

SYSTEMATIC REVIEW

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# A systematic literature review on initiatives to involve children and adolescents in evaluating their hospitalization experience

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## Abstract

**Background** Despite patient experience being an important topic in healthcare management, most research does not concentrate on initiatives targeted to patients experiencing vulnerabilities, for whom it is challenging to contribute to the processes of feedback collection. In healthcare, children and adolescents can be considered a group of patients experiencing vulnerability, particularly during a sensitive time such as hospitalization. The aim is to provide an overview of the research on patient experience collection initiatives used by healthcare service providers to facilitate children and adolescents' involvement in the evaluation of their hospitalisation experience. The study attempts to determine if these approaches exist, how they are structured, and what impact they have on services.

**Methods** This research is based on a systematic literature review. We identified 1498 articles through Scopus, ISI Web of Science, and PubMed. To guarantee transparency and replicability, we adhered to the PRISMA guidelines. The analysis focused on the main elements of the approaches used by the different providers to involve children and adolescents in the evaluation of their hospitalization experience, including the characteristics of patients targeted by the feedback collection initiatives, the methods and tools implemented by healthcare providers, the different dimensions of patient experience on which feedback is requested, the co-design of the initiative, quality and performance implications.

**Results** Fifty-eight articles were included in the final review. Patient feedback was mostly collected using qualitative tools, which seem more likely to be child-friendly. Quantitative methodologies were shown to be more suitable for standardised and systematic patient experience feedback collection initiatives. The findings indicate a scarcity of innovative tools and gamified techniques, which in turn suggests new potential areas of research by combining qualitative and quantitative methods. Feedback from paediatric patients was collected regarding different aspects of the patient experience. Physical environment and pain management emerge as crucial aspects of the patient experience with hospitalisation, despite the intensive relational service. There is a germinal trend for co-design. Most of the analysed papers only discuss future and potential quality and performance implications of the patient experience feedback collection initiative, opening to questions on its actual impact on outcomes. Mostly sporadic experiences are reported, rather than systematic initiatives of feedback collection.

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**Conclusions** This study contributes to systematising the topic of children and adolescents' involvement in evaluating their hospitalisation experience. The findings provide insights regarding the approaches service providers can take to encourage vulnerable patients' direct participation in the evaluation of healthcare services and inform directions for future research.

**Keywords** Healthcare services, Service evaluation, Vulnerabilities, Patient experience, Children and adolescents, Hospitalization

## Background

The importance of collecting patient feedback in healthcare is well-established. Research underscores its multifaceted benefits, including supporting service quality evaluation, professional self-reflection, continuous improvement, innovation, and co-production in care [1–5]. Patient feedback is also pivotal in enhancing patient-centered care [6, 7], reducing adverse outcomes like hospital readmissions [6, 8], and ensuring public accountability, even in crises [2, 9–11]. Feedback can take various forms, such as satisfaction, experience with services, and health outcomes [3, 12]. Traditionally, patient satisfaction has been used as an indicator of care quality [1–4], with many tools developed to assess it. However, satisfaction remains subjective, influenced by individual expectations and preferences [2, 13–15]. To address these limitations, the focus has shifted to measuring patient experiences, which capture specific aspects of care delivery rather than overall satisfaction [2, 12, 16, 17]. Experience measures aim to minimize the influence of prior expectations, offering more objective and actionable insights [18, 19]. Patients are typically asked about concrete aspects of their care, such as specific services, hospital episodes, or interactions with healthcare providers, making these measures easier to interpret and use. Both generic and service-specific instruments exist for collecting patient experience data, these latter providing more targeted insights.

Some institutions have developed validated PREMs (Patient-Reported Experience Measures) questionnaires for collecting patients' experiences about healthcare services, such as the Picker Institute, The Agency for Healthcare Research and Quality, and the Institute for Healthcare Improvement [20–23], but there are also many ad hoc built tools. Indeed, experience questions are instruments useful to provide managers and clinicians with specific information on what works and what doesn't work from the patient's perspective [2]. These measurements offer valuable insights into the process of care, focusing on how services are delivered according to the patient's perspective, and in terms of patient-centeredness, which includes aspects like patient and caregiver involvement, respect, physical and emotional support, information and communication [7, 15, 24]. However, patient experiences can be collected through methods other than questionnaires, such as interviews,

focus groups, patient forums, or formal complaints [2]. Patients, caregivers, users in general can also voluntarily leave feedback on social media platforms, websites provided by the healthcare systems, and through portals created and promoted by private organizations or patient advocacy groups. While global satisfaction ratings and experience measures may be useful when monitoring trends over time, they can be misleading if patients cannot comment on their care in more detail [2]. Even though patient narratives may lack scientific rigor [25], these kinds of experiential narrative feedback can be more influential in terms of word-of-mouth or patient choice [26], and, when systematically elicited, can offer a deeper understanding of patient experiences, providing essential context for both healthcare services' users and clinicians. The integration of narrative feedback on patient experience could enhance healthcare quality by informing decision-making and helping clinicians address specific concerns [26]. By focusing on the patient's story, healthcare professionals and managers can gain deeper insights into their experience with services, also considering emotional, psychological, and social contexts, leading to more compassionate, patient-centred care. To gather stories effectively, qualitative and creative methodologies are often more suitable than traditional surveys, such as in-depth interviews, diaries, and audio or video recordings. In this sense, narrative and qualitative methodologies can be tailored to capture experiences in ways that are suited to specific target groups, settings, and contexts. However, it is essential to ensure rigor and representativeness in the collection and reporting of narratives to establish their reliability as tools for healthcare performance assessments and improvement.

However, to enhance the measurement of patient experience, it's essential to broaden the focus to include diverse groups of users experimenting with vulnerabilities and who may have difficulty participating in this kind of initiatives, such as users with low literacy, children and adolescents, or people experiencing homelessness when seeking healthcare [27, 28]. The literature increasingly highlights the significance of engaging these vulnerable populations, emphasizing the need to understand and meet their specific needs [29, 30]. To open new avenues of research aimed at creating a patient-centred healthcare system, future studies should concentrate on key issues related to the collection and utilization

of experience measures for vulnerable patients. This includes identifying appropriate methodologies to capture the experiences of vulnerable patients [27]. Vulnerability experienced by users can be defined as a state of powerlessness, which occurs when the control is not in the individual's hands due to specific states, conditions, or external factors [29, 31, 32]. Healthcare users, especially patients, are often in vulnerable positions due to their lack of resources, knowledge, or power to fully engage in healthcare services practitioners [33, 34]. The complexity of healthcare, combined with the emotional stress of illness, exacerbates this vulnerability [35, 36]. A key aspect of healthcare is information asymmetry: patients depend on healthcare professionals' knowledge, skills, and competencies [18, 37, 38]. Such an imbalance in information and understanding per se creates vulnerability [39, 40]. In addition, there are specific groups of users who experience an increased vulnerability, for various reasons, including difficulties in making their voices heard [31]. One of these underrepresented groups comprises children and adolescents [41–43]. The experience of being hospitalised is a very delicate moment for children and adolescents [44]. Although children are one of the most fragile segments of the population and the hospitalisation experience can make them more vulnerable, hospitalised children usually do not have a chance to express an opinion about the care they received [42, 43]. Previous studies on paediatric patient participation in the healthcare setting usually focus on the caregiver's points of view [41, 45] as secondary users [46]. Children are rarely involved in consultations or decision-making in their care, even when paediatric patients express a desire for involvement they are often not supported, and parents are frequently asked to provide feedback about their experiences of the services their children have received [41]. In this sense, healthcare professionals and parents play a significant influence on whether children's efforts to participate are facilitated and supported in the hospital setting [41]. In recent years, the importance of asking primary users - children and adolescents - to provide information about their own experiences has been recognised and different approaches have increasingly been developed to enable them to do this [47]. Involving young people is crucial to engaging to foster inclusive and accountable systems and societies [48]. According to the Manual for Human Rights Education with Young People and to the article 12 of the UN Convention on the Rights of the Child, children have the right to express freely views on all matters affecting them, and their views should be given due weight [49, 50]. Europe has made significant efforts to strengthen this right of children to be heard, with several initiatives promoted. The Council of Europe has also released guidelines for child-friendly healthcare, emphasising the importance of considering

children's rights and needs, and facilitating their participation in decision-making. Despite these premises, there is limited published literature reporting the actual participation of children and adolescents in the evaluation of their care [41], generally with a wide scope of research and without considering the impact of these activities on the service, such as on improving quality of care [51, 52]. Lastly, an important aspect related to patient feedback is its implications for managerial practices based on these measures and data. Patient experience measures have been preferred to patient satisfaction metrics since more actionable and concrete. Despite their wide collection, researchers and practitioners are interested in improve an effective use of these measures to enhance service delivery [27, 53]. Transforming the patient voice on experience into patient-reported measures offers the advantage of integrating these insights into performance management systems, including benchmarking to compare experiences across providers, conditions, and care phases, making them versatile tools for assessing patient care in diverse subgroups and healthcare systems [19]. But some issues emerge when dealing with narratives, which are more difficult to adopt in the field of healthcare services' evaluation and improvement. Exploring effective ways to utilize patient-reported data to enhance hospital processes continues to be an important area of exploration [27].

To fill this gap, this research study aims to provide a systematisation of research on (i) whether there are specific feedback collection initiatives to directly engage children and adolescents, in providing their inputs for the evaluation and improvement of hospitalisation services; (ii) how organisations manage participation in terms of concrete methods and actual tools that have been implemented, and (iii) what quality and performance implications these initiatives have had on the service. It also aims to highlight gaps in the body of research and develop future research directions. As such, we conducted a systematic literature review (SLR) as it is a relevant method to address our research objectives [54].

## Methods

We conducted a systematic literature review (SLR) since it's a reliable, reproducible, and transparent scientific methodology [55]. The study adopts a systematic quantitative approach [56, 57] that combines qualitative and quantitative evaluation following a repeatable method in five steps: (1) determining review aims and research questions; (2) identifying search terms, databases, and selection criteria; (3) searching the databases and screening outcomes against the criteria; (4) appraising literature quality and relevance, structuring summary tables through the relevant information; (5) summarising and reporting findings and gaps. A previous scoping review

was conducted as a precursor to this study [58], to confirm the relevance of inclusion criteria and potential questions [59]. The scope of the research and the preliminary results were also discussed with practitioners from different healthcare organisations in Europe, as partners of the VoiCEs project [60]. In February 2022, we performed a search of articles from the following databases of peer-reviewed literature: Scopus, ISI Web of Science and PubMed. These sources together provide largely comprehensive coverage of the academic literature, with good coverage in English-language research, and are less biased than other sources [61]. We used the following search string, consisting of three distinct components, namely the broad object of the research (patients input such as feedback, suggestion, information about their experience with the service), the target of interest (vulnerable patients, more specifically paediatric patients including both children and teenagers up to 18 years old) and the specific type of service (ordinary admissions to hospitalisation):

*(“patient reported experience” OR “patient\* w/5 experience” OR “patient\* w/5 voice” OR “patient centeredness” OR “patient centeredness” OR “hospital experience” OR “child\* w/5 experience” OR “child\* w/5 voice” OR “experience\* of child” OR “child\* expectation” OR “child\* perspective”) AND (child\* OR adolescent\* OR teenager\* OR “pediatric care” OR “pediatric patient” OR “paediatric care” OR “paediatric patient”) AND (hospitaliz\* OR “ordinary admission” OR “hospital stay” OR “discharge from hospital” OR “child\* hospital” OR “pediatric hospital” OR “paediatric hospital” OR inpatient).*

The definition of the search algorithm is based on the previous scoping review, used to confirm the relevance of inclusion criteria and questions [58], and the definition of the most relevant synonyms as well. Also, the exclusion of the term “satisfaction” from the search algorithm was aimed at narrowing the focus of the search. The most important alternative terms were identified, including both versions in British and American English for the terms “paediatric patients” and “pediatric patients”, “paediatric care” and “pediatric care”. We adopted some limitations on the type and language of publication, namely only research articles, in English, while no time constraints were imposed, as we wanted to include all adopted tools without limiting the analysis to a specific period. Since this review focuses on initiatives and tools adopted for involving children and adolescents, the criteria adopted for quality assessment of papers were the relevance and quality of sources. We decided not to include published materials from academic conferences or working papers, since the peer-review process is widely accepted as a guarantee of the publications’ quality, and to maximise replicability. We assessed the relevance of sources to our topic by selecting only peer-reviewed

articles and applying inclusion and exclusion criteria to identify studies closely related to our area of interest. To evaluate the quality of these sources, we considered the type of peer-reviewed journals in which the research was published. While the credibility of findings can be influenced by the research methods employed—where greater emphasis is placed on results from specific research designs or larger sample sizes—we focused primarily on the tools used for data collection rather than the findings themselves. Therefore, our quality assessment was guided by the category of research strategy (qualitative, quantitative, mixed methods) and the type of methodology employed (empirical, theoretical, etc.). The inclusion and exclusion criteria relate to (i) ordinary admission as the setting of investigation; (ii) the focus of the analysis is specifically on patient experience (rather than satisfaction or outcomes. In this sense, these kinds of measures can be included if collected together with experience measures); (iii) the target group of investigation: children and/or adolescents (< = 18 years), and/or their caregivers (the studies focus exclusively on the paediatric patients’ experience of hospitalization reported either directly from the patients’ point of view or indirectly on behalf of their caregiver). If the articles did not focus on paediatric patients and their experience of hospitalization services, they were excluded. To evaluate the quality of the studies that met the inclusion criteria, we utilized the Mixed Methods Appraisal Tool (MMAT) [62]. Each study was evaluated according to the specific criteria outlined in the MMAT, designed for systematic reviews that include qualitative, quantitative and mixed methods studies. The assessment was based on a critical discussion of these criteria. Following that, a score was assigned based on the number of criteria met by each study: good for studies that addressed all elements, moderate for those meeting 3–4 elements, and poor for studies that met fewer than 3 elements. To guarantee transparency and replicability, we adhered to the “Preferred Reporting Items for Systematic Reviews and Meta-Analyses” (PRISMA) guidelines [63, 64]. At each phase, the screening of the papers was conducted by two researchers, who analysed the papers, and then compared the results. The selection process was conducted throughout three main phases. In the first phase, the screening related to titles, abstracts and keywords. After this screening, some papers fell into a grey area, since reading only titles and abstracts was not sufficient to check inclusion and exclusion criteria. Consequently, specific sections of these papers were examined in greater detail, such as introduction and discussion. The last phase was a screening of the full papers kept for the final review.

Each paper was entered into a database comprising the following information: (a) paper details (author/year), (b) journal title, (c) study location, (d) method and (e) key

findings. The analysis process began with the identification and coding of elements characterising the patient participation approach adopted in the context of the investigation. Therefore, we focused on the main elements of the approaches used by the different providers to involve children and adolescents in the evaluation of their hospitalization experience. In the following section we discussed our findings, which include (1) characteristics of patients targeted by the feedback collection initiatives, (2) ways of collecting paediatric patient feedback and suggestions, i.e., methods and tools implemented by healthcare providers in the feedback collection initiatives, (3) types of inputs that are requested from patients in the feedback collection initiatives, in terms of different dimensions of patient experience on which feedback and suggestions are requested, (4) co-design of the feedback collection initiatives, (5) quality and performance implications of the feedback collection initiatives. Also, research gaps and future research questions were highlighted in relation to this topic.

## Results

We extracted 1498 products from data banks. A total of 885 papers were excluded during the initial screening phase by reading titles and abstracts, because they did not meet the inclusion criteria, namely focus on (i) ordinary hospital admission, (ii) studying patient experience (not satisfaction or outcomes) (iii) for children and adolescents ( $\leq 18$  years) and/or their caregivers. 123 papers fell into a grey area, since it was not possible to apply inclusion and exclusion criteria by only reading titles and abstracts. After reading the full articles, 84 papers were excluded from this group. As a result, 116 articles underwent a full-text analysis in the final phase, obtaining 58 articles as the output of the search and screening process. The quality assessment of the 58 studies included in the final review resulted in 71% of studies as good, 15% as moderate, and 14% as poor. Figure 1 illustrates the output of the selection process and Table 1 provides a list of the papers included in the final review (see also the Appendix for more information and key findings about the studies included in the final review).

Over the last years, the number of studies on inpatient services' evaluation by paediatric patients increased, with 45 papers (78%) published since 2009. Studies have been conducted in Europe ( $n=28$ ), North America ( $n=19$ ), South America ( $n=1$ ), Asia ( $n=5$ ), Oceania ( $n=6$ ), with some studies conducted in more than one country. Thirty-three studies were conducted in English ( $n=33$ ), sixteen in other languages ( $n=16$ ), and nine in English and other languages ( $n=9$ ). This last category concerns articles published in English, but the studies were conducted in multiple languages available to participants. All papers analysed are empirical, and therefore report

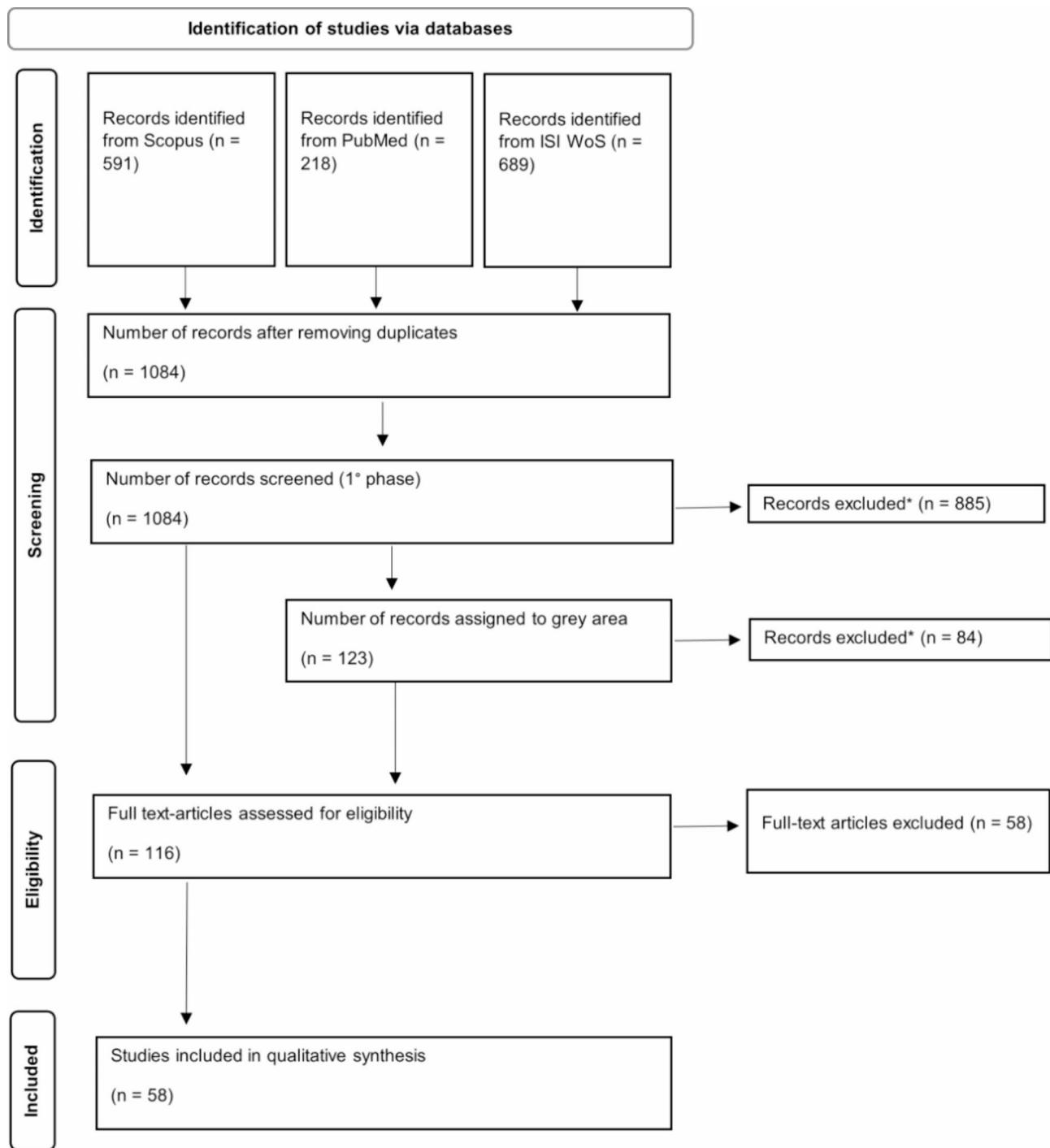
an actual collection of feedback from paediatric patients by healthcare professionals, following a hospitalisation experience. In terms of the subject area and category, we found that journals are mainly from Medicine and Nursing ( $n=54$ ), in particular Paediatrics, Perinatology and Child Health, and Health Policy. Two are from Social Science ( $n=2$ ), and two are both in Medicine and Social Science ( $n=2$ ). Appendix B includes graphs depicting the number of studies published annually, as well as data on the countries where these studies are conducted. Additionally, it presents frequency tables summarizing the results that will be discussed in the following sections.

### Characteristics of patients targeted by the feedback collection initiative

The studies mainly focused on young patients aged 7–12 years old ( $n=48$ ), and 13–18 years old adolescents ( $n=36$ ), while fewer service providers focused on very young paediatric patients, i.e., children under 6 ( $n=12$ ). In most cases, paediatric patients directly participated in the study ( $n=38$ ). However, in some cases, the feedback collection initiative encompasses the participation of caregivers together with the paediatric patients ( $n=17$ ), or they are exclusively targeted to caregivers, in particular to parents ( $n=3$ ), who are asked to report the hospitalisation experience on behalf of the paediatric patients. While attention to different age classes emerged within the target, no specific focus was found relating to children's disabilities, such as vision impairment.

### Methods and tools used in the patient feedback collection initiative

The results that emerged from this systematic literature review demonstrate that most of the feedback collection approaches on this topic used qualitative methods to directly involve children, adolescents and their families in the evaluation of services ( $n=42$ ), while less approaches are based on quantitative methods ( $n=16$ ). In the case of qualitative methods, patient feedback was primarily gathered through interviews ( $n=36$ ), which are predominantly semi-structured or conducted using some support materials (such as smile scales, images, or photos). For example, Przybylska and colleagues used activity books, videos, websites, photo books, storybooks, and a mobile device application to facilitate the direct engagement of children and adolescents during interviews [65]. Other qualitative methods frequently used by service providers in the analysed papers are art- and play-based activities ( $n=19$ ) and participant observations ( $n=15$ ). Art and play-based activities include a series of activities based on the collection of materials prepared by paediatric patients such as drawings, videos and/or photos [66–69]. Methods used to a lesser extent were focus groups ( $n=6$ ), blogs and diaries ( $n=2$ ), and information materials



**Fig. 1** PRISMA - Flowchart describing the literature search procedure

( $n = 1$ ). When healthcare organisations adopt quantitative methods for patient participation in service evaluation, questionnaires are used in surveys to collect feedback in the analysed papers ( $n = 16$ ). The results show that there are already validated questionnaires that hospitals can use to collect paediatric patient feedback on their hospitalisation experience. Some examples of these validated

questionnaires are those from the Picker Institute, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), the Child HCAHPS, and the measurement model for the Pediatric Quality of Life Inventory (PedsQL™), the Patient’s Nursing Care Perception Tool, the Scale of Degrees of Self Determination, the short version of the State-Trait Anxiety Inventory scale

**Table 1** Articles included in the SLR

Authors	Title	Journal	Year of publication
Alvarez E.N., et al.	Children's and parents' views on hospital contact isolation: A qualitative study to highlight children's perspectives	Clinical Child Psychology and Psychiatry	2020
Boyd J.R., Hunsberger M.	Chronically ill children coping with repeated hospitalizations: their perceptions and suggested interventions.	Journal of pediatric nursing	1998
Boztepe H., et al.	School-age children's perception of the hospital experience	Journal of Child Health Care	2017
Bray L., et al.	The information needs of children having clinical procedures in hospital: Will it hurt? Will I feel scared? What can I do to stay calm?	Child: Care, Health and Development	2019
Breitwieser, CL; Vaughn, LM	A Day in My life Photography Project: The Silent Voice of Pediatric Bone Marrow Transplant Patients	Journal Of Pediatric Oncology Nursing	2014
Carvalho E.O., et al.	Children's experience on hospitalization: Sociology of childhood approach	Cogitare Enfermagem	2020
Chitra P., Jeenu K.M.	Perspectives of strange environmental stressors among hospitalized children at AIMS, Kochi	Indian Journal of Public Health Research and Development	2016
Clarke S.	An Exploration of the Child's Experience of Staying in Hospital from the Perspectives of Children and Children's Nurses using Child-Centered Methodology	Comprehensive Child and Adolescent Nursing	2022
Cofer D.H., Nir Y.	Theme focused group therapy on a pediatric ward	Psychiatry in Medicine	1975
Corazza I., et al.	Benchmarking experience to improve paediatric healthcare: listening to the voices of families from two European Children's University Hospitals	BMC Health Services Research	2021
Curtis P., Northcott A.	The impact of single and shared rooms on family-centred care in children's hospitals	Journal of Clinical Nursing	2017
Dolidze K., et al.	A model of child life intervention to facilitate effective coping in a child hospitalized for heart surgery	Clinical Practice	2013
Ebrahimpour F., et al.	Symbols of Hope on Pediatric Oncology Ward: Children's Perspective Using Photovoice	Journal of Pediatric Oncology Nursing	2021
Ekra E.M.R., Gjengedal E.	Being hospitalized with a newly diagnosed chronic illness-A phenomenological study of children's lifeworld in the hospital	International Journal of Qualitative Studies on Health and Well-being	2012
Fletcher T., et al.	Building the future: Children's views on nurses and hospital care	British Journal of Nursing	2011
Forner D., et al.	Turn analysis and patient-centredness in paediatric otolaryngology surgical consultations	Clinical Otolaryngology	2020
Foster M., Whitehead L.	Using drawings to understand the child's experience of child-centred care on admission to a paediatric high dependency unit	Journal of Child Health Care	2019
Grossoehme D.H., Gerbetz L.	Adolescent perceptions of meaningfulness of psychiatric hospitalization	Clinical Child Psychology and Psychiatry	2004
Gusella J.L., et al.	The Experience of Hospitalized Adolescents: How Well Do We Meet Their Developmental Needs?	Children's Health Care	1998
Haldar S., et al.	Use and impact of an online community for hospital patients	Journal of the American Medical Informatics Association	2020
Harrison, A	Comparing Nurses and Patients Pain Evaluations - A Study of Hospitalized-Patients in Kuwait	Social Science & Medicine	1993
Hsiao J.L., et al.	Parent and child perspectives on physician communication in pediatric palliative care	Palliative and Supportive Care	2007
Hutton A., et al.	Comfort Equals Nurturing: Young People Talk About Mental Health Ward Design	Health Environments Research and Design Journal	2021
Karisalmi N., et al.	Measuring patient experiences in a Children's hospital with a medical clowning intervention: A case-control study	BMC Health Services Research	2020
Kortesluoma R-L., Nikkonen M.	'I had this horrible pain': The sources and causes of pain experiences in 4- to 11-year-old hospitalized children	Journal of Child Health Care	2004
Lambert V., et al.	Social spaces for young children in hospital	Child: Care, Health and Development	2014
Lambert V., et al.	Young children's perspectives of ideal physical design features for hospital-built environments	Journal of Child Health Care	2014
Lambert V., et al.	Meeting the information needs of children in hospital	Journal of Child Health Care	2013

**Table 1** (continued)

Authors	Title	Journal	Year of publication
Lambert V., et al.	Visible-ness': The nature of communication for children admitted to a specialist children's hospital in the Republic of Ireland	Journal of Clinical Nursing	2008
McDonnell L.	Music Therapy: Meeting the Psychosocial Needs of Hospitalized Children	Children's Health Care	1983
Moore D.E., et al.	What do children think about doctors' communication at the Teddy Bear Hospital?	Journal of Paediatrics and Child Health	2022
Muskat B., et al.	Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals	Autism	2015
Nilsson, S; et al.	Children's Perceptions of Pictures Intended to Measure Anxiety During Hospitalization	Journal Of Pediatric Nursing- Nursing Care of Children & Families	2019
Nourmusavi Nasab S., et al.	Ideal physical features of environmental design in children's hospital: Using children's perspectives	Facilities	2020
Öjmyr-Joelsson M et al.	Children with high and intermediate imperforate anus: Their experiences of hospital care	Pediatric Surgery International	2011
Pelčić G., et al.	Croatian children's views towards importance of health care information	Collegium Antropologicum	2012
Peña A.L.N., Cibanal Juan L.	The experience of hospitalized children regarding their interactions with nursing professionals [A experiência de crianças hospitalizadas sobre sua interação com os profissionais de enfermagem]	Revista Latino-Americana de Enfermagem	2011
Perry S.E.	Teaching Tools Made by Peers: A Novel Approach to Medical Preparation	Children's Health Care	1986
Petronio-Coia B.J., Schwartz-Barcott D.	A description of approachable nurses: An exploratory study, the voice of the hospitalized child	Journal of Pediatric Nursing	2020
Plummer, K; et al.	Experiences of Pain in Hospitalized Children During Hematopoietic Stem Cell Transplantation Therapy	Qualitative Health Research	2021
Przybylska M.A., et al.	Delivery of the UN Convention on the Rights of the Child in an acute paediatric setting: An audit of information available and service gap analysis	BMJ Paediatrics Open	2019
Quaye A.A., et al.	How are children's best interests expressed during their hospital visit?—An observational study	Journal of Clinical Nursing	2021
Quaye A.A., et al.	Children's active participation in decision-making processes during hospitalisation: An observational study	Journal of Clinical Nursing	2019
Rao-Gupta S., et al.	Leveraging Interactive Patient Care Technology to Improve Pain Management Engagement	Pain Management Nursing	2018
Rasmussen S., et al.	Children's perspectives in family-centred hospital care	Contemporary Nurse	2017
Rindstedt C.	Conversational openings and multiparty disambiguations in doctors' encounters with young patients (and their parents)	Text and Talk	2014
Romero R.	Autobiographical scrapbooks: A coping tool for hospitalized school children	Issues in Comprehensive Pediatric Nursing	1986
Salamone-Violi, GML; et al.	In this day and age why is it still so hard to find the right type of help? Carers' perspectives regarding child and adolescent mental health services: a qualitative study	Advances In Mental Health	2017
Savedra M.C., Highley B.L.	Photography. Is it useful in learning how adolescents view hospitalization?	Journal of Adolescent Health Care	1988
Schalkers I., et al.	'[I would like] a place to be alone, other than the toilet' - Children's perspectives on paediatric hospital care in the Netherlands	Health Expectations	2015
Stickland A., et al.	A qualitative study of sleep quality in children and their resident parents when in hospital	Archives of Disease in Childhood	2016
Toomey, SL; et al.	The Development of a Pediatric Inpatient Experience of Care Measure: Child HCAHPS (R)	PEDIATRICS	2015
Uhl T., et al.	Insights into Patient and Family-Centered Care Through the Hospital Experiences of Parents	-Journal of Obstetric, Gynecologic, and Neonatal Nursing	2013
van Ommen, J; et al.	Effective nursing care of adolescents diagnosed with anorexia nervosa: the patients' perspective	Journal Of Clinical Nursing	2009
Vejsovic, V; et al.	Children still experience pain during hospital stay: a cross-sectional study from four countries in Europe	Bmc Pediatrics	2020

**Table 1** (continued)

Authors	Title	Journal	Year of publication
Wallström R, et al.	'Don't abandon me': Young people's experiences of child and adolescent psychiatric inpatient care supporting recovery described in blogs	International Journal of Mental Health Nursing	2021
Woodgate, R; Kristjanson, LJ	'My hurts': Hospitalized young children's perceptions of acute pain	Qualitative Health Research	1996
Wray J, et al.	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	2018

(S-STAI), the Sources of Anxiety Generating Thoughts Scale (SAGTS) questionnaire, the Visual Analog Scale (VAS), and the Shared Decision-Making Questionnaire (the SDM-Q-9). Some service providers directly used the original questionnaires, or developed questionnaires based on those, such as Corazza and colleagues [70]. Other scholars used short versions of the validated tools, such as Bastemeijer and colleagues [71]. However, just a few of these questionnaires were designed in a child-friendly way. For instance, Wray and colleagues diversified questionnaire layouts for patients of different age classes, more specifically with images of animals for children and cartoons for adolescents [47]. Some hospitals adopted mixed techniques to collect paediatric feedback ( $n=7$ ), for example questionnaires with open questions to give paediatric patients the possibility to provide more insights about their experience [47]. Therefore, results highlight higher standardisation when quantitative methods rather than qualitative ones were used for the feedback collection initiatives by service providers.

Around half of the service providers adopted more than one method (qualitative and/or quantitative) in the same initiative. Most of them used two methods, such as interviews and participant observations ( $n=9$ ), and interviews and art- and play-based activities ( $n=14$ ). Eight studies used more than two tools, and five of these adopted interviews, participant observation, and art- and play-based activities. For example, in the study of Foster & Whitehead, children were asked to draw a picture of a person in the hospital, which was further explored through interviews [72]. In the study of Lambert and colleagues, data were collected using semi-participant observations, informal interviews, and activities such as drawing, writing, and stick-a-star quizzes [73]. This indicates that art- and play-based activities have typically been used in conjunction with other methods. They were utilized as the exclusive method of feedback collection in only one study. Specifically, in the study of Breitwieser & Vaughn patients were provided with a basic digital camera for a photovoice project. For 24 h, they were encouraged to take pictures of anything making their day and document thoughts about each photo in a journal [66]. In all the other studies, these activities were accompanied by alternative methods.

Results show that different modes of administration can be used with both qualitative and quantitative methods. Most of the studies used traditional modes of administration, such as face-to-face interviews ( $n=36$ ), live observations ( $n=14$ ), creative production, e.g., diaries, images, photos, and drawings ( $n=18$ ), questionnaires in a paper format ( $n=10$ ) or via phone ( $n=3$ ). A few cases of electronic and digital modes of administration of tools for feedback collection emerged ( $n=7$ ), such as interviews or questionnaires via SMS, APPs, e-mail, or web platforms. The most innovative methods of feedback collection involve the use of mobile applications for questionnaires with some child-friendly elements, such as different types of talking cartoon characters [74].

Patient feedback can be collected at different moments of the service provision. In the papers analysed in this review, feedback was mainly collected during hospitalisation ( $n=45$ ), or after ( $n=13$ ). Only in three articles the initiative of feedback collection was implemented before hospitalisation, and this happened when the service providers focused on (i) what children think about admission to hospitals [65, 68], and (ii) paediatric surgical consultations, which encompass complex interactions and decision-making processes involving family members with healthcare providers [75]. Two of these studies were conducted both before and during hospitalization, and only one was conducted before hospitalization, specifically focusing on the consultations that occur before an intervention. In some studies, paediatric patients were involved in more than one phase of the service provision ( $n=8$ ), usually during and after hospitalisation ( $n=6$ ). Five articles did not mention the administration time.

#### Dimensions of patient experience on which feedback is requested in the initiative

The analysis of the papers revealed that service providers asked for feedback and suggestions on various dimensions of the patient experience in their initiative about the hospital stay evaluation. The dimensions are reported based on the frequency with which they were cited by the papers. Most of the service providers required the participation of children and adolescents to evaluate aspects related to tangible aspects of the hospitalisation service, such as the quality of facilities and care services, comfort, and appearance ( $n=26$ ). This included

also specific aspects of the experience that catered to the environmental needs of children and adolescents, such as distractions, the presence of toys, an age-appropriate environment, the presence of other children, and pain management. The second most mentioned dimension on which feedback from paediatric patients was collected was that relating to the understanding of health information, understanding of the intervention, and explanation of what would happen and how it would feel ( $n=24$ ). In around one-third of the papers, children and adolescents were also asked to evaluate the emotional support provided by healthcare professionals ( $n=19$ ). This aspect of the patient experience was explored by asking paediatric patients feedback about fears and anxiety, experienced stress or burden due to illness, attitude towards the illness (such as confidence in recovery), factors creating hope, for example for oncologic children, and coping with the upcoming medical procedures. This dimension also included questions about staff attitude, friendliness, and courtesy of the staff. Another dimension on which patient feedback was requested in around one-third of the papers related to patient involvement and included questions about control and autonomy, freedom of choice, and trust ( $n=17$ ). Similarly, the aspect relating to the involvement of caregivers, family and friends during the service was also frequently investigated ( $n=15$ ). Two other dimensions were frequently investigated by the studies included in the review, although in less than one fifth of the papers, and related to technical aspects and overall evaluation of the experience. The first one included feedback about the care from nurses, care from doctors, teamwork, specific treatments, perception of the intervention, procedures and activities, such as psychotherapy sessions or family sessions ( $n=11$ ). The second one was about collecting feedback on satisfaction, willingness to recommend the hospital, best and worst things about the hospital stay, and suggestions for improvement ( $n=11$ ). The aspects of the experience evaluated in the feedback collection initiative that were less analysed by the articles included in the review related to accessibility and barriers to admission ( $n=5$ ), and the phase of leaving the hospital and going back home ( $n=5$ ).

#### **Co-design of the feedback collection initiative**

In fifteen per cent of cases the involvement of patients also occurs or has occurred in the design phase of the initiative of children and adolescents feedback collection ( $n=7$ ) [47, 65, 66, 74, 76–79]. Indeed, in most cases, paediatric patients and/or their caregivers were engaged to develop a tool for collecting feedback ( $n=4$ ) or the service providers used a tool previously designed with patients ( $n=3$ ). Most of the studies analysed directly engage patients in this kind of activities, while only two service providers involved caregivers [65, 79].

#### **Quality and performance implication of the feedback collection initiative**

The final category of analysis focuses on whether the articles offer insights into how the feedback was utilized, particularly regarding the changes that service providers implemented. Most studies only mention future and potential use of the feedback collected ( $n=38$ ) since service providers do not report actual performance implications but discuss potential and future developments and impacts. These studies primarily focus on proposing future quality improvement actions based on feedback, emphasize the use of feedback to develop child-friendly language, enhance communication among professionals, improve pain management, optimize the sleep environment, and guide training activities for healthcare professionals, particularly in the area of communication skills.

More than one-third of the studies analysed in the review clearly specified that paediatric patients' feedback was used to achieve specific goals ( $n=20$ ). In this case, most of the studies used patient feedback for the assessment of an intervention or program ( $n=9$ ). For example, the study by Hutton and colleagues, the patient feedback collection initiative was part of a larger hospital redesign consultation, aimed at improving children's emotional responses to the space [80]. Curtis & Northcott (2017) used feedback to evaluate the creation of single or shared rooms for paediatric patients [81]. Cofer & Nil (1975) used data to evaluate the effectiveness of theme-focused group sessions, while McDonnell (1983) evaluated an intervention based on music therapy, for improving children's fear expression and management [82, 83]. Kari-salmi et al. (2020) discussed the positive evaluation of a clown intervention [84]. In the other studies analysed, service providers mainly used feedback collected from patients for the development of a new tool for patient participation ( $n=5$ ). Few papers mentioned that the initiative of feedback collection was aimed at informing service improvement actions ( $n=3$ ). These quality improvement actions can be related to the different aspects of the patient experience on which feedback is collected. For example, service providers focused on how to improve different aspects of patient and family-centred care [85], or on how to improve important aspects of paediatric patients' health, such as the ability to sleep well and nutrition adapted to children's preferences [69]. Only one article of those included in the review focused on benchmarking and reporting of quality evaluation reported by patients ( $n=1$ ). Another one focused on the development of a new theoretical framework/model based on the feedback of patients ( $n=1$ ). One paper mentioned the use of the results of the initiative for the training of professionals, namely the development of a new children's nursing programme curriculum, and service development for a new children's hospital ( $n=1$ ).

**Table 2** Agenda for future research

Agenda for future research	
Target of patients	- How can we improve the inclusion of younger children under the age of 6 and children with different abilities in patient-reported experience measures collection initiatives? - How can tools like interviews, questionnaires, and apps be more inclusive for patients with physical and/or intellectual disabilities?
Co-design	- How can we increase early engagement of children and adolescents in the design phase of patient-reported experience measures initiatives? - Can involving pediatric patients in the design of patient-reported experience measures initiatives increase participation rates and effectiveness?
Dimensions of patient experience	- How can future research involve children and adolescents directly in focus groups or Delphi processes to understand the relevance of the different dimensions of patient experience and prioritise them?
Method and tools	- What is the effectiveness of gamified applications in engaging children and adolescents in health service evaluation feedback collection initiatives? - What are the most effective mechanisms combining qualitative and quantitative methods? - What are the differences between child-friendly and adolescent-friendly gamified approaches?
Quality improvement / use of feedback	- How can business intelligence and analytics tools enhance the uptake of managerial decisions based on feedback from vulnerable patients at various organisational levels?

It is worth pointing out that just one article reported that the service provider involved patients also in discussing the results and co-producing quality and performance improvement actions based on the results of the initiative [66].

## Discussion

This SLR aimed at extrapolating an overview of approaches used by healthcare organisations to involve children and adolescents in the evaluation of their hospitalisation experience, considered as a group of patients experiencing vulnerabilities. There has been an increasing interest in more inclusive, accountable and transparent healthcare for children and adolescents all over the world, especially from 2016 onwards. In general, publications come mainly from high-income countries. Some experiences were registered in lower-middle-income (e.g., India) and upper-middle-income countries (e.g., Turkey). No specific patterns were found by analysing results for countries or geographical areas.

The study's results can be discussed and interpreted considering the extensive existing literature. Furthermore, these findings can serve as a foundation for suggesting potential avenues for future research and developments in this topic (see Table 2). The results on the characteristics of the patients involved in the feedback collection initiatives highlighted a growing interest

in directly engaging children and adolescents in evaluating their experience with hospitalisation services. Nevertheless, there are service providers still involving caregivers instead of actual patients in their initiatives. Moreover, data on age classes demonstrate that an even more vulnerable group of patients, i.e., children under 6 are still less likely to participate directly in service evaluation activities. In this sense, still few studies are focused on the participation of the youngest patients and those with different abilities, who may experience greater vulnerability. In interpreting these results, it is essential to consider younger patients' developmental stages and cognitive abilities. Children's capacity to provide reliable feedback on their experiences may evolve as they grow. Younger children may lack the necessary cognitive and communicative skills to articulate their thoughts and feelings effectively, which may hinder their ability to participate meaningfully in feedback initiatives. Indeed, the first five years represent a critical period for development, during which children experience rapid language acquisition driven by heightened neural plasticity in the brain; during this time children's language abilities are shaped by a combination of genetic and environmental influences [86, 87]. By the age of four, language development becomes more stable, serving as a strong predictor of language abilities in adolescence [88]. However, there are some studies suggesting that children, even at younger ages, might be able to comprehend and give feedback on complex issues such as health risks and money value and use [89–92]. The important aspect to be considered is the way in which the issues are presented. As reported by Guerriero and colleagues in their different studies [93, 94], tools for collecting children feedback should be designed for them, pre-tested, discussed and revised to enhance understanding, to refine the wording, to calibrate the tool according with age and abilities, to facilitate the participation. They demonstrated, for example, that under 10-year-old children can take rational decisions when they are asked to value their own health [93, 94]. Children's participation is also influenced by the perspectives and skills of individual practitioners but also by their ability to facilitate meaningful engagement within the constraints of limited time and the complexities of their practice environments [95]. In this sense, to promote consistent and meaningful participation, it is essential to implement systemic changes that address time constraints, provide training for practitioners to understand and apply participatory practices, and actively seek children's input in service design [95]. As younger children may not fully understand the questions posed to them when asked to evaluate something or may struggle to communicate their feelings accurately, their feedback may not reflect their true experiences, leading to potential misunderstandings in service

delivery. digital technologies like facial recognition for capturing expressions and sentiments, along with gamification for adapting tools and instruments, should be explored to enhance the ability to capture the experiences of very young patients. There are existing studies on these technologies in other contexts [96–100], which should be explored in this specific setting and with this target population, following appropriate ethical considerations. Given these limitations, it is often necessary to rely on proxies, such as parents or caregivers, to gather feedback about younger children's experiences. Proxies can provide valuable insights into the child's needs and preferences, though this approach may also introduce biases based on the proxy's perceptions [101, 102]. Indeed, relying on proxy informants can lead to less accurate information [103]. The context and level of observability can contribute to uncertainty about the quality of the information obtained. Additionally, researchers often find inconsistencies in the reports provided by different informants; the correspondence among the information reported by various sources tends to be low to moderate [101, 103]. This SLR highlights a germinal and promising attention towards co-design of the feedback collection initiatives in this specific context, starting from 2011 and with an increase in the last ten years. However, patient participation is a context-dependent phenomenon, and different aspects can affect the willingness of patients to be engaged (e.g., ease of tasks to be performed, service salience) [104]. The direct involvement of people in these processes can have different positive impacts. It can not only create value by understanding and addressing their needs, but also by collaboratively developing the most effective tools for capturing their experiences. Additionally, a participatory process can empower participants [105]. Empowerment fosters autonomy by enhancing skills and competencies, offering opportunities for participation, and facilitating the creation of a network [106]. Adopting a participatory research design in this context means viewing collaboration not only to co-create tools for capturing and amplifying the voices of paediatric patients, but also as an integral part of the research objectives. This approach enables participants to work alongside professionals, researchers, and experts in a collaborative manner, fostering empowerment and shared ownership of the process. Future studies could investigate how to increase early engagement of children and adolescents in these processes and whether engaging patients in the design of the initiative can increase the propensity of participation and its effectiveness.

Furthermore, when addressing the needs of children with disabilities, especially those with intellectual disabilities, it is crucial to implement appropriate methodologies and strategies to promote inclusivity and facilitate effective communication. PREMs are rarely utilized for

this group due to the lack of suitable data collection tools and methods [107, 108]. Since there is a growing interest in involving specific groups of disadvantaged people in already vulnerable groups [43], this is certainly a topic that needs to be further addressed in future studies, considering how the tools used to engage paediatric patients in initiatives regarding collecting feedback can be more inclusive and involve patients with physical or mental difficulties. The research agenda on this topic can address these key issues, such as how to better involve younger children, under the age of 6, and how to involve children with different abilities.

The results of this SLR show that the experience of children and adolescents with hospital stay is multi-dimensional. In the literature, various aspects of the patient experience are considered fundamental measures of patient-centredness in healthcare, including different adult care services [1, 7, 12, 24, 109]. These aspects include access to care, informative support, patient involvement, coordination and teamwork, the comfort of the environment, pain management, emotional support, and satisfaction. The Picker Institute (2020) developed the patient-centeredness framework, which includes eight principles: access to care; respect; coordination and integration of care; information, communication, and education; physical comfort; emotional support; involvement of family and friends; and transition and continuity [109]. Ambresin and colleagues highlighted the importance of eight domains as central to adolescents' positive experience of care, namely accessibility to care, staff attitude, communication, medical competency, guideline-driven care, age-appropriate environments, youth involvement in care, and outcomes, including pain management [51]. Regardless of the different frameworks and categorisations found in the literature, all these dimensions have emerged from the analysis, highlighting the usefulness of collecting feedback on paediatric patients' experiences to evaluate the extent to which services are truly centred on children's and adolescents' needs values and preferences. Therefore, this SLR extends previous results that regarded adults or adolescents only to all paediatric patients in general, confirming their validity in relation to the hospital setting. Since healthcare services are intensive in relational aspects [110], emotional support and involvement could be expected to be the most considered dimensions of experience in the initiatives of feedback collection. However, even though all the dimensions of the experience were found in our analysis, when collecting feedback from children and adolescents, most studies focused on environmental and social needs, and the provision of health information. Future studies can directly involve children and adolescents in focus groups or Delphi processes to understand the relevance of the different dimensions and prioritise them.

For what concerns methods and tools used in the feedback collection initiatives, previous studies on different patient participation approaches in the management literature offer very little actionable knowledge or instruments for practitioners. Scholars call for greater efforts to translate theoretical concepts into concrete methods and actual tools that management staff can implement [111]. This SLR shows that both quantitative and qualitative methods are used with a prevalence of the first one. Both methods can have positive and negative aspects. From our results, qualitative methods such as interviews and play-and-art activities appear to be easier to adapt to paediatric patient abilities, characteristics and preferences. Consequently, qualitative methods are more suitable to directly involve vulnerable patients such as children and adolescents. In medical and health science research, qualitative research is often seen as complementary to quantitative methods, helping refine interventions, select outcome measures, and explain varied results. In the social sciences, however, qualitative research is considered an equal alternative to quantitative approaches, offering its own distinct contribution to knowledge [112]. Quantitative methodologies can be easily standardised, allowing for benchmarking, quality improvement actions, and moving from stand-alone approaches to systematic patient involvement in these types of activities [12, 45]. However, other studies in the literature demonstrate that standardised tools such as questionnaires are hardly targeted to children and adolescents and mostly directed to caregivers, even when the focus of the investigation is the paediatric experience [45]. In this sense, the results of this study highlight the value of incorporating child-friendly activities like drawing and game-based activities alongside more conventional feedback collection methods, such as interviews and questionnaires. Future studies could analyse whether the combination of different qualitative and quantitative methods could increase the direct participation of children and adolescents also allowing for standardisation and systematic collection of feedback collection initiatives. In relation to the mode of administration of the tools, it is worth noting that most studies were conducted in a traditional way, such as face-to-face interviews, with only a few examples of electronic data collection methods, e.g., via email, mobile devices or tablets. Electronic collection occurred especially in the case of questionnaires. The most innovative way of collecting feedback involved the use of mobile or web applications for administering child-friendly tools. Electronic data collection tools can facilitate the use of feedback collection results for implementing quality improvement actions in paediatric care services [45]. Digital and innovative tools can be useful to combine the advantages offered by both quantitative and qualitative methods, as mentioned above. Future research could

focus on the possibility of applying digital and innovative techniques in the initiative of collecting feedback from children and adolescents. In this context, gamification has been increasingly applied in several non-gaming contexts to create a connection with consumers [113–116]. The existing literature primarily focuses on the domains of education, learning, crowdsourcing, and health, with some recent applications of gamification in the tourism and hospitality industry [113]. In healthcare, there are examples of gamified health apps that use gamified techniques, for example for self-care or for promoting mental health [117–119]. The literature explored gamification in relation to opportunities, such as patient engagement, and active participation, and risks, for instance privacy concerns and the balance between personalisation and standardisation [117, 118]. Future research should delve into the effectiveness of gamified applications in involving children and adolescents in feedback collection initiatives of health service evaluation, exploring differences between child-friendly and adolescent-friendly approaches, and effective mechanisms combining qualitative and quantitative methods.

Another crucial theme relates to the quality and performance implications of the feedback collection initiatives. Asking for feedback about service experience is fundamental to produce implications such as assessing service quality and identifying areas for improvement, problems, or good practices [120, 121]. In healthcare, collecting inputs about the patient experience can produce key results, such as meeting patients' needs, values and preferences, and improving performance and outcomes, such as reducing hospital readmissions [6], innovating and co-producing [12, 18, 122], creating value along the healthcare journey [123], and determining the person-centeredness of the systems [6]. Nevertheless, according to Mustak et al. (2016) the connection between patient inputs and outcomes is not yet fully understood in the feedback collection initiatives [111]. They suggested the need for further research to uncover how different management approaches can impact patient participation outcomes, making the findings actionable for managers. This is indeed an important focus of this SLR, which highlights that most of the studies address the quality and performance implications of the initiatives as a potential future development. In many feedback collection initiatives analysed in this study, the real impact is not clear. Even when reported by the papers analysed, the impact of the initiatives does not directly encompass actions of quality improvement, even potential ones, but rather an assessment of an intervention or program that may or may not result in transformative actions. Sustained progress in the future will depend on stakeholder engagement and participation becoming a routine part of the culture of healthcare at all levels, from the micro-level

of individual consultations between patients and professionals, to the meso-level of quality improvement and service development, to the macro-level of regional or national policy development [18, 124].

For the sake of quality improvement, it would be essential to collect and employ feedback collected in the initiative on a regular basis [12, 45, 125]. Systematic, frequent or continuous data collection are key aspects for enhancing the uptake of the patient perspective in data-driven managerial decisions [12, 126, 127]. This is the case of Corazza and colleagues, reporting also results on web platforms in real-time to support children-driven improvements, by transforming data into knowledge and by making this latter available from the 'micro' to the 'macro' levels of the systems [19, 70, 128]. However, the studies in this SLR mainly reported sporadic experiences of paediatric patient involvement and did not include systematic initiatives. This can be explained by the fact that service providers mainly use qualitative and traditional methods to engage children and adolescents in providing feedback, which can be made standardised and/or systematic with difficulties. The results of this SLR highlight a lack of evidence on the benchmarking of paediatric feedback collection results. Benchmarking and public reporting of patient feedback are key levers for the initiative results uptake into policies and practices, since they lead to better performance in healthcare [129, 130]. Future research can study how business intelligence and analytics, with specific patient feedback reporting and visualisation tools, could improve the uptake of managerial decisions based also on vulnerable patients' feedback at the meso and macro levels. This is important considering that macro-level impact of initiative results is still quite rare in healthcare, despite may stimulate micro-level actions [131].

#### Limitations and strengths

Notwithstanding its various contributions, this review study has some limitations. Systematic literature reviews are less suited for social science than for other fields. Assessing data quality and reaching 'objective' conclusions align more seamlessly with quantitative data derived from research designs like experiments and randomised controlled trials. Systematic literature reviews rely on published research, excluding findings that have not been publicly disclosed [112]. In addition, the analysis and findings of this review cannot be generalised to all children and adolescents' participation in service evaluation literature because the current SLR used specific inclusion and exclusion criteria to select the available articles and analysed only those that met these criteria. The analysis focused on published articles from scholarly sources, excluding conference papers or working papers. This SLR focused only on those papers published in

English. As a result, some studies relevant to this domain that are published in other languages might have been excluded. Future research could enhance this analysis by incorporating grey literature, papers from conference proceedings, and working papers, as well as utilizing additional databases such as CINAHL and Medline. The search focuses on patient experience, so, as the term satisfaction was not included in the search string, articles that focus exclusively on collecting satisfaction measures are not included, while those that encompass both satisfaction and experience were included into the analysis. In this sense, studies that used the terms satisfaction and experience as interchangeably into their abstract were included, despite this is not correct. We are aware that this initial choice determined the potential exclusion of papers that were only aimed at capturing satisfaction, since part of the research design. Nevertheless, the use of robust and well-known data sources makes it possible to replicate the queries, which is essential for any SLR. In future, the search algorithm extension could increase the inclusion of additional studies within the managerial and organisational field, for example by including keywords like "consumer" or "user" instead of "patient". Furthermore, the study can be extended to other types of users experimenting with vulnerabilities or disparities in healthcare or other contexts.

#### Conclusions

This SLR frames the current state of knowledge on research about children and adolescents' participation in initiatives of feedback collection in the hospitalisation setting. The results of this SLR offer valuable and practical implications regarding strategies that service providers can adopt to actively involve vulnerable consumers in assessing healthcare services. It also provides an agenda as a basis for planning future research in this area. Among the key points that emerged from this SLR, the state of evidence shows that initiatives are still scarcely focused on very young children, and paediatric patients with different abilities. To directly involve paediatric patients in feedback collection initiatives, tools should be adapted to the characteristics, abilities, and preferences of patients. At the same time, standardised and systematic approaches emerged as a warranty of the uptake of the patient's participation results into the practice. Future research should investigate the advantages of combining qualitative and quantitative methods, as well as innovative, gamified, and digital solutions for encouraging active participation and enhancing impact on outcomes. This latter is one of the aspects that emerged as more critical. To make the initiative results more actionable for practitioners and managers, the quality and performance implications of these initiatives should be further investigated to understand the actual effects of the feedback

collection initiative in terms of performance evaluation and benchmarking, and quality improvement actions. These results' value lies in their contribution to establishing vulnerable patient engagement and participation as integral components of healthcare culture at all levels.

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-025-12486-2>.

Supplementary Material 1.

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### Authors' contributions

All authors conceptualised the study. VS and IC were responsible for performing the review, by taking care of the methodology, formal analysis, data curation and visualisation of results. VS wrote the original draft, with a contribution from IC with regards to the methods and results sections and SDR with regards to the introduction and discussion sections of the article. All authors reviewed and made minor edits to the article. SDR and MB are project administrators and acquired funding for this research, namely the VoICeS Project, co-funded by the European Union's Rights, Equality and Citizenship Programme (2014–2020) (REC-RCHI-PROF-AG-2020). The content of this study represents only the views of the authors, and it is their sole responsibility, therefore the authors declare no conflict of interest.

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### Data availability

Further data and information are provided in the Appendix, as supplementary material.

### Declarations

#### Ethics approval and consent to participate

Not applicable.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare no competing interests.

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