LEADERSHIP INSIGHTS

ON HEALTH AND MEDICAL RESEARCH AND INNOVATION



ISSUE 04

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LEADERSHIP INSIGHTS

The Leadership INISGHTS series is a unique channel for Research Australia to promote the incredible leadership of organisations we represent across the pipeline. As we feature organisations from various areas across the health and medical ecosystem, each issue has a distinctive mix of insights.

In this, our fourth issue, our authors address the risks to Australian health and medical research uncovered by COVID-19 and share their personal thoughts on how our sector can excel in post pandemic Australia.

Health data security is a major concern for health and medical researchers, and Chris Hancock, CEO of Australia's Academic and Research Translation Network (AARNET)shares advice from the frontline of data security and infrastructure for our sector. Championing data as a powerful research resource, Chris discusses the vital role of health data in the fight against COVID-19 and how researchers can safeguard patient data as the risk of breaches in our sector grows.

Victoria Bowring, the newly appointed CEO of Sanfilippo shares her insights as the leader of a small charity raising funds for research into rare and little-known conditions. Victoria shares her challenges in making the best possible investment decisions and leaning on years of experience, also sets the benchmark for turning small investments into mighty health outcomes.

Alastair Furnival, Principal Consultant at Evaluate, directs his renowned 'out of the box' thinking towards the future of collaboration between the natural sciences and humanities in public health. COVID-19 demanded multi-disciplinary collaboration on time sensitive public health decisions, Alistair now challenges us to ask who should be responsible for setting Australia's public health agenda as emerge and have the opportunity to leverage our 'gains'.o

COVID-19 has been an ultimate test of endurance for our sector's leaders and teams who have overcome pre-pandemic precedents to work smarter and more collaboratively.

Leadership shouldn't be a stoic calling and it is my hope that the collective wisdom of our amazing national alliance, including via this issue, sparks new ideas and opportunities for us all.



Nadia Levin,
CEO & Managing Director

Invitations to contribute to this publication are for Research Australia membership organisations only. Should you wish to enquire about membership to the national health and medical research peak alliance please contact us.
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Is your medical data safe?



Chris Hancock AM,
Chief Executive Officer,
AARNet (Australia's
Academic & Research
Network)

"Data" comes from the Latin "dare" meaning "to give". Data has given a lot, to researchers, industry leaders and society at large. No field more-so than in medicine, where the collection of data leads to transformative health insights.

But with giving there is taking. Large-scale medical data collection has made the industry vulnerable to cyber attacks and data breaches.

Theft of data for financial gain or geopolitical advantage is the dark power game of the digital era. Malicious attacks against Australian universities have become more prevalent and sophisticated in recent years due to the sensitive data and intellectual property they hold. A notable incident is the much-publicised Australian National University data breach in 2018.

Many major institutions in Australia have been subject to cyber-attacks. The main instigators are nation state-sponsored groups, criminal gangs and issue motivated groups, with information, financial gain and sabotage the main goals. Medical research is vulnerable to all these types of attacks. This endangers patient confidentiality and lives.

Last year, hackers launched a wave of attacks on coronavirus research facilities around the world. Russian hackers allegedly tried to steal COVID-19 vaccine information from research labs in the US, UK and Canada, with attribution linked to the same group that hacked networks before the 2016 US Presidential election. The US also accused Chinese hackers of targeting COVID-19 medical research groups and closer to home, the health sector in Australia was increasingly targeted by cyber criminals, with ransomware the most used attack.

In Europe earlier this year, stolen information relating to vaccines was released to the public by the perpetrators. Before its release, the information was modified as part of a disinformation campaign to discredit the vaccination programme. In another incident, two individuals were arrested for allegedly selling data from the Dutch health ministry's COVID-19 systems on the criminal underground. For governments, protecting the health sector is now a top priority.

But having your systems compromised is difficult, or nearly impossible, to avoid. Countries target systems to stay technologically ahead, such as the recent attack against an Australian defence contractor, while specialised groups attack simply for profit.

There is no cyber defence strong enough to protect everything in a system all the time. Even the best security systems have the same critical vulnerability: people. Cyber security costing tens of thousands of dollars can be undone by a staff member's weak password or the opening of a strange email.

The inaugural Australian Cyber Security Centre (ACSC) Annual Cyber Threat Report, July 2019 to June 2020, identifies ransomware, phishing and human error among the top threats for Australia. AARNet-instigated forums found this is true for universities in Australia and our global research and education network colleagues report similar problems for universities and research institutes in other countries.

There are efforts to fight back against these online threats. The ACSC advises AARNet to help improve the cyber security posture of our connected institutions, and in conjunction with the Australian Signals Directorate there are active measures to protect Australians through offensive cyber capabilities.

Despite these efforts, cyber threats will only increase in the future. This directly correlates with the increase in the availability of information and opportunities the internet provides society. The health and medical sector increasingly relies on data insights and the introduction of precision medicine will increase both the risk and benefit of medical data.

Last year the Australian government pledged $65 million in grant funding for precision medicine. Tailoring medical strategies, treatments and even genome mapping to specific groups and individuals means capturing unprecedented amounts of data – often of Australia's most vulnerable groups.

It's the omnipresence of the threat landscape that makes it necessary for us to have strong cyber security defences. This includes teaching good data hygiene through increased security awareness and positive messaging around collective approaches to security from everyone. Additionally, institutions must have well planned mitigation and response strategies to prevent worst-case scenarios.

The collection of medical data is a solemn pact between researchers and patients. It is a pact requiring confidentiality, accountability and empathy.

Because, in the end, medical data is simply too powerful not to use. The data-driven decision-making of the COVID-19 pandemic has exemplified this.

By sharing data, scientists around the world were able to map the SARS-CoV-2 virus genome, where they modelled its infamous molecular spike and use predictive models to combat viral spread.

University of Chicago researchers were able to develop the first full computational model of SARS-CoV-2 by combining microscopy observations and computer predictions. In the words of their team leader, Prof. Gregory Voth: "Each thing you know about the virus' life cycle and composition is a vulnerability point where you can hit it."

In Australia, the response to the COVID-19 pandemic by the research sector has been rapid and widespread, with the Doherty Institute's lab one of the first to grow the virus outside of China, the University of Queensland's vaccine development, ANU's mapping the spread of the virus in real time and CSIRO's work on a data privacy tool among a plethora of activities. In the background, AARNet has provided the networking infrastructure and collaboration services to support researchers undertaking this important work.

Research data is a vital component of the COVID-19 pandemic response and the historically quick vaccine development. Without computational tools, we would still be in the early days of understanding this virus: virologists hunched over desks, laboriously performing PCR experiments by hand while thousands continued to die with no end in sight.

This will not be the last pandemic. Environmental factors, food production methods, population density and the world's interconnectedness mean we will face more virulent diseases in future, not less. We need medical data, not just for our existing health, but to speed up our reaction to future threats.

New data analytics tools, machine learning and automated pipelines help researchers extract new meaning from large clinical and molecular datasets. This will let us respond faster to new outbreaks, but also help fight existing diseases and improve our general wellbeing.

Data isn't just numbers on a screen. It is a given. Each datum point is an indelible part of a person's health journey. When we take it, we must remember our promise to use it responsibly and keep it safe. History has too many examples of bad-faith science. As our data grow larger, so does our responsibility.

Turning small into mighty through strategic grantmaking



Victoria Bowring,
Chief Executive Officer,
Sanfilippo Children's
Foundation

Health and medical research in Australia is continually contributing to the improvement of the health and wellbeing of people all over the world. Often the ground-breaking research behind these improvements is funded by not-for-profit organisations and charities. Donors frequently have family and friends affected by the disease or condition represented by our organisations or are even affected themselves. They have both skin and heart in the game.

As grant makers in the world of health and medical research, we have a great responsibility to ensure donors' money is used for maximum impact. The research needs to be scientifically valid and significant, conducted by researchers with the right skill sets and facilities. It needs to be both timely and achievable, relevant to the community that it ultimately serves to benefit and represent value for the investment. It also needs to be innovative, collaborative, and strategic. This is no small ask, particularly in the rare disease space. So how do we as grant makers, often small organisations, representing communities affected by rare and little-known conditions, ensure that we make the best possible research investment decisions? How do we take small and turn it into mighty?

Strategic grant making can be both responsive and proactive, but both require a considered framework and robust processes to ensure the most valuable research is funded. A strong research strategy and a clear and structured grant management process maximises the impact an organisation can have regardless of the size of the funding pot. That all said, the idea of developing research strategies, robust grant management processes, competitive grant rounds, targeted calls and research roadmaps can be a daunting one.

It is through collaboration across the collectives of internal and external stakeholders in organisations that the daunting becomes doable. Internal stakeholders such as strong research program staff, a multidisciplinary Scientific Advisory Board, engaged and diverse patient representatives and a passionate and "well informed" Board of Directors, all working together to assess potential research projects is vital to a robust grant making process. External stakeholders such as international (or other national) organisations supporting the same or related conditions, hospital foundations, government and philanthropic individuals willing to invest in and support collaborative projects have an important role in amplifying the impact of strategically funded research.

Having a research strategy, particularly in the case of rare diseases, is a priority. However it doesn't need to be complex, it simply needs to be clear and include:

- the organisation's mission and purpose to ensure focus;
- prioritised outcomes such as prevention, stopping or slowing disease progression, long term goals of repairing damage and/or a focus on symptoms with the aim of improving quality of life in the here and now;
- clarity around the types of research to focus on (ie. are you building lines of research, e.g. incubator, translational grants, and/or are you building research capacity in the field, e.g. scholarships and fellowships);

- cross-disciplinary collaborations;
- collaborations across multiple research institutes; and
- co-funding opportunities with both national and international partners.

The strategy then becomes the lens through which our grant making should be viewed, whether it be via competitive grant rounds and unsolicited requests and proposals (responsive) or via targeted calls and commissioned research (proactive). This ensures organisations stay on track rather than being distracted by exciting opportunities that may not necessarily meet long term priorities, goals and objectives.

The responsive path to funding research provides an opportunity for organisations, especially in rare disease, to connect with new researchers and their institutes within the dedicated field. It also connects them with those in indirectly related or even unrelated disciplines and can unearth new and innovative ideas and projects that otherwise may not be known about. However, this also means that the research may be largely driven by the priorities of the researchers which, whilst not a negative thing, is one of the considerations for having a clear research strategy that sets out the priorities of the community as a whole.

Proactive research via targeted calls and commissioned projects is becoming more common as organisations identify priorities and gaps in research themselves, often in consultation with researchers, clinicians, patients and families. This focussed approach highlights potential new areas of benefit and directions that will have the greatest impact for patients both in the short and long term. Developing such a “research roadmap” can result in accelerated progress which, at the end of the day, is everyone’s priority.

With every good research strategy comes the need for a strong and effective process for implementation. For many organisations that fund research, especially those that are small e.g. parent led charities, this can be challenging and overwhelming. In the absence of any best practice guidelines or a one size fits all solution, when it comes to grant review processes we are forced to rely on trial and error or to reinvent the wheel. Or are we? What if we all shared what we have tried and tested? After all, like the many different rare diseases that share many commonalities, there are many different organisations that share common challenges when strategising and grantmaking.

“Tried and tested” shows that initial expressions of interest quickly highlight proposed projects aligned with the research strategy and can then reduce the number of detailed applications that need to be thoroughly reviewed. Having a strong Scientific Advisory Board or Committee following structured assessment criteria then provides validation of the scientific relevance, methodology and plausibility from different perspectives but within a common framework.

“Tried and tested” shows that external peer review potentially provides international perspective along with expert opinions on specialised topics. Likewise, there are many tried and tested models for consumer engagement in the grant review process that can help to prioritise projects that are of greatest importance to the patient community. A final review of the shortlist by a well informed and passionate Board of Directors that were instrumental in the development of the research strategy provides comfort for the organisation that the projects are aligned with the strategy and the potential return on the research investment is significant.

Hundreds of organisations around Australia have valuable tried and tested processes and frameworks for their health and medical grant programs. When these organisations share with others what they have tried and tested, strategic grantmaking becomes far less daunting. When organisations share skills and resources the daunting, becomes doable. And when organisations share knowledge, processes, resources, networks, time, projects and funding - small becomes mighty!

Will COVID elevate the role of science in public policy?



Alastair Furnival,
Principal,
Evaluate

One of the happier consequences of the COVID era has been the rapid increase in recognition and respect for public health leaders. Our Chief Medical Officers (CMOs) have never been held in higher esteem.

This offers an important opportunity to rebalance health policy. Previously, most political debate about health has been driven by short term considerations: will there be enough funding for the drugs and doctors I need if I or my family fall ill? Public health activity has mostly been relegated to campaigns to remind us that smoking is fatal whereas sunscreen is lifesaving.

In contrast, the last year of café conversation (where cafés were permitted) has included consideration of what infrastructure is required to quickly respond to an epidemic, and whether lockdowns, masks, travel bans and vaccinations were being appropriately handled.

This is encouraging, and suggests a new dawn for the influence of scientific evidence in public policy. But whether it is a true watershed moment remains unclear, and the future role of scientific analysis in public policy remains in doubt.

Much of what inspires this doubt is cultural, and certainly nothing new. A little over 60 years ago, in his notorious Rede Lecture, CP Snow rued the divide between the 'two cultures' of arts and sciences, recalling the Cambridge mathematician GH Hardy's 1930s lament that the popular definition of an 'intellectual' appeared to exclude himself and physicists such as Ernest Rutherford and Paul Dirac.

The problem with this partition is that it is 'intellectuals' who provide the foundation for public debate and public policy. And in a Parliament filled more with lawyers than scientists, there is a tendency to rely on the thinkers who speak one's own language.

Snow's solution to this problem was, in part, less specialisation in education to bridge the gap and allow productive intercourse between the two cultures.

Notably, this approach was derided by (the undoubted intellectual) Allan Bloom in his 1987 Closing of The American Mind, in which he reduced Snow's thesis to what - in the 1959 Rede lecture - reads purely as an illustration: humanists learning the second law of thermodynamics, and physicists reading Shakespeare.

For Bloom, the problem isn't cultural, rather one of keeping the focus on excellence in individual fields:

"For the scientist, the humanities are recreation (often deeply respected by him, for he sees that more is needed than what he offers, but is puzzled about where to find it), and for the

humanist, the natural sciences are at best indifferent, at worst alien and hostile."

Bloom's concern is a counterpoint to Snow's: if we insist on a broader education, we risk making it shallower.

Whichever analysis (if either) we accept, the problem of poor dialogue between science and the humanities is not restricted to the Northern Anglosphere. Closer to home, David Williamson's 1974 dramatization of his time at Swinburne Tech – The Department - has arts and engineering academics exchanging the mutually-excluding insults of 'illiterate' and 'innumerate'. Williamson is an engineer turned playwright, so he has a unique understanding of the divide between sciences and humanities.

There's no doubt much has changed since these works were written, including improvements in the rate and extent of education, and the substantial growth of the public service.

But still, it remains unclear to what extent scientific and other evidence generally trumps populism, both at the government level, and in the community mind. We certainly have the dominant climate change consensus of: 'the science is in'; but for many decision-makers this seems more redolent of a mantra than technical engagement with the evidence, and it is clearly not successful in driving current Australian policy.

At the same time, various voices competing with our public health leaders' analysis, particularly the more shrill prophets, can undermine public confidence in those we should trust. In particular, the dire warnings about side-effects of various vaccines say more about media appetite for drama than they do about the relative safety of urgent medicines. One wonders how many people would follow their normal daily prescription if it were subjected to this level of constant sensationalised scrutiny. Equally, and while it may be grist for the mill of politics, discouraging vaccination uptake while criticising the progress of the rollout lacks a coherent internal logic.

Since Snow and Bloom offered their theses on the role of science in intellectual life, the rate of technological and social change, and the increase in both the store of knowledge and the complexity of work, have been so great that perhaps the question has changed. For most of us specialisation has only increased, while at the same time we need a broader understanding of different roles which intersect with our own.

The question may now be whether we understand enough to judge to whom we might best listen. In the case of COVID-19 we have been, out of necessity, happy to cast our lot with the scientists. Hopefully it's not an experience we forget when normal service finally resumes.

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