

## POSTER ABSTRACT

# Families as Partners: Co-design of a localised model of care for children with medical complexity living in rural Australia and evaluation using the Paediatric Integrated Care Survey (PICS)

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**Introduction:** The number of children with medical complexity (CMC) residing in regional Australia is growing, challenging the health system to provide equitable care. Families of CMC experience problems in accessing appropriate care locally and they have high out-of-pocket costs and family disruptions because of long travel distances to access care in metropolitan paediatric hospitals. The Murrumbidgee Local Health District (MLHD) in collaboration with the Sydney Children's Hospitals Network (SCHN) partnered with families and local services to co-design a Model of Care (MoC) which better reflects the needs of CMC, their families and local services. The MoC was co-designed with families, local healthcare providers and the tertiary paediatric network.

**Theory/Methods:** Twelve families provided important information about experiences, needs and wants during formative evaluation interviews. Qualitative thematic analysis of interview transcripts was conducted, and common themes identified. This information was used in the codesign of a new MoC that included the following enablers: paediatric care coordination (PCC), telehealth and cross sector partnerships. The model is continuously evolving through Quality Improvement (QI) implementation methodology. Experiences of parents were evaluated using the Paediatric Integrated Care Survey (PICS) at baseline, 6 months, and 12 months after CMC were enrolled in the new MoC, in a longitudinal cohort design. Baseline PICS data have been collected for 33 children and the 6-month follow-up data collection phase has begun.

**Results:** Financial constraints, difficulties navigating healthcare systems, fragmented care, poor communication among professionals and between professionals and the family, and the impact these had on the child's health and family functioning, were key themes that emerged from analysis of interview data. This informed the design of a shared-care model including enablers: care coordination, telehealth, and cross-sector partnerships to bring primary care and hospital care closer to home. Model implementation was enhanced by involving CMC and their families in multidisciplinary team meetings, care planning and service evaluation. Baseline PICS data reflects the themes identified during the parent interviews: 87% of children had no integrated care plan, 63% said that the key medical team leaders rarely or sometimes were aware of another team's advice, and 43% of the clinical team members did not have access to the same medical records. Furthermore, 64% of parents had never/rarely discussed broader impacts on the family unit.

**Conclusions and lessons learned:** Engaging with families provides a wealth of unique knowledge, with their inclusion in service design crucial to successful integration of care. Utilising a validated tool such as the PICS periodically during implementation of the new MoC will provide feedback loops to inform models adjustments. The PICS has highlighted the need for shared care plans and recognition of the impacts of caring for a CMC on family functioning.

**Limitations:** This study is limited by its size and resourcing which limited the design to a longitudinal cohort study pre and post intervention.

**Suggestions for future research:** Ideally a step-wedge randomised controlled trial of a new MoC implemented across several sites with primary outcome measures for the family, for healthcare providers and for the healthcare system.

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**Keywords:** integrated care; care coordination; co-creation; children; chronic disease

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