Public health research in cancer control

Cancer Council Australia (CCA) is the nation's peak, non-government, cancer control organisation. Cancer Council Australia advises the Australian Government and other bodies on practices and policies to help prevent, detect and treat cancer and advocates for the rights of cancer patients for best treatment and supportive care.

The **Clinical Oncological Society of Australia** (COSA) is Australia's peak multidisciplinary society for health professionals working in cancer research, treatment, rehabilitation and palliative care with over 1600 members. COSA is an advocacy organisation whose views are valued in all aspects of cancer care. COSA provides high-level clinical advice to Cancer Council Australia.

Introduction

Cancer Council Australia represents the federal priorities of its eight state/territory member bodies. We support the individual submissions lodged by our members, whose research priorities are in some cases more specific than ours due to their in-house biomedical and public health research programs.

Our joint views on clinical research are in the separate submission lodged by COSA; this submission focuses specifically on public health.

Our recommendations and observations should be seen in the broader context of our role as a federated body responsible for the development and promotion of evidence-based national cancer control policy, drawing on the advice of a network of expert committees including researchers.

General

The overarching challenge raised most by Cancer Council researchers is the relative deficiency in research investment in Australia. As a guide, the Commonwealth invests approximately $0.8 billion each year in NHMRC research funding as part of its overall expenditure of $72 billion on health and ageing services. This represents just over 1% of expenditure compared to the industry average of 4% in research. This is a disparity that must be addressed.

A common theme among researchers in the context of this review is the poor coordination of, and access to, cancer patient data. Coordination of de-identified data through the national application of a numeric system similar to that used in the cancer registry in Western Australia could facilitate more efficient tracking and analysis of data. (See response to point 11.)

Another general concern is the need to translate basic research, clinical research, and health-services and population health research into health policy – including policy that addresses broader societal and environmental causes of disease and health inequality.

For improved health, we also need to support research into factors outside the health system, such as food policy, alcohol policy, tobacco control initiatives, urban design, advertising regulations, taxation policy and more. There is a need for less talking and more doing in this regard. The initial research may be basic biomedical research, but it could equally arise from routine health surveillance or other applied research practices.

Translation will not occur just through collaborations. Funding of research and performance accountability needs to be governed by relevant performance metrics.

Recommendations in summary

- Increase government commitment to health research, more in line with the 4% of overall expenditure invested in research by the commercial sector.

- Improve the coordination and accessibility of de-identified cancer patient data, in parallel with the development of linkages with the national e-health system.

- Increase the proportion of NHMRC funding specifically allocated to public health research.

- Prioritise research funding based on demonstrated need – including where governments delay action on urgent public health problems on the basis of insufficient evidence.

- Explore innovative models to attract and retain philanthropic funding of public health research, including funding pools and incentive-based programs for high-value returns.

- Ensure governments retain a key funding role and collaborate more effectively with independent expert groups to guide priority-driven public health research investment.

- Conduct more comprehensive cost-effectiveness analyses of public health interventions, including criteria such as productivity gains from interventions.

- Explore opportunities to translate Australia's research-driven public health success into export opportunities.

- Identify as research priorities: cancer screening, obesity/overweight, alcohol control, skin cancer and occupational cancer.

- Commit to greater support for longer-term research projects in cancer control, to build the longitudinal evidence base.

- Note Australia's global leadership in tobacco control research.

- Fund more fellowships for researchers in the post-doctoral and mid-point career phase, particularly those who have already received initial post-doctoral fellowships.

- Take a leadership role in areas of public health where longitudinal evidence is unavailable, to assist in building the evidence base.

- Call for application of interventions where need is highest, such as obesity, on best available scientific modelling.

- Develop a more systematic approach to ensure government funding decisions are based on public health research findings.

- Recommend a formal process for ensuring strong links between the national e-health system's database and the cancer research community, to help translate opportunities in public health, epidemiological and clinical research into improved health policy.

- Recommend a targeted indigenous cancer control research strategy.

Addressing the terms of reference in relation to cancer prevention

1. The need for Australia to build and retain internationally competitive capacity across the research spectrum, from basic discovery research through clinical translation to public health and health services research.

The social and economic benefits of cancer prevention are well-documented. Moreover, public health interventions for preventing cancer can also prevent other prevalent chronic diseases, as multiple risk factors are shared. However, in 2011, only 14% of NHMRC research expenditure was allocated to public health research, and the overwhelming majority was spent on medical research.[1]

Governments frequently claim lack of sufficient evidence as a rationale for underfunding prevention programs. In addition, the claim of insufficient evidence is made as a reason to avoid or deter cost-neutral but politically challenging decisions in public health. Addressing obesity/overweight in Australia is a salient example, with governments avoiding, delaying or softening urgently needed, tough decisions on policy in areas such as food advertising and labelling.

While the establishment of the Australian National Preventive Health Agency provides an opportunity to fill some of the research gaps, it remains critical that public health research, particularly into areas of high-burden chronic disease, be highlighted as a health research priority in the context of this review.

Recommendations:

- Increase the proportion of NHMRC funding allocated to public health research.

- Prioritise research funding based on demonstrated need – including where government delay action on critical health problems on the basis of insufficient evidence.

2. Current expenditure on, and support for, health and medical research in Australia by governments at all levels, industry, non-government organisations and philanthropy; including relevant comparisons internationally.

Underfunding of disease prevention at all levels is well-documented.[2] In the context of cancer, international comparisons are of limited relevance. Australia, with its relative wealth

and long life expectancy, has one of the world's highest cancer incidence rates. (Common cancers such as those of the bowel, prostate and breast become significantly more prevalent as people age.[3])

Given our wealth, high cancer incidence and ageing population Australia should be a world leader in the relative investment in cancer prevention research, particularly where there are gaps in national and international data. While Australia's relatively small population means we should in many cases seek to adapt public health research undertaken in more populous nations to an Australian setting, we are nonetheless well-placed to invest in local research and its application.

As a community-based, non-government organisation Cancer Council Australia welcomes philanthropic contributions to public health research, provided they do not translate to an abrogation of the government's overarching responsibility to assist in guiding priority-driven research. Cancer Councils collectively are the largest non-government funders of cancer research in Australia, with projects financed by income from private and commercial donors. We therefore have a high stake in philanthropic research. An exploration of social impact bonds may be one way of attracting increased corporate financing of high-value public health research projects. It would be useful to explore opportunities to create a pool of funds that would stimulate early engagement of venture capitalists and help diminish attrition rates. In general, an approach that generates incentives rather than attempts detailed system management is likely to be more rewarding for prospective funders.

Cancer Council Australia is nonetheless strongly of the view that government in Australia has a key responsibility and accountability for driving a robust, evidence-based public health research agenda, developed in partnership with expert independent groups, through the NHMRC and ANPHA.

Recommendation:

- Explore innovative models to attract and retain philanthropic funding of public health research, including funding pools and incentive-based programs for high-value returns.

3. Opportunities to improve coordination and leverage additional national and international support for Australian health and medical research through private sector support and philanthropy, and opportunities for more efficient use, administration and monitoring of investments and the health and economic returns; including relevant comparisons internationally.

See response to point 2, re opportunities for philanthropy in public health research.

In Cancer Council Australia's view, corporate and private benefactors have an increasingly important role to play if Australia is to remain internationally competitive in public health research. There is, however, an equally important role for government – both as a direct funder of public health research and in collaborating with independent, evidence-based groups to assist in guiding research priorities.

Research priorities should be driven by need; a continuous shift towards priority-driven research funding, both in terms of direct government funding and guidance to philanthropists who wish to get optimal return on their investment, should be a key recommendation of this review.

Recommendation:

- Ensure governments retain a key funding role and collaborate more effectively with independent expert groups to guide priority-driven public health research investment.

4. The relationship between business and the research sector, including opportunities to improve Australia's capacity to capitalise on its investment in health and medical research through commercialisation and strategies for realising returns on Commonwealth investments in health and medical research where gains result from commercialisation.

See response to point 2.

As a general point, there are substantial commercial gains to be made by reducing lost productivity caused by loss to the workforce of people with cancers that could be prevented through better-researched public health interventions.

As an example, while cost-effectiveness analyses of bowel cancer screening in Australia already show high effectiveness on public health criteria, there has been no research into potential benefits to business, insurers and other sectors that are affected by health costs and lost productivity. More detailed evidence on the benefits of effective public health policy could attract greater investment from business interests, as well as assist in making the case to government for further funding of programs.

It should also be noted that Australia has the potential to export its successes in research-driven public health. For example, materials used in Australia's well-research National Tobacco Campaign have been syndicated for use in other nations. There may be commercial opportunities in other areas of public health. However, these will not be forthcoming if the relative investment in public health, and public health research, remains at such a low base.

Recommendations:

- Conduct more comprehensive cost-effectiveness analyses of public health interventions, including criteria such as productivity gains from interventions.

- Explore opportunities to translate Australia's research-driven public health success into export opportunities.

5. Likely future developments in health and medical research, both in Australia and internationally.

A number of the key potential developments in clinical cancer research have been highlighted in Part 1 of this joint submission. We are also likely to see some significant developments in cancer prevention/detection research, both domestically and internationally, including in relation to:

- Cancer screening. Cancers are generally easier and less expensive to treat when detected early, yet supported population-based screening technology exists for only three cancers – cervical, bowel and breast cancers. Broader and improved cancer screening technology should be an urgent medical and health research priority. A particular challenge is prostate cancer, where organised population-based screening remains unsupported due to the inaccuracy of current early detection technology. While Australia is limited due to its relatively small population and economy, we should nonetheless identify cancer screening as a key priority in the context of this review and seek to contribute to, or adapt, emerging international research. Although

grossly underfunded and restricted to a limited age group, Australia's National Bowel Cancer Screening Program has the potential to be a world-leading initiative, with its structure and outcomes recently presented as cutting edge at an international seminar.

- Tobacco control – where Australia is a world leader in research and policy, and where developing nations face unprecedented public health challenges;

- Obesity/overweight. Australia is among the world's five most obese OECD nations, with debate continuing about best interventions to reverse this alarming trend amid claims of insufficient evidence;

- Alcohol control. The negative impact of alcohol on Australia's social and economic wellbeing is well-documented. Despite a comprehensive harm-reduction blueprint from the National Preventative Health Taskforce, governments continue to baulk at adequate policy responses amid claims of insufficient evidence;

- Skin cancer. Australia has the world's highest relative burden, due to high UV exposure of its fair-skinned population, yet is a world leader in research largely driven by the NGO sector; and

- Occupational cancer – where polices on risk reduction remain inadequate largely due to insufficient evidence.

Two general developments of significance are the increasing need for population cohort studies and for biobanks (see Part 1).

Longitudinal population cohort studies are essential to understanding the exposures and risk factors relating to the prevention, detection and diagnosis of chronic diseases. Long-term research, however, is underfunded – possibly because funding decisions are ultimately made or influenced by government treasuries focused on shorter-term political imperatives.

Recommendations:

- Identify as research priorities: cancer screening, obesity/overweight, alcohol control, skin cancer and occupational cancer.

- Commit to greater support for longer-term research projects in cancer control, to build the longitudinal evidence base.

- Note Australia's global leadership in tobacco control research.

6. Strategies to attract, develop and retain a skilled research workforce which is capable of meeting future challenges and opportunities.

One of the key challenges to maintaining a skilled health and medical research workforce in Australia is the retention of mid-career researchers.

Recommendation:

- Fund more fellowships for researchers in the post-doctoral and mid-point career phase, particularly those who have already received initial post-doctoral fellowships.

7. Examine the institutional arrangements and governance of the health and medical research sector, including strategies to enhance community and consumer participation. This will include comparison of the NHMRC to relevant international jurisdictions.

See response to point 2, re innovative approaches to engaging with multiple sectors.

8. Opportunities to improve national and international collaboration between education, research, clinical and other public health related sectors to support the rapid translation of research outcomes into improved health policies and practices. This will include relevant international comparisons.

As outlined against Point 5, Australia is uniquely placed to drive, contribute to and adapt national and international cancer research initiatives, including through improved global and inter-sectoral collaborations.

Key opportunities in the context of cancer prevention include:

- Cancer screening, where Australia's record internationally is comparatively good, despite an urgent need for progress;

- Tobacco control, where Australia is seen as a global leader, both in research and policy; and

- Occupational cancer, wherein Australia is seeking to take a leadership role but is limited by population size and resourcing.

9. Ways in which the broader health reform process can be leveraged to improve research and translation opportunities in preventative health and in the primary, aged and acute care sectors, including through expanded clinical networks, as well as ways in which research can contribute to the design and optimal implementation of these health reforms.

Translational opportunities are critical to evidence-based public health policy; longitudinal data is pivotal to the development high-level evidence (see point 5).

There is also the need for application of preliminary studies to build the evidence base. To collect sufficient high-level evidence, governments need to introduce or pilot measures based on the best available evidence in order to show efficacy.

One of the key arguments against introducing new public health policy is absence of comprehensive evidence. This, however, leads to the absurd paradox where nothing new is done because there is no longitudinal evidence to support it. (Tobacco control policies, which long-term evidence now shows led to a substantial decline in smoking prevalence over the past 40 years, were often resisted on this basis.)

Building the evidence base on cancer prevention requires the introduction of measures for which longitudinal and empirical data may not yet be available. International studies, scientific modelling and pilot programs can be used to guide policy-makers in translating potential results in demonstrated outcomes, while longitudinal studies evolve to provide higher-level evidence.

The health reform process was expected to lead a major shift towards disease prevention, with the establishment in 2008 of the National Health and Hospitals Reform Commission and

the Preventative Health Taskforce. However, the subsequent reports and government response has had limited impact on policy and practice in disease prevention. Insufficient evidence should not be used as an excuse to delay progress in further building the evidence base on cancer prevention.

Recommendations:

- Take a leadership role in areas of public health where longitudinal evidence is unavailable, to assist in building the evidence base.

- Call for application of interventions where need is highest, such as obesity, on best available scientific modelling.

10. Ways in which health and medical research interacts, and should interact, with other Government health policies and programs; including health technology assessments and the pharmaceutical and medical services assessment processes.

There is a clear disconnect between research and health programs/policies. One of the starkest examples is the delayed implementation of the National Bowel Cancer Screening Program, shown in multiple studies to have significant potential to reduce mortality on a highly cost-effective basis when compared with other public health programs.[4] The government's own health technology assessments supported the program.[5] However, decisions about its expansion have been driven by short-term economic concerns. Greater rigour between health and medical research findings, and budget priorities, is clearly required.

Recommendation:

- Develop a more systematic approach to ensure government funding decisions are based on public health research findings.

11. Ways in which the Commonwealth's e-health reforms can be leveraged to improve research and translation opportunities, including the availability, linkage and quality of data.

The introduction of a personally controlled electronic health record, scheduled for July 2012, has significant potential to enhance public health, epidemiological and clinical cancer research capacity and outcomes.

Aggregated patient data on lifestyle, histology, genetic/familial risk, treatment and care, and other cancer information derived from the system, would be of significant value to researchers across the cancer control spectrum. Cancer Council Australia supports the decision to provide scientific access to de-identified patient data derived from the e-health system.

As a general point, we ask that this review recommend a formal process for ensuring strong links between the e-health system and the cancer research community, to help translate these opportunities to outcomes.

Recommendation:

- Recommend a formal process for ensuring strong links between the national e-health system's database and the cancer research community, to help translate

opportunities in public health, epidemiological and clinical research into improved health policy.

12. The degree of alignment between Australia's health and medical research activities and the determinants of good health, the nation's burden of disease profile and national health priorities, in particular "closing the gap" between indigenous and non-indigenous Australians.

Cancer in indigenous Australians is one of the most poorly researched areas of population health. The limited available evidence indicates that indigenous Australians are twice as likely to die within five years of a cancer diagnosis as non-indigenous Australians.[6]

Key determinants of this stark disparity in cancer survival are thought to be higher relative smoking prevalence, later presentation at diagnosis, poorer access to healthcare and decreased likelihood of completing a clinical treatment plan. The paucity of evidence beyond such broad assumptions, when considered in relation to the overall disparity in survival, emphasises the urgent need for a targeted research strategy aimed at reduce cancer burden in indigenous Australians.

Recommendation:

- Recommend a targeted indigenous cancer control research strategy.

13. Opportunities for Australia's health and medical research activities to assist in combating some of the major barriers to improved health globally, especially in the developing world.

See points 5 & 8. Also, in relation to point 12, it is important to note that Australia must ensure there is substantially greater resourcing to address the domestic health crisis among its indigenous population if it is to also seek to contribute to reducing disparities internationally.

---

[1] http://www.nhmrc.gov.au/guidelines/publications/nh154
[2] National Health and Hospitals Reform Commission, A healthier future for all Australians - Final Report June 2009
[3] AIHW, Australian cancer incidence and mortality books, 2012
[4] Pignone et al, Medical Journal of Australia, 2011.
[5] Commonwealth Department of Health and Ageing, 2002.
[6] Condon et al, Medical Journal of Australia, 2004.