

Australia's next generation evidence ecosystem

Maximising the value of research
for better health

Federal Budget Submission
2018-2019

Trusted evidence.
Informed decisions.
Better health.



Executive Summary

Cochrane Australia applauds the Australian Government's commitment to increasing the volume of health and medical research funded in Australia and strongly advocates for urgent investments to maximise its value to Australia by strengthening the national evidence ecosystem.

The sustainability of Australia's health system and the health of Australians depend on the allocation of resources to the most effective and cost-effective programs and health interventions identified by relevant, reliable research. This requires the synthesis of relevant research evidence as systematic reviews, policy briefs and clinical or public health guidelines.

In the face of the rapid growth in research and health data, current synthesis approaches are no longer able to keep up. Australians are therefore often not able to access trustworthy, up-to-date research evidence for their decision-making. This leads to a 'double burden' of poorly allocated health resources and sub-optimal health outcomes. In addition, society's investment in health and medical research is eroded when knowledge gained from research is not synthesised and used by patients, providers and policymakers.

Australia is well positioned to use new technologies, processes and partnerships to strengthen our evidence synthesis capability and build a next generation evidence ecosystem. This will ensure research findings can be rapidly, effectively and efficiently translated into better health decisions, better health outcomes and a sustainable health system.

The health research and data landscape is changing rapidly. Cochrane Australia calls on the Australian Government to move quickly to invest in strengthening evidence systems so that the real benefits of research can be delivered rapidly and efficiently to Australians and the return on Australia's significant public investment in health research is fully realised.

Key recommendations

Cochrane Australia calls on the Australian Government to provide strategic investment in three key priority areas:

- 1. Next Generation Technical Systems:** Next generation technical systems to dramatically reduce the time and cost of synthesising research for decision-making and action.
- 2. Dynamic Evidence Processes:** Synthesis and use of diverse research and health data to inform point-of-care and policy-making decisions in near real-time.
- 3. Partnerships and Capacity:** Multi-stakeholder evidence partnerships to build capacity, strengthen co-production, increase efficiency and reduce duplication.

Introduction

Cochrane Australia welcomes the opportunity to make a pre-budget submission to the Treasurer in relation to the 2018-2019 Federal Budget.

High-quality, cost effective health care depends on making the right choices. To do this we need to use research evidence that is compiled, appraised and summarised in research syntheses, for example in systematic reviews, clinical practice guidelines or policy briefs. However, limitations in our current systems for synthesizing and using evidence, combined with the growing deluge of new research and health data mean this is often not achievable.

The Australian Government has recognised the need to embed research into healthcare and generate better value from research investment through a range of ongoing policy measures including establishment of the Medical Research Future Fund (MRFF) and creation of the *Australian Medical Research and Innovation Strategy and Priorities*.

Alongside government, several independent organisations, clinical practice leaders, universities and research institutions and have built world-class knowledge, expertise and infrastructure to support evidence generation, synthesis and use in Australia.

Despite major advances in clinical care and health policy achieved through these efforts, there is a critical lack of capacity in the human and technical systems that link research to changes in practice and policy. In a health system with significant sustainability challenges, where optimal resource allocation and best practice is not always achieved, there is an urgent need for Australia to improve the systems that connect research to decision-making and action.

With the national context of increasing investments in health and medical research and health data systems, and the global context of rapid technological change and increasing data deluge, this submission highlights the urgent need for Australia to start building a 'next generation' evidence ecosystem for **rapid and cost-effective synthesis and use of research evidence and health data**. With this investment, Australians will receive the best care and can continue to access a sustainable health care system.

The current evidence ecosystem

The current system for translating research into practice and policy is often conducted as a series of sequential, largely manual, resource-intensive activities.

Research questions are identified, prioritised, funded and investigated in a variety of forms and settings, but findings may conflict and vary in reliability and usefulness. Systematic reviews then use rigorous methods to 'synthesise' research findings to produce bottom line summaries that provide reliable estimates of the effects of interventions.

Multi-disciplinary groups draw on systematic reviews and other information to produce best practice guideline recommendations and policy briefs. These recommendations are translated into improved treatments and services using a range of multi-faceted 'knowledge translation' activities. The uptake of guidelines and their impact on individual outcomes can be measured through clinical registries and other health-related data sources.



Critical limitations of the current system

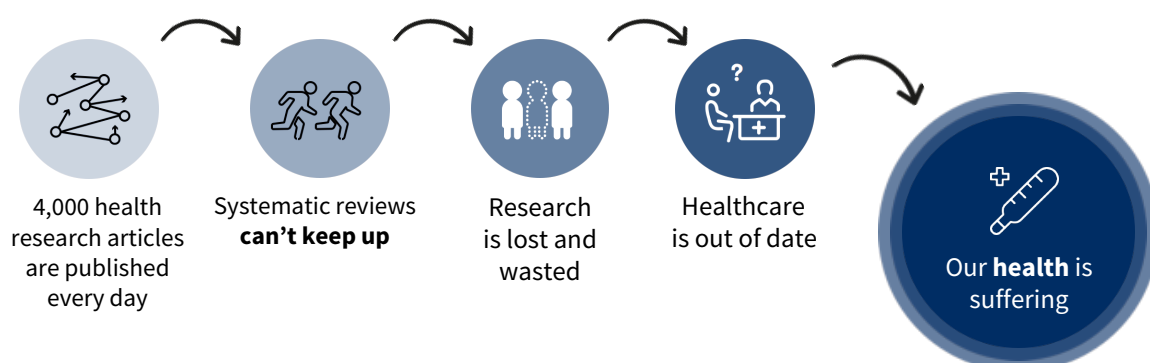
A key report by the National Health and Medical Research Council (NHMRC) in 2015 highlighted key barriers to the use of evidence in guidelines for health decision-making: inefficiency, poor quality, lack of capacity, lack of investment in technology, inaccessibility and obsolescence¹.

The reasons for this are complex and include:

- **Poorly targeted research:** Research is often designed without reference to stakeholder priorities and up-to-date systematic reviews of existing evidence, resulting in duplication and wasted research investment^{2,3}.
- **Inefficient evidence synthesis:** Processes for synthesising research are rigorous, but are inefficient and do not make best use of innovations in technology. It can take up to 6.5 years for research to be included in a systematic review⁴ and up to 17 years to reach practice⁵.
- **Information overload:** Exponential growth in research is overwhelming current systems. Over 4,000 health research articles, including more than 75 clinical trials, are published every day⁶. Practice recommendations can't be updated efficiently, so go rapidly out of date⁷.
- **Lack of co-ordination:** Multiple stakeholders are involved in evidence synthesis in Australia but limited capacity for coordinating these efforts means the system is fragmented, non-strategic and inefficient¹.
- **Limited stakeholder involvement:** Limited involvement of stakeholders throughout the research prioritisation, evidence synthesis and translation process weakens the focus on issues of importance to these groups and impairs the uptake of evidence.
- **Inaccessible outputs:** Dissemination of research, systematic reviews and guidelines is usually in unstructured text-based formats that impair discoverability, reuse and integration with clinical decision support systems, and contribute to the extreme delays in the current evidence system⁸.

The cumulative effect of this fragmented, non-strategic approach is:

- **Wasted research investment:** Research funding is allocated to low priority questions, or on research that unnecessarily duplicates existing research. Limitations in evidence synthesis and use constrains and delays the value generated by research, eroding the return on society's investment in research.
- **Wasted resource allocation and sub-optimal health outcomes:** Inefficient use of research evidence leads to a 'double burden' of poorly allocated resources and sub-optimal health outcomes. Some patients do not receive the care they need, leading to avoidable illness and health system and societal costs, and others receive care that is unnecessary, ineffective or harmful. Health service planning and delivery is not informed by evidence, eroding efficiency and sustainability of the health system.



Key investment priorities

Priority 1. Next generation technical systems

Next generation technical systems will dramatically reduce the time and cost of synthesising research for decision-making and action.

Goal: To reduce the time and cost of key steps in evidence synthesis by 75%

There is a clear consensus among governments and major organisations regarding the methods to produce trustworthy systematic reviews and guidelines, but technical systems to support these methods have lagged and in the growing research deluge are now a major impediment to evidence-informed decision-making.

Evidence teams must grapple with manual systems, which wastes expensive human resources and severely limits their productivity. For example, updating clinical guidelines often involves manually sifting through 100,000 or more research articles and appraising hundreds of clinical trials and other relevant data sources.

In response, Cochrane and partners have begun developing ‘next generation’ technical systems for evidence synthesis to drive greater efficiency, cost-effectiveness, collaboration and quality.

These systems consist of three main ‘layers’:

- **Data:** Better evidence systems must be driven by rich meta-data for discoverability and reuse of research outputs. Cochrane’s Linked Data Project⁹ is building systems that can efficiently convert the ‘noise’ of biomedical research outputs into structured datasets.
- **Automation:** Citizens and machines can help. Text mining and machine learning can now be used to accelerate key steps in the evidence cycle and citizen scientists can contribute via crowdsourcing platforms¹⁰. These systems can reduce workload by up to 80% for some tasks.
- **Software:** Cochrane and partners are developing cloud-based ‘software-as-a-service’ platforms that accelerate key steps in evidence synthesis and guideline development. These can already reduce workload for some tasks by up to a third and are being taken up globally.

Key recommendations

The building blocks for a next generation technical system have been developed, with demonstrated benefits and increasing uptake around the world; for example, by the UK National Institute for Health and Care Excellence, the world’s largest guideline developer,

The potential impact of these systems is far from being realised. Investment is needed now to build system coherence and prepare for health system-wide scale-up. This must include:

- **Data:** Support further development and adoption of standardised formats and systems.
- **Automation:** Expand the range of evidence tasks supported by machines and crowds.
- **Software:** Integrate with linked data, machine learning and crowdsourcing systems.

Priority 2. Dynamic evidence processes

Diverse research and health data will be synthesised and used to inform point-of-care and policy-making decisions in near real-time

Goal: To reduce the time from research output to point-of-care use by 75%

Synthesising vast amounts of research into reliable evidence is currently an intermittent and fragmented process. Exceedingly long delays between research and adoption mean a large proportion of the knowledge gained from research isn't being used effectively and a persistently outdated evidence base is being used to inform best practice and policy and guide future research.

This lack of currency and risk of inaccuracy erodes the value proposition of research evidence, as does the use of static and poorly accessible guidelines formats and the inability to incorporate routinely collected health data in the evidence synthesis process.

These fundamental challenges with our current evidence ecosystem are now being addressed with the development of more dynamic and integrated approaches. These include:

- **Living evidence:** Continual surveillance for new research feeds 'living' systematic reviews that are updated as soon as new research data become available. In turn, these enable 'living' guideline recommendations to be updated as soon as there is a significant change in the evidence, dramatically reducing the time from research output to point-of-care^{11,12}.
- **Implementable evidence:** New platforms are enabling the digitisation of guidelines in user friendly, multi-layered formats accessible from any device. These can be linked to decision support systems and create new opportunities for knowledge translation¹³.
- **Diverse data:** As routinely collected health data proliferate new methods are being developed to incorporate diverse data sources into evidence-based decision-making.

Key recommendations

For effective health decision-making and resource allocation, Australians need access to trustworthy evidence and guidelines that are up to date with the latest research, incorporate all relevant research outputs and other data sources, and are easily accessible and usable. To achieve this, investment is needed now to:

- **Living evidence:** Expand the living evidence model to enhance transition from intermittent updating to dynamic, near real-time incorporation of new research into living systematic reviews and guidelines.
- **Implementable evidence:** As guideline production transitions to a dynamic approach;
 - use available software to create accessible, engaging digital formats for end users,
 - link guideline recommendations to decision support-systems, and
 - harness opportunities to strengthen knowledge translation, including audit and feedback.
- **Diverse data:** Incorporate diverse data sources into living systematic reviews, particularly high quality registry data.

Priority 3. Partnerships and capacity

Multi-stakeholder evidence partnerships will build capacity, strengthen co-production, increase efficiency and reduce duplication.

Goal: To establish five initial multi-stakeholder partnerships to develop and evaluate innovative, collaborative evidence synthesis models in high-burden disease groups

In Australia and elsewhere, diverse stakeholder groups are involved in evidence synthesis and knowledge translation efforts, including patients, clinicians, health service providers, researchers, funders and policymakers.

In other fields such as basic science and clinical trials there has been a shift towards addressing important questions by harnessing the coordinated, collaborative effort of a large and diverse set of contributors. The same shift towards large-scale coordination and collaboration of large, diverse teams is now needed in evidence synthesis and translation. Strengthening strategic partnerships between these contributors will create opportunities to benefit from their diversity, reduce duplication of effort, improve the efficiency and effectiveness of evidence synthesis and use, and identify and prioritise future research.

As well as improving the efficiency and effectiveness of research effort, there is abundant evidence that broadening participation in evidence and guideline production ('co-creation') improves engagement with, uptake of, and ultimately the impact of research evidence.

Nationally coordinated, multi-stakeholder partnerships are needed to ensure the complete set of skills and perspectives are available and applied; reduce redundant effort; strengthen the role of patients and other end users in shaping evidence; and improve translation of evidence into action and better health outcomes.

Key recommendations

Critical to realising an effective and efficient evidence ecosystem will be the creation of multi-stakeholder partnerships that can draw on existing evidence and experience with engaging diverse stakeholders in evidence synthesis, guideline development, and quality improvement.

Investment is needed for:

- **Prioritisation:** Coordinate and prioritise evidence activities, strengthen the role stakeholder priorities play in the production and translation of research and reduce unnecessary duplication of effort.
- **Co-creation and use:** Engage consumers, clinicians, policymakers and other stakeholders in substantive, diverse and flexible opportunities to contribute to the production of evidence-based recommendations for practice and policy, and the systematic reviews on which they are founded.
- **Capacity building:** Use the existing capacity in Australia and other global networks like Cochrane, together with the supervision, networking and mentorship opportunities within multi-stakeholder partnerships to build Australia's evidence workforce.
- **Demonstration and evaluation:** Establish a limited number of living evidence demonstration projects to establish feasibility, refine implementation models, evaluate impact and prepare for scale-up.

Conclusion

Despite the dedicated and sustained efforts of multiple government agencies, clinical practice and research leaders, guideline developers and independent organisations such as Cochrane Australia, there are critical gaps in our capacity to synthesise and use evidence in Australia.

This delays or prevents the use of potentially transformative research, meaning Australians don't benefit and the value of research is diminished.

At a time when the Australian Government has committed to doubling its investment in health and medical research, we must act now to ensure the return on this significant public investment is fully realised.

A more effective and efficient evidence ecosystem will transform current episodic, linear, manual evidence synthesis process into a dynamic system with a broader range of inputs; an infrastructure that incorporates new technologies and drives efficiency; and collaborations and outputs optimised to translate evidence into practice and impact.

Australia is at the global forefront of developing the innovative systems, processes and partnerships needed for a next generation evidence ecosystem.

Cochrane Australia calls on the Australian Government to act quickly and invest in these technical systems and new evidence processes so that the real benefits of research can be delivered in weeks, not years.

About Cochrane Australia

Cochrane is an independent, not-for-profit organisation made up of 37,000 contributors from 130 countries. We work together to make the vast amounts of evidence generated through research useful and accessible for individuals, organisations and governments around the world.

Cochrane produces trusted health information in the form of systematic reviews that are free from commercial sponsorship and other conflicts of interest. Our evidence underpins and informs the daily decisions of clinicians, patients and carers, researchers, policymakers and funding bodies. Our work is recognised as representing an international gold standard for high quality, trusted information.

Cochrane Australia represents Cochrane's work in Australia. We undertake research and advocacy activities and work to support policy and practice in Australia through conducting and translating relevant and reliable systematic reviews. Cochrane Australia is funded by the Australian Government through the NHMRC. The NHMRC also funds a national subscription to the Cochrane Library, ensuring all Australians have free access to the best in trusted health evidence.

References

- ¹ Better informed health care through better clinical guidelines. NHMRC;2015.
- ² Emdin CA, Oduyayo A, et al. Association between randomised trial evidence and global burden of disease: cross sectional study (Epidemiological Study of Randomized Trials--ESORT). *BMJ*. 2015;350:h117
- ³ Chalmers I, Bracken MB, et al. How to increase value and reduce waste when research priorities are set. *The Lancet*. 2014;383(9912):156-165
- ⁴ Elliott JH, Turner T, et al. Living systematic reviews: an emerging opportunity to narrow the evidence-practice gap. *PLoS Med*. 2014;11(2):e1001603
- ⁵ Morris Z, Wooding S. The answer is 17 years, what is the question: understanding time lags in translational research. *Journal of the Royal Society of Medicine* 2011;104:510-520
- ⁶ Thomas J, Noel-Storr A, et al. Living Systematic Reviews:2. Combining Human and Machine Effort. *Journal of Clinical Epidemiology*. 2017;91:31-37
- ⁷ Shojania KG, Sampson M, et al. How quickly do systematic reviews go out of date? A survival analysis. *Ann Intern Med*. 2007;147(4):224-233
- ⁸ Elliott JH, Turner T, et al. Living systematic reviews: an emerging opportunity to narrow the evidence-practice gap. *PLoS Med*. 2014;11(2):e1001603.
- ⁹ <http://linkeddata.cochrane.org/>
- ¹⁰ Thomas J, Noel-Storr A, et al. Living Systematic Reviews:2. Combining Human and Machine Effort. *Journal of Clinical Epidemiology*. 2017;91(31-37).
- ¹¹ Elliott JH, Synnot A, et al. Living systematic review: 1. Introduction - the why, what, when, and how. *J Clin Epi*, 2017;91:23-30
- ¹² Elie AA, Joerg JM, et al. Living systematic reviews: 4. Living guideline recommendations. *J Clin Epi*, 2017;91:47-53
- ¹³ Khodanbashi S, Nytro O. Reviewing clinical guideline development tools: features and characteristics. *BMC Med Inform Decis Mak*. 2017;17(1):132

Cochrane Australia

School of Public Health & Preventive Medicine
Monash University
Level 4, 553 St Kilda Road
Melbourne, Victoria 3004

Phone +61 3 9903 0366
Email cochrane@monash.edu
Web www.australia.cochrane.org
Twitter @CochraneAus