Rigshospitalet
Mary Elizabeths Hospital

State of the art – Patient-Reported Experience Measures in paediatrics

PREPARE Symposium
November 18 2024

Jane Hybschmann, MScPH, PhD student

Mary Elizabeth's Hospital and Juliane Marie Centre, Copenhagen University Hospital – Rigshospitalet, Denmark

Patient-reported means:

The American Food and Drug Administration defines patient-reported (includes patient-reported outcome, PROs, and PREMs) as

"measurement of any aspect (...) that comes directly from the patient (i.e., without the interpretation of the patient's responses by a physician or anyone else)".

Health USDo, Human Services FDACfDE, Research, et al. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health Qual Life Outcomes*. Oct 11 2006;4:79.

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Patient-reported experience measures (PREMs) are tools that capture "what" happened during an episode of care, and "how" it happened from the perspective of the patient.

Bull C, Byrnes J, Hettiarachchi R, Downes M. A systematic review of the validity and reliability of patient-reported experience measures. Health Serv Res. 2019;54(5):1023-35.

PREMs are not satisfaction questionnaires

≠

"PREMs differ from the more subjective patient satisfaction measures, which are an indication of how well a patient's expectations were met"

Bull C, Byrnes J, Hettiarachchi R, Downes M. A systematic review of the validity and reliability of patient-reported experience measures. Health Serv Res. 2019;54(5):1023-35.

TYPICAL PREM TOPICS

- Information
- Respect
  - Question 1
  - Question 2
  - Question 3
- Communication
- Coordination of care
- Overall experience

How and where are PREMs used in paediatrics?

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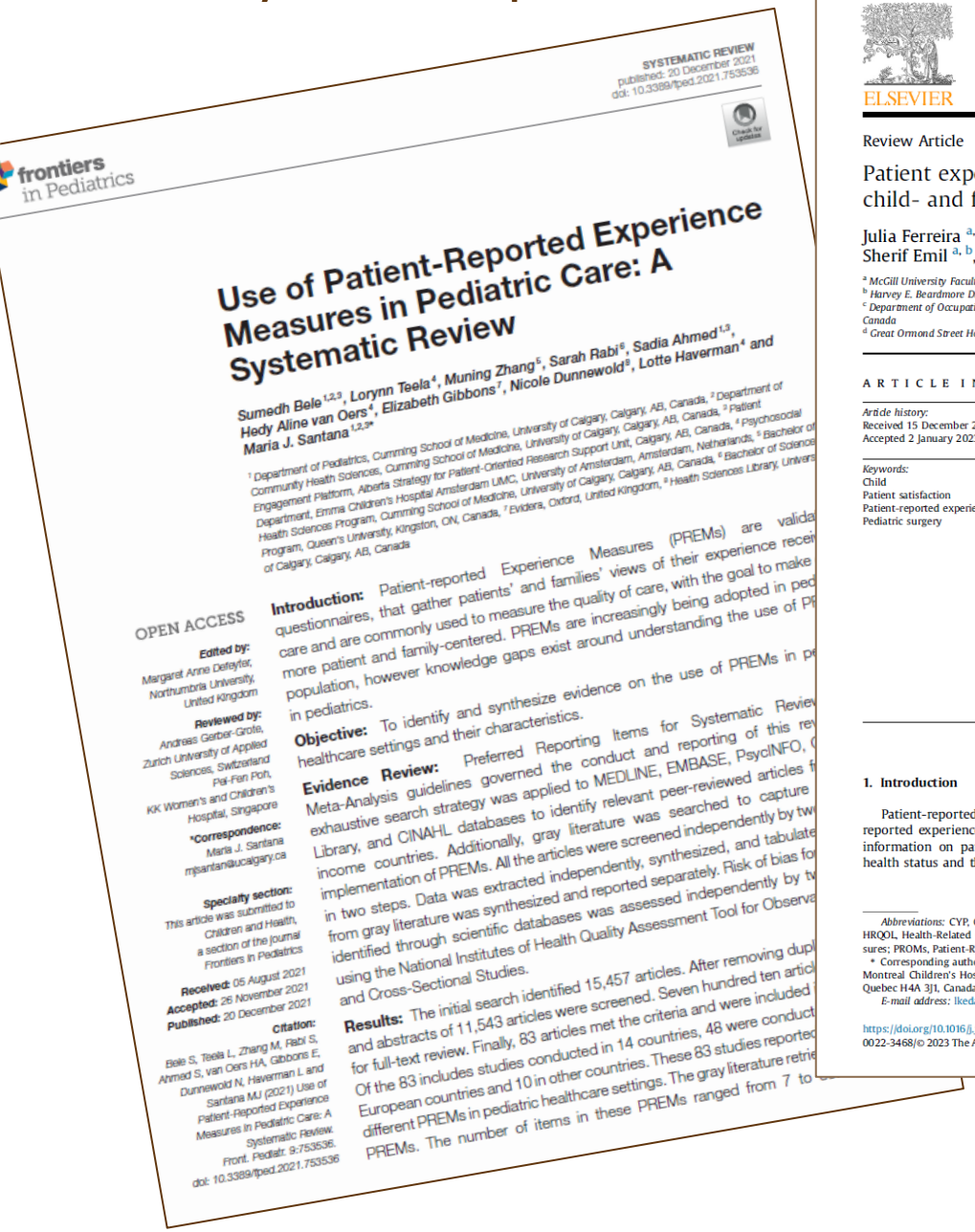

frontiers in Pediatrics

SYSTEMATIC REVIEW
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Use of Patient-Reported Experience Measures in Pediatric Care: A Systematic Review

Sumedh Bele [1,2,3], Lorynn Teela [4], Muning Zhang [5], Sarah Rabi [6], Sadia Ahmed [1,3], Hedy Aline van Oers [4], Elizabeth Gibbons [7], Nicole Dunnewold [8], Lotte Haverman [4] and Maria J. Santana [1,2,3]*

[1] Department of Pediatrics, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada, [2] Department of Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada, [3] Patient Engagement Platform, Alberta Strategy for Patient-Oriented Research Support Unit, Calgary, AB, Canada, [4] Psychosocial Department, Emma Children's Hospital Amsterdam UMC, University of Amsterdam, Amsterdam, Netherlands, [5] Bachelor of Health Sciences Program, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada, [6] Bachelor of Science Program, Queen's University, Kingston, ON, Canada, [7] Evidera, Oxford, United Kingdom, [8] Health Sciences Library, University of Calgary, Calgary, AB, Canada

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Review Article

Patient experience or patient satisfaction? A systematic review of child- and family-reported experience measures in pediatric surgery

Julia Ferreira [a,b], Prachikumari Patel [b], Elena Guadagno [b], Nikki Ow [c], Jo Wray [d], Sherif Emil [a,b], Dan Poenaru [a,b,*]

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ABSTRACT

Purpose: Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are increasingly recognized as important health care quality indicators. PREMs measure patients' perception of the care they have received, differing from satisfaction ratings, which measure their expectations. The use of PREMs in pediatric surgery is limited, prompting this systematic review to assess their characteristics and identify areas for improvement.

Methods: A search was conducted in eight databases from inception until January 12, 2022, to identify PREMs used with pediatric surgical patients, with no language restrictions. We focused on studies of patient experience but also included studies that assessed satisfaction and sampled experience domains. The quality of the included studies was appraised using the Mixed Methods Appraisal Tool.

Results: Following title and abstract screening of 2633 studies, 51 were included for full-text review, of which 22 were subsequently excluded because they measured only patient satisfaction rather than experience, and 14 were excluded for a range of other reasons. Out of the 15 included studies, questionnaires used in 12 studies were proxy-reported by parents and in 3 by both parents and children; none focused only on the child. Most instruments were developed in-house for each specific study, without patients' involvement in the process, and were not validated.

Conclusions: Although PROMs are increasingly used in pediatric surgery, PREMs are not yet in use, being typically substituted by satisfaction surveys. Significant efforts are needed to develop and implement PREMs in pediatric surgical care, in order to effectively capture children's and families' voices.

Level of evidence: IV

1. Introduction

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are critical for collecting information on patient care [1]. PROMs can measure patients' health status and the impact of a disease or treatment, including patient symptoms, functional status, quality of life, and health-related quality of life (HRQOL) [2,3]. PREMs measure patients' perception of their experience with the healthcare received [2]. The use of PROMs and PREMs has been shown to lead to shared decision-making, improved communication, and detection of overlooked problems, ensuring better and individualized care [4]. These instruments can also influence healthcare interventions, resource allocation, and policymaking [1,4,5]. PROMs and PREMs are complementary tools and should be used together to capture a complete patient-centered journey [6].

A PREM exists to capture "what" happened during an episode of care and "how" it happened from the patient's perspective [2]. PREMs cover domains like communication with staff, access to information, care received, physical and emotional support, shared

Abbreviations: CYP, Children and Young People; HIC, High-income countries; HRQOL, Health-Related Quality of Life; PREMs, Patient-Reported Experience Measures; PROMs, Patient-Reported Outcome Measures; USA, United States.

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Review

Patient reported experience measures to assess psychosocial cancer care: A rapid review of current instruments

Zoe Clothier [a], Jo Armes [a], Agnieszka Kehinde [b], Victoria Mumford [b], Kate Upshon [b], Clare Williamson [b], Rachel MacArthur [b], Rachel Stevenson [b], Sophie Otter [b], May Teoh [b], Jenny Harris [a,*]

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ABSTRACT

Purpose: Patient Reported Experience Measures (PREMs) are instruments that capture patients' perspectives of health care services and offer insight into the perceived quality of care and identify areas for improvement. This rapid review aimed to identify and evaluate existing PREMs that explore patients' experiences of psychosocial cancer care, describe their conceptual content and assess the quality of their development.

Methods: Databases (MEDLINE and PsycINFO) were searched from January 1998 to January 2023. Eligible papers included PREMs developed or tested in adult cancer populations. The psychosocial content of concepts assessed by PREMs were mapped and the quality of their development assessed using the Quality Assessment Checklist (QAC).

Results: Twenty-three articles describing the development of 20 PREMs were identified. The content of these PREMs varied in terms of psychosocial domain coverage and the rigour of the development process. Quality assessment indicated that whilst instruments were well-developed, psychometric testing at this stage was less thoroughly reported on.

Conclusion: Several patient-reported instruments are available to measure patients' psychosocial cancer care experiences; however, these differ in content and thoroughness. The choice of instrument used by researchers will therefore depend on research or clinical objectives and on striking a balance between comprehension and length. Limitations of this review are discussed.

duction

ncer patient care pathway through diagnosis, treatment and on, survivorship or palliative end of life care can be psy- demanding (Armes et al., 2009; Zabora et al., 2001; Meh- 014; Mitchell et al., 2011). As overall cancer survival rates o advances in diagnosis and treatment (Arnold et al., 2019; 020), increasing numbers of people are now living with es of cancer and its treatment for longer periods, pre- es to cancer services supporting ongoing psychosocial ackdrop of limited resources and workforce challenges 2021). Internationally, cancer care guidance has lighted the importance of services providing appropriate levels of needs-based high-quality psychosocial care (Haward, 2006, Grassi et al., 2023, Vaz-Luis et al., 2022) which may be conceptualized as encompassing emotional, social (including work and finance) and cognitive domains (Mulls et al., 2022, Soothill et al., 2001, Herschbach et al., 2004). An international survey suggests that whilst more than two-thirds (69 %) of cancer patients report needing psychological support during their cancer journey, in the UK this figure was 30 % (All.Can, 2018; All.Can, 2020). Studies consistently suggest that around a third of patients who needed such psychological support said it was unavailable (All.C.A.N, 2018; Armes et al., 2009; Sarkar et al., 2015; Fitzer et al., 2014) and a more recent UK survey found that half of patients reported the psychological support they needed was unavailable (All.Can, 2020). It is likely that the changes to practice in response to

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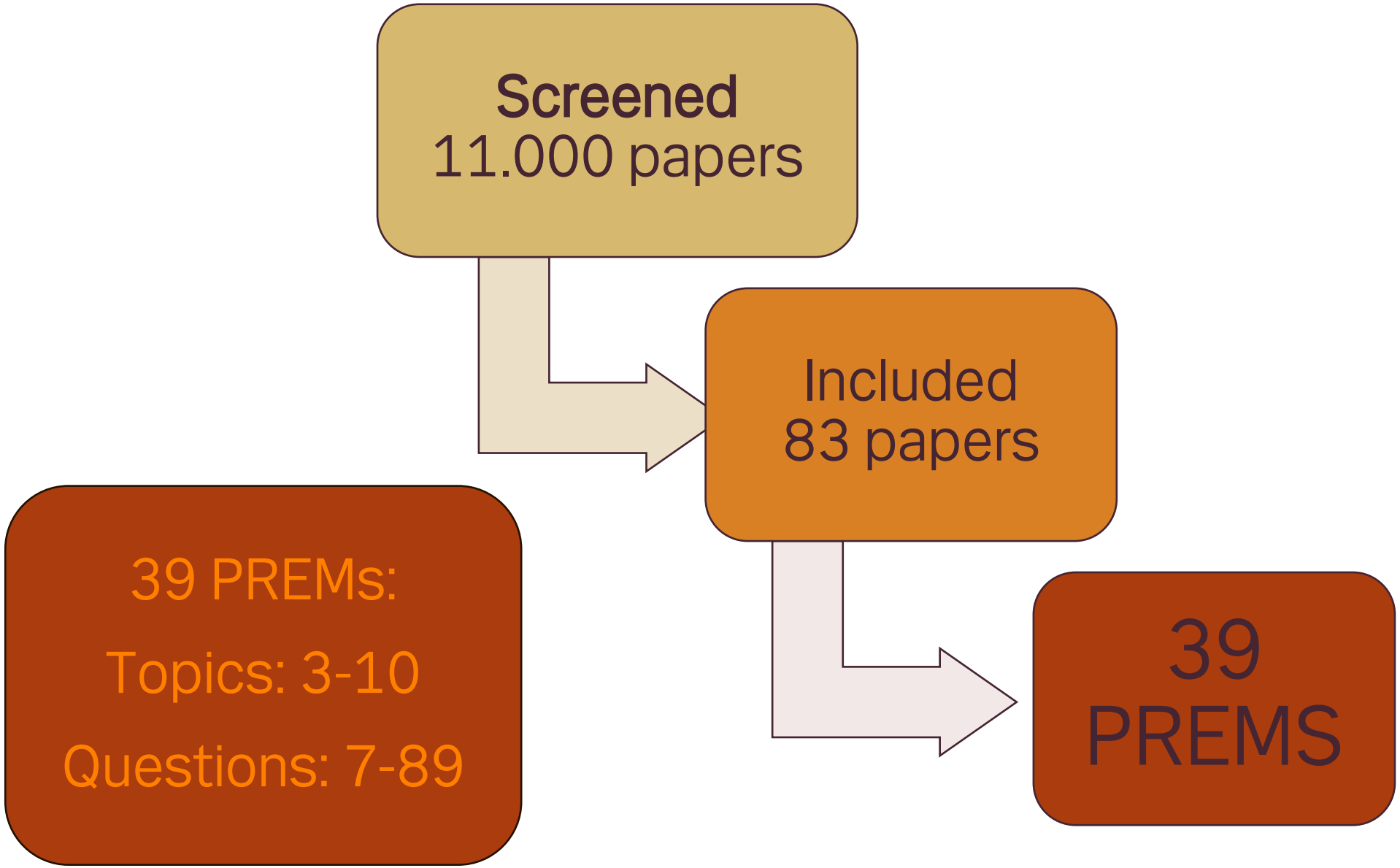

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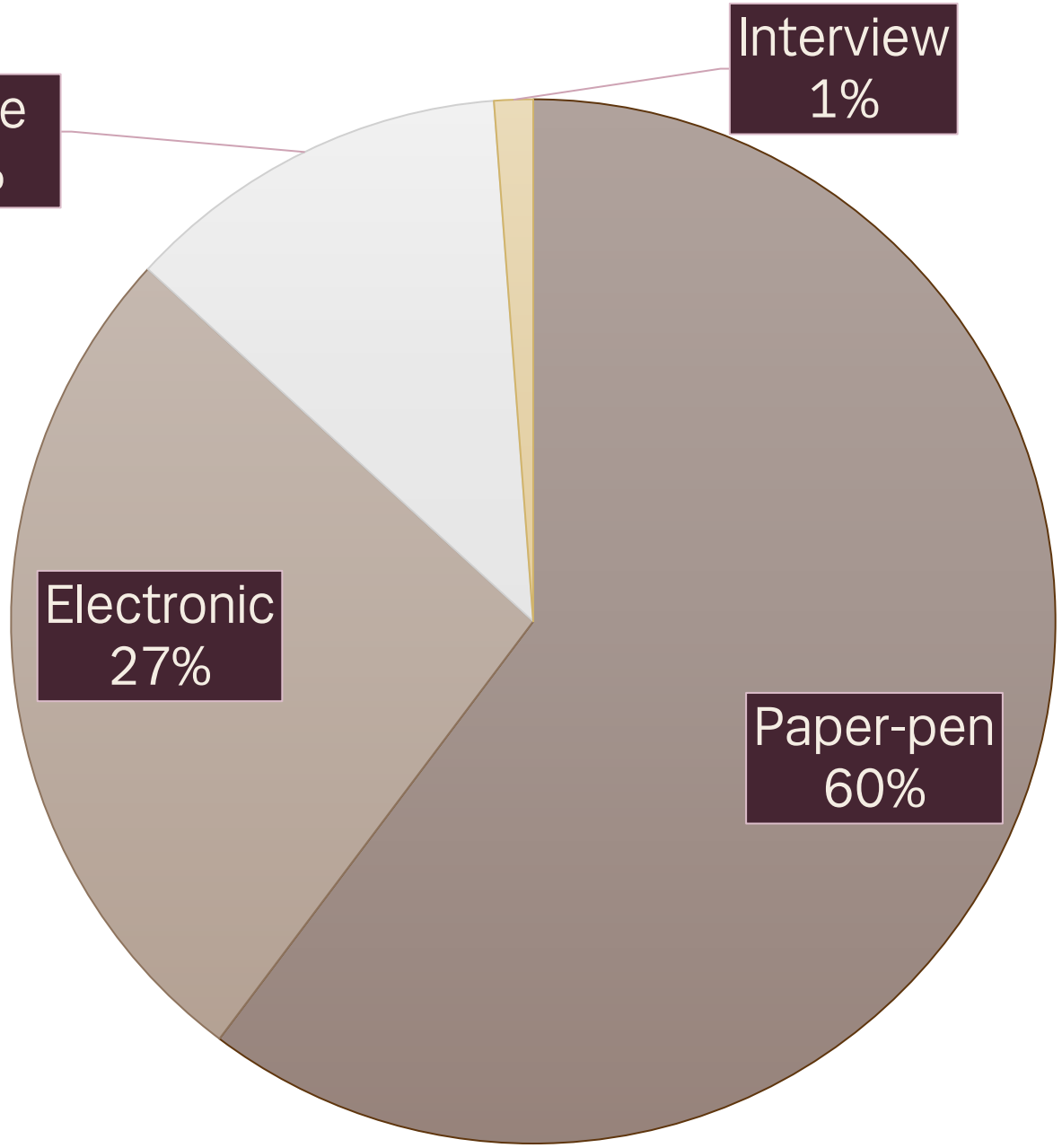

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Of 39 identified PREMs, how many do you think were developed to target children or adolescents?

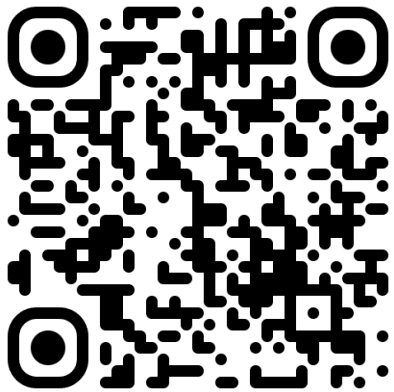
The question will open when you start your session and slideshow.

A. 0-9

B. 10-19

C. 20-29

D. 30-39



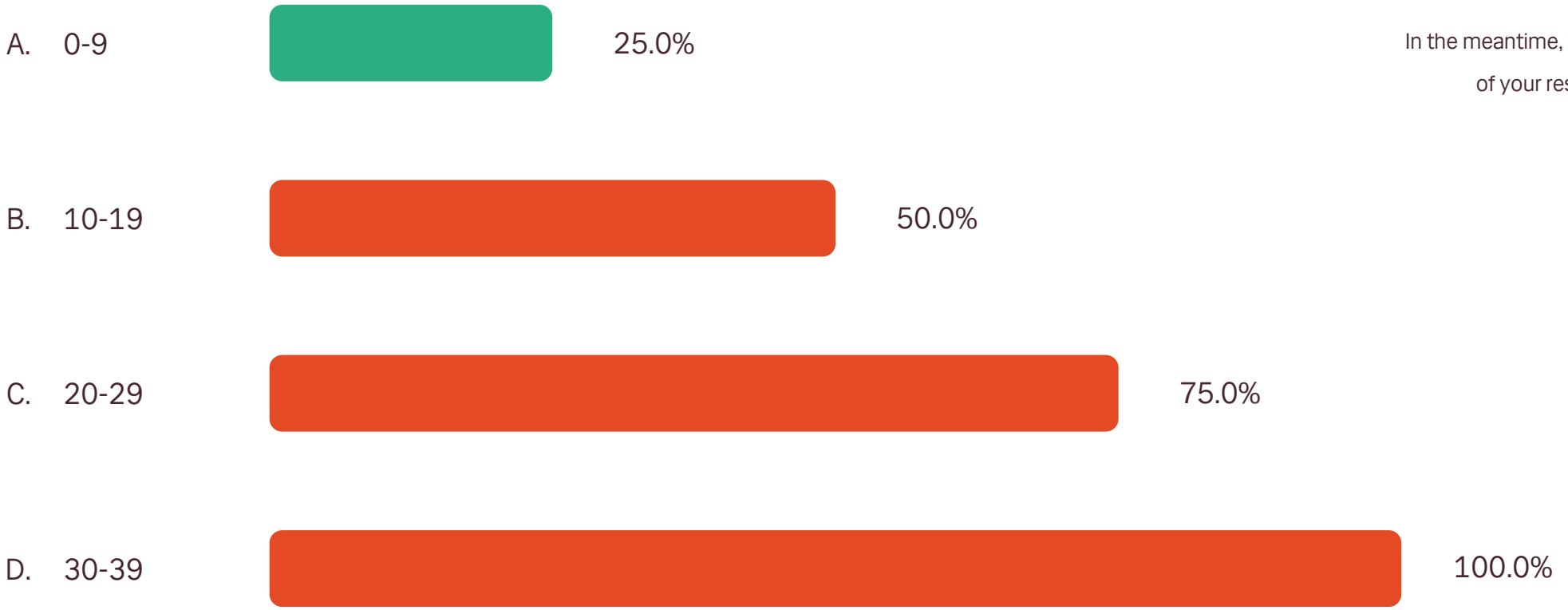
Internet	"Description of message sending methods"
TXT	"It will be inserted after you've started a session"

0 1

Time: 20s

Of 39 identified PREMs, how many do you think were developed to target children or adolescents?

We will set these example results to zero once you've started your session and your slide show.
In the meantime, feel free to change the looks of your results (e.g. the colors).



Closed

”6 out of 39 PREMs

had been explicitly developed for completion by the peadiatric patient themselves”

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- US early movers
- Trending in high-income countries
- Key marker for patient-centred care
- Central to value-based healthcare systems

Why use patient-reported experience measures?

What
can we learn about the patients who report the best experiences?

Where
are opportunities to improve quality of care?

Where
should our hospital focus efforts to improve patient experiences?

What
can we learn about our patients?

Opportunities to learn and improve patient-centred care

Which
department or hospital can I look to for best practices?