HEALTH ADVOCACY IN ACTION 17

Achieving a patient-centred healthcare system

CONFERENCE REPORT

A health policy conference for the leaders of Australian health consumer organisations.

24 & 25 FEBRUARY 2017

Introduction

Health Advocacy in Action was a policy conference held in Sydney on 24 and 25 February 2017 that brought together 24 senior leaders from 18 of Australia's major health consumer organisations.

The agenda was developed by an independent steering committee co-chaired by Julie Heraghty (CEO, Macular Disease Foundation Australia) and Richard Vines (CEO, Rare Cancers Australia). The conference was sponsored by Roche, who also provided logistical support.

This report is a summary of the conference. It includes the key points from expert speaker presentations, and a topline summary of the question-and-answer sessions and table discussions between the participants that followed.

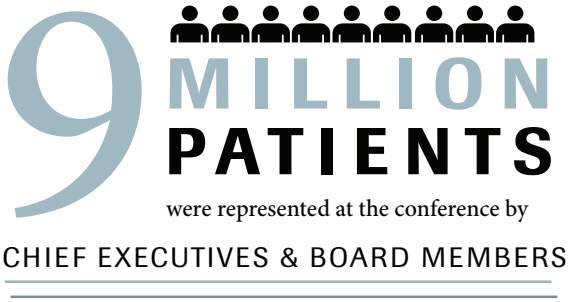
The conference participants were predominantly chief executives or board members, representing an aggregate of 9 million patients – or more than a third of the Australian population.[1] That is a significant constituency and for those organisations representing their health needs, it is a powerful voice.

The conference theme – *Achieving a patient-centred healthcare system* – reflects an aspiration to ensure patients are the primary focus of the national healthcare system.

The objective of the conference was to encourage participants to consider the challenges, opportunities and developments in health policy and to agree on achievable policy solutions that will benefit Australian patients. It is these patients who rely on the delivery of a world-class health system to meet their health needs.

The conference discussion and debate was stimulated by some challenging and provocative insights from a panel of speakers who are leaders in their fields, including health, economics and government.

Above all, the conference provided an opportunity for the leaders of health consumer organisations to challenge their current perspectives on health policy and practice, and agree on a way forward for health in Australia.



"Patients rely on the delivery of a world-class health system to meet their health needs."

Health Advocacy in Action

As the co-chairs reminded participants: "As advocates for patients, their families and carers, we are all familiar with the many challenges our healthcare system presents. However, part of our responsibility is to be dynamic, forthright and constructive in finding solutions that will drive change in health policy to achieve equitable and meaningful outcomes."

With this in mind, participants agreed at the outset of the conference on the following key principles as a starting point for future advocacy:

- Health consumer organisations are powerful when they unite behind a policy issue;
- As the end users of the healthcare system, patients must have a voice in health policy decision-making; and
- Health consumer organisations acknowledge the prevailing fiscal environment and should work with governments to frame policy solutions within that context.

"As advocates for patients, their families and carers, we are all familiar with the many challenges our healthcare system presents. However, part of our responsibility is to be dynamic, forthright and constructive in finding solutions that will drive change in health policy to achieve equitable and meaningful outcomes."

At the conclusion of the conference was the following agreement:

Governments must invest in healthcare interventions that are backed by **robust evidence** and avoid wasteful spending where a robust evidence base is absent.

Governments must consider the **value of health technologies** beyond the health portfolio, e.g. productivity gains, impacts on carers, disability payments etc.

Innovation presents the opportunity for health investment to be **more cost-effective**, leading to opportunities for savings that can be re-directed back into the health system.

Government must **prioritise data linkage** as a means of driving evidence-based policy, efficiency and better health and non-health-related outcomes.

Participant List

Co-Chairs

Ms Julie Heraghty CEO	*Macular Disease Foundation Australia*
Mr Richard Vines CEO	*Rare Cancers Australia*

Participants

Ms Heather Allan CEO	*Lung Foundation Australia*	**Ms Franca Marine** National Policy and Government Relations Manager	*Arthritis Australia*
Ms Hayley Andersen CEO	*Melanoma Patients Australia*	**Ms Maree McCabe** CEO	*Alzheimer's Australia*
Ms Shirley Baxter Member of the Executive Committee	*Cancer Voices NSW*	**Dr Matthew Miles** CEO	*MS Research Australia*
Ms Nettie Burke CEO	*Cystic Fibrosis Australia*	**Ms Bev Noble** Member of the Executive Committee	*Cancer Voices NSW*
Ms Sharon Caris CEO	*Haemophilia Foundation Australia*	**Ms Christine Nolan** CEO	*Breast Cancer Network Australia*
Mr Rob Cummins Research & Policy Director	*Macular Disease Foundation Australia*	**Mr Bill Petch** CEO	*Leukaemia Foundation*
Mr Gavin Finkelstein President	*Haemophilia Foundation Australia*	**Mr John Stubbs** CEO	*CanSpeak*
Ms Jane Hill CEO	*Ovarian Cancer Australia*	**Ms Kathy Wells** Director of Policy and Advocacy	*Breast Cancer Network Australia*
Prof Greg Johnson CEO	*Diabetes Australia*	**Mr Julien Wiggins** CEO	*Bowel Cancer Australia*
Ms Jane Kerr General Manager, Thoracic Cancer and Rare Lung Disease	*Lung Foundation Australia*	**Ms Sharon Winton** CEO	*Lymphoma Australia*
Ms Deidre Mackechnie CEO	*MS Australia*		

Conference Agenda

Day 1 – Friday 24 February

Session	Speaker
Welcome	**Svend Petersen** Managing Director, Roche (Pharmaceuticals) Australia
Preview of meeting and summary of meeting objectives	**Julie Heraghty, Richard Vines** Steering Committee Co-Chairs
Are Australian taxpayers getting a return on their investment in healthcare?	**Professor Deborah Schofield** Chair and Professor of Health Economics, Faculty of Pharmacy, University of Sydney
Changing the conversation in health – an insider's perspective	**Ben Hubbard** General Manager of Public Policy and Strategy, Maurice Blackburn Lawyers

Day 2 – Saturday 25 February

Session	Speaker
Welcome, recap and review of meeting objectives	**Julie Heraghty, Richard Vines** Steering Committee Co-Chairs
Reconciling Australia's fiscal challenges and our health needs	**Jeremy Thorpe** Partner and Chief Economist, PwC **Marty Jovic** Partner – Health Economics and Policy, PwC
What is a consumer organisation's role in shaping health policy?	**Paul Cross** Publisher, PharmaDispatch
Innovation – driving better outcomes for patients	**Professor David Thomas** Director, The Kinghorn Cancer Centre and Head of the Cancer Division of the Garvan Institute **Professor Paul Mitchell** Head of the Ophthalmology Department, University of Sydney and Director, Eye Centre at Westmead Hospital
Conference summary, conclusions and consensus	All delegates

Ensuring healthcare delivers a return on investment for taxpayers

Professor Deborah Schofield
Chair and Professor of Health Economics,
Faculty of Pharmacy, University of Sydney

Professor Schofield noted that Australia's ageing population is often framed as a cost problem, whereas it should be treated as an economic opportunity to keep an ageing population healthy and productive.

A study of disability, ageing and carers showed that 14 percent of Australians aged between 45 and 64 are not working due to a health condition, and as a result the estimated reduction in Australia's GDP due to lost workforce is around $12 billion per annum.[2] This study underscores the importance of ensuring the ageing population is also a healthy population.

Preventing long-term health conditions may help older Australians remain in the labour force longer. This would not only reduce the burden on the health system but also increase the tax base to help fund the required healthcare support for older Australians.

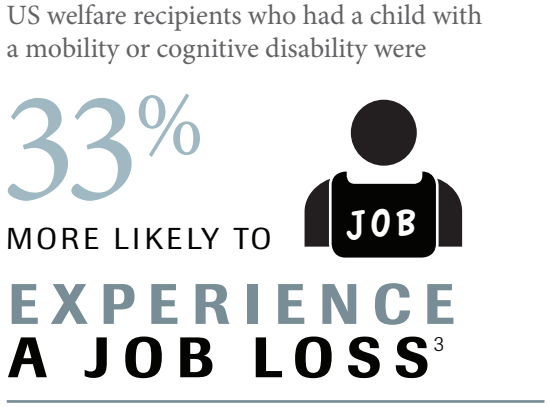
It is important that governments prioritise funding for healthcare that is backed by evidence over interventions that either do not work or have no robust evidence base to support them.

Professor Schofield also argued that in a fiscally constrained environment, it is more important than ever for new public health spending to be able to demonstrate value. This value can be assessed not only on the basis of the health outcome it delivers but also by measuring other indirect benefits. Examples include the contribution of health technology towards keeping a patient out of hospital, shortening hospital stays when they are required and ensuring a timely return to productive work.

Examples of indirect benefits accruing to other parts of the economy from investment in new health technologies might include:

- reduced testing and further treatment costs
- avoiding the need for home modifications
- positive impact on patient health, quality of life and utility
- reduced respite care and day care
- reduced transport subsidies and welfare payments
- increased labour force participation.

One study found that among US welfare recipients who were employed, those who had a child with a mobility or cognitive disability were 33 percent more likely to experience a job loss.[3]



Similarly, in the UK, parents of children with a cognitive delay reported higher rates of movement from a two-parent to a lone-parent household than those with a typically developing child. Dissolution of a relationship leads to an immediate 70 percent fall in household income and 55 percent fall in equivalised household income for married women.[4,5]

Investment in therapies to treat childhood cancer, for example, is likely not only to deliver a health benefit to the patient, but also potentially a health and economic benefit to family members as well as the long-term impact of the patient being able to enter the workforce as an adult.

Participants agreed that in the current constrained fiscal environment, where every dollar of public spending needs to demonstrate value, there is a compelling argument to model these "ripple effects" of health spending and measure value beyond the health system. This will enable decision-makers to account for multi-person and intergenerational impacts of health investment across the economy.

Summary of key points

- Governments should direct healthcare investment towards evidence-based health interventions that are proven to work, and avoid spending on areas where there is not a robust evidence base.
- In assessing the value of healthcare investment, governments should account for value beyond the health outcome.
- Investment in healthcare that can demonstrate long-term societal benefit beyond the health portfolio should be considered in supporting an increased budget for health.

Reconciling Australia's fiscal challenges with community health needs

Jeremy Thorpe
Chief Economist, PwC
Marty Jovic
Partner, Health Economics and Policy, PwC

Jeremy Thorpe and Marty Jovic described the context of the Federal Government's budget challenge, notably the appearance of a lack of confidence or consensus about how or when the budget will return to surplus. Both presenters acknowledge that the budget position remains the Government's primary focus and a lens through which all public policy is considered.

The question for the health portfolio is how to continue providing optimal healthcare for patients in a fiscal environment that demands constrained spending. This challenge is further complicated by the rising rate of expenditure growth in health. The presenters noted that if the current trajectory of health expenditure continues, the public health system will become unsustainable.

It is significant to note that the two spending areas projected to grow fastest out to 2019-20 are the Medicare Benefits Schedule and the National Disability Insurance Scheme (NDIS), while the two areas of slowest projected growth are the Private Health Insurance rebate and the Pharmaceutical Benefits Scheme.[6]

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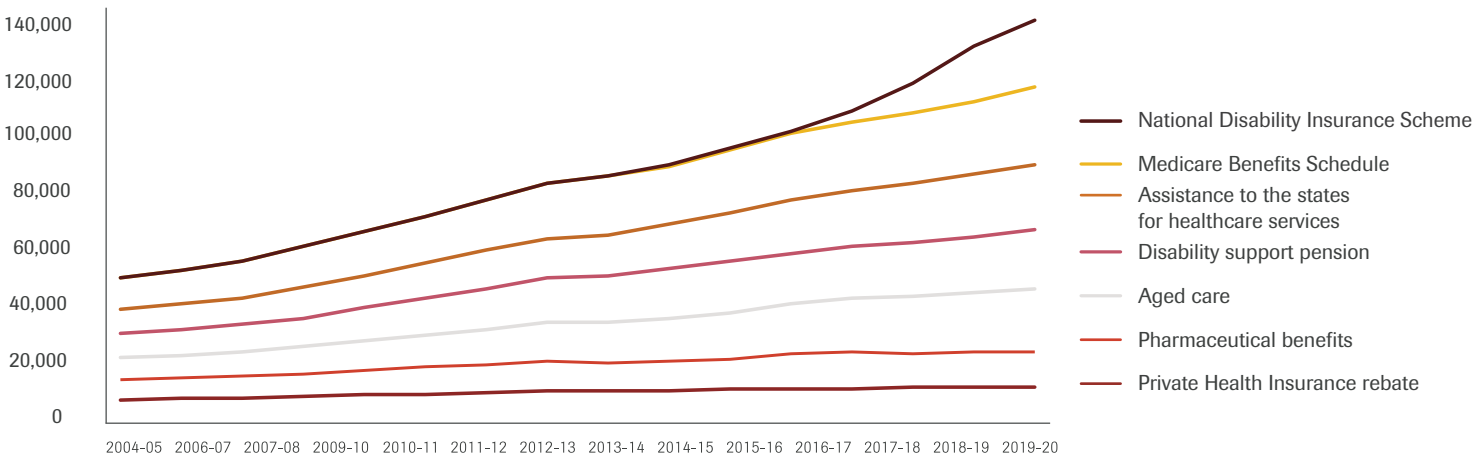

Figure: *Commonwealth expenditure, PricewaterhouseCoopers, 2017*

New trends are emerging in health as governments seek to manage spending by identifying efficiencies that deliver better value care, without impacting the quality of care. These trends form the basis of the Government's narrative and patient organisations have an opportunity to advocate in policy areas that align with this narrative.

Both presenters outlined a number of emerging focus areas for Government including:

- preventative health and primary care
- increased consideration of the social determinants of health
- investment in mental health, dementia and obesity
- evolution of health technology with emerging importance of biomarkers, genome sequencing and targeted healthcare
- changing patient expectations with the rise of health literacy and self-management.

Participants discussed the emergence of new health technologies, which presents at once a challenge and an opportunity for the Government. While these technologies are likely to demand significant taxpayer investment, they also bring the promise not only of better health outcomes for patients, but of savings elsewhere in the health portfolio and more broadly.

Participants agreed spending on healthcare should not be capped, and instead needs to be reframed as an investment in the economy rather than a cost, allowing Government to differentiate between debt that is revenue generating (such has healthcare spending) versus debt that is not revenue generating.

There was also agreement for the need to communicate to Government and other stakeholders the broader 'flow-on' benefits of new health technologies and their contribution to the overall budget e.g. productivity gains and reduced welfare burden.

Summary of key points

- Advocates must acknowledge the prevailing fiscal environment and work with Government to frame policy solutions within that context.
- Health investment can drive economic growth, so current budget challenges must not be used as an excuse for underinvestment in health.
- Robust evidence is important to demonstrate the economic and societal value of health investment.

Amplifying the consumer voice in shaping health policy

Paul Cross
Publisher, PharmaDispatch

In laying out a summary of the Federal Government's budget challenges, healthcare analyst and publisher Paul Cross pointed to a stark policy paradox: that while the Pharmaceutical Benefits Scheme has traditionally been a big target for government spending cuts and savings, current growth in medicines expenditure is lower than at any time in living memory.

Governments generally look to big-spending portfolios for savings, including the health portfolio, and the current budget challenge is making this imperative increasingly urgent. In healthcare, no public money goes in unless money comes out, creating a virtual "race to the bottom" where different items of health spending are constantly being moved around the system.

The decision for stakeholders, as this quest for efficiencies gathers momentum, is whether to partner with Government on a particular approach or oppose it. This is a significant decision for the participants given the power of their voice and the scale of their representation – more than 9 million Australian patients.

Participants agreed strongly that they should partner and work constructively with Government to drive positive policy change that would benefit the Government, the community and Australian patients. Participants expressed a keen preference for collaboration over conflict, and to support Government with ideas, consideration and solutions.

One of the challenges for health consumer organisations to manage is that policy change is incremental. While the Federal Government operates on a three-year electoral cycle, other policymakers work toward 10-20 year timelines. Health consumer organisations must identify how to work most effectively within both short-term government timelines and longer-term policy timelines. Nonetheless, stakeholder groups have a tradition and history of cooperating on reform agendas and have an opportunity to identify how best to achieve cut-through and collaborate with policymakers.

"In healthcare, no public money goes in unless money comes out, creating a virtual 'race to the bottom' where different items of health spending are constantly being moved around the system."

Participants cited the advice of Ben Hubbard, General Manager of Public Policy and Strategy, Maurice Blackburn Lawyers and conference dinner guest speaker. The Federal Government's interests are focused on short-term fiscal repair, achievable reform over the long term, and meeting its political imperatives.

Ben Hubbard also noted that advocates' have an opportunity to play to one or more of these priorities. Advocates' leverage is commensurate with network scale, capacity to organise and capacity to motivate and communicate. By all three measures, the network of Australian health consumer organisations scores highly and is therefore well equipped to advocate effectively.

Summary of key points

- Health consumer organisations are powerful when they unite behind an agreed policy issue.
- The Federal Government is operating within significant budget constraints and patient organisations agreed on the merits of working constructively with the Government to find healthcare solutions within those constraints.

Innovation as a driver of better health outcomes and greater savings

Professor David Thomas
Director, the Kinghorn Cancer Centre;
Head of the Cancer Division of the Garvan Institute
Professor Paul Mitchell
Head of the Ophthalmology Department, University of Sydney; Director, Eye Centre at Westmead Hospital

Professor Thomas and Professor Mitchell provided different perspectives of innovation in driving better health outcomes and generating savings in the health system.

Professor Thomas demonstrated the accelerating pace of medical research is reflected in the significant 10-year survival improvements across a range of cancer types over the past 45 years.[7]

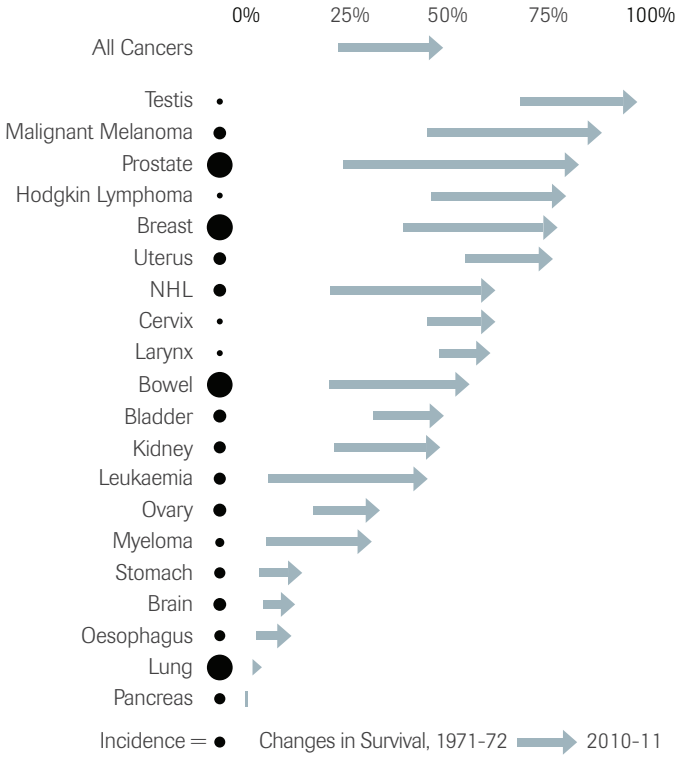

Figure: *Survival trends over time for common cancers.* Cancer Research UK.

He indicated that the opportunity to make a significant difference to the lives of Australian patients lies in society's ability to identify through research ways of improving the likelihood of survival. Research and the data it provides are integral to turning lethal diseases into chronic diseases, before eradicating the disease altogether. This process has various implications on the health system, including its distribution of funds.

Investment in rare disease remains disproportionately low because historically it has been difficult and costly to develop the evidence required to show the benefit of a treatment in small patient populations. Emerging technology is gradually allowing researchers to generate the data required. However, a more pragmatic and collaborative approach to clinical research in the earlier phases of drug development could significantly reduce the cost of drug development.

For example, the MoST program at the Kinghorn Cancer Centre in Sydney is currently recruiting patients living with rare and advanced cancer who have an unmet clinical need i.e. no treatment currently available. The program has developed a registry for rare cancers that offers publicly funded affirmative action to patients with rare cancers while collecting an evidence base.

This research offers patients access to molecular screening that may identify a clinical biomarker or genetic mutation and therefore the need for a targeted or novel therapy to treat their rare cancer via a clinical trial. This program is beginning to demonstrate how research has the potential to impact the speed and efficiency with which a treatment for a rare disease can be evaluated through the regulatory and reimbursement pathways, ultimately expediting access.

Professor Mitchell showed how innovation was driving better outcomes for patients with macular disease, noting the emergence of new treatments, including a new wave of gene-directed therapies.

Visual impairment leads to profound impacts on overall health including quality of life, mental health, independence and survival. The Blue Mountains Eye Study found that in people with vision impairment there was an increase in falls, a higher incidence of hip fracture risk within two years, a higher relative risk of greater depression and mortality. These patients were also more likely to access community support services. [8-12]

There was also a correlation between vision impairment and earlier admission to a nursing home; the study showed that nursing home rates of blindness are higher than community rates, despite accounting for the older age of nursing home residents. [13]

In the current reimbursement system there is no flexibility and limited recognition of other critical health outcomes linked to visual function. These include the ability to drive and perform functions associated with daily living, the need for supported care, experiencing falls, or more distant impacts including depression or other mental health issues. Incorporating these outcomes in the consideration of new health technologies will provide Government with a clearer picture of the value that innovation offers.

As new health technologies become available, decisions have to be made as to which innovations should be government-funded. Professor Mitchell argued that these decisions will necessarily involve choices and trade-offs, but must be informed by robust health data.

Participants agreed that linking health data via digital health records in a reliable way would provide more robust evidence on which Government can make funding decisions, and on which clinicians can base treatment decisions for their patients. This would also drive health system savings by providing Government with real-world evidence of the impacts of new health technologies, ensuring they are used only in patients who are likely to benefit.

The collection of data requires cooperation and partnership between different stakeholders to enable appropriate sharing, and care must be taken in deciding which data to capture. Participants also agreed on the importance of ensuring that individual patient data was securely and appropriately managed.

Priority genomic testing should be made available to identify individuals at high risk of imminent, serious, preventable, costly disorders. These patients and their families are uniquely placed to gain immediate benefit from genomic medicine.

"Research and the data it provides are integral to turning lethal diseases into chronic diseases, before eradicating the disease altogether."

The emergence of new health technologies demands a review of the funding process which currently applies a narrow cost-effectiveness focus without accounting for the long-term impacts of interventions such as genomic testing, which might include disease prevention and reduction in hospital admissions.

Summary of key points

- The linking of large data sets is becoming increasingly important and presents significant medical and economic opportunity.
- Governments must take a holistic view of the value of health innovations that takes into account societal benefits, indirect impacts on patients and carers, and productivity gains.
- Innovations such as genomic testing provide an opportunity to drive better health outcomes, but also to deliver savings in healthcare by reducing the use of a treatment in patients for whom it is unlikely to work.

Conclusion

The Health Advocacy in Action conference considered multiple policy issues over a day and a half, each with a view to positioning the patient at the centre of the healthcare system and achieving better outcomes for Australian patients.

Several key themes emerged from the debate.

The first was the consensus that the patient voice is powerful, particularly when it unites behind an agreed position. The participants in the room represented more than 9 million patients in Australia.[1]

Participants recognised the reality of the Government's budget position, the political implications of a significant debt and deficit, and the fiscal challenge that needs to be acknowledged in policy discussions.

The participants agreed that a constructive approach to advocacy is to work with the Government to develop health policy solutions that will best serve the interests of patients and improve health outcomes, but to do so while respecting the Government's budget imperatives.

The Government is encouraged to ensure healthcare spending is directed to innovations that are supported by robust evidence – to spend money on technologies that are going to deliver impact, and avoid wasting money on those innovations where health and non-health-related benefits are unproven.

Linking health data sets must be a priority for the Government. Doing so not only enables the delivery of cost-effective targeted healthcare, it can also drive savings across the portfolio and into the wider economy. It can provide policymakers with real-world data sets and guide investment decisions.

"Linking health data sets must be a priority for the Government."

Finally, healthcare should be seen not as a burden on the economy but as an investment that drives not just health outcomes but also broader societal and economic value. This value needs to be accounted for in the evaluation of new health technologies.

Participants agreed on the following position to be communicated to Government on behalf of the 18 organisations representing an aggregate of 9 million patients:[1]

Governments must invest in healthcare interventions that are backed by **robust evidence** and avoid wasteful spending where a robust evidence base is absent.

Governments must consider the **value of health technologies** beyond the health portfolio, e.g. productivity gains, impacts on carers, disability payments etc.

Innovation presents the opportunity for health investment to be **more cost-effective**, leading to opportunities for savings that can be re-directed back into the health system.

Government must **prioritise data linkage** as a means of driving evidence-based policy, efficiency and better health and non-health-related outcomes.

Evaluation

All participants reported that the Health Advocacy in Action conference was either useful or very useful, with all respondents reporting it had met their expectations and they would be interested in attending a similar conference again.

References

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