Sydney HealthPartners

Impact Report 2018



Bringing the pieces together



Professor Tim Shaw and Senior Research Officer Candice Donnelly from the University of Sydney. (Story page 54)

Impact Report 2018

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The Partnership

NSW Government Health Sydney Local Health District

NSW Government Health Northern Sydney Local Health District

NSW Government Health Western Sydney Local Health District

the children's hospital at Westmead
The Sydney children's Hospitals Network

The University of Sydney

ADRI Asbestos Diseases Research Institute

ANZAC Research Institute

Centenary Institute life saving research
Cancer, Inflammation, Cardiovascular.

Children's Medical Research Institute
Jeans for Genes®

Chris O'Brien Lifehouse

The George Institute for Global Health

HRI Heart Research Institute

The Westmead Institute

Woolcock
Leaders in Breathing & Sleep Research

About Sydney Health Partners

The aim of Sydney Health Partners (SHP) is to encourage faster and more effective translation of health and medical research innovations into healthcare improvements. By doing so we will deliver the benefits of research and innovation to our patients and communities more quickly and consistently.

Our partnership is led by the Northern Sydney, Sydney, and Western Sydney Local Health Districts; the Sydney Children's Hospitals Network (at Westmead) and the University of Sydney. Sydney Health Partners is further strengthened by nine affiliated independent medical research institutes; Anzac Research Institute, Asbestos Diseases Research Institute, Centenary Institute of Cancer Medicine and Cell Biology, Children's Medical Research Institute, Chris O'Brien Lifehouse, The George Institute for Global Health, Heart Research Institute, The Westmead Institute for Medical Research and Woolcock Institute of Medical Research.

In 2015, our partnership was one of the first four such organisations in Australia to be accredited by the National Health and Medical Research Council as an Advanced Health Research and Translation Centre (AHRTC) – recognition of our members' world-leading use of research to improve healthcare and health outcomes.

Sydney Health Partners aims to enhance this international competitiveness, supporting the partners to compete effectively for research resources and talent.

We facilitate a culture that cuts through the barriers to collaboration amongst researchers and clinicians. In doing so, we aim to demonstrate that a collaborative translational research model can be successfully applied in a large diverse health system.

SHP leverages the strong leadership and support of its Local Health Districts, a long history of successful collaboration in research between the University and research institutes and the large scale of its operations, that collectively serves 2.7 million people or more than 10 per cent of Australia's population.

But SHP is more than the sum of its members. By spanning jurisdictions and disciplines, SHP offers new pathways to reforms which might otherwise have been thought too hard. And by bringing together healthcare, academia and medical research in innovative ways, SHP aims to solve the puzzle of health system improvement.



Executive Director's Report



It has been a huge privilege to have had stewardship of Sydney Health Partners over the past year.

Ours is a unique partnership, which brings together world-class institutions, clinicians and academics to serve half the population of Sydney. By virtue of our diverse membership, we cross jurisdictional, institutional and disciplinary boundaries, enabling us to engage on health issues from cradle-to-grave. Through their collaboration and innovation, this critical mass of intellect and experience is contributing to better health amongst communities here – and globally.

It is a requirement of our National Health and Medical Research Council accreditation that Advanced Health Research Centres (AHRTCs) are health-service inspired and led. At SHP, we have that in spades. We benefit from the engaged leadership and direction of our four health services, each of which is at the forefront of healthcare delivery. We also take inspiration from their work and the opportunities they provide to address important questions, while facilitating translation of existing and new knowledge.

Our remit is to take questions from the clinical coalface and challenge the people who can provide answers. These answers may come from the health sector itself but are often also found in cognate faculties of the University of Sydney, in our nine diverse medical research institutes or through collaborators beyond.

This is a different kind of research; one where the outcome is not just a publication or the next grant. Its research that results in people doing things differently in their daily work at every level of the health system. In this different paradigm, we work together to achieve depth and scale, both within our partnership and in association with Australia's eight other translation centres.

The creation of the network of AHRTCs has coincided with the establishment and growth of the Medical Research Future Fund. The MRFF, which is building a $20 billion investment pool to generate up to $1 billion each year for disbursement in the form of competitive grants, is also primarily focussed on supporting the translation of research into the health system. The grants it has awarded to date have advanced the research of several groups within our partnership, and inspired some exciting new collaborations.

Last July, Sydney Health Partners received $6.1 million over three years from the MRFF to continue its Rapid Applied Research Translation (RART) program. This generous commitment, announced

> ***Sydney Health Partners is more than simply a pipeline to MRFF monies.***

in person by Federal Health Minister Greg Hunt, built on $2.1 million received in 2017.

The initial amount funded 14 RART projects during the year. These projects, which you will find featured throughout this Impact Report, are multi-institutional and multidisciplinary, with the objective of producing results of tangible benefit to the health system within a short time.

It would be very wrong, however, to conclude from this that Sydney Health Partners is simply a pipeline to MRFF monies. Nor are we another layer of bureaucracy, usurping any existing structures or institutions.

We are, instead, the sum of our membership and any SHP achievements are those of our members.

In addition to the projects funded through the Medical Research Future Fund, SHP's present activities focus on facilitating research and building capacity. In 2018, our cross-cutting themes began to address barriers to the scaling-up of research translation across our network.

Along with the other translation centres, we also contributed extensively to national working parties addressing Australian Medical Research Advisory Board priorities. We co-led the work on the better use of data to support healthcare innovation, and the involvement of consumers and communities in research. Other national initiatives included capacity-building in Aboriginal and Torres Strait Island health research, health services research, women's health, and wound care. In each case we scoped the various activities around the country, and set priorities for new research through the national network.

Meanwhile across Sydney Health Partners, building capacity in implementation science has been identified as an urgent priority. I am pleased to report that this was an area of particular progress by SHP during the year, and elsewhere in this report you can read details of our very successful implementation science educational activities.

Sydney Health Partners has a small secretariat and I am both impressed and grateful for what my team has achieved this year. Our Governing Council and its Chair Paul McClintock provide outstanding guidance and direction.

Of course, the real activity needs to take place within our partners. We have benefitted from huge support from the leadership of these organisations, as well as their clinicians, academics and support staff.

It has also been extremely beneficial to work with the Ministry of Health and our colleagues at the fellow NSW translation centres, SPHERE and NSW Regional Health Partners. Like them, Sydney Health Partners is on the way to being an integral part of health innovation in Australia. We look forward to more exciting developments in the years to come.

Professor Garry Jennings AO
Executive Director





Chairman's Message

Australia has taken some encouraging steps in recent years towards finding a more sustainable long-term model for its health system. In the face of limited budgets, there has been the widespread acceptance that health and medical research is essential to achieving better health outcomes for all Australians, while restraining costs.

Research provides us not only with better treatments and new cures, but also with evidence to discontinue low-value methods of health care, or with new interventions to prevent people from becoming sick in the first place.

It was the central challenge of improving the translation of research evidence into health system practice that led to the formation in 2015 of the first four of Australia's Advanced Health Research and Translation Centres (AHRTCs), including Sydney Health Partners.

The question asked of SHP then, remains today: how can the Partnership remove or reduce the barriers to the efficient and effective translation of health and medical research so that the benefits are delivered more readily to patients and communities.

In my three years as Chair of Sydney Health Partners it has become clear to me that finding the answers requires clinicians, researchers and academics to work together as closely as possible. Moreover, it is vital that our hospitals fully engage with – and are engaged by – their University and research institute partners.

Across Sydney Health Partners there is plenty of evidence that this three-way collaboration is working to great effect.

On behalf of everyone in the partnership I want to acknowledge the vital interest in – and generous support for – SHP by our three Local Health Districts, the Sydney Childrens Hospital Network and the University of Sydney. Combined with the involvement of our nine affiliated independent medical research institutes, this strong support and guidance allowed Sydney Health Partners to mature organisationally in 2018.

It was particularly encouraging to see SHP's growing involvement in research translation at a national level. With the support of the Medical Research Future Fund, SHP and the other AHRTCs moved to become more outwardly focussed, resulting in the formation of a truly national network in the Australian Health Research Alliance.

Towards the end of 2018 we paused to do some broader thinking about where Sydney Health Partners should go next. While that strategic review will not be completed until 2019, for me an early take-out was that we should rededicate ourselves to a collective model of Sydney Health Partners. We are to be judged by what happens across the network of our members and their collective impact.

On behalf of Sydney Health Partners I would like to thank my fellow Governing Council members for giving so generously of their time and experience during the year. In particular my thanks go to departing Council members Professor Jonathan Morris, Professor Vlado Perkovic, Danny O'Connor and Adjunct Associate Professor Vicki Taylor for their strong commitment and contributions during SHP's formative years.

In their places the Governing Council was very pleased to welcome the addition of the Kolling Institute's Executive Director Professor Carolyn Sue, and the incoming Chief Executives of NSLHD and WSLHD, Deborah Willcox and Graeme Loy.

A final and very notable addition in the Governing Council in 2018 was the appointment of our first ever consumer representative, Mohit Kumar, who brought different and valuable community perspectives to our discussions.

Finally, I'd like to thank our Executive Director Professor Garry Jennings AO for his leadership in progressing Sydney Health Partners program of work, locally and nationally, in 2018. It is clear to me that AHRTCs need people of Garry's exceptional calibre and standing in the research community in order to progress the research translation agenda.

Sydney Health Partners ended 2018 in excellent organisational shape, and with a sharpened vision for the future. While the challenges SHP has been tasked with addressing remain potentially daunting, its progress provides much cause for optimism.

Paul McClintock AO
Chairman

Partner's Message

Northern Sydney Local Health District

KOLLING INSTITUTE
Discovery *into* Reality™

Being part of such a great collaboration and member of Sydney Health Partners enables Northern Sydney Local Health District to strengthen its relationships between key medical, research and academic institutions, and continue to embed a culture of research, clinical, collaborative and innovative excellence.

Northern Sydney Local Health District has a proud history of investing in research and collaborating with medical and academic institutions such as The University of Sydney, leading to a joint research venture with the Kolling Institute of Medical Research and Northern Sydney Academic Health Sciences Centre.

Partnerships like Sydney Health Partners provide our clinicians and researchers with a leading edge in their chosen fields, making it possible for educating future generations of health professionals.

> ***"This significant partnership gives a platform for researchers and clinicians to showcase their research."***

Being a key partner of SHP means the sharing of knowledge, expertise and innovations will provide significant benefit for our patients and the people of NSW.

We are in the midst of a significant transition in the way health and medical research funding is delivered, with increasing requirements for it to be relevant, for our researchers to engage with the community at every level, and for our discoveries to be more rapidly translated into clinical practice.

This significant partnership gives a platform for researchers and clinicians to showcase their research, which will benefit patients as quickly as possible.

Deborah Willcox
Chief Executive





Partner's Message

Sydney Children's Hospitals Network (Westmead)

Over the past four years, Sydney Health Partners has brought together local health districts, academic partners and medical research institutes to integrate outstanding research, top quality education and professional practices to drive improved health outcomes and better healthcare delivery.

Sydney Health Partners has facilitated a number of collaborative projects across the partnership, with a strong focus on translating evidence into patient care and education of health professionals. The goals of Sydney Health Partners are strongly aligned with The Sydney Children's Hospitals Network focus on research. Our researchers have been heavily involved in driving genomic research initiatives within Sydney Health Partners, with the goal of realising the full potential of genomics across all of Sydney Health Partners' organisations.

For Sydney Children's Hospitals Network, this partnership has given our researchers a unique opportunity to become leaders in genomic research, furthering their understanding and capabilities in an area where there is so much potential. One of the highlights for the Network was Professor Sandra Cooper being awarded the Rapid Applied Research Translation grant from the Medical Research Future's Fund to lead and evaluate a diagnostic program across the Partnership. The program uses a new testing system to allow precise genetic diagnosis, and has enabled both precision and preventative medicine for affected families who receive a diagnosis, which has the potential to be life-changing.

> ***"This partnership has given our researchers a unique opportunity to become leaders in genomic research."***

We are honoured and proud to be part of such a strong partnership. The impact this has had in providing advanced genomic diagnostics for families is immense, and we are so excited to see what the future holds.

Dr Michael Brydon
Chief Executive



Partner's Message

Sydney Local Health District

At Sydney Local Health District, research is seen as "everyone's business".

We have a long and proud history of health and medical research across the healthcare continuum. More than 60 departments are currently involved in research, from the newborn care unit at Royal Prince Alfred Hospital to the Centre for Education and Research in Ageing at Concord Repatriation General Hospital.

Collaborative partnerships are core to a strong and sustainable research agenda for the District. The sharing of information and resources, and shared projects creates opportunities to grow and pursue research in strategically chosen areas, which are locally, nationally and internationally relevant.

In 2017 and 2018 Sydney Health Partners provided grants to seven projects to health and medical researchers from Sydney Local Health District, using funds from the Australian Government's Medical Research Future Fund through its Rapid Applied Research Translation scheme. This support has enabled us to focus on research that produces real outcomes for patients and the community, as well as harness the strengths of our partner local health districts, university and medical research institutes.

One example of this is the work of Professor Barbara Fazekas de St Groth to produce a low-cost and accessible blood test to guide lung-cancer therapy. The support of Sydney Health Partners means that our clinicians will soon be better informed of their patients' responses to immune checkpoint therapies, as well as their potential to produce stable long-term remissions before starting treatment.

Our collaborative work in the priority areas identified in Sydney Health Partners has also produced strong synergies. The newly formed Institute for Musculoskeletal Health, a partnership between Sydney Local Health District and the University of Sydney, provides a platform to both strengthen clinician-researcher alliances and also improve the translation of research into the community.

We can, and we do achieve so much more when researchers and clinicians are brought together, working as a team towards improving the health and wellbeing of the community. The close ties within Sydney Health Partners mean our scientists are not isolated from the people who are affected by the diseases we are working to overcome.

"The sharing of information and resources creates opportunities to pursue research in strategically chosen areas."

Dr Teresa Anderson AM
Chief Executive

Partner's Message

The University of Sydney

The University of Sydney is genuinely committed to enabling world-class research to improve the lives of millions across Australia, and globally. We believe that outstanding researchers, networks and partnerships are fundamental to delivering outstanding research and education. Sydney Health Partners' vision and mission strongly aligns with that of the University. Through our partnership, we are committed to transforming how research is translating into the community to improve patient care.

During the past year, together the University and Sydney Health Partners have commenced several initiatives to accelerate the transfer of research innovations into healthcare and lead cutting-edge research in a variety of areas including – but not limited to – implementation science, indigenous health and wellbeing, clinical trials, and the international imaging consortium, which enables access to a sizeable population cohort and offers unique opportunities in the development of clinical imaging.

Our partnership with Sydney Health Partners provides a unique opportunity to develop innovative approaches to tackle the increasing burden of chronic disease in a growing and ageing population. It also enables the embedding of education and research within service delivery models, informs policy and clinical practice, and enables the delivery of significant benefits for the health and wellbeing of the community.

Professor Laurent Rivory
Pro-Vice-Chancellor (Research)

> *"Together we have commenced several initiatives to accelerate the transfer of research innovations into healthcare."*





Partner's Message

Western Sydney Local Health District

Western Sydney Local Health District prides itself in providing an environment where researchers participate in the discovery of new knowledge and innovation generated by research that translates into improved health and healthcare for patients and community.

Through its vision of transforming the way research improves healthcare through strong collaboration, Sydney Health Partners, via its clinical streams, has enabled improved collaborations for researchers across the partnership around research projects. This in turn has facilitated translation of research outcomes into service provision across a broader landscape.

Graeme Loy
Chief Executive

> ***SHP, via its clinical streams, has enabled improved collaborations for researchers across the partnership.***



Section 1

Translation

Sydney Health Partners' research translation activities are structured around several thematic streams (see page 57) – or areas of research – each led by senior researchers and clinicians from across the Partnership.

Each of the streams is cross-cut by enabling themes – Implementation Science and Education, Informatics and eHealth, Clinical Trials, Biobanking, Research Enablers and Genomics – which are of mutual importance to streams in their efforts to translate research into better health outcomes.

In 2018, SHP actively fostered the academic discipline of Implementation Science as a way to manage clinical process change in the health system. Meanwhile, the partnership's Digital Health and Informatics Network undertook a number of initiatives and research projects to demonstrate how the sharing of data and use of informatics can improve patient care and health service efficiency.

SHP also took steps to assist the improvement of clinical trials infrastructure and recruitment, as well as enabling greater access and use of biobanks, ethics and governance processes, and building capacity and capability in genomic medicine.

Implementation Science and Education



Professor Anne Sales, University of Michigan

The emerging discipline of Implementation Science (IS) became a major theme of Sydney Health Partners' research translation activities in 2018. With pressure building on health systems to more quickly realise the benefits of Australia's investment in health and medical research, IS was recognised by the Partnership as a potentially effective tool for shortening the 17-year average bench-to-bedside research translation time lag.

Implementation science is defined as the scientific study of methods to promote the systematic uptake of evidence-based practices into routine clinical care. IS focuses on the "how" – how do we get evidence to drive health practice, how do we get evidence-based interventions to become standard care, and how can we upscale these interventions across health services? It also offers an important complement to quality improvement and clinical redesign efforts already routinely underway in Australian health services.

As a first step, SHP focussed on raising awareness and understanding of IS following an inaugural Implementation Science Symposium in 2017. It received enthusiastic responses from researchers, clinicians and health administrators, and a more ambitious program was undertaken in 2018. With the assistance of the University of Sydney, SHP secured University of Michigan Professor Anne Sales – the Co-Editor-in-Chief of Implementation Science journal – as the keynote speaker at the symposium.

Professor Sales was also the focal point of a program of associated activity including a two-day Concept Development Workshop which provided IS training for selected early-to-mid career researchers. Each of the 15 participants spent a day being introduced to the key concepts and principles of IS and refining their research project question. The second day of the workshop focussed on developing methodologies for implementation of their projects, and researchers were expected to report back on progress in the middle of 2019.

The week of Implementation Science activities concluded with an education seminar for local health district administrators. The event brought together the clinical redesign and quality improvement leaders from SHP's four local health districts, providing a rare opportunity for them to share experiences, identify common challenges and collaborate with one another.

> ***"Implementation Science focuses on the 'how' questions."***

The year concluded with SHP commencing a review of existing IS training options with a view to developing a unit of University study or Open Learning Environment module. SHP and the University of Sydney also agreed to co-fund the appointment of an Implementation Science Research Fellow in 2019.

Clinical Trials

Clinical trials (CTs) provide a vital link between basic scientific research and the delivery of clinical care, as well as resolving uncertainties regarding disease management. CTs provide patients with access to leading specialists and cutting-edge therapies, and the opportunity to contribute to improving health outcomes for themselves and/or others. Clinical trials have been found to provide an exceptional return on investment, with thousands of additional quality-adjusted life years resulting in billions of dollars of savings to health systems.

Despite, however, the enormous value of clinical trials for patients and the health system, opportunities exist to improve clinical trials performance and productivity in Australia. The increasing costs and complexity of clinical trials – and regulatory hurdles they must overcome – have limited performance and productivity of CTs in Australia. In addition, the conduct of clinical trials is sometimes constrained by difficulties in recruiting enough patients, and by shortfalls in the supply, capacity and capability of trials staff.

In 2016, Australia's health ministers agreed to reform the CT sector through regional redesign. In 2018, Sydney Health Partners began working with the NSW Office of Health and Medical Research (OHMR) to address some of the issues that were impacting clinical trials performance.

The OHMR proposed the establishment of a state-wide clinical trials-support platform to provide the expertise required to navigate trial start-up, improve the accuracy of trial budgeting, avoid recruitment shortfalls and improve the methodology for clinical trial design.

To inform decisions about how such a platform could best support clinical trials, SHP researchers conducted an audit of CT activity across the three Local Health Districts, Sydney Children's Hospitals Network (Westmead) and the University of Sydney. The audit combined quantitative data about the scale of CT activity with qualitative information provided by research ethics and governance managers, clinical trial investigators and coordinators, and industry partners.

The key themes that emerged from the audit were the need to improve recruitment, training, job security and retention of trials staff, as well as supporting investigators with better access to clinical trials expertise.

There was wide support for the employment of "start-up specialists" to improve the quality of applications, thereby reducing the burden on research and governance offices, and facilitating better design and more timely initiation of projects.

Following completion of the audit, Sydney Health Partners commenced worked in consultation with the OHMR to determine the best model for CT support in NSW and to develop a plan for the establishment of support units.

As part of this work, SHP will consider a new National Clinical Trials Governance Framework, which is under development and scheduled for release in July 2019. The framework is expected to generate some changes in clinical trial oversight structures and processes across SHP's health service partners.

In addition to efforts to improve CT support, Sydney Health Partners addressed trials recruitment. Securing sufficient numbers of appropriate participants is critical to the success of a clinical trial, but reviews have shown that recruitment estimates are often inaccurate and the required number of participants is not achieved. As a consequence, the power of the study can be weakened, or the trial can take longer to meet its targets requiring more resources than planned.

To assist recruitment, SHP produced four short-form videos, each featuring a patient whose life had been changed for the better by taking part in a clinical trial. SHP also commenced work with health staff and consumer representatives to develop other resources that promote research participation.



Aussie App Success Taking Clinical Trials Recruitment to Next Level

An Australian-developed software application is helping overcome the difficulties commonly encountered by medical researchers when trying to recruit patients for clinical trials.

ClinTrial Refer creates and maintains up-to-date databases of clinical trials which are currently recruiting patients, whilst its mobile applications make it easier for patients or their doctors to find a suitable trial.

Following rapid growth in demand, ClinTrial Refer is preparing for potential expansion to include all clinical trials, across all disciplines, in Australia and potentially globally.

ClinTrial Refer co-founder Roslyn Ristuccia says 90 per cent of all clinical trials conducted in Australia are delayed by difficulties recruiting sufficient suitable patients.

"Recruitment is an almost universal issue for clinical trials, but when ClinTrial Refer was first launched in 2013, haematology researchers in NSW saw an immediate and sustained improvement," Ms Ristuccia, who is a clinical research unit manager in the Haematology department at Sydney's St George Hospital, said.

"Everyone told us that patients wouldn't travel and that doctors wouldn't cross-refer. But there was a nine-fold increase in referrals and a 63 per cent increase in trial recruitment.

"Initially I thought ClinTrial Refer was changing clinician behaviour but I've come to believe the only difference is they now have the information they needed to do the best thing by their patients. A doctor can access the app and, in a couple of minutes, find the details for a clinical trial and pre-screen their patient for suitability," she said.

Fellow ClinTrial Refer co-founder Judith Trotman is the Director of the Haematology Clinical Research Unit, a Senior Staff Specialist at Concord Hospital and Clinical Professor at the University of Sydney. She says ClinTrial Refer is scaling collaboration, and breaking down hospital silos and barriers to recruitment.

"Targeted pre-screening of the patient against the inclusion and exclusion criteria listed on the ClinTrial Refer app greatly improves the actual screening-to-recruitment ratio. It has helped investigator-led studies to recruit to target," said Professor Trotman.

In 2016, Sydney Health Partners recognised the potential for ClinTrial Refer to speed-up medical research translation by funding the development of the first version of the app for other disciplines including cardiology, endocrinology and immunology.

"The SHP app was the first to go live on multiple disciplines and across a multitude of sites, effectively piloting how we could make it work for the rest of Australia," said Professor Trotman.

Further growth in demand has seen more than 20 derivative apps of ClinTrial Refer developed, representing 850 clinical trial sites, or about 60 per cent of clinical trials in Australia.

A new version of ClinTrial Refer due for launch by mid-2019 will integrate all the apps into a single digital platform and website.

Version 2.0 will solve the problems of the derivative apps creating duplication or requiring double entry of data. Users will be able to search one or several apps – or choose a global search.

In addition, ClinTrial Refer has reached agreement with the Australia and New Zealand Clinical Trials Registry and its United States equivalent to supply their data, meaning some fields will be pre-populated. In return, participating trial sites will help update the registries.

"We have a function in Version 2.0 which allows trial sites to report if recruitment for their trial has closed, addressing the common complaint that the registries are often out of date," Ms Ristuccia said.

"This is the critical difference — ours is a bottom-up approach. And because all the trial sites are contributing data they feel some level of ownership.

"ClinTrial Refer is a public good. It's about being open, it's about being collaborative and it's about crossing boundaries between private and public institutions, breaking down hospital silos, so that patients are accessing cutting edge therapies, or keeping at the cutting edge."



“This is the critical difference — ours is a bottom-up approach.”

Clinical Professor
Judith Trotman



Informatics and eHealth



Health and medical information enables clinicians and policy makers to make informed decisions that will improve healthcare at both the individual and population level. Typically, questions central to improving health outcomes and guiding policy decisions can only be answered by obtained data from large, heterogeneous populations.

The potentially transformative influence of data could be felt in many areas of Sydney Health Partners in 2018.

A project led by Dr Candice Donnelly and Professor Tim Shaw demonstrated the feasibility of using data from electronic medical records (eMRs) to compare the performance of multi-disciplinary teams treating breast and lung cancer patients at two hospitals in Western Sydney Local Health District.

Similarly, a multidisciplinary team led by Professors David Brieger from Concord Hospital and Jonathan Morris from Royal North Shore Hospital, demonstrated the feasibility of extracting data from the eMRs of patients with acute chest pain, in order to identify any variations in their clinical care and the reasons for those variations.

University of Sydney Professor Madeleine King investigated how to clinicians could be guided by Patient Reported Measures in real time. By graphically presenting data from patient questionnaires on a digital platform, it was hoped doctors could quickly understand whether further investigation or action might be required.

Using the patient data gathered by the health system in ways that aid clinicians and patients is one of the major goals of the Digital Health Informatics Network (DHIN) of Sydney Health Partners.

Led by Professor Clara Chow and in partnership, the Westmead Applied Research Centre, DHIN and SHP won a highly competitive grant from the Australian Digital Health Agency to establish the Western Sydney Cardiology Care Test Bed. The project is researching how My Health Record (MHR) data from consenting individuals can be best used to optimise patient care in Rapid Access Cardiology Clinics; and is scoping the feasibility of a cardiology-specific digital application populated with information from the MHR.

Co-leader of the DHIN, University of Sydney Professor of eHealth Tim Shaw, is Director of Research within the Digital Health Cooperative Research Centre (CRC) launched in April 2018. The CRC has been supported by $55 million from the Australian Government – and a further $56 million in funding and $118 million in in-kind contributions from industry partners.

By bringing together 40 commercial and government organisations operating across the health, aged care and disability sectors: 24 established and start-up technology, advisory and investment companies; and 16 Australian universities, the CRC created a number of potential synergies with the eHealth and informatics activities of Sydney Health Partners and the other Advanced Health Research Translation Centres around Australia.

Sydney Health Partners also began to break down the silos of information that exist at different levels of the health system. Significant progress was made towards the establishment of a high-level Data Sharing Accord that would facilitate safe, lawful and appropriate sharing of health data across the Partnership's local health districts, Sydney Children's Hospitals Network and the University of Sydney.

It was hoped that an Accord which agreed upon ethical principles and data handling solutions to facilitate the conduct of research studies would circumvent the need to create a data extraction, encryption, storage and access solution for each individual project.

SHP Project Using Data to Improve Health Care

Sydney Health Partners researchers are using cutting-edge analytics and informatics techniques to mine de-identified hospital patient records, with the aim of demonstrating that better use of data can improve healthcare.

A multidisciplinary team led by the University of Sydney Professors David Brieger from Concord Hospital and Jonathan Morris from Royal North Shore Hospital, is using previously untapped information stored in the hospital records of a select group of patients who present with acute chest pain.

The SPEED-EXTRACT project uses a variety of de-identified patient data from Royal North Shore, Ryde and Hornsby hospitals, including doctor's notes stored in Electronic Medical Records (EMR).

Utilising this information, the researchers are able to characterise the management and outcomes of patients suspected of suffering from a very serious type of heart attack known as ST Elevation Myocardial Infarction (STEMI).

"There is clear guidance for the treatment of these patients, and we are now in a position to explore and understand the reasons for variation in care across institutions in NSW," said Professor Morris, the Director of Biomedical and Health Informatics at the University of Sydney.

"One of Sydney Health Partners' aims is to demonstrate through inter-disciplinary research that, by extracting knowledge from diverse data types housed within the EMR and applying cutting-edge machine learning techniques, we can improve the appropriateness, specificity and efficiency of healthcare delivery."

The SPEED-EXTRACT project requires a multidisciplinary team of cardiologists, digital health experts, engineers and data scientists from across Sydney Health Partners' membership, including the University of Sydney, Northern Sydney, Western Sydney and Sydney Local Health Districts, The Centre for Translational Data Science and Sydney Informatics Hub.

Professor Morris said that if the study does prove the feasibility of data extraction from EMR, the next step would be to standardise the process and scale it up to improve the care of acute coronary patients across the health system.

"We hope this study will provide a foundation for a future where near real-time clinical data audits and feedback-driven practice improvement support clinical decision-making, inform continuing medical education and lead to better patient health outcomes."

> ***"By extracting knowledge from diverse data types we can improve healthcare delivery."***



Biobanking



Biobanking is increasingly recognised as a vital enabler of high-quality translational health and medical research.

Across NSW and over many decades, numerous biobanks have been established, but often independently of each other and with insecure funding sources for ongoing development and sustainability. The result is that biobanking activity is geographically scattered, not always optimally resourced and managed, and of variable quality.

In line with the NSW Health Strategic Priorities 2018-19, which acknowledges the importance of biobanking in translational research, SHP in 2018 sought to determine whether it could contribute to improved co-ordination of biobanking.

Building on surveys conducted by the NSW Office for Health and Medical Research in 2013 and the Westmead Research Hub (WRH) in 2017, Sydney Health Partners conducted a biobanking survey among its member organisations. This had two goals: to describe the types of biobanks and existing operational supports; and to understand in what ways SHP could add value in the space.

> ***"There are several areas which would benefit from better co-ordination and sharing of resources."***

The survey reaffirmed the potential for biobanking to bring together research and researchers. It also, however, confirmed anecdotal evidence that many biobanks are small, not securely resourced and of unclear quality, thus limiting future research use. At the same time, the survey identified several areas which would benefit from better co-ordination and sharing of resources.

In a report to its Partners, SHP said the results of the survey did not offer one clear option for ongoing management of these biobanks. It concluded that the capacity, expertise and resources of the NSW State Biobank are likely to be better placed to support those biobanks that have the potential for future research use.

Research Enablers

A major driver of Sydney Health Partner's activities is the removal or reduction of barriers to the translation of research into clinical practice. Assisting in overcoming these barriers is SHP's Research Enablers theme, which works towards establishing efficient, timely and cost-effective policies and processes to support research operations across partner sites.

Following its successful work with the NSW Government in 2017 to establish a standardised Material Transfer Agreement and participant consent forms for biobanking activities, SHP worked during 2018 towards the establishment of unified Site-Specific Assessment/ governance processes across partner sites.

The streamlining, harmonising and standardising of research ethics approval processes was also an area of vital interest. Sydney Health Partners conducted a confidential study of ethics and governance approval times across its major partners, and provided the results to the partners for comparative and process improvement purposes.

SHP also engaged actively with the Office of Health and Medical Research on its development of its new Research Ethics and Governance Information System – an online portal to more transparently manage approvals of human research projects in NSW and ACT.

Sydney Health Partners sought to strengthen standards and processes to better support compliance of research grant applications. It commenced planning an educational workshop to improve collaboration between the University and its health partners within a governance framework, thereby aiming to create conformity when navigating contracts for clinical trials.

Committee members also completed the first stage of a research equipment register aimed at assisting researchers to locate and access relevant equipment or infrastructure.

> ***"The streamlining, harmonising and standardising of research ethics approval processes was of vital interest."***

Also in discussion were reforms to enhance the availability of, and access to, communication infrastructure to facilitate greater collaboration between partners.

Improved sharing of knowledge including recent initiatives such as eHealth and The Hospital Connectivity project will also be a focus for the Research Enablers theme in 2019.





Professor Robyn Jamieson

"The integration of genomics into routine clinical care has faced some barriers."

New Research Investigates Ways to Make Genomic Analysis Clinically Routine

It's not an exaggeration to say that the rapid development of genomics has been a catalyst for major change in health and medical research.

The recently acquired ability to sequence a person's whole or partial genome quickly and relatively inexpensively has opened up numerous new avenues for discovery and potential treatment.

While these opportunities have been eagerly seized upon by research scientists, the integration of genomics into routine clinical care has faced some barriers.

Now with support from Sydney Health Partners, researchers have commenced a project to prove the value of genomics in mainstream healthcare, using ocular genomics as the lead project.

Led by University of Sydney Professor of Genomic Medicine Robyn Jamieson, the Genomic Medicine (GEM) Initiative has piloted integrative eye disease clinics, which include genomic variant analysis at the Children's



Hospital Westmead, Westmead Hospital, Save Sight Institute and Nepean Hospital.

"We all have a lot of subtle variations in our genes – they are part of what makes us who we are," says Professor Jamieson.

"But sometimes it is hard to work out if it's a subtle variation or a disease-causing variation – and that's where you have to have the exchange of information between the genetic specialists and the disease specialists to work out the right answer for that patient."

As part of the research project, a clinical genetics team attends the patient clinics in combination with eye specialists and also takes part in clinical team meetings.

Professor Jamieson says there is clear evidence that by improving integration of genomics into clinical care, patient clinical outcomes are significantly improved.

"This project has demonstrated the value of genomic analysis by identifying potential genetic therapies and improving the ability of clinicians to provide patients with an accurate prognosis," she said.

"Once upon a time we had no way of giving patients answers to questions such as 'am I going to go blind tomorrow, am I going blind in 20 years, is there a treatment for me, and what are the chances of my children inheriting this?'"

"Now, there is genetic and genomic information which actually pinpoints the diagnosis, and for a lot of patients this can make a huge difference – particularly those for whom there are only one or two underlying genetic variants."

As part of the GEM Initiative, Professor Jamieson's research team has developed a patient survey to measure the degree to which eye disease patients value the genomic information they receive and, if a new genomic therapy becomes available, how they feel this would impact their lives.

"Saving vision through new genetic therapies is expected to benefit patient well-being, and in this project we are also determining the impact from a health economic perspective," she said.

The third arm of the GEM Initiative is to raise the general level of genomics knowledge amongst clinicians.

"One of the issues is that this is a very new field of medicine and most clinicians don't have genomics training," said Professor Jamieson. "As a result, when the test results come back, they can find them difficult to interpret."

"There have been a few situations where a report has been interpreted incorrectly and the patient has been told something that is not entirely correct. Accuracy is important because the information can have implications not only for the patient themselves, but also for other family members."

As part of the research project, the GEM Initiative has collaborated with the University of Sydney to develop a new unit of study called "Genomics in Clinical Practice" which is available as a short course or as part of the Master of Medicine program.

"To me it's clear that there is a huge educational need to train medical students in genomics," said Professor Jamieson, "and also doctors in current medical practice."

"While our research has focussed on the treatment of eye diseases, we are recommending that genomic analysis be integrated into all appropriate clinical areas in order to improve healthcare outcomes generally."

Genomics

The Genomics theme includes clinicians and scientists from across Sydney Health Partners and its collaborators. New genomic investigations are now providing transformative opportunities in disease diagnosis, prognosis, treatment and precision medicine. Members of the genomics theme are leading the implementation of these new opportunities for best practice in patient care (see page 20).

In addition, several members are contributing to NSW Health genomic planning for further development of system-wide improvements in service delivery and translation of new research findings to clinical care.

Many members of the Genomics theme have contributed to development of a new unit of study available in the University of Sydney, Master of Medicine program, Genomics in Clinical Practice. This unit of study is suitable for clinicians of all backgrounds and scientists with an interest in clinical genomics, and focusses on contemporary genetic and genomic approaches and their applications to clinical care.

Several members will also contribute to research activity led by Associate Professor Sandra Cooper, in a Sydney Health Partners-funded project in 2019, for improved methodology in interpretation of genetic splice variants and translation to routine genomic laboratory practice.

Activities of the genomics theme also inform implementation of other emerging technologies for improved healthcare, such as transcriptomics, metabolomics and proteomics, which may provide complementary approaches with common themes developed to aid advancement.





Section 2

Investigation

The Medical Research Future Fund (MRFF) provides a long-term sustainable source of funding for endeavours that aim to improve health outcomes, quality of life and health system sustainability across Australia.

In 2018, MRFF provided Sydney Health Partners with $2 million through its Rapid Applied Research Translation (RART) scheme. SHP disbursed the funds to 14 research projects, which were chosen in a competitive process from more than 60 applicants across its network.

All of the projects were chosen for their ready ability to be translated into clinical practice and strong prospects of delivering tangible benefits to patient care within a 12-month period.

Following confirmation of ongoing RART funding from the MRFF (see page 24), SHP conducted a second grant round, ensuring that rapid applied research will continue to be a focus of its activities in 2019.

$6.1 million boost for Translation of Medical Research

The translation of Australia's world-leading medical research into patient benefit was boosted by a three-year funding commitment announced by the Commonwealth Government in July.

Federal Minister for Health, The Hon Greg Hunt MP, announced a grant of $6.1 million to Sydney Health Partners – along with matching funding for fellow Sydney AHRTC, Maridulu Budyari Gumal (SPHERE) – at a joint function held at The George Institute for Global Health in Sydney.

"This is about taking our research work from the laboratory to the lounge," said Minister Hunt at the event. "If you bring researchers, universities, hospitals together rather than in different silos, at the end of the day we can get solutions to patients dramatically faster."

The money from the Medical Research Future Fund (MRFF) was committed under the Commonwealth's Rapid Applied Research Translation (RART) program, to be used for competitive grants to researchers within the SHP network.

Responding at the launch, Executive Director, Professor Garry Jennings AO, said SHP would use the money to continue to speed-up the translation of research findings into hospital wards and health clinics.

"It's one thing to make the discovery, write the paper and get the patent," he said, "but it's another thing to make the development sufficiently useable and scalable to be applied across the health system."

"The announcement allows us to build on work we've commenced and create additional scale in the rapid translation of research into better health outcomes."

The three-year commitment followed an initial $2.25 million received by SHP from the MRFF, which was used in 2018 to support 14 one-year RART projects across the partnership as well as national AHRA projects.



Federal Minister for Health, The Hon Greg Hunt MP

Medical Research Future Fund

2018 Rapid Applied Research Translation Projects

Chief Investigators	Description
Professor Clara Chow Professor Gemma Figtree Professor Len Kritharides	Testing an alternative clinic-based method of assessing patients presenting to Emergency Departments with chest pain, in order to reduce unnecessary hospital stays. Using data to calculate the risk of patients developing coronary disease, to motivate them to make diet and lifestyle changes. **See page 44**
Professor Barbara Fazekas de St Groth	Developing a novel blood test which can predict a lung cancer patient's response to expensive and potentially life-threatening immune checkpoint therapy, before initiating treatment. **See page 28**
Dr Dinny Graham	Developing an affordable genomic test to predict which breast cancers are at higher risk of relapse and thus inform better treatment decisions for improved outcomes in disadvantaged Australian populations. **See page 30**
Professor Jacob George Professor Geoff McCaughan	Testing new interventions to maximise the hepatitis C cure rate in marginalised communities, such as those with a history of injecting drug use, and other disadvantaged socioeconomic groups. **See page 29**
Professor Sarah Hilmer	Developing and testing educational materials for patients and caregivers at discharge from acute geriatric services, to encourage them to discontinue the use of inappropriate medications identified during their hospital stay. **See page 26**
Professor David Hunter	Researching the enablers and barriers to the implementation of the evidence-based Osteoarthritis Chronic Care Program at NSW hospital sites. Piloting an education and training intervention to enhance its implementation. **See page 33**
Professor Robyn Jamieson	Researching the outcomes of integrating genomics testing into eye disease clinics, in order to identify potential genetic therapies and improve the ability of clinicians to provide patients with an accurate prognosis. **See page 20**
Professor Madeleine King	Researching the enablers and barriers to clinicians using information from patient surveys, to improve patient self-management and behaviour change, clinical care and health services. **See page 40**
Dr Sarah Maguire	Researching the extent to which the evidence-based hospital-to-community treatment pathway for children and adolescents with Anorexia Nervosa has been successfully implemented in hospitals and community health services in NSW. **See page 46**
Professor Jonathan Morris	Developing and testing educational materials which encourage clinicians and expectant mothers to delay planned births until full term, in order to improve newborn outcomes and reduce health service costs. **See page 34**
Professor Jonathan Morris	Using cutting-edge techniques to mine de-identified data about acute chest pain patients from hospital patient records, to demonstrate that better use of data can improve healthcare. **See page 17**
Professor Tim Shaw	Using EHR data to drive translation of evidence into practice, and improve cancer care provided by teams and individuals. **See page 54**
Professor Angela Webster	Trialling the use of smart phone technology to help chronic kidney disease patients from culturally and linguistically diverse backgrounds to better manage their condition and their lives. **See page 32**
Associate Professor Nicholas Wood	Researching the efficacy and safety of vaccination of pregnant women who are taking bDMARDs immune-suppressant drugs, and the impact on infant immune responses. **See page 36**

SHP Project Tackles Polypharmacy in the Elderly

For many elderly Australians, a regimen of several prescription drugs is a daily fact of life. Over time, often beginning in middle age, health consumers can accumulate prescriptions to the point where they are using more medications than is medically necessary.

This phenomenon, known as inappropriate polypharmacy, can have unintended and deleterious effects on an elderly consumer's health, potentially leading to falls and cognitive impairment.

Professor Sarah Hilmer is on a mission to promote the deprescribing of unnecessary drugs. She says inappropriate polypharmacy is almost universal amongst older public hospital inpatients, but is not addressed by routine care.

"There's been a huge increase in the number of medicines available, and people are starting to use them as preventative treatments in middle age and continuing them into old age," says Professor Hilmer.

"As the consumer's health changes over time, some of these treatments are no longer required, or become of low value. Compounding this is the issue of the prescribing cascade – doctors prescribing a drug to treat the effects of another drug, without realising they are doing so."

In a translational research project funded by Sydney Health Partners, Professor Hilmer and her team designed information to educate health consumers about inappropriate polypharmacy and the need to stop taking drugs that are no longer necessary.



"The whole idea of deprescribing is a relatively new field. The term was first coined in 2003, and clinician guidelines have only come out in the last five years or so. Providing consumers with guidelines is clearly the next step we have to take."

Professor Hilmer, who is Head of the Department of Clinical Pharmacology and a Senior Staff Specialist in Aged Care at Royal North Shore Hospital, says that up until her project almost no written resources explicitly addressing the problem had been aimed at patients. She collaborated with two University of Sydney experts in communicating with patients, Professor Parisa Aslani and Dr Jesse Jansen, to produce written resources, which target consumers.

"It's not just doctors who need to know about the problem. If the consumer doesn't know what is going on, then changes made in one part of the health system get lost as they move into the next part," said Professor Hilmer.

"We need communications in which not only is the information logical and easy to understand but where the emotional message is clear – because when it comes to stopping drugs it's not just about understanding the facts it's also about feeling comfortable with them.

"Our aim was that the information we developed would improve patient adherence to medication changes after they were discharged.

"We piloted and refined the information leaflets with the help of older people who had been in hospital recently, or their caregivers. We used questionnaires to test whether

they could understand it, know what to do with it and, importantly, would be comfortable following it."

Consumers correctly responded to nearly all of the questions and found the leaflets to be informative, well designed and a valuable resource. In the words of one, "If you're leaving hospital and not feeling terribly confident, this would certainly give you a lot of confidence, thinking 'I can follow on the leaflet'".

Multidisciplinary hospital health professionals reported that the leaflets had excellent usability, and were likely to be used by pharmacists or junior doctors depending on time and resources available. As one pharmacist said, "I think it's good to give something to the patient or carer because just telling them we're stopping is not enough."

> ***"The whole idea of deprescribing is a relatively new field."***

The consumer resources developed through the SHP project were then successfully tested in practice with patients and staff at Balmain Hospital.

The SHP project complemented work funded by a NSW Health Translational Research Grant in which Professor Hilmer and her team developed deprescribing information to guide clinicians. The clinician guides will also be included in a bundle of interventions to reduce inappropriate polypharmacy in older inpatients, which will be tested at Concord and Royal North Shore Hospitals during 2019.



Professor Sarah Hilmer

Immune System 'Memories' Guide Treatment Decisions for Lung Cancer Patients



Professor Barbara Fazekas de St Groth

In recent years, new treatments which harness our immune system have shown great promise in the fight against several cancers. It is now possible, for example, to produce stable long-term remissions in some advanced lung-cancer patients by a process called immune checkpoint therapy.

Checkpoint therapies are, however, effective in only one-in-five patients, are very expensive and can induce severe side-effects.

Now a Sydney Health Partners-funded project has developed a novel blood test which can predict a patient's response to checkpoint therapy before initiating the treatment.

The test is unusual in measuring the set state of the patient's immune system, rather than the more usual approach of measuring its response to the therapy itself.

Sydney Local Health District University of Sydney immunologist Professor Barbara Fazekas de St Groth has identified a predictive 'signature' of immune cells which is common to lung cancer patients who do not respond positively to checkpoint therapy.

"This is a major breakthrough in the field because no longer will 80 per cent of patients undergo expensive and potentially life-threatening therapy for no clinical benefit," said Professor Fazekas.

"The differences that our test reveals between the immune compartment of patients who do or do not respond to therapy are profound. It's a very positive indicator that the test will prove robust when scaled up for wide application in clinical settings."

While immune checkpoint inhibitor therapy can help the immune system fight cancers, it can also allow the immune system to attack some normal organs in the body. This can lead to side effects including fatigue, cough, nausea, loss of appetite, skin rash, and itching. Less often they can cause more serious problems in the lungs, intestines, liver, kidneys, hormone-making glands, or other organs.

The blood test for the effectiveness of checkpoint therapy was developed using the University of Sydney's Ramaciotti Centre CyTOF (cytometry by time of flight) mass cytometer, which can track up to 100 different cellular processes simultaneously and interrogate a thousand cells a second.

Professor Fazekas is confident, however, that the same test can be undertaken for lung cancer patients using more commonly available equipment.

"Medicine is all about what works and this approach is easy and isn't going to take that long," she said. "There are ways to do the test which are relatively quick and affordable, and can be done at scale."

Professor Fazekas says the discovery of an immune system signature could also be important for research into auto-immune diseases.

"The immune system is adaptive, and its current state has been shaped by events in the lifetime of your body," she said.

"We know that the immune system carries 'memories' – traces of what has happened to it in the past – and that in practical terms these traces are predictive of what will happen in the future."

Project Helps Marginalised HCV Sufferers get Treatment



Professor Jacob George

Liver disease researchers supported by Sydney Health partners are studying why the treatment revolution, which has transformed the cure of hepatitis C (HCV), is by-passing a large proportion of Australians infected with the potentially deadly virus.

In 2018, a team led by University of Sydney Professors Jacob George from Western Sydney Local Health District and Geoff McCaughan from Sydney Local Health District (SLHD) began trying to reach the large numbers of HCV sufferers who are missing the opportunity to receive the new treatments for reasons which are as much social as medical.

It is estimated that only about one third of all those infected with hepatitis C in Australia have been treated.

"When you consider that about one per cent of the Australian population is infected with HCV, that means there's a very large number of people who could be cured, but aren't receiving the new treatments," said Professor George.

HCV can now be easily treated – and in most cases cured – by taking one of a recently developed class of oral drugs called Direct Acting Antivirals (DAAs). DAAs are molecules that target specific non-structural proteins of the virus, and result in disruption of viral replication and infection. They can be taken as a daily capsules, require only 8-12 weeks of therapy, have minimal side effects and cure HCV in over 95 per cent of cases.

In March, 2016, Australia became the first country in the world to make the new drugs available without any restriction to any patient in the community through the Pharmaceutical Benefits Scheme.

"The introduction of DAAs was a total revolution in the treatment of HCV, which is a major cause of mortality and morbidity, and a risk for the development of liver cancer around the world," said Professor McCaughan.

"When the drugs were first added to the PBS we treated enormous numbers of patients very, very quickly, but after 12 months the numbers of people we were seeing in our hospital clinics fell dramatically and we were not sure why."

Professor George says people within marginalised communities often have a lot of other social and health issues to deal with.

"Our hypothesis is that because these patients may be struggling with their mental health issues or drug dependency – and because they are relatively asymptomatic – they don't see HCV as a health priority," said Professor George.

"If we understand the barriers in those individual patients and groups of patients then we can start to get them onto treatment."

The project takes treatment to places in inner-west and western Sydney where the marginalised can be found – such as opioid addiction treatment clinics, sexual health clinics, mental health clinics, Aboriginal Health Service clinics and centres providing care to the homeless.

By the end of 2018, over 1000 people had been screened, and more than 220 commenced drug treatment.

SLHD Hepatitis Coordinator Janice Pritchard-Jones says patients with chronic HCV often require several face-to-face consultations and multiple follow-up phone calls before they will initiate treatment.

Despite the challenges, she says the project has achieved encouraging results.

"Our experience shows that a combination of a hepatology outreach nurse, supported by a local nurse "champion," plus workforce development and peer education is critical to success in settings where clients have complex, competing issues, and feel marginalised," she said.

"Without the support of Sydney Health Partners to send our team into these marginalised communities, most of these people would probably not have been screened, let alone treated."

Novel Low-Cost Gene Test Could Improve Treatment of Breast Cancer

A low-cost test to more accurately predict which breast cancers are at higher risk of relapse, and thus inform better treatment decisions, was successfully trialled by researchers and clinicians in the Sydney Health Partners network in 2018.

The PROSPER-2 genomic test is a quick, low-cost and hospital-delivered alternative to currently available commercial genomic testing of breast cancer, which is often unaffordable for patients.

With support from SHP, lead investigator Dr Dinny Graham from the Westmead Institute for Medical Research sought to prove that by measuring the molecular expression of a small handful of genes, the PROSPER-2 test could predict which tumours are more aggressive and less likely to respond to conventional treatments with at least the same accuracy as the current tests.

Dr Graham says that despite multiple studies demonstrating the advantages of adding multi-gene tests to traditional prognostic tools when evaluating breast cancer cases, the uptake in Australia has been limited.

"Very few patients have these tests done because they cost several thousand dollars, there is no Medicare subsidy and for some tests the tumour sample has to be sent interstate or overseas to be tested."

For the majority of women diagnosed with breast cancer, the standard treatment is with endocrine agents, which are highly effective.



In a proportion of cases, however, clinical pathology suggests that the patient is at an elevated risk of relapsing after the tumour is removed, and they usually receive chemotherapy in an effort to reduce the risk.

"In a considerable subset of cases, traditional prognostic tools for predicting a patient's risk of relapsing return an ambiguous result," said Dr Graham.

"If the ideal treatment path for the patient is not 100 per cent clear, they might be given chemotherapy and suffer its side-effects unnecessarily."

Dr Graham's team of researchers identified the gene signature that would provide the best prediction of a breast cancer's relapse risk by analysing bioinformatics data from previous research.

This novel gene signature was then used to test breast cancer tissue samples gathered from patients being treated at the Westmead Breast Cancer Institute, Westmead Hospital. The patients were also offered a commercial molecular test.

The research showed that the PROSPER-2 test gave results consistent with commercially available molecular tests, and was likely to predict patient outcome.

In 2019, PROSPER-2 will be validated by further tests on a second cohort of breast cancer cases assembled over many years, to confirm the ability of the test to predict patient outcome. The first sample group will also be broadened to include a cohort of breast cancer patients recruited at the Royal Melbourne and St Vincent's Hospitals in Victoria.

If successful, Dr Graham and her team plan to work with NSW Pathology to translate PROSPER-2 into a test that can be readily performed in a hospital clinic setting, and at a fraction of the current cost.

"We hope to make the test broadly available to breast cancer patients throughout Australia for less than $100."

"This is potentially highly translational and we hope that what we are finding will bring low cost molecular testing into clinical practice for the treatment of breast cancer patients in the Australian public health environment."

"If we do, PROSPER-2 should result in improved treatment outcomes for breast cancer patients; longer patient survival, improved productivity and the economic benefits to the public health system that will flow on as a result from those gains."



"This is potentially highly translational."

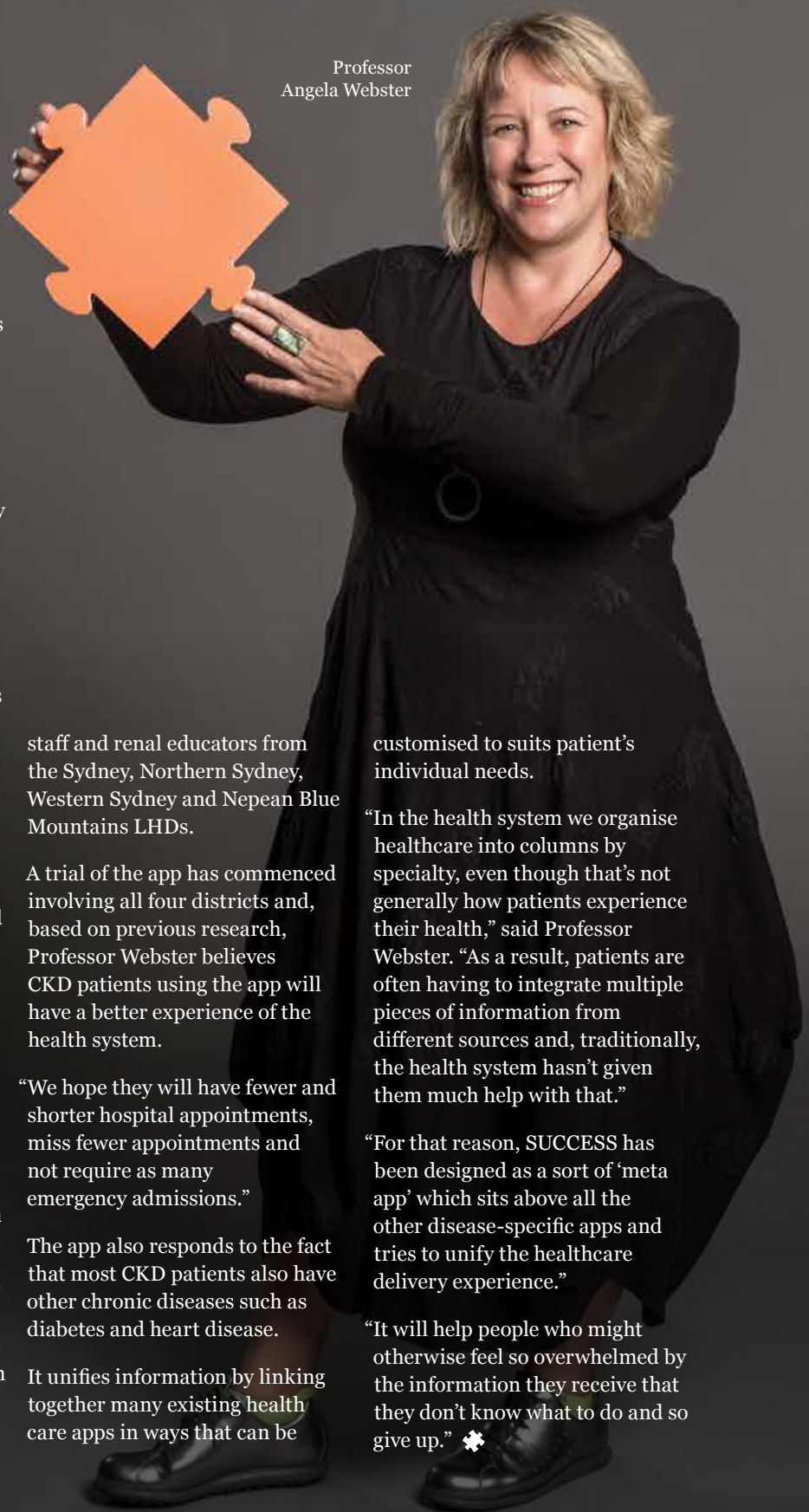
Dr Dinny Graham

Mobile Phone App Helping Kidney Disease Sufferers Take Control of their Health

Researchers across Sydney Health Partners are trialling the use of smart phone technology to help chronic kidney disease (CKD) patients to better manage their condition and their lives.

The SUCCESS smart phone app contains information and generic health literacy skills training to encourage CKD sufferers to be more involved in making decisions about their care.

Chief investigator, University of Sydney Professor Angela Webster, says the project was prompted by evidence that people with lower health literacy and from Culturally and Linguistically Diverse (CALD) backgrounds suffer from more rapid progression of CKD, and higher mortality.



Professor Angela Webster

"There is no standardised education system for CKD patients across New South Wales Local Health Districts (LHDs)," said Professor Webster. "Existing programs are often ad hoc, treatment-specific and delivered at critical decision points. That leaves patients under pressure and ill-prepared to make informed health decisions across the whole trajectory of their disease."

The app being developed by Professor Webster and her team is designed to empower patients with generic health literacy skills training and provide information that has been simplified – based on world's best-practice principles for health literacy – to make it both understandable and actionable.

Professor Webster, who is a Senior Staff Specialist in Renal Medicine and Transplantation at Westmead Hospital, says the content has been developed in consultation with patients, kidney haemodialysis staff and renal educators from the Sydney, Northern Sydney, Western Sydney and Nepean Blue Mountains LHDs.

A trial of the app has commenced involving all four districts and, based on previous research, Professor Webster believes CKD patients using the app will have a better experience of the health system.

"We hope they will have fewer and shorter hospital appointments, miss fewer appointments and not require as many emergency admissions."

The app also responds to the fact that most CKD patients also have other chronic diseases such as diabetes and heart disease.

It unifies information by linking together many existing health care apps in ways that can be customised to suits patient's individual needs.

"In the health system we organise healthcare into columns by specialty, even though that's not generally how patients experience their health," said Professor Webster. "As a result, patients are often having to integrate multiple pieces of information from different sources and, traditionally, the health system hasn't given them much help with that."

"For that reason, SUCCESS has been designed as a sort of 'meta app' which sits above all the other disease-specific apps and tries to unify the healthcare delivery experience."

"It will help people who might otherwise feel so overwhelmed by the information they receive that they don't know what to do and so give up."

Implementing New Treatments to Better Treat Chronic Osteoarthritis

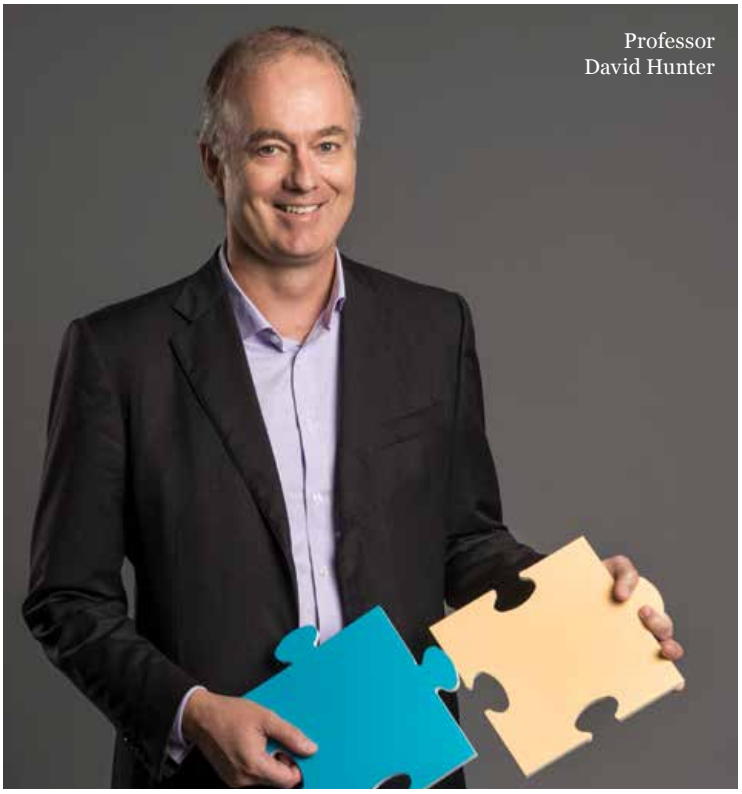
Easing the burden of chronic diseases upon Australians and the Australian health system has become a vital challenge in recent years. Without more cost-effective interventions, increasing rates of chronic disease are projected to overwhelm the resources of health services.

One such threat to health system sustainability is osteoarthritis (OA), which affects one-in-eight Australians. OA is the leading cause of premature retirement, costs the national health system at least $4 billion per annum for surgery, and is rising by ten per cent a year.

In 2018 NSW Health began the state-wide roll out of an evidence-based Osteoarthritis Chronic Care Program (OACCP), which prioritises the treatment of OA with education, self-management, and diet and exercise, before resorting to a surgeon's knife. Sydney Health Partners supported the innovation by funding a research project called OAChangeMap, which sought to understand the enablers and barriers to the implementation of the model of care and enhance its implementation in hospitals.

Chief investigator, University of Sydney Professor David Hunter, says his team found considerable variation in the way OACCP had been implemented across the state.

"At some sites, they had a physiotherapist but they didn't have a dietician; at others, they had a social worker and a psychologist but they didn't have a physiotherapist. In addition, the level of clinician's training in the new care model varied dramatically."



Professor David Hunter

Currently, about 80 per cent of people with OA are given a prescription for analgesic medication and, if pain relief doesn't work, are sent to an orthopaedic surgeon for consideration of joint replacement.

In 2011 Professor Hunter led a pilot of the new diet and exercise model. He found that 15 per cent of patients waiting for surgery had their symptoms reduced to such an extent they volunteered to be taken off the waiting list. NSW Health found that for every dollar they spent on the OACCP, they saved five dollars in joint replacements.

Despite the evidence, Professor Hunter says changing established OA treatment pathways takes time.

"In an ideal world, General Practitioners would refer the patients straight to OACCP but a lot of orthopaedic surgeons would prefer to see the patients first," he said.

"But there aren't enough surgeons, and patients can sometimes wait up to two years to see one. Even when they do receive surgery, one-in-four patients will not have a good outcome."

The OAChangeMap project plans to develop new education and training and pilot it at the Sydney and Northern Sydney Local Health Districts.

"To us, it appears that a key is providing enough education on its benefits to secure stakeholder engagement at all levels, from the chief executive of the local health district down to the on-the-ground support staff," said Professor Hunter.

"Health services are realising that having a vast tome of information about a new model of care and a manual of procedures doesn't make it easy to implement. And that's why OAChangeMap is really important."

Campaign to Encourage Full Term Pregnancies for Healthier Babies

For a long time doctors considered 37 to 41 weeks of gestation to be a "full term" pregnancy, with any birth date during that period thought to provide uniformly good outcomes for newborn babies as they grow and develop. But new evidence has recently prompted the definition of full term to be tightened to no earlier than 39 weeks.

Medical research shows that a trend towards planned births occurring before that time is associated with an increase in health problems amongst newborns, such as needing specialised care for breathing or feeding. Children born before 39 weeks are at increased risk of long-term developmental problems such as poorer school performance and Attention Deficit Hyperactivity Disorder.

University of Sydney Professor Jonathan Morris says in order to improve neonatal health outcomes and save the health system money, there is a need to halt the trend towards earlier births.

"Information from the Australian Commission on Safety and Quality in Health Care shows that 52 per cent of planned caesarean sections in the public sector are occurring before 39 weeks with no strong clinical indication, and in the private sector it's 60 per cent," says Professor Morris, who is the Director of Clinical and Population Perinatal Health Research at the Kolling Institute.



"There is a general lack of awareness amongst clinicians, mothers and their families of the short, medium and long-term implications of being born even slightly early."

In a Sydney Health Partners-supported initiative, Professor Morris and colleagues have developed a multi-lingual education campaign to encourage cultural change amongst obstetricians and midwives – and different choices by expectant mothers. Called 'Every Week Counts' the campaign provides easily understood information for both clinicians and mothers as to why even small differences in gestation time can have a big influence on a baby's development during pregnancy.

"Between 37 and 39 weeks the parts of a baby's brain responsible for learning, movement and co-ordination continue to develop," said Professor Morris. "Our education campaign promotes the message that, providing it is medically safe, it's much better for a child's development that it remains in the womb until full term."

The education campaign has been enthusiastically received during trials at several hospitals within the Sydney Health Partners region and elsewhere in NSW. Early Birth Education Project Manager Lyndsey Harvey says it has been particularly welcomed by midwives.

"We've had very positive feedback from midwives, who we found are already very much aligned with the message," said Ms Harvey. "It confirms what many of them have long believed based on their clinical experience."



The campaign has also been supported by the Australian Pre-term Birth Prevention Alliance, and also warmly received by Women's Healthcare Australasia, who wish to distribute material through their network. Encouraged by the positive reception, the education campaign was preparing to go national in the second quarter of 2019 via the launch of a dedicated website, supported by social media.

Professor Morris says that while reception at all levels has been very encouraging, it will be some time before there is clear evidence that it has made a difference to health outcomes.

"In the areas where the education materials have been distributed we are collecting data on rates of stillbirth, neonatal mortality and morbidity. It is only when we see a decline in these, and a reduction in costs to the health system, that we will be able to ascertain the effectiveness of the approach."

Addressing the Evidence Gap Regarding Immuno-suppressive Drugs Taken During Pregnancy



Associate Professor Nicholas Wood

While the effectiveness of vaccination has been overwhelmingly and repeatedly proven, there are a few very specific circumstances where caution is sometimes advised by clinicians.

One of these concerns women who become pregnant while taking one of a new class of "biological" immune-suppressant drugs called bDMARDs. Typically used to treat autoimmune conditions including Crohn's disease, ulcerative colitis, rheumatoid arthritis, lupus and psoriasis, there is some concern that bDMARDs might reduce the effectiveness of vaccinations routinely given to pregnant women.

It is also possible that the drugs might pass on to their babies in utero, suppressing their immune response and requiring an adjustment to the vaccination regime of newborns and infants.

University of Sydney Associate Professor Nicholas Wood, who heads the NSW Immunisation Specialist Service at Childrens Hospital Westmead, is leading a Sydney Health Partners-funded project that aims to produce data to guide the vaccination of this specific group of women and their babies.

He says the research will address a lack of evidence, which has made it difficult for clinicians to advise prospective mothers.

"Maternal vaccination against influenza and whooping cough is our primary strategy to prevent these infections in young infants," says Associate Professor Wood, "but information regarding its safety and effectiveness for women taking immunosuppressive drugs is lacking, mainly because they are routinely excluded from drugs trials."

"With the bDMARDs class of medications expanding rapidly and being used by more and more women, it's important that we address the evidence gap."

The project is recruiting a cohort of pregnant women using immunosuppressive drugs through three major hospitals across the Sydney Health Partnership, plus Monash Hospital in Melbourne. They will be tested for their antibody response to the flu and whooping cough vaccinations. Their response will be compared to a group of healthy women.

In addition, by the time the project concludes in 2020, the babies of these women will also have been tested for their antibody response to routine infant vaccinations.

It is intended that the research project will result in the creation of new clinical guidelines to be used in high-risk maternity clinics.

Researchers have produced a simple advice pamphlet for women attending such clinics.

"The content and style of the pamphlet was refined through feedback from obstetricians who are part of the research team, and, as a result, referrals to the NSW immunisation Specialist Service have occurred," said Associate Professor Wood.

"It's an important result because prior to this, if a pregnant woman on immunosuppressive drugs, or her doctor wanted vaccination advice, there really wasn't much available."



AHRA
AUSTRALIAN HEALTH RESEARCH ALLIANCE

Section 3

Collaboration

Sydney Health Partners advances health and medical research translation at a state and national level through its involvement in the Australian Health Research Alliance. AHRA was formed in 2017 following the accreditation of three additional Advanced Health Research and Translation Centres (AHRTCs) and two Centres for Innovation in Regional Health by the National Health and Medical Research Council.

Combined with the four original AHRTCs, AHRA's membership of clinicians, researchers and institutions spans more than 85 per cent of Australia's health and medical research community and over 70 per cent Australia's health service providers. In doing so, it provides a uniquely broad – and nationally integrated – systems-level platform for translational research leadership and innovation.

AHRA members work together and share learnings that address systems challenges commonly faced by health services in Australia. This has made them an increasingly important voice in national discussions about how to best improve health and medical research translation.

By developing an infrastructure that eliminates barriers to collaboration between researchers and clinicians, AHRA aims to build capacity and capability for translational research in Australia. It aims to demonstrate that a collaborative translational research model can be successfully applied in large and diverse health systems.

In 2018, Sydney Health Partners contributed extensively to AHRA's national systems-level initiatives by co-leading two national working parties; one on the better use of data to support healthcare innovation, and the other involving consumers and communities in research.



Consumer and Community Involvement

It is now accepted at a health policy level in Australia and internationally that increasing the involvement of consumers and communities in health and medical research can enhance the quality of the research, and assist in its effective translation. Consumer and Community Involvement (CCI) does this by ensuring the relevance of research to patient needs, improving its quality and outcomes and increasing public confidence in research and its findings.

In practice, however, involving consumers and communities in research can be complex, and there are inconsistencies between policies supporting CCI and the resources available to make it happen.

In 2018, AHRA commenced a national systems-level initiative, nominating Sydney Health Partners and the Western Australia Health Translation Network to be the co-leaders on the first phase of a project to strengthen CCI activity in Australia.

Phase One comprised three main activities: an environmental scan of over 200 publications about CCI and the work of leading international and national agencies advocating and supporting CCI; an Australia-wide survey of the extent and nature of CCI across AHRA member organisations; and a national workshop with relevant stakeholders to review the findings and develop recommendations for AHRA to progress.

Building on these activities, AHRA developed a set of vision, values, principles and recommendations which it submitted to the Department of Health in December 2018. The submission informs the second phase of the AHRA CCI project over 2019-2021.

AHRA recommendations for Phase Two include developing a minimum standards for good practice, facilitating the sharing of existing tools and resources, sponsoring research and evaluation projects, and developing formal alliances with leading agencies promoting CCI internationally.

Consumer Involvement in Australian Medical Research is Growing

A national workshop to discuss consumer and community involvement (CCI) in health and medical research held in Sydney last November heard there is a surprising level of activity in Australia including some pockets of world-class excellence.

The workshop conducted by the Australia Health Research Alliance agreed that while the principles of CCI are increasingly accepted in the research community, much more work needs to be done to support wider adoption, and demonstrate its value and measure its impact.

Co-chair of AHRA's national CCI initiative, Professor Gary Geelhoed, said there was evidently enormous passion amongst many researchers and health administrators for CCI.

"The workshop reiterated that in order to achieve faster translation of research into clinical practice you have to have consumers involved in every stage – from determining the best question for the research through to implementation of the answers in primary and hospital care."

Professor Geelhoed, who is also the Executive Director of the Western Australian Health Translation Network (WAHTN), said there was a wide variation between the states in both the level of CCI activity and the methods used to achieve it.

"While it's really taken hold in some jurisdictions and they have a more evolved system, in other places there's quite a long way to go with CCI.

"It's one of these ideas that slowly grows over many years and we need to take all the good things we are doing with CCI across Australia and share them. I'm sure that out of this meeting there will be much more collaboration realised."

AHRA conducted a review of CCI activity in Australia including a survey of almost a thousand people in the sector.

Sydney Health Partners Chief Operating Officer Aisling Forrest described the findings of the survey as a great encouragement to all those committed to promoting CCI in Australia.

"The survey tells us very clearly that consumer and community involvement in health and medical research is valued by researchers, health professionals and – importantly – by consumer and community members," said Ms Forrest.

She said the survey also indicates that while there are a wide range of tools and resources available to support CCI, "there are opportunities to increase awareness, and provide simpler pathways for consumers and the community to become involved."

SHP consumer representative Mohit Kumar said it was obvious from the workshop that there is now general acceptance of the value consumers can bring to research.

"This way we are not just delivering better health outcomes, we are also being smarter about the way we spend public funds."



(L-R) Professor Garry Geelhoed, Mohit Kumar, Aisling Forrest


Professor
Madeleine King
Dr Claudia Rutherford

How Standardising the Doctor-Patient Consultation Could Improve Health Care

"Patients are the experts about how they are feeling, and we really should be listening more carefully to that."

So says University of Sydney Professor Madeleine King, who is investigating how to successfully implement the use of Patient Reported Measures (PRMs) in a way that will inform and guide clinicians in real time when treating patients.

Professor King says that the goal of using patient feedback is a key element in the philosophy of patient-centred care. Despite being proposed in heath circles for more than two decades, it is only recently that the tools and technology to effectively achieve it have become available.

"For a very long time in health care there has been a lot of conversation about this, but there hasn't really been enough effective action," said Professor King.

"What's changed recently is that we've become much better at designing patient surveys to capture their feedback, and also better at designing the IT systems required to properly use that data. Now PRMs could finally be the lever that we need to make healthcare truly patient-centred."

In collaboration with the NSW Agency for Clinical Innovation Patient Reported Measures team, and with the assistance of a grant from Sydney Health Partners, Professor King and colleagues at the University of Sydney Quality of Life (QOL) Office have been analysing de-identified qualitative data provided by the ACI to identify the barriers and facilitators to implementing PRMs in hospitals.

"A literature review was equivocal and highlighted gaps in our knowledge," said Dr Claudia Rutherford, Deputy Director to Professor King at the QOL Office. "It pointed to the requirement for context-specific qualitative research of clinicians' attitudes within the Sydney Health Partnership area, which we hope to undertake soon."

ACI and eHealth NSW procured an IT platform to allow clinicians to access reports on PRMs in real-time, so that a clinician can see in a snapshot of whether or not the patient reports feeling better.

"Anecdotally, one of the biggest barriers to using PRMs, which we hear from clinicians, is 'oh it's just another thing I have to do and I'm already time poor,'"said Professor King. "But we believe that if done properly, accessing and reviewing patient reported measures from a PRM IT system shouldn't take clinicians any more time than talking to their patients does now. Rather it will focus the available time on the issues that matter to patients, making the clinical consultation more efficient and patient-centred."

Dr Rutherford says the PRM IT platform will standardise the questions doctors are asking their patients. For example, patients will be asked to numerically rank their level of pain, tiredness, ability to perform work or tasks, as well as a number of other symptoms related to their specific health condition(s).

Over time, or when compared to the population average, this data will tell clinicians whether how the patient feels s/he is tracking and highlight when further investigator or action may be required.

"Clinicians are already asking these sorts of questions of their patients, but PRM surveys allows that information to be gathered in a standardised way," said Dr Rutherford.

"Some clinicians currently do that really well, others not so well, so this is just a tool, a checklist to prompt a conversation. Importantly though, what it does is prioritise consultation time around the issues the patient is wanting to focus on and matters most to them.

> ***"This is just a tool, a checklist to prompt conversation."***

"This should help make care more patient-centred, and it may in turn improve quality of care and patient satisfaction with care. That's the end game."



Indigenous Health

Sydney Health Partners contributed to the development of an AHRA indigenous health initiative during 2018.

Aiming to establish a network which can build indigenous research capacity across Australia, AHRA members including SHP undertook local environmental scans that measured current levels of indigenous research activity in each region, and grouped the research in broad categories.

Across the AHRA partners, the majority of research activity was found to be concentrated within the categories of Child Health and Development, Social and Emotional Wellbeing (Mental Health), Maternal and Reproductive Health, Health Systems Effectiveness and Social Determinants of Health.

Baseline data from the national environmental scan also indicated there is room for improvement in development of structural capabilities, research co-ordination and strategic oversight.

It was agreed to hold an AHRA forum in 2019 to discuss ways to grow and support indigenous researchers and colleagues working to improve the health of Australia's First Peoples.

The conference would seek agreement on a vision and tangible actions to guide AHRA to upscale and accelerate research capacity, building on the strengths and expertise of Aboriginal and Torres Strait Islander people.

In late 2018 SHP and fellow AHRTC Maridulu Budyari Gumul (SPHERE) reached an agreement to co-fund a new University of Sydney Fellow of Indigenous Health Research for two years.

Data-driven Healthcare Improvement

In order to generate real-world evidence in an efficient manner, AHRA and its members are facilitating the use of advanced digital technologies and nationally-aligned processes that optimise the collection, linkage, management and analysis of large datasets.

In 2018 AHRA commenced a national systems-level initiative in data-driven Heath Care Improvement (HCI), which was led by Monash Partners, Melbourne Academic Centre for Health and Sydney Health Partners.

The initiative aims to collaborate and engage stakeholders, and create a community of practice to identify and address priorities in data-driven HCI. It seeks to transcend silos in order to make progress on previously intractable problems.

In 2018 the initiative focussed on creating virtual hubs for data-driven HCI within AHRA in order to engage all partners in the greater integration of data across the continuum of care, and improve data literacy and workforce capacity for healthcare professionals.

Following the engagement of stakeholders and consumer representatives, a rigorous priority-setting process resulted in a road map for national collaboration on data-driven HCI which was agreed across all Centres.

Activities in 2018 included a survey of data quality assurance within Primary Health Networks across Australia. The learnings were shared with PHNs at a national workshop in order to progress a national framework for quality primary-care data.

Sydney Health Partners also led the development of an accord to facilitate the safe, lawful and appropriate sharing of data between its four health services. The Data Sharing Accord focussed on meta-level issues in data sharing and integration in order to remove the need for each individual research projects to develop their own data extraction, encryption, and storage and access solutions.

While the Data Sharing Accord had not been finalised at the end of 2018, its core principles were shared across AHRA for adaptation and implementation as appropriate. It is intended that the accord be endorsed by partner health services in early 2019.

In the area of workforce development, AHRA scoped data training activities nationally, completed a literature review, engaged and researched with stakeholders across Australia, co-designed a curriculum and content, and partnered with a range of government and education entities to deliver at scale for national workforce development programs.

Activities involving SHP included the development of a MOOC (Massive Online Open Course) titled ‘Using clinical health data for better healthcare’. The education course will be free to registrants, and a version will be developed for NSW Health staff.





Professor Clara Chow

Forging a New Pathway for Chest Pain Patients

One of the challenges facing health services is to manage the demand for relatively scarce hospital beds while at the same time ensuring that all patients get the care they need.

A clinical trial supported by Sydney Health Partners focussed on reducing unnecessary hospital admissions by pioneering a new way to assess the large numbers of patients who present to emergency departments (EDs) with chest pain.

An alternative clinical pathway, dubbed Rapid Access Cardiology Clinics (RACCs), has been successfully established at three major Sydney hospitals to manage low-to-intermediate risk chest pain patients.

"Chest pain is a very common and its one of the leading causes of presentation to our EDs, but after investigation, it turns out that 90 per cent of these patients do not have an acute coronary syndrome," said chief investigator, university of Sydney Professor Clara Chow.



"Nonetheless, these patients are commonly admitted for a short stay in hospital under observation when they could be equally well investigated and managed in an outpatients clinic. We wanted to know whether RACCs could reduce unnecessary hospital admissions without any harm to patients."

Following an initial trial at Westmead in 2016, the Sydney Health Partners grant allowed the research to be continued at Westmead and extended to Concord and Royal North Shore hospitals. Significantly it also allowed de-identified information about thousands of chest pain patients from the three sites to be combined into a common data set.

This core data is used to calculate the risk of each patient developing coronary disease in the short to medium term, and is used by cardiologists to motivate the patients to make diet and lifestyle changes to prevent disease.

> ***"The RACCs have been adopted more quickly and demand has been greater than we expected."***

Cardiology departments at hospitals are also using the data at weekly team meetings to compare treatments at different locations and reduce clinical variation.

Early analysis of Westmead data indicates that, following the establishment of the first RACC, the proportion of chest pain emergency presentations admitted to hospital fell significantly, from 71 per cent in 2014 to 52 per cent in 2018.

Such has been the effectiveness of the alternative pathway, General Practitioners have begun bypassing EDs altogether and referring their patients directly to a RACC via a telephone hotline.

"The RACCs have been adopted more quickly and demand has been greater than we expected. We've asked referring doctors what they would have done if these rapid access clinics hadn't existed, and a substantial number said they would have felt obliged to admit the patient to hospital."

"In addition, patient surveys indicate that they really prefer to be treated in a clinic that be hospitalised."

Professor Chow says the RACC trial has also spurred other complementary research projects.

"The work funded by SHP has led to an expansion of the project in new directions, which is exactly what we hoped it would do."

"We received a grant to establish a digital health test bed (see page 16) and another grant to trial preventative health management through new digital education methods."

"Despite all our efforts cardiovascular disease remains Australia's number-one killer, and we need new approaches to preventing it and better ways of treating it."

Putting Anorexia Patients on the Right Path to Better Health



Dr Sarah Maguire

For many years the Australian health system has struggled to treat patients with Anorexia Nervosa.

Though relatively rare, this eating disorder has a mortality rate of about 5 per cent per decade, escalating to 20 per cent after 20 years' duration of illness – the highest death rate of any mental illness. Effective treatment requires complex and sustained interventions by multiple medical disciplines and, even then, only about half of patients will achieve complete remission.

Since 2013 a team from the InsideOut Institute led Dr Sarah Maguire has worked to implement the NSW Service Plan for People with Eating Disorders, including establishing evidence-based clinical pathways for Anorexia Nervosa sufferers moving through the NSW health system.

In 2018 Sydney Health Partners funded a project that measured the extent to which the evidence-based treatment pathway has been successfully implemented in hospitals and community health services around the state.

Dr Maguire said initial analysis of the data revealed considerable variation in treatment.

"The only proven effective, evidence-based, clinical pathway we have for children and adolescents who present to an emergency department suffering Anorexia Nervosa is a brief period of hospitalisation followed by comprehensive community care involving the Maudsley Family Based Treatment (MFBT)," said Dr Maguire.

"But it's really only in the last five years that we have started training clinical staff in the treatment pathway and it would be fair to say that there are places in the health system where the preferred clinical pathway is still very much under adoption."

In an effort to understand the degree of clinical variation – and the reasons for it – the project has broken new ground by linking individual patient-level data from hospitals and community services.

"Linked data on eating disorders in Australia is very rare but in the case of Anorexia Nervosa it's particularly important. That's because it's a mental illness which also has very serious physical complications. As a result patients will almost certainly come into contact with every area of the health system – from primary healthcare to presentations to the emergency department," said Dr Maguire.

"Unless we can track a patient's pathway through our health services and see whether they received the treatment they were meant to receive, we can't improve the system."

Dr Maguire says the widespread and successful implementation of MBFT and evidence-based clinical pathways requires training of clinicians, resources and reinforcement, as well as access to some sort of specialist guidance.

"As part of the NSW Service Plan for eating disorders we are trying to build virtual teams because clinicians almost never treat Anorexia Nervosa in isolation," she said.

"Because you have the mental health complexity combined with the physical health complexity, Anorexia Nervosa patients can overwhelm clinicians quite quickly. So doctors need to be able to call somebody when they don't feel like they can handle the risk."

"As a clinician I would like to know which hospital pathway I can escalate to if things deteriorate. I need access to all those ingredients in the health service mix or else I'm not going to be able to manage the patient.



Section 4

Education

Sydney Health Partners connects health services, research disciplines and locations in ways that transcend traditional organisational boundaries.

By doing so it provides new opportunities for collaboration and education.

Since the first SHP gathering was held in May 2015, diverse conferences and symposia have become an essential tool for disseminating knowledge and building the partnership.

In 2018, SHP hosted two signature events – its Annual Forum and Implementation Science Symposium – and supported several other forums in the cause of improved health and medical research translation.

SHP Annual Forum Hailed a Success

"I hope being here is part of a movement."

That was one of many enthusiastic reactions from guests at the conclusion of the 2018 Sydney Health Partners Annual Forum. More than 135 clinicians, researchers and administrators attended the event at the Children's Hospital, Westmead on August 29, to take part in discussions on the theme 'Bigger, faster and better: enabling the next era of translational medical research.'

Keynote addresses were given by the Director of the Murdoch Children's Research Institute, Professor Kathryn North AM, and the Chair of Biomedical Translation Fund Committee at Innovation and Science Australia, Peter Wills.

Some of the issues affecting the translation of research into health systems — ethics and governance, consumer and community involvement, clinical trials capacity and data sharing and use – were tackled in lively discussion panels.

Sydney Health Partners' Executive Director Professor Garry Jennings AO summarised the collaborative success of Forum by telling the audience, "I think today we learnt as much from you as you did from us."



Professor Kathryn North AM




Partners


Sydney
HealthPartners
PROGRAM
2018 Annual Forum



Science of Implementation Offers Possible Solution to Health Service Challenges

Unsustainable rises in the cost of healthcare and lengthy delays in the translation of research evidence into clinical practice mean health services should take a more scientific approach to implementing change.

That was the primary message from University of Michigan Professor Anne Sales in her keynote presentation to Sydney Health Partners' Implementation Science Symposium, which was titled UNLOCKING RESEARCH: Health System Improvement through Effective Implementation.

Professor Sales said the introduction of new technologies, procedures and clinical practices is often hampered by the pressures they place on staff.

"The biggest question is 'how do I manage my time and energy when I have to do all this new stuff?' things that feel like new pressures, expectations and demands. That's not an easy question to answer," she said.

The symposium brought 160 attendees from academia, health services, government and business to the University of Sydney to discuss how the relatively new discipline of implementation science might be applied to reduce the lengthy time lag between a health or medical research discovery, and its introduction into clinical practice.

Professor Sales said the appeal of implementation science is that it provides an intellectual and practical framework for learning from mistakes and proposing how health system changes might be optimised.

"I think there's a huge interest and appetite amongst health professionals internationally to know how do we fix the problems we have? They want to avoid the stumbles and false starts that accompany so much of change management in health services at the moment."

Sydney Health Partners executive director Garry Jennings said interest in the relatively new field of Implementation Science had snow-balled.

"There's real demand for this. While very many people are trying to make changes in the health system, a lot of us don't feel we are fully equipped with the background we need to make the changes as effectively and as quickly as we'd like," he said.









"What we learnt at the symposium is that implementation of evidence into healthcare doesn't just happen – there's a sequence of events required that involves testing at a small and then a large scale, and also understanding the policy settings.

"We believe that the application of implementation science has the potential to remove or reduce some of barriers to effective research translation," he said.

Sydney Health Partners' Senior Research Fellow in implementation science, Dr Nicole Rankin, said the high level of interest in the symposium was indicative of a change in researcher thinking.

"They're really keen to engage and to think about how we work with our teams, with our scientists and with our clinicians in a way that's going to bring about meaningful change."

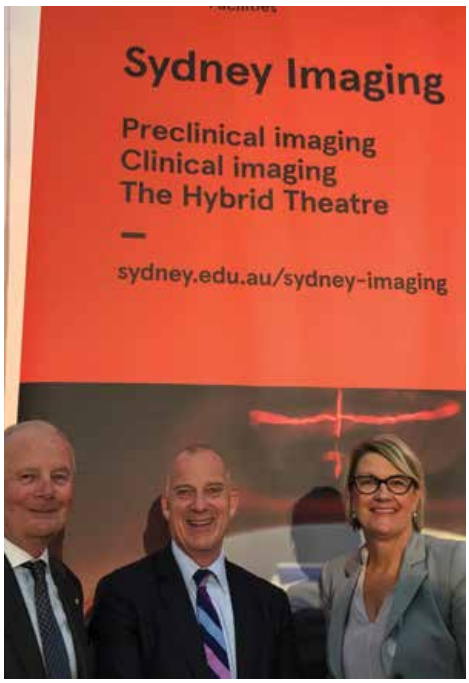
Above (L-R) Professor Anne Sales, Dr Nicole Rankin, Professor Garry Jennings



A Year in Pictures







April Top: The launch of Sydney Imaging at the University of Sydney, Bottom left: Professor Hala Zreiqat, Vicki Snelson and Professor Gemma Figtree at the CVI BioEngineering Workshop. Bottom right: Sydney Health Partners' Professor Garry Jennings, University of Sydney Vice-Chancellor and Principal Dr Michael Spence and NSW Secretary of Health, Elizabeth Koff at the launch of the Sydney Imaging Hybrid Theatre.









April Top left: The Heart Research Institute's Dr Anna Waterhouse speaking at the CVI BioEngineering Workshop.
June Middle left: University of Technology Sydney Associate Professor Brian Oliver, Woolcock Institute Executive Director Carol Armour and Sydney Health Partners Respiratory Stream co-leader Professor Jennifer Allison at a joint education seminar on asthma. Top right: NSW Premier Gladys Berejiklian, NSW Regional Health Partners' Interim Director Professor Marie Gleeson, and Sydney Health Partners' Chief Operating Officer Aisling Forrest at the announcement of an extra $150 million in funding for heart disease research.
September Bottom: Eight University of Sydney Cardiovascular Initiative (CVI) members receive Early-Mid Career fellowships from NSW Health.

Quality Care Dashboard Helps Multi-disciplinary Teams

The benefits of multi-disciplinary teams (MDTs) for the delivery of clinical care to cancer patients have been well established. But the realisation of these benefits is being hampered by the inability to assess and visualise clinically relevant data in ways that aid MDTs to improve clinical decision making and the delivery of care.

The Sydney West Translational Cancer Research Centre (SW-TCRC), led by Professor Paul Harnett, funds a flagship program "Using Emerging Health Data to Impact on Patient Care". As part of this flagship program, a project with support from both Sydney Health Partners and SW-TCRC is making important progress towards overcoming technical and organisational barriers to bringing together data from disparate sources and visualising the information in a consumable format.

Working at Western Sydney Local Health District (WSLHD), University of Sydney Professor Tim Shaw and his group, Research in Implementation Science and eHealth (RISe), have created a clinical analytics dashboard for the use of MDTs treating both lung cancer and breast cancer patients. By combining data extractions daily from two different hospital electronic medical records (eMRs), the dashboard allows MDTs to consider real-time information including surgical, radiation, and medical oncology data in a single graphical snapshot.

"This project is about analysing routinely collected data and presenting it in a useful way to the MDTs," said Candice Donnelly, Senior Research Officer, RISe. "By presenting the data in an actionable format it allows the teams to more readily monitor their delivery of evidence-based care and engage in quality improvement."

Clinically relevant sets of Quality Indicators (QIs) have been identified through a multi-site prioritisation process, online survey, and consultation with the project's breast and lung cancer working groups.

"In contrast to the traditional approach to quality indicators – which are developed at a Federal or State level – we wanted to develop QIs that clinicians care about, and enable them to reflect on practice behaviour, thereby changing the way care is delivered to the patient."

To achieve this, a number of technical and organisational challenges have had to be met. Not every eMR, for example, has a reporting server, meaning new systems for regular extraction from different data sources needed to be developed.

Candice Donnelly says that despite the hurdles, working closely with information technology and business analytics teams have made the outcomes worthwhile and sustainable.

"The dashboard allows MDTs to compare their quality measures with similar teams at two different hospitals within WSLHD," she said.

"The ability to compare clinical analytics between MDTs at other NSW hospitals provides those teams with relevant local benchmarks in addition to national and international standards."

The clinical analytics dashboard has been enthusiastically welcomed by clinicians involved in the working groups. Associate Professor Elizabeth Elder from the Westmead Breast Cancer Institute (BCI) said the process had prompted her to reflect on clinical practice.

"Knowing what you are doing, not just what you think you are doing, is the key to your whole practice," she said. "Having the data available and visualised on a screen – and being able to respond to that – creates a positive feedback loop."



Professor Tim Shaw and Candice Donnelly



Section 5

Information

Sydney Health Partners is a non-incorporated joint venture of its 14 Partners, each of whom contributes funding and in-kind support to SHP operations.

A robust governance structure guides Sydney Health Partners' activities. The Governing Council provides clear direction to the management team, while the Research and Clinical Issues Committees provide expert advice to inform the agenda of the Governing Council.

The partnership is networked by several clinical streams, each of which is focussed on new research as well as accelerating the uptake of research evidence by health services. The streams are supported by cross-cutting themes, concerned with facilitating research activity by the partners as well as identifying and removing barriers to research translation.

This lattice structure of streams and themes encourages connectivity and collaboration in order to achieve the vision of transforming the way research improves patient care and public health.

Sydney HealthPartners in 2018

11,500



Health and Medical Researchers

7,500



Scientific Publications

$247 million



Competitive Health Research Grants

2.7 million



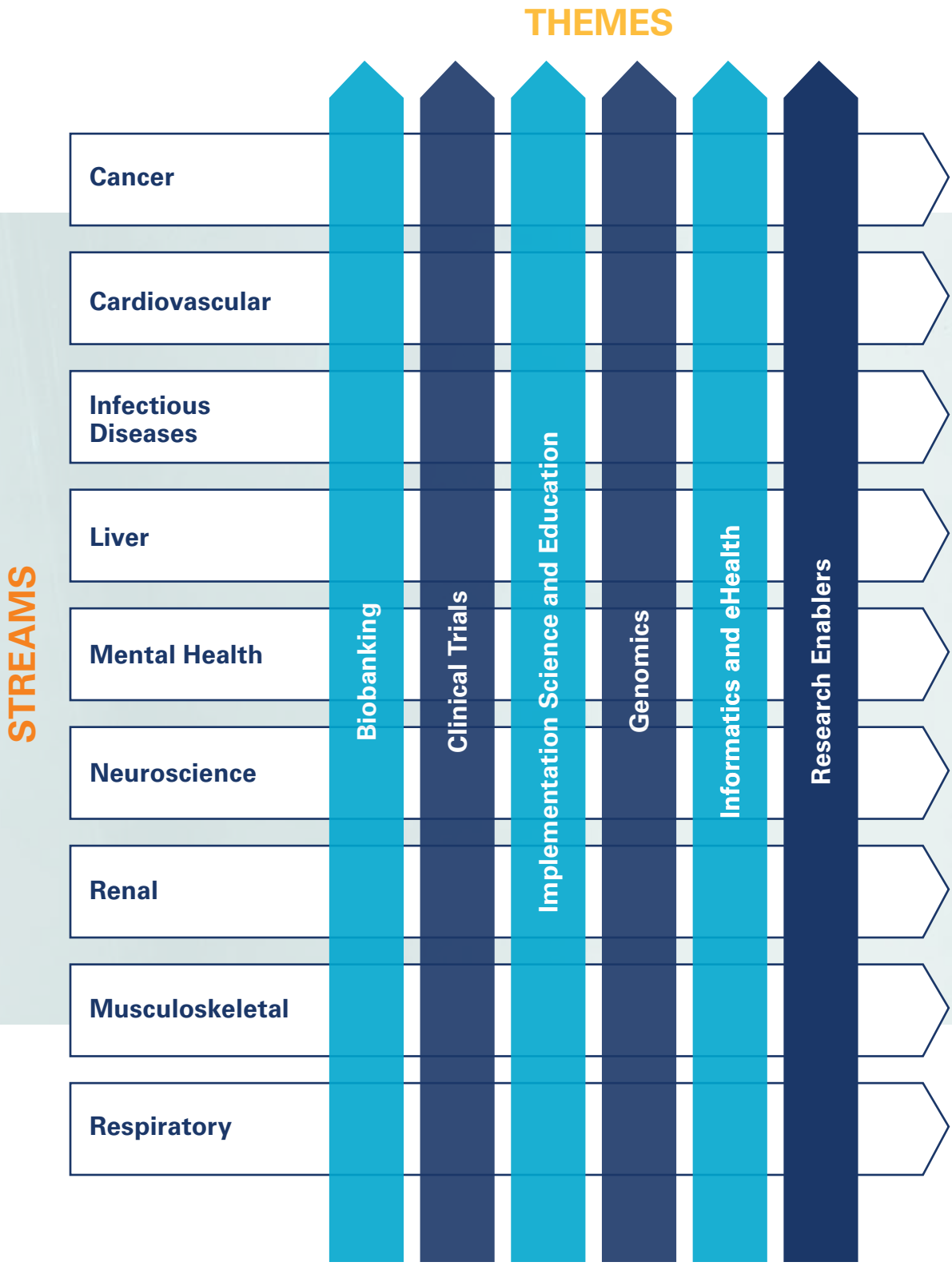
Population Served

$8 billion



Combined Budget of the Partners

Streams and Themes



Governing Council



Paul McClintock AO
Chairman



Dr Teresa Anderson AM
Chief Executive
Sydney Local Health District



Carol Armour AM
Executive Director
Woolcock Institute of Medical Research



Dr Michael Brydon
Chief Executive
Sydney Children's Hospitals Network



Professor Tony Cunningham AO
Executive Director
The Westmead Institute for Medical Research



Professor Garry Jennings AO
Executive Director
Sydney Health Partners



Elizabeth Koff
Secretary
NSW Health



Mohit Kumar
Community Representative



Graeme Loy
Chief Executive
Western Sydney Local Health District



Professor Roger Reddel
Director
Children's Medical Research Institute



Professor Laurent Rivory
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Governance and Management



The SHP Team



Professor
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Christina Alcover
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