AIHW
AUSTRALIAN INSTITUTE OF HEALTH & WELFARE

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INSIDE

Seasons Greetings

WHO Family of International Classifications Meeting 2002 a great success

The WHO Heads of Collaborating Centres for the Family of International Classifications (WHO-FIC) held their annual meeting in Australia this year from 14 to 19 October 2002 at the Royal on the Park Hotel, Brisbane.

The theme for the meeting was 'Improving health systems through quality data'. Over 90 delegates from 21 nations attended, and 100 papers were delivered on topics as diverse as underlying causes of death in HIV patients in Brazil to the classification of technical aids for people with disabilities.

The AIHW, as the Australian Collaborating Centre for WHO-FIC, was the host organisation. A planning committee, comprising staff from the AIHW's Executive Unit and Media and Publishing Unit, together with representatives from the National Centre for Classification in Health (NCCH) and the Australian Bureau of Statistics (ABS), began preliminary work in organising the meeting in October 2001.

Major sponsors were Queensland Health, ABS, AIHW and NCCH.

What is WHO-FIC?

The two core members of the Family of International Classifications are:

- the International Statistical Classification of Diseases and Related Health Problems, Version 10 (ICD 10)
- the International Classification of Functioning, Disability and Health (ICF).

ICD-10 and ICD-10-AM (its Australian Modification) are used for mortality statistics, hospital morbidity statistics and hospital medical record indexing. The National Centre for Classification in Health maintains the Australian Modification, and coordinates training in its use.

The ICF was endorsed by the World Health Assembly in May 2001. The AIHW played a significant role in ICF's development and is developing a program to implement the classification in Australian data collections.

A WHO classification currently accepted as an alpha version for testing is the International Classification of External Causes of Injury. The AIHW's National Injury Surveillance Unit at Flinders University is contributing to this work.

The Australian Classification of Health Interventions adapted for International Use (ACHI-I) has also been accepted as an alpha version for testing and is designed for use in countries without an adequate classification of intervention.

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Heads of the WHO Collaborating Centres for the Family of International Classifications, at the Brisbane meeting.

Contents

from the Director

Despite best intentions, making time to take stock of an organisation's strategic directions is not always easy. The AIHW is proud of its record of achievements. Our Annual Report 2001–02 outlines achievements for the past year, including an increase in external revenue of around $1.5 m. However, if we are to continue to prosper in our role of informing community discussion and decision making through developing and providing health and welfare statistics and information, we need to reassess our position and the environment in which we operate, and to develop strategies that will guide us into the future.

Our current Corporate Plan ends at the end of this year, and we have been working to develop a new plan for the 2003–06 triennium. The process started at the beginning of 2002 with a workshop where Jane Halton and Mark Sullivan, both newly appointed Portfolio Secretaries at that time, shared their views about the environment in which we operate. Board Chair Dr Sandra Hacker and Board member Libby Davies joined us at the workshop. The Chair encouraged us to show analytical integrity, fearless curiosity and nous.

The executive team and staff members have been working on the new Corporate Plan, which will be presented to the Board at the December meeting.

Our planning effort has not been limited to plans for the Institute alone!

A major exercise for our relatively small organisation was to host the annual meeting of the World Health Organization Heads of Centres for the International Family of Classifications.The conference forms our cover story for this edition of *Access*. The Brisbane meeting was preceded by a strategic planning meeting held in Manly, Sydney, at which Heads of the Collaborating Centres agreed on a strategic plan to guide the activities of the group for the next few years. I am grateful for the efforts of all who worked so hard to contribute to the success of those meetings.

You may have heard that the ABS has decided not to continue the collaborative arrangements with the AIHW on Aboriginal and Torres Strait Islander health and welfare statistics. These arrangements have been the driving force for major gains in this crucial field. I am pleased that the 2003 joint flagship publication is to continue the biennial report tradition established when the first report was launched by the Governor General, Sir William Deane, in Darwin in 1997.

I want to assure all Access readers that AIHW is committed to the production and use of Aboriginal and Torres Strait Islander statistics to drive improvement in the health and welfare of Indigenous Australians. We are working with other parties in this field, including the ABS, to continue the great work of the Darwin unit. I want to acknowledge also the leadership provided by the units two Directors since 1996: Tony Barnes and Janis Shaw.

As well as meeting our work program commitments (a list of our publications since the last *Access* demonstrates our efforts in that regard), we have continued to build relationships with key contributors in the health and welfare field. The Institute constantly seeks opportunities for stretching the scope of its work; our partnerships with other contributors to the sector are of vital importance to us and influence our strategic directions.

The lead-up to the end-of-year holiday period seems to become more hectic each year. Staff of the Institute join me in wishing all our friends a safe and satisfying holiday period.

WHO Family of International Classifications Meeting 2002 a great success

Continued from page 1

Other classifications under consideration for the WHO-FIC include the Technical Aids Classification and the Anatomical Therapeutic Chemicals Classification (ATC).

Aims of WHO-FIC

The aims of WHO-FIC are to:

- provide a logical framework for the definition and management of health conditions;
- establish a common language to improve communication;
- permit comparisons of data across countries, health care disciplines, services and time;
- provide systematic coding schemes for health information systems; and
- stimulate research on health conditions.

Australia plays a role in WHO-FIC that is out of proportion to our size. Of the four major WHO-FIC committees, two are chaired by Australians (Update Reference Committee, Rosemary Roberts, and Family Development Committee, Richard Madden).

In addition to agreeing a WHO-FIC Strategy and Work Plan for 2003, among the many decisions emerging from the meeting were:

- a commitment to immediate development of an electronic version of ICD-10 in both English and French
- adoption of 22 updates to ICD-10
- formation of an ICF Implementation Subcommittee to work on ICF implementation issues
- further development of Coding Guidelines for the ICF

WHO perspective on WHO-FIC 2002

Dr Bedirhan Ustun, Coordinator of Classification, Assessment, Surveys and Terminology at WHO summed up the Brisbane meeting thus:

> 'The Brisbane meeting was indeed a very stimulating meeting and the "family" concept is up and flourishing.
>
> 'We are like brain cells forming new connections and creating a better and higher-level understanding of the world.
>
> 'We are participating in a social network of world citizens as responsible scientists and civil servants to make health information accessible and fit-for-purpose for all populations. In a sense, we are establishing a civil society organisation with a public mission, taking care of its organisation and functioning.'

Host Centre closing message

In closing the meeting, Head of the host Centre and AIHW Director Dr Richard Madden gave the following message to participants:

> 'Goodbye, friends. On behalf of the Australian Centre and the Planning Committee, I trust that you found the Brisbane meeting stimulating and useful, as well as a lot of fun. It was especially gratifying to see such a large turn-up, bringing an increased breadth of ideas and contributions. It was also very pleasing to welcome our two new Centres, Nigeria and South Africa, to their first annual meeting.
>
> 'To me, one of the major developments at WHO-FIC 2002 was the increased cross-fertilisation of ideas within the family of classifications, and an increased recognition and understanding among ICF and ICD supporters of each other's "patches", or areas of expertise. It certainly fills me with optimism for our future work.'

Guests are treated to a cultural performance by Indigenous artists at the Brisbane Meeting

On the lighter side...

Quotable quote of the meeting

Dr Harry Rosenberg's sign in the Mortality Statistics office within the US National Centre for Health Statistics:

'If you're not dead we're not interested'

project reports

Project 1

Dr Richard Madden awarded *Actuary of the Year 2002*

AIHW Director Dr Richard Madden was presented with the Actuary of Year Award for 2002 at a President's Dinner in Canberra on 20 August.

The honour of Actuary of the Year is awarded for a meritorious contribution that is made to a profession, business or community and that brings identifiable credit to the actuarial profession. The award, first presented in 1987, may be for ongoing contributions to the profession or an outstanding recent achievement.

In making the award, the President of the Institute of Actuaries of Australia, Helen Martin, paid tribute to Richard's achievements.

'Richard Madden is a most suitable recipient of this award. He has been involved in many senior public sector positions throughout his career and has a high profile outside the areas regarded as traditional actuarial practice areas. He has also consistently demonstrated and promoted the value that the actuarial profession can bring to these wider areas, particularly in health and welfare.

'Richard has been closely involved in the work of the Institute of Actuaries of Australia, being an active member of the Health Practice Committee since 1998 and of the Ageing Australia Task Force. Most recently, Richard has taken a key role in developing the IAAust's new Health Financing Course.'

Dr Sandra Hacker, AIHW Board Chair, said the Institute of Actuaries award recognised Dr Madden as an accomplished administrator in the health and welfare fields.

'In short, he knows health, welfare services, finance and statistics and administration—and has an enviable record of achievement in all of these areas.

'More than this, he has truly brought the AIHW into a new era in terms of its relationships with State, Territory and Commonwealth partners.'

Project 2

Memorandum of understanding with Department of Veterans' Affairs (DVA)

On the 19 August, DVA Secretary Neil Johnstone and AIHW Director Richard Madden signed a memorandum of understanding that extends the relationship between the two organisations for another three years. The purpose of the memorandum is to facilitate work between the organisations to 'collect and make use of relevant and reliable statistics and information, which are an essential element for delivering high quality health and aged care services to the veteran community'.

This memorandum of understanding, which builds on the existing strong relationship between the DVA and AIHW, includes and has attached to it four schedules of work with several others being developed. This work covers issues relating to the health status of Korean and Vietnam war veterans, health-care usage and costs of DVA clients, general statistical support, and a health register for female Vietnam veterans.

There is great potential for further interaction between the organisations as the focus on health and welfare services for the ageing population increases. A significant proportion of the population aged 75 and over are veterans (34% of males in this age group.) This veteran population group is an important sentinel for the rest of the community and a potentially rich source of data.

Paul Jelfs (AIHW) and Tony Crivelli (DVA) help to coordinate activities between the organisations, regularly exchanging information, project ideas and occasionally staff. It is intended that a wider range of interactions will occur between the DVA and AIHW over the next three years, opening up new areas of common interest.

Project 3

Older Australia at a Glance

The Federal Minister for Ageing, the Hon. Kevin Andrews, launched the third edition of *Older Australia at a Glance* at the International Federation of Ageing 6th Global Conference in October. This report continues the tradition of the two earlier editions by providing broad information on many aspects of the lives of older people.

Older Australia at a Glance contains 38 two-page discussions on topics as diverse as population ageing, the health and wellbeing of older Australians, their contribution as care providers in the community, and their use of health and aged-care services. It also looks at other aspects of older Australians' lives such as retirement, income and housing, and examines government responses to their needs.

The report shows that older Australians are living longer, healthier lives than ever before and are making a valuable contribution to the community. Australian men and women aged 65 can expect, on average, to live for another 17 and 20 years respectively—about 6 years longer than was the case in the early 1900s. Although older people generally use hospital and medical services more often than younger people, most rate their health as either good, very good or excellent. In addition, older people are much less likely than younger people to suffer from mental disorders such as anxiety, depression and substance abuse.

The vast majority of older Australians (more than 90%) live at home, either on their own or with family members. Many are active as community members and carers—for example, more than one-third of all voluntary work is done by people aged 55 and over, and about one-fifth of those caring for people with a disability are aged 65 or more.

Older Australia at a Glance is a reference document that will be useful to academics, journalists, policy makers and others in our community interested in the demographic profile, the health and welfare status of older Australians and the services available to them.

For further information, contact Dr Anne Jenkins, AIHW, ph. (02) 6244 1108 or e-mail anne.jenkins@aihw.gov.au

Project 4

Building Ageing Research Capacity Project

The Commonwealth Department of Health and Ageing has developed a National Strategy for an Ageing Australia. One recently developed element of the National Strategy is the Building Ageing Research Capacity Project, a joint initiative of the Office for an Ageing Australia and the AIHW.

The main purpose of the project is to maximise collaboration and coordination between Australian researchers on issues related to ageing—a move regarded as vital in increasing the quality and quantity of statistical evidence available for policy development. The AIHW is keenly interested in the project because it is closely aligned with our mission to provide better statistical information on health and welfare to support the policy development and review process.

The project involves:

- developing a web-based virtual National Institute of Ageing Research
- convening a Roundtable on Ageing Research
- developing an on-line Australian Ageing Research Directory
- organising a National Symposium on Ageing Research (planned for early 2003)
- drafting a National Action Plan on Ageing Research.

Dr Diane Gibson, Head of AIHW's Welfare Division, chairs the steering committee which comprises representatives of consumers, researchers, practitioners and policy makers in the field of ageing.

The Minister for Ageing, the Hon Kevin Andrews, attended the first steering committee meeting on 4 September 2002. He spoke enthusiastically about the project and his commitment to supporting an enhanced ageing research effort in Australia.

For further information, contact Heather Logie, AIHW, ph. (02) 6244 1051 or e-mail heather.logie@aihw.gov.au

spotlight

on Jane Halton

'I want to make a difference—I want the work of the Department to be more relevant to the health of Australians, and for its staff to have a stronger sense of direction and exactly how they are contributing. This will help us deliver on the things we set out to do'.

Jane Halton, appointed Secretary of the Commonwealth Department of Health and Ageing in January 2002, is unequivocal on what she is there for.

And the AIHW?

'The AIHW is very important to our future directions and to our work generally. What we do in health policy, for example, will be based on evidence, so we look to the AIHW for the relevant statistical data and analysis.

'But that is not the only reason we value the Institute. The AIHW and its network is a vehicle by which we can work as an equal partner with the States and Territories on matters of common concern.

'I also think that the AIHW is very useful within the Health and Ageing portfolio in that we can have robust discussions, even disagreements, on various issues. I don't ever want people to just tell me things they think I would like to hear. I value independent opinions, and if we can discuss things frankly within the portfolio I think that's healthy. It's a bit like arguments at the family dinner table—things that need to be said are said, so the resulting resolution has got to be better for all.'

Are there any avenues that Jane can see for the AIHW's future development?

'As with my own department, I would suggest an increasing consumer focus in the work being done, and greater integration with whole-of-government approaches to problems.

'Another of my mantras is to focus on where you can really make a difference. This means striking a balance between continuity in the work being undertaken and being responsive to emerging concerns and issues.

'And the work has to be accessible. Academic discipline will necessarily underpin the integrity of all work, but it will have to be summarised and communicated clearly in order to contribute to the debate and make that difference.

'I think it helps if we can all think along the lines of "How do I make this piece of work help, provoke or advance the debate or developments in this area?" '

Jane Halton is not only relatively young to be appointed a Commonwealth Departmental Secretary (she's in her early forties), she is also only the second woman ever to make it.

The Public Service CEO world is still a man's world, but Jane feels that she has never had to compromise or give concessions on the basis of gender during her career.

'I've concentrated on doing the job well. Because I am in the minority, gender-wise, some CEOs might be curious about how I got to this level. But if they are, they haven't said it. In fact I've found my fellow Departmental Secretaries and equivalents very collegiate and supportive as a group.'

In joining this select group Jane has followed her father, Charles Halton, an Englishman whom Gough Whitlam recruited from Canada to head up a mega-Department of Transport. Charles also served as a Departmental Secretary under Prime Ministers Malcolm Fraser and Bob Hawke.

So, Jane arrived on Australia's sunny shores as a teenager, with what she terms a 'mangled' accent, being British by birth, but having spent five of her formative years in Ottawa, where French was also a compulsory part of the curriculum.

Jane can still speak and read French, but the mangled accent is long gone.

At university she studied psychology at honours level, specialising in research into ageing. She got her first career job at the Research School of Social Sciences at the Australian National University. Stints at the Australian Bureau of Statistics and the departments of Social Security and Finance followed before she was appointed Assistant

Secretary, Community Care, then Principal Adviser, Corporate Development Group, in the then Department of Human Services and Health.

She then progressed to being First Assistant Secretary (national program manager) of the Aged and Community Care Program in the re-named Department of Health and Aged Care. Her next appointment was at Deputy Secretary level in 1998 as Executive Coordinator, Department of the Prime Minister and Cabinet, responsible for advising in all aspects of Commonwealth Government social policy—this included health, social security, employment, education, immigration and Indigenous policy.

Jane says that when she was appointed to her current position back in her 'old' department early this year, she was on a high: 'It was like coming home'.

On the other home front, Jane has a husband and two children, aged 12 and 8. But she prides herself in her ability to 'switch off' her work as soon as she walks in the front door.

She is a strong believer in the work–family balance, and has been known to turn up with children in tow if summoned to a Minister's office at late notice.

'I've never hidden my family responsibilities. It's part of who you are. Even last Tuesday my son was here in the office when some picking-up arrangements went wrong. I still make the kids' lunches every day.

'And, though I am able to switch off work when at home, it is not a complete dividing line. There has to be give and take on both fronts. If you have to work long hours to get something finished, there has to be similar flexibility when family needs are paramount.

'Other women have told me that, having seen me being transparent about family commitments, they have been emboldened to follow my example. I really take a lot of pleasure in that.'

Running is another activity in which Jane takes a great deal of pleasure, and which she says 'keeps her sane'. She runs up to 13 km most mornings, and is a regular competitor at local fun runs and cross-country events. That's in addition to her regular gym and aerobics sessions.

Jane says that she is reluctant to name personal 'heroes' because 'as soon as you do, people assume you support every aspect of that person, which might not be the case'.

'I have a number of role models, including women in the Public Service who have achieved and contributed at high levels. I admire many Indigenous people for their persistence and commitment to issues. In fact when I think of all the people I admire, they all have that combination of persistence and commitment, coupled with honesty.'

With work, family and fitness in her life, is there room to cram in anything else? Well yes, actually. Jane and her family are 'mad skiers', and are often to be found around Perisher in the winter months. She also loves the theatre and is a 'book consumer', particularly of biographies, which she finds she typically ends up reading during long plane flights.

If she hadn't advanced in the public service, what would she have been?

Jane says she really has no idea.

'I didn't plan my career. I just seemed to go from one interesting opportunity to another, and here I am. I don't think I could have been an academic though.'

Having hit the 'top of her game' relatively early in life, what does the future hold?

'I honestly haven't considered it. I love my job. There are big challenges in it, witness the recent restructuring I have implemented in the Department. But I am enjoying what I'm doing.

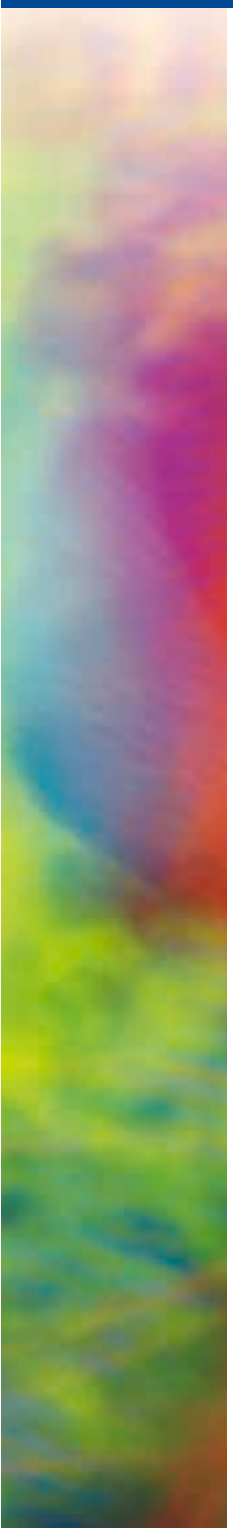
'For now I would like to do a good job and be seen to be doing a good job. But, equally, I would like to be a good help to my kids.

'In the future, like anybody I suppose, I would like to be well thought of. I would like it if people thought I had made a contribution—that I had made a difference.'

soap box

So different and yet the same — *first impressions*

RICHARD ALVAREZ



This summer I had the tremendous opportunity of visiting Australia—the first time that I have ventured to your country, fondly referred to as 'Down Under' in my part of the world. The purpose of my trip was to lead the Canadian delegation to an ISO meeting on Technical Standards for Health Informatics (ISO/TC 215). Actually, since its inception, Peter Treseder from Standards Australia has chaired this committee.

My travels took me to Sydney, Melbourne and Canberra where I met with staff from the AIHW and the Commonwealth and New South Wales Governments, and visited a couple of CEOs of Health Areas. I also managed to make a trip to Queensland to enjoy a bit of 'R & R' in the warm sunshine.

My first impressions of Oz—in a word, spectacular! Coming from the northern hemisphere, I was struck by the vastly different types of birds, wildlife, vegetation and scenery, all of which were quite incredible and breathtaking. And the more I learned about Australia, the more I felt right at home because the culture, the people and, above all, the issues facing the health system were so familiar.

Granted, the organisation and delivery of health services differ: Australia has a two-tier health system, and the Commonwealth Government, not the states, fund physicians. That said, Canada and Australia are both grappling with very similar issues—significant financial and population pressures as they relate to cost, access, quality, accountability, and the integration of information and communication technologies. Both health systems are also experiencing the unique challenge of delivering services to a significant portion of the population who are sparsely distributed across a vast land mass, in areas of extreme climatic conditions.

Learning more about electronic health records in Australia

Upon meeting with CEOs of two regions, I received an up-to-date progress report on electronic health records. I was impressed by the approach being adopted to implement the electronic health record—one that recognises the existence of legacy systems in both Health Areas. But with CEOs like Dr Diana Hovarth of the Sydney Health Area and Professor Katherine McGrath of the Hunter Health Area, who both seem to understand the value of information technology and have worked hard to realise its potential, it is hardly surprising to see that good progress is being made.

On the national front, I spoke briefly with Dr Robert Wooding and Paul Fitzgerald of the HealthConnect Program and was struck, once again, by the similarity of issues that both Australia and Canada face in achieving widespread implementation of the electronic health record. These issues include privacy and patient consent, obtaining stakeholder buy-in and support for changes in practice, and the development and adoption of consistent data and technology standards. Of course, we both deal with not having enough dollars to create the necessary infostructure or to generate the momentum to roll out the electronic health record. But despite the obstacles, most of which are unrelated to the technology, I believe that both countries have come to realise that information technology can be a major catalyst in reforming health care and dealing with many of the common issues we face.

Visiting the AIHW

It was a great honour and delight to visit the AIHW, meet with staff and deliver a seminar. The AIHW is to Australia what the Canadian Institute for Health Information (CIHI) is to Canada—we are both in the health information business with one major exception. The AIHW mandate extends to the collection and reporting of data in the welfare arena while ours does not. However, CIHI is examining and researching the non-medical determinants of health, many of which are related to an individual's health and wellbeing, through our Canadian Population Health Initiative. Also, CIHI seems to be more heavily involved in health informatics, including aspects of the electronic health records.

My first impression of the AIHW was exceedingly favourable (prior to my visit I did a little research on the Web—a wonderful thing—and was impressed by the excellent publications and products produced by the AIHW). My sense is that Richard Madden has created an organisation that values people and their contributions. There seems to be a culture of openness (or is this just the Aussie way?), togetherness and a real sense of family. Additionally, I must comment on the creativity of an organisation that manages to secure such superb artwork in its board room through an annual competition involving local schools. This is a truly innovative idea! Congratulations to Richard and his senior team and my sincere thanks to them for making my brief visit to AIHW so welcoming.

Finally, given our mandates, the globalisation of health and the common issues facing both systems, I am hopeful that CIHI and AIHW can establish a collaboration that will involve working on a comparative indicators project between our two countries. While this kind of project would support our efforts to measure the performance of the health system and provide information to improve quality of care, it would also give me a very legitimate reason to visit Oz again!

Richard Alvarez
President and CEO
Canadian Institute for Health Information (CIHI)

Richard Alvarez makes a telling point at his AIHW seminar

New AIHW release alert service

The AIHW offers a free e-mail service which automatically notifies clients of any new AIHW publications on the day of release.

This is an announcements-only list with low volume (averaging one message a week). Messages provide links to the on-line version of the report on the Institute's web site, and details on how to order the hard-copy version.

You can choose to unsubscribe to this service at any time.

For further information about this service, e-mail the Institute's Media and Publishing Unit at pubs@aihw.gov.au or visit our web site at www.aihw.gov.au/media/subscribe_notices.html

the driving force

National Health Information Management Group (NHIMG)

The NHIMG manages the National Health Information Agreement and its related structures and processes. This agreement is designed to:

- ensure that nationally relevant health information is collected, compiled and interpreted appropriately and efficiently
- improve access to uniform health information by community groups, health professionals, government and non-government organisations.

As part of its management role, the NHIMG is responsible for ensuring that agreement is reached on definitions, standards and rules relating to the collection of information and that guidelines are established for coordinating access to national health information, its interpretation and publication.

Reflecting the importance AHMAC places on nationally consistent health information, an AHMAC member or deputy has chaired NHIMG for its 10 year life. Current Chair is Patricia Faulkner, Department of Human Services Victoria.

AHMAC has also consistently financially supported the production of the National Health Data Dictionary now in its eleventh version.

The following are the key activities undertaken by the NHIMG in fulfilling these responsibilities:

- The NHIMG Health Information Development Priorities set the direction for implementation of the agreement. Progress is continuing on the development of a work plan to accompany the priorities.
- Victoria has taken the lead to write a discussion paper on the use of unique patient identifiers in statistical collections and accompanying guidelines. The paper has been endorsed by the Australian Health Ministers' Advisory Council (AHMAC) and circulated widely for comment.
- The NHIMG agreed that it is vital to develop a close working relationship between the Health*Connect* Program Office and NHIMG. The NHIMG is now represented on the Health*Connect* Stakeholder Reference Group, the National Electronic Decision Support Taskforce and the Business Architecture Working Group. The first of regular meetings between the two secretariats took place in September.
- The National Health Data Committee, a standing committee of the NHIMG, is continuing its work on definitions for the *National Health Data Dictionary*, ensuring they comply with endorsed standards. The committee has established a subgroup to look at the issues associated with including clinical data in the dictionary.
- The NHIMG Expert Group on Health Classifications acts as a point of reference for coordinating ongoing work on classifications and has established a National Family of Health Classifications.

AIHW provides the NHIMG Secretariat. Catherine Sykes currently has this challenging role.

National Health Data Committee (NHDC)

The NHDC is a standing committee of the National Health Information Management Group, a body established under the National Health Information Agreement.

The primary role of the NHDC is to assess data definitions proposed for inclusion in the *National Health Data Dictionary* (now in its eleventh version) and to make recommendations to the National Health Information Management Group on revisions and additions to each successive version of the dictionary.

This year marks the significant expansion of the dictionary to include clinical data sets. The first clinical data sets to be considered are cardiovascular disease data elements and diabetes-related items.

There is increasing interest in the role of the dictionary in the health sector, and this is evident in the work being done to make version 12 of the Dictionary more comprehensive than its predecessors. This year, the October NHDC meeting—the annual dictionary content

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web insite

Illustration by David Pope

Publications order cart

To make it easier for you to buy our publications, we have developed an order cart for our web site. This allows you to select publications from our catalogue and add them automatically to an order form that you can print out and fax to the distributors of our publications. Now, ordering Institute publications is just a few clicks away!

New… release alerts

In the last issue of *Access*, we promised a new service to alert you by e-mail to new AIHW publications as they are released.

This service is now in operation, and we already have nearly 1,000 subscribers registered. You can subscribe (and unsubscribe) yourself by going to our web site at: www.aihw.gov.au/media/subscribe_notices.html

New… on the web

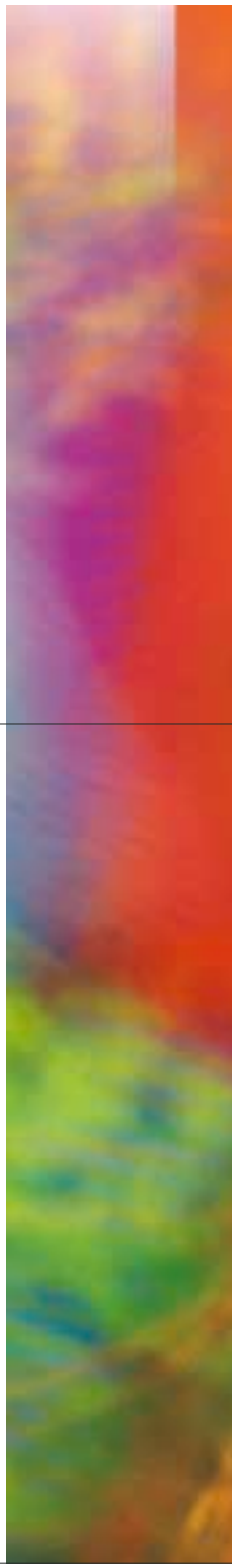
On average, 2,000 visitors a day come to our web site. We have recently added new portals on:

- Mortality (www.aihw.gov.au/mortality/) including information on the latest Australian trends in mortality.
- Veterans' health (www.aihw.gov.au/veteran/) including information on the new Female Vietnam Veteran and Civilian Health Register which the Institute is operating on behalf of the Department of Veterans' Affairs.
- International collaborations (www.aihw.gov.au/international/) including information on the work the AIHW does with the United Nations, World Health Organization and the Organisation for Economic Co-operation and Development. This area of the web site played a key supporting role in the Heads of WHO Collaborating Centres meeting, hosted by the AIHW in Brisbane in October.

New… cubes

Since last issue, we have added several new cubes on national health expenditure from 1960 onwards, and state health expenditure from 1996. Check out our new cubes at www.aihw.gov.au/dataonline/

With these latest additions, we now have 18 cubes available on our web site.



the driving force

Continued from page 10

meeting—was run over three days. This was longer than in previous years, and reflects the increased work being undertaken by the committee.

The committee also considered the new Emergency Department national minimum data set (NAPED NMDS) for inclusion in version 12 of the dictionary. This is a comprehensive new set which is planned to provide a new data collection 2003–04.

During the past year, the NHDC has made significant efforts to foster relationships with relevant Standards Australia IT 14 Groups. The committee has now begun work to include the Australian Standard on Health Care Client Identification in the AIHW-held Knowledgebase as part of a review of the structures and procedures for developing a national health metadata registry to be held by the Institute. This work is in its preliminary stages but promises to provide a high quality resource for managing national health information. The NHDC is very supportive of this work and has a keen interest in improving the current system.

from the Inside

What's a show without a stage crew?

How AIHW's business services helps get acts into gear

A show always has people on centre stage, but, equally, the stage and support crews are crucial in ensuring that everything will be 'right on the night'.

At the AIHW the people on the stage are the statisticians, epidemiologists, demographers and economists. They are the ones who analyse and present the data and associated information that goes into the 'shows' or reports for which we are known.

But with 80 shows a year, someone's got to make sure that contracts are signed, the venue is booked, the money is collected, the lighting and sound will suit the show and will work properly, and the beautiful programs will be designed, formatted and printed on time. As well, the costumes have to be readied, the media invited in the nicest possible way, the reviews placed on an attractive website and the bills paid!

In the Institute that 'someone' is the business services part of its Economics and Business Services Division.

Business services staff from the AIHW's Economics and Business Services Division

Go!

From the time a project is given the green light, the multi-faceted stage crew springs into action.

The contracts have to be written up. The Finance team assists in working out the scope of the project and the likely cost, as well as making sure that all the legal bases are covered and the funding organisation is happy with the proposed arrangements. Accounts have to be set up for receiving money, paying it out and keeping track of the budget.

Extra actors and stage crew may need to be recruited. The HR team assists with advertisements, coordination of applications and the whole recruitment process. Some players and crew may need extra training, which the HR team helps to arrange.

What is an office without desks and phones, pencils and pens? The facilities team is there to make sure we've got enough to cater for the new show.

Computers! The Data and Information Technology Unit may have to get a few more in, or upgrade one or two, then connect them into our computer networks. Safe and secure storage of the data has to be arranged, with all the necessary electronic protections. E-mail accounts have to be set up.

We're ready for stage 2.

They're here!

The new crew goes through an induction process coordinated by the HR team before meeting their fellow players and getting ready to start the new job.

Maybe a literature search would be a good start—perhaps to find out how similar projects have been undertaken, and what results have been reported. The Library assists with finding and assembling relevant books, articles and electronic resources.

And it's no good writing a report if you don't know about AIHW writing and formatting styles. The Media and Publishing team will set 'newbies' straight in a one-to-one session.

Now all that's needed are the data sets.

Data by the googol

Before any data comes to the AIHW, agreements must be in place with the data providers, such as State health, community services or housing departments. Most data providers take a great deal of comfort in the AIHW's second-to-none confidentiality and privacy provisions under which it holds data.

But, typically, there will be other restrictions and covenants, as well as file and formatting questions to be worked through before a provider will release data to the AIHW. The database managers in the Data and Information Technology Unit are 'key players' in this process.

When the data sets arrive, the expert database managers again step in. Their primary role is to 'clean up the act', i.e. ensure that the Institute's high data quality standards are maintained. A concentrated effort goes into validation and cleaning, standardisation, derivations and transformations before loading the data. This is followed by data extraction and tabulation processes for analytical and publication purposes. Along the way there will again be frequent contact between AIHW and the data provider.

Over the years the Institute has assembled huge databases. The Australian Hospital Statistics database, for instance, has over 220 million records. But there are other large collections too, ranging from housing and homelessness to the National Death Index, aged care data, and extensive cancer data, to name just a few.

So the data are in, and everything is cleaned up and ready to go. It is at this point that the statisticians, epidemiologists, demographers and economists begin their work in earnest, interrogating and analysing the data, and generating the tables and graphs that are the foundations of most AIHW reports.

Then the writing begins…

All the data that's fit to print

Writing a report can take some months, depending on its length, complexity and the number of authors and stakeholders involved. But even when the writing is finished, the job's far from over—the show is not ready for public viewing!

The report has to go through the publishing process, with the Media and Publishing Unit (MPU) team guiding it through professional editing, graphic design, desktop publishing and printing. At the same time, details of the forthcoming publication are entered into the AIHW's publishing database. This information is used to generate the AIHW's annual publications catalogue and publications lists, as well as being used dynamically by the AIHW web site's catalogue searching facility.

The steadying hand

Whatever happened to the Finance and HR teams, so heavily involved in setting up the project?

They are still there, taking a keen interest in how the project is progressing.

Having helped to cost the project, the Finance team has a vested interest in tracking expenditure on it. Fiscal alarm bells are rung if it all looks like going seriously awry, but it rarely happens. Constant liaison between the project manager and the Finance team over the course of the project helps, as does the team's advice on matters such as purchasing, travel, and reporting to funders on project expenditure.

Meanwhile the professionalism of the HR team continues to support the quality of the show with advice and assistance regarding training and enhanced performance, occupational health and safety and, of course, pay.

An untangled web to weave

As part of its commitment to placing its work in the public domain, the Institute makes full text versions of its reports available free on the AIHW web site. The support crew for this aspect of the show is the AIHW's Web team, which lives within the Library and Information Services Unit. The Web team works very closely with the Data and Information Technology Unit.

When the Media and Publishing Unit sends a publication to the printers, a portable document format (PDF) version is sent to the Web team. The document will appear on the AIHW web site the moment it is formally released to the public.

But the Web team does more than simply 'plonk' publications on the web site. The team also coordinates a system of information portals. Portals give users an overview of particular areas of health and welfare, combined with details of the work the Institute is doing in those areas. One or more portals may need to be updated with each new report release.

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Exposing a myth of the heart

Part III (final): Why 'only 50%' is a myth and why it matters

Recapping Parts I and II …

Parts I and II of this series described the epidemic of coronary heart disease (CHD) and the size of the contribution to CHD of the established risk factors—smoking, high blood cholesterol and blood pressure, physical inactivity and obesity. In an article published earlier with my colleague Robert Beaglehole, I estimated that these factors account for about 75% of CHD cases. This in marked contrast to what we have termed the 'only 50%' myth, namely that the known risk factors explain only half of CHD or even less.

Now I want to focus on the 'only 50%' myth itself—to try to understand how it might have arisen and to say why it matters anyway.

Anatomy of the myth

Overview of the findings

The first step was to chase up examples of the myth in scientific articles. We found eleven.

About half the examples simply made the 'only 50%' assertion without referring to any actual data or hinting at a rationale. The remainder at least gave references based on data. But those references all turned out to be quite inappropriate, as I'll show below. And in four cases the assertion had been secondarily quoted, perpetuating the myth.

In summary, none of the examples that used the myth made any real case for it. We couldn't find one reference or source that plausibly supported it with empirical data. (I've found a few more such references since and the story is the same.)

Let's have a look at them.

A striking recent example

One influential paper stands out. Published in 1996 in the *Annals of Epidemiology*, it mentioned at least ten CHD risk factors, including the established ones. Giving a reference, it stressed that 'when all of these risk factors are considered together they explain about 40% of the coronary heart disease that occurs'.

Strong stuff, but what were the actual facts? First, from this emphasis you would have expected the reference article to be fairly recent and to cover the ten known or possible risk factors mentioned. In fact it was a then 20-year-old (1975) study that covered only the three established risk factors, in a review of eight major US population studies.

Second, you would at least have expected the 1975 paper to find that the three risk factors explained only 40% of CHD. Well, the figure of 45% was mentioned. Only five percentage points out, so close enough maybe? Not at all. Because third, the paper had found that if *two or more* risk factors could be eliminated in the overall study population, then there would have been an expected 45% reduction in CHD cases.

So we used data from the 1975 paper to apply the real test of the contribution of the three risk factors: what if *one* or more risk factors could be eliminated? The figure we got was an expected reduction of 66%.

From this early source, therefore, the established risk factors explained about two-thirds of CHD—a dramatic and pivotal difference from the 40% asserted. The paper showed the opposite of what was being claimed.

What's more, the cut-points used in the 1975 paper were the early higher-than-optimal ones that tend to reduce the apparent impact of the risk factors. And finally—you may have guessed this if you read Part II of this series—that early paper was the very same one that I had referred to then, by Marmot and Winkelstein in the *American Journal of Epidemiology*. It was in fact one of the first to show just how much the three major risk factors contributed to levels of CHD.

Other examples

Confusing risk factors with a high point on a combined-risk distribution

What about the other sources quoted in using the 'only 50%' myth? Two papers cited a 1984 report on heart attacks from the United Kingdom Heart Disease Prevention Project. It showed that the top 15% of combined-risk distribution predicted only 32% of new heart attack cases over 5 years of follow-up. Apparently this met the bill because 32% is much less than 50%.

But it doesn't qualify at all. The study itself was not designed to see how much the risk factors explained CHD, and it made no such claim. It wasn't choosing the population with risk factors above cut-points that were optimal or even conventional at the time. It was choosing an arbitrarily high point on a combined risk scale. This construct is simply not compatible with the notion of 'the risk factors'.

Likewise for another 1976 report that applied a combined-risk model to two major US population studies, the Framingham and Western Collaborative Group studies. Again, this report made no claim about the proportion of cases explained by the conventional risk factors. The 'only 50%' claim seems to have been deduced by counting cases that could be attributed to the upper end of the combined-risk distribution.

Explaining an epidemic not same as explaining variations within it

Another source of confusion may arise from studies that asked how strongly the established risk factors could explain social and economic gradients in CHD rates. For example, the Whitehall I and II studies of British civil servants showed that those in jobs at lower levels had a 50% to several-fold higher risk than their counterparts at high levels. The established risk factors have typically explained less than half of this socioeconomic difference.

But these analyses deal with a quite different issue from explaining the overall population occurrence of CHD. There can be a big difference between explaining an epidemic and explaining modest variations *within* that epidemic, such as variations by socioeconomic level. It's like standing at the broad top of a huge mountain and trying to understand the hillocks you see up there. But what explains the mountain itself?

A key feature of the established risk factors is their ability to explain massive variations in CHD rates, including rates that are *below epidemic levels*. It doesn't follow logically that they should explain every type of variation in CHD so strongly.

Indeed the Whitehall I study itself proves that very point. Part II of this article showed that the risk factors, as defined, were able to strongly explain the full occurrence of CHD in the Whitehall population—namely about two thirds of the cases. This is in the same population where those same factors can only weakly explain the socioeconomic gradient. In other words, the two findings are perfectly compatible in the same context.

Confusing a change with a level

A further misinterpretation may arise from studies that seek to explain changing CHD death rates over time. The 'only 50%' claim might be based on several reports that have ascribed about half or less of the fall during a period to primary prevention through risk factor control.

But that is about the contribution of a *change* in risk factors to a *change* in CHD. It shouldn't be confused with the contribution of the underlying *level* of risk factors to the *level* of CHD.

In fact it's perfectly possible in theory, provided a set of factors are not the *entire* explanation of something, for a small or even modest change to occur in which they play no part at all. The known factors don't have to contribute as much to every change or variation as they do to the underlying problem. This is the same reasoning as for the previous section.

(And just for the record, studies from Iceland, Finland, a region of Australia, and elsewhere suggest that much of the observed falls in CHD can be explained by risk factor changes.)

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Dr Paul Magnus,
AIHW Medical Adviser

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Exposing a myth of the heart

Why does it matter and what are the implications?

A few main questions emerge from this 'only 50%' saga. First, what is the real contribution of the major risk factors to the coronary epidemics? Second, how on earth do these myths come about in the first place? And third, why does it matter?

I trust I've answered the first question in Part II of this series: the risk factors make a huge contribution. It is an equally huge challenge to control them fully, since only about 5% of people in countries like Australia could be regarded as truly low risk. But if we could achieve that control we could expect to reduce CHD rates by at least 75%.

I also hope I've answered the second question, by a critique of the various assumptions and methods that seem to be behind the 'only 50%' claim.

But so what—why does all this matter anyway?

The first reason is the matter of scientific rigour and the need to justify what we claim.

The second reason comes from remembering just how much is at stake with CHD. With rates of the disease rising so much in developing nations (and still high in developed ones), the time to act is now. The established risk factors show us the way, offering huge scope for prevention.

They *can* be acted upon and to great effect. This has already been partly achieved in numerous countries. The challenge is how *best* to achieve it and to do so worldwide.

A focus on the established risk factors does not imply an emphasis on identifying individuals and harassing them to improve their behaviour or giving them drugs. There can be a limited place for this—at least for encouraging, not harassing. But the widest and most effective risk factor reduction will come from broad and sustained public health approaches.

There is vital work to be done applying what we already know.

This article draws heavily on a paper in the December 10/21 issue of Archives of Internal Medicine, *by Magnus P and Beaglehole R, entitled 'The real contribution of the major risk factors to the coronary epidemics: time to end the "only 50% " myth', pages 2657–2660. (www. archinternmed.com), Copyrighted 2001, American Medical Association.*

from the Inside

Continued from page 13

What's a show without a stage crew?

The Web team also puts a lot of effort into helping the AIHW statistics 'show' to be even more accessible, in the form of data 'cubes'—multi-dimensional representations of data, which offer fast retrieval and drill-down facilities, as well as allowing you to construct your own tables.

With these innovations traffic to the web site is steadily increasing—at the moment we get around 2,000 visitors a day.

In the news

AIHW reports cannot always be front page news. But we have made the front page on many occasions—as well as morning radio bulletins and talkback shows, and the evening television news. With the release of *Australia's Health 2002,* for example, we had 41 major news items in the national press, including two page 1 lead stories (Sydney Morning Herald and the Australian), and five full-page spreads on the nation's health. AIHW staff gave 30 radio and television interviews.

The Media and Publishing Unit works closely with the statistics units to develop interesting media releases, arrange media interviews and prepare launches and conferences. All parties are always keen to remind the media and public of the role of the AIHW and to reinforce its reputation as an expert 'honest broker' of interesting and important health and welfare statistics and information.

Psst…wanna buy a report?

The web versions of our 'shows' are free, but the hard copy printed versions are sold at value-for-money prices through distributors such as InfoAccess (formerly AusInfo), the Australian Bureau of Statistics, and (for specific titles) various professional associations.

Publications are also sold at the AIHW front counter and at AIHW booths at major health and welfare conferences.

The Media and Publishing Unit handles the sales arrangements as well as producing promotional materials such as posters, brochures, advertisements and flyers.

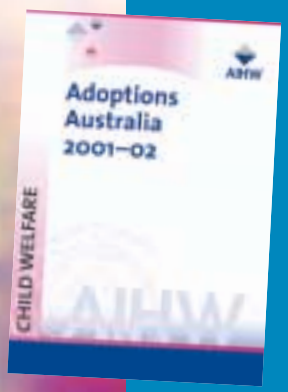
Star-gazing—the future

In producing its work the AIHW relies on an active stage and support crew.

But to keep pulling in the audiences the shows cannot remain the same. And good stage crews are seldom satisfied with marking time. Like all areas of the AIHW, the business services team is forever looking for ways to do things better.

Our place in the world of health and welfare statistics and information is characterised by increasing complexity, increasing expectations of immediacy, more complex accountability, partnership and stakeholder networks, increasing commercialisation, and a need to retain and develop our skilled staff.

The Institute's 2001–2004 Business Plan, developed by the Economics and Business Services Division in consultation with all areas of the AIHW, tackles these issues head-on, guided by the values and principles of the Corporate Plan. In this particular play the business services stage and support crew—finance, HR, facilities, data and information technology, media and publishing, the library and the web team—all have major parts.



Adoptions Australia 2001–02

Did you know that there were 561 adoptions in Australia in 2001–02? That's 47 more than in 2000–01, but far from a peak of nearly 10,000 in 1971–72.

These are some of the latest statistics presented in *Adoptions Australia 2001–02*. The report also provides information on adopted children, adoptive families and birth mothers as well as on requests for information.

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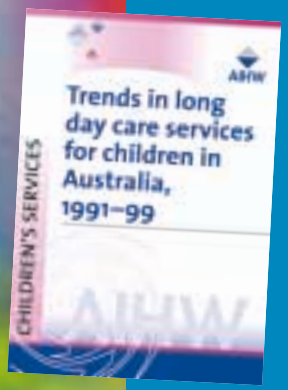

Trends in Long Day Care Services for Children in Australia, 1991–99

Long day care services for children grew rapidly in the 1990s, opening for longer hours and offering a greater variety of different services than ever before.

Trends in long day care services for children in Australia, 1991–99 presents detailed information on service provision. It also details the characteristics of children using long day care services and the staffing of those services.

AIHW cat. no. CFS 5
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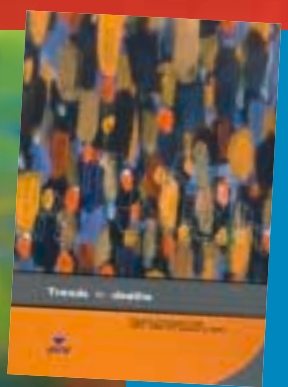

Trends in Death

Did you know that heart disease, stroke and lung cancer are the leading causes of death for men and women in Australia at the end of the 20th century?

Trends in Deaths is a comprehensive analysis of the patterns of death in Australia over the past 15 years. It presents contemporary data for 16 causes of death that are of particular interest in the heath field or whose influence could be reduced by behavioural changes.

AIHW cat. no. PHE 40
$30

Hospital Statistics, Aboriginal and Torres Strait Islander Australians, 1999–2000

The joint ABS–AIHW publication, *Hospital Statistics, Aboriginal and Torres Strait Islander Australians, 1999–2000* presents hospital statistics on Aboriginal and Torres Strait Islander patients who identified as Indigenous in public and private hospital separation records for the financial year 1999–2000. The publication presents statistics on the diagnoses of Indigenous patients, the procedures they underwent, and a range of patient characteristics.

Available from ABS shopfronts or mail order sales phone (02) 6252 5249

ABS cat. no. 4711.0
$28

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All prices include GST

October

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Dental Insurance and Access to Dental Care	Cat. No. DEN 105	FREE
Hospital Separations Due to Injury and Poisoning, Australia 1999–00	Cat. No. INJCAT 48	$25.00
Income Status of Homeless People in SAAP 1999-2001	Cat. No. HOU 70	$20.00
National Aboriginal and Torres Strait Islander Community Services Information Plan		FREE (Internet only)
National Health Data Dictionary Version 11	Cat. No. HWI 36	$16.00
Older Australia at a Glance 2002 (third edition)	Cat. No. AGE 25	$20.00
Trends in Satisfaction with Dental Care 1994-96 to 1999	Cat. No. DEN 85	FREE

September

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All prices include GST

December

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Apparent Consumption of Nutrients 1997–98	Cat. No. PHE 38	$12
Child Protection Australia 2001–02: First National Results	Cat. No. CWS 19	Free (Internet only)
Disability Support Services 2002: First National Results on Services Provided under the Commonwealth/State Disability Agreement	Cat. No. DIS 27	Free (Internet only)
General Practice Activity in Australia 2001–02	Cat. No. GEP 10	$20
Health Care Usage and Costs: A Comparison of Veterans and War Widows with the Rest of the Community, 1997–98 to 1999–00	Cat. No. PHE 42	$15
Homeless People in Australia: SAAP NDC Annual Report 2001–02 Australia	Cat. No. HOU 72	$15
Homeless People in Australia: SAAP NDC Annual Report 2001–02 States and Territories supplementary tables (8 reports)	Cat. No. HOU 73–80	$12 (each)
Hospital Statistics, Aboriginal and Torres Strait Islander Australians	ABS Cat. No. 4711.0	$28
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Trends in Deaths: Analysis of Australian Data 1987–1998 with Updates to 2000	Cat. No. PHE 40	$30
Demand for SAAP Assistance by Homeless People 2000–01	Cat. No. HOU 71	$15

November

Adoptions Australia 2001–02	Cat. No. CWS 18	$14
Aged Care Assessment Program Data Dictionary Version 1	Cat.No. AGE 26	Free (Internet only)
Alcohol and Other Drug Treatment Services in Australia 2000–01: First Report on the National Minimum Data Set	Cat. No. HSE 22	$18.00
Alcohol and Other Drug Treatment Services in Australia: Findings from the National Minimum Data Set 2000–01	Cat. No. AUS 30	$10.00
Cancer in Australia 1999	Cat. No. CAN 15	$23.50
Cervical Screening in Australia 1998–1999	Cat. No. CAN 11	Free
Diabetes: Australian Facts 2002	Cat. No. CVD 20	$20.00
Seasonality of Death	Cat. No. AUS 29	$10.00
Trends in Long Day Care Services for Children in Australia, 1991–99	Cat. No. CFS 5	$16

For publications released in August, September and October, see page 19.

Where to get AIHW publications

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Phone toll free 132 447 or use the order form supplied on the back of the address sheet.

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