

# THINKING BIG

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## Executive Summary

The **Thinking Big: YOUR priorities for OUR research** project asked the WA community to have their say on their big ideas for child health and development research at Telethon Kids Institute (the Institute).

As WA's only research Institute dedicated to kids, we have been at the forefront of involving the voices of consumers and community members in our research for more than two decades. In 2004, the Institute partnered with The University of Western Australia's School of Population and Global Health, to formalise the first consumer and community involvement program in Australia. The Institute is recognised locally, nationally, and internationally for creating a leadership role in implementing best practice involvement.

Although the Institute has undertaken previous priority-setting projects on specific topics, this was the first to ask the community for their big picture ideas for child health, wellbeing, and development research.

As Executive Director, Professor Jonathan Carapetis, has noted, we wanted to find out what's important to the community so their views can inform the Institute's decision-making for future research. High quality research is key to solving problems affecting children, youth, families, and communities. We know that research driven by the community's priorities and needs will be more relevant, useful, and used.

We consulted 800 community members in Western Australia over six months to learn about their important issues and ideas for child health, development, and well-being research. The initial survey identified 21 theme areas which were then taken to a series of consensus workshops. Results from the consensus workshops were collated to decide the final ranking of community priorities for future research. Clearly, three themes were supported as the top priorities across all workshops; **mental health of children and youth; wellbeing and support for parents and carers; healthcare services for children and youth.**

Priorities impacting children's health and well-being are interconnected and form a complex web of issues. This inter-relationship needs to be a key consideration when making decisions about future strategies for research at the Institute.



## Project Overview

The Institute's Strategic Plan, [Up for the Challenge 2019–2023](#), identified the Institute's strengths in being able to tackle some of the major health issues facing children and families today and into the future. This has the potential for us to make an even bigger difference than we already do.

We decided to ask the community to tell us about important issues and ideas on child health, well-being, and development. This will guide priority-driven research programs that can carry the Institute into the future. These large-scale programs, known as grand challenges, will help us to pursue the greatest impact in significant areas of child health research internationally.

The Thinking Big project aimed to gather input from WA community members on future research priorities. By listening to their voices, we hope to create research that truly matters to them and their families.

Initial community consultation in November 2020 indicated support for the project. We then conducted a more detailed community survey using an abridged version of the UK's James Lind Alliance [Priority Setting Partnerships \(PSPs\)](#). This abridged priority setting process, developed in 2016 to suit the WA environment, has been used in several priority-setting projects at the Institute to date.

Project progress was hampered by the COVID-19 pandemic, with the survey launch coinciding with the onset of the pandemic when attention was understandably focused elsewhere. As a result, the first round of survey promotion failed to reach the desired number of respondents. We sought to improve survey responses by seeking an Ethics amendment that would provide participants entry into a prize pool upon completing the survey. This was not accepted and instead, we decided to use a paid survey organisation to achieve our response targets.

Other challenges, including staff changes and diminished resources delayed the start of community workshops. When they commenced, despite strong registration figures and different recruitment strategies we struggled to achieve the desired numbers of attendees. Community feedback suggested this was due to research survey fatigue during the COVID-19 pandemic.

Despite these many challenges, we received 819 responses to the survey from a broad range of people representative of the WA community. Participants included young people, parents and carers, grandparents, community members, government employees, private industry, and non-government or not-for-profit organisation representatives.

### Survey participants were from



metropolitan



regional



rural WA

and were aged from



14 years through to



65+ years



**35%**

of participants were  
born outside of Australia



**12%**

identified as  
Aboriginal or Torres Strait Islander



**12%**

speaking a language  
other than English at home

## Project Team

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- 2 Professor Catherine Elliott
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## Project contributors

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## What we did

In mid-2020 researchers at Telethon Kids Institute discussed potential collaborations for a priority-setting project to understand the community's views and priorities for future research at Telethon Kids. A series of meetings was held to discuss the timeline, budget, scope, and project team members. A commencement date of August 2020 was approved. In November 2020, Project leads met with seven senior community members to seek their input on how to explain the 'big issues', rather than focus on individual health issues. Feedback from this meeting was used to frame the questions and set the context for conducting the project.

### The priority setting process:



An **online survey** was conducted to identify important issues and ideas for future child health, wellbeing, and development research that were considered important by community members



**Results from the online survey were analysed** to develop a list of themes identified by the community



**Consensus workshops** were held to present and discuss the themes identified in Stage 2 and to confirm the top community priorities for future child health research

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## Phase 1: Child Health and Wellbeing Research Priority Survey (December 2021 – June 2022)

An online survey was developed by the Project Team, consisting of a short 'About you' section followed by four open-ended questions. We asked participants to share their big picture ideas to help us set priorities for our future research efforts.

The survey was promoted, distributed, and shared online through social media posts, existing community networks (including CONNECT), Institute internal staff, Institute partners, not-for-profit organisations, Perth Children's Hospital, and a paid survey organisation (The Octopus Group).

The survey asked participants to imagine a community that is ideal for happy, healthy kids and then consider the following questions:

1. What is essential for every child and young person to grow up happy and healthy?
2. What do you see as stopping some children and young people from having happy, healthy lives?
3. How would life be different for children and young people to how they live today?
4. What are the most important issues facing you, your family and community today?

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## Phase 2: Survey analysis and workshop recruitment (July 2022)

Qualitative researchers completed content analysis of the survey results to determine the themes to be taken forward and discussed, amended, and prioritised at the workshops. Survey responses for each question were collected and analysed using a manifest content analysis approach for each question (counting the specific words participants wrote in their responses to see how often they were mentioned). The coding and subsequent themes were discussed and consistently refined by the researchers through the process. Themes were considered across questions to provide one list of survey response-derived themes to take to the workshops.

Recruitment for the workshops commenced via advertising on social media and being shared through community networks across the Institute. Community members who expressed interest in joining the workshops at the completion of the survey were invited to participate.

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## Phase 3: Consensus Workshops (October–November 2022)

Five consensus workshops were held virtually and in-person at community recreation centres in metropolitan Perth throughout October and November 2022. This mix ensured a wide range of consumers and community members across WA had the opportunity to attend.

The workshops were run by an experienced facilitator familiar with the modified James Lind Alliance PSP. Participants were given an opportunity to discuss and have direct input into the development of the list of themes for prioritising for future research and grand challenges.

**Workshop #1: Virtual, 16 participants**

**Workshop #2: Bentley, 4 participants**

**Workshop #3: Virtual, 9 participants**

**Workshop #4: Currambine, 5 participants**

**Workshop #5: Virtual: Regional, rural, remote and others 19 participants**

# 4



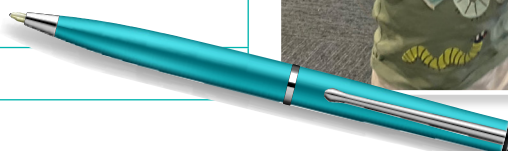
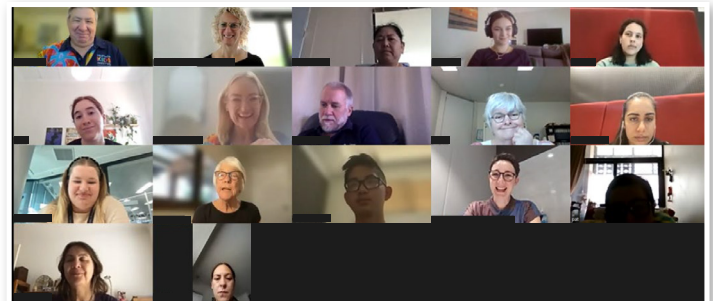
## Phase 4: Workshop analysis and reporting (December 2022–August 2023)

A report outlining the top priorities for future research will be provided to the participants and the wider community via our usual networks and communication channels, Institute staff, clinicians, and other relevant stakeholders.

### The Consensus Workshops

The top 21 themes were identified by the preworkshop survey. The consensus workshops aimed to achieve agreement on the most important themes for child health, wellbeing, and development and prioritise them for future research. Community members were sent a pre-workshop list of the themes, listed in random order, with 'questions for consideration/context' listed under each theme. Participants were asked to consider the themes and make comments prior to attending the workshop to inform the discussions.

ID	THEMES
A	Healthy living
B	Parent and carer wellbeing
C	Mental health of children and youth
D	Physical health of children and youth
E	Healthcare services for children and youth
F	Education environment
G	Providing a loving, stable home environment for children and youth
H	Child and youth safety
I	Family and domestic violence
J	Support for parent and carers
K	Work life balance for parents and carers
L	Community
M	Justice
N	Discrimination and disadvantage
O	Drug and alcohol use
P	Technology
Q	Cost of living
R	Housing
S	Climate
T	Built environment
U	Food and nutrition



## What you told us – The Research Priorities

Following the five consensus workshops, the results were collated to decide the final ranking of priorities for future research. The **top three** priorities were consistently supported as the most important across all workshops:

1. Mental health of children and youth
2. Wellbeing and support for parents and carers
3. Healthcare services for children and youth
4. Physical health of children and youth
5. Child and youth safety
6. Education environment
7. Healthy Living
8. Providing a loving, stable home environment for children and youth
9. Family and domestic violence
10. Community

The **mental health of children and youth** was clearly the most important priority at each of the five workshops, with interlinking issues and challenges, including managing mental health and accessing services.

### The community told us:

'The most important issues facing me, and my community are mental health and the stigma that exists around that.'

'Mental illness is a huge concern amongst children and young people, but also many adults.'

'The rising mental health issues, with stretched government and non-government agency resources, are leading to many young people falling through the cracks or unable to get care.'

'Our youth are really needing help, sometimes it's easier to drink, use drugs, smoke to take that mental anguish away.'

'There is plenty of awareness, but that doesn't mean that people actually understand what mental illness actually looks and feels like.'



The participants agreed to combine three themes (J, B, K) to form the new theme **well-being and support for parents and carers** which they prioritised as their second most important. The general consensus was that if the parents and carers were supported and had good physical and mental health, this would have a direct impact on the health and wellbeing of the family/ children.

**Participants noted that there is:**

'little support for parents who need it, or who lack family support'

'time pressure – difficulty fitting everything that needs to be done into the week while still having quality time with the children, exercising, as well as preparing nutritious meals.'

**Community members told us the most important things for them are:**

'spending time with loved ones in a safe and happy atmosphere'

'having a happy pleasant healthy family.'

**Healthcare services for children and youth** was highlighted as the third top priority, with participants sharing challenges they faced accessing professional providers. They also described a lack of understanding from other support people, such as school staff, GPs, and some psychologists. Limited access impacted directly on the child and the family.

**Participants mentioned:**

'Lack of access to mental health services for adults and children; lack of access to services such as drug and alcohol so people have to relocate to the city, disrupting children's lives even more; very very long waits for paediatric services; very limited allied health services.'

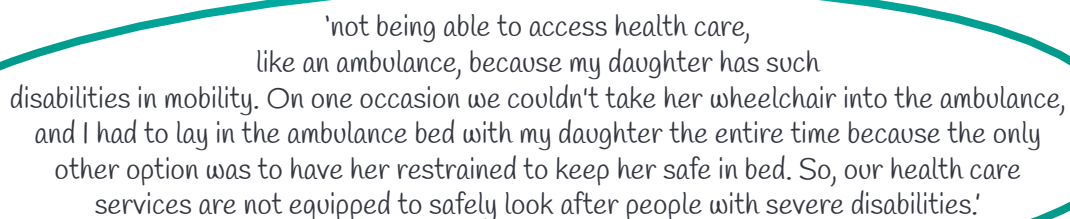
'Lack of support from health professionals – dismissal of 'first time mum' concerns, resulting in ongoing health issues for children and lack of confidence for parents.'

There were discussions about the challenges of **providing a loving, stable home environment for children and youth**. Participants saw that kids' mental health started with **parents being well supported, noting:**

'if the cost of living and housing is going through the roof, the parents are stressed and then kids suffer.'

The **child and youth safety** theme created broad discussion and concerns across many areas, including within the community, through social media and within health care.

### One family described:



'not being able to access health care, like an ambulance, because my daughter has such disabilities in mobility. On one occasion we couldn't take her wheelchair into the ambulance, and I had to lay in the ambulance bed with my daughter the entire time because the only other option was to have her restrained to keep her safe in bed. So, our health care services are not equipped to safely look after people with severe disabilities.'

Community members told us after the workshops that they felt heard and supported. They recognised that there is a huge breadth of research already undertaken at the Institute and it would be difficult to address everyone's priorities. Whilst the **mental health of children and youth** was the most important overarching priority, it was also highlighted that many other priorities impacted directly on mental health. Additionally, while the top three priorities were clear, there was consistent support for the other priorities, with minimal differences in their ranking.

## How will this influence child health research?

The community is at the heart of what we do at Telethon Kids, and your voices have been heard. The results of the Thinking Big project will now be used to inform strategy development being undertaken by the Institute's Science Leadership Team, Executive Team and The Board of Directors. Priorities from two additional surveys reaffirmed a consistent community view that the mental health of our children and youth, together with child development and the well-being of the family should be prioritised to ensure the best outcomes for our children.

With the Institute's new Research Strategy and accompanying Strategic Plan now in development, there will be further engagement with community as priorities and ideas are tested. The Institute has three Community Advisory Groups (parents/carers, young people, children) who will be actively involved in that process.

This is in addition to the hundreds of community members who are involved in consumer reference groups or are research buddies, informing the development of specific research projects across the Institute.

## Conclusion

The community gave us a strong message on the importance and value of research for the future of our children and young people. It is clear that priorities do not sit in silos, and that an integrated approach to some of the most complex and challenging issues is needed. The inter-relationship of many of the priorities needs to be considered when making decisions about future strategies for research at the Institute.

A heartfelt thank you to all the community members that have been involved in the Thinking Big project. Your support enables us to do the research that makes a difference to the health, well-being and development of children across WA and the world. We have heard what you have been generous in sharing with us and will use this to inform the future direction of our research. We look forward to taking you with us as we strive to create a future that is ideal for happy, healthy kids for life!