Health information collection and use: the Koori Human Services Unit of the Victorian Department of Human Services

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Introduction
In order to plan for and provide appropriate and effective health services for the Aboriginal peoples of Victoria, the Department of Human Services (DHS) requires the collection of accurate and timely data from a wide variety of sources. The submission of this data, however, presents unique and complex challenges for those charged with building an accurate and reliable picture of the health status and health services provided to the Victorian Aboriginal population.

This report aims to identify health information flow through an individual Unit of the DHS; to demonstrate this flow attention will be paid to the process undertaken by the DHS Koori Human Services Unit (KHSU) in the production of one of their regular reports, Koori Health Counts! A description of this process enables understanding of the breadth of information required, the types of information generated by external sources and by the KHSU itself, and the sources to which this information is transferred. For the purposes of this report, external sources are any sources of data or information produced or reported outside the confines of the KHSU.

When compared with other demographic groups, the Aboriginal population displays the poorest health status of all Australians (Australian Institute of Health and Welfare 2005a; Department of Human Services 2005). Aboriginal communities experience significant disparity in accessing medical services, a higher rate of disease prevalence and shorter life expectancies than the non-Aboriginal community (Australian Bureau of Statistics in Australian Bureau of Statistics and Australian Institute of Health and Welfare 2005, Koori Human Services Unit 2005). The disparities experienced by the Aboriginal population demonstrate the importance of gathering and analysing data relating to Aboriginal peoples to enable policy makers and service providers to improve the health of these communities.

Koori Human Services Unit
The Victorian State Government comprises ten Departments containing numerous divisions, branches and units, one of which is DHS. The KHSU sits within the Portfolio Services and Strategic Projects Division of the Social Policy Branch of the DHS. Its role is to assist in the provision of culturally appropriate health services to the Victorian Aboriginal population and to collaborate with Aboriginal communities regarding these services (Social Policy Branch 2006). To this end the KHSU produces a series of regular and ad hoc reports detailing the activities, initiatives and outcomes of the Unit and the Department of Human Services, and also undertakes the provision of Victorian data to national data collections and Victorian responses to specific reports.

Koori Hospital Liaison Officer program
The Koori Hospital Liaison program began in 1982. Initially known as Koori Hospital Liaison Officers, the Liaison Officers are now referred to as Aboriginal Hospital Liaison Officers (AHLOs), as not all Aboriginal patients are Koori (see below, ‘data definitions’) (Department of Human Services 2006, Koori Human Services Unit 2006). Originally the AHLO positions were funded by direct subsidies to the hospitals from the DHS. Since 2004-05, hospitals have received a 30% WIES Aboriginal funding supplement for all patients identifying as Aboriginal through the Improving Care for Aboriginal and Torres Strait Islander Patients program (ICAP) (Department of Human Services 2005). The proviso of this supplementary payment is that these extra funds be spent on health agency initiatives for...
improving the health of Aboriginal people. While not limited to the employment of AHLOs, many health agencies choose to use the payment for this purpose.

There are currently 23 AHLOs covering 27 metropolitan and regional Victorian hospitals; providing support, guidance, assistance and understanding to Aboriginal patients and their families. Current Victorian hospitals with an AHLO are listed in Table 1 (Koori Human Services Unit 2006).

**Table 1: Hospitals Currently Employing an Aboriginal Hospital Liaison Officer**

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Location</th>
</tr>
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<tbody>
<tr>
<td>Austin and Repatriation Medical Centre</td>
<td>Mildura</td>
</tr>
<tr>
<td>Bairnsdale Regional Health Service</td>
<td>Monash Medical Centre, Clayton</td>
</tr>
<tr>
<td>Ballarat</td>
<td>Moorabbin</td>
</tr>
<tr>
<td>Bendigo Health</td>
<td>Northern</td>
</tr>
<tr>
<td>Central Gippsland</td>
<td>Orbost</td>
</tr>
<tr>
<td>Dandenong Monash Medical Centre</td>
<td>Portland</td>
</tr>
<tr>
<td>Dimboola</td>
<td>Robinvale</td>
</tr>
<tr>
<td>Echuca</td>
<td>Royal Children's</td>
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<tr>
<td>Frankston</td>
<td>Royal Women's</td>
</tr>
<tr>
<td>Geelong</td>
<td>St. Vincent's</td>
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<tr>
<td>Goulburn Valley, Shepparton</td>
<td>Sunshine</td>
</tr>
<tr>
<td>Horsham</td>
<td>Swan Hill</td>
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<tr>
<td>Latrobe Regional</td>
<td>Warragul</td>
</tr>
<tr>
<td>Mercy Hospital for Women</td>
<td>Warrnambool</td>
</tr>
</tbody>
</table>

**Koori Health Counts!**

*Koori Health Counts!* is an annual report produced by the KHSU detailing the health status and service utilisation of Victoria’s Aboriginal population. The aim of *Koori Health Counts!* is to ‘... improve the availability of Aboriginal health information in Victoria, and to provide the information in a way that is appropriate for use both within the Aboriginal community and for mainstream health providers.’ (Koori Human Services Unit 2006: p.2.) The report is distributed widely to health and community agencies and is available for public access via the DHS website at <http://www.health.vic.gov.au/koori/counts/>.

Data is sourced from a variety of collection agencies, with the principal source being data submitted by the AHLOs. The number of Aboriginal admissions to hospital, major causes of admission, age of Aboriginal mothers, birth weights of babies and the age and causes of deaths of Aboriginal people are presented, enabling comparison between years, regions and populations (Koori Human Services Unit 2006). In addition, more specific information on selected medical conditions affecting the Aboriginal population is included to increase the knowledge of the users of the report.

**Data definitions**

The National Health Data Dictionary (NHDD) incorporates a standard devised by the Australian Bureau of Statistics (ABS) regarding the definition of Indigenous status (Australian Institute of Health and Welfare 2004). Designed to ‘improve the quality, availability and comparability of Indigenous statistics across data collections’ (Australian Institute of Health and Welfare 2004: p. 5), this data element is now a reporting requirement in many data collections (Australian Institute of Health and Welfare 2004) and has been mandatory for all Victorian Hospitals since 1993 (Koori Human Services Unit 2006).

For a person to be recorded as an Aboriginal or Torres Strait Islander by the Victorian Department of Human Services they must be of Aboriginal or Torres Strait Islander descent and identify themselves as such (Koori Information Plan Steering Committee 2004). Terms such as Aboriginal, Koori and Indigenous are all used to refer to people identifying themselves as being of Aboriginal and/or Torres Strait Islander descent. Koori is the term used in south eastern Australia:
Tasmania, Victoria, and parts of New South Wales and South Australia (Department of Human Services in press). In this report the term Aboriginal will be used to refer to people of Aboriginal or Torres Strait Islander descent unless the title of a program or publication uses an alternative term (Department of Human Services in press).

**Internal data sources**

A component of the AHLO role is the submission of monthly figures to the DHS. Data is submitted via both the Agency Information Management System (AIMS) database and direct to the KHSU. Currently an attempt is underway to streamline the reporting of data, thus contributing positively to information flow.

When submitting data to the KHSU, AHLOs may choose to use email, fax or post. The raw data submitted forms the basis of *Koori Health Counts!*, and is used as ‘a cross check on main-stream sources of information such as the Victorian Admitted Episode Database (VAED), the Perinatal Data Collection Unit (PDCU)…’ (Koori Human Services Unit 2006: p. 4).

**External data sources**

*Koori Health Counts!* makes use of Aboriginal data collected by other agencies by using this data to confirm and provide perspective on AHLO data. External sources of data can be independent agencies or other Departments or divisions within the Victorian State Government including the Registry of Births, Deaths and Marriages (RBDM). The external sources of the VAED and the Australian Bureau of Statistics (ABS) will be considered here.

Data from the VAED, including Aboriginality, is used to confirm the accuracy of data submitted by the AHLOs, enabling any identification and resolution of cases of under-identification from either reporting process. Population data published by the ABS is used by the KHSU to calculate rates and to report on the size of the Aboriginal population by jurisdiction (state), DHS region, Aboriginal status, age and sex.

**Problems affecting information flow**

While the AHLOs provide a useful cross check and another source of data, problems exist with recording Aboriginality in Victorian hospitals. Difficulties and barriers can have a negative impact on the flow of information into and through the KHSU. In order to account for differences in data these problems are recognised, compensated for and explained during the preparation and publication of information.

**Difficulties with the collection of raw data**

The Aboriginal patient dataset is continually evolving, often making comparisons difficult. It is difficult to ascertain the true size of the Aboriginal population, both as a whole and those using hospital or health care services. A significant contributing factor to this is the growing willingness for Aboriginal peoples to identify themselves as such in a hospital environment, leading to a larger Aboriginal representation in the data collection. The trap is to infer health results from this new representation rather than recognising a more accurate representation of the Aboriginal peoples’ health situation. However, even with this increased willingness and methods of adjustment there is still a well-founded concern that the Aboriginal population is underrepresented in statistics (Australian Institute of Health and Welfare 2005b).

Obtaining data presents two types of difficulties. First, there are many cultural influences and past experiences with health service providers over many generations that have impacted significantly on the health of Aboriginal people and their communities (Clarke, Andrews & Austin n.d). This affects the flow of data by influencing the accuracy and type of information Aboriginal people feel comfortable divulging. There may be a reluctance for Aboriginal people to identify themselves as such in a health care environment (Aboriginal and Torres Strait Islander Health and Welfare Unit 1997). Self identification is a vital concept (Vidgen 1996) and one on which the NHDD definition of the Indigenous status data element is based (National Health Data Committee 2003).

Second, there are the range of issues experienced by those collecting Indigenous status data at the organisation level, such as a lack of understanding as to why the question is being asked (Australian Institute of Health and Welfare 2004; Lewis & Lynch 1999), being embarrassed to ask, or a fear of being perceived as discriminatory.
Questions must be written to avoid multiple interpretations and must also be delivered in a positive and non-threatening environment. The KHSU must assume Aboriginal people would identify themselves as such if they were comfortable doing so. This assumption requires a consideration of the impact false positives and negatives have on the collection of Aboriginal data. False negatives occur when Aboriginal persons who identify themselves as such in a non-threatening or positive environment, do not in other situations, for example when they are unsure of the question being asked, if it was simply not asked, or the reason for the question was not explained. False positives are instances where non-Aboriginal people are identified as Aboriginal for reasons such as a lack of understanding of the question, errors in systems which incorrectly attribute Aboriginal status to all, or those recording the information incorrectly assuming the person is of Aboriginal descent. False positive and false negative data errors also occur when the question of status is not asked, and the status is guessed based on physical appearance. The only time false positives and negatives can be identified with any certainty is when they occur in large numbers over a short period of time, therefore an inherent aspect of Aboriginal data is that it contains false positives and negatives that will never be identified. These issues of identification and reporting are not unique to Victoria (Lewis & Lynch, 1999).

Methods of data collection vary not only between agencies but also over time, making comparisons between years or reports difficult. Definitions of Aboriginality and Indigenous status have also changed over time, adding complexity to the task of accurately interpreting data (Morrow & Barraclough 1991). The diverse nature and goals of the agencies collecting Aboriginal data results in the KHSU receiving data of differing levels of quality, with differing views on the relative importance of the data collection and a lack of understanding as to how and why the data will be used.

**Barriers to data submission**

The KHSU is attuned to the unique situations of AHLOs when submitting their data. Often the AHLOs are more comfortable presenting their information in a verbal rather than written format. Reluctance of AHLOs to use technology may result in data not reaching the KHSU. Imposing strict reporting requirements would cause many AHLOs to stop submitting data, so consideration and several data submission options are available. Depending on the hospital, AHLO access to computers, email or medical records maybe limited or non-existent, compounding the problem of complete data submission. Cultural issues make it difficult for male or female AHLOs to report on particular conditions. For example, male AHLOs may be reluctant to report data on births or obstetric admissions.

**Privacy and reporting restrictions**

Restrictions on how information can be reported impact upon its flow. In Victoria the Health Records Act 2001 imposes restrictions on why health information is collected and the uses of the information, and the Information Privacy Act 2000 regulates the collection of non-health information (Office of the Health Services Commissioner, 2004). The collection of Aboriginal data is no exception to this legislation.

Australia’s Aboriginal population was estimated in 2001 to comprise 2.4% of the total Australian population (Australian Bureau of Statistics & Australian Institute of Health and Welfare 2005: p. 3). In Victoria, the Aboriginal population accounts for 0.6% of the State’s population (Koori Human Services Unit 2006: p. 7). This results in a small dataset, impacting on the type and manner of information that can be made available. Tight restrictions ensure it is not possible to identify an individual from the number and geographical location of data published. A flow-on effect of these restrictions may be difficulty in identifying trends or problems.
Conclusion
The flow of data through the KHSU is an ongoing cycle of retrieving, cross checking and reporting, and is affected by the sources of data, methods of submission, quality and validation checks, reporting restrictions and the needs and priorities of the users. The KHSU accumulates and generates data from a variety of sources in order to provide a composite picture of the health of Aboriginal communities in Victoria, as it is recognised that no single data collection can accurately portray the situation. The KHSU uses this data to produce *Koori Health Counts!*, to inform and educate interested parties and to influence policy and resource allocation.

The transfer of data to external sources usually takes the format of reports. The KHSU is responsible for the production of and contribution towards both State and Commonwealth reports. Transferring this data back to its original source is especially important in the case of *Koori Health Counts!* AHLOs use the information in their day-to-day activities of health promotion and awareness, and the report provides an informative picture of the health status of Aboriginal people in Victoria. Information in *Koori Health Counts!* also has an impact on service provision. Information generated is used to obtain resources for services such as ‘alternative birthing services for Aboriginal women’ (Koori Human Services Unit 2006: p. 38).

The information contained in *Koori Health Counts!* is of great interest to service providers, administrators, policy makers, educators and Aboriginal communities and is distributed to many institutions and service providers in order to facilitate the improvement in health services delivered to Victorian Aboriginal communities. It is important for Health Information Managers to understand what needs to be recorded and reported and how the information impacts not only on the health service in which they work in relation to funding and decision making regarding service delivery, but also on the Victoria-wide provision and monitoring of health services.

References


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