

**Abstract Title:** Identifying research priorities in childhood chronic conditions.

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## Background

Chronic conditions are the leading cause of mortality, morbidity and disability in children. However, children and caregivers are rarely involved in identifying research priorities, which may limit the value of research in supporting patient-centred practice and policy.

## Objectives

To identify priorities of patients, caregivers and health professionals for research in childhood chronic conditions and describe the reason for their choices.

## Method

Patients aged 8 to 14 years with a chronic condition (n=3), parents/caregivers of children aged 0 to 18 years with a chronic condition (n=19), representatives from consumer organisations (n=13) and health professionals (n=38) identified and discussed research priorities. Transcripts were thematically analysed.

## **Results**

Seventy-eight research questions were identified. Five themes underpinned participants' priorities: maintaining a sense of normality (enabling participation in school, supporting social functioning, promoting understanding and acceptance); empowering self-management and partnership in care (overcoming communication barriers, gaining knowledge and skills, motivation for treatment adherence, making informed decisions, access and understanding of complementary and alternative therapies); strengthening ability to cope (learning to have a positive outlook, preparing for home care management, transitioning to adult services); broadening focus to family (supporting sibling well-being, parental resilience and financial loss, alleviating caregiver burden); and improving quality and scope of health and social care (readdressing variability and inequities, preventing disease complications and treatment side effects, identifying risk factors, improving long-term outcomes, harnessing technology, integrating multidisciplinary services).

## **Conclusions**

Research priorities identified by children, caregivers and health professionals emphasize a focus on life participation, psychosocial well-being, impact on family and quality of care.