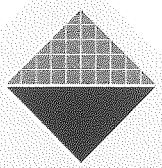
National Biomedical Risk Factor Survey

Report of workshop held 31 October 1997

Stan Bennett
Kuldeep Bhatia
Paul Magnus



AIHW

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The Australian Institute of Health and Welfare is an independent health and welfare statistics and information agency in the Commonwealth Health and Family Services portfolio. The Institute's mission is to inform community discussion and decision making though national leadership in the development and provision of authoritative and timely information on the health and welfare of Australians.

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Editors

Stan Bennett,
Kuldeep Bhatia
and
Paul Magnus

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Any enquiries about or comments on this publication should be directed to:

Dr Stan Bennett
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601

Phone: (02) 6244 1141

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The speakers at the workshop, the chairs of the plenary sessions, and the participants are thanked for the giving of their time and expertise. The involvement of the Institute's staff who contributed to the success of the workshop, particularly Sarojini Martin and Carolyn Merton, is appreciated.

Workshop planning committee

Professor Tony Adams

Dr Stan Bennett

Dr Kuldeep Bhatia

Dr Indra Gajanayake

Dr Paul Magnus

Dr Dan McCarty

Dr Edward O'Brien

Dr Andrew Tonkin

Contents

Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
GTT	glucose tolerance test
HDL	high density lipoproteins
IGT	impaired glucose tolerance
LINZ	Life in New Zealand Survey
LDL	low density lipoproteins
MACOD	Ministerial Advisory Committee on Diabetes
NHANES	National Health and Nutrition Examination Survey
RFPS	Risk Factor Prevalence Surveys
NHIA	National Health Information Agreement
NHMRC	National Health and Medical Research Council
NPHIWG	National Public Health Information Working Group
NPHPG	National Public Health Partnership Group

1 Introduction

A workshop of interested parties was held on 31 October 1997 to address growing demands for a further national survey of biomedical risk factors, especially blood indices, as part of national public health monitoring.

The Australian Institute of Health and Welfare (AIHW) convened the workshop under the auspices of the National Public Health Information Working Group (NPHIWG), a sub-committee of the National Public Health Partnership Group.

Workshop participants represented a wide range of public health areas and expertise in population health surveys. Professor Tony Adams (National Centre for Epidemiology and Population Health, ANU) welcomed participants and outlined the structure and purpose of the workshop.

The main objectives of the workshop were to discuss:

- the aims of a national biomedical risk factor survey;
- priorities for scope and content;
- sampling and data collection methods;
- potential funding sources; and
- steps to progress development of the survey beyond the workshop.

This report details the major discussion points from the workshop and provides a brief account of each of the four plenary sessions. The workshop program, a list of participants, the data issues papers provided to participants and the briefing paper for the workshop are included as appendixes to the report.

Note that while the National Public Health Partnership Group supports the development of a proposal for a national biomedical risk factor survey, the views expressed at the workshop do not necessarily represent those of the Partnership Group. There is no commitment at this time by the Commonwealth or States or Territories to assigning any funding priority to such a survey.

2 Major points from the workshop

The major points arising from the workshop are as follows:

2.1 General direction

1. The meeting endorsed the need for a national biomedical risk factor survey which includes a blood sample, and noted that such a survey had not been undertaken since 1989.
2. The workshop agreed that the broad aims of the survey would be to estimate national prevalence of selected diseases, conditions and risk factors; to determine national population distributions of selected health parameters; and to examine trends where possible.
3. The primary purpose of the survey would be monitoring, not research, although it was recognised that information collected by the survey would be useful for generating research hypotheses.
4. It was agreed that the survey should be cross-sectional and repeated at regular intervals.

2.2 Survey content

5. The survey would primarily aim to address areas of major public health significance where intervention is feasible and outcomes are measurable, and for which there are established risk factors that can be assessed from a blood sample.
6. Consequently, the workshop gave priority to the areas of cardiovascular disease, diabetes, nutrition and communicable diseases for which there are defined markers.
7. The majority view was that potential biomarkers in the areas of cancer and genetics do not have sufficient application to public health monitoring at the present stage of scientific understanding.
8. It was acknowledged that the survey would need to collect socio-demographic information, data on behavioural risk factors, physical measurements, and undertake analysis of blood samples.
9. Storing aliquots of blood samples for later analysis was not favoured.

2.3 Methods

10. Survey sampling methods should reflect the need for national estimates by ensuring the sample is representative of the target population but allows for comparisons with previous Australian surveys from the 1980s.
11. The workshop gave priority to generating national estimates; however, reliable estimates on rural and remote populations as well as estimates for States and Territories

were also considered important. The latter would require additional funding to cover the necessary sample supplementation.

12. Collecting information on population groups with relatively high prevalence of certain diseases was not favoured. This requires a special focused survey, which was not seen as the primary purpose of this survey.

13. No clear recommendation was made as to the age range to be covered. There was some support to extend the upper limit to at least the age of 74. It was also noted that 9, 12 and 15 year olds would need to be included in the survey if comparisons were to be made with estimates of blood lipid levels and iron status from the 1985 Australian Health and Fitness Survey of Schoolchildren.

2.4 Steps to progress the survey

14. It was agreed that a steering group should carry forward the planning for the survey. The steering group will be chaired by Professor Tony Adams, and include representatives from Diabetes Australia, the National Heart Foundation, the Department of Health and Family Services, the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS). Professor John Kaldor consented to join the committee at the workshop.

15. It was agreed that input from the areas of ethics and public relations would be important in due course.

16. One function of the steering group should be to investigate options for the funding and starting date of the survey.

17. Planning of the survey should aim to complement the ABS plans for future health-related data collections.

18. The steering group should report to the NPHIWG and, through it, to the Partnership Group.

3 Background presentations

Mr Geoff Sims (Head, Health Division, AIHW) chaired the first plenary session which consisted of a series of background presentations covering the national health information scene, the need for a biomedical risk factor survey, and issues involved in undertaking such a survey.

3.1 National health information scene

Dr Richard Madden (Director, AIHW) described the Institute, its Board and Ethics Committee, and links with the national health information infrastructure, particularly:

- the close working relationship between the Institute, health agencies of the Commonwealth and the States and Territories, and the ABS under the National Health Information Agreement (NHIA);
- the Institute's role in the National Health Information Management Group, which oversees the NHIA and provides the decision-making infrastructure for establishing priorities, roles and responsibilities for high-quality health information;
- the Institute's lead role for information infrastructure development under the National Public Health Partnership;
- the Institute's role in providing secretariat and other support to the NPHIWG (established by the Partnership Group) under whose auspice the workshop was convened;
- the role of the NPHIWG in identifying key public health information issues, determining gaps in the information base, and ensuring consistent definitions and classifications for national use; and
- the National Health Priority Areas process and the role of the Institute in monitoring and reporting on outcomes in the areas of cardiovascular health, cancer control, injury prevention and control, mental health and diabetes mellitus.

Dr Madden mentioned a recent meeting of the NPHPG, which had discussed the issue of a more consistent flow of money for a continuous collection of health information, and the review by the ABS of its health survey program.

3.2 General issues in blood surveys

Professor John Kaldor (Epidemiologist, National Centre for HIV Epidemiology and Clinical Research) discussed the estimation of prevalence and incidence rates, and their influence on the survey design. He noted that prevalence is easier to measure, but incidence is more useful for a number of purposes. Concerning the assessment of risk factors, Professor Kaldor noted that risk factors for disease incidence may differ from those for disease prevalence. He also commented that an ecological approach could be used for studying relationships between parameters based on blood analyses and risk factors collected at different times. The components of measurement error were seen as interpersonal, intrapersonal and machine error. Some ethical issues were raised—for example, specific or general consent;

return of results to subjects; and interpretation of findings based on a new test. Options for providing results to participants were seen as: full return with counselling; optional, subject-driven return; return of some results only; and combinations of these. The need for a good public relations strategy was emphasised. Finally, Professor Kaldor noted two special issues for infectious diseases: exposure versus carriage; and exposure markers versus vaccine markers.

3.3 An overview of blood data needs

Dr Tim Welborn (Endocrinologist, Sir Charles Gairdner Hospital) noted the importance of making the survey relevant to the five National Health Priority Areas. He suggested that the proposed survey would need to include the collection and linking of questionnaire data, physical measurements and blood tests. Further, the survey sample would need to be national and cross-sectional, and the survey would need to be repeated at five-yearly intervals. Dr Welborn proposed that the survey should address specific health problems where intervention is possible. He also noted that the survey, while useful for formulating hypotheses, would not be primarily a research undertaking. In relation to methods to be used for analysing blood samples, Dr Welborn mentioned micro-technology; standardisation and use of a central laboratory; quality control; and defined limits for abnormality (disease or risk). Concerning the individual, Dr Welborn raised the issues of informed consent (venepuncture, volume of blood and the nature of tests); incentives; response rate; right to information; abnormal results; and a follow-up plan for disseminating results.

Dr Welborn suggested four criteria for priority inclusion in the survey:

- public health issue or condition;
- relevance to the total population;
- feasible intervention; and
- measurable outcome.

In this context, Dr Welborn noted that type 2 diabetes (non-insulin-dependent diabetes mellitus) is a common disease and rising in prevalence. It is associated with high mortality, morbidity and health care burden. It has established diagnostic criteria, a long prodromal stage and its prevention is feasible.

3.4 New Zealand experience in biomedical risk factor surveys

Dr David Russell (University of Otago, New Zealand) described the methods and contents of national population health surveys conducted in New Zealand. In particular, the 1989 Life in New Zealand (LINZ) Survey (cost NZ$1.2 million) achieved response rates of 80% for the questionnaire and 56% for the clinical component. The survey collected anthropometry, blood pressure, blood lipids, 24-hour diet recall and physical activity data (the latter two on half samples each). Anthropometric measures comprised height and weight, skinfolds, girths and elbow width. Blood lipids studied were total cholesterol, HDL cholesterol, LDL cholesterol and triglycerides. The 1996–97 National Nutrition Survey (cost NZ$3.5 million) included anthropometry, measurement of blood pressure, blood samples and a general health questionnaire. Anthropometric measures were the same as in the 1989 LINZ Survey.

The blood samples were analysed for total cholesterol, HDL cholesterol, zinc protoporphyorins, C-reactive protein, transferrin receptors, ferritin, red blood cell count, haemoglobin, packed cell volume, mean corpuscular volume, mean corpuscular haemoglobin, mean corpuscular haemoglobin concentration, platelets and white cell count. The possibility of storing aliquots for future analysis was mentioned. Dr Russell emphasised that the public relations aspect was crucial to the success of these types of surveys.

3.5 Future ABS health surveys

Ms Marion McEwin (Assistant Statistician, ABS) presented an overview of the ABS social survey program and commented that demand exceeds the program's capacity. She described ABS household surveys, the monthly population surveys (labour force surveys and supplementary surveys), special social surveys (core surveys and ad hoc surveys), and the quarterly Population Survey Monitor. Ms McEwin noted that some collections were fully funded by the ABS, some were fully funded by external users, and others were a mixture of both, and she mentioned the benefits of repeating surveys. She added that the ABS had found response rates for health surveys in Australia generally quite high, at about 90%. The 1997 National Survey of Mental Health and Wellbeing had a response rate of about 80%, while the 1995 National Nutrition Survey had a low response rate of 61% possibly as a result of the methodology adopted. Ms McEwin pointed out that a good mechanism for deciding priorities and costing different options was crucial in making a case for any survey.

[Editors' note: The ABS plans to postpone the next National Health Survey (otherwise due around 2000) pending a review of its household survey program. Any proposal for a biomedical risk factor survey would need to account for this process and its outcome.]

3.6 General discussion

The following matters were raised in the general discussion that followed the background presentations:

- The ABS conducts both personal interview and telephone surveys, but the latter are not currently part of the social survey program.
- Surveys can combine data collection under the Census and Statistics Act with a voluntary component—for example, the 1995 National Nutrition Survey, which was conducted on a subset of the 1995 National Health Survey, was voluntary.
- The collection of dietary information is important; however less labour-intensive alternatives to the 24-hour dietary recall method used previously are required with direct links to biomarkers. The nutrition community needs to develop these instruments.
- Results from the proposed biomedical risk factor survey could be linked to the 1995 National Nutrition Survey at the age–sex group level (ecological analysis). However, the time interval between the collections would be a confounding factor.
- The issue of collecting blood samples in anticipation of some analyses being funded at a later date was also raised. The United States' National Health and Nutrition Examination Survey III (NHANES III) has guidelines on the storage of aliquots, and New Zealand is storing samples for nutrition-related analysis later. It was reported that 96% of participants in a rural risk factor survey in Victoria agreed to having their blood sample stored for future analysis.

- The AIHW supported the collection of blood samples for specific purposes but not the storage of samples without a presently known purpose, which would require a general, unspecific consent.
- The workshop were informed that while New Zealand provided some results to participants, the Netherlands provided no results to participants so as to avoid unwarranted fear generated by false positives.
- It was acknowledged that the need to make comparisons with past survey results would have implications for survey methods as well as the survey content.
- The importance of collecting data on older people was generally recognised, as was the importance of collecting behavioural information.

4 Priorities for blood analysis—scope and content

Plenary sessions 2 and 3, chaired by Professors Annette Dobson (University of Newcastle) and John Kaldor respectively, discussed priorities for the survey content in the focus areas of cardiovascular disease, diabetes, nutrition, cancer, genetic and other biomarkers and communicable diseases. The authors briefly introduced their papers on data issues (Appendix C), and workshop participants were invited to discuss the issues raised.

4.1 Cardiovascular disease

Dr Stan Bennett (AIHW) described the data environment for cardiovascular disease risk factors in Australia and emphasised the need for collecting blood lipid data that could be compared with previous data in adults and schoolchildren. He also stressed the need to monitor national health priority indicators relating to blood cholesterol.

- The workshop noted the deficiencies of previous National Heart Foundation Risk Factor Prevalence Surveys (RFPS), particularly the lack of coverage of rural areas and the limited age range of the subjects. Workshop participants accepted the importance of collecting information on primary schoolchildren.
- The workshop accepted the importance of collecting data on blood lipids comparable with that obtained in previous surveys. The need to ensure the future collection of biomedical information over regular intervals was also discussed.
- There was general support for determining triglyceride levels even though fasting would be required of the participant. It was noted that diabetes-related tests also requires fasting status and this would restrict the time period during which the blood could be collected. It was agreed that all fasting blood samples should be collected between the hours of 8 a.m. and 12 noon.
- The workshop identified the need to include several biochemical markers in addition to total cholesterol, HDL cholesterol and triglycerides, and it was suggested that a check of the NHANES III list would be useful. The following markers were mentioned:
  - homocysteine
  - folate
  - fibrinogen
  - inflammatory response proteins
  - Lp(a)
  - apolipoproteins.
- The meeting agreed that discussion should continue on criteria and concepts rather than on the inclusion of specific biomarkers; hence the list above does not represent a comprehensive recommendation from the forum.

- The following criteria for selecting risk factors were proposed:
  - significant epidemiological association
  - public health significance
  - measurable outcome of prevention/intervention
  - commonality across diseases
  - ability to be integrated with other pieces of information.
- The inclusion of physical and physiological measures in the survey, such as blood pressure, was considered important, as was the inclusion of behavioural risk factors.
- Concerning stroke, there was interest in the 75–80 year age group and older.

4.2 Diabetes

Dr Dan McCarty (National Diabetes Institute) pointed out that, despite apparent rising levels of diabetes in Australia, information on diabetes epidemiology was inadequate. He outlined the scope and objectives of the proposal that he and others have developed for an Australian Diabetes Prevalence Survey, and described the current debate about the merits of a single fasting blood test as against those of the glucose tolerance test (GTT), the conventional gold standard.

- There was consensus that the proposed biomedical risk factor survey would provide an excellent opportunity to validate self-reported data by comparing them with biochemical results.
- Discussion centred around biomarkers common to diabetes and cardiovascular disease. There was consensus that triglycerides and low density lipoproteins (LDL) should be high priority biomarkers.
- The workshop discussed the issue of respondent burden associated with a GTT with two-hour plasma glucose measurements, and its potential effect on response rates.
- There was consensus that the areas of cardiovascular disease and diabetes should both be included in the proposed survey.

4.3 Nutrition

Dr Karen Cashel (University of Canberra) pointed out that nutrition brings a different perspective to the survey because it is less disease focused. She described the available nutrition indicator information as opportunistic and based on non-representative samples. She emphasised the need to collect information on dietary behaviours and to interpret the 1995 National Nutrition Survey data as quickly as possible. She also identified the following priority population groups for nutrition-related information: Indigenous people, older people, the reproductive age group, and children aged younger than 15 years.

- The issues of age range and sampling specific population groups were discussed. Workshop participants noted that while the study of Indigenous and elderly populations is important, the proposed survey sample would be unlikely to have numbers sufficient to generate reliable estimates for these population groups.

- The participants agreed that biochemical markers of nutrition would be important for inclusion in the survey. The need to establish links between blood markers and data on nutritional behaviours was also emphasised.
- The need to have both quantitative and qualitative aspects of nutrition covered in the survey was accepted by the workshop, but it was emphasised that the dietary behaviour component of the survey should be as simple as possible.
- It was noted that including a nutrition behaviour component in the LINZ Survey made the time needed for a personal interview as long as 1.5 hours. The need to control the total visit time was accepted by the workshop participants.
- The inclusion of a GTT would provide the opportunity to conduct other studies as well as interview the subject (for example, to collect valid height and weight measurements). However, apart from the issue of respondent burden and possible effects on response rate, this presupposes that respondents would be available for at least two hours, and that the researchers would be able to make efficient use of that time.

4.4 Cancer

Dr Wayne Clapton (South Australian Health Commission) referred to the three aims listed in the data issues paper (Appendix C). According to Dr Clapton, appropriate tests for specific cancers at a level sensitive enough to determine differences in risk between population groups was highly important. Behavioural risk factor data collected by questionnaire methods would be necessary to complement data derived from biomedical indicators.

Dr Clapton raised the issue of the scope of a cancer component—for example, whether the survey should target all cancers or site-specific cancers only. Dr Clapton also informed the workshop that new chip technologies, which are currently under development, promise to dramatically cut down on the time required for DNA analysis within the next five years.

Dr Clapton also briefly addressed issues relating to:

the varying complexity of testing methods on different biological materials;

the need to use standardised methods in accredited laboratories to enable comparability of results; and

ethical issues relating to the provision of results to participants (particularly those which may suggest possible genetic predisposition to cancer).

- The following issues were raised during the discussion but received little support because these added complexity to the survey:
  - collecting other biological material in addition to blood, such as urine, buccal smears, hair and nail tissue, to broaden the testing possibilities and to enable some estimation of population exposures to carcinogens;
  - taking a blood film in addition to other tests; and
  - storing blood and other tissues for future analysis as new technologies become available.
- The forum also considered the possibility of developing Australia-wide reference ranges for cancer biomarkers, from data collected in this survey.
- On balance, the workshop participants did not consider the inclusion of cancer and genetic markers as a high priority, and felt that the ethical issues would be considerable.

However, it is possible that the survey could record participant's interest in future contact, with a view to follow-up and link with the cancer register.

4.5 Genetic and other biomarkers

Dr Simon Easteal (John Curtin School of Medical Research) referred to the issues paper prepared by Dr Kuldeep Bhatia (AIHW) on the background to, and usefulness of, genetic studies, and explained why the inclusion of genetic investigations need not compromise the acceptability and quality of the proposed survey.

Dr Easteal said that several genetic factors have been identified for cardiovascular disease as well as diabetes. Concerning mental health, particularly cognitive decline and senile dementia, genetic studies will become important in the near future. He also mentioned that genotype/genotype interactions and genotype/environment interactions are important in the study of epidemiology.

Dr Easteal's view was that the collection and storage of DNA samples should be among the survey's top priorities, given current knowledge of common forms of degenerative and other illnesses, and that to not do so would seriously prejudice the study's relevance to important issues of public health.

- There was discussion about logistic and ethical issues surrounding genetic investigations, and the forum considered the possibility of linking de-identified genetic data to various risk factors.
- The majority of workshop participants anticipated considerable ethical issues and, overall, there was little support for the inclusion of genetic and other biomarkers in the proposed survey for the same reasons as for cancer biomarkers.

4.6 Communicable diseases

Dr Tim Heath (National Centre for Immunisation Research) spoke on vaccine-preventable diseases and the link between disease susceptibility and prevalence in populations.

Dr Heath's view was that immunisation history tends to be an unreliable indicator of coverage against the disease, and that serological information is highly relevant and important.

He mentioned measles, rubella, tetanus, diphtheria, hepatitis A, hepatitis B, varicella-zoster (chickenpox) and herpes simplex virus type 2 as diseases that could be controlled with appropriate immunisation programs based on sero-immunity data generated in a blood survey.

- The workshop noted the existence of some evidence linking infection with coronary heart disease.
- Professor Kaldor recommended testing for hepatitis C, which requires about 2 mL of blood, assuming no wastage.
- The issue of screening blood for environmental pollutants such as lead and pesticides was discussed.
- Workshop participants agreed there were useful markers for detecting exposure to communicable diseases and that this area should be included in the proposed survey.

5 Advancing the survey

Survey priorities, ethical considerations, sampling and laboratory methods, funding issues and other matters to advance development of the survey were discussed in the final session of the workshop. This session was chaired by Professor Tony Adams.

5.1 Aims and priorities

- There was agreement on the three aims listed in Attachment 1 (p. 36) of the briefing paper.

5.2 Ethical considerations

- Different ethics committees may take different positions on the same matter, however if the proposed survey is conducted under the auspices of the Institute, it would come under the responsibility of the Institute's Ethics Committee and other ethics committees may see no need to have direct involvement.
- In this regard it was mentioned that the Australian Health Ethics Committee is preparing the ground for cross-recognition of decisions between different ethics committees.
- Informed consent, feedback of results and privacy considerations are important ethical issues for a biomedical risk factor survey.
- The public relations aspect of the survey would be very important.

5.3 Coverage

- Indications are that stakeholders are divided in their opinion on the need for State/Territory data.
  - The Ministerial Advisory Committee on Diabetes (MACOD) supports national-level estimates; the NPHIWG supports State/Territory-level estimates as well.
  - The NPHPG would want to be advised by the NPHIWG.
- There was general agreement that data for rural and remote areas would be useful.
- Preferred age ranges for different stakeholders were mentioned as follows:
  - 24 years and above for diabetes
  - 45–95 years for stroke
  - up to 75 years for cardiovascular disease
  - under 1 year for immunisation
  - 12 years and above for nutrition
  - school-age children for physical activity.

- The issue of covering a wide range of age groups through a household-based survey was discussed. However, the ABS representative reminded the workshop that households are heterogenous in their structure and composition, and that household-based information to cover all age groups would need to be carefully planned.

5.4 Ownership of the data

- The twin issues of 'who owns the data' and 'who decides whether the records can be matched' were raised. Ownership of the data was seen to be a central issue.
- The ABS considered that it could not undertake the blood collection because of its legislation. However, the AIHW could collect blood samples and the Institute Board has expressed interest in doing so.
- It was mentioned that the capacity to link the survey data with other pieces of information such as mortality would be important, and should be considered in the planning of the survey.

5.5 Survey design options

- There was consensus that the survey would be cross-sectional and not a cohort study. However, the survey could become a launching pad for cohort studies by other interested parties, and therefore the survey should be widely publicised.
- Survey design options that would need to be considered are:
  - the coverage issues mentioned above;
  - the importance of comparability with previous surveys;
  - the location of blood collecting centres (that is, a large number of smaller clusters or a small number of larger clusters);
  - the sampling frame—for example, electoral roll or ABS household sampling frame (some of the disadvantages with using the electoral roll are that highly mobile youth might not be contactable, and the population below voting age would be automatically excluded);
  - where the questionnaire should be administered, and the blood collected and analysed;
  - whether the questionnaire should be in several languages;
  - whether all persons interviewed need to be invited to take part in the blood survey;
  - variation in the response rate between population groups; and
  - cost.

5.6 Continuity with previous surveys

- Workshop participants acknowledged the importance of being able to compare results with those from previous surveys, particularly for the purpose of monitoring trends in blood lipid levels and iron status.

5.7 Funding

- The total cost of the survey is likely be $2–3 million.
- MACOD and the National Heart Foundation have both offered some support.
- The support of the NPHPG would be essential in obtaining government funds, given the competing public health priorities.
- The Commonwealth's public health programs were seen as potential major funding sources.
- States and Territories may be potential sources of funds, but they would need to assess where the survey fits in with their programs.

5.8 The way forward

Dr Madden contributed the following comments in relation to advancing survey planning beyond the workshop.

- It would probably be necessary to take a minimalist approach to the survey content and methodology.
- The scope of the survey should be decided on a priority basis using the criteria suggested at the workshop.
- Response rate considerations would be crucial.
- Comparisons with National Heart Foundation survey data would be very valuable.
- The need for cooperation between stakeholders would be important.
- Non-government organisations should be at the forefront of the survey.
- Diabetes Australia, the National Heart Foundation and other stakeholders would be very important to this exercise.
- Innovative ways to get community support should be considered.
- A steering group should be established to advance the planning of the survey, with Professor Adams as the convenor (see point 14, p. 3).

Professor Adams concluded the workshop by thanking all participants and organisers for their contributions, and sought their ongoing support for the further development of the survey.

Appendix A: Workshop program

National Biomedical Risk Factor Survey Workshop

Australian Institute of Health and Welfare

31 October 1997, 10.00 a.m. - 5.00 p.m.

Session	Time	Chair/Rapporteur	Speaker/Topic
Opening	10.00 a.m. – 10.10 a.m.		Professor Tony Adams *Welcome and introductory remarks on workshop aims and structure*
Plenary 1 Background presentations	**10.10 a.m. – 11.25 a.m.**	**Mr Geoff Sims/ Dr Stan Bennett**	
	10.10 a.m. – 10.20 a.m.		Dr Richard Madden *National health information scene*
	10.20 a.m. – 10.35 a.m.		Professor John Kaldor *General issues in blood surveys*
	10.35 a.m. – 10.45 a.m.		Dr Tim Welborn *An overview of blood data needs*
	10.45 a.m. – 10.55 a.m.		Dr David Russell *New Zealand experience in biomedical risk factor surveys*
	10.55 a.m. – 11.05 a.m.		Ms Marion McEwin *Future ABS health surveys*
	11.05 a.m. – 11.25 a.m.		Discussion
Coffee break	**11.25 a.m. – 11.45 a.m.**		
Plenary 2 Priorities for blood analysis: content and scope I	**11.45 a.m. – 12.45 p.m.**	**Professor Annette Dobson/ Dr Kuldeep Bhatia**	
	11.45 a.m. – 12.15 p.m.	Cardiovascular disease	Issues paper by Dr Stan Bennett
	12.15 a.m. – 12.45 p.m.	Diabetes	Issues paper by Dr Dan McCarty
Lunch	**12.45 p.m. – 1.30 p.m.**		
Plenary 3 Priorities for blood analysis: content and scope II	**1.30 p.m. – 3.10 p.m.**	**Professor J Kaldor/ Dr Paul Magnus**	
	1.30 p.m. – 1.55 p.m.	Nutrition	Issues paper by Dr Karen Cashel
	1.55 p.m. – 2.20 p.m.	Cancer	Issues paper by Dr Paul Jelfs and Dr Kuldeep Bhatia
	2.20 p.m. – 2.45 p.m.	Genetic and other biomarkers	Issues paper by Dr Kuldeep Bhatia
	2.45 p.m. – 3.10 p.m.	Communicable diseases	Issues paper by Dr Tim Heath
Coffee	**3.10 p.m. – 3.30 p.m.**		

Plenary 4 **Priorities, ethical considerations, methods, funding issues, advancing the survey**	**3.30 p.m. – 5.00 p.m.**	**Professor Tony Adams/ Dr Indra Gajanayake**	
	3.30 p.m. – 4.30 p.m.	Aims and overall priorities	General discussion
		Ethical considerations	
		Survey design options	
		Coverage—e.g. States/ Territories, urban/rural areas	
		Continuity with previous surveys	
		Funding issues	
		Advancing the survey	
	4.30 p.m. – 4.50 p.m.	The way forward	Dr Richard Madden
	4.50 p.m. – 5.00 p.m.	Concluding remarks	Professor Tony Adams

Appendix B: List of participants

Name	Organisation	Telephone	Fax
Dr Michael Ackland	Epidemiology Unit Department of Human Services, Victoria	03 9637 4241	03 9637 4744
Professor Tony Adams	National Centre for Epidemiology and Population Health Australian National University	02 6249 5616	02 6249 0740
Dr Tim Armstrong	Australian Institute of Health and Welfare	02 6244 1129	02 6244 1166
Mr Bernie Ayers	Consumers' Health Forum/Diabetes Australia	02 6285 3277	02 6285 2881
Ms Jeannette Baldwin	National Diabetes Strategy	02 6285 3277	02 6285 2881
Ms Jan Bennett	Public Health Division Department of Health and Family Services	02 6289 7035	02 6289 8483
Dr Stan Bennett	Australian Institute of Health and Welfare	02 6244 1141	02 6244 1166
Dr Kuldeep Bhatia	Australian Institute of Health and Welfare	02 6244 1144	02 6244 1166
Dr Karen Cashel	Department of Human Nutrition Faculty of Science University of Canberra	02 6201 2745	02 6201 5030
Ms Helen Catchatoor	National Health Priority Committee Secretariat Health Service Outcomes Branch Department of Health and Family Services	02 6289 9359	02 6289 7958
Dr Helen Christensen	Psychiatric Epidemiology Research Centre Australian National University	02 6249 5111	02 6249 0733
Mr Mark Cooper-Stanbury	Australian Institute of Health and Welfare	02 6289 7027	02 6289 8483
Dr Wayne Clapton	Epidemiology Branch Public and Environmental Health Service South Australian Health Commission	08 8226 7254	08 8226 6291
Dr Margaret Dean	Public Health Division Department of Health and Family Services	02 6289 8538	02 6289 8422
Professor Annette Dobson	Department of Statistics University of Newcastle	02 4921 5544	02 4921 7063
Professor Geoffrey Donnan	Department of Neurology Austin and Repatriation Medical Centre	03 9496 5529	03 9457 2654
Mr David Dunstan	International Diabetes Institute	03 9258 5050	03 9258 5090
Dr Simon Easteal	Human Genetics Group John Curtin School of Medical Research	02 6249 4719	02 6249 4712
Dr Vicki Flood	Department of Public Health and Community Medicine Westmead Hospital and Community Health Services	02 9845 6677	02 9689 1049
Dr Indra Gajanayake	Australian Institute of Health and Welfare	02 6244 1128	02 6244 1166
Dr Alan Goble	Heart Research Centre	03 9347 5544	03 9347 6964
Dr Julienne Grace	Royal College of Pathologists	02 9332 4266	02 9388 7551
Dr Timothy Heath	National Centre for Immunisation Research	02 9845 3075	02 9845 3082
Dr David Hill	Anti-Cancer Council of Victoria	03 9279 1181	03 9279 1250
Dr Paul Jelfs	Australian Institute of Health and Welfare	02 6244 1140	02 6244 1166
Professor John Kaldor	National Centre in HIV Epidemiology and Clinical Research	02 9332 4648	02 9332 1837
Mr Peter Liehne	Healthy Public Policy Unit Department of Health and Family Services	02 6289 7385	02 6289 8121

(continued)

Name	Organisation	Telephone	Fax
Dr Vivian Lin	Secretariat National Public Health Partnership Group	03 9616 7601	03 9616 7929
Dr Dan McCarty	International Diabetes Institute	03 9258 5050	03 9258 5090
Ms Marion McEwin	Australian Bureau of Statistics	02 6252 7068	02 6252 5172
Dr Richard Madden	Australian Institute of Health and Welfare	02 6244 1100	02 6244 1111
Dr Paul Magnus	Australian Institute of Health and Welfare	02 6244 1140	02 6244 1166
Dr Edward O'Brien	National Centre for Disease Control Department of Health and Family Services	02 6289 8403	02 6289 6963
Professor Kerin O'Dea	Deakin Institute of Human Nutrition	03 9244 5405	03 9244 5406
Professor David Russell	University of Otago New Zealand	+ 64 3 479 8993	+ 64 3 479 8332
Professor Rob Sanson-Fisher	National Cancer Control Initiative	03 9279 1332	03 9279 1320
Mr Geoff Sims	Australian Institute of Health and Welfare	02 6244 1168	02 6244 1166
Dr Andrew Tonkin	National Health Foundation	03 9321 1545	03 9321 1585
Dr Tim Welborn	Department of Endocrinology and Diabetes Sir Charles Gairdner Hospital, Perth	08 9346 2467	08 9346 3221
Dr David Wilson	South Australian Health Commission	08 8226 6292	08 8226 6291
Ms Margaret Williamson	Health Survey Program NSW Health	02 9391 9206	02 9211 7532
Ms Marion Worcester	Heart Research Centre	03 9347 5544	03 9347 6964

Appendix C: Workshop data issues papers

Data issues paper no. 1: cardiovascular disease

Background

There is clear evidence from epidemiological, animal and clinical studies that high blood cholesterol levels are a major causal factor in coronary heart disease. Mean cholesterol level is a significant determinant of population risk of coronary heart disease. Clinical trials have shown that reducing cholesterol level lowers rates of the disease. For populations, diet is the main determinant of blood cholesterol level, specifically saturated fat.

The National Health Priority Area of cardiovascular health has adopted two indicators that relate to blood lipids:

- the average blood cholesterol of persons aged 20–69 years; and
- the proportion of persons aged 20–69 years with high blood cholesterol.

The latest data for these indicators are for 1989.

The main risk factor for stroke is high blood pressure. The relationship between stroke and total cholesterol is uncertain.

Aims

- To determine the average population levels of plasma cholesterol, high-density lipoprotein, triglyceride and derived lipoprotein fractions.
- To determine the prevalence of raised plasma cholesterol and raised triglyceride levels.
- To compare results with equivalent estimates in 1980, 1983 and 1989 (adults in capital cities).

Proposed blood analyses

Plasma total cholesterol

High-density lipoprotein

Triglyceride

Issues

- Fasting is required for measuring triglyceride.
- The need to collect information on other major risk factors for cardiovascular disease—for example, high blood pressure, smoking and physical activity.

- The need to collect data on covariates – for example:
  - whether taking the oral contraceptive pill (women);
  - body mass index;
  - smoking status; and
  - alcohol intake.
- The need to collect dietary intake information.
- The importance of comparison with the 1985 survey of schoolchildren which collected blood lipid levels on 9, 12 and 15 year olds.
- Feedback of results (normal or abnormal) to participants and/or their general practitioner.

Data issues paper no. 2: diabetes

Australian Diabetes Prevalence Survey

Background

Accurate data on prevalence and risk factors for non-insulin-dependent diabetes mellitus (NIDDM) are urgently needed in Australia. Current estimates are based on surveys of self-reported diabetes and very little is known about impaired glucose tolerance (IGT), a precursor of NIDDM, and the extent of undiagnosed NIDDM in the community. Since NIDDM is the 'tip of the iceberg' in a cluster of cardiovascular disease risk factors, the original plans for a pure diabetes survey have been expanded to included the metabolic syndrome (hyperinsulinemia, insulin resistance, dyslipidaemia, central obesity and hypertension), associated environmental risk factors (diet, physical activity measures, smoking, etc.), and health knowledge, attitudes and practices. This study will build on previously collected data from the National Heart Foundation's Risk Factor Prevalence Surveys (RFPS) and the ABS National Health Surveys.

Aims

1. To survey a representative sample (n = 13,000) of adult Australians aged 25 years and above to obtain an accurate national profile of:
   - self-reported medically diagnosed conditions
   - undiagnosed NIDDM
   - features of the metabolic syndrome
     - hyperinsulinemia
     - insulin resistance
     - dyslipidaemia
     - central obesity
     - hypertension
   - associated diabetes and cardiovascular risk factors
     - diet/nutrition
     - physical activity
     - smoking
   - health knowledge, attitudes and practices
2. To establish a cohort for follow-up prevalence surveys

Proposed methods

1. We will consult with the ABS to identify representative urban and rural communities (six to eight) using stratified cluster sampling techniques.

2. Interviewers will be hired from each local community. After training, these interviewers will conduct door-to-door surveys. The purpose of these surveys is to:
   a) conduct a census of the area;
   b) obtain information on non-respondents;
   c) administer an abbreviated health questionnaire; and
   d) to invite every fourth person (age 18 years and over) to the survey centre for a more detailed examination. These volunteers will be asked to fast overnight.
3. A survey site will be established in a local health clinic, community centre, shopping centre, etc. within each of the selected communities.
   - The test site will operate for about two or three weeks, seeing about 75 to 100 people a day.
   - Only people who have fasted overnight will be tested. Therefore, the survey will operate from about 7 a.m. to 2 p.m.
   - A laboratory can be established at the test site to conduct glucose tests and store samples.
4. A detailed 2 ½ hour examination at the survey centre will include;
   - registration
   - height, weight and waist measurements
   - a fasting blood draw
     - plasma glucose (determined on site)
     - HbA1c (determined on site)
     - lipids (LDL, HDL cholesterol, triglycerides)
     - insulin (subsample?)
     - genetics (?)
   - 75 g oral glucose load
   - knowledge, attitude and practice questionnaire
   - 24-hour food frequency questionnaire
   - physical activity questionnaire
   - detailed health history questionnaire
   - resting blood pressure measurements (x 3)
   - 2-hour blood draw
     - plasma glucose (determined on site)
     - insulin (subsample)
   - Complications screening for people with known diabetes
     - diabetes questionnaire
       - history
       - management/complications
       - health services
     - retinal photography
     - abbreviated neurological exam

- urine sample (next morning)
  - microalbumin / creatinine ratio

Sampling frame

20,000 subjects (>18 years) to be invited for the full survey. Anticipating a response rate of 65–75% (this will yield a study population of >13,500 subjects) that will have the statistical power to place a 95% confidence interval around the diabetes estimate of <1% (for example, prevalence = 6.0, 95% confidence interval = 5.5–6.4).

Based on the assumption of a 75% follow-up of the original cohort (n = 10,100), a future survey will have the power to detect a 1% change (either higher or lower) in diabetes prevalence.

Follow-up

Careful liaison with general practitioners before and during the study will be essential to facilitate effective follow-up and after-care of newly identified NIDDM and IGT, and those with risk factors.

Data issues paper no. 3: nutrition

Background

The diet-related diseases of greatest public health significance to the majority of Australians are the chronic, preventable, non-communicable, lifestyle-related conditions associated with over-consumption of food and inactivity. These include coronary heart disease, hypertension, stroke, non-insulin-dependent diabetes mellitus, and some cancers. The most common nutritional deficiency condition is iron deficiency.

A workshop of over 50 representatives from a wide range of stakeholders was held in Canberra in 1993, under the sponsorship of the National Health and Medical Research Council (NHMRC) and the then Department of Health and Community Services to define the objectives and broad parameters of the 1995 National Nutrition Survey. One outcome of the workshop was some broad directions on priorities for blood tests. Early in 1994, an expert technical working group chaired by Professor Stewart Truswell considered the outcome of the workshop and recommended the priorities shown in the table which follows.

This National Biomedical Risk Factor Survey offers the opportunity to consider three further specific issues. First, the opportunity to obtain baseline data on nutritional status indicators beyond those that have been identified by the previous, limited Australian studies (that is, studies of iron status, risk factors for major chronic disease (cholesterol, triglyceride, glucose) and specific disorders (for example, folate)). These aspects are either well identified or well supported as key health issues. However, we know very little about the status of Australians for other nutrients such as zinc, selenium, folate, thiamin, retinol, carotenoids, vitamin E in the elderly, and vitamin D. All of these have raised concern and discussion in the nutrition community, and have led to recommendations for some nutrients (for example, vitamin D and the housebound/institutionalised elderly) and action (for example, thiamin and folate). Without data and evidence of significant clinical problems, it is difficult to identify groups at risk and to justify the need for either monitoring or intervention programs. This survey offers the first opportunity to obtain such data.

Second, some tests may need to be broadly based across the community while others (for example, vitamin D, folate) may be conducted on adequate samples of specific, high-risk groups. The need to address groups at risk of poor nutritional and health status such as Indigenous Australians particularly needs be considered, in terms of methodology and the tests required.

Third, the issue of collecting key dietary data alongside these biomedical tests, and by what method, also needs to be considered. The link between dietary indicators and biomedical status would be invaluable for future monitoring in food and nutrition.

Aims

- To obtain baseline data on the nutritional status of Australians.
- To link this data to key dietary indicators where possible.
- To enable the identification of nutritional risk factors and of at-risk groups in the population.
- To inform the development of public health interventions.

- To inform the development of future food and nutrition monitoring, including biomedical monitoring.

Proposed blood analyses

As a basis for initiating discussion, the following are the recommendations of the 1994 expert technical working group.

Priority one	Priority two	Priority three	Not measured
Ferritin	Retinol	Zinc	Vitamin C[b]
Complete blood count	Vitamin E[c]	Selenium	Vitamin D
Folate	Carotenoids[c]		Thiamin
Red cell distribution width	Triglycerides[c]		Lead
Haemoglobin			Cadmium
Iron and total iron binding capacity			
Cholesterol (total and HDL)			
Albumin			
Glucose[c]			
Insulin[a][c]			

(a) Insulin was not considered by the workshop but was added by a sponsor for its analysis.

(b) Vitamin C requires storage at –70°C.

(c) Fasting measures, if possible.

- Priority one tests were recommended for blood collected from all participants aged 16 years and over (rural, metropolitan and ex-metropolitan).
- Priority two tests were recommended for blood collected from participants aged 16 years and over in metropolitan areas only.
- It was also recommended that all analyses for the main analytes be performed by the same analytical laboratory.

Issues

- Identify the minimum set of nutritionally related biomedical data needed for the whole population.
- Identify baseline data needed to support current public health nutrition interventions – for example, thiamin and folate fortification of foods.
- Specify and prioritise those aspects of nutritional status for which we have no biomedical data but about which concerns have been raised.
- Identify specific population groups at high risk of poor nutritional status – for example, Indigenous Australians – and specify any additional tests required for these groups.
- Identify groups as 'at risk' for particular nutrients and who may need to be 'over sampled' – for example, women of reproductive age and folate; housebound/ institutionalised elderly and vitamin D.
- Assess the potential for collecting key dietary data alongside of these biomedical tests (including identification of methods and data).

Data issues paper no. 4: cancer

Background

Cancer represents a range of diseases that originate in particular organs or tissues. It is a group of diseases that result from genetic mutations. These mutations can occur as a result of external influences (for example, environmental) or internal influences (for example, hormonal) or through random genetic errors.

Elements in blood represent opportunities to: (a) indicate the body's activities in response to cancer initiation; and (b) indicate the body's predisposition to cancer. These opportunities exist because cancer cells spread via the blood system and blood components are capable of indicating cancer risk.

Aims

To determine the appropriate blood tests for specific cancers, at a level that is sensitive enough to:

(a) indicate a significant difference in risk between population groups;

(b) indicate a significant difference within individuals at different times during the course of the disease which would affect the treatment regimen; and

(c) indicate intervention points for preventative treatment.

For the purposes of the blood survey the focus should be on (a), although consideration should be given to comparative analyses with (b) and (c).

Proposed blood analyses

To be determined based on:

- cancer types to be focused on
- cost of the analyses
- benefits according to the aims (see above)
- potential impact on survey design and methods.

Examples of potential biomarkers include DNA adducts, mutated oncogenes and disabled tumour suppressor genes.

Issues

- We are not dealing with one disease but a group of diseases that are amenable at different levels to screening, diagnosis and treatment.
- We are dealing with an incidence risk of all cancers in the population of 1 in 3 before the age of 74 years, but with much lower incidence risk for site-specific cancers.
- There is a need to collect information on other major risk factors for cancer—for example, age, sex, smoking history, occupational exposures, diet, UV exposure.

- There is a need to collect data on covariates—for example, oral contraceptives or other hormone therapies.
- The feedback of results (normal or abnormal) to participants and/or their general practitioner must be determined.

Data issues paper no. 5: genetics

Background

A blood sample provides high resolution, linked information on a wide range of risk factors, disease markers and environmental exposure indicators. Current genetic techniques help integrate this information, including that obtained using physiological, immunological and biochemical techniques, to generate multi-faceted information. The approach is useful not only for producing individual-specific profiles but also for helping obtain useful biomedical information at a population level.

Good quality genetic information on the Australian population as a whole and its various groups has not been collated lately. Piecemeal information is available on sections of human genome (for some segments of the community), but information on the genetic structure of this evolving multicultural society has not been attempted. Estimates of allele frequencies for several of the monogenic disorders, immunological markers and disease susceptibility genes are based on small, often non-representative samples.

To link normal variation in physio-chemical and immunological aspects of health with genetic markers, using a representative national sample, is a pioneering scientific endeavour. Although epidemiological studies have been undertaken to determine these relationships, the resource-intensive nature of these studies has restricted the scope of the work. The National Biomedical Risk Factor Survey offers a historic opportunity to determine these associations using a large body of data.

There is a lingering suspicion that any talk of genetic investigations may compromise the acceptability and quality of the survey. Genetic markers are not incommensurables in a biomedical risk factor survey; the workshop will not be making impossible choices between oranges and apples. Besides, the volume of blood sample required for undertaking genetic studies is small. Current PCR techniques allow amplification of relevant sections of the human genome using small amounts of DNA. Moreover, the component of blood required for undertaking genetic studies (buffy coats) is not commonly used for other biomedical analyses.

The debate about genetic studies has been vigorous over the past several years. There is a real need to educate the general public and planners about the nature and quality of the surveys that include genetic investigations. There is also a need to assure the general public that the biological material itself and the proposed genetic analysis will be conducted under strict privacy considerations.

Genetic studies have strong implications for developing public health strategies. Surprisingly, public health dividends from genetic investment will not be in the form of high technology but simple population preventive strategies. Genetic information would be a unique component of the survey that must be carefully debated, but progressed.

Aims

- To provide background genetic information on physiological, biochemical and immunological variables to be covered by the survey.
- To contribute to the identification of disease susceptibility genes for cardiovascular disease, asthma, diabetes, cancers and other conditions.

- To generate information on the frequency of carriers for several monogenic traits in the population.
- To determine the genetic heterogeneity of the Australian population and its relevance to variation in disease prevalence.

Proposed analyses

A list of relevant genetic markers will be identified for analysis at a later date. However, given the current technologies, it is now possible to look at scores of genes cost-effectively. The workshop may like to provide direction as to priority genetic investigations.

Issues

- Should genetic investigations be treated as 'givens' in any biomedical risk factor survey?
- How can the genetic information best be linked to other types of health information?
- Should genetic studies be limited to markers for the National Health Priority Areas?
- How can the general public be best informed about the usefulness of genetic investigations?

Professional input

There are several workshop participants who have a strong background and interest in genetic studies. In particular, Dr Simon Easteal, head of the Human Genetics Group at the John Curtin School of Medical Research, has strong interests in evolutionary genetics and views human health from that particular perspective. Dr Kuldeep Bhatia, head of the Population Health Unit at the Australian Institute of Health and Welfare has a strong interest in the genetic basis of population health. Both participants will be glad to make an input on genetic issues and their relevance and importance to the proposed survey.

Data issues paper no. 6: communicable diseases

Vaccine-preventable diseases

Background

Recent experience in America, the United Kingdom and western Pacific countries suggests that measles elimination is a realistic goal. A national measles elimination strategy is currently being considered and will probably incorporate a mass school-based vaccination campaign to commence in spring 1998. Age-specific susceptibility data can help predict measles outbreaks and plan preventive interventions. For measles, and several other vaccine-preventable diseases, adult susceptibility becomes increasingly important during the elimination phase of disease control. An ongoing (triennial) mechanism is being devised to monitor measles susceptibility—and susceptibility to other vaccine-preventable diseases—for Australians aged 0–75 years. The planned surveillance system relies on a convenience sample or sera sent routinely for diagnostic testing to public health laboratories around Australia. This type of 'serosurveillance' has been used routinely in Britain since the 1980s. The first such survey in Australia is planned for 1998. It is likely that the representativeness of this methodology will be disease specific. For example, a population of 'patients' may be more likely to be hepatitis B positive than the general population, but may provide unbiased estimates of measles susceptibility. To establish the validity of data obtained using this opportunistic surveillance method, it would be very valuable to compare them with data from a more rigorous sampling method. Adult vaccination records are usually unavailable, and self-reported vaccination and vaccine-preventable disease histories are unreliable, so these sources of information are not useful for this purpose. A national seroepidemiological survey, based on random sampling methodology, would provide a landmark opportunity to validate this opportunistic method of surveillance.

Vaccine-preventable disease seroepidemiology priorities include:

- measles—to help plan elimination methods, and to validate opportunistic laboratory based serosurveillance;
- rubella—which could also be eliminated, because a measles catch-up vaccination is likely to be undertaken using a rubella-containing vaccine;
- diphtheria and tetanus—to evaluate the effectiveness/implementation of the current immunisation guidelines;
- hepatitis A and B—to help plan the most cost-efficient method for universal and catch-up immunisation against these agents;
- herpes zoster infection—to increase chances that it will be preventable in the elderly in the future using live attenuated vaccines (A serological survey would provide valuable quantitative data regarding the epidemiology of varicella-zoster infection, and the potential usefulness of varicella-zoster vaccine, particularly in tropical versus temperate Australia.); and
- herpes simplex virus, type 2 (HSV-2)—vaccines are currently being trialled in Australia (Age-specific susceptibility data would help plan the future use of these vaccines.).

Aims

To determine in Australians aged 18 years and older, the age-specific prevalence of:

- measles and rubella susceptibility
- hepatitis A susceptibility
- hepatitis B susceptibility and infectivity
- protective diphtheria and tetanus antitoxin titres
- susceptibility to varicella-zoster, by region
- susceptibility to HSV-2.

Proposed blood analyses

Test	Workshop priority	Method	Minimum serum required*
Measles IgG antibodies	High	ELISA	100 µL
Rubella IgG antibodies	High	HAI	200 µL
Hepatitis A IgG antibody	High	ELISA	100 µL
Hepatitis B and surface IgG antibody and surface antigen	High		200 µL each
Diphtheria and tetanus toxin antibodies	Medium	ELISA	200 µL each
Varicella IgG	Medium	ELISA	100 µL
HSV-2 specific IgG antibodies	Low	ELISA and Immunoblot	500 µL

* For medium and high priority testing, a minimum of ~1.3 mL of serum in total. Double the quantities required if whole blood is used.

Issues

- It is possible to measure antibody levels using EDTA treated blood, but for most tests there has been more experience and standardisation using serum, and there is less risk of false positive ELISA tests (complement flaxation tests are not possible with EDTA blood). In general, heparinised blood is not suitable for serology.
- The most useful supporting information for these studies is likely to be collected as core demographic characteristic data—for example, date, country and place of birth, and place of residence at the time of the survey. For those resident in Australia during adolescence, it would be useful to collect place of residence during secondary school.
- Hepatitis B infection is treatable, under certain circumstances, using alpha interferon. Transmission in the household setting is preventable through vaccination of contacts.
- Further work is required to establish the most appropriate serological testing methods for each disease. This will depend on the blood collection methods and quantity of blood available for each test.

Infectious diseases and coronary heart disease

Background

In several seroepidemiological studies performed overseas, both *Chlamydia pneumoniae* and *Helicobacter pylori* have been found to be associated with coronary heart disease. These

findings have been strengthened by recent work showing their presence in atherosclerotic lesions in adults. A small study showed provisional evidence suggesting that azithromycin therapy can reduce the risk of post infarction complications in persons who are *C.pneumoniae* seropositive. Cytomegalovirus has also been implicated in coronary heart disease by seroepidemiological studies, by *in-vivo* detection in atherosclerotic lesions, and by its link with post-cardiac transplant vasculopathy which is similar to atherosclerosis. Less compelling associations have been found between Coxsackie B4 virus, and HSV-1 & 2. *C.pneumoniae* and *H.pylori* should be considered as potential confounders in a survey examining risk factors for coronary heart disease.

In addition, *H.pylori* infection has been clearly implicated in the aetiology of peptic ulcer disease, and this adds to its considerable public health importance. Most persons with peptic ulcer disease are infected with *H.pylori* and relapse is prevented by antimicrobial therapy. However, *H.pylori* is not sufficient to cause the disease. Only a small proportion of infected persons – about 15–20% – will develop peptic ulcer disease in their lifetime. Other risk factors, such as smoking, may interact with *H.pylori* infection to cause the disease. A high prevalence of *H.pylori* infection has been demonstrated in diabetes, which could relate to impaired gastric motility. Vaccines are currently bring developed in Australia to prevent *H.pylori* infection.

Aims

To determine in Australians aged 18 years and older:

- the age-specific cumulative incidence of infection with cytomegalovirus, *H.pylori*, and *C.pneumoniae*; and
- prior infection with agents that might contribute to coronary heart disease, in individual survey subjects.

Proposed blood analyses

Organism	Workshop priority	Method	Minimum serum required
Cytomegalovirus	Medium	ELISA	200 µL
H.pylori[(a)]	Medium	Latex	200 µL
C.pneumoniae	Medium	IF (3 species)	500 µL

(a) For *H.pylori* epidemiology it would be valuable to collect data regarding the history of endoscopically confirmed peptic ulcer disease, +/– prior therapy for peptic ulcer disease and *H.pylori* eradication.

Appendix D: Briefing paper on National Biomedical Risk Factor Survey

Background to the workshop

Strong support for a national biomedical risk factor survey which includes a blood sample has been indicated from a number of government and non-government sources. This movement reflects a major gap in national surveys of risk factors, medical conditions and diseases in Australia. The large National Health Surveys, run five-yearly by the Australian Bureau of Statistics, have given valuable and extensive information on self-reported factors. The most recent survey acted as a vehicle for biophysical measures such as body size and blood pressure, but did not include a blood sample. The last time a blood sample was obtained in a large nationwide survey was in 1989 when the National Heart Foundation ran its third and most recent national Risk Factor Prevalence Survey (RFPS) of adults living in capital cities.

This means there are no up-to-date estimates of the prevalence of major Australian risk factors, such as high levels of blood cholesterol and other important factors that can only be assessed via a blood specimen. It follows that for blood lipids, presently there can be no examination of trends from the 1980s through the 1990s; also, there are very little data for rural areas. This has led to recent calls for a national 'blood survey' from a range of significant health groups, including the Advisory Committee for the National Cardiovascular Monitoring System which includes representatives from Commonwealth and State health departments, the National Heart Foundation, medical colleges and epidemiologists. The National Heart Foundation has recently pledged a $100,000 contribution towards the conduct of such a survey. The diabetes community has also expressed a very strong interest in a national survey that includes a blood sample. The Ministerial Advisory Committee on Diabetes (MACOD) has indicated that a diabetes prevalence survey is a high priority, and has provided $100,000 to Diabetes Australia to develop a proposal.

The situation has received the interest of the National Public Health Information Working Group (NPHIWG), a sub-committee of the National Public Health Partnership Group recently established by the Australian Health Ministers and served by the AIHW. NPHIWG has decided to auspice the development of a national biomedical risk factor survey and has also recognised the importance of ensuring that a risk factor survey meets the needs of a range of stakeholders so that necessary funding and support are obtained. Therefore, it has established a steering committee, chaired by Professor Tony Adams from the National Centre for Epidemiology and Population Health, Australian National University, to organise a workshop of potential stakeholders.

The workshop, to be held on 31 October 1997, has been organised to demonstrate support for, and assist in the development of, a broad-based survey which best meets national

interests. The workshop will include experts from the areas of diabetes, cardiovascular disease, cancer, nutrition, genetics and communicable diseases.

The rest of this briefing paper outlines the workshop's aims, suggests some issues that might be discussed at the workshop, and attaches other background information.

Objectives of the workshop

The proposed survey has generated interest among many health groups, and provides an excellent opportunity for collaboration. However, resource and timing issues will require that the content of such a survey be prioritised. It is essential that the collection of neglected, important data via blood samples be given high priority. Collection of core person data to help interpretation is essential, but additional information is only secondary unless directly related to a particular blood analysis.

The main objectives of the workshop are to assist in the planning of the survey by advising on:

- the aims of the survey (draft 'aims' are given at Attachment 1)
- the priorities for scope and content of the survey
- the survey's methods
- the potential funding sources
- the next steps to advance the survey beyond the workshop.

This will require the workshop to integrate data requirements in the areas of diabetes, cardiovascular disease, cancer, nutrition, genetics and communicable diseases; to address the monitoring requirements of the National Health Priority Areas process; and to point the way forward in the planning process.

Suggested issues to consider

Consideration of the issues below may be useful in developing a proposal for the survey. They are offered as a guide only, for discussion at the workshop, and are not meant to be prescriptive:

- the survey and its data should focus on the most important public health issues;
- proposed data items, which are already well covered by other national surveys, would need to be specially justified;
- comparability of the results with those of previous national surveys is highly desirable, and this may have implications for the survey methodology (see Attachment 2);
- the survey should be able to provide estimates of national prevalence estimates and reference distributions;
- there may be an additional need to provide estimates for high risk sub-groups or at the level of State, rural versus non-rural etc.;
- the survey should be designed with a view to applying the results to major national initiatives such as the National Health Priority Areas, and specifically to:
  - achieve effective public education campaigns
  - plan health services

- conduct further monitoring
- identify regions or groups needing special attention
- identify issues needing further research;

- the choice and number of items to be measured may affect other important survey aspects such as:
  - the response rate and the burden on individual respondents
  - ethical and privacy issues;
- the stakeholders for the survey, their roles and potential funding sources need to be identified; and
- the processes that need to be set up to advance the survey development beyond the workshop need to be identified.

Attachment 1: Aims of the survey

Broad aims of the survey, for discussion and development at the workshop, are as follows:

- to estimate the national prevalence of selected diseases, conditions and risk factors;
- to determine national population reference distributions of selected health parameters; and
- to examine trends in selected diseases and risk factors.

Attachment 2: Comparability with previous Australian and international surveys

There have been four national or quasi-national surveys in Australia that have included the collection and analysis of a blood specimen. An important issue is the extent to which these surveys should influence the design of the proposed survey. Comparison with international data may also be an influencing factor.

Previous national blood surveys in Australia

Three surveys were conducted during the 1980s by the National Heart Foundation in cooperation with the Federal Department of Health to monitor the prevalence of cardiovascular risk factors in adults (Table 1). The surveys, conducted in 1980, 1983 and 1989, each included a questionnaire, physical measurements, blood pressure measurement and a fasting blood sample. The 1983 survey included a 24-hour dietary recall component. The 1983 and 1989 surveys also contained questions relating to diabetes. A total of over 20,000 adults living in capital cities participated in these surveys. Data collection took place at designated Risk Assessment Centres, often located in the National Heart Foundation's Divisional Offices. Response rates for the three surveys were each very close to 75%.

In 1985, the health and fitness of Australian schoolchildren were assessed by a national survey of some 8,500 students. Data collection teams visited participating schools. The survey included a questionnaire, field tests, physical measurements and blood pressure, and a 24-hour dietary record. Fasting blood specimens were collected from children aged 9, 12 and 15 years.

A blood sample was included in the pilot-testing phase of the 1995 National Nutrition Survey but the lack of funds prevented its inclusion in the survey proper.

Table 1: Biochemical assessments in previous 'national' Australian blood surveys

1980 adults (10 mL)	1983 adults (12.5 mL)	1989 adults 12 mL)	1985 schoolchildren (15 mL)
Total cholesterol	Total cholesterol	Total cholesterol	Total cholesterol
HDL cholesterol	HDL cholesterol	HDL cholesterol	HDL cholesterol
Triglycerides	Triglycerides	Triglycerides	Triglycerides
	Glucose		
		Iron	Iron
		Ferritin	Ferritin
		Transferrin	Transferrin

The National Health Survey

The 1995 National Health Survey was the second in a series of regular five-yearly population surveys designed to obtain national benchmark information on a range of health-related issues and to enable the monitoring of trends over time. Surveys in this series comprise a core data set that is repeated in successive surveys and a supplementary data set that can be varied from survey to survey to address key health issues of the day. The 1995 survey was conducted throughout the 12-month period February 1995 to January 1996 and collected information from 54,000 residents of a sample of 23,800 private and non-private dwellings.

The surveys covered the following topics, in addition to an extensive range of demographic and socioeconomic information:

- recent illness
- long-term conditions
- self-assessed health status
- general health and wellbeing
- inpatient episodes in hospitals
- visits to casualty/emergency; outpatient units; day clinics
- use of natural/herbal medications; vitamins/minerals; other medications
- days away from work/school
- other days of reduced activity
- smoking
- alcohol consumption
- exercise
- height and weight
- sun protection
- breastfeeding
- women's health issues (supplementary)
- injury accidents.

The National Nutrition Survey

A subset of respondents to the 1995 National Health Survey was invited to participate in the National Nutrition Survey. Dietitian interviewers called at the home to collect food and nutrition information and physical measurements, including blood pressure. Blood collection was pilot tested but did not form part of the survey proper because there was insufficient funding. The following topics were included in the 1995 National Nutrition Survey:

- 24-hour dietary recall
- food frequency questionnaire
- additional dietary questions—for example, dietary habits, attitudes and food security
- weight, height, waist and hip measurements
- blood pressure (for respondents aged 16 years and over).

Recent international blood surveys

In the USA, a series of national health examination surveys (the NHANES program) has been conducted since 1960. The most recent survey, NHANES III, conducted in two phases between 1988 and 1994, included the collection of urine and blood specimens. Volumes of blood collected from participants ranged from 7 mL from children aged 1–3 years to 100+ mL in some adults aged 20–59 years. The main elements of the cardiovascular disease components in NHANES III were measurement of blood pressure, measurement of blood

lipid levels, and electrocardiograms. The diabetes-related laboratory examination included an oral glucose tolerance test for those aged 40–74 years. Related information included data collected in the diabetic retinopathy and vision components. Data collection used Mobile Examination Centres. A full list of blood and urine assessments collected in NHANES III is attached for information (see Attachment 3).

The Health Survey for England, an annual series of surveys of the adult population (aged 16 years or over) living in private households, provides regular information about various aspects of people's health and monitors some targets in the Government's Health of the Nation Strategy. Cardiovascular disease was the principal focus from 1991 to 1994, and surveys in those years included a first-stage interview and a follow-up visit by a nurse who took anthropometric measurements and a blood sample (16 mL). First-stage interviews were carried out with 15,809 persons—a response rate of 71%. The effective response rate for the blood sample was 51%—that is, blood samples were obtained for 51% of the initial sample of adults. This represented 66% of adults in cooperating households. Samples were analysed for serum total cholesterol, plasma fibrinogen, haemoglobin, serum ferritin, glycated haemoglobin, gamma gt and serum cotinine, and a small sample was stored (with consent) for possible future analysis.

Attachment 3: Blood and urine assessments in NHANES III

Age group				
1–3 years	4–5 years	6–11 years	12–19 years	20 years and over
		Whole blood		
CBC[a]/RDW	CBC[a]/RDW	CBC[a]/RDW	CBC[a]/RDW	CBC[a]/RDW
Platelets	Platelets	Platelets	Platelets	Platelets
3-cell differential	3-cell differential	3-cell differential	3-cell differential	3-cell differential
Differential smear	Differential smear	Differential smear	Differential smear	Differential smear
Lead[e]	Lead[e]	Lead[e]	Lead[e]	Lead[e]
Protoporphyrin[e]	Protoporphyrin[e]	Protoporphyrin[e]	Protoporphyrin[e]	Protoporphyrin[e]
	Red cell folate	Red cell folate	Red cell folate	Red cell folate
	Glycated haemoglobin[e]	Glycated haemoglobin[e]	Glycated haemoglobin[e]	Glycated haemoglobin[e]
		Serum		
Iron[e]	Iron[e]	Iron[e]	Iron[e]	Iron[e]
Total iron binding capacity[e]	Total iron binding capacity[e]	Total iron binding capacity[e]	Total iron binding capacity[e]	Total iron binding capacity[e]
Ferritin[e]	Ferritin[e]	Ferritin[e]	Ferritin[e]	Ferritin[e]
	Folate[e]	Folate[e]	Folate[e]	Folate[e]
	Apolipoprotein A_1B[d,e]	Apolipoprotein A_1B[d,e]	Apolipoprotein A_1B[d,e]	Apolipoprotein A_1B[d,e]
	Total cholesterol[e]	Total cholesterol[e]	Total cholesterol[e]	Total cholesterol[e]
	HDL cholesterol[e]	HDL cholesterol[e]	HDL cholesterol[e]	HDL cholesterol[e]
	Triglycerides	Triglycerides[e]	Triglycerides[e]	Triglycerides[e]
	Lp (a)[b,e]	Lp (a)[b,e]	Lp (a)[b,e]	Lp (a)[b,e]
	Cotinine	Cotinine	Cotinine	Cotinine
	C-reactive protein[e]	C-reactive protein[e]	C-reactive protein[e]	C-reactive protein[e]
	Rheumatoid factor	Rheumatoid factor	Rheumatoid factor	Rheumatoid factor
	Vitamin A (retinol)[e]	Vitamin A (retinol)[e]	Vitamin A (retinol)[e]	Vitamin A (retinol)[e]
	Carotenoids[e]	Carotenoids[e]	Carotenoids[e]	Carotenoids[e]
	Retinyl esters[e]	Retinyl esters[e]	Retinyl esters[e]	Retinyl esters[e]
	Vitamin E[e]	Vitamin E[e]	Vitamin E[e]	Vitamin E[e]
	Vitamin B_{12}[b]	Vitamin B_{12}[b]	Vitamin B_{12}[b]	Vitamin B_{12}[b]
	Methyl malonic acid[b]	Methyl malonic acid[b]	Methyl malonic acid[b]	Methyl malonic acid[b]
	Homocysteine[b]	Homocysteine[b]	Homocysteine[b]	Homocysteine[b]
	Helicobacter pylori[d]	*Helicobacter pylori*[d]	*Helicobacter pylori*[d]	*Helicobacter pylori*[d]
	Tetanus	Tetanus	Tetanus	Tetanus
		Hantavirus (ages 10+)[d]	Hantavirus[d]	Hantavirus[d]
		Vitamin C	Vitamin C	Vitamin C
		Hepatitis A	Hepatitis A	Hepatitis A
		Hepatitis B/delta	Hepatitis B/delta	Hepatitis B/delta
		Hepatitis C	Hepatitis C	Hepatitis C
		Varicella	Varicella	Varicella

(continued)

Age group				
1–3 years	4–5 years	6–11 years	12–19 years	20 years and over
		Serum		
		Diphtheria	Diphtheria	Diphtheria
		Hepatitis E	Hepatitis E	Hepatitis E
		Rubella[e]	Rubella[e]	Rubella[e]
			Herpes simplex I and II	Herpes simplex I and II
			HIV 1 (ages 18+)[c,e]	HIV 1[c,e]
			Toxoplasmosis[e]	Toxoplasmosis[e]
			Vitamin D (25-hydroxyvitamin D_3)	Vitamin D (25-hydroxyvitamin D_3)
			Total/ionized calcium	Total/ionized calcium
			Selenium[e]	Selenium[e]
			Thyroxine (T_4)	Thyroxine (T_4)
			Thyroid-stimulating hormone (TSH)	Thyroid-stimulating hormone (TSH)
			Antithyroglobulin antibodies	Antithyroglobulin antibodies
			Antimicrosomal antibodies	Antimicrosomal antibodies
				FSH/LH (females; ages 35–60)
				Insulin
				C-peptide
			Biochemistry profile[e]	Biochemistry profile[e]
			Total carbon dioxide	Total carbon dioxide
			Blood urea nitrogen	Blood urea nitrogen
			Total billrubin	Total billrubin
			Alkaline phosphatase	Alkaline phosphatase
			Total cholesterol	Total cholesterol
			AST (SGOT)	AST (SGOT)
			ALT (SGPT)	ALT (SGPT)
			LDH	LDH
			GGT	
			Total protein	
			Albumin	
			Creatinine	
			Glucose	
			Calcium	
			Chloride	
			Uric acid	
			Phosphorus	
			Sodium	
			Potassium	

(continued)

Age group				
1–3 years	4–5 years	6–11 years	12–19 years	20 years and over
		Plasma		
				Glucose (ages 20–39 and 75 years and over)
				GTT (ages 40–74)
				Fibrinogen (ages 40 and over)[e]
		Urine		
		Cadmium	Cadmium	Cadmium
		Creatinine	Creatinine	Creatinine
		Albumin (micro)	Albumin (micro)	Albumin (micro)
		Iodine	Iodine	Iodine
			Cocaine[b,c] (ages 18 years and over)	Cocaine[b,c]
			Opiates[b,c] (ages 18 years and over)	Opiates[b,c]
			Phencyclidine[b,c] (ages 18 years and over)	Phencyclidine[b,c]
			Amphetamines[b,c] (ages 18 years and over)	Amphetamines[b,c]
			Marijuana[b,c] (ages 18 years and over)	Marijuana[b,c]
				Pregnancy test (females ages 20–59 years)
		White cells		
			Storage/banking[e]	Storage/banking[e]

(a) Includes hematocrit, haemoglobin, red and white cell counts, mean corpuscular volume, mean corpuscular haemoglobin, and mean corpuscular haemoglobin concentration.

(b) Phase 2 only.

(c) Anonymous.

(d) Phase 1 only.

(e) Home examination also.

There are growing demands in Australia for a national survey of biomedical risk factors, especially blood indices, as part of national public health monitoring. In response, the Australian Institute of Health and Welfare convened a workshop in late 1997 under the auspices of the National Public Health Information Working Group, a subcommittee of the National Public Health Partnership Group. Workshop participants discussed the aims of the National Biomedical Risk Factor Survey; priorities for scope and content; sampling and data collection methods; potential funding sources; and steps to progress development of the survey beyond the workshop. This report is an account of that workshop, its deliberations and outcomes.