

The image features a dark grey background with a network of thin grey lines connecting several large, dark grey circles. One circle is in the top right, another is in the middle left, and a third is partially visible in the bottom left. The text is positioned in the upper left and middle left areas.

**RESEARCH**  
**AUSTRALIA**  
CONNECTING ■ ENGAGING ■ INFLUENCING

**Healthy  
Australians,  
Healthy  
Economy**

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**A pre-election statement from Research Australia on behalf  
of Australia's health and medical research sector**

**RESEARCH  
AUSTRALIA**  
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# Healthy Australians, Healthy Economy

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## ABOUT THIS STATEMENT

Research Australia is the national peak body for Australia's health and medical research sector. We envision 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.

On 27 March 2018, Research Australia convened peak representative organisations spanning the whole of Australia's health and medical research sector at a Pre-election Summit at Old Parliament House in Canberra. In anticipation of the next Federal election, participants discussed the common public policy issues that unite our sector and why health and medical research and innovation is important to both the health and wealth of Australians. Participants were addressed on the day by representatives of the three major parties:

- Hon Greg Hunt MP, Minister for Health
- Hon Catherine King MP, Shadow Minister for Health and Medicare
- Senator Dr Richard Di Natale, Leader of the Australian Greens

In the months following our Pre-election Summit we have worked closely with our membership to track movements in health and medical research policy and the views of our sector.

This pre-election statement captures what the Australian health and medical research and innovation sectors need from a future Australian Government, of any political persuasion, to deliver better health outcomes for Australians, better value for taxpayers and a stronger economy.

We recognise that the next Federal election can be held at any time between now and 18 May 2019.<sup>1</sup> We will continue to regularly review and update this statement between now and the next election to ensure it reflects relevant developments; for example, amendments to the Research and Development Tax Incentive and the Government's continuing response to the Productivity Commission's report on Data Availability and Use.

### Supporters of this Statement:

We acknowledge the significant investment we, as a sector, have enjoyed from past Australian governments, both Coalition and Labor. The post mining boom search for the Australian industries of the future presents enormous opportunities for growth in the global healthcare sector.

In this statement, we have identified the adjustments needed to current policy settings to enable Australia's health and medical research and innovation sector to respond to the challenges and opportunities of the future.

The following organisations participated in the Pre-election Summit:

- The Association of Australian Medical Research Institutes
- The Australian Clinical Trials Alliance
- ARCS Australia
- AusBiotech
- Australian Health Economics Society
- Medicines Australia
- Medical Technology Association of Australia
- QIMR Berghofer Medical Research Institute
- Rare Voices Australia
- Research Australia

1. 18 May is the latest possible date that avoids a separate half senate election.

## AREAS FOR ACTION

### 1. Long-term, stable funding

Health and medical research and innovation are crucial to the wellbeing of all Australians.

Long term and stable funding for research and innovation is vitally important to achieving this, but in recent years we have seen a real decline in funding for our key research agencies, the NHMRC and ARC.

Directing funding to the MRFF is not enough; the MRFF only funds the last part of the pipeline of innovation and translation. Increased long term stable funding for the NHMRC and ARC are crucial to feeding the pipeline of ideas which spur on commercial activity and lead to new treatments.

We must turn this decline in funding around to ensure the wellbeing of the community now and into the future.

### 2. A fully-funded, transparent, Medical Research Future Fund

Long-lasting reforms require strong political consensus.

The Medical Research Future Fund has the potential to change lives now and into the future, but to realise its true potential it needs to be backed by all political leaders.

Supporting the MRFF by committing to fully funding it and to ensuring transparency and contestability are what will guarantee that all Australians benefit into the future.

### 3. A standardised national approach to clinical trials

Clinical trials are vital to ensuring an effective and efficient healthcare system as well as delivering health and medical research breakthroughs, but the system needs improvement.

At the moment, there is too much inconsistency across jurisdictions and not enough co-ordination between relevant bodies. Clinical trials are not embedded as a day to day part of the health system and referral pathways to link consumers with clinical trial options are often non-existent or under developed, especially for rural and regional Australians.

We need further investment in clinical trials infrastructure and clinical trials network; both those already in existence and those that will develop in future years to ensure Australian consumers can access the latest clinical trials and that Australian health innovators can efficiently conduct trials onshore.

### 4. Open up digitised health data for research

Digital health records can drive extraordinary benefits in our healthcare system and revolutionise our research capabilities.

We are on the cusp of achieving significant public health breakthroughs, and if greater access to these de-identified data can be provided to our researchers, the entire community will benefit.

This is only possible if the community has confidence in the system.

We understand that this is the public's data, not the property of researchers, and it is imperative the public has faith in this system.

### 5. Promoting Australian Health Innovation

Australia has a proud history of developing innovative solutions to complex problems.

Central to the health of Australians, now and into the future, is driving new discoveries in health and medical research into new innovations.

To achieve this innovative potential, it is crucial the Government provide stable support for the sector and give certainty to our innovators, thus driving positive change for the benefit of all Australians.

### 6. A consistent approach to rare disease

A consistent approach to funding research and support for the almost 2 million Australians living with a rare disease is desperately needed. This not only provides a clear rationale for research funding but also, importantly, it raises the level of transparency around funding levels and eligibility criteria.

Our health and medical research sectors hold the key to unlocking cures to these rare diseases and a framework to better support this can ensure effective and equitable access to treatments.

## CONTEXT: WHY INVEST IN AUSTRALIAN HEALTH AND MEDICAL RESEARCH?

All Australians benefit from strong investment in health and medical research and innovation.

Improving the health of the Australian population is central to improving national productivity. Australian health and medical research leads to new medicines, technologies and treatments that cure us when we are ill or injured. It plays a significant role in disease prevention through the development of vaccines, as well as technologies for early disease diagnosis. Most importantly, health and medical research in Australia continues to lead the way internationally on how best to deliver healthcare, providing critical evidence that addresses clinically important unanswered questions.

Australia spends \$181 billion each year delivering healthcare in our hospitals, GP clinics, community health centres, pharmacies and other locations.<sup>2</sup> It is through health and medical research that we identify even small improvements in the efficiency and effectiveness of this health system which lead to big savings: for every dollar invested in Australian health research and development, an average of \$3.90 in health benefits is returned.<sup>3</sup>

Health and medical research and innovation can lead to efficiencies that help constrain health expenditure; reducing the call on the taxpayer, and the cost to consumers through health insurance premiums and out of pocket expenses.

According to the Australian Commission on Safety and Quality in Healthcare, there is a \$5.80 return on each dollar invested in clinical trials conducted by Australian networks.<sup>4</sup> For example, a clinical trial conducted in Australian intensive care units demonstrated that it was just as effective to treat

patients with normal saline rather than the far more expensive human albumin solution. This discovery has led to a change in international guidelines and practice, saving hundreds of millions of dollars per year, not only in Australia but also worldwide.<sup>5</sup>

Australian health and medical research has traditionally been world class, but our record in translating our discoveries into new products, treatments and medicines has not been as good. An assessment by Innovation and Science Australia for the Australian Government identified that fewer than 10% of Australian companies across all industries introduced new-to-market product innovations (new products and services) compared to 21% for the top five performing OECD countries.<sup>6</sup>

The encouraging news is that this percentage is increasing. In the health and medical research and innovation sector, the last decade has seen the development of greater expertise in the commercialisation of new discoveries and more sources of funding for the long process of bringing new medicines, vaccines and medical technologies to market. There is an opportunity to significantly increase Australia's exports in the trillion dollar global healthcare sector, adding new jobs in advanced manufacturing and other related industries. But we need to act now and capitalise on what has been put in place to date.

2. Australian Institute of Health and Welfare 2018. Health expenditure Australia 2016–17. Health and welfare expenditure series no. 64. Cat. no. HWE 74. Canberra: AIHW. P.5.

3. KPMG Economic Impact of Medical Research in Australia, October 2018, Commissioned by the Australian Association of Medical Research Institutes.

4. <https://www.safetyandquality.gov.au/our-work/clinical-trials/>.

5. See ACTA and NHMRC, 2015, Report on the Activities & Achievements of Clinical Trials Networks in Australia 2004 – 2014 for this and other examples.

6. Innovation and Science Australia, Performance Review of the Australian Innovation, Science and Research System 2016, p.xi.

# ACTIONS TO UNLOCK THE POTENTIAL OF AUSTRALIAN HEALTH AND MEDICAL RESEARCH AND INNOVATION

The following six areas require action to unlock the health benefits and economic potential of Australian health and medical research and innovation.

## 1. Long-term, stable funding

### Actions:

- Real increases of 3% per annum over the course of the next Parliament to redress the decline in The National Health and Medical Research Council's funding for research that has occurred since 2014/15.
- Similarly, increase funding for the Australian Research Council funding programs to redress the decline that has occurred since 2013/14.
- Task Innovation and Science Australia with a review of indirect research costs to determine the appropriate level of funding and the best model for its delivery.

The Australian Government invests significantly in health and medical research through a range of programs – particularly in our universities and medical research institutes. Over half of health and medical research in Australia is conducted in Australian universities<sup>7</sup> and they, along with our equally impressive medical research institutes, are the foundation upon which Australian health and medical innovation is built.

Adequate funding for the programs of the Government's premier funding bodies, the National Health and Medical Research Council (NHMRC) and the Australian Research Council (ARC), is crucial if Australia is '...to embrace the new ideas in innovation and science, and harness new sources of growth to deliver the next age of economic prosperity in Australia', as is the ambition of the Government's National Innovation and Science Agenda.

In recent years, we have seen a renewed focus on the need for STEMM (Science, Technology, Engineering Mathematics and Medicine) skills. New graduates in these disciplines have the capacity to transform Australia's future, but only if we are prepared to fund their efforts.

While we can expect and hope that an increasing proportion of STEMM graduates will find roles in the private sector in coming decades, the reality is that many young researchers will remain reliant on NHMRC and ARC funding, and are faced with increasingly insecure employment. Success rates for research funding in the programs administered by the NHMRC and ARC have fallen significantly in recent years and morale in many areas is low. In 2017, only 16.4% of applications were funded.<sup>8</sup> Many worthy research proposals, with the potential to lead to valuable new discoveries and cures were unable to proceed because of a lack of available funds. Around one in four PhD-qualified researchers have less than two months of job security.<sup>9</sup> We risk losing a whole new generation of researchers and their talents.

7. Analysis by Research Australia using Australian Bureau of Statistics data, <https://researchaustralia.org/category/hmr-facts/>.

8. NHMRC, Summary of Results, 2017 Application Round, compiled 6 December 2017.

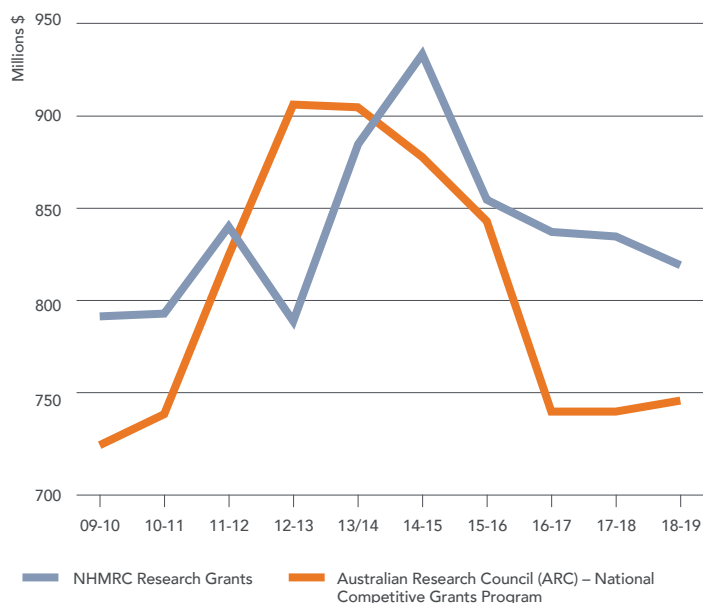
9. ASMR Health and Medical Research Workforce Survey. Building knowledge, supporting innovation, 2016, <http://www.asmr.org.au/Workforce16.pdf>.

# Healthy Australians, Healthy Economy

A pre-election statement from Research Australia on behalf of Australia's health and medical research sector

Action is being taken within the NHMRC and ARC to reform funding programs and while welcome, by itself it will not be enough. The Medical Research Future Fund (MRFF) is also a crucial part of the research mix, but addresses only the last part of the pipeline of innovation and translation. The research funded by the NHMRC and the ARC provide the foundation upon which the MRFF's later stage of medical research and medical innovation is built. The MRFF's grant programs are designed to build on and complement the funding of the NHMRC (and to a lesser extent the ARC) by focusing on translation and innovation, and the MRFF's success will be compromised by a continued decline in NHMRC and ARC funding. The following graph uses data from the Department of Industry, Innovation and Science, and illustrates a real decline in funding for research from both the NHMRC and ARC in recent years.

**NHMRC and ARC expenditure 2009/10 to 2018/19 (forecast); inflation adjusted (2016-17 dollars)<sup>10</sup>**



Government funding for research must keep pace if Australia is to reap the benefits of a new, knowledge-based economy and a safer, higher quality and more effective health system.

At the next Federal election, we seek a commitment from all sides of politics to real increases of 3% per annum over the course of the next Parliament to redress the decline in the NHMRC's funding for research that has occurred since 2014/15.



Based on the 2018 Budget forecasts for the next four years, such an increase would see funding to the NHMRC's research program from the Government rise from a little over \$800 million in 2016/17 to around \$1 billion per annum by 2022/23.

We seek a similar annual real increase in funding for the Australian Research Council funding programs to redress the decline that has occurred since 2013/14.

In addition to the direct costs of conducting research, there are indirect costs. Indirect costs include items like salaries for administrative staff, utility bills, maintenance of buildings and equipment. There are different schemes for funding indirect research costs but generally, funding for indirect research costs is only available to some organisations for some kinds of funding and the rate is generally too low.

We need a resolution to the ongoing issue of government funding for indirect research costs. We endorse the call made by the MRFF Advisory board in 2016 for a whole-of-government approach to the funding of indirect research costs and seek a review by Innovation and Science Australia, to determine the appropriate level of funding and the best model for its delivery. Funding for research is provided by multiple portfolios, including Education, Health, Industry, Innovation and Science, Defence, and Foreign Affairs and Trade. Only a whole-of-government approach can provide a consistent and equitable outcome.

<sup>10</sup> Government, Dept. of Industry, Innovation and Science, SRI Budget Tables 2018-19, Programs, Table 2. Australian Government R&D programs and activities valued at over \$100 million in 2018-19, 2009-10 to 2018-19 (\$m inflation adjusted, 2016-17 dollars) selected data.

# Healthy Australians, Healthy Economy

A pre-election statement from Research Australia on behalf of Australia's health and medical research sector

## 2. A fully-funded, transparent Medical Research Future Fund

### Actions:

- All parties commit to the full capitalisation of the Medical Research Future Fund (MRFF), namely \$20 billion by 2021.
- Give clarity to the separate, but complementary, roles of the NHMRC, ARC and MRFF and their differentiating factors.
- Promote transparency and contestability of MRFF funding by:
  - ensuring the quantum of funding disbursed and the disbursement process are determined on the advice of the Australian Medical Research Advisory Board (AMRAB)
  - including rotating ex officio attendees at AMRAB meetings
  - issuing a communique from each AMRAB meeting.
- The Health Minister should use the existing powers under the MRFF Act to seek the advice of the AMRAB on specific matters, including:
  - the amount of money that should be committed to each specific priority over the two-year period (best specified as a range rather than a single amount)
  - how the money should be disbursed, e.g. targeted call for applications, open call for applications, tender to provide a particular service, grant to a specific organisation or group.
- Implementation of a framework for the MRFF with specific goals, measurable impact and a clear rationale for complementing other research funding.
- One health and medical researcher, one health consumer, one health services researcher, one clinician-researcher and one philanthropist should be appointed to two rotating seats at meetings of the AMRAB Board with 'observer' status.

Established in 2015, and with the first funding announced in mid-2017, the MRFF is a once-in-a-generation opportunity for innovation in health. The plan is for a fund with \$20 billion in capital, from which the earnings are used each year to fund medical research and medical innovation, with a primary focus on translatable, or translational, research complementing the existing funding available from the NHMRC and other sources. By doing so, MRFF funding enables the sector to extend and build on this earlier stage research, to ensure that the promise of better, higher quality, safer and more efficient healthcare is achieved.

Committing \$20 billion of capital to an endowment fund like the MRFF is a necessary investment in containing the burgeoning costs of our health system by improving health outcomes. This is not only about new therapies and interventions, but building the evidence base where there is uncertainty about the most appropriate treatment options, it is about understanding and supporting the key roles that the clinical trial networks and clinical quality registries provide in driving a self-improving, value-based health care system, ultimately improving quality of care, patient outcomes and reducing the rate of expenditure. It is about better managing health to prevent disease, and being able to intervene earlier to prevent the need for expensive treatments and therapies later. Both current systems and new technologies and better use of data can help deliver this revolution in health (as it does in other industries), but only if we invest in it now. We urge all of Australia's political parties to commit to the full capitalisation of the MRFF, namely, \$20 billion by 2021.

The AMRAB is comprised of Australian leaders of health and medical research and innovation to inform Government decision-making on MRFF disbursements. The AMRAB is appointed by the Minister to determine the Australian Medical Research and Innovation Strategy and the Australian Medical Research and Innovation Priorities. AMRAB does not make decisions on how MRFF funds will be used; this responsibility currently rests with the Health Minister of the day, although the transparency around the Government's decision-making requires significant improvement.

As the MRFF matures and the funding it provides annually reaches a transformative scale, so too should the Strategy and Priorities become more specific in determining the quantum of funding that should be committed to each priority over a two-year period (best specified as a range, rather than a single amount) and the disbursement process.

The MRFF is a very significant investment by the Australian Government on behalf of taxpayers. While we believe this investment is worthwhile, it is important the research community and all Australians have confidence that MRFF funding is going where it is most needed and can be most effective. Greater transparency in MRFF processes will instil this confidence.

One way to provide greater transparency would be to allow two ex officio attendees to the AMRAB meetings. These could be rotating positions, and should include early career researchers, health professionals, patient and consumer representatives and philanthropists.

This is an opportunity to broaden the perspectives and understanding of the mechanics of the decision making around significant funding for research in our sector.



# Healthy Australians, Healthy Economy

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## 3. A standardised national approach to clinical trials

### Actions:

- Greater national coordination to further streamline and standardise registration, timely commencement, recruitment and reporting protocols.
- Further invest in permanent clinical trials infrastructure through the current and emerging/future clinical trials networks to achieve, amongst other things, a reduction in the costs and timeframes associated with the almost universal current practice of establishing new trials infrastructure for each clinical trial.

While much has been done to improve the environment for clinical trials in Australia in the last decade, further progress is needed. A continued and intensified focus on improving Australia as a place to conduct clinical trials is needed, with action required on a range of measures and from multiple participants. Leadership from the Commonwealth Government is essential if we are to succeed. Greater national co-ordination is required to further streamline and standardise registration, timely commencement, recruitment and reporting protocols across state boundaries and between sites. Greater national coordination could also support a range of other measures, including workforce development, dissemination of best practice, promotion of Australia as a clinical trials destination, and the ongoing streamlining of governance processes across jurisdictional boundaries.

We also need further investment in clinical trials infrastructure. Many clinical trial networks have established world-class infrastructure to undertake trials. However, in many disciplines, much of the infrastructure in terms of specific personnel and facilities is developed on a trial by trial basis – requiring constant reinstatement and reinvention, and creating unstable employment. This increases the cost, limits the opportunity overall as well as limits the impact by constrained engagement, and unnecessarily prolongs the timeframes associated with clinical trials.

The return on clinical trials is stunning, delivering both improved health outcomes and a more efficient healthcare system. Provision of more permanent clinical trial infrastructure will improve health outcomes, further enhancing our capacity to undertake clinical trials and our reputation as a destination for clinical trials. In turn, greater clinical trial activity would make the provision of infrastructure on a permanent basis more viable and affordable. A bold, strategic plan for clinical trials infrastructure needs to be funded in the next triennium. Sufficient support for the range of current, emerging and new clinical trial networks should be one outcome from greater understanding of their role in a self-learning health system, with a cornerstone commitment of funding from the Commonwealth.



# Healthy Australians, Healthy Economy

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## 4. Digitise health data and open it up for research

### Actions:

- Implement the Productivity Commission's recommendations on greater and more rapid access to data for research purposes.
- Invest in capacity building in Commonwealth departments and agencies to enhance their capacity to securely capture, manipulate and analyse data, and their capability to link data and to prepare secure, de-identified datasets for public release.
- Improve access to health service electronic medical records and national administrative and statistical datasets for health and medical research purposes.
- Complete the national roll-out of My Health Record and provide de-identified data for research and public health purposes.
- Engage the State and Territory governments to play their part in adopting the Productivity Commission's recommendations so that we have a truly comprehensive and national response.

The capacity for the better use of data to revolutionise the way we deliver healthcare is enormous. Making better use of data in healthcare also offers the prospect of safer and higher quality healthcare, improving Australians' wellbeing and boosting productivity. In a 2015 report for the Minister for Health, the Productivity Commission identified that there were significant opportunities to improve the Australian health system, and that one of the keys to doing so was to make better use of data.<sup>11</sup> More recently, the Productivity Commission's report on Data Availability and Use concluded that across all of government, some of the greatest gains could be made through making health data more available.<sup>12</sup>

Several barriers to the better use of data remain:

- Not all health data is digitised – much of it is still recorded on paper.
- Data is entered in different systems, which can't talk to each other.

- We have no reliable way of knowing that different records are talking about the same person.
- Those responsible for looking after and collecting data (the custodians) neither have the skills and resources required to make datasets available for research purposes, nor are they empowered to do so.
- There are barriers to the use of data for research.

It is acknowledged that progress is being made. The Australian Digital Health Agency has released a Digital Health Strategy and is now working on the Framework that will see this implemented. The Department of Health has also developed a Framework to guide the release of de-identified data from the My Health Record for research purposes.

The Government's proposed Digital Economy Strategy provides the opportunity to accelerate and guide this activity, and to promote the more systematic adoption that will enable the greatest benefits to be derived. It also provides an opportunity to encourage the crossover of technologies from other sectors of the economy such as banking, which is a leader in the use of technology to interact and transact with consumers.

The Government has responded to the Productivity Commission's Report of its Inquiry into Data Availability and Use, broadly adopting the Commission's recommendations. Implementation of the Report's recommendations will create a policy framework that provides researchers with much greater access to data while providing greater protection for consumers.

At the next Federal Election, all parties should commit to continuing to implement the policy and legislative framework recommended by the Productivity Commission's Report on Data Availability and Use. In particular, we ask all parties to commit to improving access to health service electronic medical records, and national administrative and statistical datasets for health and medical research purposes.

We understand that this is the public's data, not the property of researchers, and it is imperative that the public has confidence in a system that prioritises security, privacy and personal control. This requires not only legislation but also ensuring Commonwealth Government departments and agencies have adequate resources and capacity.

11. Productivity Commission 2015, *Efficiency in Health*, Commission Research Paper, Canberra. P.4.

12. Productivity Commission 2017, *Data Availability and Use*, Report No. 82, Canberra Pp. 5-6.

# Healthy Australians, Healthy Economy

A pre-election statement from Research Australia on behalf of Australia's health and medical research sector

Consistent with the Productivity Commission's Report on Data Availability and Use, all parties should commit to investing in Commonwealth departments and agencies to enhance their capacity to securely capture, manipulate and analyse data, and their capability to link data and to prepare secure, de-identified datasets for public release.

Access to reliable and current health data makes public health interventions both more efficient and more cost effective, and makes it possible to respond more quickly to emerging issues. In addition to making the data available, it requires a meaningful commitment by governments to evidence-based policy development and implementation.

The secondary use of My Health Record data for research and public health purposes is going to be central to achieving this ambition and is supported by the Australian public. In public polling undertaken on behalf of Research Australia in mid-2017, 93% supported the use of patients' medical records for research purposes, and 98% supported the use of this data to monitor the outbreaks of new diseases.<sup>13</sup> Polling undertaken in June 2018 on attitudes to the use of My Health Records data for research purposes found 90% support for deidentified data from My Health Records being made available for research.<sup>14</sup>

At the next Federal election, all sides of politics should commit to completing the national rollout and further development of My Health Record, and the resourcing of the System Operator and the Australian Institute of Health and Welfare to prepare, link and provide de-identified data for research and public health purposes.

The State and Territory governments have jurisdiction over much of the Australia's health information, and the extent to which this is utilised for research purposes varies significantly. All parties should commit to engaging the State and Territory governments to play their part in adopting the Productivity Commission's recommendations so that we have a truly comprehensive and national response.

## 5. Promoting Australian health innovation

Actions:

- Provide policy certainty for health innovators by all parties committing to no changes to the R&D Tax Incentive in the term of the next Parliament.
- Reinvest savings from the R&D Tax Incentive to supporting Australian innovation through other programs.
- Create a patent box incentive to support advanced manufacturing in Australia in research intensive industries.
- Ensure long term, sustainable, increased funding for Government R&D as a key element in Australia becoming a top tier innovation nation by 2030.

The Australian Government provides many programs to support private sector innovation but its main initiative, the R&D Tax Incentive, has been subject to regular tinkering. A review undertaken on behalf of the Government in 2015 concluded that the scheme should be restricted in several areas to ensure it better supported genuine R&D activity that would not otherwise be undertaken.

The Government committed in the May 2018 Budget to cutting the rate of the refundable R&D Tax Incentive offset and placing a cap on the refundable R&D Tax Incentive, but exempting clinical trials from this cap. It has also proposed a new intensity measure for larger companies.

Amongst other things, clinical trials provide early access for Australian patients to promising new treatments -often in areas where effective treatments don't exist. Clinical trials also drive significant economic activity, support STEM jobs and attract foreign investment. Relative to many other sectors, the commercialisation of health and medical research has longer timeframes, due to significant scientific and regulatory hurdles to reach market (patients), and there is higher expenditure on R&D, particularly in later stages with activities like clinical trials. These trials are expensive, which is why the exemption for the cap is so important for clinical trials.

As a truly research-intensive sector, health and medical research looks to the R&D Tax Incentive as a key enabler of the kinds of health innovation which become the drugs and technologies that build better health, bringing clinical trials to Australian patients and access to cutting-edge therapies. It is in everyone's interest to ensure the Scheme's long-term success.

13. Research Australia, Australia Speaks! 2017 Research Australia Opinion Polling <https://researchaustralia.org/reports/public-opinion-polling-2/>.

14. Research Australia, Australia Speaks! 2018 Opinion Polling for health and medical research <https://researchaustralia.org/reports/public-opinion-polling-2/>.

# Healthy Australians, Healthy Economy

A pre-election statement from Research Australia on behalf of Australia's health and medical research sector

We oppose the proposed reduction in the rate of the tax offset for smaller companies, while recognising that the exemption of clinical trials from the cap will protect many smaller companies in the health and medical research and innovation sectors from some of the impact of the cap. The intensity measure for large companies has the perverse effect of disadvantaging companies that undertake other activity in Australia, such as manufacturing, and should not be implemented.

If/when the latest amendments to the R&D Tax Incentive are resolved by the Parliament, we seek a commitment from all parties to no further amendments being made to the R&D Tax Incentive in the term of the next Parliament. It is essential that we achieve policy certainty in this critical area if we are to foster a truly innovative culture and economy in Australia.

The proposed changes to the R&D Tax Incentive are forecast to generate significant future savings. We seek a commitment from all parties that any savings from the R&D Tax Incentive will be redirected to supporting Australian innovation through other programs.

Research is the creation of new knowledge; the second stage is the application of this knowledge to the development of new products and services. The final step is the manufacture of these new products and their sale to consumers.

Australia aspires to be a manufacturer and exporter of high value-added goods including pharmaceuticals, diagnostics tests, medical technologies and devices. There are, however, many barriers to manufacture in Australia including geographic isolation, a small domestic market, relatively high labour costs and a corporate tax rate that is higher than many of our competitors. One way to improve Australian competitiveness in manufacturing and to make the most of our investments in research and development is through the adoption of the Australian Innovation and Manufacturing (AIM) Incentive, which would function as a type of "patent box" to foster intellectual property returns.<sup>15</sup>

Such an incentive provides an offset against the tax payable on profits derived from the innovation and manufacture in Australia of qualifying patented Australian intellectual property. The patents / licences need to have a connection to Australia to qualify for the Incentive, such as being the product of research conducted in Australia.

As of 2015, 16 countries offered a patent box; all but three of them were members of the Organisation of Economic Cooperation and Development.<sup>16</sup>

The introduction of the AIM Incentive would require no upfront government outlay and is designed to stem the flow of manufacturing offshore whilst providing jobs future jobs for Australians. It would help to complete the transition to a more innovative economy which supports the scientific research needed to develop new knowledge, promotes the innovation needed to apply that new knowledge, and encourages domestic manufacture of the products that create jobs and generate export revenue.

We call on all parties to commit to the AIM Incentive to support advanced manufacturing in Australia in research intensive industries.

In 2017, Innovation and Science Australia produced a landmark report, *Australia 2030: prosperity through innovation*. It articulates the jobs of the future and skills we need to ensure Australia's world class research can translate into global outcomes.<sup>17</sup> Medical research currently employs over 32,000, and there are a further 78,000 people employed in the downstream medical technologies and pharmaceuticals sector. Medical research jobs are high-value knowledge-based jobs, contributing \$134,000 per FTE to the economy.<sup>18</sup>

Research Australia agrees with the Report's view that Australia's future prosperity depends on Australia's private sector becoming more innovative and more R&D intensive. To achieve this change in Australian industry the Plan does not propose any increase in Government funding as a percentage of GDP, beyond the long-term average for existing funding programs and commitments. Instead, it is relying on the redirection of existing programs to provide more effective incentives to increase business R&D as a means of closing this gap.

While we accept that there are areas where the Government's R&D expenditure could do more to incentivise private sector investment, the question remains whether redirecting existing Government funding will be enough to achieve the required transformation in our economy. There is the risk that underinvestment means we miss the opportunities presented by emerging fields in science and new technologies. This risk is too great to simply rely on maintaining existing funding levels.

We call on all parties to commit to long term, sustainable, increased funding for Government R&D as a key element in achieving the 2030 Plan's goal of Australia becoming a top tier innovation nation by 2030.

15. <https://www.ausbiotech.org/policy-advocacy/aim-incentive>.

16. United States of America Congressional Research Service, 2017, Patent Boxes: A Primer, [www.crs.gov](http://www.crs.gov).

17. Innovation and Science Australia 2017, *Australia 2030: prosperity through innovation*, Australian Government, Canberra.

18. KPMG Economic Impact of Medical Research in Australia, October 2018, Commissioned by the Australian Association of Medical Research Institutes.

# Healthy Australians, Healthy Economy

A pre-election statement from Research Australia on behalf of Australia's health and medical research sector

## 6. A consistent approach to rare disease

### Actions:

- Create a Rare Disease Framework to provide a structured approach to funding research and infrastructure that helps ensure effective and equitable access to therapies for the almost 2 million Australians living with a rare disease.

While individually they are rare, there are 8,000 different rare diseases and collectively they affect almost two million Australians.<sup>19</sup> For many Australians, research holds the promise of better health in the future. For many families with a child with a rare disease, research is the only hope for any future at all. The only available treatments are often experimental, and even securing a diagnosis can take years.

With so many different rare diseases, and often only a handful of Australians affected at any one time by a particular disease, deciding which diseases to tackle can seem an impossible task. Health and medical research is undertaken around the world and improvements in survival are related to global research rather than specifically to the volume or subject of Australian research. The implications of funding rare disease research in Australia include considering the relative need for research on a global scale; identifying areas where Australia has specific expertise and can best contribute to the global research effort; and the opportunity to promote and support international collaborations. The latter can play a significant role in providing the opportunity for Australian patients with rare diseases to participate in clinical trials, which are often the only hope for an effective treatment.

We acknowledge that both the Coalition and Labor have committed to a Rare Disease Framework. The proposed Framework provides a structured approach to funding research and the accompanying infrastructure that helps ensure funding is used in the most effective and equitable manner, and facilitates the participation of Australian patients in international research as well as supporting Australian research into rare disease. It is a model that has been implemented in many countries overseas and works effectively.

Such a Framework provides the best opportunity for Australia's health and medical research and innovation sector to contribute to rare disease research, and provides the greatest opportunity for those Australians currently suffering from one of the many rare diseases without treatment options.

We urge all parties to commit to the development of a Rare Disease Framework to provide a structured approach to funding research and infrastructure that helps ensure effective and equitable access to therapies for the almost two million Australians living with a rare disease.

In addition to providing a clear rationale for research funding, such a Rare Disease Framework provides the opportunity for long term funding stability and transparency about the level of funding available and the eligibility criteria. This helps support the development of research in rare disease areas in a sustainable manner and encourages engagement with patient groups and the health system. It also helps to depoliticise the decisions about how and where funding is allocated.

Research Australia welcomes the recent announcements by the major political parties in relation to rare disease and looks forward to a Rare Disease Framework being implemented.



19. <https://www.rarevoices.org.au/page/15/what-is-a-rare-disease>.

# Healthy Australians, Healthy Economy

A pre-election statement from Research Australia on behalf of Australia's health and medical research sector

## CONCLUSION

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The barriers to delivering better health outcomes for Australians, better value for taxpayers and a stronger economy are significant but not insurmountable. The solution lies in longer term, more stable and transparent funding for health and medical research and innovation. It lies in better connecting research and innovation to our health system and global markets by making better use of data and improving the environment for clinical trials. It lies in better supporting our entrepreneurs and in enabling Australians with rare diseases to connect earlier and more reliably with the best research in Australia and overseas.

In short, the solution lies in the six areas for action outlined in this document, and Australia's health and medical research and innovation sectors stand ready to work with the next Australian Government to deliver these outcomes for the benefit of all Australians.

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