

Australian Health Measurement Survey

Report on the pilot test

November 2004

Australian Institute of Health and Welfare
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Abbreviations

ABS	Australian Bureau of Statistics
AHMAC	Australian Health Ministers' Advisory Council
AHMS	Australian Health Measurement Survey
AIHW	Australian Institute of Health and Welfare
AusDiab	Australian Diabetes and Lifestyle Study
DoHA	Australian Government Department of Health and Ageing
GP	General practitioner
HDL	High density lipoprotein cholesterol
IDI	International Diabetes Institute
IGSC	Inter-Governmental Steering Committee
LDL	Low density lipoprotein cholesterol
NHANES	National Health and Nutrition Survey
NHS	National Health Survey
PHIDU	Public Health Information Development Unit
WHO	World Health Organization

Executive summary

In May 2002, the Australian Health Ministers' Advisory Council endorsed the conduct of a pilot test of the proposed Australian Health Measurement Survey (AHMS). This was with a view to conducting the first AHMS in conjunction with the 2004–05 Australian Bureau of Statistics National Health Survey (NHS), providing funds were available and the pilot was successful. The AHMS proposal was developed by Australian Government Department of Health and Ageing, the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW), with assistance from Public Health Information Development Unit and the Inter-Governmental Steering Committee.

The pilot, jointly funded by the Australian Government Department of Health and Ageing and the AIHW, was run in early 2003 by the ABS and AIHW. The measurement fieldwork was undertaken in Adelaide, Melbourne and regional Victoria by the International Diabetes Institute and involved just over 500 participants aged 2–74 years. To reflect a survey proper, eligible participants were recruited at the end of a pilot test of the NHS. The NHS component was conducted by the ABS.

The AHMS fieldwork involved a home visit to collect demographic information, physical measurements (height, weight, waist circumference, blood pressure and lung function) and a saliva specimen. Participants aged 12 years and over were also asked to complete a food frequency questionnaire and to visit a local pathology collection centre for the collection of blood and urine specimens – a home visit was arranged if needed. Half of the participants were required to fast before the blood samples were taken, in order to test the effect of fasting on the response rate. Depending on the fasting status, the blood was analysed for total cholesterol, HDL cholesterol, LDL cholesterol, triglycerides, homocysteine and glucose. Urine was analysed for albumin, albumin/creatinine ratio and iodine.

Selected results were sent to all adult participants and to the parents/guardians of children who participated. If participants wished, these were also sent to their doctor. Feedback of urgent adverse results was handled immediately by a survey doctor.

The pilot was overseen by the AHMS Project Group with representation from the Australian Government Department of Health and Ageing, the ABS and AIHW. Ethical approval was obtained from AIHW's Ethics Committee. The main ethical concerns were respondent burden, obtaining adequate consent (and assent from children) and ensuring the safety of those entering the home.

The main objective of the AHMS pilot was to test response rates at each stage of recruitment and to assess response rates among those allocated to a fasting or non-fasting sample. Following recruitment losses in the NHS, just under half (47.9%) of eligible individuals consented to being contacted about participating in the AHMS component. Of the total eligible sample, physical measurements were obtained from 39.3% of participants, blood samples from 23.0% and urine samples from 21.6%. There were no significant differences in response rates between fasting and non-fasting samples.

Although the conduct of the pilot was considered to be successful, these response rates were not satisfactory to justify running a full AHMS based on this approach as part of the 2004–05 NHS, and there was no funding available for further pilot testing or for the AHMS proper.

Future development of an AHMS program should consider a protocol involving a standalone survey to reduce respondent burden and thus the number of potential drop-out

points, the omission of participants aged less than 18 years of age as the response rate among 12-17 year-olds was particularly low, and reducing the range of measurements taken. In addition, linking an AHMS with a detailed national nutrition survey should also be given consideration because of the overdue need for these data.

Introduction

In May 2002, the Australian Health Ministers' Advisory Council (AHMAC) considered a proposal that an Australian Health Measurement Survey (AHMS) be conducted every six years, in association with every second Australian Bureau of Statistics (ABS) National Health Survey (NHS), beginning in 2004–05. As a first step a pilot test was agreed to.

The proposal¹ (also referred to as 'the business case') had been prepared for the Australian Government Department of Health and Ageing (DoHA) by the Public Health Information Development Unit (PHIDU) at the University of Adelaide, under the supervision of an inter-governmental steering committee². A reference group³ provided expert technical advice. The two committees ensured that the survey design reflected a national policy perspective by engaging all jurisdictions and that expert technical advice was obtained regarding the survey design, content and methodology.

The objectives of the proposed AHMS as stated in the business case were to:

- determine the prevalence of selected disease outcomes (e.g. diabetes) and risk factors/determinants in the Australian population and subpopulation groups, as a basis for policy and strategy development
- monitor trends in the prevalence of identified disease outcomes and risk factors/determinants in the Australian population and subpopulation groups
- examine the relationships among selected diseases and risk factors/determinants
- 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.

The survey would provide population health information relevant to priority health problems such as coronary heart disease, stroke, diabetes, hypertension, high cholesterol and other chronic disorders that have significant health, social and economic impact.

This report summarises processes leading to the development of the business case and describes methods and key results of the pilot study endorsed by AHMAC and run in early 2003.

Historical context

In 1997, the Australian Institute of Health and Welfare (AIHW) held a national workshop of interested parties on the need for a national biomedical risk factor survey. Here a decision was made to develop a proposal for AHMAC. The broad aims of the survey identified at the workshop were to estimate national prevalence of selected diseases, conditions and risk factors; to determine national population distributions of selected health parameters; and to

1 The 'proposal' or 'business case' refers to the document titled *A proposal for the Australian Health Measurement Survey Program* which documented the benefits of such a program for Australia; the proposed design, content and methodology; associated ethical issues; and likely costs. It is not attached to this report but underpinned the development of the pilot.

2 Further information about this group, including membership, is provided in the business case.

3 As above.

examine trends with previous surveys where possible. It was agreed that the primary purpose of the survey would be monitoring, not research, although it was recognised that information collected in the survey would be useful for generating research hypotheses. To this end, a steering committee was established and AIHW undertook the planning of the survey and proposal development. The proposal was forwarded to AHMAC in 1999 following endorsement by the National Public Health Partnership. AIHW provided further advice on funding to AHMAC, having estimated that a single survey would cost at least \$3 million. The need for such a large investment led the (then) Australian Government Department of Health and Aged Care and AIHW to agree to an additional process of planning and development.

This led to the establishment of the Inter-Governmental Steering Committee (IGSC), with representation from the Australian Government, ABS, AIHW and state and territory jurisdictions. The role of the IGSC was to guide the progress of the survey development. Following extensive consultation, the IGSC determined that a program of surveys rather than a single survey was required. The result was a proposed AHMS program of cross-sectional surveys that included a component of objective measurement. The best measures to be included in the survey program were determined by the expert technical reference group. The IGSC explored a range of options to deliver the survey program. These included a stand-alone survey or one that could be linked with the NHS. Following several discussions with the ABS the latter option was favoured.

The ABS NHS option involved inviting participants at the end of the NHS interview to consent to a nurse visiting their home to take a range of measures. The ABS tested likely levels of recruitment using this format in an AHMS skirmish conducted in November–December 2001. The results of the skirmish indicated that a viable proportion of people who had participated in the NHS would also consent to participate in an AHMS.

Consequently, in May 2002, AHMAC agreed that an AHMS pilot test should proceed, with further consideration given to conducting the survey proper depending on the pilot findings. In response, AIHW conducted a pilot test of the proposed AHMS during February–March 2003.

Objectives

The **primary objective** of the AHMS pilot test was to test response rates at each stage of the data collection process (including response rates of fasting and non-fasting participants) and to assess reasons for non-participation.

Secondary objectives:

- to test the AHMS pilot consent forms and questionnaires
- to obtain ethical approval for the AHMS methodology, in particular arrangements for collection of specimens
- to test the fieldwork activities including:
 - implementation of the AHMS pilot protocols for physical measurement and specimen collection (including the time taken and emergency protocols)
 - flow of consent forms/identified information following the NHS component
 - efficiency of appointment making and reminder process (including the proportion of reminders required and of missed appointments)

- efficiency and effectiveness of the personnel taking the physical measurements and specimen samples
- efficiency and effectiveness of the specimen transport and analysis agency
- process of feeding back results to participants/general practitioners (GPs).
- to test the post-fieldwork activities including:
 - provision of advice to participants who had a test result outside a specified range
 - accessibility and usability of the NHS-AHMS pilot datafile.

Management and oversight

AHMS Project Group

The overall direction and coordination of the development and conduct of the AHMS pilot was the responsibility of the AHMS Project Group (see Appendix A for Terms of Reference). The Group comprised senior representatives from DoHA, ABS and AIHW.

Other groups kept informed of progress, particularly in relation to funding, survey content and timing, included the IGSC, DoHA's Departmental Management Group and the ABS NHS Reference Group. The protocol for the AHMS pilot test was submitted to the AIHW Ethics Committee for consideration and final ethical approval.

AHMS Indigenous Reference Group

An AHMS Indigenous Reference Group was established to address the specific issues of relevance to Indigenous people, in particular issues for Indigenous people who may be selected in the sample and the question of linking the AHMS survey to the Indigenous Health Survey. The Group acknowledged that extensive consultation would be needed with Indigenous people before an AHMS survey specifically for Indigenous people could be done.

AHMS Nutrition Technical Reference Group

An AHMS Nutrition Technical Reference Group was established to advise on whether the inclusion of a nutrition component would add value to the physical and biochemical measures to be collected in the proposed AHMS and, if so, to advise on acceptable measures.

Survey methods

The pilot was a complete test of the proposed survey methods for the AHMS. Development of the survey methods built on the experience gained in previous Australian surveys that included a physical examination (e.g. National Heart Foundation Risk Factor Prevalence Surveys, the 1995 National Nutrition Survey and the 1999–2000 Australian Diabetes and Lifestyle Study (AusDiab)) and in major international surveys and programs (e.g. National Health and Nutrition Survey (NHANES) (United States), Health Survey of England (United Kingdom), National Nutrition Survey (New Zealand), World Health Organization (WHO) STEPS initiative).

Subject recruitment

The ABS NHS fieldwork provided the recruiting mechanism for the AHMS pilot (Appendix B provides a detailed description of the fieldwork procedures). The ABS selected a sample size of 1,130 dwellings for the pilot, with the majority of these located in Victoria. They also randomly allocated households to fasting/non-fasting, although to remove possible interviewer effects this information was not known to the interviewer.

The pilot comprised just over 500 participants aged 2–74 years living in private dwellings in Melbourne, Adelaide and rural Victoria. People in non-private dwellings such as hospitals and nursing homes were not included. Within each household, one adult aged 18 years or older, one child aged 7–17 years, and all children aged 2–6 years were eligible for AHMS.

Consent

At the end of the NHS interview the ABS interviewer sought the consent of eligible participants aged 18–74 years to be contacted by the AIHW about taking part in the AHMS. The NHS participant was able to agree at the time of the NHS interview for themselves and/or eligible children aged 2–17 years, or to return the consent form later regarding their (or their children's) participation. It was made clear that participation in the survey was voluntary and that they could withdraw at any stage.

Written consent was obtained from adults aged 18 years and over. For children, written parental consent as well as written assent from children aged 12–17 years and verbal assent from children aged 4–11 years were obtained before the home visit and again before specimens were collected.

AHMS pilot fieldwork

Fieldwork for the pilot was tendered out by the AIHW. The International Diabetes Institute (IDI) was the successful tenderer and was responsible for organising the pilot test in accordance with the survey protocol, including the hiring and training of staff, provision of equipment and reporting on the conduct of the pilot test (see Appendix C for further information about the tenderer's responsibilities).

The fieldwork involved a home visit by teams of two people. In each case, the AHMS's field staff comprised at least one registered nurse. Interviews conducted in the home collected demographic information, physical measurements and a saliva specimen, and provided an explanation of the food frequency questionnaire. Participants (aged 12 years and over) were then asked to visit a local pathology collection centre for the collection of blood and urine specimens. The option of a home visit for specimen collection was also offered to those who were unable or unwilling to attend a pathology collection centre. Half of the participants were required to fast for 12 hours before the blood samples were taken, in order to test the effect of fasting on the response rate. All pathology specimens were transported to a central analytical laboratory for analysis.

It is important to note that the survey methods used in the pilot deviated from those outlined in the business case. The option of a protocol involving a separate pathology visit instead of collecting blood in the home (as proposed in the business case) was recommended by AIHW, in consultation with an expert panel of biochemists. This decision was also supported by the AIHW Ethics Committee. The decision arose because some analytes (notably homocysteine) required immediate centrifuging and because all blood samples needed to be treated as potentially infectious so home collection posed a health risk, particularly from spills and from aerosolising during centrifuging. In addition, from a logistical perspective, fasting samples needed to be collected in the morning and this would have considerably lengthened the amount of time needed to conduct both the pilot and the survey proper.

Measurements taken during the AHMS home visit

For each participating household member, depending on their age, the survey team:

- completed a questionnaire on demographic and other data relevant to the physical measurements being taken
- collected physical measurements and a saliva specimen
- invited participants aged 12–74 years to attend a pathology collection centre to give blood and/or urine samples (a home visit option was offered to those unable or unwilling to attend a pathology collection centre)
- asked participants who were willing to give blood several questions to ensure that it was safe for them to do so
- explained and left a food frequency questionnaire for self-completion and return by mail.

Information collected

Demographic and other data

Sex

Age

Date of birth

Pregnancy status (where appropriate)

Physical measurements and saliva sample

Blood pressure (12 years and over)

Height (2 years and over)

Weight (2 years and over)

Waist circumference (2 years and over)

Saliva specimen (4 years and over) to measure cotinine as an indicator of exposure to tobacco smoke

Lung function measurements (7 years and over), including forced expiratory volume in the first second, forced vital capacity and peak expiratory flow

Nutrition

Food frequency questionnaire (12 years and over)

Blood and urine analysis

Blood and urine samples were collected at a local pathology collection centre although participants were given the option of collection in the home if they were unable/unwilling to attend a centre. Samples were sent to a central analytical pathology laboratory for processing. Those participants who fasted had all specified tests performed on their blood samples. A restricted set of analyses applied to blood samples from participants who did not fast.

Blood analyses (12 years and over)

For fasting samples

HDL cholesterol

Glycosylated haemoglobin

Red cell folate

Vitamin B12

Carotenoids

Triglycerides

Homocysteine

Glucose

Insulin

LDL cholesterol (calculated)

For non-fasting samples

HDL cholesterol

Glycosylated haemoglobin

Red cell folate

Vitamin B12

Carotenoids

Note, to minimise costs glycosylated haemoglobin, red cell folate, vitamin B12, carotenoids, and insulin were not tested in the pilot but were proposed for the survey proper.

Urine analyses (12 years and over)

Dipstick test for albumin

Spot urine for albumin/creatinine ratio

Iodine

Measurement protocols, questionnaires, forms and brochures

Protocols were developed for taking the physical measurements and for the collection and analysis of the specimens included in the pilot based on advice from technical and scientific experts and on experience gained in previous Australian biomedical surveys, Australian data standards, international protocols and WHO recommendations. Strict adherence to the protocols was required.

The questionnaires, forms and brochures were developed by the AIHW, working with DoHA, the ABS and the PHIDU. These, together with staff training manuals, feedback forms and the measurement protocols, can be found at AIHW's web site (<http://www.aihw.gov.au>). A complete copy is also held in AIHW's library.

Brochures were developed informing participants of:

- what their participation would involve
- what data would be collected, who would collect it and how it would be used
- the confidentiality of their information
- the availability of a toll-free 1800 number or an email address to obtain further information.

Staff training

IDI provided the AHMS's field staff with three days of training before they went into the field. They were trained in measuring blood pressure, height, weight, abdominal circumference and lung function, and in collecting a saliva specimen to a standard described in the measurement protocol. They were also provided with an instruction manual and answers to frequently asked questions to assist in these tasks.

A pathology nurse from the pathology company also attended part of the in-house training. At this session they were given an interviewer instruction manual which provided additional advice on the purpose and aims of the survey, and on the questionnaires and consent forms that needed to be completed when a participant presented to a collection centre or blood was collected in the home. Further staff training was not undertaken, although the company was able to rapidly disseminate written material to each of the nominated collection centres.

Feedback of results

All participants in the pilot test received feedback on their results. They were also given the option of having their results sent to a doctor of their choice. Parents or guardians were given similar options for their children's results. Depending on the age of the participant, results for height, weight, body mass index, blood pressure, total cholesterol and HDL cholesterol were provided. Participants who fasted were also given results for triglycerides and glucose. Results for lung function, homocysteine, urinary microalbumin, urinary iodine and salivary cotinine were not provided as they were deemed to be too difficult for participants to interpret. The results of measurements taken in the home (weight, height, waist circumference and blood pressure) were given on request during the home visit but not routinely provided.

For some measures there is scientific agreement on a normative range and these were used when providing feedback. Results outside the normative range were indicated on the feedback form, which included general information that medical advice should be sought for such readings. All results were reviewed individually by a survey doctor who made this assessment. A brochure was also sent with the results to explain what the tests measured.

The toll-free 1800 line included access to the survey doctor who was able to give more information if required and to refer participants to their GP where appropriate. Participants could ring the number any time of day, seven days a week, during the conduct of the pilot test although access to the survey doctor was only available during normal business hours. Any person with adverse results (such as high blood pressure) was reported immediately to the survey doctor. The survey doctor then followed up with the participant or their GP, as appropriate.

Ethical aspects

The protocol and survey design for the AHMS pilot test was submitted to the AIHW Ethics Committee for consideration and ethical approval. The DoHA Ethics Committee was also kept informed of ethical issues pertaining to AHMS. Relevant ethical issues are detailed below.

Respondent burden

Respondent burden was high and required careful management. A typical scenario for each individual selected in the household was:

- participating in the NHS component (40 minutes; although an NHS interview is normally 45 minutes it was shortened slightly for the pilot test)
- listening to ABS staff explain the purpose of the AHMS and seeking consent to be contacted (5 minutes)
- participating in a subsequent home visit for blood pressure, physical measures, saliva collection and lung function test (45 minutes)
- completing and returning a food frequency questionnaire (20–30 minutes)
- visiting a pathology collection centre for blood sampling and urine collection (20 minutes plus travel).

If there was more than one respondent in the household the time per person was reduced.

Safety and privacy issues associated with the measurement protocols

Measurement protocols for specimen collection took into account safety issues such as:

- the safety of the AHMS participant and the AHMS data collector(s) in the home. IDI chose to send two people into the home to minimise any risk to their safety, particularly as many of the appointments were in the evening
- safety issues for any visit to a pathology collection centre
- indemnity issues
- data security.

Method of subject recruitment

A summary of the method of subject recruitment was provided earlier in this report. The primary ethical concerns were that participation in the survey be voluntary and that participants could withdraw at any stage.

Informed consent and assent

The following procedures were followed for seeking informed consent to undertake the physical measures and specimen collection, consistent with national ethical guidelines⁴, the age of the survey participants and the nature of the procedures (Table 1).

Table 1: Procedures for seeking informed consent and assent

Age/ nature of procedure	Consent procedure
Adults, 18 years and over Home visit and pathology collection centre	Written consent for the in-home component and pathology collection centre component separately
Children 12–17 Home visit and pathology laboratory	Written consent from parent or guardian and written assent from child for the in-home component and pathology collection centre separately
Children 4–11 Home visit only	Written consent from parent or guardian and verbal assent from child for the in-home component
Children 2–3 Anthropometric measures only	Written consent from parent or guardian and cooperation of the child

Written consent to take physical measurements was obtained from adults at the time of the home visit or a consent form was left to be returned later. Consent for children (less than 18 years) was sought through parents or guardians, and children aged four or more agreed (assent) either verbally or in writing depending on their age. Clear explanations of the purpose, benefits and implications of participation were provided in print and orally, and any need for fasting (12 hours maximum) was made clear.

Written consent for specimen collection was obtained from adults at the time of the pathology collection centre visit. Consent for children aged 12–17 years was sought through parents or guardians as well as assent in writing from the children.

Feedback of results

A summary of the feedback of results to participants was provided earlier in this report. The primary ethical concern was that all participants in the pilot test received feedback on their results, including the option of having their results sent to a GP of their choice.

4 The National Statement on Ethical Conduct in Research involving Humans specifies two principles in relation to consent from children under the age of majority:

- provision to participants, at their level of comprehension, of information about the purpose etc.
- the exercise of voluntary choice to participate.

Confidentiality and privacy

The survey was conducted under the *Australian Institute of Health and Welfare Act 1987*, which guarantees privacy protection for information about individuals.

None of the eleven Information Privacy Principles were breached. Relevant AHMS forms used in the pilot test included an AHMS identification code that assisted with data collection and enabled response rates to be calculated by linking with the NHS data. Measures were in place to protect all AHMS information collected in the pilot test from loss, misuse or unlawful access. Quality control mechanisms were in place to ensure that the AHMS pilot data were accurate and complete. The AHMS pilot data were password-protected and accessed only by authorised personnel. Only de-identified data have been stored electronically by AIHW. The completed questionnaires are kept at AIHW in a locked cabinet. Specimens collected in the AHMS pilot tests were not retained beyond the timetable and direct needs of the pilot test.

Special groups

The pilot test included groups such as children, Indigenous people, people of non-English-speaking background, people with low literacy levels and people with diabetes. For the purposes of the pilot test, material associated with obtaining informed consent was not available in various languages but would be provided in a survey proper. For the pilot, a telephone interpreter service was available. Plain English was used in all survey material. An AHMS Indigenous Reference group was consulted on Indigenous issues. People who may have been unable to fast for medical reasons, such as people with diabetes, were asked to call the toll-free 1800 number for advice.

Other concerns

The AIHW Ethics Committee also raised the following points in relation to the future conduct of this survey:

- the need to consider reimbursing participants for travel associated with attending pathology clinics
- the need to 'Australianise' the blood and urine collection protocols, as those used in the pilot were sourced from United States NHANES
- a protocol involving an in-home component (questionnaire only for physical measurements and other data collection) and a separate laboratory-testing phase (for specimen collection). Respondents will be given the option of having specimens collected in the home if they are unable/unwilling to attend a centre; however, there will be no centrifuging of blood in the home. As mentioned earlier, the AIHW Ethics Committee prefers the collection of blood at a pathology collection centre rather than in the home.

Findings of the pilot test

The pilot test was successfully conducted by the ABS, AIHW and the IDI. All phases of its operation were assessed and potential modifications and improvements to management, fieldwork and documentation identified. Response rates to the home visit were very good, but those for blood and urine testing were not sufficient to warrant a survey proper.

Key results

Response rates

Table 2 outlines the response rates to key steps in the survey (including the NHS component) and estimates an overall 'bottom line' response rate. Results to note are:

- The total household response rate to the NHS component was 72.5%.
- Among eligible individuals in responding households, 64.4% consented to being contacted about the AHMS component with a view to participating. A further 1.7% asked for the consent form to be left with them.
- This means that, at best, 47.9% of eligible individuals consented to being contacted about participating in the AHMS component.
- Of those subsequently contacted, visits were made to 82.1%, which is equivalent to 39.3% of eligible individuals.
- Of those visited at home, almost all who were eligible agreed to have their blood pressure, height, weight and waist measured.
- Of those visited at home, 89.5% of eligible participants agreed to give blood (comprising 85.3% who said they would go to a pathology collection centre and 4.2% who expressed preference for a home visit). A blood sample was obtained from 58.4%, giving a 'bottom-line' response rate for blood sample collection of 23.0%. Comparable figures for providing a urine sample were 55.0% and 21.6%.
- Bottom-line response rates for those asked to fast before giving blood were higher than for those who did not fast (24.4% compared with 21.3%), but the difference was small.
- Response rates for blood collection increased with age: 12–17 year olds (9.6%); 18–50 year olds (15.5%); and 51–74 year olds (27.1%).

Logistical issues

Both the ABS, as part of their role in undertaking the NHS component, and the IDI, in their role in undertaking the AHMS component, provided reports on the pilot. These reports contain specific recommendations for future conduct of the AHMS based on the survey methods used in the pilot. A summary of their recommendations follows.

NHS component

- Reword the introduction to AHMS on the NHS form, and make the children's introduction less repetitive. ABS's involvement in the NHS and AIHW's involvement in AHMS also needs to be clarified in the introduction.
- Consider combining adult's and child's consent onto one form.
- Improve training of NHS interviewers so that they are better equipped to answer questions about AHMS, particularly as this may have a beneficial effect on participation rates.

AHMS component

- Improve the accuracy of collection of demographic data in the NHS component to facilitate following up people who agreed to be contacted about AHMS. It may be preferable, however, to consider combining the NHS and AHMS into a single survey to minimise these problems as well as minimising 'participant fatigue'.
- Concentrate home visits and telephone calls between 6pm and 8pm Mondays to Thursdays. This is particularly important in contacting people of working age who are typically the most difficult adult age group to access.
- Consider increasing the number of participants per cluster to minimise the amount of time spent travelling by field staff and to decrease the survey cost.
- Consider using one consent form per household.
- Consider developing specific protocols for large households as there were some concerns about the protection of equipment and quality of measurements where there were several children participating.
- Consider using the domiciliary blood testing service as an alternative to visiting a pathology collection centre, and to making available home visits from 7am onwards.
- Allay concerns about adequate access to pathology collection centres. If pathology collection centres are used in future surveys it is preferable that they are located in a regional centre for non-metropolitan sites and within the suburb being tested for metropolitan sites. Also, field staff should visit the collection centre on the first day of testing in an area to ensure full knowledge of procedures, although there may still be issues, for example because of changes of staff within the centre. Despite these concerns, the use of a pathology company to collect all the samples greatly simplified some of the logistical issues related to handling and transport.
- Undertake detailed review of the quality of the spirometry data to determine the adequacy and usefulness of these measurements.

In addition to these recommendations, the IDI reported the following:

- Although weekend home visits were encouraged by the project office, less than 20% were booked for Saturdays and Sundays. The most popular times were from 6.30pm to 8pm on

Mondays to Thursdays. This is an important consideration in scheduling appointments into blocks within geographical areas and was made more difficult by the small cluster sizes used in the NHS component.

- Children's participation was enhanced by incentives (commercially purchased stickers and thank you certificates).
- Explanation of the food frequency questionnaire went smoothly and based on analysis of a small sample of the returned forms they appear to have been completed accurately and appropriately.
- Field staff were often asked to comment directly to participants about the results, but wherever possible such comments were avoided.
- Feedback of results to each participant proceeded smoothly with no significant problems encountered.

Table 2: Response rates from the NHS pilot and the AHMS pilot

		Number	Number eligible	Per cent eligible	Response rate (%) ^(a)	Applicable age group
NHS:					Base=100	
households	Selected	1,130	1,054			
	Responding	764	1,054	72.5	72.5	
NHS:						
respondents	Persons eligible for AHMS		974			2-74
	AHMS consent form signed	627	974	64.4	46.7	
	AHMS consent form left	17	974	1.7	1.3	
	Total	644	974	66.1	47.9	
AHMS	Consent forms received	622	613			2-74
	Appointment kept	503	613	82.1	39.3	
	Blood pressure	380	380	100.0	39.3	12-74
	Height	498	503	99.0	38.9	2-74
	Weight	498	503	99.0	38.9	2-74
	Waist	497	503	98.8	38.9	2-74
	Spirometry	412	428	96.3	37.9	7-74
	Saliva	447	478	93.5	36.8	4-74
	Food frequency questionnaire	325	380	85.5	33.6	12-74
	Blood	222	380	58.4	23.0	12-74
	Urine	209	380	55.0	21.6	12-74
BLOOD BY FASTING STATUS	Asked to fast	129	208	62.0	24.4	12-74
	Not asked to fast	93	172	54.1	21.3	12-74
BLOOD BY AGE ^(b)	12-17 years	n.a	n.a	24.3	9.6	12-17
	18-50 years	n.a	n.a	39.3	15.5	18-50
	51-74 years	n.a	n.a	69.0	27.1	51-74
BLOOD BY AREA	Adelaide	n.a	n.a	66.3	26.1	12-74
	Melbourne	n.a	n.a	54.2	21.3	12-74
	Regional Victoria	n.a	n.a	61.2	24.1	12-74

(a) The response rate is based on the number of eligible households selected in the NHS and assumes the same number of eligible people per household in responding and non-responding households. All calculations in this column are based on the response rate among 2-74 year old respondents in the NHS.

(b) The response rate for blood collection by age is based on the total eligible sample i.e. 613 respondents for whom consent forms were received.

Comments

These results, especially the bottom line response rates, would not be considered satisfactory for a survey proper. If they are to be improved to acceptable levels it is important to examine possible reasons for them. These include:

- The ABS's 'NHS' component was not an NHS proper and achieved a considerably lower response rate (72.5%) than the usual 90–95% that is achieved in the NHS itself.
- The AHMS component, being a pilot, could not draw on the extensive background publicity that would be used to maximise the response rate in a survey proper.
- It was not possible in the pilot to provide survey material in the most common languages spoken other than English, as would be done for the survey proper.
- The pilot involved a heavy respondent burden, with three main stages involving decisions, arrangements, time and possible inconvenience. The interview and physical measurement components were long, and visiting a pathology centre involved logistics and other considerations. To complete the pilot, participants faced at least six significant decision points and it is understandable that this led to progressive 'drop-out' through the stages.
- The inclusion of children added further challenges for parents in the areas of informed consent, and securing and coordinating their attendance for both physical measurements and provision of blood samples.
- The small degree of 'clustering' in the NHS sample meant that many individuals had to travel further than perhaps desirable to visit a pathology collection centre.
- There is potential for reducing the sample loss between the home visit and attendance at a pathology centre. There was about a 40% loss in the AHMS pilot (23.0% compared with 39.3%). This compares with a 32% sample loss in the Health Survey of England, where blood was taken in a second home visit, and a 27% sample loss in the New Zealand survey, in which all information was collected in a single home visit.

If this particular survey method were to be used again it is important that these and other issues be addressed to improve the response rates. The AusDiab survey undertaken in 1999–2000 achieved a response rate of about 28%; their protocol involved a mobile clinic to obtain physical and biomedical measures. Other countries, using similar and different methods from the AHMS pilot (including home and clinic visits), achieved response rates ranging from 36% to 47% for provision of a blood sample, compared with the AHMS pilot's 23%. These rates, while higher than the AHMS pilot, are not especially high and would traditionally be considered unacceptable for making cross-sectional estimates. It is possible that data from surveys with lower response rates may still be useful for monitoring purposes, especially where there is substantial information available on non-respondents, as would be the case if the NHS operated as the recruitment mechanism for the AHMS.

Despite this it is desirable to consider variations to the survey methods that could be tested in the future to achieve the best response rates. Particular consideration needs to be given to:

- Reducing the number of potential drop out points – a stand-alone survey may be a better way of achieving this than linking AHMS to the NHS, thus maximising the starting sample size of eligible participants (which was less than 50% in the pilot). This may also minimise the logistical issues raised by the ABS in their review of the NHS component of AHMS and by the IDI in relation to the transfer of demographic data of sufficient quality

to enable follow-up of potential AHMS participants. In this approach, clustering design techniques could be used to reduce costs.

- Omitting children (i.e. those aged under 18 years among whom response rates were lower) from a survey protocol of this kind. This is likely to improve response rates among adults who have 'eligible' children under the existing protocol by reducing their respondent burden. Obtaining physical and biomedical measures from children may be better achieved through a school-based approach as occurred in the 2004 New South Wales School Physical Activity and Nutrition Survey.
- Reducing the range of biochemical tests because of processing complexities and safety issues if blood was to be collected in the home. Of the tests canvassed for the pilot test, non-fasting blood samples collected in the home could be analysed for total cholesterol, HDL cholesterol, glycosylated haemoglobin, red cell folate, vitamin B12 and carotenoids. Tests not performed would include triglycerides (and LDL cholesterol), homocysteine, glucose and insulin. (Note that urine samples collected in the home could be analysed for creatinine/albumin and iodine.) Fasting would be a difficult option because it would require morning home visits, which present significant practical difficulties. Similar to the protocol used in the National Health Survey of England, fasting blood could be obtained from a subsample of participants scheduled for early morning visits.

One last comment is that the need for detailed food and nutrient intake data to be collected in Australia is as important as the long-overdue need for biomedical data. Whether a national nutrition survey is linked to an AHMS or an AHMS is linked to a national nutrition survey or the two are kept separate needs to be given careful consideration in the future conduct of national risk factor surveys.

Appendix A: Terms of reference of the AHMS Project Group

The AHMS Project Group will consist of representatives at the senior executive level from the DoHA, the AHIW and the ABS.

The role of the Project Group is to provide overall direction and coordination, and to grant approval to operational and management matters relating to the development and conduct of the AHMS pilot and survey proper.

The Project Group will be advised by the AHMS IGSC, which was established to oversee the survey's development. The AHMS IGSC 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.

The Project Group will also be informed by DoHA's Departmental Management Group and the ABS NHS Reference Group, particularly in relation to funding, survey content and timing.

The Project Group will meet as required throughout the development of the AHMS program. It is expected that these will be face-to-face meetings held in Canberra.

AHIW will provide secretariat functions to the Group.

Specific issues requiring decision include:

- endorsement of the tendering process, including the need to advertise for tenders in the pilot
- approval of the successful subcontractor to perform the fieldwork (including taking physical measurements and specimen collection)
- approval of the successful subcontractors to transport and analyse the specimens
- confirmation of the AHMS content
- nutritional component
- location options to conduct the fieldwork
- the involvement of children.

Appendix B: Walk-through of fieldwork procedures

The following procedures describe the processes that were followed to recruit participants to the AHMS and to collect the physical measurements and pathology specimens. The step-by-step walk-through shows how each of the forms and brochures are used in the pilot.

- 1 ABS randomly assigned households selected to be in the NHS to fasting and non-fasting samples.
- 2 An AHMS identification number (7 digits) was allocated as follows – the first 4 digits were the ABS NHS Household Form serial number, the next 2 digits were the person number (01, 02, 03, etc.) and the last digit indicated if the household was fasting (1) or non-fasting (0).
- 3 ABS sent out the *NHS Primary Approach Letter* and the *NHS Overview brochure*.
- 4 NHS interview:**
 - 4.1 AHMS was introduced to eligible adult respondent (aged 18–74) at end of NHS interview using *Introduction to AHMS (questionnaire and prompt card)*.
 - 4.2 NHS adult respondent was asked if they would consent to being contacted by the AHMS field agency regarding participation (theirs and any eligible children aged 2–17) in the AHMS.
 - 4.3 If consent to be contacted was given immediately, NHS adult respondent signed *Consent to be contacted form(s)*, sealed it in reply-paid envelope and gave it to NHS interviewer to post to the AHMS field agency that day.
 - 4.4 If NHS adult respondent wanted to think about giving consent to be contacted, NHS interviewer left *Consent to be contacted form(s)* and reply paid envelope with NHS adult respondent and followed up with respondent by phone (or letter) within 2 days. If consent was given, NHS adult respondent posted signed *Consent to be contacted form(s)* to AHMS field agency. Note: NHS interviewer needed to ask respondent to post back *Consent to be contacted form(s)* within three days.
 - 4.5 *AHMS Overview Brochure* was left with all NHS adult respondents except those who did not consent to be contacted.
- 5 AHMS field office operated a 1800 phone help line and email address for the duration of the pilot.
- 6 AHMS field agency rang NHS adult respondent within 2 weeks of receiving signed *Consent to be contacted form(s)* and:**
 - 6.1 explained the AHMS and what it involved
 - 6.2 asked if respondent (and children if relevant) were willing to take part
 - 6.3 if respondent was willing to take part in the AHMS, made an appointment for the AHMS' field staff to visit respondent's home to take their physical measurements and saliva sample
 - 6.4 if respondent had children aged 2–17 years who took part in the NHS and was willing for them to take part in the AHMS, made an appointment for the AHMS' field staff to take each child's physical measurements and saliva sample.

- 7 AHMS field agency posted to the adult respondent confirmation of the AHMS' field staff appointment(s) and instructions on how to prepare for the home visit for all participants in the household, and *Examination Brochure(s)*.
- 8 AHMS' field staff confirmed appointment(s) with each household's adult respondent the day before appointment.
- 9 AHMS' field staff checked and calibrated equipment each day before first appointment.
- 10 AHMS' field staff arrive at respondent's house and:**
 - 10.1 confirmed identity of adult respondent
 - 10.2 asked adult respondent to sign *Consent/parental permission for physical measurements (adults)*
 - 10.3 if consent form was signed, AHMS's field staff completed the *Physical Measurement Questionnaire* and took physical measurements and saliva sample in accordance with the specified protocols for the adult respondent
 - 10.4 invited adult respondent to visit a pathology collection centre to give blood and urine samples
 - 10.5 if adult respondent was willing to take part in specimen collection, AHMS' field staff screened them for eligibility to give a blood sample, and asked them to visit a specified pathology collection centre
 - 10.6 left a *Pathology collection form and instructions* for the respondent to take to their appointment
 - 10.7 if respondent was required to fast, field staff advised them of this
 - 10.8 made an appointment for a home visit if adult respondent was not able or willing to visit a pathology collection centre, and left a *Pathology collection form and instructions*
 - 10.9 asked adult respondent to sign *Consent to forward results form*
 - 10.10 explained the *Food Frequency Questionnaire* to adult respondent and left a copy for respondent to complete and post to AIHW
 - 10.11 if there were any participating children:
 - 10.11.1 confirmed the identity of each participating child
 - 10.11.2 asked parent / guardian (i.e. adult respondent) to sign *Consent/parental permission for physical measurements form* for each participating child
 - 10.11.3 if parent/guardian consented, field staff asked each child aged 4–17 years⁵ for their assent to participate. Children aged 12–17 years were asked for written assent (*Assent for physical measurements form*) and children aged 4–11 years were asked for verbal assent
 - 10.11.4 if parent/guardian consented and child assented, field staff completed the *Physical Measurement Questionnaire (A12)*, took child's physical measurements⁶ and saliva sample⁶ in accordance with the specified protocols, and explained and left the *Food Frequency Questionnaire* (for children aged 12–17)

5 Only parental permission was obtained for children aged 2–3 years.

6 On *AHMS Physical Measurement Consent Form*, respondent indicated the physical measurements they were willing to have taken and also whether they consented to give a saliva sample.

- 10.11.5 invited adult respondent to take any participating child aged 12 years and over to pathology collection centre to give blood and urine samples
 - 10.11.6 if adult respondent was willing to allow their child (aged 12+ years) to take part in specimen collection, AHMS's field staff screened the child for eligibility to give a blood sample and asked them to visit a specified pathology collection centre
 - 10.11.7 left a *Pathology collection form and instructions* for the respondent to take to their appointment
 - 10.11.8 if participating child was required to fast, the field staff advised the adult respondent of this
 - 10.11.9 made an appointment for another home visit if adult respondent was not able or willing to visit a pathology collection centre, and left a *Pathology collection form and instructions*
 - 10.11.10 asked adult respondent to sign *AHMS Consent To Forward Results Form(s)* for participating child(ren).
- 11 After each home visit, AHMS's field staff packaged saliva samples in accordance with the specified protocol.
 - 12 Each day, AHMS's field staff batched packaged saliva samples and delivered them to the closest pathology collection centre.
 - 13 AHMS's field staff contacted AHMS field manager if any problems were encountered during that day's home visits.
 - 14 At the end of each week, AHMS's field staff batched up *Physical Measurement Questionnaires* and posted priority paid to AHMS field manager.
- 15 At pathology collection centre (or home visit option):**
- 15.1 Collection centre staff member confirmed identity of adult respondent and transcribed personal details (i.e. name, sex, age and date of birth) from *Pathology collection form and instructions* to *Pathology Collection Questionnaire*.
 - 15.2 Collection centre staff member asked adult respondent to sign *Consent/parental permission for specimen collection form*.
 - 15.3 If consent form were signed, the collection centre staff member completed the *Pathology Collection Questionnaire* and collected blood and urine samples⁷ in accordance with the specified protocols from the adult respondent.
 - 15.4 If there was a participating child aged 12 years and over, collection centre staff member confirmed identity of the participating child and transcribed personal details (i.e. name, sex, age and date of birth) from *Pathology collection form and instructions* to *Pathology Collection Questionnaire*.
 - 15.4.1 Collection centre staff member/AHMS's field staff asked parent/guardian (i.e. adult respondent) to sign *Consent/parental permission for specimen collection form* for the participating child.
 - 15.4.2 If parent/guardian consented, collection centre staff member asked the child for their written assent (*Assent for specimen collection form*) to participate.

7 On *AHMS Specimen Collection Consent Form*, respondent indicated the specimens they were willing to give.

- 15.4.3 If parent/guardian consented and child assented, collection centre staff member completed the *Pathology collection questionnaire* and collected blood and urine samples⁸ in accordance with the specified protocols from the child.
- 16 After each specimen collection, pathology collection centres processed any blood samples requiring immediate processing in accordance with the specified protocols.
 - 17 If home visit option for specimen collection were used, collection centre staff took samples to pathology collection centre for immediate processing according to the measurement protocols.
 - 18 Each day, pathology collection centres packaged all specimens in accordance with the specified protocols for overnight transportation to the central pathology laboratory for processing and analysis.
 - 19 Pathology collection centres/technicians contacted AHMS field manager if any problems were encountered during that day's specimen collection.
 - 20 At the end of each week, pathology collection centres batched up *Pathology collection questionnaires* and posted priority paid to AHMS field manager.
 - 21 Central pathology laboratory analysed specimens for each participant and transcribed results onto *Specimen analysis form*.
 - 22 At the end of each week, central pathology laboratory batched up *Specimen analysis forms* and posted priority paid to AHMS field manager.
 - 23 Central pathology laboratory destroyed all blood, urine and saliva samples at the end of the pilot
 - 24 AHMS field office maintained regular contact with field staff, pathology collection centres and central pathology laboratory for duration of pilot.
 - 25 AHMS field office undertook data processing of all *Physical Measurement Questionnaires*, *Pathology collection questionnaires* and *Specimen analysis forms* as they arrived.
 - 26 AHMS field office created clean de-identified AHMS pilot unit record file.
 - 27 AHMS field office mailed physical measurement and blood and urine results to each participant⁹, and to their doctors if requested by the participant, within 12 weeks of the participant's pathology collection centre visit.
 - 28 AHMS field office included with the results a brochure that explained the meaning of the pathology results and the survey doctor handled urgent adverse results.
 - 29 AHMS field office sent clean de-identified AHMS pilot unit record file to AIHW at end of pilot.
 - 30 AHMS field office provided a report to AIHW on the conduct of the pilot.
 - 31 ABS provided a report to AIHW on the NHS component of the pilot.

8 On *AHMS Specimen Collection Consent Form*, respondent indicated the specimens they were willing to give.

9 Results for children were sent to the adult respondent.

Appendix C: Responsibilities of the successful tenderer

The fieldwork was contracted out by the AIHW following a selective tender process. The activities that the successful tenderer were responsible for included:

- ensuring the survey teams were trained in interviewing, taking the measurements and explaining the nutrition questionnaire. They needed to be prepared for and able to handle the variety of situations that they might encounter in entering people's homes (e.g. non-English-speaking backgrounds) and be fully equipped (with consent forms, brochures, measuring equipment, protocols) to undertake the home visits
- ensuring that the participating pathology collection centres were informed of the AHMS pilot, sent appropriate manuals and protocols, and trained accordingly
- arranging home visit appointments and specimen collection for households recruited to the AHMS pilot through the NHS, including follow-up and reminders, as needed
- arranging for pathology specimens to be collected in the home if participants were unable or unwilling to attend a pathology collection centre
- arranging for the transport of pathology specimens to the central analytical laboratories for analysis
- operating a 1800 information line throughout the NHS and AHMS pilot to handle queries from participants about the AHMS
- maintaining regular contact with the survey staff in the field, pathology collection centres, central analytical laboratories and AIHW during the pilot
- collating home visit results with the pathology specimen collection results and providing feedback to each participant, and to their doctor if requested by the participant
- ensuring that all personal details were kept confidential
- providing the results of the AHMS pilot to the AIHW at the end of the pilot for matching with the NHS records
- contributing to an assessment of the objectives of the AHMS pilot test by providing a report that detailed all problems encountered during the pilot and how these were resolved or might be resolved in the future, and data from the pilot that were necessary for the calculation of the specified response rates and costs
- undertaking all of the above within an agreed timeframe and budget.

To assess the AHMS pilot, AIHW as the managing agency fully debriefed the IDI at the completion of the pilot.