

# Research and innovation as core functions in transforming the health system

A vision for the future of health in Australia



Australian Academy of Health and Medical Sciences



The Australian Academy of Health and Medical Sciences acknowledges the traditional custodians of the lands on which our offices stand and on which we hold our meetings and events across the country. Aboriginal and Torres Strait Islander peoples were the nation's first scientists, and they remain the spiritual and cultural custodians of their land. We pay our respects to elders past and present. We especially thank those who have shared their knowledge and perspective as this project has progressed.

The Australian Academy of Health and Medical Sciences would like to thank the working group Chair, Professor Christina Mitchell AO FAHMS, for her leadership of this project, and all members of the working group for their significant contributions and commitment to this work. The Academy would also like to thank the review group, roundtable participants, interviewees, survey respondents and all other individuals who contributed to the project.

The Chair would like to thank the Academy's secretariat, in particular Catherine Luckin and Lanika Mylvaganam, for their support for the working group.

This report is published by the Australian Academy of Health and Medical Sciences. It was developed by the working group, reviewed by an independent external review group, and approved for publication by the Academy's Council.

Funding for the production of this report has been partially provided by the Australian Government. The views expressed in this report do not necessarily reflect the views of the Australian Government.

All references were accessed in August 2022.

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Date of publication: October 2022

Suggested citation: Australian Academy of Health and Medical Sciences (2022). *Research and Innovation as Core Functions in Transforming the Health System: A Vision for the Future of Health in Australia.* www.aahms.org

# About the Australian Academy of Health and Medical Sciences

The Australian Academy of Health and Medical Sciences is the impartial, authoritative, crosssector voice of health and medical science in Australia. We advance health and medical research in Australia and its translation into benefits for all, by fostering leadership within our sector, providing expert advice to decision-makers, and engaging patients and the public.

We are an independent, interdisciplinary body of Fellows – elected by their peers for their outstanding achievements and exceptional contributions to health and medical science in Australia. Collectively, they are a representative and independent voice, through which we engage with the community, industry and governments.

The Academy is uniquely positioned to convene cross-sector stakeholders from across Australia to address the most pressing health challenges facing society. We focus on the development of future generations of health and medical researchers, on providing independent advice to government, and on providing a forum for discussion on progress in health and medical research with an emphasis on translation of research into practice.

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## **Executive summary**

Australia's health system is facing significant challenges. An expert committee convened by the Australian Academy of Health and Medical Sciences has prepared this report to argue a case for urgently developing and implementing plans to further integrate health and medical research and innovation within the health system, in order to transform health outcomes for the community, enhance health system management, and optimise the economic benefits of Australian innovation.

During the COVID-19 pandemic, health, research and innovation worked together to deliver an effective response to one of the biggest health threats in a generation, based on the best available evidence. We must use this experience to turbocharge improvements across the health system that will ensure we can address current and future health challenges facing the nation.

Australia's health system and our health and medical research and innovation sector are both individually outstanding and competitive on the world stage. However, by bringing them into closer alignment, Australia can elevate both sectors and create a world-leading health system, which is driven by cutting-edge research and the latest evidence. As demonstrated in this report, this strategy has been shown to be effective internationally.

We believe this is possible in Australia, and we have a vision for a system and culture that embeds research and innovation as core functions. It is built on four pillars that use the current environment as a springboard to create a research-rich health system in Australia, outlined in Figure 1 below.

The conclusions, recommendations and commitments set out in this report outline a three-year plan that we believe will set Australia on a path to:

- address the ongoing challenges of delivering high-quality healthcare, and bring about more effective, more efficient care that meets the needs of the community
- further build health and medical research and innovation as a sector of the economy, which is in increasing demand and which brings substantial growth opportunities
- continue to improve the quality of care and patient outcomes
- deliver better patient and staff experiences
- generate a world-leading health and medical research environment that fosters innovation and attracts global investment.

Our vision and the underlying pillars provide a blueprint for the whole system to work together to build momentum towards these aims and deliver impactful change. This report will be of interest to governments, health service providers, research funders, consumers, academia, health professionals, clinician researchers, medical research institutes, industry, policymakers, and peak and professional bodies.

### Our vision:

A system and culture that embeds research and innovation as core functions of the health system

### Pillar one

## A skilled and enabled workforce

A research-active health workforce – at the heart of which sits a cohort of world-class clinician researchers – underpins an integrated, continuously improving health system

### Pillar two

#### Targeted funding for research and innovation

Australia maximises the value of current investments to increase research funding embedded in the health system, driving translation and improving health outcomes

### Pillar three

#### Consumer and community involvement

The whole community has more equal opportunities to shape, participate in and benefit from research that is relevant to them, as active and valued partners

### Pillar four

#### Integrated teams and cross-sector collaboration

An active healthacademia-industry interface works dynamically to enable fully integrated research teams, supported by healthcare executives and research institution directors

Figure 1: The Academy's vision for embedding research and innovation in the health system and the four underlying pillars for delivering that vision

# Current challenges facing the health system

Australia's health system delivers high-quality care, and our population experiences an aboveaverage overall health status compared to other OECD countries.<sup>1</sup> Nevertheless, the system faces considerable challenges. Many of these are not unique to Australia, but rather, signify the emergence globally of more complex health needs over time. Our population is ageing, and many more people are living with chronic and complex conditions, increasing demand on health services. One in five people in Australia have experienced a mental health condition, and there are considerable inequities in health outcomes and access to care.<sup>2-5</sup> Antimicrobial resistance is a growing threat, and climate change is an urgent health priority. New technologies are continually evolving and offer opportunities for better health, but must be integrated appropriately to reap the benefits.

Additionally, we face new health issues, with the COVID-19 pandemic providing a stark example of the additional health burden that an unexpected disease outbreak can create.<sup>6</sup> The pandemic has taken its toll on Australia's health system and on the staff who provide world-class care to Australians every day – further exacerbating existing issues, reflecting international experience.7 There have been delays in surgery, increased demands on emergency departments resulting in capacity overflow and ambulance ramping, and staff reports of very challenging work environments with high levels of burnout.<sup>6,7</sup>

A combination of these and other factors have led to an inevitable increase in the costs of maintaining a quality, safe and affordable health system for all.

Health system expenditure is rising faster than economic growth and is predicted to do so until 2030 in almost every OECD country.<sup>8</sup> Australia is no exception – we currently spend 10.2% of GDP on health, and the OECD projects that this will rise to 13% by 2030.<sup>1,9</sup> Compounding this trend of increasing expenditure, it has been estimated that, on average, only 60% of healthcare aligns with evidence or consensus-based guidelines.<sup>10</sup> Within the remaining 40% a considerable amount is comprised of some form of waste or is of low value (30%) and, alarmingly, 10% of care is associated with harm.<sup>10</sup> This suggests that there are inefficiencies in the system, and illustrates the urgent need to get research translation right. This is more likely to happen where research and innovation are integral to healthcare delivery.

We believe that hospitals and health services can better integrate and invest in research and innovation to drive and sustain improvements for the whole population.

# Research and innovation to drive improvement in health

Embedding high quality research and innovation in healthcare can fast-track Australia's efforts to rise to the multiple challenges facing the health system outlined above. Implementing health and medical research findings throughout the health system will result in improved health outcomes. Despite the current economic climate, Australia can, with the right focus and strategies, use existing resources in health, research and innovation to improve health outcomes.

International evidence tells us that research-rich health environments are better for patients and staff, delivering higher quality of care, reduced mortality, improved patient experience, increased staff satisfaction, and more efficient uptake of new innovations (as explained in Chapter 2). Indeed, a culture of enquiry and improvement in health delivery settings brings benefits that:

- extend beyond the patient population involved in a particular trial or study
- are not restricted to academic or universityaffiliated services, but are also seen in smaller local hospitals, primary care settings and public health systems.

- cannot simply be attributed to practical factors that might be associated with research activity, but relate to the presence of research and clinician researchers
- occur across a range of specialties and disease areas.

We know this is also an approach that patients and the public support. Australian consumers consistently rank health, including health research and innovation, among the most important areas for public investment, recognising the value of health and medical research in delivering societal benefits.<sup>11</sup> Data from 2022 show that most Australians think medical research is vitally important to the country's future, and 83% agree that medical research plays a critical role in securing Australia's health and prosperity.<sup>12</sup>

"By taking part in a clinical trial, I can contribute to the advancement of scientific knowledge and in some cases improve health for myself and others"

Roundtable participant (consumer)

#### In short: research and innovation should be core functions of the health system, and integral to patient care.

Building a health system in which research and innovation are better integrated will also benefit research institutions and help Australia reap economic benefits, since we know that, at the national level, investing in health research and innovation:<sup>13-17</sup>

- drives economic growth and productivity
- creates jobs
- opens up opportunities for commercialisation and inward investment.

## How can Australia harness these benefits to improve health?

Australia has established a strong platform for reaping the benefits of research to improve the health of our patients and communities. It is home to a vibrant health and medical research and innovation ecosystem.<sup>18-20</sup> Australia's researchers are some of the best in the world. Discoveries and innovations here in Australia have had profound impacts on health at home and globally. This has been brought into sharp focus by the pandemic. Never has the importance of being able to efficiently undertake and translate research in a health setting been so clear, and so dependent on basic biomedical research – translation is not possible without discovery.

However, as a nation we are not reaching our full potential of making research and innovation core functions of the health system. There are barriers that prevent us from doing so, which need to be addressed. Throughout our project, we heard the same message from across sectors, disciplines, professions and career stages: the key is an organisational culture that values research and innovation. One senior healthcare executive summed it up when they said, "I think when it comes to setting up a good system that supports research, it starts with leadership, it starts with having the right culture, and having a vision and strategy that embeds research into it."

The health system does not currently harness all the benefits that research and innovation offer. We have not put in place the mechanisms to underpin such a culture. For instance, clinician researchers (who combine clinical and academic roles) are central to a workforce that can embed research in the health system. At present, we do not know how many clinician researchers there are in Australia, and they have no clear training pathway and face many barriers in pursuing this career path.

The contribution of federal, state and territory government expenditure to health and medical research is not clear, making it difficult to assess the efficiency of the system, where the investment is "We know that all the best hospitals around the world are academic hospitals that are renowned for their research."

Roundtable participant (healthcare executive)

occurring and who is paying. In addition, coordination across the research pipeline from bench to bedside, and then into clinical practice and health policy, is not set up to enable innovation for patient benefit. This is indicative of the need for better integration across the fragmented components of Australia's system – across state, territory and federal governments, public and private health services, primary and acute care, public health, rural, regional, remote and urban settings, and at the academia– health–industry interface.

These challenges are not new. Researchers, health professionals and others across the sector have been calling for this for decades – for instance, many of the same issues were raised in the 2013 McKeon Review.<sup>21</sup> Many positive changes have been implemented as a result, but there is still much work to be done, especially at the interface of health, academia and industry.

Our three-year plan involves 14 Recommendations. While all recommendations are equally important, to facilitate planning and delivery, we identify the priorities that are most urgent — an overarching recommendation and one recommendation under each of our four pillars:

• The Australian Government and the state and territory governments should establish an inclusive, continuing mechanism that is empowered to develop and implement strategies for embedding research and innovation as core functions of the health system. An Australian alliance for transforming healthcare through research would bring key partners together to enable collective working towards this aim.



- The Australian Federal Government should develop a national strategy and implementation plan for building a world-class clinician researcher workforce, including a formal, harmonised clinician researcher training and career pathway. The strategy should be developed in partnership with state and territory health departments, and should address issues such as the need for a standard dual employment contract template for clinician researchers.
- The Australian Federal Government should introduce a mechanism for stronger strategic harmonisation between funders, particularly the NHMRC and the MRFF, so that there is an optimal coordinated research response to established and new threats to the nation's health.
- A more consistently applied framework should be developed to improve and broaden consumer and community involvement in health and medical research. An Australian alliance for transforming healthcare through research would provide the leadership necessary to achieve this outcome. This work should be supported from the outset by consumer members and a consumer advisory panel.

• The NHMRC-accredited Research Translation Centres should receive meaningful, continuing funding to stimulate the formation of integrated research teams at their local health-academiaindustry interface.

### The role of the Academy

Our vision, described in this report, will help cultivate a system and culture that embeds research and innovation as core functions of the health system. It is based on a wide-ranging evidence-collection process that drew on the expertise, perspectives and lived experience of individuals from across health, academia, industry, government and consumers, as well as evidence from national and international literature.

We are deeply committed to advancing this important agenda, and throughout this report, we outline our own commitments, as Australia's Learned Academy for the health and medical sciences, to support this work. We will work in partnership with all relevant stakeholders to bring our vision to fruition and ultimately benefit of the nation's health.

#### EXAMPLES OF CURRENT HEALTH SYSTEM CHALLENGES AND PRESSURES



Ageing population Proportion of Australians aged over 65 will increase from 16% today to as high as 23% in 2066



Chronic diseases 50% of the population have at least one chronic condition



Mental health 1 in 5 Australians have experienced a mental health condition

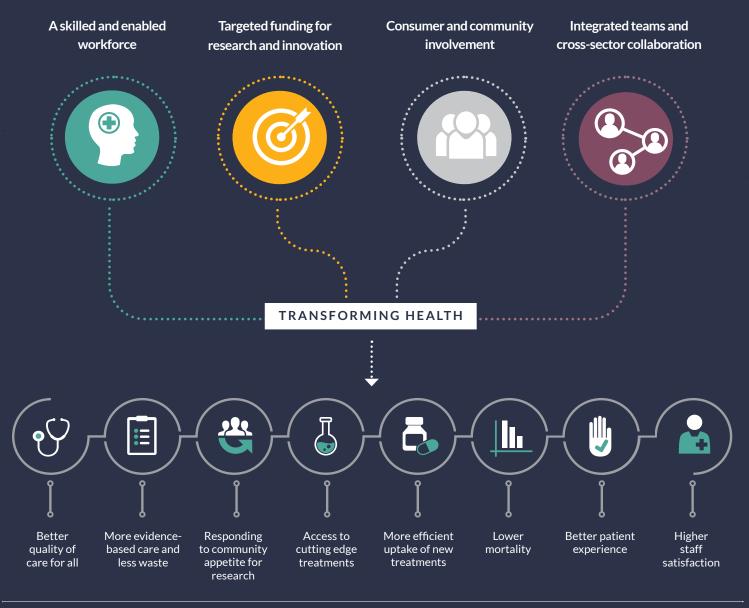


Managing demand 50% of patients waited at least 48 days for elective surgery in 2020-21



Infectious diseases COVID-19 state and territory health responses and vaccine rollout have cost the Australian Government \$11.6bn

## To solve these challenges research and innovation must be embedded as core functions of the health system through:



Sources

Ageing: bit.ly/vision-ageing Chronic diseases: bit.ly/vision-chronic diseases: Mental health: bit.ly/vision-mentalhealth Managing demand: bit.ly/vision-demand Infectious diseases: bit.ly/vision-IDs

## Recommendations

The Academy proposes these recommendations as a three-year plan, with five key priorities identified for more urgent action. We are keen to work with partners to advance these recommendations, and will undertake an evaluation at the halfway point to track progress.

### Overarching

PRIORITY: The Australian Government and the state and territory governments should establish an i and innovation as core functions of the health system. An Australian alliance for transforming health of the state and innovation as core functions of the health system.

### Pillar one: A skilled and enabled workforce

2. PRIORITY: The Australian Federal Government should develop a national strategy and implementation plan for building a world-class clinician researcher workforce, including a formal, harmonised clinician researcher training and career pathway. The strategy should be developed in partnership with state and territory health departments, and should address issues such as the need for a standard dual employment contract template for clinician researchers.

3. Academic institutions and health service providers should work in partnership to support and grow the clinician researcher workforce by establishing formal clinician researcher positions that incorporate time in clinical service and research, and allow for flexible arrangements for different individuals.

4. Professional bodies should work with governments to develop clinician researcher training pathways and implementation plans that deliver clear provision of functional pathways across the full spectrum of clinical training.

- For medicine, this means working with the Specialist Medical Colleges, which should provide flexibility for clinical trainees to take up research training opportunities, and should appropriately recognise and incentivise research activity and its implementation as part of training and continuing professional development.
- For nursing, midwifery and allied health, this means working with universities, state and territory health departments, health providers and industrial bodies to develop systems and structures that enable individuals who undertake research training to continue their careers as clinicians.

5. For health professionals undertaking research, but not formally as clinician researchers, health providers should recognise these activities as a core part of position descriptions, and should allocate dedicated time for these endeavours.

### Pillar two: Targeted funding for research and innovation

6. The Australian Federal Government should increase the NHMRC's budget beyond indexation over the next five years to return investment to at least 2010 levels in real terms.

PRIORITY: The Australian Federal Government should introduce a mechanism for stronger strategic harmonisation between funders, particularly the NHMRC and the MRFF, so that there is an optimal coordinated research response to established and new threats to the nation's health.

O. The Australian Federal Government should provide greater transparency in the use of public funds for health and medical research, to ensure optimal alignment between national priorities for research and the application of resources.

### recommendation

nclusive, continuing mechanism that is empowered to develop and implement strategies for embedding research are through research would bring key partners together to enable collective working towards this aim.

### Pillar three: Consumer and community involvement

PRIORITY: A more consistently applied framework should be developed to improve and broaden consumer and community involvement in health and medical research. An Australian alliance for transforming healthcare through research would provide the leadership necessary to achieve this outcome. This work should be supported from the outset by consumer members and a consumer advisory panel.

10. Health and medical research funders should allow the included in grant proposals as direct research costs, and should work towards including consumer and community involvement as an essential element of relevant research projects, ultimately making it a criterion for success of those applications.

11. Those measuring research impact and researcher track records should incorporate measurements that place greater value on work to develop community and consumer involvement, including with priority populations such as Aboriginal and Torres Strait Islander communities – as an acknowledgment of not only the importance of these endeavours, but also the time commitment required to do them meaningfully. Examples of where this is needed include:

- criteria that research institutions use for staff promotions
- prioritising advice from NHMRC Consumer and Community Advisory Group (CCAG) in relation to NHMRC funding mechanisms
- criteria applied to MRFF funding mechanisms
- Australian Research Council (ARC) Engagement and Impact Assessment.

### Pillar four: Integrated teams and crosssector collaboration

12. PRIORITY: The NHMRC-accredited Research Translation Centres should receive meaningful, continuing funding to stimulate the formation of integrated research teams at their local health-academia-industry interface.

13. The health and medical sciences sector should establish targeted programs to build a generation of cross-sector knowledge brokers who can collaborate and mobilise across health, academia and industry to drive Australian research and innovation in health and medicine.

14. Healthcare providers and academic institutions should collect and publish data on the clinician researcher workforce.



## Introduction

The landscape for health and for health and medical research and innovation has changed substantially over the past decade in Australia. The recent census ranks mental health, asthma, diabetes, and heart disease as some of the most prevalent chronic diseases.<sup>22</sup> The challenges facing the health system reflect the existing and new complex health needs of the population. We now experience higher rates of chronic disease, poorer mental health and have an ageing population.<sup>23</sup> The COVID-19 pandemic provided a stark example of an unexpected and unprecedented health burden that can significantly impact every aspect of the health system.<sup>23</sup>

Establishing health and medical research and innovation as core functions of the health system can help tackle these challenges. However, the health system and the health and medical research and innovation sector still largely operate separately. Closer alignment is needed to improve health, economic and societal outcomes, and to improve quality, safety, and workforce recruitment and retention.

In 2013, the "Strategic Review of Health and Medical Research" (the McKeon Review), investigated the

state of health and medical research in Australia and made recommendations about the strategic direction of the sector. The review provided a detailed analysis of areas such as research funding, commercialisation, infrastructure needs, and workforce training and development.<sup>21</sup> It set a path to 2020 and beyond for improving the efficiency of health and medical research and innovation, and ways of working at the nexus of research and its implementation. The review made <sup>21</sup> recommendations that have led to important improvements, including the formation of the Medical Research Future Fund (MRFF) and Australia's research translation centres.

It has been almost a decade since the McKeon Review was published. It is therefore timely to take stock of the review outcomes and the opportunities to further advance the impacts of health and medical research and innovation on the country's health. As the nation's Learned Academy for health and medicine, and an independent and expert voice, the Australian Academy of Health and Medical Sciences is ideally placed to identify a way forward.



### **Project delivery**

### Working group

The project has been overseen by an expert working group chaired by Professor Christina Mitchell FAHMS, Dean of the Faculty of Medicine, Nursing and Health Sciences at Monash University. The working group, made up of 15 of Australia's health and medical research sector leaders, provided experienced perspectives from across the sector, disciplines, specialties and professions. The working group members are listed in Appendix A. The group's expertise spans healthcare, health services, biomedical research, health economics, public health, health policy, and Aboriginal and Torres Strait Islander health. The working group met every 4-6 weeks between March 2021 and July 2022. They undertook an extensive evidence collection process to capture perspectives from a wide range of stakeholders to inform the report.

#### **Evidence collection**

In 2021 and 2022, the Academy heard from over 260 individuals who contributed perspectives from a diverse range of backgrounds, disciplines and sectors through a series of roundtables, individual interviews and an open survey.

Roundtables and interviews explored the following themes:

- Senior healthcare administration
- Early-career research
- Mid-career research
- Research translation
- Research funding
- Research leadership
- Health and medical technology
- Drug development and clinical trials
- Aboriginal and Torres Strait Islander health and research
- International health and medical research

# More than 260 contributors

# From all eight states and territories

Including 31 consumers

Through these roundtables and interviews, we spoke to healthcare professionals (across medicine, nursing and midwifery, and allied health), researchers, research funders, healthcare administrators, consumers, industry representatives, peak body representatives, charitable and philanthropic funders, government representatives, Aboriginal and Torres Strait Islander researchers, and individuals from rural and remote settings. Contributors can be seen in Appendix B.

### **Desktop research**

In addition to widespread consultation, the project included desktop research to identify key gaps and opportunities, as well as local and international examples of health and medical research and innovation embedded in health systems.

#### **Report review**

The report has been reviewed by an external independent panel appointed by the Academy's Council. The review group membership (listed in Appendix A) incorporates relevant expertise across the breadth of the report. The review process was undertaken to ensure the report meets the project terms of reference, is informed by an extensive process of evidence collection, and makes formal recommendations on the basis of that evidence. Review group members were not asked to endorse the report, its findings, or its recommendations.

### Project objectives and scope

#### **Project terms of reference**

The working group was tasked by the Academy's Council to develop a high-level vision for strategically embedding research – and its effective and efficient translation – into the health system, and to identify practical steps required to deliver it and improve health outcomes. The working group was asked to undertake an evidence collection process and produce a report to address the following project terms of reference:

- Bring together national and international evidence on the value of embedding research in the health system, to inform an Academy position on the place of research in the delivery of health in Australia.
- Describe the current stakeholder roles and responsibilities associated with embedding and translating research in the health system, and identify how the current landscape should be developed to improve the process of embedding and translating research.
- Identify the most significant barriers to effective interaction and partnership between academia and the health system, and solutions to address those barriers.
- Identify targeted recommendations, and the associated key stakeholders, to deliver the Academy's vision, including priorities for action and timelines for implementation.

### **Project scope**

In reporting on these terms of reference, the project reflects on relevant recommendations from past work, including the McKeon Review – identifying progress made, impacts seen, and remaining or emerging priorities that will help see the aspirations of that review further advanced. We also reflect on how research has been conducted in health settings during the pandemic. The project considers relevant aspects of basic, clinical (including medicine, nursing, midwifery, and allied health), public health and health



services research, across primary care, the hospital sector, community care, and aged care.

There are many parts of the ecosystem that, while important, were beyond the scope of this study:

- detailed analysis of the regulation and governance of health research (e.g. approvals/ ethics processes)
- review of specific grants structures/ awards processes
- review of the barriers associated with commercial translation.

While we may indicate their role in the overall picture or recommend further work, the working group was not asked to make specific recommendations in these areas.

### **Project audience**

This report is aimed at Australian governments and policymakers – federal, state and territory – health service providers (administrators, executives and managers), academic institutions including universities and medical research institutes (MRIs), research funders, researchers at all levels, health professionals, Medical Colleges, regulatory bodies, industry, and the public. It is not limited to those with expertise or specific interest in health or in health and medical research and innovation.

### **Report structure**

Following the Executive summary, this report comprises eight chapters:

#### 1. Introduction

This chapter sets out our rationale for undertaking this project and provides an overview of the project approach.

# 2. A research-rich health system is better for health and patient care

This chapter draws on international evidence to highlight the value of research rich health systems in improving patient outcomes and quality of care.

#### 3. Setting the right culture

A research and innovation culture that sits at the heart of our health system is crucial to the Academy's vision of embedding these endeavours as core functions to improve the nation's health. This chapter outlines some of the key drivers to this culture shift, including the need to enable a coordinated and collective approach more proactively.

#### 4. Pillar one: A skilled and enabled workforce

A research-active health workforce underpins an integrated, continuously improving health system. This chapter details the need to nurture the workforce, including clinician researchers, to drive culture change and accelerate the beneficial impacts of research and innovation on healthcare systems and outcomes.

# 5. Pillar two: Targeted funding for research and innovation

Achieving an optimised health system will depend on strategic and coordinated funding that supports research and innovation embedded in health. Australia can maximise the value of existing investment to boost the benefits of embedded research. This chapter explores current funding mechanisms and proposes opportunities to optimise their use.

# 6. Pillar three: Consumer and community involvement

This chapter explores the importance of consumer and community involvement in health and medical research by considering the ethical and moral imperatives for conducting this type of research, and the overarching benefits for research design, interpretation, implementation and dissemination.

# 7. Pillar four: Integrated teams and cross-sector collaboration

Integrated teams and cross-sector collaboration are critical to advancing a research-rich culture within the health system. This chapter highlights the importance of integrated teams, and the role of the health-academia-industry interface in bringing ideas and people together to ensure research and innovation are embedded as core functions of the health system.

#### 8. Conclusion

We conclude by summarising how each of our four pillars could contribute to a future system in which research and innovation are successfully integrated as core functions of the health system.

2. A research men. for health and patient care A research-rich health system is better

### **Key messages**

- There is consistent and growing evidence that health services that integrate research and innovation as core functions see direct benefits in patient outcomes and quality of care, compared to those that are less active in research. This includes reduced mortality, more efficient and cost-effective care, better patient experience, benefits to staff recruitment and retention, and more efficient uptake of new innovations.
- Outcomes extend beyond patients involved in individual studies and trials, and benefits are not restricted to academic centres or large institutions.
- Engaging in research provides potential • opportunities for Australian hospitals and health services (including public health) to enhance their performance against KPIs associated with patient outcomes and quality of care.
- Analysis of clinical trials shows that efficient • implementation of results into clinical practice is associated with improved health outcomes and reduced health service costs. One study found overall cost savings of \$5.80 for every \$1 invested in trials.
- Research findings add weight to calls for research to be better embedded in the Australian health system.

"Patients will have access to the latest trials and treatments if research is embedded in the clinical care"

Roundtable participant (healthcare executive)

### Introduction

- There is mounting evidence to suggest that health services that actively participate in research and innovation perform better in several aspects of patient care, including reduced mortality, higher quality of care, more efficient and cost-effective care, better patient experience, benefits to staff recruitment and retention, and more efficient uptake of new innovations. In fact, these benefits often:
- extend beyond the patient population involved in a particular trial or study
- are not restricted to academic or universityaffiliated services, but are also seen in smaller local hospitals, primary care, and public health systems
- cannot simply be attributed to practical factors that might be associated with research activity, but relate to the presence of research and clinician researchers
- occur across a range of specialties and disease areas.

A 2015 review article analysed 33 papers on this topic and concluded that research engagement by clinicians and healthcare organisations is associated with improved performance in terms of both health outcomes and processes of care (such as whether guidelines are followed, or a particular treatment used).24

This chapter outlines key findings around the various ways in which patients benefit from research-rich health systems.

## How can hospitals and health services benefit from research and innovation?

### **Reduced mortality**

Several studies show that mortality rates are lower in research-active settings. For example, a 2015 study from the UK looked at patient outcomes for acute admissions and found that the most research-active National Health Service (NHS) Trusts (local groups of hospitals and service providers) had the best emergency mortality outcomes.<sup>25</sup> Since this study looked at acute admissions, the researchers were able to show that better outcomes were not limited only to research participants (because fewer patients are enrolled in research in these settings). In addition, further analysis showed that these outcomes were not simply the result of better staffing numbers or other structural factors that might have improved in the presence of research; the improvements were still seen after the results were adjusted for these factors. Research in 2018 reinforced these findings using a broader data set over a longer period higher research activity was associated with lower Summary Hospital-level Mortality Indicator scores, which measure deaths in hospital or within 30 days of leaving hospital.<sup>26</sup>

In the above studies, research activity was measured in terms of research funding or patient recruitment into studies. Using a different measure of research activity still shows the same outcome. Another study used academic output (measured by citations), and found lower mortality rates in settings with higher academic output.<sup>27</sup>

Building on these general findings, such outcomes are also evident in specific disease areas. In oncology, a UK study of people with colorectal cancer found that NHS Trusts with high research participation had a lower risk of death after surgery, and better longterm survival rates for all colorectal cancer patients – not just those in a study. Moreover, outcomes improved even further for NHS Trusts with a high level of research over a sustained period: those deemed to have a sustained high level of research saw a 3.8% improvement in survival and a 1.5% decrease in mortality. These improvements were not restricted to academic centres or large institutions, but were seen across all colorectal cancer care settings, and were still seen after the results were adjusted for other possible causal factors associated with research activity.<sup>28</sup> In cardiology, a US study found that patients treated at hospitals participating in trials had significantly lower rates of mortality (from all causes) than those not participating in trials.<sup>29</sup>

### Higher quality of care

Quality of care also appears to be higher in researchactive settings. Indeed, studies have measured quality in multiple ways, but still get consistent results.

Better treatment usually improves survival. Therefore, one measure of care quality is adherence to the latest evidence-based clinical guidelines. A German study of people with ovarian cancer found that patients treated in hospitals involved in research studies were more likely to receive treatment in accordance with national guidelines. In fact, patients in such hospitals were twice as likely to receive standard treatment as those in non-study hospitals. The sub-optimal treatment was associated with lower survival rates - for those with advanced disease, the median overall survival time for patients treated in study hospitals was 35 months, compared to 25 months for those in non-study hospitals. These results applied to all patients, not only those directly enrolled in a study.30

The US cardiology study referred to above in relation to mortality also explored adherence to guidelines and found that hospitals participating in trials had higher rates of guideline adherence.<sup>29</sup> Another study showed similar results in breast cancer, where US health providers involved in research networks were more likely to provide treatment in accordance with the relevant guidelines.<sup>31</sup>



Quality of care is monitored by national regulators, which provides another option for measuring performance. In England, the Care Quality Commission (CQC) monitors, inspects, and scores providers based on whether care is safe, effective, caring, and responsive to patient needs. Increased research activity is associated with higher CQC scores.<sup>26</sup>

### More efficient and cost-effective care

It is also known that improving the implementation of research findings and new innovations can lead to cost savings, and this has been shown in the Australian context. The Australian Commission on Safety and Quality in Health Care and the Australian Clinical Trials Alliance looked at 25 high-impact clinical trials and found that if the results of those trials were implemented into clinical practice for 65% of eligible patients for one year, the gross benefit would be approximately \$2 billion, as a result of the improved health outcomes and reduced health service costs. For the 25 trials, they found an overall cost saving of \$5.80 for every \$1 invested, and the trial results only needed to be implemented in 11% of eligible patients for the benefits to exceed costs.<sup>17</sup>

Through clinical trials, patients can get access to cutting-edge medicines and devices earlier than they otherwise might, and clinical trials can also contribute to the costs of patient care (whether patients are enrolled in the control or the trial group), which can benefit health services financially.

#### **Better patient experience**

Higher clinical research activity can have a measurable positive impact on patient perceptions of health provider performance. A study that looked at inpatient surveys found that in more research-active settings, inpatients not only reported a better overall experience, but had more confidence in the doctors treating them and the decisions made, and received better information – for example on how to manage their medicines.<sup>32</sup>

"My idea is if more people are involved in clinical trials, it may reduce the time it takes to make the new intervention widely available."

Roundtable participant (consumer)

# Benefits to staff experience, recruitment, and retention

For staff, research is similarly valued, improving job satisfaction, enhancing staff recruitment and retention, and reducing the chance of burnout. A US study asked doctors what aspects of their work they found most personally meaningful; research was second only to patient care – importantly, if doctors spent more time working on their most meaningful activity, they were at lower risk of burnout.<sup>33</sup> A survey by the Royal College of Physicians of London found that dedicated time for research makes physicians more likely to apply for a role.<sup>32,34</sup> This is likely to be in part because clinicians themselves believe that research improves patient care.<sup>34</sup>



# Why is research associated with better performance?

There are many potential explanations for the precise mechanisms through which research activity delivers better performance. It might be that research participation leads to better knowledge among staff or provides some other benefit to human capital, or perhaps there are changes to institutional structures or mechanisms, or access to infrastructure or resources that can be used more broadly in care. Internal processes may be changed for the better as a result of conducting studies, or it may be that research encourages more collaboration between organisations, teams, and individuals. Health providers that embed research and innovation are better at taking up new innovations and treatments, and at stopping practices that are not benefitting patients – this could explain why benefits extend beyond a single trial or study.<sup>35</sup> Similarly, if research-engaged health organisations are more likely to follow the most recent clinical guidelines, as the research suggests, this might also contribute to better performance and potentially apply to guidelines outside of the particular studies or trials in which a health professional is involved.

It may also be that better-performing providers are more likely to participate in research, rather than the research activity driving performance.

# 3.

# Setting the right culture

### Key messages

- Researchers, health professionals, healthcare executives and consumers all value research and innovation, but our health system is currently facing barriers to optimally integrating research and innovation.
- A key barrier is the fragmentation and disconnect between the many stakeholders working to improve the nation's health, healthcare, and research and innovation. Better coordination is needed to enable stakeholders to work together to address these challenges.
- To translate the outcomes of research into benefits for patients, Australia must position research and innovation as everyone's business. By doing this, research and innovation can become core functions and enablers of healthcare – with input from, and impact across, the whole health system, from primary care to hospitals, public health and the community.

## Introduction

We heard repeatedly during our evidence collection from stakeholders across all sectors that Australia needs to invest in ensuring that a strong research and innovation culture sits at the heart of our health system. This culture shift is crucial to the Academy's vision of embedding these endeavours as core functions in health. The recommendations made throughout this report aim to enhance the current system to deliver an environment in which such a culture can flourish, and consequently, accelerate efforts to achieve better health and better healthcare. We know this is possible in research-rich health systems (as outlined in Chapter 2). "I would personally like to see the research culture just embedded in the health system. We know it improves patient outcomes so why not just make it part of every patient's journey?"

Roundtable participant (early- or midcareer researcher, EMCR)

### Drivers of culture change

A recurring theme throughout this report is the fragmentation of the health system, and its disconnect from research and innovation in Australia. A key message from our evidence collection was that greater coordination is needed between health and academia, between federal, state and territory governments, and with other key partners such as funders, industry, and consumers.

Australia delivers healthcare across many different settings – rural and regional healthcare looks very different to that provided in urban settings, primary care is different from hospital care or aged care, and public health and prevention is different again. For health and medical research and innovation, health, academia, industry and consumers are all critical to success, but also operate very differently across different settings.

These are long-standing issues, which to date have not been resolved. In the context of our report, they have a significant impact on Australia's ability to drive culture change and to reap the benefits of aligning health, research and innovation more closely. The four pillars that make up our vision – a skilled and enabled workforce, targeted funding, consumer and community involvement, and integrated teams "The care that you get on the ward is completely indistinguishable from being on a clinical trial. And that ethos and culture is something that we are really keen to roll out."

Roundtable participant (healthcare executive)

and cross-sector collaboration – are fundamental to overcoming these barriers. Each of these pillars represents a key part of the health system that can contribute towards the advancement of a culture that values research and innovation. We believe that the recommendations outlined in this report can drive this culture change for the long-term benefit of the health system and those who operate within it.

We heard through our evidence collection that advancing a research-rich culture is everyone's responsibility. A health system that values research and innovation must be equally matched by a research and innovation sector that acts to benefit the health system. We believe that in addition to the pillars in this report, and the associated recommendations, these advances would be enhanced by a collective approach to driving culture change. A central mechanism that brings stakeholders together to identify and address the barriers to more fully embedding research and innovation in health could enable this progress.

The challenges described above are not new, in Australia or overseas. For instance, in the early 2000s, the UK identified a disconnect between the various stakeholders involved in clinical research, which was preventing the NHS from delivering effective and efficient translation of scientific advances into patient care.<sup>36</sup> The UK Clinical Research Collaboration (UKCRC) was created in 2004 to position the NHS as the world leader in clinical research, and ultimately to improve national health and increase national wealth.<sup>37</sup> The UKCRC brings together the major stakeholders in clinical research to re-engineer the clinical research environment. The UK is now seen as a powerhouse for clinical research and a leader in nurturing clinician researchers. The creation of the UKCRC was an important step in setting the UK on this path, as explained in Box 3.1.

Similarly, the US established a Clinical Research Forum in 1996 to discuss the unique and complex challenges and opportunities of clinical research, drawing on perspectives from leaders in academia, industry, and government. Still active today, it was founded on the premise that "the success for our nation's translational research enterprise will require the development of an integrated system with the capacity to efficiently translate a burgeoning pipeline of basic research into high quality clinical care and improved health outcomes".<sup>38</sup>

Australia faces similar challenges, identified throughout this report. A mechanism to facilitate partnership and coordination between stakeholders across health, research and innovation would turbocharge progress towards bringing healthcare and health research and innovation into closer alignment. An Australian alliance for transforming healthcare through research would drive culture change by bringing key stakeholders together to collectively identify, develop and deliver solutions, and therefore reap the associated benefits for both health and wealth.

### **Recommendation 1**

The Australian Government and the state and territory governments should establish an inclusive, continuing mechanism that is empowered to develop and implement strategies for embedding research and innovation as core functions of the health system. An Australian alliance for transforming healthcare through research would bring key partners together to enable collective working towards this aim. This new mechanism would incorporate selected representatives from partners including federal, state and territory governments, public funders of health and medical research, public healthcare providers, academia, and consumers. This proposal is not intended to create a new governance mechanism or increase bureaucracy, but to provide a forum for collaboration, coordination, and partnership. In fact, we propose it in response to the feedback received during our extensive evidence gathering. We heard of a strong desire from stakeholders across the sector for more coordination and joint working to bring about better integration of research and innovation in health. However, they highlighted the lack of a mechanism to facilitate this outcome.

### Box 3.1: UK Clinical Research Collaboration (UKCRC)

The UKCRC was established in 2004 to address the disconnect between the many stakeholders involved in clinical research in the UK.<sup>37</sup> Its stated aim is to establish the UK as a world leader in clinical research.

The UKCRC works by providing a forum through which partners work together to transform the clinical research environment in the UK. The forum enables a strategic approach to identifying and addressing obstacles to clinical research. It operates through a board made up of representatives from 29 partner organisations and chaired by the UK Department of Health Chief Scientific Advisor. It provides major stakeholders in clinical research, such as research funding bodies, academia, the NHS, regulatory bodies, industry, and patients, the opportunity to come together twice a year.

A strength of the UKCRC partnership model is that

it brings together partners across jurisdictions. In the UK, responsibility for healthcare is devolved to England, Scotland, Wales, and Northern Ireland, all of which are involved. Although the UK health system is different from Australia, the UKCRC shows that it is possible to overcome the challenges of multiple jurisdictions to build clinical research capacity. For research and innovation to be embedded as core functions of the health system in Australia, coordination is needed between the federal, state, and territory governments, alongside funders and other stakeholders.

The UKCRC has facilitated many successful initiatives. One example is the UKCRC Public Health Research Centres, which were established in 2008 to develop a coordinated approach to improving the UK public health research environment. An evaluation published in 2019 concluded that the success of these Centres had exceeded expectations.<sup>39</sup> This was made possible by coordinated investment from a consortium of UKCRC funding partners, who committed more than £20 million initially, rising to a total of £37 million over ten years. One of the key outcomes of this initiative has been a step change in how research is aligned with the needs of health policymakers and practitioners, at both local and national levels. Research led by the Centres has generated evidence that has informed important health reforms and prevention programs in a range of areas, including healthy transport policies, physical activity, promoting health in schools, and policies related to smoking and a sugar tax.<sup>39</sup> Other impacts have included capacity building, nurturing early-career researchers, and leveraging additional research funding.

4.

# Pillar one: A skilled and enabled workforce

### Our vision

A research-active health workforce underpins an integrated, continuously improving health system. At the heart of this workforce is a cohort of world-class clinician researchers from across the professions, which drives a culture change that accelerates the beneficial impacts of research and innovation on healthcare systems and outcomes.

### **Key messages**

- There are no clear data on the proportion of the health workforce that is research active or formally employed in clinician researcher roles, making it difficult to support this workforce. This also creates difficulties developing strategic approaches for clinician research workforce development.
- There currently is no clear career pathway in the health system for clinician researchers leading to substantial uncertainty about future employment. This has been highlighted by many reports but never addressed, because no single organisation, body, or government is clearly responsible for developing and implementing a pathway.
- To improve health and care, the health workforce is key to shifting the culture of the health system to be more evidence-based and research-engaged.
- Clinician researchers need a formal, harmonised training and career pathway that allows them to undertake work as both a researcher and a health professional.
- Research-active health professionals, who are involved in research but not formally as clinician researchers, need to be more supported and celebrated, including through dedicated

research time and recognition in job descriptions.

- Australia needs to foster an environment in which clinician researchers are supported to grow and flourish, working in integrated teams.
- Existing diversity and inclusion issues in the health and medical research workforce may hinder efforts to develop a high performing research workforce.

## Introduction

To generate a research-rich health system, Australia needs to stimulate a culture change. This is only possible through the health professionals working in the system. Australia must develop an appropriately trained and supported healthcare workforce, which embraces and champions research from all professions, services, and locations.

Clinician researchers are the cornerstone of such a system. Also referred to as clinician scientists, physician scientists or clinical academics, they hold posts across both clinical services and research institutions. Clinician researchers can be doctors, nurses, midwives, or allied health professionals, working across the full spectrum of health settings, including primary care, hospitals, community care, public health, and aged care. Clinician researchers, working within teams, deliver research that targets patient needs and they support implementation of research findings into practice (provided they work within a culture that supports this). They identify opportunities for improvement, construct important research questions, and translate findings into evidence-based solutions. They also facilitate collaboration and communication between other researchers and practitioners.<sup>40</sup> It is therefore unsurprising that they account for 37% of Nobel Prize winners in Physiology and Medicine.<sup>41</sup> In short, clinician researchers are ideally placed to drive culture change, identify and respond to patient needs, and maximise the impact and relevance of research across the system. Boxes 4.1 and 4.2 provide an example of how this works in practice.

Despite increased investment in health and medical research in Australia over the past decade, the number of clinician researchers is falling.<sup>42</sup>

Australia needs to foster an environment in which clinician researchers flourish. By working within integrated teams that draw on expertise from across sectors and disciplines, they can generate high-quality research and target pressing health challenges. Australia has a solid foundation for health and medical research, as outlined in Pillar two (Chapter 5). The next step is to nurture a health system that encourages research and innovation, and enables findings to reach the community. "I also say that the value of clinicians who do research, it creates optimism in our health system because if you've got a problem, you have the tools to fix it. You can investigate what that problem actually is, what that problem actually looks like, and then test ways to solve the problem. And having clinicians embedded in a health system that researches is a really good way of doing that."

Roundtable participant (EMCR)

In this chapter, we explore how Australia can work towards a health system in which clinician researchers, other health professionals, non-clinical staff, and researchers can drive a culture shift towards a more research-rich, evidence-based environment. Key enablers for such a system include:

- federal, state and territory governments
- research institutions, including universities and MRIs
- health service providers, including executives, managers, and administrators.



### Box 4.1: Professor Clare Scott AM FAHMS - case study

Professor Clare Scott is Joint Head of the Division of Clinical Translation at the Walter and Eliza Hall Institute of Medical Research (WEHI) in Melbourne. <sup>43</sup> As a medical oncologist (a doctor that diagnoses and treats cancer) and clinician researcher, she has established a laboratory program that investigates rare ovarian cancers.

Professor Scott's integration of research and clinical practice has seen her develop a creative and individualised approach to tackling the most aggressive ovarian cancers, some of which are not curable with current therapies. Working with patients and studying their individual cancer cases, Professor Scott has been able to design novel treatments, moving away from a 'one-size-fits-all' approach, and identifying potentially drug resistant aspects of the tumours before beginning treatments.

Professor Scott's contributions have improved our understanding of rare and aggressive cancers and have helped develop new treatment pathways, which are now also being explored for other types of cancer.<sup>44</sup>

"As little as ten years ago, ovarian cancer was a death sentence. Today survivorship is starting to improve due, in part, to our ability to better identify disease subtypes and implement appropriate treatment early on."

Professor Clare Scott AM FAHMS<sup>44</sup>

# Clinician researchers: the current picture in Australia

The Australian Government recognises the value of clinician researchers. The most recent Australian medical research and innovation priorities, which guide investment through the MRFF (noting that at the time of writing, these were still in draft and waiting to be approved by Parliament), state the need to: <sup>45</sup>

"Support and enhance Australian health and medical research capacity, especially clinician researchers, with a focus on multidisciplinary engagement and improving the translation and integration of evidencebased research into primary through to tertiary care and commercial outcomes. This includes fostering gender equity and opportunities for early to mid-career researchers in the research workforce."

This recognition is widespread, including at the state and territory level and across the health professions. For instance, the Chief Nursing and Midwifery Officer in Queensland noted in 2020 that:<sup>46</sup> "The importance of research to the nursing and midwifery professions cannot be overstated. Research is the primary source of the discrete professional knowledge upon which our professions are based, and upon which major gains have been made in the health of people locally, nationally, and internationally ... We must nurture and develop research capability and capacity within our professions."

Despite such recognition, there is no formal sustainable clinician researcher pathway for health professionals in Australia, whether they are doctors, nurses, midwives, or allied health professionals. This issue has been highlighted many times over the past decade, from the McKeon Review in 2013 and more recently by organisations including the National Health and Medical Research Council (NHMRC), Group of Eight (Go8), Australian Medical Association (AMA), the Medical Deans Australia and New Zealand, and a cross-specialty working party coordinated by the Royal Australasian College of Surgeons.<sup>21,42,47-51</sup>

However, the problem has not been addressed. For instance, although the MRFF identifies clinician

researchers as a key priority, funding has not been set aside to enable such a pathway to fund individuals' salaries—only to support the research component.

"I think clinician researchers have greater credentials to be able to advocate, in terms of advocating for their patients, advocating for research, advocating for resources, and being able to influence policy."

Roundtable participant (EMCR)

As recently as 2021, the NHMRC reported that clinician researcher training in Australia remains fragmented and poorly understood, including that:<sup>51</sup>

- There is no clear picture of how many clinician researchers there are in Australia, the training pathways they have taken, the settings in which they work, or their employment arrangements.
- Little is known about the optimal training pathway for this cohort – for example, whether a PhD is the right gateway to this career, whether there is an optimal time to undertake one, and what other skills might be valuable for this profession.

"I think the other thing is a career structure for [clinician researchers] ... I think it's helpful because we do need to ensure that people have a strong career structure. That is about funding, yes, and we shouldn't ignore the funding word, but it is also about us having the vision to create those career structures across our health services"

Roundtable participant (healthcare executive)

- There is very little data about how effective existing supports, such as grants, are in training and sustaining individuals in clinician researcher careers.
- It is not known whether training pathways used overseas could be repurposed in Australia.

A key issue is that no single organisation, body or government is clearly responsible for developing and implementing a clinician researcher career pathway. Most research takes place within universities and MRIs, which (although linked) are separate entities from health services. Even within health services, responsibility (and funding) is split across federal and state or territory governments. Consequently, there are very few clinician researcher positions within health services jointly supported by clinical and academic sectors, and there is no consistent process where health services and academic organisations plan in a coordinated way. The Go8 has reported that the number of clinician researchers within the Australian health workforce has fallen over the past decade.42

# Why is it so challenging for clinician researchers?

Clinician researchers need to strike a balance between time spent on research, postgraduate training, and the provision of clinical service. There are many barriers to this career path that need to be addressed. During our evidence collection, we heard from early- and mid-career clinician researchers about the main barriers they have faced, which include:

- limited funding available for research activity for salary support for research time, as well as funding for direct and indirect research costs (see also Chapter 5)
- insufficient time allocated for research many roundtable participants reported having to conduct research in their personal time,
   e.g. evenings and weekends
- a culture that does not encourage career breaks for research purposes

"The biggest barrier I've already mentioned is the excessive demands on my time trying to balance all the different parts of my job. And I think what I would like to see change here is the creation of dedicated training schemes for clinician researchers that start right from the beginning."

Roundtable participant (EMCR)

- a lack of support from some senior healthcare executives
- limited mentoring opportunities from senior colleagues
- cumbersome and time-consuming governance processes for research approvals
- lack of a research 'culture' in the clinical setting, resulting in limited value being placed on enabling research activities by hospital administrators and some clinical colleagues
- slower career progression and lower salary compared to colleagues – clinician researchers taking time out to complete a PhD fall behind their peers in terms of progressing to consultant level, and once at that level, they have less time for private clinical practice
- limited infrastructure for support and training needs.

"I'm supposed to be working 0.6 clinically and 0.4 in a research role. My fellowship started in February and I'm still not backfilled to do my research. So currently I do my research on weekends because I just can't let the clinical stuff suffer."

Roundtable participant (EMCR)

It is important to acknowledge that training clinician researchers is not easy. Providing time for clinicians to undertake research training, progress research projects, and develop their roles as research leaders has impacts on service delivery as their clinical roles need to be covered. The COVID-19 pandemic has increased pressures on health services and clinicians, which has made this even more challenging. The pandemic has also highlighted the critical importance of clinician researcher capacity and leadership, because they are the ones undertaking studies and developing new approaches based on the latest outcomes.

If we do not overcome these challenges, we cannot unlock the opportunities to improve care and patient outcomes. The benefits of nurturing this group more than compensate for the challenges presented by their training and research activities. This has been recognised by health systems overseas, as outlined in Box 4.4.

Under current arrangements, clinician researchers essentially need to secure two positions – one clinical and one research – and both entities need to have mechanisms in place to enable joint employment. How this occurs varies across the country, but most clinician researchers need to make their own arrangements, usually liaising with two different employers. This brings complex challenges, for example being subject to two different enterprise agreements and salary scales associated with their two employers. With few incentives or supports in place, they often face an uncertain future.

Early- and mid-career researchers (EMCRs) across all disciplines face considerable challenges in pursuing this career, including a lack of secure employment (since many are employed on a string of short-term contracts) and increasingly limited options to access to grant funding (due to historically low grant success rates from funders such as NHMRC).<sup>52</sup> Clinician researchers face these challenges while also trying to pursue their training and career as a clinician. "And I think just the barriers for us as junior [staff] is that the clinical load is just a bit too much and the study as well. I'd love to be involved in more research in the last two years, but I don't really think it was feasible if I was going to be doing my service job to a satisfactory degree."

Roundtable participant (EMCR)

# How can we better support clinician researchers?

We know from international evidence that building the clinician researcher workforce is best facilitated by investing early. Individuals who start on this pathway often go on to hold professorships and other academic posts, consequently helping to develop research excellence at the academia–health interface.<sup>53-55</sup>

There are examples of programs in Australia designed to support clinician researcher training, some of which are highlighted in Box 4.3. The popularity of these programs demonstrates that despite the barriers, there is genuine appetite at all levels to pursue research within clinical careers. For example, The University of Queensland introduced a Clinician Scientist Track in 2010, which enabled medical students to take up a higher degree by research (HDR), such as a PhD or MPhil. In the decade prior to its introduction, only 13 medical students undertook an HDR. In the 12 subsequent years, the numbers of enrolments increased seven-fold to 123.<sup>56</sup>

However, Box 4.3 also shows the fragmented approach that exists in Australia, which:

- does not provide enough positions or sufficient accessibility to build the necessary cadre of clinician researchers associated with the Academy's vision
- inhibits a strategic approach that addresses areas of need, such as particular specialties or geographic locations

• limits access for current health professionals, leading to unequal opportunities.

To combat these current challenges and shortcomings, urgent action is needed in Australia at two levels:

"And if you say that investing in local people to develop skills that will then enable them to undertake their own research, that they are then able to lead other research agendas. To me, that's one of the biggest gifts that research can provide."

Project interviewee (Aboriginal or Torres Strait Islander researcher)

# 1. A harmonised pathway for clinician researchers

Australia aspires to remain globally competitive in health and medical research, but we are losing ground compared to other countries. The UK has a well-established career pathway for clinician researchers, giving them the flexibility to work and move across health and research. Such countries are reaping the benefits of research-rich health systems (see Box 4.4).

In Australia, there is no national strategy or coordination between federal, state and territory governments to enable a clinician researcher career pathway, and there is no liaison across states and territories about how it might be standardised. A national strategy and implementation plan would ensure the next generation of research leaders have time and mobility to flourish, both as clinicians and researchers. A strategy is required that describes a formal, harmonised clinician researcher training pathway – across medicine, nursing, midwifery and allied health – and articulates where these roles are required.

The Deans of Medical Faculties operating under the Go8 has developed a proposal for

an Australian Integrated Clinician Researcher Training Pathway (AICRTP). It outlines a model for clinician researchers in medicine that would provide time for both research and clinical service, from pre-vocational training (i.e. the first two years of postgraduate training), through to vocational (specialist) training and into postvocational stages.<sup>42</sup> They report that to ensure a sustainable cohort of medical clinician researchers, 5% of medical graduates need to enter a research training pathway, and 3% need to continue to post-PhD and post-vocational level.<sup>42</sup> They also note that parallel programs are needed in nursing, midwifery and allied health.

#### 2. Local coordination between academic institutions and health service providers to make it easier for individuals to secure employment across the two institutions.

In our evidence collection, we heard that the way clinician researchers secure positions varies not only between states and territories, but even between hospitals and service providers in the same city (see Box 4.3).

Some states and territories have tried to address this in a more standardised way. For instance, New South Wales (NSW) has a policy to facilitate the work of clinician researchers within the public health system.57 It provides a mechanism through which an individual with a relevant academic appointment in a university can also secure (and be remunerated for) a position in clinical service. This is a welcome step by the NSW Ministry of Health, but there are still limitations. For instance, it still requires substantial local negotiation and coordination across the university and the health provider, with much of the onus still being placed on the individual. This kind of arrangement also does not address issues such as remuneration, where the research component is often considerably less than the clinical component (especially since research is often done in place of private practice). In addition, it only covers medical staff, and not nurses, midwives or allied health professionals (although some universities and health services have arrangements in placed for conjoint positions in these professions).

"We're competing against a very big, lucrative private practice. So, you've got to have a very attractive reason for why you'd want to stay as a clinician scientist on significantly less salary."

Roundtable participant (EMCR)

Across Australia, the picture is mixed. Some states and territories have similar arrangements – South Australia and Western Australia, for example – but they all differ from one another.<sup>58,59</sup> Other states (Victoria, for instance) do not appear to have such an arrangement in place.

We heard that a standard dual employment contract template needs to be available for clinician researchers. It should be flexible and adaptable to ensure that local partners, including health providers and academic institutions, can provide an appropriate combination of time in clinical service as a doctor, nurse, midwife or allied health professional, and in research.

### **Recommendation 2**

The Australian Federal Government should develop a national strategy and implementation plan for building a world-class clinician researcher workforce, including a formal, harmonised clinician researcher training and career pathway. The strategy should be developed in partnership with state and territory health departments, and should address issues such as the need for a standard dual employment contract template for clinician researchers.

### **Recommendation 3**

Academic institutions and health service providers should work in partnership to support and grow the clinician researcher workforce by establishing formal clinician researcher positions that incorporate time in both clinical service and research, and allow for flexible arrangements for different individuals.

# The need for opportunities across the professions, disciplines, and specialties

In Australia, Medical Colleges are responsible for training and continuing professional development (CPD) for medical specialties. Consequently, the Colleges play a critical role in encouraging and enabling clinicians to pursue research careers. They should celebrate, recognise and incentivise research. There is variation among the Medical Colleges in the extent to which they do so. For example, the Royal Australasian College of Surgeons (RACS) has held symposia on this topic and has a standing Clinician Researcher Committee to provide guidance on this issue.<sup>60,61</sup> This report does not intend to provide a detailed analysis of each Medical College. However, it is important to acknowledge the critical role of the Medical Colleges in:

- supporting flexibility for clinical trainees to take up research training opportunities
- giving greater weight and recognition to research activity and the implementation of research as part of CPD for established staff.

Nurses, midwives and allied health professionals who want to have both a clinical and research career face different challenges. Due to a lack of integration between the health system and academia, they are often unable to pursue both. These challenges are reflected in international data, showing for instance that only a small proportion of nurses or midwives who have a PhD or similar work in research positions in clinical practice.<sup>46</sup>

By not facilitating clinician research career pathways within nursing and midwifery, more strain is being added to a workforce already under pressure. The Australian College of Nursing has described how nurses are reaching breaking point due to the pressures of COVID-19 and a disjointed healthcare system.<sup>62</sup> There is also a shortage of midwives in Australia and globally.<sup>63</sup> Meanwhile, Allied Health Professions Australia (AHPA) has drawn attention to the increasing pressures on this workforce, for example in relation to aged care, where residents receive less access to allied health care services now than they did a year and a half ago.<sup>64</sup>

By increasing opportunities for clinician researchers, the clinical capabilities of researchers – currently not being sufficiently utilised – can be maximised. Additionally, increasing research opportunities can improve staff satisfaction and therefore assist with retention, which would also help to address some of the system pressures.

The NHMRC has highlighted the importance of ensuring nurses, midwives and allied health professionals can follow this pathway, committing to work with professional bodies to develop career pathway models for these fields.<sup>51</sup> Internationally there are examples of how this can work in practice,

"People don't know what to do with nurses with PhD in the clinical setting ... on paper, they are a university person ... When the chips come down and they want to write a policy or something, there's no guarantee that they'll get asked at all, even if it's about their content area, and even if they're doing the trials in the hospital that they're using to reference in their policy document."

Roundtable participant (researcher)

one example being the Integrated Clinical and Practitioner Academic (ICA) Programme for nurses, midwives and allied health professionals in England, described in Box 4.4.

Queensland Health published its Nursing and Midwifery Research Framework in June 2020, which provided a structure for research activities that advance nursing and midwifery. It aimed to build state-wide capacity and capability for the nursing and midwifery professions to embed research translation into culture, policy and practice. It reported that "The development of clinical academic researcher pathways is identified as a core strategy to promote a culture of research in nursing and midwifery".<sup>46</sup> Professors of allied health embedded in health services have highlighted that sustainable career structures for clinician researchers in these professions, alongside strategic funding, would facilitate the development of cost-effective solutions for the benefit of consumers and the community.<sup>65</sup> It can be very challenging for individuals in these professions to find time for research.

A new Australian alliance for transforming healthcare through research to enable coordination and partnership across the sector (see Recommendation 1 above) would substantially enhance efforts to address these issues.

### Box 4.2: Professor Sant-Rayn Pasricha – case study

Professor Sant-Rayn Pasricha is the recipient of the 2022 AAHMS Jian Zhou Medal, awarded to rising stars in health and medical research. As a researcher and a haematologist (a doctor who treats blood conditions), he has been able to establish one of the world's preeminent global health anaemia research programs, which has led to the delivery of evidence-based care on a global scale.

Anaemia is a reduction in the blood's oxygen carrying capacity. It affects 4.5% of Australians and more than 1.7 billion people globally.<sup>66,67</sup> The majority of this burden falls in low- and middleincome countries.

Professor Pasricha's work has led to the development of six World Health Organization (WHO) guidelines in low- and middle-income countries. These guidelines have been implemented in more than 50 countries worldwide, which has improved the availability of evidence-based care and is helping the WHO to work towards its target of reducing anaemia by 50% by 2025.

Recently, Professor Pasricha has completed a large randomised controlled trial evaluating the functional impact of iron interventions in Bangladeshi infants, which provides new evidence on the clinical effect of WHO policies.<sup>68</sup> Professor Pasricha and his team also performed mathematical modelling of the impact of iron interventions and their net benefit and cost-effectiveness across 78 countries.<sup>69</sup>

Professor Pasricha says his work as a clinician has been heavily influenced by his work as a researcher and vice versa. He says being a clinician researcher has helped him achieve his successes in research, the translation of research into practice, and the capacity to help improve health outcomes worldwide:

"Being a clinician helps ensure that my research questions are always tethered in what is clinically important, whilst being a scientist helps me creatively explore the fringes of what might seem clinically plausible in the moment. Today's crazy ideas are tomorrow's new treatments, tests or policies. Being a clinician with experience in haematology has greatly strengthened my ability to contribute to and influence high-level policy discussions, for example at the World Health Organization."

Professor Sant-Rayn Pasricha

### **Recommendation 4**

Professional bodies should work with governments to develop clinician researcher training pathways and implementation plans that deliver clear provision of functional pathways across the full spectrum of clinical training.

- For medicine, this means working with the Specialist Medical Colleges, which should provide flexibility for clinical trainees to take up research training opportunities, and should appropriately recognise and incentivise research activity and its implementation as part of training and continuing professional development.
- For nursing, midwifery and allied health, this means working with universities, state and territory health departments, health providers and industrial bodies to develop systems and structures that enable individuals who undertake research training to also continue their careers as clinicians.

# What do we know about the clinician researcher workforce?

Another significant barrier to supporting clinician researchers is the lack of data about this part of the workforce. We do not know how many individuals are working in roles across clinical service and research, the extent to which they are doing so, or the training and career pathways they have followed. It is very difficult to support a workforce that is hidden.

There have been attempts to pull together this data. The NHMRC, using data from the Australian Health Practitioner Regulation Agency (AHPRA) annual workforce surveys, reported that less than 1.5% of registered health professionals spend time on research. However, they stressed the limitations of the data used, noting that they were able to capture only one part of this workforce.<sup>51</sup> In addition, NHMRC was not able to source any data about the training pathway or qualifications (such as PhDs and other research qualifications) held by those individuals. Consequently, they made recommendations to identify and track the career trajectories of clinician researchers - targeted at the Australian Department of Health and Aged Care, AHPRA, and NHRMC itself.<sup>51</sup>

This national-level data collection and analysis is important but must be accompanied by parallel efforts more locally, which may provide more granular data to inform local decisions. Barriers at the local level impact a health service's ability to attract and retain clinician researchers. During our evidence collection, we heard from researchers who had to leave clinical practice because their health employer would not support their continuing research. This is reflected in the NHMRC's report, which stated that AHPRA data suggests a high attrition rate among researchers across the health professions.<sup>51</sup> As noted above, health providers face considerable service pressures. However, enabling clinicians to undertake

"Clinical life takes over from time to time and you have to push it back a little bit. But as we all know clinical [work] is very hard to just switch off. You can't just go, 'All right, this is your 50% time now. I'm just going to stop paying attention to patients' calls or questions, etc.' So I think that's always a constant battle."

Roundtable participant (EMCR)

research is a valuable incentive to keep highperforming clinicians in the healthcare workforce, as we explain in Chapter 2.

Without this kind of data, health services, research institutions and the nation cannot make strategic decisions to develop the clinician researcher workforce, for instance in terms of specialties and geography.

States and territories should collect and collate data on what proportion of the workforce have both a formal clinical role in the health system and a research role with an academic institution, and the respective time fractions allocated to each, as well as information about informal arrangements (e.g. honorary appointments with a research institution or other ways that clinicians may conduct research without such an affiliation). In NSW, the policy directive that exists to allow clinician researchers to undertake clinical service (described above) means that such data exist. We understand from the NSW Ministry of Health that as of July 2022, there were 182 individuals making use of this mechanism across metro, rural and regional, and state-wide health services.70

Although this does not reflect the full extent of the clinician researcher workforce, collating this kind of data will help services to:

• understand what attracts individuals to enter and remain in this career path

"When I first embarked upon research training, I went back to my clinical employer and said, 'Hey, I've got research skills, but I have some projects I'd like to continue and return to practice'. And they said, 'We're not paying you to do research. We're paying you to do see patients'. I ended up leaving clinical practice to go and do a PhD because at that time, [about] 2011, there was no place for me within my department as a clinical researcher. So I left practice ... I think the key thing is the existence of clinical academic pathways."

Roundtable participant (EMCR)

- understand this cohort's experiences and how they can be better supported
- provide more targeted support, based on experiences in the local context
- undertake workforce analysis and planning to make more strategic decisions about where clinician researchers are needed.

We discuss this further and make associated recommendations in Chapter 7.



## Box 4.3: Examples of clinician researcher programs in Australia

There are some good examples of Australian programs that enable clinician researchers to combine their academic and clinical training, some of which are highlighted below. Establishing programs at this local level is difficult and institutions' efforts to set them up should be celebrated, as they can be modelled by others. However, these programs also demonstrate the fragmentation that exists in Australia, as highlighted throughout this chapter. Some examples are included below, but do not constitute a comprehensive or exhaustive list.

## Undergraduate opportunities

#### Medical school MD-PhD options

Several Australian medical schools have options for their students to undertake a dual degree, i.e. training that results in the award of both a clinical degree (e.g. MD or MBBS) and a research doctorate degree (e.g. PhD), although this is not a universal offering in Australian medical schools. It is usually open to high performing medical students and extends the duration of their undergraduate training, but provides a solid grounding for those wishing to pursue a career as a clinician researcher.

## One example is the University of Queensland Clinician Scientist

Track, which was introduced in 2010 to enable high performing medical students to undertake a higher degree by research (HDR) after their second year of their medical degree. Introduction of the program saw a substantial increase in the number of medical students enrolling for HDR. It is too early to draw firm conclusions about the program's impacts on subsequent research career success, but early indications show that junior doctors who completed the program are now securing early career research funds, scholarships (e.g. Fulbright), fellowships, and high profile publications in journals such as Nature and Cell.

## Postgraduate opportunities

#### Melbourne Academic Centre for Health (MACH)-Track

MACH-Track is a structured, mentored and fully funded career development program for research-minded doctors, which provides time for them to combine clinical and research (PhD) training. It is a program available to doctors undertaking clinical (vocational) training in accredited hospital specialties, general practice and public health. The MACH-Track program is run by the MACH and runs for six years:<sup>71</sup>

- Year 1: Pre-PhD start year of the program – 80% clinical training / 20% PhD preparation
- Years 2–4: PhD scholarship 80% PhD / 20% clinical role
- Year 5: Post-PhD 80% clinical training / 20% preparation for post-doctoral fellowship application
- Years 6 and beyond: The arrangement is as for Year 5 until clinical training is completed and, ideally, a post-doctoral fellowship secured.

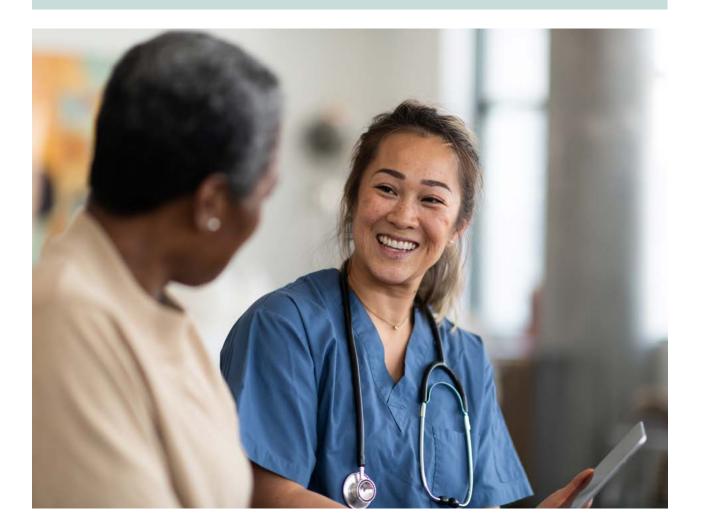
#### Melbourne Children's Campus Clinician Scientist Fellowships

The Melbourne Children's Campus (which incorporates the Royal Children's Hospital, Murdoch Children's Research Institute (MCRI) and The University of Melbourne's Department of Paediatrics, as well as the Royal Children's Hospital Foundation, who support the Fellowship program) offers Clinician Scientist Fellowships to postdoctoral clinical researchers from medical, nursing, midwifery and allied health, with funding and a supportive environment to advance their research endeavours. Importantly, the

fellowships provide support to clinician researchers post-PhD, which is currently very rare in Australia. Approximately 4–7 fellowships are awarded each year, providing up to five years of salary support for each of the two levels offered for either early- or mid-career researchers. The scheme has seen immense success, with nine Fellows having been appointed to senior leadership roles (including eight who are Research Group Leaders within MCRI, and four appointed as Team Leaders within MCRI).  $^{72}\,$ 

The Campus also offers scholarships at an earlier stage to support health professionals who are undertaking research on the campus to pursue postgraduate research training.

Academic and health leadership Some health settings have embedded academic staff in senior health leadership positions, to encourage a culture change from the top. For instance, the Alfred Hospital in Melbourne has an arrangement with its academic partners (e.g. Monash University) where the head of the clinical unit is also the head of the academic unit. The individual in that post is therefore able to optimise clinical service and research activity at the same time. We heard during our evidence gathering that there has been a step change both in high quality clinical activity, and in the amount of research activity as a result.



### Box 4.4: Examples of clinician researcher programs overseas

#### **United Kingdom**

England has had a formal clinician researcher training pathway since 2006, known as the Integrated Academic Training (IAT) Programme.<sup>73</sup> It supports individuals to gain research experience during their clinical training, from foundation to specialty training, including through:

- Academic Clinical Fellowships (ACFs), which provide funding for doctors and dentists in the early stages of specialty training to spend 25% of their time on research and to access Masters-level research training. Evidence shows that trainees see these posts as attractive and that the vast majority of ACFs move into academic roles, complete PhDs, and support translational and clinical research throughout their career.<sup>74</sup> The National Institute for Health and Care Research (NIHR) funds approximately 270 of these per year for doctors and dentists across the UK.73 7.9% of medical graduates in England have access to an ACF.42
- Clinical Lectureships (CLs), which provide a clinical and academic training environment for doctors and dentists to establish

themselves as independent researchers and leaders, allowing them to spend 50% of their time in specialist clinical training and 50% in research or educationalist training. The NIHR funds approximately 110 of these per year and 3.3% of medical graduates have access to such positions.<sup>73,42</sup>

The above positions are supported by a range of Clinician Scientist Fellowships that allow postdoctoral clinician researchers to build an independent research program while undertaking senior professional clinical practice. These Fellowships are offered by a range of funders including the UK Medical Research Council.<sup>75</sup> It is currently challenging in Australia to secure funding at this level for clinician researchers.

There is also an Integrated Clinical and Practitioner Academic (ICA) Programme designed for nurses, midwives and allied health professionals, which comprises four schemes that support individuals throughout the career stages:<sup>76</sup>

- Internship Scheme
- Pre-doctoral Clinical and Practitioner Academic Fellowship (PCAF) Scheme

- Doctoral Clinical and Practitioner Academic Fellowship (DCAF) Scheme
- Advanced Clinical and Practitioner Academic Fellowship (ACAF) Scheme.

#### **United States**

In the US, the National Institutes of Health (NIH) fund the Medical Scientist Training Program (MSTP), through which several medical schools offer dual degrees, similar to those highlighted above in Australian medical schools. The NIH stresses that "with the dual qualification of rigorous scientific research and clinical practice, graduates are equipped with the skills to develop research programs that accelerate the translation of research advances to the understanding, detection, treatment and prevention of human disease, and to lead the advancement of biomedical research".<sup>77</sup> This is the most common training route for clinician researchers in the US, and 3.3% of medical students complete this program.42

## The broader health and medical research workforce

While clinician researchers lead research by developing research programs and becoming international leaders in their fields, many more individuals contribute to the successful delivery of research within the health system. One group is the research-active health professionals, who support research by:

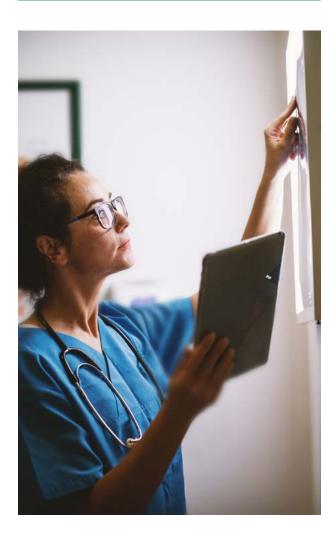
- helping shape research questions or priorities
- advising on research relevance to health services and patients
- supporting the establishment and delivery of studies
- disseminating research findings and helping implement them in different contexts.

These individuals are crucial to research and reaping the associated benefits. They should be allocated dedicated research time to undertake these activities as a core part of their role, and this should be formally recognised by their health employer, for instance in their position description. Their involvement also enables more meaningful consumer engagement and involvement.

All health professionals should understand research so that they are confident talking to patients about research opportunities and implementing new approaches that result from research findings. Similarly, non-clinical staff, such as health systems researchers, health economists and implementation scientists, are also important to delivering research and can drive culture change. Research and healthcare only benefit more when both clinical and non-clinical staff are integrated in research teams, as we explain in Chapter 7. An Australian alliance for transforming healthcare through research (Recommendation 1 above) would be well placed to bring together relevant employers to facilitate this outcome.

#### **Recommendation 5**

For health professionals undertaking research, but not formally as clinician researchers, health providers should recognise these activities as a core part of position descriptions, and should allocate dedicated time for these endeavours.



## Addressing diversity and inclusion to nurture the best researchers

The vision set out in this report can only be adequately delivered if we nurture the most talented individuals to become health and medical researchers. A research workforce that reflects the full diversity of the population in which it works is best equipped to understand and address the health challenges faced by all the individuals and communities within it. Unfortunately, when it comes to health and medical research careers, some groups are still disadvantaged, including women, LGBTQI+, Aboriginal and Torres Strait Islander, and culturally and linguistically diverse (CALD) researchers.

Analysis from the NHMRC shows that for its Investigator Grants scheme, men apply in higher numbers and are proportionally more likely to receive funding.<sup>78</sup> Consequently, men are awarded more grants and more funding than women. There is particular concern regarding the ongoing predominance of male applicants at the most senior levels of the scheme, where budgets tend to be largest.<sup>79</sup> NHMRC is undertaking work to explore options to introduce measures to address these gender disparities.<sup>78</sup> This trend is also evident for the broader health research workforce collated by the Science in Australia Gender Equity (SAGE) Initiative, as shown in Figure 2. Furthermore, the impacts of the COVID-19 pandemic on research activity and output, and therefore potentially on careers, disproportionately affected women, especially those with young children since they took on more of the additional care duties.<sup>80-82</sup>

For clinician researchers, the fact that they must balance their research with clinical training and service responsibilities further exacerbates preexisting challenges, and disincentivises this career path. The consequence is that we are failing to tap into the full potential of the clinician researcher workforce, hindering our capacity to maximise our performance in this area.

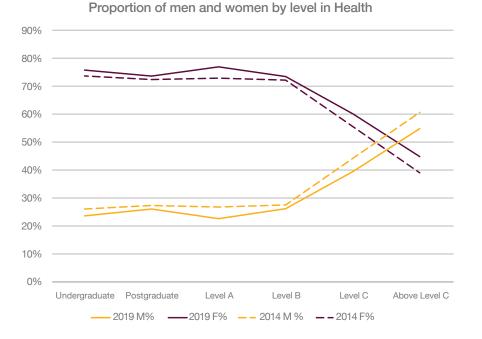


Figure 2: Student completions (in headcount and percentage) and academic staff (in full-time equivalents and percentage) in 2014 and 2019, by level and gender, in health. Levels referred to in the document refer usually to: A—Associate Lecturer/ Research Associate; B—Lecturer/Research Fellow; C—Senior Lecturer/Senior Research Fellow; Above C—Associate Professor/ Professor. Source: Higher Education Statistics Staff and Student Data, 2014 and 2019, collated by SAGE.<sup>83</sup>

## Aboriginal and Torres Strait Islander researchers

Aboriginal and Torres Strait Islander peoples make up a very small portion of the clinician researcher workforce, and the wider health and medical research workforce. Consequently, efforts to develop a thorough understanding of the unique experiences of this important group have been insufficient. The NHMRC reported that Aboriginal and Torres Strait Islander clinician researchers face the same barriers as the wider workforce, but also face significant additional challenges, which prevent them from thriving, including:<sup>84</sup>

- workplace racism, or not feeling that they have a culturally safe workplace
- very limited career opportunities, and the perception that a successful clinician research career is less achievable
- perceptions that research is not as relevant compared to other critical roles that address Aboriginal and Torres Strait Islander health and wellbeing
- limited support and low numbers of Aboriginal and Torres Strait Islander senior colleagues for mentorship
- not feeling well understood by non-Indigenous clinicians or researchers, for example because they did not feel they had a shared understanding.

As noted in the 2022 Close the Gap report, *Transforming Power: Voices for Generational Change*, structural reform is needed to:<sup>85</sup>

"Develop an Aboriginal and Torres Strait Islanderled research agenda for health and wellbeing, with a particular focus on the impacts of systemic racism in health systems. This should include an investment in knowledge translation and research impact". "We need more Indigenous researchers. We need more Indigenous researchers who are able to be self-determined without having a system overlaying them saying if you identify as an Aboriginal person or a Torres Strait Islander person that you're going to want to do all of your research in Aboriginal and Torres Strait Islander perspectives."

Project interviewee (Aboriginal or Torres Strait Islander researcher)

Aboriginal and Torres Strait Islander researchers also report the challenge to conduct research that is self-determined, as opposed to research strictly into Aboriginal and Torres Strait Islander health and wellbeing priorities. Researchers from different backgrounds should not be expected to undertake research only within their communities. Diverse researchers bring a perspective that is important for all research agendas, and should be valued and nurtured to reflect the significance of their contributions.

The Academy welcomes the Australian Government's 'National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan 2021-2031', which includes health and medical research as an area for growth.<sup>86</sup> This Framework puts forward a strengths-based approach focusing on the strengths of people, communities and organisations as a driving force for change. We believe this ethos should be central to all principles and strategies to grow the diversity of the health and medical research workforce.

## **Role of the Academy**

The Academy is committed to supporting a skilled an enabled workforce, and we have active programs targeted at building and nurturing Australia's clinician researcher workforce:

- Our Life as a Clinician-Scientist symposia are held across Australia and see Academy Fellows and other experts share insights from their own careers with students, doctors, health professionals and early-career researchers. This program is unique in Australia, and inspires, encourages and supports individuals across the country to pursue research careers in the health and medical sciences. It provides aspiring clinician researchers with role models who have navigated the barriers to this career path and delivered impacts beyond their immediate clinical practice - and does so across the full spectrum of medicine, nursing, midwifery and allied health. Since it was established in 2016, we have attracted over 4,000 registrations across more than 20 symposia in five states and online.
- Our Mentorship Program is a distinctive program in Australia, in which emerging health and medical research leaders are mentored by Academy Fellows. Mentees receive individualised support, tailored to their career needs, from the country's most eminent researchers. The program tackles a critical career point, where individuals are growing their independent research careers and looking towards leadership positions. Even the most talented researchers can leave research at this point. More than 80 mentees have been accepted into the three-year program since it was created in 2016.

These programs help improve the environment for clinician researchers in Australia, alongside which we advocate for better support for health professionals pursing this career. In addition, we actively profile role models to promote diversity and inclusion within health and medical research, including through our Fellowship election and awards, such as our Medal for Outstanding Female Researcher. "It has truly been life changing. If I think back to where I was three years ago and where I am today, it is a period of enormous personal and professional growth, which I attribute in large part to this program."

AAHMS Mentorship Program alumni

As the nation's Learned Academy for health and medical sciences – an independent and authoritative voice and home to programs that support clinician researchers across the country – we are ideally placed to participate in an Australian alliance for transforming healthcare through research and to support the development of a national strategy and implementation plan for building a world class clinician researcher workforce.

As a Learned Academy, we celebrate excellence across the health and medical sciences, and our Fellowship includes the nation's leading researchers across the health professions. We will continue to recognise outstanding research and innovation across the full spectrum of health professions, as well as in basic biomedical research, social sciences, humanities, and contributions from industry.

We are also working with partners across the sector, including:

- the National Network for Aboriginal and Torres Strait Islander health researchers to explore opportunities for us to support aspects of their work such as through a tailored mentorship program
- the NHMRC as they explore opportunities to improve the gender balance of the Investigator Grants.
- the RACS Clinician Researcher Committee in relation to their work to grow the clinician researcher workforce.

# 5.

## Pillar two: Targeted funding for research and innovation

#### Our vision

Australia seizes an unprecedented opportunity to maximise the value of current investments to increase research funding embedded in the health system. This funding is used to drive translation into consumer and economic benefits, and to improve health outcomes, without detriment to other crucial research and innovation endeavours.

### Key messages

- The full picture of federal, state and territory government expenditure on health and medical research in Australia is currently unclear. There are gaps in the data on how much is being spent, on what and on whom. It is therefore impossible to know how much is available to support research, identify opportunities to optimise its use, or build a picture of what this looks like strategically.
- The NHMRC has seen a decrease in real terms in its funding over the past decade. By correcting this, the government can increase the capacity of the NHMRC to support clinical, health services and public health research, and clinician researchers – without further eroding its ability to support vital basic biomedical research.
- The MRFF funding distribution to date does not appear to clearly map onto the goals, strategies and priorities of the fund, and there does not seem to be a clear plan to provide more clarity here.
- Australia has made good progress in building an ecosystem that supports health and medical research and innovation across the pipeline of discovery and translation. However, the current system is not performing to its full potential.

- State and territory governments play a crucial role in funding research and innovation, and in funding time for health professionals to undertake research.
- We have a critical opportunity to optimise existing funding streams and initiate greater strategic coordination and harmonisation between them.
- There needs to be better coordination and harmonisation between the MRFF and the NHMRC to reduce complexity and duplication of effort for the sector.

## Introduction

For our health system to successfully embed research and innovation, Australia needs sufficient resources, appropriately deployed. As a nation, we have established a firm foundation in our health and medical research capacity, meaning we have an unprecedented opportunity to ensure the benefits flow.

The NHMRC and the MRFF together provide a valuable underpinning for a world-class, evidenceinformed health and medical research and innovation system. They sit at the heart of an ecosystem designed to incorporate basic biomedical and public health research, alongside translation into consumer and economic benefits, and better health outcomes. In this chapter, we identify opportunities to refine the delivery of existing investments so the nation can harness the full potential of this system, and ultimately unleash the potential benefits brought by embedding research and innovation within the health system.

## Maximising the value of the NHMRC

The NHMRC supports a broad range of competitive, investigator-driven funding initiatives for individuals, teams and projects across the research pipeline (see Box 5.1 for additional information).<sup>87</sup> The NHMRC Act requires it to pursue activities that:<sup>88</sup>

- raise the standard of individual and public health throughout Australia
- foster the development of consistent health standards between the states and territories
- foster medical research and training, and public health research and training throughout Australia
- foster consideration of ethical issues relating to health.

This breadth of activity makes the NHMRC a crucial component of Australia's health and medical research and innovation landscape. It is the main funder of discovery and public health research, and also pursues a range of strategies to promote research translation into clinical practice and support the commercialisation of research discoveries.<sup>87</sup>

Despite its importance, the NHMRC's funding has declined in real terms over the decade from 2010 to 2020, from an equivalent value of \$964 million to \$900 million annual funding. This represents a drop in funding per capita over the same period from \$43.50 to \$35.00 (Figure 3). There was a particularly sharp drop in funding in 2015–16.

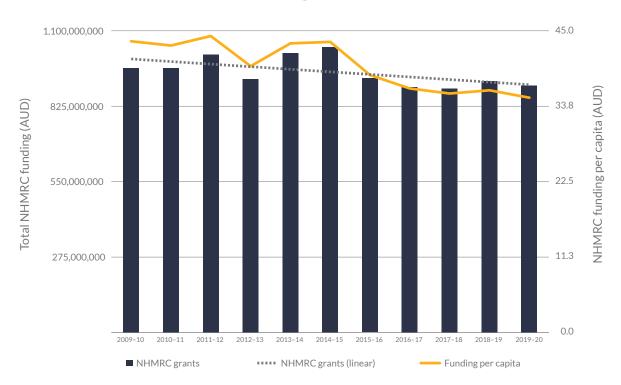
Reducing the NHMRC's funding reduces Australia's capacity for discovery and translational research. The NHRMC itself notes that "rapid growth in grant application numbers and rising costs of research have led to funding rates for NHMRC's major grant schemes falling to historical lows ... having a range of negative effects on Australian health and medical research".89 Underinvestment impacts the nation's capacity to generate an evidence base for improving health, to develop a workforce able to generate and translate such evidence, and to advance consumer and community involvement in research. All these aspects are necessary for fostering a culture of research in the health system, as outlined throughout this report.

By correcting this real terms drop in funding, the government can increase the capacity of the NHMRC to support clinical, health services and public health research, and clinician researchers, without further eroding its ability to continue supporting vital biomedical research. This can be done by increasing investment in the NHMRC beyond indexation over the next five years, to return its funding to be at least equivalent to 2010 levels. Such investment is crucial to delivering the Academy's vision for a research-rich health system.

Furthermore, in the current economic climate, Australia must invest in areas that drive economic growth. Data from Australia and overseas consistently show that investing in health and medical research brings exceptional returns, creates jobs and attracts commercial investment. Australia sees a return of \$3.90 for every \$1 invested in health and medical research, and these endeavours create high value, knowledge-based jobs.<sup>13</sup> Research in the UK has shown this to be the case across multiple disease areas, from mental health to cardiovascular disease to musculoskeletal conditions – health and medical research drives economic growth.<sup>15,90</sup>

#### **Recommendation 6**

The Australian Federal Government should increase the NHMRC's budget beyond indexation over the next five years to return investment to at least 2010 levels in real terms.



NHMRC funding 2009/10 - 2019/20

Figure 3: Total NHMRC funding (bars and dotted line) and NHMRC funding per capita (line), 2009/10 – 2019/20. Prices are constant, based on the professional health workers wage rates index deflator. Source: Australian Institute of Health and Welfare, Health Expenditure Australia 2020–21 report and Australian Bureau of Statistics.<sup>91</sup>

## Maximising the value of the MRFF

The MRFF was established in 2015 and has been a valuable addition to the funding landscape, enabling a more dedicated source of support for translating research into health benefits. It is a \$20 billion, priority-driven endowment fund, set up to support medical research and innovation to improve health outcomes, drive economic growth and contribute to health system sustainability. The first grants were awarded in 2017 and since then the MRFF has awarded funds worth more than \$1.8 billion (funds committed as of 30 June 2021) across a range of activities, including clinical trials, research missions, commercialisation funds and support for researchers.<sup>92</sup> The MRFF is administered by the Health and Medical Research Office (HMRO) within the Australian Department of Health and Aged Care. Funds are awarded based on areas of national priority that are identified by the independent Australian Medical Research Advisory Board (AMRAB), in consultation with the sector and the public. AMRAB sets the Australian Medical Research and Innovation Strategy, which is updated every five years, and informs a set of Australian Medical Research and Innovation priorities, which are set every two years by AMRAB (though we note that proposed changes to the MRFF Act 2015 under the Investment Funds Legislation Amendment Bill 2021 would change these to six years and three years respectively, if passed).93-95 Both these outputs sit under a 10-year investment plan.<sup>93,96</sup> The Minister for Health and Aged Care decides which research initiatives to fund, taking the MRFF priorities into account. Box 5.1 provides further information on how the MREE functions.

There is a clear opportunity for the MRFF to play a major role in harnessing research for better health, and unleash its potential to build clinician researcher capacity and capability.

The fund is still relatively young, and the process of optimisation often takes time. However, several reports, including a 2021 review by the Australian National Audit Office (ANAO), have identified opportunities to improve the program. At this early stage in its development, it is an important to engage actively with this feedback. Key issues include:

- It is not clear how the MRFF strategy and priorities map onto longer term plans. Funding is most effective when it is invested strategically. The ANAO reported that "there is no evidence of how the design of the MRFF 10-Year Plan was influenced by the Australian Medical Research and Innovation Strategy (MRFF Strategy) and Australian Medical Research and Innovation Priorities (MRFF Priorities)" and that "there is no direct relationship between the initiatives in the 10-year Plan and the MRFF Strategy and MRFF Priorities and it is not clear how the 10-year Plan was designed" (though we note that a new 10-year investment plan was published in March 2022 – after the ANAO report).<sup>92,96</sup>
- There is a lack of clarity regarding how the awarded funds align with the MRFF strategy and priorities. The ANAO reported that the Department of Health (as it was named at the time) "has not consistently advised the Health Minister of the MRFF Priorities that the proposed grant opportunities would address". AMRAB undertakes a process of open consultation in setting the MRFF strategy and priorities.<sup>97</sup> To meet community expectations, it is therefore crucial that spending maps onto these documents.
- More robust processes are needed for evaluating and monitoring MRFF performance. For a priority-driven funding scheme, it is critical to know whether the programs in place and the funds awarded are adequately addressing the agreed priorities. According to the ANAO, "The Department of Health does not have adequate

performance measures for the MRFF and has not effectively measured and reported on the performance of MRFF financial assistance in its annual performance statements".<sup>98(p2)</sup>

- Funding awarded through the MRFF appears to prioritise the fatality burden of disease over the disability burden. Researchers have highlighted that although the aims of the MRFF are to improve the health of all Australians, allocations to date have been shown to favour disease groups with a high fatality burden, rather than reflecting the disability burden of non-fatal disease in Australia.<sup>99</sup> There are opportunities for future MRFF funding allocations to be more equitable across the disease burden spectrum.
  - "I for one have not seen a single substrate that is pre-clinical, or even an early pre-clinical novel compound, that has come out of all the funding by the MRFF for translation. I don't expect that there will be any new substrates coming out of MRFF funding. I think that needs to be very seriously looked at – how it is being distributed ... I don't believe that we are lacking funding, I think it's the way it is being distributed."

Roundtable participant (researcher)

In summary, the MRFF funding distributed to date does not appear to clearly map onto the goals, strategies and priorities of the fund, and there does not seem to be a clear plan to provide more clarity here or to evaluate progress. Expertise from within the sector should be deployed to ensure that the most strategic, and therefore beneficial, approach to the MRFF is taken.

The sentiments we heard from researchers throughout our evidence gathering for this report echo these points. It is clear the research community greatly values the MRFF, but does not have a strong sense of how funding maps onto priorities, the fund's impacts, or the process for assessing those impacts. Researchers acknowledge that the MRFF is only a few years old, but there is a feeling that it has been in place long enough to be able to determine and communicate these aspects clearly.

"The other thing that's really key is coordination. I think there is a huge challenge around coordination and research funding in Australia, both government and non-government alike, and I think I have this vision of a utopia where there's minimised duplication and gaps between all of the different federal, state, local, philanthropic, and other funding sources in Australia. I think that would be a wonderful thing for the research sector, and I think we would get a lot more value out of our research sector, but it's certainly not an easy task."

Roundtable participant (research funder)

#### **Operation and management of the MRFF**

The MRFF is crucial to delivering the Academy's vision for a research-rich health system, but to do so there should be better harmonisation and coordination of funding with NHMRC. The ANAO has reported that the Department of Health "has not formalised arrangements with NHMRC for coherent and consistent coordination of MRFF funding and NHMRC programs".<sup>92</sup> Many of the researchers, funders, consumers and other stakeholders consulted during this project held similar views, and noted a lack of clarity in relation to the coordination of health and medical research funding across Australia.

There are already some mechanisms in place for planning and coordinating funding between NHMRC and MRFF. However, they are not widely known or recognised, and more importantly, are not used to their fullest advantage—as conveyed by the roundtable participants, survey respondents and consumers consulted for this project. Consequently, there is a lack of clarity within the sector about how funding programs fit together and the overarching strategy.

Better coordination could have a considerable impact on efforts to maximise the value of existing funding streams, with more clearly defined roles for the NHMRC and the MRFF. Australia cannot reach the levels of research investment achieved by larger nations, but we can optimise the harmonisation and coordination of our funding streams to maintain our competitiveness. As the biggest government funders, the NHMRC and the MRFF should set the tone for an integrated and transparent funding landscape. A more harmonised funding landscape would also be better able to participate in and contribute to an Australian alliance for transforming healthcare through research (Recommendation 1).

However, harmonisation between funding sources is not enough to unleash the full potential of the MRFF. The governing mechanisms of the MRFF and the NHMRC should also be more closely aligned. The importance of investing in administrative support for awarding and managing research funding cannot be overstated. Although it may seem to take some resources away from the funds available for research, the return in terms of efficient and effective management is considerable. If used effectively, this backing will help to ensure that investments in research provide value for money and reflect agreed strategic aims, with clearly differentiated roles for the NHMRC and the MRFF.

> There's lots of funders out there, but it's about bringing people together to make sure that we're working on something in the most strategic way possible."

Roundtable participant (research funder)

#### **Recommendation 7**

The Australian Federal Government should introduce a mechanism for stronger strategic harmonisation between funders, particularly the NHMRC and the MRFF, so that there is an optimal coordinated research response to established and new threats to the nation's health.

#### **Evaluation and monitoring of the MRFF**

A positive aspect of the MRFF is the consultation process undertaken to determine the fund's strategy and priorities. This helps to ensure investments can be made in line with community expectations. However, this process alone cannot provide such assurance – it must sit alongside a suitable evaluation and monitoring framework.

According to the Department of Health and Aged Care's monitoring, evaluation and learning strategy, the first impact evaluation to assess broader MRFF performance is not scheduled until 2024 – almost ten years after the fund was established, and seven years after the first grants were awarded.<sup>100,101</sup> This should be brought forward to provide assurance to the government and community, and to identify ways to optimise delivery of the goals, strategies and priorities of the fund.

We acknowledge that the MRFF only reached full funding capacity in 2020. However, it makes funding commitments that last several years into the future. For instance, MRFF expenditure at 30 June 2021 was \$1.2 billion, but the total value of MRFF grants awarded – and therefore committed in future years – at this date was \$1.8 billion.<sup>92</sup> This formative stage is a crucial time for evaluation, to ensure that the programs and structures through which funds are dispersed are performing optimally. The first five years of awarding funds run from 2017 to 2022, providing an excellent opportunity for a five-year evaluation.

## Building a clear picture of health and medical research funding

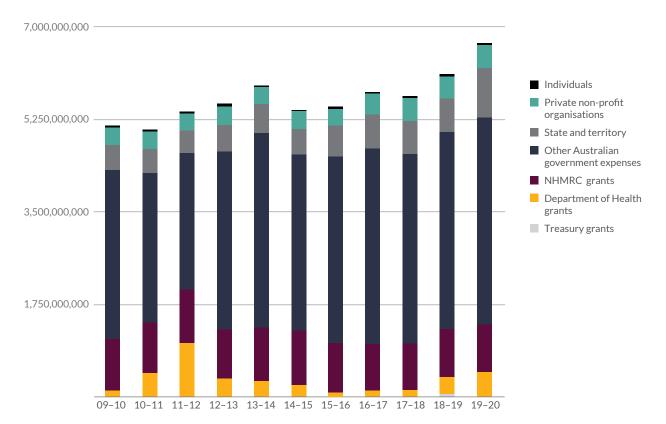
#### Australian Government funding

The Australian health and medical research funding landscape is a complex ecosystem of different sources interacting independently and in conjunction with one another. It includes a mix of funding from government (federal, state and territory), non-government (charitable/philanthropic) and industry/private sector sources. Box 5.1 provides an overview of these funding sources.

Australia spent \$6.66 billion on health research in 2019–20.<sup>102</sup> Figure 4 summarises the funding flows from government and non-profit sources (comparative data from industry were not available) based on data from the Australian Institute of Health and Welfare (AIHW). The NHMRC and the MRFF provided a significant proportion of government funding. Combined, they awarded almost \$1.3 billion of competitive funding in 2019–20, and this will rise to more than \$1.5 billion in 2021–22, as the MRFF reaches full capacity.

The largest proportion of funding for Australian health and medical research, however, is reported by the AIHW as "other Australian government expenses" - \$3.92 billion in 2019-20 (Figure 4). This amounts to more than half of the total reported expenditure. Despite this, all we know is that it incorporates government-funded university research and non-university research. for example in MRIs.\* Further detail on this expenditure does not appear to exist. Consequently, it is very difficult to assemble a comprehensive picture of how federal government expenditure on health and medical research is used in Australia and the extent to which it provides value for money. We do not know, therefore, how much of this funding is supporting activities that embed research in the health system. To maximise the value of existing and future investments, and to ensure these align with community expectations, it is crucial that we understand the source of these funds and how they are being deployed.

\*Confirmed to AAHMS in correspondence with the AIHW.



#### Health expenditure on research 2009/10 - 2019/20

Figure 4: Health expenditure on research by the Australian government, state/territory governments and non-government sources, 2009/10 – 2019/20. Prices are constant, based on the professional health workers wage rates index deflator. Source: Australian Institute of Health and Welfare, Health Expenditure Australia 2019-20.<sup>102</sup>

An overarching strategy for health and medical research and innovation in Australia is needed to support greater coordination between the NHMRC and the MRFF, and also more broadly.103 A strategy would assist in delivering long-term stability for the sector and a coherent overview that can guide funding and workforce plans. Embedding health and medical research and innovation within the health system, as described in this report, would be a crucial component of any such strategy. To maximise the value of such a strategy, the Australian Department of Health and Aged Care should develop clearly defined goals and identify mechanisms to evaluate and assess delivery of the strategy against those goals from the outset. This strategy should be developed in consultation with the health sector, researchers,

policymakers, consumers and communities. In their input into this project, funders stressed the importance of incorporating broad stakeholder consultation into priority-setting.

It is also important to acknowledge that setting a strategy is only the first step. To realise the intended benefits, implementation and monitoring will be key. The Australian Government will need to track expenditure and map it onto the priorities outlined in the strategy. This requires appropriate infrastructure to pinpoint all components of health and medical research spending more accurately. If more than half of the reported government spending is currently not easily traced, this needs to be addressed for Australia to make the most of this strategic opportunity.

## State and territory funding for teaching, training and research (TTR)

At a state and territory level, an important source of funding is known as teaching, training and research (TTR) funding. It is a portion of the funding provided to states and territories by the federal government through the National Health Reform Agreement (NHRA).<sup>104</sup> Teaching and training funds are used to support the acquisition of knowledge, or development of skills and expertise, e.g. for specialist training.<sup>105,106</sup> Research, or the "R" in TTR, is defined as "activity undertaken to improve consumer and patient health outcomes and/or performance".<sup>105</sup>

The story here is similar to federal government funding for health and medical research. Although the NHRA requires local hospitals to state the functions of their TTR funding, expenditure on each component (i.e. each of teaching, training and research) is not reported.104 It is therefore impossible to know how much funding is available through this stream to support research in the health system.

This presents another hurdle to grasping the full picture of health and medical research expenditure, making it difficult to understand how much money is being spent, how spending maps onto any overarching "Funding that goes in towards research in the healthcare sector needs to be monitored, built, and outcomes measured. There is that pool of funding that's hard to get a clear crisp definition of where it is and what it is, which I think is called TTR. The Teaching Training and Research, which goes federally into the state, and seems to disappear down lots of different cracks."

Roundtable participant (research leader)

vision or strategy for health research in Australia, and – importantly – the extent to which this represents value for money.

We believe work is needed to investigate how these funds are being used so that governments can be sure that the value of these investments is maximised. This needs to be undertaken as an independent review by expert health economists.

## Box 5.1: Who funds health and medical research in Australia?

Australian health and medical research funding is complex. As part of the evidence collection for this project, the Academy held a roundtable with research funders from across the sector. It was clear from this meeting that the funding system is made more challenging because funders see differences in their remits based on their origins, purpose, and the individual, organisation or group to which they are accountable. The information below describes the major Australian funding groups noted in this chapter and their overarching role in the broader funding landscape.

#### Australian government

The **NHMRC** and the **MRFF** are key funding mechanisms of the Federal Government. The NHRMC play a crucial role in funding activities from discovery research, through to supporting researchers across career stages and funding schemes to facilitate and scale up academic research for clinical benefit. It awards funds from the Medical Research Endowment Account (MREA), with grants awarded in 2019–20 totalling \$900 million.

The MRFF focuses on supporting researchers and industry to address research gaps and areas of unmet need. It considers potential capacity within the sector when establishing the objectives and scope of MRFF grant opportunities. It awards funds from an endowment that was set up in 2015, which was fully capitalised at \$20 billion in July 2020 and now provides \$650 million total annual research funding.

NHRMC and MRFF funds are governed by different processes. The NHMRC is an independent statutory agency that sits within the portfolio of the Health Minister. It awards grants mainly through four schemes: investigator grants, synergy grants, ideas grants, and strategic and leveraging grants (sometimes also undertaking targeted calls in specific areas). Grants are provided based on rigorous peer review of applications to ensure transparency, probity and fairness.<sup>89</sup> The NHMRC CEO recommends grants to the Minister, who approves the funding. In doing so, the CEO receives advice on expenditure for each grant scheme from the NHRMC Council. which in turn receives advice from the NHMRC Research Committee.<sup>107</sup>

MRFF awards funds under four themes: patients, researchers, research missions and research translation. MRFF activities are based on areas of national priority that are identified by the independent Australian Medical Research Advisory Board (AMRAB), in consultation with the sector and the public. AMRAB sets the Australian Medical Research and Innovation Strategy and the Australian Medical Research and Innovation priorities.<sup>93</sup> There is also a 10-year investment plan.<sup>96</sup> The Minister for Health and Aged Care decides which research initiatives to fund, taking the MRFF priorities into account.

The ARC is also an important funder of biomedical research in Australia through its National Competitive Grants Program (NCGP). The ARC does not support research with direct medical human health aims, but does support basic biomedical research. In 2021, ARC supported 35 grants classified as medical and health sciences, collectively worth \$21 million (approximately 3% of the ARC's total for the same period, which was \$673 million across 1,126 grants).^

## State and territory governments

State and territory governments have relatively smaller health and medical research budgets, and perceive their role as protecting, providing and investing in services through facilitation of health translation and implementation of research outcomes into healthcare. There are various funding streams, which differ in each jurisdiction, but teaching, training and research (TTR) funds are common to all state and territories because they relate to the NHRA.

## Non-government organisations (non-profit)

For charitable and philanthropic funders, budget constraints often result in a narrower funding focus. For example, an individual or organisation might focus on a particular disease, capacity building, research translation or medical research infrastructure. Hospital foundations have a particular role in supporting and translating the needs and expectations of their donors. A narrower scope can allow for some flexibility in funding arrangements, for instance to encourage strategic, larger-scale, multi-disciplinary research on emerging issues, perhaps cofunding with a source like the MRFF and partnering with other charities with similar goals.

## Industry and private sector

Industry and private sector funds come from a range of sources, which mostly target mid- to late-stage development and commercialisation, although sources such as venture capital and angel investors support the earlier stages.

<sup>^</sup>Data drawn from the ARC's "NCGP Trends: Areas of Research" resource, available from: https://www.arc.gov.au/grants-and-funding/apply-funding/grants-dataset/trend-visualisation/ncgp-trends-areas-research. Figures represent funds commencing in 2021 listed under Field of Research Code 11 (Medical and Health Sciences) – data access 22 April 2022.

#### **Recommendation 8**

The Australian Federal Government should provide greater transparency in the use of public funds for health and medical research, to ensure optimal alignment between national priorities for research and the application of resources.

### **Role of the Academy**

The Academy enjoys an excellent relationship with Australian funders including the NHMRC and MRFF. We will continue to work with them constructively, in any way we can, to ensure that the value of Australia's investments in health and medical research and innovation are maximised and particularly to ensure they are deployed to help deliver the Academy's vision for a research-rich, evidence-based health system.



# 6.

## Pillar three: Consumer and community involvement

#### Our vision

The whole community has more equal opportunities to shape, participate in and benefit from research that is relevant to them, as active and valued partners, participating with fully informed consent.

### **Key messages**

- Involvement of people with lived experience of a health issue in research design, interpretation, implementation and dissemination is an ethically and scientifically essential component of health and medical research.
- Individuals and communities with lived experience of a health issue provide critical perspectives for generating research questions, setting research priorities, understanding how research can be translated into practice, and monitoring the effectiveness of implementation in practice.
- Active and equal partnerships between people with lived experience of a health issue, health and medical researchers, and those who deliver healthcare are key to valuing these perspectives and avoiding tokenistic consumer involvement.
- Barriers faced by researchers seeking to involve consumers relate mostly to time, funding, access, resources, and a limited understanding of how best to involve consumers.
- Barriers faced by consumers who are keen to engage in research relate to limited knowledge of, or access to, research, lack of appropriate training or communication, and not feeling their perspectives are valued.
- Priority populations are underrepresented in health and medical research. Authentic

partnerships that actively engage the full diversity of the whole community and the public are an important lever in advancing health equity.

• Consumer and community involvement done well can enhance the responsiveness and relevance of research to the country's health needs.

## Introduction

Throughout this report, we outline a vision for how Australia's health system can benefit from embedding research and innovation as core functions, and we describe how this can bring about better health for the nation. A crucial aspect of creating such a system is to ensure that research and innovation involves and meets the needs of the whole Australian community, by:

- 1. Involving consumers in all stages of research including design, interpretation, implementation and dissemination.
- 2. Ensuring that research addresses the needs of all people.

Australia has made good progress towards achieving these goals, particularly over the last decade. There have been significant efforts across the health and medical research sector to involve consumers more meaningfully in research as part of the team, not only as participants or patients. Many consumers, consumer organisations (such as the Consumers Health Forum of Australia), health and medical research funders, governments, research institutions, researchers and health services have worked to advance research that is most likely to meet the country's health needs. It is important to note that working with consumers is a core principle for the delivery of healthcare in Australia. The National Safety and Quality Health Service Standards (NSQHS) outline the expected level of care in Australia, and they include "Partnering with consumers" as one of two standards that underpin all others (alongside a standard on clinical governance).<sup>108</sup> This standard refers to the involvement of consumers in overall governance, policy and planning within health service organisations, including in relation to research. Box 6.1 outlines what we mean by consumer.

This is a welcome shift, but researchers and consumers still report barriers preventing faster and more meaningful progress. During our evidence collection, we spoke to consumers from around Australia. They told us about their experiences of being involved in health and medical research, and shared their perspectives on how the sector can advance existing efforts to improve consumer and community involvement. We also heard from researchers who reaffirmed the importance of consumer involvement, and articulated a desire to see further change.

In this chapter, we consider ways to advance consumer and community involvement to ensure it becomes an essential platform and standard practice for health and medical research. This cannot be done effectively without enabling all people to have more equal opportunities to become, and remain, involved. However, at present participation in health and medical research in Australia does not adequately reflect the diversity of the population. We therefore also highlight gaps in Australia's approach to ensuring diversity, equity and inclusive consumer involvement in research; and we identify opportunities to do better and to learn from researchers and communities that are on the right track.

Involving consumers and communities as part of research teams, for instance in co-design, interpretation, implementation and dissemination, is different in practice to involving consumers as participants or patients in research studies. This chapter addresses both types of involvement holistically, and makes recommendations that can be built upon to develop more nuanced and targeted solutions that cater for these different facets of research.



### Box 6.1: Who is a consumer?

The language used to describe people who use the health system is important. A shift away from the term "patient" has become increasingly accepted in clinical and research contexts. For many, the word "patient" implies passivity, a recipient of care who does not actively participate in the process. Words like "consumer" and "user" have become popular alternatives because they aim to describe a more equal relationships between the healthcare professional and recipient, addressing any implicit power imbalance associated with other terms or phrases (see Figure 5).

Consumers are people who have lived experience of a health issue, and the wider public who have used, or will use, the health system. They include patients and those around them, such as family, friends, carers and communities. In this report we use several terms, but it is important to be clear that the Academy envisions an active and full partnership between researchers, clinicians and people with lived experience of a health issue.

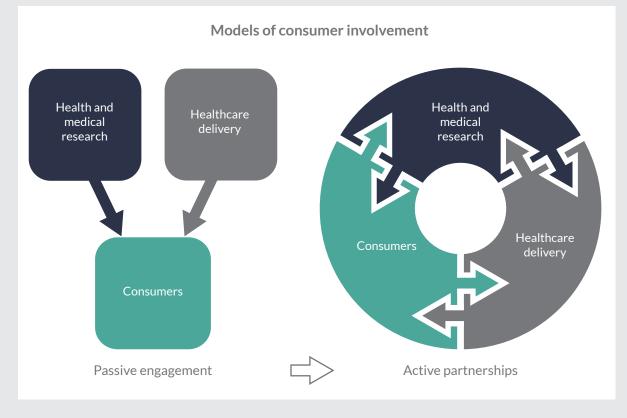


Figure 5: Old models of consumer involvement in research positioned them as essentially passive participants. A partnership model, in which consumers are equal and essential participants, is preferable.

## Consumer and community involvement in all stages of research

There is a clear moral and ethical imperative to involve people with lived experience of a health issue, and the wider public, in all stages of research including design, interpretation, implementation and dissemination. Consumers have the right to be included in investigations and decision-making around matters that will impact them, to the extent to which they wish to be involved – and, of course, with their consent. By empowering individuals, groups and communities to partner across the full spectrum of health and medical research, they can play an active and informed role in managing their health issues.

Beyond the moral and ethical considerations, consumers and communities have important knowledge that can enhance the value and efficiency of research. Over the past few decades, it has become widely recognised that consumer and community involvement has many benefits – Figure 6 outlines some examples. Growing evidence locally and internationally shows the positive impact of this involvement on legislation, policies and funding towards improving health.<sup>109</sup> Consumer and community involvement, when done well, "[Consumer engagement] also gives your patients the opportunity to contribute to research. And for many patients, that's very important and very fulfilling. Sadly, we do see a lot of kids who don't have treatable disorders, but being able to, for their families, to take part in research really has meaning for them to contribute to better understanding of disease."

Roundtable participant (researcher)

can tap into unique perspectives that can influence research planning, funding, translation, monitoring and evaluation, and by doing so, can enhance the responsiveness and relevance of research to the country's needs. It is important to ask what this looks like in practice, who should be included, and how we can do more to address superficial or tokenistic approaches to consumer involvement. Box 6.2 summarises some of the key characteristics for developing a research ecosystem that involves consumers and communities meaningfully and authentically.

#### Consumers

- Greater agency over research questions and designs related to their health
- Better access to the latest health information, treatments and technologies
- Improved health literacy
- Improved awareness and curiosity about research
- Engenders a social responsibility to contribute to public health

#### Researchers and the health system

- Greater relevance and responsiveness of research to health needs, and therefore better quality research
- More effective research translation into healthcare delivery
- More efficient implementation of research into policy
- Improved impact on health outcomes
- Greater trust and stronger relationships
  with consumers
- Better opportunities for research funding

#### Society

- Improved dissemination of research findings to the community
- Improved public health and subsequent economic benefits
- Better public engagement in
- Improved public confidence
- Improved health literacy

#### Meaningful and authentic community and consumer involvement

Figure 6: Benefits of consumer and community involvement in health and medical research

## Box 6.2: Characteristics of diverse, equitable and inclusive consumer and community involvement

The Academy's vision seeks to build a research-rich ecosystem that enables people with lived experience of a health issue, researchers and healthcare professionals to partner in driving better health outcomes. Diverse, equitable and inclusive consumer and community involvement would see each of these partners playing an active and equal role in growing and supporting a system that generates mutual benefit. Levers from across the sector must be utilised, and opportunities for leadership should be seized to create holistic change.

To move towards this goal, consumers and communities should be:

- valued as equal partners in research
- recognised appropriately and compensated for their participation
- involved in all aspects of health and medical research, from the beginning
- provided with the support, resources, training and access to become involved in, and remain active in, research
- enabled to become champions of health and medical research.

Health and medical researchers should:

- be incentivised to conduct research that involves consumers at all stages
- be provided with the necessary training, time, resources and support to involve consumers meaningfully and authentically. This includes acceptance of consumer involvement as a direct research cost by funding bodies
- have access to greater opportunities and infrastructure that supports research that is co-designed, executed, monitored and evaluated with consumers
- have better access to consumers who are ready to participate in research
- sustain relationships with consumers and communities
- promote a research culture that involves consumers.

The Academy envisions a research and healthcare landscape in which these characteristics are entrenched within health and medical research governance, policy, funding, infrastructure, workforce culture and public engagement. As health services increasingly formalise consumer involvement in their governance structures, there is the opportunity to align with consumer involvement in research that is embedded within those services.

In this report, we highlight opportunities to build a research culture within the health system and increase research activity in these settings. By doing this inclusively and equitably across the country, the Australian health and medical research sector will be better equipped to involve a range of consumers and communities with lived experience of health issues. In addition, an inclusive system is a diverse system in which representation matters. An important step towards improving this will be to grow the diversity of the health and medical research workforce to reflect the population in which it works, and we address this in Chapter 4.

#### The current picture in Australia

Consumer involvement is widely accepted in Australia as being best practice in health and medical research, and we know there is an appetite among consumers to support research, motivated by a desire to be agents of change and contribute to a meaningful cause. Box 6.3 outlines some of the motivations for why consumers engage in research.

The advantages of consumer and community involvement are well known, and its importance is recognised across guidelines and policies nationally. People with lived experience can make valuable contributions across the research pipeline, including generating research ideas and questions, evaluating healthcare practices, and developing and disseminating guidelines based on research.<sup>110,111</sup> Consumer-driven research is listed as a top priority in the most recent set of Australian medical research innovation priorities that guide investment through the MRFF (noting that at the time of writing, these were still in draft and waiting to be approved by Parliament).<sup>45</sup> It states the need to conduct:

"Research that is driven by meaningful consumer involvement and partnerships, to incorporate priorities, needs, values and experiences to deliver fit-for-purpose outcomes that can be adopted by consumers, carers, healthcare professionals and other end-users"

There are many examples in Australia of good progress in consumer and community involvement in health and medical research. For instance, this has been a priority for the Research Translation Centres (RTCs, explained further in Chapter 7), both individually and collectively. The RTCs work together through the Australian Health Research Alliance (AHRA), which has a Consumer and Community Involvement (CCI) Initiative that "aims to embed the involvement of consumers and the community in health and medical research policy and practice".<sup>112</sup>

The NHMRC has recognised the importance of this agenda, having released a toolkit for researchers, research organisations, consumers and consumer/ community health organisations to guide them through all stages of research.<sup>111</sup> The NHMRC has a Consumer and Community Advisory Group (CCAG)

that provides strategic advice, routinely appointing consumer and community representatives to the Council and Principal Committees.<sup>111</sup> Similarly, the MRFF Consumer Reference Panel (CRP) aims to strengthen consumer involvement in the implementation of the MRFF, providing advice directly to the Chief Executive Officer of the Health and Medical Research Office.<sup>113</sup> Other guidelines, frameworks and toolkits from various state, territory and national organisations, including peak bodies, consumer groups, government departments of health and research translation centres, have also been developed for the same purpose. For example, in 2021 the Western Australian Health Translation Network (WAHTN - an RTC) worked with AHRA to develop a practical handbook for organisations, researchers and consumers, to assist them in involving consumers in health and medical research.<sup>114</sup> There are also examples of progress in the context of specific health conditions.<sup>115</sup>

"We went through many sessions with everybody involved in the research, but what we picked up mostly was new researchers, clinicians interested in research ... They all became interested once we started with the patient and only the patient first. And that generated some significant excitement amongst the whole research crew."

Roundtable participant (healthcare executive)

Australia's overall track record in advancing consumer and community involvement in health and medical research has been positive, and this seems to be reflected in the experiences of consumers. We heard from consumers who felt that they were developing a better understanding of research and how it contributes to their health, more willingness to become involved, and better access to research opportunities. However, there is still a long way to go for meaningful consumer and community involvement to become standard practice. At present, there is limited information available that details the involvement of consumers across the full spectrum of research in Australia. <sup>115-117</sup> Consequently, it is challenging to establish where we are as a nation in advancing efforts to involve people with lived experience of a health issue and the wider public in health and medical research.

## Box 6.3: Why do consumers engage in health and medical research?

As part of the evidence collection for this report, the Academy convened a roundtable to better understand the experiences and perceptions of consumers who engage with health and medical research. Participants described several altruistic and personal motivations behind their engagement, including:

- improving the experience of others and being 'agents of change'
- contributing to a meaningful cause
- contributing an underrepresented perspective
- believing in the power of research
- making a difference for a loved one
- giving something back to the health system
- gaining a better understanding of health problems and research
- improving personal health
- feeling valued and empowered
- gaining new skills and learning new information.

"By taking part in clinical trials, I can contribute to the advancement of scientific knowledge and in some cases to improve health for myself and others with the same disease and condition."

Roundtable participant (consumer)

## Barriers within health and medical research

In our evidence collection, we heard about barriers that prevent health and medical researchers from involving consumers and communities meaningfully and authentically in their research. A lack of time, funding and resources remain key issues. We also heard that researchers face challenges associated with understanding how to meaningfully engage with consumers, and developing the confidence to do so successfully.

Some practical areas where limitations were felt most acutely include:

- finding consumers who are informed and prepared to be involved in research, or able to provide training to inform and prepare consumers
- finding consumers who reflect the diversity of the Australian community, including priority populations
- developing capacity to provide sustained, targeted and appropriate consumer communication
- having enough time and resources to build trust
- developing and sustaining relationships with communities
- overcoming cultural, language or other communication barriers.

"A lot of researchers don't know how to involve consumers in a meaningful way."

Roundtable participant (consumer)

There has been some progress in recent years to address many of these issues, but while researchers report experiencing more opportunities to engage consumers and communities, we heard that many of these fundamental challenges still exist in practice. It is important that these endeavours are seen as valid components of grant funding applications.

National guidelines and principles do exist, such as those developed by NHMRC, but they are yet to be widely adopted, causing a fragmented and inconsistent approach across organisations and institutions. These guidelines and principles should be promoted to ensure consistent adoption of consumer and community involvement, and to ensure it is valued as an essential platform to good research.

Co-design is an example of an important approach to involving consumers and communities in research that has been promoted by research institutions, consumer organisations and research funders across the sector. Co-design done well can enable researchers and consumers to build trusting and authentic relationships, and share power in research planning, decision-making, execution and evaluation. Importantly, co-design facilitates dynamic approaches to research, allowing it to be shaped by, and meet the needs of, each individual circumstance. Although co-design is clearly valued across the sector, current approaches are inconsistent. Researchers, consumers and communities would benefit from stronger guidelines and principles that can be adapted where needed.

It is important to acknowledge that funding is a crucial lever to facilitate meaningful and authentic consumer and community involvement. Efforts by Australia's major health and medical research funders to advance this agenda have significantly contributed to progress. However, researchers still report that consumer and community involvement is perceived as a "nice to have", rather than an essential component of research. Health and medical research funders, working with researchers and consumers, should look more closely at the ways in which consumers are involved in research. This will help to determine areas that can be advanced to position consumer and community involvement as standard practice, and reduce tokenistic approaches. An Australian alliance for transforming healthcare through research would be well placed to facilitate a coordinated approach to advancing this area. Such an alliance should be a champion for consumer and community involvement in research by promoting adherence to current national principles and guidelines, and widespread adoption and implementation of best practice approaches. It should be guided by meaningful input from consumers and communities.

Having a clear picture of the state of consumer and community involvement in research is important. Frameworks to quantitatively track progress of consumer and community involvement, for example through funding applications, could help build our understanding of the current landscape and provide a basis for suggested improvements in the future.

#### **Recommendation 9**

A more consistently applied framework should be developed to improve and broaden consumer and community involvement in health and medical research. An Australian alliance for transforming healthcare through research would provide the leadership necessary to achieve this outcome. This work should be supported from the outset by consumer members and a consumer advisory panel.

#### **Recommendation 10**

Health and medical research funders should allow the costs of consumer and community involvement to be included in grant proposals as direct research costs, and should work towards including consumer and community involvement as an essential element of relevant research projects, ultimately making it a criterion for success of those applications.

#### **Barriers for consumers**

Consumers report experiencing numerous barriers to becoming and staying involved in research, often personal to their circumstances. During our evidence collection, we heard of common challenges, including:

- limited knowledge of health and medical research opportunities
- limited access to researchers and research settings
- lack of knowledge or confidence in their role
- past negative experience
- lack of time and training to feel prepared and informed
- concerns about privacy and anonymity
- lack of support and communication from researchers to address questions or concerns
- distrust in health and medical research
- limited or non-existent follow up and access to information regarding research outcomes
- the design of research studies making participation challenging
- feeling that their time or participation is not sufficiently valued.

In short, consumers are not seen as critical members of health research teams.

Many of these barriers are amplified for people in priority and marginalised population groups, each group experiencing different impacts that define their relationship to health and medical research. Older Australians, Aboriginal and Torres Strait Islander peoples, those from culturally and linguistically diverse (CALD) communities, low-income earners, people with low health literacy, and rural, regional and remote communities are examples of groups that experience challenges.

To enable consumers to participate in health and medical research, the sector should create more straightforward pathways for people across the community to become and remain involved. During our evidence collection, consumers told us they want to be involved in research from the beginning, and they would value the opportunity to develop better relationships with researchers. Box 6.4 outlines enablers for participation and pathways to consumer and community involvement that should be built on. These include:

- trusting and open relationships with researchers
- consistent and clear communication
- involvement from the beginning
- coordination between healthcare delivery and research.

In addition to meaningful consumer involvement in the design and delivery of research, it is important to enable and improve consumer recruitment to participate in health and medical research studies. The Join Us register at The George Institute for Global Health Australia is an example of an easy pathway for consumers to become participants in research, and for researchers to partner with those who have signed up.<sup>118</sup> This register provides a secure platform for participants to allow their personal and health data to be collected, enabling the register to match participants to studies they are eligible for.<sup>118</sup> "What went wrong for me was the relationship between the doctor as a clinician and the doctor as a researcher, and me as a patient and me as a research participant."

Research participant (consumer)

There are also good international examples of structures that facilitate consumer and community involvement. For example, England's NIHR BioResource recruits (and stores samples from) patients with common and rare diseases who would like to be invited to participate in research – it currently has just over 203,000 participants.<sup>119</sup> NHS Research Scotland's Share initiative is a register of almost 300,000 volunteers who have agreed to share their clinical data and unused elements of routine tests on blood and other body fluids.<sup>120</sup>

Consumers and researchers would both benefit from the development of pathways that make the process and experience of becoming involved in research simpler and more accessible. Such efforts must always be accompanied by regular communication to ensure those who sign up feel informed, even if they are not currently participating in a study.

"And it's people not being aware that, for instance, I have a latestage cancer, homeless people have cancer. Some [research is] not looking after the disenfranchised."

Research participant (consumer)

### Box 6.4: Consumer enablers for participating in research

As part of the evidence collection for this report, the Academy convened a roundtable where consumers shared their experiences of participating in health and medical research. Most consumers had engaged in more than one research project, having had different experiences each time - both positive and negative. Consumers heard about research through multiple channels, and had various reasons for wanting to contribute again or stop completely. Something that came across strongly was a deep desire to improve care and experiences for others. Some consumers were willing to recall negative, sometimes even traumatic, experiences to

help improve services for others. These types of experiences must guide how we treat this important relationship. The following themes emerged as key enablers to consumers becoming, and remaining, involved in research:

#### **Relationship building**

Consumers consistently highlighted positive experiences in health and medical research as ones where researchers spent time and effort building relationships. One consumer was part of a university sector research project where they went through a six-month, one-on-one program with the research team. They felt listened to and supported. Conversely, one consumer described an experience in which the research team lacked empathy, training and accountability, which made the consumer feel vulnerable and angry. As highlighted elsewhere in this chapter, researchers need sufficient time to do this properly.

#### Consistent, clear communication and growing consumer knowledge

Consumers reported that consistent communication was key to a smooth process. It was noted that communication should continue even after the project has been completed. Several consumers expressed



that they would like to have been made aware of the research outcomes. Some also felt that researchers use too much "research language" to communicate, which did not help their understanding of the project or their role. Consumers also felt it was important for researchers to expand consumer knowledge around research processes and set expectations. For example, one consumer said they were not aware research can take 15–20 years to be translated into practice. They felt that informing the public

could lead to more realistic expectations and greater engagement, which is important for the wider health and medical research community to consider.

## Involving consumers at an early stage

Consumers shared multiple experiences as participants during the execution of health and medical research. Many consumers described a desire to be involved from the beginning so they could have a say all the way through from research design to evaluation. This was important from a practical perspective, for example one consumer described a study that required specific visits to a healthcare facility that were unmanageable alongside commitments such as work.

For consumers who give more time to this level of involvement, it is also important that their time is valued and recognised – for instance through honoraria. This does not apply to all those involved in research, but for instance to those who contribute to co-design.

#### Coordination between those who deliver healthcare and research teams

Some consumers described their general practitioners (GP) as being their entry point into health and medical research. This usually occurred either because the GP was involved in the research, or because they had connections with someone else involved. However, one consumer reported that they felt their GP's research agenda was interfering with their care. We heard that better coordination and communication between health professionals and researchers could improve consumer experiences.

## Ensuring research addresses everyone's needs

Consumer and community involvement in all stages of research can only be truly successful if all people in Australia have equal opportunities to shape, participate in and benefit from research that addresses their needs. At present, participation in health and medical research is skewed towards population groups with higher health literacy, who are less diverse, and who have greater access to health services.<sup>121</sup> This means that consumer and community involvement in research does not adequately reflect the diversity of the population, making any potential benefits less relevant to, or appropriate for, those not represented.

Authentic partnerships that actively engage the full diversity of the whole community in health and medical research are an important lever in advancing health equity. When research is designed, executed and translated with a lack of understanding of the social, cultural and economic experiences of priority populations, results can be mismatched to the realities of people's lives - often leading to inappropriate interventions. For example, clinical trials can enrol homogenous populations that do not accurately represent the people served. A 2020 analysis of global participation in clinical trials, conducted by the US Food and Drug Administration, highlighted a vast difference in the diversity of enrolled participants and the global population. Of nearly 300,000 participants in clinical trials globally, approximately 76% were white, 11% were Asian and 7% were Black.<sup>122</sup> In comparison, the distribution of the global population is approximately 59% in Asia, 18% in Africa, 9% in Europe, 8% in North America, 5% in South America and 1% in Oceania.123

In Australia, Aboriginal and Torres Strait Islander peoples, rural, regional and remote communities, and CALD communities do not have equal opportunities to become involved in research.<sup>124</sup> Many organisations and groups are working to improve this. For instance, in many ways, research with Aboriginal populations has been at the forefront of consumer involvement. Aboriginal communities were some of the first to clearly articulate how research that does not genuinely involve Aboriginal consumers and communities as partners is inappropriate and unethical.<sup>125</sup> Other organisations are contributing by growing our knowledge around the demographics of consumers involved in research, and identifying areas for change. For example, the Australian Clinical Trials Alliance (ACTA) undertook a project to better understand approaches to improve clinical trial awareness, involvement, and access with, and for, people from CALD background.<sup>126</sup> They found that there is poorer awareness and access to clinical trials in these communities when compared to the general population. ACTA concluded that approaches to engage CALD individuals and communities from the outset should be established and implemented.

A lack of diversity and equity in health and medical research could have significant social and ethical implications – as has already been seen in some circumstances in Australia and internationally.<sup>122</sup> This could leave certain groups with limited access to potentially beneficial research and healthcare, or build mistrust among priority populations – with both outcomes further exacerbating health inequities.

One example of this is rural, regional and remote health and medical research. Almost one-third of Australia's population lives in non-metropolitan settings. People living in these communities experience higher rates of hospitalisation, deaths and multimorbidity, and poorer access to health services, than people living in metropolitan areas.<sup>127</sup> People with lived experience of health issues unique to these settings have the right to partner with researchers investigating these issues, and researchers need a system that facilitates this. However, there are several systemic and structural barriers impacting researchers attempting to work with rural, regional and remote communities including:

- limited funding
- limited access to research settings or infrastructure
- challenges balancing service delivery and research

"The challenge people always believe is that [they've] got the mainstream solution and tell Aboriginal and Torres Strait Islander people to adapt it. What we're saying is we've actually got solutions that have been proven across generations and time. Why can't you adapt ours to have a better health for every person."

Project interviewee (Aboriginal or Torres Strait Islander researcher)

- limited support
- challenges relocating
- lack of incentives to relocate or conduct research in these settings
- better offers elsewhere
- fewer opportunities for career growth and development.

Rural, regional and remote consumers face their own unique challenges to participating in research.

Variability across research settings and communities presents one of the most significant challenges for the sector in driving forward a more diverse, equitable and inclusive ecosystem. Research cannot be done the same way in all settings to achieve the same outcomes. Consequently, standardised approaches and principles to guide consumer and community involvement must be dynamic to ensure research can be shaped to meet the needs of each circumstance. While this presents a challenge, it is crucial that we accelerate progress to address the systemic and structural barriers to a diverse, equitable and inclusive research ecosystem, by advancing efforts to promote the key characteristics mentioned earlier in this chapter.

#### Aboriginal and Torres Strait Islander-led research: Lessons from a community making progress

In our evidence collection, we heard from Aboriginal and Torres Strait Islander researchers and experts across the sector, and from those working with Aboriginal and Torres Strait Islander communities. They provided their perspectives on the impact of the historical, and in some cases current, approaches to research into Aboriginal and Torres Strait Islander health and wellbeing. Since colonial times, most research relating to First Nations peoples has been conducted on these communities rather than with them; the deficit discourse around First Nations health and wellbeing (which refers to disempowering patterns of thought, language and practice that represent people in terms of deficiencies and failures) has influenced researchers and the type of research they choose to conduct. This, among other factors, has contributed to the health inequities facing Aboriginal and Torres Strait Islander peoples and communities today.128

"For Aboriginal and Torres Strait Islander people, we think in generations. We think in, if you invest in this one person now, and it's the investment in people then [there will be] longer term generational impact, and that's why lots of First Nations people talk about generational responsibility and the impact on generations. We're not interested in just the here and now, that's a quick fix. That means that we will have exactly the same problem coming up, every cycle."

Project interviewee (Aboriginal or Torres Strait Islander researcher) More recently, models and approaches to health and medical research have begun to shift. Through the advocacy and activism of Aboriginal and Torres Strait Islander peoples and organisations, more self-determined health and medical research is being conducted with Aboriginal and Torres Strait Islander communities.<sup>125</sup> Aboriginal and Torres Strait Islander-led research has been instrumental in driving change towards higher levels of research that involve communities as active and valued partners.

Despite facing significant barriers, Aboriginal and Torres Strait Islander researchers who conduct research with Aboriginal and Torres Strait Islander communities have, in many cases, found ways to engage meaningfully and authentically. These groups continue to make progress, and there are many lessons to be learned that could advance consumerdriven research for the wider Australian population.

Some key principles from our evidence collection for better community involvement are:

- Each Aboriginal and Torres Strait Islander person and community is treated as unique.
- More research is responsive to the needs of the community.

"If we're in a relationship with a community, irrespective of whether we've got a major grant going ... we'll hold three or four morning teas a year. Just so that they still see that even though we're not actively in grants or we're not actively researching at the moment, we are actively maintaining a relationship."

Project interviewee (Aboriginal or Torres Strait Islander researcher)

- Flexibility and adaptability in research processes are essential to account for community needs.
- Greater emphasis is placed on protecting Aboriginal and Torres Strait Islander community ways of knowing and being, and self-determination.
- Long-term and generational impact is always considered.

#### **Recommendation 11**

Those measuring research impact and researcher track records should incorporate measurements that place greater value on work to develop community and consumer involvement, including with priority populations such as Aboriginal and Torres Strait Islander communities – as an acknowledgment of not only the importance of these endeavours, but also the time commitment required to do them meaningfully. Examples of where this is needed include:

- · criteria that research institutions use for staff promotions
- prioritising advice from NHMRC Consumer and Community Advisory Group (CCAG) in relation to NHMRC funding mechanisms
- criteria applied to MRFF funding mechanisms
- Australian Research Council (ARC) Engagement and Impact Assessment.

By following these principles and building and sustaining community relationships, researchers can avoid creating or exacerbating community perceptions that they are only approached when they are 'valuable' to researchers. Investing in these relationships is key and means moving beyond grant-to-grant engagement to connect with communities outside of this cycle.

There are currently limited resources to engage in this kind of capacity strengthening, despite the long-term benefits to communities and the health and medical research sector. Although Aboriginal and Torres Strait Islander research has been paving the way for decades, researchers, organisations and communities have endured significant challenges to maintain progress.

We need a system that empowers communities and researchers to deliver research that follows these principles across the spectrum of health and medical research.

## The use of patient data

Health data are an important tool for better understanding disease, and for improving health, care and treatment. The recent exponential growth in the collection and availability of electronic health data has created new opportunities to advance health and medical research. To build clinical research capability in Australia, we must capitalise on opportunities to make use of the ever-increasing volume of health data. The Academy published a report in June 2022 that highlighted the need for Australia to generate an environment that enables the safe and secure use of patient data for legitimate research purposes, balanced with protecting the rights and interests of individuals.<sup>129</sup>

Our report stressed the need for more coordinated and coherent data infrastructure, assets, policies, governance and ethics processes. In particular, it called for a national linked data asset that could be used across disciplines and sectors, and which follows the FAIR (findable, accessible, interoperable and reusable) and CARE (collective benefit, authority to control, responsibility and ethics) principles. Such an asset would create opportunities for research that responds to patient needs.

## **Role of the Academy**

The Academy was delighted to engage with consumers in our evidence collection for this project and we hope that we have done justice to their generous contributions. The Academy is still a young organisation, and this was our first major engagement with consumers. We are committed to maintaining and improving this aspect of our work, especially in relation to our policy projects – in line with the conclusions and recommendations of this chapter. For instance, we will endeavour to involve consumer expertise as early as possible in relevant future policy projects.

We will also work to celebrate consumer-driven research by:

- exploring how we can better account for and recognise meaningful consumer and community involvement in our Fellowship election, recognising efforts to develop ongoing relationships with communities including priority populations
- finding opportunities to celebrate the work of our Fellows and Associate Members who have impacts in consumer and community involvement
- ensuring that, through our Fellowship election, we recognise research and innovation that addresses the health needs of all Australians, including Aboriginal and Torres Strait Islander peoples.

We will also continue our efforts to communicate the outcomes of health and medical research more broadly, and the processes involved in research, as a more general response to what we heard from consumers about the need for good communication.

# 7.

## Pillar four: Integrated teams and cross-sector collaboration

#### Our vision

An active health-academia-industry interface that works dynamically to enable fully integrated research teams. These teams are supported by healthcare executives and research institution directors who see research and innovation as core functions of health.

## Key messages

- Australia is not currently maximising health innovation and commercialisation opportunities.
- Addressing patient needs and improving healthcare through cutting-edge research is best achieved by integrated research teams that incorporate multidisciplinary insights and expertise. More work is needed to develop a health-academia-industry interface that facilitates the work of integrated teams.
- Clinician researchers and health services need to develop capabilities in commercialisation.
- Australia should invest in individuals and organisations that bring people and ideas together to help build a research and innovation culture, which takes work.
- Research Translation Centres (RTCs) have broad coverage across country, providing an established mechanism for facilitating translation. They work locally, but also come together nationally through AHRA. They should be supported and strengthened, and their coverage broadened to include as much of Australia as possible. Access to core funding would help them to develop this role.
- Investment in implementation science is needed to ensure that research is rapidly translated into practice.

## Introduction

The desire to see more collaboration was frequently raised by stakeholders during our evidence collection. Senior healthcare executives told us that this needs to be better integrated in the health system, stressing the importance of collaboration over competition for the ultimate benefit of patients. We also heard that Australia needs to do more to encourage industry engagement, commercialisation and entrepreneurship.

#### "I see the best impact on patients when we have collaboration and it's teams upon teams upon teams"

Roundtable participant (healthcare executive)

Throughout this report, we discuss the importance of culture, including the crucial role of the workforce in driving culture change. They can only do so in the context of a thriving health–academia–industry interface, from clinician researchers working in joint roles across academia and health, to clinicians and industry working together to deliver trials of cuttingedge new treatments. Fragmentation is a recurring theme in our findings and has a negative impact on efforts to nurture an active and dynamic health– academia-industry interface. A thriving culture for research and innovation – and their implementation – in the health system requires:

- 1. **Integrated teams** that incorporate insights and expertise from across sectors, disciplines, specialties, and different health settings and geographies.
- 2. Knowledge brokers that bring people and ideas together to help align agendas and pull towards a common goal; they can be either organisations or individuals.

Consumers and communities are also important in supporting a strong culture through contributions to the design and delivery of research – they must be at the centre, as addressed in detail in Chapter 6.

In this chapter, we explore how Australia can build a strong research and innovation culture by building capability and capacity at the nexus of the health– academia–industry interface. The issues raised here reinforce the potential value of an Australian alliance for transforming healthcare through research, which would play a crucial role in improving this landscape, since it would bring together key stakeholders to foster a more collaborative environment.

## Building integrated teams in health

Integrated teams incorporate insights and expertise from across health, academia and industry, within and alongside the community, to:

- ensure that research is informed by patient and system needs
- deliver research outcomes that are more relevant to the health setting and therefore easier to integrate into practice
- tackle contemporary health challenges, which increasingly require insights from multiple areas of expertise and experience.
- reduce silos and support a more systems-based approach to research and innovation

• broaden the scope of potential solutions, by engaging a wider range of expertise.

Integrated teams enable working across sectors, disciplines and specialties. They recognise that it is not only health professionals such as medical, nursing, midwifery and allied health practitioners who are required to optimally embed research in the health system, but non-clinicians too. Data scientists, biostatisticians, health economists, health services researchers, public health experts, implementation specialists, regulatory experts and others all bring crucial expertise. The increasing digitisation of health information is one transformative change to healthcare delivery. Researchers who can produce, collect, store and interpret this data can help integrated teams advance approaches to research design, delivery and evaluation.<sup>129</sup>

The COVID-19 pandemic showed the value of embedding research in health, and building integrated teams that can rapidly respond to evolving situations. Australian research helped to deliver high-quality evidence that informed the treatment of critically ill patients from a very early stage, as outlined in Box 7.1.

"If you look at some of the really cutting-edge centres ... you've got not just the clinicians working together with the academics, but you've got industry onsite as well. It might be pharma [or] a huge range of small start-up companies that form an ecosystem. And that really is a fantastic stimulus for good research. The one bit that I think is sometimes omitted from the conversation is the role of patients as well. If we're talking about collaboration, it has to bring the patients into the conversation with all the research that we're doing, especially the translation side."

Roundtable participant (healthcare executive)

In recent years, Australia has developed precincts as hubs for health and medical research and innovation. This can create fertile grounds for establishing integrated teams. Parkville in Melbourne, for instance, is made up of over 40 hospitals, medical research institutes (MRIs), universities and biotechnology organisations. The Westmead Health Precinct in Sydney is home to four major hospitals, four MRIs, two university campuses and a researchintensive pathology service.<sup>130</sup>. These were highly productive sites for research and innovation during the pandemic.<sup>131</sup> Similar developments also exist across Australia, for example the Herston Health Precinct in Brisbane, and the Gold Coast Health and Knowledge Precinct.<sup>132,133</sup> Some precincts are further integrating with the broader research and innovation environment, for example the Sydney Biomedical

Accelerator, which is being developed in Sydney's Tech Central precinct and involves NSW Health, Sydney Local Health District and the University of Sydney.<sup>134</sup> However, these approaches should not be pursued at the expense of those based outside of these hubs, especially those based in rural and regional areas.

These kinds of integrated teams reflect a broader trend for team science across all disciplines, not only health and medicine. One of the strengths of the MRFF has been the work undertaken to build capacity for team science in health and medicine. Its research missions bring together cross-sector stakeholders and patients to tackle major health challenges, enabling a national response. There are currently eight missions, addressing topics including genomics, mental health and Indigenous health.<sup>135</sup>

### Box 7.1: Health and medical research in the pandemic

The COVID-19 pandemic was caused by a novel coronavirus, SARS-CoV-2. When the pandemic hit, very little was known about the virus, but it was clearly leading to severe illness and death in some individuals. Treatments were needed, and fast.

A global study known as REMAP-CAP (Randomised, Embedded, Multifactorial Adaptive Platform trial for Community-Acquired Pneumonia) was one of the first COVID-19 trials in the world, recruiting its first Australian COVID-19 patient as early as 10 March 2020.<sup>136</sup> The study was designed to be embedded in routine care, with an online eligibility system that was used by clinical staff 24/7 and all interventions were delivered in an open-label manner prescribed by clinical staff. It provided rapid evidence-gathering regarding effective treatments, as well as ineffective and harmful treatments. This evidence was incorporated into international guidelines and consequently had a significant impact on the care of critically ill patients in Australia and across the world.

This was only possible because the team was ready to go. Many of its members were clinician researchers, other health professionals and researchers who had worked through the 2009 influenza pandemic. Based on that experience, they had developed a trial protocol that was approved and ready to go since 2016. When a disease outbreak started, they were ready to rapidly start testing treatments. One of the key team leaders was Australian Principal Investigator, Professor Steve Webb FAHMS, a Senior Staff Specialist in Intensive Care at the Royal Perth Hospital and Professor of Critical Care Research at Monash University. He was the inaugural international study chair and led the platform through the pandemic. The global study, recruiting at 360 hospitals in 26 countries, was led and coordinated from the Australian and New Zealand Intensive Care Research Centre at Monash University. His perspective as a clinician researcher working in intensive care during the 2009 influenza pandemic had led him to appreciate the need for rapid initiation of studies when an infectious disease outbreak hits.

## The role of research translation centres (RTCs)

A key tool in nurturing integrated teams is RTCs, which were introduced to help reduce fragmentation. The NHMRC's RTC Initiative provides accreditation for hubs of research translation, namely:<sup>137</sup>

- Advanced Health Research and Translation Centres (AHRTCs), of which there are currently seven
- Centres for Innovation in Regional Health (CIRHs), of which there are currently three.

The centres are one of the major vehicles in Australia for embedding research in health. They are - or should be - empowered to foster an active healthacademia-industry interface. The aim is to "encourage excellent health research and translation in Australia by bringing together researchers, healthcare providers, education and training to improve the health and wellbeing of patients and the populations they serve, including in regional/remote areas for CIRHs".138 Accreditation by the NHMRC recognises "the value of leadership and excellence in research, translation, collaboration, and the training of health professionals in an evidence-based environment".137 They were created in 2014 following discussions within NHMRC and recommendations of the McKeon Review.<sup>21,138</sup> The two different types of centres have been formed over time to acknowledge the different needs of urban centres versus those serving regional, rural and remote areas.

It is important to note that the initiative only provides accreditation – it does not provide funding, for example for translation projects. This has been the subject of some discussion, regarding whether a lack of funding constrains the centres' potential. The NHMRC states that its recognition provides the centres "with the opportunity to demonstrate their value to potential funders – that is, to demonstrate their impact in improving the health and wellbeing of Australians and bringing benefits to health services".<sup>138</sup> "Healthcare and research exist in separate silos and yet the cost and efficiency of research would be massively lower if we had a single integrated silo."

Roundtable participant (research leader)

The RTCs were identified by contributors to our evidence collection as a crucial driver for a more active health-academia-industry interface, and for a shift towards a research-rich culture within the health system. As one roundtable participant (from an AHRTC) put it, "the centres and the need for this whole agenda of driving evidence-based improvement in healthcare is a large-scale systemschange initiative. And if it's not thought about with the centres as some of the key vehicles, I think we will fail."

However, it is also widely acknowledged – and we heard this from multiple stakeholder groups – that while RTCs are a welcome development, there is variation in what they do and perceptions of their effectiveness. There was a general feeling that they are not being used to their full potential. We heard that the primary role of RTCs is to enable and facilitate, more specifically to:

- act as a **broker between research and healthcare delivery** (including consumers)
- **advocate** at a national level, through "influence without power"
- strengthen consumer involvement, creating a bridge between health consumers and health researchers
- **build capacity and capability** to improve the number and skillsets of researchers and clinicians, including the role of clinician researchers
- support implementation science, which is key to reaping the benefits of research and to developing a research culture, because it makes more of research by connecting the agendas of research and the health system more explicitly.

#### Brokering – advocacy – consumer engagement – capacity building – supporting

Ultimately, RTCs play a crucial role in helping to deliver greater efficiency with existing resources, because they seek to speed up translation by bridging the gap between research, innovation and health (and consumers). They also seek to ensure that research answers relevant questions and that health implements the findings in a timely manner. Put more simply, RTCs assist in taking research from the bench to the bedside and community, and back again. As a contributor working within an AHRTC explained: "Really practical brokering that supports research that's meaningful to our healthcare partners." More work is therefore needed to unleash this potential.

## "I don't think we've made the most of AHRTCs."

Roundtable participant (healthcare executive)

RTCs also have the potential to bring together some of the most research-rich health services with less research-active services, which can lead to more rapid translation of research findings, and also improve research culture more broadly.

The idea that RTCs wield "influence without power" received considerable attention among those we heard from. While this might seem like it could be a weakness, many perceived this as a positive because it reflects the crucial facilitation role of RTCs, as opposed to them having a key role as a research funder, for instance (which most agreed they should not). For instance, one contributor involved with AHRTCs described how they had seen a lot of research that had not been implemented because the individuals and organisations needed to lead implementation had not been involved (e.g. health providers or government). The RTCs can bring these stakeholders into the process, better identifying the questions that need to be asked and therefore increasing the likelihood that the research outcomes will be implemented and translated into benefits for patients.

#### "For me, it's almost like influencing without authority is the critical component of the AHRTCs"

Roundtable participant (research funder)

However, it was also noted that "influencing without power" does require baseline capacity, which is currently limited within the RTCs. There is debate about whether RTCs require central funding. From our evidence, the critical question was whether they have the capacity - in the form of a core operational workforce - to play this advocacy role. Without this stability, it is difficult for RTCs to reach their full potential. We heard that annual core funding for each centre to provide operational funding, including a CEO and a small operational team would yield a significant improvement in RTCs' capacity to foster connections at the health-academia-industry interface. It would also improve their capacity to leverage further funding into the system and to deliver other targeted schemes to meet the needs of the community as they arise. The MRFF would be in a suitable position to provide this resourcing under its translation and commercialisation priority, which aims to "provide a focus on research translation, implementation and commercialisation by facilitating collaborations between the research sector, industry and community".<sup>45</sup> This would require an annual investment of \$10 million for the ten centres currently established.

"In conversations I've had with some of my colleagues, particularly senior colleagues in the healthcare system ... they do get frustrated at getting the perfect answer to a question that no one had asked."

Roundtable participant (AHRTCs)

We heard of several other potential avenues through which RTCs could be better empowered, including:

- further developing the relationships with the NHMRC and other government organisations, including the MRFF, especially around implementation science in the rapid delivery of evidence into the health system
- learning from international models and best practice
- advancing the science of research translation
- progressing their work with primary care to develop better linkages with other parts of the health system.

The RTCs were seen as a good model for delivering these functions because they allow local responsiveness. The fragmented nature of Australia's health services means there is a very different picture between locations, including between different states and territories, and in urban or rural settings. The RTCs work with local partners to address the local context. The role of AHRA, which provides a mechanism for collaboration between all ten RTCs, was also seen as complementary and useful here, allowing RTCs to liaise nationally and share learnings while still acting locally. They should be supported by individuals, organisations and governments alike.

#### **Recommendation 12**

The NHMRC-accredited Research Translation Centres should receive meaningful, continuing funding to stimulate the formation of integrated research teams at their local health– academia–industry interface.

### Nurturing knowledge brokers

Crucial to building successful integrated teams are knowledge brokers that bring ideas and people together, building collaborations and partnerships. According to CSIRO, "A knowledge broker tailors the communication of specific information according to their audience and can play a significant facilitatory role in communicating concepts and synergies across disciplines, across diverse knowledge systems, and across partners and stakeholder groups".<sup>139</sup>

Knowledge brokers can be organisations or individuals, and in fact a mix of the two is ideal. Australia has begun to grow capability here and the RTCs support these endeavours. We must also nurture and support a cohort of individuals who can work at the health-academia-industry interface. This is a unique skillset and difficult to nurture, since it ideally requires an individual to have had exposure to all three domains.

It is possible to develop these sorts of skills - for instance, the UK Academy of Medical Sciences has established the Future Leaders in Innovation. Enterprise and Research (FLIER) programme for people working in the life sciences sector and managing projects or teams that are involved in interdisciplinary working.<sup>140</sup> It is a two-year program that brings together a cohort of emerging leaders from across academia, industry, the NHS, and government and policy organisations, who are growing cross-sector collaboration, and maximising opportunities to work together and with wider networks to solve future research and healthcare challenges. This program has built confidence among the participants in their roles as knowledge brokers, and improved their leadership skills, mindsets, sector awareness and operational knowledge.

Beyond this, it is crucial to acknowledge wider skills needs – not only those working in brokering roles, but all those working in research contexts. This has been recognised globally, for instance, a UK report concluded that:<sup>141</sup> "There is increasing recognition that training in softer skills – such as business and entrepreneurship, leadership, and patient and public involvement – are important. In particular, communication and teamworking skills will be essential for working in integrated teams that bring together people from different disciplines and/or sectors. Alongside this, the development of leaders capable of operating and driving cultural and system change across sectors will be increasingly required. Such training could be delivered through Continuing Professional Development (CPD) programmes and credentialing, apprenticeships and cross-sector mobility, and leadership schemes."

Academic institutions, specialist Medical Colleges and professional associations should incorporate training in skills such as business and entrepreneurship, leadership, patient and public involvement, communication and teamworking – starting with undergraduate education, through to postgraduate training and continuing professional development.

Nurturing health professionals and researchers with these skills will ensure they are able to work to maximum effect within integrated teams and with knowledge brokers - as long as they are formally provided with dedicated time to do so, and recognition within career structures, particularly in health. This will mean they themselves are better equipped and incentivised to move into brokering roles. Programs have been established in Australia to address such skills needs, for instance, MTP Connect's Clinical Entrepreneur Program, which is currently in pilot phase and aims to develop the innovation and entrepreneurial mindset of Australia's clinicians and healthcare professionals.<sup>142</sup> These sorts of programs are valuable and must be complemented by:

- a broader and more coordinated effort to begin developing these skills as a core part of medical, health and research training
- development a cadre of knowledge brokers, for instance, via a program similar to the UK's FLIER program.

#### **Recommendation 13**

The health and medical sciences sector should establish targeted programs to build a generation of cross-sector knowledge brokers who can collaborate and mobilise across health, academia and industry to drive Australian research and innovation in health and medicine.

### Health, academia and industry

#### The role of health services

Despite the challenges, Australia's health system has done incredibly well to manage the significant demands placed on it during the COVID-19 pandemic.

However, emerging from the pandemic, the health system is facing significant pressures – some of which existed before the pandemic, while others have been exacerbated or created by it. This has led to calls for reform. Australia must see research and innovation within the health system as a crucial component of reform, since they can help address mounting pressures and generate a system that delivers highquality care with maximum efficiency.

"I think research is very important because it ensures that care is provided at the highest possible standard and it's always underpinned by evidence. And I think it allows the provision of care and decision-making is always evidence based."

Roundtable participant (healthcare executive)

As a first step, we should celebrate the achievements of the health system, including its research, innovation and clinician researchers, across primary care, public health, aged care and hospitals, in medicine, nursing, midwifery and allied health.<sup>143</sup>

There are currently no formal incentives for health services such as hospitals and primary care facilities to undertake research, and very little data on current research activity. We reviewed publicly available key performance indicators (KPIs) set by state and territory governments, but where they exist, they relate to very specific processes such as the speed of study approvals. Although these sorts of targets are important, they do not incentivise or reward research or efforts to embed research in the system, and they do not enable effective monitoring of staff or patient experiences with research. Yet, the Australian Commission on Safety and Quality in Health Care (ACSQHC) states that clinical research is core health service business, a view that was refected by the healthcare executives we heard from for this project.<sup>144</sup> And we know that research-rich health systems see better outcomes associated with other KPIs, such as those related to patient outcomes, quality of care, and the efficient and effective use of resources, as outlined in Chapter 2.

"I'd like also to have local health district executives' accountability for funding of research, accounting for where those funds go, and relating that to the impact of that research. I'd like to see clinical research as embedded in the organisation, but also not only with KPIs about their own research relevant to the organisation, but with performance KPIs supporting research and researchers within their department."

Roundtable participant (healthcare executive)



The barriers to seeing research and innovation truly embedded as core functions of healthcare do not result from a lack of appreciation for the value of these endeavours but relate more to practical implementation. A broader set of measures is therefore needed to incentivise efforts to embed research and innovation, and to encourage stakeholders, such as healthcare executives, to value and promote these endeavours within their services.

"I think structurally that health systems should have as a KPI, an ability to demonstrate research having an impact on patient care. I think if there was much more integrated accountability for research then the health systems might respond."

Roundtable participant (EMCR)

There was agreement among the stakeholder groups consulted for this project that this would be valuable, for instance, one senior healthcare administrator told us that "You can't value what you can't measure, and I don't think we measure impact of research within our organisations particularly well ... I'm not sure we know enough about the research that's going on. And I think that would be helpful." This reflects the issues raised in Chapter 4 in relation to the limited data available on the clinician researcher workforce. We heard that measuring translation should be an aspiration but is challenging. However, it would be possible to get a sense of research activity. In fact, the newly published National Clinical Trials Governance Framework includes many suggested potential measurements.<sup>144</sup> In addition, we have seen examples from health services now collecting detailed data, which provide a rich picture of the level and quality of trials being undertaken, such as:

- the number of studies and trials
- the types of studies and trials
- patient recruitment (e.g. numbers and speed)
- patient feedback in relation to research studies
- studies and trials involving certain groups, such as Aboriginal and Torres Strait Islanders
- the development of health literacy resources associated with research.

Such insights are highly valuable in assessing the research readiness and activity of a service. We urge this kind of data collection to become standard and to extend beyond trials, to a wider range of research studies that would further build the picture.

"The other thing that we can measure (and we have started to measure and my organisation) is research culture. Getting a sense of 'what is the research culture?', because when it comes to setting up a good system that supports research, it starts with leadership. It starts with having the right culture and having a vision and strategy that embeds research into it. We are trying to get a sense with our engagement survey with staff—adding questions to measure research culture."

Roundtable participant (healthcare executive)

Establishing formal KPIs is challenging as they require a specific target. Without baseline data – as is currently the case – it is hard to identify and set appropriate targets. Work needs to be done with state and territory departments of health and healthcare executives to establish what a set of KPIs might look like. In the first instance, we propose a single KPI be introduced for healthcare executives and services – that they should collect data on research activity and publish a smaller set of headline data that provides an indication of the level of that activity. This might include:

- number/proportion of health professionals (including medical, nursing, midwifery and allied health) with joint appointments with academia (highlighted in Chapter 4)
- number/proportion of health professionals with dedicated research time and an indication of time allocated and the clinical areas in which they work, for example total time or average time per staff member (highlighted in Chapter 4)
- number/proportion of research support staff, such as clinical trials coordinators, nurses and pharmacists, available to support clinician researchers
- number/proportion of patients enrolled or participating in research studies
- research priority setting activities and research strategies undertaken regularly by health services, including primary care facilities, to inform targeted research and its translation.

We are deliberately not proposing a prescriptive list since we know that different services and facilities will collect different data. However, the data published should indicate the level of research activity and should be accompanied by a short narrative to provide more detail and context. This data might be used in future as a basis for developing KPIs that set appropriate research activity targets.

These measures would help shift the dial towards a "learning health system", referred to by multiple healthcare executives consulted for this project, in which research is purposeful and provides evidence for improving day-to-day patient care.



Other nations, such as the UK, have recognised these opportunities. Regulators are now actively incorporating research into inspections. In 2018, following a partnership with the UK's NIHR and others, the CQC, the body that regulates care quality in England, introduced questions about research activity into its inspection framework. The questions aim to assess how well NHS services integrate research into corporate strategies and planning, and how good they are at communicating research opportunities to patients. This kind of approach could be considered by the ACSQHC, to strengthen its commitment to clinical research as a core health service business.<sup>144</sup>

Aboriginal and Community Controlled Health Organisations (ACCHOs) are an important part of healthcare delivery in Australia. Box 7.2 highlights some of the research activity being undertaken within ACCHOs. "I think what I would say is that a learning healthcare system will work best when we've got alignment between researchers and healthcare delivery at the highest level. And in Australia, unfortunately, we have a split right at the top. The Commonwealth funds universities and research, and the states [and territories] fund health service delivery."

Roundtable participant (healthcare executive)

### Box 7.2: Aboriginal Community Controlled Health Organisations

Many Aboriginal and Torres Strait Islander peoples define health as more than simply the absence of disease. To this population, health considers the community's social, cultural, physical, emotional and spiritual wellbeing.<sup>145</sup> Healthy communities enable each human being within them to achieve their full potential. This concept of health is adopted in Aboriginal Community Controlled Health Organisations (ACCHO), operated by the local Aboriginal community. They aim to provide holistic and culturally responsive primary healthcare and are more frequently being recognised by healthcare professionals and policymakers as the preferred method for primary healthcare delivery for Aboriginal and Torres Strait Islander peoples.

Today, Australia is home to more than 140 ACCHOs across 550 sites, which serve 410,000 people each year. The National Aboriginal Community Controlled Health Organisation (NACCHO) operates as a national peak body.145 Standard Australian primary healthcare services, such as local GPs, typically operate under a small business model. ACCHOs differ by having a locally elected Board of Management, which controls each centre's operations and can adopt objectives and goals that are responsive to the community's needs.

The work of ACCHOs goes beyond just delivering primary healthcare and providing initiatives and activities that target the social determinants of health and involve the local community.146 Different ACCHOs have adopted programs that respond directly to their community's needs. Some ACCHOs participate in community engagement programs and provide transport for consumers while others include a broader range of services, such as employment, housing and financial services. ACCHOs have promoted better cultural safety of their primary healthcare delivery by working to build a strong Aboriginal and Torres Strait Islander practitioner workforce, with nearly 60% of their staff identifying as either Aboriginal or Torres Strait Islander.145

Some ACCHOs have identified culturally responsive research as a priority area, such as the Institute of Urban Indigenous Health (IUIH), which operates in Southeast Queensland.147 The Board of Members at IUIH have operationalised a policy, evaluation and research unit, allowing research to be integrated into primary healthcare and be guided by the community. Currently, IUIH employs research staff as a part of their healthcare workforce, with some staff even holding

both clinical and research positions. This allows research staff to work on the ground and gain familiarity with the centre itself and its consumers. The presence of research staff removes some barriers for consumer involvement, promoting research as a collaborative process.

IUIH's research targets health needs across the lifespan, for example:

- the "Work It Out" program uses an interdisciplinary allied health team to improve risk factors associated with cardiovascular disease.<sup>148</sup> An evaluation of the program found improvements in blood pressure, body mass index and mobility among participants
- the "Birthing in Our Community" program aims to provide more culturally responsive antenatal support for mothers.<sup>149</sup> One study found that mothers who elected to be part of the intervention overall had better outcomes than those in standard care, including a reduced rate of babies born prematurely.

These examples demonstrate the positive outcomes of integrated research in healthcare when consumers, health providers and academia can work together.

#### The role of academia

Just as health services need to enable clinicians to undertake research, research institutions must empower and enable their staff to undertake clinical work where relevant, and should ensure that individuals in joint research and clinical roles have access to the same career opportunities as those working solely as researchers.

Although some research institutions have strong relationships with the health system, much of the Australian system is fragmented, with research and healthcare mostly operating separately. Internationally, we see much closer working between the two. For instance, in the US, at centres such as Harvard and the Mayo Clinic, clinicians are employed by universities to work in hospitals – something we rarely see in Australia.

Research institutions should publish data about the academic staff who have joint clinical appointments, as an indication of their openness to enabling such arrangements, as recommended in Chapter 4.

### **Recommendation 14**

Healthcare providers and academic institutions should collect and publish data on the clinician researcher workforce.

#### The role of industry

Although a detailed analysis of the barriers associated with commercial translation were out of scope for this project (since they are complex and require in-depth analysis), industry plays a critical role in health and medical research and innovation in Australia – we intentionally talk about the health–academia–industry interface, with all three components being crucial. "The number of times I've seen really good ideas coming up and being licensed overseas, and that's the last you see of them ... We just don't have the capacity here to actually take things on and see whether or not they really could work. If we want to make a difference to our healthcare system, it's identifying some of the products that could make a difference to people's health, and really running with them and seeing if we can actually take them through to commercialisation."

Roundtable participant (industry)

During evidence collection for this report, we spoke with industry stakeholders from a range of settings from pharma, biotech companies, start-ups and industry bodies. Their views reflected those we heard from across the sectors: culture is key. Specifically, a culture that encourages activity at the health-academia-industry interface, and particularly for industry, a culture that embraces entrepreneurship and risk-taking. There was agreement that the quality of the life sciences sector in Australia is high, but it is the next stage where we see the main barriers, i.e. translation and commercialisation. Consequently, ideas generated in Australia are often developed overseas – meaning we lose the IP and research talent.

Many of those we spoke to acknowledged that there had been progress towards improving commercialisation and industry engagement over the last four to five years. They welcomed the messaging and initiatives from the Australian government around the need to build stronger industry links, and to improve Australia's commercialisation capacity.<sup>150</sup> "Just being able to get to a situation where there's mutual understanding from both industry partners and academic partners as to the sort of criteria that need be met for a product to go into a development pipeline would be incredibly helpful."

Roundtable participant (industry)

Progress can be accelerated by addressing the following areas:

- **Culture** developing an understanding among clinicians and researchers about the 'business' side, such as industry's developmental considerations, or "the sorts of preclinical data packages that are required by regulatory agencies and other considerations that might range to manufacturing and upscaling and so forth" (as an industry representative put it).
- Skills the need to adopt an entrepreneurial and a risk-taking mindset, develop skills for running a business, understand strategy and pitching to investors, and have the training and focus to be able to work with start-ups.
- **Capacity** especially a critical mass of industry to drive these mindsets.
- Infrastructure and financing which is limited in some areas, for example for researchers undertaking early-stage validation and refinement of a new technology, before it even gets to the stage of working with industry.
- Mobility improving flexibility for individuals to move between academia and industry – e.g. for those who move from academia to industry, there is no clear route back, which acts as a disincentive. This is shifting, but not quickly enough.

### **Role of the Academy**

The Academy is committed to supporting efforts to foster an active and dynamic health-academiaindustry interface in Australia. As part of our forthcoming strategy, we will bolster our commitment to championing the role of industry in the health and medical research sector in Australia.

The convening power of Academies is important in this context. Under our new strategy for 2023–25, AAHMS will provide an independent forum for convening cross-sector, multidisciplinary stakeholders to discuss pressing issues and cuttingedge science, thereby acting as a knowledge broker to bring ideas and people together at the healthacademia-industry interface.

"We need a critical mass of biotech here, which will attract people and talent, and attract capital"

Roundtable participant (industry)



Professor Ian Frazer. Photo: University of Queensland

# Conclusions

### Our vision:

A system and culture that embeds research and innovation as core functions of the health system

#### Pillar one

## A skilled and enabled workforce

A research-active health workforce – at the heart of which sits a cohort of world-class clinician researchers – underpins an integrated continuously improving health system

### Pillar two

#### Targeted funding for research and innovation

Australia maximises the value of current investments to increase research funding embedded in the health system, driving translation and improving health outcomes

### Pillar three

#### Consumer and community involvement

The whole community has more equal opportunities to shape, participate in and benefit from research that is relevant to them, as active and valued partners

### Pillar four

#### Integrated teams and cross-sector collaboration

An active healthacademia-industry interface works dynamically to enable fully integrated research teams, supported by healthcare executives and research institution directors

Australia has a significant opportunity to transform the nation's health and create a world-leading health system that is driven by cutting-edge research and the latest evidence.

To achieve this outcome, we need to embed research and innovation as core functions of health, and facilitate connections between all stakeholders. This is how Australia can generate a health system that meets pressing health challenges with the latest evidence – just as we have done during the COVID-19 pandemic. In this report, we have set out a vision for how Australia can do so, built on four key pillars:

- A skilled and enabled workforce
- Targeted funding for research and innovation
- Consumer and community involvement
- Integrated teams and cross-sector collaboration

Implementing all the recommendations made in our report and building up these four pillars will help to ensure a sustainable future for our health system, and will bring benefits for Australian health and medical research and innovation, and our broader economy. The Australian Academy of Health and Medical Sciences looks forward to working with government, health, academia, industry and consumers to deliver this vision for a world-leading, research-rich health system.

## Appendix A: <u>Working group and review group membership</u>

#### Working group

The Academy is most grateful to the working group members who gave their time, energy and expertise to this project between March 2021 and September 2022.

Note: Working group members participated in a personal capacity and not on behalf of their affiliated organisations or other roles. Job titles and affiliations were correct at the time of publication.

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Academic Vice-President and Dean, Faculty of Medicine, Nursing and Health Sciences, Monash University

#### Dr Teresa Anderson AM

Chief Executive, Sydney Local Health District

#### Professor Michael Berk FASSA FAHMS

Alfred Deakin Chair of Psychiatry, Deakin University and Director, Institute for Mental and Physical Health and Clinical Translation

#### Professor Jeffrey Braithwaite FAHMS

Foundation Director, Australian Institute of Health Innovation, Macquarie University

#### Professor Jonathan Carapetis AM FAHMS FAA

Executive Director, Telethon Kids Institute and Professor, University of Western Australia

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#### Professor Ian Frazer AC FRS FAA FTSE FAHMS

Professor, The University of Queensland and Chair, TRI Foundation Board

#### Professor Jane Gunn FAHMS

Dean, Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne

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#### Associate Professor Sebastian King

Paediatric Surgeon, The Royal Children's Hospital, Melbourne and Group Co-Leader, Surgical Research, Murdoch Children's Research Institute

#### Professor Don Nutbeam FAHMS

Professor of Public Health, University of Sydney and Executive Director, Sydney Health Partners

#### Scientia Professor Vlado Perkovic FAHMS

Scientia Professor and Dean of Medicine, UNSW Sydney

#### Professor Claire Rickard FAHMS

Professor of Infection Prevention and Vascular Access, The University of Queensland and Metro North Hospitals and Health Service

#### Professor Sir John Savill FRS FAHMS

Executive Director, Melbourne Academic Centre for Health

#### Professor Paul Scuffham FAHMS

Director, Menzies Health Institute Queensland, Griffith University

#### **Review group**

This report was reviewed by an independent group of experts appointed by the Academy's Executive and Council, and chaired by a member of the Academy's Executive. Reviewers were asked to assess whether the report delivered on the project terms of reference, and to consider whether the evidence and arguments presented in the report were robust and supported the conclusions. Reviewers were not asked to approve or endorse the final report or its findings and recommendations.

The Academy is most grateful to the members of the review group for their thorough analysis of the report's contents.

Note: Reviewers participated in a personal capacity and not on behalf of their affiliated organisations or other roles. Job titles and affiliations were correct at the time of publication.

**Professor Kathryn North AC FAHMS (Chair)** Director, Murdoch Children's Research Institute

**Professor Christine Kilpatrick AO FAHMS** Chief Executive, The Royal Melbourne Hospital

#### Professor Louise Maple-Brown FAHMS

Senior Principal Research Fellow, Menzies School of Health Research; Head of Department of Endocrinology, Royal Darwin Hospital

#### Ms Jennifer Richter AM

Non-Executive Director, South Australian Health and Medical Research Institute

**Ms Jessica Taylor** President, QENDO

#### Professor Andrew Wilson

Director, Menzies Centre for Health Policy and Economics, The University of Sydney

#### Secretariat

Dr Amanda Rush, Policy Manager, AAHMS (lead secretariat until February 2022)

Lanika Mylvaganam, Policy Manager, AAHMS (lead secretariat from March 2022)

Catherine Luckin, Chief Executive Officer, AAHMS (lead secretariat excluding April–September 2021)

Dr Cath Latham, Interim Chief Executive Officer, AAHMS (April–September 2021)

Emily Todd, Policy Officer, AAHMS (from June 2022)

The Academy is grateful for the support of additional team members who have played a crucial role in the delivery of this project, in particular Katie Rowney and Margaret de Silva.

## **Appendix B: List of Contributors**

The Academy is most grateful for the expertise and insights shared by a great many contributors to our evidence collection for this report. Contributors listed participated in a roundtable or interview.

Contributors are noted here to acknowledge with gratitude their contributions. They participated in an individual capacity and were not asked to approve or endorse the final report or its findings and recommendations.

Roundtable discussions were chaired by working group members, who are not included in the list below. Two of the roundtables were kindly hosted by Professor Ranjeny Thomas AM FAHMS and Professor Andrew Wilks FTSE FAHMS, and the Academy is most grateful for their expertise in leading these discussions.

Roundtables and interviews covered the following themes:

- Senior healthcare administration
- Early-career research
- Mid-career research
- Research translation
- Research funding
- Research leadership
- Health and medical technology
- Drug development and clinical trials
- Aboriginal and Torres Strait Islander health and research
- International health and medical research

The Academy also received more than 100 responses and submissions through our open survey, as noted in Chapter 1, which are not listed.

We also acknowledge those who contributed at our consumer roundtable, which included 31 participants, however their names are not listed for privacy and confidentiality reasons. **Contributors** 

Dr Jason Agostino Dr Mark Ashton Professor Andrew Baillie Adjunct Professor Merrilyn Banks Associate Professor Frances Batchelor Dr Glenn Begley FAHMS Dr Chris Behrenbruch Dr Janelle Bowden Professor Alex Brown FAHMS Dr Tanya Buchanan Professor Tracey Bucknall Dr Steve Burnell Dr Christopher Burns Professor Stuart Carney Ms Lorraine Chiroiu Dr Marianne Coleman Dr Rob Commons Ms Kathy Connell Mr Craig Connelly Ms Cathryn Cox Dr Michael Cusack

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Dr Masha Somi Professor Alan Sanford AM Adjunct Professor Ruth Stewart Mr Michael Still Dr Michael Strong Mr Mark Sullivan Professor Helena Teede AM FAHMS Dr Benjamin Teh Professor Ranjeny Thomas AM FAHMS Dr Kelly Thompson Dr Fabio Turatti Associate Professor Jason Tye-Din Professor Frank van Haren Professor Euan Wallace AM FAHMS Professor Andrew Way Professor Steve Webb FAHMS Professor Steve Wesselingh FAHMS Dr Clare Whitehead Professor Andrew Wilks FTSE FAHMS Dr Christine Williams Dr Phoebe Williams Dr James Williamson Professor John Zalcberg OAM FAHMS Ms Anne Zielke

## **Appendix C: Abbreviations/Glossary**

## Aboriginal Community Controlled Health Organisation (ACCHO)

A primary health service run by its local Aboriginal community to serve the health needs of Aboriginal and Torres Strait Islander peoples.

#### Accreditation

Official recognition for an organisation or person to hold a particular status or be qualified to perform an activity.

#### Allied Health

A broad range of university-qualified health practitioners who specialise in a particular area of expertise relevant to treating, preventing and diagnosing illnesses and conditions.

### Australian Health Practitioner Regulation Agency (AHPRA)

National organisation for implementing the National Registration and Accreditation Scheme across Australia (adapted from website).

#### Allied Health Professionals Australia (AHPA)

Peak professional body for allied health practitioners in Australia, representing and advocating for the profession.

#### Australian Health Research Alliance (AHRA)

The body through which Australia's NHMRCaccredited research translation centres collaborate, i.e. the Advanced Health Research and Translation Centres and Centres for Innovation in Regional Health.

### Advanced Health Research and Translation Centres (AHRTCs)

An NHMRC-accredited centre for research translation, utilising research organisations, healthcare providers and educational institutions.

#### Australian Institute of Health and Welfare (AIHW)

Independent statutory Australian Government agency producing information and statistics surrounding Australian's health and wellbeing (adapted from website).

## Australian Integrated Clinician Researcher Training Pathway (AICRTP)

A proposed model for providing a clear avenue for a career in clinical research in Australia, proposed by the Deans of Medical Faculties of the Group of Eight.

#### Australian Medical Association (AMA)

Peak professional body for doctors Australia.

#### Australian Medical Research Advisory Board (AMRAB)

Advisory body to the Minister for Health and Aged Care on MRFF spending priorities.

#### Australian Research Council (ARC)

Australian Government agency which funds research, assesses the quality, engagement and impact of research, and provides feedback to the government on research matters in Australia.

#### Biostatistician

A person specialising in the statistics related to public health, biology and medicine.

#### Care Quality Commission (CQC)

The independent regulator of health and social care in England.

#### Centre for Innovation in Regional Health (CIRH)

An NHMRC-accredited centre for research translation, utilising research organisations, healthcare providers and educational institutions.

#### Clinician

A health professional who has direct contact with patients.

#### Clinician researcher

A health professional who holds posts in both clinical and research capacities, also known as a clinician scientist or clinical academic.

## Commonwealth Scientific and Industrial Research Organisation (CSIRO)

A government-funded body initiating and conducting scientific research in Australia to assist in the development of industries.

#### Consumer

Explained above in Box 6.1.

### Consumer (and community) engagement (or involvement)

The processes of making decisions with or by consumers, instead of about, to or for them.

### Consumer and Community Advisory Group (CCAG) of NHMRC

Working committee providing strategic advice from consumer and community perspectives to NHMRC on health and research matters (adapted from website).

#### Continuing professional development (CPD)

The skills and knowledge an employee gains beyond their initial training that improve their abilities within a role.

#### Culturally and linguistically diverse (CALD)

Term referring to members of the population from communities of differing languages, ethnic backgrounds and cultures.

#### Data scientist

A person specialising in the storage, analysis and interpretation of data, especially in order to assist decision-making.

#### Doctor of Philosophy (PhD)

A degree awarded to a person after completing advanced research in a particular field.

#### **Discovery Research**

Research that generates new knowledge and insights.

#### Early- and mid-career researcher (EMCR)

An individual in the early or middle stages of their research career, as opposed to a senior researcher.

#### General practitioner (GP)

A community-based medical doctor, treating minor and chronic disease, and referring serious conditions to hospitals or specialists.

#### Group of Eight (Go8)

Organisation comprising of eight Australian researchintensive universities.

#### Health and Medical Research Office (HMRO)

Office within the Australian Department of Health and Aged Care that oversees the Medical Research Future Fund (MRFF).

#### Health economist

A person who examines the allocation, efficiency and cost-effectiveness of health and medical resources.

#### Health inequities

Systematic differences in health outcomes between population groups, resulting from the social conditions people experience.

#### Higher Degree by Research (HDR)

An Australian Qualifications Framework Level 10 qualification where the at least two-thirds of the program's assessable content is research.

#### Implementation science

The investigation of the uptake of new research, ideas and practices into regular use by practitioners and policymakers.

#### Key performance indicators (KPI)

Quantifiable measures used to track the performance of a person or organisation for a specific objective.

#### Knowledge broker

An individual or organisation that brings people and ideas together to help align agendas and pull towards a common goal, bridging the gap between the creators of information and those who use it.

#### McKeon Review

A report released in 2013 outlining the state of Australia's health and medical research as well as a long-term vision for an integrated health and medical research sector.

#### Medical Colleges or Specialist Medical Colleges

Professional bodies that support training, continuing professional development and standards for the medical specialties.

#### Medical Deans Australia and New Zealand

Peak professional body for entry-level medical education, training and research in Australia and New Zealand.

#### Medical Research Endowment Account (MREA)

Fund through which the Australian Government supports medical research, governed by the NHMRC.

#### Medical Research Future Fund (MRFF)

Fund through which the Australian Government supports health and medical research, administered by the HMRO within the Department of Health and Aged Care.

#### Medical research institute (MRI)

Research organisations working across laboratorybased research and clinical practice.

#### National Competitive Grants Program (NCGP)

Fund through which the Australian Government supports research and training, governed by the ARC.

### National Health and Medical Research Council (NHMRC)

An independent statutory authority under the Australian Government's Minister for Health and Aged Care, providing research funding, health guidelines and ethical standards.

#### National Health Reform Agreement (NHRA)

A commitment by the Australian Government and all states and territories to improve the sustainability of Australia's health system through better coordination of emergency departments, hospitals and primary health care.

#### National Health Service (NHS)

General term for the publicly funded healthcare systems operating in the United Kingdom.

## National Institute for Health and Care Research (NIHR)

A government body that funds, enables and delivers health and social care research in the United Kingdom.

#### Primary care

The healthcare provided at the community level by GPs, nurses, and other health professionals, usually associated with the first presentation by a patient.

#### Research translation centre (RTC)

In the context of this report, RTCs refer to NHMRCaccredited AHRTCs or CIRHs (as noted above).

#### Royal Australasian College of Surgeons (RACS)

Peak professional body for surgeons in Australia and New Zealand, providing training and maintaining surgical standards.

#### Teaching, training and research (TTR)

Teaching, training and research (TTR) funding is a portion of the funding provided to states and territories by the federal government through the National Health Reform Agreement (NHRA).

#### UK Clinical Research Collaboration (UKCRC)

Explained above in Box 3.1.

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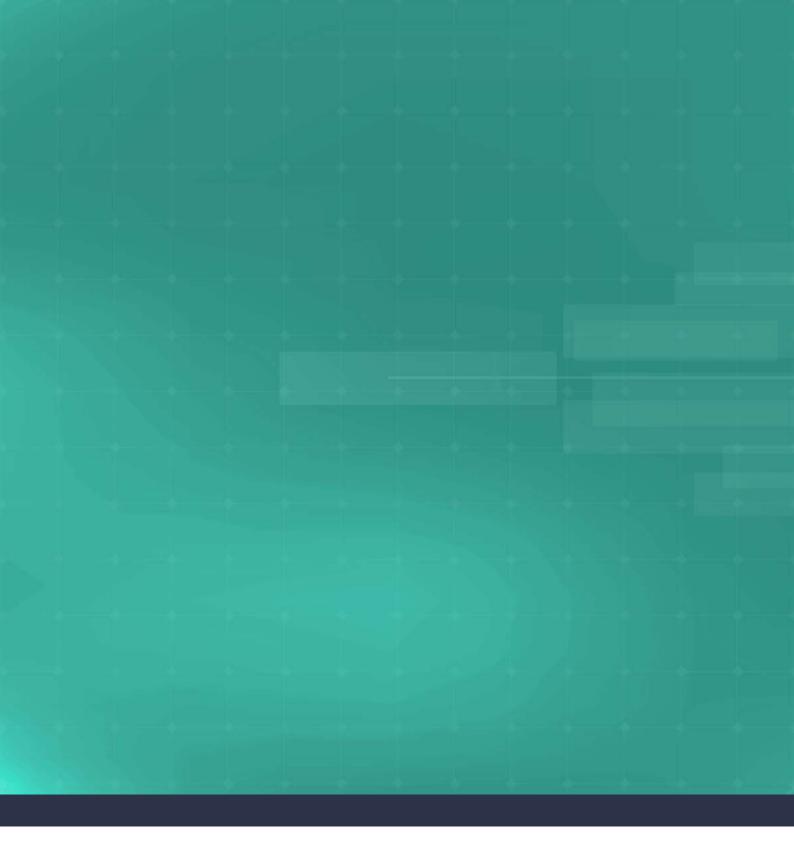
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