Australian Government
Australian Institute of Health and Welfare

AIHW
Stronger evidence,
better decisions,
improved health and welfare

Dr Stephen King
Commissioner
Productivity Commission
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Melbourne VIC 8003

Dear Dr King

Comment on draft report into Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to make comment on the Productivity Commission's draft report on introducing competition and informed user choice into human services: reforms to human services.

The AIHW provides accessible information and statistics on a wide range of topics about Australians' health and wellbeing. We aim to inform good decisions—and improve the health and welfare of all Australians—through strong evidence that is timely, reliable, relevant and trusted.

This submission is based on the extensive experience AIHW has gained from working closely with national health and welfare data in relation to human services, our stakeholders as well as our expertise in data linkage methods to explore fundamental policy questions.

We trust you find the attached information useful. Should you have any queries or wish to seek additional data from the AIHW, please contact our Parliamentary Manager, Ms Joanne Gardner

Yours sincerely

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Australian Institute of Health and Welfare
13 July 2017

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Introduction

The Australian Institute of Health and Welfare (AIHW) welcomes the draft report of the Productivity Commission (PC) examining possible reforms to human services.

We support the recognition of the critical role of high quality data in targeting, managing and implementing effective reform. The AIHW has made, and will continue to make, a valuable contribution across the 6 service types identified for reform in the report. This is demonstrated by the number of references to AIHW publications and data in support of the recommendations within the report.

The report provides a number of options aimed at improving data and, in particular, coverage across the sector. While the compilation of a broader Human Services evidence base is outside the scope of the report, we refer the PC to previous AIHW submissions to the Data Availability and Use and National Education Evidence Base inquiries. There is a recognised need for better evidence to support the maintenance, enhancement and ultimate reform of the system. It would be useful to include a statement of support for a vision of an overall evidence base to help promote the compilation of data necessary to assess how people traverse the human services network.

The AIHW has built effective relationships with key data suppliers and has robust technological, administrative and personnel infrastructure to support data sharing and compilation. Examples include the construction of National Minimum Data Sets (NMDSs) to bring together data from multiple sources and the establishment of AIHW's Data Integration Services Centre. The AIHW will continue to play a key role in ensuring health and welfare data is made available in order to realise the gains that can be achieved through effective use of these assets.

This submission presents information specifically relating to Recommendations 4.5, 6.4, 10.1 and 10.2. Additional supporting information on the governance processes and legislative arrangements which further describe AIHW's capabilities to handle and use human services data are presented in Appendix 1 and 2.

Comments on AIHW's role in improving knowledge base for end of life care

DRAFT RECOMMENDATION 4.5

The Australian, State and Territory Governments should ensure that there are sufficient data to enable governments to fulfil their stewardship functions by monitoring how well end-of-life care services are meeting users' needs across all settings of care.

Governments should work together to develop and implement an end-of-life care data strategy that leads to the provision of, at a minimum, linked information on:

- place of death
- primary and secondary diagnoses
- details of service provision at time of death (what, if any, health or aged care did they receive, at what level and for how long)
- whether they had an advance care plan.

The AIHW believes that access to effective, appropriate and high quality palliative care and end-of-life care services for all Australians is of increasing importance given Australia's growing and ageing population; and the associated increasing prevalence of chronic disease.

The number of Australians who will die each year is expected to rise substantially over the next 50 years, resulting in increased demand for high quality palliative care and end-of-life care services to meet the needs and expectations of individuals, their carers and their families. Palliative care and end-of-life care is provided in many health and social care settings in Australia, including neonatal units, paediatric services, public and private acute hospitals, general practices, and residential and community aged care services. Support services are also delivered to people in their own homes.

The AIHW concurs with the PC's assertion that current data and information relating to palliative care and end-of-life care in Australia is fragmented and incomplete. Issues with these data for national reporting purposes are well recognised. In the 2012 report Palliative Care in Australia, The Senate Community Affairs Reference Committee recommended: "the development and introduction of consistent national data collection specifically provide for the recording and reporting of palliative care data". This finding is echoed by the findings of the Victorian Auditor-General's Office report into Victoria's palliative care service published in 2015, which stated in relation to measuring and monitoring: "Some activities cannot be tracked because reporting mechanisms are not adequately developed to measure progress".

A range of health professionals, other workers, carers and volunteers provide end-of-life and palliative care services. These include nurses, medical practitioners, allied health professionals, social workers, spiritual and pastoral carers, personal care assistants, chaplains, massage therapists, music therapists, informal carers and volunteers. The availability of comprehensive and reliable information and data is critical to the development of evidence-based policies, effective program management and service planning today and into the future.

Current reporting

Since 2011, the AIHW has published the Palliative care services in Australia (PCSiA) report annually. The aim of the PCSiA report is to provide a "one stop shop" of available national palliative care information that will be of value to a broad range of stakeholders. However, to date the PCSiA reports have only included data from available national data collections. As such, there are a range of recognised data gaps in relation to reporting on palliative care-related activity using these data collections.

While the terms end-of-life care and palliative care are frequently used synonymously, it should be noted that these are distinct concepts which provide different challenges in relation to research and analysis as well as data development and improvement activities. As is the case with palliative care, available data collections do not allow for reporting on a range of aspects relating to end-of-life care.

Part of the challenge for analysis and reporting is identifying palliative care and end-of-life care within health and other care settings. For example, while activity which occurs in a hospice or palliative care ward in an acute hospital can be readily identified as being related to palliative care and the end-of-life period, in most other settings there are challenges, using existing data collections, to identify this activity.

Data development activities

The Commonwealth Department of Health recently contracted the AIHW to undertake a range of palliative care and end-of-life care information and data development activities to address known data gaps and support the implementation of the revised National Palliative Care Strategy, due to be finalised in late 2017.

The AIHW is undertaking a program of activities aimed at improving both the scope and quality of palliative care and end-of-life care information and data in Australia. Broadly, the types of activities to be undertaken include:

- Improving access to existing data sources.
- Developing new data sources.
- Improving and/or modifying existing data sources.

It is important to recognise that these activities cannot be successfully achieved in isolation and each requires the engagement and participation of a range of stakeholders including; the Australian Government, state and territory governments and the private and not-for-profit sectors. It is worth noting this work will have a financial cost and typically there will be long lead times before robust and reliable data becomes available.

Improving access to existing data sources

As previously noted, the AIHW's PCSiA reports have to date only included data from available national data collections. Existing state and territory health information systems could be used to address some of the recognised data gaps, such as palliative care-related expenditure, the number of palliative care beds in acute and subacute hospitals, and various aspects of the palliative care workforce.

Developing new data sources

With the cessation of the Bettering the Care and Evaluation of Health (BEACH) survey of general practice activity there is no data source available to report on general practitioners palliative care-related activity. In order to address this new data gap, alternative data sources, including the potential development of a national general practice data collection, should be investigated.

There are also currently no routine, national data sources available which would allow routine analysis and reporting on the uptake of advance care plans in the general population or care settings. Whilst some current research activities are underway to provide an understanding of the uptake of advanced care plans in healthcare settings, there are no plans for routine collection of this type of data.

Improving and/or modifying existing data sources

As noted previously, there are challenges with identifying palliative care and end-of-life care related activity outside of specialist palliative care services. One option is to add a palliative care/end-of-life care 'flag' (i.e. a specific data item(s)) to appropriate data collections to enhance reporting on this activity. Another option is to augment existing data collections. For example, new data items could be added to the existing Palliative Care Outcomes Collaboration to address data gaps in relation to available data on specialist palliative care services.

Existing population-based surveys could also be augmented to provide information on the awareness of palliative care and end-of-life care as well as experiences of care. Relevant surveys include the Australian Bureau of Statistics National Health Survey, General Social Survey and the Patient Experience Survey.

The National Palliative Care Strategy and data development

The first National Palliative Care Strategy - A National Framework for Palliative Care Service Development - was developed by the Palliative Care Intergovernmental Forum (PCIF) and endorsed by the Australian Health Minister's Advisory Council (AHMAC) in October 2000. As previously discussed, the Strategy is currently being refreshed following an evaluation by the Urbis consultancy. This affords a unique opportunity to reinforce the importance of establishing the necessary data collections and reporting mechanisms to achieve nationally consistent reporting on palliative care provision in Australia.

The AIHW would like to see the following specific actions taken to enhance nationally consistent palliative care reporting:

- Establishment of clear national governance and accountability for the data aspects of the revised Strategy via AHMAC.
- Development of an implementation plan to support the revised Strategy with identified objectives, actions, responsibilities, and indicators.
- Development of a national Palliative Care Information Priorities document/plan to outlining national priorities for developing palliative care information over the life of the revised Strategy.

Comments on AIHW's role in improving data that are collected on social housing and tenant outcomes

DRAFT RECOMMENDATION 6.4

State and Territory Governments, in conjunction with the Australian Institute of Health and Welfare, should improve the data that are collected on:

- the efficiency of social housing
- tenant outcomes, including high-cost housing payment and service recipients who choose to rent in the private housing market.

State and Territory Governments should clearly define the outcomes they are seeking to achieve to support the commissioning of tenancy management and tenancy support services, and put in place frameworks to assess their success in meeting these outcomes over time. Outcomes data should, to the extent possible, be consistent and comparable to that developed for family and community services (draft recommendation 7.3).

The AIHW supports the view presented in this draft report that the ability to measure and evaluate the performance of the social housing sector as well as tenant outcomes is of paramount importance to all levels of government.

The AIHW collects data and manages national housing and homelessness data collections, producing several public reports each year. We also provide information to other government bodies, such as the PC, cross-jurisdictional councils, and external researchers as well as directly back to data providers. We report in formats that suit their purposes and allow them to place their service provision in a wider context.

We also develop, maintain and promote data standards to ensure that data collected are nationally consistent, which supports the draft recommendation outlined above.

It is important to note that while the AIHW works closely with responsible state/territory governments and Commonwealth departments, to improve the evidence base for the Australian housing and homelessness system, we do not make final or binding determinations about which measure, indicator or measurement should be used. Rather, we make recommendations to state/territory governments and Commonwealth departments about which concepts might be measured, as well as providing advice around how a concept or indicator might best be meaningfully measured.

Data development, improvement and gaps

There have been many challenges in improving the data for reporting purposes. In recent years, the AIHW has worked (and continues to work) with all state and territory governments and Commonwealth departments, via the Housing and Homelessness Data Network (HHDN) to make improvements to housing and homelessness data.

Housing officials have agreed that further work is required to assess the current data and evidence base for housing and homelessness to ensure that governments have the information they need to make policy and service design decisions about housing and homelessness. Better information about the housing and homelessness system will enable more strategic decisions around resource allocation, funding arrangements and government interventions to improve housing outcomes.

The AIHW is working with relevant stakeholders and the HHDN, with specific action focusing on possible improvements to community housing scope and coverage, the ability to link housing data with other datasets to enable better measurement of tenant outcomes and improvement to the identification of vulnerable groups within the homelessness collection.

The AIHW is managing an on-going cross-jurisdictional data development program aimed at enhancing the current data and evidence base for housing and homelessness.

As announced in the 2017 Commonwealth budget, the development of a new National Housing and Homelessness Agreement with state and territory governments is underway. The AIHW will work with and support all states and territories, as well as the Commonwealth, in the development of better data on outcomes to support the new national agreement.

The AIHW are leaders in health and welfare data as well as being drivers of data improvements. We are committed to engaging as a trusted partner with all levels of government about how to best ensure outcomes and efficiency in the social housing sector.

Relevant data collections managed by the AIHW

The AIHW manages several data collections that are directly relevant to the issues identified and draft recommendations in this report. These collections include social housing data collections managed in collaboration with State/Territory Housing Authorities, who retain ownership of the data. These are described in the table below.

Collection	Description
Public rental and State owned and managed Indigenous housing (PH & SOMIH).	These collections contain annual data about public rental and State owned and managed Indigenous housing dwellings, the households and tenants assisted and households on waitlists. These data are an administrative by-product of the management of housing programs run by State/Territory housing authorities.
Community Housing (CH)	This collection contains annual data about in-scope community housing providers, the dwellings and tenancy rental units they manage, households and tenants assisted and households on waitlists. Data are sourced directly from community housing providers and from State/Territory housing authorities. There are some data quality issues reflecting incomplete scope and coverage, gaps in data item reporting and poor data quality at the source.
Indigenous Community Housing (ICH)	This collection contains annual data about in-scope Indigenous community housing providers, the dwellings they manage and the households assisted. Data are sourced directly from Indigenous community housing providers and from State/Territory housing authorities. There are limitations in how this data can be used due to scope and coverage issues and poor data quality at the source.

Home Purchase Assistance (HPA)	This collection contains annual data about direct lending (including government loans, shared equity loans and bridging loans), deposit assistance, interest rate assistance, mortgage relief, and other home purchase assistance grants. It excludes non-financial assistance (including advisory and counselling services), home renovation/maintenance services, and sale to tenant programs. These data are an administrative by-product of programs primarily administered by State/Territory housing authorities.
Private Rental Assistance (PRA)	This collection contains annual data about bond loans, rental grants, rental subsidies, relocation expenses and other assistance grants. It excludes non-financial assistance including tenancy support services and tenancy guarantees. These data are an administrative by-product of programs administered by State/Territory housing authorities.
Specialist Homelessness Services (SHS)	This collection contains data about people who receive services from agencies that are currently funded under the NAHA or the National Partnership Agreement on Homelessness to provide specialist homelessness services. Some data is also collected about people who seek but do not receive assistance. Data are sourced directly from specialist homelessness services.
National Social Housing Survey	This survey is a biennial survey of social housing tenants and their experiences. The 2016 survey sampled tenants of public housing, state owned and managed Indigenous housing and community housing programs. As noted in the draft report, the NSHS is the main data available on tenant outcomes.
Australian Government Housing Dataset	This data set contains annual data about income units in receipt of Centrelink payments. Data are sourced from the Department of Social Services.

Comments on AIHW's role in strengthening the MyHospitals website

DRAFT RECOMMENDATION 10.1

The Australian, State and Territory Governments should strengthen and expand their commitment to public reporting in the National Health Reform Agreement to better support patients and their general practitioners to exercise patient choice, and encourage performance improvement by hospitals and specialists. This should include a commitment by all jurisdictions to:

- provide data and other assistance to the Australian Institute of Health and Welfare (AIHW) to enable it to strengthen the MyHospitals website as a vehicle for supporting patient choice and provider self-improvement, as detailed in draft recommendation 10.2
- adopt a general policy of publicly releasing any data that a jurisdiction holds on individual hospitals and specialists unless it is clearly demonstrated that releasing the data would harm the interests of patients
- make the information that a jurisdiction publicly releases on hospitals or specialists available in a format that other organisations can readily incorporate in advisory services they provide.

To facilitate reporting on individual specialists, there should also be a commitment by:

- the Australian Government to amend the *Health Insurance Act 1973* (Cwlth) so that medical specialists are required to participate in public information provision, as specified by the AIHW
- the State and Territory Governments to oblige all specialists serving public patients in their jurisdiction to participate in public information provision, as specified by the AIHW.

DRAFT RECOMMENDATION 10.2

The Australian Government should, in consultation with State and Territory Governments, direct the Australian Institute of Health and Welfare to transform the MyHospitals website into a vehicle that better supports choice by patients and encourages self-improvement by hospitals and specialists. The changes should:

- draw on lessons from overseas examples of information provision, including the National Health Service website used to inform patients in England
- be based on market research on who would use an improved MyHospitals website, how their needs and health literacy vary, what indicators are useful to them, and how they could be informed by using best-practice approaches to presenting health information online
- put greater emphasis on reporting outcomes, such as by publishing patient-reported outcome measures, user ratings and reviews, and clinical outcomes such as readmission rates
- include the phasing-in of reporting on individual specialists as data become available, possibly beginning with registration details, followed by process data (such as location, levels of activity and out-of-pocket charges), user ratings and reviews, and, in the longer term, whether clinical outcomes are within an acceptable range.

The MyHospitals website was created in 2010 to report hospital-level performance information under the COAG-agreed Performance and Accountability Framework (PAF). Subject to the availability of high-quality and nationally comparable data, the AIHW aims to report as many of the PAF indicators as possible on this website. The information on the website is not solely focused on patient choice and can attract a broad audience, including consumers, clinicians, hospital administrators, researchers/academics, policy-makers and journalists. Further research and analysis would be useful in understanding how the website is used by different sections of the public, and how its usefulness may be improved.

The AIHW supports investigating the approaches taken and the measured results achieved by overseas websites, such as the UK's National Health Service (NHS) website, to improve and enhance the MyHospitals website to further encourage performance improvement. We caution that while user ratings and reviews may aid patient choice, they would not necessarily align with data quality and other standards required of performance reporting. This may require a distinction to be drawn in publicly presenting different kinds of information for different audiences.

The privacy aspects of public performance reporting on individual medical specialists on the MyHospitals website would need to be considered carefully.

Appendix 1: What does the AIHW do?

The AIHW is a nationally recognised independent information management agency. We enable other organisations to improve their policies and services and achieve their goals by making better use of evidence-a fundamental requirement for good decision making.

Under Australia's constitution, health and welfare services are primarily delivered by the states and territories, which are also mainly responsible for the collection of statistics on these services. A fundamental aim of the AIHW is to promote consistency among national, state and territory statistics, in order to produce comprehensive national data of the highest standard.

The AIHW is committed to providing high-quality national data and analysis across the health, housing and community services sectors, presented in meaningful and relevant ways and delivered in a timely manner. Accurate statistical information, comprehensive data development and high-quality analyses support an increased understanding of health and welfare issues. This evidence base is critical to good policy-making and effective service delivery, which have a direct impact on the lives of Australians.

We are custodians of several major national health and welfare data collections, and maintain close engagement with our data providers to ensure the quality and integrity of our work. We aim to communicate our data, information and analytical products as widely as possible in accessible formats to key stakeholders and the broader public.

Provided that a project fits with our mission, values and legislation, AIHW can carry out virtually any task related to health and welfare data. This can include surveys and other data collection activities through to developing national data standards and data sets, linking data, analysing it, and writing objective and independent reports that are valued and respected by governments and the community. We have approximately 320 expert statistical, administrative and communications staff in Canberra and in our Sydney office, backed by numerous data holdings, unmatched knowledge of the health and welfare sectors in Australia, robust governance arrangements, strong privacy and confidentiality controls, state-of-the-art business processes and infrastructure, and access to a network of government, research, education and private sector collaborators from around Australia.

In the interests of independence and transparency, nearly all of AIHW's work is released to the public—while also protecting individual privacy.

AIHW's products and services

AIHW publishes over 180 outputs each year, ranging from comprehensive national reports to technical documents and guides, to innovative web-based products. As required by the Parliament, flagship reports, Australia's health and Australia's welfare, are published in alternate years.

We have an expanding range of web sub-sites, including for mental health services, specialist homelessness services and Indigenous health and welfare. We are increasingly using interactive data visualisation services on these sites.

Several interactive health and welfare data sets are publicly available on our website, and we have produced 3 apps available for free download from Apple's App Store—Ozhealth, Ozwelfare and Indigenous info.

Robust and reliable data and evidence

AIHW plays a central role in developing performance indicators for national performance reporting in health, ageing, early childhood, education, housing and homelessness, disability care and closing the gap on Indigenous disadvantage.

In recent years AIHW developed the Specialist Homelessness Services data collection, including an online data collection portal and client management tool.

We are also continuing to work with the Department of Social Services to build and develop the National Aged Care Data Clearinghouse for policymakers, researchers and consumers. In a similar vein, for many years we have operated the National Cancer Statistics Clearinghouse, in collaboration with the Australasian Association of Cancer Registries.

We have also been custodians of the National Hospital Statistics databases for over 25 years.

Summary of AIHW capabilities and experience

- *Expertise*—we are the leading health and welfare statistics agency in Australia, with an enviable track record of over 2,500 health, welfare and housing reports over the last 25 years.

- *Data linkage experience*—we carry out 50–80 linkage projects a year of varying size, complexity and scope. We were the first organisation, for example, to undertake data linkage between hospitals and residential aged care, and between child protection, juvenile justice and homelessness services.

- *Extensive networks*—the AIHW has a strongly collaborative approach to its work, with strong relationships with the Commonwealth, and state and territory governments, universities and other expert groups, national committees, and with the private sector.

- *Access to data*—because of our reputation and our networks we have an enviable record in being able to arrange access to a wide variety of useful government and non-government datasets for data linkage purposes. As both a national 'node'—or linkage centre—within the Population Health Research Network, and as an Integrating Authority, we are uniquely placed to enable safe and secure linkage to data from state and territory databases as well as to Commonwealth data. And we also hold some of the most useful large health, welfare and housing databases ourselves. This can still take time but we work with data custodians to enable safe use of their data for important research.

- *Trust*—our extensive and effective data governance framework helps ensure that we deliver on our mission of providing authoritative information and statistics to Australians while also complying with our legal, regulatory and governance obligations in acquiring, handling and releasing data.

- *Ethics*—we work with an experienced, effective and independent AIHW Ethics Committee with efficient online application and approval processes (all data linkage projects need ethical approval).

- *Value-for-money*—our rates are comparable to our private and public sector competitors, and we have been carrying out projects under contract since we were established in 1987.

Governance of data sharing, collection and release activities

The AIHW is an Australian Government statutory agency established under the *Australian Institute of Health and Welfare Act 1987*. The Act contains very strong confidentiality protections for all data held, and requires the AIHW to publish two key biennial reports in alternate years: *Australia's health* and *Australia's welfare*. Numerous other reports are produced each year, all of which are available free of charge on the AIHW website.

Accountability and independence

As an independent statutory entity AIHW is accountable to the Australian Parliament, and is governed by a Board comprising independent and government members.

The Board is subject to the general oversight of the Minister for Health, but cannot be directed by the Minister unless he/she undertakes a consultative process with the states and territories, as set out in the AIHW Act.

Governance, privacy and confidentiality

In support of data sharing infrastructure and initiatives, data governance arrangements for data sharing are becoming more streamlined. Alongside recent guidance on data sharing activities for Australian Government Entities published by the Department of Prime Minister and Cabinet in April 2016 a simplified committee structure has been established to discuss data issues across Australian Government agencies. AIHW is currently a member of the Deputy Secretaries Data Group, DSDG, (reporting to the Secretaries Data Group) and also has representation in the Data Champions network. Groups such as the DSDG are available to consider cross-agency data issues that will impact on the availability and use of data, such as in the health, welfare and education spheres.

AIHW manages data professionally, with due respect for its sensitivity, and with privacy and confidentiality assured through legislation, rigorous data policies and procedures, and the scrutiny of a legally-constituted and independent Ethics Committee.

The AIHW is bound by 2 sets of confidentiality and privacy requirements—those contained in the Privacy Act and those contained in section 29 of the AIHW Act.

The Privacy Act establishes obligations on all private and public sector organisations for collecting, using or disclosing personal information.

Section 29 of the AIHW Act places very strong protections on the release of information concerning individuals and organisations. The AIHW cannot be forced to divulge such information, even by a court of law. The AIHW Act also recognises that AIHW must comply with written terms and conditions imposed by data providers.

The public has the right to expect that AIHW will manage data professionally, with due respect for its sensitivity, and with privacy and confidentiality assured.

As an information agency, we rely on strong data governance to retain the trust of our many data providers, data recipients and other stakeholders.

The AIHW's Data Governance Framework is a 24-page document that explains general data governance concepts, and details the AIHW's robust data governance arrangements. A copy of the full Framework is available from the AIHW.

AIHW's Data Governance Framework identifies and provides an overview of the AIHW's robust data governance arrangements, including:

- a description of key concepts in data and data governance;
- the legal, regulatory and governance environment in which AIHW operates;
- core data governance structures and roles;
- an overview of AIHW data-related policies, procedures and guidelines;

- systems and tools supporting data governance; and
- compliance regimes.

These data governance arrangements apply to data: collected and/or enhanced by the AIHW; collected on the AIHW's behalf (for example under collaborative or sub-contractual agreements); and data obtained from all external sources.

As an information agency, AIHW relies upon strong data governance to perform its functions effectively and maintain a trusted reputation amongst its many data providers, data recipients and stakeholders.

This Framework recognises that a combination of supporting legislation, roles, policies, practices and supporting tools and technologies is required to deliver effective data governance arrangements at AIHW.

In summary the data governance arrangements at AIHW help us to achieve our mission of providing authoritative information and statistics about Australians while complying with our legal, regulatory and governance obligations in acquiring, handling and releasing data.

Legislation supporting AIHW activities in data sharing and use

The AIHW Act

The *Australian Institute of Health and Welfare Act 1987* (the AIHW Act) establishes the AIHW as a Commonwealth corporate entity and sets out the Institute's functions, powers and governance arrangements. The main functions of the AIHW are to collect, analyse and disseminate health- and welfare-related information and statistics.

The AIHW Act enables the release of information for public benefit while protecting the identity of individuals and ensuring that data providers can be confident that the AIHW will adhere to data supply terms and conditions.

Section 29 of the AIHW Act contains a confidentiality provision which prohibits the release of information 'concerning a person' held by the AIHW unless one of three specific exceptions applies. These are:

- express written permission to release the information to a specific party has been given by the relevant data provider(s)

- release has been approved by the AIHW Ethics Committee, and such release is consistent with the terms set by the data provider when supplying data to the Institute

- release is in the form of publications containing de-identified statistics, information and conclusions.

The confidentiality requirements in section 29 protect a broader range of information than the Privacy Act, including information about deceased persons.

Privacy Act

The *Privacy Act 1988* creates obligations on Commonwealth agencies and private sector organisations in relation to collecting, using or disclosing personal information. The AIHW is therefore bound by two sets of confidentiality and privacy requirements—those contained in the Privacy Act and those contained in section 29 of the AIHW Act.

Freedom of Information Act

Under the *Freedom of Information Act 1982* (FoI Act), 'documents' held by agencies (which includes information in databases) are subject to access by members of the public unless a legislative exception applies. Section 32 of the FoI Act provides that data protected by the confidentiality provisions of section 29 of the AIHW Act are exempted from release under freedom of information.

Decisions on whether AIHW documents can be released under the FoI Act are made by the AIHW's Freedom of Information Officer in the first instance.

Roles and organisational structures to support AIHW's data governance activities

Board

The AIHW is governed by a Board established under the AIHW Act. The Board has 15 members who have knowledge or experience relevant to the work of the AIHW and who come from a wide range of Commonwealth, State and other organisations. The Board has approved the Data Governance Framework.

Ethics Committee

The AIHW Act establishes an AIHW Ethics Committee whose main functions are to form an opinion on ethical grounds of the acceptability of any activities being conducted by the AIHW, or the release of identifiable data for research purposes. It may impose any conditions it thinks appropriate in performing its functions.

Significantly, the Ethics Committee may authorise:

- the release of personal information for medical research that would otherwise be a breach of a privacy principle in the Privacy Act; and/or
- the release of health-related or welfare-related information as provided for in section 29 of the AIHW Act.

Further information about the AIHW Ethics Committee and its processes, including a list of approved projects is available at www.aihw.gov.au/ethics/.

Data Governance Committee

The Data Governance Committee, comprising 7 senior staff of the Institute, makes recommendations on data governance and data-related matters to the Executive Committee.

Data custodians

A data custodian is a staff member with delegation from the Director to exercise overall responsibility for a specific data collection, in accordance with legislation, policies, guidelines and any specific conditions for use applicable to that data collection. Subject to these requirements, a data custodian has the power to release data to other bodies or persons.

Prescribed security roles

Effective security risk management is required of *all* AIHW personnel and contractors. More specifically, the Australian Government's Protective Security Policy Framework (PSPF) prescribes key security roles for agencies. In AIHW, the Head of the Business and Governance Group is the Security Executive, responsible for agency protective security policy and practices, while the AIHW Facilities Manager is the Agency Security Adviser, responsible for day to day protective security functions. The Unit Head, ICT Operations, is the AIHW's Information Technology Security Adviser responsible for co-ordinating information technology security.

Data linkage

The AIHW is accredited to integrate Commonwealth data for high-risk research projects. The AIHW performs data linkage through its Data Integration Services Centre (DISC), a physically secure area within AIHW that can be accessed solely by authorised, specialist staff. Within the DISC, all data integration projects are conducted on a separate secure network and best practice data protection methods are employed.

Policies, guidelines and procedures

The AIHW's internal data policies, guidelines and procedures are designed to ensure that all staff, and especially those with delegated authority to make data-related decisions, have clear sources of information to guide them in performing their roles effectively and appropriately. These documents cover the acquisition, management, linkage, security, confidentiality, quality, publication and retention of data.

Systems and tools supporting data sharing activities

ICT systems

The AIHW's ICT systems support secure and auditable data governance processes. In particular, access to data is separately restricted at the network, data server and database level, requiring individual authorisation.

AIHW data catalogue

The AIHW's Data Catalogue is the official listing of all AIHW data collections. It:

- identifies past and present data custodians for each AIHW data collection; and
- describes each AIHW data collection, including its scope, format, period of coverage, sub-collections, availability for research, links to relevant publications, whether the collection contains identifiable data, and related datasets (if any).

A limited public version of the *Data catalogue* is available on the AIHW website.

METeOR

METeOR, which is managed by the AIHW, is Australia's registry of national metadata standards for the health, community services and housing assistance sectors. Through METeOR users can find, view and download over 2,600 data standards.

These standards provide a structured description of the characteristics of data. METeOR allows free online access to a wide range of nationally endorsed data definitions, and tools for creating new definitions based on existing already-endorsed components.

Validata^{TM}

The AIHW works with its data providers to maximise the currency and quality of data collections. The AIHW's online data receipt and validation product, Validata^{TM}, has been designed to improve the quality and timeliness of data supplied by jurisdictions and non-government organisations. It enables data providers to quickly check and validate the quality of their data submissions against a set of validation rules.

Compliance and monitoring of appropriate data usage

The AIHW Ethics Committee requires regular monitoring of the progress of projects it has approved and audits of particularly sensitive data collections. The audits occur as part of the internal audit program, with outcomes reported to the Board through the Audit and Finance Committee.

Data collections held by AIHW may also be subject to audit by data providers (for example, under conditions specified in data supply agreements) and by statutory office holders such as the Auditor-General and the Privacy Commissioner.

The AIHW Act and Australian Public Service Code of Conduct require staff to be diligent in preventing breaches of information security. A breach of the confidentiality requirements of section 29 of the AIHW Act constitutes an offence punishable by law, including imprisonment.

Appendix 2: Data linkage at the AIHW

The AIHW is an accredited Commonwealth Integrating Authority with a strong record and capacity for data linkage. The operation of the Data Integration Services Centre provides infrastructure and supports governance for the AIHW to deliver an accessible service facilitating cost effective health research. The centre maintains AIHW's standing as an accredited Integrating Authority by ensuring compliance with the newer and more stringent security and governance arrangements required of agencies wishing to undertake data linkage involving Commonwealth data where the project is classified as high risk. The centre also manages AIHW's membership of the Population Health Research Network.

The AIHW undertakes a wide range of data linkage work for researchers, both internal and external to the AIHW. This work supports a variety of innovative analyses about the health and welfare of Australians, such as longitudinal analysis and movements between health and welfare services. This work thereby acts to increase the value of individual data sets.

Data security for linked data

To secure accreditation as one of only three Commonwealth Integrating Authorities AIHW has met extremely stringent criteria covering project governance, capability, data management, security, and the protection of privacy and confidentiality.

A few of the many measures involved include: use of the 'separation principle' to ensure privacy—where personal information is stored in separate files from transactional information; a physically secure area with access available only to data integration staff; a separate secure network; all access logged; integrated data confidentialised; and data encrypted as part of the archiving process.

In carrying out its data linkage activities the AIHW abides by the National Statistical Service (NSS) *High level principles for data integration involving Commonwealth data for statistical and research purposes* and *Best practice guidelines.*

Consistency of data enhances/enables linkage and sharing activities

The consistency with which linkage variables are reported across the data sets affects how accurately linkage processes can match records for the same person across collections. Inconsistencies can result from simple reporting or processing errors (for example, in date of birth and sex). However, some variables can be expected to change over time. Three areas that have been identified as likely to impact on data linkage between education and training collections include:

- change of residential address
- consistency of reported name
- stability of person identifiers.

Examples of data linkages undertaken by the AIHW

At the AIHW, data linkage projects come in all sizes, grades of complexity and scope, on a very wide variety of topics related to the health and wellbeing of Australians.

A 'routine' health data linkage project might involve matching people who received treatment 'X' with subsequent hospital attendances or how long they lived after treatment.

At the other end of the spectrum it could be possible to link various health, welfare, education and income and support payments datasets to show how to get better outcomes and value from health and welfare programs and expenditure.

Examples of projects under way or completed at AIHW include:

- *Pathways in Aged Care (PIAC)*—this linked dataset covers aged care assessments and use of 7 different Commonwealth aged care service programs from 2002 to 2011, as well as deaths. The study showed that even where people are eligible for residential aged care they prefer to remain in their homes for as long as they can.

- *Cancer risk in people exposed to computed tomography scans*— Medical Benefits Schedule data on 680,000 CT scans were linked to the Australian Cancer Database to examine if there was increased incidence of cancer after CT scan exposure. The study showed exposure to CT scans in childhood increased the incidence of cancer.

- *Impact of a population-based HPV vaccination program on cervical abnormalities*—this collaborative study between the Australian Institute of Health and Welfare (AIHW) and the Victorian Cytology Service (VCS) linked the National HPV Vaccination Program Register with Victoria's Pap test Register. The study was the first in the world to show a population-based HPV vaccination program resulting in a fall in cervical abnormalities within 5 years of implementation.

- *Dementia care in hospitals*—this study, commissioned by Alzheimer's Australia, used linked data to investigate the experience of people with dementia in the New South Wales hospital system. It showed that people with dementia stay in hospital longer than other patients and have higher costs of care, and that the condition is often not recorded in patient records.

- *Diabetes Care Project*—this 3-year pilot study was conducted by McKinsey and Company, with AIHW being contracted to coordinate the data linkage components across a range of health data sources. The study evaluated whether new models of care deliver better-quality outcomes for people with diabetes.

- *Homelessness, income support and employment pathways*—we are undertaking a project funded by the Department of Social Services to link Specialist Homelessness Services client data with income support and employment services data from the Commonwealth Departments of Human Services and Employment. The study will to identify the service delivery patterns and pathways used by clients.

- *Child Protection data and educational achievement*—this project involves linking Child Protection data with educational achievement data as measured by NAPLAN (National Assessment Program—Literacy and Numeracy) testing.

- *Child immunisation and health*—two projects we are undertaking in 2014–15 involve linking child immunisation and health outcomes data.