A proposal for the Australian Health Measurement Survey program

Public Health Information Development Unit

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Acknowledgment

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EXECUTIVE SUMMARY

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2. Survey programs of this nature have been conducted for many years in the USA, some European and Asian countries, the United Kingdom and, more recently, in New Zealand and serve as the base to support health policy, health research and prevention strategies in those countries.

3. In Australia, there has been an investment by governments and others in the collection of health information and concomitant biochemical and other measures, but the majority of those studies are no longer current, leaving significant gaps in our knowledge of the health of the population. The National Heart Foundation's surveys of risk factors were conducted in all capital cities in the 1980s and provided the first population data on risk of cardiovascular disease. In 1999, the International Diabetes Institute (IDI) received funding for a large study into the prevalence of diabetes and cardiovascular disease and associated risk factors (The Australian Diabetes, Obesity and Lifestyle Study (AusDiab)). The AHMS program will build upon this investment, and the lessons from these studies.

4. Without current data on diseases, risk factors and other health determinants, information about the Australian population's health and functional ability is inadequate. Time trends of risk and protective factors for chronic diseases are unavailable. There is little information about the factors that are important for family health and nutrition. More needs to be known about the determinants of health and their effects on the age-trends of health and functional capacity.

5. The measures to be included in the AHMS program are crucial for the development and monitoring of services for conditions which have been responsible for at least two-thirds of the mortality gain in the last 30 years, and which still offer the greatest prospects for mortality gain in the future – especially the National Health Priority Areas of circulatory conditions and diabetes, but there are also implications for major cancers.

6. To obtain the necessary information to underpin health policy and program development, there is a need for health measurement surveys to be carried out at regular intervals and to include a broad range of measures. The proposed AHMS program will provide an up-to-date, comprehensive picture of health in the population by studying the prevalence and determinants of

most significant health problems and the associated need for prevention, care and rehabilitation. Information will also be collected on health determinants and on health disparities between population groups and geographic regions. Time trends of adult health will be assessed by comparing the findings with earlier data. This information is currently unavailable to health policy-makers and researchers in Australia.

Australian Health Measurement Survey (AHMS) Program

Outline of the proposal

It is proposed that a series of cross-sectional health measurement surveys, which include physical and biochemical measures of health status and potentially modifiable risk factors and determinants of health, be conducted every 6 years in association with every second Australian Bureau of Statistics (ABS) National Health Survey.

Each survey would provide much needed population health data to inform policy and interventions on priority health problems such as diabetes, cardiovascular disease, hypertension, hypercholesterolaemia, and other chronic diseases that have significant economic, health and social impact.

The first AHMS would:
- Be conducted in conjunction with the 2004/5 ABS National Health Survey.
- Include physical measurement and the collection of data on a range of disease outcomes and risks.
- Be nationally representative of Australians of different ages, sex, geographic area and socioeconomic circumstances.
- Cover the age range 2 to 74 years, with appropriate consent procedures for all participants.
- Measure height; weight; abdominal circumference; blood pressure; blood (cholesterol and lipid levels, homocysteine, fasting glucose, glycosylated haemoglobin and insulin) and possibly other biological markers.
- Be developed by the Commonwealth Department of Health and Ageing, the Australian Institute of Health and Welfare and the ABS.
- Be underpinned by wide consultation on ethical issues, with final ethical approval to be sought from the AIHW Ethics Committee.
- Be piloted in February 2003.
- Cost approximately $7.2 million excluding GST for a survey linked to the NHS.

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7. Australia's National Public Health Information Development Plan (endorsed by the Australian Health Ministers Advisory Council (AHMAC) in 1999) was developed 'to identify the action needed to improve public health information in Australia'. One of its identified components was the need for the development of a national biomedical risk factor or health measurement survey (AIHW & NPHIWG 1999, Recommendation 1.1.1).

8. A substantial amount of planning and research is needed in order to ensure that the significant investment of money required for surveys of this

kind is realised in valuable and useful results that lead to better health strategies for the population, and that wide support is built for the survey program from the start. This approach has been adopted for Australia.

9. A developmental process was undertaken with an Inter-Governmental Steering Committee (with membership from the (now) Commonwealth Department of Health and Ageing (DoHA), the Australian Institute of Health and Welfare (AIHW), the Australian Bureau of Statistics (ABS) and State/Territory jurisdictions; see page xi) and a scientific Reference Group (see page xiii). Both structures were necessary to ensure a national perspective regarding policy input from across all jurisdictions and technical expert advice on the survey design, content and methodology. This proposal is the result of their deliberations and of wider consultations within their jurisdictions.

10. The proposed AHMS program has been developed as a program of cross-sectional surveys that include a component of physical and biochemical measurement, and will examine a range of disease outcomes and risks. It will be nationally representative of people of different ages, sex, geographic area and socioeconomic circumstances. It will combine questionnaire answers and physical and biochemical measures (such as measurement of height and weight; analyses of samples of blood, urine, and saliva; and tests of function).

11. The AHMS program has been designed to be policy relevant and to maximise related research and development opportunities for policy-makers and health researchers. The program allows for the inclusion of a wider range of content areas than a single 'stand-alone' survey, and will include respondents from the ages of two to 74 years.

12. The AHMS program is recommended to commence in association with the Australian Bureau of Statistics' National Health Survey (ABS NHS) in 2004/5. There are two parts to the linked NHS/AHMS program. The first of these contains the subjective questions in the NHS. The second part comprises the physical and biochemical measures undertaken in the AHMS. It is proposed that the AHMS be repeated after six years, with the possibility of more frequent surveys, once the initial results have been analysed and their contribution to policy development, program planning and research assessed. The decision to link the AHMS program with the NHS will allow validation of the subjective, self-reported data that is collected in the NHS. The conduct of the AHMS with the NHS also represents a considerable cost saving, as compared to the cost of a 'stand-alone' health measurement survey program.

13. Work with the ABS on the AHMS program development resulted in a skirmish being undertaken in November 2001 to assess initial elements of the recruitment process to AHMS. Preliminary results indicate adequate response rates that are similar to surveys of this kind overseas. A full pilot

test is now required to test all aspects of the survey process, including the taking of measures.

14. The survey program is strongly supported by the divisions of the DoHA, the AIHW and the ABS. The States and Territories have also indicated high-level support and interest, particularly in broad, policy relevant content coverage. Firm support has also been received from the scientific Reference Group, comprising leading health academics, advising the AHMS Inter-Governmental Steering Committee.

15. It is envisaged that the cost of the first survey would be $6.3 million (excluding GST) over six years. With the inclusion of Departmental costs and the costs for the management of the survey contract, the total cost rises to $7.2 million. An annual allocation of $1.2 million would support developmental costs, data collection, analysis and reporting for an ongoing survey program. It is expected that the benefits of this investment would far outweigh the costs incurred, through better-informed policy formulation and program planning.

16. Up-to-date information on the population's health is critical for informed decision-making and, to date, comprehensive health data have not been collected regularly in Australia. A lack of information hampers health policy and planning. Research on health promotion and disease prevention suffers from the absence of timely data and information on the population's health, health risks and their determinants. The information obtained by the AHMS program is an essential basis for national health policy formulation and health planning for the next decades. This national survey program will also have the advantage of reducing the need for ad hoc health data collecting activities.

TERMS OF REFERENCE

The Inter-Governmental Steering Committee will oversee the survey's development and will be required to:

- Identify the strategic policy areas and health issues that would benefit from information derived from a national population health survey with physical and biochemical measures;

- Examine, assisted by advice from the Reference Group, the methodological, legal and ethical factors related to the survey's design;

- Examine the issues related to the end use of the survey data; and,

- Develop a business case containing recommendations regarding the feasibility, scope, content and funding of a national population health survey with physical and biochemical measures, prior to the meeting of AHMAC in February 2001.

The Inter-Governmental Steering Committee endorsed these terms of reference in March 2000. As a result of the additional time required for consultation, the final term of reference was amended in September 2001 to 'May 2002' (instead of 'February 2001').

INTER-GOVERNMENTAL STEERING COMMITTEE MEMBERSHIP

Name	Organisation
Professor John Mathews (Chair)	Deputy Chief Medical Officer & Medical and Scientific Director, Population Health Division Commonwealth Department of Health and Ageing
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LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACHPER	Australian Council for Health, Physical Education and Recreation Inc.
AHMAC	Australian Health Ministers Advisory Council
AHMS	Australian Health Measurement Survey
AIHW	Australian Institute of Health and Welfare
ARIA	Accessibility/Remoteness Index of Australia
AusDiab	Australian Diabetes, Obesity and Lifestyle Study
BMI	Body Mass Index
CAPI	Computer-Assisted Personal Interviewing
CURF	Confidentialised Unit Record File
DHAC	Commonwealth Department of Health and Aged Care (see DoHA)
DoHA	Commonwealth Department of Health and Ageing
EPA	Environment Protection Agency
HSE	Health Survey for England
IDI	International Diabetes Institute
NBRFS	National Biochemical Risk Factor Survey
NGOs	Non-Government Organisations
NHANES	National Health and Nutrition Examination Survey
NHMRC	National Health and Medical Research Council
NHPA	National Health Priority Area
NHPAC	National Health Priority Action Council
NHS	National Health Survey
NNS	National Nutrition Survey
NPHIWG	National Public Health Information Working Group
NPHP	National Public Health Partnership
OGTT	Oral Glucose Tolerance Test
PHIDU	Public Health Information Development Unit
STEPS	Stepwise Approach to Surveillance Initiative
WHO	World Health Organization

1. A NATIONAL HEALTH MEASUREMENT SURVEY PROGRAM FOR AUSTRALIA

A national population health survey program using physical and biochemical measures is proposed for Australia. The Australian Health Measurement Survey program (AHMS) offers a number of new opportunities to provide a sound, current information base for future national health policy development, health program planning and health research in ways that have not previously been possible.

The AHMS program, recommended to commence in association with the Australian Bureau of Statistics' National Health Survey (ABS NHS) program in 2004/5, will complement the subjective information collected by the NHS with the collection of more objective health measures for the Australian population.

1.1 Background

1.1.1 Primary reasons for undertaking national population health surveys using physical and biochemical measures

Monitoring and forecasting the population's health and health determinants are prerequisites for knowledge-based health policy and the development of health care at national, regional and local levels. National health measurement surveys are characterised by the collection of subjective information through questionnaires, and the gathering of more objective information via measurement of height, weight and body mass; factors in saliva, blood and/or urine; lung function; mental health and cognitive state; or childhood development.

From an examination of the use of surveys of this type that have been undertaken around the world, the following purposes have been identified:
- the monitoring within a population of certain high priority health goals and targets relating to the prevention of various diseases or conditions at one point in time, and over time as surveys are repeated regularly;
- the provision of baseline data related to particular health issues or policies;
- the contribution to particular research questions about health and related conditions and their treatment or eradication;
- the surveillance of infective agents or other factors that impact negatively on the population's health or may do so in the future; and
- the collection of information at a population level - to assist in the development of policy and planning of services or determining need, to assess the degree of success of health promotion or illness prevention strategies and to contribute to a greater understanding of health and illness.

Survey programs of this nature have been conducted for many years in the USA, some European and Asian countries, the United Kingdom and, more recently, in New Zealand, and serve as the base to support health policy, health research and prevention strategies in those countries.

1.1.2 The AHMS program and its place in the longer term direction of national population health information development

There has been an investment by governments and others in the collection of health information and concomitant biochemical and other measures in Australia, but the majority of those studies are no longer current, leaving significant gaps in our knowledge of the health of the population. The National Heart Foundation's surveys of risk factors were conducted in all capital cities in the 1980s and provided the first 'national' population data on risk of cardiovascular disease. In 1999, the International Diabetes Institute (IDI) received funding for a large study into the prevalence of diabetes and cardiovascular disease and associated risk factors (The Australian Diabetes, Obesity and Lifestyle Study (AusDiab)). However, issues have been raised regarding the accuracy of estimates produced in the study because of the sample design and sub-optimal response rates.

To obtain the necessary information to underpin health policy and program development, there is a need for these health surveys to be carried out at regular intervals and to include a comprehensive range of measures. Without current data on diseases, risk factors and other health determinants, information about the Australian population's health and functional ability is inadequate. There is little information about the factors that are important for family health and nutrition. Time trends of risk and protective factors for chronic diseases are unavailable. Information on health determinants needs to be gathered simultaneously with information on health and functional capacity, and more needs to be known about the effects of these determinants on health and on the age-trends of health and functional capacity.

The main aim of the proposed AHMS program is to provide an up-to-date, comprehensive picture of health in the population by studying the prevalence and determinants of most significant health problems and the associated need for prevention, care and rehabilitation. This information is currently unavailable to health policy-makers and researchers in Australia.

The AHMS program will gather physical and biochemical information on the population's health. Information will also be collected on health determinants and on health disparities between population groups and geographic regions. Time trends of adult health will be assessed by comparing the findings with earlier data.

Forecasts concerning the future need for health care will use AHMS information as a starting point. It can be expected that in the period when the baby boom cohort move into older age groups (a person born in 1946 will be 65 years old in 2011), there will be ever-increasing pressures on the Australian health system and an urgent need for accurate population health information. Therefore the AHMS surveys in 2004/5,

2010/11 and 2016/17, will provide a substantial information building block for the Australian health system in the decades ahead.

Up-to-date information on the whole population's health is critical for informed decision-making and, to date, comprehensive health data have not been collected regularly in Australia. A lack of information hampers health policy and planning. Research on health promotion and disease prevention suffers from the absence of timely data and information on the population's health, health risks and their determinants. The information obtained by the AHMS program is an essential basis for national health policy formulation and health planning for the next decades. This national survey program will also have the advantage of reducing the need for ad hoc health data collecting activities.

1.2   Overview of the developmental process undertaken

National population health surveys containing a component of physical and biochemical measurement have been used both in Australia and overseas to add to the information about the state of health of a population and to complement research into particular issues, diseases or directions in health policy. Australia's National Public Health Information Development Plan (endorsed by AHMAC in 1999) was developed 'to identify the action needed to improve public health information in Australia'. One of its identified components was the need for the development of a national biomedical risk factor or health measurement survey, subject to piloting to confirm that adequate response rates could be achieved (Recommendation 1.1.1).

To this end, the Australian Institute of Health and Welfare (AIHW) undertook initial planning and costing for such a survey and a proposal was submitted to AHMAC in 1999. However in November 1999, the National Public Health Partnership (NPHP), on the advice of AIHW and the National Public Health Information Working Group (NPHIWG), endorsed the need for further development of a business case for the survey (formerly called the "National Biomedical Risk Factor Survey"). It was agreed that the (now) Department of Health and Ageing (DoHA) would take the lead, in partnership with the AIHW and with the involvement of all jurisdictions and the ABS.

An Inter-Governmental Steering Committee was established, reporting to the NPHP, with Commonwealth, AIHW, ABS and State/Territory membership (see page xi). The role of the Steering Committee was to guide the progress of the survey development. A Reference Group was also established to provide expert technical advice to DHAC, AIHW and the Steering Committee (see page xiii). Both structures were necessary to ensure a national perspective regarding policy input from across all jurisdictions and technical expert advice on the survey design, content and methodology.

A substantial amount of planning and research is needed in order to ensure that the significant investment of money required for surveys of this kind is realised in valuable and useful results that lead to better health strategies for the population, and that wide support is built for the survey program from the start. This approach has been adopted for Australia.

From the outset, a number of broad questions were considered.

- What are the longer-term policy questions or issues that should form the basis of a national population health survey that includes physical and biochemical measures?
- What health issues are important to consider now, and which are likely to emerge as significant for our nation over the next ten or twenty years?
- What are the important gaps in information currently that a survey of this kind could help to remedy? Can these be addressed in a single survey or is there a need for a program of periodic surveys?
- Are there certain population groups that should be considered as a priority for inclusion?
- What are the directions for future population health surveying and data collection nationally, and how does a national health measurement survey program fit within a longer-term view?

These questions formed the basis of the developmental process that was undertaken and the Inter-Governmental Steering Committee and Reference Group met regularly from early 2000. This proposal is the result of their deliberations and of wider consultations within their jurisdictions. The Business Case documents the benefits of such a survey program for Australia, the proposed design, content and methodology, associated ethical issues and likely cost. If this proposal is supported, further developmental work will be required, including survey piloting and wider community and health industry consultation.

The opportunity to invest in a national population health survey program that contains physical and biochemical measures will provide a firmer foundation for health policy development in Australia in the new century.

1.3   Outline of the proposed Australian Health Measurement Survey program

The proposed AHMS program has been developed as a program of cross-sectional surveys that include a component of physical and biochemical measurement, and will examine a range of disease outcomes and risks. The broad aim of the program is the collection of population health information at a national level – specifically designed to assist in the development of health policy and service planning, to assess the degree of success of health promotion or illness prevention strategies and to contribute to a greater understanding of health and illness in Australia via research.

The AHMS program will be nationally representative of people of different age, sex, geographic area and socioeconomic circumstances. It will combine questionnaire responses and physical and biochemical measures (such as measurement of height and weight; analyses of samples of blood, urine, and saliva; and tests of function). The program of surveys allows for the inclusion of a wider range of content areas than a single 'stand-alone' survey. The design contains a 'core' of measures, which is repeated at each survey, with one or more modules on subjects of special interest undertaken

opportunistically. This model has been implemented successfully in the UK and the USA.

There are a number of national health policy areas that have been identified as important for inclusion in the AHMS program, such as chronic disease comorbidities, onset of risk factors in childhood, overweight and obesity, mental health, lack of physical activity and nutrition, in addition to cardiovascular disease and diabetes mellitus. The survey will provide national prevalence estimates for a range of chronic diseases and conditions across relevant age groups.

Two frameworks, *The National Health Performance Framework* (devised by the National Health Performance Committee (NHPC 2001) and AHMAC endorsed) and *Preventing Chronic Disease: A Strategic Framework,* (devised by the National Public Health Partnership (NPHP) (2001) and AHMAC endorsed) provide a mechanism to ensure national data collection develops in a coordinated way to fill information gaps in Australia. The AHMS program offers an important opportunity to collect information to fill some gaps highlighted by these frameworks.

The AHMS program is recommended to commence in association with the NHS. The first survey of the AHMS program would be conducted with the NHS in 2004/5, preceded by a dress rehearsal in 2003/4. The AHMS is, in effect, in two parts. The first of these comprises the subjective measures undertaken in the NHS. The second includes the physical and biochemical measurement undertaken in the AHMS. It is proposed that the survey be repeated after six years, with the possibility of more frequent (e.g. three yearly) surveys once the initial results have been analysed and their contribution to policy development, program planning and research assessed.

The proposed objectives of the AHMS program are:
- to determine the prevalence of selected disease outcomes and risk factors/determinants in the Australian population and selected population groups, as a basis for policy and strategy development;
- to monitor trends in the prevalence of identified disease outcomes and risk factors/determinants in the Australian population and selected sub-population groups;
- to examine the relationships among selected diseases and risk factors/determinants; and,
- to validate self-report of selected risk factors/determinants using biological measures, in order to assess the validity of time trends in health indices obtained using self-report.

Information from the surveys will be used:
- to generate reliable evidence over time to be used for population health planning and the evaluation of several major disease prevention and control activities, including the National Health Priority Area (NHPA) strategies;
- to examine the relationships among selected diseases and risk factors/determinants to assist in focusing research efforts and policy developments;

- to provide the infrastructure for "opportunistic" testing of issues of concern (for example, lead or other pollutants) that may arise in the future; and,
- to validate the self-report measures that are collected in face-to-face health surveys and potentially provide weights for adjustment of those surveys.

Future opportunities for consideration within the AHMS program exist for administrative data linkage to cancer and death registries, possible sample storage and for the inclusion of a longitudinal component to allow follow-up of some participants over time, all subject to participant consent. These issues have been considered for the initial AHMS, but require considerable community consultation and ethical debate, and have therefore been excluded from the proposed AHMS program at this time.

1.3.1 Two examples of possible outputs from the survey program and their value to health policy and planning

The content areas of each survey will determine the outputs derived from the proposed AHMS program. Two examples highlighting survey programs overseas serve to identify the potential benefits of having accurate, up-to-date information about the population's health to underpin health policy and program development.

Folate status in US childbearing women

In 1992, the US Public Health Service recommended that women of childbearing age increase their consumption of the vitamin folic acid, to reduce the occurrence of spina bifida and other neural tube defects in their offspring. To this end, national efforts were implemented to increase awareness and encourage the use of dietary supplements containing folic acid prior to conception. In 1996, the U.S. Food and Drug Administration (FDA) authorised the addition of folic acid to enriched grain products, with compliance mandatory by 1998.

To assess the success of the preventive strategy, the US Centers for Disease Control and Prevention compared serum and red blood cell folate concentrations for childbearing-aged women who participated in the 1999 National Health and Nutrition Examination Survey (NHANES 1999), to the same measures in childbearing-aged women who participated in the Third National Health and Nutrition Examination Survey (NHANES III, 1988-1994). Results from the NHANES 1999, which was conducted after implementation of food fortification and educational efforts to increase folate consumption, showed that these public health actions had been effective in increasing folate status among U.S. women of childbearing age (MMWR 2000).

One of the US national health objectives for 2010 is to increase the proportion of pregnancies begun with an optimum folic acid level among nonpregnant women aged 15-44 years (Objective 16-6b). On the basis of the results of the NHANES 1999, this objective has been met.

<u>Predicting likely demand for cholesterol-lowering drugs</u>

Pharmaceutical treatments for risk factors are a significant driving force in the Pharmaceutical Benefits Scheme budget growth, and current prevalence estimates would therefore be valuable for economic modelling of likely future demand.

In Australia, for the period April 1999 to March 2000, serum lipid-reducing drugs contributed the greatest increase in cost of drugs to Government (up $ 106.7 million). Simvastatin was the top PBS drug by cost to Government at a cost of $196.1m. Atorvastatin and Pravastatin, also statin drugs, were the second and seventh highest, at costs of $163.7m and $58.5m respectively (DHAC 2000).

However, the use of lipid-lowering agents (the 'statins') has demonstrated survival and other benefits in secondary and primary prevention of coronary heart disease in those people with substantial risk (NHMRC 1996; Hulley et al. 2000). Information from the proposed AHMS program would give more accurate estimates of current prevalence of raised blood lipids across age groups to support economic modelling of future demand and cost-effectiveness of these medications.

In the UK, national guidelines for the prescription of statins, for people who either have established cardiovascular disease or are at high risk of developing it, have been issued. Using data from the Health Survey for England 1999, researchers reported recent data that showed that there were high rates of raised blood lipids among English adults, but that only 1 in 50 adults were taking lipid-lowering drugs (Primatesta & Poulter 2000). This research suggested that a significant number of adults with elevated blood lipids were a possible target for cholesterol-reducing treatment in England, and provided the basis to determine the likely budgetary impact if the guidelines were followed more rigorously.

1.4   Relevance of the AHMS program

The development of the AHMS program will align Australia with the USA, the UK, a number of European and Asian countries, and New Zealand. The proposed AHMS program underpins the national strategy for monitoring health trends and expectations, and for identifying and responding to disease problems as they emerge. In particular, the AHMS program will provide physical and biochemical measures of health status in addition to subjective, self-reported health information. This will provide significant information to underpin prevention and management of chronic conditions such as obesity, diabetes, hypertension, heart disease, and respiratory disease. The relationships between physical and biochemical and subjective measures of health, and measures of health service utilisation, will also provide important insights into health awareness, expectation and access to services. Surveys repeated over time will monitor trends in selected chronic disease risk factors and outcomes.

The AHMS program has been designed to be policy relevant and to maximise related research and development opportunities for health researchers. The physical and biochemical measurements in this program of surveys have been developed to complement and enhance current population health information collected in Australia,

and particularly the NHS and the recent AusDiab. These measures are crucial for the development and monitoring of services for conditions which have been responsible for at least two-thirds of the mortality gain in the last 30 years, and which still offer the greatest prospects for mortality gain in the future – especially the National Health Priority Areas of circulatory conditions and diabetes, but there are also implications for major cancers.

The decision to link the AHMS program with the NHS will allow validation of the self-reported data that is collected in the NHS. Work with the ABS on the AHMS program development resulted in a skirmish being undertaken in November 2001 to assess initial elements of the recruitment process to AHMS. Preliminary results indicate adequate response rates that are similar to surveys of this kind overseas. Additional piloting is now required, including the taking of measures (Appendix C: AHMS Skirmish Report (ABS)).

The survey program is strongly supported by the divisions of the Department of Health and Ageing (DoHA), the AIHW and the ABS. The States and Territories have also indicated high-level support and interest, particularly in broad, policy relevant content coverage. Strong support has also been received from the scientific Reference Group, comprising leading health academics, advising the AHMS Inter-Governmental Steering Committee.

2. OVERSEAS AND AUSTRALIAN POPULATION HEALTH MEASUREMENT SURVEYS

2.1 Experience in other countries

Numerous countries such as Finland, Germany, India, the Netherlands, Denmark, Latvia, Greenland, Canada and Australia have conducted single national health measurement surveys. The majority have focused on cardiovascular health and included measures of body dimensions, blood pressure and analyses of blood samples.

However, other countries have now established, or are developing, ongoing programs of population health surveys using physical and biochemical measures. The key design features of these programs are summarised in Table 2.1. Of these, the programs in the US and the UK are the most sophisticated, and survey results and analyses have been highly valued for use by policy-makers and researchers. Each conducts their survey on an annual, rolling basis and includes a wide range of physical and biochemical measures. Both of these programs survey children, offer interview and measurement in respondents' homes (or in mobile clinics), have a longitudinal component for follow-up of participants, some linkage to administrative data and store collected samples for further research. Further details about these programs are contained in Appendix A.

A number of international surveys across countries have been established. The current WHO initiative, Stepwise Approach to Surveillance (STEPS) of non-communicable disease risk factors, uses standardised questions and measurement protocols at three levels of monitoring, depending on available resources across developing and more developed countries worldwide (Bonita et al. 2001).

Many countries are now favouring the survey design developed for the UK Health Survey for England (HSE), which has a core content component (measured at every survey), and special interest modules (measured less frequently or opportunistically). The core content is designed to monitor general health, common risk factors and the socioeconomic determinants of health over time. Special interest modules examine particular health-related questions on an occasional or rotating basis in order to examine certain issues in greater depth. For example, HSE undertook special interest modules focusing on cardiovascular disease (1994 and 1998); asthma, accidents, and disability (1995); children and young people (1997); ethnic groups (1999); and older people, and social exclusion (2000) (National Statistics and Department of Health, UK 2001). The Scottish, New Zealand, and the US NHANES survey have also adopted this model (see Table 2.1).

Table 2.1: Programs of population health measurement surveys including physical and biochemical measures: Overseas experience

Country and survey program	Frequency	Inclusion of children	Sample size (per survey)	Location	Physical and biochemical measures	Linkage to admin. data *	Sample storage
USA **National Health and Nutrition Examination Survey (NHANES)**	Annual continuous [1] (from 1999); previously a series of multi-year surveys (since 1960)	✓ from 2 months old (since 1988)	5 000 (per annum)	Mobile centre or in the home	**Core measures**: Blood pressure, height, weight, body dimensions, analyses of blood and urine **Measures on sub samples**: include ECG, audiometry, balance testing, bioelectrical impedance, cardiovascular fitness, body composition, bone densitometry, dermatology exam, lower extremity disease exam, muscular strength testing, oral health, vision testing, TB skin test, spirometry, allergy testing	✓	✓
England **Health Survey for England (HSE)**	Annual (from 1991)	✓ from 2 yrs.	20 000	Home	**Core measures**: Blood pressure, height, weight, body dimensions **Measures related to individual survey topics**: Cardiovascular disease (blood) Asthma/accidents/disability (blood, saliva, spirometry)	✓	✓
Scotland **Scottish Health Survey**	Triennial (from 1995)	✓ from 2 yrs.	13 000 (1998)	Home	**Core measures**: Blood pressure, height, weight, body dimensions, lung function, blood analyses **Measures related to individual survey topics**: Cardiovascular disease (blood)	✓	✓

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[1] From 1999, each annual sample is representative of the population; previously the total multi-year survey was required to achieve a representative sample.

Singapore **National Health and Morbidity Survey**	5-7 years (from 1992)	✗	4 700	Clubs and community centres	**Core measures:** Blood pressure, ECG, height, weight, body dimensions, blood analyses **Every survey focused on**: Diabetes and cardiovascular disease	n.a*.	n.a.
Germany **National Health Examination & Interview Survey**	6-8 years	✗	7 200	n.a.	**Core measures**: Blood pressure, height, weight, body dimensions, blood and urine analyses, mental health exam., tests of function, nutritional status	n.a.	n.a.
New Zealand **National Survey Program** (secured funding – to be run 2001/2)	Biennial (National Nutrition Survey 1996/7 then every 5-10 yrs.)	✓	5 000	Home	**Core measures**: Height, weight, body dimensions, bio-impedance, blood pressure, blood analyses **Measures related to individual survey topics**: Child nutrition (1st survey) Mental health Disability	✓	To be deter-mined
Finland **Health 2000**	Five-yearly (from 2000) Previous survey 1978/9	✗	10 000	Home or mobile clinics	**Measures:** Height, weight, body dimensions, bio-impedance, blood pressure, tests of physical and mental functioning, vision and hearing, oral and dental health, ECG, spirometry, Blood, saliva, urine, and faecal analyses	n.a.	✓

n.a* = Details not available in English

2.2   Previous Australian experience

Several national population based studies conducted in previous years in Australia have included the collection of physical and biochemical measurements. The key features of these surveys are outlined in Tables 2.2 and 2.3.

Many smaller surveys, usually focused on particular geographic areas or special populations of interest, have also included physical and biochemical measurements but only 'national' population based surveys are described below. The National Heart Foundation's Risk Factor Prevalence Study surveys of capital cities have been repeated over time. Thus, these surveys provide a time series of data on cardiovascular health that could be built on by the AHMS program. Many of these studies demonstrate that the taking of physical and biochemical measurements, including in children, is likely to be acceptable to the Australian community.

Table 2.2: National population health surveys using physical and biochemical measurement in Australia

	Survey design	Sample size	Physical and biochemical measures
National Heart Foundation: Risk Factor Prevalence Study	Three cross-sectional surveys in all capital cities in 1980, 1983 and 1989	5 000 to 10 000 adults (aged 20+)	Related to cardiovascular health: blood, blood pressure, fasting glucose (only first two) and body measurements
Aust. Council for Health, Physical Education and Recreation Inc.: Australian Health and Fitness Survey	Cross-sectional national survey of schoolchildren in 1985	8 500 students aged 7 to 15 years	Related to cardiovascular health: blood, blood pressure and body measurements
Environmental Protection Authority: National Survey of Lead in Australian Children	Cross-sectional national survey in 1995	3 000 children (aged 1-4)	Related to blood lead levels: blood
ABS: National Nutrition Survey	Cross-sectional national survey in 1995 (undertaken on a sub-sample of the ABS NHS)	13 800 children and adults (2+)	Body measurements, and blood pressure (16+)
International Diabetes Institute: Australian Diabetes, Obesity and Lifestyle Study (AusDiab)	Cross-sectional national survey in 1999	10 000 adults (aged 25+)	Related to cardiovascular disease and diabetes: blood, oral glucose tolerance test, body measurements, bioimpedance, spot urine and ECG; (foot screening, sensory tests and retinal photography in a sub-sample)

Table 2.3: Physical and biochemical measures collected in previous national surveys in Australia

1980 NHF Risk Factor Prevalence Study	1983 NHF Risk Factor Prevalence Study	1989 NHF Risk Factor Prevalence Study	1985 ACHPER Australian Health and Fitness Survey	1990 Pilot Survey of Adult Fitness	1995 EPA National Survey of Lead in Children	1995 ABS National Nutrition Survey	1999/2000 IDI AusDiab
Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire	Questionnaire (incl. food frequency)	Questionnaire
	24hr dietary recall		24hr dietary recall			24hr dietary recall	Food frequency questionnaire
Physical measurements	Physical measurements	Physical measurements	Physical measurements	Physical measurements		Physical measurements	Physical measurements
BP	BP	BP	BP	BP		BP>16y (included in the pilot only)	BP, ECG >40y (incl. autonomic neuropathy)
Fasting blood sample -10mL Total cholesterol HDL cholesterol Triglycerides	Fasting blood sample –12.5mL Total cholesterol HDL cholesterol Triglycerides Glucose	Fasting blood sample -12mL Total cholesterol HDL cholesterol Triglycerides Iron Ferritin Transferrin	Fasting blood sample -15mL Total cholesterol HDL cholesterol Triglycerides Iron Ferritin Transferrin	Fasting blood sample -10mL Total cholesterol HDL cholesterol Triglycerides	Blood lead sample	Blood sample (included in the pilot only)	Blood samples – 8.5mL Total cholesterol HDL cholesterol Triglycerides Glucose (whole blood & plasma) Hb A1c Oral GTT Urine – 8mL Creatinine Albumin
			Fitness tests	Fitness tests			
				Lung function			
							Foot screening/ sensory tests
							Eye examination (retinal photography)

3.   DEVELOPMENTAL PROCESS UNDERTAKEN

The last decade has seen the development of several survey programs overseas that include physical and biochemical measurement, and an increasing interest in Australia for establishing a similar, coordinated national program. The first Australian proposal began as a single biochemical risk factor survey to repeat, and build on, the information obtained from the 1989 National Heart Foundation survey (see Section 2.2 Previous Australian experience).

The proposal has since developed to follow the model adopted by the UK and USA, that of a coordinated national program of periodic population health measurement surveys to cover a range of public health issues over time. The development of the proposed AHMS program is described below.

3.1   The proposal for a National Biochemical Risk Factor Survey

In 1997, the AIHW held a national workshop of interested parties on the need for a biochemical risk factor survey for Australia and a decision was made to develop a proposal for the Australian Health Ministers Advisory Council (AHMAC). A Steering Committee was established and the AIHW undertook the planning of the survey and proposal development. The proposal detailed the need for a single national biochemical risk factor survey and identified a range of biologic measures that focused on cardiovascular disease, diabetes mellitus, communicable diseases and nutrition (priorities determined by invited participants at the initial workshop). The proposal canvassed a range of issues including coverage of children less than 18 years, and of rural and remote communities; storage of collected sera for further research; and the linking of results to other AIHW and ABS collections. Survey design issues, such as linkage to the NHS, were not determined at that stage.

The proposal was endorsed by the National Public Health Partnership (NPHP) in February 1999 and forwarded to AHMAC in April 1999. AHMAC referred the proposal back to the NPHP for advice on funding. The NPHP commissioned the AIHW to prepare a business case that was presented to the National Public Health Information Working Group (NPHIWG) in September 1999. It identified that the single survey would cost at least $3 million. The need for such a large investment led the (then) Commonwealth Department of Health and Aged Care (DHAC) and AIHW to agree to an additional process of planning and development.

Following discussion at the DHAC Policy Forum on 20 September 1999, the Public Health Information Development Unit (PHIDU) was asked to provide further advice on survey development issues including the linking of the survey to the NHS.

In November 1999, the NPHP endorsed an approach that focused on:

- developing a strong rationale and business case for the survey, with particular focus on policy implications, future information needs and cost;
- planning the content, scope, design and methodology for the survey and involving researchers and other parties to assist with those matters;
- engaging the attention and interest of policy makers across health portfolios in all jurisdictions, through a formal consultation process, in order to consider longer-term policy perspectives and implications, to identify other initiatives which could add value to the survey, and to determine support for such a survey; and,
- engaging consumer groups and the wider community in the survey planning to ensure that their interests and concerns are addressed and to determine their support for such a survey.

3.2 The development of the AHMS program

Following endorsement of the terms of reference, a new Inter-Governmental Steering Committee was established to develop the proposal further (see page xi for the Committee membership). The Committee determined that a program rather than a single survey was required, in order to provide the breadth of necessary health information that was currently unavailable. The Committee proposed the name, the Australian Health Measurement Survey program.

A consultative process was undertaken with Commonwealth, State and Territory jurisdictions to ascertain their policy priorities in order to frame potential program content in a policy context. A number of national health policy areas were identified as important, including chronic disease comorbidities, onset of disease risk factors in childhood, overweight and obesity, mental health, lack of physical activity and nutrition, in addition to cardiovascular disease and diabetes mellitus. There was interest across jurisdictions for the AHMS program to provide national prevalence estimates for a range of chronic diseases and conditions across relevant age groups.

Two frameworks, *The National Health Performance Framework* (devised by the National Health Performance Committee (NHPC 2001) and AHMAC endorsed) and *Preventing Chronic Disease: A Strategic Framework,* (devised by the National Public Health Partnership (NPHP 2001) and AHMAC endorsed) provide a mechanism to ensure national data collection develops in a coordinated way to fill information gaps in Australia. These frameworks were used to determine the scope that was required of the AHMS program.

After several iterations, a content framework was developed based on these frameworks (see Appendix B: A framework for considering the content of the AHMS program). An expert technical Reference Group was convened to provide advice on the best measures for the content areas contained in the framework (see page xiii for the Reference Group membership). Other

experts were approached on the advice of the Reference Group, and a separate teleconference was organised with members of the Communicable Diseases Network of Australia and New Zealand, to discuss information needs and content issues in the area of communicable diseases.

The proposed AHMS program was developed as a program of cross-sectional surveys that include a component of physical and biochemical measurement, and that will examine a range of disease outcomes and risks. It will be nationally representative of people of different ages, sex, geographic area and socioeconomic circumstances. It will combine questionnaire answers and physical and biochemical measures (such as measurement of height and weight, analyses of samples of blood, urine, and/or saliva and tests of function).

The Steering Committee explored a range of design options around the concepts of a 'stand alone' survey or one that could be linked with the NHS. After a number of discussions with the ABS, it was agreed that linking the NHS and AHMS would be the most constructive way forward. Advice was also sought from the ABS to address specific design issues raised by the Steering Committee.

3.3 Linkage to the ABS National Health Survey

Three important issues were identified by the ABS that impinge on a linked design:
- the ABS advised that the *Australian Bureau of Statistics Act 1975* prohibits their staff from collecting physical and biochemical measures; so an external agency or agencies would be needed to conduct the AHMS component of a linked survey;
- the ABS is prohibited by this Act from releasing the names or addresses of respondents agreeing to participate in the AHMS to an external agency; thus, the respondent would need to contact the external agency directly; and,
- if an external agency knew the identities of the examined respondents, confidentialised unit record files (CURFs) for the entire survey could not be released by the ABS, because the external agency could potentially identify the files by matching them to their results' records.

In relation to the issues detailed above, the ABS proposed a range of options under which the NHS could be associated with the AHMS program. The following approach was selected.

At the conclusion of the NHS interview, respondents will be asked if they would be willing to consent to a nurse visiting their home for the AHMS during which a range of measures would be taken. The ABS interviewer would then provide the respondents with a consent form together with a reply paid envelope addressed to the external AHMS agency. If signed at the

time, the ABS interviewer would offer to accept the form for passing to the external agency. Respondents who do not consent at the time will be able to mail their consent forms to the AHMS agency. The ABS will also make further contact with respondents who have accepted the consent form but want more time to consider their decision, to encourage them to participate. The AHMS agency will then contact the respondents to arrange a time for a nurse to visit them in their home to take the measurements.

The results of the tests will be sent back to the ABS to be matched to the NHS interview. As a list of names has been held by the external agency, no CURF will be able to be released. Data access arrangements are outlined in Section 7.1 Data access.

The Commonwealth, States and Territories agreed with the proposed method detailed above, and it was on this basis that the ABS undertook the skirmish.

3.4   Skirmish results and proposed pilot test

The AHMS skirmish conducted by the ABS (November/December 2001, simultaneously in NSW and SA) tested levels of recruitment to the AHMS program. Respondents were asked whether they would agree to being contacted to make an appointment for the series of samples (blood, saliva and urine) and physical measurements (height, weight and waist circumference) to be taken. Intent to allow the measurements to be taken was tested, rather than willingness to sign a consent form. No consent forms were produced for signing, and no actual measurements were taken.

A sample size of 677 dwellings in NSW and SA was selected. Interviewers randomly selected one (usual resident) adult aged 18 years and over (using the next birthday method) per household for the NHS interview and this person was also interviewed for the AHMS. Respondents who were parents were also asked whether they would agree to have their children involved in the AHMS, although this was not followed through with the children themselves.

The NHS questionnaire was shortened so that the full skirmish interview averaged 45 minutes per household. After asking the NHS questions, interviewers introduced the AHMS. Following the introduction, respondents were asked whether they would agree to having another organisation contact them to arrange an appointment to have the measurements and samples taken. After this, respondents were informed that they had been involved in a test of respondent reaction to such a survey and that the AHMS was not being conducted at this point in time. They were then asked a further series of questions on their reasons for agreeing/not agreeing to participate. Those who had agreed were asked their preference of location for tests (at home or at a clinic). Those who had not agreed were asked whether there were

conditions that would change their decision regarding agreement (such as removal of certain tests, change of location).

3.4.1 Response rate

The total NHS response rate for the skirmish was 68.1% (fully responding) and 59.0% of these agreed to being contacted for the AHMS measurements. This response rate was achieved without any of the usual ABS survey follow up protocols for refusals, or employment of interpreters where language difficulties existed (fully responding response rates achieved in recent NHS's have been well over 90% with such follow up).

Generally, interviewers reported that respondents were receptive to the AHMS, and they felt that the number of persons agreeing could be increased by a variety of actions (such as providing more information on how results would benefit the general public, providing a copy of test results to participants, and following up those who thought they were 'too healthy', 'too old' or were currently having tests regularly). On the basis of these potential follow up actions, ABS advised that the final response rate for the AHMS could be increased to 75% of those people fully responding to the NHS. However, overseas experience suggests that a drop off rate of about 16% may be expected prior to respondents actually seeing a nurse.

3.4.2 Reasons for agreement and non-agreement

The major reasons given by those who agreed to be contacted for the AHMS (256 persons) were 'I wanted to contribute to a good cause' (43%); 'Assume I will get results/interested to see my results' (41%); and 'will help understand risk factors' (41%).

The major reasons given by those who did not agree (178 persons) were 'already having these tests/would prefer to go to own doctor' (22%); 'no time/too busy' (31%); and 'types of tests/physical nature of tests' (21%).

A total of 41% of those who did not initially agree, would agree to have some measurements or samples taken. (See Appendix C: AHMS Skirmish Report (ABS) for more details.)

3.4.3 Full pilot test recommended

Following the skirmish, the ABS recommended that a full pilot test be run to provide more information on drop off rates and to clarify response rates achievable from initial agreement to consent (at the nurse interview) and the actual collection of measurements and samples. The pilot test would also ascertain the number of children (in addition to their parents) who give their agreement (not tested in the skirmish).

If results of the full pilot test were favourable, the agency undertaking the contract to conduct the first AHMS, would then undertake a dress rehearsal prior to the conduct of the survey proper.

3.5 Issues considered but not included in the initial AHMS

A range of design issues were considered but were rejected by the Steering Committee for inclusion as part of the initial survey, and these are detailed below.

3.5.1 Sample storage for future research purposes

Storage of collected blood samples for possible later use (such as further analyses) was extensively discussed. Samples are successfully stored in both the long running US and UK health measurement surveys (NHANES and the Health Survey for England). However, the need to obtain open-ended consents (to allow for analyses not known at the time of obtaining consent) from participants recruited to AHMS was regarded as a likely impediment to achieving the necessary high response rates for the survey. The Steering Committee also felt that there were significant ethical, legal and privacy issues regarding the storage of samples that required further consideration and consultation. The likely high cost of storage was also identified.

3.5.2 Administrative data linkage

The linkage of AHMS respondents' data to administrative collections (such as cancer and deaths registries) with consent was considered as a potential design element. Comparable overseas surveys have linked respondents' data to administrative and other data collections. However, the ABS is not currently in a position to undertake administrative data linkage for the NHS, and any decision regarding data linkage within the AHMS was therefore delayed pending the outcome of the ABS' review of their position.

3.5.3 Longitudinal follow-up component

The follow-up of some participants over time in subsequent surveys, adding a longitudinal component to the cross-sectional AHMS (and NHS), was another design element considered. Longitudinal follow-up has been successfully undertaken in the US for instance, in the NHANES I Epidemiologic Followup Study, designed to provide data on mortality, morbidity, and hospital utilisation as well as changes in risk factors, functional limitation, and institutionalisation. However, it was decided not to include this element in the AHMS program design until evidence of the value of the survey becomes clear.

3.5.4 Indigenous populations

The conduct of the AHMS on a sub sample of respondents to the 2004/5 NHS means that the 1.1% of the Australian population (which includes 17.8% of all Indigenous people) who live in the sparsely settled areas of Australia will be excluded. Due to current NHS sample size restrictions, it may not be possible to produce reliable estimates for Indigenous people for (at least) the first survey in the AHMS program.

Over-sampling of Indigenous populations and inclusion of the sparsely settled areas are to be considered in the AHMS program, depending on ABS advice on methods to improve coverage in these areas and consultation with Indigenous communities. The potential for individual surveys in the associated NHS and AHMS program to over-sample in Indigenous populations is under consideration.

4. SURVEY CONTENT

The proposed AHMS survey design will allow both physical and biochemical measurements and subjective (self-reported) health information to be collected from the same respondents. In the NHS, respondents will be interviewed in their homes on a range of health subjects. At the conclusion of the NHS interview, respondents will be asked if they would be willing to consent to a nurse visiting their home for the AHMS during which a range of measures would be taken. The ABS interviewer would then provide the respondents with a consent form together with a reply paid envelope addressed to the external AHMS agency. If signed at the time, the ABS interviewer would offer to accept the form for passing to the external agency. Respondents who do not consent at the time will be able to mail their consent forms to the AHMS agency. The ABS will also make further contact with respondents who have accepted the consent form but want more time to consider their decision, to encourage them to participate. The AHMS agency will then contact the respondents to arrange a time for a nurse to visit them in their home to take the measurements. (See Section 5.3 - The AHMS program design, for more detail.)

Thus the physical and biochemical measures from the AHMS will be supplemented by the subjective information collected through self-report by respondents to the NHS interview. These include the prevalence of selected disease conditions and associated risk factors (such as tobacco exposure, physical activity, food and supplement intake, alcohol intake), psychosocial factors, health management, mental health, socioeconomic status and demographic information.

Core content will, over time, allow for the monitoring of the Australian population with respect to:
- body dimensions;
- selected diseases, risk factors and socioeconomic determinants of health;
- relationships between selected diseases, risk factors and determinants (for example, the relationship between cardiovascular disease, smoking and socioeconomic status);
- the progression of risk over the life course;
- the contribution of risk factors and socioeconomic determinants of health to the overall disease burden.

Once a commitment to link the NHS and the AHMS is in place, and if funding for the AHMS is confirmed, the content of the NHS and AHMS will need to be aligned, in order that the overall usefulness of data gained from each is maximised for policy and research purposes. Thus, both components are necessary to answer the desired policy questions and to enhance the usefulness of the NHS when it is not run in conjunction with an AHMS.

The content of the NHS should ensure the necessary self-reported data is present to maximise the validation possibilities flowing from the measured prevalence of selected diseases and associated risk factors. It will also be necessary to confirm that the best information on the non-health determinants of health (such as socioeconomic status) is available to identify any associations with the health data.

Discussions are continuing with the ABS regarding the initial AHMS content of the NHS in 2004/5. While there are many agencies with an interest in the outputs from the NHS, the DoHA, as a significant contributor to the funding of the NHS should also be recognised as a stakeholder with a major interest in its content. Suggested NHS content to make the best use of the AHMS data is contained in Table D.2 in Appendix D (Proposed content for the AHMS program).

It is proposed that the AHMS program have two content components: a core set of physical and biochemical measures at every AHMS, and opportunistic special interest modules. These are described in detail below, in Section 4.3 – Core set of physical and biochemical measures, and in Section 4.4 – Special interest modules.

4.1   Selection criteria to determine AHMS program content

The Steering Committee used the following criteria to select the broad content areas that should be included in the AHMS program. The content areas should:

- be issues of national public health importance and reflect government health objectives;
- address problems that could be changed through public policy and strategy initiatives; and,
- have reliable, replicable and valid measures that are easy to administer and that link with other areas for which physical and biochemical measures are required.

4.2   Development of a framework for the AHMS program content

A consultation process was held with DoHA, AIHW and the State and Territory jurisdictions to elicit their policy priorities. This information was incorporated into a comprehensive framework that was based upon *The National Health Performance Framework* (devised by the National Health Performance Committee (NHPC 2001) and AHMAC endorsed) and *Preventing Chronic Disease: A Strategic Framework,* (devised by the National Public Health Partnership (NPHP 2001) and AHMAC endorsed). This framework is in Appendix B – A framework for considering the content of the AHMS program.

The AHMS framework included a range of health conditions that are current National Health Priority Areas, and outlines:
- their public health importance, priority and estimated burden;
- their risk factors and determinants;
- related government policy and strategy initiatives;
- relevant physical and biochemical measures to determine prevalence; and,
- potential uses of the information gained from the physical and biochemical measures.

The framework summarises the three rounds of consultation undertaken to date. All measures included in the framework met the selection criteria outlined in Section 4.1. The risk factors and determinants common to a range of selected diseases form the basis of the core of measures for the AHMS program (see Section 4.3 - Core set of measures).

4.3   Core set of physical and biochemical measurements

It is proposed that a core set of measures be collected in every survey in order to provide a consistent picture of common diseases, their risk factors and socioeconomic determinants of health over time. This approach is used in the Health Survey for England, which includes in its core content the measures of height, weight, body dimensions and blood pressure, as well as subjective measures of general health, risk factors and socioeconomic status gained through interview. In Australia, the subjective measures would be collected by the NHS.

The core set of measures for the first AHMS is proposed as:
- physical measurements:
  - height
  - weight
  - abdominal circumference
  - blood pressure
  - lung function tests: spirometry.

- biochemical measurements:
  - analyses of blood: serum lipids (cholesterol, LDL, triglycerides, HDL); homocysteine, red cell folate and Vitamin B12; glucose; glycosylated haemoglobin (HbA1c); and insulin;
  - analyses of saliva: cotinine
  - analyses of urine: dipstick test urine, and spot urine for albumin/creatinine ratio.

The Steering Committee has determined that most of the blood samples need to be taken after a period of fasting (for twelve hours). This will allow comparison with the data from the National Heart Foundation's and other

surveys (which used fasting samples) to provide time trends. The inclusion of a fasting requirement for participants has implications for the survey design, response rates and survey costing. The impact of fasting on response rates should be piloted in the ABS pilot test of the first AHMS.

The following table (Table 4.1) identifies the proposed core measures (indicated by ●) for the first and subsequent surveys. Potential respondent age ranges for each measure are also shown.

Table 4.1:   Agreed physical and biochemical measures, by age of respondent, for the first AHMS

	Age of respondent (in years)					
	2-11	12-14	15-19	20-29	30-64	65-74
Agreed physical and biochemical measures						
Physical measurements:						
Height	●	●	●	●	●	●
Weight	●	●	●	●	●	●
Abdominal circumference	●	●	●	●	●	●
Blood pressure		●	●	●	●	●
Lung function - spirometry	●7+	●	●	●	●	●
Biochemical measures: blood analyses						
Serum lipid levels: (cholesterol, LDL, triglycerides (fasting), HDL (fasting))			●	●	●	●
Homocysteine (fasting)		●	●	●	●	●
Red cell folate, Vitamin B12 (fasting)		●	●	●	●	●
Glucose (fasting)			●	●	●	●
Glycosylated haemoglobin (HbA1c)		●	●	●	●	●
Insulin (fasting)		●	●	●	●	●
Biochemical measures: saliva analyses						
Cotinine (tobacco exposure)	● 4+	●	●	●	●	●
Biochemical measures: urine analyses						
Dipstick test urine		●	●	●	●	●
Spot urine for albumin/creatinine ratio		●	●	●	●	●

Note: proposed core measures shown as ●

The following measures (not shown in Table 4.1) were considered by the Steering Committee, but excluded from the first AHMS at the present time:

- Biochemical measures from analyses of blood:
  - C-reactive protein (measure of inflammation);
  - Oral glucose tolerance test (OGTT) (proposed for a sub-sample; related to diabetes);
  - Serum creatinine (related to renal disease);
  - Measures of fruit and vegetable intake (carotenoids (lutein, cryptoxanthin, lycopene, beta carotene); measures related to certain cancers and nutrition generally).
- Biochemical measures from analyses of saliva:
  - Cortisol (measure of ongoing psychosocial stress).

All the measures proposed (those that have been agreed and those that were discussed but excluded) are shown in Table D.1 in Appendix D. The relevance of each measure to the identified policy area of interest is also listed (for example, cardiovascular disease, diabetes, renal disease, etc.).

4.3.1 Relevance of the measures selected

a)   Height, weight, body dimensions

Measures of height and weight are required to calculate the Body Mass Index (BMI), which is used to identify cut-offs for classifying proportions of the population as underweight, overweight, or obese. Body dimensions, such as abdominal circumference, also reflect nutritional status and are used to assess distribution of body fat.

Being overweight (either excess weight or obesity) is one of the most common factors influencing the development of high blood pressure and diabetes. These conditions, in turn, are two important risk factors for heart disease and stroke.

Evaluation of body measurements will also provide nationally representative data on selected body measurements, overall and for age and gender categories; provide estimates of the prevalence of overweight and obesity; provide data to study the association between body measures and body composition, other health conditions and risk factors such as cardiovascular disease, diabetes, hypertension, and physical activity and dietary patterns; and monitor physical growth and development in children.

b)   Blood pressure

Raised blood pressure is an important risk factor for cardiovascular disease, (both coronary heart disease and stroke). The risk of cardiovascular disease increases as the level of blood pressure increases. Although less is known about the distribution of blood pressure in children than in adults, evidence supports the idea that the roots of essential hypertension extend back to early adulthood (Lauer & Clarke 1989). Blood pressure is known to have a stronger relationship with age, height and weight in children than in adults (Chen et al. 1995; Clarke et al. 1986; Kaas Ibsen 1985).

c)   Lung function tests

Spirometry measures lung function and, by using predictive equations (based on reference populations, for age, height, and gender), provides a measure of difference between the measured and expected lung function. Cross-sectional estimates of spirometric function allow declines in function to be inferred and are predictive, in a population, of systematic airflow obstruction and premature mortality (G Marks, personal communication). Tests of lung function using spirometry can be made on children from the age of 7 years on, to identify the presence of diseases that interfere with the growth of lung function. Tests of airways resistance (in development 2002, likely to be useable in population surveys by 2004) potentially extend the ability to test lung function in populations from 2 years old, and would be preferred to spirometry for children aged between 2 and 7 years (G Marks, personal communication). A challenge test for asthma is not recommended for inclusion in a survey conducted in the home environment.

d)   Blood lipids

High blood cholesterol is linked with the development and progression of atherosclerosis and subsequent coronary heart disease (Law et al. 1994). Blood lipid components contribute disease risk in specific ways. Elevated levels of total blood cholesterol, low density lipoprotein (LDL) cholesterol, and triglycerides increase cardiovascular disease risk, while higher levels of high density lipoprotein (HDL) cholesterol exert a protective, risk lowering effect.

e)   Homocysteine levels in the blood

Blood homocysteine levels are an important, independent risk factor for clinical atherosclerosis and venous thrombosis (Malinow 1999). Elevations in serum homocysteine are associated with early coronary artery disease and stroke and with venous thromboembolic disease. It is thought to add to the risk of cardiovascular disease by provoking both atherosclerosis and clot formation.

Vitamin B12 and folate are essential cofactors required for homocysteine metabolism and are important determinants of homocysteine levels in the blood. All are affected by food intake. As blood levels of homocysteine are dependent on folate and vitamin B12, these need to be measured simultaneously.

f)   Folate and Vitamin B12 levels in the blood

Folate plays an important role in the prevention of neural tube defects among women of childbearing age. Because of the interaction of vitamin B12 with folate metabolism, the nutritional status of both the factors needs to be assessed simultaneously.

g)   Glucose, glycosylated haemoglobin and insulin levels in the blood

The accurate diagnosis of diabetes requires clinical tests, such as the two-hour oral glucose tolerance test (OGTT) and the evaluation of related symptoms in a clinical examination, which are beyond the scope of this survey. Nonetheless, information on the prevalence of diabetes markers and risk factors will be collected. Specifically, the diabetes measurements in the survey will provide population data to determine national estimates of the prevalence of diabetes markers and risk factors in people with diagnosed and undiagnosed diabetes. There are also several common risk factors and indicators associated with both diabetes and cardiovascular disease including overweight and obesity, high blood pressure and high blood lipids. Many of the anthropometric and blood measurements described above for nutrition and cardiovascular disease are also relevant to diabetes.

Glycosylated haemoglobin (HbA1c) is an index of average blood glucose level for the previous 2 to 3 months and is used to monitor blood sugar control in diabetic people. Although not as sensitive as OGTT in the diagnosis of diabetes, HbA1c is a practical marker of diabetes risk in population-based surveys. It appears to be a marker of the increased risk of developing

atherosclerosis, myocardial infarction, strokes, cataracts and loss of the elasticity of arteries, joints and lungs. It is also associated with psychological measures of stress in a number of studies, both in non- and in diabetic people (Kelly, Hertzman & Daniels 1997). Fasting blood glucose is also used to assess diabetes and its inclusion in the survey will help estimate the prevalence of glycaemia in the sampled population. Serum insulin is a measure of insulin resistance.

h)   Salivary cotinine

Cotinine is a metabolite of nicotine. It is one of several biological markers that are indicators of smoking (others include carbon monoxide and thiocyanate), and is generally considered the most useful. The measurement of cotinine levels provides an objective crosscheck on self-reports of smoking behaviour, which are known not always to be accurate. Inaccuracies in reporting arise in part from difficulties informants may experience in providing quantitative summaries of variable behaviour patterns, but in some cases arise from a desire to conceal the truth from other people, such as other household members who may be present during the interview. Limitations on the ability of self-report to provide accurate quantitative responses are particularly marked in relation to exposure to other people's smoking (passive smoking).

Salivary cotinine will be used to assess the prevalence of exposure to tobacco smoke (both passive and active) and to validate self-reported exposure.

i)   Dipstick urine and spot urine analysis for albumin/creatinine ratio

Dipstick tests of urine and spot urine analyses for albumin/creatinine ratio are used to assess the prevalence of early renal impairment, through the detection of microalbuminuria, the earliest stage of renal disease and an independent risk factor for cardiovascular events (Borch-Johnsen et al. 1999, Lydakis & Lip 1998), and predictive of progression to renal failure in both diabetic and non-diabetic renal disease (Rossing et al. 1993, Ruggenenti et al. 1998a). Albumin/creatinine ratio in spot morning urine samples is a precise indicator of proteinuria and a simple and inexpensive procedure in establishing severity of renal disease and prognosis (Ruggenenti et al. 1998b).

4.4   Special interest modules

As described, a modular survey design is proposed for the AHMS program, with a core set of measures (maintained over time for trend comparisons), together with one or more modules on subjects of special interest.

Special interest modules would be undertaken opportunistically in individual surveys (once only, occasionally, or on a rotating basis) in order to examine particular health issues in greater depth. Special interest modules can be focused on disease outcomes, risk factors, and age or population groups.

Special interest modules used by the Health Survey for England have included cardiovascular disease (1994 and 1998); asthma, accidents, disability (1995); children and young people (1997); ethnic groups (1999); older people and social exclusion (2000). Modules planned from 2001 to 2006 are disability, asthma, accidents, physical activity, eating habits, oral health, cardiovascular disease, and social exclusion for various age and ethnic groups (Department of Health, UK 2000).

Special interest modules proposed for AHMS were:
- the Metabolic Syndrome or Syndrome X^2 (proposed for the first survey);
- nutrition (proposed for the second survey).

Since the original decision for a modular design, the number of items added to the core set of measures for the first survey in the AHMS program has increased to the extent that there is currently little opportunity to include any additional special interest measures in this survey. However, the possibility may arise to include a short questionnaire module on a topic of interest as part of the rapport-building process used by the nurse (see Section 5.3.4).

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[2] The World Health Organization has classified a specific clustering of risk factors as the Metabolic Syndrome (Syndrome X). Insulin resistance–-either impaired glucose tolerance, impaired fasting glucose or diabetes–-is thought to be the underlying defect in this syndrome. In addition to insulin resistance, a person with the Metabolic Syndrome will usually have one or more of the following risk factors: high cholesterol, high blood pressure and central obesity. The syndrome vastly increases a person's risk of developing type 2 diabetes or cardiovascular disease (AIHW 2002, in press).

5. SURVEY DESIGN

5.1 Overview

As noted above, it is proposed that the AHMS program be conducted in conjunction with the NHS. The NHS is conducted approximately every three years (2001, completed; 2004/5, 2007/8 and 2011/12, proposed). It is proposed initially that the AHMS be conducted every six years.

5.2 Survey coverage

The NHS approaches a sample of the Australian population living in private dwellings (as determined by the ABS's multi-stage stratified probability sampling design). One adult, one child/adolescent aged 7 to 17 years and all infants and children aged below 7 years are currently selected in each household in the NHS. The AHMS will take a sub-sample of this population (see Section 5.4 - Sample design and selection, below).

It should be noted that the NHS does not include the homeless or those living in institutions (e.g. hospitals, prisons and nursing homes). These groups may have poorer health than those in the proposed sample and this will need to be considered when interpreting the AHMS results.

In addition, the NHS does not include the 1.1% of the Australian population who live in the sparsely settled areas of Australia. These areas are excluded because of the sparsely settled nature of their population and the costs and other difficulties associated with surveying in such areas. Their exclusion is of particular importance, as 17.8% of all Indigenous people live in these areas, compared with only 1% of the non-Indigenous population. It is not currently possible to produce reliable estimates from the NHS for Indigenous people, a group that has the poorest health in Australia: their exclusion will also need to be considered when interpreting the AHMS results.

The ABS has been consulting with Indigenous groups and agencies, to ascertain ways to improve the coverage of data in the NHS from the sparsely settled areas. It is proposed that the 2004/5 NHS include a larger sample of the Indigenous population: in addition, the method of conduct of household interviews and the survey content is to be reviewed to ensure their relevance to Indigenous people in these remote areas. Inclusion of the sparsely settled areas, with their Indigenous population, in the AHMS program will be considered in relation to subsequent surveys, depending on the outcomes of the ABS processes described above.

5.3 The AHMS program design

5.3.1 Recruitment to the AHMS

It is proposed that, at the conclusion of the NHS interview, respondents aged less than 75 years be asked if they would be willing to consent to a nurse visiting their home for the AHMS, during which a range of physical measures would be taken. The ABS interviewer would then provide the respondents with a consent form together with a reply paid envelope addressed to the external AHMS agency. If signed at the time, the ABS interviewer would offer to accept the form for passing to the external agency. Respondents who do not consent at the time will be able to mail their consent forms to the AHMS agency. The ABS will also make further contact with respondents who have accepted the consent form but want more time to consider their decision, to encourage them to participate. The AHMS agency will then contact the respondents to arrange a time for a nurse to visit them in their home to take the measurements.

5.3.2 Nurse visit to the home

The nurse will contact respondents to the NHS, who agree to a nurse visit, and a time made to visit the respondent at their home. At that visit, the nurse will seek consent to take a range of physical and biochemical measurements. Where fasting is required for blood analyses, appropriate information will be supplied and arrangements made for the nurse to call back and take the measurements.

International survey experience suggests a nurse visit to the home is the best way to maximise response, and home visits and mobile clinics have now been incorporated in models in other countries (see Section 2.1, Experience in other countries). Results from the skirmish undertaken by the ABS in November 2001 also indicate a preference for a nurse to visit the home. Home visits are particularly feasible for the first survey of the AHMS program because the measures proposed require simple, portable equipment. In subsequent surveys, when more complex measures requiring additional equipment might be included, the AHMS could be conducted in a venue outside of the home.

5.3.3 Population covered and consent

It is proposed that the population to be covered in the AHMS be those aged from 2 to 74 years from the NHS interview who agree to participate in the measurement phase. Information will be obtained directly from those aged 12 to 74 years. Information about children aged from 2 to 11 years will be obtained from a parent, with the child present.

Consent for the collection of physical and biochemical measures will be obtained from all respondents 18 years and over and from the parents of

those under 18 years. Assent, as distinct from parental consent, will be obtained from those under 18 years before any measurements are taken.

For the physical and biochemical measures, it is proposed that:

- height and weight will be taken from those aged 2 to 74 years;

- abdominal circumference will be taken from those aged 2 to 74 years;

- lung function tests will be performed on those aged 7 years and over;

- a blood sample will be collected from those aged 18 years and over;

- a blood sample (by venepuncture after the application of anaesthetic cream) will be taken from those aged 12 to 17 years;

- a saliva sample for cotinine assay will be collected from those aged 4 years and over; and

- a urine sample will be collected from those aged 12 years and over.

5.3.4   Estimated time for taking measurements

The Health Survey for England, where it takes a nurse between 3 to 10 minutes in respondents under 4 years, and up to 40 minutes in respondents over 65 years, provides the most reliable information available regarding the time required to take the measurements. The times include (depending on age) the taking of blood, saliva, blood pressure, lung function tests and waist, hip and demi-span measures.

The times exclude:

- the measurement of height and weight, because, in the HSE, the interviewer takes them;

- the time necessary to ensure that the person identified in the NHS interview (and consenting to the nurse visit) is, in fact, the person from whom the nurse is to take the measures; and

- the time for the nurse to establish rapport with the respondent.

With regard to the last point, the ABS have advised that, in undertaking the National Nutrition Survey in 1995, time was needed to establish rapport with the respondent before taking the measurements (in that case, measures of height, weight, blood pressure and waist and hip circumference for participants aged 16 years and over). The ABS advice indicates that it would be appropriate to do this by asking a number of straightforward, but related, questions for up to 10 minutes. These could include the socioeconomic status questions identified in the policy consultations for the AHMS program, but not currently contained in the NHS interview, or a short module on a topic of interest such as nutrition. It is important to note, however, that it is not intended that the AHMS incorporate a lengthy questionnaire.

If children or others are offered anaesthetic cream for the taking of blood samples, then these times would increase, as the cream needs to be applied at least an hour before venepuncture, to be effective. Should this approach be adopted, there would be more time in which to ask a range of questions specific to children and families, while waiting for the cream to work.

5.4   Sample design and selection

5.4.1   Overview

There are a number of considerations in determining the size of the sample. Aside from cost, which is discussed in Section 9, the most important of these is the expected prevalence in the population of the health conditions for which measurements are being collected in the AHMS program. Examples are given below of the number of people for whom measurements would be needed in order to determine the prevalence of certain conditions.

The AHMS program is proposed as a national survey, with the availability of estimates at the State level being purely opportunistic (and related to the State's size and, therefore, share of the national sample). However, there is considerable interest in the extent to which estimates might be available at a regional level, whether by capital cities and the rest of Australia, or by some other categorisation, such as the Accessibility/Remoteness Index of Australia (ARIA)[3]. In the initial survey, it is unlikely that data would be available for more than the first three of the five remoteness classes, and any 'residual' results for the combination of the two remote classes would be statistically unreliable. Should it be possible to include in a later survey a larger sample of the population of the sparsely settled areas of Australia (as discussed above), the possibility of producing estimates for some topics and measurements would be increased. Ultimately, the final sample design will be determined in conjunction with the ABS.

5.4.2   Sample size considerations

As noted above, the expected prevalence of the health conditions for which measurements are being undertaken in the AHMS program will determine the size of the sample. The following examples show the number of people for whom measurements would be needed in order to determine the prevalence of high total cholesterol, and depressed cholesterol levels, in the population. The examples are summarised in Table 5.1.

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[3] The ARIA Index, comprising five remoteness classes, was developed for the Commonwealth Department of Health and Aged Care (DHAC 1999) to compare information about populations based on their access, by road, to service centres (towns) of various sizes. The ABS has developed a modified version (ARIA+) for use in the NHS and other collections. The first three classes cover the most accessible areas of Australia and the last two cover the most remote areas.

Example 1: High total cholesterol

In order for the survey to be able to identify a particular risk factor in the blood that has a prevalence of 50% with a 95% confidence interval range from 45% to 55%, an estimated total of 12,229 blood samples would be required to provide estimates for the following age/sex groups from 12 to 74 years (12-17, 18-24, 35-44, 45-55, 55-64 and 65-74 years).

That is, just over 1,000 blood samples are required per age/sex group to report the finding, for example, that 50% of a particular age group (by sex) has a high total cholesterol (5.5 mmol/l or higher), (95% confidence interval from 45% to 55%). Note that these estimates apply to each of the age/sex groups 12-17, 18-24, 35-44, 45-54, 55-64, and 65-74 years.

Example 2: Depressed HDL-*cholesterol levels*

In order for the survey to be able to identify a particular risk factor in the blood that has a prevalence of 10% with a 95% confidence interval range from 7% to 13%, an estimated 9,662 blood samples would be required to provide estimates for the following age/sex groups from 12 to 74 years (12-17, 18-24, 35-44, 45-55, 55-64 and 65-74 years).

That is, a total of 9,662 blood samples are required to report the finding that 10% of a particular age group (by sex) has depressed HDL-cholesterol (<1.0 mmol/l), with a 95% confidence interval from 7% to 13%. Note that these estimates apply to each of the age/sex groups 12-17, 18-24, 35-44, 45-54, 55-64, and 65-74 years.

Table 5.1: Sample size estimates for selected prevalence rates

Examples	Blood Samples
Prevalence: 50% ± 5% Age groups[1] by sex	12,229
Prevalence: 10% ± 3% Age groups[1] by sex	9,662

[1] Age groups 12-17, 18-24, 35-44, 45-54, 55-64, and 65-74 years.
Note: These estimates incorporate a design (or cluster) effect of 1.6 in the high prevalence (50%) example.

Under the design outlined in Table 5.2 (below) the sample size would be insufficient to achieve the level of precision for the estimated prevalence in *Example 1* (high total cholesterol). However, it would be possible to estimate this variable with a lower level of precision (± 6%, rather than ± 5%). In this case, a 95% confidence interval ranging from 44% to 56% would require an estimated 8,504 blood samples, which is within the number estimated from the sample size proposed.

In light of this analysis, it was determined that around 10,000 blood samples were required. This would also allow the detection of trends over time by comparing with past estimates.

5.4.3 Estimates of response rates by type of measurement

The AHMS sample will be drawn from the NHS sample. The 2001 NHS sample comprised 24,000 private dwellings with a possible 26,980 people being interviewed (8,200 aged from 0 to 17 years and 18,800 aged 18 years and over). The 2004/5 sample is expected to be of a similar size.

Estimates of response at each stage from the NHS interview to the taking of physical and biochemical measurements are presented in Table 5.2. They are based on the 2001 NHS sample (adjusted to exclude people aged 75 years and over, or under two years of age); the likely response rate in the NHS; the response rate achieved in the AHMS skirmish; and an estimated response drop between measurements at the nurse visit (based on response data from the Health Survey for England). It has been assumed that 90% of people who complete the NHS interview will be asked to participate in the AHMS.

Subject to the achievement of these levels of response (and the impact of any requirement for fasting, as discussed below), this design would deliver the sample size required to provide the number of blood samples in the examples presented above. More details of the calculations in Table 5.2 are in Appendix G.

It should be noted that the skirmish did not involve advice to participants that they would be required to fast before the taking of samples. However, if measures from the AHMS were to be comparable with those from earlier surveys (which used fasting samples), at least a sub-sample of the AHMS samples would need to be fasting. The requirement for fasting, and the number of hours of fasting required (e.g. eight hours as recommended by the WHO, or 12 hours as is usually the case in Australia), are yet to be determined. The proposed pilot test will need to ascertain the impact that fasting has on recruitment to the AHMS and on obtaining the fasting samples (and the impact on response rates) and the number of nurse visits needed to achieve fasting samples (and the impact on costs)[4].

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[4] Note that the HSE response rate data used to estimate response drop between measurements are from a non-fasting sample.

Table 5.2: Estimated response to the AHMS program

ABS NHS	Children & youth		Adults	Total
	2-11	12-17	18+	
ABS NHS:				
Estimate of people fully responding	4,519	2,457	18,017	24,993
AHMS (recruitment and nurse visit):				
Asked to participate in AHMS[1]	4,067	2,211	16,215	22,494
Consented to see a nurse	2,981	1,621	10,602	15,204
Measurements taken				
had height, weight measured	2,945	1,601	10,426	14,972
had waist-hip measured	2,945	1,601	10,422	14,969
had BP measured	2,910	1,582	10,422	14,914
gave a saliva sample (from age 4 years)	2,910	1,582	10,242	14,734
agreed to give a blood sample	n.a.	1,360	8,805	10,165
gave a blood sample	n.a.	1,304	8,446	9,750

[1] Estimated as 90% of those aged 2 to 74 years fully responding in the NHS.

6. ETHICAL ISSUES

The ethical, legal and social issues that arise from a survey program of this kind are numerous, and will be determined largely by the survey design and its implementation. A range of ethical issues was identified as part of the developmental process for the AHMS program and is contained in Appendix F. A number of broad policy issues emerge that will require discussion and resolution during the further development of the proposed AHMS program.

6.1 Ethical overview

In Australia, research involving human participation must be conducted in accordance with agreed ethical considerations as set out in the *National Statement on Ethical Conduct in Research Involving Humans* (NHMRC 1999).

Research must be so designed that respect for the dignity and well being of participants takes precedence over the expected benefits to knowledge (NHMRC 2000). Research involving human participation is also subject to a variety of legal requirements at Federal, State and Territory levels. All research must comply with any relevant Commonwealth and State/Territory legislation (NHMRC 2000).

The process of conducting a national population health survey using physical and biochemical measures leads to ethical issues arising at each step in the process. For example, the design of the survey program, once agreed, will have ethical issues peculiar to it. The selection of children for inclusion in the sampling frame, subject recruitment, the choice of specific content areas and their selected forms of measurement, and the issues surrounding the feedback of results to participants, all have ethical implications. Informed consent and its scope, confidentiality and privacy of information are also important considerations.

Participants in the survey program and the Australian community as a whole must be assured that each of these areas has been examined in detail and ethical considerations addressed. There is a responsibility to involve community members in the identification of ethical issues and in finding satisfactory solutions to resolve them. A range of strategies can be employed to undertake this, from consultation with consumer organisations and community representatives, to the use of focus groups and cognitive testing, to pilot testing of the survey processes.

Consumer involvement in a survey of this kind will be critical in determining its success, given the response rates that are needed to ensure that sampling is representative of the population(s) of interest. Significant investment will be required to encourage consumer participation and support at every stage of the survey. Consumer confidentiality and privacy concerns will require a

concerted effort and a planned strategy to ensure issues of data collection, storage, security and access to researchers for analyses are handled ethically. Consumer anxieties are also likely to be heightened when sampling, particularly of blood, is initially raised in the public domain. The benefits of the survey and aspects of the methodology will need to be asserted and discussed fully, and community confidence maintained if the AHMS program is to achieve its objectives and thus benefit the Australian community.

There are a number of ways to proceed. Clearly each of the issues identified above requires careful thought and discussion. Existing Australian ethical guidelines will provide direction in some areas (NHMRC 1991). Advice will also be sought from researchers and agencies in Australia and overseas who have experience in the conduct of surveys of this kind. The determination of the most appropriate solutions will be part of the more detailed planning of the survey, which will be required if agreement in principle is gained from AHMAC.

A continuing process of consultation with consumer organisations, ethnic and Indigenous groups, and community representatives will also be required to explore community attitudes and concerns about ethical issues, and to determine the way to proceed with the survey program's development and execution. Ultimately, any proposed survey will be subject to the usual processes of ethical oversight by an Institutional Ethics Committee before it can commence. It has been suggested that this be the AIHW Ethics Committee, given that it is likely that the AIHW will have oversight of the further development of the AHMS program.

7. OUTPUTS FROM THE AHMS PROGRAM

The data collected by the AHMS program will be a unique resource for policy-makers and researchers working within government and non-government organisations, educational facilities and other research institutes. The NHANES program in the US, for example, has been very successful at generating value added research with over 200 journal publications using its name in their titles from 1997-1998 alone. In order to maximise the research opportunities associated with the AHMS program, arrangements for access to survey data will need to be put in place.

7.1 Data access

Results from the NHS and the combined NHS/AHMS will only be available from the ABS. Due to confidentiality requirements, the ABS will not release a confidentialised unit record file (CURF).

The ABS will facilitate access to the data in a number of ways. These include:
1. ABS to undertake tabulations to user specifications on a cost recovery basis.
2. ABS to work jointly with research analysts on specific projects and papers, which are identified as being significant for research.
3. The development of a synthetic survey data file designed to enable preparation and testing of programs for remote submission to the ABS data laboratory.
4. Remote submission of user generated programs using software, such as SAS and SPSS, to the ABS data laboratory. ABS will monitor outputs from these programs to ensure that confidential information is not released.

7.2 Dissemination

A dissemination strategy will be developed jointly by DoHA, ABS, AIHW and other major stakeholders. This strategy will define in some detail the publications and spreadsheets to be released from the AHMS data on its own and in conjunction with the NHS data.

It is expected that the ABS and the AIHW will both publish a range of reports using the AHMS data. The initial publication from the combined AHMS/NHS results will be released by the ABS. Based on the agreed dissemination strategy, AIHW will release a series of reports focusing on the AHMS data. As well these publications will be complemented by reports prepared by AIHW, DoHA and other research analysts under the access arrangements described in section 7.1.

8. FURTHER DEVELOPMENT AND MANAGEMENT OF THE AHMS PROGRAM

There is a range of issues that require further work, development and decisions if the first survey of the AHMS program is to be conducted for the first time in 2004/5, together with the NHS.

They include:
- ethical and legal issues;
- professional and consumer consultations;
- AHMS publicity/marketing;
- data and sample ownership;
- data access issues;
- AHMS questionnaire development;
- development of AHMS documentation (measurement and sample collection protocols);
- conduct of a pilot test and dress rehearsal;
- AHMS fieldwork; and
- data analysis, dissemination and reporting.

The work can be divided into three separate stages:
1) survey development,
2) conduct of the survey, and
3) data analysis, dissemination and reporting.

It is envisaged that the work on the AHMS will be led by DoHA in strategic partnership with AIHW and in close cooperation with ABS.

An outline of how the work on the AHMS program is proposed to be managed through these three stages follows.

8.1 Stage 1 – Survey Development

Work on the development of the AHMS program will continue through the 2002/3 and 2003/4 financial years. By the end of 2003/4, the first AHMS is expected to be fully developed and ready to enter the next stage focused on the conduct of the survey. Stage 1 will involve the development of a detailed timeframe and the conduct of a pilot test in 2002/3 and a dress rehearsal in 2003/4. The NHS is due to commence in late July or early August 2004/5.

It is likely that some aspects of the developmental work, such as the development of the questionnaire and the measurement and sample collection protocols, will continue beyond 2002/3, in order to take into account the outcomes of a pilot test. Some work relating to promoting the

survey to the public in order to ensure as high as possible response rate may also be carried out closer to the commencement of the survey.

The developmental phase will require the cooperation of the partnership agencies, namely the DoHA and the AIHW, as well as the close involvement of the ABS. Considerable technical expertise will also be required. States and Territories will be involved through the NHIMG and the NPHIWG.

Two groups will oversee development and implementation of the Survey: a new AHMS Reference Group and the AHMS Project Group. Their functions and composition are outlined below.

AHMS Reference Group

Role

The role of the Reference Group will be an advisory one. The Reference Group will provide strategic policy, scientific and technical directions for the AHMS program and ensure that input is provided through consultations with the jurisdictions, scientific and technical experts, consumers and non-government organisations, and that all relevant issues are considered and endorsements and decisions are sought as appropriate.

The Terms of Reference for the Reference Group will be developed to provide quality assurance for the first survey and to provide advice on issues involved in survey development, conduct of the survey, and data analysis and reporting.

Composition

The AHMS Reference Group will include representatives/nominees from:

1. Jurisdictional representatives
   - DoHA (one of them to chair the Committee)
   - AIHW
   - ABS
   - NPHIWG (3-4 State/Territory representatives)
   - National Health Priority Action Council
2. Non-Government Organisations and Consumers, for example
   - National Heart Foundation
   - Consumers Health Forum
3. Scientific and Technical Experts
   - Members of the former Scientific Reference Group, as required.

Modus operandi

It is envisaged that the Reference Group will be flexible in the way it functions, and cost-efficient. It is anticipated that input from the Reference Group will be sought on particular issues as needed in a way that is the most suitable and practical to progress the development of the AHMS in a timely manner.

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AHMS Project Group

The AHMS Project Group will be a senior executive level group consisting of 1-2 representatives of the DoHA, AIHW and ABS. Their role will be to grant final approval to matters relating to the AHMS program development and conduct that require decisions or directions from senior executive level in the DoHA, AIHW and ABS.

Some specific issues that the AHMS Project Group will be expected to approve relate to a tendering process, including approval of the tender brief and selection of a subcontractor.

8.2 Stage 2 – Conduct of Field Work

The management of the AHMS fieldwork will rest with the AIHW. The MoU between the DoHA and the AIHW will provide a vehicle for relevant arrangements between the two agencies. The AIHW will sub-contract the conduct of the survey to another agency (such as a University) and will have high-level oversight of the management, the subcontracting arrangements and of the day-to-day conduct of the AHMS program.

To progress the first survey, and to guide and assist the AIHW, the AHMS Reference Group and the AHMS Project Group will continue through stages 2 and 3, providing quality assurance and problem solving functions.

8.3 Stage 3 – Data Analysis, Reporting and Dissemination

In addition to the data held by the ABS and disseminated as noted in Section 7.1, it is expected that a range of post-survey work will be undertaken by the AIHW under the MoU arrangements with DoHA. The scope and details of the work to be carried out will be determined at a later stage, in accordance with priorities established by the Reference Group.

9. ESTIMATED COST OF THE FIRST SURVEY

An estimate has been made of the cost of conducting the first survey in the AHMS program in association with the 2004/5 NHS. A number of assumptions have been made in producing the estimate. These include the number of staff working in the agency contracted to conduct the AHMS (4 FTE); the period over which survey development, conduct and reporting would occur (including 12 months prior to the survey, the survey period of approximately 44 weeks and 8 months subsequent); the rate of recruitment of NHS respondents to the measurement phase and their rate of retention for each of the measures; the impact of fasting on recruitment and on the number of call backs needed for the nurse to obtain valid blood samples; the number of nurses required to conduct the measurement phase; the cost of equipment and laboratory analyses; and the cost of reporting, including the provision of results of the measurements to participants, or their general medical practitioner. Details of the assumptions made in preparing the estimates are shown in Appendix G.

Some of the estimates are based on relatively firm information and others are subject to greater error until a detailed pilot test is undertaken. For example, the cost of nurses is based on a weekend rate for a nurse trained in venepuncture, and the estimate is likely to be relatively reliable. The estimate of the number of nurses that will be required is less so. It will depend on a number of factors, including the number of contacts required to make an appointment and the time taken to complete the measurements at each dwelling. If, as is likely, participants will be required to fast before the measurements are taken, the nurse will need to re-schedule the appointment where the participant fails to fast. This could add considerably to the cost of the nurse visits. The other large cost item in the budget is the cost of analyses of the samples. The list of analyses on which the quote was based (Appendix G) is more extensive than is likely to be required in the survey. With a smaller number of tests, and under competitive tendering, these costs are likely to be lower. When a decision is made as to the final range of measures to be taken, it will be possible to obtain a better estimate.

As noted, the estimates include the cost of providing a telephone information line during the conduct of the survey for participants or potential participants in the AHMS to seek information regarding the survey. They also include the cost of providing results of the measurements to the participant or their general medical practitioner, on the participant's advice. No provision has been made for participants to contact AHMS staff to discuss their results. However, the report of the results will include general advice as to steps that participants might take in relation to their particular results.

The estimated cost of conducting the first survey in the AHMS program is $6.3 million (excluding GST) (see Table 9.1). These costs include the conduct

of a dress rehearsal; pilot test costs are being met separately. It is anticipated that the management of the AHMS program will be undertaken by the AIHW who will manage the development process (including community and professional consultations), the conduct of the survey, and the secretariat to the new Reference Group. These costs have not been included in Table 9.1, but with their inclusion, the total cost rises to $7.2 million. With a program cycle of six years, this equates to a cost of $1.2 million per annum.

Table 9.1: Australian Health Measurement Survey Costs

Component	Estimated Costs ($m)
Survey development & conduct	
Staff – Director and support staff (4 FTE over 2.5 years)	)
Data specification, client liaison	)
Measurement protocols, training manuals	)
Coding manuals (with ABS involvement)	) 1.1
Specification of edit checks for measurements, samples; etc.	)
Editing	)
Weighting	)
Data preparation (assuming CAPI collection)	0.05
Publicity & Promotion	0.1
Analysis	)
Reporting – publications (incl. printing)	) 0.1
Web site development/ maintenance	)
Survey info line & reporting – written feed back to respondents/ GPs	0.1
Payment to ABS	
Respondent recruitment & non-response adjustment	) 0.17
Output processing and data handling	) 0.09
Client support and dissemination	) 0.28
Field costs: measurements (incl. staff on costs & insurances)	
Recruitment & training of nurses	)
In-home time (measurements) (incl. mileage)	)
Non-response follow-up	) 1.78
Supervision/ quality checks	)
Equipment (scales, sphygmomanometer, etc.)	)
Samples	
Bottles, needles etc.	)
Local storage, collection & transport	) 1.57
Laboratory analysis & reporting	)
Survey developmental and operational costs	**5.34**
Dress rehearsal	**0.38**
Contingency – 10%	***0.57***
Total Survey Costs excluding GST	**6.3**

Note: see Appendix G for details of assumptions and calculations.

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