



**Submission to the Strategic Review of Health and Medical
Research in Australia**

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Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF welcomes the opportunity to provide input to the Strategic Review of Health and Medical Research in Australia (the Review). Health consumers have a strong interest in maintaining and building a viable, internationally competitive health and medical research sector, as they will ultimately benefit from the outcomes of research.

However, as this submission outlines, there must be consideration of how the health and medical research sector in Australia can evolve so that truly consumer-centric health and medical research can take place. This submission puts forward two areas which should be a focus for funding and support in the development of the 10 year strategic health and medical research plan that is to be the outcome of the Review: active consumer participation in research, and comparative effectiveness research that has as its goal improving treatment modalities and outcomes for patients.

Benefits to consumers of investment in Australian health and medical research

Numerous submitters to this Review will outline the benefits of ongoing investment in health and medical research in Australia. These benefits are well-articulated through campaigns such as *Discoveries Need Dollars*,¹ and include health and economic implications.

For consumers, there are two areas of particular benefit. First, Australian consumers are usually the first to benefit from Australian discoveries. The *Discoveries Need Dollars* website cites examples of Australian patients having first access to colony stimulating factors (CSFs), which are used for treating cancer patients undergoing chemotherapy, as well as having early clinical trial access to new targeted anti-cancer-cell survival medicines for the treatment of lymphoma and other blood cancers.²

The benefits of access to clinical trials for Australian consumers are articulated in the report of the Clinical Trials Action Group:

¹ www.discoveriesneeddollars.org.au

² 'Benefits of medical research', online at www.discoveriesneeddollars.org/why_protect_research/benefits_research/, accessed 21 March 2012. Further examples are provided in Access Economics 2008 *Exceptional Returns: The Value of Investing in Health R&D in Australia II*, prepared for the Australian Society for Medical Research, Canberra.

*Generally patients on trials have better outcomes due to close monitoring and careful application of the best evidence-based clinical care. New, improved treatments are often available many years in advance of commercial availability at lower cost to the health sector and providing immediate benefit to patients on trials.*³

Consumer benefits are not limited to early access to treatment. Continuing to invest in Australian health and medical research will mean that research can be targeted at the areas where Australia's disease burden is highest, and where improvements in treatment options are needed. Australia has well-articulated National Health Priority Areas, 'which contribute significantly to the burden of illness and injury, and which have potential for health gains and reduction in the burden of disease':

- Arthritis and musculoskeletal conditions
- Asthma
- Cancer control
- Cardiovascular health
- Diabetes mellitus
- Injury prevention and control
- Mental health
- Obesity.⁴

These National Health Priority Areas provide a guide to where Australian investment in health and medical research should be directed, with consideration given to both the disease burden and the cost burden associated with each area when allocating funding. Ultimately investment in research can lead to reductions in cost and disease burdens through improved treatment and reduced severity and duration of illness. A reduction in investment in health and medical research carries risks that international research might not address some of these priority areas, and that research that is undertaken may not be relevant to the Australian context. Further, continued investment in Australian health and medical research will enable research that is focused on issues of particular relevance to Australia, notably Indigenous health and 'closing the gap'.

The benefits of continued investment in Australian health and medical research are accepted by the Australian population. A survey conducted for Research Australia in 2011 found that 95 percent of Australian voters think it is important for Australia to have a strong health and medical research industry.⁵

CHF recommends that the Review Panel recognises the benefits to Australian health consumers from ongoing investment in Australian health and medical research.

³ Commonwealth of Australia 2010 *Clinically Competitive: Boosting the Business of Clinical Trials in Australia. Clinical Trials Action Group Report*, Australian Government, Canberra.

⁴ Department of Health and Ageing 2010 'Chronic Disease', online at www.health.gov.au/internet/main/publishing.nsf/Content/chronic, accessed 21 March 2012.

⁵ JWS Research 2011 'Research Australia National and Marginal Seats Survey Results April 2011', online at www.researchaustralia.org/Publications%20Public%20Opinion%20Polls/Research%20Australia%20Survey%20Results.pdf, accessed 21 March 2012.

Active consumer participation in research

CHF argues that Australian health and medical research will be enhanced through the increased involvement of consumers. Involving consumers not just as research subjects, but as active participants in all stages of the research process, is essential in improving the relevance, impact and quality of health research. The involvement of consumers in all areas of research development, including setting research priorities and questions, designing protocols, collecting, analysing and interpreting data and disseminating findings, will ensure that health research reflects consumer needs.

In 2001, CHF and the National Health and Medical Research Council (NHMRC) developed a *Statement on Consumer and Community Participation in Health and Medical Research*,⁶ which highlighted the fact that consumers are in an optimal position to provide valuable input to health and medical research as users of healthcare services. In addition, the Statement points out that it is imperative that this input is facilitated if high quality research is to continue.

In the United Kingdom, it is a statutory requirement that government-funded research must involve consumers as active participants. This requirement has been positively received and has resulted in the formation of groups such as *Involve*, which aim to empower citizens to be involved in research and influence decisions that affect them.⁷

CHF argues that health and medical research in Australia will benefit if a Consumer Health Research Centre, similar to *Involve*, is funded and established in Australia. The aim of such a body would be to conduct high quality consumer-oriented research and provide a consumer-focused health research agenda. The Centre could be charged with supporting and funding consumer involvement in research in order to:

- Identify consumer priorities for research (including gaps in current research)
- Influence priorities and practice in health research
- Ensure research findings are accessible to a range of stakeholders, including consumers.

Consumers have been calling for the funding and development of a Consumer Health Research Centre for many years. At the *Involving People in Research Symposium* in 2008, a communiqué was endorsed recognising this need and calling for the establishment of an organisation to support consumer participation in health research.⁸ To date, there has been no Government commitment to the establishment of such a body.

CHF recommends that the Review Panel supports mechanisms to increase active consumer participation in research, including the establishment of a Consumer Health Research Centre.

⁶ Online at www.nhmrc.gov.au/files_nhmrc/publications/attachments/r23.pdf

⁷ See www.invo.org.uk

⁸ See www.sph.uwa.edu.au/community/involving-people/symposium_communique

Improving treatment options through comparative effectiveness research

The bulk of health and medical research in Australia is centred around randomised clinical trials. While these provide an important evidence base for new knowledge and treatment modalities, CHF argues that consumers would benefit from a greater focus on research that examines how treatments are used in a clinical setting, as well as comparing treatment options in these settings – comparative effectiveness research.

In a recent article in the *Medical Journal of Australia*, Zalcborg outlines the flaws with a reliance on clinical trial research alone:

...evidence from clinical trials necessarily involves small and very carefully selected populations with particular demographics and disease characteristics. Hence, the results of clinical trials are often not directly relevant to clinical reality. In addition, the scientific basis of “standard therapy” against which new interventions are compared has not necessarily been rigorously tested. Uncertainty about how best to use such new evidence versus the range of alternative options available in the “real world” may create variable practices and impair patient outcomes.⁹

Comparative effectiveness research will arguably deliver benefits to consumers. This research could result in an improved understanding of how the different treatment options for a condition compare in terms of risks and benefits; for example, the medication dosage or treatment duration that are actually required for treatment to be effective, or whether an invasive or high-risk treatment will actually be more effective than a lower-risk intervention. The Institute of Medicine in the United States describes it succinctly as ‘*a way to identify what works for which patients under what circumstances*’.¹⁰ As Krumholz writes,

...what if these studies, done well, revealed that some medications were better than others? What if they overturned conventional wisdom about understudied drugs, demonstrating that many patients were receiving ineffective treatments? What if they showed that some patients were actually being harmed? What if more knowledge about the benefit and risk of treatments in medicine, compared with their alternatives, is just what patients need?¹¹

There has been an increasing focus on comparative effectiveness research in the United States,¹² in recognition of the value that this research can provide to the delivery of treatment in clinical settings. This has been criticised by some as being part of a broader effort to reduce healthcare costs, but, as Krumholz writes:

⁹ Zalcborg, J. 2012 ‘Comparative effectiveness research – a proposal for a new NHMRC funding stream’, *Medical Journal of Australia* 196(1):22-23.

¹⁰ Institute of Medicine 2009 *Initial National Priorities for Comparative Effectiveness Research*, National Academies Press, Washington.

¹¹ Krumholz, H.M. 2011 ‘Niaspan and how comparative effectiveness research was done well’, online at www.kevinmd.com/blog/2011/06/niaspan-comparative-effectiveness-research.html, accessed 22 March 2012.

¹² See, for example, Institute of Medicine Op Cit.; Patient Centered Outcomes Research Institute (PCORI) 2012 ‘Patient Centered Outcomes Research’, online at www.pcori.org/patient-centred-outcomes-research, accessed 16 March 2012.

It would be a nice dividend if these studies identified wasteful practices that could be eliminated, but our dire need is to illuminate the many areas of darkness that still exist in medicine, where we are practicing based on our intuition and knowledge of basic biology – but with little understanding of the benefits and risks of alternative approaches. And we are discovering more and more that what we might anticipate from our knowledge of basic science does not always pan out when we study what happens to patients. ... we need to commit to research that will reveal the trade-offs of different strategies and inform the choices of individuals. How can good decisions be made when the critical information about how strategies compare is missing?¹³

The potential to reduce healthcare costs cannot be ignored, but the key issue, from CHF's perspective, is the opportunity to build knowledge around treatment options and improve treatment outcomes for consumers. Zalberg proposes a new funding stream, resourced from within the existing health portfolio, to encourage research that:

1. *Rigorously tests scientifically based variations in approved or standard health interventions that are publicly funded*
2. *Directly compares the relative roles of approved, publicly funded components of treatment algorithms.¹⁴*

Whether comparative effectiveness research is funded through existing funding pools or a new funding stream, CHF argues that it should be a central component of the Review Panel's strategic plan for the next ten years of health and medical research in Australia.

CHF recommends that the Review Panel supports the inclusion of comparative effectiveness research as a central component of future health and medical research planning in Australia.

Conclusion

CHF welcomes the opportunity to provide input to the Review, and supports its goal of 'optimising Australia's capacity to produce world class health and medical research to 2020'. Australian consumers will benefit from a strong and viable health and medical research sector, and ongoing investment in research is essential.

In addition to supporting ongoing support and investment for Australian research, this submission has identified two ways in which the Australian research sector can be enhanced: through greater inclusion of consumers as informed and active participants in research, and through support for comparative effectiveness research which examines treatment options in clinical settings. Inclusion of these elements in the ten-year strategic plan for health and medical research will allow Australia's research sector to evolve to become truly consumer-centric, therefore more reflective of the needs of those who use and pay for health services.

CHF looks forward to the outcomes of the Review in December 2012.

¹³ Krumholz, H. 2011 'Medicine's Drip of Uncertainty', online at www.forbes.com/sites/sciencebiz/2011/03/02/medicines-drip-of-uncertainty/, accessed 16 March 2012.

¹⁴ Zalberg Op cit.



The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- prevention and early intervention
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach millions of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.