



Australian Government

Australian Institute of
Health and Welfare

*Authoritative information and statistics
to promote better health and wellbeing*

McKeon Review Secretariat
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Strategic Review of Health and Medical Research 2012

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to make a submission to the Strategic Review of Health and Medical Research 2012. The AIHW supports the review's focus on optimising Australia's capacity to produce world class health and medical research.

In progressing research in the health and medical arena, it would be useful to include a focus on evaluation in addition to the development of evidence-based strategies. It would also be desirable for there to be some focus on the social determinants of health, including for example, factors such as overcrowded housing and education attainment.

In its submission, the AIHW has highlighted some opportunities available in pursuing data linkage to provide a greater wealth in data sets for socio-economic, health and clinical research purposes as well as some gaps where research could be considered in relation to Indigenous health issues.

The AIHW looks forward to contributing to research work arising from this review.

Yours sincerely

David Kalisch
Director

4 April 2012

Encl. AIHW Submission to the Strategic Review of Health and Medical Research 2012

AIHW Response to the Strategic Review of Health and Medical Research 2012

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to make a submission to the Strategic Review of Health and Medical Research 2012.

Background

The AIHW is the national agency set up to provide information and statistics on Australia's health and welfare. We are a statutory authority governed by a Board and accountable to the Australian Parliament. Our work is used to inform debate and decisions on policy and services.

We publish more than 150 reports each year, ranging from our two flagship publications in alternate years, *Australia's health* and *Australia's welfare*, to substantive reports, 'in brief' publications, journal articles and short discussion papers. We have an expanding range of innovative web products, including the *MyHospitals* website reporting individual hospital data, the *Closing the Gap Clearinghouse*, and online interactive health and welfare data sets.

Collaboration is also important in the work we undertake on the national administrative data sets for which we are the custodian. We collaborate with a range of experts from around Australia, including Australian Government, State and Territory government health, housing and community services agencies, universities and research centres, and peak non-government organisations.

We enjoy national and international recognition for our expertise in analysis and reporting of health, housing and community services information; our leadership in data integration; our management of national data collections and health registers; and the development of data set specifications, data definitions and classification systems. An important part of our work is promoting consistency among national, state and territory statistics so that we can produce and compare comprehensive national data of the highest standard.

Our work also contributes to international statistics and draws upon international standards reported by bodies such as the World Health Organization and the Organization for Economic Cooperation and Development.

Response

What are the health and medical research strategic directions and priorities and how might we meet them? (Terms of Reference 5, 12 and 13)

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

Data linkage

Data linkage, also known as data integration or statistical integration, is a set of procedures that combine personal unit record data from two or more administrative and/or survey

processes to provide new merged data sets for socio-economic, health and clinical research purposes.

Data linkage has a number of advantages as a tool for health and medical research. It maximises the use of existing data sets without any further burden on the respondents. It can include the whole population under study, or very large samples, and is thus also generally cost-effective, particularly compared with the resources required to conduct a survey or special study. Data linkage processes are based on well-developed and long-standing theory and practice, both in Australia and overseas. As with other research, there can be issues of privacy and confidentiality with data linkage, but these can be well-handled under appropriate frameworks.

There is substantial public benefit to be gained from research using linked data. This research methodology can identify evidence of cause and effect and the nature and strengths of relationships over time and across traditionally separated domains of data collection. The demand to create and provide access to linked data is growing, and the number and breadth of projects in Australia involving data linkage is expanding rapidly.

Australia has considerable data linkage experience, at both national and state levels. In the health research arena the Australian Institute of Health and Welfare (AIHW) has been undertaking data linkage projects for a number of years for both internal and external researchers. Recently the Commonwealth has developed principles and protocols for the integration (linkage) of Commonwealth data. These are designed to make linked data more available for research, while ensuring rigorous privacy and confidentiality requirements are met. In particular, data from the Medical Benefits Scheme and the Pharmaceutical Benefits Scheme are critical resources for health research and may become more available for appropriate linkage projects.

Data linkage units in Western Australia and NSW have been building state level master linkage files that enable the efficient linkage of a variety of state health and other data sets for research purposes. Other states and territories are starting to build similar capacity with the establishment of a national infrastructure for data linkage working under the framework of the Population Health Research Network (PHRN), funded by the Department of Innovation, Industry, Science, Research and Tertiary Education as a national research infrastructure priority.

These two streams of development were initially working in parallel but are now beginning to converge, which should provide greater capacity for research utilising data linkage. The AIHW is a member of PHRN and is in the process of becoming an Integrating Authority as required under the Commonwealth guidelines, ensuring it has the appropriate security measures in place to manage privacy and confidentiality issues. The AIHW also has established expertise in managing a number of critical national health data sets so is in a position to play a role in the development of a more integrated national data linkage system.

For example, the AIHW holds the National Death Index, the Australian Cancer Database and the National Diabetes Register, and requests for linkage to these national data bases have increased markedly over the last few years to over 80 per year. There is a range of clients including federal and state health departments, academic researchers, practitioners and health organisations.

Linkage is undertaken for a wide variety of research purposes, for example, to establish patterns of mortality and incidence of cancer, to analyse the outcomes of specific health treatments, or to explore associations between exposure to various conditions and mortality.

An increasingly common purpose is for the updating of disease registers, often necessary due to imperfect information on the deaths of those on the register.

In conclusion, data linkage represents a cost effective and powerful means of undertaking large-scale complex population health research. Necessary infrastructure and protocols are being developed across Australia to greatly enhance our nation's capacity to undertake research using data linkage and AIHW commends it as a future development that should be appropriately used to its potential.

ToR 12. 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

AIHW notes the importance of quality research related to what encourages healthy lifestyles, and addressing overweight and obesity, chronic disease and high smoking rates and substance use amongst certain populations. It would be useful for this research to include a focus on evaluation in addition to the development of evidence-based strategies. It would also be desirable for there to be some focus on the social determinants of health, including for example, factors such as overcrowded housing and education attainment.

In addition to the work on closing the gap between Indigenous and non-Indigenous Australians, consideration should be given to highlighting the need for research relevant to refugee and culturally and linguistically diverse populations.

In relation to Indigenous health, research is required on:

- Understanding the interaction between the complex range of factors that underpin this gap, including the historical context, individual and family characteristics, community level factors, service-related factors, and the policy context in a way that will allow interventions, programs, and policies to be directed more effectively.
- Communities/ areas in which Indigenous health status/health outcomes are better than might be expected in order to understand the mechanisms behind positive outcomes and their implications for improving health in other areas. Effective service engagement and treatment practices/ protocols along the spectrum from public health strategies to medical treatments that have led to positive outcomes, including screening, prevention strategies, identification of risk factors and risk factor reduction, early identification and treatment of conditions, and management of chronic conditions.

Addressing these research areas requires high quality data that can be linked at the individual level across sectors (e.g. hospital, GP, community health, schools), over time, which can be geocoded to permit the analysis of the impact of both place and policy, and which can be reliably disaggregated by Indigenous status. For example, Australia does not currently have a linked birth-death data set which can be used to analyse the range of perinatal factors that may contribute to infant mortality overall and to explaining the gap in infant mortality rates between Indigenous and non-Indigenous babies.

Data linkage related to Aboriginal & Torres Strait Islander people is a particular area of expertise being developed by the AIHW. The AIHW also has geospatial software (Mapinfo) which can be used to measure proximity and special access to health services and to create geographically based health indices.

The AIHW has a role in monitoring performance against various health key performance indicators and targets in relation to both the Indigenous and general population. This is an important area of research addressing key priorities of governments.

The Closing the Gap Clearinghouse is an online source of evidence-based research on overcoming Indigenous disadvantage. The Clearinghouse collects and synthesises research and evaluation evidence for policy makers and service providers in an easy to read format.

Clearinghouse issues papers and resource sheets identify the key issues on the topic, critically examine the evidence on the effectiveness of relevant programs and initiatives, and summarise what works (or doesn't work) in a paper suitable for policy makers and other interested parties. Topics covered in Clearinghouse publications include reducing alcohol and other drug related harm, anti-tobacco programs, healthy lifestyle programs, increasing Indigenous employment, and school attendance and retention.

All Clearinghouse publications are available on-line, along with access to the Clearinghouse collections of research on overcoming Indigenous disadvantage. The Clearinghouse also presents its research findings at public seminars in capital cities.

It will be important to foster interest and capacity in linking research across the different priority areas, for example drawing together research focused on environmental sustainability or protection from invasive diseases and pests with potential health-related effects.

AIHW

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