Panel discussion

Paediatric Patient-Reported Experience Measures: Possibilities and challenges

Facilitated by

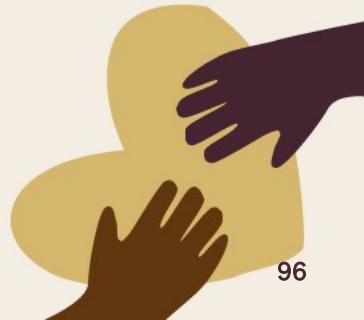
Jane Hybschmann

PhD student

&

Olivia Braad Honoré,

Expert by experience, peer-researcher, and youth panel member



Paediatric Patient-Reported Experience Measures: Possibilities and challenges

Kate Oulton

Vita Steina

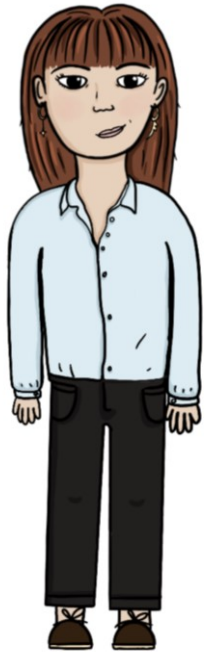
Eva Brostrøm

Claus Sixtus

Joan Vinyets Rejon

Line Klingen Gjærde

Who am I?



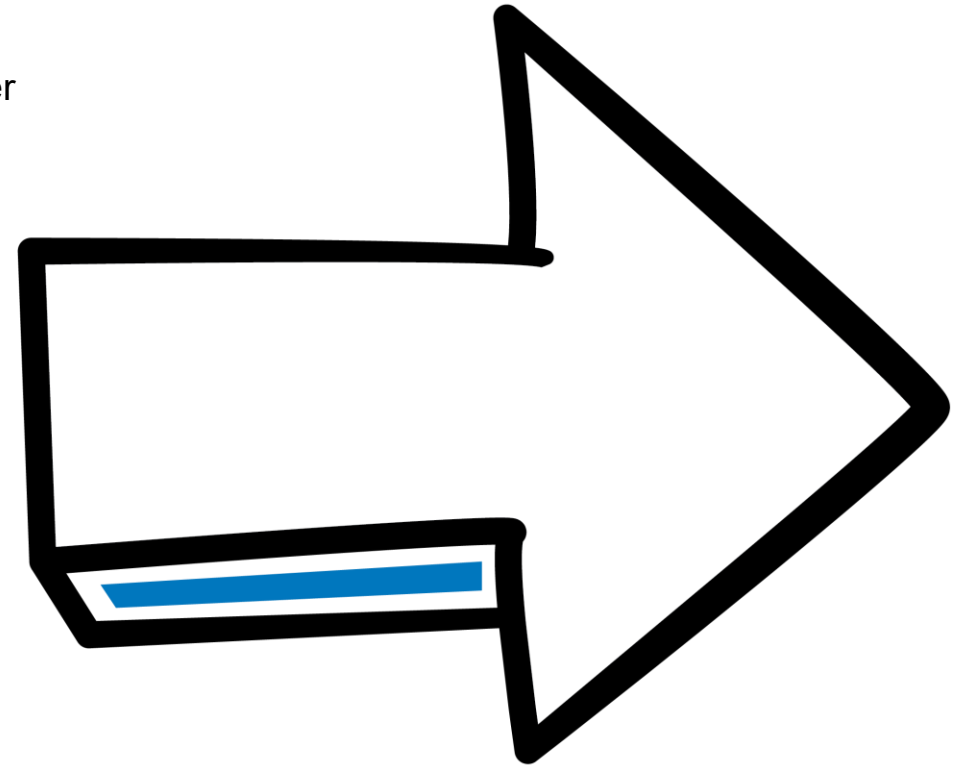
Dr Kate Oulton

Consultant Nurse for Family Engagement and Co-production

Patient and Public Involvement Lead for the GOSH Children's Cancer Centre

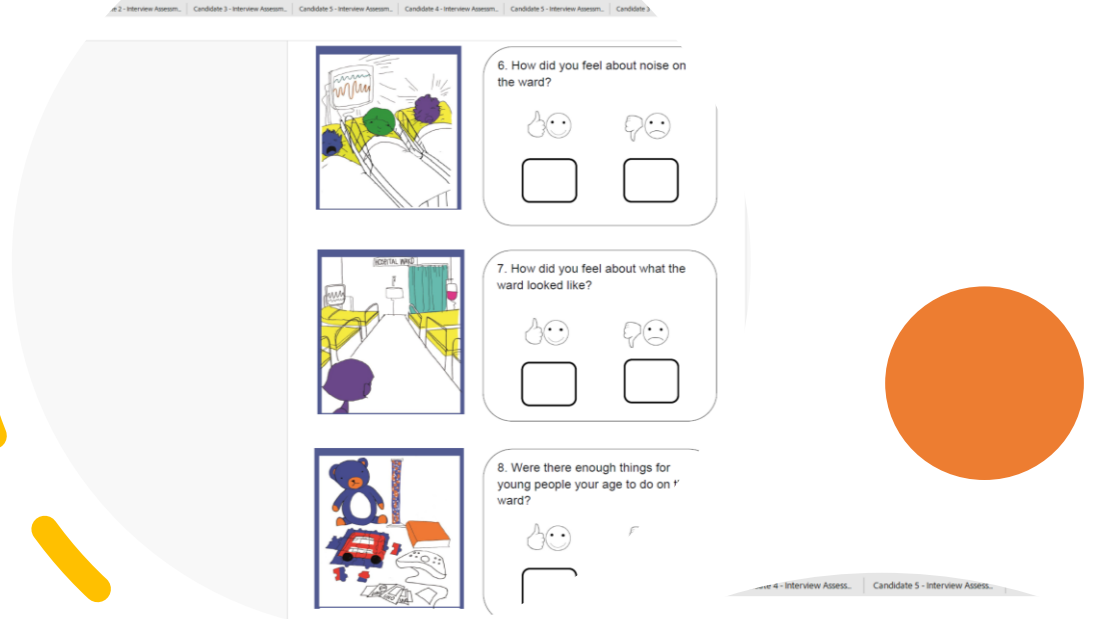
Senior Research Fellow in Centre for Outcomes and Experience Research in Children's Health, Illness and Disability

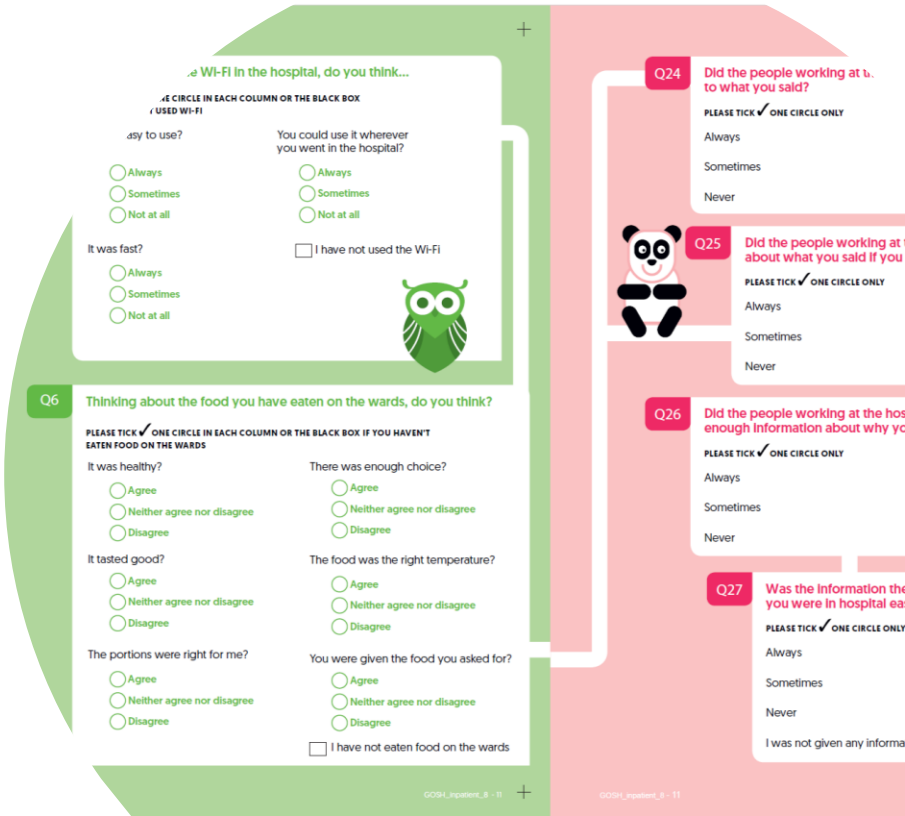
Chief Investigator
Pay More Attention Study - Equity of hospital care (2015-2020)
Seen and Be Heard Study - Equity of cancer care (2023-2025)



Use of PREMs

- Six PREMs developed and tested *by* children and young people *for* children and young people
- Age groups: 8–11, 12–13, 14–16 years
- Accessible version for children and young people with a learning disability
- Setting: Inpatient and outpatient
- Translated into four different languages for international use





Wray J, Hobden S, Knibbs S, et al Hearing the voices of children and young people to develop and test a patient-reported experience measure in a specialist paediatric setting. Archives of Disease in Childhood 2018;103:272-279.

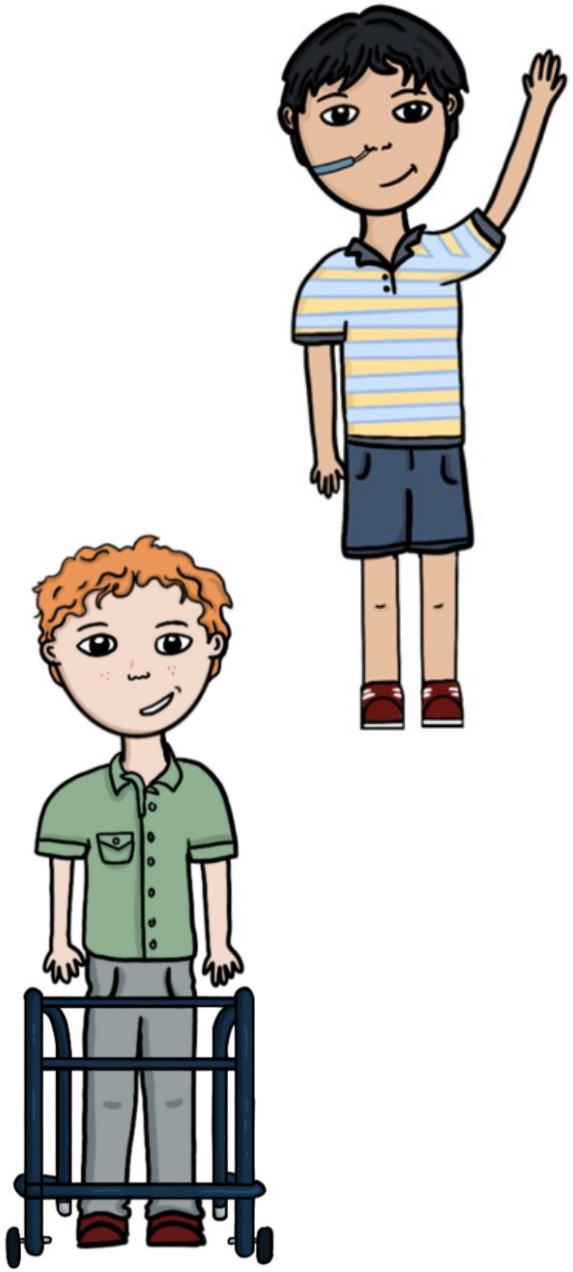
Nafees Z, Ferreira J, Guadagno E, Wray J, Anderzén-Carlsson A, Poenaru D. Adaptation, translation, and validation of a patient-reported experience measure for children and young people for the Canadian context. J Pediatr Surg. 2024 May;59(5):810-817

Nordlind A, Anderzén-Carlsson A, Sundqvist AS, Ängeby K, Wray J, Oldham G, Almblad AC. Translation, cultural adaptation and validation of a patient-reported experience measure for children. Health Expect. 2024 Feb;27(1):e13924

Current role

- Further development and testing accessible version
- Further development and testing with 4-7year olds
- Use with other patient cohorts
  - Disease specific – children/young people with cancer
  - Children/young people who are autistic
  - English as second language

- Rollout process
  - Timing
  - Data capture
  - Data analysis
  - Reporting
  - Feasibility
  - Resources



Patient experience: Latvia

Vita Šteina

Patient experience expert at Riga East University hospital & Pauls Stradins University Hospital

Advisor to Health Minister of Latvia

Chair of Patient Experience Association of Latvia

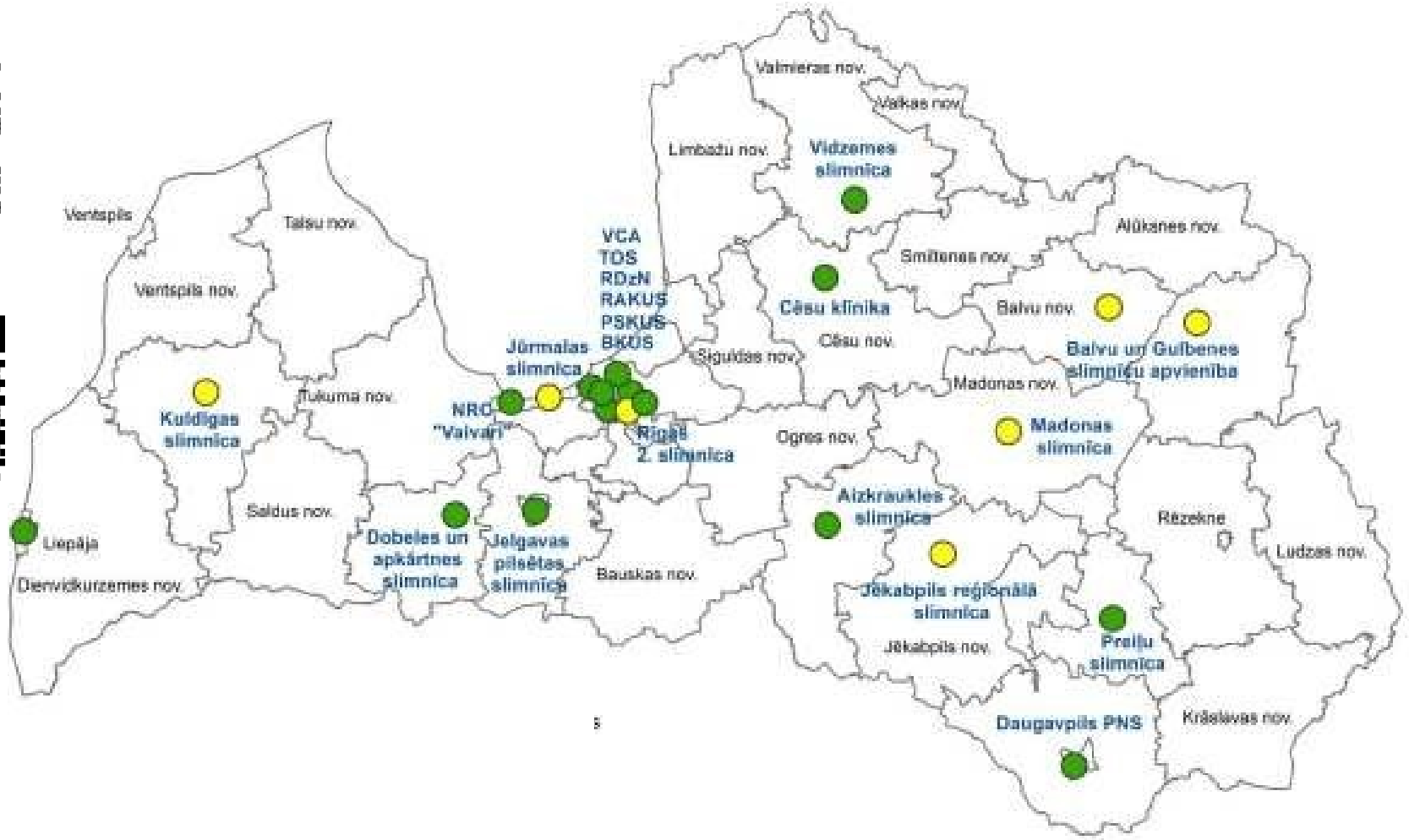
Member of Global Council and Fellow at The Beryl Institute

NATIONAL PATIENT EXPERIENCE QUESTIONNAIRS

IN-PATIENTS

OBSTETRICS

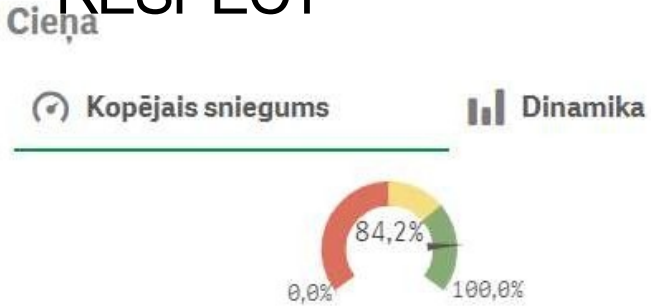
MENTAL



OUT-PATIENTS...

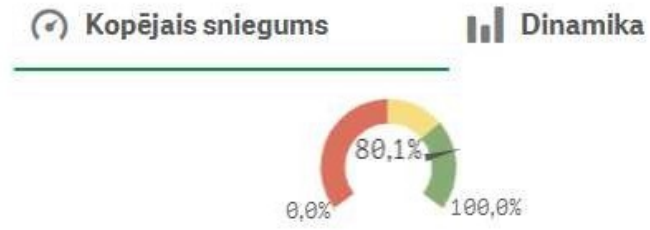
SUPPORT

RESPECT



SAFETY

DISCHARGE



COMFORT

COMMUNICATION

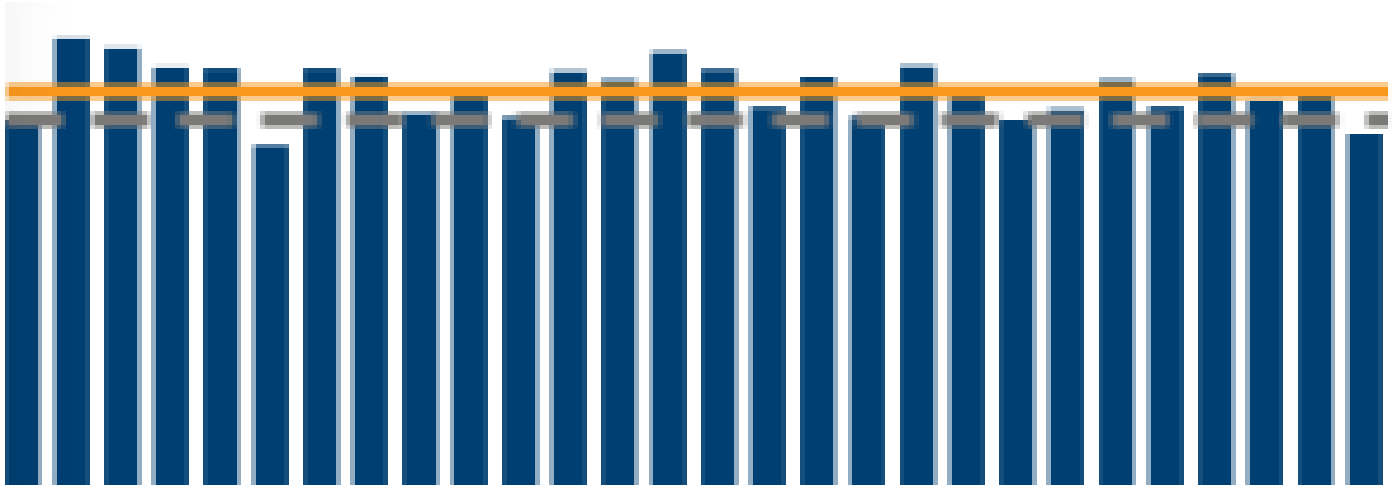
SHARED DECISION

MEDICATION

Jautājums	TopBox
Vidējais	**78,0%**
Cik bieži, Jūsuprāt, personāls pret Jums izturējās ar cieņu? [Ārsti]	89,5%
Vai slimnīcas izrakstā norādītā informācija Jums bija pietiekami saprotama?	88,0%
Lūdzu, novērtējiet, cik bieži zemāk minētie apstākļi palātā Jūs apmierināja: [Gultas veļas tīrība]	84,4%
Pirms Jūs izrakstīja no slimnīcas, vai veselības aprūpes speciālisti sniedza saprotamu informāciju: [kā jāturpina ārstēšanos un/vai aprūpi]	84,3%
Cik bieži, Jūsuprāt, personāls pret Jums izturējās ar cieņu? [Māsas/ārsta palīgi/vecmātes]	83,7%
Pirms piekrītāt ārstēšanai, vai Jūs saņēmāt no ārstniecības personas saprotamu informāciju par iespējamiem ieguvumiem un riskiem/ sarežģījumiem/ komplikācijām Jūsu ārstēšanas procesā?	79,6%
Cik bieži, Jūsuprāt, personāls pret Jums izturējās ar cieņu? [Citi nodaļas darbinieki (māsas palīgi, sanitāri un citi)]	79,4%
Lūdzu, novērtējiet, cik bieži zemāk minētie apstākļi palātā Jūs apmierināja: [Apgaismojuma]	78,6%
Pirms Jūs izrakstīja no slimnīcas, vai veselības aprūpes speciālisti sniedza saprotamu informāciju: [kā lietot izrakstītos medikamentus, ieskaitot tos, kurus lietojāt pirms ārstēšanās slimnīcā (piemēram, laiks, kad jālieto zāles, iespējamās blakusparādības, utt.)]	78,4%
Cik bieži uz uzdotajiem jautājumiem Jūs saņēmāt saprotamas atbildes no: [Ārstiem]	78,0%
Pirms Jūs izrakstīja no slimnīcas, vai veselības aprūpes speciālisti sniedza saprotamu informāciju: [ar ko sazināties, ja mājās rodas veselības problēmas (piemēram, ar stacionāra ārstējošo ārstu, ģimenes ārstu, neatliekamo medicīnas palīdzību, vai kādu citu)]	76,8%
Vai Jūs pietiekami iesaistīja lēmumu pieņemšanā par Jūsu ārstēšanas procesu?	75,6%
Lūdzu, novērtējiet, cik bieži zemāk minētie apstākļi palātā Jūs apmierināja: [Telpu tīrība]	73,9%
Vai, Jūsuprāt, veselības aprūpes speciālisti darīja visu iespējamo, lai palīdzētu mazināt sāpes?	73,8%
Pirms Jūs izrakstīja no slimnīcas, vai veselības aprūpes speciālisti sniedza saprotamu informāciju: [kam turpmāk jāpievērš uzmanība (piemēram, iespējamie simptomi, sajūtas un veselības problēmas), un ieteikumus, kā šajās situācijās rīkoties]	73,0%
Lūdzu, novērtējiet, cik bieži zemāk minētie apstākļi palātā Jūs apmierināja: [Naktsmiers]	71,5%
Cik bieži uz uzdotajiem jautājumiem Jūs saņēmāt saprotamas atbildes no: [Māsām/ārsta palīgiem/vecmātēm]	70,0%
Vai Jūs slimnīcā jutāties pārliecināts par savas ārstēšanas un aprūpes drošību?	68,3%
Lūdzu, novērtējiet, cik bieži zemāk minētie apstākļi palātā Jūs apmierināja: [Temperatūra]	62,5%
Cik bieži ārstniecības personāls pirms zāļu ievadīšanas/došanas: [Jums pastāstīja, kādam nolūkam tās paredzētas]	62,2%
Vai veselības aprūpes speciālisti, kuri Jūs izvaicāja, izmeklēja un ārstēja, iepazīstināja ar sevi – nosauca savu vārdu, uzvārdu, amatu?	61,9%
Cik bieži uz uzdotajiem jautājumiem Jūs saņēmāt saprotamas atbildes no: [Citiem darbiniekiem (māsas palīgiem, sanitāriem un citiem)]	61,7%
Lūdzu, novērtējiet, cik bieži zemāk minētie apstākļi palātā Jūs apmierināja: [Klusums]	60,3%
Cik bieži ārstniecības personāls pārliecinājās par Jūsu identitāti (pajautāja Jūsu vārdu, uzvārdu, pārbaudīja pacienta identifikācijas aproces datus) pirms ievadīja/iedeva zāles, veica diagnostisku izmeklējumu vai ārstniecisku manipulāciju?	59,4%
Vai uzturēšanās laikā veselības aprūpes speciālisti palīdzēja Jums pārvarēt bailes un satraukumu par Jūsu veselības stāvokli?	54,8%
Cik bieži ārstniecības personāls pirms zāļu ievadīšanas/došanas: [Jums saprotamā veidā izskaidroja iespējamās blakusparādības]	46,5%
Lūdzu, novērtējiet, cik bieži zemāk minētie apstākļi palātā Jūs apmierināja: [Ēdināšana]	45,3%
Cik bieži pēc "trauksmes pogas" nospiešanas Jūs saņēmāt tūlītēju palīdzību?	41,9%
Vai ārstniecības laikā saņēmāt psihoemocionālo atbalstu?	31,4%

SHARED DECISION MAKING

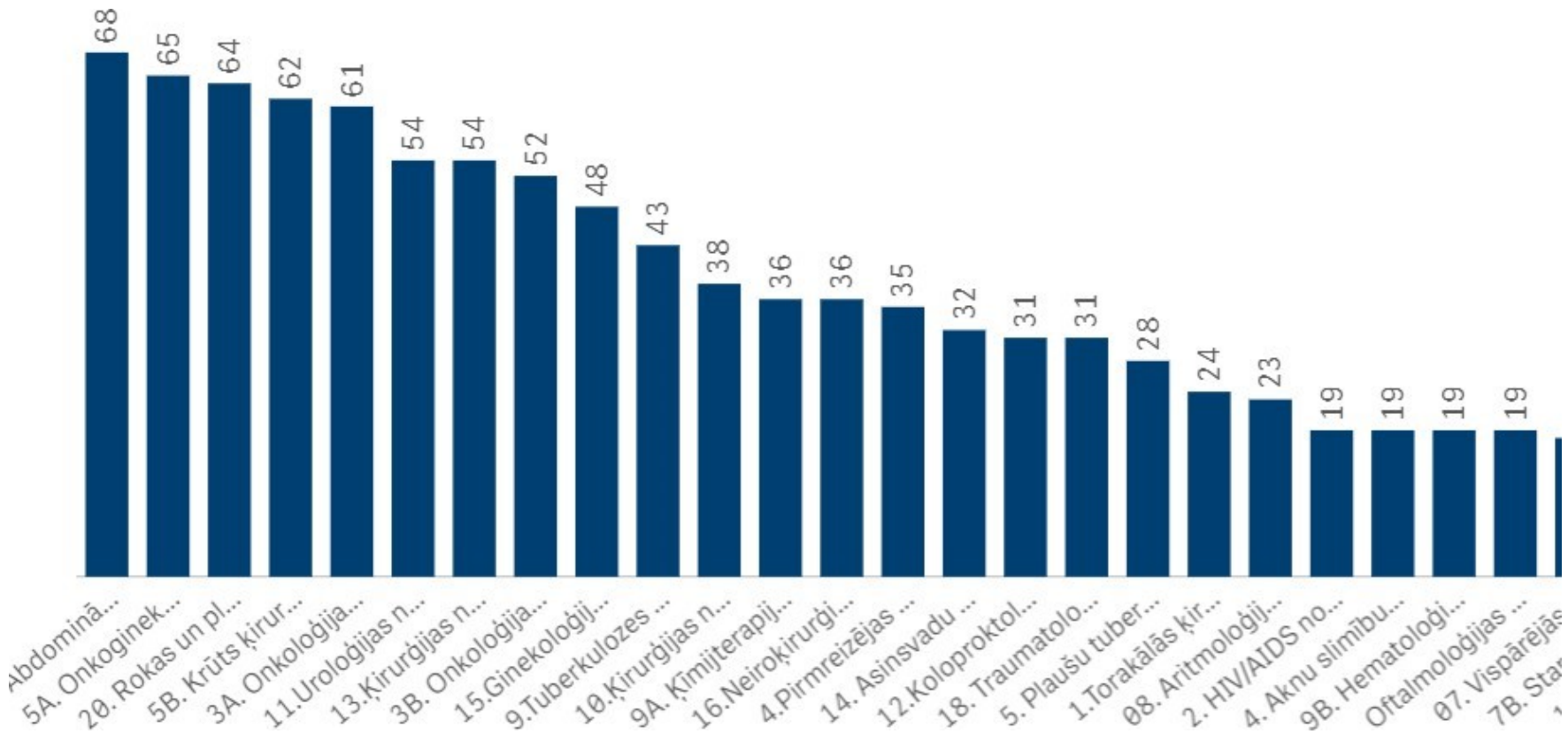
DYNAMICS



Department (80,6%)

Hospital (75,0%)

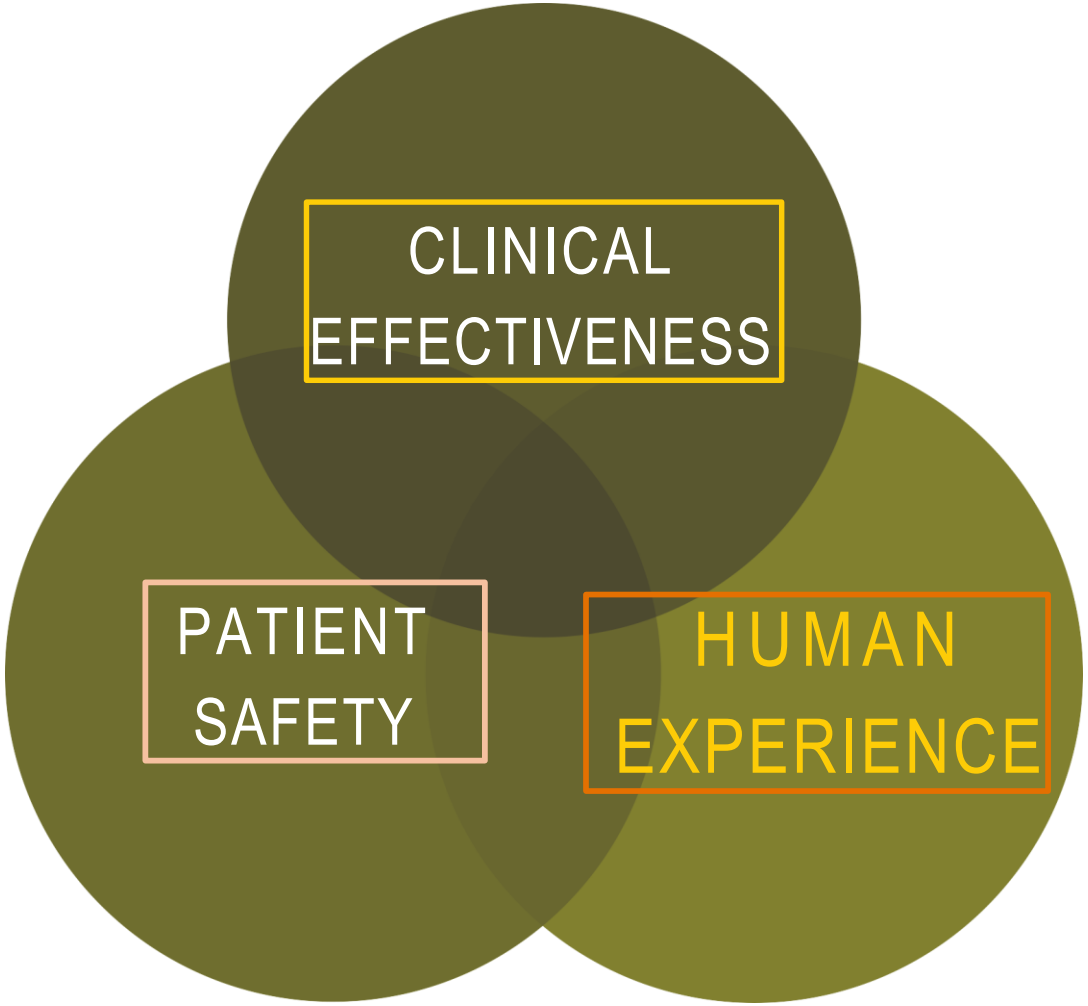
My ID was not checked



NATIONAL HEALTHCARE QUALITY STRATEGY

World Health Organization

Veselības ministrija



VITA
STEINA

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PREM-Ped For children by children

Development of Patient Reported Experience Measures in Pediatric Healthcare (PREM-PED)

Eva Broström, Professor, Karolinska University Hospital/Karolinska Institutet
Cecilia Bartholdson, Associate Professor, PhD, Karolinska Institutet
Marika Wenemark, Associate Professor, PhD, Linköpings Universitet, Karolinska Instituet
Johanna Granhagen Jungner, Assistent Professor, PhD, Karolinska Institutet
Maura Iversen, Professor, Harvard Medical School, Karolinska Institutet

Practices for PREM-Ped at Astrid Lindgren Children's Hospital

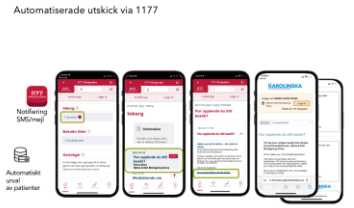
Principles for questions

Few questions with easy language

Response options that match the children's spontaneous answers

2019 Management decision – to develop a generic PREM-PED → PREM-Ped 16 questions → 2020 PREM-Ped 12 to 9 questions → 2022 PREM-Ped 5 questions → 2024 7 questions in-patient

- Automated process from nov 2022 in Swedish Healthcare Guide 1177
- <12 years: guardians together with children
- >13 years: children themselves



1. Focus group	2. Cognitive interviews
	4 rounds
	24 children aged 4-17

Will be professional translated in the next step

How good were the healthcare staff at listening to you?

Very good

Pretty good

Pretty bad

Very bad

Child with positive response:

They asked me how I felt and everything [Josef 11]

Child with negative response:

When they talk to the parents, but it is the child who is in pain [Karen 14]

How good were the healthcare staff to explain things to you?

Very good

Pretty good

Pretty bad

Very bad

Issa 6 years old

Hm… pretty good. But it is a lot of things I don't understand.

Interviewer: How would you like them to explain?

[Thinking] That they show me. Then I understand better - when they show me.

A more direct question about involvement in decisions didn't work because it was difficult to read and understand.

The new easier question capture that they try to understand what the child need by asking questions directly to the child, by listening to what they describe and trying to respect how for example the child want a procedure to be done.

Patient-reported experience measures (PREM) in paediatrics: panel debate about possibilities and challenges".

Claus Sixtus Jensen

PhD, MHSc(Nurs), RN
Associate Professor in Children's Nursing and Clinical Nurse Specialist

Unit for Research and Development in Nursing for Children and Young People
Department of Paediatrics and Adolescent Medicine, Aarhus University Hospital
Research Center for Emergency Medicine, Aarhus University Hospital and Aarhus University

SCAN ME

Mail: claus.sixtus@skejby.rm.dk

Current use of or practices for patient-reported experiences measures (PREM) at your institution

Survey Outpatient Clinic (n=356)

Ongoing research

Paper vs Online

Mail: claus.sixtus@skejby.rm.dk

PREPARE panel Discussion

"Patient-reported experience measures (PREM) in paediatrics: panel debate about possibilities and challenges"

Sant Joan de Déu Barcelona · Hospital

Joan Vinyets i Rejón, PhD
Head of Patient Experience at SJD Children's Hospital, Barcelona
joan.vinyets@sjd.es

The SJD Barcelona Children's Hospital

We are a specialized paediatric center dedicated to comprehensive care for women, children, and adolescents

More than **450,000** children treated per year

WHO ARE WE?

- OHSJD paediatric monographic hospital
- University Hospital
- Private Non-profit
- Long-term agreement with Public System

WHAT DO WE DO?

- Basic and reference activity (national and international)
- Complex and rare diseases

In numbers - Year 2023

ACTIVITY

- # Discharges: **25.760**
- # Emergencies: **125.213**
- # Consultations: **352.423**
- # Deliveries: **3.412**
- # Surgeries: **16.325**

RESOURCES

- # Beds: **353**
- # Professionals: **3.406**

Current use of PREM at HSJD

We don't rely only on PREMS

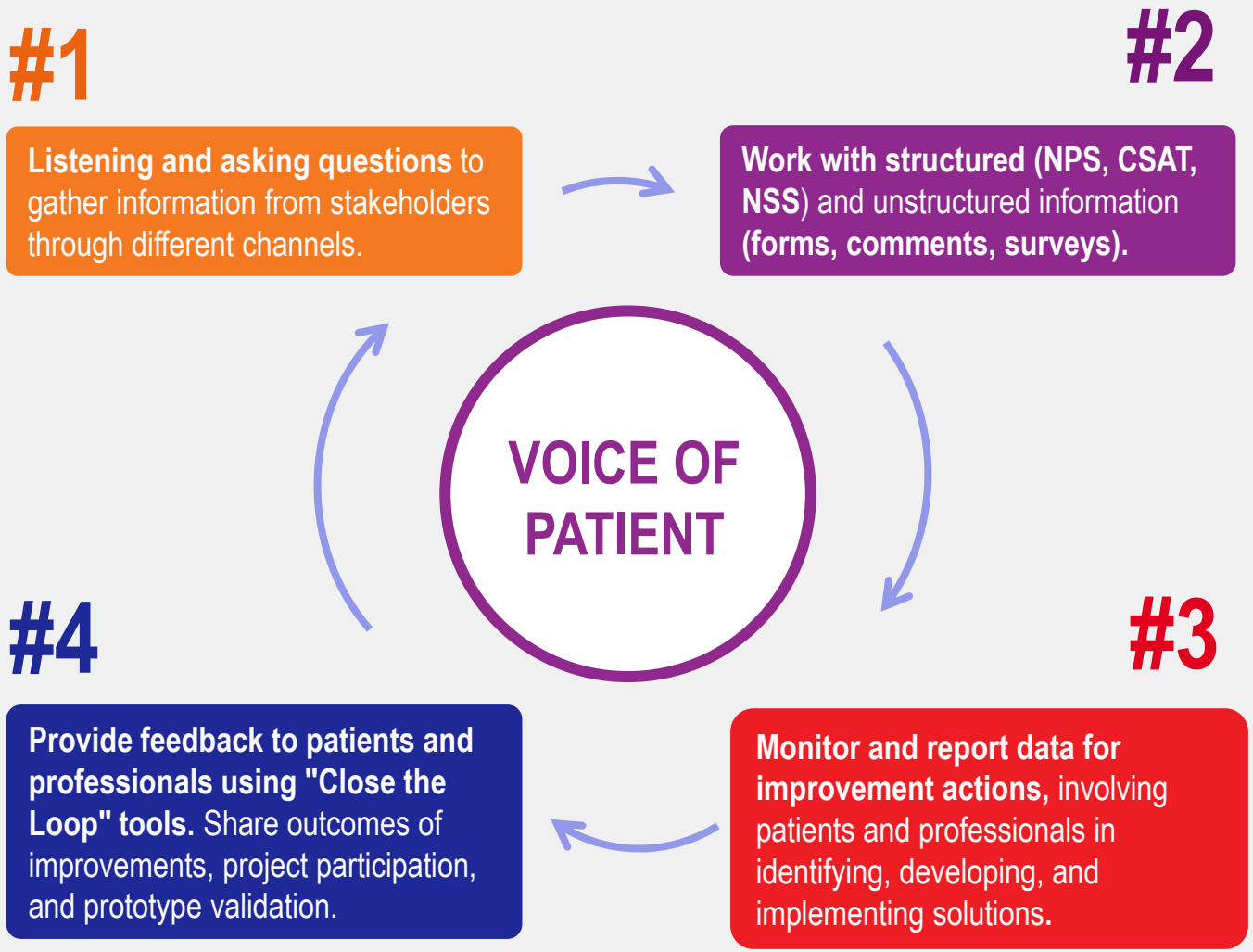
We gather patient experience in a wide variety of ways - questionnaire surveys, personal interviews, focus grups and in-depth interviews- to collect data and gain insights into patient's experience and preferences.

Other sources of feedback on patient experience include:

- NPS surveys -transactional (24 hours after) and relational (> 50.000 inputs/year)
- Complaints and compliments received by open-ended question after they have given their rating in the NPS survey
  (Sentiment Analysis)
- Comments and feedback from patient-families and from social media (Sentiment Analysis)
- Comments and feedback from specific council groups - family council and young patients council
- Patient experience specific research projects

The team:

Patient feedback: 4 professionals + Patient experience: 6 professionals



Food for thought

- **Child-patient instruments that currently hospital employ are normally based on the expectations of adults, administrative goals set by the Health Care Authorities or the Hospital**
- **Children have a unique awareness of their own experiences and can convey their thoughts if they are given the opportunity.**
  - » Are we gathering their own experiences..?
  - » Are we taking into account variations in cognitive development and language, age, sex, health status, and presence of longstanding psychological or emotional conditions...?

Challenge:

There is a clear need for the development of patients-appropriate instruments that capture the direct feedback of hospitalized children, on their experiences in an age-appropriate and culturally accessible way.

Rigshospitalet
Mary Elizabeths Hospital

MyHospitalVoice
A PREM for pediatric patients at MARYS

PREPARE Symposium 2024
Line Klingen Gjærde, MD, PhD
Mary Elizabet's Hospital

Project group:
Jane Hybschmann, PhD student
Adam Bruun, Aisha Zafar & Olivia Braad Honoré, peer-researchers (youth patient representatives)
Jette Led Sørensen, MD, PhD, Professor
Helle Pappot, MD, PhD, Professor
Helena Hanson, MSc, RN, PhD
Thomas Frandsen, MD, PhD, Senior Medical Director

Measuring the effect of play/playfulness

Original research

Open access

BMJ Open

Play interventions for paediatric patients in hospital: a scoping review

Line Klingen Gjærde ,[1] Jane Hybschmann,[1] Daniel Dybdal,[1] Martha Krogh Topperzer,[1] Morten Arnborg Schrøder,[1] Jenny Louise Gibson,[2] Paul Ramchandani,[2] Elisabeth Ida Ginsberg,[1] Bent Ottesen,[1,3] Thomas Leth Frandsen,[1] Jette Led Sørensen[1,3]

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► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2021-051957).

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[2]Centre for Research on Play in Education, Development & Learning, Faculty of Education, Cambridge University, Cambridge, UK
[3]Department of Clinical

ABSTRACT

Objective Play is a non-invasive, safe and inexpensive intervention that can help paediatric patients and their families manage difficult aspects of being ill or hospitalised. Although play has existed in hospitals for decades, research on hospital play interventions is scarce. This review aimed to categorise and synthesise the last 20 years of research on hospital play interventions.

Design Scoping review.

Data sources PubMed, CINAHL, CENTRAL, ERIC and PsycINFO (1 January 2000– 9 September 2020).

Study selection and data extraction We systematically searched for original peer-reviewed articles, written in English, on hospital play interventions in paediatric patients (0–18 years) in non-psychiatric settings. Two reviewers independently screened titles and abstracts, reviewed full text of relevant articles and extracted data. We thematically synthesised the data from the included studies, and a descriptive analysis, based on a developed framework, is presented.

Results Of the 297 included articles, 78% came from high-income countries and 56% were published within the last 5 years. Play interventions were carried out across all ages by various healthcare professionals. Play interventions served different roles within four clinical contexts: A) procedures and diagnostic tests, B) patient education, C) treatment and recovery and D) adaptation. Across these contexts, play interventions were generally facilitated and purpose-oriented and had positive reported effects on pain, stress, and anxiety.

Conclusions Play in hospitals is an emerging interdisciplinary research area with a significant potential benefit for child and family health. Future research should further describe principles for play in hospitals. High-quality studies investigating short-term and long-term effects are needed to guide when and how to best integrate play in hospitals.

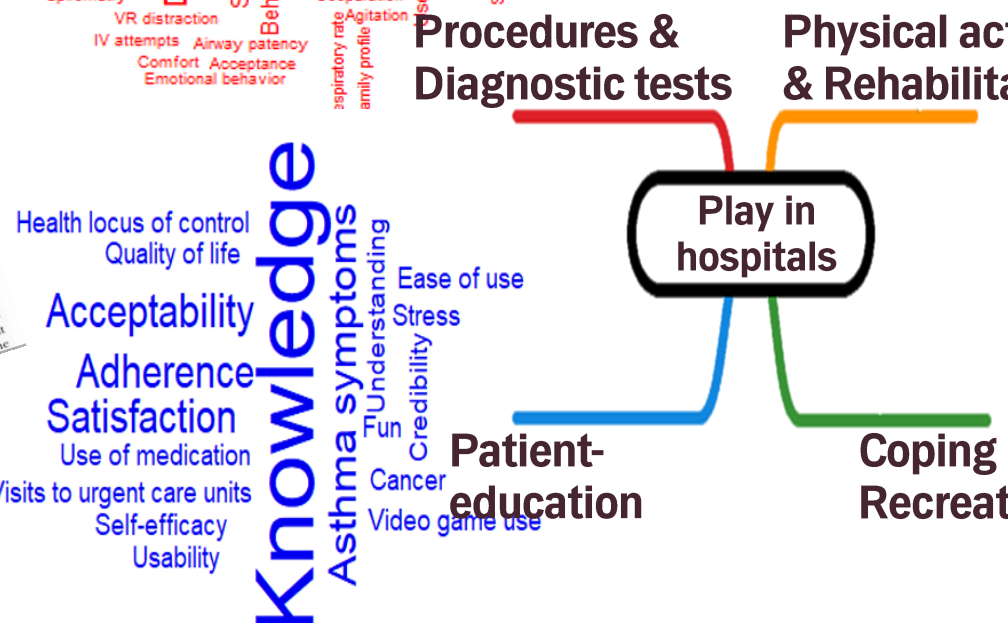
Strengths and limitations of this study

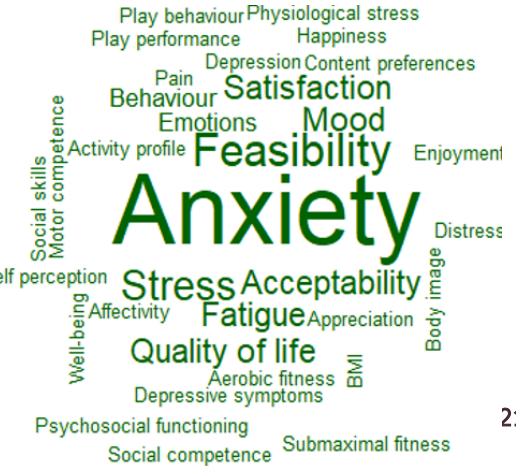
- This review provides a comprehensive overview of 297 systematically collected original articles on play interventions in hospitals.
- The scoping review methodology allowed for assessing a wide variety of articles and identifying significant gaps in the literature.
- Drawing conclusions about implementation of play interventions remains difficult, as the existing literature is heterogenous with great variation in participants, comparator groups, study designs and outcomes.
- Grey literature, articles not written in English and unpublished studies were excluded.

INTRODUCTION

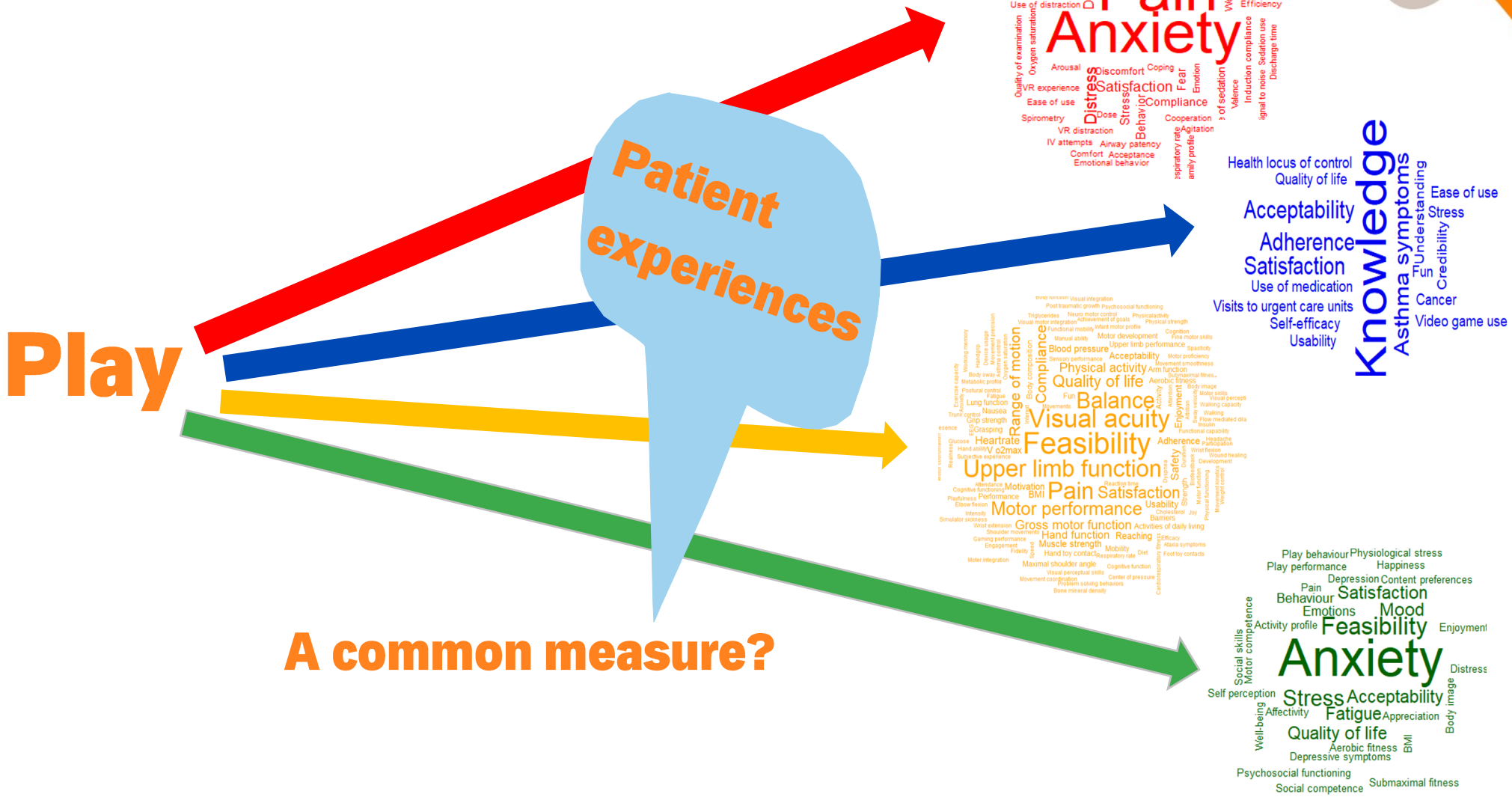
Play, long viewed as a means for children interventions into the treatment and care of paediatric patients may reduce developmental regression.[2] The WHO's standards of children's rights in hospital include the right to play. Recently, the WHO recommended that *all* doctors and nurses utilise play within treatment and care and that hospitals promote research on using play.[5]

Rapid turnover of hospitalised children with few staying for longer periods, limits opportunities for playful relationships and comfortable familiarity with hospital playrooms.[6] Consequently, hospital play interventions are often individualised and treatment-oriented. In some countries play facilitated by specially trained staff for selected patients, rather than a normal, everyday activity.[6 7] Moreover, hospital resources, children's health status and treatment needs, expectations about illness and health behaviour influence the





Measuring the effect of play/playfulness

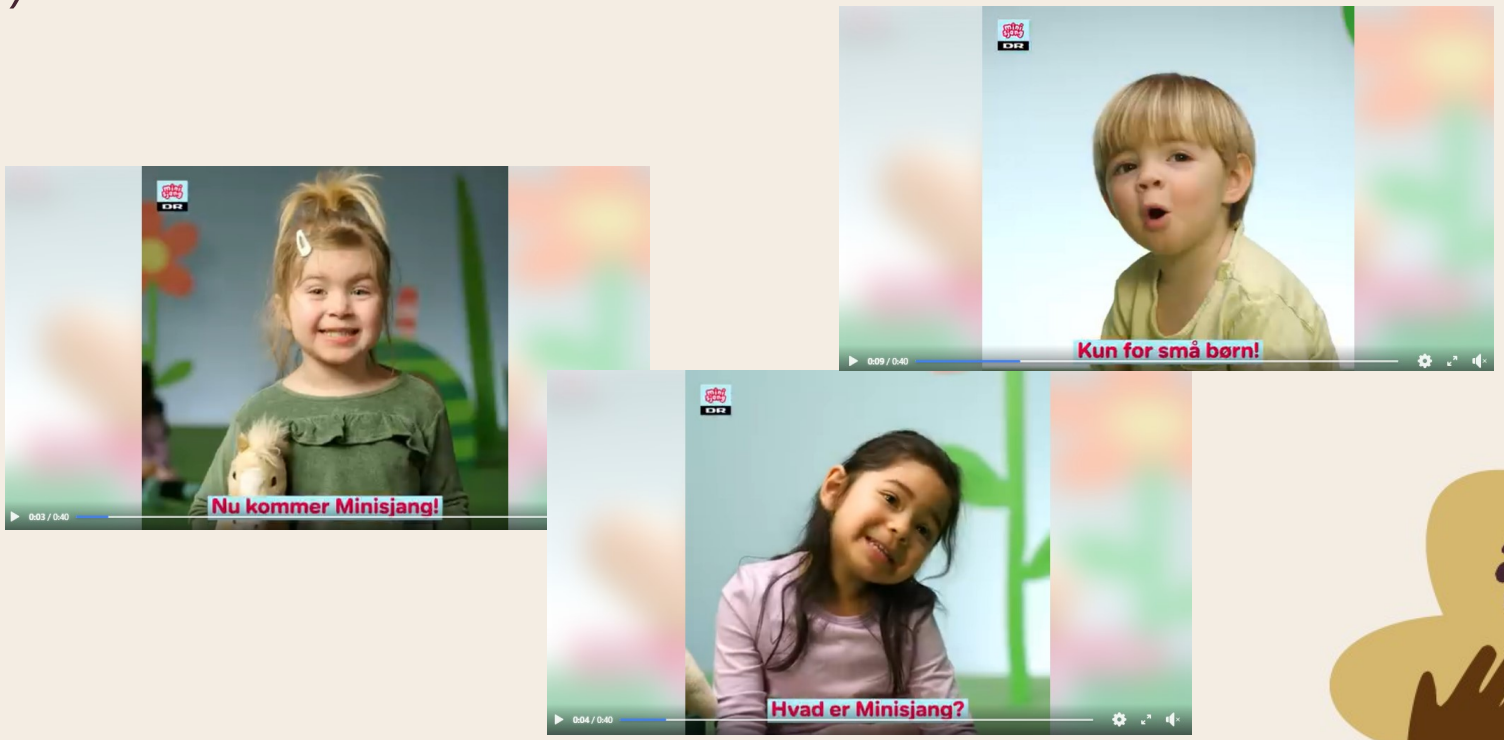


Easy to use and for all pediatric patients (also preschool children)

- Short questionnaire (5-10 min long)
- Danish translation of the Swedish PREM, developed by the Karolinska team
- Digital questionnaire
  - REDCap
    - Child friendly opportunities for answering (e.g. smilies)
    - Reading aloud opportunity
- The questionnaire will be sent out the day the child/young person leaves the hospital
- Young patients as co-researchers

A PREM promoting pediatric patients rights in hospital

- Rights-based focus:
  - An introductory peer-to-peer video about why to answer
  - (maybe a closing video)



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