

BLUEPRINT FOR CHRONIC DISEASE SURVEILLANCE



Australian Health Ministers' Conference

Blueprint for nation-wide
surveillance of chronic
diseases and associated
determinants

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Contents

| | |
|--|-----------|
| Summary | 1 |
| 1. Introduction | 3 |
| Goal, objectives and principles | 3 |
| Context | 3 |
| Scope | 4 |
| Mandate | 4 |
| Rationale | 5 |
| 2. System-based surveillance | 9 |
| Agreed definition and scope | 9 |
| Governance | 10 |
| Tools for organising information and setting priorities for surveillance | 10 |
| <i>Figure 2.1: Summary of the National Health Performance Framework (NHPF)</i> | 10 |
| An Australian tool to support improved priority setting policies | 11 |
| <i>Figure 2.2: An Australian Priority Setting Tool</i> | 11 |
| Harmonisation | 12 |
| Data management | 13 |
| A chronic disease surveillance network | 13 |
| Capacity and resources | 14 |
| 3. Action plan | 15 |
| <i>Action 1: Chronic Disease Surveillance Network</i> | 15 |
| <i>Action 2: Reporting on existing data</i> | 16 |
| <i>Action 3: Agreed national policy-relevant indicators</i> | 17 |
| <i>Action 4: Capacity building</i> | 17 |
| Appendix 1: A hypothetical example | 19 |
| Appendix 2: Working Group and consultations | 21 |
| References | 22 |

Summary

Chronic diseases now make up the major proportion of the total burden of disease and injury in Australia. Many of these conditions are amenable to preventive measures. However, effective action to prevent and control disease is dependent on timely access to accurate and reliable information, both to inform where resources should best be targeted, and to monitor and evaluate the impact of the actions taken.

This document is a Blueprint for the establishment of a surveillance system for Australia to improve the quality, access and availability of information for chronic disease prevention. As such, it provides the basis for delivering the information needed for effective action under the National Chronic Disease Strategy, such as changing patterns of dietary behaviours and physical activity among different population groups, and ensures that we are alert to opportunities for intervention.

The Blueprint sets out the essential elements of a national surveillance system (Chapter 2), describes an Australian Priority Setting Tool for agreeing information priorities and methods, and proposes immediate actions to establish the system.

It is recognised that many of the components needed for the surveillance of chronic diseases and associated determinants are already in place and working effectively. For example, most states and territories conduct regular population health surveys, and have high quality analytic capacity. At a national level, valuable information on the prevalence and trends in chronic diseases and their associated determinants are provided by the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW), and through a variety of publications and reporting processes. The ABS conducts large household surveys to monitor aspects of health and disability in the population.

However, significant gaps remain, and it is widely agreed that outcomes can be improved by building on, harmonising and complementing existing activities. Bringing all the various elements together as part of a collaborative and coordinated nation-wide information system—as proposed under the Blueprint—will improve consistency, reduce duplication of effort and enhance efficient use of existing data. Ensuring ‘value-for-money’ in data collection and reporting for chronic disease prevention will be an important outcome, along with enhanced capacity for planning and evaluation.

The objectives of the Blueprint are to:

- improve the immediate and ongoing availability of surveillance and monitoring information for chronic disease prevention; and
- develop effective mechanisms which enable surveillance and monitoring information to contribute to improved development of policy and interventions for chronic disease prevention.

This Blueprint advocates the need for:

1. governance of the surveillance system;
2. a tool for organising information and prioritising indicators and data collections, within a policy context;
3. a harmonised approach to all aspects of data development;
4. establishment of a national Chronic Disease Surveillance (CDS) Network that will develop and implement a data management work plan;
5. capacity and resources, incorporating workforce development and mechanisms to ensure sustainability of agreed priority data collections; and
6. all elements to be sustained over the long term.

The Blueprint is a response to, and is consistent with, a number of policy frameworks, including:

- The National Health Information Agreement (NHIA) 2004–2009;
- The National Public Health Information Plan 2003–2006 project to “Develop a Nation-wide Chronic Diseases Monitoring and Surveillance Strategy and Action Plan (CDSS) to improve information necessary to plan, inform and evaluate Public Health action reducing the burden of chronic disease”;
- The agreement by the Australian Health Ministers’ Conference of July 2003 to develop a National Chronic Disease Strategy (NCDS). The Blueprint can be seen as a companion surveillance strategy to support this initiative; and
- Australia’s international obligations to provide surveillance data (e.g. to the World Health Organization); the Blueprint will improve capacity to provide these data.

This Blueprint concludes in Chapter 3 with an Action Plan that is needed to establish this surveillance system. The key initial actions are highlighted in the box below.

While the Blueprint builds on existing capacity and infrastructure, additional investment and funding opportunities may arise for the delivery of priorities resulting from implementation of the Action Plan.

In summary, this surveillance system will be put into practice through a national network of participating stakeholders, namely the CDS Network. This CDS Network will be responsible to, and will be overseen by, the National Public Health Information Working Group for the coordination of monitoring and surveillance data on chronic diseases and the determinants of chronic disease.

ACTION ITEMS

Action 1: Chronic Disease Surveillance (CDS) Network

Establish a national network to develop and support the ongoing collection, analysis and dissemination of nation-wide surveillance and monitoring data for chronic diseases and associated determinants.

Action 2: Reporting on existing data

Publish a combined report on chronic diseases and their determinants utilising currently available data from state and territory population health surveys, national health surveys and other sources.

Action 3: Agreed national policy relevant indicators

Develop an agreed prioritised set of national policy relevant indicators for chronic diseases and associated determinants. These indicators will be drawn from existing indicators and based on the Australian Priority Setting Tool for chronic disease surveillance proposed in this Blueprint.

Action 4: Capacity building

Build on current capacity by continuing the development of nation-wide standards for health surveillance as well as fostering an adequate and sustainable workforce able to contribute to and benefit from the surveillance system. This includes the sharing of skills and knowledge, as well as the sharing of infrastructure.

1. Introduction

This document outlines a proposal for building a systematic approach to improving information management and increasing access to key data elements for the surveillance of chronic diseases and associated determinants of health in Australia. It sets out the essential elements of a national surveillance system, describes a tool for agreeing priorities and methods, and proposes a set of actions that will establish the surveillance system.

The Blueprint acknowledges that most of the system elements are in place and are reported to be working effectively, but that the surveillance outcomes can be improved by building on, harmonising and complementing existing activities and relationships.

GOAL, OBJECTIVES AND PRINCIPLES

The goal of the *Blueprint for Nation-wide surveillance of chronic diseases and associated determinants* is to establish a system for local and national public health surveillance of preventable chronic diseases and the determinants of chronic diseases. The objectives are to:

- improve the immediate and ongoing availability of surveillance and monitoring information for chronic disease prevention; and
- develop effective mechanisms which enable surveillance and monitoring information to contribute to improved development of policy and interventions for chronic disease prevention.

All actions undertaken under the Blueprint (see Action Plan) will be designed to put into practice the following principles:

- support a population health approach;
- inform action to address health inequalities and the needs of priority populations;
- facilitate a 'clustered' approach to prevention, through recognition of the common determinants and processes that underlie chronic diseases;
- use a consensus approach based on collaboration and coordination, and recognise and build on existing work by the National Public Health Partnership (NPHP), the National Health Priority Action Council (NHPAC), the Australian Institute of Health and Welfare (AIHW), the Australian Bureau of Statistics (ABS), jurisdictions and non-government agencies;
- improve the scope and quality of national and regional information, while enabling local flexibility; and
- provide information that has direct relevance to action to prevent and control chronic diseases.

CONTEXT

The surveillance system proposed is based on a model of the continuum of care, as identified as one of the key elements of the National Chronic Disease Strategy. It focuses on preventable chronic disease and associated determinants, which include both well understood behavioural, biological and environmental risk/protective factors as well as 'upstream' factors such as socio-economic position.

In line with the NPHP's forward planning priorities, the chronic disease surveillance system will complement existing and developing surveillance systems for communicable

diseases and environmental health. It will utilise existing infrastructure, data collections and systems throughout Australia and will promote a systematic, criterion-based approach to identification of critical gaps in available data.

BOX 1.1 Context for the Blueprint

Available:

ABS National Health Survey (since 1977/78, now three-yearly)
National Nutrition Survey 1995
AIHW National Drug Strategy Household Survey (since 1985)
National Physical Activity Survey (1997, 1999 and 2000)
States & territories CATI¹ based population health surveys (from 1990)
NHFA² Risk Factor Prevalence Study (1980, 1983 and 1989) and AusDiab (2000).

Gaps include:

- Population trend data on diet, nutrition and physical activity
- Physical and biomedical measurement information.

What the Blueprint does:

- Builds on existing infrastructure and data collections
- Defines a systematic approach to nation-wide surveillance.

SCOPE

The Blueprint responds to the need to improve available information on chronic diseases related to the continuum of care, but has a key focus on public health aspects. It concerns itself mainly with information relating to prevention, early detection and trends in key population health indicators, all of which fall within the purview of public health activity. It embraces the concept of determinants of chronic disease.

The Blueprint will build and enhance the evidence base for public health policy and program development.

MANDATE

The mandate for a co-ordinated, efficient and effective surveillance system arises from a number of bases. First, the National Health Information Agreement (NHIA) 2004–2009 has as three of its principal objectives to:

- promote the collection, compilation, analysis and dissemination of relevant, timely, accurate and reliable health information concerned with health status and risks in accordance with nationally agreed protocols and standards;
- develop and agree on projects to improve, maintain and share national health information; and
- cooperate in the provision of resources necessary to address national health information development priorities efficiently and effectively.

1 Computer Assisted Telephone Interviewing

2 National Heart Foundation of Australia

This document responds to these principles and embodies the spirit of the Agreement.

Second, the National Public Health Partnership Group (NPHPG) has endorsed work on developing a chronic diseases surveillance strategy and action plan. Accordingly, the National Public Health Information Plan 2003–2006 includes a project to “Develop a Nation-wide Chronic Diseases Monitoring and Surveillance Strategy (CDSS) and Action Plan to improve information necessary to plan, inform and evaluate Public Health action reducing the burden of chronic disease”. This Blueprint is the implementation of this project.

Third, in recognition of the need for the health system to respond in a consistent and practical way to address the burden due to chronic diseases, the Australian Health Ministers’ Conference of July 2003 agreed to the development of a National Chronic Disease Strategy (NCDS). A companion surveillance strategy—this Blueprint—will be critical to providing the ongoing information base that will enable tracking of the Strategy’s outcomes, and will assist in improving data on health system performance related to chronic disease interventions.

Fourth, Australia regularly needs to respond to international requests for surveillance data (e.g. to the World Health Organization); and these needs are not adequately met by current arrangements. This plan will improve the nation’s capacity to provide these data.

And finally, given that the majority of public health activity is managed in the government sector, it is simply good stewardship of public money to make the best use of limited resources. This Blueprint is underpinned by a ‘value-for-money’ imperative.

RATIONALE

BOX 1.2 Rationale for the Blueprint at a glance

Why is a surveillance system needed?

Significant resources are being committed to chronic disease prevention programs with only a limited evidence-base that is being informed by a range of disparate health data collections at both the Federal and State levels. This places serious limits on our capacity to target and track the impact of these investments. Current practice is neither sustainable nor efficient, and an alternative approach is required.

What difference will this Blueprint make?

Implementation of this Blueprint will contribute to improving public health outcomes. The Blueprint outlines how systematic delivery of effective chronic disease surveillance measures, based on better use of existing capacity and resources, can improve the evidence-base to inform Australia’s response to the growing burden of chronic diseases. The quality, accessibility and utility of data for timely, ongoing nation-wide indicator reporting on chronic diseases will improve.

The importance of chronic diseases and their associated determinants

Chronic diseases³ are among the most prevalent, costly and preventable of all health problems (NPHP, 2001); the prevention and management of chronic disease is considered one of the most significant challenges facing organised health care systems.

3 Chronic diseases are usually characterised by complex causality, multiple risk/protective factors, a long latency period, a prolonged course of illness, functional impairment or disability, and, in many cases, the unlikelihood of cure (NPHP, 2001).

Around 70% of the total burden of illness and injury currently experienced by Australians is due to chronic diseases, and this is expected to increase to 80% by 2020 (NPHP, 2001). In 2001, 52% of Australians reported at least one long-term condition within the group of National Health Priority Areas (AIHW 2004); seven in 10 general practice attendances related to the management of one or more chronic diseases (AIHW 2004). Socio-demographic changes, the ageing population and the longer life span mean that chronic diseases will place increasing demands on the health sector, and the national economy.

Many chronic diseases are amenable to prevention by controlling their risk and protective factors (AIHW 2002). Many others can be successfully managed and brought under control through public health initiatives such as screening and early intervention. However, several of the preventable chronic diseases are still among the most prevalent in the population and are therefore the focus of public health attention in Australia. These diseases:

- contribute significantly to the burden of illness, disability and mortality;
- can be prevented or controlled through public health approaches to targeting risk and protective factors; and
- share common developmental and causal paths, and often occur simultaneously.

These epidemiological features offer excellent scope for lowering the burden of chronic diseases through systematic application of public health interventions. In addition, gains in reducing the impact of chronic diseases will have a benefit to society and the national economy.

In view of these possibilities, the Australian Health Ministers' Advisory Council (AHMAC) endorsed the NPHP background paper on preventing chronic diseases in Australia (NPHP, 2001) as the basis for further development of action in this area. The paper recommended that nation-wide surveillance and monitoring be directed at a defined set of diseases, including heart disease and stroke, Type 2 diabetes, renal disease, lung and colorectal cancers, chronic lung disease and depression. It should be noted that the selection of these chronic diseases is not guided by the clinical feature of chronicity but by their high prevalence, significant overall burden, high preventability and shared determinants.

These determinants, both alone and in combination, affect the onset, maintenance and prognosis of chronic diseases and their complications. Modern sedentary lifestyles, poor diet, environmental factors, psycho-social factors, socio-economic position, the increasing prevalence of obesity, and the risk behaviours of tobacco consumption and alcohol misuse, will add to the increasing prevalence of chronic conditions.

Underlying trends in these factors must be analysed in the context of trends in health outcomes, both to understand the underlying relationship and to undertake projections. Synergies therefore need to be developed between processes for collecting, analysing and reporting data on both risk/protective factors and health outcomes.

Hence surveillance of these factors is an integral part of chronic diseases monitoring. Surveillance aids in forecasting levels and trends, and provides an opportunity for early intervention at a population level (AIHW 2002).

Challenges with current data, structures and processes

A large body of data already exists, in the form of health surveys, disease registers, administrative collections and research based data on the burden of chronic diseases and their associated determinants. Most states and territories currently have high-quality surveillance systems established, which to a large extent are in harmony with each other and with major national collections such as the ABS National Health Survey.

There are a number of issues regarding the scope, coverage, access, analysis and application of data on chronic diseases and associated determinants. These include ensuring that:

- there is consistency in content among many of the collections for chronic disease determinants;
- there is stability in content of data collections over time;
- gaps in existing information are identified;
- data collections and reporting are timely;
- information is made available on priority population groups including children and youth, older people, Aboriginal and Torres Strait Islanders, people from non-English speaking backgrounds, and regional population groups; and
- there is adequate capacity for integrated, nation-wide reporting.

Other issues requiring attention for effective nation-wide surveillance include ensuring that:

- there is a national policy framework for decision-making regarding surveillance priorities;
- there are recognised governance arrangements for the surveillance of chronic diseases and associated determinants;
- there are agreed mechanisms for managing nation-wide data;
- there are obligations for jurisdictions to meet local needs in their data collections; and
- shortfalls in the public health workforce capacity and capability are addressed.

The contribution of surveillance to prevention

Surveillance refers to the ongoing collection, analysis and interpretation of data essential to the planning, implementation and evaluation of public health programs. Systematic, regular and properly integrated health information not only gives us basic facts about the extent of the problem (incidence, prevalence, morbidity etc.), but also provides:

- insights into the distribution of various diseases, across population groups and geographical regions;
- substantiation of, and underlying trends in, causal and associated determinants of health;
- opportunities to identify emerging public health issues; and
- capacity to test the strength and direction of the relationship between various risk/protective factors and chronic diseases in different settings.

This information can be successfully applied to:

- targeting of public health interventions;
- undertaking evaluation of strategies and interventions; and
- long-term projections in risk and protective factors or disease incidence/prevalence.

This Blueprint identifies opportunities for improving surveillance data related to chronic diseases and associated determinants in Australia. Implementation of the Blueprint will result in improved access to timely information, provision of timely nation-wide data for time-series reporting on selected key indicators, improvements in quality and coverage of the data, more appropriate analysis of surveillance data, and facilitation of better use of existing data. Jurisdictions will be able to benchmark state-specific surveillance data against nation-wide estimates.

2. System-based surveillance

There are currently no adequate ongoing data collections in Australia that are dedicated to nation-wide surveillance of chronic diseases and associated determinants. The ‘system’ in its simplest form is about drawing together the range of existing and possible new data collections, supported by fundamental system infrastructure, such as: governance, policy context, priority-setting mechanisms, analysis and reporting frameworks. There is a need for a commitment to build and sustain a system that coordinates the management of data, harmonises the components of data collection and underpins the capacity and resources required to maintain the system.

Actions to implement the Blueprint are discussed in Section 3 of this report and come under the broad action areas of:

- Chronic Disease Surveillance Network;
- reporting on existing data;
- agreed national policy-relevant indicators; and
- capacity building.

SYSTEM COMPONENTS

The requirements at a policy level for the various elements necessary to bring existing and any new data collections together into a system are now described.

Agreed definition and scope

The following definition is proposed as the basis of the system⁴:

Surveillance is the systematic and on-going tracking and forecasting of population-level health status, events, outcomes, risk/protective factors or other determinants through the collection, integration, analysis and interpretation of data and the timely dissemination of the information to those who need to know, to inform action.

The key features of the system captured by this definition are that it is ongoing, it uses and builds on existing data sources, it involves analysis and interpretation, and it produces information that can be used for action.

As noted in Section 1, the scope of this Blueprint—and the system it prescribes—addresses surveillance information that relates to public health activity for chronic diseases, with a focus on prevention for well and at-risk populations. The Blueprint also has application to the need for improved nation-wide information on aspects of chronic disease management and the ability of the health system to respond to the burden of chronic diseases. This scope deals with information about populations, about conditions and risk/protective factors that can be affected at a population level, and about public health interventions that operate in a variety of settings (including primary care).

⁴ Adapted from *Health Canada*.

Governance (Action 1, page 15)

Collecting and delivering surveillance information is a complex task that requires sustained resources and good organisation. There is a need for an overarching body to ensure coordination of activities, to oversee the integration of information, to facilitate the sharing of ideas, and to drive the agenda forward.

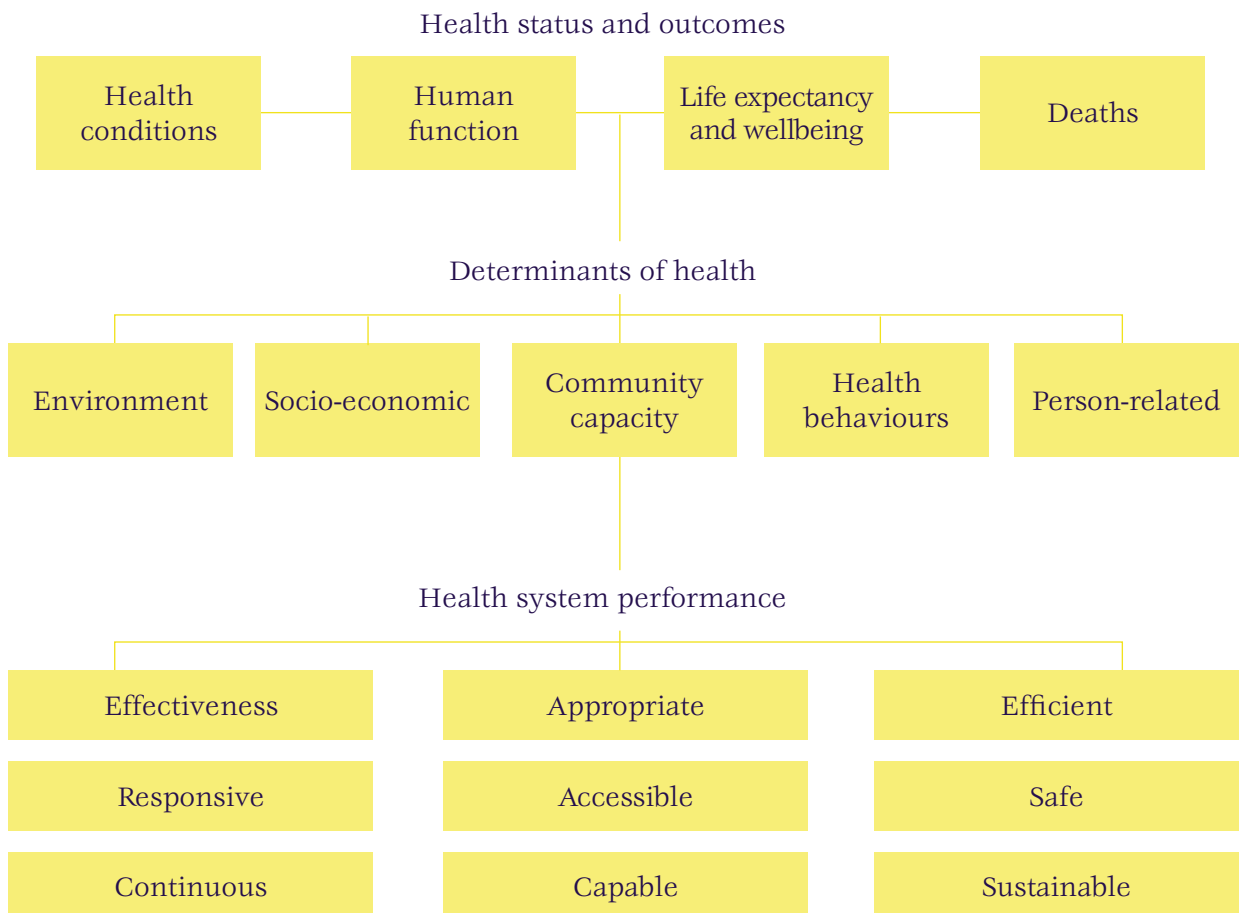
The National Public Health Information Working Group (NPHIWG) is the body which has the role of coordinating public health information in Australia. The NPHIWG provides advice to AHMAC and Health Ministers through the NPHPG and the National Health Information Group (NHIG). With jurisdictional representation and public health information expertise, it is able to provide a coordinating mechanism for driving the development and management of key health information areas described below. NPHIWG has a reporting and advisory relationship to both the NHIG—the peak health information governance body—and the NPHPG. The NPHIWG is well placed to oversee the proposed action plan, especially to the extent that it supplants or complements the National Public Health Information Plan.

Tools for organising information and setting priorities for surveillance (Action 2, page 16)

Background

The scope, quality, and depth of data for the surveillance and monitoring of chronic diseases and associated determinants in Australia are variable and complex. The accessibility of data, approaches to analysis (including record linkage) and reporting also vary. Several models and frameworks, originally proposed for systematising public health information, can be objectively applied to organise information on chronic diseases and their determinants.

Figure 2.1: Summary of the National Health Performance Framework (NHPF)



One of the more comprehensive health information frameworks is the National Health Performance Framework, NHPC 2001, which covers a wide range of health issues in the three tiers of *Health status and outcomes*, *Determinants of health*, and *Health system performance*. This framework not only allows scoping of various issues across health outcomes and risk/protective factors but also guides the development and organisation of information to monitor the performance of the health system as a whole. The Framework identifies a number of information categories within each of its three tiers (see Figure 2.1).

The NHPF is consistent with the paper *Preventing Chronic Disease: A Strategic Framework* (NPHP, 2001) which advocates for a ‘clustering’ approach to prevention and argues for initial effort on a small set of:

- preventable chronic diseases and conditions;
- biological risk factors/markers; and
- risk and protective factors, comprising behavioural, psychosocial, and early life factors.

These three groups align well with the top two tiers in the NHPF.

The other key framework to be considered is the World Health Organization’s STEPwise framework, which is the WHO-recommended tool for setting priorities in the surveillance of non-communicable diseases and their risk factors. The STEPwise approach allows for the development of an increasingly comprehensive surveillance system, depending on local needs and resources, and is currently being implemented in 35 countries across four WHO regions (Bonita et al. 2001; WHO 2001). The primary focus of STEPS is on risk factor assessment, starting with gathering information on key risk factors by the use of questionnaires (Step 1), then moving to simple physical measurements (Step 2), and then to the collection of blood samples for biomedical assessment (Step 3). Within each of the ‘steps’ WHO specify core, expanded, and optional modules, designed for settings where resources and local surveillance needs allow a more comprehensive evaluation of the key risk factors.

The WHO STEPwise framework does not meet the needs for priority setting in the Australian context. In particular, ‘STEPS’ focuses on only three levels of data collection (self report, physical and biomedical measurement) and does not facilitate information priority setting based on the wide range of data sources currently accessible in Australia.

An Australian tool to support improved priority setting policies (Action 3, page 17)

Figure 2.2: An Australian Priority Setting Tool⁵

| Types of Data | Nation-wide Priority 1 | Nation-wide Priority 2 | Jurisdiction Options |
|--------------------------------------|------------------------|------------------------|----------------------|
| Vital Statistics | | | |
| Self report (Survey) | | | |
| Physical measurement | | | |
| Biomedical measurement | | | |
| Disease register | | | |
| Hospitalisations | | | |
| Other (including screening, MBS/PBS) | | | |

⁵ A hypothetical example of the types of data that would fit within this Australian Priority Setting Tool is presented in Appendix 1.

An analysis of the above approaches indicates that, while each has its merits, and the NHPF serves as a tool for organising and presenting information, there is still a need for a tool for setting priorities in policy based indicators. The integrated Australian Priority Setting Tool (Figure 2.2) is proposed as the template for priority setting of surveillance information in Australia. It provides a matrix to categorise information requirements both in relation to the types of data sources and the level of priority needed.

Adoption of this tool as a basis for action will enable Australia to focus attention on priority information requirements derived from both existing data sources and data sources yet to be established (data gaps). This Australian Priority Setting Tool will retain the capacity to inform the NHPF and is not intended to replace it.

There are numerous nation-wide data sources for most of the items that could be expected to be included in the *Nation-wide Priority 1* column, although data are neither current nor comprehensive for some of the self-reported risk and protective behaviours. Basic prevalence and incidence data are also lacking or are of poor quality. Vital statistics data are sufficient to meet most nation-wide and jurisdictional needs; however potential privacy concerns limit small area analysis of mortality patterns, and data quality concerns limit analysis for socioeconomic groups and Indigenous and culturally and linguistically diverse peoples. In addition, there is a paucity of data related to children and youth under the age of 18 years.

The tool also points clearly to the most pressing priority for Australia, namely to collect, through a representative population survey, integrated data on nutrition, physical activity, and physical and biomedical measurements. This should include the physical measurements of height and weight, waist circumference and blood pressure, and biomedical measures of key markers of chronic disease, such as blood glucose and cholesterol levels. However, this Blueprint does not examine (or advocate) specific detail of items that need to be determined.

The highest level of priority for information would provide the basis for generation of key 'Headline Indicators'. It is proposed that a set of criteria be established to allow this matrix to be populated with appropriate data items/indicators.

Harmonisation (Action 4, page 17)

Harmonisation is essentially about a shift towards a common set of standards and values in generating surveillance data across the country. Without a harmonised approach to surveillance at a state, territory and national level it is unlikely that a nation-wide chronic diseases and associated determinants of health surveillance system could be established in Australia.

The major attributes of the surveillance system that will require harmonisation are:

- data content;
- data quality;
- analytical techniques and approaches; and
- reporting and other outputs.

Much progress has been achieved recently in the harmonisation of content and quality of state-based population health surveys, as evidenced by the work of the Computer-Assisted Telephone Interview Technical Reference Group (CATI TRG—an advisory committee to NPFIWG) in producing standardised health surveillance modules across a range of topics including demographic characteristics, alcohol consumption, asthma, diabetes and tobacco consumption.

This harmonisation strategy would need to be extended to other data collections nation-wide, and to the other attributes listed above.

Data management (Actions 1–3, pages 15–17)

A critical component of the surveillance system will be a mechanism to ensure that all relevant data are handled in an effective, efficient and secure manner. Much work will be required to make sure that relevant data being collected across the country can be utilised for reporting of chronic diseases and associated determinants at a nation-wide level. The adoption of the Australian Priority Setting Tool will have a primary purpose of informing state and territories policy and programs, while serving the secondary purpose of facilitating nation-wide data pooling and reporting. The tasks required include:

- development of standard content and processes for data collection;
- integration and pooling of data;
- development of systems for the secure transfer and storage of data;
- establishment of arrangements for appropriate access to data; and
- implementation of best practice in data analysis and reporting.

Analysis and reporting could be made more succinct and focussed by the development and use of an agreed set of policy relevant indicators nation-wide. These agreed indicators will inform and focus public health interventions. The notion of ‘Headline Indicators’ could be applied to the chronic diseases field, an approach that would be consistent with international initiatives. Indicator-based reporting—in particular through a website—is an excellent contemporary means to facilitate rapid dissemination of information.

In addition to standard epidemiological measures for the whole population, differentials between various sub-groups, especially for rural and remote populations, Indigenous Australians, and a number of socioeconomic groups, should also be monitored. Small area analysis, multivariate analysis and estimation of attributable fractions are other analytical approaches that should be considered.

Already the AIHW reports information on chronic diseases and associated determinants biennially through *Australia's Health* and additional selected publications. This vehicle could be enhanced and supplemented by a regular series of monitoring reports and surveillance summaries. The ABS also reports regularly on health topics in publications such as the annual *Year Book Australia* and *Australian Social Trends*, in addition to reports from the health and disability surveys. State and territory reports from their health and behavioural risk factor surveys supplement the national information provided by ABS and AIHW.

A chronic disease surveillance network (Action 1, page 15)

To give a more prominent profile to these surveillance functions, and ensure practical delivery of this new surveillance system a national Chronic Disease Surveillance (CDS) Network should be established. This national CDS Network would be made up of relevant experts, epidemiologists and stakeholders across the country and would have a principal role in developing a nation-wide data management work program. The Network would include representatives from the National Monitoring Centres established for the National Health Priority Areas.

An appropriate national agency, such as AIHW, should be nominated to coordinate and facilitate the work program of the proposed CDS Network, to produce national reports, and to facilitate access by third parties to the various data sources. The NPHIWG would oversee the work program of the agency and the CDS Network. The agency's role would be similar to that currently in place for managing and coordinating other major health data collections that are derived from state systems, such as the National Hospital Morbidity Database. In this scenario the AIHW, or another appropriate agency, would operate as a ‘virtual centre’ supporting data management and data analysis activities in the work program. The CDS Network would operate under agreed terms of reference.

The immediate priority for the NPHIWG will be to determine the terms of reference and develop the work program for the CDS Network. The Network will be charged with developing criteria that will be used for prioritising agreed national policy relevant indicators. The Australian Priority Setting Tool will be used as a template for this priority setting process.

Capacity and resources (Action 4, page 17)

The success of a nation-wide surveillance system will depend on its quality and sustainability over time. There is no value in setting up a surveillance system as a one-off project, as this defeats the principal objective which is to generate a stable set of appropriate indicators that can be populated with data and reported on over time. In addition, the system would be responsive to emerging public health issues. Accordingly, there is a need for capacity building in some states and territories, along with the maintenance of current effort in others.

It is clear that previous Australian Government funding has led to significant advances in jurisdictional effort in states such as Victoria, Tasmania, Western Australia, South Australia and the Northern Territory. It will likely be important for states and territories to allocate resources on a needs basis in order to develop and maintain infrastructure adequate for their components of a nation-wide system. In addition, the AIHW would ideally have an important role in providing intellectual and technical support for the system.

Workforce issues across all jurisdictions also need to be addressed. There are inconsistencies in the capacities and capabilities of the public health workforce across jurisdictions to deal with the technical and policy-related aspects of surveillance. Significant effort will be required across the public health community to develop adequate workforce capacity and skills. For example, La Trobe University's School of Public Health is currently developing post-graduate public health training programs in biostatistics, epidemiology and surveillance.

There may be a need for further enabling infrastructure to support the system operating effectively and efficiently. While the NHIA already provides an overarching operational charter, specific uses of data may need detailed protocols to support, for example, the exchange of data between jurisdictions as well as the national aggregation of data. Issues such as this are currently being investigated in the course of assessing the feasibility of pooling state and territory CATI surveillance data.

3. Action plan

The Blueprint will be implemented by the NPHIWG, an advisory committee to the NHIG and the NPHP. The surveillance system and CDS Network will provide ongoing policy-relevant information to enhance public health surveillance capacity of chronic diseases and associated determinants. This CDS Network will be responsible to, and will be overseen by, the NPHIWG.

While the Blueprint builds on existing capacity and infrastructure, additional investment and funding opportunities may arise for the delivery of priorities resulting from implementation of this Action Plan.

The following actions are required to give effect to the Blueprint:

Action 1: Chronic Disease Surveillance (CDS) Network

Establish a national network to develop and support the ongoing collection, analysis and dissemination of nation-wide surveillance and monitoring data for chronic diseases and associated determinants.

Establish the network for the surveillance of chronic diseases and associated determinants with:

- agreed terms of reference and a business plan;
- membership made up of relevant experts, epidemiologists and stakeholders;
- responsibility for developing criteria for prioritising agreed national policy relevant indicators (see Action 3);
- development of a nation-wide data management work program for surveillance of chronic diseases and associated determinants that addresses:
 - data collection methods and infrastructure eg secure sampling for jurisdictional health surveys;
 - surveillance of chronic diseases and associated determinants in Indigenous populations and in remote regions;
 - data pooling and/or integration—policies, strategies, business rules, data definitions;
 - data security and storage;
 - data access principles and procedures—business rules;
 - data analysis and reporting principles and procedures;
 - mechanisms to support jurisdictions in collection of data that meet national and jurisdictional priorities;
 - finalising of agreement on the indicators supported by the surveillance system; and
 - monitoring the use of surveillance information in policy development and decision making.
- determination of the appropriate location (eg AIHW/ABS/Other) for nation-wide coordination of the CDS Network work program, with an existing unit, a virtual or a new establishment that would facilitate analysis and reporting of nation-wide data with outputs designed to inform policy and investment decisions relevant to chronic diseases; and
- The CDS Network would be supported by a Secretariat based on a re-alignment of the duties of the CATI TRG Secretariat. It is assumed that the CATI TRG functions could operate, and be enhanced in the future, from within the context of the CDS Network.

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|------------------------|--|
| Rationale: | The NPHP in its forward planning is intending to develop a major stream of work on chronic disease prevention. The CDS Network will be a key platform in ensuring an adequate evidence base is available for this work. |
| Resources: | Supported by relevant experts, epidemiologists and stakeholders. Work program facilitated by an existing agency (eg AIHW, ABS). Secretariat—sourced from re-alignment of CATI TRG Secretariat role. In kind support from jurisdictions and agencies participating in the CDS Network. |
| Timetable: | Establishment over six months. |
| Deliverables: | Annual national report and web reports. Data access for third parties. |
| Responsibility: | NPHP through NPHIWG. |

Action 2: Reporting on existing data

Publish a combined report on chronic diseases and their determinants utilising currently available data from state and territory population health surveys, national health surveys and other sources.

With appropriate governance protocols to be established and monitored through NPHIWG, facilitate immediate reporting on existing data for selected indicators of chronic diseases and the determinants of chronic diseases, in an AIHW publication:

- determine indicators for initial reporting;
- access and use best available nation-wide estimates (jurisdictional data, ABS National Health Survey data, and other sources as appropriate); and
- inclusion in the next and subsequent editions of *Australia's Health*.

This reporting will bring together existing data from a number of sources and will for the first time combine jurisdictional data related to chronic disease and associated determinants in one set of nation-wide indicators.

| | |
|------------------------|---|
| Rationale: | Provide an up-to-date overview of current key indicators of chronic disease and associated determinants as a resource for public health policy developers and program planners. |
| Resources: | CDS Network agency work program. Publications through the AIHW. |
| Timetable: | Prepared over six months. |
| Deliverables: | Publication and web reports. |
| Responsibility: | NPHIWG through CDS Network. |

Action 3: Agreed national policy relevant indicators

Develop an agreed prioritised set of national policy relevant indicators for chronic diseases and associated determinants. These indicators will be drawn from existing indicators and based on the Australian Priority Setting Tool for chronic disease surveillance proposed in this Blueprint.

This action includes:

- development of a set of criteria for determining the priority level assigned to all relevant indicators;
- population of the cells of the Australian Priority Setting Tool with relevant indicators;
- identifying existing data sources for indicators at each of the three levels of priority;
- using the Australian Priority Setting Tool to highlight nation-wide data gaps (in priority order) relevant to all agreed indicators: and
- identification of “Headline Indicators” for nation-wide reporting.

This action item will be a major activity of the CDS Network and the content of the matrix will be drawn initially from existing agreed indicators. It is anticipated that the CDS Network would be convened face-to-face to address these items as major components of its work program.

| | |
|------------------------|---|
| Rationale: | Provide a criterion-based approach to identifying the most important policy-relevant indicators that can be reported nation-wide. |
| Resources: | Supported by members of the NPHP, the CDS Network and additional stakeholders. In kind support from jurisdictions and agencies participating in the CDS Network, eg contributing to designing criteria for setting priorities. |
| Timetable: | Developed and agreed over twelve months. |
| Deliverables: | Publication and web reports. |
| Responsibility: | CDS Network. |

Action 4: Capacity building

Build on current capacity by continuing the development of nation-wide standards for health surveillance as well as fostering an adequate and sustainable workforce able to contribute to and benefit from the surveillance system. This includes the sharing of skills and knowledge, as well as the sharing of infrastructure.

Building on current capacity, the surveillance system member jurisdictions and agencies need to foster and develop an adequate and sustainable workforce. In particular, there is a need for:

- maintenance of current progress on the harmonisation of content and quality of state-based population health surveys. This incorporates:
 - testing of questions to ensure reliability and validity;
 - agreement on module manuals; and
 - extension of harmonisation to other data collections nation-wide.
- skills and knowledge sharing, particularly between jurisdictions and agencies, for example through the use of web-based bulletin boards;
- infrastructure sharing between jurisdictions and agencies (such as ‘buddy’ and ‘piggy-back’ arrangements);

- workforce development strategies, including training and national forums;
- facilitating technical capacity, such as the sharing of sampling methods; and
- data standard dissemination.

| | |
|------------------------|--|
| Rationale: | Existing infrastructure, skills and workforce require further development in order to deliver a national chronic disease surveillance system. |
| Resources: | Funding to be sought for specifically identified activities, such as post-graduate training, web-based communication tools and technical development projects. |
| Timetable: | Ongoing. |
| Deliverables: | For example, manuals on question modules for alcohol consumption, asthma, cardiovascular disease, demographic characteristics, diabetes, food behaviour and tobacco consumption. Web-based information resource; targeted training programs. |
| Responsibility: | Jurisdictions and the CDS Network |

Appendix 1:

A hypothetical example

| Type of data | Nation-wide Priority 1 | Nation-wide Priority 2 | Jurisdiction Options |
|--------------------------------------|---|---|---|
| Vital statistics | Cause-specific deaths | Life expectancy at birth Years of life lost | Avoidable mortality profiles |
| Self report (survey) | Smoking, Alcohol Nutrition Physical Activity | Self reported health status Disease management plan Employment status | K10/SF36 ¹ Social capital |
| Physical measurement ² | Height Weight | Hip girth | Skin fold thickness |
| Biomedical measurement ³ | Cholesterol | HbA 1c | Cotinine |
| Disease register | Cancer incidence | Diabetes register type 1 treatment modes | Disease specific survival categories |
| Hospitalisations | Ambulatory care sensitive condition admissions, eg asthma, diabetes | Length of stay Admitted care costs | Small area profiles of admissions |
| Other (including screening, MBS/PBS) | Breast & cervical cancer screening participation Pathology procedure rates | Procedure cost indicators | Prostate cancer screening Equity in care |

1 K10: 10 item Kessler Psychological Distress Scale

SF36: 36 item short form of the Medical Outcomes Study questionnaire

2 Trends in physical measures such as height, weight, hip girth and skin fold thickness are currently not available.

3 Trends in biomedical measures such as cholesterol HbA 1c and cotinine are currently not available.

Data Gaps: Selected self-report (survey) indicators are delivered by the ABS and jurisdictions (eg three-yearly National Health Survey and CATI population health surveys).

It is necessary as a high priority to develop integrated data on nutrition, physical activity, and physical and biomedical measurements. Physical and biomedical measurement indicators of the determinants of chronic diseases and food/nutrition and physical activity are the most significantly deficient in terms of availability and quality of nation-wide data.

Appendix 2: Working Group and Consultations

WORKING GROUP

| | |
|----------------------------|---|
| Dr Michael Ackland (Chair) | Victorian Department of Human Services |
| Dr Ching Choi | AIHW |
| Mark Cooper-Stanbury | AIHW |
| Dr Joy Eshpeter | Australian Government Department of Health and Ageing |
| Catherine Harper | Queensland Health |
| Karen Roger | National Public Health Partnership |
| Colin Sindall | Australian Government Department of Health and Ageing |
| Dr Merran Smith | Department of Health, WA |

CONSULTATIONS

| | | |
|---|-----------------------------------|--------------------|
| Victoria | Melbourne | 18 February 2005 |
| Tasmania | Hobart | 24 February 2005 |
| South Australia | Adelaide | 9 March 2005 |
| Western Australia | Perth | 10 March 2005 |
| Northern Territory | Darwin | 11 & 14 March 2005 |
| Queensland | Brisbane | 29 March 2005 |
| New South Wales | Sydney | 30 March 2005 |
| Australian Bureau of Statistics | Canberra | 22 March 2005 |
| Australian Department of Health and Ageing | Canberra | 22 March 2005 |
| Australian Institute of Health and Welfare | Canberra | 23 March 2005 |
| Indigenous National Health Survey Reference Group Members | Canberra | 28 April 2005 |
| National Public Health Partnership, National Program Advisor | Melbourne | 9 May 2005 |
| SIGNAL & SIGPAH | Hobart | 24 February 2005 |
| SIMC | Canberra | 23 March 2005 |
| National Chronic Disease Strategy Working Group Members (except WA) | During jurisdiction consultations | |

References

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