RESEARCH AUSTRALIA

CONNECTING · ENGAGING · INFLUENCING

Post pandemic opportunities for health & medical research & innovation

Consultation paper



ABOUT RESEARCH AUSTRALIA

Research Australia is the national alliance representing the entire health and medical research pipeline, from the laboratory to patient and the marketplace.

OUR VISION: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

OUR MISSION: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

OUR ROLE:

Engage
Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect
researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence
government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

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INTRODUCTION

As the national peak body for health and medical research, Research Australia represents stakeholders across the health and medical research pipeline and this includes researchers and innovators along with health service providers and consumers or consumer representative groups. Regardless of where our members sit on this pipeline, we have witnessed how the global pandemic has impacted them, exposing both flaws and opportunities in many parts of our national systems.

COVID has demonstrated unequivocally the value of medical research - from breakthrough basic sciences research that established the basis for mRNA vaccines; through to rapid research responses to identify promising treatments; to excellent public health research to develop and refine public health measures and communications. Australia's research community has contributed fully to international and local responses to COVID.

In turn, the pandemic has also exposed some of the underlying fragility of our research infrastructure, and caused significant dislocation to established research programs and activity.

Over-reliance on imports generally, but in this instance on crucial medical equipment, has also been highlighted by the pandemic. We are also too dependent on income generated by international students to fund vital research in higher education.

As we emerge out of the pandemic, it is essential that the economic value health and medical research offers Australia is fully recognised and expanded. A strong health and medical research sector enables greater productivity through better health; drives efficiencies across Australia's expensive health system and delivers new revenue opportunities through the export of health innovations.

Australia is in the fortunate position of having among the world's top talent in health and medical research ***and*** the institutions to underpin new economic activity and greater clinical outcomes due in large part to the contribution made by the Commonwealth Government over many decades through the National Health and Medical Research Council. Our seeming sluggishness to better translate this research into effective and meaningful practice must be addressed. We all talk about it, so why not take steps to try and improve this?

Research Australia has been working with our members to closely examine how we tackle the challenges and opportunities presented by the pandemic. Together, we can emerge with a stronger health and medical research sector capable of delivering even better health and economic outcomes for Australians.

According to Research Australia's own analysis there has been over 550 recommendations proposed by the 20 health and medical reviews conducted nationally in the last 15 years. Some of these recommendations have been partially or fully implemented, many have not. Consistent themes can be identified across these recommendations:

- Driving greater efficiencies and improvements in health and medical research funding;
- Developing a research informed health system;
- Improving the relationship between research and industry and increasing the capacity for research commercialisation; and
- Concerns about the research workforce.

The most consistent recommendation across almost all the reviews has been to improve the funding structure of health and medical research. These recommendations do not just propose increasing funding, but rather suggest improving the structure of health and medical research funding to be more streamlined and efficient. Over half of the 20 reviews also recommend establishing a national health and medical research strategy and governing body to help drive these efficiencies and improvements in funding.

The reforms explored in the following pages both draw on the previous recommendations and seek to address new challenges presented or exacerbated by the COVID-19 pandemic. Many of the adjustments proposed are structural changes that will take many years to deliver. Research Australia is very conscious of the enormity of this task. Not all of the change that is needed can be delivered at once and part of our consultation with the health and medical research sector will be to understand the priorities for immediate focus, what must be done in the medium term, and what will require long-term change.

Research Australia seeks the views of those with a stake in health and medical research on a range of proposed reforms. We are interested in hearing from consumers, government, clinicians, industry, and perhaps most importantly, health and medical researchers themselves.

At a high-level, the reform areas suggested for further examination are:

Strategic reforms to improve the health and medical research sector

1. Strategic coordination of funding for health and medical research
2. Future-proofing Australian health and medical research and the bodies that conduct research

Realising the potential of research for its end users (beneficiaries)

1. Imagining the Australian health industries of the future
2. Meeting the needs of state and territory health systems
3. Putting patients and the public at the centre of health innovation

1. STRATEGIC COORDINATION OF FUNDING FOR HEALTH AND MEDICAL RESEARCH

Challenge: Uncoordinated funding sources for health and medical research leads to breaks in the pipeline, inefficiencies and exclusions

Health and medical research is funded and administered by at least five separate federal portfolios (Health, Education, Industry/Innovation, Defence & Foreign Affairs). State and territory governments are also providing varying levels of funding, so too are non-government organisations across philanthropy, private healthcare and industry.

While each provides valuable funding, these sources have grown independently with little inter-scheme coordination, resulting in duplication of effort and inefficient allocation of funding in some places. Most importantly, running multiple, uncoordinated streams of research adds to the administration costs for funders. It is a disincentive for attracting funding from other sources, including private capital and philanthropy.

Another area of focus is consistency of funding. Funding and incentives are available for some stages along the journey for both commercial and non-commercial translation, but the connections between these different stages are tenuous, or do not exist. While the National Health and Medical Research Council (NHMRC), Medical Research Future Fund (MRFF), Australian Research Council (ARC) and other programs provide strong funding for projects at particular stages, there is not seamless support for research and innovation from concept to delivery. There are too many barriers to collaboration between publicly funded researchers, the private sector and the health system.

Multiple funding streams exacerbate the problem that researchers expend several months every year submitting numerous applications to programs with low success rates.

As a consequence of this lack of strategic coordination, Australia is not fully exploiting health and medical research and innovation as a resource to improve the efficiency and productivity of our health system and its health workforce.[1] With Australian healthcare expenditure in 2018-19 estimated to be $196 billion, even small improvements in efficiency and productivity can provide significant dividends benefitting the health of Australians, and the broader economy.[2] We are also failing to capitalise on the full commercial potential of our research and innovation, and the job opportunities and prosperity doing so can provide.

There are examples in other parts of the Australian economy we can draw on, such as the drive for clean energy. Basic research is undertaken at universities, funded by the Australian Research Council. Translational research is undertaken by a broader range of organisations, including universities, the CSIRO, Cooperative Research Centres and companies, and is funded from a broader range of sources. Demonstration programs are implemented by companies with support from research organisations and funded by the Australian Renewable Energy Agency (ARENA)3. Funding for early stage commercial deployment of technology by companies is funded by the Clean Energy Finance Corporation[3].

1 Similar issues lead to the creation of the UK Office of Strategic Coordination of Health Research https://www.nihr.ac.uk/about-us/our-contribution-to-research/our-place-in-the-UK-research-landscape/oschr.htm.
2 Australian Institute of Health and Welfare 2020. Health expenditure Australia 2018–19. Health and welfare expenditure series no.66. Cat. no. HWE 80. Canberra: AIHW.
3 https://www.cefc.com.au

We're seeking your input on:

The amount of time spent preparing research application grants and whether this needs improving

The differentiation between health and medical research funding schemes

The right mix of priority and investigator led funding streams

The number of funding schemes and their criteria

Funding and skill sets for types and stages of research

A National Health and Medical Research Strategy

Imagining and preparing for the Australia we want in 50 years' time must start today. An overarching national research strategy that ensures coordinated, strategic public investment in all stages of research, would maximise impact in areas of greatest need and exploit areas of international competitive advantage.

Over half of the 20 reviews into health and medical research conducted in Australia over the last 15 years recommend establishing a National Health and Medical Research Strategy. The McKeon Review said a national strategy would, '...deliver the vision to build and maintain a healthy and wealthy Australia that has the world's best and most efficient health system.'[4]

A 2021 report from Industry, Innovation and Science Australia (IISA) recommends whole-of-government innovation, science and research priorities to drive investment decisions. The IISA report also recommends appropriate funding for the indirect costs of research and ensuring investment in basic research does not fall below current levels (22% of overall R&D investment).[5]

Similarly, the 2020 National Strategic Action Plan for Rare Diseases recommends a national research strategy '...to foster, support and drive all types of research for rare diseases, contributing to agreed priorities and systematically addressing gaps'.[6]

There is support from the sector itself for reframing Australia's 'system' for funding health and medical research.[7]

As a result of COVID-19, now, more than ever, there is public goodwill toward this national capability. A modern National Research and Innovation Strategy for Health could be focused around:

- a clearly defined process for funding health and medical research from basic research to translation (commercial and non-commercial) with clearly articulated, complementary roles for the multiple streams of federal funding;
- implementation, including manufacture, of a product or technology and/or adoption as routine clinical care;
- connecting research innovation to improved public and patient outcomes;
- a coordinated plan for selecting priority translational Australian biomedical research; and
- situating health and medical research within national research priorities of related areas including industry and innovation policy.

We're seeking your input on:

Whether a national strategy should be pursued to coordinate all Australian Government funding streams for health and medical research

The major barriers to developing such a national strategy

What a national strategy should address

How a national strategy could enable researchers to have greater impact on health outcomes

Whether a national strategy should be pursued to coordinate the investments made by governments, philanthropy, the private sector and the internal budgets of research organisations

4 Department of Health, Strategic Review of Health and Medical Research Summary Report, 2013 https://cheba.unsw.edu.au/sites/cheba2/files/blog/pdf/Strategic_Review_of_Health_and_Medical_Research_Feb_2

5 https://www.industry.gov.au/data-and-publications/driving-effective-government-investment-in-innovation-science-and-research

6 https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases

7 Research Australia polled 1200 medical researchers in June 2020 and Nearly two thirds of medical researchers (62.5%) support a longer-term restructure of Australia's health and medical research funding framework.

Challenge: Who drives a National Health and Medical Research Strategy?

While there are currently different bodies responsible for parts of health and medical research policy and funding, there is no body with the remit for a whole-of-government national strategy.

Such a body could provide guidance on high-level national research priorities and the collaborations that can be formed to support those priorities. Its role would include an information exchange to avoid unnecessary duplication of research efforts and funding programs within the Commonwealth, as well as with the state and territory governments and other sources such as philanthropy and industry.

Such a body will require careful implementation. It must be cognisant of the roles and activities of state and territory governments and provide opportunities for their participation, particularly as providers of health services. It should not replicate or replace the AMRAB or the NHMRC's Research Council.

The United Kingdom's independent Office for Strategic Coordination of Health Research (OSCHR) offers a possible model for Australia.[8]

The OSCHR was created to facilitate a cultural change among the public funders of health research to address the barriers to research collaboration and to support the application and translation of basic research into patient care and economic benefit.[9]

The OSCHR Board is made up of key representatives from government departments and agencies, universities, medical research institutes (MRIs), research funding bodies (like Australia's MRFF, NHMRC, ARC) and other representatives from the Wellcome Trust, Association of Medical Research Charities and Research England.

We're seeking your input on:

Whether a new national body is needed to better coordinate existing funding programs

How such a new national body or similar would function

Any existing body or governance mechanism that could be expanded or used to develop and implement a national strategy

How should such a body include the states and territories

How industry should be represented

Whether a body like the United Kingdom's independent Office for Strategic Coordination of Health Research (OSCHR) would be useful in Australia to monitor and coordinate multiple streams of funding

Any other models or examples that should be considered

8 https://mrc.ukri.org/about/what-we-do/spending-accountability/oschr/
9 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/228984/0118404881.pdf

2. FUTURE-PROOFING AUSTRALIAN HEALTH AND MEDICAL RESEARCH

Challenge: Job security for researchers & the right skills mix to deliver the research Australia needs

A lack of job security for early to mid-career researchers is diminishing Australia's capacity to conduct world leading research by limiting researchers' capacity to take risks, innovate and spend time on translation and commercialisation. 54% of researchers at universities and 74% of researchers at MRIs are employed on a contract basis. By far the most common contract term is 12 months. This is far higher than the national average use of contract employment across the economy.[10] It is also significantly shorter than the grants provided by funding bodies, which typically have terms of three to five years. This suggests that while research grants are often identified as the culprit, the sector also needs to look at its own employment practices.

This type of fixed term contract employment creates an insecure environment which in turn has an impact on attracting and retaining high calibre recruits. Many researchers' incomes and careers are dependent on their ability to attract research income such as NHMRC and ARC grants. As employers, research organisations (universities, MRIs and others) have to supplement grant funding to be able to pay researchers' salaries. If the combined funding from grants and other sources is insufficient to fund the research or is exhausted before the research can be completed, the researchers are out of a job. Apart from the loss of income, this directly affects researchers' careers, which are driven by being able to publish research findings.

The COVID-19 pandemic has revealed differences in the security of employment of different workers and occupations across our economy. Most people would be surprised to learn that for many, a career in health and medical research and innovation is one of the more insecure in our economy.

The situation is particularly difficult for women, for whom the rates of insecure employment are highest.[11] The research sector and governments must define the workforce the country needs and wants for the future. This means creating a stable environment for early and mid-career researchers, who have been most affected by the financial impact of COVID-19 on universities. Greater clarity of career pathways is essential to help individuals visualise and direct their careers.[12] Well defined pathways between academia and industry must be established, encouraged and incentivised to build new industries and foster true innovation. The private sector research and innovation workforce is a critical component of this mix, but a relatively small component in the Australian context. Increasing employment in private sector research organisations and increasing private sector R&D are critical to the long term future of our entire research and innovation workforce.

Australia must plan now for the workforce we need to solve the research challenges of the future. This means creating capacity in a range of required disciplines and areas of expertise, and across the entire pipeline from basic research to translation.

We're seeking your input on:

Job security for researchers and the reliance on competitive grants to fund research

The approach to research grant funding and maintaining excellence

Job security as a major consideration in the design of research funding programs

The development of a national health and medical research workforce strategy and what its focus should be

10 Research Australia, 2020, The impact of COVID-19 on health and medical researchers, available at https://issuu.com/researchaustralia/docs/covid-19_series_report_final
11 Research Australia, 2020, The impact of COVID-19 on health and medical researchers, available at https://issuu.com/researchaustralia/docs/covid-19_series_report_final
12 See, for example https://mrc.ukri.org/skills-careers/interactive-career-framework/

Challenge: Insufficient funding for indirect research costs

Lack of funding from both government and industry for the indirect costs of research conducted in Australia's universities and MRIs is a longstanding problem and far from international best practice. While funding contributes to the direct costs of research, such as paying researchers' salaries and purchasing necessary equipment and experimental materials, it does not typically cover indirect costs like business development and commercialisation, legal, finance, IT, philanthropy, communications, facility management and core facilities such as imaging, bioinformatics, and biostatistics.

This situation has been exacerbated by the recent emphasis on universities partnering with industry on research projects and reduced revenue of higher education institutions. Teaching revenues from domestic and international students subsidise research expenditure, including covering indirect costs. The reduction in universities' international teaching revenues caused by COVID-19 has further limited how universities contribute to meeting indirect research costs.

Funding for indirect research costs was raised as an issue during the public consultation on the inaugural five-year strategy and two-year priorities for the MRFF conducted by the MRFF Advisory Board in 2016. While the MRFF Advisory Board subsequently drew attention to the issue of funding for indirect research costs, it did not offer a solution:

A whole-of-government approach is needed to address the issue of research costing to ensure the research sector can continue to thrive. MRFF funding cannot in isolation solve the conundrum that surrounds indirect costs and may with the injection of new funds increase the need for a solution...Collaboration between Government and funded bodies to identify an equitable solution should be prioritised.[13]

A report by the House Standing Committee on Education recommended that 'the administration of research block grants be reviewed to provide more timely and adequate support for the indirect costs of research'.[14] More recently, Industry, Innovation and Science Australia has identified the issue of indirect research costs as a major issue for all publicly funded research. It has called for action to ensure 'the costs of conducting research (including researchers, administration and infrastructure) are met by Government or other investors.'[15] Action is needed to increase both the amount and transparency of funding for indirect research costs.

We're seeking your input on:

The funding of indirect research costs and who is responsible

Whether industry partners should fund the full costs of research conducted on their behalf by universities and medical research institutes and the challenges that may come with this

13 Australian Government, MRFF Advisory Board, 2016, Australian Medical Research and Innovation Strategy 2016-2021, p.7
14 Employment and Training at the request of the Minister for Education. The Committee's report, tabled on 26 November 2018
15 Australian Government, Industry, Innovation and Science Australia, 2021, Driving effective Government investment in innovation, science and research, Action 3



3. IMAGINING THE AUSTRALIAN HEALTH INDUSTRIES OF THE FUTURE

Challenge: Little incentive for health innovators to stay and thrive in Australia

For a wealthy country, Australia's economy remains poorly diversified. Government expenditure on R&D across all areas fell to less than one half of one percent of GDP in 2019-20.[16] A decline in the export value of just a few key commodities can jeopardise our whole economy.

COVID-19 has exposed how vulnerable Australia is because of our relatively narrow manufacturing base. 26 of the world's nations accounted for 95% of global pharmaceutical exports in 2018, valued at $570 billion. The world's number one exporter of pharmaceutical products was Germany with 16.5% of global pharmaceutical exports. Number 26 was Australia, with 0.44%.[17] In the same year (2018), Australia imported pharmaceutical products valued at $7.17 billion, or 1.26% of global pharmaceutical imports.[18]

The health sector provides an opportunity for Australian business to meet local demand and build export markets for products and services. There is a role for governments to create momentum for domestic commercialisation of Australian research and realise the return on the significant public investment in research. Work is already underway through the University Research Commercialisation Scheme and the Modern Manufacturing Initiative to build opportunities for local advanced medical manufacturing.

Australia can become a regional gateway for the provision of world class medical services and clinical trials, capitalising on our ethnic diversity and strong networks of hospitals, pathology and pharmacy. This can reinforce our global reputation as the regional flagship health system, helping to improve health in the Asia-Pacific region, boosting national security and regional alliances.

Attracting and incentivising new businesses to establish and thrive in Australia will create markets, skills and products that not only serve the population, but create new export opportunities. We have shown that we can create new and globally significant businesses over the years with companies like CSL. We need to expand on our successes of the past both in terms of size and scale of commercial endeavour. A modern economy must include a mix of enterprise, incentivising small and medium enterprise along with larger commercial players.

We're seeking your input on:

Whether the Government should commit to increasing its spending on research and development to a specific target, for example to 0.75% of GDP annually

Whether Australia should set ambitious goals to grow our medical manufacturing sector

The level of risk governments should take when funding research with the potential for commercialisation

16 Australian Government, Science, Research and Innovation (SRI) Budget Tables, 2020-21, Australian Government investment in R&D by sector and sub-sector, and other analyses Table 6, Australian Government investment in R&D as a percentage of Gross Domestic Product. A $1 billion boost one off boost to the Research Support Program in 2020-21 has temporarily increased the R&D expenditure to 0.60, still below the long term average of 0.61%.

17 Sourced 19 November 2020 from https://atlas.cid.harvard.edu/explore?country=undefined&product=129&year=2018& productClass=HS&target=Product&partner=undefined&startYear=undefined

18 Sourced 19 November 2020 from https://atlas.cid.harvard.edu/explore?country=undefined&product=129&year=2018&tradeDirection=impor t&productClass=HS&target=Product&partner=undefined&startYear=undefined

National stocktake of health and medical research funding

A national 'stocktake' of the public, private and philanthropic programs funding Australia's research efforts in the last two decades will provide a clearer picture of what health and medical research is underway around Australia and where resources are best directed.

With a clearer picture of Australian health and medical research funding, we can begin to understand instances of duplication of research efforts, gaps in the research funding pipeline, and identify areas of national strength and global competitive advantage. We can also better align our research efforts with national health priorities.

There is a view amongst researchers that the same or similar research projects are too often funded, leading to duplication. A national stocktake would help test the extent to which this is true.

The findings of such a national stocktake of health and medical research could form the basis of a series of recommendations on where funding needs to be increased or redirected. This approach would also be valuable in informing a National Health and Medical Research Strategy.

We're seeking your input on:

How we best understand instances of duplication of research efforts, gaps in the research funding pipeline, and identify areas of national strength and global competitive advantage

Whether a national stocktake of health and medical research funding is the best means to achieving this goal

4. MEETING THE NEEDS OF STATE AND TERRITORY HEALTH SYSTEMS

Challenge: Incentivising state and territory health systems to rapidly invest in and adopt the latest and best evidence

Research can identify new practices that support the delivery of better, safe and higher quality health care, leading to faster and more complete recoveries and fewer readmissions, which are key drivers of cost. By identifying practices that are ineffective or sub optimal, research can reduce unnecessary expenditure on procedures, imaging and pathology.

Beyond hospitals and clinics, research provides the opportunity to prevent illness, injury and death through the identification of behaviours that increase mortality and morbidity and the design of programs that modify these behaviours.

However, this could only happen if our health systems can properly translate research findings into routine practice. In many areas we lack an understanding of the health outcomes that a particular research or innovation activity will support, or the process to achieve these outcomes. While change is everywhere, improvement in health system performance has flatlined: 60% of care on average is in line with evidence or consensus-based guidelines, 30% is some form of waste or of low value, and 10% is harm. The 60-30-10 ratio has persisted for three decades.[19]

In addition to being funders of and participants in research, state and territory health systems and health providers are a crucial 'end user' of health and medical research. We need to do more to engage the states and territories in the identification of research priorities and the design and conduct of research.

Doing so will help build commitment to the adoption of research. This requires a more research aware and research active health system, as well researchers who are more engaged with end users of research.

Successive meetings of the Council of Australian Governments have emphasised the need for a whole-of-governments approach to innovation if we are to transform the delivery of healthcare.[20] Although activity-based funding continues to be the preferred predominant approach for health care funding in Australia, alternative funding models such as outcomes based and value-based funding models are being considered. These alternative funding models seek to align financial incentives with meeting a set of defined measures or are conditional on certain outcomes being achieved.[21]

These can have implications for how state and territory health systems and health providers participate in and utilise research.

We're seeking your input on:

How to better engage health and medical research across our health system

Areas of research that are the responsibility of states and territories to fund

Specific barriers to the creation and adoption of research by state and territory health systems, not for profit health providers, and private for profit health providers and health practitioners

Whether different approaches to funding healthcare can create incentives and opportunities for research with our health systems

19 https://lighthouse.mq.edu.au/article/august/hospital-is-unsafe-for-one-in-ten-patients
20 At the December 2015 Council of Australian Governments meeting, the principle of a shared responsibility of the Commonwealth, state and territory governments for the planning and provision of healthcare was adopted.
21 The new National Hospital Reform Agreement Addendum 2020-25 introduces 6 long-term health reforms, and opportunities to establish the frameworks for system-wide attention to value-based health care https://www.health.gov.au/initiatives-and-programs/2020-25-national-health-reform-agreement-nhra

5. PUTTING PATIENTS AND THE PUBLIC AT THE CENTRE OF HEALTH INNOVATION

Challenge: Applied Research and innovation is not being directly informed by the needs of patients and the public

For research to have its greatest potential impact, consumers need to be an integral part of health innovation as co-designers and co-developers. As England's former Chief Medical Officer, Professor Dame Sally Davies noted, "No matter how complicated the research or how brilliant the researcher, the patients and the public always offer unique, invaluable insight."[22]

Consumer co-design improves research outcomes by aiding effective translation of research and ensuring relevance to community needs. Any Australian, no matter their literacy or knowledge of the policy making process, should be able to contribute.

While standard community consultations under the MRFF may invite consumers to respond on the decision-making process, they do not take a consumer-centred approach. For example, the Australian Medical Research Advisory Board (AMRAB) consults the public about MRFF priorities every two years. Members of the public are welcome to make submissions which are required to align with specific criteria set out under the ***Australian Medical Research and Innovation Strategy*** and the ***Medical Research Future Fund Act 2015***. This top-down approach is an important step in the policy making process but does not create an accessible opportunity for consumers to contribute to the decision-making process.

Other methods of gathering consumer input in similar policy areas, such as the NHMRC's Community and Consumer Advisory Group, also have some limitations.

This kind of consumer advisory panel is made up of 'specialist' consumer advisors, such as executives of disease specific advocacy groups who are representatives of the needs of their consumer base as a whole, and of an organisation. Whilst these consumer specialist advisor panels undoubtedly provide benefit, citizen panels add value through consultation with consumers who are aware of their own needs through lived experience.

The Australian Government has recognised the importance of effectively engaging the public in policy development and program design. The Australian Public Service's Framework for Engagement and Participation states that engaging with members of the public goes beyond disseminating policy decisions or submission-based consultations, to include other forms of consumer involvement through deliberation and collaboration.[23]

This is just as true of health and medical research as it is of government policy and service delivery.

We acknowledge the significant advances made by various organisations such as the Consumers Health Forum and NHMRC, in creating an environment which values the input and guidance of patients and the public. The challenge is to build on, and extend consumer engagement, drawing on what is currently working well in Australia and overseas.

We're seeking your input on:

Whether researchers engage the public and patients as research end users well

The challenges in engaging the public and patients in research

22 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5606526/.
23 https://www.industry.gov.au/sites/default/files/2019-11/aps-framework-for-engagement-and-participation.pdf.

Building further consumer co-design into research through citizen panels and juries

Citizen panels are large representative groups that reflect a cross-section of society who provide input and guidance to complex public policy and practice. They provide an insight into consumer values and interests, thus making a meaningful contribution to decision-making. For example, citizen panels may be made up of consumers with lived experience who input into the co-design of funding programs and initiatives related to their disease or condition.

Another example, in the case of spinal cord injury, researchers and funders assumed that new surgeries and treatments would be the highest priority for patients. However, qualitative consultation through citizen panels uncovered that better management of urinary tract infections had the greatest impact on quality of life.[24] Citizen panels have also been used with great success in Canada by McMaster University to capture citizen values and insights and link them with evidence to spark change.[25] Infrastructure Victoria has also used citizen panels to scope community responses to changes in how travellers paid for transport.[26]

Deliberating with consumers on policy matters through citizen panels or juries allows consumers to make a substantive contribution to the decision-making process. This kind of substantive co-design with consumers not only helps government ensure policy aligns with citizen needs but drives community trust and support of government decision making.

We're seeking your input on:

Whether citizens panels and juries would build further consumer co-design into research

Effective methods, tools and techniques that have provided meaningful end user input

24 https://www.behaviourworksaustralia.org/the-method-book/chapter-4-stakeholder-consultation-to-improve-behaviour-change/
25 https://www.mcmasterforum.org/spark-action/citizen-panels
26 https://www.infrastructurevictoria.com.au/project/research-transport-network-pricing/

WHERE TO NOW?

Consultation

This document has been released as an online consultation questionnaire to garner the views of Research Australia members and friends.

The issues are many and multilayered and we acknowledge this. Far from being a disincentive to doing anything, Research Australia takes the view that canvassing some of the issues we know are most pressing, and pushing for adjustments or even wholescale reform, is an opportunity that must be explored and conversations across the pipeline have signalled there is appetite for change.

Capitalising on Australia's research excellence and investment in our systems to date, the opportunities to enable innovation, both commercial and clinical, are too good to pass up.

A sustainable and impactful system is not beyond our reach.

Courage and consensus must be part of our efforts to design or adjust the eco system for such outcomes. Importantly, a lateral and realistic approach is needed to navigate the complexity of what we are proposing, and we look forward to your responses and ideas to advancing the thinking around this.

In practical steps, Research Australia will run virtual working groups to delve further into key issues arising from this consultation feedback.

This consultation process will culminate in a Statement of Strategic Intent, setting out the key policy changes the health and medical research sector can work towards. The Statement of Strategic Intent will inform and guide much of the work Research Australia does with governments and our members in enabling the changes we talk about. We also remain responsive and agile to emerging issues.

Research Australia is grateful to those of you who have provided early input and advice to this document and to HealthConsult for their experience and assistance in facilitating this consultation process and advising on the Statement of Strategic Intent.

Share your views via our consultation hub here

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