

INSPIRE

RESEARCH AUSTRALIA SHOWCASES HEALTH & MEDICAL RESEARCH

A FOCUS ON THE
CONSUMER'S
ROLE IN HEALTH
AND MEDICAL
RESEARCH



CELEBRATING 20 YEARS
OF ADVOCACY

FOREWORD

When we put out the call for articles for our previous issue of INSPIRE we were overwhelmed by the response from our members to the theme of keeping the consumer in focus.

We quickly realised that there is a wide range of perspectives to be covered, so we carried the theme over two consecutive editions. This is the second.

As the peak body representing the entire health and medical research pipeline, Research Australia sees a growing expectation from consumers that they be consulted all the way from basic research, through translational and transformative research, and on to commercialisation. The phrase “nothing about us, without us” pops up again and again in discussion groups, and that attitude is reflected in the rise of consumer-funded research studies, and the influence of patient advocacy groups, amongst others.

Consumers aren’t alone in this view. Funders, too, increasingly expect that the due diligence and consultation has been done to ensure that scarce research dollars are going to proposals that have been shored up by patient-generated insights. Organisations representing medical researchers, like ACTA – the Australian Clinical Trials Alliance (see their article in this edition) – now have dedicated working groups looking at best practice for consumer engagement. And regulatory bodies like the Therapeutic Goods Administration are upping the requirements for consumer inputs as

part of their licencing processes.

But directed consumer interactions aren’t a part of the standard academic path for researchers, and there are still some who are sceptical about the benefits of including non-specialists when designing research. Equally, many consumers will feel unqualified and at a disadvantage if asked to contribute to a discussion about technical or medical matters.

In this edition of INSPIRE we’ve asked a cross-section of researchers to tell us how they have engaged with consumers, and whether that resulted in better research or programs. We hear from Sydney Children’s Hospitals Network about the importance of speaking the patient’s language with culturally and linguistically diverse young people, and from University of Queensland on the need for early and sensitive collaboration with people living with dementia. The Genetic Support Network of Victoria shares the development of their guidelines for involving children in research, and Edith Cowan University looks at communicating with patients, post ICU treatment. Other contributors discuss integrating patients’ points of view much earlier in the research pipeline, and Sydney Health Partners’ Professor Don Nutbeam wraps the whole thing up in the Final Word.

The role of patients and consumers in research is only going to increase,

and it’s a privilege to be able to present this important work to the 7000 readers of INSPIRE. We thank our contributors for sharing with us.

Fittingly, we close out the year celebrating our amazing researchers and their supporters, including advocates and philanthropists at the 18th annual Health and Medical Research Awards in early December. Our thanks to the nominators and their nominees for their incredible achievements and our congratulations to our amazing finalists – we are indeed lucky to have such great Australian talent.

Healthy wishes,

Nadia and the Research Australia Team
CEO – Research Australia



RESEARCH AUSTRALIA HEALTH & MEDICAL RESEARCH AWARDS 2020-21

***Gala Dinner and Award
Ceremony Thursday 9
December 2021***

Four Seasons Hotel Sydney

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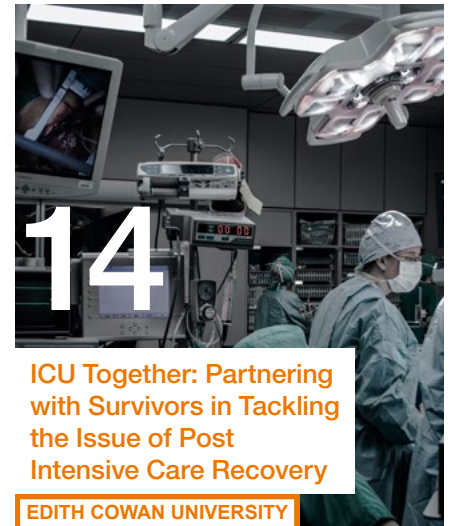
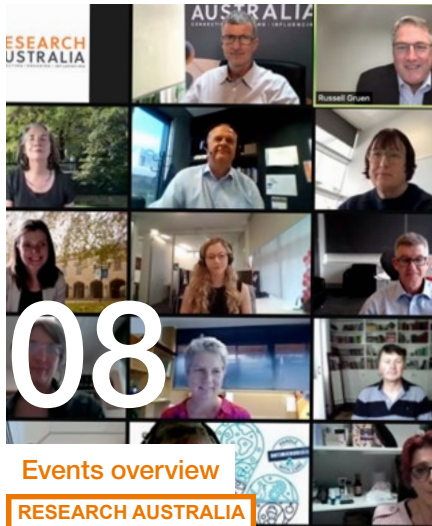
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Who can submit articles?

Any current member of Research Australia who would like to share a relevant story that affects their organisation including, philanthropic donations and their outcomes, research findings, and any other related health and medical research topic that affects the Australian population.

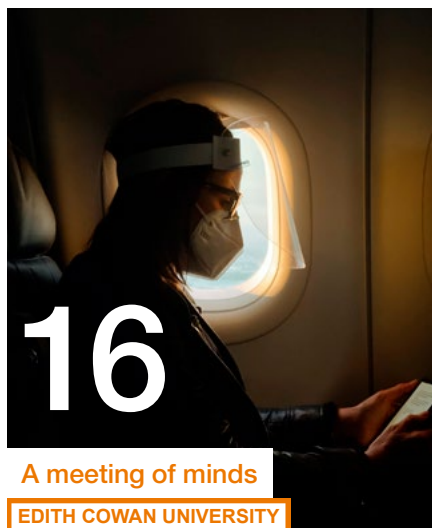
Submission guidelines & deadlines

For information regarding how to submit and publishing deadlines visit the Research Australia [website](https://researchaustralia.org).

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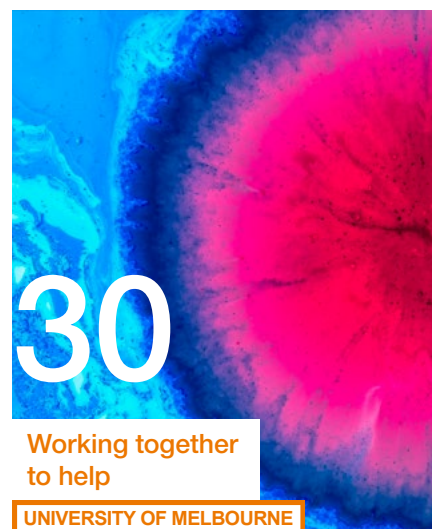
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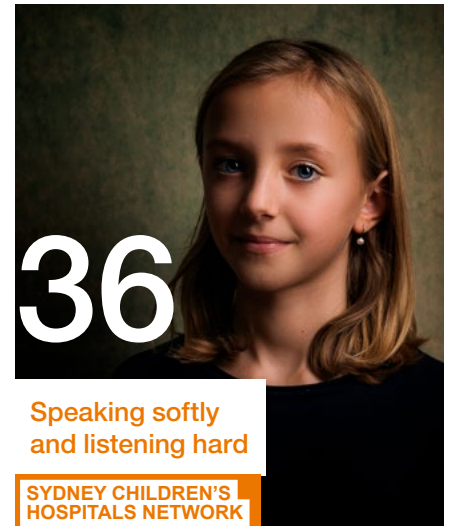
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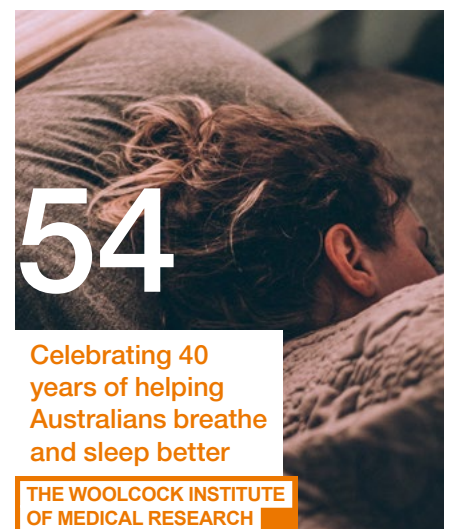
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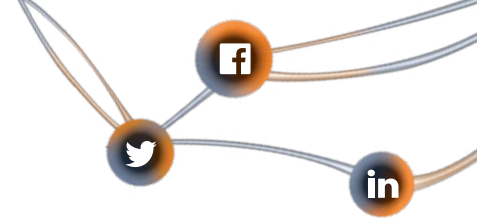
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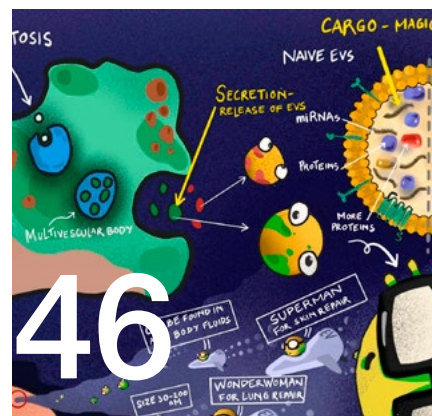
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SYDNEY HEALTH PARTNERS

ROUNDTABLE ROUND-UP

Research Australia convenes regular special-interest roundtables throughout the year to gain insights from key experts and refine our focus on the issues that matter most to our members. Three key Roundtables were held in recent months:

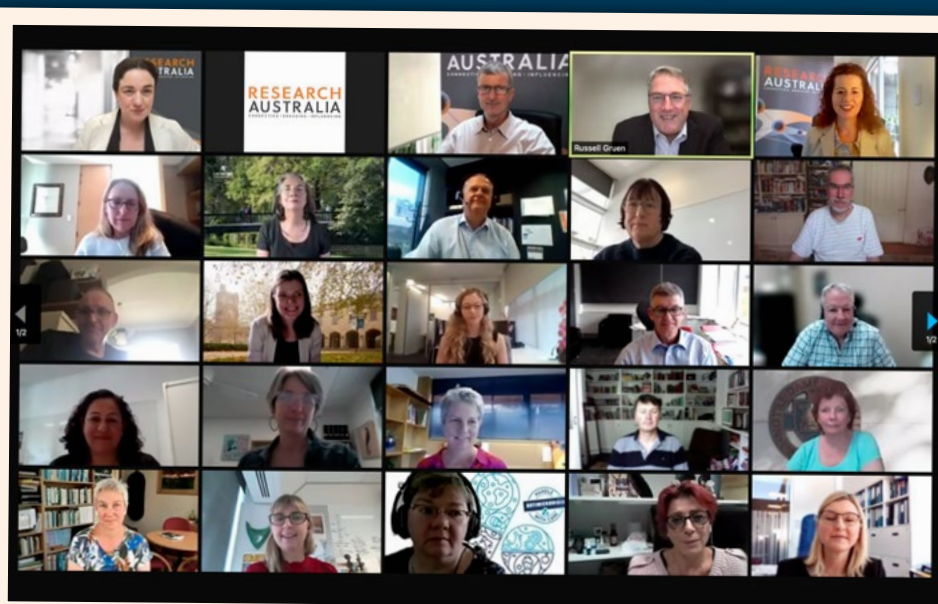
UNIVERSITY ROUNDTABLE

This year the University Roundtable has explored the role of those who both undertake medical researchers and provide health care. This important group are often referred to as 'clinician researchers', or 'health practitioner researchers' (PR). In August, the University Roundtable looked at the career paths, training pathways and the role PRs play as a crucial link between research and the health system. The Roundtable was joined by 41 representatives from 30 universities, each bringing a distinct perspective, and we were pleased to hear from a uniquely qualified panel including:

- Dr Teresa Anderson AM, CEO of Sydney Local Health District, a major capital city public health provider
- Di Ritson, CEO, Lishman Health, Bunbury WA, a regional health organisation; and
- Martin Bowles AO, PSM, CEO of Calvary Health, a private non-profit provider of public and private hospitals, retirement and aged care facilities and community care and a Director of Research Australia.

The discussion covered the different contributions PRs make, how their roles can be better supported, and the different ways our health systems, research organisations and funding bodies can better utilise the set of skills, perspective and experience of PRs.

The last University Roundtable for the year will be held in November, and will be looking ahead, to the role of universities in Australia's future.



PHILANTHROPY ROUNDTABLE

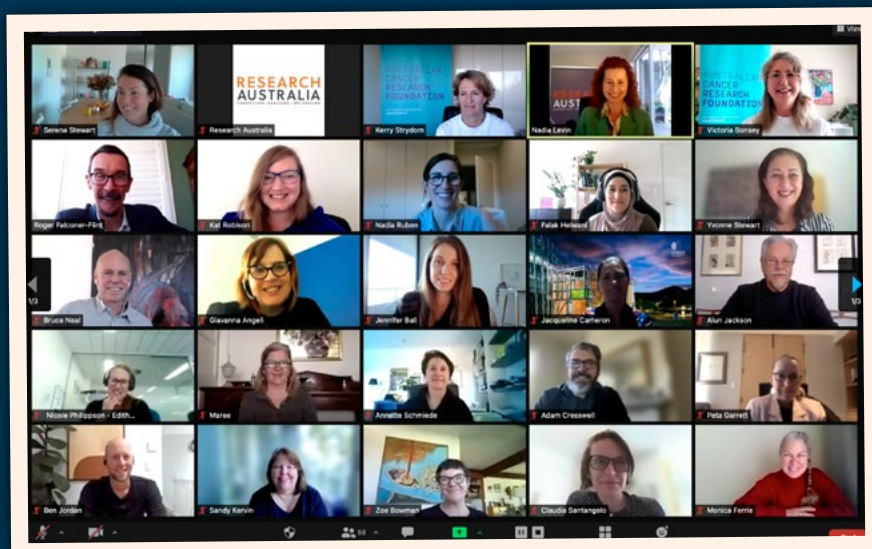
It is a challenging time for organisations dependent on philanthropy. JB Were's Charitable Giving Index report from July 2021 showed that giving peaked in Australia just after the Bushfire Emergency on the east coast of Australia in February 2020 and has fallen 16% from the previous year. It's now back to 2016 levels. However, Research Australia's 18th annual opinion poll amongst 1000 Australian adults found a small positive trend towards donating to health and medical research because of COVID.

In this September Roundtable, chaired by Research Australia CEO Nadia Levin, we looked at how research funding is sourced and used at the Institute or Foundation level, and some of the solutions to finding funds that our members have come up with against the background of the pandemic.

Guest speakers from Cure Brain Cancer, Australian Cancer Research Foundation, Royal Australian & New Zealand College of Radiologists, Sydney Children's Hospitals Foundation, The George Institute and Rare Voices Australia gave examples of adapting to the changing times from their own organisations. These included pivoting their communications and fundraising to digital and social media, looking outside of Australia for funding, launching high-involvement processes for donor engagement (borrowed from industries as diverse as Hollywood movie-deal brokering) and engaging with the patients more closely in order to represent their needs more authentically.

A common thread in the presentations was "let no crisis go to waste". The COVID-19 pandemic has upended many old ways of securing funding, but it has also added urgency and given organisations licence to try out new ways.

Keep an eye out for our next Philanthropy Roundtable in Q2 next year.



ROUNDTABLE ROUND-UP

HEALTH ECONOMICS ROUNDTABLE

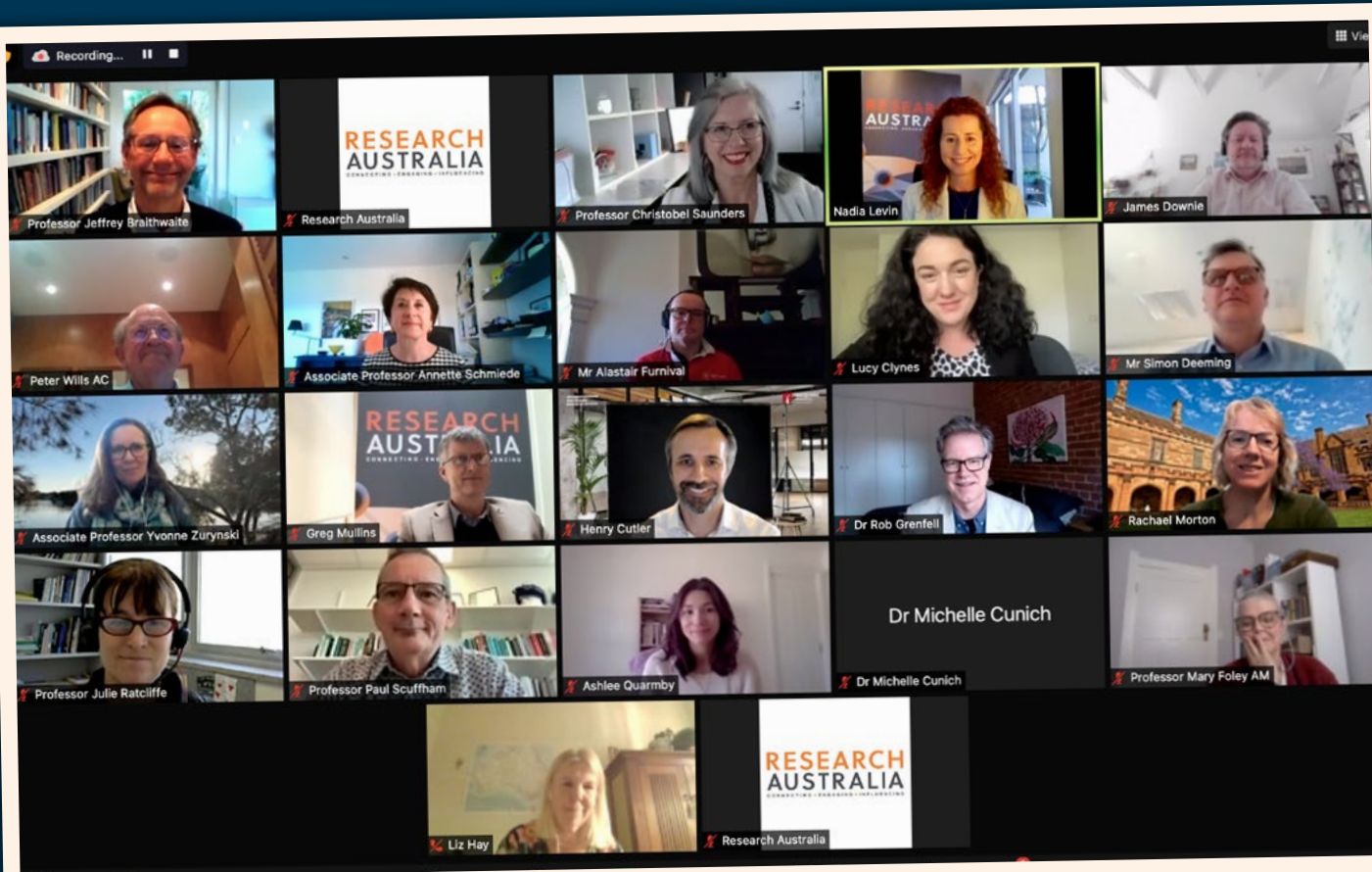
We have seen an increased push to employ value-based funding in Australia with the aim of achieving better value and delivering improvements for both patients and Australia's health system. Research Australia's ninth Health Economics Roundtable held in October focused on the role for health and medical research in national moves towards value-based health care.

The Roundtable was Research Australia's most attended to date – in no small part to the keen interest across the health and medical research community sector in value-based health care. Guests spanned the entire pipeline across academia, medical research institutes, pharmaceutical companies, health systems and government and their disciplines ranged from health services researchers, implementation scientists and clinician researchers.

Guests heard from leaders from across the health and medical research pipeline and from federal and state governments. Professor Christobel Saunders AO from the University of Western Australia discussed her work trialling value-based health care initiatives for cancer

care. Professor Jeffrey Braithwaite from the NHMRC Partnership Centre for Health System Sustainability and James Downie, CEO of the Independent Hospitals Pricing Authority discussed the Macquarie University Indexes of Healthcare Productivity and the critical role of research in creating a better health system for Australia. The Roundtable also heard from Liz Hay at NSW Health who discussed the state's approach to value-based healthcare and how they may work better with the research community to ensure evidence based, quality clinical practice in NSW. Professor Helena Teede AM from the Monash Partners Academic Health Science Centre concluded the Roundtable presenting her Learning Health System Framework which aims to guide the journey from what are the health system, community and stakeholder priorities, through to how researchers have impact in the health system; and how health economics is integrated into this.

Research Australia is excited to convene the Health Economics Roundtable next year, hopefully in a face-to-face format.



RESEARCH AUSTRALIA HEALTH & MEDICAL RESEARCH AWARDS 2020-21



GSK AWARD FOR RESEARCH EXCELLENCE

2020 WINNER:

PROFESSOR MARK FEBBRAIO

Professor Mark Febbraio is the 2020 winner of the GSK Award for Research Excellence for leading the development of a new potential treatment for metabolic diseases such as obesity and type 2 diabetes.

Ground-breaking research led by Professor Febbraio synthesised a protein, called IC7Fc, which has the potential to treat metabolic diseases known to be protected by exercise, by improving glucose metabolism and preventing weight gain. Professor Febbraio and his team have discovered how to leverage the relationship between IC7Fc and metabolism to address the underlying causes and effects of metabolic diseases.

This discovery has the potential to evolve into treatment options for potentially millions of patients across the globe with some of the world's most common serious conditions.

Professor Febbraio is the Head of the Cellular and Molecular Metabolism Laboratory within the Drug Discovery Program at Monash University. The \$80,000 prize money has supported Professor Febbraio and his team in preparing for phase one clinical trials to determine the application of this discovery in developing a treatment to address currently unmet treatment needs.

Due to COVID-19, Professor Febbraio was unable to receive the 40th GSK Award for Research Excellence in 2020, and will be formally presented with his award this year. The GSK Award for Research Excellence is one of the most prestigious awards available to the Australian medical research community. It has been awarded since 1980 to recognise outstanding achievements in medical research with a focus on human health. It has awarded almost \$3 million* to support Australian research and innovation through the last 40 years.



*2020 value of cumulative grant calculated by adjusting for inflation on the yearly grant value via the Reserve Bank of Australia Inflation Calculator. This is a guide only and should not be regarded as and 'official' calculations.

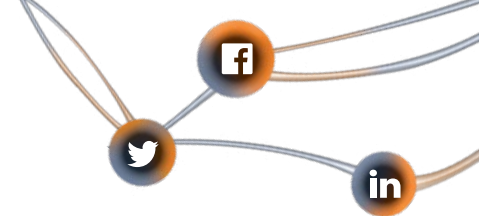
THE MANY VOICES OF A NATIONAL HEALTH DATA ASSET

Health study data is often only available to the researchers involved. But do consumers believe the findings should be shared with the wider research community?

The Australian Clinical Trials Alliance (ACTA) recently ran a stakeholder consultation process to inform the new Health Studies Australian National Data Asset (HeSANDA) initiative, led by the Australian Research Data Commons (ARDC).

The initiative aims to build a national collection of data generated through Australian investigator-initiated clinical trials, focused on the ethical sharing and secondary use of data with other Australian researchers.

By supporting the secondary use of data, HeSANDA aims to stimulate new research ideas, increase the impact of health research, increase the benefits of investment in health research, and ultimately improve the health and wellbeing of people in Australia.



However, ARDC acknowledges that this asset will only be effective if trial participants and other consumers are considered early and often. To ensure all voices have an opportunity to be heard from the start of this project, ARDC engaged ACTA to build on their early consultation process.

According to ARDC's HeSANDA Project Manager, Kristan Kang, ARDC had already undertaken some consultation activity and had developed some initial principles and investment areas.

"We wanted to check this initial thinking with people involved in clinical trials in Australia. We also wanted to explore researcher and trial participants' willingness to share data from clinical trials to support other research activities. And we wanted to hear about any issues that should be considered in relation to different types of data or types of clinical trials", Kristan said.

ASKING THE BIG QUESTIONS

In June 2021, ACTA facilitated targeted consultations with the Australian investigator-initiated clinical trials sector to build on ARDC's previous consultation findings and inform the design of the asset. Consultations focused on gathering insights from:

- **consumers** – people from consumer organisations with an interest in clinical research, including consumer advisory groups from clinical trial organisations
- **clinical trial participants** – people who are currently or who have previously taken part in a clinical trial in Australia
- **clinical trialists** – people and organisations involved in designing and running investigator-initiated clinical trials in Australia.

ACTA's HeSANDA Project Manager, Fiona Nemeh said, "Consumer input was key to the HeSANDA stakeholder consultation project. To do this, we actively engaged consumers early and throughout the entire process. Three consumers joined the HeSANDA consultation working group and helped plan the consultation process, shape the background documentation, and gave important feedback on the findings. Some working group members even became champions of the HeSANDA initiative, attending several consultation sessions and sharing their thoughts on why the use of secondary health data is important."

“For some of the consumers involved, there was a similar sense of altruism and beneficence that can underpin a decision to participate in a clinical trial. This further reinforces the importance of making optimal use of data generated through research.

LISTENING TO THE CONSUMER VOICE

Consumer confidence and trust in the integrity of the process is paramount.

93 people participated in the consultation sessions and 23 of these were consumers. Overall, these consumers were very positive about the intent of HeSANDA.

Mitch Messer, a consumer advocate at Telethon Kids and part of the HeSANDA working group said, "Consumer involvement is critical in all areas of research. Their lived experience brings greater understanding of their issues and adds value by seeing the subject through a different lens".

"Consumers want to see the best/most efficient use of research funding, as they are aware that there is not a bottomless bucket of funding. Secondary use of data has the potential to improve efficiency and use data to strengthen research outcomes. Consumers who participate in research want to ensure that their time is valued and see that this project is a way to do that. Secondary use has the potential to improve design, improve the use of finite funding resources and improve the process for participants", Mitch said.

WHAT'S NEXT?

Overwhelmingly, the discussions with all consultation participants highlighted three key themes for the initiative's development:

- The importance of informed consent for sharing of data from clinical trials
- Concerns about potential identification of individuals through data sharing
- Concerns about misuse or misrepresentation of shared data.

Four working groups, that include consumers, will continue to help guide and shape the design and development of the data asset with ARDC. The success of this initiative will be underpinned by effective co-design and engagement with the sector and consumers, while the long-term benefits will be felt by generations to come.

ARDC gratefully acknowledges initiative funding from the Australian Government. ACTA gratefully acknowledges operational funding from the Australian Government's Medical Research Future.

Author: Fiona Nemeh, PhD, Senior Project Officer, Australian Clinical Trials Alliance

A background image of an Intensive Care Unit (ICU) showing various medical monitors, IV stands, and equipment. The text 'ICU TOGETHER:' is overlaid in large, bold, orange letters.

ICU TOGETHER:

PARTNERING WITH SURVIVORS IN TACKLING THE ISSUE OF POST INTENSIVE CARE RECOVERY

A collaborative approach to the development of a unique e-health, individualised recovery program to enhance survivorship after ICU.

Millions of people are admitted to Intensive Care Units (ICU) across the world every year. These units are the most technologically advanced areas where the most critically ill patients are cared for by highly skilled teams of nurses, doctors and allied health practitioners. Severity of illness determines that mortality is generally higher than other areas of the hospital¹.

Admission to ICU can be necessitated by a raft of conditions or experiences, all of which can be life threatening and usually require invasive and complex interventions to sustain life and promote recovery.

Due to advances in critical care medicine and technology, survival rates from an ICU experience are increasing². However, this comes at a cost for survivors who have increased incidences of anxiety and depression, PTSD and reduced quality of life as a direct result of their illness and ICU experience^{3,4,5}. These rates of complications are higher than the general population and are associated with a higher uptake of health care services⁶.

There has been widespread exploration of a range of interventions to promote recovery following ICU discharge, but as yet there is no agreed evidence-based strategy in Australia and worldwide to support survivors. A lack of methodological rigour, the complexity of interventions and

- 1 Weissman C, Sprung CL. What can be learned from crude intensive care unit mortality? Methodological implications. *Journal of Critical Care*. 2020;59:130-5. doi: 10.1016/j.jcrc.2020.06.011.
- 2 Kim DY, Lee MH, Lee SY, Yang BR, Kim HA, Chang J. Survival rates following medical intensive care unit admission from 2003 to 2013. *Medicine*. 2019;98(37). doi: 10.1097/MD.00000000000017090.
- 3 Secombe P, Stewart P, C. Long-term morbidity and mortality in survivors of critical illness: a 5-year observational follow-up study. *Rural remote health* [Internet]. 2016; 17(3908).
- 4 Hodgson CL, Udy AA, Bailey M, Barrett J, Bellomo R, Bucknall T, et al. The impact of disability in survivors of critical illness. *Intensive Care Medicine*. 2017;43(7):992-1001. doi: 10.1007/s00134-017-4830-0.
- 5 Langerud AK. Health-related quality of life in intensive care survivors: Associations with social support, comorbidity, and pain interference. *PLoS One*. 2018;13(6).
- 6 Jeitziner M-M, Zwakhalen SMG, Hantikainen V, Hamers JPH. Healthcare resource utilisation by critically ill older patients following an intensive care unit stay. *Journal of Clinical Nursing*. 2015;24(9-10):1347.



selection bias has limited the ability to undertake rigorous comparisons of published evidence⁷.

CONSUMERS INTEGRAL TO ICUTOGETHER

The aim of this study is to evaluate the impact of a web-based recovery program (ICUTogether) on the mental well-being of survivors. A group of consumers with the lived experience of ICU survivorship were integral to the content development of the program, as well as the look and feel of the site itself.

A lack of specialised support during recovery has resulted in survivors being unaware of what to expect: what is normal or abnormal, when they should seek help, or how long it may take to reach an acceptable state of recovery⁸. This population is notoriously difficult to engage in research, so the program provides a safe space for them to engage with an intervention which may aid their recovery.

The initial consultation with the consumers comprised a focus group which informed the basic construction

of areas within the site. When we had developed the pilot site, it was tested by the consumer group who provided feedback on all components of the site including usefulness of the content and the navigational aspects of the site. This enabled the development of a consumer focused program.

The site comprises evidence-based resources, a chat room and a reflective journaling component, which is designed to meet the unique needs of ICU survivors during recovery. A strength of this program is the ability for survivors to access the content on any device at any time and to connect with each other, share their experiences and potentially understand their experiences of recovery with each other and gain support from their shared experiences.

Partners in the project are currently ICUs at Joondalup Health Campus, Sir Charles Gairdner Hospital and Rockingham General Hospital.

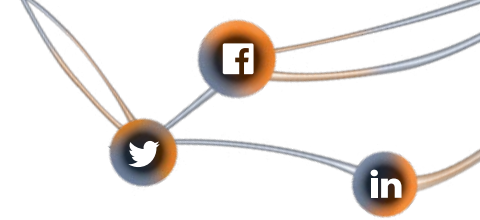
Authors: Associate Professor Beverley Ewens, Dr Deb Sundin, Professor Lisa Whitehead, Dr Mandy Towell-Barnard, Ms Rebecca Carman. School of Nursing and Midwifery, Edith Cowan University, Perth, Western Australia.

7 Mehlhorn J, Freytag A, Schmidt K, Brunkhorst FM, Graf J, Troitzsch U, et al. Rehabilitation interventions for postintensive care syndrome: A systematic review. *Critical Care Medicine*. 2014;42(5):1263-71. doi: 10.1097/CCM.0000000000000148.

8 Ewens B, Hendricks J, Sundin D. Never ending stories: visual diarizing to recreate autobiographical memory of intensive care unit survivors. *Nursing in Critical Care* [Internet]. 2014.

A MEETING OF MINDS





Drawing public health lessons from panic-induced travel during COVID-19

CCOVID-19 has threatened global health, economies, and well-being, with unexpected effects on human behaviour. General uncertainty has persisted as our understanding of the disease evolves, yet pandemic-related news reports can perpetuate misinformation.

A key aspect of COVID-19 – travel concerns – remains particularly salient; mobility is unavoidable but fuels viral transmission. Transparent communication is essential to public safety. Expert insight from the fields of media communication, psychology, consumer behaviour, and tourism and hospitality management will help researchers make medical knowledge more accessible to the general public.

Mobility has played a substantial role in the spread of COVID-19. Border closures and regional lockdowns were common following the pandemic's emergence in Wuhan, China in late 2019. These safety measures have continued to varying degrees as the pandemic has ebbed and flowed. Australia and New Zealand represent success stories – they are two of the countries most resilient against COVID-19, thanks in large part to their stringent lockdown policies and other proactive responses. Per data recorded as of March 13, 2021, both countries ranked within the world's top 10 in their handling of the pandemic based on metrics including confirmed cases/deaths and testing. Australia began instituting travel restrictions in February 2020 and has imposed intermittent lockdowns to control the virus with great effect.

From a public health standpoint, the four main methods of epidemic prevention include:

1. containing and mitigating the pathogen (as seen in New Zealand's and Australia's containment efforts);
2. letting the pathogen spread until herd immunity has been reached (as some countries implemented at the very beginning of the COVID-19 pandemic);
3. testing, tracking, and isolating of the disease (as is being done globally); and
4. preventing and treating the disease (vaccination and treatments).

Restricting mobility has proven essential to stemming the tide of the pandemic. Yet travel cannot always be avoided. Many colleges and universities chose to transition to distance learning amid the pandemic, and dormitory closures forced some students – particularly international students – to travel. Others simply wished to return to the comforts of home. Evidence suggests that COVID-19 can be transmitted on flights. Additionally, young adults tend to be less risk averse than other travelers.

It is therefore important to educate this demographic and others about the ongoing risks associated with travel and COVID-19, especially as the Delta variant begins to threaten several countries.

“ A particularly useful strategy would be to bring together experts in multiple fields to draft informational campaigns on COVID-19 and the importance of protective measures, ranging from handwashing and social distancing to travel restrictions and vaccination. Professionally developed communications can promote transparency and public responsibility.

Medical scientists are well equipped to contribute to this effort. By partnering with professionals in other disciplines, campaigns can be targeted to specific industries (e.g., travel and tourism) while ensuring accurate and readily digestible information. Above all, assuming a consumer-oriented perspective is paramount; individuals can more easily adapt their behavior if they understand its implications for public health.

Author: Dr Jun Wen, Ph.D Dr. Jun Wen is a lecturer in tourism and hospitality management at the School of Business and Law, **Edith Cowan University (ECU)**, Australia. He is devoted to interdisciplinary research involving mental health, public health, and tourism in collaboration with experts in fields such as the hard sciences. By assuming a cross-disciplinary perspective on the medical/health and social sciences, Dr. Wen and his collaborators focus on academic and practical contributions that make medical research more understandable, digestible, and usable.

PATIENTS SPIN RESEARCH PRIORITIES



“Finding a cure for neurological disorders would be brilliant. But that is 30 or 40 years in the future. I want to see solutions that help me to live a good life now, and until then!” (Participant in consumer workshop to develop research priorities, November 2019).

A research priority-setting workshop for people living with neurological conditions was the first activity for SPIN (Systematic Profiling In Neurological conditions) – a program established by a multi-disciplinary team of researchers at Edith Cowan University and funded by MSA (Multiple Sclerosis Australia).

The SPIN registry will form the basis for targeting interventions with precision medicine in mind. Twenty-two people with a range of neurological conditions attended the workshop and arrived at the top ten priority areas which will guide and focus the interventions trialled. An online questionnaire was distributed after the workshop to enable those who could not attend on the day to contribute to the research priorities, confirming that the priorities held for others, as well. Trials are already underway in improving movement and sleep, which was one of the top ten priorities.



“ Consumer engagement is crucial to the success of the research program, particularly with recruiting participants to engage with the registry and in the intervention trials.

Consumers report wanting to share their stories and their biopsychosocial information to help others, and the perspectives of those with lived experience is highly valued by researchers.

Consumers have been appointed to governance committees and we have developed policies and procedures to guide their engagement throughout the project. A broader consumer reference group will meet regularly to provide advice to the researchers, assist with recruitment and develop processes and program resources to ensure relevance and user-friendliness.

The next stage of the research program will include studies related to mental health and well-being, nutrition

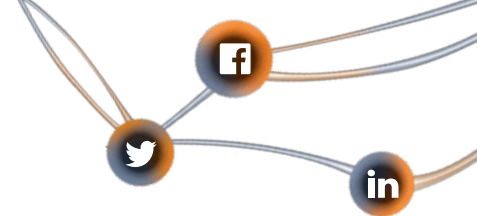
and health, and digital literacy. Each of these studies have consumers as co-researchers and will be very much guided by those with lived experience whilst addressing research priorities. The focus is on quality of life: both for people living with neurological conditions, and for their carers. The involvement of the consumers is empowering for them and provides an opportunity to contribute and exercise agency at the same time as making sure that research is relevant and makes a difference to people's lives. At a time when consumers are wanting to have greater input into healthcare and research, the program values the contribution from people with lived experience.

Author: Assoc Prof Mandy Stanley on behalf of the SPIN team; Prof Moira Sim, Prof Simon Laws, Prof Amanda Devine, Prof Natalie Ciccone, Assoc Prof Chris Abbiss, Prof Rob Newton, Dr Travis Cruickshank, Dr Onno van der Groenen, Dr Danielle Bartlett, Prof Barbby Singer, Mrs Manja Laws.



INVOLVE AUSTRALIA

Involve Australia



Like all good ideas, Involve Australia was born out of a cup of coffee, some brainstorming of solutions to frustrations and a commitment to create change.

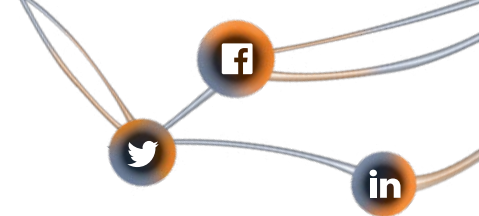
This particular frustration was about the lack of meaningful engagement and involvement of consumers in Australian research. We talk about it, we agree it's a good idea, we have many toolkits and methodologies, training courses and supports but implementation has been driven by everyone except consumers. There's nothing designed by consumers for consumers to optimise involvement in research.

"I am part of the genetic, undiagnosed and rare disease community. I know how much involvement means. Research engagement, (if indeed there is research happening at all in this challenging area), is often designed and presented to us when it's ready for submission for a grant application round. There is missed opportunity to explore different perspectives and to seek opportunities to translate research outcomes to improve lives. That's what we all want, it's not about the research outcomes, it's about the way the research outcomes are implemented to improve lives." Monica Ferrie

Involve Australia is an Australian Genomics initiative which aims to promote the effective involvement of consumers in genomic research. The primary objective is to develop guidelines for use by genomic researchers to involve the public, consumers of health technology, patients and other people affected by genomics research. This will involve partnering with patient support and advocacy groups, members of Indigenous communities, patients and carers, interested members of the public with a representative distribution, and members of the genomic research and clinical community.

Engagement in genomics research means shared power, giving the public, patients and health technology consumers more control around decision making.





Involving people in this way is the best way to ensure genomics initiatives reflect the diversity of priorities in populations. It has been widely demonstrated that involving people in research improves the relevance and equity of research. Involving people increases public trust, acceptability and participation in genomics. It can also improve recruitment, ethical oversight and ultimately the quality of research outcomes and translation. If genomics initiatives do not align with people's values, there is a risk that entire populations (in particular those at greater risk of exploitation, such as Indigenous peoples) will not participate in future initiatives, affecting the potential positive impact of genomics for decades.

THE PERSPECTIVE OF NON-RESEARCHERS

Unlike most pre-existing guidelines, Involve Australia will build its guidelines from the perspective of non-researchers. This will allow patients and carers, as the end users of healthcare research, to highlight what they need if they are to maintain their involvement in research. Ultimately, Involve Australia aims to ensure that everyone's needs are built into genomic researchers' consumer involvement strategies before projects begin, and set the standard for involvement in other areas of healthcare research.

We are not seeking to reinvent or duplicate existing resources and we value work already completed, but the importance of clear guidelines co-created with consumers has never been more critical. The drive for genuine, tangible (not tokenistic) involvement is at an all-time high across all levels of research. It will be very easy for the research community to unintentionally increase the burden on people whose lived experiences already ensure challenging lives, requiring extraordinary resilience just to get through each day. For many, there is the desire to engage but simply no accessibility.

Involve Australia will be informed by current public and health consumer involvement models in the landscape of Australian healthcare research and appropriately use resources that currently exist. We will also administer a public survey to determine who does and doesn't want to be involved in research, what capacity they would like to be involved in, and what barriers prevent involvement in research.

The Involve Australia project team has convened a specialist multidisciplinary working group. This group includes: John Cannings OAM, Monica Ferrie (Project Lead), Anne McKenzie AM (Project Lead), Sean Murray (Project Lead), Jack Nunn, Gregory Pratt and Fiona Russo and supporting the project from Australian Genomics is Tiffany Boughtwood, Isabella Sherburn and Keri Finlay.

A broader consultation and engagement strategy is also under development. A scoping review of public involvement resources used in genomics research will inform the working group. The data will also inform support for people who wish to be involved in research, helping understand what is required for their initial and sustained involvement. The Involve Australia team is focused on ensuring that community voices who don't often have the opportunity to contribute, and are under-represented in our research, have the opportunity to have their voices heard.

***“ Together, consumers are progressing Involve Australia activities by advising on methods used to conduct the scoping review and guideline development, the effective involvement of consumers and the community, how best to evaluate the impact of guidelines, as well as revision of key output documents. The working group will also inform and engage in the socialisation of the guidelines to all and the implementation and educational activities which are identified.*”**

Involve Australia will report their work using the novel tool, Standardised Data on Initiatives (STARDIT) in order to ensure transparency and accessibility. While the report is currently prospective, it will be updated throughout the stages of the initiative, and used to report multiple aspects of the work, including who has been involved in which tasks, and any outcomes or impacts.

Involve Australia is committed to engagement that translates to improved lives. The project will unfold over the next two years and challenge research conventions regarding how consumers are engaged and involved in research.

We are thrilled to be part of the development of Involve Australia genomic research guidelines and to be part of the working group.

Another demonstration of the importance of coffee and conversation...

Author: Monica Ferrie, CEO Genetic Support Network of Victoria, Involve Australia - Associate Investigator. Jack Nunn, Director of Science for All, Involve Australia - Working Group



EARLY CAREER RESEARCHERS ADVANCING 21ST CENTURY SCIENCE

Early career, upcoming researchers hold the key to revolutionising scientific research and accelerating the pace of innovation

There is no doubt that early career researchers are the future of innovative research and medical discoveries.

Supporting the next generation of researchers is critical to advancing medical care and improving the overall health and wellbeing of millions of Australians. Their research will be responsible for key research breakthroughs and will drive life-saving medicines, devices and treatments to help tomorrow's patients.

Griffith Health's Dean (Research) Professor Bonnie Barber says acknowledging talent and excellence in our sector is not only key to producing transformative health and medical breakthroughs, but it's also paramount to encouraging future generations of world-class researchers.

"Recognising early career researchers and the significant work they do is pivotal to our research capacity and future medical discoveries," Professor Barber says.

"To enhance global innovation, we must nurture and recognise the skills of Australian scientists and clinical researchers. Those doing this foundational science now are the ones laying the groundwork for lifesaving medical and technological breakthroughs in the future."

"Without investing in researchers at the start of their journeys, we won't have a workforce in the future to tackle significant health challenges."

Professor Barber says it can often be difficult for researchers to gain the support, recognition and encouragement they need to succeed in the research sector.

"Scientific breakthroughs don't happen overnight—taking a research project from an idea to a final product that is ready for clinical use is a long and expensive process," she notes.

"It can be a really hard road, when you're first starting out, especially in health and medical research—there's a lot of hurdles to overcome, including attracting funding support, managing time and workload pressures, and developing key collaborations."

As part of Griffith longstanding commitment to early career researchers, the University is sponsoring Research Australia's Health and Medical Awards for a fifth consecutive year.



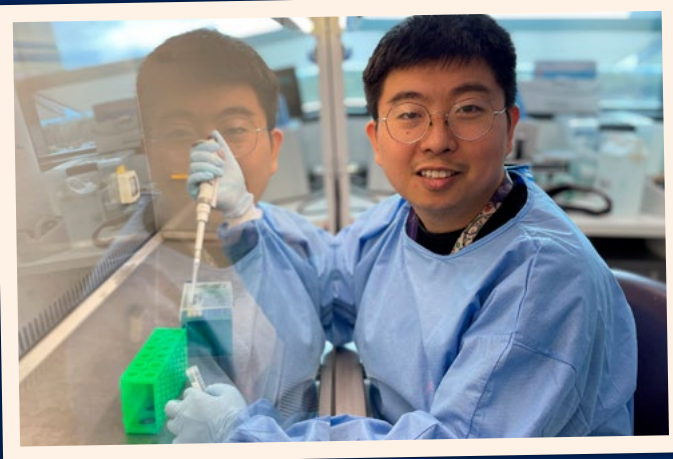
Professor Bonnie Barber says the University is committed to supporting emerging research leaders.

“We are proud to sponsor the Griffith University Discovery Award. As a community it is so important to recognise and support these researchers and the outstanding contribution they are making to the advancement of science.” Given the recent challenges of our times that have acutely impacted the health and medical research sector, now, more than ever, we must encourage and support these research leaders of tomorrow.”

GRIFFITH UNIVERSITY FINALISTS

This year, two of the six finalists for the Discovery Award are from Griffith University.

DR MO CHEN



Every day in Australia at least one person's life is devastated by spinal cord injury.

Dr Mo Chen from the Menzies Health Institute Queensland (MHIQ) and the Griffith Institute for Drug Discovery (GRIDD) at Griffith University is working tirelessly to drive a treatment for spinal cord injury.

He has developed a revolutionary technique to create cellular nerve bridges for treating spinal cord injury. His invention uses a modified organoid culture method which enables the cells to form stable cell-cell connections and to have layers and functions similar to real nerves.

Dr Chen says his research gives thousands of Australians hope that paralysis doesn't have to be forever.

“Being nominated for Research Australia's Griffith University Discovery Award is recognition of the potential impact of my discovery and invention,” says Dr Chen.

“Along with my colleagues, we hope that this will revolutionise cell therapy for spinal cord injury.” My hope is that more researchers can use this technology to treat other conditions, so it is extremely important that more people know about our work.”



DR LARISSA DIRR

Human parainfluenza viruses (hPIVs) are one of the most prevalent causes for childhood croup, bronchiolitis and pneumonia.

Apart from being a significant childhood illness, hPIVs are a major concern for chronically ill, elderly and immunocompromised people—with mortality rates of up to 50 percent. Despite ongoing efforts, there is currently no treatment or vaccine available.

Dr Larissa Dirr from Griffith University's Institute for Glycomics is currently investigating the cause of human parainfluenza viruses and has developed a potential antiviral drug to fight this significant disease.

“An antiviral drug against hPIVs would have a huge impact on human health, particularly on hospitalisations of infants and young children,” Dr Larissa Dirr says.

“A treatment would also reduce the socioeconomic burden associated with this disease and minimise the high mortality rate of immunocompromised patients.”

OTHER FINALISTS

The other four finalists (in alphabetical order) are:

- Dr. Natalie Hyde, Deakin University
- Dr Danielle Joy Ingle, Australian National University
- Dr Jiao Jiao Li, University of Technology, Sydney
- Dr Heidi Staudacher, Deakin University

CELEBRATING OUR FINALISTS

Griffith University would like to congratulate all finalists in the Griffith University Discovery Award category.

Professor Bonnie Barber says, “it's extremely exciting to see such a promising group of young, inspiring researchers who are committed to solving some of the most challenging problems in health and wellbeing.”

“This is a wonderful opportunity to recognise the important work that these researchers are doing and to celebrate all of their successes. We are extremely excited to see the innovations they are going to bring us in the future.”

The 18th Research Australia Health and Medical Research Awards will be announced on December 9 at a gala event in Sydney. More information, including how to get tickets, is available [here](#).

REVOLUTIONISING REHABILITATION AND REDEFINING DISABILITY

Connecting consumers, practitioners, industry, researchers and policymakers to deliver better solutions for people with disability.

Disability is one of the most significant challenges the Australian community will face over the next decade. Nearly 40 percent of Australians live with a disability or a disabling health condition and almost everyone will experience disability at some stage in their life – for some it will be temporary, but for others it will become a permanent part of their lives.

Regardless of the type or impact of a disability, all citizens have the fundamental right to be treated with respect and to participate in society. Disability should never be a source of exclusion and the mantra of the disability sector for decades has been “nothing about us without us”.

Researchers at Griffith University have spent many years putting this mantra into practice. They are committed to an inclusive future where people with disability can participate in all aspects of life to help solve the most complex challenges they face in society. By bringing together clinicians, expert academic researchers, community practitioners, policymakers and consumers, the University is leading the translation of research into policy and clinical practice in this field.

The University’s unique approach has led to research driven by people with disability in partnership with leading experts and industry. The goal is to develop new products, practices and places that are responsive to the needs of people with disability and geared towards high-quality outcomes.

Professor Elizabeth Kendall, Director of The Disability and Rehabilitation Program at Griffith’s Menzies Health Institute

Queensland, says it is not unusual for new innovations to fail, to be left in hallways and cupboards or to remain unused because they do not quite meet the needs of the people they were designed to help.

“Instead, we want to make a permanent impact on the system by building the capability of people with disability to engage with researchers and designers at all stages of the process. It is not until we really listen to people with disability that we will be asking and answering the right research questions and designing the innovations that can really make a difference. By working directly with teams of people with disability, we will be more clearly defining the challenges, finding better solutions and more quickly turning those results into scalable and sustainable innovations.

“ Consulting consumers and end-users of research is always useful but working closely with people who have a disability to design research has driven an entirely different research agenda and new ways of working.

“We now want to engage the disability and rehabilitation workforce in designing innovative solutions, but most of all, we want to develop a new generation of researchers, innovators and designers who know how to listen to and work with people with disability,” says Professor Kendall.

Griffith University is committed to upholding the dignity of people with disability through respectful interactions, appropriate language and inclusive research methods. It



is embracing models of citizen science where research is led entirely by people with disability, drawing on more seasoned researchers as needed.

Revolutionising Rehabilitation: The BioSpine Project

Professor Elizabeth Kendall says Griffith University is committed to bringing together knowledge from a range of disciplines and crossing boundaries to promote innovation in rehabilitation for people with acquired disabilities.

“Rehabilitation research is often conducted from a single discipline or in a siloed approach—which rarely capitalises on the latest technology and innovation,” Professor Kendall said.

Dr. Dinesh Palipana OAM, Griffith University Research Fellow and Biospine Project co-lead, has been driving ground-breaking research using brain-computer interfaces in the BioSpine Project.

“What we are doing at the University is extremely exciting because it integrates research from a range of complementary fields to generate creative and revolutionary approaches to rehabilitation. By working with me, the team has designed research that can truly make a difference,” says Dr Palipana.

REDEFINING DISABILITY: THE DIGNITY PROJECT

A key citizen-led research initiative at the University is Dignity Project, which is building a supportive citizen research community.

The project is run by a team of citizen researchers and

aims to understand how dignity is experienced by people with disability in all aspects of their life. It draws on these collective stories to disrupt stereotypes, break down the barriers and find innovative ways of creating an accessible, inclusive future.

Kelsey Chapman, Griffith University Research Fellow and Dignity Project research lead, trains and supports citizen researchers. She says they have created a safe and committed space to share data, analyse and re-contextualise experiences so we can produce real change through our research.

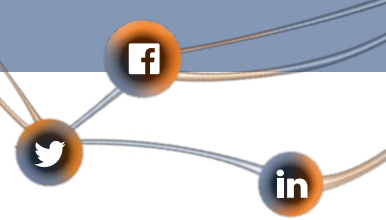
“The project challenges and disrupts the environmental, attitudinal, systemic and physical barriers that limit participation in society and restrict access to essential services. Our researchers are co-designing research with our citizen scientists to produce knowledge that can really make an impact.”

Author: Professor Elizabeth Kendall is a world-class researcher at the Menzies Health Institute Queensland (MHIQ) at **Griffith University**. Elizabeth is the Program Director of the Disability and Rehabilitation program and Foundation Director of The Hopkins Centre. She is a leading expert at the University and continues to build a strong research agenda in rehabilitation and service systems for people who are managing the consequences of serious injuries, disabilities or chronic conditions.

THREE STEPS PROJECT-BASED FIRMS CFOs TOOK TO STEER THEIR FIRMS THROUGH 2020

As project-based firms navigated 2020, finance teams stepped up to ensure business stability. We spoke to three CFOs to find out how.





Deltek®

Firms in project-based industries already deal with a competitive, fast-changing landscape.

But the impact of COVID-19 made their situations even less predictable over the course of 2020. And while much has changed, age-old challenges around changing customer demands and savvy competitors adopting new tactics continue to put pressure on firms.

As a result, project-based firms have been forced to re-evaluate everything from resource and project management to forecasting and cashflow. And often, this responsibility has fallen on finance teams.

So how have finance leaders overcome the hurdles of 2020 – and helped their businesses overcome short and long term disruption? We spoke to three finance leaders in project-based firms to find out.

You can explore their answers in full and discover practical tips for future-proofing your organization in our latest white paper. Or, for a sneak peek, read on as we look at three steps our CFOs took to face the challenges of COVID-19 head on.

STEP #1: BUILD BETTER BUDGET VISIBILITY

With so much uncertainty arriving almost overnight, accurately predicting the financial impact of COVID-19 was an impossible task for firms – however tempting it was to try. Instead, financial teams needed to structure forecasts around confirmed work, to get visibility into budgets and revenue. This meant teams only had to predict a few variables, rather than all of them, which kept firms flexible during this unpredictable period.

For Buro Four's Finance Director Steve Slade, adopting a new forecasting approach required a rethink of the budget process. By revising the budgets based on 'secured work' (projects that wouldn't be cancelled) the finance team was able to optimize their planning process, and adjust easily if any projects were delayed.

STEP #2: ALLOCATING RESOURCES EFFICIENTLY AND EFFECTIVELY

The initial onset of the pandemic also forced finance leaders to think carefully about resource allocation. And that required getting accurate, rapid, data-driven insights.

For many of the firms we spoke to, this meant leveraging systems with robust resource planning functionality, such as Deltek's ERP solutions. Armed with clear insights into which projects would be most profitable – and the

resources available for assignment – the finance leaders could streamline resource planning and keep schedules full.

For example, if a project was deferred suddenly by a client, the organization could spot gaps in the diary and fill them with another task – keeping existing projects moving and enabling quick, accurate decision-making.

And the benefits go beyond short-term fixes. With finance teams more in the spotlight than ever, and firms relying on CFOs to ensure spot-on modelling and allocation, implementing resource planning systems now can provide long-term support and accurate information.

STEP #3: PUTTING PEOPLE FIRST

COVID-19 was a new situation for everyone – and that meant clear, accurate data was hard to come by. To keep teams focused and supported, many financial leaders looked inwards and found new ways to provide the care, compassion and transparency employees needed to feel safe during an uncertain time.

Each of the CFOs we spoke to took different approaches to support their people. But all shared one common goal: to provide clear, informative messages about the global situation and how the business was responding.

For Ryan Latchford, CFO at ADG Engineers, a COVID central response team and 'state of the nation' calls provided much-needed transparency and kept employees informed and engaged. Meanwhile, Katarina Strivall, CFO Sweden at Norconsult, arranged weekly COVID meetings with the management team. These catchups allowed leaders to address any immediate business concerns and track key 'soft' KPIs like team morale and mental wellbeing.

PLANNING FOR THE FUTURE

Despite the challenges created by 2020 – and the existing ones it exaggerated – a new pace of change was also created new opportunity for finance teams. From long-term remote working to digital innovation and a reliance on data-driven insights, firms were forced to update processes and embrace new tools and techniques.

To see how the CFOs we spoke to are seizing these new opportunities in 2021 and beyond, download our guide: [**CFO Perspectives: How project-based firms survived and thrived in 2020.**](#) It's packed full of great insights and practical tips for project-based firms looking to the future.

WORKING TOGETHER TO HELP AUSTRALIANS MAKE SENSE OF STEM CELLS

Stem cells, and their potential to transform healthcare, has captured public attention in Australia and around the world.

Latest discoveries regularly feature in the news and many of us already know someone whose life has been saved following a bone marrow or blood stem cell transplant for leukaemia or another blood disorder. Indeed, the belief that stem cell research would improve our way of life in the future is widely shared. Surveys have indicated that more than 95% of Australians are aware of this area of biotechnology, markedly higher than other emerging technologies.

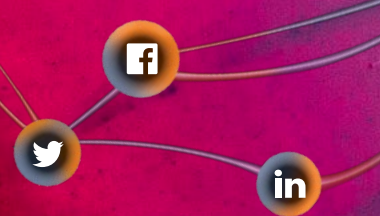
While regenerative medicine has much to offer, to date there are few recognised stem cell-based therapies beyond the use of cord and blood stem cells for haematological malignancies and grafting of tissue to repair damaged skin or the cornea of the eye. Other possible treatments are being evaluated in clinical trials or are still in development in the lab. It will take time before new products are shown to be safe and effective and approved by regulators, and of course not all candidates that are being investigated will deliver on the therapeutic promise of stem cell science.

However, spend even a cursory amount of time online, and you will quickly find clinics selling stem cell treatments for a myriad of conditions. These range from pills to combat aging and promote healing, to cures for arthritis,

diabetes, multiple sclerosis, autism, Parkinson's and many more 'hard to treat' diseases. You will also find stories and testimonials of people who believe they have benefited from such treatments, as well as warnings from doctors, researchers and other concerned experts who question the legitimacy of curative claims and the potential for physical, financial, and psychological harms given the lack of evidence that these costly products work or are even safe. For anyone curious to know more about whether stem cell therapy is an option that they should consider now or in the future, this can be a very difficult terrain to navigate.

This is particularly true for people who may feel that conventional medicine has nothing more to offer them or their loved one, and that stem cells are their only hope to alleviate their suffering. Our research found that Australians wanting to explore stem cell treatment were frustrated by a 'maze' of information and an inability to find people with scientific and medical expertise they could turn to. Likewise, professionals consulted by patients and their families, particularly those who worked in patient advocacy and support services, reported feeling ill-prepared to adequately respond to inquiries and expressed concern about not wanted to take away people's hope¹.

1 Tanner C, Petersen A and Munsie M (2017) No one here's helping me, what do you do?': addressing patient need for support and advice about stem cell treatments. *Regenerative Medicine* 12(7): 791-801.



A NEW ONLINE RESOURCE

To help Australians better navigate the online stem cell information labyrinth, we have partnered with leading Australian patient advocacy and support organisations to develop a new online resource. The recently launched Stem Cells Australia website – www.stemcellsaustralia.edu.au – is a collaboration between academics at the University of Melbourne, patient advocates and community group representatives and is supported by partners including MS Australia, MND Australia, MSK Australia, CP Alliance, Spinal Cure and the Chronic Illness Alliance. We have taken advantage of knowledge within our group around how to display and curate complex scientific content in a way that is easily accessible for people with diverse and divergent interests. We also use findings from our previous empirical research and have sought input directly from people with lived experience of trying to decide if stem cell treatment is an option for them.

Information can be accessed through a series of questions ranging from ‘What are stem cells?’ and ‘Can stem cells help me?’ to ‘How are new treatments developed?’ and ‘What questions should I ask my doctor?’. Within these pages are embedded links to pertinent resources prepared by the Therapeutic Goods Administration, Australian Clinical Trial Alliance, National Health and Medical Research Council and peak international stem cell and regenerative medicine organisations.

For those simply curious about what stem cell research is being conducted in Australia, there are a series of bite-size videos where scientists and clinicians from across the country talk about their work, their aspirations, and the techniques they use. There is also a dedicated education resource for high school teachers to help them introduce stem cells as part of their classroom activities under the national curriculum.

This new resource, supported by the University of Melbourne, builds on the learnings and networks fostered through the Australian Research Council’s Special Research Initiative scheme (2011-2019). It unites researchers with community groups and individuals who share the common goal of promoting hope in stem cell research while acknowledging the complexities involved in its translation into safe and effective therapies. There is far too much at stake to leave hype and misinformation unchallenged.

Author: Professor Megan Munsie, School of Biomedical Sciences and Melbourne Medical School, University of Melbourne

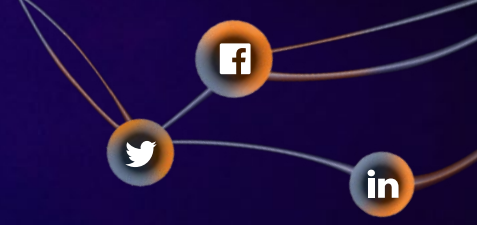
DEVELOPING A SYSTEMATIC APPROACH TO CONSUMER ENGAGEMENT IN A DIVERSE RESEARCH CENTRE



It is broadly recognised that involving health consumers throughout the research process results in research outcomes that are more meaningful to health consumers.

In practice, however, consumer engagement often falls to individual researchers to identify and engage with health consumers without institutional guidelines and supports. This leads to practices which are inconsistent and, at times, sub-par or even tokenistic. A systematic approach is needed within research centres to enable researchers to authentically engage health consumers.

The Centre for Healthcare Transformation (CHT) at Queensland University of Technology is a multidisciplinary health services research centre which brings together



clinicians, health economists, statisticians and implementation scientists from a variety of fields including nursing and public health. CHT aims to transform research evidence, using practical insights, to enable effective change and to provide relevant and proven real world practical solutions. We generate high impact research applicable to the real world.

As part of our commitment to high-quality, meaningful research, CHT is committed to developing streamlined processes and resources for researchers to effectively and authentically work with health consumers in the design, oversight, interpretation and dissemination of research projects. A survey of CHT research staff and students identified that our researchers have a strong commitment to engaging health consumers in research, but without strategic coordination and support, current practice varies greatly between projects and teams.

RESEARCH DIVERSITY WITHIN THE CENTRE PRESENTS CHALLENGES

The primary challenge in developing a model of consumer engagement for CHT has been the complexity of the Centre, meaning a tailored model is necessary. CHT has a diverse range of research programs and teams. Our research spans acute, sub-acute and primary care settings, covers the entire life spectrum and addresses a broad range of health issues such as cancer, palliative care, dementia, mental health, cardiac health, childhood illnesses, and COVID-19.

In many cases, for our health system research the end user of our research is not a health consumer, it is health care providers and others working within the health system such as clinicians, students, support staff such as cleaners, or health administrators.

“ There has been debate within CHT around whether health consumer input is relevant in these studies. Guidelines are needed to support researchers to determine whether health consumer input is appropriate for their research.

USING IMPLEMENTATION SCIENCE TO DEVELOP THE MODEL

We are conducting a systematic process, informed by implementation science, to understand the context, perspectives, experiences, learning and resource needs of researchers within our Centre. This will inform the development of our consumer engagement model, resources, guidelines and supports for both researchers and health consumers.

UNDERSTANDING CONTEXT – THE EXPLORATION PHASE

Using a robust context assessment process we have developed a detailed understanding of the needs of our stakeholders and are able to adapt the CHT consumer engagement model accordingly. The Exploration Preparation Implementation Sustainment (EPIS) Framework, complemented by constructs from the Consolidated Framework for Implementation Research (CFIR) have been used to guide our investigation. We conducted a research and practice scan and consulted with key stakeholders including our researchers, health consumers and experts in consumer engagement. Barriers and enablers to consumer engagement in research were identified and strategies were developed accordingly.

AVOIDING TOKENISM

Our survey found that CHT researchers feel strongly that consumer engagement must be authentic. Tokenistic engagement can lead to poor outcomes for health consumers as well as poor research outcomes. Authentic engagement takes work, time, funding, and development of relationships between researchers and health consumers. It also requires support from experts in engagement who can link researchers with appropriate health consumers and groups.

PRELIMINARY FINDINGS

Three models have been proposed for consideration. We are currently in the process of testing the models for acceptability and feasibility, with a view to commencing implementation in 2022. All models ensure that the consumer voice is central to decision making on the selection and development of resources, procedures and guidelines for consumer engagement.

NEXT STEPS

The findings of our context assessment will inform the design and implementation of the consumer engagement model for CHT. This will ensure it best meets the needs of our research staff and students, health consumers, and other key stakeholders. We will continue to adapt the model over time based on feedback and evaluation.

Author: Dr Olivia Fisher is a Research Fellow in Implementation Science and Consumer Engagement Working Group Lead, Centre for Healthcare Transformation, Queensland University of Technology
Dr Shelley Kulperger is a consultant to the Consumer Engagement Working Group with expertise in consumer engagement strategies
CHT Consumer Engagement Working Group

“WHAT ABOUT THE MONEY, BABE?”

Working together with people with brain injury to reduce their vulnerability to online and romance scams

Last year, Australians reported losing \$851m to scammers (ACCC, 2021). Although anyone can become victim to a scam, some people, including individuals with acquired brain injury (ABI), may be more at risk. Whilst this may seem obvious now, in 2014, awareness of scam susceptibility was negligible within the ABI sector.

It was Colin's unfortunate experience of becoming a financial and psychological victim to an online romance scam in the years since his ABI, and the myriad attempts by neuropsychologist and research fellow Dr Kate Gould to help Colin recognise, extricate, and emotionally recover from the scam, that ultimately catalysed a fruitful collaborative partnership in promoting cybersafety for others with ABI. Cyberscams are fraudulent means of accessing personal information or monetary gain using online platforms.

In their trialling of recovery strategies, Colin and Kate presented workshops at international ABI conferences and delivered awareness campaigns to inform other people with living experience of ABI, family members and clinicians about avoiding and recovering from cyberscams. Crucially, Colin sharing his story helped others gain the insight that they had also been scammed.

“I was conned for a long while...and then it took that one time someone [Colin] was talking about it and I brought up that I'd been conned too.” Alf, Romance scam survivor

The impact of this work on the neurorehabilitation community was more widely recognised by the Australasian Society for the Study of Brain Impairment

(Clinical Innovation Award, 2018). Through research led by Dr Gould at Monash University, funded by the Summer Foundation, our team quantified the benefits of these awareness workshops, finding that clinicians significantly increased their skills, knowledge and confidence in working with clients with ABI avoid and recover from cyberscams. We learnt that half of 101 neurorehabilitation colleagues we surveyed had identified cyberscamming of their clients with ABI. Lack of insight and awareness were speculated to be leading risk factors for people with ABI. Concerningly, about a third of clients had experienced multiple online scams and no highly effective prevention or intervention strategies were identified.

Our collaborative CYBERABILITY team grew to include partnership with Li-Ve Tasmania, a large disability support service who had in parallel heard from 100 people with disability of their need for greater cybersafety skills. It was clear that we needed to better understand cyberscam experiences in order to develop tailored cybersafety approaches for people with ABI. We conducted 30 qualitative, in-depth interviews with cyberscam survivors with and without ABI and their family members and carers. Participants shared the complexities of the journey towards online romance scams and fraud victimisation, which we encapsulated in a relatable nautical metaphor of the hidden dangers when at sea: factors steer you towards being scammed, you may miss the red flags and are taken for a ride, you need a trusted lookout to throw you a life-ring and help you back to safety. Vulnerability was underpinned by ABI-related cognitive impairments impacting identification



and recall of scam warning signs, and their social isolation which increased their desire to seek connection online. Confusion, denial and disbelief were barriers to scam recognition. Beyond the known financial losses of scams, the emotional impact was profound, including severe shame and distress. Scams triggered arguments and loss of trust within families. Attempts to resolve the situation by families, therapists and law enforcement were largely ineffective.

PREVENTION IS BETTER THAN CURE

With funding from the Transport Accident Commission and support from the eSafety Commissioner, we have co-developed tailored online training resources to help people with ABI learn how to safely navigate technology and avoid scams. Recognising the value of peer learning, we include videos of people with ABI and their family talking about their own cyberscam experiences:

“**People understand real life stories”,**
Alf, Romance scam survivor.

To further ensure the training materials reflect the sectors' needs, the content was designed with and for people with ABI and cyberscam experience through active collaboration and focus groups. The nine participants in these co-design groups found that working together to pioneer tailored cybersafety training validated their scam experiences. To our delight, a strong sense of peer support also emerged:

“The profound change there is when you're amongst a group of peers...to hear other people who are suffering

the same thing...It's a weight lifted from you.” Jimmy, Romance scam survivor with brain injury

Alongside our progress understanding cyberscam vulnerability and co-creating tailored resources, we have expanded our research to address a gap in objectively assessing susceptibility to online victimisation. We are now working with cyberscam survivors with ABI and clinicians to develop a novel co-designed measure of cyberscam vulnerability for people with ABI.

Sparked by one person's living experience, we've found that consumer co-design has not only enhanced the quality, reach and impact of our research, it has also been personally instrumental, for Colin, and others, in their transformation from cyberscam victims to advocates.

Author: (Lead) Dr Kate Gould, Clinical Neuropsychologist and Research Fellow (BBNSc (Hons), DPsych (Clin. Neuropsych), Turner Institute for Brain and Mental Health, and Monash-Epworth Rehabilitation Research Centre, School of Psychological Sciences, Monash University. **(Co-Lead) Jao Carminati**, PhD Candidate (Clinical Neuropsychology) and research assistant, Turner Institute for Brain and Mental Health, and Monash-Epworth Rehabilitation Research Centre, School of Psychological Sciences, Monash University

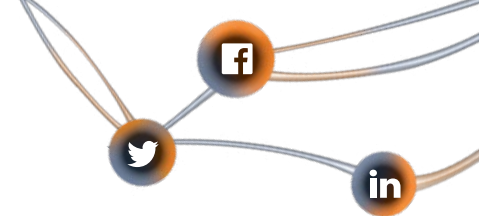
SPEAKING SOFTLY AND LISTENING HARD

Our experience in involving young voices from culturally and linguistically diverse schools in child health research



Over the years, the active involvement of community members and consumers in all types of health and medical research has gained recognition as an important consideration of any research study, with evident benefits to the quality and direction of research. Although community and consumer involvement (CCI) has been actively incorporated into health and medical research in recent years, the inclusion of children and young people in all stages of research – from research design to implementation, particularly from culturally and linguistically diverse communities continues to be rare, with most CCI typically only involving adults.

The lack of youth engagement in CCI can be linked to a number of challenging factors, including having to navigate gatekeepers such as parents, schools and the ethics committees, and the often-misjudged perception that young people are unable to critically understand and contribute to research planning, implementation and evaluation. Although there is countless research about children and young people in Australia, only a minority of the research conducted with children and young people has involved them in the design, analysis and dissemination of research.



ESTABLISHING A YOUTH RESEARCH ADVISORY GROUP

The crucial need to include the voices of children and young people in research fuelled our work in establishing a Youth Research Advisory Group (YRAG) in South-West Sydney (SWS). This initiative was established through an existing academic (translational research) group called BestSTART-SWS (Systems Transformation and Research Translation) established in 2018 to optimise the health, development and wellbeing of children in SWS.

The YRAG aims to integrate the voices of children and young people from the SWS Local Health District, an area with a population of over 900,000 with culturally diverse backgrounds and large economic disparity.

- Approximately 1.6% of the district's population identified as Aboriginal or Torres Strait Islander, and 45.2% of the population is born overseas
- 54% of the population reported speaking a language other than English at home
- The most common local languages were Arabic, Vietnamese, Spanish, and Cantonese
- The district is also a major point of settlement for refugees with approximately 10,932 refugees — 41.7% of all refugees in NSW (2005–2011)

Our work involved 115 students from the ages of 11–18 (school Years 7 to 12) taking part in at least one of five sessions spanning across three years (2019–2021). Sessions were organised flexibly and lasted between 1 and 1.5 hours, taking place at participating schools or the research facility hosting the BestSTART-SWS research group. In total, our team carried out 26 sessions, with five to 30 students in each.

We wanted the students' responses to come from genuine feelings, thoughts and experiences, rather than what they perceived to be "correct". With that in mind, to establish a clear distinction between 'normal school work and rules' and our YRAG sessions, we created an informal setting by allowing the usage of mobile phones, incorporating humour in discussions by using Graphical Interchange Formats (GIFs) and memes and using active listening strategies to demonstrate engagement. The facilitators' age and background (the Middle East and South America) was another contributing factor to the establishment of trust with the students.

WHAT WE LEARNED

The initial engagement plan with students was organised to share BestSTART-SWS's research strategy document with students to ensure that it met the priorities of the community in the area. This strategy included four research streams based on the expertise of the research team: healthy beginnings, population child health, health

systems research, and equity.

By establishing a level of trust in these consultation sessions, we were able to successfully break down barriers between researchers and students, allowing them to open up and reveal their main areas of concern – mental health and stress. In response to this, we included 'Mental Health' as a new research stream, recruiting experts who could lead this stream and ensuring students remained engaged in determining the kinds of activities for inclusion in the stream. Despite barriers to engaging with students at some stages, we worked closely with the schools to increase student engagement and focused on talking about their mental health priorities which in turn brought about real change in the direction and strategies of child health research in SWS.

This focus on mental health was revisited at multiple stages, most recently in a session before Sydney went into lockdown, which led to surprising results.

***“ For example, while previous work had indicated that students were interested in technological solutions to their mental health concerns, such as by using text-messaging services or tele-health, our last conversation with students revealed a change of mind, as students stated clear preferences for face-to-face rather than online services.*”**

To ensure sustainability in our consultation process, we kept a “long-view” of our relationship with schools. Indeed, as the socio-cultural landscape changes, it is the team's hope that engagement with students can continue, as—perhaps more than any other group—they are the heartbeat of the present. It is our hope that these kinds of efforts can be replicated elsewhere to ensure that research is grounded in community needs and experiences.

Our full work 'Speaking Softly and Listening Hard: The Process of Involving Young Voices from a Culturally and Linguistically Diverse School in Child Health Research' published in the International Journal of Environmental Research and Public Health can be found [here](#)

Author: Kids Research, Sydney Children's Hospitals Network; Population Child Health, UNSW; BestSTART-SWS – Nora Samir, Prof Valsamma Eapen, Dr Antonio Jose Mendoza Diaz, Michael Hodgins, Prof Raghu Lingam & (NSW Dept of Education - Simone Matic, Samira Bawden, Jessica Khoury)

FAMILIES IN THE DRIVING SEAT TO DEVELOP SANFILIPPO RESEARCH ROADMAP

Sanfilippo Children's Foundation is a strategic funder of research, working closely with clinicians and researchers.



Whilst our strategy is driven by evidence and the need for scientific rigor, at our very heart we are a family-founded, consumer-driven organisation. This dual focus has a single purpose: the pursuit of better outcomes for families affected by Sanfilippo syndrome.

This philosophy was at the forefront in our recent work to develop a Global Roadmap for Sanfilippo Therapeutics. In developing this Research Roadmap we drew on the expertise of clinicians, researchers and industry representatives from around the globe.

However, it was the input from our colleagues in international family-led organisations and individual family members from our Australian Sanfilippo community that helped mould the Roadmap into a document that wholly represents the aspirations and priorities of the people for whom we all work.

Sanfilippo syndrome is a rare genetic condition, a devastating childhood dementia, that causes progressive brain damage and debilitating long-term impacts on the body. Symptoms include hyperactivity, disordered sleep, loss of speech and cognitive decline. There is no treatment or cure currently available and most individuals with Sanfilippo never reach adulthood.

While significant advances have been made in Sanfilippo research and clinical trials initiated, progress could be accelerated through a focused, coordinated and

collaborative approach.

The Roadmap aims to facilitate this by setting out the key research pillars and enablers around which the research community can coalesce.

Developing a research roadmap is in large part an academic exercise, reviewing the existing literature and the clinical trials landscape to date. However, we also interviewed clinicians, researchers, industry representatives and a significant number of family members and representatives from family-led foundations who have fundraised for and driven research.

REVEALING THE COMMON THEMES

Often, workshops are utilised for such a project, but we felt that too often only the loudest voices are heard in this setting, and important opinions missed. To this end, interviews were conducted one on one, with a set of core questions to guide the conversation, but allowing a free discussion of the most important aspects according to each individual and stakeholder group.

They all named the key research gaps, the blockers that need removing, the resources that they felt could help move the field forward and the opportunities they could see on the horizon.

All of this information was then synthesised to reveal the



common themes. It resulted in a Roadmap comprising three core research themes or pillars, all underpinned by a set of enabling initiatives and resources - data, research tools, collaborative platforms - that could support multiple aspects of research along the entire therapy development pipeline.

From the outset the family perspectives were amalgamated into the overall analysis and development of the themes. Our strategy of hearing all the voices was successful. However, in synthesising and interconnecting the large body of both published literature and the interview responses, there is always a danger of losing sight of some of the nuance and subtle angle changes that come with different perspectives. Researchers and industry players, quite crucially, all have their particular expertise, field of study, favourite biological pathway or treatment modality and firm views on the resources required to move forward.

Clinician's perspectives bring us closer to the patients, their unmet medical needs, understanding of the daily challenges faced by patients and their families, and the practicalities of clinical trials and delivering care within health systems.

However, for any research roadmap to succeed, families will need to be part of the implementation process. First and foremost the destination(s) of the Roadmap must be the right destinations from their perspective. But

their participation is crucial, as the driving-force behind the research, as the providers of data and samples, and as participants in research studies and clinical trials - success is dependent on their buy-in.

Therefore, to ensure that the volume of the families' voices was again lifted in the final drafting of the Roadmap it was crucial to seek a final review from families. In this case, these were families who are closely watching the research developments, but who are not actively immersed and embedded in the research world. Their clarity on what they would like to see come out of the research and the areas they felt had been neglected to date brought the Roadmap into much sharper focus.

They flagged the neglected subtypes of Sanfilippo, the neglected symptoms, the challenges they and their children face in participating in studies and trials with severely disruptive symptoms and disabilities. Their thoughts helped us to hone the themes and incorporate missing details.

The final Roadmap, we believe, now fully represents the converging routes and intersecting junctions of all the stakeholders, but most importantly the people waiting anxiously at the end of the road for us all to arrive.

**Author: Lisa Melton, PhD – Head of Research
Sanfilippo's Children's Foundation.**



BUPA FOUNDATION EMERGING HEALTH RESEARCHER AWARD 2021

The Bupa Foundation has invested more than half a million dollars over the past 10 years, supporting early career researchers through its Emerging Health Researcher Award

The award recognises the dedication of early career researchers and their valuable contribution to improving the health and wellbeing of all Australians. This year, nominations were open to researchers focused on improving mental health and wellbeing and/or the link between environmental and human health.

Bupa's Director of Community Engagement, Julie Bissinella said sustainability and mental health are significant issues that are important to Bupa's people, customers, and the broader community.

"As a health and care organisation, we want to help develop mentally healthy and resilient communities. This is of particular importance as we navigate the short and long-term challenges arising from the COVID-19 pandemic."

The 2021 finalists showcase the high calibre of early career researchers, working in men's mental health, the

mental health of the elderly, the association between mental health and eating disorders and body image and the health impacts of air quality and climate change.

The winner of this year's Award and \$30,000 in prize money is Dr Zac Seidler, Research Fellow, Orygen for his research into men's mental health focused on understanding their experiences of mental healthcare, improving the service they receive and reducing the high and rising male suicide rate.

Dr Seidler was a standout for the Award given his experience in translational research, advocacy and thought leadership relating to men's mental health including the development of 'Men in Mind', a world first online training intervention, to upskill mental health practitioners working with men.

Dr Seidler tailored both a 'gatekeeper' training course and a suicide safety planning app to engage men to respond to suicidality in their male friends and family and provided expert policy advice to the Prime Minister's National Suicide Prevention Task Force and a leading WHO health policy document on 'Mental Health, Men and Culture.

"Our Award aims to identify and profile the outstanding contributions of early career

2021 AWARD RECIPIENTS

RECEIVING A TOTAL PRIZE OF \$30,000



WINNER: DR ZAC SEIDLER, RESEARCH FELLOW, ORYGEN

<https://www.zacseidler.com/>

Dr Zac Seidler is a clinical psychologist and researcher who aims to understand men's experiences of mental healthcare, improve the service they receive and reduce the high and rising male suicide rate. He has been selected as the Winner for the 2021 Emerging Health Researcher because of his track record of translational research, advocacy and thought leadership relating to men's mental health.

FINALISTS – EACH RECEIVING A \$5,000 PRIZE



Dr Carly Johnco, Senior Research Fellow and NHMRC Emerging Leadership Fellow Senior Research Fellow and NHMRC Emerging Leadership Fellow, Macquarie University

<https://researchers.mq.edu.au/en/persons/carly-johnco>

Dr Carly Johnco is a clinician researcher who aims to investigate improvements in the treatment of anxiety in depression in order adults, a group for whom psychological therapy was thought to be ineffective. She is selected as a Finalist for the 2021 Emerging Health Researcher because of her international reputation as a leader in this area, her extensive community engagement and track record for turning academic research into clinical interventions.



DR LONG KHANH-DAO LE, ALFRED DEAKIN POSTDOCTORAL RESEARCH FELLOW, DEAKIN UNIVERSITY INSTITUTE

<https://www.researchgate.net/profile/Long-Le-7>

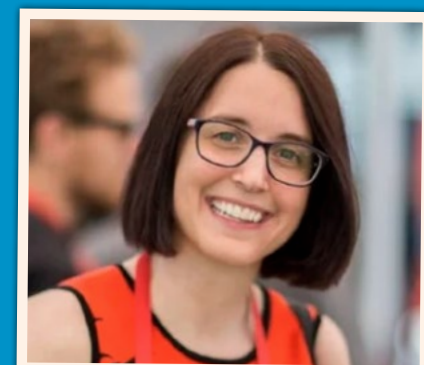
Dr Long Khanh-Dao Le is a health economist who evaluates the cost-effectiveness of prevention and treatment approaches developed for a breadth of mental health conditions, with a particular focus on eating disorders. He has been selected as a Finalist for the 2021 Emerging Health Researcher Award for his body of research and academic outputs that have directly impacted policy and practice.



DR SHANSHAN LI, SENIOR RESEARCH FELLOW AND DEPUTY HEAD OF MONASH CLIMATE, AIR QUALITY RESEARCH UNIT, MONASH UNIT

<https://research.monash.edu/en/persons/shandy-li>

Dr Shanshan leads a program of research looking into the health impacts of air quality and climate change as well as improving the available methods for assessing environmental impacts on health which have been widely used within the field. She has been identified as a Finalist for the 2021 Emerging Health Researcher Award for her international leadership on building the evidence for the link between environmental and human health, informing policy development and her advisory and advocacy roles.

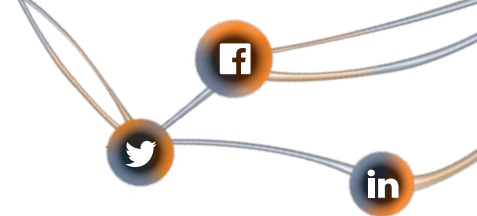


DR GEMMA SHARP, NHMRC EARLY CAREER SENIOR RESEARCH FELLOW & CLINICAL PSYCHOLOGIST, MONASH UNIVERSITY

<https://research.monash.edu/en/persons/gemma-sharp>

Dr Emma Sharp is a clinical psychologist who with her team investigate the causes of, and develop novel online treatments for, body image concerns which include eating disorders, but is also anxiety, depression, substance abuse and obesity. She has been selected as a Finalist for the 2021 Emerging Health Researcher Award on the basis of her innovative research, partnerships for translation and advocacy to promote positive body image in young people.

CONSUMER AND COMMUNITY INVOLVEMENT FOR BETTER EVERYDAY OUTCOMES: AN EXAMPLE FROM DEMENTIA RESEARCH



The importance of involving people with living or lived experience of a condition in co-designing research has become more widely recognised by advocacy and support organisations, universities, and funding bodies across Australia¹.

An important distinction should be made between the terms ‘involvement’, ‘participation’ and ‘engagement’ in research. Involvement means that people with living and lived experience actively work in partnership with researchers and research organisations such as funding bodies, to deliver research outcomes that are important to them. Research is developed and carried out ‘with’ or ‘by’ people with living or lived experience rather than ‘about’ or ‘for’ them². In contrast, participation means that a person consents to take part in a study and data is collected from or about them by researchers. Community engagement is where researchers raise awareness of their research, for example by giving talks at open days, science fairs or to community groups, and may often be the first step in generating interest in more active involvement.

Active involvement in research may include:

- making decisions about research priorities
- reviewing grant applications and recommending research projects to receive funding
- co-designing research projects and co-applying for research funding
- advising on funded research projects in a steering or advisory group
- developing and commenting on research materials
- carrying out research activities
- disseminating research findings to the wider public.

¹ NHMRC. Expectations and Value - Framework for Effective Consumer and Community Engagement in Research. Online resource accessed on 20/08/21: <https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>

² NHMRC National Institute for Dementia Research (2019). Becoming Involved in Research: A Guide for People Living with Dementia, Their Care Partners and Family Members.

USE OF LANGUAGE

The term 'Public and Patient Involvement' is often used as an over-arching term within the health sector³, as well as the term 'Consumer and Community Involvement'^{4,5}. However, these terms, despite being widely used in research and medical settings, are not always preferred, or accepted by people with living and lived experience of cognitive impairment and dementia. Language is important, and there needs to be broader discussion about alternative terminology that acknowledges the active involvement and expert experience of people living with these conditions, as well as their support persons, family members and advocates. The co-design of and involvement in research projects by people with living experience can ensure that appropriate language is used throughout the research process.

THE EXPERIENCE OF THE DEMENTIA AND NEURO MENTAL HEALTH RESEARCH UNIT CONSUMER AND COMMUNITY INVOLVEMENT GROUP

The Dementia and Neuro Mental Health Research Unit (DNMHRU) at the University of Queensland has established a Consumer and Community Involvement Group (CCIG) that includes people with living experience of cognitive impairment, dementia and Parkinson's disease, their supporters and wider community groups such as Lions Australia. The members have a diverse range of backgrounds and experiences, live across Australia and have been meeting monthly with researchers via a video-conferencing platform. The CCIG was formed in 2020, initially to co-design a research project focusing on the development and testing of a psychotherapeutic intervention to treat anxiety in people living with cognitive impairment.

The CCIG is now involved in all research projects conducted by the DNMHRU, and at every stage of the research cycle. For example, members discuss ideas for proposed projects, review grant applications, advise on and review the research design, intervention, and participant materials, assist with advertising the project, and interpreting and disseminating results. Members can be involved as much or as little as they wish, with flexibility to support individual needs and preferences for example, reviewing printed rather than on-line material. Members are provided with gift vouchers to acknowledge their contribution.

Ann Pietsch has found involvement in the CCIG to be satisfying: "I feel that I have been able to represent people

like myself and add to the researchers' understanding of dementia and about living with dementia. I have been involved in reviewing research proposals and felt respected, valued, and supported by the committee and researchers. I hope that my involvement will contribute to making the research relevant and meaningful for people with dementia. It also keeps me aware of the current dementia research and helps to keep my brain active."

Another CCIG member, Dennis Frost, points out the importance of co-design in enhancing the internal validity of the research:

“ Having participated in many research projects, I found that the used language and methodologies are often tokenistic and guided by the researchers' preconceived ideas about dementia. This makes the researchers ask invalid questions, disregarding how people living with dementia engage. Being involved in this CCIG gives me confidence that the used methodologies will be appropriate and the findings are valid.”

The benefits of a co-design mindset extends to training the new generation of researchers and practitioners in early stages of their career, as they collaborate with and learn from people with living or lived experience. PhD candidate Dana Pourzinal has found: "the integration of advice from those with living or lived experience of Parkinson's disease has astronomically enhanced the quality of my research. The collaboration with the CCIG has helped to promote our research to a wider audience of prospective beneficiaries."

The involvement of people with living or lived experience, their families, supporters, and wider community groups in research co-design achieves better health outcomes. Their contribution means that the research undertaken by the DNMHRU is aimed at real-life concerns and unmet needs, which leads to the development of meaningful interventions that can enhance quality of life.

Author: Dr Deborah Brooks is a postdoctoral research fellow at the DNMHRU, Centre for Clinical Research, **University of Queensland** and actively engaged in Consumer and Community Involvement initiatives, supporting people with lived experience of dementia to become involved in research beyond the role of participant. Dr Nadeeka Dissanayaka is supported by the NHMRC Boosting Dementia Research Leadership Fellowship and directs the DNMHRU.

3 INVOLVE (2012). Briefing notes for researchers: public involvement in NHS, public health, and social care research. INVOLVE Eastleigh

4 NHMRC. Expectations and Value - Framework for Effective Consumer and Community Engagement in Research. Online resource accessed on 20/08/21: <https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>

5 Cancer Australia Consumer Involvement Toolkit. Online Resource accessed 20/08/21: <https://consumerinvolvement.canceraustralia.gov.au/>



NEW FRONTIERS OF TISSUE REPAIR

Harnessing extracellular vesicles for healthier and sustainable future.



Most conventional pharmacological interventions use single molecules with limited number of actions, administered to the body in an untargeted, shot-gun fashion. In contrast, extracellular vesicles (EVs) shuttle a 'cocktail' of biomolecules that influence multiple cells and tissues in numerous and coordinated ways¹.

EVs are membranous lipid nanoparticles that are secreted ubiquitously by cells and play fundamental role in intracellular communication, tissue homeostasis and tissue regeneration – made by cells for cells. Harnessing this regenerative potential of EVs would revolutionise the way tissues damaged by injury or disease are treated and repaired.

'MULTISHOTS' THAT DRIVE FUNCTIONAL TISSUE REPAIR

While regenerative medicine has focused on cell-based therapy, EVs, which are derived from stem cells, have substantial benefits when compared with whole-cell approach². For example, EVs can be delivered precisely to the target site, their nano size allows them to reach spaces that are inaccessible to the whole cell. Moreover, EVs show good biological safety, stability, and low immunogenicity. Importantly, EVs inherit the regenerative capacity of their parent cells while avoiding various limitations associated with living cells such as tumorigenesis and loss of potency during storage and transplantation. EVs secreted from

human adipose tissue-derived mesenchymal stem/stromal cells (ASCs) from healthy donors have already proved to promote for example skin regeneration and became commercially available, ASCE+ (ExoCoBio, South Korea). The fact that the cells to produce EVs are 'donated' by donors emphasises the critical role of society in developing new generation medicine.

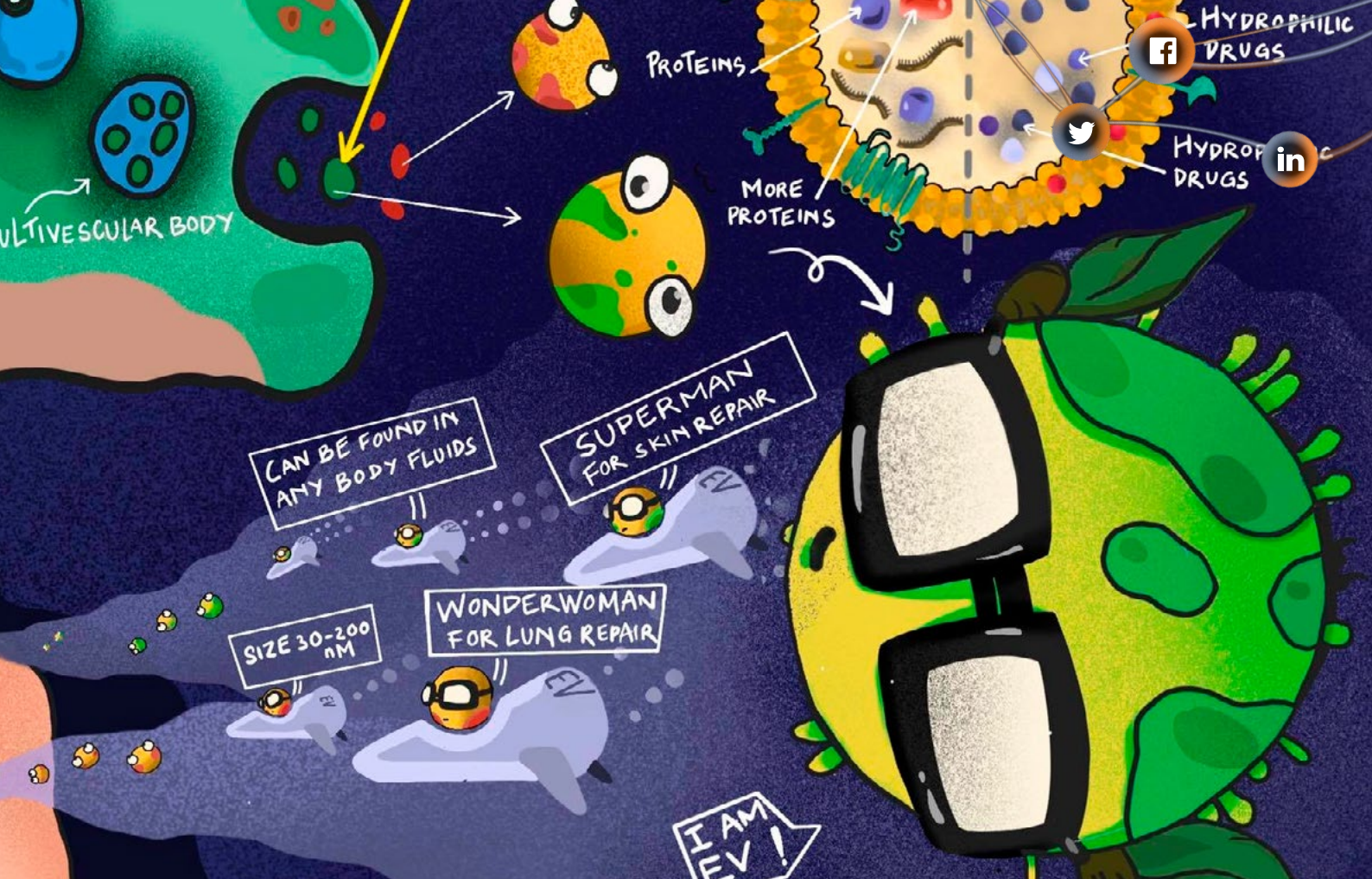
EVs' capability to promote tissue repair stems from their unique and complex composition, i.e. proteins, nucleic acids, RNAs that are encased in a lipid bilayer, which protects them from degradation and provides long-term stability. Excitingly, the regenerative effects of EVs can be potentiated by modulating conditions in which the parent cells are cultured. We showed that EVs produced by a specific type of placental stem cells, which are naturally exposed to a hypoxic environment, were able to reduce oxidative stress and promote tissue regeneration in a lung injury model³. In other words, EVs produced from cells in a hypoxic environment, which we termed specialised EVs, helped cells in another environment to repair damage from oxidative stress. Specifically, our cells to produce specialised EVs are derived from the placenta of women donors who delivered their babies. Beyond the specifics of lung injury, these specialised EVs can enhance wound healing and aid integration of metal implants, which raised the tantalising possibility that the composition of EVs can be manipulated to treat different conditions⁴.

1 Tang, T.T., et al., Extracellular vesicle-based Nanotherapeutics: Emerging frontiers in anti-inflammatory therapy. *Theranostics*, 2020. 10(18): p. 8111-8129.

2 Keshkar, S., N. Azarpira, and M.H. Ghahremani, Mesenchymal stem cell-derived extracellular vesicles: novel frontiers in regenerative medicine. *Stem Cell Res Ther*, 2018. 9(1): p. 63.

3 Kim, S.Y., et al., Placenta Stem/Stromal Cell-Derived Extracellular Vesicles for Potential Use in Lung Repair. *Proteomics*, 2019. 19(17): p. e1800166.

4 Pansani, T.N., et al., Extracellular-Vesicle-Based Coatings Enhance Bioactivity of Titanium Implants-SurfEV. *Nanomaterials (Basel)*, 2021. 11(6).



EVs can be used as vehicles for delivery of exogenous biomolecules and drugs that support tissue repair. Because of their surface composition they can effectively target different sites in the body and improve the efficacy of delivery of miRNA, proteins, and small-molecule drugs. In the context of personalised therapy, the cells to produce EVs are directly taken from the individual patient, then expanded, engineered (e.g. loaded with additional therapeutic agents) to enhance functionality, subsequently re-injected to the same patient. In this way, any potential risk of immune rejection will be mitigated. This strategy exemplifies those patients should be an integral part of the process of developing and using EVs as medicines.

TRANSLATIONAL LANDSCAPE AND CRITICAL ROLES OF PATIENTS IN THE DEVELOPMENT OF EV-BASED PRODUCTS

The excitement around the therapeutic potential of EVs is reflected by the continuously increasing number of EV-based products in clinical trials, the exponential growth of government, industry, and private investments. In the last decade at least 45 companies have developed EV-based products. Notably, FDA approved Direct Biologics to conduct a Phase II trial for the use of ExoFlo™, a bone marrow-derived EVs product, in the treatment of COVID-19 associated with acute respiratory distress syndrome (ARDS) patients. According to the database, 120 patients received a single intravenous dose of ExoFlo™ and the results showed that ExoFlo™ can restore oxygenation, downregulate the inflammation and reconstitute immune systems of the patients.

For rapid implementation of EV-based products, building

the integration between biomedical science and social science and encouraging patient engagement are required. It is fundamental to modulate the perception of society by educating people about EV-based products and their implication in practice. Importantly, patients need to be updated about the health benefits of EV-based products, their safety to make informed decision about their use, and finally, the expected timeline to use them as mainstream medicines.

CHALLENGES AND A BRIGHT FUTURE FOR MEVCINE

Like other biologicals, there are still some challenges before we can harness the full potential of EVs for healthier and sustainable future. Scaling up the production for commercial use, establishing standardised quality control, and understanding pharmacokinetics and pharmacodynamics of EVs are three main challenges in this field. Nevertheless, building on the success of different biologicals in clinic and increasing number of EV-based products in clinical trials, we believe that EVs will soon become mainstream medicines.

Author: Thanh Huyen Phan, Wojciech Chrzanowski, The University of Sydney, Sydney Nano Institute, Faculty of Medicine and Health, Sydney School of Pharmacy, Pharmacy and Bank Building A15, Camperdown, NSW 2006, Australia.

AUSSIE DRY EYE DRUG TARGETING UNMET CLINICAL NEED SEEKS FUNDING

Two Australian ophthalmologists are repurposing a common cholesterol-lowering drug into a topical ocular therapy for dry eye and blepharitis, which was given to a patient as part of an initial trial who went 90 seconds without blinking after treatment.

Dry eye is the most common eye disorder¹ and is frequently accompanied by blepharitis (eyelid inflammation) which has an overall prevalence of nearly 40% (ranging from around 20% in 10–19-year-olds to 70% in those over 60).

People with dry eye and blepharitis have their daily activities disrupted and work productivity lowered² due to recurrent blurred vision and ocular discomfort and red

eyes from increased tear evaporation. Dry eye may also occur due to damage to the lacrimal gland for example in Sjogren's syndrome which is associated with a variety of autoimmune conditions. A number of medical as well as ocular conditions, medications, dietary deficiencies and environmental factors can also cause dry eye³.

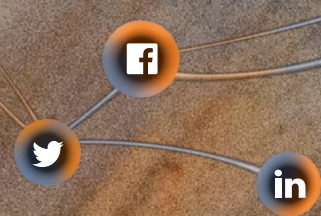
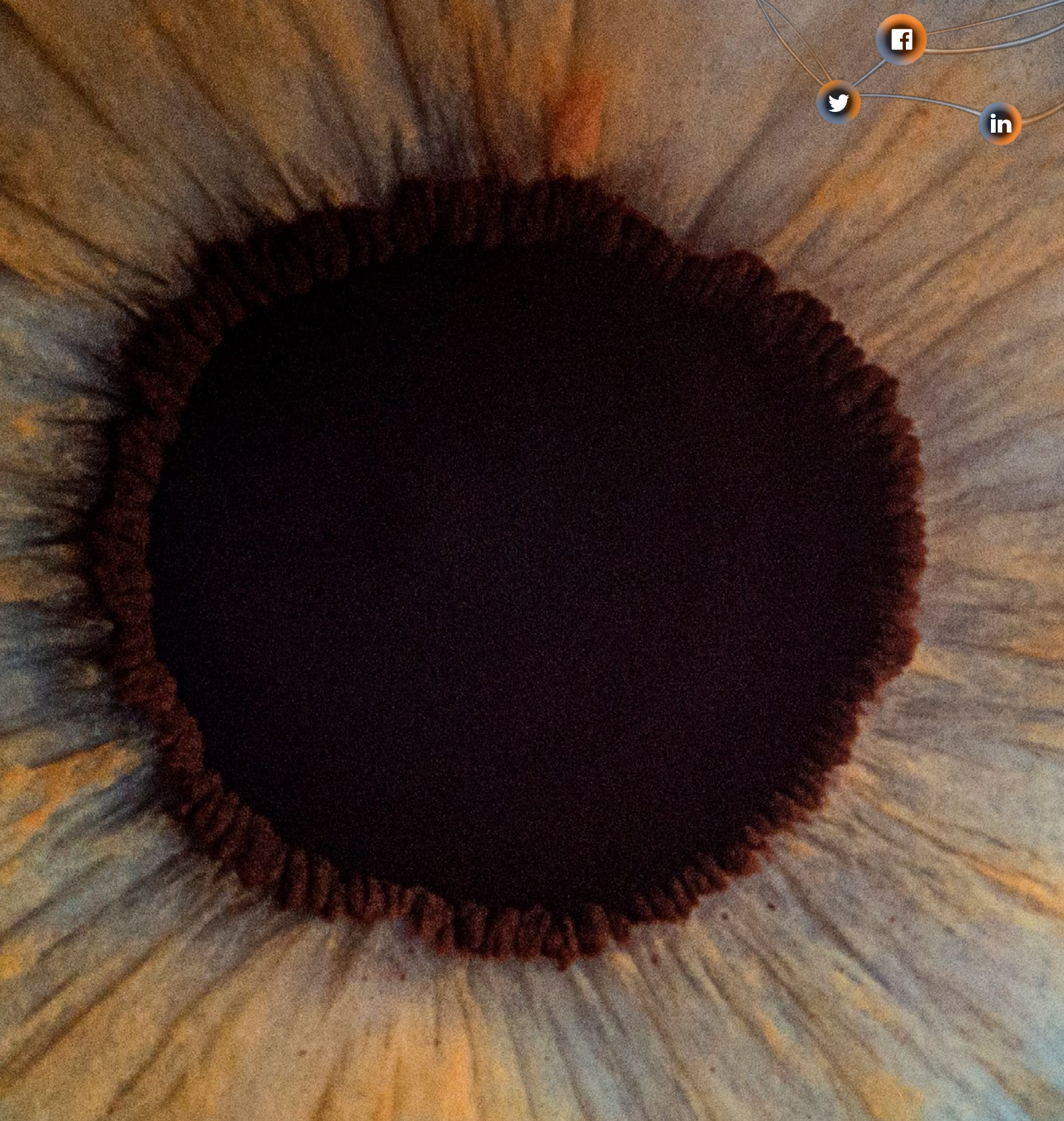
Moderate to severe dry eye damages the ocular surface and can lead to blindness following infection⁴. The

1 Albiets JM. Prevalence of dry eye subtypes in clinical optometry practice. *Optom Vis Science*, 2000. 77(7): p. 357-63.

2 Patel VD, Watanabe JH, Strauss JA, Dubey AT. Work productivity loss in patients with dry eye disease: an online survey. *Curr Med Res Opin*. 2011 May;27(5):1041-8.

3 Vehof J, Snieder H, Jansonius N, Hammond CJ. Prevalence and risk factors of dry eye in 79,866 participants of the population-based Lifelines cohort study in the Netherlands. *Ocul Surf*. 2021 Jan;19:83-93

4 Tseng SC. Staging of conjunctival squamous metaplasia by impression cytology. *Ophthalmology* 1985;(92): p. 728-733.



consequences of these common conditions occur despite maximal use of lubricating drops and ointments, which address only the symptoms and not the underlying cause.

Dr Kenneth Ooi and Professor Stephanie Watson, from the University of Sydney's Save Sight Institute, have completed a Phase 1 study of their novel therapy called topical Atorvastatin, which they believe has the potential to treat both evaporative and aqueous deficient forms of dry eye disease.

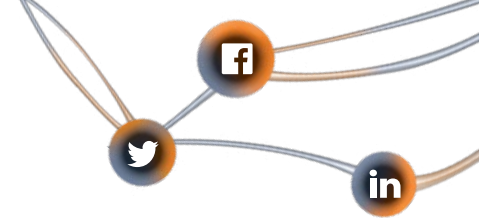
Unlike other therapies on the market, the formulation has multiple mechanisms of action and, if successful, could fill a distinct gap in a global market estimated to be worth

up to \$7.7 billion within the next five years. However, the research will need to overcome funding hurdles to reach the next phase of development.

The tear film stabiliser has been repurposed from oral statins, which have well known cholesterol-lowering and immunomodulatory properties. Pfizer's Lipitor is the gold standard statin and continues to generate roughly \$2 billion per year in sales, despite its patent expiring eight years ago.

Drs. Ooi and Watsons' use of statins as a topical ocular therapy for dry eye and blepharitis is novel. It is non-steroidal with no steroid-like related cataract, glaucoma





and infection side effects. According to Dr. Ooi, the Australian market is reflective of much of the western world, with treatment choices largely limited to LFA-1 inhibitor lifitegrast (Xiidra) and variants of cyclosporine (such as Restasis, Cequa and more recently Ikervis).

There are many over-the-counter therapies with a number that are wetting agents that do not address the underlying mechanisms of dry eye. For minor dry eye these have their place but there is still an unmet need for cost-effective side-effect free treatments for moderate to severe dry eye.

“Atorvastatin is multi-modal in its mechanism of action compared to a number of competitors on the market or in the pipeline which have only one or predominantly one mechanism of action,” he said.

In a recent pilot study of 10 patients with blepharitis and dry eye, which often co-exist, Dr. Ooi recorded positive results with reduced corneal fluorescein staining and conjunctival redness, improved tear break-up times (TBUT) and normalised Schirmer’s wetting. There was improved blepharitis, as well as dry eye symptom scores⁵.

“One patient in particular was able to keep her eyes open after treatment (without blinking) for 90 seconds. Her initial TBUT was four seconds and her Schirmer’s wetting, initially at 7mm, stabilised to 15mm after one month of treatment,” he said.

“No local or systemic adverse effects were recorded and patients favourably rated acceptability and ease of use of topical statin therapy.”

In terms of safety, Dr. Ooi said the formulation used in the Phase 1 trial achieved Australian Therapeutic Goods Administration Clinical Trial Notification scheme clearance due to it being a previously approved drug at much lower concentration than what is used systemically. In the trial, no side effects were reported, as well as no changes in vision, intraocular pressure, lens clarity or local ocular surface toxicity. A follow-up safety questionnaire also noted no deleterious long-term sequelae.

Dr. Ooi now has his sights set on a Phase 2 trial costing approximately \$400,000, involving 30 patients to optimise the dosing frequency. With unsuccessful government funding applications, they are approaching the pharmaceutical industry and venture capitalists locally and overseas to fund the work.

He hoped Atorvastatin may one day be used to treat evaporative dry eye, as well as the aqueous deficient form, including post-cataract and refractive surgery dry eye, post-intravitreal injection dry eye and Sjogren’s syndrome.

Dr. Ooi and Professor Watson have been developing Atorvastatin for several years, with the work sparked by Dr. Ooi’s research into statins as a potential oral steroid-sparing agent for uveitis at the Institute of Ophthalmology through University College London.

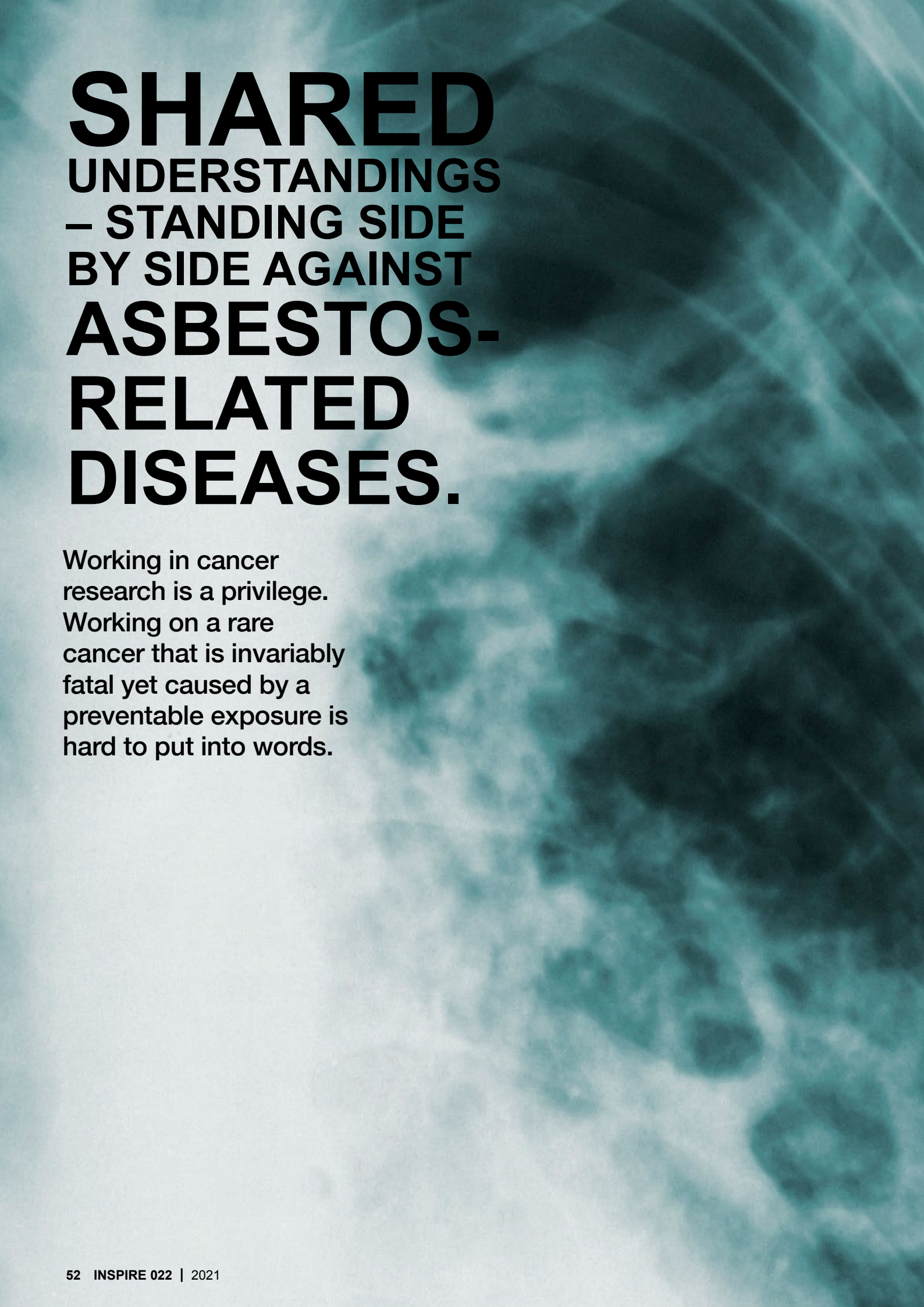
“It came to me that inflammation is the same everywhere,” he said. “Knowing that inflammation is associated with dry eye and that research indicates there may be an excess of free cholesterol in the lipid layer in blepharitis-associated meibomian gland dysfunction contributing to evaporative dry eye, statins came to me as being potentially ideally placed as repurposed novel tear film stabilisers.”

In light of his discovery, Dr. Ooi has secured patents for topical statins as a novel tear film stabiliser in Australia, Japan and Europe, and is currently filing in the US. There is the potential for novel spin-off patent generation as well.

He believes its treatment indications could also extend to allergic conjunctivitis and allergic dry eye, ocular surface disease associated with glaucoma therapies, ocular inflammatory disease in the form of episcleritis and scleritis, ocular pain and corneal wound healing.

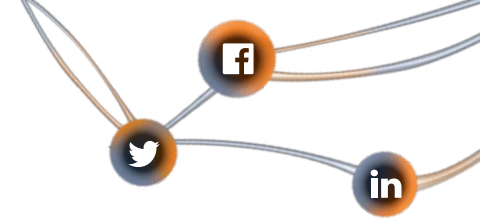
⁵ Ooi KG, Wakefield D, Billson FA, Watson SL. Efficacy and Safety of Topical Atorvastatin for the Treatment of Dry Eye Associated with Blepharitis: A Pilot Study. *Ophthalmic Res.* 2015;54(1):26-33.

Author: Dr Ken Ooi, The University of Sydney



SHARED UNDERSTANDINGS – STANDING SIDE BY SIDE AGAINST ASBESTOS- RELATED DISEASES.

Working in cancer research is a privilege. Working on a rare cancer that is invariably fatal yet caused by a preventable exposure is hard to put into words.



Researching the deadly asbestos caused cancer mesothelioma has always meant more than laboratory work for our team at the National Centre for Asbestos Related Diseases (NCARD), based at the University of Western Australia and Institute for Respiratory Health. In Perth, we constantly pass the asbestos fences and garden sheds that are ubiquitous in our built environment, and know why our State has the largest rate of mesothelioma, per capita, in the world. We learn that those who have lived in Wittenoom and spent their lives wondering if they will be next - or those who have already died of mesothelioma - include our friends' parents and grandparents and our own, our neighbours, our builders, our mentors.

As a consequence of the Wittenoom blue asbestos mine and its deadly legacy, the consumer organisation Asbestos Diseases Society of Australia (ADSA) has a proud history of supporting members and their families who were exposed to asbestos. ADSA advocacy was instrumental in creating the original federal funding for a national centre.

This shared history means that NCARD and ADSA have fostered close links which go beyond medical research. NCARD and ADSA walk side by side at awareness raising events such as the annual walk, leaving our lab benches to march through the city streets and up to Parliament House. Invited senior researchers present at annual meetings, hand out trophies at the golf day fundraiser, lobby in parliament house, and attend the Christmas picnic.

Some of our NCARD team have had out of the ordinary experiences for people who aren't medically trained. We have attended hospices and joined in family singalongs; sat with a patient receiving their chemo; held the hand of a dying man, and attended funerals.

But what we do best is research. So we welcome patients, their families, and interested members of the public to community forums, where we explain the work we do with presentations like "Why does research take so long?" We use plain language descriptions of complex concepts such as tumour immunology, chemotherapy combined with immunotherapy, and biomarkers. And we invite the public to tour our laboratories – but only if they're wearing appropriate shoes! The Laboratory Managers, Research Assistants and PhD students come into their own conducting laboratory tours, and their excitement and enthusiasm about science is infectious. People with mesothelioma and their families can be seen learning how to pipette, about tissue culture, and viewing mesothelioma cells down a microscope.

Importantly, we also seek advice from consumers about

our funding applications and future research plans. The NCARD Consumer Advisory Panel has been operating for several years. Early in the year we discuss our new research ideas, and later we present our progress. Our panel believe so fervently in the work we are doing that they also 'feel the pain' of unsuccessful grant applications! They review lay summaries and patient information and consent forms, give input on our clinical information sheets, and remind us to set aside funds for study participants to park on-site. The notion of consumers is particularly difficult in a cancer where those who have been heavily exposed, or who have been left behind, need to speak on behalf of the sufferers. With mesothelioma, there are no survivors.

We also get a small insight into the experience from the patient's perspective. Each new team member, from Honours student to postdoctoral researcher, attends a mesothelioma outpatient clinic.

“It's an important experience, and a unique one that I've never had with other research. Working in a lab is quite isolating so it's good to have that exposure to get a bigger picture and really establish why we're doing this work” is how a recent new researcher put it.

Patients have welcomed our research team as observers, and our researchers might hear about their asbestos exposure, or get a glimpse into treatment side effects, the impact on families, or the complexities of pain relief.

Each year the ADSA holds a poignant memorial service in a chapel awash with the scent of huge bunches of rosemary.

Part of the formal service is a lighting of coloured candles: white for those we have lost, green for those who have been exposed, blue for carers.

A red candle is lit for researchers. We're there – reminding ourselves of the importance of our work and setting aside a moment to reflect on those we have cared for as health professionals. In recent years a screen has been added, projecting photos of those who have died. Laughing at weddings and parties, with family or partners, young and old, the photos of more and more familiar faces pass by. It's impossible to take your eyes off them.

Authors: Tracy Hayward and Anna Nowak.
National Centre for Asbestos Related Diseases,
University of Western Australia and Institute for
Respiratory Health.

CELEBRATING 40 YEARS OF HELPING AUSTRALIANS BREATHE AND SLEEP BETTER

“It’s a proud moment to see four decades of world-class research behind us,” says executive director Professor Carol Armour. We won’t stop there.”

Our passionate and dedicated team is constantly striving to improve the respiratory and sleep health of all Australians.

The Woolcock Institute of Medical Research is marking 40 years as a world-leading, award-winning specialist sleep and respiratory research centre. The centre invests in bench-to-bedside projects that make meaningful differences for patients, and has a proven track record for fostering the next generation of researchers.

The Woolcock has proven to be a trailblazer in the field of research and treatment of debilitating respiratory diseases like asthma, emphysema, chronic obstructive pulmonary disease (COPD) and lung cancer, as well as sleep conditions, including insomnia, sleep apnoea and narcolepsy.

“Our environment is so important for good lung health,” says group leader Professor Guy Marks. “We are faced with threats from air pollution, bushfires, climate change and, most recently, COVID-19. This is an exciting time to be an epidemiologist because we have so many opportunities for our research to lead to positive change in the world.”

The Institute established the Woolcock Emphysema Centre, Australia’s only research centre dedicated to the fight against COPD. Among major achievements, the team found that the anti-inflammatory protein tristetraprolin can reduce hallmark features of COPD and so, in future, researchers may be able to switch off damaging inflammation in this disease. The centre also ran a number of clinical trials using telemonitoring to improve at-home care for people suffering with COPD, and established a breathlessness clinic to help people in the community.

Among some of the biggest developments, the Woolcock’s Respiratory and Environmental Epidemiology Group established the Australian Centre for Airways disease Monitoring to collate and interpret data that helps prevent chronic airways diseases. The team also conducted a large scale Childhood Asthma Prevention Study and investigated health effects of unflued gas heaters in NSW primary schoolchildren, prompting a \$400 million government-funded heater replacement project.

The Sleep and Circadian Research Group has spent 20 years at the forefront of obstructive sleep apnea (OSA) research. Group Leader Professor Ron Grunstein was involved in the first trials of continuous positive airway pressure (CPAP), now known as the gold standard OSA treatment. Since then, the group has gone on to show CPAP can improve depression and quality of life, and successfully test the use of dental devices as a CPAP alternative for OSA. What’s more, researchers launched the Woolcock Clinic, Woolcock NeuroSleep Clinic, and the high-density EEG Facility for Sleep and Circadian Research, a state-of-the-art research facility to explore the impact of sleep disorders on cognition, brain ageing and neurodegeneration.

TRANSLATION TO THE CLINIC

The Woolcock established the Respiratory Technology Group in 2012 to help translate the Institute’s discoveries to the clinic in the form of drug formulation and device development. Since then it has set up a pharmaceutical company, Ab Initio Pharma, to rapidly translate benchtop discoveries to clinical trial products, and developed a Master’s level training program to build capacity in the MedTech workforce.



Over the decades, the Airway Physiology and Imaging Group has uncovered the physiological mechanisms behind airway hyperresponsiveness and impaired small airway function in asthma and COPD. The team also shaped technical guidelines for two tests of lung function which are increasingly used in respiratory clinics globally. “We were the first group internationally to establish a combination of cutting-edge measures of airway function with 3-dimensional imaging, in airways diseases,” group co-leader Professor Greg King says. “The findings from our research program have contributed a large bulk of the knowledge that underpins the use of such physiological measurements in research and clinical practice today.” The team has also pioneered the use of telemonitoring technology to monitor lung function in asthma and COPD in Australia, and sophisticated data analytics to predict future asthma or COPD attacks.

The Respiratory Cellular and Molecular Biology Group has been involved in several seminal discoveries, including a breakthrough observation that there is increased airway smooth muscle cell proliferation in asthma, which partially explains why there is more muscle in the airways of people with the condition. They also uncovered why bronchodilators don’t work well in people with asthma when they have a common cold, and discovered the importance of the respiratory virome, viruses which can be found in both healthy and diseased lungs.

The Clinical Management Group has also had several breakthroughs, including creating gold standards for inhaler use in the management of asthma, COPD and allergic rhinitis, which are now embedded within disease management guidelines. Significantly, there is now a new

treatment regimen to reduce the risk of mild asthma, that has been implemented in 35 countries, including Australia. “The high quality clinical, qualitative and epidemiological research by our group has led to major changes in Australian and international guidelines,” says asthma expert and chair of the GINA scientific committee, Professor Helen Reddel.

These researchers have also influenced the development of novel inhalers with digital technologies and e-connectivity, and formed a national network of pharmacists who are immersed in research and respiratory disease care in the community. This work demonstrates the potential of pharmacists to screen and manage people with sleep disorders, and reduce exacerbations and improve medication use in COPD and asthma patients.

The Institute opened the Woolcock Centre for Lung Cancer Research in 2019 to establish more effective therapies and diagnostic tests for patients suffering from lung cancer. The Centre and the associated Lung Cancer Network have developed biomarker testing for predicting patient response to cancer therapy, and identified new pathogenic gene variants for the most common type of hereditary cancer syndrome. “We want to see a future where lung cancer is no longer considered a stigma for patients,” says Centre leader Professor Majja Kohonen-Corish.

Author: Professor Carol Armour, The Woolcock Institute of Medical Research



THE CIC CANCER PROJECT

Improving outcomes
that patients really want.

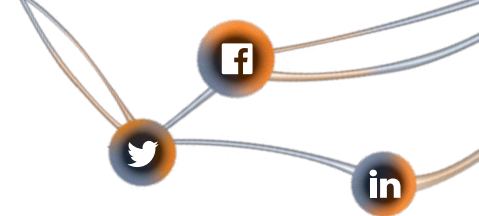
Currently, there are over a million Australians who are living with cancer and about 145,000 new cases of cancer are diagnosed each year. In recent decades, there have been significant improvements in the treatment of many cancers, leading to survival of more than 90% for some cancers.

However, life after treatment can be a challenging experience, due to the myriad of side effects that can impair a person's wellbeing. In addition, the financial impact of some cancer treatments can add another layer of difficulty to patients, further impacting their quality of life.

THE CIC CANCER PROJECT

The Continuous Improvement in Care - Cancer (CIC Cancer) Project is Australia's first concerted effort to implement value-based healthcare (VBHC) in cancer care across both public and private healthcare systems. Through a synergistic partnership between consumers, clinicians, health service providers, health economists and researchers, this project aims to improve the outcomes that matter the most to patients.

In a nutshell, the CIC Cancer Project seeks to improve outcomes while finding ways to reduce health care costs, guided through the feedback received from patients. The



CIC Cancer Project collects Patient Reported Outcome Measures (PROMs) and clinical data across five cancer types: breast, prostate, colorectal, ovarian and lung, based on datasets from the International Consortium for Health Outcomes. Datasets touch on all stages of the care pathway, from diagnosis and treatment to survivorship and end-of-life care.

Analyses of these data aim to inform different stakeholders about gaps and variations in cancer care and ways to improve it, possible needs for additional clinical intervention and ways to promote the improvement of clinical units – all based on patients' perspectives and needs.

CIC Cancer is also developing analytics and visualisation protocols, and mapping of adherence of care to current optimal care pathways. A long-term goal is to identify ways to improve outcomes and incorporate value based health into these pathways.

“Putting the cancer patient and their family at the centre of any health care system – measuring the outcomes that we can achieve which are most important to that patient, and tracking the cost of delivering those excellent outcomes – is the only way we can get real value in our health practices,” said Christobel Saunders AO, Professor of Surgical Oncology at UWA and Chief Investigator of the CIC Cancer Project.

RECENT OUTCOMES

The CIC Cancer team is collecting and analysing data from four hospitals, across four cancer types: lung, breast, ovarian and colorectal. A specialised IT platform has been implemented in both the public and private sectors to aid with the capture of data. To date, PROMs have been recorded for approximately 400 patients.

Earlier this year, the CIC Cancer team held the inaugural conference on Value-Based Health Care in Perth, Western Australia, from 27 - 28 May 2021. The conference brought together 353 participants, including clinical health professionals, hospital and health service managers, policymakers, consumers, academics, and health services researchers from across Australia, Singapore, the United Kingdom and New Zealand. The conference highlighted

multiple examples of implementations of the VBHC model into real-life settings, and the CIC Cancer team is now working towards the publication of a series of articles based on some of the work presented at the conference.

Another important outcome of the CIC Cancer Project has been the implementation of a proof-of-concept project to provide a bundled care payment approach. The project focuses on women diagnosed with early-stage breast cancer, who have chosen to receive care through the private health system. It brings together health care providers, including surgeons, radiologists, oncologists, and allied health, along with private health insurers, researchers, a major radiation oncology provider and patients. The goal is to offer patients the best quality care and outcomes for the most efficient cost possible.

With the support of these stakeholders and the guidance of a patient navigator, participants of this project will see the first year of their treatment pathway mapped. Information about treatment options and out-of-pocket costs will be clearly outlined. Also, out-of-pocket expenses will be capped, and patients will have someone available to guide them through their treatment. The proposed model aims to:

- provide patients with upfront knowledge of all the costs of their care over a 12-month period;
- provide support from a patient care navigator during and after their treatment;
- offer the option of payment by instalments; and
- have clear disclosure of care offered, and services available.

The CIC Cancer Project aims to ensure that all the outcomes that matter to patients are incorporated into the standard of cancer care, ultimately improving cancer care provision.

“Our vision is that we can offer excellent cancer care that provides the best value both for the individual patient, the health service provider and the system overall, incorporating both value based care and a person centred approach, whilst improving the equity of our cancer services,” Prof Saunders said.

Author: Karl Gruber Gonzalez. UWA Medical School

Consumer involvement in health research: the other side of the coin



Professor Don Nutbeam, Executive Director, and Associate Professor Angela Todd, Research Director, Sydney Health Partners (SHP). SHP is one of 10 research translation centres accredited by the NHMRC as a leader in health research and the translation of evidence into excellent patient care.

The current and most recent editions of Inspire draw attention to the potential and benefits of consumer involvement in health and medical research. These benefits include generating research questions that more accurately address patient priorities, lead to study and intervention designs that are more pragmatic and aligned with patient preferences, and ultimately contribute to more effective dissemination of results and translation of evidence into clinical practice.^{1,2}

Most researchers now include references to consumer involvement in their funding applications, in part because they are required to do so by funding organisations. Sadly, this 'involvement' too often appears tokenistic (meeting the requirements of the application), or instrumental (designed to improve patient recruitment into studies). Examples of genuine partnership between consumers and researchers, including co-designing research questions and methods, remain relatively rare.

The reasons for this are many and varied but are frequently related to the difficulties experienced by researchers in building and sustaining productive working relationships with consumers. There is also often a simple cultural mismatch between the desire (and perceived need) for a high level of control by researchers, and the adaptability required to respond meaningfully to consumer needs and preferences. This can be especially frustrating when funding organisations demand consumer engagement but grant application reviewers fail to accommodate the need for methodological flexibility that comes with it, or fail to discriminate and reward 'good' consumer involvement efforts from poorer ones.

If consumer and community engagement is to evolve in ways that deliver potential benefits, there will need to be significant improvement in our understanding of what this involves, and more consistent recognition of its importance of among researchers, funders, reviewers and consumers.

1 Mullins CD, Abdulhalim AM, Lavalley DC. Continuous patient engagement in comparative effectiveness research. JAMA. 2012;307(15):1587-8.

2 Forsythe LP, Carman KL, Szydlowski V, Fayish L, Davidson L, Hickam DH, et al. Patient engagement In research: early findings from the Patient-Centered Outcomes Research Institute. Health Affairs. 2019;38(3):359-67.

Research Australia found that more than 75% of community participants agree that using the latest research and evidence to update medical practice is important for improving Australia's health system.³ Despite this, most people report that they have never been asked to be involved in research, including by their health care providers. Public appreciation of the importance of medical research provides an important foundation but doesn't directly address what patients and health consumers feel about being personally involved in research. Limited research on this subject reveals some consistent themes that emphasise communication, relationships, respect and resources.^{4,5}

There is no single "right consumer" for a project, and not all consumers will want to be involved in all kinds of research. But, if we want consumers to be involved as partners in research, we need to invest in building relationships. This requires honest and open communication about our research, the research process, and the commitments that are needed from our consumer partners. Consumers are not researchers, but we should respect the fact that they are experts in their own health and care needs, and they each bring different backgrounds, perspectives and experiences to the research enterprise. Different engagement processes will be needed to engage diverse patient or community groups.

Terms like participating, engaging, involving, co-designing and co-producing are not interchangeable. 'Participating' in research refers to being a participant or subject in a research project. 'Involving' a consumer in research might mean helping to generate research ideas, working with researchers to design projects, developing patient information sheets or survey tools, interpreting results and their implications, and/or helping to disseminate research findings.

For most of us, researchers and consumers, this remains unfamiliar territory. If we want to partner with consumers in research, we (as researchers) often need training on how best to do so. There are a small but growing number of online programs emerging to help us learn about working together (for example^{6,7,8}).



Last but not least, there is the issue of "value" in a partnership. While reimbursement of expenses incurred by consumers (such as travel and meals) is common practice, increasingly consumers are also being paid for their time. Too often, in a research team the only person whose time is not paid is the consumer "volunteer". Paying for their time can be an important signal that consumers' contributions are valued.

In NSW, Sydney Health Partners is working closely with Health Consumers NSW to build capacity among researchers and consumers to partner in research. Nationally we are one of a network of 10 research translation centres collaborating with Consumers Health Forum of Australia to progress this agenda across Australia's health research sector.⁹ This is helping to address one part of the challenge of achieving meaningful consumer engagement in research, by building capacity and confidence among researchers and consumers. This needs to be matched by research funding agencies responding in ways that ensure that the existing rhetoric about consumer involvement is consistently supported through the peer review and grant assessment process, and that recognition is given to the cost of meaningful consumer engagement in research budgets and timelines.

Author: Professor Don Nutbeam, Executive Director, Sydney Health Partners (SHP).

3 Research Australia. 2020 Public Opinion Poll on Health & Medical Research & Innovation: Research Australia; 2021 [Available from: <https://researchaustralia.org/reports/public-opinion-polling-2/>].

4 Todd A, Nutbeam D. Involving consumers in health research: what do consumers say? Public Health Research and Practice 2018;28(2):e2821813.

5 Research4Me, Health Consumers NSW. Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective. 2017. [Available from: http://www.hcnsw.org.au/wp-content/uploads/2018/11/Involving_health_consumers_in_health_and_medical_research_online_print.pdf]

6 Health Consumers NSW. Introduction to consumer involvement in health research: joint training for consumers and researchers: Health Consumers NSW and Sydney Health Partners; 2020 [Available from: <https://www.hcnsw.org.au/training-events/health-research-training/>].

7 Consumer and Community Involvement Program. Consumer and Community Involvement in Health Research: Consumer and Community Involvement Program; 2021 [Available from: <https://retprogram.org/training/consumer-and-community-involvement-in-health-research/>].

8 Monash Partners. Welcome to Consumer and Community Involvement: Monash Partners; 2020 [Available from: <https://monashpartners.org.au/education-training-and-events/cci/>].

9 Australian Health Research Alliance (AHRA). Consumer and Community Involvement: AHRA; 2021 [Available from: <https://ahra.org.au/our-work/consumer-and-community-involvement/>].

