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IMPACT
REPORT



KIDS are at the ♥
of everything we do



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MESSAGE FROM OUR
DIRECTOR

Jonathan Carapetis AM



Here at Telethon Kids, our vision is to improve the health and wellbeing of children through excellence in research.

We have a proud history of producing high quality research. We have an excellent track record when it comes to securing research funding, publishing research papers and training our next generation of researchers.

But that's not enough, we want our research to make a real and tangible difference for kids, families and communities. We want our research to have impact.

This impact comes in many shapes and forms.

It could be a new piece in the research puzzle that builds global understanding of a health issue or moves knowledge forward. It could be a new device, technique or guideline that can help change the way we treat or manage disease. It could be a change to policy that results in new programs or new ways to tackle a problem.

Ultimately, everything we do here at Telethon Kids needs to demonstrate impact. We want to be doing research that is not only of the highest standard, but has a greater impact and a stronger voice.

This Impact Report highlights research at various stages of the impact pipeline. Some is making a difference right now, some is on its way to having an impact on kids and families, and some is changing the way we think about complex problems.

We also highlight some of the collaborative partnerships - with community, service providers, government, industry - that are helping us to have an impact locally, nationally and internationally.

I'm proud of the work that everyone at Telethon Kids does to make a difference.

To find out more, visit our website at telethonkids.org.au

Jonathan Carapetis AM
Director

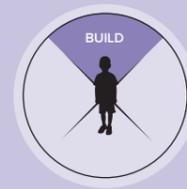


Our special thanks to those who have contributed to this report: Tammy Gibbs, Elizabeth Chester, Caroline Wise, Tamara Hunter, Marnie McKimmie, Stephanie Pegler, Dailé Pepper, Stacey Campbell, Amanda Lewis, Jean Perkins, Amy Birch, Kate Harford, Rebecca Byrne, Tobias Schoep, Amy Sewell, Tony McDonough, Rob Duncan and the researchers and families whose stories we have shared.

OUR RESEARCH AT A GLANCE

The impact of research can be measured in many ways. For us at Telethon Kids, it's about how we make a difference for children, families and communities.

Here, we delve into the metrics that help define our success. This includes traditional indicators as well as the broader ways our research contributes to the global understanding of disease, influences policy and practice, builds capacity and collaboration, and has a direct effect on the lives of children.



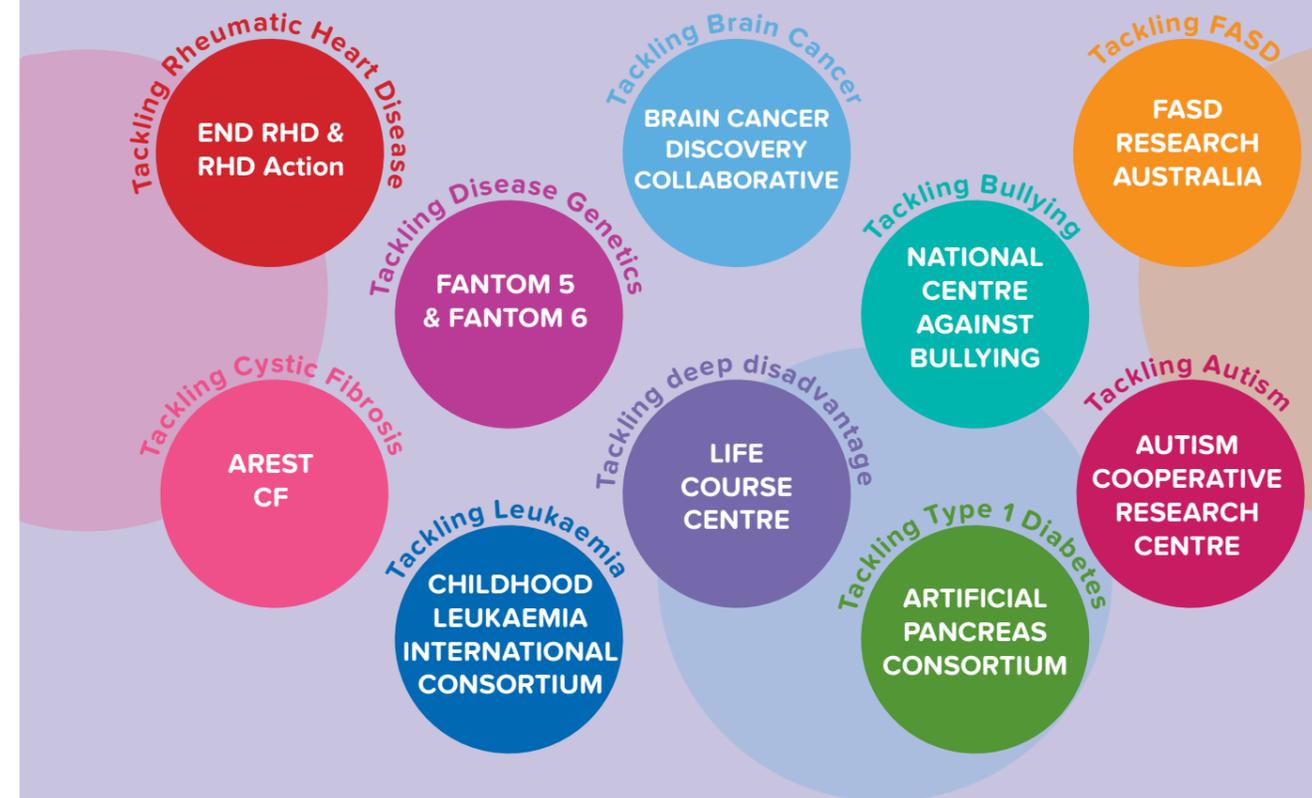
BUILD

RESEARCH CAPACITY BUILDING

We are committed to training the next generation of researchers and ensuring we build collaborative networks to support child health and development research in Western Australia and beyond



WE JOIN WITH OTHERS IN LARGE COLLABORATIONS TO IMPROVE THE LIVES OF CHILDREN. OUR RESEARCHERS WERE INVOLVED IN A TOTAL OF 57 NATIONAL AND INTERNATIONAL COLLABORATIVE NETWORKS INCLUDING:



STUDENTS FROM AROUND AUSTRALIA AND ABROAD CHOOSE TO STUDY AT THE TELETHON KIDS INSTITUTE

In 2017, we had **144** students



Over the past 5 years



have successfully obtained their DOCTORATE

Enrolled through:

1	Charles Darwin University
14	Curtin University
2	Edith Cowan University
6	Murdoch University
3	University of Notre Dame Australia
1	University of Melbourne
2	University of Queensland
1	University of South Australia
114	The University of Western Australia
144	Total



UNDERSTAND

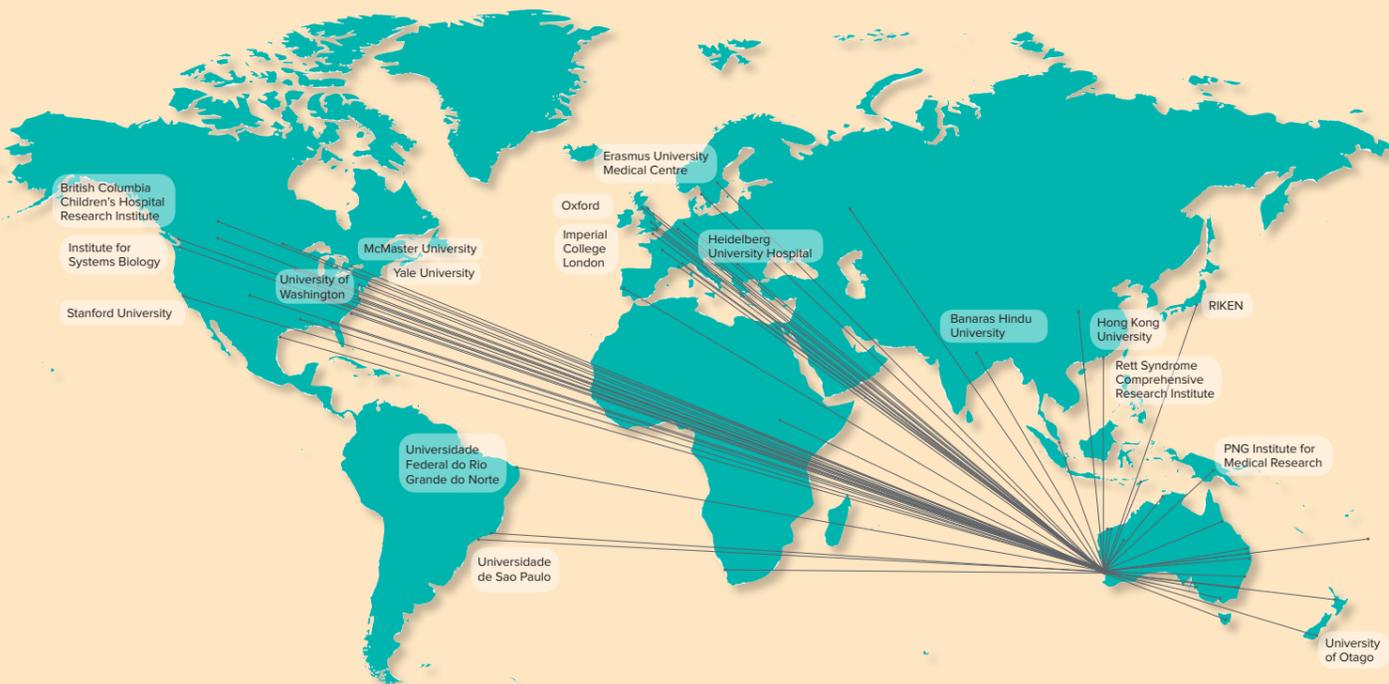
ADVANCING KNOWLEDGE

Our researchers contribute significantly to the global bank of information on child health and development



WE ARE ACTIVELY COLLABORATING WITH COLLEAGUES AND ORGANISATIONS AROUND THE WORLD IN A UNITED EFFORT TO DISCOVER MORE ABOUT CHILD HEALTH AND DEVELOPMENT

Selected collaborators named



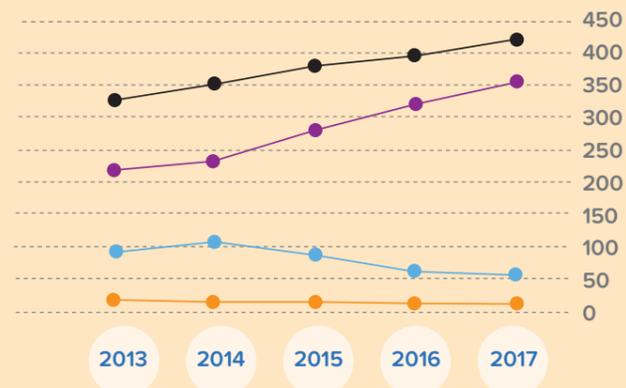
WE ARE SUCCESSFUL AT SECURING A DIVERSE MIX OF RESEARCH FUNDING WHICH HELPS BUILD KNOWLEDGE ON HEALTH AND DEVELOPMENT



TOP INDUSTRY PARTNERS CHOOSE TO WORK WITH US TO MAKE A DIFFERENCE FOR CHILDREN



OUR KNOWLEDGE BENEFITS CHILD HEALTH AND DEVELOPMENT RESEARCHERS WORLDWIDE



TOTAL publications



Peer reviewed journal articles



Other publications and reports

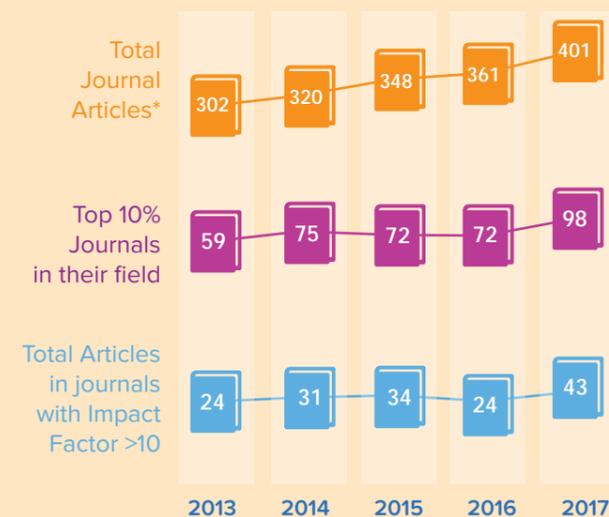


Books and book chapters



WE PUBLISH IN THE MOST INFLUENTIAL JOURNALS AROUND THE WORLD

Publications over the past 5 years



*articles, letters, editorials, case reports and reviews



OUR RESEARCHERS ARE REGARDED AS INTERNATIONAL LEADERS IN THEIR FIELD



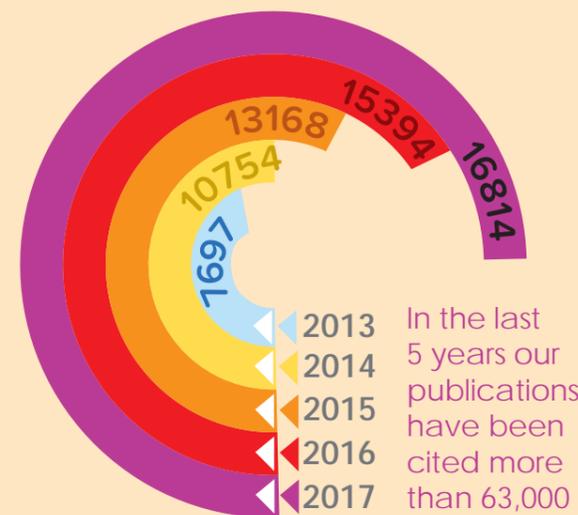
12 of our RESEARCHERS have a Scopus H-index* GREATER than 40

*H-index of 40 is proposed to characterise outstanding scientists likely to be found only at the top universities or major research laboratories (Hirsch 2005 PNAS)



SCIENTISTS AROUND THE WORLD USE OUR WORK ON CHILD HEALTH AND DEVELOPMENT TO ADVANCE THEIR KNOWLEDGE AND RESEARCH

Number of Citations*



In the last 5 years our publications have been cited more than 63,000 times.

*Citation refers to a quotation or reference in a scientific article written by other researchers around the world



INVOLVE

INFORMING DECISION-MAKING

We are working with the most relevant people around the world to ensure we make a difference for children, families and communities



THE COMMUNITY IS INVOLVED IN INFORMING THE WORK THAT WE DO, ENSURING IT REMAINS RELEVANT AND TRANSLATABLE

In 2017 at Telethon Kids we had:

293

consumers involved with

57

committees, projects and programs

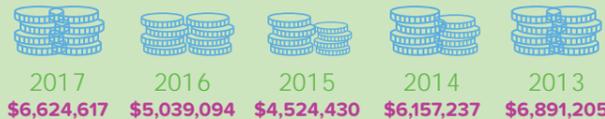


supported by the Consumer and Community Involvement program



WE WORK CLOSELY WITH GOVERNMENT TO ENSURE OUR RESEARCH HAS AN IMPACT ON GOVERNMENT POLICY

We have received over **\$29m** in government contracts between 2013-2017



14

Reports provided to government on topics such as fetal alcohol spectrum disorder, vaccination and early years development



OUR RESEARCHERS ARE ACTIVELY INVOLVED IN EXTERNAL DECISION MAKING GROUPS THAT ARE WORKING TOWARDS IMPROVING THE LIVES OF CHILDREN AND FAMILIES.



37 on Committees or Councils
18 on Boards

35 on Advisory groups
51 Other



ORGANISATIONS SEEK OUT OUR EXPERTISE TO INFORM THEIR WORK ON CHILD HEALTH, WELLBEING AND DEVELOPMENT

TOTAL TIMES OUR EXPERTISE WAS PROVIDED

73

TOTAL TIMES OUR EXPERTISE WAS INVITED

57

Sanofi Pasteur

Australian Research Alliance for Children and Youth (ARACY)

Ombudsman Western Australia

Commission into Child Sexual Abuse

Global Research Network on Children in the 24/7 Economy

Australian Law Reform Commission

Western Australian Data Linkage Infrastructure Project (WADLIP)

Royal Commission into the Protection and Detention of Children in the Northern Territory

Beyond Blue Ltd.

The sixty-eighty session of the World Health Organisation (WHO) Regional Committee for the Western Pacific Region



TRANSLATE

EFFECTING CHANGE

We ensure our research is translated into real-life outcomes that make a tangible difference to the lives of children, families and communities



OUR CLINICAL RESEARCH INCLUDES IMPROVING THE DIAGNOSIS OF DISEASES AND THE TESTING OF NEW THERAPIES AND DEVICES TO ENSURE CHILDREN RECEIVE THE BEST TREATMENT FOR THEIR CONDITIONS. WE ARE ACTIVELY INVOLVED IN INTERVENTION STUDIES IN THE FOLLOWING AREAS:

UNDERSTANDING HUMAN DEVELOPMENT & DISEASE

- ▶ Infections & Vaccines
- ▶ Ear Disease
- ▶ Language Development
- ▶ Newborn Encephalopathy
- ▶ Obesity
- ▶ Nutrition
- ▶ Hypospadias
- ▶ Asthma
- ▶ Genetic Disorders
- ▶ Developmental Origins of Disease

THERAPY

- ▶ Asthma
- ▶ Bronchiolitis
- ▶ Dermatitis
- ▶ Cystic Fibrosis
- ▶ Autism Spectrum Disorders
- ▶ Gastroenteritis
- ▶ Mental and Youth Health
- ▶ Infectious Diseases
- ▶ Allergy
- ▶ Cancer
- ▶ Disability

DIAGNOSIS

- ▶ Cystic Fibrosis
- ▶ Biomarkers of Obesity
- ▶ Diabetes

PREVENTION

- ▶ Vaccines including:
 - Influenza
 - Hib
 - Meningococcal
 - Pneumococcal
- ▶ Allergic Disease
- ▶ Asthma

DEVICES

- ▶ Diabetes
- ▶ Obesity
- ▶ Autism



OUR RESEARCH DRIVES REAL WORLD CHANGES THROUGH CONTRIBUTIONS TO GUIDELINES, POLICY AND PRACTICE

In 2017, we contributed to*:

WA Youth Health Policy 2018-2023 - Strong body, strong minds - stronger youth

WA Child Ear Health Strategy 2017-2021

WA Suicide Prevention Data Taskforce Endorsement of Recommendations to Improve the Quality of Emergency Department Data

The prevalence of mental health disorders and symptoms in children and adolescents with cerebral palsy: A systematic review and meta-analysis

Former Department for Child Protection and Family Support's Building Safe and Strong Families - Early Intervention and Family Support Strategy

*Selected contributions named



OUR RESEARCH HAS DIRECT COMMERCIAL RELEVANCE, WHICH WE PROTECT TO ENSURE THAT THE INVENTIONS HAVE THE POTENTIAL TO MAKE IT TO THE CLINIC



19 active patents

TRANSLATION

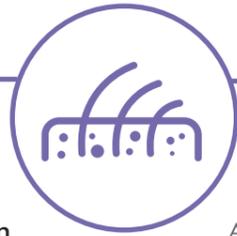
TRANSLATION

This research has been actively translated into policy or practice



NEW NATIONAL GUIDELINE SET TO TACKLE SKIN INFECTIONS

When health organisations in the north-west of WA requested urgent action to address the region's high rate of skin infections, Dr Asha Bowen answered the call.



Named Woodside Early Career Scientist of the Year at the 2017 Premier's Science Awards, Dr Bowen is dedicated to reducing the burden of infectious diseases in Aboriginal children and has a key focus on skin infections – a major cause of health problems in remote communities.

Dr Bowen, who is Head of Skin Health at the Wesfarmers Centre of Vaccines & Infectious Diseases, based at the Telethon Kids Institute, teamed up with the nation's expert skin health clinicians and researchers to address the major issues surrounding skin infections.

"Our research has shown us that 45 per cent of Aboriginal children living in remote communities have a skin infection at any one time – half of the kids in a classroom – plus hospitalisation rates for these children are a staggering 15 times greater than for non-Aboriginal children," Dr Bowen said.

"While skin infections like skin sores and scabies can seem minor, we know they can lead to serious, life-threatening illnesses such as chronic heart and kidney disease.

"A big part of the problem is that skin infections have become so common that they are considered 'normal', even by health care providers, and are left untreated, allowing germs to spread and infections to become more severe. This is something we urgently need to change.

"We knew the answer needed to be something that would help tackle this national issue as a united front, and it had to be provided in a way that is user-friendly, filled with images of various skin infections and easily accessible in the communities where it is needed most."

Led by Dr Bowen and her team at the Institute, the Australian Healthy Skin Consortium spent three years developing Australia's first-ever National Healthy Skin Guideline to help health care providers easily diagnose, treat and prevent skin infections. Available to view online throughout Australia, it includes a suite of learning tools such as photographs, a visual clinical handbook and an interactive questionnaire.

The Guideline was launched by Indigenous Health Minister Ken Wyatt in early May, and is now expected to play a vital role in reducing the long-term consequences of painful skin infections.

"Making these infections easier to recognise and treat, as well as teaching the prevention message on how to stop the spread of germs and keep skin strong and healthy, will make a huge difference in improving the health of children in remote communities," Dr Bowen said.

"The Guideline has been very well-received so far, including endorsements by close to 20 health organisations around the country, and I'm sure momentum will continue to grow as it becomes a well-used, practical tool in the day-to-day clinical setting.

"The major driver for me is seeing improved health and development outcomes for Aboriginal children, so I look forward to seeing how use of the Guideline translates into greater community awareness around skin infections and, in turn, a significant reduction in the number of cases."



The Wesfarmers Centre of Vaccines & Infectious Diseases has been supported by Wesfarmers since 2013.

View the new National Healthy Skin Guideline at telethonkids.org.au/skin-guidelines

"Making these infections easier to recognise and treat, as well as teaching the prevention message on how to stop the spread of germs and keep skin strong and healthy, will make a huge difference in improving the health of children in remote communities"
- Dr Asha Bowen

WHAT'S NEXT

- Dr Bowen is also the lead researcher in the first comprehensive skin control program for WA, named the StoP Trial.



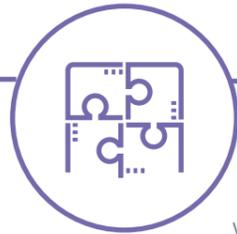
The program is a collaboration with health services and communities in the Kimberley, working within the school environment to halve the incidence of skin infections in Aboriginal children.



Dr Asha Bowen (right) and Marianne Mullane, Project Manager for Skin Health

NEW AUTISM GUIDELINE A LIFELINE FOR FAMILIES

The time has finally come. Professor Andrew Whitehouse tells how Australia's first national guideline for the diagnosis of autism spectrum disorder are going to transform the way the condition is assessed and managed, vastly improving the experience for families.



It is the biggest project Angela Wright Bennett Professor of Autism Research Professor Whitehouse has ever undertaken. The head of the Autism Research Team at the Telethon Kids Institute has submitted the new National Guideline for the Assessment and Diagnosis of Autism to the National Health and Medical Research Council for review, with an anticipated publication date in the second half of 2018.

Approval will give medical professionals across the country a new standard to abide by, eliminating the postcode lottery which now faces families – whose journey to autism spectrum disorder diagnosis and management can vary hugely depending on where they live and the clinician they see.

"The current confusion on the ground seriously damages lives, and if we can find a way to create a consistent national protocol for how you diagnose autism, that will genuinely change the way that many children and their families interact with the health system. That's got to be a good thing."
- Professor Andrew Whitehouse

"The current confusion on the ground seriously damages lives, and if we can find a way to create a consistent national protocol for how you diagnose autism, that will genuinely change the way that many children and their families interact with the health system," Professor Whitehouse said.

"That's got to be a good thing."

The project, commissioned by the National Disability Insurance Agency and Autism Cooperative Research Centre, was based at the Telethon Kids Institute and jointly led by Professor Whitehouse and Dr Kiah Evans.

The project produced an 80 page document, backed by more than 1000 pages of evidence, that will now spell out recommendations for assessing and diagnosing a child with the neurodevelopmental disorder. The guideline outlines the comprehensive process for assessment, from the time an individual is referred to the point when assessment results are communicated to the family.

People with autism experience varying degrees of communication difficulties, impacting on their social skills. They may also engage in some repetitive behaviours.

The draft guideline was released for consultation in September 2017, and is the product of the advice of autistic adults, family members, policy makers and clinicians.

The research team engaged with more than 1000 people to learn what could be improved when it came to the diagnosis process, and what was already working.

The new guideline will help families learn about the condition, the impacts it will have on their lives and work out the types of support they need. They will be assured the advice they receive is of a suitably high standard.

"The biggest impact that we hope is that kids and their families will be provided the most accurate, efficient and rigorous process to commence along the autism journey," Dr Evans said.

"This whole project was done in partnership with medical researchers like myself, and the government agency (NDIA). And through that we have been able to create something that will create lasting change to practice. That's a genuinely big impact."
- Professor Andrew Whitehouse

The guideline will also shine a spotlight on the glaring disparity between the recommendation process of assessment and the funding necessary to achieve it.

Dr Whitehouse said there was a very strong case for a lot more government funding to enhance the system.

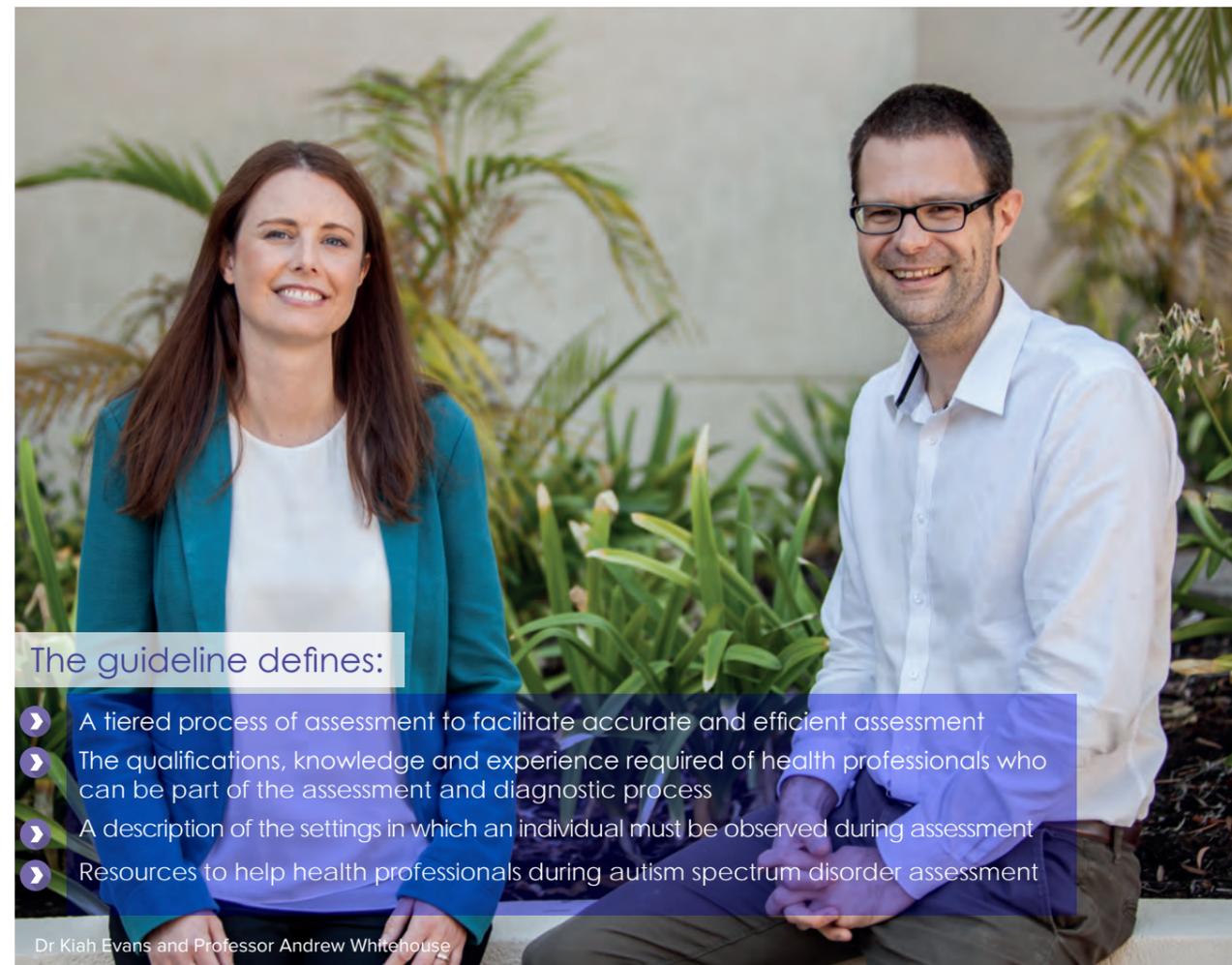
"The current funding mechanisms from the government are not adequate to meet the process of assessment that we describe," he said.

It was hoped the autism community would now lobby the government to rectify the situation.

"This whole project was done in partnership with medical researchers like myself, and the government agency (NDIA)," Dr Whitehouse said. "And through that we have been able to create something that will create lasting change to practice. That's a genuinely big impact."

WHAT'S NEXT

- The team will be working with key stakeholders to develop a set of web resources to help individuals, families and clinicians to implement the Guideline.

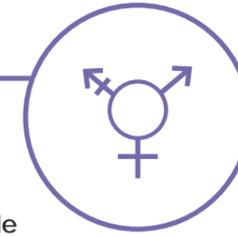


- The guideline defines:**
- A tiered process of assessment to facilitate accurate and efficient assessment
 - The qualifications, knowledge and experience required of health professionals who can be part of the assessment and diagnostic process
 - A description of the settings in which an individual must be observed during assessment
 - Resources to help health professionals during autism spectrum disorder assessment

Dr Kiah Evans and Professor Andrew Whitehouse

TRANS PATHWAYS PROVIDES EVIDENCE BASE TO IMPROVE MENTAL HEALTH OF TRANS YOUTH

A ground-breaking survey by Telethon Kids researchers has become the new reference point to guide policy change and educate health providers to better support trans and gender-diverse youth in Australia.



Trans Pathways, released in September 2017, is the largest ever survey conducted into the mental health of trans young people in Australia, and the first to include the experiences of parents of trans young people.

The survey found that trans young people – young people who identify as a gender that does not match the sex assigned to them at birth – are at high risk for suicide and are approximately 10 times more likely than other young Australians to experience serious depression and anxiety.

Senior researcher Dr Ashleigh Lin said the survey had created a critical evidence base that had not previously existed.

“We could see there was a strong need for evidence to get the attention and funding that trans young people desperately need and deserve,” Dr Lin said. “Since publishing the results, we’ve noticed that people are thinking differently, responding differently. It’s more in people’s consciousness.”

Researchers surveyed 859 trans young people aged 14-25 years, along with 194 parents and guardians of trans young people, and found almost half the youth surveyed had attempted suicide. Eighty per cent had self-harmed at some point.

“The finding that one in every two trans young people we heard from had attempted to end their life is a sobering statistic that demonstrates the urgent need for services that are better equipped to support gender diverse young people,” Dr Lin said.

“These are vastly different figures to the general young population, with the 2015 Young Minds Matter survey indicating that one in 40 young people aged 12-17 had attempted suicide, and one in 12 had self-harmed.”

Three quarters of the young trans participants surveyed – 74.6 per cent – had been diagnosed with depression, compared with 7.7 per cent of adolescents in the general population.

The report also found 68.9 per cent of participants had experienced discrimination, and 78.9 per cent had

experienced problems at school, university or TAFE. Almost two thirds had felt a lack of family support – with many relaying personal stories of rejection and hostility – and nearly 90 per cent had been rejected by their friends or peers.

Another key objective of the study was to identify gaps in medical and mental health services for trans young people. Trans Pathways found 42.1 per cent of trans young people had reached out to a service provider who did not understand, respect or have previous experience with gender-diverse people, while 60 per cent of participants had felt isolated from medical and mental health services.

“We could see there was a strong need for evidence to get the attention and funding that trans young people desperately need and deserve.”

Since publishing the results, we’ve noticed that people are thinking differently, responding differently. It’s more in people’s consciousness.”

- Dr Ashleigh Lin

Lead author Penelope Strauss said the barriers trans young people faced when accessing medical and mental health services often stemmed from a lack of awareness from service providers.

“Trans young people told us there is a desperate need for gender services to be expanded, and for current service providers to receive training in gender diversity and the specific health needs of trans people,” she said.

The research team said the recommendations and guidelines provided in the Trans Pathways report had been overwhelmingly successful in prompting further discussion with policymakers and service providers.

Since being launched in September 2017, the report had been used widely as a reference point for statistics around trans youth in Australia.



Dr Ashleigh Lin, Trans Pathways ambassadors Leon and Drew, Penelope Strauss

“Up until now, there hasn't been this base point to help influence policy change and advocate for funding in this area,” Ms Strauss said.

Amongst other things, Trans Pathways' findings have been used in the first ever Australian Standards of Care and Treatment Guidelines for Trans and Gender Diverse Children and Adolescents – standards which all GPs and health practitioner treating trans youth should follow.

The report has also received international recognition after being cited in the recent United Nations report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity.

The results have also supported advocacy efforts and opened new funding doors, including to secure funding for *Parents of Gender Diverse Children*, the largest parent support group of trans children. In addition, Dr Lin and Ms Strauss have travelled across the country, delivering more than 30 presentations to academics, policymakers, educational institutions and the wider community. They have met with the Office of the Chief Minister in Canberra, Health and Human Services in the Victorian Government, and various Federal and State politicians across Australia.

“Trans Pathways has opened unprecedented lines of conversation with policymakers to influence policy change,” Dr Lin said.

“Trans young people told us there is a desperate need for gender services to be expanded, and for current service providers to receive training in gender diversity and the specific health needs of trans people.”

- Penelope Strauss

Penelope Strauss taking the Trans Pathways report to Canberra



WHAT'S NEXT

- As a result of the report's impact, the Youth Mental Health team has secured funding to investigate the effectiveness of peer mentoring and buddy networks as a suicide prevention tool. They are also in the process of adapting a serious game called TranSPARX to help prevent depression in trans young people.
- The team will present at several upcoming international conferences and collaborate with policymakers to aid the continued improvement of services for trans and gender diverse young people.
- Given the high rates of homelessness and the demonstrated impact of parental acceptance on mental health, the team is working on projects to develop parent education materials and online social networking interventions to increase acceptance by parents, so trans youth are more supported at home.
- Given that GPs are the first point of call for trans young people, the team is building educational and awareness materials to be disseminated to GPs to help improve capacity, as this was an area found to be lacking.



What are the results of Trans Pathways?



Mental health issues

- 4 out of 5 trans young people have ever self-harmed (79.7%)
 - This is compared to 10.9% of adolescents (12-17 years) in the Australian general population
- Almost 1 in 2 trans young people have ever attempted suicide (48.1%)
 - This is 20 times higher than adolescents (12-17 years) in the Australian general population
 - This is 14.6 times higher than adults (aged 16-85 years) in the Australian general population
- 3 in 4 trans young people have ever been diagnosed with depression (74.6%)
 - This is 10 times higher than adolescents (12-17 years) in the Australian general population
- 72.2% of trans young people have ever been diagnosed with anxiety
 - This is 10 times higher than adolescents (12-17 years) in the Australian general population
- 22.7% of trans young people had been diagnosed with an eating disorder
- 25.1% of trans young people had been diagnosed with post-traumatic stress disorder

Risks for poor mental health

- 89% had experienced peer rejection and 74% had experienced bullying
- 78.9% had experienced issues with school, university or TAFE
- 68.9% had experienced discrimination
- 65.8% had experienced lack of family support
- 22% had experienced accommodation issues or homelessness.



TRANS PATHWAYS BREAKS DOWN BARRIERS FOR TRANS YOUTH

The Trans Pathways report had an immediate impact for those it concerned most – trans young people struggling to find understanding and support within the community.

When Trans Pathways ambassador Drew, 17, came out as trans three years ago, the biggest hurdle for him was the availability of services and the time it took to access support.

"The help needs to be more readily accessible and faster," Drew said. "It takes a long time to get into the system to get the help that sometimes is really necessary."

He said research such as that which led to the Trans Pathways report was vital in raising awareness, educating people, and turning around judgment and misunderstanding in the community and amongst service providers.

"Trans people really need the support of the people around them. If we can make people understand and make that information more available, there's less likelihood that there will be hate or misunderstandings which can result in mental health issues."

Since the release of Trans Pathways, there had been a definite shift. The report's high profile had made it easier to explain trans experiences, including the severity of what trans youth experienced, and people around him had found it easier to understand his experiences.

"Instead of telling people to just google the word transgender and hope something useful comes up, I can now tell them to search for Trans Pathways," Drew said. "It's got

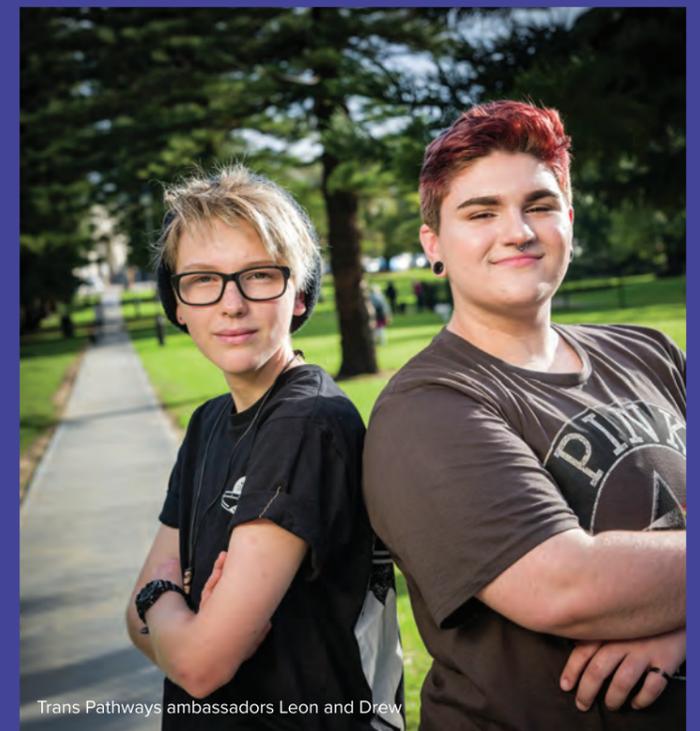
"The availability of clear and accurate information has made life so much easier, in that there's now some pretty widely accepted stats and easily accessible information. It's just made everything so open."
- Drew

everything they need to know.

"When it first came out there was a couple of school people that came up to me and said they read some of it, and they understood everything a lot better straight away.

"The availability of clear and accurate information has made life so much easier, in that

there's now some pretty widely accepted stats and easily accessible information. It's just made everything so open."



Trans Pathways ambassadors Leon and Drew

The Trans Pathways survey was carried out by the Telethon Kids Institute in collaboration with The University of Western Australia, Curtin University, YouthLink (Youth Mental Health, Western Australian Department of Health), and the WA AIDS Council's Freedom Centre.

STATEMENTS OF SUPPORT ISSUED BY POLICY MAKERS INCLUDING:

- WA Commissioner of Children and Young People
- WA Equal Opportunity Commissioner
- Senator for Victoria Janet Rice
- Member for North Metropolitan Perth Region Alison Xamon



TRANS PATHWAYS RESEARCHERS INVITED AS MEMBERS ON COMMUNITY REFERENCE GROUPS INCLUDING:



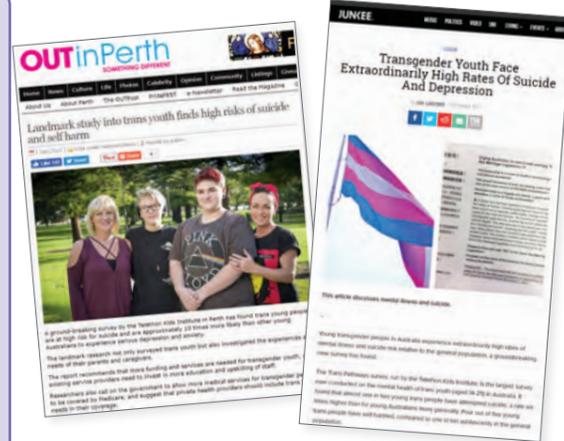
The LGBTI Stakeholder Group for Commissioner of Children and Young People



The Department of Health WA LGBTI Health Strategy Reference Group

ROADSHOW OF PRESENTATIONS AROUND THE GLOBE INCLUDING:

- The World Congress on Public Health
- The Australian and New Zealand Professional Association for Transgender Health Conference
- The Society for Mental Health Conference
- Health in Difference Conference
- The Equality Project's Better Together Conference
- Australian Children's Commissioners and Guardians' group
- International Conference on Early Intervention in Mental Health, Boston
- World Professional Association for Transgender Health, Buenos Aires



ENGAGEMENT WITH HEALTH SERVICE PROVIDERS TO INCREASE AWARENESS & IMPROVE SERVICES FOR TRANS YOUTH INCLUDING:



- headspace Midland
- Mental Health Professionals Network Perth Gender Group
- WA AIDS Council
- Bentley Health Service
- Sir Charles Gairdner Hospital
- Lifeline
- Living Proud

TRANS PATHWAYS FEATURES PROMINENTLY ON HIGH-IMPACT WEBSITES INCLUDING:

- Australian Institute of Family Studies
- National Library of Australia
- Queensland Child and Family Commission
- Australian Psychological Society



MEDIA EXPOSURE AROUND THE WORLD INCLUDING:



- ABC National News (TV and Radio)
- Channel 10 News
- SBS News
- Triple J
- The Australian
- Huffington Post
- BuzzFeed
- Vice NZ



LANDMARK LANGUAGE STUDY DRAWS TO A CLOSE - BUT THE WORK IS JUST BEGINNING

Ask any mum or dad what they consider a key milestone in their child's development and more often than not they will say it is language development.



While all children progress at different rates, certain milestones offer a rough guide to what is 'normal'. By two years most toddlers can say around 50 words and are starting to join two or three words together.

However, almost one in five children will be 'late to talk' and show signs of language delay at this point. About 80 per cent of those who are late to talk will catch up by seven years of age, with the remaining 20 per cent continuing to have trouble.

This late language emergence has been a key focus of the landmark Looking at Language study, which wrapped up last year after spending 15 years working closely with thousands of Western Australian children – including 700 sets of twins.

The internationally unique study, which commenced in 2002, followed the language development of more than 2,000 Western Australian children from the ages of 2-14 years.

A joint initiative between the Telethon Kids Institute, The University of Western Australia, the University of Kansas and Nebraska University, it is the world's only study to conduct such a detailed assessment of language and literacy development from infancy through the formative adolescent years.

Professor Steve Zubrick, Head, Brain & Behaviour at Telethon Kids and one of Looking at Language's four lead investigators, said the study had placed the Institute at the forefront of research and literacy worldwide and produced new knowledge about the epidemiology and

natural history of language delay and language impairment.

"Our approach and our research crosses a multitude of disciplines and sits within number of the Institute's Research Focus Area," Professor Zubrick said.

"Looking at Language combines epidemiological, behaviour genetics and molecular genetics methods to study language development, language impairment, reading and reading impairment from infancy to adolescence."

He said the ability to continue following the children in the study through early adolescence had been ground-breaking.

"It is vitally important that we understand the developmental course of language and literacy from infancy and what different trajectories mean for young people's opportunities at school and beyond," Professor Zubrick said.

"Partitioning of childhood into infancy, toddlers, pre-schoolers, and school-age children, and the way policy and services focus on a particular age group, has not allowed for a more holistic view of language development and change."

Amongst the study's findings so far, Looking at Language has shown that genetic factors are important in explaining why some children do not develop language as expected. It has also demonstrated that catch-up is

possible – but on the flipside, it is possible for young children to start on track and fall behind as they get older.

"A positive finding is that some children can catch up," fellow lead investigator Professor Cate Taylor said. "However, one in five children with a late start were still behind at age 7.

"We just have to do everything we can to make sure kids start off on track, otherwise the kids who are left behind have to do something quite extraordinary – they have to develop faster than the typically developing kids to catch up.

"At same time, other children who start off well can fall behind later on, and it's now understood that these patterns of change are partly due to children growing into and out of language delay risk factors and the effect of these changing over time."

"We just have to do everything we can to make sure kids start off on track, otherwise the kids who are left behind have to do something quite extraordinary – they have to develop faster than the typically developing kids to catch up. At same time, other children who start off well can fall behind later on, and it's now understood that these patterns of change are partly due to children growing into and out of language delay risk factors and the effect of these changing over time."

- Professor Cate Taylor

Professor Taylor said the study's findings showed constant monitoring of language was needed to cater for this. Parents also needed opportunities to feed into the process and say 'I'm worried about my child'.

"At every age, we want to be doing everything we can to boost children's language," she said. "But really we need to get the whole story before we can even tell part of the story."

Co-lead investigator Professor Mabel Rice, of the University of Kansas,

said Looking at Language had provided a unique opportunity to investigate the extent to which Specific Language Impairment (SLI) could be attributed to genetic variation, known as heritability. Children who are late to acquire language without an obvious reason for the delay, such as hearing loss or other developmental delays, are said to have SLI.



Professors Mabel Rice, Stephen Zubrick and Cate Taylor

It had also provided important findings around language acquisition in twins.

“Our study has provided the first robust, empirical evidence that demonstrates delayed language acquisition in twins, in comparison to single-born children,” Professor Rice said.

“Twins have comparatively delayed language skills at 24 months, with the gap reducing at four and six years, suggesting that twins are able to catch up. These findings alone help us better understand language acquisition, not just for twins but also singletons as well.”

Professor Taylor said with data collection complete, all effort now would focus on data analysis and dissemination of results to enable the ‘whole story’ of language development to emerge and be seen for the first time.

“The next 15 years will focus on using the data, but first we must acknowledge the incredible efforts of the Looking at Language team that collected this information – the psychometric assessments, interviews, questionnaires and DNA samples,” she said.

“We also want to thank all the WA children and families in the study who have really understood that it’s important for us to have that ‘long view’ – from 2 to 14-years-old – to advocate for children with language difficulties.”

Professor Rice said the team was aware of the importance of the task ahead, and took very seriously the fact they were custodians of the information collected from study participants.

“Our job now is to tell this story accurately and tell it in a way that the twins, other children and families of the future are going to be able to benefit from the science,” she said.

The *Looking at Language* study:

- ▶ Looking at Language is the largest, longest and most comprehensive study of language and literacy development in the world and the only one to attempt to comprehensively map trajectories in language development at 2, 4, 6, 9 and 14 years of age.
- ▶ The study commenced in 2002, with data collection ending in 2017.
- ▶ Although the study is an international collaboration, all study participants and data collection were based in Western Australia.
- ▶ Looking at Language involved 5,000 children and families overall and included 7,000 full assessments – equating to more than 24,500 hours of testing.
- ▶ The data gathered by the study will be used to determine both genetic and environmental pathways in language development, and are expected to help improve services and supports for children with language difficulties.
- ▶ The project is a joint initiative between the Telethon Kids Institute, The University of Western Australia, The University of Kansas (USA), and the University of Nebraska (USA).
- ▶ The 15-year study was funded by the prestigious USA National Institutes of Health, receiving three successive grants from the National Institute on Deafness and Other Communication.



Twins Erika and Chloe

MENINGOCOCCAL VACCINE PROVIDES EXTRA PROTECTION FOR BUBS

In 2017, a steep rise in cases of meningococcal disease caused by the W strain sparked a wave of concern for parents in Western Australia.

With 46 cases of the life-threatening disease reported – and half of the cases caused by the W strain – it was clear urgent action was required to minimise the danger for age groups most at risk.

There are five strains known to be responsible for causing the disease – A, B, C, W and Y – and while vaccination is the only effective way to prevent meningococcal disease, there is no single vaccine that can protect against all five strains.

Prior to 2018, all babies received a Meningococcal C vaccine at 12 months of age and vaccines for Men ACWY and Men B were available via private prescription only, at a cost that was prohibitive for many parents.

Professor Peter Richmond, Head of the Vaccine Trials Group at the Wesfarmers Centre of Vaccines & Infectious Diseases, based at Telethon Kids Institute, said although a free Men ACWY vaccine program was rolled out to 15-19-year-olds throughout 2017 in response to the increase in cases, extra protection was required for babies and young children under five years of age.

“This age group is at high risk of contracting meningococcal disease, and purchasing the vaccine privately was out of reach for most families,” Professor Richmond said.

“We felt that toddlers and young children should have access to the Men ACWY vaccine, and this meant we needed evidence that the vaccine produced protective antibodies after a single dose so that it could be considered for inclusion on the National Immunisation Program.”

He said the group’s research, especially recent studies involving babies 12 months of age, was used to inform the WA Health Department on the effectiveness and safety of the Men ACWY vaccine – particularly around the protection it provides against the W strain of the disease.

In addition, it was announced that children in Western Australia aged one to four years would be given a free ‘catch-up’ Men ACWY vaccine throughout 2018.

“This evidence also supported a subsequent recommendation to include the Men ACWY vaccine on the National Immunisation Program for all Australian children from July 1st, providing it at 12 months instead of the previous Men C-only version,” Professor Richmond said.

“Importantly, this recommendation means that the vaccine will continue to be provided free for all children. We are confident this will see a reduction in children being diagnosed with this devastating disease into the future.”

“It’s fantastic to see our research playing a major role in guiding the Government’s decision to prioritise the Men ACWY vaccine at this critical time – allowing young people to be protected from the deadly disease when they need it most.”
- Professor Peter Richmond



WHAT'S NEXT

- A safe and effective vaccine is also available against the B strain, but it is currently only available on private prescription due to its high cost in comparison to the occurrence of the disease.
- Professor Richmond’s team is currently involved in a South Australian study involving 35,000 school-aged children, investigating the effectiveness of the Men B vaccine in large community groups.

'ARTIFICIAL PANCREAS' HELPS EASE DIABETES BURDEN

Type 1 diabetes is exhausting and unrelenting. It can be life threatening and there is never a break from it. It is affected by every mouthful of food and exercise — even sleeping, stress, fatigue, puberty and illness can affect blood glucose levels. The burden on patients and their families is enormous and extremely stressful.



The Children's Diabetes Centre, based at Telethon Kids Institute, is doing extensive research on how technology can be used to treat type 1 diabetes and reduce its burden.

The Centre is currently involved in an international effort to develop revolutionary closed-loop 'artificial pancreas' technology. It is also leading a multi-centre Australian trial of these portable devices at home in young people with diabetes.

Professor Tim Jones, co-director of the Children's Diabetes Centre and paediatric endocrinologist at Perth Children's Hospital, said the Hybrid Closed-Loop Outpatient Trial – for which he is chief investigator – involved participants testing an automated insulin delivery system to see if it was better at optimising blood glucose levels than standard insulin therapy.

"The system automatically controls blood glucose levels and delivers the required insulin and by doing so, keeps patients safer as it prevents their blood sugar levels from going too high or too low," Professor Jones said.

"It's a bit like the development of a self-driving car – without the system you have to check your own blood glucose levels, so it's something you have to spend every part of your day thinking about. The object of the hybrid closed loop is to take some of that thinking away."

Professor Jones said feedback from those involved in the trial had been positive.

"Families are reporting less stress and that it's a lot easier on them," he said. "The participants like the system and don't want to give it back so that's also telling."

"If patients get better control of their diabetes, cardiovascular, eye and kidney complications in later life will be reduced."

"One major outcome of this research will be a reduced rate of those complications so that children grow up to be healthy adults. Life expectancy will be extended if you reduce the complications — it's as simple as that."

- Professor Tim Jones

"The preliminary reports are that blood glucose levels are being controlled much better and that people with diabetes are having to work less hard to control their diabetes."

"If patients get better control of their diabetes, cardiovascular, eye and kidney complications in later life will be reduced."

"One major outcome of this research will be a reduced rate of those complications so

that children grow up to be healthy adults. Life expectancy will be extended if you reduce the complications — it's as simple as that."

Professor Jones hoped the system could be made available to patients as early as next year.

"We are feeling very positive that the hybrid closed loop system is making a difference," he said.

"We ultimately hope this will be another step forward to making the lives of people with type 1 diabetes a lot easier and produce better outcomes — better blood glucose levels, fewer complications and lift the burden of diabetes."



Professor Tim Jones

WHAT'S NEXT

- "The next stage with all technology is further improvements and iterations to make the system better, and ultimately we want to have a system we give to people that controls their diabetes automatically without them having to put as much effort and care into it." – Professor Tim Jones



This research is funded by the Type 1 Diabetes Clinical Research Network, an innovative clinical research program led by JDRF Australia and funded by a Special Research Initiative through the Australian Research Council.

HANDING OVER THE REINS: LETTING TEENS TAKE CHARGE

"I've definitely gotten used to having type 1 diabetes but there are periods where I give up a little bit. I won't grow out of diabetes. It's always there. There's no escape from it."

Georgia Egan was diagnosed with type 1 diabetes when she was nine. Despite having lived with the chronic disease for nearly half her life, the 17-year-old said she was finding it tough being a teenager with diabetes.

"Diabetes is always on the back of my mind — there's never a break from it," she said. "I feel as if I'm always testing my blood sugars, bolusing (dose of insulin taken to handle a rise in blood glucose) and counting carbs. I know it's not a hard thing to do but it gets really annoying having to remember to do it all the time."

"These types of trials plant a seed of hope that researchers will develop something that will be a long-term solution or even help cure diabetes. I want to be part of the solution that can help make life easier for those living with diabetes."
- Georgia Egan

"When I was first diagnosed it was easier, as mum would remind me to test myself, but now that I'm meant to have more control, I don't do it as much. There are days where I really don't want to deal with diabetes — but that's not really an option as this is the reality of my situation."

Mum Belinda agrees the teenage years have so far been the family's biggest challenge.



Professor Tim Jones with Georgia and her mum Belinda

"When Georgia was younger it was easier to manage her diabetes because you're in charge of what she eats, where she goes out and testing," she said.

"Teenagers are far more independent so you need to hand over the reins a little bit. I feel I'm always on Georgia's case but if she forgets to change her pump site and then goes high (hyperglycaemia) or forgets to bolus or test, which can lead to highs or lows (hypoglycaemia), it's very frustrating."

Belinda says teenagers have enough to cope with without adding diabetes into the mix.

"Georgia's juggling Year 12, a social life and type 1 diabetes and unfortunately, life sometimes gets in the way of managing her condition and staying on track," she said.

"We're really focusing with her on making sure we're doing everything to help her, but she's got to meet us halfway and want to do it."

Being involved in research at the Children's Diabetes Centre has helped to ease some of the burden. Georgia recently completed the Hybrid Closed-Loop Outpatient Trial, an at-home trial of a device that is a step towards an artificial pancreas.

"This system definitely helped with my diabetes management, especially overnight, and helped to keep my blood sugars as stable as possible which was fantastic," Georgia said. "I didn't go low as much."

"These types of trials plant a seed of hope that researchers will develop something that will be a long-term solution or even help cure diabetes. I want to be part of the solution that can help make life easier for those living with diabetes."

Children's Diabetes Centre researchers work hard to improve the lives of young people living with type 1 diabetes so naturally it is young people we turn to for input on what issues they find important to help drive our research.

One research area young people have been particularly interested in has been exercise. While physical activity is an essential part of diabetes management, blood glucose response to exercise is affected by many factors which can stop people from being active.

To help young people exercise safely, Centre researchers are working

alongside adolescents and young adults with type 1 diabetes to help develop new exercise guidelines for patients.

Professor Liz Davis, co-director of Children's Diabetes Centre, says the Centre is unique in its approach in that it holistically focuses on the family and is guided by an active community group.

"This means we are conducting research work that is really directly applicable to families," Professor Davis said. "It's about feeding information back into the community rather than just into a scientific journal."



Professor Liz Davis

AEDC TRANSLATION TOOLKIT HELPS SCHOOLS HELP KIDS

A toolkit designed to help schools use AEDC data to inform planning of early childhood programs and encourage engagement with the broader early childhood community is making a difference.

Every three years, the Australian Early Development Census collects information on children's physical health and wellbeing, social competence, emotional maturity, language, cognitive and communication skills, and general knowledge.

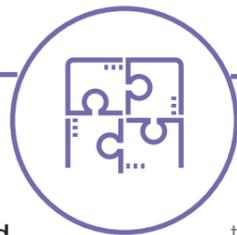
But up until now, many school administrations had failed to see how they could use this data to help make a difference for children's education. Education departments around Australia were seeking to support their educators and leaders to use the AEDC data in their planning.

A research-policy-practice partnership was developed to tackle the challenge. Yasmin Harman-Smith and her team from the Fraser Mustard Centre worked with policy makers, early childhood and school leaders and educators to develop a suite of resources that spoke the language of schools and connected the AEDC to their core business.

Dr Harman-Smith, who is Deputy Director of the Centre, said the toolkit helped school leaders understand and use the data – a real snapshot of the development of children in the community – rather than make assumptions about their communities based on socio-economic status.

"The AEDC tells us what happened for children before school, and effectively predicts how they're going to go once they get to school," Dr Harman-Smith said. "A child vulnerable in one domain is twice as likely to fall behind their peers once they start school."

She said some schools hadn't understood how the census information could help them,



in partnership with other organisations, better prepare children for success at school. The new resources, however, had helped them to bridge the divide between the early years and the schooling years. "The data shows us what are the contexts children are living in, and how to make

education planning more nuanced towards meeting the beliefs and needs of the community," Dr Harman-Smith said.

"The education becomes valuable, meaningful, culturally and contextually specific."

Dr Harman-Smith's team researched current practice and understandings of the AEDC to inform the development of the resources for school use. Three schools in Queensland were chosen to trial them, while resources were also developed for schools and early care

organisations in Western Australia, South Australia and New South Wales.

"These resources will be used by school leadership teams and prep teachers to continue to support children's early learning and development and transition to school, making links with the Australian Curriculum and other relevant schooling policy frameworks," Dr Harman-Smith said.

The resources would enhance continuity between early learning environments and prep, and support efforts to focus on holistic early childhood development across all five AEDC domains in the prep year. They helped align the AEDC to age-appropriate teaching pedagogies and would demonstrate the value of the AEDC in school planning and programming for all schooling sectors.

"The data shows us what are the contexts children are living in, and how to make education planning more nuanced towards meeting the beliefs and needs of the community. The education becomes valuable, meaningful, culturally and contextually specific."
- Dr Yasmin Harman-Smith



Dr Harman-Smith said school administrators often needed support to work out how best to use the data, to fit in with what they already did in terms of planning supports for children and families.

"When kids get to school there's this totally different world that they're expected to fit into, and in the early years there is this very different philosophy and approach to children," she said.

"In the early years it is all about growing these little people – being, belonging and becoming. When they get to school it's all about literacy and numeracy."

The new toolkit would help organisations bridge that divide.

The Fraser Mustard Centre is a joint initiative between the Telethon Kids Institute and the South Australian Department for Education.

IT'S POWERFUL: THE CRANBROOK STATE SCHOOL EXPERIENCE

By his own admission, Cranbrook State School principal Jeffrey Capell was initially resistant to the idea that the school could better support the development of children before they were old enough to actually enrol in school.

He had tried running a playgroup, but it hadn't achieved much and anyway, he believed it wasn't the school's role to work in the early education space. He felt the school did the best it could with its transition program as children started prep.

When Mr Capell agreed to participate in the trial of the new AEDC toolkit, he was pretty sure he already understood his students and couldn't see how the data would benefit school program planning.

Now, however, it's a different story. He describes the effect of using the toolkit as 'pretty powerful'.

"We worked with the Institute developing the tools, and more importantly the process of working with stakeholders," Mr Capell said.

"That was the part we didn't have right. We thought 'here is a problem', but we'd fix it ourselves, working in isolation. Through using the tools we were able to see what sorts of stakeholders could be involved and could impact on AEDC data.

"(We realised) we'd been putting our efforts in the wrong place. Using the resources we are able to bring everyone together and then work out the best way forward."

What had been a scattergun approach when trying to support vulnerable children changed to a determined focus. The school brought together a broad network of people, including the

Department of Housing, several Aboriginal services, and the local council.

They learned how the school was connected to the community and how it could work together to support kids and families. A playgroup offering a range of services was born.

"(We realised) we'd been putting our efforts in the wrong place. Using the resources we are able to bring everyone together and then work out the best way forward."
- Jeffrey Capell



Jeffrey Capell and daughter Addison

"I was somewhat skeptical, but I went in wholeheartedly. The feedback from the teachers was amazing – they said we can't afford not to continue. We have got four or five weeks extra learning in, because these kids are turning up to day one and know all about school – allowing teachers to start teaching what they'd normally have to wait at least a month to begin."
- Jeffrey Capell

The playgroup team connected with the 33 per cent of families the AEDC data identified as most vulnerable – children who would not usually have any experience with school before they started. They had not attended the first attempt at starting a playgroup, but became enthusiastic through the collaborative approach.

Mr Capell's attitude has now completely turned around.

"I was somewhat skeptical, but I went in wholeheartedly. The feedback from the teachers was amazing – they said we can't afford not to continue. We have got four or five weeks extra learning in, because these kids are turning up to day one and know all about school – allowing teachers to start teaching what they'd normally have to wait at least a month to begin."

He was looking towards investing more in the early years and hoping to see the benefits at school.

"Families are getting access to services. Instead of parents having to find them, the services would come to the families," he said.

NORTHERN TERRITORY BUILDING ON STRENGTHS

While the AEDC identified high levels of developmental vulnerability in children in the Northern Territory, the resources available to unpack and communicate the data were not culturally appropriate. So researchers designed a toolkit which included practical methods for working with vulnerable families in remote communities.

Dave Guy, senior manager with the Northern Territory Department of Education's Literacy for Parents Program, has worked with Aboriginal communities using the toolkit and been blown away by the results.

The researchers worked in partnership with Mr Guy and a reference group of community members to create a community engagement tool to help unpack AEDC data and communicate it with Aboriginal families.

"It's basically about having a conversation about children's development, showing them a little bit of data for that region, which is usually community profile data, then we go through the AEDC storyboard, which is a toolkit to take people on a journey of the vision people have," Mr Guy said.

"We ask what do they want to see for their children's future, then move to talking about who are you going to need to help you change this story, and then what is the action required."

Mr Guy and the research team used this process in very remote communities with high levels of developmental vulnerability, and said the impact of the new resources had been extremely exciting. Mr Guy said the toolkit was potentially going to be adopted more broadly by the Northern Territory government as a community engagement tool to deal with some of the toughest issues communities faced.

"It exceeded our expectations in terms of engagement and people really understanding its potential," he said.

"Very rarely do individuals or groups get to see data or evidence around children's development. And if they do, it's



usually done with graphs that a lot of people can't understand or follow. (In this case) they got ownership of it, the different domains of the AEDC, and then they could reflect on what was happening at the time data was being collected."

Mothers especially understood the importance of the information presented and developed methods for educating their communities about child development.

"We didn't present the data in a comparative way to any other place, we just showed the community their pattern in the data," Dr Harman-Smith said.

"We showed areas that were both high in developmental readiness and low in developmental readiness.

"The families had never been told before that they were doing a good job with their kids. So these mums that came to the trial sessions were sitting back in the room away from me and the storyboard for a long time. Then by the end of the couple of hours they were all in close.

"Initially they were talking with whispered voices. By the end they were talking with loud voices and had a plan – it was their plan, not something we created. They thought of themselves as leaders in the community on child development. It was an amazing experience."

"Initially they were talking with whispered voices. By the end they were talking with loud voices and had a plan – it was their plan, not something we created. They thought of themselves as leaders in the community on child development. It was an amazing experience."
- Dr Yasmin Harman-Smith

PARADIGM

PARADIGM SHIFT

SHIFT

This research changes the very way we think



PREMMIE TWINS DEFY THE ODDS

When Samuel and James Considine were born in October 2003, perilously close to what the medical world describes as the limit of viability, each weighed just 700 grams and could fit into the palm of their father's hand.



James and Samuel Considine



Born at 24 weeks' gestation, the Perth twins would spend the next three months at King Edward Memorial Hospital, hooked up to machines that did their breathing for them, fighting off infections, undergoing tests, and swinging in and out of surgery to address complications arising from their prematurity.

led by Telethon Kids Institute lung health researcher, Dr Shannon Simpson.

The study, published in March in *The Lancet Child & Adolescent Health*, spent almost a decade following the progress of 200 babies born at less than 32 weeks' gestation, along with 67 controls born at full term. Study participants had an average gestation of 28 weeks and average birth weight of 975 grams, with the earliest baby born just at 22 weeks.

The biggest study of its kind since significant improvements in neonatal critical care during the 1990s drastically improved the chances of survival for preterm babies, it found that survivors of very preterm birth are at risk of declining lung function as they get older – rather than growing out of any lung problems as previously believed.

"Some of these kids have no respiratory symptoms and have gone on to become athletes or play rugby, but others are really sick. We just don't know yet how to tell which babies are going to have problems and which ones aren't."

- Dr Shannon Simpson

"It was very touch and go," father John Considine said. "I was told at the time most hospitals in the world won't even try at less than 26 weeks. It was confronting."

Their first few years were similarly fraught, with respiratory viruses and chest infections repeatedly landing one or other of the boys in hospital and, on one memorable occasion, resulting in a dash to Perth aboard a Royal Flying Doctors flight.

"For the first three years there were about eight hospitalisations between them," John said. "There were lots of respiratory viruses, and they were on asthma medication for their breathing until they were aged about six or seven years."

In 2011, when the boys were aged eight, they were invited to be part of a study into the long-term lung function of premature babies,

"What we found is that over time, those kids born at less than 32 weeks' gestation are showing some level of decline in their lung function as a group, compared to the term-born controls – so their lung health gets worse as they get older," Dr Simpson said.

The results were worse for children who had had bronchopulmonary dysplasia – one of the most significant complications of pre-term birth – as babies; for children who showed certain changes on their chest CT scans; and for children who had been exposed to cigarette smoke during their childhood.

Dr Simpson said the findings contradicted the long-held belief that any lung issues experienced by preterm babies in infancy would resolve over time. "Previously, it was thought that when you are born preterm you experience something called 'catch-up growth' – which means that by the time you start school your lungs are the



James Considine

same as a child who was born at term – and that any lung damage that you did have was the consequence of life-saving treatments administered in the neonatal intensive care unit (NICU)," she said.

"However our data suggests there may be some sort of active process going on in some children that would lead them to having these declines through life."

Dr Simpson said it was important to note that not all the preterm children studied showed declining lung function.

"Some of these kids have no respiratory symptoms and have gone on to become athletes or play rugby, but others are really sick," she said. "We just don't know yet how to tell which babies are going to have problems and which ones aren't."

James and Samuel are among the luckier ones, with John feeling that at this stage, the twins have bucked the trend identified in the study.

He's been sure to encourage a sense of adventure in the boys, who are now 14, and they lead active lives pursuing sports including skateboarding, surfing, free-diving and rock-climbing.

"I have been very mindful of their medical conditions and their limitations, but 99 per cent of the time it hasn't stopped them from being able to do things," John said. "I've made sure to get them involved in exercise, making sure they're fit and healthy."

"There's certainly been a degree of anxiety, especially early on, but I can't remember when they last had asthma medication and at this stage I can't see any indication that their lung function is declining."

"I think they'll be alright."

John said the boys had been thrilled to be part of the study and to contribute to research which could help other children like them.

"The thing I hoped for in being involved in the study was the boys would get a better sense of the things that have afflicted them," he said. "If there was an outcome that meant I could get a bit more of a sense of what was going to happen to them over time, that'd be great."

"But whatever we can do to contribute to that body of knowledge and to help other children, we're very happy to do."

"Were it not for the research, children like this wouldn't survive. If we didn't find ways of keeping them alive and then mitigating the effects on their health of things like intubation, then they would either die or lead pretty miserable lives. We've come a long way in terms of how to manage babies born this early."

- John Considine

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WHAT'S NEXT

- Dr Simpson and her team have received National Health and Medical Research Council (NHMRC) funding to carry out further follow-up on the study subjects, now aged in their late teens, to see whether their lung function is continuing to decline.
- The team also have NHMRC funding for a simultaneous intervention trial of a drug commonly used to treat asthma.

This study was funded by the National Health and Medical Research Council of Australia and Princess Margaret Hospital Foundation and Raine Medical Foundation, and carried out in collaboration with Curtin University, King Edward Memorial Hospital, The University of Western Australia and Princess Margaret Hospital for Children.



Jan and David Lord have been supporting the preemie babies research of Dr Shannon Simpson.

LUNG STUDY HELPS HISTORY-MAKING GENERATION GET A HANDLE ON THEIR HEALTH

The lung function study carried out by Dr Shannon Simpson provided the most comprehensive follow-up of very pre-term children of any study so far carried out on the lung health of this vulnerable group.

Researchers used four different kinds of lung function tests to follow children as they grow, for the first time combining them with CT scans to provide imaging of the chest.

The scans enabled researchers to spot abnormalities, including those suggestive of an inflammatory process which could be an active lung disease. Children who showed these changes had more decline in function than those without such changes.

"This is a really important finding because it might open up an avenue for us to be able to treat these children and stop the lung disease where it is," Dr Simpson said. She said the findings also made an argument for coordinated lung health follow-up after leaving the NICU – not currently clinical practice.

"The intensive care time is so intense and once the babies are well enough to leave the NICU there's an assumption that they just keep on improving," Dr Simpson said. "There's a lack of coordinated approach to long-term respiratory follow-up and that's a problem – we're being a bit complacent. "It might just be useful for kids to have their

lung function tested when they are six years old to try and get some kind of baseline, or have some regular follow-up so we can further understand why these kids are declining and at what point we need to do something about it."

She said it was also important to let families of preterm babies know that smoking around their children may have long-term lung health outcomes. This was true for all kids, but especially this vulnerable group.

The study has added to what is currently a very modest body of evidence around the ongoing lung health of babies who survived very early birth.

"The kids we are looking at now are in some ways history-makers," Dr Simpson said. "It's really only been the last 25 years that babies born so early have been able to survive, and that's thanks to modern treatments that started to become available in the 1990s."

"But that also means we don't know an awful lot about their long-term trajectories, especially in relation to lung health. There hasn't really been a lot of long-term follow-up of survivors of very preterm birth."

"This research has given us valuable information and offers us the opportunity to intervene earlier to make sure these kids grow up with healthier lungs."

It has also laid the groundwork for further research looking at how the children in the study fare as they grow older, and whether doctors can learn how to predict which babies are likely to have problems.

"At the moment we just can't predict in the NICU which of these kids are going to go on to live absolutely normal, happy, productive lives and which ones are going to go on to have health issues – be that neurodevelopmental, lung or other issues," Dr Simpson said.

"We have now secured funding to answer these questions as well as to try and discover a tool that will predict what's going on and whether we can make that prediction earlier in life."



Dr Shannon Simpson with Kaedin and Toni who were both born preemie.

BANKSIA HILL PROJECT A GAME CHANGER FOR YOUNG PEOPLE IN DETENTION

A ground-breaking Telethon Kids Institute study, which revealed that almost every young person being held in the Banksia Hill Detention Centre had some form of neuro-disability, has sparked concern and conversation across Australia and the world.



The Banksia Hill Project, carried out over two years, was the first study in Australia to assess and diagnose young people in a youth custodial setting for Fetal Alcohol Spectrum Disorder (FASD).

Although the team of Telethon Kids Institute researchers led by Professor Carol Bower set out to assess specifically for FASD, they were shocked to find evidence of much broader brain impairment.

"Of the 99 young people who completed full assessments we found 36 of them – more than one in three – had FASD," Professor Bower said. "Of this 36, only two had been previously diagnosed."

This was the highest known prevalence of FASD in a custodial/corrective setting worldwide, and almost double the previous highest Australian estimate in a non-custodial setting.

"Just as worryingly, we found that 89 per cent of the sentenced young people had at least one severe neurodevelopmental impairment, whether they had FASD or not," Professor Bower said. "Similarly to FASD, this is amongst the highest reported rate of neuro-disability amongst sentenced youth in the world."

The kinds of neurodevelopmental impairments identified by the team included problems with executive function, such as not being able to relate cause and effect or to plan, and problems with language, memory, cognition,

motor skills, attention, social skills and adaptive behaviour.

Almost half of the young people had severe problems with language, how to listen and understand, and how to reply and explain what they think.

"These are all really important neurodevelopmental aspects of a young person's life, yet the majority of these problems had not been previously identified," Professor Bower said.

"For many this was the first time they had received a comprehensive assessment to examine their strengths and difficulties, despite attending school and, in many cases, despite their prior engagement with child protection services and the justice system."

- Dr Raewyn Mutch

Fellow Telethon Kids researcher Dr Raewyn Mutch, one of the clinicians who conducted the assessments, said many of the young people assessed had previously been written off as 'naughty children', when they in fact were profoundly impaired.

"For many this was the first time they had received a comprehensive assessment to examine their strengths and difficulties, despite attending

school and, in many cases, despite their prior engagement with child protection services and the justice system," said Dr Mutch.

In addition to the assessments researchers undertook a qualitative study, speaking with 38 of the young people to explore their views about the assessments. Qualitative researcher Sharynne Hamilton said that for most of them, the assessments had been valuable and an opportunity for increased self-awareness.



Carol Bower, Hayley Passmore, Raewyn Mutch

"Of the young people who participated in the qualitative study, 89 per cent were Aboriginal, and most have come from families and communities where the traumatic effects of past child removal, criminal justice policies, and other colonising processes have significantly impacted their life chances," Ms Hamilton said.

The young people had also found it valuable to be provided with feedback on their strengths and difficulties.

"Many of the young people had never been told their strengths and did not know what they were good at," Ms Hamilton said. "In addition, it is apparent that despite extensive involvement with services such as child protection and education, the young people have not had their disabilities recognised or treated, and have received little or no support.

"The prevalence study provides a model for strength-based assessments of young people which could be implemented when a young person and their families encounter these systems." Dr Mutch said earlier recognition of the young people's impairments may have permitted alternative community care,

with targeted health and educational interventions and rehabilitation.

A paper detailing the research was published in *BMJ Open* in February and made immediate waves, generating widespread media and social media attention and sparking interest from governments, agencies, and people working in youth justice as far afield as New Zealand, Canada and the United States, as well as across Australia.

The Western Australian Government welcomed the results, with Corrective Services Minister Fran Logan pledging to push the findings of the study through the government's agencies to identify brain impairments among troubled youths earlier, and help them.

Staff at Banksia Hill Detention Centre also embraced the findings, and have since flocked to a series of training sessions conducted by PhD candidate Hayley Passmore, using training materials developed by the research team with input from staff and young people at the centre. The training aims to help staff understand and work more effectively with the young people in their care.

"We originally only had three sessions planned but they asked me to come back again and again, and we've now trained over 100 staff – mostly custodial but also some non-uniform staff," Ms Passmore said.

She is now formally evaluating the results, but said staff responses had been overwhelmingly positive.

"They're saying things like 'We should have had this information earlier – this is so vital to our job'; 'This should be in the academy training before we even start this role'; and 'This is something all staff need to know about'." So that's a

positive indication that the staff training has been beneficial already," said Ms Passmore

Following the assessments, the team prepared individualised reports for each young person to help Banksia Hill staff and the young person's wider circle of care understand their difficulties, and create tailored rehabilitation plans building on their relative strengths.

"They're saying things like 'We should have had this information earlier – this is so vital to our job'; 'This should be in the academy training before we even start this role'; and 'This is something all staff need to know about'. So that's a positive indication that the staff training has been beneficial already."

- Hayley Passmore

They also recommended that young people be fully assessed upon entry into the youth justice system, and preferably much earlier, so any vulnerabilities could be picked up and appropriate interventions and care plans could be put in place – potentially steering them away from a youth justice path altogether.

Since the paper's release, the findings have had a profound impact on those charged with caring for and managing young people who may find themselves in trouble.

At a State level, the Banksia Hill Project team has met with the Ministers for Education, Health, Justice, and Communities, and has a commitment to present to the Cabinet sub-committee for WA Community Safety and Family Support, on how the research results can be used to help get full assessments and better management strategies in place.

In the meantime, the Department of Justice is exploring a new Model of Care for youth detention, which aims to identify and consider the complex needs of the young people in a multidisciplinary manner.

Comprehensive health assessments for young people who enter the youth justice system have also been included as a priority in the new WA Youth Health Policy 2018-2023, launched in April, with the Banksia Hill Project findings cited in the policy's companion document.

In addition, the Banksia Hill findings have contributed to the Perth Children's Court

“Just putting some numbers on it has really sharpened everyone's attention on the issue and given them another way of thinking about kids in the justice system. There are a lot of complex lives here. We always say society has failed these young people and we need to be doing a better job, and now there is a great will to do it better. We just need to operationalise that and keep on the case.”
- Professor Carol Bower

ordering more multi-disciplinary team assessments as part of the pre-sentencing process; and the study has led to a legal precedent in the WA Supreme Court of Appeal.

The team's diagnosis of a convicted teenager with FASD provided a deeper understanding of his health and neurodevelopmental circumstances, and led to a review of his sentence and of the services and supports he requires. In granting the appeal, Chief Justice Wayne Martin expressed frustration at the inadequacy of assessment

of FASD in Western Australia and warned that unless assessment arrangements improved, justice-involved youth were at risk of injustice, and the opportunity to reduce the risk to the community would be lost.

“Our study has definitely provided an impetus for those working in this area to consider the neurodevelopmental aspects of these kids – in their assessments, in their management – that hasn't been there before,” Professor Bower said.

“Just putting some numbers on it has really sharpened everyone's attention on the issue and given us another way of thinking about kids in the justice system. There are a lot of complex lives here. We always say society has failed these young people and we need to be doing a better job, and now there is a great will to do it better. We just need to operationalise that and keep on the case,” said Professor Bower.

Professor Bower said that in order to give young people with neurodevelopmental impairment the best chance to succeed, it was important not only to identify their strengths and limitations, but provide appropriate support to help them do better while in detention and once they were released.

“I think that's a key thing that can be taken from our study, identifying their strengths and difficulties and playing to the strengths to support the difficulties – because these young people will be released at some stage and we want them to have the best opportunity to be law-abiding citizens upon their release,” she said.

Some of the ways the Banksia Hill Project

has shaken up the thinking around young people in detention:

A comprehensive **communications plan** including videos, a media release, fact sheet, and media briefing with the Australian Science Media Centre ensured the paper achieved wide coverage both nationally and internationally, with almost 50 articles across print, online, television and radio at the time of release, and more since

The story generated **so much social media traffic** that the **Telethon Kids Institute** began trending

The **paper has had such significant reach** that it is **ranked in the top 5% of more than 11 million research publications ever tracked by Altmetric**, a site which measures the online attention generated by a piece of research; and in the **top 2% of research publications from BMJ Open**. The site measures broad public reach including social media mentions, news articles and other online mentions globally

The **research has been discussed by the ACT and Western Australian Parliaments**, cited in court cases, and referenced by the Royal Commission into the Protection and Detention of Children in the Northern Territory

NGOs and other agencies providing services to young people have **requested information about the study findings, and evaluations of their services**, to help them work more effectively with their clients

Members of the research team have **been invited to present the findings at conferences, meetings and seminars** nationally and internationally, including the National Conference on Indigenous Incarceration in Queensland, and will present at the European Conference on FASD in Berlin

The **team have been invited to address Australian and New Zealand Commissioners for Children and Young People**

Dr Raewyn Mutch presented to the **Judicial Conference of Australia**, the representative body of the Australian judiciary, and was subsequently asked to provide training for judges in Queensland

Dr Mutch and Dr Amy Finlay-Jones have also met with the **Queensland Department of Youth Justice** to discuss replicating the study in that State's juvenile detention facilities; and Dr Mutch has been **asked to advise a roundtable to the New Zealand government**.



A scene from 'Sentence' (short film included in video training resources)



"Ensuring we understand them and identifying what resources and support they need means that not only do these children have a better chance at succeeding, but we also have a safer community."

Dr Mutch said the research had been paradigm shifting – and was a fitting way to cap off the career of Professor Bower, who had spent decades making a difference in the lives of young people, particularly through her research into the ability of folate fortification to reduce birth defects, and her research into FASD.

"She was tentative about dipping into the area of juvenile justice," Dr Mutch said. "But what better way for her to hand on the baton for child health research than to have conducted something that has had such a widespread national and international impact, that has caught the attention of government and has already had buy in, at least in spirit, to agree that something different has to be done."

WHAT'S NEXT

- The team has applied for new grants to enable them to conduct further research into pre-natal alcohol exposure, FASD, neurodevelopmental impairment and disability amongst young people in the justice system.
- The team is actively investigating funding opportunities to develop the training program for use beyond justice, in other agencies such as education and child protection, and to make it widely available across Australia and beyond.
- The team will continue to liaise with relevant government agencies to work on getting comprehensive assessments and appropriate multi-disciplinary staff, resources and services in place, to identify and support affected young people.

Young people's comments about impairments when interviewed by Banksia Hill Project team

"I think pretty much everyone here got a different brain." – 15yo in detention

"They should know if someone's different. To help 'em maybe, cos if they don't know they can't help 'em." – 19yo in detention

"He's a 7-year-old in a 17-year-old's body." – 17yo in detention

"Like me I don't know how to read the best but yeah...you gotta find a way not to get in trouble." – 15yo in detention

Staff comments about impairments when interviewed by Banksia Hill Project team

"When you're interacting and working with kids you gotta sorta take a step backwards...like give an instruction – can he hear what you're saying? Does he understand what you're saying?" – Custodial officer

"If they're not understanding what you're saying... there's going to be no progress... and you're gonna expect too much." – Custodial officer

"So if I give a set of chopsticks to someone who's never used chopsticks before and I expect them to be able to use chopsticks, then everyone's standing around watching them failing at chopsticks, they're gonna get frustrated with it. You know, so it's not good enough for me to say 'Well you need to be better at chopsticks'." – Custodial officer

Young people's comments on assessments and feedback from the qualitative study

"I am glad I did the assessments. I hope it will help me learn more about myself."

"I liked the assessments because they gave me a challenge."

"I'm surprised I'm good at something."

"I can't wait to find out how my brain works."

"I am pleased to hear that my brain works well."

"It's good to know your strengths and weaknesses."



BANKSIA HILL PROJECT FACT SHEET

KEY FINDINGS

- The **Banksia Hill Project** is the first study in Australia to assess and diagnose young people in a youth custodial setting for Fetal Alcohol Spectrum Disorder (FASD)
- FASD is a neurodevelopmental disorder caused when an unborn child is exposed to alcohol in the womb
- The Telethon Kids Institute assessment team was made up of health professionals including a paediatrician, occupational therapist, speech pathologist, and a neuropsychology team
- They worked with more than 100 young people aged 10-17 years who were sentenced to various periods of time at Banksia Hill Detention Centre during 2015 and 2016
- 99 young people completed full assessments
- Domains assessed were: brain structure/neurology, cognition, attention, executive functioning, motor, language, memory, adaptive skills and social communication, and academic skills.
- 89% had at least one of these domains meeting the level of severe impairment
- 65% had at least three domains severely impaired
- Only 11 of the young people who completed full assessments had no domains of severe neurodevelopmental impairment
- 36 young people in the study (36%) were identified as having FASD – the highest known prevalence of FASD in a custodial/corrective setting worldwide – with several more suspected but unable to be confirmed
- Of those 36, only two had been previously diagnosed
- Of those given a diagnosis of FASD, severe impairments were identified across the following domains: academic (86% of young people with FASD), attention (72%), executive function (78%), language (69%), memory (56%), motor skills (50%), and cognition (36%)
- Of those without a FASD diagnosis, severe impairments were identified across the same domains but at lower levels: academic (48% of those not diagnosed with FASD), attention (44%), executive function (40%), language (32%), memory (29%), motor skills (17%), and cognition (13%)
- 24 young people were assessed to have an IQ score less than or equal to 70 – 15 with FASD and 9 without FASD.

About FASD

Fetal Alcohol Spectrum Disorder (FASD) is characterised by severe neurodevelopmental impairment resulting from an unborn child's exposure to alcohol during pregnancy. The effects of prenatal alcohol exposure are life-long and may not be seen at birth. Problems include brain damage leading to delayed development, social, behavioural and learning problems. These can lead to secondary outcomes such as poor school performance, unemployment, substance abuse, mental health problems and early engagement with the justice system. FASD affects communities worldwide and is a leading cause of preventable non-genetic intellectual disability in Australia.

RESEARCH ENRICHING THE LIVES OF GIRLS WITH RETT SYNDROME

A program developed by Telethon Kids Institute researcher Dr Jenny Downs has led to dramatic improvements in the functioning of Chinese children with Rett syndrome, and could change the world.



Jenny Downs is understandably excited to share the findings of her study into improving the capabilities of children with Rett syndrome through her enriched exercise program.

Her team's work has sparked a new way of thinking about how to structure a day in the life of a child with the condition, and should change how the syndrome is managed around the world.

Rett syndrome is a genetic disorder which has serious consequences for the development of motor functioning and cognitive skills.

A diagnosis comes as a major shock to parents of girls who are affected – children who were born without any signs of the condition but then lose developmental skills over time.

The syndrome is rare – on average only one girl born in Western Australia each year will be diagnosed.

Dr Downs, co-head of Child Disability at the Institute, said while much was now known about the condition first described 50 years ago, until recently not much had been known about how to help.

A grant from the International Rett Syndrome Foundation allowed her to work with 12 girls to test the effects of an enriched environment for building gross motor skills.

"I hope what I have done will have important implications for daily management of affected children," Dr Downs said.

"We looked at children who were young because we wanted to take advantage of

neuroplasticity – a concept which means our brains are more responsive to learning opportunities when we are younger – and so we did an intensive intervention to build their skills then."

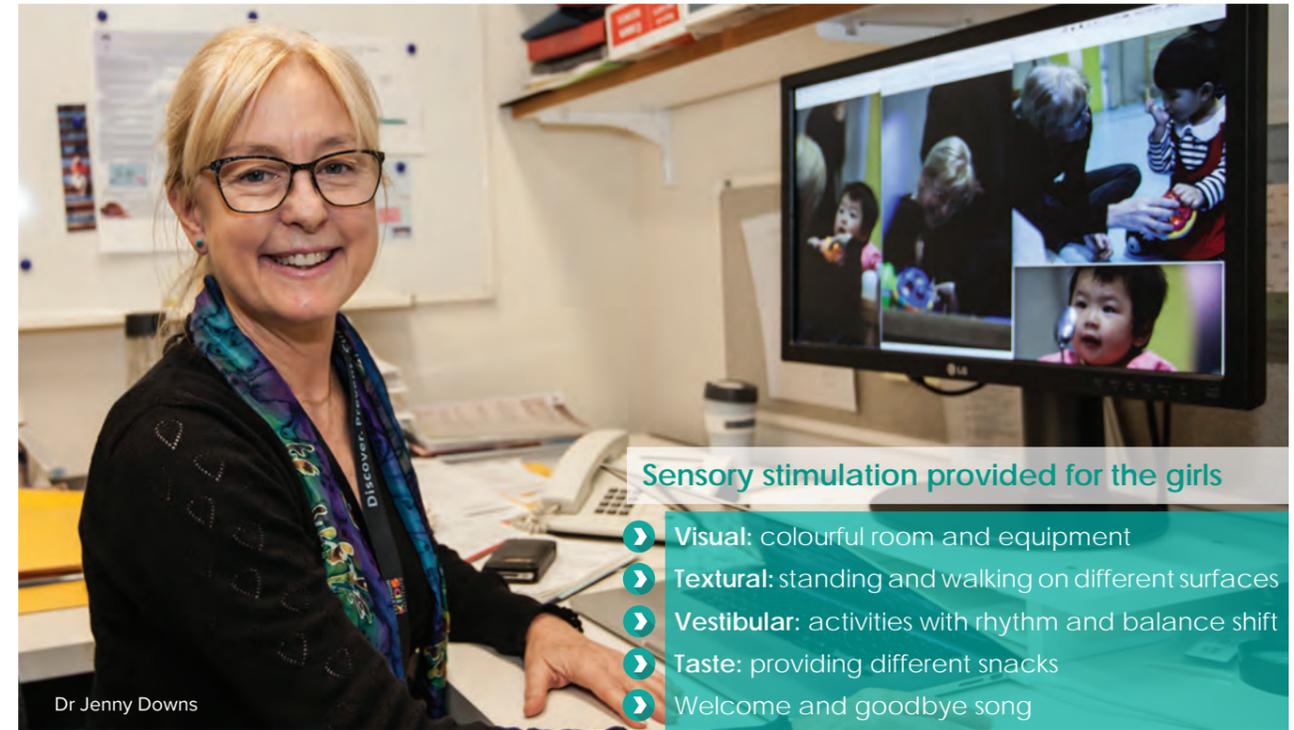
The average age of the children involved in the study was three years.

"We provided a program of activities and exercise within an environment that was enriched with social activity, choice-making, lots of sensory stimulation, lots of practice, and giving the girls time to achieve each task," Dr Downs said.

She said the kindy-like setting was fun, with the children starting and ending each session with a song. Mothers enjoyed bringing their daughters and realised there was hope for them to learn and improve their abilities.

"With approximately two hours a day of enriched activity, the girls learned skills. It was heartening to see some dramatic changes in the girls. One child went from not being able to sit up, to being able to sit on her own and then even walk with assistance. On average, each girl gained eight points using a 45-point gross motor skills scale. And there were also biological changes."

Girls with Rett syndrome have reduced production of Brain Derived Neurotrophic Factor (BDNF), a protein required for normal neuronal development and brain function. It serves to facilitate synapses between cells in the brain. The researchers measured BDNF in the blood at points throughout the study. Prior to participating in the study, BDNF levels were low compared to the general population. But six months into the program, BDNF levels had doubled or tripled.



Dr Jenny Downs

Sensory stimulation provided for the girls

- ▶ Visual: colourful room and equipment
- ▶ Textural: standing and walking on different surfaces
- ▶ Vestibular: activities with rhythm and balance shift
- ▶ Taste: providing different snacks
- ▶ Welcome and goodbye song

Dr Downs said the change was similar to what happens to mice with Rett syndrome, which develop better coordination through practice and exhibit biological responses of increased BDNF if given an enriched environment.

"Often you have findings in animal studies and it isn't replicated in human studies," Dr Downs said.

"But we demonstrated biological responses to exercise as well as the development of new functional skills. We couldn't believe that the results were so positive."

Dr Downs chose to recruit from the InterRett database and conduct the study in China, because the very large population meant there would be enough participants and costs were not prohibitive. But conducting a project across international borders presented some difficulties her team fought hard to overcome.

"It took a lot of determination and relationship building," she said. "The team in China, however, joined in with so much energy, we tackled challenges and the study ran extremely well."

A research paper published earlier this year, titled *Environmental enrichment intervention*

"With approximately two hours a day of enriched activity, the girls learned skills. It was heartening to see some dramatic changes in the girls. One child went from not being able to sit up, to being able to sit on her own and then even walk with assistance. On average, each girl gained eight points using a 45-point gross motor skills scale. And there were also biological changes."

- Dr Jenny Downs

for Rett syndrome: an individually randomized stepped wedge trial, sparked international interest and Dr Downs will speak at two European conferences this year.

She said she hoped the findings would improve life for families around the world with daughters who had been diagnosed with Rett syndrome, and boost the quality of life of those with the condition.

"It's really important that we understand what the problems are for affected children, and it's really important that we now understand how we can help and provide support," she said.

WHAT'S NEXT

- Dr Downs wants to develop a comprehensive web resource to provide health practitioners and families with a mass of ideas about how to provide the kinds of activity that will improve skills. She is looking for funding to support this project.

TECHNOLOGY POWERING RESEARCH

For many of us, it's the first thing we look at in the morning and the last thing we see before bed. We use them to get our news, connect with family and friends, shop, watch videos, play games, read books, check emails, do our banking, and make the odd phone call. They are smartphones, and according to the 2017 Mobile Consumer Survey by Deloitte, 88 per cent of Australians own one.



Digital health researcher Rebecca Nguyen says the technologies available today provide a powerful opportunity for rapid translation of research to the community.

"With smartphones being widely available and mobile apps being used on a daily basis, health researchers are uniquely placed to take advantage of these technologies to capture data, implement research interventions and disseminate information," Ms Nguyen said.

"Researchers at Telethon Kids are harnessing the power of apps and other online tools to ensure the results of their research reach those who need it most – children, young people and families."

Ms Nguyen says digital health encourages innovative thinking and builds collaborations between researchers, consumers, community health professionals, government, and the technology sector.

"Technology today is opening doors never thought possible and connecting us with people we may not have been able to reach previously.

"It really is changing the way we not only do research, but how we ensure our results are translated into tangible outcomes for kids and families."

Telethon Kids digital health researchers use a 'best practice' design thinking process, called UX (user experience) design, that is commonly used world-wide for the development of apps. It not only supports



Rebecca Nguyen

the delivery of research outcomes and findings, it also ensures the technology enhances the user satisfaction by providing meaningful experiences as well as good usability and accessibility when interacting with the app. Researchers work in consultation with consumers to design end products such as apps and websites.

Ms Nguyen says digital health spans a pipeline from the initial idea through to early stage development, consumer workshops, refinement of the app, identifying funding sources and working with app developers to bring it to life.

"There are so many opportunities for digital technologies to be used to improve the health and development of children and young people," Ms Nguyen said. "I'm looking forward to working with many more of our researchers to see how technology and apps can be used in their work."

Shelley Gorman, Gail Alvares, Andrew Whitehouse and Yael Perry.



Sun safety tool for teens

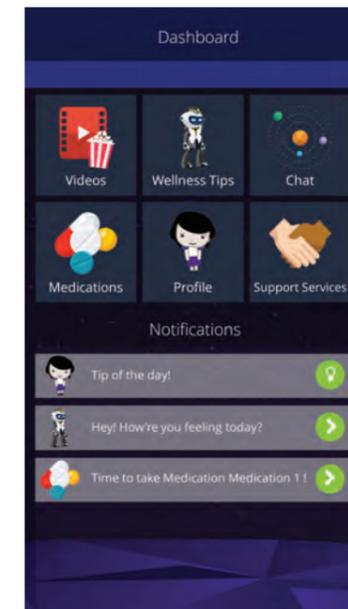
Dr Shelley Gorman is developing a prototype online tool to foster safe sun exposure practises in teenagers. Twelve and 13-year-olds will be recruited as 'co-researchers' to help develop the tool as a new intervention to support teenagers to make better decisions around sun protection and sun exposure. It's hoped this online tool will support young people to make more balanced and healthy decisions around their sun behaviours to reduce their risk of developing skin cancers in later life, and provide them with sufficient vitamin D for optimal bone health. The study is a collaboration with Cancer Council WA, The Australian National University and Curtin University and is funded by Healthway.

Online game to reduce mental health issues for trans youth

Giorgetta Family Fellow Dr Yael Perry and her team will tailor the Auckland-based online interactive game SPARX for trans youth to help prevent the onset of depression. The innovative online fantasy-based game, allows players to select and personalise an avatar that represents them. The game is based on cognitive behavioural therapy and teaches skills focused on keeping active, learning how to identify unhelpful thoughts, and assertiveness. The study is funded by Healthway.

CyFi Space

Dr Cindy Branch-Smith, Ms Bec Nguyen, Dr Jacinta Francis and Professor Donna Cross have developed a smartphone app designed to break down the social isolation of young people battling the most common life-shortening disease in children, cystic fibrosis (CF). Due to the threat of cross infection, young people with CF are unable to meet others with CF in-person. CyFi Space allows users to keep socially connected to their peers and aims to improve their mental health and wellbeing. Alvi, their virtual avatar buddy, will encourage the user to manage their CF through medication reminders, and provide uplifting and entertaining videos, wellness tips and support services when feeling down. The app could be used in the future for diseases like diabetes, cancer and other chronic conditions.



App-based game to help children with autism

Dr Gail Alvares and Professor Andrew Whitehouse have been testing the Therapy Outcomes By You (TOBY) iPad app and have shown that while iPad-based apps are not a replacement for traditional therapy, they may be a cost effective addition to therapist-delivered intervention. Children with autism who used the app over a six-month period alongside their usual therapy were found to have greater improvements in several areas of development compared with the children who received therapy as usual. The areas of improvement included simple problem solving, fine motor skills and the understanding of words.

TOBY was developed by a multidisciplinary team of researchers from Deakin and Curtin universities, Autism West and specialist psychologists and speech pathologists, led by Alfred Deakin Professor Svetha Venkatesh.

Image Up

Image Up is a social media image sharing app developed by the Institute's Cyber Savvy team and co-designed by Cyber Leaders (more than 70 students from across Perth schools) that aims to assist users in making safe decisions when sharing images. Image Up allows you to post simultaneously to Instagram, Twitter and Facebook at the push of a button, then manages and orders your images, giving you instant feedback such as likes and tweets. Other than the ability to share images to multiple social media accounts, the app includes a unique feature in the form of 10-15 second targeted videos about image sharing, which encourages users to consider and/or rethink (pause for thought) whether the image being posted is appropriate.

Diabetes and exercise

Exercise is crucial to type 1 diabetes management but it can also impact on blood glucose levels if not done safely — a risk which often stops people with the condition from being active. To combat this, researchers from the Institute's Children's Diabetes Centre, with input from young people with type 1 diabetes, are developing a new exercise guidelines app to help reduce hypoglycaemia risk and increase safe exercise practices. Researcher Vinutha Shetty said technology was a huge part of young people's lives so it was natural that this age group would choose technology (app) to help manage physical activity and diabetes. The app will be developed once the new exercise guidelines are finalised.

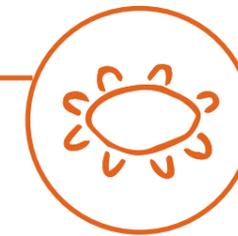
LABORATING FOR IMPACT

*This research shows how we
work with others to make a
difference*



ELDERS LIFT THEIR VOICES TO BRIDGE THE GAP FOR KIDS

Led by nine Elders, the Ngulluk Koolunga Ngulluk Koort Project is working to generate a better understanding of early childhood development from an Aboriginal/Nyoongar perspective. The team hopes their work will lead to a deeper, more meaningful and respectful connection between the Aboriginal community and others.



The Elders have been described as the 'engine room' of this important research project. They lead a passionate project team who, over the past 2-3 years, have worked together to identify the priorities of Aboriginal people from across the Perth metropolitan area when it comes to their children.

After consulting with the community, three big ticket items were identified to concentrate on: child protection/removal; provision of appropriate housing; and early childhood education and care.

The Elders are now working to take their solutions and ideas to the boardrooms of government and non-government agencies and service providers to work alongside these organisations to better meet the needs of Aboriginal people.

"Our children are disempowered and voiceless...working with Telethon Kids provides an international platform that gives our children a voice, that's why it's so important to take this to the community and have the community voice their children's needs and their perspective," Elder Millie Penny said.

"We all came in with a passion for our children, and we have been learning more about the socio-economic disadvantages between our community and other communities. It's been a learning curve that reinforces our lived experiences."

Among the Elders' recommendations are ensuring Elders are given a real and

powerful voice in the child protection system as it makes decisions regarding Aboriginal children, and to encourage the Government to provide systems that support, rather than punish parents.

The Elders are also working to ensure that there is adequate Aboriginal input into the development of WA's housing policies particularly regarding appropriate and fit-for-purpose housing design and allocation. They would like to see a range of dwelling types and tenancy options made available to meet the needs of Aboriginal families.

Senior Research Fellow Brad Farrant said the team was engaging with a range of stakeholders, policymakers, politicians and Aboriginal community organisations to help facilitate change in how

they meet the needs of Aboriginal people.

"In many areas the underlying issue is a lack of trust," Dr Farrant said. "The community has told us that there has been a lot of damage done to the trust between Aboriginal people and government and other service providers.

"In terms of childcare and early schooling, there's a sense among the community that many organisations and schools don't have an adequate understanding of Aboriginal/Nyoongar culture and the different values and priorities Aboriginal families have.

"Therefore, Aboriginal families and kids often feel they are negatively judged in these contexts."

"United you stand, divided you are going to fall. It's a two-way learning, so let's all work together and make a lot of changes happen."

- Elder Uncle Albert McNamara

The project has been looking at the priorities of Aboriginal parents and how these differed from non-Aboriginal values. There has been a lack of acknowledgement of the strengths of Aboriginal children.

"Difference doesn't always mean deficit," Dr Farrant said.

Research Focus Area Head, Aboriginal Health, Glenn Pearson said Elders were the engine room of the project, with the nine Co-Researchers answering to a wider group of 90 Elders.

About 60 Elders attended the most recent meeting to discuss the strengths of Aboriginal families and the challenges they faced.

WHAT'S NEXT

- The Elder Co-researchers and the research team will work with policymakers, key stakeholders and service providers to improve the way services are delivered to Aboriginal children and their families.

"This is massive, not only in terms of the number of Elders participating in the project, but also the number of families, parents, children and communities this allows us to connect with, and them to us," Mr Pearson said.

He said a key to the success of the project was building trust between families and organisations and connecting people from organisations who were motivated to learn how to better interact with the community with an Elder.

He hoped the project would generate a deeper, more meaningful and respectful connection between the Aboriginal community and other communities.

"We need really good science behind this data, but it also needs to transfer into effect," he said.

"In many areas the underlying issue is a lack of trust.

The community has told us that there has been a lot of damage done to the trust between Aboriginal people and government and other service providers."

- Dr Brad Farrant



CYBERBULLYING WORK FINDS INTERNATIONAL AUDIENCE

Schools from around the globe – with significant differences in languages spoken, uniforms worn and even lunchbox contents – have turned to the Telethon Kids Institute, seeking access to invaluable lessons learned from Australian students on how to effectively reduce harm from cyberbullying.

There has been huge interest over the past year in the Institute's Friendly Schools Plus program – a set of comprehensive, evidence-based resources found to reduce bullying behaviour – with schools or school-focused groups in Denmark, Norway and New Zealand recently picking it up.



"There has been tremendous interest and many schools in these countries either want to replicate our programs or take on the resources, adapting and translating them for their own use," Professor Cross said.

They join schools in the USA, United Kingdom, Singapore and South Africa, along with 3,000 local Australian schools already using the effective whole-school approach developed by Professor Donna Cross and her team.

The program, which supports not only those being bullied or cyberbullied but the students who are doing the bullying and bystanders as well, is based on evidence gained in 11 trials involving 30,000 Australian students, carried out over 20 years with research partners at Curtin University and the Child Health Promotion Research Centre at Edith Cowan University.

The program's powerful reach means Professor Cross often finds herself on an overseas phone call or a plane, having been appointed to advisory boards or having entered formal international agreements with educational institutes and research partnerships with universities. She is currently a member of Denmark's Princess Mary Foundation expert panel guiding the implementation of anti-bullying strategies.

"Our work has been dynamic, relying on young people's input into the issue and their ideas to address each new development."

- Professor Donna Cross

She said the Institute had been among the first in the world to do the most rigorous work in bullying prevention, carrying out its first randomised control trial in 1999.

"And then, as behaviours changed, with cyberbullying we were the first to lead a trial investigating student-developed interventions – a randomised control trial called the Cyber Friendly Schools program," she said.

"Our work has been dynamic, relying on young people's input into the issue and their ideas to address each new development.

"The component the overseas groups are now most interested in is our Cyber Friendly Schools research. They want to adapt, use and test our tools and resources with the young people in their country."

Professor Cross said bullying and cyberbullying trends among children and teens were similar around the world, with a common shift from overt to covert bullying, similar levels of prevalence, and behaviour peaking at around 10 to 11 years-old.



Professor Donna Cross

In secondary school, however, differences emerged in the online environment. Young people in Germany, for example were shown to be more likely to bully in chat sites, young Australians were more likely to do so via social networks, and in parts of Asia such as South Korea, gaming sites were the more common venue for bullying.

“Some of the overseas groups have taken on our program based on the Australian findings,” Professor Cross said. “Others, such as Norway and a group in Denmark and New Zealand, are keen to formally test it in their environment whilst implementing it, to ensure it is having similar effects to those that we have found.

“Given our resources here in Australia were co-developed by young people of a similar age group as those using them, we have encouraged each of these countries to engage locally with their young cyber leaders to critically review our Australian resources and adapt them to suit their unique needs.

“These countries have really liked the formative process that we used and they have tried to replicate the ways we engaged with young people – so much so that the cyber leader resources we developed are freely available online so they can replicate our methodology.

“Even at the individual school level, cyber leaders can be engaged to help promote positive and proactive cyber behaviour. It’s much better than waiting until an incident occurs and being on the back foot.”

Cyber leaders can benefit the whole school community by facilitating educational opportunities for the full range of stakeholders within the school, including other students, teachers and other school staff, and parents.

WHAT'S NEXT

- Researchers urge each school to appoint a Cyber Leader Group. These cyber leaders receive training and resources to support them to act as positive role models and advocate, encourage and inspire good digital and online behaviour.
- The team is seeking funding to develop new strategies identified by the Institute's young Cyber Savvy ambassadors as having the potential to help parents better understand the online environment, and create positive relationships around cyber behaviour.
- Researchers are helping teachers and others who work with young people to safely use social media as a teaching aid to engage with young people, through the further development of Cyber Strong Schools program tools.
- The team is helping parents of very young children use digital technology more effectively, by developing an online system using machine learning that will provide guidance and reminders, tailor appropriate responses and identify and mitigate potential risks.

Cyber safety

CAN LEARN LESSONS FROM SWIMMING POOL SAFETY

Rather than just banning and blocking, Professor Cross said it was vital parents created an on-going positive relationship around cyber behaviour and focus efforts on finding more ways to keep children and teens safe when immersed in the online environment.

Similar tactics could be looked at to those already in place for swimming pool safety, including monitoring safety and teaching first aid and appropriate behaviour.

She said Institute cyberbullying research already suggested there may be a need for widespread mental health first aid training, as peers are often the first stop for help when young people are dealing with a negative online environment.

In the case of pool safety, older children and teens were not only given rules to follow but were also encouraged to learn first aid, so they can help others and themselves if they get into trouble in the pool, says Professor Cross.

For young children, fences are built to keep them out but they are also provided with swimming lessons and parents are encouraged to spend time with them in the pool to help them enjoy it in a safe and fun manner.



CYBER-BULLYING

Cyberbullying can have a lasting effect on young people's self-esteem and mental health. They may nevertheless avoid telling their parents about such experiences, due to fear that their access to the Internet and mobile devices will be taken away.



YOUNG AMBASSADORS KEEP RESEARCHERS ON THEIR TOES

Flat out trying hard to keep up with the ever-changing threats from cyberbullying, the Telethon Kids Institute counts itself fortunate to have youth on its side.

Professor Cross' research team relies on an army of young advisors – in particular 70 14-year-old Cyber Savvy ambassadors who develop concepts for teen-friendly apps – as well as a research team that includes those still in their early 20s.

On top of this, another 30,000 Australian students were involved in the 11 anti-bullying trials that have informed the team's work, with many providing feedback that led to new directions in research.

"This is such a new area of investigation in terms of developing new knowledge – unlike areas such as road safety, where our research can only value-add to work that has been done in the past. With cyberbullying, it is virgin territory in terms of knowledge and understanding," Professor Cross said.

"The really exciting feature for us is the opportunity to work with young people to develop these resources, because if you're older than about 14 years of age you're getting too old to have a deep understanding of what is the best way to intervene."

"Just when we thought we had it nailed, social media became really interesting to young people and so their behaviours switched from texting and blog-based delivery of content to quite different and even faster interaction."

- Professor Donna Cross

It was an incident over a decade ago that convinced Professor Cross of the importance of allowing young people to direct her research.

"The really exciting feature for us is the opportunity to work with young people to develop these resources, because if you're older than about 14 years of age you're getting too old to have a deep understanding of what is the best way to intervene."

- Professor Donna Cross

"I remember back in 2006, when we were running a secondary bullying prevention trial called Supportive Schools, a few students mentioned for the first time being bullied through their mobile phone," she said.

"Fortunately, I was working with a young team of early career researchers who were quick to recognise the importance of this finding. And they had the skills and understanding of mobile phones that we older researchers did not.

"So we then began talking to more young people and asked 'Can you tell us more about this mobile phone bullying? What does it look like? How are you experiencing it?'

"And we ran three large formative studies talking to young people, teachers and parents to try and understand what each of those groups' perspective was on that behaviour. At the same time, we were asking their advice about what they needed to support them in this environment. "Our follow-up studies spent time designing

and trialling models to try and keep up with the rate of technology change.

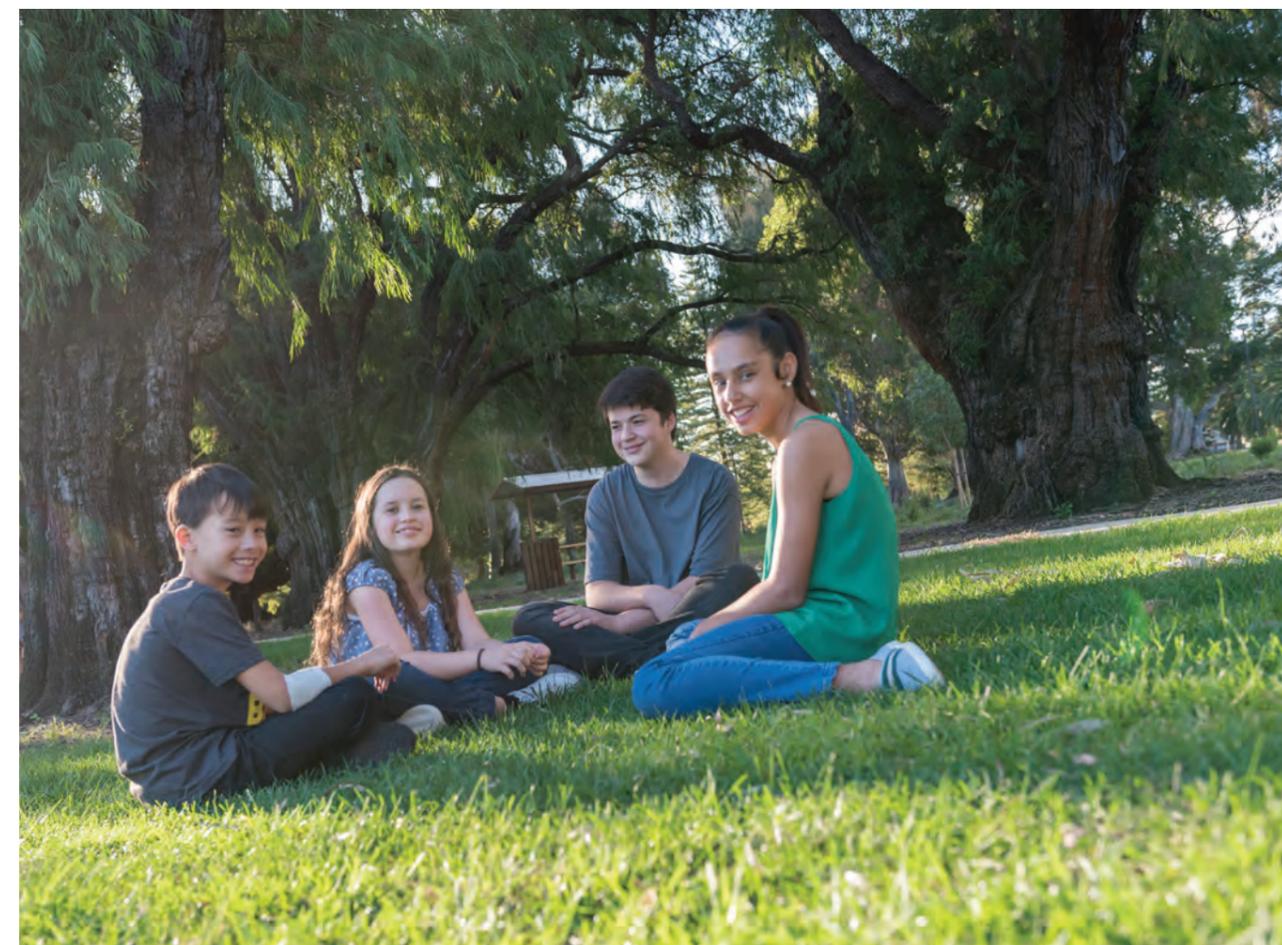
"Just when we thought we had it nailed, social media became really interesting to young people and so their behaviours switched from texting and blog-based delivery of content to quite different and even faster interaction.

"So we have needed to make sure we have a constant reference group of young ambassadors on-hand, who give us advice about the latest trends online and enable us to be able to adapt our resources or develop new ones."

Armed with pens and butchers paper, in just 12 hours these teens came up with the concept for the Institute's highly successful Image Up app. The app can post images to sites like Facebook and Instagram, but stores a 'sent' photo for 10 seconds while in-the-moment humorous and education-based messages are delivered, encouraging the young person to pause and reconsider sending inappropriate, explicit or illegal images.

"So we have needed to make sure we have a constant reference group of young ambassadors on-hand, who give us advice about the latest trends online and enable us to be able to adapt our resources or develop new ones."

- Professor Donna Cross



ORIGINS PROJECT SHINES LIGHT ON EARLY CHILDHOOD DEVELOPMENT

A collaboration between the Telethon Kids Institute and Joondalup Health Campus is poised to be a game-changer for early childhood development.



The ORIGINS Project – a longitudinal birth study which will track the progress of 10,000 children born at the northern suburbs hospital over their first five years – will provide a wealth of information that can be used by researchers around the world.

With increasing evidence that a child's wellbeing may be programmed at a very early stage, the community-based research project aims to find better ways to intervene to promote a healthy start to life and reduce the risk of chronic disease in childhood and later years.

Project Co-Director and paediatric immunologist Professor Susan Prescott said ORIGINS will enable participants to help make a real difference for the next generation.

All up, researchers are seeking to recruit 10,000 families. Active participants will be offered health check-ups during pregnancy and when the child is aged one, two-and-a-half and five years old.

With parental lifestyle and diet plus environmental factors playing a role in a child's future health, the study will also delve into several aspects of family life from the time the baby is in utero, including family dynamics, physical activity, dietary habits, work, sleep patterns and electronics use, and involve the collection of blood, saliva and hair samples.

The information will be used to assess how a young child's environment, genetics and their parents' overall

health influence their risk of developing a range of conditions such as allergies, asthma, autism, diabetes, obesity, cardiovascular disease and mental ill-health.

Professor Prescott said it was one of the most comprehensive studies of pregnant women and their families in Australia.

"We see this as a local project with a global vision," she said. "Although we are focussed on trying to achieve meaningful changes in the lives of the families in the Joondalup-Wanneroo area, we hope, and are very confident, that the results will translate much more generally and be of global interest."

"We see this as a local project with a global vision."
- Professor Susan Prescott

"By understanding that a substantial proportion of risk is programmed very early in life, finding ways to improve resilience and health from the first moments of life is really the best way to address the disease burden."

"It's a wonderful opportunity where we can integrate our research program into the daily activities of clinical care."

ORIGINS can become part of every family's journey."

- Professor Susan Prescott

Professor Prescott said ORIGINS is intervention-based, with the findings translated and integrated into clinical practice and community education.

Parents are given follow-up support when a risk factor was identified, to help prevent or better manage potential health problems.

"It's a wonderful opportunity where we can integrate our research program into the daily activities of clinical care," Professor Prescott said. "ORIGINS can become part of every family's journey."

"With paediatrician follow-up at one, two-and-a-half and five years, we'll be keeping a close watch on their health, their development, their allergies, and this will create an opportunity for early referrals if any problems are identified."

"We don't just want to observe, we want to make a difference, so we are aiming to have a number of nested intervention studies within ORIGINS."

Some of the associated research programs include:

- ▶ **SYMBA study:** boosts a woman's gut health with prebiotics during pregnancy and breastfeeding in a bid to reduce allergies in her child
- ▶ **CARE-Dads study:** evaluates the risk of diabetes and cardiovascular disease in expectant fathers
- ▶ **Pregnancy Lifestyle Activity and Nutrition (PLAN) program:** examines whether lifestyle intervention via diet, exercise and wellbeing advice in early pregnancy can reduce offspring obesity
- ▶ **Testosterone and Language in Kids (TALK) study:** aims to understand how testosterone exposure in the womb relates to brain growth and language development in early childhood

The ORIGINS Project is open to pregnant women and their partners planning to deliver their baby at Joondalup Health Campus.



The decade-long study began last year, receiving \$26 million in funding from the Federal Government and the Paul Ramsay Foundation.



Professor Desiree Silva and Professor Susan Prescott

WHAT'S NEXT

- New ORIGINS sub-studies are in development including one around personalised medicine using genomic information; another into the use of screen time on electronic devices by families; and a Nature Play study into the behaviour of pre-school aged children which will see how more exposure to nature can help combat anxiety.



ORIGINS FAMILY FINDS COMFORT AND COMMUNITY

A Quinns Rocks family who became the 1000th family to sign up for the ORIGINS Project is excited to be contributing to such ground-breaking research.

Jessica Mason, an early childhood teacher who is expecting her second baby in August, said she was told about the project during her first appointment at Joondalup Health Campus. She was interested to learn that it would give her family free access to extensive tests and screening, as well as a team of specialists.

"We signed up because I have allergies myself and would like to help prevent my baby and future family members from suffering from asthma and eczema," Mrs Mason said.

"I'm also an early childhood teacher and can see the value in early intervention and research. There's an increasing incidence of allergies and anaphylaxis, autism, speech problems, OT problems, and anxiety. It would be awesome to identify these at an earlier age.

"This is ground-breaking research – looking at environmental factors as well as genetics and parents' health."

The Masons are also taking part in the SYMBA study for allergies, the TALK study for language and speech, and dad Michael is involved in the CARE-Dads Study, which focuses on fathers' cardiovascular health.

Mrs Mason said it had been easy to sign up and all appointments were scheduled during hospital visits.

"We receive a lot of extra health screening at no cost," she said. "The baby will receive paediatrician assessments and full allergy screening."

Project Co-Director Professor Desiree Silva said participants could also attend drop-in sessions.

"We are getting wonderful feedback that by participating in the project, they are getting a greater sense of community and belonging," Professor Silva said. "And we know that having connectivity with other people in the community has positive health outcomes."



ORIGINS Co-Director Professor Desiree Silva with Jessica Mason, husband Michael, and two-year-old son Eli



COLAB EARLY YEARS INITIATIVE

As we all know, we only get one start in life. Like the Minderoo Foundation, our partners in CoLab, we are determined to ensure that every start is a strong one for children across Australia.



To achieve this, parents need to be able to get the support they need, in an accessible location, delivered by a known and trusted person. Ideally this would all be available within pram pushing distance of their house, for example at their local primary school.

test and evaluate evidence-informed community-led approaches to child development in four communities across metropolitan, regional and remote Western Australia.

However, every Western Australian community is different and there is no one-size-fits-all approach.

Communities would be supported to develop and implement plans with a singular target – to maximise the developmental status of children before they enter school (measured by the Australian Early Development Census, or AEDC).

Telethon Kids and the Minderoo Foundation, working together as CoLab, are partnering with the Western Australian Government on an unprecedented 10-year project which will try new approaches at a community level to see what differences they can make to children's learning and development.

"Despite having a singular target, the Early Years Initiative has many goals," Mr Ansell said.

The Early Years Initiative will be rolled out in four communities and reach thousands of children. It will bring researchers, families, community leaders, government, business and philanthropic organisations together to redesign services and build community capacity to improve the learning and development of children from birth to four years.

"We want to better understand how we can improve outcomes for young children and their families and how this can be effectively applied in different communities.

CoLab Co-Director of Policy Mr David Ansell said the Early Years Initiative would trial,

"We know that early childhood development is complex and this cannot be solved by Government alone - it requires a united effort. The Early Years Initiative will do exactly that."
- Community Services Minister Simone McGurk

"This initiative is about listening to WA families who are best placed to understand the needs of the children and communities, and how services in their local area can be improved. I believe this will result in genuine change."
- Premier Mark McGowan

"Meanwhile, communities want more say in how services are delivered. Governments need to know what works, for whom, and in what circumstances – rather than just providing new and different services. Philanthropists are determined to have greater impact. They all agree that to achieve their separate but related goals collaboration is essential," said Mr Ansell.



How will it work?

Four communities (one each from very remote, remote, rural and urban settings) will be invited to participate.

Communities will be supported by government and researchers to assess the needs of all children and families and develop their own 10-year evidence-informed community plans. The WA Government has committed to re-design services to align with the plan, and researchers will work with communities both in developing the plan and providing a rapid assessment of new programs and initiatives. The whole Initiative will be supported by a board with representatives from the State Government, Minderoo Foundation and Telethon Kids.

Why do it?

This Initiative is needed for a number of reasons. Most importantly, despite significant investment in the early years, the developmental gap between children living in high and low socioeconomic areas has widened since 2009.

In Australia, one in every five children is considered developmentally vulnerable. These are children whose health, social competence

or language skills are at a level that makes them less likely to join their peers 'school ready'.

Secondly, researchers have tended to focus on the environmental conditions children need for optimal development (attachment, cognitive stimulation); and not on how to create these environments for every child.

Thirdly, perhaps the most ambitious of all goals, the evidence shows a strong connection

“The Early Years Initiative is an opportunity to bring long-term thinking and innovation to an important social challenge.

Minderoo is making a commitment to invest in our children and deliver the state a significant generational dividend in the future.

This type of long-term investment is exactly the role philanthropy can and must play.”

- Nicola Forrest

between the income of families and child development status. Importantly, research has shown that population-level outcome change for vulnerable children will not result from the implementation of a single program, but rather from a portfolio of services and community programs tailored to suit the needs of communities.

What does this mean for research?

The Initiative will test and provide innovative ways to get research into the hands of those who need it most – policymakers, practitioners and parents – in real time.

Researchers will need to work in different ways, providing rapid assessment of what appears to work with which groups; to help adapt what doesn't work; and then translate and communicate these findings to external stakeholders. This process will be developed to build stronger bonds with policymakers.

Will it achieve its bold goals?

Only time will tell, but this Australia-first project is off to a good start. Research, philanthropy, and Government have been able to work together to produce a coherent integrated plan within six months, using what evidence shows are the key ingredients for success.



WHAT'S NEXT

CoLab will:

- Work with Early Years Initiative partners to invite four communities to take part in the Initiative. What we learn from the Initiative will be shared and used to improve early childhood practices across the State.
- Bring together the major voices in early childhood development in Australia, to collectively develop a 'core story' to enhance the public understanding and confidence to act to support young children and their families – especially those experiencing adversity. An ongoing public awareness campaign will be delivered in 2018 and 2019.
- Develop a ground-breaking app to provide parents and caregivers with tailored brain-building information and skills building.
- Launch the pilot Child Development Atlas, the first resource of its kind in Australia to bring together and map in one place a range of data sources that are specifically focused on children's development. The atlas will provide easy access to comprehensive information on the development and wellbeing of children and young people in each Western Australian community.
- Continue working with leading national and international economists to develop a systematic Cochrane-type Review that will encompass multi-sectoral evidence to support investment in the early years, and develop a measure that will combine cross-sector approaches to assess return on investment in the early years.



CoLab was made possible by Minderoo's founding commitment of \$1million annually.

SETTING RESEARCH GOALS HAND IN HAND WITH THE COMMUNITY

The Telethon Kids Institute has long been recognised for the research it produces. But the way the Institute collaborates with the community – asking what they most want or need to know about and tailoring research to deliver those outcomes – is also leading the way.



In April, Western Australia finally got something it had long needed – a formal health policy designed specifically for its young people.

The WA Youth Health Policy 2018-2023, launched by Minister for Health Roger Cook at the Telethon Kids Institute, came after a long process of consultation with the very people it affected most – young people who in the past have sometimes struggled to find health services that would treat them with respect and provide honest and understanding advice.

The policy aims to benefit the health and wellbeing of young people and to help others, including families and carers, community/advocacy groups, and health professionals, contribute to better outcomes for youth.

Its development came with significant help from the Telethon Kids Institute, including members of the Consumer and Community Health Research Network, who facilitated a series of community conversations with young people across WA to find out what was important to them.

Network Head Anne McKenzie said all up, her team spoke with 122 young people in Perth, Bunbury and Broome.

“The kids were amazing, the things they came up with,” Ms McKenzie said.

“They really identified gaps about where to go for credible information, the one-stop-shop and having youth-friendly services available.”

It was not the first time the Institute had asked

young people to guide its work priorities. The Telethon Kids Youth Advisory Group was formed in 2016 after the Institute’s leadership team realised there was limited input from young people informing their research priorities.

The group, made up of 23 young people aged 15-25 years, helped develop the questions to be asked during the Youth Health Policy community conversations process.

The new policy identified areas for improvement including better access to services, building knowledge and promoting participation, achieving equitable health outcomes, collecting comprehensive data, and building skills for effective interactions with young people.

The Telethon Kids Institute currently has 298 community members sitting on decision-making committees.

“It’s the way business is done at Telethon Kids, but it’s quite different to the rest of the country,” Ms McKenzie said.

Other research groups at Telethon Kids also have major collaborations with consumers, with FASD Research Australia Director and Senior Principal Research Fellow Professor Carol Bower in particular a champion of community involvement in research about alcohol in pregnancy and fetal alcohol spectrum disorder (FASD).

Professor Bower and colleagues established a national Community Reference Group as an integral part of their Centre of Research Excellence (FASD Research Australia). In

“It’s the way business is done at Telethon Kids, but it’s quite different to the rest of the country.”
- Ms Anne McKenzie



Ms Anne McKenzie and Professor Carol Bower

“The public are ultimately paying for this research, and it’s about them, and often on them.
We should be involving them in it to make sure that we do it in the right way and find out the things they want to know.
It’s the right thing to do.
That’s been my motto.”
- Professor Carol Bower

collaboration with the Reference Group and the Consumer and Community Health Research Network, they engaged in a priority-setting partnership to find out what members of the public across the country wanted from research in this area.

“We really wanted to engage with people, consumers, across the country to find out what they thought was important in research about alcohol in pregnancy and FASD,” Professor Bower said.

“Researchers have their ideas and can sometimes go off on a tangent without really necessarily understanding what the community might want to know. What’s important to the community might not be as high on the researchers’ list.”

Through national surveys and a consensus workshop, community participants arrived at



Members of the Consumer and Community Health Research Network and Youth Advisory Group

YOUTHFUL VOICES HAPPY TO BE HEARD

Twenty-year-old Emma Wignell, a proud member of the Telethon Kids Institute Youth Advisory Committee, was one of the dozens of young Western Australians involved in the community conversations which helped shape the State's first Youth Health Policy.

"We want to be included, we want to be consulted and we want to be listened to. "(Being involved meant) we could make sure that what was being developed was what young people really want and need.

Ms Wignell said the process had given young people a voice in the preparation of the policy and ensured they had input into the way the health system worked.

I think all the young people I know who were involved in the community conversations agreed that it was really important."

"I think it's incredibly important," she said. "I've done some work for local government, and it was amazing to see how disconnected some policies and plans were from the people they wanted to implement them for."

"We want to be included, we want to be consulted and we want to be listened to.

"(Being involved meant) we could make sure that what was being developed was what young people really want and need.

I think all the young people I know who were involved in the community conversations agreed that it was really important."

- Emma Wignell

Ms Wignell, who is studying population health at The University of Western Australia, said she had discovered services out there she hadn't even known existed.

"But there were also gaps in terms of accessibility," she said. "Encouraging places to open at different times of the day and to advertise more in social media and the spaces that young people are actually in was important.

"There are so many services being funded, but if you don't have young people actually using them, what's the benefit in that?"

She said young people who were given the chance to be involved and contribute ideas and thoughts to the development or delivery of a program were more likely to engage in the end product.

their top 10 priorities for research on alcohol use in pregnancy and FASD.

"The public are ultimately paying for this research, and it's about them, and often on them. We should be involving them in it to make sure that we do it in the right way and find out the things they want to know. It's the right thing to do," Professor Bower said. "That's been my motto."

It turned out the community wanted more research on understanding societal views and beliefs about alcohol use in pregnancy. Seven of the top ten topics related to healthy pregnancy or prevention of prenatal alcohol use – areas that researchers will explore further.

Ms McKenzie said the consultation represented a good practice model of involvement, with the method being used and further refined for other areas of research.

WHAT'S NEXT

- Researchers want to find ways to measure the impact of community involvement in research.



The Youth Advisory Group (Emma centre)

COMMUNITY COLLABORATION ENSURES ENDING RHD IS EVERYBODY'S BUSINESS



Collaboration is the driving force behind 'END RHD Demonstration Communities' – a new community-driven, research-backed approach to tackling rheumatic heart disease (RHD) in remote Australia.

A completely preventable disease, RHD is caused by an abnormal reaction to Strep A infection of the throat and skin, and can lead to permanent disability and premature death.

In Australia, RHD occurs overwhelmingly in Aboriginal and Torres Strait Islander communities, with 6,000 people already living with the disease and 400,000 thought to be at risk. Young Indigenous Australians are 55 times more likely to die of the disease than their peers.

Funded by the *END RHD Centre of Research Excellence (END RHD CRE)* based at Telethon Kids, and run in partnership with Menzies School of Health Research, the END RHD Demonstration Communities work with remote Indigenous communities at highest risk of the disease to deliver tailored, culturally-appropriate strategies that address both the prevention and management of rheumatic heart disease and acute rheumatic fever (ARF).

Dr Rosemary Wyber, general practitioner and Head of Strategy for END RHD, said the project differed from other established RHD control programs, which were largely clinic-based and focused solely on treatment of the disease.

"Central to the project is the leadership of Aboriginal Community Workers who live in communities with a high burden of RHD," Dr Wyber said.

"We are working with those community workers to raise awareness about how to prevent Strep A infection, as well as to help those with ARF and RHD navigate the healthcare system and

other service providers."

The project, currently in its pilot phase and active in two communities in the Northern Territory, aims to create an effective, comprehensive, cross-sectoral model of care to be rolled out across Australia in other communities with high rates of RHD.

Associate Professor Anna Ralph, who is leading the project at the Menzies School of Health Research, said this approach was exciting because it is the kind of model Aboriginal people have been asking for.

"Our research to date shows how fundamental community engagement is for effective delivery of care, yet it's not possible to do this effectively by reaching out from the clinic, it needs to be a grass-roots initiative starting with and driven by community members themselves," Associate Professor Ralph said.

She is working with project manager Angela Kelly, who travels regularly to participating communities to support the Aboriginal Community Workers.

Ms Kelly said creating a community-led model of care was pivotal to ending the disease.

"Take for example, complexities around local language," she said. "Germ theory as causation of disease is a difficult concept to

translate, so Aboriginal Community Workers play the critical role of being able to explain the best way to prevent contracting a Strep A infection in the local context."

Ms Kelly said for many people living in remote communities, sore throats and skin sores were commonplace, and since it took only one case of acute rheumatic fever to cause the irreversible heart damage known as RHD, the stakes were high.

"Central to the project is the leadership of Aboriginal Community Workers who live in communities with a high burden of RHD,"
- Dr Rosemary Wyber



Community members Tanya and Zenikki

"This project is so important because skin sores and sore throats in these communities have been normalised – but they're not normal. They can have serious complications, and they need to be treated," she said.

Given that preventing Strep A infection requires people to have access to appropriate health and hygiene infrastructure – in turn helping to close the gap in Aboriginal and non-Aboriginal health outcomes – those involved in the project hope its benefits will stretch beyond simply tackling RHD.

"This model can address a lot more than just rheumatic heart disease. Knowledge of working health hardware and hygiene practices can help prevent other serious streptococcal infections and trachoma," Ms Kelly said.

"Our research to date shows how fundamental community engagement is for effective delivery of care, yet it's not possible to do this effectively by reaching out from the clinic, it needs to be a grass-roots initiative starting with and driven by community members themselves,"

- Associate Professor Anna Ralph

Importantly, she said, the community is advocating for these basic rights.

"Recently, one of the Aboriginal Community Workers was told that someone at high risk of rheumatic fever recurrence in the community had no access to hot water. The worker went straight to the Department of Housing representative in the community and said it needed to be fixed – and the next day, it was."

Ms Kelly said feedback from the communities taking part in the trial had been positive and there had been an improvement in awareness.

"In one of the local schools, enthusiasm for the project has been huge – so much so that kids want to make a video to support children in other communities to

Project participants Marius and his mother Tracey

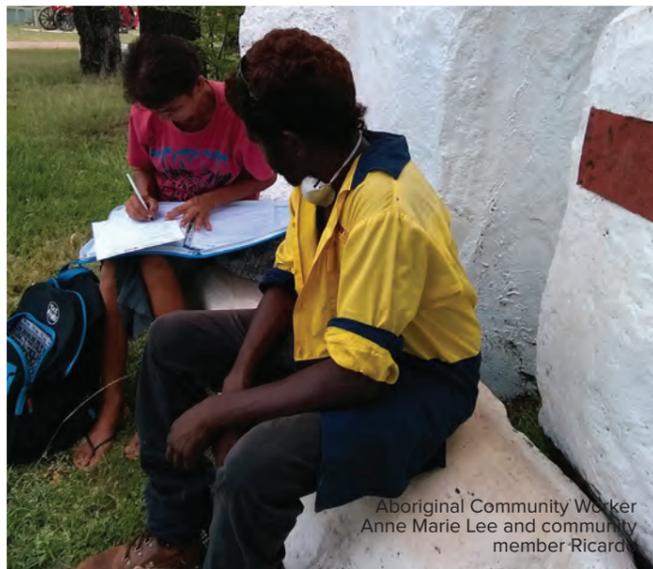


learn more about RHD, and what they need to be doing to help reduce their risk.”

Beyond the communities, support for the model has been widespread. At the RHD Roundtable convened by Indigenous Health Minister Ken Wyatt in February, the community-led approach was broadly endorsed by the Aboriginal Community Controlled sector, researchers, jurisdictional health department representatives, peak bodies, and Commonwealth Government representatives.

“At the end of the day, health is everyone’s business, and that’s why the development of this community-led initiative is so important,” Associate Professor Ralph said.

By channelling the power of collaboration between community and research, we can make ending rheumatic heart disease everyone’s business.



Aboriginal Community Worker Anne Marie Lee and community member Ricardo

WHAT'S NEXT

- Ongoing capacity building, engagement, and data collection in the pilot communities in order to understand how the model can be optimised further.
- Planned expansion of the program to new communities, in conjunction with partners.
- Presentation of the END RHD CRE ‘Endgame Report’ to the Commonwealth Government in 2020, which will outline a comprehensive plan to eliminate RHD in Australia by 2031.

This project is made possible thanks to funding for the END RHD CRE from the National Health and Medical Research Council, and a Vanguard Grant from the Heart Foundation.



An aerial shot of one of the END RHD Demonstration Communities in the Tiwi Islands

Photo by Allan Laurence

HOW TO WIN FRIENDS AND INFLUENCE PEOPLE: CANCER RESEARCHERS TALK THE TALK FOR BIG RESULTS

Being a researcher isn't just about working in a lab. A significant part of the role involves talking to people: communicating with other research teams and lobbying policy-makers and funding organisations so resources can be devoted to key areas.



In the field of cancer research, lobbying efforts by the Telethon Kids Cancer Centre have contributed to major initiatives including Australia's first personalised medicine program for children with high-risk cancer, and a mission to boost survival rates in brain cancer patients.

Co-head of Brain Tumour Research at the Telethon Kids Institute, Brainchild Fellow Dr Raelene Endersby, said that if researchers are to succeed in influencing policy decisions or funding priorities, it is essential they make decision-makers aware of the huge impact childhood cancer has on the community.

"We firmly believe that research and the application of our discoveries in clinical practice will be what creates change for our patients in the future," Dr Endersby said. "In order to get this message through to the government, we joined forces with colleagues across Australia and with families affected by childhood cancer, and collectively engaged with decision-makers in Canberra to communicate our vision, how we planned to achieve it and what the outcomes would be."

Dr Endersby said the Zero Childhood Cancer program had initially only been funded in NSW – a decision overturned after a spot of determined lobbying.

"By working together, we were able to convince the Government to upscale the program to a national level and ensure that every child in Australia, regardless of where they live, will be able to access the program," she said.

"Personalised or precision medicine isn't a far-fledged, futuristic goal – it is happening already."
- Dr Raelene Endersby

The Zero Childhood Cancer program will enable scientists from 13 research institutes including Telethon Kids, along with doctors from Australia's various children's cancer centres, to work together to identify new treatment options for children with the most aggressive cancers – whose chance of survival on standard treatments is less than 30 per cent – or for children whose cancers fail to respond to treatment.

The program recognises that each child's cancer is unique, so it is hoped that detailed laboratory analysis of cancer cells will help identify the drugs most likely to kill each child's specific disease.

About 25 West Australian children will be among the 250 children enrolled in the program nationwide, and data will be shared with the clinical and research partners in Australia, the United States and Europe.

"Personalised or precision medicine isn't a far-fledged, futuristic goal – it is happening already," Dr Endersby said.

"With the right information, we should be able to personalise the treatment using each patient's genetic information. The ultimate result will be that physicians will be able to select the most effective cancer treatments specific to each unique cancer, then define the right dose for each individual child. We believe this approach will push the survival rate upwards towards 100 per cent while at the same time reduce toxic side-effects.

"In the case of brain tumours, we might know of a good drug to target a protein within a brain cancer but

we can't actually get the medicine into the brain, so we need to find other approaches."

Dr Endersby said collaboration was vital in cancer research.

"Childhood cancer is rare, and there are many different types of cancer that affect children," she said. "We simply wouldn't be able to make significant discoveries if we only studied the patients we see locally.

"To make those important discoveries, we have to study as many patients of each cancer type as possible. Therefore it's a no-brainer that we are more effective working together both nationally, internationally, and across culturally diverse communities.

"Communication amongst researchers is essential. To reduce duplication and make inroads faster, we need to be constantly aware of what our colleagues are doing."

Dr Endersby said funding from government and philanthropic sources was also essential.

"Our work simply cannot rely on government funding alone, there just isn't enough money in the budget dedicated to medical research, and even less is directed towards cancer research in children.

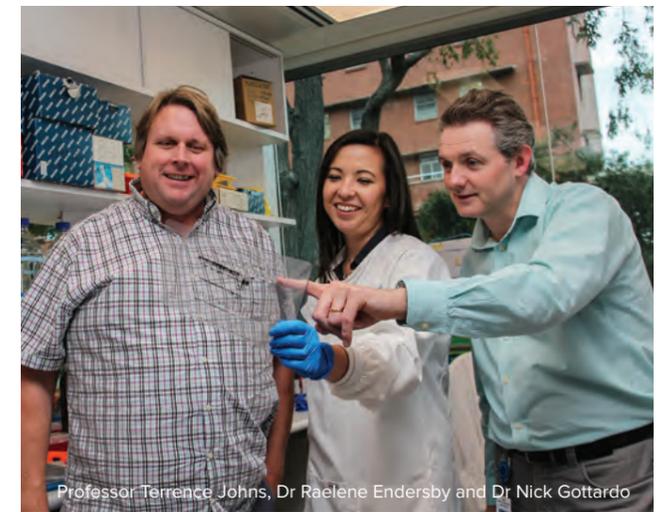
"Almost all large-scale research projects in childhood cancer have been initially supported to get started and off-the-ground by philanthropic funding. We then use the data we generate to convince other funding agencies to get on-board to help expand the work and realise its full potential."

Another huge project Telethon Kids researchers are involved in is the \$100 million, 10-year Australian Brain Cancer Mission – funded by the Federal Government and other organisations including Minderoo Foundation's Eliminate Cancer Initiative.

It seeks to consolidate national research, clinical and funding efforts in a bid to double survival rates and improve quality of life of people for living with brain cancer.

Last year, Telethon Kids Cancer Centre Head Professor Terrance Johns appeared before the Senate Select Committee into Funding Research into Cancers with Low Survival Rates, to provide expert opinion on the state of brain cancer research in Australia.

Following his testimony, he was invited to be part of a roundtable that devised the roadmap for the Brain Cancer Mission, including the priorities of how the money



should be spent to improve survival rates.

Professor Johns said a significant proportion of the funds would be spent on paediatric brain cancer, leading to improved survival in these young patients.

With brain cancer killing more Australian children than any other disease, he said a key objective was to ensure every patient had the opportunity to participate in clinical trials.

WHAT'S NEXT

- With money allotted to clinical trial groups to ensure Australians can be part of international trials, patients here will have access to trials not previously available.
- The Zero Childhood Cancer program will generate a huge amount of new data, which will be shared and combined with data generated by overseas collaborators – providing an invaluable research repository for the future.
- Telethon Kids researchers expect to gain insights into the underlying genes that drive the formation and growth of various childhood cancers, and the most effective ways to apply treatments that target these drivers in individual children. They will then be better placed to define the best treatments for children with cancer.



The Children's Leukaemia & Cancer Research Foundation has supported our cancer research program for three decades.

DATA GOLDMINES YIELD PRICELESS BREAKTHROUGHS

Child health and development researchers are increasingly turning to Western Australia's extensive population datasets for their ground-breaking work.



As a vital research tool, data linkage connects pieces of information that are thought to relate to the same person, family or event, in a way that does not breach their privacy.

These data cover a spectrum of life experiences from birth and death, early childhood development, education and hospital admissions, to electoral, housing and justice records.

Over the years, WA's linked data have supported a range of population health research that has changed public policy, improved clinical practice and delivered better patient outcomes.

This increased reliance on data for research, here and elsewhere, is one of the factors that in May this year, prompted the Federal Government to announce a raft of data reforms, including the creation of a national data commissioner role.

It was a move welcomed by Telethon Kids Institute Patron Professor Fiona Stanley, who said Australia's data was a major national resource.

"These reforms will provide better opportunities for innovation in the medical sector, as well as improve our ability to stay at the forefront of medical research and innovation, while protecting individual privacy," Professor Stanley said at the time.

"The ability to share data across government agencies at both a Federal and State level will enable more rigorous evaluation of services and allow us to truly develop evidenced-based policies to improve health."

"The ability to share data across government agencies at both a Federal and State level will enable more rigorous evaluation of services and allow us to truly develop evidenced-based policies to improve health."

- Professor Fiona Stanley

The Telethon Kids Institute's Linked Analytics and Social Policy Team has been a key participant in the pioneering process of linking de-identified longitudinal, population-based data collected by the Institute, NGOs and government agencies, to create a valuable research resource which in turn informs government decision-making and policy planning.

The landmark Developmental Pathways Project (DPP) was set up in 2005 to investigate the factors leading to differences in developmental outcomes, and the pathways to problems such as juvenile offending, child abuse, poor physical and mental health outcomes, and student absenteeism.

Linked Analytics and Social Policy Team head Dr Rebecca Glauert said the DPP was instrumental in the linkage of

a large amount of non-health government agency data to health data in WA.

"Through the DPP's collaboration with the Data Linkage Branch at the WA Health Department, and 11 other State government agencies, researchers now have access to linked data from WA Police, Education, Justice, Housing, Child Protection, and Disabilities," Dr Glauert said.

"Data linkage allows researchers to access unbiased data on entire populations. The breadth of data that are available through the linkage of administrative datasets far exceeds the data that could be collected via surveys or other means.

"Population researchers can use the linked data to investigate rare outcomes, as well as common outcomes, for entire populations.



Dr Megan Bell, Scott Sims, Dr Melissa O'Donnell, Dr Rebecca Glauert and Dr Hannah Moore

In addition, they are able to identify the characteristics of individuals who are at risk of certain outcomes – which in turn helps clinicians and government target those people appropriately."

In the 13 years since it began, the DPP has facilitated numerous projects which have shed light on subjects as diverse as attention deficit hyperactivity disorder, traumatic brain injuries, preterm births, alcohol-related harm, and the effects of diet on educational outcomes.

A recent study into the pathways of young people in contact with multiple government agencies aimed to identify the characteristics and patterns of service use by a cohort of young people born between 1994-1997 who had used four government services – child protection, mental health, courts and corrections.

The study found young people in contact with multiple government agencies comprised a relatively small group of clients, but they had a disproportionately high level of service use. About 0.5 per cent had dealings with all four agencies, accounting

"Data linkage allows researchers to access unbiased data on entire populations. The breadth of data that are available through the linkage of administrative datasets far exceeds the data that could be collected via surveys or other means."

- Dr Rebecca Glauert

for 16 per cent of all service contacts. Of those, nearly half were Aboriginal and 64 per cent were male.

The findings highlighted the need for extra resourcing for the early identification and targeting of services at at-risk youth who were likely to become caught up in a 'revolving door' of service use.

Another of the DPP's innovative ideas is the Western Australian Child Development Atlas, which will map a number of important child

CONVICTED PARENTS

Data on parental convictions and early childhood development have been used in a Telethon Kids Institute study that could promote a better understanding of how to respond to the needs of children with convicted parents. These children are currently not adequately supported by child- or adult-oriented services.

The study used linked de-identified administrative data from WA's Department of Justice to determine that 7 per cent of the 19,000 children born between 2003 and 2004 had parents who had served community-based orders or prison terms.

These records were merged with children's scores on the Australian Early Development Census, which measured their physical, social, emotional, communicative and cognitive development.

Lead researcher Megan Bell said the study found that children of convicted parents had a high risk of being developmentally vulnerable across all measured domains, with children of imprisoned parents experiencing even greater risk.

Dr Bell recommended the introduction of standard procedures in Australia to identify children of convicted parents and support their development.

MALTREATMENT VULNERABILITY

A recent Telethon Kids Institute study investigating the risk of child maltreatment across various disabilities relied on records covering more than half a million WA children.

Children with disabilities are three times as likely to experience abuse and neglect, and the study highlighted how different risk levels related to disability types.

The researchers examined linked de-identified records from a number of sources, including Birth Registrations, Western Australian Register of Developmental Anomalies and the Department of Child Protection and Family Support, for 524,534 children born in Western Australia between 1990-2010.

Data analyst Scott Sims, from the Developmental Pathways Project, said children with an intellectual disability, mental health problems or conduct disorders were at highest risk compared to those with autism, Down syndrome, cerebral palsy or birth defects.

The findings indicated that not only was more support needed for families caring for a child with a disability, but those services could be better targeted for the high-risk groups.

development and wellbeing indicators across geographical areas of WA, as well as the locations of various services and programs.

This will help to provide a picture of the overall health and wellbeing of particular communities and assist government with its resource allocation. "The project is currently in the 'proof of concept' phase, involving the development of a pilot Atlas," Dr Glauert said. "This will be demonstrated to stakeholders and end users and feedback sought on the functionality and utility of the Atlas, with feedback informing the development of the full version of the Atlas in the next phase."



WHAT'S NEXT

- The team is currently working on several projects and initiatives to try to increase researchers' access to data. They are also seeking a new grant to expand the DPP to investigate adult outcomes across the life course.

Linking survey data with population datasets like NAPLAN can also provide unique insights.

GRANDPARENTS' EDUCATION

Telethon Kids Institute researchers used data from a long-running nationwide study to determine that the educational level of grandparents has a direct effect on how well a child does at school.

Exploring how educational advantage played out across several generations, they found that grandparents with higher levels of education had grandchildren with higher NAPLAN scores in Year 3.

Lead researcher Kirsten Hancock said children with four or more family members with a diploma or university qualification were two years ahead of students without any highly-qualified family members.

She said the gaps caused by these different family histories presented a significant challenge for schools to overcome. Her team was keen to monitor how these gaps changed as children progressed through school.

The researchers examined data from the Longitudinal Study of Australian Children, which has been collecting information on the educational, health and developmental outcomes of 10,000 children and their families since 2004.



Dr Megan Bell



Scott Sims



Kirsten Hancock

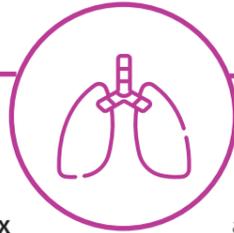


IN THE PIPELINE

*This research is
in the pipeline
towards translation*

IN THE PIPELINE

WATERSHED APPROACH TO IMPROVE CYSTIC FIBROSIS TREATMENT



Telethon Kids researchers are pioneering an exciting new approach to clinical trials, which aims to fast-track the best treatments for people with rare and complex diseases.

In traditional clinical trials, two treatment strategies are assessed at a time – which can needlessly delay improved treatment and quality of life for participants.

Instead, Telethon Kids researchers will try an 'adaptive platform trial' – a type of 'learning health care' model which will allow researchers to learn as quickly as possible which treatments are best, which treatments aren't, and in whom.

Patients with cystic fibrosis will be the first to take part in the Australia-wide platform trial to find improved ways to manage the condition.

Dr Tom Snelling, from the Institute's Wesfarmers Centre of Vaccines and Infectious Diseases, said the BEAT-CF trial would analyse multiple treatments at once in different areas of management to optimise treatment of lung infections, or exacerbations.

"Trials to date have only assessed two treatment strategies at a time, which can delay translating the results into improvements for participants," Dr Snelling said. "This new approach provides a faster, more effective way to assess which treatments are best for particular patients."

A web-based tool, currently in development with Murdoch University, will enable clinicians to readily access patient information, including known allergies and medication lists, and receive recommended treatments for each patient based on computer algorithms that analyse the clinical trial data.

Dr Snelling said patients would also report their symptoms, such as coughing and fatigue, their ability to attend school and participate in sport, the effect on appetite, and the overall burden of treatment.

"We are very keen to capture some of this other information about symptoms so we can make sure that whatever treatments are being promoted through this adaptive process not only improve the function of the lungs but also improves quality of life as well," he said.

Dr Andre Schultz, honorary research fellow at the Telethon Kids Institute and director of the Cystic Fibrosis Centre at the Perth Children's Hospital, where the first patients will be enrolled, is confident that BEAT-CF will revolutionise the treatment of cystic fibrosis.

"We have so many questions around exacerbations that have not been answered with conventional clinical trials," Dr Schultz said.

"If we used conventional randomised-controlled clinical trials to answer these questions, it would take us many decades. So what we're trying to do at BEAT-CF is use a different approach and compare multiple treatments against each other at the same time.

"The web-based platform will allow data entry by clinicians at the bedside, but also by patients. We hope to get patient outcomes collected in real time – telling us how the patient feels as opposed to just what the doctor measures."

Dr Snelling hopes the trial will eventually become accessible to the more than 3,000 children and adults with cystic fibrosis across Australia. He believes a major bonus is that these participants will benefit from better treatments during the course of the trial.

"Because we are always looking at the new data as it is accumulating, we can progressively assign more patients to whatever treatment or combination of treatments are looking most promising," he said. "It means that patients within the trial are more likely to receive the best treatment for them, rather

"This new approach provides a faster, more effective way to assess which treatments are best for particular patients."

- Dr Tom Snelling

than waiting until the trial is over."

It is hoped that BEAT-CF will be used as a leading example of how platform clinical trials can be implemented, so other researchers will be more likely to use novel clinical trial designs for other complex and serious diseases.

As the first WA research project to benefit from the Federal Government's Medical Research Future Fund, the BEAT-CF trial was awarded a \$3.4 million, five-year grant this year. Together with funding from the BHP Blue Sky Awards scheme, this has enabled the preparatory work to begin, such as consulting key stakeholders, fine-tuning the study protocol, refining the algorithms, and finalising the patient subgroups. A philanthropist has sponsored development of the data capture tool for patients.

"We've had all these ideas but you can't take it further without some funding," Dr Schultz said. "It's very valuable for us to get going with this massive project."



What is cystic fibrosis?

Cystic fibrosis is a chronic, life-shortening genetic condition. Physiotherapy, medication, nutrition and exercise all play a role in treatment plans.

People with cystic fibrosis experience recurrent lung infections, which can potentially cause permanent lung damage.

Dr Andre Schultz and Dr Tom Snelling

WHAT'S NEXT

- The first patients are expected to be recruited in 2019 at Perth Children's Hospital and Sir Charles Gairdner Hospital, after which the trial will expand to other Australian sites. "The idea is that this trial doesn't stop, it keeps rolling on and answers more and more questions we have as clinicians so we can improve treatments for patients continuously," Dr Schultz said.
- The platform could also be used to evaluate the new disease-modifying drugs over a longer period of time and look into other aspects of cystic fibrosis management, such as nutrition and psychological needs.



This research is supported by a BHP Blue Sky Award.

CHANGING THE WORLD FOR KIDS ONE BIG IDEA AT A TIME

In 2017, we launched Think Big, the next phase of our research strategy. It's all about big ideas, thinking outside the box and being innovative. Think Big brings together our research teams, collaborative networks of external researchers and health professionals, as well as consumers and community partners to develop ideas which could lead to large programs of research. Two big ideas were chosen and with strategic funding from key partner BHP, researchers are bringing to life these bold ideas that could help solve some of the most pressing child health problems of our time.



THINKING BIG TO TACKLE KIDS' BRAIN DEVELOPMENT



If there's one thing modern researchers and health professionals now understand, it's that for so many diseases and conditions affecting children and adolescents, early intervention is crucial.

Yet for many families with children at risk of problems, a diagnosis can be a long time coming. This is a particular problem for children with neurodevelopmental disorders. Up to 15 per cent of children are affected by neurodevelopmental disorders such as autism, fetal alcohol spectrum disorder (FASD), ADHD and intellectual disability.

They're conditions which can lead to marked and lifelong difficulties, affecting cognition, language and speech, motor skills, behaviour, learning, and executive function (which refers to the ability to plan, pay attention, remember things, prioritise and undertake tasks).

Currently the diagnosis of such disorders depends on the assessment of behavioural symptoms that don't start to emerge until 2-3 years of age. As a result, children are often not diagnosed until they reach school age – several years beyond the ideal window for intervention.

According to Telethon Kids researcher Dr Amy Finlay-Jones, being able to identify kids at risk of neurodevelopmental disorders as early as possible – between birth and two years of age – has the potential to make a significant difference to their developmental outcomes.

"That's because this is a period of peak neuroplasticity, when babies' brains are rapidly growing and forming new neural connections," Dr Finlay-Jones said. "We believe that being able to identify and provide support for kids and families during this time will give them the best chance of positive outcomes now and in the future."

"Waiting until kids are diagnosed when they're five or six years old means we miss this critical

window and it can be a very stressful and uncertain time for kids and their families."

Enter Think Big, a BHP-funded research scheme initiated by the Telethon Kids Institute in 2017 to encourage researchers from different disciplines to work together to tackle bold and relevant questions around child health and development.

Just as importantly, the scheme aims to provide the structural support researchers need to get their ideas off the ground and successfully apply for a shrinking pool of research funding.

To win Think Big support, researchers had to come up with big ideas for new research programs that were highly collaborative, combined the expertise of the Institute's diverse research teams, and were likely to have a high impact.

More than 20 big ideas were submitted, eventually coalescing into five formal proposals. Of these, two were chosen late last year to receive prioritised support in 2018 – \$100,000 in seed funding per project, plus a shared project manager to help plan a formal research program and develop the large-scale grant applications needed to bring it to life.

A proposal led by Dr Finlay-Jones and fellow Telethon Kids researcher Associate Professor Jenny Downs, tackling the issue of early identification and intervention for kids at risk of neurodevelopmental disorders, was one of the two winning projects.

"We want to harness emerging research to find out how early we can identify kids at risk, so we can provide them with early supports that address their individual developmental needs," Dr Finlay-Jones said.

"We want to harness emerging research to find out how early we can identify kids at risk, so we can provide them with early supports that address their individual developmental needs,"

- Dr Amy Finlay-Jones

“We also want to find out what happens for these kids over time – do they go on to develop a neurodevelopmental disorder? Do they stay in a generic ‘at risk’ category and not meet the criteria for a disorder, or do they get back onto a healthy developmental trajectory?”

Dr Finlay-Jones said the BHP-backed scheme gave the researchers a chance to pursue an area of research which might not get funded in traditional ways because of its pioneering nature.

“Most research in this area focuses on a specific disorder (such as autism), whereas what we’ll be doing here is looking across the broad category of kids with multiple forms of neurodevelopmental risk,” she said.

“This allows us to combine big data sets to see what we can pick up on in those early years, and develop early interventions that target individual profiles rather than broad diagnostic categories.

“We are confident that this is a really useful avenue of inquiry but we need this money in order to collect and synthesise the relevant data. We believe this will make us very competitive for future funding.”

Associate Professor Downs said one of the best things about the scheme was it brought together multiple researchers with specialist expertise in different areas, allowing them to combine their knowledge to work on this common and important problem. The project includes



Dr Jenny Downs and Dr Amy Finlay-Jones

“We also want to find out what happens for these kids over time – do they go on to develop a neurodevelopmental disorder? Do they stay in a generic ‘at risk’ category and not meet the criteria for a disorder, or do they get back onto a healthy developmental trajectory?”

- Dr Amy Finlay-Jones

researchers from the Autism, FASD, and Child Disability research teams, as well as researchers working in immunology and precision medicine.

Associate Professor Downs said the \$100,000 grant was a significant chunk of seed funding, while the addition of a project manager would help to keep the team on track.

“We think if we can develop this into a really big program of research it will completely

revolutionise the way vulnerable kids can develop and build their future lives,” she said.

“It will change it from a situation where they’re either not diagnosed or misdiagnosed until they’re aged five or six, to a situation where we can identify kids at risk and start them on a track to healthy development in the very early childhood years.”

WHAT'S NEXT

- The teams behind the two successful Think Big proposals will work with a shared project manager to plan a research program likely to attract large-scale funding.
- The Institute's Research Development staff will continue to work with the remaining three proposals which emerged from the ideas submitted to the Think Big scheme, with the aim of further developing their ideas into fundable large research programs.



These research projects are supported by BHP Think Big Awards.

DIRECTING IMMUNE DEVELOPMENT TO CURB SKY-ROCKETING DISEASE

Once upon a time it was infectious diseases like polio, measles or tuberculosis that most worried parents. With these threats now largely under control, parents face a new challenge – sky-rocketing rates of non-infectious diseases such as asthma, allergies and autism.

Collectively known as non-communicable diseases, or NCDs, non-infectious conditions including respiratory, allergic, metabolic, neurodevelopmental and mental illness disorders are impacting our kids more than ever before, and now make up the majority of the childhood disease burden.

It's now recognised that virtually all NCDs have their origins in early life, at a time of heightened developmental plasticity – and it is here that researchers will hunt for answers as part of the second Think Big proposal chosen to receive prioritised support in 2018.

A large team made up of scientists from multiple research groups at the Institute will come together to investigate immune development as a way of understanding and tackling NCDs.

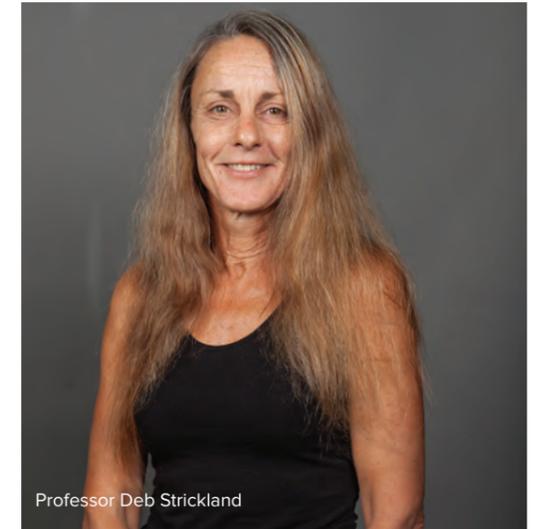
Lead investigator Associate Professor Deb Strickland, Head of the Institute's Experimental Immunology team, said there was growing understanding that impaired immune development likely played an important role in NCDs which had not been previously recognised as having an immune component.

“Immune development is shaped both by a child's genetics and the sum of their beneficial and harmful environmental exposures,” Associate Professor Strickland said.

“We plan to use cutting-edge techniques to create an ‘immune development atlas’ which will map how environmental and genetic factors are

“If successful, this project will revolutionise our understanding of the early origins of non-communicable diseases, and has strong potential to identify new early interventions.”

- Associate Professor Deb Strickland



Professor Deb Strickland

linked with variations in immune development during the first 1000 days of life, and how these are in turn linked with different risks for NCD onset.”

The researchers plan to look for links between immune development and asthma, allergy and obesity – fields in which they have a track record of success. In collaboration with relevant experts (including the other Think Big group receiving support in 2018), they will continue to expand their focus to address the other most common NCDs afflicting Australian kids – one such study looking at links between immune function and autism is already underway.

The proposal's co-investigators are Dr Anthony Bosco, Head of the Systems Immunology Team, Dr Shelley Gorman, Head of the Cardiometabolic Sunhealth Team, and Associate Professor Alex Larcombe, Head of the Respiratory Environmental Health Team, with researchers from other teams at the Institute joining as the project expands.

“If we can determine how to promote healthy immune development, we can develop new personalised prevention and treatment strategies to reduce the impact of NCDs in Australia and beyond,” Professor Strickland said.

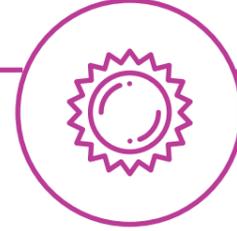
“If successful, this project will revolutionise our understanding of the early origins of non-communicable diseases, and has strong potential to identify new early interventions.”

“This is clinically significant and an example of where UV is not all bad.”
- Professor Prue Hart



Professor Prue Hart

UV OFFERS NEW HOPE IN FIGHT AGAINST MS



People at risk of developing multiple sclerosis (MS) have been offered a beacon of hope thanks to research into UV exposure.

Led by Telethon Kids Institute researcher Professor Prue Hart, a trial delivered narrowband Ultraviolet-B treatment to a small group of people with Clinically Isolated Syndrome, who had shown a first sign of the disease but had not yet progressed.

Half of the 20 participants received the UV-B phototherapy three times a week for eight weeks. Of those, 30 per cent had their progression of MS halted. All those who did not receive phototherapy went on to develop MS.

Professor Hart, Head of the Institute's Inflammation team, said it was the first time the therapy – an effective treatment for people with the skin condition psoriasis – had been shown to delay MS in high-risk people.

“This is clinically significant and an example of where UV is not all bad,” she said.

“We've been too strict with the messaging around exposure to the sun and people are not getting enough UV exposure because of a fear of skin cancer.”

She said further studies were needed to determine the balance between the risks and benefits of sun exposure.

Professor Hart has been studying the effects of ultraviolet radiation (UVR) on health for the past two decades and hopes to translate the work she has done into innovative approaches for patient treatments.

With mice studies having shown that UVR can regulate immune responses, she believes phototherapy may also help people who have had a stroke or type 1 diabetes.

“As UVR exposure is proposed as an immunosuppressive, the results are relevant for all autoimmune conditions,” she said.

It could also signal that MS patients may be advised to get more sun exposure. Vitamin D supplementation trials for MS and many non-skeletal disorders had not shown the reduced disease progression that was hoped for.

Professor Hart said the findings from the small-sample trial had been received with excitement in Scotland, where researchers were heading into a replication study.

“We've been too strict with the messaging around exposure to the sun and people are not getting enough UV exposure because of a fear of skin cancer.”
- Professor Prue Hart

“Scotland is an ideal place for follow-up, as there are more cases of MS there and background UV radiation exposure is low,” she said. “The further one lives from the equator, the less ambient UV and the higher the incidence of MS.”

Professor Hart said for patients showing early signs of MS, UVR was a good alternative to strong disease-modifying therapies that could have side effects.

Researchers also took blood samples to find markers to understand why some people developed MS.

“We have a very extensive ongoing program studying changes in biobanked blood cells and serum,” Professor Hart said.

“Do they tell us something about disease progression from pre-MS to MS? The studies are important as it is very rare to have studies of drug-naïve pre-MS individuals. Most investigators study patients once diagnosed with MS, and their progression from a relapsing-remitting phase to progressive disease. Importantly, our participants are totally drug-free.”

WHAT'S NEXT

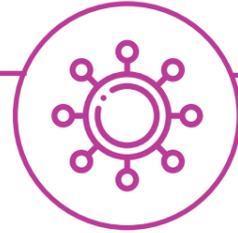
- Studying the biobanked blood samples. “We are not only studying pre-MS to MS progression but also how does UV exposure affect immune cells even if they are unrelated to MS disease. Perhaps what we identify may be related to other conditions.”

What is MS

MS is a condition that affects the central nervous system - the brain, spinal cord and optic nerves. It can cause problems with muscle control, balance and vision.

It is the most common neurological disease in young adults and is more common in women.

'NATURAL KILLERS' POTENTIAL NEW CANCER WEAPON



Doctors are well aware that cancer treatment can be a double-edged sword, particularly for tiny patients like babies and young children.

Although chemotherapy can be highly effective at destroying cancer in kids, it is also toxic and can leave them with life-long problems including cognitive problems or health issues like diabetes.

The Cancer Immunology team at Telethon Kids is investigating how the body's 'natural killer' cells can be harnessed to fight cancer – whilst also protecting kids from nasty chemotherapy side effects.

Telethon Kids cancer researcher Dr Bree Foley said the main advantage of using cellular therapy to treat cancer in kids was that cancer patients would receive less exposure to chemotherapy and other drugs.

"Conventional cancer treatments are still very toxic," Dr Foley said. "This is particularly true of brain tumours – patients receive radiation to the brain and will often have cognitive problems for the rest of their lives.

"We need to have better, safer and more effective treatments for childhood cancers."

Dr Foley's latest research, still at the pre-clinical stage, focuses on engineering a type of immune cell known as a natural killer or 'NK' cell.

"They're called natural killer cells because they're exactly that – immune cells that have naturally evolved to eliminate cancer in the body," Dr Foley said.

This new cellular therapy using NK cells will be able to be used to treat many more patients than the existing T-cell immunotherapy – which involves taking immune cells from the patient, engineering them in the lab so they can recognise cancer cells, making up a huge army of these T-cells, and then infusing them back into the body to fight the cancer.

Dr Foley said while the clinical response rates for T-cell immunotherapy were over 90 per cent, not all patients could have their immune cells harvested for the treatment.

"Previous cancer treatments the patient might have received, such as chemotherapy or other drugs, have often damaged their immune cells too much, so we can't engineer their T-cells to fight the cancer," she said.

"In the cases of little babies who are diagnosed with leukaemia, they don't have fully developed immune systems yet – so they don't have the T-cells to donate."

Using NK cells overcomes this problem, as these cells are readily taken from the blood and can be transferred from a healthy person to the patient.

"The goal with NK cell therapy is to have an off-the-shelf approach," Dr Foley said.

"We could create a bank of donated NK cells that are engineered to target the cancer, waiting in the freezer, ready to use to treat a patient as soon as the cancer is detected."

WHAT'S NEXT

- The team is looking at the application of these therapies to treat blood cancers like leukaemia and lymphoma, but Dr Foley says this kind of cellular therapy can potentially be used to treat any kind of cancer.
- At the moment, only patients who have exhausted all conventional treatments receive immunotherapy treatments, by which stage their immune cells are usually too damaged to use. Dr Foley hopes the team's research will show that, by bringing cellular therapy up in the treatment schedule, remarkable results are possible.
- The first phase of clinical trials of NK cell therapy is expected to be in about four to five years.

Amazing Aroha

BRINGS COMFORT TO OTHER SICK KIDS

Emma White, a registered nurse, suspected for several months that something was wrong with her 7-year-old daughter Aroha, but couldn't get answers despite visiting numerous GPs.

"Aroha had been very ill with asthma and the common cold," Ms White said.

"She started to get fractures, and in the lead-up to me taking her to the hospital we saw numerous GPs as well as the local ED."

By the time Aroha was admitted to hospital, she was yellow and her mother knew her liver wasn't working.

"When she was admitted into Princess Margaret Hospital in October 2016, I was told she was in a critical condition – her platelets and haemoglobin levels were at nothing."

Aroha was diagnosed with acute lymphoblastic leukaemia, and is now a year-and-a-half into a two-and-a-half year chemotherapy regime. The treatment has come at a cost, with Aroha suffering other complications.

"She has diabetes due to the treatment and both her vision and hearing has been impacted," Ms White said.

These are side effects Dr Bree Foley believes could be reduced by the kinds of cellular therapy treatments she is currently working to develop. Such treatments could eventually reduce toxic chemo treatments, she said, in turn leading to fewer

"Training the immune system to treat cancer is revolutionising treatments for kids with cancer. In our lab we hope to continue to find better and more effective ways to fight cancer and limit the collateral damage current treatments cause."

- Dr Bree Foley

adverse impacts on kids like Aroha.

"Training the immune system to treat cancer is revolutionising treatments for kids with cancer," Dr Foley said. "In our lab we hope to continue to find better and more effective ways to fight cancer and limit the collateral damage current treatments cause."

After spending Christmas 2016 as an inpatient in the cancer ward at PMH,

last year Aroha took on the huge task of sewing 65 Christmas stockings for other sick children who needed to spend Christmas in hospital.

"She's a little powerhouse, that girl," Ms White said.

She said she hoped advances in immunotherapy research would help Aroha and other kids like her.



Bree (centre) with Aroha and her family

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of everything we do



For further information about donating to the Telethon Kids Institute, subscribing to our mailing list or joining us for a tour of our facilities, please contact us on:

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