

NSW Health and Medical Research Strategic Review

2012



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Foreword



A strong and vibrant health and medical research enterprise is important to New South Wales. Health and medical research can help deliver better treatments and interventions, improve health services delivery and improve clinical and population health outcomes.

Investing in research also benefits the state's economy, stimulating it directly as biotechnology industries grow to translate basic research into practice. Indirectly, the indisputable gains that come from health and medical research in improvements in length and quality of life mean that, roughly speaking, every dollar invested in health and medical research returns in excess of two dollars in health benefits.

The NSW Health and Medical Research Strategic Review has consulted extensively. More than 500 experts have provided input to the Review. Best practice examples from national and international jurisdictions have been collated and past reports, published articles and international benchmarks have been considered.

NSW has an impressive record of achievement in health and medical research – our researchers have made significant contributions to health and medical discoveries internationally.

NSW has many strengths and competitive advantages that support our health and medical research effort. These include a large and diverse population, a high quality health system, excellent researchers and clinicians, outstanding medical research institutes and universities with a global track record in a broad range of health and medical research.

Despite these natural advantages, NSW has work to do to fulfil its potential. The Review found that:

- NSW attracts less than its population share of National Health and Medical Research Council funding.
- There is a perception that the NSW Government and health services have not placed the same high value on health and medical research as their counterparts in other states, and as a consequence, NSW has a less robust research culture.
- Although NSW Government research infrastructure funding is valuable, there is strong dissatisfaction with the quantum and inconsistent application of this funding within the research sector.
- The lack of career pathways, poor remuneration for research workers in relation to other health and medical careers, lack of support for early to mid-career level researchers and job insecurity were identified by many stakeholders as pressing issues.
- Clinician researchers are a limited resource and there is a perception that the time that clinical staff specialists dedicate to research has been eroded over time.

It is our conclusion that NSW given its potential, should:

- Foster the translation of research into policy and practice, by encouraging and endorsing health service innovation and experimentation, take a leadership role in clinical trials, using research wherever possible in the development of policy, focusing on deriving benefit from intellectual property accumulated through research and supporting early-stage venture capital in taking research from the laboratory into commercial product development;

- Build globally relevant research capacity through enhancing interactive research hubs, strengthening the research workforce, improving research infrastructure support, building research assets such as equipment and buildings, leveraging investment and improving the management and administration of research; and
- Provide strategic leadership to health and medical research through establishing a strategic investment approach.

The Review has adopted a ten-year horizon. During that time NSW should move progressively through a range of improvements to achieve the vision of a vibrant global leader in health and medical research. The Review makes several recommendations that we consider will help to achieve these outcomes. These recommendations are comprehensive and together will position NSW to realise the full benefits of health and medical research.

Implementing the Review recommendations will be complex and will require a robust, integrated program. This necessitates the establishment of an implementation committee and resourcing the Office for Medical Research to drive implementation. Key performance indicators should be established to enable progress to be measured.

I commend this Report to the Minister for Health and Minister for Medical Research, the Hon. Jillian Skinner MP. It has been a pleasure to Chair this Review. I look forward to continuing to work with the members of the Advisory Committee to action the 10-year plan for health and medical research in NSW.



Mr Peter Wills, AC
Chairman, NSW Health and Medical Research
Strategic Review

The NSW Health and Medical Research Strategic Review Advisory Committee

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Acknowledgements

The Chairman and Committee of the NSW Health and Medical Research Strategic Review would like to acknowledge the valuable assistance and input received from the following people.

- All individuals and groups that have provided feedback to the review (see Appendix 2).
- Project Management and Secretariat (see below)

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Executive Summary

The world is making great strides in health and medical research with revolutionary advances in many fields including the mapping of the human genome and understanding the molecular basis of illness. Information technology is transforming our ability to study and use substantial data sets, bringing insights from the population to bear on the needs of the individual. These advances position us at the start of arguably the most exciting era of health and medical research. It is no longer fanciful to anticipate further major growth in research that will push back the barriers of knowledge about cancer, ageing, psychiatric disorders and degenerative disease and usher in significant health gains.

It is timely for New South Wales, with its proud history of outstanding health care and medical achievement, to be at the front of these developments, with strong commitment, support for its research workers, and the backing of the community. A leadership role and the adoption of a long term vision for health and medical research will improve the quality, longevity and economic lives of the people in our State.

Setting the scene

In 2011, the NSW Government established the Health and Medical Research Strategic Review to develop a ten-year plan. The Review undertook an extensive analysis of the facts, including consultation with experts and the public, identified best practice examples from Australia and overseas and considered research output and quality benchmarks.

Research is inherently competitive and the Review found that NSW already has many advantages, arising from our strong clinical networks, our clinical trial capacity, leadership in translational research and a strong science base. NSW has several world-class research institutions, many high quality research assets and a cutting-edge science capability that has led to the successful application and commercialisation of research, including medical devices. Global companies, such as Cochlear and ResMed, have established their headquarters in this state and

developed front-line technologies that dramatically improve quality of life, creating high value jobs and generating wealth for NSW.

Each year, NSW government invests millions of dollars in research infrastructure, buildings, and directly supports research relevant to health policy and clinical practice.

Future investment will need to be better coordinated and policy settings will have to effectively capitalise on our strengths. Increasingly, research will be collaborative, bringing many disciplines together from laboratories, population health research centres, to primary care locations and hospitals and aged-care settings.

A strategic investment in health and medical research will build upon recent discoveries to address unsolved health problems, find better ways to improve our quality of life, and identify efficiencies in the way we provide health care. Such an investment will also have substantial direct and indirect benefits to the NSW economy.

The vision

NSW will have a global reputation as a resilient, innovative centre of excellence for health and medical research that strongly supports a high-quality health system that is highly responsive to scientific advances and that generates health, social and economic benefits for the state and beyond.

Achieving the vision

NSW will deliver on:

1. A priority-driven approach to research and innovation in our health services that will generate new evidence and translate knowledge into the delivery of a better health system and improve health;
2. Improving research infrastructure to enable research organisations to build critical mass, maximise their success in securing competitive grants and build centres of global relevance;

3. Building and optimising the use of shared research assets, such as strategic investments in bio-banking and data linkage, to build research capacity and contribute to research excellence;
4. Leadership in clinical and other health intervention trials to improve clinical care, lead to better treatments and medical devices and improve health.

The foundation of the new approach will be political commitment, strategic leadership, collaboration, greater accountability and good governance. NSW should reward research excellence, collaboration and translation and support the development of a strong research workforce.

The approach

NSW should take a partnership approach to build progressively and systematically on two broad strategies:

- Foster translation and innovation from research
- Build world class research capacity.

Strategy 1: Foster translation and innovation from research

This strategy focuses on the translation of evidence derived from basic, clinical and population health research that has the potential to improve health, clinical care and the quality and performance of health services. It is a major rationale for increased investment by the NSW Government.

Translating the results of health and medical research is challenging. It requires the right research to be generated and applied through a team effort by many talented individuals in research, clinical settings, not-for-profit organisations and business, many of whom may have no experience of the process of translation or research generation. Research translation can continue to generate economic benefits through commercialisation of ideas and products.

Theme 1: Encourage research and innovation in health services

Health services across NSW make a significant investment in research. Research activity within health services attracts Australia's best and brightest practitioners to public hospitals, and increases quality of care. Health services engagement in research, with incentives and accountability

for excellence and impact, is therefore an essential component of delivering high-quality health care in NSW.

What needs to be done?

- Build a dynamic and supportive research culture in Local Health Districts through strategic leadership and governance
- Establish a research grant program to support practitioner researchers to generate new evidence through collaboration among clinicians, policy makers, health services managers, scientists and academics
- Attract and retain high-quality practitioner researchers in Local Health Districts
- Provide training for practitioner researchers and facilitate access to research support
- Strengthen business, human resources, information technology and financial service processes that support research activities.

Theme 2: Leadership in clinical trials

Clinical trials evaluate the safety and efficacy of medications, medical devices or changes in models of health services delivery. Such trials provide reliable evidence that can lead to better treatments and interventions, improved health services delivery and better health. NSW taking a leadership role in clinical trials will be critical in enhancing innovation in the health system.

What needs to be done?

- Establish a clinical trial support team within the Office for Medical Research
- Develop phase I clinical trial capability in NSW
- Reduce barriers to clinical trials by faster start-up times and greater opportunities to recruit trial participants and engage clinical staff.

Theme 3: Maximise the use of research in policy, practice and health service delivery

The generation and use of high-quality, relevant research evidence will improve health policy and program effectiveness, achieve better health and help build efficient services.

What needs to be done?

- Strengthen the capacity of NSW Health to use existing research evidence in policy and the implementation of programs
- Commission or undertake high-quality research, including intervention research, to inform major policy and programs where there are evidence gaps
- Fund rigorous evaluation of policies and programs to ensure effective implementation of research evidence and ongoing adherence to best practice
- Increase collaboration among policy makers, practitioners and researchers.

Theme 4: Focus intellectual property expertise

Commercialisation of intellectual property is complex and typically involves research organisations, commercialisation offices and company partnerships. NSW researchers should have access to the best commercialisation skills available to ensure the consumer, employment and commercial benefits of their discoveries are realised in NSW.

What needs to be done?

- Develop an intellectual property framework that could act as a model for multiparty publicly funded research
- Enhance researchers knowledge and understanding of commercialisation resources
- Promote greater capability in commercialisation offices for use by multiple institutes, universities and Local Health Districts
- Improve opportunities for researchers to develop business and commercial skills.

Theme 5: Support early-stage venture capital

Early-stage venture capital is one mechanism to create value for researchers, institutions, investors, patients and Government by creating new products or services from research output. NSW should focus on helping researchers develop prototypes and business plans to commercialise early stage ideas, particularly for innovative medical devices.

What needs to be done?

- Establish a pilot program to develop medical devices and apply to other areas of investment if successful.
- Align NSW research with Commercialisation Australia processes to increase the 'pipeline of ideas'.

Strategy 2: Build Globally Relevant Research Capacity

This strategy focuses NSW investment on nurturing and supporting current areas of excellence and building globally competitive research capacity.

Theme 6: Enhance health and medical research hubs and collaboration

Conducting research in hubs provides numerous advantages, particularly as research is becoming more complex and multifaceted. Hubs consist of geographically close research enterprises in a functional relationship. Hubs aim to enhance collaboration, translation and the efficient sharing of expensive equipment, buildings and support services. There are eight primary research hubs across Sydney, Newcastle and the Illawarra. To support such a large number across a relatively small population requires each hub to focus on distinct areas of expertise where it can be world class.

What needs to be done?

- Require research hubs to develop strategic plans that foster translation and innovation and build research capacity
- Hubs should report annually to the Office for Medical Research on an agreed set of performance indicators
- Review and align existing research networks to this Review.

Theme 7: Strengthen the research workforce

High-quality health and medical research needs a strong and vibrant workforce across universities, medical research institutes, health services, non-government organisations and the private sector. NSW must work energetically to retain its workforce whilst concurrently attracting quality researchers to the state.

What needs to be done?

- Establish an Elite Researcher Scheme to attract leading Australian and international researchers to NSW
- Establish a Research Fellowship Program targeted at early to mid-career researchers
- Provide additional financial incentives through a 'Scholarship Top-Up Program' to attract high quality PhD students

- Grow successful research training programs in areas of high need.

Theme 8: Improve research infrastructure support

Research infrastructure comprises the facilities and services that allow researchers to undertake organised research. Infrastructure funding for universities and medical research institutes is complex. The Australian Government runs programs tied to competitive research grants whilst the NSW Government programs have different criteria and purpose. NSW should reform its research infrastructure funding to drive increasing research competitiveness by ensuring the quantum and scope of research infrastructure support is at the appropriate level.

What needs to be done?

- Align NSW Health funding programs to two principles: rewarding excellence and scale or developing capacity in key priority areas
- Restructure the Medical Research Support Program to reward excellence, promote critical mass and support other strategic goals
- Enhance and reform the Capacity Building Infrastructure Grants program
- Work with the Australian Government to coordinate and streamline an open, fair and transparent infrastructure funding program for health and medical research.

Theme 9: Build and optimise the use of shared research assets

Research assets include major equipment and research platforms such as bio-banks, cohort studies, record linkage capability, genomics sequencing and microarray technology. Access to these assets is an important contributor to research excellence that enable world class research. Shared assets should be accessible by researchers across organisations and geographical boundaries to increase capability and utility, maximise cost-effective research activity and encourage collaboration.

What needs to be done?

- Develop a register of major research assets in NSW
- Identify research asset gaps and develop a 10-year strategic plan to address them
- Ensure scale and funding sustainability for existing research assets with that focus on: bio-banking, bio-

informatics, population-based cohort studies and record linkage.

Theme 10: Leverage all investment sources

Government and non-government support of health and medical research in NSW is substantial. NSW should therefore seek to leverage its own investment to maximise the funding NSW receives from the Australian Government and other sources, with specific initiatives for philanthropy, business and overseas grants.

What needs to be done?

- Provide assistance to hubs, research organisations, research networks, LHDs and consortia for competitive grant applications
- Co-invest in large (greater than \$10million) philanthropic donations that have state-wide significance and align with the Review Strategy
- Develop, refine and implement programs to attract individual, corporate and not-for profit investment in health and medical research
- Expand industry-partnered collaborative research programs.

Theme 11: Improve NSW Health research administration

Within the NSW health system, each research proposal involving human participants is assessed by a Human Research Ethics Committee. Authorisation for research to proceed also requires a site-specific governance assessment, irrespective of where the research grant was given ethical endorsement. Further work is required to streamline this process.

What needs to be done?

- Reform site specific authorisation (research governance) processes
- Improve research ethics and governance data collection management and analysis capabilities
- Include research ethics and governance metrics as a monitoring measure in the LHD Performance Management Framework
- Appropriately resource LHD research offices to undertake research ethics and governance functions.

Delivering on the strategy

Implementing the strategy depends upon political commitment, strategic leadership, collaboration, greater accountability and good governance. An Implementation Committee should coordinate, monitor and report on this strategy (see full recommendations on page 59). This Committee could transform into an Advisory Board as the implementation task is completed.

Delivering on this strategy will require an increased investment of resources from all sources and a strong partnership across the sectors and Agencies (the key partnerships are outlined in the full report). Between 2005 and 2010, the NSW Government invested over \$190million each year in support for health and medical research, not including that invested in clinical research embedded in LHDs.

The Review considers that the increased investment in health and medical research should be phased in over 10 years. This increased investment should be reflected in the achievement of agreed, clear metrics and milestones. The NSW Government approach should leverage the substantial Australian Government investment, which delivered over \$800million to the NSW health and medical research sector in 2011.

How will we know if the Strategy is a success?

In ten years time, if the strategies are implemented successfully, NSW will have a vibrant research sector delivering health and economic benefits to the state. A mid-term review of progress is required to measure the return on investment. Whilst a set of detailed criteria should be developed by the Office for Medical Research, the high-level indicators of success to be reported annually are:

- A better health system and improved health
 - Evidence that NSW is recognised nationally and internationally as a centre of excellence in fostering the use of research evidence and that research is routinely considered as part of health policy making and translated into practice
 - Ministry of Health and Local Health District annual research reports demonstrate effective research governance and development and transparent, effective investment in research
 - Research indicators in Local Health Districts show

short turn-around times in ethical review and site specific authorisation.

- Ministry of Health population health and performance reports indicate better health for the people of NSW and an improved health system that can be plausibly related to increased effectiveness of research
- Globally-relevant high quality research.
 - NSW researchers have more highly-cited publications reflecting greater local, national and international collaboration
 - NSW attracts excellent researchers and receives a greater number of competitive grants and fellowships from the Australian Government and other prestigious sources
 - Shared research assets are sustainable and frequently accessed and utilised by the research community
 - Increased early adoption of new research evidence into practice
 - Increased access to clinical trials.
- Increased investment and employment.
 - There is a significant increase in competitive national and international research funds flowing to NSW
 - NSW increases its investment in health and medical research based on the strategic priorities of the State
 - Clinical trials are seen as a good investment in NSW due to reduced start-up times and removal of other barriers to effective conduct
 - Medical devices developed in NSW demonstrate a return on investment through application and commercialisation
 - A greater number of researchers are based in NSW
 - Infrastructure investment demonstrates the research institutes and hubs are working in collaboration with greater accountability of public funds.

Recommendations

Strategy 1: Foster translation and innovation from research

Theme 1: Encourage research and innovation in health services Recommendations		Responsibility
1.1	Build a dynamic and supportive research culture in LHDs through strategic leadership and governance	LHDs MoH – OMR ACI
1.2	Establish a research grant program to support practitioners to generate new evidence through collaboration between practitioners, policy makers, health services managers, scientists and academics	MoH – OMR ACI, CINSW
1.3	Attract and retain high-quality practitioner researchers in LHDs	MoH – OMR ACI, CINSW LHDs
1.4	Provide training for practitioner researchers and facilitate access to research support	LHDs MoH – OMR
1.5	Ensure business, human resources, information technology and financial service processes that are able to properly support research activities	MoH LHDs

Theme 2: Leadership in clinical trials Recommendations		Responsibility
2.1	Establish a clinical trial support team within the Office for Medical Research	MoH – OMR
2.2	Develop phase I clinical trial capability in NSW	MoH – OMR Universities
2.3	Reduce barriers to clinical trials by faster start-up times and greater opportunities to recruit trial participants and engage clinical staff	MoH, LHDs CINSW Universities MRIs

Theme 3: Maximise the use of research in policy and practice and health service delivery Recommendations		Responsibility
3.1	Ensure capacity within NSW Health to use existing research evidence in policy and the implementation of programs	MoH ACI, CEC, CINSW
3.2	Commission or undertake high-quality research, including intervention research, to inform major policy and programs where there are evidence gaps	MoH ACI, CEC, CINSW
3.3	Fund rigorous evaluation of policies and programs to ensure effective implementation of research evidence and ongoing adherence to best practice	MoH ACI, CEC, CINSW

Theme 4: Focus intellectual property expertise Recommendations		Responsibility
4.1	Develop and implement an intellectual property framework for multiparty publicly funded research	MoH-OMR DTIRIS
4.2	Enhance researchers knowledge and understanding of commercialisation resources	DTIRIS MoH – OMR
4.3	Promote greater capability in commercialisation offices for use by multiple institutes, universities and LHDs	DTIRIS MoH – OMR
4.4	Improve opportunities for researchers to acquire business and commerce skills	MoH – OMR Universities

Theme 5: Support early-stage venture capital Recommendations		Responsibility
5.1	Establish a pilot medical device seeding program	MoH-OMR DTIRIS
5.2	Align NSW research with Commercialisation Australia processes to increase the 'pipeline of ideas'	DTIRIS MoH – OMR

Strategy 2: Build Globally Relevant Research Capacity

Theme 6: Enhance health and medical research hubs and collaboration Recommendations		Responsibility
6.1	Require research hubs to develop strategic plans that foster translation and innovation and build research capacity	MoH – OMR Hubs
6.2	Hubs should report annually to the Office for Medical Research on an agreed set of performance indicators	MoH – OMR Hubs
6.3	Review and align existing health and medical research networks with this Strategy.	MoH – OMR CINSW

Theme 7: Strengthen the research workforce Recommendations		Responsibility
7.1	Establish an elite researcher scheme to attract leading Australian and international researchers to NSW	MoH – OMR Universities, MRIs
7.2	Establish a Research Fellowship Program targeted to early to mid-career researchers	MoH – OMR
7.3	Provide additional incentives through a Scholarship ‘Top-Up’ Program to attract high quality PhD students	MoH – OMR
7.4	Grow successful research training programs in areas of need	MoH, HETI, Universities

Theme 8: Improve research infrastructure support Recommendations		Responsibility
8.1	Align NSW Health funding programs to two principles: rewarding excellence and scale or developing capacity in key priority areas.	MoH – OMR MoH – Population Health CINSW
8.2	Restructure the MRSP to reward excellence, promote critical mass and support other strategic goals	MoH – OMR
8.3	Enhance the Capacity Building Infrastructure Grants program	MoH – Population Health
8.4	Work with the Australian Government to coordinate and streamline an open, fair and transparent infrastructure funding program for health and medical research	MoH – OMR DTIRIS

Theme 9: Build research assets and maximise their use Recommendations		Responsibility
9.1	Develop a register of major research assets in NSW	MoH – OMR and Health System Support
9.2	Identify research asset gaps and develop a 10-year strategic plan to address them	MoH – OMR and Health System Support
9.3	Scale up and fund to ensure sustainability for existing research assets with a particular focus on: biobanking, bioinformatics, population-based cohort studies and record linkage	MoH, CINSW, LHDs Universities MRIs
9.4	Require organisations that hold NSW Government-funded major assets to develop plans and protocols to promote sharing and access and to regularly report asset utilisation	MoH – OMR and Health System Support CINSW, LHDs, Universities, MRIs

Theme 10: Leverage all investment sources Recommendations		Responsibility
10.1	Provide assistance to hubs, research organisations, research networks, LHDs and consortia for competitive grant applications	MoH – OMR
10.2	Co-invest in large (>\$10million) philanthropic donations that have state-wide significance and align with the Review priorities	DPC
10.3	Develop, refine and implement programs to attract individual, corporate and not-for profit investment in health and medical research	DTIRIS MoH – OMR
10.4	Expand industry-partnered collaborative research programs	DTIRIS MoH – OMR

Theme 11: Improve NSW Health research administration Recommendations		Responsibility
11.1	Reform site specific authorisation (research governance) processes	MoH – OMR
11.2	Improve research ethics and governance data collection management and analysis capabilities	MoH – OMR LHDs
11.3	Include research ethics and governance metrics as a monitoring measure in the LHD Performance Management Framework	MoH – OMR
11.4	Appropriately resource LHD research offices to undertake research ethics and governance functions	LHDs

Recommendations: Adopt a strategic investment approach		Responsibility
12.1	Increase transparency and accountability of state-level health and medical research funding programs	MoH DTIRIS ACI, CEC, CINSW
12.2	Establish criteria for setting priorities in health and medical research	MoH – OMR
12.3	Provide ongoing analysis of NSW current areas of research excellence and competitive advantage to drive strategic investment decisions	MoH – OMR Universities MRIs LHDs
12.4	Identify gaps and enhance research collaborations and programs in important areas through single-purpose capacity building grants	MoH ACI, CEC, CINSW

Recommendations: Adopt a robust implementation approach		Responsibility
13.1	Provide additional resources to commence the implementation process	MoH - OMR
13.2	Rename the Office for Medical Research the Office for Health and Medical Research	MoH
13.3	Establish the Office for Medical Research leadership, Advisory Board, resources and processes to achieve the aims of the NSW health and medical research strategy, including communication and advocacy	MoH - OMR
13.4	Agree on a comprehensive set of result areas and key performance indicators to measure progress against strategic objectives	MoH - OMR

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Introduction

Australia has an impressive record of achievement in health and medical research. Australian researchers have made significant contributions to health and medical discoveries internationally. Six Australians have received the Nobel Prize in physiology and medicine, and health and medical research undertaken in Australia is highly cited.

Health and medical research is undertaken by people working in universities, hospitals, medical research institutes and business; each contributes to a productive and commercially innovative health and medical research sector in New South Wales (NSW).

The case for investment in health and medical research is that it delivers, both directly and indirectly, high returns to the population through improved longevity and health outcomes.

Australian health research and development expenditure between 1992-03 and 2004-05 is estimated to return a net benefit of approximately \$29.5billion. For the average dollar invested, \$2.17 in health benefits is returned.¹ The major return on investment is the gain in wellbeing achieved from lowering mortality rates and associated morbidity.

Research can help deliver better treatments and interventions, improve health service delivery and improve clinical and population health outcomes. A strong research culture within the public health system helps to attract and retain high quality researchers and clinicians in NSW and facilitates education and training.

Investment in health and medical research also leads to commercial gains to industry and the economy linked to production of preventive and therapeutic interventions. Investment in research can also strengthen the competitiveness, productivity and innovative capacity of the state.

Background to the review

In recognition of the key role that research can play in improving health, social and economic outcomes for NSW, the *Better Patient Care: Boost for Medical Research* 2011 policy committed the NSW Government to develop a 10-year health and medical research strategy for NSW that enables the state to contribute to the discovery and application of new treatments and diagnostic techniques and devices that will be a major contributor to health reform into the future.¹

The NSW Health and Medical Research Strategic Review, led by Mr Peter Wills AC, was established to work with the research community, the health sector, industry representatives and other interested parties to develop the plan. Mr Wills was supported by an Advisory Committee, appointed by the Hon. Jillian Skinner, Minister for Health and Minister for Medical Research. The Terms of Reference and the composition of the Advisory Committee are detailed in Appendix 1.

The Review undertook extensive consultation with health and medical research experts and members of the public. Over 360 submissions were received and 181 people participated in individual or group interviews. The Review considered best practice examples from national and international jurisdictions as well as past reports, published articles and international benchmarks.

During the Review a Fact Base, Issues Paper and Discussion Paper were written and distributed and are available at <http://www.health.nsw.gov.au/omr/review/>. An implementation plan will be developed after the recommendations from this Report have been considered by government.

The vision for health and medical research in New South Wales

NSW will have a global reputation as a resilient, innovative centre of excellence for health and medical research that strongly supports a high-quality health system that is highly responsive to scientific advances and that generates health, social and economic benefits for the state and beyond.

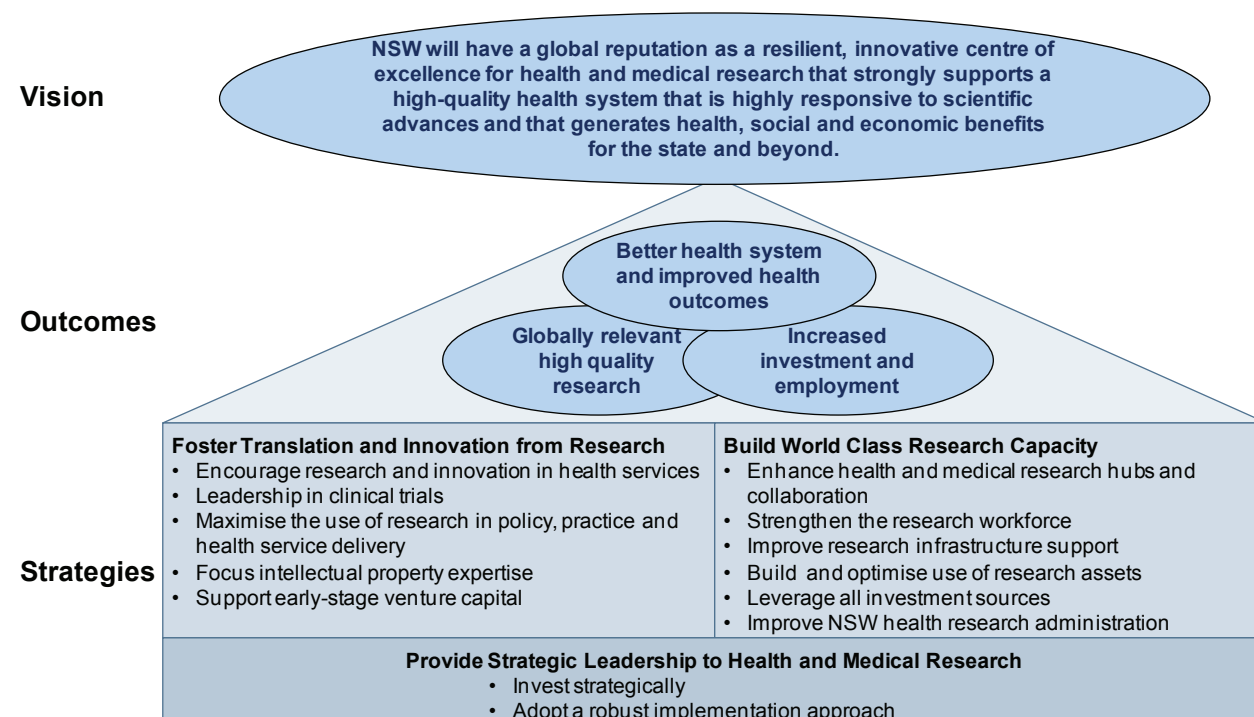
The Review Advisory Committee recognises the importance of balance between investigator-initiated and priority-driven research and the important contribution to be made to clinical and health gain from other fields other than classical biomedicine (e.g., the social sciences, information and communication technology and nanotechnology).

The Review defines health and medical research broadly, to include biomedical, clinical, health services, health policy and population health research.

Achieving the vision

The Strategy Framework for Health and Medical Research (Exhibit 1) presents a comprehensive approach to strengthening health and medical research in this state

Exhibit 1: Strategy framework for health and medical research in NSW



To achieve the vision, NSW will need to deliver on:

- A priority-driven approach to research and innovation in our health services that will generate new evidence and translate knowledge into the delivery of a better health system and improve health;
- Improving research infrastructure to enable research organisations to build critical mass, maximise their success in securing competitive grants and build centres of global relevance;

- Building and optimising the use of shared research assets, such as strategic investments in biobanking and data linkage, to build research capacity and contribute to research excellence.
- Leadership in clinical and other health intervention trials, including the development of early phase trial capacity, to improve clinical care, lead to better treatments and improve health.

The foundation of the new approach will be political commitment, strategic leadership, collaboration, greater accountability and good governance. NSW should reward research excellence, collaboration and translation and support the development of a strong research workforce. These characteristics are fundamental underpinnings for a quality research endeavour that delivers a better health system, improves health outcomes and contributes to economic growth.

NSW should build progressively and systematically focus on two broad strategies:

- Foster Translation and Innovation from Research
- Build World Class Research Capacity

Specific recommendations linked to these two strategies are discussed in detail in the following sections.

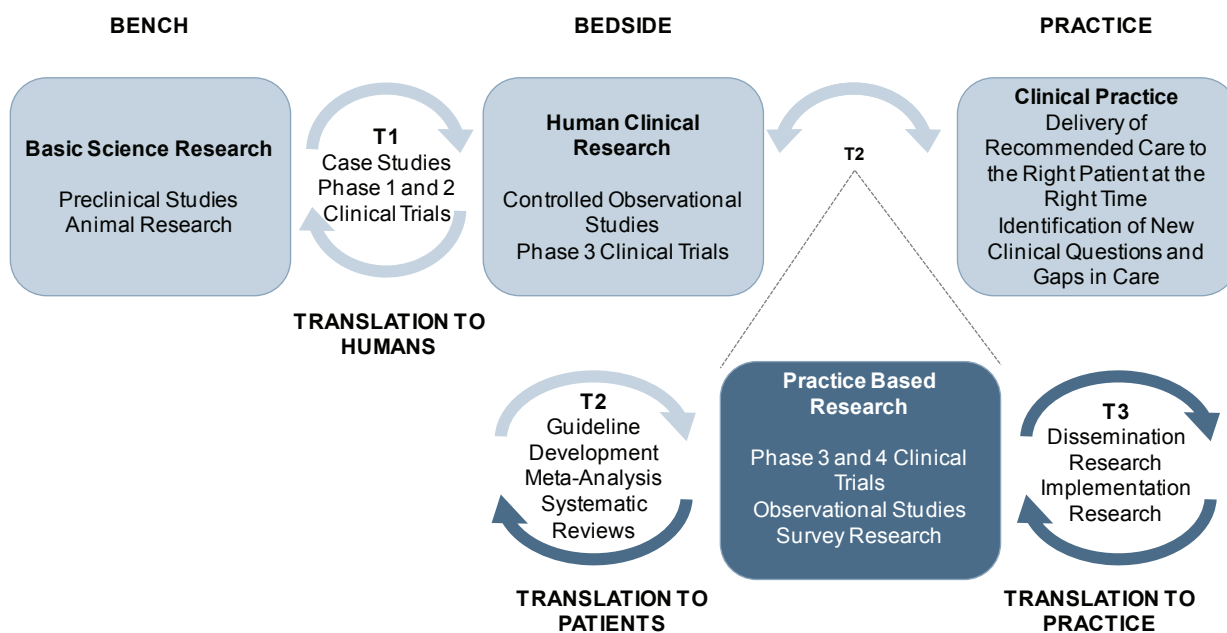
STRATEGY 1

Foster Translation and Innovation from Research

While there are many definitions of research translation, for the purpose of the Review, we are using the term to mean the application of information and insights derived from basic, clinical and population health research to the provision of health services. This Strategy focuses on: encouraging health services innovation; leadership in clinical trials; leveraging research in policy; focusing intellectual property expertise; and supporting early-stage venture capital.

The US National Institutes of Health roadmap² describes research translation according to the context within which the research is undertaken (Exhibit 2). This includes: treatment and intervention development (T1); testing efficacy and effectiveness of treatments and interventions (T2); and dissemination and implementation research for system-wide change (T3).

Exhibit 2: US National Institutes of Health model for research translation



While the National Institutes of Health model focuses on translation of basic biomedical research to clinical practice, its principles are fully applicable to the translation of population health and health services research into population health programs and health service delivery.

The translation of research evidence has the potential to improve clinical care, population health and the quality and performance of health services; it is a major determinant

for increased investment by the NSW Government in health and medical research.

Research translation can also generate economic benefits through commercialisation of ideas and products. These benefits can include royalties from licensing intellectual property and high value jobs in internationally renowned companies such as Cochlear and ResMed.

Despite its close connection to health gain, translating the results of health and medical research is often difficult. It requires a team effort from many talented individuals in research, clinical settings, not-for-profit organisations and business, who may not have a natural cultural affinity for each other or for the process of translation.

Incentives and change management are required to improve the culture of collaboration which will be critically important to achieve effective translation of research into health services to improve health outcomes. The Cancer Institute NSW Translational Cancer Research Program provides an example (Exhibit 3).

Exhibit 3: Translational Cancer Research Program

The Translational Cancer Research Program funds large scale collaborations to breakdown traditional boundaries between clinicians and researchers. The aim of the program is to have insights from practice informing research and ensuring the rapid adoption of findings for improved patient outcomes.

Seven collaborative centres have been funded around the hubs of academic and clinical leaders, with substantial cancer treatment facilities and leading research programs in relevant clinical disciplines, to integrate interdisciplinary and translational enterprises related to cancer control. The research portfolio spans biomedical, clinical, health services and implementation research. Across the program there are investments in: programmatic projects; people (e.g. clinician research fellow); and infrastructure (e.g. biobank).

The centres will focus on research and translation along the whole spectrum encompassing 'bench to bedside' and 'bedside to system-wide uptake into practice'. A critical element of this translational research program will be the establishment of collaborative and networking infrastructure to enable:

- continued development and translation of best evidence into care (including an active program of implementation research focused on improving uptake of evidence)
- continued development and translation of current and new diagnostic and prognostic tests, new therapies and interventions into patient care
- translation of clinical problems into research questions
- leading collaborations between clinical and research disciplines, leading centres of research and clinical services.

Source: Cancer Institute NSW

THEME 1: Encourage research and innovation in health services

In NSW, public health services engage in research as an essential adjunct to the delivery of the highest quality care. Research activity within hospitals attracts and retains Australia's best and brightest practitioners to public teaching hospitals, ensuring that public health services are associated with excellence.³ The National Health and Hospital Reform Commission notes that research evidence should drive investment and disinvestment in health services.⁴ Furthermore, hospitals that participate in research have been demonstrated to provide better care (measured through adherence to clinical guidelines) and to have lower case-adjusted mortality rates.⁵

It is important to ensure that practitioners in NSW conduct excellent research in a supportive environment and that

this research is applied to drive system change. This section focuses on research undertaken in LHDs primarily by practitioners (for the purpose of this report this term covers nurses, doctors, allied health professionals and population health practitioners). Detail on increasing the uptake of research evidence into policy and practice is covered in Theme 3.

In NSW, there is strong support for health services engagement in research as an essential component of delivering the highest quality health care.

..... research activity must be a fundamentally integral part of routine, best practice clinical care in NSW health facilities. It means ensuring research (both use of research previous findings and generation of new research findings) is considered part of routine health-care practice... [Research Manager, University]

NSW Health should create and foster a culture of research throughout the entire health system..... Involvement in research should be viewed as an expectation and supported accordingly. [Policy Advisor, Industry]

Why is research important? It leads to a different level of discussion in hospitals, attracts staff, changes the culture of the organisation...but research leads to quality of care. That's why we do it. [Ministry of Health Senior Executive Roundtable]

Issues

Three main issues have emerged during the Review: the importance of a research culture, the need to engage and support practitioner-researchers and infrastructure support.

Research culture

The culture and management of research at the LHD level varies across the state. It is accepted that LHDs by virtue of their location will vary greatly in their capacity to conduct research. However, even among those LHDs that have a tradition of research, many do not have an overall picture of the research undertaken, its purpose or its outcomes. This poses both a management and a communication problem. The research community may be doing less than it might to communicate what they are achieving and may not be required to give an account of the quality and impact of their research. This lack of communication and accountability diminishes the political significance of research, an attribute necessary for sustained investment of government funds.

One enabler is to recognise the research that is being done in the health system. We could get a list [of research undertaken] in 15 minutes from medical research institutes and universities. When we ask the question for the health service, we can't find it. [Ministry of Health Senior Executive Roundtable]

Clinical service plans should have in parallel research specific plans (in collaboration with Medicare Locals AND the community)... Flexibility should be allowed in hospital/district Board Budgets to permit matching resources to be allocated. [Director, Research Network]

Engaging and supporting practitioner-researchers

It is often difficult to engage practitioners in research. The Review was informed that practitioner research careers are not promoted, fostered or mentored adequately from the undergraduate period right through to the vocational or specialty training periods. Further, those practitioners with enthusiasm for research find the pressure of clinical or other health service work overwhelming with much of their research carried out in their own time.

The preference of medical science students for medical practice as opposed to research is overwhelming. This reflects the uncertain and insecure nature of the career path in medical research. [Researcher, University]

...the culture of actually encouraging health research is largely lost in NSW. Few in administration pay more than just lip service to actually doing research. 'If you want to do it, great, but get those reports done first.' [Clinician Researcher, Hospital]

The Review was also informed that it is important to fund and support practitioners to do research.

There is no [support for] developing research concepts into a valid research protocol. There are no biostatisticians available to assist investigators. There is no expertise available for investigators to produce a quality research publication that will enhance District profiles, attract research funding, and secure commercialisation. [Research Administrator, Hospital]

Clinicians see their patients every day. They have ideas, want to do it robustly; they need research support to help them do that...for example, [a clinician had a hypothesis based on professional experience]. All he wanted was help to crunch data – he couldn't get it. [Peak Body Roundtable]

For academic and public health organisation clinicians, protection of clinician time for those who demonstrate aptitude and emerging excellence in research is critical in order to allow him or her to develop competitive research groups. [Clinician Researcher, Hospital]

Early career practitioner researchers who plan combined clinical and research careers face particular challenges including obtaining protected paid research time, simultaneously developing complementary career paths and pressures to follow an accelerated path to independent research.⁶ Mentorship, ongoing education and networking were suggested strategies to address this problem.

The level and type of support required for practitioner-researchers is dependent on career stage. There are different types of practitioner-researchers and this strategy focuses on those who lead or participate in multi-disciplinary medium to large-scale research activities. Relationships between practitioner researchers, academics and staff in medical research institutes can increase the level of support available to practitioner-researchers.

Exhibit 4: NHMRC Practitioner Fellowships Scheme

Funding and infrastructure support

The Practitioner Fellowships Scheme provides support for active clinicians and public health or health services professionals to undertake research that is linked to their practice or policy. The Scheme is not intended to support academic researchers who may have clinical / public health responsibilities. Practitioner Fellowships are open to all active clinicians and public health or health services professionals in Australia who have a sustained track record of significant research output as demonstrated in peer-reviewed literature, and a strong commitment to quality research outputs as judged relative to opportunity.

NHMRC expects applicants to plan to combine clinical / public health duties with their research, and be able to demonstrate that the research associated with the Practitioner Fellowship is designed to maximise the application or transfer of outputs into policy or practice. Practitioner Fellowships offered by NHMRC are prestigious and highly competitive awards for high performing researchers. Recipients of Practitioner Fellowships are generally performing in the top 10% of their field of research.

Source: <http://www.nhmrc.gov.au/grants/types-funding/-z-list-funding-types/fellowship-awards>

Many Review stakeholders commented that LHDs will require specific funding to support research beyond current levels. Under the current National Health Reform Agreement, the funding model for teaching, training and research (TTR) in public hospitals is currently being determined; it is crucial that support for practitioner-led research is part of that determination.

The universities and the medical research institutes have had strong financial incentives to ensure their business processes support, profile and count research developments. The National Health Reform Agreement provides a similar incentive for the health system. [Manager, LHD]

The Review identified a number of international, national and state organisations that manage schemes to support excellence in practitioner research. Such programs are established in Canada (e.g. the Canadian Institutes for Health Research and the Council of Academic Hospitals in Ontario) and in Singapore. In Australia, the NHMRC Practitioner Fellowship Scheme is the leading support scheme for practitioners (Exhibit 4) and in NSW the Cancer Institute NSW Clinician Fellowship program aims to strengthen and support clinician research in hospitals by providing opportunities for cancer clinicians to develop and sustain long-term careers in cancer research.

LHDs already provide a range of support infrastructure for the research conducted at their sites (e.g. information technology, space, human resources and financial services). Yet, the Review found that practitioner researchers repeatedly reported their frustration that the clinical and administrative focus of these services is at odds with their requirements.

A major constraint on the employment of researchers is the long tedious process of approvals to employ regardless of whether a staff freeze is in operation [Research Administrator, University]

Promote a health service corporate culture that is supportive of research. This would include ... research-supportive IT... research-related financial administration... efficient recruitment processes... position descriptions and classifications that suit research... The business processes established to promote [the] prime objective [of the health service] are not the same as the requirements for high quality research. [Manager, LHD]

Principles

- Health and medical research is integral to the business of LHDs
- LHDs need a clear strategic direction for research, a strong research culture and support the uptake of relevant, high-quality research
- Practitioners have protected time to conduct approved research and have access to appropriate research support
- Practitioner-researchers find it easy to access additional training, expertise or research support (e.g. statisticians, health economists and interpreter services) required to conduct high-quality research
- Practitioner and LHD executives use the outcomes of research to improve health services.

Recommendations		
Theme 1: Encourage research and innovation in health services		Responsibility
1.1	Build a dynamic and supportive research culture in LHDs through strategic leadership and governance	LHDs MoH – OMR ACI
1.2	Establish a research grant program to support practitioners to generate new evidence through collaboration between practitioners, policy makers, health services managers, scientists and academics	MoH – OMR ACI, CINSW
1.3	Attract and retain high-quality practitioner researchers in LHDs	MoH – OMR ACI, CINSW LHDs
1.4	Provide training for practitioner researchers and facilitate access to research support	LHDs MoH – OMR
1.5	Ensure business, human resources, information technology and financial service processes that are able to properly support research activities	MoH LHDs

1.1 **Build a dynamic and supportive research culture in LHDs through strategic leadership and governance**

A dynamic and supportive research culture should span clinical, health services and population health research and support multidisciplinary research undertaken by nurses, doctors, allied health, primary care, population health professionals, health service managers and policy makers.

To foster a strong research culture, the Ministry of Health should work with LHDs, the Agency for Clinical Innovation and the Clinical Excellence Commission to:

- Establish LHD health and medical research committees to support local research
- establish or maintain LHD Research Director and research management infrastructure
- develop research strategic and implementation plans, aligned with the NSW health and medical research strategy, to address local and state priorities
- ensure appropriate governance of LHD-controlled research organisations
- provide LHD resources to support research
- develop a set of research output and impact metrics used to guide improvements in research and impact on health services change
- include these metrics in the LHD Performance Management Framework
- monitor and annually report on LHD research processes, programs and outcomes.

1.2 **Establish a research grant program to support practitioners to generate new evidence through collaboration between clinicians, policy makers, health services managers and academics**

A priority-driven research grant program should be established by the Ministry of Health in collaboration with the Agency for Clinical Innovation, the Clinical Excellence Commission and the NSW Population Health Network to support the implementation of practitioner-initiated research projects. The primary aim would be to support the generation of research immediately relevant to clinical, health service and population health practice in NSW and should be available on an annual basis to researchers employed within the NSW health system. A secondary aim would be to provide a source of funds to develop projects to a stage where the chance of funding success from other sources, such as the NHMRC, is increased. The amount

provided through the Program may be sufficient to cover all the costs of the research or it may be part, for example, of an NHMRC linkage grant.

This grant program should be competitive and peer-reviewed that rewards excellence and requires collaboration among a range of partners from the LHDs, Ministry of Health, universities and medical research institutes. Funded projects must have a demonstrated potential for translation to clinical services or population health practice and address questions that have system-wide relevance. Funding could be used to support the back-filling of the clinician's time required to work on the project.

Initially, the program should be established as a pilot scheme with an evaluation process developed to establish whether the program is achieving its strategic intent. If successful, the program should be expanded with more grants.

1.3 **Attract and retain high-quality practitioner-researchers in LHDs**

A NSW Clinician Scientist Program should be established to support excellence in practitioner researchers and enable protected time for research. The NSW government should explore the potential for co-funding NHMRC Practitioner Fellowships with the intent to increase the number of Fellowships awarded to NSW. It is recommended that up to four co-funded fellowships be offered on an annual basis. Co-contributions from universities and MRIs should be considered.

Initially, the program should be established as a pilot scheme with an evaluation process developed to establish whether the program is achieving its strategic intent. Four fellowships should be offered annually (each fellowship is for a five year period).

The Cancer Institute NSW (CINSW) should maintain its current research funding program that includes a range of clinician-researcher schemes, and possibly broaden them to encompass non-clinical practitioners.

Refer also to Theme 7 for broader research workforce support recommendations.

1.4 **Provide training for practitioner researchers and facilitate access to research support**

The Ministry of Health and LHDs should establish training and support for clinician researchers:

- Establish a biostatistician and health economic consultancy service that can be accessed by LHD practitioner researchers using a transparent prioritisation process
- Promote existing training opportunities available to clinician researchers provided through the university and non-government sector

1.5 **Ensure business, human resources, information technology and financial services processes that are able to properly support research activities**

The Ministry of Health should work with LHDs and Health System Support to:

- develop guidance for LHD on research-compatible information management and technology processes
- align business processes in LHD to effectively support research activities.

Refer also to Theme 11 for research ethics and governance infrastructure.

THEME 2: **Leadership in clinical trials**

This theme relates to investigator-initiated, cooperative-group and commercially sponsored clinical trials conducted in a variety of settings. Frequently the trials are conducted in multiple sites inside Australia and beyond. Whilst this theme focuses on clinical trials it is also applicable to other health or health service intervention trials and these applications should be enabled wherever possible.

Clinical trials can be investigator-initiated or can be sponsored by collaborative research groups or industry. Clinical trials evaluate the safety and efficacy of medications, medical devices or, occasionally, changes in models of health services delivery that can lead to better treatments and interventions, improve health services delivery and improve clinical and population health outcomes.

...paediatric cancer clinical trials which in many ways have become the standard of care and fully embedded in clinical service delivery rather than an 'optional extra'....There is good evidence that this high level of engagement in clinical trials is a driver in the tremendous improvement in childhood cancer outcomes. [Research Manager, Research Institute]

Clinical trials also have a significant economic impact, as they are often funded by global pharmaceutical companies. The clinical trials sector in Australia is worth approximately A\$1billion per annum, with pharmaceuticals clinical trials alone worth A\$450million per annum.⁷

The final report of the Clinical Trials Action Group (CTAG) was published by the Australian Government in June 2011.⁸ Its findings are highly relevant to NSW; they recommend several ways to improve support for the conduct of clinical trials in Australia including:

- implementing a national single ethical review system (whereby one ethics committee would approve the trial for conduct at all study sites)
- establishing a standard fee-for-service for clinical trials (e.g. site initiation costs, pharmacy fees, institutional overheads)
- ensuring clinical trials can take advantage of the developing e-health system
- improving patient recruitment (e.g. through clinical trial registries and consumer advocacy groups)
- facilitating better national coordination and collaboration across clinical trial networks.

Issues

Three main issues have emerged during the Review: current performance; barriers to undertaking trials; and capacity and support for clinical trials.

Current clinical trial performance

Australia's competitive advantage for attracting clinical trials includes the quality of our academics and clinicians, a stable, high-quality health system and (to some extent) the cultural diversity of the Australian population.

Across Australia, the number of clinical trial sites notified to the Therapeutic Goods Administration (TGA) between 2003-04 and 2010-11 grew by an average of just 2.6% per year. In 2010-11, NSW and Victoria had the largest number

of new trial sites, with 813 sites in NSW and 835 sites in Victoria of a national total of 2,817.⁹

Increased globalisation of industry-sponsored clinical trials has occurred in recent years, with pharmaceutical, device and biotechnology companies locating more trials in Asia, Eastern Europe and Latin America.¹⁰

Australia faces increasing competition from countries in regions such as Asia and Eastern Europe which can run clinical trials at a lower cost and have more volunteers. Costs and delays in gaining ethical approval may have also influenced a decline in Australia's competitiveness in this area. [Chief Executive, Not for Profit Organisation]

Based on data on phase II and phase III studies registered on the US Clinical Trials Registry, between January 2006 and December 2010, Australia was ranked 12 in world for industry-sponsored trials. The majority of clinical trials undertaken in Australia are phase II and III. However, the number of phase I clinical trials undertaken in Australia has grown by an average of 15% per annum since 2003-04.

Barriers to undertaking clinical trials

The reported barriers that inhibit companies from establishing clinical trials in NSW include slow start-up times, difficulty in recruiting trial participants, inability to engage clinical staff in research and increasing costs and institutional overhead charges. Due to these barriers, several pharmaceutical companies have withdrawn support for local clinical trials.

... clinical research in NSW is usually of a high standard. However [NSW] needs to deliver more consistently on three areas in order to remain competitive: cost start-up times ... [and] recruitment of adequate patient numbers [Research Manager, Industry]

Review stakeholders reported that it is increasingly difficult for hospitals to participate in clinical trials because they lack research staff to identify, recruit and monitor trial participants and because of rising costs, including variable institutional overhead charges.

There has been a shift over the past decade toward increased cost-recovery for all clinical research activities. Clinical investigators... are subject to fees from all hospital departments for services used, as well as the cost of employing

research staff and institutional overheads, which can be as high as 25% per head of research FTE. The impact of this is that research is becoming unaffordable for both commercial studies, as well as investigator-initiated research. [Chief Executive, Health Service]

Patient participation in clinical trials is low and it is important to increase the expectation that patients will be offered the opportunity to be involved in clinical trials.

For major teaching hospitals there should be a culture of expectation from the patient perspective that they will be offered trial involvement as part of their care options. Current public hospital patient participation is less than 1% - cancer has targeted double digit participation rates and these should be encouraged across all therapeutic areas. The UK NHS has a 2011 strategic goal that 50% of all NHS patients will be considered for trial involvement as part of their care options. Increased participation rates is the key to growing the trials [Research Manager, Not for Profit Organisation]

Capacity and support for clinical trials

The Review was informed that NSW has a high level capability for investigator-initiated clinical trials.

...[there is an] extraordinary and unique capacity (in Australian terms) held within NSW for high-quality investigator-initiated clinical trials research....through a number of organisations based in NSW. [Senior Academic, University]

Although NSW is host to several productive clinical trial units, such as the George Institute for Global Health and the NHMRC Clinical Trials Centre, the Review was informed that there is potential for greater early phase clinical trials capacity in NSW. The establishment of an international state-of-the-art clinical trials centre at a major teaching hospital in Sydney which will include an FDA-compliant phase I (i.e. first-in-human), the first of its kind in NSW is a significant step forward.

Such an activity would make a huge impact on progress towards turning around NSW's poor record in offering participation in clinical trials to appropriate patients. [Academic, University].

The NSW Clinical Trial Business Development Centre (CTBDC) was established in late 2007 by the former Department of Industry and Investment. The Centre's objective was to increase clinical trial activity in the state. An independent review found that the establishment of the Centre had sent a positive signal to industry that the NSW Government was committed to clinical trials, but concluded that its focus had been narrow and was primarily a central contact point for local industry to navigate regulatory processes.¹¹ The CTBDC has not been operational since December 2009. Several stakeholders commented that such a Centre may have a useful role as part of a more comprehensive strategy to attract clinical trials to NSW

Several clinical trial networks are based in NSW or have been supported by NSW Government funding. Examples include the:

- Australian and New Zealand Breast Cancer Trials Group
- Cancer Institute Clinical Trials Network
- National Paediatric Clinical Trial Network
- Multiple Sclerosis Clinical Trials Network
- Spinal Cord Injury Network.

These networks facilitate collaborative research, identify potential investigators and sites for clinical trials, and build clinical trial capability and skills. Their ultimate aim is to increase the number and quality of clinical trials available to patients (Exhibit 5).

Exhibit 5: Cancer Institute NSW Clinical Trials Network

The NSW Cancer Trials Network facilitates high quality clinical trials in cancer throughout NSW and provides a forum for clinical cancer researchers to exchange ideas and pursue research collaborations and thereby promote a culture of research and innovation in cancer services.

The NSW Cancer Trials Network is unique in Australia in terms of size of investment, the number of staff supported and geographical coverage. The Network has been supported by Cancer Council NSW and the Cancer Institute NSW (from 2012 the Institute will be the sole funder). Several initiatives make up the NSW Cancer Trials Network, together providing partnerships, grants, collaborations and infrastructure support programs. The network is comprised of:

1. Dedicated resources within clinical trial units based in hospitals to encourage patient participation in trials (Cancer Trials Nurses and Data Managers)
2. Cancer Trials Support Offices across LHDs to streamline and support clinical trial processes across trial units
3. Funding to support specialised Cancer Clinical Trials Research Groups

Key achievements of the program include:

- an increase in the number of cancer trials open to recruitment each year, from 190 in 2004 to 295 in 2010 (55% increase in 6 years)
- an increase in the number of patients enrolled on cancer trials each year from 1054 (3%) in 2004 to 2340 (6.4%) in 2010 (122% increase in 6 years) of incident cases
- the number of patients in long-term follow-up on trials has increased from 4559 in 2004 to 9032 in 2010 (98%)

Source: Cancer Institute NSW

Principles

- NSW has world standard clinical trial capability across all phases and disciplines
- NSW undertakes high-quality investigator-initiated and collaborative group clinical trials
- NSW is internationally competitive and attracts high-quality, commercially-sponsored clinical trials

Recommendations		
Theme 2: Leadership in clinical trials		Responsibility
2.1	Establish a clinical trial support team within the Office for Medical Research	MoH – OMR
2.2	Develop phase I clinical trial capability in NSW	MoH – OMR Universities
2.3	Reduce barriers to clinical trials by faster start-up times and greater opportunities to recruit trial participants and engage clinical staff	MoH, LHDs CINSW Universities MRIs

2.1 Establish a clinical trial support team within the Office for Medical Research

A clinical trial support team within the Office for Medical Research would act as a system navigator for those individuals and groups wishing to undertake clinical trials in NSW. These individuals and groups need access to a range of information and advice and in some cases the timing is highly critical. It should have a particular focus on addressing the challenges faced by companies, hospitals and patients in initiating and being involved in clinical trials. It should also monitor and report the performance of NSW in initiating clinical trials.

The clinical trials support team would provide the following functions:

- Act as a point of contact for individuals and organisations wishing to undertake trials in NSW
- Be responsible for developing policies that improve research ethics and governance processes within the NSW health system (See Theme 11)
- Work with stakeholders to investigate mechanisms to increase patient recruitment, e.g. through consumer information and advocacy groups (including Research Australia special interest groups), facilitation of rural and regional; culturally diverse and Aboriginal patient involvement in clinical trials, establishing clinical trial recruitment data bases, patient recruitment through Medicare Locals
- Develop links with clinical trial networks and investigate opportunities to encourage the development of new networks in research priority areas

- Establish a NSW clinical trial coordinator network to provide professional support, training and build partnerships
- Monitor and report on clinical trial activity, patient recruitment and trial outcomes and report to the NSW Government, industry and consumers.

The team would liaise with existing clinical trial networks and clinical networks (e.g. through the Agency for Clinical Innovation and Cancer Institute NSW) to assist, where required, in the identification of appropriately expert and willing investigators and trial sites, promote cooperation and coordination rather than competition across institutions and investigators and build research capability and expertise across all phases of clinical research.

An analysis of the former NSW Clinical Trial Business Development Centre should inform the establishment of the clinical trials support team.

2.2 Develop phase I clinical trial capability in NSW

NSW needs world-class phase I clinical trials capability to effectively translate discoveries into medicine. This capability must support commercially sponsored, collaborative group and investigator-initiated clinical trials from across the state.

The NSW Government should determine how it can best support the development of this capability, including an assessment of opportunities for investment, business viability and partnerships with LHDs, universities, medical research institutes and industry.

2.3 Reduce barriers to clinical trials by faster start-up times and greater opportunities to recruit trial participants and engage clinical staff

- Adopt the NHMRC Harmonisation of Multicentre Ethics Review (HoMER) (national single ethical review) system
- Adopt standard costs for clinical trial services developed through the Clinical Trials Action Group (CTAG) process
- Participate in Australian Health Ministers Advisory Council discussions on access to e-health records for clinical trial participants.

In October 2006, the Australian Health Ministers' Advisory Council (AHMAC) agreed to implement a national system enabling the recognition of a single scientific and ethical review process within and across all Australian jurisdictions. This includes reciprocity between university and public health organisation ethics committees. NHMRC is coordinating the inter-jurisdictional development of the national system. The NHMRC continues to develop and finalise the tools and documents that will support the HoMER initiative and is working with the jurisdictions to resolve outstanding challenges to the implementation of this system in the public health sector. It is expected that HoMER will be implemented in NSW the first half of 2012. Fourteen NSW HRECs have been certified by the NHMRC to undertake single ethical review within the national system. Formal adoption of HoMER within NSW Health will require the integration of tools and resources within NSW Health policy directives.

The CTAG report recommends that a table of national standard costs associated with conducting clinical trials be developed for all trial sponsors in alignment with Australian Government health reform initiatives as they are introduced. The NHMRC has developed a table of standard items which is available at <http://www.nhmrc.gov.au>. The next stage in this process is for the proposed independent hospital pricing authority (IHPA) to establish the efficient cost of the service reflecting the actual activity in accordance with cost recovery principles. The NSW Ministry of Health and LHDs should use the standard costs when introduced and review their impact.

The CTAG report recommends that the Parliamentary Secretaries for Health and Innovation propose to AHMAC that it:

- introduce policy and/or systems that allow access (both on-site and remote) by clinical trial monitors and auditors to the electronic health records of clinical trial participants; and
- request National e-Health Transition Authority (NEHTA) and state and territory governments to make the clinical research system a key consideration when designing, developing and implementing e-health standards, specifications, strategies, frameworks, systems and programs.

The NSW Ministry of Health should be an active participant in these developments.

THEME 3: Maximise the use of research in policy, practice and health service Delivery

The use of high-quality, relevant research would strengthen health policy and program effectiveness, achieve better health and improve health services (Exhibit 6). This approach also assists in wise investment of scarce resources, when research evidence is considered alongside other forms of policy-relevant data. The research evidence can be drawn from multiple sources, both within and beyond Australia,

Exhibit 6: The Veterans Health Care System (VA) in the United States of America

There is a population of over 26 million veterans and their families of the US military, naval and air services, of whom 6.5 million have their health care provided for by the VA.

As a result of a major redesign of the VA in the mid-1990s, quality of care improved on 12 of 13 leading quality indicators between 1995 and 2000. Research evidence featured strongly in the reform. For example, VA increased diabetes control from 51% to 94% for over 3.5 million patients. These achievements occurred while reducing costs per patient by 25%.

One of the levers of system improvement was changing the culture to one of continuous improvement by embedding innovation, monitoring and research into national and local health services.

Source: Research Organisation Submission

The Ministry of Health and Long Term Care in Ontario, Canada have developed a holistic approach as a foundation for system-wide change and identifies the three key components of an effective research uptake program:

- Improve access to existing research that can influence system change
- Strengthen the capacity of the health system to receive and use existing research findings, and
- Support the generation of research relevant to health service priorities where there are gaps in knowledge and it is judged that research can be helpful.

Issues

Three main issues canvassed during the Review include: increasing the uptake of existing research evidence; building capacity to use research; and generating relevant research.

Uptake of existing research evidence

The Review was informed that there is considerable scope for health gain and service efficiency if knowledge from existing research was applied.¹²

Arguably, considerable gains in health are likely to come from the effective implementation of what we know now... [Director, Research Organisation]

NSW does not always need to do the basic research if it can become adept at applying innovations discovered elsewhere.... [NSW Treasury]

...an example is thrombolysis/angioplasty. When this research came out there were good clinical outcomes. It was great for those in metropolitan areas, but not in the rural areas... Nowhere was there consideration of models of care for community as a whole. This is an opportunity for the future – we need to use existing evidence. [MoH Senior Executive Roundtable]

There was strong support for groups such as the Agency for Clinical Innovation, the Clinical Excellence Commission and the NSW Population Health Network to take a leadership role in increasing the uptake of existing evidence in the development of policy and programs that result in practice change.

We also have the Agency for Clinical Innovation and the Clinical Excellence Commission; groups of clinicians which allow us to take ideas to translation....the ACI is a good vehicle for this. [Ministry of Health Senior Executive Roundtable]

The NSW Population Health Network ... will also play a key bi-directional role in ensuring that health service changes and population health policies are implemented, monitored and evaluated for improvements in healthcare delivery. [Director, Medical Research Institute]

While NSW has growing expertise and demonstrated national leadership in beginning to address the challenge of research uptake, more work in understanding how research evidence is disseminated and adopted will lead to health benefits and create new knowledge.

...researching the best methods to achieve change will have significant health service gains and contribute internationally leading knowledge in high impact journals. [Director, Research Organisation]

The Canadian Institute of Health Research 'Best Brains Exchange' is an example of an approach to access high-quality, timely and relevant evidence that is of immediate interest to policy makers (Exhibit 7).

Exhibit 7: Best Brains Exchange

Best Brain Exchanges are one-day, in-camera meetings for decision and policy makers, and researchers with expertise on a topic that has been identified as a high priority by provincial/territorial Ministries of Health and Health Canada. The objectives of the Best Brains Exchange program are to:

- provide the ministry with an overview of the latest research evidence
- improve participants' knowledge of and access to research evidence in the topic area
- enable the Ministry and Health Canada to consult with researchers for their knowledge and perspectives on particular questions
- provides an informal forum for interaction, exchange and mutual learning between researchers and decision makers in order to support and facilitate the sharing and use of information on a high priority topic.

Source: <http://www.cihr-irsc.gc.ca/e/43978.html>

Building capacity to use research

The policy environment is not always receptive to the use of research evidence. Policy development is complex and includes managing a range of competing interests, the pressure to act quickly, diverse understandings of the nature of evidence (scientific, political, experiential), and of public values and democracy.^{13, 14, 15} Policy makers are perceived to not always be aware of or cannot easily access relevant research evidence.¹⁶

Policy makers often don't understand research, and don't frame research questions well. They want answers immediately; researchers are not good at this. [Health Services Research Roundtable]

The complexity of policy formation is not often fully understood by research workers, and if translation is to occur, then the research community, also, must learn the basics of the language of policy formation and practice.

The critical importance of focusing on system-wide change has been eloquently described by the former Chief Medical Officer of England, Sir Liam Donaldson "Good practice often spreads slowly, like treacle. We need to make it flow like mercury from one part of the health system to another." It is surprisingly difficult to make changes across the health system even when there is compelling evidence for the value of models of care. [Senior Academic, Research Organisation]

We know that knowing what to do is not enough to get evidence into practice and bring about practice change...We need to fund and support studies of new methods and processes around knowledge implementation (such as the use of knowledge brokers and knowledge facilitators)... Until we address these factors better, we will continue to generate evidence which is not fully utilised. [Clinician, Hospital]

Evidence for effective strategies that support the uptake of research evidence is limited.¹⁷ A long-term systematic approach is needed to demonstrate the value of research evidence and research thinking in informing policy, to open up more access pathways to increase existing evidence, to generate new policy-relevant research and links between researchers, policy makers and those providing front-line health care.¹⁸

Whilst we strive for new knowledge, what we do know often languishes in papers when it should be in practice. Researchers feel that the job is done when it is published – we need to assess how to efficiently get research findings into practice [Manager, Research Organisation]

...there is a huge amount of research which is of little interest to people except researchers. No one reads it, cites it. It is interesting to understand what is influential.... [there are] two key things: people who [are] seen as influential by peers and ministers.... [and] researchers who have 'post- result' strategies to get the information out there... [it's] more than publishing in journals, they go out and talk about it to policy makers. [Population Health Research Roundtable]

...opportunities for more structured collaboration between researchers and policy makers and practitioners are needed that facilitate capacity in doing research that is relevant to policy and practice. [Policy Maker, NSW Ministry of Health]

Generating relevant research

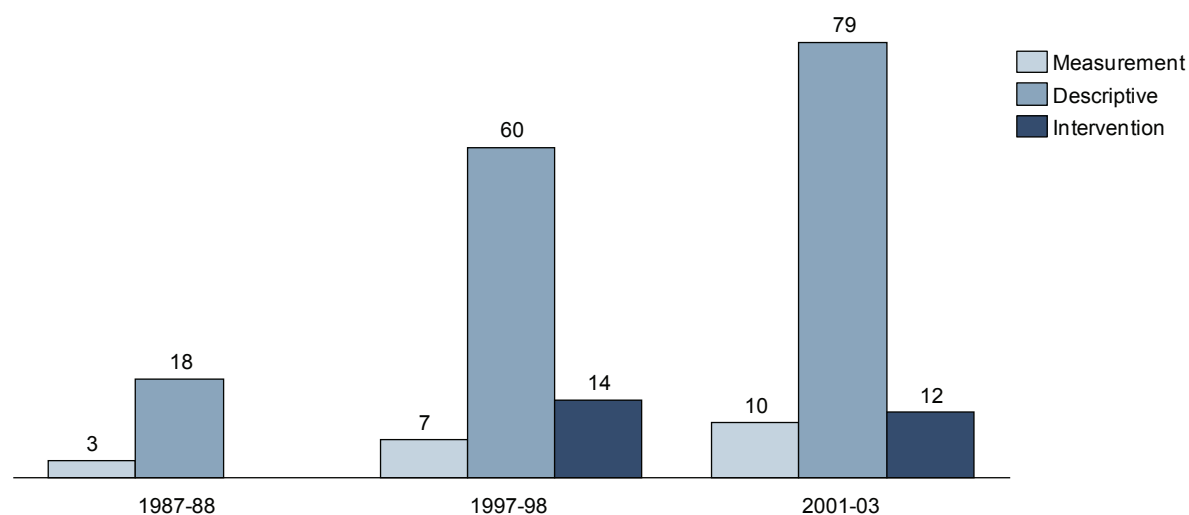
Although the scope of competitive health and medical research funding in Australia has broadened in recent decades, the majority supports investigator-driven research. Three types of research relevant to policy makers are intervention, implementation and evaluation research. Intervention research rigorously assesses what works to improve health services delivery and health outcomes. Implementation and evaluation research uses science to explore the mechanisms and processes (both qualitative and quantitative) that operate when new health programs are put into practice: Did the program perform as expected? If not, why not? What can be gleaned from the way it worked that might be used to make the program even more successful? Much more can be achieved by planning this research as part of the implementation than by trying to answer these questions after the fact.

A critical element in successful policy formation is the context. Policy is always context-specific. The policy that led to the eradication of smallpox had to be adapted thousands of times to fit highly varied local contexts. Research that is done within tightly controlled environments must then be tested in context to determine its policy applicability.

Further, research that describes the nature of a health problem and stops there does not solve a problem and hence is of limited value to policy makers.¹⁹ A review of population health research supported by the NHMRC in 2008 found most described problems and less than 7% of

funded studies implemented or evaluated an intervention.²⁰ In another review, only 10% of publications on Aboriginal health assessed an intervention and 80% were descriptive studies (Exhibit 8).²¹

Exhibit 8: Proportion of published data by study type



Source: Sanson-Fisher

In recognition of this challenge, the NHMRC is increasing its role in intervention research. Over the next three years, it will establish a Research Translation Faculty; support Advanced Health Research Centres; and fund partnership centres and policy and practice research centres¹⁴. NSW should take an active interest in assisting with these initiatives.

In NSW, the Ministry of Health has co-funded several partnership research centres to ensure close working relationships among researchers, policy makers and service providers to generate the evidence required to develop policies and programs and to assist in translation (Exhibit 9).

Exhibit 9: NSW Ministry of Health support for policy-relevant partnership research centres

The NSW Ministry of Health provides funding support for several research centres relevant to NSW Health priorities. These include:

- The Sax Institute
- Physical Activity, Nutrition and Obesity Research Group (PANORG), USYD
- Injury Prevention Research Centre, UNSW
- NSW Healthy Built Environments Program, UNSW
- National Centre in HIV Social Research, UNSW
- The National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases, USYD

- National Centre in HIV Epidemiology and Clinical Research, UNSW (now known as the Kirby Institute).

These centres help to build the evidence base in policy-relevant areas and facilitate the adoption of research findings in policy and programs through the synthesis and dissemination of research findings and provision of advice in strategy development.

Source: NSW Public Health Bulletin 22(1-2); 2011

Principles

- The Ministry of Health policy, programs and practice are informed by research evidence
- Practitioners are involved in the identification of research translation priorities and programs
- The Ministry of Health embeds research and evaluation into the implementation of major policies and programs
- The Ministry of Health invests to build capacity to provide policy-relevant research in priority areas.
- The Ministry of Health and LHDs invest to develop systems that ensure the uptake of research evidence into policy and practice.

Recommendations		
Theme 3: Maximise the use of research in policy and practice and health service delivery		Responsibility
3.1	Ensure capacity within NSW Health to use existing research evidence in policy and the implementation of programs	MoH ACI, CEC, CINSW
3.2	Commission or undertake high-quality research, including intervention research, to inform major policy and programs where there are evidence gaps	MoH ACI, CEC, CINSW
3.3	Fund rigorous evaluation of policies and programs to ensure effective implementation of research evidence and ongoing adherence to best practice	MoH ACI, CEC, CINSW

3.1 **Ensure capacity within NSW Health to use existing research evidence in policy and the implementation of programs**

The Ministry of Health should:

- develop and implement a systematic long-term strategy to ensure research uptake
- require that all policies be evidence-informed, including an assessment of the quality of evidence. This could be modelled on the Ontario Ministry of Health research evidence tool which requires that policy makers use research.²²
- provide training to senior policy makers in research methodology and critical appraisal skills, where required, to improve receptivity to research evidence.

3.2 **Commission or undertake high quality research, including intervention research, to inform major policy and programs where there are evidence gaps**

Commissioning or undertaking research where there is limited existing research on a critical, state-wide health policy matter should remain the responsibility of the relevant Divisions within the Ministry of Health, the Cancer Institute NSW and the Agency for Clinical Innovation. Specifically encouraging intervention research in population health and health service delivery is the best way to acquire the necessary evidence.

The Ministry of Health, Agency for Clinical Innovation, Clinical Excellence Commission, the Cancer Institute NSW and the Population Health Network should:

- establish mechanisms to develop collaborative partnership proposals to better leverage funding schemes such as NHMRC Partnership Project Grants and Partnership Centres and Australian Research Council Linkage Grants and Centres of Excellence

The Office for Medical Research should take an overseeing role.

3.3 **Fund rigorous evaluation of policies and programs to ensure effective implementation of research evidence and ongoing adherence to best practice.**

The Ministry of Health's policy development system requires monitoring of policy directive implementation. However, the roll-out of state level policy and programs provides a significant research opportunity given the large scale implementation (usually not feasible for investigator initiated research) and the potential for more rigorous research methodologies.²³

The Ministry of Health and the Agency for Clinical Innovation, Clinical Excellence Commission and the Cancer Institute NSW should increase the expectation that research is undertaken, in collaboration with the academic sector, to support intervention research and to build evaluation costs into the roll-out of significant new policies and programs. The US Department of Health and Human Services requires that for all large-scale programs 7-10% of the program budget is allocated to research and evaluation.

THEME 4: **Focus intellectual property expertise**

Commercialisation of intellectual property typically involves eight phases, encompassing research organisations, commercialisation offices and company partnerships. This process is complex and non-linear.

Simply described, medical research institutes, universities and LHDs perform the core research, publish papers and create potential intellectual property. Commercialisation offices play an important bridging role by identifying and protecting intellectual property and linking it to investors. When operating well, these offices identify ideas with commercial prospects and their market potential, encourage proper patenting and intellectual property protection when appropriate, and engage likely commercialisation partners. Potential investors will then address any knowledge gap in the technical nature of the research product, and assist translation of the science into business language and market-ready products. Companies may then be formed or otherwise license intellectual property to be included in marketable products or services.

Most universities and medical research institutes have access to a commercialisation office. In NSW and Victoria each university has an office, while the University of Queensland's UniQuest supports multiple institutions within the state and interstate. The commercialisation activities of UniQuest are only one facet of the business; it operates largely as a professional advisory body.

In NSW, commercialisation offices are largely based in universities, for example:

- The University of New South Wales operates through NewSouth Innovations Pty Ltd
- The University of Sydney operates Sydnovate and has an investment and commercialisation committee
- The University of Technology Sydney has a Research and Innovation Office and a commercial partner, UniQuest, with UniQuest managers of innovation and commercial development embedded within university faculties
- The University of Newcastle operates through Newcastle Innovation.

NSW Government has previously invested in building commercialisation capacity with the establishment of Bio-Link, which now operates as a commercial provider of services to many of the state's medical research institutes. Some larger medical research institutes (e.g. the Garvan Institute) have also established in-house business development capacity.

Issues

Three major issues have emerged during the Review: scarcity of commercialisation skills specialised in medical fields; education of researchers in business skills; and lack of a mechanism for reaching timely multiparty agreements regarding intellectual property ownership and management.

Scarcity of commercialisation skills

Commercialisation is an inherently challenging task and the skills required to achieve commercial success in health and medical research are in very short supply, and often specific to quite narrow fields. This requirement would indicate a priori that scaling-up across multiple institutions to leverage scarce skills to maximum effect would be a superior approach to one commercialisation office for each institution. Researchers in a given institution may be captive to the in-house commercialisation office, which may limit

the ability for ideas to flow freely to those with the best capability to capture economic value from them.

The NSW health and medical research sector has a diversity of approaches to managing intellectual property and pursuing commercialisation opportunities, and use internal and external expertise.

In recent years the major benefits in commercially relevant research have come from partnerships between public sector research organisations and companies that have positive mindsets towards innovation and collaboration, rather than through the invention and exploitation of de novo IP...There has been much activity in NSW recently between universities and MRIs seeking to build mutual platforms for collaboration in relation to commercialisation of their research. A more uniform approach to IP and to commercialisation would make NSW health research players more effective and attractive partners in development of health-related industries, services and products.' [Senior Academics, Universities]

One approach to managing commercialisation and intellectual property is the open source model being trialled by UNSW (Exhibit 10). This avoids the need for legalistic intellectual property protection and allows companies or other researchers to leverage ideas for commercial benefit. In other industries, an open source foundation grows markets faster and ultimately leads the creation of companies that add value to the core open source technology.

Another approach may be to focus more on a free/open source model many companies in the USA are built upon eg. RedHat, WordPress.

Exhibit 10: The University of New South Wales Easy Access intellectual property program

The University of New South Wales has a knowledge exchange and commercialisation company, New South Innovations (NSi), that is pilot offering intellectual property to the private sector at no cost via an Easy Access IP program. By making its intellectual property freely available the university hopes to bolster industry partnerships and improve the rate at which research can be developed. While for some intellectual property, NSi will continue to seek potential licensees or create spin-off companies, for the majority of intellectual property, NSi will use the Easy Access IP intellectual property approach.

Easy Access intellectual property IP provides a number of significant benefits to collaborating parties:

- Easy Access intellectual property IP is free with no obligated payments to NSi or UNSW
- Access to state of the art technology, innovation and research
- Provides exclusive worldwide rights to the intellectual property, royalty free
- 3-Three year period for development of the intellectual property
- Any patent cost at the discretion of the licensee
- Simple transaction and agreement
- Access to opinion leaders, research excellence and subject matter experts.

The university aims to benefit through the development of new relationships with potential users of UNSW research outcomes as companies will be required to acknowledge UNSW's contribution to the development and exploitation of the intellectual property. In addition, there are no limitations on UNSW's use of the intellectual property IP for the universities own research (though ideally ongoing research will move ahead collaboratively with the Easy Access IP licensee).

Source: <http://www.nsinnovations.com.au/unswstaff/easy-access-guideline-companies.pdf>

Universities in NSW also use the services of UniQuest (Exhibit 11).

Exhibit 11: UniQuest

'UniQuest' acts as a 'contact research and marketing organisation' to provide industry and Government with access to world class university expertise and facilities. UniQuest facilitated the first of several mechanisms to overcome a funding gap for early stage university technologies: The University of Queensland in partnership with the University of Melbourne launched the \$20 million seed fund, Uniseed Pty Ltd. Since then, through investment commitment from Westscheme, the University of New South Wales and further investment from founding Universities, the fund has grown to \$61 million. Annual revenues and transaction in 2010 exceeded A\$100m. Uniquest has been associated with several internationally renowned innovations:

- Cervical cancer vaccine Gardasil
- Magnetic resonance imaging technology company Magnetica
- Drug development company QRx Pharma
- Bioimpedance device company ImpediMed
- Triple P Positive Parenting Program
- Drought-resistant plant marketer Aussie Colours

Source: <https://www.uniquet.com.au/>

The Australian Government, through the Department of Education, Employment and Workplace Relations (DEEWR) and its predecessors regularly undertakes a national survey on research commercialisation offices in Australia. In 2009 according to commercialisation office metrics, UniQuest ahead in some areas, with 120 staff compared to ~25 at other leading universities. Key performance indicators of commercial success such as Value of running royalties yielded from active LOAs (Licences/Options/Assignments) and Value of all Capital Raising Activities Undertaken show the UniQuest approach outperforms the leading universities in NSW and Victoria. UNSW is a clear leader in the number of consultancies and contracts undertaken during this period.

Education of researchers in business

The primary gap in NSW in the commercialisation process appears to be a shortage of investment-ready ideas developed from its research base. This scarcity of commercially viable projects is the main reason there is a relatively small pool of venture capital available to be deployed. It is unclear, however, whether NSW is producing research output that has commercial potential that fails to be realised due to downstream process failure. What is clear from consultations is that there is a cultural divide between researchers and investors.

Some researchers believe that investors are greedy and short sighted, and some investors believe researchers are naïve and overestimate the value of their research. A better understanding of the cultures and needs of different groups within the commercialisation process is needed. The underlying drivers are:

- Researchers are often not educated in the business, marketing and legal skills required for commercialisation
- Investors will only invest if there is a market for the innovation, clear intellectual property ownership, and an ability to manage the risks inherent in taking a product to market.

These issues have been partially addressed by in the province of Alberta, Canada, through PhD training (Exhibit 12).

Exhibit: 12: Alberta Innovates – Health Solutions PhD PLUS

PhD PLUS is a trainee program designed to support the creation of high quality, broadly trained PhD level health researchers by focusing on technical/scientific training and on professional skill development. Awardees completing the program have the knowledge and experience to bridge academic research and other areas of expertise, such as clinical competence, policy development and decision making, entrepreneurship, research management, project management, health literacy, knowledge translation, or teaching competence.

The program provides up to one year of protected time for trainees to gain experience in environments including: trainees could seek a training or internship opportunity in education, business, industry, government and/or health policy, clinical sites or other research related environments.

The program covers a maximum of four years of support for PhD training and up to 12 months support for cross sectoral training or experience through the PLUS component.

Source: <http://www.albertainnovates.ca/>

Mechanisms to reach timely multiparty agreements

In 2009, the NSW Government committed to resolve the issues surrounding intellectual property ownership and management, by developing an effective and efficient system that simplified and clarified the intellectual property negotiation process for stakeholders. A decision framework was developed outlining the supporting criteria (such as inventive contributions). Although the framework was made publicly available, it was not promoted effectively, and so has not been widely adopted within the research community.

Most medical research institutes, universities and teaching hospitals have their own frameworks for intellectual property, making a single standardised template difficult to implement. Where an intellectual property framework does not exist, a standard developed by the NSW Government could be used.

The ownership of intellectual property is particularly fraught where multiple parties have contributed to the underlying research. Risks around intellectual property ownership were cited by investors as a reason investment may be difficult. A key element of the framework is the approach to resolving multiparty agreements (Exhibit 13).

Exhibit 13: Medical research commercialisation in the Hunter region

This approach in the Hunter is underpinned by the establishment and implementation of commercial agreements designed to provide harmonisation between The Hunter Medical Research Institute, Hunter New England LHD and The University of Newcastle. Mutual understandings around the sharing of royalties, inventor ship, and use of facilities, for instance, are pre-determined so that collaborating with industry partners or raising investment funds is clean and unencumbered by intellectual property rights. The commercialisation arm of the University of Newcastle, Newcastle Innovation is charged with the process of capturing new IP and assistance in the commercialisation process.

This test could potentially improve the health outcomes for mothers and premature babies by allowing better preparation for, and possibly prevention of, their early delivery. The commercialisation of the technology is progressing with secured investment from The Medical Research Commercialisation Fund and Commercialisation Australia. The initial proof of concept development program is nearing completion in December 2011. Once results are known and reviewed, investment in product development could begin in 2012.

Raising investment for early stage research discoveries is a difficult task; however this harmonious approach has given our investor confidence not only in the science but also in the willingness of the organisations supporting it to give it every chance at commercialisation.

Source: Newcastle Innovation

Principles

- Universities, medical research institutes and LHDs have appropriate access to world class commercialisation expertise
- Commercialisation bodies and support networks are simple for researchers to access and use
- Researchers can access training to appreciate and manage the commercialisation implications of their work
- There is a clear intellectual property framework for research shared across multiple research entities with appropriate guidelines and procedures to clarify ownership and sharing among research participants and contributors.

Recommendations		
Theme 4: Focus intellectual property expertise		Responsibility
4.1	Develop and implement an intellectual property framework for multiparty publicly funded research	MoH-OMR DTIRIS
4.2	Enhance researchers knowledge and understanding of commercialisation resources	DTIRIS MoH – OMR
4.3	Promote greater capability in commercialisation offices for use by multiple institutes, universities and LHDs	DTIRIS MoH – OMR
4.4	Improve opportunities for researchers to acquire business and commerce skills	MoH – OMR Universities

4.1 **Develop and implement an intellectual property framework for multiparty publicly funded research**

A standardised approach to intellectual property in NSW could simplify and reduce risk for investors and make health and medical research venture capital a more attractive investment category, particularly where multiple parties are involved. Given that the NSW Government has already produced an intellectual property framework, where an intellectual property framework does not exist, a concerted effort should be made to use the proposed standard. Where research is funded by the NSW Government, it should be strongly encouraged that resulting intellectual property be managed under the common framework. Where multiple parties are involved in the research, the protocols developed should be used to assign fair share of ownership amongst parties.

4.2 **Enhance researchers knowledge and understanding of commercialisation resources**

There are several commercialisation offices that provide services to medical research institutes, universities and health services in NSW. While performance is measured by the National Survey of Research Commercialisation, there is a lack of understanding of key capabilities and services provided by each office. In addition, commercialisation resources are provided by the NSW Government (through the Innovation Pathways Program) and Australian Government (through Commercialisation Australia).

In consultation with stakeholders regarding the terms and parameters of the data collection, the Office for Medical Research should collect information about existing commercialisation offices to identify strengths and areas of particular expertise and map available government resources. This information should be made available to researchers via the Office for Medical Research website.

4.3 **Promote greater capability in commercialisation offices for use by multiple institutes, universities and LHDs**

UniQuest in Queensland employs approximately five times as many staff as in NSW university commercialisation offices and has achieved greater *Value of running royalties from active LOAs* (Licences/Options/Assignments) and *Total new registered IP rights filed* than NSW counterparts from less research output. Once there is greater clarity about the relative effectiveness of different approaches, the Office for Medical Research should facilitate discussions about building scale among universities:

- Encourage collaboration or mergers between sub-scale offices. Enhanced collaboration or mergers encouraged through involvement of Commercialisation Australia for complying bodies.
- In consultation with the sector, consideration should be given to a shared, subsidised not-for-profit commercialisation unit using membership fee model. An alternative model could be to create an entity independent of any one entity.

4.4 Improve opportunities for researchers to acquire business and commerce skills

This should include:

- Scholarships for PhD students for existing business programs and promote existing short courses to researchers in business and commercialisation To enhance the translation and commercialisation skills of researchers up to 60 competitive scholarships per year should be available for PhD students to access existing business programs in NSW business schools, and to promote existing short courses to researchers in business and commercialisation. This would provide a 6-month scholarship and tuition fees
- Encouraging business and industry internships. Driven by industry, this initiative could be through paid or unpaid internships with industrial firms such as ResMed or Cochlear, or investment companies. Several universities have models for such internships in business or commerce law faculties
- Leveraging Commercialisation Australia's mentoring program with the possibility of establishing a mentoring program to develop collaboration, leadership and commercialisation skills
- Providing tools and resources to better establish collaborations for commercialisation, such as quality assurance systems, project management training, understanding contracts and intellectual property issues.

THEME 5: Support early-stage venture capital

Early-stage venture capital is one mechanism to create value for researchers, institutions, investors and consumers by creating new products or services from research output. Health care and life sciences attracted a significant share of Australian venture capital funding with over A\$300million invested in over 250 transactions, or 46% of transactions in the past 5 years. It is not known what proportion of this investment was made in NSW.

There are also some Government programs available to NSW entrepreneurs that provide early-stage venture assistance to entrepreneurs:

- Commercialisation Australia is a merit-based, competitive assistance program of the Australian Government that provides services to take products and processes to market for proof of concept and early stage commercialisation activities. Commercialisation Australia has funding of A\$278million over the 5 years to 2014.
- The Australian Government has introduced R&D tax credits to encourage investment in innovation.
- The Medical Research Commercialisation Fund (MRCF) invests in early-stage development and commercialisation opportunities emanating from Australian medical research institutes and allied research hospitals. The MRCF was founded through collaboration between Australia's leading medical research institutes and Statewide and Westscheme Superannuation funds, with support from the state Governments of Victoria, NSW (until 2011-12), Western Australia and Queensland.

NSW has had success in the past with commercialisation, particularly with medical devices, ResMed and Cochlear Ltd are two examples that have delivered for NSW and so further investment could be beneficial. Market capitalisation data collated on life sciences and medical device companies by state indicates that Victoria and NSW are comparable in terms of number of total medical device, biotechnology and pharmaceutical companies. When focusing purely on medical devices, NSW has a dominant presence with almost half of firms and over 80% of market capitalisation.

The Review identified some concerns about a strategy which solely focused on medical devices when other low-risk investments, such as diagnostics and the identification of biomarkers, could also be supported. Further, NSW researchers are considered to be poised at the forefront of the next revolution in health provision: personalised medicine.

While research and development into devices may more obviously lead to commercialisation opportunities... [we need] to be mindful of the opportunity cost of not incentivising bio-technology, such as the development of new therapeutic molecules. [Non Government Organisation]

Issues

Two main barriers have been defined during the Review: perceived lack of commercial success and incentives for commercialisation.

Perceived lack of commercial success

There is a myth that the relative lack of commercial success from NSW research is due to a lack of venture capital or the short term approach of investors. If this were true, the few health and medical venture capital funds operating in NSW would have a plethora of good ideas to choose from, with little competition, allowing them to deliver extraordinary returns to their investors. In fact, this has not occurred.

This indicates that the system is failing between researchers, where research output is demonstrably world class, and investors, who are able to invest in world class companies such as Cochlear and ResMed or less risky private equity.

Venture capital is an industry where past results are correlated with ongoing success, so if returns improve, then the pool of venture capital is likely to increase. Without a strong track record of delivering improved investment returns in NSW, future access to domestic venture capital for health and medical research is likely to be limited. There are no barriers to inventors seeking venture capital offshore, particularly in the USA, but the spin-off companies are then likely to be established offshore too.

...NSW [is] Australia's medical device cluster. Let's hope we can continue to work towards its expansion and hope that, with the right networks, it can succeed as well as those in San Diego, Boston and San Francisco. [Chief Executive, Company]

The idea around NSW focusing its developmental research (and hence commercialisation effort to follow) around medical devices for example might be a good strategy. A focused approach may build some special expertise and reputation that will attract venture capital funding...and may help NSW to find a niche to stimulate economic develop and jobs. [Manager, MRI]

Incentives for commercialisation

NSW has enjoyed success with two world class medical device firms, but needs greater focus to build on this for the future. Medical devices have a number of attributes that make it an attractive area of focus for NSW:

- NSW has an industrial base in devices, engineering and manufacturing that can develop concepts into working prototypes efficiently

- NSW has a base of managers and investors who understand how to commercialise devices
- The aggregate investment required to bring a product to market can be realised from Australian investors and is lower than that needed to bring drugs to market, which requires the clout of global pharmaceutical companies
- Device manufacturing is a high-skill, high value-added activity that can be undertaken competitively in NSW.

NSW has been at the forefront of medical device commercialisation in Australia since 1965 when the Nucleus was founded...Cochlear and ResMed now form the backbone of the local medical device industry not only in NSW, but Australia [Director, Company]

In the past NSW has done medical devices well and we need to build on this [Commercialisation Roundtable]

There are many excellent medical device technologies that are being invented or developed at NSW institutions, both universities and hospitals (including by individual clinicians) as well as spin-outs from other small companies. Australia [Director, Company]

Principles

- NSW actively encourages venture capital investment in health and medical research in the state, particularly in medical devices

Recommendations		
Theme 5: Support early-stage venture capital		Responsibility
5.1	Establish a pilot medical device seeding program	MoH-OMR DTIRIS
5.2	Align NSW research with Commercialisation Australia processes to increase the 'pipeline of ideas'	DTIRIS MoH – OMR

5.1 Establish a pilot medical device seeding program

Venture capital firms have established funds to invest in emerging life sciences companies. Given NSW has a relative strength in the medical devices sector, this is an area that should be promoted by NSW Government via incentives. One of the aims of health and medical research in NSW is to be internationally recognised in specified areas: encouraging investment in medical devices will directly contribute to this aim. If this pilot scheme is successful it could be applied to other areas such as diagnostics and biomarker screening.

In order to support a pilot seeding program, the NSW Government should:

- build on existing state and federal programs and initiatives
- encourage linkages between research hubs, commercialisation offices and domestic and offshore investors in medical devices (and the extension of these linkages to other areas once they are established)
- streamline clinical assessments and trials of innovative medical devices to assist greater uptake of NSW innovations by the NSW health system
- consider applying the model to other areas of investment.

5.2 Align NSW research with Commercialisation Australia processes to increase the 'pipeline of ideas'

NSW commercialisation initiatives should be aligned with Commercialisation Australia processes so that research ideas that can be translated to commercial products in an effective manner and attract funding from the Australian Government.

Commercialisation Australia provides skills and knowledge support to commercialise intellectual property, providing funding of up to \$50,000 to pay for specialist advice and services:

- Experienced Executives program provides funding of up to \$200,000 over 2 years to assist with the recruitment of a Chief Executive Officer or other executive
- Proof of Concept grants of \$50,000 to \$250,000 to test the commercial viability of a new product, process or service; and
- Early Stage Commercialisation repayable grants of \$250,000 to \$2million to develop a new product, process or service to the stage where it can be taken to market.

Alignment of processes will enable NSW projects to best leverage these services and should be coordinated by the Department of Trade and Investment, Regional Infrastructure and Services to align with non-health and medical research innovation.

STRATEGY 2

Build globally relevant research capacity

NSW is recognised for its excellence and success across a range of health and medical research fields. The state's universities are world class across 20 health and medical research fields, according to the 2010 Excellence in Research Australia (ERA) initiative. This strategy focuses NSW investment on nurturing and supporting current areas of excellence and build globally competitive research capacity by:

- Identifying and investing in hubs and research collaborations that effectively generate research and translate research evidence
- Attracting, retaining and supporting leading Australian and internationally recognised researchers
- Improving research infrastructure support so that Australian and State Government programs are aligned, and reward excellence, scale and collaboration
- Building shared research assets
- Improving NSW leverage of all available investment sources
- Improving the efficiency and effectiveness of NSW research administration.

THEME 6: Enhance health and medical research hubs and collaboration

Collaboration in research and development provides numerous advantages, particularly when the research topic is complex and multifaceted. Collaboration can catalyse developments across research, make the best use of the research workforce and promote the relevance and uptake of research in clinical practice.^{24,25} It can also facilitate large scale studies (Exhibit 14).

...a closer relationship between university or medical research institute- based researchers and their clinical colleagues... works effectively in both directions providing both a quicker path for the expression of research as clinical outcomes and in assuring that clinically-relevant research is undertaken. It is a great basis for the future.
[Senior Researcher, University]

Exhibit 14: Large scale collaborative studies to solve important clinical dilemmas

The George Institute for Global Health has built extensive collaborative networks that facilitate the conduct of large multicentre national and international clinical, population health and health services studies and trials. All these studies address important clinical questions on the management of common conditions, with major implications for health services. An example includes:

- The SAFE (Saline versus Albumin Fluid Evaluation) Study: this was a collaboration of the George Institute with the Australian and New Zealand Intensive Care Society Clinical Trials Group and the Australian Red Cross Blood Service. It received peer reviewed funding from the NHMRC and the Health Research Council of New Zealand as well as support from CSL (Melbourne, Victoria) and from the health departments of Australia, NSW, Western Australia, South Australia, Queensland, Victoria and the Northern Territory. The trial compared survival in 7000 critically ill patients treated with either normal saline or 4% albumin, after admission to 16 Intensive Care Units, 14 in Australia and 2 in New Zealand.
 - The trial was conceived in response to publications suggesting that this choice affected survival, including a Cochrane meta-analysis suggesting increased risk of death in those receiving albumin. The study showed that albumin administration did not increase mortality but that equivalent outcomes and substantial cost savings could be achieved by the administration of normal saline. The trial was published in the New England Journal of Medicine, the editorial of which recognised it as a landmark study for the specialty of intensive care, and the trial led to a letter from the US FDA, revising its advice to all doctors in the USA.
- The George Institute is a great example of the comfortable co-location of all three major applied health and medical research fields: clinical, population health and health services

Source: The George Institute

Collaboration between research and clinical services is well established in the USA, Canada, the Netherlands, Singapore and more recently in the UK.^{26,27} After a review of the UK National Health Service (NHS), major new funding was provided to bring research, service delivery and education together.²⁸ The UK is piloting two clusters for life science to encourage collaboration between university, health services and industry (Exhibit 15).

Exhibit 15: UK health care and life sciences blue print for growth

In 2009 The Life Sciences Blueprint signalled a new approach to supporting translational research collaborations between industry and the public sector by committing to pilot Therapeutic Capability Clusters to capture and promote the UK's world-leading capability. The clusters work by providing a way for academic institutions, the National Health Service (NHS) and industry in life sciences to work together.

The Life Sciences Blueprint called for a new approach to collaboration in life sciences: an approach that would provide opportunities for engagement of academic and NHS communities with the commercial life sciences sector to develop new drugs and interventions for patient and economic benefit. From this, the concept of Therapeutic Capability Clusters was born, in which academic and NHS centres with expertise in specific therapeutic areas come together to work more closely with industry on early clinical development of new drugs and interventions. This would bring patient and economic benefits and further scientific pursuit and endeavour in areas of high therapeutic need. Therapeutic Capability Clusters will therefore focus in areas where:

- there is expertise in the UK NHS/academic community
- where industry has significant research interests and pipeline activity
- where there is significant infrastructure and enabling technologies in place.

Source: www.bis.gov.uk

In NSW, the Macquarie Hearing Hub is local example of a precinct where several thousand people from academic, health, research, industry and not-for-profit sectors will be co-located in a number of purpose built buildings working on different aspects of hearing (Exhibit 16).

Exhibit 16: The Macquarie Hearing Hub

Macquarie Hearing Hub is a precinct under development on the Macquarie University campus. The groups to be co-located include Australian Hearing Services (a Commonwealth Government Statutory Authority), and its research arm National Acoustics Laboratory, as well as branch offices of The Shepherd Centre (a not-for-profit group engaged in early intervention), Sydney Cochlear Implant Centre, and the Royal Institute for Deaf and Blind Children. Certain Macquarie University departments such as the Department of Audiology and Department of Early Childhood Development as well as the Macquarie Centre for Cognitive Science (including the magnetoencephalography facility) will also form part of the Hearing Hub. A \$100 million purpose built building to house these groups is under construction and scheduled for completion in September 2012.

Cochlear Limited, a publically listed company specialising in implantable devices for the hearing impaired (including cochlear implants) has already re-located to the Macquarie University campus in a 25,000 m² building (which opened November 2010) opposite the new Hearing Hub building. The Cochlear facility will include its global headquarters as well as research and development and manufacturing. There is planning for Cochlear to build further buildings over the next 25 years to support its growth plans. Cochlear will also have a presence in the Hearing Hub building.

An important feature of the groups in this precinct is the complementary nature of the activities. Hearing covers many disciplines, and the disciplines to be co-located at Macquarie University will be the broadest of any hearing research group anywhere in the world.

Source: S.Schwartz, Vice-Chancellor, Macquarie University

In the Australian context, the report of the International NHMRC Review Panel²⁹ identified a lack of modern Academic Health Science Centres delivering research, health care and education; it is expected that the NHMRC will announce the establishment of Academic Health Research Centres (AHRC) in response to this concern.

In NSW, hubs are geographically close or contiguous research enterprises in a functional relationship, with or without satellite research groups that work as parts of a virtual hub. They enhance the efficient sharing of expensive equipment, accommodation and support services. Research workers who are members of a hub have the opportunity to interact with one another and to stimulate creative thinking.

...a medical research Hub...provides the optimal framework for collaborative research, translation of research between research institutes, universities and teaching hospitals and a mechanism for establishing high technology facilities to drive today's technology intensive research...It eliminates the isolation of high tech biomedical research institutes and offers access to high technology essential for the work of outstanding clinical and translational researchers...Furthermore it provides a bridge between universities and teaching hospitals. [Hub Executive]

Three features appear necessary for a successful hub:

- There are established, strong research groups that have high national and international standing, located close to one another with sufficient goodwill towards one another to perceive the value of collaboration, especially sharing of expensive infrastructure
- Research institutes, teaching hospitals and a university presence is represented in the hub
- The potential for linking with academic teaching and commercial development is present.

In 2008, the NSW Government identified eight primary research hubs at Central Sydney, Darlinghurst, Hunter, Illawarra, Northern Sydney, Randwick, Liverpool and Westmead. Several of these research hubs are acknowledged as world class in specific fields of research

NSW has several strong research hubs complemented by several emerging hubs. This is both a strategic advantage and a potential challenge...Conversely, NSW does not have a single research precinct in which researchers can concentrate their efforts and cross-collaboration. The latter can be overcome by ensuring that the innovative use of incentives and communication creates virtual networks of researchers working in the same research areas despite the fact that they may be from different disciplines and geographically dispersed. [Chief Executive, Government Organisation]

The NSW Government has previously supported several research networks. Funding was provided to: establish network coordinators; undertake pilot studies to aid in further leveraging of Australian Government funds; and make the network self sustaining. The funds to establish these networks have been fully allocated.

Two main issues have emerged during the Review: hubs and collaboration across universities, medical research institutes and health services; and the support required to support hubs and sustain collaboration.

Hubs and collaboration

Although there are good examples of research collaboration between universities, medical research institutes and health services in NSW, discrete silos and competitive practices remain.

Collaboration is a particular strength of research in NSW. There are increasing numbers of research networks and clinical trial groups which facilitate such collaboration. [Researcher, University]

Huge investments have been made in research buildings in NSW in the past 5 years but the risk is the old dividing lines between universities, medical research institutes and health services will be entrenched rather than transcended. [Company Director, Private Company]

A key issue is integration between the three major domains: medical research institutes, university and hospitals. The last decade has seen a progressive disintegration of the linkages between these domains. This fragmentation has led to lost opportunities and wastage of energy and resources. [Clinician Researcher, Hospital]

The Review was consistently informed that hubs help build critical mass, foster excellence and provide an effective mechanism to support collaborative research. Stakeholders also noted that hubs could create efficiencies (e.g. through shared corporate services).

[Hubs] create and support a research culture in health facilities that promotes innovation and the uptake of best practice. [Director, Research Institute]

Research hubs that bring together skills and resources help achieve a critical mass that have the ability to drive further investment and create even more jobs. [Policy Advisory, Industry]

Creating operational, administrative and purchasing efficiencies can assist in delivery of excellence, and can free up more funds for actual research, research infrastructure and research staff. [Non-Government Organisation]

Some existing hubs lack a clear strategic plan that identifies and addresses critical gaps such as composition, governance or focus. Not all hubs have the necessary features for success. Leadership is critically important. Formal agreement among the hub partners is a necessary prerequisite for growth and development, however, prescribed governance approaches were not favoured by some Review stakeholders.

While there are many examples of successful life science hubs or clusters around the world, there is not one simple formula for success. However it is a combination of supporting infrastructure that is physical, social and commercial the clear themes that is central to their competitive advantage. [Chief Executive, Industry Association]

Trust is one of the most important impediments to the formation and development of a Hub and must be built gradually, focusing on common goals which reflect the best possible way to support the researchers on campus. [Hub Executive]

Further, there was strong support for centres of excellence consistent with the NHMRC proposed academic health research centres. Although the current hubs may not yet be at the scale required for an academic health research centre, the elements that would be expected in such centres appear in many of the existing hubs.

The Federal Government is considering moving towards an Advanced Health Centre model of closer collaboration between hospitals and universities, such as exists in the USA and the UK. It is envisaged that the existing hubs will naturally form the basis of any advanced health centres in NSW. [Director, Research Institute]

The establishment of Academic Health Centres is a very exciting and real opportunity for NSW to demonstrate strong leadership. [Research Organisation]

As it is still not clear how academic health research centres will be defined or rewarded, NSW will need to remain vigilant about how it can position itself to attract support for such a centre when details are announced.

Support for hubs and collaboration

Collaboration comes at a cost, as it: requires more time in planning and negotiation before research commences; generates numerous transaction costs (that increase with the number of partners involved); can diminish the control and recognition of individual organisations; and introduces new risks to the management and performance of a project.

Research is extremely competitive, and collaboration takes time and energy. There are a number of barriers to collaboration including the competitive nature of grants, as well as the difficulty in establishing trusting relationships, difficulty in agreeing on appropriate contributions and appropriately acknowledging the contributions of each partner. [Policy Maker, NSW Ministry of Health]

In Australia, considerable progress has been made by the NHMRC and other funding agencies in promoting collaborative research through, for example, Centres of Excellence and partnership grants. Nevertheless the majority of research is funded using project grants, which may not always encourage or cover the incremental costs of collaboration. Stakeholders consistently commented that collaboration requires incentives for success, particularly when it is multidisciplinary, multi-institutional and cross-sectoral.

Currently the issue of indirect costs are forming the biggest barrier to research collaboration... more administration and support costs are needed to oversee the running of multi-institutional collaborations. [Director, Research Institute]

The challenge now is to create incentives for teams to work together across institutional boundaries. [Clinician Researcher, Hospital]

Review stakeholders suggested that hubs require government support and that this should be separate to research infrastructure programs such as the Medical Research Support Program.

...there should be a relatively small amount of funds devoted to subsidise maintenance of the Hub core high technology facilities...Such a Hub premium could be formulaic, based on the size and productivity of the individual institutes and teaching hospital research, or it could be on the basis of grant applications, detailing the plant of equipment which needs to be maintained and its running cost. [Hub Executive]

We would encourage a principle whereby the critical mass and collaborations derived from having "hubs" cannot be mandated, but can be actively encouraged by provision of support for shared facilities, equipment and initiatives. This should be through a separate NSW scheme whereby government can determine their health research priorities (which will change over time) and fund accordingly. [Director, MRI]

NSW can only support a limited number of hubs: supporting too many could reduce the impact and quality of output.

.....strengthening research hubs and networks... will continue to build on the gains that have already been made over the past seven years of collaborations across NSW... [Director, MRI]

There was strong support for networking rural and regional research clusters into larger urban hubs. Further, some stakeholders suggested that where there is limited research capacity, there was potential benefit in creating 'virtual hubs' in areas such as primary care, public health and health services research, with formal structures and support.

...the physical hub concept seems to imply an aggregation of research excellence at a few, probably urban and already established locations. This concept is less applicable to research areas such as primary care, rural health, health services and population health research, which have relatively smaller critical mass and where current excellence is dispersed across multiple locations

but where strategic importance is high. Perhaps some "hubs" could be conceptualised as research "networks" or "partnerships" involving both urban and rural nodes, and underpinned by e-health connectivity and collaborative support tools. [Senior Academic, University]

Review stakeholders suggested other mechanisms to support collaboration, including supporting research networks, integrating collaboration into research funding programs, developing a greater focus on joint applications to partnership research grants programs (see Section 4.5) and communication and networking.

...the NSW Government needs to break out of the traditional silos of how research is conducted by establishing a network and agenda to further understand the cross-sectional parts of each research within the state and where motivation exists for willingness and potential to collaborate. [Chief Executive, Non-government Organisation]

The state Government can play a key role in promoting greater and more effective collaboration by the way in which it funds research. Most of the major Victorian state funding initiatives over the past 10 years have had a prerequisite of multidisciplinary and multi-institution collaboration [Director, National Research Organisation]

[Organisation x] believes understanding each of the groups' drivers is important; increasing familiarity between the different groups and incentivising them to interact are vital for discovery and commercialisation of research. [Industry Peak Organisation]

Stakeholders commented that the relationships between health services and universities and the need to identify responsibilities and accountabilities e.g. through memorandums of understanding, are also important aspects of collaboration.

While the importance of encouraging and resourcing appropriate linkages and partnerships between key organisations, people and infrastructure was clearly recognised, stakeholders believed collaboration should not be forced or create another layer of bureaucracy.

The encouragement to 'collaborate' must be appropriate to the context [across the 'Bench-Bedside-Practice' translation continuum]. Government funding should not have collaboration requirements that lead to perverse incentives to collaborate on paper only. [Medical Research Institutes]

Principles

- NSW Government supports existing hubs
- NSW promotes hubs that are internationally renowned, that are Australian leaders in particular fields
- NSW promotes hubs that include universities, medical research institutes, teaching hospitals, links with rural research groups and the potential for engagement with industry
- NSW Government supports collaboration between universities, medical research institutes and health services.

Recommendations

Theme 6: Enhance health and medical research hubs and collaboration		Responsibility
6.1	Require research hubs to develop strategic plans that foster translation and innovation and build research capacity	MoH – OMR Hubs
6.2	Hubs should report annually to the Office for Medical Research on an agreed set of performance indicators	MoH – OMR Hubs
6.3	Review and align existing health and medical research networks with this Strategy.	MoH – OMR CINSW

6.1 **Require research hubs to develop strategic plans that foster translation and innovation and build research capacity**

The Office for Medical Research should work with existing hubs to develop 5-year strategic plans that:

- specify the research fields of pre-eminence
- ensure involvement of universities, LHDs, MRIs, teaching hospitals and industry
- encourage networks with rural research groups
- ensure sound governance management and accountability that delivers integrated approaches and not simply individual units operating in isolation
- identify areas where support is required to achieve national and international standing and outline funding requirements.

The Office for Medical Research should work with the Hubs on their strategic plans and, where appropriate, provide funding for large collaborative grant applications (see Theme 10).

6.2 **Hubs should report annually to the Office for Medical Research on an agreed set of performance indicators**

The Hubs are to report annually to the Office for Medical Research on performance against their strategic plans. In response, the NSW Government should make available resources to support hub coordination. This funding would be contingent on matched funding from hub partners and satisfactory implementation of the hub strategic plan.

6.3 **Review and align existing health and medical research networks with this Strategy.**

The impact of government funding of research networks should be reviewed. Any health and medical research network should be aligned with the Strategy and linked to the Agency for Clinical Innovation to increase efficiencies in network coordination. Any Government funding should be matched from other sources, e.g. non-government organisations. Funding should include funding the costs of collaboration, including meetings, travel time (particularly for rural participants), communication systems (e.g. web-conferencing) and data bases.

THEME 7: Strengthen the research workforce

A strong and vibrant research workforce is a key enabler for a high-quality health and medical research sector. This workforce is employed by universities, medical research institutes, health services, non-government organisations and the private sector. Workforce strategies specific to practitioner researchers are covered in Section 3.1.

Approximately 23,500 research and support staff are employed in Australian medical research institutes and universities,³⁰ of whom an estimated 6,300 work in NSW.

The Australian Government has recognised the need to increase the number of research qualified and highly skilled people. It invests in the research workforce in two ways: through research training (i.e. funding to universities) and through direct research support (i.e. fellowship and competitive grant programs). Research Skills for an Innovative Future identifies five challenges for the research workforce over the coming decade: meeting the anticipated demand for research skills; improving the standard and relevance of research training programs; enhancing the attractiveness of research careers; facilitating research workforce mobility; and increasing participation in the research workforce.³¹

Issues

Two main issues were raised during the Review: attracting and retaining researchers; and gaps in the research workforce.

Attracting and retaining researchers

The lack of career pathways, poor remuneration in relation to other health and medical careers, lack of support for early to mid-career level researchers and job insecurity were identified as pressing issues by many informants to the Review and has been reported by others.^{232,33,34}

The most urgent issues facing the health and medical research workforce include: low attractiveness of research as a career due to increased casualisation of the workforce, over reliance on short term grants, lack of a sustainable career path and low salary scales relative to industry and other professions.....
[Director, MRI]

...it is difficult to use a more optimistic term than *tenuous* when describing the career security for a research scientist. Hence many scientists find it hard to honestly encourage their students to stay in science (as opposed to trying medicine).
[Researcher, University]

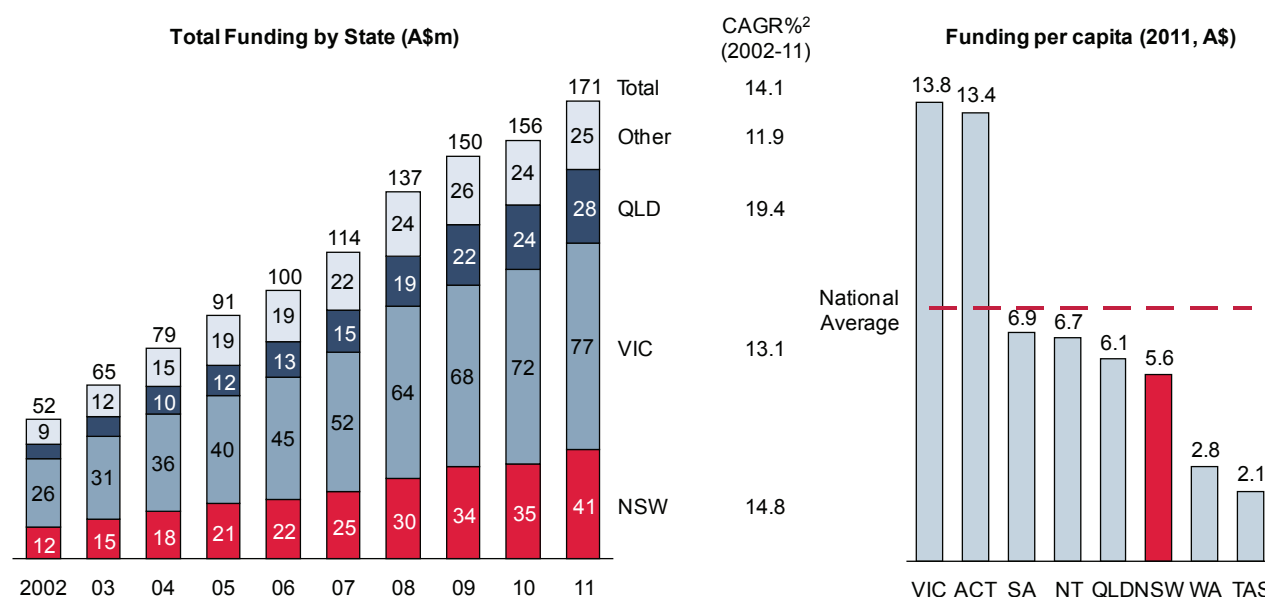
Although information on the number, age and skill profile of research staff in NSW is not available, the composition of the Australian health and medical research workforce is a concern³². In particular the age profile of academics indicates there is:

- a significant and growing proportion of academics in Australia aged over 50 years; and
- a declining proportion of academics aged between 30 to 39 years

Based on current attrition rates over the 10 years to 2019, 6,250 members of the Australian health and medical research workforce will retire and meeting replacement demand will be a key issue over the next decade²⁸.

NSW does not attract its population share of NHMRC people support funding (e.g. Fellowship Awards, Career Development Fellowships, Early Career Fellowship and Postgraduate Scholarships) (Exhibit 17). In 2011, the NSW per capita share of NHMRC people support funding was below the national average (\$7). NSW received \$6 per capita, while Victoria received \$14 per capita and the ACT received \$13 per capita.

Exhibit 17: NHMRC funding for building capacity (people support), A\$m, 2002-11



Note: 1. Other includes, NT, ACT and Tas
2. Cumulative average growth rate
Source: NHMRC Grants Funding for the Current Decade - 2002 - 2011

There was strong support from Review stakeholders for a range of fellowship programs and enhancing the value from NHMRC people support programs for researchers based in NSW.

Careful consideration needs to be given to career pathways for research within the NSW Health service. This should start with investigating options for enhancing the value gained from NHMRC people support schemes. [Clinician Researcher, Hospital]

Funding support...to assist researchers to be competitive in attracting federal and other salary sources... [For example, we have provided] fellowships to scientists or clinicians who have recently completed their PhD. This has ensured they become independent researchers over a 2-3 year period. All recipients have proceeded to obtain nationally competitive fellowships or tenured positions. [Director, MRI]

NSW must ensure that the net migration of quality researchers is in its favour; both internationally and from other states. Internationally, there are many highly talented researchers who wish to work in Australia, both from established economies and emerging nations. NSW should adopt strategies to attract the best international researchers to this state. This flow of excellent international researchers will help strengthen international research partnerships.

...health and medical researchers operate in a very competitive global marketplace. Top researchers are highly sought after as they are responsible for most of our breakthrough research and the research with the greatest commercialisation potential. In order to become a leading destination for high quality health and medical researchers, NSW must put in place programs to encourage talented researchers and clinician researchers with proven track records to base themselves here. [Research Manager, MRI]

...investment in attracting researchers from interstate may be most economical and yield the fastest return on the NSW government's investment. [Senior Academic, University]

An international example, iCORE, comes from the Government of Alberta in the field of information and communication technology (Exhibit 18).

Exhibit 18: Canadian iCORE researcher attraction program

iCORE was established in October 1999 by the Government of Alberta to foster an expanding community of exceptional researchers in the field of informatics encompassing the diverse areas of computer science, electrical and computer engineering, physics, mathematics and other disciplines related to information and communications technology (ICT).

The program involved C\$10m-C\$13m per annum Government contribution that was at least matched by the universities. The program offered a five-year contract with one option of renewal and C\$800 000 per annum in research operating costs. In a short period of time the program attracted 35 leading scientists from around the world, which in turn attracted other researchers and investment from industry. The program took a very deliberate approach to attracting the researchers and worked on the premise of 'what will it take to get them to come to Alberta.'

Source: <http://www.albertatechfutures.ca/Corporate/History/iCORE.aspx>

Gaps in the research workforce

The Review was informed that there is an increasing demand for biostatistics and bioinformatics, although there are some existing programs and capabilities, e.g. the NSW Biostatistical Officer Training Program (Exhibit 19) and the bioinformatics centre at the Garvan Institute. A gap in health economics capacity and basic biomedical sciences was also noted. Some stakeholders recommended the establishment of targeted fellowships in these areas.

The need for an investment in health economics training has long been recognised...In the last seven years, there have been ten new chairs in health economics created in Australian universities, all except one outside NSW. Whereas NSW could once claim to be a leader in this field, it is now being rapidly overtaken by the other States. [Senior Academic, University]

There is a world-wide shortage of bioinformaticians. Strong global demand for their skills together with limited state-government funding has made it very difficult to attract talented bioinformaticians to NSW. [MRI]

Exhibit 19: The NSW Biostatistical Officer Training Program

The need for evidence-informed population health and the associated volume of increasingly complex health data has resulted in a growing demand for high-level biostatistical skills. In recognition of this need, the Ministry of Health established a 3-year Biostatistical Officer Training Program in 2000. The Program aims to increase the biostatistical capacity of the NSW health system.

Trainee Biostatistical Officers are supported financially to undertake the Biostatistics Collaboration of Australia Master of Biostatistics degree through the University of Sydney part-time (through distance learning). The Trainees are employed by the NSW Ministry to work full-time in six, 6-monthly placements where they apply the biostatistical theory to current policy projects.

As well as direct involvement in policy relevant research studies, other ways in which Trainees increase biostatistical capacity in the NSW health system are through statistical consultancies and the development of statistical analytical tools and reporting systems. The cohort of Trainees provides a statistical consulting service to the Rural Research Capacity Building Program of the Clinical Education and Training Institute - Rural Division to address the particular area of need for biostatistical support in rural NSW.

Source: http://www.health.nsw.gov.au/pubs/2010/pop_health_research_strat.html

Some stakeholders recommended the establishment of a critical mass of biostatisticians and bioinformaticians with whom interested researchers can collaborate. An international model is the UK and European Bioinformatics Institute (Exhibit 20).

Exhibit 20: European Bioinformatics Institute

The European Bioinformatics Institute (EBI) is a non-profit academic organisation. EBI is a centre for research and services in bioinformatics. EBI attracted over €39 million in internal and external funding in 2009. EBI aims to:

- provide freely available data and bioinformatics services to all facets of the scientific community in ways that promote scientific progress
- contribute to the advancement of biology through basic investigator-driven research in bioinformatics
- provide advanced bioinformatics training to scientists at all levels, from PhD students to independent investigators
- help disseminate cutting-edge technologies to industry.

Source: <http://www.ebi.ac.uk>

Principles

- NSW attracts and retains the best researchers
- NSW supports the careers of researchers across their career paths

Recommendations		
Theme 7: Strengthen the research workforce		Responsibility
7.1	Establish an elite researcher scheme to attract leading Australian and international researchers to NSW	MoH – OMR Universities, MRIs
7.2	Establish a Research Fellowship Program targeted to early to mid-career researchers	MoH – OMR
7.3	Provide additional incentives through a Scholarship 'Top-Up' Program to attract high quality PhD students	MoH – OMR
7.4	Grow successful research training programs in areas of need	MoH, HETI, Universities

7.1 **Establish an elite researcher scheme to attract leading Australian and international researchers to NSW**

The Ministry of Health should establish, in partnership with NSW universities and medical research institutes, a prestigious and high-profile program to attract leading researchers to NSW. This program should be informed by the Canadian Institutes of Health Research and the Alberta Researcher Attraction Programs. A five-year program should be developed to attract 20 elite researchers to NSW. This should be a 50:50 joint venture with universities and medical research institutes to cover salaries and research costs similar to overseas experience.

7.2 **Establish a Research Fellowship Program targeted to early-to-mid career researchers**

An early-to-mid career research fellowship program for researchers should be established to assist researchers to become competitive in attracting Australian Government career support grants. These fellowships should be co-funded with universities or medical research institutes and offered in NSW research priorities or in those areas where a particular skill gap has been identified (e.g. health economics, biostatistics, bioinformatics and biomedical science). A four-year program should be developed with the aim of offering ten fellowships per year. This should be a 50:50 joint venture with universities and medical research institutes to cover salaries and research costs.

7.3 **Provide additional financial incentives through a Scholarship Top Up Program to attract high quality PhD students**

The Scholarship Top Up program would provide top-up funding to 10 PhD students in NSW each year. This program should link to existing Australian Government scholarship programs. Some NSW Scholarship Top Ups could be directed to encourage Aboriginal students and students in regional and rural areas and in those areas where a particular skill gap has been identified. Co-funding by universities, medical research institutes and not-for-profit organisations should be sought.

7.4 **Grow successful research training programs in areas of high need**

The Ministry of Health should work with the academic sector to identify researcher training programs and identify where there are gaps and sustainability challenges. This includes, but is not limited to the fields of biostatistics, bioinformatics and health economics.

THEME 8: Improve research infrastructure support

Research infrastructure funding support needs to be sustainable, allow for growth and have transparent criteria. Recipients of Government infrastructure support should have good governance and reporting requirements.

For the purposes of this review the term 'infrastructure' comprises the assets, facilities and services that support organised research across the innovation cycle and that maintain the capacity of researchers to undertake organised research. This definition excludes salaries for the investigators and their indirect costs such as consumables, normally covered by research grants. This section also excludes discussion of capital investment for major research assets and capital (building) infrastructure which is covered in Theme 9.

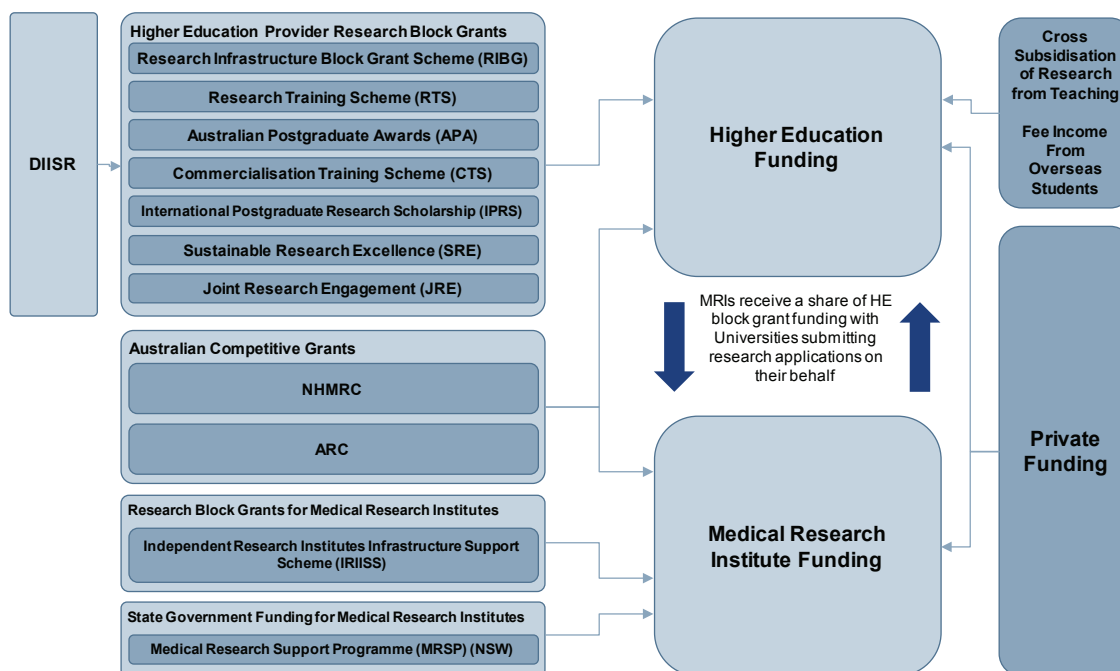
The costs associated with supporting research have been well documented internationally; for every dollar in grant funding received, it is estimated that an additional 60 cents is needed to support the indirect costs, depending on the type of research.^{35,36,37}

Australian Government research infrastructure funding is complex. Research infrastructure funding for universities and medical research institutes is tied to competitive research grants, and includes:

- IRIISS - Independent Research Institutes Infrastructure Support Scheme
- SRE - Sustainable Research Excellence
- RIBG - Research Infrastructure Block Grants Scheme
- JRE - Joint Research Engagement

The 2008 Review of the National Innovation System noted that the gap between the funding and full cost of research is a significant risk to the quality and sustainability of research in universities.³⁸ These funding shortfalls have resulted in administrative arrangements between teaching hospitals, medical research institutes and universities to partially fill the funding gap (Exhibit 21).³⁹

Exhibit 21: Administrative arrangements between universities and medical research institutes

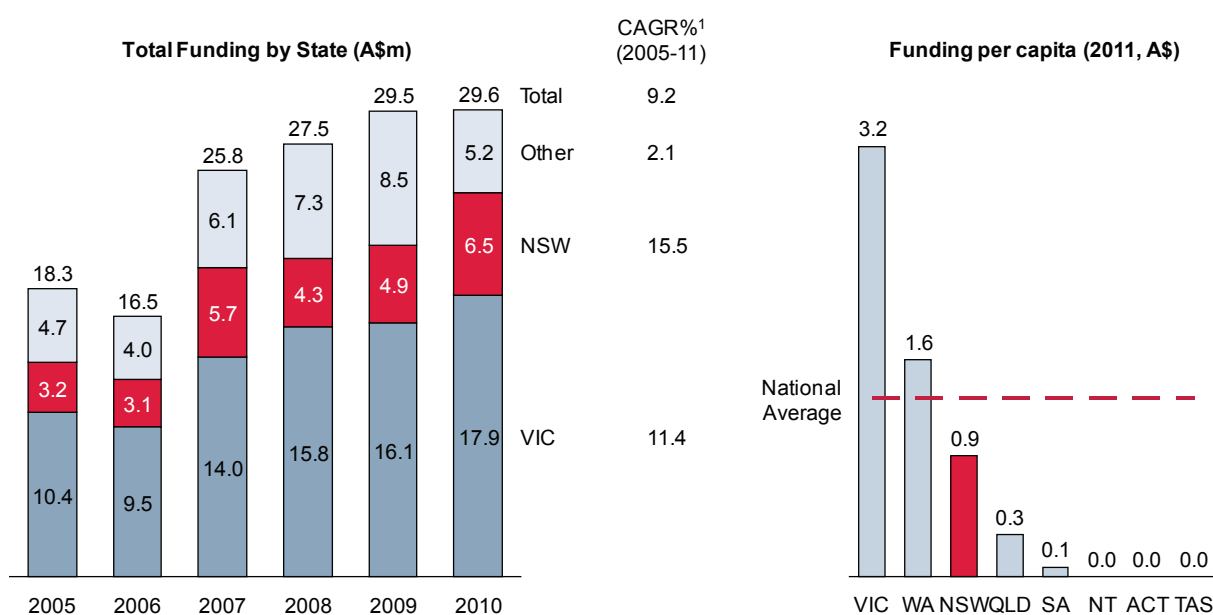


Source: NSW Health

Between 2009 and 2011, NSW received the largest quantum of all research block funding provided to universities (A\$1,276million). On a per capita basis, NSW is at the national average for this source of infrastructure funds. NSW growth in block funding (10.4%) is higher than the national average (9.2%).

Between 2005 and 2010, NSW received the second highest quantum of funds through the Independent Research Institutes Infrastructure Support Scheme (IRIIS) (Exhibit 22). At \$0.90 per capita, NSW is below the national average (\$1.32 per capita).

Exhibit 22: IRIIS funding for Australian medical research institutes, 2005-2010



Note: 1. Compounded Annual Growth Rate
Source: IRIIS

The NSW Government provides research infrastructure funding through several programs:

- MRSP - Medical Research Support Program (for independent medical research institutes)
- CBIG - Capacity Building Infrastructure Grants (for public health and health services research organisations)
- Cooperative Clinical Trials Infrastructure Grants (for national cancer cooperative groups)
- Mental Health (infrastructure grants to support mental health research (e.g. the Schizophrenia Research Institute and the Black Dog Institute).

The NSW Ministry of Health also includes infrastructure costs into core funding for several health and medical research organisations in priority areas, for example, the Sax Institute and the Physical Activity, Nutrition and Obesity Research Group at The University of Sydney. Further, research commissioned by the Ministry of Health often includes a component for infrastructure.

Other states provide research infrastructure funding through a range of programs (Exhibits 23 and 24).

Exhibit 23: Indirect research funding programs by state, 2011-12

State	Name of Scheme	Description	Institutes Supported	Annual Value (2011-12)	Funding Criteria and Eligibility
VIC	Operational Infrastructure Support (OIS)	Indirect cost support for MRIs	13	\$25.7m	<ul style="list-style-type: none"> • Two components, growth (2/3 of OIS) and innovation (1/3 of OIS); • Growth components is applied to peer-reviewed grants. If funding require exceeds the pool, the OIS is allocated on a pro-rata basis • Innovation component is available to projects which provide evidence of 'added value' to Victoria
NSW	Medical Research Support Program (MRSP)	Indirect cost support for MRIs	17	\$32.3	<ul style="list-style-type: none"> • Pool is allocated based on share of eligible grant funding over last 3 years
QLD	Queensland Department of Health	10-year overhead funding support	3	Est.\$5 – 10m (confidential contracts)	<ul style="list-style-type: none"> • Individually negotiated between MRIs and the QLD Dept. of Health with the aim to reach commercial self-sufficiency by the conclusion of the program
	QIMR	Indirect funding Support	1	Approx. \$15m	<ul style="list-style-type: none"> • Specific contract for QIMR only
WA	Medical and Health Research and Infrastructure Fund (MHRIF)	Indirect support for MRIs, units and hospitals	3	\$5m	<ul style="list-style-type: none"> • Wide range of eligible grants for funding support

Source: Research Australia: Shaping Up: Trends and Statistics in Funding Health and Medical Research

Exhibit 24: The Victorian Research Infrastructure Support Program ⁴⁰

Victoria

The Operational Infrastructure Support provides funding for independent Victorian Medical Research Institutes. The program provides essential funding towards indirect research costs that are not provided for by competitive grants. It contributes to meeting costs associated with infrastructure (physical, technical and/or competency), overheads, support services, commercialization and clinical exploitation of the institutes research endeavours and equipment maintenance essential to grant-funded research

Only independent medical research institutes are eligible for this program. The eligibility criteria revolve around an institute's primary purpose, independence of function (legally and financially) and its ability to win research funding of at least \$1 000 000 per year from peer-reviewed sources based on a running average of the last 3 years. As a general principle, research departments of hospitals, universities and fund-raising organisations are not eligible. The program provided \$25.7million to 13 institutes in 2009/10.

Source: NSW Office for Medical Research

Issues

Two main challenges emerged during the Review: the quantum and scope of research infrastructure support; and the research infrastructure funding process.

Quantum and scope

Although state government research infrastructure funding is seen to be very valuable, the Review was consistently informed of strong dissatisfaction with the quantum and inconsistent application of this funding within the research sector.

The MRSP provides vital infrastructure support to foster and promote excellence in HMR in NSW. Infrastructure support is underfunded compared to the real cost of conducting research [Senior Academic, University]

.....funding for the so called 'indirect costs' of research remains an issue. Any new funding model must include a substantially increased allocation to assist meeting these indirect costs (or overheads).... [MRI sector]

Infrastructure costs in terms of funding research support staff is still vastly underfunded by state and federal governments... [Director, Research Organisation]

The Medical Research Support Program is considered limited in scope because it excludes research groups that are not independent. Some commented that this is divisive and is an impediment to cross-sectoral collaboration.

Infrastructure support funding within Australia is complex because of the different providers and intermediaries (Commonwealth: RIBG, IGS, SRE; NSW: MRSP and Population Health support; University sector: University based grants) and it is hard to navigate especially if research is conducted within a Public Health Organisation... [our organisation] has been significantly disadvantaged by this complexity which impacts seriously upon our financial sustainability. Despite [our organisation] managing a research operation similar to many other Medical Research Institutes in NSW, it has not been eligible for State or Commonwealth research infrastructure funding such as provided via the MRSP or other funding

schemes. [Research Director, Public Health Organisation]

There is a significant danger in the current climate that silos in government will continue to place more emphasis on the boundaries between the entities rather than recognising the gains of making it easy for us to collaborate. Universities, MRIs and hospitals have different primary functions, and different primary roles in research, and yet research is equally core to our success in each case. Funds to support the real cost of research is also essential to fostering collaboration between these three vital partners in health and medical research. [Academic, University]

There has been a decline in value for both the MRSP and the CBIG. At its inception, MRSP provided around 40c in the dollar for NHMRC peer review grants to complement other sources of infrastructure funding; in recent years, this amount has fallen to 24c–30c in the dollar. Research Institutes may have access to other infrastructure funds as outlined in Exhibit 22. This relative decrease in value has occurred because fixed funding is shared across all grant winners; the more medical research institutes are collectively winning research grants, the less infrastructure funds each medical research institute receives per grant dollar. This impact is compounded as the MRSP allocation is retrospective. CBIG awards grants of up to \$500,000 each year; the funding quantum has not changed since the program's inception in 2003.

Funding processes

There is a perceived lack of coordination of the NSW Government research infrastructure programs.

Infrastructure is variously provided to hospitals and MRIs through multiple schemes. This should be simplified and made transparent [Director, Research Network]

Until 2011-2012, recurrent funding for the MRSP was set at \$17.3million per annum with ad hoc enhancements. Funding for the last three years was allocated on an annual basis, which does not allow for long-term planning. Further, the eligibility criteria for the MRSP have become more complex over time with many exceptions to the funding rules.

Defects in the research infrastructure funding system undermine the long-term interests of the research community in NSW. Time that could be spent doing research is wasted on efforts to procure research infrastructure from multiple sources. Although this partly relates to Australian Government funding, NSW can take a leadership role to address the transparency of indirect cost funding, and to ensure the best allocation of state funds within this complex funding environment.

Principles

- NSW research organisations have the infrastructure required to undertake excellent research, build scale to leverage funding and attract a high-quality workforce
- NSW Government has an integrated and transparent approach to delivering health and medical research infrastructure funding that complements the Australian Government's system
- Infrastructure funding is structured to reward excellence and build capability, wherever that research is undertaken
- The criteria for infrastructure funding reduce perverse incentives and the opportunity for manipulation and encourage optimal leveraging from all sources.

Recommendations		
Theme 8: Improve research infrastructure support		Responsibility
8.1	Align NSW Health funding programs to two principles: rewarding excellence and scale or developing capacity in key priority areas.	MoH – OMR MoH – Population Health CINSW
8.2	Restructure the MRSP to reward excellence, promote critical mass and support other strategic goals	MoH – OMR
8.3	Enhance the Capacity Building Infrastructure Grants program	MoH – Population Health
8.4	Work with the Australian Government to coordinate and streamline an open, fair and transparent infrastructure funding program for health and medical research	MoH – OMR DTIRIS

8.1 **Align NSW Health funding programs to two principles: rewarding excellence and scale or developing capacity in key priority areas.**

Aligning infrastructure support provided through the NSW Government to the principles of rewarding excellence and scale or developing capacity in key priority areas will be critical in ensuring a strategic approach to funding the indirect costs of research. The Ministry of Health should undertake a review of all NSW Government health and medical research programs to identify where an infrastructure component is incorporated. Programs which do not incorporate an infrastructure component will be the subject of further discussion with the relevant agencies to ensure all NSW Government programs are aligned in this respect.

8.2 **Restructure the Medical Research Support Program to reward excellence, promote critical mass and support other strategic goals**

The goal of the MRSP is to help build world class health and medical research capability in NSW. The Program intends to fill the research infrastructure funding gap and contribute to the true cost of conducting quality research. The focus is on independent institutes where access to infrastructure funding from other sources is limited. The MRSP should support independent health and medical research institutions which are operating at an effective scale to perform high quality research with globally relevant reputations and are collaborating in recognised hubs.

The key features of the restructured MRSP should:

- Be a two-tiered system with eligibility tied to independence, peer review grant income, research workforce, collaboration and translation
- Allocate funding transparently to reward excellence and attached to all Australian Competitive Grants Register (ACGR) peer-reviewed grants
- Have funding targets of up to 60c in the dollar from all sources for the indirect costs of peer-reviewed funded research
- Use a 4-year funding cycle

To achieve the infrastructure funding target (60c in the dollar from all sources) will require an increased investment, in addition to the current infrastructure funding levels.

The Medical Research Support Program (MRSP) should be renamed as the Medical Research Infrastructure Program (MRIP) to reflect the new directions. Implementation should be monitored to ensure that the return of State investment and reviewed prior to the second round (2016-17).

8.3 Enhance the Capacity Building Infrastructure Grants Program

The CBIG program aims to build capacity and strengthen public health and health services research that is important to NSW Health and leads to changes in the health of the population and health services in NSW.

To redress the relative decline in value of the grants provided, NSW Government should provide a funding boost for the CBIG program. The funding boost should be calculated on Consumer Price Index (CPI) increases since the Program's inception in 2003 and introduced in the next CBIG round of funding (commencing in 2013). Program grants should then be indexed to the CPI on an annual basis.

A 4-year funding cycle should be introduced to ensure greater certainty for research organisations supported by the program and to bring it into line with the MRSP.

8.4 Work with the Australian Government to coordinate and streamline an open, fair and transparent infrastructure funding program for health and medical research.

The NSW strategy for funding the indirect costs of research should be aligned with Australian Government funding

strategies as well as state priorities to ensure that the indirect costs of research are being met in a transparent manner across the sector. As such, it is critical for the Ministry of Health to understand funding flows and where research activity actually occurs. To do this, the Office for Medical Research will need to actively engage with the Australian Government to:

- ensure reporting of grant performance reflects the institution conducting the research as well as the administering institution
- clarify infrastructure funding for health and medical research and ensure parity across all parts of the health and medical research sector.

THEME 9: Build research assets and maximise their use

Research assets include buildings, major equipment and research platforms and facilities such as biobanks (repositories of human biological material), cohort studies, record linkage capability, genomics sequencing and microarray technology. They are an important contributor to research excellence in this state.

The intent of shared research assets is that they can be accessed by researchers across organisations and geographical boundaries to increase capability, maximise cost-effective research activity and encourage collaboration.⁴¹

We will derive maximum benefit from...a wider provision of access to ... facilities and databases for researchers from across the State... Discovery phase medical research moves at a rapid pace, and over the past few years we have seen significant developments in equipment that allows for high-throughput analysis and improved resolution. The costs of such equipment will rarely be justified for use by a single institution and future purchases will need to be accompanied by innovative access and governance arrangements. [Senior Academic, University]

Although distributed research infrastructure and assets may be appropriate in some cases a single facility or asset is more suitable. A national example is the synchrotron in Victoria, and in NSW there is the BioResources Facility (Exhibit 25).

Exhibit 25: The Australian BioResources Facility

Australian BioResources Pty Ltd is a state-of-the art facility for the breeding and holding of research mice, owned and operated by the Garvan Institute on behalf of the medical research community of NSW. The facility provides capacity to house the rapidly increasing number of 'lines' or varieties of genetically modified mice that underpin progress in modern medical research. These colonies are critical for progress in research across all health priority areas, including cancer, mental illness, arthritis, asthma, heart disease, diabetes and obesity. Mice held in the facility are 'owned' by individual research groups, but managed and cared for by the highly trained staff of the facility. They are shipped to the relevant institution when needed for research. Research institutes and universities who have reserved space within the facility are known as Partner Institutes.

Source: <http://www.abr.org.au/>

The NSW Government is also a key partner in a number of significant NSW-based cohorts including the 45 and Up Study (Exhibit 26) and the Study of Environment on Aboriginal Resilience and Child Health; these assets are collaboratively funded across sectors and NSW is nationally recognised as leading the field in this area. These studies provide invaluable data to researchers in a timely and cost-effective way.

Exhibit 26: The 45 and Up Study

The 45 and Up Study is the largest cohort in the southern Hemisphere and is unique research infrastructure of international quality. Over 265 000 people aged 45 and over, one in every 10 people in this age group in NSW, have been recruited to the 45 and Up Study, and have provided information about their health, lifestyle and physical and social environments. This information is linked to their medical records – including information about their use of acute care services, general practice care (through MBS), pharmaceuticals (through PBS) and contained in registries such as the cancer registry, death registry and special purpose registries. Participants are followed up every 5 years and for special purpose studies between these follow-ups.

Source: <http://www.45andup.org.au/>

Record linkage is an asset that applies technology to enable data collected on a routine basis to be used as a powerful resource for research. Linked records can be used to investigate the safety and quality of healthcare, the effectiveness of prevention and screening programs, and the patterns, costs and outcomes of health care for people with specific conditions such as diabetes, cancer and heart failure. NSW has developed a high-quality record linkage capability in the Centre for Health Record Linkage (CHeReL) (Exhibit 27). The CHeReL has developed a Master Linkage Key linking 36 million records on 8 million

people. Researchers can now access large amounts of historical data and will be able to access future data whilst minimising prohibitive costs and development of one-off links for individual projects.

Exhibit 27: The Centre for Health Record Linkage (ChReL)

The Centre for Health Record Linkage (ChReL) was established in 2006 to create and maintain a record linkage system for health and human services in NSW and the ACT. The record linkage system provides a mechanism for health data to be used for projects that are for the benefit of the public. Over 120 projects, within health, education, human services, justice and transport, have used ChReL's linkage services. Notable projects include:

- Follow-up of people with rare conditions or outcomes reported through population health datasets
- Morbidity and mortality associated with infectious diseases
- Follow-up of researcher supplied cohorts to obtain information on service utilisation or health-related outcomes

Source: <http://www.cherel.org.au/>

The state government and universities have co-funded INTERSECT Pty Ltd, a peak e-research, not-for-profit organisation which has been successful in providing e-research services and solutions for universities, government and private agencies. This organisation presents tools to assist with the coordination of e-health data and other data sets, however its funding will soon expire.

Issues

Two main issues arose during the Review: the need for strategic investment in new research assets and sustainability and use of existing assets.

Strategic investment in new research assets

In NSW, we lack a clear picture of our current research assets and our plans to develop these further.

There are significant investments in [NSW research] infrastructure, but there is no concerted plan to avoid needless duplication, or to make these investments work for all researchers.
[Researcher, University]

In terms of capital infrastructure the NSW government funding is significant. Since 05/06, the Ministry of Health has provided approximately \$171million in capital funding for research institutes including the Westmead Research Hub Building, Hunter Medical Research Institute, Ingham Health Research Institute, Kolling Institute, Children's Hospital Westmead Research Facility, the Tweed Heads Hospital Clinical Education and Research Institute and Children's Medical Research Institute. However, submissions to the Review convey a perception that funding for capital infrastructure and assets in NSW has been ad hoc, and that some opportunities have been lost because Australian

Government-funded projects have not received state support.

A mechanism for longer term strategic planning and capital investment, rather than ad hoc funding is important to the further development of the sector and the leveraging of federal and philanthropic funds. [Director, MRI]

Capital funding for major asset management is ad hoc and unplanned. A strategic plan is required for future capital funding identifying priorities for new works, equipment and refit.
[Manager, MoH]

Stakeholders strongly supported a long-term, strategic approach to future planning for investing in key research assets in NSW, for example, data linkage, cohort studies and biobanking.

[We] would like to highlight the importance of research assets such as The 45 and Up Study and the Centre for Health Record Linkage (ChReL) for population health and health services research infrastructure. These resources utilise both survey and administrative health databases, enabling data linkage to provide a rich data source for population research which has broad scope and the high potential to impact on policy. [Research Group]

There needs to be agreed state-wide standard operating procedures for biobanking and no specimen should be banked without adhering explicitly to the agreed protocols. This would include the quality of the specimen, the quality of the data and access to fellow bankers as an

absolute minimum. Such a resource across the whole of Health would be a vital resource for positioning NSW on the international stage. [Chief Executive, Government Organisation]

Biobanks, especially those with biospecimens linked to epidemiological information, are vital for the investigation of the risk factors for chronic disease and biomarkers for improved disease understanding and aid the evolution of more personalized treatment approaches. [Chief Executive, Research Organisation]

The Australian Biospecimen Network was noted as a good example of a network that enables researchers to use an online system to search multiple biobanks to locate biospecimens. The Cancer Council NSW is also seeking investment and support for a biobank linked to the epidemiological information collected through the 45 and Up Study making this population-based biobank a world class asset.

Sustainability and use of existing assets

Sustainability of research assets should be informed by a clear investment strategy and the lack of long-term funding creates instability for researchers and research organisations.

For example, with the growing volume and complexity of information, better access to a broad range of existing administrative and research data sets, and high-quality record linkage and biostatistics infrastructure is essential. Yet, adequate and recurrent core funding for CheReL has not been secured and additional investment for improving access by researchers and the planned expansion of the Master Linkage Key to include additional data sets has not been identified.

Exhibit 28: A review of cancer related biobanks in NSW

Within NSW, 23 tumour collections were identified, 17 of which were confirmed as formalised tissue banks. All exist as non-profit organisations or as departments (or units within departments) within hospitals or research institutions. The report provides an overview of consent, collection, storage and distribution of specimens, information management systems, researcher access and performance measures and governance arrangements. Several opportunities exist for maximising the potential of biobanking in NSW. First, alternative organisational or networking models of existing biobanks could be considered. These range in complexity from minimal changes to the current arrangements and infrastructure to substantial change and restructure. Second, core infrastructure requirements could be examined including the current role of pathology providers in tissue banking, data management and linkage platforms.

The Centre for Health Record Linkage places NSW in a strong position on the world stage to conduct cutting edge population health research. Linked health record data of this type is only available from a limited number of countries worldwide. [Director, Non-Government Organisation]

There is currently insufficient utilisation of administrative data to undertake research to support health system decision making and policy. This would be facilitated by programmatic funding for health services researchers, but also by better systems for accessing data in a timely way. NSW Health could do much to support this, in particular to ensure that access to data is not prohibitively expensive for researcher [Researcher, University]

Furthermore, charges for access to shared assets do not always cover the full cost of the service provided and compensatory fee-for-service support always raises questions of equity of access among researchers.

...a user-pays approach... tends to favour successful researchers towards the end of their career. [Researcher, University]

The existing biobanks in NSW are often small operations operated independently. The Cancer Institute NSW recently reviewed biobanking facilities in NSW and identified 17 tissue banks constituted as non-profit organisations or as departments within hospitals or research institutions⁴² (Exhibit 28).

Source: <http://www.incite.cancerinstitute.org.au>

Cohort studies require ongoing funds and often find recurrent funding difficult to achieve.

There is limited funding for key collaborative infrastructure for health research (e.g. cohort studies). Too often, the support of key pieces of infrastructure depends on the vagaries of competitive grant funding designed for research projects rather than infrastructure [Chief Executive, Research Organisation]

For NSW to capitalise on its research assets, the infrastructure and resources need to be used and a skilled workforce is needed to manage and use them.

The skilled technicians who operate research assets are hard to find and, when they are, they need career security and support.

... there is an argument to centralise a single resource for major equipment to optimise use and sustainability of resources. This would require capital and recurrent costs with specific technical support built into the model for each piece of equipment....there is the risk that capital expenditure is not optimised because machines are not properly maintained. [Chief Executive, Government Organisation]

With record linkage many researchers not only need timely access to comprehensive data but also the biostatistical skills required to conduct complex analysis. Building capability in biostatistics and bioinformatics was seen as a critical issue for NSW (see also Theme 7).

Principles

- NSW has comprehensive, quality research assets to support excellent, efficient research
- NSW Government-funded research assets are shared
- For shared research assets pricing and access rules are fair and transparent
- Research assets are at an appropriate scale, efficiently run, have clear governance and long-term plans for sustainability.

Recommendations

Theme 9: Build research assets and maximise their use		Responsibility
9.1	Develop a register of major research assets in NSW	MoH – OMR and Health System Support
9.2	Identify research asset gaps and develop a 10-year strategic plan to address them	MoH – OMR and Health System Support
9.3	Scale up and fund to ensure sustainability for existing research assets with a particular focus on: biobanking, bioinformatics, population-based cohort studies and record linkage	MoH, CINSW, LHDs Universities MRIs
9.4	Require organisations that hold NSW Government-funded major assets to develop plans and protocols to promote sharing and access and to regularly report asset utilisation	MoH – OMR and Health System Support CINSW, LHDs, Universities, MRIs

9.1 **Develop a register of major research assets in NSW**

Understanding existing major research assets, including capital assets, in NSW is the first stage in establishing a more strategic approach to investment in this area. The Ministry of Health should undertake an environmental scan to identify major research assets, their location and where appropriate, access rules. Universities and medical research institutes should be involved in the process. The register should be made publicly available and updated on a regular basis.

9.2 **Identify research asset gaps and develop a plan to address them**

Using the register of research assets as a base, the Ministry of Health should work with key stakeholders to identify research asset gaps. The Ministry of Health should also develop a 10-year capital plan which aligns with the 10-year NSW health and medical research strategy.

Criteria should be established to prioritise investment to fill these asset gaps, including state wide relevance, the alignment with NSW research priorities and areas of current research excellence, and the ability to leverage funds from other sources (e.g. through Australian Government funding).

9.3 **Scale up and fund to ensure sustainability for existing research assets**

In the first instance, the NSW Government should commit to

- establishing a NSW biobank network or state-wide facility
- developing capacity in bioinformatics
- supporting population-based cohort studies
- providing the long-term, sustainable resourcing required to maintain and expand record linkage to include a greater range of data sets, including data from other government departments.

Building on the work of Cancer Institute NSW in relation to cancer biobanks, all NSW biobank facilities should be mapped and an analysis of current operations and potential for improvements undertaken. Biobanks should encompass biospecimens from clinical trials, population based studies

(where relevant) and from routine clinical practice. A plan for the future should be developed with input from all stakeholders. Adequate funding must be made to both establish new and maintain existing biobanking networks.

The Centre for Health Record Linkage should work with state and national data custodians from health and other agencies to develop a strategy to expand the record linkage key to incorporate a broad range of data sets. Consultations with key stakeholders, the Privacy Commissioner, the Population Health Research Network and the NSW community are essential to success.

These strategies to address research asset gaps will require significant new resources. Costs and sources of funding will need to be identified as part of the planning process.

9.4 **Require organisations which hold NSW Government-funded major assets to develop plans and protocols to promote sharing and access and to regularly report asset utilisation**

The Ministry of Health should work with organisations that hold state government funded research assets to develop plans and protocols that identify:

- governance arrangements
- improved researcher access, including timeliness, streamlined access and a transparent pricing policy
- plans for sustainable long-term funding
- asset utilisation

THEME 10: **Leverage all investment sources**

NSW health and medical research should maximise the funding it obtains from non NSW Government sources, such as philanthropy, business, Australian Government funding and overseas grants.

...any improvement in the State's relative position in health and medical research will be over decades, rather than years. This requires focused, consistent and strategic funding and associated support for major initiatives in order to leverage Commonwealth, granting agency and philanthropic funds. [Senior Academic, University]

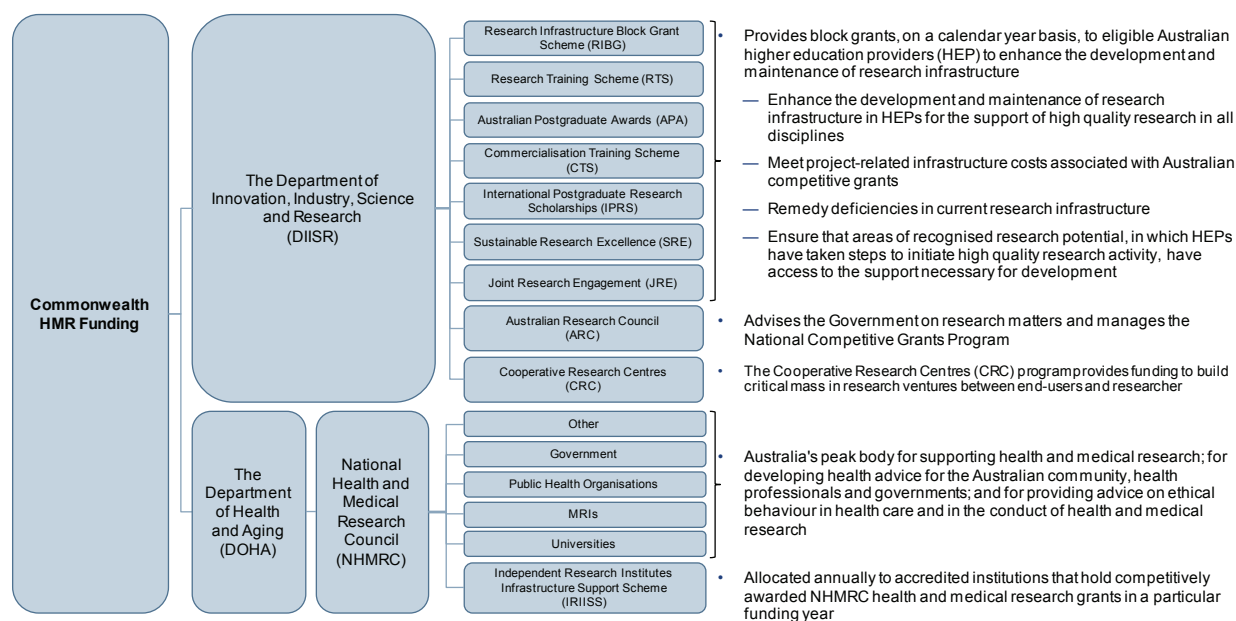
Issues

Two main issues were identified during the Review: understanding health and medical funding and using state government funds to leverage other sources.

Understanding health and medical research funding

The Australian Government funding landscape for health and medical research is complex (Exhibit 29).

Exhibit 29: Sources of Australian Government funding for health and medical research



Source: NHMRC, ARC, SRE, CRC, IRIIS

The Review was informed that non-government support of health and medical research is substantial.

Not-for-profit organisations provide significant support. For example, The Cancer Council of NSW provided \$14million of support to research in 2009-10 and in 2010-11 the Juvenile Diabetes Research Foundation invested \$9.8million into research.

Private business is also a significant source of funding for health and medical research with a reported \$837million invested in Australian in 2007/08.

Further, philanthropic organisations and individuals generously contribute to the Australian health and medical research sector. Other states attract a greater share than NSW; since 2001, Atlantic Philanthropies grants awarded to

Australia have totalled \$230million, of which \$135million has been awarded to Queensland-based medical research institutes and universities.

... the combination of clinical and research excellence was key to securing a \$25M donation from a single benefactor toward the Kinghorn Cancer Centre... and upwards of \$40M from another benefactor toward the establishment of Melanoma Institute Australia... [Chief Executive, Hospital]

Though investment from overseas sources is small compared to Australian Government and state funding (the US National Institutes of Health [(NIH)] awarded \$19million to Australian states from 2008 to 2011), NSW has also underperformed in awards from this source of funding.

Victoria has been awarded \$9.7million of NIH grants compared with NSW's \$2.2million since 2008.

...support of regional collaborative research efforts particularly in the Asia Pacific region with potential to leverage through international agencies (for example, the Gate Foundation, Asian Development Bank, World Bank, Global Fund etc.) These are significant opportunities for NSW based clinical and public health researchers. [Research Manager, Institute]

Using state funding to leverage other sources

Many stakeholders suggested that the state government should consider how its investment adds value to other funding sources, and that funding partnerships should be considered as one mechanism for this.

In order to support research activities strategically at state level, the State Government should consider forming a holistic partnership network with broad funding providers, e.g. develop a thorough understanding of 'who is funding what from which sector'; compare the funding availability and the funding needs to identify how the Government can partner with not only industries but with not for profit organisations, as well as funding available at universities/institutes, to effectively serve the funding needs without duplicating the effort and to use the limited funds in a smarter way. [Director, Research Network]

If NSW is to fully realise its potential, then the State Government must lead the investment in research both directly and through partnerships with others. Further, it seems logical that future investment must be targeted to focus and emphasise research excellence in identifiable areas... We all want to allocate scarce resources toward initiatives that will generate the best outcomes and this logic works for both governments, the private sector and philanthropists. [Chief Executive, Public Health Organisation]

Review stakeholders suggested refocusing and enhancing the Science Leveraging Fund (SLF) to leverage a broader range of national and international grants as well as

philanthropic donations. The recent demise of the Australian Government's International Science Linkages program has reduced support for such engagement; and stakeholders noted the Queensland Smart State initiative of matching philanthropic donations as another example.

Use of the Science Leveraging Fund to attract competitive grant funding, international funding (e.g. NIH) and philanthropic funding (e.g. Gates Foundation) would certainly be supported...a mechanism to support NSW-based researchers to engage in international collaborative activities would be extremely useful. [Senior Academic, University]

...all leveraging funding allocation should be by a transparent and competitive mechanism, and based on the quality of the research project proposed. Timeliness is another essential factor – a commitment of leveraging funds must be made prior to submission of a proposal to a major grant scheme. It is not sufficient to indicate that the NSW Government will negotiate leveraging funding should an application be successful... the commitment [must be] made up front and specified within the application... [Senior Academic, University].

The TechVouchers Program is an example of funding from the Science Leveraging Fund used to leverage industry collaboration (Exhibit 30)

Exhibit 30: NSW Technology Vouchers (TechVouchers) Program

The NSW Technology Vouchers (TechVouchers) Program is a \$1.6 million pilot program implemented by the NSW Government to encourage collaboration between small-to-medium enterprises (SMEs) and public sector research organisations. TechVouchers assists small-to-medium enterprises by providing vouchers to the value of up to \$15,000, matched by the applicant (cash or in-kind)

Eligible activities for potential TechVoucher projects include:

- seeding a research project in partnership with a public sector research organisation
- funding a preliminary research activity that will lead to further funding applications to programs such as Australian Research Council Linkage Projects
- product/process design activities e.g. using engineering or technical design expertise to determine prototype structure, function and materials
- trial production runs or processes to demonstrate a technical concept of a project or part of a project; and testing of toxicity, health and safety attributes of materials, including nanomaterials
- validation or demonstration of the technical capabilities of a product, process or service, scale-up, stability or reproducibility of a process.

Source: <http://ww3.business.nsw.gov.au/TechVouchers/Business/About-TechVouchers.aspx>

Review stakeholders also suggested working more closely with not-for-profit organisations

*The State Government should know which independent [not-for profit organisations] are operating in the sector and examine where judicious funding of operating costs would release considerable funds for research that has the potential to improve outcomes for all citizens.
[Not-for-Profit Organisation]*

Further, building a community culture where individual and corporate support for health and medical research gains strong acceptance. Research Australia is working with the philanthropic, financial and corporate sectors to develop new ways of attracting philanthropic support for health and medical research through the Research Australia Philanthropy Centre (Exhibit 31).

Exhibit 31: Research Australia Philanthropic Centre

The 2005 report 'Giving Australia', funded by the Prime Minister's Community Business Partnership, reports total giving of \$11 billion per annum comprising \$7.7 billion from individuals and \$3.3 billion from businesses. Following this report, Research Australia commissioned an inquiry by Queensland University of Technology's Centre for Non-profit Studies to conduct an independent study of international trends, experiences and best practice in health and medical research philanthropy from a range of comparator countries. The Queensland University of Technology report, 'Lifting the Life Giving Dollar' found:

- Leading research nations have multiple funding sources for health and medical research
- Funding from philanthropic sources can complement and address gaps in government and industry funded research
- Increases in government funding are generally paralleled by increases in philanthropy
- A specially tailored, capacity-building approach to health and medical research philanthropic funding has been successful in increasing health and medical research philanthropic funding overseas.

Research Australia has developed a Philanthropy Toolkit to provide information, advice and resources to guide and promote philanthropic giving to health and medical research. The Toolkit details how one can seek philanthropic support for health and medical research from charitable trusts and foundations, corporations and individual philanthropists. Those wishing to either make a one off donation, or set up a planned philanthropic grant making scheme are provided with guidance to support them.

Source: <http://researchaustraliaphilanthropy.org/publications/toolkit.html>

Principles

- NSW attracts more than its population share of Australian Government funding
- NSW is a natural destination for business, not-for-profit and philanthropic health and medical research investment.

Recommendations		
Theme 10: Leverage all investment sources		Responsibility
10.1	Provide assistance to hubs, research organisations, research networks, LHDs and consortia for competitive grant applications	MoH – OMR
10.2	Co-invest in large (>\$10million) philanthropic donations that have state-wide significance and align with the Review priorities	DPC
10.3	Develop, refine and implement programs to attract individual, corporate and not-for profit investment in health and medical research	DTIRIS MoH – OMR
10.4	Expand industry-partnered collaborative research programs	DTIRIS MoH – OMR

10.1 Provide assistance to hubs, research organisations, research networks, LHDs and consortia for competitive grant applications.

Consideration should be given to establishing a health and medical research leveraging fund or expanding the Science Leveraging Fund to support large scale bids for Australian Government grants including, Cooperative Research Centres, ARC Centres of Excellence, Education Investment Fund, Health and Hospital Fund and international research funding,

In addition, the relevant Divisions within the Ministry of Health should establish clear criteria and processes to support smaller partnership funding grant applications.

10.2 Co-invest in large (>\$10m) philanthropic donations that have state-wide significance and align with the Review priorities

A mechanism for determining state government support of large philanthropic donations should be established. This will send the message that NSW is 'open for business' and would require a transparent process including the creation of:

- an initial point of contact within the Office for Medical Research
- processes for decision making, including
 - initial feasibility assessment or triaging
 - criteria including: state-wide significance; economic benefits; opportunity linked to a NSW research priority; opportunity linked to a research hub; and potential to strengthen researcher collaboration.

10.3 Develop, refine and implement programs to attract individual, corporate and not-for profit investment in health and medical research

An advisory service for individuals, corporate and not-for-profit organisations or foundations wishing to invest in health and medical research should be established. This service should assist potential investors to direct their donations to more strategic opportunities and to leverage additional funds.

The Ministry of Health should also look for opportunities to work with Research Australia and the Department of Trade and Investment, Regional Infrastructure and Service in promoting philanthropy for health and medical research.

10.4 Investigate an industry-partnered collaborative research program

To encourage collaboration between academia, health services and industry, an industry-partnered collaborative research program should be considered. NSW Government has previously invested in the TechVouchers Program and consideration should be given to reviewing its impact for the purpose of enhancing the Program.

Authorisation for research to proceed requires a site-specific assessment.

In 2007, NSW was the first state in Australia to introduce single ethical review for multicentre research within the state. Previously, if research was to be conducted at several sites, each site would need to have local ethical approval. Single ethical review was accompanied by the introduction of site-specific assessment (SSA) whereby in a health care facility the chief executive or their delegate authorises the research after ensuring that local governance standards along with the multisite ethics requirements are met.⁴⁵ An overview of the process is shown below (Exhibit 32).

THEME 11: Improve NSW Health research administration

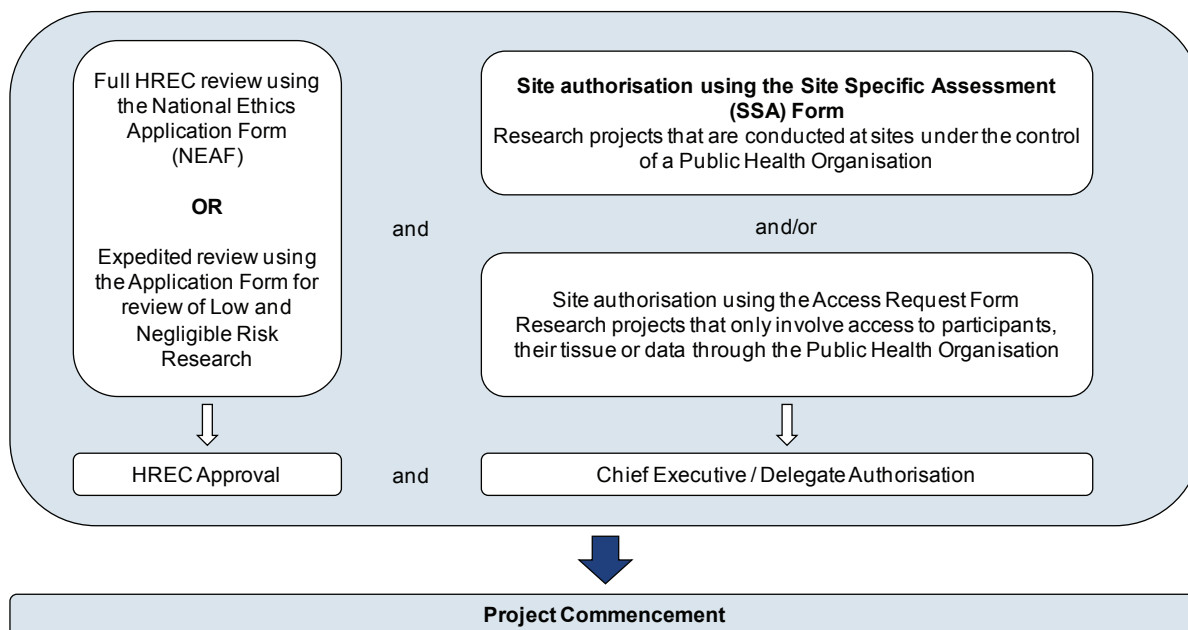
All human research must meet ethical and scientific standards codified by The National Statement on Ethical Conduct in Human Research⁴³ developed by the NHMRC and endorsed by the Australian Research Council and the Australian Vice-Chancellors' Committee. State-based legislation governs the ethics of animal experimentation.

An independent evaluation assessed whether the new system had met its objectives to expedite research proposal approval.⁴⁶ In response to the evaluation recommendations, in 2010, NSW Health introduced a modified application process for low-risk research and new standard operating procedures for HREC executive officers and research governance officers. A suite of standard clinical trial agreements and a policy on insurance and indemnity requirements have also been released.

Within the NSW health system, each research proposal involving human participants in NSW is assessed by a Human Research Ethics Committee (HREC), or if animals are used, an Animal Ethics Review Committee. HRECs review research applications to ensure the nationally agreed principles are upheld.⁴⁴

Nationally, in 2006, the Australian Health Ministers' Advisory Council commissioned the NHMRC to lead the development of the Harmonisation of Multicentre Ethical Review (HoMER) initiative. HoMER is expected to be

Exhibit 32: NSW process for Human Research Ethics Committee approval and site authorisation



Source: NSW Health Procedures

implemented in the first half of 2012. NSW is currently working with Victoria and Queensland to introduce mutual acceptance of ethical review for clinical trials undertaken in public health organisations. This initiative uses resources developed by HoMER and will trial the national approach within a smaller sub-set of research studies.

Other countries are grappling with systems for research ethics and governance. For example, a recent report from the UK concludes that ‘governance arrangements within the National Health Service are the single greatest barrier to health research’.⁴⁷ This report cites an analysis by Cancer Research UK that showed that after funding for a study has been agreed, it takes an average of 621 days to recruit the first patient. The UK has proposed a central triage system where there is a single point of contact for HREC approval and national level governance checks, supplemented by local feasibility assessments. The USA is currently revising regulations for ethics review to improve effectiveness and enhance protections, e.g., through simplifying processes for minimal risk research and guidance on patient information and consent.⁴⁸

Issues

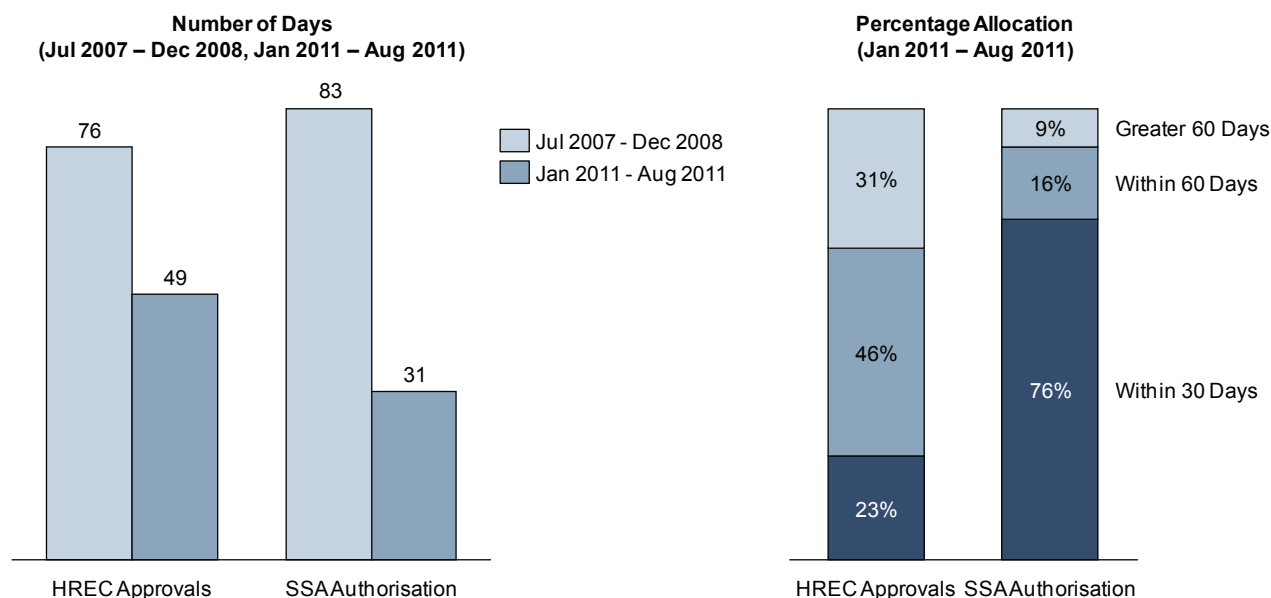
Three main issues were raised during the Review: timeliness of approvals; site authorisation; and research office workload.

Timeliness of approvals

Researchers often raise delays in ethics and governance approval as a major frustration, however the analysis of the data shows that there have been marked and as such better communication of these more positive results is required.

Time taken for ethics approval and site authorisation has shortened significantly in NSW. In the first eighteen months after the introduction of single ethical review in 2007, the average time for ethical approval was 76 days and the average time for site authorisation was 83 days for all categories of research, including clinical trials. This compares to 49 and 31 days in 2011 for HREC approval and site authorisation respectively in 2011 for clinical trials only (Exhibit 33).

Exhibit 33: Time taken for Human Research Ethics Committee approvals and site authorisation in NSW, July 2007 – December 2008, January 2011 – August 2011



Source AU-RED data base

The majority of clinical trials in NSW obtain HREC approval within 60 days, which is an established benchmark and most SSAs are authorised with 30 days.

Notwithstanding these improvements, the Review was consistently informed that research ethics and site authorisation processes in NSW are onerous and slow and in the case of site authorisation, inconsistent between LHDs. Research workers find the requirements of completing the ethics and governance applications cumbersome; application forms are often poorly understood which also leads to delays.

Clinical research has been hampered in NSW in recent years due to the immense bureaucracy that has crept in under the new ethics review system. The delays to getting research started, especially multicentre trials, [are] completely unacceptable. The whole system needs to be overhauled to allow a sensible approach to be established. [Researcher, Hospital]

Although some see NSW as worse than other states in this regard, others refer to NSW being at the forefront of the national harmonisation process (HoMER) and some have had positive experiences. Systematic data on ethics approval and site authorisation in other Australian states are currently not publicly available.

The Ministry of Health has committed to public reporting of ethical approval and site authorisation timeframes, which for many stakeholders is a welcome development.

...setting up of a feedback process to centrally monitor ethics review and governance turnaround times. Currently there is no feedback loop for industry in terms of these processes... [Pharmaceutical Company]

Inconsistent data entry and technical impediments to generating reports from the IT system used to track these applications have made systematic reporting unachievable in the short term.

Site authorisation

Site authorisation as part of the governance review of proposed research is generally a more significant contributor to delays as the governance requirements often concern matters of detail over contracts, research record-keeping, intellectual property and liability and these matters, frequently legal in nature, are slow.

There is a perception in industry that 'ethics' slows things down. This is a fallacy. 'Governance' is where the delays occur, often at the industry end rather than the researcher or institutional end. [HREC Chair, University]

...while Australia is one of the fastest countries in which to gain ethics approval, Australia's performance drops off significantly in terms of the time it takes to initiate trial sites. We believe that a major contributor to the drop off in performance are issues associated with research governance. [Pharmaceutical Company]

Research office workload

Research offices that handle ethics and governance vary in the number and experience of their staff, their grading, and the scope of duties. Such offices often speak of work overload and the stress of dealing with frustrated research workers. Other research offices report that executive support and appropriate resources can enable LHDs to provide high quality and prompt ethics approval and site authorisation (Exhibit 34).

Exhibit 34: Children's Hospital Research Office

The Kids Research Institute at The Children's Hospital at Westmead reviewed the operations of its Research Office, which includes grants management, innovation management, research financial management, laboratory and transgenic facility management, clinical trials and the operations of the Sydney Children's Hospitals Network's research ethics and governance review and approval processes.

One key element of this review was to confirm the drafting and appointment of a Research Governance Manager (RGM) position with a classification of HSM3. Due to the separation of responsibility of Ethics approvals to HRECs and Governance approvals by LHDs, we identified that the RGM needed to be a senior management position that would be required to provide well informed and clearly articulated recommendations to the Chief Executive of Sydney Children's Hospitals Network or his or her delegate to approve or not approve research projects. We have since found that this role is not about not approving projects but facilitating quality research projects.

By recruiting staff with these qualifications and experience Sydney Children's Hospitals Network has also been able to ensure formal review of research associated contracts, such as material transfer agreements, non-disclosure agreements, research collaboration agreements (national and international), IP agreements, research contract funding agreements which has provided an additional research governance support to research conducted at Sydney Children's Hospitals Network.

Source: Sydney Children's Hospitals Network

Principles

- Ethics and governance review are of high quality and meet established benchmarks on timelines
- Data on the timeliness of ethics approval and site authorisation are publicly available.

Recommendations		
Theme 11: Improve NSW Health research administration		Responsibility
11.1	Reform site specific authorisation (research governance) processes	MoH – OMR
11.2	Improve research ethics and governance data collection management and analysis capabilities	MoH – OMR LHDs
11.3	Include research ethics and governance metrics as a monitoring measure in the LHD Performance Management Framework	MoH – OMR
11.4	Appropriately resource LHD research offices to undertake research ethics and governance functions	LHDs

11.1 Reform site-specific authorisation (research governance) processes

Delays in site authorisation are a significant problem in NSW and other Australian and international jurisdictions.⁴⁹ Timelier site authorisation will make a significant difference to start up times for research.

A review is the first step in reforming site specific authorisation. This review should

- examine state-level policy and guidelines for site-specific assessment
- audit LHD practices and resources
- assess business processes to identify opportunities for simplification
- make recommendations for change to NSW policy and practice
- establish a 'model' site authorisation process

11.2 Improve research ethics and governance data collection management and analysis capabilities

The ethics and site authorisation application process could provide a rich source of information about the number and type of research projects undertaken across the Ministry of Health. This information, however, is currently not captured when reporting performance.

The Ministry of Health now uses the AU RED research ethics database developed by Infonetica Research Solutions (Infonetica). The Ministry of Health has recently commenced the initial requirements-gathering phase of a project that seeks to deliver an enhanced information management and technology platform to serve the needs of the Ministry, research office staff, research workers and other stakeholders.

There is potential to develop a more integrated, agile information management system that can interface and exchange data with other health and research systems. Currently, due to technical limitations, some research office staff enter data into legacy systems as well as AU RED. This duplication should be eliminated and other efficiencies achieved by developing a system that supports all information management requirements associated with research ethics and governance assessment and approval.

11.3 Include research ethics and governance metrics as a monitoring measure in the LHD Performance Management Framework

The NSW Ministry of Health decided to introduce key performance indicators (KPIs) pertaining to research approval and management for chief executives of public health organisations, following evaluation of the NSW Health single ethical review system in 2009. Draft KPIs were prepared.

Following assessment of the draft KPIs by the Ministry's Health System Quality, Performance and Innovation Division, it was proposed that 'timeliness of research authorisation' measures be adopted as a monitoring measure, rather than as a KPI. In addition to KPIs, the NSW Ministry of Health will continue to monitor a broad range of measures. Should a performance issue emerge with one or more of the Monitoring Measures, the issue will be discussed with the LHD. If the performance issue continues, the NSW Ministry of Health may determine to notify the LHD of a transfer of the Measure(s) to become a KPI(s) until the performance issue is resolved.

Monitoring Measures form one of a broad range of indicators monitored by the Ministry.⁵⁰ Should a performance issue emerge with one or more of these broader monitoring indicators, the Director General may determine to amend the Health Service's Performance Agreement and transfer the indicator to become a KPI until the performance issue is resolved.

In 2010, the total number of clinical trials initiated within the NSW public health system was established as a NSW Treasury KPI.

The following metrics should be incorporated into the Performance Measures from 2012-2013:

1. Total number of clinical trials initiated within the NSW public health system
2. Research applications (HREC review and site specific assessment) of more than low risk to participants authorised within 60 days
3. Research applications (HREC review and site-specific assessment) of low and negligible risk to participants authorised within 30 days.

Four timelines for authorisation should be reported using data from AU RED:

1. Median or average time for HREC review by LHD.
2. Median or average time for site specific assessment by LHD.
3. Median or average time to authorisation by LHD (ethics and governance).
4. Median or average time to authorisation across the NSW public health system (ethics and governance).

Measurement, review and management of these measures should fall within the responsibility of the Office for Medical Research. Time lines should be reported publicly.

This analysis should inform local action required to ensure high quality and efficient research ethics and governance services at the LHD level.

11.4 **Appropriately resource LHD research offices to undertake research ethics and governance functions**

Each LHD Research Office must be sufficiently resourced so that it can provide an efficient and effective service for ethical review and research governance

LHD should assess the:

- Current workload and timeframes for ethics approval and site authorisation
- Support provided to the Research Office from other LHD departments (e.g. HR, IT)
- Current staffing numbers and levels of appointment
- The management support and escalation processes that are in place to support research ethics and governance at the local level
- Adequacy of current practices for monitoring the conduct of research undertaken at sites within the LHD

Based on this assessment, LHDs should determine appropriate resourcing requirements and provide additional resources as required.

Delivering on the strategy

Provide strategic leadership

Most funding for investigator-driven health and medical research comes from the Australian Government. This funding supports the highest quality research and the generation of new knowledge as judged by peer review of research proposals, and to a lesser extent, targeted research and approaches for particular health outcomes.⁵¹

This Review recognises the significant investment in health and medical research by the NSW Government. It proposes that state government investment is driven by a practical issue that the people of NSW benefit from life-extending and life-enhancing research discoveries. This Review considers that NSW Government funds should be invested strategically in a range of programs that are targeted to:

- generate research that answers questions of local relevance for clinical and population health practice, health services management and policy and program development and implementation;
- improve the effectiveness and efficiency of the local health system it manages;
- leverage and secure jobs in the research sector, largely supported by Australian Government investment.

The NSW Government approach should also leverage the substantial Australian Government investment, which delivered an estimated \$800million to the NSW sector in 2011. An increase in investment by the NSW Government should support all the recommendations of the Review and be linked to clear metrics and milestones to measure progress. The programs that require significant new investments are research infrastructure (Theme 8), the research workforce (Theme 7) and shared research assets (Theme 9).

Adopt a strategic investment approach

Governments face the challenge of deciding how to invest public resources for the maximum benefit. The rationale for NSW Government investment in health and medical research is primarily to improve the health of the people of NSW. Therefore, NSW Government investment should be informed by health priorities so that research can contribute to the achievement of health goals.

Notwithstanding this emphasis on health priorities, the Review accepts the need to strike a balance between discovery and priority-driven or strategic research. Strategic and priority-driven investment by the NSW Government complements the substantial Commonwealth and global investment in health and medical research, much of which is discovery research.

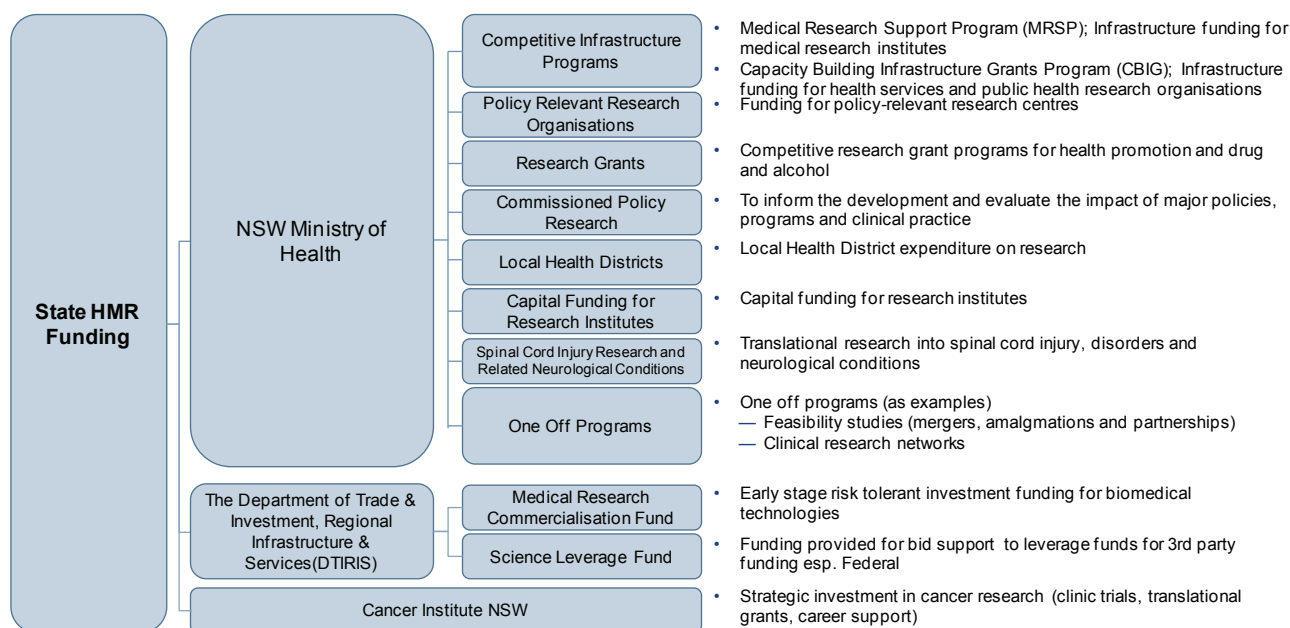
Issues

Three main issues have emerged during the Review; a more strategic approach to investment of state government funding; priorities for state government investment; and building on NSW strengths.

State government funding

The NSW Government invests significantly in health and medical research. Between 2005 and 2010, investment was about \$190million each year through programs administered variously by the NSW Ministry of Health (MoH), the Department of Trade and Investment, Regional Services and Infrastructure (DTIRIS), the Cancer Institute NSW (CINSW) and LHDs (LHDs) (Exhibit 35).

Exhibit 35: State funding for health and medical research



Source: NSW Ministry of Health

Stakeholders noted a lack of coordination among state government funding programs, judging the way that the NSW Government directs or funds research to be non-strategic, even obscure and at time arbitrary.

The state government has initiatives but these tend to be quite disparate and I suggest not widely publicised. My experience in NSW is that initiatives tend to be dominated by interest groups and that at any one time there might be a number of separate projects trying to achieve the same thing. [Researcher, University]

...successive state governments have promoted and supported a plethora of disconnected, poorly capitalised and poorly funded research institutes, largely driven by ego and political opportunism. This has resulted in an entirely fragmented and dysfunctional research infrastructure in this state, and has meant that NSW languishes below the other main states, despite the apparent success of its lead institutions. [Researcher, University]

Some stakeholders highlighted the need for a competitive and transparent funding process. It is acknowledged that criteria may vary dependent on the aims and objectives of different funding programs.

The fragmented approach to state funding in the health and medical field has historically seen many projects funded on political inclination, without careful examination of research quality and value of investment [we] strongly encourage the Committee to ensure that all future funding decisions are made based on research quality and comparative merit, with reference to available metrics, via an open and transparent competitive process. [Senior Academic, University]

Funding decisions are best made by people who have no vested interest in the outcomes...in a manner independent of tribal considerations and may well be best made by those with appropriate credentials but no formal linkage to NSW institutions. [Academic, University]

Many stakeholders perceived that research funding in NSW has a strong medical orientation with limited funds available for health services research, primary care research, population health intervention research and research related to the translation of research into improved policy, services and health outcomes for the NSW population. Many of these fields relate closely to the application of research to priorities for health care and prevention.

The vast majority of patients receive medical care in the primary care setting, yet the majority of health research funded in NSW focuses on care delivered in the acute care environment. Academic primary care, which, among other areas, tests the external validity of research interventions where most patients receive most of their care most of the time, is significantly underfunded relative to other health and medical research areas [Policy Maker, Non Government Organisation]

Priorities for state government investment

Many Review stakeholders commented that NSW currently has poorly articulated health and medical research priorities, and that there is no clear or coordinated approach to determining or communicating them.

Research is haphazard and not well aligned with NSW health and medical priorities. It is difficult for government to support research if government is not clear about the general directions of research that it wants to support. [Research Director, Medical Research Institute]

There was strong support for the development of research priorities. Many stakeholders believe this is a fundamental step towards a more strategic approach to state government investment in health and medical research.

Before the funding process can be improved, we need to identify state priority research areas. From them, appropriate and targeted funding mechanisms can be developed which will reduce duplication, increase opportunity for areas of need and allow us to measure success. [Research Administrator, Non Government Organisation]

A research structure that takes into account looking at the research future horizons and being ready for new opportunities in a planned and organised manner with defined funding sources and structured process to enable pre-emptive planning so that the 'scatter gun' approach to 'who does what' is not the path taken. [Chief Executive, Public Health Organisation]

However, there were a wide range of opinions on potential research priorities, often based on individual interests and organisational imperatives.

A lively discourse is growing both nationally and internationally about setting priorities for research.^{52,53} Yet there is scant published literature that documents how research priorities are set at present or how health system decision makers can be engaged in developing a research agenda.⁵⁴ Thus, the Review considers that criteria for setting research priorities should be established, and that these be applied by different groups in different settings to establish research priorities relevant to the context (e.g. research funding programs, service provisions, policy development). This process should be proactive, informed by health need and involve a range of individuals and groups.

The process for determining priority areas of research should be based on clinical and health services need... The focus should be on prevalent clinical problems that have a large impact on the quality of life of persons in NSW and consume large segments of our precious health-care resources. [Clinician, Hospital]

However, setting research priorities should not limit researcher's capacity and autonomy to explore new and emerging areas, as this could have a negative long-term impact on research capacity. Thus, academic independence, discovery research and flexibility to respond to emerging fields of research innovation remain important.

While it is understood that the state should have a focus on areas of immediate concern, this limited approach could see the rich texture of world-class research currently undertaken in our institutions becoming limited and/or lost. We would encourage...space in the 10- year strategy for funding and support to be allocated to 'blue sky' research...responses to unforeseen crises... [and] research into fields that have global implications. This broader approach would also ensure that NSW is not limited in attracting or leveraging Commonwealth and other funding for research not specifically prioritised by the state [Senior Academic, University]

Building on NSW strengths

Review stakeholders suggested that key research strengths in NSW include cancer, cardiovascular disease, neuroscience and mental health, HIV and other infectious diseases, gene discovery, medical devices, health services research, epidemiology, population health research and translational research.

Yet, the comparative research advantages of NSW are not clearly defined and will change over time. Further work should be undertaken to develop a better understanding of NSW research strengths and these strengths should then be used to position NSW as a world leader in niche areas, thus complementing the global research effort.

...‘research resource mapping’ [should be undertaken] to identify and capture the full research capabilities of NSW versus other states. This analysis will ensure that research strengths are identified as well as matched to interstate and international relevant research objectives to prevent duplication of research effort. [Chief Executive, Research Organisation]

Instead of developing and strengthening research capacity and expertise across the priority areas, it will be more effective to identify the ‘niche’ of existing research capacity in NSW and strengthen that area first before moving into broadening the overall research capacity. ...Given the limited resource and funding availability, the real question should be ‘How does NSW strategically grow research capacity and capabilities locally that would position NSW as the hub of world-class research leaders, whilst leveraging existing research expertise and capacity of other states and countries and complementing the overall research needs by trading on its ‘niche’. [Chief Executive, Non Government Organisation]

By way of example, the Ministry of Health has, on occasion, provided core funding to build research capacity in areas of strategic importance, for example the Sax Institute (Exhibit 36).

Exhibit 36: The Sax Institute

The Sax Institute was established in 2002 through a collaboration between universities and with core funding from NSW Health. It was established in response to an agreed need to build capacity and collaboration in public health and health services research and to increase the impact of this research on policy and practice. The Institute has established long-term partnerships and world class infrastructure and had a significant impact on capacity and research outcomes. It recently received an NHMRC Centre for Research Excellence scheme grant to examine the impact of strategies to increase the use of research in policy. The Sax Institute has been able to provide a systematic and integrated approach to building capacity, collaboration and translation.

Major programs run by the Institute include:

- The 45 and Up Study with more than 265 000 participants or one in ten people in this age group in NSW. Ninety research projects including many with government are using the data
- SEARCH, a long term study of the health of 1600 urban Aboriginal children being conducted with Aboriginal Medical Services
- Population Health Research Network, a series of initiatives that helps researchers make best use of NSW’s unique repositories of routinely collected health data
- Evidence Check has helped policy makers to commission 90 rapid, targeted reviews of research to inform their decision making.

Source: Sax Institute

Principles

- NSW Government balances its investment in priority-driven research with appropriate support for basic research
- Research priorities are informed by NSW health priorities and policy goals
- All research funding programs are predictable and have objectives that contribute to the NSW Government's Strategy Framework for Health and Medical Research.

Recommendations		
Recommendations: Adopt a strategic investment approach		Responsibility
12.1	Increase transparency and accountability of state-level health and medical research funding programs	MoH DTIRIS ACI, CEC, CINSW
12.2	Establish criteria for setting priorities in health and medical research	MoH – OMR
12.3	Provide ongoing analysis of NSW current areas of research excellence and competitive advantage to drive strategic investment decisions	MoH – OMR Universities MRIs LHDs
12.4	Identify gaps and enhance research collaborations and programs in important areas through single-purpose capacity building grants	MoH ACI, CEC, CINSW

12.1 Increase transparency and accountability of state-level health and medical research funding programs

The health and medical research supported by the NSW government should be subjected to a desk-top review to assess how the goals, objectives and strategies fit with the NSW Health and Medical Research Strategy Framework and the principles and recommendations outlined in this Review.

Divisions within DTIRIS, Ministry of Health, the Agency for Clinical Innovation, Clinical Excellence Commission and Cancer Institute NSW should be responsible for ensuring that their research investment is consistent with the health and medical research strategy framework and priorities, through:

- a regular assessment of research investment against the Strategy Framework
- a regular assessment of research investment against priorities
- adjustment of funding processes if required.

All new research funding initiatives should include this analysis in their development.

Further, the Office for Medical Research should establish an annual reporting process, including level of investment, how funding and programs align with the NSW Strategy Framework for Health and Medical Research and the impact of these programs. The annual report, plus an overview of all funding programs, should be available on the Office for Medical Research website.

12.2 Establish criteria for setting priorities in health and medical research

Clear criteria for priority setting should be applied to determine priorities for state government health and medical research strategies and programs. The proposed health and medical research implementation committee should oversee the development of criteria for priority setting.

The implementation committee should:

- Agree on a priority framework (e.g. capital works, shared research assets, research grants programs, workforce) and define its purpose and use
- Establish robust, transparent criteria for priority⁵⁵ setting, relevant to NSW Health services and research funding programs, e.g. relevance to and consideration of:
 - research excellence
 - burden of disease
 - current health system problems and strategic priorities
 - NSW research strengths and competitive advantages
 - balance across the research continuum (basic science, clinical, health services, policy and population health research)
 - opportunity to:
 - support collaboration
 - leverage additional funding sources
 - build new research capability
 - ability of the research to:
 - influence health outcomes, practice or health system change
 - influence decision making
 - remove gaps in knowledge
 - address health inequity

These criteria should be used by relevant groups to identify priorities for research funding programs, policy and service provision at the local and state level. Priority setting processes should involve a range of stakeholders including policy makers, clinicians (including medical, nursing, allied health and population health practitioners), researchers and others to inform research directions. Priorities should be published on the Ministry of Health website.

12.3 **Provide ongoing analysis of NSW current areas of research excellence and competitive advantage to drive strategic investment decisions**

In order to better understand and foster NSW areas of research excellence and competitive advantage, the NSW Government should undertake a comprehensive analysis on a periodic basis. This analysis requires examination of information from a number of sources including:

- areas of success in category one competitive funding (e.g. NHMRC and Australian Research Council funding);

Excellence in Research for Australia (ERA) reports

- the national survey of research commercialisation
- other sources such as the Primary Care Research Initiative and contract research.

12.4 **Identify gaps and enhance research collaborations and programs in important areas through single-purpose capacity building grants**

In response to the analysis of NSW research strengths and competitive advantage (5.1.3), the implementation committee should identify areas for enhancement, based on strategic opportunities and emergent health issues for NSW. Examples may include Aboriginal health, rural health, mental health, aged care, population health, primary health care and health services research. The potential for collaborative funding for capacity building enhancements should be explored.

Adopt a robust implementation approach

Research is inherently a long-term enterprise, with researchers requiring many years to reach maximum productivity, and meaningful research projects often requiring 5 or more years for completion. The Review considers that the consistent and long-term approach that a 10-year strategy will allow is the best mechanism to deliver optimum returns to the state.

Implementing the recommendations of the NSW Health and Medical Research Strategic Review will be complex and will require a robust, integrated program involving:

- NSW Government
- Ministry of Health
- Office for Medical Research
- Cancer Institute NSW
- Agency for Clinical Innovation
- Clinical Excellence Commission
- Department of Trade and Investment, Regional Infrastructure and Services
- National Health and Medical Research Council
- NSW universities, medical research institutes and other research institutions
- Local Health Districts
- Non Government Organisations

Clear accountability is a prerequisite for success in implementing the Review recommendations. This means assigning the task of planning, coordinating and monitoring implementation of the recommendations accepted by the NSW Government to a single body.

The first step required to sustain progress is to form a committee to oversee the next 12-18 months of the Review implementation program. For example, the 1998 Strategic Review of Health and Medical Research in Australia⁵⁵ proposed an Implementation Committee to ensure that its agreed recommendations would be implemented:

[Given] the far reaching implications of these recommendations, we suggest that an independent process be established to supervise implementation and provide continuity for the Government and the community in the process of planning health and medical research into the new millennium.

Experience from the 1999 Wills Review suggests that an implementation committee is necessary to drive change, especially where multiple parties must cooperate to achieve success. This approach allowed rapid translation of the recommendations into action. Several helpful observations were made by the 2004 review of progress of the 1998 Review (also known as the Grant Review)⁵⁶:

- *The rapid appointment of an implementation Committee is critical to sustain momentum and meet expectations generated by the Review*
- *The composition of the Implementation Committee and Secretariat is critical for success*
- *The Implementation Committee should, as far as possible, use the same language, structure and numbering to describe and manage implementation*

to avoid recommendations ‘falling between the cracks’

- *Where restructuring is necessary, the Implementation Committee should provide an audit trail to maintain clear accountability*
- *Once the Implementation Committee has completed its brief, responsibility for completing specific actions can be diluted by the machinery of government, unless ... [there is] a clear mandate and accountability for delivery.*

The implementation approach for the Review should therefore build from the best practice established by the 1999 Wills Review, but with specific modifications to take into account the lessons learnt.

The NSW Government should have two structures with different but complementary roles.

1. The Implementation Committee to coordinate, monitor and report on implementation across all stakeholders
2. The Office for Medical Research to oversee NSW investment in health and medical research, drive implementation of the review within NSW Health and provide some secretariat services to the implementation committee.

Principles

- A single body should be accountable to the NSW Government for the coordination and monitoring of implementation
- The Office for Medical Research should be the peak NSW body with responsibility for maximising the impact of health and medical research in NSW
- The foundations for success are in place as soon as possible

Recommendations		
Adopt a robust implementation approach		Responsibility
13.1	Provide additional resources to commence the implementation process	MoH - OMR
13.2	Rename the Office for Medical Research the Office for Health and Medical Research	MoH
13.3	Establish the Office for Medical Research leadership, Advisory Board, resources and processes to achieve the aims of the NSW health and medical research strategy, including communication and advocacy	MoH - OMR
13.4	Agree on a comprehensive set of result areas and key performance indicators to measure progress against strategic objectives	MoH - OMR

13.1 Provide additional resources to kick-start the implementation process

An Implementation Committee should be appointed by the Minister, reporting directly to the Minister, as soon as possible after the Review is publicly released, supported by a secretariat. The implementation committee should consist of 10-12 people with a mix of the skills in research and research management, health services, commercial expertise and the executive authority required to implement the accepted Review actions. The implementation committee should have an independent chairperson.

It is recommended that the committee should comprise 10-12 individuals with the following mix:

- 3 members of the NSW Health and Medical Research Strategic Review Advisory Committee
- The Director-General DTIRIS or delegate
- 2 members from the NSW Ministry of Health
- 1-2 members with research experience, at least one of whom should be a clinical researcher
- 1-2 members from a university or medical research institute
- 1-2 members with experience in industry
- 1-2 members with commercialisation experience in a health and medical research based company or venture capital
- 1-2 members from non-government organisation or consumer organisation.

The Implementation Committee will need a small executive team to complete its work. This team will require a mix of skills to support the committee, including the ability to:

- manage a complex implementation program
- operate effectively in a public sector environment
- manage a multi-disciplinary extended team in different locations
- provide high quality staff to work to assist decision making.

13.2 Rename the Office for Medical Research the Office for Health and Medical Research

The renaming of the Office will better reflect the continuum of research that is of importance to the state.

13.3 Establish Office for Health and Medical Research leadership, Advisory Board, resources and processes to achieve the aims of the NSW health and medical research strategy, including communication and advocacy

A leader for the Office for Health and Medical Research should be recruited to report to the Director General, with an appropriate organisation structure and resources driven by the core functions of the Office.

13.4 Agree on a comprehensive set of important result areas and key performance indicators to measure progress against strategic objectives

The Office for Health and Medical Research should produce an annual report card of key performance indicators identified in the Review, or subsequently, that will collectively monitor the state's performance against the strategic objectives in the strategy. These KPIs should include:

- Number of researchers by role by age
- NHMRC and other peer-reviewed grants awarded
- Number of trial sites notified by NSW compared to other states
- Monitor LHD research processes, programs and outcomes
- Commercialisation office performance metrics (e.g. new registered intellectual property rights, running royalties yielded, number of consultancies undertaken)
- Ranking of hubs in the international field for area of expertise
- Funding source and destination reported
- Incorporation of collaboration and translation performance measures into all relevant research funding agreements with NSW Government.

How will we know if the Strategy is a success?

The Review has proposed that the underlying rationale for sustained and focused investment in health and medical research is to improve the health and quality of life of the people of NSW. These benefits will be delivered by advances in prevention, patient treatment and population health, as well as improvements in accessibility, efficiency and effectiveness of services. In addition, wider economic benefits will accrue from high value research jobs and the commercialisation of health research into services, treatments and products.

This investment is necessarily complex and long term, and will deliver broad social and economic benefits. The range of performance indicators should therefore include a mix of both output and intermediate measures. For example, publications and citations are an intermediate measure but one that would be expected to lead to health benefits in the longer term.

The appropriate metrics for success should align with the Strategy Framework for Health and Medical Research in NSW, with a focus on the following desired outcomes:

- Globally relevant high quality research
- Better health systems and improved health outcomes
- Increased investment and employment.

Whilst a set of detailed criteria should be developed by the Office for Medical Research, the high-level indicators of success to be reported annually are:

- **A better health system and improved health.**
 - Evidence that NSW is recognised nationally and internationally as a centre of excellence in fostering the use of research evidence and that research is routinely considered as part of health policy making and translated into practice
 - Ministry of Health and Local Health District annual research reports demonstrate effective research governance and development and transparent, effective investment in research
 - Research indicators in Local Health Districts show

short turn-around times in ethical review and site specific authorisation.

- Ministry of Health population health and performance reports indicate better health for the people of NSW and an improved health system that can be plausibly related to increased effectiveness of research

- **Globally-relevant high quality research.**

- NSW researchers have more highly-cited publications reflecting greater local, national and international collaboration
- NSW attracts excellent researchers and receives a greater number of competitive grants and fellowships from the Australian Government and other prestigious resources
- Shared research assets are sustainable and frequently accessed and utilised by the research community.

- **Increased investment and employment.**

- There is a significant increase in competitive national and international research funds flowing to NSW
- NSW increases its investment in health and medical research based on the strategic priorities of the State
- Clinical trials are seen as a good investment in NSW due to reduced start-up times and removal of other barriers to effective conduct
- Medical devices developed in NSW demonstrate a return on investment through application and commercialisation
- A greater number of researchers are based in NSW
- Infrastructure investment demonstrates the research institutes and hubs are working in collaboration with greater accountability of public funds.

The Office for Medical Research should produce an annual report on the state of health and medical research in NSW. These annual reports should describe progress of the Review implementation. More comprehensive reviews of implementation should be undertaken in 2016 and 2021. A mid-term review of progress is required to measure the return on investment.

APPENDIX 1

The NSW Health and Medical Research Strategic Review

1. Terms of Reference

The Strategic Review is focusing on the current performance of health and medical research in New South Wales (NSW) and will recommend a strategy covering the next 10 years.

In particular the Review will:

1. Identify how well the health and medical research profile meets the health needs across the metropolitan and regional areas of the State and how it may contribute to the evolving health system in the future.
2. Identify the current profile of the NSW health and medical research workforce and assess its capacity to support the State's future research developments.
3. Make recommendations on measures which might be taken to ensure NSW's research capacity is matched to the need.
4. Develop an economic framework to support the recommended strategic strategy.
5. Ensure appropriate links with industry to ensure commercialisation of new discoveries.

In addressing its Terms of Reference the Review will also give consideration to:

- Benchmarking NSW's health and medical research performance against other Australian States and relevant international comparisons;
- How the current NSW research infrastructure and support funding system may be structured in order to provide the required support and encourage greater efficiencies through critical mass and economies of scale within the sector;
- How the NSW health and medical research sector can expand its current capacity in population health, clinical and health services research and align with the future health needs;
- How NSW can leverage its capacity in biotechnology, medical and health outcomes and attract national and international public and private sector support;
- How the State support for health and medical research

is optimised in terms of leveraging funding from the Australian Government, overseas funding bodies and philanthropic donations;

- How to structure more efficient, co-ordinated and productive outcomes from within the health and medical research sector entities;
- Examining present and potential links to industry to develop commercialisation of health and medical research discoveries; and will
- Specifically comment on development of a clinical trials infrastructure for NSW, including how NSW can increase its attractiveness as a location for conducting clinical trials including streamlined ethical review, patient recruitment and costs.

2. The Strategic Review Process

The NSW Health and Medical Research Strategic Review is being conducted from July 2011 with a final report expected to be released in February 2012.

A Fact Base was compiled to provide data on the state's performance against a number of research metrics, including research funding, research activity and outputs (publication and citations), workforce, research organisations and commercial success. Where data are available, NSW performance has been compared to other Australian states.

The consultation spanned three phases:

1. The first phase of consultation (21 July – 15 August 2011) included an online survey open to all stakeholders and a series of Roundtable discussions and individual interviews with a broad range of stakeholders. More than 350 people participated in the first phase of consultation. The themes emerging from the online survey, group and individual interviews and the key findings from the Fact Base informed the development of an Issues Paper.

2. The second phase of consultation (5 September – 26 September 2011) elicited feedback on the Issues Paper. Key individuals and organisations in Canada, Sweden and Singapore were consulted to ensure international best practice perspectives were considered. Eighty-seven people provided feedback on the Issues Paper and people from 16 international research organisations were interviewed. The findings from the first two phases of the Review have informed the development of a Discussion Paper.
3. The third phase of consultation (31 October – 18 November 2011) elicited feedback on the Discussion Paper.

Three hundred and sixty eight submissions were received and approximately 181 people participated in individual or group interviews.

The Fact Base, Issues Paper and Discussion Paper are available at <http://www.health.nsw.gov.au/omr/review/>.

An implementation plan will be developed after the recommendations from the Interim Report of the NSW Health and Medical Research Strategic Review have been considered by government.

Key Themes Emerging from the Review Consultations

The first phase of consultation focused on current performance, strengths and areas for improvement:

- NSW has many strengths and competitive advantages including: a large and diverse population; a high-quality health system; excellent researchers and clinicians; outstanding medical research institutes; and universities with strong track records in a broad range of health and medical research.
- The NSW Government provides a range of support to research organisations. There are some good collaborative models between research institutes, universities and health services and there are several examples of strong research networks and collaborations.
- A large number of pharmaceutical and device companies are headquartered in NSW and there is a high concentration of not-for-profit organisations

supporting health and medical research in this state.

- Key research strengths include cancer, cardiovascular disease, neuroscience and mental health, HIV and other infectious diseases, gene discovery, medical devices, health services research and population health research.
- Key opportunities for NSW include genetic research, bioinformatics and research collaboration in the Asia-Pacific region.

The research performance of NSW was assessed using metrics for competitive grant funding, publications and commercial success:

- With the exception of health services research, NSW does not attract its expected share of funding from the NHMRC
- NSW produces a high number of highly cited publications
- NSW biotechnology companies' market capitalisation is second to Victoria; however NSW is particularly strong in medical devices.

The second phase of consultation elicited feedback on the Issues Paper and in particular the proposed options for action.

- Most respondents considered the Preliminary Strategy Framework presented in the Issues Paper to be comprehensive (91%) and useful (98%). Respondents considered the options for action addressed the key issues for health and medical research in this state (84%) and the potential outcomes were considered to be appropriate (93%).
- Many respondents noted that the list of actions was ambitious and needed to be narrowed into a manageable plan that could be implemented. Respondents were asked to nominate the top five actions to improve health and medical research in NSW. The priority actions (and the percentage of respondents who cited this action as one of their top five) were:
 - Strengthen the research workforce (51%);
 - Improve research infrastructure to reward success (50%);
 - Foster links and partnerships for multidisciplinary and cross-sector collaboration (37%);
 - Strengthen and focus health and medical research hubs and networks (31%);
 - Support knowledge-led innovation in clinical practice,

health services delivery and population health programs (29%);

- Improve the efficiency of research ethics and governance processes (24%); and
- Provide clear political and organisational leadership to ensure the successful implementation of the NSW 10-year health and medical research strategy (22%).
- Strong feedback was received to broaden the scope and to include more emphasis and actions related to:
 - The spectrum of health care researchers (Issues Paper is very medically focused)
 - Biomedical, health services, population health and policy research (Issues Paper is very clinically focused)
 - Research conducted in hospitals and community settings (Issues Paper is MRI and university focused)
 - Discovery research (Issues Paper is very priority focused)
 - Rural and international research (Issues Paper is very metropolitan focused)
- Respondents also suggested the need for a stronger focus on community and consumer involvement in the decision-making and conduct of research; a whole of government approach; and stronger involvement of non health agencies that have relevance for health. Furthermore, consideration of implications of the National Health and Hospital Reforms and how the Review relates to these reforms was recommended.

Sixteen international research organisations were visited in Canada, Sweden and Singapore. Key ideas generated by the site visits included:

- **Attract, retain and support careers in health and medical research across the sector:** A career program could be developed to attract the world's leading researchers to NSW, which may be able to capitalise on the global financial crisis by offering desirable relocation packages. This approach was used by the Alberta Government in Canada, which has established a program over 3-5-year period to attract the 35 best researchers in the world.

A 'PhD plus' program to provide an additional year of scholarship for management training could help to develop a generation of researchers with an understanding of management and the process of innovation.

- **Maximise economic benefit to NSW:** a not-for-profit commercialisation unit to service multiple entities, may benefit research organisations, particularly

those that do not have commercialisation capacity.

- **Build capacity and critical mass:** Two international examples highlighted how funding can be structured to build capacity and critical mass; Singapore has redirected some infrastructure funding to entities into shared platforms. In Canada, program and project grants are given a higher weighting if they are collaborative and interdisciplinary.

The third phase of the consultation elicited feedback on the Discussion Paper.

Respondents described the Discussion Paper as thoughtful and comprehensive. They considered that it addressed the major issues facing the health and medical research sector in NSW. The Vision, Strategy Framework, Principles and Actions were largely supported and endorsed. It was noted that many of the issues raised in the previous rounds of consultations had been taken on board.

Many respondents considered the Discussion Paper ambitious and noted that the Review has raised a high degree of expectation in the NSW health and medical research sector of a commitment by the NSW Government to establish structures to support the delivery of the plan and funding to deliver the new programs. Many commented that targeted funding is required for projects that have the capacity to influence the system, rather than a reliance on incremental and gradual change.

Other issues raised included the following:

- The Discussion Paper is still very medically-focussed, lacks an emphasis on basic science and biomedical research and population and policy research, and is still Sydney-centric
- Funding should not be limited to research that aligns with NSW Government priorities and localised health issues. Space should be provided for emerging research fields to ensure that NSW stays innovative and at the leading edge of research
- The responsibility for providing LHD resources to support priority research programs will need to be shared by the Ministry of Health and that research in LHDs needs management infrastructure beyond Directors of Research.
- There should be more emphasis on the capacity in NSW for high-quality investigator-initiated clinical trials
- Many respondents considered that the section on intellectual property required additional work to link

the conclusions drawn with the evidence and to better reflect the complex and multi-faceted process. The Ministry of Health may be able to further leverage developments in the national innovation framework.

- Some respondents supported a focus on medical devices, but more commented that this strategy should not focus solely on medical devices but should include other areas such as pharmaceutical and bio-technology products and e-packages for education, surveys and interventions.
- The focus of the workforce strategy should not be solely linked to hubs or NSW research priorities and movement between personnel between universities, hospitals, research organisations and industry should be encouraged.
- Many respondents considered improve research infrastructure support to be one of the most critical aspects of the Review. Comments on the proposed tiered system for the Medical Research Infrastructure Program included that:
 - The tiered system will favour big organisations who have already reduced their infrastructure costs through scale efficiencies
 - It does not foster research in population health and health service delivery.
 - New institutes, e.g. those affiliated with new medical schools in regional areas would never be competitive or grow their potential if stuck in a lower funding tier
- Setting and prioritising capital projects is not straightforward. Resources will be needed to support the plan and extensive consultation will be required to develop a sound process for deciding how State funding will be allocated between competing worthy infrastructure projects
- Emphasis should be placed on winning more national and international grant funding. Further examination of mechanisms for better communication between NSW, the Federal Government, the MRIs and NGOs would be useful.

APPENDIX 2

NSW Current Performance in Health and Medical Research

This section summarises key performance indicators on research funding, research activity and outputs, research organisations and commercial success. These data have been accessed from a range of sources including the National Health and Medical Research Council (NHMRC), Australian Institute of Health and Welfare (AIHW), Therapeutic Goods Administration (TGA), NSW Health and private organisations. Where comparable data are available, NSW's performance has been compared with data from Victoria, Queensland, South Australia and Western Australia. More data are available at <http://www.health.nsw.gov.au/omr/review/>.

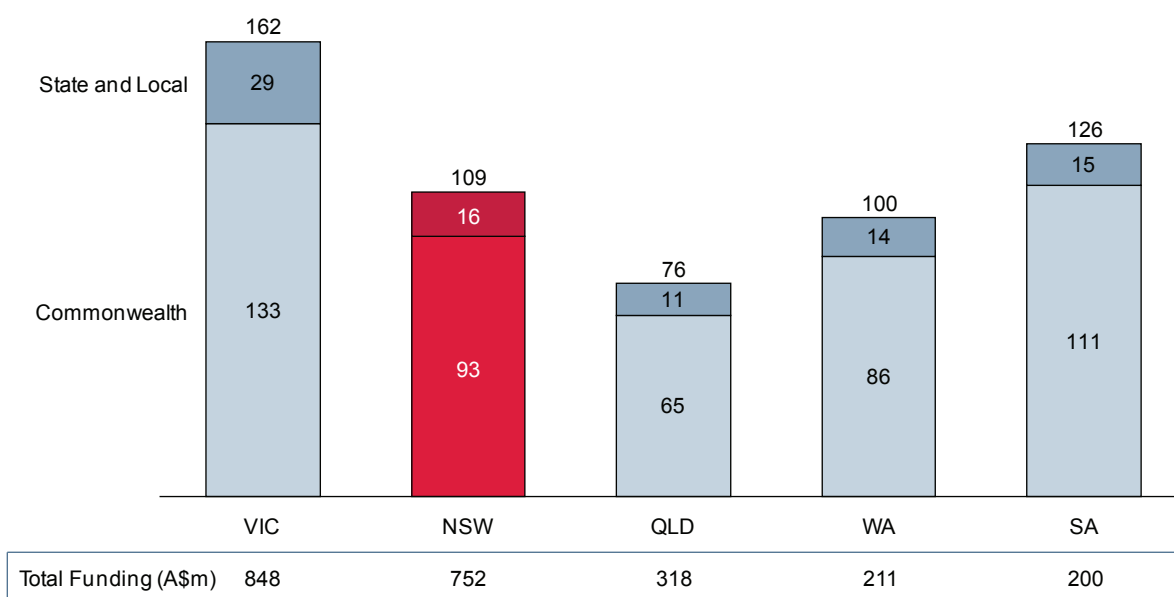
There are several gaps in the data presented. For example, the Australian Bureau of Statistics no longer does a breakdown of research expenditure by state due to data quality issues. Data on research undertaken in the health system, workforce and private sector have been difficult to obtain.

Research Funding

Research funding for health and medical research is provided by the Australian and State Governments, the private sector and philanthropic sources. This system is complex with a myriad of programs that support different types of research, researchers and research infrastructure. The largest source of funding is provided by the Australian Government through competitive funding via the NHMRC.

In the 2007-08 financial year, NSW received the second highest quantum of funds (after Victoria) for health and medical research from Australian and State Governments and local sources. However, on a per capita basis, NSW receives less funding than Victoria and South Australia and receives similar per-capita funding to Western Australia (Exhibit 37). Note that the data presented in Exhibits 1 and 2 are not directly comparable due to differences in data definition and collection methods.

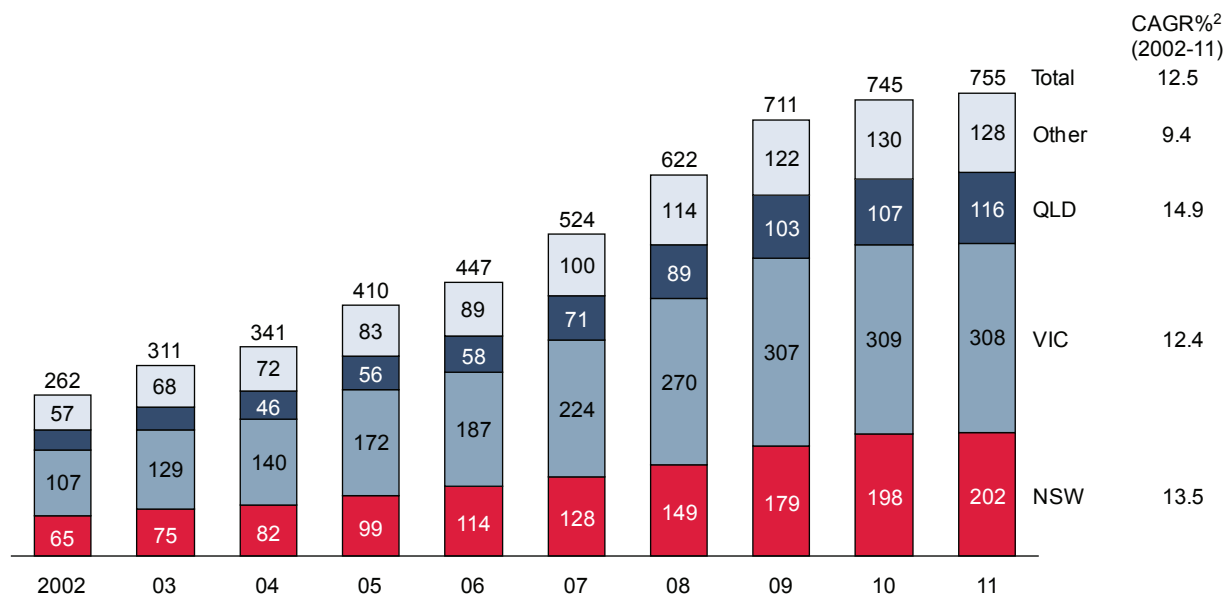
Exhibit 37: Health and medical research expenditure by source of funds per capita, A\$, 2007-08



Source: Research Australia: Shaping Up Trends and Statistics in Funding Health and Medical Research July 2011, Australian Institute of Health and Welfare: Health Expenditure Australia 2007-08

Between 2002 and 2011, NSW received the second largest amount of National Health and Medical Research Council funding in Australia (Exhibit 38). Between 2002 and 2011, the three largest states, Victoria, NSW and Queensland have all grown funding at, or greater than, the overall growth in NHMRC funds.

Exhibit 38: National Health and Medical Research Council (NHMRC) funding by state, A\$m, 2002 to 2011



Note: 1. Other includes, NT, ACT and TAS
 2. Compound Annual Growth Rate
 Source: NHMRC Grants Funding for the Current Decade - 2002 - 2011

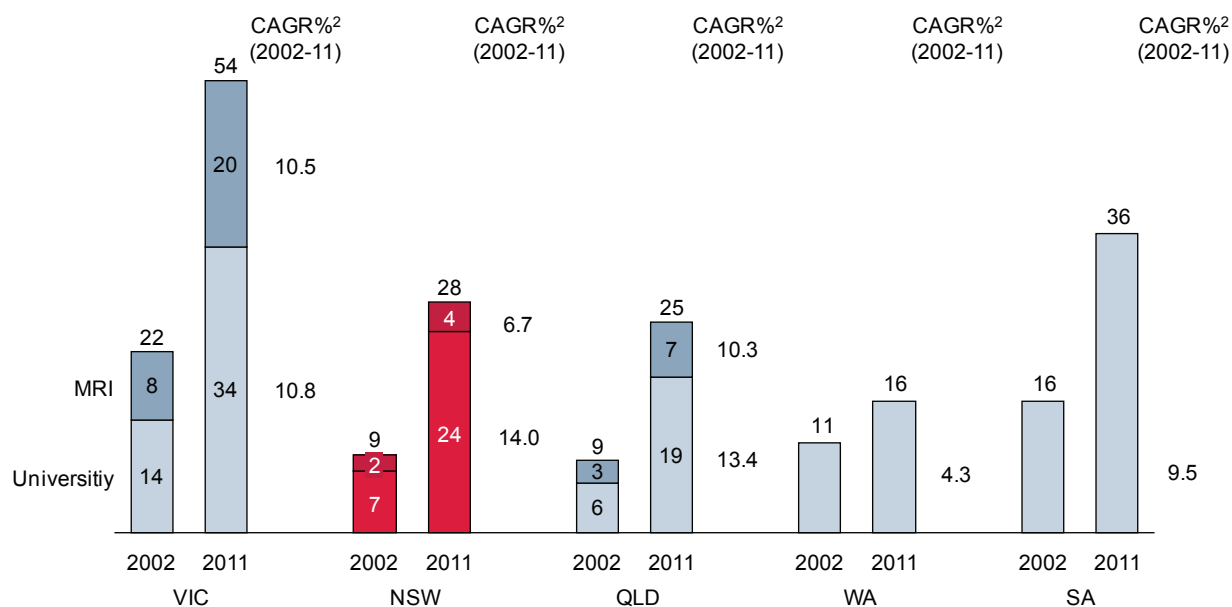
In 2011, the NSW per capita share of NHMRC funding was below the national average (\$33). NSW received \$28 per capita, while Victoria received \$55 per capita and Queensland received \$26 per capita.

NHMRC funding to NSW is at, or below, the national average spend per capita for all categories of research

with the exception of health services research, where NSW receives 48% of the total allocation.

In 2011, NHMRC per capita funding to universities and medical research institutes in NSW was less than Victoria, and South Australia (Exhibit 39).

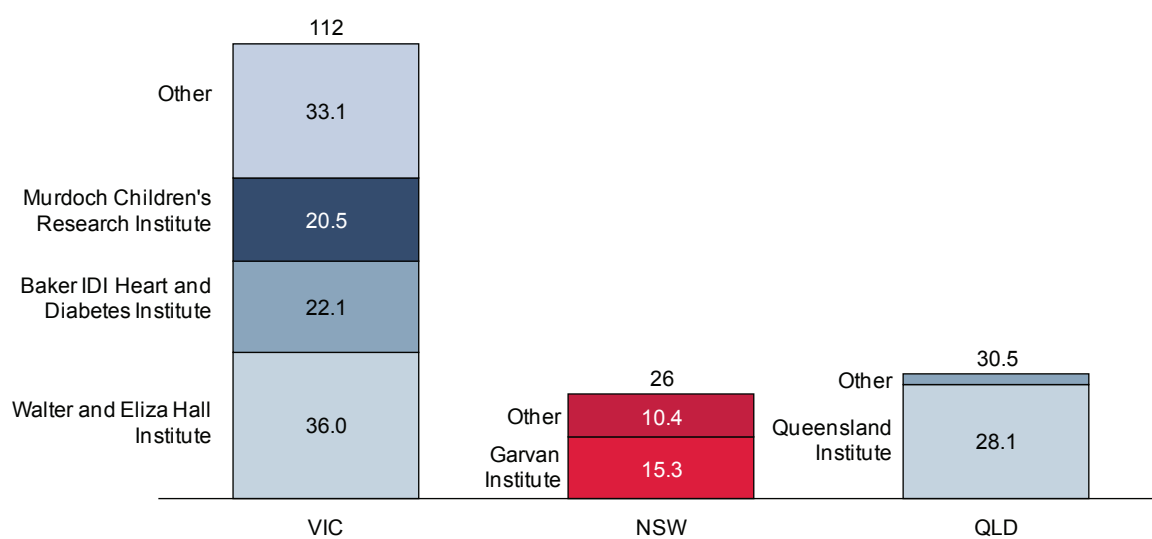
Exhibit 39: National Health and Medical Research Council (NHMRC) funding by state by sector per capita, A\$, 2002 and 2011



Note: 1. Excludes Hospital, Government and Other
 2. Compound Annual Growth Rate
 Source: NHMRC Grants Funding for the Current Decade - 2002 - 2011, ABS

Notably, NHMRC per capita direct funding to medical research institutes located in NSW is five times less than that to medical research institutes in Victoria (Exhibit 40). The NHMRC data may understate the extent of research funding for medical research institutes in NSW as some grants are administered by universities, adding further complexity to an already intricate research funding environment.

Exhibit 40: National Health and Medical Research Council (NHMRC) medical research institutes funding by state, A\$m, 2011

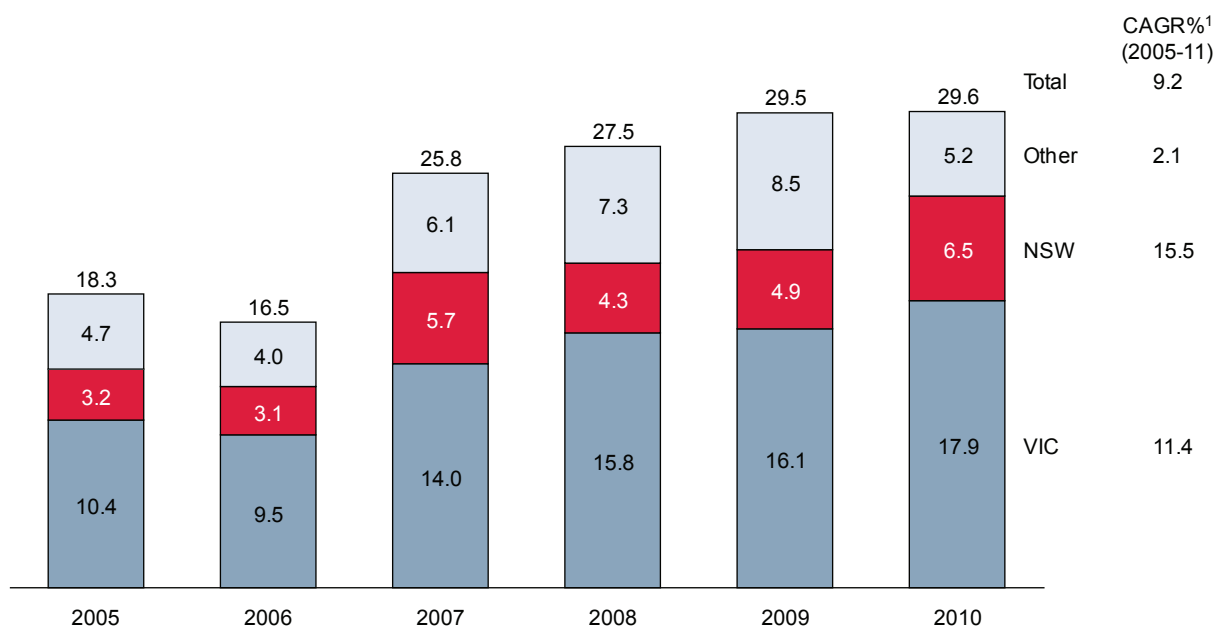


Source: NHMRC Grants Funding for the Current Decade - 2002 - 2011

In 2011, NSW received a similar quantum of funds from the Australian Research Council (ARC) for biological sciences as Victoria and Queensland. When examined on a per capita basis, the Australian Capital Territory received significantly more (\$175.4) than the national average (\$29.5). NSW (\$29.4) and Victoria (\$31.6) received close to the national average.

Between 2005 and 2010, NSW received the second highest quantum of funds through the Independent Research Institutes Infrastructure Support Scheme (IRIIS) (Exhibit 41). At \$0.90 per capita, NSW is below the national average (\$1.32 per capita) and receives less than Victoria (\$3.20 per capita) and Western Australia (\$1.60 per capita). However, cumulative average growth for NSW is higher than the national average, and funding to NSW has doubled since 2005.

Exhibit 41: Independent Research Institutes Infrastructure Support Scheme (IRIIS) funding for Australian medical research institutes, A\$m, 2005 to 2011



Note: 1. Compound Annual Growth Rate
Source: IRIIS

Between 2009 and 2011, NSW received the largest quantum of research block funding provided to universities. Note that these figures include funding to all research areas. On a per capita basis, NSW is at the national average for this source of infrastructure funds. NSW growth in block funding (10.4%) is higher than the national average (9.2%).

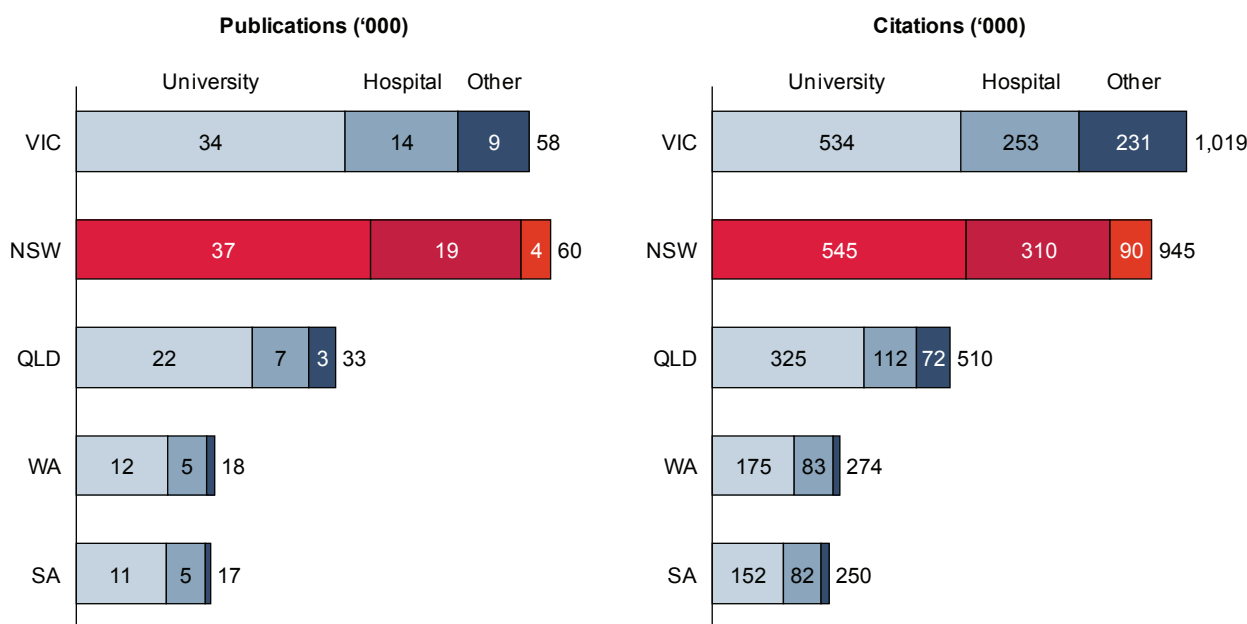
Research Activity and Outputs

Research activity and outputs have been measured by the number of research applications to NSW public health organisation Human Research Ethics Committees (HREC), publication and citation rates and the number of clinical trial notifications to the Therapeutic Goods Administration (TGA).

In the 2010-11 financial year 1545 research applications were submitted to NSW public health organisation HRECs. The number of research applications has grown by 6.5% since 2007.

Despite receiving less research funding, NSW produced the highest number of health and medical research publications (2001 – 2011) than other states (Exhibit 42). Citations can be used as a measure of research quality, as more influential research is cited by others. On this measure, Victoria is slightly ahead of NSW.

Exhibit 42: Number of health and medical research publications and citations by state, 2001-02 to 2010-11



Source: Thomson Reuters

While universities have the greatest publication output, medical research institutes produce publications with a higher citation rate (Exhibit 43). This pattern is consistent across Victoria, NSW and Queensland.

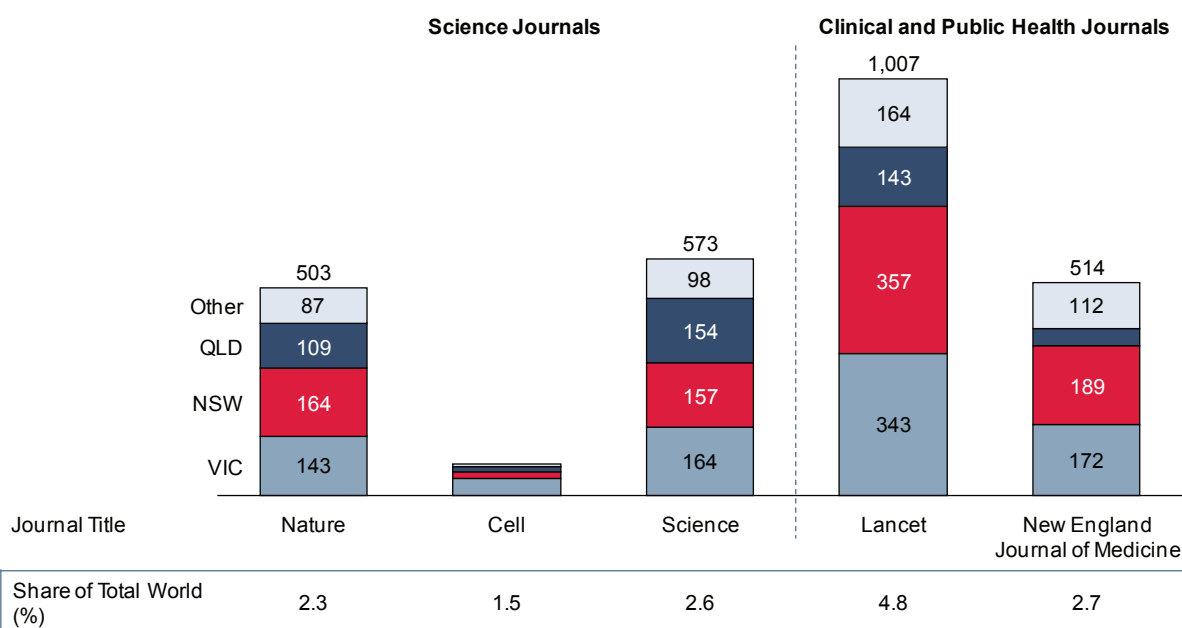
Between 2001 and 2010, NSW and Victoria had the highest number of articles appearing in key international journals (Exhibit 44).

Exhibit 43: Citations per health and medical research related publications, by research sector (%), 2001-02 to 2010-11



Note: Citations total reflects some double counting if publication has been written by more than one research entity
Source: Thomson Reuters

Exhibit 44: Number of NSW publications in key journals, 2001-02 to 2010-11



Source: Thomson Reuters

Although Australia has just 0.3% of the world’s population, our share of publications in these journals ranges between 1.5% and 4.8%, with better performance in clinically focused journals. This statistic reinforces two findings from previous health and medical research reviews: Australia has a comparative advantage in conducting high quality health and medical research due to our highly educated population and advanced health system; and Australia can achieve additional impact by focusing on niches which do not require the scale provided to countries with large populations (such as the USA in 2011, China and India in 2050).

Research Organisations

Nationally, the bulk of health and medical research is performed by universities. NSW has 11 universities and their NHMRC grants and total funding is close to the national average, although the rate of growth in funding for NSW universities is higher than the national average.

NSW and Victoria have a higher number of medical research institutes than other states. However, over the past decade, medical research institutes in NSW have received significantly fewer NHMRC grants and less total funding than those in Victoria. The growth in funding for medical

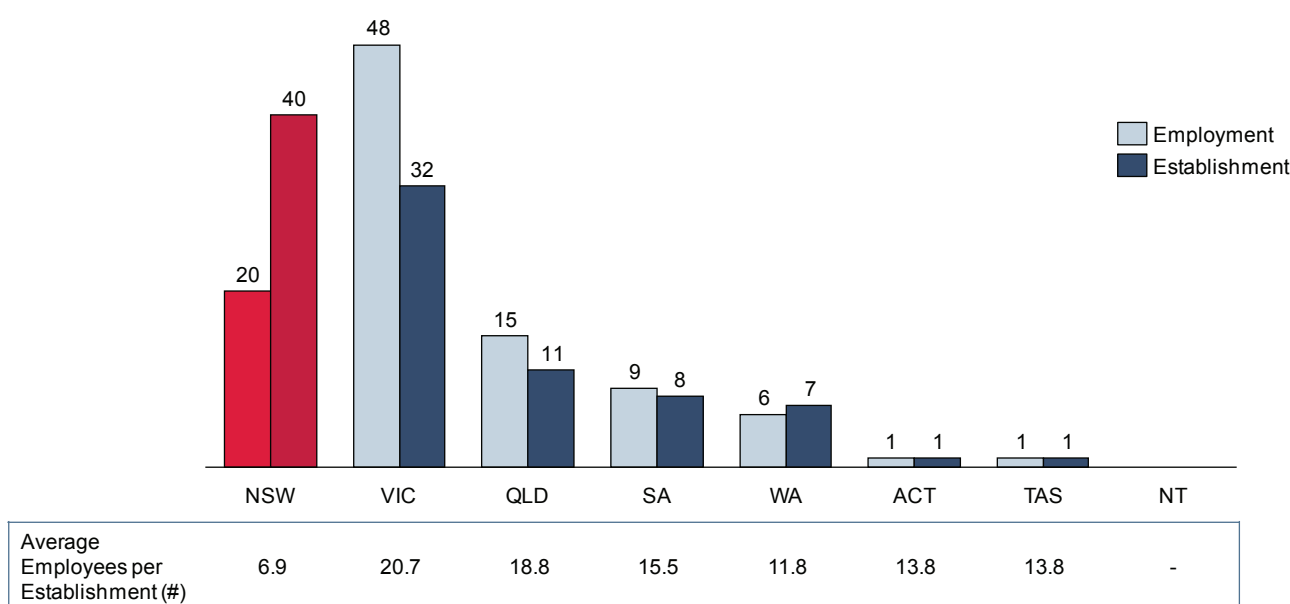
research institutes based in NSW between 2002 and 2011 was less than the national average. Seven out of the top 10 medical research institute recipients of NHMRC funding in 2011 are based in Victoria, and for NSW, only the Garvan Institute and the Victor Chang Cardiac Research Institute are in the top 10.

A significant amount of research is undertaken in NSW public health organisations. Although NHMRC funding to hospitals has decreased by approximately 18% since 2002 (due in part to an increased number of grants being administered by affiliated universities), the number of research projects undertaken in NSW public health organisations has grown by 6.5% since 2007.

Commercial Success

In 2011, NSW had the largest number of listed biotechnology firms and total biotechnology firms in the country. Many of these are very small, with an average of only seven employees per establishment, which is the lowest in Australia (Exhibit 45). Larger biotechnology firms appear to be located in Victoria and Queensland. Employment in biotechnology companies over the last 6 years appears to be stable across all states.

Exhibit 45: Australian distribution of biotechnology employment and establishments, %, 2011

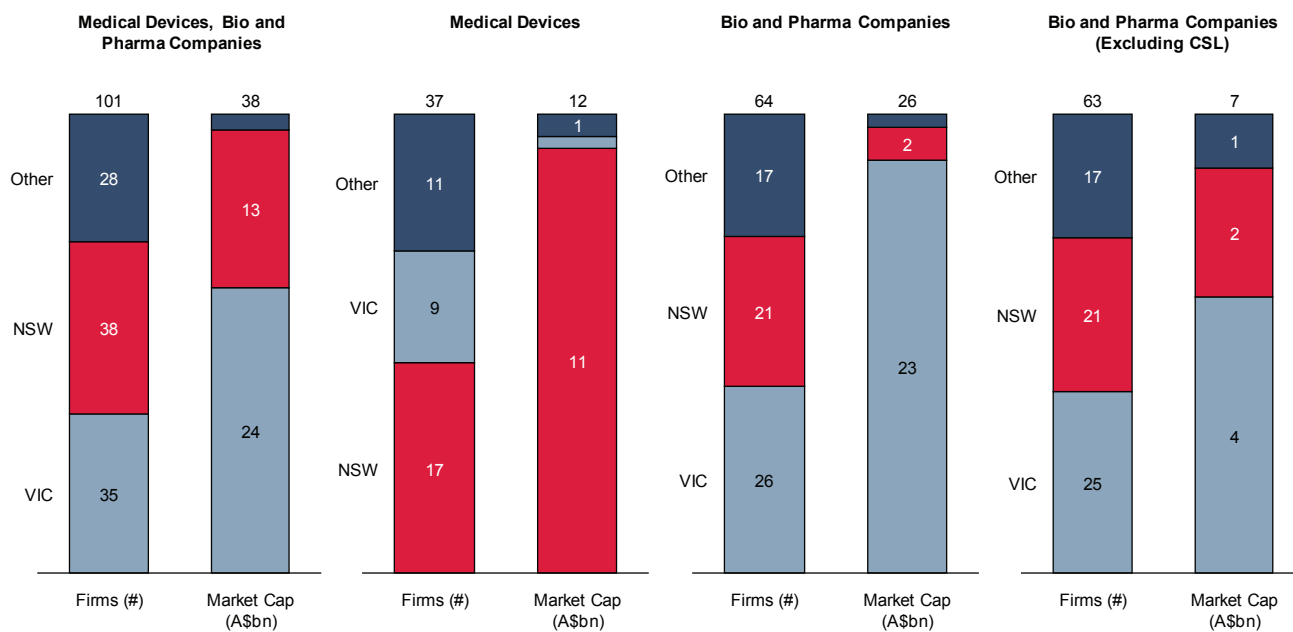


Source: BIS World

Australian biotechnology industry revenue has grown by approximately 4.5% per annum between the 2001-02 and 2010-11 financial years. In the third quarter of the 2010-11 financial year, 101 life science indexed companies had a total market capitalisation of A\$38.1billion. Victorian

companies have greater commercial success overall; however, NSW is particularly strong in medical devices (Exhibit 46).

Exhibit 46: Number of life science indexed companies, by market capitalisation, A\$m, January – March 2010-11



Source: PWC Bioforum June 2011

Victoria's strong performance is in part due to CSL (formerly the Commonwealth Serum Laboratories which was privatised in 1994). When CSL is excluded from the analysis of biotechnology and pharmaceutical companies, Victorian companies' market capitalisation drops to A\$4billion compared to A\$1.85billion in NSW.

Research Strengths

While not definitive, two perspectives on research strengths were examined: analysis of excellence in universities data and success in NHMRC funding.

According to the Excellence in Research Australia (ERA) 2010 National Report, there are several fields of research where universities in NSW are on the world stage (Exhibit 47).

Exhibit 47: NSW universities Excellence in Research Australia (ERA) evaluations

ERA 2010 Medical and Biological Sciences – NSW plus Top Performing Universities (2 Digit FoR Code)										
	Charles Stuart University	Macquarie University	Southern Cross University	University of New England	University of New South Wales	University of Newcastle	University of Sydney	University of Technology Sydney	University of Western Sydney	University of Wollongong
Medical and Health Sciences	1	2	1	2	5	4	5	2	2	3
Medical and Health Sciences	1	3	2	1	3	3	4	3	3	3
Biological Sciences	3	5	1	2	5	4	3	3	3	3

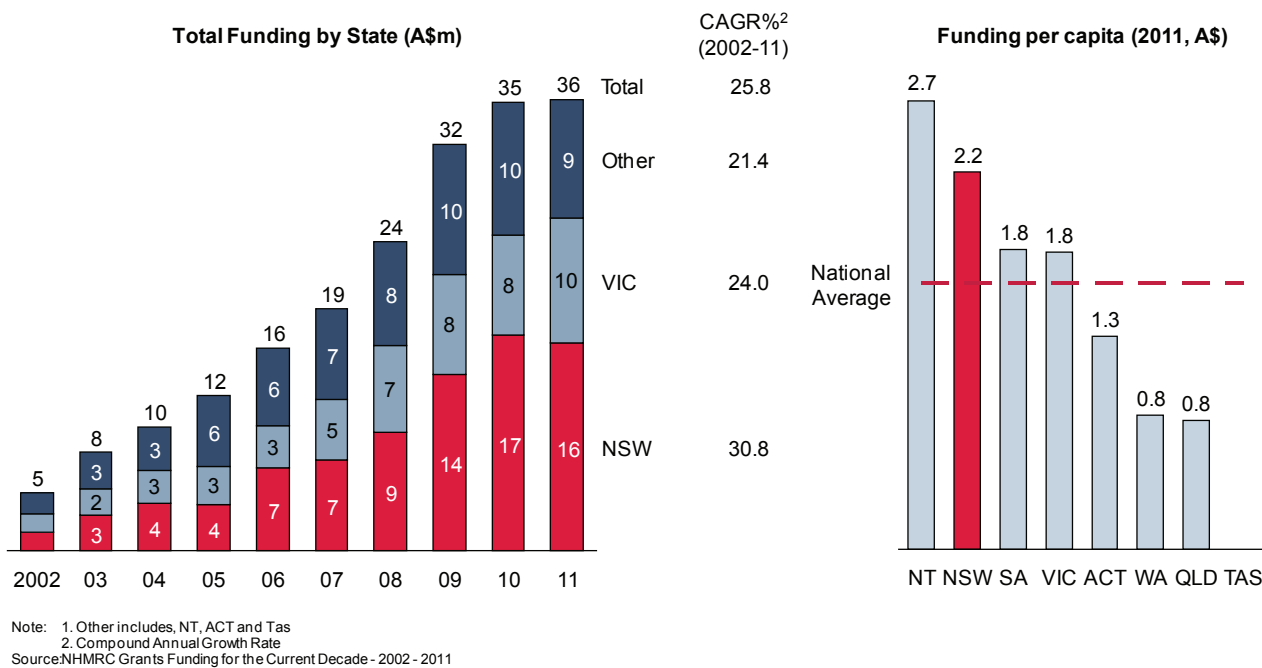
ERA 2010 Medical and Biological Sciences – NSW plus Top Performing Universities (4 Digit FoR Code)										
	Charles Stuart University	Macquarie University	Southern Cross University	University of New England	University of New South Wales	University of Newcastle	University of Sydney	University of Technology Sydney	University of Western Sydney	University of Wollongong
Medical Biomechemistry and Metabolomics							4			
Cardiovascular Medicine and Haematology					5	5	5			
Clinical Sciences	1	2			5	3	5	3	2	3
Complementary and Alternative Medicine										
Dentistry							3			
Human Movement and Sports Science					5	3	4			3
Immunology					5	5	4			
Medical Microbiology					3	1	4			
Neuro Sciences		3			4	3	4		2	1
Nursing	2		3			3	2	4	3	
Nutrition and Dietetics						2	5			3
Oncology and Carcinogenesis					4	5	5			
Ophthalmology and Optometry					3		5			
Paediatrics and Reproductive Medicine					1	3	2			
Pharmacology and Pharmaceutical Sciences	1				4	4	3			
Medical Physiology					4	3	4			
Public Health and Health Services		2		1	3	3	4	2	1	1

ERA Ranking	Definition
1	Well below world standard
2	Below world standard
3	At world standard
4	Above world standard
5	Well above world standard

Source: Excellence in Research for Australia (ERA) Initiative

NHMRC funding to NSW is at, or below, the national average spend per capita for all categories of research with the exception of health services research, where NSW receives 48% of the total allocation (Exhibit 48). This is a small but emerging field: the proportion of NHMRC health services research funding has risen from 1% of total funding in 2001 to 5% in 2010.

Exhibit 48: National Health and Medical Research Council (NHMRC) funding by research area – health services research, A\$m, 2002-11



APPENDIX 3

Individuals and groups who participated in the first consultation phase

1. Phase 1 Consultations

Individual interviews

Professor Bruce Dowton*	Dowton Consulting International Inc.
Professor Margaret Harding*	University of New South Wales
Professor Mary O’Kane*	NSW Chief Scientist and Engineer
Professor John Shine*	Garvan Institute of Medical Research
Hon Ron Phillips*	Sydney Breast Clinic
Ms Elizabeth Carr*	Macular Degeneration Foundation
Mr Mike Hirshorn	Four Hats Capital
Dr Anna Lavelle	AusBiotech
Dr Christine Bennett*	University of Notre Dame
Professor Stephen Leeder*	Menzies Centre for Health Policy, University of Sydney
Professor Penny Hawe	Population Health Research Initiative of Canada
Professor David Currow	Cancer Institute NSW
Ms Jane Halton	Department of Health and Ageing
Professor Warwick Anderson	National Health and Medical Research Council
Mr Graeme Head	Department of Health and Ageing
Professor Andrew Wells	Australian Research Council
Ms Patricia Kelly	Department of Innovation, Industry, Science & Research
Hon. Mark Butler	Minister for Mental Health and Ageing
Mr Doron Ben-Meir	Commercialisation Australia
Professor Don Iverson*	University of Wollongong
Professor Richard Head	Director, Preventative Health Flagship
Mr Neville Stevens	Cooperative Research Centres
Dr Chris Roberts	Cochlear
Mr Alex Harvey	Macquarie Bank

*Member of NSW Health and Medical Research Strategic Review Advisory Committee

Group interviews

University Deputy and Pro Vice Chancellors

Professor Mike Calford	University of Newcastle
Professor Jill Trehwella	University of Sydney
Professor Attila Brungs	University of Technology
Professor Les Field	University of New South Wales
Professor Margaret Harding	University of New South Wales
Professor Jim Piper	Macquarie University
Professor Andrew Cheetham	University of Western Sydney
Professor Judy Raper	University of Wollongong
Professor Sue Thomas	Charles Sturt University
Professor Annabelle Duncan	University of New England

Professor Neal Ryan	Southern Cross University
Professor Thomas Martin	Australian Catholic University

Research Australia

Dr Christine Bennett	University of Notre Dame
Ms Elizabeth Foley	Research Australia
Ms Rebecca James	Research Australia

NSW Health Senior Executive Forum

Ms Amanda Larkin	South Western Sydney LHD
Mr Chris Crawford	Northern New South Wales LHD
Mr Danny O'Connor	Western Sydney LHD
Ms Elizabeth Koff	Sydney Children's Hospitals Network
Ms Lyn Weir	Greater West LHD
Mr Matthew Daly	Northern Clinical Support Cluster
Mr Matthew Hanrahan	Central Coast LHD
Dr Maxwell Alexander	Southern NSW LHD
Mr Mike Wallace	South Western Sydney LHD
Mr Nigel Lyons	Northern Clinical Support Cluster
Mr Robert Rust	Health Infrastructure NSW
Professor Steven Boyages	Clinical Education and Training Institute
Mr Steven Rubic	St Vincents and Mater Health Sydney
Mr Stewart Dowrick	Mid North Coast LHD
Mr Stuart Riley	Far West LHD
Ms Susan Weisser	Murrumbidgee LHD
Dr Teresa Anderson	Sydney LHD
Ms Vicki Taylor	Central Coast LHD
Mr Terry Clout	South Eastern Sydney LHD
Ms Kim Browne	Hunter New England LHD

Westmead Research Hub

Professor Tony Cunningham	Westmead Millennium Institute
Ms Helene Abouyanni	Western Sydney LHD
Professor Chris Cowell	Kids Research Institute
Mr Mark Dado	Westmead Millennium Institute
Ms Karyn Joyner	Kids Research Institute
Mr Ralph Mitchell	Children's Medical Research Institute
Professor Roger Reddel	Children's Medical Research Institute
Professor Stephen Leeder	Western Sydney LHD

Medical Research Institutes

Professor Tony Cunningham	Westmead Millennium Institute
Mr Nick Pearce	Centenary Institute
Professor Maree Gleeson	Hunter Medical Research Institute
Professor Robert Baxter	Kolling Institute for Medical Research
Professor Peter Schofield	Prince of Wales Medical Research Institute
Professor David Handelsman	ANZAC Research Institute
Dr David Andrews	Woolcock Institute
Professor Roger Reddel	Children's Medical Research Institute
Associate Professor Vlado Perkovic	George Institute

Professor Bob Graham	Victor Chang Cardiac Research Institute
Dr Peter Wejbor	Children's Cancer Institute Australia
Professor Paul Seale	Woolcock Institute

Pharmaceutical companies

Ms Deborah Monk	Medicines Australia
Ms Cheryl Townsend	Merck Serono Australia
Ms Kerry Strydom	Quintiles
Mr Mitch Kirkham	Novartis
Ms Kathy Connell	Janssen
Dr David Lloyd	Southern start Research
Ms Jane Frost	Pfizer
Ms Pip Palmer	Merck Sharp & Dohme
Mr Charles Kent	Roche Products
Ms Lynn Montgomery	Roche Products

Sydney Children's Hospitals Network

Professor Bruce Robinson	Kolling Institute of Medical Research, University of Sydney
Professor Peter Smith	Faculty of Medicine, University of NSW
Professor Chris Cowell	The Children's Hospital at Westmead
Mr Roger Corbett	Sydney Children's Hospitals Network
Ms Elizabeth Koff	Sydney Children's Hospitals Network

Population Health Research

Professor Bruce Armstrong	School of Public Health, University of Sydney
Professor Ian Caterson	Boden Institute of Obesity, Nutrition & Exercise, University of Sydney
Professor Michael Farrell	National Drug & Alcohol Research Centre
Professor Mark Harris	Centre for Primary Health Care & Equity, University of New South Wales
Professor Guy Marks	Woolcock Institute of Medical Research, University of Sydney
Professor David Cooper	Kirby Centre
Dr Greg Stewart	Population Health, Western Transition
Associate Professor John Wiggers	Northern Transition Organisation & Hunter Medical Research Institute
Professor Andrew Penman	Cancer Council NSW
Ms Catherine Holliday	Cancer Council NSW
Dr Vitali Sinchenko	Centre for Infectious Diseases Microbiology, Westmead Hospital
Professor Annemarie Hennessy	School of Medicine, University of Western Sydney
Ms Julieanne Mitchell	National Heart Foundation
Professor Simon Chapman	School of Public Health, University of Sydney
Professor Raina MacIntyre	School of Public Health & Community Medicine, University of New South Wales
Professor Rob Sanson-Fisher	Health Behaviour Research Centre, Newcastle Uni
Associate Professor Kate Conigrave	Addiction Medicine, Central Clinical School, University of Sydney
Professor Susan Thompson	Healthy Built Environment Program, University of NSW
Professor David Perkins	Australian Rural health Research Collaboration, University of Sydney
Professor Peter McIntyre	National Centre for Immunisation Research & Surveillance, University of Sydney
Professor Stephen Lord	Neuroscience Research Australia
Ms Kim Browne	Northern Transition Organisation & Hunter Medical Research Institute
Professor Wayne Smith	Environmental Branch
Ms Gabriel Moore	Public Health Association of Australia

Health Services Research

Professor Jane Hall	Centre for Health Economics, University of Technology Sydney
Professor Ken Hillman	Simpson Centre for Health Research, University of NSW
Professor George Rubin	South Eastern Sydney LHD
Associate Professor Stephen Jan	George Institute
Dr James Gillespie	Menzies Centre for Health Policy
Professor Mary Chiarella	Sydney Nursing School, University of Sydney
Professor Sally Redman	Sax Institute
Professor Jeffery Braithwaite	Australian Institute of Health Innovation, University of NSW
Professor Clifford Hughes	Clinical Excellence Commission
Ms Julieanne Mitchell	National Heart Foundation

Biotechnology and medical device companies

Dr Anna Lavelle	AusBiotech
Mr Arthur Brandwood	Brandwood Medical
Mr David Irving	Australian Red Cross
Dr Greg Roger	Australian Surgical Design & Manufacture
Mr David Radford	Nanosonics
Dr Alan Robertson	Pharmaxis
Dr Ron Weinberger	Nanosonics
Mr Alan Liddle	Immune System Therapeutics
Mr Stephen Pattillo	AusBiotech
Mr Victor Sklandnev	AI Medics
Mr Neil Anderson	Waterfall Commercialisation Group [please check list
Mr Hamish Hawthorn	ATP Innovations

Early stage commercialisation

Dr David Fisher	Brandon Capital – Medical Research Commercialisation Fund
Dr Chris Nave	Brandon Capital – Medical Research Commercialisation Fund
Dr Deborah Kuchler	Biomed North Limited
Mr Warren Bailey	Enterprise Partnerships & Commercialisation
Dr Fiona Cameron	University of Western Sydney
Mr Gavin Dixon	University of Wollongong
Mr Randal Leeb-du Toit	University of Sydney
Dr Jim Henderson	NewSouth Innovations

NSW Research Networks

Mr Peter Neilson	Children's Cancer Cytoskeleton Network
Professor Peter Gunning	Children's Cancer Cytoskeleton Network
Professor Carol Pollock	Cardiovascular Research Network
Ms Kristina Cabala	Cardiovascular Research Network
Dr Stephanie Williams	Australia and New Zealand Spinal Cord Injury Network
Mr Duncan Wallace	Australia and New Zealand Spinal Cord Injury Network
Professor Bernie Tuch	Stem Cell Network
Dr Lilian Jackson	Stem Cell Network
Dr Ruth Hadfield	Multiple Sclerosis Research Network
Mr Jeremy Wright	Multiple Sclerosis Research Network

Information Communication Technology

Mr Suresh Rao	Sax Institute
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Dr Michelle Cretikos	NSW Department of Health
Ms Helen Wadell	NSW Department of Health
Dr Ian Gibson	Intersect

Philanthropic organisations

Mr Mike Wilson	Juvenile Diabetes Research Foundation
Ms Julie White	Macquarie Group Foundation
Dr Noel Chambers	Research Australia Philanthropy
Ms Elizabeth Foley	Research Australia Philanthropy
Mr Andrew Giles	Garvan Foundation
Mr Eric d'Indy	Westmead Medical Research Foundation

Research Organisations

Professor Gordon Parker	Black Dog Institute
Professor Ian Hickie	Brain and Mind Institute
Professor David Cooper	Kirby Institute (University of NSW)
Mr Daren Draganic	Kirby Institute (University of NSW)
Professor Miles Davenport	Centre for Vascular Research
Professor Michael Barton	Ingham Health Research Institute
Professor Frank Billson	Save Sight Institute
Professor Mark Willcox	Vision Cooperative Research Centre (CRC)
Professor Chris Cowell	Kids Research Institute, The Children's Hospital at Westmead
Mr Philip Bert	Asthma and Airways CRC
Professor Nico van Zandwijk	Bernie Banton Institute (Asbestos Disease Research Institute)
Professor Michelle Haber	Children's Cancer Institute Australia

On-line Submissions

	Name	Organisation
1	Mr Neil Anderson	Waterfall Commercialisation Group
2	Professor Vaughan Carr	UNSW and Schizophrenia Research Institute
3	Mr Michael Lodge	Mental Health and Drug and Alcohol Office, NSW Health
4	Ms Julie Charlton	St Vincent's Hospital
5	Associate Professor Howard Gurney	Westmead Hospital, Medical Oncology
6	Mr Philip Cunningham	Institute of Virology
7	Mr Peter Todaro	Multicultural Health Communication Service
8	Ms Maureen Ryan	Royal Prince Alfred Hospital
9	Dr Craig Godfrey	Western Sydney LHD
10	Anonymous	Anonymous
11	Professor Henry Brodaty	University of NSW
12	Professor Terry Campbell	University of NSW
13	Dr Roy Byun	South Western Sydney LHD
14	Associate Professor Tony Lower	Australian Centre for Agricultural Health & Safety
15	Ms Kay Tennant	Health Reform Transition Organisation Western
16	Dr Lionel Hebbard	University of Sydney, Storr Liver Unit
17	Mr Paul van den Dolder	Illawarra Shoalhaven LHD
18	Professor Brian Draper	Prince of Wales Hospital
19	Associate Professor Jim Greenwood	University of NSW Rural Clinical School and School of Psychiatry
20	Dr Julie Redfern	The University of Sydney; The George Institute
21	Dr Anne M Jensen	University of Oxford, UK
22	Dr Lisa Keay	The George Institute for Global Health and University of Sydney
23	Dr Katie de Luca	Chiropractor

24	Mr Alex Fielding	Private Practice
25	Dr Dennis Richards	Richards Chiropractic
26	Professor William L Ledger	School of Women's and Children's Health
27	Dr Larissa McGlade	Carers Advisors Association of NSW
28	Mrs Sharon Clark	The Tweed Hospital
29	Mr William Bonney	Black Dog Institute
30	Professor Hans Peter Dietz	Sydney Medical School Nepean
31	Mr Andrew Giddy	Nucleus Network
32	Ms Lea Kirkwood	NSW Health
33	Dr Jason Parkes	Boambee Chiropractor
34	Dr Anthony Zehetner	Central Coast Local Health Network
35	Ms Margaret Murphy	SWAHS
36	Dr Michael Roche	University of Technology Sydney
37	Professor Sharon McKinley	University of Technology Sydney and Northern Sydney LHD
38	Dr Chris Nave	Medical Research Commercialisation Fund / Brandon Capital Partners
39	Professor Rodney J. Scott	Hunter New England Health Service and the University of Newcastle
40	Ms Pip Palmer	Merck Sharp and Dohme (Australia)
41	Scientia Professor Philip Mitchell AM	University of New South Wales (School of Psychiatry)
42	Dr Sarah Dennis	University of New South Wales
43	Dr Jacqueline Close	Prince of Wales Hospital and Neuroscience Research Australia
44	Dr Bryce Conrad	Reliance Medical Centre
45	Dr Vlasios Brakoulias	Nepean Blue Mountains Health Service
46	Professor Robyn Ward	University of NSW
47	Professor Nicholas Hawkins	University of NSW
48	Professor Levon Khachigian	Centre for Vascular Research
49	Ms Jessica Stewart	Centre for Aboriginal Health, NSW Health
50	Ms Nicole Raschke	Northern NSW & Mid North Coast LHDs
51	Mr Andrew Thirlwell	Lupus Association of NSW Inc
52	Professor Caroline Homer	University of Technology Sydney and St George Hospital
53	Dr Bryce Vissel	Garvan Institute
54	Dr Anne Vertigan	Hunter New England Allied Health
55	Children's Cancer Institute Australia	Children's Cancer Institute Australia
56	Ms Caron Bowen	NSW Department of Health
57	Ms Elizabeth Kepreotes	John Hunter Children's Hospital
58	Ms Patricia O'Riordan	NSW Department of Health
59	Ms Caitlin van Holst Pellekaan	NHMRC Clinical Trials Centre, University of Sydney
60	Associate Professor Stacy M. Carter	University of Sydney
61	Dr Guy Lyons	University of Sydney/Royal Prince Alfred Hospital
62	Dr Margaret Smith	Kolling Institute
63	Mr John Dodson	University of Sydney Physiology
64	Dr Kristof Mikes-Liu	University of Sydney
65	Professor J. P. Seale	Woolcock Institute of Medical Research
66	Professor John Fletcher	University of Sydney, Westmead Hospital
67	Dr Tony Roscioli	School of Women and Children's Health, University of Sydney
68	Dr Robert Loblay	University of Sydney & RPAH
69	Dr Mark Graham	Children's Medical Research Institute
70	Professor Philip O'Connell	Westmead Hospital
71	Dr Ian Seppelt	Department of Intensive Care Medicine, Nepean Hospital
72	Professor David Hunter	University of Sydney
73	Dr Lowenna Holt	Garvan Institute of Medical Research
74	Associate Professor Geraldine O'Neill	The Kids Research Institute, Children's Hospital at Westmead

75	Dr Robert Welachinger	Westmead Millennium Institute
76	Dr Robert Tynan	Sydney University School of Medicine
77	Dr Kim Moran-Jones	Garvan Institute of Medical Research
78	Dr Kharen Doyle	Garvan Institute of Medical Research
79	Dr Greg Sutherland	University of Sydney
80	Associate Professor William Phillips	University of Sydney
81	Dr Antony Harding	University of Sydney
82	Dr Ewan Millar	Garvan Institute and St George Hospital
83	Dr Bevan Hokin	Sydney Adventist Hospital Pathology
84	Professor Ewa M. Goldys	MQ BioFocus Research Centre, Macquarie University
85	Dr Georgia Frangioudakis	Garvan Institute
86	Dr Anne Grunseit	Prevention Research Collaboration, University of Sydney
87	Dr Amina Khambalia	University of Sydney
88	Associate Professor Anthony Harris	University of Sydney
89	Dr Tri Phan	Garvan Institute
90	Dr Pamela Johnson	University of Sydney
91	Dr Heather Lee	Garvan Institute
92	Mrs April Davis	Westmead Millennium Institute
93	Ms Kristina Cabala	NSW Cardiovascular Research Network
94	Mr Philip Pogson	The Leading Partnership
95	Dr Spring Cooper	University of Sydney
96	Professor Phyllis Butow	Psycho-Oncology Co-operative Research Group and Centre for Medical Psychology and Evidence-based Medicine, University of Sydney
97	Dr Camille Raynes-Greenow	University of Sydney
98	Dr John Grigg	University of Sydney
99	Professor David Allen	University of Sydney
100	Dr Stuart Fraser	University of Sydney, Discipline of Physiology
101	Professor Judy Simpson	University of Sydney
102	Dr Jaiprakash Gupta	South East Sydney Local Hospital District
103	Dr Hunter Watt	Agency for Clinical Innovation
104	Dr Michelle Cretikos	NSW Department of Health
105	Dr Jennifer Smith-Merry	University of Sydney
106	Ms Belinda Platzler	Garvan Institute of Medical Research
107	Professor Andrew Cheetham	University of Western Sydney
108	Dr. William E. Hughes	The Garvan Institute of Medical Research
109	Ms Elizabeth Foley	Research Australia
110	Dr Colin Sutton	NHMRC Clinical Trials Centre
111	Dr Helen Achat	Epidemiology, former Sydney West Area Health Service
112	Professor Chris Rissel	University of Sydney
113	Professor Barry J Allen	St George Hospital
114	Dr David Lloyd	Southern Star Research Pty Ltd
115	Dr Peter Middleton	Westmead Hospital
116	Mr Tony Thirlwell OAM	Heart Foundation
117	Dr Rosalie Pockett	The University of Sydney
118	Associate Professor Kate Curtis	Sydney Nursing School and St George Hospital
119	Dr Lisa Askie	Australian New Zealand Clinical Trials Registry
120	Professor Christopher Levi	Hunter New England Health; University of Newcastle; Hunter Medical Research Institute
121	Mr Christopher Oliver	Blackmores Ltd
122	Mr Chris Williams	The George Institute, School of Public Health, University of Sydney
123	Ms Christiane Klinner	Centre for Values, Ethics and Law in Medicine, University of Sydney

124	Ms Sue Baker-Finch	Illawarra Health and Medical Research Institute
125	Professor Ian Caterson	Boden Institute of Obesity Nutrition Exercise and Eating Disorders, University of Sydney
126	R Yeow	Medical student
127	Associate Professor John B. Ziegler	Sydney Children's Hospital
128	Dr Helen Englert	Westmead Hospital
129	Mr Alan Brotherton	ACON
130	Professor Norbert Berend	Woolcock Institute of Medical Research
131	Associate Professor Janette Burgess	The Woolcock Institute of Medical Research
132	Mr Daron Green	Agricultural and Life Sciences Group
133	Ms Eui-Soo Choi	NSW Health
134	Dr Gilles J. Guillemin	University of New South Wales
135	Ms Julie Tall	Population Health Western Transition Organisation
136	Professor Robert Graham	Victor Chang Cardiac Research Institute
137	Professor Jane Hall	Centre for Health Economics Research UTS
138	Ms Sally Josh	Southern NSW LHD
139	Ms Sally Crossing AM	Cancer Voices NSW
140	Professor Nicholas Manolios	Westmead Hospital
141	Professor Roger Daly	Garvan Institute of Medical Research
142	Professor Richard Epstein	St Vincent's Hospital
143	Dr Rajesh Puranik	University of Sydney
144	Associate Professor Peter Williamson	Personal Submission
145	Dr Gerard Cudmore	Amgen Australia
146	Professor Trevor Biden	Garvan Institute of Medical Research
147	Professor Paul Haber	RPA Hospital/University of Sydney
148	Dr Anna deFazio	Westmead Hospital / Westmead Millennium Institute
149	Dr Catherine Holliday	Cancer Council NSW
150	Professor Rob Herbert	The George Institute for Global Health
151	Dr Diana Adams	Macarthur Cancer Therapy Centre
152	Dr Lorraine Chantrill	SSW LHD Department of Oncology Clinical Trials
153	Ms Patricia Boow	Department of Health
154	Mr Paul Field	Bio-Link Australia Pty. Ltd.
155	Mr Gerald Edmunds	Brain Foundation
156	Dr Naomi Conlon	Belrose Chiropractic
157	Dr Louise Stone	Centre for Values, Ethics and the Law in Medicine, University of Sydney
158	Ms Lesley King	Prevention Research Collaboration, University of Sydney
159	Professor Peter R Schofield	Neuroscience Research Australia
160	Dr Stephanie Williams	Spinal Cord Injury Network
161	Professor Leslie White	NSW Department of Health
162	Ms Christina Dryden	NSW Department of Health
163	Mr Gabriel Moore	The Public Health Association NSW Branch
164	Professor Michael Barton	Ingham Institute
165	Ms Tegan Cox	Northern Sydney LHD and University of Sydney Incorporating the Kolling Institute of Medical Research
166	Mrs Sue Browbank	Illawarra Shoalhaven LHD
167	Ms Carla Saunders	General Practice NSW
168	Dr Rod MacQueen	The Lyndon Community, and the Murdi Paaki Drug and Alcohol Network
169	Ms Clare Walsh	The Heart Research Institute
170	Professor Sally Redman	The Sax Institute
171	Ms Joanna Knott	Spinal Cure Australia
172	Professor Mark Harris	Centre for Primary Health Care and Equity, UNSW

173 Mr Terry Clout	South Eastern Sydney LHD
174 Mr Mark Lacey	Central Coast LHD
175 Mr Rob Cummins	Macular Degeneration Foundation
176 Mr Will Delaat	Pharmaceuticals Industry Council
177 Professor Janet Hiller	Australian Catholic University
178 The George Institute for Global Health	The George Institute for Global Health
179 Professor Julie Byles	Australian Association of Gerontology, NSW Division
180 Ms Elizabeth Koff	Sydney Children's Hospitals Network
181 Associate Professor Amanda Sainsbury-Salis	Garvan Institute of Medical Research
182 Professor Andrew McLachlan	University of Sydney and Concord Hospital
183 Associate Professor Gideon Caplan	Prince of Wales Hospital
184 Professor Marion Haas	Health Services Research Association of Australia and New Zealand
185 Dr Anna Lavelle	AusBiotech Limited
186 Professor David Currow	Cancer Institute NSW
187 Professor Maree Gleeson	Hunter Medical Research Institute
188 Ms Helen Waddell	Public Health Intelligence Unit, Centre for Epidemiology & Research, Population Health Division, NSW Department of Health
189 Dr Kristina Cook	UNSW Lowy Cancer Research Centre
190 Mr Rod Cook	NSW Department of Health
191 Professor Chris Cowell	Sydney Children's Hospitals Network
192 Mr Jeremy Wright	MS Research Australia
193 Associate Professor Geoffrey Morgan	Northern LHD / University Centre for Rural Health - North Coast
194 Professor Mike Calford	The University of Newcastle
195 Associate Professor Rosalie Viney	Australian Health Economics Society
196 Professor William O. Tarnow-Mordi	NHMRC Clinical Trials Centre, University of Sydney and Westmead Hospital
197 Mr Hamish Hawthorn	ATP Innovations Pty Ltd
198 Dr Nick Pearce	Centenary Institute of Cancer Medicine and Cell Biology
199 Ms Kim Russell-Cooper	NHMRC clinical Trials Centre
200 Professor Jill Trehwella	University of Sydney
201 Ms Anne Trimmer	Medical Technology Association of Australia
202 Mr Michael Lodge	NSW Ministry of Health
203 Professor Annemarie Hennessy	University of Western Sydney School of Medicine
204 Professor Maree Gleeson	Hunter Medical Research Institute
205 Dr Anne Vertigan	Hunter New England Allied Health

2. Phase 2 Submissions

1	Associate Professor Kate Curtis	Sydney Nursing School/St George Hospital
2	Professor Guy Marks	Woolcock Institute of Medical Research
3	Dr Nicole Gerrand	Hunter New England LHD
4	Mr Andrew Giddy	Nucleus Network
5	Associate Professor John B. Ziegler	Sydney Children's Hospital
6	Professor Matthew Kiernan	University of New South Wales
7	Professor Ralph Nanan	Sydney Medical School Nepean, The University of Sydney
8	Professor Hans Peter Dietz	University of Sydney
9	Dr Angela Todd	Kolling Institute of Medical Research
10	Professor Richard Epstein	St Vincent's Hospital, Sydney
11	Professor Levon Khachigian	Centre for Vascular Research
12	Ms Lesley Brydon	Painaustralia
13	Mr Matthew Allen	22 Linton St, Baulkham Hills, NSW, 2153
14	Dr Margaret Lesjak	Population Health, Far West LHD
15	Mr Steven Rubic	St Vincent's Research Precinct - on behalf of the St Vincent's Research Community
16	Dr Kelvin Hopper	Biofusion Capital Pty Ltd
17	Dr David Fisher	Brandon Capital Partners
18	Professor Vaughan Carr	Schizophrenia Research Institute
19	Professor Michael Barton	Ingham Institute and SWS LHD
20	Associate Professor Catherine Dean	Macquarie University
21	Ms Sue Baker-Finch	Illawarra Health and Medical Research Institute
22	Professor David A Cooper and Mr Philip Cunningham	Institute of Virology (joint venture of St Vincent's Centre for Applied Medical Research and Kirby Institute)
23	Sydney LHD	Sydney LHD
24	Dr Peter Middleton	Westmead Hospital , Westmead Millennium Institute; Sydney Medical School
25	Ms Helene Abouyanni	Western Sydney LHD
26	Professor Barry J Allen	Universities of Western Sydney, Sydney, NSW and Wollongong
27	Dr Judith Trotman	Concord Hospital, University of Sydney
28	Professor James Colebatch	Prince of Wales Hospital
29	Professor Ron Grunstein	NHMRC CCRE for Interdisciplinary Sleep Health (CIRUS)
30	Mr W. Bruce Kirkpatrick	Meniere's Research Fund Inc.
31	Ms Lisa Ochiel	South Eastern Sydney LHD
32	Professor Sally Redman	The Sax Institute
33	Mr Ben Artup	Penrith Business Alliance
34	Ms Patricia O'Riordan	Mental Health and Drug and Alcohol Office, NSW Department of Health
35	Dr Jim Henderson	NewSouth Innovations Pty Ltd
36	Dr Lisa Askie	Australian New Zealand Clinical Trials Registry
37	Professor Judy Raper	University of Wollongong
38	Professor Mike Calford	University of Newcastle
39	Dr Louise Dunn	Australian Society for Medical Research
40	Ms Anne Trimmer	Medical Technology Association of Australia
41	Dr Siun Gallagher	Ambulance Service of NSW
42	Dr Deborah Kuchler	Biomed North Limited
43	Roche Products Pty Limited	Roche Products Pty Limited
44	Professor Cheryl Jones	The University of Sydney and The Children's Hospital at Westmead
45	Professor John Simes	NHMRC Clinical Trials Centre
46	Professor Les White	NSW Health

47	Ms Caron Bowen	NSW Department of Health
48	Ms Elizabeth Koff	Sydney Children's Hospitals Network
49	Professor Ian Caterson	Boden Institute, University of Sydney
50	Mr Jeremy Wright and Dr Ruth Hadfield	Multiple Sclerosis Research Australia
51	Ms Tegan Cox	Northern Sydney LHD and the University of Sydney incorporating the Kolling Institute of Medical Research
52	Dr Alison Butt	National Breast Cancer Foundation
53	Ms Deborah Monk	Medicines Australia
54	Mr Peter Neilson	Oncology Children's Foundation
55	Professor Chris Cowell	Sydney Children's Hospitals Network and Kids Research Institute
56	Professor Maree Gleeson	Hunter Medical Research Institute
57	Centenary Institute of Cancer Medicine and Cell Biology	Centenary Institute of Cancer Medicine and Cell Biology
58	Amgen Australia Pty Ltd	Amgen Australia Pty Ltd
59	Professor Christopher Levi	John Hunter Hospital
60	Mr Darryl O'Donnell	AIDS/Infectious Diseases Branch, NSW Department of Health
61	Department of Trade and Investment, Regional Infrastructure and Services	Department of Trade and Investment, Regional Infrastructure and Services
62	Dr Alastair Robertson	CSIRO
63	Dr Fiona Cameron	S7 group of Sydney Universities
64	Ms Elizabeth Foley	Research Australia
65	Garvan Institute of Medical Research	Garvan Institute of Medical Research
66	Health System Support, NSW Department of Health	Health System Support, NSW Department of Health
67	Dr Helen Monks	-
68	Ms Jennie King	Central Coast LHD
69	Mr Jim McBride and Dr Warren Kaplan	Bioinformatics at Garvan
70	Professor Tony Cunningham	Westmead Research Hub
71	Mr Mike Wilson	Juvenile Diabetes Research Foundation
72	Ms Kristina Cabala	NSW Cardiovascular Research Network
73	NSW Medical Research Institutes	NSW Medical Research Institutes
74	NSW Treasury	NSW Treasury
75	Professor Andrew Cheetham	University of Western Sydney
76	Professor Attila Brungs	University of Technology, Sydney
77	Professor Mike Calford	NSW Deputy and Pro Vice-Chancellors' Research Committee
78	Professor Richard Henry and Dr Michael Spence	UNSW and University of Sydney
79	Professor Tony Cunningham	Westmead Millennium Institute for Medical Research
80	Professor Roger Reddel	Children's Medical Research Institute
81	Dr Leslie Bolitho	Royal Australasian College of Physicians
82	Professor Stephen Myers	Southern Cross University
83	Mr Tony Thirlwell	National Heart Foundation of Australia – NSW Division
84	Professor Herma Buttner	Australian Nuclear Science and Technology Organisation (ANSTO)
85	Ms Catherine Briffa	Member of the public
86	Dr Catherine Foley	CSIRO
87	Professor John Mattick	Institute for Molecular Bioscience, University of Queensland
88	Professor Terry Campbell	St Vincent's Hospital and UNSW Medicine

3. Phase 3 Submissions

	Name	Organisation
1	Professor Paul Haber	Royal Prince Alfred Hospital, Sydney LHD
2	Professor Shih-chang Wang	University of Sydney and Westmead Hospital
3	Professor Jane Hall	CHERE, University of Technology Sydney
4	Dr Lorraine Chantrill	Sydney South West LHD Oncology Clinical Trials
5	Mr Philip Pogson	The Leading Partnership Pty Ltd
6	Associate Professor Rupert Leong	Sydney LHD Concord Hospital
7	Mr Paul Field	Bio-Link Australia Pty Ltd
8	Dr Angela Todd	Kolling Institute of Medical Research/University of Sydney
9	Dr Kate Jackson	NSW Older People's Mental Health Policy Unit, Mental Health and Drug and Alcohol Office, NSW Ministry of Health
10	Dr Alastair Robertson	CSIRO
11	Mr Chris Oliver	Blackmores Ltd
12	Professor Michael Barton	Ingham Institute of Applied Medical Research
13	Professor Perminder Sachdev	University of New South Wales and Neuropsychiatric Institute, Prince of Wales Hospital
14	Mr Danny O'Connor	Western Sydney LHD
15	Professor Peter McCluskey	Save Sight Institute
16	Dr Louise Dunn	Australian Society for Medical Research
17	Professor Peter Gunning	University of New South Wales
18	Ms Jane Carpenter	University of Sydney
19	Professor David Cooper and Mr Philip Cunningham	Institute of Virology (joint Centre of St Vincent's Hospital and Kirby Institute UNSW)
20	Mr Steven Rubic	St Vincent's Research Precinct - on behalf of the St Vincent's Research community
21	Professor Michael Heinrich	Southern Cross University
22	Dr Hunter Watt	Agency For Clinical Innovation
23	Professor Allan Spigelman	UNSW St Vincent's Clinical School
24	Ms Jennie King	Central Coast LHD
25	Ms Emma Evans	Southern Cross University
26	Professor Sally Redman	Sax Institute
27	Professor Wilf Yeo	Director Medicine and Emergency Illawarra and Shoalhaven LHD, Deputy Director Illawarra Health and Medical Research Institute
28	Ms Kristina Cabala	NSW Cardiovascular Research Network
29	Professor Ronald Grunstein	Professor of Sleep Medicine, University of Sydney and RPA Hospital
30	Ms Elizabeth Foley	Research Australia
31	Ms Sue Baker-Finch	Illawarra Health and Medical Research Institute
32	Professor Richard Epstein	St Vincent's Hospital and Garvan Institute for Medical Research
33	Professor Maree Gleeson	Hunter Medical Research Institute
34	Professor Kenneth Walsh	Illawarra and Shoalhaven LHD and University of Wollongong
35	Dr Lilian Jackson	Australian Diabetes Council
36	Professor Andrew Cheetham	University of Western Sydney
37	Ms Larissa Zimmerman	National Financial Fitness Pty Ltd
38	Ms Anne Trimmer	Medical Technology Association of Australia
39	Mr Adrian Bootes	ARCS Australia Ltd
40	Associate Professor David Perkins	Australian Rural Health Research Collaboration
41	Mr Tony Thirlwell	Heart Foundation
42	Professor Stephen N Hunyor	University of Sydney at Kolling Institute, Royal North Shore Hospital

43	Associate Professor Alessandro Zagami	Institute of Neurological Sciences Prince of Wales Hospital
44	Hunter Medical Research Institute Public Health Program	Hunter Medical Research Institute
45	Professor Brett Garner	University of Wollongong
46	Professor David Currow	Cancer Institute NSW
47	Professor John Simes	NHMRC Clinical Trials Centre
48	Ms Catherine Holliday	Cancer Council NSW
49	Ms Lisa Ochiel	South Eastern Sydney LHD
50	Dr Sandy Muecke	Ambulance Service of NSW
51	Professor Stephen Colagiuri	Boden Institute of Obesity, Nutrition, Exercise and Eating Disorders
52	Professor Chris Cowell	Sydney Children's Hospitals Network
53	Dr Anna Lavelle	AusBiotech Ltd
54	Stephen Geoffrey Braye	Hunter Area Pathology Service and Pathology North
55	Professor Sandy Middleton	Australian Catholic University and St Vincent's and Mater Health Sydney
56	Professor Christine Clarke	University of Sydney
57	Ms Michele Murphy	Finance Branch, NSW Ministry of Health
58	Dr Jeff Armitstead	ResMed Ltd
59	Ms Merela Ghazal	South Western Sydney LHD
60	Mr David Henderson	UniQuest Pty Ltd
61	NSW Medical Research Institutes	NSW MRIs
62	Professor Jane Dahlstrom	ACT Pathology and Australian National University
63	Dr Michael Spence, Professor Caroline McMillen and Professor Richard Henry	University of Sydney, University of Newcastle and University of New South Wales
64	Professor Mike Calford	NSW Deputy and Pro Vice-Chancellors' (Research) Committee
65	Professor Annabelle Duncan	University of New England
66	Dr Teresa Anderson	Sydney LHD
67	Mr Bruce Kirkpatrick	Meniere's Research Fund Inc.
68	Ms Sara Pantzer	Amgen Australia Pty Ltd
69	Dr Deborah Kuchler	Office of Commercialisation, NSW Health
70	Dr Emma Webster	Clinical Education and Training Institute, Rural Directorate
71	Professor Tailoi Chan-Ling	University of Sydney
72	Ms Isobel Hubbard	Hunter New England Health
73	Professor Tony Cunningham, Professor Roger Reddel, Professor Chris Cowell, Professor Stephen Leeder and Professor David Harris	Westmead Research Hub
74	Professor David James	Garvan Institute
75	Professor Attila Brungs	University of Technology, Sydney
76	Dr Bruce Sanderson	Central Coast LHD
77	Mr Mark Paterson	NSW Department of Trade and Investment , Regional Infrastructure and Services
78	Ms Carmen Parter	Centre for Aboriginal Health, NSW Ministry of Health

APPENDIX 4

Acronyms and Abbreviations

ABS	Australian Bureau of Statistics
ACI	Agency for Clinical Innovation
ARC	Australian Research Council
CBIG	Capacity Building Infrastructure Grants Program
CEC	Clinical Excellence Commission
CINSW	Cancer Institute New South Wales
CTAG	Clinical Trials Action Group
DPC	Department of Premier and Cabinet
DTIRIS	Department of Trade and Investment, Regional Infrastructure and Services
ERA	Excellence in Research Australia
HETI	Health Education and Training Institute
HMR	Health and Medical Research
HR	Human Resources
HREC	Human Research Ethics Committee
IRIIS	Independent Research Institutes Infrastructure Support Scheme
IT	Information technology
LHD	LHD
MoH	Ministry of Health
MRCF	Medical Research Commercialisation Fund
MRI	Medical Research Institute
MRSP	Medical Research Support Program
NHMRC	National Health and Medical Research Council
NHS	National Health Service (UK)
NIH	National Institutes of Health (US Department of Health and Human Services)
NSW	New South Wales
OMR	Office for Medical Research
RIBG	Research Infrastructure Block Grants Scheme
SRE	Sustainable Research Excellence
SSA	Site specific assessment
TGA	Therapeutic Goods Administration
TTR	Teaching, training and research

APPENDIX 5

Definitions

Biomedical research

Laboratory research with the goal of understanding cell functioning at the molecular, cellular, organ system and whole body levels, including development of tools and techniques to advance this goal; and developing new therapies that improve health or quality of life of individuals, up to the point of human trials.

Bioinformatics

The use of computer science, mathematics, and information theory to model and analyse biological systems, especially systems involving genetic material.

Biostatistics

Biostatistics is the application of statistical techniques to scientific research in health-related fields, including medicine and public health. Biostatisticians play essential roles in designing studies, using statistics to analyse data and creating methods to solve research problems.

Clinical research

Research for the purpose of improving the diagnosis and treatment of disease (including rehabilitation and palliation) and injury and improving the health and quality of life of individuals.

Clinical trials

Set of procedures in medical research conducted to allow safety (or more specifically, information about adverse drug reactions and adverse effects of other treatments) and efficacy data to be collected for health interventions (e.g., drugs, diagnostics, devices, therapy protocols).

Commercialisation

Commercialisation is the process of patenting research findings, forming companies to own patents, and creating drugs, devices or therapies that generate revenue, jobs and improve health outcomes.

Health policy research

Concerns itself with how health policy is created, the critical appraisal of the evidence that is adduced in the formation of policy, the application of research evidence from clinical medicine and public health in the formation of policy, the behavioural and political science elements in the policy process, what enables, and what militates against, the formulation of quality policy and its implementation. It also includes evaluation research that concentrates upon assessing the achievements, failures, costs and consequences of health policy.

Health services research

Multi-disciplinary research activity with an implicit objective of improving the health services patients receive. Thus it is an area of applied rather than 'basic' research - it uses theories of human behaviour from contributing disciplines, along with evidence from the medical sciences, to generate and test hypotheses about the delivery of health care. The focus on services is what distinguishes health services research from other multi-disciplinary health research activities.

Infrastructure

Infrastructure for research consists of the essential institutional resources underpinning research that are not covered by research grants.

Innovation

Innovation is the application of fresh ideas that enable a business to better compete in the future. Such ideas can include any new or significantly improved goods or services and operational processes or managerial processes.

Population health research

Investigation and analysis of factors that influence the health status of groups or whole populations, as well as the testing and evaluation of policies and interventions to improve population health outcomes.

Translational research

Refers to the process of using the findings of research to produce innovation in health care settings. This includes: treatment and intervention development (T1); testing efficacy and effectiveness of treatments and interventions (T2); and dissemination and implementation research for system-wide change (T3).

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