



access

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Commemorative edition: a farewell to Richard Madden



Senator the Hon. Kay Patterson launches *Australia's Welfare 2005* at the National Library of Australia.

Australia's Welfare 2005: connected challenges, connecting response

The Australia's Welfare 2005 conference and launch on 30 November at the National Library of Australia, Canberra, capped an extraordinarily busy period for the Institute in the second half of 2005.

Australia's Welfare 2005 was launched in front of a crowd of more than 200 people by the Minister for Family and Community Services, Senator the Hon Kay Patterson. This is the seventh biennial report on welfare services by the AIHW, and is a legislative requirement under the AIHW Act. Every edition has a special thematic chapter and this year features an extended chapter on children, youth and families.

In launching the report, Senator Patterson said that she was pleased to see the 2005 edition acknowledge individuals and the different types of support they receive at each stage of their lives.

'I believe the focus on people and their individual needs should be at the very heart of social policy. And I think the thing that we need to understand too, is that those needs change and they change with time.

'The principle of focusing on the individual is reflected in the way the Government designs and delivers almost all of its social policies and programs—problems affecting individuals in a given phase in

their life course often influences their opportunities at a later stage, as well as their children's.

'For instance, what happens in childhood, in teenage years, in the educational work, in finding a partner, in having children, when families break down, in being unemployed, planning for retirement and so on, influences the quality and happiness of people's lives from birth right through to old age.'

Senator Patterson then drew attention to a number of specific projects and issues covered in the report and the key priorities for government in the welfare field.

A passionate advocate for the recognition and support of carers, the Minister spoke about 'the tremendous job that carers do' and the support the Government has given them in recent times.

'The Australian Government continues to recognize and support carers and people with a disability, with additional funding for respite services payment of bonuses to carers and the recently announced \$200 million package paving the way for families to secure financially the future care needs of a son or daughter with a severe disability.'

Minister Patterson said in the past, some regulations had hindered, rather than helped people provide care for their children. She said it was heartbreaking to hear the story of a woman in her eighties caring for her disabled adult son.

'The house she bought in 1950 is now worth \$600,000, and her only assets are her house. If she were to move into a retirement village, and put \$300,000 into that, and \$300,000 into a group home to assist her dependent son, she would lose her pension (through the gifting rules) and he would lose his pension (because he would fail an assets test).'

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The Australia's Welfare Conference, 'Connected Challenges, Connecting Responses', was held at the National Library on 30 November 2005. The conference provided insights into key issues facing Australia's community services and housing assistance sector. The one-day program commenced with the launch of *Australia's Welfare 2005* by Senator Kay Patterson, Minister for Family and Community Services and concluded with Dr Jeff Harmer, Secretary, Department of Family and Community Services, giving the closing plenary. Australia's Welfare is the nation's most comprehensive and authoritative source of welfare statistics and related information. You can read further about the conference and the publication in the article beginning on page 1.

The Hon. Julie Bishop, Minister for Ageing launched the AIHW report *Arthritis and Musculoskeletal Conditions in Australia 2005* at Old Parliament House at the end of October. The report provides clear information on the extent of a major health issue which impacts on many Australians. Minister Bishop also launched the National Centre for Monitoring Arthritis and Musculoskeletal Conditions, established at the Institute and assisted by a grant from the Australian Government under the Better Arthritis Care Initiative. The Centre will conduct systematic surveillance and monitoring of these conditions and put this information in the public domain on a regular basis. Further information can be found on page 8.

Parliamentary Secretary Christopher Pyne launched the detailed findings of the National Drug Strategy Survey on 22 November 2005 on the Gold Coast. This attracted a great deal of media interest and showed the capacity of the Institute in working in sensitive areas such as illicit drugs.

Together with fellow National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) members, I recently attended an Indigenous Health Measurement Group meeting in Vancouver. The meeting brought together government representatives, researchers and representatives of Indigenous organisations from Australia, Canada, New Zealand and the United States, to discuss health and health measurement issues for the Indigenous populations and to consider the organisation of an international collaborative group to address these issues. You can see the full article on page 6.

The Australian contingent at the meeting has returned inspired to make sure that we continue our excellent progress in Indigenous health statistics. NAGATSIHID is a group dear to my heart. I was delighted to be part of the team which so strongly demonstrated Australia's commitment to have Indigenous and non-Indigenous people work together on this vitally important topic.

In keeping with tradition and in the interest of health lifestyle, Institute staff entered the annual Melbourne Cup walk, run and cycle races. Participation levels were high and with the weather being turned on, a good day was had

by all. Special thanks are due to John Harding. We look forward each year to his organisation of the races, based on a complex handicap system.

After more than eight years at the Institute, Margaret Fisher, the Head of the Executive Unit, is leaving the Institute early next year to teach aviation English to students at the Shen Yang Institute of Aeronautical Engineering in China. I would like to thank Margaret for her creativity, diplomacy and support over the years and wish her all the best with her new career. Margaret has been Secretary to the AIHW Board and the Executive Group. In the latter role, all five Executive members thank her especially for her persistence in making sense of complex, lengthy and occasionally heated debates.

As I indicated in the September edition of *Access*, I did not seek a third term as Director of the Institute so I shall be finishing up at the end of the year. I have accepted a position as Professor and Director of the National Centre for Classification in Health at the University of Sydney. The Centre is the Australian centre of excellence in health classifications and will provide an opportunity for continuing interaction with those involved in health and welfare. I am looking forward to this new challenge and trust I can continue to have an impact on health statistics and classifications both in Australia and globally.

My time at the AIHW has been challenging, rewarding and fulfilling. I have worked with a great team of intelligent, committed staff. We have enjoyed stimulating discussions, endured hectic efforts to meet publication deadlines, and worked collaboratively to make achievement of the Institute's mission a reality. I am proud of the AIHW and its status in the Australian scene. I applaud our staff and collaborators for their superlative achievements, and I thank the many friends of the Institute who have so generously contributed to and supported our work program. I have been fully supported throughout the 10 years by the AIHW Board, particularly Professor Jan Reid, Dr Sandra Hacker and the Hon Peter Collins who have chaired the Board during my time at the Institute.

I would like to wish you all a safe and happy festive season and all the best for the future.

Richard Madden, Director, AIHW.



'My time at the AIHW has been challenging, rewarding and fulfilling. I have worked with a great team of intelligent, committed staff.'

Australia's Welfare 2005: connected challenges, connecting response

► Continued from page 1

Patterson said the publication proved 'valuable in targeting assistance to those in need'.

'It reveals the benefits of running a strong economy, providing more job opportunities and more funding to areas of need, as well as identifying where more work still needs to be done.'

On a personal note, the Minister thanked Dr Madden for his 'vision, untiring efforts and leadership' of the Institute during the past ten years.

At the launch, AIHW Board Member, Professor Heather Gardner said that the Board saw the report as 'an opportunity' as well as a legal requirement.

'It's an opportunity for us to present an objective, statistically-based view of the complex but comprehensive mosaic that makes up the nation's system of welfare services and assistance.'

'It's an opportunity for us to present an objective, statistically-based view of the complex but comprehensive mosaic that makes up the nation's system of welfare services and assistance.'

'It also an opportunity to present that view to as many people as possible, from the Minister to administrators, academics, students, service providers, clients and interested citizens.'

Professor Gardner paid tribute to the Australia's Welfare authors, its editorial committee headed by AIHW Welfare Division Head, Dr Diane Gibson, and the Institute's Information Services and Publishing and Business

Promotion and Media Units which produced the report and organised the conference and launch.

This year's theme for the *Australia's Welfare 2005* conference was 'connected challenges, connecting responses'. The conference itself gave an insight into the key issues facing Australia's community services and housing sector. It also assessed current welfare statistics and demonstrated the relevance of these figures to existing and future welfare practices and reforms.

Keynote speakers were AIHW Director, Dr Richard Madden, and Secretary of the Department of Family and Community Services, Dr Jeff Harmer.

In his final speech as Director of the Institute, Dr Madden commented on the role of statistics in the Australian society. He also spoke about the evolution of the report on Australia's Welfare, and reflected on 10 years at the AIHW.

Dr Madden said that 'good official statistics' underpinned a democratic society. He said that regular publishing of reliable and unbiased information allowed governments to be held to account, and provided a base for decision making by all sectors of the community.

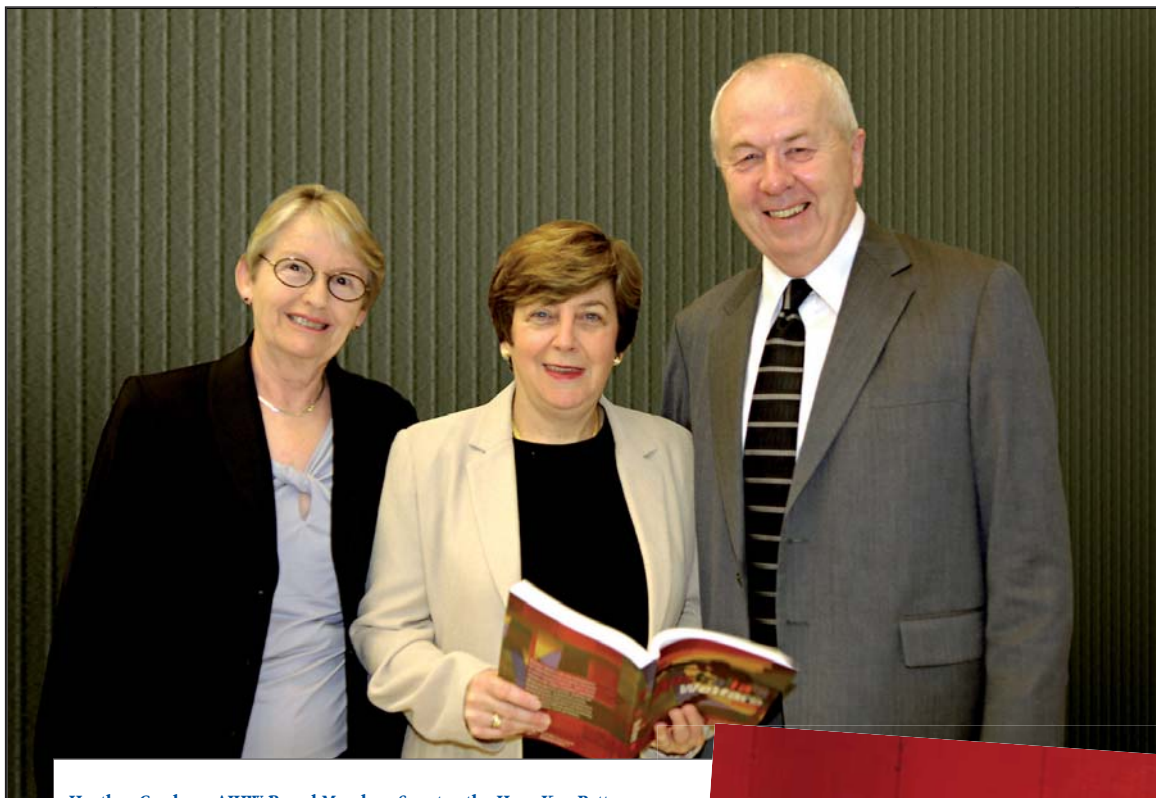
And he added that 'undemocratic societies control their statistics and the people who produce them.'

He gave the example of a prominent African staff member at Statistics South Africa who told him that Africans were not allowed to staff the statistics office in the apartheid era.

Closing the conference, Dr Jeff Harmer presented the keynote address and spoke of the importance of the conference from his perspective—to 'improve the lives of Australians'. He discussed the role of the 'new Family and Community Services', the importance of data, and future challenges for the Institute.

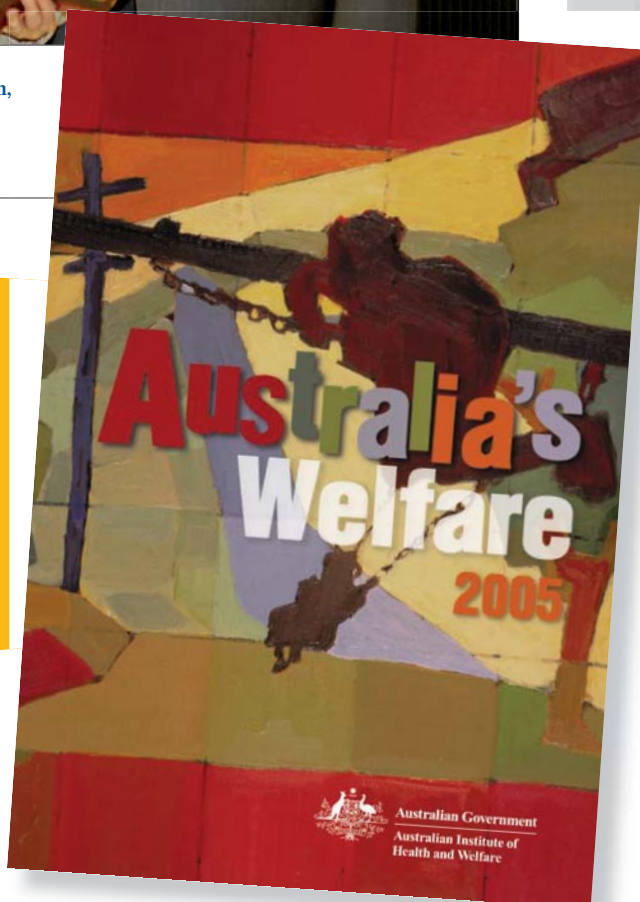
Australia's Welfare authors and welfare sector experts presented concurrent sessions on their areas of expertise including: children youth and families; participation, ageing and disability; welfare-related outcomes and resources; and housing and homelessness. Chairs for these sessions included: Stephen Hunter, Deputy Secretary, Department of Family and Community Services; Heather Gardner, Adjunct Associate Professor, School of Public Health, La Trobe University; Ian Spicer, AIHW Board Member; and Owen Donald, Director of Housing, Department of Human Services (Victoria).

These sessions often sparked lively debate among conference delegates—most of whom were welfare or community services professionals, researchers, policy makers, practitioners and academics working across all industry and government fields.



Heather Gardner, AIHW Board Member, Senator the Hon. Kay Patterson, Minister for Family and Community Services and Richard Madden, AIHW Director, celebrate the launch of *Australia's Welfare 2005*.

Australia's Welfare 2005 (500pp.) is on sale for \$55 from CanPrint (tel. 1300 889 873), the Australian Bureau of Statistics, or over the counter at AIHW (\$10 discount if purchasing from AIHW).



Indigenous Health Measurement Group meeting in Vancouver, Canada

Project 1

Richard Madden and Fadwa Al-Yaman, Head of the Aboriginal and Torres Strait Islander Health and Welfare Unit, attended the first meeting of the Indigenous Health Measurement Group, in Vancouver, Canada on 4–5 October 2005.

Several National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data members attended, including Ted Wilkes, Dea Delaney Thiele, Ian Anderson and Ian Ring also attended. They were part of a 12-member Australian contingent that included representatives from the Australian Bureau of Statistics, the Australian Department of Health and Ageing Office for Aboriginal and Torres Strait Islander Health. The meeting was held in conjunction with the second meeting of the International Network on Indigenous Health, Knowledge and Development (INIHKD) on 1–4 October.

The Indigenous Health Measurement Group meeting brought together government representatives, researchers and representatives of Indigenous organisations from Australia, Canada, New Zealand and the United States, to discuss health and health measurement issues for the Indigenous populations in the four countries and to consider the creation of an international collaborative group to address these issues.

The participants discussed a number of possible research topics for the Measurement Group to pursue over the next two years. The focus was on practical outcomes that would lead to improvements in the health and wellbeing of Indigenous communities. Participants outlined a number of principles that the research program should follow, including: the Indigenous right to be counted; Indigenous leadership and participation; the need to involve community members as well as governments in these activities; the need to build data skills within the communities; the recognition that collaboration should be both across countries and within countries (nation–provinces/states–communities); the need to share the results of these projects across countries; the need to present statistics in an appropriate way and the

Measurement Group activities should be transformative e.g. data collection/analysis/dissemination should be linked to improvements in health; the need to serve as a facilitator, an honest broker and information provider to the Group and those interested in improving the health of Indigenous people so that the information can inform national decision making.

Australian data, and its governance, seemed to be in better shape than in Canada and the United States. Some Indigenous people are largely invisible in Native American statistics.

On the other hand, Australians could give more thought to the nature of presentation of Aboriginal and Torres Strait Islander data ensuring the context and positive aspects are brought out.

The Group will continue to communicate regularly by tele-conference and email and will hold meetings every two years.

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AIHW reports on Indigenous housing needs

Project 2

Housing is an important part of human welfare and is closely related to health. Many of the significant advances in health in the 19th and 20th centuries were achieved through improvements in housing and public hygiene. Yet, today, many of Australia's Aboriginal and Torres Strait Islander people still live in sub-standard housing.

The Aboriginal and Torres Strait Islander Health and Welfare Unit at AIHW recently produced, for the first time, a report on *Indigenous Housing Needs: A Multi-measure Needs Model 2005*, which details the state of the housing occupied by Indigenous people. The report examines information about homelessness, overcrowding, affordability and condition of the dwelling and connection to essential services among Indigenous people. Security of tenure, appropriateness of housing and emerging needs were also examined, but in less detail.

In 2002, of the estimated 165,700 Indigenous households, 30% owned their homes, 66% were renting and 4% were in rent-free accommodation. Of those owning homes, 65% had a mortgage. Of those renting, 37% were in the private rental market, 57% in social housing and 5% were other renters.

In 2001, between 7,500 and 10,500 Indigenous people in Australia were homeless. They include people with no accommodation, staying with relatives, using Supported Accommodation Assistance Program (SAAP) services or living in boarding houses. Homelessness was three times as high among Indigenous people as among non-Indigenous people, and the use of SAAP services by Indigenous people was eight times as high.

Using one of several overcrowding standards, 10% of Indigenous households were overcrowded. In 2001 overcrowding was more prevalent in the Northern Territory than elsewhere and among households occupying Indigenous Community Housing. In the Northern Territory, 61% of Indigenous people were living in overcrowded households. Overall, the rate of overcrowding in Indigenous households is six times that of non-Indigenous households.

Affordability of housing is defined by the proportion of income spent on providing housing among households in the lowest income distribution. In 2001 it was estimated that 31,255 Indigenous households (or 37%) of low income households were paying more than 25% of the household income in rent. They were therefore in a condition of 'affordability need'. Around 30% of non-Indigenous

households were in the same situation. More Indigenous households in the private rental market were in affordability need than those in public housing. Affordability need was greatest in the cities and lowest in rural areas.

'Dwelling condition' is a measure of whether a dwelling is in need of repair or replacement. In 2001, around 27% of houses on discrete Indigenous communities were in need of major repair or replacement. Some houses occupied by Indigenous households were not connected to essential services: (47 not connected to water; 257 not connected to electricity; and 301 not connected to a sewerage system). All of these were located in outer regional, remote or very remote areas.

Security of tenure is relatively easily defined, but information is difficult to collect systematically. For example, it was estimated that in 2001 around 1,800 Indigenous people were housed in caravan parks where security of tenure can be an issue. Those in private rental houses also appear to be at risk. Information from the ABS National Aboriginal and Torres Strait Islander Social Survey (2002) suggests that 38% of Indigenous households in privately rented housing had moved house in the last 12 months and 15% had moved twice in that time. Census data show that 45% had moved in the preceding 12 months. Some of this mobility can be related to insecure tenure.

'Appropriateness' is a measure of whether a house provides its occupants with a reasonable quality of life, access to work, social contacts and services. The report explains that a method for measuring this dimension of Indigenous housing is yet to be developed.

The emerging need for housing for the Indigenous population was examined by looking at population growth trends. The report concluded that the Indigenous population can be expected to grow at a faster rate than the non-Indigenous population and that, as a result, housing need will increase.

The report attracted more than the usual media interest because it was released in the midst of a public debate on Indigenous housing.

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National Centre for Monitoring Arthritis and Musculoskeletal Conditions in Australia

Project 3

The Australian Institute of Health and Welfare has recently established the National Centre for Monitoring Arthritis and Musculoskeletal Conditions in Australia. The Centre was launched by The Hon. Julie Bishop, Minister for Ageing at Old Parliament House on 31 October 2005.

The establishment of the Centre under the Better Arthritis Care Initiative follows the declaration of arthritis and musculoskeletal conditions as a National Health Priority Area by Australian Health Ministers in July 2002.

Technically, arthritis is inflammation of a joint. However, the term is used much more generally to describe any pain producing damage to the joint. Given the large number of joints in the human body (213 bones with about 360 joints), the number of arthritic problems encountered is large. More than 150 forms of arthritis are already recognised in the literature. The term 'musculoskeletal conditions' includes all disorders associated with bones, muscles and connective tissues of the body, including arthritis. Monitoring this vast array of conditions is a formidable task.

The surveillance and monitoring of arthritis and musculoskeletal conditions in Australia has evolved slowly. There is a perception that chronic diseases such as these do not change appreciably over time. A corollary to that is that not much can be done to alleviate their impact quickly. The establishment of the National Monitoring Centre by the Institute is the first major step to correct this lag, says Dr Ching Choi, Head of the Health Division of the Institute.

'The monitoring system for arthritis and musculoskeletal conditions requires a special orientation', according to Dr Kuldeep Bhatia, head of the newly established Centre. 'The type of information required differs both in emphasis and content. The National Mortality Database—otherwise one of the best sources of information for disease monitoring—is of limited use because of the largely non-fatal nature of most of the musculoskeletal conditions. Similarly, hospital separations constitute a small proportion of health service use for these diseases and conditions. The focus of the Centre has to be on health service use in primary care settings and associated disability.'

In addition to monitoring changes in the magnitude of the problem and health outcomes, the Centre plans to track underlying trends in risk factors. Changes in health practice and prevention and management activities will also be monitored. The focus of the activities of the Centre initially would be on

osteoarthritis, rheumatoid arthritis and osteoporosis, three of the most prevalent diseases and conditions.

A variety of technological innovations over the last few decades has increased opportunities for reducing disability associated with arthritis and musculoskeletal conditions. Many people disabled by arthritis can be treated with pharmaceuticals, or, extreme cases, through joint replacement. The spread of assistive devices, home and occupational modifications has also improved the opportunities for independent living. Monitoring the impact of these innovations and disease management will be central to the activities of the Centre.

Another major focus of the Centre's work is planned to be on osteoporotic fractures. National information on the incidence of osteoporotic fractures, and associated complications and mortality, is currently available in several, incongruent databases. Using record linkage and other similar approaches, the Centre plans to monitor these adverse health outcomes of osteoporosis in a systematic fashion.

Out-of-pocket expenses incurred by people with arthritis to manage their condition also needs to be monitored. The burden is particularly heavy on socioeconomically disadvantaged segments of the community. The Centre plans to monitor and report trends in these expenses regularly.

The staff of the new Centre has a wealth of experience in epidemiology, risk factors and quality of life aspects of various musculoskeletal conditions. Dr Bhatia, has worked on immunogenetic aspects of various arthropathies both at the National Institute of Arthritis, Diabetes and Kidney Diseases and Papua New Guinea Institute of Medical Research. Dr Naila Rahman, an epidemiologist trained at the National Centre for Epidemiology and Population Health, has recently compiled the baseline report on arthritis and musculoskeletal conditions in Australia. Ms Tracy Dixon, a statistician, has worked on issues related to knee and hip replacements both in Australia and abroad. The Centre also has access to expertise in disability, morbidity and mortality issues within the Institute.

The work program of the Centre will be advised by the Data Working Group of the National Arthritis and Musculoskeletal Conditions Advisory Group.

For further information please contact Kuldeep Bahtia;
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New report on arthritis and musculoskeletal conditions in Australia

Project 4

The Hon. Julie Bishop, Minister for Ageing launched the AIHW report *Arthritis and Musculoskeletal Conditions in Australia 2005* at Old Parliament House in October 2005 'For the first time, we have a report that provides clear information on the extent of a major health issue which impacts on the lives of so many Australians', Ms Bishop said.

Around 6.1 million Australians are estimated to have arthritis or a musculoskeletal condition. Prominent among these are back pain, osteoarthritis, rheumatoid arthritis and osteoporosis. There are also numerous less common diseases and conditions covered under the rubric of arthritis and musculoskeletal conditions.

'Almost one in five persons with arthritis and musculoskeletal conditions reportedly has activity limitations associated with their condition', said Minister Bishop. 'Lifestyle changes such as regular exercise, weight loss, improved nutrition and giving up smoking are important management factors for these persons.'

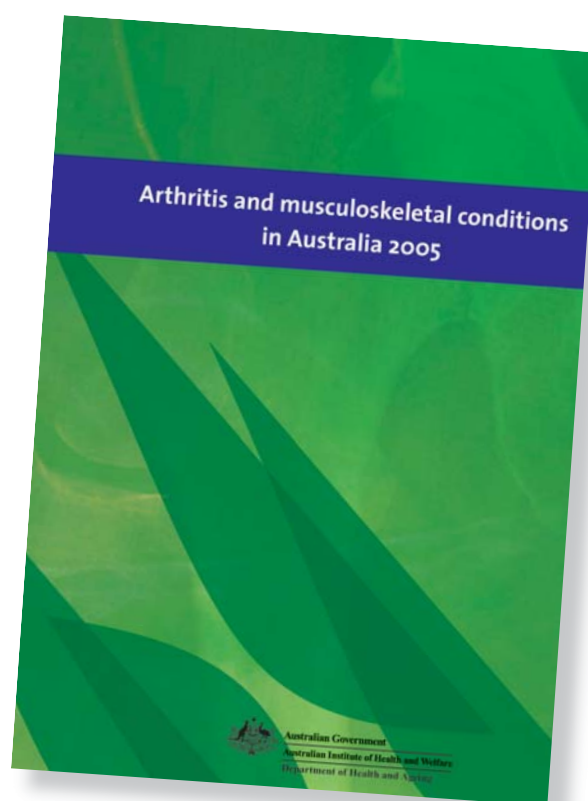
Associate Professor Lyn March congratulated the authors, Dr Naila Rahman, Ms Elizabeth Penm and Dr Kuldeep Bhatia of the AIHW National Centre for Monitoring Arthritis and Musculoskeletal Conditions, for covering such a broad range of issues under one title. Baseline information on the extent of the problem, associated disability and mortality, treatment and management and health expenditure is included in the report.

The focus of the report however is on osteoarthritis, osteoporosis and rheumatoid arthritis, three of the most prevalent diseases and conditions in Australia. The report also provides an overview of the surveillance of these arthritis and musculoskeletal conditions in Australia.

The production of the report has been made possible with funding from the Department of Health and Ageing. The preparation of the report was guided by the Data Working Group of the National Arthritis and Musculoskeletal Conditions Advisory Group.

Professor Peter Brooks, Executive Dean of the Medical Faculty, University of Queensland, contextualised the declaration of arthritis and musculoskeletal conditions as a National Health Priority Area in July 2002. 'This initiative by the Australian Health Ministers was in line with the efforts underway internationally through the World Health Organization's Bone and Joint Decade 2002–2011', Professor Brooks added.

Minister Bishop also launched the National Centre for Monitoring Arthritis and Musculoskeletal Conditions, established at the Institute through a grant from the Australian Government under the Better Arthritis Care Initiative. The Centre will conduct systematic surveillance and monitoring of these conditions and put this information in the public domain on a regular basis.



National Dementia Data Development and Analysis

Project 5

Dementia is a growing health and social issue and has now been identified as a National Health Priority. It is one of the largest contributors to disability burden experienced in Australia, and is the most expensive health condition among the older population, largely due to the costs associated with residential care.

The National Dementia Data Development and Analysis project is analysing available data about people with dementia in Australia, and developing a guide for national data collection about dementia that could inform future policy and service planning and reporting. The project is a collaborative effort of three units at AIHW—the Ageing and Aged Care, Summary Measures and National Data Development and Standards Units. A reference group with expert members from clinical, service provider, data development and policy advising backgrounds is providing advice to the project.

Primary objectives of the project are to:

1. Review definitions of dementia and approaches to its identification in various classifications and data sources including the relationship with cognitive impairment.
2. Provide updated estimates of the prevalence and incidence of dementia, examine the characteristics of people with dementia and their carers, including their use of formal services, and estimate the burden of disease and expenditure on services associated with dementia.
3. Review currently collected data about dementia and identify modules of possible data items that would increase the comprehensiveness of information collected about dementia.

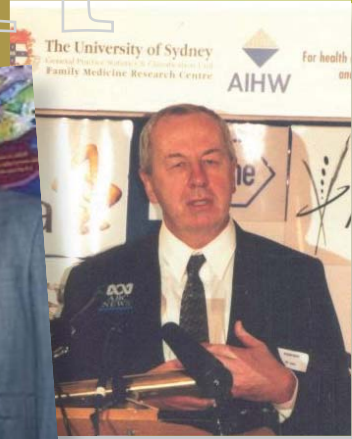
A wide array of data sources are being reviewed and analysed for the project, among them the ABS Survey of Disability, Ageing and Carers, the Aged Care Assessment Program minimum data set and the Alzheimer's Australia data set.

The report is scheduled for release in early in 2006.

For further information please contact Ann Peut;
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Richard Madden

Richard Madden has led the Australian Institute of Health and Welfare for 10 years. An inspiring and talented leader, Richard has unstintingly devoted his expertise, mind and heart to building the institution that the AIHW has become. In doing so, he has lived the Institute's values for which he has been such a powerful advocate.



Richard the Statistician, instilling a rigorous approach to the Institute's work.



Richard the Facilitator,
working with partners and
clients in a consultative and
collaborative way.



Businessman

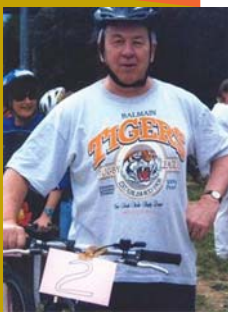


Richard the Businessman, creating a range of business opportunities through Memoranda of Understanding with key Australian Government agencies and demonstrating his entrepreneurship by investing in the innovative METeOR.





Richard the Team Player. Richard always made it clear that the Institute's people are its most valuable asset, and made time, in our highly productive environment, to play.



Team
Player

National Community Services Information Strategic Plan 2005–2009

The National Community Services Information Agreement 2005–2009 requires that the National Community Services Information Management Group (NCSIMG) develops a work program, responsive to the needs of both policy makers and the community, to be endorsed annually by the Community Services Ministers' Advisory Council.

The first National Community Services Information Development Plan (NCSIDP) was developed at the request of the then Standing Committee of Community Services and Income Security Administrators and was published in 1999. Since then, the NCSIDP has driven the NCSIMG Work Program.

The original Information Development Plan focused on areas where, in 1999, there was little data development activity. By August 2004, the general national information environment had changed over time and NCSIMG had finalized the priority tasks. It was agreed that development of a new NCSIMG Strategic Plan to guide the future work program was required.

After a special meeting of NCSIMG focussed on strategic directions (November 2004), a sub-committee was established to develop the new strategy. Over recent months the Plan has been developed through an interactive process of consultation and revision involving key stakeholders. The new National Community Services Information Strategic Plan 2005–2009 (NCSISP) is a comprehensive document which provides both an overview of the national information system and sets clear directions for the future.

The NCSISP is presented in two main parts to reflect the two main purposes of the document:

- Part 1 'Environment' tells you all you ever wanted to know about the NCSIMG. It provides information about the environment within which NCSIMG operates, its achievements against the previous plan, and the relationships it has with other organisations.
- Part 2 'Priorities' highlights emerging challenges as well as future work priorities for the NCSIMG organised into the following three areas:
 - data standards infrastructure priorities
 - sector-specific priorities
 - cross-sectoral priorities.

NCSIMG members are grateful for the advice of non-government organisations, peak bodies and other key stakeholders whose views informed the final version of the Plan. The NCSIMG presented the Plan to Community Services Ministers' Advisory Council on 6 October 2005. The Plan was endorsed and is currently being printed. Keep an eye on our web site as the plan will also be available at <http://www.aihw.gov.au/committees/ncsimg/index.cfm>.

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Sizing up sin and other things—the population attributable fraction: part 2

Say you were thinking about how to reduce the onset and impact of a health problem to their barest minimum. What would be a good approach?

An early step in your thinking, naturally, would be to see if you knew which factors cause the problem in the first place. Then you would try to work out how much each factor contributes to the problem. The answers may suggest some priorities. Finally you would gauge your practical options for preventing the problem by eliminating the causes or at least curbing them.

The second of these steps—working out the fraction of a particular health problem that can be attributed to a particular cause or risk factor—was the subject of the first part of this two-part article. Part 1 of *Sizing up sin* explained the basic thinking behind the population attributable fraction (PAF) and how a formula can be used to estimate it.

Basically, the PAF depends on how many people have the risk factor and how strongly it typically raises their risk. To explain this in a relatively easy way, Part 1 looked at the PAF of cigarette smoking in the case of lung cancer. It noted that over 80% of today's lung cancer deaths could be put down to smoking. The clear message was that we could cut lung cancer drastically if we could cut smoking.

In Part 2, I want to deal with some issues that arise when we're trying to deal with health problems that don't have such a dominant cause as the relationship between smoking and lung cancer. Let's take a disease like coronary heart disease (CHD), for example. In this case, it is widely agreed that there are several major causes if not more. The risk factors most often cited include high blood cholesterol, high blood pressure, cigarette smoking (again!), physical inactivity, obesity and diabetes.

This raises a few questions:

- What do we mean by 'having' a risk factor and how does our answer affect the PAF?
- Instead of just considering the factors and their PAFs individually, how can we look at their *combined* impact and therefore the full scope they suggest for reducing coronary heart disease?
- Also, how do we handle the problem of one expert choosing one set of causes and another choosing a set that seems quite different?

Choosing a realistic cut-point for a risk factor

The trouble with saying people 'have' a risk factor like high blood cholesterol is that it suggests the world is divided into the 'have its' and the 'don't have its'. In reality there's rarely a magic division. As the blood cholesterol level increases so does the risk of CHD, all other things being equal. There is said to be a relationship of continuous risk and it starts at very low levels of cholesterol. This is the case with many risk factors, including blood pressure levels.

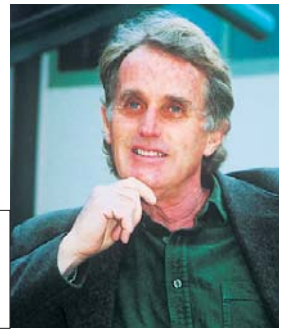
Yet to help us decide when something's a worry—and so may need corrective action or at least a watchful eye—we need to have some idea of what's 'high' or maybe 'borderline'. (And of course, when thinking at the population level, we certainly can't work out a PAF if we don't do this.) This means choosing a point, often called a cut point, above which things are 'high' and a person 'has' the risk factor or is at risk; and below which a person is 'not at risk' or at low risk.

How do we choose that point? The criticism has been made that if we choose a cut point that is very low, for example, with the cholesterol level, almost everyone will be regarded as exposed and at risk because most of them would exceed the cut point. We would then arbitrarily have a very large PAF for high cholesterol levels and attribute a huge amount of CHD to it. Others of us would argue, however, that with blood cholesterol it *really is* the case that most of us are exposed to unhealthy levels, given our high-fat Western diet.

Perhaps the best way is to choose a cut-point that carries a low risk for CHD but is realistic and also shows no counterbalancing risk for other things. Realistic means that many people have that level in our society already and that it is also widely represented in other societies, where it may even be the norm in some cases.

The great epidemiologist Jeremiah Stamler and his colleagues followed this rule when they chose a cholesterol cut point of 5.2 mmol/L in a major 1999 study that examined CHD risk among many thousands of US men and women. This cut point was much lower than the

Dr Paul Magnus
AIHW Medical Advisor



traditional 'high' mark of 6.5 mmol/L or more. But Stamler noted that levels below 5.2 were common in a range of other countries such as China, Japan, Greece, Italy and South Africa, as well as among certain groups such as the Seventh Day Adventists.

When Stamler looked at men and women in the US group whose cholesterol fell below this cut-point, who did not smoke and had a good blood pressure level as well, he found they had about one-fifth the risk of CHD death, or better, than the rest of the population. What's more, they had about half the overall risk of death *and* a considerably lower risk of cancer. So the cut points chosen were reasonable.

In a related major study of over 350,000 middle-aged US men published a decade earlier, Stamler found that almost half, 46%, of their CHD deaths could be attributed to blood cholesterol levels of 4.7 mmol/L or more. In other words, the PAF of having a higher than desirable cholesterol level was close to 50%.

The PAF of combined risk factors

When a health problem has several important risk factors, the point has often been made that we shouldn't just focus on the risk posed by those factors taken one at a time. What we are interested in is their combined impact. Otherwise we won't be able to gauge the full preventability of the problem.

The trouble is that we can't just add up the individual PAFs for the various factors—say smoking, high blood cholesterol and high blood pressure in the case of CHD—and get a sensible answer. Doing it this way, the resulting percentage will almost always be falsely high and can even add up to more than 100%. This problem can arise especially if the PAFs of the individual risk factors are taken from separate studies.

Again, in their earlier study Stamler and colleagues showed how we can get around the problem provided we have a very large study population like theirs. As explained above, they compared the death rates of those who had 'no' risk factors with the rates among the rest. In this case the rest were those who had any one or more of the following factors: a blood cholesterol level of 4.7 mmol/L or more, a diastolic blood pressure of 90 mmHg or more, or being a cigarette smoker. In effect, the rest were treated as a single 'high risk' group.

Stamler worked out that if everyone in his study had the same death rates as the low risk group, there would have

been 560 deaths over the six years of observation. Since there were in fact 2,258 deaths, the difference—1,698 deaths or 75% of the total—could be attributed to the combined risk factors. This is the same as a PAF of 75%. If they had calculated the frequency and relative risk of this any-risk-factor group, then used the PAF formula (see Part 1 of this article), the result would have been the same. Put another way, if risk factor levels could have been reduced to those of the low risk group, 75% of CHD deaths could have been prevented.

When causes seem to clash

Now to a quite different sort of problem that can arise with PAFs. It occurs when people see causes from different viewpoints. Some commentators may argue, for example, that at least 90% of the CHD epidemic is due to social and economic causes. Others may respond that no, the vast majority of CHD can be attributed to the factors mentioned above such as high blood cholesterol, cigarette smoking and so forth.

Others of us would argue that both claims are true. It's just a matter of where you look at the causal chain and where you think you can intervene to best effect. From this viewpoint it is the general economic and social conditions of a country like Australia that result in so many of us having a high-fat Western diet, avoiding physical activity and smoking cigarettes. This in turn leads to undesirable effects on our body weight, blood pressure, blood fat levels and many other things. And *within* this overall socioeconomic background, economic and social differences will mean that some groups of people will be even more likely to have risk factors than others.

(In principle, to reduce population levels of CHD we might need to consider whether to intervene at the social end, the medical end, somewhere in between or all of the above. For CHD the answers would depend partly on our philosophy about societal intervention and partly on the chances of success with medical approaches to problems such as high blood pressure. The same kinds of questions would apply to smoking-related cancers and a range of other so-called lifestyle diseases, but for the former the prospects for medical success are often not so good.)

So the two perspectives don't need to clash at all, at least in terms of causation. Commentators may still disagree about the best practical ways of improving things, of course, but they may often find they are just talking about different aspects of the same causal web.



Data, information, science and knowledge for mental health

Information is vitally important for all areas of health, and is especially so for mental health. For a long time mental health information was seen as separate, private, possibly stigmatising and 'too difficult'. It was also complex because the symptoms of mental health problems or disorders were earlier seen as part of the spectrum of human behaviour, as something that could be voluntarily changed and thus not an illness. There was not a biological test that would confirm the diagnosis, adding to the perception that perhaps these illnesses were not 'real' conditions, for instance with depression. However while psychotic illnesses were more readily identified, in earlier days people with such illnesses were separated from society. Adequate information about them was frequently not available.

Under the National Mental Health Strategy there have been great advances in both the development of mental health information systems, and systematic reporting on the data derived from them. These initiatives, under the auspices of the Information Strategies Committee of the National Mental Health Working Group, have provided a number of important strategic reports, the most recent of which are National Mental Health Information Priorities (Department of Health and Ageing 2005) and National Performance Indicators for Australian Public Mental Health Services (NMHWG 2005). The fulfilment of these will provide a wealth of information building on the high level of reporting of national minimum data sets, activity and progressively on mental health outcomes, and eventually against performance indicators.

Other important information has been provided through the National Surveys of Mental Health and Well-Being: Adult component (ABS 1998) and Child and Adolescent Component (Sawyer et al. 2000), plus their associated reports and analyses, including the Low Prevalence Disorder study (Jablenski et al. 2000). These have provided powerful information about incidence, prevalence and correlates of disorder and to a degree, levels of unmet need (Andrews and Henderson 2000). The Australian Burden of Disease Study (AIHW: Mathers

et al. 1999) has further extended recognition of the enormous human and economic impacts of mental illnesses as they affect the Australian population. The ABS studies of population data have further contributed to the information available on mental health (ABS 2003a, 2003b, 2003c).

All this growth in information, in data available, can contribute to building the knowledge base to deal with the 'epidemic' of mental ill health. The excellent reports produced by the AIHW (e.g. AIHW 2005) highlight some of the implications, for instance in terms of patterns of service delivery, and other reports contribute in a number of areas. Nevertheless there are a number of important challenges to be met in ongoing ways.

- (i) The analysis and synthesis of the wealth of information collected from many sources to change this resource from data collections to knowledge that can inform understanding of, and response to, mental illnesses will be an ongoing challenge. This requires critical evaluation not only of the quality of collections, but also their worth in contributing to such goals. This involves ways of making such information accessible, comprehensible and of value to governments, public and private sector health system managers, and to clinicians providing mental health care. This knowledge can inform policy makers, financiers, but also those affected—those needing mental health care, and their families and carers. The use of this data resource can provide knowledge that will inform decision making, and that can contribute to cycles of evaluation and change: change with the aim of making things better, both for those affected and for the population at large. Too much information can constitute a burden so that analyses are prolonged, delayed and lose their cogency, or are seen as of little value to those providing the data, or from when it is gained. Data collections information systems and their outputs need to be such that they do not form a 'growing burden of data' alongside the

growing burdens of disease (Stewart G, 2004, pers. comm.). Such collections may need to be culled and refined to achieve what is needed. Their purpose and capacity to achieve this need to be clearly assessed and resolved. Data and information are not necessarily virtuous in their own right, although we often believe them to be so. Their virtue for mental health will be in how they contribute to knowledge, and how this makes things better.

- (ii) The purpose of information may not be clear to those who collect it. It may be to inform clinical care; for accountability; to establish levels of access, costs, or outcomes of interventions; to identify the work of providers; for public health or population health purposes—to name a few. Nor may those about whom and from whom information is collected understand either its purpose for others or its meaning for them. Public and population health information and clinical information need to be able to be linked together to provide knowledge about mental health issues, yet the information and service provision cultures may make this difficult. It is often also difficult for individuals to understand how information about them may be 'safe'; how their privacy may be preserved when their data contribute to either service system or population level aggregates that are reported. There are challenges in progressing not only clinical data which may be believed to be of intrinsic value for 'care', and for use by trusted clinicians, but also population data that can contribute to the 'big picture', to monitoring large scale patterns and even, with 'surveillance', to monitoring change over time.
- (iii) Data and information complexities and subtleties require consultation, interpretation, compromise, responsiveness and creativity in the ways in which they are dealt with. For instance, information on the mental health of culturally and linguistically diverse peoples who constitute major components of the Australian population requires further development. The needs of Aboriginal and Torres Strait Islander peoples require information system developments that will be responsive to their history, their culture and their disadvantage, and that can be 'owned' by



Professor Beverley Raphael, Professor of Population Mental Health and Disasters, UWS and Professor of Psychological Medicine, ANU

them. Information on children's and adolescents' mental health needs further and continuing commitment to take into account issues such as social, psychological and behavioural development. Measuring strengths as well as morbidity and vulnerability has not been adequately addressed, except perhaps in the use of the Strengths and Difficulties Questionnaire with children and young people. Integrating mental health, physical health, drug and alcohol information systems and data to advance understanding of the interrelationships of these domains is critically important in improving health outcomes more broadly. Similarly, the relevance of social domains and determinants must be measured and integrated.

The knowledge from addressing these themes, and many others, such as emerging issues like the impact of the terrorist threat, globalised information exchange and so forth will be critical to understanding and improving health and mental health issues, both now and in the future.

- (iv) Science is a critical base for mental health, from the molecular biology and genetics, neurochemistry, to epidemiology and many other research frameworks relevant to the basic sciences and clinical contexts. How these data, these sources of information, and information collected from formal information systems are usefully brought together is another



important challenge. How this science and the sciences that contribute to information analysis and synthesis from formal systems can contribute to a shared and valued knowledge base is critical for the future. In addition, how can wisdom be gained and incorporated into necessary knowledge—for instance, the wisdom that people require genuineness, empathy, compassion and warmth from their providers, to make them better—or how can social capital be improved to improve mental health? How can belief be challenged—for instance that ‘the more the better’ applies to all information collection for mental health?

- (v) The ultimate challenge, however, is that of building knowledge, knowledge that is of value. The collection of information has become a ‘virtuous’ activity. How can it be converted to valuable knowledge and who will be responsible for doing this, for sustaining it, for disseminating it? How curiosity, observation and scientific skill can be channelled effectively to contribute to knowledge development is another aspect of this challenge. The Western Australian Aboriginal Child Health Survey is in many ways a model of research, data information linkage, consultation and collaboration in ownership, sensitivity to data meanings and differences, and custodianship of the knowledge and its use (Zubrick et al. 2005). How such a model may be further developed to optimise our understanding and use of the information we are gathering; to integrate it with recognition of the issues of science, wisdom and belief; how it can be sustained and shaped as required over time—these are the challenges for AIHW, the National Mental Health Strategy and for us all.

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Improving information on disability and functioning: A forum for people who need, use or develop information

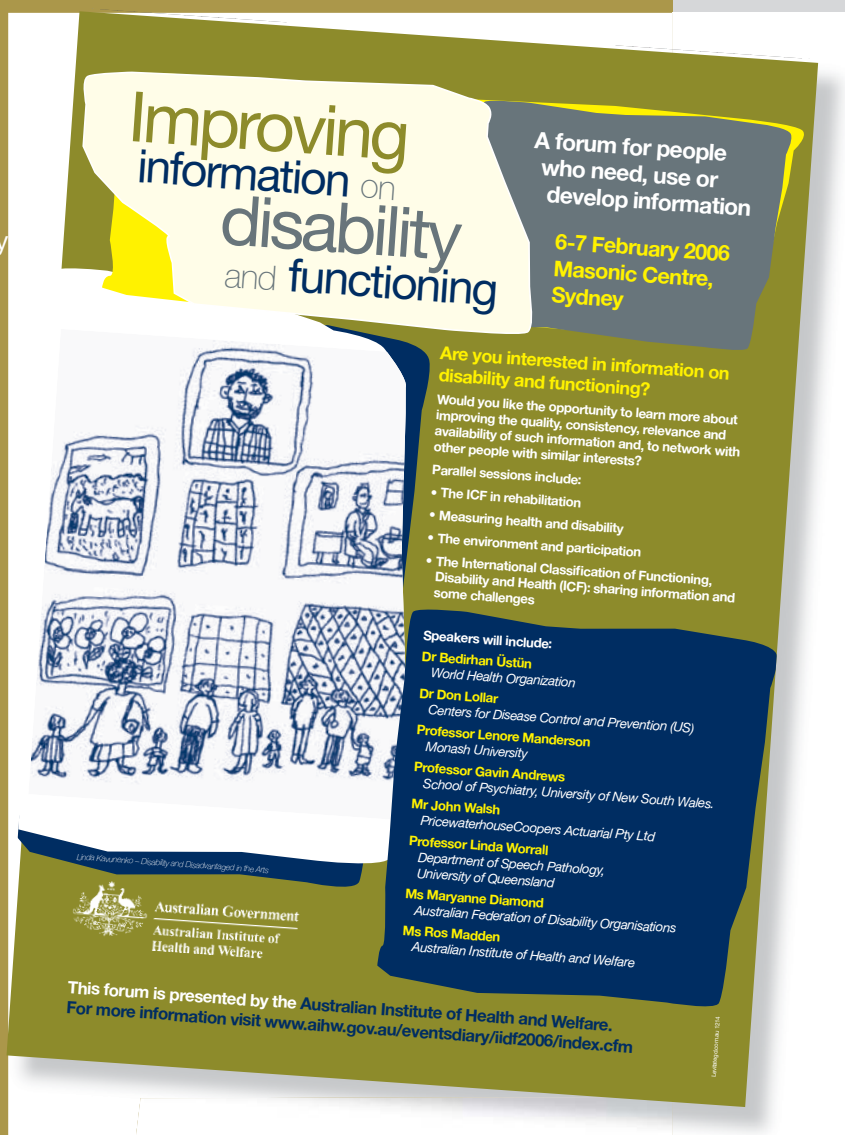
Improving information on disability and functioning is an important and challenging task. The AIHW is working with a range of stakeholders and advisors to improve the quality, consistency, relevance and availability of such information.

In Sydney, on 6-7 February 2006 the AIHW will be holding a forum to discuss and further these aims. Speakers from a broad range of disciplines will be presenting, including representatives from the World Health Organization (WHO), US Centers for Disease Control, non-government organisations, consumer groups, public and private agencies and influential clinicians and researchers from Australian and international universities.

The AIHW is the Australian Collaborating Centre for the WHO Family of International Classifications, including the International Classification of Functioning, Disability and Health (ICF). The ICF is proving to be a foundation stone of Australia national data standards and collections.

The ICF provides a common framework and language to improve policies, services and information related to functioning and disability. This conceptual framework allows consistent data across sectors, thereby supporting a 'whole of government' approach to health and community care. The forum will provide an opportunity for users to share information about the ICF and its implementation.

A registration form with further information about the event is enclosed in this edition of Access and is also available from <http://www.aihw.gov.au/eventsdiary/iidf2006/index.cfm>.



Improving information on disability and functioning

A forum for people who need, use or develop information

6-7 February 2006
Masonic Centre, Sydney

Are you interested in information on disability and functioning?

Would you like the opportunity to learn more about improving the quality, consistency, relevance and availability of such information and, to network with other people with similar interests?

Parallel sessions include:

- The ICF in rehabilitation
- Measuring health and disability
- The environment and participation
- The International Classification of Functioning, Disability and Health (ICF): sharing information and some challenges

Speakers will include:

- Dr Bedirhan Üstün**
World Health Organization
- Dr Don Lollar**
Centers for Disease Control and Prevention (US)
- Professor Lenore Manderson**
Monash University
- Professor Gavin Andrews**
School of Psychiatry, University of New South Wales.
- Mr John Walsh**
PricewaterhouseCoopers Actuarial Pty Ltd
- Professor Linda Worrall**
Department of Speech Pathology, University of Queensland
- Ms Maryanne Diamond**
Australian Federation of Disability Organisations
- Ms Ros Madden**
Australian Institute of Health and Welfare

Linda Kouroukos - Disability and Discharge in the Arts

Australian Government
Australian Institute of Health and Welfare

This forum is presented by the Australian Institute of Health and Welfare.
For more information visit www.aihw.gov.au/eventsdiary/iidf2006/index.cfm

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New partnership broadens access to AIHW data

The Australian Institute of Health and Welfare (AIHW) has now become the primary contributor of statistical information to the National Data Network (NDN), providing 43 of the 58 data sets now available on the Internet library.

The Institute has long made its information available on its own web site, but now that information is also available through the NDN.

AIHW Director Dr Richard Madden congratulated the Australian Bureau of Statistics (ABS) in leading the development of the NDN and said the partnership provides another way for policy makers, researchers and the community to access Institute statistics and other information.

'The AIHW website currently has over 2,000 visits per day, and we believe that through this partnership that number will increase, and more people will become aware of the quality and breadth of data that AIHW offers', Dr Madden said.

Head of the AIHW's Business and Information Management Division,

Dr Anny Stuer, said an important point about the partnership with NDN is that it provides a model for sharing best practice with the community of information developers and users.

'A valuable aspect of the NDN is that it allows partners to share best practice principles, particularly in such critical areas as privacy protocols, and information standards.

'Through the NDN, users can also access METeOR, AIHW's Metadata Online Registry, which contains the all-important definitions that underlie our statistics.

'These definitions help ensure the statistics collected are of the highest quality and can be meaningfully compared across different data collections', Dr Stuer said.

AIHW information currently available through the NDN includes medical labour force, cancer, homelessness and supported accommodation, mortality, disability, health and welfare expenditure, drug use and treatment services, mental health information, and many other topics.

AIHW experience implementing the first NDN node

The NDN consists of a central entry point known as NDN Central. NDN Central contains general information about the NDN, a searchable registry of available data, and connections by means of hyperlinks to web sites of participating organisations. The participating web sites are referred to as NDN nodes. The Institute became the first node in October this year.

Prior to the NDN the AIHW already had a process in place for publishing details about available data collections on its own web site. This is an integral part of the AIHW strategy for making data available. This process is tied in with the AIHW's internal data management processes, particularly its privacy and access control procedures. The details about data collections are published in the AIHW's Data Catalogue. This information closely matches the information about data collections published by the NDN in its central registry.

Since potentially suitable information was already available on the AIHW web site in the Data Catalogue, it was supplied electronically to the NDN using XML by means of an application especially developed for that purpose. At the same time, as a participating node on the NDN, the Institute needed to establish a dedicated server to support the connection between the Institute's web site and the NDN. This architecture enables all Institute data to remain within the Institute's own environment and control, thus ensuring all Institute data continues to be protected by the Institute's existing well established privacy and security protocols and processes.

The information published on the NDN is information already available on the Institute's web site, together with hyperlinks to the Institute's web site.

AIHW participation in the Interim Governing Board (IGB)

An Interim Governing Board oversees the development of the NDN. It is chaired by the ABS and membership consists mainly of representatives of participating, or potentially participating organisations. In its capacity as a participating organisation, the AIHW is an active member of the IGB.

In order to ensure that privacy issues are fully addressed the Privacy Commissioner is also a member of the IGB.

Further information: Dr Anny Stuer, AIHW, tel. 02 6244 1010, or Mike McGrath (technical inquiries), AIHW tel. 02 6244 1106

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