From voice to impact

- Capturing and utilising children's experiences of healthcare within Swedish paediatric care

av

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Abstract

One of the core principles of the United Nations Convention on the Rights of the Child is that children have the right to freely express their views on all matters affecting them. Thus, the paediatric healthcare sector has a responsibility to promote children's participation at both the individual and collective level. A central part of high-quality paediatric care is giving children the opportunity to share views on their experiences.

This thesis explores how children's right to share their views on their healthcare experiences can be facilitated and integrated into Swedish paediatric care. It contains four studies focusing on (I) describing how Swedish paediatric departments encourage children's voices regarding their healthcare experiences and how children's perspectives are taken into account in quality-improvement work; (II) translating, adapting and validating the six versions of the Children and Young People – Patient-reported Experience Measure (CYP-PREM) for use in a Swedish healthcare context; (III) piloting the Swedish versions of the CYP-PREM (Swe-CYP-PREM) questionnaire in paediatric care; and (IV) exploring first-line managers' and quality-improvement workers' perspectives of using PREMs in paediatric units. The findings indicate that integrating children's right to express their views regarding their healthcare experiences into clinical practice requires a systematic, flexible and context-sensitive approach grounded in organisational commitment to listening to children's voices. Swe-CYP-PREM appears to be a valuable tool for facilitating this process, although challenges remain in achieving sustainable and systematic integration of children's perspectives into paediatric care.

Keywords: Children, Healthcare experiences, Instrument development, Paediatric care, PREMs