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Assessment of Barriers and Enablers for Implementing a Population-Based Childhood Cancer Registry in Chennai, India

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Introduction: Despite most childhood cancer cases being diagnosed in low and middle-income countries, there is a significant deficit of population-based childhood cancer registries (PBCCRs) in these regions. To address this critical gap, we established India's first dedicated PBCCR in Chennai on 4th October 2022, covering age 0-19 years. This study aims to identify the barriers and enablers to implementing the Chennai PBCCR.

Methodology: Between April 2023 and March 2024, a sequential explanatory mixed-method study was conducted across 10 of the 16 centers in Chennai that agreed to support the PBCCR. A total of 25 professionals agreed to participate in the quantitative phase utilizina structured questionnaire. For the qualitative phase, in-depth interviews were conducted with 23 participants, including 16 from the quantitative phase, two stakeholders, and five caregivers. The interview guide was constructed, and the responses were analyzed using the Consolidated Framework for Implementation Research.

Results: Themes from the qualitative analysis revealed technological constraints, poor record-keeping, insufficient details captured in case records, and inadequate human resources as impediments. At the same time, factors such as knowledge, belief in sharing high-resolution data, the requirement and advantages of implementing a childhood cancer registry, professional self-efficacy, work infrastructure, and collaborative networks emerged as facilitators to the successful implementation of PBCCR.

Conclusion: Our experience and the findings of this study serve as a model for successfully implementing and operating PBCCRs in India and other countries. Registry data are vital to improving the understanding of childhood cancer burden and offer hope to children and their families.