

## POSTER ABSTRACT

### Care coordination for children with chronic and complex conditions in Australia: significant benefits for patients and their families

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Yvonne Zurynski<sup>1</sup>, Lisa Altman<sup>2</sup>, Christie Breen<sup>2</sup>, Susan Woolfenden<sup>3</sup>

1: Discipline of Child and Adolescent Health, The University of Sydney and the Australian Paediatric Surveillance Unit, Kids Research Institute, Sydney Children's Hospitals Network, Sydney, Australia;

2: Sydney Children's Hospitals Network, Sydney, Australia;

3: Sydney Children's Hospitals Network, Sydney, Australia and Discipline of Child and Maternal Health, The University of NSW, Sydney Australia

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**Introduction:** The Sydney Children's Hospitals Network implemented the Kids Guided Personalised Service (Kids GPS) Care Coordination initiative in July 2015. Children with chronic and complex conditions are eligible for the service. Kids GPS Care Coordinators (CCs) work closely with families and with medical teams to improve access to care in a coordinated way, to source care closer to home and to link families with NGOs and welfare agencies where needed.

**Methods:** A link to the digitised version of the Paediatric Integrated Care Survey was emailed to a random sample of 50 parents of children enrolled in the Kids GPS Care Coordination. The PICS addresses five domains: 1) access to care, 2) care goal creation, 3) family impact, 4) communication with the care team and 5) team functioning and quality. In addition, the number of school absences kilometres of travel avoided was calculated for the total 447 children enrolled in the service.

**Results:** Eighteen parents (36%) completed the PICS. All reported having excellent access to health care were they never or rarely experienced delays because of waiting lists or difficulties getting information about services. The majority (83%) said that their care team listened carefully to their concerns and over 50% felt they were an equal partner in the care team. In terms of perceptions of care team functioning, only 8(44%) said that all care team members had access to the same medical records, and only 30% said that all team members knew about advice provided by another team member. Half or less of the parents said that care team members asked about family functioning and stress on parents and siblings. Only 7(39%) had been offered communication via email, phone, skype, or telehealth, and only 2 parents were provided with information about peer support. Approximately 370 school absences and 51,416 kilometres of travel had been avoided. The cost savings for travel are estimated at \$98,317.

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**Discussion and Lessons Learned:** All parents whose children were enrolled in Kids GPS Care Coordination had excellent access to health care. However, multidisciplinary care teams need to take into account the broader impacts including stress on the family. Families should be linked with peer support networks, respite care and psychological services to optimise their ability to care for the sick child while maintaining healthy family functioning. Although many thousands of kilometres of travel was saved, this could further increase if health advice was provided through means other than a face-to-face visit. Parents were aware of communication difficulties among members and parents were often responsible for sharing results of investigations and consultations with other care team members. Communication among team members should be further supported through shared eMR and regular case conferencing.

**Limitations:** The response rate was relatively low and the 18 parents may not necessarily represent experiences of all parents of children enrolled in Kids GPS Care Coordination.

**Suggestions for future research:** In-depth interviews with parents are planned to ascertain a detailed understanding of their experiences including benefits and hindrances while navigating the health care system for their child.

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**Keywords:** care coordination; paediatric; consumer; complex; chronic

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