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## **PROJECT CONSORTIUM**

**La Trobe University**

**Public Health Information Development Unit, Adelaide University**

**Victorian Public Health Research and Education Council**

**Menzies School of Health Research/CRC for Aboriginal & Tropical Health**

# Table of Contents

1. Background and Methodology	2
2. International Trends	5
Increased Emphasis on Behavioural Risk Factor Surveillance	5
Integration of Existing Data Sources	7
Harmonisation of Existing Data Collections	8
Population Health Surveys with Components of Objective Measurement	9
Small Area and/or Population Data	9
3. The Australian Context	12
Administrative Data	12
National Survey Data	12
State-Based Data	14
Data Analysis, Integration and Dissemination	17
4. Framework(s)	19
The Strategic Framework for Preventing Chronic Disease	19
The National Health Performance Framework	20
The World Health Organization Stepwise Framework	24
5. Rationale, Objectives and Definition	26
6. Priorities for Action	28
7. A Nation-wide Behavioural Risk Factor Information and Monitoring Program	30
The Core CATI Concept	31
Data Development	32
Data Collection	33
Data Warehousing and Integrated Reporting	34
Specialised Data Analysis and Dissemination	34
Connection to National Health Survey	36
Review Process	36
Specialist Chronic Disease and Risk Factor Monitoring and Information Units	37
Implementation plan	38
Funding	40
8. Conclusion	41
Benefits	41
Costs	42
Technical Feasibility	42
Support	42
Table A: Initial Development and Implementation Plan	43
Table B: Participants and Role	44
Appendix A: Key Stakeholder Consultation Questions	45
Appendix B: SNAPS+ Questions	48

Abbreviations and Acronyms	65
References	65

# 1. Background and Methodology

Chronic non-communicable diseases are now responsible for most of the disease burden in all developed (and many developing) countries. In Australia, around 70 per cent of the total burden of illness and injury experienced by the population can be attributed to chronic disease, and this proportion is expected to increase to close to 80 per cent by 2020.<sup>1</sup> In proposing a strategic framework for meeting this challenge, the National Public Health Partnership recommended building the national prevention effort around three key domains of activity:

- Ensuring an effective information base to guide action
- Strengthening prevention and health promotion
- Improving systems of care for those with chronic disease<sup>2</sup>.

In elaborating the functions of an effective information base, the framework discussion paper stated that:

"In the area of surveillance, systems are required to monitor and assess chronic disease mortality and morbidity, and the level of exposure to risk factors and their determinants in the population; together with mechanisms which enable surveillance information to contribute to policy making, advocacy and the evaluation of both preventive programs and health care services. The design of surveillance systems and instruments to enable effective tracking of health and health behaviours in sub population groups, in order to assess progress in addressing health inequalities, is of critical importance."<sup>3</sup>

This framework for chronic disease prevention was endorsed by the Australian Health Ministers Advisory Council (AHMAC) in May 2001.

In seeking tenders to conduct the current feasibility study, the then Commonwealth Department of Health and Aged Care (now the Department of Health and Ageing) expressed concern that current data collections in Australia did not provide the capacity for integrated, nation-wide, surveillance and monitoring of chronic diseases and associated behavioural risk factors. It stated that:

"The national health information systems that have been established focus on acute episodes, communicable disease, and specific disease registers that do not, and are not designed to, encompass co-morbidities. The current state of knowledge on basic population health chronic disease issues such as the epidemiology of established or emerging behavioural risk factors is poor."

The feasibility study is being undertaken by a consortium of the Faculty of Health Sciences, La Trobe University; the Victorian Public Health Research and Education

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<sup>1</sup> National Strategies Coordination Working Group, National Public Health Partnership (2001). **Preventing Chronic Disease: a Strategic Framework: draft discussion paper, p.12**

<sup>2</sup> *ibid.* p.6

<sup>3</sup> *ibid.* p.40

Council; the Public Health Information Development Unit, University of Adelaide; and the Menzies School of Health/CRC for Aboriginal and Tropical Health, Darwin. The consortium is working closely with, and being advised by, the National Public Health Information Working Group and its committees.

The project has four parts:

1. an audit of chronic disease and associated risk factor monitoring and surveillance policies and practices and international best practice;
2. an analysis and audit of existing chronic disease and associated risk factor data collections;
3. A feasibility study on the development of a nation-wide integrated behavioural risk factor information and monitoring system through coordination and harmonisation of approach across all jurisdictions including options and costings; and
4. a feasibility study on the development of supplementary behavioural risk factor information and monitoring systems, focusing on Aboriginal and Torres Strait Islander people and on remote regions.

The audit phase of the project (Parts 1 and 2) was carried out between May and September 2001 by the Public Health Information Development Unit, University of Adelaide. It generated a number of documents, namely:

- Best practice examples: International developments
- Best practice examples: Australian developments
- List of all audit candidate sources
- Audit report
- An audit summary
- Harmonisation examples
- Final report of the audit phase.

These documents are being summarised into a single document (with appendices) for the final project report.

Part 3 of the project, which has been conducted by the Australian Institute of Primary Care, Faculty of Health Sciences, La Trobe University, has been based on and has built upon the work of the audit stage. The conclusions, recommendations and options arising from the audit phase of the project have been tested with stakeholders, with particular reference to the development of the behavioural component of a nation-wide chronic disease and associated risk factor information and monitoring system. There has also been input from the AIHW/DHA workshop on "Issues and Priorities in the Surveillance and Monitoring of Chronic Diseases in Australia" (Canberra, November 8–9, 2001) and the CATI Forum (Sydney, November 27–28, 2001).

A discussion paper based on the results of the audit stage was produced and circulated to stakeholders in early October 2001, along with a list of questions for consideration (see Appendix A for questions). During October and early November, consultations were held with senior officers from all State and Territory Health Departments, as well as the then Commonwealth Department of Health and Aged Care, and the Australian Institute of Health and Welfare.

The criteria that have been adopted for testing feasibility are that:

- i. **Benefits** to all key stakeholders can be demonstrated
- ii. **Costs** of implementation are acceptable to the key stakeholders
- iii. New arrangements are **technically feasible** and will produce information of sufficient quality to be useful within a reasonable timeframe
- iv. Key stakeholders **support** the proposed arrangements and are prepared to engage in a process to implement them.

The current report is complemented by a report covering the development of supplementary behavioural risk factor information and monitoring systems, focusing on Aboriginal and Torres Strait Islander people and on remote regions (Part 4), prepared by the Menzies School of Health/CRC for Aboriginal and Tropical Health in Darwin.

## 2. International Trends

An audit of over 30 international monitoring systems working on chronic disease and associated risk factor reporting was carried out in order to identify best practice in this area at a global level. Information arising from the 'Monitoring Health Behaviours – Towards Global Surveillance' Conference (Helsinki, October 1–3, 2001) has also been taken into account.

The major trends to emerge are:

Increased Emphasis on Behavioural Risk Factor Surveillance

Most developed nations have well-established administrative systems for reporting mortality, morbidity associated with hospitalisation, and cases of serious infectious disease. Self-reported prevalence rates for major chronic diseases have also been increasingly documented over the past 20 years, often through one-off or repeated large-scale health surveys.

However, as the prevention of chronic disease has become an important objective in public health, attention has shifted from the prevalence to the need for a greater understanding of the behavioural risk factors that are most strongly associated with chronic disease as these are the foci for public health intervention. Thus, attention has increasingly been turned to the need to track those risk factors at the population (and sub-population) level.

The best-known behavioural risk factor monitoring system is the US Centres for Disease Prevention and Control (CDC) Behavioural Risk Factors Surveillance System (BRFSS). It is a "harmonised" system (see discussion of harmonisation below), which brings together data based on continuous surveillance from different US States. Because of its reputation and its applicability to a federal system of government, the BRFSS was one of the specific systems that the feasibility study was asked to consider as a possible model for Australia.

Formally established in 1984 by the CDC and 15 participating states, the BRFSS now tracks major behavioural risks associated with premature morbidity and mortality in all 50 states of the US on a monthly basis. CDC funded about 2,500 interviews per state in 1999; some states funded their own additional interviews. The CDC coordinates the BRFSS, designs a substantial part of the questionnaire, provides logistical support, and supplies core funding. The questionnaire has evolved to three parts: a core component, common for all states and prepared by the CDC, consisting of fixed, rotating, and emerging core questions; optional modules prepared by the CDC but selected for inclusion by each state; and questions that are developed or acquired by each state. Each state conducts its own survey.

The most frequently cited advantages of the BRFSS divide into three categories: 1) those related to the frequency of data collection; 2) those related to the flexibility provided by the inclusion of fixed, rotating and optional questions; and 3) those related to the nature of the federal-state relationship. Some of the advantages put forward for the continuous time series with monthly intervals for fixed core questions are that it reflects temporal changes more accurately and in more detail than less frequent data collections, that the effects of a program or policy can be tracked over time as well as on a before/after basis and that the effects of seasonality

on reported health behaviours can be examined. Survey employees can be retained on a continuing basis, and interviewers can be highly trained, gaining experience and consistency over time. According to Umphrey et al.,<sup>4</sup> the ability to add state-based questions is rated highly for utility by BRFSS program directors, and is believed to make it easier to address local issues, such as the impact of new state programs.

A major disadvantage of the BRFSS is that it is limited almost totally to self-reported risk factors, and therefore does not allow exploration of relationships between these factors and health conditions (with the exception of self-reported asthma and diabetes), and is unsupported by objective measures. The narrow focus on traditional "lifestyle" oriented behavioural risk factors has also been criticised as reflecting the public health knowledge base of the 1980s, when the BRFSS was established — although this can now be compensated for to some extent by the ability to add and drop modules. The very small sample at state level (around 300 persons interviewed per month) limits its usefulness for small population data (for instance, ethnic minorities or particular socio-economic groupings). The smallest geographical area of analysis is the state level, although a number of states stratify their samples to allow them to estimate prevalence for regions within the state. The BRFSS has also had some difficulty determining national estimates from aggregated state data, since it currently determines its national estimates from state averages, rather than pooling the original data.

In recent years, the World Health Organization (WHO) has played a leading role in encouraging the development of chronic disease risk factor surveillance among its member states. According to WHO:

"A well functioning NCD [Non Communicable Disease] surveillance system is an integral part of public health surveillance and the wider health information system. It provides information for planning, implementation, monitoring and evaluation of public health intervention programmes. The use of the information determines the data collected and the speed necessary for the information flow within the system. Surveillance needs to be grounded in evidence based approaches."<sup>5</sup>

WHO has developed a recommended methodology for surveillance, the WHO Stepwise Approach to Surveillance of NCD Risk Factors, which has been adopted as one of the frameworks for the present feasibility study, and which is discussed in more detail below. The WHO Stepwise approach has been utilised in the WHO Mega Country Surveillance Initiative, which focuses on 11 countries with a population of more than 100 million (Bangladesh, Brazil, China, India, Indonesia, Japan, Mexico, Nigeria, Pakistan, Russia and the US). The Mega Country Surveillance program is in part modelled on the US BRFSS but collects self-reported information by mail, or face-to-face interview where telephone use is impractical.<sup>6</sup>

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<sup>4</sup> Umphrey, GJ et al. (2001) "Assessing the Surveillance Capability of Canada's National Health Surveys". *Chronic Diseases in Canada* 22(2):50–56

<sup>5</sup> Bonita, R., de Courten, M., Dwyer, T. et al. *The WHO Stepwise approach to surveillance (STEPS) of NCD risk factors*. Geneva, September 2001, p.11

<sup>6</sup> *ibid.* p20

WHO Stepwise is also being trialed in selected parts of the Western Pacific Region, including Vietnam and Fiji.

WHO recommends a surveillance system based on a limited number of risk factors known to be common to the major chronic diseases. These include smoking, alcohol, nutrition, physical inactivity, obesity, raised blood pressure, blood glucose and blood lipids. However, discussion at the Helsinki conference centred around the need to understand how the broader social context modifies the effects of behaviour on health, and the way in which social determinants fundamentally change the social and individual meaning of health behaviours, as well as the choices and chances for change.

### Integration of Existing Data Sources

In developed countries, much of the information needed for monitoring chronic disease and associated risk factors already exists but needs to be drawn together to correspond with current frameworks for chronic disease and its determinants.

Integrated reporting generally utilises indicators or summary measures.

Existing data sources include administrative records (hospital admissions, vital statistics), surveys (such as population health surveys), and registers (such as cancer registers). New data collections are only necessary to fill specifically identified gaps. “Data warehousing”, where the primary data collections from which indicators are derived are ‘housed’ together, can support integration by allowing the investigation of a range of data sources from one place. There are a number of data warehousing initiatives for this purpose, most notably the DATA2000 data warehouse that supports the US Leading Indicators for Healthy People 2010.

Healthy People is a significant and innovative health initiative designed to provide information to: (1) address disparities in health status and health outcomes between diverse population groups; and (2) improve the overall health of the United States population. It reports a small set of leading health indicators on issues that have been identified as significant, modifiable and of relevance to the general public, non-health organisations, and traditional public and private health organisations. These indicators, called the *Leading Indicators for Healthy People 2010*, are drawn from a range of existing data sources. The key features of the indicator set are that it has:

- a set of standard criteria for selecting indicators;
- broad indicator domains which include non-health topics such as poverty and the physical environment;
- a summary (reduced) indicator set of *leading* indicators (10 only), for the specific purpose of galvanising action by the population;
- an emphasis on motivational communication for action; and
- a dissemination strategy<sup>7</sup>.

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<sup>7</sup> Chrvla, CA and Bulger, RJ [eds] (2000). *Leading Health Indicators for Healthy People 2010: Final Report*. Washington DC: Institute of Medicine

The Public Health Observatories, which have recently been set up in each of the UK National Health Service Regions, are also expected to play a strong developmental role in maximising the usefulness of existing data collections and strengthening future collections, through means such as critically assessing regional and national datasets, and identifying areas of strength and weakness in the application of each to strategy objectives.

### Harmonisation of Existing Data Collections

Harmonisation is a method of deriving broad area data (e.g., national, continental, world-wide) from a combination of smaller area (state, national) collections. There are two different types of harmonisation. The first involves harmonising the *output* of a range of data collections in order to obtain comparability or equivalence. This requires adjusting for the different populations sampled by the different collections. The second is *input* harmonisation that aims to standardise monitoring tools used by the various collections such as questionnaires, questions or coding frames.<sup>8</sup> Harmonisation poses a range of difficulties and the question of best practice in the field is currently being debated.

The BRFSS, discussed above, is an example of a harmonisation system. Another example is the EUROpe ALIMentation (EURALIM), which collects and recodes cardiovascular risk factor variables from different European studies. EURALIM originally focused on output harmonisation but found that pooling and harmonising data from independently conducted surveys was not a suitable strategy for a risk factor surveillance system. The EURALIM team has since proposed an intermediate solution based on a short monitoring instrument common to all locales and added to all risk factor surveillance instruments (i.e., input harmonisation).

The EURALIM approach contrasts with that of the WHO *MONItor trends in Cardiovascular diseases project* (MONICA), which was established in the early 1980s in 21 countries (41 Centres) around the world to monitor trends in cardiovascular diseases, and to relate these to risk factor changes in the population over a 10-year period. The project has developed data collection methodology for standardised coronary and stroke event registration, and a range of other standard collection instruments and methodologies. The MONICA experience, however, suggests that complete standardisation of instruments between collections is not possible. Some of the disadvantages are described as the high level of funding required, resistance to complying with a centrally run system that overrides local needs and considerations, variation in conditions for surveillance in member countries, a push towards Internet-driven centralisation (rather than physical centralisation), and the perceived constraints of a rigid protocol and full standardisation in discouraging participation by those who desire flexibility to their population's priorities and needs. Lastly, full standardisation is perceived to result in excessive delays in releasing timely information to the public<sup>9</sup> (Morabia, 2000).

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<sup>8</sup> Jensen, L (2000). Prospects for European Social Statistics. *Eurostat News*: Sigma 3/2000

<sup>9</sup> Morabia, A (2000). Worldwide Surveillance of Risk Factors to Promote Global Health *American Public Health Association* <http://www.apha.org/journal/editorials/editmora.htm>

## Population Health Surveys with Components of Objective Measurement

Ongoing population surveys with components of objective measurement have been developed, or are being developed, in several countries including the US, the UK, NZ and Canada. These surveys generally contain a core component on general health that is repeated at every survey and rotating modules that focus on particular health issues. The Health Survey for England, for example, is an annual survey that collects nationally representative information on the health of the population through interviews and direct physical examination. The physical examinations take place in a nurse visit to the home. Topics investigated include general health at every survey (high blood pressure, high blood cholesterol, obesity etc.) and different special interest modules each year such as cardiovascular disease, asthma, accidents and disability and particular population groups (ethnic, elderly etc.). The US National Health and Nutrition Examination Survey (NHANES) is another example of a survey of this type.

The primary value of these surveys is that they generate objective evidence over time based on representative samples of the population for the full spectrum of age groups. They produce data covering a range of largely chronic disease outcomes (e.g., diabetes) and biological states (e.g., high blood pressure) that cannot be obtained by questions asked of survey participants or by reliance on activity-based administrative data collections. Such surveys can also examine the relationships between chronic disease states and risk factors and determinants, provide an opportunistic data source for further testing if blood is taken and stored, and can validate the vast amount of self-report information that is the primary source of current chronic disease information.

The major disadvantage of such surveys is their cost. As with other types of surveys, their usefulness can also be limited if they cannot be linked to intervention strategies.

## Small Area and/or Population Data

Many countries are increasingly aware that because health status, including the distribution of chronic diseases (and their associated risk factors), varies substantially between different areas and different sub-populations, effective intervention to reduce these inequalities requires valid data at the small area or population level. Small area data are particularly useful for making program investment and evaluation decisions.

Several initiatives designed to meet this need are now emerging. The Canadian Community Health Survey (CCHS), which started in September 2000, consists of two surveys alternating annually in a two-year cycle. The first year's survey was designed for use at health region level, and had a customised component to meet the individual priorities of the 136 health regions. The aggregate sample of 130,750 consisted of 115,000 computer-assisted personal interviews (CAPI) and 15,750 computer-assisted telephone interviews (CATI), breaking down into samples of 2,000–42,260 per province, 800–900 per territory and 280–3410 per health region. The second-year provincial level survey will consist of 30,000 CAPI interviews.

The CCHS broadly covers health determinants, health status and health system utilisation. The 45-minute health region-level survey has 30 minutes of common content, 10 minutes of optional content selected from a set of modules, and five minutes of socio-economic and demographic content. Quarterly release by Stats Canada of high-level population health indicators is planned, beginning in May 2002, with the dissemination of around 40 indicators (by age, sex and health region) via the internet.<sup>10</sup>

In the US, a single standardised survey mechanism known as the State and Local Area Integrated Telephone Survey (SLAITS) has been developed by the National Centre for Health Statistics to allow for the collection of population-based data at the state and local level to address emerging health and health-related issues. To a certain extent, SLAITS can be seen as an attempt to compensate for some of the difficulties inherent in the BRFSS, particularly in relation to generating local and national level data. A related factor that lies behind the development of SLAITS is the 'new federalism' policy which arose in the US in the 1990s, in which states have assumed increased responsibility for the design and administration of social policy, and accountability for the resulting programs.<sup>11</sup> For some states, these responsibilities have been further devolved to regional or local levels. This is seen as driving the need for social indicator data at state and local levels, as well as increasing the need for expertise to use data effectively.

SLAITS uses the same random-digit-dial telephone design approach and sampling frame as the ongoing and very large National Immunisation Survey conducted by the CDC. SLAITS is not an ongoing survey and is not conducted at regular intervals. Rather, key sponsors may implement SLAITS surveys at any time. Existing survey modules cover health, child wellbeing and welfare, early childhood health, and children with special health care needs. The unique feature of SLAITS is its ability to collect comprehensive data on specific health- and welfare-related topics for specific at-risk sub-domains of the population.<sup>12</sup>

In the UK, the establishment of Public Health Observatories in 2000 in each of the eight National Health Service Regions also reflect a greater emphasis on small area level data, although they were developed in response to a philosophically different approach by government, designed to improve the health of the population overall while reducing inequalities. The Public Health Observatories' main tasks are to support local bodies by:

- monitoring health and disease trends and highlighting areas for action;
- identifying gaps in health information;

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<sup>10</sup> Umphrey, G., Kendall, O. & MacNeill, I. (2001). 'Assessing the Surveillance Capability of Canada's National Health Surveys' *Chronic Diseases in Canada* 22(2):50-56; personal communication, Larry MacNabb, Stats Canada, February 2001)

<sup>11</sup> Brown, B. (1998). *Tracking the Well-being of Children within States: the Evolving Federal Role in the Age of Devolution*. Number A-21 in Series, *New Federalism: Issues and Options for States*. Washington: Urban Institute. <http://newfederalism.urban.org/html/anf21.html> accessed 8 November 2001

<sup>12</sup> Ezzati-Rice, T., Cynamon, M., Blumberg, S. & Madans, J. (1999). *Use of an existing sampling frame to collect broad-based health and health-related data at the state and local level* Atlanta, Georgia: National Centre for Health Statistics, CDC.

- advising on methods for health and health inequality impact assessments;
- drawing together information from different sources in new ways to improve health;
- carrying out projects to highlight particular health issues;
- evaluating progress by local agencies in improving health and cutting inequality; and
- looking ahead to give early warning of future public health problems.

As well as building data warehouses and reporting against specific government plans and targets within them, the Public Health Observatories have a strong developmental role in relation to maximising the usefulness of existing data collections and strengthening future collections through means such as critically assessing regional and national data sets and identifying areas of strength and weakness in the application of each to strategy objectives.

### 3. The Australian Context

Although Australia does not currently have a chronic disease and associated risk factor monitoring and information system, it does, like most developed countries, collect, analyse and disseminate a considerable amount of information on the prevalence or incidence of chronic diseases, and on associated risk factors. Broadly speaking, there are three types of data currently being collected that might contribute to a nation-wide system: administrative data, national survey data, and state-based survey data that might be harmonised to generate nation-wide data.

#### Administrative Data

There are several existing administrative data sets held by the AIHW that provide national information on the incidence of chronic diseases. These are:

- The National Mortality Database/National Death Index – contains information on causes of death compiled from State/Territory Death Registers.
- The National Hospital Morbidity Database – contains information on almost all hospital separations in Australia, including diagnoses.
- National Cancer Statistics Clearing House – brings together information on cancer incidence and mortality collected compulsorily by State/Territory Cancer Registries.
- National Diabetes Register – operated by AIHW using data from Diabetes Australia and the Australasian Paediatric Endocrine Group. Collects information about people who have been diagnosed with insulin-treated diabetes since 1 January 1999.
- The National Health Data Dictionary plays an important role in standardising administrative and other health data. The Dictionary contains definitions of data elements that are included in National Minimum Data Set collections in the health sector, including data elements used to derive performance indicators required under Australian Health Care Agreements. Responsibility for the National Health Data Dictionary lies with the National Health Information Management Group and its standing committee, the National Health Data Committee. AIHW provides the Secretariat for this Committee.

#### National Survey Data

The audit phase of this project identified 88 existing or proposed data collections in Australia that could potentially supply information to a nation-wide chronic disease and associated risk factors information and monitoring system. The criteria used to assess these data sets were:

- a) whether data sources have 'nation-wide' population coverage (that is, whether data is available at the state/territory and national level);
- b) whether a stable time series is available;

- c) whether the collection picks up most cases, or a representative sample of cases;
- d) whether data is available by disaggregations for: age, sex, indigenous status, ethnicity, socio-economic status, and geographic area of residence.

The audit found several well-established national time-series data collections that met all or most of the above criteria and which could contribute to a nation-wide system. Of these, the most important was the ABS National Health Survey. Conducted in 1989, 1995 and 2001, the NHS will now be conducted triennially, with the next survey due to take place in 2004.

The 1995 survey sample consisted of 21,800 households and 54,000 persons. The NHS collects basic data on recent and long-term medical conditions experienced by respondents, actions people have taken in response to those conditions, and aspects of their behaviour that may affect their health. With specific reference to behavioural factors, the NHS covers smoking, physical activity, diet, dietary supplements and medications (although only for people with specific conditions), alcohol use, analgesic use, preventive dental behaviour and breastfeeding. The survey design enables information for all topics to be analysed in relation to other topics, and in relation to a range of demographic and socio-economic characteristics.

In 1995, nearly 40% of the sample (21,200 people) was also selected to take part in a National Nutrition Survey. Respondents were asked questions about the types and quantities of food eaten as well as having certain measurements (height, weight, hip circumference) taken. Those aged over 16 also had their blood pressure taken. A major limitation of the NHS is that data cannot generally be disaggregated to the regional level, thus restricting its use as a tool for planning and/or evaluating program interventions at the sub-state/territory level. In the past, the long period between survey periods, as well as time lags in reporting, also limited the usefulness of the NHS as a data source.

Other important and potentially relevant national time-series data collections are the ABS Census of Population and Housing, the ABS Survey of Disability, Ageing and Carers, the National Dental Telephone Interview Survey, the National Drug Strategy Household Survey, and the Australian Secondary School Students' Alcohol and Drug Survey.

An important new addition to the above list will be the ABS General Social Survey. This triennial survey, commencing in 2002, will enable measurement of multiple social disadvantage across peoples' lives, as well as providing information on one key population health indicator, that of self-reported health status. This will allow the health status of individuals to be linked to potential stressors such as unemployment, divorce or separation, violence, gambling problems and social support. Data will be available at the capital city/rest of state/territory level.

The proposed, but currently unfunded, Australian Health Measurement Survey (AHMS) program would complement and validate some existing self-report health data by collecting objective measures on biological conditions. The survey program would include core measures taken at every survey, covering the major risk factors and determinants for chronic disease, and special interests modules that will change

at each survey and will focus in more detail on particular disease or topics of interest. It has been proposed that the surveys include children as well as adults and contain a longitudinal component of 10 years linkage, for example, to the national cancer and death registers. It has been proposed that the survey will be run every six years, probably in conjunction with the ABS National Health Survey. The Business Case for the survey is currently being completed and will be put to the Australian Health Ministers Advisory Council in 2002. The ABS tested the likely public response rate to such a survey in November 2001.

In addition to the above, there have been a few important one-off or discontinued national time-series collections that could potentially provide valuable baseline data if they were repeated, or if some of their measures were incorporated into ongoing data collections. Examples include the 1995 ABS National Nutrition Survey (mentioned above), the National Heart Foundation Australia's Risk Factors Prevalence surveys carried out during the 1980s, the International Diabetes Institute's AusDiab survey carried out in 1999/2000, and the 1997 National Survey of Mental Health and Wellbeing.

#### State-Based Data

Individual state/territory health departments have increasingly been undertaking their own health surveys designed to address their particular health priorities, policies and programs. One of the factors that made this financially viable has been the development of Computer Assisted Telephone Interview (CATI) technology, which is less expensive than the personal interview methodology traditionally adopted by health surveyors. Other advantages of CATI are improved timeliness of reporting (since the need to transfer data from paper to a computerised data base is eliminated), reduced reporting burden because of the (necessary) short duration of telephone interviews; flexibility of content; ease of interviewer training and supervision; and the generation of a less clustered sample than that produced by face-to-face household interview surveys. Although initially (and to some extent still) used for one-off surveys, there has been a trend towards the use of CATI methodology to generate time-series data through programmatic health surveying using core data collection modules. Some states, most notably NSW, WA and SA, are now moving beyond the concept of discrete surveys towards continuous surveillance, which requires both ongoing infrastructure and financial support.

There has been a considerable amount of interest at both the state and federal level in the development of consistent and comparable CATI surveys. Informal liaison and discussion among interested parties led to the formal establishment in 1999 of a National CATI Health Survey Technical Reference Group as a sub-committee of the National Public Health Information Working Group. Achievements of the Technical Reference Group to date have included initiating work on the development by of standardised modules on demographics, asthma and diabetes for inclusion in population health surveys; organising and participating in CATI Forums both in Australia and internationally at which the latest developments in the field have been presented and discussed; and the implementation of "buddy" surveys which have allowed the states with the greatest experience in CATI methodologies to assist other states. Groupings used for these surveys have been SA/WA/NT; and

Victoria/Tasmania. Collections for the ACT have been conducted by NSW. Most recently, the CATI TRG has agreed on core modules for smoking, nutrition, alcohol, physical exercise and stress.

Progress in the area of CATI health surveys is occurring rapidly, both in terms of cooperation between jurisdictions, and at the individual state/territory level. The situation of each state/territory as at December 2001 is summarised below:

### **Australian Capital Territory**

Although the Department of Health and Community Care does not have its own CATI survey program, it has a partnership with NSW and participated in the 1999 Older Persons survey.

### **New South Wales**

The Epidemiology and Surveillance Branch of the New South Wales Health Department has the most highly developed CATI health survey program of the Australian states and territories. Between 1997 and 2001, the NSW Health Survey Program conducted four state-wide surveys — two adult health surveys (16+ population), one child health survey, and one older persons survey. From January 2002, the Program will commence continuous data collection relating to the whole state population from birth upwards. The NSW Health Survey Program will continue to use a core set of questions and modules previously developed. These modules will be reviewed regularly and additional modules will be developed and successively added while others will be removed. The survey will focus on providing information to support the public health priority areas in Healthy People 2005 (the NSW Chronic Disease Prevention Strategy), social determinants of health, individual or behavioural determinants of health, major health problems, population groups with special needs, settings, partnerships and infrastructure. The program will conduct at least 2,000 interviews per month for 11 months of the year, generating an annual total of at least 22,000 interviews. Data can be disaggregated to the level of Area Health Service regions.

### **Northern Territory**

Territory Health has participated with SA and WA in the 2000 WANTSA survey. Because of the nature of its population, in particular its large remote and Aboriginal population, the CATI methodology (which assumes a high rate of home telephones) is of little value in the NT, at least outside Darwin and Alice Springs. The benefit of involvement in WANTSA has been that it has involved program-makers in thinking about the population level information base needed for planning health interventions.

### **Queensland**

Ad hoc CATI health surveys have been operating in Queensland Health since 1993 on specific issues, including a general health survey in 1998 with a sample of 5,600. Data can only be disaggregated for Brisbane and the rest of the state. Queensland is

now formulating a seven-year plan for health surveys in order to move towards a more systematic approach.

### **South Australia**

Population health surveys in South Australia commenced in 1988 with the development of the SA Health Omnibus survey. This is an annual health interview survey of people in face-to-face interviews. It currently selects a random sample of 4,500 people from ABS Collectors' Districts. The Omnibus survey is self-funded, with users paying for their own questions. SA trailed the adding of a physical measurement component to this survey in 2001.

South Australia developed the first CATI state-wide health survey system, SERCIS (Social, Environmental and Risk Context Information System), in 1995. It has conducted at least one state-wide survey per year since 1997. South Australia is planning to introduce a monthly rolling survey of 600 interviews, the South Australian Monitoring Survey (SAMS), in early 2002. This will be similar to the NSW and WA CATI health survey programs. The core question set will include chronic diseases, risk factors and health behaviours. Each interview will take about 15 minutes. Data will be aggregated over time and then disaggregated geographically to provide a metropolitan/non-metropolitan breakdown after one year, and breakdowns for each of the eight health regions by the end of the second year of the program.

### **Tasmania**

Tasmania undertook a one-off CATI survey focused on community capacity, health and wellbeing in late 2001, with Victorian technical assistance. The sample of 2500 was drawn from four selected communities.

Tasmania carried out a mail-back household survey with a sample of 25,000 in 1998 because it found CATI to be too costly for a small jurisdiction. At this point, Tasmania has no plans or resources to institute an ongoing CATI health survey program.

### **Victoria**

Following a pilot study in 1998 and a demonstration survey in 1999, Victoria commenced a three-year CATI health survey program involving five surveys in August 2001. This health population survey had a sample of 7,500 and data will be disaggregated and published at the level of Department of Human Service regions. Another population survey will be carried out in 2002, as well as a topic specific survey. The Victorian Health Promotion Foundation is making a financial contribution towards this program.

Victoria also assisted Tasmania to carry out a CATI survey in 2001.

## Western Australia

Western Australia carried out its first state-wide health survey in 1995. In 2000, it undertook a state-wide CATI survey on health and wellbeing in cooperation with SA and NT, and is planning to institute its own continuous CATI surveillance program in February 2002. This will generate 6,000 interviews per year, with data eventually available at the regional level. There will be four different versions of the survey, one for adults, one for children, one for adolescents and one for older adults (70+). However, all will include questions on chronic diseases, risk factors, and wellbeing.

### Data Analysis, Integration and Dissemination

Despite the collection of considerable amounts of data on chronic diseases and their associated risk factors in Australia, as outlined above, the absence of an information system focused on chronic disease prevention means that analysis and dissemination of this data is highly fragmented. Difficulties faced by program staff can include:

- the large number of different data sets and surveys, often using inconsistent definitions;
- a lack of available expertise in judging which measures from which collections are most appropriate for use in program planning and evaluation;
- an absence of locally relevant data;
- a lack of appropriate comparative data;
- gaps in available data;
- a lack of timely or current data.

As the discussion of international trends showed, data integration, including the use of indicator sets, can be an important tool in overcoming this difficulty.

Australia has developed indicator sets for each of the six National Health Priority Areas — cardiovascular disease, cancers, injuries, mental problems, diabetes, and asthma. Most of the measures in these indicator sets relate to prevalence or incidence, although the cardiovascular indicator set includes eight health risk factors, including smoking and physical activity. An audit of the five NHPA indicator sets existing at the time of AIHW's *Australia's Health 2000* reporting showed that more than 60 out of 120 indicators were unable to be reported, and that 45 out of 120 also had no baseline data. Moreover, the majority of those indicators that could be reported were using data from 1998 or previous periods. Berkelman et al. note that "rapid turn-around of data is usually more important than absolute accuracy and completeness, rarely have provisional data driven major public health decisions in directions different from those that would have been based on final data".<sup>13</sup>

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<sup>13</sup> Berkelman, RL, Stroup, DF, and Buehler, JW. "Public health surveillance" in Detels, R et al. [eds] (1997). *Oxford Textbook of Public Health*, Vol 2 The Methods of Public Health. 3<sup>rd</sup> ed. New York: Oxford University Press. P746

Data from the NHPA indicator sets is brought together in the biennial AIHW publication, *Australia's Health*, which reports national level data on each of the NHPA diseases and conditions, as well as on a number of other major chronic diseases, namely chronic obstructive pulmonary disease, arthritis and other musculoskeletal disorders, nervous system disorders, end-stage renal disease and cirrhosis and other chronic liver diseases. *Australia's Health* is the major reference work on patterns of health and illness in Australia, determinants of health, supply and use of health services and health services costs and performances. It provides a valuable overview of chronic disease, and is frequently used for benchmarking. *Australia's Health* will be complemented by the newly released AIHW publication *Chronic Diseases and Associated Risk Factors in Australia, 2001*.

In addition, some of the available data on chronic diseases and associated risk factor is currently made available to users in a more flexible format through the Healthwiz software program, produced by DHA. HealthWIZ provides a range of data including death statistics, hospital morbidity data, cancer registry data, and health survey data across population groups, including geographical areas, sexes, ages and ethnic groups. Its advantages are that users are able to carry out their own analysis, and to find data for the sub-population that they are concerned with. Its disadvantages are that it is still not particularly easy to use, and that the data are rather old and incomplete. Small numbers in some cells can lead to interpretation problems for the uninitiated. Nevertheless, HealthWIZ has been very important in enabling non-computer experts to access data in the area of chronic disease and associated risk factors.

In summary, trends in Australia in the area of monitoring chronic disease and its associated risk factors appear to be moving in the same general direction as those in comparable developed countries. In particular, Australia has well-established administrative and national survey data collections, rapidly developing expertise in the use of appropriate and inexpensive data collection techniques and in data harmonisation, and a number of relevant indicator sets. The main deficiencies that emerged from a comparison of best practice internationally and in Australia were a lack of data on small areas and priority population groups, limited integrated reporting, and a lack of timely data.

## 4. Framework(s)

Three complementary health system frameworks have been used as a basis for the feasibility study. The first two, the Strategic Framework for Preventing Chronic Disease and the National Health Performance Framework, were used by the audit phase of the project to consider questions relating to content at a conceptual level and from a system monitoring perspective. They were used to construct a proposed information framework for the monitoring of chronic disease and associated risk factors in Australia.

In addition, the World Health Organization's Stepwise approach has been used for Part 3 of the project, because it applies specifically to the issue of behavioural risk factor surveillance, and provides a model for the prioritisation and staging of surveillance programs.

The Strategic Framework for Preventing Chronic Disease

This conceptual framework, shown as Figure 1 below, maps a "cluster" of risk and protective factors, biological risk factors (or markers) and preventable conditions, broadly aligned with the National Health Priority Areas, which it proposes should comprise the long range focus for chronic disease prevention effort:

"The intention in the first instance is to improve coordination around a manageable number of related conditions which are known to be preventable, share common risk factors, and constitute a significant proportion of the total burden of disease."<sup>14</sup>

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<sup>14</sup> National Strategies Coordination Working Group *op cit* p.7

**Figure 1: "Clusters" of chronic disease conditions and risk factors**

<b>Risk and Protective Factors</b>	<b>Biological Risk Factors/Markers (eg)</b>	<b>Preventable Chronic Diseases and Conditions</b>
<p><b>Behavioural Factors</b></p> <ul style="list-style-type: none"> <li>▪ Diet</li> <li>▪ Physical Activity</li> <li>▪ Smoking</li> <li>▪ Alcohol misuse</li> </ul> <p><b>Psychosocial Factors</b></p> <ul style="list-style-type: none"> <li>▪ "Sense of control"</li> <li>▪ Social support/social exclusion</li> <li>▪ Resilience and emotional well-being</li> </ul> <p><i>Possible inclusion:</i></p> <ul style="list-style-type: none"> <li>▪ Chronic stress</li> </ul> <p><b>Early Life Factors (eg)</b></p> <ul style="list-style-type: none"> <li>▪ Low birthweight</li> <li>▪ Childhood infections</li> <li>▪ Abuse and neglect</li> </ul>	<ul style="list-style-type: none"> <li>▪ Obesity</li> <li>▪ Hypertension</li> <li>▪ Dyslipidemia (disordered lipids, including elevated cholesterol)</li> <li>▪ Impaired Glucose Tolerance</li> <li>▪ Proteinuria</li> </ul>	<ul style="list-style-type: none"> <li>▪ Ischaemic Heart Disease</li> <li>▪ Stroke</li> <li>▪ Type 2 Diabetes</li> <li>▪ Renal Disease</li> <li>▪ Chronic Lung Disease (COPD &amp; Asthma)</li> <li>▪ Certain Cancers (eg colorectal, lung)</li> <li>▪ Mental health Problems/Depression*</li> </ul> <p><i>Possible inclusion:</i></p> <ul style="list-style-type: none"> <li>▪ Oral health*</li> <li>▪ Musculo-skeletal disease</li> </ul>
<p><b>Non modifiable factors:</b> Age, sex, ethnicity, genetic make-up, family history  <b>Socio-environmental determinants (may or may not be modifiable):</b> Socio-economic status, community characteristics (eg presence/absence of social capital), working conditions, environmental health etc</p>		

\* can also be defined as risk/protection factors

The Strategic Framework for Preventing Chronic Disease is important because it provides an overall conceptual model for the link between chronic disease and associated risk factors. As an AHMAC-endorsed Framework it provides an important context for the further development of a national approach for the prevention of chronic disease, which also informs the development of monitoring and surveillance approaches. The framework clearly indicates that behavioural risks are an important component of the overall set of risk and protective factors associated with chronic disease.

The National Health Performance Framework

Published in August 2001 by the National Health Performance Committee, the new National Health Performance Framework (see Figure 2 opposite) has been adapted from the Canadian Institute for Health Information framework developed as part of the Canadian Roadmap Initiative. The framework is intended to provide relevant information on high-level goals and objectives of the Commonwealth and state health systems.

**Figure 2: National Health Performance Framework**

<b>Health Status and Outcomes</b>			
<b>How healthy are Australians? Is it the same for everyone? Where is the most opportunity for improvement?</b>			
<b>Health Conditions</b>	<b>Human Function</b>	<b>Life Expectancy and Wellbeing</b>	<b>Deaths</b>
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.

<b>Determinants of Health</b>				
<b>Are the factors determining good health changing for the better? Is it the same for everyone? Where and for whom are these factors changing?</b>				
<b>Environmental Factors</b>	<b>Socioeconomic Factors</b>	<b>Community Capacity</b>	<b>Health Behaviours</b>	<b>Person-related Factors</b>
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.

<b>Health System Performance</b>		
<b>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?</b>		
<b>Effective</b>	<b>Appropriate</b>	<b>Efficient</b>
Care, intervention or action achieves desired outcome.	Care/intervention/action provided is relevant to the client's needs and based on established standards.	Achieving desired results with most cost effective use of resources.
<b>Responsive</b>	<b>Accessible</b>	<b>Safe</b>
Service provides respect for persons and is client orientated. It 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 or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered.
<b>Continuous</b>	<b>Capable</b>	<b>Sustainable</b>
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).

The framework consists of three tiers: Health Status and Outcomes, Determinants of Health and Health System Performance. According to the NHPC report:

"These tiers do not represent a hierarchy but reflect the fact that health status and health outcomes are influenced by the impacts of health determinants and health system performance. Questions are posed for each tier and dimension and it is anticipated that performance indicators will be chosen or developed to provide answers to the questions that will give us a guide as to how well the health system is doing."<sup>15</sup>

The National Health Performance Framework is a useful tool for positioning the monitoring and surveillance of chronic disease and associated risk factors within an overall context. As an AHMAC-endorsed framework it provides important guidance for the further development of national systems of indicator development and data collection.

The audit phase of this project constructed a proposed information framework for monitoring chronic disease and associated risk factors by populating the National Health Performance Framework with topics taken from the Chronic Disease Prevention Strategy Framework (see Figure 3).

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<sup>15</sup> National Health Performance Committee. **National Health Performance Framework Report : a report to the Australian Health Ministers' Conference** August 2001 p.1

**Figure 3: Conceptual framework for monitoring chronic disease and associated risk factors**

<b>HEALTH STATUS AND OUTCOMES</b>				
<b>How healthy are Australians? Is it the same for everyone? Where is the most opportunity for improvement?</b>				
<b>Health Conditions</b>	<b>Biological Conditions</b>	<b>Human Function</b>	<b>Life Expectancy and Wellbeing</b>	<b>Deaths</b>
Ischaemic heart disease Stroke Certain cancers † Mental health problems /Depression * Musculoskeletal dis (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	
<b>DETERMINANTS OF HEALTH</b>				
<b>Are the factors determining health changing for the better?</b>				
<b>Person-related Factors</b>	<b>Health Behaviours</b>	<b>Community Capacity</b>	<b>Environmental Factors</b>	<b>Socioeconomic Factors</b>
	Tobacco exposure: - smoking - passive Risky Alcohol intake Physical inactivity Exercise (asthma) Diet	Characteristics of communities & families such as: Housing quality Community services eg support, transport etc Literacy level Health literacy	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 inc employment status, relations & condtns Parents' occ at time of birth Food security Systems, eg taxation, social welfare Policies
<b>Early Life Factors</b>	Supplements (musculoskeletal dis) Food chemicals Analgesic use Substance use Medications  Preventative dental behaviours	<b>Psychosocial factors</b> Psychosocial stress (life stress) eg arising from interpersonal violence, discrimination, etc (cortisol) Support & relationships - Low social capital - Low social support Low resilience		
Low birth weight Low breastfeeding rate Intrauterine growth retardation Poor early childhood devlpmnt Abuse, neglect & exposure to domestic violence				
<b>HEALTH SYSTEM PERFORMANCE<sub>§</sub></b>				
<b>How well is the health system performing in delivering quality health actions to improve the health of all Australians?</b>				
<b>Effective</b>	<b>Appropriate</b>		<b>Efficient</b>	
<b>Responsive</b>	<b>Accessible</b> Accessibility to treatments for each of the health conditions above Accessibility to prevention programs		<b>Safe</b>	
<b>Continuous</b>	<b>Capable</b>		<b>Sustainable</b>	
<b>Contact with health system and disease management</b>				
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; § health system performance factors are being considered here only as risk factors for chronic disease.

## The World Health Organization Stepwise Framework

The third framework which was seen as relevant to the study, and in particular to Part 3, was the WHO Stepwise approach to monitoring non-communicable disease risk factors. As discussed above, WHO has taken a leading role in encouraging member states to develop strategies for the prevention of chronic disease, partly through the development of tools such as the Stepwise approach.

According to WHO, four considerations should guide the choice of risk factors for inclusion in surveillance activities:

- **the significance of the risk factor for public health** in terms of the nature and severity of the morbidity, disability and mortality of the non-communicable diseases (NCDs) with which it is associated;
- **the cost of collecting valid data** on a long-term and repeated basis;
- **the availability and strength of the evidence** that intervening on the factor will influence it and reduce NCDs in the community; and
- **the ability to measure the risk factor burden uniformly** in different settings to ensure comparability and to measure changes over time.<sup>16</sup>

The WHO Stepwise approach is based on two key premises: collection of standardised data and sufficient flexibility for use in variety of situations and settings. It encourages the development of an increasingly comprehensive and complex surveillance system, while emphasising that small amounts of good data are more valuable than large amounts of poor quality data. Figure 4 below sets out the conceptual framework for the WHO Stepwise approach. Step 1 represents self-report measures, Step 2 self-report plus physical measures, and Step 3 self-report plus physical plus biochemical measures.

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<sup>16</sup> Bonita, R, de Courten M, Dwyer T et al. **The WHO Stepwise Approach to Surveillance (STEPS) of NCD Risk Factors**. Geneva, World Health Organization, 2001 p.7

**Figure 4: WHO STEPwise Approach to Surveillance**

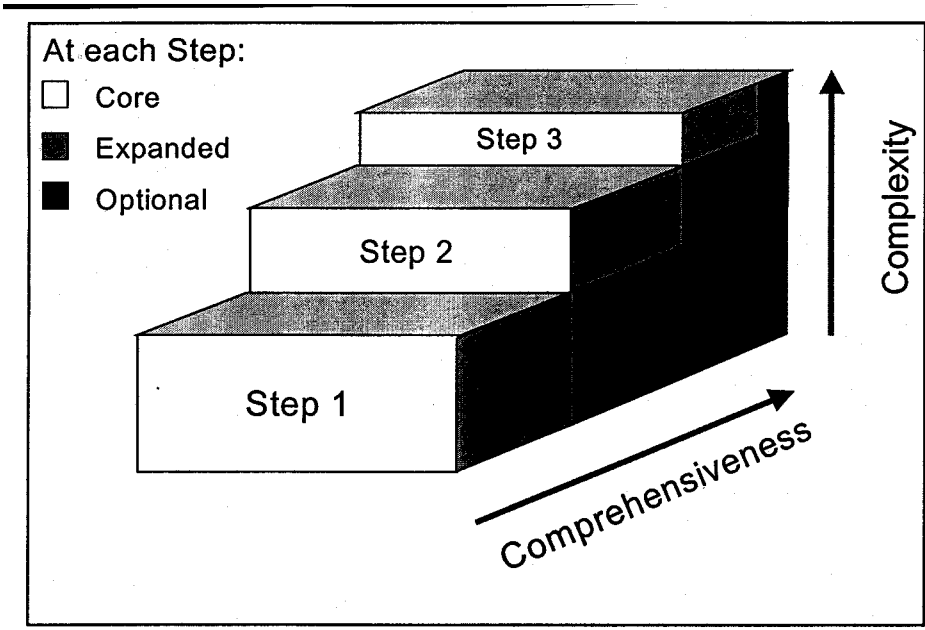


Table 1 below sets out the core and expanded core risk factors recommended for monitoring by the Stepwise approach, as well as some examples of optional additional variables.

**Table 1: STEPS Levels of Risk Factor Data Assessment**

Measures Level	Step 1 (Verbal)	Step 2 (Physical)	Step 3 (Biochemical)
<b>Core</b>	Demographic, Tobacco, Alcohol, Nutrition, Physical inactivity	Measured weight + height, Waist girth, Blood pressure	Fasting blood sugar; Cholesterol
<b>Expanded Core</b>	Education, Household Indicators, Dietary pattern	Hip girth	HDL-Cholesterol, Triglycerides
<b>Optional (examples)</b>	Other health-related behaviours; Knowledge + attitudes regarding health;	Timed walk, Skinfolds, Pedometer	Oral glucose tolerance test; Urine examination

## 5. Rationale, Objectives and Definition

The discussion paper distributed to key stakeholders suggested that a nation-wide chronic disease and associated risk factor information and monitoring system had the potential to inform public health policy, practice and action in a number of important ways. In particular, it could be used to:

- detect trends in chronic diseases and suggest prevention and control measures;
- contribute to an understanding of disease etiology and natural history;
- evaluate prevention and control measures;
- detect changes in associated risk factors;
- detect changes in related health practices;
- facilitate planning of health policies and programs.

In undertaking the feasibility study, the consultants worked on the assumption that, provided stakeholders accepted the above rationale, the essential choice was between developing a new nation-wide system, or creating a nation-wide system utilising existing data collections. In either case, the potential users of such a system would extend beyond Commonwealth and state/territory departments and agencies, and would include, for example, Divisions of General Practice, local government, Primary Care Partnerships, and non-government organisations.

The extent to which there was consensus among stakeholders as to the need for a chronic disease and associated risk factor monitoring and information system to adequately meet these needs depended to a considerable extent upon how narrowly or broadly the word "system" was defined. The then DHAC in particular felt strongly that a lack of integrated data that could be disaggregated to the small area level was hindering Australia's effective response to the challenge of chronic disease. They pointed to a number of Commonwealth initiatives in chronic disease prevention and control, which they believed could be better supported and evaluated if such a system was in existence. These included:

- Population health projects in Divisions of General Practice, including the SNAP (smoking, nutrition, alcohol, physical activity) framework for developing integrated approaches to behavioural risk factor management within General Practice.
- Rural health initiatives.
- Aboriginal and Torres Strait Islander Health.
- Chronic disease initiatives under the Enhanced Primary Care program, including Sharing Health Care (formerly the Chronic Disease Self Management initiative) and the Coordinated Care Trials.
- The Commonwealth's contribution to national strategies such as nutrition, physical activity, tobacco and alcohol.
- Mental health initiatives, such as Mind Matters.

- Health inequalities research initiatives.

Other jurisdictions, however, did not necessarily share the Commonwealth's sense of urgency. Some felt that the data they were collecting (or were planning to collect) at state or territory level, along with benchmarking data from existing national surveys, would largely meet their population health monitoring needs. Leaving aside the already well-developed proposal for a national health measurement survey, there was no support among other jurisdictions for the establishment of a "new" data collection based on the BRFSS, particularly if it involved the contribution of financial and/or human resources by states and territories. In general, stakeholders felt that gaps in data could be better remedied through development of existing data collection systems. There were also concerns expressed about the imposition of further data collection requirements onto states and territories by the Commonwealth, and the possible uses to which the Commonwealth might put unit level data provided to it by other jurisdictions.

On the other hand, stakeholders from most states and territories could see some potential advantages in greater partnership between jurisdictions organised through an inclusive nation-wide coordinating mechanism. Within such an arrangement, jurisdictions were interested in further development, harmonisation, analysis and dissemination of existing administrative and population health data collection systems at both the national and state/territory level. In this sense, stakeholders could be said to support the development of a nation-wide system.

The audit phase of the project generated the following proposed objective for a nation-wide chronic disease and associated risk factor information and monitoring system:

To provide ongoing trend information about chronic disease outcomes and their associated risk factors, socio-economic determinants and health practices, in order to inform public health action including the planning and evaluation of health policies, strategies, programs and other prevention and control measures.

This recommendation supports Recommendation 1 of the Chronic Disease Prevention Strategy, namely ensuring an effective information base to guide action, including strengthening national capacity to track change in the risk profile of the population.<sup>17</sup> This objective was generally acceptable to stakeholders, although some made the point that surveillance should be seen as an integral part of public health action, rather than merely as informing action. Stakeholders agreed that the functional elements of such a system would be made up of data collection, data analysis, interpretation, dissemination and use. All elements should be designed and carried out in ways that were relevant to both policy and practice. Stakeholders envisaged these elements as making up a circular, feedback model, in which users of the data are able to contribute to the further development of the system, rather than an input/output model.

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<sup>17</sup> *ibid.* p.50

## 6. Priorities for Action

The audit phase of the project developed the conceptual framework proposed in Figure 3, which was generally acceptable to stakeholders. Acceptance of this framework signals an understanding and acceptance of the fact that chronic disease is caused by the interaction of a wide variety of individual, social and environmental factors. It suggests that over the longer term it may be possible to develop a complex nation-wide information and monitoring system in which many different types of data are collected using multiple strategies, and are brought together in different combinations for different users. However, as discussed below, there were considerable differences in opinion as to which elements of the framework should be prioritised for immediate action.

The audit also recommended that information for a nation-wide system be developed using a combination of the following four strategies:

- a) use of existing data collections;
- b) development of components of state-wide collections so data can be harmonised;
- c) development of a national survey with components of objective measurement; and
- d) repetition of past, one-off national surveys to obtain time series data.

Overall, stakeholders supported this approach, which was in line with their preference for a partnership-based system coordinated through NPHIWG and built upon existing elements. In terms of specific strategies, there was little active support for the repetition of one-off national surveys. Where past surveys had generated valuable baseline data, stakeholders preferred to create time series data by incorporating relevant questions or measures into other, ongoing data collections.

Beyond this general level of agreement, however, there was considerable disparity of views as to the priorities for future action, in terms of content areas, information development strategies, and the elements of a nation-wide system that should be progressed most quickly.

The Commonwealth's views on this matter were clearly set out in the original tender document, which stated that Part 3 of the project should consist of a "feasibility study for developing a nation-wide behavioural risk factor surveillance system", with an emphasis on "the coordination and harmonisation of approaches across all jurisdictions". The present report therefore concentrates on the issue of behavioural risk factor monitoring.

Nevertheless, it is important to note that while no one who took part in the consultations disputed the importance of individual behavioural risk factors, or was opposed in theory to greater coordination and harmonisation, this was not necessarily a high priority (or even a priority) for all jurisdictions. Some stakeholders felt that their needs for behavioural risk factor data were (or would be) reasonably well met by their state surveys combined with the use of NHS data for benchmarking and validation. They were often more interested in the development of data on other types of risk factors (for example, in areas such as community capacity and cohesion,

and environmental risks) and/or in the development of the health system performance tier of the information framework. Some jurisdictions have a particular interest in specific population groups, such as Aboriginal and Torres Strait Islander people, young people or children, and see the development of data on these groups as being of high priority.

Some stakeholders felt that the issue of coordination and harmonisation was not currently relevant to them, because their jurisdiction could not afford to implement a health survey system. Others reported that they were not funded at a level that would make it possible for them to devote additional time and resources to coordination and harmonisation.

We conclude on the basis of the consultations that there is support for the development of a nation-wide partnership model between jurisdictions for the collection, analysis and reporting of data on behavioural risks associated with chronic disease. However, we found that it is neither feasible nor desirable to duplicate the US Behavioural Risk Factor Surveillance System in Australia, although the concepts and the lessons are highly relevant. Moreover, while there is scope for further harmonised and coordinated behavioural risk factor monitoring and information, it will be difficult to achieve this unless it takes place within the context of a broader process which acknowledges the varying priorities of different jurisdictions with respect to the monitoring of chronic diseases and their associated risk factors.

## 7. A Nation-wide Behavioural Risk Factor Information and Monitoring Program

Taking into account the findings of our consultations, we recommend the introduction of a nation-wide behavioural risk factor information and monitoring program which would initially involve the development, collection, analysis and dissemination of a limited amount of data on the four core SNAP areas — smoking, nutrition, alcohol misuse, and physical inactivity. The program should be reviewed after implementation and, if successful, could be expanded to cover other behavioural and associated risk factors. However, participation in the initial program would not entail an open-ended commitment to participate in an expanded program. Overall responsibility for the coordination, development and implementation of the program would lie with the NPHP and specifically the NPFIWG.

NPFIWG already brings together representatives of all the key players who would participate in the program — the Commonwealth, the states and territories, the Australian Institute of Health and Welfare (AIHW), and the Australian Bureau of Statistics (ABS). This role would fit comfortably within its Terms of Reference, which are to:

- contribute to the direction, development and review of public health datasets, supported by a well-developed information plan and work program, within the provisions of the National Health Information Agreement;
- make recommendations to the Partnership Group on national public health information priorities, work programs, funding implications and other policy issues;
- liaise with other Partnership working groups as well as with the National Health Information Management Group on data issues; and
- consult with other groups and individuals for the collection and dissemination of public health information that will contribute to the selection and implementation of appropriate public health interventions.

Moreover, NPFIWG is already actively involved in a consideration of these issues through its Chronic Disease Monitoring and Surveillance Sub-Committee.

Commitment and participation by jurisdictions, however, will be critical to success in implementing our recommended option. In particular, there is significant potential for building on and enhancing existing CATI programs conducted by states and territories and a closer linkage between these programs and the National Health Survey conducted by the ABS. The Commonwealth, through the Department of Health and Ageing (DoHA), has an important role to play in providing the necessary additional resources required to develop and implement the program that we propose.

The functional elements of the program would be as follows:

- **development** of data items through an inclusive process under the auspices of the **NPHIWG**;
- **collection** of data using CATI by participating **states/territories**;
- **warehousing** of data and integrated **reporting** and **dissemination** by **AIHW**;
- detailed (especially small area) **analysis** of data, and **technical support** to all participants by a new **AIHW Collaborating Unit**;
- **connection** to the National Health Survey through **ABS** participation in the NPHIWG process;
- **review** of program by NPHIWG.

In addition, we recommend the establishment of a number of **specialist chronic disease and risk factor monitoring and information units**, each of which would focus on the development and collection of data on a sub-population of particular concern.

#### The Core CATI Concept

Building on the existing CATI collections is central to the proposed program. Following international experience and in accordance with the WHO Stepwise framework, we believe there is value in limited input harmonisation. To this end we support the development of a Core CATI based on the collection of data on smoking, nutrition, alcohol, and physical activity (SNAP) for systematic incorporation into existing State CATI systems.

The Core CATI would consist of a limited number of questions that would be integrated into existing state/territory health survey/surveillance programs. The choice of the four SNAP topics as the content is made on both theoretical and practical grounds:

- These are the four "classic" behavioural risk factors associated with the major chronic diseases included in the Strategic Framework for Preventing Chronic Disease (see Figure 1). They also correspond (along with basic demographic data), to the core items contained in Step 1 of the WHO Stepwise approach (see Table 1).
- SNAP data is directly relevant to many if not all Commonwealth initiatives in the area of chronic disease prevention and control. In particular, a SNAP Framework has been adopted by the Joint Advisory Group of General Practice and Population Health as a major General Practice initiative.
- Most states/territories already collect data in these areas and are currently working together voluntarily through the CATI TRG process to harmonise data collection.

There are also strong arguments for, and interest in, adding a psycho-social measure (possibly the Kessler Psychological Distress Scale) to the SNAP variables either from the outset, or as a second stage in the development of the core CATI concept.

## Data Development

In December 2001, the CATI TRG hosted a workshop to determine whether core, and optional (highly recommended) content for state-wide population health surveys and/or continuous surveillance programs using CATI methodology could be agreed for SNAP(s)<sup>18</sup> topic areas. The workshop, which was attended by representatives of all states except Tasmania, agreed on 25 core questions: 2 on smoking, 3 on nutrition, 2 on alcohol consumption, 6 on physical activity, 10 on stress (the Kessler Psychological Distress Scale), and 2 on Body Mass Index (height, weight). The workshop also reviewed modules on demographics, asthma and diabetes previously sent to the ABS for cognitive testing and agreed on 13 core content questions or topics — 10 on demography (including social determinants of health), 2 on asthma and 1 on diabetes. Core content was defined as those questions that are or will be asked all the time, giving a minimum of national reporting. Details of the questions agreed to are included as Appendix C to this report.

It is recommended that the provisional core CATI should consist of either:

- a) The 15 SNAP questions plus 10 demographic questions adopted at this meeting.
- b) The 25 SNAP(s) questions plus 10 demographic questions.

The demographic questions cover the following variables: household size/structure, postcode/locality, indigenous status, number of telephone numbers in household, number of White Pages listings, age, sex/gender, highest level of education attained, employment status and household income. The inclusion of these questions in the core CATI means that it can be used both as a stand-alone survey tool and as one component of a larger survey, and that the data can be disaggregated in a number of standard ways. This is also consistent with the inclusion of demography in the core component of Step 1 of the WHO Stepwise approach.

Data development based on the provisional core CATI should proceed under the auspices of the NPHIWG. The NPHIWG should have responsibility for strategic leadership and coordination of these activities, building on the well-developed collaborative relationships that have been established.

By agreement among participants, data collected during 2002 and 2003 should be treated as test data for the program. It is anticipated that the proposed new AIHW collaborating unit (see Data Dissemination below) would work closely with the states/territories from early in 2003 to review and analyse this data. The results of this process would be shared internally among all participants and would feed into the NPHIWG data refinement process, with a view to commencing formal data collection under the nation-wide program at the beginning of 2004. Although individual states/territories would of course continue to publish some or all of their own data during this period, external distribution or publication of any aggregated or cross-jurisdictional data collected during the period 2002/2003 would only be possible with the express consent of all participants.

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<sup>18</sup> smoking, nutrition, alcohol, physical inactivity and stress

This timetable assumes an overlap between data development and the institution of the formal nation-wide program. However, none of the agreed provisional core questions is experimental. All have been used before in either state or national surveys. Thus, in balancing up the need to begin collecting and producing data against the requirement for high quality and stable time series data, there is a strong argument for allowing data collection and further refinement of the data questions (and associated protocols) to proceed to some degree simultaneously, in the expectation that the "final" core CATI questions (coding categories etc.) will not differ substantially from those included initially.

## Data Collection

Core CATI data will be collected by states/territories under an agreement with DoHA. Recommended funding arrangements are set out below.

It is recommended that core CATI data should be collected annually by all jurisdictions. This would allow for any rapid changes in behaviour as a result of intervention programs to be detected reasonably quickly as time series data becomes available. Any agreed changes to definitions, data collection methods, etc. would be instituted from the beginning of the calendar year. In the short to medium term, the question of how to handle seasonality issues that may arise from different data collection periods within the annual cycle should be considered as part of the ongoing NPFIWG process. Ideally, in the longer term, all jurisdictions would be involved in continuous data collection.

Agreed sample sizes for each state/territory should be calculated on the basis that the data will be disaggregated to appropriate health region levels. Determination of appropriate regions will depend on Commonwealth, state and territory administrative arrangements and may vary from jurisdiction to jurisdiction to ensure the information that is collected and reported is useful for program planning and evaluation. Over time, the potential for commonality for small area analysis should be explored around the use of catchments for Divisions of General Practice. This will potentially allow researchers, planners and evaluators from different jurisdictions to explore regional differences in health-related behaviours, to focus intervention measures, and to assess the effectiveness of regionally-based programs.

As described above, most states have already decided to implement the core CATI questions as part of their normal survey/surveillance program. Although this minimises their cost of participation (in terms of both time and human resources), it should be recognised that they will nevertheless incur at least some additional expenses. They may need to increase the size of their survey sample (see below) and/or the frequency of data collection. Copies of the data will need to be forwarded to AIHW within an agreed timeframe (see below). They will need to devote a higher level of human resources to participation in NPFIWG and the structures it sets up to implement the program. Once they have entered into an agreement to participate in the program, agreements will need to be reached to ensure that surveys are continued on an agreed basis for the life of the program.

In the case of those states/territories that do not have an ongoing CATI program, there are two options:

- i. They could be funded to a level that would enable them to carry out an annual survey including or comprising the core CATI.
- ii. Larger adjacent States could be funded to work in partnership with them to carry out an annual survey. This process was successfully achieved through the "buddy" surveys conducted recently in SA/WA/NT and Victoria/Tasmania, and has worked on an ongoing basis for ACT with NSW.

In the case of the NT, CATI surveying may only be feasible for Darwin and Alice Springs. Possible alternative arrangements for ATSI and remote area communities are proposed in a separate report (Part 4), and below under Specialist Chronic Disease and Risk Factor Monitoring and Information Units.

#### Data Warehousing and Integrated Reporting

The AIHW is the most appropriate body to house and provide summary reporting on the nation-wide core CATI data, and its Act provides appropriate privacy protection. As mentioned above, AIHW already houses and provides integrated reports on several harmonised administrative and survey data collections that provide information on chronic disease and associated risk factors. By adding information from harmonised state-based CATI surveys on the major behavioural risk factors to these collections, AIHW will be in a position to provide enhanced integrated reporting on trends in chronic disease and associated risk factors in Australia.

Under formal agreements entered into with AIHW, states/territories would forward a copy of their de-identified unit record data, including some geo-coding, to AIHW within an agreed period of time after collection. In turn, AIHW would clean and edit the data and report annually on the data at a national and state/territory level, probably as part of a larger regular report on chronic diseases and associated risk factors. The complete turnaround time for the data should be less than 12 months; that is, data collected within a particular calendar year should be reported before the end of the following calendar year.

AIHW would also be responsible for the timely dissemination of annual national data files to all jurisdictional participants, including DoHA. These files should allow for the analysis of data at state/territory and regional level. Protocols governing publication of regional level data by participants should be developed. The potential for additional methods of data dissemination should be explored. These could include making master files available to universities for use by approved research projects.

#### Specialised Data Analysis and Dissemination

It is proposed that AIHW also appoint a specialist collaborating unit to undertake a number of specialised tasks not covered by AIHW's broader responsibilities for data warehousing, reporting and dissemination in this area.

The collaborating unit would be expected to play a major role in developing Australia's capacity to collect, analyse and communicate behavioural health data as it relates to chronic disease. It would place a high priority on strengthening capacity in the area of small area health statistics, and on the development of mechanisms that will integrate the collection, analysis and communication of data more effectively into the processes of policy development and program design.

The collaborating unit's specific functions would include the following:

1. Undertake additional and in-depth policy relevant analyses of data; in particular, small area health statistics analysis. As explained above, state-based health behaviour survey samples would be calculated to allow for disaggregation to the health region level. However, provided that postcode is included in the core data, it should be possible to re-categorise the data into other "small areas" with comparably sized populations, such as Divisions of General Practice. Protocols should be developed to allow the Collaborating Unit to disseminate small area data to jurisdictional participants and for its publication. Additional and in-depth related analyses of other national health behaviour survey, such as ABS National Health Survey data, would also be an important function.
2. Undertake additional data dissemination, with particular reference to the development of innovative, non-standard formats and small area data dissemination. The potential for using HealthWIZ as one method of data dissemination should be explored. Other relevant models may include the WA product Web-tool, and the Social Health Atlas of Australia.
3. Work with jurisdictional participants to develop additional means of effectively communicating information generated by the health behaviour surveys to ensure the information contributes to policy and program development. Audiences could include the public, health professionals, policy-makers and program staff. Methods could include newsletters, articles, powerpoint presentations, and workshops. Particular emphasis should be given to addressing the question of how health behaviour survey processes can be most effectively and efficiently integrated with the processes involved in the design and evaluation of intervention programs in the area of chronic disease prevention.
4. Provide expert technical assistance specifically related to the collection, analysis and communication of behavioural health data to all participants (including the population health observatories proposed below), both on an individual and group basis. This would include the provision of expertise in the development and use of health behaviour survey techniques, and in the field of small area analysis. In addition to responding to specific requests for assistance by program participants, the collaborating unit would be expected to play a proactive role in improving capacity and expertise through, for example, the provision of workshops, training sessions, technical papers and so on. Special attention should be paid to the needs of those jurisdictions with less expertise and experience in this area. The collaborating unit could also assist in the development of nation-wide capacity by encouraging exchange programs between staff from different jurisdictions and supporting "buddy" arrangements.

In addition, the collaborating unit would be expected to keep abreast of technological, social and legislative trends overseas and in Australia which might impact on the use of health behaviour survey methodology, with a view to developing appropriate response options for consideration by program participants.

5. Through the NPHIWG process, provide expert technical support to jurisdictional participants in the initial and ongoing harmonisation of state-based CATI survey items, and in the harmonisation of CATI survey items with other national data collections, including the NHS (see below).

It is envisaged that the AIHW collaborating unit would be located within an independent institution, possibly a university. It would maintain a close and ongoing contact with all participants in the program, including AIHW, state/territory health departments, DoHA, ABS, the sub-population observatories (see below) and NPHP groups.

It should be noted that the existence of the collaborating unit would not preclude participants from entering into other types of agreements to collaborate in the collection, analysis and/or dissemination of data.

#### Connection to National Health Survey

The National Health Survey is highly regarded by all stakeholders because it provides high quality data at the national and state/territory level that can be used for benchmarking and validation, and to guide broad investment decisions. At the same time, there were some comments about the difficulties of influencing the ABS's decision-making processes with respect to both samples and content. In particular, several stakeholders expressed a desire for a process that would allow for some harmonisation between the NHS and state/territory CATI surveys, and possibly also some rationalisation of questions. This is a desirable development, which should be progressed by ABS involvement in the behavioural risk factor monitoring program through NPHIWG.

The potential for harmonisation with other ABS surveys which touch on issues relevant to chronic disease and associated risk factors, such as the General Social Survey, should also be explored, as should linkages to other, non-ABS national surveys such as the Drug and Alcohol Survey and the proposed AHMS.

#### Review Process

In practice, the data development and review stages of this program would be part of a continuous process undertaken under the auspices of NPHIWG. Ideally, both functions would proceed simultaneously.

## Specialist Chronic Disease and Risk Factor Monitoring and Information Units

It is recommended that DoHA establish and partially fund three or four specialist chronic disease and risk factor monitoring and information units in different Australian states/territories, each focusing on chronic disease prevention and associated risk factors among a sub-population of particular concern. Examples of relevant sub-populations are:

- Aboriginal and Torres Strait Islanders
- Children and young people
- Rural communities
- Low Socio-Economic Status Communities
- Culturally and Linguistically Diverse Communities.

These units could be auspiced by a state health authority or located within a larger institution, such as a university or research institute with an established record in public health research, especially with reference to the relevant population group. They would also be expected to already have or to establish ongoing alliances with agencies and organisations involved in program delivery to the population group. Organisational and management arrangements for observatories should provide for strong state/territory involvement, as well as links to NPHIWG and the AIHW collaborating unit. The possibility of states/territories providing matching funding should be explored, as should other possible sources of funding, such as the NHMRC. It is recommended that units be selected through an Expression of Interest process.

The functions of the units would include:

1. The analysis and publication of existing data on chronic disease and associated risk factors, particularly behavioural risk factors, among their target sub-population.
2. The development and collection of additional data on the target sub-population. Initial data collection would probably concentrate on the sub-population within the particular state/territory in which the unit is located. However, the units would also have a national responsibility, and would be expected to play a leadership role in, for example, developing appropriate data collection and analysis methodologies, testing new data modules and tracking international developments in the specified area.
3. Assisting in the design and, in particular, the evaluation of interventions intended to prevent or control chronic disease among the relevant sub-population.
4. Forwarding data (not necessarily in unit record form) to the AIHW for use in integrated reporting.
5. Communicating expertise and information at the local, state/territory and national level.

More generally, the units can be seen as an important exercise in building capacity and skill in the monitoring of chronic diseases and associated risk factors, and in the linking of monitoring to program intervention. In this sense, their role complements that of the AIHW collaborating unit. It is therefore suggested that they should be located in different states/territories.

## Implementation Plan

It is proposed that implementation of the proposed behavioural risk factor information and monitoring program be staged over a three-year period beginning in 2002. The major implementation tasks are as follows:

**1. Ensure strategic management and coordination of the development of nation-wide behavioural risk factor monitoring.**

This will be an ongoing responsibility for NPHIWG. However, the way in which the early stages are managed, and in particular the inclusiveness of the process, will be crucial to the success of the program, especially the willingness of all jurisdictions to enter into formal agreements to participate.

Inclusiveness can be enhanced by adequate resourcing. It is therefore recommended that DoHA provide funding to NPHIWG to: i) employ a dedicated project officer to work with all participants on the initial development of the program; and ii) cover the costs of meetings and workshops associated with Task 2 below.

It is recommended that the project officer position be initially created for a 12-month period, and then reviewed. It is possible that the need for this position will diminish once the AIHW collaborating unit (see Task 3) is established and is able to offer support to program participants.

**2. Test and develop the CORE CATI module.**

As described above, members of the CATI TRG have already agreed to begin asking the provisional CORE CATI questions in their health surveys. This will involve a number of states in collecting data during 2002. From the point of view of the behavioural risk factor monitoring program, this should be regarded (subject to the agreement of the participants) as initial field-testing.

Some questions have already been forwarded to the ABS for cognitive testing. It is recommended that the remaining questions are also forwarded to the ABS, with a view to more rigorous field testing, hopefully involving all states and territories, in 2003.

**3. Create capacity to assist jurisdictions in the development, implementation, analysis (including small area analysis) and interpretation of behavioural risk factor monitoring and provide technical assistance as required.**

Given the likely availability of some test data for analysis by the end of the 2002<sup>19</sup>, and the advantages of being able to offer technical assistance to program participants during and beyond the testing period, it is recommended that a high priority be given to establishing the AIHW collaborating unit by the beginning of 2003.

In terms of confidence building among the jurisdictions, there is a strong argument for having this unit operational prior to states/territories being required to enter into formal agreements to forward unit record data to AIHW for inclusion in its official reports.

**4. Develop protocols and establish agreements for the nation-wide collection, analysis and reporting of CORE CATI data.**

It is recommended that these formal processes, which will involve NPHIWG, DoHA, AIHW and the state/territory governments, should take place in 2003, with a view to commencing formal data collection in 2004.

It is recommended that for those states which already have a survey program, additional annual funding equivalent to a 0.5EFT position be provided by the Commonwealth, with the state providing the same amount. In the case of smaller states/territories with more limited capacity, additional funding will be required.

**5. Create capacity for the processing, storing, analysis and reporting by AIHW of the CORE CATI data provided by jurisdictions.**

AIHW will require some additional capacity in order to handle this additional data collection. This will need to be in place by the beginning of 2005.

**6. Create capacity for collection, analysis and publication of data on specific sub-population groups.**

This task refers to the creation of the specialist units. If possible, these should be in place by the beginning of 2003, with a view to generating data on sub-population groups within a comparable timeframe to that of the mainstream CORE CATI data. However, it would be possible to establish the units at a later date, and/or to stage their establishment.

**7. Implement nation-wide collection of CORE CATI.**

It is proposed that collection of formal CORE CATI data commence at the beginning of 2004.

This would not, however, preclude the dissemination of all or some of the test data that had been collected during 2002 and 2003 among program

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<sup>19</sup> The preliminary results of the 2001 National Health Survey are also expected to be published in late 2002, providing a valuable opportunity for data comparison with a view to future cooperation.

participants by agreement between participants, and/or the analysis of this data by the AIHW collaborating unit on the same basis.

**8. Implement formal analysis and reporting of CORE CATI data by AIHW.**

Proposed for 2005.

**9. Review CORE CATI implementation.**

In one sense, the review of the CORE CATI implementation should be an ongoing process, beginning early in 2002. However, it is also important to recommend a later point in time at which participants might reasonably make a decision about whether or not to extend the program beyond the original CORE CATI module. We propose that this should occur in late 2004, after all states/territories have gone through the process of formal collection of the CORE CATI.

It could be argued that this is too late in time, given the long preparatory period involved in bringing data into a nation-wide program. However, the proposed review date would not preclude the provisional development and testing of additional core data before that date.

Conversely, it could be argued that it is unreasonable to expect jurisdictions to make a decision about expanding the program until the first year's CORE CATI data has been officially reported by AIHW, and cycle is therefore complete. There is some justification for this argument. However, rather than extend the review data by another year to late 2005, and preclude the possibility of expanding the program until then, we prefer to set 2004 as a target review date, in the expectation that confidence between all the parties will have reached the point where they will be willing to make a decision.

## Funding

Indicative costings for each component of the program are set out in Table A. If the suggested implementation timetable is followed, the additional costs would rise from \$80,000 in 2002 to approximately \$500,000 per annum from 2004 on for implementation of the core CATI. It is estimated that the specialist units would cost an additional \$200,000–\$300,000 each per year in Commonwealth funding to carry out basic functions. However, in order to achieve their potential effectiveness, these units would also need to generate additional funding from state/territory governments and other funding sources, such as the NHMRC.

Summaries of the initial implementation and development plan, and of the roles and functions of participants, are set out below in Tables A and B.

## 8. Conclusion

The audit phase of this project found that Australia, like most developed countries, already possessed several of the components upon which a chronic disease and associated risk factor information and monitoring program might be based. Developments in Australia in this area were generally in line with international trends. The feasibility study revealed that although stakeholders in Australia did not support the establishment of a formalised national Behavioural Risk Factor Surveillance System, there was general support for greater coordination of behavioural risk factor monitoring. The proposed Nation-wide Behavioural Risk Factor Information and Monitoring Program meets each of the criteria adopted for the feasibility study, as follows:

### Benefits

The program will deliver demonstrable benefits to all key stakeholders:

#### **Commonwealth Department of Health and Ageing**

1. At a minimum, will receive regular, timely and harmonised nation-wide data on the behavioural risk factors most closely associated with chronic disease in a form that can be matched up with target populations of many of its program initiatives.
2. Will also receive data on sub-populations of particular concern through specialist units.
3. At best, program may expand to cover wider range of behavioural risk factors.

#### **States/Territories**

1. Will be able to build (or enhance) their infrastructure, capacity and skill in health surveillance.
2. Will receive comparative data on behavioural risk factors in a timely manner and format that will allow them to make comparisons with other states/territories, and between their own regions and specific regions in other states/territories.
3. Will have access to expert advice and analysis through AIHW collaborating unit for small area analysis and specialist units.
4. Will have greater opportunity to participate in planning of nation-wide health information and monitoring.

## **Australian Institute of Health and Welfare**

1. Will have access to new source of data for integrated reporting on chronic diseases and associated risk factors.
2. Will expand its collection of health databases.
3. Will further develop its technical expertise through the new collaborating unit.

## Costs

The proposed program is sustainable and cost efficient, because:

1. It builds on existing arrangements.
2. It concentrates on adding value to data, much of which would be collected anyway.
3. It emphasises the use of inexpensive data collection methodologies, predominantly involving CATI and self-report.

## Technical Feasibility

The proposed program is technically feasible, in that:

1. It is based on established and proven methodologies and technologies.
2. It will generate data of sufficient precision to be useful and usable within a reasonable timeframe.
3. Much of the capacity and skill required to implement the program is already available.
4. The implementation timetable allows for further development of skills without delaying data generation.
5. The data involved can be collected, analysed, disseminated, and reported around a useful time cycle.

## Support

We believe that support for the program will be forthcoming because:

1. The feasibility study has provided all major stakeholders with an opportunity to explain their interests in the collection etc. of data on chronic diseases and associated risk factors, and the proposal is firmly based on the results of these consultations.
2. The fact that most states have already entered into a voluntary agreement to collect core CATI items indicates an interest in and willingness to undertake coordinated data collection in the behavioural area. The proposed program builds on that interest, and does not attempt to impose a ready-made "system" on to the existing, complex Australian situation.

**TABLE A: BEHAVIOURAL RISK FACTOR INFORMATION AND MONITORING PROGRAM  
INITIAL DEVELOPMENT AND IMPLEMENTATION PLAN**

<b>Task</b>	<b>Responsibility/Involvement</b>	<b>Timeframe</b>	<b>Indicative Costs</b>
1. Ensure strategic management and coordination of the development of nation wide behavioural risk factor monitoring	NPHIWG	Begin early 2002 Ongoing	Project Officer Meetings \$80,000 for first year, then review
2. Test and develop CORE CATI module	NPHIWG/jurisdictions /ABS/AIHW in advisory capacity)	Begin 2002 Complete by end 2002	
3. Create capacity to assist jurisdictions in the development, implementation, analysis (including small area analysis) and interpretation of behavioural risk factor monitoring and provide technical assistance as required by establishing AIHW Collaborating Unit	NPHIWG/AIHW	In place by end 2002	\$100,000 per annum
4. Develop protocols and establish agreements for nation wide collection, analysis and reporting of Core CATI data	NPHIWG/jurisdictions/AIHW/DoHA	Complete by end 2004	\$50,000 per State/Territory per annum (ie, half a position). Additional start- States up funding may be required by some /Territories
5. Create capacity for the processing, storing, analysis and reporting of the Core CATI data provided by jurisdictions	NPHIWG/AIHW	In place by end 2004	\$50,000 - \$100,000 per annum
6. Create capacity for collection, analysis and publication of data on specific sub-population groups (eg. ATSI, youth, CALD) by establishing specialist chronic disease and risk factor monitoring and information units)	NPHIWG/DoHA	In place by end 2002	3 or 4 @\$200,000-\$300,000 (Cwlth funding only – would require additional funding from States/NHMRC/other sources)
7. Implement formal collection of CORE CATI	jurisdictions	2004	See above
8. Implement formal analysis and reporting of CORE CATI data	AIHW	2005	See above
9. Review CORE CATI process, decide whether to proceed with further harmonisation	NPHIWG	Late 2004	

**TABLE B: BEHAVIOURAL RISK INFORMATION AND MONITORING PROGRAM  
PARTICIPANTS AND ROLE**

<b>PARTICIPANT</b>	<b>ROLE</b>
<b>NPHIWG</b>	<p>Provide strategic leadership for development and implementation of core CATI and possible further harmonisation of State/Territory based data collection</p> <p>Provide structure for partnership between all players involved in chronic disease and associated risk factor monitoring</p>
<b>DoHA</b>	<p>Ensure that data collection meets Commonwealth requirements</p> <p>Provide financial incentives to encourage participation by other jurisdictions, agencies</p>
<b>State, Territory Health Departments</b>	<p>Play an active role in development of core CATI (and any further harmonisation of data collection)</p> <p>Collect core CATI data and forward to AIHW annually</p> <p>Develop, test, implement, analyse and report on additional data items in area of behavioural and associated risk factors at State/Territory level</p>
<b>AIHW</b>	<p>Enter into agreements with jurisdictions for transfer, storage, analysis and reporting on core CATI data</p> <p>Store, analyse and report annually on core CATI data</p> <p>Distribute data files annually to all participants</p>
<b>AIHW Collaborating Unit</b>	<p>Assist jurisdictions in the development, collection, interpretation and communication of behavioural risk factor monitoring data and provide technical assistance as required.</p> <p>Undertake additional analysis (especially small area analysis) and dissemination of data.</p>
<b>Specialist chronic disease and risk factor monitoring and information units</b>	<p>Collect, analyse and publish data on specific sub-population groups (eg. ATSI, youth, CALD)</p>
<b>ABS</b>	<p>Participate in harmonisation of NHS and other relevant data collections with core CATI data collection (and any future harmonised CATI items).</p> <p>Finalise development of CATI modules on asthma, diabetes and demographics</p> <p>Provide other technical advice and assistance as required.</p>

## **APPENDIX A: KEY STAKEHOLDER CONSULTATION QUESTIONS**

### **Rationale**

What advantages could a nation-wide chronic disease and associated risk factor information and monitoring system offer (a) the health system in general (b) your specific jurisdiction and/or area of responsibility?

### **Objective(s)**

What should be the objective(s) of such a system? (see Recommendation 1)

### **Framework**

Overall, is the monitoring framework set out in Figure A appropriate to meet system objectives? (see Recommendation 2)

Are there content areas that should be added to/dropped from the framework?

Are there specific topics that should be added to/dropped from the framework?

How would you prioritise content areas and/or topics within or across the framework?

### **Strategies**

Do you agree with the overall strategic approach set out in Recommendation 3?

### **Use of existing data collections**

Do you agree that if a monitoring system was established, it should move forward immediately to develop and report on indicators for which data is currently available? (see Recommendation 4)

Do you agree with the criteria which have been used to identify eligible data for inclusion? (see Recommendation 4)

Do you wish to comment on the current or potential usefulness of particular data collections, such as the National Health Survey and the Disability, Ageing and Carers Survey?

Do you have specific priorities or requirements with respect to the development of indicator sets? Do you wish to comment on the criteria which should be used to develop indicator sets?

### **Development of components of state-wide collections for harmonisation**

Do you support the concept of including harmonised state-wide data in the proposed monitoring system?

Do you agree that the topics marked in blue in the framework are appropriate candidates for harmonisation? Are there topics which should be added to/dropped from this categorisation?

What mechanism(s) should be put in place to progress this strategy?

What would the funding implications be?

What would be a realistic timeframe?

### **Development of a national survey with components of objective measurement**

What priority do you attach to the development and implementation of objective measures of prevalence data on health and biological conditions? Is the proposed Australian Health Measurement Survey potentially an appropriate means of overcoming current deficits in these areas of data collection? (see Option 1). If not, what are the alternatives?

### **Repetition of past, one-off national surveys**

Should the feasibility of repeating the National Nutrition Survey be explored? If not, are there alternative methods of collecting ongoing data on diet and nutrition

which should be considered? Are there other one-off surveys which should be considered for repetition?

#### Small area/population reporting

What are your needs in relation to data on small areas/small populations? How well do ongoing national data collections currently meet these needs? How could these collections alter or expand their samples to better meet your needs? What would the funding implications and responsibilities be?

#### Data collection and reporting intervals

Please comment on appropriate data collection/reporting intervals for specific indicator areas/sets, and on acceptable turnaround times for reporting.

Do you have any comments on appropriate reporting media and/or formats?

### **Implementation and Funding Issues**

Do you agree with the list of functions suggested in the discussion paper? Are there functions which should be added to or dropped from the list?

What type of organisational model would you propose for a national system? Should the primary responsibility be given to a single agency/body? If so, which specific agencies/bodies should be considered for this role?

Which other agencies/bodies would you envisage playing an active role in the operation of a national system? Please comment with respect to specific functions/roles.

Which jurisdictions should be involved in funding the establishment and ongoing operation of any national system? What should be their respective role? Please also comment on funding responsibilities with reference to specific data development strategies, especially the harmonisation of statewide data collections.

Beyond the feasibility study, what process should be adopted to implement a national system?

## APPENDIX B: SNAPS+ QUESTIONS

### Smoking, Nutrition, Alcohol misuse, Physical inactivity, Stress and

### Other modules: Demography, Social determinants of health, Asthma, Diabetes

### Agreed Core content and Optional items in topic order

#### Topic area: SMOKING

#### Core or common content

Prevalence (current smokers)	<p><b>The following questions are about tobacco smoking. This includes cigarettes, cigars and pipes.</b></p> <p><b>Which of the following best describes your smoking status?</b></p> <ol style="list-style-type: none"> <li>1. I smoke daily</li> <li>2. I smoke occasionally</li> <li>3. I don't smoke now, but I used to _ <i>Go to Passive smoking question</i></li> <li>4. I've tried it a few times but never smoked regularly _ <i>Go to [next module]</i></li> <li>5. I've never smoked _ <i>Go to Passive smoking question</i></li> </ol> <p>Don't know _ <i>Go to Passive smoking question.</i></p> <p>[Source: NSW Health Survey 1997, 1998]</p>
Passive smoking	<p><b>Which of the following best describes your home situation?</b></p> <ol style="list-style-type: none"> <li>1. My home is smoke free (<i>includes smoking is allowed outside only</i>)</li> <li>2. People occasionally smoke in the house</li> <li>3. People frequently smoke in the house</li> </ol> <p>Don't know</p> <p>[Source: NSW Health Survey 1997, 1998]</p>

Any formal testing could include variant question forms.

#### Optional (highly recommended) content

Age stopped smoking	<p><b>When did you finally stop smoking daily?</b> (NB: Refers to most recent stop smoking date)</p> <p>day _____ / month _____ / year _____.</p> <p><b>OR</b></p> <p>_____ weeks ago <b>or</b></p> <p>_____ months ago <b>or</b></p> <p>_____ years ago.</p>
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	<p><b><u>OR</u></b></p> <p>_____ years old.</p> <p>[Note that this question needs to be preceded by a question additional to the core questions above, that elicits the information that the respondent <u>was</u> a daily smoker. The NHDD uses the following sequence:</p> <p><b>3. Have you ever smoked tobacco <b>daily</b>?</b></p> <p>1<input type="checkbox"/> Yes, I smoke daily now (only tick if answered “daily” to at least one earlier question).</p> <p>2<input type="checkbox"/> Yes, I used to smoke daily.</p> <p>3a. When did you finally stop smoking daily?]</p> <p>[Source: NHDD]</p>
Age started smoking	<p><b>At what age did you first start smoking daily?</b></p> <p>_____ years old.</p> <p>[Source: NHDD]</p>
Addiction	<p><b>How soon after you wake up do you usually smoke your first cigarette?</b></p> <p>Single response:</p> <p>0-14 minutes <input type="checkbox"/></p> <p>15-29 minutes <input type="checkbox"/></p> <p>30-59 minutes <input type="checkbox"/></p> <p>1-2 hours <input type="checkbox"/></p> <p>More than 2 hours <input type="checkbox"/></p> <p><b>OR</b></p> <p>Free response coded as above.</p> <p>[Source: WANTSA 2000]</p>
Consumption	<p><b>On average how many cigarettes do you smoke per day or each week?</b></p> <p>Single response:</p> <p>Daily _____</p> <p>Weekly _____</p> <p>Monthly _____</p> <p>Don't know <input type="checkbox"/></p> <p><b>OR</b></p> <p>Free response coded as above.</p> <p>[Source: WANTSA 2000]</p>

## Topic area: NUTRITION

### Core or common content

Vegetables	<p><b>How many serves of vegetables do you <u>usually</u> eat each day? A ‘serve’ is ½ cup cooked vegetables or 1 cup of salad vegetables.</b></p> <p>Note that ‘vegetables’ includes potatoes (as per the NHMRC Guidelines), although this should not be mentioned in the question.</p> <p>Uncategorised responses to include “Don’t know”.</p> <p>Recording of actual responses (rather than category responses such as “4 to 5 serves”) preferred in order to report against Australian indicators.</p> <p>[Source: National Nutrition Survey 1995, ABS]</p> <p>[Note that Marks et al. (2001: 45) suggest that ‘vegetables’ would normally be defined in terms of the major types to be included or excluded eg potatoes, tomatoes, leafy vegetables, root, tuber and stem vegetables, peas and beans, pumpkin type; and, that the question should also indicate whether vegetables that are part of a mixed dish should be included or excluded and specify the forms of vegetables (fresh, cooked, dried, frozen and tinned) that should be included or excluded.]</p>
Fruit	<p><b>How many serves of fruit do you <u>usually</u> eat each day? A ‘serve’ is 1 medium piece or 2 small pieces of fruit or 1 cup of diced pieces.</b></p> <p>Uncategorised responses to include “Don’t know”.</p> <p>Recording of actual responses (rather than category responses such as “2 to 3 serves”) preferred in order to report against indicators.</p> <p>[Source: National Nutrition Survey 1995, ABS]</p> <p>[Note that Marks et al. (2001: 47) suggest that ‘fruit’ would normally be defined in terms of the major types to be included or excluded eg apples and pears, bananas and other tropical fruit, citrus, stone fruit, berries and other such as melons; and, that the question should also indicate whether fruit that is part of a mixed dish should be included or excluded and specify the forms of fruit (juice, fresh, cooked, dried, frozen and tinned) that should be included or excluded.]</p>
Type of Milk (fat indicator)	<p><b>What type of milk do you usually consume?</b></p> <p>Free response to be coded:</p> <ul style="list-style-type: none"> <li>Whole;</li> <li>Low or reduced fat;</li> <li>Skim; Soya;</li> <li>Other;</li> <li>None of the above;</li> <li>Don’t know.</li> </ul>

	<p>[Source: National Nutrition Survey 1995, ABS; with 'consume' substituted for 'have' as being more precise]</p> <p>[Note that Marks <i>et al.</i> (2001: 61) recommend that for some population groups it could be important to define the source (cow, other animal milk, vegetable based milk such as soya) as well as the type; and, to indicate whether only one or one or more response categories constitute a useable response to the question.]</p>
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**Optional (highly recommended) content**

Chips	<p><b>How often do you eat chips, French fries, wedges, fried potatoes or crisps?</b></p> <p>Response options: frequency per day/week/month; rarely or never; Don't know/can't say.</p> <p>[Source: Dietary Key Indicators Study 1996, NHMRC]</p>
Breakfast cereal	<p><b>How often do you eat breakfast cereal? (ready-made, home-made or cooked)</b></p> <p>Response options: frequency per day/week/month; rarely or never; Don't know/can't say.</p> <p>[Source: Dietary Key Indicators Study 1996, NHMRC]</p>
Expanded cereals (pasta, rice, noodles, other cooked)	<p><b>How often do you eat pasta, rice, noodles or other cooked cereals? (not including cooked breakfast cereals)</b></p> <p>Response options: frequency per day/week/month; rarely or never; Don't know/can't say.</p> <p>[Source: Dietary Key Indicators Study 1996, NHMRC]</p>
Bread	<p><b>How often do you eat bread? (Include bread rolls, flat breads, crumpets, bagels, English or bread type muffins.)</b></p> <p>Response options: frequency per day/week/month; rarely or never; Don't know/can't say.</p> <p>[Source: Dietary Key Indicators Study 1996, NHMRC]</p>
Processed meats	<p><b>How often do you eat meat products such as sausages, frankfurters, Belgium, devon, salami, meat pies, bacon or ham?</b></p> <p>Response options: frequency per day/week/month; rarely or never; Don't know/can't say.</p> <p>[Source: Dietary Key Indicators Study 1996, NHMRC]</p>

## Topic area: BMI

### Core or common content

Height	<p><b>What is your height without shoes?</b></p> <p>OR</p> <p><b>How tall are you without shoes?</b></p> <p>Form of question not as important as “without shoes”.</p> <p>Free response in metric or imperial.</p> <p>Continuous variable.</p> <p>Used to calculate BMI.</p> <p>[Source: NHS &amp; NNS 1995, ABS]</p>
Weight	<p><b>What is your weight?</b></p> <p>OR</p> <p><b>How much do you weigh?</b></p> <p>Free response in metric or imperial.</p> <p>Continuous variable.</p> <p>Used to calculate BMI.</p> <p>[Source: NHS &amp; NNS 1995, ABS]</p>

**BMI (Body Mass Index)** is body weight in kilograms divided by the square of height in metres (NNS 1995).

ABS advise: the groups used in the NNS are those recommended by the World Health Organization (1995):

Underweight	Less than 18.5
Acceptable weight (a)	18.5 to less than 25
	20 to less than 25
Overweight	25 to less than 30
Obese	30 and greater

(a) Acceptable weight range split to enable comparison with NHMRC categories.

### Optional (highly recommended) content

None.

**Topic area: ALCOHOL MISUSE**

**Core or common content**

How often	<p><b>How often do you usually drink alcohol?</b></p> <p>Free response, coded to following categories:</p> <p>I don't drink alcohol [ ] <i>Go to Next module</i></p> <p>Less than once a week [ ]</p> <p>On 1 or 2 days a week [ ]</p> <p>On 3 or 4 days a week [ ]</p> <p>On 5 or 6 days a week [ ]</p> <p>Every Day [ ]</p> <p>Refused [ ]</p> <p>[Source: as used by WANTSA 2000, SERCIS 2001]</p>
How much	<p><b>A Standard Drink is equivalent to a schooner or midi of full strength beer, a glass of wine or a nip of spirits.</b></p> <p><b>On a day when you drink alcohol how many standard drinks do you usually have?</b></p> <p>Free response, coded to following categories:</p> <p>1 or 2 drinks [ ]</p> <p>3 or 4 drinks [ ]</p> <p>5 to 8 drinks [ ]</p> <p>9 to 12 drinks [ ]</p> <p>13 to 20 drinks [ ]</p> <p>More than 20 drinks [ ]</p> <p>Refused [ ]</p> <p>[Source: as used by WANTSA 2000, SERCIS 2001]</p>

**Optional (highly recommended) content**

Binge drinking	<p>Three questions using the Graduated Quantity Frequency (GQF) method, one of three methods recommended by WHO (2000) for asking people to estimate their recent alcohol consumption. The GQF asks how often people drink specified amounts of alcohol in one day, starting with large amounts and graduating to smaller quantities to encourage full reporting.</p> <ol style="list-style-type: none"> <li><b>1. In the past four weeks (28 days) how often have you had 20 or more standard drinks in a day?</b></li> <li><b>2. In the past four weeks how often have you had 11 to 19 standard drinks in a day?</b></li> <li><b>3. In the past four weeks how often have you had 7 to 10</b></li> </ol>
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	<p><b>standard drinks in a day?</b></p> <p>Open ended response, coded:</p> <p>Don't drink [0]</p> <p>Less than once a week [8]</p> <p>Refused [9]</p> <p>No. of days [0-7]</p> <p>[Source: WHO 2000, as used in NDSHS 2001, CATI form, with modified time period]</p>
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Note that field testing will give more information.

[Form currently used in the National Drug Strategy Household Survey (CATI questionnaire) 2001, is [six part question, QF13A-F]:

QF13A. **IN THE PAST 12 MONTHS, how often have you had 20 OR MORE standard drinks in a day?** FOR STANDARD DRINK DEFINITION, ESC H

EVERY DAY.....	1
5 TO 6 DAYS A WEEK	2
3 TO 4 DAYS A WEEK	3
1 TO 2 DAYS A WEEK	4
1 DAY A WEEK.....	5
2 TO 3 DAYS A MONTH	6
ABOUT 1 DAY A MONTH	7
LESS OFTEN	8
NEVER	9
CAN'T SAY/CAN'T RECALL	10]

IF HAVE NOT DRUNK 20 OR MORE STANDARD DRINKS EVERYDAY IN THE PAST 12 MONTHS (NOT CODE 1 ON QF13A.), ASK:

QF13B. **IN THE PAST 12 MONTHS, how often have you had 11-19 standard drinks in a day?** [responses as above]

QF13C. ... **7-10 standard drinks in a day?** [responses as above]

QF13D. ... **5-6 standard drinks in a day?** [responses as above]

QF13E. ... **3-4 standard drinks in a day?** [responses as above]

QF13F. ... **1-2 standard drinks in a day?** [responses as above]

Note that short term 'risky' drinking is defined at different levels of alcohol consumption for men (7 to 10 standard drinks on a single occasion) and for women (5 to 6 standard drinks on a single occasion) (NHMRC 2001). See the table below, reproduced from *Alcohol Consumption in Australia: Data requirements for health surveillance* (AIHW DISU 2001b).

<b>Risk of harm in the short term</b>			
	Low risk (standard drinks)	Risky (standard drinks)	High risk (standard drinks)
Males (on a single occasion)	Up to 6	7 to 10	11 or more
Females (on a single occasion)	Up to 4	5 to 6	7 or more

Source: NH&MRC Australian Drinking Guidelines 2001.

## Topic area: PHYSICAL INACTIVITY

### Core or common content

<p>Core Active Australia questions (6 questions)</p>	<p><b>B. CORE PHYSICAL ACTIVITY QUESTIONNAIRE</b></p> <p>The next few questions are about any physical activities that you may have done in the last week.</p> <p><b>1 In the last week, how many times have you walked continuously, for at least 10 minutes, for recreation, exercise or to get to or from places?</b> (Single Response. Enter number of times. Enter 0 if none) 1. None [ 0 ] Go to question 3 2. Enter number of times ___ __ 3. Not stated/Don't know [999]</p> <p><b>2 What do you estimate was the total time that you spent walking in this way in the last week?</b> (Single Response. Enter number of hours AND/OR minutes.) 1. Hours ___ __ 2. Minutes ___ __ 3. Not stated/Don't know [999]</p> <p><b>3 The next question does not include gardening. In the last week, how many times did you do vigorous household chores which made you breathe harder or puff and pant?</b> (Single Response. Enter number of times. Enter 0 if none) 1. None [ 0 ] Go to question 5 2. Enter number of times ___ __ 3. Not stated/Don't know [999]</p> <p><b>4 What do you estimate was the total time you spent doing these vigorous household chores in the last week?</b> (Single Response. Enter number of hours AND/OR minutes.) 1. Hours ___ __ 2. Minutes ___ __ 3. Not stated/Don't know [999]</p> <p><b>5 This question excludes household chores or gardening. In the last week, how many times did you do any vigorous physical activity which made you breathe harder or puff and pant? (e.g. tennis, jogging, cycling, keep fit exercises).</b> (Single Response. Enter number of times. Enter 0 if none) 1. None [ 0 ] Go to 9 2. Enter number of times ___ __ 3. Not stated/Don't know [999]</p> <p><b>6 What do you estimate was the total time that you spent doing this vigorous physical activity in the last week?</b> (Single Response. Enter number of hours AND/OR minutes.) 1. Hours ___ __</p>
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	2. Minutes __ __ 3. Not stated/Don't know [999] [Source: Active Australia recommended, as asked by SERCIS, 1998]
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**Optional (highly recommended) content**

None.

Note that although several questions attempting to measure Occupational physical activity; Gardening (vigorous); and Housework/chores were discussed, the group preferred to wait on better instruments when they become available.

## Topic area: STRESS

### Core or common content

<p>Kessler Psychological Distress Scale (‘K10’)</p> <p>(10 questions)</p>	<p><b>The next 10 questions are about how you have been feeling in the last 4 weeks, that is, since about this time last month. If you feel uncomfortable with any question, just tell me and I will move onto the next question.</b></p> <p><b>As I read each statement, please give me the one answer that comes closest to the way you have been feeling; is it all of the time, most of the time, some of the time, a little of the time, or none of the time?</b></p> <p><b>G2. In the last 4 weeks, about how often did you feel tired out for no good reason?</b> (<i>Read options 1-5, single response</i>)</p> <ol style="list-style-type: none"><li>1. All of the time</li><li>2. Most of the time</li><li>3. Some of the time</li><li>4. A little of the time</li><li>5. None of the time</li><li>6. Don’t know</li><li>7. Refused (<i>Interviewer: Use only as a last resort.</i>)</li></ol> <p><b>G3. In the last 4 weeks, about how often did you feel nervous?</b> (<i>Read options 1-5, single response</i>)</p> <ol style="list-style-type: none"><li>1. All of the time</li><li>2. Most of the time</li><li>3. Some of the time</li><li>4. A little of the time</li><li>5. None of the time (<i>go to G5</i>)</li><li>6. Don’t know (<i>go to G5</i>)</li><li>7. Refused (<i>go to G5</i>) (<i>Interviewer: Use only as a last resort.</i>)</li></ol> <p><b>G4. In the last 4 weeks, about how often did you feel so nervous that nothing could calm you down?</b> (<i>Read options 1-5, single response</i>)</p> <ol style="list-style-type: none"><li>1. All of the time</li><li>2. Most of the time</li><li>3. Some of the time</li><li>4. A little of the time</li><li>5. None of the time</li><li>6. Don’t know</li><li>7. Refused (<i>Interviewer: Use only as a last resort.</i>)</li></ol> <p><b>G5. In the last 4 weeks, about how often did you feel hopeless?</b> (<i>Interviewer: Read options 1-5, single response</i>)</p> <ol style="list-style-type: none"><li>1. All of the time</li><li>2. Most of the time</li><li>3. Some of the time</li></ol>
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4. A little of the time
5. None of the time
6. Don't know
7. Refused (*Interviewer: Use only as a last resort.*)

**G6. In the last 4 weeks about how often did you feel restless or fidgety?** (*Read options 1-5, single response*)

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time (*go to G8*)
6. Don't know (*go to G8*)
7. Refused (*go to G8*) (*Interviewer: Use only as a last resort.*)

**G7. In the past four weeks about how often did you feel so restless that you could not sit still?** (*Read options 1-5, single response*)

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time
6. Don't know
7. Refused (*Interviewer: Use only as a last resort.*)

**G8. In the last four weeks about how often did you feel depressed?** (*Read options 1-5, single response*)

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time
6. Don't know
7. Refused (*Interviewer: Use only as a last resort.*)

**G9. In the last four weeks about how often did you feel everything was an effort?**

(*Read options 1-5, single response*)

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time
6. Don't know
7. Refused (*Interviewer: Use only as a last resort.*)

**G10. In the last four weeks, about how often did you feel so sad that nothing could cheer you up?** (*Read options 1-5, single response*)

	<ol style="list-style-type: none"><li>1. All of the time</li><li>2. Most of the time</li><li>3. Some of the time</li><li>4. A little of the time</li><li>5. None of the time</li><li><b>6. Don't know</b></li><li><b>7. Refused</b> (<i>Interviewer: Use only as a last resort.</i>)</li></ol> <p><b>G11. In the last four weeks, about how often did you feel worthless?</b> (<i>Read options 1-5, single response</i>)</p> <ol style="list-style-type: none"><li>1. All of the time</li><li>2. Most of the time</li><li>3. Some of the time</li><li>4. A little of the time</li><li>5. None of the time</li><li>6. Don't know</li><li>7. Refused (<i>Interviewer: Use only as a last resort.</i>)</li></ol> <p>[Source: Kessler and Mroczec (1992) as used in Vic Population Health Survey 2001]</p>
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**Other modules: Demography, Social determinants of health,  
Asthma, Diabetes**

**Topic area: DEMOGRAPHY**

**Core or common content**

Household size/structure	<b>Including yourself how many people aged 18 and over live in this household?</b> _____
Geographical marker 1 postcode 2 locality	<b>What is your postcode?</b> _____ AND/OR <b>What is your suburb, town or community?</b> _____
Indigenous status	<b>Were you born in Australia?</b> <b>Are you of Aboriginal or Torres Strait Islander origin?</b> Yes No <i>(Interviewer instruction: prompt if necessary)</i> <b>Which are you?</b> 1 Aboriginal 2 Torres Strait Islander 3 Both [Source: Census]
RDD core	<b>How many residential telephone numbers (including mobile phones) can be used to speak to someone in this household?</b> _____
EWP core	<b>How many times (does this/do these) number(s) appear in the White Pages?</b> _____

**Optional (highly recommended) content**

None.

**Topic area: SOCIAL DETERMINANTS OF HEALTH**

**Core or common content**

<p>Age</p> <p>[Note three alternative methods]</p>	<p>Three alternatives:</p> <p><b>As some of the next questions relate to certain groups of people only, could you please tell me ...</b></p> <p><b>Could you please tell me your date of birth? [prefer]</b></p> <p><i>(Interviewer: If R is hesitant about answering this sort of question say: " Date of birth is asked as most people find it easier to remember their date of birth than their age. ").</i></p> <p>_____</p> <p>OR</p> <p><b>2 What was your age last birthday?</b></p> <p>_____</p> <p>OR</p> <p><b>3 Which age group are you in? Would it be ...</b></p> <p>(Read Options, Single Response)</p> <ol style="list-style-type: none"> <li>1. 18 to 24 years [ ]</li> <li>2. 25 to 34 years [ ]</li> <li>3. 35 to 44 years [ ]</li> <li>4. 45 to 54 years [ ]</li> <li>5. 55 to 64 years [ ]</li> <li>6. 65 to 74 years [ ]</li> <li>7. 75 years or over [ ]</li> <li>8. Refused [ ]</li> </ol> <p>[Sources: Omnibus 2001, SERCIS 2001]</p>
<p>Sex/gender</p>	<p><i>(Gender: if not obvious, ask:)</i> <b>What is your sex?</b></p> <ol style="list-style-type: none"> <li>1. Male [ ]</li> <li>2. Female [ ]</li> <li>3. Neither male nor female</li> </ol> <p>[Source: NSW Health Survey 1997/1998]</p>
<p>Education – highest level attained</p> <p>[Note <u>topic agreed but not final wording or categories.</u>]</p>	<p><b>What is the highest level of education you have completed?</b></p> <p><i>(Single response)</i></p> <p>University, CAE or some other tertiary institute degree, including post university (ie Post Graduate Diploma, Master, PhD) [ ]</p> <p>TAFE or trade certificate or diploma [ ]</p> <p>Completed high school [ ]</p> <p>Some high school (age/year level left) [ ]</p>

	<p>Completed primary school <input type="checkbox"/></p> <p>Some primary school (age/year level left) <input type="checkbox"/></p> <p>Never attended school <input type="checkbox"/></p> <p>Other (specify) <input type="checkbox"/></p>
Employment status	<p><b>Which of these best describes your current employment status? Are you . . .</b></p> <p>Self employed? <input type="checkbox"/></p> <p>Employed for wages, salary or payment in kind? <input type="checkbox"/></p> <p>Unemployed? <input type="checkbox"/></p> <p>Engaged in home duties? <input type="checkbox"/></p> <p>A student? <input type="checkbox"/></p> <p>Retired? <input type="checkbox"/></p> <p>Unable to work? <input type="checkbox"/></p> <p>Other (specify) <input type="checkbox"/></p>
Income (household) [Note different forms]	<p>Different forms:</p> <p><b>Can you tell me the approximate annual gross income of your household? That is, for all people in the household before tax is taken out. I'll read out some categories and could you please tell me into which one your household's income falls?</b></p> <p>(Read Options. Single Response)</p> <p>1. Up to \$12,000 <input type="checkbox"/></p> <p>2. \$12,001 - \$20,000 <input type="checkbox"/></p> <p>3. \$20,001 - \$40,000 <input type="checkbox"/></p> <p>4. \$40,001 - \$60,000 <input type="checkbox"/></p> <p>5. \$60,001 - \$80,000 <input type="checkbox"/></p> <p>6. More than \$80,000 <input type="checkbox"/></p> <p>7. Not stated/refused <input type="checkbox"/></p> <p>8. Don't know <input type="checkbox"/></p> <p>[Source: SERCIS]</p> <p>OR</p> <p><b>Which of the following categories does your total gross annual household income from all sources fall into? That is the total income from all members of your household before tax is deducted. Would it be:</b></p> <p><i>(Interviewer: Read out categories 1 to 4)</i></p> <p>1 Less than \$25 000</p> <p>2 \$25 001 - \$50 000</p> <p>3 \$50 001 - \$100 000</p> <p>4 Over \$100 000</p> <p>5 Don't know</p> <p>6 Refused to answer</p> <p>[Source: Qld Omnibus 2001]</p>

**Optional (highly recommended) content**

Main language spoken at home	<p><b>Do you speak a language other than English, at home?</b></p> <p>Yes No</p>
Country of birth	<p><b>In which country were you born?</b></p> <p>Australia Other (specify) _____</p>
Marital status	<p><b>What is your current marital status?</b></p> <p>Married Living with a partner Divorced Separated Widowed Never married</p>
Year of arrival in Australia	<p><b>In which year did you arrive in Australia?</b></p> <p>_____</p>
Living arrangements	<p><b>Including yourself, how many people aged 18 years and over live in this household?</b></p> <p>_____</p>
Number of hours worked per week	<p><b>How many hours do you work per week?</b></p> <p>_____ hours</p>
Main job, main occupation [Note <u>topic agreed but not final wording</u> ]	<p><b>In the main job held during your working life, what was your main occupation?</b></p> <p>_____</p>

[Sources: if not stated, form of questions is from ABS cognitive testing working notes ex Qld]

## Topic area: ASTHMA

### Core or common content

[Note – need to revisit original CATI-TRG questions]

Prevalence (ever)	<b>The next questions are about asthma and asthma symptoms.</b> <b>Have you ever been told by a doctor [or nurse?] that you have asthma?</b> Yes No (Go to .....)
Prevalence (current)	<b>Have you had symptoms of asthma or taken treatment for asthma in the last 12 months?</b> Yes No (Go to .....)

### Optional (highly recommended) content

None.

## Topic area: DIABETES

### Core or common content

Diabetes (prevalence)	<b>The next questions are about diabetes and high sugar levels.</b> <b>Have you ever been told by a doctor [or nurse?] that you have diabetes?</b> Yes (Male go to .....; female go to .....) No (Go to .....) <b>Have you ever been told by a doctor [or nurse?] that you have high sugar levels in your blood or urine?</b> Yes (Male go to .....; female go to .....) No (Go to .....)
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### Optional (highly recommended) content

None.

[Sources: if not stated, form of questions is from ABS cognitive testing working notes ex Qld]

>> end of topics <<

## Abbreviations and Acronyms

AA	Active Australia
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ATSI	Aboriginal and Torres Strait Islanders
IPAQ	International Physical Activity Questionnaire
NDS	National Drugs Survey (National Drug Strategy Household Survey, DHAC)
NDSHS	National Drug Strategy Household Survey (DHAC)
NHS	National Health Survey (ABS)
NNS	National Nutrition Survey (ABS)
NHDD	National Health Data Dictionary (AIHW)
RF	Risk Factor

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