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## AIHW starts work on National Diabetes Register

**New year 1999 was the beginning of a new chapter in the AIHW's history — data collection for the National Diabetes Register began.**

The AIHW was awarded a contract to manage and operate the National Diabetes Register which is part of the National Diabetes Strategy and Implementation Plan, and is funded by the Commonwealth Department of Health and Aged Care.

The Register provides a record of Australian residents diagnosed with diabetes after 1 January 1999 who are using insulin. The information collected will help fill a long-term void in national-level diabetes research. Future benefits include accurately establishing the extent of diabetes in the community and a capacity to monitor trends to see whether the disease is being controlled or not. This will inevitably lead to better provision of services and products needed by people with diabetes.

At present the prevalence of diabetes in Australia can only be derived or extrapolated from localised studies.

The information collected will also be a 'gateway' to possible follow-up research by epidemiologists and clinicians on the causes, prevention and complications of diabetes. Research of this kind requires the approval of the AIHW's Ethics Committee, and the express consent of people on the Register to participate in any proposed study.

The Institute won the tender not only on the basis of its established independent national role in health and community services statistics,



and providing value for money for its services, but on the data confidentiality protection afforded by the Australian Institute of Health and Welfare Act. Two particularly strong provisions in the Act are that AIHW employees are not only prohibited from divulging information about an individual, or information that could identify an individual, but also cannot be forced, even by a court, to reveal such information.

Information for the Register is provided through the National Diabetic Services Scheme (NDSS) operated by Diabetes Australia, and, for young people with diabetes, through the Australasian Paediatric Endocrine Group (APEG).

The NDSS is a Commonwealth Government program that provides blood and urine testing strips, syringes, and needles for special injection systems at subsidised prices to people who register with the scheme. Diabetes Australia is a federation of 12 State- and Territory-based diabetes organisations.

*Continued on page 4*

The National Diabetes Register team (from left): Project Managers, Phil Trickett and Bonnie Abraham; Head of the AIHW Disease Registers Unit, Dr Paul Jelfs; and Project Officer, Michelle Maher.

**The National Diabetes Register Helpline number is 1800 643 587**

**For more information on diabetes call the Diabetes Australia Helpline on 1800 640 862**



# from the Director



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### **Welcome to the first edition of *AIHW Access*.**

**It takes over from its predecessor, *NHWI News*, in bringing you informative articles about data developments in the health and welfare services sectors, profiles of Institute people to give you a more personal insight into our organisation, and news items about recent and upcoming releases.**

*Access* goes further though, with thought-provoking articles supplied by leaders in our own or related fields, a column by our Medical Adviser, the good Dr Magnus, and the latest on electronic dissemination from our Web Administrator.

Through a combination of circumstances, this publication symbolises the beginning of a new phase in the Institute's development as it continues to grow against an ever-changing external environment. For example, there have been some significant changes to the Commonwealth's health and community services portfolio structures following the recent election. The AIHW remains within the auspices of Dr Michael Wooldridge, formerly Minister for Health and Family Services, but now Minister for Health and Aged Care. Mrs Bronwyn Bishop is the Minister for Aged Care. Disability services, children's services, and the Supported Accommodation and Assistance Program (SAAP) have moved to the Department of Family and Community Services, under Senator Jocelyn Newman. About 25% of the AIHW's activities are directly related to the functions of this new Department, so the Institute has a new and important client.

It is therefore opportune that work has started on the development of our 1999-2002 Corporate Plan. The Plan will provide the foundations of our strategic direction and work program for the next three years. As with the

previous plan, which has served us well over the last three years, the new Corporate Plan will be developed collaboratively by staff under the guidance of the AIHW Board.

A related development currently in progress is our Corporate Capability Statement. Some readers may know that the Institute receives about half its funding from government appropriation, with the remainder coming from grants from government and non-government sources. We need to explain our skills to prospective clients in a succinct, easy-to-read information package, which is what the Capability Statement is designed to be.

Another aspect of the new phase for the Institute is an increased emphasis on formal collaboration with other organisations. We have had a Memorandum of Understanding with the Department of Health and Aged Care for some time now to cover a range of projects. We have just signed an agreement with the Heart Foundation of Australia (see the item on page 4). We are also talking to the Health Insurance Commission (HIC), which administers Medicare, the Pharmaceutical Benefits Scheme, and the Australian Childhood Immunisation Register. There are substantial benefits to both parties from collaboration, and we look forward to working more closely with HIC in the near future.

We hope you enjoy our new publication. As always, your comments and feedback are welcome.

*Richard Madden, Director, AIHW*



## SAAP contract extension

**Following an initial three-year contract, the Commonwealth Department of Family and Community Services has extended the Institute's involvement in the SAAP National Data Collection until the end of 1999, in line with the current Commonwealth/State SAAP Agreement.**

The key deliverables under the current contract will include the management of five main collections:

- the ongoing Client Collection—a register of all clients assisted by SAAP-funded agencies (in excess of 150,000 per year);
- the two-week Unmet Demand Collection, which records details of people who request support or accommodation under the program but, for some reason, cannot be provided with that assistance;
- the two-week Casual Client Collection, which records basic details about assistance of a short-term nature such as information, referrals and meals;
- the Administrative Data Collection, which collates information from State and Territory departments about all agencies funded under SAAP (currently in excess of 1,100); and
- the yet to be defined 'special issues' collection.

Reporting requirements include the provision of individual reports to each SAAP-funded agency on a six-monthly basis and the production of nine substantive published reports (one national and one for each State and Territory) on a financial year basis. Nationally comparable data are also provided to the Productivity Commission for the compilation of the annual *Report of Government Service Provision*.

Allowance has been made in the current contract to substantially improve reporting

procedures through the development of more efficient report production utilities. Confidentialised unit record files will continue to be produced for the Commonwealth and each State and Territory on an annual basis to enable more detailed analysis by these departments. Additionally, 1,000 hours of analysis time has been incorporated into the current contract to respond to information requests from SAAP-funded agencies and government departments responsible for administering SAAP. Provision has been made to radically improve the response times for such requests.

One of the major tasks to be commenced under the new contract is the major upgrade of the National Data Collection Agency (NDCA) database application. The complex upgrade from Oracle Forms 3 to Oracle Forms 5 is expected to continue past the end of the current contract; however, improved data processing efficiency and more cost-effective implementation of required changes will be the end result.

The Institute will also continue the implementation of the SAAP Management and Reporting Tool (SMART). SMART is a database application provided free of charge to SAAP-funded agencies and will assist agencies to accurately and efficiently collect information required for the National Data Collection, as well as other information that agencies can use for their own monitoring and evaluation purposes. SMART is currently being used by over 300 agencies; remaining agencies will be brought on-line progressively over the next six months.

In response to the findings of the recent evaluation report of the NDCA by RPR Consulting, the new contract allows for a greater emphasis on communication between all stakeholders and on quality assurance measures to significantly improve the reliability of data from the collection.

One of the major tasks to be commenced under the new contract is the major upgrade of the National Data Collection Agency (NDCA) database application.

For further information, please contact Rosangela Merlo, AIHW, on ph. (02) 6244 1206 or e-mail: [rosangela.merlo@aihw.gov.au](mailto:rosangela.merlo@aihw.gov.au)



## AIHW collaboration with the Heart Foundation of Australia

The Institute's association with the Heart Foundation of Australia began in the late 1980s with the conduct of the 1989 Risk Factor Prevalence Survey, which is still the most recent source of nationwide data on blood lipids and iron status. For the past three years, the Heart Foundation has provided the chair of the Advisory Committee for the Institute's National Centre for Monitoring Cardiovascular Disease. This close association, between Australia's national agency for health and welfare statistics and information, and Australia's lead agency in the continuing fight against cardiovascular disease, has been recognised in the recent signing of a Memorandum of Understanding (MoU) between the two organisations. This MoU covers two current projects and provides the structure for future collaboration.

Currently, the Institute is working with the Heart Foundation to produce fact sheets for cardiovascular disease, on topics such as risk factors, disease prevalence and incidence, treatment, management and health care costs. Together, these fact sheets will form a report to be called *Heart, Stroke and Vascular Diseases*,

*Australian Facts*. Data on high risk population groups such as the Indigenous population and people who are at a socioeconomic disadvantage are included, as are data on people living in rural and remote areas of Australia.

The Institute is also updating and maintaining national registers of cardiac surgery and percutaneous transluminal coronary angioplasty (PTCA) procedures performed in Australia, on behalf of the Heart Foundation. The reports *Cardiac Surgery in Australia 1994* and *Coronary Angioplasty in Australia 1995* have recently been jointly published, and further reports are in preparation.

For further information, please contact Stan Bennett, AIHW, on ph. (02) 6244 1141 or e-mail: [stan.bennett@aihw.gov.au](mailto:stan.bennett@aihw.gov.au)

*Continued from page 1*

APEG is a group of medical practitioners and other health professionals involved in the clinical care of children under 15 with diabetic and endocrine disorders. The Group sets standards of care, keeps its own databases, and undertakes research activities.

Whenever a person registers for the NDSS or with the APEG, they will also be asked to agree to being included on the National Diabetes Register.

Participation on the Register is voluntary, but will be strongly encouraged. Without high participation there will inevitably be an underestimation of the needs of the diabetes community, and a drop in the quality of any epidemiological or clinical follow-up research.

At the AIHW the Register will be managed by the Disease Registers Unit within the Health Division. Head of the Unit is Dr Paul Jelfs, and the project manager is Ms Bonnie Abraham.

A National Diabetes Register Helpline (1800 643 587) has been established at the AIHW for people seeking further information, and a publicity program is under way, principally with organisations and providers of services to people with diabetes.

The focus of the publicity program is to raise community awareness of the Register, and encourage participation in the Register by people newly diagnosed with diabetes who are using insulin.



# spotlight

## on Sandra Hacker

**The hills are always alive with the sound of music for newly appointed AIHW Board**

**Member, Sandra Hacker.**

As the Federal Vice-President of the Australian Medical Association, Dr Hacker has enjoyed a diverse career in psychiatry—which began not long after a stint at the Conservatorium of Music in Melbourne.

But in the early stages of her medical career, Dr Hacker didn't know whether she wanted to be a singing doctor or a consulting soprano.

'Singing at the Conservatorium provided a light diversion from medicine but I wouldn't say there was a career for me there,' Dr Hacker said.

Indeed, it is her work in psychiatry over the last 25 years, and her interest in public health issues that attracted Dr Hacker to working on the Board of the AIHW in the first place.

'As a psychiatrist, I can make a contribution to the Board. The AIHW is clearly a very interesting and exciting group and it produces a lot of significant material—particularly for the medical profession. It has a good reputation in this country,' she said.

Dr Hacker brings a long standing medical and academic background to the Board of the AIHW. This includes her work as: a medical administrator for Ramsay Health Care in Victoria; a coordinator of Psychotherapy Services at Melbourne's Royal Park Hospital; honorary senior lecturer at Monash University; and a sessional psychiatrist and senior psychiatric registrar at Melbourne's Prince Henry Hospital.

Dr Hacker has a diverse range of interests, both in her working and personal life.

She currently works as a psychiatrist in private practice in Melbourne conducting long-term psychotherapy with adults who were sexually abused as children. She is also a liaison

psychiatrist at the Alfred Hospital's Heart-Lung Transplant Unit, and chairs a working party to reduce the incidence of motor exhaust-related suicides in Australia.

'In a clinical sense, working with the group of patients I have at the moment and with sexually abused women are some of the real highlights. I also worked on the test case of female genitalia mutilation in Victoria.

'The work I'm involved in is varied and extremely interesting, and in demanding and challenging areas. Above all, it provides the capacity to work with different people in other professional groups—there's often a cross-fertilisation in these areas.'

Apart from her passions for public health, Dr Hacker's other interests include a medley of opera, music, reading, watching British and European films, and travel.

'I've just spent the summer travelling in South America and my next ambition is to go to Africa. I love seeing other countries and experiencing the different cultures and food—in fact the whole way of life. There's also the advantage that you can get away from the phone and the fax machine for a while,' she said.

### **And what makes a good doctor?**

'Doctors usually like people—they like talking, communication and problem-solving, and they're fairly autonomous. The best thing about being a doctor is that medicine is so diverse and it's practised all around the world,' Dr Hacker said.

'I really just want to be happy, healthy and wise. I'm doing a lot of interesting things in my career right now and I'd like to continue my clinical practice and the work that I do.'



The best thing about being a doctor is that medicine is so diverse and it's practised all around the world





# soap box

For the first edition of *AIHW Access* we are delighted to have received an article from Stuart Hamilton, Executive Director of the Australian Vice-Chancellors' Committee. Stuart writes from a university perspective on the issues of data collection and access to data.

The Institute hopes that Soap Box will allow people outside the Institute to contribute to the debates and discussions concerning data and information. Soap Box will give voice to discussion without prejudice or bias. Therefore it must also be stated that the views contained in Soap Box are not necessarily the views held by the Institute.

## Healthy lesson for

*My views regarding data collection and access to data in the education sector have received coverage in the national press. I believe they are equally relevant in the health field.*

In any enterprise, serious efforts to improve product or service quality will be firmly based on a continuing search for the best available data. Potential users of the services also require reliable data about quality and outcomes.

This requirement has been given an extra urgency in recent years as governments have, more and more, conflated improvements in quality with reductions in costs.

For universities this has meant—to an extent which is probably only understood outside the education sector by those in the health sector—enormous pressure to see that the data collected on the sector is timely, objective and comprehensive, to give university teachers the greatest chances of salvaging the quality of our higher education; as well as respond to the reasonable demands from users and funders for accountability.

Yet there is a fundamental impediment in the way of better data in higher education which does not exist in health. At present, the Department of Employment, Training and Youth Affairs (DETYA) is the main holder of higher education data, compiling the detailed returns from universities and other publicly funded institutions.

There are three basic problems with this.

First, as the funder and direct adviser to the Government, the collection, publication and analysis is focused on the needs of the funding system, and ensuring accountability for the use of public funds. This is not to deny that DETYA provides a basic service of information provision and supports a range of worthy research project. Nevertheless, this makes more difficult the debates we are having about the way data on performance are collated and adjusted. To be frank, providers do not necessarily trust funders—hardly a surprise!



# education in data collection

Secondly, the data are limited to organisations that receive funding; and even more narrowly, on services those organisations provide with that funding. There are a number of private institutions and activities not included. As a result, we cannot see the full picture, only the funded services picture. While data is tied to funding we will not overcome this.

The third problem lies in the fact that the collections in DETYA are discrete to the higher education sector. Data on vocational and schools education is compiled by others using other parameters. Without an understanding of how higher education data fits into the bigger picture, we are limited in how we can respond to inter-sectoral opportunities.

Clearly, as the major funder of higher education, DETYA requires fundamental data about the system but there is no necessary reason for it to be compiler of that data, especially the comprehensive level of data that it currently collects. Indeed, in this day of outsourcing, it is surprising that DETYA's in-house data collection has survived for so long.

The Australian Vice-Chancellors' Committee (AVCC) is now considering how a new body for collating and analysing higher education data could be set up, covering all education to overcome the issues of data spread among Commonwealth, State and private collections.

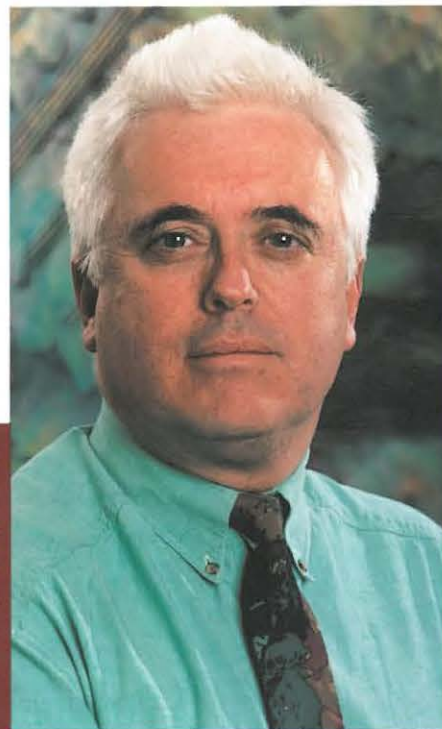
If we were to pursue such a body there are a number of questions about what it should do, in terms of collection, analysis and publication; and there would be issues about the structure to be resolved in terms of the balance between State and national representation.

However, there seems no obvious reason in principle why these could not be resolved; and especially so as there is, at least, one good model to work from, namely that of the Australian Institute of Health and Welfare.

As readers to this publication will be aware, the AIHW receives data from all health and welfare sources and publishes and analyses that

## Stuart Hamilton

Stuart Hamilton is the Executive Director of the Australian Vice-Chancellors' Committee and was the Secretary of the Department of Health, Housing and Community Services from 1988 to 1993.



data, essentially independent of the particular barrows of State and Commonwealth public servants, or of service providers.

The independence of the AIHW allows for a consistent data framework for the entire health sector, which, in turn, makes possible the development of consistent quality and performance indicators. A new body for education data, modelled on the AIHW, would overcome the incompatibility of the data collected in the many different sub-sectors of education, to provide over time no doubt a consistent classification framework.

We are not tied to a particular model at this stage, and are also examining others. For example, the Australian Bureau of Statistics has proposed it undertake the role, pointing to its crime statistics responsibilities as a precedent. In the UK, there is a separate Higher Education Statistical Agency, though with a more limited remit.

Responsibility for quality outcomes should not be dependent on ownership of data about the system. If there is to be continuing quality improvements in higher education, the Government is going to have to untie itself from ownership of data collection. Only with the knowledge derived from data which is collected and analysed in a comprehensive, consistent and disinterested way is there likely to be public confidence that we are continuing to improve higher education quality.

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# the driving force

The launch of *AIHW Access* provides an opportunity to inform readers about the two Management Groups that are of vital importance to health information development. This is because the two Groups are key 'drivers' of quality, consistent national health and community services information to support decision-making by all levels of government and the community. This, in turn, contributes to the provision of more appropriate and improved services and outcomes for the Australian community.

## National Health Information Management Group

The National Health Information Management Group, or NHIMG, directs the implementation of the National Health Information Agreement (NHIA). The Agreement, signed by Commonwealth, State and Territory health and statistical authorities is the cornerstone of national health information development in Australia.

The NHIA aims to ensure that the collection, compilation and interpretation of nationally relevant health information is appropriate and carried out efficiently. This requires agreement on definitions, standards and rules of collection of information and on guidelines for the coordination of access, interpretation and publication of national health information. The

Agreement aims also to improve access to uniform health information by community groups, health professionals, and government and non-government organisations.

The NHIA came into effect on 1 June 1993, initially to run until 31 May 1998. It was subsequently extended to 31 May 2003. The parties to the Agreement are:

- Commonwealth Department of Health and Aged Care
- New South Wales Health Department
- Department of Human Services Victoria
- Queensland Health
- Health Department of Western Australia
- Department of Human Services, South Australia
- Department of Health and Human Services Tasmania
- Territory Health Services
- Department of Health & Community Care, ACT
- Australian Institute of Health and Welfare
- Australian Bureau of Statistics

Proceedings are under way to include the Health Insurance Commission (HIC) in the Agreement.

The NHIMG comprises a representative from each of the signatory organisations and a Chair appointed by the Australian Health Ministers' Advisory Council (AHMAC). The New Zealand Ministry of Health has observer status. The Institute supports the Management Group not only through membership, but by providing the Secretariat. David Filby from the Department of Human Services, South Australia, is the current NHIMG Chair.

The machinery of development comprises a National Health Information Development Plan and associated National Health Information



Work Program. Information developments coordinated through the National Public Health Partnership, established in 1997, proceed in close consultation with the NHIMG. Development activities are also responsive to the reporting needs occasioned by work in the National Health Priority Areas.

The National Health Data Committee is the only standing committee of the NHIMG. Its primary role is to check compliance and consistency of data element definitions to go into the *National Health Data Dictionary*. The *Dictionary* is the authoritative source of national health data definitions and contains definitions of data elements (or discrete items of information) that have been described according to a standard set of rules, and endorsed by the NHIMG as the national standard to apply whenever this information is collected in the health field.

For further information, please contact Michele Flint, AIHW, on ph. (02) 6244 1123 or e-mail: [michele.flint@aihw.gov.au](mailto:michele.flint@aihw.gov.au)

## National Community Services Information Management Group

The National Community Services Information Management Group, or NCSIMG, is responsible for the management of the National Community Services Information Agreement (NCSIA). The Agreement, which operates under the auspices of the Standing Committee of Community Services and Income Security Administrators (SCCSISA), provides a framework for structured and nationally

consistent community services information development. It operates for five years from 1 March 1997, and may be extended subject to agreement by all the parties.

Signatories to the NCSIA are the community services authorities of the States and Territories of Australia, the Commonwealth Departments of Health and Aged Care and Family and Community Services, Centrelink, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. The Agreement covers data collected about aged care (including residential and community care), disability services, child care (including preschools), family support services, child welfare (including juvenile justice), supported accommodation assistance and emergency relief services, but not long-term housing.

The NCSIMG comprises representatives from each of the NCSIA signatory organisations, and is chaired by Richard Deyell from the Department of Human Services, South Australia. The AIHW provides the Secretariat for the Group.

Development of national community services information is currently at a vital stage. The Management Group has developed, in consultation with key stakeholders, the National Community Services Information Development Plan which identifies future priorities. SCCSISA has endorsed the Plan, and work is being done to develop a business case to present to SCCSISA so that progress can be made on the Plan's top three priorities.

For further information, please contact Margaret Fisher, AIHW, on ph. (02) 6244 1033 or e-mail: [margaret.fisher@aihw.gov.au](mailto:margaret.fisher@aihw.gov.au)





## RATIONALE

As the Institute has changed over the past few years, the need for a redesign of the AIHW web site became obvious. Rather than being change for its own sake, the redesign achieves streamlined functionality and simple frameless browsing (overcoming identified problems with the existing site)

## The new AIHW web site

The Internet is a living, growing mass communication medium, through which the Institute is committed to disseminating timely, accurate data and information. It is, in many ways, a window to the world through which the world can look in on the services provided by the Institute. Those services include media releases, a comprehensive electronic catalogue of Institute publications, many of which are in a downloadable format (PDF\* and the occasional HTML\*\*), and promotional material for the Institute's services and major conferences.

The web site was launched in October 1996 by the then Minister for Health and Family Services, Dr Michael Wooldridge, and its maintenance and development was entrusted to the Communications and Public Affairs Unit within the AIHW.

The redesign achieves several things:

- It improves functionality by streamlining the physical and virtual structure on the Timelord (internal) and Gallifrey (external) servers, and with respect to the Oracle Application Server (or web server).
- It removes frames which cause problems for older browsers, browser navigation and file bookmarks, and provides a new look, in keeping with a frameless design.

- It adopts folder sets which allow easy addition of new sets such as data service information and Infobytes (FAQs).

The redesign also refreshes the appearance and appeal of the site. It was recently approved by the AIHW Executive Committee and will be online by Mid April 1999.

## Structure

The redesigned web site is represented by the following site map:

### AIHW Front Page

**The Institute** – About Us, Contact Us, Copyright & Groups (e.g. AIHW Ethics Committee and National Health Information Management Group)

**Events** – Conferences (e.g. Australia's Health 1998), Projects & Workshops

Releases – 1999, 1998, 1997 & 1996

**Publications** – Catalogue, Corporate, Health (e.g. Australia's Health 1998), Welfare, External & How to Order

**Infobytes (FAQs)** – Corporate, Health (e.g. prominent cancer statistics), Welfare & External

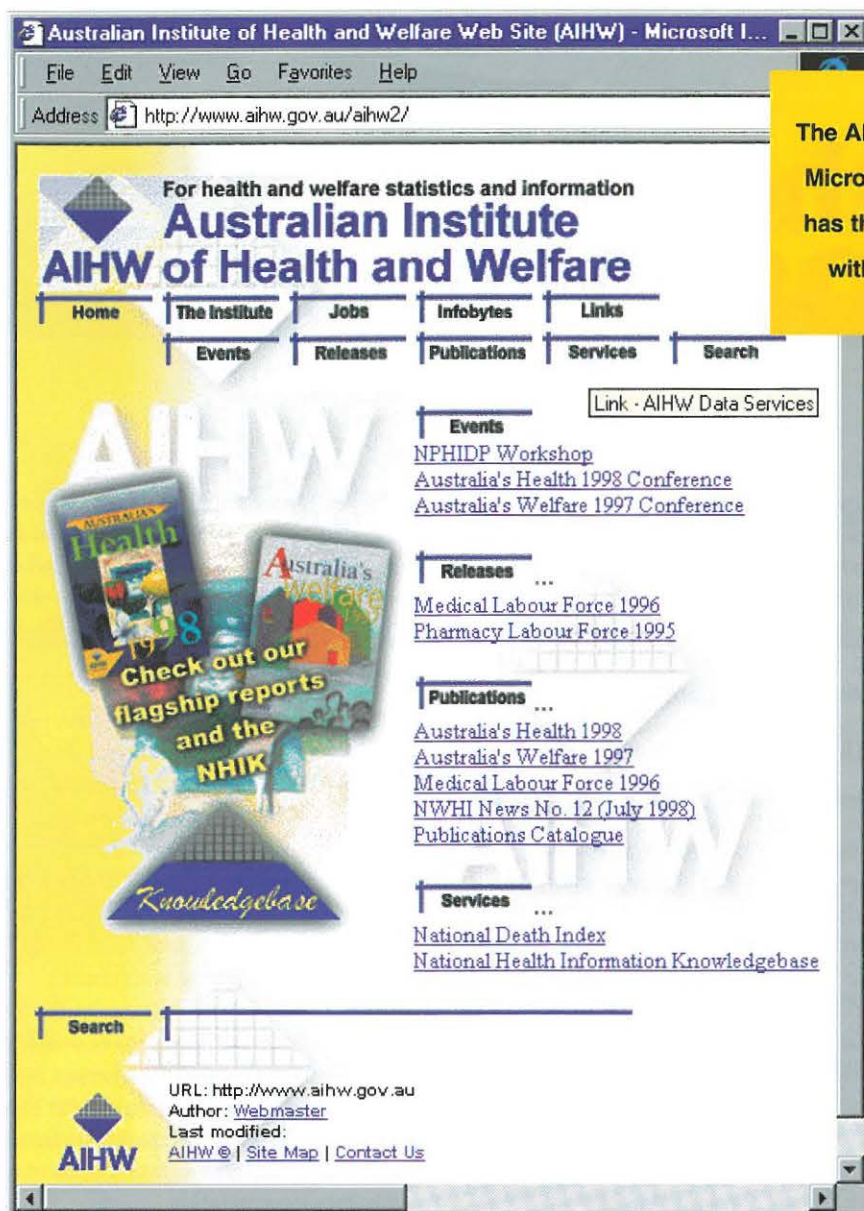
**Jobs** – Latest, 1999, 1998, 1997 & Requirements

**Services (Client Services)** – Availability and Access, Corporate (e.g. the Knowledgebase), Health (e.g. National Hospital Morbidity Database and the National Death Index), Welfare and External

**Searches** – Site Map and Infoseek Search Engine

**Links** – Related and Associated Organisations





The AIHW web site redesign viewed with Microsoft Internet Explorer 4.0. The site has the same appearance when viewed with Netscape Communicator 4.06.

Please access our web site at:

<http://www.aihw.gov.au>

\* **PDF (Portable Document Format)** is a file format, created and licenced by Adobe, which is used to represent a document in a manner independent of the application software, hardware, and operating system used to create it.

\*\* **HTML (HyperText Markup Language)** is a collection of tags used to mark blocks of text and assign them special meanings, which are interpreted by a document writer. It is an instance of Standard Generalised Markup Language (SGML), a standard for describing markup languages.



For further information contact the AIHW Web Administrator, Chris Stevenson, Communication and Public Affairs Unit, AIHW, ph. 02 6244 1029 or e-mail: [webmaster@aihw.gov.au](mailto:webmaster@aihw.gov.au)



# from the Inside

## The Disease Registers Unit

**The Disease Registers Unit (DRU) within the Health Division of the AIHW is a dynamic group of 15 staff, covering a broad spectrum of health information-related activities.**

It has been in existence for several years under various names and has experienced rapid growth in the past 18 months. The highly dedicated staff have diverse backgrounds (professional and social) and a wide range of skills, which are brought together into a successful and adaptable combination. These characteristics, together with a friendly and professional approach to our work, make for a pleasant and productive working environment, with satisfying results and positive recognition of our work by our peers and clients.

The Unit sets out to develop standards for, and to maintain and link, national databases of disease incidence and mortality. From these databases and their combinations, work is undertaken to monitor and investigate disease patterns, identify risk factors and facilitate epidemiological studies.

The DRU has responsibility for several core databases: the National Cancer Statistics Clearing House, the National Death Index and the National Mortality Database. It has recently started development on the National Diabetes Register and a Breast and Cervical Cancer Screening Database.

The National Cancer Statistics Clearing House (NCSCH) is an important database of all cancers diagnosed between 1982 and 1996, and is supported by the State and Territory cancer registries. The database is used for projects such as the annual *Cancer in Australia* publication detailing incidence and mortality patterns, and specialised publications such as the *Breast*

*Cancer in Australian Women and Breast Cancer Survival in Australian Women.*


The database is made accessible, under certain conditions, including clearance by the Institute's Health Ethics Committee, to client requests for information. For example, clinicians, patients, pharmaceutical companies and governments may wish to use the database for purposes as diverse as resource planning, marketing and policy formulation. The staff responsible for dealing with client requests—Anne-Marie Waters, Edith Christensen and Robert van der Hoek—have developed a strong feel for the quality, coverage and uses for the data and have strong links with the data providers. They are able to assist clients in formulating their information requests, and with data interpretation.

The National Death Index (NDI) is a collection of information about all deaths that have occurred in Australia between 1980 and 1998 and is maintained in cooperation with State and Territory Registrars of Births, Deaths and Marriages. Subject to Ethics Committee approval, the database may be used in conjunction with data matching software for survival analyses by external clients undertaking epidemiological research. These data are often combined with data from the National Mortality Database to provide a standardised underlying cause of death.

These data are also used to support the AIHW's mortality surveillance reports, which examine the trends in mortality rates over the last decade for numerous causes of death. The latest version, covering the 1986–1997 period is the work of Unit staff members Carolyn Dunn and Justine Boland. Users of the NDI include Commonwealth, State, and Territory government departments, the Red Cross,

The highly dedicated staff have diverse backgrounds (professional and social) and a wide range of skills, which are brought together into a successful and adaptable combination.





universities, industry, and clinicians. Much of the output from the studies using the NDI will be used to help frame policy, direct resources and facilitate a better understanding of disease patterns and health outcomes.

The National Diabetes Register has been a focus of the Unit's attention in the last 12-18 months and has also been a topic for debate amongst the diabetes community. The project has been funded as part of the National Diabetes Strategy. The project has been directed by Bonnie Abraham with support from Michelle Maher and Trish Burton. This exciting development in diabetes information is covered in some detail on the front page of this issue of *Access*.

The Institute has recognised that record linkage is an important part of managing health information. It has mounted a project, funded by the Australian Health Ministers' Advisory Council, that is seeking access to a range of health-related databases in order to bring them together to investigate specific health issues. One of the outcomes of the project is to develop practical approaches to record linkage using both identified and de-identified health records. This project, managed by Bonnie Abraham and Rebecca Bentley, has been able to bring together valuable knowledge on managing record linkage using de-identified hospital morbidity data (related to revascularisation procedures).

One of the essential components of the investigation has been the validation of their results using source data with complete identifiers, so that the procedures can be generalised and applied in other circumstances. Running parallel to this are the organisational arrangements which are being negotiated to allow more direct, but controlled, access to as yet untapped health related data collections.

Breast and cervical cancer screening are major public health expenditures and the Institute has become involved in monitoring the results from these programs under an arrangement with the

Department of Health and Aged Care. It has undertaken this work together with screening experts and State and Territory program directors. The project has involved significant effort to meet the program staff, understand their operations and involve them in developing new data standards and indicators which are comparable nationally. This work has been undertaken from the Institute's end by Norma Briscoe, Carolyn Dunn, Janet Markey and, in the early stages, Karen Bishop. The first ever national report on breast and cervical cancer screening in Australia was produced in 1998.

One of the most recent additions to the work program, and certainly a logistically challenging one, is the Department of Veterans' Affairs-funded Vietnam Veterans Validation Study. This study seeks to validate certain self-reported medical conditions of Vietnam veterans (approximately 8,000) and their children using medical practitioners and disease registers. The results of this study will have a direct impact on policies for veterans and their children with health problems. The study has involved almost all Unit staff in some way, but the bulk of the work has been carried by Mieke van Doeland, AIHW Medical Adviser Paul Magnus, Sylvia Sheffield, Sally Martin and Mark Alvey.

The Disease Registers Unit is managed by Dr Paul Jelfs, who has been at the Institute for almost 10 years. Paul also acts as the data custodian for the core databases.

The Unit places great emphasis on making the information we manage available to those who need it as quickly as possible. This has included making the Unit's publications available on the Institute's web site, and acting as the main conduit to the Ethics Committee review process for clients wishing to use the databases that we manage.

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Dr Paul Magnus  
AIHW Medical Adviser

## What is public health?

It's a curse writing under the banner of 'trust me'. Please don't do that too much, at least not about the topic that follows. That's because I'm going to try to give my views on what's meant by the term public health. And for everyone that wants to tell you, you'll get a different version.

*Australia's Health 1998*, the Institute's latest biennial health report, describes public health as:

*– health activities which aim to benefit a population. Prevention, protection and promotion of health are emphasised, as distinct from treatment tailored to individuals with symptoms–*

The report gives a few examples:

- providing a clean water supply and good sewerage
- anti-smoking education campaigns
- screening for diseases such as cancer of the breast and cervix

In fact the range is great and the methods very wide: immunisation; regulations for what goes into our food; sex education; public warnings about outbreaks of infection or food poisoning; checking people's blood pressure and cholesterol levels; slip, slop, slap campaigns; and so on.

Public health is hardly new, although it has broadened its work. It began centuries ago to try to cut health inequalities across the population, to buffer people against the elements, to protect them from dietary deficiency, and especially to curb crowding and unsanitary conditions that help the spread of infections. Those traditional interests are still vital, particularly for developing countries. All societies must be vigilant about infectious diseases.

But in recent decades the work has widened to tackle the so-called twentieth century lifestyle epidemics such as heart attacks, lung cancer and older-onset (Type 2) diabetes. As it should, public health has worked on the 'personal' factors that greatly increase an individual's risk of the lifestyle diseases, such as cigarette smoking.

But in doing so it is increasingly looking at the wider social and economic forces that influence how much a society smokes, what it eats and so forth—and especially why some groups, almost always those with less income or education, end up being at so much greater risk. These broad background forces are increasingly international. Public health activity has to include a social view. It can easily blend into politics and many argue that it must.

What distinguishes public health, then—what's not public health? Ironically, just below 'public health' in the glossary of *Australia's Health 1998* is the entry for 'public hospitals'. Crucial these hospitals certainly are. And yes, they are there for the public and they do a great deal for it. But despite their name they represent the other end of the health service spectrum. They can't possibly reach the whole population all at once or even large chunks of it. They have to handle acute illness and tailor their treatment to symptoms in the sick individual. And they obviously get people too late to prevent illness (at least the illness in question), although they often prevent complications and future episodes.

Here we've touched upon a big problem with the name 'public health'. It's hardly surprising that many people, as well as the media, confuse public health and the work of public hospitals.

So another way of thinking about public health activities is that they are the services that can help improve our health but generally don't occur in hospitals or when we get care for feeling unwell or having an illness. In fact, many of us will hardly know that we're on the receiving end of much public health activity. It goes on around us and adds up gradually. Even less will we know whether it's actually done us any good at the personal level, because we can't know for sure what problems we would have otherwise had.





# data speak

Who delivers public health services? National, State, Territory and local governments, because they have the widest public responsibility and (usually) the capacity. And it's clear that health departments are not the only arms of government which serve health—virtually all parts play a role whether they see it or not. GPs and other health professionals and educators are obviously important, because they see so many people and can help keep them healthy. Voluntary agencies such as the anti-cancer councils and heart foundations are heavily involved, because they have long had an interest in prevention. Many others contribute, including the media, although in their case we can debate whether health is an aim—and therefore a service—or just a happy by-product.

So, to summarise a few key features of public health:

- It aims to benefit many people and uses a wide range of methods with wide-ranging effects.
- It places a strong emphasis on prevention and tries to work on the causes of health and disease.
- Most of those whom it aims to benefit will be well, although it can also help the sick.
- It understands that small improvements spread over many people ultimately bring larger community gains than big improvements in a few people.

Finally, public health is a main reason why the Commonwealth, State and Territory Health Ministers agreed a few years ago to collaborate in tackling the five National Health Priority Areas: injury, cardiovascular disease, cancer, diabetes and mental health. They all affect a lot of Australians and can be serious if not prevented. Prevention and health promotion, using many approaches, can play a large part in reducing their burden and building a healthier population.

**The Institute's clients, information resources, and staff are vital to its continuing success. To support access to and application of our information resources by both clients and staff, the Data Management Unit has introduced an innovative data management and documentation system called Datahound.**

Datahound is structured on international standards for the description and documentation of data and incorporates an easy-to-use World Wide Web interface. The system will initially be available on the Institute's Intranet. Datahound will add value to existing data resources by linkage of information concerning data custodians, managers and users of data, the location, structure and form of data holdings and details of data management and access rights. Datahound also encourages the broader application of data by providing easy-to-use and accessible information on each data element in a collection, including information relating to the source of the data. Datahound will reinforce the Institute's commitment to security of its data holdings by providing a central registry of constraints regarding access to confidential information.

The system has two principal components:

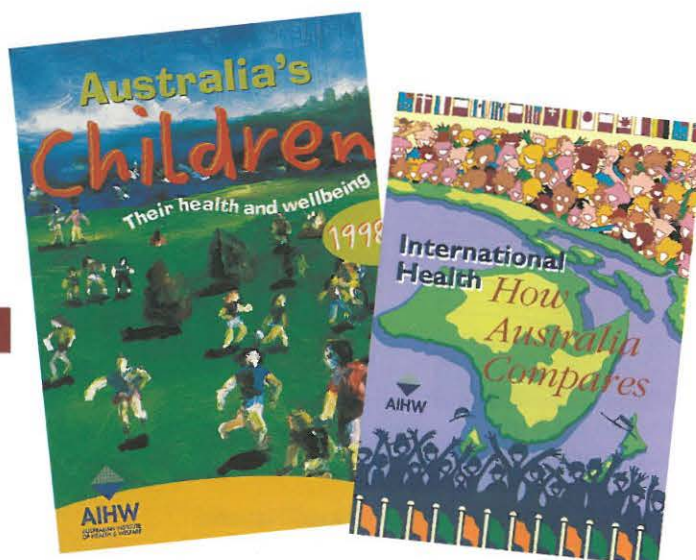
- a user-focused, easy to use Web interface which encourages the efficient exploration of the data registry by clients, managers and data custodians; and
- a set of Oracle forms for entering the necessary information.

The principles applied to the development of Datahound mean it could be used in many other areas of information management. Within the Institute, other uses could include servicing the Health and Welfare Ethics Committees and even easing the administrative burden of developing and maintaining our telephone directory and organisational charts.

For further information, please contact  
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## AIHW publications



### Australia's Children: Their Health and Wellbeing 1998

– includes information on important diseases and injuries, major risk factors and wider determinants of health and wellbeing for children in Australia. Separate sections report on the health status of particular priority groups (Indigenous children, children living in rural and remote locations, overseas-born children, and children from socioeconomically disadvantaged groups). International comparisons are included.

*Australia's Children: Their Health and Wellbeing 1998* (304 pp.) is available from AusInfo at a cost of \$35.00 (AIHW cat. no. PHE 7).

### International Health – How Australia Compares

– examines our international standing for a range of different health and health-related indicators. It provides most recent and trend data for 70 different indicators in comparing Australia with 19 other developed countries.

Areas examined include population, fertility and pregnancy, important causes of ill-health, mortality, health services and resources, and health determinants.

*International Health: How Australia Compares* (164 pp.) is available from AusInfo at a cost of \$25.00 (AIHW cat. no. PHE 8).



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