

## Giving Children with Osteogenesis Imperfecta a Voice: Overview of a Participatory Approach for the Development of an Interactive Communication Tool

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**Abstract :** Osteogenesis Imperfecta (OI) is a genetic disorder of childhood onset that causes frequent fractures after minimal physical stress. To date, OI research has focused on medically- and surgically-oriented outcomes with little attention on the perspective of the affected child. It is a challenge to elicit the child's voice in health care, in other words, their own perspective on their symptoms, but software development offers a way forward. Sisom (Norwegian acronym derived from 'Si det som det er' meaning 'Tell it as it is') is an award-winning, rigorously tested, interactive, computerized tool that helps children with chronic illnesses express their symptoms to their clinicians. The successful Sisom software tool, that addresses the child directly, has not yet been adapted to attend to symptoms unique to children with OI. The purpose of this study was to develop a Sisom paper prototype for children with OI by seeking the perspectives of end users, particularly, children with OI and clinicians. Our descriptive qualitative study was conducted at Shriners Hospitals for Children® - Canada, which follows the largest cohort of children with OI in North America. Purposive sampling was used to recruit 12 children with OI over three cycles. Nine clinicians oversaw the development process, which involved determining the relevance of current Sisom symptoms, vignettes, and avatars, as well as generating new Sisom OI components. Data, including field notes, transcribed audio-recordings, and drawings, were deductively analyzed using content analysis techniques. Guided by the following framework, data pertaining to symptoms, vignettes, and avatars were coded into five categories: a) Relevant; b) Irrelevant; c) To modify; d) To add; e) Unsure. Overall, 70.8% of Sisom symptoms were deemed relevant for inclusion, with 49.4% directly incorporated, and 21.3% incorporated with changes to syntax, and/or vignette, and/or location. Three additions were made to the 'Avatar' island. This allowed children to celebrate their uniqueness: 'Makes you feel like you're not like everybody else.' One new island, 'About Me', was added to capture children's worldviews. One new sub-island, 'Getting Around', was added to reflect accessibility issues. These issues were related to the children's independence, their social lives, as well as the perceptions of others. In being consulted as experts throughout the co-creation of the Sisom OI paper prototype, children coded the Sisom symptoms and provided sound rationales for their chosen codes. In rationalizing their codes, all children shared personal stories about themselves and their relationships, insights about their OI, and an understanding of the strengths and challenges they experience on a day-to-day basis. The child's perspective on their health is a basic right, and allowing it to be heard is the next frontier in the care of children with genetic diseases. Sisom OI, a methodological breakthrough within OI research, will offer clinicians an innovative and child-centered approach to capture this neglected perspective. It will provide a tool for the delivery of health care in the center that established the worldwide standard of care for children with OI.

**Keywords :** child health, interactive computerized communication tool, participatory approach, symptom management

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