Appendix 2:

Shortcomings in Aboriginal health data

Governments make every effort to provide accurate information on major health problems for the whole state/territory or country, and routinely collect data from health services. The information from this is used for policy and planning. Inevitably there are some problems with the quality of information that health services such as hospitals provide. Important clinical information is also not recorded in these ‘administrative’ data, so they are limited in what they can tell us. Often the information provided tells us about numbers of occasions of service (e.g., admissions) but not about numbers of people, because the anonymous information cannot tell one person from another.

When undertaking research regarding health inequity in Aboriginal populations there are additional problems that reduce the accuracy of the data. These include the undercounts of Aboriginal people in these sources because not all Aboriginal people’s records show that they are Aboriginal. Thus, Aboriginal people are under-identified in routinely available information. Also, because Aboriginal people make up only 3% of the population in WA, the numbers of Aboriginal patients are small, statistically speaking, and thus statistical methods may not be able to give conclusive results.

Information can also be collected in an inappropriate way (e.g., tests/questionnaires may not be validated for Aboriginal people) and people may not accurately recall information so that results may not be accurate.

The BAHHWA researchers have used data linkage methods (Box 2) to evaluate the quality of administrative information related to Aboriginal heart health. This research helps with conducting studies and interpreting study findings from other projects.

Four articles were written on challenges that the shortcomings of administrative data present to methods for studying Aboriginal health:

1. A literature review on the quality of Aboriginal identification in linked administrative health data in Australia

   **Findings:**
   Poor identification of Aboriginal status in administrative health datasets has different effects for different diseases. This problem generally results in under-estimation of Aboriginal health indicators, but may perversely overestimate Aboriginal rates and differentials in the setting of stigma-associated conditions such as sexually transmitted and blood-borne virus infections. There is also under-counting of Aboriginal people in Census surveys, resulting in population denominator undercounts in Aboriginal health research. Under-identification of Aboriginal status can be substantially reduced through data linkage, but ultimately the information should be better collected and recorded.

2. Analysis of linked hospital and death data to determine how much under-counting of Aboriginal cardiovascular patients there is in hospital and death data

   **Findings:**
   Linking hospital and death records increased the identification of Aboriginal patients in routinely collected information. Under-identification was highest in metropolitan and high socio-economic areas, and in older people. Death records, if unlinked, would under-estimate Aboriginal deaths by up to 25%.
3. Analysis of linked hospital and death data to determine by how much first-ever heart attack rates are under-estimated when existing cases are not removed from population figures used in the calculation

Findings:
The under-estimation of rates (caused by not removing existing cases from the population denominator) increased with age, was higher for men than women, and substantially greater for Aboriginal than non-Aboriginal people. However, this underestimation had little impact on the relative difference in Aboriginal and non-Aboriginal rates. The method used to correct the problem, while more accurate, is difficult to apply and would add only modestly to our understanding of differentials in rates.

4. Analysis of linked hospital data to evaluate the accuracy of identifying diabetes in Aboriginal and non-Aboriginal heart patients

Findings:
The accuracy of identifying diabetes in heart patients is improved in linked health data by using at least 10 years of hospitalisation history. Use of this method would reduce errors when measuring time trends in diabetes occurrence in heart patients. Measures are as reliable in Aboriginal as non-Aboriginal patients.

Recommendations

- Encourage the use of linked data to investigate Aboriginal health, while recognising that this does not replace prospectively collected clinical data
- Establish systems to improve identification of Aboriginal status in health records
- Use linked data to improve accuracy of Aboriginal identification in routinely collected health information—provide a range of results using different methods of identifying Aboriginal people—no single method is best
- Use linked data to improve accuracy of identifying chronic diseases (e.g., diabetes) in routinely collected health information
- Adjust for age and also calculate separate rates for younger (<55 years) and older age groups when analysing differences in rates between Aboriginal and non-Aboriginal people. This is recommended because the age profile is so different between the Aboriginal and non-Aboriginal people