

Children's Health Queensland

Research Annual Report 2020







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An electronic version of this document is available at www.childrens.health.qld.gov.au/research/our-research/strategy-reports





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Children's Health Queensland pays respect to the traditional custodians of the lands on which we walk, work, talk and live. We also acknowledge and pay our respect to Aboriginal and Torres Strait Islander Elders past, present and future.

Artwork nictured left. Deen Water Lalunii 2010 | Acrylic on canvas | Artist. Danhne de Jersey

In addition to being one of the most active artists in the Western Cape York region, Daphne works as a Senior Indigenous Health Practitioner with Apunipima Cape York Health Council. Lalunji is a Mapoon language name for seaweed. At certain times of the year the seaweed breaks off and covers the beaches, a sign that bream are plentiful.

On the cover: Ten-year-old Harrison Roxby is a participant of a randomised multi-centre study led by Children's Health Queensland that is designed to assess the safety and efficacy of transdermal cannabinoid gel as a treatment for anxiety in children and adolescents (aged 3 to 18 years) with Fragile X Syndrome. Photographer: Rick Guidiotti.

Message from the Chief Executive and Board Chair

Research plays a vital role in protecting and promoting the health and wellbeing of Queensland's children and young people. Children's Health Queensland Hospital and Health Service is committed to embedding research in everything we do, from prevention and early detection of serious childhood illness and injury, to delivering lifesaving treatments, and building sustainable person-centred healthcare systems.

Despite the many challenges of 2020, our researchers have produced outstanding, globally significant results. Studies undertaken by our leading clinician-researchers have advanced the knowledge of infection, respiratory disease, nutrition, oncology, sepsis and mental health in early childhood. This national and international calibre work has contributed changes to international guidelines for antibiotic use in bronchiectasis and chronic cough, revised practices for rotavirus diagnosis for Queensland children, delivered new methods of diagnosing sepsis nationally, and produced insights into how preschool-aged children dealt with changes brought about by the COVID-19 pandemic. Throughout the year, we have also made considerable advances in the growth of research in community health and across agencies. These, and our many other advances, help the continual improvement of disease prevention, diagnosis and treatment for children and young people, as well as the promotion of health and wellbeing equity.

We have made significant progress on strengthening our research and service capabilities by enhancing our support structures and governance frameworks. This work led to the appointment of our first Board Research Committee in May 2020 and the establishment of our Research Council, led by our Director of Research, Associate Professor Andy Moore and including senior clinician researchers and executive leaders in July 2020. The Research Council serves as an advisory body, representing the voice of our research community, working to identify opportunities, and inform and deliver on strategic research priorities.

Our achievements at Children's Health Queensland continue to be supported by strategic partnerships with government, leading universities, health and social services, private and non-government organisations. Together we continue to promote Queensland as a leader of innovative and translational paediatric research. In the past year, our partnership with Children's Hospital Foundation through the Children's Health Research Alliance has focused on building a stronger alignment of research priorities that focus on reducing the burden of disease on the health system and the broader Australian economy. Children's Hospital Foundation also directly supports these priorities through its research grant funding schemes, the purchase of specialist equipment to aid research and clinical care and by investing in, and launching, collaborative research centres. We seek to influence and invest in areas that have the most potential for improvement, in line with the Children's Health Queensland Strategic Plan 2020-2024, and the Children's Health Queensland Research Strategy 2018-2025, and the clinical needs of Queensland children.

As part of advancing our research agenda, we are committed to establishing a statewide Queensland Children's Research Collaborative to help build local capacity and capability, leverage funding, avoid duplication and ensure our research endeavours complement the delivery of child and vouth health services in local communities across the state. In uniting the collective strengths of paediatric research organisations throughout Queensland, we aim to address the needs of Queensland children, young people, and their families to drive improvements in service delivery and evidence-based care.

Our goal remains focused on improving the health outcomes of children and young people. We feel confident that with the advances our researchers have made in 2020, we are well on our way to realising this vision.

Frank Tracey

Chief Executive

David Gow





About Children's Health Queensland

Our vision

Leading life-changing care for children and young people – for a healthier tomorrow.

Our values

Respect

Teamwork, listening and support 'We listen to others'

Integrity

Trust, honesty and accountability 'We do the right thing'

Care

Compassion, safety and excellence 'We look after each other'

Imagination

Creativity, innovation and research 'We dream big'

Our purpose

To improve the health and wellbeing of children and young people through world-class care, research, advocacy and leadership.

Our strategies

We value all people

Creating an inclusive environment where all people feel valued, safe, engaged and empowered.

We generate knowledge and innovate

We build and harness creativity, research, technology and collective expertise to prepare for the future.

We collaborate in care

We work together with a shared purpose to create a connected system of care.

We perform at our best every time

We adapt and improve to achieve sustainable, high-quality outcomes.



Our research strategy

Children's Health Queensland's research strategy is driven by our vision to lead life-changing care for children and young people – for a healthier tomorrow.

Our efforts are guided by the Children's Health Queensland Research Strategy 2018-2025, the Children's Health Queensland Strategic Plan 2020-2024 and informed by the clinical needs of Queensland children, young people, and their families.

We acknowledge research has the potential to create life-changing advances in treatments, prevention, and outcomes for all. That's why our mission is to deliver statewide translational research to drive evidence-based care, service improvement and innovation.

It is through research that we can prioritise care that matters most. We are doing this across three strategic research themes:

- prevention and early detection
- better care, and
- health services and systems research.

We use data insights including population and clinical statistics to track emerging trends and ensure our research is clinically informed, clinically relevant, and clinically impactful. We embed research into day-today clinical care through clinical trials and evidence-based interventions and share our clinical insights to translate research into practice.

Our research strategy is evolving as our programs mature. We are growing our funding and investment and collaborating widely to build research capacity and capability. Our strategic priorities continue to be developed and refined to foster the growth of our expanding pool of nationally and internationallyrenowned clinician researchers.

The breadth and commitment to research at Children's Health Queensland is truly remarkable, with service areas across the organisation undertaking a range of research projects and clinical trials. Highlights from some of our most research-active clinical services and departments are featured in this report.

Our research aim

To inform the development of a statewide integrated, sustainable children's healthcare system that is responsive to contemporary needs and driven by research, evidence and innovation.

Our research vision

To positively change the trajectory of the life of every child throughout Queensland.

Our research mission

In partnership, deliver statewide paediatric translational research that drives evidence-based care, and service improvement and innovation for children, young people and their families.

Research strategy

Prevention and early detection

Better care

Health services and systems research

Building our research leaders, profile and culture AND

Prevent disease and create healthcare for the future building Queensland generations

Take our child health research and health services expertise to the world

Rapidly translate our research into better health outcomes using contemporary approaches including health economics, biostatistics and evaluation techniques



Message from the **Board Research Committee Chair**

In line with the priority role of research to the achievement of Children's Health Oueensland's overall strategy, our Board Research Committee was established to provide intentional strategic oversight of research governance, activity and priorities which form part of our strategic research agenda.

The Committee draws on expertise that already exists across our Board and Executive in the areas of clinical research, collaborative research enterprises. commercialisation structures and applications, and philanthropy. Additionally, the external networks that committee members bring enable new insights and perspectives to be contributed as we continue to build our research capacity with intention.

This report reflects the Committee's oversight contribution to date, and we are excited about the role our research agenda will contribute to outcomes both nationally and internationally.

Heather Watson

Board Research Committee Chair



Message from the Director of Research

Research is a key element in realising Children's Health Queensland's vision of leading life-changing care for children and young people – for a healthier tomorrow. Across the organisation we aspire to generate knowledge and innovate, to find better ways to prevent and treat the health conditions that affect our children. We strive to lead research that is clinically informed, clinically relevant and clinically impactful.

Our strong research focus is embedded in the clinical care we provide.

We explore a range of important factors that influence health and care, and acknowledge health outcomes are not only about medicine, but also social and educational factors. Our widereaching research seeks to reduce the overall burden of disease through a multifaceted approach.

Undeterred by the disruptions of 2020, our world-leading researchers delivered outstanding results, with several research projects and clinical trials transforming treatments for children and young people. This includes our globally significant work in the early detection of sepsis, a condition that leads to death for one child a week in Queensland, and the model of care for adolescents moving from paediatric services into the adult health system for rehabilitation.

Overall, our researchers authored more than 400 journal articles and book chapters, which is a tremendous output for a paediatric hospital and health service. In addition, the Children's Health Queensland human research ethics committee approved 154 studies, reflecting the volume of research activity and our researchers' commitment to finding answers to clinical questions. More than half of these were at the later phases in the clinical trial pipeline,

at Phase III or Phase IV, with the major areas of new activity in oncology, respiratory medicine, neurology and intensive care.

More than 40 new clinical trials opened at Children's Health Queensland in 2020, facilitating Queensland children's access to novel treatments and informing better models of care.

Additionally, more than \$45.6 million of grant funding was awarded to our researchers as Chief Investigators, including more than \$8 million of research income received directly by Children's Health Queensland in 2020.

Throughout 2020 we have seen the incredible impact research has had on global health. The collaborative efforts to characterise COVID-19, determine its genomic sequence, evaluate a range of treatments through clinical trials and develop safe, effective vaccines within one year speaks to the extraordinary achievements researchers can accomplish when they are enabled to do so. The success of COVID-19 research has also highlighted the power of collaboration. Collaboration has always been central to everything we do at Children's Health Queensland, whether it be through the delivery of care or research. Children's Health Queensland is enormously grateful to the host of local, national and international

collaborators we partner with in our research endeavours.

Finally, I would like to thank the Children's Health Queensland Board and Executive for their support of research at our hospital and health service, as well as the tireless efforts of the Children's Health Queensland Research Directorate team who are critical to the delivery of ethical, robust and effective research.

Most importantly, thank you to the children, young people and their families who participate in the research we undertake at Children's Health Queensland – it is with you, and for you, that we seek to improve outcomes through research.

Associate Professor Andy Moore

Director of Research





Performance summary

2020 research highlights

Projects and approvals



human research ethics approvals

Clinical trials



42 new clinical trials

1500+ patients recruited to clinical trials

Grants and research income

\$45.6 million+ grant funding contributed or led by Children's Health Queensland Chief Investigators** \$3.8 million clinical trial income

\$4.2 million+ grant funding received***

Publications and collaborations



400+ published research articles and book chapters in 2020 Collaborated with leading institutions located in

452 cities across

125 countries



Research at Children's Health Queensland

Children's Health Queensland seeks to improve the health and wellbeing of all children through life-changing care, supported by world-leading research.

Our researchers investigate risk and protective factors, treatments and outcomes through collaborations with a range of strategic partners across government, private and non-government health and social services, education and research institutions and organisations.

While our clinical work is focused primarily on improving outcomes for children in Queensland, our research is aimed at improving health outcomes for children and young people globally.

To support our research priorities our Board Research Committee provides strategic oversight, with insights, engagement and leadership from the Children's Health Queensland Research Council.

Children's Health Queensland Board Research Committee

The Children's Health Queensland Board Research Committee was established in May 2020. It provides oversight and recommends strategies to the Children's Health Queensland Board in relation to building long-term collaborations in research and enhanced clinical service delivery founded on sustainable and trusting partnerships with shared vision and value. The Committee helps Children's Health Queensland to build expertise, and guides engagement and collaboration to ultimately position Children's Health Queensland as a world-class health service of national and international significance.

The Committee was founded with eight members, including:

- Heather Watson, Children's Health Queensland Board member (Chair)
- David Gow, Chair of the Children's Health Queensland Board
- Cheryl Herbert, Children's Health Queensland Board member
- Suzanne Cadigan, Children's Health Queensland Board member
- Associate Professor Frank Tracey,
 Children's Health Queensland Chief Executive
- Associate Professor Steven McTaggart, Children's Health Queensland Executive Director of Medical Services
- Associate Professor Andy Moore, Children's Health Queensland Director of Research
- Dr Sandra Pavey, Children's Health
 Queensland Business Manager Research



Children's Health Queensland Board Research Committee, pictured from left to right: Associate Professor Steven McTaggart, Suzanne Cadigan, David Gow, Heather Watson Associate Professor Frank Tracey, Cheryl Herbert, Associate Professor Andy Moore and Dr Sandra Pavey. Photo by Ray Cash.



Centre for Children's Health Research. Photo by Ray Cash.

Children's Health Queensland Research Council

The Children's Health Queensland Research Council is an advisory body, providing senior Children's Health Queensland research clinicians with an opportunity to inform and help deliver our strategic research priorities, in line with the overall health service strategy.

Established in July 2020 with Children's Health Queensland's Director of Research, Associate Professor Andy Moore as Chair, this advisory group includes more than 40 senior clinician researchers representing the full spectrum of clinical services and departments, and members of the Children's Health Queensland's executive leadership team.

Centre for Children's Health Research

The Centre for Children's Health
Research was Queensland's first
integrated research facility dedicated to
generating internationally competitive
research for advances in child and
adolescent health.

Co-located with the state's only tertiary and quaternary paediatric hospital – the Queensland Children's Hospital, the nine-level centre houses wet and dry laboratories, pathology services and clinical research facilities to allow close

collaboration between researchers, scientists and clinical staff, as well as consumers involved in clinical research projects and trials.

The centre promotes collaboration and partnership between Queensland Health, Children's Health Queensland, Queensland University of Technology, The University of Queensland, the Translational Research Institute and Pathology Queensland.

Children's Health Research Alliance

The Children's Health Research Alliance was established in late 2016 as a joint venture between Children's Health Queensland and Children's Hospital Foundation to identify research priorities that align with research and service capabilities of Children's Health Queensland and its partners, and that will positively impact the burden of childhood disease in Queensland.

The Alliance encourages and supports the undertaking of world-class paediatric research in Queensland and especially research that supports the delivery of paediatric services across the state by Children's Health Queensland.

These research activities are focused on evidence-based research priorities determined by the Board of the Alliance in alignment with Children's Health Queensland's research strategy.

The Alliance aims to:

- transform health outcomes for children
- make a major contribution to global research
- build research capacity in targeted research areas; and
- reduce the burden of disease on the health system and broader economy.

The members of the Children's Health Research Alliance Board include:

- Professor Allan Cripps AO, Independent Chair
- Associate Professor Frank Tracey, Children's Health Queensland Chief Executive
- Associate Professor Andy Moore, Children's Health Queensland Director of Research
- Cheryl Herbert, Children's Health Queensland Board member
- Associate Professor Leanne Johnston, Children's Health Queensland nominee
- Rosie Simpson, Children's Hospital Foundation Chief Executive Officer
- Dr Veronica McCabe, Children's Hospital Foundation Director of Research and Grants
- Kenneth (Mac) Drysdale, Children's Hospital Foundation Board member
- Dr Michelle Hannan, Children's Hospital Foundation Board member.

Previous Board members in 2020 include Dr Celia Webby, Children's Hospital Foundation Chief Mission Related Services.

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Ethics and governance

Human Research Ethics Committee and research governance

Children's Health Queensland's Human Research Ethics Committee (HREC) reviews the ethical and scientific validity of proposed research within the Children's Health Queensland Hospital and Health Service and in partner agencies across Australia. Together with researchers, the HREC works to ensure valid research studies are conducted ethically for the benefit of the wider community. This involves protecting the mental and physical welfare, rights, dignity and safety of participants, and promoting highquality and responsible research.

The HREC is certified with the National Health and Medical Research Council to conduct paediatric clinical trials (Phases I to IV), involving drugs and devices, interventional research, other health and medical research, mental health, justice health and paediatric population health research.

The Children's Health Queensland
Research Governance Office assists
researchers with site-specific
assessment application forms and
the application processes for site
authorisation, negotiation of research
contracts, guidance regarding
legislation, policies and standards,
education and training for new and
experienced researchers and monitoring
of research. Of the studies authorised
to commence at Children's Health
Queensland in 2020, approximately
one-quarter were clinical trials.

Through enrolment of participants for national and international clinical trials, Children's Health Queensland has made a significant contribution to the development and testing of novel treatments. These trials have included new drug therapies, surgical procedure innovations, the use of new medical devices or different ways to use existing equipment, treatment combinations, and other adaptations to existing care models.

Human Research Ethics Committee highlights:

Summary of approved projects

Single centre	87
Multi-centre	51
Ethics waiver	68
Total approved	206

Post-approval monitoring

Amendments	525
Safety reporting	172
Annual/final reports	292
Total approved	989

Research governance highlights:

Summary of authorised projects

Clinical trials	42 (23%)
Research projects excluding clinical trials)	95 (77%)
otal of Research Governance Office authorisations*	137

^{*}Reported through Children's Health Queensland Research Governance Office submissions.



Prevention and early detection

Children's Health Queensland has a strong focus on primary and secondary prevention of injury and illness, as well as improving the social determinants of health.

Our areas of study include physical activity, child development including social and emotional wellbeing, nutrition and growth, family health, injury prevention, sun safety, oral health and immunisation, as well as boosting investment in population research and sustainable services. Our research and findings are shared with Queensland Health's Preventative Health Branch, to embed the enhancements in clinical practice.

In 2020 our researchers advanced international understanding of key conditions that affect millions of children and young people around the world. These included three projects each into genomics and infectious diseases, two projects studying neurodevelopmental disorders, and research into immunisation, traumatic stress reactions and diabetes.

A collaboration with our Healthy Hearing Program to conduct tests for congenital cytomegalovirus (CMV) has proved feasible, with health economic investigations continuing into its costs and benefits.

Children's Health Queensland researchers contributed to new management guidelines for paediatric type 2 diabetes, including specific care considerations for Aboriginal and Torres Strait Islander peoples.

Laboratory testing procedures were enhanced following research to reduce false positives and over-diagnosis of rotavirus infections in infants. Through research, vaccine-type rotavirus could be identified, if clinically required, and clinicians could implement effective infection control if the wild-type virus was detected.

In the field of oncology, new consistent guidelines for statewide presentations of febrile neutropenia were created. There is also ongoing national research to improve treatment and outcomes through improved data collection and enhancing processes.



Prevention and early detection highlights

11 research projects

13 publications

1 clinical trial

Across 6 areas of research



Diabetes



Genomic



Infectious



Neurodevelopmental disorders



Traumatic stress reaction



A global leader in paediatric sepsis research

Children's Health Queensland is leading the world in its studies into "silent killer" sepsis. In 2020 alone, our clinician researchers were awarded more than \$2.8 million in overall grants to support their work in improving the diagnosis and treatment of sepsis.

The condition, in which infection can lead to multi-organ dysfunction, is one of the leading causes of preventable death and disability in children. This causes around 500 children across Australia and New Zealand to require lifesupport each year. With its vague and diffuse symptoms, the life-threatening infection can be extremely challenging to recognise and diagnose effectively – costing time that can be critical for children experiencing the cascading infection and potential organ failure. Delays in sepsis recognition increase the

risk of death in this medical emergency.

Our clinicians have played a key role in advancing Queensland Health's Queensland Paediatric Sepsis Project, which aims to generate sustained improvement in the experience and health outcomes of children, young people and families affected by sepsis. The project was awarded the 2020 Global Sepsis Alliance Award, in recognition of outstanding sepsis awareness and education initiatives. The unique, multi-faceted and innovative approach of the project includes, targeted education and support, statewide support systems for local care networks, peer mentoring, telehealth systems, the first paediatric sepsis clinical nurse consultant in Australia, and development of the first multi-centre Paediatric Antimicrobial Stewardship in sepsis research.

Children's Health Queensland also leads Australia's largest paediatric sepsis study, with the goal of using geneexpression testing to reduce the time it takes to diagnose the life-threatening infection. The three-year study was awarded a \$2.4 million grant in 2020 as part of the Federal Government's Genomics Health Futures Mission, funded by the Medical Research Future Fund (MRFF) and supported by Children's Hospital Foundation.

Our additional work in this area includes trialling whether a blood test and genomic sequencing can effectively detect the sepsis-causing bacteria. Personalised testing of blood antibiotic levels is also underway to determine if this can optimise treatments and reduce overuse of antibiotic medications. Investigations into diagnosis and treatment of the life-threatening condition continue with the support of Queensland Genomics. This work builds on the program of worldleading sepsis research established by a team of researchers at Children's Health Queensland, who have also worked extensively on sepsis pathogens and intensive care management of children with sepsis.



Above: Tiffany Ritchie and Paediatric Sepsis Clinical Nurse Consultant Amanda Harley. Photo courtesy of Gold Coast University Hospital and the Emergency Medicine Foundation

Researcher profile: Associate Professor Julia Clark Paediatric infectious disease specialist Associate Professor Iulia Clark draws on her patient care across infectious disease, oncology, respiratory medicine and intensive care to research ways to improve diagnoses and treatments for children. "The interest comes from clinical presentations," she said. "That's where nearly all of my interest is, in clinical translation and improving outcomes." Despite the disruptions of COVID-19 in 2020, Dr Clark continued her research into febrile neutropenia, fungal and viral infections in the immune-compromised, congenital CMV infection, and parechovirus, as well as leading surveillance of vaccine preventable diseases with the Paediatric Active Enhanced Disease Surveillance network. Within these collaborations, she was the Queensland lead investigator for a \$4.16 million National Institutes of Health grant investigating the impact of repeated influenza vaccinations on the immune response, studying the real-world outcomes on a long-held concern that ongoing inoculations reduce an individual's protection from the virus. In addition, she was involved in producing a total of 16 research publications, including a paper in prestigious Clinical Infectious Diseases. Dr Clark said as an infectious disease clinician and researcher, there were immense benefits in working across Children's Health

Queensland's multidisciplinary teams.

of mechanisms."

"Clinically we interlink with just about every subspeciality," she said.

and pathologists and microbiologists for our tests and understanding

"Research-wise, we really benefit from the expertise of scientists

Photo by Janine Riel

Researcher profile: Dr Adam Irwin

Children's Health Queensland paediatric infectious disease specialist and The University of Queensland academic Dr Adam Irwin's research targets the rapid identification of pathogens and the improvement of antimicrobial use for infections in children.

"We have a responsibility to improve the care of children throughout the state and beyond," he said. "We can achieve that by developing and testing really important translational questions in a clinical setting."

In 2020 he was awarded a \$447,603 National Health and Medical Research Council Investigator Fellowship to lead a national surveillance study of Gram-negative bacteria in bloodstream infections. This research has potential global implications for the use of antibiotics in children, the results will assist the future priorities, and the design of clinical trials of antibiotics in children.

During the year, he was also part of a team established to reduce acute severe respiratory events in healthcare workers during the COVID-19 pandemic.

Notably, he was a Chief Investigator on a project that evaluated pathogen genomics for the rapid identification of sepsis in critically ill children and adults, with the support of \$292,000 in funding from Queensland Genomics and the Brisbane Diamantina Health Partners.

"Rapid genomics could substantially reduce the time to pathogen identification from the current culture-based testing that we do in the laboratory," he said. "The technology is innovative and has great potential to reduce the time for treatment, and ultimately, reduce deaths."

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Better care

Children's Health Queensland seeks continuous improvement in the care afforded to our state's children and young people. Research underpins this philosophy. Through our research and clinical trials, we are helping to determine better care through improved diagnosis, novel treatments, and strategies to prevent complications of injury and illness.

Specific areas of focus include respiratory medicine, intensive care, burns and trauma, orthopaedics, emergency and metabolic medicine. In oncology there were 19 new projects, including 10 new clinical trials approved and 37 research papers published. In neurology, 20 projects were authorised to commence in 2020 including eight clinical trials and at least 15 publications.

We increased capacity and capability for research across all disciplines within the hospital and health service, informing all levels of service delivery. In 2020, 97 new projects were authorised to commence to ultimately provide better care for children.

The total value of the grants supporting Better Care, in which the Chief Investigator was a Children's Health Queensland staff member was more than \$14.2 million. This included 42 new clinical trials in the 12 months and more than 360 publications, reaching high-impact journals of Nature Review, Lancet and Lancet Oncology.

Significant impacts from our research include the establishment of the Queensland Renal Biopsy Registry, the first of its kind in Australia. Studies also highlighted where healthcare can improve, including confirmation of widespread deficiencies in paediatric burns first aid and the importance of screening, early intervention and long-term follow up for adolescents who had surgery for congenital heart disease as infants, and a \$2.5 million Medical Research Future Fund grant to improve the diagnosis of spinal cord, bone and ligament injuries.



Better care highlights

research projects

publications

42 clinical trials

Across 17 areas of research





Burns and



Cardiology and cardiac surgery



Cerebral palsy and rehabilitation



Child health















Mental Metabolic



Intensive care



Nephrology

Neurology and neurodevelopmental paediatrics





Orthopaedics



> Transforming respiratory medicine

Children's Health Queensland's respiratory medicine service collaborates with researchers globally to improve diagnoses, treatments and outcomes for children and young people. Specific areas of research expertise include cystic fibrosis, bronchiectasis, sleep disorders and asthma.

In 2020 the respiratory service was involved in 11 new clinical trials ranging from assessments for the management of bronchiectasis, to the evaluation of long-term ivacaftor treatment for children with cystic fibrosis, and preventing early-onset pneumonia in Aboriginal and Torres Strait Islander infants through maternal immunisation.

Ongoing trials include adenotonsillectomies for mild to moderate obstructive sleep apnoea in young children,

behavioural interventions for sleeping concerns in children with attention deficit hyperactivity disorder and Down syndrome, and determining lung disease risk factors in infants with cystic fibrosis.

Research conducted through Children's Health Queensland has contributed to new and better guidelines to treat bronchiectasis around the world. Our researchers have been awarded grants totalling more than \$21 million in 2020, from the National Health and Medical

Research Council, the US Cystic Fibrosis Foundation and Children's Hospital Foundation.

The respiratory medicine service maintains strong collaborative links with researchers from the University of Queensland, the Queensland University of Technology and Darwin's Menzies Institute for Health Research.

Respiratory medicine highlights:

Summary of research activity investigating better care

Cystic fibrosis	į
Bronchiectasis	2
Asthma	2
Other	7
Total projects	16



Unveiling pandemic's impact on children's mental health

When the global COVID-19 pandemic reached Australia in early 2020, it shaped our lives in ways we could not have foreseen or expected.



Photo by Ray Cash.

Children's Health Queensland's Dr Alex De Young, Evaluation and Research Coordinator at the Queensland Centre for Perinatal and Infant Mental Health Service, wanted to find out how those events impacted young Australian children.

Together with researchers from The University of Queensland, Griffith University, The University of Melbourne and the University of Southern Queensland, Dr De Young launched a longitudinal online survey with caregivers of children aged one to five years.

The first COVID-19 Unmasked survey, completed during May-June 2020, found up to 20 per cent of children were experiencing mild to moderate emotional or behavioural difficulties such as increased tantrums, sleeping difficulties and clinginess. Around five to 10 per cent of children were experiencing mental health difficulties within the severe range.

"Young children have been affected in many ways by the pandemic, but we find the mental health needs of this group are often forgotten," she said.

"Overall, our young children are resilient. But some preschool-aged children experienced confusion, worry and unhelpful thoughts and behaviours related to COVID-19."

Survey reports revealed the lived experience of children at the time of surveys in May-July 2020 and August-November 2020.

The results from the later survey revealed children who experienced the extended restrictions in Victoria were more vulnerable to anxiety, depression and attachment-seeking. One in four Victorian caregivers reported moderate to extremely severe levels of depression, anxiety and stress. Whilst overall the children living in other states were reported by their caregivers to have good mental health, one in four were still experiencing moderate levels of anxiety.

Dr De Young is also leading the COVID-19 Unmasked Global Collaboration with studies now underway in the US, Spain, Poland, the Netherlands, UK, Turkey, Cyprus and Greece.

Researcher profile: Professor Claire Wainwright

For more than a decade paediatric respiratory physician Professor Claire Wainwright has been studying the causes, diagnoses and treatments of infections experienced by people

In 2020 this culminated in a multifaceted, international collaboration that not only delves into the efficacy of current treatments for mycobacterium abscessus, a highly multi-antibiotic resistant infection, but increases the research capacity of scientists in Australia to conduct these complex studies.

"It's the first in the world," she said. "It's an unusual trial because it has multiple options. It's an adaptive, multiarm study that is effectively a trial that never ends, you keep using the data."

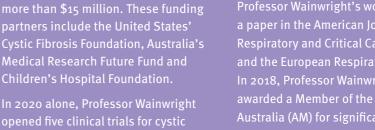
Over three years, Professor Wainwright and the broader research team have undertaken a range of international studies funded by grants that total



partners include the United States' Cystic Fibrosis Foundation, Australia's Medical Research Future Fund and

opened five clinical trials for cystic fibrosis-related studies at Children's Health Queensland. There were more than 10 publications stemming from

Professor Wainwright's work, including a paper in the American Journal of Respiratory and Critical Care Medicine In 2018, Professor Wainwright was awarded a Member of the Order of Australia (AM) for significant service to medicine as a respiratory clinician, and for leadership in the study of



Researcher profile: Professor Anne Chang



Paediatric respiratory physician Professor Anne Chang's research has transformed global guidelines to treat lung conditions bronchiectasis and chronic cough. She was announced as a recipient of the prestigious Royal Australasian College of Physicians (RACP) Howard Williams Medal in October 2020 for her research contributions to evidencebased management and clinical care in the areas of paediatric cough, asthma, bronchiectasis and Aboriginal and Torres Strait Islander children's lung health.

In 2020 alone her research with collaborators - notably concerning lung disease in remote Aboriginal communities was published in renowned international journals including Lancet, European Respiratory Journal, Chest, Lung and Lancet Child and Adolescent Health. Together with her team, Professor Chang confirmed the effective use of antibiotics for children with bronchiectasis.

This research had immediate benefits for children in the study and the findings were integrated into global treatment guidelines, reflecting the international impact of her research.

"We know if we treat children properly in the initial phase we can actually cure them," she said.

Professor Chang is also a National Health and Medical Research Council (NHMRC) Practitioner Fellow, Head of Child Health Division at Darwin's Menzies School of Health Research and leads the Cough and Airways Group at the Queensland University of Technology's Australian Centre for Health Services Innovation, and has published more than 500 papers and book chapters. In 2019 Professor Chang was awarded a Member of the Order of Australia (AM) for significant service to paediatric respiratory medicine as a clinician and researcher.



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Health services and systems research

Children's Health Queensland aims to translate our impactful research into better health outcomes across disciplines. Our work leverages into health economics, biostatistics, evaluation techniques and consumer and community involvement using multidisciplinary approaches.

We use data-driven methods to assess and evaluate care, health and wellbeing, in order to improve health service innovation.

Throughout 2020 our researchers undertook 29 projects. More than \$18.6 million in grant funding was awarded to our staff as Chief Investigators. Our researchers published 37 papers in leading journals including JAMA Psychiatry and Biological Psychiatry.

Key areas of investigation were healthcare evaluation and policy, training and capacity building, child and youth mental health, population health and integrated care.

Telehealth research was also a strong focus, given the significant uptake in phone and video health consults during 2020. Telehealth studies included the Queensland Interdisciplinary Paediatric Persistent Pain Service's investigation of telehealth for paediatric chronic pain, led by Dr Mark Alcock. In addition, Melanie Mildenhall devised a new model of care for the integration of general practitioner and rehabilitation services to improve outcomes when patients move from the hospital to the community. The Healthier Together program tailored a culturally relevant community obesity-prevention plan for Maori and Pacific Islander children and families.



Health services and systems research highlights

29 research projects

37 publications

Across 4 areas of research



Child and youth mental health



Evaluation and policy



Population health and integrated care



Training and capacity building



Delivering children's cardiology services closer to home

When long-term neurodevelopmental follow-up was established for Queensland children with congenital heart disease (CHD) just under a decade ago, they had to travel from their homes to access the cardiac centre-based program in the state's capital.

A partnership project with the Queensland Child and Youth Clinical Network developed a transformative model of service delivery using a statewide approach for children at high risk of developmental challenges.

Families access follow-up services as close to home as possible, saving them time and effort and with the aim of improving overall care and outcomes.

In 2020, Children's Health Queensland Cardiology Service's CHD LIFE Program

continued the next step in the project's development.

With \$2.99 million funding through Medical Research Future Fund Cardiovascular Health Mission Congenital Heart Disease and led by the Australian Centre for Health Services Innovation (AusHSI), this project will enable the evaluation of this statewide model of care. Models used in other centres nationally will also be evaluated, with the aim of developing recommendations which facilitate accessible, high-quality

neurodevelopmental surveillance and care for this patient group.

Clinical Nurse Consultant in Cardiac Maternal Fetal Medicine and the CHD LIFE Program, Karen Eagleson, said the program's evolution had gone from identifying the need for follow-up care to developing the statewide model, and now working to a national approach.

"We wanted to evaluate the work we've been doing to make sure it's achieving what we hope for healthcare providers and families," she said.

"We are also partnering with cardiac services across the country, as well as neurodevelopmental experts, to develop national developmental surveillance models."

The team continues to partner with national not-for-profit organisation, HeartKids to ensure the voice of children and their families are included in the services.

"Our consumer engagement is really important to us, to ensure we capture not only what is needed at a health service level, but from the child and family perspective as well," she said.

The team also published an overview of their experience revising the model of care in the Journal of Pediatrics and Child Health.

Neurodevelopmental care is a priority in the National Strategic Action Plan for Childhood Heart Disease, with the care model identified as an exemplar.



Karen Eagleson, Bronagh McAlinden, Susan Pagel. Photo by Damian Pointon



Photo by Ray Cash



The Quality of Care Collaborative of Australia (QuoCCA) for Education in **Paediatric Palliative Care** project was extended in 2020, following the receipt of a \$4 million grant from the Australian Department of **Health's National Palliative** Care Project funding.

QuoCCA is a long-running national program, led by Children's Health Queensland, designed to build and strengthen the capacity, skills and confidence of health professionals to provide compassionate paediatric palliative care to help and support patients and families.

It provides holistic support and education to healthcare professionals, family members, schools and the broader community when children with life-limiting conditions are not expected to live past the age of 18 years.

A specific focus is on supporting communities in regional, rural and remote areas using "pop-ups", where nurse educators, allied health educators and doctors travel to the family's community to provide education and training. During COVID-19 much of this support was provided virtually.

Project lead, Associate Professor Anthony Herbert said QuoCCA was evaluating its long-term impacts on education, upskilling and mentoring of healthcare professionals' care for children and their families.

"There is a need for further research around whether people retain the knowledge and the confidence they built during education sessions in the longer term," Associate Professor Herbert said.

"We've also been able to interview families around their experiences in what is called discovery interviews. These interviews capture the voice of



Associate Professor Anthony Herbert Photo courtesy of QUT.

the child and family which in turn is incorporated into and informs many aspects of the education and research."

The funding facilitated the current network of paediatric palliative care services in Australia (provided by the Australian Government Department of Health), with the addition of the Australian Capital Territory as the most recent participant. The project also works closely with the newly formed Paediatric Palliative Care Australia and New Zealand (PaPCANZ) and Queensland University of Technology.

Associate Professor Herbert said the needs of caring for children with lifelimiting conditions, and their caregivers, required different knowledge and skills than for adults.

"The conditions that require palliative care in paediatrics are quite different to those cared for by adult services and are often rare conditions," he said.

"You're looking after parents, brothers and sisters, and grandparents and there is an emotional intensity to that. The decision-making around how care is provided can also be complex."



Extending regional genomic testing to detect rare neurodevelopmental disorders

A key research pilot in 2020 enabled paediatricians to use genomic testing to assist diagnoses of rare neurodevelopmental disorders.

The Supporting Diagnostic Access for Rare Neurodevelopmental and Complex Multisystem Disorders across Queensland project, led by Children's Health Queensland Medical Director of Child Development Associate Professor Honey Heussler, sought to upskill paediatricians to employ genomic sequencing technology in Brisbane and two key regional centres.

As part of the \$6 million project support by Queensland Genomics,

Associate Professor Heussler worked with doctors and patients in Brisbane, Townsville and Mackay to educate and increase their skills.

"It's a model of care enabling general paediatricians better access to genetic diagnoses," Assoc Prof Heussler said. "It involves upskilling with a clinical geneticist available to answer paediatricians' questions, and a genetic counsellor supporting the process. It enables people to access whole-exome sequencing."

As well as assisting the clinicians, it also allows children and families to be supported closer to home.

The additional whole-exome testing boosts diagnoses rates from the

standard 20 per cent for intellectual disabilities and neurodevelopmental disorders in young children to about 50 per cent, which can provide a significant impact on families.

Dr Heussler said having a diagnosis meant increased knowledge and awareness of their potential future for families, as well as reducing parental guilt over the condition.

"It helps them to understand what the future might hold," she said. "I'm a great believer that knowledge is key."

Assoc Professor Heussler's research reflects her broad clinical practice, spanning neurodevelopmental disorders, sleep medicine and rare genetic disorders.



Above: Associate Professor Honey Heussler. Photo by Ray Cash.

Main image: Bella Jacombs. Photography by Rick Guidotti.



Our research enablers

Person-centred care

Children's Health Queensland's approach to person-centred care considers children, young people and their families as true partners in their care, and places individual social, emotional, cultural, mental and physical care needs at the heart of a healthcare journey. This approach not only underpins our clinical activity but drives our research pursuits. Our researchers, clinicians and support staff actively strive to work collaboratively with each other, with patients, families, and with our service partners to deliver the best possible health outcomes for every Queensland child.

Our people

Children's Health Queensland research stands apart for its end-to-end translational research capability, which is powered by the clinical expertise of our people. Our medical, nursing and allied health professionals strive to be at the forefront of research, innovation, education and the application of evidence-based practice to improve health outcomes for children and young people. This requires training and opportunities to engage in research activities of significant scale. In 2020, 106 staff reported having researchbased higher degrees, and 42 of our health professionals also supported the education and training of higher degree students through the supervision of their studies. In addition, our Clinical Research Managers play an important role to enable our people to facilitate new clinical trials and research projects, with the support of Children's Hospital Foundation. Overall, we remain

committed to supporting and mentoring clinicians to engage in research, and empowering early and mid-career researchers to achieve even greater outcomes.

Partners

Children's Health Queensland is proud to collaborate with strategic partners across government, health, social services, education, research, private and non-government organisations to develop, share knowledge and translate innovation into practice. Our valued partnerships with The University of Queensland, Queensland University of Technology, the Translational Research Institute, Children's Hospital Foundation and the Brisbane Diamantina Health Partners (part of the Australian Health Research Alliance) are integral to influencing and driving investment in sustainable health services that deliver significant clinical outcomes for Queensland children and their families.

Infrastructure

As a leader in paediatric healthcare, education and research, our purpose-built infrastructure across the Queensland Children's Hospital precinct, located in South Brisbane, encompasses the state's largest and only dedicated tertiary and quaternary paediatric hospital and the Centre for Children's Health Research. As Queensland's first fully-integrated research facility focused on child and adolescent health research, the ninelevel research centre houses wet and dry laboratories, pathology services, a gait laboratory, a nutrition laboratory and specialised clinical research facilities.

This infrastructure enables a unique opportunity to integrate the translation of paediatric research from the laboratory to the patient bedside. This knowledge further benefits Queensland children through our integrated network of healthcare services, driving improved outcomes for children nationally and across the globe.

Statistical support and consultancy service

Children's Health Queensland researchers have access to a biostatistics clinic and consultancy service provided by QFAB Bioinformatics, where researchers can access assistance in all aspects of project design, analyses and reporting as well as support for grant applications. The service supported over 50 researchers across 25 research programs at Children's Health Queensland in 2020. A series of biostatistical workshops were delivered by QFAB Bioinformatics throughout the year, providing researchers with training and education on a breadth of areas including experimental design, data analysis methods and interpretation of results. Researchers have access to the SPSS statistical software platform and NVivo transcription software, which provides automated transcription for audio and video data in qualitative and mixed methods research.

The biostatics support services and programs are co-funded by Children's Hospital Foundation.



Publications

Children's Health Queensland research is having a globally significant impact on the health and wellbeing of children. In 2020, our researchers published more than 400 research articles and book chapters.

Our research articles featured in international news*

81 countries

We contributed to*

World Health Organization (WHO) policy mentions associated with COVID-19

We contributed to publications attracting global attention*

An investigation of infant high-grade gliomas to identify that they are clinically distinct in infants to older children, and require a change in diagnostic practice and management

Surviving Sepsis Campaign International Guidelines for the Management of Septic Shock and Sepsis-Associated Organ Dysfunction in **Children** (Intensive Care Medicine)

Screening, assessment and management of type 2 diabetes mellitus in children and adolescents: Australasian Paediatric Endocrine Group guidelines (Medical Journal of Australia)

Whole genome, transcriptome and methylome profiling enhances actionable target discovery in high-risk paediatric **Cancer** (Nature Medicine)

11 international news stories

Popular news stories

We can't close schools every time there's a COVID outbreak

Should all kids with cancer get genetic testing?

The link between teen chewing pace and obesity

Our research attracted

across academic. online and social media platforms

Our researchers were published in leading journals

American Journal of Respiratory and Critical Care Medicine

Biological Psychiatry New England Journal of Medicine

Nature Medicine Nature Reviews Disease Primers

The Lancet Diabetes and Endocrinology

Acta Neuropathologica

JAMA

JAMA Oncology

Lancet

*Sourced from Altmetric.com

Lancet Oncology

We published in 15 National Health and Medical Research Council fields of research





Clinical sciences

Human movement and

sports science



Immunology



OQ.



Medical physiology







Pharmacology and pharmaceutical sciences



Paediatrics and reproductive medicine



Cardiovascular medicine

and haematology

Oncology and carcinogenesis

Ophthalmology and optometry



Public health and health services

Global collaborations and partnerships

Children's Health Queensland researchers collaborated with leading institutions located in 452 cities across 125 countries





The best care for every Queensland child



www.childrens.health.qld.gov.au





