



Research priorities for childhood chronic conditions – a workshop report

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THE UNIVERSITY OF
SYDNEY



The Sydney children's
Hospitals Network



Research priority setting partnerships

- What are they?
 - They bring together patients, caregivers and healthcare providers to identify priorities for research
- Why?
 - So research addresses questions that are important and relevant to people living with the illness, their families, and healthcare professionals who care for them
- What has been done before?
 - childhood disability, eczema, cleft lip and palate, asthma

Why conduct a research priority setting partnership?

- To reduce mismatch – what is being researched and what is actually needed
- To reduce research waste

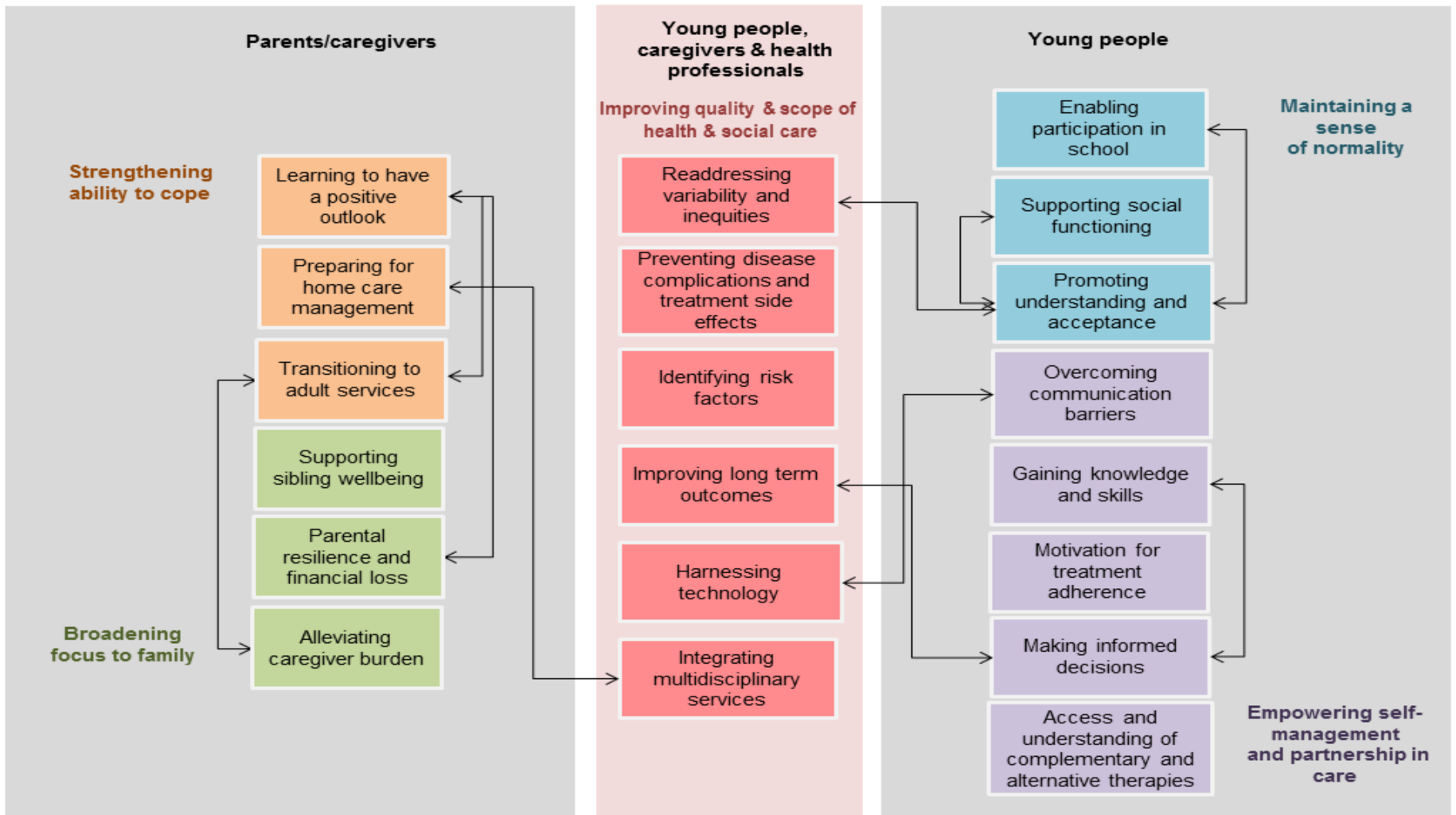
Methods

- Inclusion criteria:
 - young people aged 11 to 18 years
 - parents/caregivers of children aged 0 to 18 years of age
 - consumer organisations
 - health professionals
 - researchers
 - policy makers
- Individual and group invitations

- Preparatory task
- 7 small break-out group discussions
- Participants voted
- Plenary feedback
- Transcribed and thematically analysed

Results

- 73 participants:
 - 3 young people, 19 parents/caregivers, 13 consumer organisation representatives and 38 health professionals
- Areas of expertise covered:
 - cardiology, endocrinology, gastroenterology, general paediatrics, genetics, hepatology, immunology, nephrology, neurology, oncology, psychiatry, respiratory and rheumatology
- 78 research questions/topics





Maintaining a sense of normality

Enabling participation in school

"What are the ways to provide educational support to children with chronic conditions?" (parent)

Supporting social functioning

"How can we work together as families, health professionals and educators to optimise social and emotional development of children with chronic disease at school?" (parent / teacher)

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

"To empower the children to be able to be heard in a hospital setting. To change current clinical practice." (female, researcher)

"The young teenager compliance issues are a real concern. I don't know the best strategies to promote compliance." (parent)



Strengthening ability to cope

Learning to have a positive outlook

'fear and anxiety into positive ones such as trust, knowledge and power'

Preparing for home care management

"You know, it's ironic, you kind of only talk to my parents you don't really involve me and then, you know five days before my 16th birthday you go, off you go, now you're an adult."

Transitioning to adult services

(physician/researcher – paraphrasing a patient)



Broadening focus to family

Supporting sibling well-being

“exploring the perspectives and experiences of sibling relationships in the context of childhood chronic illness” (parent)

Parental resilience and financial loss

“Because if a carer burns out, two people then need support.” (male, consumer org representative)

Alleviating caregiver burden



Improving quality and scope of health and social care

Readdressing variability and inequities

Identifying risk factors

Preventing disease complications and treatment side effects

"There must be some scope for standardising some practices. I'd say looking at barriers before providing the service" (female, parent/nurse)

"We've got an increasing number of [diabetic] children who are so anxious about that prospect [losing consciousness] , even though they have never experienced it, it's actually crippling their lives." (female, clinician)



Improving quality and scope of health and social care

Improving long-term outcomes

Harnessing technology

Integrating multidisciplinary services

"I think where it's an App or something that reminds parents that you know, your child is due for hearing, dental appointment." (female, parent)

"There are too many different government organisations to keep up with. The child is fragmented." (female, parent)

Top three questions from each break-out group

Research questions		Preference score
Group 1		
1	What support networks are in schools and other organisations (e.g. sporting clubs) for children with chronic disease?	8
2	How can we better address the needs of children and families, particularly in culturally and linguistically diverse groups, struggling to manage chronic disease?	7
3	What is the mental health outcome of a child with chronic disease, and does this reflect parental coping strategies?	6
4	How can the system improve connection and support between parents/families of children with chronic disease?	6
Group 2		
1	What is the best way to improve communication programs to empower families and children dealing with a chronic disease?	17
2	What training/educational programs optimise functional outcomes in children with a chronic illness?	14
3	What are the barriers (e.g. demographic, socio-economic) to health interventions and research experienced by children with a chronic illness and their families?	11
Group 3		
1	What are the triggers of anxiety in children with chronic illness and their families?	21
2	What does knowledge transfer, support and empowerment look like for families with a diagnosis of chronic condition?	14
3	What is the best model to coordinate care across health and education sectors (GP, specialists, allied health, schools, families) which improves outcomes (quality of life, symptoms) for children with chronic disease?	9

Group 4		
1	What do children and adolescents experiencing chronic illness identify as important outcomes?	24
2	What is the short/long term impact (e.g. behavioural/psychosocial outcomes, stigmatisation, social isolation, symptom management) of the education system and processes on children with chronic illnesses?	15
3	What are the early-life determinants of long-term outcomes (e.g. health, academic, psychosocial) for children with chronic illnesses?	9
Group 5		
1	What type of education/training programs for families affected by chronic conditions are the most effective to improve self-management and quality of life?	18
2	What interventions help children with chronic conditions develop resilience?	11
3	What interventions empower and support carers whilst dealing with a child with a chronic disease?	8
Group 6		
1	What communication and care frameworks currently exist that would increase the quality and consistency of chronic care and outcomes?	12
2	How can we lessen the social impact of the stigma/knowledge gaps around different chronic diseases?	12
3	Most are the most effective ways to engage young people in their own management of their chronic illness?	11
Group 7		
1	What are the different coping strategies used by parents and caregivers to overcome difficult situations?	15
2	What programs are available in schools to improve social and educational outcomes for students who frequently miss school?	13
3	What is the best way to enable teenagers to manage/maintain and optimize adherence to treatment (e.g. medication, lifestyle)?	9

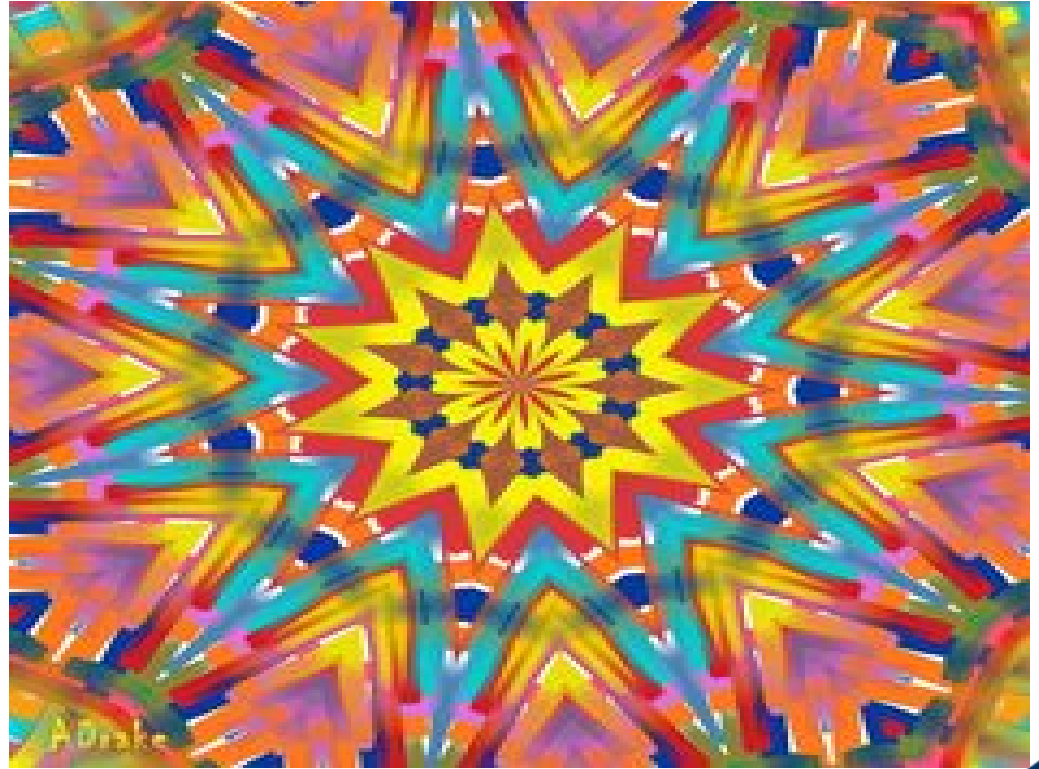
Conclusion

- 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

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Thank you



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