

# Care coordination for children with medically complex CP: the experiences and perspectives of caregivers and families.

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## BACKGROUND AND AIMS

- Children with medically complex cerebral palsy (CP) have high care needs and health care service utilisation.<sup>1,2</sup>
- High parent and family care demands that are involved,<sup>2</sup> impacts parent and caregiver personal, social, financial and family lives.<sup>3</sup>
- The Royal Children's Hospital (RCH) in Melbourne has a complex care program, the Complex Care Hub (CCH), however evidence for the impact of such programs is limited.
- CCH service eligibility relates to the chronicity, complexity, instability and functional limitations associated with the child's condition.

This study explored the health care experiences and perspectives of parents/caregivers of children with medically complex CP who were supported by the CCH and those who received regular care.

## METHODS

- This qualitative, descriptive study was co-designed with caregivers of children with CP and healthcare professionals.
- All children met eligibility for the CCH.
- Twelve semi-structured interviews were completed; five caregivers who had received CCH services and seven who had received usual care.
- Data were analysed thematically.<sup>4</sup>
- Both groups were analysed concurrently with ongoing comparison to understand similarities and differences in experiences between groups.<sup>5</sup>

## RESULTS

- Three themes were found (Table 1). A diagrammatic representation of the relationship between key themes and concepts developed during analysis is illustrated in Figure 1.

Table 1. Themes & sub-themes

Theme:	Sub-themes
Care coordination leads to reassurance and less time in hospital	<ul style="list-style-type: none"> <li>• One point of contact</li> <li>• Coordination and organisation</li> <li>• Challenges getting on the system</li> </ul>
Navigating the healthcare system	<ul style="list-style-type: none"> <li>• Being supported to learn to navigate the system and self-advocate versus learning to navigate through experience</li> <li>• Managing planned and unplanned service use</li> <li>• Practical considerations for families with medically complex children navigating the system</li> </ul>
Family centredness and shared decision making	<ul style="list-style-type: none"> <li>• Being kept informed during service use</li> <li>• Being listened to and respected; shared decision making</li> <li>• Support me to support my child</li> </ul>

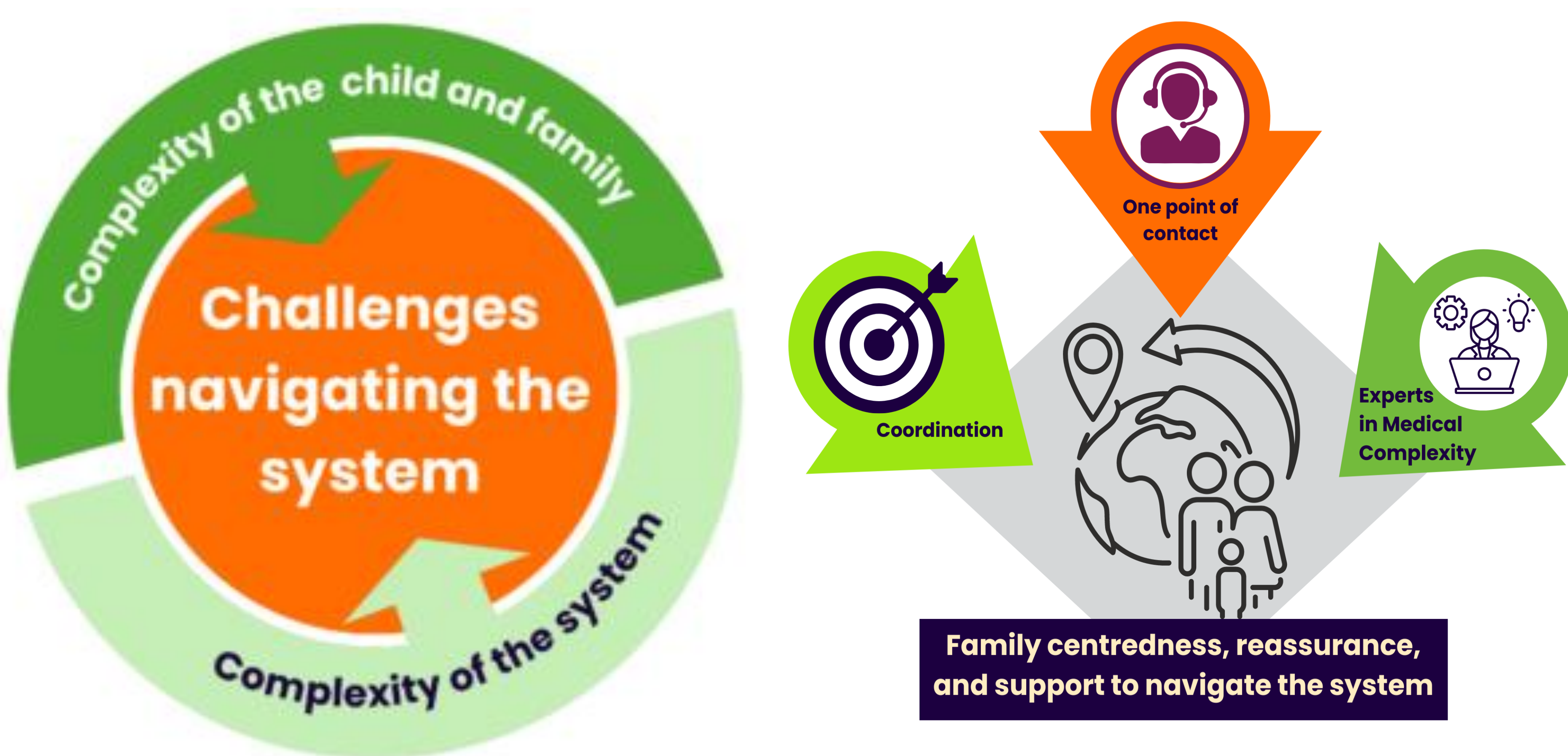


Figure 1. Summary of findings

## CONCLUSIONS:

- Families are required to navigate care across a variety of departments and professionals within the hospital.
- Families who accessed the CCH described the reassurance of having one main point of contact, better coordination of appointments and greater ease of navigating the healthcare system.
- Families who received usual care described longer wait times for appointments, inconsistent appointment times, and greater administrative and advocacy burden in navigating the system.

## NEXT STEPS:

- Explore clinician experiences of providing care
- Co-design a service delivery pathway and outcomes framework for children with medically complex CP

Further information about the complex care hub project can be found by scanning the QR code below

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### ACKNOWLEDGEMENTS

Generously supported by a Melbourne Disability Institute seeding funding grant

