



FACULTY OF HEALTH

2023

ANNUAL RESEARCH HIGHLIGHTS





Welcome

As we end an extremely successful year in the Faculty of Health, I am reminded how our achievements are the result of our shared commitment towards research excellence.

We have exceeded our external research income target by 46%. Our research quality has been rewarded with nearly 100 Category 1 competitive grants and strong growth in private sector and philanthropic funding, which is truly outstanding.

Our strong team culture has ensured that our achievements are shared by early and mid-career researchers as well as senior staff. This highlights our commitment to supporting all staff to achieve their potential, ensuring opportunities to fine-tune research ideas, craft proposals for funding, and identify the best expertise through incubator sessions, peer review and grant writing support.

We are ambitious. This year we launched our new research Institute, INSIGHT, which will connect our disciplines in health and across the university. This pan-university enterprise is working to improve the health and wellbeing of older people, those living with dementia, chronic disease and palliative conditions, women and children, and Aboriginal and Torres Strait Islander people, as well as delivering innovative digital solutions and systems adaptations to mitigate the effects of climate change on health.

We are focused on nurturing new talent, particularly our higher degree research (HDR) students, who bring a range of rich industry experience to bear in identifying clinical and policy innovations to address local, national and international health challenges.

This year we have strengthened our partnership with the North Sydney Local Health District (NSLHD), launching an embedded clinician HDR program at the Kolling Institute in November.

We have also been growing our research collaboration with NSLHD across nursing, midwifery and allied health, and we are developing projects focusing on palliative care and functional wellbeing. This work has been strengthened through three conjoint clinical professor roles that add to existing industry positions with Prince of Wales Hospital and Sydney Children's Hospital Network. We have also built collaborations with the Centenary Institute that will connect and scale up research in ageing and wellbeing.

Internationally, we have been developing our relationships with Johns Hopkins University and King's College London, and with partners through the World Universities Network and UTS Key Technology Partnerships. Our research has informed enterprise learning to scale up evidence-based clinical practice in stuttering and anxiety. Our international HDR student projects

from Africa, the Middle East, Asia, Europe, Latin and North America and Oceania ensure that our work is truly global and linked to the sustainable development goals in line with our commitment to address health inequity with a focus on First Peoples first.

This report showcases our research excellence and impact across the Faculty. It is a testament to the hard work and dedication of all who have contributed throughout the year, and I would like to thank everyone for their part in our success.

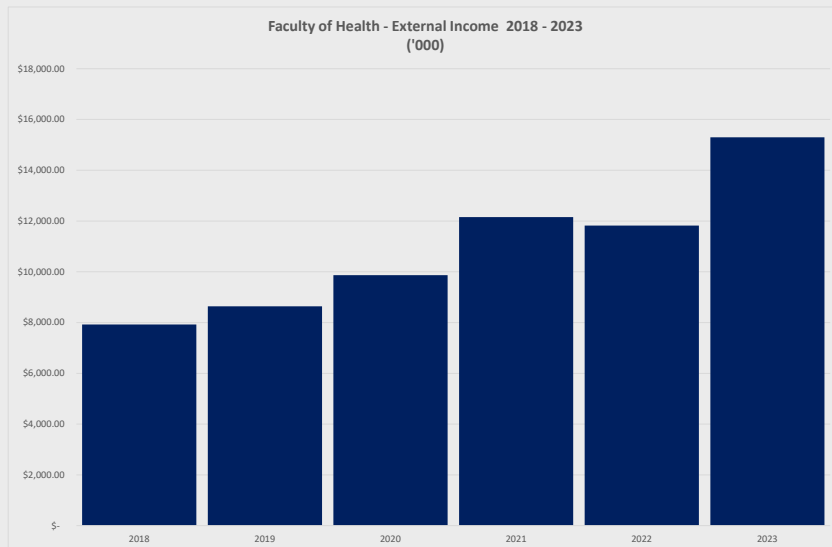
Angela

Professor Angela Dawson
Associate Dean of Research
UTS Faculty of Health

UTS HEALTH: OUR PERFORMANCE

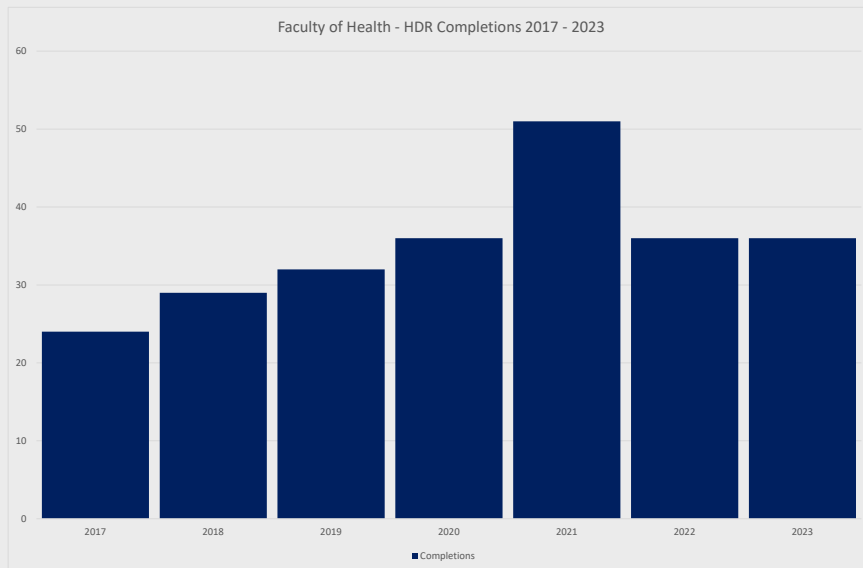
Once again, I am pleased to report on our overall research performance for 2023.

External Research Income (ERI 2023)



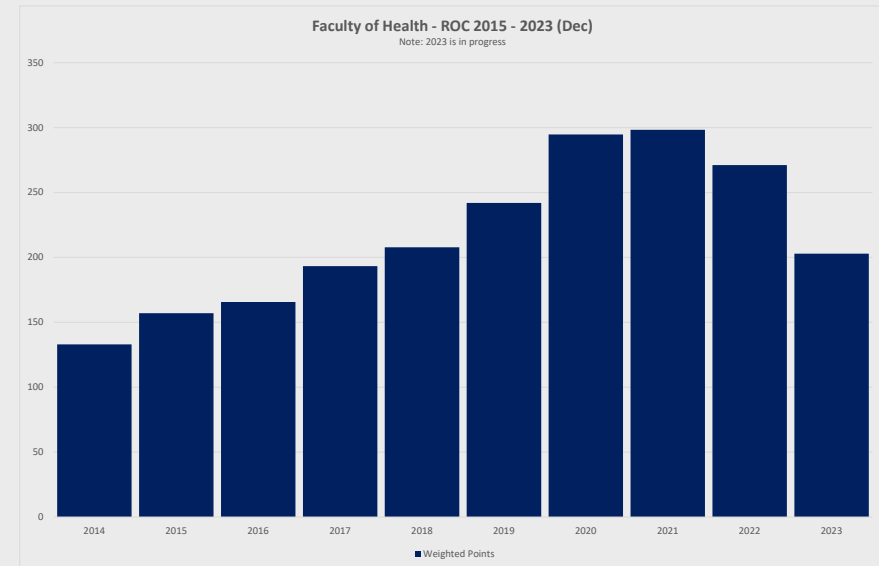
The Faculty of Health 2023 ERI results was well above what we expected in relation to the budget set for the faculty. The Faculty ERI has surpassed expectations, reaching an impressive \$15,297M, a positive variance of 46% compared to the budgeted amount of \$10,475M. This outstanding achievement is a testament to the exceptional work of our dedicated research academics, research assistants and faculty research team, whose hard work and commitment have played a pivotal role in our remarkable and outstanding success.

HDR Completions



The Faculty of Health recognises the excellent research undertaken by our emerging researchers as part of the PhD and Masters by Research degrees. Reviewing the year to date Faculty HDR completions, I am pleased to report that we have had 36 completions for 2023.

Research Output Collection (ROC 2023)



In relation to the annual Research Outputs Collection (ROC), the chart shows that our weighted average points for publications for the calendar year 2023 is 203. UTS ROC 2023 assessment period completes in May 2024 and final reports will published in June 2024.

INSIGHT 2023 Achievements

INSIGHT was formally launched at the end of June 2023. It comprises two centres with established track records of excellence, the Centre for Health Economics Research and Evaluation (CHERE) and the Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT); four collaboratives that mobilise experts across disciplines in ageing research, climate change and health, digital and virtual health and women's and children's health; and two hubs that bring methodological excellence in biostatistics, epidemiology and data science and clinical trials.



We have spent this year undertaking industry roundtables and knowledge exchanges to inform our strategic planning, and building collaborative research opportunities with Local Health Districts and NSW Health. We have started cementing relationships across siloes within UTS, and are now well-positioned to support collective activity to tackle complex and embedded population health issues and reduce persistent inequities in health outcomes, working in partnership with our external stakeholders.

Professor Susan Morton
Inaugural Director, INSIGHT

Our Impact

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A long and distinguished career

PROFESSOR ANN PACKMAN, WHO RETIRES THIS YEAR, HAS MADE AN EXTRAORDINARY CONTRIBUTION TO OUR UNDERSTANDING OF STUTTERING.

Stuttering is a potentially lifelong speech fluency issue that affects up to 2% of people, causing a public health burden as significant as cardiovascular disease or diabetes in terms of reduced quality of life.

Many people who stutter will go on to experience lifelong social, educational and professional impacts. They're also 16 times more likely to develop social anxiety.

Professor Ann Packman, who retires from UTS at the end of 2023, has redefined the way we view the cause of stuttering.

Her work at the UTS [Australian Stuttering Research Centre](#) (ASRC) has contributed to developments of new treatments that have benefitted thousands of people.

ASRC Director Professor Mark Onslow says Professor Packman's work has underpinned the Centre's success, which includes development of the [Lidcombe Program](#) for young children who stutter, the [Camperdown Program](#) for adults who stutter, and a highly successful [treatment program for social anxiety in adults](#), which has been used by nearly 2,000 people from 44 countries.

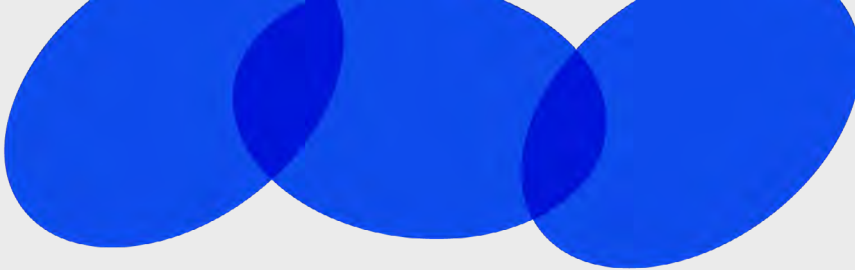


Professor Ann Packman

“Her contribution to our understanding of the cause of stuttering has provided broader directions for how it can be treated, particularly in the early years of life,” Professor Onslow says.

Professor Packman's career as a speech pathologist has been long and distinguished, spanning more than four decades. She first became interested in stuttering when she was studying speech therapy in Sydney in the early sixties and participated in an intensive stuttering program as part of a student clinical placement at the Prince Henry Hospital. Because of that, she realised that her father stuttered, and it had led him to avoiding social situations throughout his life.

She qualified as a speech pathologist in 1964 and worked at the Prince Henry and the Royal Prince Alfred Hospitals in Sydney. Her first peer-reviewed journal publication was in 1971, and in 1973 she began a formal research career in the School of Communication Disorders at Cumberland College of Health Sciences (which was later to become part of The University of Sydney).



During the 1970s, her work on stuttering treatment in residential formats laid the foundation for subsequent developments in the field, and many of the residential treatment practices established in those years are still used today.

She is a founding member of the ASRC, which was established at The University of Sydney in 1996. Her research there laid the foundation for seminal developments in behavioural control of stuttering, which ultimately led to the current best practice method in use today.

Professor Packman was the first to provide a comprehensive theoretical understanding of how stuttering is a physical rather than just linguistic or psychological problem.

Her model of stuttering is that only three factors can explain the conditions necessary for stuttering to develop in early childhood and subsequently trouble a speaker throughout life. These factors are interruptions to the brain processing involved in planning spoken language, combined with triggers in the form of the features of spoken language such as syllabic stress and linguistic complexity, and internal factors such as physiological arousal and cognitive overload.

Her model was confirmed with a brain imaging study she led, which is the only such study conducted before stuttering develops. Results with newborn babies genetically at risk for stuttering have provided evidence that reduced integrity of white brain matter has a causal role in stuttering.

With ASRC colleagues, she also published reviews in 1999 and 2011 of emerging evidence showing the dire psychological effects of chronic stuttering. Those reviews contributed greatly to a paradigm shift in understanding of the disorder.

Working with colleagues from the Murdoch Children's Research Institute, she conducted a community cohort study of stuttering development that confirmed social anxiety was an effect of the disorder, not part of its cause. That study also showed that one in 10 preschool children stutter – a much higher prevalence than previously thought. This research has had a significant impact on clinical practice.

Professor Packman is the second most published scientist in the history of stuttering research. During her career, she has obtained \$19 million in research funding, involving continuous support from the NHMRC and the ARC.

She has been a Chief Investigator on three consecutive NHMRC Program Grants for the period 2006–2025. Those Program Grants are the only ones ever held in the discipline of speech pathology.

Throughout her career, Professor Packman has engaged with people who stutter in the community as a board member of the Australian Speak Easy Association. She was the first Australian to be appointed to the Fluency Committee of the International Association of Logopedics and Phoniatrics, which is an influential, European-based society for the study of communication disorders, with members in more than 50 countries.

She has been an editor for top-tiered journals in her field, and she has supervised 22 PhD students who have gone on to lead successful national and international academic careers.

“Her achievements are particularly striking considering that for the bulk of her career as a university researcher from 1996 to the present she was, for family reasons, only able to work part-time,” says Professor Onslow.

Professor Packman retires at the age of 80. She is one of three Chief Investigators on a \$6.3 million NHMRC Program Grant for the period 2018–2025, awarded to the ASRC, and will continue her role as such as UTS Emeritus Professor.

Improving health outcomes for First Nations women and their families

UTS RESEARCHERS ARE WORKING WITH THE COMMUNITY TO UNCOVER IMPORTANT INSIGHTS INTO VACCINE HESITANCY IN ABORIGINAL WOMEN

It was in her first job as an operating theatre nurse in the late nineties that Associate Professor Anne-Marie Eades really appreciated the health disparity between Aboriginal and non-Aboriginal communities.

“There were young Aboriginal men coming in with lower limb wounds which led to amputation, the equivalent to the surgical procedures I was seeing in non-Aboriginal men in their sixties,” says Associate Professor Eades, a Noongar woman from WA.



Associate Professor Anne-Marie Eades

“We hear about the gap, but this is what I was seeing first hand.”

Throughout her career as a Registered Nurse and health researcher, Associate Professor Eades has worked by sharing knowledge that supports the upskilling of service providers and building resilience in Aboriginal and Torres Strait Islander health.

Her current project at UTS aims to improve coverage, confidence and knowledge about COVID-19 vaccination among Aboriginal women of childbearing age and mothers of Aboriginal babies in metropolitan Perth and southwest Western Australia.

There is still a significant disparity nationally in vaccine uptake among Aboriginal women compared to non-Aboriginal women, especially by the third dose of the COVID vaccine.

The Ngarngk Koolangka Moorditj Yarning (Mothers and Babies solid yarning) project uses yarning, interviewing and survey-based data collection to understand the decision-making of Aboriginal women around vaccine uptake.

“If we can overcome vaccine hesitancy, then that in itself allows women and their babies to be prepared for any pandemic.

“This project is not about getting people to have a vaccine, it’s about understanding why people choose to have it or not. If we can understand decision making around peoples choices, we can adapt our behaviours as health professionals for pandemic management and responses that are effective and culturally appropriate,” Associate Professor Eades says.



The project is funded by a Medical Research Future Fund (MRFF) Indigenous Health Research grant, and uses Aboriginal participatory action research, which co-designs the research questions and methods with Aboriginal women and Elders.

The results of the mixed-methods research will be used to inform future pandemic planning and will be translated into resources for services, which include WA Health.

“This research is important because what we uncover will be invaluable for guarding against future pandemics and responses that are effective and culturally appropriate for First Nations women and their families,” Associate Professor Eades says.





Professor Emily Callander

Providing evidence for better cost efficiency and equity in maternal health services

NEARLY HALF OF ALL BIRTHS IN AUSTRALIA ARE EXPECTED TO BE PERFORMED VIA C-SECTION BY 2023. AUSTRALIA'S LEADING MATERNAL AND WOMEN'S HEALTH ECONOMIST PROFESSOR EMILY CALLANDER IS QUANTIFYING THE TRUE COSTS OF THE BURGEONING RATE OF BIRTH INTERVENTION.

Maternal care is the largest routine and most expensive element of health care – and the costs are soaring.

According to a [November 2023 paper](#) by Emily Callander, Professor and Head of Discipline for Health Services Management in the School of Public Health, the costs of maternal health care increased by 65% in the six years to 2021, without delivering corresponding health outcome improvements.

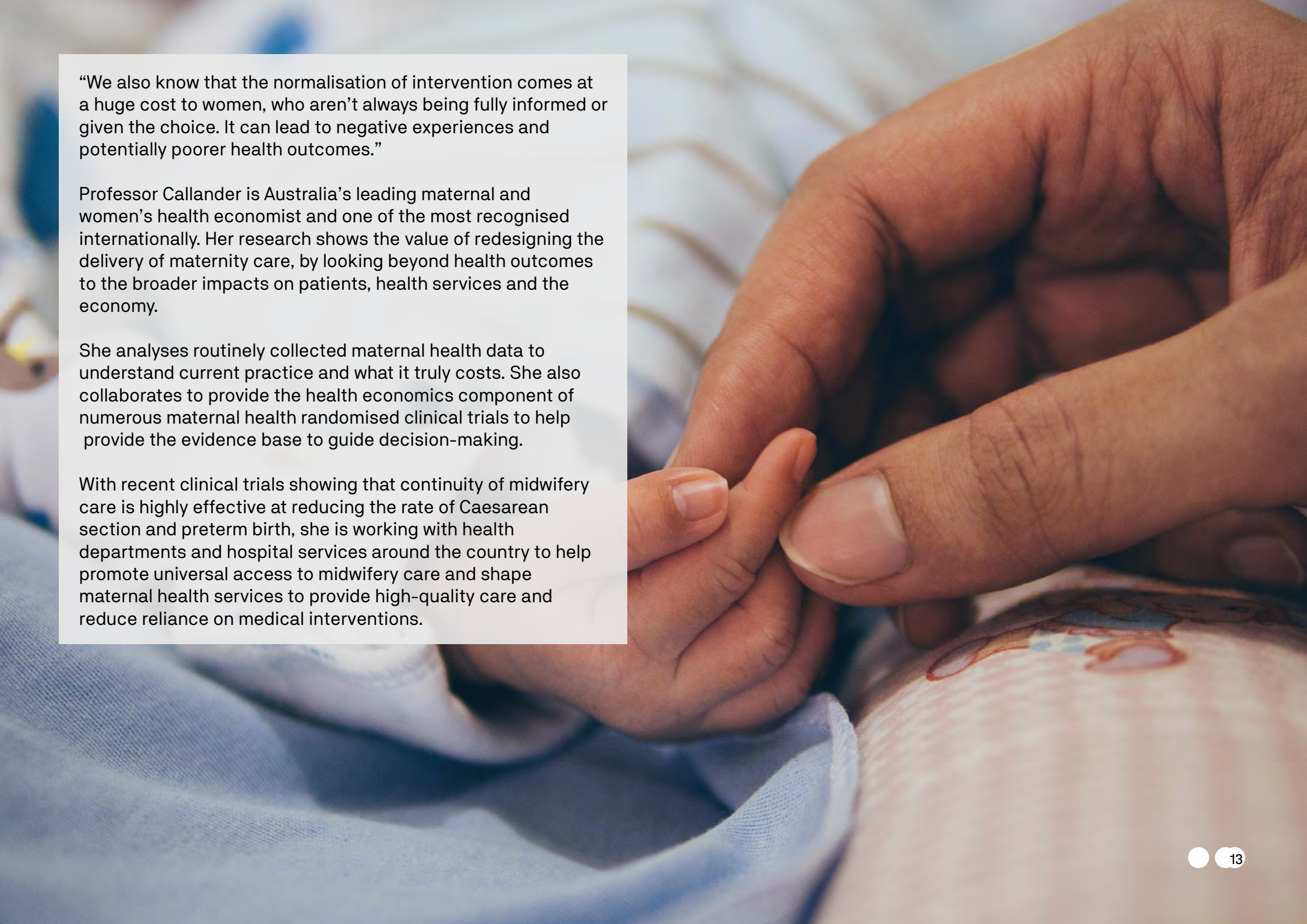
Key points

- The rate of birth interventions is rapidly increasing in Australia.
- The costs of medical intervention in maternity care cannot be sustained indefinitely.
- We need to contain costs while maintaining quality to provide accessible, high-value, high-quality maternity care.

Her analysis of routinely collected Queensland data – which can be extrapolated to the rest of Australia – showed that in 2021, only one in three women gave birth spontaneously without a Caesarean section or induced labour. By 2023, caesarean section births are expected to reach 45% of all births.

Her findings have important implications for the delivery of maternal health services in Australia. Not only will demand for interventions potentially outstrip available funding, she says, but access to midwifery services could be reduced as there may be insufficient beds or midwives to cope.

“Increasing use of Caesarean section and increasing rates of preterm birth, before 37 weeks, are quite substantial cost drivers. Caesarean sections cost about \$10,000 more per birth, so this increase is potentially costing Australia billions of extra dollars,” Professor Callander says.



“We also know that the normalisation of intervention comes at a huge cost to women, who aren’t always being fully informed or given the choice. It can lead to negative experiences and potentially poorer health outcomes.”

Professor Callander is Australia’s leading maternal and women’s health economist and one of the most recognised internationally. Her research shows the value of redesigning the delivery of maternity care, by looking beyond health outcomes to the broader impacts on patients, health services and the economy.

She analyses routinely collected maternal health data to understand current practice and what it truly costs. She also collaborates to provide the health economics component of numerous maternal health randomised clinical trials to help provide the evidence base to guide decision-making.

With recent clinical trials showing that continuity of midwifery care is highly effective at reducing the rate of Caesarean section and preterm birth, she is working with health departments and hospital services around the country to help promote universal access to midwifery care and shape maternal health services to provide high-quality care and reduce reliance on medical interventions.

World-leading research to demystify chronic pain in children

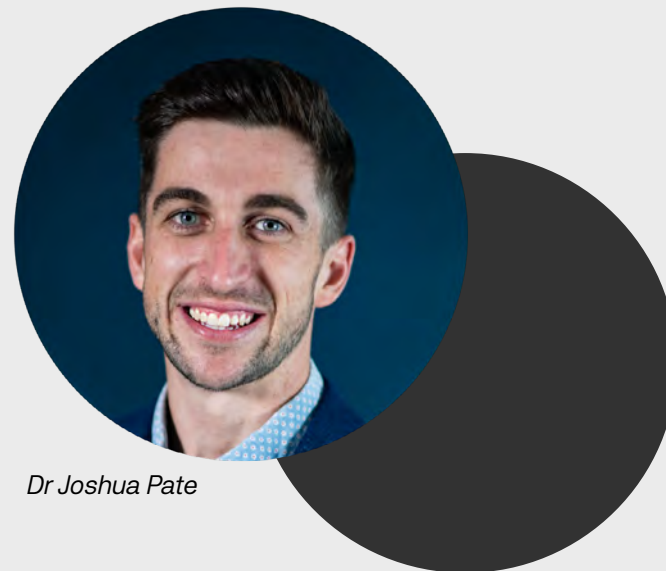
UTS'S 'DR KARL' OF PAEDIATRIC PAIN MANAGEMENT IS BRIDGING THE GAP BETWEEN HEALTH AND EDUCATION TO IMPROVE UNDERSTANDING OF KIDS' PAIN EXPERIENCES.

There is a large body of research showing our experience of pain is influenced by many complex biological, psychological and social factors. No two individuals experience pain in the same way; for some, an injury will quickly resolve and their pain will disappear, while for others their pain lingers long after an injury or tissue damage has healed.

What is less understood is how children experience chronic pain – and what parents and teachers can do to minimise its impact.

With as many as two primary school children experiencing chronic pain in every classroom – defined as pain that lasts for more than three months – Dr Joshua Pate is working to improve understanding of the complexities of their experience to increase empathy and reduce stigma.

He and his PhD students and collaborators have run a pilot study in schools to see how health messaging about the neuroscience of pain can be applied in educational settings to improve the management of children with pain and their parents.



Dr Joshua Pate

“The challenge with chronic pain in children is working out when it’s something to worry about and when it’s not – for example, is it safe to go back to school, or to do sport?” Dr Pate says.

“We’re trying to understand whether earlier educational training about pain is better for healthy populations than when waiting until someone is spiralling into the vicious cycles of pain and fear and disability.”

Dr Pate, a Senior Lecturer in Physiotherapy at UTS and an expert in pain management, became interested in paediatric pain when he was working as a physiotherapist at The Children’s Hospital at Westmead.

He says children can develop chronic pain for many reasons, including injury or disease, a genetic condition, or with specific conditions like juvenile rheumatoid arthritis (JIA). Common presentations such as chronic lower back pain or abdominal pain may be harder to tease out, and the reasons underpinning this pain may not be immediately obvious on a scan or test.

Data shows that children who have chronic pain miss up to a day of school every week on average, which over time adds up to significant lost educational and social opportunities. They are more likely to develop a reliance on pain medication in later life.

To manage their pain effectively, it is important that everyone around them understands the science of pain – including parents, doctors, physiotherapists, psychologists, coaches and teachers.

“Otherwise kids and their parents can become fearful; they have all the tests, and often after months or years they are told it must be all in your head and the family is left with that,” Dr Pate says.

He is now a world authority on this new and specialised area of pain research. He communicates the science in a way that resonates with patients and families, hoping one day to have a positive societal impact like familiar science communicators such as Dr Karl Kruszelnicki. He has written for TED-Ed resources on pain, had has written a series of five children’s books called *Zoe and Zak’s Pain Hacks*.



In 2021, he was involved in a review team for the WHO Guideline for Chronic Pain in Children, and in December 2023 he was a part of the launch of PICH Down-Under, an Australian-based consortium based on Canada’s Pain in Child Health (PICH) research training program.

Dr Pate says working with families and teachers in schools has been an insightful and meaningful process.

“It has helped us to identify new areas of research within our exciting niche area – we are now discovering new questions that we didn’t previously know were an issue,” he says.

Read more from Josh about the neuroscience of pain:

- [The mysterious science of pain](#)
- [Can you still feel a limb that’s gone?](#)
- [Turning down the volume of pain – how to retrain your brain when you get sensitised](#)
- [Why does my back get so sore when I’m sick? The connection between immunity and pain](#)

Improving nutrition for people with swallowing disability

PHD SCHOLAR LILY CHEN IS INVESTIGATING THE USE OF 3D FOOD PRINTING TO MAKE PUREED FOOD MORE APPETISING FOR OLDER PEOPLE.



Ms Lily Chen

As an Accredited Practising Dietitian working in aged care, Lily Chen saw first-hand the challenges of maintaining nutrition for older adults with swallowing difficulties.

Food in aged care is often served soft or pureed for people who have dysphagia (difficulty swallowing). It might be hard for the older person to identify what the food is on the plate.

“And the shape and texture of the food doesn’t have much visual appeal. Sometimes it’s served cold or it doesn’t have any shape,” says Ms Chen. “This might reduce the person’s desire to eat and ultimately mean they are not eating enough for good nutrition.”



After she arrived in Sydney from her native New York, Ms Chen worked as a research assistant and then won a PhD scholarship to complete her doctoral studies with advisor Professor Bronwyn Hemsley, a speech pathologist who specialises in creating safe and enjoyable meals for people with swallowing disability, and Associate Professor Deborah Debono, a public health researcher.

Ms Chen’s PhD is part of a larger ARC Discovery Project investigating whether 3D printing could make texture-modified food more appealing, thereby improving nutrition, safety, and enjoyment for residents with swallowing difficulty. The research team is working with a 3D food printer housed at Uniting, using pureed food as the ‘ink’ which is ‘printed’ into food-like shapes.

In 2023, Ms Chen published the world’s first [systematic review](#) examining the association of nutrition, food shaping, and older adults with swallowing difficulties. It showed that food shaping for older adults with swallowing difficulties could enhance nutrition and well-being, especially when used along with other nutrition strategies.

The systematic review also looked at new food-shaping methods such as 3D food printing, and found they could potentially create food to meet specific standards to enhance nutrition.

While using 3D food printing may currently be costly and difficult to implement, the review noted that 3D printed foods could be fortified with vitamins, minerals and protein powders.

Ms Chen says using 3D food printing to improve the colour, flavour and shape of food could give people with swallowing difficulties more options, make food more appetising, and improve swallowing, nutrition and quality of life.

“Older people with trouble swallowing often eat in the same dining room as everyone else, so they can feel left out if their food looks nothing like the main meal.

“We’re still in the very early stages, but the hope is that eventually 3D printed food would be easy to use and create main meals that look exactly the same as what’s on the menu for everyone else,” she says.

The next stage of Ms Chen’s PhD is to work with dietitians to determine whether 3D printing would be acceptable and feasible in aged care settings.



Pic: Bronwyn Hemsley UTS used with permission

First Nations disability sector strengthening

PROFESSOR SCOTT AVERY HAS RETURNED TO UTS TO OVERSEE AN EXCITING PROGRAM OF WORK ON INCLUSION FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH DISABILITY.

Professor Scott Avery is a profoundly deaf and Aboriginal scholar from the Worimi people. His PhD five years ago at the UTS School of Public Health has revolutionised the way we consider the perspectives of Aboriginal and Torres Strait Islander with lived experience of disability.

As part of his PhD, Professor Avery travelled around NSW, the Northern Territory and South Australia, attending community gatherings and asking First Nations people with disability to tell their stories.

“Our one question to First Nations people with disability was: ‘What is your story?’ I didn’t even ask what was their disability. I just asked them to tell me about their experiences and the barriers to identity, inclusion and belonging,” Professor Avery says.

The results provided the first empirical proof of intersectional disadvantage for people who are both Aboriginal and Torres Strait Islander and have a disability.

“I found the level of social inequity that Aboriginal and Torres Strait Islander people with disability have is greater than if they were Aboriginal or Torres Strait Islander, or if they just had disability.” Professor Avery says.



Professor Scott Avery

However, he found that Aboriginal or Torres Strait Islander people with disability were included in their community at the same rate as everybody else. “In Indigenous community settings, you have equality - it’s just when you’re engaging with the system outside.”

The results were published as a book *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*. It was the first research that had actually talked to Aboriginal people with disability about their lived experiences.

Since its publication in 2018, Professor Avery’s work has been used widely by Closing the Gap. It is cited in the Australia’s Disability Strategy 2021–2031 and has been drawn on heavily by the Disability Royal Commission.

After a stint at Western Sydney University, Professor Avery has now returned to UTS to undertake a program of work funded by the Commonwealth under the Disability Sector Strengthening Plan, part of Closing the Gap.

He will oversee three streams of work: developing the next generation of narratives from First Nations people with disability, with a focus on healing; a data project to that intersects Aboriginal and disability datasets to inform better decision making; and working with the service sector on developing a quality assurance framework.

Professor Avery says connecting the Aboriginal and Torres Strait Islander sector with the disability sector will take time, but the Commonwealth's interest is an important step in the right direction.

“It will take a lot of time to bring the change that's needed. We want to get another generation of First Nations disability researchers and advocates to learn what we have done and recreate it,” he says.



Moving from consulting towards genuine research partnerships with people with lived experience

CONJOINT ASSOCIATE PROFESSOR JO RIVER (MENTAL HEALTH DRUG AND ALCOHOL NURSING) IS LOOKING AT WHAT IT TAKES TO SUPPORT YOUNG PEOPLE WITH LIVED EXPERIENCE TO PARTNER IN RESEARCH.



Associate Professor Jo River

Most researchers and research funders understand the benefits that can be gained from co-designing or co-producing research with people who have lived experience of a health issue. But in practice, genuine partnership in research with people with lived experience is rare.

“Evidence suggests that people with lived experience tend to be recruited as subjects rather than as active agents in research, or are consulted in tokenistic ways. But there are things you just don’t see or understand when it’s the academics asking the questions and making all the decisions in research,” says Associate Professor Jo River.

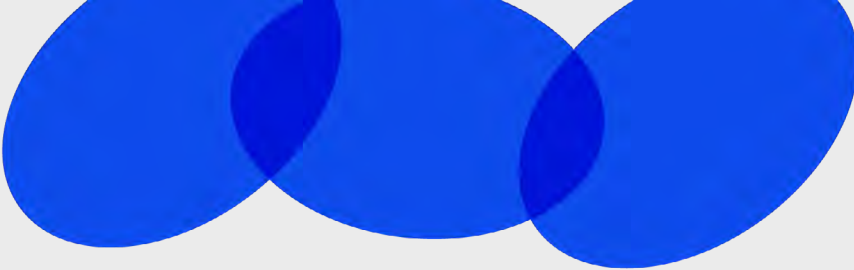
It is often even harder for people with lived experience to participate in research if they are young or have a mental health challenge or disability. This is because young people may be doubted in their capacity as knowers, not only on the basis of their age but also because of their mental health challenges or disability.

“The exclusion of people with lived experience from research based on factors such as age, mental health, disability, or any other characteristic, is sometimes called an epistemic injustice or knowledge injustice, because people have a right to participate in research that impacts on their lives,” says Associate Professor River.

With funding from the Mental Health Commission of NSW, participatory research expert Associate Professor River has worked with their research team to co-design the [Raising the Bar](#) model to support people with lived experience, researchers and clinicians to work together as equal partners in mental health research.

They have also been funded by the [Youth Insearch Foundation](#), Australia’s leading peer-led youth trauma recovery organisation, to trial the Raising the Bar model with young people with lived experience to support them in partnering in suicide prevention research.

“As the name suggests, our team aims to raise the bar in mental health research. Instead of treating people with lived experience as subjects of research, or involving them in tokenistic ways, we aim to get teams to work together, co-deciding in all phases of the research, including the planning, designing, conducting and disseminating of the research,” says Associate Professor River.



To date, the Raising the Bar team has trained more than 300 researchers across clinical, academic and community sectors, and has produced guides to co-design and co-production research, as well as undertaking evaluations of the Raising the Bar model. This includes the [Co-design Kickstarter](#), a guide to co-design research, the development of which was funded by the peak body for community mental health organisations in NSW, the Mental Health Coordinating Council and the Community Mental Health Drug and Alcohol Research Network.

Top tips for gold standard co-design with people with lived experience

- Co-design is about co-deciding through all stages of the research process – planning, defining the design, conducting the research and disseminating the findings
- At least half the team should consist of people with lived experience – including a diversity of relevant experience, knowledge, expertise and skills
- Lived experience researchers in co-design research teams need to be paid fairly for their work
- Teams need to consider power dynamics and how power might silence people with lived experience, and practise deliberate egalitarianism with fair decision-making processes
- Understand that co-design is not a one off, tick-box activity – it is an iterative process of exploration, dialogue, action and reflection.

Since the Co-design Kickstarter was launched in August, the resource has already been downloaded 500 times and is being used by major research organisations all around Australia.

In November, Associate Professor River and team also published a paper on the Raising the Bar model that specifically outlines and evaluates the model with people with lived experience, as part of a special issue of the *International Journal of Qualitative Methods* on inclusion in research of people with lived experience.

Associate Professor River says genuine research partnerships with people with lived experience can lead to numerous benefits, including new kinds of research questions, outputs and priorities, as well as improving the translation of research, in ways that are more relevant, resonant and accessible to the community.

“We have shown that working in this way raises the quality of research questions, priorities, translation and interpretation,” they say.

“Often a problem and the solution reside together – doing research with people with lived experience brings their unique skills and knowledge to play to help researchers see problems in new ways and find new kinds of solutions.”



Associate Professor Nicolas Hart

Thirty years ago, cancer patients were recommended bed rest as it was believed exercise could exacerbate the spread of cancer cells around the body.

But in more recent years, exercise has been shown to be beneficial in many types of cancer as it improves overall health and quality of life.

In 2017, Associate Professor Nicolas Hart provided the first unequivocal proof that an exercise program was both safe and feasible for people with bone metastases (where cancer has spread to the bone from prostate or breast cancer in his studies). His findings have been used in the most recent international clinical guidelines and he is one of 28 global advisors to the World Health Organization on the development of a cancer rehabilitation package for low and middle-income countries provided to all 194 WHO Member States and their health ministries.

Using exercise as medicine to defeat cancer

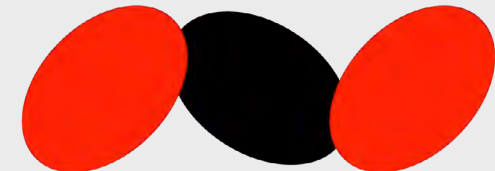
ASSOCIATE PROFESSOR NICOLAS HART'S WORLD-FIRST FINDINGS SUGGEST THAT EXERCISE CAN SLOW THE GROWTH OF TUMOURS, CHANGE CANCER BIOLOGY, AND PROLONG SURVIVAL.

Since he arrived at the UTS School of Sport, Exercise and Rehabilitation late last year, his work has gone further – to provide the world's first clinical evidence that exercise influences the tumour itself.

Funded by prestigious fellowships from the National Health and Medical Research Council and the Cancer Council of Western Australia to study the role of exercise in people with advanced or metastatic cancer, his work indicates that exercise suppresses tumour growth and improves cancer-specific and overall survival as well as quality of life.

His clinical studies indicate the pattern is the same for solid tumours (such as prostate or breast cancer) as well as multiple myeloma, which is a blood cancer.

Associate Professor Hart is now focusing his research on how that happens. While not yet published, his early results indicate that exercise reverses or disrupts many of the biological processes that support tumours to-grow.



I have cancer – how much should I exercise?

The overarching recommendation for people with localised cancer (cancer that hasn't spread) are to try to do 75 to 150 minutes of moderate to vigorous aerobic physical activity per week.

It doesn't need to be all in one go – you can just do 10 minutes at a time.

“Moderate to vigorous intensity is highly effective as addressing toxicity of cancer. The more exercise you can do, the better – but just do as much as you can,” says Associate Professor Hart.

People with advanced or metastatic cancer may aspire to achieve the same amount of physical activity. However people should talk to a clinical exercise physiologist for a tailored program to ensure it is safe and feasible. Ask your GP about a chronic disease management plan that will pay for up to five sessions.

For example, tumours create hypoxia (lack of oxygen) by shrinking blood vessels and changing their permeability. Exercise can restore normal vasculature and therefore help chemotherapy drugs to reach the cancer cells.

Recently published pre-clinical work on cancers which spread to bone indicates that exercise can slow tumour growth by as much as 80% – similar to what can be achieved by chemotherapy.

This means exercise could potentially be used as an additional treatment modality that also provides physical, psychosocial and quality of life benefits, Associate Professor Hart says.

“This work is world-leading and one day could lead to new international standards and recommendations for survivorship management.

“Once we are able to prove the clinical effectiveness on cancer specific outcomes like disease progression and overall survival, it will become standard of care,” he says.



How much does cancer really cost?

THE COSTS OF CANCER LAST FAR BEYOND DIAGNOSIS. HEALTH ECONOMICS RESEARCH IS PROVIDING EVIDENCE FOR WHAT SHOULD BE DONE.

Dr Maryam Naghsh Nejad knows the impact cancer can have on a person's life, with the diagnosis of several family members in recent years.

"It can change in one day the trajectory of your life. The ramifications of cancer last for many years, it's not just one incident," she says.

As a health economist working as a Senior Research Fellow in the Centre for Health Economics Research and Evaluation (CHERE), Dr Naghsh Nejad is providing valuable insights into how cancer impacts individuals and their families beyond their health, in order to inform policy.

She is using a new Australian Bureau of Statistics dataset (PLIDA) that links, for the first time, healthcare use data, tax records, Census and superannuation data for the Australian population.

"Of course cancer is a health issue and needs treatment, but what's given less attention is how people experience cancer, how it is impacting their families, and whether there is any lasting impact," Dr Naghsh Nejad says.



Dr Maryam Naghsh Nejad

Her recent work in this area, yet to be published in peer reviewed journals, has shown that people with cancer requiring chemotherapy are more likely to withdraw their superannuation before retirement age.

"Someone who is dealing with cancer might not be able to work. They exhaust their sick leave and there is no other government support while they are on treatment, and they're not considered for disability support.

"My research has found people with cancer are more likely to be under financial stress and to dip into their superannuation well before age 60, especially those who have a mortgage. This has important policy implications as cancer survivors usually have a long time to live so they will have fewer savings for retirement," Dr Naghsh Nejad says.

The new ABS dataset enables researchers to look beyond individuals to the impact of cancer on their families for the first time.

Dr Naghsh Nejad has researched the impact on families of having a child with cancer. She found that mothers' engagement with the workforce and salary drops for 4 to 5 years after a child's diagnosis, especially in more traditional households where fathers are less likely to be engaged in chores. The negative impact on work is however alleviated by having a female boss.

A third research project found adolescent children of parents with cancer are less likely to go to university, engage in university, or finish their course.

“What my work shows is that, if families have this awful thing happen to them, they need a lot more support,” says Dr Naghsh Nejad.

“Hopefully it will provide the evidence for designing policies that go beyond just treating cancer to considering how it affects people's lives.”

This work was conducted as part of the NHMRC Centre for Excellence (CRE) on Value-Based Payment in Cancer Care and was supported by a Merck MSD grant.



Improving diversity and inclusion in cancer clinical trials

BEYOND TRANSLATION: WHY ARE CALD COMMUNITIES UNDERREPRESENTED IN CANCER CLINICAL RESEARCH IN AUSTRALIA?

Diversity in cancer clinical trials is important because pharmacogenetic research has revealed there are significant differences in the metabolism, clinical effectiveness and side-effects of medications among people of different ethnic backgrounds.

But there is inequitable access to cancer clinical trials in Australia, and people from culturally and linguistically diverse (CALD) communities are significantly underrepresented in patient cohorts, says Dr Rayan Saleh Moussa, the Cancer Symptom Trials Postdoctoral Research Fellow.


That's not just due to a lack of English language proficiency or health literacy among CALD communities, she says. The trial sponsors, sites and researchers are also partly responsible.

“While there tends to be an intense focus on patient-sided challenges like language, it's crucial to recognise the broader spectrum.

“Consideration must extend to spiritual and cultural intersections often overlooked in discussions about research,” Dr Saleh Moussa says.



Dr Rayan Saleh Moussa



Dr Saleh Moussa, a first-generation Australian of Lebanese heritage, is studying the perspectives of healthcare professionals and researchers to better understand the barriers to cancer clinical trial access and inclusion from the Arabic-speaking community in Australia.

Widespread communication problems, time constraints and a lack of appropriate resources and training are all significant impediments, she has found.

She says it's also important to address additional, less highlighted, barriers like workforce diversity, time constraints in clinical consultations, and the absence of culturally suitable resources from sponsors and clinical trials sites.

She has found clinical trial researchers may unknowingly appear to be insensitive to some members of CALD communities. For example, members of the Muslim community may balk at experimental treatment due to Islam's focus on protecting and preserving the body.

Visit the [CST Diversity and Inclusion website](#) for a repository of resources to assist with diversity and inclusion in research design including webinars, guidelines and translated patient resources.

Find out more about [consumer engagement](#).

Join our [Cancer Symptoms Trials](#) or [Palliative Care Clinical Studies](#) collaboratives.

“Some patients may not be able to separate a potential therapeutic intervention from the requirements of their religion,” she says.

“If a trial is not aligned with the cultural and spiritual values of participants, and if sponsors or sites do not allocate sufficient resources to accommodate these aspects, the probability of participation from these communities diminishes.”

The solution is to increase diversity in clinical trial research teams, and in genuine engagement with CALD communities, she says.

“Don't waste money translating anything until you have connected with the community you wish to recruit from – not just the leaders and people who will volunteer as consumer representatives, you need to immerse yourself in that community and get to know it better and allow time for that relationship to strengthen.”

“Don't approach communities with pre-determined priorities and solutions, go in with an open mind and learn the community's priorities and generate solutions together.”

Dr Saleh Moussa has also been collaborating on a Cancer Institute NSW-funded study that will result in a co-designed trial navigator model that will train bilingual community educators to deliver in-language information around research literacy and health literacy, and assist clinicians in improving access for CALD communities to clinical research.

Find out more

For more information about our research impact in the Faculty of Health or for collaboration opportunities, contact:

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