4 Outcomes

The workshop did not set out to make any direct recommendations on issues and priorities in chronic disease surveillance and monitoring but chose to provide broad guidance and direction on specific issues. The outcomes, given in dot point format below, therefore broadly summarise the nature and direction of discussions at the workshop. A recurring theme at the workshop was the need to undertake the Australian Health Measurement Survey (AHMS), identified as the highest priority in chronic disease surveillance and monitoring.

4.1 General

- 4.1.1 A comprehensive surveillance and monitoring system is a requirement in efforts to help prevent and effectively control chronic diseases in Australia.
- 4.1.2 An effective surveillance and monitoring system would need to look across the continuum of care, from prevention through to treatment and management.
- 4.1.3 The fixed costs of information infrastructure should be recognised as national investment; marginal costs for additional information collected through that infrastructure should be a separate issue.

4.2 Framework

- 4.2.1 The National Health Performance Framework (NHP Framework), developed by the National Health Performance Committee (NHPC) and endorsed by AHMAC, was identified as a suitable framework for the surveillance and monitoring of chronic diseases, and could be used alongside the Strategic Framework for Preventing Chronic Disease, developed by the National Public Health Partnership Group (NPHP).
- 4.2.2 The World Health Organization (WHO) stepwise approach to surveillance (STEPS) of risk factors for non-communicable diseases was considered a useful framework. It is simple and comprehensive in showing how behavioural, physical and biomedical factors interlink. It also demonstrates how an increasingly comprehensive surveillance system, depending on local needs and resources, can be developed.

4.3 Data collection

- 4.3.1 Risk factor information is the centrepiece of chronic disease surveillance and monitoring, with behavioural risk factors forming the key plank.
- 4.3.2 In regular surveillance of SNAP behavioural risk factors (smoking, nutrition, alcohol abuse, physical inactivity), the first phase in the WHO STEPS approach—frequency and timeliness of data—is important. State-based computer-assisted telephone interview (CATI) health surveys can help meet these requirements.
- 4.3.3 A health measurement survey that will generate biomedical information was considered to be the utmost national priority.

- 4.3.4 The Australian Health Measurement Survey (AHMS), proposed to be held in conjunction with the 2004 National Health Survey (NHS), may be an opportunity to fill this gap.
- 4.3.5 Wide consultation is required to determine appropriate measures to be included in the AHMS. This is being undertaken as part of the development of the AHMS Business Case.
- 4.3.6 The following criteria should be used for determining the disorders and biomarkers to be covered in the AHMS:
 - markers relate to a broad range of chronic diseases and risk factors;
 - markers relate to factors that meet rigorous causal criteria;
 - disorders are of considerable prevalence; and
 - standard measurement issues (feasibility, reliability, validity) are addressed.
- 4.3.7 Blood cholesterol and diabetes markers should have the first priority in the proposed survey.
- 4.3.8 Consideration should be given to the inclusion of spirometry along with other physical (weight and height) and blood (pressure, cholesterol) measures in the survey. Urine sampling, while yielding useful biomedical data, would prove difficult and should not be a high priority.

4.4 Measurement issues

4.4.1 Analysis of blood pressure and cholesterol levels should take into consideration that these are continuous variables and that the standard cut-offs do not include all people who are at risk of poor health outcomes, particularly stroke and heart attack.

4.5 Indicators

- 4.5.1 A useful but manageable set of indicators should be developed for regular monitoring, building on the work done for the National Health Priority Areas (NHPA).
- 4.5.2 The NHP Framework should be used as the reporting framework for chronic disease surveillance and monitoring. The WHO STEPS approach was also considered to provide a suitable model for interlinking information on various risk factors.
- 4.5.3 An analytical framework, such as the one presented in the NPHP background paper (*Preventing chronic disease: a strategic framework*), should be displayed side by side with the NHP Framework. The two frameworks will thus provide a useful checklist for key issues in chronic disease surveillance and monitoring.

4.6 Regional issues

4.6.1 State/Territory and Commonwealth needs go beyond national needs in the important area of health service delivery. Therefore national collections need to have appropriate samples for regional dis-aggregation and a capacity to include additional modules for State/Territory and Commonwealth purposes.

4.7 Coordination across jurisdictions

- 4.7.1 There is a need for coordination of surveillance activity on a nationwide basis to assist the States and Territories in achieving their objectives, such as common CATI questions and an integrated sampling framework.
- 4.7.2 A paramount issue identified at the workshop was the need to ensure appropriate access to the surveillance data and its various outputs at all jurisdictional levels.

4.8 Harmonisation

- 4.8.1 The need for harmonisation of data collections was recognised. Potential exists for good alignment of the ABS NHS, jurisdiction-based CATI surveys, and the proposed AHMS.
- 4.8.2 Diversity in the types of instruments and information currently collected for chronic disease surveillance is an asset, rather than a liability, but NPHIWG could coordinate further harmonisation of these data.
- 4.8.3 Standard questionnaire modules on specific health topics should be developed. This work is already being auspiced by the NPHP. A minimum set of data items could be applied across the collections so that the concepts and definitions are consistent.
- 4.8.4 The lack of metadata (information about the data) limits the use of many existing data sets. Provision of information such as collection methodology, sample design, sample size, questions in the survey, editing procedures, response categories of data items, definitions of data items, and scope of collection would lead to greater use of these and new data sets.
- 4.8.5 An audit of data sources, i.e. a national compilation and review, would be an important step towards the harmonisation of data. This work has been undertaken for health surveys by the La Trobe Consortium as part of the feasibility study.
- 4.8.6 Existing administrative and non-administrative data collections could be used more effectively. One way to increase the use of existing collections would be to develop record linkages between various data sets.

4.9 Linking data to intervention and policy development

- 4.9.1 Involvement of policy makers in the development of data collection and information systems would help to ensure that the information is used for policy and program planning purposes.
- 4.9.2 Any data development should take into account public health agendas and policy objectives, which in turn need to be based on evidence.
- 4.9.3 A major limitation in trying to link surveillance and monitoring with policies is the social context in which interventions take place. Since interventions occur at different levels, it is important for surveillance and monitoring to take place at appropriate levels.

4.10 Dissemination of results

4.10.1 It is important to determine the audience being addressed and to disseminate results in forms appropriate to that audience. Some uniformity or agreed system between jurisdictions for publishing results would allow population groups distributed across more than one jurisdiction to better understand their situation.