

1**Introduction**

The National Public Health Information Development Plan (NPHIDP) provides a set of recommendations designed to improve the quality, coverage and use of public health information across Australia. The Plan seeks to address the need for improved public health information at the national level while recognising the information requirements of other levels of government and activity, including the local government and community levels.

Wherever possible, the Plan adopts the strategy of building on current public health information activity and developments, and exploiting the opportunities provided by the increasing pace of redevelopment and extension of existing health information systems. Emphasis is placed on 'mainstreaming' public health information needs within the health sector and on the need to ensure support for a population health perspective wherever health and health service information systems are being considered, designed or refurbished.

The Plan also emphasises the need for improved coordination of public health information development activities between different jurisdictions and levels of government, and between the health sector and other human services and environmental organisations. Vigorous development and promulgation of information and data standards which better meet public health surveillance and monitoring needs will be a key mechanism for achieving this aim.

The National Public Health Partnership (NPHP) will oversee implementation of the Plan through its National Public Health Information Working Group (NPHIWG). It is also expected that many of the recommendations of the Plan will be useful at many levels of public health and find their way into the broader domain of national health information through the National Health Information Agreement (NHIA) and other suitable vehicles.

Chapter 2 of the Plan provides a conceptual framework for public health information and some background on the current situation with respect to public health information in Australia. Chapter 3 sets out the recommendations to develop public health information. These are grouped into three categories: improving the scope and coverage of public health information; improving the use and delivery of public health information; and developing public health information capacity and infrastructure. Chapter 4 outlines the implementation of the recommendations.

2 Background

2.1 Public health in Australia

The term ‘public health’ means different things to different people. Many people understand public health to mean attention to clean drinking water, good sanitation and the control of rats, mosquitos and other disease vectors. Others associate public health with immunisation clinics or campaigns promoting healthy lifestyles.

In fact, all of these activities fall, at least to some extent, within the ambit of the widely-used definition of public health adopted by the Partnership: the organised response by society to protect and promote health and to prevent illness, injury and disability. There are two key characteristics of public health activity which are implied by this definition. The first is that public health activity implies coordination and cooperation between individuals, government agencies and private and community-run organisations. The second is that public health interventions tend to be focused on improving the health of populations or population subgroups, rather than of particular individuals, by seeking to modify the determinants of health and ill-health in those populations.

2.2 Characteristics of public health information

Public health information is needed as a basis for the development of health policies and actions that are aimed at addressing:

- those factors that affect a population’s health and causes of illness (determinants);
- the health status of a population, and groups within it, as opposed to the individual;
- the promotion and protection of health and prevention of illness rather than treatment alone; and
- the relationships among these elements.

The range of determinants that are of interest encompasses:

- structural determinants of health, including the social environment, economic status, social and economic gradients in health, cultural and geographic factors, age and sex distribution, income distribution, education and ethnicity;
- health hazards, or phenomena that are considered capable of adversely affecting health—these exist in a variety of domains including the physical environment, in food, and in behaviour such as abuse of alcohol and other drugs; and
- protective factors, such as wellbeing, support networks and the maintenance of healthy lifestyles.

The scope of information required to support public health action extends beyond measures of the determinants. Decisions about public health action also need to be informed by:

- information on population health status and the incidence of diseases, injuries and other adverse health events; and
- information about the implementation of interventions to improve health and the effectiveness of those interventions.

Information is used for:

- monitoring trends in the health and wellbeing of the community;
- monitoring health determinants, including structural factors, hazards and protective factors;
- assessing risks of adverse health effects associated with designated hazards and of positive effects associated with protective factors;
- helping to establish priorities for investment in interventions aimed at modifying health determinants;
- contributing to the design (or redesign) and management of these interventions;
- monitoring and evaluating the implementation of these interventions, their cost and their outcomes; and
- surveillance of emerging health issues.

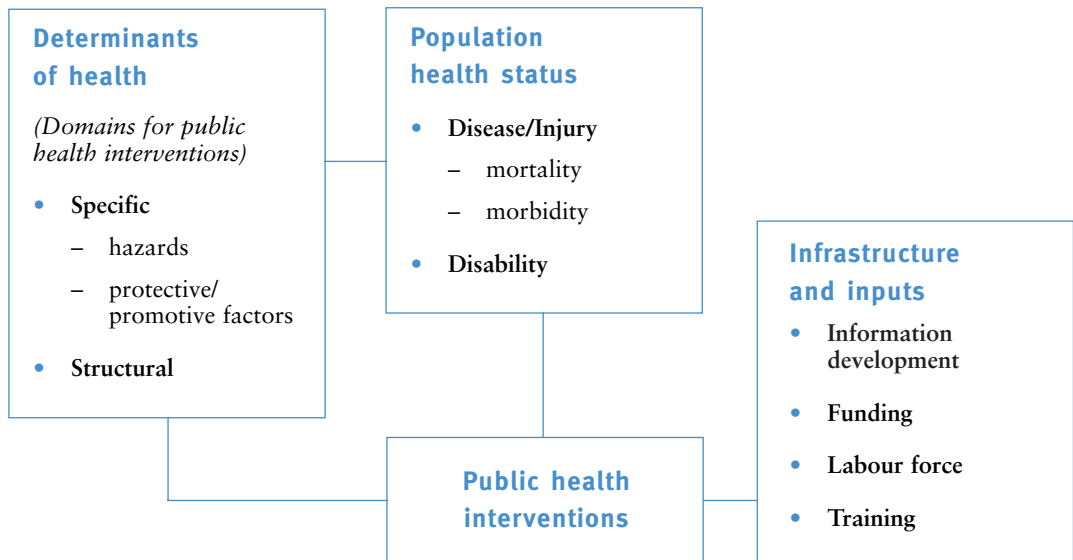
2.3 A conceptual framework for public health information

Colin Mathers and Colleen Fogarty proposed a conceptual framework for public health information in 1996, as part of work done for the Public Health Division of the then Commonwealth Department of Health and Family Services. This framework has been modified and simplified to align it with the draft 1998 National Public Health Partnership Planning and Practice Framework, which characterises public health practice in terms of a focus on the identification, analysis and management of determinants of health. See Figure 2.1, page 4.

The major dimensions of the framework, which can also be used to describe categories of public health information, are:

- population health status
- determinants of health
- public health interventions
- inputs and infrastructure.

Figure 2.1: Conceptual framework for public health information



Priority populations are not identified but can be regarded as an additional axis of the framework. Priority populations most commonly identified as disadvantaged in relation to public health include:

- Indigenous peoples
- groups for which there are equity or access concerns:
 - people with mental disorders
 - people with disabilities
 - chronically ill (e.g. HIV)
 - ethnic groups
- socioeconomically disadvantaged groups
- certain geographically-defined groups (e.g. people living in rural and remote areas).

Overseas-born Australians, particularly those of non-English-speaking background, are often included as a priority population, although their health is often better than that of the Australian-born population. However, there are specific priority areas and aspects of lifestyle where there is a need to have information on Australians from particular ethnic backgrounds. In addition, there is concern about the equity of access to health services and health information of Australians whose first language is not English.

2.4 Current public health information in Australia

There is already a great deal of public health information activity. The Commonwealth, States and Territories collect a range of population health data through their administrative information systems, through special-purpose surveillance systems and disease registers and through a range of population and issue-specific health surveys.

Most of this activity has been planned and developed at the local or jurisdictional level to meet specific local or jurisdictional requirements for information. This is, of course, entirely appropriate, but it means that some significant opportunities for improving national public health information are being missed due to the lack of comparability of data collections between jurisdictions and over time.

Some initiatives to address these issues have already commenced. These include:

- the recent establishment of the National CATI (Computer Assisted Telephone Interview) Health Survey Technical Reference Group to promote best practice in computer-assisted telephone interviewing in all jurisdictions and greater national data comparability and survey coordination;
- a project to develop agreed national public health expenditure classifications and improve national public health expenditure reporting;
- the inclusion of some population health measures into the current national General Practitioners' Survey; and
- ongoing work by cancer registries to converge their data standards and definitions and pool their data through the National Cancer Data Clearing House.

Clearly there is a great deal more of this type of work to be done.

2.5 Identifying gaps and deficiencies in public health information

Using the conceptual framework (Figure 2.1) for public health information, the various sources that might be used to obtain the four classes of information (population health status, determinants of health, public health interventions, infrastructure and inputs) are set out in Table 2.1, page 6. This provides a guide for the identification of data needs and gaps. The scope of this table indicates the huge range of data which is required to assemble a comprehensive picture of public health in Australia.

These four classes of information also provide the source data from which a number of important measures can be derived. Among these are economic measures such as burden of disease, quality-adjusted life years (QALYs), disability-adjusted life years (DALYs) and cost-effectiveness measures as well as health gain and health outcome indicators.

The most important gaps and deficiencies in national public health information, together with recommendations to address them, are identified in Chapter 3 of the Plan.

Table 2.1: Public health information development

Types of information	Possible information sources and collections
<p>Population health status</p> <ul style="list-style-type: none"> • Morbidity measures <ul style="list-style-type: none"> – disease prevalence – disease/injury incidence • Disability (prevalence) • Mortality (Note that all of the above may be focused on target populations) 	<ul style="list-style-type: none"> • Population surveys <ul style="list-style-type: none"> – Australian Bureau of Statistics – State/Territory – other • Demographics of target population • Disease registers • Surveillance systems • Death registers • (For some domains) hospital morbidity databases • GP surveys
<p>Determinants of health</p> <ul style="list-style-type: none"> • Structural • Hazard • Protective factors 	<ul style="list-style-type: none"> • Population surveys—as above • Environmental surveys • Environmental monitoring and regulatory data
<p>Public health interventions</p> <ul style="list-style-type: none"> • Information related to intervention specifications, e.g. target population coverage, participation levels 	<ul style="list-style-type: none"> • Program information • Target population information
<p>Infrastructure and inputs</p> <ul style="list-style-type: none"> • Labour force • Funding • Training 	<ul style="list-style-type: none"> • Agency information systems (staff and finance) • Public finance expenditure information • Population census (occupation) • Educational institution information

2.6 Development of national health information

National health information is health information which is either national in coverage or has relevance nationally. The term does not necessarily mean large centralised data collections. The essential characteristics of national information are the nation-wide consistency, comparability and relevance of the information.

The needs of consumers and providers of health care, the health industry and governments for quality health data that were comparable across jurisdictions led to the signing of the National Health Information Agreement. This is a multi-lateral agreement between the Commonwealth, State and Territory health authorities, the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW) which has been in place for five years and was recently extended for a further five years.

The National Health Information Agreement established the national infrastructure needed for developing, agreeing on and implementing both content and process aspects of national health information. The achievement of good quality consistent national health information is a fundamental purpose of the Agreement. The National Health Information Management Group (NHIMG), responsible for managing the Agreement, identifies national information development priorities and coordinates major national health information development activities. The development of national health data and meta data standards is a crucial element of that work.

The National Health Information Development Plan, developed by AIHW under the auspices of the Management Group in 1995, identified the major areas of national health information requiring priority action.

2.7 Purpose of the National Public Health Information Development Plan

The purpose of the National Public Health Information Development Plan, is to identify the action needed to provide appropriate, timely and valid public health information. This will allow public health policy makers, practitioners, researchers, analysts, advocates and consumers to monitor health status, respond to health problems and to support planning, implementation, and evaluation of health interventions and public health programs in Australia.

Preparation of the Plan has been guided by National Public Health Partnership documents establishing national frameworks for public health policy development and planning, monitoring and evaluation. The Plan has also drawn on the National Health Information Development Plan.

Preparation of the Plan has also involved broad consultation, including a workshop, convened to discuss the Plan and attended by some 120 people, which was held from 16 to 17 September 1998 in conjunction with the Public Health Association Conference in Hobart. There has also been considerable consultation and debate through the Partnership structure.

3 Recommendations for public health information development

3.1 Improving the scope and coverage of public health information

3.1.1 Health determinants

An enhanced national survey program is needed to improve data about potentially modifiable determinants of health, including physiological and behavioural risk factors and physical, social and economic environments.

The Australian Bureau of Statistics National Health Survey series has been the main source of national data on health determinants. However, data from these surveys have been under-utilised, and the survey vehicle criticised on the grounds of inflexibility, long delays in data availability, inadequate State sample sizes and expense.

In order to provide regular, relevant data on health determinants, many States have established their own health survey series, in most cases using computer-assisted telephone interview technology. These State-based surveys have developed independently to meet State needs, with some sharing of expertise and methods through informal interstate partnerships. The National Public Health Partnership now provides a platform for developing and promoting nationally agreed methods and standards for these surveys.

None of the existing survey mechanisms incorporate the collection of blood samples and physical measurements, such as body weight and blood pressure. Such a survey series is required to monitor determinants that cannot be reliably ascertained by self-report, or may not be recognised by subjects themselves, as well as to provide ongoing validation of self-report measures.

In addition, none of the current survey mechanisms yield national, comparable data on physical, social and economic environments as they relate to health. Development of agreed approaches to measuring these constructs is an important priority.

The current review of the ABS Health Survey Program provides an opportunity to address some of those information needs. It is proposed to run a revamped National Health Survey in 2001 and possibly every two years thereafter.

The conduct of a national biomedical risk factor survey in conjunction with the 2001 National Health Survey would provide an excellent opportunity to link physiological measurement data with self-reported data on determinants such as use of alcohol and physical activity levels. The utility of such a survey, however, is dependent upon obtaining an adequate response rate.

Another likely result of the current ABS review of its household survey program is the establishment of a General Social Survey (GSS) series, which could provide an ongoing source of information on how physical, social and economic environments affect health.

The recently formed National CATI (Computer Assisted Telephone Interview) Health Survey Technical Reference Group, which includes representation from the ABS, offers an opportunity for better coordination of State-based and national surveys. This group will develop a coordinated work program to improve the overall coverage of survey data, facilitate the sharing of data between jurisdictions and provide a basis for establishing agreed national minimum data sets for priority areas.

Recommendations

- 1.1.1 Conduct of a national biomedical risk factor survey in conjunction with the 2001 National Health Survey, subject to piloting to confirm that adequate response rates can be achieved.
- 1.1.2 Development by the Australian Bureau of Statistics of a General Social Survey, and the associated development of agreed methods to measure physical, social and economic environments as they relate to health. The General Social Survey should complement the National Health Survey and State/Territory health surveys.
- 1.1.3 Development of a national work program to improve the overall coverage of survey data, facilitate the sharing of data between jurisdictions and provide a basis for establishing agreed national minimum survey data sets for priority areas.

3.1.2 Indigenous peoples

The National Public Health Partnership members should seek to actively implement within their own jurisdictions the public health aspects of the National Indigenous Health Information Plan, already endorsed by Australian Health Ministers' Advisory Council. These include the need for 'over-sampling' of Indigenous peoples in population-based health surveys in order to ensure that the survey results for Indigenous peoples are sufficiently reliable, as well as placing emphasis on the improved identification of Indigenous peoples in all health and health-related data collections, particularly mortality data collected in the eastern States in which Aboriginal and Torres Strait Islander people are seriously under-enumerated.

Recommendations

- 1.2.1 Active implementation within jurisdictions of the public health aspects of the National Indigenous Health Information Plan.
- 1.2.2 Development of data collections so that the environmental and social causes of ill-health in Indigenous communities are identifiable.

3.1.3 Socioeconomic disadvantage

Socioeconomic disadvantage affects both health and access to health services and therefore needs to be considered in any examination of health status or health service utilisation.

There are a number of well-established instruments for measuring socioeconomic status or socioeconomic disadvantage. These are commonly used in population-based surveys—such use should be encouraged and standardised. It would be desirable to collect similar information on socioeconomic status as part of all population-based health data collections, although this may not always be feasible or socially acceptable.

Recommendations

- 1.3.1 Standardisation of the instruments or questions used to measure socioeconomic status or socioeconomic disadvantage in all population-based health surveys.
- 1.3.2 Examination of the feasibility and social acceptability of the routine collection of indicators of individual socioeconomic disadvantage as part of routine population-based health data collections.

3.1.4 Intersectoral information and data on the physical environment

A great deal of information which is relevant to public health is not generated within the health sector. Examples include:

- housing, with particular reference to rural and remote health
- road safety
- school and workplace safety
- water and air quality
- climatic and meteorological data.

Currently the routine consolidation of these types of data by public health functions at the State/Territory and Commonwealth level is the exception rather than the rule.

Recommendation

1.4.1 Establishment of a cooperative work program to:

- (a) develop national data standards for intersectoral data which meet public health requirements; and
- (b) establish regular flows of information (in both directions) between the public health sector and the non-health and local government agencies which collect or produce this information.

3.1.5 Health promotive environments

Health promotive environments are aspects of the physical, social, cultural and economic environments that encourage practices and behaviour that are conducive to good health. Examples include:

- no-hat-no-play sun protection programs in schools;
- promotion of healthy food in school canteens and tuckshops;
- smoke-free work and public places to discourage smoking and reduce passive exposure to tobacco smoke;
- traffic-calming policies and practices to slow suburban traffic and reduce the rate and severity of road and pedestrian accidents; and
- provision of adequate and safe footpaths, cycleways and parks to encourage regular exercise.

The lack of data on the existence, maintenance and effectiveness of such health promotive environments in Australia is clearly an important gap. This particular gap was identified as being one of the 'Higher priority development directions' in the National Health Information Development Plan.

Recommendation

- 1.5.1 Establishment of a work program, in collaboration with education, transport, employment and related environmental agencies, to measure the extent of health promotive environments in Australia and to collect data on their establishment, use, maintenance and impact on health outcomes.

3.1.6 Geographic classifications

Large geographical variations in health status are often evident in many public health monitoring and surveillance data collections. However, examination of these variations is often hampered by a lack of consistency in the geographical boundaries and identifiers used by different agencies to define and denote location. Location is currently assigned in many health data collections on the basis of local government administrative boundaries, which tend to change over time as local governments merge or adjust their boundaries, or on Australia Post postcode areas, which are poorly defined and changed frequently in order to maximise the efficiency of letter delivery. It is recommended that a set of standard national geographical boundaries, identifiers and aggregations be developed and promulgated for use in all population-based health data collections and surveys. Such a geographical classification should attempt, as far as possible, to strike the best compromise between the competing aims of:

- consistency with existing health and local government boundaries;
- maximum homogeneity of socioeconomic characteristics of the population resident in the geographical region, so that variations in health status are not masked by having a mixture of low and high socioeconomic sub-populations within the one region; and
- ability to split or aggregate into regions with approximately the same populations so as to minimise differences in sampling variation between regions.

Additionally, development, perhaps in conjunction with the private sector, of a reliable and affordable mechanism of coding current and historical address information to this national health geographical classification is required.

Once developed, use of the standard classification in all large-scale surveys and population-based health data collections should be encouraged.

Recommendation

- 1.6.1 Development and promulgation of a set of standard national geographical boundaries, identifiers and aggregations for use in all population-based health data collections and surveys and a mechanism for coding current and historical address information to this classification.

3.1.7 Financial and economic assessment of public health programs

Increasingly, there is a need at all levels of government to be able to justify health expenditure. In public health the first step is to identify public health programs and the expenditure associated with them and to measure their output and estimate their impact on health. These tasks must be carried out in a standardised fashion so that valid comparisons can be made between different jurisdictions and populations and so that the true cost-effectiveness of different types of public health programs and interventions can be assessed. Information on public health expenditure is also required to support arguments for increases in current funding levels. This points at a wider task for public health to inform decision-making on resource allocation across the health sector from the population health perspective.

While there is increasing pressure for funding based on health outcomes, very little attention has been given to the actual requirements to do so. These requirements include:

- a common metric to quantify health outcomes, particularly changes in health outcomes brought about by health interventions; quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs) are two such measures. The Australian Institute of Health and Welfare and the Victorian Department of Human Services are currently carrying out burden of disease studies quantifying the amount of ill-health from over 100 diseases, injuries and risk factors in DALYs. As more States become involved in burden of disease studies it will be important to agree upon nationally acceptable and comparable methods.
- knowledge of the effectiveness of interventions. Studies that measure the effectiveness of interventions are very expensive and cannot be replicated in every new setting. However, we can learn a lot from experiences documented elsewhere. Systematic reviews of the available evidence on the efficacy or, preferably, the effectiveness or cost-effectiveness of (public) health interventions help to make a judgement of the likelihood that a similar impact can be expected in our own contexts. There should be a standard set of agreed national guidelines on how to perform these systematic reviews. The vast amount of work required to do these reviews across different health domains can then be shared between jurisdictions.

- the costs associated with interventions. Current expenditure on health programs and services which can be regarded as having an exclusively public health focus is still quite small relative to the national health budget, although quite substantial in absolute terms. The first requirement is the development of comprehensive lists of programs and services which do and don't qualify as 'public health programs'. Many programs clearly have a public health focus, e.g. immunisation services. For others it is not so clear, e.g. some jurisdictions define the measurement of environmental pollutants as a public health function while others do not. Clarification of the organisational activity is currently being undertaken by the Australian Institute of Health and Welfare, and a draft classification of public health has been developed. In addition, the Institute is conducting a National Public Health Expenditure Survey to assess direct and readily identifiable expenditure on public health programs at the State and national level.
- the current coverage of interventions, i.e. the proportion of eligible recipients who currently benefit from the current mix of interventions (e.g. the proportion of women between 50 and 64 who have had a mammogram in the last two years) and thus the additional number of cases who stand to gain from improved access to the interventions.

When combined, these sources of information will enable cost-effectiveness ratios to be calculated. Comparison of cost-effectiveness ratios of alternative interventions for the same health problem helps to inform decisions on allocation of resources that will give optimal health gain. The great advantage of using a common metric to quantify health outcome in cost-effectiveness analyses is that comparisons between very different interventions for different health problems is possible, thus allowing judgements about the allocative efficiency across the health sector. Where such sector-wide comparisons favour preventive over curative interventions they strengthen the case for increased investment in public health.

Recommendations

- 1.7.1 Further development via a consultative process of the Australian Institute of Health and Welfare classification of public health activity.
- 1.7.2 Continuation of the Australian Institute of Health and Welfare National Public Health Expenditure Survey project.
- 1.7.3 Development and promulgation of sets of guidelines for the:
 - conduct of burden of disease and cost-effectiveness studies, and the collection of evidence by systematic reviews of the literature; and
 - measurement of the output from, and impact of, different types of public health programs and services (including public health information programs).

3.1.8 National public health indicators

Currently there is no agreed set of national public health indicators, which are needed to provide basic accountability for the sector and to allow benchmarking between States and Territories and health service administrative regions.

Two major purposes have been identified for national public health indicators: monitoring and surveillance. Monitoring covers current priority strategies for public health, although health status data monitored would also provide relevant long-term indicators of progress. Surveillance offers a warning system for identifying health issues which might need to be addressed by public health activities.

Development of such a national public health indicator set is a high priority and needs to proceed quickly in order to inform development of data collections, such as the forthcoming National Health Survey. However, it is vital to achieve acceptance and ‘ownership’ of the indicators throughout the public health community. Accordingly, the development process will involve consultation to establish an agreed purpose, scope and reporting framework for the indicators, criteria for indicator selection, standard analytic methods, and a process for ongoing review and validation of the indicator set. The indicators should build on relevant existing sets of indicators, particularly the priority indicators for National Health Goals and Targets (developed in 1996). Indicator development should not be constrained by the current availability of data—rather proposed indicators should be classified as ‘currently feasible’ or ‘currently infeasible’. The latter category should help drive the development, revision and extension of public health data collections from which indicators are calculated.

Recommendation

- 1.8.1 Development of an agreed set of national public health indicators through a consultative process.

3.2 Improving the use and delivery of public health information

It is often assumed that once adequate data have been collected and assembled, the analysis and reporting of those data is a straightforward task and the resulting publications will automatically reach the appropriate audience.

In fact, each of these assumptions warrants further exploration.

3.2.1 Analysis and presentation of information

Although there are a number of well-established epidemiological and statistical conventions for the analysis and reporting of population health data, these conventions are not uniformly observed and some basic standards, such as which reference population to use for the commonly used technique of direct age/sex standardisation, are not well defined.

Correct interpretation of many public health indicators and statistics requires the reader to possess or acquire some degree of epidemiological and statistical literacy, yet there has been little systematic work done on the best ways of presenting and explaining the necessary concepts to both lay and professional audiences.

There also remain a number of unresolved and unexplored issues relating to the reporting of population health data, such as the best methods for simultaneously presenting the estimated value of a measure and an indication of the precision of that estimate or the degree of confidence which the reader should have in it. Although this latter issue is of little concern at the national, State or Territory level, it is vitally important whenever population health information is reported at the local level. There is a need for further research into best practice for the analysis and presentation of small area and local data in a way which provides the optimum balance between the competing needs for detail, reliability and general applicability, and the protection of the confidentiality of individuals, institutions and communities.

Recommendation

- 2.1.1 Research into best practice for the analysis and presentation of small area and local data, and into improved methods of communicating epidemiological and statistical concepts to lay audiences.

3.2.2 Information delivery and access

Information, and especially public health information, only has value if it reaches and can be used by a range of public health decision makers, practitioners and consumers.

Traditionally, reports on population health status and public health indicators have been produced as typeset and bound documents. Publication costs have necessarily limited the detail, specificity and currency of such reports—they have generally been designed to meet at least some of the information needs of as large an audience as possible on a periodic (often annual or biannual) basis. Once published, such reports are often not marketed as widely or as strongly as they might be.

However, the startling development of the Internet (and of intranets within larger organisations and ‘extranets’ between associations of organisations) challenges these traditional methods of information dissemination. Access to the Internet is rapidly becoming ubiquitous amongst health professionals, health service administrators and planners, government agencies (including local governments), students at all levels and certain elements of the general public. The next few years will see the widespread introduction of facilities for public access to the Internet for the purpose of interacting with government agencies—this will include the potential for widespread access to public health and population health information.

This shift to electronic delivery of information demands that many of the assumptions which underpinned traditional reporting practices be re-examined. Given that the marginal costs of expanding the size of electronic publications is much less than for printed publications, what level of detail is it appropriate to provide, and how can this extra detail best be structured and presented? Should electronic publications be ‘customised’ for and targeted at very specific audiences, such as individual local government organisations or particular community or ethnic groups? To what degree is it practical to do this?

Recommendation

- 2.2.1 Organisations and agencies responsible for the reporting of public health data should actively develop their capacity for electronic publication and explore methods for exploiting this capacity.

3.2.3 Marketing of information

Finally, regardless of whether public health information is produced in printed or electronic form, it must be ‘marketed’ and its use promoted far better than it is at present. For example, opportunities exist for the use of population health information to be incorporated into secondary school curricula and in all tertiary courses which have a social, economic or political focus.

Recommendation

- 2.3.1 Agencies responsible for the reporting of public health information should consider the promotion and marketing of public health reports and publications at all stages of their design, publication and distribution, with a view to further increasing the use of public health information in all spheres of government and community activity.

3.3 Developing public health information capacity

3.3.1 Record linkage

Record linkage refers to the process of linking or matching the records contained in two (or more) databases or data collections which were not originally designed to be combined. In the absence of unique identifiers (such as a number) which are common to both data collections, a series of non-unique partial identifiers such as name or initials, date of birth, sex, residential address or postcode or country of birth are usually used to link the records, using probabilistic or ‘fuzzy’ matching techniques. The purpose of doing this is to yield more information than is available from the two databases by themselves, often at far less cost than would be required to establish a new data collection to collect the same information. Much routinely collected health service data relates to individual episodes of care. Record linkage techniques make it possible to yield longitudinal ‘person-oriented’ information from many of these administrative

databases. Such longitudinal data is essential for assessing health outcomes and the effectiveness of our health services.

Western Australia is already well advanced with a large-scale strategic record linkage project in which nearly all data which is routinely collected by or on behalf of the Western Australian Health Department is linked into a single database. New South Wales Health has also been using record linkage between specific databases for over five years in order to carry out public health surveillance and to investigate service utilisation and health outcomes questions. The service offered by the Australian Institute of Health and Welfare in which cohorts of patients can be linked to a national index of deceased persons and/or national cancer incidence data is another practical example of record linkage.

Examination of the feasibility and usefulness of potential approaches to linking health records was identified by the National Health Information Development Plan (NHIDP) as one of the highest priorities.

Although there are clear benefits from record linkage activities, these must be weighed carefully against the potential for the unwarranted invasion of personal privacy as well as the potential for breaches in the confidentiality of health information due to the necessity of using identified or partially identified information during the linkage process. In addition, there are numerous technical challenges to be addressed in this relatively new field of information processing. Linkage would benefit from a uniform national approach and establishment of a best practice approach.

Recommendation

3.1.1 Systematic investigation of the appropriateness, utility, feasibility and cost-effectiveness of the application of record linkage techniques to existing data collections at and between all levels of government.

3.3.2 Sentinel surveillance networks and communicable disease surveillance

Sentinel surveillance networks use information collected in a timely fashion from selected health care providers (such as general practitioners) on the incidence or prevalence of specific diseases or conditions amongst the patients presenting to that service provider. Traditionally sentinel surveillance has been used to identify or monitor outbreaks and epidemics of infectious diseases or to monitor the activity or severity of conditions which change rapidly in response to environmental conditions, such as asthma. Because they are not population-based, sentinel surveillance networks cannot be used to measure or estimate the absolute magnitude of disease incidence or prevalence—they are only useful for monitoring changes in incidence or prevalence over short periods of time.

Despite these limitations, sentinel surveillance networks have a valuable role to play, particularly in the monitoring of common conditions such as influenza, chicken pox and herpes simplex type 2 infections which cannot feasibly be monitored using the mandatory notification systems employed for other communicable diseases.

Currently a number of sentinel surveillance networks are operated by different levels of government, by general practice professional bodies and by academic groups. It is recommended that better coordination of these networks be undertaken in close cooperation with the Royal Australian College of General Practitioners and local Divisions of General Practice, bearing in mind that the continuing success of these networks depends entirely on the goodwill of the general practitioners who participate in them.

The possibility of extending the general practice sentinel surveillance model to hospital emergency departments should also be investigated. Sentinel surveillance techniques may also be useful for monitoring the impact of health promotion and health education campaigns.

Following a national workshop in 1995, the Chief Health Officers of the States, Territories and Commonwealth agreed to the development of a National Communicable Diseases Surveillance Strategy. The Strategy consists of three components:

- the development of a strategic blueprint for national communicable diseases surveillance;
- the review of laboratory surveillance necessary to support national surveillance; and
- the development of protocols to facilitate outbreak control at local and national levels.

The Strategy is currently being implemented. However, in order to improve the responsiveness of communicable disease surveillance systems at all levels of government, there is an urgent need to establish technical and administrative standards for the electronic transfer of (highly confidential) notifications of communicable disease from laboratories, medical practitioners and hospitals to State and Territory health authorities. Many notifiers are in the private sector.

Additionally, in the last few years a number of new or previously unrecognised infectious diseases have emerged in Australia. In most of these, 'species jumping' was involved, highlighting the need for greater and swifter interchange between those responsible for human health and animal health.

Recommendations

- 3.2.1 Development of mechanisms to enable better coordination of sentinel surveillance networks and pooling of data, including general practice data in close cooperation with the Royal Australian College of General Practitioners and local Divisions of General Practice.
- 3.2.2 The National Communicable Diseases Surveillance Strategy should continue to be implemented.

3.3.3 Sharing of and access to public health data

Mechanisms which permit both the pooling and sharing of public health data at the national level are critical to the success of this Plan. Commonwealth bodies such as the Australian Institute of Health and Welfare and the Department of Health and Aged Care require pooled national data to undertake their core business; State and Territory governments increasingly require information at the national level in order to compare and benchmark their own performance and progress on public health issues against other jurisdictions; academic institutions benefit greatly from access to national data when undertaking public health research.

Technical barriers to data pooling and sharing caused by inconsistent data definitions and standards are addressed elsewhere in the Plan. However, a more important but often unacknowledged source of barriers to data sharing are political and administrative sensitivities regarding the uses to which shared data might be put. Health is a political issue. Data, once shared, can be used to make comparisons between jurisdictions. It is recommended that guidelines for the responsible, ethical and, in some cases, controlled release of information based on shared or pooled data be developed and promulgated as a first step in overcoming these barriers.

Recommendation

- 3.3.1 Development and promulgation of guidelines for the responsible, ethical and, in some cases, controlled release of information based on shared or pooled data.

3.3.4 Development of a systematic approach to national public health information

A systematic, coordinated approach to the collection and management of public health information at the national level in Australia is required to ensure that:

- data are consistent and comparable across jurisdictions;
- there are technical and administrative mechanisms for sharing data between jurisdictions; and
- data are regularly aggregated and reported on at the national level.

Such a systematic approach does not imply centralisation of collections (although this may be appropriate in some circumstances), but rather the aim should be consistency, comparability and accessibility of data across collections and jurisdictions. This would be expected to reduce costs through a reduction in the cost of developing or revising data collections. Existing infrastructure for the management of public health data and information standards and definitions, such as the *National Health Data Dictionary* (NHDD), the National Health Information Model, and the Knowledgebase—Australia’s Health and Community Services Data Registry, should be used wherever possible to achieve these aims.

Additionally, there needs to be a systematic examination of the scope and coverage of existing public health data collections in order to identify gaps at the national level, and a work program established to address these gaps.

The desirable frequency of the collection depends upon the purpose of the data. Communicable disease surveillance requires frequent collection and reporting, however, collection of population data on cardiovascular disease which change slowly, need only occur every few years.

In its submission to the current review of the national Australian Bureau of Statistics Household Survey Program, the National Public Health Information Working Group has suggested that it undertake a coordinating role to assist the Bureau in the development of a structured national public health survey program. A considerable amount of time and effort is needed to set up the basic infrastructure required for carrying out health and risk factor surveys. A rolling program of data collection would minimise start-up and development costs, and maximise the retention of expertise and consistency of data quality.

Such a public health survey program should coordinate Australian Bureau of Statistics’ surveys with other national and State/Territory survey activity, e.g. the 1997 Secondary Students, HIV/AIDS and Sexual Health Survey (sexual risk behaviours and knowledge) conducted by the Australian Department of Health and Aged Care, the National Drug Household Survey, State CATI health surveys, and the Women’s Longitudinal Health Survey.

In developing that program, factors to be considered include:

- a continuous program of data collection might enable better coverage of specific topics while maintaining respondent burden at an acceptable level and enable specific population sub-groups to be targeted; major periodic surveys are often unable to cover adequately all topics of interest because of respondent burden;
- improved use of existing health services and other data collections;

- specific information needs change over time. A rolling data collection program might increase the ability to respond to changing needs in an appropriate and timely manner while maintaining core data items; and
- in order to monitor trends over time it is important that the information collected is comparable over time.

Recommendation

- 3.4.1 Development of a framework for the systematic collection, aggregation and use of public health information at the national level.

3.3.5 An infrastructure for managing the national development of public health information

Currently there is no national infrastructure or process through which the development of public health information can occur. Nor is there a body which can represent the particular information needs of the public health sector and act as an advocate for a population perspective in national and international health information forums. A great deal of public health data is derived from acute care information systems, which are largely outside the public health sector's influence. A single voice will improve the negotiating strength of the public health sector in dealing with other health sectors.

The development of the National Public Health Partnership has laid down the foundations for a public health infrastructure. This infrastructure has been expanded to address national public health information issues through the National Public Health Information Working Group. What is lacking are structures and agreed processes for development and adoption of information policy and standards by Partnership member organisations.

In the general health sector the National Health Information Management Group has, under the umbrella of the National Health Information Agreement, provided the leadership role in developing and defining standards and championing the importance and resourcing of national health information development. The Management Group is recognised by the Australian Health Ministers' Advisory Council as its chief source of technical advice on health information. Although the Management Group has an excellent track record in its support of public health information issues, its focus has understandably been on the information requirements of acute health care services. There is now a need for a body similar to the National Health Information Management Group which focuses on public and population health information issues. Like the Management Group, such a public health information body would need to develop agreed mechanisms for the development and approval of information policies and standards.

At this stage, it is unclear whether the Working Group within the Partnership can take on these roles or whether a new body needs to be formed. As the implementation details of the National Public Health Information Development Plan are worked out, it will also become clear whether additional technical and secretariat resources are required to support this management and advocacy infrastructure.

Recommendation

- 3.5.1 Development of a body which has well-defined mechanisms for making decisions affecting national public health information and which can represent the information needs of the public health sector and can act as an advocate for a population perspective in national and international health information forums.

4 Implementation of the Plan

This chapter has been kept deliberately brief in the 1999 Plan.

The 1999 Plan has a scope of three years and its implementation may need to be modified during that time to reflect changing conditions and priorities. The National Public Health Information Working Group (NPHIWG) will develop a program of work based on the Plan to cover the activities necessary for its implementation. Although existing processes for the development, management and promulgation of information standards, such as the National Health Information Management Group and National Health Data Committee will be used wherever possible, additional resources may be required to initiate some of the coordination tasks contained in or implied by the Plan's recommendations. Specification of the necessary infrastructure will be a priority for the Working Group as it works on implementing the Plan.

Ownership of the Plan and responsibility for its implementation will be in the hands of the Working Group. It will coordinate and manage the implementation activities, formulate requests for resources if required and report regularly on progress through the National Public Health Partnership to the Australian Health Ministers' Advisory Council. The process of allocating tasks and resources will be transparent and based on the principles of mutual consent and, where appropriate, contestability.

Successful implementation of the Plan will require substantial and sustained effort on the part of those responsible for public health within Partnership member organisations. Of particular importance will be their active participation in the design and development of all health information systems which are relevant to public health information. Also of importance is the need to improve the level of communication and cooperation with non-health sector, local government and community-based organisations who have a vital part to play in both the collection of public health information and its effective use.

