

Measuring Population Health: an Australian Perspective

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1 Introduction

This paper outlines Australian systems for monitoring health status. It describes the relevant Australian population surveys, then recent developments of health indicator sets and associated frameworks. It is shown that the Australian systems have a robust basis and have general acceptance among all key players in Australia. It is argued that attempts to find international instruments for measuring population health status need to follow the same principles if they are to win acceptance.

2. Australian health status measurement systems

It is not possible to outline all relevant Australian work in a short paper, as there are many people in health and related fields working on aspects of measurement. The paper aims rather to present the scope and flavour of this work. This section deals with:

- How we measure health status in population surveys
- Application and measurement: a wide range of developments
- Data definitions and classifications: development and collaboration

2.1 Measuring health status in national population surveys

Concepts of health and health status used in: health surveys, mental health surveys, and the disability, ageing and carers surveys.

2.1.1 ABS National health survey

The National Health Survey (NHS) has been conducted by the Australian Bureau of Statistics (ABS) in 1977, 1983, 1989/90, 1995 and will be held three yearly from 2001.

The NHS is a household-based population survey which aims to indicate the health status of the Australian population, describe use of services and other responses to illness, and describe the levels and patterns of health-related lifestyle behaviours and other health risk factors.

Health status indicators can be divided into two types: self perceived health status and ill-health (in particular the prevalence of recent and/or long-term conditions).

In 1995, there were two measures of self perceived health status: the simple "In general, would you say that your health is excellent, very good, good, fair or poor?" as well as the SF 36 measures. In 2001, self-assessed health status and change in health status over time will be obtained. The SF36 will not be included and it is proposed that the Kessler Psychological Distress Scale -10 be used.

Recent illness is defined as illness or injury experienced in the two weeks prior to the survey interview; long-term conditions are defined as medical conditions (illness, injury or disability) current at the time of the survey which have lasted at least six months, or which the respondent expects to last for six months or more. Recent illness may include long-term conditions, and vice versa. In the previous NHS (1983 to 1995) conditions were classified according to a classification developed by the ABS, based on ICD-9. With the introduction of the new NHS series, the conditions' classification is being redeveloped, to be based on ICPC-2. ICPC-2 was selected as the basis for 2001 and future NHS classification in preference to other classifications in national or international use because it is better suited to self-reported conditions data of the type obtained in the survey.

In the classification to be used in the 2001 survey, many of the ICPC-2 categories will be combined to a level of detail at which the survey sample is capable of supporting reliable estimates. Further, ICPC-2 categories which relate to medical procedures or non-illness reasons for encounter will be removed.

The 2001 NHS will give special focus to conditions covered by the National Health Priority Areas (NHPA). More detail is provided later in the paper.

It is planned to provide a linkage between the new classification and the classification used in previous NHSs to support time series analysis, and a linkage to ICD-10 to facilitate possible future use of NHS results in conjunction with data from administrative data sets.

While the content of the 2004 and future NHSs is yet to be determined, it is expected that self-reported conditions (recent and/or long-term, and possibly disability) will remain a key component of the surveys.

Indigenous people will be surveyed in increased numbers in the 2004 survey and each six years thereafter to allow regular reporting on Indigenous health issues.

2.1.2 National Survey of Mental Health and Wellbeing

The 1997 National Survey of Mental Health and Wellbeing provided the first reliable information on the prevalence and types of mental health disorders in Australia. As well as providing a range of broad-based epidemiological data on the mental health status of the population, it also provides information related to mental health service delivery. It comprised three component investigations:

- an ABS national mental health survey;
- a representative survey of children's and adolescent's mental health undertaken by the University of Adelaide and collaborating centres; and
- a study of low-prevalence disorders, or psychotic disorders, in selected urban centres coordinated by the University of Western Australia.

The ABS Mental Health Survey was conducted in 1997 using a nationally representative sample of 10,600 people aged 18 and over (response rate of 78%).

The ABS measured mental health and wellbeing using a modified version of the Composite International Diagnostic Interview (CIDI). The CIDI was originally developed through a collaborative study that involved 17 contributing centres for use in epidemiological studies of mental disorders in general population groups in different countries. The WHO Training and Reference Centre for CIDI at the University of New South Wales developed a computer-based survey instrument incorporating the CIDI and specific disability and service use modules.

The strength of the comprehensive interview instrument is that it is designed to provide diagnostic information—it translates self-reported symptoms to a diagnostic category based on the ICD-10 classification. The survey provides information on the higher prevalence mental health disorders (anxiety disorders, affective disorders and substance use disorders). 18% of survey respondents reported that they had experienced the symptoms of a mental disorder at some time during the twelve-month period before interview. In addition to the diagnostic module, several other measures were employed.

Details of the other two surveys listed above can be provided if desired.

2.1.3 Mental health-related measures of health and health status used in National Health Survey

The 1995 National Health Survey collected information on general mental health status using the Mental Component Summary (MCS) of the SF-36 instrument. It is anticipated that the 2001 ABS Health Survey will employ Kessler Psychological Distress Scale-10 as the measure of general mental health.

2.1.4 ABS Disability Ageing and Carers survey

The ABS has conducted four national surveys on disability, ageing and carers, in 1981, 1988, 1993 and 1998. Further surveys are planned on a six-yearly basis. The surveys have been based on the concepts of the ICIDH-1 and the ABS has remained abreast of the concepts being developed for ICIDH-2.

The 1998 Survey defined 'disability' as the presence of one or more of 17 limitations, restrictions or impairments (Box 1). The screening questions for the survey, designed to capture as many people as possible, were framed around this list and then became the effective definition of disability.

There were 3.6 million people (or 19% of the total population) reporting disability in Australia in 1998.

To be more consistent with the definitions in the draft ICIDH-2, the 1998 survey used the concept of 'activity restriction' instead of 'handicap'. There were five 'specific restrictions' which were equivalent to areas of handicap in the 1993 survey. These are restrictions in the three core activities of daily living (self-care, mobility and communication), as well as schooling and employment restrictions (see Box 2).

In 1998 there were 2,048,600 people aged under 65 years who had an activity restriction (12.5% of the population in that age group) of whom 655,000 (4.0% of the population aged under 65) reported a profound or severe core activity restriction, meaning that they always or sometimes needed personal assistance or supervision with activities of daily living (Australia's Welfare, AIHW 1999).

The survey also asks questions relating to the 'main disabling condition' and these are coded using the ICD.

Box 1: Areas of limitation, restriction or impairment identified by the ABS, 1998

Affirmative responses to any of the following categories 'screen' the person into the ABS survey, where the limitation, restriction or impairment has lasted or was likely to last for six months or more:

- *loss of sight, not corrected by glasses or contact lenses;*
- *loss of hearing, with difficulty communicating or use of aids;*
- *loss of speech;*
- *chronic or recurring pain that restricts everyday activities;*
- *breathing difficulties that restrict everyday activities;*
- *blackouts, fits, or loss of consciousness;*
- *difficulty learning or understanding;*
- *incomplete use of arms or fingers;*
- *difficulty gripping or holding things;*
- *incomplete use of feet or legs;*
- *a nervous or emotional condition that restricts everyday activities;*
- *restriction in physical activities or physical work;*
- *disfigurement or deformity;*
- *head injury, stroke or any other brain damage with long-term effects that restrict everyday activities;*
- *needing help or supervision because of a mental illness or condition;*
- *treatment or medication for any other long-term condition or ailment and still restricted; or*
- *any other long-term condition that restricts everyday activities.*

This list thus creates the implicit definition of disability for the ABS 1998 Disability, Ageing and Carers Survey (ABS 1999).

Box 2: ABS 1998 Disability, Ageing and Carers Survey: restrictions and their severity

Specific restrictions are:

Core activity restrictions; and/or

Schooling or employment restrictions

Core activities are:

Self care – bathing or showering, dressing, eating, using the toilet and managing incontinence;

Mobility – moving around at home and away from home, getting into or out of a bed or chair; and using public transport; and

Communication – understanding and being understood by others: strangers, family and friends.

A **core activity restriction** may be:

Profound – unable to perform a core activity, or always needing assistance;

Severe – sometimes needing assistance to perform a core activity;

Moderate – not needing assistance, but having difficulty performing a core activity; or

Mild – having no difficulty performing a core activity, but using aids or equipment because of disability.

Source: ABS 1998 Survey of Disability Ageing and Carers, 1999

2.1.5 Disability module

The ABS has used a 'disability module' in a number of its population surveys, for instance on time use and household expenditure. The module is based on the survey. The ABS is working to refine the module and align its results more closely to survey results.

2.2 Application and measurement: a wide range of developments

This section covers some national developments and indicates the scope of other work at national level.

2.2.1 Health status monitoring

A context for health status monitoring in Australia has been provided by collaborative work by national and State governments to address health and health system priorities. Six National Health Priority Areas (NHPAs) have been identified and adopted by Health ministers since 1995: cardiovascular health, cancer, injury, mental health, diabetes mellitus and asthma. A heavy focus in the initial period of development of the program has been on establishment of a small set of indicators (about 20) for monitoring each area. The parsimonious approach to reporting drew on a framework for health outcome indicators as a guide to indicator selection.

The NHPA framework's matrix structure defined primary outcome indicators, risk indicators and process and quality indicators on one dimension, against interventions aimed at prevention, management and maintenance on another dimension. For most priority areas a good spread of indicators across the cells of the matrix has been achieved and baseline reports have been released. Development work remains to be undertaken to improve adequacy of indicator coverage, particularly in mental health and diabetes. Ongoing reporting on progress against the indicators will be included in the AIHW's biennial Australia's Health reports.

2.2.2 Health system performance

A separate national reporting system, focussing on health system performance, is being developed by a new National Health Performance Committee (NHPC) established by Australian Health Ministers in 1999. The scope of this committee is broader than earlier performance reporting on behalf of Health Ministers, which focussed on acute admitted patient care. The Committee has chosen a broad indicator framework adapted from the Canadian Roadmap Initiative. This framework was found to be consistent with a conceptual model of health that has been used in Australia's Health reports and also with work undertaken by AIHW on a framework for public health indicators, implemented in recent AIHW reports on child and youth health. A first tier of the NHPC indicator framework focuses on health status and outcomes. Second and third tiers recognise respectively determinants of health and health system performance as major influences on health status and outcomes. It thus has a lot in common with the first dimension of the NHPA indicator framework.

As in the Canadian framework, separate components of each tier define particular domains for indicators. The first report against that framework is expected to be compiled in 2001.

2.2.3 Summary measures of health

As well as developing indicator approaches to health monitoring, Australia has undertaken work on summary measures of health, specifically in the Australian Burden of Disease and

Injury Study (AIHW, Mathers 1999). The study used methods largely based on those developed by Murray and Lopez, adopted for the WHO's Global Burden of Disease Study (WHO 1999). The Australian Study, conducted in conjunction with a regional burden of disease analysis for the State of Victoria, adapted Disability Adjusted Life Years (DALY) methodology from the GBD study to suit the Australian context and the need for greater detail in measuring the size of health problems that are important in Australia. Estimates of burden were produced for 176 disease and injury categories, for 10 major risk factors and for selected populations. Incidence of deaths and of disease and injury, estimated from Australian sources were combined using disability weights for non-fatal health outcomes from a Dutch study, supplemented by weights used in the GBD study for some conditions. Age weights used in the GBD study were not used in the Australian analysis.

2.2.4 Development of national risk factor data standards

National standards for the measurement, collection and analysis of data on risk factors have been developed by the Australian Institute of Health and Welfare under the auspices of the National Health Information Agreement. The standards are intended for use in population surveys and health care settings, and provide standard methods and definitions for measuring and reporting on the prevalence of risk factors in Australian adults. The standards are incorporated into the National Health Data Dictionary. Standards exist for body fatness, smoking and physical activity, and work is about to commence for blood pressure and blood cholesterol. The developmental process includes expert opinion, consideration of existing local and international methods, and national consultation.

2.3 Data definitions and classifications

National data development in Australia is structured to ensure agreement is reached among all jurisdictions about priorities for development and resulting data definitions. National data dictionaries for the health and community services fields are published. These dictionaries are then used to as the basis for national minimum data sets for health and community services and for associated population surveys.

National organisations such as the ABS and the AIHW also work to participate in and conform to international developments in the relevant fields. Australia has a strong tradition of using international statistical classifications (or national modifications of them), including ICD and ICIDH. It therefore participates actively in international classification development activities.

3 International development of health status measures

The material earlier in this paper describes the inter-related sets of approaches currently used in Australia to measure population health status. The structure has been built up over a lengthy period, and has wide ownership amongst all relevant groups in Australia (statistical agencies, policy departments, academics).

This structure is built upon well established and widely accepted infrastructure: definitions, classifications and instruments.

It is recognised that the Australian systems for health status measurement have been constructed for national purposes. As described, international classifications and instruments have been widely used in the Australian context, but there is little capacity for international comparisons.

Australia has therefore been most interested in recent moves towards international sets of social indicators. In particular, the **OECD** set of indicators has been a welcome development (Pearson, Arjona and Scherer, *Social Indicators: a Proposed Framework and Structure*, Siena Group Meeting, Maastricht, 2000). That indicator set is limited in scope and is parsimonious, two key characteristics for social indicator sets. One of the four components of the OECD set is Health, where 10 indicators have been identified. 5 of these 10 are health status indicators (disability, accidents, life expectancy, potential years of life lost and infant mortality). As well, there are additional health status indicators included under Social Cohesion (Suicides, Age of women at first childbirth, Drug Abuse and Deaths). Data on these indicators are generally available for most OECD countries, although there are significant problems of comparability in some areas, notably disability. The OECD is now leading work through the Siena Group, an informal but widely representative group of social statisticians from the majority of OECD countries, to resolve comparability issues.

Australia is also closely monitoring social indicator developments in the **European Union** (Everaers P, *Comparable results in European Social Statistics: key social indicators, harmonisation, integration and core variables*, Siena Group Meeting, Maastricht, 2000).

Another interesting international development is the **DISTAB** project. DISTAB is an NCHS-sponsored evaluation of ICIDH-2 using WHO's Protocol #5, being undertaken in collaboration with centres developing the ICIDH-2, with UN technical assistance. The project aims to specify standard international statistical tables on disability that relate to the draft ICIDH-2 and are obtainable from existing national collections. Australia has not yet participated in the exercise, but could provide the standard tables in the future because of its consistency with ICIDH.

The agenda for the October 2000 Ottawa meeting includes a presentation of a '**WHO generic framework**' for measuring population health status. The agenda describes this proposal as 'a standardised set of descriptions of individuals' health status that can be adopted in national health interview surveys'.

There will be great interest in Australia in these proposals. In line with our established practice of full involvement in international statistical developments, Australia would be keen to participate actively in discussion of such proposals.

Australia recognises that the various international developments are taking place in the different contexts of the organisations involved. Eurostat work is limited to the western European context, and the EU provides a supra-national structure which can in time lead to mandated uniformity across member States (as has already occurred in the ECHP). OECD developments are designed for a wider group of developed countries, which generally have well developed, comprehensive national systems of social statistics. Significantly, the OECD has designed its social indicators as far as possible to be based on data generally available in OECD countries.

WHO approaches will no doubt take a broader view than either Eurostat or the OECD, given WHO's world-wide responsibilities. Data collection capacity is far less in the non-OECD countries, and this justifies consideration of alternative approaches.

Use of ICIDH in Health Status Measures

Fortunately, these WHO initiatives are taking place just as the redevelopment of one key piece of the necessary statistical infrastructure, the ICIDH, is being completed. ICIDH2 is currently on schedule to be adopted by the World Health Assembly in May 2001. The new

classification provides a robust system for the description of the outcome of health conditions, using three dimensions: body, person and society. There has been extensive international and national consultation on the redevelopment of the ICIDH, led by WHO, over the past six years. This has resulted in general acceptance across a wide spectrum of interest groups, ranging from organisations of people with disabilities to epidemiologists and national statistical organisations. (The redevelopment process is a tribute to those who have taken part, both within WHO, collaborating centres (including the Australian Institute of Health and Welfare), non-government organisations and many expert individuals). As an illustration of the depth of the redevelopment process, Appendix 1 outlines the Australian redevelopment work over the six year period. The result of this six year process is wide exposure and general acceptance of the draft ICIDH-2, among interested parties, of a robust classification based on well understood concepts.

This acceptance has been hard won, and has depended on extensive consultation within each participating country and among NGOs. It is important that ICIDH-2 be finalised in accordance with the concepts embodied in the Beta 2 draft, and health status indicator development then use the ICIDH to the extent possible. The ICIDH will have many other applications (already it has been used in national definitions in Australia). Any uncertainty on this issue should be discussed at the Ottawa meeting.

Building International Consensus

Efforts to build internationally comparable indicator sets and measurement instruments deserve general support. But the process is necessarily long and difficult if a consensus is to be reached. In particular, it is essential that countries like Australia can both participate in the international work and consult with their respective national policy agencies and interest groups. Australia will be keen to ensure that there is sufficient continuity in its health monitoring and measurement programs to allow time series comparisons to continue, that respondent burden remains manageable in its survey program, and that our national social statistics priorities (recently reviewed and now in place) are maintained.

Australian work on developing the ICIDH-2

The AIHW is a WHO Collaborating Centre for the revision of the ICIDH. The ICIDH-2 has undergone a long and transparent process of development. The Australian work over this period illustrates one country's efforts. In the last six years the AIHW has participated in Beta-1 and Beta-2 testing.

Beta 1 testing included four specific tests on: the applicability of the classification to people with intellectual disability, responses to WHO 'basic questions', development and testing of Participation qualifiers, and applicability of the concepts in Indigenous communities,

Beta-2 testing included carrying out the three WHO recommended test protocols: Linguistic evaluation (Study 1); the consensus conferences on the basic questions (Study 2); Feasibility and reliability of ICIDH-2 (Study 3). Reports on all these tests have been forwarded to WHO. The additional tests of the Environmental factors, requested by WHO, have also been carried out and data transmitted to WHO.

An early Australian application of the Beta-2 draft has been made in the new National Community Services Data Dictionary in Australia, which will include, as a trial, disability data elements based on the 1999 draft ICIDH-2.

The AIHW has reported regularly to WHO, including recommendations on the ICIDH-2, most recently in June and September 2000.

To encapsulate our position on the finalisation of ICIDH2:

- **The body/person/society plus environmental factors conceptualisation of the draft ICIDH-2 is strong** and should not be revisited.
- **Applications should locate themselves in the WHO health framework (including ICIDH), not re-define it.** The ICIDH has been designed and tested to be as useful as possible in a wide array of applications. No one application should dictate its structure.
- The ICIDH-2 can assist in the conceptualisation of 'health' and related applications.
- The capacity-performance dichotomy, if needed, can be accommodated within the ICIDH-2 framework as it stands, with the use of qualifiers.
- The Participation dimension and the Environmental factors are crucial components of the ICIDH-2 conceptualisation.
- The focus of further work should be on improved operationalisation, for instance by refining the classification to clear up perceived Activity-Participation overlap, and by developing training materials, guides for use and indexes.