Issues and priorities in the surveillance and monitoring of chronic diseases in Australia

Report of a workshop held 8–9 November 2001, Canberra

Hosted by

Australian Institute of Health and Welfare and

Commonwealth Department of Health and Ageing

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Acknowledgments

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Abbreviations

ABS	Australian Bureau of Statistics
AHMAC	Australian Health Ministers' Advisory Council
AHMS	Australian Health Measurement Survey
AIHW	Australian Institute of Health and Welfare
AusDiab	The Australian Diabetes, Obesity and Lifestyle Study
CAPI	Computer-assisted personal interview
CATI	Computer-assisted telephone interview
CHD	Coronary heart disease
COPD	Chronic obstructive pulmonary disease
CVD	Cardiovascular disease
DALY	Disability-adjusted life years
DoHA	(Commonwealth) Department of Health and Ageing
DHS	Department of Human Services (Victoria)
HOIST	Health Outcomes Information Statistical Toolkit
ICD-9	International Classification of Diseases, ninth revision
ICD-10	International Classification of Diseases, tenth revision
ICPC-2	International Classification of Primary Care, second revision
ISC	Inpatient Statistics Collection
LGA	Local Government Area
NCD	Non-communicable disease
NGO	Non-government organisation
NHIMG	National Health Information Management Group
NHPA	National Health Priority Area
NHPAC	National Health Priorities Action Council
NHPC	National Health Performance Committee
NHP Framework	National Health Performance Framework
NHS	National Health Survey
NPHIWG	National Public Health Information Working Group
NPHP	National Public Health Partnership
NSW	New South Wales
PHIDU	Population Health Information Development Unit
SES	Socioeconomic status
SNAP	Smoking, nutrition, alcohol abuse, physical inactivity
SPICE	Surveillance for policy, intervention, control and evaluation
STEPS	Stepwise approach to surveillance

VPHS	Victorian Population Health Survey
WHO	World Health Organization
YLD	Years of healthy life lost due to disability
YLL	Years of life lost due to premature mortality

1 Introduction

Chronic diseases are a major health challenge in Australia and other parts of the world. Prominent among these are heart and circulatory problems, several cancers, diabetes, arthritis and depression. Most chronic diseases are not immediately life threatening, but they contribute to much illness and disability over the course of life and eventually to a large proportion of deaths. Many of the chronic diseases can be prevented early by tackling some well-known risk factors. Others can be managed effectively to avoid further complications.

Regular surveillance and monitoring is a central plank in any strategy aimed at prevention and management of chronic diseases and their risk factors. All policy initiatives for chronic disease prevention and management should be supported and underpinned by timely and accurate data.

Surveillance and monitoring of chronic diseases is made difficult by their complex origins, long periods between exposure to a risk factor and symptoms, and lack of one-to-one correspondence between risk factors and disease outcomes. Several risk factors may contribute to more than one chronic disease. The disease outcomes also show significant variation, with many chronic diseases often interacting with other diseases, conditions and risk factors causing illness and death.

In addition to mortality, morbidity and disability statistics, surveillance data on prevalence of risk factors are required for effective planning, implementation and evaluation of preventive policies and programs for chronic diseases. There is also a need to integrate information from a range of administrative and non-administrative data sources. To ensure comparability over time and across locations, standardisation and harmonisation of data collections and their analysis is also necessary.

Any surveillance and monitoring of chronic diseases and their risk factors needs to consider all these issues in totality rather than by a piecemeal approach. However, given the wide range of issues, priorities must be established in data development, analysis and dissemination. As a first step in this process, the National Public Health Information Working Group (NPHIWG) convened a workshop on issues and priorities in chronic disease surveillance and monitoring in Australia. The workshop, which was hosted by the Australian Institute of Health and Welfare in conjunction with the then Commonwealth Department of Health and Aged Care, now the Commonwealth Department of Health and Ageing (DoHA), was held in Canberra on 8–9 November 2001. Among those attending the workshop were senior policy makers, health information specialists, nutritionists, epidemiologists, clinicians and representatives of non-government organisations.

This report describes the outcomes of the workshop as well as provides a summary of the workshop proceedings.

2   Aims and objectives of the workshop

Overall aim

To seek input into and progress work on nationwide surveillance and monitoring of chronic diseases and associated risk factors in Australia.

Objectives

1.   To identify issues and priorities for nationwide surveillance and monitoring of chronic diseases and associated risk factors.

2.   To progress the development of a chronic diseases and associated risk factors information framework.

3.   To address issues relating to the integration and harmonisation of data on chronic diseases and associated risk factors.

4.   To seek input into the cost effectiveness of data collection, development and management with respect to chronic diseases and associated risk factors.

5.   To obtain comment for the optimal use and application of chronic diseases and associated risk factors data for public health activities in Australia.

3 Organisation of the workshop

The workshop was held over two days (8–9 November 2001) at Saville Park Suites in Canberra. An organising committee assisted in planning the workshop, and the resulting program is shown in Attachment A.

The workshop was attended by a wide range of stakeholders, including senior health policy makers, health information specialists, nutritionists, epidemiologists, clinicians and representatives of non-government organisations (NGOs). Since the emphasis of the workshop was on information-related issues, all members of the National Public Health Information Working Group (NPHIWG) also participated in the workshop. A full list of participants is given at Attachment B.

The first day of the workshop focused on the key issues in the surveillance and monitoring of chronic diseases and their risk factors. These were:

- a framework for surveillance and monitoring;
- data requirements at various levels of government; and
- linkage of surveillance and monitoring to public health interventions and policy development.

Three plenary sessions and a number of distributed papers laid the foundation for small group workshops on each one of these issues.

Priorities for chronic disease surveillance and monitoring were covered on the second day of the workshop. Priorities identified for discussion by small group workshops were:

- biomedical risk factors and markers;
- behavioural risk factors and other psychosocial variables; and
- utilisation and harmonisation of various types of data.

The workshop also took into consideration the work done by the La Trobe Consortium to determine the feasibility for a nationwide chronic diseases and associated risk factors information and monitoring system.

The following documents were provided as background to the workshop:

- *National Health Performance Framework Report*, a report to the Australian Health Ministers' Council from the National Health Performance Committee;
- *Preventing chronic disease: a strategic framework*, endorsed by the Australian Health Ministers' Advisory Council (AHMAC) as the basis for further national collaborative action;
- *Feasibility study for developing a nation-wide chronic diseases and associated risk factors information and monitoring system*, a discussion paper prepared by the La Trobe Consortium; and
- *Chronic diseases and associated risk factors in Australia, 2001*, draft baseline report prepared by the Australian Institute of Health and Welfare.

In addition to the documents distributed prior to the workshop, participants in each of the small group workshops were provided with one-page background papers. These background papers are given at Attachment C.

4   Outcomes

The workshop did not set out to make any direct recommendations on issues and priorities in chronic disease surveillance and monitoring but chose to provide broad guidance and direction on specific issues. The outcomes, given in dot point format below, therefore broadly summarise the nature and direction of discussions at the workshop. A recurring theme at the workshop was the need to undertake the Australian Health Measurement Survey (AHMS), identified as the highest priority in chronic disease surveillance and monitoring.

4.1   General

4.1.1   A comprehensive surveillance and monitoring system is a requirement in efforts to help prevent and effectively control chronic diseases in Australia.

4.1.2   An effective surveillance and monitoring system would need to look across the continuum of care, from prevention through to treatment and management.

4.1.3   The fixed costs of information infrastructure should be recognised as national investment; marginal costs for additional information collected through that infrastructure should be a separate issue.

4.2   Framework

4.2.1   The National Health Performance Framework (NHP Framework), developed by the National Health Performance Committee (NHPC) and endorsed by AHMAC, was identified as a suitable framework for the surveillance and monitoring of chronic diseases, and could be used alongside the Strategic Framework for Preventing Chronic Disease, developed by the National Public Health Partnership Group (NPHP).

4.2.2   The World Health Organization (WHO) stepwise approach to surveillance (STEPS) of risk factors for non-communicable diseases was considered a useful framework. It is simple and comprehensive in showing how behavioural, physical and biomedical factors interlink. It also demonstrates how an increasingly comprehensive surveillance system, depending on local needs and resources, can be developed.

4.3   Data collection

4.3.1   Risk factor information is the centrepiece of chronic disease surveillance and monitoring, with behavioural risk factors forming the key plank.

4.3.2   In regular surveillance of SNAP behavioural risk factors (smoking, nutrition, alcohol abuse, physical inactivity), the first phase in the WHO STEPS approach—frequency and timeliness of data—is important. State-based computer-assisted telephone interview (CATI) health surveys can help meet these requirements.

4.3.3   A health measurement survey that will generate biomedical information was considered to be the utmost national priority.

4

4.3.4 The Australian Health Measurement Survey (AHMS), proposed to be held in conjunction with the 2004 National Health Survey (NHS), may be an opportunity to fill this gap.

4.3.5 Wide consultation is required to determine appropriate measures to be included in the AHMS. This is being undertaken as part of the development of the AHMS Business Case.

4.3.6 The following criteria should be used for determining the disorders and biomarkers to be covered in the AHMS:
- markers relate to a broad range of chronic diseases and risk factors;
- markers relate to factors that meet rigorous causal criteria;
- disorders are of considerable prevalence; and
- standard measurement issues (feasibility, reliability, validity) are addressed.

4.3.7 Blood cholesterol and diabetes markers should have the first priority in the proposed survey.

4.3.8 Consideration should be given to the inclusion of spirometry along with other physical (weight and height) and blood (pressure, cholesterol) measures in the survey. Urine sampling, while yielding useful biomedical data, would prove difficult and should not be a high priority.

4.4 Measurement issues

4.4.1 Analysis of blood pressure and cholesterol levels should take into consideration that these are continuous variables and that the standard cut-offs do not include all people who are at risk of poor health outcomes, particularly stroke and heart attack.

4.5 Indicators

4.5.1 A useful but manageable set of indicators should be developed for regular monitoring, building on the work done for the National Health Priority Areas (NHPA).

4.5.2 The NHP Framework should be used as the reporting framework for chronic disease surveillance and monitoring. The WHO STEPS approach was also considered to provide a suitable model for interlinking information on various risk factors.

4.5.3 An analytical framework, such as the one presented in the NPHP background paper (*Preventing chronic disease: a strategic framework*), should be displayed side by side with the NHP Framework. The two frameworks will thus provide a useful checklist for key issues in chronic disease surveillance and monitoring.

4.6 Regional issues

4.6.1 State/Territory and Commonwealth needs go beyond national needs in the important area of health service delivery. Therefore national collections need to have appropriate samples for regional dis-aggregation and a capacity to include additional modules for State/Territory and Commonwealth purposes.

4.7   Coordination across jurisdictions

4.7.1   There is a need for coordination of surveillance activity on a nationwide basis to assist the States and Territories in achieving their objectives, such as common CATI questions and an integrated sampling framework.

4.7.2   A paramount issue identified at the workshop was the need to ensure appropriate access to the surveillance data and its various outputs at all jurisdictional levels.

4.8   Harmonisation

4.8.1   The need for harmonisation of data collections was recognised. Potential exists for good alignment of the ABS NHS, jurisdiction-based CATI surveys, and the proposed AHMS.

4.8.2   Diversity in the types of instruments and information currently collected for chronic disease surveillance is an asset, rather than a liability, but NPHIWG could coordinate further harmonisation of these data.

4.8.3   Standard questionnaire modules on specific health topics should be developed. This work is already being auspiced by the NPHP. A minimum set of data items could be applied across the collections so that the concepts and definitions are consistent.

4.8.4   The lack of metadata (information about the data) limits the use of many existing data sets. Provision of information such as collection methodology, sample design, sample size, questions in the survey, editing procedures, response categories of data items, definitions of data items, and scope of collection would lead to greater use of these and new data sets.

4.8.5   An audit of data sources, i.e. a national compilation and review, would be an important step towards the harmonisation of data. This work has been undertaken for health surveys by the La Trobe Consortium as part of the feasibility study.

4.8.6   Existing administrative and non-administrative data collections could be used more effectively. One way to increase the use of existing collections would be to develop record linkages between various data sets.

4.9   Linking data to intervention and policy development

4.9.1   Involvement of policy makers in the development of data collection and information systems would help to ensure that the information is used for policy and program planning purposes.

4.9.2   Any data development should take into account public health agendas and policy objectives, which in turn need to be based on evidence.

4.9.3   A major limitation in trying to link surveillance and monitoring with policies is the social context in which interventions take place. Since interventions occur at different levels, it is important for surveillance and monitoring to take place at appropriate levels.

4.10 Dissemination of results

4.10.1 It is important to determine the audience being addressed and to disseminate results in forms appropriate to that audience. Some uniformity or agreed system between jurisdictions for publishing results would allow population groups distributed across more than one jurisdiction to better understand their situation.

5   Background presentations

5.1   Plenary 1: Surveillance and monitoring of chronic diseases and associated risk factors

5.1.1 Welcome and opening remarks

Richard Madden, Director, Australian Institute of Health and Welfare and Co-Chair, National Public Health Information Working Group

One of the aims of the AIHW is to develop suitable measures and indicators for monitoring the health and welfare of Australians, including chronic diseases and their associated risk factors. The Institute integrates information from various health-related data collections and provides value-added analysis. It also helps establish high-level frameworks for data development, including identification of data gaps and deficiencies, and helps plan and develop new health-related collections. The AIHW also undertakes surveillance and monitoring of a variety of risk factors (psychosocial, socioeconomic, behavioural and biomedical) associated with various chronic diseases.

For example, the Australian Burden of Diseases and Injury Study, conducted by the AIHW, generated summary statistics (including incidence, prevalence, and disability-adjusted life years or DALYs) on a large number of chronic diseases and conditions. The results of this study are extremely useful for any surveillance and monitoring of chronic diseases in Australia but must be supplemented by a variety of other types of information.

NPHIWG has established a subcommittee to oversee the surveillance and monitoring of chronic diseases in Australia, and has sought action on recommendations in NPHP's chronic disease prevention paper. NPHIWG would like the information on chronic diseases and associated risk factors in Australia to be developed within a clearly defined framework. The NHP Framework should be adapted for organising chronic disease information in Australia. However, two additional dimensions of chronic diseases need to be considered in adapting this framework, namely chronic diseases across various stages of the lifecycle, and its extension to surveillance and monitoring at regional/local area levels. The framework should also place additional emphasis on risk factors, central to chronic disease surveillance and monitoring.

5.1.2 Surveillance across the continuum of care

Richard Smallwood, Chair, National Health Priorities Action Council

Chronic diseases are complex and have numerous co-morbidities that further complicate our understanding of them. However, since many chronic diseases are linked to affluent lifestyles, there is considerable scope for their prevention.

In managing chronic diseases, we need to look across the spectrum from prevention through primary care to tertiary care. Areas where there appears to be the greatest gain are tobacco smoking, lack of exercise and obesity. There have been some successes in the reduction of tobacco use, however this has not been achieved fully in the disadvantaged groups.

Two important issues that need to be addressed in the surveillance and monitoring of chronic diseases in Australia are the ageing population and the increasing demand for, and cost of, health care and prevention. Our aim should also be to develop first-class information systems to monitor time trends.

5.1.3 Surveillance and monitoring of chronic diseases and associated risk factors in Australia

Kuldeep Bhatia, Australian Institute of Health and Welfare

Although most chronic diseases are not immediately life threatening, ultimately they are a large cause of mortality. In 1998, the set of 10 chronic diseases and conditions included in the AIHW's draft baseline report were listed as the underlying cause in almost 60,000 deaths, about 47% of all deaths that year. However, mortality from many of the chronic diseases is on the decline. In addition to coronary heart disease (CHD), stroke and lung cancer, one of the diseases with significant decline in death rates has been chronic obstructive pulmonary disease (COPD), mostly attributable to reduction in tobacco smoking.
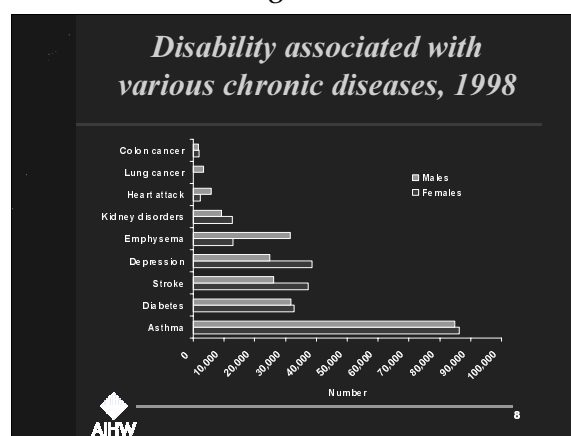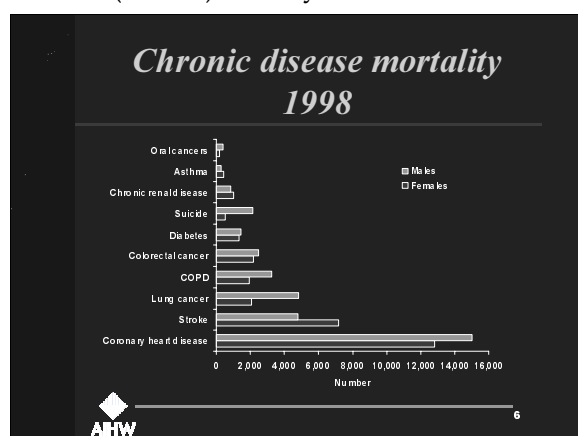
Disability is an accompaniment of most chronic diseases; asthma, depression, emphysema, stroke and diabetes are large contributors to disability. Coronary heart disease is the largest contributor to disability-adjusted life years (DALYs), but most of that due to premature mortality (YLL). The contribution from asthma, on the other hand, is mostly in terms of years of healthy life lost due to disability (YLD). COPD both disables and kills in large numbers.

About 30% of DALYs can be attributed to seven biomedical and behavioural risk factors. Tobacco smoking is the greatest contributor, followed by physical inactivity, high blood pressure, alcohol harm, excess weight, high blood pressure and poor diet.
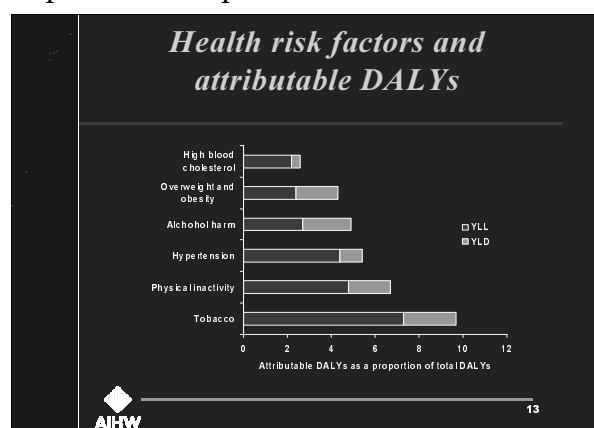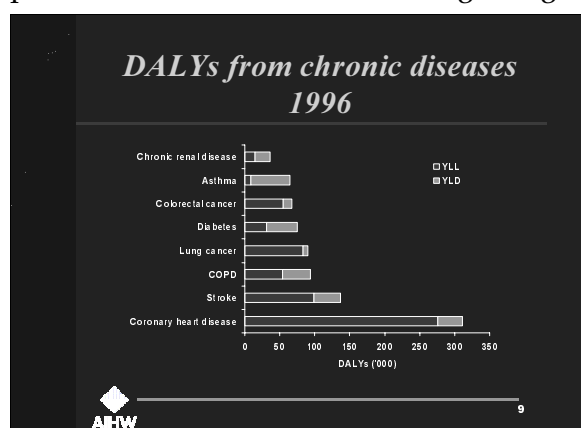
The number of chronic diseases and their risk factors to be monitored is much larger than those covered by the AIHW report. This requires the development of a comprehensive, integrated surveillance and monitoring system. Some of the steps to developing such a system include establishing an information framework, setting up monitoring indicators, scoping the information base, developing baselines, and regularly reporting against the defined set of indicators.

5.1.4 Strategic issues and options for chronic disease surveillance in Australia

Vivian Lin, School of Public Health, La Trobe University

The La Trobe Consortium's current audit and feasibility study has identified several important issues for chronic disease surveillance. These include:

- the need for local as well as national information;
- how to bring some uniformity ('harmonisation') into data collections from diverse data sources;
- how to prioritise between health status measures, risk factor information, biomedical markers, and measures of health system performance;
- the development of surveys alongside regular surveillance systems; and
- balancing data definition and collection ('front end') issues with analysis and dissemination ('back end').

The audit has uncovered significant gaps in comparability and types of information. Therefore a number of strategic choices need to be made, involving some compromises:

- Should we have a singular, national information system or multiple harmonised vehicles (ABS surveys, national strategies' surveys, State CATI surveys, health measurement surveys)?
- Can we reconcile the various frameworks for chronic disease monitoring (including the chronic disease prevention framework, the health performance monitoring framework, and the WHO STEPS framework)?
- Can we develop a 'leaderful' system, using the expertise and resources of all the stakeholders (States/Territories, Commonwealth, ABS, AIHW, NHPAC, NPHP, NHIMG) rather than relying on one of them for 'singular leadership'?
- Can we develop a partnership between producers (with their sets of collection methodologies, analytical techniques, content area development, special studies) and users (including the jurisdictions, with their various infrastructures)?
- What kind of investments should we make in infrastructure, additional modules, repeated national/state surveys or continuous monitoring, or in workforce capacity-building?

In summary, the major challenges can be identified as:

- What are the most efficient and effective mechanisms for linking with users (policy-makers, program planners, etc.)?

- What should be the process by which priorities can be set for information development (for filling gaps, for harmonisation, for analyses, etc.)?

- How to pool investment in infrastructure and capacity development in a productive manner?

5.2 Plenary 2: Surveillance and monitoring of chronic diseases: State/Territory perspectives

5.2.1 Chronic disease surveillance and monitoring in South Australia

Anne Taylor, Department of Human Services, South Australia

South Australia has undertaken annual population surveys since 1990 (including CATI surveys since 1995), looking at a range of chronic diseases and their risk factors state-wide. Sample sizes have also allowed region-level analysis.

The uses of these surveys can be summed up by the acronym SPICE: surveillance for policy, intervention, control and evaluation. Surveillance of diabetes is an example of the *policy* uses of such surveys, with measurements of prevalence at the State and regional levels, and in Indigenous communities. However, the response rates in Indigenous surveys have been low, which may affect the estimates.

Results of the surveys are used to monitor *interventions*, such as the promotion of influenza vaccine for those aged 65 and over, the Quit campaign, and asthma management plans. In the context of chronic diseases, *control* refers to the surveillance and monitoring of risk factors, particularly for asthma and diabetes. *Evaluation* of potential public health issues will also be facilitated by data from the surveys, e.g. HRT use among women aged 55 and its possible implications for cardiovascular disease and osteoporosis in the future.

The relative usefulness and reliability of the mode of the survey (door-to-door or CATI), need to be considered. For example, self-reported height and weight information has not varied much over time, whether measured by door-to-door surveys or by CATI surveys. However, smoking prevalence rates generated by the two types of surveys have been quite different.

Current HRT Use
1991-2000

Smoking prevalence in South
Australia, 20 years and over
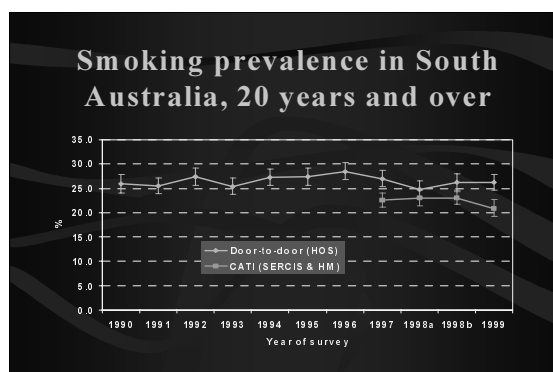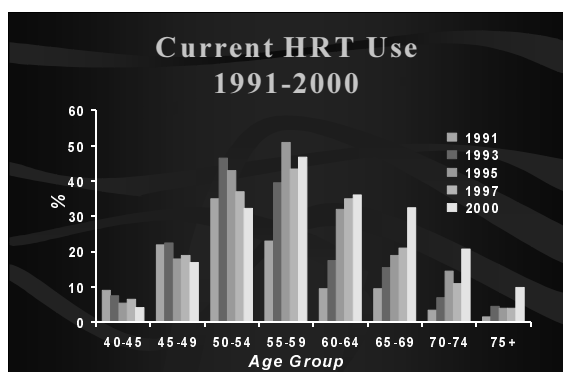
5.2.2 Applications of surveillance: a practical perspective from the Victorian Department of Human Services

Mike Ackland, Department of Human Services, Victoria

Chronic disease and risk factor surveillance is seen as 'core business' for Victoria's Department of Human Services (DHS). For example, the Better Health Victoria 2010 Plan has nine core domains for public health: building capacity, eating well, active living, tackling drugs, stopping disease, closing the gaps (reducing inequalities), starting young, strengthening communities, and creating healthy environments. Surveillance initiatives have been further developed to contribute improved information that has relevance and application to these (and other) strategic policy directions for the Department.

Surveillance outputs in Victoria include estimates of life expectancy at birth by DHS region, local government area (LGA) and socioeconomic status (SES), YLL by main cause of death in urban and regional areas, and summary estimates of the burden of disease in DALY terms at state, regional and LGA levels.

Life expectancy at birth
in rural and urban Victoria 1988–1999

Changes in Male Life Expectancy at Birth by LGA
Victoria 1992–1996 and 1996–1999
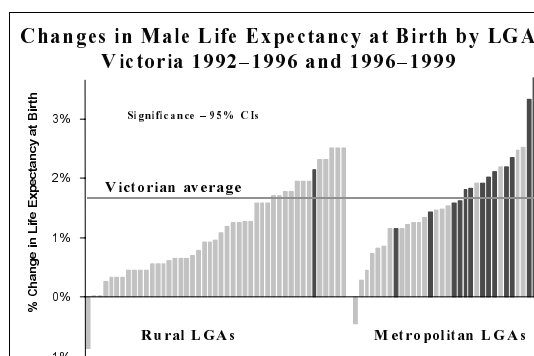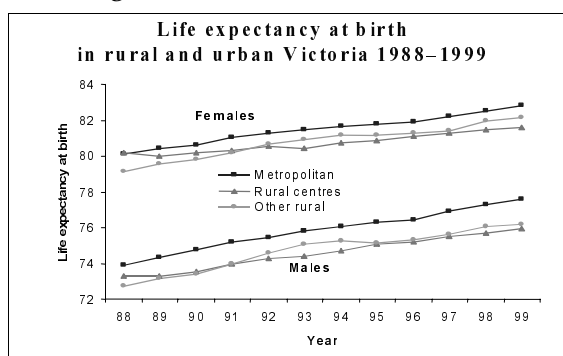
Recent time-series analyses of Ambulatory Care Sensitive Condition hospitalisations are also contributing to a better understanding of issues such as access to primary care services as well as differentials in health for Victorians.

The Victorian Population Health Survey (VPHS), a CATI-based survey, is a cost-effective approach to filling information gaps and provides a source of new evidence to support policy development and program evaluation. For example, the VPHS will allow new analyses of the attribution of disease burden to risk factors (new estimates obtained through the survey). The 2001 VPHS covers:

- health care use;
- mental health status;
- asthma and diabetes;
- nutrition, alcohol and smoking;
- physical activity/inactivity;
- gastroenteritis;
- socioeconomic determinants; and
- community and societal characteristics.

Rates of Years of Life Lost by main cause
in rural and urban Victoria 1996 and 1999

Comparison of DALYs by Socio-economic Status
Victoria 1996

DALY rates per 1,000 males
in selected LGAs 1996
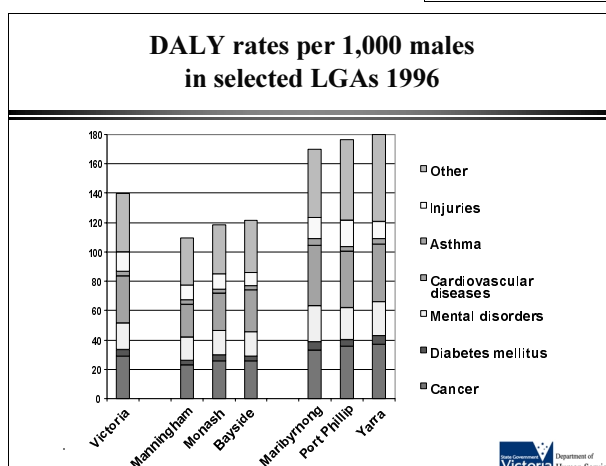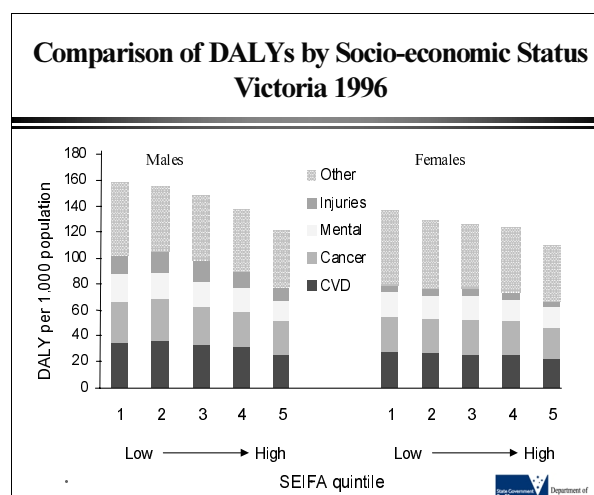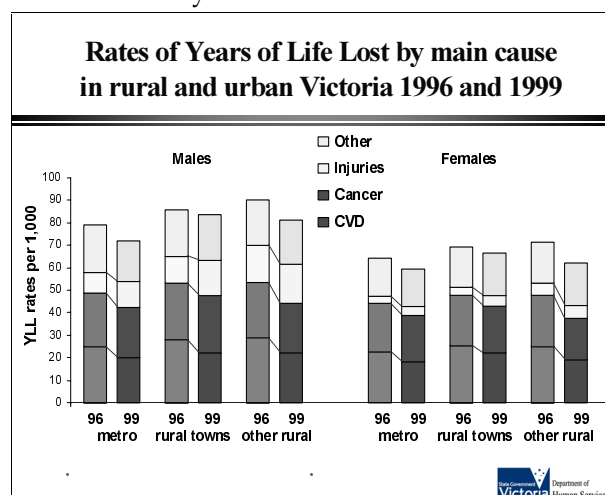
Surveys such as VPHS are just one part of a broad program of surveillance initiatives now in place to fill information gaps in Victoria.

5.2.3 Information base for the surveillance of chronic diseases in New South Wales

Margo Eyeson-Annan, New South Wales Health

New South Wales (NSW) has been actively building an information base on chronic diseases for more than 10 years through its population health surveillance program. The aim of the program is 'to ensure that there is appropriate, timely and valid population health information to monitor health status and respond to health problems, and to support planning, implementation and evaluation of health services and programs'.

In 1997, as part of the development of the Strategy for Population Health Surveillance in NSW, information gaps were identified which included risk factor, incidence and prevalence data for chronic diseases. Problems with existing data sets were also identified including coding of at-risk groups (e.g. Aboriginality and ethnicity), problems with the designation of codes, inadequate coding and identification of secondary diagnoses, recording of demographics and timeliness of data sets.

In order to meet some of the identified information needs, the Health Survey Program was established in 1997 to provide state-wide and Area Health Service-level data on health status, health risk factors, use of and access to health services, and satisfaction with health services. Adult surveys were conducted in 1997 and 1998, followed by age-specific studies in 1999 and 2001. From 2002 onwards, the Continuous Health Survey Program began collecting information, including:

- social determinants of health;
- individual or behavioural determinants of health;
- major health problems;
- population groups with special needs;
- settings;
- partnerships; and
- infrastructure.

The survey is based on a sample of the whole population with interviews being conducted each month in all Area Health Services simultaneously. It has the capacity to exclude questions and include additional ones, as required.

NSW has also established the Health Outcomes Information Statistical Toolkit (HOIST), a SAS-based population health data warehouse comprising epidemiological data sets (such as mortality, hospital separations and NSW Central Cancer Registry data) in a standardised format, plus a range of analytical programs.

HOIST has recently been expanded to include new data sets including social capital information (e.g. crime data), Health Insurance Commission data (Medical Benefits Scheme and Pharmaceutical Benefits Scheme data), National Coronial Information System and environmental health (water and meteorological) data.

Probabilistic data linkage in HOIST can be used to match records on the basis of date of birth, country of birth, sex, insurance status, language spoken at home, address and so on. Linked data available on HOIST includes:

- cancer treatment—linkage of most recent Central Cancer Registry data to NSW Inpatient Statistics Collection (ISC), 1992–93 to 2000–01;
- readmission data—internal linkage of ISC 2000–01;
- estimates of the number of persons who were receiving haemodialysis—internal linkage of ISC 1997–98); and
- utilisation and outcomes of birthing services—linkage of NSW Midwives Data Collection and ISC 1999.

Web-based reporting systems are being developed for the NSW Health Survey data, mortality data and the ISC. This will further improve the existing dissemination of

information through the *Report of the NSW Chief Health Officer, NSW Mothers and Babies Report,* the *NSW Health Survey Report* and the *NSW Public Health Bulletin.*

5.3 Plenary 3: Surveillance and monitoring of chronic diseases: other perspectives

5.3.1 Chronic diseases: a Commonwealth perspective

Colin Sindall, Commonwealth Department of Health and Ageing

The World Health Organization (WHO) has established a global strategy for the prevention and control of non-communicable diseases (NCD), mainly cardiovascular disease (CVD), diabetes, and cancer. The strategy sets out country-level guidelines which call on nations to generate an information base for action. This would enable governments to assess and monitor NCD mortality and the level of exposure to risk factors in the population, as well as provide a mechanism for surveillance information to contribute to policy making, advocacy and the evaluation of health care.

The policy context in Australia builds on and expands these guidelines. Effective monitoring of health trends such as levels of obesity, the Type 2 diabetes epidemic and mental health problems is needed, together with a focus on health inequalities and the ageing population. Monitoring is also required to inform action, for example implementation of national nutrition and physical activity strategies. Taking a life-course perspective extends understanding of preventive opportunities.

The NPHP background paper, *Preventing chronic disease: a strategic framework,* outlines the goals of national health policy in this area. These aim to:

- improve health and wellbeing of all Australians and reduce health, social and economic impacts of chronic disease on Australian society;
- reduce avoidable morbidity and mortality associated with the conditions identified in the framework; and
- reduce health disparities (socioeconomic status, gender, ethnicity, location) with regard to the diseases and risk factors identified in the framework.

In view of these goals, there is a strong need for a nationwide chronic disease and risk factor surveillance and monitoring system. Such a system would:

- provide timely, accurate data to support national chronic disease prevention strategies;
- inform health policy, planning and effective targeting of resources;
- identify short-term and long-term trends and emerging issues of national importance in chronic disease prevention;
- evaluate effectiveness of policies and interventions;
- pinpoint action on health inequalities and groups with special needs;
- compare progress and trends across Australia;
- contribute to national health performance assessment; and
- develop and track leading health status indicators.

The desirable characteristics of a nationwide monitoring system are that it would equitably meet the needs of all jurisdictions, be consistent with national requirements, and reflect an understanding of chronic disease aetiology and control. Such a system would also need to be sufficiently flexible to reflect local context and needs, but with core elements that allow for comparison and aggregation across issues of common interest and national policy importance. It would incorporate a range of linked objective and self-report measures—attitudinal, behavioural, biomedical—collected with appropriate frequency. It would also be sustainable, building on existing systems and expertise, at all levels.

Our current information system is not limited to AIHW, ABS and State/Territory collections and products, but also includes innovative projects developed by the private sector, NGOs and universities, along with strong administrative data collections.

A number of weaknesses in the current system, however, can be identified, including:

- limitations in behavioural data;

- discontinuity in objective risk factor data sets;

- limited capacity for social determinants monitoring; and

- lack of agreed national objectives regarding prevention.

In relation to chronic disease information development, the NPHP has recommended the development of a framework for systematic collection, aggregation and use of public health information at the national level. It also recommended the development of a national work program to improve overall coverage of survey data, facilitate sharing of data between jurisdictions and provide a basis for establishing agreed national minimum survey data sets for priority areas.

NPHP Background Paper *Preventing Chronic Disease: A Strategic Framework*

Risk & Protective Factors	*Biological Risk Factors/Markers*	*Preventable Chronic Diseases & Conditions*
Behavioural Factors • Diet • Physical Activity • Smoking • Alcohol misuse **Psychosocial Factors** • "Sense of control" • Social support/social exclusion • Resilience and emotional well-being **Early Life Factors** • Maternal health • Low birthweight • Childhood infections • Abuse and neglect	• Obesity • Hypertension • Dyslipidemia • Impaired Glucose Tolerance • Proteinuria	• Ischaemic Heart Disease • Stroke • Type 2 Diabetes • Renal Disease • Chronic Lung Disease (COPD & Asthma) • Certain Cancers (eg colorectal, lung) • Mental health Problems/Depression* *Possible inclusion:* • Oral health • Musculo-skeletal conditions
*Non modifiable factors:* Age, sex, ethnicity, genetic make-up, family history	

Socio-environmental determinants

Proposed "cluster" of chronic diseases and risk factors

Attending to these recommendations, the priorities proposed by the NHIMG are to:

- develop data collections to incorporate a range of risk factors, including behavioural, biomedical and socioeconomic, recognising the priority of special needs groups;

- conduct a national survey that includes biological measurement of major modifiable risk factors;

- coordinate behavioural risk factor surveys to promote best practice and development of a national strategy; and

- develop and implement analytical techniques for reporting on health inequalities and the health of vulnerable populations.

Several Commonwealth-funded initiatives will further these objectives. The business case for the AHMS proposes a program of cross-sectional surveys with physical measurement

components. The AIHW is undertaking information development, data analysis and national reporting on chronic diseases and associated risk factors. The La Trobe Consortium has undertaken a feasibility study for nationwide chronic disease and risk factor surveillance and monitoring. The ABS 2001 NHS will enhance our knowledge of various chronic diseases and behavioural risk factors. DoHA has funded ABS to support an enhanced NHS program, with more frequent (triennial) surveys and supplementary Indigenous sampling, with the AHMS linked to the NHS, and the development of CATI modules harmonised with the ABS computer-assisted personal interview (CAPI) modules. DoHA has also funded States and Territories to undertake 'buddy' CATI health surveys.
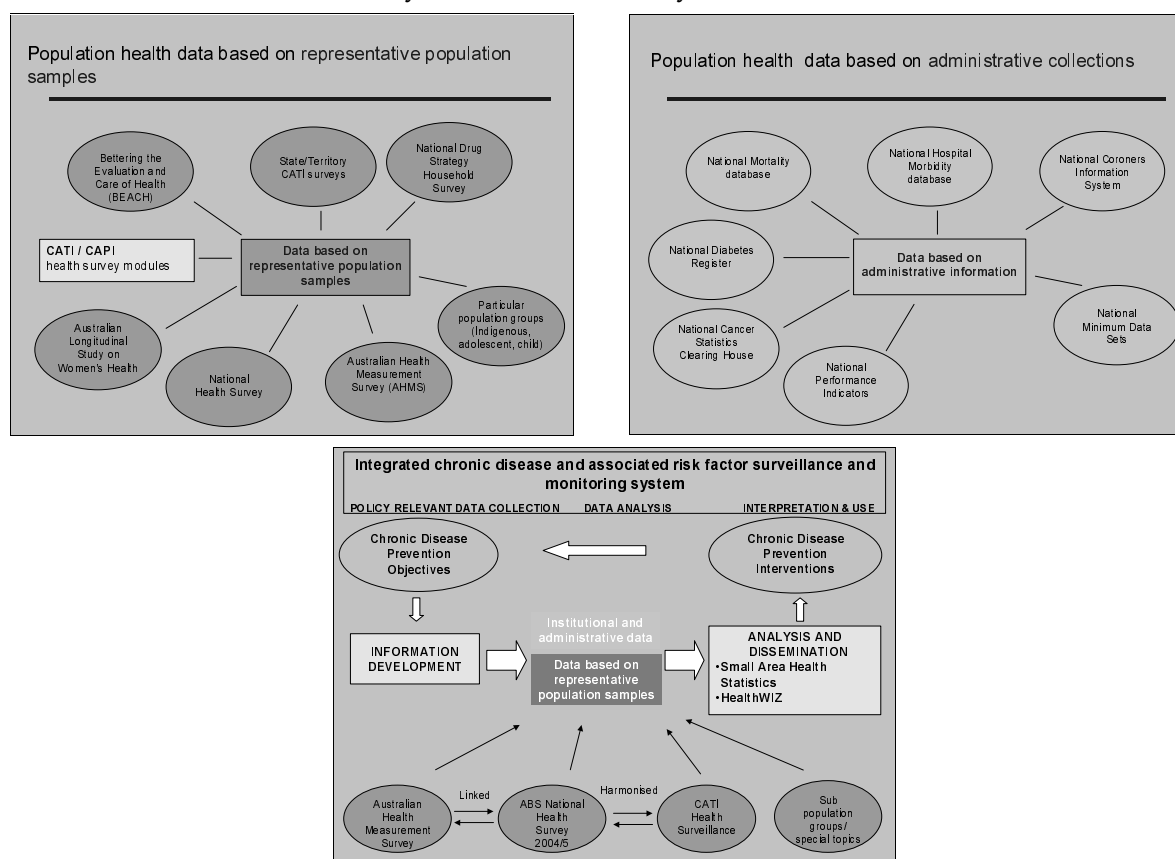
5.3.2 Chronic disease surveillance and monitoring: the non-government organisations' perspectives

Andrew Tonkin, National Vascular Disease Prevention Partnership

Among other initiatives, NGOs such as the National Heart Foundation and Diabetes Australia aim to inform policy makers and influence strategy. There are, however, limitations to what NGOs can do in the absence of quality data.

There is a strong need for robust national and regional data. At present, there is not as much data for rural areas as there is for metropolitan areas. This lack of information is likely to translate into problems in providing appropriate health services in rural areas. There are also implications for disadvantaged groups, such as the Indigenous community, in this regard.

The dichotomous classification of many risk factors (such as 'high' vs 'low' cholesterol or blood pressure) presents problems, as these are continuous variables. For example, one-third

of people with CVD have cholesterol levels of less than 5.5 mmol/L, the cut-off point for high blood cholesterol. A similar situation exists in the relationship between stroke and high blood pressure. It is therefore important to generate data on these risk factors along the continuum of variation.

Also, absolute risk for future events depends on the intensity of a variety of risk factors. Such clustering of risk factors should be captured in surveillance efforts.

5.3.3 Perspectives of the users and producers of chronic disease data

Hal Swerissen, School of Public Health, La Trobe University

The School of Public Health at La Trobe University is heading a consortium examining the feasibility of developing a nationwide information and monitoring system for chronic diseases and associated risk factors. This study has involved extensive consultations with users and producers of data. Preliminary drafts of the reports from the consultations have been circulated for comment, and the final reports are in preparation.

Most of those consulted are generally supportive of establishing such a system, with an emphasis on monitoring to assist decision making (policy, investment, planning, evaluation). A second emphasis is on the need for data for small area utilisation.

Discussions on which framework to use for monitoring chronic diseases elicited varied responses. There was some support for using the NHP Framework for developmental purposes. Further work is needed on specific data elements to be included in different sections of the framework. There was also some support for a 'continuum model' focusing on administrative data, self-reported information and objective measurements.

Integrating frameworks

	Step 1	Step 2	Step 3
Risk factors	Self report	+ physical	+Bio-medical
Morbidity	Admission counts by age/sex	+CD, NCD, Injury	Full cause
Mortality	Death by age/sex	+CD, NCD, Injury	Full certifi-cation

Some support for continuum model focusing on administrative data, self report & objective measurement.

In relation to data collections, there was strong support for using existing collections (hospital morbidity, mortality, CATI surveys and NHS), but the limitations of these for 'hard to get to' groups was also recognised. It was also recognised that there is a need to harmonise components of state-wide collections for developing a national picture, where that is lacking in the NHS. The development of national surveys with objective measures was also supported but there were mixed views on which objective measures should be use.

There were also mixed views on the importance and priority of fully harmonised national coverage, and some stakeholders suggested a more modest approach be adopted. The value of time-series data, as well as the need for disaggregation and small area analysis, was also widely recognised.

Strategic considerations included costs (further development of existing systems, addition of new elements, and increased transaction costs) and benefits (higher quality and more efficient data collection; enhanced benchmarking and analytical capacity; and more efficient and effective investment in expertise, capacity and infrastructure). In addition, the interests and needs of the various jurisdictions, and their capacity to contribute, along with the interests of funders, data producers and data users were also considered important.

5.4 Plenary 4: Measurement issues in the surveillance and monitoring of chronic diseases

5.4.1 Australian Health Measurement Survey (AHMS)

Jeanette Pope, Population Health Information Development Unit, University of Adelaide

The AHMS is proposed as a program of national population health surveys that will undertake objective measures (as opposed to self-reported information) of blood pressure, height, weight, and waist circumference, and obtain blood and other biological specimens. It is proposed that it be run in conjunction with the 2004 NHS, and that it include all age groups including children, as is now standard in similar surveys in other countries. A steering committee is developing the survey.

The objectives of the AHMS are to:

- determine and monitor the prevalence of selected disease outcomes and risk factors and determinants in the Australian population and selected population groups;

- examine the relationships between selected diseases and risk factors and their determinants; and

- validate self-reported measurements that are collected by a range of other Australian surveys.

A set of selection criteria has been established for determining the types of disease outcomes and risk factors for inclusion in the program, and a broad range of topics were tested by a reference group.

It has been proposed that the AHMS has two components, similar to the Health Survey of England and the Canadian Community Health Survey. The core component will be measured at every survey and should include blood pressure, blood cholesterol, glucose levels and body measurements. These will be complemented by core subjective measures on risk and socioeconomic factors as part of the NHS interview. The core component will allow for the monitoring of issues such as:

- progression of risk over the life-course;

- relationship between the major risk factors and other health determinants; and

- trends in body measurements.

Special interest modules, to examine particular health issues in greater depth, would be included on a one-off or occasional (or rotating) basis. The proposal for the first AHMS is to include special interest modules on metabolic syndrome and mental health. Nutrition should be considered for the second AHMS.

It is envisaged that at the end of the NHS interview, the ABS interviewer will gain consent from the respondent for a nurse (from an agency external to the ABS) to visit them in their home to take objective measurements. This information will then be returned to the ABS for matching with the NHS data file. The ABS will not release a unit record file of the AHMS but will instead create a synthetic data file to assist researchers in developing data extraction programs. The ABS will then run these programs against the file and, after ensuring confidentiality, provide the results to the researcher. Other data release formats will include publications and 'tables on request'.

To determine how much time the recruitment of respondents will take, and to examine issues about consent, the ABS has run a skirmish test. The skirmish involved 400 households who were given a cut-down version of the NHS and then asked if they would be willing to consent to the AHMS. In addition to timing how long it takes to recruit respondents, the interviewers also asked respondents a series of questions about the types of tests they may not wish to undergo (particularly blood and urine) and whether travel to a community centre to take the tests would make a difference.

There is still work to be done on the AHMS before a business case is ready to be presented to AHMAC. The funding issues also need to be examined by DoHA. The steering committee will meet again, once the results of the skirmish are in, to finalise content and design issues. A consultation will then be held with a wide range of stakeholders and consumer bodies, and an ethical process will be undertaken to ensure the success of the survey when it goes into the field.

5.4.2 The WHO STEPS approach

Terry Dwyer, Menzies Centre for Population Health Research, Hobart

Non-communicable diseases (NCDs) were estimated in 1999 to have contributed to almost 60% of deaths in the world and 43% of the global burden of disease in DALY terms. Based on current trends, by the year 2020 these diseases are predicted to account for 73% of deaths and 60% of DALYs worldwide. Most of these increases will result from the epidemiological transition current in developing countries, although the burden of NCDs in developed countries also continues to increase steadily.

A system for the surveillance of risk factors for these diseases on a global basis, known as STEPS (stepwise approach to surveillance), has also been developed by the WHO. The goals of this system are to obtain a picture of emerging patterns and trends in major NCD risk factors and to measure the effectiveness of primary prevention interventions. It is important to have a broader approach because certain risk factors need global solutions, due to their 'infectious' spread. Examples of such contagions include the spread of tobacco smoking and the proliferation of fast food restaurants noted for selling foods high in fat content.

There are a number of reasons why the key risk factors of tobacco smoking, poor nutrition, alcohol misuse and physical inactivity have been selected. These include:

- they have the greatest impact on NCD mortality and morbidity;
- there is evidence that their modification is possible and effective in primary prevention;
- their measurements have been validated;
- the forms of measurement can be easily applied in both developed and developing countries, and comparison across countries will be meaningful; and

- consistent measurements can be obtained by following appropriate technical and ethical standards.

The WHO approach has three levels (core, expanded and optional) of risk factor monitoring at each of the three 'steps' of complexity. Most countries should be able to begin at the first step, and then move to the other steps as their capacity to undertake such surveys develops.

The first step uses standard survey questionnaires to obtain information on 'core' demographic items, tobacco and alcohol use, nutrition and physical activity. This could be expanded to include other socioeconomic characteristics with measures of knowledge and attitudes regarding health, quality of life, and healthy behaviour being further optional modules.

The second step involves physical measurements of weight, height, waist circumference and blood pressure. This could be expanded to include hip circumference and skinfold measures. The third step would involve blood samples to measure cholesterol, glucose and triglyceride levels, and possibly other biochemical measures based on urine samples.

Standard definitions and methods would need to be used (as developed by the WHO) to allow comparability across countries and over time. While this may be a difficult hurdle for some countries, it is necessary to ensure good quality data. One of the guiding principles of this approach is that limited, good information is better than either large amounts of poor data or no data at all.

5.4.3 CATI health surveys

Mark Cooper-Stanbury, Australian Institute of Health and Welfare

CATI is a form of telephone interviewing supported by sophisticated software that can produce output within hours of the fieldwork. It is quite flexible in terms of changing the content of the questionnaire, and eliminates the need for clustered sampling design and interviewer travelling costs. CATI surveys have a place in the surveillance and monitoring of chronic diseases and behavioural risk factors, alongside administrative, clinical and other forms of survey data.

There are obvious limitations to this method: respondents are limited to those with access to a telephone; physical measurements cannot be taken; the complexity of the questions must be limited as prompt cards cannot be used; and interviewers cannot pick up on non-verbal cues. Results also often underestimate the prevalence compared with other modes, for

example, estimates of illicit drug and tobacco use from CATI surveys are usually lower than those obtained from personal interviews.
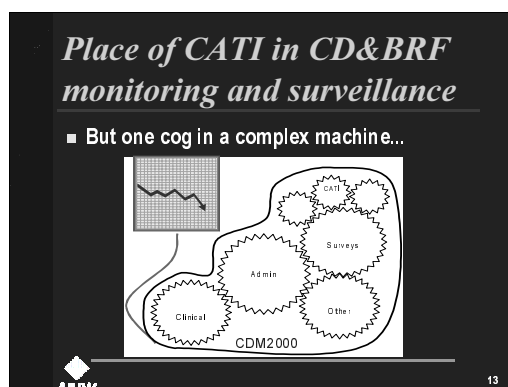
Current CATI survey topics include self-assessed health and wellbeing, biological features (e.g. height and weight), health behaviours (such as tobacco smoking, alcohol intake, physical activity, diet and supplements, medication use, substance use, preventive dental behaviours, and injury avoidance), community capacity, psychosocial factors, and socioeconomic factors. Health system performance can also be assessed through CATI surveys, with topics to be covered including access to services and prevention programs, satisfaction with services (the 'responsiveness' of the system), clinical management, management of complications, and so on.

NPHIWG has established the CATI Technical Reference Group which focuses on technical aspects of CATI surveys and on drawing together the expertise and experience of the States and Territories. The NPHP has endorsed a project to develop and publish manuals on CATI modules for chronic diseases and behavioural risk factors. The ABS is managing parts of this work, notably pre-testing (including cognitive testing). It is necessary to streamline the current process and get at least a common set of core questions.

The challenges currently facing the wider use of CATI surveys include the increasing digitalisation and mobilisation of the telephone network, harmonisation of State/Territory surveys (in terms of standard questions and survey timing), and the development of complementary collections for Indigenous, non-English-speaking, homeless and institutionalised individuals.

5.4.4 The National Health Survey

Marelle Rawson, Australian Bureau of Statistics

The ABS has conducted five National Health Surveys (NHS) between 1977 and 2001. In addition to these regular surveys, the ABS has conducted two user-funded surveys: the National Nutrition Survey in 1995 (attached to the 1995 NHS) and the National Survey of Mental Health and Wellbeing of Adults, in 1997. Beginning in 2001, the NHS will be conducted at 3-yearly intervals, the increased frequency being supported by a funding partnership with DoHA. The 2001 NHS included an additional Indigenous survey sufficient to produce national estimates, while from 2004, a large Indigenous survey will be attached to the NHS every 6 years.

Another important survey for chronic disease monitoring is the Survey of Disability, Ageing and Carers, the first in 1981 and the most recent (the fourth) in 1998. The ABS plans to continue this program at 6-yearly intervals.

The 2001 NHS, the results of which are due to be released in 2002, covered long-term conditions, recent injuries, mental health (using the K-10 instrument), risk factors and behaviours, use of services, self-assessed health (using the SF-12 instrument), socio-demographic measures and women's health. Mental health and women's health were not covered in the Indigenous component.

Special questions were included in the 2001 NHS on long-term conditions such as cancer, CVD, diabetes, asthma, eyesight and hearing. Although this is self-reported information, participants were asked if the condition had been diagnosed. The conditions were coded according to ICPC-2, and mapped to ICD-9 for comparison with the 1995 results. They will also be mapped to ICD-10 for future comparisons.

Risk factor information such as height and weight, dietary habits, and behaviours regarding tobacco, alcohol, exercise, breastfeeding, sun exposure, and dental consultations collected in the 2001 NHS was also based on self-reports. The format for collecting this information was the same as in the 1995 NHS.

6   Small group workshops

This section summarises discussions at six small group workshops held to focus on specific issues. These summaries should be read in conjunction with the background paper for each workshop, given at Attachment C.

6.1   An information framework for the surveillance and monitoring of chronic diseases

This workshop discussed the important issue of an appropriate framework for the surveillance and monitoring of chronic diseases and their associated risk factors in Australia. Discussion focused on the NHP Framework and its adaptation by the La Trobe Consortium for chronic disease information and monitoring.

The group supported the use of the NHP Framework, as opposed to developing a new one, as the reporting framework for chronic disease surveillance and monitoring in Australia. However, parts of the framework, in particular its third tier (health system performance), could not be adequately populated with the information currently available. In addition, distributional issues ('Where is the opportunity for improvement?') are not well informed by the NHP Framework. The possibility of a reordering of the columns and boxes of the framework was also considered.

It was suggested that the framework would be more useful to policy makers if the analytical basis of chronic disease surveillance and monitoring was also explained. The workshop agreed that an analytical framework, such as the one presented in the NPHP background paper (*Preventing chronic disease: a strategic framework*), should be used in conjunction with the NHP Framework. The two frameworks will thus provide a useful checklist for covering key issues in chronic disease surveillance and monitoring.

6.2   Regional and local area issues versus national monitoring

This workshop discussed information requirements for chronic diseases and risk factors monitoring at various levels, from local through to national. Two main issues addressed were:

- Why is chronic disease and risk factor information needed at various levels of organisation? and

- What methodological issues are involved in collecting data at various levels?

The group recognised that State/Territory and Commonwealth information requirements go beyond national needs in the important area of service delivery. Therefore, the national collections need to have appropriate regional samples and a capacity for additional modules to meet jurisdictional data requirements. The need for national coordination of this surveillance activity, in order to assist jurisdictions in achieving their objectives such as common CATI questions and central collection of samples, was also identified. This arrangement should reduce duplication of efforts in data collection and management. A paramount issue identified at the workshop was the need to ensure appropriate access to data and its various outputs at all levels.

In balancing nationally agreed and Commonwealth/State/Territory priorities, it was agreed that the proposed AHMS would probably be a better investment than any other new data collection. Assurance of the AHMS and other significant national data collections being in place over time would allow the States/Territories and others to plan and focus on other collections.

6.3 Linking chronic diseases surveillance and monitoring to public health interventions and policy development

The participants in this workshop identified three key issues for discussion:

- What are the prerequisites to bring about these linkages?
- What information is relevant for specific target groups? and
- What are the limitations of such linkages?

Several prerequisites for developing linkages between surveillance, interventions and policy development were identified. Early involvement of policy makers in the development of information systems would help ensure good use of various collections. It would also be useful to have someone from the policy side involved in the overall data development process, such that this person could explain the data attributes, history and quality issues to policy makers. In addition, data development should take into account public health agendas and policy objectives, which in turn need to be based on evidence.

In relation to the relevance of information for specific population groups, it would be important to identify the type of audience being addressed and the format in which to disseminate the relevant information. Some uniformity or an agreed system for releasing information across jurisdictions would allow various population groups to better understand their own particular situation. However, the presentation of information comparing various groups must be done in a culturally sensitive manner.

A major limitation in trying to link surveillance with policies is the social context in which interventions occur. Since interventions take place at different levels, it is important for surveillance to happen at the appropriate level as well. However, the cost-effectiveness of surveillance systems at different levels needs to be studied.

6.4 Biomedical risk factors and markers

The history of collecting biomedical information in national surveys was reviewed at the beginning of the workshop. The participants noted that:

- the National Heart Foundation has conducted three risk factor surveys, which also included collection of blood samples for certain biomedical information, in 1980, 1983 and 1989;
- the 1995 National Nutrition Survey, conducted by the ABS, included physical measures but not the markers in blood; and
- the 1999–00 AusDiab Survey also collected information on blood-based measures, but the low response rate (30%) has led to concerns about the statistical validity of the estimates.

The AHMS, proposed for 2004 in conjunction (and linkage) with the NHS, should provide the best opportunity to collect biomedical information in the near future. The workshop was

informed that an inter-governmental steering committee is currently preparing a business case for the AHMS.

The participants discussed a list of potential biomedical markers for coverage by the AHMS. The list related mostly to cardiovascular disease, stroke and diabetes. Markers or measures of respiratory disease, mental health and cancers were somehow lacking, even though many of these are inexpensive to collect—with the relevant tests easy to administer—and provide valuable information. An example was given of spirometry, an easy to administer field test, to measure lung capacity.

The workshop agreed upon the following criteria for biomedical markers and clinical disorders to be covered by the AHMS:

- markers should relate to a range of chronic diseases;

- markers should reflect causal pathways;

- disorders should be of considerable prevalence; and

- standard measurement criteria (feasibility, reliability, validity) should be met.

It was assumed that the list of proposed markers meets the above criteria. There was concern that some of the proposed tests are not suitable for a household survey, e.g. the oral glucose tolerance test and the urine samples.

It was considered necessary to establish priorities for the inclusion of various markers in the survey. The group agreed that the measurement of blood cholesterol and glucose levels is the first priority.

6.5   Behavioural risk factors and other psychosocial variables

In determining which behavioural risk factors to focus on, this workshop initially scanned the boxes labelled 'health behaviours' and 'psychosocial factors' in the schema of causal pathways influencing chronic disease and health outcomes, as described in the NPHP background paper, *Preventing chronic disease: a strategic framework*. The 'health behaviours' box covers smoking, diet, physical activity and alcohol use. The workshop participants added sun exposure and cancer screening to this list. The 'psychosocial factors' box includes self-efficacy, sense of control, resilience, health literacy and social support.

The need for consistency in terminology, e.g. physical activity or inactivity, drug use or misuse, was considered. Consistency across various jurisdictions in defining risk factors was also discussed. The workshop considered it necessary to identify the risk factors for which the States/Territories and the Commonwealth were collecting information.

The workshop participants discussed the value of using the NHS as a vehicle for generating information on health-related behaviours. It was suggested that the NHS should have core components, with agreed definitions, and the jurisdictions could replicate these in their own CATI surveys with other components added to meet their specific data requirements. It was suggested that the 'minimum data set' for the NHS could be developed along the lines of the WHO STEPS approach. However, it was felt that while the NHS offers the advantages of consistency between jurisdictions and over time, the survey may not be held sufficiently frequently for some Commonwealth/State/Territory policy makers.

6.6   Utilisation and harmonisation of various types of data

The workshop began by identifying gaps in health data collections that affect their effective utilisation. It was agreed that:

- Lack of harmonised data collection seriously affects the pooling and synthesis of information from various data sources. In particular, cross-validation of data from different collections is difficult in the absence of objective measures and standard definitions. It was noted that measures in a collection are usually designed to 'fit a purpose', e.g. to report against certain indicators, rather than to generate consistent information.

- Inadequate identification and representation of certain population groups in health databases—such as Indigenous people, residents of nursing homes and other institutions, and the prison population—was also pointed out as a major gap in the chronic diseases and risk factors information base.

- Lack of suitable information about outpatient visits was identified as another major gap in the information base for chronic diseases and risk factors. The outpatient data sets require significant enhancement, in line with hospital inpatient data, which have steadily been improved over the past several years.

Other factors that limit the effective utilisation of existing data sets for chronic diseases and risk factors surveillance are lack of metadata (information about the data). The cost of ABS unit record files was seen as a significant barrier to accessing data.

Several steps were outlined to improve access to and harmonisation of various data collections:

- An audit of data sources, i.e. a national compilation and review, was considered an important first step towards the availability and harmonisation of various chronic disease-related data collections. An audit of the health survey data is being undertaken as part of the La Trobe Consortium feasibility study.

- Another important step would be to make data and information about the data (metadata) available on the web. To assist users, a directory of data sets, containing information about what data sets are available and where these are held, should be established on the web. The workshop participants noted that many CATI collections are currently listed on the Social Sciences Data Archive web site. Similarly, AIHW has data cubes and printed publications for several chronic diseases available on their web site free of charge, and the Commonwealth has distributed HealthWIZ as a Community Service Obligation product. The metadata should include up-to-date information on collection methodology, sample design, sample size, questions in the survey, editing procedures, response categories of data items, definitions of data items and scope of the collection.

- Linking of various data sets, as done in Western Australia, was considered to be another important step in better utilising the available data. The health research community would like the ABS and the AIHW to undertake record linking, in particular the linkage of NHS data with information available on health registers. The feasibility of record linkage between administrative data sets—such as morbidity, nursing homes and mortality collections and various registers (cancer and diabetes)—should also be investigated.

- Health risk factor information using objective measures, such as those proposed under the AHMS, is a priority. Validation of self-reported information using objective measures should also be considered.

- Standard question modules relating to specific health topics should be developed. This is currently underway, auspiced by the NPHP, under the leadership of the ABS and funded by the Commonwealth. A minimum set of data items could be embedded in various collections so that the concepts and definitions are consistent across various data sets.

- Further attention should be paid to the identification and representation of certain population groups in the chronic diseases and risk factor information base. Priority groups include Indigenous people, residents of nursing homes and other institutions, and the prison population.

- Generation of suitable information about outpatient visits should be given high priority.

The development of standard indicators and the harmonisation of future data collections for consistent reporting was also strongly emphasised.

7 Summation

7.1 Commonwealth perspective

Judy Straton, National Centre for Disease Control, Commonwealth Department of Health and Ageing

The workshop has been very interesting and useful, and the expertise of the participants has made this all possible. There is no doubt that we need national chronic disease and risk factor data, as a basis for developing our policies, committing funds for various programs and for evaluating these programs. These data would also be useful for international and inter-State/Territory comparisons. Indeed, we need both a national system and a national approach to health data, including CATI health survey data, in concert with national strategies for uniformity and harmonisation in data collections.

Partnerships and cooperation in this venture is essential. We are in the business of using data to improve the health of the nation, not to raise the profiles of the Commonwealth or the States/Territories. We therefore need to show leadership and move forward on a nationwide system.

7.2 State and NPHIWG perspective

Merran Smith, Co-Chair National Public Health Information Working Group and Western Australian Department of Health

The State and Territory data collections for chronic diseases are already in place and are of reasonably good quality. The ABS national surveys help to supplement these collections. There is strength in this diversity in data collections.

Over the years, strong links have been built between various committees, from AHMAC to the NPHP, then on to NHIMG, NPHIWG, and the CATI Technical Reference Group. A proper focus on chronic diseases should flow from interactions between these important structures, but it is important now to move on to the next step, a national health measurement survey.

7.3 Overall perspective

Vivian Lin, School of Public Health, La Trobe University

The five questions I posed at the beginning of the workshop are useful in summarising the workshop.

1. How many vehicles do we need?

The WHO STEPS approach has a useful framework that is simple and comprehensive in showing how behavioural, physical and biomedical measures interlink. There is potential for good alignment between CATI-based surveys and the AHMS through the NHS. Harmonisation processes are also underway for various collections. However, some large

surveys, such as those related to tobacco and drugs, have not been included and this needs to be considered in the process.

2.   Can we reconcile the various frameworks?

We have agreed that it is possible and acceptable to reconcile the NPHP's chronic disease prevention framework with the NHP Framework. What we lack most are the variables that constitute appropriate measures or indicators about the health system. This part of the framework requires further attention.

3.   Can we develop a 'leaderful' system?

We still seem to be debating the issue of leadership. In reality, the issues of collective leadership and agency leadership are not mutually exclusive. NPHIWG has an important role in terms of collective leadership for a nationwide system. The AIHW has an important role to play, particularly in relation to data warehousing, analysis and publication of comparative information. The States and Territories also play important roles in information development and analysis, including ensuring information is made relevant to policy and program development. They may also contribute to a range of information about small areas or special population groups, through the development of public health observatories. DoHA can play a leadership role in looking at appropriate investments across different information collection vehicles and in ensuring national strategies and surveillance systems are linked.

4.   Can we develop a partnership between producers and users?

This workshop has allowed for some conversation and engagement between some stakeholders who do not necessarily see each other at the same forums. We still need to progress stronger links between developers and users. We have seen models of liaison or brokerage positions, as well as active training of frontline personnel. These are good examples. We also need to start to disseminate information from the various CATI surveys on a national basis, so that users become aware of these activities and what information is available.

5.   What kind of investments should we make?

We have not addressed this issue very much, other than to share some collective frustration. Funding issues need to be addressed both at the State/Territory and national levels. Consideration needs to be given to the fixed cost of information infrastructure and to the marginal cost of additional information. We need to think about 'what is currently invested in surveys with single issues versus what the costs would be in continuous surveillance of a number of issues'. In the ideal world, dollars from Bill 1 might support the AHMS and dollars from Bill 2 might contribute to CATI systems. This would all present a neat picture, but not everyone must necessarily be signed on to do it. The Commonwealth can separately commission work, just as States and Territories (however many of them) may wish to pool their resources to pursue shared priorities.

Some of the key take home messages for the La Trobe Consortium's audit and feasibility study are:

- Keep it simple—it's better to get on with it and demonstrate the practical possibilities than to get bogged down agonising about the perfect data set.

- Any system should focus on the opportunities for interventions and the benefits of having multiple topics in any particular vehicle.

- The producers and users of information need to decide on how best to split topics, questions, and frequency across the various vehicles.

- We all need to get focused and disciplined—it is important to have a set cycle, comparable to the institutional information system, such that questions are finalised by a certain date in order to get them into the next collection. This way, comparable information will be obtained and the system will be able to progress.

7.4   Closing

Richard Madden, Director, Australian Institute of Health and Welfare and Co-Chair, National Public Health Information Working Group

This workshop has re-emphasised the importance of chronic disease surveillance. It is a major issue and Australia is not alone in this effort. Surveillance implies follow-up of the interventions to improve health outcomes. Prevention is important but it needs to be promoted alongside treatment and management of these diseases.

The existing health data (mortality, morbidity, disability etc.) are voluminous and have a lot of useful information, but are highly under-utilised. The challenge is how to use this resource intelligently, including ways to appropriately link the various data sets.

The NHP Framework is applicable for the surveillance of chronic diseases. It needs to be populated with existing data, at various levels, and useful sets of indicators based on the Framework need to be developed and disseminated.

Gaps in the existing data have dominated some of the conversations at the workshop, suggesting perhaps a lack of leadership in this area. However, a great deal of progress has been made by the States and Territories in the 3 years since these issues were raised at the NPHIWG workshop in Hobart. The report from the La Trobe Consortium should help move this area forward. The CATI surveys have also progressed, despite some 'rough spots', but much more development of these is possible.

There has been much frustration with the AHMS; the only progress on this front has been in getting more people to join in the frustration. The AHMS must go ahead, and it should be a part of the ABS program of regular national surveys (as in the USA, Canada and New Zealand) and not be an imposition on the health budget. We need to recognise a common purpose in this area and move this important issue forward.

Attachment A: Workshop program

Issues and priorities in the surveillance and monitoring of chronic diseases in Australia

Saville Park Suites
84 Northbourne Avenue, Canberra

Hosted by the Australian Institute of Health and Welfare and the Commonwealth Department of Health and Ageing

8–9 November, 2001

Day 1: Thursday, 8 November 2001

Time	Event
9:00 am	**Registration**
9:30 am	**Plenary 1** *Surveillance and monitoring of chronic diseases and associated risk factors* **Chair: Robert Griew, Commonwealth Department of Health and Ageing**
	Welcome and opening remarks *Richard Madden, Director, Australian Institute of Health and Welfare and Co-Chair, National Public Health Working Group* Surveillance across the continuum of care *Richard Smallwood, Chair, National Health Priorities Action Council* Chronic diseases and associated risk factors in Australia: an overview *Kuldeep Bhatia, Australian Institute of Health and Welfare* Strategic issues and options for chronic disease surveillance in Australia *Vivien Lin, School of Public Health, La Trobe University* Questions and discussion
10:40 am	**Morning tea**

Day 1: Thursday, 8 November 2001 (continued)

Time	Event
11:00 am	**Plenary 2** ***Surveillance and monitoring of chronic diseases: State/Territory perspectives*** **Chair: Judy Straton, Commonwealth Department of Health and Ageing**
	Chronic disease surveillance and monitoring in South Australia *Anne Taylor, Department of Human Services, South Australia* Applications of surveillance: a practical perspective from the Victorian Department of Human Services *Mike Ackland, Department of Human Services, Victoria* Information base for the surveillance of chronic diseases in New South Wales *Margo Eyeson-Annan, New South Wales Health* Questions and discussion
12:00 pm	**Short break**
12:10 pm	**Plenary 3** ***Surveillance and monitoring of chronic diseases: other perspectives*** **Chair: Paul Magnus, Australian Institute of Health and Welfare**
	Chronic diseases: a Commonwealth perspective *Colin Sindall, Commonwealth Department of Health and Ageing* Chronic disease surveillance and monitoring: the non-government organisations' perspective *Andrew Tonkin, National Vascular Disease Prevention Partnership* Perspectives of the users and producers of chronic disease data *Hal Swerissen, School of Public Health, La Trobe University* Questions and discussion
1:10 pm	**Lunch**
2:10 pm	**Workshops (concurrent)** ***Effective surveillance and monitoring of chronic diseases***

	Workshop 1:	Workshop 2:	Workshop 3:
	An information framework for surveillance and monitoring of chronic diseases	Regional and local area issues versus national monitoring	Linking chronic diseases surveillance and monitoring to public health interventions and policy development
	Facilitator: Geoff Sims AIHW	Facilitator: Kuldeep Bhatia AIHW	Facilitator: Mike Ackland DHS, Victoria

Time	Event
3:30 pm	**Afternoon tea**
4:00 pm	Report back from workshop facilitators Chair: Merran Smith, Co-Chair, National Public Health Information Working Group

5:00 pm	Close

7:00 pm	**Workshop dinner**
	The Republic, 20 Allara Street, Canberra
	Guest speaker: Tony McMichael, National Centre for Epidemiology and Population Health, Australian National University

Day 2: Friday, 9 November 2001

Time	Event
8:45 am	**Plenary 4** *Measurement issues in the surveillance and monitoring of chronic diseases* **Chair: Paul Jelfs, Australian Institute of Health and Welfare**
	The WHO STEPS approach *Terry Dwyer, Menzies Centre for Population Health Research, Hobart* Australian Health Measurement Survey *Jeanette Pope, Population Health Information Development Unit, University of Adelaide* The National Health Survey *Marelle Rawson, Australian Bureau of Statistics* CATI surveys *Mark Cooper-Stanbury, Australian Institute of Health and Welfare*
10:00 am	**Morning tea**
10:15 am	**Workshops (concurrent)** *Data development issues and priorities*

	Workshop 4: Biomedical risk factors and markers Facilitator: Stan Bennett AIHW	**Workshop 5:** Behavioural risk factors and other psychosocial variables Facilitator: Margo Eyeson-Annan NSW Health	**Workshop 6:** Utilisation and harmonisation of various types of data Facilitator: Alan Mackay ABS

11:30 am	Report back from workshop facilitators and panel discussion: Where to from here? Chair: Cathy Mead, National Public Health Partnership Secretariat
12:45 pm	Summation and close of the workshop Richard Madden, Director, Australian Institute of Health and Welfare and Co-Chair, National Public Health Information Working Group
1:00 pm	**Lunch**

Attachment B: List of participants

Dr Mike Ackland   Epidemiology Unit, Department of Human Services, Victoria

Dr Fadwa Al-Yaman   Children Youth and Families Unit,
Australian Institute of Health and Welfare

Mr Jason Armfield   Dental Statistics Research Unit, University of Adelaide

Dr Tim Armstrong   Cardiovascular Disease and Diabetes Monitoring Unit,
Australian Institute of Health and Welfare

Dr Katrine Baghurst   Health Science Nutrition, CSIRO, Adelaide

Dr Stan Bennett   Cardiovascular Disease and Diabetes Monitoring Unit,
Australian Institute of Health and Welfare

Dr Kuldeep Bhatia   Health Monitoring and Development Unit,
Australian Institute of Health and Welfare

Professor Helena Britt   Family Medicine Research Centre, University of Sydney

Dr Magnolia Cardona   Queensland Health

Ms Ingrid Coles-Rutishauser   Australian Food and Nutrition Monitoring Unit

Mr Mark Cooper-Stanbury   Population Health Data and Information Services Unit,
Australian Institute of Health and Welfare

Ms Jean Douglass   Population Health Division,
Commonwealth Department of Health and Ageing

Dr Terry Dwyer   Menzies Centre for Population Health Research,
University of Tasmania

Dr Joy Eshpeter   Population Health Division,
Commonwealth Department of Health and Ageing

Ms Margo Eyeson-Annan   Epidemiology and Surveillance Branch, NSW Health

Ms Susan Garner   Health Priorities and Quality Branch,
Commonwealth Department of Health and Ageing

Dr John Glover   Public Health Information Development Unit,
University of Adelaide

Mr Robert Griew   Head, Population Health Division,
Commonwealth Department of Health and Ageing

Mr Steve Guthridge   Territory Health Services, Northern Territory

Mr John Harding   Health Registers and Cancer Monitoring Unit,
Australian Institute of Health and Welfare

Dr Alison Heywood   AusAID

Professor Ian Hickie   Beyond Blue—The National Depression Initiative

Ms Rosie Hippel   Health Advancement Division,
Department of Health and Human Services, Tasmania

Dr Paul Jelfs   Population Health Unit, Australian Institute of Health and Welfare

Dr Wilawan Kanjanapan	Population Health Division, Commonwealth Department of Health and Ageing
Dr Chris Kelman	Portfolio Strategies Division, Commonwealth Department of Health and Ageing
Dr Amanda Lee	SIGNAL (Strategic Inter-Governmental Nutrition Alliance)
Professor Vivian Lin	School of Public Health, La Trobe University
Mr Stephen McDonald	Australia and New Zealand Dialysis and Transplant Registry
Professor Tony McMichael	National Centre for Epidemiology and Population Health, Australian National University
Mr Alan Mackay	Australian Bureau of Statistics
Dr Richard Madden	Director, Australian Institute of Health and Welfare
Ms Ros Madden	Disability Services Unit, Australian Institute of Health and Welfare
Dr Paul Magnus	Medical Advisor, Australian Institute of Health and Welfare
Dr Guy Marks	Institute of Respiratory Medicine, Sydney
Dr Cathy Mead	National Public Health Partnership Group Secretariat
Dr Paul Meyer	Health Monitoring and Development Unit, Australian Institute of Health and Welfare
Dr Graeme Miller	Family Medicine Research Centre, University of Sydney
Ms Jeanette Pope	Public Health Information Development Unit, University of Adelaide
Ms Marelle Rawson	Health Section, Australian Bureau of Statistics
Ms Sally Rubenach	Clinical Outcomes and Epidemiology Centre, The Canberra Hospital
Ms Renata Rustowski	Commonwealth Department of Health and Ageing
Mr Geoff Sims	Health Division, Australian Institute of Health and Welfare
Mr Colin Sindall	Commonwealth Department of Health and Ageing
Professor Richard Smallwood	Chief Medical Officer, Department of Health and Ageing
Dr Merran Smith	Department of Health, Western Australia
Mr Andrew Stanley	Department of Human Services, South Australia
Dr Judy Straton	Commonwealth Department of Health and Ageing
Dr Hal Swerissen	Australian Institute for Primary Care, La Trobe University
Ms Nicola Tatham	Health Monitoring and Development Unit, Australian Institute of Health and Welfare
Dr Anne Taylor	Department of Human Services, South Australia
Ms Margaret Thomas	NSW Health
Professor Andrew Tonkin	National Heart Foundation of Australia
Dr Gavin Turrell	Queensland University of Technology
Ms Kim Walker	Mental Health Branch, Commonwealth Department of Health and Ageing

Ms Victoria White   National Tobacco Strategy, Anti-Cancer Council of Victoria
Dr Xingyan Wen   Disability Services Unit, Australian Institute of Health and Welfare

Attachment C: Background papers for small group workshops

Workshop 1: An information framework for surveillance and monitoring of chronic diseases

Facilitator: Geoff Sims, Australian Institute of Health and Welfare

Background

Presentations in Plenary 1 and the NHP Framework will provide background and form the basis for discussion at this workshop.

Rationale

Information frameworks provide structure and guidance for the development, implementation and utilisation of health information. They inform, enable consistency and comparability, and guide the interpretation and dissemination of information linked to public health programs and strategies.

The NHP Framework (Figure 1.1), was endorsed by the Australian Health Ministers Advisory Council (AHMAC) in August 2001. The NHP Framework has been proposed as the basis for surveillance and monitoring of chronic diseases and associated risk factors in Australia, although other frameworks have been developed and may also be appropriate.

An adaptation of the NHP Framework for surveillance and monitoring of chronic diseases and risk factors has been proposed (Figure 1.2). Two other dimensions of chronic diseases need to be considered in adapting the NHP Framework:

- chronic diseases across various stages of the lifecycle, and
- surveillance and monitoring at regional/local area levels.

Focus

> Input on various components of the framework in the context of chronic diseases and associated risk factors surveillance and monitoring.

Focus questions

1. Does the NHP Framework broadly meet the requirements for nationwide monitoring of chronic diseases and associated risk factors?

2. Are there aspects of chronic disease information that are not covered by the Framework and should be introduced?

3. Are there components of the Framework which should receive additional emphasis for information development?

4. Figure 1.2 shows that the La Trobe Consortium has concentrated on the first two tiers of the NHP Framework (health status and outcomes; determinants of health). How appropriate has this been? What about the third tier (health system performance)?

5. What is the applicability of this Framework to strategies for prevention of chronic diseases and associated risk factors and provision of relevant services and care?

Figure 1.1: The NHP Framework

Health Status and Outcomes **How healthy are Australians? Is it the same for everyone? Where is the most opportunity for improvement?**			
Health Conditions	**Human Function**	**Life Expectancy and Wellbeing**	**Deaths**
Prevalence of disease, disorder, injury or trauma or other health-related states.	Alterations to body, structure or function (impairment), activities (activity limitation) and participation (restrictions in participation).	Broad measures of physical, mental, and social wellbeing of individuals and other derived indicators such as Disability Adjusted Life Expectancy (DALE).	Age and/or condition specific mortality rates.

Determinants of Health **Are the factors determining health changing for the better? Is it the same for everyone? Where and for whom are they changing?**				
Environmental Factors	**Socioeconomic Factors**	**Community Capacity**	**Health Behaviours**	**Person-related Factors**
Physical, chemical and biological factors such as air, water, food and soil quality resulting from chemical pollution and waste disposal.	Socioeconomic factors such as education, employment, per capita expenditure on health, and average weekly earnings.	Characteristics of communities and families such as population density, age distribution, health literacy, housing, community support services and transport	Attitudes, beliefs knowledge and behaviours, e.g. patterns of eating, physical activity, excess alcohol consumption and smoking.	Genetic related susceptibility to disease and other factors such as blood pressure, cholesterol levels and body weight.

Health System Performance **How well is the health system performing in delivering quality health actions to improve the health of all Australians? Is it the same for everyone?**		
Effective	**Appropriate**	**Efficient**
Care, intervention or action achieves desired outcome.	Care/intervention/action provided is relevant to the client's needs and based on established standards.	Achieving results with most cost effective use of resources.
Responsive	**Accessible**	**Safe**
Service provides respect for persons and is client orientated, and includes respect for dignity, confidentiality, participation in choices, promptness, quality of amenities, access to social support networks, and choice of provider.	Ability of people to obtain health care at the right place and right time irrespective of income, physical location and cultural background.	The avoidance of or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered.
Continuous	**Capable**	**Sustainable**
Ability to provide uninterrupted, coordinated care or service across programs, practitioners, organisations and levels over time.	An individual's or service's capacity to provide a health service based on skills and knowledge.	System or organisation's capacity to provide infrastructure such as workforce, facilities and equipment, and be innovative and respond to emerging needs (research, monitoring).

Figure 1.2: The NHP Framework, as adapted by the La Trobe Consortium, for chronic disease monitoring

HEALTH STATUS AND OUTCOMES How healthy are Australians? Is it the same for everyone? Where is the most opportunity for improvement?				
Health Conditions	Biological Conditions	Human Function	Life Expectancy and Wellbeing	Deaths
Ischaemic heart disease, Stroke, Certain cancers† Mental health problems/ Depression*, Musculoskeletal disorders (falls)†, Oral health conditions* Type 2 Diabetes Mellitus Renal disease†, Chronic lung disease (COPD and asthma)	Obesity*, Underweight* Hypertension*, Dyslipidaemia* Impaired Glucose Tolerance*, Insulin resistance*, Elevated HbA1c*, Proteinuria* Urinary tract infections* Infections*	Disability days Reduction of function Activity limitation Restriction in participation Deteriorating strength, reflexes, balance & vision	Self-rated health	

DETERMINANTS OF HEALTH Are the factors determining health changing for the better?				
Early Life Factors	Health Behaviours	Community Capacity	Environmental Factors	Socioeconomic Factors
Low birth weight, Low breast feeding rate Intrauterine growth retardation, Poor early childhood development Abuse, neglect & exposure to domestic violence **Person-related Factors**	Tobacco exposure: — smoking — passive Risky alcohol intake Physical inactivity Exercise (asthma) Diet supplements (musculoskeletal disorders) Food chemicals Analgesic use Substance use Medications Preventative dental behaviours	Characteristics of communities & families such as: Housing quality, Community services e.g. support, transport etc. Literacy level Health literacy **Psychosocial Factors** Psychosocial stress (life stress) e.g. arising from interpersonal violence, discrimination, etc (cortisol) Support & relationships — Low social capital — Low social support Low resilience	Natural environment — Exposure to allergens — Exposure to sunlight Products & technology — Exposure to pollution — Hazardous environs — Lack of exposure to fluorides	Education, Income, Economic capacity, Wealth, Poverty, Ownership of resources Housing, Area of residence, Occupation including employment status, relations & conditions Parents' occupation at time of birth Food security systems, e.g. taxation, social welfare policies

HEALTH SYSTEM PERFORMANCEξ How well is the health system performing in delivering quality health actions to improve the health of Australians?		
Effective	Appropriate	Efficient
Responsive	Accessible	Safe
	Accessibility to treatments for each of the health conditions above; Accessibility to prevention programs	
Continuous	Capable	Sustainable
Contact with health system and disease management Contact with health system (inc primary care): Early Detection & Screening; Use of complementary medicine; Clinical management; Management of complications; and, Self management		

* also considered risk factors; † requires further specification; ξ health system performance factors are being considered here only as risk factors for chronic disease.

Workshop 2: Regional and local area issues versus national monitoring

Facilitator: Kuldeep Bhatia, Australian Institute of Health and Welfare

Background

Presentations in Plenary 2.

Rationale

Small area differences in health outcomes constitute an important indicator of both underlying heterogeneity in the distribution of risk factors and possible variations in their prevention and management. Surveillance and monitoring of chronic diseases and risk factors at a small area level is therefore likely to prove extremely useful for tailoring public health prevention strategies and provision of health services.

However, because of small population numbers and low event occurrence—the increasing number and sophistication of health-related data collection and analysis notwithstanding—the interpretation of much health statistics information at levels below State/Territory jurisdiction remains difficult. Synthetic approaches of demography and epidemiology can be used to generate estimates of small area mortality, morbidity and disability, and then applied for estimating attributable fractions for various risk factors. However, these procedures often mean probabilistic assumptions that may make the results redundant or difficult to interpret.

The issue of suitable data collections at a small population level for chronic disease surveillance and monitoring therefore requires careful consideration, in particular because risk factor information (the centrepiece of chronic disease surveillance and monitoring) may at best be obtained indirectly.

Focus

    Recommendations to progress information development for chronic diseases.

Focus questions

1. What are the specific data and information requirements for surveillance and monitoring of chronic diseases and associated risk factors at various levels?

2. What are the important issues at local, jurisdictional and nationwide levels?

3. What aspects of chronic diseases and risk factors should be monitored at the national level, and what should be monitored at state/territory or local area level?

4. How are data collections at various levels to be managed?

Workshop 3: Linking chronic diseases surveillance and monitoring to public health interventions and policy development

Facilitator: Mike Ackland, Department of Human Services, Victoria

Background

The presentation in Plenary 1 by Vivian Lin, 'Strategic issues and options for chronic disease surveillance in Australia'.

Rationale

The development and persistence of chronic diseases is often a lifelong process that requires a range of prevention strategies and management. Any public health intervention and policy development therefore must address all risk factors and disease points through the course of life. The surveillance and monitoring of chronic diseases and risk factors must also occur accordingly.

An important strategy in linking surveillance and monitoring with public health interventions and strategies is the identification of critical stages for intervention and suitable information to support and evaluate these interventions across the continuum of care. Another issue in this context is the regularity with which the information should be collected for input to policy development.

Focus

Recommendations as to the means for linking surveillance and monitoring information with public health interventions and policy development.

Focus questions

1. How can surveillance and monitoring of various stages of chronic disease development and management facilitate public health interventions and policies?

2. How can chronic disease information be used for program and process evaluation?

3. How can risk factor information be effectively linked to health outcomes?

4. How can routinely collected information be used for coordination of care?

Workshop 4: Biomedical risk factors and markers

Facilitator: Stan Bennett, Australian Institute of Health and Welfare

Background

Presentations in Plenary 4.

Rationale

A variety of biomedical risk factors have been identified as important pathological and pathophysiological steps in the development and manifestation of chronic diseases (see Tables 4.1 and 4.2). Given that they represent bodily disturbance, these factors can often be more closely and precisely linked to the point of disease and its various complications; but there is no one-to-one correspondence between most of the known biomedical risk factors and disease outcomes. Many of these are no more than mere biomarkers of the impending problem.

Due to this lack of correspondence and the high costs associated with collecting laboratory-based information at a population level, biomedical information on chronic diseases is scanty and many years out of date. There are virtually no reliable national data sets on a whole range of biomedical risk factors. The state of this aspect of health information is inadequate in comparison with developments and collections in other western countries.

Recent developments in molecular genetic and immunological sciences have opened up opportunities for generating information on a range of biomarkers that may be linked to many of the pathophysiological steps leading up to chronic diseases. An added advantage is that a large variety of biomedical risk factors and markers can be easily studied through a small blood sample. Another source of biomedical information that can be tapped into is data from pathology labs.

Ethical and operational issues associated with collecting biomedical information, and storage of blood samples for tests later as the technology develops, require careful attention. Privacy issues in relation to any genetics-based markers also need to be considered.

Focus

> Input into the progression of biomedical risk factor data development for effective surveillance and monitoring of chronic diseases.

Focus questions

1. Which biomedical risk factors have the highest priority for inclusion in a surveillance and monitoring system for chronic diseases?

2. How often do we require biomedical risk factor data collection for effective chronic disease surveillance and monitoring?

Table 4.1: Biomedical risk factors and markers proposed in the Australian Health Measurement Survey (AHMS)

Measurement	Relevant chronic disease[1]
Physical measurement	
Blood pressure	CHD, stroke, diabetes complications, renal disease
Height	CHD, stroke, diabetes
Weight	CHD, stroke, diabetes, colorectal cancer, musculoskeletal diseases
Abdominal circumference	CHD, diabetes
Upper arm circumference	CHD
Blood measurement	
Total cholesterol	CHD, stroke, diabetes complications
HDL cholesterol	CHD, stroke, diabetes complications
LDL cholesterol	CHD, stroke, diabetes complications
Triglycerides	CHD, stroke, diabetes complications
C-reactive protein	Nutrition
Homocysteine	CHD, stroke (linked with atherosclerosis & clot formation)
Glucose	Diabetes (prevalence of glycemia)
Oral glucose tolerance test	Diabetes (diagnosis of)
Glycosylated haemoglobin (HbA1c)	Diabetes (indicator of glycemic control/diabetes, marker of diabetes risk)
Insulin	Diabetes (marker for insulin levels)
Creatinine	Diabetes, renal disease (indicates kidney function)
Red cell folate	CHD, stroke (marker of dietary folate inc. supplements)
Carotenoids	CHD, colorectal cancer (antioxidant status indicators—markers of fruit and vegetable intake)
Urine measurement	
Albumin/creatinine ratio	Diabetes, renal disease (indicates kidney function)
Saliva	
Cotinine	Lung cancer, chronic lung disease (marker of recent tobacco exposure, validates self-reported data)
Cortisol	Mental health (marker of psychosocial stress)
Possible blood measurement	
Apolipoprotien A1	CHD (major protein component of HDL)
Apolipoprotein B	CHD (major component of LDL)
Omega-3 fatty acids	CHD, diabetes, COPD

[1]CHD, stroke, colorectal cancer, lung cancer, mental health (depression), musculoskeletal, oral health, Type 2 diabetes, renal disease, and chronic lung disease (COPD, asthma).

3. Are the current cut-offs for determining high or low levels of various biomedical risk factors appropriate for surveillance and monitoring of chronic diseases in Australia? For example, are the cut-off points for high blood pressure and high blood cholesterol appropriate to chronic disease monitoring?

4. Is it appropriate to utilise suitable biological markers in the absence of clear-cut risk factor information?

Table 4.2: Biomedical risk factors and markers used in AusDiab

Measurement	Relevant chronic disease
Physical measurement	
Blood pressure	CHD, stroke, diabetes complications, renal disease
Pulse rate	(Heart failure, PVD, arrhythmia)
Electrocardiogram	CHD, arrhythmia, cardiomyopathy
Height	CHD, stroke, diabetes
Weight	CHD, stroke, diabetes
Abdominal circumference	CHD, diabetes
Hip circumference	CHD
Body fat	CHD
Blood measurement	
Total cholesterol	CHD, stroke, diabetes complications
LDL cholesterol	CHD, stroke, diabetes complications
HDL cholesterol	CHD, stroke, diabetes complications
Triglycerides	CHD, stroke, diabetes complications
Fibrinogen	Stroke (haemorrhagic)
Glucose	Diabetes
Oral glucose tolerance test	Diabetes (for diagnosis)
Glycosylated haemoglobin (HbA1c)	Diabetes
Insulin	Diabetes
Creatinine	Diabetes, renal disease
Urine measurement	
Microalbumin/creatinine ratio	Diabetes, renal disease
Haematuria	Renal disease, renal cancer

Workshop 5: Behavioural risk factors and other psychosocial variables

Facilitator: Margo Eyeson-Annan, New South Wales Health

Background

Presentations in Plenary 4.

Rationale

Chronic diseases are mostly the product of multifactorial, multi-step pathophysiological changes, embedded in a behavioural and psychosocial environmental milieu. Strategies aimed at reducing the impact of chronic diseases therefore need to operate at all levels of disease development including its antecedents.

In 1982, the Institute of Medicine of the U.S. National Academy of Sciences released a report suggesting that individual behaviours—such as cigarette smoking, diet and exercise—may be associated with at least 50% of all chronic illness. The Australian Burden of Disease and Injury Project has also attributed a large proportion of disability-adjusted life years to the behavioural risk factors. These numbers clearly indicate that surveillance of behavioural risk factors should be a central plank in the surveillance and monitoring of chronic diseases.

Focus

Input into the progression of behavioural risk factor data development for effective surveillance and monitoring of chronic diseases.

Focus questions

1. Which behavioural risk factors and psychosocial variables have the highest priority for inclusion in a surveillance and monitoring system for chronic diseases?

2. What is the current status of behavioural risk factor data in relation to chronic diseases at national and state/territory levels?

3. Are there any gaps or deficiencies in collecting data on behavioural risk factors and other psychosocial variables?

Workshop 6: Utilisation and harmonisation of various types of data

Facilitator: Alan MacKay, Australian Bureau of Statistics

Background

As chronic disease surveillance and monitoring typically relies on systems designed for some other purpose, the ability to effectively combine data from a variety of sources and levels ('harmonisation') is critical.

Presentations on the WHO STEPS approach to chronic diseases and associated risk factors monitoring, the AHMS, the NHS and CATI surveys set the scene for this workshop.

The harmonisation and discussion papers (provided as background material) produced by the La Trobe Consortium are also relevant for this workshop.

Rationale

A variety of methods are being used to collect behavioural (face-to-face interviews, CATI) and biomedical (health measurement; self-reports; clinical) risk factor information relevant to a range of chronic diseases. The collections are occurring at all levels, both jurisdictional and at specific population levels. Information is also being collected on various disease outcomes (both administrative and non-administrative), although it is not consistent across the continuum of care and disease severity. While most of the information being collected remains under-utilised, information on certain risk factors is being collected with some regularity. In contrast, information on a variety of important biomedical factors is woefully inadequate at both national and jurisdictional levels. It is therefore important to develop a strategy to justify the future collections in an efficient and cost-effective manner. It is also important to tag the collections in a complementary manner so as to allow integration of information at all levels, where possible through record linkage. There is also the need to extract best information from existing collections.

Focus

Utilising and harmonising data from various sources in the most effective and efficient manner.

Focus questions

1. What factors increase a data collection's quality and acceptability to users?
2. What factors increase a data collection's accessibility?
3. How can the useability of data collections be optimised?
4. What are the advantages of integrating administrative and non-administrative data?
5. What would be the most efficient means of integrating data from various sources?
6. How can comparability between data collections be achieved, both over time and between data sources?