

PAEDIATRIC NEED ASSESSMENT FRAMEWORK 2026



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An overview of all declarations of interests is available in Supplement 1 of this report.

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
EQ-5D-5L	EuroQol 5 dimensions 5 levels
EQ-5D-Y-5L	EuroQol 5 dimensions Youth 5 levels
EQ-TIPS	EuroQol Toddler and Infant Populations
HCP	Healthcare provider
HRQoL	Health-related Quality of Life
HTA	Health technology assessment
KCE	Belgian Health Care Knowledge Centre
MeSH	Medical Subject Headings
NEED	Needs Examination, Evaluation and Dissemination
OECD	Organisation for Economic Co-operation and Development
PICU	Pediatric Intensive Care Unit
QALY	Quality-Adjusted Life Year
YLDs	Years Lived with Disability
YLLs	Years of Life Lost
yrs	years



■ SCIENTIFIC REPORT

1 INTRODUCTION

KEY POINTS

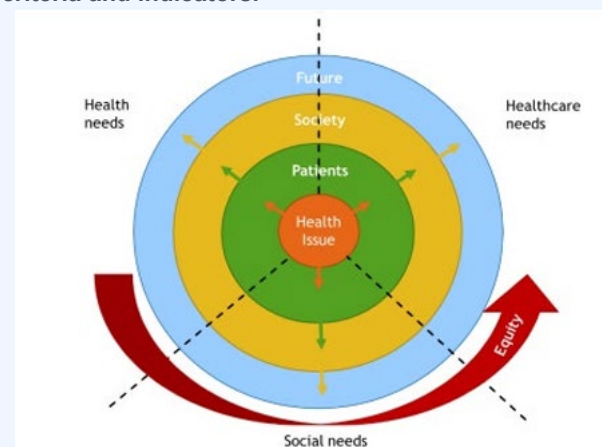
- The NEED initiative promotes a needs-driven approach to healthcare innovation by identifying and measuring patients' and societal unmet health-related needs independently of potential solutions.
- Children remain under-represented in clinical research, contributing to important evidence gaps, clinical uncertainty and persistent unmet therapeutic needs in paediatric populations.
- Unmet health-related needs in children are shaped by biological and developmental stages, family circumstances and age-specific healthcare needs.
- A dedicated paediatric NEED framework is needed to capture paediatric and age-related specificities while maintaining conceptual and methodological consistency with the adult NEED framework.

Innovation in healthcare is driven by multiple factors. While scientific knowledge about diseases remains central, commercial profitability is also a major driver of innovation, particularly for private for-profit actors. As a result, research and development tends to concentrate in areas with higher expected returns on investment, rather than on health problems associated with substantial unmet needs but limited market attractiveness. In order to move away from a more supply-driven innovation system, based on financial attractiveness, the NEED initiative pleads for creating a more needs-driven approach, by measuring and evaluating the unmet health-related needs in different disease areas and stimulating innovation in those areas with the highest or most important unmet needs. Patient and societal needs, as defined in the NEED framework¹⁻³ (see Box 1), are independent of potential future products or treatments. Unmet needs must first be identified as such, while the types of solutions to address them should be evaluated in a subsequent step.

To standardise the collection of data on patients' and societal unmet health-related needs, a generic NEED framework, with 26 criteria and 50 indicators,^{1, 2} along with a needs assessment protocol⁴ and a toolbox,⁵ has been developed. The toolbox consists of eight assessment tools including, an online survey and a qualitative interview guide for patients and their proxies, highlighting the patient-centered approach of the NEED initiative.⁵ Several studies have since been conducted to identify unmet health-related needs in adult health conditions such as Crohn's disease,⁶ malignant melanoma,⁷ psychotic disorders,⁸ and chronic fatigue syndrome.⁹ The scientifically-collected unmet needs data relate to these health conditions was integrated into the NEED database. This publicly available NEED evidence database on patient and societal unmet needs was developed in order to be used by researchers, health product developers (e.g. devices, digital tools, medicines, etc.), research funders, regulators, health technology assessment (HTA) agencies, policy makers, patients, and healthcare providers for prioritising areas for research. Furthermore, thanks to the level of detail provided in the database, the database can be used to assess the extent to which proposed 'solutions' aim to address the most pressing unmet needs of patients or society.

Box 1 – Key components of the NEED framework

To identify health-related unmet needs, the NEED framework is structured along dimensions, domains, criteria and indicators.



- **Dimensions:** relate to the perspectives taken to identify and measure needs: patient, societal, or future (with equity as a transversal dimension)
- **Domains:** relate to the type of health-related need: health, healthcare, or social.
- **Criteria:** represent the different needs by domain and within each dimension.
- **Indicators:** assess to what extent health related needs identified by the criteria are met or unmet.

The imbalance between what comes on the market and the existing unmet needs is particularly evident in paediatrics. Limited commercial incentives, increased costs and greater risk of liability are associated with lower levels of private investment and a strong reliance on public and academic funding, resulting in the continued under-representation of children in clinical research. Children account for only 6-12% of registered clinical trials, despite representing approximately one quarter of the global population and contributing substantially to the global burden of disease and disability.¹⁰ In selected conditions with high paediatric burden, a marked mismatch has been observed between disease burden and research activity. While diseases in children contribute substantially to the overall disease burden (up to approximately 60%), they correspond to a much smaller proportion of registered clinical trials than adults (around 12%).¹¹ This gap is also relevant for conditions occurring predominantly or exclusively in childhood, for which dedicated paediatric studies are needed but may be particularly scarce.¹² In addition, trials involving children are typically small; two-thirds enroll fewer than 100 participants.¹³ One of the key challenges in generating evidence in paediatric populations, is the epidemiological structure of these populations, which is largely characterised by low-prevalence conditions. The resulting evidence gaps translate into clinical uncertainty, reflecting in the frequent off-label use of medicines in paediatric populations (11-31% of paediatric prescriptions in outpatient care to up to 65% in hospital settings), and persistent unmet therapeutic needs, as many medicines remain insufficiently evaluated and authorized for children.^{14, 15} Growth and maturation continuously influence drug handling by the body, while disease patterns and progression may differ substantially from those observed in adults, with some conditions occurring exclusively in childhood.^{16, 17, 18}

The original NEED framework was not designed for a specific age group, although its initial development was primarily based on needs in adult populations.² Extending the framework to paediatric populations is therefore essential in light of the previously identified therapeutic unmet needs, but also from a life-course perspective. Childhood and adolescence constitute key stages of the life course characterized by increased developmental plasticity, during which health conditions may have consequences that extend beyond the immediate period of occurrence.¹⁹ This is particularly relevant for conditions that may already have their onset in childhood or adolescence, including many mental health disorders.^{20,21} Furthermore, when comparing disease burden across different pathologies, as in the NEED project, chronic conditions with an earlier onset may result in a greater cumulative lifetime burden because they expose individuals to a longer duration.²²

Paediatric patients partly present fundamentally different needs that may not be adequately captured by the current NEED framework for adults. The importance of adopting a child-specific and development-sensitive approach to health assessment is also reflected in the recommendations of the WHO-UNICEF-Lancet Commission²³ and, in the Belgian context, in the *Care for the Children and Young Persons* plan.²⁴ The rationale for such an approach lies in key processes of biological, developmental, and psychosocial maturation, which are themselves shaped by genetic and environmental determinants. The same health condition may occur across the life course, while its impact, expression, and the relevance of specific health domains and indicators may vary according to the person's developmental stage. For example, the determinants of quality of life change with age: in early childhood, they are closely related to movement, play, and family interactions, whereas in adolescence they more prominently include autonomy, social relationships, and participation in school life.²⁵ Consequently, the assessment of unmet health-related needs requires age-appropriate criteria and indicators that capture these developmental differences while remaining applicable across the life course.

Another paediatric-specific unmet need concerns the impact of a child's condition on closely related people. Children typically grow and develop within a family or other caregiving contexts, with parents or other primary caregivers serving as their primary source of support in daily life and health-related decision-making. A child's condition might impact the functioning of the family unit, including caregiving demands, family dynamics, and, in some cases, the health of family members. Compared to the adult NEED framework, which already includes criteria and indicators related to informal caregiver burden, their scope in paediatric populations may be broader and more complex, reflecting the central role of the family in paediatric health and daily life contexts.

Paediatric healthcare delivery is characterised by different features than adult care, that can potentially lead to specific unmet needs. Paediatric healthcare systems operate within a child rights-based framework, grounded in principles of best interests, participation, and safe, high-quality care.^{26, 27} This includes respect for the child's evolving capacities, with a gradual shift from protection towards empowerment, as well as the child's right to participate in decisions affecting their health, alongside shared decision-making with parents or legal guardians. This approach also includes specific features related to the care context, such as age-appropriate participation of the child in care and interactions with healthcare professionals, including communication that is responsive to the needs of the child and family.²⁸ In this regard, specific healthcare-related unmet needs might be present that are not yet fully captured within the adult-oriented NEED framework.

Another healthcare area of concern is the transition from paediatric to adult care, which represents a distinct challenge at the interface between childhood and early adulthood that is not already captured in the adult-oriented NEED framework. This transition is characterised by a shift from family-centred paediatric care to patient-centred adult care, with greater expectations regarding patient autonomy and reduced family involvement in care.²⁹ Although this transition has received increasing attention in both research and clinical practice, it remains an area of unmet need. Common barriers include insufficient patient and family preparedness, limited self-management skills, limited disease insight,^{30, 31} difficulties establishing relationships with adult healthcare providers, negative expectations regarding adult care, and limited access to appropriate adult and community services.^{32, 33} These barriers may compromise continuity of care, decrease treatment adherence and contribute to loss to follow-up, ultimately putting adolescents and young adult at risk for negative health.³⁴ Evidence suggests that structured transition programs may improve continuity of care, follow-up, and selected patient outcomes, although the evidence remains heterogeneous and no single model has been shown to be consistently superior across conditions.^{34, 35}

Taken together, these biological, developmental, familial, life-course, and healthcare-specific characteristics indicate that the adult NEED framework does not fully capture unmet health-related needs in paediatric populations, supporting the development of a dedicated paediatric framework. This framework should, however, remain anchored in the structure of the existing adult framework to ensure conceptual continuity. Such alignment would facilitate the assessment of health conditions that begin

in childhood and persist into adulthood, while also enabling meaningful study and comparison of childhood-specific conditions that do not necessarily extend into adulthood.

2 AIMS

The aim of this project is to develop a paediatric NEED assessment framework to measure the unmet health-related needs in conditions occurring (only or also) in children, while ensuring conceptual and methodological consistency with the existing adult NEED framework. This approach enables consistent assessment of unmet health-related needs across the life course.

This aim was pursued through three research questions:

1. Which criteria and indicators best reflect unmet health-related needs in relation to paediatric conditions?
2. What age-related adaptations of these criteria and indicators are required?
3. How should each indicator be defined and measured?

3 METHODS

KEY POINTS

- A mapping literature review was conducted to obtain a broad overview of health-related unmet needs across paediatric populations. Given the volume of retrieved studies, data saturation prevented assessment of conceptually redundant studies.
- The identified needs were deductively mapped onto the adult NEED framework to maintain consistency with its overall structure and methodology.
- An inductive analysis was conducted to identify paediatric-specific concepts and age-related differences not captured by the adult NEED framework.
- Targeted pragmatic literature reviews were used to explore paediatric-specific concepts in greater depth and inform their definition, measurement and age-specific considerations.
- The preliminary framework was refined based on input from clinical experts and experts by experience.

3.1 Mapping literature review

A **mapping literature review** was conducted to provide an overview of health-related (unmet) needs in paediatric patient populations. The extracted data were subsequently mapped to the adult NEED framework and analysed using a framework analysis combining deductive and inductive approaches to develop a preliminary paediatric NEED framework (see chapter 3.1). The preliminary paediatric framework was iteratively refined through **expert process consultation** with KCE experts and external stakeholders, including clinicians and experts by experience, to ensure its completeness, relevance, and alignment with the NEED methodology for assessing unmet health-related needs across the life course (see chapter 3.2).

A mapping review is relevant when one wants to describe existing evidence, rather than synthesizing evidence. More specifically, a mapping review “*collate[s], describe[s], and catalogue[s] the available evidence relating to the question of interest*” (retrieved from James et al., 2016, page 6).³⁶ In a mapping review, the evidence related to the research question is usually presented via visual and interactive outputs. This type of review is recommended when an existing framework is used to categorize eligible studies.³⁷

This mapping review described evidence from all types of studies and mapped the identified health-related unmet needs according to the dimensions, domains, criteria, indicators of the adult NEED framework. Visual thematic maps were used to present some of the criteria and indicators to inform decision-making.

3.1.1 Search strategy and study selection

The search strategy used the relevant terms and term combinations related to unmet needs which had been developed in the study on the applicability of the NEED framework to rare diseases.³⁸ These terms were combined with paediatric terms, both generic (e.g., pediatric, paediatric, PICU) and age-specific, including terms related to early childhood (e.g., babies, neonate), childhood (e.g., kindergarten, minor), and adolescence (e.g., adolescent, teen). These age-specific terms were inspired by the predefined paediatric age-specific filter available in OVID MEDLINE.³⁹ The review was conducted in MEDLINE, EMBASE and COCHRANE in May 2025. The search strategy used both free-text terms and Medical Subject Headings (MeSH terms) to search MEDLINE, and Emtree terms to search EMBASE and the Cochrane Library. The final search strategy was reviewed and refined in collaboration with an expert in literature review. The full search strategy (keywords and logical combinations per database) is available in Appendix 1.

All identified studies were uploaded to Rayyan, and duplicates were removed.

3.1.1.1 Inclusion of studies

Eligibility criteria

Studies were included if they provided information about (1) needs related to the paediatric population and/or paediatric health system, (2) if they were published between January 2014 and April 2025 and (3) if they were available in English, French, or Dutch.

The paediatric population was defined as individuals from birth up to 17 years of age, encompassing infancy, childhood, and adolescence, in line with commonly accepted paediatric age classifications.^{40, 41}

The 10-year time window was chosen to balance comprehensiveness with relevance, ensuring that evidence reflected contemporary health needs and paediatric care practices, and current methodological standards.

There were no restrictions on study design, allowing the inclusion of quantitative, qualitative or mixed-type designs, as well as psychometric studies and literature reviews. Also, no restrictions were applied regarding the child's health conditions, as the NEED framework is intended to be applicable to a large range of health conditions.

Studies were excluded if (1) they exclusively focused on the prenatal period, (2) they concerned populations aged 18 years or older, or if findings for participants younger than 18 years of age were not reported separately, (3) they described an intervention or research methodology without measuring paediatric (unmet) needs, (4) they exclusively targeted health-related needs in the period of the COVID-19 pandemic, (5) they assess health-related needs in non-OECD countries, unless they used a questionnaire validated in an OECD country that had not been identified elsewhere in the literature mapping; or (6) consisted of study protocols, commentaries, or letters to the editor.

Two researchers (JP, CO) independently and blindly screened all titles and abstracts. Discrepancies were resolved through internal discussion (CM, JP, CO). One researcher subsequently screened the full text (JP).

DATA SATURATION ASSESSMENT PROCESS

In addition to the eligibility criteria, a data saturation assessment process was applied to optimize the review process by reducing the number of studies requiring assessment, while ensuring comprehensive coverage of the main paediatric themes. As the mapping review aimed to identify broad categories of unmet health-related needs rather than all disease-specific manifestations of these needs, saturation was assessed at the level of concepts relevant to the framework.

This process required the extraction of the following information for all studies meeting the eligibility criteria: (i) study type, (ii) population type, (iii) types of needs, (iv) study's main topics.

- (i) Study type: a) literature review; b) study with a quantitative design; c) study with a qualitative or mixed-study design; d) psychometric studies.
- (ii) Population type: a) children with a diagnosed health condition (or their relatives); b) children in situation of vulnerability characterized by social or contextual risk factors that increase exposure to difficulties without being identified as a health condition in the study (such as poverty, migration, trauma, minority status, or educational needs) (or their relatives); or c) children from the general population who had neither a diagnosis nor an identified vulnerability (or their relatives).
- (iii) Type of needs: a) children's needs; b) needs of parents and other family members; or c) both children's and families' needs.
- (iv) Study's main topics: either derived from the adult NEED criteria and indicators when the abstract results fitted the description (e.g., quality of care), or from the results in the abstract, when it did not fit the description of any of the adult NEED criteria and indicators (e.g. social media use, transition from paediatric to adult care)

The data saturation assessment process was applied during full-text screening. Decisions to exclude studies were made once two full-text articles addressing the same main research topic, the same population type, and the same type of studied needs had been assessed and found not to contribute new information relevant to the framework. Subsequent studies on the same topic were therefore excluded. This process was not applied to literature reviews or studies focusing on children from the general population because of their limited number. Therefore, the data saturation assessment process was applied to studies involving children (or their relatives) with a health condition or in situations of vulnerability and using quantitative, qualitative or mixed-methods, or psychometric design.

3.1.2 Data extraction and mapping to the adult NEED framework

Data extraction and preliminary mapping were conducted by one researcher (JP). To support transparency and subsequent review of the mapping, all extracted themes were retained in a comprehensive supporting file together with the original quotes or findings from which they were derived.

For each included study, descriptive information (title, authors, year, and geographic region) and key methodological characteristics were extracted, including study design, participant characteristics, whose needs were assessed (child, parents, or whole family), targeted age groups, and study objectives.

Results regarding unmet health-related needs in paediatrics were then extracted verbatim without any intermediate analysis or secondary interpretation and were mapped onto the adult NEED framework (dimensions, domains, criteria, indicators). Data extraction was intentionally inclusive: all reported themes or findings potentially related to paediatric health-related needs were extracted, irrespective of their perceived relevance to the final framework.



For studies with a **quantitative design**, the numerical findings were directly extracted (e.g., “Overall, 59 % of families waited more than 12 months from their initial neurology appointment for a Dravet syndrome diagnosis”).

For **psychometric studies**, the questionnaire domains, the scoring category, and an example item for each domain were extracted (e.g., the MANTIC questionnaire includes a domain entitled “Physical needs”, with items such as “We need advice about managing pain”). When this information was not available, a pragmatic literature search to complete this information for the questionnaire was performed.

For studies with a **qualitative or a mixed-typed design**, we extracted the reported themes, subthemes and codes together with an illustrative participant quote where needed to clarify the findings (e.g. Theme: “Coordination of care”, subtheme: “Contact person”, explanation of the subtheme: “They desired a contact person who could act as a co-ordinator for the individual support needed”).

For **literature reviews**, the findings reported in the results section that related to (unmet) health-related needs were extracted, together with an example illustrating these findings, such as a percentage, a conceptual model, or clinical recommendations (e.g., Percentage: “immunosuppressant-related physical changes affect 80% of the population”, illustrated by the example: “physical changes such as moon face, striae, acne, hirsutism”).

For the mapping process, the extracted data were subsequently entered into a structured spreadsheet organised according to the adult NEED framework (dimensions, domains, criteria and indicators). The purpose of this step was solely to organise the extracted findings within the structure of the adult NEED framework. No interpretation or synthesis of the extracted data was undertaken at this stage. Each extracted quote or item was provisionally assigned to the corresponding component of the adult framework. When no corresponding component could be identified, it was provisionally entered into a dedicated “child-specific” column to be examined during the subsequent framework analysis.

3.1.3 Framework analysis

Following the preliminary mapping, the extracted data were analysed using framework analysis. Unlike the mapping step, which consisted solely of organising the extracted findings within the adult NEED framework, the framework analysis involved interpreting and synthesising these mapped data to determine whether they corresponded to existing concepts in the adult NEED framework or required the development of new paediatric-specific concepts.

A framework analysis is a way of describing the themes that appear in the corpus by identifying recurrent patterns or commonalities.⁴² It is not an in-depth analysis but rather a descriptive analysis, primarily deductive and based on a pre-specified framework, although it can also be complemented by an inductive approach. The inductive approach is likewise a descriptive strategy aimed at reducing the data, but it starts from the data themselves rather than from a predefined framework. Framework analysis was used in this project to analyse the extracted data, which had been mapped to the adult NEED framework, in order to develop a preliminary paediatric NEED framework using both deductive and inductive approaches. The deductive approach consisted of assessing whether the mapped data corresponded to existing components of the adult NEED framework, whereas the inductive approach was used to identify child-specific concepts that were not represented in the adult framework.

To achieve this, a categorisation rule was developed to assign the extracted quote or item to a criterion, or indicator according to their level of specificity and their hierarchical alignment with the

adult NEED framework definitions^a, ensuring an exhaustive and coherent categorization of paediatric needs consistent with the adult NEED framework. The following rules were developed for the analysis:

- If the original quote/item extracted **corresponded to the definition** of a criterion or an indicator in the adult NEED framework, the corresponding denomination from the adult framework was retained. For example, difficulties reported in paediatric studies relating to “Organizing the child’s care across settings” corresponded to the definition of “Coordination and Continuity of Care”, therefore the denomination from the adult NEED framework, was retained rather than developing a new one.
- **When several disease- or situation-specific quotes described closely related sub-aspects of the same underlying concept, they were grouped under the corresponding criterion or indicator.** For example, descriptions of treatment side effects reported across different health conditions were grouped under the adult NEED indicator “*Burden of side-effects*”.
- **If the original quote/item extracted did not correspond to the definition of an existing criterion or indicator in the adult NEED framework but represented a distinct concept, a new child-specific criterion or indicator was developed.** This was achieved either by using terminology that closely reflected the original quote or by reformulating it as “*Impact on...*” or “*Need for...*”, according to the definition of health-related unmet needs (i.e., “*Impact on...*” for the impact of the disease or treatment burden, and “*Need for...*” for care or support not received despite being needed). For example, the quote “*finding the right tools to assess pain both for healthcare providers and for parents to understand and make decisions*” was used to develop the child-specific indicator “*Appropriate assessment*” while the quote “*lack of timely diagnosis of mental disorders*” was reformulated as “*Need for timely diagnosis*”.

Following the framework analysis, the resulting preliminary paediatric NEED framework was compared with the adult NEED framework. In this comparison, items were classified as (i) shared between frameworks, (ii) paediatric-specific, or (iii) adult-specific.

In addition, given the central role of the family in children’s health and development, a mind map was created to visually identify where in the framework the family was involved or impacted.

3.2 Expert consultations

3.2.1 Internal KCE expert consultations

The preliminary paediatric framework was discussed within the KCE NEED team that developed the NEED methodology and adult NEED framework and presented to a senior paediatrician working at KCE. Eight internal meetings were held from September 2025 to December 2025 (two with the paediatrician and six within the NEED team). The supporting file containing each criterion and indicator, their definition, and representative extracted quotes was used throughout these discussions. The preliminary mapping and categorisation proposed by the researcher were reviewed by the KCE internal experts. Each indicator and criterion of the preliminary version of the paediatric framework was discussed according to the following conditions:

- **Measurability:** the indicator must be measurable at either the patient level or the societal level.

^a the definitions of the hierarchy of elements of the adult NEED framework were applied: *dimensions* relate to the perspectives taken to identify and measure needs: patient, societal, or future (with equity as a transversal dimension) *domains* relate to the type of health related need: health, healthcare, or social, *criteria* represent the different needs by domain and within each dimension, *indicators* assess to what extent health related needs identified by the criteria are met or unmet.



- **Avoiding duplication:** the criterion or indicator should not overlap with another patient or societal need; duplication should be avoided to prevent double counting and challenges in weighting.
- **Commonality with the existing framework:** criteria or indicators already included in the adult NEED framework and relevant for children should be retained.
- **Relevance and specificity to the paediatric population:** criteria or indicators relevant and specific to children should be retained.

The criteria or indicators that did not meet all the above conditions were not retained. A modified version of the preliminary paediatric framework was then developed to be presented to external experts. In addition, where necessary, rapid pragmatic literature reviews were conducted for child-specific items to further explore the broad themes identified during the mapping review and to better characterise the different types of unmet needs encompassed within each theme. Unlike the mapping review, these targeted searches were not restricted to the 2014-2025 period or to paediatric populations alone (e.g. adult literature was also considered where relevant to the specific concept under investigation, such as transition from paediatric to adult care). These reviews aimed to inform the definition of the indicator, the selection of appropriate data collection methods, and the identification of age-specific considerations relevant to its development. Priority was given to literature reviews and meta-analyses, as well as to validated assessment tools relevant to the measurement of the indicator.

3.2.2 *External expert consultations*

A two hour meeting was organised with 11 experts-by-experience and a separate one with 11 clinicians (December 2025) to gather their feedback on the preliminary paediatric framework.

Experts-by-experience were recruited in Belgium and in France through their involvement in patient organisations. They included representatives of parents of children affected by health conditions, as well as adults who had experienced a health condition during childhood (before the age of 18). The selection aimed to ensure diversity in terms of types of health conditions and age at onset.

Clinicians were Belgian physicians or nurses from different paediatric specialties, recruited through their involvement in professional associations or their previous participation in KCE reports,⁴³ and who combined both clinical and research roles.

Before the meeting, the preliminary paediatric framework with the criteria, indicators along with their definitions, measures and data collection methods was shared with experts. They were asked to indicate whether they considered each criterion to be of high, medium, or low relevance for characterizing paediatric health-related needs. Experts were also encouraged to add comments on the proposed criteria, indicators, measures and data collection methods.

Indicators and criteria that were considered by at least 60% of experts as being of high relevance were kept in the framework. Below this 60% the indicator or criterion was considered to be a candidate for discussion. The discussion themes were prepared based on the relevance rating, as well as the experts' written comments.

4 RESULTS

KEY POINTS

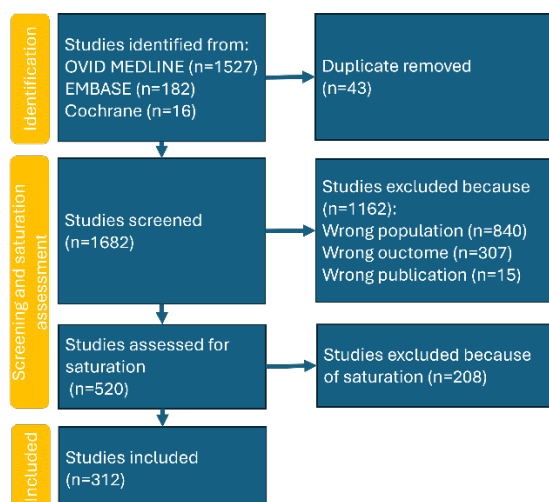
- The mapping review included 312 articles covering all paediatric age groups. Most studies focused on children with health conditions or their relatives (78%), while children from the general population (16%) and those in vulnerable situations (6%) were less frequently represented.
- The preliminary paediatric NEED framework comprised 36 criteria and 95 indicators and was substantially refined based on expert feedback regarding relevance, measurability and overlap.
- The final paediatric NEED framework comprises 25 criteria and 52 indicators applicable to all paediatric age groups, together with 1 additional criterion and 5 additional indicators applicable to selected paediatric age groups.
- Paediatric-specific elements address child development and self-esteem, child-adapted inpatient care, preparation for transfer to adult care, communication with healthcare providers, siblings' well-being, and unmet family support needs.
- Age-specific adaptations concern health-related quality of life, self-esteem, education and early skill learning, communication with healthcare providers, usefulness and clarity of received information, involvement in treatment decisions, participation to treatment, adolescent romantic relationships and sexual life and preparation for transfer to adult care.

4.1 Mapping literature review

Out of 1 682 screened articles, 520 corresponded to the eligibility criteria, and 312 articles were included for final analysis after applying the data saturation process (Figure 1). The complete list of included articles can be found in Appendix 10.

Saturation was reached for all study topics, leading to the exclusion of 208 articles. The saturation assessment process excluded studies from of all types (psychometric, studies with qualitative or mixed-type design, studies with quantitative design), except literature reviews.

Figure 1 – Flow chart of the mapping review





4.1.1.1 *Studies included*

The final pool comprised 312 articles, including literature reviews (9%), studies with a quantitative design (38%), studies with a qualitative or mixed-type design (38%), and psychometric studies (15%) (Figure 2C). Among the 29 literature reviews, 10 were systematic reviews and 2 systematic reviews with meta-analysis.

The populations included in the studies were predominantly children with health conditions or relatives of children with health conditions (78%), children from the general population or relatives of children from the general population (16%), and children in vulnerable situations or relatives of children in vulnerable situations (6%) (Figure 2A).

Children with a health condition included: (i) children with a health condition described under a generic term (e.g. disability); (ii) children with specific clinical conditions, including neurodevelopmental disorders, mental health disorders, chronic physical diseases, cancer, and rare/genetic/congenital conditions; (iii) children experiencing acute events or undergoing specific care (e.g. surgery); (iv) neonatal intensive care and early-life conditions.

Children in situations of vulnerability included (i) health-related vulnerability (e.g. food hypersensitivities), (ii) school-related vulnerability (e.g. special educational needs), (iii) socio-economic vulnerability (e.g. children living in foster care), (iv) minority-related vulnerability (e.g. immigration).

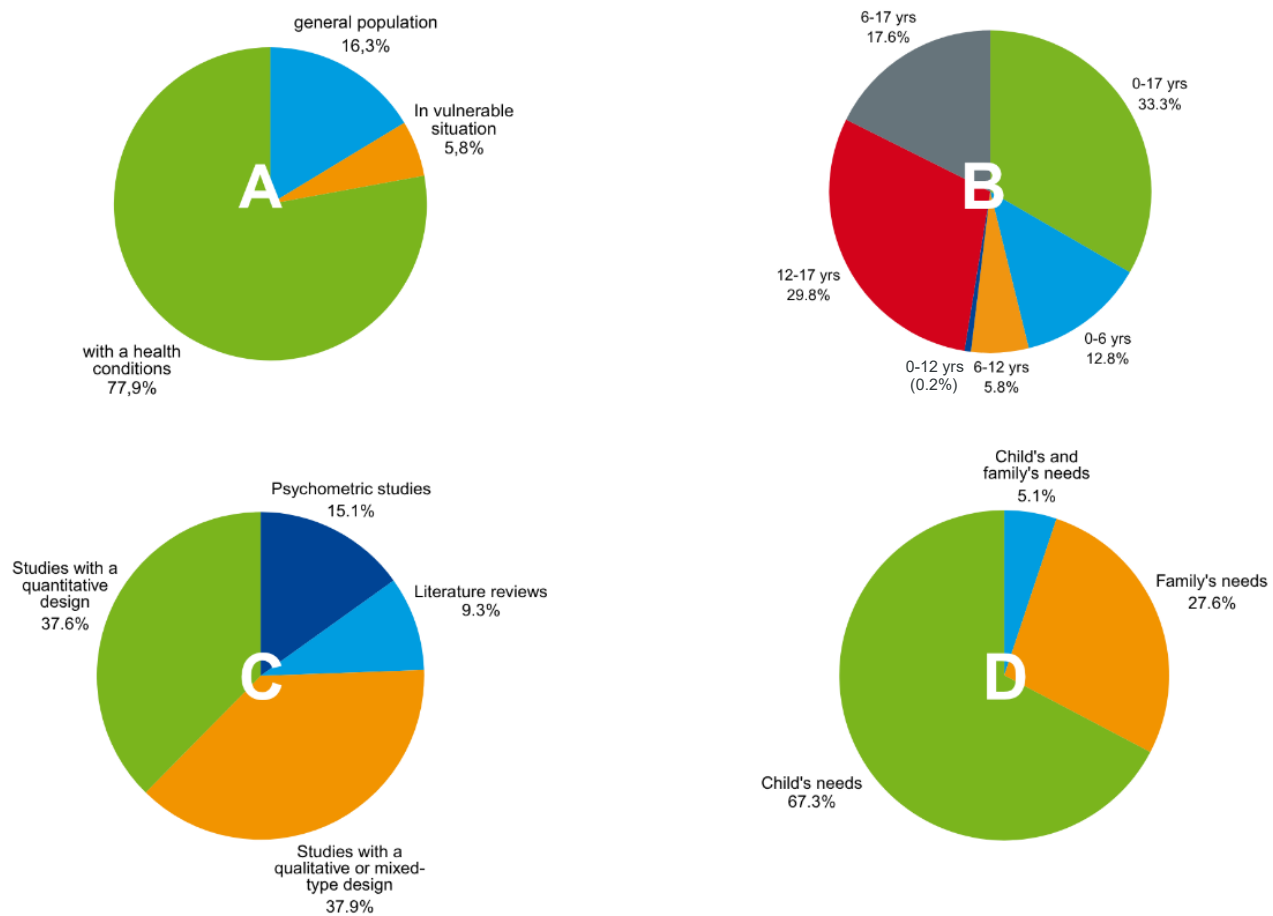
Children from the general population were those who had neither a diagnosis nor an identified vulnerability identified in the study (Figure 2 A).

All age groups were represented in the paediatric populations, with one-third of the articles including children across the full paediatric age range (0-17 years), followed by adolescents (12-17 years; 29.4%) (Figure 2B).

Most studies focused on children's needs, whereas fewer investigated families' needs, and only a small proportion addressed the needs of both children and their families (Figure 2D).



Figure 2 – Overview of included studies: population (A), age groups (B), study design (C), and needs-related focus (D)





4.1.1.2 Development of the preliminary paediatric NEED framework

The framework analysis resulted in a preliminary paediatric NEED framework, comprising all criteria and indicators of the adult NEED framework together with additional criteria and indicators specific to paediatric populations. The preliminary paediatric framework included 36 criteria and 95 indicators. These were organised into patient, societal and future dimensions within which health needs, healthcare needs and social needs were measured, thereby maintaining the architecture of the adult NEED framework. Although most criteria and indicators were the same in both the adult and the preliminary paediatric framework, several indicators and criteria were new for the preliminary paediatric framework, and a few were present in the adult framework but not relevant for the paediatric framework (Appendix 2, Column 1-2).

4.2 Decisions informed by experts' feedback on the preliminary version of the paediatric NEED framework

Following expert discussions, 54 items (45 indicators and 9 criteria) were removed from the preliminary version of the paediatric framework (Appendix 2, Column 3-6).

Among these, 35 items were deleted according to the pre-established conditions:

- 3 lack relevance for children (e.g. *Presenteeism of patients*) (1 criterion, 2 indicators)
- 10 were not measurable (e.g. *Engagement in clinical trials*) (7 indicators, 3 criteria). The rationale for non-measurability is provided for each item in Appendix 2 and;
- 22 were duplicates or overlaps with existing indicators (e.g., *Need for early screening* was considered to overlap with Appropriateness of diagnostic timing) (18 indicators, 4 criteria)

In addition, 3 indicators were merged into 1 indicator, and 1 indicator was deleted because it was more family-centred than child-centred (i.e., *Impact on family health-related quality of life*).

A total of 15 indicators were not retained as standalone indicators but incorporated into existing indicators, as they aligned with the definition of an existing indicator (e.g., *Impact on behaviour* was incorporated into the list of symptoms in the indicator *Emotional burden and psychological symptoms related to the health condition*).

Furthermore, the criteria and related indicators on the impact of a child's disease on their family were moved from the patient dimension to the societal dimension, as they were considered to affect persons other than the child with the health condition (Appendix 3).

The possibility of introducing a new "family" dimension was considered, given the particularly close interrelationship between child and family health. However, the existing dimensions of the NEED framework were retained to preserve conceptual consistency and comparability with the adult framework. Family-related needs and consequences are nevertheless explicitly captured through dedicated criteria (e.g. impact on family) and indicators (e.g. impact on siblings' well-being) across the paediatric framework.

4.3 The final paediatric NEED framework

The final paediatric NEED framework comprises 25 criteria and 52 indicators common to all paediatric age groups, with 1 additional criterion and 5 additional indicators included for selected age groups. The framework is organized according to the dimensions (patient, society & future) and domains (health needs, healthcare needs and social needs) of the adult NEED framework.

Table 1 illustrates the comparison with the adult framework and Table 2 describes the definition, the age-group specificities and the proposed data-collection methods of each indicator of the paediatric NEED framework.

While sharing a large number of criteria and indicators with the adult framework (section 4.3.1), the paediatric framework includes child-specific indicators and criteria that are not present in the adult framework (section 4.3.1.2). Conversely, the adult framework includes adult-specific criteria and items that are not shared with the paediatric framework (section 4.3.1.3). The paediatric framework also accounts for age-related specificities across childhood (0-17 years), including age-adapted indicators and criteria, as well as indicators and criteria specific to certain age groups (section 1.1.1).

4.3.1 Comparison between the paediatric and adult NEED framework

Twenty-four indicators (42%) and 20 criteria (77%) share the exact same definitions in both frameworks. Twenty-five indicators (44%) and 4 criteria (15%) were adapted (named differently or described differently), 2 criteria (8%) and 8 indicators (14%) were paediatric-specific. In addition, 2 indicators were adult-specific and therefore absent from the paediatric framework.

4.3.1.1 Shared items, but renamed or described differently in the paediatric framework

Terminological adaptations

One criterion and 9 indicators retained the same underlying concept but were renamed to reflect paediatric terminology (see indicators highlighted in blue in the sixth column of Table 1 and criteria marked with *).

- The indicator *Forgone social support* was renamed *Forgone child social support* to distinguish it from the newly developed indicator *Forgone family support*.
- The 6 health-related quality of life indicators were aligned with the domains of the paediatric tool (EQ-5D-5L, EQ-5D-Y-5L, and EQ-TIPS-5L).
- The term "informal caregiver" was replaced with "parents" in 1 criterion: *Burden on informal caregivers' health* was changed to *Burden on parents' health*; and 2 indicators: *Impact on informal caregivers' health* to *Impact on parents' health*; and *Impact on informal caregivers' social life* to *Impact on parents' social life*.

Conceptual adaptations

Three criteria and 12 indicators share the same underlying concept, but their definition was adapted for the paediatric framework (see Table 1; criteria marked with * and indicators highlighted in blue).

The criterion *Impact on sexual and reproductive health* was adapted to reflect developmental stage. Experts recommended retaining sexual life, removing reproductive health, and incorporating romantic relationships as a more developmentally appropriate concept. Consequently, the criterion and indicator were renamed *Impact on adolescents' romantic relationships and sexual life*.

For the criteria and indicators related to productivity (criteria: *Productivity losses*, *Forecasted productivity losses*; indicators: *Forecasted Productivity losses attributable to the health condition*, *Work reduction or early labour force exit of patients*, and *Absenteeism of Patients*), the term "parent" replaced "patient" or was introduced, as appropriate. In addition, the definition of productivity losses was adapted by excluding the indicators *Presenteeism of Patients*, as parents may have difficulty estimating productivity losses attributable to their child's illness. Experts also recommended assessing *Work reduction or early labour force exit* for both the responding and non-responding parent to provide a more comprehensive measure.

In the definition of the paediatric indicator *Impact on personal relationships*, relationships with parents was added because it was highlighted as fundamental for the development of children's social functioning in the mapping literature review.

The indicator assessing the impact on education in adults was not appropriate for children aged 0-3 years, for whom formal education has not yet started. It was therefore adapted into *Early foundational skills learning* (i.e. learning language, play, motor skills, basic problem-solving, and early numeracy).



skills), while the original concept of the indicator *Impact on education* was retained for children aged 4 years and older.

Experts highlighted the importance of distinguishing between the perspectives of parents and children aged 12 years and older for the three following indicators “*Received Information*”, “*Involvement in treatment decision*”, and “*Quality of communication with health care providers*”. These two perspectives are therefore described and measured separately for each indicator in the paediatric framework.

The indicator *Informal carers’ time burden* was renamed *Parents’ caregiving time burden*. The frequency of parental intervention or presence related to the child’s health condition was used rather than the time spent caring, as in the adult framework. The frequency instead of time was considered easier to measure, as caregiving time naturally occurs for all children, not only for those with a disease.

Paediatric-specific elements integrated into existing indicators

Ultimately, 5 indicators common to both the paediatric and adult framework incorporate additional paediatric-specific elements. These indicators are: *Experienced Burden of physical symptoms related to the health condition*, *Experienced burden of psychological symptoms and emotional impact related to the health condition*, *Burden of treatment side-effect*, *Forgone care*, *Non-healthcare costs*. For example, the *Impact on the child’s optimism about the future* was incorporated into the list of emotional impacts within the indicator *Emotional impact and physical symptoms related to the health condition*. These additional paediatric-specific elements will be integrated into the forthcoming paediatric versions of the NEED toolbox.

4.3.1.2 Child-specific items

Compared to the adult framework, 2 criteria and 8 indicators were developed specifically for the paediatric framework (criteria marked with ** in the seventh column of Table 1 and indicators highlighted in blue).

The indicator *Developmental delay* includes in the criterion *Impact on development* are both new. This indicator measures the consequences of the disease, its treatments (e.g., medication, radiation), or associated circumstances (e.g., missing schooling for a long period) on four aspects: cognition, socio-emotional abilities, motor skill, language skills. It is measured through clinical expert input, which provides an averaged view across the patient population as well as a longitudinal assessment of the long-term impact (i.e. persistent or transient). The rationale is described in Appendix 5.

The indicator *Child-adapted inpatient environment* includes in the criterion *Quality of care* is new. This indicator comes from the broader context of child-friendly healthcare. Across the multiple attributes that characterise child-friendly healthcare, this indicator results from a combination of child-friendly environments and spaces (child-adapted signage, comfort, child-centred decoration, cleanliness, family and interactive spaces), social interaction (activities, emotional and informational support, protection), and development facilitation (play, learning, nutrition, health education, health monitoring and management).²⁸ Most of the other attributes are measured under other indicators of the paediatric framework (rationale in Appendix 6). For example, the attribute “child participation in decision-making, in the design of care, and in service and policy evaluation” is partially included in the indicator *Involvement in treatment decision* (children aged 12-17 years) and *Participation to treatment* (children aged 4-11 years).

The indicator *Impact on self-esteem* includes in criterion *Impact on psychological health* is new. Self-esteem has been variously defined in literature but means an overall evaluation of one’s worth or value as a person, including how much they like, respect and accept themselves. In addition to this global evaluation of self-worth, another commonly used definition conceptualises self-esteem as an evaluation of one’s competence across different domains, such as physical appearance, athletic competence, social competence, or academic competence.⁴⁴⁻⁴⁶ We used these two definitions, along with examples from questionnaires to develop the NEED indicator. As with other indicators assessing

the impact of the health condition in the NEED frameworks, this indicator measures the negative impact of the health condition on self-esteem. This distinction is particularly important, as age-related differences in self-esteem have been reported in the literature.^{47, 48} Measuring the negative impact of the health condition, rather than self-esteem itself, was considered less sensitive to age-related variation (rationale in Appendix 7).

The indicator *Preparation of transfer from paediatric to adult care* includes in criterion *Quality of care* is new. It can be defined as the “process of building the capacity of adolescents and those involved in their care to prepare for, enter, continue and complete transition”.⁴⁹ While the “child’s readiness of transfer” is most commonly measured in clinical practice, this NEED indicator was conceptualized by experts to focus on the quality of care provided by the healthcare system, more specifically assessing whether healthcare professionals support this preparation (rationale in Appendix 8). A criterion with the same name was created for this indicator.

The indicator *Quality of communication with health care providers (HCP)* includes in criterion *Quality of care* is new and will be considered as part of a future update of the adult framework. It comes from several elements from the mapping literature review, such as parents’ need to feel listened to by healthcare providers, need to feel that HCPs are committed to the child’s and family’s needs; need of empathic, supportive, and family-centred communication, need to be reassured about the quality and safety of care (including pain management),⁵⁰⁻⁵² as well as need to feel confident in the qualifications and stability of respite and case-management workers.⁵³ For children, key elements include perceiving HCPs as compassionate, honest, skilled, empowering, approachable, non-judgmental, and culturally competent.⁵⁴⁻⁵⁷ The NEED indicator integrates the aspects of parents feeling listened to by HCPs and the aspect of a respectful, supportive and age-appropriate communication from HCPs to children.

The criterion *Impact on family* was developed to integrate all non-health related impacts on family, more particularly the indicators *Impact on siblings’ well-being*, the *Impact on parents’ social life* and *Forgone family support*.

The indicator *Impact on siblings’ well-being* includes in criterion *Impact on family* is new. In the literature, this impact can be neutral, negative or positive and might affect any domain of the sibling’s life (physical, psychological or social, including educational).^{58, 59} In the NEED framework, this indicator refers to the negative impact of the child’s health condition on siblings’ well-being, encompassing physical, psychological and social impacts (rationale in Appendix 9).

The indicator *Forgone family support* includes in criterion *Impact on family* is new. It was adapted from the indicator *Forgone child’s social support*, with its definition revised to reflect family members’ support needs. It covers unmet support needs among family members, including practical, psychological, educational, administrative, and community-based support, as well as workplace accommodations and respite resources.

4.3.1.3 Adult-specific items not retained for the paediatric NEED framework

Compared to the adult framework, 2 indicators were not retained for the paediatric framework (Appendix 2).

The indicator *Presenteeism of patient* was not relevant for children neither measurable in parents according to experts, and was therefore not kept in the paediatric framework.

The indicator *Transfer from paediatric to adult care*, included in the adult framework for young adults aged 18-26 years, was not relevant for the paediatric framework. In the literature and expert consultations, the transfer process itself is rarely experienced during paediatric ages.^{60, 61} Consequently, for adolescents aged 16-17 years, the paediatric framework assesses the preparation of transfer rather than the transfer itself.



4.3.2 Age-related adaptations in the paediatric framework

The indicator *Involvement in treatment decision* is measured only in children aged 4 years and older, using an age-appropriate approach. For children aged 4-11 years, it refers to active participation in treatment (e.g. making minor choices or participating in simple care tasks like holding equipment), whereas for children aged 12-17 years, it refers to involvement in treatment decisions like in adults (e.g., being addressed directly when treatment options are discussed).

Similarly, the indicator *Received information*, i.e., the extent to which they receive easy to understand and useful information from HCPs, is measured only for adolescents aged 12-17 years. Both the use of health information and participation in decision-making increases with age. In fact, adolescence is characterised by marked improvements in cognitive capacity and health literacy, supporting better understanding, self-management, and decision-making involvement.^{62, 63}

For children aged 4-17 years, the impact of the health condition on education is assessed through the indicator *Impact on education*. For children aged 0-3 years, the measurement of this indicator was adapted to reflect the impact on early developmental learning, including language acquisition, play, motor development, basic problem-solving, and early numeracy skills.

Age-related adaptations were also required for the assessment of the health-related quality of life measures (HRQOL). HRQOL tools provide both an average total score, as well as a separate score for each dimension of the HRQOL. While belonging to the same family of EUROQOL tools and sharing the same 5 levels of severity, the EQ-TIPS-5L (children aged 0-3 years)⁶⁴ contains 7 dimensions while the EQ-5D-Y-5L (ages 4-15)⁶⁵ and the EQ-5D-5L (ages 16-17)⁶⁶ contain only 5 dimensions. The following five dimensions could be aligned across the three tools and became separate indicators, with different names in each version:

- *Pain* (EQ-TIPS-5L) aligns with *Pain/discomfort* (EQ-5D-Y-5L & EQ-5D-5L);
- *Managing emotions* (EQ-TIPS-5L) aligns with *Feeling sad, worried or unhappy* (EQ-5D-Y-5L) and *Anxiety/Depression* (EQ-5D-5L);
- *Eating or Drinking* (EQ-TIPS-5L) aligns with *Looking after Myself* (EQ-5D-Y-5L) and *Self-care* (EQ-5D-5L);
- *Movement* (EQ-TIPS-5L) aligns with *Mobility* (EQ-5D-Y-5L & EQ-5D-5L);
- *Play* (EQ-TIPS-5L) aligns with *Usual activities* (EQ-5D-Y-5L & EQ-5D-5L).

Two EQ-TIPS-5L dimensions: "Sleep" and "Interacting with others", are included in the total HRQOL score for children aged 0-3 years but are not disaggregated as standalone indicators. The rationale for selecting these tools to measure health-related quality of life from 0 to 17 years old is detailed in Appendix 4.

Finally, 3 indicators and 2 criteria were considered relevant only for specific age groups. The indicator *Impact on self-esteem* was included only for children 4-17 years old, the criteria and related indicators *Preparation of transfer from paediatric to adult care* and *Impact on adolescent's romantic relationships and sexual life* were included only for children aged 16-17 years. While for the two last indicators, the rational of age can be easily inferred, the rationale of age for the self-esteem indicator is presented in Appendix 6.

Table 1 – The paediatric NEED framework and comparison with the adult NEED framework

	Criteria	Indicators	Age group (years)	Comparison with the adult NEED framework		
				Same	Modified	Added (Child-specific)
PATIENT DIMENSION						
Health needs	Impact on Life expectancy	• Years of life lost per death	• 0-17			
		• Years of life lost per case	• 0-17			
	Impact on general health-related quality of life	• Years of life lived with disability (per case) (YLD)	• 0-17			
		• EQ-TIPS-5L score	• 0-3			
		• EQ-5D-Y-5L score	• 4-15			
		• EQ-5D-5L score	• 16-17			
	Impact on physical health	• Experienced burden of physical symptoms	• 0-17			
		• Impact on pain/discomfort	• 0-17			
	Impact on development**	• Developmental delay	• 0-17			
	Impact on psychological health	• Managing emotions	• 0-3			
		• Feeling worried, sad or unhappy	• 4-15			
		• Anxiety/Depression	• 16-17			
		• Experienced burden of psychological symptoms and emotional impact related to the health condition	• 0-17			
		• Impact on self-esteem	• 4-17			
	Impact on autonomy	• Movement	• 0-3			
		• Mobility	• 4-17			
		• Eating or drinking	• 0-3			
		• Looking after myself	• 4-15			



	Criteria	Indicators	Age group (years)	Comparison with the adult NEED framework		
		• Self-care	• 16-17			
		• Play	• 0-3			
		• Usual activities	• 4-17			
	Impact on adolescents' romantic relationships and sexual life*	• Impact on adolescents' romantic relationships and sexual life	• 16-17			
Healthcare needs	Treatment effectiveness	• Effectiveness of current overall treatment (standard of care)	• 0-17			
	Burden of treatment	• Burden of treatment side-effects	• 0-17			
		• Burden of treatment	• 0-17			
	Quality of care	• Coordination and continuity of care	• 0-17			
		• Received Information (parents)	• 0-17			
		• Received information (children)	• 12-17			
		• Involvement in treatment decision (parents)	• 0-17			
		• Participation to treatment (children)	• 4-11			
		• Involvement in treatment decision (children)	• 12-17			
		• Time from first presentation to diagnosis	• 0-17			
		• Appropriateness of diagnostic timing	• 0-17			
		• Quality of communication with health care providers (children)	• 0-17			
		• Quality of communication with health care providers (parents)	• 0-17			
		• Child-adapted inpatient environment	• 0-17			
		• Preparation of transfer from paediatric to adult care	• 16-17			
	Access to care	• Treatment availability	• 0-17			
		• Forgone care	• 0-17			

	Criteria	Indicators	Age group (years)	Comparison with the adult NEED framework		
	Research gaps	Research gaps	0-17			
Social needs	Impact on social life	Forgone child social support	0-17			
		Impact on personal relationships	0-17			
	Impact on education	- Impact on early foundational skills learning - Impact on education	0-3 4-17			
		Financial consequences	Out-of-pocket healthcare costs (per patient)	0-17		
	Financial difficulties attributed to the child’s health-condition		0-17			
	Non-healthcare costs		0-17			
	SOCIETAL DIMENSION					
Health needs	Frequency	Prevalence or incidence	0-17			
	Transmissibility	Contagiousness	0-17			
	Burden on parents’ health*	Impact on parents’ health	0-17			
Healthcare needs	Preventability	Implementation of effective primary prevention strategies	0-17			
	Value for money of care	Healthcare costs relative to the effectiveness of standard of care	0-17			
Social needs	Parents’ productivity losses*	Parents’ absenteeism related to the child’s health condition	0-17			
		Parents’ caregiving time burden	0-17			
		Work reduction or early labor force exits of parents	0-17			
	Impact on family**	Forgone family support	0-17			
		Impact on siblings’ well-being	0-17			
		Impact on parents’ social life	0-17			
		Greenhouse gas emissions related to the standard of care	0-17			
		Hazardous waste related to standard of care	0-17			





4.3.3 Indicators definitions and data collection methods

Definitions for shared indicators (section 4.3.1), were derived from the adult framework, while new definitions were developed for paediatric-specific indicators (section 4.3.1.2)

Table 2 presents the definition of each indicator together with its preferred and, where applicable, complementary data collection tool. The data collection tools are based on the eight existing instruments developed for adults and available in the NEED toolbox.⁵

To support the implementation of the paediatric framework, these instruments should be supplemented with questions addressing paediatric-specific indicators and adapted where necessary to reflect the paediatric context.



Table 2 – Final paediatric NEED framework

	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
EQUITY	PATIENT DIMENSION					
	Health needs	Impact on Life expectancy	• Years of life lost per death (YLLs)	• 0-17	The number of years of life lost (YLLs) due to the health condition, per death	Database analysis
			• Years of life lost per case (YLLs)	• 0-17	The number of years of life lost (YLLs) due to the health condition, per case	Database analysis
	Impact on general health-related quality of life		• Years of life lived with disability (per case) (YLDs)	• 0-17	The part of the year of life in perfect health lost due to disability or ill-health caused by the health condition, per case, over a period of one year.	Database analysis
			• EQ-TIPS-5L score	• 0-3	Average score of health-related quality of life (HRQOL) today, and the difference in the score today compared to prior to symptom onset, measured along 5 or 7 domains depending on the age-appropriate tool: • EQ-TIPS-5L : 0-3yrs • EQ-5D-Y-5L : 4-15 yrs • EQ-5D-5L : 16-17 yrs	Preferred: Paediatric NEED survey Complementary: Interviews
			• EQ-5D-Y-5L score	• 4-15		
			• EQ-5D-5L score	• 16-17		
	Impact on physical health		• Burden of physical symptoms related to the health condition	• 0-17	The level of burden of physical symptoms experienced by children over the last 2 years.	Preferred: Paediatric NEED survey Complementary: Interviews
			• Impact on pain/discomfort	• 0-17	The level of pain or discomfort due to the health condition, and the difference in the level of pain or discomfort today compared to before the onset of the first symptoms, measured using the age appropriate EUROQOL tool: • EQ-TIPS-5L : 0-3yrs • EQ-5D-Y-5L : 4-15 yrs • EQ-5D-5L : 16-17 yrs	Preferred: Paediatric NEED survey Complementary: Interviews



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
		Impact on development	Developmental delay	0-17	The level of functional impact and the persistence of this impact over time experienced by children in the 4 domains of cognition, socio-emotional, motor skills, and language skills. This impact can be as a consequence of the disease, its treatments (e.g., medication, radiation), or associated circumstances (e.g., environmental stimulation). Although developmental impacts may appear anytime from early infancy to around five years of age, their effects may persist beyond this age.	Clinical expert survey
		Impact on psychological health	- Managing emotions - Feeling worried, sad or unhappy - Anxiety/Depression	0-3 4-15 16-17	The level of problems with emotions due to health conditions, and the difference in the extent of emotional problems today compared to before the onset of the first symptoms, measured using the age appropriate EUROQOL dimension: - Managing emotions (EQ-TIPS-5L, 0-3 yrs) - Feeling sad, worried or unhappy (EQ-5D-Y-5L, 4-15 yrs) - Anxiety & depression (EQ-5D-5L, 16-17 yrs)	Preferred: Paediatric NEED survey Complementary: Interviews
			Experienced burden of psychological symptoms and emotional impact related to the health condition	0-17	The burden of psychological symptoms and emotional impacts experienced by children over the last 2 years.	Preferred: Paediatric NEED survey Complementary: Interviews
			Impact on self-esteem	4-17	The extent to which the health condition negatively interferes with the child's self-esteem. Self-esteem is defined here through two components: - Self-worth (how much individuals like, respect, and accept themselves, both in their own eyes and in the eyes of others) and; - Self-competence (feeling proud and believing in one's ability to succeed).	Preferred: Paediatric NEED survey Complementary: Interviews
		Impact on autonomy	- Movement - Mobility	0-3 4-17	The level of problems in movement or mobility due to the health condition, and the difference in the extent of movement or mobility problems today compared to before the onset of the first symptoms, measured using the age appropriate EUROQOL dimension:	Preferred: Paediatric NEED survey Complementary: Interviews



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
					• Movement (EQ-TIPS-5L, 0-3 yrs) • Mobility (EQ-5D-Y-5L, 4-15 yrs and EQ-5D-5L, 16-17 yrs)	
			• Eating or drinking • Looking after myself • Self-care	• 0-3 • 4-15 • 16-17	The level of problems with self-care due to the health condition, and the difference in the extent of self-care problems today compared to before the onset of the first symptoms, measured using the age-appropriate EUROQOL dimension: • Eating or drinking (EQ-TIPS-5L, 0-3 yrs) • Looking after myself (EQ-5D-Y-5L, 4-15 yrs) • Self-care (EQ-5D-5L, 16-17 yrs).	Preferred: Paediatric NEED survey Complementary: Interviews
			• Play • Usual activities	• 0-3 • 4-17	The level of problems with performing usual activities due to the health condition, and the difference in the extent of performing usual activities today compared to before the onset of the first symptoms, measured using the age-appropriate EUROQOL dimension: • Play (EQ-TIPS-5L, 0-3 yrs) • Usual activities (EQ-5D-Y-5L, 4-15 yrs; EQ-5D-5L, 16-17 yrs).	Preferred: Paediatric NEED survey Complementary: Interviews
			• Impact on adolescents' romantic relationships and sexual life	• 16-17	The level of impact of the health condition on children's romantic relationships and sexual life. Romantic relationships is described here as an interpersonal process characterized by emotional closeness, trust, reciprocity, and self-disclosure, which emerges in early adolescence and continues to evolve throughout adolescence, leading to increasingly diverse close relationships, including romantic ones.^{67, 68} The negative impact of the disease may occur during the formation or maintenance of a romantic relationship and may alter the initiation or continuity of sexual life.	Preferred: Paediatric NEED survey Complementary: Interviews
	Healthcare needs	Treatment effectiveness	• Effectiveness of current overall treatment (standard of care)	• 0-17	The overall effectiveness level of the current treatment. Treatment may include various interventions such as medications, surgery, medical procedures, medical devices, physical therapy, psychological therapy, and other forms of (clinical) interventions to cure the specific health condition, to target symptoms caused by the condition, or to prevent complications.	Clinical expert survey and literature review



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
		Burden of treatment	• Burden of treatment side-effects	• 0-17	The level of burden of side-effects associated with the treatment or management of the child's health condition over the last 2 years.	Preferred: Paediatric NEED survey Complementary: Interviews
			• Burden of treatment	• 0-17	The burden associated with the treatment on management of the child's health condition over the last 2 years, excluding treatment side-effects.	Preferred: Paediatric NEED survey Complementary: Interviews
		Quality of care	• Coordination and continuity of care	• 0-17	Coordination and continuity of care refer to patient care that is well-organised and planned over time, having a healthcare professional responsible for coordinating the care, as well as having continuity in the healthcare professionals who attend to the child.	Preferred: Paediatric NEED survey Complementary: Interviews
			• Received Information (parents) • Received information (children)	• 0-11 • 12-17	The extent to which the parents receive useful and understandable information regarding the child's health condition. By 'useful' we mean information which is up to date and coherent, and which helps the parents better understand and better manage the child's health condition. In addition, for children aged 12-17 years, the extent to which the child receives easy to understand and useful information from the health care professionals. By useful in children, we mean which helps him/her to better understand and better manage the health condition.	Preferred: Paediatric NEED survey Complementary: Interviews
			• Involvement in treatment decision (parents) • Participation to treatment (children) • Involvement in treatment decision (children)	• 0-17 • 4-11 • 12-17	For parents, the extent to which the parents would like to be more involved in the choices about the treatment for the health condition of their child. "Being more involved" refers to the possibility to state preferences, review treatment options, and have their views considered in the decision process. For children aged 4-11 years , the extent to which healthcare professionals encourage the child to take an active role in his/her care or treatment (medication, rehabilitation...). "Taking an active role" refers, for example, to being invited to express opinions, make minor choices, or participate in simple care tasks (e.g., holding equipment), and for older children, to independently recall their medication schedule.	Preferred: Paediatric NEED survey Complementary: Interviews



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
					For children aged 12-17 years , the extent to which healthcare professionals involve the child aged 12-17 years, in decisions regarding his/her care or treatment. "Involvement" refers, for example, to being addressed directly when treatment options are discussed, being encouraged to express opinions, and having those views considered in the decision-making process.	
			• Time from first presentation to diagnosis	• 0-17	The amount of time that has passed between the child's first medical appointment for the health condition and the diagnosis.	Preferred: Paediatric NEED survey Complementary: Interviews
			• Appropriateness of diagnostic timing	• 0-17	For diseases with an identifiable optimal diagnostic timing in the disease course, this indicator measures to what extent diagnosis tends to occur too late (causing avoidable disease progress or complications) or too early (leading to overdiagnosis).	Clinical expert survey
			• Quality of communication with health care providers (children) • Quality of communication with health care providers (parents)	• 0-17 • 0-17	The extent to which the parents feel listened to by the child's main healthcare professional (HCP). "Being listened to" refers to situations in which healthcare professionals pay attention to parents' concerns, acknowledge their input, and respond in a respectful and appropriate manner. The extent to which the healthcare professionals communicate with the child (0-17 years) in an age-appropriate, supportive, and respectful manner. "Appropriate communication" refers to practices that help the child feel comfortable, able to express themselves, and respected.	Preferred: Paediatric NEED survey Complementary: Interviews
			• Child adapted inpatient environment	• 0-17	The extent to which the hospital inpatient environment supports the comfort, well-being and ease of children who have had an overnight hospital stay within the last two years. For children aged 0-11 years old , a child-adapted environment is described as one that promotes parental involvement in care, offers the possibility for parents to stay overnight, and provides a reassuring atmosphere, adapted play or activities, and appropriate pain management.	Preferred: Paediatric NEED survey Complementary: Interviews



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
					For children aged 12-17 years old , a child-adapted environment is described as a comfortable and age-appropriate setting, including suitable activities or spaces, a respectful and reassuring atmosphere, and appropriate pain management	
			• Preparation of transfer from paediatric to adult care	• 16-17	The extent to which children receive adequate information and support from healthcare professionals to prepare for the transition from paediatric to adult care, such as guidance, planning, or introduction to adult services.	Preferred: Paediatric NEED survey Complementary: Interviews
		Access to care	• Treatment availability	• 0-17	The extent to which children can access medical treatments for a given disease. It encompasses not only the existence of treatments, but also their authorisation, commercialisation, affordability and practical accessibility for patients within a specific country.	Clinical expert survey
			• Forgone care	• 0-17	Forgone care refers to health care that the child is not receiving (e.g. treatment, consultations, medical tests, rehabilitation, or other) despite needing it. This can be due to several reasons, including costs, waiting lists, or transport difficulties.	Preferred: Paediatric NEED survey Complementary: Interviews
		Research gaps	• Research gaps	• 0-17	The extent to which research gaps exist in the following areas: pathophysiology, diagnosis, pharmacopredictive biomarkers, prognostic biomarkers, treatment, primary prevention, inequities, and other possible additional areas.	Clinical expert survey and scientific literature review
	Social needs	Impact on social life	• Forgone child's social support	• 0-17	The extent to which the child needs additional social support (e.g. psychological support, school support) because of their health condition, without getting it.	Preferred: Paediatric NEED survey Complementary: Interviews
			• Impact on personal relationships	• 0-17	The level of negative impact of the child's health condition on the relationships between: • Children and parents. For children aged 0 to 3 years, this might include problems in bonding and emotional security, such as the responses to the baby's needs, the quality of interactions, and the baby's interest in the parents' voice.	Preferred: Paediatric NEED survey Complementary: Interviews



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
					Children and parents. For children aged 4-17 years, it might include communication problems or less qualitative interactions. Children and peers and friends, both at school/creche and outside of school/creche	
		Impact on education	- Impact on early foundational skills learning - Impact on education	0-3 4-17	For children aged 0-3 years, the extent to which the health condition has affected children early foundational skills learning in terms of learning language, play, motor skills, basic problem-solving, or early numeracy skills. For children aged 4-17 years, the extent to which the health condition has affected children schooling or studies, in terms of attendance, performance, success, or study choices.	Preferred: Paediatric NEED survey Complementary: Interviews
		Financial consequences	Out-of-pocket healthcare costs (per patient)	0-17	Healthcare costs that the child's family must pay themselves when accessing healthcare, due to incomplete coverage by public health insurance for certain medical goods and services.	Preferred: database analysis Complementary: - literature search - Interviews
			Financial difficulties attributed to the child's health-condition	0-17	The extent to which the child's family experience financial difficulties due to the child's health condition or its medical treatment	Preferred: Paediatric NEED survey Complementary: Interviews
			Non-healthcare costs	0-17	Costs that the family must cover for aspects other than medical care, but that are nevertheless a consequence of the disease. This indicator covers several types of costs, such as transportation, accommodation, adaptations of the home, the workplace or the car, support and assistance for day-to-day activities, institutionalisation, specialised equipment, technology and subscriptions, education, School-related or learning-related costs, personal hygiene items, specific diets or nutritional supplements, prescribed sporting activities, adapted clothing or shoes, increased energy costs, increased waste costs, additional insurance costs, additional costs for leisure activities or travel.	Preferred: The evaluation of the checklist can be based on any or a combination of the following methods. - Expert consultation, including patient representatives - Literature research - Interviews



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
						These sources are considered equivalent, and there is no order of priority to follow.
	SOCIETAL DIMENSION					
	Health needs	Frequency	Prevalence incidence or	0-17	Prevalence: the total number of individuals in the population who have the health condition in a given time period. Incidence: the number of individuals who develop the health condition during a particular time period.	Database analysis
		Transmissibility	Contagiousness	0-17	The extent to which an infectious disease can be directly or indirectly transmitted from one person to another. This is measured by the basic reproduction number (average number of secondary infections produced by a typical case of an infection in a population where everyone is susceptible).	Scientific literature reviews
		Burden on parents' health	Impact on parents' health	0-17	The extent to which the health condition negatively impacts the physical and psychological health of the respondent parents.	Preferred: Paediatric NEED survey Complementary: Interviews
	Healthcare needs	Preventability	Implementation of effective primary prevention strategies	0-17	The extent to which effective primary prevention strategies are implemented for the given health condition.	Clinical expert survey
		Value for money of standard of care	Healthcare costs relative to the effectiveness of standard of care	0-17	Healthcare costs of standard of care refer to those costs borne by the healthcare payers (including the public healthcare payer and patients), per year and per patient, for standard of care. Standard of care refers to the clinical management of the disease, including the diagnostic approach and treatment that is widely accepted by medical experts as appropriate for managing a specific disease and is commonly used in clinical practice, also known as best practice, standard medical care, or standard therapy.	Preferred: database analysis Complementary: scientific literature review
	Social needs		Parents' absenteeism related	0-17	The parents' absence from work due to the child's illness.	Paediatric NEED survey



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
		Parents' productivity losses	to the child's health condition			Database analysis in case the linkage between the child's and the parents is available
			Parents' caregiving time burden	0-17	The frequency with which a child requires additional parental assistance or supervision because of their health condition. This can include for example personal care (such as dressing/undressing, going to the toilet...), household tasks (such as playing, doing homework...), or practical support (such as accompanying the child to medical or other appointments...) or psychological support (help coping with the disease). It only accounts for additional needs attributable to the health condition, beyond those expected for a typically developing child of the same age.	Preferred: Paediatric NEED survey Complementary: Interviews
			Work reduction or early labour force exits of parents	0-17	The extent to which the child's health condition has impacted the respondent parent and the non-respondent parent (if known by the respondent parent) ability to remain professionally active since the child's diagnosis, causing a reduction in working hours.	Preferred: Paediatric NEED survey Complementary: Interviews
		Impact on family	Forgone family support	0-17	The extent to which the family need additional social support because of the child's health condition, without getting it. It covers unmet support needs among family members, including practical, psychological, educational, administrative, and community-based support, as well as workplace accommodations and respite resources.	Preferred: Paediatric NEED survey Complementary: Interviews
			Impact on siblings' well-being	0-17	The extent to which the child's health condition negatively affects the well-being of the other children living in the same household, including psychological, physical, and social dimensions.	Preferred: Paediatric NEED survey Complementary: Interviews
			Impact on parents' social life	0-17	The extent to which the child's health condition negatively impacts the parents' social life.	Preferred: Paediatric NEED survey Complementary: Interviews



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
		Environmental impact of standard of care	Greenhouse gas emissions related to the standard of care	0-17	The estimated amount of direct greenhouse gas emissions (scope 1: emitted by healthcare providers), and indirect greenhouse gas emissions (scope 2: derived from primary resources, and scope 3: derived from products used by healthcare providers) related to the standard of care for the health condition.	Scientific and/or grey literature review
			Hazardous waste related to standard of care	0-17	The estimated volume of hazardous (e.g. radioactive, infectious) waste generated as part of the standard of care for the health condition.	Scientific and/or grey literature review
			Use of natural resources and raw materials related to standard of care	0-17	The estimated volume of natural resources and raw materials utilised in the standard of care for the health condition.	Scientific and/or grey literature review
	FUTURE DIMENSION					
	Health needs	Forecasted burden of disease	Forecasted incidence or prevalence	0-17	The total number of individuals in the population who are estimated to have the health condition at a specific period of time in the future.	Database analysis
			Forecasted years of life lost, per death	0-17	The future number of years of life lost (YLLs) due to the health condition, per death	Database analysis
			Forecasted years of life lost, per case	0-17	The future number of years of life lost (YLLs) due to the health condition, per case	Database analysis
			Forecasted years lived with disability, per case	0-17	The future part of the year of life in perfect health lost due to disability or ill-health caused by the health condition, per case, over a period of one year (YLDs)	Database analysis
	Healthcare needs	Forecasted healthcare costs	Forecasted healthcare costs attributable to the health condition	0-17	This indicator reflects the projected healthcare costs associated with the specified health condition, covering costs borne by both public healthcare payers and patients in future years. For this indicator the perspective from the society is taken, and it is presented as a cost in Euros per 100 000 inhabitants.	Preferred: database analysis Complementary: scientific literature research
	Social needs	Forecasted parents'	Forecasted parents' productivity losses	0-17	This indicator reflects the projected productivity losses attributable to the specified health condition. Productivity losses may occur due to	Preferred: database analysis



	Domain	Criterion	Indicator	Age group (years)	Definition	Data collection method*
		productivity losses	attributable to the health condition		absenteeism, as well as through early labour force exits and work reduction. In the context of the indicator on forecasted productivity losses, the focus lies on those losses linked to absenteeism. To be coherent with the indicator (absenteeism), this indicator is measured (in days absence) but not valued (in Euros). Since, for this indicator on forecasted productivity losses, the perspective from the society is taken, it is presented per 100 000 inhabitants in a given year.	Complementary: scientific literature research

Data collection methods are based on the NEED Toolbox, which provides detailed guidance on the different instruments, including a systematic search strategy to perform systematic literature reviews, patient (or proxy) surveys, patient (or proxy) interviews, a checklist of non-healthcare costs, database analyses, and clinical expert consultation. A paediatric adaptation of some of these tools, such as the NEED survey, is being developed.⁵

5 DISCUSSION

The paediatric NEED framework builds on the adult NEED framework by extending the assessment of unmet health-related needs to paediatric health conditions and health conditions with onset during childhood. While maintaining the conceptual architecture of the adult framework, its adaptation to paediatric populations required the addition, modification and removal of several indicators to reflect the specificities of the paediatric population.

CONCEPTUAL CONTRIBUTION OF THE PAEDIATRIC NEED FRAMEWORK

When considering the indicators and criteria of the paediatric NEED framework, substantial overlap is observed with the International Classification of Functioning, Disability and Health-Child and Youth⁶⁹, and assessment initiatives identifying key health-related domains and unmet needs in paediatric populations^{54, 70-72}, as well as with family-oriented models.^{73, 74} This convergence indicates conceptual and thematic alignment with existing models and suggests that the framework captures domains widely recognised as important for children's health and well-being, although it does not constitute formal evidence of content validity. These models primarily aim to guide individual clinical care, whereas the conceptual contribution of the paediatric NEED framework lies in bringing together these domains within an integrated unmet-needs perspective. The framework uses individual-level data not as an end point for clinical decision-making, but as a means of understanding and quantifying unmet health-related needs at the aggregated population level to inform research, innovation and health policy. While its content is largely consistent with existing frameworks and initiatives, its conceptual organisation differs by integrating the patient's perspective, societal consequences, and future health considerations within a single operational framework while embedding equity as a cross-cutting dimension throughout the framework. Furthermore, whereas most existing frameworks focus on functioning, quality of life, or family impact separately, the NEED framework combines these dimensions with broader societal impacts, such as healthcare utilisation and costs, within a common conceptual structure.

The harmonised architecture of the paediatric and adult NEED frameworks further extends this contribution by providing a unique opportunity to assess unmet health-related needs across the lifespan, from childhood to adulthood. Ensuring comparable indicator definitions across age groups represents a first step towards this objective. Nevertheless, comparable definitions alone do not guarantee measurement equivalence across developmental stages. For example, even when indicators are conceptually aligned, such as *Involvement in treatment decision-making*, the way in which the underlying construct is expressed may differ across developmental stages. Although the indicator is defined identically for adolescents and adults and adapted for younger children to reflect participation in treatment, its measurement equivalence should be demonstrated empirically before scores are compared across age groups.

Future NEED studies should therefore evaluate measurement invariance of the harmonised indicators using appropriate psychometric approaches.^{75, 76} For health-related quality-of-life indicators, this work may build on the harmonisation efforts currently undertaken by the EuroQol group.

CONCEPTUAL ADAPTATION TO PAEDIATRIC POPULATIONS

The paediatric-specific features of this framework were guided by three key conceptual adaptations. First, unmet health-related needs were adapted to child development, taking into account the evolution of children's cognitive, physical, emotional and social capacities. Second, the role of parents was defined by recognising their dual role as partners in the child's care and as contributors to the child's social development, particularly through the parent-child relationship. Third, the central role of the family in paediatrics was taken into account in the societal dimension of the framework, including for instance siblings' well-being.

These principles guided several adaptations throughout the framework, including indicator and criterion definitions to reflect children's development, the development of child-specific items, and the



exclusion of elements that were not relevant in the paediatric context. Among these adaptations, two merit particular discussion because they required conceptual choices that differ from existing assessment approaches.

Assessing the impact of health conditions on child development presents a particular challenge because existing development assessment tools are primarily designed to identify developmental delay rather than to evaluate unmet health-related needs.⁷⁷⁻⁸⁰ The proposed indicator therefore aims to assess the extent to which the health condition, its management or its consequences have influenced the child's development throughout childhood and adolescence. Rather than relying solely on the child's developmental status at the time of assessment, clinicians are asked to consider the overall impact of the condition over the course of childhood, including whether developmental delays persist over time or whether children catch up. Although assessed cross-sectionally, the indicator therefore captures clinicians' judgement of the child's developmental evolution rather than a single point-in-time assessment. This shifts the focus from identifying developmental impairment to assessing unmet health-related needs affecting child development.

Existing approaches to the transition from paediatric to adult care mainly assess patients' transition readiness^{81, 82} or outcomes following transfer to adult care. The NEED framework instead evaluates whether healthcare professionals provide adequate preparation for transfer, rather than whether the young person is ready for transition. Accordingly, the paediatric framework includes preparation for transfer as a process indicator, while the adult framework captures transition-related unmet needs experienced after transfer as an outcome indicator. Together, these indicators reflect the transition process across both paediatric and adult care and are consistent with current conceptual models and international recommendations.^{29, 60, 83} By combining process and outcome indicators across the paediatric and adult frameworks, the NEED framework provides a unique opportunity to identify and assess unmet health-related needs across the transition from paediatric to adult care, which is particularly relevant for individuals with chronic conditions originating in childhood.

METHODOLOGICAL CONSIDERATIONS

Literature mapping and stakeholder consultations are considered complementary approaches for conceptual framework development, combining broad conceptual coverage with clinical relevance.⁸⁴⁻⁸⁶ Including all study designs in the mapping review reduced the risk of overlooking unmet health-related needs that have received limited research attention, particularly those emerging from qualitative research. However, because mapping reviews prioritise conceptual coverage over critical appraisal, the methodological quality of the included studies was not formally assessed. In addition, most included studies were observational, which are inherently more susceptible to certain sources of bias than experimental study designs. Consequently, some concepts incorporated into the framework may be supported by limited or lower-quality evidence.

From the preliminary paediatric framework informed by the literature mapping, the removal of a substantial proportion of initially identified indicators and criteria in developing the final paediatric NEED framework primarily reflects the expected consolidation of an intentionally broad, literature-derived framework, as most elements were removed because of duplication or conceptual overlap. The literature review was complemented by structured consultation with clinicians, experts by experience and researchers. This stakeholder triangulation strengthened the relevance and conceptual consistency of the framework, while supporting the retention of indicators that were only sparsely represented in the literature, such as the environmental impact of healthcare and future-oriented indicators and criteria. The use of predefined decision criteria further improved the transparency and consistency of the refinement process by providing a structured basis for discussion and decision-making, while reducing reliance on individual expert opinion.

As the paediatric framework builds on the adult NEED conceptual architecture validated through a formal Delphi consensus process,¹ this study focused on identifying and validating paediatric-specific adaptations rather than re-establishing consensus on the overall framework structure. Future NEED

researchers should nevertheless determine the feasibility and measurement properties of the proposed indicators.

The mapping review included studies involving children with a wide range of health conditions, as well as children from the general paediatric population and vulnerable populations. Including these diverse populations broadened the range of unmet health-related needs considered during framework development beyond those identified in clinical populations. This supports the applicability of the framework across a broad range of paediatric health conditions. Like the adult NEED framework, the paediatric framework was intentionally developed as a generic instrument to enable comparison of unmet health-related needs across health conditions. Although this approach may not capture every disease-specific nuance, it provides a common framework for consistently assessing unmet health-related needs across diverse paediatric conditions.

Developmental stage, rather than chronological age alone, guided the adaptation of the framework. As child development is a continuous process, age categories were used as a pragmatic way to operationalise developmental stages rather than as strict cut-offs. The resulting framework includes specific adaptations for children aged 0-3, 4-11, 12-15, and 16-17 years, broadly reflecting developmental stages described in the paediatric literature.^{41, 72, 87, 88} The most substantial adaptations concerned adolescence, reflecting emerging needs such as preparation for transition to adult care and romantic relationships and sexual life. Although the neonatal period and infancy are sometimes recognised as distinct developmental stages, neither the mapping review nor stakeholder consultation identified the need for dedicated indicators. Existing indicators, including mortality, feeding, parent-infant interactions, a child-adapted care environment including specific infant aspects, diagnostic delay and family-centred care related indicators, were considered sufficient to capture unmet health-related needs during this period. Whether additional neonatal-specific indicators are required should be explored in future studies specifically involving neonatal populations.

LIMITATIONS

The mapping review focused on peer-reviewed literature and did not include a grey literature search. Relevant unmet needs, particularly in under-researched populations may have been overlooked. This risk was partly mitigated by expert consultations. Future updates could consider a more systematic inclusion of grey literature.

The selection of indicators was constrained by their feasibility of measurement. Consequently, some concepts considered relevant to paediatric unmet health-related needs were not retained because no scalable and measurable approaches were found within healthcare systems. As health information systems and measurement methods evolve, these concepts may become suitable for future versions of the framework. The concerned themes are reported in the table below:

CONCEPTS TO BE CONSIDERED IN FUTURE VERSIONS OF THE FRAMEWORK

FROM THE PRELIMINARY VERSION OF THE PAEDIATRIC FRAMEWORK

Implementation of clinical guidelines

Engagement in clinical trials

Appropriate assessment

Supportive child-friendly environment

DISCUSSED DURING EXPERT CONSULTATIONS

Healthcare professionals with appropriate paediatric expertise

Language and cultural barriers with healthcare professionals

The framework analysis and initial categorisation were conducted by a single researcher and were not independently duplicated, which may have introduced some interpretative subjectivity. However, the supporting file linking framework components to representative extracted data was reviewed during



internal expert discussions, and comments were incorporated into the final paediatric NEED framework.

The use of the generic EQ-5D-5L was intended to support a standardised assessment of quality of life within and across diseases, but generic EQ-5D instruments may not capture all aspects relevant to specific paediatric conditions. In particular, the mobility dimension is primarily interpreted in terms of walking ability, with uncertainty regarding the use of assistive devices, and may not fully reflect the extent of mobility abilities nor the functional impact of mobility limitations. Other limitations have been raised regarding content validity, such as limited coverage of communication, social engagement and difficulties in proxy-reporting subjective domains such as pain and emotions, and potential limitations of the “today” recall period for fluctuating health states. These issues will be taken into account when interpreting EQ-5D-5L data in future NEED studies and when refining the paediatric measurement approach.^{89, 90}

Implementing the framework may be challenging in paediatric populations because many childhood conditions are rare. This may limit condition-specific analyses and, in some situations, require broader diagnostic groupings. The rare disease adaptation of the NEED framework may partly address this challenge by enabling analyses based on broader families of conditions rather than individual diagnoses.³⁸ A similar issue may arise in very early childhood, where diagnostic classification is often evolving and broader groups of diagnoses may be more appropriate. Finally, the optimal frequency for reassessing unmet health-related needs remains uncertain and is likely to differ according to disease characteristics and the pace of therapeutic innovation. Some clinical caveats already exist for re-assessment.⁷²

As the framework starts at birth, unmet needs specific to the prenatal period were out-of-scope. Nevertheless, prenatal exposures and determinants may still be relevant insofar as they shape postnatal health conditions, unmet needs, or research gaps, and may therefore be captured through other relevant indicators within the framework.

FUTURE RESEARCH

The next step is the operationalisation of the paediatric NEED framework by defining measurement methods and data collection tools for each indicator.^{4, 5} This process will largely build on the methods and instruments developed for the adult NEED framework (i.e., NEED protocol and NEED Toolbox), given the alignment of most of the indicators across both frameworks. Existing adult tools, including the online survey and qualitative interview guide, are currently being adapted to paediatric populations to reflect the paediatric framework. Additional adaptations address paediatric-specific considerations related to data collection, including the integration of both child and parent perspectives, the identification of the most appropriate respondent according to the child’s age and developmental stage to ensure that children are represented even when self-report is not appropriate or possible, and the need for some subjective domains to be preferentially assessed from the child’s own perspective. These adaptations will also define age-appropriate consent and assent procedures and appropriate data-protection safeguards for collecting health-related data from children, in accordance with applicable regulatory requirements. Following adaptation, these paediatric measurement tools should be validated to ensure their reliability, validity, and appropriateness across paediatric age groups before their wider implementation.

Equity considerations are already embedded in NEED data collection through diverse recruitment strategies, the collection of relevant sociodemographic characteristics, and subgroup analyses where sample sizes allow. The paediatric adaptation extends this approach by also considering specific situations, such as children living in out-of-home care.

The application of the paediatric NEED framework is currently underway in a study on the unmet health-related needs of adolescents and adults with sickle cell disease, providing an opportunity to evaluate the feasibility of the framework and its associated measurement tools in practice. As the paediatric framework is part of the broader NEED initiative, data collected in future paediatric NEED

studies will be integrated into the existing NEED database. This integrated database will create opportunities to assess unmet health-related needs across the lifespan within the same health condition and across different health conditions. However, before comparing or aggregating results across age groups, future research should evaluate the comparability of paediatric and adult indicators using appropriate harmonisation methods.

In addition, although the NEED framework currently adopts a cross-sectional approach, the harmonised architecture of the paediatric and adult frameworks provides a common conceptual framework that could facilitate future longitudinal research on the evolution of unmet health-related needs across the life course. Generating such data, whether for conditions with onset in childhood that persist into adulthood or for conditions specific to paediatric populations, is particularly relevant in the context of recognised gaps in paediatric data. Finally, the current framework focuses on the systematic identification and measurement of unmet health-related needs in childhood health conditions, whether they occur exclusively during childhood or also affect other age groups. A logical next step is the development of priority-setting methods that build on data collected using the framework, enabling unmet health-related need assessments to support structured healthcare decision-making, research prioritisation and healthcare innovation.

6 CONCLUSION

The development of the paediatric NEED framework represents an important step towards a needs-driven approach to healthcare innovation and policy in paediatrics. By extending the NEED initiative to children, it provides a structured framework for assessing unmet health-related needs while accounting for the specific developmental, familial and societal context of paediatric care. By integrating these perspectives within a common conceptual structure, the framework provides a foundation for generating evidence that can better inform research priorities, healthcare innovation and policy decisions.

A key strength of the paediatric framework is that it preserves the conceptual architecture of the adult NEED framework while introducing adaptations where required. This shared architecture enables unmet health-related needs to be identified from patient, societal and future perspectives and allows paediatric data to be integrated into the NEED database. It also establishes the basis for a harmonised assessment of unmet health-related needs across the life span, provided that appropriate measurement harmonisation is achieved.

The next phase of the initiative is the operationalisation of the paediatric framework through the adaptation of the existing NEED protocol and toolbox to paediatric populations. The protocol will define the measurement methods for each indicator, while the toolbox will provide the corresponding measurement instruments, including adapted versions of the online survey and qualitative interview guide. These tools will support the systematic assessment of paediatric health-related unmet needs and the generation of comparable evidence across health conditions.

The NEED framework has been conceived as an evolving initiative that will continue to be refined as new evidence, measurement methods and health data become available. Its first application is currently underway in a study investigating the unmet health-related needs of adolescents and adults with sickle cell disease, providing the first opportunity to evaluate the framework and its associated measurement tools in real-world practice and to inform their further refinement. Future applications across a wider range of paediatric health conditions will further strengthen the framework, enhance its measurement properties, and contribute to a more robust evidence base for needs-driven healthcare decision-making. Ultimately, the paediatric NEED framework provides the foundation for a systematic and comparable assessment of unmet health-related needs across paediatric health conditions, while ensuring continuity with the adult framework to support needs-driven healthcare decision-making across the life span.



■ APPENDICES

APPENDIX 1. FULL SEARCH STRATEGY

Date	06/05/2025	
Database	OVID	
Search number	strategy	Results
#1	*Surveys and Questionnaires/	50144
#2	*Self Report/	8886
#3	*Qualitative Research/	11939
#4	*Interviews as Topic/	5045
#5	*Focus Groups/	3388
#6	*Patient Participation/	17397
#7	*Needs Assessment/	9913
#8	*Patient Outcome Assessment/	2270
#9	*Health Services Research/	16146
#10	Survey*.ti,kf	233721
#11	Questionnaire*.ti,kf	64207
#12	(Health adj2 Research).ti,kf	19965
#13	(Self adj2 report*).ti,kf	28049
#14	(Qualitative adj2 stud*).ti,kf	2750
#15	((patient* OR child*) adj2 assessment*).ti,kf	
#16	((patient* OR child*) adj2 participation).ti,kf	
#17	((patient* OR child*) adj2 engagement).ti,kf	
#18	(health adj2 service*).ti,kf	72645
#19	(need* adj2 assessment*).ti,kf	4738
#20	Focus group*.ti,kf	8054
#21	Interview*.ti,kf	51304
#22	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21	596723
#22	(Unmet adj6 (need? or demand?)).kf,ti.	6464
#23	(societal adj6 (need? or demand?)).kf,ti.	61
#24	(Population adj6 (need? or demand?)).kf,ti.	1408
#25	(Community adj6 (demand? or need?)).kf,ti.	2200
#26	(Health adj6 (need? or demand?)).kf,ti.	15575
#27	(Healthcare adj6 (demand? or need?)).kf,ti.	2021
#28	(care adj6 (demand? or need?)).kf,ti.	14645
#29	(Medical adj6 (demand? or need?)).kf,ti.	3718
#30	(therap* adj6 (need? or demand?)).ti,kf.	2642
#31	(child* adj6 (need? or demand?)).kf,ti.	5943
#32	(new-born* adj6 (need? or demand?)).kf,ti.	1
#32	(newborn* adj6 (need? or demand?)).kf,ti.	170
#33	(toddler* adj6 (demand? or need?)).kf,ti.	29
#34	(adolescent* adj6 (need? or demand?)).kf,ti.	1391
#35	(infan* adj6 (demand? or need?)).kf,ti.	611
#36	(pre-school adj6 (demand? or need?)).kf,ti.	11
#37	(preschool adj6 (demand? or need?)).kf,ti.	62
#38	(bab* adj6 (need? or demand?)).kf,ti.	163
#39	(juvenil* adj6 (demand? or need?)).kf,ti.	74
#40	(kid? adj6 (need? or demand?)).kf,ti.	52
#41	(minors adj6 (need? or demand?)).kf,ti.	14
#42	(neonat* adj6 (demand? or need?)).kf,ti.	372
#43	(p?diatric adj6 (demand? or need?)).kf,ti.	1095
#44	(puber* adj6 (need? or demand?)).kf,ti.	16
#45	(school* adj6 (need? or demand?)).kf,ti.	1095
#46	(teen* adj6 (need? or demand?)).kf,ti.	126
#47	(youth* adj6 (need? or demand?)).kf,ti.	650
#48	(youngster* adj6 (need? or demand?)).kf,ti.	3
#49	(NICU adj6 (need? or demand?)).kf,ti.	40



#50	(PICU adj6 (need? or demand?)).kf,ti.	7
#51	(boy* adj6 (need? or demand?)).kf,ti.	32
#52	(girl* adj6 (need? or demand?)).kf,ti.	100
#53	(underage? adj6 (need? or demand?)).kf,ti.	4
#54	(under-age? adj6 (need? or demand?)).kf,ti.	3
#55	(kindergarten adj6 (need? or demand?)).kf,ti.	7
#56	(neonat* adj6 (need? or demand?)).kf,ti.	372
#57	#22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56	46513
#58	limit 57 to (yr="2014 -Current" and "all child (0 to 18 years)")	1527
	EMBASE	
#1	'questionnaire'/exp/mj	49,672
#2	'self report'/exp/mj	11,769
#3	'qualitative research'/exp/mj	28,397
#4	'interview'/exp/mj	23,795
#5	'patient participation'/exp/mj	12,099
#6	'needs assessment'/exp/mj	7,853
#7	'health services research'/exp/mj	11,223
#8	'patient engagement'/exp/mj	1,275
#9	'patient empowerment'/exp/mj	296
#10	survey*:ti,kw	283,529
#11	questionnaire*:ti,kw	88,227
#12	(qualitative NEAR/2 research):ti,kw	30,063
#13	(qualitative NEAR/2 stud*):ti,kw	56,408
#14	interview*:ti,kw	56,788
#15	'focus group*':ti,kw	9,494
#16	(patient* NEAR/2 participation):ti,kw	3,420
#17	(need* NEAR/2 assessment*):ti,kw	6,391
#18	(health NEAR/2 service*):ti,kw	78,735
#19	(health NEAR/2 research):ti,kw	23,395
#20	(self NEAR/2 report):kw,ti	9,454
#21	(child* NEAR/2 participation):ti,kw	904
#22	(child* NEAR/2 empowerment):ti,kw	43
#23	(child* NEAR/2 engagement):ti,kw	181
#24	(patient* NEAR/2 engagement):ti,kw	3,394
#25	(patient* NEAR/2 empowerment):ti,kw	1,326
#26	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26	649,452
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#29	(population NEAR/6 (need? OR demand?)):kw,ti	858
#30	(community NEAR/6 (need? OR demand?)):kw,ti	1,755
#31	(health NEAR/6 (need? OR demand?)):kw,ti	11,703
#32	(healthcare NEAR/6 (need? OR demand?)):kw,ti	1,639
#33	(care NEAR/6 (need? OR demand?)):kw,ti	10,826
#34	(medical NEAR/6 (need? OR demand?)):kw,ti	1,915
#35	(therap* NEAR/6 (need? OR demand?)):kw,ti	948
#36	(child* NEAR/6 (need? OR demand?)):kw,ti	4,975
#37	('p?diatric*' NEAR/6 (need? OR demand?)):kw,ti	956
#38	('newborn*' NEAR/6 (need? OR demand?)):kw,ti	64
#39	(toddler* NEAR/6 (need? OR demand?)):kw,ti	21
#40	(adolescent* NEAR/6 (need? OR demand?)):kw,ti	1,203
#41	(infan* NEAR/6 (need? OR demand?)):kw,ti	293
#42	('preschool*' NEAR/6 (need? OR demand?)):kw,ti	70
#43	('bab*' NEAR/6 (need? OR demand?)):kw,ti	70
#44	('juvenil*' NEAR/6 (need? OR demand?)):kw,ti	56
#45	(kid? NEAR/6 (need? OR demand?)):kw,ti	14
#46	(puber* NEAR/6 (need? OR demand?)):kw,ti	5
#47	(school* NEAR/6 (need? OR demand?)):kw,ti	705
#48	(teen* NEAR/6 (need? OR demand?)):kw,ti	102
#49	(youth* NEAR/6 (need? OR demand?)):kw,ti	594
#50	(youngster* NEAR/6 (need? OR demand?)):kw,ti	3



#51	(nicu NEAR/6 (need? OR demand?):kw,ti	26
#52	(picu NEAR/6 (need? OR demand?):kw,ti	6
#53	(boy* NEAR/6 (need? OR demand?):kw,ti	14
#54	(girl* NEAR/6 (need? OR demand?):kw,ti	54
#55	(kindergarten NEAR/6 (need? OR demand?):kw,ti	5
#56	(neonat* NEAR/6 (need? OR demand?):kw,ti	121
#57	(teen* NEAR/6 (need? OR demand?):kw,ti	102
#58	'unmet medical need'/exp	4,274
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#60	#59 AND #26	7,969
#61	#60 AND ([newborn]/lim OR [infant]/lim OR [child]/lim OR [preschool]/lim OR [school]/lim OR [adolescent]/lim) AND [2014-2025]/py	1,260
#62	#61 NOT ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)	1,067
#63	#62 NOT [medline]/lim	182
	COCHRANE	
#1	[mh ^"Surveys and Questionnaires"[m]]	264
#2	[mh ^"Self Report"[m]]	153
#3	[mh ^"Qualitative Research"[m]]	208
#4	[mh ^"Interviews as Topic"[m]]	28
#5	[mh ^"Focus Groups"[m]]	41
#6	[mh ^"Patient Participation"[m]]	175
#7	[mh ^"Needs Assessment"[m]]	18
#8	[mh ^"Patient Outcome Assessment"[m]]	36
#9	[mh ^"Health Services Research"[m]]	21
#10	survey*:ti	3364
#11	questionnaire*:ti	2513
#12	(self NEAR/2 report):ti	379
#13	(qualitative NEAR/2 research):ti	72
#14	(qualitative NEAR/2 stud*):ti	1799
#15	Interview*:ti	2836
#16	(Focus Group*):ti	156
#17	(Patient NEAR/2 Participation):ti	94
#18	(child* NEAR/2 Participation):ti	69
#19	(need* NEAR/2 Assessment*):ti	90
#20	(Patient* NEAR/2 engagement):ti	222
#21	(child* NEAR/2 engagement):ti	19
#22	(Patient* NEAR/2 assessment*):ti	675
#23	(child* NEAR/2 assessment*):ti	102
#24	(Health NEAR/2 Service*):ti	1285
#25	(health NEAR/2 research):ti	254
#26	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25	13992
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#28	(societal NEAR/6 (need? or demand?):ti	0
#29	(community NEAR/6 (need? or demand?):ti	50
#30	(population NEAR/6 (need? or demand?):ti	24
#31	(health NEAR/6 (need? or demand?):ti	216
#32	(healthcare NEAR/6 (need? or demand?):ti	28
#33	(care NEAR/6 (need? or demand?):ti	394
#34	(medical NEAR/6 (need? or demand?):ti	65
#35	(therap* NEAR/6 (need? or demand?):ti	248
#36	(child* NEAR/6 (need? or demand?):ti	214
#37	(newborn* NEAR/6 (need? or demand?):ti	13
#38	(toddler? NEAR/6 (need? or demand?):ti	2
#39	(infan* NEAR/6 (need? or demand?):ti	43
#40	(adolescen* NEAR/6 (need? or demand?):ti	57
#41	(preschool NEAR/6 (need? or demand?):ti	14
#42	(neonat* NEAR/6 (need? or demand?):ti	20

#43	(bab* NEAR/6 (need? or demand?)):ti	4
#44	(underage? NEAR/6 (need? or demand?)):ti	0
#45	(girl* NEAR/6 (need? or demand?)):ti	2
#46	(boy* NEAR/6 (need? or demand?)):ti	0
#47	(kindergarten NEAR/6 (need? or demand?)):ti	0
#48	(NICU NEAR/6 (need? or demand?)):ti	2
#49	(PICU NEAR/6 (need? or demand?)):ti	0
#50	(youngster* NEAR/6 (need? or demand?)):ti	0
#51	(youth NEAR/6 (need? or demand?)):ti	13
#52	(teen* NEAR/6 (need? or demand?)):ti	4
#53	(school* NEAR/6 (need? or demand?)):ti	16
#54	(puber* NEAR/6 (need? or demand?)):ti	0
#55	(p?ediatric NEAR/6 (need? or demand?)):ti	25
#56	(minors NEAR/6 (need? or demand?)):ti	0
#57	(juvenil* NEAR/6 (need? or demand?)):ti	1
#58	(kid? NEAR/6 (need? or demand?)):ti	1
#59	#27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58	1328
#60	[mh ^"Adolescent Health Services"]	227
#61	[mh ^"Adolescent Health"]	73
#62	[mh ^Adolescent]	136477
#63	[mh ^"Child Care"]	156
#64	[mh ^"Child Development"]	2702
#65	[mh ^"Child Health Services"]	500
#66	[mh ^Child]	72181
#67	[mh ^"Parent-Child Relations"]	1605
#68	[mh ^"Child Health"]	275
#69	[mh ^"Child, Preschool"]	39692
#70	[mh ^"Infant Health"]	102
#71	[mh ^Infant]	30635
#72	[mh ^"Infant Care"]	612
#73	adolescen*:ab,ti	39013
#74	bab*:ab,ti	14194
#75	boy*:ab,ti	8443
#76	girl?:ab,ti	9771
#77	child*:ab,ti	174562
#78	infan*:ab,ti	50317
#79	juvenil*:ab,ti	2434
#80	kid?:ab,ti	1990
#81	minors:ab,ti	424
#82	neonat*:ab,ti	29102
#83	newborn*:ab,ti	13151
#84	p?ediatric*:ab,ti	45450
#85	preschool*:ab,ti	5954
#86	puber*:ab,ti	2104
#87	school*:ab,ti	38258
#88	teen*:ab,ti	3755
#89	toddler?:ab,ti	2396
#90	underage?:ab,ti	229
#91	youth*:ti,ab	11348
#92	youngster*:ti,ab	208
#93	kindergarten*:ti,ab	1039
#94	PICU:ti,ab	1237
#95	NICU:ab,ti	3737
#96	#60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72 or #73 or #74 or #75 or #76 or #77 or #78 or #79 or #80 or #81 or #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95	386247
#97	#26 and #59 and #96	16



APPENDIX 2. PRELIMINARY VERSION OF THE PAEDIATRIC FRAMEWORK AND DECISION FROM INTERNAL AND EXTERNAL DISCUSSIONS

	Preliminary framework Criteria	Preliminary framework Indicator	Decision from internal discussion	External expert (<60% relevance: yellow, > 60% green, absent: white)	Final decisions after external expert discussions (if blank: decision from internal discussion adopted)
PATIENT DIMENSION					
Health needs	Impact on Life expectancy	Years of life lost (YLL)	Kept		
		Mortality rate*	Deleted, duplicate with YLL and YLD		
	Impact on general health-related quality of life	Years of life lived with disability (per case) (YLD)	Kept as it is relevant in children		
		EQ-5D-5L score	Kept, as EQ-TIPS-5L score (0-3 yrs), EQ-5D-Y-5L (4-15yrs), EQ-5D-5L (16-17yrs)		
		Impact on the family quality of life	Deleted because of being too family-centred		
	Impact on physical health	Experienced burden of physical symptom related to the health condition	Kept, but elements in measurement categories were added		
		Pain/discomfort before disease vs today	Kept, as <i>Pain</i> (EQ-TIPS-5L, 0-3yrs), <i>Pain/discomfort</i> (EQ-5D-Y-5L, 4-15 yrs; EQ-5D-5L, 16-17 yrs)		
		Impact on growth/development	Incorporated in the list of physical symptoms in <i>Burden of physical symptoms</i> and the list of side-effects in <i>Burden of treatment side-effects</i>		
		Impact on sensorimotor development*	Duplicate with Impact on Development		

		Impact on fatigue	Incorporated in the list of physical symptoms in <i>Burden of physical symptoms</i>		
		Impact on sleep	Kept		- Measured for 0-3 years as one dimension of the EQ-TIPS-5L - Incorporated in the list of physical symptoms in <i>Burden of physical symptoms</i> and in the list of side-effects in <i>Burden of treatment side-effects</i>
		Impact on communication function	- Deleted, overlap with impact on social relationships - Audition and vision incorporated into the list of list of physical symptoms in <i>Burden of physical symptoms</i> and the list of side-effects in <i>Burden of treatment side-effects</i>		
		Impact on nutrition/eating & elimination	Deleted, duplicate with the EQ-TIPS-5L dimension : eating and drinking.		
	Impact on psychological health	Anxiety/Depression before disease vs today	Kept, as <i>Managing emotions</i> (EQ-TIPS-5L), <i>Feeling sad, worry or unhappy</i> (EQ-5D-Y-5L, 4-15 yrs), <i>Anxiety/Depression</i> (EQ-5D-5L, 16-17 yrs)		
		Experienced burden of psychological symptom related to the health condition	- Kept, modified as <i>Emotional burden and psychological symptom related to the health condition</i> - Elements in measurement categories were added		
		Impact on the child's self-esteem	Relevant, but no measurable indicator available yet for all age groups		- Kept for 4-17 years - Answered by children 12-17 years



		Impact on behaviour	Incorporated in the list of symptoms in <i>Emotional burden of physical symptoms related to the health condition</i>		
		Impact on the child's optimism about the future	Relevant, but no measurable indicator available yet		Incorporated in the list of <i>Emotional impact and psychological symptoms related to the health condition</i>
		Impact on the child's development of identity and autonomy	Deleted, duplicate with the indicators of the criterion <i>Impact on autonomy</i>		
	Impact on the child's cognition	Impact on cognitive and intellectual abilities	- Incorporated in the list of symptoms in <i>Emotional burden of physical symptoms related to the health condition</i> - Criterion <i>Impact on child's cognition</i> deleted		
		Impact on neurodevelopment *	- Kept as a new indicator <i>Developmental Delay</i> and new criterion <i>Impact on Development</i> - Applicable to children 0-17 yrs		
	Impact on the child's daily activities	Self-care before disease vs today	Kept, as <i>Eating and drinking</i> (EQ-TIPS-5L, 0-3 yrs), <i>Looking after Myself</i> (EQ-5D-Y-5L, 4-15yrs), <i>Self-care</i> (EQ-5D-5L, 16-17 yrs)		
		Mobility before disease vs today	Kept as <i>Movement</i> (EQ-TIPS-5L, 0-3 yrs), <i>Mobility</i> (EQ-5D-Y-5L, 4-15yrs; EQ-5D-5L, 16-17yrs)		
		Usual activities before disease vs today	Kept as <i>Usual activities</i> (EQ-5D-Y-5L, 4-15yrs), kept as <i>Play</i> (EQ-TIPS-5L, 0-3yrs)		
	Impact on sexual and	Impact on sexual health**	Kept but adapted in <i>Impact on intimacy and sexuality</i>		Kept as <i>Impact on adolescents' romantic relationships and sexual life</i>

	reproductive health				Intimacy as close relationships already measured in <i>Impact on social life</i>
		Impact on reproductive health**	Deleted, not measurable in children (not appropriate/overlap with this indicator in the adult framework)		
Healthcare needs	Treatment effectiveness	Effectiveness of current overall treatment (standard of care)	Kept		
		Guidelines implementation	Deleted, not measurable as of yet (no practical and sufficiently robust measurement approach identified)		
	Burden of treatment	Experienced burden of treatment	Kept		
		Experienced burden of treatment side-effects	Kept, and elements in measurement categories were added		
		Burden on time between childhood activities and treatment	Incorporated as example in <i>Burden of treatment</i>		
	Quality of care	Support to manage the disease at home	Incorporated in the list of supports in <i>Forgone family support</i>		
		Appropriate assessment	Deleted, not measurable as of yet (no practical and sufficiently robust measurement approach identified)		
		Service readiness and child-friendly care	Potentially relevant		Kept as <i>Child-adapted inpatient environment</i> Aspect related to language and cultural barriers not kept as non <i>measurable</i> as of yet (no practical and sufficiently robust measurement approach identified)
		Routine and specialized follow-up	Deleted, duplicate with <i>Coordination and continuity of care</i>		
		Coordination and continuity of care	Kept		



		Appropriateness of diagnostic timing	Kept		
		Time from first presentation to diagnosis	Kept		
		Diagnosis comprehensiveness	Deleted, duplicate with <i>Quality of communication with healthcare providers & Received information</i>		
		Family needs for emotional support	Moved to societal dimension & incorporated in the list of supports in <i>Forgone family support</i>	Forgone Family support	
		Family needs for parenting and caring skills	Moved to societal dimension & incorporated in the list of supports in <i>Forgone family support</i>		
		Need for healthcare providers and workers with technical and interpersonal skills and commitment	- Kept as <i>Quality of communication with health care providers</i> - Aspect related to: <i>Healthcare professionals with appropriate paediatric expertise</i>: deleted not measurable as of yet: no practical and sufficiently robust measurement approach identified for individual health conditions. Aspects related to social and respite workers fall outside the primary scope of NEED - Deleted quality and safety of care aspects as overlap of <i>Treatment effectiveness, Child-adapted inpatient care environment</i>	Quality of communication with health care providers	Kept but divided to reflect parents & children perspectives separately
		Received information	Kept		Kept but divided to reflect parents & children perspective separately
		Involvement in treatment decisions	Kept but divide it to reflect both parents & children perspectives		Kept as such for children 12-17 yrs & parents Adapted in <i>Participation to treatment</i> for children aged 4-11 yrs

		Engagement of the child (decision and treatment)	- Deleted, duplicate with <i>Involvement in treatment decisions</i> - Legal barriers (e.g., requirement for parental consent) and healthcare professional attitudes (e.g., judgmental attitudes) were incorporated in the list of the potential reasons for <i>Forgone care</i>		
		Parents' involvement in treatment decision and recognition	Deleted, duplicate with <i>Involvement in treatment decisions</i>		
	Need for timely intervention	Need for timely intervention	Deleted (both criterion and indicator), not measurable and overlap with <i>Time from first presentation to diagnosis</i>		
	Need for early screening	Need for early screening	Deleted (both criterion and indicator), overlap with <i>Appropriateness of diagnostic timing</i>		
	Engagement in clinical trials	Engagement in clinical trials	Deleted (both criterion and indicator), not measurable as of yet: no practical and sufficiently robust measurement approach identified for individual health conditions) and partial overlap with <i>Research gaps</i>		
	Access to care	Forgone care	Kept, and elements in measurement categories were added		
		Treatment availability	Kept		
	Scientific Research	Research gaps	Kept		
	Transition child-adult care	Structured and supported transition process** Emotional and psychological support** Life skills and community integration**	Merged into one indicator <i>Transition from child to adult care</i>		Kept as <i>Preparation of transfer from child to adult care</i> in the paediatric framework (both criterion and indicator) & <i>Transfer from child to adult care</i> in the adult framework to

					be added to the adult framework
Social needs	Impact on social life	Forgone social support	- Kept, changed naming for <i>Forgone child's social support</i> - Elements in measurement categories were added		
		Impact on personal relationships	Kept but distinguish impact on relationships with parents and impact on relationships with peers		
	Impact on education	Impact on education	Kept		Kept but formulation adapted for 0-3 yrs: <i>Impact on early foundational skill learning</i>
	Impact on work	Impact on missed future vocational opportunities	Deleted, overlap with <i>Impact on Education</i>		
		Reduction in (patient) working time	- Deleted, not relevant in children - Criterion <i>Impact on work</i> deleted		
	Educational and health needs at school	Flexible and Adapted Learning Pathways	- Incorporated in the list of supports in <i>Forgone child's social support</i> - Criterion <i>Educational and health needs at school</i> deleted		
		Emotional support and social inclusion			
		Communication and collaboration			
	Financial consequences	Health support and medical integration at school			
		Out-of-pocket healthcare costs	Kept		
Perceived (patient) financial difficulties related to the health-condition		Kept, renamed <i>Financial difficulties attributed to the child's health condition</i>			
	Non-healthcare costs	Kept but elements in measurement categories were added			
SOCIETAL DIMENSION					
	Frequency	Prevalence or incidence	Kept		

Health needs	Transmissibility	Contagiousness	Kept		
	Burden on informal parents health	Impact on informal parents health	Kept, renamed <i>Impact on parents' health</i>		
	Burden on parenting role	Burden on the balance between roles	Deleted (both criterion and indicator), overlap with <i>Parents' caregiving time burden</i>		
Healthcare needs	Preventability	Implementation of effective primary prevention strategies	Kept		
	Value for money of care	Healthcare costs relative to the effectiveness of standard of care	Kept		
		Cost effectiveness	Deleted, duplicate with <i>Healthcare costs relative to the effectiveness of standard of care</i>		
Social needs	Family financial consequences	Family out-of-pocket expenses (per patient)	- Deleted, duplicate with <i>Out-of-pocket healthcare costs (per child)</i> - Costs related to "Individual childcare when the child cannot go to creche or school" were incorporated to <i>Non healthcare costs</i>		
		Family financial distress and nonhealthcare costs	- Deleted, duplicate with <i>Financial difficulties attributed to the child's health condition</i> - Financial consequences kept in patient dimension, criterion <i>Family financial consequences</i> deleted		
		Access to disability financing	Deleted, hard to measure in a reliable and valid way and partial overlap with <i>Financial difficulties attributed to the child's health condition</i>		
		Absenteeism of patients	Kept, renamed <i>Parent's absenteeism related to the child's health condition</i>		Add the absenteeism of the non-respondent parent



	Productivity losses	Presenteeism of patients	Deleted, not relevant for children (and not measurable in parents)		
		Early labour force exit or work reduction of patients	Kept		
		Impact on parents' work	Deleted, overlap with <i>Absenteeism of parents</i> and <i>Work reduction or early labor force exits of parents</i>		
		Informal caregiving time burden	Kept, renamed <i>Parents' caregiving time burden</i>		
	Impact on family	Impact on family functioning	Kept as <i>Impact on family climate</i>		- Deleted, duplicate with <i>Parents' caregiving time burden</i> - Criterion kept <i>Impact on family</i>
		Impact on siblings	Kept		- Renamed <i>Impact on siblings' well-being</i> - The measure includes all "other children living in the same household"
		Impact on relationships with family	Deleted, duplicate with <i>Impact on personal relationships</i>		
	Environmental impact of standard of care	Greenhouse gas emissions related to the standard of care	Kept		
		Hazardous waste related to standard of care	Kept		
		Use of natural resources and raw materials related to standard of care	Kept		
	Burden on informal parents' social life	Impact on informal parents' social life	Kept, renamed <i>Impact on parents' social life</i>		

	Supportive child-friendly environment	Supportive environment	child-friendly	Deleted (both indicator and criterion), not measurable as of yet		
FUTURE DIMENSION						
Health needs	Forecasted burden of disease	Forecasted prevalence or incidence		Kept		
		Forecasted years of life lost (per death/case)		Kept		
		Forecasted years lived with disability per case		Kept		
Healthcare needs	Forecasted healthcare costs	Forecasted healthcare costs attributable to the health condition		Kept		
Social needs	Forecasted productivity losses	Forecasted productivity losses attributable to the health condition		Kept, renamed <i>Future parents productivity losses attributed to the child's health condition</i>		

* apply only to children aged 0-6 years, ** apply only to children aged 12-17 years. **In column 3**, Indicators are colour-coded as follow: adult indicators also relevant for children, according to the paediatric mapping review, are highlighted in green; adult indicators absent from the paediatric mapping review are highlighted in orange; and new indicators from the paediatric mapping review that are absent from the adult framework are highlighted in red. **In column 5**, blue boxes represent an indicator rated > 60% relevant, white boxes are indicator that were not presented to experts, red boxes highlight an indicator with < 60% relevance.



APPENDIX 3. MIND MAPS OF THE IMPLICATION OF FAMILY IN THE PRELIMINARY VERSION OF THE PAEDIATRIC FRAMEWORK

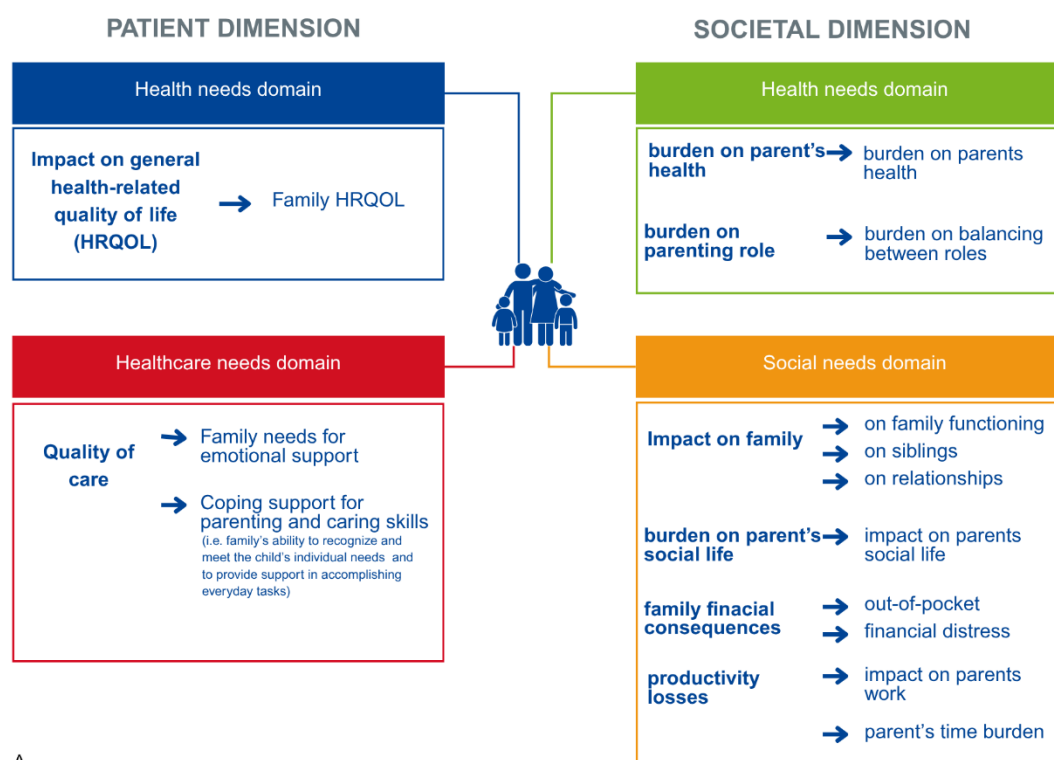
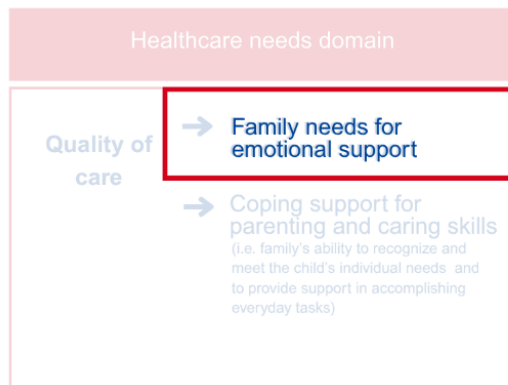
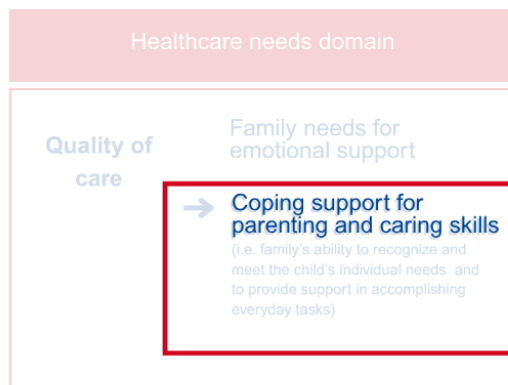


Figure A shows the elements of the preliminary version of the paediatric framework directly related to the family. Each box represent a domain, the bold text indicates criteria, and the text following the arrows represents the associated indicators.



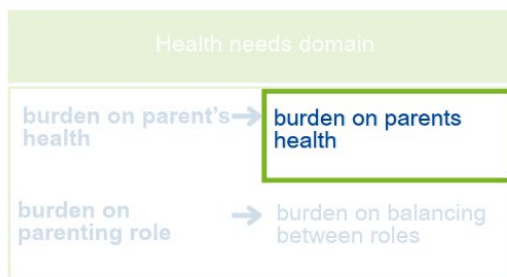
1) Do your family received from healthcare providers the support they need to relieve stress/to cope with emotions related to your chids' disease?. Do you receive support , excluding from healthcare providers, to relieve stress/cope with emotions ? (new)

Foregone family support: 2) Due your child's [the disease], what types of additional support do your family need but have not been able to obtain so far?(several answers possible) (new-adapted from generic)



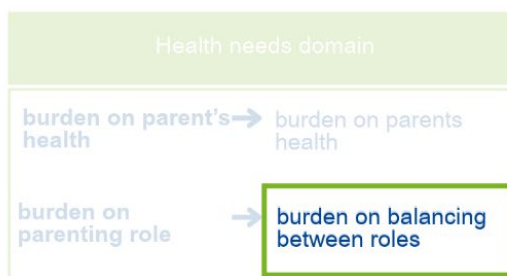
Do you feel supported to develop or maintain skills (make progress) to help your child ? For example recognizing his needs, provide support to help with schoolwork and activities, prepare your child for life in the future, caring for the child, adapting the environment (new)

B



"In your opinion, to what extent is your physical and/or psychological health negatively affected by your role as a carer ?" (generic)

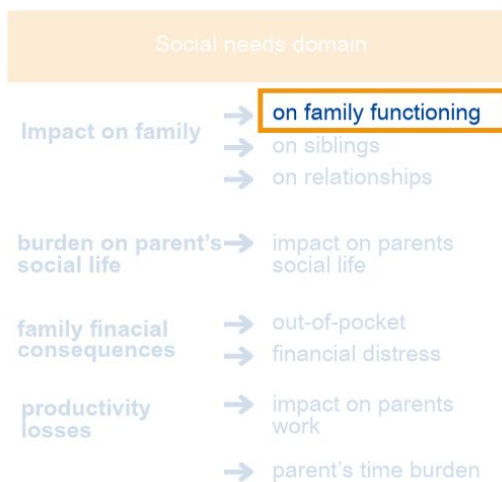
"In your opinion, to what extent is the family members health (physical and/or psychological) negatively affected by caring of your child ?" (generic adapted)



1) Foregone caregivers support (new) (eg bureaucratic challenges, coordination tasks, participating to the child's daily life care)

In the proxy interview: "What is difficult to manage today in your role as a carer?" In terms of: Relationship with healthcare professionals: for example, receiving understandable and comprehensive information from healthcare professionals /Relationship with carers: for example, taking into account the non-medical skills of the carer in the care provided /Ability to delegate certain tasks to professionals /Ability to find a good balance between the role of carer and other roles/Managing his/her symptoms (new)

C



Over the last 7 days, to what extent did the situation of the child's disease negatively affected your family organisation? For example coming back home earlier from social activities, modifying home organisation, ignoring other's wishes and desire (new) OR "How often has child's behavior limited or interrupted the types of activities you could do as a family?" (new)

In your opinion, to what extent the siblings health is affected by the child's disease ? (new)



D



Social needs domain

Impact on family → on family functioning
→ on siblings
→ **on relationships**

burden on parent's social life → impact on parents social life

family financial consequences → out-of-pocket
→ financial distress

productivity losses → impact on parents work
→ parent's time burden

In your opinion, to what extent is the family climate negatively affected by the consequences of your child's disease ? Taking into account the relationship between family members, the love, joy and affection toward each other, the time spend with each other, the communication between each other members. (new)

In your opinion, to what extent is the relationship between you and your child with [disease] negatively affected by the consequences of the [disease]? Not at all/Slightly/Moderately/A lot/Extremely/I don't know (new)

(0-3YO) Early relational attachment: ie "foundational, culturally embedded and developing set of positive, responsive, and reciprocal interactions from birth that nurture and build emotional connections between caregivers, infants, and young children and result in emerging confidence, competence, and emotional well-being for all." In your opinion, to what extent the consequences of the [disease] affects negatively your relation with your child ? For example your responses to your infant needs/cues, the quality of interactions, infant interest in or the response to your stimuli. (new)

To what extent is your social life negatively affected by the consequences of your child's illness? (generic, adapted)

Social needs domain

Impact on family → on family functioning
→ on siblings
→ on relationships

burden on parent's social life → **impact on parents social life**

family financial consequences → out-of-pocket
→ financial distress

productivity losses → impact on parents work
→ parent's time burden



Social needs domain

Impact on family → on family functioning
→ on siblings
→ on relationships

burden on parent's social life → impact on parents social life

family financial consequences → **out-of-pocket**
→ financial distress

same measure than for adult

productivity losses → impact on parents work
→ parent's time burden

Social needs domain

Impact on family → on family functioning
→ on siblings
→ on relationships

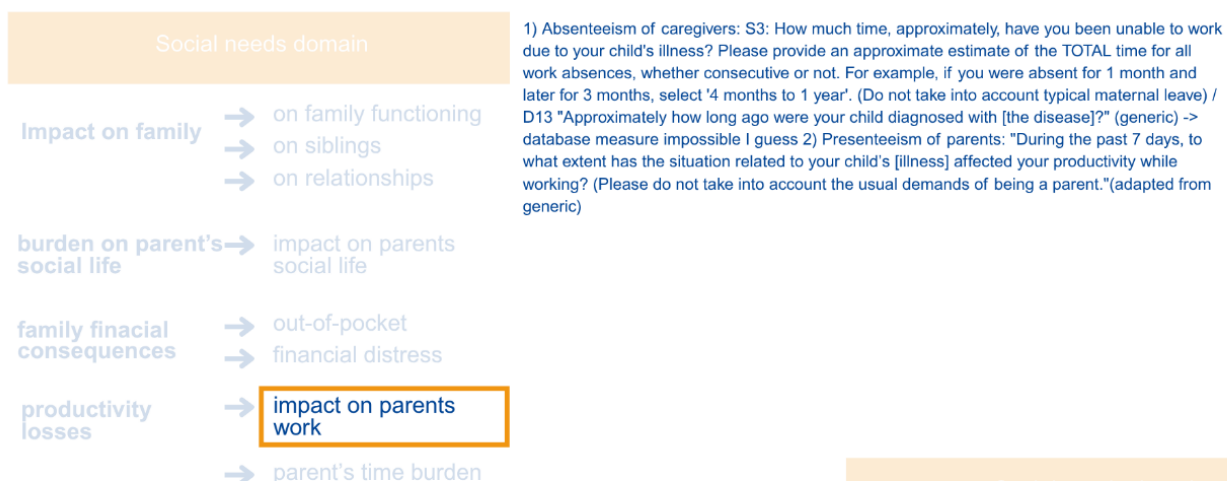
burden on parent's social life → impact on parents social life

family financial consequences → out-of-pocket
→ **financial distress**

productivity losses → impact on parents work
→ parent's time burden

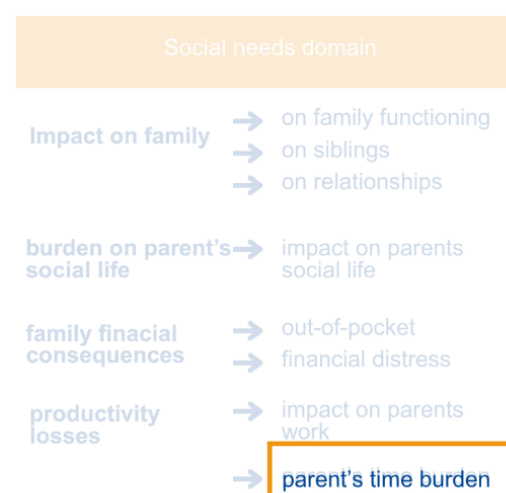
To what extent is the child's [disease] or treatment causing you (your family) financial difficulties? (generic)

F



Over the last 7 days, how much hours did you spend helping your child ? Do not count hours devoted to help your child in activities that another typically developing child of the same age would have done. For example, help might be in personal care (such as dressing/undressing, going to the toilet...), daily life tasks (such as playing, doing schoolwork...), psychological support (such as helping to deal with the disease), or practical support (such as accompanying to medical or other appointments...). (adapted from generic)

G



Figures B to G describe the indicator level and the associated measurement proposals for assessing its measurability.



APPENDIX 4. RATIONALE FOR THE CHOICE OF THE HRQOL TOOLS

In the adult NEED framework, the EQ-5D-5L measure is used to assess health-related quality of life.⁶⁶ In addition to the total score, which reflects the overall impact on quality of life, the five dimensions of the EQ-5D-5L are also disaggregated and integrated as separate indicators in the patient dimension (domain health). In addition, it allows for the generation of utility scores, which are particularly useful in Health Technology Assessments.

In the paediatric population, numerous measures of health-related quality of life exist, including both generic instruments and health condition-specific instruments.^{91, 92} The challenge is that very few instruments are designed to cover the full age spectrum from 0 to 17 years, resulting in tools with different and non-comparable domains across age groups. For example, DISABKIDS was developed for children aged 4-17 years,⁹³ KIDSCREEN for 8-18 years,⁹⁴ TAPQOL for 1-4 years,⁹⁵ or PedsQL for 2-18 years.⁹⁶ Although some instruments use a single questionnaire across multiple paediatric age ranges (e.g., KIDSCREEN, DISABKIDS), others apply different questionnaires for specific age groups, reflecting the developmental nature of some domains of health-related quality of life. An exception is the EuroQol suite of instruments, which covers the full 0-17 year age range using age-specific versions, namely the EQ-5D-5L⁶⁶ recommended for adolescents aged 16-17 years (and adult), the EQ-5D-Y-5L⁶⁵ recommended for children aged 4-15 years, and EQ-TIPS-5L⁶⁴ developed for children aged 0-3 years. Given that the aim of the NEED framework is to identify unmet needs in paediatrics across the entire age spectrum, while ensuring continuity with the adult population, this tool was preferred.

The EQ-5D-5L comprises five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension is assessed using five severity levels ranging from no problems to extreme problems or inability to perform the activity. Responses generate a five-digit health profile that can be converted into a utility score. The instrument also includes a visual analogue scale (EQ VAS), on which respondents rate their overall health from 0 ("the worst health you can imagine") to 100 ("the best health you can imagine"). The EQ-5D-Y-5L retains the same five dimensions and five response levels as the adult EQ-5D-5L, but uses child-friendly wording to improve comprehension and facilitate comparisons across paediatric and adult populations. The EQ-TIPS-5L also uses the 5 same levels of severity but includes 7 dimensions. The dimensions are reflecting key aspects of infant and toddler development and wellbeing: movement (e.g., bringing hands to the mouth, head control, reaching, sitting, crawling, walking, running), eating or drinking (e.g., sucking, swallowing, keeping food down), sleep (e.g., falling asleep, staying asleep, amount of sleep), pain (e.g., crying continuously, restlessness or unusual stillness, facial expressions, moaning, or verbal expression of discomfort), managing emotions (e.g., being comforted when upset), interacting with others (e.g., eye contact, smiling, laughing, gesturing, talking), and play (e.g., exploring objects or toys, playing games, pretend play). The five dimensions of the EQ-5D-(Y)-5L, incorporated into the generic framework as indicators, were structured consistently in the paediatric framework. A correspondence was established with the five domains of the EQ-TIPS-5L: the "mobility" domain (EQ-5D-5L) corresponds to "movement" (EQ-TIPS-5L); "self-care" (EQ-5D-5L) corresponds to "eating and drinking" (EQ-TIPS-5L); "usual activities" (EQ-5D-5L) corresponds to "play"; "pain" is identical in both instruments; and "anxiety/depression" (EQ-5D-5L) corresponds to "managing emotions" (EQ-TIPS-5L). The two additional domains of the EQ-TIPS-5L, namely "sleep" and "interacting with others," are included in the total score but are not considered as independent disaggregated indicators in the paediatric framework.

APPENDIX 5. RATIONALE FOR THE DEVELOPMENT OF THE INDICATOR DEVELOPMENTAL DELAY

In the NEED studies, we aim to measure the consequences of the disease, its treatments (e.g., medication, radiation), or associated circumstances (e.g., missing schooling for a long period).

In the literature, the individual-level assessment such as the Bayley Scales of Infant and Toddler Development 2nd edition (Bayley II)⁷⁷ or milestone checklists like the Ages and Stages Questionnaire,⁷⁸ include a large number of questions for each age range and are typically designed to be administered through observation or in discussion with the healthcare professional, which cannot be done in NEED studies. At the population level, several tools exist, the most referenced being the Early Childhood Development Index (ECDI) 2030 for children aged 2-5,⁹⁷ the CREDI for ages 0-3⁹⁸ the IDELA (Save the Children) for ages 3-6,⁸⁰ and the WHO GSED package for ages 0-2.⁷⁹ However, these tools were developed for low- and middle-income countries, requiring parent and professional input and a representative large sample that cannot be guarantee for each age range in NEED studies. In addition, both individual and populational level assessment apply only within a narrow age window (under 5 years old) while the NEED approach aims to assess the long-term impact of development, even after 5 years old, specifically, whether the consequences of treatment or associated circumstances are reversible or persist.

For this reason, experts decided to rely on the clinical expert perspective, which provides an averaged view across multiple patients as well as a longitudinal assessment of the long-term impact, whether persistent or transient.



APPENDIX 6. RATIONALE FOR THE DEVELOPMENT OF THE INDICATOR CHILD-ADAPTED INPATIENT CARE ENVIRONMENT

The development of the *child-adapted inpatient care environment* indicator originates from the literature review. As defined by the Council of Europe, child-friendly healthcare is a child- and family-centred approach ensuring that care “*is delivered at the right time, in the right place, by appropriate professionals, within an environment that promotes safety, effectiveness, equity and a positive care experience*” (retrieved from... page...).²⁶ It emphasizes children’s rights in health policy, taking into account their needs, developmental capacities and views, while recognizing the importance of family involvement throughout the care pathway. Child-friendly healthcare also promotes children’s participation in decision-making according to their age and maturity, and integrates prevention, health promotion, protection from harm, and the efficient delivery of services to support the overall well-being of children and families.^{26, 99}

The scientific literature also describes this concept as an intersection between paediatric healthcare excellence and children rights, promoting an environment that is accessible, welcoming, reassuring and respectful of the child’s perspective.¹⁰⁰ The conceptual review of Huang et al. (2025) further details its attributes, grouped into five dimensions: child-interest-prioritised quality services (communication, warm attitudes and behaviours, therapeutic play, equity, respect, pain management, adapted information, etc.); child-friendly environments and spaces (child-adapted signage, comfort, child-centred decoration, cleanliness, family and interactive spaces); social interaction (activities, emotional and informational support, protection); child participation (in decision-making, in the design of care, and in service and policy evaluation); and development facilitation (play, learning, nutrition, health education, health monitoring and management).²⁸

The internal expert group decided to focus this new indicator on the child-adapted hospital environment, as several of the other attributes were already captured by other indicators within the NEED framework, such as treatment effectiveness, appropriateness of diagnostic timing, time from first presentation to diagnosis, information provision, parents and child communication with healthcare professionals, involvement in treatment decisions, and coordination and continuity of care. The external expert group helped refined the definition to ensure age-specific relevance.

APPENDIX 7. RATIONALE FOR THE DEVELOPMENT OF THE INDICATOR IMPACT ON SELF-ESTEEM

Self-esteem has traditionally been measured via questionnaires, either self-reported or proxy-reported. Self-reporting is usually preferred to improve reliability, like other psychosocial concepts. The concept can be measured using a standalone questionnaire, such as the Rosenberg Scale,¹⁰¹ or as part of a broader construct like health status, where specific items capture aspects of self-esteem, such as the Child Health Questionnaire,¹⁰² the General Health Questionnaire,¹⁰³ the Miami Pediatric Quality of Life Questionnaire,¹⁰⁴ DISABKIDS,⁹³ the Healthy Pathways Child-Report Scale,¹⁰⁵ the Child Health and Illness Profile,¹⁰⁶ and the Infant & Toddler QOL Questionnaire.⁹⁵ In those questionnaires, the measure of global self-esteem includes, in addition with the overall appraisal of one's self-worth, self-pride, feeling valued by oneself and the others, as well as the feeling of competence without specifying which competence (scholastic, athletic...). Some of those elements were added in the NEED indicator *Impact on self-esteem*.

Regarding the changes appearing with age, a recent meta-analysis shows that self-esteem slightly increases from ages 4 to 11, remains stable between 11 and 15, and rises again from around age 15 into mid-adulthood before declining.⁴⁷ However, other factors also appear to be important when assessing self-esteem. Inter-individual differences were observed depending on the recruitment method (with higher self-esteem in online samples compared with representative samples), and the way items are formulated moderate the age difference, particularly negative items seem to be more sensitive to age.⁴⁸ The questionnaire items are all formulated in a way that they do not reflect consequences of the disease but assess the self-esteem (whatever the cause). In the NEED framework, the consequence of the health condition is assessed, therefore separating (artificially) the development of self-esteem and the impact of a health condition on self-esteem. By doing so, it was hypothesized that, if the NEED item was positively and appropriately formulated, the measure becomes less sensitive to age. The measurement of this concept usually begins at 6-8 years of age, and in some questionnaires as early as 3 years old. Based on these age recommendations and discussions with the external experts, it was decided to start measuring this concept at 4 years old using a proxy-report for children aged 4-11 years and a self-report for adolescents aged 12-17 years. For some children, particularly those with neurocognitive disabilities, the impact on self-esteem may not be meaningfully measurable and the indicator may therefore not be applicable. As each NEED case study focuses on a specific health condition, the questionnaire is tailored accordingly, and indicators that are not relevant or applicable can be omitted.



APPENDIX 8. RATIONALE FOR THE DEVELOPMENT OF THE INDICATOR PREPARATION OF TRANSFER FROM PAEDIATRIC TO ADULT CARE

Transfer of care can be defined as the process through which adolescents and young adults with health conditions move from paediatric to adult healthcare systems, addressing their medical, psychosocial, and educational or vocational needs, with the aim of supporting their progression toward independent adulthood.^{60, 107} The transition period is recommended to start around ages of 14 and 18 and being effective around 17-21 years.

Among the various indicators identified, external expert discussions supported focusing within the paediatric framework on “preparation for transition”, while assessing transition outcomes within the generic adult framework (18-26 years). Experts also highlighted that transition practices remain insufficiently structured, leading to variability in implementation. This is partly driven by differences between paediatric (developmental, family-centred) and adult (diagnosis-driven, individual responsibility) care models, contributing to discontinuities such as fragmented services, reduced family support, and loss of a safety net.¹⁰⁸ Evidence from a recent European mental health study further shows that transition at age 18 is not universally beneficial: adolescents may remain in paediatric care, be discharged, or be referred elsewhere.⁶¹ These findings underline that, while age-based indicators are useful, transition should be guided by individual needs. They also point to suboptimal and poorly evaluated transition processes, and highlight that readiness depends not only on the adolescent but also on the healthcare system, which remains insufficiently assessed.⁶¹

Preparation for transition can be defined as the “*process of building the capacity of adolescents and those involved in their care to prepare for, enter, continue and complete transition*”.⁴⁹ It is commonly measured through the adolescent’s readiness, including their willingness and ability to develop autonomy and manage their health independently,⁸¹ which underpins most existing questionnaires. However, the internal expert group decided to conceptualise this indicator by focusing on the quality of care provided by the healthcare system, rather than the adolescent’s individual capacities, specifically assessing whether healthcare professionals support this preparation. This indicator is assessed among adolescents aged 16-17 years. As preparation for the transition to adult care is recommended to begin around ages of 14-15 years, the internal expert group considered that, if this process has not been initiated by ages 16-17 years, this may indicate an unmet need.

To operationalise this concept, the indicator was grounded on the outcomes associated with successful transitions, including the individual outcomes such as understanding of the condition and its complications, knowledge of treatments, self-management skills,¹⁰⁹ and the different formats used to help the child prepare to the transition such as a written transition plan, telephone support, educational workshops, or joint meetings involving paediatric and adult care teams.^{60, 110}



APPENDIX 9. RATIONALE FOR THE DEVELOPMENT OF THE INDICATOR IMPACT ON SIBLINGS' WELL-BEING

In the literature, contrasting impacts on siblings' well-being are observed. On the one hand, several studies report negative consequences, including increased levels of medical prescriptions,⁵⁹ a deterioration in quality of life, particularly in psychological domains, and a higher prevalence of internalising behaviours (e.g., depression, low self-esteem) and externalising behaviours (e.g., delinquent activities) compared with control groups.^{58, 111} Siblings also tend to receive less parental attention, express concerns about their sibling's health, and may take on caregiving roles within the family.⁵⁸ A decline in academic performance is also observed in 11-23% of children.¹¹² On the other hand, some studies report neutral or even positive effects, including good psychological adjustment, higher levels of prosocial behaviour, and positive sibling relationships, with no significant impairment in self-perception.⁵⁸ These variations can be explained by multiple factors, including disease characteristics (notably disease trajectory, severity, and treatment intensity rather than disease type),^{58, 112} as well as children's age and gender (with older children generally demonstrating better coping abilities and girls showing more prosocial behaviours),⁵⁸ in addition to family and social factors.

Following discussions with external experts, who emphasized the importance of including a specific indicator for siblings, it became clear that the impact extends beyond quality of life to encompass overall well-being. This perspective is consistent with the existing literature and led to the retention of the indicator in this broader form. Furthermore, experts highlighted the diversity of family structures; therefore, the term "children living in the household" was preferred over a strict definition of siblings. Support to siblings were also incorporated into the definition of the *Forgone Family Support* indicator.



APPENDIX 10. LIST OF THE 312 ARTICLES INCLUDED IN THE MAPPING REVIEW

1. Agrawal H, Wright OK, Carberry KE, Sexson Tejtjel SK, Mery CM, Molossi S. Family perception of unmet support needs following a diagnosis of congenital coronary anomaly in children: Results of a survey. *Congenital heart disease*. 2017;12(6):721-5.
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4. Akintobi TH, Lockamy E, Goodin L, Hernandez ND, Slocumb T, Blumenthal D, et al. Processes and Outcomes of a Community-Based Participatory Research-Driven Health Needs Assessment: A Tool for Moving Health Disparity Reporting to Evidence-Based Action. *Progress in community health partnerships : research, education, and action*. 2018;12(1S):139-47.
5. Akobirshoev I, Parish S, Mitra M, Dembo R. Impact of Medical Home on Health Care of Children With and Without Special Health Care Needs: Update from the 2016 National Survey of Children's Health. *Maternal and child health journal*. 2019;23(11):1500-7.
6. Al-Dhawyani A, Al-Hinai K, Chan MF, Al-Azri M. Factors Contributing to the Unmet Needs of Primary Caregivers of Omani Children Diagnosed with Leukemia. *Oman Medical Journal*. 2022;37(2).
7. Alamdari G, Kelber MS. The Child and Adolescent Needs and Strengths as an Outcome Measure in Community Mental Health: Factor Analysis and a Validation of the Short Form. *Community mental health journal*. 2016;52(8):1118-22.
8. Aldosari MA, Bukhari OM, Ruff RR, Palmisano JN, Nguyen H, Douglass CW, et al. Comprehensive, School-Based Preventive Dentistry: Program Details and Students' Unmet Dental Needs. *The Journal of school health*. 2021;91(9):761-70.
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11. Alsem MW, Siebes RC, Gorter JW, Jongmans MJ, Nijhuis BGJ, Ketelaar M. Assessment of family needs in children with physical disabilities: development of a family needs inventory. *Child: care, health and development*. 2014;40(4):498-506.
12. Alugo T, Malone H, Sheehan A, Coyne I, Lawlor A, McNicholas F. Development of a 22q11DS psycho-educational programme: exploration of the views, concerns and educational needs of parents caring for children or adolescents with 22q11DS in relation to mental health issues. *Child: care, health and development*. 2017;43(4):527-35.
13. Alves E, Severo M, Amorim M, Grande C, Silva S. A short form of the neonatal intensive care unit family needs inventory. *Jornal de pediatria*. 2016;92(1):73-80.
14. Alves e Luna AC, Godoy F, de Menezes VA. Malocclusion and treatment need in children and adolescents with sickle cell disease. *The Angle orthodontist*. 2014;84(3):467-72.
15. Ames JL, Massolo ML, Davignon MN, Qian Y, Cerros HJ, Croen LA. Transitioning youth with autism spectrum disorders and other special health care needs into adult primary care: A provider survey. *Autism : the international journal of research and practice*. 2021;25(3):731-43.



16. Amorim M, Alves E, Kelly-Irving M, Silva S. Needs of parents of very preterm infants in Neonatal Intensive Care Units: A mixed methods study. *Intensive & critical care nursing*. 2019;54:88-95.
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