

# EHMA 2024

Shaping and managing  
innovative health ecosystems

## Capturing the voice of youth in hospital experiences: A Delphi Study involving children, caregivers and experts

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#EHMA2024

# Introduction

The active involvement of patients and their families in enhancing services is essential.

**Children and adolescents can have difficulties in making their voices being heard and typically**

**feedback and experiences from caregivers and families are collected** (Coyne, 2008; O'Neill J et al., 2018; Karisalmi

et al., 2020; Wray et al., 2020).

Therefore, the assessment and enhancement of healthcare services' quality currently do not align with the preferences, needs, and values of the paediatric patients (Picker Institute. Patient centered care 2015)



- The study is part of the **VoICES Project** – «**Value of including Children Experience for improving their rights during hospitalization**», aimed at designing and implementing a system ensuring that hospitalized children can continuously be involved and heard (De Rosis et al., 2023).
- The study is co-funded by the the European Union's Rights, Equality and Citizenship Programme (2014-2020) (REC-RCHI-PROF-AG-2020).

# Aim

This study aims **to develop a standard set of Paediatric Patient-Reported Experience Measures (PREMs)** through a collaborative, consensus-building process.

# Method <sup>(1)</sup>

## Delphi Process

- Three rounds
- Multiple choice questions and open-ended questions
- English and Italian
- Online administration and digital data return
- Panel members: patients, families (and representatives of), professionals , scholars, experts from
- All project partners
- Participants from the project Supporting Bodies
- Other experts

# Method (2)

## Delphi Process

### First round

- 74 participants, out of 85 contacted
- Characteristics of the tool: target, content, length, etc.
- Selection of relevant dimensions and subdimensions

### Second round

- 64 participants, out of 76 contacted
- Agreement on the general characteristics of the tool for collecting the children's patient reported experience
- Selection of questions to investigate the subdimensions identified in the 1st round

### Third round

- 54 participants, out of 74 contacted
- Approval of the number and type of questions by age category
- Selection of the questions to be removed or maintained, to define a short and functional final version of the tool

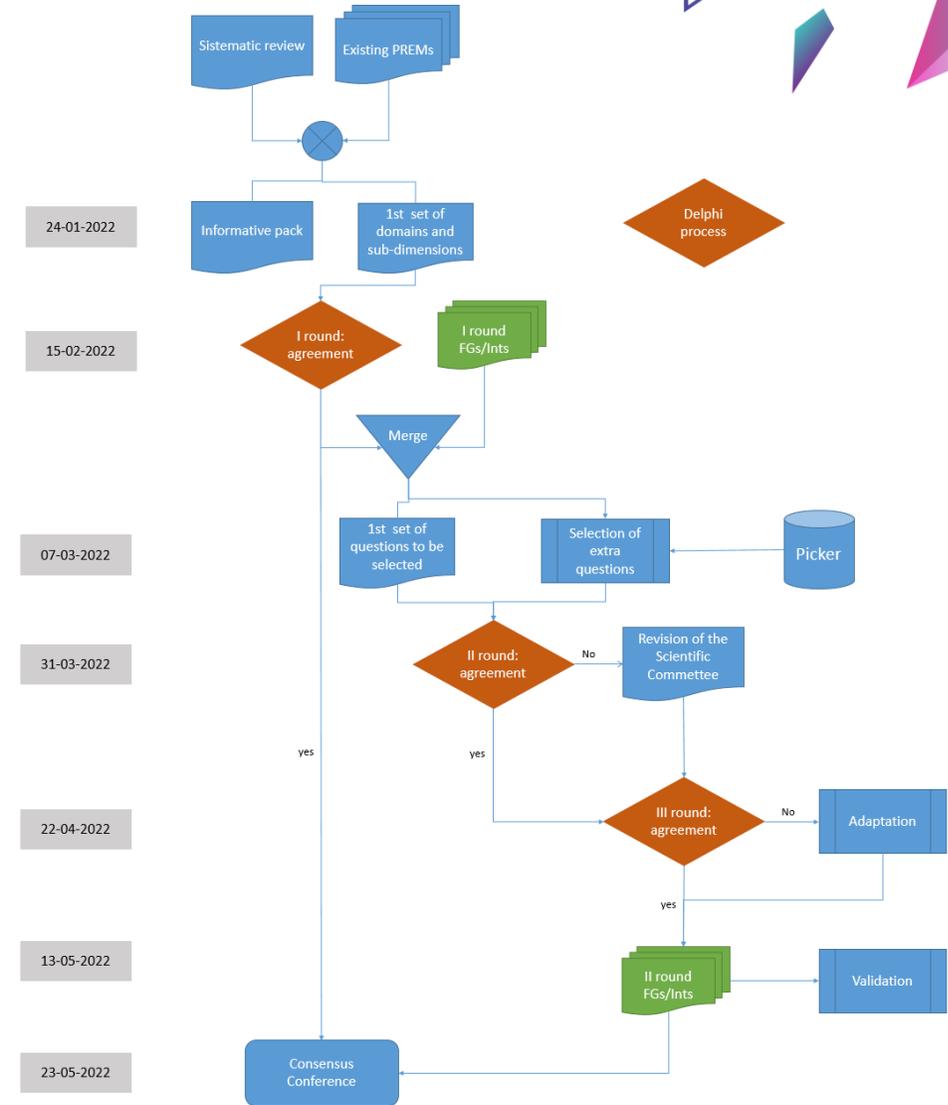
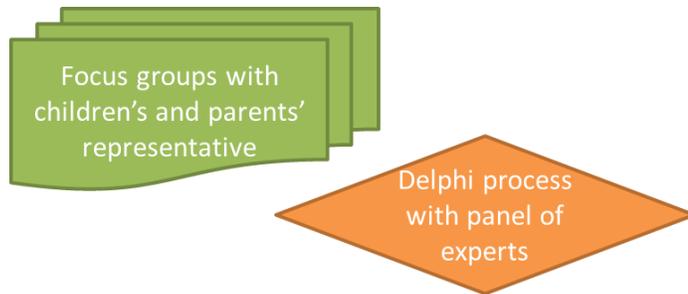
# Method (3)

## Delphi Process

**Integration of two qualitative components** to ensure data collection and opinions sharing involving actively different stakeholders

### Participants:

- 47 Children/Adolescents
- 42 Caregivers



# Results <sup>(1)</sup>

## Final questionnaires

### Characteristics of the questions:

- Three points answer scale
- Enriched questionnaire for age groups 4-7 and 8-13 with:
- Visual tools
- Smiley's answer scale
- Audio reproduction of questions (depending on technical requirements)

### Content:

- The questions have been selected based on both Delphi and interviews
- Some questions have been reframed for children in age groups 4-7 and 8-13

### A different version of the questionnaire was developed for each age group, with the addition of:

- 2 to 4 general questions;
- 2 questions for chronic patients.

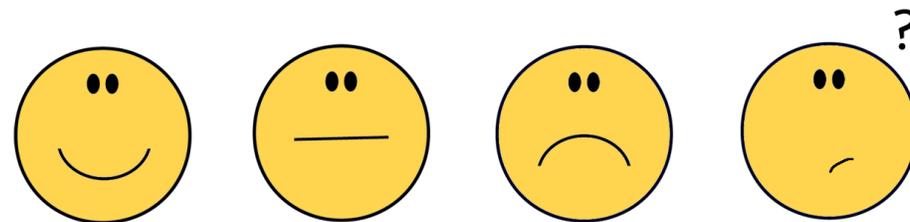
Age group	# questions
0-3 (through caregivers)	5
4-7	10
8-13	15
14-17	17
Caregivers	15

# Results <sup>(2)</sup>

## Enriched questionnaire for age groups 4–7 and 8–13

### Smiley answer's scale:

- Three points' scale
- Neutral option (I don't know/I don't remember)



# Results (3)

## Enriched questionnaire for age groups 4-7 and 8-13

\* Il personale ospedaliero si è comportato nei tuoi confronti in modo amichevole e comprensibile?



\* Quando hai provato dolore, il personale ospedaliero ti ha aiutato a stare meglio?



\* Il personale ospedaliero ha parlato di te come se non ci fossi?



\* Hai avuto fiducia nel personale ospedaliero che si è preso cura di te?



# Results (3)

\* Al momento del ricovero sei stato accolto con gentilezza e cortesia dal personale ospedaliero?



● Scegliere solo una delle seguenti voci

-  Sono stato accolto con molta gentilezza e cortesia
-  Sono stato accolto con sufficiente gentilezza e cortesia
-  Sono stato accolto senza alcuna gentilezza o cortesia
-  Non lo so/Non ricordo

\* Com'era il cibo dell'ospedale?



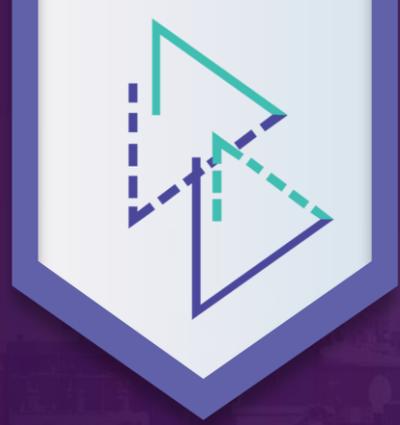
● Scegliere solo una delle seguenti voci

-  Il cibo era davvero buono
-  Il cibo era abbastanza buono
-  Il cibo non era affatto buono
-  Non lo so/Non ricordo
- Non ho mangiato il cibo dell'ospedale

# Discussions

This study emphasizes **the importance of engaging people for tailoring evaluation tools to different targets.**

The developed questionnaires will support healthcare organizations' efforts **to properly collect the paediatric patients' feedback** and to **use them** to improve healthcare services. The collaborative process has contributed to the development of a European Observatory of the paediatric experience with hospital stay.



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# Thank you

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