



Australian Association of Gerontology

Position Statement – Standardising access to administrative datasets on aged care programs for research purposes

Overview

- 1 The Australian Association of Gerontology (AAG) considers that the development of standardised processes and protocols to facilitate access to administrative datasets on aged care programs for research purposes is essential to advancing evidence-based policy and programs.
- 2 Standardised approaches are required to address the varied arrangements that currently apply to accessing datasets held by various government departments and agencies, and in particular to facilitate access to de-identified unit record data for researcher initiated projects.
- 3 It is recognised that the primary purpose of these data collections is the administration of government programs, but the value of using them for research must also be acknowledged as they are a significant source of evidence for evaluating services and informing policy and program development.
- 4 Systems developed to govern access to other government databases and which are used by a number of research centres provide a guide for enhancing access to aged care databases, but do not replace the need for systems and protocols specific to aged care datasets.
- 5 In standardising protocols, the experience of the Australian Institute of Health and Welfare (AIHW) in developing measures to address quality and release of data, and the guidelines established by the National Health and Medical Research Council (NHMRC) for enabling access to databases, should be taken into account.
- 6 It is emphasised that the owners of various datasets and those seeking access to them frequently have a shared interest in using the data, and that both can be frustrated by the lack of protocols that address the interests of all parties.
- 7 Standardisation provides a means of addressing six main problem areas that arise in relation to consistency in practice, data quality and documentation, timeliness, enabling access for exploratory investigation, cost-effectiveness, and privacy and confidentiality.

- 8 Strategies for developing standardised approaches should include a review of recent requests to the Australian Government Department of Health and Ageing (DoHA) for access to data and responses to these requests, and a comparison of arrangements covering different datasets to establish and enhance best practice that can be applied in standardising access to aged care datasets.
- 9 Given its role in advancing research in ageing, DoHA should be given responsibility for implementing strategies for standardising access to administrative datasets.

Scope

This Position Paper focuses on datasets covering national aged care programs administered by the Australian Government and in conjunction with States and Territories. Table 1 shows that these datasets are held by different agencies and that access to them is governed by different arrangements.

Context

Interest in increased access to administrative data for aged care programs arises in the wider context of growing recognition of the power of using routine datasets for research. Initiatives such as the National Collaborative Research Infrastructure Strategy (NCRIS) are designed to enhance this research potential. The Australian Social Sciences Data Archive at the Australian National University (ANU), which is part of NCRIS, has well-established procedures for researchers seeking to access the datasets it holds, which include data from the Australian Bureau of Statistics (ABS) and other large-scale surveys. Entities such as the Centre for Health Record Linkage in New South Wales and the Western Australian Data Linkage Unit (WADLU) also provide mechanisms for health data to be used for projects that are for the benefit of the public. The systems developed by these agencies facilitate use of data by researchers, provide privacy protocols and governance systems, and also enable appropriate ethical approval for bona fide research projects, while vesting approval to access the data with the appropriate data custodian.

Aged care researchers have made use of Medicare and Pharmaceutical Benefits Scheme data, and ABS surveys such as the National Mental Health Survey. In some cases, researchers have been able to access Medicare data directly through DoHA, the Department of Veterans' Affairs and Medicare

This Position Statement represents the views of the Australian Association of Gerontology. It was endorsed by the AAG National Council on 19 November 2009. Enquiries about the statement should be directed to the AAG Executive Officer, Dr Tony Coles, at eoag@aag.asn.au

Table 1: Administrative datasets on national aged care programs

Dataset	Owned by	Held by	Arrangements for accessing unit record data
Aged Care Services List	Department of Health and Ageing	Department of Health and Ageing	Open access via http://www.health.gov.au
Residential Aged Care Program, including packages and transition care	Department of Health and Ageing	Department of Health and Ageing	Covered by the <i>Aged Care Act 1997</i> . Applications for access to unit record data must go to Department of Health and Ageing.
Home and Community Care (HACC) Program	Joint Commonwealth, State and Territories HACC Officials Group	HACC National Data Repository	Protocol in place, applications to HACC Officials Group, forms available online
Aged Care Assessment Program	Department of Health and Ageing and State/Territory officials	Department of Health and Ageing; until 2008, National Data Repository for Aged Care Assessment Program was at La Trobe University.	No standard arrangements in place. Release of data subject to Department of Health and Ageing agreement.
National Respite for Carers Program	Department of Health and Ageing	Department of Health and Ageing	No standard arrangements in place
Veterans' Home Care (and other Department of Veterans' Affairs' programs)	Department of Veterans' Affairs	Department of Veterans' Affairs	Application to Department of Veterans Affairs

Australia. In other cases, researchers have been able to use these data for subjects in surveys who have given consent for their records to be accessed. Examples of the latter approach include the Dubbo Study Longitudinal Study (<http://www.dubbostudy.org/>) and the Australian Longitudinal Study on Women's Health (<http://www.alswh.org.au/>).

Many research projects using these databases have generated results of value to policy and program development. Analysis of large-scale administrative datasets has been particularly useful for identifying areas or groups for special attention on one hand, and for enabling generalisation from small-scale studies on the other. Table 2 details examples of studies reported in the *Australasian Journal on Ageing* over the 5 years to mid 2009, and projects carried out by the AIHW.

It is acknowledged that access to datasets has to be negotiated separately for each research project, and that this has occurred successfully in many instances. At the same time, there are reports of less positive experiences, with researchers having projects constrained by difficulties in accessing datasets, or thwarted by not being able to access needed data at all. These difficulties cannot be attributed to researchers' inexperience as they have been reported by well-established research teams holding large grants from major funding bodies. Nor are these problems trivial; WADLU reports that between 2005 and 2009, only 9 of 23 requests for release of Commonwealth data, including from aged care datasets, had been granted, with delays of up to 2 years jeopardising projects with funding in excess of \$11 million, mostly from nationally competitive NHMRC grants.

The need for standardisation of access to datasets is not unique to ageing and aged care, and there are lessons from

other areas of government programs where progress has been made. Most relevant are the roles of the AIHW and guidelines of the NHMRC.

Roles of the AIHW

The AIHW is the main body with responsibilities for collecting and reporting on a wide range of data on behalf of the Commonwealth, States and Territories, and its roles are covered by legislation. The AIHW is committed to providing statistical information that governments and the community can use to promote discussion and make decisions on health, housing and community services. At the same time, the AIHW has responsibilities to ensure that data privacy and confidentiality are maintained. Data release must be approved by the AIHW Ethics Committee (information about this policy and process is available at http://www.aihw.gov.au/dataonline/privacy_of_data.cfm). National data standards approved by relevant national committees are also available through the AIHW's Metadata Online Registry (METeOR).

The AIHW has experience in releasing data to others, is familiar with large-scale datasets (particularly with regard to developing data standards and ensuring quality), and has experience in using these databases for research. Four levels of release of data adopted by AIHW warrant note in considering standardised protocols for accessing databases more widely:

- 1 There may be restrictions or special conditions governing the public availability of data holdings. Under the confidentiality provisions contained in the *Australian Institute of Health and Welfare Act 1987*, and also under the *Privacy Act 1988*, there are some data holdings that cannot be made publicly available.

Table 2: Examples of research projects using aged care program administrative datasets

Project	Researchers	Databases used	Source
General practice encounters with older Australians	O'Halloran and Britt	BEACH: Bettering the Evaluation and Care of Health Program	Australasian Journal on Ageing, 23 (2004):7–12
Dementia and ethnicity in the New South Wales Aged Care Assessment Program, 1996 and 2001	Lister and Benson	Aged Care Assessment Team Minimum Data Set	Australasian Journal on Ageing, 25 (2006):24–30
Epidemiology of hip fracture in the Australian Capital Territory	Fisher, Davies, Rubenach, LeCouter and McLean	Hospital separation data, 1994–1999	Australasian Journal on Ageing, 26 (2007):45–51
The acute-aged care interface	Travers, McDonnell, Broe, Anderson, Karmel, Duckett and Gray	National hospital and aged care administrative data bases, accessed via Australian Institute of Health and Welfare	Australasian Journal on Ageing, 27 (2008):116–20
Prevalence of depression in older people	O'Connor and Parslow	National Survey of Mental Health and Well-being	Australasian Journal on Ageing, 27 (Suppl 1) (2008): A24
Identification of dementia cases and death rate estimates	Zilkins, Spillsbury, Bruce and Semmens	Linkage of data on all hospitalised persons with a diagnosis of dementia and death records, through Western Australia Data Linkage System	Australasian Journal on Ageing, 27 (Suppl 1) (2008): A60
Pathways in Aged Care cohort study (PIAC)	Australian Institute of Health and Welfare	Linked data from Aged Care Assessment Program, Residential Care, Community Aged Care Packages, Extended Aged Care at Home, Home and Community Care, Veterans' Home Care and the National Death Index.	Australian Institute of Health and Welfare website
Influence of hospital-based dementia services on patient outcomes and post-hospital destinations for people with dementia	Australian Institute of Health and Welfare	Hospital data, linked internally to create total patient stays, also linked with Aged Care Assessment Program and residential aged care data. Survey of relevant hospital services will also be carried out.	Australian Institute of Health and Welfare website

- 2 Access to other datasets may be available subject to special approval, which in some of these cases must be given by the data providers themselves.
- 3 In other instances, access is available by means of tables prepared by the AIHW in response to specific requests and charges apply in these cases.
- 4 Some data are made available through online cubes, free of charge, including hospitals data and general practice data (see <http://www.aihw.gov.au/dataonline.cfm>). These data cubes allow simple analyses and cross-tabulations.

Regarding aged care data, the AIHW receives a copy of certain datasets for its legislated reporting purposes. But the AIHW does not own or have custodian responsibilities for these data. In broad terms, the AIHW can respond to queries about these data and can provide tables and analysis subject to privacy and confidentiality provisions, but AIHW cannot provide access to unit record data from this source.

NHMRC guidelines and processes

Access to administrative datasets, particularly unit record data, raises a number of concerns about privacy and confidentiality. The NHMRC has developed guidelines on these and other aspects of research and much research in ageing is covered by these provisions. The ways in which these guidelines apply to accessing existing datasets can contribute to standardisation of protocols for aged care datasets.

According to the NHMRC guidelines, before deciding to waive the requirement for consent (other than in the case of research aiming to expose illegal activity), a Human Research Ethics Committee or other review body must be satisfied that:

- (a) involvement in the research carries no more than low risk to participants;
- (b) the benefits from the research justify any risks of harm associated with not seeking consent;
- (c) it is impracticable to obtain consent (e.g. due to the quantity, age or accessibility of records);
- (d) there is no known or likely reason for thinking that participants would not have consented if they had been asked;
- (e) there is sufficient protection of their privacy;
- (f) there is an adequate plan to protect the confidentiality of data;
- (g) in case the results have significance for the participants' welfare there is, where practicable, a plan for making information arising from the research available to them (e.g. via a disease-specific website or regional news media);
- (h) the possibility of commercial exploitation of derivatives of the data or tissue will not deprive the participants of any financial benefits to which they would be entitled;
- (i) the waiver is not prohibited by State, federal or international law.

These guidelines have two implications of particular relevance to researchers and Human Research Ethics Committees in dealing with clearance of access to de-identified unit record data in administrative datasets.

First, research using such data comes within the category of low-risk research as defined by the NHMRC. Low risk means that using the data will not harm the participants in any way, nor will it deprive them of any benefits to which they would otherwise have been entitled. Furthermore, de-identification means that participants' privacy and confidentiality are well protected.

Second, Human Research Ethics Committees established under NHMRC guidelines need to be familiar with the different ethical considerations involved in the use of pre-existing administrative datasets and special-purpose survey data. Many Ethics Committees that deal mostly with clinical research that requires informed consent from individual participants in any study are, however, not familiar with these differential ethical considerations. Failure to acknowledge these considerations (e.g. the impracticality of adhering to principles such as obtaining informed consent at the time of data collection) can lead to unnecessary delays in Ethics Committees granting approval for research projects submitted to them.

The case for standardisation of data access protocols

Standardisation of approaches to accessing data provides a means for addressing a number of problems faced by those who own datasets and who are responsible for approving access to them, and by those seeking access to them. Although approaching access to data from different perspectives, data owners and researchers have many common interests in making greater use of data, and also encounter common problems in working to this end. Six key concerns that could be substantially resolved by adopting standardised protocols have been identified.

1. Consistency in practice

A lack of clarity about processes to be followed on the part of data owners and those seeking access to data can result in conflicting advice and differential access between jurisdictions, and on different occasions, even for access to the same dataset. These uncertainties can undermine trust on all sides.

As well as expediting the research process for all concerned, consistency in approaches would yield advantages by way of reducing duplication of researchers' efforts in data collection and increasing capacity to conduct large-scale projects of direct relevance to policy and program development. By providing a common set of rules, standardisation would achieve consistency for owners of data and researchers, and for others collaborating in research activities, including providers and consumer groups.

2. Data quality and documentation

Not all datasets are equally well documented, making it difficult for users to know that they are interpreting the data

appropriately or correctly. The AIHW has developed a number of data dictionaries and standards to ensure quality of data collection, including some of the aged care program datasets. The expertise of the AIHW could be engaged where appropriate to consider where further data documentation is required. Data documentation can also usefully extend to technical aspects of electronic data transfer and security, and a register of all users of different datasets could usefully be maintained to facilitate contact between parties with interests in particular datasets.

3. Timeliness

Currently, applications for access to government datasets are not always dealt with in a timely fashion, and protracted delays in receiving data can make it difficult for researchers to complete projects on time and on budget. Standardisation of timelines for steps in accessing datasets would avoid delays in planning and conducting research and facilitate staging of projects, especially where later lines of inquiry depend on findings from earlier stages; it would also assist in managing project resources and staff.

4. Enabling access for exploratory investigation

To date, the limited use of many datasets means that their potential is not easily ascertained. Yet research proposals often call for quite detailed specification of analyses to be undertaken. Some datasets may have far more potential for analysis than might be anticipated on the basis of data that have been reported, but in other cases, the range of analyses may be much more limited than anticipated. The dilemma of specifying analyses to be undertaken with relatively unknown datasets could be resolved by making provision for access to samples of real or dummy data in standard protocols. Together with viewing full documentation of the content and quality of the database, accessing a sample of data for preliminary investigation enables researchers to test that planned analyses can in fact be undertaken.

5. Cost-effectiveness

As collecting data incur a cost for providers and government, further use of datasets adds value to this expenditure. Under-utilisation of administrative datasets means that there is little return on the investment made in data collection beyond basic reporting of aggregate data, and providers have little way of knowing how their services and clients fare in comparison to other services. Use of data for research can, in turn, contribute to refinement of data collection and enhancement of quality, again increasing cost-effectiveness.

While access to data would ideally be free, the time and effort involved in assembling the database requested by researchers needs to be taken into account in setting costs. Costs can be limited by making full datasets available rather than data owners having to undertake extensive editing and selection. Minimising selection enables researchers to assess the fullest possible range of use of the data, and provisions in access protocols can require consultation on the actual extent of

analyses to be carried out in any particular project. Issues of data selection and editing are particularly important for data linkage where investigators need to be able to select the data items that are most consistent across databases and that will maximise the usefulness of data analysis.

6. Privacy and confidentiality of data

Considerations about privacy and confidentiality are central to data owners' concerns about what the data are to be used for. While established NHMRC processes, as noted above, are available to safeguard use of data, responsibility for clearance of release and use of administrative datasets is currently unclear and differs between jurisdictions and agencies. The result is that at times there is confusion and tension between ethics committees established by agencies holding data, such as DoHA, and ethics committees in universities, health services and other bodies set up in accord with NHMRC guidelines and recognised in submissions for funding from the NRMHC and other funders. These different ethics committees should have complementary roles, and standard protocols would provide a means of harmonising their roles. Standardised protocols would establish a common ground for all parties in areas such as the limits on the use of data by specifying that data can only be used for the approved project, that data must be stored securely, and that data cannot be transferred to any other user. Data repositories, such as the Australian Social Science Data Archive, have strict procedures that could provide models for standard protocols covering access to aged care databases.

Strategies for advancing standardisation

Two broad strategies are proposed for advancing standardisation of access to aged care datasets for research purposes. First, experience with requests for access to various databases over the last 5 years and responses to these requests need to

be reviewed to identify factors that have either facilitated or posed barriers to access. In this review, particular consideration should be given to the measures applied to maintain data protection and ensure that ethical standards have been upheld, in accord with NHMRC guidelines. The roles of the DoHA ethics committee vis-a-vis other institutional ethics committees also need to be taken into account. Furthermore, the interests and involvement of service providers and consumer groups also need to be considered.

Second, protocols and processes covering access to different databases need to be compared to identify approaches that are seen to be most effective for all parties. Establishing current best practice provides a basis for standardisation of access to other datasets by prompting consideration of how current practice could be further enhanced and by identifying the extent and nature of changes required to bring access to other databases into line. This strategy should include investigation of the roles of various data repositories and clearing houses that store and disseminate relevant data to interested parties.

Action to advance standardisation of access to aged care datasets through these strategies comes within the responsibilities of DoHA. An initiative to this end would build on the Department's carriage of the Building Ageing Research Capacity initiative and the ARC/NHMRC Research Network in Ageing Well over the last decade, and its ongoing management of the Ageing Research Online directory. Standardisation of access protocols would not only bring benefits for researchers, but would increase use of administrative databases and thereby realise a number of benefits for governments, for service providers, and ultimately for those who are actual or potential clients of various programs.