

6 Small group workshops

This section summarises discussions at six small group workshops held to focus on specific issues. These summaries should be read in conjunction with the background paper for each workshop, given at Attachment C.

6.1 An information framework for the surveillance and monitoring of chronic diseases

This workshop discussed the important issue of an appropriate framework for the surveillance and monitoring of chronic diseases and their associated risk factors in Australia. Discussion focused on the NHP Framework and its adaptation by the La Trobe Consortium for chronic disease information and monitoring.

The group supported the use of the NHP Framework, as opposed to developing a new one, as the reporting framework for chronic disease surveillance and monitoring in Australia. However, parts of the framework, in particular its third tier (health system performance), could not be adequately populated with the information currently available. In addition, distributional issues ('Where is the opportunity for improvement?') are not well informed by the NHP Framework. The possibility of a reordering of the columns and boxes of the framework was also considered.

It was suggested that the framework would be more useful to policy makers if the analytical basis of chronic disease surveillance and monitoring was also explained. The workshop agreed that an analytical framework, such as the one presented in the NPHP background paper (*Preventing chronic disease: a strategic framework*), should be used in conjunction with the NHP Framework. The two frameworks will thus provide a useful checklist for covering key issues in chronic disease surveillance and monitoring.

6.2 Regional and local area issues versus national monitoring

This workshop discussed information requirements for chronic diseases and risk factors monitoring at various levels, from local through to national. Two main issues addressed were:

- Why is chronic disease and risk factor information needed at various levels of organisation? and
- What methodological issues are involved in collecting data at various levels?

The group recognised that State/Territory and Commonwealth information requirements go beyond national needs in the important area of service delivery. Therefore, the national collections need to have appropriate regional samples and a capacity for additional modules to meet jurisdictional data requirements. The need for national coordination of this surveillance activity, in order to assist jurisdictions in achieving their objectives such as common CATI questions and central collection of samples, was also identified. This arrangement should reduce duplication of efforts in data collection and management. A paramount issue identified at the workshop was the need to ensure appropriate access to data and its various outputs at all levels.

In balancing nationally agreed and Commonwealth/State/Territory priorities, it was agreed that the proposed AHMS would probably be a better investment than any other new data collection. Assurance of the AHMS and other significant national data collections being in place over time would allow the States/Territories and others to plan and focus on other collections.

6.3 Linking chronic diseases surveillance and monitoring to public health interventions and policy development

The participants in this workshop identified three key issues for discussion:

- What are the prerequisites to bring about these linkages?
- What information is relevant for specific target groups? and
- What are the limitations of such linkages?

Several prerequisites for developing linkages between surveillance, interventions and policy development were identified. Early involvement of policy makers in the development of information systems would help ensure good use of various collections. It would also be useful to have someone from the policy side involved in the overall data development process, such that this person could explain the data attributes, history and quality issues to policy makers. In addition, data development should take into account public health agendas and policy objectives, which in turn need to be based on evidence.

In relation to the relevance of information for specific population groups, it would be important to identify the type of audience being addressed and the format in which to disseminate the relevant information. Some uniformity or an agreed system for releasing information across jurisdictions would allow various population groups to better understand their own particular situation. However, the presentation of information comparing various groups must be done in a culturally sensitive manner.

A major limitation in trying to link surveillance with policies is the social context in which interventions occur. Since interventions take place at different levels, it is important for surveillance to happen at the appropriate level as well. However, the cost-effectiveness of surveillance systems at different levels needs to be studied.

6.4 Biomedical risk factors and markers

The history of collecting biomedical information in national surveys was reviewed at the beginning of the workshop. The participants noted that:

- the National Heart Foundation has conducted three risk factor surveys, which also included collection of blood samples for certain biomedical information, in 1980, 1983 and 1989;
- the 1995 National Nutrition Survey, conducted by the ABS, included physical measures but not the markers in blood; and
- the 1999–00 AusDiab Survey also collected information on blood-based measures, but the low response rate (30%) has led to concerns about the statistical validity of the estimates.

The AHMS, proposed for 2004 in conjunction (and linkage) with the NHS, should provide the best opportunity to collect biomedical information in the near future. The workshop was

informed that an inter-governmental steering committee is currently preparing a business case for the AHMS.

The participants discussed a list of potential biomedical markers for coverage by the AHMS. The list related mostly to cardiovascular disease, stroke and diabetes. Markers or measures of respiratory disease, mental health and cancers were somehow lacking, even though many of these are inexpensive to collect – with the relevant tests easy to administer – and provide valuable information. An example was given of spirometry, an easy to administer field test, to measure lung capacity.

The workshop agreed upon the following criteria for biomedical markers and clinical disorders to be covered by the AHMS:

- markers should relate to a range of chronic diseases;
- markers should reflect causal pathways;
- disorders should be of considerable prevalence; and
- standard measurement criteria (feasibility, reliability, validity) should be met.

It was assumed that the list of proposed markers meets the above criteria. There was concern that some of the proposed tests are not suitable for a household survey, e.g. the oral glucose tolerance test and the urine samples.

It was considered necessary to establish priorities for the inclusion of various markers in the survey. The group agreed that the measurement of blood cholesterol and glucose levels is the first priority.

6.5 Behavioural risk factors and other psychosocial variables

In determining which behavioural risk factors to focus on, this workshop initially scanned the boxes labelled 'health behaviours' and 'psychosocial factors' in the schema of causal pathways influencing chronic disease and health outcomes, as described in the NPHP background paper, *Preventing chronic disease: a strategic framework*. The 'health behaviours' box covers smoking, diet, physical activity and alcohol use. The workshop participants added sun exposure and cancer screening to this list. The 'psychosocial factors' box includes self-efficacy, sense of control, resilience, health literacy and social support.

The need for consistency in terminology, e.g. physical activity or inactivity, drug use or misuse, was considered. Consistency across various jurisdictions in defining risk factors was also discussed. The workshop considered it necessary to identify the risk factors for which the States/Territories and the Commonwealth were collecting information.

The workshop participants discussed the value of using the NHS as a vehicle for generating information on health-related behaviours. It was suggested that the NHS should have core components, with agreed definitions, and the jurisdictions could replicate these in their own CATI surveys with other components added to meet their specific data requirements. It was suggested that the 'minimum data set' for the NHS could be developed along the lines of the WHO STEPS approach. However, it was felt that while the NHS offers the advantages of consistency between jurisdictions and over time, the survey may not be held sufficiently frequently for some Commonwealth/State/Territory policy makers.

6.6 Utilisation and harmonisation of various types of data

The workshop began by identifying gaps in health data collections that affect their effective utilisation. It was agreed that:

- Lack of harmonised data collection seriously affects the pooling and synthesis of information from various data sources. In particular, cross-validation of data from different collections is difficult in the absence of objective measures and standard definitions. It was noted that measures in a collection are usually designed to 'fit a purpose', e.g. to report against certain indicators, rather than to generate consistent information.
- Inadequate identification and representation of certain population groups in health databases – such as Indigenous people, residents of nursing homes and other institutions, and the prison population – was also pointed out as a major gap in the chronic diseases and risk factors information base.
- Lack of suitable information about outpatient visits was identified as another major gap in the information base for chronic diseases and risk factors. The outpatient data sets require significant enhancement, in line with hospital inpatient data, which have steadily been improved over the past several years.

Other factors that limit the effective utilisation of existing data sets for chronic diseases and risk factors surveillance are lack of metadata (information about the data). The cost of ABS unit record files was seen as a significant barrier to accessing data.

Several steps were outlined to improve access to and harmonisation of various data collections:

- An audit of data sources, i.e. a national compilation and review, was considered an important first step towards the availability and harmonisation of various chronic disease-related data collections. An audit of the health survey data is being undertaken as part of the La Trobe Consortium feasibility study.
- Another important step would be to make data and information about the data (metadata) available on the web. To assist users, a directory of data sets, containing information about what data sets are available and where these are held, should be established on the web. The workshop participants noted that many CATI collections are currently listed on the Social Sciences Data Archive web site. Similarly, AIHW has data cubes and printed publications for several chronic diseases available on their web site free of charge, and the Commonwealth has distributed HealthWIZ as a Community Service Obligation product. The metadata should include up-to-date information on collection methodology, sample design, sample size, questions in the survey, editing procedures, response categories of data items, definitions of data items and scope of the collection.
- Linking of various data sets, as done in Western Australia, was considered to be another important step in better utilising the available data. The health research community would like the ABS and the AIHW to undertake record linking, in particular the linkage of NHS data with information available on health registers. The feasibility of record linkage between administrative data sets – such as morbidity, nursing homes and mortality collections and various registers (cancer and diabetes) – should also be investigated.

- Health risk factor information using objective measures, such as those proposed under the AHMS, is a priority. Validation of self-reported information using objective measures should also be considered.
- Standard question modules relating to specific health topics should be developed. This is currently underway, auspiced by the NPHP, under the leadership of the ABS and funded by the Commonwealth. A minimum set of data items could be embedded in various collections so that the concepts and definitions are consistent across various data sets.
- Further attention should be paid to the identification and representation of certain population groups in the chronic diseases and risk factor information base. Priority groups include Indigenous people, residents of nursing homes and other institutions, and the prison population.
- Generation of suitable information about outpatient visits should be given high priority.

The development of standard indicators and the harmonisation of future data collections for consistent reporting was also strongly emphasised.