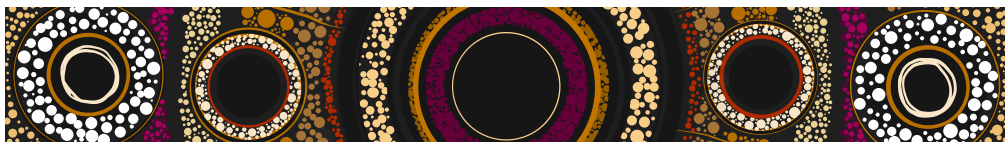


Better together

A strategic plan for research in the ACT health system 2022–2030

High value research driving optimal health and wellbeing for all





Acknowledgment of Country

ACT Health Directorate acknowledges the Traditional Custodians of the land, the Ngunnawal people. The Directorate respects their continuing culture and connections to the land and the unique contributions they make to the life of this area. It also acknowledges and welcomes Aboriginal and Torres Strait Islander peoples who are part of the community we serve.

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Foreword



Research is vital in health. The improvements to people's lives delivered through research support the work of health professionals, services and systems. By fostering a learning health system, discoveries that advance knowledge and technologies, translate interventions and design system-wide models of care can improve health outcomes for all. Fundamentally, research improves our health, our wellbeing and our quality of life.

This strategy is for our dedicated frontline health workforce looking to innovate to deliver better outcomes for their patients. It's for researchers in the community and experts across our world-class university sector. Fostering and bringing together these strands of research delivers a more sustainable health care system, nurtures the creative brilliance of our health care workers and delivers better outcomes for Canberrans.

Better together: A strategic plan for research in the ACT health system 2022-2030 sets the ACT Government's vision for a vibrant, learning health system where research drives optimal health and wellbeing. Our aim is to deliver world-class research, better outcomes for consumers and sustainability. The Strategy sets out three strategic objectives and 10 accompanying strategic actions that the ACT Government will deliver with our partners across universities, health services and consumers to realise this vision.

This plan demonstrates the benefits of working together and has been developed through the collaborative efforts of a wide range of partners in the ACT's health system. I thank the ACT Health and Wellbeing Partnership Board's Research Working Group and the ACT Health Directorate's Centre for Health and Medical Research for its work leading the development of this plan.

I look forward to seeing the implementation of this Strategy and the continuous improvement of ACT healthcare policy, planning and delivery for our community.

Rachel Stephen-Smith MLA
Minister for Health
July 2022

Summary of vision, mission, objectives and actions



Vision

A vibrant, learning health system where research drives optimal health and wellbeing for all.

Mission

Our health system will, in partnership with the people of the ACT, use and generate high value research to optimise health and wellbeing, through continuously improved healthcare policy, planning and delivery.

Strategic objectives

Objective 1



The ACT health system becomes a learning health system

A continuously learning health system builds on real-time access to evidence to guide health protection, promotion, prevention and care while simultaneously capturing information about the consumer experience to improve policy, initiatives, services and health outcomes, built on effective partnerships between clinicians, consumers and other stakeholders, and a supportive culture. Such systems are efficient at translating research into practice because there are effective processes and staff employed to generate evidence, implement, monitor and evaluate.

Objective 2



ACT people have capacity to undertake high value research in the health system

This requires both development and support of staff and stakeholders and targeted recruitment to build research capabilities and collaborations, all the while ensuring diversity and sustainability to meet the future healthcare needs of the ACT.

Objective 3



ACT research infrastructure supports high value research

Investment in research includes investing in platform capabilities that enable research, funding strategically important projects, and ensuring a portfolio of staff have dedicated time for research generation, translation and implementation.



Strategic actions

Underpinning this plan are ten key actions that the ACT Government and its partners in the ACT health system will undertake to realise the strategic objectives.

Action 1



Self-determination and health equity

Affirm to be guided by the principles of self-determination and of equity in health and wellbeing outcomes for Aboriginal and Torres Strait Islander people and therefore develop and implement this plan only in consultation and partnership with Aboriginal and Torres Strait Islander communities and their leaders.

Action 4



Investment

Commit through strategic investment in projects, initiatives, people and infrastructure to supporting a consumer-centred, high-performing, integrated, sustainable health system: one that continuously improves by generating research and implementing it in the service of value-based healthcare.

Action 2



Responsiveness

Collaborate to establish research priorities derived from consumer and health system needs.

Action 5



Leadership

Collaborate to facilitate recruitment and joint management of clinician research leaders; including development of overarching Memorandums of Understanding and suitable instruments and governance for building research capacity in the ACT health system.

Action 3



Alignment

Collaborate to develop and implement aligned health research strategies in and for the ACT, with optimised research governance, leveraging capacity across the ACT health system.

Action 6



Performance

Commit to support a strong research culture through the support of dedicated research positions and the incorporation of research performance indicators at individual and organisational levels.



Action 7



Engagement

Evaluate the extent to which health consumers are engaged in research and collectively commit to increase this involvement through support for consumer and researcher development.

Action 9



Infrastructure gaps and barriers

Collaborate to audit the health research infrastructure assets of the ACT in order to assess the gaps, redundancies and organisational barriers to their development and use.

Action 8



Capacity-building gaps and barriers

Collaborate to audit and identify current gaps or bottlenecks in research support services and key disciplines, as a basis for strategic, coordinated capacity-building under this plan.

Action 10



Connections

Investigate the potential benefits and feasibility of a single ACT-wide research Hub, including both virtually and physically co-located research infrastructure assets, under joint governance.

Better together: A strategic plan for research in the ACT health system 2022-2030



Vision

A vibrant, learning health system where research drives optimal health and wellbeing for all.

Mission

Our health system will, in partnership with the people of the ACT, use and generate high value research to optimise health and wellbeing, through continuously improved healthcare policy, planning and delivery.

Purpose

This plan outlines the eight-year vision for the ACT Government and its partners to drive research which strengthens the health of our communities through a strategic approach to investment and collaboration.

Strengthening the health of our community refers broadly to the ACT community and communities in surrounding regions of NSW who are users of the ACT health system.

This plan acknowledges and recognises the important role of the social determinants of health, and the significance of research which occurs beyond the parameters of the health system – for example in the housing, education and justice sectors. Research that strengthens health is understood, for the purposes of this plan, as occurring predominantly within the health system. The plan views the system as including all the people, organisations and resources engaged in improving the health and wellbeing of these communities.

In order to achieve a strategic focus, this plan and the actions it advises concentrates on research occurring within a broadly defined health system, spanning pre-clinical or biomedical, clinical, translational, public, population and preventive health as well as health services research.

Strategic alignment

The plan supports the realisation of Strategic Goal 3 of the ACT Government's vision to deliver a person-centred health system outlined under [Accessible, Accountable and Sustainable: A Framework for the ACT Public Health System 2020-2030](#).

This research strategic plan aligns with the [ACT Government Wellbeing Framework](#) which provides a structure for understanding impact on the community's lived experiences and wellbeing. It aligns with the [ACT Preventive Health Plan](#) which supports enjoyment of the highest standards of health at every stage of life, and is informed by the [Territory-wide Health Services Plan](#) which aims to foster a health system supporting individuals and families to take a lead role in their health and healthcare.

It aligns with and is guided by the [ACT Aboriginal and Torres Strait Islander Agreement 2019-2028](#). This means that all elements of the plan are subject to meaningful consultation and partnership with the Aboriginal and Torres Strait Islander people of the ACT and their leaders.



Partnership approach

While this plan is owned by the ACT Government, the ACT Government alone cannot achieve the actions set in this plan without working in partnership with the whole ACT health system. As a result, this plan has been developed under the direction of the [ACT Health & Wellbeing Partnership Board](#).

The Partnership Board, established in 2018, supports the prioritisation and integration of efforts across the health education, research and service delivery systems in the ACT. Key stakeholders represented on the Partnership Board include the

ACT Health Directorate (ACTHD), Canberra Health Services (CHS), Calvary Public Hospital Bruce, Capital Health Network (the ACT Primary Health Network), the Australian National University (ANU), the University of Canberra and the ACT Healthcare Consumers' Association. Additional key stakeholders involved in research in the ACT health system include but are not limited to UNSW Canberra, the Australian Institute of Sport and the Canberra Institute of Technology.

The ACT Government alone cannot achieve the actions set in this plan without working in partnership with the whole ACT health system.



Rationale

It is critical that research undertaken in the ACT is of high value, where investment in research results in benefits to consumer and community health and wellbeing outcomes. Research can make the biggest difference and be of the highest value when it is strategic and aligned with overarching research priorities and consumer and health system needs. Impactful research efficiently leverages existing infrastructure and capacity and creates an enduring legacy leading to positive health outcomes. High value research therefore most readily arises in a shared ecosystem where partners align to drive research investment, innovation, translation, implementation and impact.

The health and wellbeing of our community is a high priority for the ACT Government. Obviously, research and evidence are a vital foundation of an effective health system. Less obvious, however, is the profoundly interconnected way in which partners in the ACT's health and medical research sector co-exist. Changes to one part of the system can have significant impacts on other parts of the system. Put simply, research is better when the various parts of the system work together. This is true in a range of ways – for example, when researchers from one organisation can use the research infrastructure or expertise in another organisation, meaning both the infrastructure and expertise is better utilised and researcher capacity is enhanced.

It is also true in terms of the vital connections between research and practice, where both can be enhanced by being informed by the other. It is also true simply in terms of workforce and consumer capacity and capability. A well informed and skilled workforce and consumer base leads to better health outcomes. Finally, there are the benefits of cross-pollination – where research teams can come together, sharing their expertise and varying perspectives for the benefit of the research.

Our community has a range of health needs that can be met or improved through a learning health system and engagement of our people in research to improve consumer and community outcomes, patient care, health systems, and policies that influence health. Like all health systems, the ACT health system faces many challenges and ongoing changes that can be better managed through well-aligned, high value research which focuses on consumer, community and system priorities. Strategic investment in research means investing in our people to better enable them to think and act effectively and creatively to solve our healthcare challenges. Supporting our people to be innovators through research drives a learning health system where enquiry leads to better health outcomes for our communities. It strengthens our workplaces and workforce through engaged and motivated staff.

Put simply, research is better when the various parts of the system work together.



Measuring success

Implementation of this strategic research plan can lead to a transformation of healthcare and prevention to provide each person in our communities with the best health outcomes, best experience, greatest choice, at the right time, in the right place, with access to the right team supported to make the best decisions. We aim to improve consumer and community engagement and knowledge of evidence-informed healthcare, ensure the research undertaken is of high value, and foster the organisational systems that will support a learning health system.

Successful implementation of the plan will be measured by how well we engage with consumers as partners to undertake health research. We must draw on clinical and academic leadership and collaborate with policymakers, agencies, researchers, consumers and funding bodies that have the capacity to lead innovation, build frameworks and maximise value for money invested in research. This creates a network of passionate people who share a vision for change and continuously build shared purpose, principles, and practice. This all must be built on the bedrock of high value research activities that demonstrate value to consumers and providers, and ensure high quality, equitable and accessible healthcare.

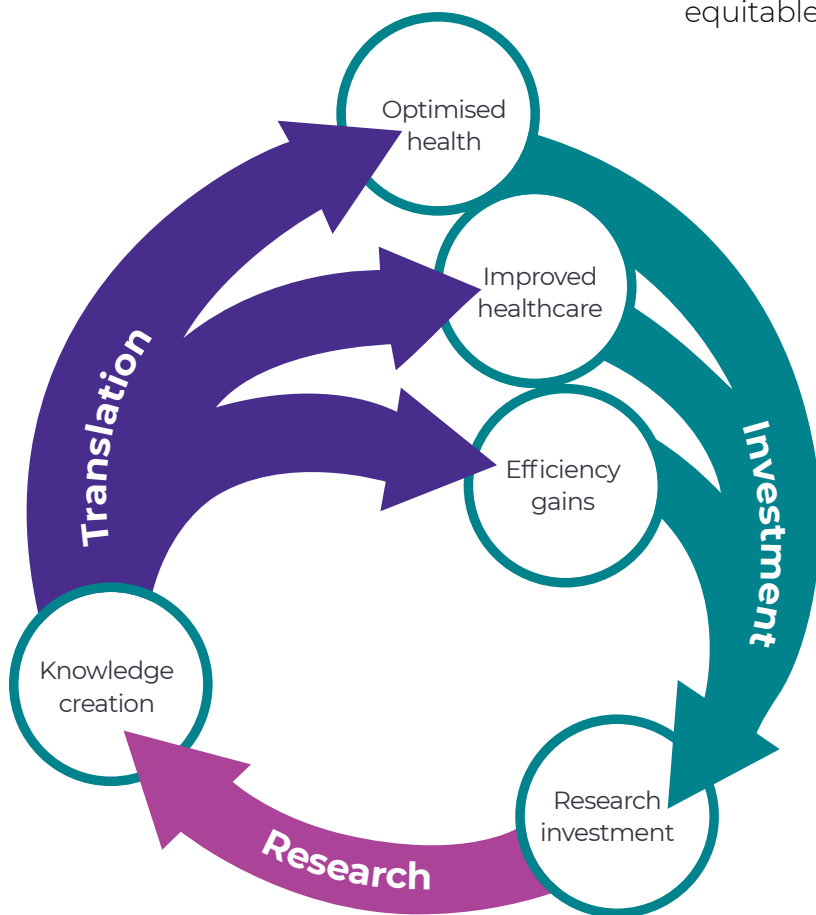


Figure 1: A learning health system

Strategic objectives

Underpinning this plan are three key strategic objectives. Each will be a focus of investment, developed in partnership with consumers and the community and aligned with broader strategies of the ACT Government. The three objectives mutually reinforce each other, articulating goals and strategies for the ACT as a health ecosystem, driven by its people and their knowledge, and supported by their workplaces and other infrastructure.

Objective 1: The ACT health system becomes a learning health system

A continuously learning health system builds on real-time access to evidence to guide health protection, promotion, prevention and care while simultaneously capturing information about the consumer experience to improve policy, initiatives, services and health outcomes, built on effective partnerships between clinicians, consumers and other stakeholders, and a supportive culture. Such systems are efficient at translating research into practice because there are effective processes and staff employed to generate evidence, implement, monitor and evaluate.

Objective 2: ACT people have capacity to undertake high value research in the health system

This requires both development and support of staff and stakeholders and targeted recruitment to build research capabilities and collaborations, all the while ensuring diversity and sustainability to meet the future healthcare needs of the ACT.

Objective 3: ACT research infrastructure supports high value research

Investment in research includes investing in platform capabilities that enable research, funding strategically important projects, and ensuring a portfolio of staff have dedicated time for research generation, translation and implementation.

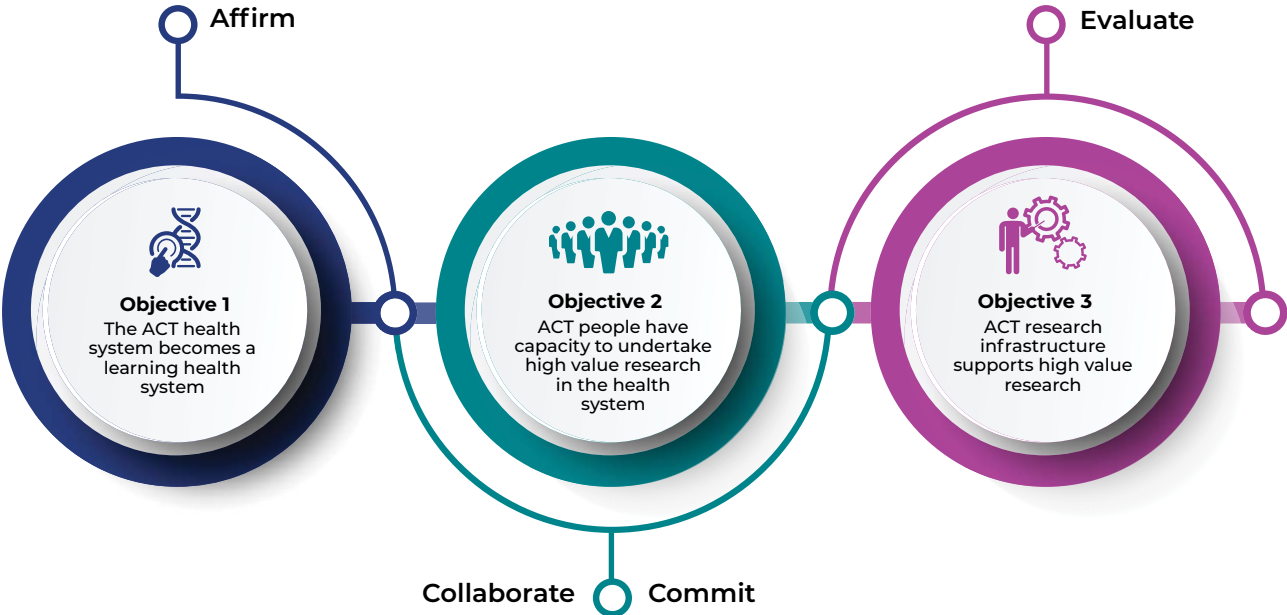


Figure 2: Strategic objectives



Objective 1: The ACT health system becomes a learning health system

The ACT has a health system that comprises healthcare services, health protection and promotion programs, policies, actions and strategies, funded by the ACT and Commonwealth governments and by consumers and insurers.

It is bound together by the expertise and behaviours of diverse researchers and health professionals, many affiliated with our university partners, and by the circumstances, needs and actions of the people of the ACT and the surrounding regions of NSW.

Research in the ACT health system is a force to inform the whole, so that it continuously responds to the needs of its people, moving through cycles of monitoring, evaluation and research to generate new knowledge, translating this knowledge into practice.

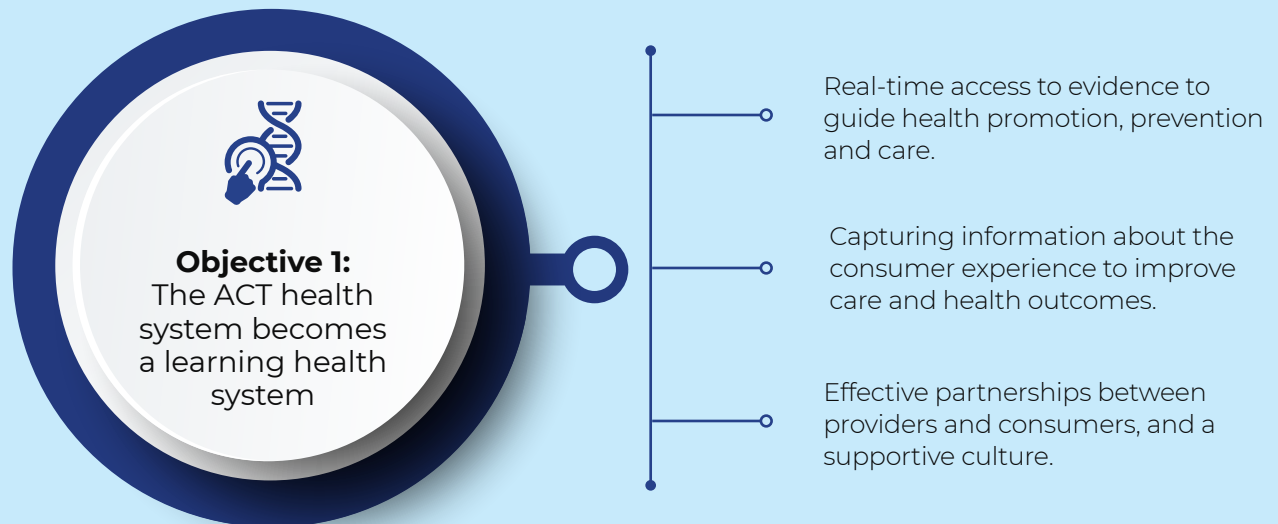


Figure 3. Fostering a learning health system

Key capabilities

Components of a learning health system include:

- a trained and capable workforce, with dedicated time to focus on generating, analysing and implementing data
- data systems amenable to mobilising routine data for decision making as part of continuous improvement; and generation of new questions and innovative mechanisms for answering these
- collaborative teams including consumers, clinicians, researchers, administrators, in tertiary and primary care and cross-sector settings
- resourcing and embedding of expertise to catalyse research and implementation within different components of the health sector
- implementation platforms for communication; adaptation of new ideas; talent investment; and scale-up beyond ACT
- a system for determining and registering priorities and for proposing improvements from community and other stakeholders.



A learning health system is open and respectful to the needs of its community. In particular, it must be guided by a commitment to equity and self-determination as evidenced through improved health outcomes for Aboriginal and Torres Strait Islander peoples, increased capacity of Aboriginal and Torres Strait Islander researchers in the ACT, and increased direction of research affecting Aboriginal and Torres Strait Islander peoples by those communities and those researchers. A position statement of commitment to equity and self-determination as evidenced through improved health outcomes for Aboriginal and Torres Strait Islanders will be included as a living addendum to this plan.

Just as a learning health system must be responsive to and incorporate the impact of exogenous shocks such as pandemics and bushfires, or changes to technology such as the introduction of a digital health record, it must also be responsive to the ever-expanding and increasing understanding of the lived experiences of its consumers.

This plan will use a series of living addendums as a method to respond over time as new issues emerge and the context changes. This series of addendums, added to over time as required, also provides an opportunity to define terms and consider issues in depth.

Scaling up and investing in new initiatives to drive a learning health system will support the health system to improve and deliver great outcomes for the people of the ACT by being better aligned and more capable. It will also enable the ACT to exploit its distinctive advantage as an Australian jurisdiction. The ACT is small but diverse and has relatively few institutional moving parts. Its health system could be mobilised to give insights into the whole population, and the totality of people's health experience. Uniquely in Australia, the ACT could aspire to understand and address the full mix of social, environmental, clinical and biological factors that impact on the health and wellbeing of its people.

Related actions



Action 1

Self-determination
and health equity



Action 3

Alignment



Action 2

Responsiveness



Action 4

Investment

Case studies

IN ACTION: ACT Health and Wellbeing Partnership Board

ACT Health and Wellbeing Partnership Board is a collaboration of key ACT health organisations from primary to tertiary care, University of Canberra and the Australian National University, and the Healthcare Consumers Association.

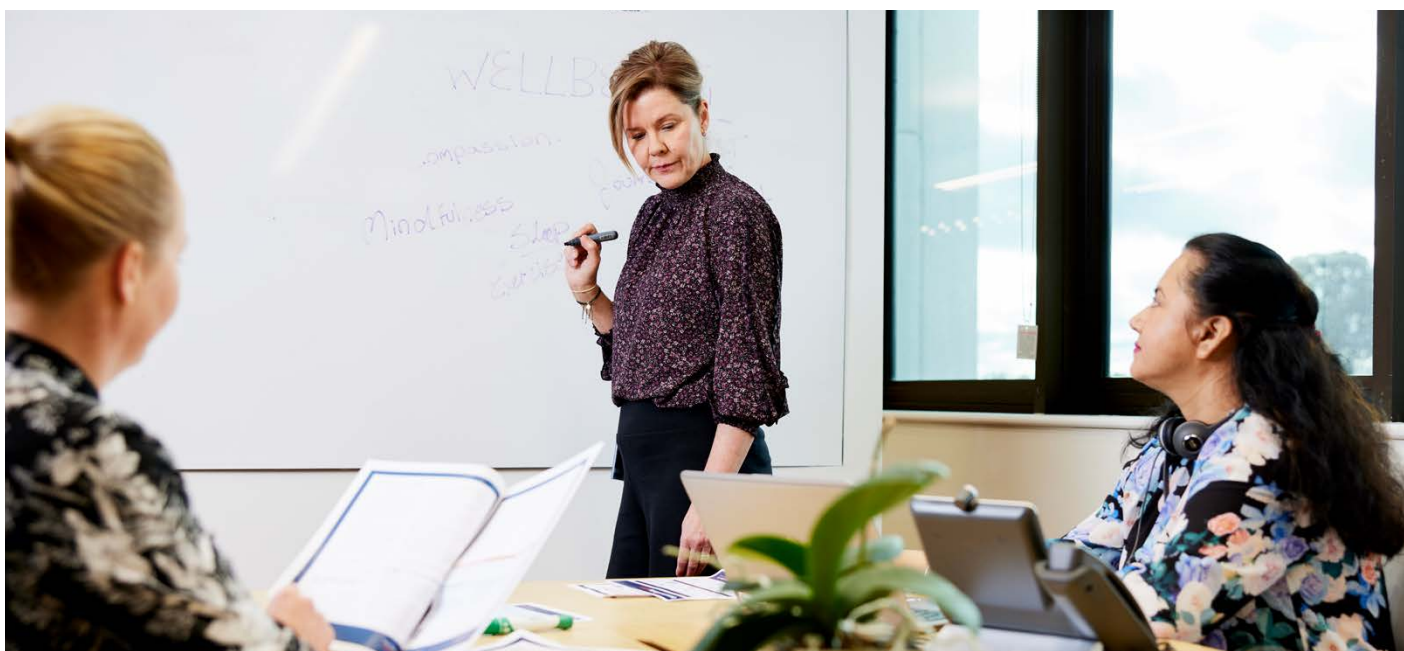
The Partnership Board offers the opportunity for alignment of research priorities and initiatives, and a system for providing high level oversight over priority-setting, and systems to embed monitoring, evaluation, research to generate and implement new knowledge.

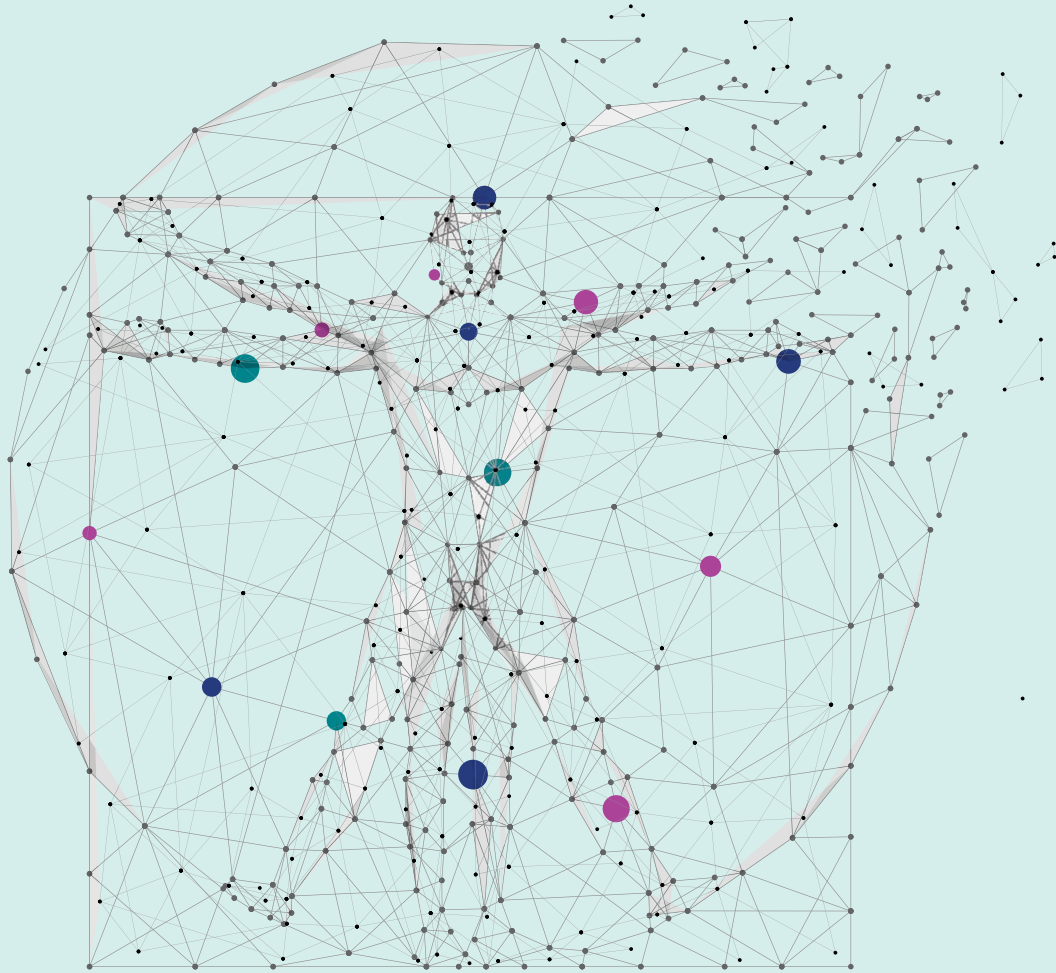
INTO THE FUTURE: Partnerships for research translation

A range of collaborative initiatives are emerging across the ACT aiming to enable research translation to harness knowledge and evidence through consumer, university and health service collaborations. Examples include HealthANSWERS 2.0, the Integrated Care Project, and the Rural Regional and Remote Clinical Trial Enabling Program.

These collaborations are designed to enable research to generate health and healthcare improvement and

have the potential to make significant positive changes, such as providing an implementation platform and capacity development for translational research that extends from the ACT to regional NSW, improved integration across the service system to support seamless transitions of care as patients and carers move through primary, community, acute, outpatient and residential health care settings, and nesting the delivery of cutting edge clinical trial personalised treatments across our region.





Objective 2: ACT people have capacity to undertake high value research in the health system

This plan intends to enable the people of the ACT to generate the knowledge through research that a learning health system needs, and without which it cannot deliver improved health and wellbeing.

This objective recognises the roles in research of all who work in the system, whether employed by ACT health services or by partner organisations. It recognises that ACT health system workplaces are crucial to training health professionals, and that research training is integral to delivery of advanced healthcare.

Finally, it recognises that the capacity of consumers must be supported so they can participate effectively in priority setting, governance, design and management of research programs.

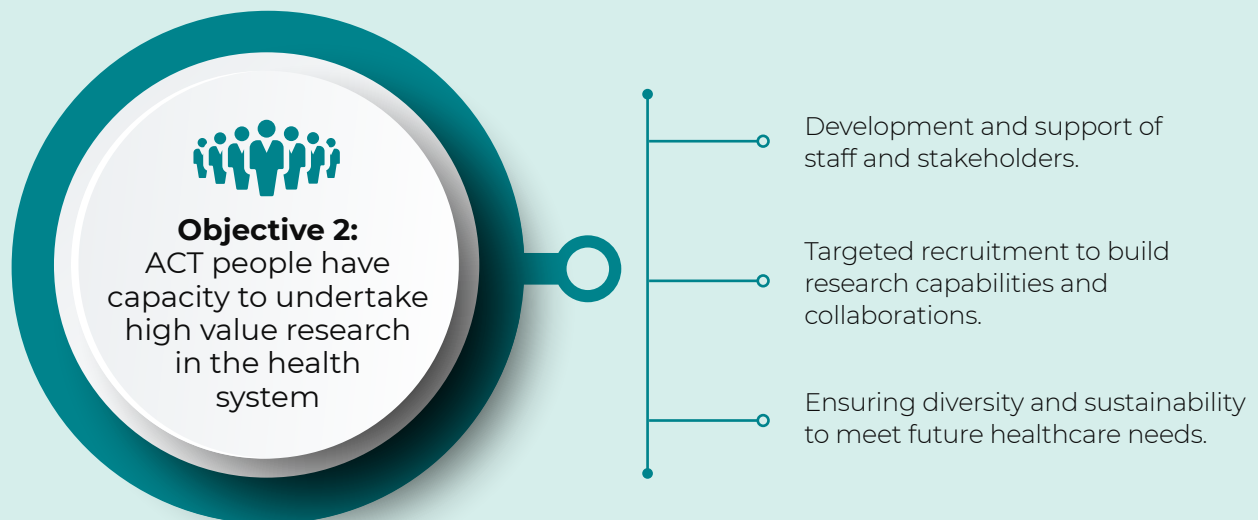


Figure 4. Guiding investment in the people who serve the ACT health system

Key capabilities

The plan therefore calls out that high value research, suitable to address the health or wellbeing problem at hand, is most likely to be delivered in the ACT health system if research teams:

- mobilise an appropriate mix of disciplines to address the problem
- are trained and supported to use high-quality methods
- can access patient or community-based populations to reach outcomes promptly, and at a scale sufficient to answer questions effectively
- are led by investigators who are experienced and accountable for delivery of research outcomes in the health system
- engage and collaborate with consumers and other end-users.

These characteristics are also those that will attract external investment in health research to the ACT. Commonwealth research funding through both the National Health and Medical Research Council (NHMRC) and the Medical Research Futures Fund (MRFF) prioritises research conducted at scale in highly capable clinical- or population-based health research environments. Increasingly, to attract large-scale funding, research programs must also show a comprehensive mix of expertise from discovery through translation, to implementation science and economic evaluation.



Capable research environments that can operate at scale are also those most attractive to investment from industry, NGOs and philanthropy. Investment in human capital of the ACT health research ecosystem will therefore bring leveraged investment that benefits the people of the ACT.

Finally, a strong, research-capable workforce and research training environment will attract and retain health practitioners with the best clinical skills and thereby support delivery of the highest quality clinical care. There is a powerful synergy, and a virtuous circle, between research, training and clinical care.

Roles of partners

Partners in the ACT health system have distinct and complementary roles in developing and sustaining the research capability of those who work within it and enabling them to conduct high quality research.

The health service providers, in addition to employing research-focused staff, can foster a strong research culture through valuing research track record and leadership at recruitment and research commitment at performance review. This requires recognition of research as a key output of those organisations.

The university partners play a critical role through direct support of recruitment of clinical leaders and teachers but coordination of these opportunities is needed to make the most of them and to populate key positions in a strategic way. Heads of agreement, pre-developed instruments and processes for joint advertisement and selection, and alignment of strategies to build capacity in priority areas are needed to ensure the best outcomes. In a resource-constrained environment, the health services can benefit from

partnering to develop clinician researcher trainee positions where the academic investigators have succeeded to attract grant support for research. Conversely, the academic partners have a powerful incentive to develop and support clinical research appointments and traineeships that leverage and develop their basic and translational research, and these imperatives are clearly acknowledged in their research strategic plans.

University partners populate the ACT health system with students and professional trainees in most health disciplines. In a learning health system, the universities will remain engaged in post graduate training in order to evaluate the outcomes of their degree programs and respond accordingly. Conversely, continued engagement of healthcare staff in the postgraduate clinical experience and in research can be strongly enabled by short courses, research studentships and professional development opportunities provided by universities or their clinical leaders.

More broadly, research support offices, preventive health programs, clinical trials and biostatistics units and health economic and policy teams play a major role in lifting capability. All partners have a stake in ensuring these core nodes of expertise and support function well and have capacity to disseminate expertise in the system. Capacity is always limited in recently developed or rapidly evolving disciplines such as implementation science or digital health, and partners may need to coordinate to strategically recruit them to the ACT.

Finally, for health consumers and the community to participate in priority-setting, co-design of research and evaluation of the ACT health research system, then the system should provide training opportunities to build consumer capacity and commit to integrating them into the system, through the various partners.

Related actions



Action 4

Investment



Action 7

Engagement



Action 5

Leadership



Action 8

Capacity-building
gaps and barriers



Action 6

Performance

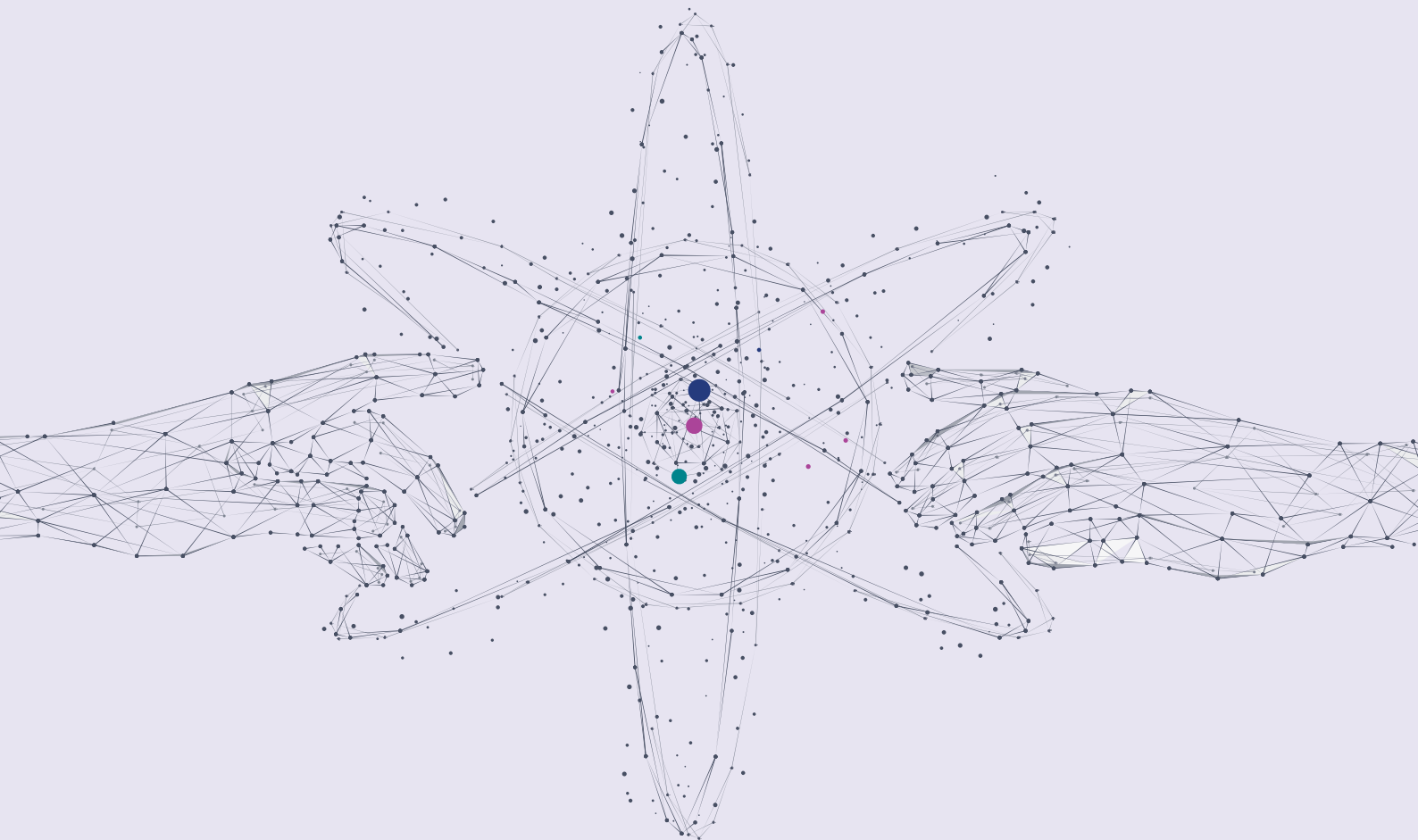
Case studies

IN ACTION: Investing in people

ACTHD and CHS currently invest with the University of Canberra in conjoint professor roles in Nursing, Midwifery, Mental Health Nursing and Allied Health. These embedded roles support capability development in these disciplines and bring research leadership capability to the health system. The roles provide opportunities for clinicians and researchers to collaborate, supporting the translation of research outcomes and the development of future clinician researchers.

INTO THE FUTURE: Supporting collaborative health research

Considerable research support is provided by ACT health research partners, particularly through the research offices of the universities and the ACTHD Centre for Health and Medical Research. An opportunity exists for these functions to efficiently support collaborative health service-based research while maintaining their core, independent roles for their organisations. This could be operationalised through an ACT research services advisory board that regularly reviews barriers of opportunities and/or mutually accepted processes and approval for example.



Objective 3: ACT infrastructure supports high value research

If the ACT healthcare ecosystem is integrated as a learning health system, and its people are trained and supported to generate and apply new knowledge, then investment in research and research infrastructure will reinforce those strategic directions and drive improvement in health and wellbeing in the ACT.

This plan takes a broad and agnostic view of the value of different research approaches, paradigms and methods. It considers only that research and research infrastructure invested in by the ACT should meet two tests: that it is high quality, and that it is designed to deliver value to the ACT and its health consumers.

Proposed investments should therefore ideally take place in a value-based research framework, where researchers and consumers work in partnership to deliver quality research that meets the needs of the community and promotes the translation of research into improved policy and practice.

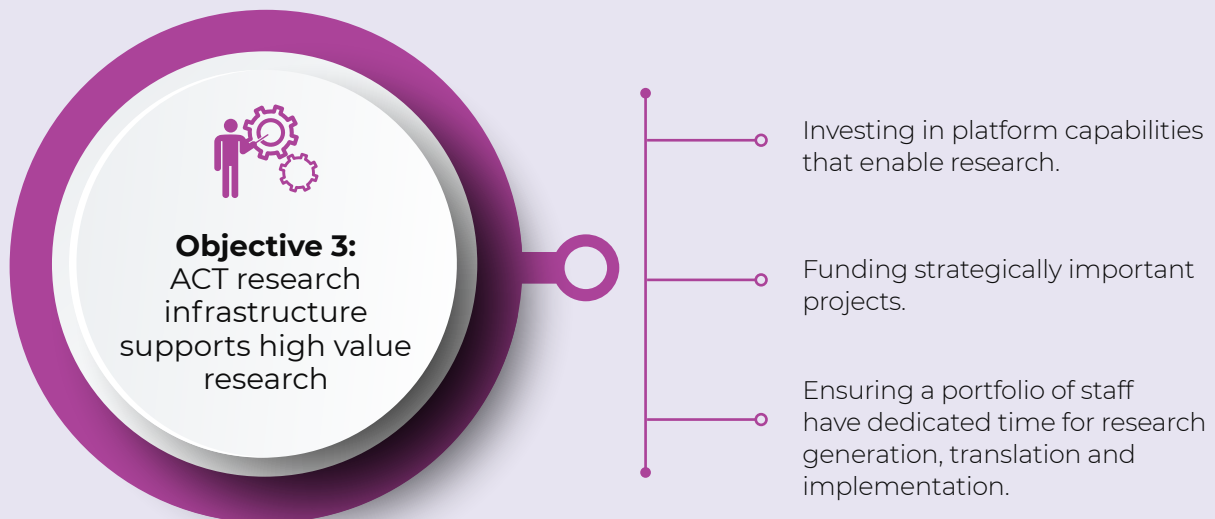


Figure 4. Fostering a learning health system

Key capabilities

Attention needs to be given in implementation of this plan to key research capabilities that are platforms to continuously transform the ACT health system. These include:

- data systems that capture, describe and analyse the reality of healthcare and wellbeing in the ACT, including patient-reported outcomes, and which respect First Nations data sovereignty principles
- physical infrastructure in healthcare facilities and the community that supports high value data collection from populations, individuals and their biospecimens
- mechanisms to monitor consumer values and preferences and support consumer co-design and engagement in research
- platforms to establish efficacy of new clinical interventions and to investigate and support their implementation
- health economic expertise that elucidates the burden of unaddressed deficits in health and wellbeing and the costs and benefits to the ACT of alternative solutions
- mechanisms that bring evidence to policy and continuously update research priorities under the plan.



Such platform capabilities consolidate and attract talent, empowering the people of the ACT health ecosystem to solve the problems that matter to them.

The success of this plan will also depend on the ACT fostering best-practice structures to support optimal research design, management of the research life cycle, ethics, governance, compliance and the management of intellectual property.

Implementation of this objective should begin with a comprehensive audit and benchmarking of research infrastructure assets and research support processes in the ACT. Such an audit is likely to conclude that these assets, where they exist, have not yet been deployed in a coordinated way by individual partners and therefore lack scale, are underdeveloped and are working to disconnected strategic and operational plans.

Alignment and coordination of partners

This plan should promote consolidation of the research assets of the ACT health system and coordinate future investments in research by its partners through a joint ACT health research hub.

Research capabilities, whether hard infrastructure, concentrated in specific locations, or soft systems distributed more widely, can strongly align the strategic objectives of a health system with those of its embedded partners. For our ACT universities, especially, their mission of social transformation and benefit through new knowledge of human health and wellbeing requires access to and investment in these same platforms. In other health jurisdictions around Australia, independent medical research institutes have often co-located with health services to achieve such synergies.

These other health jurisdictions have in various ways put in place specific partnering arrangements for coordination of investments, and joint governance and operation of key research infrastructure through research hubs. This has proven to be efficient, reducing duplication and enabling access to advanced technologies and processes by local health systems faster than would otherwise have occurred. NHMRC has strongly encouraged these trends through its Advanced Health Research Translation Centres accreditation mechanism. Universities, medical research institutes and health services have been able to use these mechanisms to concentrate capability and invest in vibrant environments that deliver high-quality research ranging from fundamental discovery to patient-centred implementation science.

The ACT currently lacks such mechanisms, or the partnership agreements that underpin them, with the outcome that key platform capabilities are under-developed and poorly integrated. However, the nature and size of our jurisdiction means that a whole-of-ACT approach to planning and investment in key platforms is feasible. The opportunity is there to create a distinctive research environment in which knowledge about health and wellbeing will be gained more comprehensively and deeply in the ACT than anywhere else and returned as benefits to our citizens like nowhere else.

Implementation of this plan should therefore address, as an early priority, the feasibility of a joint research hub structure to align the actions of partners around this goal.

Driving change through strategic projects and initiatives

The plan embraces the need to drive further change in researcher and partner behaviour through action and incentives. Investment by ACTHD or Canberra Health Services in research projects and programs can be more strongly targeted at every opportunity to proposals that have these characteristics:

- a problem of sufficient importance to the ACT and its people
- addressed by a collaborative team, including diverse disciplines and professional perspectives
- informed by the input of health consumers and patient perspectives as partners in research

- utilising ACT platform capabilities
- a clear pathway to implementation into practice in the health system
- analysis of the economic costs and benefit
- a plan for dissemination of outcomes and evaluation of impacts in the ACT health system.

Implementation of this plan requires a complementary set of targeted research initiatives, which will deliberately test the strengthening of the ACT health research system, as well as delivering outcomes in their own right.

Related actions



Action 4

Investment



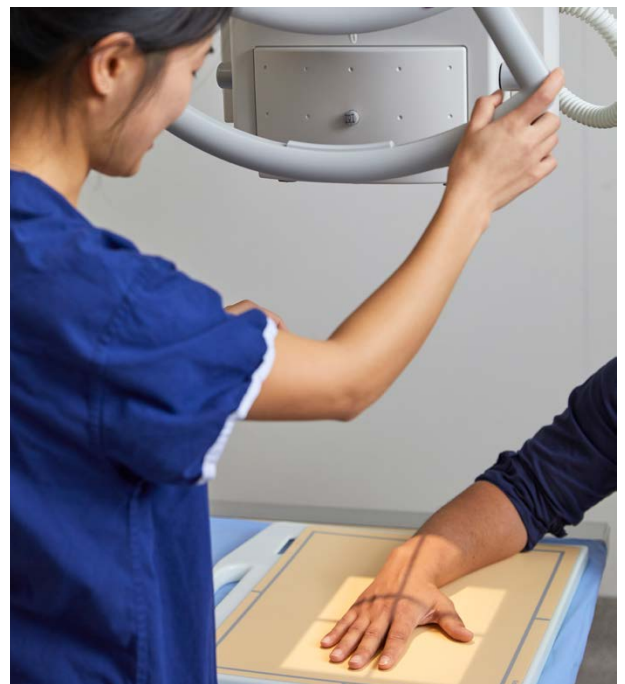
Action 10

Connections



Action 9

Infrastructure gaps and barriers





Case studies

IN ACTION: Canberra Clinical Genomics

Canberra Clinical Genomics (CCG), a partnership between the ANU and the ACT Government, is a diagnostic genomic service providing clinicians with access to state-of-the-art whole exome sequencing to improve patient diagnosis. A multidisciplinary team at the service provides clinicians with information about genomic variation and help find answers to complex genetic health conditions.

CCG aims to make a real difference to patient lives building on the research and discovery pipeline established by the ANU's Centre for Personal Immunology and providing a pathway for true translation of discoveries. CCG represents a partnership approach to support patients with complex diseases by sequencing their genome and finding treatments that are personalised to their condition. Whole exome sequencing is performed at ANU and funded for patients by the ACT Government. The routine work of the laboratory encompasses the molecular diagnosis of genetic disorders via whole exome sequencing using next generation sequencing technologies.

INTO THE FUTURE: Co-location opportunities

A 2019 review by Nous seeking to identify changes which would drive transformation and respond to the evolving needs of the ACT's health and medical research community led to a series of recommendations, including to explore opportunities to create a new, possibly standalone, medical research entity in the ACT. The report did not identify a specific entity model that would be suitable for the ACT but cited the Hunter Medical Research Institute in NSW and the Menzies School of Research in the Northern Territory as examples from which the ACT could learn.

More information

The plan is supported by a series of living addendums, added to over time, which elaborate on the key concepts and can evolve and respond to changes in the health system context and research environment.

These addendums, and further information about *Better together: A strategic plan for research in the ACT health system* can be found at www.health.act.gov.au/research.



