

8 Recommendations for methodology / data enhancement

A great number of reports have been written concerning the health of Aboriginal and Torres Strait Islander people and they arrive at the same conclusion—that the data collected is of lower quality than that which could potentially be obtained and reported. Several factors have been put forward to explain the poor quality of data including: antiquated and convoluted administrative systems, privacy concerns, legislative barriers, inadequate funds, cultural misunderstandings and insufficient urgency.

A key recommendation of many of the reports mentioned in this chapter was for the improved identification of Aboriginal and Torres Strait Islander people across the health spectrum.

Primary health care estimates

Both this report and the first report relied on surveys to make estimates of the use of medical and pharmaceutical services by Aboriginal and Torres Strait Islander people and the cost. Surveys are inherently unreliable due to sample error, and when one is attempting to measure usage by a small group in society, such as Aboriginal and Torres Strait Islander people, the sample error is higher. In addition there are non-sampling errors such as under-identification.

The only way to reduce sample error is by substantially increasing the size of the survey, but this can be quite expensive. It is more accurate and efficient if the data can be collected as a by-product of routine administrative collections.

A major step forward in enabling the collection of comprehensive information on Medicare and Pharmaceutical Benefits Scheme (PBS) usage would be a voluntary identifier through the Medicare enrolment system as to whether a person was Aboriginal and/or Torres Strait Islander. Because of the voluntary nature there would need to be a statistical adjustment of the data to enable valid estimates of Medicare and PBS usage to be made, and it may be several years before reliable data is gathered.

In addition the Medicare number needs to be linked to pharmaceuticals issued under the PBS. The Commonwealth Government announced (in the May 2000 budget) there would be a linkage of the Medicare number with the PBS. This commenced from 1 January 2001 but, due to a transition period, supplying a Medicare number to obtain PBS prescriptions was not compulsory. Therefore linkage was not made for all PBS prescriptions.

Under-identification of Aboriginal and Torres Strait Islander people is the chief problem in the collection of data related to health expenditure. In service records under-identification may be reduced by better placement of the Indigenous status

questions on the next BEACH (Bettering the Evaluation and Care of Health) survey form. In addition, greater emphasis of its importance needs to be conveyed to participating doctors.

The Department of Veterans' Affairs also does not identify Aboriginal and Torres Strait Islander status on its records. This should be rectified so that reliable information pertaining to the health of Aboriginal and Torres Strait Islander veterans can be obtained.

Hospital data

Other measures to improve data quality might include improved education of staff working on administrative records in hospitals on the need for accurate and informative data and the importance of cultural sensitivity. The joint AIHW and ABS assessment of identification of Aboriginal and Torres Strait Islander people in hospital records (AHMAC, AIHW & ABS 1999:19) found the accuracy of identification in hospital records varied from 55% to 100%. The report stated that 'the proportion of Aboriginal and/or Torres Strait Islander people living in a hospital's catchment area appeared to be a major factor influencing the accuracy of recording of Indigenous status' (AHMAC, AIHW & ABS 1999:19). The pilot project in the report compared the results of interviews with hospital patients (conducted mostly by Aboriginal and or Torres Strait Islander people) with information obtained from hospital records. In order to improve the accuracy of recording Indigenous status in hospital records it would be advisable to follow the methodological procedures outlined in the publication above in all hospitals around Australia, every two or three years.

Community and public health

Community and public health boundaries are difficult to delineate. This makes the funding delineation for Aboriginal and Torres Strait Islander health programs rather unclear. It is important to collect this data by region and particularly for the mainstream community and public health programs. Collection methods need to be developed which separate out the different types of services, so as to identify whether they are of a community health nature, a preventive nature or a welfare nature.

Mortality data

Many jurisdictions do not have adequate identification to allow for national reporting of Aboriginal and Torres Strait Islander births and deaths data. For example, the Australian Bureau of Statistics currently publishes detailed death statistics for Aboriginal and Torres Strait Islander people for only Western Australia, South Australia and the Northern Territory. Furthermore, most survey-based information about Aboriginal and Torres Strait Islander people; for example, the

Australian Bureau of Statistics (ABS) National Aboriginal and Torres Strait Islander Survey, has been collected on only one occasion and no assessment of trends is possible until such surveys are repeated (McLennan & Madden 1999).

It is crucial to improve the collection and reporting of mortality data as limitations in the quality and availability of data also compromise our ability to assess changes in Indigenous mortality over time, both in absolute terms, and relative to the rest of the Australian population.

The use of data (in particular mortality data) from Western Australia, South Australia and the Northern Territory as proxies for making generalisations about Aboriginal and Torres Strait Islander health across the country is thought to no longer be an appropriate practice. Our analysis of regional mortality trends was restricted to these States and the Northern Territory, with the variation in regional residential patterns between these Western States and Australia shown in Appendix 2. *The Aboriginal and Torres Strait Islander Health Information Plan* (AIHW 1997) suggests that this practice increases the potential for masking differing population characteristics, needs or service utilisation patterns across Aboriginal and Torres Strait Islander people living in different regions in Australia.

Extent of data needs and implementation

The Health is Life: Report on the Inquiry into Indigenous Health (Standing Committee on Family and Community Affairs 2000) noted that additional resources should be allocated if necessary to support data collection (Recommendation 33). The report recognised that this additional support from the Commonwealth must be sufficient to encourage the States and Territories to improve existing data or establish new data collections; however, ultimately data collection is a State or jurisdictional matter.

The Aboriginal and Torres Strait Islander Health Information Plan... This time, let's make it happen (AIHW 1997) takes the discussion of comprehensive data collection to another level. The report reveals gaps in information about Aboriginal and Torres Strait Islander health, including a wide range of diseases and conditions which are difficult or impossible to measure on a national scale, and many of which have a particular public health implication on Aboriginal and Torres Strait Islander communities. Interestingly, the report also notes that there are no accurate national data on issues such as emotional and social well-being or, for that matter, reliable data on patterns and levels of nutritional intake, or the prevalence of different types of disability among Aboriginal and Torres Strait Islander people. The report asserts that while many of these diseases and conditions are often not life-threatening in themselves, taken together they can be responsible for very high levels of 'low-grade' chronic morbidity and social disadvantage.

The Aboriginal and Torres Strait Islander Health Information Plan also makes note of a publication by Smith in 1978 which advocated twenty-two years ago the routine collection nationally of Aboriginal and Torres Strait Islander health statistics. Since then insufficient progress has been made to have accurate data collections on Aboriginal and Torres Strait Islander people and comprehensive feedback to health

providers, Aboriginal and Torres Strait Islander communities and the population as a whole. The report asserts that a common thread amongst many of the earlier initiatives and reports on Aboriginal and Torres Strait Islander health information 'is the apparent inattention to implementing recommendations—at all, let alone in a planned, cohesive and nationally coordinated way' (AIHW 1997: 2). *The Aboriginal and Torres Strait Islander Health Information Plan* blames inadequate collection and/or breakdowns in the system for the lack of recording or reporting of Aboriginal and Torres Strait Islander status. It identifies several goals to facilitate the collection of quality health information, including:

- all health-related collections to separately identify Aboriginal and Torres Strait Islander persons and have appropriate quality control checks in place;
- all major collections to use common identification classifications and collection protocols (i.e. common classification standard as in the *National Health Data Dictionary* (AIHW 2000c) and the mandatory Indigenous status questions);
- to review the suitability of definitions used and estimates for deriving Aboriginal and Torres Strait Islander statistics;
- to make regular assessments of the quality of population estimates; and
- to develop a national survey collection system which provides all essential national and State Aboriginal and Torres Strait Islander statistics at sufficient frequency to allow jurisdictions to adequately report on nationally agreed performance indicators and to make comparisons between Aboriginal and Torres Strait Islander and non-Indigenous persons and between jurisdictions.

Summary and conclusion

The recommendations outlined in this section should improve the methodology used when collecting data as well as enhance the quality of the data.

Recommendations relating to the introduction of a voluntary identifier of Indigenous status on the Medicare enrolment records are progressing. Simplified Medicare enrolment forms for Indigenous customers have been introduced. It is anticipated that a hotline for Indigenous customer enquires will be introduced in the next financial year.

From 1 January 2002 all PBS pharmaceuticals dispensed will be linked to a Medicare number in accordance with the Improved Monitoring of Entitlements to Pharmaceutical Benefits legislation.

- If the BEACH survey is to be used to estimate Aboriginal and Torres Strait Islander Medicare and pharmaceutical benefits, changes to it need to be made. The recommendations relating to the BEACH survey are to adjust the survey form for better placement of the Indigenous status questions and emphasise to participating doctors the importance of reporting Indigenous status. General practitioners participating in the survey should use the approved ABS questions to identify Aboriginal and Torres Strait Islander patients.

- In relation to hospital data, improvements should be made in the training of staff working on administrative records in hospitals, emphasising the importance of cultural sensitivity and the need for accurate and informative data. Every hospital in Australia should make comparisons every two to three years between the results of interviews with hospital patients and the information obtained from hospital records.
- Collecting data as a by-product of routine administrative collections, collecting adequate births and deaths data from all jurisdictions and collecting more survey-based information about Aboriginal and Torres Strait Islander people would enable trends to be assessed over time. More detail regarding these recommendations is provided in *The Aboriginal and Torres Strait Islander Health Information Plan* (AIHW 1997).

In considering these recommendations, one must remember that health is also determined by social and cultural factors such as employment levels, cultural cohesion and family history, and by the availability of infrastructure such as clean water and adequate housing. But the level of health services available and provided does have an impact on health as well. For instance, a systematic risk factor treatment program in the Tiwi Islands in the Northern Territory led to marked improvements in blood pressure, stabilisation of renal function and reduction in new cases of end-stage renal disease.

While interventions of this nature require time to show their full effects, some short-term improvements can be expected. So, in addition to improving data at the front end of collection, an ongoing assessment of the impact of service delivery in a few case studies would assist in filling the gaps between identification of needs and the extent to which those needs have been met after intervention—that is, linking the input and outcome data. A combination of statistical collections and evaluation of the impact of interventions would, we believe, alleviate some of the perennial shortcomings in documenting the health status of Aboriginal and Torres Strait Islander people and their use of health services.