediatric patient experience, and participatorily developed a standardised set of tools for collecting children and adolescents' feedback, with a particular focus on experiences during hospitalisation.

A collaborative, consensus-building process engaged children, adolescents, families, experts, and healthcare professionals in several European countries. The study combined a Delphi study with in-depth interviews to paediatric patients across four European children's hospitals. Stakeholder involvement was pivotal in refining the dimensions, sub-domains, and questionnaire items of paediatric experience with hospital stay.

Age-appropriate, multilingual questionnaires were developed for collecting Paediatric Patient Reported Experience Measures (Paediatric PREMs) from hospitalized children and their caregivers, separately. The tools cover various dimensions of the hospital experience according to respondent group. For children aged 8–14 years, visual elements were included to support comprehension and engagement.

This study highlights the importance of tailoring participation and evaluation tools to different age groups. The Paediatric PREMs offer valuable resources for healthcare managers, providers, and patient experience experts seeking to incorporate young patients' perspectives into quality improvement and healthcare management processes. They also contribute to the development of a European Observatory on paediatric hospital experiences.

## 1. Background

Children and adolescents are a particularly vulnerable group among healthcare service users, especially during hospitalisation. Their experiences, needs, and perspectives therefore require specific attention. In paediatric care, patient-centred approaches necessarily entail recognising children and young people as active subjects with the capacity and the right to express their views on healthcare encounters, rather than considering them solely through the perspectives of parents or caregivers (Coyne et al., 2016). A substantial body of literature has highlighted the importance of children's voice and participation in healthcare contexts, emphasising both ethical considerations and practical challenges in ensuring meaningful involvement, especially during hospitalisation. Several authors and institutions have called for a clear focus on patient-centeredness for fragile groups of patients such as paediatric patients and their families (Davidson et al., 2017).

### 1.1. Patient-centred care

Patient-centred care (PCC) has been widely promoted as a guiding principle for improving healthcare quality, commonly defined as care that respects and responds to patients' preferences, needs, and values.

The IOM (Institute of Medicine) defines patient-centred care as: "*Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.*" (Committee on Quality of Health Care in America.

---

* Corresponding author at: Sant'Anna School of Advanced Studies, Piazza Martiri della Libertà, 33 – 56127, Pisa, Italy.
*E-mail address:* sabina.derosis@santannapisa.it (S. De Rosis).

https://doi.org/10.1016/j.actpsy.2026.106821
Received 20 May 2025; Received in revised form 9 April 2026; Accepted 10 April 2026
Available online 9 May 2026
0001-6918/© 2026 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

IOM, 2001). The International Alliance of Patients' Organisations (IAPO, 2007: 12), stated that "*the essence of patient-centred healthcare is that the patients are at the centre of the healthcare system and therefore that the system is designed around them*" (IAPO Patient-Centred Healthcare Review 2nd edition, 2007). A review by Scholl et al. (2014) identifies key principles, enabling factors, and activities that characterize patient-centeredness within the literature (Scholl et al., 2014). The principles include: the essential characteristics of healthcare professionals, the clinician-patient relationship, recognition of the patient as a unique individual, and the consideration of a bio-psycho-social perspective. Enabling factors encompass effective clinician-patient communication, integration of health and non-healthcare services, teamwork and collaboration, access to care, and continuity in treatment. The activities associated with patient-centred care involve providing information to patients, actively engaging them in their care, involving family and friends, empowering patients, and offering both physical and emotional support. Importantly, these activities can be evaluated by incorporating patient feedback into the assessment process. The Picker Institute further supports this concept, describing patient-centeredness as an approach that prioritizes the individual needs, preferences, and experiences of patients (Picker Institute, 2015). This approach places patients at the core of the healthcare process, highlighting their active involvement not only in decision-making and overall health management (NEJM Catalyst, 2017; Scholl et al., 2014.), but also in the evaluation and improvement of healthcare.

In paediatric settings, however, PCC takes on specific meanings. PCC in childhood should not be understood as a simple adaptation of adult-centred models, but as an approach that recognises children as active subjects with age-specific capacities, relational dependencies, and rights to express their views on care, while accounting for the mediating role of families and institutions (Cabiati & Levy, 2021; Coyne, 2008; McLaughlin, 2009; Van Dijck & Steen, 2024). It has been operationalised through different but related concepts, including family-centred care, child-centred care, and patient- and family-centred care. Although these approaches share an emphasis on partnership and respect, they differ in the extent to which children's own experiences are directly foregrounded or mediated through adults. Family-centred care and patient- and family-centred care have been widely adopted in paediatric healthcare to promote partnership, respect, and shared decision-making between professionals and families; however, in these models, children's experiences are often mediated through parents or caregivers rather than captured directly (American Academy of Pediatrics, 2012; Kuo et al., 2011). Child-centred care (CCC) explicitly shifts the focus from the family as proxy to the child as an active subject of care, emphasising children's own perspectives, preferences, and communicative capacities as central to healthcare processes and evaluation (Carter et al., 2024; Coyne et al., 2016). This conceptual distinction is particularly relevant for paediatric patient experience measurement, as tools grounded in FCC or PFCC may fail to fully capture what matters to children themselves, while CCC-oriented approaches explicitly support the direct elicitation of children's experiences (Coyne et al., 2016; Kuo et al., 2011).

### 1.2. *Children's voice and participation in paediatric healthcare*

Recent research indicates that enhancing the hospitalisation experience for paediatric patients necessitates the creation of more precisely customized tools tailored to various age groups and to the diverse needs of healthcare service users (Power et al., 2024). Additionally, it is crucial to implement child-friendly approaches when collecting feedback on children's experiences with hospitalisation (Corazza et al., 2021; Spataro et al., 2025). These gaps indicate the need for further research and provide the rationale for the present study.

Organisations should facilitate the participation of all patients in service experience evaluation since healthcare service users' feedback is a key asset for organisations for improving their services. "*The inclusion of young people in the development and evaluation of measures provides a means to effectively understand the appropriateness of a given measure for a population.*" (Power et al., 2024). Service users' experience is increasingly recognised as a key resource for service management and value creation, with important implications for organisational improvement (De Rosis et al., 2022; De Rosis, Jamieson Gilmore, & Nuti, 2023; Nuti et al., 2017; Peruzzo, Seghieri, et al., 2025; Peruzzo, Vainieri, & De Rosis, 2025). From this perspective, studying how to support healthcare organisations in facilitating their more fragile users to participate into evaluation activities has been particularly important.

A recent systematic literature review showed that there are still various gaps to fill-in (Spataro et al., 2025). Gaps remain in co-design approaches that meaningfully engage paediatric patients, especially younger children, early in the development of feedback tools, as well as into processes of healthcare service evaluation and improvement,. For example, more evidence is needed on child- and adolescent-friendly methods, such as gamified tools, and their effectiveness in capturing experience data.

### 1.3. *Measuring paediatric patient experience: PREMs*

Recognising the importance of fostering active engagement from individuals in improving services, by integrating their viewpoints, is essential for measuring how much the care is centred on the patients themselves.

This is crucial also because every interaction with healthcare throughout a person's life journey has the potential to shape the enduring relationship between citizens and healthcare systems and providers (Berry, 2019; Bonciani et al., 2020). The experience with healthcare services is per-se a delicate moment during which the patients are sick and in a situation of information asymmetry. They can have difficulties in making their voices being heard, and in this way can experience vulnerability. In this context, it is a right of children and adolescents to have their voices heard when it comes to their own experience of hospitalisation. On the contrary, children experiencing healthcare services are often not involved in the evaluation of their experience (Karisalmi et al., 2018; O'Neill et al., 2018), and even much less in the construction of measures for evaluating healthcare services (Power et al., 2024).

The assessment of patients' experiences has increasingly relied on Patient-Reported Experience Measures (PREMs), which aim to systematically capture individuals' perceptions of healthcare processes and interactions. In paediatric care, the development and use of PREMs present specific methodological challenges related to age-appropriateness, cognitive development, and the frequent reliance on proxy reporting. Recent reviews have documented a growing number of paediatric PREMs while also highlighting persistent limitations, including limited involvement of children and young people in instrument development, heterogeneity of formats, and weak evidence of routine implementation and use for service improvement (Alarilla et al., 2024; Bartholdson et al., 2024; Bele et al., 2021). Recent empirical work has also begun to explore the co-development of paediatric PREMs with children and young people, highlighting both the feasibility and the added value of involving them directly in instrument design (Barr et al., 2024). Nowadays, only a few attempts to continuously and systematically collect the experience reported by paediatric patients with respect to their hospitalisation are documented in the international literature (Corazza et al., 2021; De Rosis et al., 2020). Additionally, when initiatives are put in place to gather feedback on paediatric care, these typically concentrate on obtaining insights from caregivers and families who recount the children's experiences, not involving directly the paediatric patients (Coyne, 2006; Wray & Oldham, 2020; Bele et al., 2021; Bartholdson et al., 2024). It has been shown that when a parent or guardian serves as an alternative source of information, there is a likelihood of losing the child's role as an informant (Clemente et al., 2012). Although proxy reports present important conceptual limitations (Lopez et al., 2023), multi-informant approaches combining proxy and self-reported measures may help address them, while still requiring the direct involvement of children and adolescents whenever possible (Power et al., 2024). The development of standardised measures for youth experiencing care services remains both rare and crucial (Corazza et al., 2021; De Rosis, Bonciani, et al., 2023; Power et al., 2024; Spataro et al., 2025). Standardisation enables comparability across studies, enhances statistical modelling, and supports evidence generation for underrepresented subgroups (De Bienassis et al., 2021; Mcelroy et al., 2020). However, these core sets should complement, rather than replace, alternative tools to preserve innovation and inclusivity in research design (Power et al., 2024).

Importantly, a distinction should be made between the use of paediatric PREMs as research instruments and their use as tools for routine service monitoring and managerial decision-making. Within research contexts, the development of standardised and age-appropriate PREMs grounded in children's and young people's perspectives holds significant potential to support future quality improvement initiatives, provided that appropriate governance and implementation mechanisms are in place. However, while PREMs are increasingly collected in paediatric settings, evidence that they are systematically used to inform organisational change remains limited (Alarilla et al., 2024; Spataro et al., 2025). As a result, the assessment and enhancement of healthcare services' quality currently do not align with the preferences, needs, and values of the specific more vulnerable patient groups.

### *1.4. Aim and contribution of the study*

Against this background, the present study aims to identify and develop the most appropriate approach for assessing children's and young people's hospital experience through a collaborative, multi-stakeholder Delphi process. Rather than assuming a specific measurement tool a priori, the study explicitly explores which methods and instruments are considered most suitable by key stakeholders, including clinicians, researchers, caregivers, and children and young people themselves.

Our final tool, consisting of questions and response options, was used to create age-appropriate and multilingual questionnaires designed to collect Paediatric Patient-Reported Experience Measures (Paediatric PREMs), which could then be adopted as a common co-assessment tool across various children's hospitals worldwide.

The process led to the development of age-specific paediatric PREMs questionnaires, subsequently refined through qualitative inquiry and cognitive testing. By adopting this exploratory and iterative design, the study seeks to contribute to the methodological debate on how paediatric patient experience can be meaningfully and rigorously assessed across different care contexts.

## 2. Setting

The study was conducted within the VoiCES project (acronym of *Value of including the Children's Experience for improving their rightS during hospitalisation*) (De Rosis, Bonciani, et al., 2023). The principal investigator conducting the study is a public university in Italy (Sant'Anna School of Advanced Studies of Pisa).

Multiple paediatric hospitals located in different European countries participated in the study, thus ensuring the representation of diverse healthcare systems, organisational practices, and linguistic contexts. This heterogeneity represented both a key challenge and opportunity for the development of a shared approach to assessing paediatric patient experience, as it required balancing cross-contextual comparability with sensitivity to local meanings and practices. Four Children's Clinical University Hospitals from different European countries were directly involved as partners of the project:

- Meyer Children's University Hospital, in Florence, Italy (AOU Meyer)
- Children's Clinical University Hospital, in Riga, Latvia (CCUH)
- HUS New Children's Hospital, in Helsinki, Finland (HUS)
- Erasmus University Medical Center, Sophia Children's Hospital, in Rotterdam, The Netherlands (EMC)

Another partner in the consortium was UNICEF, thereby assuring international and local experience, competences and skills on children's rights' promotion.

The network of the VoiCES project included several supporting bodies, such as:

- The European Children's Hospitals Organisation (ECHO);
- The Italian Association of Children's Hospitals (AOPI);
- The Picker Institute, with competence on patient experience measurement.

The collaboration between universities and children's hospitals ensured the integration of a scientific approach and interest in new knowledge with a commitment to action and engagement to improve the real-life experiences of children and adolescents during hospitalisation. Researchers, hospital managers, and professionals with clinical competences work together to understand general and context-specific opportunities and challenges. Furthermore, hospitals were crucial for the direct engagement of paediatric patients.

In fact, children and adolescents were actively involved, not only as the primary target of the project, but also as participants at multiple stages of the study. They contributed to the exploration of paediatric patient experience and informed the development of the measurement tools within the participatory Delphi process, and took part in in-depth interviews aimed at refining the instruments. Hospitals were responsible for their enrolment, and for the interviews, both according to the guidelines developed within the project.

Given the diversity of the participating settings, no specific measurement instrument was assumed a priori. Instead, the choice of the most appropriate method for assessing children's hospital experience was explicitly explored through the Delphi process, allowing stakeholders to consider the feasibility and relevance of different options across contexts. The multilingual and multicultural nature of the study setting also implied the need for careful attention to translation and cultural adaptation processes, which were subsequently addressed during the instrument development and refinement phases.

## 3. Methods

The VoiCES project was inspired by the human rights-based approach to healthcare (WHO & OHCHR, 2014), which ensures availability, accessibility, acceptability, and quality of health services for paediatric patients (WHO & the Office of the High Commissioner for Human Rights (OHCHR), 2014). It emphasised non-discrimination, accountability, and addressing healthcare inequalities. The project focused on both outcomes and processes, empowering paediatric patients as rights-holders to make claims, and strengthening children's hospitals as duty-bearers to meet their obligations, using patient-centred care as a foundation (NEJM Catalyst, 2017).

This study adopted a multi-stage, mixed-methods, participatory-informed design, combining qualitative inquiry, consensus-building techniques, and iterative refinement of study outputs. The participation of children was a key strategy of the project, which has been promoted both as a means to an end and as an end in itself, as advocated by UNICEF. Children's involvement across multiple stages of the study was intended to ensure that their perspectives and needs could directly inform the development process. Consistent with established frameworks on participation (Arnstein, 1969; Hart, 1992), stakeholder involvement in this study primarily took the form of structured consultation. Children and adolescents contributed through qualitative interviews and cognitive testing of draft items, providing feedback on topics of interest, relevance, wording, and comprehensibility. They also participated with clinicians, researchers, and caregivers in Delphi rounds. However, they were not involved in study governance, data analysis, or decision-making roles.

The collaborative consensus-building process, adopted in this study, employed a mixed-methods approach, namely a Delphi study, interviews and focus groups (Fig. 1).

The Delphi process was designed not only to achieve consensus on content domains and item priorities, but also to explore and agree upon the most appropriate methodological approach for assessing paediatric patient experience across diverse settings. The members of the Delphi panel were asked to express their opinions within their domain of expertise.

The Delphi study was combined with in-depth interviews (IDIs) and focus groups (FGs) with children, teenagers, and their parents, to ensure their wider, deeper and more effective involvement in the research process. The first round of FGs/IDIs was organised to merge their results with those of the first round of the Delphi process. The second round of FGs/IDIs was organised after the third round of Delphi, to cognitively test the questions and to support the process of cultural and local adaptations of items, drawing on established principles of cognitive interviewing (Willis, 2005). In addition, the second round of FGs/IDIs included a discussion on how to effectively involve the patients in initiatives to collect their voice, according to different age groups or characteristics of the target population.

In addition, the project team was informed by suggestions and feedback from the Scientific Committee of the VoiCES project, which participated in discussing the results of the participatory process. The final consensus conference finalized the process, formalised the consensus reached and produced the final outputs in terms of concrete tools to be used to directly collect the paediatric patients' voice in

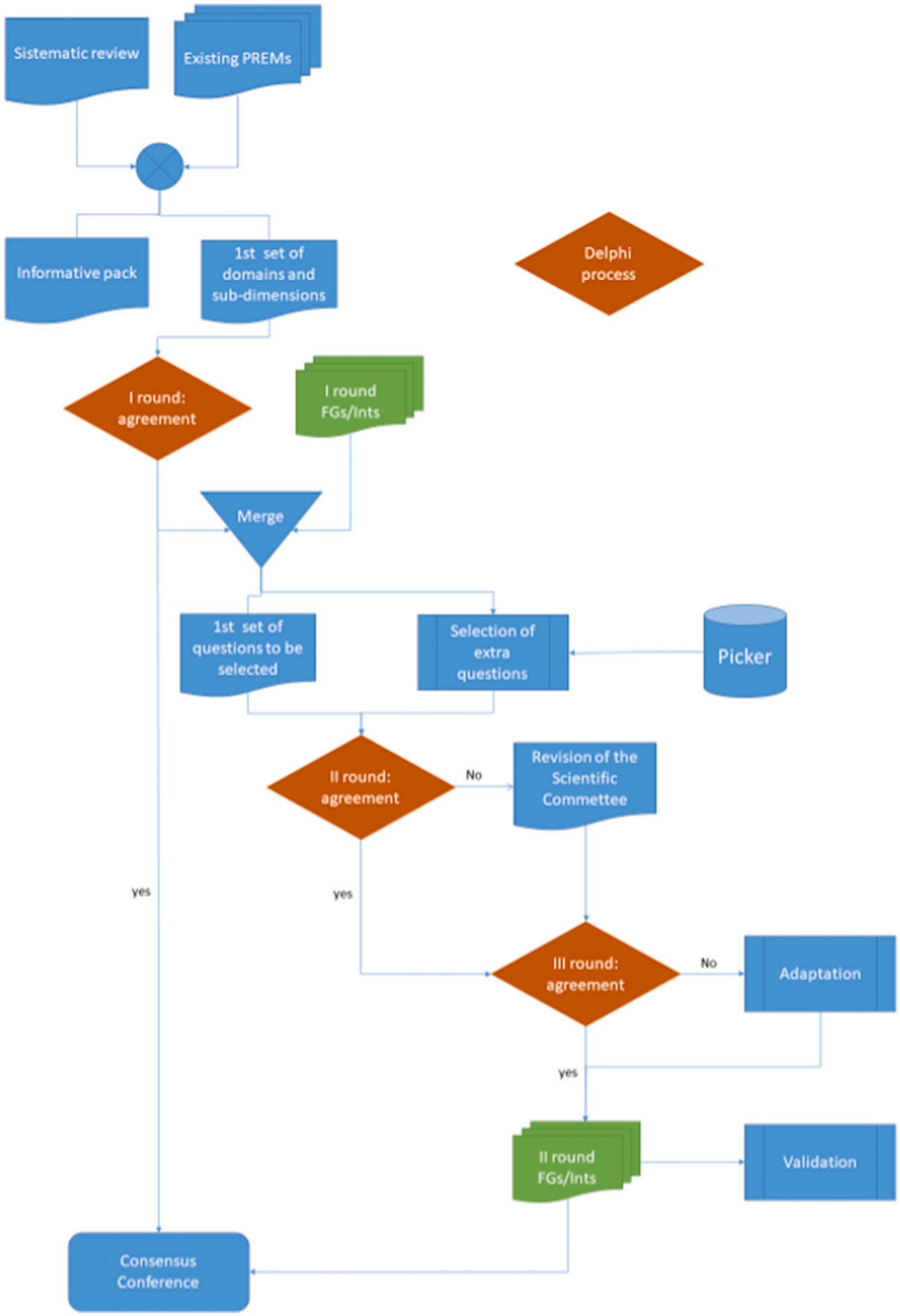

**Fig. 1.** Scheme of the participatory consensus-building process implemented in the VoiCEs project.

addition to the voice of parents and guardians.

Fig. 1 illustrates the scheme of the participatory consensus-building process adopted in this study. It encompassed the systematization of results of two previous steps of the projects, namely, (i) a systematic review (Spataro et al., 2025), and (ii) the analysis of existing paediatric PREMs - or alternative ways of involving children and adolescents in the evaluation of healthcare services - within the consortium of partners. Other authors stressed the importance of starting from existing measures for care-experienced youth, alongside involving them in developing new ones (Power et al., 2024). The panel members received an informative kit, including the above-mentioned material and information on their participation to the study, a few weeks before starting with the Delphi process. We did not pre-determine the number of rounds to be held. At the end, three rounds of Delphi process followed, integrated with two rounds of in-depth interviews (green) and a phase of revision by the Scientific committee of the VoiCES project.

In Appendix A, we reported more details on the methodology employed in the various steps of participatory process. This information is more briefly reported in the following paragraphs.

## 4. Delphi process

### 4.1. Inclusion criteria, sample & recruitment

The Delphi panel included professionals such as paediatricians, psychologists, and representatives of paediatric patients/parents, all required to have English proficiency. Panellists committed to participating in up to three rounds of online surveys.

Aiming for at least 50 participants in Round 1 to accommodate potential dropouts (Hasson et al., 2000), the study involved experts from multiple countries and organisations, including children and adolescents. The number and characteristics of the panellist are described in the Results section and in the Appendix A and B. Recruitment was led by the university, the children's hospitals and supporting institutions.

### 4.2. Data collection

Conducted over five months, the surveys were built on a literature review and past experiences, as anticipated. LimeSurvey was used for survey administration, and participants were provided with preparatory materials and invited to a workshop. Follow-up emails ensured survey completion across three rounds.

1. Round 1: Survey included 98 closed and 22 open-ended questions, focusing on the target population, tool design, dimensions, and subdimensions of paediatric hospital experiences.
2. Round 2: Based on Round 1 and interviews, participants rated the survey content and proposed items using a 10-point scale.
3. Round 3: Finalized questions and answer scales, with participants selecting which items to retain for specific age groups.
4. Consensus Conference: final validation step of the participatory process.

The consensus conference brought together 54 experts, healthcare professionals, and stakeholders in a 4-hour session held in the HUS New Children's Hospital, in Helsinki. During the conference, participants were presented with findings from the qualitative interviews and the Delphi study, as well as the draft versions of the questionnaires. Structured point-by-point discussions focused on reviewing and refining key dimensions, response formats, and item wording, particularly in relation to clarity, usability, and age-appropriateness. The final versions of the questionnaires were approved during the conference.

## 5. Interviews & focus groups (IDIs/FGs)

The study used qualitative methodologies to explore target groups, hospitalisation phases, tool design, timing of administration, and dimensions of the hospital experience, according to the specific phase of the process in which IDs/FGs were conducted. This method was also employed to validate the final versions of the questionnaires, including their linguistic and cultural appropriateness. Validating measures is essential when using them with young people who have experienced care (Power et al., 2024). The second round of qualitative interviews was explicitly designed to support cognitive testing of draft materials, drawing on established principles of cognitive interviewing (Willis, 2005). Participants were invited to paraphrase questions, explain their interpretations, and comment on wording, response options, and overall format, allowing the research team to identify issues related to comprehension, relevance, and age-appropriateness.

Interviews were conducted following a standardised protocol across participating hospitals (Appendix C). Data collection took place in person within hospital settings, in quiet and dedicated spaces. Each session was led by a trained interviewer and supported by at least one additional researcher responsible for note-taking and audio recording. Children and adolescents directly engaged in the interviews were able to participate autonomously, while parents/caregivers were involved in separate sessions. A structured guide was used to ensure consistency across sites. Sessions typically lasted between 45 and 90 min (shorter for younger children). More details are available in the Appendix A.

### 5.1. Inclusion criteria, sample & recruitment

For conducting the FGs/IDIs, the children's hospitals received a guideline document illustrating the methodology to adopt, including indications on how to recruit participants among patients and their parents (Appendix C). Paediatric patients aged 7–18, along with their caregivers, were included. Separate groups were formed for different age ranges, and participation was encouraged through activities like drawing and games for younger children. A sample of 100 participants was targeted across two rounds of FGs/IDIs.

## 6. Data analysis

Both quantitative and qualitative methods were employed. Descriptive statistics summarized closed-ended responses, using SAS software. The consensus of the Delphi was defined according to the kind of measure adopted: (i) a mean score of 4 out of 5, (ii) a mean score of 7 out of 10, (iii) greater than 75% of Delphi participants. The open-ended questions and aggregated reports of FGs/IDIs were analysed by three researchers independently, following the approach of Braun and Clarke (2006). This thematic analysis identified key themes that were integrated into the Delphi process and the results of the participatory process.

Qualitative data analysis followed two phases. The analysis followed the phases of thematic analysis as described by Braun and Clarke (2006), including familiarisation with the data, theme development, and refinement. Data were analysed based on audio recordings and detailed notes, and no dedicated qualitative software was used.

In the first phase, qualitative data were analysed within each study site by local teams using a shared analytical framework. Audio-recordings were transcribed and integrated with field notes by local team researchers. After a familiarisation with the data, they performed an initial coding and theme identification. Each local team produced a report, with complete results supported by quotes.

Site-level summaries were then synthesised through a cross-case analysis conducted by three independent researchers to identify convergent themes and areas of divergence. After a step of familiarisation with the site-level summaries, a final phase of theme development and refinement followed. Coding was primarily inductive and focused on semantic meanings emerging from participants' accounts. The shared analytical framework, derived from the interview guide, supported consistency across sites and comparability of findings (see

Appendix C for further details on data collection and analysis procedures).

## 7. Translation and cultural adaptation

Given the multilingual and multicultural study context, translation and cultural adaptation were integral components of the instrument development process. Draft materials were translated using a forward–backward translation procedure, followed by reconciliation by bilingual experts. Emphasis was placed on conceptual equivalence rather than literal translation, and adapted versions were pre-tested with children and caregivers to identify culturally sensitive or ambiguous wording. This approach is consistent with recommended practices for paediatric PREMs development (Nordlind et al., 2024).

## 8. Results

This section reports the results of the three Delphi rounds and the two rounds of in-depth interviews (IDIs). Focus groups were not conducted due to COVID-19-related safety concerns; therefore, only individual interviews were carried out. As anticipated, children and adolescents contributed to the process in two complementary ways: first, by participating in the Delphi panel (representatives aged >14 years), together with other stakeholder groups; and second, by taking part in IDIs (with caregivers for younger children), which were used to clarify areas where Delphi agreement was not reached, to resolve ambiguities, and to strengthen decisions in line with children's perspectives. This section presents the main substantive outcomes of the study, organised around the key decisions and insights that emerged regarding how paediatric patient experience should be assessed and which aspects of hospitalisation matter most to children and adolescents. While the results are grounded in a multi-stage process, the focus here is on the findings rather than on the procedural steps, which are reported in detail in tables and supplementary materials (Appendix A - B).

### 8.1. Participant characteristics

Eighty-five panellists were invited to Round 1, and 74 responded. Participation decreased to 64 respondents in Round 2 and 56 in Round 3. Italy represented the largest share of participants, reflecting the prominence of Italian partners within the consortium, while additional contributions were received from Latvia, Finland, and the Netherlands (the other three EU countries involved in VoiCES), with smaller participation from other EU countries. Children's and adolescents' representatives participating in the Delphi panel were all older than 14 years. A profile of the panellists invited and participating in each round is reported in Table 1.

### 8.2. General results of the Delphi and interviews

Across Delphi rounds, consensus progressively converged on the need for a structured, standardised approach to assessing paediatric patient experience, with particular emphasis on relational aspects of care, communication, and emotional support during hospitalisation. While alternative methods were initially considered, a questionnaire-based PREMs was ultimately identified as the most feasible and scalable option across settings, provided that age-appropriate wording and formats were ensured.

Qualitative interviews with children and adolescents played a central role in shaping the direction and content of the final outputs, complementing the Delphi process by providing in-depth insights into lived hospital experiences and highlighting areas of convergence and tension across stakeholder groups. In the initial phase, interviews contributed to identifying and refining key dimensions of the hospital experience from the perspective of children and caregivers. In later stages, they were used to test and refine questionnaire items, supporting their cognitive, linguistic, and cultural validation (see Appendix A for further details). For example, feedback from interviews led to simplifying item wording and confirming the use of a limited response scale to improve comprehension and usability among younger age groups.

A convenience sample of children (aged 7–17 years) and caregivers was involved across participating hospitals, ensuring variation in age, background, and health conditions (see Appendix A for detailed characteristics). Despite differences in roles and perspectives, interviews revealed substantial convergence around core experiential domains, particularly regarding communication, emotional reassurance, and the organisation of daily hospital routines. Divergences primarily concerned the framing and prioritisation of these aspects, rather than their relevance.

Insights from the qualitative phase directly informed the refinement

**Table 1**
Profile of the panel members who were invited and took part to the three rounds of the Delphi process.

| Profile group | Subgroup | First Round Invited (no.) | First Round Participants (no.) | First Round Total participants (no.) and response rate on invited people | Second Round Invited (no.) | Second Round Participants (no.) | Second Round Total participants (no.) and response rate on invited people | Third Round Invited (no.) | Third Round Participants (no.) | Third Round Total participants (no.) and response rate on invited people |
|---|---|---|---|---|---|---|---|---|---|---|
| *Key target group* | *Children* | 2 | 2 | 6 | 2 | 1 | 7 | 1 | 1 | 7 |
| | *Parents* | 4 | 4 | | 6 | 6 | | 6 | 6 | |
| *Professionals* | *Clinician* | 20 | 18 | 37 | 18 | 15 | 31 | 15 | 14 | 27 |
| | *Nurses* | 12 | 9 | | 9 | 7 | | 7 | 5 | |
| | *Psychologist/ Psychotherapist* | 3 | 3 | | 3 | 2 | | 2 | 2 | |
| | *Communication expert* | 3 | 3 | | 3 | 3 | | 3 | 3 | |
| | *Manager* | 5 | 4 | | 4 | 4 | | 4 | 3 | |
| *Experts* | *Professor* | 5 | 3 | 31 | 3 | 3 | 26 | 3 | 1 | 22 |
| | *Researcher* | 14 | 13 | | 13 | 12 | | 12 | 10 | |
| | *Patient experience expert* | 5 | 4 | | 4 | 4 | | 4 | 4 | |
| | *Children issues expert* | 12 | 11 | | 9 | 7 | | 7 | 7 | |
| Total participants (no.) and response rate on invited people | | 85 | 74 | 87% | 74 | 64 | 86% | 64 | 56 | 88% |

of the proposed instrument, leading to the rewording of items, the exclusion of redundant content, and the adjustment of response formats to enhance clarity and age-appropriateness. In these phases, tensions emerged less around the relevance of these domains than around how they should be translated into measurement tools. In particular, researchers and other expert stakeholders tended to prioritise comparability, standardisation, and richer response formats, whereas children, adolescents, and caregivers more often emphasised simplicity, clarity, and age-appropriate wording and response options.

Children's and adolescents' perspectives played a dual and substantive role in shaping the final outputs of the study. First, representatives aged over 14 years actively participated in the Delphi panel alongside other stakeholders, contributing directly to consensus-building on key methodological and content-related decisions. Second, in-depth interviews with children, adolescents, and caregivers were used strategically to inform and refine decisions emerging from the Delphi process. In particular, interviews were conducted to clarify areas where Delphi agreement was weak or ambiguous, and to reorient discussions when children's perspectives suggested a different emphasis from that initially proposed by adult stakeholders.

This complementary use of interviews ensured that children's voices were not limited to validation but actively influenced the prioritisation, wording, and format of the final instrument, strengthening its child-centred orientation. Further methodological and process-related details, including the integration of interview findings across rounds, are provided in Appendix A.

### 8.3. *Decisions on measuring paediatric patient experience*

Across stakeholder groups, strong consensus emerged on the need for a structured and systematic approach to capturing paediatric patient experience, applicable across different hospital settings while remaining sensitive to age-related differences. Participants agreed that both paediatric patients and caregivers should be involved as respondents, with age-specific differentiation considered essential.

Age stratification was consistently supported, with distinct versions envisaged for children aged 0–3 (caregiver-reported), 4–7, 8–13, and 14–17 years. Differentiation by age was considered necessary to account for cognitive development, communication abilities, and varying levels of autonomy in healthcare interactions.

Regarding the choice of method, several options were initially considered. However, a questionnaire-based Patient-Reported Experience Measure (PREM) emerged as the most highly endorsed approach across age groups, particularly for adolescents, provided that formats and language were adapted to younger children. The questionnaire was therefore not assumed a priori, but identified through consensus as the most feasible and scalable solution across diverse contexts.

### 8.4. *Core dimensions of paediatric hospital experience*

The integration of Delphi responses and in-depth interviews with children, adolescents, and caregivers led to the identification of a set of core experiential dimensions that were consistently perceived as central to paediatric hospitalisation. These dimensions extended beyond clinical outcomes and focused primarily on relational, emotional, and organisational aspects of care.

Key dimensions included: relationships with healthcare professionals and family members; communication and information provision; emotional support and management of fear, anxiety, and pain; opportunities for social interaction and play; the physical hospital environment; and clarity and support at discharge.

Although stakeholders differed in how they prioritised specific aspects, there was substantial convergence on the relevance of these domains across age groups. Interviews with children and caregivers reinforced the importance of everyday interactions and emotional experiences, highlighting that these elements strongly shape children's overall perception of hospital care.

### 8.5. *Key design choices and resolved tensions*

Some design-related tensions emerged during the development process and were progressively resolved through the integration of quantitative consensus and qualitative feedback. A first tension concerned the balance between methodological standardisation, favoured especially by researchers and expert stakeholders, and developmental appropriateness, more strongly emphasised by children, adolescents, and caregivers. While some stakeholders favoured uniform questions across age groups, children's and caregivers' feedback highlighted the need for age-specific wording and formats, leading to differentiated versions of the same questions.

Another area of discussion concerned response scales. Researchers and other expert participants raised concerns that a shorter scale would reduce measurement sensitivity and explanatory potential (they preferred a (almost) five-point Likert scale), whereas children, adolescents, and caregivers consistently preferred simpler and more intuitive response options, particularly for younger age groups. On this basis, a three-point scale, supplemented by visual and audio elements where appropriate, was retained. This issue was discussed extensively during the consensus conference.

Finally, the length and focus of the questionnaire were refined to prioritise domains that healthcare staff can realistically influence, while limiting less actionable environmental aspects. These decisions reflect a pragmatic compromise between methodological rigour, feasibility, and the lived experiences of children during hospitalisation.

### 8.6. *Final questionnaire*

Table 2 outlines key dimensions and sub-dimensions of the hospital experience, categorized by age group and caregiver involvement, eventually involved in the final version of the VoiCES questionnaires. The dimensions of the paediatric-patient experience with hospital stay are three (admission, ward stay and discharge) following the patient pathway within the hospitalisation, with a final section of additional questions. For each of them, subdimensions and questions were derived, as summarized in the following lines:

1. Admission: it focuses on the attitude of hospital staff upon arrival and their knowledge of the patient's medical record, with relevance to all age groups (0–17) and caregivers.
2. Ward Stay: it covers various aspects of the hospital stay, including staff attentiveness, providing age-appropriate communication, trust in staff, and pain management. Special attention is given to pain management and the staff's age-appropriate interactions for all age groups. Caregivers are also involved. Social interactions, catering, and the environment (temperature, cleaning, night rest) are considered for all ages. Older children (8–17) have additional concerns like Wi-Fi availability, safety of treatment, and involvement in care decisions.
3. Discharge: Emphasizes clear communication from hospital staff on post-discharge care, covering all ages (4–17) and caregivers. Information on returning to normal activities and dealing with concerns after discharge is also addressed.
4. Final: for older children and caregivers, aspects like chronicity, frequency of hospitalisation, general health, and overall satisfaction with the hospital stay are rated, including a 0–10 scale for satisfaction.

Across all dimensions, the framework of paediatric-patient experience with hospital stay ensures age-appropriate measures and comparability of experiences, facilitating the participation of paediatric patients in addition to the involvement of their caregivers.

**Table 2**
Summary of dimensions and sub-dimensions of paediatric (and caregivers') experience with hospitalisation as resulted by the participatory research process of VoiCEs.

| Dimension | Sub-dimensions | Reframed for children | 0–3 (Care givers) | 4–7 | 8–13 | 14–17 | Care givers |
|---|---|---|---|---|---|---|---|
| Admission | Attitude of the staff upon arrival in the hospital ward | | | x | x | x | x |
| | Knowledge by hospital staff of what is reported in the medical record | x | x | x | x | x | x |
| Ward stay | Being listened to carefully by hospital staff | | | x | x | x | x |
| | Clear information from staff about the risks and benefits of treatment | | | | | | x |
| | Provision from hospital staff of easy-to-understand explanations for child patient | | | | | | x |
| | Speaking and acting of hospital staff towards the child patient in a way that is appropriate for his/her age | x | x | x | x | x | |
| | Feeling confident about the safety of treatment and care | | | | | x | x |
| | Trust in hospital staff | | | x | x | | |
| | Pain management | x | x | x | x | x | |
| | Hospital staff speaking in front of the patient as if he/she was not present | | | | x | x | |
| | Being treated by hospital staff with courtesy and respect | x | x | x | x | x | x |
| | Support from hospital staff in dealing with fears and anxieties | x | | x | x | x | x |
| | Availability of hospital staff when the child patient needs attention | | x | x | x | x | |
| | Involvement in the choices regarding the care of the child patient | x | | | x | x | x |
| | Proximity and contact | | | x | x | x | x |
| | Social interactions | | | x | x | x | |
| | Catering | | x | x | x | x | x |
| | Temperature | | | x | x | x | |
| | Cleaning of ward | | | | x | x | x |
| | Night rest/tranquility | | x | x | x | x | x |
| | Toys, books, games based on the age of the child patient | x | x | x | x | x | |
| | Wi-fi availability | | | | | x | x |
| Discharge | Clear information from hospital staff on how to take care of the child patient after leaving the hospital | | | | | | x |
| | Clear information from hospital staff on what to do or who to talk to, if there are concerns about something after leaving the hospital | | | | | x | x |
| | Clear information by the hospital staff on how to look after yourself after leaving the hospital (II) | | | x | x | x | x |
| | Clear information from hospital staff on what would happen once out of the hospital | x | | x | x | x | x |
| | Clear information from hospital staff on when the child patient may return to normal activity | x | | x | x | x | |
| Final | Cronicity | | | | | | x |
| | Frequency of hospitalisation | | | | | | x |
| | General health condition of the patient | | x | x | x | x | |
| | General satisfaction with hospital stay | x | | x | x | x | x |

## 9. Discussion

Children's hospitalisation represents a particularly sensitive experience, characterised by dependence on adults, presence of unfamiliar environments, and limited opportunities for autonomous expression. These features make paediatric patient experience qualitatively different from that of adults and raise specific challenges for its assessment. Children may struggle to articulate their experiences using tools designed for adult populations, while reliance on proxy reporting risks overlooking children's own perspectives. As a result, the development of appropriate approaches to capture paediatric experience remains a methodological and practical challenge. In this study, these challenges are addressed by empirically examining how different stakeholders, including children and adolescents themselves, contributed to defining the most appropriate way to assess paediatric hospital experience.

Recent reviews consistently show that, while the core domains of paediatric hospital experience are well established, existing PREMs remain highly fragmented and largely reliant on caregiver proxy reporting rather than children's direct perspectives (Bartholdson et al., 2024; Bele et al., 2021). Moreover, evidence on the routine use of paediatric PREMs to inform service improvement is still limited, with substantial uncertainty regarding how collected data are interpreted and acted upon in practice (Alarilla et al., 2024). Against this background, our findings contribute to the development of appropriate, child-centred instruments by showing how a participatory and iterative process can lead to consolidated experience domains without assuming a specific instrument a priori. The resulting paediatric PREMs should therefore be understood as the outcome of a negotiated process that integrated multiple stakeholder perspectives, including those of children and adolescents themselves. Importantly, the study shows that participation is not simply a procedural requirement: children's contributions need to be actively interpreted and protected from being diluted by adult-centric priorities and institutional constraints (Cabiati & Levy, 2021; McLaughlin, 2009; Van Dijck & Steen, 2024). In this sense, one of the main contributions of the study is methodological, both illustrating how consensus-building and qualitative inquiry can be combined to make divergences visible and to incorporate children's perspectives into substantive design choices, and by providing a child-friendly tool for collecting the paediatric patients' perspective on hospital care.

The importance of recognising children's voices in healthcare research has been widely discussed, particularly in relation to the limits of adult-centred approaches and proxy reporting. The literature on children's participation has long emphasised that giving voice to children within institutional contexts is not a neutral process, as participation is shaped by power relations, information asymmetries, and organisational constraints (Cabiati & Levy, 2021; McLaughlin, 2009). In healthcare settings, children's perspectives are often mediated by adult stakeholders, raising questions about whose voices are ultimately heard and how they are translated into institutional tools. Recent work has further shown that participatory processes may reproduce existing hierarchies if children's contributions are filtered through adult-centric logics of relevance and feasibility (Van Dijck & Steen, 2024). Against this background, the findings of this study show that tensions between children's perspectives and adult viewpoints did not disappear during the development process, but instead became visible and required active negotiation. These tensions emerged particularly between children, adolescents, and caregivers on the one hand, and researchers, expert stakeholders, and healthcare professionals on the other, especially when experiential priorities had to be translated into concrete measurement choices.

The collaborative Delphi approach enabled dialogue across stakeholder groups and supported agreement on key aspects of paediatric experience assessment. At the same time, the process made visible the above-mentioned areas of divergence, particularly with regard to methodological choices that could not be resolved through consensus alone. Rather than treating areas of weaker agreement as residual, these points were deliberately explored further through qualitative interviews with children, adolescents, and caregivers. This combination of consensus-based and qualitative approaches allowed the development process to remain responsive to children's perspectives while maintaining a structured and transparent decision-making framework.

The findings highlight several tensions that are central to the development of paediatric patient experience measures.

A first key tension concerned the balance between standardisation and developmental appropriateness. While standardised tools are often advocated to support coherence and comparability, previous work on children's voice and participation has emphasised how institutional instruments may struggle to accommodate children's diverse capacities and modes of expression (McLaughlin, 2009; Van Dijck & Steen, 2024). In line with this literature, children and caregivers in this study emphasised the need for age-appropriate wording, formats, and response options. This led to the development of different versions by age group, reflecting a pragmatic compromise between conceptual consistency and developmental suitability, consistent with concerns raised in reviews of paediatric PREMs (Bartholdson et al., 2024; Bele et al., 2021). Prior research has similarly highlighted the scarcity of validated tools for younger children, particularly under the age of six (Corazza et al., 2021; Lapp, 2019; Power et al., 2024; Wray et al., 2018). The use of multiple age-specific versions, together with caregiver items, therefore represents an attempt to reconcile standardisation with developmental diversity while enabling data triangulation.

This tension also reflects a broader trade-off between the development of core, standardised measures and the need to preserve flexibility and innovation in measurement. While standardisation supports comparability and statistical modelling, it may also risk constraining the scope of enquiry and marginalising dimensions that are meaningful to children but less easily operationalised (Power et al., 2024). To mitigate these risks, the questionnaires developed in this study include open-ended questions, allowing for the collection of rich, child- or adolescent-generated content alongside structured items. This design choice aims to balance the benefits of standardisation with the need to preserve children's agency and to capture aspects of experience that may not be fully anticipated within predefined frameworks.

A second tension emerged between the desire for detailed measurement and the need to ensure usability and comprehension for children. This tension was especially visible between researchers and other expert stakeholders, who tended to favour richer response scales and greater analytical granularity, and children, adolescents, and caregivers, who consistently preferred simpler, clearer, and more manageable response formats. From a measurement perspective, richer response scales may appear desirable; however, research on children's participation and agency highlights the risk that overly complex formats can limit meaningful engagement (Cabiati & Levy, 2021; McLaughlin, 2009). Evidence from paediatric instrument development and cognitive interviewing further shows that complex response formats may impose a substantial cognitive burden on younger respondents (Nafees et al., 2024; Willis, 2005). Consistently with these insights, children in this study favoured simpler response options. The choice of a three-point scale, supported by enriched formats, reflects an attempt to balance analytical sensitivity with accessibility. The use of age-adapted visual elements further facilitates direct participation by children and adolescents and supports comparability across age groups (Wray et al., 2018).

A third tension concerned the role of caregiver involvement and proxy reporting. Child-centred care (CCC), although still an emerging and ambiguously defined concept, emphasizes children's agency, participation, communication and involvement in decisions about their care, distinct from traditional family-centred approaches that may prioritise caregiver involvement (Carter et al., 2024). This distinction underlines the importance of developing experience measures that go beyond proxy reporting and capture the voiced perspectives of children and adolescents themselves. In fact, while proxy reporting is widely recognised as a pragmatic solution in paediatric research, particularly for very young children, it also raises concerns regarding the partial displacement of children's own perspectives (Cabiati & Levy, 2021; McLaughlin, 2009). Reviews of paediatric PREMs confirm that reliance on caregivers remains common despite persistent concerns about interpretive misalignment (Alarilla et al., 2024; Bele et al., 2021). In this study, caregiver involvement served a dual role. On the one hand, proxy reporting was retained when direct participation by children was not feasible, particularly for children aged 0–3. On the other hand, caregivers were recognised as direct users of hospital services, whose own experiences reflect how care pathways and organisational processes support families. The parallel collection of children's and caregivers' perspectives therefore allows examination of whether specific dimensions of experience are perceived as equally relevant and as positive or negative by the two target groups, and whether divergences emerge between them. Caregiver involvement was thus conceived not merely as a substitute for children's participation, but as a complementary and legitimate source of information.

A further tension that was expected to play a central role, yet emerged only partially, concerns contextual and cultural differences. Given the diversity of healthcare systems and institutional arrangements involved in the VoiCES project (Belardi et al., 2023; Corazza et al., 2021; Lenzi et al., 2020; Noto et al., 2019; Tavoschi et al., 2022), substantial divergence in stakeholder priorities might have been anticipated. However, the Delphi process revealed a high level of agreement across countries regarding the core dimensions of paediatric hospital experience. This convergence was echoed in the qualitative interviews with children, adolescents, and caregivers. Contextual sensitivity emerged more clearly at the level of language and formulation, with participants emphasising that accessibility and validity depend heavily on wording and framing. Terms related to parents, family, or “home” were identified as potentially problematic for some groups, including care-experienced youth (Power et al., 2024). These issues extend beyond translation, as language choices are intertwined with relational and experiential constructs. Accordingly, the questionnaires underwent cultural and linguistic validation in four European countries to preserve shared experience dimensions while ensuring contextual appropriateness.

Our findings are consistent with previous research identifying core dimensions of hospital experience, including respect and dignity, emotional support, physical and informational support, patient involvement, family involvement, professionalism, and comfort of the facility (Bartholdson et al., 2024; Bele et al., 2021; Coulter et al., 2009; De Rosis et al., 2020; Morales et al., 2001; Picker Institute, 2015; Scholl et al., 2014). Importantly, when articulated directly by children and adolescents, emotional reassurance, clarity of information, and accessibility of communication emerged as particularly salient. While these dimensions are present in established frameworks, they tend to be differently weighted when experience is inferred through adult-centred instruments. Rather than introducing new experience domains, this study contributes by rebalancing their relative salience from a child-centred perspective, showing how dimensions that are already well established in the literature, acquire greater prominence when experience is articulated directly by children and adolescents.

Beyond instrument design, the study also highlights implications for how paediatric PREMs are implemented and used. Evidence suggests that the routine collection of PREMs does not automatically translate into service improvement, underscoring the need for organisational strategies that support interpretation and use of experience data (Alarilla et al., 2024). In this respect, digital channels represent a key enabling condition. Different groups of paediatric patients should not only be approached with different questions, but also engaged through channels aligned with their preferences and capabilities (De Rosis et al., 2019; Pennucci et al., 2022). Digitalisation supports the customisation of formats by age group and facilitates participation by both children and caregivers, strengthening the integration of experience measures into routine evaluation processes.

The VoiCES questionnaires are therefore best understood as components of broader, multi-dimensional evaluation systems rather than as stand-alone tools. Integrating paediatric PREMs within such systems can enhance their interpretability and usefulness for organisational learning and quality improvement (De Rosis, 2024; Nuti et al., 2017; Vainieri et al., 2020). At the same time, initiatives promoting standardised core sets of measures highlight the importance of combining comparability with flexibility, ensuring that standardisation does not crowd out methodological diversity or innovation (de Boer et al., 2022; Power et al., 2024; Schäfer et al., 2011).

Finally, the results of this study differ from other paediatric PREMs in several respects. Few existing tools have been co-designed with multiple stakeholders, including children, adolescents, and caregivers, and participatory approaches remain relatively rare in practice (Morales, 2001; Spataro et al., 2025). Many instruments primarily capture paediatric experience through caregiver reports, as in Child CAHPS or the Children and Young People's Patient Experience Survey by the Picker Institute, while others focus on adults or adolescents only (Corazza et al., 2021, 2022; Spataro et al., 2025). Child-friendly formats are still uncommon and often lack comparable caregiver versions (Wray et al., 2018). The VoiCES questionnaires address these gaps by combining age-adapted formats, direct participation of children and adolescents, parallel caregiver perspectives, and digital delivery within a single, coherent framework. This approach supports inclusivity and comparability while preserving flexibility and innovation in the assessment of paediatric hospital experience.

## 10. Implications for policy and practice

From a practical and policy perspective, this study shows that the design of paediatric patient experience measures is not a purely technical exercise, but reflects implicit assumptions about children's capacities, roles, and legitimacy as informants (Cabiati & Levy, 2021; McLaughlin, 2009; Van Dijck & Steen, 2024). Choices regarding formats, response scales, age-specific versions, and the inclusion of caregivers shape whose experiences are made visible and how they are interpreted within healthcare organisations.

The availability of differentiated versions of the VoiCES questionnaire offers a pragmatic solution for assessing paediatric experience across a wide age range, while preserving children's perspectives as much as possible (Power et al., 2024; Wray et al., 2018). Combining direct child-reported measures with caregiver perspectives allows healthcare organisations not only to collect information where children cannot participate directly, but also to recognise caregivers as legitimate users of hospital services with distinct experiential needs. Moreover, the parallel collection of children's and caregivers' data makes it possible to explore convergences and divergences in how experience dimensions are perceived in terms of relevance and positivity or negativity (Alarilla et al., 2024; Bele et al., 2021).

At the organisational level, the study provides healthcare managers, providers, patient representatives, and patient experience experts with a stakeholder-approved, child-friendly tool that can support the systematic inclusion of paediatric perspectives in quality evaluation and improvement processes (Esmail et al., 2015; Goodman & Sanders Thompson, 2017; Stelfox et al., 2015). However, administering differentiated questionnaires for different age groups requires dedicated resources, specific competencies, and a clear commitment from top management. Implementation is also tightly linked to administration channels: different paediatric groups should be engaged not only with different questions, but also through channels aligned with their preferences and capabilities, and digitalisation can enable such tailoring and support participation at scale (De Rosis et al., 2019; Pennucci et al., 2022).

Importantly, existing evidence indicates that the routine collection of paediatric PREMs does not automatically translate into service improvement (Alarilla et al., 2024). The findings therefore underline the need for organisational strategies that support data interpretation, feedback, and integration into decision-making processes. In this sense, the VoiCES questionnaire represents an enabling tool rather than a standalone solution.

Finally, as a standard yet adaptable instrument, the VoiCES questionnaire can be adopted and tested by healthcare organisations beyond the four partner hospitals and in other countries. It provides a potential baseline for building a European Observatory on paediatric patient experience, allowing comparability across contexts while leaving room for local adaptation and integration with other evaluative tools and performance systems (de Boer et al., 2022; De Rosis, 2024; Nuti et al., 2017; Power et al., 2024; Schäfer et al., 2011; Vainieri et al., 2020).

### 10.1. *Strengths and limitations*

This study has several limitations related to design, participation, and context. First, although the Delphi process involved international participants, stakeholder priorities and interpretations may have been influenced by the specific project context. Children's participation was necessarily shaped by ethical, organisational, and legal constraints, which affected both the depth and form of their involvement, an issue widely discussed in participation scholarship (McLaughlin, 2009; Van Dijck & Steen, 2024).

Second, operational constraints significantly affected data collection. Due to privacy and child-protection policies, invitations to children were mediated by hospitals, making direct engagement with this population challenging. These difficulties were further exacerbated by the COVID-19 pandemic, which prevented focus groups and limited opportunities for collective discussion. As a result, individual in-depth interviews were conducted with children, adolescents, and caregivers. While this approach enabled the direct involvement of 47 children and adolescents and 42 parents and caregivers, it may have reduced opportunities for shared deliberation among participants.

Third, the composition of the Delphi panel represents a further limitation. Although the international panel encompassed a wide range of expertise and stakeholder groups, and response rates were consistently high across rounds, academic participants and healthcare providers were more strongly represented than healthcare users. This highlights the need for future research to further develop mechanisms for sustained and direct involvement of children, adolescents, and caregivers in participatory research designs.

Finally, the panel included a relatively high number of participants from Italy, reflecting the composition of the VoiCES project consortium. While this may raise concerns about generalisability, the analyses did not reveal substantial differences across countries. Nevertheless, further research is required to conduct psychometric validation, assess comparability across versions and contexts, and examine how paediatric PREMs are implemented and used in practice to support organisational learning and quality improvement (Alarilla et al., 2024; Bartholdson et al., 2024; Bele et al., 2021; Peruzzo, Vainieri, & De Rosis, 2025).

Future studies should also explore appropriate administration channels tailored to different age groups, including enriched questionnaires for younger children, gamified tools for pre-adolescents, and age-appropriate digital formats for adolescents.

## 11. Conclusions

By combining a wide-ranging Delphi process with qualitative interviews embedded in a broader collaborative framework, and by engaging an international, multi-stakeholder panel, this study supported the development of an age-specific and child-friendly tool for collecting feedback on hospitalisation experiences from children, adolescents, and their caregivers. Rather than assuming a predefined instrument, the iterative process enabled stakeholders, particularly children and adolescents, to contribute directly to defining the most appropriate format and content for assessing paediatric patient experience.

The resulting tool consists of a standardised questionnaire available in six languages and tailored to five distinct age groups, with complementary versions for caregivers. This structure allows the systematic collection of paediatric patient experience data while accounting for developmental differences and diverse expressive capacities. By integrating children's and caregivers' perspectives within a single, coherent framework, the tool provides a robust basis for capturing experiences that are often underrepresented in conventional patient experience measurement.

Overall, the study demonstrates how collaborative and participatory approaches can be operationalised in the development of paediatric PREMs, resulting in instruments that are both methodologically sound and responsive to children's perspectives. The questionnaire developed through this process offers healthcare organisations a practical means to strengthen the visibility of paediatric patients' voices and to support the use of experience data in the improvement of hospital services.

## Abbreviations

| | |
|---|---|
| AOPI | Italian Association of Children's Hospitals |
| AOU Meyer | Meyer Children's University Hospital |
| CCUH | Children's Clinical University Hospital |
| ECHO | European Children's Hospitals Organisation |
| EMC | Erasmus University Medical Center |
| EU | European Union |
| FG | focus group |
| GDPR | General Data Protection Regulation |
| HCAHPS | Hospital Consumer Assessment of Healthcare Providers and Systems Survey |
| HUS | HUS New Children's Hospital |
| IDI | in-depth interview |
| IOM | Institute of Medicine |
| PREM | Patient-Reported Experience Measure |
| SD | Standard Deviation |
| UNICEF | United Nations International Children's Emergency Fund/ United Nations Children's Fund |
| VoiCES | Value of including the Children Experience for improving their rightS during hospitalisation |
| WHO | World Health Organisation |

## CRediT authorship contribution statement

**Sabina De Rosis:** Writing – original draft, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Veronica Spataro:** Writing – review & editing, Project administration, Formal analysis, Data curation. **Jan A. Hazelzet:** Writing – review & editing, Validation, Investigation, Conceptualization. **Elisa Peruzzo:** Writing – review & editing, Project administration, Data curation. **Manila Bonciani:** Writing – review & editing, Validation, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

## Ethical considerations and approval

Given that the study involved interaction with human participants, including minors, ethical aspects were carefully addressed throughout the project. The overall VoiCES European project protocol was reviewed and approved by the Ethics Committee of the Sant'Anna School of Advanced Studies and Scuola Normale Superiore of Pisa (approval date: March 25, 2022; protocol number 07/2022). In addition, all participating hospitals submitted the protocol to their respective local Ethics Committees for approval of the research activities conducted at their sites, such as interviews.

Each participating institution was responsible for defining context-specific ethical procedures, including informed consent processes, data management and confidentiality measures, and compliance with applicable regulations. Particular attention was given to the protection of minors and sensitive data. A common data protection and sharing framework was developed to guide all partners, ensuring alignment with European and national regulations, including the General Data Protection Regulation (GDPR) and the Convention on the Rights of the Child.

All participating institutions had and followed its own Child Protection Policy.

## Consent for publication

Not applicable.

## Funding

The VoiCES (Value of including the Children Experience for improving their rightS during hospitalisation) project was co-funded by the European Union's Rights, Equality and Citizenship Programme (2014–2020) under grant agreement REC-RCHI-PROF-AG-2020.

## Declaration of competing interest

The authors declare that they have no competing interests.

## Acknowledgements

The authors thank all the panel members, as well as paediatric patients and their parents who took part in the interviews.

A particular acknowledgment goes to Professor Milena Vainieri, principal investigator of the VoiCES project, and to Professor Sabina Nuti for their vision and scientific contribution. The authors are also grateful to the researchers of the Management and Healthcare Laboratory (MeS) of Sant'Anna School for their continued support, in particular Elisa Conti.

The authors want to thank the partners of the VoiCES project, especially Barbara Sibbles from the Department of Public Health of the Erasmus University Medical Center (Rotterdam, the Netherlands), Katariina Gehrmann from the Helsinki University Children's Hospital (Helsinki, Finland), Francesca Menegazzo and Michela Sica from the Meyer Children's Hospital IRCCS (Florence, Italy), Vita Šteina from the Children's Clinical University Hospital (Rīga, Latvia), and.

Elise M Chapin from the Italian National Committee for UNICEF (Rome, Italy).

## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.actpsy.2026.106821.

## Data availability

Data will be made available on request.

## References

Alarilla, A., Terrell, K., Kelly, P., Chesters, H., Gibson, F., Oldham, G., … Wray, J. (2024). Routine use of patient-reported experience and outcome measures for children and young people: A scoping review. *Systematic Reviews, 13*(1), 293. https://doi.org/10.1186/s13643-024-02526-3

American Academy of Pediatrics. (2012). Patient- and family-centered care and the pediatrician’s role. *Pediatrics, 129*(2), 394–404. https://doi.org/10.1542/peds.2011-3084

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35*(4), 216–224. https://doi.org/10.1080/01944366908977225

Barr, K. R., Nikolovski, J., White, L., Elliott, S., McCartney, L., Treadgold, C., & Eapen, V. (2024). Co-developing a paediatric patient-reported experience measure: The perspectives of children and young people. *Patient Experience Journal, 11*(3), 64–72. https://doi.org/10.35680/2372-0247.1829

Bartholdson, C., Broström, E., Iversen, M. D., & Granhagen Jungner, J. (2024). Patient-reported experience measures in pediatric healthcare: A rapid evidence assessment. *Journal of Patient Experience, 11*, Article 23743735241290481. https://doi.org/10.1177/23743735241290481

Belardi, P., Corazza, I., Bonciani, M., Manenti, F., & Vainieri, M. (2023). Evaluating healthcare performance in low- and middle-income countries: A pilot study on selected settings in Ethiopia, Tanzania, and Uganda. *International Journal of Environmental Research and Public Health, 20*(1). https://doi.org/10.3390/ijerph20010041

Bele, S., Teela, L., Zhang, M., Rabi, S., Ahmed, S., van Oers, H. A., … Santana, M. J. (2021). Use of patient-reported experience measures in pediatric care: A systematic review. *Frontiers in Pediatrics, 9*, Article 753536. https://doi.org/10.3389/fped.2021.753536

Berry, L. L. (2019). Service innovation is urgent in healthcare. *AMS Review, 9*(1–2), 78–92. https://doi.org/10.1007/s13162-019-00135-x

Bonciani, M., Corazza, I., Lupi, B., & De Rosis, S. (2020). How to improve the maternal pathway for migrant women: Insights for retention strategies from Tuscany region. *Micro & Macro Marketing, 29*(3), 585–607. https://doi.org/10.1431/97641

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Cabiati, E., & Levy, S. (2021). 'Inspiring conversations': A comparative analysis of the involvement of experts by experience in Italian and Scottish social work education. *The British Journal of Social Work, 51*(2), 487–504. https://doi.org/10.1093/bjsw/bcaa163

Carter, B., Young, S., Ford, K., & Campbell, S. (2024). The concept of child-centred care in healthcare: A scoping review. *Pediatric Reports, 16*(1), 114–134. https://doi.org/10.3390/pediatric16010012

Clemente, I., Heritage, J., Meldrum, M. L., Tsao, J. C., & Zeltzer, L. K. (2012). Preserving the child as a respondent: Initiating patient-centered interviews in a US outpatient tertiary care paediatric pain clinic. *Communication & Medicine, 9*(3), 203. https://doi.org/10.1558/cam.v9i3.203

Corazza, I., Gilmore, K. J., Menegazzo, F., & Abols, V. (2021). Benchmarking experience to improve paediatric healthcare: Listening to the voices of families from two European children's university hospitals. *BMC Health Services Research, 21*(1), 93. https://doi.org/10.1186/s12913-021-06094-z

Corazza, I., Spataro, V., Hazelzet, J., Bonciani, M., & De Rosis, S. (2022). Rethinking youth's engagement in evaluating the experience of hospitalization. In *Excellence in services 21th international conference*. Accessible at: https://sites.les.univr.it/eisic/wp-content/uploads/2022/10/Corazza-Spataro-Hazelzet-Bonciani-De-Rosis.pdf.

Coulter, A., Fitzpatrick, R., & Cornwell, J. (2009). *Measures of patients' experience in hospital: Purpose, methods and uses*. London: King's Fund. Accessible at: https://www.researchgate.net/profile/Angela-Coulter/publication/230687403_The_Point_of_Care_Measures_of_Patients'_Experience_in_Hospital_Purpose_Methods_and_Uses/links/09e415082af673d0d5000000/The-Point-of-Care-Measures-of-Patients-Experience-in-Hospital-Purpose-Methods-and-Uses.pdf.

Coyne, I. (2006). Children's experiences of hospitalisation. *Journal of Child Health Care, 10*(4), 326–336. https://doi.org/10.1177/1367493506067884

Coyne, I. (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies, 45*(11), 1682–1689. https://doi.org/10.1016/j.ijnurstu.2008.05.002

Coyne, I., Hallström, I., & Söderbäck, M. (2016). Reframing the focus from a family-centred to a child-centred care approach for children's healthcare. *Journal of Child Health Care, 20*(4), 494–502. https://doi.org/10.1177/1367493516642744

Davidson, J. E., Aslakson, R. A., Long, A. C., Puntillo, K. A., Kross, E. K., Hart, J., Cox, C. E., Wunsch, H., Wickline, M. A., Nunnally, M. E., Netzer, G., Kentish-Barnes, N., Sprung, C. L., Hartog, C. S., Coombs, M., Gerritsen, R. T., Hopkins, R. O., Franck, L. S., Skrobik, Y., & Curtis, J. R. (2017). Guidelines for family-centered care in the neonatal, paediatric, and adult ICU. *Critical Care Medicine, 45*(1), 103–128. https://doi.org/10.1097/CCM.0000000000002169

De Bienassis, K., Kristensen, S., Hewlett, E., Roe, D., Mainz, J., & Klazinga, N. (2021). Measuring patient voice matters: Setting the scene for patient-reported indicators. *International Journal for Quality in Health Care, 33*(1). https://doi.org/10.1093/intqhc/mzab002

de Boer, D., van den Berg, M., Ballester, M., Bloemeke, J., Boerma, W., de Bienassis, K., … Rijken, M. (2022). Assessing the outcomes and experiences of care from the perspective of people living with chronic conditions, to support countries in developing people-centred policies and practices: Study protocol of the international survey of people living with chronic conditions (PaRIS survey). *BMJ Open, 12*(9), Article e061424. https://doi.org/10.1136/bmjopen-2022-061424

De Rosis, S. (2024). Performance measurement and user-centeredness in the healthcare sector: Opening the black box adapting the framework of Donabedian. *International Journal of Health Planning and Management, 39*(4), 1172–1182. https://doi.org/10.1002/hpm.3732

De Rosis, S., Bonciani, M., Spataro, V., Corazza, I., Conti, E., Sibbles, B., … Vainieri, M. (2023). Value of including the children's experience for improving their rights during hospitalisation: Protocol for the VoiCEs project. *JMIR Research Protocols, 12*(1). https://doi.org/10.2196/42804

De Rosis, S., Cerasuolo, D., & Nuti, S. (2020). Using patient-reported measures to drive change in healthcare: The experience of the digital, continuous and systematic PREMs observatory in Italy. *BMC Health Services Research*, 1–17. https://doi.org/10.1186/s12913-020-05099-4

De Rosis, S., Ferrè, F., & Pennucci, F. (2022). Including patient-reported measures in performance evaluation systems: Patient contribution in assessing and improving the healthcare systems. *The International Journal of Health Planning and Management.*. https://doi.org/10.1002/hpm.3596

De Rosis, S., Jamieson Gilmore, K., & Nuti, S. (2023). Reverse compassion: Value-in-use and value-in-context of healthcare services during crisis. *TQM Journal, 35*(9), 332–351. https://doi.org/10.1108/TQM-12-2022-0339

De Rosis, S., Pennucci, F., & Seghieri, C. (2019). Segmenting adolescents around social influences on their eating behavior: Findings from Italy. *Social Marketing Quarterly, 25*(4). https://doi.org/10.1177/1524500419882059

Esmail, L., Moore, E., & Rein, A. (2015). Evaluating patient and stakeholder engagement in research: Moving from theory to practice. *Journal of Comparative Effectiveness Research, 4*(2), 133–145. Newlands Press Ltd https://doi.org/10.2217/cer.14.79.

Goodman, M. S., & Sanders Thompson, V. L. (2017). The science of stakeholder engagement in research: Classification, implementation, and evaluation. *Translational Behavioral Medicine, 7*(3), 486–491. https://doi.org/10.1007/s13142-017-0495-z

Hart, R. A. (1992). *Children's participation: From tokenism to citizenship. Innocenti essays no. 4*. Florence: UNICEF Innocenti Research Centre. Papers inness92/6, Innocenti Essay https://ideas.repec.org/p/ucf/inness/inness92-6.html.

Hasson, F., Keeney, S., & McKenna, H. (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing, 32*(4), 1008–1015. https://doi.org/10.1046/j.1365-2648.2000.t01-1-01567.x

IAPO Patient-Centred Healthcare Review 2nd edition. (2007). *What is patient-centred healthcare? A review of definitions and principles*.

IOM - Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century*. National Academy Press. https://doi.org/10.17226/10027

Karisalmi, N., Stenhammar, H., & Kaipio, J. (2018). What constitutes the patient experience of children? Findings from the photo elicitation and the video diary study. *Patient Experience Journal, 5*(2), 54–68. https://pxjournal.org/journal/vol5/iss2/9/.

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2011). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal, 16*(2), 297–305. https://doi.org/10.1007/s10995-011-0751-7

Lapp, V. (2019). The patient's voice: Development of an adolescent hospital quality of care survey (AHQOCS). *Journal of Paediatric Nursing, 49*, 43–50. https://doi.org/10.1016/j.pedn.2019.08.006

Lenzi, J., Noto, G., Corazza, I., Lepiksone, J., & Fantini, M. P. (2020). Measuring the quality of care in small countries: The empirical analysis of 30-day mortality following acute myocardial infarction and ischaemic stroke in Latvia. *Health Policy, 124*(7), 695–700. https://doi.org/10.1016/j.healthpol.2020.05.017

Lopez, A., Tinella, L., Caffò, A., & Bosco, A. (2023). Measuring the reliability of proxy respondents in behavioural assessments: An open question. *Aging Clinical and Experimental Research, 35*(10), 2173–2190. https://doi.org/10.1007/s40520-023-02501-z

McElroy, E., Villadsen, A., Patalay, P., Goodman, A., Richards, M., Northstone, K., … Ploubidis, G. B. (2020). *Harmonisation and measurement properties of mental health measures in six British cohorts*. London: CLOSER. Accessible at https://closer.ac.uk/wp-content/uploads/210715-Harmonisation-measurement-properties-mental-health-measures-british-cohorts.pdf.

McLaughlin, H. (2009). What's in a name: 'client', 'patient', 'customer', 'consumer', 'expert by experience', 'service user' - What's next? *British Journal of Social Work, 39*(6), 1101–1117. https://doi.org/10.1093/bjsw/bcm155

Morales, L. S., Weidmer, B. O., & Hays, R. D. (2001, February). Readability of CAHPS 2.0 child and adult core surveys. In *National Center for Health Statistics, seventh conference on health survey research methods* (pp. 83–90). Accessible at: https://collections.nlm.nih.gov/master/borndig/101643774/conf07.pdf#page=87.

Nafees, Z., Ferreira, J., Guadagno, E., Wray, J., Anderzén-Carlsson, A., & Poenaru, D. (2024). Adaptation, translation, and validation of a patient-reported experience measure for children and young people for the Canadian context. *Journal of Pediatric Surgery, 59*(5), 810–817. https://doi.org/10.1016/j.jpedsurg.2023.12.014

NEJM Catalyst. (2017). What is patient-centered care? *NEJM New England Journal of Medicine.*. https://doi.org/10.1056/CAT.17.0559

Nordlind, A., Anderzén-Carlsson, A., Sundqvist, A. S., Ängeby, K., Wray, J., Oldham, G., & Almblad, A. C. (2024). Translation, cultural adaptation and validation of a patient-reported experience measure for children. *Health Expectations, 27*(1), Article e13924. https://doi.org/10.1111/hex.13924

Noto, G., Corazza, I., Kļaviņa, K., Lepiksone, J., & Nuti, S. (2019). Health system performance assessment in small countries: The case study of Latvia. *The International Journal of Health Planning and Management, 34*(4), 1408–1422. https://doi.org/10.1002/hpm.2803

Nuti, S., De Rosis, S., Bonciani, M., & Murante, A. M. (2017). Rethinking healthcare performance evaluation systems towards the people-centredness approach: Their pathways, their experience, their evaluation. *Healthcare Papers, 17*(2), 56–64. Accessible at: https://shorturl.at/EUzci.

O'Neill, J., Reeks, G. R., & Kearney, L. (2018). Can an interactive application be used to collect meaningful feedback from paediatric patients and their parents in a hospital setting? *Patient Experience Journal, 5*(2), 69–75. https://doi.org/10.35680/2372-0247.1290

Pennucci, F., De Rosis, S., Murante, A. M., & Nuti, S. (2022). Behavioural and social sciences to enhance the efficacy of health promotion interventions: Redesigning the role of professionals and people. *Behavioural Public Policy, 6*(1), 13–33. https://doi.org/10.1017/bpp.2019.19

Peruzzo, E., Seghieri, C., Vainieri, M., & De Rosis, S. (2025). Improving the healthcare user experience: An optimization model grounded in patient-centredness. *BMC Health Services Research, 25*(1), 132. https://doi.org/10.1186/s12913-024-11960-7

Peruzzo, E., Vainieri, M., & De Rosis, S. (2025). Enhancing learning systems in using patient experience data: An exploratory mixed-method study in two Italian regions. *International Journal of Health Planning and Management.*. https://doi.org/10.1002/hpm.3912

Picker Institute. (2015). Patient-centered care 2015: Scenarios, vision, goals & next steps. Accessible at: https://www.yumpu.com/en/document/read/8991019/patient-centered-care-2015-scenarios-vision-goals-next-steps.

Power, L., Davidson, G., Jacobs, P., McCusker, P., McCartan, C., & Devaney, J. (2024). Identifying core measures to be used in mental health research with care experienced young people: A Delphi study. *Children and Youth Services Review, 157*. https://doi.org/10.1016/j.childyouth.2023.107380

Schäfer, W. L., Boerma, W. G., Kringos, D. S., De Maeseneer, J., Greß, S., Heinemann, S., … Groenewegen, P. P. (2011). QUALICOPC, a multi-country study evaluating quality, costs and equity in primary care. *BMC Family Practice, 12*. https://doi.org/10.1186/1471-2296-12-115

Scholl, I., Zill, J. M., Härter, M., & Dirmaier, J. (2014). An integrative model of patient-centeredness-a systematic review and concept analysis. *PLoS ONE, 9*(9). https://doi.org/10.1371/journal.pone.0107828. Public Library of Science.

Spataro, V., Corazza, I., Hazelzet, J. A., Bonciani, M., & De Rosis, S. (2025). A systematic literature review on initiatives to involve children and adolescents in evaluating their hospitalisation experience. *BMC Health Services Research, 25*(1). https://doi.org/10.1186/s12913-025-12486-2. BioMed Central Ltd.

Stelfox, H. T., Niven, D. J., Clement, F. M., Bagshaw, S. M., Cook, D. J., McKenzie, E., … Zuege, D. (2015). Stakeholder engagement to identify priorities for improving the quality and value of critical care. *PLoS ONE, 10*(10). https://doi.org/10.1371/journal.pone.0140141

Tavoschi, L., Belardi, P., Mazzilli, S., Manenti, F., Pellizzer, G., Abebe, D., … Vainieri, M. (2022). An integrated hospital-district performance evaluation for communicable diseases in low- and middle-income countries: Evidence from a pilot in three sub-Saharan countries. *PLoS ONE, 17*(3 March). https://doi.org/10.1371/journal.pone.0266225

Vainieri, M., Noto, G., Ferre, F., & Rosella, L. C. (2020). A performance management system in healthcare for all seasons? *International Journal of Environmental Research and Public Health, 17*(15), 1–10. https://doi.org/10.3390/ijerph17155590

Van Dijck, C., & Steen, T. (2024). Engaging experts by experience as co-producers: Challenges and strategies. *Public Management Review, 26*(8), 2242–2259. https://doi.org/10.1080/14719037.2023.2183244

WHO (World Health Organization) & OHCHR (Office of the High Commissioner for Human Rights). (2014). Technical guidance on the application of a human rights-based approach to the implementation of policies and programmes to reduce and eliminate preventable mortality and morbidity of children under 5 years of age. Accessible at: https://www.ohchr.org/en/health/publications-and-resources.

Willis, G. B. (2005). *Cognitive interviewing: A tool for improving questionnaire design.* Thousand Oaks, CA: Sage.

Wray, J., Hobden, S., Knibbs, S., & Oldham, G. (2018). Hearing the voices of children and young people to develop and test a patient-reported experience measure in a specialist paediatric setting. *Archives of Disease in Childhood, 103*(3), 272–279. https://doi.org/10.1136/archdischild-2017-313032

Wray, J., & Oldham, G. (2020). Using parent-reported experience measures as quality improvement tools in paediatric cardiothoracic services: Making it happen. *International Journal for Quality in Health Care, 32*(2), 140–148. https://doi.org/10.1093/intqhc/mzaa001