

Child UnLimited – What are the priorities for families impacted by a chronic illness?

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Background

The Child Unlimited (formerly K2A) is a national research alliance of clinicians and researchers from Australia's leading child health services and research organisations, **working together with parents and young people**. Our shared mission is to enable children and young people with chronic illnesses to live their best lives now and into the future. The goals of Child Unlimited are to build on the current work of child health research organisations nationally through collaborative research focused on ensuring children affected by chronic illness can successfully navigate the journey to adulthood, supported by their families and communities. We aim to build a sustainable and enduring national alliance that drives both awareness that chronic illness affects all facets of the life of a child with chronic illness and their family and culture change to adapt the management of the chronic illness to minimise the long-term impacts on a child's life. At the heart of what we are trying to achieve in Child Unlimited is ongoing meaningful involvement of children, young people, families, and practitioners in all activities to ensure the relevance and impact of the research.

The Child Unlimited commenced in 2019 with the following areas recognised as key priorities:

1. Consumer consultation and involvement
2. Measuring the impact of chronic illness
3. Models of integrated care
4. Building resilient, well informed, and connected families
5. Education & participation

The importance of involving children and young people with chronic illness and disability, their families, and service providers in defining research priorities is increasingly recognised.[1-3] Stakeholder involvement in priority setting has been found to promote positive impacts across the entire research and translation pipeline, including the development of user-relevant research questions and objectives, greater engagement and retention of participants in research, more consumer-focused interpretation of research findings, and more successful implementation, dissemination and translation of evidence into policy and practice.[3, 4] Despite this, it is well established that the research questions and directions defined by researchers do not always reflect the priorities of children and young people with chronic illness and disability, their families, and service providers.[5-7] A previous review of 258 research priority-setting studies found that only 19% of studies involved both patients and clinicians[8]; moreover, a review of 83 priority-setting studies focusing on paediatric chronic

disease found that only 4% involved children and young people with chronic illness and disability.[9] It was recommended that priority-setting for paediatric chronic disease follow a systematic and explicit process, to develop a translational research agenda that is meaningful for children and young people with chronic illness and disability, parents, clinicians, and researchers alike.[9]

Preliminary work in New South Wales with children, parents, and clinicians dealing with paediatric chronic illness identified education, psychosocial wellbeing, self-management, quality of care, and family impact as key priorities for research.[10] This work highlighted commonalities in priorities across a diverse group of child chronic conditions and disabilities. The proposed research seeks to extend this preliminary work, by seeking input from a larger, nationally representative sample of children and young people with chronic illness and disability, families, and health professionals, and advocacy representatives, including those living in regional, rural, and remote locations. The proposed work will become the bedrock for our Kids to Adults Alliance **national translational research strategy** to improve the lives of children in Australia living with chronic illness and disability.

Building on previous research and consultation both in NSW and Western Australia, Child Unlimited wants to co-design a programme of translational research with young people and parents; we will not only consult with parents and young people, but we want the programme to be driven by them through a **national network of children and young people's, and parents/carers health forums**. [11, 12] In essence there should be **"no research about me without me"**. [13] Young people have unique insights and engagement with them at a national level is essential to understand their needs.

As part of this engagement, a workshop was held with parents, carers, and patient representatives with the intent to utilise the voices of children, young people, and families and to inform how we deliver health care to the children of Australia.

Method

- Consumers were invited (appendix 1) to one of two workshops. Consumers were defined as representatives of young people with chronic illnesses. Whether a parent, a carer, or a representative from a consumer patient support group.
- Recruitment of consumers was via the Child Unlimited Alliance national research membership.
- Each participant completed a pre-workshop questionnaire that provided general demographic details.
- Before the workshop participants were provided with pre-reading (appendix 2)
- Nine people registered for the workshop and eight attended the workshop

- The workshop was moderated by a senior clinical psychologist (Dr. Ursula Sansom-Daly) with research and clinical expertise working with children, adolescents, and young adults with cancer and their families, and in facilitating consumer-focused health initiatives and partnerships.
- The participants comprised parents, carers, and consumer group representatives which spanned across Australia. With representation from Victoria, NSW, Western Australia, and Queensland. There was a cross-section of chronic illnesses and disabilities including rare epilepsy syndromes, childhood cancer, cystic fibrosis, mental health conditions, cardiac disease, intellectual disability, and childhood dementia.
- A wide array of chronic illnesses represented the spectrum of presentations, some were treated and cured but as a result of the original diagnosis had ongoing chronic illnesses, others were ongoing conditions requiring substantial support and there were also conditions that are degenerative.

Discussion

After introductions, the group discussed the following Child Unlimited Streams.

Each stream was introduced by the moderator to contextualize for participants

- 1. Models of care – this stream aims to improve the physical and mental health of young people and how families are functioning as well as improve access to services**

Families' experiences: a complex system that is difficult to navigate

After an acute admission, young children presenting with a complex condition described being left to navigate a complex and fragmented system. Families were also not supported in understanding and processing the impact of the diagnosis. Appointment of a staff member to families to assist them to navigate the health system after a complex diagnosis/presentation is lacking. Participants expressed a need for mental health support for the entire family.

The medical and disability sectors are fragmented, and families are left to navigate both systems in which there is little communication, or collaboration.

Parents are expected to manage their child's conditions from diagnosis. Essentially, they become their child's case manager. On diagnosis, there was a lot of support to build a team for the child however support for the parent or extended family was non-existent.

Support services for families with a child with a chronic illness such as an eating disorder exist but were found to be lacking, specifically for family members. Parents have gone on to develop a support group to fill the gap in order to feel support and a sense of being listened to.

Coordination and communication between service providers such as GP, hospital, and specialists, and ancillary staff lacked cohesion. Often multiple professionals had input into the patients' care, at times in excess of 10 people. Co-ordination of this complexity is required with consideration across all chronic diseases. Complex children managed between private doctors and the public system can also complicate accessing services.

Families with chronic illness often see more than one specialist who meets the criteria of complex and should activate a support system for all on an equal basis. Currently, more well-known conditions have a smooth transition into complex care.

For families with complex medical conditions where disabilities are part of the picture, there needs to be an intersection between these two service sectors – health and disability.

Recommendations/needs identified

A clear acknowledgment of chronic and complex conditions is required to build ongoing support into the patients' care pathway. "Parents should not have to come knocking for support".

Chronic condition pathways would be beneficial. When families go home and require more than one specialty it is often left to the family to navigate and then coordinate the health care team.

Patients with Cystic Fibrosis can't interact with others with Cystic Fibrosis – never met another person with the same condition. Having professionals that understand your chronic illness and treatment pathways allows for better treatment and support.

Expansion of multidisciplinary clinics where a number of treating health care providers can be seen in one day. There is an even greater need for rural families.

Lack of psychological support for patients was noted. Patients have to be of a certain age to access psychological supports. Service providers acknowledge the difficulty of a diagnosis, like cancer, but services are not accessible to prevent the long-term impact on the patient and family's wellbeing. Access to ancillary supports during treatment is essential not just after once the problem/complications have arisen.

2. Resilient families - Develop and trial services that support optimal mental health and resilience in families living with and caring for children with chronic illness

Families' experiences: Vulnerable families are falling through the cracks. Hospitals are very good at meeting the needs of inpatients but how far does that duty of care extend?

In rare, or not-so-well-known conditions, parents are often educating the health care providers about the child and family's needs. Complex and degenerative conditions have varied access

to inpatient assistance due to terminal diagnosis. Rare diseases often sit on the outside of services and do not easily slot into the health system. There is no 'give' in the system and participants expressed the system needs to bend to meet the more complex health needs.

Psychological support in the public health system is finite. Whilst recognition the support is needed, the experience described by families was flawed with gaps in finding help when and where needed.

Parents have to prioritise their medically complex child which sees siblings and other family members 'missing out' and leaves parents feeling like they are not meeting all family member's needs.

Parents of children with chronic illness have to educate a wide array of people not only on their child's condition but how to manage the intricacies of the illness – any carer (formal or informal) needs training. This can be a full-time job for family members.

Siblings can bear witness to the challenges their brother or sister endures but also see the impact of raising a child with a chronic illness on their parents. Siblings watch medical procedures whether in an emergency or on a day-to-day basis. Parents feel like they cannot protect their children from this exposure.

Parents are feeling overwhelmed with the push and pull of caring for their child with a medical complex and other family members.

Funding for supporting families with chronic illness falls short and funding bodies often try to resolve the challenges with a fixed mindset when a growth mindset is required. A flexible and capacity-building approach is required.

Recommendations/needs identified:

Extended family members such as grandparents need support however this should be facilitated by someone other than the parents. This burden needs to be shifted. Parents are not the case managers and a central point of contact who checks in with the family is required.

If all supports, such as National Disability Insurance Scheme (NDIS) and complex care pathways, were optimal, parents might have more time to focus on themselves and their siblings. Often interventions are offered however parents have described that it is difficult to access in order for the interventions to have a positive impact on them.

All parents have different backgrounds and cultural considerations, and thoughtfulness is required to accommodate the individuality between families. Another important aspect is different levels of health literacy.

3. Transition

Develop and trial services that provide clear and effective pathways for young adults to transition from paediatric to adult health services.

Families' experiences:

The transition from paediatrics to adults can be challenging. As children age, their chronic illness can become more complex. The paediatric health system is very insulated however once you reach adult services you are on your own, inclusive of navigating becoming your child's nominee/guardian. Many more children with chronic illnesses are surviving leaving parents to steer the ship solo. Bridging the gap on transition is crucial. Provision of tangible supports is needed not just navigation tools.

The lack of services for many conditions in the adult health system was highlighted by many families, in particular those with rare diseases. Participants felt the many of the gaps in transition sat within the adult system and often the

Other relevant transitions which posed pressure points for families of complex health and disabilities.

- Transition from hospital to home requires consideration & co-ordination.
- Integration to kindergarten for a medically complex child is not streamlined.

There is a disconnect between state and federal funding for everything. For example, the education department will pay for integration however will not pay for the hoist to move a child safely. Nurse training has to be done through the children's hospital but that can only be funded through the NDIS. For parents to get their child into an appropriate education setting they can be coordinating many different departments, both state and federal.

Children with chronic illness can miss a lot of school and this can lead to loss of academic skills along with increased anxiety for the child. The cumulative effect of missing school can add up over the lifetime of the chronic illness and/or across the school years.

Covid-19 has also added to this adding further pressure on the young person and compounded the impact.

Often the support is available in the hospital, however outside the hospital setting requires more coordination by parents. Finding the right school may take more than one go and what works for one child may not work for another.

Children, who move between hospital and school and home, which is often dictated by their illness, are not sure where they fit in? Where do they identify with the most- school hospital or home? Just being present in the classroom can be more important than the academic impact.

School systems are rigid in their approaches and finding an appropriate school for a child who needs extra support can take time.

WORKSHOP KEY THEMES:

- Support for the whole family throughout the whole trajectory of the chronic illness
- Support to navigate the system/s
- Co-ordination of complex care
- Transition to adult services – health AND disability sectors
- Vulnerable families – not every family has the resources to advocate for themselves.
- Constant advocating – it is unrelenting
- Siblings are significantly impacted and need support
- Parental Relationships – breakdown in marriage is higher in this cohort
- Parents who have been in the system can mentor and support newer parents
- Access to data - the data needs to follow each patient not be owned by institution
- The impact of caring for a child with a chronic illness is linked to the mental wellbeing of other family members

Importantly, the group agreed, words and language matter.

Conclusions and research questions:

How can clinician/researchers involve consumers in strengthening the areas of need in the chronic illness landscape?

How can clinicians/health structures support and coordinate complex care patients throughout the whole trajectory of chronic illness?

How can we further support children living with chronic conditions transition from paediatric care to adult care?

REFERENCES:

1. Murad, M.H., et al., *Individuals with diabetes preferred that future trials use patient-important outcomes and provide pragmatic inferences*. *Journal of Clinical Epidemiology*, 2011. **64**(7): p. 743-8.
2. Elliott, M.J., et al., *Perceived significance of engagement in research prioritization among chronic kidney disease patients, caregivers, and health care professionals: A qualitative study*. *Canadian Journal of Kidney Health and Disease*, 2018. **19**(5).
3. Brett, J., et al., *Mapping the impact of patient and public involvement on health and social care research: a systematic review*. *Health expectations: An international journal of public participation in health care and health policy*, 2014. **17**(5): p. 637-50.
4. Crocker, J.C., et al., *Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis*. *BMJ*, 2018. **363**: p. k4738.

5. Crowe, S., et al., *Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch*. Research Involvement and Engagement, 2015. **1**(2).
6. Tallon, D., J. Chard, and P. Diepper, *Relation between agendas of the research community and the research consumer*. Lancet, 2000. **355**: p. 2037-40.
7. Jun, M., et al., *Assessing the extent to which current clinical research is consistent with patient priorities: a scoping review using a case study in patients on or nearing dialysis*. Canadian Journal of Kidney Health and Disease, 2015. **1**(2): p. 35.
8. Stewart, R. and S. Oliver, *A systematic map of studies of patients' and clinicians' research priorities*. 2008, London: James Lind Alliance.
9. Odgers, H.L., et al., *Research priority setting in childhood chronic disease: a systematic review*. Archives of Disease in Childhood, 2018. **103**(10): p. 942-951.
10. Lopez-Vargas, P., et al., *Research priorities for childhood chronic conditions: a workshop report*. Archives of Disease in Childhood, 2018. **0**: p. 1-9.
11. Fleming, J., *Young People's Involvement in Research: Still a Long Way to Go?* Qualitative Social Work, 2011. **10**(2): p. 207-223.
12. McLaughlin, H., *Involving Young Service Users as Co-Researchers: Possibilities, Benefits and Costs*. The British Journal of Social Work, 2006. **36**(8): p. 1395-1410.
13. Horobin, A.H., D. *No research about me without me – Why researchers should welcome the patient's voice*. . 2018; Available from: <http://blogs.biomedcentral.com/on-medicine/2018/03/02/no-research-about-me-without-me-researchers-welcome-patients-voice/>.

APPENDIX1: CONSUMER INVITATION



KIDS TO ADULTS CONSUMER ENGAGEMENT WORKSHOP - INVITATION

What is K2A?

The K2A Alliance is a group of clinicians (health professionals) and researchers from Australia's leading child health services and research organisations, **working together with parents and young people**. Our shared mission is to enable children with chronic illness to live their best lives now and into the future. To achieve this, we are supporting child health research to make sure children and young people affected by chronic illness can successfully navigate the journey to adulthood, supported by their families and communities.

Why do we want to hear from you?

Involving children, young people, families and health professionals in a meaningful way is at the heart of everything we do at K2A. This helps us make sure that the research we support is relevant and will make a big difference to the lives of young people affected by chronic illness, and their families.

Across 2016-2018, K2A developed a number of areas to focus on based on previous research through the Kaleidoscope project, which involved

1. Reviewing international studies about what is important to families with a young person with a chronic illness, and then
2. Collecting feedback on important issues from Australian families. 73 stakeholders provided input about the most important areas for future research to support families with a young person with chronic illness, including parents, young people, and healthcare professionals.

Consumers are what drives K2A's mission and to this end we want to explore our current priorities and get your input to shape our future direction.

Workshop details

We are inviting you to take part in a short (2 hour) online workshop, together with a small group of up to 10 other young people with a lived experience of chronic illness. We want to hear your opinions about what we are doing at K2A, and what you think is important for us to do next.

Date: November 13th, 2020

Time: 2pm to 4pm

Who?

You are welcome to join this event if :

- you currently care for (or have cared) a child or young adult with a lived experience of chronic illness;
- you work for an organisation which represents children and/or young adults with chronic illness

We would like to hear from a wide range of young people, from across Australia. Participants will be reimbursed with a visa gift card valued at \$50.00 to thank you for your time at workshop and for reading some information about K2A before the meeting.

Places are limited.

On confirmation of attendance you will be sent further information and zoom link,

RSVP: Kris Pierce by November 5th, 2020

kristine.pierce@unsw.edu.au or 0408323863

APPENDIX 2 – PRE-READING-DOCUMENT



KIDS TO ADULTS ALLIANCE (K2A) HELPING FAMILIES TO STAY RESILIENT, INFORMED, AND CONNECTED

Helping children with chronic illness and disability live their best lives

CHILDHOOD CHRONIC ILLNESS

1 in 5 Australian children are living with chronic illness. Their life course is not the same as that of children without chronic illness.

These children and their families face many problems every day - poor physical health and school achievement, disrupted social networks, significant distress, and financial toxicity.

CURRENT CHALLENGES & OPPORTUNITIES

Medical advances across paediatrics mean that children with previously incurable diseases are now surviving to adulthood. This success has created a new challenge: the health system is overloaded managing long-term, chronic conditions.

There is a substantial gap in life attainment, mental and physical health when children with chronic illness enter adulthood.

Technical and knowledge advances mean we can better predict and manage these whole-of-child problems.

K2A GOALS

- To create national consumer groups to guide and inform our work.
- To assess the burden of chronic disease, variance in outcomes, and models of care.
- To improve current models of care to enable simpler clinical management.
- To ensure the cost-effectiveness of the new models of care.
- To provide better and more tailored support for children and their families.
- To improve educational services for children who miss school due to chronic illness.

Watch the Kids to Adults (K2A): The Chronic Illness Alliance – [Animation here!](#)

K2A RESEARCH STREAMS

K2A has several working groups/streams which focus on a key priority for young people with chronic illness and their families.

These priorities were developed across 2016-2018 based on previous research through the Kaleidoscope project, which involved

1. Reviewing international studies about what is important to families with a young person with a chronic illness, and then
2. Collecting feedback on important issues from Australian families. 73 stakeholders provided input about the most important areas for future research to support families with a young person with chronic illness, including parents, young people, and healthcare professionals.

GUIDING PRINCIPLES - IDENTIFYING CONSUMER PRIORITIES

K2A seeks to identify the research questions that are considered most important by young people with chronic illness and their families.

1. MEASURING THE IMPACT OF CHILDHOOD CHRONIC ILLNESS ACROSS AUSTRALIA

The goal of research in this stream is to establish a national system that measures the impacts of chronic illness and disability in children and adolescents in Australia to ensure progress towards better, more equitable outcomes.

Aspiration: A national system that measures the whole-of-life impacts of chronic illness and disability on children and their families.

Improving the health of children with chronic illness requires an in-depth knowledge of where the system currently fails, and an ability to measure the impact of interventions. Right now, population-based information is limited in scope, of low quality, non-uniform and patchy in coverage. What is available is often difficult to source.

There are several reasons for this. Health services in Australia are fragmented across state, territory, and commonwealth jurisdictions. Administrative health service data are strong but focused on in-hospital care. Health data collected for research purposes lack breadth. No one source provides a complete picture of chronic illness in children receiving various models of care. Nor is there available data on the health-related quality of life outcomes of these children.

We can't address the welfare of children with chronic illness until we have better data.

2. OPTIMISING MODELS OF CARE

K2A seeks to innovate and translate evidence into policy and practice, to drive the development and implementation of models of care that reduce the burden and improve outcomes.

Aspiration: Integrated models of care for children (and their families) with chronic illness and disability.

Right now, our health care system does not cater to the significant whole-of-life problems experienced by children with chronic illnesses. Children bounce between care settings (hospitals, GP practices, and community centers), private and public providers, and mental and physical health services.

These issues are even more problematic for children from marginalised communities including those who are poor, Aboriginal, rural, and from culturally and linguistically diverse backgrounds. These children have the highest burden of illness, reduced access to care and worse health outcomes.

There's a strong imperative to create a truly integrated system, one that is delivered across service provider groups, across clinical settings, across the mental and physical health divide, and between education, community services and health. Data from the UK and US shows that integrated care models improve health-related quality of life in children and young people. In Australia, there have been promising early results of developing and implementing integrated models for childhood healthcare.

3. RESILIENT FAMILIES

Develop and trial services that support optimal mental health and resilience in families living with and caring for children with chronic illness

Aspiration: Innovative programs to improve the mental health and resilience of young people with chronic illness and disability and their parents, siblings and grandparents.

Childhood chronic illness has serious mental health implications not just for the individual, but also for parents and extended family members. Grandparents of children with chronic illness experience mental health concerns including distress and depression, and siblings are more likely to engage in risky health behaviours such as heavy drinking, self-injury and suicide attempts.

Interventions which target mental health in these families are lacking. We need better evidence around anxiety-management programs, the transition from childhood to adult mental health management and how children and family members can be supported.

4. SUPPORTING CHILDREN TO ACHIEVE THEIR ACADEMIC AND VOCATIONAL POTENTIAL

Develop and trial education services that provides chronically ill children with the same opportunities for participating, engaging and learning at school as their healthy peers.

Aspiration: Appropriate and accessible educational models for children with chronic illness and disability.

The data is abundant and clear: chronic illness and disability has a negative impact on children's education.

Many children with chronic illness (75%) miss more than one term of school, and 63% miss more than one whole year of schooling due to treatment, appointments, ill-health, and the need for recovery at home. These children experience reduced academic achievement, lower rates of schooling completion, higher incidence of grade repetition, and need greater special education provisions than their healthy peers.

Children absent from school also miss opportunities for interactions with peers. This places them at risk of social isolation, anxiety, depression, adjustment difficulties and poor psychosocial health.

Many children with chronic illness are still willing and able to participate in education and learn when they are convalescing, even if they aren't able to physically attend school. But many barriers exist, including lack of understanding and limited formal communication pathways involving hospital, school, parents and students. Staff at schools often don't know how best to help children with chronic illness, how to offer illness adjustment or how to make accommodations for the child's learning needs.