Sydney HealthPartners



Amplifying Research Impact

Impact Report 2021–2023

Our Partners

NSW GOVERNMENT

Nepean Blue Mountains Local Health District

Sydney Local Health District

Northern Sydney Local Health District

Western Sydney Local Health District

The Children's Hospital at Westmead

THE UNIVERSITY OF SYDNEY

ADDRI Asbestos and Dust Diseases Research Institute

ANZAC RESEARCH INSTITUTE

Centenary Institute

Children's Medical Research Institute – Jeans for Genes

Chris O'Brien Lifehouse

The George Institute for Global Health

HRI Heart Research Institute

Kolling Institute – Bridging Medical Research and Health

Melanoma Institute Australia

The Westmead Institute

Woolcock – Leaders in Breathing & Sleep Research

Australian Government – National Health and Medical Research Council

NHMRC ACCREDITED RESEARCH TRANSLATION CENTRE

About Sydney Health Partners

Sydney Health Partners is a partnership of five major health services, one of the world's leading universities and 11 medical research institutes. As a partnership our unique advantage comes from the opportunity to align the capacity and capability of our researcher communities with the needs and priorities of our health organisations. Together we are finding effective ways to translate research discoveries into evidence-based healthcare. We are demonstrating that new interventions can be successfully implemented and scaled-up in large and diverse health systems to deliver benefit to our patients and wider community.

At the heart of Sydney Health Partners are our *Clinical Academic Groups*. The CAGs facilitate dialogue between our researcher communities and health organisations, to support practical actions for research translation and impact.

Sydney Health Partners works with the CAGs and our Partners on four operational priorities:

Supporting people -
by fostering the next generation of clinician-researchers

Improving innovation -
by linking promising research ideas to clinical priorities

Enabling research -
by improving research governance, data sharing, consumer involvement in research, and clinical trials support, and

Increasing impact -
by advancing the science of research translation through our *Implementation Science Academy*

We also work closely with NSW Health and its agencies to help facilitate health and medical research and to improve the alignment of our Partnership's extensive research capabilities with local and state healthcare priorities.

The National Health and Medical Research Council accredits us as a Research Translation Centre (RTC), one of 14 such centres in Australia. Through the *Australian Health Research Alliance*, we collaborate with the other RTCs to embed research in healthcare, better calibrate Australia's health and medical research with national healthcare priorities, and enable research translation for the benefit of patients, the public and the economy.

Introduction

It is my pleasure to introduce Sydney Health Partners' third Impact Report, which presents highlights of the Partnership's activity and achievements between 2021 and 2023.

By their nature, partnerships are dynamic, and Sydney Health Partners (SHP) has grown and evolved over this period. Like everyone else, we had to adapt to the unique challenges of the COVID-19 pandemic.

When I returned to the Executive Director's role in 2020, we were in the midst of the pandemic and our health services and medical researchers were being challenged in previously unimagined ways. At that time, Sydney Health Partners was at the end of a start-up phase, during which we had tested various strategies and methods to deliver our mission – to transform the way research improves patient care and public health in our health system.

Learning from the experience of those early years, we were much better placed to determine where and how our Partnership could add the greatest value for our researcher communities and health partners. This has enabled us to focus on practical ways of working with and through our Partners to improve the conditions and processes that influence research translation.

Our unique advantage comes from our opportunity to better align the capacity and capability of our researcher communities with the needs and priorities of our health organisations. This provides the best chance of ensuring that research questions of practical importance are answered in ways that are most likely to have impact on clinical and public health practice.

In the three years since, this practical approach to enabling research translation has created ripples that have radiated outwards, embracing our Partners and amplifying research impact, the theme of this report.

Alignment of interests requires dialogue. That's why we created 11 Clinical Academic Groups (CAGs) - to facilitate dialogue between our researcher communities and health organisations, and to support practical actions for research translation and impact. Several of the case studies in this Report stem from the work of the CAGs.

They are also front and centre in our efforts to build clinical research capacity across all organisations in the Partnership. Much CAG work is focused on supporting the development of earlier career clinician researchers, and this capacity-building is supported and extended by a range of other initiatives.

Most notable is our Research Translation Fellows program, and you'll find stories about the achievements of the five Fellows at intervals throughout this Report.

The CAGs are also benefitting from our longstanding commitment to develop the science of research translation – implementation science. This commitment was consolidated in 2023, with the establishment of our Implementation Science Academy. Alongside the University of Sydney, the Academy is working with our researcher communities to build capacity and capability in implementation science, while advancing the science through original research. Our growing community of practice, Academy Fellowship and Masterclasses are ensuring that our research community have access to the best advice on how to conduct research with impact.

As this report chronicles, Sydney Health Partners has a maturing program of work that is tightly focused on addressing the barriers to, and enablers of, research translation. Much of this work is unglamorous and sometimes unseen, but it is highly valued by our researcher communities. This includes sustained work across our Partners to help streamline and harmonise ethics and governance processes, to improve safe access to hospital and research data, and to advance meaningful involvement of consumers and the community in research.

In 2021 we were re-accredited for a further five years by the National Health and Medical Research Council as a Research Translation Centre following an open, nationally competitive process. This external recognition and all of the achievements described in this report could not have been achieved without the leadership and unwavering support of our Partners, and the enthusiasm of the growing ranks of clinicians and researchers who contribute their time, talent and ideas to our various programs.

I trust you will all find in this report evidence and encouragement that your efforts are having an impact, and that as Partners we are making progress towards translating research into better health outcomes for our patients and communities.

Professor Don Nutbeam
Executive Director,
Sydney Health Partners



Chair's Message



Professor Mary O'Kane AC

More than three years has passed since I was asked to chair the Board at Sydney Health Partners, and during that time it has become clearly apparent to me that there is a deep and unmet need for research translation.

Health and medical research organisations, whether they be within universities or research centres or institutes, have typically operated somewhat independently of our health services. Research Translation Centres (RTCs) like Sydney Health Partners have allowed us to consider how the health system can better use those research capabilities to solve really deep-seated barriers to delivering higher-quality health care.

SHP now has a wonderfully diverse program of activities that pick up on and leverage those capabilities.

While there are many initiatives of note, I've been particularly pleased by the way Sydney Health Partners has sought to create opportunities for postdoctoral early-career researchers and its work to enable clinical trials, and I've been thrilled by the evolution of the work we do with consumers.

None of these programs or their achievements would be possible without partnership and collaboration. Professor Don Nutbeam's international reputation and extensive networks have been crucial in building the required relationships. He is deeply respected for his knowledge of the issues around research translation, and he has brought all his experience to bear in building Sydney Health Partner's program of work and advancing a research-translation agenda at local, state and federal levels.

Don and the rest of the SHP team have built strong cooperative working arrangements with the other NSW Research Translation Centres – Maridulu Budyari Gumal SPHERE and NSW Regional Health Partners – and the other RTCs across Australia through the Australian Health Research Alliance. In doing so, the Centres have clearly been able to benefit from each other's strengths and particularities.

Australia needs to develop a research culture that is less inward looking and more oriented towards community and economic benefit. During my time as a researcher, I found that my most interesting work resulted from people and organisations knocking on my door and asking for help. Sydney Health Partners creates a space in which health services can describe their needs and priorities to researchers, and researchers can respond by proposing solutions that are designed from the outset with implementation and scalability in mind.

We also need to develop a better research culture in our health services and make them more supportive of research and, in particular, clinicians who undertake research. During my time as Chair, it's been very pleasing to observe that the five health services within our Partnership – all of which were already research friendly – have taken additional steps to become even more research active.

Sydney Health Partners is playing a key role in bringing our research ecosystem and our health services closer together. It is disappointing then, that SHP and the other RTCs have not received long-term funding from the Commonwealth.

It is obvious to me and my fellow board members that they are getting a great return on their investment in Sydney Health Partners.

Professor Mary O'Kane AC

Highlights

2021

Re-accredited for a further five years as a Research Translation Centre by the National Health and Medical Research Council (NHMRC).



Signed Memorandum of Understanding with Maridulu Budyari Gumal (SPHERE) and NSW Regional Health Partners to work in partnership and exchange experience and learnings in order to build capacity and capability in health research translation in NSW.

Received $7million from Cancer Institute NSW to establish Sydney Cancer Partners.

Nominated as Chair of the Australian Health Research Alliance (AHRA) Council for two years.



Awarded Research Translation Fellowships to five early and mid-career clinician-researchers.

Received funding from the AHRA Women's Health Research Translation and Impact Network to build capacity among early and mid-career female researchers. Eight researchers within the Partnership awarded grants.

Held first Implementation Science Masterclass for clinicians and researchers.



Established a Consumer Advisory Panel to provide advice to the Sydney Health Partners Board.

In conjunction with the NHMRC Clinical Trials Centre, appointed as one of nine infrastructure development nodes of the Health Studies Australian National Data Asset.

Welcomed the Melanoma Institute Australia to Sydney Health Partners.



Commenced a Clinical Academic Groups program with the appointment of six groups.

2022

Welcomed Nepean Blue Mountains Local Health District to Sydney Health Partners.

Received funding from NSW Office of Health and Medical Research to work with consumers to raise awareness of the benefits of participating in clinical trials.



Led organisation of the IRNet National Aboriginal and Torres Strait Islander Health Research Showcase.

Appointed five additional Clinical Academic Groups to Sydney Health Partners.

Hosted a research translation showcase for NHMRC, co-organised with SPHERE and the Sax Institute

Held first NSW summit of Human Research Ethics Committee leaders.



Launched Annual Awards for early career clinician-researchers at the Sydney Health Partners Annual Forum.

2023

Organised ISHCA 23 (Implementation Science Health Conference Australia), headlined by keynote speakers from Canada and the United States.

Launched an Implementation Science Academy, including new programs to support capacity and capability, innovation in implementation science, and collaboration and partnerships.



Announced 17 clinicians and researchers as inaugural Fellows of the Implementation Science Academy.

Held inaugural annual workshop for clinical trials professionals.

Expanded annual Implementation Science Pilot Grants program to 10 recipients.

Table of Contents

1 Alignment & Impact

Clinical Academic Groups 14
FluCARE Next Level 17
Unearthing Genetic Secrets 18
Covid-era Innovation 20
Treating Nerve Damage 22
Diverting Cardiac Patients 24
Eyles Fellowship 26
Prehabilitating Surgical Patients 28
Annual Forums 30

2 Implementation Science

Implementation Science Academy 34
Pilot Grants 38
Hip Fracture Recovery 42
Williams Fellowship 44
Implementation Science Conference 46

3 Clinical Trials

Strengthening Clinical Trials 48
Innovative Trials Workshop 50
Award-winning Trial 52
Ma Fellowship 54

4 Enabling Research

Governance Checklist 58
Support for HRECs 60
Data-sharing Initiatives 62

5 Consumer Involvement

Researchers and Consumers 66
Clinical Trials Recruitment 69
Findlay Fellowship 71

6 Capacity & Capability

Sydney Cancer Partners 74
Indigenous Research Showcase 76
Sierla Fellowship 78

7 Partnership & Collaboration

New Partners 82
National Collaboration 84
NSW Collaboration 86
Board and Secretariat 88
Committees 90



1
Alignment & Impact

Clinical Academic Groups Point the Way Forward for SHP

Sydney Health Partners has taken a strategic step towards better research translation with the successful establishment of a Clinical Academic Groups (CAGs) program.

Launched in December 2021 as a way of bringing together people from across the partnership with common research interests, the CAGs embrace doctors, academic researchers, nurses, allied health professionals and health administrators.

"Sydney Health Partners believes that improving the translation of research evidence into sustained clinical practice requires more effective collaborations between researchers, clinicians and administrators at all levels," said Sydney Health Partners Executive Director Professor Don Nutbeam at the time of the launch.

"The CAGs are working with our health partners to test, develop and implement innovations that deliver value-based care aligned with their needs and priorities."

The first six CAGs were appointed through an open, competitive process, and a further five groups joined SHP in November 2022. A 12th CAG was awarded develop-mental status.*

Each CAG is united around a clinical problem, discipline or population group, and addresses either important health priorities, health services priorities or innovations in healthcare.

While each of the CAGs has distinctive features, all are primarily focused on building capacity and capability in research translation, ensuring community and consumer involvement in research, fostering collaboration, and improving impact and competitiveness.

The Reproductive, Maternal and Newborn Health CAG was appointed in the second round. Co-chair Professor Dharmintra Pasupathy believes the CAG offers a way to more closely align research with the needs of the health services.

Clinical Academic Groups

Health Priorities

Cancer; Cardiovascular; Musculoskeletal; Diabetes and Obesity; Sleep Health; Child and Adolescent Health

Health Service Priorities

Geriatric Medicine; Perioperative Care; Reproductive, Maternal and Newborn Health; Child Development and Mental Health

Health Innovations

Virtual Care; Genomics and Precision Medicine



Kavisha Shah - Virtual Care CAG

"We sometimes find ourselves in a position where we are doing research which is giving us answers to questions not necessarily of primary concern to our health services," he said. "But because our CAG sits at the interface of clinical research and clinical service provision, it can engage not only with the wider discipline, but also the service leaders and decision makers within the Local Health Districts. So that feeds back and helps inform the research agenda."

The CAG used some of their capacity building funding to hold a successful research translation capacity building seminar for neonatal nurses and midwives.

The Genomics and Precision Medicine CAG believes that by working with doctors and other professionals from multiple areas of medicine, their group can support more genetic and precision medicine diagnoses and solutions.

"Being a whole new area of medicine compared with established fields, our CAG aims to develop a framework for broad implementations across NSW and Australia to make genetic testing and genetic therapies more available and accessible, including to regional areas," said Co-chair Professor Robyn Jamieson.

The CAGs receive organisational support and seed funding to develop a collaborative research-translation project for an externally funded grant application.

Each CAG is supported by a strong leadership team, drawn from across the partnership. The teams bring together people with diverse clinical, academic and administrative expertise and at different stages in their research careers.

In the case of the Diabetes and Obesity CAG, its establishment brought together researchers from different disciplines, but with common interests, for the first time.

"While there was very good will between isolated groups of diabetes and obesity researchers across Sydney Health Partners, we were not integrated as a whole," said CAG Co-chair Professor Louise Baur AM.

"The CAG unifies diabetes and obesity-translation initiatives across our different sites, providing a platform for collaborative research across the lifespan."

Fellow Co-chair Professor Stephen Twigg said the CAG was also playing an important role in capacity and capability building. →

"The Diabetes and Obesity CAG more formally brings early and mid-career researchers together with senior researchers, encouraging mentorship and development. And it will enable us to engage consumers more directly with an equity focus, which is important because we are particularly interested in looking at fairness of healthcare delivery".

For Sydney Health Partners, the CAGs have become the cornerstone of SHP operations, uniting various SHP activities in ways that align with priorities of its health service partners.

"The CAGs tie it all together. SHP provides support in consumer involvement and implementation science training, and with this, in addition to their own expertise, the CAGs are able to build capacity in translation across their research communities," said SHP CAGs Program Manager Andria Ratchford.

"For example, our Implementation Science Academy works closely with individual CAGs to help them consider from the outset how their project might be implemented in clinical practice. And we are training CAG members about best practice methods for engaging consumers in research."

The groups also engage in their own consumer activities. For example, a 'Consumer and Clinician Engagement in Research' webinar was hosted by the Sydney Musculoskeletal CAG, with practical tips for engaging clinicians and consumers in research. The Perioperative Care of Surgical Patients CAG held co-designed workshops with consumer involvement during the planning of their perioperative dashboard project.

The unique focus on research translation and clinical priorities has provided the SHP CAGs with opportunities for collaborations with existing University of Sydney research networks. For example, the CAGs leverage connections with existing University networks in cancer, cardiovascular, digital health and musculoskeletal health to promote their research-translation capacity building opportunities.

Since the inception of the program, membership of the Clinical Academic Groups has grown rapidly.

By July 2023, the CAGs had a combined membership of over 2000, including 150 senior clinicians and academics in the leadership teams.

Co-chair of the Cardiovascular CAG Professor Clara Chow said the Clinical Academic Groups are notable for the diversity of membership they have attracted.

"I think the CAGs provide a space where we can bring together academics that are not clinicians, clinicians that are not academics and people who are both, encourage diversity of thought, and understand the different roles each of us play in the process of research translation for patient benefit." ●









Developments Take FluCARE to the Next Level

In a classic case of adapting an existing innovation to meet an unforeseen need, Sydney Local Health District (SLHD) has taken a novel web-based application it designed to help residential aged care facilities (RACFs) to more effectively identify and respond to influenza outbreaks, and developed it to manage outbreaks of COVID-19 and respiratory syncytial virus (RSV).

The in**Flu**enza outbreak, **C**ommunication, **A**dvice and **RE**porting (FluCARE) app was first developed by SLHD in 2019, in consultation with the district's Aged Health, Chronic Care and Rehabilitation Team, local RACFs and the NSW Ministry of Health.

FluCARE was designed to address three key challenges identified in focus group discussions with RACF managers in the district.

They cited difficulties in remembering the outbreak criteria and therefore in recognising a potential outbreak, the need to fill out cumbersome spreadsheets and submit them daily via fax or email, and time-consuming phone calls and communications with the district public health unit and all the residents' General Practitioners, once an outbreak has been declared.

In 2020 a planned clinical trial of the app, supported by a Sydney Health Partners grant and involving several local RACFs, was disrupted by the pandemic. In just two months FluCARE was adapted to capture COVID-19 outbreak data such as time to notification, outbreak spread, duration and severity.

The primary objectives of FluCARE are to reduce delays to notifications, thereby reducing the spread and impact of an outbreak, and ease the workload on RACF staff.

Evaluation of the results indicated the app was safe, acceptable, and helped RACF staff to recognise and manage COVID-19 outbreaks as well as the flu.

The Senior Staff Specialist at SLHD, Dr Andrew Penman, said the trial demonstrated the value of an algorithm-driven decision support system like FluCARE.

"Outbreaks in aged care facilities place significant burdens on elderly residents and health services in the district," he said. "An application that can help RACF clinicians, hospital clinicians and public heath officers to intervene early and reduce outbreak duration, can save lives."

In early 2022, following the clinical trial, FluCARE was rolled out to 50 of the 51 RACFs within SLHD, so they could use it to report suspected cases of flu and COVID-19 during the autumn-winter respiratory virus season.

But while the application was widely implemented, its lack of purpose-developed functionality for COVID-19 presented challenges.

"We could get a notification of a COVID-19 outbreak from the app, but it couldn't provide RACF staff with decision support for their subsequent actions," said Dr Penman.

"In addition, during the pandemic our virus testing became a lot more sophisticated, allowing us to test for multiple viruses at the same time, so we wanted to redevelop the app to account for that."

The upgraded version of FluCARE provides aged care staff and GPs with disease-management support for cases of RSV, as well as seasonal flu and COVID-19.

When the new version of the app identifies a likely outbreak, it automatically sends an email alert to nominated RACF staff and the Public Health Unit at SLHD.

Once a potential or confirmed outbreak situation is triggered, FluCARE automatically sends an email to GPs and other stakeholders to advise them of the outbreak.

The RACF is provided with an action check list and links to posters, fact sheets and additional educational and instructional resources.

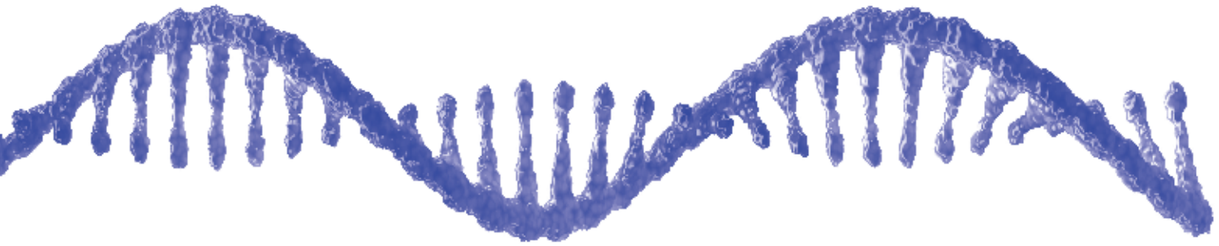
Dr Penman says the app has demonstrated its flexibility and is a good example of an innovation proven in the field.

"FluCARE doesn't replace the need for contact with the aged care provider but allows for real-time monitoring and updates for the duration of the outbreak, supporting timely communication with relevant stakeholders," said Dr Penman.

"We are now at the stage of refinement and scale-up, and FluCARE will become an important part of Sydney Local Health District's strategy of using digital means to integrate our healthcare service partners." ●

Beyond the Code: Unearthing Genetic Secrets in Patient RNA

Inherited cancer predisposition, muscular dystrophy, cystic fibrosis, ß-thalassaemia, motor neurone disease – these genetic conditions have few symptoms in common, but they can share a similar origin linked to RNA splicing errors.



RNA splicing is a crucial part of gene expression. When the body produces proteins, the DNA (its genetic code) provides the instructions to build them. Those instructions are captured by a molecule called RNA.

The RNA creates a blueprint for the protein that retains the coding parts of the DNA (called exons) and edits out the non-coding parts (called introns). It's at this RNA editing point that splicing errors can occur.

"During the splicing process, you have to cut out all the introns and glue the exons together perfectly so that recipe for the protein can be read," said Professor Sandra Cooper, Scientific Director of the Kids Neuroscience Centre at the Children's Hospital at Westmead, the University of Sydney and the Children's Medical Research Institute.

"Splicing errors change how exons and introns are cut and pasted together so that the protein code just turns into gobbledygook."

Some splicing errors are harmless, but others can drive the development of lifechanging genetic disorders. With initial support from Sydney Health Partners seed funding, Professor Cooper is helping researchers and clinicians to better predict the outcomes of these errors with the launch of a world-first data-prediction tool.

Called SpliceVault, this novel data catalogue has analysed the RNA present in 335,000 human cell and tissue specimens. By ranking the most common splicing mistakes that occur naturally, SpliceVault can predict with 92 per cent accuracy how splicing errors will impact a person's RNA.

"SpliceVault is a catalogue of all natural splicing mistakes. By knowing what splicing mistakes can happen, we can predict the splicing mistakes that will happen with a genetic variant," Professor Cooper says.

"It's the first evidence-based way to predict how the RNA will be disrupted."

Not random, but reproducible

Like most scientific breakthroughs, SpliceVault is an overnight success years in the making. Back in 2019, Professor Cooper was running a diagnostic program to test for RNA splicing variants — the first of its kind in Australia.

At the time, she was working with a cohort of patients who had the symptoms of genetic disorders but were unable to obtain a diagnosis, even after DNA sequencing at some of the world's leading institutions.

"We did RNA testing on those 50 undiagnosed families and found splicing variants in 46 out of the 50," she said.

"So I just knew that RNA splicing variants would be the big, new area."

Understanding just how and why those splicing mistakes occurred was the next mountain to climb. Armed with empirical RNA testing results for a hundred clinical cases, Professor Cooper's team made the discovery that every single splicing mistake identified in patient RNA was already captured in SpliceVault.

The key learning was that splicing mistakes that occur very rarely in healthy controls are the same ones activated in patients who have a DNA variant that causes an RNA splicing error.

Previously, clinicians around the world had to make an educated guess as to how a splicing error would manifest in a patient's RNA. Professor Cooper's team and SpliceVault shows the answer is unexpectedly simple — the same splicing errors recur across all 200,000 introns within the human genome.

It was reproducible, incontrovertible evidence of distinct patterns, rather than random occurrences.

"Think of a splice site as a set of traffic lights on a busy Sydney road," Professor Cooper says.

"What we did is we watched a million cars go down the road at all times of day over a year, and we watched what happened when the lights sporadically went out and which shortcuts the cars took around the backstreets.

"We catalogued all those shortcuts and listed the top four most common shortcuts taken by the cars. So essentially, if those traffic lights go out again, you've got a 95 per cent probability that the car will take one of those four most common detours."

The result is a tool that addresses a pressing challenge for researchers and clinicians, who often struggle to find the genetic cause of patients' inherited conditions.

Currently, only 30 to 40 per cent of patients will receive a clear genetic answer from DNA sequencing, the standard test for genetic disorders. Without a diagnosis, the remaining 60 to 70 per cent will struggle to access appropriate treatments and clinical trials.

"SpliceVault gives clinicians evidence about whether or not you're going to have a mistake in the protein, and what that mistake might mean for the patient," Professor Cooper said.

"Diagnostic rates sort of hover around 30 to 40 per cent from DNA sequencing at the moment. I really believe we can get that up to at least 60 per cent if we can bring RNA in."



Professor Sandra Cooper

Transforming the field of genetic medicine

Professor Cooper's work might represent a dramatic leap forward in the field of genetic medicine, but in the early days, RNA splicing research was a pretty hard sell. Even after the success of her 2019 RNA testing program, Professor Cooper says she struggled to secure funding.

"I tried to get money from everywhere — I kept saying, 'RNA, it's going to be all about RNA', but I just couldn't persuade anybody to fund the work."

When Sydney Health Partners stepped forward with a $200,000 Rapid Applied Research Translation Grant, Professor Cooper used it to scale up her diagnostic program. To date, she and her team have completed RNA testing for about 240 cases, with a diagnostic rate of about 75 per cent; this clinical data was critical to both discover and validate SpliceVault's accuracy.

Since then, the work has taken off with funding flowing in from the National Health and Medical Research Council, Luminesce Alliance and Lenity Australia.

In 2022, Professor Cooper received $3 million from the Medical Research Future Fund Genomic Health Futures Mission for what has now become a national project: RNA for Rare Disease (RNA4RD).

Over three years, in partnership with 23 hospitals, nine universities and six genetic testing laboratories, she'll be focused on embedding RNA testing into standard practice in genetic pathology labs across the country.

That means more confidence for clinicians, more answers for patients, and enhanced access to treatments and clinical trials that can help people living with a vast range of genetic conditions to achieve better health outcomes.

Says Professor Cooper: "RNA can provide a genetic answer for literally thousands of people every year." ●



Dr Michelle Barakat-Johnson

Covid-era Innovation Flourishes Post-pandemic

Amid the first wave of the COVID-19 pandemic in 2020, the Executive Clinical Research Lead and Manager of Skin Integrity at Sydney Local Health District (SLHD) decided to turn a national emergency into an opportunity.

Dr Michelle Barakat-Johnson used a Sydney Health Partners grant from the Medical Research Future Fund to trial a virtual wound care centre, which combined use of telehealth and a digital application to treat people with chronic wounds.

Three years later, Barakat-Johnson was on hand for the official opening of Australia's first Wound Care Command Centre at the RPA Virtual Hospital in Camperdown.

She told the launch that the Sydney Health Partners trial proved that a digitally enabled, virtual-based model of care could be successfully used to treat patients with wounds.

"During the COVID-19 pandemic we were able to expand our reach to locked-down wards and patients in their homes, ensuring expert wound care regardless of physical location," said Barakat-Johnson.

"Inspired by this success, we envisioned a Wound Care Command Centre —a place where every person with a wound receives tailored specialist treatment, through a combination of virtual and in-person visits, unlimited by geographical location."

Patients who have a chronic wound from a pressure injury or venous leg ulcer typically require ongoing community management. Traditionally, when a patient experiences a such a wound, they schedule an appointment with their GP, and often face a waiting period before they can receive the necessary care. If they need advice urgently, they might present to Emergency, sometimes unnecessarily.

The Sydney Health Partners clinical trial built on Barakat-Johnson's initial 2019 research trial of Tissue Analytics - an artificial intelligence-powered wound application developed in the United States.

The app, which can be loaded onto a phone, uses an image-recognition algorithm to analyse photos of wounds taken by the patient or their local clinician. It provides quantitative data on the wound enabling clinicians to remotely monitor progress and provide treatment advice.

For the patient, the app provides immediate guidance and support, including reminders to change dressings, without the need for physical visits or long waiting times.

In the Sydney Health Partners trial, Tissue Analytics served as a key point of communication between the patient and a wound consultant based at a hospital. The information was verified by the consultant during regular consultations via video conference and automatically uploaded into the patient's electronic medical record.

Fifty-one patients – half from Sydney and half from regional or rural NSW – were enrolled over seven months.

The trial proved the viability and acceptability of the model of care, finding that the virtual wound care centre improved patients' timely access to care, ease of communication with their wound specialist, and self-empowerment to manage their wounds.

The trial found that remote monitoring of wounds did not decrease the quality of care or increase risk to the patient.

The success of the clinical trial led to Therapeutic Goods Administration approval of the new model of care, and its implementation, via RPA Virtual, to serve the whole of Sydney Local Health District.

In January 2023, the Wound Care Command Centre at RPA Virtual began operations, initially serving 50 patients, who were referred by hospitals, Residential Aged Care Facilities and General Practitioners.

The centre is staffed by a Transitional Nurse Practitioner and two Clinical Nurse Consultants who share care with the patient's GP, treating practitioner or wound care specialist.

Barakat-Johnson says this innovative, multidisciplinary approach has multiple benefits.

"The program brings consistency to chronic wound management by minimising treatment variations and allocating resources efficiently. The shared-care approach also empowers patients to play an active role in their own healing process."

The Wound Care Command Centre allows patients to contact their wound specialist at any time and from anywhere - and access a file that records the chronological progression of their wounds. In addition, the patient's primary carer can use the service to access expert advice.

"It avoids patients being admitted to hospital and enables the earlier discharge of patients into their own home, which can aid their recovery," said Barakat-Johnson. "The patients also report that the program enhanced their experience and satisfaction with the healthcare system."

Barakat-Johnson and the team at SLHD are working with a health economist to evaluate the cost-effectiveness of the program, and confirm promising early signs that it will save money by reducing demand on the hospital system.

By mid-2023, the program had avoided 42 hospital admissions, and for those who were admitted, reduced the length of their hospital stay by between three and five days.

The scale-up of the program includes linking with regional and rural health services, including the Far West and Murrumbidgee Local Health Districts, to reduce gaps in access to specialist wound care and advice.

"Our mission is to provide expert care and advice through in-person or virtual visits, and by using the app," said Barakat Johnson. "Geographical barriers should never limit access to specialised wound care." ●



Implementing Early Identification and Treatment of Nerve Damage in Cancer Patients

A Sydney Health Partners supported project has raised hopes of better outcomes for cancer patients who suffer nerve damage because of chemotherapy treatment.

The project, which was part-funded by an SHP Implementation Science pilot grant, has proven that better screening of patients for early signs of Chemotherapy-Induced Peripheral Neuropathy (CIPN) can be routinely performed in clinical practice.

Now the researchers are investigating how to combine the early screening with better treatment for patients suffering CIPN and overcome the practical barriers to the wider implementation of the improved clinical pathway in New South Wales.

University of Sydney Associate Professor Susanna Park and medical oncologist at Chris O'Brien Lifehouse Associate Professor Peter Grimison began the project because CIPN was under-recognised and under-treated.

"There hasn't really been a guide as to how to ask patients about symptoms of CIPN and there is a huge amount of variability as to whether and how clinicians were screening for it," said Park.

"We thought that if we could standardise the way that screening was done – in particular using validated patient-reported outcome measures which have been shown to pick up early signs of neurotoxicity – we could identify patients suffering CIPN earlier and achieve better clinical outcomes."

CIPN happens when the nerves which are located outside of the brain and spinal cord are damaged as a side effect of cancer chemotherapy. While no two cases are exactly the same, the nerve damage typically causes pain, tingling or numbness in the hands and feet.

Other symptoms may include muscle weakness, dizziness, balance problems, ringing in the ears, hearing loss and constipation. While the symptoms often abate over time, they can be permanent and greatly affect a patient's quality of life.

CIPN can be reduced or stopped if it is identified early, and the chemotherapy dosage is reduced or given at greater intervals to allow the nerves time to recover.

Symptoms can also be managed by a variety of means including pain killers, exercise, physiotherapy, occupational therapy and podiatry, providing the CIPN is detected early.

"We are now aware that the proportion of chemo patients suffering from lasting neuropathy is dramatically higher than we thought even 10 years ago," said Park. "It is experienced by probably 30 percent of people who receive chemotherapy, but it's really undertreated."

Research into the implementation of enhanced screening for CIPN involved oncology clinicians at Chris O'Brien Lighthouse, which is part of Sydney Local Health District, and Prince of Wales Hospital in the South Eastern Sydney Local Health District.

"I think the clinicians believed they were already doing a good enough job of screening for neurotoxicity," said Grimison. "So, implementing the enhanced screening at the two test sites has been a big cultural change and a big technical challenge as well.

"The easiest way to screen the patient is to give them a paper questionnaire. But the problem with that is that someone has to remember to give the questionnaire, which is more difficult than you would think. And then someone has to look at the questionnaire and enter the data into some sort of record where we can see it.

"So, we wanted a sophisticated electronic solution, where people could answer the questions in their phones while in the waiting room or at home – and then the information could go into a database where people can see it."



Associate Professor Susanna Park, Associate Professor Peter Grimison

As a result of the project, the screening has been implemented into routine clinical workflows and results are incorporated into the hospitals' Electronic Medical Records systems, ensuring that patient CIPN information is routinely available to clinicians.

Associate Professor Park says the research identified the need to develop a clinical pathway with standardised suggestions as to what should happen if the screening identified a patient at risk of CIPN.

"Some people questioned the purpose of identifying CIPN early, given that we don't currently have a drug or similar that can reduce the toxicity," she said. "But we felt strongly that there is a real benefit to these patients because there are clinical interventions that can improve their quality of life, even while we continue to research for cures or strategies to prevent the nerve damage."

Oncologists, neurologists, nurses, allied health clinicians and consumers were consulted to develop a consensus on key elements of the clinical pathway.

"Our pathway identifies the circumstances in which you refer people to neurology for further investigation of unusual symptoms," said Park. "It also looks at pain and the drugs that can be used to relieve that. So, it's basically about getting the specialties together to better address CIPN."

As a result of their Sydney Health Partners project, Park and Grimison subsequently received a grant from the Avant Foundation, in collaboration with colleagues including Professor David Goldstein, to support continued development of the new CIPN clinical pathway.

In late 2023 they also received a larger grant from the Medical Research Future Fund, allowing them to test the implementation of / the clinical pathway, extending it to St George Hospital as the Mater Hospital Sydney, as well as Chris O'Brien Lighthouse and Prince of Wales Hospital.



"We are tailoring the clinical pathway to take account of the differing circumstances in these hospitals," said Park. "That's the trick with implementation – it's so much more difficult than you think. Even just the differences in systems between two hospitals in the same health district or the way things are done by two clinicians. So, there's no one-size-fits-all solution, which is why you just have to build relationships with the clinicians at each site, get nurses on board and more organically bring it together."

Associate Professor Grimison says the research team has learned that if there is not buy-in from senior staff, the new intervention "just won't happen."

"I've been a medical oncologist for long enough to understand how much effort it takes to implement something new. If the leaders are not interested and the clinicians are busy then there's not really any motivation to do it," he said.

Associate Professor Park says it is incumbent upon researchers to think not just about the outcome, but also about the best way to get to that outcome.

"I think it's evident to us now that we need to think more critically," she said. "When we propose enhanced screening, for example, we should ask ourselves,'Who is going to do that. How are they going to be compensated? How can we make it happen without adding a burden to frontline nursing staff who already have a list of tasks beyond what they might be able to do?'" ●

Saving Lives and Money by Diverting Cardiac Patients Away from the ED

One of the challenges facing emergency departments (EDs) is the large number of patients that present with chest pain. In Australia, 500 000 patients present to an ED with chest pain each year, making it the second most common reason of adult presentation.

At Westmead, Concord and Royal North Shore hospitals, these patients are now routinely assessed and treated in another part of the hospital away from the ED using an outpatient model of care.

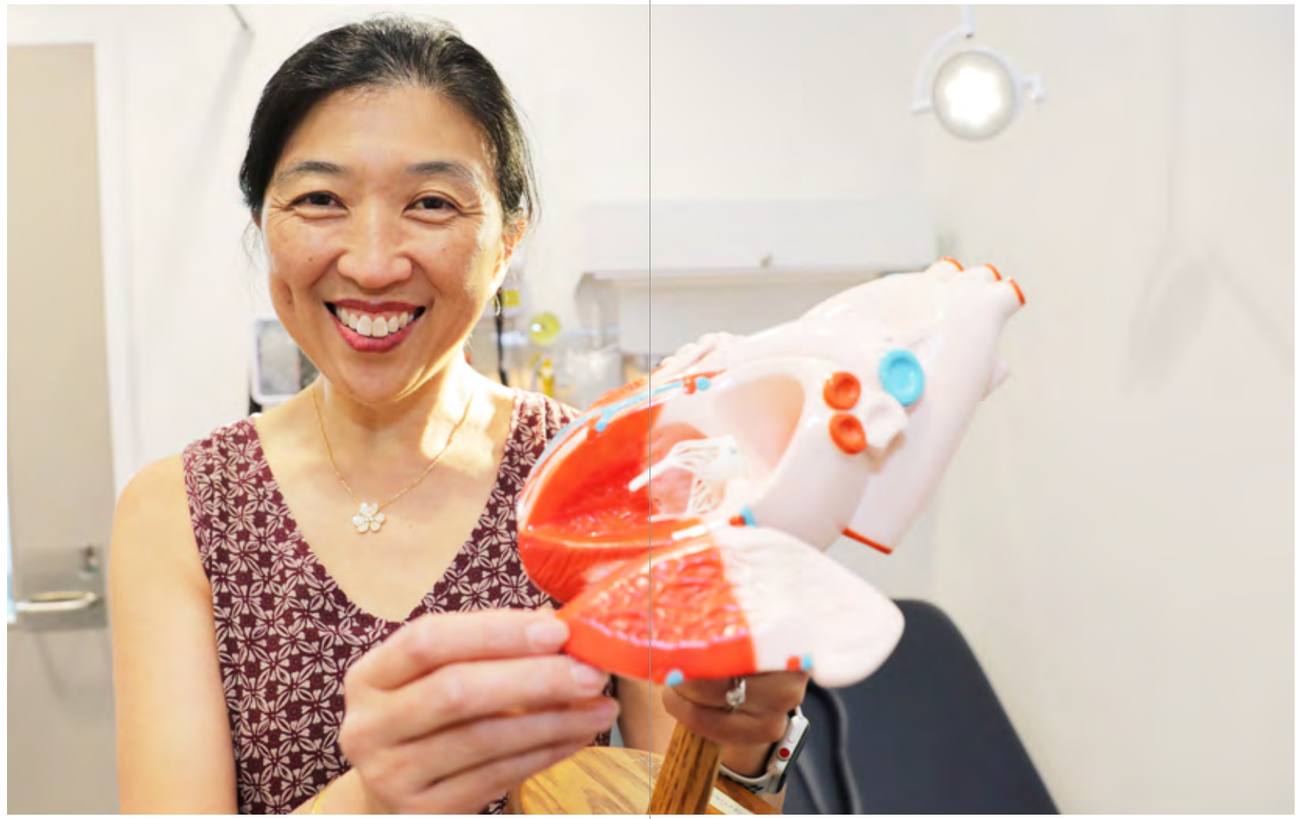
These Rapid Access Chest pain (or cardiology) Clinics (RACCs) are not only reducing pressure on over-stretched EDs and health budgets, research shows they are also saving lives.

In EDs, concerns about potential underlying cardiac causes of chest pain and care for patient safety often result in unnecessary and costly hospitalisations. The new model of care was first developed by Cardiologist and Clinical Lead, Community-based Cardiac Services at Westmead Hospital, Professor Clara Chow AM. She did so in response to evidence that up to 90 per cent of people who present to EDs with chest pain do not have acute coronary syndrome (ACS) and do not need to be admitted for observation or treatment.

"We know that the majority of chest pain presentations to Australian emergency departments are not ACS and that the assessment of such patients in emergency departments and hospitals is costly, lengthy and consumes significant resources," said Professor Chow. "Our model of care is a response to this growing need to improve the efficiency of chest pain management."

The RACC model of care was first piloted at Westmead in 2016 and became operational at Concord and Royal North Shore hospitals in 2018-19 with the support of a Sydney Health Partners Rapid Applied Research Translation grant from the Medical Research Future Fund.

In each RACC, a cardiologist is on duty to provide rapid assessment of whether the patient requires hospitalisation or can be safely sent home.



Professor Clara Chow AM

The original SHP clinical trial of the RACC model showed that the proportion of patients presenting to the ED with chest pain who were admitted to hospital fell significantly, from 71 percent in 2014 to 52 percent in 2018.

A year after initial presentation, the number of RACC patients who had subsequently suffered an unplanned cardiovascular hospitalisation, or had died, was 11.2 percent versus 23.1 percent amongst patients given usual care via an ED – a reduction of 59 per cent.

There were clear financial savings as well. Professor Chow says that while the RACCs in the three hospitals each operated slightly differently, they all showed a similar and significant net cost benefit per patient compared to inpatient hospital care.



"Despite their differences, all three clinics showed a similar cost per patient in the range of AUD$427–$474, and a similar net cost benefit per patient in the range of AUD$1,149 –$1,196," she said. "Scaling up to a national level could represent an even larger benefit for the Australian public health system."

Accordingly, since 2022, Professor Chow and other cardio-vascular researchers from Sydney Health Partners have been leading a national RACC initiative.

The network is bringing together researchers and clinicians from across Australia to compare various rapid access models of care being used to screen people with chest pain and other possible CVD symptoms.

"RACCs have popped up independently in several public and private hospitals elsewhere in Australia and we think they are each operating slightly differently and for different reasons," said Professor Chow.

"There are limited data to determine the most effective approach, so the network is mapping these rapid access services to see what their points of commonality or difference are, identify the data these RACCs have so we can benchmark and potentially harmonise them, and use what we learn as a case study in how to scale up such services nationally."

Meanwhile in Sydney, Professor Chow says she and her research-translation team are investigating additional opportunities to improve patient health outcomes through the rapid-access model of care.

"Our focus initially was just chest pain but as cardiac arrythmia becomes a more common health problem, we have explored using the rapid-access pathways for treating that," she said.

"But more generally, we often find that, while these patients may not have ACS, they do have one or more risk factors for CVD. So, when they are being assessed in the RACC, it presents us with an opportunity for disease prevention." ●

Research Translation Fellow: Jillian Eyles

In 2021, Kolling Institute researcher Dr Jillian Eyles was frustrated. A Sydney Health Partners-funded project she had worked on with Professor David Hunter at Northern Sydney Local Health District (NSLHD) had clearly identified several reasons why some patients in New South Wales were not receiving the recommended model of care for their osteoarthritis (OA).

More work was needed to find ways to overcome these barriers but the project, called OAChangeMap, had stalled due to a lack of ongoing funding.

So Dr Eyles applied for and was awarded one of just five Sydney Health Partners Research Translation Fellowships. It was a breakthrough moment for the early-career researcher, and for OAChangeMap.

"We didn't have the resources to take OAChangeMap to the next level. But receiving my fellowship allowed us to co-design solutions to the intervention-level, staff-level and system-level barriers we'd identified in 2019," she said.

"Now we're seeing the snowballing effect of the work supported by Sydney Health Partners, which has resulted in two other related research projects, both supported by Commonwealth grants."

NSW's OsteoArthritis Chronic Care Program (OACCP) is a model of care developed by the Agency for Clinical Innovation and based on research by Professor Hunter.

Developed in response to the ballooning demand for joint replacement surgery, OACCP has the ability to delay the need for surgery, and in some cases, remove patients from the surgery list entirely.

"It's a myth, perpetuated by a few in the medical profession, that everyone with osteoarthritis should have surgery, but in reality, less than 20 per cent of people with OA will ever need a knee or hip replaced," said Dr Eyles.

"OACCP recommends that before resorting to joint surgery, patients should be encouraged to learn about self-management for their condition, and try exercise and weight management to manage their OA symptoms."

Although this model of care is effective for some patients, and receives strong support from the NSW Ministry of Health, there is evidence that some sites report better outcomes than others, and the adoption of the model is not always optimal.

"One of the biggest barriers to the implementation of OACCP is its acceptability to patients. People often have preconceived and deeply ingrained ideas about what osteoarthritis is and what are effective treatments for it," said Dr Eyles.

"Sometimes they've been told that their joint is 'bone-on-bone' and that nothing but surgery will fix them, whereas OA is really a dynamic process that can be positively influenced by exercise and diet.

"My research team and I concluded that we needed some high-quality patient-education resources to help bust the myths around osteoarthritis and support patients to make more informed decisions."

The Researchers collaborated with a group of consumers to co-design the educational materials.

"The consumers pointed out to us that the language clinicians use is really important and that people with osteoarthritis really wanted hear and read motivating and positive things that promote physical activity and weight management, rather than words like 'degenerative' and 'worn-out'," said Dr Eyles.

The OACCP model of care is designed to be delivered by a Multi-Disciplinary Team (MDT), typically consisting of a physiotherapist acting as the program coordinator, a dietician and an occupational therapist. Depending on the size and resources of the healthcare facility, the MDT might also include a doctor or nurse, a psychologist or social worker, and an orthotist.

The first phase of the OAChangeMap project found that some clinicians in the MDTs thought there were aspects of osteoarthritis care not adequately covered by OACCP.

For example, most Program coordinators did not feel able to answer patient questions about medications.

"There were several OACCP locations which didn't have a doctor or nurse on hand as part of the MDT and when there were questions about medications and whether they needed a review by their GP, the coordinators didn't feel confident enough to advise the patient because it's traditionally out of their scope," said Dr Eyles.

"So, we identified that it would be quite helpful for them to have a bit more training about medications.

"They might also not have a dietician at their site, and an important part of OACCP is supporting people to manage their weight. That's very difficult for a physiotherapist and not within their traditional scope of practice."

Eyles' interviews with OACCP co-ordinators also revealed the importance of goal setting and person-centred care to support long-term behaviour change by the patient.

In response, during her Fellowship, Eyles and colleagues developed an online learning program called ATLAS (Arthritis Training Learning And upSkilling) to support the site coordinators in person-centred care, in motivational interviewing techniques, to increase their knowledge of medicines and address other knowledge and skills gaps amongst MDT members.

Dr Jillian Eyles





Further OAChangemap research also identified a need for a group exercise program for OA patients. This issue sparked an idea for a new project. Prof David Hunter, Dr Sarah Kobayashi, Dr Vicky Duong and Dr Eyles, were successful in a Medical Research Future Fund grant to adapt a proven program from the United States, called Walk with Ease for the Australian context, once again involving consumers in the process.

The study team plans to roll out the localized version of Walk with Ease through arthritis consumer groups in NSW and elsewhere in Australia, supported by social media.

As an additional arm, they are also evaluating the implementation of Walk with Ease in the OACCP at NSLHD, supported by a Ramsay Research and Teaching grant.

An unexpected challenge created by efforts to implement and scale-up OACCP has been dealing with its popularity. At NSLHD, for example, the majority of referrals to the Program are now from General Practitioners, rather than from surgical waiting lists. Coordinators of OACCP identified a need to stratify the model of care so that more people can be treated.

"Some people in the Program need only a light touch and get results quickly and easily," said Dr Eyles. "But others – perhaps because of psychosocial issues or family problems – need more intense face-to-face treatment."

Professor Hunter, Dr Jocelyn Bowden, and Dr Eyles secured a grant from National Health and Medical Research Council for a project comparing the standard OACCP with a version delivered via telehealth and a third version using a mobile app.

Called COASTAL, the aim of the research project is to learn which kind of patients should receive what method of OACCP treatment.

The expansion of research into the implementation of OACCP is a credit to Dr Eyles and her colleagues, but she is adamant that they wouldn't have come this far without Sydney Health Partners' support.

"We didn't have the resources to take it to the next level and now we're seeing the snowballing effect of the work supported by SHP.

"Along the way, I've been able to share what we've learned about research translation with other clinicians, who are keen researchers in their own right. So, I think it's not just patients who are benefitting from this project and its spin-offs, it's also clinicians within the Sydney Health Partners catchment.

"They can see now that implementation is about how you deliver care, and how you do that better." ●

Nepean Implements Wider Prehabilitation of Surgery Patients through Telehealth

Researchers at Nepean Blue Mountains Local Health District (NBMLHD) are investigating a novel means by which hospitals can meet NSW Health's requirement that patients undergo prehabilitation before elective surgery.

Short for pre-operative rehabilitation, prehabilitation helps to make people fitter for surgery by promoting physical exercise, better diet and a positive mindset.

Evidence shows that prehabilitation before major surgery can lead to a faster recovery, better health outcomes, improve the patient's experience and save the healthcare system money.



But only three NSW hospitals currently offer prehabilitation, and there are numerous logistical and geographical barriers to its wider implementation.

In an attempt to solve the problem, NBMLHD Clinical Specialist physiotherapist Dr Anwar Hassan and University of Sydney Research Fellow Dr Sviatlana Kamarova are investigating whether the same prehabilitation program can be effectively delivered via telehealth.

Dr Kamarova, who is a Fellow of Sydney Health Partners' Implementation Science Academy and works at the Allied Health Research Support Center at NBMLHD, says the randomised control trial, supported by a Sydney Health Partners Implementation Science Pilot Grant, will compare the effectiveness of the telehealth-delivered prehabilitation program with the usual face-to-face version.

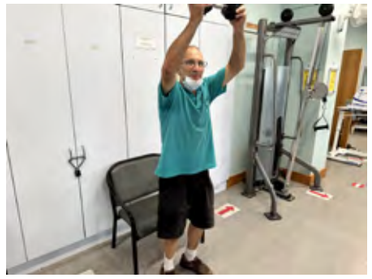
"We know prehabilitation works, but up until now, there's been no real evidence about what the most effective way is to deliver it to the patients, so there is nothing to guide clinicians trying to decide whether to do the prehabilitation face to face or via teleconferencing," said Dr Kamarova.

"In addition to patient outcomes, we are also analysing the trial outcomes at an organizational or system level, looking at the average length of patient stays in hospital and the health economic outcomes of that."

Dr Anwar has been at the forefront of developing and evaluating prehabilitation since 2018, when he established a service at Nepean Hospital for people scheduled for major abdominal or thoracic surgery called the Preoperative Education and Prehabilitation Program (PrEPP).







After three years in operation, analysis of PrEPP patient data showed that the length of hospital stay was reduced from an average of 10 days to 8.7 days. Unplanned ICU admissions were also significantly lowered.

"That has significant financial implications because just one day in an ICU costs the health system $5,000," said Dr Anwar. "And that's not to mention the reduced burden on patients and the health system that results from prehabilitation minimizing postoperative complications like pneumonia, deep vein thrombosis and wound infections."

The proposal to expand the reach of PrEPP through the use of telehealth arose as a result of the COVID-19 pandemic in 2020-21.

Nepean Hospital receives surgery patients from the central west of NSW as well as western Sydney and the Blue Mountains. With all elective surgery cancelled and clinicians unable to see patients face to face, Dr Anwar and his PrEPP team pivoted to consulting those on surgical waiting lists via video conferencing.

"We wanted to continue the prehabilitation of patients while we waited for elective surgeries to resume, and we had the idea that it would be possible via computer and phone. What we didn't quite expect was that some of those patients – the ones who lived in places far from the hospital like Lithgow, Bathurst and Orange – actually preferred receiving the prehabilitation program online."

In the telehealth trial, some of the patients who would normally attend physiotherapy at the hospital two days each week, do the exercises at home instead, supervised via teleconference. On three other days each week, they do home exercises without the supervision.

"One of the things we are looking at is patient compliance rates – are they doing the exercises? said Dr Kamarova. "That will tell us a little bit more about the barriers to the uptake of this telehealth from a patient perspective."

Dr Hassan says Australia lags behind comparable western health systems in prehabilitation, where it has been in use for a long time. He believes that part of the solution lies in convincing surgeons of its value.

"We are dealing with lots of surgeons, all of whom are quite busy people. So, getting them to think about referring their patient to prehabilitation when they schedule them for surgery can be a challenge."

"But the Agency for Clinical Innovation has made prehabilitation one of its four initiatives for elective surgery improvement in NSW, so people have started coming on board now and are taking a lot of interest."

Whether online or in person, Dr Anwar believes that a large part of PrEPP's success to date has been due to its "multimodal" approach to preparing patients for surgery.

"We do several different things simultaneously to improve a patient's readiness for surgery – physios work on their physical strength and fitness, dietitians review their eating habits, physicians assess their cardiovascular and lung health, and we might refer them to the acute pain team to make sure they understand pain management after surgery."

At its heart, prehabilitation is about empowering the patients.

"Most patients don't know what's going to happen in surgery or understand what happens when they go under general anesthesia," said Dr Hassan. "And when they wake up in the intensive care unit, they don't know what's going to happen next, who they will see, what their responsibilities are, how the pain is being controlled, and what the benefits are of getting up and starting to mobilize early.

"Done well, prehabilitation can prepare them mentally, as well as physically, for all of those things." ●

Annual Forums Help Develop the Research Translation Agenda

Between 2021 and 2023, Sydney Health Partners' Annual Forum established itself as an important event in the calendar of the NSW health and medical research community.

The trio of events featured a who's who of health and research leaders, becoming both an attention-getter and agenda-setter for improved research translation.





The first Sydney Health Partners Annual Forum was held in 2018 to a very positive reception. Substituted the following year by an implementation science-focused event, the scheduled return of the Annual Forum in 2020 was postponed due to the COVID-19 pandemic.

When the Annual Forum returned in June 2021 as a hybrid in-person and online event, it was warmly welcomed by a community seeking greater connection following more than a year of various social restrictions.

The keynote speech was given by the Secretary of NSW Health, Elizabeth Koff, who spoke about the ways research informs policy and practice in New South Wales.

"Every health entity needs to, in my mind, have some form of research endeavour and if they need support or collaboration with others, we should be able to facilitate that," she said.

The 2021 Forum also marked five years since the commencement of Sydney Health Partners, reviewing efforts to advance research translation, facilitate clinical trials and achieve research impact.

Cardiovascular CAG leader Professor Gemma Figtree said it was exciting to reach the milestone.

"On the fifth anniversary I think Sydney Health Partners has done a wonderful job with pretty much small amounts of seed funding," she said. "I think it's worth a lot more than the dollars and I think that's the thing that is special."



The theme of the 2022 Annual Forum was Innovation and Change, both of which had been experienced by the health services during the COVID-19 pandemic.

The Executive Director - Health Protection NSW, Dr Jeremy McAnulty PSM, gave the keynote address, providing an insider's view of the unfolding of the public health crisis in 2020. Fellow keynote presenter and Director of Evidence and Evaluation at the NSW Ministry of Health, Dr Andrew Milat, discussed some of the lessons from COVID and how they might inform future strategy and priorities for health and medical research in NSW.

The Executive Director of Sydney Health Partners, Professor Don Nutbeam, said that during the pandemic, there had been an observable acceleration of the translation of innovation and intelligence from research into clinical and public health practice and policy.

"We heard numerous examples during the course of the Annual Forum of the health ministry and health services making decisions based on the best available evidence," he said.

"We should take heart from that and lessons about how we can condense the time it takes to get innovation and good evidence into sustained clinical and public health practice."

The third successive annual forum looked forward from the pandemic, focusing on greater support for research in the hospital system. Addressing the theme *Aligning Research, Adding Impact*, presenters examined the opportunities and challenges involved in making health services more research active and making researchers more responsive to health service needs.

Keynote speakers were the incoming CEO of the National Health and Medical Research Council, Professor Steve Wesselingh and the Deputy Secretary, Clinical Innovation and Research at the NSW Ministry of Health, Adjunct Professor Jean-Frederic Levesque. →



(L-R) Professor Don Nutbeam, Dr Teresa Anderson AM, 2022 award winners Nicola Clayton, Leonie Cranney, Stephanie Partridge and Rebecca Sutherland, Professor Mary O'Kane AC





2023 Award winners: Janani Thillainadesan, Christina Abdel Shaheed, Nicole de la Mata.

The Chief Executive of Sydney Local Health District, Dr Teresa Anderson, told a discussion panel that "we can only have truly great health services if we have research, teaching and clinical practice intertwined and integrated."

"Collaboration has to be fundamental to what we do, and I think that's where the Research Translation Centres like Sydney Health Partners come to the fore, because they are built on collaboration."

A highlight of the 2022 and 2023 forums was the presentation by Sydney Health Partners of annual awards, celebrating the achievements of early career clinician-researchers.

2022

Dr Nicola Clayton – Sydney Local Health District
Award for Research Collaboration Across the SHP Partnership

Leonie Cranney – The University of Sydney
Award for Translational Research Addressing a Health Priority

Dr Stephanie Partridge – The University of Sydney
Award for Consumer Involvement in Health Research

Dr Anna Singleton – The University of Sydney
Award for Significant Research Contribution to Women's Health

Dr Rebecca Sutherland – Sydney Children's Hospitals Network
Award for Using Research to Change Health Practice

2023

Dr Nicole de la Mata – The University of Sydney
Award for Significant Research Contribution to Women's Health

Dr Christina Abdel Shaheed – The University of Sydney
Award for Consumer Involvement in Research

Dr Janani Thillainadesan – Sydney Local Health District
Award for Using Research to Change Health Practice

2 Implementation Science

Pioneering Implementation Science Program Leads to New Academy

Since the formation of Sydney Health Partners, high priority has been given to advancing the study of methods that increase the uptake of research findings into routine healthcare.

Known as implementation science, SHP's involvement in the discipline expanded substantially between 2021 and 2023 to become both a method for greater engagement and a source of academic and practical support for thousands of clinicians and researchers across the Partnership.

The seeds of the program's current success were planted in 2021 when Sydney Health Partners awarded 15 pilot grants in two rounds. The grants supported collaborative teams of researchers and clinicians to pilot test the implementation of a research innovation in clinical practice, with expectation that the outcomes would help the recipients secure further funding from larger grant schemes.

Announcing the grants, the then-Director of SHP's Implementation Science Program, Associate Professor Nicole Rankin, said the projects were chosen for their well-defined implementation and evaluation plans, as well as their diverse teams across the multiple Sydney Health Partners sites.

"Implementation at its best involves engagement and perspectives from multidisciplinary and collaborative teams," she said.

"All projects were required to nominate two principal investigators – one academic, and one from one of SHP's health service partners. This ensured the projects answered the clinical questions of our health services, while tapping into the academic expertise of the University of Sydney."

In November 2021, the Implementation Science Program sharpened its focus on building implementation science capacity and capability in the health workforce by awarding five Research Translation Fellowships.

Primarily funded by a Medical Research Future Fund grant to Sydney Health Partners, the two-year Fellowships provided salary to enable the Fellows to dedicate up to half of each week to their research and upskilling in research-translation methods while remaining in their substantive clinical positions.

Dr Alan Ma, a Clinical Geneticist at the Sydney Children's Hospital Network at Westmead, said his Fellowship helped to overcome a dilemma faced by many clinician-researchers.

"There's always this tension when you're a clinical academic – when do you do research and when do you do clinical work?" he said. "So, the greatest thing that this fellowship did is free up some of my clinical time to really focus on that clinically informed research."

Sydney Health Partners also launched a dedicated implementation science website, to support a growing community of practice.

The website provided the community with access to a library of academic resources and implementation-science tools.

Capacity and capability also developed through the teaching of annual Implementation Science Masterclasses.





(L-R) Dr Heather Shepherd, Dr Mitchell Sarkies, Associate Professor Leanne Hassett

The two-day events mix lectures with discussions and group work, supporting health professionals and health researchers to develop innovative research concepts.

The Masterclasses cover implementation theories, models and frameworks, as well as methodology development, including study-design selection and implementation-strategy determination.

"For me, talking about stakeholder relationships and scalability were real lightbulb moments," said 2023 Masterclass graduate Dr Sviatlana Kamarova from Nepean Blue Mountains Local Health District.

"Involving stakeholders and looking at how scalable our practices will be is something that we need to address much earlier in our research process."

In March 2022 Nicole Rankin moved to a new role at the University of Melbourne, and Sydney Health Partners took the opportunity to reshape the program to enable further growth.

Three University of Sydney academics were seconded to form an expanded leadership team.

Associate Professor Leanne Hassett, from the Sydney School of Health Sciences, was joined by NHMRC Emerging Leadership Fellow Dr Mitchell Sarkies and Dr Heather Shepherd, from the University's Susan Wakil School of Nursing and Midwifery.

Supporting them in advisory roles were Professor of Allied Health at Sydney Local Health District Andrew Baillie and University of Sydney Professor of Public Health Julie Redfern.

When the appointments were announced in October 2022, Dr Sarkies said Sydney Health Partners provided him with a rare opportunity to align research with clinical priorities. →



"It seems like Sydney Health Partners is in this really nice position to help implement the research coming out of institutes and make them work in the health service and communicate the needs of the health services back to those research institutes," he said. "That was quite a big motivator to be involved."

In March 2023, the program expanded to become the Sydney Health Partners Implementation Science Academy, supported by a completely revamped website.

At the launch of the Academy, Sydney Health Partners Executive Director Don Nutbeam said it represented a wonderful opportunity to consolidate and expand the work SHP had been doing in implementation science.

"Seven years ago, we decided that if we wished to improve health and medical research translation, we needed to understand the nature of change and the science of implementation," he said. "So, while the Academy has not come about overnight, it has found its moment."

It was announced that the Academy would undertake three interconnected initiatives: Capacity and Capability, led by Associate Professor Hassett, Innovation and Methods led by Dr Sarkies, and Collaboration and Partnerships, led by Dr Shepherd.

"I'm very excited about the Academy," said Associate Professor Hassett. "It's a great team, there's such a great opportunity with all our partners, and it really feels like we can make a change in how health is delivered here."

Boosted by the announcement of the Academy, the community of practice grew to over 1,300 members by December 2023.

"We continue to use the term community of practice to refer to our membership within the Academy because community is important to the successful implementation of health and medical research," said Dr Shepherd. "We need all the stakeholders to work together as a community, with everyone equal around the table."

In July 2023, the Academy recognised those clinicians and researchers working at the cutting edge of implementation science by announcing the appointment of 17 inaugural Fellows (see list), including the recipients of the previous Research Translation Fellowships and several graduates of Implementation Science Masterclasses.

The Fellows were invited to become advisors to one of the Academy's three initiatives, and more broadly, encouraged to share their expertise with others.

Sarah Reedman from The University of Sydney described being made a Fellow of the Academy as a great opportunity.

"To me, being a Fellow of the Implementation Science Academy means joining a collaborative group who are really passionate about translating research into practice and learn more about how I can improve implementation where I am working now."

In the same month, Sydney Health Partners' awarded a third round of Implementation Science Pilot Grants.

Dr Shepherd said that as part of Sydney Health Partners' commitment to fostering the next generation of clinical researchers, the program encouraged applications for projects led by early to mid-career researchers (EMCRs).

"It's increasingly difficult for EMCRs to win grants without having prior grant success, so we hope that this program will make a difference to the development of their research careers."

Having established a successful model for developing introductory-level skills in implementation science, the Academy is now turning its attention to how best to meet growing interest in the field.

The Academy team will work with the University's Faculty of Medicine and Health Academic Implementation Science Network to deliver more intermediate and advanced skills and maximise the reach and impact of the training.

It is also prioritising support for Sydney Health Partners' Clinical Academic Groups (CAGs), encouraging those teams to develop their pilot projects from the outset with an eye to their implementation.

This includes leadership workshops, support for CAG members applying for the translational research grants, advice for members seeking to embed implementation science in their projects, and reserving places in Implementation Science Masterclasses for CAG participants.

Co-chair of the Sydney Musculoskeletal CAG Professor Cathie Sherrington welcomed the Academy's support.

"It's fantastic to have a resource and have mechanisms to be connected with other people also seeking to learn more about implementation," she said. ●



Masterclass 2022

Implementation Science Pilot Grants

Sydney Health Partners provides pilot funding for collaborative teams of clinicians and researchers who wish to test the implementation of an evidence-based intervention, program or innovation.

Each of the projects is funded for two years and has two principal investigators – one research-based and the other clinically based.

The projects help the teams build translational research foundations, which will lead to longer-term impacts on health services and policy.

2023

Feasibility and acceptability pilot of a self-management intervention "My Personal Recovery Plan" (MyPREP) for people with serious mental health conditions

Academic PI: Dr Alyssa Milton, Senior Research Fellow, Faculty of Medicine and Health, The University of Sydney

Clinical PI: Professor Nick Glozier, Senior Staff Specialist, Sydney Local Health District and Professor of Psychological Medicine, Faculty of Medicine and Health, The University of Sydney

Helping clinicians and patients make sense of HPV-related oropharyngeal cancer: implementation of an information resource

Academic PI: Dr Rachael Dodd, Senior Research Fellow, Faculty of Medicine and Health, The University of Sydney

Clinical PI: Associate Professor Purnima Sundaresan, Senior Staff Specialist, Sydney West Radiation Oncology Network, Western Sydney Local Health District

Tailoring a bereavement model of care for the respiratory service of Nepean Hospital

Academic PI: Dr Nicci Bartley, Postdoctoral Research Associate, Faculty of Science, The University of Sydney

Clinical PI: Dr Laura Kirsten, Principal Psychologist, Nepean Blue Mountains Local Health District (NBMLHD)

Implementation pilot of virtual reality intervention to reduce adolescent/young adult distress in emergency departments

Academic PI: Dr Brad Ridout, Deputy Chair, Cyberpsychology Research Group, Discipline of Biomedical Informatics & Digital Health, The University of Sydney

Clinical PI: Dr Margaret Murphy, Senior Clinical Nurse Consultant (CNC), Westmead Hospital, Western Sydney Local Health District (WSLHD)

Tele-Prehabilitation for major abdominal and thoracic surgery to improve patient outcomes

Academic PI: Dr Sviatlana Kamarova, Research Fellow, Faculty of Medicine and Health, The University of Sydney and Nepean Blue Mountains Local Health District (NBMLHD)

Clinical PI: Anwar Hassan, Clinical Specialist Physiotherapist, Nepean Blue Mountains Local Health District (NBMLHD)

Impact of an interactive workshop on physiotherapists' implementation of an evidence-based e-health resource for people with musculoskeletal conditions in tertiary care

Academic PI: Professor Trudy Rebbeck, Professor of Clinical Translation in Allied Health, Faculty of Medicine and Health, The University of Sydney

Clinical PI: Ms Dragana Ceprnja, Health Professional Educator – Physiotherapy, Western Sydney Local Health District (WSLHD)

The acceptability of digital supports for families waiting for neurodevelopmental assessment

Academic PI: Dr Kelsie Boulton, Research Fellow, Faculty of Medicine and Health, The University of Sydney

Clinical PI: Dr Antoinette Hodge, Senior Clinical Neuropsychologist, Sydney Children's Hospitals Network

Evidence-based physiotherapy exercises for all

Academic PI: Professor Lisa Harvey, Senior Researcher, Kolling Institute, The University of Sydney

Clinical PI: Dr Joanne Glinsky, Physiotherapist, John Walsh Centre for Rehabilitation Research, Northern Sydney Local Health District

Move to improve: prescribing physical activity and deprescribing paracetamol: a pilot feasibility study

Academic PI: Dr Paula Beckenkamp, Senior Lecturer in Physiotherapy, Faculty of Medicine and Health, The University of Sydney

Clinical PI: Dr Mark Halliday, Physiotherapy Team Leader – Musculoskeletal Health, Sydney Local Health District (SLHD)

A digital tool for clinicians to improve the uptake of resistance training in cardiac rehabilitation (LIFT-CR)

Academic PI: Dr Matthew Hollings, Postdoctoral Research Fellow, The University of Sydney

Clinical PI: Mr Robert Zecchin, Nursing Unit Manager – Cardiac Rehabilitation, Western Sydney Local Health District (WSLHD)

2021

Online mindfulness-based stress reduction for chronic musculoskeletal pain: A pilot randomised controlled trial

Academic PI: Dr Anita Amorim, Lecturer at the School of Health Sciences, Faculty of Medicine and Health, The University of Sydney

Clinical PI: Dr Charlotte Johnstone, Anaesthetist/Pain Medicine Specialist at the Department of Anaesthesia, Royal Prince Alfred Hospital, Sydney Local Health District

Clinician created multimedia and multicultural cardiovascular m-Health education – EDUCATE_MI

Academic PI: Dr Liliana Laranjo, Community and Primary Health Care Practice, Faculty of Medicine and Health, University of Sydney

Clinical PI: Dr Aravinda Thiagalingam, Senior Staff Specialist, Cardiology Department, Westmead Hospital, Western Sydney Local Health District

Digital psychosocial assessment for adolescents in hospital settings: The HEEADSSS implementation study

Academic PI: Professor Katharine Steinbeck, Chair in Adolescent Medicine, Discipline of Child and Adolescent Health, Faculty of Medicine and Health, University of Sydney

Clinical PI: Dr Daniel Waller, Research Officer, Academic Department of Adolescent Medicine, Sydney Children's Hospital Network (SCHN Westmead)

A student-led speech-pathology telerehabilitation program for head and neck cancer survivors – an implementation study

Academic PI: Dr Emma Wallace, Lecturer/Researcher, Faculty of Medicine and Health, Discipline of Speech Pathology

Clinical PI: Ms Danielle Stone, Clinical Specialist Speech Pathologist, Department of Speech Pathology, Royal North Shore Hospital, Northern Sydney Local Health District

2020

An electronic integrative tool to facilitate adverse drug-reaction reporting at Blacktown Hospital

Academic PI: Professor Kate Curtis

Clinical PI: Dr Ronald Castelino

Other Collaborators: Dr Connie Van, Mr Raymond Li, Professor Bandana Saini, Ms Liz Ellankil, Associate Professor Lukas Kairaitis

BOOST: Boosting inpatient exercise after hip fracture using an alternative workforce: an implementation evaluation

Academic PI: Associate Professor Alison Harmer

Clinical PI: Ms Marie K March

Other Collaborators: Associate Professor Sarah Dennis, Professor Jim Elliot, Ms Katie Lee, Dr Stephanie Polley, Dr Bijoy Thomas

Enhancing transition from hospital to community-based exercise for patients with musculoskeletal disorders: pilot implementation study

Academic PI: Dr Marina B Pinheiro

Clinical PI: Mr Andrew Wood

Other Collaborators: Professor Catherine Sherrington, Dr Leanne Hassett, Mr Joshua Wakefield, Dr Mona Marabani, Dr Chris Needs, Dr Bethan Richards, Professor Adrian Bauman, Mr Fred Menz

Improving screening for chemotherapy induced peripheral neurotoxicity: A feasibility study

Academic PI: Associate Professor Susanna Park

Clinical PI: Associate Professor Peter Grimison

Other Collaborators: Professor Lisa Horvath, Professor Fran Boyle, Ms Tracy King, Professor David Goldstein, Dr David Mizrahi

A web-based intervention to support families following sudden cardiac death in the young

Academic PI: Assoc Prof Jodie Ingles

Clinical PI: Prof Chris Semsarian

HIPFFIT: HIP Fracture and Frailty Improvement Translational project

Academic PI: Prof Maria Fiatarone Singh

Clinical PI: Dr John Cullen

Medical Imaging for Covid-19 Efficacy (MICE)

Academic PI: Prof Sarah Lewis

Clinical PI: Dr Marion Dimigen

Implementing an oncologist-delivered intervention for fear of cancer recurrence: Adoption, costs, barriers and facilitators

Academic PI: Prof Phyllis Butow

Clinical PI: Prof Jane Beith

TAperiNG Opioids in older people with low back pain, hip or knee osteoarthritis (TANGO)

Academic PI: Prof Manuela Ferreira

Clinical PI: Prof David J Hunter

Implementing Navigate in NSW: An implementation study of a decision-aid for men with prostate cancer

Academic PI: Assoc Prof Ilona Juraskova

Clinical PI: Prof Manish Patel

Pilot implementation of *mypainhub* – an online resource for people with musculoskeletal conditions and their healthcare professionals

Academic PI: Assoc Prof Trudy Rebbeck

Clinical PI: Ms Katherine Makra

Using An Alternative Workforce to Boost Hip Fracture Recovery





Dr Marie March

One of the many challenges that can face those who wish to implement research evidence into routine clinical practice is securing enough staff to undertake and sustain the new intervention.

Senior physiotherapist at Western Sydney Local Health District (WSLHD) Dr Marie March was interested in the evidence from a clinical trial in Victoria, which had shown that providing hip-fracture patients with more frequent physiotherapy sessions was effective in improving their mobility and reducing the length of their hospital stay. But there simply weren't enough physios to make it happen.

It's a practical problem that inspired Dr March and fellow principal investigator Associate Professor Alison Harmer to propose and test a novel solution.

"We wanted to replicate the findings of the Victorian study, accounting for local differences in physio service provision, but our physiotherapist workforces have been stretched for a very long time," said Dr March. "The volume of patients we have to deal with in our hospitals is growing but the funding to support more workers on the ground is not. And at the same time, the clinical complexity of the patients we are seeing is increasing."

Dr March and Associate Professor Harmer's proposed solution was to explore whether an alternative workforce of pre-registration physiotherapy students and allied health assistants could, with supervision, provide hip fracture patients with physiotherapy exercises several times on weekdays, plus opportunistic intervention on the weekends.

Supported by an implementation science pilot grant from Sydney Health Partners, the BOOST pilot trial evaluated whether such high frequency physiotherapy using the alternative workforce was safe, acceptable, feasible, effective and cost effective.

"Hip fracture patients are a clinically challenging group," said Dr March. "They are usually older and frail and may have been on the cusp of needing nursing home placement at the time of their injury. The fracture is often the straw that breaks the camel's back of their frailty."

Dr March says the high-frequency physio model of care addresses the barriers to the discharge of these patients from hospital.

"The factors which typically limit their discharge are regaining sufficient strength, balance and the ability to walk. But these patients fatigue very quickly, so we found that a 'little and often' approach to physiotherapy exercises works better for them."

The researchers interviewed patients and carers to learn what they thought of the high frequency treatment.

"As part of a patient-centred approach, we wanted to understand the acceptability of high-frequency physio from their perspective, not just from the point of view of the staff implementing it," said Dr March.

"In WSLHD, we have over 150 languages spoken and the idea that you should increase exercise while you're recovering from surgery, rather than rest in bed, is often in contrast to common cultural practices.

"But hip-fracture patients told us that they see regaining mobility as synonymous with recovery more broadly, and that high-frequency physio met their goal of going home as soon as possible."

The intervention met health system goals as well. When trialled at Northern Sydney Local Health District's Hornsby Hospital and at WSLHD's Blacktown hospital, the BOOST model reduced the length of hospital stay in the acute ward from an average of eleven days to eight days.

"It was an important result because in the acute setting every bed day counts," said Dr March. "When someone is an inpatient for a long time, it's someone else's grandma that's stuck in ED with their hip fracture and can't come up to the ward because there's no bed.

"And so that was an amazing result and it's a credit to my colleagues across all the sites who worked hard to accomplish the clinical trial, despite some very difficult circumstances during the COVID-19 pandemic."

Dr March and her colleagues are now looking at ways the BOOST model of care can be spread to rural and remote areas of NSW and whether other workforce types - including nursing students, wardspeople or volunteers - can supervise the physio exercises.

"Hip-fracture care is a team sport and it's not just what the physio can do, it's actually what the whole team can do." ●



Research Translation Fellow: Nicholas Williams

Unwarranted clinical variation is a problem that concerns many healthcare systems. The processes and outcomes of healthcare can vary considerably depending on where and when a patient is treated.

For Sydney Health Partners Research Translation Fellow Dr Nicholas Williams, his concern about variations in the management of extremely preterm infants took his career in an unexpected direction, and changed the way he explains what he does.

"I've got Sydney Health Partners to thank for a lot of things," said Dr Williams. "Two years ago, I would have never said I was going to be an implementation scientist. In fact, I was never going to be a researcher, I was always going to be a straight clinician. And yet here I am."

Dr Williams took his first research steps in Vancouver, Canada in 2016, when he led a team that redeveloped the provincial guidelines for the perinatal management of anticipated extremely preterm births. This work was published in 2020, but adoption of the guidelines was frustratingly slow due to a lack of sustained funding for the project and difficulty achieving widespread acceptance amongst clinicians.

"I think this is where being a clinician as well as a researcher has its advantages," said Dr Williams. "I can see how clinical practice becomes set in stone and is incredibly hard to reverse."

It's a challenge that inspired Dr Williams – now back in Australia and working as a neonatologist in Sydney Local Health District – to successfully apply for a Research Translation Fellowship to develop similar evidence-based guidelines for extremely preterm births in New South Wales.

His first step was to determine if healthcare variation existed here.



Dr Nicholas Williams

"My initial idea was to analyse the conversations doctors have with parents who are expecting an extremely preterm infant, including discussions about whether they should pursue intensive versus palliative care.

"But data from those conversations is not routinely collected. Instead, by looking at what interventions were implemented in the delivery room, we were able to show quite clearly that there is a large degree of clinical variation across perinatal centres in NSW. Put bluntly, our review showed that even if you present at the exact same gestation, what you get offered in one local health district – and the resulting health outcomes – could be completely different to those if you presented to a different local health district."

Dr Williams' next step was to undertake a systematic review of clinical guidelines recently published elsewhere in the world, using the best parts of those to develop draft guidelines specific to NSW. It's expected that the draft will be completed in 2024 and distributed to neonatologists for feedback.

Their feedback, not just on the draft but also the potential implementation challenges and strategy, will inform refinement of the guidelines and the development of a plan to support statewide uptake.

Dr Williams says he had no experience in implementation science prior to his Fellowship and that the education he received from Sydney Health Partners fundamentally changed some of his thinking.

"I can vividly remember sitting in an Implementation Science Masterclass, which was being led by Professor Andrew Baillie, and almost arguing with him, saying, 'but I'm a clinician and this is what I think is probably going to the best way.' Now I can clearly see that having a measured, well-thought-out plan, and thinking about implementation right at the beginning of the project, will increase your chances of closing the knowledge-to-practice gap."

Dr Williams says the Research Translation Fellowship has also strengthened his resolve about the direction of his career.

"I'm sure now that I don't want to run randomized controlled trials, or to be involved in long-running bench science to find the next evidence.

"What I really want to be doing is work with those people to implement the evidence that they find, so that it results in real-world changes. I think at the end of the day, as a clinician, that's what I want to see - patient improvements, better outcomes."

And what does he tell people he does now?

"I do feel somewhat proud of how I've grown in this time. You know, now I definitely call myself a clinician researcher, and every now and then I catch myself saying I'm an implementation researcher." ●

Sydney Health Partners Leads International Implementation Science Conference

More than 300 people attended the second annual Implementation Science Health Conference Australia (ISHCA) in Sydney in March 2023.



With the theme "Scale, sustain, success," ISHCA 23 was headlined by international leaders in the fast-developing discipline of implementation science.

Keynote speaker Associate Professor Rachel Shelton, from Columbia University in New York, presented on the importance of sustaining evidence-based interventions after they have been implemented in health service settings.



Associate Professor Rachel Shelton



Professor Jeremy Grimshaw from the University of Ottawa, Canada presented the Day 2 keynote, describing the establishment of implementation "laboratories", which use new audit and feedback methods to enhance quality-improvement activities in hospitals.

ISHCA 23 also featured a dozen invited speakers from around Australia, 30 abstract presentations, 18 rapid-fire presentations and 43 posters.





Organisation of the two-day conference was led by Sydney Health Partners, with strong support from Maridulu Budyari Gumal SPHERE, the National Centre of Implementation Science, NSW Agency for Clinical Innovation, Health Translation South Australia, NSW Regional Health Partners, South Australian Health and Medical Research Institute, Melbourne Academic Centre for Health and Monash Partners.

3

Clinical Trials

Supporting National Efforts to Strengthen Australia's Clinical Trials System

Australia is home to a vibrant clinical trials culture. Between 2006 and 2020, over 18,000 trials commenced here — more than the UK, the USA and numerous European countries on a per capita basis over the same time period.[1] Positioning Australia as a go-to destination for clinical trials is a priority for the Australian Government.

But despite these successes, the clinical trials environment is hampered by a number of systemic shortcomings. These include sub-optimal management systems, lengthy ethics and governance processes and a lack of alignment across states and territories.

"The clinical trials landscape is very fragmented," saidAssociate Professor Angela Todd, Research Director of Sydney Health Partners.

"There's a lot of activity, but coordination between activities varies greatly – sometimes [it's] very good and sometimes not so good."

In 2022, the Australian Commission on Safety and Quality in Health Care released the National Clinical Trials Governance Framework in an effort to ensure greater consistency in clinical trials activity across the country, as well as to strengthen the clinical and corporate governance arrangements that underpin trials.

In the lead-up to the Framework's release, Sydney Health Partners received $467,000 from NSW Health to help build additional clinical trials expertise across the partnership. The funding, which was made available between 2019 and 2022, supported a range of initiatives that were overseen and guided by a new Clinical Trials Advisory Panel.

"The Clinical Trials Advisory Panel was set up initially to help build capacity and support clinical trials within Sydney Health Partners," said Professor John Simes AO, Chair of the Advisory Panel and the Senior Associate Director of the NHMRC Clinical Trials Centre.

"We wanted to look at a range of strategies to help do clinical trials better, particularly in terms of how we could integrate clinical trials research as a routine part of healthcare.

"Clinical trials are so important for providing evidence that can inform improvements in healthcare services and treatments."

Strengthening clinical trials recruitment

One of the first pieces of work to be delivered under the Panel's strategic direction was an environmental scan of clinical trials activity across the breadth of Sydney Health Partners.

Led by Project Manager Joan Torony, a clinical trials expert who was recruited to bring the Panel's vision to life, the review included interviews with 18 partner representatives. It identified 23 barriers to effective clinical trials activity in three key areas: recruitment, workforce planning and operations/infrastructure.

As a result of the scan, Torony worked with colleagues across partner organisations to focus on recruitment and retention of trial participants, a crucial but often highly challenging component of the clinical trials journey.

For example, in partnership with musculoskeletal researchers at the Kolling Institute and Northern Sydney Local Health District, a pilot project was launched to develop and evaluate a centralised clinical trials recruitment service.

Included in the pilot project was an investigator-led, placebo-controlled trial of surgery led by researchers from the Kolling Institute, which was facing recruitment challenges.

"Recruitment into surgical trials is known to be very difficult. Recruitment into placebo trials of surgery is 10 times harder," said Professor Manuela Ferreira, who leads the trial.

"One of the key issues is getting buy-in from clinicians and discussing what placebo surgery is with potential participants."

The initial aim was to set up a recruitment service that could help the research teams identify and overcome these barriers. But when COVID-19 hit and hospitals went into lockdown, the project team shifted to reviewing recruitment activities for already-established trials.

[1] Australia New Zealand Clinical Trials Registry (2020). *Latest update of the clinical trials landscape in Australia.*



Professor Manuela Ferreira



Their investigations revealed an ad-hoc approach and opportunities for better planning in the early stages. These findings led to the development of a planning tool and strategy template that will help research teams take a more structured approach to clinical trials recruitment.

"They came up with a very comprehensive plan of recruitment, from the pre-award stage, which is before you get funded for the trial, through to the point at which you're actually recruiting," said Professor Ferreira.

"It has really changed the model that we use to staff clinical trials. Now what we're trying to do is get one person to dedicate their time to recruitment across different trials."

The planning tool and strategy template are now publicly available on the Sydney Health Partners website, part of an extensive suite of clinical resources that were developed using the NSW Health project funding.

Other helpful tools include the Electronic Trial Master File, produced through a collaboration with the University of Sydney Clinical Trials Support Office, which helps researchers to organise and manage their clinical trials documentation.

A Being Audit Ready resource kit, designed in partnership with Maridulu Budyari Gumal (SPHERE) and NSW Regional Health Partners, contains tools, including checklists, guidelines and presentations, to help clinical trials teams prepare for the audit process.

It's accompanied by *Clinical Trials in Focus*, a podcast series co-produced by the three research-translation centres that explores the procedures and processes involved in auditing and monitoring clinical trials in NSW.

Enhancing the GCP capacity of the clinical trials workforce

In addition to these digital resources, Sydney Health Partners has also invested in providing access to Good Clinical Practice (GCP) training. GCP is an international standard for the design, conduct, recording and reporting of clinical trials, which ensures safe and ethical conduct.

Importantly, the new National Clinical Trials Governance Framework requires all staff working in clinical trials to complete GCP training and maintain up-to-date certification.

In collaboration with SPHERE and an authorised GCP educator, Sydney Health Partners sponsored a train-the-trainer program for GCP. Staff within partner organisations who complete the program can go on to deliver introductory and refresher GCP courses to clinical trial and other research staff.

"The introductory course provides an outline as to why GCP was first established, how to set up a research study, the importance of focusing on the health and welfare of research participants, best practice data management and safety reporting," said Quoc Nguyen, a project officer at the Kolling Institute who completed the train-the-trainer program.

Between June 2022 and July 2023, Nguyen delivered nine training sessions for staff at the Kolling Institute, Northern Sydney Local Health District and the University of Sydney, with 52 researchers obtaining their GCP certification as a result.

As well as building GCP knowledge and capacity within the NSW clinical trials workforce, Nguyen says the training supports his organisation to achieve its strategic and professional goals.

"I'm the Project Officer for the Kolling Institute's Research Strategy. One of the key objectives of the strategy is to enhance the Kolling's reputation for research excellence," he said.

"By offering an on-site GCP certification training program, Kolling researchers will be well placed to conduct clinical trials that will meet, not only the requirements of the National Clinical Trials Governance Framework, but also international clinical trials standards."

The NSW Health project funding has now concluded, but the Clinical Trials Advisory Panel will continue to guide Sydney Health Partners' work to support clinical trials activity. ●



Clinical Trials Staff Welcome Innovative Workshop

In September 2023, clinical trials staff from across Sydney Health Partners gathered for a unique one-day workshop.

Titled *Trials Without Tribulations*, the workshop at the Westmead Innovation Centre was attended by a capacity audience of 160 people after being significantly oversubscribed.

Attendee Frances Daley, a project manager with an osteoarthritis clinical research group at the University of Sydney, said there was "a real buzz about the day."

"It was really well organised and I appreciated the opportunity to connect with colleagues new and old around common concerns in the field of clinical trials," she said. "The sessions on audit and more diverse participants in clinical trials were particularly relevant and helpful to me."

The workshop mixed presentations with group activities, and most of the program was delivered by senior staff from across Sydney Health Partners organisations.

Suchit Handa from the Australian Commission on Safety and Quality in Health Care gave the opening address on initial learnings from the roll-out of the National Clinical Trials Accreditation Framework.

Other sessions included the need to plan and prepare for external audits, budgeting for industry-sponsored studies and strategies for getting paid for common hidden costs, and improving the recruitment of participants from more diverse backgrounds.

During a closing summation, Professor Manuela Ferreira from the Kolling Institute described the workshop as a very valuable opportunity for information exchange.

"Clinical trials staff rarely get the opportunity to compare notes with people doing the same or similar jobs elsewhere," she said. "The main thing we heard across the day was the need for more consistency in processes and procedures across clinical trials sites."

The Clinical Research Manager at Western Sydney Local Health District, Sharon Lee, said feedback from her colleagues who attended the event was "overwhelmingly positive."

"My staff thought it was great to have clinical trials people from the University of Sydney and the local health districts all in one place," she said. "And they were happy to be involved in the group work because they felt they were contributing to something that would be useful for everyone."

Research Development Manager at Sydney Children's Hospitals Network, Dr Helen Goldsmith, said the Trials Without Tribulations workshop revealed an unmet need for professional networking and knowledge exchange.

"We are all busy working within our silos and these frontline clinical trials staff don't often get opportunities to go to conferences like researchers do," she said. "I think that's one of the reasons why it was so well attended."

Among the most popular sessions of the day was a panel discussion on career progression in clinical trials.

Workshop convenor and Sydney Health Partners Research Director Associate Professor Angela Todd said planning the workshop revealed a big gap in professional education and training for clinical trials staff.

"It became apparent that there are only a few structured training opportunities for study coordinators, and those that exist are often expensive," she said.

"Better support for the professional development of trials staff is another important way to improve clinical trials and develop and retain great staff." ●





Winning clinical trial team (from left to right): Dr Bethan Richards, Dr James Edwards, Hannah Storey, Dr Gustavo Machado, Dr Danielle Coombs, Dr Chris Needs

Award-winning Clinical Trial Reduces Opioid Use by Changing ED Practice

A clinical trial supported by Sydney Health Partners has won multiple awards for significantly reducing the use of opioids to treat emergency department (ED) patients suffering acute back pain.

The Sydney Health Partners Emergency Department (SHaPED) trial tested ways to implement evidence-based clinical guidelines that recommend patients receive non-opioid treatments in the first instance.

SHaPED won the Trial of the Year Award from the Australia and New Zealand Musculoskeletal Clinical Trials Network in 2022, the 2018 NPS MedicineWise Award for Excellence in eHealth Resources and the 2018 Lyn March Award for Excellence from the Agency for Clinical Innovation (ACI). It was also a finalist in the 2019 NSW Health Awards (Value Based Healthcare) and was highly commended at the 2019 Sydney Local Health District (SLHD) Quality Awards.

Trialed in four EDs at SLHD and Dubbo Health Service, SHaPED encouraged busy doctors and nurses to follow the clinical guidelines of the ACI.

Co-led by Dr Gustavo Machado, Dr Danielle Coombs and Dr Bethan Richards from the Institute for Musculoskeletal Health (IMH), SHaPED showed that an implementation strategy combining clinician education, education resources, and audit and feedback avoided use of opioids in 12 per cent of patients who presented to an ED with back pain.

The treatment did not negatively affect the patients' satisfaction with care, pain scores or the impact of the back pain on their physical ability.

IMH Director Professor Chris Maher AM said opioid use for musculoskeletal conditions should be minimised where possible.

"While there is no evidence that opioids are an effective treatment for acute back pain, we have plenty of evidence about the harms caused by opioid use," he said. "Most of the thousands of people who have died in the United States from prescription opioid consumption, started taking the drugs because they had back pain."

The SHaPED team received $90,000 of seed funding from Sydney Health Partners in 2016, $315,000 from the NHMRC in 2017, and $20,000 from NSW Health's ACI in 2018.

The trial found that a key to changing the treatment approach of ED doctors and nurses was presenting data about the scale of the opioid problem.

"As a part of the trial, we accessed almost real-time data on the number of opioids used for back pain and presented it to the ED clinicians using data visualisation in the form of a dashboard," said Professor Maher.

"When we showed them the data, they said, 'oh no, that's not us, that's another hospital'."

"So, the doctors and nurses, because they were very busy, didn't realise the scale of the problem, but when it was presented to them, they wanted to be part of the solution."

The ACI model of care for acute back pain suggests that patients should not be prescribed strong and potentially harmful pain medications like opioids before safer alternatives are tried.

"ED clinicians should use non-pharmacological strategies such as heat wraps first, simple pharmacological strategies such as Non-Steroidal Anti-Inflammatory Drugs second, and only then in selected people might they have to prescribe an opioid in the lowest dose for the shortest period possible," said Professor Maher.

A follow-up study showed that the effect of the SHaPED trial on the behaviour of ED doctors and nurses was sustained for up to 30 months after the implementation of the clinical guidelines. There was also a significant improvement in the clinicians' knowledge and beliefs about back pain.

"Back pain is one of the top 10 conditions seen in EDs, but most ED clinicians are not taught the best way to manage it," said Dr Coombs.

The SHaPED trial demonstrated it is possible to change clinical practice at scale and, by doing so, benefit many patients.

"We had four hospitals, 269 clinicians and 4,491 patients involved in the trial," said Dr Coombs.

"It was also very much real world. Sometimes, for example, we had to reschedule the training as the ED was full of emergency cases and staff were literally run off their feet. If you can work in partnership with the staff to improve care in a less-than-ideal environment, then it is possible in other settings."

"The SHaPED trial also demonstrated that if we can get researchers and clinicians working together and moving between the two worlds, we will get research into practice more quickly."

Dr Machado said a major implementation lesson from the trial was the importance of gaining support from senior stakeholders.



"The key to this was getting the ED directors and senior consultants on board," he said. "They are the ones who can spread the word and motivate the junior ED clinicians to follow the recommendations.

"At a trial site where we had great buy-in from the ED director and some of the senior consultants and nursing staff, we saw the greatest reduction in opioid use."

In 2023, a team of clinician-researchers at Royal Brisbane and Women's Hospital began trialing a local adaptation of the SHaPED intervention in their ED. Results from the trial are expected by the end of 2024.

In 2022, Dr Machado and colleagues received a $2.8 million grant from the Medical Research Future Fund to test the effectiveness, cost-effectiveness, and scalability of a primary contact physiotherapy service in managing musculoskeletal conditions in EDs.

The RESHAP-ED study is a randomised controlled trial comparing primary contact physiotherapy management to usual care – which is managed predominantly by ED doctors and nursing staff.

"Musculoskeletal conditions are one of the top five reasons for presenting to EDs in Australia," said Dr Machado. "So, it's a substantial burden on the health system.

"This trial is investigating whether having patients with musculoskeletal pain primarily managed by a physiotherapist improves ED efficiency by reducing waiting and treatment times, as well as improves patient satisfaction and health outcomes." ●

Research Translation Fellow: Alan Ma

One of the biggest challenges when translating research into routine clinical practice is achieving scale. New evidence-based interventions can often be resource intensive, limiting the number and distribution of patients who can benefit from them.



Dr Alan Ma

A determination to overcome this implementation challenge is driving the research career of clinical geneticist and Sydney Health Partners Research Translation Fellow Dr Alan Ma.

Overwhelmed by the rapidly growing demand for genetic advice and input from clinical genetics services, Dr Ma and fellow clinical geneticists, genetic counsellors, and lab geneticists at the Sydney Children's Hospitals Network (SCHN) had resorted to meeting online to jointly consider numerous clinical cases and genomic results.

At the time, he says, these virtual genomic Multi-Disciplinary Teams (MDTs) were a pragmatic response to challenging circumstances.

"We couldn't keep answering random emails and phone calls for advice all the time because the demand for genomics input into every area of medicine kept increasing," said Dr Ma. "We had to find better ways of working, so out of desperation we started to do these virtual genomic MDTs."

MDT discussions were held via Zoom and ranged from 60-90 minutes. Simple cases were recommended for quick testing, while cases involving rare genes, complex results, or gene therapies received longer discussion and management planning.

"We'd sit in a virtual room with paediatricians, many in rural locations, and help them work out if their patient needed a genetic test, tell them how to order it, and guide them through the process," said Dr Ma. "Sometimes we would even help them interpret the results and advise how to talk to the family."

The skyrocketing demand for genomic medicine is the result of technological advances since a breakthrough in 2003, when the whole human genome – a complete set of genetic instructions in human cells – was mapped for the first time. That project took 13 years and cost $US 2.7 billion. Now, a person's genome can be sequenced in a few days for less than a thousand dollars, and an increasing number of genomic tests are now funded through Medicare.

A genomic test can provide doctors with important information about a patient's condition, including revealing an underlying illness and its genetic cause. Genomic understanding can also help stratify patients for appropriate treatment and provide information about their likely response to treatment.

Interpreting genomic data often requires collaboration between experts in molecular, clinical and functional genomics, as well as in organ-specific specialty areas. While the MDT approach has proven highly effective in other areas of medicine, most notably cancer treatment, its suitability for the implementation and delivery of genomic medicine was unclear.

Dr Ma used his Fellowship to lead a systematic review of whether the MDT model was the best way to facilitate genetic diagnostics and precision medicine and mainstream it into the health system.

"It was just something we were doing, but nobody had ever evaluated the evidence of the genomic MDT model's effectiveness or otherwise, or tried to establish any protocols to improve it," said Dr Ma.

"I wanted to know whether it was beneficial, improved outcomes or helped to propagate genomics into other areas.

"Another question was whether engaging highly specialized clinicians and scientists in MDT meetings was the most effective and efficient use of their limited time.

"I also wanted to know which factors determined the successful implementation and sustainment of the genomic MDT, and how those factors could inform future models of multi-disciplinary genomic care."

The systematic review, published in the European Journal of Human Genetics, found that the genomic MDT model facilitated higher diagnostic rates and improved the clinical management of patients.

The findings of the review were backed up by an evaluation of the genomic MDT approach at SCHN, which included surveys and interviews with stakeholders.

"When we surveyed the clinicians who had attended MDTs, most of them said it was a beneficial exercise," said Dr Ma.

"They were able to get a genetic test and a diagnosis that they might otherwise have been on a three-year waiting list for."

Dr Ma also found that an additional benefit of the MDT model was that it improved the acceptability of genomics within health services.

"It helped to mainstream the emerging discipline within health services by better informing the non-genetics workforce.

"Basically, because we couldn't do it all ourselves and there was a long waitlist, we were effectively teaching people how to do genomic medicine." →



Dr Ma's research is now being used by NSW Health's Agency for Clinical Innovation to assist in the development of guiding principles for genomic MDTs throughout the state.

Dr Ma is also an active member of Sydney Health Partners' Genomics and Precision Medicine Clinical Academic Group, which is focusing on genomic multidisciplinary models of care, its integration into non-genetics specialties, and building capacity and capabilities for better patient access to genomics and precision medicine.

"This group is exploring the of scope for genomic MDTs to inform scaling up and mainstreaming of genomics beyond the traditional Local Health District (LHD)," said Dr Ma.

"What we're doing with our virtual genomic MDT model is also improving access and equity. Patients from elsewhere in NSW can obtain an expert genomics opinion regardless of which LHD they are being treated by, and this promotes equity and access.

"So rather than having, for example, an expert in eye genetics in every LHD, maybe it makes more sense to have a couple of them located in one centre of expertise where they can advise services throughout the state. We can then examine the feasibility of scaling up that service. I think that's the next step to look at." ●

4 Enabling Research

New Governance Checklist Reduces the Research Admin Burden

When is a checklist more than just a checklist? When it eradicates countless hours of red tape that act as a barrier to research approval and, ultimately, research translation.

This idea sits at the heart of the Common Research Governance Checklist, a collaborative project to streamline the governance review process at multiple research sites across Sydney and NSW.

What started off as a small project within Sydney Health Partners to make research governance review processes more consistent ended up involving representatives from eight health organisations across NSW.

The Checklist, which was launched in November 2022, aims to ensure researchers are asked for the same information when submitting governance applications at multiple sites, and that governance teams are using identical processes when reviewing the applications.

"It's particularly useful for multi-centre research, but it also helps research at a single site, because it helps cement exactly what's needed," said Sharon Lee, Clinical Research Manager at Western Sydney Local Health District, who chaired the project working group.

"The Checklist tells you what's needed to submit your site-specific application."

At its core, research governance is about assessing the various risks of a proposed research project. All researchers must meet the governance requirements of the site/s at which their projects will take place.

But, despite all governance teams having a singular goal — to assess the risk for patients, researchers and organisations in service of high-quality research outcomes — the information requested by research sites, and their processes for collecting it, are often very different.

This can be frustrating for researchers, particularly those who are trying to establish projects across multiple sites, says Lee, who had been fielding an increasing number of complaints from researchers about the administrative burdens these processes were creating.

In 2022, she decided to take a closer look at just what researchers were being asked to submit. She conducted a quick review of WSLHD requirements and then jumped on the phone with a colleague at the Sydney Children's Hospital Network.

"I said, 'What do you ask for?' And it turned out they asked for different things," she said.

"We worked with Sydney Health Partners to get a group together and go through a mapping exercise, point by point, and rationalise why we were asking for everything. Did we really actually need it? What was it adding? Why was it part of the governance assessment, and did it need to be?"

In the early days of the project, the group was comprised of representatives from three health organisations, but word spread quickly. Soon, Lee was fielding calls from other health services wanting to join, including several from outside Sydney Health Partners. By the time the working group was in full swing, there were eight organisations involved.

And the work was illuminating. Not only were the governance teams requesting different things from researchers, but the variations were also so significant that it wasn't always clear how — or whether — the requested items supported the risk-assessment process.

"A classic example is CVs. About half the LHDs were requesting CVs for every researcher, and half weren't," Lee said.

"But hospitals will check researchers' employment details, so why did the governance officer need to recheck that? It was a waste of everybody's time and storage."

From the outset, the working group engaged in lengthy discussions about what, exactly, a governance checklist should include. What genuinely made sense from a risk assessment process? What could — and should — be removed from the list? What had to stay?

The work resulted in some robust conversations, but participants remained collaborative and engaged throughout.

"The big win for this project was that all of the groups that were involved did so in good faith. There was a lot of give and take," Lee said.

"People would say, 'Even though we've always asked for this at our institution, we probably don't need it, so let's get rid of it and take that step and fall into line together'."

The resulting Common Research Governance Checklist is a streamlined resource that's now in use among all eight organisations. When a researcher applies for governance approval at one or more sites that fall within a participating LHD or hospital network, all governance teams will ask for the same information.

The common checklist now used by governance officers is accompanied by a matching checklist for researchers, which helps them to put together the required documents in preparation for submission. If they supply everything listed on the checklist, they are unlikely to be asked for anything more.

The result is a win for researchers, who now can experience reduced delays around completing the governance-approval process. And it's also a win for research-governance professionals.



Sharon Lee

"The majority of research-governance managers are very keen to have consistency with reviews. Now we're all on the same page with what's being asked for and how projects are being reviewed," said Dr Lucia Smith, the Research Governance Manager for the Sydney Children's Hospital Network and a member of the checklist working group.

These checklists will also support governance professionals like Dr Smith to uphold what they see as one of their key responsibilities: supporting researchers to launch their projects as quickly and safely as possible.

"I think a lot of people feel as though governance officers are trying to make researchers' lives difficult," she said.

"That couldn't be further from the truth. We really want to try and facilitate their research projects to start in a timely manner."

The checklists have been in use since November 2022 and the working group continues to meet regularly to keep them up to date.

Participating organisations

Western Sydney Local Health District

Northern Sydney Local Health District

Sydney Children's Hospital Network

Sydney Local Health District

South Western Sydney Local Health District

St Vincent's Hospital, Sydney

Nepean Blue Mountains Local Health District

Central Coast Local Health District ●

New Support for Human Research Ethics Committees

A new online training course is helping human research ethics committee (HREC) members from the partner organisations of Sydney Health Partners and Maridulu Budyari Gumal (SPHERE) meet their annual development requirements at low cost.

Called Introduction to HREC Fundamentals, the course was developed by Sydney Health Partners and SPHERE in collaboration with clinical research education and training provider PRAXIS Australia.

This initiative overcomes existing barriers to HREC training, which often requires a significant commitment of time and funds.

"Accredited ethics committees have an obligation to provide annual training, but we know that many existing courses are quite time-consuming, onerous and expensive," said Associate Professor Angela Todd, Research Director of Sydney Health Partners.

"Research office staff who support HRECs are also under a lot of work pressure that can limit opportunities to provide regular training."

The new course is comprised of three modules covering research ethics, governance and clinical trials as they relate to human research ethics.

Content draws on the on-the-ground HREC knowledge of both Sydney Health Partners and SPHERE, combined with PRAXIS's curriculum expertise.

Introduction to HREC Fundamentals was released in August 2022 to positive feedback and is now available to staff of Sydney Health Partners, SPHERE and their partner organisations at a cost of $100 per person.

As at August 2023, 89 people had registered for the training.

HREC Leaders' Summit

In October 2022, Sydney Health Partners and SPHERE hosted a pioneering event for HREC leaders in New South Wales.

Called the HREC Leaders '22 Summit, this free event drew together 77 HREC chairs and ethics and governance leaders, offering a unique opportunity for HREC professionals to come together and workshop pressing issues in the research-ethics space.

According to event co-organiser Merrilee Kessler, the goals of the Summit were to create a knowledge-sharing and professional development opportunity for HREC professionals, as well as to celebrate the role of HRECs as a fundamental component of research.

"We wanted to give them that opportunity to share knowledge about the particular things they have to make decisions about as HREC chairs or leaders within a research office," said Kessler, Project Officer, Clinical Trials at SPHERE.

Event content spanned four key themes: engaging researchers in the ethics-review process, the ethical issues of consent and data sharing, ethical challenges raised by new research methods, and best practice involving consumers.

Professor Ingrid Winship, Chair of the NHMRC Australian Health Ethics Committee and Chair in Adult Clinical Genetics at the University of Melbourne, delivered a keynote address on the roles and responsibilities of HREC committees and the potential impacts of changing ethics review processes on academic and clinical research.

Other sessions included a presentation on the 'value add' of HRECs and a discussion about 'tricky' research-ethics issues that delegates themselves had identified. These included opt-out consent, accessing data from social media for research purposes, and useful approaches to framing the feedback that HRECs provide to researchers.

Participants reported favourably on the Summit, with more than 97 percent indicating that they were satisfied with the event and 95 percent agreeing that it met their expectations.

Professor Ingrid Winship





HREC Calendar

In 2021, Sydney Health Partners made Human Research Ethics Committee (HREC) meeting dates across its health service partners available in one place for the first time, with the creation of a HREC calendar.

Researchers who want to conduct health and medical research in the NSW public health system must receive ethics approval from an appropriate HREC, however this approval can be from any committee that falls within the National Mutual Acceptance agreement.

Within Sydney Health Partners there are five ethics committees across the health service partners, which collectively hold three or four meetings a week, offering researchers multiple opportunities to submit their work for review.

The calendar makes it easier for researchers to find the next available, relevant HREC meeting across the Partnership to which they can submit their research for ethics review. By displaying all dates in a single place, it allows users to filter for meetings depending on their research needs.

At Northern Sydney Local Health District (NSLHD), the HREC grants up to 200 human-research-ethics approvals a year, and roughly one quarter come from researchers outside of the district.

Former chair of the Northern Sydney Human Research Ethics Committee Associate Professor Geoff Herkes worked on the original Directory project. He said the combined calendar was an opportunity to smooth the path for researchers before they submit projects for ethics review.

"It's an important initiative, which gives as much information as possible to researchers in an accessible format, so that they can move their projects along smoothly," he said.

Research Strategy and Partnerships Manager at NSLHD, Rebeka Freckleton, worked with the cross-Partnership team that oversaw the project. She said there was enormous pressure for research to be "done yesterday."

"Getting the upfront administration done, including ethics, is sometimes seen by researchers as a hurdle," she said. "Anything we can do to improve efficiency and make things easier for researchers is a good thing." ●

New Data-sharing Initiatives to Transform Health and Medical Research

We live in the age of Big Data – according to some estimates, we're set to create and consume 175 zettabytes of data globally by 2025. This mass proliferation of information has the potential to deliver new and exciting insights into some of the greatest problems facing the world today.

But in the Australian health and medical research sector, gaining access to meaningful data that will enable the production of new knowledge remains an ongoing challenge.

"Health services and data custodians have a traditional position of being very protective of patient data — and rightly so," said Associate Professor Angela Todd, Research Director of Sydney Health Partners.

"As a result, accessing health data, even de-identified data, for research purposes can be difficult."

Over the last few years, Sydney Health Partners has been working to help overcome these data-access challenges both locally and nationally. In 2019, the organisation led the development of a Data Sharing Accord that was intended to provide a consistent approach to data access, security and reporting for researchers and signatory organisations.

In 2022, in collaboration with a team at SPHERE who had signalled their interest in adapting the Accord for their own use, Sydney Health Partners launched a project to update the Accord and make it fit for purpose in a changing data landscape.

"We knew there had been some legislative changes nationally, so we wanted to check that it was still current," said Associate Professor Todd, who led the work.

"We also knew that NSW Health was reviewing its data access policy, so we wanted to see if there was anything coming down the pipeline that we should build into the revised Accord."

Like its predecessor, the updated Accord will continue to facilitate the lawful and secure sharing of de-identified patient health data for use in health and medical research.

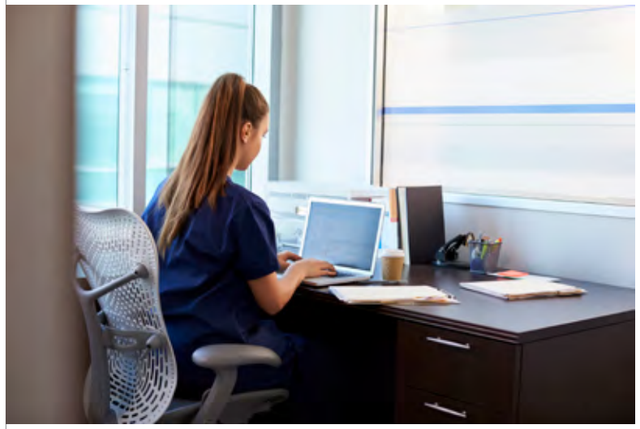
In doing so, it will give health services the confidence that researchers will be bound by rigorous data-use standards. It also provides researchers with a single set of requirements that apply to multiple data sources.

"It was really an attempt to reassure health services that we could put a whole bunch of checks and balances in place and standardise them across the partnership," Associate Professor Todd said.





Professor Angela Webster



Over a six-month period, the team conducted a review of the existing Data Sharing Accord and Checklist, as well as a review of other key state and national data-access documents.

They also consulted broadly within Sydney Health Partners and SPHERE, including hosting two online webinars for health and university staff and consumers to provide input, and engaged with NSW Health to better understand the ongoing revision of the NSW Health Data Access Policy.

The updated Accord incorporates the Five Safes framework, an internationally recognised approach to assessing and managing data-disclosure risk.

"We revised the content that was in the original Accord under this Five Safes framework and presented the information in a much more robust way," Associate Professor Todd said.

Draft documents were circulated to the Sydney Health Partners Research Development Committee and Board for review and feedback, as well as other stakeholders across our partnership. To date, the revised Data Accord has been signed by all five health service organisations of Sydney Health Partners, as well as seven medical research institutes.

Signatories to the revised Sydney Health Partners Data Sharing Accord

ADDRI

ANZAC Research Institute

Chris O'Brien Lifehouse

Heart Research Institute

The Kolling Institute

Melanoma Institute of Australia

Nepean Blue Mountains Local Health District

Northern Sydney Local Health District

Sydney Children's Hospital Network

Sydney Local Health District

Western Sydney Local Health District

Westmead Institute for Health Research →

Australia's first-ever national data-sharing platform

At a national level, Sydney Health Partners is also supporting the development and rollout of a new data-sharing initiative that aims to make clinical trials data available for secondary use.

Called the Health Studies Australian National Data Asset (HeSANDA), the program is an initiative of the Australian Research Data Commons (ARDC) and is intended to become Australia's first national data-sharing platform.

The platform, named Health Data Australia, includes centralised infrastructure and local nodes that facilitate access between researchers who want to share data.

Sydney Health Partners is collaborating with the NHMRC Clinical Trials Centre (CTC) to lead the SHP-CTC node, one of nine local nodes in Australia. The work was originally supported by $300,000 in ARDC funding as well as in-kind contributions from node partners.

"A national data-sharing platform will support the production of high-quality, cost-effective health and medical research by reducing research duplication and helping to synchronise research efforts across the country," said Professor Angela Webster, Director of Evidence Integration at the NHMRC CTC.

"This project will also help develop Australia's data culture and enable meaningful integration with growing international pressure to maximise value from research data."

The platform will house the metadata of a vast range of clinical trials, including study protocols, data dictionaries, publications and dataset descriptions. Secondary researchers can search the Health Data Australia catalogue to identify trials that are likely to contain data of interest to their work.

Researchers can then submit a data access request to the data custodian, who reviews the request in line with the node's data-sharing guidelines, including the custodians' local data-access policies. If the request is approved, both parties will enter into a data-sharing agreement that will provide the researcher with access to the de-identified data in full.

"All Health Data Australia users will be bound by a set of shared standards around data access, security and storage," said Dr Talia Palacios, Project Manager for the HeSANDA Sydney Health Partners-CTC node.

"This process will create an unparalleled opportunity for researchers to access a wealth of data that may otherwise be out of reach or difficult to obtain."

The project has been split into three key phases. In the design phase, which took place from July to December 2021, node representatives worked together to create coherent data practices, models and frameworks in four key areas: information design, data access, ethics and consent, and technology.

During the development phase, which commenced in December 2021 and ran for 12 months, the teams established the HeSANDA infrastructure at their respective sites. The SHP-CTC node also developed the technological, administrative and research processes required to share clinical trials metadata between Sydney Health Partners' partnering organisations and the Health Data Australia platform.

Now, in the test-and-deployment phase, which commenced in January 2023, the nodes have included the metadata for 114 clinical trials to demonstrate how the system will work.

While the technical work is full steam ahead, the road to a national data-sharing platform is far from smooth. Merely building the platform won't be enough to transform it into a widely used resource.

"We need a change of mind and a change of culture about how important data sharing is, not only for researchers but for patients too," said Dr Palacios.

To this end, node teams have also received $50,000 in additional funding to develop a series of communication and dissemination resources to support project uptake. All HeSANDA nodes have worked together to develop a suite of videos to address the needs of HeSANDA users and highlight the benefits of data sharing. The SHP-CTC node has also developed interactive guidelines to simplify the process of managing data requests.

Health Data Australia was launched on 18 July, 2023, opening the door to a new era of data sharing that could transform health and medical research in Australia. ●

5 Consumer Involvement

Two Pieces of the Same Puzzle: Bringing Researchers and Consumers Together

Consumer and community involvement (CCI) is becoming a non-negotiable component of health and medical research in Australia. Increasingly, grant-funding schemes require researchers to integrate CCI into their research planning and activities.

Despite growing recognition of the value CCI brings to health and medical research, in Australia, it remains in its infancy. Developing a robust culture of CCI that puts the patient at the front and centre of research outcomes is an important pathway to research translation.

Over the past two years, Sydney Health Partners has invested in a number of key projects designed to help researchers engage more effectively with consumers, as well as to support consumers to better understand the value they can offer to the research process.

In 2021, a Consumer Advisory Panel was established to provide strategic oversight of CCI activities across the partnership. Initially chaired by the then consumer representative of the Sydney Health Partners Board, Mohit Kumar, and comprised of 12 partnership representatives, the Panel works to help ensure that consumers play a guiding role in the development of CCI initiatives moving forward.

At the operational level, an ongoing collaboration with Health Consumers NSW (HCNSW) remained a key driver for CCI activity over the period of this report.

Building on the findings of a previous environmental scan of existing consumer and community involvement in Sydney Health Partners research, Sydney Health Partners and HCNSW co-produced three interrelated documents – guiding principles, a guiding framework and a language guide – that will assist future CCI engagement. These documents are now available for use across the partnership.

Alongside consumer network members from Sydney, Western and Northern Sydney LHDs, Sydney Health Partners also produced a brochure to help consumers understand how – and why – to engage with health and medical research.



"Consumers can contribute to research in many different ways, but often people don't realise there are opportunities available that they can easily take part in," said Linda Komarek, a project manager who leads Sydney Health Partners' CCI program.

"The many different options for involvement are outlined in the brochure."

Sydney Health Partners' earlier CCI research also highlighted an increased and ongoing need to facilitate collaborative relationships between consumers and researchers. In response, staff from Sydney Health Partners and HCNSW worked together to design two training modules to prepare consumers and researchers to work effectively together.

They also facilitated a series of online and face-to-face events to encourage networking, relationship building and collaboration between these two groups. This work has built capacity among researchers and consumers who are interested in working together.

"The best partnerships happen when researchers and consumers are able to establish a trusting relationship and understand where the other is coming from," Komarek said.

"Our CCI work is largely focused on facilitating and supporting those relationships to drive better translational outcomes.

"Increasingly, we're focusing on bringing people together."

A continued commitment to CCI

Beyond New South Wales, Sydney Health Partners continued investing and engaging in a range of CCI initiatives through our membership with the Australian Research Health Alliance (AHRA).

AHRA is the voice of 14 Research Translation Centres (RTCs) that are either fully accredited or recognised as emerging centres by the National Health and Medical Research Council. AHRA's priorities are to embed research in Australian healthcare; achieve better alignment of research capacity with clinical priorities; and enable more, better and faster research translation.

Between 2017 and 2021, Sydney Health Partners co-led AHRA's CCI activity in collaboration with fellow RTC the Western Australian Health Translation Network. The two organisations led the rollout of Stages 1 and 2 of the AHRA CCI program, leveraging decades of pioneering work in Western Australia.

"There's no doubt that Western Australia has provided significant leadership in consumer involvement work in health research nationally," said Associate Professor Todd.

"When we set up the CCI initiative through AHRA, it really was about how do we leverage the expertise that comes from 20-something years of experience in Western Australia as well as more recent work undertaken by other member centres that can be adapted and used?" →



AHRA's Stage 2 projects included developing a handbook to support organisations to embed CCI in their health and medical-research processes, scoping a central online CCI knowledge repository and evaluating existing tools that help to measure the impact of involving consumers in research. All three initiatives, which were led by different AHRA member organisations, were completed in 2021.

"We've had three really productive years of bringing representatives across translation centres together and trying to coordinate work that would help everybody," said Associate Professor Todd.

"This kind of national collaboration helps us develop shared knowledge and resources and a more coordinated approach, as well as to avoid duplication and wasted effort."

Building 1:1 connections

This involvement in AHRA has also resulted in the development of a strong working relationship with Melbourne-based RTC Monash Partners. Since 2021, Sydney Health Partners has been collaborating with Monash Partners to develop and co-host a series of online webinars.

"We both have a very strong and active commitment to consumer involvement in research as part of our stated priorities," said Associate Professor Todd.

"We're both in similar places on that journey, so that makes it helpful to share learnings with each other."

The webinars were designed to raise awareness of the importance of involving consumers in clinical trials. They form part of a broader program of work to help health organisations prepare for the National Clinical Trial Governance Framework, which was introduced in July 2022.

The Sydney Health Partners/Monash Partners collaboration delivered four 90-minute webinars on various aspects of consumer involvement and empowerment in clinical trials, such as engaging more culturally and linguistically diverse consumers as trial participants.

Each event attracted between 150 and 300 people, including consumers, researchers, peak body representatives and other health and pharmaceutical industry participants. Recordings of these webinars are available on the Sydney Health Partners website.

Taking on the Challenge of Clinical Trials Recruitment, with Conviction

Successful participant recruitment is a major challenge for clinical trials, with anecdotal evidence indicating only about 60 percent of trials in Australia recruit the number of patients they are seeking and only 20 percent meet their recruitment timeline.

With the financial support of the NSW Office for Health and Medical Research (OHMR), Sydney Health Partners partnered with Health Consumers NSW, Northern NSW Local Health District and the clinical trials and patient-engagement consultancy AccessCR, to work with consumers to raise awareness of the benefits of participating in clinical trials.

In 2022, a 12-person consumer group that was formed called itself ConViCTioN (Consumer Voices in Clinical Trials in NSW) and through a co-design process, produced a set of well-received promotional materials.

ConViCTioN's consumer co-chair, Sonia Dixon, described the project as "an overwhelmingly positive experience."

"I think it's unusual to achieve as much as we did in the first year but it's a really committed group and they want to do something," she said. "As a consumer, it feels good to be doing something concrete and be supported to do something. You feel like you're really helping."

A key piece of work by the consumer group was the development of a checklist of questions a consumer might wish to ask their doctor, nurse or a clinical trial team when considering whether to enroll in a trial. The checklist also included links to more detailed information about clinical trials. →



A poster was also co-designed which lists, in patients' own words, the benefits of clinical trial participation such as receiving more attention from clinicians, early and free access to new treatments and learning more about their own health.

A third resource was the development of a promotional video, featuring a diverse group of people in a group discussion about their experiences of clinical trials.

"People telling their stories is honestly one of the best ways to talk about clinical trials," said Ms Dixon.

"But I think it's good to show that consumers don't just want to say it, they want to do it and our enthusiasm to keep going with ConViCTioN has been a good representation of that."

In 2023, the NSW Agency for Clinical Innovation provided additional funds to continue to support ConViCTioN and to enable them to recruit new members to further diversify the group's representation and promote the consumer resources more widely.

Carrie Hayter from Health Consumers NSW is part of the team that supports ConViCTioN. She believes the project broke new ground.

"The strength of ConViCTioN is in the members, all of whom have incredible networks in different disease groups and local communities, a huge diversity of lived experience of healthcare and clinical trials, as well as experience as consumer representatives," said Ms Hayter.

"I think the three resources they produced are incredible because they are designed by consumers for consumers. Anyone working in clinical trials should be using these resources to encourage consumers to be involved."

Research Director for Sydney Health Partners Associate Professor Angela Todd was the original project lead.

"Bringing together project partners and consumers from across NSW who have coalesced into a high-performing group has been an amazing experience," she said.

"Our consumers had a diversity of past experiences with clinical trials – from none to some – and raised a lot of important questions about what other consumers might like to know about clinical trials. I think working with ConViCTioN has taught all of us a lot."

Managing Director of AccessCR Dr Janelle Bowden said that despite all the money invested in addressing the problem, clinical trial recruitment remains an ongoing challenge for the health and medical research sector.

"The needle hasn't really moved, so it's time for a new approach," she said. "We need to better understand what it is the community wants to know, and needs, to facilitate their participation in research.

"ConViCTioN's diverse collective of voices from across NSW have been powerful in providing those perspectives. It has been an enjoyable, inspiring and educational experience listening and partnering with these consumers to develop the resources for other consumers. But there is more to do, and the members of ConViCTioN are ready to roll up their sleeves and contribute." ●

ConViCTioN
Consumer Voices in Clinical Trials in NSW

ConViCTioN's resources and other information can be accessed at:
clinicaltrials-consumervoices.com.au



Clinical Associate Professor Merran Findlay

Research Translation Fellow: **Merran Findlay**

Clinical Associate Professor Merran Findlay knows the importance of nutritional management for people with head and neck cancer – in fact, she led the development of internationally endorsed guidelines on the subject.

But what she wanted to explore further was the impact of models of nutrition supportive care, not just in terms of patient and clinical outcomes but from a health-economics perspective as well.

With the support of a Sydney Health Partners Research Translation Fellowship (RTF), she launched a project to learn more.

"As a cancer-supportive care-research lead with a background as an oncology-specialist dietitian, my current research and previous clinical work have focused on people with head and neck cancer," she said.

"Because of their high risk of malnutrition and a related condition called sarcopenia, or low muscle mass, they have very high nutrition and supportive care needs.

"We know from the best available evidence that these are patients that really require early and ongoing access to the best supportive nutrition care. Essentially, my RTF is looking at value-based healthcare in terms of how we improve outcomes that matter to patients at the most responsible use of the health service dollar."

Supported by almost $120,000 in RTF funding, Associate Professor Findlay is leading a program of research titled 'Leading Better valuE SupporTive CARE for patients with head and neck cancer' (BEST CARE).

The research builds on what's already known — that effective nutrition care for people with head and neck cancer drives better outcomes — by trying to understand the economic impacts of different models of supportive care and of the unwarranted clinical variations that result from cancer-related malnutrition and sarcopenia.

"These conditions increase the risk of poor patient outcomes, and they can be very costly to the healthcare system if they go undiagnosed and untreated," she said.

"For example, if we don't provide best supportive care to outpatients, they're very often likely to become inpatients. That's not ideal for them and it's also not ideal for the health system.

"It's a little short-sighted not to invest in the services that support these people as outpatients, because they can lead to really costly unplanned admissions." →

In fact, Associate Professor Findlay's previous research, which was funded by an NHMRC Translating Research into Practice (TRIP) Fellowship, showed that each unplanned admission of patients with head and neck cancer costs the health system around $30,000.

Through her Sydney Research Partners'-funded PhD Scholarship, she further demonstrated that unplanned admissions for patients with low muscle mass was three times more costly than for those without.

Associate Professor Findlay's work has also shown that for every $1 invested in treating these patients in line with evidence-based nutrition care guidelines, there was close to $15 in costs avoided to the health system – "an excellent return on investment," she said. Identifying the most effective models of supportive care is therefore key to delivering high-value care.

As part of her RTF, and under the mentorship of renowned health economist Associate Professor Richard De Abreu Lourenço, who has guided her interest in health economics since the early days of her NHMRC TRIP Fellowship, Associate Professor Findlay has now completed a scoping review of existing models of nutrition-supportive care in Australia.

This review, which she presented at the 2023 Australia and New Zealand Head and Neck Cancer Society's annual conference, has revealed the key elements that make effective models successful.

Associate Professor Findlay's RTF has also supported her to complete a course called Modelling Cost-Effectiveness in Healthcare at the London School of Health Economics and Political Science.

While she's not a health economist by training, understanding how to look at her research through a health-economics lens will be key to the success of her fellowship.

"I wanted to tap into the health-economics language of why this matters to patients, which of course is vital, but also to multidisciplinary team members and healthcare administrators. We should all care about this," she said.

"We need to be speaking in a language that appeals to decision makers, because the pool of funds for cancer care is finite."

But, while identifying effective care models is important to achieving better outcomes, it's only the first step towards driving meaningful, implementable change.

The next steps will involve Associate Professor Findlay's other professional passion: implementation science, or the study of methods to increase the uptake of research findings into routine healthcare practice.

In 2023, Associate Professor Findlay was named one of 10 inaugural Fellows of Sydney Health Partners' Implementation Science Academy.

In this role, she mentors other researchers and clinicians while continuing to growing her own implementation science expertise in order to translate her research findings into real-world practice.

"It's one thing to have guidelines, but they sit on the shelf and collect dust if nobody's using them," she said.

"They take enormous effort and resources to produce, so you want them in the hands of people who can bring them to life where patients will benefit."

It's no surprise, then, that the end goal of Associate Professor Findlay's RTF project sits at the intersection of her Research Translation Fellowship and her Implementation Science Academy Fellowship.

"Through collaboration with data-science experts, I'm aiming for a data-driven approach to unwarranted variations in supportive care in cancer. I think that's where I'm heading with all the pieces of the puzzle that have led to this point," she said.

"I have a goal of being able to marry together the different fellowship opportunities into a common vision for the future, and that is to look at unwarranted variation in nutrition and supportive care at scale in a way that supports rapid action to improve patient care and outcomes." ●

6 Capacity & Capability





Clinical Associate Professor Kate Mahon, Dr Dannel Yeo

Sydney Cancer Partners Builds Capacity to Embed Research into Clinical Care

Sydney Health Partners took a step towards making research a more integral part of clinical care in 2021, when it received a $7 million Translational Cancer Research Capacity Building Grant from the Cancer Institute NSW (CINSW).

The grant established Sydney Cancer Partners, a five-year program led by Chief Investigator Professor Anna DeFazio AM, to optimise cancer research translation by building capacity, capability and consumer involvement.

A key element of the Sydney Cancer Partners program involves embedding research as a discipline in the Multi-Disciplinary-Team (MDT) model of caring for patients with cancer.

Sydney Cancer Partners took the novel approach of pairing clinicians with researchers through two joint fellowships, to better enable the process by which research addresses clinically relevant questions.

The joint fellowships – each of which is worth up to $300,000 per year over three years – are designed to develop a cancer-research group or initiative that spans from the laboratory to the clinic.

Postdoctoral research fellow Dr Dannel Yeo from The Centenary Institute at The University of Sydney and Clinical Associate Professor Kate Mahon from Chris O'Brien Lifehouse work together to explore ways to improve the management and outcomes for patients with colorectal and appendiceal cancers that have metastasised to the peritoneum.

Dr Yeo and Associate Professor Mahon say that peritoneal metastases from colorectal and appendiceal cancers confer poor prognosis and are not well understood.

"Treatment options are limited, and the only potentially curative treatment involves surgical removal of the peritoneum followed by instillation of heated chemotherapy. However, recurrence is very common" said Dr Yeo and Associate Professor Mahon.

"Our translational research project aims to identify liquid biopsy biomarkers to aid clinical decision making, develop tumour models to test new therapies and ultimately improve outcomes for patients."

The second partnership brought together paediatric oncologist Dr Bhavna Padhye from the Children's Hospital Westmead and computational biologist Dr Rebecca Poulos from the Children's Medical Research Institute (CMRI) to embed newly developed, clinically relevant, proteomic technology into the cancer clinic.

"We will use mass spectrometry (MS) to first focus on neuroblastoma to address an area of unmet clinical need by defining signatures that improve prediction of treatment response, and then apply these methods to other paediatric cancer types with poor outcomes. Our goal is to establish a real-time platform at CMRI for MS-based proteomics of paediatric cancer patients," said Drs Padhye and Poulos.

Announcing the Translational Research Fellowships, the Director of Sydney Cancer Partners, Professor DeFazio, said the novel partnerships would increase the likelihood of impact on clinical outcomes and research culture.

"To ensure impact, the Fellows are connected with – and supported by – a relevant clinical or multi-disciplinary team," she said. "The format of these fellowships is based on our experience that impactful translational outcomes can be generated by clinicians and researchers working closely together to solve a common problem."

As part of its efforts to build research capacity and capability, Sydney Cancer Partners awarded several additional grants in late 2022.

Four researchers received Pilot Study Grants, enabling them to undertake work to increase competitiveness of their applications for external funding. In addition, Sydney Cancer Partners awarded seven seed grants, designed to support early-to-mid-career researchers to conduct a semi-independent project that will assist their career development and applications for future research funding.

A Strategic Enhancement Grant scheme was developed and implemented in collaboration with the Maridulu Budyari Gumal (SPHERE) Cancer Clinical Academic Group. This joint and co-funded initiative was designed to build translational cancer-research capacity in NSW by supporting leaders of mature, translational cancer-research programs, which spanned both Sydney Cancer Partners and SPHERE member institutions, to facilitate successful applications for significant funding from national, international or commercial sources.

Professor Jeff Holst from UNSW and Associate Professor James Wilmott from the Melanoma Institute Australia and The University of Sydney were awarded $280,000 over two years for a project to validate a physiological ex vivo platform to rapidly test novel immunotherapy combinations in patient tumours.

Professor Hilda Pickett from the Children's Medical Research Institute and The University of Sydney and Associate Professor Liz Caldon from the Garvan Institute of Medical Research also received a $280,000 grant to lead a program investigating telomere remodelling in drug-resistant breast cancer.

In 2023, Sydney Cancer Partners assumed responsibility for leading the monthly NSW Cancer Research Education State-wide Seminar Series and continued with the organisation of the Molecular Tumour Board sessions, which are held as part of the series.

Sydney Cancer Partners, SPHERE and NSW Regional Health Partners worked with CINSW on the development of the Cancer Research Education (CREd) Portal, a SharePoint site hosted by NSW Health to support knowledge sharing and collaboration between cancer researchers across the state.

Often grant applications do not include a budget item for reimbursing the time for consumers involved in research. In November 2022, after consultation with consumer organisations and The University of Sydney, Sydney Cancer Partners launched a Consumer Remuneration and Reimbursement scheme. Using the Health Consumers NSW guidelines, SCP members can apply for small amounts of funding to reimburse or remunerate consumers involved with their research.

"This modest funding stream has allowed our researchers to not only engage meaningfully with consumers knowing they will be able to offer appropriate financial compensation, but also to comply with grant-application requirements, which increasingly require evidence of consumer involvement in project design," said Professor DeFazio.

"We hope the availability of this scheme will increase awareness and action from researchers to improve consumer engagement across Sydney Cancer Partners, and support people, their families and carers in their involvement in cancer research." ●

IRNet Showcase Supports Next Generation of Indigenous Health and Medical Researchers

An Australian Health Research Alliance (AHRA) program, which supports the development of Indigenous researchers working in Aboriginal and Torres Strait Islander health, blossomed in 2022 with the success of an ambitious national conference.

The IRNet National Aboriginal and Torres Strait Islander Health Research Showcase attracted almost 500 leaders in Indigenous health and medical research from across Australia for three days of presentations and discussions at the University of Sydney's Charles Perkins Centre.

The highlight of the IRNet Showcase was the launch of OCHRe, a culturally secure and inclusive network of Indigenous researchers seeking to improve the health and wellbeing of Indigenous peoples. One of its leaders, Professor Gail Garvey of the University of Queensland, said the ground-breaking $10 million NHMRC-funded program prioritised "consensus, inclusion, and our values and ways of working."

"Having over 90 of us mob come together for a single grant application is quite significant in itself," she said. "But it also tells us the story that we're ready to come together and collaborate in Aboriginal and Torres Strait Islander health and medical research."

The Showcase featured sessions on Indigenous data sovereignty, genomics, emerging diseases, vaccinations and trust, and the ongoing importance of advocacy and activism in Indigenous health.

IRNet Showcase attendees heard from Elders and founding members of the Aboriginal Medical Services in the Sydney suburb of Redfern Uncle John Delaney and Aunty Dulcie Flower AM.

The University of Sydney's Deputy Vice-Chancellor of Indigenous Strategy and Services, Professor Lisa Jackson-Pulver AM, paid tribute to the Elders, saying: "I doubt we would even be meeting today if they did not do what they did then."

The IRNet Showcase was hosted and supported by Professor Jackson's office, with additional support from the Charles Perkins Centre and OCHRe, and extensive organisational backing from Sydney Health Partners.







In addition to bringing together current leaders in the field, the event focused on supporting early and mid-career Indigenous health researchers. Emerging researchers were invited to participate in an IRNet Capability Building Day, during which they gave oral presentations and received feedback from experienced researchers in a culturally safe environment.

University of Sydney PhD candidate Simone Sheriff said it was nice to be in a room with people that had shared experiences.

"It felt so comfortable to be around people who know what you've been through as you're trying to do research for our communities," she said.

The Capability Building Day also featured presentations on navigating collaborations and leading research by Pro-Vice-Chancellor at Murdoch University Professor Rhonda Marriott AM and the Director of the Poche Centre for Indigenous Health at the University of Queensland, Professor James Ward.

Associate Dean, Indigenous Health at Western Sydney University Professor Aunty Kerrie Doyle presented advice on publishing research while University of Sydney Associate Professor Michelle Dickson chaired a panel discussion on developing a research career.

"It's all about building and nurturing relationships, but more than that it's about creating opportunities for people to step through those doors," said Professor Dickson.

The University of Melbourne's Professor Sandra Eades AO expressed optimism for the future of Indigenous researchers working in Aboriginal and Torres Strait Islander health.

"There are a lot of people who have trained over the last 10-to-15 years who are now really leaders, so I think probably the next 10-to-15 years will look a lot different," she said. "There's critical mass, there's the ability to come together at scale and have those conversations with each other."

Research Translation Fellow: **Robyn Sierla**



Dr Robyn Sierla

Many of us have had what we thought was a great idea and then said, "Yeah, but someone else must have already done that."

Dr Robyn Sierla waited almost a decade for someone to produce the software she could see was greatly needed by clinicians treating lymphoedema, before finally concluding that she would have to do it herself.

"Those of us who have been treating lymphoedema for many years have had to develop our own individual systems to capture and report the condition of our patients," she said. "This has created an environment where patient assessment is hampered by inconsistencies in how changes in their condition is reported, and treatment decisions are made on a trial-and-error or resource-led basis.

"I didn't have ambitions to be an entrepreneur, but I sat there for 10 years thinking that it's ridiculous that I'm using paper measurement sheets and having to do mental arithmetic, which I'm rubbish at, to monitor treatment effect and progression. All that time I thought somebody's going to come up with a solution, but it just didn't happen."

The term lymphoedema describes chronic swelling. Unless treated early, lymphoedema becomes a chronic condition in which body tissue (usually of the arms and legs) swells and alters in composition due to an accumulation of protein-rich fluid normally drained through the lymphatic system. Severe cases can affect the ability to move the affected limb and lead to skin changes and infections such as cellulitis.

In 2009, Dr Sierla undertook research training to realise her aspirations of being a clinician-researcher and explore the potential for a digital platform for lymphoedema clinicians. Following her PhD, she founded Lymbase, a free and online tool designed to support therapists to make clinical decisions, create efficiencies within lymphoedema clinics, promote patient engagement in the self-management of their condition, and reduce clinical variation.

In 2021, Dr Sierla was awarded a Sydney Health Partners Research Translation Fellowship to evaluate the system in clinical practice and to determine how the subsequent changes in assessment processes and communication impacted patient care.

She says her Fellowship project highlighted the differences between research and its implementation in routine clinical practice.

"During my PhD, all steps of the research were aimed at seeking consensus from clinicians initially to narrow and define the necessary data set for assessing lymphoedema," said Dr Sierla. "A prototype platform, informed by the dataset, was then built and technology acceptance was evaluated to see whether the clinicians thought it would meet their needs.

"The final version of Lymbase was informed by this research, but the actual uptake and use of the platform has differed according to the individual therapist and their clinical context.

"What I've found is that I need to create a platform that can be flexible, so the clinician is not required to do anything apart from that which they really find useful. You really can't create something that's one size fits all."

A feature of Lymbase is a search engine and auto-generation of orders for the thousands of compression garments stocked by NSW Health. Previously, catalogues of the garments were only available to therapists in printed form.

Dr Sierla says the database makes it easier for therapists to investigate and order off-the-shelf options rather than custom-made compression garments, which generally cost double.

"Our main weapon for treating lymphoedema is the use of compression garments – but they've got to fit really well to be effective," she said.

"There are currently 500,000 permutations of fabric sizing and design in the Lymbase garment search engine and most are available through NSW Health.

"By making it easier for clinicians to find and source the right off-the-shelf option, Lymbase has the potential to save taxpayer dollars, whether funded through Health, the National Disability Insurance Scheme or aged care."

Lymbase has been warmly welcomed by patients, who have found it helps them adhere to their prescribed treatment plan.

"One of the things that we have introduced as a result of the implementation evaluation with patients is the ability for the system to email or print a personalised treatment plan at the touch of a button," said Dr Sierla.

"It was clear that while all patient respondents reported they could recall the agreed plan from their clinic visit, many expressed in the free text comments a desire for a documented plan." →

The other feature of Lymbase that is supporting treatment adherence is its ability to show patients that the treatment is reducing swelling.

"There's that old saying about knowing something as well as the back of your hand, but most people are actually very poor at detecting changes in swelling and whether their lymphoedema is getting better," said Dr Sierla.

The system automates calculations for circumference measures and provides a graph-based visual display of size change.

"The implementation has shown that pretty much all the patients found value in the graphs.

"Based on the circumference measures routinely taken, Lymbase calculates an overall limb volume. There are many instances where we can show a reduction of more than a litre from the lower leg of someone who has been wearing a compression garment or bandage for a couple of days.

"That's the kind of thing that gets buy-in. People can see and understand that the treatment is worthwhile."

Lymbase was initially evaluated by patients and clinicians at Royal Prince Alfred and Concord Hospitals in Sydney Local Health District. Feedback informed changes to the platform before it was introduced to Royal North Shore Hospital in Northern Local Health District and Liverpool Hospital in South Western Sydney Local Health District.

Dr Sierla's longer-term goal is that the patient data being collected at these hospitals can be employed to inform practice.

"We have very clear evidence that compression and weight loss have a beneficial effect on lymphoedema," she said. "We also know that if you put these together with lymphatic massage and other more experimental modalities such as laser therapy, you get a slightly better effect, but we have no evidence base to inform individual treatment decisions.

"So, I'd like Lymbase to become a learning health system for lymphoedema, collecting clinic-level data, which we can interrogate to better understand what works for patients at various stages in different presentations."

Dr Sierla says that implementing Lymbase into clinical practice has taken longer and been more involved than she expected.

"I think that any change is challenging, especially when you've got long waiting lists and there is a time cost in changing your processes," she said. "So, you really have to provide a lot of benefit for people to be willing to change.

"Despite that, everyone wants to continue using Lymbase, so I think that's the endorsement that I was hoping I would get." ●

7

Partnership & Collaboration



Nepean Hospital

Sydney Health Partners Grows with Addition of New Partners

Nepean Blue Mountains Local Health District (NBMLHD) and Melanoma Institute Australia (MIA) have joined Sydney Health Partners, adding to the critical mass and reach of the research translation partnership.

NBMLHD serves more than 380,000 people living in the Penrith, Hawkesbury, Blue Mountains and Lithgow local government areas. Nepean Hospital is currently undergoing a two-stage, $1 billion redevelopment to meet the growing healthcare needs of the District, the population of which is projected to reach 530,000 by 2036.

Announcing the addition of NBMLHD in November 2022, Sydney Health Partners Executive Director Professor Don Nutbeam said it was a great fit for the Partnership.

"Critical mass is an important contributor to the success of partnerships like ours, and there is a natural fit with Nepean Blue Mountains LHD," he said.

"The Nepean Blue Mountains LHD already has relationships with several of our founding partners, including a University of Sydney clinical school and links in research and service delivery with our other health partners.

"And with its mix of urban, rural and peri-rural areas, the District has brought to SHP the opportunity to extend the benefits of our support for research translation."

NBMLHD Chief Executive Kay Hyman said the District's strong engagement with research partners would lead to better health outcomes for its patients.

"Joining Sydney Health Partners will help us translate research into real-world healthcare solutions," said Ms Hyman. "Our health district prides itself on evidence-based care. This new collaboration will connect our researchers with leading health science and medical research organisations, accelerating innovation and bringing real benefits to our patients faster."

In December 2021, Melanoma Institute Australia became the 11th medical research institute in the Partnership.

MIA is a nationally affiliated network of melanoma researchers and clinicians based in Sydney at The Poche Centre, the world's largest melanoma research and treatment facility.

Its SHP membership builds on MIA's existing affiliations with four founding members of Sydney Health Partners: The University of Sydney, and Sydney, Northern Sydney and Western Sydney Local Health Districts.

Professor Nutbeam welcomed MIA, saying: "Culturally, there's a great fit between Melanoma Institute Australia and what we are aspiring to achieve across the health system with our health partners."

"Like MIA, we seek a faster, better fit between the world-class research that's going on across all our Partners, the quality care we are looking to deliver to our patients and the public benefit that we are trying to deliver to wider society."

"I think that because of their track record and experience MIA have a fair bit to teach us about how to get this right and get the closest possible connection between outstanding research and great clinical care."

Co-Medical Director of MIA Professor Georgina Long AO said Melanoma Institute Australia shared Sydney Health Partners' focus on more rapidly translating research evidence into patient benefit.

"You can have great ideas but you've got to test the ideas and, ultimately, if the idea is worthwhile and impacts outcomes for patients then you've got to make sure that gets introduced to the rest of Australia and the rest of the world," she said.

Fellow Co-Medical Director Professoor Richard Scolyer AO described joining Sydney Health Partners as "a fantastic opportunity to work with people with the breadth of experience, knowledge and skills to have those research findings implemented."

"To make things happen, you need policy, you need energy and you need advocacy – and that can only be done when you bring the right groups of people, with different skills sets, together," he said.

Commencing operations in 2016 with 14 members, Sydney Health Partners subsequently welcomed the Kolling Institute of Medical Research in 2019.

With the addition of NBMLHD and MIA, Sydney Health Partners became one of the largest academic health science centres in the world.

Collectively, the Partners provide care to 2.7 million people, representing more than 10 per cent of the Australian population. ●



(L-R) Professor Don Nutbeam, Professor Georgina Long AO, Professor Richard Scolyer AO

National Collaboration Builds Support for Research Translation

Sydney Health Partners has been working closely with fellow NHMRC-accredited Research Translation Centres (RTCs) in an effort to build Australia's capacity and capability to undertake research translation.

Between 2021 and '23, SHP Executive Director Professor Don Nutbeam assumed Chairmanship of the Australian Health Research Alliance (AHRA).

As the peak body representing the RTCs, AHRA advocated to the Australian government and its agencies for increased support for research translation in order to achieve better alignment between Australia's investment in health and medical research, and health needs and priorities of communities.

In 2023, the Australian Academy of Health and Medical Sciences released a report titled 'Research and Innovation as Core Functions in Transforming the Health System', which strongly supported the role of the RTCs.

It recommended they be strengthening and sustained through meaningful, continuing funding to stimulate the formation of integrated research teams.

In a written response, AHRA welcomed the AAHMS report, saying it provided "a vision for a health system in Australia that is at the cutting edge of healthcare innovation driven by health and medical research embedded within the health system."

"We strongly endorse the report recommendations to optimise the contribution that health and medical research can make to deliver better health for all Australians. We are committed to contribute to its successful implementation," said the AHRA response.

AHRA also supported the AAHMS recommendation that the federal government develop a national strategy and implementation plan for building a world-class clinician-researcher workforce, including a formal, harmonised clinician-researcher training and career pathway.

"The AHRA Centres, individually and collectively, are fully engaged with research capacity building activities that complement and extend the existing roles of our university and health partners. We have unmatched reach into and across the health and research sectors," it said.

In 2021, the RTCs formed a capacity-building network to support women in health and medical research.

The Women's Health Research, Translation and Impact Network (WHRTN) received $5 million from the Medical Research Future Fund to increase national and international collaboration on women's health, build health workforce capacity, and develop leaders in women's health.

In 2022, WHRTN awarded career-development support grants of up to $15,000 to 36 women undertaking research into women's health issues.





Eight Sydney Health Partners-affiliated researchers in the early and mid-stages of their careers received the grants to engage, train and connect with other women in women's health research and translation.

Award recipient Dr Phoebe Williams, who is a consultant paediatrician at the Sydney Children's Hospitals Network and lecturer at the University of Sydney, used her grant to investigate the causes of serious infections in newborn babies in low and middle-income countries.

"As a mother of four children juggling an early research career with clinical commitments as a paediatrician and infectious diseases physician, I am enormously grateful for the support provided by this award. It will enable research support to establish key data seeking to improve the health of infants in under-resourced countries," she said.

Another AHRA capacity and capability-building program was the National Indigenous Research(er) Capacity Building Network (IRNet) which staged the 2022 IRNet Showcase with extensive support from Sydney Health Partners (see page 76).

AHRA also assumed national leadership in the area of consumer and community involvement. As reported on page 66, SHP worked with the nation-wide CCI initiative to disseminate best practice in CCI.

The RTCs also demonstrated their ability to come together and make a positive impact on clinical care in under-researched areas of health.

AHRA's Wound Care Initiative was a unique national collaboration which undertook several projects in response to a request from the Australian government for evidence about the burden of wound care on the health system and the community, and how to address it.

"This was an under-researched area of healthcare, and of great importance to our partners. With sufficient funding, we were able to respond in a nationally coordinated process," said Professor Nutbeam.

AHRA also collaborated with the NHMRC in November 2022 to stage a two-day research-translation symposium, which combined in-person events in five states with the national program of presentations via video stream (see page 86).

Professor Nutbeam said the Research Translation Centres have a unique role in Australia's health and medical research eco-system.

"Nationally, our centre partnerships include 367 hospitals, 28 universities, 53 medical research institutes, 33 First Nations community groups and primary care networks.

"This unmatched reach across health and research makes AHRA well-placed to deliver on Australian and state government ambitions to achieve better alignment between investment in research and health needs and priorities, and better health, social and economic outcomes from our health and medical-innovation system." ●

NSW Collaboration Showcases Research Translation Success

Notable examples of research translation were the highlight of a unique event staged in late 2022 by Sydney Health Partners, Maridulu Budyari Gumal (SPHERE) and the Sax Institute.





Organised as the NSW live site for the National Health and Medical Research Council's *Research Translation Long Weekend*, the event brought together a community of researchers, clinicians, and administrators to celebrate successful research translation.

Professor Sandy Middleton from Australian Catholic University launched proceedings with a discussion of the successful rollout of the Quality in Acute Stroke Care program across Australia and Europe. The program, which involves nurses trained to monitor a patient's temperature, blood-sugar levels and ability to swallow immediately after a stroke, has been shown to reduce the risk of death and disability by up to 16 percent.

Professor Middleton said researchers need to be mindful of the minimum intervention required to be effective. "It's easy to over-egg the pudding when it comes to implementation science," she said. "We need to think of implementation like a drug trial – what's the lowest dose of intervention that will be enough?"

The idea of making intervention as simple as possible, while still being effective, was echoed in the presentation by Professor Luke Wolfenden from the University of Newcastle. He discussed his team's work on the school lunchbox-education program called SWAP IT, and how it was simplified as it evolved from a pilot study to an Australia-wide program.

Professor Wolfenden said the process of scaling up the program showed the value of having a financial partner who is a stakeholder in the research. "Having skin in the game is important," he said. "Unless you have partners, you'll never have translation."



Professor Sandy Middleton

Sydney Health Partners Research Translation Fellow Associate Professor Merran Findlay spoke about her involvement in creating new clinical guidelines for the nutritional support for people with head and neck cancer, and then implementing them in hospitals. "It's a challenging process, the sands often shift beneath your feet," she said. "You need to be prepared to adapt."

She emphasised the importance of interviewing patients, carers and clinicians before and after the intervention, to give "everyone a voice" and to ensure that the intervention was suitable for patients.

The importance of scalability in research translation was further explored by Adjunct Professor Andrew Milat, who was the then Director of Evidence and Evaluation at the NSW Ministry of Health (and later a Special Advisor to Sydney Health Partners).

He said NSW Health's COVID-19 response was "an amazing example of how quickly research translation can occur" and cited the Sax Institute's Translational Research Framework as a great resource for early-career researchers.

The four presenters took part in a panel discussion on the factors contributing to successful research translation, such as embedding researchers into health service organisations and developing research partnerships and funding.

The event continued with networking sessions that reflected the 'Embracing Diversity' theme of the NHMRC Research Translation Long Weekend. Sessions focused on rural and remote communities, people living with disabilities, Aboriginal and Torres Strait Islander communities, and culturally and linguistically diverse communities. ●



Professor Luke Wolfenden



Adjunct Professor Andrew Milat

Sydney Health Partners Board

Board Chair



Professor Mary O'Kane AC
Professor O'Kane has an exceptional breadth and depth of experience in innovation, research and public policy. As a computer engineer, Professor O'Kane undertook pioneering work in artificial intelligence and was the Vice-Chancellor of the University of Adelaide from 1996-2001. Between 2008-18, Professor O'Kane served as New South Wales' first Chief Scientist and Engineer, during which she was instrumental in establishing the NSW Medical Devices Fund.

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Sydney Health Partners would like to acknowledge and thank the following for their valuable contributions as Board members during the period 2021-2023:

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